

Disability Disaggregation Project

India Mid-Term Review Report

September 2015

Emma Jolley, Pauline Thivillier

Table of contents

Acronyms.....	3
Executive summary.....	4
Summary	4
Methodology.....	4
Overview of findings	4
Background.....	6
<i>Disability Disaggregation</i>	6
Data Collection Process at VC and OC.....	6
Data Collection Process at the hospital	8
Mid Term Review.....	8
Methods	8
Questions and tools	8
RESULTS.....	10
Policy/ decision makers and project managers	10
E. What are the views of project managers on the sensitisation/ training provided to their staff and how do they perceive it has affected the way they conduct their work?	10
F. How useful is the data provided by the data collection system to the work of policy/ decision makers and is it to the correct level of detail?	11
G. How has the data collected to date been used in any way by policy/ decision makers?	12
H. How does the appropriate data collection methodology and technology impact on the quality and timeliness of the data available to policy/ decision makers?	13
I. What data would policy/ decision makers like to have access to that remains unavailable? .	15
J. How have policy/ decision makers integrated any aspect of this project in to other project over which they have control, including disability awareness and collecting data on disability?.....	15

K.	How have different partners collaborated on this project and what impact can they attribute to partnership working?	16
L.	How can lessons learned from this project be captured to implement this work in other projects and to share with partners and other organisations?	17
	Staff collecting/ analysing the data	18
M.	How do the staff collecting/ analysing the data understand disability and how can the training best orient them to the definition provided by the Washington Group?	18
N.	How does orientation on disability issues affect the way staff interact with project clients/ patients with disabilities or impairments?.....	18
O.	How do staff collecting / analysing the data understand the purpose of data disaggregated by disability and how can the training best orient them to understanding the importance of accurate data collection?	19
P.	How often do staff require refresher trainings or support to maintain high quality data collection?	19
Q.	How can the tools and processes currently used by staff to collect client data be best adapted to include disability data?	19
R.	How do the tools and guidelines developed specifically for this project fulfil their purpose and how could they be improved?	20
S.	How does the appropriate technology, including hardware and software, impact on how staff are able to collect and analyse data?.....	20
T.	For data collectors based outside of health facilities: how do staff feel that community knowledge/ attitudes/ norms affect the collection of this data and do they experience more challenges in specific groups within communities?.....	20
U.	How have staff working on this project integrated any aspect of this project in to other work over which they have control, including disability awareness and collecting data on disability? ..	21
V.	What are the experiences of staff in administering the extra questions to project clients, including the reaction of clients to being asked these questions and using the tools provided for the purpose?	21
W.	What extra burden does collecting the disability data place on the staff working with the data in terms of their time and taking them away from other duties?	22
X.	How accurately can the data be transferred through the information system from the point	22
	General feedback from data analysis	23
	Spot-check at the VC	23
	PROJECT MANAGEMENT	23
	CONCLUSION.....	24
	NEXT STEPS	25

Acronyms

CO Country Office

DFID Department for International Development

FGD Focus Group Discussion

HMIS Health Management Information System

M&E Monitoring and Evaluation

MPUSP Madhya Pradesh Urban Eye Slum Project

MTR Mid-Term Review

NGO Non-Governmental Organisation

OA Ophthalmic Assistant

OC Outreach Camps

OPD Outpatient Department

PEC Primary Eye Care

PDA Programme Development Advisor

PWDs People with Disabilities

UN United Nations

VC Vision Centre

WG Washington Group

Executive summary

Summary

This Mid Term Review (MTR) report contains information on the first six months (July – March) of the disability disaggregation pilot project taking place in Bhopal, India. The report includes information on the processes in place at the different locations to collect data disaggregated by disability and initial results. It also captures attitude, knowledge and experiences of programme managers, decision makers and data collectors around disability, their challenges, and the experiences of Sightsavers' implementing staff.

The main objective of this report is to provide a record of the situation six months after the start of the pilot. Findings can be compared against the baseline report¹ and will also be useful as part of the final evaluation. Additionally it reports qualitative information that will inform future disaggregation of data in Sightsavers' projects and enable us to share externally how we have gone about this project.

Methodology

This report does not include the data collected over the past six months as questions remain over its accuracy. There are still challenges in the data collection process that require further analysis. The information in this report is qualitative in nature and was captured through face to face interviews of four project managers and decision makers, and focus group discussions (FGD) among data collectors who are using the questionnaire on a daily basis. This report also captures a number of observations of Sightsavers staff implementing the project to reflect on some of the challenges that have arisen since the start of the project.

Overview of findings

A basic analysis of the data collected during the first six months of the pilot shows that:

- Prevalence of disability varies greatly depending on the cut-off used. The Washington Group recommended cut-off (everyone with at least one domain that is coded as a lot of difficulty or cannot do it at all) to define the populations with and without disabilities appears to highlight accessibility issues and barriers for people coming to our services.
- There is a significant difference between the data collected using the WG questionnaire and the national census question (are you disabled? Yes/No).
- Accessibility is linked to the location of services and the age of the patients.
- Half of the people accessing our services report a difficulty in seeing.

There is no single approach to data disaggregation. A different approach will be required in different environments. Data collectors can spend a lot more time with patients in a small Vision Centre (VC) than in a busy public hospital. We are already aware of the challenges in busy environments, such as delays in registration and lack of confidentiality.

Data disaggregation does not have to be an extra burden. People often view the collection of additional data as an extra burden and cost, but integrating the WG questionnaire into existing practices saves time and energy. Moreover, the training of data collectors gives staff confidence, and with practice they get quicker at asking questions.

¹ <http://www.asksource.info/sites/asksource.info/files/Sightsavers%20Baseline%20Report%20-%20Disability%20Disaggregation%20of%20Data.pdf>

People need to understand why data is important. Buy-in and ownership by partners and data collectors ensure the collection of good quality data, but these are not enough. We found that patients are much more inclined to respond to the WG questionnaire when they know why they are being asked the questions.

Just collecting data will not create change. Partners feel that they have a responsibility to use the data collected because, by asking questions, they raise people's expectations. Various unexpected initiatives have been reported to ensure people with disabilities are aware they can access services and have a right to treatment. We now realise that referrals to other services need to be integrated to the process.

Background

Disability Disaggregation

The aim of this pilot is to expand how we disaggregate data in order to include people with disabilities and share our experience of disaggregation with others whilst advocating for the need to collect data specifically around people with disabilities.

The pilot was launched in June 2014 with an inception workshop in Bhopal to introduce the project to partners, programme managers and data collectors. The findings of this workshop, including current situation, expectations of stakeholders as well as experience from programme managers, can be found in the baseline report published in December 2014.

Madhya Pradesh Urban Slum Eye Care Programme in Bhopal, India

The project is piloting the establishment of a system of Primary Eye Care (PEC) through community resource building and strengthening human resources required in the slums of Bhopal and Indore. The project started in late 2013 and the total project duration will be four and half years. Project partners include the development agency, AARAMBH, and the eye hospital, Sewa Sedan. The project incorporates PEC in urban slum situation to address problems associated with massive population growth in these areas.

Disaggregation of data by disability was incorporated in to all paper based data collection tools at points where patients/clients demographic data is collected i.e. Outreach Camps (OC), Vision Centres (VC) and hospital. An electronic Health Management Information System (HMIS) was introduced in the VC in June 2015 and will allow us to compare paper based data collection against electronic data collection as part of the evaluation.

A local administrator was hired to gather all the learning necessary for the pilot and assist with data collection, spot-check, exit interview and basic analysis. It was decided by the programme managers and partners that she would be based with AARAMBH to ensure that the partners have full ownership of the project.

