Community engagement in eye care: working with and for communities

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Community engagement and participation in the health system are fundamental elements of primary health care and are at the heart of the Alma-Ata Declaration of 1978, that: “people have the right and duty to participate individually and collectively in the planning and implementation of their health care.” At least half of the world’s population still does not have full coverage of essential health services, progress towards changing this will only be possible with community participation. A community is a group of people with diverse characteristics linked by social ties, common perspectives, problems, and issues, and who engage in joint action in different or the same geographical locations or settings.

“Empowered people and communities” is one of the three key components of primary eye health. This means that people know what causes eye disease, what to do to remain healthy, where to go when they become sick, and how to be inclusive of those who have irreversible visual impairment.

When communities are engaged and empowered, they can gain the knowledge (health literacy) and ability (agency) to bring about any changes that may be needed.

It is well established that mobilised and empowered communities can play a crucial role in all health processes, such as in planning, allocating resources, delivering services, promoting health, and monitoring health systems. Communities have vast resources – skills, knowledge, and social networks, all of which are building blocks for good eye health. Thus, it is important to enable communities to take control of their health.

Meaningful and effective partnerships between eye health service providers and communities can improve access by bringing services closer to communities, reducing the cost of eye care services, and increasing the efficiency of eye health systems. Community-based eye care activities may be conducted outside the premises of formal health facilities (e.g., hospitals, health centres, and clinics) in
About this issue
Community engagement and participation in the health system are fundamental elements of primary health care. In this issue, we explore the challenges of reaching those people most in need of eye care, learn how to work with communities to improve their access to eye care, and why it matters to involve the community in monitoring the quality and impact of health care interventions.

Contents
1 Community engagement in eye care: working with and for communities
Kriti Shukla
3 Engaging communities in planning and delivering eye care services
GVS Murthy and BR Shamanna
5 Overcoming the challenge of the last mile
Hannah Faal, Andrew Bastawrous and Elmen Wolvaardt
7 Engaging with communities to generate demand and improve the uptake of eye care
Yesunesan Devanesam and Suresh Kumar Rajaram
10 Community-based monitoring: people’s health in people’s hands
Kriti Shukla
13 Amplifying the voices of disabled people: a model for better community engagement in eye health
Syeda Munazza Gillani and Leena Ahmed
15 Social behaviour change interventions in eye care: lessons from the field
Sumrana Yasmin and Nazaradden Ibrahim
18 Vision guardians for community eye health: the LV Prasad Eye Institute model in India
Srinivas Marmamula, Rajashekar Varada, Jachin D Williams and Rohit C Khanna
20 Demand-side financing: can it help deliver eye care for all?
BR Shamanna, GVS Murthy, Thulsiraj Ravilla and Iain Jones
22 Case Study: Sri Lanka
Asela Abeydeera
23 Case Study: Bangladesh
Johurul Islam Jewel and Mohammad Muhit
24 Case Study: Nepal
Manisha Shrestha
26 Community involvement in eye care
Sumrana Yasmin, Hannah Faal, Thulsiraj Ravilla, GVS Murthy and BR Shamanna
28 KEY COMMUNITY EYE HEALTH MESSAGES

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community-based structures (e.g., schools, places of worship, congregate settings, elected local body offices, open groups).

By involving local communities in planning and implementing eye health initiatives, communities can become more self-reliant and empowered. Moreover, community engagement can yield positive results, such as improved case-finding and treatment outcomes, raised awareness regarding eye diseases, community advocacy and monitoring of eye care services, and improved uptake of eye health services. Last, but not least, when communities develop strong leadership and the power to assert their health care needs and interests, they have tremendous scope to channel the distribution of resources towards their required health needs. This, in turn, supports eye care providers to deliver effective eye care services that meet real needs.

Community engagement requires that communities and service providers work together, as equal partners. However, the responsibility for initiating, supporting, and sustaining this work lies with those who have the means: mainly service providers, or civil society organisations, who are in a position to support eye care initiatives.

Where possible, service providers should take the initiative to:

• engage with communities and understand their needs
• work with communities to plan eye care services
• provide the eye care services communities need
• be accountable to communities, and give them the means to hold eye care providers accountable.

Understanding the key concepts of community engagement, participation, and accountability is a must for eye care providers. In this issue, we introduce these key concepts and look at examples from different regions. We also discuss how communities can monitor services and provide feedback to improve health care services; and how adopting different intervention strategies ensures that eye care services are inclusive, reach the last mile, are sustainable, and bring positive eye health outcomes.

Reference
Engaging communities in planning and delivering eye care services

Eye care services are successful when they meet the needs of the community, are easy and convenient to access, and have the desired outcomes. This article shows how involving the community in the planning and delivery of eye care services can help to achieve this.

The WHO defines community engagement as “a process of developing relationships that enable stakeholders [e.g., eye care providers and the community] to work together to address health-related issues and promote well-being to achieve positive health impact and outcomes.”

There cannot be a uniform approach to community engagement in the planning of eye care services, as there are socio-cultural differences across countries. However, there are some common principles that apply in all settings, such as fairness, open communication, and transparency. For example, if a community is asked to contribute to the cost of building an eye centre, it would only be fair that they help to decide at what times the centre should be open (e.g., after normal working hours, so that workers can attend appointments) and what level of fees would be sustainable or affordable for them. If this is communicated clearly from the start, and eye care providers provide regular updates and a forum where community members can ask questions, such a venture will be more likely to succeed.

Another benefit of involving communities when planning eye care services is the improved uptake of such services. This is because community engagement can enable changes in behaviour and practices within communities, resulting in better uptake, acceptance, and use of health care services.

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According to the Ottawa Charter for Health Promotion,² community engagement requires:

- developing the personal skills of people in the community so they can prepare themselves to cope with a health problem
- strengthening community action by empowering communities to decide for themselves what is best for them and what the benefits of community ownership and control of services are
- creating supportive environments by sustaining natural resources and encouraging a work-leisure balance to improve health
- building healthy public policy, which includes legislation, taxation, health system changes, etc.
- re-orienting health systems, with more emphasis on disease prevention and health promotion, rather than only concentrating on curative services.

Community engagement and health education leading to eye health-seeking behaviour is something that is central to integrated, people-centred eye care, which is proposed as the way to achieve universal access to eye health care in the World Report on Vision.³

Community engagement is a dynamic process. It can be conceptualised as incremental steps of evolution, from minimal engagement to optimal engagement. It means that, over time, health providers (such as hospitals, clinics, or non-governmental organisations) and communities work together to slowly move in the direction of substantial ownership and control of eye care services by the community – such as a vision centre established and managed by a community.

Figure 1, adapted proposes a model of different stages of engagement in eye care, (see Figure 1). This has been adapted from an illustration of the degrees of community participation in malaria.⁴

Examples
Engaging with communities when planning services
Operation Eyesight Universal supported the vision centre-based community eye health project model in India in 2018. It was designed to promote health-seeking behaviour in communities served by its partner eye hospitals. In this model, vision centres were established as an interface between the target communities and the partner hospitals. Their purpose was to provide underserved and marginalised communities with access to affordable eye care on a sustainable basis. Planning the project involved two steps, namely:

1. Engaging community members by assessing their access to eye care services, preferred eye health providers, the number of people who are visually impaired in the villages, and so on. This was known as a ‘participatory approach to community eye health (PACEH)’.
2. Carrying out a structured knowledge, attitude and practice (KAP) survey amongst community members to identify any knowledge gaps or behaviours that negatively impacted eye health, and then developing and implementing an appropriate and targeted behaviour change communication strategy to address these.

Engaging with communities to improve uptake
Where fear of surgery is found to be one of the main barriers to communities seeking eye care, inviting a patient advocate or satisfied service user (someone who has undergone successful surgery) to motivate others is a time-tested method that has been documented over the last few decades.⁵ The eye care team can support patient advocates by providing a set of messages, such as how long surgery takes, how it is done, and when people can return to productive work. It is important to recognise the work of patient coordinators publicly, and – where possible – give them feedback about how many of the people they referred came forward for surgery. This improves their engagement and motivation.

Involving communities in eye care delivery
The LVPEI Eye Health pyramid model⁶ has, at the base of the pyramid, the Vision Health Guardians (VHGs), who serve a population of 5,000 people each. VHGs are drawn from the community they serve and are either volunteers or receive a small honorarium. They are trained locally for 2 weeks in all aspects of primary eye care and some aspects of primary health care. The main task of a VHG is to create community awareness, conduct school and community screening, distribute spectacles, screen for diabetes and hypertension, and work in coordination with other types of community health workers. A similar system, known as “Friends of the Eye – Nyateros” is also operational in the Gambia.

Conclusion
Community outreach programmes in eye health build on community engagement as an important cog in the wheel of planning, delivery and becoming sustainable.

Although many innovative approaches have been tried, the long-term sustainability of an innovative idea requires careful thought and planning. However, a new idea takes time to mature and show results, and therefore both communities and providers should have the patience to wait, and work for, success – rather than abandoning excellent ideas and innovations prematurely. There is no such thing as a one-size-fits all approach to community engagement, and therefore countries and hospitals need to try out ideas which are relevant in their context.

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5. Aravind Eye Care Systems. Reaching the Unreached: Community-Based Eye Care Outreach in Developing Nations. Outreach Department, Aravind Eye Hospital, India, 2016.
Despite the significant achievements of the United Nations, Millennium Development Goals global project, millions of people are still being left behind, especially those living in poverty and those who are disadvantaged because of their sex, age, disability, or ethnicity. Three-quarters of these groups live in the ‘last mile’: i.e., remote or hard-to-reach areas that have insufficient provision of education, health care, water, and sanitation.

