



# Diabetic Retinopathy / Diabetes Mellitus Service Delivery and Integration into the Health System in Pakistan: A Qualitative Study

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## List of Abbreviations

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AIEH	Al-Ibrahim Trust Eye Hospital
DM	Diabetic Mellitus
DR	Diabetic Retinopathy
FGD	Focus Group Discussion
FHF	Fred Hollow Foundation
GP	General Physician
HFH	Holy Family Hospital
HMIS	Hospital Management Information System
HOD	Head of Department
IAPB	International Agency for the Prevention of Blindness
IDF	International Diabetic Federation
IDI	In-depth Interview
IEC	Information, Education and Communication
IOL	Intra-Ocular Lens
KPI	Key Performance Indicators
KEMC	King Edward Medical College University
LHW	Lady Health Workers
MO	Medical officer
MT	Medical Technician
MTR	Mid-Term Review Report
NDSP	National Diabetic Survey of Pakistan
NSTDR	Non-Sight Threatening Diabetic Retinopathy
OPD	Outpatient Department
OT	Ophthalmic Technician
PHC	Primary Health Care
PPIU	Provincial Program Implementing Unit
DHQ	District Head Quarter
DPIU	District Program Implementation Unit
SCB:	Standard Chartered Bank
SiB	Seeing is Believing
STDR	Sight Threatening Diabetic Retinopathy

# Executive Summary

## Background and objectives

The National Diabetic Survey carried out in Pakistan in 2016-2017 estimated an overall age-adjusted prevalence of Diabetes Mellitus (DM) in adults of 26.3 per cent. Diabetic retinopathy (DR) is a common complication of DM that requires early diagnosis, routine monitoring and treatment to control. Since 2014, Sightsavers has been implementing a five-year programme designed to strengthen the response to DR in three districts of Karachi, Lahore and Rawalpindi. The project supported the provision of equipment, related infrastructural investments and the training of human resources needed to provide integrated DR services in the catchment districts.

This study aimed to explore the experiences of the delivery and integration of DM/DR services at the three tertiary level facilities participating in the project.

## Methods

This report presents findings from a qualitative study carried out during the first quarter of 2019 with 144 participants, including patients, health care staff, project managers and lady health workers. Data were collected through 37 individual in-depth interviews and 14 focus group discussions. Data were analysed thematically using the NVIVO software. Ethics approvals have been granted by the research and ethics committees in the three study locations.

## Summary of key findings

The experiences of patients and healthcare staff provide interesting insights into the ways in which DR services are organised and delivered in these settings. Our findings show that at present, there are a number of ways through which patients with suspected diabetes access diagnostic and treatment services in Pakistan: lady health workers (LHWs) and general physicians (GPs) at the community level; GPs, medical officers (MOs) and medical technicians at secondary hospitals; and outpatient department (OPD) clinics at tertiary hospitals. However, the majority of patients attending DM/DR facilities at present appear to be self-referrals at both the multi-speciality hospitals and the eye hospital, despite the fact that seeking care is not an immediate priority in many patients' lives and many people delay consultations with formal healthcare providers.

Among primary care providers referring patients with diabetes, clinical staff, such as GPs or medical officers, were reported to be more effective than community-based lady health workers. DM/DR clinic healthcare workers reported that the majority of people referred to DR services by LHWs did not attend the clinic. Some community members felt that LHWs were not very knowledgeable about complex matters, such as eye diseases, so taking action based on LHWs' advice and referral slips was not very common. In addition, LHWs are not monitored and not required to report on eye related diseases by their local departments of

health and did not consider DM/DR referrals as a priority in the package of services they delivered. Also, LHWs had limited interactions with the male members of the community, which affected the uptake of screening by men.

Several barriers to uptake of referrals and treatment were identified in this study. This included poverty and associated financial constraints, long waiting time at public sector hospitals for some people, the lack of public transportation, overcrowded and overburdened health facilities, and cultural norms restricting women's travel outside their community.

One important observation made in this study is that the private hospital with less overcrowded facilities, less overworked staff and more conveniently arranged services provided on one site, was perceived to be of high quality and the patients reported high levels of satisfaction with the care they received there. On the other hand, the two government hospitals with large numbers of patients, long queues, inconveniently located services and uncomfortable premises were a deterrent of hospital visits, even though most patients appreciated the free care and the professionalism of staff in these facilities. The findings clearly show that many patients associate good quality care with cleanliness of premises, convenient location and positive attitudes of staff.

Additional initiatives introduced by the project, such as counselling, a patient tracking system with automated reminders of the appointments and interdepartmental linkages within the hospitals, proved to be effective and were appreciated by both healthcare providers and diabetes patients. It is important that the project facilities find ways to sustain these services beyond the life of the project.

## Conclusions

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The study sought to build understanding of the pathways for referral and treatment of DM/DR and the organisation of service delivery at three large tertiary hospitals in Pakistan. It also explored the factors enabling or hindering adherence to referrals and treatment follow-up in these settings. The study has a number of programme implications regarding training and support systems for LHWs, the nature and role of counselling; and the approaches needed to enhance women's access to DM/DR services. The results of this study also call for finding the models of care, which are responsive to the needs of diabetes patients, i.e. delivered through smaller and less overburdened facilities, closer to patients' home and with more convenient opening times. Mobile services and innovative technologies should be considered as part of these alternative models of care. Monitoring systems should be adapted to ensure inclusion of diabetes, DR and other vision care issues.

# 1. Introduction

## 1.1. Diabetes Mellitus and its complications

Globally, an estimated 415 million people are living with diabetes mellitus (DM) [1]. More than 70 per cent of them are in low and middle-income countries (LMICs).

The National Diabetic Survey carried out in Pakistan in 2016-2017 estimated an overall age-adjusted prevalence of diabetes among adults aged 20 years and above to be 26.3 per cent. Only nineteen percent of these cases were aware of their diagnoses, meaning four out of every five people with DM in Pakistan are unaware. Prevalence of diabetes was high in both urban (28.3 per cent) and rural (25.3 per cent) areas. Geographically, the highest prevalence of diabetes was reported in Sindh province (32.3%) followed by Baluchistan (29.5 per cent), Punjab (13.2 per cent) and Khyber Pakhtunkhwa (13.2 per cent)[2].

