

Geert Vanneste

Breaking Down Barriers



How to Increase the Cataract
Surgical Rate

CONTENTS

Foreword		6
Feedback		7
Terms		7
Abbreviations		7
1	Introduction	8
2	Barriers between cataract patients and hospitals (eye units)	9
2.1	Barriers concerning patients, relatives and the community	10
2.1.1	Barriers concerning patients. Fear Age Distance Slow process of cataract blindness: "I'm fine!" Patients think the cataract needs to be mature One eye still OK!	
2.1.2	Barriers concerning close relatives Aged people: 'no priority' Cost: 'no money' No escort /caretaker to accompany Discrimination against women Social roles of blind people Unsure of total cost: corruption, and follow-up treatment Wait for free treatment from a Service Club	
2.1.3	Barriers in the community at large Information barrier: unawareness that cataract treatment exists Cultural and religious beliefs about blindness and eye treatments	
2.2	Barriers concerning the hospital (eye unit)	13
2.2.1	Quality of the surgery and general handling of the patient	
2.2.2	Lack of active social marketing and 'public relations'	
2.2.3	Private practice by eye doctors	
2.2.4	High cost of cataract surgery	
2.2.5	Corruption makes prices unpredictable for the patients	
2.2.6	Low motivation of eye staff	
2.2.7	No permanent cataract surgeon	
2.3	Barriers on the side of the health staff in general	15
3	How to overcome barriers?	16
3.1	What can be done WITHIN the hospital/eye unit?	16
3.1.1	Good surgery: provide cure, not care	
3.1.2	Appraisal of skills and motivation of hospital staff	
3.1.3	Professional ethics	
3.1.4	How can an eye unit tackle the issue of 'fear'?	
3.1.5	Train eye staff to deal respectfully with blind people	
3.1.6	Control corruption: all-in price for cataract surgery	
3.1.7	Always have a cataract surgeon available!	
3.1.8	Alternative ways of payment, better booking and fundraising	
3.2	Social marketing of your eye work	20
3.2.1	VERY IMPORTANT	

a.	Provide precise and full information	
b.	Cataract patients are not always thought of as blind people	
c.	Aim at convincing family members!	
3.2.2	Which communication channels reach the population in your area?	
3.2.3	Radio (or TV?)	
	Educative programmes	
	Identify some 'News'	
3.2.4	Train and involve staff at health-centres, dispensaries, local healers and use posters	
3.2.5	Provide flyers	
3.2.6	Give eye-talks to community gatherings, and provide flyers	
3.2.7	Primary schools	
3.2.8	Provide outreach clinics	
3.2.9	One week of free treatment!	
3.2.10	Organise 'one month cataract surgery for patients without caretaker'	
3.2.10	Visit cataract patients with a 'happy' operated cataract patient	
3.2.12	Find out where your patients are coming from!	
3.2.13	Why did your patients not come sooner?	
3.2.14	Keep records of 'lost' cataract patients	
3.2.15	More ideas	
3.3	Train a staff member to work in the community:	
	a Cataract Surgical Rate worker (CSRw).	25
	What is a CSRw?	
	Good CSRws are extremely cost-effective!	
	Profile for selection of a CSRw: a 'social worker' type of person	
	Means of transport	
	Gender	
	Training curriculum for CSRws and other community cataract workers/motivators	
	Who should train, recruit, employ and manage a CSRw?	
	Budget items to be considered, for employing a CSRw	
	Advice	
	Systematic approach towards the job of a CSRw	
3.4	Collaborate with Official Registrations of Disabled People, CBR Programmes, PHC and HIV/AIDS Programmes, Disability Groups	28
	Official Registration of Disabled People	
	How can CBR programmes assist us?	
	How can PHC and HIV/AIDS programmes assist us?	
	Disability Groups	
4	Post-operative community-based follow-up of cataract patients	30
5	Collaboration with service clubs	31
	Sample of a Memorandum of Understanding between a local service club and an eye unit	
6	Cataract Assessment Monitoring Form	34
7	Useful tools for creating awareness about cataract (surgery) in the communities	36
7.1	Flyer	36
7.2	Cataract Picture Flipchart	36
8	Some research reports on cataract surgery barriers	37
	Feedback sheet	38

Foreword

There are an estimated 50 million blind people in the world. This figure is increasing by 1-2 million every year. The cause of more than half of this blindness is a very treatable disease, cataract. How can this problem be solved?

There would seem to be three essential requirements: firstly the eye surgeon and team; secondly, the equipment and materials; and thirdly and most important, the patient. In many situations the surgeon and facilities are available, but they are under-utilised because patients who would benefit from cataract surgery stay at home.

In this manual Mr Vanneste, who has worked with communities in Africa for more than 14 years, explains the reasons why patients are reluctant to have sight-restoring surgery, and how these barriers can be overcome. The manual is practical and emphasises the need for good planning, efficient management and a desire to listen and respond to the needs of communities and their people.

The knowledge and experience imparted in the manual are important, and can be helpful for all those involved in reducing blindness, whether they are programme managers, community workers or the eye surgeons delivering the service.

Dr Allen Foster
Medical Director of CBM

Feedback

We welcome any suggestions for improving the booklet, particularly any part in which the meaning is unclear or thought to be incorrect. Readers are invited to fill in the Feedback form (enclosed, at the end of the booklet) and to return it to:

CCBRT
 Geert Vanneste
 PO Box 23.310 Dar es Salaam
 Tanzania

A Feedback Form as e-mail attachment is also available from vanneste@intafrika.com

Terms

This booklet aims to communicate with eye workers and health workers in many countries and at various professional levels, for whom English may be a first, second or third language. Drafts of the booklet have been reviewed by an English mother tongue editor and some changes made. The English terms used here have to some extent been simplified, and readers are requested to understand the reasons for this. For example, one might use 'cataract patient' (which has a medical or hospital sound), or use 'person with visual impairment caused by cataract' (which is more acceptable to disability groups in some countries). We have mostly used the simpler, shorter 'cataract patient', but without any wish to offend people who might have preferred something else.

Abbreviations

CBM	Christoffel Blind Mission
CBR	Community Based Rehabilitation
CCBRT	Comprehensive Community Based Rehabilitation in Tanzania
CRW	Community Rehabilitation Worker
CSRw	Cataract Surgical Rate worker
ECCE	Extracapsular Cataract Extraction
ICCE	Intracapsular Cataract Extraction
IOL	Intra Ocular Lens
OPD	Out Patients Department
PHC	Primary Health Care

1 Introduction

The main aim of this booklet is to increase the number of cataract operations within existing eye services, so that less people suffer avoidable blindness or remain needlessly blind.

There are social, cultural, and organisational barriers that limit the acceptability and accessibility of eye treatment, separating hospitals and eye units from people with cataracts and other eye problems.

Some barriers originate with hospitals, and can be solved only there. Even more exist with the patients, their families and the community, e.g. in general health behaviour and cultural/religious beliefs, which can have an important impact on the care-seeking behaviour of patients. These barriers can be addressed by media campaigns and by community workers who reach right into people's homes. However, community-based-programmes are not available everywhere, so hospitals and eye units need to take the initiative.

There are three objectives: to sharpen awareness among eye doctors and staff that most services reach only a minority of all eye patients, and of cataract sufferers in particular; to highlight the commonest barriers that prevent services reaching people who need them; to promote practical ideas on how to overcome barriers (a) within services, (b) by outreach to communities, and (c) by collaboration with existing community structures. Practical ideas are also provided on successful detection of cataract patients, and monitoring outcomes so as to improve services.

The booklet focuses on cataract because it is the world's commonest cause of curable blindness. However, effective measures to overcome barriers between cataract patients and services will also lead to other eye patients being better served. This will happen through improved awareness of eye service availability, better information on costs and logistics, and better treatment at the hospitals and units.

Geert Vanneste
Dar es Salaam, November 2000
vanneste@intafrika.com

2 Barriers between cataract patients and hospitals (eye units)

This chapter addresses the variety of barriers between eye patients and eye services, while the next

chapter shows ways to overcome barriers and to get the services to the patients and the patients to the services.

BARRIERS	
CATARACT PATIENTS FAMILIES AND COMMUNITY	<ul style="list-style-type: none"> • Fear • Cost • Distance • Age • No major problem to be blind. • Not sure about total cost: corruption? follow-up? • Unaware about availability of eye treatment and wrong information • Cultural & religious beliefs about eye treatment and blindness • Being blind also has advantages: taken care off, gets money through begging • Stories by patients (about the hospital) • No major problem to be blind, got used. • Investment no priority to family (survival needs) • No guide/caretaker to accompany to the hospital • (Often) not considered as 'blind' • Bad reputation of former type of surgery (often no spectacles which led to complete blindness!) • Fear for losing remaining vision • Blindness associated with being 'old' • Don't dare to come back after having missed one booking for surgery • Prefers to wait for free treatment from service club • More female elderly people (with cataract) but males have the money • Being blind, their family doesn't have to pay local taxes. • Social role as a blind person • Went but eye doctor was absent • Discrimination against women
	<ul style="list-style-type: none"> • Bad results of former type of surgeries • High cost of cataract surgery • Bad surgeries • Patients came but the eye doctor was not there (was on leave) and decided not to come back • Low motivation of the staff • Price unpredictable due to corruption at hospital • Lack of regular outreach within the community • Patients are booked for surgery at a time that they have no money (and don't dare to tell. Afterwards they don't dare to come back). • Eye doctors spend most time in their private clinics • Former training of health staff: <ol style="list-style-type: none"> 1. 'cataract needs to be mature' !! 2. unilateral => no surgery !! • Hospital has a bad reputation • No public relations and social marketing of cataract surgery
	EYE UNIT EYE HOSPITAL

2.1 Barriers concerning patients, relatives and the community

The barriers discussed in this chapter almost all relate both to the patients and to the relatives, and also to the community members at large. We have however divided them in three parts, referring to the level at which these barriers need to be tackled in order to overcome them.

2.1.1 Barriers concerning patients

Fear

Nobody likes to undergo surgery. Facing eye surgery is even worse.

Especially for cataract patients who are not blind but have low vision or at least some perception of light, putting the remaining vision at risk is absolutely frightening; all the more so, given that the former type of surgery (without IOL) did not give good results.

The good or bad reputation of the eye unit, and of the IOL surgeries performed, will here be a main factor.

Age

Going for eye surgery is frightening for many cataract patients, even more so when they are elderly. Even in their younger years, going to 'the city' may have been an effort, which they undertook only when there was 'no other way'.

This factor of age may not often be the main barrier, but it will often be a reason why comparatively little efforts are made to overcome some of the other factors (detailed below) such as not finding an escort/caretaker, cost, distance, being a woman.

'Old age' is an easy and much-used argument by family members for not bringing in their blind relative. Experience suggests however that often other problems may be behind the reluctance. There may be barriers that are more easily overcome such as lack of information about the total cost, or lack of transport. In this respect, a community based outreach worker can do a good job.

Distance

The factor of distance is closely, but not totally, related to the one of 'cost'. The greater availability of public transport is one of the main reasons why Asian eye units have fewer problems getting cataract patients, than is the case in the African context.

Eye units in major cities will have less problems related to distance. First there is more transport to the city. Secondly, rural people may be used to going to the city for other reasons as well, which decreases the barrier. Thirdly, many rural families know people in the city, or even have relatives, with whom the escort/caretaker can stay. This makes the decision to leave the village easier, and also reduces the cost.

