



Sightsavers

Issue 2 December 2010

# Insight Plus

Community  
approaches  
to eye health



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Front cover photo:  
Preventing onchocerciasis in Kachia,  
Kaduna State, Nigeria: community-  
directed distributor Livinus Thaddeus  
measures Abubakar Ibrahim for the  
correct dose of Mectizan® tablets



## From the editor

Claire Stevens, Learning Support Officer

**Welcome to the second issue of Insight Plus, Sightsavers' bi-annual learning review.**

Working with partners across Africa, Asia and the Caribbean, Sightsavers' aim is to eliminate avoidable blindness and promote equality of opportunity for disabled people. This series collates learning and best practice from across our programmes, with each issue focusing on a different thematic area.

In this issue, we look at community approaches to eye health and the role that community members can play in identifying their health needs, planning and implementing appropriate interventions, and ensuring long term sustainability.

Featured case studies include pioneering work in the integrated control of neglected tropical diseases in Nigeria, the training of community nyateros, or friends of the eye, in The Gambia, and strengthening the community health system in the remote islands of the Sundarbans region in India.

I hope you enjoy reading Insight Plus, and welcome your comments and suggestions. Please send your feedback to [learning@sightsavers.org](mailto:learning@sightsavers.org)

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# Foreword

**Simon Bush**, Director of Advocacy and African Alliances

The Alma Ata Declaration of 1978<sup>1</sup> marked a momentous occasion in the field of public health, being the first international declaration to underline the importance of ‘full community participation’ in both the planning and delivery of appropriate health services. This issue of Insight Plus will highlight some of the approaches that Sightsavers and its partners have taken to mainstream this declaration, as well as the learning we have drawn from these approaches.

One important example of Sightsavers’ work involving communities is our relationship with the African Programme for Onchocerciasis Control (APOC). Sightsavers’ work in onchocerciasis goes back to the 1950s when our founder, Sir John Wilson, did so much to highlight the disease to the international community through supporting much of the early research work. Indeed, it was Sir John and Lady Wilson who first coined the name ‘river blindness’ for the disease when they were visiting endemic areas of northern Ghana. In the late 1980s and early 1990s Sightsavers-supported projects in Mali, Nigeria and Uganda led the development of community-based treatments which went on to become the backbone of onchocerciasis control programmes in Africa; community-directed treatment with ivermectin (CDTI).

Sightsavers has been involved with the APOC partnership since its inception and in 2010 we celebrated our 150 millionth treatment with Mectizan® in our supported programmes. From about five million treatments in 2009, we now support the treatment of 22 million people in 14 African countries (about a third of all treatments in Africa). Without the donation of Mectizan® by Merck, and the partnership that APOC facilitates between donors, governments and communities, we would not have been able to reach such levels.

Our contribution to the overall treatment for onchocerciasis in Africa is important for Sightsavers; we believe that partnership and



**Village leaders meet to examine community treatment records in Zamfara, Nigeria**

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community ownership will lead to a long lasting legacy for Africa. Sightsavers is keen to move from control to elimination of onchocerciasis in our supported programmes, where this is feasible and within the guidelines that APOC has agreed. We are developing a 'fast track initiative' for onchocerciasis elimination and this plan will highlight what additional areas of programme development we need to support to make our contribution to the elimination of the disease in Africa, such as surveillance and even supporting new countries and programmes. In addition, we are doing the same for trachoma, which will start to move us from the control of the disease to the elimination of blinding trachoma in our programmes by 2020, through implementation of the full World Health Organization-supported SAFE (surgery, antibiotics, facial cleanliness and environmental improvement) strategy.

For me, community ownership and partnership is embedded in our support to the training of community-directed distributors (CDDs). As part of work with APOC, we support this training in 14 African countries, contributing to the network of about one million CDDs in around 500,000 communities in Africa. During a recent trip to Zamfara State, I met Mr Usman Malamai, who has been a CDD in Fulfuri for 16 years, since the very start of programme support to this community. In his perfectly kept record books is the evidence of treatment and coverage that will demonstrate the feasibility of eliminating the transmission of onchocerciasis in Zamfara State.

My trip also highlighted the real potential that community-directed interventions can offer to global health. Zamfara state, with support from Sightsavers and other partners, has undertaken comprehensive mapping for onchocerciasis, trachoma, soil transmitted

helminths and schistosomiasis. This is the first time this has been done in any state in Nigeria, Africa's most populous country. With support from Sightsavers, the state then set about delivering mass drug administration for these diseases through community-directed interventions and school-based treatments. Again, this is the first time this has happened in Nigeria for this set of neglected tropical diseases (NTDs). The extra cost to deliver drugs for the five focus NTDs is minimal, given the strength of the partnerships between the state and Sightsavers, the donated drugs and the delivery 'vehicle' that community-directed interventions offers. In some areas of Zamfara this community-directed approach is being used in areas that have previously not been treated for onchocerciasis; here the principles of CDTI are being used to introduce this successful approach. Programme partners are also starting to investigate the potential to involve CDDs in the distribution of bed nets against malaria.

As APOC moves from a control programme to an elimination programme, Sightsavers is ready to continue playing our part in the most successful private-public partnership for health in Africa. I believe that the power of this partnership – with community engagement as a key to delivery – is a lesson for the control of NTDs in Africa and Asia. For public health more broadly, community-directed interventions have proved effective both in terms of cost and results. However, limited community participation in the planning, management and monitoring of health programmes is still a major challenge. By sharing the approaches we have used, we hope that the sector will be able draw out lessons which will enable communities to become an integral part of both implementation and decision-making processes.

<sup>1</sup> International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978  
[http://www.who.int/hpr/NPH/docs/declaration\\_almaata.pdf](http://www.who.int/hpr/NPH/docs/declaration_almaata.pdf)



# Stakeholder involvement: the key to effective community mobilisation

Dr Wahidul Islam, Country Director: Bangladesh

Mohammad Rofiqul Islam, Senior Project Manager: Bangladesh

Syeda Asma Rashida, Project Officer: Bangladesh



A happy couple after their cataract operations

## Summary:

Bangladesh is a small country with a huge population and a considerable percentage of people living below the poverty line. In developing countries such as Bangladesh, blindness represents an additional socioeconomic burden, with poor and urban slum communities being particularly vulnerable to eye problems and associated disadvantage.

Sightsavers, with support from Standard Chartered Bank, has been implementing the Dhaka Urban Comprehensive Eye Care Project (DUCECP) since October 2008, targeting these urban slum populations. Through the project, more than 50 community-based organisations

(CBOs) in Dhaka received training in primary eye care and resources such as flip charts, flash cards, and leaflets. The CBO members were very active in raising awareness about eye health issues, resulting in a significant increase in the referral of eye patients from slum communities and also in the number of post-operative follow ups.

## The Dhaka Urban Comprehensive Eye Care Project:

According to the Bangladesh National Blindness and Low Vision Survey (2003), cataract is the

major cause of blindness among adults over 30 years old in Bangladesh. For the country as a whole, approximately 4,200 people per million population are blind due to cataract. Using an estimate of 12 million for Dhaka's population, the number of adult cataract cases in the city is about 50,400, with 10,000 new cases occurring each year. Among the urban poor, the number of cataract cases in Dhaka is about 15,120 bilateral and 22,000 unilateral cases, with an annual incidence of around 3,000 cases. The estimated number of child cataract cases is 1,200 bilateral and 1,800 unilateral.

To address this issue, Sightsavers started implementing the DUCECP, a five year project running from October 2009 to September 2013. This project is supported by Standard Chartered Bank under its Seeing is Believing Phase IV initiative and is implemented in partnership with Islamia Eye Hospital (IEH). Acting as lead hospital, IEH also coordinates three more local partners; Dhaka Bangladesh National Society for the Blind, Ad-din Hospital, and Salauddin Specialized Hospital Ltd. This collaboration allows for good geographical coverage of the 15 constituencies in Dhaka.

Working towards the elimination of avoidable blindness in Dhaka by the year 2020, DUCECP focuses on poorer communities and target groups such as women and disabled people. Specifically, the project aims to:

- > Increase demand for eye care services, including blinding conditions and non-blinding conditions
- > Reduce the prevalence of cataract
- > Increase usage of refraction and low vision services
- > Encourage preventative eye care measures
- > Increase the capacity of partners to provide counselling services

DUCECP is working to establish links with community-based organisations (CBOs) who provide primary health care services within the project area, and also with other government and NGO health service providers. This collaboration is expected to improve the integration of eye care into existing public health services such as the Urban Primary Health Care Programme, and to increase the use of static eye health facilities throughout Dhaka.