If untreated and uncontrolled, diabetes can lead to many health complications including diabetic retinopathy (DR), sight threatening DR (STDR) and ultimately blindness. Population-based studies conducted in Pakistan suggest that approximately 25 per cent of people with diabetes have DR and 10 per cent progress to STDR [3]. Patients with advanced retinopathy require immediate interventions. DR screening has been recommended by the International Agency for Prevention of Blindness (IAPB), as an entry point for prevention of vision loss and blindness among people with diabetes.

## 1.2. Diabetes Mellitus/Diabetic Retinopathy project

Sightsavers has been working in Pakistan since 1985 to reduce avoidable blindness caused by different eye threatening conditions, including DR. To date, Sightsavers has supported vision screening for millions of Pakistanis and more than 800,000 surgical interventions aiming at restoring vision.

In collaboration with partners, Sightsavers is implementing a project focused on strengthening the country's response to DR operating out of a tertiary hospital in each of the three districts of Karachi, Lahore and Rawalpindi. The three health facilities are located in the urban areas, but they are different in terms of organisation and delivery of services.

### Karachi

In Karachi, the project is based at Al-Ibrahim Trust Eye Hospital (AIEH) – a specialised private health facility. From screening to treatment, all DR services are provided on the same floor at this hospital. The diagnostic laboratory and pharmacy services are also available in the same premises. The health facility has spacious waiting areas. Patients with other conditions like gynaecology or cardiology are referred to another hospital located in an adjacent building.

## Lahore

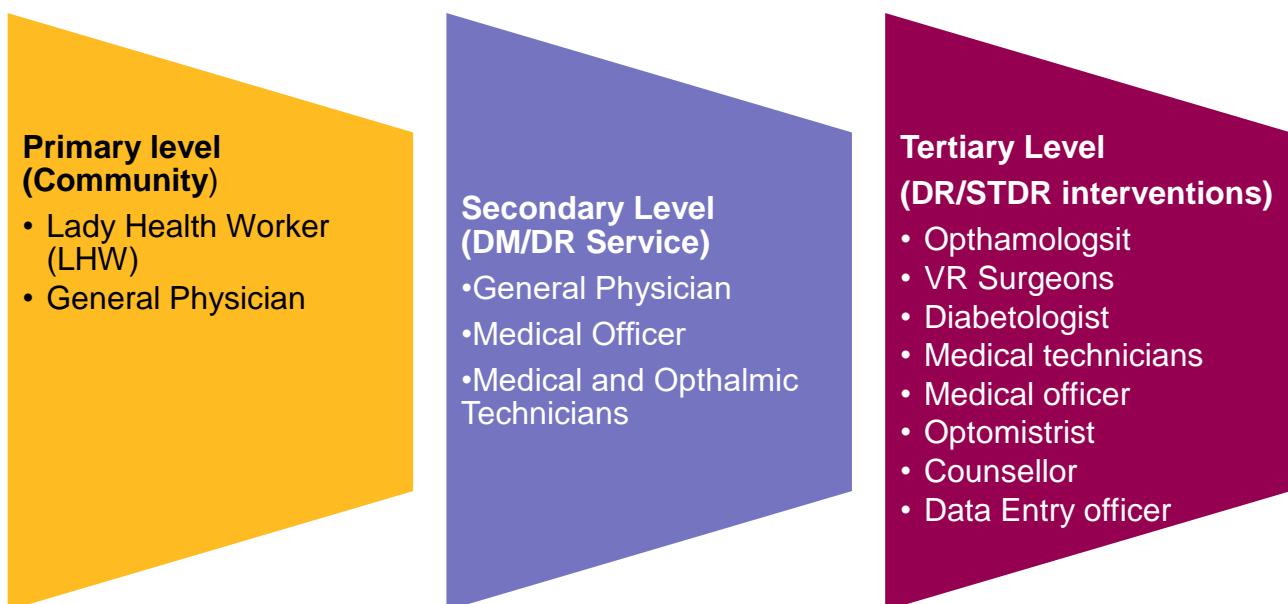
In Lahore, the project is based at Mayo hospital – a leading public sector hospital in Punjab province. The hospital is also a teaching hospital for the King Edward Medical College (KEMC), a prominent medical University in Pakistan. All professors and senior surgeons of the College are associated with the hospital. This is a very large hospital with many departments and facilities. The hospital tends to be busy and overcrowded most of the time. Screening for DR is conducted at the Outpatient Department (OPD) of the hospital. The screened DR patients are referred to the eye department for management. The eye department is located at about one kilometre from the OPD.

## Rawalpindi

In Rawalpindi, the project is based at the Holy Family Hospital (HFH) – one of the three public sector hospitals in the district. It is located in the centre of the city and provides a wide range of health services to patients from Rawalpindi and neighbouring towns. This is another very busy hospital which tends to be overcrowded most of the time. DM and DR services are available in the same building – on the ground floor of the building with accessible pathways. The waiting area is spacious with good seating arrangements.

This five-year project is funded by Standard Chartered Bank through the Seeing is Believing (SiB) initiative. The main goal of the project is to strengthen and integrate service delivery to reduce avoidable blindness due to DR and STDR. The project set out to strengthen inter- and intra-departmental linkages and referral mechanisms between DM and DR services at three different levels of the health system (see **Figure 1** below). The services were linked to provide regular screening for early detection of DR and follow up with medical or surgical interventions.

**Figure 1: DM/DR service delivery model**



Pakistan has a relatively large primary health care infrastructure. As of 2017, this included approximately 5,000 basic health units, 600 rural health centres, 7500 other first-level care facilities staffed with general physicians (GPs) and over 100,000 lady health workers (LHWs), providing services across the country [4]. LHWs are recruited from within the community and act as a bridge between the community and the formal health system. The LHWs initiative was specifically established to address the healthcare needs of women and people residing in rural communities by providing essential primary health care (PHC) services. These primary health care services are supported by a network of more than 980 hospitals at community, district and provincial levels.

To date, the DM/DR project supported by Sightsavers has trained more than 3,800 LHWs and 100 GPs working in the project catchment areas to support referrals and compliance with referrals for DM and DR. The training modules have been reviewed and approved by the national committee for eye health. The trained LHWs and GPs were also provided with Information, Education and Communication (IEC) materials to support community education and awareness about DM/DR and STDR. At the secondary level, 30 medical technicians (MTs) have been trained on DM/DR. At the tertiary level, the project has supported the training of four ophthalmologists for laser treatment and two ophthalmologists for vitreo-retinal surgical skills to carry out surgical interventions at the two public sector hospitals.

