Data transparency
and information sharing

A case study from the Combatting Blindness in Peru project

Project background

A rapid assessment of avoidable blindness conducted in Peru in 2011 found a prevalence of blindness of 2% amongst people aged over 50, and 83% of all causes of blindness could be treated or prevented. The main cause of blindness was due to cataracts (58%), equivalent to 348,000 people.

CBM has been working on the prevention of blindness in Peru since 1990 and working with eye care providers over many years. In 2012, CBM brought these partners under one national blindness prevention cluster.

Between July 2014 and June 2018, CBM ran a project entitled Combatting Blindness

Figure 1 Departments covered by the project

in Peru. The project was delivered through a cluster of six partner organisations across 13 regions[1] (Figure 1) in Peru with support from the Seeing is Believing initiative, funded by Standard Chartered and CBM.

Project aims included:

- Provision of high quality cataract surgery, and patient care to 250,000 patients.

- Strengthening community work, conducting 1,494 outreach campaigns and enhancing access to cataract services.

- Improvements to the quality, efficiency and sustainability of seven eye care partners.

- Strengthening networks among partners and building alliances with external stakeholders to advocate for improved eye care services in Peru.

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[1] Regions shown in Figure 1 are Amazonas, Apurímac, Arequipa, Cuzco, Ica, La Libertad, Lambayeque, Lima, Loreto, Piura, Puno, San Martín and Tumbes.

About the data transparency case study

Through project monitoring, anecdotal evidence was collected about high levels of data and information sharing between some partners throughout the project. In order to investigate this element of the project further, CBM developed a case study about data transparency, which collected information from partners to understand the causes and effects of sharing between partners, as well as any challenges encountered.

In order to do this, the case study explored the following research questions:
- How and to what extent did the project support partners to share data?
- What factors facilitated data sharing amongst partners?
- What were the benefits to partners of sharing?
- What were the challenges to sharing data and how was it overcome?

As part of a final evaluation of the project, semi-structured interviews were conducted individually with senior clinicians and managers at partner organisations, in order to further explore lessons learnt relating to data transparency and information sharing within the project.

Follow-up calls were made by CBM staff to gain further details where necessary. Interviews were recorded and transcribed, and analysed using thematic analysis. All quotations included in this report are from interviews with partners.

About the partners

In 2012, CBM grouped partners under a national cluster for blindness prevention. This has allowed partners to work more holistically, and this has a more significant regional and national impact. The cluster was formed of the six partners who implemented this project:

1. Lead partner. Main and largest partner of the project. It is an established NGO located in South Lima, which has worked with CBM since 2000. Over the years of working with CBM, this partner has developed a business model to provide eye care services to prevent blindness in low income communities in South Lima and other areas of Peru. In 2007, the partner signed a contract with the Ministry of Health to work together on the prevention of blindness at national level.
2. NGO that works with a private clinic (for profit organization) in preventing blindness in low income communities in Arequipa (Southern Peru). CBM's partner since 1997.
3. NGO that works in preventing blindness in low income communities in Piura (Northern Peru). CBM's partner since 1999.
4. Ophthalmologic Centre that is part of the Diocese of Abancay. It is the smallest partner of the project and has worked with CBM since 1998.
5. NGO that provides low cost eye care services through its clinic, supporting low income communities in Trujillo. CBM's partner since 1998.
6. NGO that works in providing eye care services and visual education in Peru's Amazon area. CBM's newest eye health partner: the organisation has been working with CBM since 2014.

All partners are NGOs, with four working through private profit-making clinics. One is an entirely non-profit organisation, and the lead partner is an NGO which has grown from a small eye clinic; its main aim is the prevention of blindness.

The lead partner took on the role of coordinator of the cluster; the Project Manager for the cluster was based at its offices in Lima.

How and to what extent did the project support partners to share data?

The project supported data transparency amongst partners through creating opportunities to share data, and improving the capacity of partners to collect data, through investment in and knowledge sharing about data collection systems.

Requirements and expectations surrounding data and information sharing and communication were discussed and agreed by partners and CBM during an early planning meeting in Lima. Data related to project indicators, such as service coverage, referral to surgery conversion rate, and post-surgery visual acuity outcomes, were reported by each partner to the project coordination office, who organised meetings and compiled project documents and reports.

"When we met to plan the project, the transparency of the information was one of the things that was most discussed. The agreement reached by all the participants was that everyone should provide information on topics such as indicators, when someone needs it."

There was no formal requirement for partners to share project data with each other.

"There was no signed agreement - it was more a voluntary matter."

Annual project meetings provided opportunities for partners to share data on the progress of the project and discuss key issues and challenges related to their data collection systems and processes.