The term ‘last mile’ was initially used by businesses to define which of their target customers were the last to receive specific products and services. More recently, development agencies have adopted the term to refer to populations who are the hardest to reach.

Where is the last mile?

In rural areas, access to the last mile is characterised by footpaths, poor roads, and broken or absent bridges; in some seasons they may not be accessible at all. Transport is often limited to walking or cycling. For people living near rivers or in river deltas (such as the Sundarbans in India), access is made even more difficult due to floods, oil spillages, dependency on canoes or motor boats, and infrequent services.

In urban or peri-urban areas, the last mile includes areas such as urban slums or ‘townships’ that are not connected to basic services such as water, sanitation, electricity, internet, cellphone access, and transport networks. In 2018, one billion people, or 24% of the world’s urban population, were estimated to be living in urban slums.

Who lives in the last mile?

People living in the last mile are those who are not being reached by health care services, including eye care services, and/or who cannot take the steps needed to reach out for the basic eye care or other health care services they need. They can include:

- disadvantaged groups, such as people living in extreme poverty, women, migrants, refugees, and internally displaced people (due to conflict, climate change, and/or natural disasters)
- minority groups (due to their ethnicity, religion, or sexual orientation) and indigenous communities
- people with health or physical challenges, such as older people who have chronic health conditions, people with disabilities (including intellectual disabilities), neurodiverse individuals (i.e., those with autism, dyslexia, dyspraxia, and/or attention deficit disorder), and people with mental health conditions (including depression, anxiety, and other conditions).

Why is there a last mile?

Apart from physical distance, there are three factors that contribute to the existence of the last mile and keeps people trapped there: cultural or belief systems, values and prioritisation, and communication barriers.

Cultural or belief systems. Cultural or belief systems may stigmatise some groups or make them dependent on others for permission and/or the resources they need to seek health services: e.g., women, children, and widows in male-dominated societies.

Values and prioritisation. Political values often reflect society’s values, and this can determine how and where resources are allocated. For example, health providers and governments may prioritise spending on specialist tertiary care (which benefits wealthier urban populations), while neglecting community and primary health care.

Communication barriers. These include physical barriers such as a lack of cellphone access or radio coverage. In addition, an absence of translated, localised, and culturally sensitive communication and...
health information strategies means that communities are not aware how important eye care services, such as glaucoma or diabetes screening, are for preventing visual impairment and blindness. As a result, eye care may not be a top priority for communities in the last mile unless there is an emergency or trauma, or in the late stages of disease when vision is already affected and cannot be restored.

Why is reaching people in the last mile difficult?

Data gaps and connectivity. We know the least about those we are not reaching, which makes it harder to develop targeted, specific interventions. Communities in the last mile often do not have internet or cellphone connectivity, and therefore teleophthalmology and other real-time (or synchronous) data sharing activities – which optimise service delivery – may not be possible.

Distance. People in the last mile, by definition, are furthest from services, which presents a range of barriers. In urban slums, the geographical distance to service points may be relatively low, but the environmental degradation and poverty level may be so high that access to services remains impossible for the population.

Cost. The cost to overcome these barriers, for either patient or provider, may be too high. On the provider side, this may be because the cost of reaching the last mile was not included in national health or eye care plans, and so are not budgeted for.

What is the implication for population eye health of poor last mile delivery?

People in the last mile are already members of the most disadvantaged group in society. It is staggering to realise that they are also the ones most likely not to receive the care they need – and will therefore remain visually impaired, in pain, or unsupported.

This equity gap will continue to grow unless the last mile is addressed. The sooner the better, since – as populations grow – the number of people in the last mile will also increase, making it even harder to reach them in an affordable way.

How to reach people in the last mile: practical steps

Establishing a primary eye health care service (see Community Eye Health Journal No. 113: Primary eye health care), as close to last mile communities as possible, is an important first step. The primary health care service not only functions as the base for developing outreach services to reach the last mile community, but also links people to the secondary and tertiary eye care services they may need.

Although every country and situation is different, the steps below can help with planning relevant and workable approaches to reaching people in the last mile and supporting them to increase the demand for, and uptake of, services.

1. Situation analysis

a. Define the population

Agree with governments or programme leaders on the criteria for defining last mile populations and/or locations (rural and urban).

b. Estimate the population size

Estimate the number of people living in the last mile (as defined) or use data from other public health programmes, e.g., polio immunisation or other population-wide health campaigns.

c. Estimate the need

Find out what proportion of the population in the last mile needs eye care services. For example, in our recent issue on primary eye health care, authors Clare Gilbert and Mapa Prabhath Piyasena estimated that 27% of community members in Asia, 20% of community members in Africa, and 17% of community members in Latin America needed preventive, curative, and rehabilitative eye care services. These estimates are very general, and will differ significantly between countries and among different groups in the same country. If available, use data from Rapid Assessment of Avoidable Blindness (RAAB) surveys, which produce detailed estimates of eye care need. Data from over 300 RAAB surveys worldwide are available, free of charge, at www.raab.world.

Using the known population size in the defined last mile area, and the estimated proportion of people who need care, you can work out the number of people estimated to need care in the last mile. This is the denominator against which to measure current access and any future progress.

d. Current access and gaps

If possible, find out how many people in the last mile population have had contact with eye care over the past year. Comparing this to the number of people estimated to need care gives an idea of the number of people who are not being reached at all.

However, simply reaching people is not enough. Referral and follow-up systems need to work well too. For example, try to find out: of those who were reached, what proportion received help such as near vision spectacles or eye drops immediately, and what proportion was referred? Of those who were referred, how many attended, and how many did not? What were the factors responsible?

Just as important is understanding the quality of the clinical care provided, and people’s experience of the eye service. Poor outcomes and bad experiences (e.g., long waiting times or being treated as second-class citizens) will harm the reputation of the service and reduce demand and uptake.

e. Assessment of strengths: what is available in the last mile?
Engaging with communities to generate demand and improve the uptake of eye care

During the pandemic, when traditional eye camps could not take place, Lions Aravind Institute of Community Ophthalmology worked with 14 eye hospitals to plan and deliver innovative approaches to finding people in rural areas who need eye surgery.
Vision loss is a major public health problem in low- and middle-income countries. Access to comprehensive eye care services is inadequate for people living in rural areas, compared to those living in urban and semi-urban areas. Access to eye care, and the costs associated with access, have long been reported as significant factors affecting the uptake of eye care services.

Comprehensive eye screening camps have been widely used as a strategy to generate demand in rural areas and to overcome the challenges of access and affordability. However, the COVID-19 pandemic and the ensuing restrictions meant that eye screening camps could not be organised, which added considerably to the existing backlog of untreated eye conditions and low uptake of services. This made it necessary to identify and implement alternative strategies to find people who need eye surgery, particularly cataract surgery, and to encourage them to come to the hospital for surgery.

**Identifying strategies**

Lions Aravind Institute of Community Ophthalmology (LAICO), the consultancy and training arm of Aravind Eye Care System, invited 14 partner eye hospitals from India, Bangladesh, Nigeria, and Kenya to a virtual brainstorming session to collectively propose and discuss different approaches to increase the demand for, and uptake of, eye care services.

Together, the group selected and refined a shortlist of six innovative approaches. Each hospital then chose one or more of the strategies to implement in their own setting. They considered:

- the resources (financial, human, and technological) available at the hospital
- the health infrastructure and human resources already available in the community
- the hospital’s current level of engagement with various stakeholders in the community.

The initiative was carried out as an eight-month long collaborative mentoring programme organised by LAICO (from February to September 2021). A core implementation team of at least three members (hospital leader/opthalmologist, hospital manager, and outreach coordinator) was formed at each hospital. A LAICO faculty member was then paired with each hospital to provide feedback once a week and to share an external perspective.

The hospital teams adapted their chosen approach (or approaches) to suit local conditions and developed the process flow, data collection templates, and monitoring mechanisms. Data from the field were captured using a simple Excel spreadsheet and integrated hospital management software (IHMS) was used to capture data in the hospital. WhatsApp was used as a communication tool between the community members and the hospital staff members.

Weekly reports were also shared with LAICO faculty members for individual feedback and discussion. LAICO organised monthly meetings involving all the hospitals to discuss the successes and challenges, which provided useful learning for everyone.

**Implementation**

The six approaches are described in more detail below, with reference to the hospitals that adopted them.

1. **Networking with health workers**

Two hospitals in India – Srikiran Institute of Ophthalmology, Kakinada and Trilochan Netralaya, Sambalpur – adopted this approach. It involved training accredited social health activists and village health nurses – who were already working in rural communities to create awareness about health and support people’s access to health-related services – to identify people with eye problems and refer them to the hospitals for further investigation and treatment. The hospitals put in place a referral tracking mechanism using a simple Excel spreadsheet saved on a computer at their hospital. They used it to record:

- the name of the referring health worker
- the name of the patient
- details about the referral
- the eventual diagnosis.

Both hospitals set up a system for receiving patients and providing treatment. Using the information recorded in the spreadsheet, hospital staff gave timely feedback to the referring health workers on their accuracy in identifying eye problems. This was done during meetings or by making individual phone calls. The referring health workers were paid for surgical referrals, according to current government guidelines.

Thanks to these referrals from community health workers, at the end of the eight-month period Srikiran Institute of Ophthalmology had carried out 926 cataract operations (21% of the total number carried out in the eight months), and Trilochan Netralaya had performed 601 cataract operations (10% of its total).

2. **Referral by community organisations and volunteers**

This method was adopted by three hospitals: Eye Foundation’s Deseret Community Vision Institute in Ijebu-Imushin, Nigeria, Aravind Eye Hospital in Tirupur, India, and Sharda Netralay in Dhule, India.