## Collaboration with community-based organisations:

DUCECP is being implemented by four hospital partners in assigned geographical areas of Dhaka. In order to reach poor and marginalised communities, the hospitals are linking with local CBOs who run existing programmes within these communities. To strengthen this process, and for more effective coordination, DUCECP has signed a memorandum of understanding with Dhaka City Corporation and with the various CBOs involved. Together they are organising patient screening programmes to bring eye care services to the poorest people in Dhaka, including targeted screenings for specific groups such as drivers, students and garment workers.

The project provides primary eye care (PEC) training to front line CBO employees, with over 1,300 field workers from 21 organisations having received training to date. The curriculum covers common eye diseases, with an emphasis on cataract, childhood blindness, refractive error and low vision. Participants also receive training in social mobilisation skills and information about Vision 2020 and the aims of DUCECP. For teachers, the project provides training on refractive error and how to screen and identify students with vision problems.

After receiving PEC training, the CBO field workers play an active role in disseminating eye care messages to beneficiaries. They share these messages with members of various community groups, who then help to raise awareness in the wider community. Using their PEC training, the CBO field workers are also able to identify cataract patients and refer them to the appropriate patient screening programme, organised in conjunction with DUCECP. In some cases, beneficiaries themselves act as community ambassadors, referring fellow community members with eye problems to the screening programmes. This work at the community level has been very effective in increasing the flow of patients presenting at eye departments within the project's partner hospitals.

## Results from October 2008 to June 2010:

- > Primary eye care training was delivered to 1,321 field workers from 21 different community organisations. 64 percent of the trainees were female.



- > 506 eye screening camps were organised in collaboration with local CBOs. 77,380 adults and 18,497 children were examined, with 12,217 cataract surgeries subsequently performed and 9,428 patients prescribed with spectacles
- > 30 school screening programmes were organised with training provided to 300 teachers. 12,969 students were examined as part of these programmes, of which 2,423 were identified with vision problems. 510 free spectacles were provided.
- > 16 patient screening programmes were organised for target groups such as drivers and garment factory workers. 12,923 people were examined and 1,618 were identified as having vision problems. 893 patients were prescribed with spectacles of which 509 received these free of charge from the project

**Primary eye care training for members of community-based organisations**

## Conclusion:

At the beginning of the project, awareness about eye health issues was low among community members, as confirmed by a baseline survey conducted by DUCECP. However, through initiatives such as patient screening events within communities, primary eye care training for CBOs and the use of posters, leaflets, folk songs and community meetings, DUCECP has reported higher awareness and increased demand for eye care services.

Involvement of the community in organising these screening camps and awareness raising activities increases day by day. This is due to the programme's collaborative approach, where local partners participate right from the planning stage and are encouraged to take ownership of the programme. DUCECP is an example of a public-private partnership targeting eye health issues in urban communities. The model is replicable to other mega cities in Bangladesh and other countries.





# Community approaches to eye health – the nyatero concept

Dr Jerreh Sanyang, Country Director: The Gambia



A community screening session

## Introduction:

After 15 years of successfully implementing the National Eye Care Plan (NECP), The Gambia has seen a 40 percent reduction in the prevalence of blindness (1996 national survey), with eye care services accessible to about 80 percent of the population. However, despite these achievements, a team of external evaluators noted that some poorer communities do not access services because they are either not aware that they are available or because they cannot afford the cost of treatment.

This prompted the NECP to develop a more community-directed approach to the provision of eye care services. The programme invited all stakeholders to review the evaluation

recommendations and, as a result, the 'nyatero' concept was developed. This unique approach encourages communities to identify members who can be responsible for eye care services within that community. Each nyatero, or friend of the eye, is identified by members of his or her community and trained by the community ophthalmic nurse covering that district. They are then responsible for identifying eye health problems within the community, referring people to the next level, and raising awareness about good eye health practices and the types of services available. Nyateros are equipped with basic equipment like an E chart and torch light, and are monitored by the community ophthalmic nurse.



A nyatero visiting households in the village

## Piloting the nyatero concept:

With full support from Sightsavers country office, the NECP organised a meeting of all community level stakeholders in Mansa Konko, the regional capital of the Lower River Region. In order to pilot the nyatero concept, these stakeholders agreed that communities within this region should each identify a nyatero to be responsible for the eye health of a maximum of 250 people. In some communities, the National Nutrition Agency had already trained community volunteers to distribute vitamin A and it was therefore recommended that these volunteers should also become nyateros. In communities with no existing distributors, the villagers would identify members to be trained as nyateros by the eye care programme staff. The communities were encouraged to identify people who were likely to stay in the community and not emigrate to the capital city or other countries.

## Training phase:

The programme embarked on a pilot training of nyateros in June 2003. A training manual was developed, followed by a training of trainers course for community ophthalmic nurses working in rural areas. These nurses would then train the nyateros on basic eye anatomy and recognition of common eye conditions like 'red eye', conjunctivitis, eye

injuries, cataract and corneal scars. They also provided training on how to guide a blind person, information about available eye care services in their district and region, and when to refer patients for treatment or further examination. Upon completion of the training, each nyatero was issued with pictures of common eye conditions, a torch light and an E chart. These were presented to them at a ceremony attended by members of their community, along with community leaders and district administrators.

## Results:

The pilot proved successful and the programme noted an increase in early referral and treatment, together with a reduction in complicated eye conditions being presented at health facilities. It was agreed that the nyatero concept should be expanded to all regions of the country from 2004 onwards.

By 2006, over 2,000 nyateros had been trained by the eye care programme and were taking responsibility for the eye health of their communities. They performed household visits, encouraged eye patients to visit the community ophthalmic nurse, promoted clean faces for children and environmental cleansing exercises, and collaborated with traditional eye practitioners.

This regular interaction between an eye care worker and members of the community has the following advantages:

- Bringing services closer to the community
- Encouraging uptake of services
- Enabling the early identification and treatment of eye conditions
- Leading to a reduction in complicated cases
- Reducing the cost of services both to the patient and to the provider
- Making communities more aware about good eye health practices
- Acting as a form of community empowerment

Since the implementation of the nyatero concept, the programme has seen a drastic decline in the number of complications due to traditional eye practices and a reduction in patients presenting at the clinics with advanced eye conditions. Awareness of eye health issues within the community has also increased, as confirmed by the NECP evaluation of 2008.



# Strengthening control of diabetes-related blindness: a community participation case study from Pakistan

Niaz Ullah Khan, Country Director: Pakistan  
Munazza Gillani, Programme Manager: Pakistan  
Muhammad Bilal, Programme Officer: Pakistan



Lady health worker Samina uses a visual chart to raise awareness of eye health issues

## Summary:

Although there is variation in the estimates of diabetes mellitus (DM) in Pakistan, the majority of public health experts agree with a prevalence of eight percent to 10 percent in the 20 to 79 year age group. Around 27 percent of patients with diabetes mellitus are likely to have diabetic retinopathy, a related condition involving damage to the retina of the eye. In order to create awareness, promote screening and seek changes within communities, a social mobilisation strategy was adopted by Sightsavers Pakistan and local partners. This involved networking with

local service providers, community health workers and community-based organisations. Operational research was also initiated in order to understand the barriers towards changes in eating habits and health seeking behaviour, and to develop necessary information, education and communication (IEC) materials.

## Background:

In Pakistan, it is estimated that there are at least 7.1 million people affected by diabetes mellitus (DM)<sup>1</sup> and the magnitude is projected to reach 10.5 million by the year 2030. The





**Samina making community visits**

prevalence of new cases of Type I DM per 100,000 population per year in children under 14 years is 0.5 percent and about 88,000 deaths per year in the 20 to 79 year age group are attributable to DM<sup>2</sup>. In terms of numbers of people affected by DM, Pakistan ranks 7th in the list of countries compiled by the International Diabetes Federation.

Diabetic retinopathy (DR) is a disabling complication of DM that can result in visual impairment or blindness and lead to a serious socioeconomic burden, particularly in the working age group. DR is a major cause of blindness in about four percent of patients suffering from Type I DM, and 1.6 percent of those suffering from Type II DM. Early screening for ocular changes can prevent blindness, but this requires patients to contact appropriate health care facilities early in the process of the disease and commit to regular monitoring regimes. Appreciation of the need for eye examinations encourages people to seek medical assistance in the prevention and control of DR<sup>3</sup>.

The Pakistan National Blindness Survey carried out in 2004 estimated the prevalence of blindness at 0.9 percent across the country, a total of 1.5 million people<sup>4</sup>. Out of those, less than 0.5 percent suffered from diabetes-related eye conditions<sup>5</sup>. However, global data

supports the assumption that DR will be one of the most important causes of blindness in the future. Lack of awareness about the condition has been observed as a key risk factor, highlighting the need to control and prevent DR through better patient education and screening<sup>6</sup>.