The project has also procured eye care equipment for two participating public sector hospitals and one private hospital to strengthen these facilities' ability to provide quality services to patients diagnosed with DM/DR.

Treatment adherence for patients has been enhanced through counsellors operating at the tertiary level who support patients and their families to follow their individual treatment plans. In addition, the project developed a patient tracking system to help record patient data in a systematic manner and support automated follow up reminder messages to patients' cell phones and project teams' emails.

### **1.3. Research objectives**

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This study was designed to explore the experiences of the delivery and integration of DM/DR services at the three tertiary level facilities participating in the project. The study had the following specific objectives:

1. To understand and describe the patient referral and treatment pathways at each of the three delivery sites.
2. To explore and understand patient and staff experiences of the applied models of care and their integration with other healthcare providers.
3. To explore how LHWs perceived their role regarding DM/DR and primary eye care generally, and how well equipped they were to implement their role.

## **2. Methodology**

### **2.1. Study design and research questions**

The study used a qualitative design utilising focus group discussions (FGDs) and in-depth interviews (IDIs), as data collection approaches. FGDs were conducted with patients and LHWs from project areas. IDIs were carried out with health professionals at both secondary and tertiary facilities, project staff, patients, LHWs and their supervisors. FGDs generated a range of themes, which were further explored during IDIs.

The topic guides used in the study centred around patients', health care providers', and managers' views on the DM/DR project, organisation of services, patient referral and treatment pathways, health provider roles, attitudes and patient relationships, with the aim to better understand how the project supported the integration of DM/DR care into the broader health system at different levels.

### **2.2. Sampling and recruitment**

To capture a range of experiences, the study sought to recruit a diverse group of participants: women and men, people of different ages, patients, health professionals, managers and other stakeholders. The hospital database was used to identify patients with different characteristics and different treatment adherence patterns. Based on a simple database stratification, 98 patients (52 women and 46 men) were purposefully selected for 11 individual in-depth interviews and 11 focus group discussions. Purposive sampling was also used to select 21 health professionals and managers and 25 other stakeholders for 26 individual in-depth interviews and three focus group discussions.

### **2.3. Data collection, management and analysis**

In-depth interviews and focus group discussions took place during the first quarter of 2019 and were completed by two interviewers (one female and one male) in Urdu or Punjabi languages. They lasted between 30 and 90 minutes. The interviewers were trained social scientists who were independent of the project.

Most interviews and FGDs were audio-recorded and later transcribed, translated into English, and coded by the data analysis team consisting of the two interviewers and two study co-investigators. A few participants however did not feel comfortable being recorded so during interviews with them, notes were taken. NVIVO software version 12 was used for data coding and analysis.

After reading the first batch of transcripts, the analysis team collaboratively developed a codebook, which was tested with the next batch of transcripts, discussed and adjusted. All the remaining transcripts were then coded by two senior social scientists using the final version of the codebook. Interactive discussions were held within the team to validate data interpretation and resolve any discrepancies. A list of themes and sub-themes was reviewed and finalised for the presentation in this report.

## **2.4. Ethical considerations**

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The study protocol was reviewed and approved by the research and ethics committees (RECs) in the three study provinces: the Institutional Review Board (IRB) of Isra Postgraduate Institute of Ophthalmology Karachi (protocol #: A-00088), the IRB of the College of Ophthalmology and Allied Visual Sciences at Mayo Hospital, Lahore (ref #: COAVS/73/19) and the IRB of the Rawalpindi Medical College (ref #: R.73/RMU). All participants were informed about the purpose of the study, had an opportunity to ask questions and provided informed written consent.

## 3. Findings

The findings are presented in a number of themes and sub-themes that emerged from the analysis of the transcripts.

### 3.1. Participant characteristics

A total of 144 participants were interviewed in this study.

**Patients:** Among 98 patients, 41 were female. The age ranged from 40 to 73 years with the majority of patients being under 60 years. Five patients were single, and the rest were married. Most patients had been aware of their diabetes diagnosis for two to eight years, with the longest period being 20 years. Nearly three-quarters of the patients interviewed had no work due to diabetes complications or additional reasons and were dependent on others for their livelihoods. A few were engaged in small-scale businesses and trades and only four were in formal salaried employment.

**Lady Health Workers:** Twenty LHWs agreed to participate in the study, all of whom reported a minimum of 10 years of formal education. Their median age was 38 years (range 26–56 years); LHWs from Karachi were younger than those from Lahore or Rawalpindi. Most had been working as LHWs for three to 10 years; a few had been in the role for more than 15 years. About 79 per cent of the LHWs were married.

**Health professionals, managers and other stakeholders:** Among other participants, 10 were eye care specialists, nine were clinicians from other clinical departments like diabetes and gynaecology, and four of these were in senior leadership positions at their hospitals. We also interviewed two programme counsellors (one female and one male); two project personnel with clinical backgrounds and three behavioural/social science specialists.

### 3.2. Emerging themes

This section explores issues related to teachers' knowledge about eye health and vision screening, including their selection, training and support once in post after the training.

#### 3.2.1. Patient care and referral pathways

There were multiple channels of patient referrals to the DM/DR facilities reported in the study. First, at the community level, LHWs and general physicians referred suspected diabetic cases for DM/ DR screening. Screening for DR was only reported to be available at tertiary health facilities usually located in the provincial centres.

Another source of referrals was from GPs, medical officers (MOs) and medical technicians working in hospitals in the project areas. These personnel were mobilised and trained by the project to identify and refer diabetic patients they came across.

The third source of referrals was through endocrinology, medicine departments or OPD clinics of public sector hospitals.

The referral route which brought in the highest number of patients for DM/DR screening at the specialised eye hospital (AIEH), was the walk-in patients (self-referrals or by word of mouth) and internal referrals at the two public sector hospitals.

Most patients referred by GPs, MOs or MTs took up their referrals to the DM/DR units. Among patients referred by LHWs, only few took up the referrals. Patients referred by GPs, MOs and MTs said that their consultations with the clinical staff at the primary and secondary levels were the reason they went to the hospital as a matter of urgency. According to some patients, health care personnel explained the potential health complications of diabetes and addressed their questions much better than the LHWs; the latter were not perceived to be very knowledgeable and well prepared to consult about the DM/DR screening.