It involved working with local community service organisations such as Lions Club, Rotary Club, a youth welfare club, and individual community members (such as village leaders or school teachers) and inviting them to refer patients with eye care needs to the hospital. Some of these organisations and community members had actively supported the hospitals’ outreach activities in the past.

Each hospital team held meetings with their local groups and individual volunteers to let them know that screening camps may not be held for some time due to the pandemic. They also explained that, compared to screening camps, their involvement in direct referral of patients would require less time, effort and money on the part of hospitals and the community.

Next, the hospitals handed out referral guidelines as well as referral cards in which volunteers could record patients’ vital signs, such as their blood pressure and random blood sugar level (patients had to get these from their general medical practitioner). Blood pressure and blood sugar levels had to be known before patients could be referred, so that people wouldn’t have to travel to hospital, only to find out they were not eligible for surgery due to systemic health issues.

The referral cards also had a space for the referer to indicate whether or not they felt the patient required a free service. This was always accepted by the hospital, which indicates the high level of trust that existed between hospitals and the community organisations and volunteers. The hospital also kept the person who made the referral informed (via WhatsApp) about the patients’ visit and their treatment at the hospital. The community volunteers reported feeling motivated by receiving such immediate feedback.

This approach accounted for 1,858 cataract operations over the eight months, which amounts to 18% of the total number of cataract operations the three hospitals carried out in that time. Sharda Netralay had carried out 1,402 cataract operations; this
was over 90% of the number of operations that resulted from their usual (and more expensive) methods of outreach before the COVID-19 pandemic. This was a strong encouragement for them to continue this approach in future.

3. Satisfied patients referring others
Patients tend to be happy if they have a good hospital experience and good visual outcomes, and satisfied patients can often be persuaded to refer other people in their community who also need surgery.

This approach was suggested by Kumudini Hospital (Bangladesh). It was adopted by 5 of the 14 hospitals: Kumudini Hospital (Bangladesh), Eye Foundation Deseret Community Vision Institute (Nigeria), and by Sharda Netralay, Sankara Eye Hospital, and Sitapur Eye Hospital (all three in India).

This approach could be implemented with almost no additional financial investment from the hospitals. It involved printing and handing out referral cards to satisfied patients and explaining how to use the cards to refer others with eye problems. Hospitals then sent a note of gratitude to the patients who referred people for treatment, which helped to motivate them to continue doing so.

As a result of this low-cost approach, a total of 1,014 cataract operations were performed by the five hospitals, amounting to over 4% of the total number of cataract operations they performed in eight-month period. As a further step, Sharda Netralay was able to identify a few patients who became their regular outreach community sponsors; these patients now organise regular outreach camps in their respective communities.

4. Working with optometrists in the community
Midnapore Rotary Eye Hospital in India, one of the partner hospitals, reported having an arrangement with a local optometrist to refer patients who needed eye surgery. This idea was adapted to create a structured approach for involving optometrists in extending the reach of eye care services.

Netaji Eye Hospital, Purulia and Sharda Netralay also adopted this method. They identified several service-minded optometrists locally, had discussions with them, and set up a structured referral process that involved optometrists referring patients to the hospital for surgery, and the hospital referring patients back to the optometrists after surgery for spectacle prescriptions.

Optometrists were given guidance on:
- the type of patient to be referred
- the process of referring a patient to the hospital
- post-surgery follow-up care (including spectacle provision).

The hospitals gave feedback to the optometrists about each patient they referred and also held periodic review meetings with optometrists to monitor and improve their referral. This approach enabled the three hospitals to perform 1,710 cataract operations (11% of the total number of operations they carried out).

5. Village council (gram panchayat) outreach camps
Trilochan Netralaya suggested an innovative way of carrying out screening and referral camps in individual villages (a gram panchayat), which complied with the rules prohibiting large gatherings. The key differences were:
- Limited geographic coverage. Just one large village or two small villages were covered. In regular screening camps, all villages within 10–15 km of the camp location would have been covered.
- New ways of advertising. Volunteers from the village used local announcement channels to encourage patients to come for screening, rather than the more expensive, conventional hoardings (advertising boards), notices, or vehicle announcements.
- A smaller team. A three-member team – consisting of an optometrist or ophthalmic assistant, a field worker or outreach person, and a driver – visited the village by bus to screen the patients, instead of the usual eight or nine members in the case of a regular screening camp.

At times, the same three-member team was able to visit two sites in a single day, which would not be feasible in regular camps.

The hospital team transported those who needed cataract surgery to the hospital by bus, with social distancing measures and other COVID-19 protocols in place. The costs of the transport and community visits were paid by the respective hospitals. Patients with other eye problems were advised to visit the hospital on their own and seek treatment. Six hospitals adopted this approach, which resulted in 5,422 cataract operations (21% of the total number of operations they carried out).

6. Cataract finders
The objective of this approach was to recruit and train ‘cataract finders’ – local community members who are able to identify and refer cataract patients.

Kisii Eye Hospital, Kenya implemented this approach. The cataract finders were trained to assess visual acuity and recognise common eye diseases, including cataract. They were provided with motorcycles that allowed them to visit remote villages for screening. Each cataract finder had their own toolkit, containing a 6/18 visual acuity chart, a torch, measuring rope, and referral cards.

The cataract finders conducted door-to-door screening in their allotted villages, checked visual acuity, and identified patients with cataract. Screening data were documented in a prescribed format. Patients identified with cataract were referred to the hospital, and transport was provided for those who needed help. This approach resulted in 161 cataract operations being carried out at the hospital, accounting for just over 25% of the total for this period.

Outcomes and next steps
Analysis of data from the 14 participating hospitals showed that the number of cataract operations made possible thanks to these six approaches contributed to almost 19% of the total number of cataract operations carried out across all the hospitals in the eight-month period (February to September 2021). This was possible because of the commitment of the hospitals to reach out to the community and the support of the people in the community.

None of the six approaches required much additional financial investment, and all 14 hospitals were able to implement at least one of them without needing additional staff members or resources. As a result, the hospitals were able to continue the strategies that worked well in their respective local conditions.

It is worth noting that all the strategies may not work well for every eye care provider. Local relevance and inherent or existing opportunities will determine the suitability of a strategy. Therefore, multiple approaches may have to be considered to create demand and enhance the uptake of eye care services.

In conclusion, responding to a health crisis (such as the COVID-19 pandemic) and ensuring continuity of care for those in need...
is a key responsibility of any health care provider. Innovative strategies and engagement with the community can help reach more people in need. Strategies that have proved to be effective need not be restricted to pandemic times but can be integrated into the mainstream to supplement the traditional outreach activities of the hospitals. Above all, ensuring the availability of services to every patient – from screening to postoperative follow-up – makes all the difference.

References

Community-based monitoring: people’s health in people’s hands

Community-based monitoring of health services can put people back in control of their health and the health services they need.

In Thane, India, 17-year-old Ankita, who has drug-resistant tuberculosis (DR TB), required an essential tuberculosis drug, administered orally. However, due to a lack of stock at the Directly Observed Treatment Short-course (DOTS) centre, where the drug is provided free of cost to all tuberculosis (TB) patients, she was put on alternative drugs that had to be injected. These are very painful and have serious side effects, including the risk of hearing loss. Not having enough money to pay for a private prescription of her usual medication, and not knowing what to do, Ankita contacted Ganesh – a TB supporter and activist – for help. In India, TB activists and supporters have formed a countrywide network to help TB patients and to advocate for issues around TB. They stay in constant contact with each other, and with patients, by phone and WhatsApp. Community TB champions visit DOTS centres and connect with patients, making it easy for patients, such as Ankita to reach out to peer supporters like Ganesh.

Next, Ganesh reached out to other TB activists and supporters. With many of them having had similar experiences of drug shortages, and realising that this was a wider issue, the TB support groups initiated a community-based monitoring system. They collected information on drugs that were out of stock, diagnostic kits that were unavailable, and the number of TB patients requiring these services. They shared this information with the government and asked for action to be taken; they also contacted the media to highlight the challenges of TB treatment. As a result of their constant monitoring and advocacy, the government promised to deal with drug shortages. In 2022, officers from the government’s TB programme also began to convene monthly meetings with activists, patients, TB survivors, and non-governmental organisations (NGOs) to discuss the needs of TB patients and the challenges of treatment.

The actions taken by Ganesh and the TB activists to support Ankita (and others in a similar situation), are an example of community-based monitoring – a way for patients and the wider community to check whether health programmes and health services are effective, are accessible to everyone, are of good quality and have the desired impact.

The key principle of community-based monitoring is that the community decides what to monitor and how to act upon the data collected.

In the example above, the TB activist community:
• continually monitored and documented the availability of essential TB medicines and diagnostic tests
• kept in touch with service users (TB patients) to understand their concerns
• shared this information with decision makers (e.g., government) so they could act quickly to prevent future medicine shortages and to provide access to treatment for all.

Community-based monitoring can provide an efficient feedback mechanism and ensures that service providers are accountable to...
the service users (the public or community). This shifts the focus away from the providers and their work, to the community and their needs, and how well these are being met. In other words, community-based monitoring helps to create a people-oriented public health delivery system. It works both ways: community-based monitoring also helps communities to understand the challenges faced by the government and/or service providers. This can result in community members and decision makers working collaboratively to solve issues as they arise in real time. All of this helps to foster communities’ active participation in health care and empowers them to claim their rights to health.

**How does community-based monitoring relate to eye care?**

Patient- or community-led advocacy and monitoring may not yet be well established in all areas of eye care. However, some of the vital components of eye care – such as vitamin A distribution, nutrition, environmental safety, and essential medicine availability – are already being monitored by communities in various countries, as are some of the key determinants of eye health such as age, gender, poverty, and disability.