## Programme initiatives and approach:

Towards the end of 2005, Sightsavers initiated a pilot project on the prevention and control of diabetes-related blindness in Gadaap Town, Karachi. Home to approximately 16 million people, 10 percent of the population of the country overall, Karachi is the largest city in Pakistan and has been divided up into 11 administrative units called 'towns'. Gadaap Town has a mixture of urban and rural dwellings and is one of the least developed areas, with visible poverty, low literacy rates, a lack of health awareness and limited health facilities.

The project focuses on three levels of prevention. It provides screening facilities at the primary level, medical diagnosis and treatment at the secondary level, and surgical intervention and low vision care at the tertiary

level. Four eye care centres were established within existing government primary health care (PHC) facilities in Gadaap Town to provide screening and diagnosis. Over 36,000 patients attended as outpatients and 1,500 vitreoretinal surgeries were performed for patients with DR. These surgeries took place at Al Ibrahim Eye Hospital (AIEH), the participating tertiary hospital.

At the start of 2005, a participatory rapid assessment (PRA) was conducted with the communities of Goth Memon Murad Abad in Gadaap Town to find out their perceptions of local development and diabetes-related issues. In addition to poverty, unemployment and shortage of irrigation water for growing crops, the community provided deep insights about health issues related to diabetes. The community proposed the following interventions:

- > Information, education and communication (IEC) materials to educate municipal officials, local councillors and resident communities
- > Support to the primary health care system in screening diabetic patients, ensuring that early detection is possible
- > Training for local PHC workers in identifying DR cases and raising awareness about preventive measures
- > Strengthening Al-Ibrahim Eye Hospital to cater for patients with diabetic retinopathy and providing outreach community services at PHC centres
- > Developing links between local community-based organisations (CBOs) and non-governmental organisations, critical for ownership of the programme

## Social mobilisation strategy:

Based on the PRA described above, AIEH and Sightsavers developed a social mobilisation strategy for the control of diabetes-related blindness. A team was formed to undertake social mobilisation activities; this was comprised of a community ophthalmologist, a refractionist and a social organiser with qualifications in social work and expertise in working with communities. The strategy revolved around training lady health workers (local PHC workers resident in the communities) on diabetes-related issues, developing links with existing health service providers and creating awareness among communities. The intervention resulted in networking between local CBOs, health management teams, religious leaders, educational institutes, general physicians (GPs), and social activists.

## Enhancing the capacity of the primary health care workforce:

Lady health workers (LHWs) are the front line health workforce, working directly with the community and attached to a first level health facility; a basic health unit or rural health centre, depending upon the size of the village. Each LHW is responsible for providing primary health care and family planning to 125 to 150 households, reaching a population of up to 1,000 people. In the project area, 400 LHWs were trained as part of the strategy to strengthen eye health within PHC, with a focus on diabetes, its complications and the need for prompt referrals. The LHWs were provided with the necessary IEC materials for distribution within the communities and worked with the AIEH social mobilisation team to motivate community members to visit PHC centres and hospitals for treatment. The LHWs proved

Year	Patients screened for diabetes at Al Ibrahim Eye Hospital			Referred by LHWs from communities	Self-referrals
	Males	Females	Total		
2008	3,429	7,013	10,442	3,196	1,822
2009	2,412	3,832	6,244	1,886	1,509
Jan to Sept 2010	2,320	2,977	5,297	929	1,831
<b>Total</b>	<b>4,732</b>	<b>6,809</b>	<b>11,541</b>	<b>2,815</b>	<b>3,340</b>

helpful in bringing patients to the health facilities where they could be examined by the medical officer and referred to the tertiary centre if surgical intervention was required. About 18 percent of patients seen by LHWs were referred for diabetes screening in the first three years of the project, and 39.4 percent of all patients attending PHC centres with eye care facilities were referred by LHWs.

Involvement in primary eye care work has been vital in raising the general profile of LHWs within their communities; confidence among community members has increased by virtue of LHWs addressing additional health issues, and the stigma associated with their work on family planning has been markedly reduced.

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## Improving the skills of health professionals:

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GPs are a key resource for the initial diagnosis and referral of patients. All GPs working in Gadaap Town received training on the issues and implications of visual impairment relating to diabetes. This was carried out by the social mobilisation team from AIEH and the GPs also went on exposure visits to hospitals. This not only resulted in increased knowledge and awareness, but also strengthened the referral pathways for detailed eye examinations.

In addition, the Diabetic Association of Pakistan provided technical support to the GPs and services to those referred by the project. They were involved in the development of IEC materials for the communities and also provided training to medical officers and information about the referral of new cases of general diabetes.

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## Operational research:

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As part of the project, a knowledge, attitude and practice (KAP) survey was undertaken to determine the causes of DR and the reasons for the lower uptake of eye health services by the community. One aspect concentrated

on the possible relationship between the prevalence of diabetes and the nutritional habits and body mass index in the community. The results indicated that health is not a priority for the community due to factors such as poverty, lack of awareness regarding health and diseases, professional apathy to public health issues, lack of community-based support and low confidence in health providers within the community.

In addition, other pre-KAP and post-KAP surveys were conducted in the project area to develop appropriate IEC materials. Based on the results of the KAPs, awareness and advocacy materials were developed for different tiers of stakeholders. The information was prepared in the local language for wider usage and coverage. The post-KAP studies also indicated that the project's interventions have been effective for raising community awareness regarding issues of diabetes and DR.

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## Key lessons and learning:

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The PRA approach was not only useful in identifying community perceptions about the problem of diabetes and DR, but also played a key role in developing the implementation strategy, which took on board community suggestions received through PRAs and the social mobilisation process. A well defined social mobilisation strategy which targets different tiers of the community is invaluable in raising awareness and creating confidence amongst different stakeholders.

Operational research was also a key component of the implementing strategy. It was helpful in designing and refining the IEC materials, provided information about patterns and trends, and helped to evaluate the effectiveness of different strategies.

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<sup>1</sup> International Diabetes Federation, (2009) Diabetes Atlas 4th edition <http://www.diabetesatlas.org/map>

<sup>2</sup> Ibid.

<sup>3</sup> Dervan, E., Lillis, D., Flynn, L., Staines, A., & O'Shea, D. (2008). Factors that influence the patient uptake of diabetic retinopathy screening. *Ir J Med Sci*, 177, 303-308.

<sup>4</sup> Jadoon MZ et al. Prevalence of Blindness and visual impairment in Pakistan: the Pakistan National Blindness and Visual Impairment Survey. *Investigative ophthalmology & visual science*, 2006, 47(11):4749-55

<sup>5</sup> Dineen B et al. Causes of blindness and visual impairment in Pakistan: the Pakistan national blindness and visual impairment survey. *Br J Ophthalmology*, 2007, 91(8):1005-10

<sup>6</sup> Huang, O. S., Tay, W. T., Tai, E. S., Wang, J. J., Saw, S. M., Jeganathan, V. S. et al. (2009). Lack of awareness amongst community patients with diabetes and diabetic retinopathy: the Singapore Malay eye study. *Ann Acad Med Singapore*, 38, 1048-1055.



# Community participation: the entry point to integrated control of neglected tropical diseases in Nigeria

Anita Gwom, Project Officer: Nigeria



A community leader is the first to receive a blood test during mapping for lymphatic filariasis

## Summary:

Active community participation in onchocerciasis control programmes using the community-directed intervention (CDI) approach has contributed to a reduction of the disease burden in Nigeria. Building on their experience and existing community structures, Sightsavers Nigeria expanded their focus in 2010 and started an integrated programme for the control of onchocerciasis and four additional neglected tropical diseases (NTDs). NTD control programmes using community-directed approaches are generally recognised as cost-effective public health care interventions.

This programme started with integrated

mapping and baseline studies of lymphatic filariasis, soil-transmitted helminthiasis and schistosomiasis in five states in Nigeria. Community participation in these activities was key to their success, and the survey results provided vital data on the prevalence of NTDs and justification for starting the co-administration of drugs to control them. This article looks at the key components and success factors in this community-directed approach.

## Introduction:

Neglected tropical diseases (NTDs) affect mostly the world's poorest, particularly those



**Conducting a baseline survey in the community at night**

living in remote rural areas or in urban slums. The diseases thrive under conditions related to poverty such as poor sanitation, unclean water, poor housing, and breeding sites for insects. Children, women and those living in remote areas with limited access to effective health care are the most vulnerable to NTDs and to related problems such as malnutrition, anaemia, serious or permanent disability (including blindness), illness, and death<sup>1</sup>. Often, individuals are infected with multiple NTDs simultaneously.