Collection of data by disability started in September 2014 at the VC and OC and in December at the Hospital and different data collection processes are in place.

Data Collection Process at VC and OC

As part of this pilot, two data coordinators were hired to help with the collection of data on disability at the three VC and various OC. This means that in two VC, a dedicated person is asking the WG questionnaire and in the last VC, the Ophthalmic Assistant (OA) is doing the registration, asking the WG questionnaire and giving spectacles. At the time of the MTR, only the two VC with the extra data collectors were operational; the other one started in March 2015.

The data collection process is as follow:

- 1) When a patient enters the VC, the OA records the patient demographic information on the patient record form.

- 2) If there is an extra data collector for the WG questionnaire, the OA then gives the form to that person who records the WG questions on the back of the form. If there is no data collector, the OA does it him/herself.
- 3) The same data (name, sex, age and WG questionnaire) is also recorded at into a registry book.
- 4) At the end of each day, the relevant data is transferred into an excel spreadsheet.



Data collectors at the OC



OA and Data collector at the VC

Sightsavers
M.P Urban Slum Eye Care Programme
 Patient Record Form
 Patient Name: Sutradya Ganesh
 Address: ...
 Complaints: (P2) Bilateral redness
 Refraction: RE 6/60 LE 6/6
 Base Hospital: Sewa Sadan Eye Hospital, Sant Hirdaram Nagar, Bairagarh, Bhopal

WG Questionnaire (Back of form):
 1. क्या आपको देखने में परेशानी आती है? हाँ - 2
 2. क्या आपको सुनने में परेशानी आती है? हाँ, थोड़ी परेशानी है - 2
 3. क्या आपको खाने में परेशानी आती है? हाँ, थोड़ी परेशानी है - 2
 4. क्या आपको चलने में परेशानी आती है? हाँ, थोड़ी परेशानी है - 2
 5. क्या आपको बात करने में परेशानी आती है? हाँ, थोड़ी परेशानी है - 2
 6. क्या आपको कोई बात याद रखने में परेशानी आती है? हाँ, थोड़ी परेशानी है - 2
 7. क्या आपको खाने में परेशानी आती है? हाँ, थोड़ी परेशानी है - 2
 8. क्या आपको अपनी भाषा में बातचीत करने में परेशानी आती है? हाँ, थोड़ी परेशानी है - 2
 9. क्या आप मानसिक / शारीरिक तौर से निराशत या विकलांग हैं? हाँ - 1

Front (demographic information) and back (WG questions) of the patient form

Registry Book

Sl. No.	Name	Age	Sex	Diagnosis	1	2	3	4	5	6	7	8	9	Total
105	Kami Devi	65	F	Chond bad	1	1	1	1	1	1	1	1	1	10
107	Anchal	18	F	Chond bad	1	1	1	1	1	1	1	1	1	10
108	Poonam	26	F	Semra	1	1	1	1	1	1	1	1	1	10
231	Suman	20	F	Semra	1	1	1	1	1	1	1	1	1	10
232	Gyan Bai	53	F	Chond Bad	1	1	1	1	1	1	1	1	1	10
233	Ramkrishna	60	F	Chond Bad	1	1	1	1	1	1	1	1	1	10
234	Balabai	31	M	Semra	1	1	1	1	1	1	1	1	1	10
235	Chandani	28	M	Chond bad	1	1	1	1	1	1	1	1	1	10
236	Chand Vimal	42	M	Chond bad	1	1	1	1	1	1	1	1	1	10
237	Chand Bai	49	F	Chond bad	1	1	1	1	1	1	1	1	1	10
238	Chand Bai	23	M	Chond bad	1	1	1	1	1	1	1	1	1	10

Registry Book

Data Collection Process at the hospital

Data collection was initially taking place at the reception counter, at the same time than the registration. However this had to be abandoned as there were too many people at the same time at the counter and receptionists were overwhelmed, unable to ensure privacy and creating important delays. To avoid delays and optimise the waiting time of the patient, an extra step in the registration process was added (between registration and examination by the ophthalmologist). After the registration, the patient goes to another counter where a dedicated member of staff from the hospital asks the WG questionnaire. At the time of the MTR, only one person was trained to ask the questionnaire.

Data on disability is not integrated in the existing processes and tools and collection of data only started in December 2015. Data is collected separately and directly into a register. In the same way it is transferred into an excel spreadsheet at the end of the day.



Data collector at the hospital

Mid Term Review

It was decided to schedule the MTR in February 2015 so we could look at 6 months of data for the VC and OC and the past 3 months at the hospital as well as gather experience of people directly involved in the process of disaggregating data by disability. The MTR was carried out by the Monitoring Officer during a 4 days trip to Bhopal which included:

- Meeting with Country Office (CO) to get feedback from programme managers;
- Meeting with the partners and visit to the facilities to look at the data collection process;
- Refresher training with the data collectors and group exercise on issues identified;
- Meeting with programme managers and management staff to discuss next steps.

Methods

Questions and tools

Prior to the start of the pilot, a number of questions were identified as important by the project team for evaluating the pilot project's success and capturing the experiences of people coming in to contact with

the data system at a wide range of levels. Following initial interviews with key project stakeholders, further questions were identified and integrated in to the Evaluation Plan, the final version of which is detailed in Appendix 1. The methods used to answer these questions and the frequency with which they will be examined are also described in Appendix 1.

The India MTR report reflects on experience of programme managers and partners with the new system and starts formulating an answer for the following questions:

- E. What are the views of project managers on the sensitisation/ training provided to their staff and how do they perceive it has affected the way they conduct their work?
- F. How useful is the data provided by the data collection system to the work of policy/ decision makers and is it to the correct level of detail?
- G. How has the data collected to date been used in any way by policy/ decision makers?
- H. How does the appropriate data collection methodology and technology impact on the quality and timeliness of the data available to policy/ decision makers?
- I. What data would policy/ decision makers like to have access to that remains unavailable?
- J. How have policy/ decision makers integrated any aspect of this project in to other project over which they have control, including disability awareness and collecting data on disability?
- K. How have different partners collaborated on this project and what impact can they attribute to partnership working?
- L. How can lessons learned from this project be captured to implement this work in other projects and to share with partners and other organisations?
- M. How do the staff collecting/ analysing the data understand disability and how can the training best orient them to the definition provided by the Washington Group?
- N. How does orientation on disability issues affect the way staff interact with project clients/ patients with disabilities or impairments?
- O. How do staff collecting/ analysing the data understand the purpose of data disaggregated by disability and how can the training best orient them to understanding the importance of accurate data collection?
- P. How often do staff require refresher trainings or support to maintain high quality data collection?
- Q. How can the tools and processes currently used by staff to collect client data be best adapted to include disability data?
- R. How do the tools and guidelines developed specifically for this project fulfil their purpose and how could they be improved?
- S. How does the appropriate technology, including hardware and software, impact on how staff are able to collect and analyse data?
- T. For data collectors based outside of health facilities: how do staff feel that community knowledge/ attitudes/ norms affect the collection of this data and do they experience more challenges in specific groups within communities?
- U. How have staff working on this project integrated any aspect of this project in to other work over which they have control, including disability awareness and collecting data on disability?
- V. What are the experiences of staff in administering the extra questions to project clients, including the reaction of clients to being asked these questions and using the tools provided for the purpose?
- W. What extra burden does collecting the disability data place on the staff working with the data in terms of their time and taking them away from other duties?
- X. How accurately can the data be transferred through the information system from the point it is collected from the client, to the final version received by policy/ decision makers?

RESULTS

Policy/ decision makers and project managers

E. What are the views of project managers on the sensitisation/ training provided to their staff and how do they perceive it has affected the way they conduct their work?

