



Preventing blindness due to Diabetic Retinopathy in India: Need for a paradigm shift

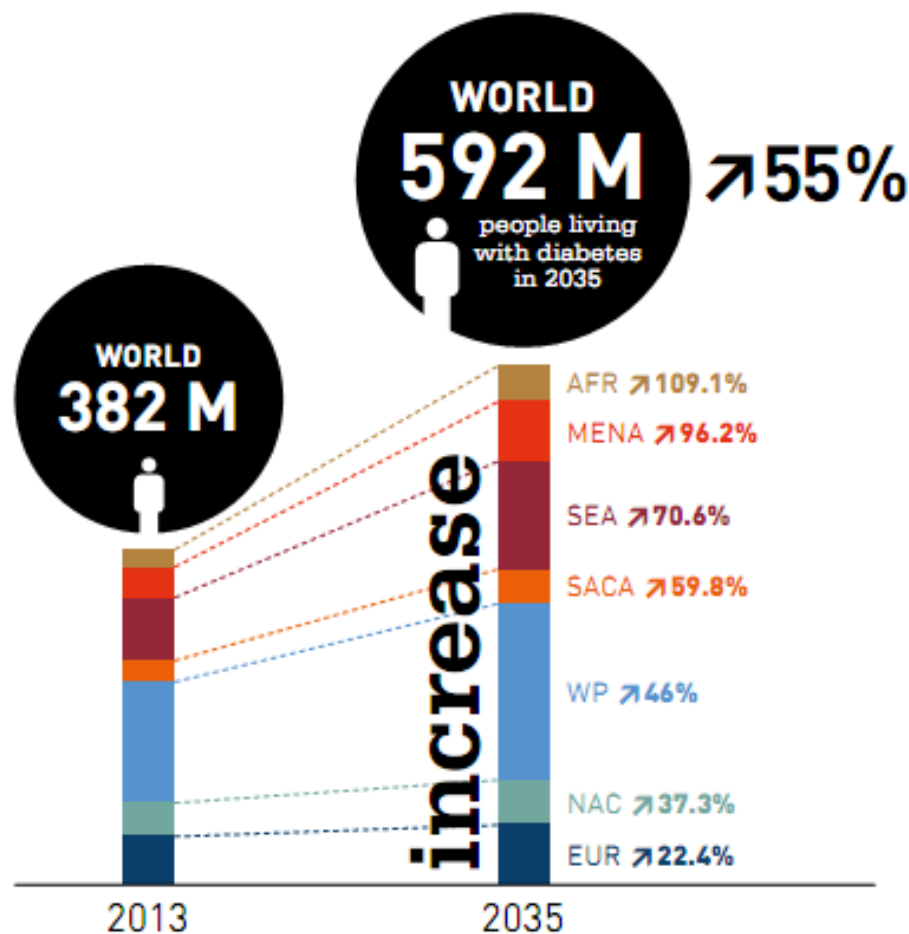
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Global trends in diabetes

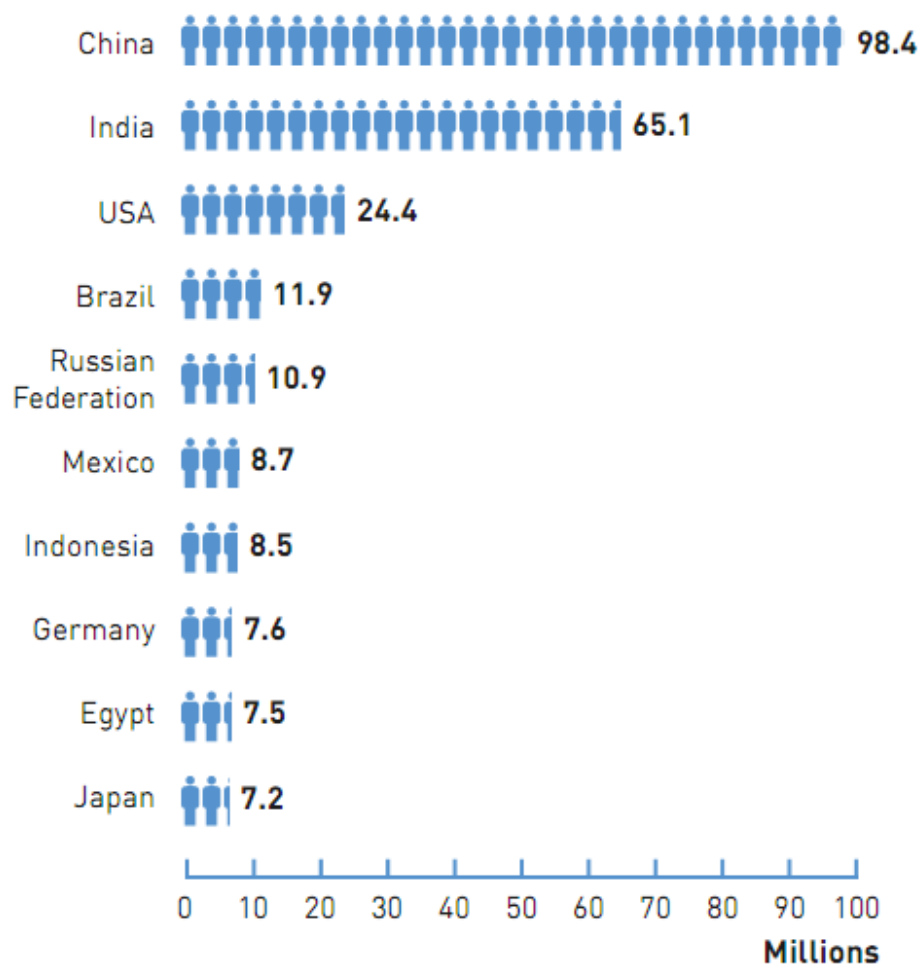
- 382 million adult diabetics globally (2013)
- 175 million (50%) were undetected.
- By 2030 projected to increase to 592 million (1.5 times increase)
- 8.3% of adults have diabetes
- 80% in low and middle income countries
- Highest increases in low and middle income countries
- Population affected: working age group- 40-59 years are the largest group affected