In addition, monitoring is especially important in conditions such as glaucoma, diabetic eye disease, trachoma, and pediatric eye care.

Eye care organisations, on their own or in partnership with grassroots organisations and civil society organisations (CSOs), can support or offer training to communities to help them actively and independently monitor and collect data regarding eye care services. Some examples are:

- providing community score cards at eye health facilities (see below) and carrying out patient satisfaction surveys
- establishing strong and streamlined grievance mechanisms
- facilitating social audits of eye care services.

All of these approaches can lead to better provision of services and ensure that communities have more say in the way services are provided.

**How community-based monitoring works**

Community-based monitoring can be viewed as a five-stage process (Figure 1), with communities taking the decisions and leading the work at each stage, supported by community service organisations, health activists or movements, and by non-profit health organisations.

1. **Data or information gathering.** This can involve directly observing conditions and services; interviewing service users; conducting focus group discussions, public hearings, and meetings of local governing bodies; carrying out participatory appraisals and social audits; and so on. Organisations can help communities learn about and adopt suitable data collection and case documentation methods.

2. **Analysing information and translating it into actionable insights.** Communities can identify what is working well and the gaps that need to be addressed, such as identifying which primary health care facilities have long queues and over-full waiting rooms; where there are medicine shortages and/ or inadequate equipment; where appointments are often cancelled; and so on. Organisations can also help communities to understand their own health status, their entitlement to health, and their rights relating to health.

3. **Disseminating findings.** This involves sharing the insights gained with a wide range of groups and individuals (including health providers, government, officials and policy makers) from the local to national level. Health providers from clinic level through to the ministry of health can support communities by being willing to listen to them and providing opportunities for the community to give feedback.

4. **Advocating for change.** It is essential to start advocacy at the facility level by making facility managers aware of issues, persuading them to address the issues, and holding them accountable. Health providers can support this process by responding positively to any issues raised and working with the community to develop solutions.

To communicate advocacy messages to policy makers and hold them to account, the media – both print and electronic – can be a powerful resource, as in the TB example. The media can also play an important role in educating the public and can be engaged to raise the visibility of the problems faced by communities – which can also prompt policy makers to act.

5. **Monitoring the implementation of promised changes.** Communities can monitor the status of the commitments made by health providers and policy makers. For instance, a local commitment to build a new vision centre or eye clinic may not be followed through, perhaps due to a shortage of staff. This would require further advocacy and action.

The reason for engaging communities in health care is rooted in the understanding that health is also influenced by various non-medical determinants: the conditions in which people are born, grow, work, and live; their age, gender, behaviour, and lifestyle; and political conditions. It’s very difficult for health providers to know whether the available services are meeting everyone’s needs – it is therefore vital to involve communities in monitoring how well their needs are being met. For example, women or people with disabilities will know best what challenges they face when they access services, so they are the best people to monitor how well access is going for them and to give that feedback to eye care providers via community groups or forums.

Community-based monitoring is a participatory process which requires resources and support from other grassroots organisations and social activists. It also requires evidence gathering and advocacy. Therefore, concerted efforts are required to build capacity and empower communities to engage with public health systems so they can realise their right to health.

When health providers and officials at various levels support community-based monitoring, they are effectively putting people’s health in people’s hands – where it belongs.
An example of community-based monitoring

A useful example in the Indian health system is the National Health Mission’s community-based monitoring framework. This interactive system of monitoring is designed to keep communities in the centre, with the aim of increasing public participation in, and monitoring of, health care – from the village level to the level of the state.

There is a monitoring committee for each level of the system (see Figure 2). Each committee includes representatives from the community such as local self-elected members (panchayat members), community health workers (ASHAs), Anganwadi workers/ Integrated Child Development Services workers, community-based women’s collectives, members of patient welfare committees, NGO representatives, and medical officers.

The monitoring committee at each level reviews the functioning of the health care facilities at that level and work to streamline grievance procedures, collect reports, and take action to improve patient care and welfare. Committees report issues that require further intervention to the next level up, for example, from a district health committee to the state health committee.

Rather than relying solely on reports, each of the committees interact directly with the community in their area by conducting public hearings every six months. At these hearings, they receive feedback from the community regarding the quality and accessibility of services, and about patients’ experience of these services.

A recent concern about the unavailability of diabetes medication (usually provided free of cost) would be unavailable for several days due to issues with the supply chain. As a result, they had to purchase their own medicine from a private pharmacy, and some stopped using the medicine as they couldn’t afford it. After discussing the issue at a village meeting, a representative from the village attended a meeting of PHC’s patient welfare committee to explain what had happened.

The patient welfare committee dealt with the immediate challenge by using their own funds to supply the medicine to patients in the short term, so they would not have to face further inconvenience or cost. The committee also reported the procurement issue to the district health committee so they could take action to avoid this same issue happening again.
According to the World Health Organization World Report on Disability, 2011, there is a strong relationship between disability and poverty: disability can increase the risk of poverty, and poverty can increase the risk of disability, with access to health care being an important factor.

In Pakistan, high levels of discrimination and social exclusion affect individuals with disabilities and their families, making it difficult for them to afford eye care and get access to the eye care they need.

To address this challenge, and after testing a similar model in India, Sightsavers set up an inclusive eye health programme in four districts in Pakistan in 2018. Inclusive eye health means ensuring that eye care services are set up in consultation with people with disabilities and their representative organisations. It also means ensuring that eye care services are accessible and welcoming for everyone. Services are then more accessible for all neglected groups, particularly women, children, and people with disabilities.

The project focused on two key areas:
- Generating demand for eye care among people with disabilities in the community
- Ensuring that services were accessible and inclusive, and that they met the community’s eye care needs.

The project’s main implementing partner was the charity hospital network Layton Rahmatulla Benevolent Trust (LRBTT). To ensure equity and inclusion, we partnered with a national organisation of people with disabilities, known as Special Talent Exchange Programme (STEP). The project consisted of several stages:
1. Situational analysis & stakeholder mapping
2. Identifying barriers
3. Addressing provider-side barriers
4. Improving demand for eye care
5. Advocacy and policy change
6. Monitoring and evaluation.

1. Situational analysis
For each of the four districts, we collected baseline data on the level of access of people with disabilities, identified areas where poverty and disability are more prevalent, and collected sociodemographic information.

We also mapped and analysed who was involved in, or could influence, the success of the programme, and what their level and area of influence might be. These included community leaders, religious scholars, and local political figures who could influence and advocate for improved uptake of, and access to, health care for local communities in general and disabled people in particular.

2. Identifying barriers
We engaged with local organisations of people with disabilities and asked them to help us to identify any barriers in the way of inclusive eye health.

In addition to provider-side barriers (see Table 1), we also identified a lack of demand for eye care in the community. This was due to a lack of awareness in the community about the eye care needs of people with disabilities, a lack of awareness in the community and among people with disabilities themselves about the services that are available, as well as unhelpful attitudes towards people with disabilities.

3. Addressing provider-side barriers
In our partnership with organisations of people with disabilities, we learned that bringing services nearer to the communities through eye care screening camps and making services available at the primary health
care level is a great motivator for marginalised people who otherwise cannot access eye health services. However, once we create demand for eye care services, it is equally important that services are accessible, inclusive, and equitable.

Local organisations of people with disabilities were invited to carry out disability access audits of eye hospitals and recommending essential infrastructural modifications. With the local self-help groups (see below), they actively supported disability awareness raising – via sensitisation training – for hospital staff. They also helped us to establish a database of persons with disabilities so we could monitor who was receiving care.

4. Improving demand for eye care

To address the lack of demand, we needed to improve everyone's understanding of the eye care needs of disabled people and the services that are available for them. We also had to challenge negative attitudes towards eye care for disabled people amongst community members, leaders, and decision makers.

Setting up self-help groups

As a first step in addressing lack of demand, we worked with the elected union councils (also known as village councils) in each of the four districts to create self-help groups that included people with disabilities. In Pakistan, self-help groups are relatively common. They are informal groups of local people (such as teachers, political and religious leaders, and representatives from women's empowerment focused-groups and others) who come together to discuss issues and problems they have in common. Self-help groups, as the name implies, look for solutions on a self-help basis but they do sometimes seek help from local government institutions, such as union council offices. The groups also promote social cohesiveness through local cultural events and gatherings, street theatres to promote a collective approach towards social issues, and health and hygiene sessions.

Initially, Sightsavers’ project team supported the organisation of these self-help groups and encouraged the inclusion of people with disabilities. A total of 57 self-help groups were created in the four districts, and each included an average of 10–12 people with disabilities. The self-help groups worked closely with LRBT hospital staff members to arrange accessible and dedicated eye care outreach screening camps for people with disabilities and other marginalised groups who otherwise could not come to the hospital themselves.

District coordination committees

District coordination committees were organised in each of the four districts to coordinate the work of the self-help groups and to better link them with local government structures. Members of local organisations of people with disabilities were also made members of the district coordination committees in order to amplify their voices in local decision-making processes.

Together, the district coordination committees helped more than 100 people with disabilities to get their disability certificates and special national identification cards. Similarly, the medical assessment of people with disabilities (which are needed before disability certificates can be issued) is a very lengthy and cumbersome process that requires a visit to the main hospital in each district, usually very far away. However, with the support of the district coordination committees, eye health screening camps were arranged in the villages nearer to the communities.