- ✓ Staff is appropriately trained
- ✓ Training has a positive impact on the way staff interact with people with disabilities
- ✓ Refresher trainings are necessary to keep motivation and ensure quality
- ✓ Training should not be limited to staff collecting the data

Programme managers and partners agree that sensitisation on disability and training on the WG questionnaire are necessary to ensure that data collectors have an appropriate behaviour towards people with disabilities and collect good quality data. According to them, staff involved in the disability disaggregation pilot was appropriately trained at the start of the project in June 2014.

'[Training is] very important and that is why we need to keep training people to ensure that they ask the questions well and respect the people.'

'Without training they [data collectors] will ask questions very blankly and their language and attitude will not be very positive resulting in poor responses.'

'At present staff is appropriately trained.'

It was felt by programme managers and partners that training had a positive impact on themselves as well as data collectors. It has changed the way they interact with people with disabilities and are more aware of the difficulties they face in terms of access to services. Various initiatives have been reported such as referrals of people with disabilities to appropriate facilities and awareness raising activities.

'It has impacted on my thinking and the person who is asking the questions and the thinking of medical directors. We are now used to think: how we can make possible or we can improve the conditions for the differently able persons.'

'Yes I can see that in the way that they are asking the questions. I can tell that something has changed and that they have a better understanding. They are now looking at the person in the eye when asking the questions and try to give them places where they could go when the Vision Centre cannot assist'

'Drastically changed staff because I am seeing people like R. who said that he never used to respect people but now when someone with a disability comes, he gets up and helps them.'

Even though they think that the staff is appropriately trained, programme managers and partners unanimously agree that refresher trainings are necessary to ensure that staff keeps a good understanding of the project and guarantee collection of quality data. These sessions should ideally take place every six months.

'I think refresher trainings and discussions like we have today are crucial to make sure they keep having a good understanding of the project, disability and the questionnaire.'

'They [data collectors] need refresher trainings to keep their motivation levels. We should have more refresher trainings, every six months to boost up their motivation and enhance their knowledge. Training could focus on different areas thus updating them with knowledge.'

'Definitely there has to be some more training. One time will not do. We need to have planned refresher training'

Training should not be limited to people who collect data on disability but also involve key stakeholders. One of the reasons why the start of data collection was delayed in the hospital is related to the lack of buy-in from management staff and trustees. Partners and programme managers organised a sensitisation workshop at the hospital with key members of staff. It gave them a better understanding of disability and the questionnaire, which made it possible for the project to start.

'Initially it was difficult to convince management because they see this as wasting the time of patients. It took us time to convince managers and think about the best way to implement it. [...] We had a sensitisation workshop in the hospital with trustees, reception staff, paramedics and admin staff who take on operation and admin staff [...]. After the sensitisation they understood why the project is important. And then it started and now it is going fine.'

'They need a better understanding of disability but this should not be limited to the data collectors.'

F. How useful is the data provided by the data collection system to the work of policy/ decision makers and is it to the correct level of detail?

- ✓ **Data is good enough for now**
- ✓ **Analysis is already taking place and further analysis will help identify where more data is needed**
- ✓ **Data is reliable**

It was reported that the data collected is to the correct level of details for now but it will need to be reviewed at the end of the pilot.

'Data is more than enough but we have to look at the analysis again after six months'

'For now it is okay but it would be good to review the data collected at the end of this exercise. So we can look at the differences, challenges and what we can do to address it.'

'At present we feel this data is sufficient.'

'For the time being this is good enough.'

They use the data to see the level of access per domains of disability, link between age, sex and disability and the comparison between the WG data and the national census data. They are also aware that, due to Sightsavers' mandate, it is likely that more people with visual impairments will be coming to the camps and this need to be factored in the analysis. Comparison between the data collected at the VC

and OC and the hospital will also give a good indicator of accessibility at different locations. In the longer term, analysis of the data collected will help them to identify challenges, gaps and where more data might be needed.

'The maximum numbers of people you see are disabled because of visual, hearing, locomotive and hand movements. You have to think about it correlate with the census data that we have regarding the type of disability.'

'Since we are into the seeing business, the response of people having difficulties is more compared to other domains. That is something we need to look at i.e. whether it is the situation or because of what we do. [...] The data is also showing a difference between VC and hospitals so it is also something we need to further explore.'

'More analysis especially on age would be useful so we can analyse from this angle'

Programme managers and partners often go to the facilities to witness the data collection process. They reported that seeing the process i.e. how the questions are asked, recorded and patients' reactions is very positive. They can see that there is a strong process in place and that people are being sincere. As such they think that the data collected is reliable.

'It is very authentic because sometimes I go to the camps and I look at how they ask the questions and record the data so I can see that people are sincere when they answer the question and that the data is being properly recorded.'

'The way patient are responding to the questionnaire is positive, that's a good sign that we are recognising the people and those who really have problems.'

'I also visited one of the VC and it was really good to know how this is going along. So I kind of observed how they are doing and how the data is being captured and observing the whole process to understand.'

G. How has the data collected to date been used in any way by policy/ decision makers?

- ✓ **Data is used for planning of activities**
- ✓ **Bigger number and further analysis are necessary before data is used**

AARAMBH's director reported that the data collected is used for planning of activities, as partners are now able to know whether or not people with disabilities are accessing services. If, when they look at the data, they realise that people with disabilities are not accessing services they plan some awareness raising activities. He also feels that, as they are collecting information on disability, they have a responsibility to provide information and as such refer people to existing facilities that provide relevant services.

'I am currently reviewing the data collected by my staff to see if we can make better progress and if things needs to be reviewed / changed'

'It is very important especially for our planning so we can go out and give more services to the people who need it. [...]. So we feel that we must use this data and link it to the existing programme for disabled people so that they can get the services provided by the government.'

'It [data] was missing up to now but now with the questionnaire we are able to provide advice and link them [people with disabilities] to the facilities that we know can help the'

Sightsavers' programme managers and the hospital partner reported that it was too early to use the data because the numbers are not big enough and they have not been able to perform sufficient analysis.

'With bigger numbers we can draw more conclusions on the types of disability we see'

'Not really, because we want to analyse the information to see what kind of information is coming up. Information would be useful see if we can improve our intervention.'

H. How does the appropriate data collection methodology and technology impact on the quality and timeliness of the data available to policy/ decision makers?

- ✓ **Good process ensure quality**
- ✓ **Process is highly dependent on the setting/environment**
- ✓ **Electronic record of data collection are frequently checked**
- ✓ **HMIS would improve the process**

Programme managers and partners have confidence in the quality of the data and the data collection process.

'The quality of the data is really good.'

'I am confident in the process we currently use in the Vision Centre and the quality of the data collected.'

This project is being implemented in two different locations where different challenges have been identified.

At the VC and OC, the process is very efficient and integrated. However it is important to keep in mind that in the two VC running at the time, an extra person is collecting the answers to the WG questionnaire. The VC with the OA doing registration and asking the questionnaire started in March 2015 and a comparison exercise needs to take place.

At the hospital, after piloting the collection of data at the registration counter, it was decided to add an extra step to the process. The reception counter is always very busy which creates time pressure and lack of privacy. At the time of the MTR, only one person was trained to ask the questionnaire, which means that it was impossible to collect this data for all the outpatient department (OPD) patients. This is to be addressed in the next six months of the project.

'That is that because now we [AARAMBH] completely integrated the process in our day to day work and are getting the data'.