As part of a new strategic direction, Sightsavers aims to demonstrate eye health approaches that are scalable, adaptable and cost effective. As a result, Sightsavers Nigeria is expanding its current onchocerciasis control programme to support the integrated control of onchocerciasis, trachoma, schistosomiasis, lymphatic filariasis and soil-transmitted helminthiasis in five states using the community-directed intervention (CDI) approach. Successfully used in onchocerciasis control in Nigeria and elsewhere in Africa, the CDI strategy is an approach in which communities themselves direct the planning and delivery of an intervention<sup>2</sup>. It has proved to be very effective and efficient in terms of both cost and coverage.

As part of their expanded programme, Sightsavers Nigeria piloted the integrated control of these five NTDs in Zamfara state. This commenced with mapping and baseline surveys of trachoma, schistosomiasis, lymphatic filariasis and soil-transmitted helminthiasis, mapping for onchocerciasis having already been carried out in 1996.

The surveys were followed by mass drug administration using the CDI strategy. Supporting the control of five NTDs was a new and unique experience for Sightsavers Nigeria and the organisation as a whole; being the first time that control for the top five NTDs had been implemented in one programme and across an entire state.

## **The CDI approach:**

Community participation is about mobilising a group of people to support an intervention that will benefit an entire community. The first and most obvious principle of community participation is that as many community members as possible, if not all, are involved in and own the process. In addition, the following factors have been identified as crucial to the success of such an initiative:

- Knowledge of the community's location and its benefits and limitations
- An appreciation of the history of the community
- Understanding of the community structure and hierarchy
- Use of influential persons and existing systems
- Clearly stated roles and time commitments for community members
- Commitment by partner organisations to the process

The entry point to working with a community is the traditional leaders, who are seen as the most respected level of leadership. The NTD control programme met with these leaders and informed them about NTDs and the potential impact and benefits of the survey on disease control. The presence of some NTDs would already have been obvious within the community; blood in the urine and stool, for example, a sign of schistosomiasis and soil-transmitted helminthiasis, or people with thickening of the skin, a symptom associated with lymphatic filariasis. On being made fully aware of these and other less obvious diseases, community leaders then met with and informed other leaders such as religious, political and other community heads during community meetings and religious gatherings. The various leaders then educated their members using loud hailers on markets days, community meetings, announcements



in prayer houses and other such methods. Meeting with community leaders in this way is essential to ensure that health education messages are passed on, leaders are informed of the planned intervention, and that roles and responsibilities of both community members and implementing partners are agreed.

## Mapping and baseline survey for the top five neglected tropical diseases:

Utilising the CDI approach, community participation forms a key component of the planning, implementation and evaluation of the Nigeria NTD control programme. Communities are supported to take part in the planning process, to co-administer the relevant drugs, to keep records and to gather data relating to the programme. Community support and participation also contributed immensely to the successful NTD mapping exercises and baseline surveys in Nigeria.

Disease mapping and baseline surveys were conducted for lymphatic filariasis in the five states of Kebbi, Kwara, Kogi, Kaduna and Zamfara, while integrated mapping was done for schistosomiasis and soil-transmitted helminthiasis in Zamfara. It is worth noting that Zamfara is the first state in Nigeria, and in Sightsavers programmes, to receive statewide-integrated NTD mapping. This has positioned Sightsavers as a key actor in NTD control and built the capacity of its partners. Maximum cooperation was given by community leaders in Zamfara, enhancing overall community participation in both the initial mapping and

subsequent NTD control for the state.

The communities were not only the subject of the surveys, but were also fully involved in their planning and implementation. Community members gave their time to supervise data collection and sampling activities, and to raise awareness and understanding of these activities among their neighbours. The sampling process involved dealing with large numbers of people and could be hectic, particularly when collecting samples from children. The lymphatic filariasis survey also involved working during unsociable hours, as blood samples needed collecting between 10pm and 2am. Despite these challenges, community members supported the process throughout and the timely and successful completion of the exercise was down to their full participation and commitment.

## Key success factors:

- Effective advocacy to community leaders and key stakeholders
- Effective community mobilisation and health education
- Strong community participation and ownership
- Use of key influential and respected people
- State, local government and community level capacity building in how to implement NTD control activities
- Enhanced collaboration with the Federal Ministry of Health, state ministries of health and academic institutions



Advocacy visit to a community leader



## Lessons learnt:

- > Communities will always support a health intervention if the disease is perceived as a priority
- > Community members are ready to volunteer their time, although other paid health interventions, such as polio campaigns, may discourage them

## Challenges:

- > Lymphatic filariasis mapping was delayed by the late arrival of immuno-chromatographic test cards, which are used to detect the filarial worm antigen in blood samples
- > The logistics involved were complicated and required a larger workforce
- > Large mapping and baseline exercises such as these require significant amounts of funding

## Conclusion:

The rationale for community participation in NTDs and other health interventions has been well documented and, in the experience of Sightsavers Nigeria, it has certainly been key to achieving an effective NTD control programme. Early and sustained participation by community members and leaders is crucial in achieving community ownership and sustained programmes. The communities themselves can also be involved in research or act as change agents to achieve health and other social outcomes.

The Zamfara NTD control experience is a model that should be showcased to other organisations for possible replication elsewhere. The control of NTDs is key in achieving some of the Millennium Development Goals (education, health, poverty); it becomes imperative that other development organisations see it as vital.

## Case study:

**With Sightsavers' support, Ntong Bigng had previously benefited from both cataract surgery and Mectizan® treatment for onchocerciasis.**



Ntong was aware of the benefits of Sightsavers-supported Mectizan® and eye care programmes in the Jaba district of Kaduna State, and she became an advocate for community members to participate in the NTD programme. Ntong was one of many local people who willingly waited through the night to give blood samples as part of the mapping exercise for lymphatic filariasis. Talking about her involvement, Ntong said “a health worker that performed cataract surgery for me informed [me] of this exercise, and I have been taking Mectizan® tablets yearly. He helped me to regain my sight through cataract surgery. I will participate in whatever he tells me to be involved in. I am here for the LF night bleeding; I will stay until I am attended to”.

<sup>1</sup> Skolnik, R. and Ahmed, A. (2010) *Policy brief: Ending the Neglect of Neglected Tropical Diseases*, Population Reference Bureau. <http://www.prb.org/pdf10/neglectedtropicaldiseases.pdf>

<sup>2</sup> UNICEF/UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases, 1996. *Community-directed treatment with ivermectin: report of a multi-country study*. Geneva: TDR (TDR/AFR/RP/96.1).

# Strengthening the community health system: a case study from the Sundarbans, West Bengal

Sudipta Mohanty, Programme Manager: North East India



Boats connect remote villages in the Sundarbans

## Summary:

Access to health care was a real challenge for inhabitants of the remote islands of the Sundarbans. That is until the Sundarban Social Development Centre (SSDC) started its intervention to provide eye care services. Initially designed to provide rehabilitation services to blind people, the programme was subsequently expanded to address broader issues relating to eye health and issues of ocular morbidity. In terms of the World Health Organization's health system building blocks<sup>1</sup>, this initiative demonstrates how integration between the health workforce, health financing, and leadership and governance components can help to establish effective service delivery mechanisms and, in the long term, enhance

the quality of eye health services. This paper details how these components were brought together and how they have led to an improved village health system in the Sundarbans.

## Background:

West Bengal lies in the eastern part of India. It is the twelfth largest state in terms of geographic size and ranks fourth in terms of population. Formed by the tributaries of the river Ganges as they meet the Bay of Bengal, the Sundarbans region is considered to be the largest delta of its kind in the world; the whole area is criss-crossed by rivers and stretches for about 100 kilometres. It consists of 102 islands spread over the North 24 Parganas and South



24 Parganas districts of West Bengal. The villages in the intervention area are situated in the remote belt of the Sundarbans and poor infrastructure is the main reason for the overall underdevelopment of this region. The location and topography of the region means that communication and transport is difficult. With many people relying on water transport, quick access to facilities at village level, and beyond at district and city level, is not easy for the people of the Sundarbans.

## Sundarban Social Development Centre:

Sightsavers support to SSDC started in 2002 in the form of a community-based rehabilitation project. However, with the prevalence of blindness at 1.2 percent and an overwhelming demand for cataract surgery in the community, Sightsavers supported the construction of an eye hospital in 2004. In its second term, the programme adopted a multi-stakeholder approach to ensure full community participation and promote the integration of eye health into the overall health agenda of the community. A team of community volunteers was created and is working towards establishing a community health system. This includes an effective primary level health workforce, adequate funds for emergent health needs in the community, and local ownership and leadership by the village health committee. The provision of health information and an adequate supply system is also being addressed.

## Health workforce:

From the start of this initiative, SSDC has adopted a multi-stakeholder approach whereby

various community-based institutions have been linked together to promote and facilitate health services within the region.