Magnitude of Diabetes Mellitus



IDF Diabetes Atlas 2013

Top 10 countries/territories of number of people with diabetes (20-79 years), 2013



Almost **half** of all people with diabetes live in just **three** countries

China
India
USA

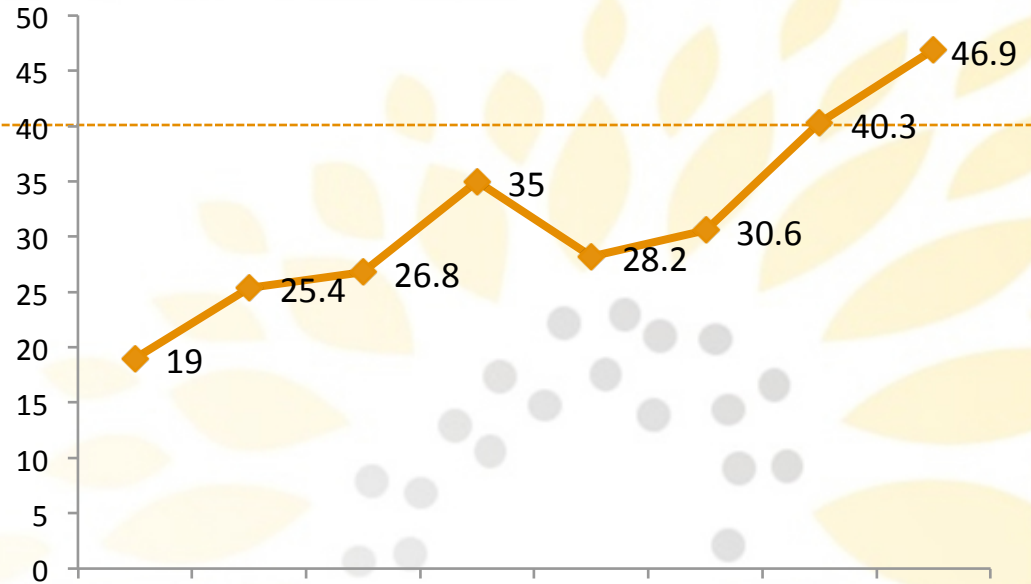
Pooled Global Estimates of DR

- Pooled prevalence estimates standardized to 2010 population aged 20-79 years.
- 35 population-based studies (1980-2008) reviewed (22,896 diabetic individuals)
- Overall prevalence of:
 - 34.6% [95% CI: 34.5-34.8] for any DR
 - 6.96% [95% CI: 6.87-7.04] for PDR
 - 6.81% [95% CI: 6.74-6.89] Diabetic Macular edema
 - 10.2%[10.1-10.3] for Vis Threat DR (VTDR)
- Estimated 93 mil with DR; 17 mil with PDR; 21 mil with diabetic macular edema; 28 mil with VTDR