'I think yes in terms of trying to integrate into the VC and it is come to a level where we can say it can be done on a regular basis. We now have a different situation where people hired for this project are

collecting data in 2 VC and an OA is collection it in one vision centre. So we need to see the difference between the 2 data'

'When we [Sewa Sedan hospital] start implementing the pilot at the reception counter we realised that the reception counter is not the right place because too crowded and there is a waiting of the patient after registration and before it goes to examination. So we placed the person [asking the WG questions] in the middle to utilise the waiting time and that helped to convince them'.

'The persons at reception do manual entry, electronic entry in computer and also have to fill in the patient form so it takes a lot of time at reception when adding disability question. Patients also get frustrated and it does not give a good impression. We have found a solution to the problem and we are now getting good numbers'.

'R. is the only person who is asking the questionnaire and the OPD load in the hospital is too high. If we have to match with the OPD numbers, we also need an extra person to collect the data'

The WG questionnaire was integrated in the existing tools at the VC and OC but new tools had to be created at the hospitals which make the comparison with OPD data complicated. All programme managers and partners reported that the process is lengthy as the current tools do not allow an easy analysis of the data. They also explained that the integration of the questionnaire in an HMIS would be useful and facilitate the analysis.

Partners stated that they usually look at the Excel spreadsheet with disability data and not the paper files. Nevertheless, spot-check of the paper files are frequently taking place. Partners are encouraged by Sightsavers' programme managers to check and review their own data to ensure ownership and ultimately improve quality.

'The second challenge we initially faced was with the data collection as the data collectors were collecting it in the registers and we were unable to consolidate and analyse. Now since, we have laptops in place, all the information is entered in Excel which is easier to consolidate. It would be more helpful to have the HMIS in place.'

'I used to tell [data collectors] them it is better that you disaggregate all the project data in the Excel sheet at the end of every day so we can have the data directly in our hand so if somebody is asking us what is the number of people with disabilities accessing the programme is available. I look at the Excel spreadsheet not the paper form'

'I used to visit the data at least weekly. I asked the person on a daily basis how many person you have asked in the disability programme. Weekly, fortnightly and sometimes monthly I look at the data, how many male, females have interacted, how many people have responded to these nine questions. [...]But we are trying for these questions to also be part of the registration so maybe it should be in the hospital MIS but I don't know if this is possible or not and how much time it will take'.

'The ownership is there they [partners] review their own data on a monthly basis, identify the gaps, try to fill the gaps. Otherwise the quality of data will not be good for using.'

'I frequently spot-check the data.'

'To review the data, the data collectors are called in the office to check what and how they are doing with their registers and laptop to match the numbers. I found that the process and data was correct. But I have been always behind them for maintaining data quality. It is the evidence of our pilot study which we are going to showcase to others. People who visit to the centre should feel the quality of the data maintained by them.'

I. What data would policy/ decision makers like to have access to that remains unavailable?

- ✓ **Data on children with disabilities**
- ✓ **Patients who visit the hospitals or VC for the second time**
- ✓ **Data from other organisations**

We currently do not ask the questionnaire to children and patients attending the VC or hospital for the second time. Programme managers and partners would like to have access to this data so they can plan their intervention better and make sure they do not miss out on children with disabilities or patients who developed a disability after their first visit. More information on the cause of disability will also be helpful when planning the intervention. They would also like to see data on disability from other organisation so they can compare it to their own data.

'We are missing children although it is something we have excluding now. But children are also coming to the facilities so it is something we need to think about in the future and maybe use a different questionnaire'

'It would be interesting if other organisation working with other types of disabilities see the same results. It is too early for now because other agencies are not using it.'

'We can also further explore the cause of disability. It is because the services are not good; patient can't follow up, not properly using the treatment. Once we know the reason we can plan the intervention better. To see how much of beneficiaries are actually disabled and how can we have more inclusive programme for eye health and other themes.'

J. How have policy/ decision makers integrated any aspect of this project in to other project over which they have control, including disability awareness and collecting data on disability?

- ✓ **Integration in awareness raising activities of other projects**
- ✓ **Too early to integrate but we are still sharing our experience**

The partner organisation AARAMBH who is running the VC and OC has incorporated some aspects of this project in other part of their work. They have sensitised their partners working in school so they can identify children and people with disabilities and inform them of the activities taking place. They are also sharing their experience of disability disaggregation during meeting with staff working on other project so they can identify how this initiative could be integrated and benefit other projects.

'We have other partners with us so we are integrating with other people [...]We are telling our partners working in schools that they need to identify people with disabilities and send them to us so they can beneficiate from our programmes'

'Working with school is very positive so when we have planning and staffs meeting people discuss their work there on other projects. All the project people also hear about the data disaggregation and are aware of the initiative and are taking disability seriously. They discuss how the data disaggregation project could benefit other projects and try to integrate the project. It is positive that all the projects people are more aware of disability'

'Since, there are provisions to undertake awareness programmes under Urban Eye Care Programme, the project staff take the opportunity to speak about disability and this project purpose among different target groups such as community, teachers and stakeholders.'

Sightsavers' programme managers and hospital staff both declared that it was too early to integrate disability disaggregation in other part of their work. They need to see more results before they do so. Nevertheless, they are talking about the process with partners so people know that this activity is taking place.

'We have not yet integrated in any other programmes as we are not sure if it is working or not. Let us see what the results are and then plan for integration.[...]Nevertheless we have already discussed this with partners whenever we go. It is just a discussion but we cannot share it unless we are sure about the data. Final sharing will be done once we have the final results.'

K. How have different partners collaborated on this project and what impact can they attribute to partnership working?

- ✓ **Challenging to work with two partners**
- ✓ **Communication is key and join review meeting are helpful**
- ✓ **Ownership is also a necessary condition**

This pilot involves two different partners who are implementing different parts of the project. AARAMBH is setting up the OC and VC whereas Sewa Sedan Hospital is managing the hospital. Sightsavers' staff reported that working with two different partners was initially a challenge. The fact that they are working on different projects and in different settings means that they face different kind of challenges. The project took off very quickly at the VC whereas there were more difficulties to get things started at the hospital.

'Working with one organisation is easy but we have two partners (hospital and development agency) working on different projects [...] There were challenges between these organisations in terms of coordination, understanding, planning etc. such challenges were resolved by bringing them together and holding coordination meetings thus strengthening the relationships for better results.'

'Initially AARAMBH was basically more into this project but slowly even the hospital is interested in looking at the result.'

Sightsavers' programme managers also reported that communication is a key factor in the success of this project. Communication between partners ensures better coordination of activities and as such review meeting were always held with both partners. This allowed them to exchange directly on the process, success and challenges. These meetings ensure that the partners work well together and that the project is successful.

'So far they have worked well together and we had a few meetings where we discussed coordination and how we can improve data collection. So I can say that now it is a good coordination between the two partners.'

'In the past, there has been a problem of coordination due to lack of planning and communication. Communication is important and they have to really communicate with each other and share their plans.'

Now both are doing well with good coordination. To have a better understanding, I always keep the review meeting for both the partners together’.

It is also crucial that partners have ownership of the project as they are ultimately the ones implementing the pilot. It is important that they collect information that is useful for them to guarantee quality. To ensure ownership, they are responsible for reviewing their own data, identify gaps and come up with solutions that can be shared during the review meetings.

‘Ownership is really important and for that I give them freedom to plan, monitor the data and suggest how they can improve the data quality. Ultimately after two years the programme will exit and the VC staff has to take up the work. They should have the feeling that it is their programme.’

‘This is condition [coordination] for the project to be successful because the ownership of the partners has to be there. If they are only collecting this information for Sightsavers it is not going to help us. The ownership is there they review their own data on a monthly basis, identify the gaps, try to fill the gaps. Otherwise the quality of data will not be good for using’

L. How can lessons learned from this project be captured to implement this work in other projects and to share with partners and other organisations?