The central health committee functions at the panchayat<sup>2</sup> level and includes representatives from the village health committee. This village level committee is formed of members from the various community groups depicted in the diagram below, together with government health workers such as accredited social health activists and auxiliary nurse midwives. Each member of the team is trained to address the basic health needs of the community and the group works on preventive measures such as improving sanitation and hygiene practices in the village, raising awareness about vitamin A deficiency among children and pregnant mothers, as well as other issues such as personal hygiene, sexual health among adolescents, immunisation and nutrition. In order to engage the committee in eye health issues, a team of volunteers has been developed and trained to conduct preliminary eye screening using a simple rope method.



Using a simple rope method to screen villagers





This vision screening is done at the community level and those who have potential eye health problems are referred to the nearest vision centre. In cases where surgery is needed, the patient is transported to the base hospital by the volunteer. These health volunteers are responsive to the needs of their community, ensuring the best possible eye health outcomes for community members, given circumstances and available resources.

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## **Health financing:**

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A village health fund has been developed by members of the village to raise adequate funds for emergent health needs and ensure that services are available to the poorest families within the community. This village fund is linked to a central health fund which takes care of health financing for the entire panchayat. In the Durbachati panchayat, six village health committees have been formed, with each holding around 3500/- INR as a reserved health fund for that community.

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## **Supply management system:**

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A drug distribution centre has been created within each community to provide essential drugs at an affordable rate. The vision centre in the island provides equitable access to comprehensive eye health services which are cost effective and of assured quality. Aside from eye-related issues, SSDC also produces a nutrition pack for children made from locally available produce and has instigated the local production of sanitary napkins for adolescent girls and women. The availability of high quality, cost effective drugs, products and services contributes to quality health service delivery for the people of the Sundarbans.

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## **Health information system:**

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A health register is maintained by the village health committee to keep track of the health needs of the villagers. Health mapping as a tool was used by the group to identify potential houses where health risks are at the highest level and the government health worker also keeps a note of all newborn babies and pregnant women. Apart from keeping information on health needs, the village health committee also collects data on health determinants such as the availability of drinking water, immunisation for newborn babies and

pregnant women, and the use of traditional medicine within the village. This database of health information allows the committee to monitor the overall health status of the village. It also helps SSDC to provide health services that are relevant to the needs of the community, or to raise awareness of existing government services.

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## **Leadership and governance:**

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Through a series of awareness raising events, the programme has empowered community leaders and government health workers to provide leadership on eye-related and general health issues. At the community level, the elected panchayat representatives were encouraged to prioritise the eye health needs of their community, and at the district level a pressure group was created to leverage funds for the construction of a vision centre on the island, thereby improving accessibility of services. Leadership has also been instilled within the community from a human rights point of view, with community members themselves demanding eye services and advocating for their overall health needs at appropriate meetings. The village development council, supported by SSDC, ensures that eye care services reach each and every household in the community, and that steps are taken to support the health needs of the poorest families. Within the panchayat, leadership skills training has been provided to self help groups and village development committees.

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## **Key learning:**

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The active involvement of the village and central health committees in raising awareness of village health needs has resulted in better service delivery and increased demand for eye health and general health services. The participation of all age and demographic groups within the community has also been vital in the effective functioning of the community health system. This participation and collaboration in turn results in the overall development of the community.

By intervening through the various building blocks of the community health system, and advocating for a packaged service based on the needs of the population, access to comprehensive care has been greatly improved for the people of the Sundarbans. Focusing only on eye health needs may not ensure

sustainability of a project intervention so a community-based health needs approach, with a focus on the overall health agenda, is crucial.

This programme has tried to integrate into the government health system via primary health centres, vision centres and government health workers wherever possible, whilst also ensuring that affordable and high quality eye health services are available to this remote population. Multi-stakeholder intervention at different levels and convergence with the government programme is required to ensure long term impact.

## Way forward:

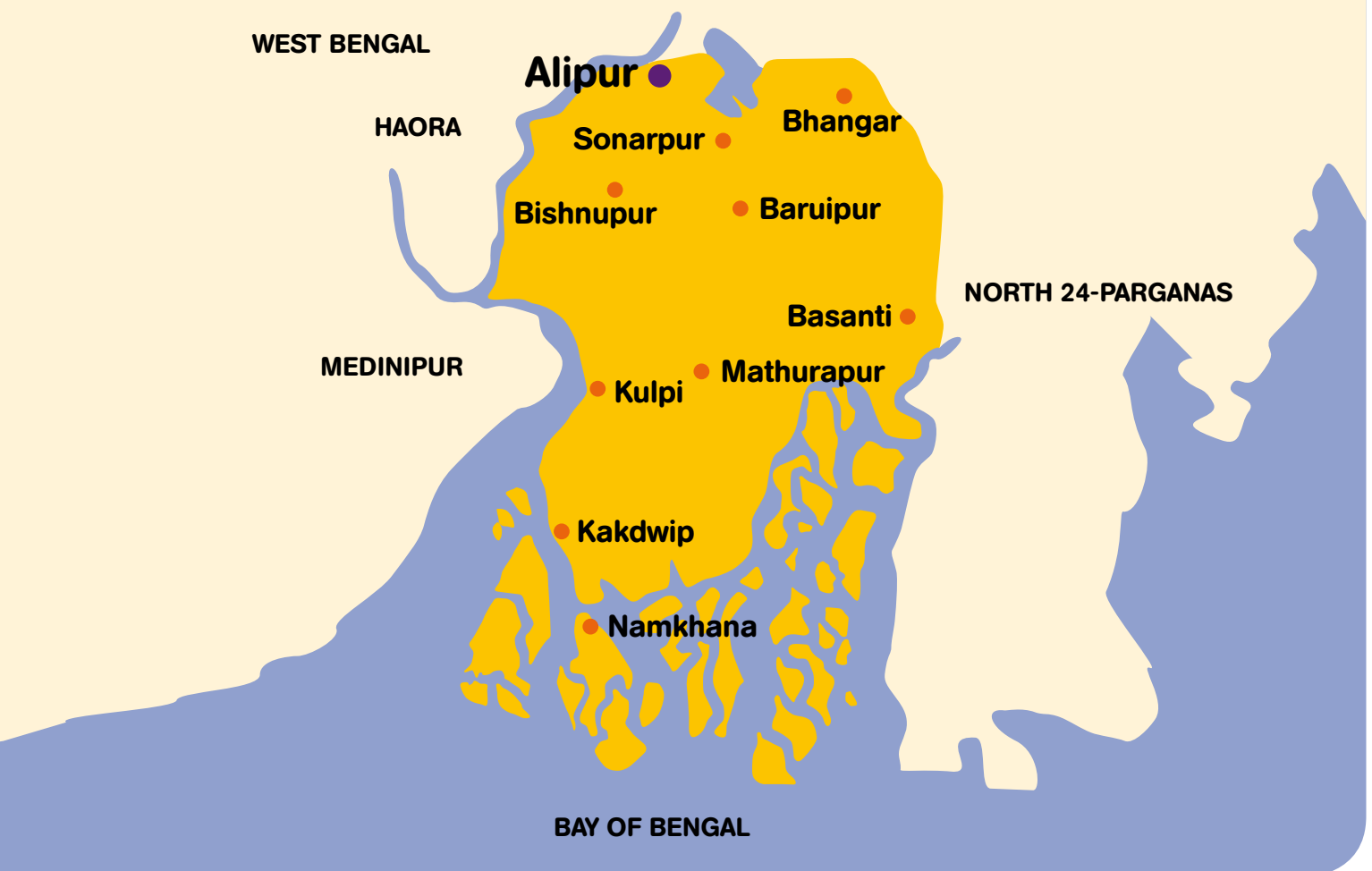
The programme will aim towards achieving a greater level of convergence with the government programme in the future years. Steps have been taken to establish vision

centres within existing government primary health centres and to train government health workers to provide eye health services.

There is a need to establish a wider network of village and central health committees and to consolidate this process at block or district level. This would provide effective leadership and act as a platform for advocacy on overall health issues. In terms of reaching out to the poorest people, the programme will make an effort to collaborate with health insurance agencies to provide them with protection from health adversity.

The programme also aims to build its own capacity to address other diseases, such as diabetic retinopathy and glaucoma. This would allow the local community to access comprehensive services in one location, rather than being referred to several different service providers.

## South 24-Parganas



<sup>1</sup> World Health Organisation, 2007. Everybody's business: Strengthening health systems to improve health outcomes. Geneva: WHO [http://www.who.int/healthsystems/strategy/everybodys\\_business.pdf](http://www.who.int/healthsystems/strategy/everybodys_business.pdf)

<sup>2</sup> Panchayats are local governments at the village or small town level in India



# Mobilising the community health workforce in Colombo and Kandy

Dr Sunil Fernando, Country Director: Sri Lanka



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Training session for primary health midwives

## Introduction:

Sri Lanka has a population of around 20 million, with an estimated 150,000 people who are blind and one million who have uncorrected refractive error. The Vision 2020 National Plan for the Prevention and Control of Blindness in Sri Lanka was launched in October 2007 and highlighted the urgent need to provide eye care services at the community level. Five priority diseases were identified in this plan, including cataract, refractive error and low vision.