Creating social behaviour change programmes to generate demand

The self-help groups and local organisations of people with disabilities took active part in the design and delivery of a social behaviour change campaign to improve the uptake of eye care services by all, especially people with disabilities. This involved:

- disseminating printed eye health information and

<table>
<thead>
<tr>
<th>Barriers identified</th>
<th>Solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Attitudes of staff members</strong></td>
<td>Sensitisation training for hospital staff on disability and gender rights</td>
</tr>
<tr>
<td><strong>Physical infrastructure and organisational development</strong></td>
<td>Inviting people with disabilities to assess how accessible and disability-friendly health facilities are (known as an ‘accessibility audit’)</td>
</tr>
<tr>
<td></td>
<td>Retrofitting facilities with disability-friendly and accessible infrastructure</td>
</tr>
<tr>
<td></td>
<td>Improving communication between eye care and other health or rehabilitation services to ensure better referrals and follow-up</td>
</tr>
<tr>
<td><strong>Communication barriers</strong></td>
<td>Providing accessible communication material, e.g., written information in Braille or audio material for people who are blind or visually impaired, and sign language interpretation for people who are hearing impaired</td>
</tr>
<tr>
<td><strong>Transportation barriers</strong></td>
<td>Providing dedicated outreach camps closer to the communities or offering free or subsidised transportation</td>
</tr>
</tbody>
</table>

Table 1 Provider-side barriers and their solutions.
Social behaviour change interventions in eye care: lessons from the field

Social behaviour change interventions can help to increase the demand for eye health services and encourage communities to seek eye care.

Social behaviour change (SBC) is about understanding and influencing healthy and inclusive behaviours and providing a supportive social environment in which these behaviours can flourish. If we can encourage people to change their everyday behaviours, then we might get some way towards having healthier and more inclusive societies.

Supporting individuals and wider communities to make meaningful, long-term changes to their behaviour, including how they look after their eye health and how (and when) they seek eye care, is vital if we are to achieve the World Health Organization's Sustainable Development Goals.

Educational materials
- carrying out communal awareness raising activities such as street theatres
- people with disabilities acting as role models and speaking at communal forums during eye care outreach camps (see panel).

5. Advocacy and policy change
Local organisations of people with disabilities supported advocacy by engaging community leaders in fighting the stigma of disability, supported by the project and other data, research, and best practice guidelines. It helped that the project was planned in close alignment with the existing national health plan (National Health Vision of Pakistan 2016-2025); which endeavours to develop a well-informed and gender-responsive national plan to tackle several health challenges, maintaining and prioritising universal health coverage as its ultimate goal.

6. Monitoring and evaluation
The team collected data separately for people with disabilities, and by gender (known as gender- and disability-aggregated data) to measure inequality in access and to monitor the progress of the project.

Outcomes and next steps
The project has created an inclusive eye health model that can be scaled up and replicated, especially in government health facilities. As a result, Pakistan's national eye care plan now has strong elements of equity and inclusion embedded within it, forming an integral part of the design.

Quantitative published data from the project is not yet available. However, so far, the qualitative feedback and the evaluation report showed that the project has made the partner hospitals more accessible and welcoming for people with disabilities. They also showed that access to eye care has improved, thanks to community outreach screening eye camps that have boosted the uptake of eye care services in marginalised communities, especially people with disabilities. It is anticipated that self-help groups will continue to be part of the local organisational structures in the community, eventually extending beyond eye health to support broader thinking and consultation on a range of issues.

The effective inclusion of people with disabilities in eye health services will pave the way for people with disabilities to demand the same in other areas of health. We hope that this will ultimately lead to achieving universal health coverage in Pakistan and ensuring that people with disabilities are not left behind.

References

Sumrana Yasmin
Deputy Technical Director, Eye Health and URE: Sightsavers, Islamabad, Pakistan.

Nazaradden Ibrahim

Improved access to school vision screening following community-based social behaviour change activities. LIBERIA
Lessons from across a range of eye health programmes

Focus points for behaviour change interventions

Table 1 An example of a social behaviour change plan using the six lessons from the project.

<table>
<thead>
<tr>
<th>Project objective</th>
<th>What behaviour do we want to change or promote?</th>
<th>Supporting behaviour</th>
<th>What is known about current behaviour and our target audience(s)?</th>
<th>What are the gaps in our knowledge on how to create change?</th>
<th>What needs to change for the behaviour to be practised?</th>
<th>How to create the change (Intervention categories and materials)</th>
<th>Project outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase school attendance of girls with disabilities aged 6–14 years</td>
<td>Girls with disabilities aged 6–14 should attend school every day during the school term</td>
<td>Parents must make sure their children with disabilities attend school every day</td>
<td>Mothers currently prioritise their daughters’ housework over school attendance</td>
<td>What we need to understand the community’s cultural beliefs, and how to leverage or challenge them</td>
<td>Establish school attendance for children with disabilities as an aspiration and social norm for parents</td>
<td>Community interpersonal communications are key for shifting cultural beliefs and perceptions about disability at the school</td>
<td>Improved school attendance of girls with disabilities, resulting in increased participation and better education outcomes</td>
</tr>
</tbody>
</table>

Table 1 gives a worked example, with the objective of increasing school attendance of girls with disabilities aged 6–14 years.

The social behaviour change plan example and useful tips are based on the Sightsavers’ Social Behaviour Change Toolkit. You can learn more about Sightsavers’ social behaviour change learning journey at https://bit.ly/3ezeB5y

Development Goals.1

People’s behaviour is influenced by many factors, including gender, age, disability, and personal beliefs (at the individual level); family income, class, religion, and location (at the family level); cultural practices and beliefs (at the community level), and the political situation (at the community or national level).

As we saw in the recent Community Eye Health Journal issue on primary eye health care (bit.ly/DeliverEye), health promotion actions that bring about better eye health involves both improving the knowledge, attitudes, and behaviour of individuals, and influencing the physical, cultural, and policy environment needed to support health and health-seeking behaviour.

Behaviour change interventions can be instrumental in improving access to, and the use of, eye care services. It is therefore vital to invest more in health promotion and education. It is equally important to review the impact of embedding behaviour change strategies in eye health programmes and to identify any lessons learnt.

The steps of a behaviour change intervention

Planning a behaviour change intervention starts with answering the following questions.

- What behaviour do we want to change or promote?
- What supporting behaviour will be needed?
- What do we know about the behaviour and our target audience?
- What are the gaps in knowledge on how to create change?
- What needs to change for the behaviour to be practised?
- How do we create the change? (intervention categories and materials)
- What outcome do we want to achieve?

Table 1 gives a worked example, with the objective of increasing school attendance of girls with disabilities aged 6–14 years.

Focus points for behaviour change interventions

Lessons from across a range of eye health programmes supported by Sightsavers indicate that the success of behaviour change interventions relies on following a robust approach that focuses on the following:

1 Clarity. There must be a focus on specific behaviours and audiences. We need to remember that people will not be able to change too many behaviours all at once, and what works for one group might not work for another. Experience has shown that identifying target audiences and the specific behaviours to be encouraged or discouraged is a key step to designing an effective behaviour change programme. Audiences could be children, women, teachers, or community members, depending on the planned project or service.

2 Structure. There needs to be a step-by-step process to analyse, design, deliver, and monitor behaviour change interventions. A project and communications plan should identify the issues to be addressed; changes that are desired; the audience to be targeted; key messages and channels of communication; and the proposed solutions.

3 Evidence-based analysis. Early analysis is important to avoid assumptions and understand what will motivate communities to change. This needs to be an engaging and collaborative process. It is also important to draw on the existing evidence base to find out what behaviour change strategies could work in particular settings.

4 Community participation. It is important to make sure that planned activities are piloted and suitable for local audiences, which should include all stakeholders, including people with disabilities. Messages, materials, and visuals must be suitable for the local context, preferably using local imagery, language, and design.

5 Gender- and disability-inclusion. It is important to develop behaviour change messages and visuals that are clear, accessible, and inclusive of all groups in society who might be excluded or have less influence in that context: e.g., women, people with disabilities, and nomadic groups.

6 Innovation and technology. Technology platforms, including...
mobile health (mHealth) and social media, can be useful to reach a broader audience. The messaging needs to be cohesive and succinct to ensure consistency and long-term impact.

7 Regular and consistent communication. A mix of different channels – such as face-to-face interactions, community radio, and community events – can increase the likelihood of communications resulting in the desired change. For maximum impact, it is important to:

• use plain and straightforward language
• create simple, brief, clear, and accessible messages to convey core concepts
• combine written text with visual information so it can be understood by all.

8 Community influencers and role models. Women’s groups, religious leaders, and organisations of persons with disabilities can be co-opted to serve as role models and motivators for behavioural change.

An integrated school health programme

Lack of adherence to treatment and to the use of spectacles is a common problem in many low- and middle-income countries, which is often the result of lack of knowledge of eye health as well as negative perceptions, attitudes, and misconceptions about wearing spectacles.¹

Using a targeted social and behaviour change approach, the school health integrated programme in Liberia, implemented between 2019-2021, aimed to provide vision screening to 76,000 children of school age. However, nearly 123,000 children were screened (far more than expected) and 590 received corrective glasses. This outcome was achieved by clearly identifying our target audience and the behaviour we needed to address, and by using local content and approaches. The lessons from Sightsavers’ school health integrated programme in Liberia, and a similar programme in Pakistan, showed that understanding why girls and boys wear (or do not wear) spectacles will help us to design effective behaviour change interventions that address barriers to their use. Some of the common barriers include:

• lack of awareness
• negative perceptions
• traditional beliefs about the use of spectacles, especially by girls
• distance
• cost.

Developing appropriate information and communication materials to target the barriers will go a long way in creating awareness about eye health services and products.

Gaining community support by engaging with parents (through parent-teacher associations) and with traditional and religious leaders may help to address misconceptions and traditional beliefs.