- ✓ **Sensitisation and disability awareness is key**
- ✓ **Good planning is important**
- ✓ **Frequent meeting to ensure monitoring**
- ✓ **Sharing experiences and data with others**

Programme managers and partners all reported that sensitisation of staff is a necessary condition for this project to be successful. Staff needs to have a good understanding of the functional aspect of disability and receive proper training on the WG questionnaire. This goes against the argument that data collectors might not necessarily need to be trained to ask the questionnaire.

‘One definitely is that the functional aspect of disability is something we need to understand and make other understand’.

‘People involved in the project should also have proper training and necessary skills on disability related issues and WG questionnaire’

Integration of this extra component in a project requires good planning and monitoring. Processes and methods of data collection need to be well thought through including the adaptation of the tool. Close monitoring of the project is also necessary to see how things are progressing, what the challenges are and identify solutions. Frequent meetings and reports are a good way to ensure that everyone is up to date on the project.

‘My learning experience is that good planning is needed before starting any project [...]Process has to be systematic and we need to be very clear what do we want to achieve at the end. We need to focus on planning and the monitoring of the data. At the same time during every quarter review meeting within the MP Urban Staff, I make sure that we discuss the progress of the project. At the same time I have also asked the administrator to visit the hospital to support and guide the data entry person.’

Partners think it is important to share the experience of the data collectors with others as they are ultimately the ones collecting the data and using the WG questionnaire on a daily basis. Once further

analysis has been done, they want to share the data to show people that it is possible to collect good quality data on disability. They also want to use the data to prove it can be used to initiate changes.

'The first thing is looking at our data and the population reached, experience of the data collectors how we are collecting it, knowing that you can modify the questions. I will be happy to share my learning with other to learn.'

'We should share the data collected here in India with others so they can understand that it can be done and how and what change it can bring.'

'You also need to look at the data, analyse it and use it. Just collecting data will not bring any change.'

Staff collecting/ analysing the data

M. How do the staff collecting/ analysing the data understand disability and how can the training best orient them to the definition provided by the Washington Group?

- ✓ **They understand disability according to the functional definition**
- ✓ **Training should be more relevant to the context of disability in India**
- ✓ **Training needs to cover communication with patients**

Data collectors feel that training is vital to ensure accurate collection of data. They all agree that training gave them a better understanding of disability, based on the functional definition of disability. Moreover, it helped them understand the aim of this pilot and why it is important to collect this data.

Even though, the training provided them with a good knowledge of disability, it lacked information relevant to the context in which they operate. They reported that training should focus more on disability in India, including policy and legislation in place, the current situation at the hospital and VC and OC as well as existing services for referrals.

Training should also cover the communication around the questionnaire, including how to introduce the questionnaire to patients, deal with patients refusing to answer or giving inaccurate answers and what to do when patients report a disability. Tips on how they can provide relevant information to people with disabilities such as services available and government's schemes would also have been useful. They are trying to encourage people to go to relevant services for their disabilities but lack information of what is out there.

N. How does orientation on disability issues affect the way staff interact with project clients/ patients with disabilities or impairments?

- ✓ **Staff is more attentive to the needs to people with disabilities**
- ✓ **Staff provides people with disabilities with information on services available**

Staff reported that, before this project, they were not paying attention to people with disabilities. They even used to have pity for them but now they respect them more. After the sensitisation, they now understand the barriers people with disabilities face and give them special attention. For example the data collector at the hospital always ensures that people with disabilities have a seat, even if this means giving up his own. Similarly in the VC and OC they encourage people to go to appropriate services and refer them to relevant structures.

O. How do staff collecting / analysing the data understand the purpose of data disaggregated by disability and how can the training best orient them to understanding the importance of accurate data collection?

- ✓ **Staff understands why collection data is important**
- ✓ **Information on children is missing**
- ✓ **More practice as part of the training will guarantee better accuracy**

Data collectors understand that by collecting this data, they are able to know the number of people with disabilities accessing the services and the different types of disabilities. They believe that this data will ultimately improve services and their accessibility for people with disabilities. They also understand the difference between the WG questionnaire and the data that was collected as part of the national census. However they feel that we are missing information on children.

More practice as part of the training was recommended in order to ensure accurate data collection. Mock interviews will allow the data collectors to familiarise themselves with the questionnaire and identify early on potential challenges. These could then be discussed as part of the training.

P. How often do staff require refresher trainings or support to maintain high quality data collection?

Data collectors feel that more training is necessary and will allow them to share their experiences and challenges. They would like these sessions to take place every six months.

Q. How can the tools and processes currently used by staff to collect client data be best adapted to include disability data?

- ✓ **Recording the data is time consuming**
- ✓ **Current process does not ensure privacy**
- ✓ **Extra resources are necessary at the start**

Staff reported that it is more time consuming to record the data than ask the questions. In the VC and OC, the data is recorded in 3 different forms (1) Patient form (2) Register (3) Excel Spreadsheet. They all agree that keeping the patient form but only using the register or the computer will save time.

'Data recording is much more time consuming than asking the questions'

Staff also reported that it is difficult to ensure privacy, especially in a setting like the hospital. This is one of the reasons why they stopped asking the questions at the reception counter. However the questions are still asked in the waiting room where a lot of people are present. The VC have on average 30 patients a day so it is easier to guarantee confidentiality.

At the start of the project, programme managers reported that programme staff felt that this project was an extra burden and as such they were in a hurry to hire the extra resources. In the hospital, even though no extra resources were funded by the project, there is a dedicated person asking the questionnaire. In both cases, including the questionnaire in the HMIS or hospital's MIS has been identified as a potential solution.

'Initially when the project started, we had asked the VC staff to collect the information. They expressed that it was an extra work for them as they are already overloaded such as providing spectacles,

counselling, doing registration and then asking the WG questions. So we were in a hurry to appoint data collector who is trained to ask these questions.'

'Not adding burden on my workload because we have a separate person asking the questions supported by reception and paramedics'

R. How do the tools and guidelines developed specifically for this project fulfil their purpose and how could they be improved?

- ✓ **Current guidelines and tools are satisfactory**
- ✓ **More information for patients is needed**
- ✓ **Review the translation of the WG questionnaire to solve challenges identified in first 6 months.**

Staff feels that current guidance provided as part of the training was satisfactory. When it comes to the WG questions, they reported that the questionnaire covers a satisfactory range of disability. On a scale of 1 to 10 (1 meaning the data is completely inaccurate and 10 meaning the data is completely accurate) they ranked the questionnaire 8.2.

They feel that more guidance should be given to patients regarding the choice of answers as the difference between answers b (some difficulties) and c (a lot of difficulties) is ambiguous and people often ask for clarifications.

They also recommend the following:

- Introduction of the questionnaire to patients: Patients do not understand why they are asked questions about their health and why they should answer.
- Review of the translation: Sequencing of the questions on seeing and hearing was problematic in practice and the translation of the communication and self-care questions need to be reviewed as patients asked a lot of follow-up questions.
- Establish standardised examples that can be given to patient who have difficulties to understand the question to ensure consistency.

S. How does the appropriate technology, including hardware and software, impact on how staff are able to collect and analyse data?

- ✓ **Electronic data collection would be useful**
- ✓ **Electronic data collection would be challenging in busy environment**

They all agree that electronic data collection system would be beneficial, either by entering the data directly into the computer on Excel or using an HMIS. HMIS would especially be useful when it comes to analysing the data. However concerns were raised at the hospital and OC. It might be difficult to input the data directly into the system due to the high number of patients. This should not be a problem at the VC.