As well as overcoming barriers, we should avoid creating new ones. It seems more strategic in cost-benefit terms to create new eye/ataract surgical units in cities or in major towns that act as a focus for their region, rather than in rural areas; and also to locate units on roads with good transport services.

Slow process of cataract blindness: "I'm fine!"

When someone suddenly goes blind due to trauma or some other condition, even poor communities will usually put some money together to have the person taken to the nearest hospital or eye unit without delay.

Cataract blindness however does not appear in one or two days. It often takes years before the person gets 'functionally blind', and in the meantime nobody realizes that anything is happening. At a certain stage, it appears that the person will need spectacles. The patient may even have tried some old spectacles from other villagers, without much success. Finally comes the day when someone recognizes that the pupils are becoming opaque. They realize that he/she will become blind, and that the patient should be brought to a hospital.

Due to the very slow decrease of vision, however, the rural patient is able to continue most of the daily activities, even when 'functional blindness' has already occurred. Female patients can still fetch water, prepare food, take care of children and feed the cattle. For male patients, given their age, it may be enough that they can still be guided to a place, sit down, chat with others and go to the church, mosque, to community gatherings or the local bar. They remain quite integrated, there seems to be no major problem, basically they are 'fine'.

Consequently, especially in poor communities, people may see no reason to spend money on eye treatment for slow loss of vision in an older person.

Patients think the cataract needs to be mature in both eyes.

In the era of surgeries without IOL, it was true that surgeons preferred to operate only on mature cataracts. Many people were sent away with the message 'come back when both your eyes have mature cataracts'. For decades, also health staffs have been trained/told NOT to transfer patients with unilateral and immature cataracts. We should stress in our information campaigns that this is no longer true for IOL surgeries.

One eye still OK!

One reason for the big gap between statistics on cataract patients and figures on numbers of cataract surgeries is that most patients still have one eye with adequate vision. Unilateral cataract hardly has any disabling effect on rural people. This would be different for instance for a taxi driver, or for a woman who earns her living with a needle.

We should not expect a unilateral cataract to be a high priority for investment, in poor communities.

2.1.2 Barriers concerning close relatives

Aged people: 'no priority'

Families who have hardly enough food or money for school fees may be less likely to spend money for treatment of an old person. This may not only be the case for treatment of a cataract, but also for other age-related health problems.

This factor goes closely together with the factors of fear, and of money.

Cost: 'no money'

The factor of cost is often over-estimated or misunderstood. It is true that people do not have money at 'any' moment of the year. Money is however available at certain periods of the year, for example after harvesting, or when their son comes back from town, etc.... But not necessarily when YOU wish the patient to come in for surgery. So it is important to provide people with some choice about when they wish to come in for surgery. If they are 'booked' at a time at which they don't have money, they are unlikely to appear for surgery and then may be afraid to return for a second booking.

This is one of the reasons why e.g. service clubs provide free surgery during eye camps. It

may not be the right moment for the people to have money available, so the treatment must be free or there may be only a small number attending.

Hospital staff often underestimate the cost for a surgery, thinking only about the 'official' cost of a surgery at the hospital. For patients and their families, however, there is often a wider range of costs:

- buy some small things for the trip (according to local culture on how one should dress when staying in a hospital, maybe some additional food, etc...)
- transport for patient and escort/caretaker
- place to stay for the escort/caretaker, in town or at the hospital
- registration at the hospital for OPD
- ward registration
- fees for surgery
- bribes?
- food for two persons
- post-operative drugs
- post-operative medicines
- small gifts, if staying with a relative in town
- loss of income for the escort/caretaker, for the duration of the trip
- transport back home.

Even if the cost is high, when people are aware of the TOTAL price and know that they can go for treatment at any time of the year, then a time will come when they have the amount of money needed. We therefore advise hospitals/eye units to advertise an 'all-in price' for cataract surgery (see section 3.1.6).

No escort/caretaker to accompany

By far the most cataract surgeries performed in Africa are on unilateral cataract patients. The reasons are simple: (a) on average they are a bit younger and more mobile; but most of all (b) these patients still have vision in the other eye, and do not need a close relative to take them to the hospital. Even if they do wish to have an escort/caretaker, it can be anyone of the village, as there is no need for assistance with very personal activities such as washing, clothing, toilet.

Not having an escort/caretaker is however one of the main barriers for blind cataract patients to come for surgery. In fact, one close relative needs to accompany the patient, which means someone needs to make him/herself available for a certain

period of time. This also increases the cost of transport, accommodation and food. Even more, there may be a loss of income for the escort/caretaker for as long as the trip will take.

One can see that community-based workers can have a very important role to play in overcoming this barrier, by making clear the advantages of surgery, and thus encouraging the family.

Discrimination against women

In most countries, there seem to be more women than men, and women tend to live longer. (It is not so in South Asia, where gender discrimination acts at every stage to reduce women's lives). The greater number of women in most countries, and their longer lives, should result in more women getting cataract and being presented for surgery.

The reality is often different. In some areas, up to 70 % of operated cataract patients are men. Is it because they 'have' the money? Is it because women are mostly not the breadwinners and consequently are considered of less importance? Is it because of the general discrimination against women, which results in giving priority to men's problems such as daily access to alcohol or other types of leisure? Is it because in some cultures women do more hard labor than men, resulting in being less mobile in old age and less likely to go for surgery?

Discrimination on gender grounds is of course very culture-related, and it may take generations to overcome. However, community workers can have an important and very effective role to play, in encouraging the families to bring women for surgery.

Social roles of blind people

The common image of blind people being 'unable to do anything' is wrong. Due to age, their roles may indeed be limited; but blind people do have roles to play. In some cultures, particularly in Muslim countries, some tasks are customarily allocated to blind people, like in Egypt, where blind men are often the ones to give the call to prayer from the mosque or to recite the scriptures at the start of any public event.

Also at home, especially in poor communities, simply everyone, including the blind, has a role to play. Often, blind people more than others will have roles that are very functional to the family.

They 'take care of the house' or of the children, they are 'always there', 'always available'.... and so make it possible for others to be out more often than they could be if the blind person were not in the house. These realities certainly contribute to eye surgery not being regarded as a priority by many families and sometimes even to them refusing a treatment when it is offered.

Unsure of total cost: corruption and follow-up treatment

Corruption at the level of the hospital is an important barrier. Firstly it increases the total cost. Secondly, it makes the price unpredictable which is an additional barrier for family members to decide for treatment and to contribute to the cost. 'Who knows what it will cost! Maybe you will run out of money and have to come back without treatment', is often heard. Thirdly, even when people have enough money, they naturally resent being forced to pay bribes.

Also the situation of not knowing whether follow-up and consequent costs will be needed after the surgery makes an additional barrier. It will therefore be important to provide free follow-up services and make this clear through your information campaign.

Wait for free treatment from a service club

Wherever Service Clubs have been organizing free eye treatments, people are likely to wait for surgery 'until they come back'. Often, however, 'activities' only take place once a year and then can serve only a small number of people.

Wherever permanent eye units are available, it is therefore highly recommended that Eye Units and Service Clubs would work together. We shall elaborate on this in chapter 5.

2.1.3 Barriers in the community at large

Information barrier: unawareness that cataract treatment exists

The fact that most cataract patients don't come for services, even if surgery is available, is not an isolated problem. It is part of people's general health behaviour, which is often restricted by lack of information.

Regarding cataract surgery, this is only the first or second generation of people for whom modern, highly effective, very low-risk operations

2.2

have been available. Until recently the only 'modern' type of surgery that was available required thick post-operative lenses and provided only very poor vision, leaving some patients functionally disabled.

With a poor, ageing population in rural areas, and with the better-off young generations leaving for towns and cities, the information on available services reaches the rural areas very slowly. Much work remains to be done by the eye units as well as by community-based programmes to provide health education and information on available services.

Cultural and religious beliefs about blindness and eye treatments

People sometimes try to avoid surgery through a particular interpretation of religious or cultural beliefs. For example, some Muslims and some East Asians do not wish to have cataract surgery, as they believe that their body should remain complete and whole if they wish to enter heaven. The very small loss of body (eye) liquid in cataract surgery is enough for them to choose to remain blind. (If this seems a strange belief to people who do not share it, we should remember that every religion and culture has some parts, or some interpretations, that seem equally strange to outsiders.)

There is no point in telling lies to people who see an obstacle of this sort. A good approach is to try to make use of positive resources within that same religion or culture. For example, one may visit such patients together with another Muslim who has had a successful operation, or even with one of their Mosque leaders, if these people feel that there is no strict religious reason against cataract surgery. Interpretations of religious rules seem to vary, and to change over time, as modern technology makes better treatment available.

In many cultures, there are blind people who are so highly respected that there is no way that anyone would suggest bringing them for surgery! Of course, it is good that these blind people have a position of respect, which may have some positive impact on attitudes towards disabled people in general; but it may have the unwanted side-effect of reducing the motivation to seek treatment, even when the blindness is curable.

2.2 Barriers concerning the hospital (eye unit)

2.2.1 Quality of the surgery and general handling of the patient

Successfully operated ex-patients are the best promotion for your cataract work. It is therefore essential that people are generally well treated at the eye unit by all the staff; and of course, that the quality of surgery is good (see 3.1.1; 3.1.2).

2.2.2 Lack of active social marketing and 'public relations'

Many of us know the picture of the cataract-blind child with an earring made of an empty Coca-Cola tin. The area in which the child lives obviously has access to Coca-Cola, but seemingly not to cataract surgery.

Good soft drinks are made all over the world, but people seem to prefer Coca-Cola from Atlanta. Why? The drink may simply be tasty, but the main reason is of course the worldwide advertising campaigns, which the company runs on a permanent basis. It would be very interesting to compare the total publicity budget of Coca-Cola with their over-all budget. It may well amount to 20-30%. By contrast, what are eye units doing to create awareness? Apart from the publicity generated by treated patients the awareness-creation activities in many cases are zero.

Making publicity for health services is in most (all?) countries even subject to restrictions and rules, probably also for good reasons. However, lack of awareness and information on existing health services is one of the main reasons why many patients remain untreated. There is some work here for health policy makers. Further on, we shall provide ideas on how to circumvent this problem.

2.2.3 Private practice by eye doctors

Developing countries still have very few ophthalmologists, and they are not distributed according to the needs of the population. Many of them want to control cataract blindness through a profit-making business approach instead of a service approach.

The result is that the very few trained ophthalmologists tend to congregate in cities, doing either full-time or part-time private practice. So even when cataract services are available they are not affordable, with the result that even less surgeries are performed at eye hospitals.

2.2.4 High cost of cataract surgery

We have to acknowledge the different situation here of 'eye hospitals' or eye units with a certain independent functioning within general hospitals, and eye units that are run under the over-all administration and accounting of a general hospital. The latter will have to be very diplomatic, if they wish to implement some of what follows.

Approximately 90 % of the costs for running an eye unit are 'overhead costs' such as maintenance of infrastructure, staff (salaries), administration, security, cleaning. Consequently, whether a hospital provides 100 cataract surgeries per year, or provides 500, still 90% of the costs do not change. Only the other 10% would then become higher. This is just one more reason for trying to increase the number of good-quality surgeries, to make a more efficient use of the investment in overheads.