Different operational strategies should be employed to address the problem of distance to eye care services. For example, to reduce the distance that children may have to travel for refraction and spectacles, a central location can be designated for eye health services within a cluster of schools.

Cost recovery mechanisms can be put in place to ensure that services and spectacles are affordable for everyone. Considering the large population of out-of-school children in low- and/or middle-income countries, these programmes also sought to identify the best approaches for encouraging both enrolled and non-enrolled school-aged children to participate in vision screening and deworming activities. Approaches included the use of peer groups (mostly made up of enrolled children who had been screened and received their deworming tablets) to encourage non-enrolled children to access the service. Engagement with community-based organisations, community volunteers, and town criers can also helped to spread information.

Further reading


References


Vision guardians for community eye health: the LV Prasad Eye Institute model in India

Vision guardians recruited from the local community can engage with people to support their eye care in the long term.

Vision loss affects over a billion people worldwide. Although over 90% of vision loss is avoidable, several barriers limit the availability and uptake of services. The World Health Organization has adopted ‘universal eye health’ as a part of universal health coverage, which aims to ensure that “all people have access to promotive, preventive, curative and rehabilitative health services, of sufficient quality to be effective, while also ensuring that people do not suffer financial hardship when paying for these services.”

Community engagement is vital for the successful implementation of health interventions at a place where people need services. LV Prasad Eye Institute (LVPEI) developed a pyramidal eye care model which has vision guardians as its foundation (Figure 1).

Figure 1 LV Prasad Eye Institute eye care service delivery pyramid

<table>
<thead>
<tr>
<th>Total centres: 264</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Centre of excellence</td>
</tr>
<tr>
<td>Serves &gt; 50 million people</td>
</tr>
<tr>
<td>3 Tertiary care centres</td>
</tr>
<tr>
<td>Each serves &gt; 5 million people</td>
</tr>
<tr>
<td>22 Secondary eye care centres*</td>
</tr>
<tr>
<td>Each serves 500,000 – 1 million people</td>
</tr>
<tr>
<td>234 Primary eye care centres**</td>
</tr>
<tr>
<td>Includes 53 technology enabled vision centres</td>
</tr>
<tr>
<td>Each serves 50,000 people</td>
</tr>
<tr>
<td>Vision health guardians</td>
</tr>
<tr>
<td>Each serves 5,000 people</td>
</tr>
</tbody>
</table>

*Secondary centres **Vision centres

Vision guardians are the part of the eye care system that is closest to the community. Vision guardians form an essential link that connects eye care services with the community, thereby providing a framework for community engagement on a continuous basis.

Vision guardians are recruited from the local community. They are people who know the community and are known in the community; this promotes mutual trust and makes their work much easier. Each vision guardian looks after the eye health of about 5,000 community members. Their activities include:
- door-to-door vision screening to identify people with eye health issues
- eye health screening in schools
- referring people to the next level of care
- checking that patients with sight-threatening eye conditions have attended their referral appointments
- monitoring patients after surgery
- supporting community health activities, including health promotion and awareness programmes
- checking up on vulnerable individuals
- engaging with all stakeholders in the community: government and non-government bodies as well as village groups, including village health committees.

Selection, recruitment, and training of vision guardians

Vision guardians are either volunteers who work part time, or are employed full time (and paid) by LV Prasad Eye Institute (LVPEI). Community organisations identify potential candidates from the local area for enrolment as vision guardians. Community involvement in the selection and recruitment of vision guardians promotes local ownership and acceptance of vision guardians by
the community, all of which is essential for the success of this initiative.

Typically, women aged 18 and older who can write in the local language, are willing to travel in the field, and have good communication skills, are preferred. However, nobody is excluded on the basis of their gender, and there are instances where men who have met the prerequisites have been recruited.

Vision guardians are trained in:

- understanding the structure and functions of the eye
- identifying common conditions that cause vision loss in adults and children
- vision screening, basic torchlight examination, and documentation
- basic record keeping (for tracking referrals)
- counselling.

The training is predominantly hands-on and conducted over one week. A refresher course is provided once a year.

### Monitoring indicators for vision guardians

Monitoring often improves outcomes and also ensures that the programme is moving in the right direction. Monitoring indicators are used to track performance, identify challenges, and provide additional training as and when required. For example, if the referral rate (%) is too low or too high for a particular vision guardian as compared to others in the region, it may be due to some issue with the screening protocol or due to selective screening of individuals, and may warrant further investigation and an appropriate resolution. A full-time supervisor is appointed for every ten vision guardians and is responsible for their routine monitoring and reporting from the field.

The parameters for monitoring vision guardians include the following:

- **Population coverage (%)**: Proportion of people screened at the household level in the catchment population
- **Referral rate (%)**: Proportion of people identified with eye problems and referred to the next level of care from among those screened
- **Referral uptake (%)**: Proportion of people seeking the next level of care from among those referred
- **Eye health promotion**: Number of awareness sessions conducted per month
- **Community engagement**: Number of community visits and interactions with stakeholders per month, including participation in local committee meetings in the community.

There are no specific monitoring indicators for volunteer vision guardians, except for regular communication through updates on referral of patients from their area and post-operative surveillance. Offering volunteers (and their families) incentives such as free eye care services, and involving them in events to celebrate the anniversary of the eye centre and World Sight Day, has been found to motivate them to continue their contribution as vision guardians. Winning societal recognition is another motivating factor for volunteering as vision guardians.

### LVPEI Experience: Community Linked Initiative Project (CLIP)

LVPEI implemented the Community Linked Initiative Project in one of its catchment areas to demonstrate the application of the vision guardian concept in eye health.

#### Project summary

- **Location**: Jainad sub-district in Adilabad district in Telangana (52 villages)
- **Total population**: 47,904 (Census 2011)
- **Population covered**: 38,829 (81.1% coverage)
- **Number of vision guardians**: 23 (all women volunteers)
- **Duration**: 3 years (2011–2014)

#### Key statistics

- 38,829 people screened; 3,616 (9.3%) people identified with eye problems and referred
- 8,646 children screened through school screening programmes; 622 (7.2%) children identified with eye problems and referred
- 2,171 pre-primary school children (at Anganwadi centres) screened; 55 (2.5%) children identified with eye problems and referred
- spectacles dispensed to 1,472 people
- sight restoration surgeries performed on 472 people
- 30 people with irreversible visual impairment rehabilitated
- over 100 awareness programmes conducted.

At the end of the three-year project, the vision guardians have continued to support eye health initiatives through referrals and follow-up care. They have continued as volunteers and are the link with the local communities.

In addition, vision guardians can help to identify other disabilities alongside assessing eye health in vulnerable populations. For instance, in Rayagada, a tribal district of Odisha, over 100,000 people were screened at their doorsteps and referred to the next level of care. In addition to 9.4% of the people screened who had vision impairment, 2.8% of those screened were found to have other disabilities and were referred.

#### Key challenges and way forward

A strong service delivery base is essential for the successful implementation of the vision guardian programme. Referral linkages, the capacity to recruit and train vision guardians, and a robust system for regular monitoring are important elements for the success of the programme. Vision guardians should be considered as an extended arm of service delivery. Over time, vision guardians, irrespective of whether they are paid or are volunteers, will become the ‘go-to’ persons in the catchment community for eye health issues.

In our experience, using the services of volunteer vision guardians is less expensive, but inconsistent in terms of the output delivered as volunteers’ commitment tends to wane over time. A paid vision guardian system is more expensive in terms of programme costs, but more consistent in delivering output for lasting impact. Currently, LVPEI has over 70 paid vision guardians in various community activities. The number of volunteer vision guardians at any given time is not fixed. LVPEI is considering a study to assess the impact of paid vision guardians and volunteer vision guardians in order to gain more insights about the effectiveness of the two approaches.
Another area that needs to be investigated pertains to strategies to attract and retain volunteer vision guardians. Our experience is that, to sustain the project, we need to have a fixed number of paid vision guardians (typically one for a population unit of 5,000) in addition to volunteer vision guardians. A cluster of ten paid vision guardians can be monitored by a community supervisor, who will also engage with the volunteer vision guardians in the catchment area from time to time. This hybrid model, using a combination of paid and volunteer approaches, is a helpful way to achieve universal eye health in a given region.

References


Demand-side financing: can it help deliver eye care for all?

Demand-side financing mechanisms in eye care can be a tool to achieve universal eye health coverage by increasing access and utilisation of key eye health services.

Many people in low- and middle-income countries have inadequate access to affordable eye care.1 This is, in part, due to the way eye care services are financed – financing arrangements influence what services are provided, where services are available, who has access to them, and how people pay for them. Most health care financing in low- and middle-income countries supports the supply of services, channelling payments to service providers. For example, governments allocate budget to hospitals to ensure they provide services to address population health needs. This is known as supply-side financing.

However, insufficient or poorly allocated supply-side financing can lead to inadequate and unequal distribution of certain health services. This can result in poor quality of care and service provision focused on urban populations, leaving many people in rural areas with limited access to affordable care. However, efforts to achieve financial risk protection and to improve access and quality of service provision for all have fostered different financing arrangements – demand-side financing mechanisms.

Demand-side financing

The World Health Organization’s World Report on Vision noted that the use of eye care services is determined by the availability, accessibility, affordability, and acceptability of such services.1 Barriers, including the actual and perceived direct and indirect cost of eye care, can mean that people do not access and use eye health services. Demand-side financing (see panel) provides a way of channeling scarce resources in a way that increases the use of health services amongst specific groups, especially those that cannot afford them. The core features of this type of financing are:2 a pre-specified target group, such as poor households; financial transfers to the beneficiaries, such as vouchers or conditional cash transfers; and a rationale for the choice of services covered, such as services with limited supply or services that are not demanded due to market failures.
Demand-side financing offsets part, or all, of the cost of a health service by providing funds or subsidies directly to people to increase their purchasing power. People are given direct access to a health care ‘budget’ that allows them to choose, within predetermined limits, from which providers they would like to purchase health services (e.g., cataract surgery).