T. For data collectors based outside of health facilities: how do staff feel that community knowledge/ attitudes/ norms affect the collection of this data and do they experience more challenges in specific groups within communities?

Challenges reported at the OC were similar to other health facilities. However they reported a higher number of people struggling to understand the questions because of language barriers or age.

U. How have staff working on this project integrated any aspect of this project in to other work over which they have control, including disability awareness and collecting data on disability?

Staff working at AARAMBH reported participating in some awareness raising activities and talking to colleagues or volunteers about this initiative.

V. What are the experiences of staff in administering the extra questions to project clients, including the reaction of clients to being asked these questions and using the tools provided for the purpose?

- ✓ **Patients with disabilities are happy to be listened to**
- ✓ **Understanding of the questionnaire is dependent on the age and level of education of the patient**
- ✓ **Language is a barrier and proxy might be required for translation**
- ✓ **Patients do not understand why they are asked the questionnaire**

Partners and data collectors reported that they are enjoying working with the questionnaire as it allows them to identify people with disabilities and refer them to services they did not know about. Patients are keen to talk about the difficulties they face and feel taken care of. However, the questionnaire also raises expectations; patients are expecting to receive treatment if they report functional limitations. This is one of the reasons why the VC and OC started referring people to other facilities.

'We are enjoying working with the questionnaire and it is a part of the project that we running now so when we asking the questions patients feel like they are taking care of and that we are here to help them.'

Understanding of the questionnaire by patients is highly dependent on age. More explanations often need to be given to people over 50 years old who have hearing difficulties or need a bit more time to comprehend. This gets even more problematic with people over 70.

Difficulties were also reported with people who are illiterate or less educated. Data collectors have to adjust the questionnaire and provide additional explanations and examples. When this gets too challenging they seek the assistance of the person accompanying them and are usually able to get an answer.

Language can also be a barrier as some patients come from different states or regions and only speak local languages. Data collectors rely on the person accompanying them to assist. In the absence of third person, they try to use sign language.

Patients often seem confused about why they are asked questions about health when they are coming to receive eye care. It was reported that people often do not want to answer the questions because:

- They are in a hurry and feel like it is a waste of time because the registration process is taking too long already.
- They feel like the data collectors are making fun of them which results in them feeling upset, annoyed and refusing to respond.
- It is obvious whether or not they have a disability so they are confused and annoyed to be asked an obvious question.

- They feel uncomfortable being asked directly about disability when question 9 (national census) comes.

Data collectors agree that about 15% of people do not answer questions correctly. As they do not tell them why they are asking these questions, patients do not see the point and refuse to answer or rush their answers saying no to all questions. However, if they introduce the questionnaire and explain to them the objectives of the questionnaire it is very easy and quick to get good responses.

‘As we don’t tell them the objective of asking these questions, they try to avoid answering’

W. What extra burden does collecting the disability data place on the staff working with the data in terms of their time and taking them away from other duties?

- ✓ **Questionnaire takes less than 5 minutes when people do not ask questions**
- ✓ **Data collectors are getting quicker with practice**
- ✓ **When people ask questions it can take up to 15 minutes.**
- ✓ **Understanding is linked to age**

Data collectors reported that it takes between 5 and 15 minutes to ask the 9 questions to patients and this is highly depend on the level of understanding of the patient. They all agree that they are now quicker because they know the questions well and do not need to refer to the paper. As such, if a patient does not ask questions, it now takes them less than 5 minutes. To maximise time, data collectors in the VC and OC record the patient demographic information in the registry book at the same time than the OA does it in the patient form. It avoids asking patient the same information twice.

It can take more than 5 minutes when patients ask why they are being asked the questionnaire and data collectors have to give more background information. Moreover, the understanding of the patient seems to be linked to age. Patients aged 18 to 40 usually have no issues understanding the questions and answer straight away. For patient over 50, data collectors often have to repeat the questions, give further explanations or provide example. This process can therefore take up to 15 minutes. Other factors also increase the time required for the questionnaire, including literacy level of the patient, language and disability.

X. How accurately can the data be transferred through the information system from the point

Spot-checks of the data are carried out every month and focus on 1 day of data collected in each VC, OC and the hospital. The dates for each month are determined by the programme manager. This exercise considers both accuracy (no mistakes were made by the person transferring the data) and completeness (no data was left out by the person transferring the data.).

As the data collection process in the VC and OC involves 3 steps, spot-checks focus on the transfer of data between the patient form and the register as well as the transfer of data between the register and the Excel collation sheet. In the hospital only the later spot-check is carried out as data is not recorded on the patient form. At the time of the MTR, only VC and OC data were spot-checked. The first hospital spot-check was scheduled for April 2015.

Spot-checks mainly identified accuracy issues at the start of the project. Fewer errors are found now that the data collectors are used to the tools. We are expecting even fewer errors at the time of the evaluation.

General feedback from data analysis

The general analysis of the data revealed that out of the 11,718 data entry, 4 did not have information regarding the sex of the patient. Moreover, this questionnaire is designed for adults and out of the 635 children who came to the facilities, 10 were asked the questionnaire.

Spot-check at the VC

From December to March, 48 data entries were spot-checked in the two VC running, Results show some completeness and accuracy issues.

- **Completeness:** On one occasion, an answer to the WG questionnaire was not recorded in the patient form, only in the register.
- **Accuracy:** Dates and ages were not properly transferred to the register on two separate occasions. Discrepancy regarding sex was also identified once. Four answers to the WG questionnaire did not match, however these did not affect the answers which are relevant for the cut-off.

From October to March, 74 data entries were spot-checked in the two VC running, Results show some accuracy issues. Even though the questionnaire is only aimed at adults, one child was asked the WG questionnaire. Discrepancies were identified on three occasions for sex data and twice when it comes to age. Seven answers to the WG questionnaire were not properly recorded and one actually involved answers included in the cut-off.

PROJECT MANAGEMENT

UK office capacity

If the start of the project and especially the start-up workshops required a strong involvement of the staff based in Head Office, the implementation of the pilot was mainly done at CO level. The involvement of head office was limited to quarterly phone calls to review data, monitoring reports and update of action plan (about 10% of their time).

The MTR was carried out by the Monitoring Officer during a four day trip to Bhopal to meet with programme managers and partners and witness the process. Refresher training on disability and the WG questionnaire also took place. It was a good opportunity for data collectors to share their challenges and for the group to collectively decide how to address them. However, not all of the issues uncovered were resolved during the MTR and the involvement of Head Office was more important after the MTR with tasks such as:

- Data analysis of the past 6 months
- Drafting a spot-check guidance and form
- Creation of the data summary form
- Drafting of the MTR report.

Again, the involvement of head office is expected to go down until the evaluation as the implementation is mainly dealt with at CO level.

Country office and Partners buy-in and capacity

The pilot is very well managed by Sightsavers' CO and frequent meeting are taking place with the partners, data collectors and administrator to ensure that the project is on track. Both the programme

manager and country director have been visiting facilities to witness the data collection process. The CO is also keen to advocate with the government and promoted this initiative as part of World Sight Day.

Local partners are very involved in this project and are facing different challenges which they can share during the monthly meetings that take place at Sightsavers' office in Bhopal. All partners reported that they frequently look at the data and counsel their staff when needed. The feedback was really positive and they both agree that this pilot is useful for them.

Data collection staff buy-in and capacity

As part of the MTR, a one day workshop took place with data collectors on disability awareness and the WG questionnaire. Understanding of the functional definition of disability was still good after six months but a refresher proved useful for the new members of staff that were not present in June 2014 for the first workshop. Data collectors and community volunteers in India are still very enthusiastic. They all reported positive changes in their attitude towards people with disabilities.