“They [LHWs] don’t do their duty like it should be done. There are women that are old, ill, and not educated. LHWs should tell about health practices, and I think this is the duty of LHWs... but they don’t do their work the way it is supposed to be done.”. **[Male patient, 50 years, Rawalpindi]**

Irrespective of gender, patients referred by LHWs tended to consult other healthcare workers at the community or district level for ‘a more professional opinion’ before making a trip to the DM/DR facility. In some instances, patients had to consult a provider in a nearby public hospital, followed by a consultation in a private facility before they eventually decided to travel to the DM/DR units. The explanation given for these multiple consultations was mistrust of government health facilities and the quality of services they provide. When patients would eventually turn up at the DM/DR facility, they would present a referral slip issued by a public or private health facility they consulted and not the one initially issued by the LHW.

The number of patients taking up referrals also varied across the three participating hospitals. For example, the private hospital in Karachi reported receiving a large number of patients, many without any referral slips. This is a large and well-known specialist eye hospital, which has an arrangement to make subsidies for patients who cannot afford to pay the entire cost of the treatment. Most patients interviewed praised this facility for the subsidy arrangement and the high quality of services.

On the other hand, the number of people taking up referrals or walking into the public hospital in Rawalpindi was relatively small. This was attributed to the presence of many other welfare eye hospitals in Rawalpindi, which also provided good inexpensive healthcare services. The health care workers interviewed at this project facility told us that they saw few referred patients and more walk-in patients from the areas outside the project catchment areas.

Mayo Hospital in Lahore, like in Rawalpindi, is a public sector tertiary facility surrounded by several other public and charity hospitals. Healthcare workers at this facility also reported a low uptake of referrals, some participants reported it as low as 10 per cent.

“If we look closely then we might come across that less than 10 per cent of people reported” **[Project manager, Mayo Hospital, Lahore]**.

## **3.2.2. Organisation of services at the hospitals**

The project was designed to link diabetic retinopathy screening and treatment services with already existing diabetic clinics at the participating hospitals. The services at these facilities included screening for diabetes, grading of severity of diabetes, eye examinations, testing visual acuity, refraction and fundus imaging of retina to diagnose the nature and stages of DR. The three participating hospitals were different in their approaches to the delivery of these services.

### **3.2.2.1. ‘One window’ set-up at the private sector hospital**

The DM/DR facility in Karachi was set up to deliver services as a ‘one window’ service. All services from screening to treatment are provided on the same floor at this facility.

Consultation rooms for different healthcare professionals are adjacent in line with the steps followed in the treatment protocol. Each health care specialist sits in a separate room and patients move from one room to the next to get the services. The laboratory and pharmacy rooms are also situated close by.

The facility has spacious waiting areas with organised seating arrangements. When patients arrive at the front desk, their data are entered in the hospital information management system in real time. The same data is later entered in the project online database, which is linked to the system for tracking follow up treatments. A registration slip with a code number is issued to the patients for their identity. Then the patients sit and wait for their turn in the waiting area.

While patients are waiting for their turn, they are consulted by the programme counsellor, who organises group sessions to talk about potential complications of DM, its management and lifestyle changes. This was the counsellor’s own initiative and patients interviewed in the study highly commended her for these efforts.

As part of the behaviour change communication (BCC) activities, IEC materials such as posters about diabetes and eye health were developed and are displayed in the waiting areas so that patients could get more information about diabetes, its management and its impact on vision.

Patients come with different stages of DM. Patients with high glucose level are referred to a dialectician for management. All patients with confirmed DM are screened for DR. Diabetic patients with significant retinopathy (STDR) requiring intervention, are referred to an ophthalmologist. Patients found not to have DR are advised to come back for the follow up checks on bi-annual or annual basis as appropriate. The follow-up date is recorded in the patient’s file and database. This is used in generating patient reminders and tracking follow ups in the database.

Patients felt that the organisation of service delivery in this hospital was time and cost efficient because different types of examinations and tests are carried out in a short span of time and the laboratory results are often available on the same day. Beds and food at the facility are free or subsidised depending on the financial circumstances of individual patients.

At the end of every day when patients leave the hospital, the registration clerk at the facility cross checks that they have not missed any rooms or steps to ensure complete information is available for follow ups.

### **3.2.2.2. Public sector health facilities**

Mayo Hospital is a large compound with several speciality departments (including the eye care department) located in different buildings, at a distance from one another. Screening for DM/DR at this facility is organised in the outpatient department (OPD), which provides services to a variety of patients with different conditions.

Healthcare workers and patients interviewed complained about the crowded OPD facilities with more than 100 patients attending every day. The corridors at the facility are narrow, making the movement of elderly patients and wheelchair users challenging. The seating arrangements at the facility are not adequate to accommodate large numbers of patients.

Patients with suspected STDR are referred to the eye department for management, which is located about one kilometre away from the OPD in the same compound. Some patients reported difficulties in walking such a distance and some decided not to go to the eye department, as prescribed. The distance was reported to be particularly challenging for patients with severe diabetes, elderly people and people with disabilities.

At the other public sector facility in Rawalpindi, the DM/DR screening rooms are spacious and are on the ground floor. Similar to the private hospital in Karachi, the DM/DR screening and treatment services are available in the same building. The patients reported that the elevator and ramps available at this facility made access to services easier. There are separate wards for male and female patients to ensure comfort and privacy in all facilities. The wards were reported to be reasonably clean and equipped with basic equipment for everyday care. Beds and food are provided free to the patients admitted in the wards.

At both public hospitals however, diabetic patients reported that the washrooms, which they frequently required, were located far away. It was also reported that the washrooms were not clean and usually crowded. Despite these challenges at the facilities, several study participants reported that they were happy with the services they had received - that their vision was cared for and they had fewer eye related problems.

Patients praised the professionalism of health care providers at the government hospitals. Many patients complained about overcrowding and dirty facilities but acknowledged that the doctors at these government hospitals were very experienced, knowledgeable and skilful. They reported that prior to the surgery, the healthcare staff had carefully monitored their condition. Patients' sugar level and blood pressure were also monitored. It was reported that the doctors would not carry out any surgical interventions until the patient was physically stable and psychologically ready for the treatment.