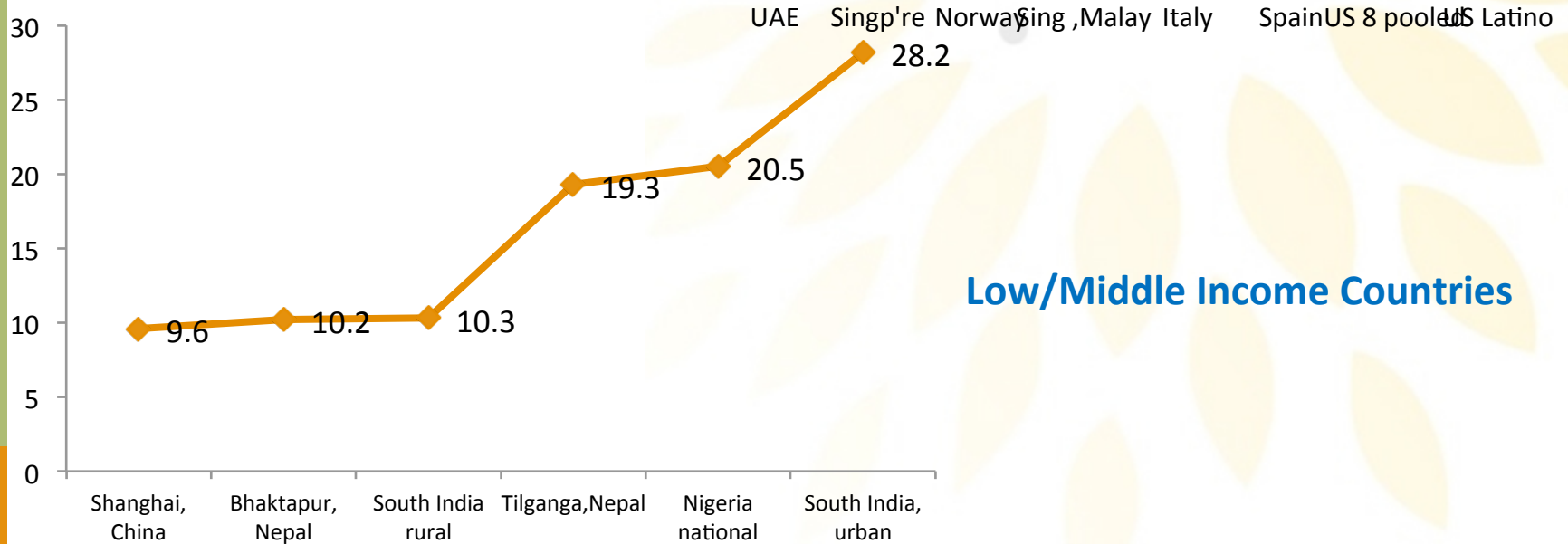
Prevalence of DR Among Known Diabetics 40+ years %)