"We realised that by sharing information, we learned more and we could improve."

However, all partners to varying extents shared more project data with each other than minimally required, usually in the context of promoting project and organisational effectiveness at annual partner meetings, through presentations and discussions.

"In annual meetings, partners got the chance to share information about their performance, but they also discussed problems and how to solve them."

Exchanging information and maintaining good levels of communication were considered to be integral to effective joint working. Outside of annual meetings, partners generally demonstrated high levels of openness with each other through informal communication channels such as telephone calls, instant messaging (WhatsApp) and conversations at medical conferences. Information sharing was not limited to the cluster project. Email was considered to be less efficient and effective for sharing information and collaborating to resolve issues.

"In addition, we shared information about the projects that we are developing externally."

Before the project started, there were a range of starting points in terms of how developed partners' organisational processes were. Three partners collected information manually (such as patient information, medical records, campaign planning, cash flow etc.). Three partners, including the lead partner, collected information through a software package that was not customized for the clinic's needs. The project funded software implementation and customization for one partner, and customization of existing software for another; other partners introduced and customized software packages with their own funds.

Partners improved or modified their systems with help from the lead partner to better align with project reporting needs.

"A successful result of sharing information was that all partners established as organisations with clear processes."

This allowed them to capture data required for the project and provided more information to use for planning.

"We had to make changes ... separating men from women, and children from adults."

Partners were confident that, going forward, they would continue to use and adapt their systems developed under the project.

Information sharing most commonly took place between individual partners and the lead partner. As part of the project, the lead partner delivered administrative, accounting and clinical capacity building, including training in software customisation and data management, low cost business models, and medical services.

"Communication with [the lead clinic] was high and ... [they were] a fundamental pillar in the development of this project."

What factors facilitated data sharing amongst partners?

A number of factors facilitated high levels of data sharing amongst partners during the project.

Trust, friendship and history of collaboration
Strong histories of collaboration and established working relationships facilitated high levels of data sharing on the project. Five out of six partners for the project had previously collaborated with CBM, and partner staff operated within the relatively tight-knit ophthalmology community in Peru. Some of the partners had over 20 years' experience of working together to prevent blindness in Peru and some had worked successfully together on projects with other INGOs. Although one clinic was a new partner to CBM for this project, the medical director had established relationships with the directors of the other partners.

"The medical circle of ophthalmology is small and allows us to have enough contact."

Many partners have a long history of sharing clinical and organisational information with each other.

"All the partners knew each other and had extensive experience. Without a doubt this was the strength of the cluster."
"Before the arrival of CBM we already shared courses, events and other academic activities."

There were strong friendships in place amongst some key members of staff.

"The presidents and directors of each institution are our friends, therefore in the face of any difficulty there is joint support."

Exchanging information and maintaining good levels of communication were seen by partners as integral to effective joint working.

"When one works with a common goal, it is necessary that there be a closeness from years ago … It is very difficult to make a work group between people you do not know."

However there was also a recognition that even without these relationships, sharing information would have remained mutually beneficial. One partner commented that, **"if he wasn't friends with cluster partners, we would have still shared information."**

However, trust, integrity and reputation were considered to facilitate information sharing by engendering confidence that shared information would not be misused.

"In order to share information, you must trust the rest, knowing that the information will be used in a good way."

"We shared more with them because of the confidence we had in them."

Common goals for information sharing and collaboration

At the outset, partners committed to working together closely in order to raise public awareness and influence government for best results. Partners established a positive ethos of collaborating, with an expectation that information would be shared and used constructively. One partner stated that,

"We do not seek to compare the work of each one. What we were looking for was for each one to improve."

Structure of the project

The formation of a cluster to implement the project appeared to enhance the sense of cohesion and to establish the sense of working together towards a shared goal.

"We entered the cluster with the idea of forming a team which is consolidated in numbers and results."

Topics discussed through cluster meetings included surgical procedures, project progress, organisational capacity, and advice and support.

"The premise was always to help and contribute."

Through the organisational structure of the cluster established for the project, and the project funding for training activities led by the lead partner, the lead partner was able to play a wide-ranging, mentoring role to facilitate data sharing. Partner staff visited the lead partner for training, and this helped to cement the pre-existing relationships between partners.

Organisational characteristics

Partners were more likely to communicate and share more information with other partners that had similar backgrounds, perspectives, cultures and modes of working.

"You had to help according to the functions of each place."

Partners with similar management structures, or with obviously successful models, tended to be used as role models for other partners to learn from in developing their systems. One partner remarked of the lead partner:

"We had a closer relationship because they were a management model for us. Their service strategy was very similar to ours."