### **3.2.3. Utility of the patient tracking system**

There were differences in opinions about the use of the patient information systems at the project facilities. At Mayo hospital for example, some participants indicated that they did have a functional data management system, while others said that the system was not in place. Study participants pointed to a large number of patients reporting to the hospital on a daily basis, but there was no meaningful medical record system to allow for an easy entry and access to their information by different health care providers.

The private facility in Karachi on the other hand, has had a strong and functional health information system since the 1990s. Their rich database holds more than 2 million patient records. The DM/DR project team has been granted access and is using this database for data management and learning.

At all three project facilities, the project set up a patient tracking system. The system is linked with the hospital databases and is used to generate lists of patients scheduled for follow up two days before their appointment. The system was reported to be useful in sending reminders to the patient mobile phones.

“Yes, we do have a system for calling back. This system generates message reminders when six months or one year follow ups are due. These follow up messages are generated based on the dates entered in the computer. The counsellor receives this ... on his email ... a day before the due date. He calls ... to remind them [patients] about the follow up. Or WhatsApp messages are sent. He [the counsellor] has to make these calls from the list on a daily basis”. **[Healthcare worker, Mayo Hospital, Lahore]**

Patients reported that the messages or phone call reminders were very helpful to ensure the visit to the hospital on the scheduled date. Female patients found them particularly helpful, as they needed to make multiple arrangements before their visit, get permission from their husband, organise childcare and find transport and a companion.

“This [follow up calls] is a good thing, and in case the husbands are strict and don’t let their wives out, then one can call the husband’s number again and again and send them text messages. Only then, the husbands get worried that the doctor is calling them and there has to be a serious case for it. Otherwise, they think that their wives do it intentionally just to wander about in the hospital or somewhere else or to avoid work.” **[Female patient, 40 years, Rawalpindi].**

Patients waiting for surgeries were also reminded to report to the health facility using the tracking system. Ophthalmologists praised this tracking system and said it was critical for early detection of diabetes complications and prevention of DR and STDR.

### 3.2.4. Managing patient flow

At the community level, the referral slips were issued in different noticeable colours. This was supposed to facilitate an easy identification of the source of the referral and differentiate community referral slips from the hospital registration slips. Front office staff at the DM/DR facilities were made aware of the differences. They were further asked to facilitate smooth access of the referred patients to the consultations and their movements between different rooms and departments. Similar agreements were made with other support staff, for example gatekeepers.

At the private hospital, the number of counters was increased from one to two, to manage the increased number of DM referrals. Thanks to the additional counter, patients did not have to wait long to get their registration. To avoid long waiting times this hospital also decided to limit the number of patients served daily to 50. There were no reported cases of staff refusal to attend to patients beyond 50.

Similar arrangements were not possible at the two public hospitals. Due to the large number of patients and limited number of eye doctors and other health professionals at the public hospitals, the quality of care at these facilities was thought to be suboptimal. The facilities were thought to be busy, overcrowded and did not have any special rooms or staff to attend to elderly patients or patients with disabilities. However, when asked about the interactions between patients and healthcare staff at these hospitals, many patients reported that they felt comfortable to communicate their problems. Some could even discuss their financial constraints in getting the treatment and received discounted rates or treatment free of charge.

“Only last day [yesterday] they told ... me 6500 rupees will be charged. But I pleaded to them that I am a poor man. Then they gave me a slip, it was filled with the reduced fee and I deposited 4000 rupees.” **[Male patient, 65 years, Karachi]**

### 3.2.5. The role of counsellors

Counsellors deployed in the project facilities are trained in behavioural or social sciences and are an integral part of the DM/DR project teams. Their role is to raise awareness and guide and counsel patients about potential complications of uncontrolled diabetes. They provide counselling based on the severity of diabetes and DR grading. They work to motivate patients to follow the prescribed treatment to save their vision and avoid blindness. IEC materials are also disseminated and explained to the patients by the counsellors. Counsellors also work with patients to adjust personal diets, behaviours and lifestyles.

At the two public facilities, the counsellors are placed in the DM clinics. At these two hospitals, they share a room and work closely with the screening staff. The counsellor at the private hospital in Karachi has a separate room to ensure patient privacy. All patient data, including investigations, prescriptions and retina images are available to her in the computer. The counsellors working at the public facilities do not have access to such information.

In addition to the automated messages being sent on patients' phones, counsellors at all three project facilities make phone calls to patients to remind them about their follow up visits. They engage and try to convince some reluctant patients to attend their scheduled visits. The role of the counsellor was acknowledged and highly appreciated by the patients interviewed. The patients also said that the counsellors were their key contacts in seeking help in their day-to-day management of diabetes and eye related problems.

### 3.2.6. Lady health workers and their working environment

LHWs are recruited from within the communities they serve and do get a monthly salary from the government. Their role is to visit households to collect health data, such as children's weight, provide some basic interventions and raise awareness of health services and disease control programmes. They work closely with the communities to ensure that people can come forward with their health-related issues.

The relationship is particularly strong with women in the community. Most female patients interviewed in this study said they could openly discuss their personal health issues and family matters with the LHWs and seek their advice. When referring to LHWs, women used the names ‘Baji’ or ‘aunty’, which means ‘elder sister’.

LHWs address the issues they encounter in the community either by themselves or through the referrals to public sector facilities. One issue raised by the LHWs interviewed in this study was a need for better coordination of their work with other NGO programmes that work to improve population health.

In addition to visiting households, LHWs conduct monthly sensitisation sessions to create awareness about health and hygiene in the communities. They also conduct health education sessions in schools. Some sessions are organised specifically for men. A few LHWs interviewed in this study, argued that the uptake of health services by women and children could only be improved if men were engaged and understood their health issues. LHWs also work with religious scholars, administrative councillors and other influential people in the community to raise their awareness, change attitudes and gain their support.

LHWs interviewed in this study reported that they focused primarily on health issues monitored by the government and those required in their monthly reports. They keep records of various data and referrals made from the communities. However, they also noted that the health department was not interested in the eye health related data, including DR, and did not issue them with the referral slips related to eye care.