The Urban Comprehensive Eye Care Project (UCECP) is working to target poor urban communities in the Colombo and Kandy

municipal districts of Sri Lanka. Colombo has a population of over two million with a density of 3,410 people per square kilometre. Over half of the population live within the city's 63 slum areas, where housing is poor and three or four families may live together in a single dwelling. Located in the central province, Kandy is the third most populated district in Sri Lanka, with a population of 1,279,000. A recent prevalence study in the central province indicated a significant number of children with uncorrected refractive error.

UCECP is implemented by the Ministry of Health in collaboration with Sightsavers and Standard Chartered Bank, who provide funding through their Seeing is Believing programme.

The project provides primary eye care (PEC) training to primary health care (PHC) workers and also trains school teachers to screen their pupils for refractive error. It interfaces with the PHC workforce of the municipal councils in Colombo and Kandy, and with the school medical inspection teams in these districts.

## Increasing primary eye care capacity:

Historically, Sri Lanka has a well established PHC system with PHC workers regularly visiting local houses to provide advice and referrals on maternal and child health and immunisation. They function as the link between the community and the government health system and therefore play a key role in any PEC programme. If PHC workers are equipped with sufficient training in primary eye care, they can treat basic eye conditions within the community itself, reducing the need for patients to travel to hospitals. They can also ensure that more complicated or advanced conditions are referred promptly to the appropriate service provider, ensuring swift treatment and reducing avoidable blindness.

However, until recently, the capacity of PHC workers to address eye care issues has been limited. As a result, hospital eye units are overcrowded with patients who could easily be treated at the primary level. UCECP is working to train PHC workers in primary eye care; enabling them to disseminate eye health education, screen for eye problems, identify simple eye conditions and refer more complex cases to specialist eye clinics or hospitals for treatment. After receiving their training, PHC workers in Colombo organised eye clinics in the premises of existing health and maternity clinics run by the city council via their health management division. The inclusion of PEC services within these clinics has improved access to eye care for the poorer slum communities that they cover and promoted the sustainable integration of eye care services in the PHC system.

- > **711 PHC workers in Colombo were trained in PEC via a series of workshops.**
- > **Each trainee was provided with a PEC kit, comprising of two vision charts (letters and symbols), one rechargeable torch, eye pads and dressings and a field handbook**

- > **Nine outreach clinics were conducted in the urban slum areas of Colombo.**
- > **1,565 people were screened and 1,328 identified as presbiopic and in need of spectacles**
- > **165 people were found to have cataract and 162 with other eye diseases**
- > **65 people were referred to the eye hospital for further examination and treatment**

Increasing the accessibility of eye care services for slum communities is an important issue for the Colombo Municipal Council. The distance between people's homes and the nearest eye unit or hospital was identified as a key barrier for many people and it was recommended that a number of satellite clinics be established. Attached to base hospitals, these would cover peripheral areas and initially act as refraction centres. Six such units were identified and an ophthalmic technician visits on a regular basis to screen people referred by PHC staff. Once the refraction unit is functioning properly a regular visit of an ophthalmologist will be considered.

## School screening in Colombo and Kandy:

The Ministry of Health (MoH) implements a school screening programme throughout the country, carried out by primary health inspectors (PHIs). This programme covers children in grades one, four and seven, but the limited number of PHIs and their heavy workload prevents them from screening all children in the schools that they have been assigned. In addition, although PHIs screen children for general health issues, eye health is often neglected and the programme has no provision to treat any problems that are identified, other than referring the child to hospital. In cases of refractive error, spectacles are not currently provided through the MoH programme and are typically too expensive for parents to purchase without assistance. UCECP therefore aims to complement the existing government screening by ensuring that spectacles are available free of charge to poorer children, including those from the urban slum communities. UCECP also equips





**School children at a spectacle distribution event**

teachers to become focal persons for eye care within their respective schools, training them to screen pupils for refractive error. This will help to reduce the workload of the PHIs and ensure that all children are screened for eye problems. The teachers also receive training to increase their understanding of eye health issues in general.

In Kandy, UCECP held introductory workshops to inform people about the school screening programme. This was attended by teachers, but also by school principals, who would be crucial in ensuring full school cooperation in the programme. 132 participants attended these initial workshops, with 89 teachers being selected to lead the screening process at their respective schools. These teachers received screening tools and were taught how to identify pupils with refractive error. During the school screening programme in Kandy, 8552 children were screened and 449 were found to have refractive error and were provided with free spectacles. The programme also identified three children with cataract, 24 with squints, 50 with amblyopia, two with keratoconus, four with low vision and one with glaucoma.

In Colombo, discussions were held between UCECP, the Vision 2020 secretariat and the regional director for education. As a result, additional schools were added to the school screening programme in this district from June 2010. This has increased the programme's coverage and to date a total of 68,598 children have been screened. 4475 children were identified as having refractive error and 3254 have so far been provided with free spectacles.

## Conclusion:

Through the activities outlined above, UCECP has worked to increase the accessibility of eye health services for urban slum communities and to strengthen the school screening programme in the districts of Colombo and Kandy. The project works through established structures such as the government PHC system, regional directors of health and municipal councils, leading to a more sustainable programme.

A large number of people from urban slum populations have received eye health services

and the Vision2020 secretariat is now receiving requests for outreach services from religious institutions and other welfare organisations, indicating increasing interest from various sectors of the community.

The school screening programme has strengthened the eye health knowledge and capacity of PHC workers, and has demonstrated the importance of providing free spectacles to children. It is expected that this work will be absorbed into the MoH's free health service provision. UCECP is also introducing spectacle production labs in both Colombo and Kandy, and these will eventually

be managed by the MoH towards the end of the programme. As a result of UCECP's work, the Vision 2020 secretariat has initiated similar school screening programmes in several other districts in Sri Lanka.

## Case study:



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### **Dharmaseelan is 13 years old and lives in Kandy.**

He attends the Hindu Senior School, which caters for many students from poorer families. During a student screening programme conducted at the school by UCECP, Dharmaseelan was found to have cataract in both eyes. Due to his vision problems, he found it difficult to cope with day to day activities at school as well as at home. Dharmaseelan's parents were not aware that his vision could be corrected and could also not afford to take him to the eye unit.

UCECP project officers counselled Dharmaseelan's parents and persuaded them to admit him to the eye unit of the nearby teaching hospital in Kandy. Dharmaseelan received cataract surgery on his right eye and today has a visual acuity of 6/6 in this eye. Overjoyed with his improved vision, he is hoping to receive surgery on his other eye in the near future.

The cost of intraocular lens and post operative care for Dharmaseelan was covered by a grant from UCECP. His parents offered their sincere thanks to the project and staff of the eye unit for the services provided to their son. Having returned to school, Dharmaseelan is now acting as an ambassador for UCECP and raising awareness among his fellow students.



# Brokering change for trachoma in Pakistan

Niaz Ullah Khan, Country Director: Pakistan

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Dr Haroon Awan, Director: Programme Innovations and Technical Cooperation



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**Before and after – the village now enjoys clean, safe drinking water**

## Introduction:

Killa Virkan is one of 233 villages in Pakistan identified with endemic trachoma through a national situation analysis undertaken from 2003 to 2004. Trachoma is a neglected tropical disease spread by flies and caused by poor hygiene, lack of water and poor sanitation. Before intervention by Sightsavers Pakistan and local partners, the village was littered with solid waste and invaded by flies. Less than 15 percent of the community had latrines, with the local primary school for girls having only a dysfunctional one. Water used by the villagers for drinking was highly contaminated due to nearby industrial waste, there were no

sewers, no piped cooking gas, and the local dispensary was registering a very high rate of diarrhoeal disease. To address these issues, Sightsavers Pakistan applied the World Health Organization's recommended SAFE (surgery, antibiotics, facial cleanliness and environmental improvement) strategy for trachoma control in the selected villages. This article focuses on how Sightsavers collaborated with the Killa Virkan community to control trachoma.

## The challenges:

To find out about community attitudes to development and health issues within

their village, the programme conducted a participatory rapid appraisal (PRA) session. This is a participatory process that engages communities and finds out their views on critical issues about their village and living areas. At the first PRA session, community members did not identify eye infection due to trachoma as one of their priorities. The communities were more concerned, and rightly so, about the dangers of contaminated water and the general ill-health of the community at large. Unless these key concerns were met, they had no interest in trachoma.