An example of this is the Pradhan Mantri Jan Arogya Yojana national health protection scheme launched in India in 2018 (see panel), which was adopted across the country with some local modifications. Each family is given a ‘health card’, which can be used to pay for services, with some boundaries on procedures and providers. Initial information available from the information portal has indicated an increase in people’s access to care, particularly surgical procedures. It puts the power of ‘purchasing health’ in the hands of the buyer; meaning that people can get their health care from where they want and when they want it. It is administered under an insurance mechanism to reduce misuse and make it easier to manage efficiently.

There are several examples of demand-side financing in the health sector, including cash transfers and voucher schemes to help tackle malaria and improve maternal health. The lessons from these initiatives are as follows.

- Demand-side financing empowers consumers by increasing their purchasing power; there has been increased use of services in many schemes.
- It encourages innovation.
- There is a better use of resources and improved efficiency of service providers.
- There is the positive impact of involving community health workers, working with local communities to identify people most in need, raising community awareness, and fostering community ownership.

**Limitations**

Demand-side financing also has its limitations. Initiatives seem to work best when there is an established supply of service providers and enough health workers. Demand-side financing may not be sustainable in remote areas where service provision is limited unless there is significant, complementary supply-side investment. In many parts of the world, people live far away from hospitals and simply getting to the nearest health provider is a challenge. People in these circumstances do not have access to a range of hospitals or health care providers to choose from. In these communities, investing to improve the quality of the health systems and delivery of primary eye health care services would be needed before an effort is made to encourage the use of services through demand-side financing.

**Opportunities for demand-side financing in eye care**

An early example of demand-side financing in eye care in a low- and middle-income country is an initiative in Bangladesh. A voucher scheme for cataract surgery in a district programme was introduced in the mid-2000s, but it is yet to be part of the national programme. The programme conceptualised and provided opportunities for people who needed cataract surgery to use a range of providers (public and private) for their surgery on redemption of a voucher.

So, what should be the role of demand-side financing in increasing the accessibility and affordability of eye care services? There is no doubt that these mechanisms are tools that could be used to achieve universal eye health coverage by increasing access and utilisation of key eye health services. However, supply-side issues and sustainability challenges need to be thought through carefully before implementing demand-side financing initiatives. There is a need to generate more evidence on the impact, costs, cost-effectiveness, and equity implications of these initiatives to ensure the best use of limited resources. This knowledge will help define when, where, and how demand-side mechanisms could help in delivering integrated, people-centred eye care and making eye care affordable to all.

**References**

Case study: a community-led outreach programme to improve eye care service delivery in Sri Lanka

A community in Sri Lanka got together to ask for, co-fund, and co-ordinate the eye care services they needed.

The latest national blindness survey conducted in Sri Lanka has estimated that there are over 100,000 adults over the age of 40 in the country who are blind due to unoperated cataract. However, access to eye care is limited as more than 80% of the population lives in rural areas; the COVID-19 pandemic has further restricted access.

To address the situation, the Association of Community Ophthalmologists of Sri Lanka (SLACO) has been carrying out regular, free outreach eye care visits in remote areas for the last five to six years. The main purpose of these visits are to offer free reading spectacles and refer patients for free cataract surgical services. SLACO members give their time free of charge.

Before SLACO will agree to carry out an outreach visit, the following criteria must be met:

- The area must be more than 20–25 km from the nearest secondary eye unit.
- A local or community organisation must be willing to organise and promote the event.
- There must be funding to cover the local costs of hosting the event, such as refreshments and utility bills. SLACO relies on donations to cover the cost of travel, surgery, medicines, and follow-up examinations.

Example: Niunhalla village

An outreach visit to the village of Niunhalla, 40 km from the capital Colombo, demonstrates how the community joined forces to ask for, co-fund, and co-ordinate the eye care services they needed.

- A local organisation for older people in the village of Niunhalla, 23 km away from the nearest secondary eye unit, recognised the need for eye care in their local community and contacted SLACO to request an outreach visit. They also promoted the event and the village leader supervised pre-registration.
- A local philanthropist offered to pay some of the costs of providing near vision spectacles and cataract surgery.
- The village leader (known as grama niladhari) offered to coordinate the event.
- The chief monk of the local Buddhist temple provided a large hall in the temple where eye examinations could be carried out.
- Tzu-Chi Foundation Sri Lanka, a Taiwan-based international Buddhist charity organisation, offered free transport for the team and pratical support during the visit: volunteer members from the charity were trained to register patients on arrival and to assess their visual acuity.

Numbers were limited to 125, on a first-come, first-served basis, in accordance with the restrictions issued by the health authorities to minimise the spread of COVID-19. Community members who registered were given different arrival times to avoid overcrowding and comply with COVID-19 safety measures. SLACO chose to host the event on a public holiday in order to improve participation and make it as convenient as possible for everyone involved.

On the day

After registration, distance and near visual acuity of patients was assessed and their eyes were examined. The community ophthalmologist from SLACO examined 143 people, as walk-in patients were permitted, and 120 people received near-vision spectacles.

Forty-three people had operable cataract and were given pre-operative assessments on the day (ECG, fasting blood sugar, and a blood pressure check). SLACO arranged for them to be taken to a charity eye hospital in Colombo as the three nearest government eye units had a two-year waiting list.

Cataract surgery

The cataract patients were transported to the hospital for day surgery and received free pre- and postoperative eye drops and meals.

Postoperative examinations were conducted by a member of SLACO who visited the village one day, seven days, and thirty days surgery. Thereafter, patients were discharged from follow-up.

References


Comprehensive eye care for children in rural Bangladesh: community- and school-based service models

Timely eye care for children in underserved regions was made possible through community- and school-based eye care programmes in Bangladesh.

CSF Global, in collaboration with government and non-governmental agencies in Bangladesh, and with financial support from the United States Agency for International Development (USAID), designed and implemented two eye care programmes for children in the most underserved regions of Bangladesh. The programmes were implemented in the four northern districts of Kurigram, Lalmonirhat, Nilphamari, and Gaibandha, and the three coastal districts of Patuakhali, Bhola, and Barisal in 2014–2017. The programme areas included the remote char land or river islands of Rangpur division and the sea islands in the Bay of Bengal, in Barisal division.

The programmes were based on two strategies:

- the key informant method (KIM) programme, which involves community-based screening
- a comprehensive school screening initiative.

**Key informant method programme**

The programme team used the key informant method to identify children with blindness and severe visual impairment. These children are relatively few in number and often drop out of school. They also tend to live in remote rural communities, and have no access to sight-restoring cataract operations, low vision assistive devices such as white canes, visual rehabilitation (vocational training), or mobility training.

The team reached out to these children through community volunteers called **key informants** who underwent detailed training in how to identify children with visual impairments. They referred the children who were identified to nearby eye camps where an ophthalmologist carried out formal diagnostic assessments. Parents were recruited as key informants or referral ambassadors; they were also involved in disseminating information to raise eye health awareness. The programme team established a referral network with eye hospitals, inclusive education centres, and rehabilitation centres, and referred children to these services, as needed. They also provided spectacles to children with low vision.

The programme identified 30,000 children who were blind or had severe visual impairment. A total of 500 children received vision-restoring cataract surgery, 1,000 received white canes and rehabilitation training, and 500 received low vision devices.

**Comprehensive school screening initiative**

The comprehensive school screening initiative identified school children in remote areas with mild to moderate visual impairment due to uncorrected refractive error. There are, relatively, a larger number of children with these issues. Most of them are in regular schools in rural areas, where affordable and accessible eye and vision care services are limited or lacking.

School teachers and older students were trained to serve as vision screening volunteers. After screening, the volunteers made a list of children with vision impairment. These children were examined and given...
refraction. They received spectacle prescriptions, and were given appropriate spectacles by an optometrist who was available on call. Any child needing further examination by an ophthalmologist was referred to an eye hospital. Free spectacles were given to 12,000 children who were identified with refractive error during the programme period.

The long-term programme objective is to collect information to map children needing eye care services, and to develop and strengthen a network of key informants, government and non-government agencies, and ophthalmologists to provide treatment and rehabilitation services. The goal is to improve children's wellbeing, school attendance, academic performance, and overall functioning through timely eye care.

So far, 3,500 people have been trained to become key informants. Any committed member of the community can volunteer to be trained as a key informant.

Health communication leaflets, posters and billboards, face-to-face meetings, and seminars have been helpful in raising community awareness regarding comprehensive eye care for children. Increased awareness within the community is essential for the long-term sustainability of eye health programmes.

Challenges

The following are some of the problems that were encountered:

- limited pool of people from which to select appropriate key informants
- restrictions on movement due to political unrest
- unavailability of specialised eye care services locally (i.e., in the programme area)
- access difficulties due to floods, especially during the monsoon (three to four months of the year).

To address the challenges, the team involved government health and education departments, non-governmental agencies, and local leaders in programme implementation. Importantly, the projects were run with community participation, which is the key to implementing a health programme covering a vast area and a large population in a short time and with limited resources.

Further reading

London School of Hygiene and Tropical Medicine. Using the Key Informant Method to identify children with disabilities: a working guide [Internet]. Available from: https://bit.ly/3wed5jO

Providing eye care services to the indigenous Chepang people of central Nepal

Community involvement has been critical in eye care delivery to the marginalised Chepang people of Nepal.