Another partner had shared more information with a particular manager at another clinic **"because he has a very successful management of his project."** Having a lead partner with long-established systems (in place for more than ten years) and expertise that were evident during training visits is likely to have increased the potential value of collaborating for other partners.

Geographical proximity increased the likelihood of sharing information due to the additional opportunities to meet in person and develop relationships, and because different parts of the country had different cultures and needs.

"Less was shared with these groups due to geographical location and local reality."

Another partner commented:

"Not much information was shared [with a particular partner], because they respond to another context."

The geographical relationship is necessary because it allows you to visit each other … There is a relationship of geographical affinity.

The difference between private clinics and non-profits was considered on the whole to be of limited relevance.

"Due to the maturity of the project, we do not care [when] sharing information [if with] NGO or private entity."

Most partners were highly motivated to establish a sustainable business model to facilitate access to low cost services for people with low incomes, whether running subsidised services within a private clinic or an income-generating clinic within an NGO. However, one partner felt these differences in organisational goals made transparency particularly important when working together:

"The two visions are totally different, so it is necessary to establish a union, which is achieved with transparency."

What were the benefits to partners of sharing?

Sharing information was seen as mutually beneficial to further project progress and organisational capacity

Partners often communicated with each other in order to solve problems and provide **"joint support".**

"Sometimes there was even material and personnel support".

For example, two partners stepped in to support a partner that lacked an ophthalmologist with surgical campaigns.

"The conversations always reached a positive point ... There are always [project] challenges, but in the same way we could always solve them."

Improved systems were linked to positive changes in patient care and financial sustainability

All partners described the importance and utility of an electronic system to collect and analyse data and generate reports. As a result of computerisation, **data was available in real time**, saving time and increasing ease of access to data.

"Having software to collect information is a basic need nowadays."
"The database is essential to generate plans."

New or improved systems had wider benefits, leading to clearer medical, administrative and accounting processes. Collecting information through customised software rather than manually reduced the time required to plan surgeries. The quality of medical record registration improved. New or improved systems made it easier and quicker to analyse data for campaign planning and cash flow control. This allowed decision-making by partners to be better informed by evidence. It was also easier to ensure the right medications and consumable supplies were available to meet demand for treatment.

The time saved due to increased efficiency may, to various degrees, have contributed to improvements in waiting times, staffing efficiency, patient care

and satisfaction, and income. This had potential effects on attracting patients and converting them to surgery where prescribed through positive recommendations.

"Systematisation has helped to generate income through efficiency... I am convinced that extra time to devote to patients generates good recommendations."

Patients' waiting time was reduced through the project from 120 minutes to 60 minutes and patient satisfaction improved, making it easier to attract more patients.

"When the project started, everything was done manually … changes that we made allowed us to maximize our number of surgeries."

What were the challenges to sharing data and how was it overcome?

No partner reported any major barriers to sharing information, although the level of information sharing was not equal across all partners. Indeed, there was appetite from partners for more data sharing through the project; in particular, for more formal data sharing alongside the informal forms of collaboration.

Infrequent formal opportunities for information sharing

Whilst there was a high degree of data sharing informally, the opportunities for formal data sharing tended to be limited to annual partner meetings and submitting data to the project coordination office for donor reporting. Several partners commented that it would have been good to have more formal sharing of the progress made by different partners through the project coordination office. They felt that the project could have supported more formal activities for data sharing between partners, such as exchange visits. One partner commented that **"there was no specific activity … In general, this was the biggest limitation".**

Perceived sensitivity of data shared

The sensitivity of the data shared, and its potential to impact on long-standing relationships between partners, was clearly a consideration for partners as well. One partner commented that **"we preferred to give our numbers at the end, so that nobody feels bad"** in case they had outperformed other partners. Another partner said that **"modesty is an essential factor"** when sharing information. Financial information was highlighted as an area of particular sensitivity for sharing, although this information was shared to some extent during the project.

Time and effort required

Sharing data effectively requires an investment of time and effort. One partner suggested that the format for reporting to the project coordination office would have needed to change to allow for more frequent formal data sharing; in particular, submitting more regular but shorter reports.

> **"For us the annual reports were very long, they should have been quarterly or biannual. On the other hand, the biannual publications should have been monthly."**

Differences in context reduced the relevance of data sharing

Although levels of formal and particular informal information sharing were high overall during the project, they were uneven between different partners. Partner staff noted they tended to seek information from and share with other partners based on the perceived similarities between their geographical and historical context, and the value of the expertise they could share (which led to considerable data sharing with the lead partner, who was perceived as leading the way in many areas).

Staff turnover

One partner, who was **"one of the most isolated"** from other partners, had a higher turnover of senior staff, which made it challenging for other partners to maintain contact.

"In the meetings with the partners we offered to support them, but there was no response."