## Dealing with the challenges:

From experience, Sightsavers Pakistan has learnt that community development is not a one stage process, but rather a complex series of steps that involve consultation, confidence building, formal cooperation, a conducive environment, enhancing capabilities, and a willingness for conjoined action; otherwise known as the 6-Cs. We discovered that there were various stages - information sharing, consultation, decision making, empowerment and accountability - through which the relationship with communities developed. In order to design our interventions at community level, we tested various methodologies and finally, in 2004, we developed a community model that would meet the needs of our various interventions and approaches.

This community model was refined into five key stages, known as the 5-Ps:

- > **Piloting** – this follows initial confidence building, through which the community agrees to test an intervention. It involves a series of PRAs and other community mobilisation techniques to build confidence.
- > **Partnership** – when the pilot intervention is successful, the community feels encouraged to enter into a formal agreement or memorandum of understanding that clarifies the roles and responsibilities of various stakeholders.
- > **Participation** – during this stage, the community becomes an active stakeholder and participates in designing, implementing, monitoring and evaluating interventions.
- > **Promotion** – encouraged by the success of the wider intervention, the community begins to advocate the model to neighbouring communities. Members of these communities visit the project site, interact with local people and the transfer of knowledge and skills takes place.
- > **Policy** – the community recognises that it needs a formal structure to access local development funds. This community structure is officially registered and becomes the voice of the community for development and other issues. It advocates to local government officials and the local political representative for relevant changes in rural development policy.



*The 5-P and 6-C Model for Community Development.*





A lady health worker teaches the importance of hand and face washing

## What worked:

We realised that we needed a regular presence in the community in order to understand its needs and cultural practices. We therefore appointed a social organiser; an expert in working with communities, facilitating dialogue and developing linkages both within the community and beyond. He advised on power dynamics and decision making structures, and organised community meetings for the programme teams.

Through a series of PRAs, we were able to agree on the priorities for the community – clean water, proper sanitation, a clean village environment, a functioning school latrine, paved streets, and the availability of cooking gas. One critical factor was ensuring that leadership and ownership rested with the local councillor and political representative for the area, and that this person was accountable to the local committee.

## The outcome:

Following the 5-P 6-C model, within three years the situation in the village had been transformed.

## Surgery and antibiotics:

The project works through lady health workers (community health workers) to identify trachoma and refer cases for surgery. These surgeries are referred to district eye units where trichiasis surgeries are performed. The lady health workers, together with the social organiser, are also responsible for administering antibiotics to treat trachoma.

## Facial cleanliness:

Boreholes have been sunk in the village to provide water. In one instance, the local councillor donated his land for digging a deep bore hole and constructing an overhead tank for water. There are separate water taps for men and women, and over 90 percent

of households take water daily from this and many other safe drinking tanks in the community. Using participatory communication techniques, villages are now aware of the need for facial cleanliness and are practicing regular face washing.

## Environment:

The fly density is down to a negligible amount owing to periodic spraying and the clearing of all solid waste and stagnant pools of water by community members. Following the construction of sample latrines for public use, over 90 percent of the community have now constructed their own household latrines. In addition, the school has been equipped with two functioning latrines.

The prevalence of diarrhoeal disease has dropped markedly by more than 70 percent, clean and safe drinking water is now available, and the school has been upgraded to a secondary school. As a result of these changes, the incidence of trachoma has also been reduced.

## Advocating for development:

In addition to the above aspects of SAFE now in operation, and thanks to the innovative 5-P 6-C model, a citizens community board (CCB) has been formed. This board worked to mobilise the local government to provide the village with piped cooking gas, surface all alleyways with brick and provide cemented drains.

The community has registered itself with the local government as a CCB and is eligible to receive funding from the local government for development, provided they raise 20 percent themselves. The CCB has become the voice of the community; establishing priorities for development, mobilising funds and being accountable to local people.

## Key learning:

- > The role of a social organiser is immensely useful for community-based interventions
- > It is vital that one understands the power dynamics and decision making structures within a community
- > Community development is a slow process; don't hurry it, do it in stages
- > Listen to the communities to explore their wisdom and knowledge. Cultivate their potential through engagement and dialogue
- > Envisage the institutional change you want to see and work towards it

## Resources and further reading:

*Report of the National Trachoma Rapid Assessment*, National Trachoma Task Force, National Committee for Prevention of Blindness, 2002

*Evaluation Report of the pilot phase of the National Trachoma Control Programme*, National Trachoma Task Force, National Committee for Prevention of Blindness, 2008.

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Khan, AA., Khan, N., Bile, KM. and Awan, H., Creating synergies for health systems strengthening through partnerships in Pakistan – a case study of the national eye health programme. *Eastern Mediterranean Health J*, Vol. 16 Supplement 2010



# Focus on...

## community participation in Satum, Cameroon

**Sightsavers' partners work with local communities to raise awareness of eye health issues and how to address them. Through involvement in their planning and delivery, communities are empowered to take ownership of eye care services, and to make appropriate decisions about their own health.**

This approach is demonstrated by our support to the community-directed treatment of onchocerciasis in Satum, a village in the South West Province of Cameroon. Onchocerciasis, or river blindness as it is also known, is a blinding disease that is spread by the black flies that breed in the local Manyu River. To prevent it, the villagers must take Mectizan® tablets, which are distributed by community volunteers annually. The success of the programme depends on the participation of the whole village, as described in the profiles below:

### The community volunteer

**Kekema Martin** is 36 years old and has been a community volunteer for 10 years. Martin says "I noticed what river blindness was doing, and chose to take this job because I like being able to help my community". Visiting each household in the village, Martin's job is to educate people about onchocerciasis and the benefits of taking Mectizan®. When the time comes to distribute the drug, Martin measures each person to ensure they receive the correct dose and keeps records of how many people have been treated. Since becoming a volunteer, he says he has seen the effects of onchocerciasis "reduce drastically".

**"I am very pleased to be able to help"**

**Kekema Martin,  
community volunteer**





## The district supervisor

**Felix Amate** is Chief of the Bureau of Health for Mamfe district, where Satum is located. He oversees the work of community volunteers such as Martin. Originally trained as a volunteer himself, Felix has been in his current post for seven years. He is responsible for ensuring that 100 percent of communities in the district are covered by Mectizan® and that 80 percent of people receive the drug, allowing for pregnant women and children under five years who are unable to take it. Felix enjoys meeting people in his district and seeing that the need for Mectizan® is understood and accepted, explaining that villagers are educated about the drug at community meetings.

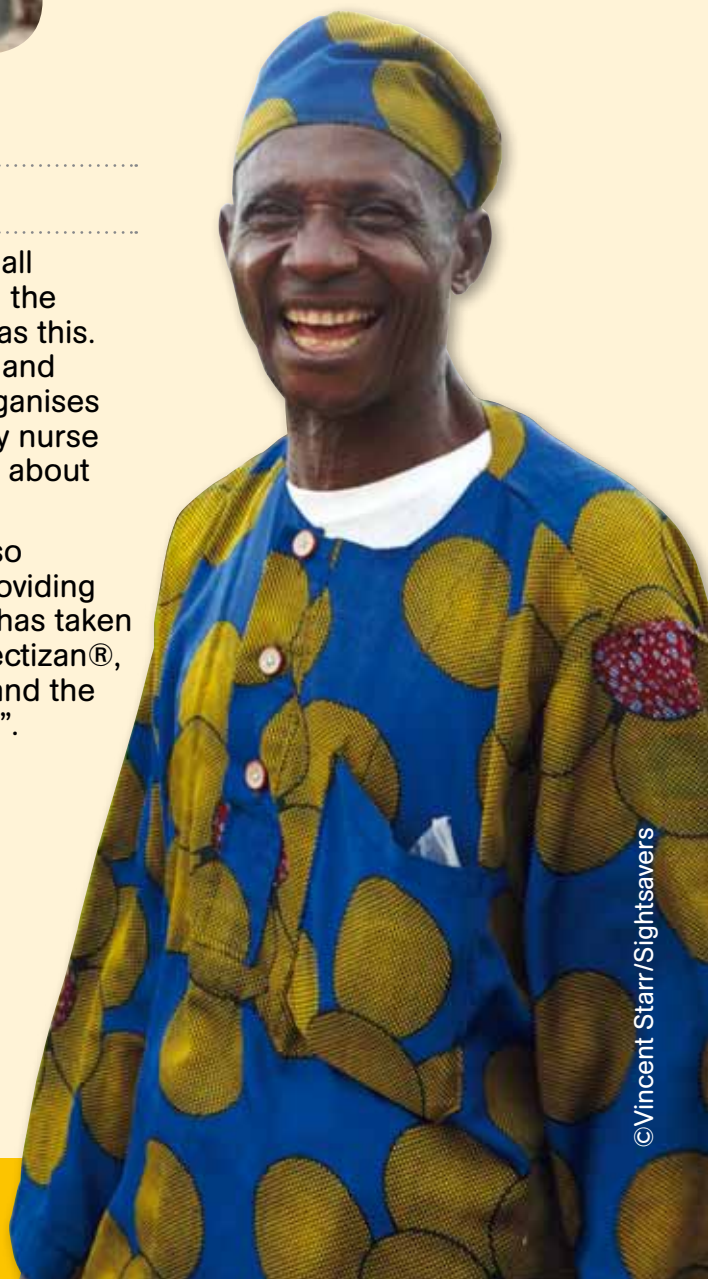
## The village leader

**Agbor Peter** is 56 years old and has lived in Satum all of his life. As village leader, Peter plays a key role in the success of community-directed programmes such as this. He is enthusiastic about the benefits of Mectizan® and has been taking it himself for seven years. Peter organises regular village meetings in which he and community nurse Elsie address the villagers' questions and concerns about onchocerciasis and other eye health issues.