Data collectors were really engaged during the workshop. They shared their challenges and came collectively with ways to address them. Data collectors and administrator presented their findings to the rest of the group. The CO staff was running the workshop in Hindi which led to better involvement and participation from the data collectors. This is in line with our findings in the baseline report where we recommended conducting future training in local languages.

During the workshop, the following changes were performed:

- 1) Add an introduction to the questionnaire to ensure that people understand why we are asking the questions and to ensure they give good and honest answers.
- 2) Review the sequencing of the question on seeing and hearing. Enquire first about whether they have spectacles and hearing aid and then ask whether they face difficulties in the relevant domain even with the assistive device.
- 3) Consistent examples should be provided for each question in case people have difficulties understanding the questions.
- 4) Review the translation of Q8 because currently it only focuses on the Hindi language instead of general communication.
- 5) Review the translation of Q5 as there is confusion between washing (bathing) and washing (laundry).

CONCLUSION

The MTR was a good opportunity to assess the progress of the pilot after six months and look for the first time at the data collected. It was an interesting insight on how data disaggregation works in practice and a chance to witness the process.

Interviews of policy/decision makers as well as focus group discussions with data collectors provided us with important information that will inform the implementation of this current pilot but also future projects. The discussions with partners and data collectors mainly focused on the challenges encountered during implementation and their experience of the WG questionnaire. The feedback from programme managers, partners and data collectors was overall positive. Even though, the process is challenging and increase their workload, the benefits of collecting the data were recognised by all.

As highlighted in this report, there is no single approach to data disaggregation and it is important to understand the context in which we operate and the existing tools before starting to collect data. As such, careful planning and monitoring are essential. This was highlighted as a necessary condition for the

success of the pilot by our programme manager. Flexibility is also important; the tool that we started using in September had to be adjusted to respond to existing challenges around the locations of services and communication with patients. All stakeholders involved in the project worked together to identify solutions to existing challenges and we were able to make some changes to the tool and process during the workshop.

During the first six months of the pilot, programme managers and partners focused on the process around data collection to ensure and guarantee the collection of quality and accurate data. Now that the approach has been refined, it will be interesting to look at the impact of the changes made during the MTR, the data itself and how they are going to use it.

NEXT STEPS

- Produce a Policy Brief describing Sightsavers' current position on the collection of data on disability from among our projects for better external dissemination.
- Prepare the evaluation of the pilot
- Review new project opportunities and future research questions.
- Plan phase 2 of the project focusing on inclusive eye health approach.

Appendices

Appendix 1. Evaluation Plan

To be answered by the pilot phase:

1. How can data disaggregated by disability be collected on a project level in a resource-efficient way that is useful to policy and decision makers?

To be answered by the disability disaggregation project:

2. How does the availability of project data disaggregated by disability impact on the accessibility of the project for people with disabilities?
3. How does the availability of project data disaggregated by disability impact programme design?

Main questions to be answered:

How can project data be disaggregated by disability be collected in a resource-efficient way that is useful to policy and decision makers?

1. How does the data collected from this project compare with existing data on disability available for the project data and what may explain differences?

Policy/ decision makers and project managers

- A. How do policy/ decision makers understand issues around accessibility of People with Disabilities to projects, and how do they see data as playing a role in accessibility?
- B. How useful is the definition of disability provided by the Washington Group to policy/ decision makers and how does it complement their own understanding of disability?
- C. What are the views of policy/ decision makers on the data currently available to them related to People with Disabilities and their access to projects, and how do they think it can be improved?
- D. What are the expectations of policy/ decision makers of a data collection system that disaggregates project data by disability and how do they envisage it impacting on their decisions/ work?
- E. What are the views of project managers on the sensitisation/ training provided to their staff and how do they perceive it has affected the way they conduct their work?
- F. How useful is the data provided by the data collection system to the work of policy/ decision makers and is it to the correct level of detail?
- G. How has the data collected to date been used in any way by policy/ decision makers?
- H. How does the appropriate data collection methodology and technology impact on the quality and timeliness of the data available to policy/ decision makers?
- I. What data would policy/ decision makers like to have access to that remains unavailable?
- J. How have policy/ decision makers integrated any aspect of this project in to other project over which they have control, including disability awareness and collecting data on disability?
- K. How have different partners collaborated on this project and what impact can they attribute to partnership working?
- L. How can lessons learned from this project be captured to implement this work in other projects and to share with partners and other organisations?

Staff collecting/ analysing the data

- M. How do the staff collecting/ analysing the data understand disability and how can the training best orient them to the definition provided by the Washington Group?
- N. How does orientation on disability issues affect the way staff interact with project clients/ patients with disabilities or impairments?

- O. How do staff collecting/ analysing the data understand the purpose of data disaggregated by disability and how can the training best orient them to understanding the importance of accurate data collection?
- P. How often do staff require refresher trainings or support to maintain high quality data collection?
- Q. How can the tools and processes currently used by staff to collect client data be best adapted to include disability data?
- R. How do the tools and guidelines developed specifically for this project fulfil their purpose and how could they be improved?
- S. How does the appropriate technology, including hardware and software, impact on how staff are able to collect and analyse data?
- T. For data collectors based outside of health facilities: how do staff feel that community knowledge/ attitudes/ norms affect the collection of this data and do they experience more challenges in specific groups within communities?
- U. How have staff working on this project integrated any aspect of this project in to other work over which they have control, including disability awareness and collecting data on disability?
- V. What are the experiences of staff in administering the extra questions to project clients, including the reaction of clients to being asked these questions and using the tools provided for the purpose?
- W. What extra burden does collecting the disability data place on the staff working with the data in terms of their time and taking them away from other duties?
- X. How accurately can the data be transferred through the information system from the point it is collected from the client, to the final version received by policy/ decision makers?

Project clients providing the data

- Y. How do project clients comprehend the questions as they are asked to them?
- Z. How do project clients feel about being asked these questions?
- AA. How do project clients understand the reasons for the data being collected?

Methods for collecting the data

Question	Data collection method	When	Who
1. How does the data collected from this project compare with existing data on disability available for the project data and what may explain the differences?	Project data collected using the agreed designed/ adapted tools. Census data as publically available online.	In quarterly reports.	Project staff as agreed in the monitoring plan.
A. How do policy/ decision makers understand issues around accessibility of People with Disabilities to projects, and how do they see data as playing a role in accessibility?	In-depth interviews with policy/ decision makers involved in the project. This should include people who were involved in designing and managing the project as well as anyone who looks at or uses the project data that is produced. This work should include: <ul style="list-style-type: none"> • Mapping the key stakeholders • Developing an interview guide that can be used to ensure the questions are covered in detail • Conducting the interviews with a tape recorder if possible • Transcribing/ translating the interviews • Analyse the interviews for themes and patterns. Depending on the number of interviews this could be done by hand or using a software package. • Following up with some stakeholders at key points 	At the beginning and end of the project	This will require one or possibly two people to conduct the interviews, plus support with transcription/ translating. It is likely the interviewers would want to be involved in data analysis.
B. How useful is the definition of disability provided by the Washington Group to policy/ decision makers and how does it complement their own understanding of disability?		At the beginning and end of the project	
C. What are the views of policy/ decision makers on the data currently available to them related to People with Disabilities and their access to projects, and how do they think it can be improved?		At the beginning of the project only	
D. What are the expectations of policy/ decision makers of a data collection system that disaggregates project data by disability and how do they envisage it impacting on their decisions/ work?		At the beginning of the project only	
E. What are the views of project managers on the sensitisation/ training provided to their staff and how do they perceive it has affected the way they conduct their work?		Halfway through the project	
F. How useful is the data provided by the data collection system to the work of policy/ decision makers and is it to the correct level of detail?		Halfway through and at the end of the project	