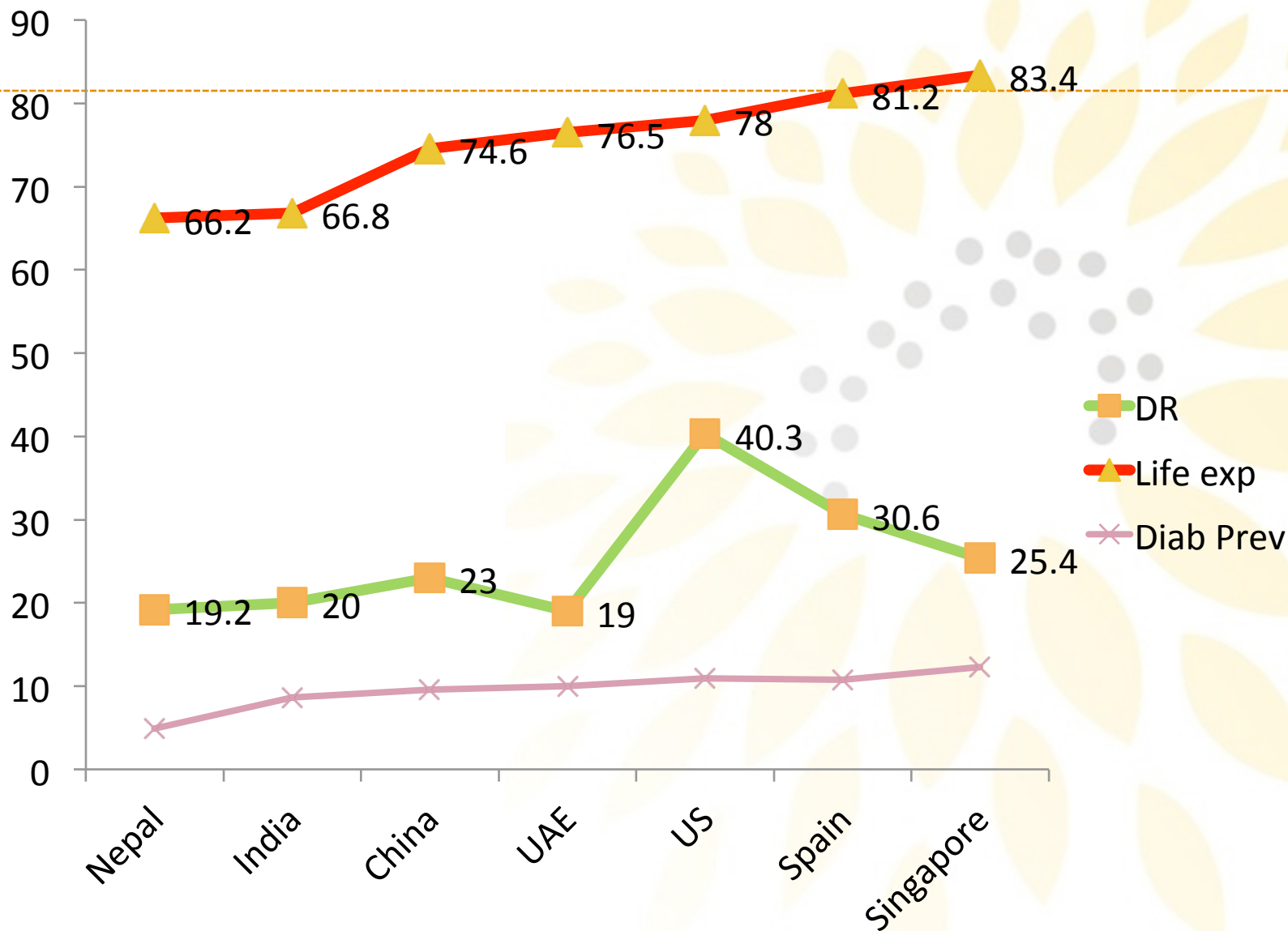
High Income Countries



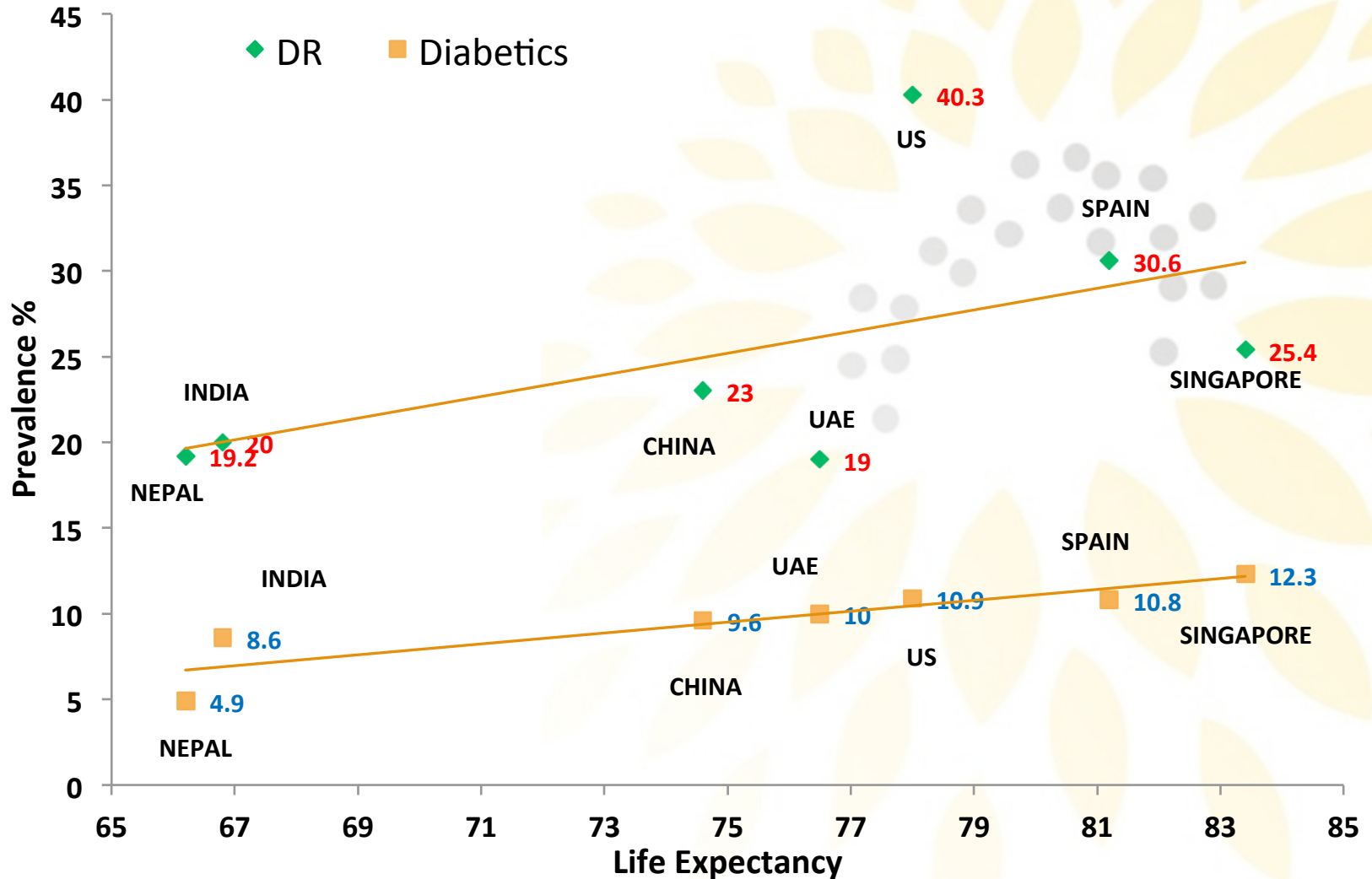
Low/Middle Income Countries



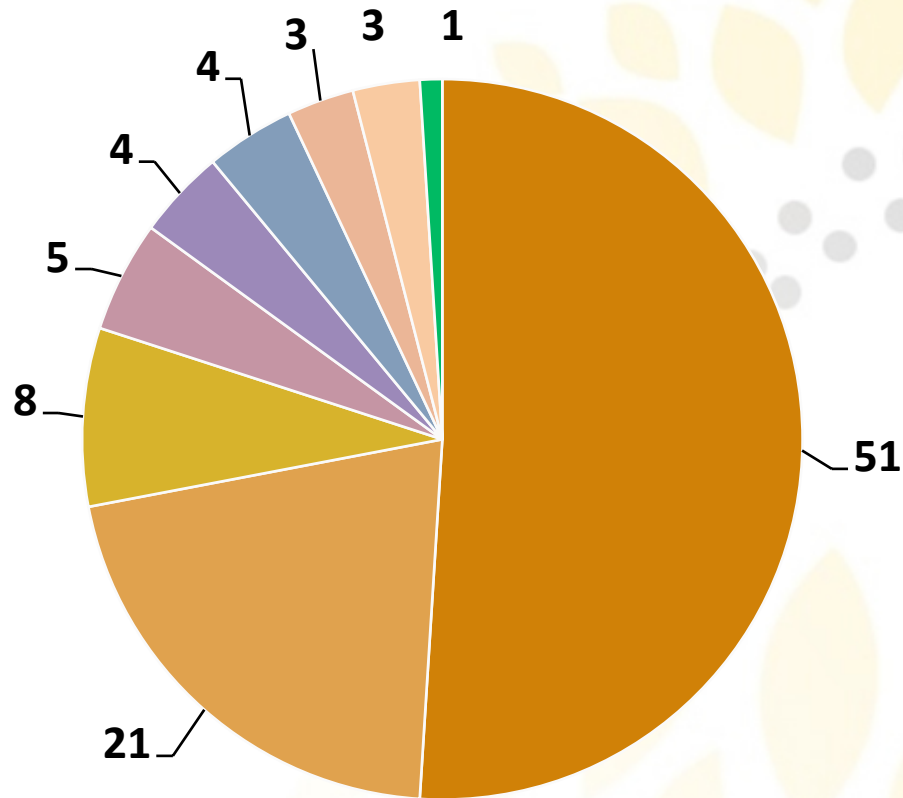
Life expectancy, diabetes & DR prevalence