Working with the community volunteers, Peter is also responsible for monitoring drug distribution and providing coverage reports to the government. Peter says "It has taken time to convince villagers that they need to take Mectizan®, but through constant messages through the radio and the local health centre, we are starting to see a change".

**"More and more people are taking Mectizan®, and I am very happy about this"**

**Agbor Peter, village leader**







## The community nurse

**Elsie Takor** serves as community nurse and midwife for Satum and has been helping with Mectizan® distribution since 1983. Elsie meets with the community volunteers to find out whether any villagers have refused treatment. She visits these individuals; saying “I tell them the benefits. They have to take it for 15 years and everyone has to take it. If one household doesn’t take Mectizan®, oncho could still exist in the community”

Elsie also monitors the community for any side effects, returning to Satum after the drug has been distributed. She has never seen any serious side effects. The most common complaint is itching, but Elsie explains that this is caused by the disease and that people should continue taking Mectizan®.

**“I like all of the roles of my job... the reason why I enjoy what I do is to see people happy”**

**Elsie Takor, community nurse**



## The villager

**Tasha John** is a farmer in Satum. He is 21 years old and has been taking Mectizan® for six years.

He says “I know that river blindness is bad, and that without Mectizan®, my eyes would become itchy, I would have bad skin, and eventually I would become ill”. He heard about Mectizan® from the community volunteers and is committed to taking it.

**“I am very happy to be taking this drug, and to continue doing so”**

**Tasha John, local farmer**

# Mobilising communities for eye health – learning from our programmes

Taitos Matafeni, Head of Monitoring and Evaluation Systems

**‘The individual is helpless socially, if left to himself... if he comes into contact with his neighbour, and they with other neighbours, there will be an accumulation of social capital which may immediately satisfy his social needs and which may bear a social potentiality sufficient to the substantial improvement of living conditions in the whole community.’**

Hanifan, L.J. (1916)<sup>1</sup>

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## Introduction

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There is an increasing awareness of how development initiatives can improve the well-being of local communities, if those same communities (particularly those experiencing disadvantage) are somehow engaged in the initiative. In public health, such engagement can take the form of communities deciding for themselves what the need is, or health care service providers can establish the need and provide the framework for community input. Evidence shows that community development initiatives which involve local people in decision-making result in improved health outcomes<sup>2</sup>.

In Africa and Asia, Sightsavers has developed and adapted a range of community approaches and practices which are driven by local people. One of the most successful approaches developed by Sightsavers in public health is the community-directed treatment with ivermectin (CDTI) approach, which has been adopted by the World Health Organization as the preferred method for treating onchocerciasis.

The preceding chapters have described and discussed some innovative methods and approaches. Here, we reflect on these articles with a view to drawing out learning that may be useful for other professionals and organisations in public health.

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## Learning points:

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### **1. Build on what the community values, as an entry point to community engagement.**

Community value systems are at the heart of sustainable development. In a study conducted in three communities in Senegal and The Gambia, the community expressed how they cared for those aspects which they had reason to value<sup>3</sup>. Furthermore, in pursuing the view of development as freedom, Sen argues that ‘we have to examine, in addition to the freedoms involved in political, social and economic process, the extent to which people have the opportunity to achieve outcomes that they value and have reason to value’<sup>4</sup>.

Our programmes have embraced the above and demonstrated that working through valued leaders, decision-making bodies and locally relevant structures/institutions is vital in getting communities energised to collaborate on public health initiatives.

### **2. Leverage existing local institutional efforts:**

The geographic focus and structural make up of community-based organisations (CBOs) has positioned them as partners of choice in working with communities. Community-based organisations are set up by the collective efforts of people living or working within the same environment. As such their spheres of influence rarely extend beyond their immediate communities or neighbourhood<sup>5</sup>.



To make headway in successfully mobilising communities to own and participate in public health initiatives, a multi-stakeholder approach is essential. As a prerequisite, such an approach should be supported by a thorough exploration of areas where synergies between CBO stakeholders and external agencies can be built or strengthened. Following such exploration, collaborative efforts that leverage the CBOs' areas of expertise are essential in ensuring uptake and sustainability of efforts.

### **3. Generate the energy and resources needed to effect changes in the community:**

Developing structures and mechanisms to energise the community to fully engage in health initiatives is pivotal to sustained public health. An approach that has been known to achieve this is the 'social mobilisation' strategy. Care needs to be taken when adopting a social mobilisation strategy to ensure that both energy creation, and the resources to sustain it, are in place<sup>6</sup>. In the majority of cases, practitioners often focus on energising communities at the expense of the resources element. Such a strategy is not going to be sufficient to fully engage and sustain community efforts.

As evidenced in the articles in this publication, many strides have been taken to ensure a full social mobilisation strategy is in place. Initiatives such as the trachoma and diabetic retinopathy programmes in Pakistan and neglected tropical disease control in Nigeria, to name a few, have successfully applied the twin track strategy in mobilising and brokering change in the community through embedding structures and resources to sustain energy and drive.

### **4. Foster linkages with primary health workers:**

Linkages with primary health workers are an important aspect of sustainability, given the finite nature of external resources. A key aspect of all public health interventions that Sightsavers supports is the promotion of primary health care. Concordant with this

approach is working with and building the capacity of primary health workers. Being members of the communities in which we operate, they have been a pivotal driving force in our community engagement efforts as demonstrated in the preceding articles.

### **5. Invest in operational research:**

Although many sector wide studies on engaging communities have been undertaken, operational research still plays an important part as far as adapting theory and past research to local circumstances. Case studies presented in this publication have demonstrated the importance of using operational research and pilots to adapt approaches to local circumstances and to cater for the uniqueness of each community that we serve. This area, however, still continues to be under resourced and we need to make conscious efforts across the sector to invest more time and money.

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## **Conclusion:**

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In engaging with communities to address problems they have collectively identified, or those for which a framework has been developed by health service providers, Sightsavers has essentially made pragmatic strides towards putting social capital principles in motion. The perspective of social capital is an interesting one for Sightsavers as it challenges us to look beyond people's participation in an initiative, to aspects that generate energy and allow communities to sustain and continue managing the initiatives independently. Our approaches have looked at how to engage with communities by building on their value systems, how to sustain efforts by working with local organisations, how to build local capacities, and how to strengthen local health systems. A prominent aspect has been operational research and the documentation of our work to inform the scale up and replication of our approaches.

<sup>1</sup> Hanifan, L.J., 1916, The rural school community center Annals of the American Academy of Political and Social Science 67:130-138. <http://ann.sagepub.com/content/67/1/130.full.pdf+html>

<sup>2</sup> Royal College of Nursing, 2002. The community approach to improving public health: community nurses and community development. London: RCN [http://www.rcn.org.uk/\\_data/assets/pdf\\_file/0005/78512/001445.pdf](http://www.rcn.org.uk/_data/assets/pdf_file/0005/78512/001445.pdf)

<sup>3</sup> Faal, H., Matafeni, T., Du Toit, R., Manneh, K., Ullah Khan, N. and Awan, H., 2010, *Development, vision and eye health: perceptions of communities in Senegal and The Gambia*, Sightsavers.

<sup>4</sup> Sen, A., 1999, *Development as Freedom*, Oxford: Oxford University Press

<sup>5</sup> Abegunde, A., 2009. The role of community based organisations in economic development in Nigeria: The case of Oshogbo, Osun state, Nigeria. *International NGO Journal* Vol. 4 (5), pp. 236-252 <http://www.academicjournals.org/INGOJ/PDF/Pdf2009/May/Abegunde.pdf>

<sup>6</sup> Social Mobilisation for Health Promotion, [http://www.wpro.who.int/NR/rdonlyres/8BF69A4E-2AA1-4B7D-803D-819C9FC457F4/0/hp\\_social\\_mobilization.pdf](http://www.wpro.who.int/NR/rdonlyres/8BF69A4E-2AA1-4B7D-803D-819C9FC457F4/0/hp_social_mobilization.pdf)

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