For 'independent' eye units, there is an interesting way of looking at this. The higher the price to the patient, the more patients can't afford it and don't turn up. Since the overhead costs must still be met, each 'no-show' patient increases the unit cost (or 'real' price) per surgery. On the other hand, if we reduce the price to the patient and promote this by effective advertising, than more patients may come which in turn reduces some of the costs per surgery.

As far as 'lack of money' is a barrier to cataract surgery, there is something like 'poverty related cataract patients'. By providing more surgeries, an independent eye unit is in a position to reduce the price for surgery, and to offer surgery to greater numbers of people.

As mentioned above, this may be difficult in general hospitals, where cataract surgery is often an important source of income, needed to subsidize other important treatments, which are even more poverty-related and affect young people.

2.2.5 Corruption makes prices unpredictable for the patients

A cataract patient once told us that she had to 'provide tea' (meaning that she had to give bribes) to three staff at the hospital before she had been attended by someone who 'looked into her eyes'. Is this an extreme case? Unfortunately it is well-known that in some hospitals, bribing three staff may just be the average of what one has to do up

to the moment of returning home after surgery. This increases the cost for the patient, but even more important it will be communicated to the village where it becomes an additional barrier for other potential patients. This means that corruption not only directly increases the cost of surgery for the patient, but also has indirect effects, as less patients will risk the investment of going to the hospital.

2.2.6 Low motivation of eye staff

Eye units suffer of course the same problems of other components of the social sector. It would however be wrong to think that nothing can be done to improve the motivation of your staff. Do they have a clear job-description, providing them with their own responsibilities, or is everyone responsible for everything? Do you have ways of enhancing the status of your best staff? Is there some way in which they can come up with good ideas, which may improve the eye unit? Do you involve your staff in management meetings? Do you provide additional training, upgrading and opportunities for appraisal? Do you involve them in training people within the community on eye problems? Do you evaluate and show appreciation for their work? (see chapter 3).

2.2.7 No permanent cataract surgeon

Often people will tell us that 'one day' they brought their blind family member to the hospital, but the eye doctor 'was out'. He/she may have been attending a seminar, maybe was on home leave, or just sick. He may also have been 'too busy' with administrative matters. They were told to 'come back', after which they decided to return home. Afterwards, not being sure if the same would occur or what would happen, they just could not decide again to invest the money for the long trip. The other people within the village of course quickly knew the story of what happened. Some people had already told them that there was no cure for cataract, and even felt that this had now been proved, since the 'main hospital in the region had been unable to assist'...

The same often happens with patients coming to the hospital on e.g. a Thursday or a Friday, and being told to 'come back on Monday'...., or when patients have to be sent back home because the eye unit ran out of IOLs...

2.3 Barriers on the side of the health staff in general

Some years ago, before IOL surgery became available, indications for cataract extraction were strictly:

- When the patients with cataracts in both eyes had marked reduction of vision for counting fingers, or even less vision – preferably mature cataracts.
- In case of unilateral cataract, a surgery would only be considered as treatment for preventing complications of the cataract, as the vision in the other eye was still good. The patient's vision would then however not improve when prescribed aphakic glasses.

These indications reflected very much the teaching to medical and paramedical eye staff, stressing NOT to transfer an immature cataract patient for surgery as this would make surgery more difficult and then the patient would not gain better functional vision after surgery.

Another reason why health staff used to be (and still are!) reluctant to send cataract patients for surgery was that operated patients could not afford to buy the post-operative spectacles or simply could not get hold of aphakic spectacles. This might turn the whole investment into a waste of money. It often resulted in blame falling on the health worker who had transferred the patients for surgery, and also in general dissatisfaction in regard to cataract surgery.

The ECCE + IOL type of surgery has however changed the situation completely. Unilateral and single-eyed cataract patients can be operated with good result, and those with bilateral cataracts no longer need to wait until they fail to walk unaided! It is therefore important that eye units undertake efforts to explain very clearly this change of technology to all health staff in the region, and in particular ophthalmic assistants, community eye nurses etc... To do so is as important as the continued efforts to provide in-service training on ECCE + IOL to eye surgeons.

3 HOW TO OVERCOME BARRIERS?

3.1 What can be done WITHIN the hospital/ eye unit?

The overall reputation of the hospital or eye unit is of course very important. Don't expect low visioned people to risk their remaining sight, by going to a hospital of which they 'expect the worst'. A strong organisational structure with competent well utilized personnel at all levels is required to lessen different types of constraints and overcome barriers.

However, even very good hospitals face a lot of barriers. There are several strategies by which these can be overcome.

3.1.1 Good surgery: provide cure, not care

This is not a booklet about how to perform technically good cataract surgery. However, it should be said here that providing good surgery is by far the best publicity, and is a prerequisite for long-term success with your other means of overcoming barriers.

With this in mind, we strongly advise that one rather 'neutral' person at the eye unit should take the visual acuity of all pre- and post-operated patients. These data on 'vision outcome' should be carefully recorded and preserved for regular monitoring and evaluation. This will stimulate surgeons to raise the quality of their surgery, rather than being satisfied merely with statistics on quantity.

The importance of good quality surgery is shown by the fact that in many eye units that have started IOL surgery many more patients suddenly came in. Certainly, while the former type of surgery was more like 'care', the ECCE/IOL type of surgery is very much like 'cure' and automatically generates more convincing publicity! Probably there is also more widespread publicity, as IOL operated patients have such good vision that they more easily regain their former mobility and social life, and the message reaches more people. The better patients can see, the more likely they will become 'mobile promoters' of cataract surgery.

However, even technically competent surgery can generate negative publicity. The public judges surgeons not on the technical quality of intervention, but on regained sight/vision. The braver you sometimes may be as a surgeon, the more you may be confusing the public by sending cataract patients back with only little progress.

Avoiding the risk that less successful surgeries become barriers

- a) Before doing a surgery, it is important to counsel/educate the patient as well as the escort/caretaker(s) on the prognosis of the intervention.
- b) Giving even a symbolic reduction on the price of surgery may be an appropriate means of underlining for the patient and escort/caretaker, and also for the stories the community members will hear at their return, that this was not a regular cataract intervention with the usual prognosis.
- c) In case of patients going back to a rural village, it is very useful to provide them with a letter for their local chief, explaining in simple terms the reason why this cataract surgery has not been as successful as it is usually is.

In other words, even if the outcome can't be perfect, make sure people return home with the message that cataract surgery normally has a very good outcome, and that the people at the eye unit are 'serious'.

3.1.2 Appraisal of skills and motivation of hospital staff

A good or even high salary does not guarantee that staff will be fully motivated. Some elements that can help are:

- Make sure that each staff member has a job-description clearly indicating their own responsibilities. It is very important that each staff-member has a well-defined area/task for which he/she is solely responsible when on duty. For example, if one person is responsible for the operating theatre, things will go better than if three people are supposed to be responsible at all times.
- Find ways to increase the status of your staff, within as well as outside the hospital structure. Install a 'Best Staff-Member of the Month' award; let them represent/promote the eye unit in social community gatherings; involve eye nurses in training people within the community on eye problems; etc...
- Involve as many staff as possible in management meetings, let them voice their ideas and take into account what they think. Create different ways through which they can come up with good ideas to improve the eye unit. Even if some suggestions are not practicable, thank

each contributor for offering their input.

- Provide additional formal and informal training. Give certificates.
- Have regular internal and external evaluations. Involve former patients.
- Show appreciation for the work of staff at all levels. Let them know and feel that their work is as essential as the work done by the eye specialist.

In other words.... this is all about facilitating the difference between this:

"I'm an **eye surgeon**, not a sociologist! My job is to fix eyes, not to reorganise the financial priorities of rural families!"

"I'm an **eye nurse**. It's up to the management if they want to have an advertising campaign or change the price of surgery."

"I'm paid to **clean** the floors and toilets and empty the bins. It's not my job to talk to patients or families. I just wish they wouldn't make such a mess all over my floors. You'd think they were blind, some of them!"

AND THIS:

"I'm the **eye surgeon**, but in this unit we work as a team. I take an interest in everyone's work and we all help each other to solve problems. Many of our staff have unexpected skills, apart from their actual job. For instance, our driver speaks four tribal languages, which is very useful when patients come in from the hills."

"I'm an **eye nurse**, and I also go into the community and do awareness sessions in schools. I've learnt a lot from the community worker, and she has learnt a lot from me. Together we run a team of volunteers who are keen to bring cataract patients in for surgery and to make things run smoothly."

"I keep this place **clean**. In the old days, the surgeons never used to say even 'Good Morning' to us cleaners. But under the new director we are part of the team and they notice our work, and it's a happier place now. They gave us a talk about the patients and the eye operations. Now I understand what goes on in the operating room. Sometimes I have a word with the patients, to cheer them up!"

3.1.3 Professional ethics

Issues of professional ethics should be discussed during staff meetings. It will be important to give examples of situations that go against good ethics.

In order to give an opportunity to the patients to voice their experiences, you should have a simple 'message box' with writing material and paper available, through which patients can express themselves straight to the management meeting. Discuss these messages openly in meetings with all staff.

It may be good initially to organise a formal training on professional ethics done by some local experts. Make sure that you, as a manager, are also present!

3.1.4 How can an eye unit tackle the issue of 'fear'?

'Fear' is closely associated with the fact that cataract patients still have some remaining vision. Putting this at risk by going for surgery, is the main reason why patients fear treatment.

In addition, the former type of surgery was known not to give a very good result. People often remained functionally blind. We can hardly expect people to put their remaining sight at risk for something in which they do not have much faith.

It is therefore important that we create a lot of awareness about the improved quality of services through IOL implants. We should very actively promote the 'new type of treatment' (IOL) for cataract, so that people know and believe that much better treatments are available now.

Many people will still not be convinced. One very successful way of convincing those people will be to visit them accompanied by a successfully operated and happy patient, who can explain how well he/she is now seeing. We will explain below several practical ways to go about it.

It also happens that patients get scared when they are already admitted. They may have heard stories by operated patients in the same ward. A good way to assist these people is to employ an operated patient at the hospital as a cook, gardener or cleaner and to teach him/her how to counsel such patients.

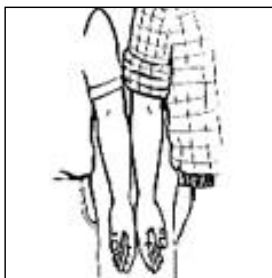
3.1.5 Train eye staff to deal respectfully with blind people

As we are dealing with a majority of rather elderly people, sensitive and demanding as they can be, the way that your patients are generally treated at the hospital will often be as important a promotive factor (positive as well as negative), as the quality

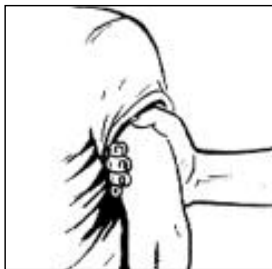
3.1

of surgery. Did your eye staff receive some training in how to guide blind people properly? Did they learn about the practical problems, and special needs? In a one or two-day workshop, an experienced rehabilitation worker from a nearby school for the blind or a CBR programme, will be able to teach your staff the skills needed for dealing competently and respectfully with low visioned and blind people.

In terms of guiding a blind person, the three main techniques are the following:



1. *Establishing contact: lightly touch the back of the hand of the blind person and say: "Please take my arm."*



2. *The Blind person should take the arm of the guide above the elbow, and hold it firmly so as not to lose contact with the guide as they walk forward.*



3. *While walking the guide should keep the arm in a normal position. Walk slowly. Don't forget: the person is blind, not deaf (!), so please talk to the blind person and certainly tell him/her where you are going.*

By the way: eye workers as well as other staff often tend to speak only to the escort/caretaker of the blind person and not at all with the blind person, which is very disrespectful towards the latter. Note that it is the blind person who is most in need of information, not only because he/she is the person who has to undergo each and everything, but also because ... they do not see what is happening!