Life expectancy, diabetes & DR prevalence

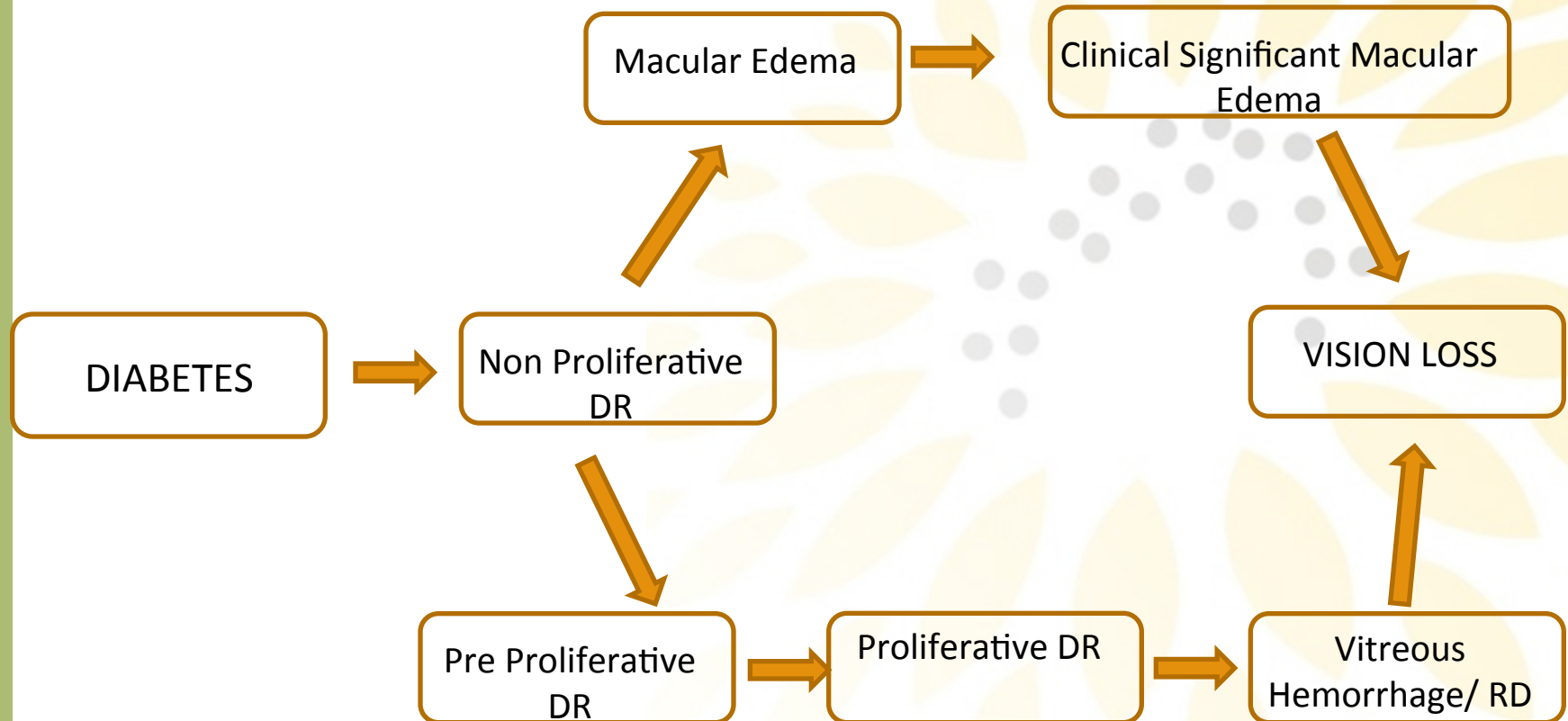


Global Causes of Blindness (%) 2010



- Cataract
- Undeterm
- Glaucoma
- AMD
- Childhood
- Cor Opac
- Ref Err
- Trachoma
- DR