However this was an exception and most partners did not have any problems with staff turnover, allowing the project to leverage the established personal relationships in place at the start of the project to facilitate high levels of informal collaboration.

Conclusions and lessons learned

A key driver for sharing data amongst partner organisations was the desire to improve the quality of programme implementation and to attract more patients. There was a receptiveness to act on best practice and advice shared because of the focus on programme quality and attracting patients. This was underpinned by a common commitment to work on programmes with a social aim, to reach the most marginalised communities.

Informal information sharing was strong amongst most partners, who had worked together for many years. Forming a cluster is likely to have enhanced teamwork, although cohesion between various partners was already high. Modes of communication included calls, messaging and conference attendance rather than emails alone, which tended to be less useful for this kind of sharing. These were used to exchange technical advice, provide project progress updates, solve project challenges, provide mutual support and maintain relationships.

A number of findings of the case study may be relevant for similar health projects to consider:

- For partners working together on a project, making an explicit commitment to share data and work together to facilitate problem solving and the achievement of best practice at the outset of a project can be valuable, establishing common goals and values of transparency and collaboration.

- The value of investment in administrative and data management systems to improve service delivery should not be underestimated. This project has shown that changing these systems can enable improved data analysis and learning, thereby leading to tangible improvements for patients in terms of care, resulting in better outcomes. Consequently, partners have been able to operate at higher volumes that are more cost efficient.

- Where partner organisations have long histories of working together and well-established personal relationships between senior staff, projects should leverage the trust generated to promote close working and sharing of information. In such cases, projects should encourage informal collaboration to improve partners' ability to learn from each other, through face-to-face meetings or using instant messaging, going beyond the use of email communications. Budgeting for frequent meetings for partners to come together can further build trust and personal relationships, and provide opportunities for sharing of best practice which can make a tangible difference

to project progress and problem solving. Trainings, particularly when delivered at partner sites, and mentoring visits can also serve this function.

- Projects should invest sufficient resources to ensure information shared with project management staff and with donors is also shared amongst implementing partners. An annual or six monthly basis for formal data sharing was not considered sufficiently frequent for partners during this project. However, the benefits of more frequent formal methods of information sharing should be weighed against the extra time required. Formal sharing of output and outcome data should also be carried out carefully amongst implementing partners, based on the levels of trust amongst partners and with an emphasis on learning rather than comparison; financial data may be more difficult to share than project data related to outputs or outcomes.

- Knowledge sharing amongst partners was seen to be particularly valuable where there were similarities in operating contexts, or technical expertise to learn from. Having a partner who is able to provide significant technical leadership is likely to be important to facilitate collaboration and consolidate the value of openness and information sharing. It may also be valuable for projects to encourage collaboration between sub-sets of partners with similar contexts, for example through regional meetings.

This project has shown that sharing information transparently and improving data systems, along with good relationships between partner organisations and effective planning, can make a significant difference for eye health staff and patients. With supportive and transparent relationships in place, fostered through working together on this project, the partner organisations involved are keen to continue working as an eye health cluster into the future.

Annexes

About CBM

CBM is an international Christian disability and development organisation working in over 60 countries to transform the lives of people with disabilities, their families and communities. CBM addresses poverty as a cause and a consequence of disability, and works in partnership to create an inclusive society for all, through healthcare, education, rehabilitation, livelihood development and service delivery in, including in humanitarian situations.

CBM saves sight by:

- Enabling adults and children to access sight-restoring cataract surgery, including through outreach camps in remote places far from the nearest eye hospital.

- Treating blinding diseases like river blindness and trachoma.

- Training specialist doctors, nurses and other health workers to identify and treat eye conditions, and equipping hospital eye departments.

- Supporting screening programmes that find people who need help and enable them to access treatment.

- Supporting Governments in countries where we work to improve eye health services for the long-term.

- Providing glasses and low vision devices to people who are visually impaired.

About Seeing is Believing

Seeing is Believing is Standard Chartered's global community investment programme to tackle avoidable blindness.

For more than a decade, Seeing is Believing has helped over 150 million people in Asia, Africa, the Middle East and Latin America tackle avoidable blindness and visual impairment.

By partnering the International Agency for the Prevention of Blindness (IAPB) and other leading international eye care organisations, Seeing is Believing has improved access to eye care in communities where help is most needed.

List of participants for case study fieldwork

Partner	Job title
1	Medical Director Administrative Director
2	Medical Director
3	Medical Director Administrator
4	Administrator
5	Medical Director Administrative Director
6	Medical Director Project Manager
CBM	Inclusive Eye Health Regional Advisor Latin America Regional Office Programme Unit Coordinator Latin America Regional Office Country Programme Officer