3.1.6 Control corruption: all-in price for cataract surgery

Staff demands for bribes, which are a form of theft, cannot be avoided completely but can be made more difficult. One way to do so is to have a single standard all-in price for each treatment, and to provide this information in clear wording and on posters to the escort/caretaker and patient at arrival. Once they know that e.g. they will pay 30 US\$ in total, and that this includes registration, all treatments and surgery, post-surgical care and food, then they will be less likely to agree to staff demands for bribes. They may also be less afraid that a denial of the request for bribes will lead to a refusal to provide treatment. At the same time, when the total price is predictable and is known by all, other patients back home will know what amount is needed and will more easily decide they can afford the money. Then as soon as they have it, they come for treatment.

Your promotion campaigns for cataract surgery will also be more effective when you are able to inform people of one all-in price.

3.1.7 Always have a cataract surgeon available!

To avoid the risk of people being turned away at certain periods of the year, even after all the other barriers have been overcome, you should have a cataract surgeon available at all times. If not, you will get a lot of bad publicity in the villages, where some people will imagine that the return of the cataract patient as a person still blind simply confirms that 'there is still no (accessible) treatment'.

Here collaboration is indicated between eye units, which can exchange staff; or if needed, collaboration with international organisations which are often happy to send an experienced surgeon for 2-3 weeks, to replace a permanent surgeon 'on leave'. Also service clubs can be good partners in solving this problem.

Ensure that at all times there are sufficient consumables and IOLs in stock, so that a sudden shortage does not result in patients being sent away untreated.

3.1.8 Alternative ways of payment, better booking and fundraising

There will always be people who cannot afford to pay for cataract surgery. Should they stay blind?

Most hospitals do have some alternative ways

of payment or provide free surgery each year to a certain number of poor patients. Yet the fact that it is done 'on a charitable basis' does not mean that it should be done casually. A careful, systematic approach is more likely to result in poor people finally getting surgery. Some ideas:

Social Worker.

If you can afford it, employ a social worker to interview those people who 'say' they can't afford the cataract surgery (or other treatment). If you can't afford a social worker, then maybe one of the administrative staff can give this a try. An experienced person will know how to make a distinction between the 'real poor' and others. This social worker should have some alternatives to offer such as:

a. Payment in instalments.

In some countries it does work to let people pay part of the cost at the time of surgery and to let them and their escort/caretaker sign an agreement to make further payment. The fact that we are mostly dealing with 'respectable' elderly people, who want to set an example to others, adds to the feasibility of this system.

b. Find other cataract patients.

One system that has been successfully tried is to have the relatives of the cataract blind person search for two other cataract patients (= 'people with the same problem in their eyes') in their own area. When they get these people to the hospital, and provided that these patients pay the normal price, then their family member gets free or cheap surgery.

c. Reduced price.

Why not have three prices? One rather expensive price will be for people who wish to have a private room, some extra comfort and better food. A second (normal-standard) price will be for people who stay in a ward with not too many beds and get basic food. A third cheap 'sponsored' price will be for people who stay in a ward with many beds and family members have to bring food. This last category may be sponsored through the first one.

More appropriate system of booking surgeries.

Even poor people may have funds at certain times of the year. But not necessarily when YOU wish the patient to come in for surgery. If their surgery

date is booked for a period when they do not have money (though it may be a time convenient for the eye unit), they are unlikely to appear for surgery. They may also be afraid to return later to make another booking. Let them choose their date for booking. It does not necessarily have to be the first open spot in the register.

The process of booking the date and the way it is handled may seem like 'simple routine' to the staff, but it can be very important to the prospective patient and escort/caretaker, especially if they are poor and worried. They have often had a journey, they have waited some time, they have been seen by a doctor, there have been some unfamiliar and worrying tests, they have usually been told things that they did not fully understand, a decision has been taken, they may have signed some papers without being able to read the small print, and they are drawing near to leaving. Whatever they may have said or agreed to earlier, the time when they see their name being put down against a date in the register will symbolise a contract or commitment.

This may be the point when they finally come out with things that will affect the question of whether they do actually return on the date, have their surgery, and make some payment; or whether they go away and are never seen again. The balance may swing one way, if the person booking the date listens sympathetically and communicates that the staff are looking forward to the return of the prospective patient for a successful outcome. It may swing the other way, if there is any impatience, indifference or feeling that needy people should be grateful for whatever is given to them. Things said at this time by prospective patients and escorts may be a useful indication of the sort of barriers that remain in people's minds, which may still need to be addressed by the hospital or unit staff.

Some 'poor patient' fundraising at hospital level

Develop a flyer on cataract, in which you explain about the great numbers of poor blind patients in your area, who 'can see again'. Provide this flyer to your 'wealthy' patients (and to their family members) and ask if they wish to contribute to the payment of a surgery for a poor patient.

3.1.9. Provide more information to patients admitted in the eye ward.

A hospital is a strange environment to any patient, and certainly to visually impaired people. They may have lots of questions, whilst all people around them seem extremely busy... Several staff may have the duty to provide different types of practical information, but do they really do so? Always?

For the comfort of the patients, in order to make sure that new in-patients are well informed, one easy system is to play an audio tape 2-3 times each day, including information on practical issues such as duration of stay, payments, follow-up after surgery etc...

Before and after the spoken text, some music can be played which alerts patients for the message to come. Any information relevant to their stay can be included, but don't make it too long.

Having heard this information several times each day, your patients are also more likely to spread the same 'correct' information to others once back home, instead of wrong information which they somehow picked up from others...

Which is one additional way of avoiding barriers.

One example is the following:

Example of content for an audiotape to be used in a specific Eye Ward – to be played twice per day at fixed times.

(starts with 10 seconds of local music)

„Dear patients,
Welcome to the eye unit of ...(name hospital ...)!!
We are very happy to have you here with us. We do everything we can to make your stay as pleasant as possible. We are here for you. Therefore we will tell you more about how the hospital works.

This is a message for patients who are admitted for eye surgery. Most of you stay here just for two nights, one night before the surgery and one night after. When the doctor sees that your eyes are OK, he/she will tell you when you can go back home. He will also tell you when to come back for a check up of your eyes. The check ups are free of charge, till two months after your stay here. When you come for your check up, it is important to bring your discharge card with you! And also take some extra money in case you need more medicines.

Please note that the payment you have made

for the surgery covers ALL your costs. This includes the examinations, the surgery, the bed, hospital uniform, and also your food from the day you arrived till you will leave, is already included. So during your stay here, nobody should ask you to pay extra money.

For everybody who gets the doctors advice to buy spectacles, you can go to our spectacle shop. For already Tzs 4.500 you can buy spectacles there.

The petty shop is open from 8:30 a.m. till 5:30 p.m. There you can also buy telephone cards. There's a public phone at the entrance of the hospital. Your family members can visit you only between:

7:00 – 7:30 a.m.

1:00 – 2:30 p.m.

4:30 – 6:00 p.m.

If you need more information about our hospital and our services, our nurses will be happy to advise you. If you have any suggestions or remarks on how to improve our services please let us know.

All the staff of the CCBRT hospital again welcomes you, and we hope you will tell other people about our services.

THANK YOU“

(+10 seconds of local music)

3.2 Social Marketing of your eye work

Depending on the demographic, geographic and topographic type of area where you are working, you will decide on the type of communications/publicity that will be cost-effective. Ideally you will use several systems and try to find out at your eye unit about the most cost-effective ones. Ask your staff at the registration desk to find out how the new patients got to know about your eye unit, so that in the future you will be able to focus on the most cost-effective means of communication with the public.

3.2.1 VERY IMPORTANT

a. Provide precise and full information

If lack of information is a big barrier, lack of correct and full information may sometimes be an even bigger barrier. You can be sure that any information which you do not provide, will be filled in by guesswork, imagination, stories, in other words by additional barriers.

Therefore, whatever type of communication channels you choose, the information provided by any of your 'advertisements' (radio-mes-

sages, flyers, brochures, posters) should be as complete as possible. They should indicate:

- 1) How much will the cataract operation cost IN TOTAL, including registration, examinations, all treatments and surgery, post-surgical medicines, food, etc... We already mentioned above that an all-in price for cataract surgery is indicated.
- 2) Number of days to stay at hospital? Minimum? Maximum?
- 3) Should the escort/caretaker stay at the hospital? If yes: cost for bed? Food?
- 4) Is food provided / available at the hospital? Price? Or should they bring food, cooking utensils, firewood?
- 5) Should they bring bed sheets, mattress?
- 6) What is the cataract operation all about? (What is it NOT about?). Let them know it's safe. Provide the number of patients treated over the last years...
- 7) Expected result? E.g.: 'almost all' operated cataract patients get good vision restored.
- 8) Will the patient later need to come back for follow-up? Cost? (preferably free).

b. Cataract patients are not always thought of as blind people.

Whatever means of communication and cataract detection you find most appropriate, do not talk of cataract patients as 'blind people'. As we explained above, even functionally blind people are often not thought of as being blind, and may be disregarded if your information campaigns and detection systems focus too much on 'blind people'. It is better to speak of 'people with a very bad vision and with white pupils'. However, in many cultures there is a local term for cataract that is well known by the people.

c. Aim at convincing family members!

Family plays an important role in the lives of rural people. Not only for financial and for practical reasons (transport, escort/caretaker) family members are a main key to cataract surgery. What they think about blindness, medical treatment in general and eye care in particular is very important.

We have seen posters and brochures that aimed primarily to convince cataract patients themselves. Our information campaigns and detection systems should be aware that the family members, often

more than the cataract patients, need to be informed, counselled, and convinced. Information on the 'new' type of (IOL) cataract surgery, the limited risks, and especially the very good results, is also very important.

3.2.2 Which communication channels reach the population in your area?

Ask yourself the following questions:

- Is there only one language spoken or many?
- Can most people read? (If so, in which language?)
- Do many people read the newspaper? Which newspaper?
- Do many people listen to the radio?
- Do many people watch TV?
- What methods of advertising are being used by government and business?
- Which advertising campaigns have been popular?
- Is there a type of social gathering attended by most people? Church? Mosque? Political? Administrative?
- Can most people easily reach us (by road, public transport), or shall we have to reach them for screening (mobile clinics)?

Note: the opinions of your ward orderlies, drivers and cleaners about the success or failure of an advertising campaign may be a more accurate guide to its impact on the 'general public', than the opinions of your senior staff!

Depending on the answers, you may decide to use some of the following means of communication.

3.2.3 Radio (or TV?)

Certainly in areas where only one or two languages are spoken, this may be a very cost-effective way of creating awareness. 'Publicity' for eye care may not be allowed or may be expensive but there are other ways:

Educational Programmes

Most radio and TV stations have educational programmes, for which they are even more likely to get funding from government or donors. So they are often searching for issues that appeal to the public. For many reasons, the issue of cataract may be attractive to them. "Half of the blind people can see again! Cure is available!" (Be

sure that 'blind people' extends to include those with low vision, or who still have one good eye!)

Try to get involved in some educational programmes on health issues. This will be free publicity for your eye work and may reach out far into remote communities where the radio may be the only 'permanent' contact with the outside world and thus a popular source of information and discussion.