Pathway to Vision Loss in Diabetes



Evidence on Risk Factors for DR

| Risk factor | Modifiable | Level of evidence |
|------------------------------|-----------------------|-------------------|
| Duration of diabetes | No | Good |
| HbA1c levels (Control level) | Yes | Excellent |
| Hypertension | Yes | Excellent |
| Pregnancy | No (counseling) | Good |
| Renal disease | No | Good |
| Age | No | Good |
| Smoking | Yes (No effect on DR) | Poor |
| Hyperlipidaemia | Yes(No effect on DR) | Good |
| Alcohol | Yes(No effect on DR) | Ambiguous |
| Antioxidants | Yes(No effect on DR) | None |

Why the interest in Diabetic Retinopathy?

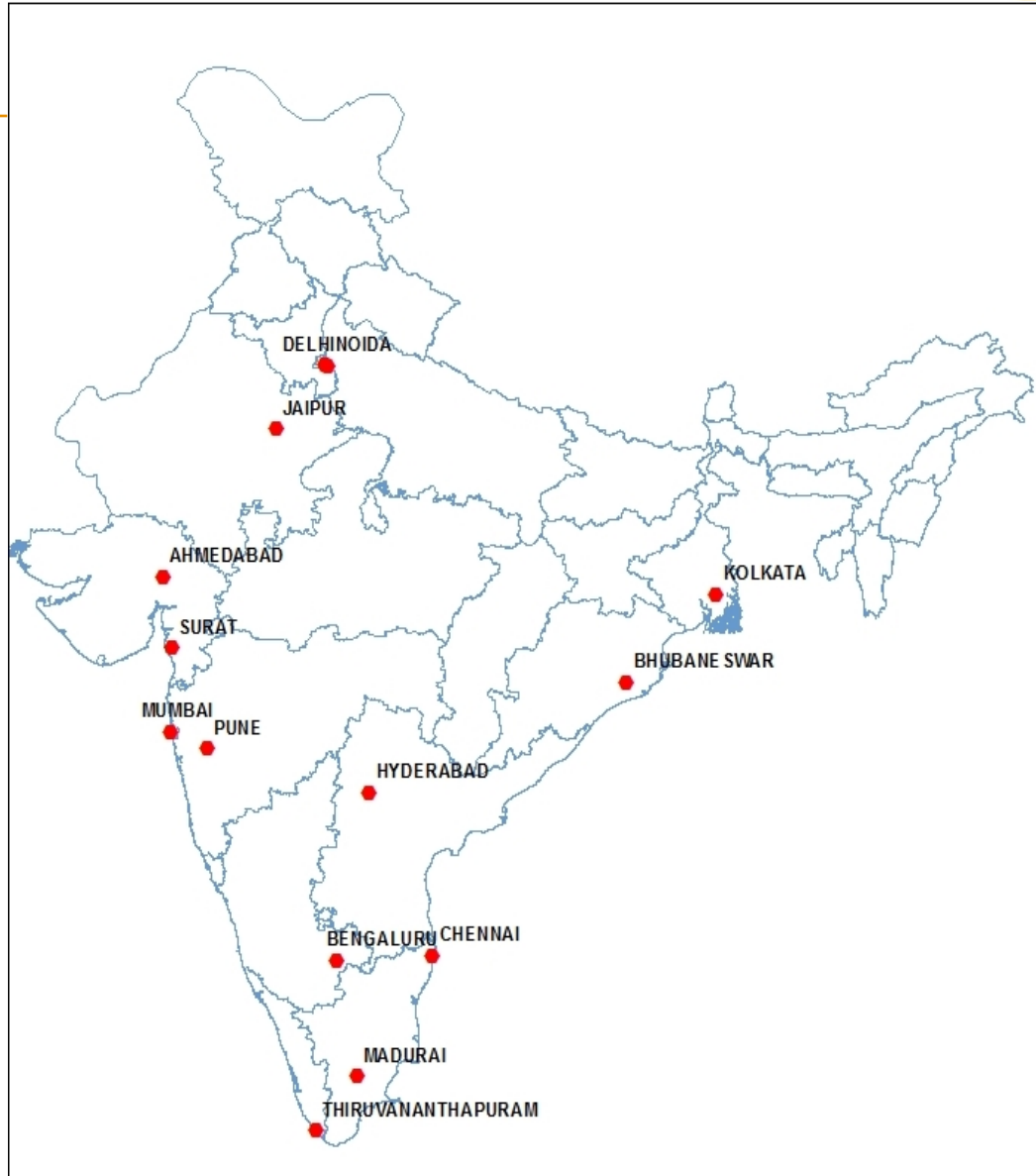
- 20-40% of diabetics develop retinopathy
- Blindness/ visual impairment seen in productive years of life
- 90% of blindness/ visual loss is preventable
- Huge economic cost both of diabetes management & blindness
- 80% of diabetics need adequate management of risk factors to reduce risk of complications
- Very few visit an ophthalmologist when referred