Question	Data collection method	When	Who
G. How has the data collected to date been used in any way by policy/ decision makers?	throughout the project including after they have received a first set of data disaggregated by disability and at the end to see how their expectations and views change and how the data is meeting their needs.	Halfway through and at the end of the project	
H. How does the appropriate data collection methodology and technology impact on the quality and timeliness of the data available to policy/ decision makers?		Halfway through and at the end of the project	
I. What data would policy/ decision makers like to have access to that remains unavailable?		Halfway through and at the end of the project	
J. How have policy/ decision makers integrated any aspect of this project in to other project over which they have control, including disability awareness and collecting data on disability?		Halfway through and at the end of the project	
K. How have different partners collaborated on this project and what impact can they attribute to partnership working?		Halfway through and at the end of the project	
L. How can lessons learned from this project be captured to implement this work in other projects and to share with partners and other organisations?		Halfway through and at the end of the project	
M. How do the staff collecting/ analysing the data understand disability and how can the training best orient them to the definition provided by the Washington Group?	Staff who will be involved in collecting and analysing the disability disaggregated data will participate in focus group discussions. <ul style="list-style-type: none"> • These will be small groups of 5-8 peers who are likely to feel comfortable talking in front of each other; • There will be an interview guide developed for the interviewer to guide the discussion to ensure the groups cover all important questions; • They should be recorded, 	To be discussed on a quarterly basis	This will require one or possibly two people to conduct the interviews, plus support with transcription/ translating. It is likely the interviewers would want to be involved in data analysis.
N. How does orientation on disability issues affect the way staff interact with project clients/ patients with disabilities or impairments?			
O. How do staff collecting/ analysing the data understand the purpose of data disaggregated by disability and how can the training best orient them to understanding the importance of accurate data collection?			
P. How often do staff require refresher trainings or support to maintain high quality data collection?			

Question	Data collection method	When	Who
<p>Q. How can the tools and processes currently used by staff to collect client data be best adapted to include disability data?</p> <p>R. How do the tools and guidelines developed specifically for this project fulfil their purpose and how could they be improved?</p> <p>S. How does the appropriate technology, including hardware and software, impact on how staff are able to collect and analyse data?</p> <p>T. For data collectors based outside of health facilities: how do staff feel that community knowledge/ attitudes/ norms affect the collection of this data and do they experience more challenges in specific groups within communities?</p> <p>U. How have staff working on this project integrated any aspect of this project in to other work over which they have control, including disability awareness and collecting data on disability?</p>	<p>transcribed and translated;</p> <ul style="list-style-type: none"> • They will be analysed for themes and patterns. Depending on the number of groups this could be done by hand or using a software package. • At least some of the groups should be repeated at the end of the project to investigate how expectations and understandings have changed and how the project can be improved. 		
<p>V. What are the experiences of staff in administering the extra questions to project clients, including the reaction of clients to being asked these questions and using the tools provided for the purpose?</p> <p>W. What extra burden does collecting the disability data place on the staff working with the data in terms of their time and taking them away from other duties?</p>	<p>Staff administering the questions plus those involved in maintaining the data can maintain regular 'diaries' or their experiences with collecting the data. They should be encouraged to record their experiences of explaining to the clients and asking them questions, recording the data and the extra time it takes them to gather this data in addition to their other duties. The diaries will be collected by project staff on a regular basis, collated and analysed for themes, possibly using a software package.</p>	<p>This should happen throughout the project and the diaries should be collected at monthly meetings</p>	<p>This will require one person to collect the diaries, collate the information and analyse the data contained.</p>

Question	Data collection method	When	Who
X. How accurately can the data be transferred through the information system from the point it is collected from the client, to the final version received by policy/ decision makers?	This can be checked through auditing a sample of the data collected. By choosing one or two indicators presented to decision makers, the numbers can be traced back through the data management system to original records. Discrepancies at each stage should be noted and remedial actions should be sought.	This could happen sporadically on a sample of data - with one or two indicators being audited every quarter.	This will require a detail orientated person to choose the indicators, trace them back and record discrepancies and note remedial actions.
Y. How do project clients comprehend the questions as they are asked to them? Z. How do project clients feel about being asked these questions? AA. How do project clients understand the reasons for the data being collected?	A very brief survey of a sample of clients leaving the vision centres/ mobile services. <ul style="list-style-type: none"> • The surveys should be developed to be very brief and easy to understand. It can include quantitative close ended questions and some open ended questions if required. • Not every client has to be asked – every second or third client leaving over one day could be asked. • The clients should be asked if they mind sparing 5 minutes to answer questions about their visit today. • The surveys could be recorded on paper or straight on to a laptop data base if it is possible to take that to the location. • The data can be analysed using appropriate software. 	Quarterly at each location	One person to collect the data. Depending on how it is collected, they may require support to input the data to a computer and analyse the data.



Outputs

An initial report can describe the baseline understandings and expectations of the stakeholders and data collection staff at the beginning of the project.

Half way through a second report can summarise any data collected at that point, problems with quality gathered from the data audit, staff experiences from the diary collection, client experiences per surveys conducted at that point, plus and reactions from the stakeholders to any data they may have received at that point.

A final report should provide summary of the first two reports plus further updates on data, quality, experiences of staff and clients, plus further stakeholders and staff interviews and focus groups. This report should also include a summary of how the MP Urban Slum Eye care Programme and the organisations involved plan to progress with collecting data disaggregated by disability. It should make recommendations to other project managers interested in collecting similar data to how their projects can be best designed.

Appendix 2. English version of the WG questionnaire (revised version following the MTR)

We would like to get some health related information from you. The information given by you would be very helpful for us in improving our services.

1. Do you use or wear spectacles?

a. Yes -1

b. No -2

(If yes, then ask the question number 2)

(If No, then you may ask the question number 3)

2. Do you have difficulty in seeing, even after using the spectacle ?

a. No- no difficulty -1

b. Yes – some difficulty -2

c. Yes – a lot of difficulty -3

d. Cannot do at all -4

3. Do you have difficulty in seeing ?

a. No- no difficulty -1

b. Yes – some difficulty -2

c. Yes – a lot of difficulty -3

d. Cannot do at all -4

4. Do you have difficulty in hearing?

a. No- no difficulty -1

b. Yes – some difficulty -2

c. Yes – a lot of difficulty -3

d. Cannot do at all -4

5. Do you use a hearing aid ?

a. Yes -1

b. No -2

6. Do you have difficulty in walking or climbing steps? (For example pain in the knees)

a. No- no difficulty -1

b. Yes – some difficulty -2

c. Yes – a lot of difficulty -3

d. Cannot do at all -4

7. Do you have difficulty in remembering or concentrating? (For example -while doing any work, you are unable to concentrate or you kept things in some place and next day you are unable to remember)

- a. No – no difficulty -1
- b. Yes – some difficulty -2
- c. Yes – a lot of difficulty -3
- d. Cannot do at all -4

8. Do you have difficulty in taking care of yourself (for example taking a bath or dressing etc) ?

- a. No – no difficulty -1
- b. Yes – some difficulty -2
- c. Yes – a lot of difficulty -3
- d. Cannot do at all -4

9. Do you face difficulty in understanding or making others understand while communicating in your usual language ?

- a. No – no difficulty -1
- b. Yes – some difficulty -2
- c. Yes – a lot of difficulty -3
- d. Cannot do at all-4

10. Are you mentally/physically disabled ?

- a. Yes -1
- b. No -