Note: for a radio talk it may be better to ask an experienced eye-nurse or an eye-trained social worker, rather than an eye doctor who is used to giving formal lectures to general health practitioners!

Discuss with other staff how to keep a balance between using a 'friendly, informal' tone and the need to communicate accurate information with a sense of urgency.

Identify some 'News'.

Another way to get some free publicity on the radio is to identify a reason for your eye unit to become subject of news-coverage. Did you perform the 1,000th. cataract surgery?? Invite the local governor, and the press including the radio/TV. In addition, provide the lucky 1,000th patient with a cheque refunding the cost of one cataract surgery! It may not be much money, but from that moment on everyone may know the price of one sight-restoring cataract surgery at your eye unit.

(PS: you may have to give an incentive to the journalists, and to the governor; but perhaps his mother may even have a cataract....).

3.2.4 Train and involve staff at health-centres, dispensaries, local healers and use posters

It is a well-known fact that the majority of untreated cataract patients have been 'seen' at least once by a health worker at the local health unit. It is remarkable that these health workers are often unaware about the services provided by your eye unit.

How to involve them? You may pay them a visit and even provide them with some training. Don't over-train. Let an eye nurse provide the training, at an effective, practical level. There is a lot of literature on curricula for this type of training (see section 3.3 below).

It will be very useful to invite them to your eye unit. Let them meet and talk with your staff. Let

them observe a cataract surgery. If one or two show a particular interest, arrange for them to visit again soon to develop their knowledge further.

Don't let this remain a one-time event. Invite them once a year. Provide a small gift to the health worker who has sent most patients for surgery. Once a year, provide some calendars or diaries or send them a 'happy new year' card. Let them know that they are part of the common aim of preventing blindness.

Still, some eye patients attending the health unit will not get the information they need. An additional poster, well positioned, can provide further information to their family members. Keep this poster simple. The main message should be: "Eye problems? This is where to get help at affordable prices. Cataract surgery is also available and cheap." Have a local artist produce it for you. A local businessman may be happy to pay for the cost of printing, if you are willing to let him put his business name and logo on the poster.

There have been good experiences of training 'local healers'. Generally, these people are happy to work together, as long as they are able to provide better services. It is important in a tactful way to show them the (often irreversible) results of some of their medications. You may be able to provide them with some of your better drugs, or to convince them that for some type of problems they will do a good service to their clients by referring them to your eye unit. This will certainly be the case where cataract surgery is concerned. Getting to know the local healers, respecting their social role, inviting them to your eye unit and even provide training, or at least communicating with them in a friendly way, will always be better than simply competing with them and refusing any type of contact.

3.2.5 Provide flyers

Many people have made good use of small flyers (approx. 10 / 8 cm). These can be printed very cheaply, especially because printing companies may have a lot of waste paper, which is still large enough for this purpose. Compared to e.g. radio the flyer has the advantage of carrying fuller and more reliable information. People can save them and so become less reliant on guesses and stories.

The text should be simple, and it may be important to add a small map indicating the eye unit loca-

tion. See section 7.1 for an example of such a flyer.

Producing flyers is one thing. Getting them to the right people, at low cost, is another. Flyers will usually not be aimed directly at cataract patients, as most of them stay home and may be too low visioned to read. So who is your best target person? Their grandchildren who are now at school? They are certainly easier to reach. Their children who are now young adults? How to reach them? In social gatherings: schools, religious, political, administrative, social?

Think about getting a free ride on an existing distribution system. For example, can your flyer go out in every copy of a local newspaper? (Next day most copies of the newspaper are thrown away, or cut up for other uses; but people may save the flyer if they think the information is worth keeping.)

Decide for yourself what is feasible. The next option may even be better.

3.2.6 Give eye-talks to community gatherings, and provide flyers

Simply handing out flyers can be done by 'anyone', which makes it very cheap. More effective will be to provide some basic information on your eye unit in general and on cataract in particular and complement the information by providing a flyer summarizing the essentials. For this, however, you will need to have your staff going out into the communities or to train other people at community level.

We strongly recommend making a standard protocol for this type of eye-talks within the community. Of course, some community workers or other people whom you may engage for the job may perform well after just some basic training. On the other hand, if you make a standard presentation, from A. 'What is a healthy eye?', to B. 'Cataract', to C. 'Cure is available and cheap', with D. being the distribution of your flyer, then you will be more certain that a competent job is being done.

Giving out flyers at the end of the presentation will assist the 'public' to take home a fuller and correct story of what they heard.

Also effective is to show an IOL lens during all your community eye talks. Let people hold it. This will generate additional inspiration for talks on cataract surgery once back home.

3.2.7 Primary schools

Some of the most effective promotion for cataract surgery has been done through the use of primary school students. It is quite simple and not necessarily expensive. The human resource needed can be a member of your eye staff or a Cataract Surgical Rate Worker (CSRw, see section 3.3 below) or other community health workers or even volunteers. These people will seek permission to have 30 minutes time in each classroom of a certain primary school. Start not far from the Eye Unit, where there is a road and public transport to the Eye Unit. Again, develop a standard procedure for the presentation (see above). In primary schools, the presentation needs to be very focused, simple. Concentrate on cataract. The large cataract picture book available from the Fred Hollows Foundation is an ideal instrument to be used (see chapter 7). It simply provides eight black and white pictures, designed so that the presenter will tell a short story with each picture. It makes clear how to recognise cataract; that in the past treatment for cataract was not so good; that now good quality (IOL) treatment is available. The community worker of course explains where to get this treatment. According to the local situation of your eye unit other information can be added, preferably also on a flyer.

After or during this brief talk on cataract, the presenter asks who has grandparents, or who knows people who already had cataract and who got surgery. Let these children talk. Some will say they know someone with cataract, but who did not go for surgery. Certainly, provide a flyer to those children. Better is to collect information on the locality/home of these children/patients and to pay home-visits. Most effective is the system where the presenter has a motorbike at his/her disposal after the 'lesson' he/she accompanies some of the children to their homes.

It is also possible to make this into a more regular school activity. Provide the teachers with a simple notebook and encourage them to ask once a week if anyone has found other cataract patients. Let them register the results, which you check once a month. Provide a small gift or award for the most successful teacher and the most successful pupil in each class. It can become a competition. Teach children a simple and catchy song that includes the name of the eye unit, 'cataract', and that 'children are helping to stop blindness'.

3.2

Of course, this will be easier in the context of a community-based programme; however, you may consider this to be a worthwhile additional component to your eye unit. The next chapter will provide more ideas on how to go about this.

3.2.8 Provide outreach clinics

Mobile outreach clinics have been provided since the first 'modern' providers of eye care began working in Africa and Asia. Most eye units in developing countries run some mobile outreach work.

Outreach clinics tend to see lots of itchy eyes, presbyopes etc. Their success has often been judged simply on the 'number of people seen', rather than on the added value in terms of vision. Which do you think is the better way of evaluating success? Be careful - outreach clinics tend to encourage people to stay at home and wait for help to come, rather than making their own effort to attend an eye unit as soon as an eye problem occurs. Rather, advertise outreach clinics for 'people who cannot see well in the distance', 'elderly people with white pupils', etc.

In terms of prevention of blindness, it is ineffective to look at outreach clinics as a long-term strategy. Consider them as one step towards raising awareness about this 'modern' type of eye care in general and for the services provided by your permanent eye unit in particular. Outreach clinics are expensive and are quite a luxury in poor communities. In order not to waste resources it is important that within a limited timeframe people with eye problems will automatically go to the nearest eye unit. As part of this strategy the clinic should always start with an eye-talk, explaining the most common eye diseases in the area, of course also about cataract and about your eye unit, where it is and what are the prices for treatment, surgery, spectacles. Some flyers (see above) can also be very effective here. This eye-talk is a highly important aspect of the outreach work, so prepare it properly and take sufficient time for it.

It is often more effective to visit a few places (e.g. general health units) at regular intervals, e.g. three times per year, rather than many more units only once per year. The reasons are evident. The short intervals between each visit will make it possible already to announce the next visit to the patients, who will take the message back home. Regular visits will also result in more close

contacts between the local health unit and the eye staff. The message that the eye unit is coming will be communicated better and will be nearer to the day of the visit. The patients will also be more inclined to seek information 'when the eye unit is coming back?' Regular eye work also generates more publicity, better follow-up, and better results than occasional irregular visits.

3.2.9 One week of free treatment!

For people who have never heard of the 'modern' type of eye treatment and who may be sceptical about it, 'cost' is often an additional barrier for not 'giving it a try'. To overcome this barrier some eye units have organised 'one week of free treatment'. This can be offered to the whole local population and of course needs to be advertised and promoted in the community.

There are different options to make. You may invite the population at large or only children under 15, or only people above the age of fifty, depending on your main target group. If your target group is cataract patients, you will of course invite people above 45 or 50. At the same time, the accompanying family members will learn about the eye work that you are doing and may come in soon for treatment or spectacles.

You may provide 'only' free examinations or also free treatment (medicines), or also reductions to the prices of spectacles and surgery. It is important that your information campaign should make all of this very clear in advance, so that people don't feel cheated by what is actually available.

3.2.10 Organize 'one month of cataract surgery for patients without a caretaker'

Above we have noted that 'not having an escort/caretaker' is one of the main barriers for blind cataract patients to come for surgery. When people are already afraid to risk their remaining vision and when funds are short cataract patients will not try very hard to persuade a family member to accompany them to the hospital for an (unknown) period of time.

Especially for those patients, organise for a certain period the opportunity to come in for surgery, without the need of a permanent caretaker. Family members may be willing to serve as an escort for the journey only, knowing that they can then go home and later return to escort the patient back home.

During that period, you will need a number of extra staff to take care of these patients, or maybe volunteers such as older schoolchildren, women's groups or other community health workers. This can be very worthwhile.

3.2.11 Visit cataract patients with a 'happy' operated cataract patient

Patients who have been able to discuss cataract surgery with someone else in a relaxed, informal way, are more likely to come in for surgery. This can be just a community member who heard about cataract surgery being available or maybe a health worker.

Without any doubt the most successful way of convincing cataract patients to come for treatment is to visit them accompanied by a 'happy' operated cataract patient, who tells them about the surgery, that it was painless... that people were kind... how their life improved since being able to see clearly, etc...

This may be expensive and not so easy for an eye unit to organise. However, collaboration with community-based workers as explained in the following chapters, may make it feasible.

3.2.12 Find out where your patients come from!

Eye units often have no idea where their patients come from. This is important information, especially to find out why patients are coming from certain areas, and not from others.

It is important to establish a map of your region, indicating how many eye patients and cataract patients have come in each month/year from each administrative unit.

This will first of all assist you to focus your awareness and cataract detection campaigns more accurately. You may also come to realise that some areas have no access to eye care, because there is no public transport, or for topographic reasons such as a river with no bridge. You may decide to organize mobile clinics and cataract detection and referral work in those areas. You may organise regular transport from those areas for eye and cataract patients. For example, once a month: arrange a free 'cataract bus'!

3.2.13 Why did your patients not come sooner?

For the same reason, find out why your patients did not come sooner. Those patients brought in by

community outreach can be especially useful resources for getting a better understanding of the socio-cultural and other barriers between patients and eye services in your area. This will help you to be better focused in your strategies to overcome barriers.