Why DR is of concern to India

- India is home to 66 million diabetics which will increase to 109 million by 2035
- 1 in 5 diabetics have some degree of retinopathy
- 10% (6 million) have sight threatening retinopathy today
- DR is likely to become the leading cause of blindness globally over the next 20 years

Situational Analysis : Rationale

- Study conducted in 11 cities in India
- Low hanging fruits the first port of call
- Study conducted in 2013-2014
- Funded by the Queen Elizabeth Diamond Jubilee Trust
- Results will be used to develop need-based strategies which can be scaled up in the region and globally



Objectives

- Assess HR & infrastructure at public and private sector institutions providing services for DM & DR (physician/eye care)
- Ascertain the workload and strategies adopted for DR & referral pathways;
- Determine the proportion of diabetics who know about eye complications of diabetes, and had a retinal/eye examination;
- Assess the capacities of eye care hospitals (both private and public sector) to manage DR

Sampling

- Stratified by size for selection of hospitals

Eye Hospitals

- Individual/ Group practitioners managing DR
- Hospitals with 20 or more inpatient facilities with specialty services

Diabetic Care Centres

- Stand alone diabetic clinics/ Polyclinics
- Multispecialty hospitals with 100 or more inpatient beds

Selection of Sample

| Diabetic Units | <8m cities | >8 m cities | Sampling process |
|--------------------------------------|------------|-------------|--|
| Large government DM/ general clinics | 2 or 3 | 4-5 | Randomly selected if more |
| Large private DM clinics | 2 or 3 | 4-5 | Randomly selected if more |
| Small private practitioners | 4 to 6 | | Purposive / snow balling |
| Total: | 10-12 | | |
| Persons with diabetes | 5-6/clinic | | Purposive: men & women: 40-59yrs (x3); >=60 yrs (x3) |

Selection of Sample

| Eye Units providing services for DR | <8m cities | >8m cities | |
|---|------------|------------|---|
| Large government eye hospitals/clinics | 2 or 3 | 4-5 | Randomly selected if more |
| Large private eye hospitals/clinics | 2 or 3 | 4-5 | Randomly selected if more |
| Private not for profit eye hospital/clinics | 1 or 2 | | Randomly selected if more |
| Private for profit eye practitioners | 4 to 6 | | Purposive / snow balling |
| Persons with DR | 5-6/clinic | | Purposive: men & women: 40-59yrs (x3); >=60 yrs (x3) |

Methods

- Data collection instruments and methodology was finalized through a wide stakeholder consultation
- All instruments piloted at hospitals outside sample
- Study adopted a multi method approach (both quantitative and qualitative)
- 6 teams collected data simultaneously after a 2 day standardization workshop at Hyderabad