The arrangement with the project was that LHWs refer known diabetic patients to the project hospitals or to other health facilities with DR screening services in the local area, as appropriate. The LHWs interviewed said that their role in eye care could be improved but only if eye health was included in the 'priority list' of the Department of Health, and if they were required to report eye health indicators on a monthly basis.

Male patients interviewed in the study also discussed their limited engagement with LHWs and LHWs' focus on specific health issues, such as polio immunisation campaigns. They argued that men learnt about LHW activities only through their spouses or other female family members. Almost all male patients interviewed were referred to the DM/ DR facilities by GPs or medical officers (MOs), or were walk ins. Male diabetes respondents stressed that it was very important for LHWs to engage with men and particularly male elders, making them aware of diabetes complications, as many people in the community listened to them.

"LHWs do visit for administering polio drops, but they have never enquired about any other things.... No, not a single time. They have not checked our sugar ... They only visit our homes to administer polio vaccine and ask ... how many people live here."

**[Male patient, 68 years, Rawalpindi]**

Most LHWs interviewed in the study reported that the training they had received from the DM/DR project was helpful in identifying, guiding and referring patients suspected of suffering with diabetes and/or eye diseases. They also said that prior to the training, they had been unaware of the importance of the levels of sugar for diabetic care or eye related complications. They also highlighted a need for refresher courses on DM/DR.

The healthcare professionals interviewed in the study were confident that if appropriately trained, LHWs could play a critical role in early identification of DM and in prevention of DM complications, including DR. The critical aspect of their role from eye care professionals' perspective, was encouraging patients to seek care early enough and to adhere to treatment. They however pointed out that careful considerations should be given to the LHWs' workload and support system.

Several participants raised concerns about the lack of visible eye health promotion campaigns in the media, in contrast to the campaigns that were organised for polio, dengue fever or relating to reproductive health. Many respondents reasoned that the cause may be a lack of sufficient government support to integrate eye health into the primary healthcare programmes, at the national level.

LHWs also mentioned the numerous challenges they faced with patient referrals. For example, many patients referred by the LHWs thought that they would be seen in the hospital immediately without queues. When the patients found out that it was not possible, they were disappointed and upon returning to their communities, would spread negative rumours about the project there.

*"I had this man and another woman who visited the hospital. I sent them and [they] came back to the community at night without seeing a doctor. They said to me and other people in the community that our slip had no value, that it was a waste of time and money to go there and line up for the whole day, and no doctor sees you"*

**[LHW, Karachi]**

LHWs further highlighted that there was a considerable gap in their training curriculum about DM/DR. LHWs did not have adequate information about the referral pathways and the ways tertiary facilities were working. This left them in the situations where they could not provide the right information or answer patients' questions. It was only during the household visits that the LHWs come to learn of what some patients were going through when visiting the hospitals. Some patients told them that they were reluctant to go back to the DM/DR units, because there were too many patients on the OPD days or because of the way the patients were treated. When such things happened, LHWs tried to engage with the project staff and find solutions. The Lahore team for example advised LHWs to refer patients on specific days, when the facilities were less crowded.

Other challenges mentioned by LHWs included shortages of referral slips and an overburden of other duties and priorities. Some also said that given that LHWs were carrying scales to weigh babies, some patients wanted them to have the necessary equipment for measuring blood pressure and glucose levels.

### **3.2.7. Availability and cost of medicines**

One of the main reasons many patients visited public sector hospitals was the availability of free medicines at these facilities. However very often, these hospitals experienced stock-outs. Patients reported that doctors would prescribe medicine at the hospital and ask the patient to go and buy it from the market outside the hospital. The medicines at the private pharmacies were reported to be very expensive and the prices varied from place to place, raising patients' concerns about the quality of cheaper medicines. Many patients also perceived that the free medicines provided at the public hospitals were of poor quality and less effective, compared to the medicines available in private hospitals and pharmacies.

For insulin dependent patients registered with government facilities, the Punjab government provided insulin free of charge. Patients interviewed at Mayo Hospital in Lahore confirmed that they received insulin from the hospital. Eye health medicines were also supposed to be provided at the public hospitals in Lahore and Rawalpindi. However, due to high numbers of patients attending eye departments in these hospitals, they reported frequent stock-outs and subsequently could not provide medicines to all patients. Most patients from public hospitals participating in the study, reported that they had to buy medicines from private pharmacies, as in many instances the medicines were not available in the hospitals.

"We do have good quality medicines. However, the problem is that all the medicines are distributed as we have high turnout of patients and in that case, they [patients] have to buy them from the market". **[Doctor, Mayo Hospital, Lahore]**

Both patients and healthcare staff reported that surgeries in public sector hospitals in project locations, were provided free of charge. Surgical kits and eye lenses were available for free for 'qualifying patients.' Those patients who could afford buying a surgical kit or lens, were asked to buy them from the private pharmacies, so that the more 'qualifying patients' could be subsidised or receive free eye care treatment.

The hospital in Karachi had its own pharmacy within the hospital premises. All types of medicines related to diabetes and eye diseases are available to hospital patients at discounted prices, cheaper than in private pharmacies. The glucometer and diabetic strips to test the blood sugar level are also highly discounted for the convenience of the DM patients.

### **3.2.8. Challenges in the delivery of DM/DR care**

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#### **3.2.8.1. Financial constraints**

Poverty was reported to be one of the major factors affecting individual lifestyles and health seeking behaviour of people in the studied communities. The majority of patients interviewed in the study were not working. For many, other basic needs, such as shelter, food, education, were of higher priority than health. Many families had only one or two breadwinners for a household of six to eight members, and the costs of meeting the basic household needs accounted for a major share of the available income. In such families, individual health needs were not an immediate priority. Many people reported buying medicines from pharmacies outside the hospital on an ad-hoc basis and many used homemade and herbal remedies. Most patients, irrespective of their age and sex, delayed consulting health professionals unless the problem got out of control.

"We are a poor family. My son drives a rickshaw and when he has time and money, he brings me [to the hospital], if the pain becomes unbearable." **[Female patient, 60 years, Rawalpindi].**

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### **3.2.8.2. Long waiting times at hospitals**

Patients reported that visiting hospitals was time consuming. Long queues and waiting times were reported to be significant barriers to follow up visits and uptake of referrals. Those who were working could not take a full day to visit the hospital. Hospitals were reported to be overcrowded, there were long queues first to register and then, to consult a doctor. For most patients it took the entire day to visit the hospital and come back home. In addition, waiting long hours was painful for patients with advanced diabetes. Some respondents reported that several patients known to the staff managing the patients' inflow, could bypass the queues, which was very frustrating. In some instances, when the hospitals were too full and the working day was over, patients were asked to leave without seeing a doctor and told to come back the next day.