3.2.14 Keep records of 'lost' cataract patient

Keep accurate records to be able to follow up on 'lost' patients, i.e. those who came to the eye unit and promised to come back another day but did not show up. Make sure that your records include information on where each patient lives. This requires not only good record keeping by your administration, but also good communication with the staff at OPD and ward. Let community workers follow-up those patients.

3.2.15 More ideas

- Many eye and cataract patients will not come to the eye unit for examination because they cannot get a bus back home on the same day. Offer a facility for those travelling from far to be able to stay the night for a small fee. Or have a 'priority queue' for those who need to be seen quickly. Make sure your registration staff know what the transportation systems are like from place to place.
- Offer the happy cataract patient a free pair of reading spectacles if he/she brings in a new cataract patient.

3.3 Train a staff member to work in the community: a Cataract Surgical Rate worker (CSRw)

What is a CSRw?

The CSRw is a person attached to an Eye Unit whose job is to sensitise and inform the community in general, and cataract patients and their families in particular, about cataract, i.e. about the possibility of cure at the Eye Unit. The CSRw's job is specifically to get as many patients as possible presenting for surgery. He/she will provide talks on cataract in community gatherings, will systematically detect cataract patients through the use of primary school children, by conducting home-visits, will organise outreach screening clinics, etc... The CSRw will also be involved in organising transfers of cataract patients from

remote areas. The job of a CSRw really depends much on the local situation. He/she should be one of the key people to put into practice some of the ideas in this booklet in terms of reaching out into communities.

Good CSRws are extremely cost-effective!

One or two CSRws attached to an eye unit will increase the budget a little, but they may increase by 50-300% the number of cataract patients coming for surgery, this of course depending on the actual figures. This means that over-all the eye unit can become much more cost-effective. Because of this, you may be able to reduce the price paid by the patient for a cataract surgery, which will in turn reduce your operational cost per surgery.

Profile for selection of a CSRw: a 'social worker' type of person

Not too young; the communication skills of this person and the respect he/she will get in the community will be more important than any academic degree. An academically trained social worker may not be comfortable in a 95% 'field job' with no obvious opportunity of promotion. Employ people who will be able to communicate well with community leaders and hospital staff, as well as with patients and their families.

Means of transport.

Motorbike (rural) or public transport (cities) (or bike??).

Gender

If possible, consider female candidates. However, in rural areas and particular cultures you might have to employ male CSRws for reason of transport and security. You may also find that some male CSRws are more convincing in front of community gatherings.

Training curriculum for CSRws and other community cataract workers/motivators.

The training of CSRws should include at least the following:

1. Recording of visual acuity.
2. Identifying a normal healthy eye.
3. What is cataract? Causes? Identification of Cataract and other Eye problems. Difference from corneal scar, AvitA, measles.

4. At what stage should cataract be operated? Is it a painful operation? Duration? What is the prognosis in terms of regained vision?
When should patients be brought to the collaborating hospital? Day? Season? When NOT?
Cost of cataract surgery. Need for follow-up?
5. Religious/cultural beliefs about cataract and blind people.
6. Detection of cataract patients.
Different systems + additional local applications (through workshop) of cataract detection.
Barriers between patients and eye units. How to overcome barriers.
7. More explanations about cataract surgery.
Attend one surgery (on screen). Provide information, which might be useful when trying to encourage patients (and their families) to come for surgery.
8. Understanding and recording of assessments (using a Cataract Detection Monitoring Document, see chapter 6).
9. The activities and responsibilities of the eye unit and its staff (spend time at eye unit)
10. Communication skills. How to meet with a family, i.e. how to introduce him/herself, the eye unit, etc. How (not) to explain about cataract (surgery).
11. During the training, the CSRw will meet with at least ten 'detected' cataract patients before their surgery; have a discussion why they didn't come sooner, etc...

Who should train, recruit, employ and manage CSRws?

In case there is no community-based programme in the area, the eye unit will be best placed to go ahead with it, and maybe to involve some outside people to cover some components. Experience suggests that an experienced eye nurse will be a more effective trainer than an ophthalmologist.

In case a CBR or PHC programme already exists in the region, it may be better to collaborate with them. In the first place, it should not be a problem for them to identify and send you cataract patients from the (often very limited) areas where they are providing home-based services (see section 3.4).

If you wish to deploy CSRws in those areas around your eye unit where the community-based programme is not working, then first discuss with

them to find out who would be best placed to provide the training, to recruit, employ and manage these CSRw(s).

Are you (or your colleagues) able to teach communication skills? These will be crucial in the CSRw's future work. Maybe the community-based programs are in a better position to train your CSRws, given their experience working in communities and trying to overcome barriers between (poor) patients and medical units. It may however be better that the eye unit acts as the employer, as this will ensure better communication between the CSRw and the eye unit staff. Evaluation of the CSRws' work should be easy. You will simply see the number of patients coming in! Implement a way to find out which patients were sent by your CSRw (e.g. use a referral note).

Budget items to be considered for employing a CSRw.

- i) Salary
- ii) Bicycle or motorbike + maintenance (petrol, repairs, etc.)
- iii) Insurance for the person + for the motorbike - or money for public transport
- iv) Paper + access to a photocopier
- v) Bonuses for meeting monthly targets of appropriately identified clients who actually do reach the unit.

Advice.

- a) CSRws should not have their own personal office. They should be 95% of the time in the field!
- b) The CSRw's superior should be (one of) the 'manager' of the eye unit, preferably not the ophthalmologist, but the head nurse.
- c) CSRws should be recognised as members of the eye unit staff. Encourage them to attend the eyeunit staff meetings.
- d) The most fruitful time for the CSRws to achieve good results is likely to be during the weekend because that is when most social gatherings take place. These are ideal opportunities to reach many people. Churches, political and other social gatherings, etc. should be addressed. The person you select should know of this and clearly agree to it before accepting the job.

Systematic approach towards the job of a CSRw.

1. Get information/research on barriers and how to solve them

1.1 Have a discussion with the eye unit manager and other staff

- a. How many more surgeries are they able/willing to do per week/month.
- b. When should patients arrive, which patients and how many (e.g.: each Monday five patients with bilateral cataract)
- c. Other details? (caretaker has to stay at the clinic? total cost for treatment? Bring food? how many days at hospital? See complete list of information to be provided in 3.4.1)

1.2 Do more research on barriers

Check out the realities of possible barriers within the eye unit/hospital (see chapter 2) and concerning the patients by getting:

- a. info from treated patients at eye unit
- b. info from untreated cataract patients who are at home
- c. info from eye unit staffs: eye clinicians, ward and OPD staff etc...
- d. info from administrative staff registering patients
 - how many 'booked' cataract patients did not come for surgery?
 - Why not?
 - from where do most operated patients come?
 - from which areas do you get few/no patients? Why?

1.3 Which existing programmes, projects, institutions, centres could assist in the future?

- a. Some local authorities? Do they have regular meetings where I could market the eye unit/ataract surgery?
- b. Schools?
- c. Religious institutions, churches, mosques, temples
- d. Primary health care programmes
- e. Local health centres
- f. Community-based rehab. programs
- g. Other community programmes
- h. Service clubs

2. Deal first with the barriers at the eye unit

- a. Try to get the price down?

3.4

- b. Try to convince the eye unit to advertise an ALL-IN price?
- c. Possibility to perform more surgeries?
- d. Training for surgeon in IOL surgery?
- e. + (remove other barriers, depending on the specific situation)
- f. Make (in collaboration with eye unit staff) a good flyer with all essential information (see 3.4.1)

3. Marketing and Detection

- a. Make use of a good flyer agreed upon by eye unit
- b. Presentations/talks in community gatherings/bodies (see 1.3)
- c. Public Relations in the media (radio/newspapers...) How? Cost?
- d. House to house surveys? By whom?
- e. Inform all potential partners: 1.3 and make a memorandum of understanding with them (see example, section 5).

4. Organise transfers

- a. Facilitate referrals of patients from remote areas
- b. Through collaborations with partners (see 1.3)
- c. By the use of a minibus?

5. Evaluate the outcome of your different strategies

Find ways to learn which of your approaches have been more successful and why.

6 Adjust your strategies

3.4 Collaborate with Official Registration of Disabled People, CBR Programmes, PHC and HIV/AIDS Programmes, Disability Groups

Official Registration of Disabled People

In many countries, disabled people receive some type of financial grant, once per month some food, or other advantages such as free use of bus or train. It may be organised nationally, or just in one region. In any case, there must be a system of registration and a place where these concessions can be obtained. However and wherever this happens, try to use this channel for identification and transferring of cataract patients! (An added incentive

for the government office is that every cataract patient whom they refer is likely to mean one less person needing a monthly handout).

How can CBR programmes assist us?

It is estimated that about five per cent of human beings (some 300 million people) are noticeably disabled in one way or another, and are in need of some formal services (apart from the informal, everyday help they may receive from family and neighbours). About eighty per cent of disabled people live in developing countries. Among these, less than five per cent have access to formal services.

This picture, as well as some positive experiences with home-based health service provision, has led to a re-think on how services can best be provided to people with disabilities. Community-based rehabilitation (CBR) is the product of this changed thinking.

There are many different ways of doing CBR work - some more realistic and effective than others, depending on the nature of the community itself. Common themes of nearly all CBR programmes are:

1. The training of local community rehabilitation workers who provide or facilitate other people in providing services to disabled people at their homes and within their communities,
 2. using locally available human, material, infrastructural resources,
 3. within a certain organisational structure.
- Rehabilitation goals in CBR are to enable people with disabilities:
1. to take care of themselves and to be as personally independent as possible (the individual factor);
 2. to have social relationships and to take part in the activities of the community such as getting equal access to existing health and education facilities (the social factor);
 3. to contribute towards their own and their families' livelihood (the economic factor).

In practical terms, after receiving training by experts such as special educators, physiotherapists and eye doctors, the local community rehabilitation worker (CRW) visits up to five disabled people a day at their own homes, assessing needs in the fields of mobility, hearing, vision, education, skills acquisition, etc. One person might be refer-

red for eye surgery; a disabled mother might need help in learning special skills to improve her parenting and domestic tasks; another person will need to perform regular exercises to maintain muscle tone in his legs; a disabled father may need to earn a living for his family by making carpets, and selling them at the local market. The CRW will then, with expert back-up, develop individual training programmes with the family, all of which aim at reducing or overcoming the disability or disability-related problem. The goal is to make the general living conditions of that family better. This will often include advice on such matters as vaccinations, going to school, getting suitable work, and becoming an active participant in the community itself. The CRW will him/herself receive regular visits from CBR specialists and supervisors, who provide diagnoses, help to formulate suitable action plans, monitor progress, and provide technical, material and moral support to the field worker.

Most CBR programs in developing countries are organised within a limited geographical area by non-government organisations (NGOs), which receive a large part of their funding from donor organisations. The main costs are salaries and transport. Some CBR programs are highly cost-effective, mostly those run by NGOs. In some of the bigger CBR programmes run by governments, the attempt to work with unpaid volunteers, or to use staff who have other work responsibilities, often reduces the program's effectiveness. In recent years therefore, government agencies doing CBR work have begun to collaborate more with the NGOs working in this field.

CBR programs can make an important contribution to the field of prevention of blindness, by systematically identifying people with eye problems, and referring them for treatment. Especially interesting in the context of barriers between cataract patients and eye services is the fact that CBR workers are specifically trained to work with disabled people, to counsel their families, to empower them by training, and to try to let the disabled people have equal access to health and education services. More than anyone else, a good CBR local worker will be able to identify the 'real' barriers within each specific case and be able to encourage and even organize a referral to the hospital.