N epal's national society for comprehensive eye care, Nepal Netra Jyoti Sangh (NNJS), introduced the 'National Eye Sight Program' in 2008 with the aim of 'Reaching the Unreached' across the country. According to the Nepal Blindness Survey conducted in 1979–80, cataract and childhood blindness were the major eye health challenges in Nepal.¹

In order to tackle these challenges and meet the VISION 2020 objectives, NNJS has been conducting eye care outreach activities such as diagnostic, screening, and treatment (DST)camps, surgical eye camps, and school eye health programmes through its eye hospitals and centres across the country, with a focus on reaching marginalised groups.²

One of these groups is the nomadic Chepang community, a highly marginalised community of around 70,000 people³ who live in the Chitwan, Makwanpur, Gorkha, and Dhading districts in central Nepal. These areas all fall within the catchment area of Bharatpur Eye Hospital.

Eye care services for the Chepang people are provided through mobile diagnostic, screening, and treatment camps. Three or four camps are organised every year, where cataract examinations are carried out, simple cases of conjunctivitis, dry eye, and refractive error are treated, and spectacles are dispensed free of cost to those who need them. People who need surgery are either brought to Bharatpur Eye Hospital or operated on during surgical eye camps, which are organised regularly. A total of 1,143 cataract operations were performed in the year 2020–21.⁴ The programme has a 10-year goal of clearing the treatment backlog of visual impairment among the Chepang community and building community leadership that will improve the uptake of eye health services.

Community involvement and support

To set up an eye camp, Bharatpur Eye Hospital, in coordination with the district health office, will first establish communication with the head of the village so they can work together to plan the eye camp and recruit volunteers and community motivators, which are both vital to the success of the programme. Volunteers can include younger members of the Chepang community, who have previously worked with immunisation or literacy programmes. Motivators are usually older community members, some of whom have had eye surgery and are satisfied with the treatment. Where possible, school
teachers from the neighbourhood and female community health volunteers are mobilised to educate the community about improving their eye health-seeking behaviour. Involving members of the community and showing appreciation for their efforts empowers them and motivates them to further work for their community.

Volunteers are taken to Bharatpur Eye Hospital, where they are taught about the importance of eye health and current measures to end preventable blindness. The volunteers, along with the hospital’s field workers, make door-to-door visits in the community, identify those with visual impairment and eye disease, and refer them to the eye camp. The most common eye problems faced by the Chepang are cataract, glaucoma, chronic dacryocystitis, and refractive error.5,6

Resource mobilisation
The cost of surgery and other interventions at Bharatpur Eye Hospital is met by donor agencies (in particular, Seva Foundation) who are committed to long-term support. Volunteers use printed information, education, and communication (IEC) material (mainly with figures/illustrations for easy comprehension) to create awareness and disseminate information. The expenses for this and for publicity through FM radio are borne by local non-governmental organisations (NGOs). The cost of food and transportation, basic medicines, and spectacles is covered by NGOs, banks, and philanthropists.

Challenges and strengths
The challenges to health service delivery are the remote and scattered location of Chepang community members, their lack of formal community leaders, low levels of health awareness, lack of literacy and poor socioeconomic status. Chepang communities are often isolated, and it is usually only the chief male member of the household who ventures outside the community; this tends to keep women, children, and older people away from health facilities and, often, unaware of their existence.

The efforts of the volunteers and motivators from the Chepang community are therefore of the utmost importance in influencing health-seeking behaviour and increasing eye health service uptake among other Chepang people. The motivation of community volunteers, cooperation by community members, the support of NGOs, and the existence of close community clusters all contribute to improved uptake of eye health services. Eventual integration of the programme with the government health service delivery system and financial support from long-term donors also support the programme’s long-term sustainability.

References
Community involvement in eye care: a health systems perspective

Active community participation in the six pillars of the health systems strengthening framework is vital if we are to achieve universal access to eye care.

There are 2.2 billion people around the world who have a visual impairment. Almost half of them have an eye condition which is either preventable or treatable, and is yet to be addressed. Of these, 1.1 billion people who are still in need of eye care, 55% are women and girls and most live in low- and middle-income countries, where they have limited access to eye health services due to various socio-economic and cultural barriers, made worse by the COVID-19 pandemic.

The World Health Organization’s World Report on Vision (2019) and The Lancet Global Eye Health Commission on Global Eye Health highlight key priority areas for action that include the integration of eye care into universal health care (UHC) and delivering integrated people-centred eye care for all. Most of this can be managed and sustained through routine primary health care services (see previous online issue: https://www.cehjournal.org/primary-eye-care/).

Engaging with communities and empowering them to be part of this journey – right from the outset – is vital to maximise efforts to improve the delivery, acceptance, and uptake of eye care services. If we want to ensure that this engagement is effective and optimises eye care, we need to place communities in the driver’s seat. This article describes what should be in place to make this possible, with reference to the six pillars of the health systems strengthening framework: service delivery, the health workforce, health information systems, essential medicines (here extended to include supplies), financing, and leadership/governance. Communities should be involved in all six pillars where possible, through active participation and engagement in planning and implementation.

Service delivery

Communities, as well as local and national governments, must be included in the design and delivery of eye health programmes and interventions. It is more effective in the long term to use a participatory approach and to work in consultation with community leaders to ensure all voices are heard. Communities can be empowered to engage in delivering eye care, to support access to screening, treatment and surgery, and to strengthen referral pathways. It is just as important
to listen to different groups in the community to ensure that their needs are being met and that any barriers to access are removed. This is vital to ensure equity of access to eye health services by different population groups, e.g., women, people with disabilities, and everyone regardless of their gender identity or sexual orientation.

**Health workforce**

Health systems should be well equipped with competent staff members who have the skills and tools to provide eye care. There must be training and continuous support for different categories of health workers at community, primary, secondary, and tertiary levels of care. A competent and well-resourced eye health workforce that is integrated into the health system and accessible to communities in need will not only increase access to care but will also help to ensure a continuum of care for patients – from initial detection/screening to treatment, follow-up, and rehabilitation (if needed). As we take eye care to village and household levels, the community can play a critical role in providing volunteer workers that can help to mobilise patients or carry out simple screening, thereby supplementing the efforts of skilled health workers. Such a ‘community health system’ is informal, traditional, and familiar, which can support people to overcome barriers such as fear and distrust.

**Health information systems**

National and provincial/regional eye health programmes must be represented within the national health information management system (HMIS) and integrated with other relevant databases. However, quantitative data alone doesn’t capture the complete story. It is equally important to focus on human stories from and by the communities who are impacted by these programmes. A mechanism to bring the ‘human’ focus into information management needs to be considered at the community level. Data about resource availability and performance should not only be captured in the information system but also compared against the data on the eye care needs of the community. Such denominator-driven health information systems are essential if we are to know where we are in the journey towards universal health care.

**Supplies and technology**

Addressing vision impairment requires strengthening the supply of medical products, spectacles, assistive technologies, and data management at all levels. Private sector providers, such as community pharmacies, can also play an important part if appropriately trained, regulated, and integrated with the health system. Since primary eye health care is a key strategy, we will need to ensure that supply chain challenges are addressed in areas that are difficult to reach (known as the ‘last mile’). This will have a lasting and sustainable impact on the affordability and quality of eye care, particularly for underserved communities and groups.

**Finance**

Sustaining eye health services in low and/or middle-income countries is a major challenge, which makes it necessary to select and implement appropriate business models for public and private eye health facilities and systems as early as possible. Domestic financing and community-based financing mechanisms can help to build cost-effective, well-resourced, cross-sectoral delivery models for eye care and strengthen health system financing. Policy integration of this aspect is vital to ensure sustainability and coverage of essential eye health services across the population, so that we leave no one behind.

**Leadership and governance**

High-level leadership is mostly engaged in advocating for the elimination of unaddressed vision impairment. However, in many contexts, community-level groups can be involved in advocacy and governance. These include education and rehabilitation groups, organisations of people with disabilities, and women’s groups. These groups can hold eye care service providers to account, ensuring they are more responsive to local needs. To strengthen the health system through the development of comprehensive primary eye care, there is an urgent need for leadership to focus on enabling policies relating to investigations, treatment, and rehabilitation.

**Mobile communications technology**

An aspect not covered in the health systems strengthening framework is communications technology, particularly as it relates to cellphones (also known as mobile phones) and how they are being used to support community mobilisation and eye care delivery. Other articles in this issue (bit.ly/CEHJcommunity), and in our recent issue on communication technology for eye care (bit.ly/CEHJtech), offer useful examples.

In conclusion, active community participation in the six pillars of the health systems strengthening framework, as well as community engagement in the implementation of policies, is vital if we want to achieve universal eye health coverage.

**References**

Key community eye health messages

Community health workers in eye care delivery

- Community health workers are health care providers who live in the community they serve.
- They have enormous potential to extend health care services to communities living in remote areas and to marginalised and vulnerable populations.
- They can encourage uptake of eye health services by creating awareness, providing health education, delivering diagnostic or clinical care, and collecting data and maintaining records.

Community-based monitoring of healthcare

- includes a set of activities or processes conducted by communities to understand the availability, accessibility, quality, and effectiveness of the services
- provides an efficient feedback mechanism and ensures that service providers are accountable to the service users
- includes tools such as community scorecards, patient satisfaction surveys, social audits, resources and budget tracking, and complaint and grievance mechanisms.

Engaging the community in eye care planning calls for

- building trust with the community, establishing rapport, and meeting community groups – formally and informally
- understanding the needs of the community, the issues faced, and gaps in services
- involving the community in planning agenda and pursuing meaningful strategies to address those needs.