Some clinical procedures, such as dilation of the pupil, can also be time consuming. To address this challenge and speed up the examination process, the project bought more advanced eye screening technology, such as a non-mydriatic camera, which does not require the dilation of the pupil.

### **3.2.8.3. Gendered decision-making**

Female patients were reported to have additional barriers, as they were required to get permission from their husband to visit the hospital; they also needed someone to accompany them. In the words of two female patients:

“In our community, females cannot move alone. I do not want to come with anyone other than my son or daughter in law. This was the reason for the delay” **[Female patient, 70 years, Karachi]**

“I don’t have a permission to go out without a … family member”. **[Female patient, 56 years, Lahore]**

### **3.2.8.4. Travel and transportation**

Challenges with the availability of public transport were also reported to be a major barrier to the uptake of referrals. For example, it was reported that the public transport that directly reaches the project DM/DR unit in Karachi is not available. Many patients have to change buses two to three times to reach the facility. The trip is particularly challenging for old people and those with advanced diabetes. The costs of private taxis are too high, and the majority of patients cannot afford them.

In Lahore and Rawalpindi, the project facilities are located in the middle of the cities. However, busy roads and the lack of public transport was also reported to be a barrier for some patients in these cities.

### **3.2.8.5. Overcrowded and overburdened health facilities**

As mentioned above, busy and overcrowded facilities with large numbers of patients and overburdened staff, were reported to be a significant discouraging factor undermining the uptake of referrals and follow up by many patients. The problem was mainly reported in the two public facilities participating in the project.

Most patients referred by the LHWs were reluctant to visit government facilities because they were overcrowded and overstretched. Patients had to wait for hours for registration and check-ups, which was very difficult for patients with pain, high blood pressure, fluctuating sugar levels, frequent urination and swelling of feet.

Doctors and other medical staff in these facilities were reported to be short of time; they were rushed and could not spend sufficient time with patients. This is how one doctor from Lahore described his busy schedule:

“... we have cases of orbit, ... tuberculosis, patients with glaucoma, squint ... we see kids, adults, elderly .... If today I start seeing diabetes patients, I will have lots and lots of patients with diabetes alone. Every day we are doing 12-13 VR surgeries, every day .... Here we see a lot of patients with a range of diseases”. **[Doctor, Mayo Hospital, Lahore]**

Some patients said that they preferred visiting community GPs, who were available in the evenings and could check their blood pressure and sugar level at a small fee. Many said they were dreading trips to the tertiary facilities and visited them only when the situation was ‘getting out of control’.

### **3.2.8.6. Lack of awareness and information**

Most patients interviewed in this study were aware of the effects of diabetes on their daily routine and wellbeing. They were also aware of the effects of diabetes on feet, heart or kidneys. Patients seemed to be less aware of the impact of diabetes on eyes and vision. Even those who were reasonably well educated, for example retired government employees, did not seem to be aware of eye related complications of diabetes. Some of the referred patients said that they had been told about the effect of diabetes on vision by LHWs.

### **3.2.9. Inter-departmental linkages and opportunities for integration**

The DM/DR project team developed and strengthened linkages with other clinical departments at the participating hospitals. These linkages were thought to be important for addressing other diabetes complications, for example neuropathy or gestational diabetes in pregnant women.

The DM/DR project team reached out and engaged with the heads of other departments through meetings and visits. Some patients argued that these relationships helped them to access a comprehensive package of services in one hospital, saving trips to multiple hospitals or private laboratories for various tests. The patient referral system was reported to work both ways, patients from the DM/DR unit were referred to other services, while patients visiting other departments were referred to the DM/DR facility.

"I am not aware of the system the hospital was following earlier... Now, every department is aware, they have information. They keep referring their patients. We keep on sending them biannual reminding letters through our heads." **[Manager, Mayo Hospital, Lahore]**

The project team also sent DM/DR specific IEC materials to other departments in the hospitals. This helped to ensure that other hospital departments had the necessary information and referred their patients.

"...we go to different departments and give them diet charts and retinopathy charts. It was a reminder for the doctors; and when distributed among patients, many come to consult". **[Counsellor, Mayo Hospital, Lahore]**

This collaborative way of working between the departments also strengthened the hospital leadership, improved the use of real-time hospital data and facilitated cross-departmental research and learning.

"... as a result of this closer working, we recently had a few research projects.... One ... is on the topic 'Diabetic retinopathy and pregnant women" **[Doctor, Al-Ibrahim Trust Eye Hospital, Karachi].**

## 4. Discussion

This study explored the experiences of strengthening the DM/DR services in three tertiary facilities in Pakistan, as well as the levels of integration of these services with the primary and community healthcare systems. The study focused on both patient and provider perspectives.

The findings are broadly consistent with earlier literature on the uptake of referrals and adherence to treatment in low- and middle-income settings<sup>[5-8]</sup>. Some common barriers, such as overcrowded facilities, long waiting times, user fees and the lack of transport, are well known and have been repeatedly reported in many similar contexts<sup>[9-12]</sup>. However, this study also provides some additional interesting insights into how these common challenges manifest and are either exacerbated or mitigated by different care delivery models.

Our findings on the referral pathways show that at present, there are a number of ways through which patients with suspected diabetes access diagnostic and treatment services in Pakistan. The majority of patients appear to be self-referrals, although it was also clear from our findings that seeking care is not an immediate priority in patients' lives and many people delay consultations with formal healthcare providers. In this study we did not analyse data on walk-in patients to assess whether those showing up at the facilities differed somehow, e.g. have better education, or have more advanced stages of the disease. Such analysis will be necessary in the future to make more definitive conclusions on the drivers of health seeking behaviour of walk in patients.