Those CBR programs that are also working with blind adults may already have contacted your eye unit and may already be sending patients. Other CBR programs that may only be working with physically and mentally disabled people can however also become useful to your eye unit. Contact the management. Convince them of the great need in the area for eye services. Let them visit your eye unit, and let them understand that the majority of blind people can actually see again. Explain to them about the barriers between patients and services. They may be keen to collaborate with you. One additional argument you can give them is that this type of work will increase the respect with which their CBR workers are regarded in the community. Direct and noticeable (even spectacular) results can be expected in eye work, whereas work with people having other disabilities often gives results that are noticeable (to the community) only after many years of work. This will considerably increase the reputation of their CBR workers within the community, and that may lead to better collaboration in more difficult fields where long-term family and community participation is necessary.

How can PHC and HIV/AIDS programmes assist us?

Primary Health Care (PHC) and HIV/AIDS programmes often work at the homes of people. In case such a programme exists in the area of your eye unit, depending on the quality of their field-work, the local PHC/HIV workers may know many people with cataracts. After studying the organisational potentials of the PHC/HIV programme, you may find that they are actually in a good position to become your cataract detectors. In that case, you can approach them in the same way as described above. Offering some incentives may be an extra motivation.

In regard to a training curriculum for CBR and PHC/HIV workers, may we refer to the curriculum provided in the chapter on Cataract Surgical Rate workers (CSRws).

Disability Groups.

Many cataract patients are registered as members of disability groups or of other movements such as women's groups. Offer to train people within those groups to identify and refer cataract patients.

4 Post-operative community-based follow-up of cataract patients

Ex-patients are the best promotion for your cataract work. It is therefore very important that once the surgery has been provided patients should be happy with their general situation. We can improve this by providing follow-up services. These are necessary, certainly in case of a surgery without IOL.

As already noted above, when surgery has not been very successful it would be good if the surgeon, or an eye nurse, could explain to the patient and the caretaker why this is so. If a program providing services to blind persons is available, refer the patient to them.

Home based follow-up.

An eye unit can do follow-up by training nurses, CBR or PHC workers, or the CSRws, on how to explain to patients and family members the following items, at the hospital and preferably also at the home of the patient:

A. How to administer the post-operative medicines and for how long to continue.

(Note: some patients may be afraid to go back to the eye unit for a check-up, because they know they did not use the drugs correctly as prescribed. Often several drugs have been prescribed at discharge, in the same type of bottles or tubes. Try to give different colours to the labels!)

B. The eye unit should give patients a small card recording their vision at discharge. Community workers doing follow-up of cataract operated patients should be trained how to check vision and especially how to compare it with the recorded vision at discharge. Certainly it should be the same if not two or three lines better. If it has reduced then the patient must be encouraged to return for a check-up. If it is the same or better, then generally all is okay unless pain, mistiness etc. is reported.

C. Re-integration of the operated person who used to be blind: encourage family members and other people to involve the formerly blind person in ordinary activities outside the home, such as collecting water, going to the market, women's gatherings, religious meetings, local bar, etc...

Some 'new-vision exercises' may help them to make use of their sight again, to live again as a

seeing person. There is a difference between passively 'being able to see' and actively using one's sight, looking and perceiving. Walk out with the patient. "Look at that tree. Which type of tree is it? Do you see those people there? How many? Do you recognise this person?" Etc...

D. Where patients have received cataract spectacles, they should be told:

- How to attach spectacles to the ears so they do not fall off and break
- How (not) to clean spectacles
- Safe place to put spectacles at night, so that they are easy to find again
- What to do if spectacles are broken (where to get new ones and what will be the price).

If a CBR/PHC worker or CSRw can pay home visits to do this work, these follow-up services should take approximately six visits: one during the first week, second week, third week, fourth week, second month and one during the sixth month.

5 Collaboration with service clubs (e.g. Rotary, Lions, Women's Federation, etc.)

In many areas in developing countries, service clubs have often been the only or main service providers of eye care. Often however, they are offering a service in the same area where other people have started permanent eye units, and this has led to conflicts resulting in competition amongst the two and great confusion among the patients.

This is completely unnecessary, since both have the same objective. Eye units however often blame service clubs for providing free eye services and even free spectacles, which they say is inconsiderate in terms of general health education and counterproductive in terms of long-term results (e.g. trachoma) and sustainability of eye care in particular. They also blame them for often caring more about the press coverage and the service club banner or plaque in front of their eye camp; and for focusing on numbers treated, rather than the quality and effectiveness of treatment.

Service clubs often blame the eye units for being too expensive for most people to afford, for sitting inside their building and waiting for eye patients to appear rather than going out to serve them and for all the other problems and barriers noted in the present booklet!

It is imperative that both should work together. First, it would be good if Service Clubs would avoid working in areas where a hospital is trying to set up sustainable eye care. If that is not possible then at least it is important to collaborate.

It would be preferable that service clubs should never undercut the price of a nearby existing eye unit, as long as the unit's prices are considered affordable to the majority of the people. If the clubs wish to do something for the poorest, that will be extremely useful. They should be requested to sponsor the existing eye unit for a number of surgeries (see below).

Fortunately, more and more service clubs have understood the importance of collaborating with existing eye units. To assist in setting up long-term effective collaboration, we provide here an example of a Memorandum of Understanding between an Eye Unit and a Service Club. Even if collaborations happen between friends, it is often better to formalise agreements so that each party knows its responsibilities. When there is a written agreement, better and more detailed procedures of collaboration can be discussed which will often

lead to better services to more people. A written agreement can also more easily be carried over towards eventual new managers, which increases the sustainability of the collaboration.

In what follows, obviously the details like days of the week, times of day, frequency, costs etc should be varied according to the local situation and needs.

Sample of a Memorandum of Understanding between a local Service Club and an existing local Eye Unit

Art.1 Introduction

The Eye Unit (name) and the (name Service Club) are committed to collaborate for the benefit of cataract patients in the area. In order to achieve efficient cooperation it has been agreed that a Memorandum of Understanding will be signed, so that both parties know their responsibilities in this effort. Problems that might occur which have not been considered in this Memorandum will be solved according to the spirit of the existing Memorandum, always considering the benefit of the patients.

Art.2 Rationale

Cataract patients often do not seek and/or receive appropriate services. Reasons include, amongst others, lack of accessible eye services, lack of awareness about existing facilities, lack of funds and transport.

Art.3 Objective

The objective of this co-operation is to provide appropriate services to Cataract Patients, in particular to those who cannot afford the normal cost of treatment.

Art.4 Duties of the Eye Unit (name)

1. Technical Commitment.

At the eye unit (name), all patients will be examined, operated and discharged under the responsibility of an ophthalmologist. Some aspects of pre- and postoperative care may be delegated by the ophthalmologist, under his/her supervision, to other qualified medical staff such as Eye Nurses, Ophthalmic Medical Assistants or Opticians.

2. Medical Discretion

The Eye Unit (name) undertakes to act with due discretion and confidentially in respect of all medical information that will be received, by permission of the patient / family.

3. Availability of Surgery

The Eye Unit (name) will be available to operate cataract patients sent by the (name Service Club) two days per week, that is on (e.g.) Tuesday and Thursday. The cataract-patients should arrive at the Eye Hospital one day before the day of the surgery, which means respectively on Mondays or Wednesdays, before 2:00 p.m.

4. Equipment

The Eye Unit (name) will use its own equipment and consumable supplies. No equipment or supplies need be provided by the (name Service Club).

5. Post Operative Care

The Eye Unit (name) is responsible for all the post-operative care, including the required medical care, provision of spectacles or IOL's and follow-up of the operated patients.

6. Medical problems

In case of post-operative eye problems, the Eye Unit (name) is responsible for the proper treatment of the patient, provided the latter returns for treatment.

7. The Eye Unit (name) will sign the standard Service 'Record-Keeping' and 'Patient Registration Card' Documents from the (name Service Club), mentioning the names of the patients; the type of services provided and information relevant to the Club. These documents may be used for internal purposes within the International Service Foundation.

The (name Service Club) will be free to take pictures of the operated patients, only if the latter have no objection to this. The patients should be informed of the purpose of the pictures.

Art.5 Duties of (name Service Club)

(1) The (name Service Club) will provide to each cataract patient to be referred to the Eye Unit (name) for surgery, a standard document in

which the (name Service Club) declares that it will pay (or has paid) for the expenses as agreed in the Memorandum (see further).

(2) This document must be signed by one of the (name Service Club) co-signatories of this Memorandum.

(3) The (name Service Club) will pay the Eye Unit (name) for each patient operated the amount of 30,500 LC (local currency), which is the total of:

- 500 LC admission fee / administration
- 5,000 LC for food (4 days)
- 10,000 LC for medicines, anesthetics etc...
- 15,000 LC for examination fees, operating theatre, surgery and other post-operative medicines and treatments.

Total: 30,500 TSH per patient.

(4) The (name Service Club) is responsible that each patient and escort/caretaker will be able to return home, after being discharged by the ophthalmologist. Whenever this is not the case, the Eye Unit will advance the required money, and claim back from the service club.

Art.6 Further Practical Arrangements

1. In case a patient develops another illness during his/her stay at the hospital, the Medical Staff will inform the service club and will treat the patient to the best of their ability. These costs will need to be met by the Service Club, who may charge the patient. The Service Club will also have to pay for an eventual referral to another hospital, if required.
2. In case a longer stay at the eye unit is needed than the foreseen 4 days, then the (name Service Club) will pay 1,000 LC supplementary for each day.
3. The (name Service Club) will take reasonable steps to avoid becoming an easy channel for free cataract surgery for patients who in reality can easily afford to pay.

Art.7 Agreement, duration, evaluation and amendments

To this end the (name Service Club) and the Eye Unit (name) have agreed on the above area and method for cooperation.



5

The duration of the co-operation is one year after the date of signature by both parties.

The Memorandum will be evaluated and reviewed annually, starting 11 months after the signing of this Memorandum of Understanding, in order to determine the best methods for future collaboration. The evaluation team will consist of the signatories of the MoU from both the (name Service Club) and the Eye Unit (name) and maximum three other delegates from both parties. This team may suggest and discuss amendments to the existing Memorandum of Understanding. A new MoU may then be amended and signed accordingly.

Art. 8

During the implementation, practical matters arising will be dealt with by:

- for the (name Service Club) Mr./Mrs.
- for the Eye Unit (name): Mr./Mrs./Dr.

Signed in four copies of four pages each:

Mr. Mr./Mrs./Dr.
 Chairperson Manager Hospital/Eye Unit
 (name Service Club) (Date... th. of ...year)

Signature: Signature:
 (Name Place)

6 Cataract Assessment Monitoring Form

At a hospital base, 'registration' of a cataract patient will automatically lead to a booking for surgery, provision of a date, and mostly that will be enough to have the patient present him/herself on the day of surgery.

However, when community workers or even mobile teams are doing cataract detection through home visits or other types of outreach into the communities (see above), it will mostly not be possible to provide the patients immediately with a date for surgery. In that case, it will be very important that whoever is registering these patients, will come back with the information needed for you to decide on the action to follow. In other words, it would not be useful to the eye unit if the mobile unit or a community-based worker comes back with the information that he/she 'found 18 cataract patients'. Do these patients want surgery? Do they have money? Which surgeries are urgent? Who has mature cataracts? Where do they live? Age? The answers to all these questions will be very important to finally being able to decide who will get priority, and to find the right people again to refer them for surgery.