Among primary care providers referring patients with diabetes, clinical staff, such as GPs or medical officers, appear to be more effective than community-based lady health workers. Our findings show that there are a number of reasons for this and that the training of LHWs on DM/DR alone is not sufficient to increase the number of referrals from the community. First, neither the LHWs themselves, nor their supervisors at the local health departments see eye care as a priority in their intervention package. LHWs are neither monitored nor required to report on DM/DR or any other eye conditions<sup>[13, 14]</sup>. Second, the LHW initiative was put in place to provide basic community-level health services to women and children<sup>[15]</sup> – so expanding their scope of work and mandating them to mobilise patients for eye care, creates an additional workload and must be balanced with their other responsibilities. In addition, LHWs may not be particularly effective in communications with and referrals of male patients, as traditionally, men have not been their primary target group. LHWs appear to be more effective in engaging with women. However, as our findings suggest, many women in Pakistan are not the decision makers regarding their health seeking behaviour. To be able to travel to a distant facility, they need permission from their husband and must be accompanied by someone from their community. Therefore, LHWs' engagement with men is critical for the uptake of referrals by both men and women, but this may require additional training and changes to their original set of responsibilities.

Further, some community members felt that LHWs were not very knowledgeable about the "complex matters pertaining to the eyes", so taking action based on LHWs' advice and referral slips was not very common. Also, it appears that some members of the community assumed that a referral from a LHW entitled them to a faster service at the tertiary facility, which led to patients' frustration when they realised that was not the case. It is not clear what

the source of this misinformation is, but as suggested by the LHWs themselves, their training curriculum requires revisions to include more detailed information on both diabetes and the way the tertiary facilities worked.

Given that LHWs are an integral part of community healthcare in Pakistan<sup>[16]</sup>, it is possible that they can play a more significant role in diabetes care, including education of patients, referrals and adherence to treatment and follow up. However, to make their role more effective, more system level changes are required. Diabetes care, including eye care, should be part of their scope of work; they should be adequately trained, supervised and monitored on the delivery of DM/DR activities, including changes in their accountabilities and reporting systems. This should of course be balanced with their existing responsibilities and workload to avoid them becoming overburdened.

Similar to earlier studies<sup>[17, 18]</sup>, this research showed that patients' decisions on the uptake of DM/DR referrals and treatments, are influenced by a range of social and health system factors. Poverty and financial constraints for example, were shown to be an important barrier to seeking care when experiencing health problems and to taking up treatment, when a treatment is prescribed. Although all three facilities participating in this project had provisions for poorer patients through user fee exemptions or subsidised fees, direct costs of medicines and indirect costs of transport or time off work, were challenging for many patients and prevented them from the referral uptake. Existing literature from other settings highlight a variety of strategies people adopt when delaying seeking care<sup>[19, 20]</sup>. In this study, participants reported using medical stores, home treatments and herbal remedies as their first points of care. It may be useful to explore how these existing local opportunities can be better used in health education and behaviour change communication<sup>[21]</sup>. These community-based alternatives may not be particularly effective in diagnosis and treatment of DR and STDR, but they may help in influencing patient diet and lifestyles, which are essential for prevention of both diabetes and its health complications.

This project involved both public and private sector providers and showed the differences in their delivery models. We also explored how these different delivery models impacted on patients' perceptions of services and subsequently referral and treatment uptake, although it is important to note that we did not measure the uptake of referrals or treatments in these three hospitals in any objective way. A detailed analysis of the project database will be necessary to make more definitive conclusions on the differences reported during the interviews.

One important observation made in this study is that the private hospital with less overcrowded facilities, less overworked staff and more conveniently arranged services provided on one site, was perceived to be of higher quality and the patients seemed to be more happy about the care they received there. On the other hand, the two government hospitals with large numbers of patients, long queues, inconveniently located services and uncomfortable premises were a deterrent of hospital visits, even though most patients appreciated the free care and the professionalism of staff in these facilities. Study findings clearly show that smaller and more convenient health facilities, located closer to patient homes and open at convenient times, are likely to increase the uptake of referrals and follow ups. In this study for example, some patients preferred to visit their GPs for blood pressure and glucose level measurements, even though they had to pay for these services. The

finding is in line with other research in Pakistan and elsewhere, which shows that many patients associate good quality care with cleanliness of premises, convenient location and opening times and positive attitudes of staff. Opportunities for developing screening and treatment services for DM/DR in smaller, more conveniently located facilities needs to be explored. The use of mobile facilities and technologies should also be explored to facilitate this alternative care.

Counselling for DM/DR patients at both tertiary and secondary health facilities was shown to be important and should not be neglected. It is important that the project facilities find ways to sustain these services beyond the life of the project. Such counselling sessions should also consider patients' personal circumstances and social context. Our study for example found that women were highly dependent on their husbands not only for financial resources, but also for permission to travel and consult a doctor. Counselling sessions should therefore not only target the patients but also the key decision-makers of their households.

Another important initiative of this project was a patient tracking database, which helped to monitor patients' referrals and follow ups in a more systematic way and supported the automated reminders of the appointments sent to patients' mobile phones. The system was thought to be effective from both patient and provider perspectives and it is important that the project hospitals find a way to maintain it beyond the life of the project.

The cross-departmental linkages and collaboration established by the project in the three participating hospitals were thought to be beneficial for both patients and healthcare staff. The linkages ensured continuity of care and improved institutional governance and coordination. The hospital with closer linkages reported more positive experiences than those with looser integration, where services were provided in various parts of the larger campus. Literature suggests that the institutional changes of this nature become sustainable when they are fully integrated within the organisational culture, structures and processes [22]. An assessment of cross-departmental linkages and referral systems after the project, will be beneficial to better understand to which extent the three project facilities managed to sustain the benefits they gained.

In conclusion, the project made significant efforts to improve the response to the growing threat of diabetic retinopathy in Pakistan. It built health system capacities to identify, refer and treat patients at risk of DR and STDR at the primary, secondary and tertiary health levels. It demonstrated strengths and weaknesses of different patient referral pathways and different care delivery models. The results of this study point to the need for finding the models of care which are responsive to the needs of diabetes patients, i.e. delivered through smaller and less overburdened facilities, closer to patients' home and have more convenient opening times. Mobile services and innovative technologies should be considered as part of these alternative models of care. There is also a need for strengthening links with the community providers, such as lady health workers. In order to make the services of LHWs more effective, several systemic changes, including their remit of work, training, supervision and reporting, will be required. These changes however should be considered carefully, taking into account their current responsibilities and workloads.

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