The best way to go about this is to develop a monitoring tool, to be filled up by the person detecting the patient, and to be provided to the eye unit at his/her return. The following is an example of such a tool.

Notes on the different columns (see page 35).

Name Patient

Speaks for itself.

Year of Birth

May be important in case of very young or very old patients. You may e.g. give priority to children; decide to have these patients referred for surgery only when an anaesthetist is available.

Address/Village

Being able to find the patient again at home may be important in case a community worker will be involved to refer the patient for surgery. In some communities, you may need to write the name of the father here as well, in case you or someone else wishes easily to find the home again later on.

Cataract Eyes

Bilaterally blind persons will get priority.

Condition of Cataract

For a mature cataract the registrar will put a cross. In case of a surgery without the use of IOL, two mature eyes may get priority.

Cataract confirmed by ophthalmologist or by eye worker?

It is sometimes relevant to know which cataract patients have been 'confirmed' by a more trained person, especially when it comes to deciding on the number of patients to 'call in' per operating day. In case a community worker (volunteer?) has been registering your patients, then more mistakes will have been made in the assessment of the cataract, and a greater percentage of people will not be operated. This can lead to frustrations at the level of the surgeons. To avoid that, it is better to invite more patients than the required number to come for surgery on the same day.

Patient desires surgery?

For the same reason as above this is very important information.

Is the patient able to pay Local Currency.

Those who find this person in his own community or even in his own home, are in a better position to assess whether this person/family can afford the normal price of a surgery. In case they have reasons to believe that this is not the case, then they can explain the reason in the next column, and specify the amount that they believe the person should be able to contribute.

Remarks? Other expected barriers?

Any information relevant to the eye unit, also in regard to possible barriers to be expected and suggestions on how to overcome.

Date

Date of the assessment or case-finding.

Reg. No.

It may be appropriate to use registration numbers.



6

Cataract Assessment Monitoring Form

Month: Cataract Assessment Form Nr.:

Name of CRW/SV:

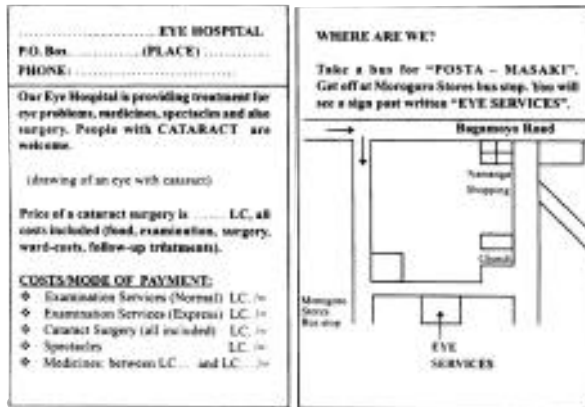
Newly Detected Cataract Patients:

Patient's Name	Year of birth	Address/ Village	Cataract eyes		Condition of Cataract Mature = X		Cataract confirmed by Ophthalmologist / Eye worker		Patient desires surgery?		Patient is able to pay? If not: how much?		Remarks? Other Expected Barriers?	Date	Reg No.
			Right	Left	Right	Left	Yes	No	Yes	No	Yes	No			
1.															
2.															
3.															
4.															
5.															
6.															
7.															
8.															
9.															
10.															
11.															
12.															
13.															
14.															
15.															
16.															
17.															
18.															
19.															
20.															

7 Useful tools for creating awareness about cataract (surgery) in the communities

7.1 Flyer

The following is an example of a flyer, which has given very good results in one country.



7.2 Cataract Picture Flipchart

The Fred Hollows Foundation has developed a picture flipchart which is an ideal tool for creating awareness about cataract (surgery) in the communities. It provides eight black and white pictures. The pictures have been taken in Africa. CCBRT has now reprinted this flipchart.

A good eye nurse, or a community worker, can easily tell a story about each picture, which provides the patient and his/her family with information that tries to overcome some of the barriers (as described above).

a. Picture of a lady with bilateral cataract.

Story: This is what cataract looks like. Cataract is common with old age, but there is no need for it to result in blindness.

b. Picture of an eye doctor and an eye nurse, nicely dressed up in 'white', in front of an eye unit and an 'E chart'.

Story: Cataract can be treated with a short, simple operation, at an eye unit.

c. Picture of a man after surgery with (heavily damaged) spectacles.

Story: There are two types of operations available. The old type of surgery helps you to see better, but you need to use spectacles which are not so easy to wear, can get lost, or can break.

d. Picture of two playing children: only the middle of the picture is sharp.

Story: also the result of this old type of surgery is not so good as the new type of surgery. The view with glasses is distorted which makes moving around difficult.

e. Picture of the same cataract patient as (1) after IOL surgery (no spectacles). Patient smiles.

Story: if you get the new type of surgery, then you don't have to wear glasses, so you can't break them.

f. Picture of an IOL lens.

Story: ... the reason is that by this type of surgery the eye doctor puts a small lens into the eye. This lens will stay inside your eye for the rest of your life and does not need to be replaced. You don't feel that it's there!

g. Picture of the same two children as (four), this time completely sharp.

Story: After this type of surgery, the patient sees very well ...

h. Picture of an old person and a child watching each other.

Story: ... the patient actually sees just as well as when he/she was young!

The title of this cataract flipchart is: "The way forward - New Sight, New Life - The FHF Answer to cataract blindness - IOL." You can order it by writing to:

CCBRT

Mr. Vanneste

PO Box 23310

Dar es Salaam

Tanzania

e-mail: vanneste@intafrika.com

fax: (255) 22-2601544

8 Some research papers on cataract surgery barriers

Vaidyanathan K, Limburg H, Foster A, Pandey RM (1999) *Changing trends in barriers to cataract surgery in India. Bulletin of the World Health Organization*, 77(2): 104-109.

The situation of cataract sufferers and barriers to cataract surgery are discussed, with some recent trends and recommendations.

Fletcher AE, Donoghue M, Devavaram J, Thulasiraj RD, et al (1999) *Low uptake of eye services in rural India: a challenge for programs of blindness prevention. Archives of Ophthalmology*, 117(10):1393-99.

Among 749 rural adults with eye problems who were studied, under 7 per cent attended an outreach eye camp, though more than a third of non-attenders were recommended for cataract surgery. The main barriers were: fear, costs, family responsibilities, age discrimination, fatalism and existing ability to cope.

Limburg H, Kumar R (1998) *Follow-up study of blindness attributed to cataract in Karnataka State, India. Ophthalmic Epidemiology*, 5(4): 211-23.

Among just under 22,000 people aged 50 and over, study found almost 5 per cent prevalence of cataract blindness, with district variation from over 7 per cent to under 2 per cent. Barriers to surgery were changing, and were linked to service providers.

Snellingen T, Shrestha BR, Gharti MP, Shrestha JK et al (1998) *Socioeconomic barriers to cataract surgery in Nepal: the South Asian cataract management study. British Journal of Ophthalmology*, 82(12):1424-28.

Major socio-economic barriers to cataract surgery continue in rural Nepal. This study found take-up was below 60 per cent even among patients with severe visual impairment who were offered transport and free surgery. Constraints of finance, logistics, fear and lack of time were prominent. The study recommends greater sensitivity to cultural, social and economic factors perceived by the community when planning services.

Johnson JG, Goode Sen V, Faal H (1998) *Barriers to the uptake of cataract surgery. Tropical Doctor*, 28(4): 218-20.

Major barriers to surgery identified in the Gambia were cost, lack of information, fear, transport problems, lack of an escort. Recommends improved communication by eye care personnel.

Auduge A, Schemann JF, Auzemery A, Ceccon JF, Ducouso F (1998) [French: *Strategies to control cataracts*]. *Sante*, 8(2): 144-48.

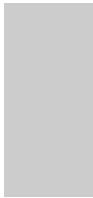
Cataract surgery in Africa deals with only about 1% of the prevalence rate or 10% of the incidence. Vigorous measures are needed to increase effective public information and to ensure patient satisfaction with the quality, cost and delivery of treatment.

Courtright P, Kanjaloti S, Lewallen S (1995) *Barriers to acceptance of cataract surgery among patients presenting to district hospitals in rural Malawi. Tropical & Geographical Medicine*, 47(1):15-18.

Cost and lack of family support continue to be major barriers in Malawi, especially among women. Interview results suggest that motivation on a personal level, e.g. by successfully operated cataract patients could be effective.

G. Natchiar, Alan L. Robin, Ravilla D. Thulasiray, Senthil Krishnaswamy (1994) *Attacking the Backlog of India's Curable Blind. The Aravind Eye Hospital Model. Archives of Ophthalmology*. July, 1994 Volume 112:987-993.

Ideas on bridging barriers from one of the most 'busy' eye hospitals in the world.



Feedback sheet

Feedback Sheet

Thank you for requesting this book. We take pleasure in enclosing this feedback sheet, and would be grateful if you could kindly complete and return it in order to help us improve the next edition.

If you would prefer to respond to this feedback sheet on your computer, you can receive a form by sending an e-mail to vanneste@intafrica.com

Please return this form to:

CCBRT
Geert Vanneste
PO Box 23.310 DAR ES SALAAM
TANZANIA

Your Name:

Full Postal Address:

E-mail or fax:

1. Your profession:

- Eye Doctor – Eye Nurse/Medical Assistant
- Manager of eye work
- Representing an organisation
- CBR Worker/ Manager/Trainer
- Teacher of disabled people
- Other:

2. How many people have read a copy of this book?

3. What part of the book was most useful to you? Please explain.

4. What part of the book was least useful? Please explain.

5. Do you have some method or experience that has been really useful in your area for increasing cataract surgical rate (CSR)? Alternatively do you know of some other aspect of reaching much greater numbers of eye patients with effective treatment, which you would like to share with other people? Please attach a description, or copy of a published article.

6. Any other comments.





The main aim of this booklet is to increase the number of cataract operations within existing eye services, so that less people suffer avoidable blindness or remain needlessly blind.

There are social, cultural, and organisational barriers that limit the acceptability and accessibility of eye treatment, separating hospitals and eye units from people with cataracts and other eye problems.

Some barriers originate with hospitals and can be solved only there. Even more exist with the patients, their families and the community, e.g. in general health behaviour and cultural/religious beliefs, which can have an important impact on the care-seeking behaviour of patients. These barriers can be addressed by media campaigns and by community workers who reach right into people's homes. However, community based programmes are not available everywhere, so hospitals and eye units need to take the initiative.

There are three objectives: to sharpen awareness among eye doctors and staff that most services reach only a minority of all eye patients, and of cataract sufferers in particular; to highlight the commonest barriers that prevent services reaching people who need them; to promote practical ideas on how to overcome barriers (a) within services, (b) by outreach to communities, and (c) by collaboration with existing community structures. Practical ideas are also provided on successful detection of cataract patients and monitoring outcomes so as to improve services.

The booklet focuses on cataract because it is the world's commonest cause of curable blindness. However, effective measures to overcome barriers between cataract patients and services will also lead to other eye patients being better served. This will happen through improved awareness of eye service availability, better information on costs and logistics and better treatment at the hospitals and units.

Geert Vanneste
Dar es Salaam,
November 2000
vanneste@intafrika.com