Data Collection Protocol

Provider perspective

- Clinician Interviews
- Observations using observational check list

Client perspective

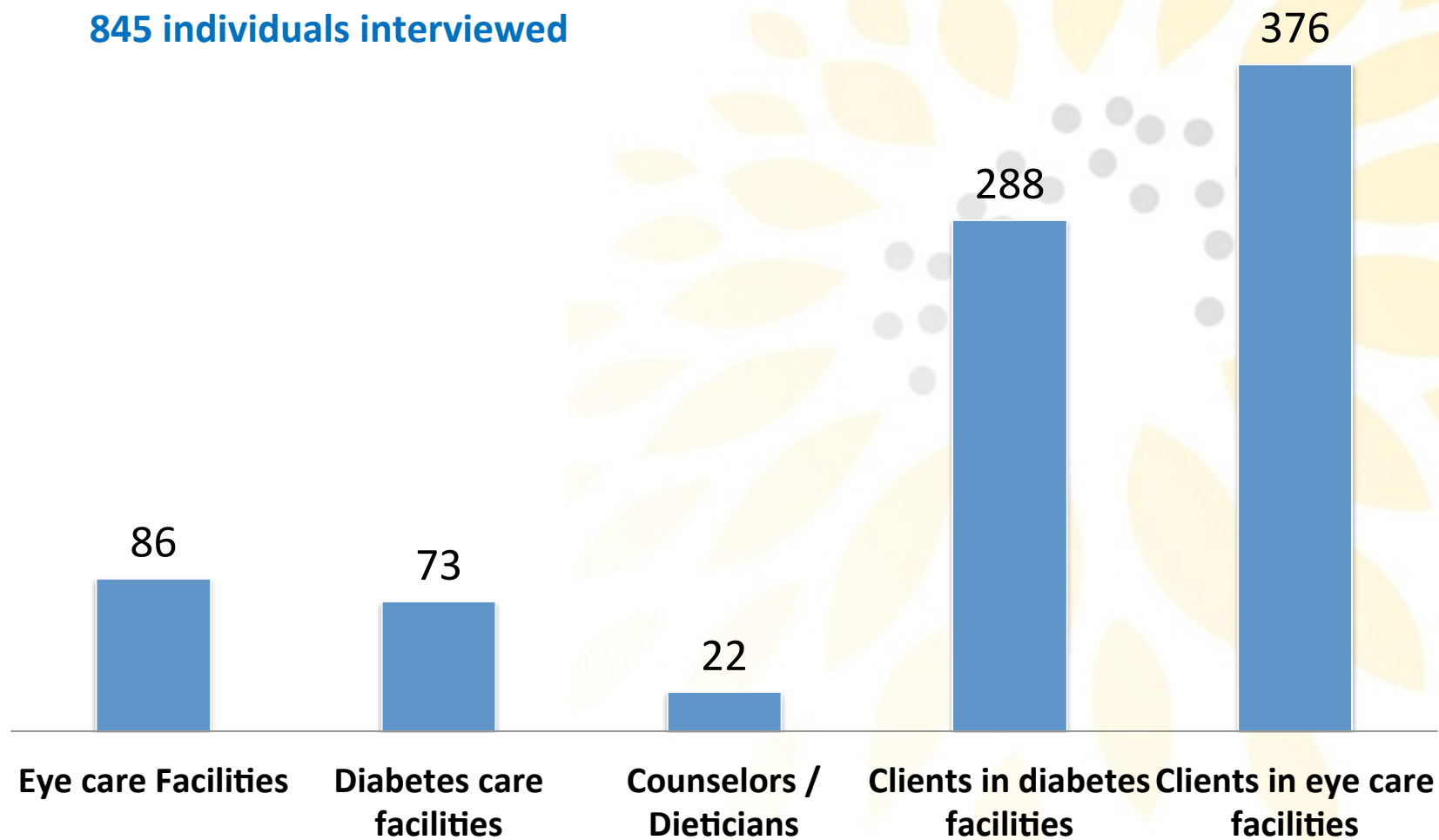
- Interviews at diabetic clinics
- Interviews at Retina/Eye clinics

Interview/Observation process

- Structured interviews with department heads
 - Assess staffing and skills; workload; what they do about DR
- In depth interviews with services providers after consent
 - Observation of equipment, protocols etc
 - Interviews with other staff , if available e.g. dieticians
- Interviews with persons with diabetes after written consent :
 - What they know about DR; How DR detected
 - Have they had an eye examination
 - Their challenges, barriers and mode of control etc.

Coverage

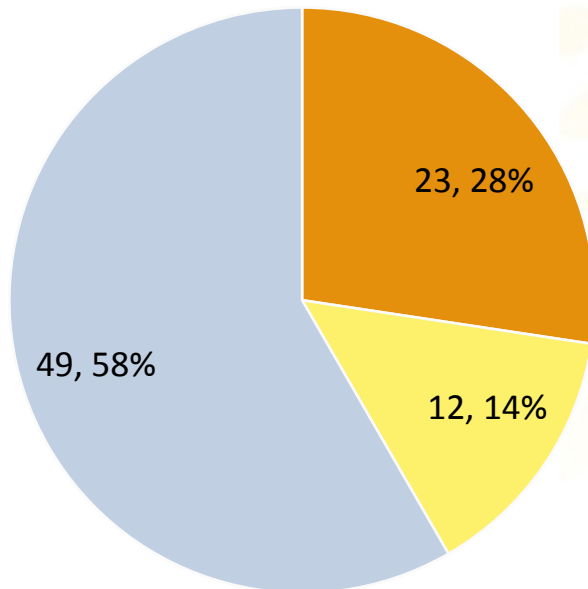
845 individuals interviewed



Distribution of respondents

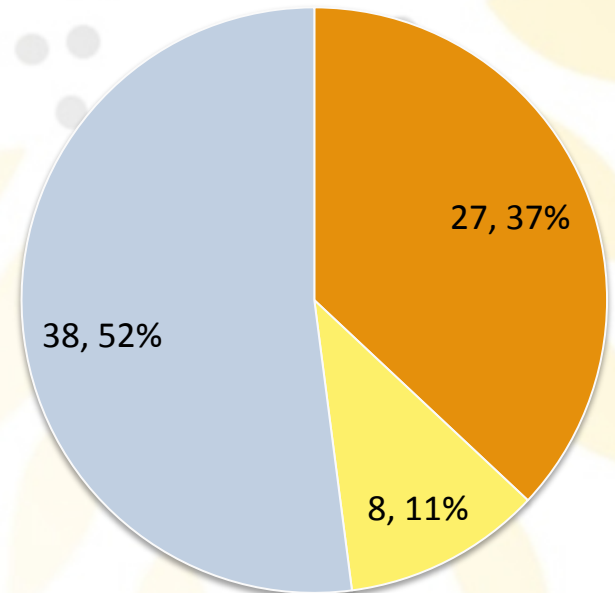
Eye Care

- Public
- Private not for profit
- Private for profit



Diabetic Care

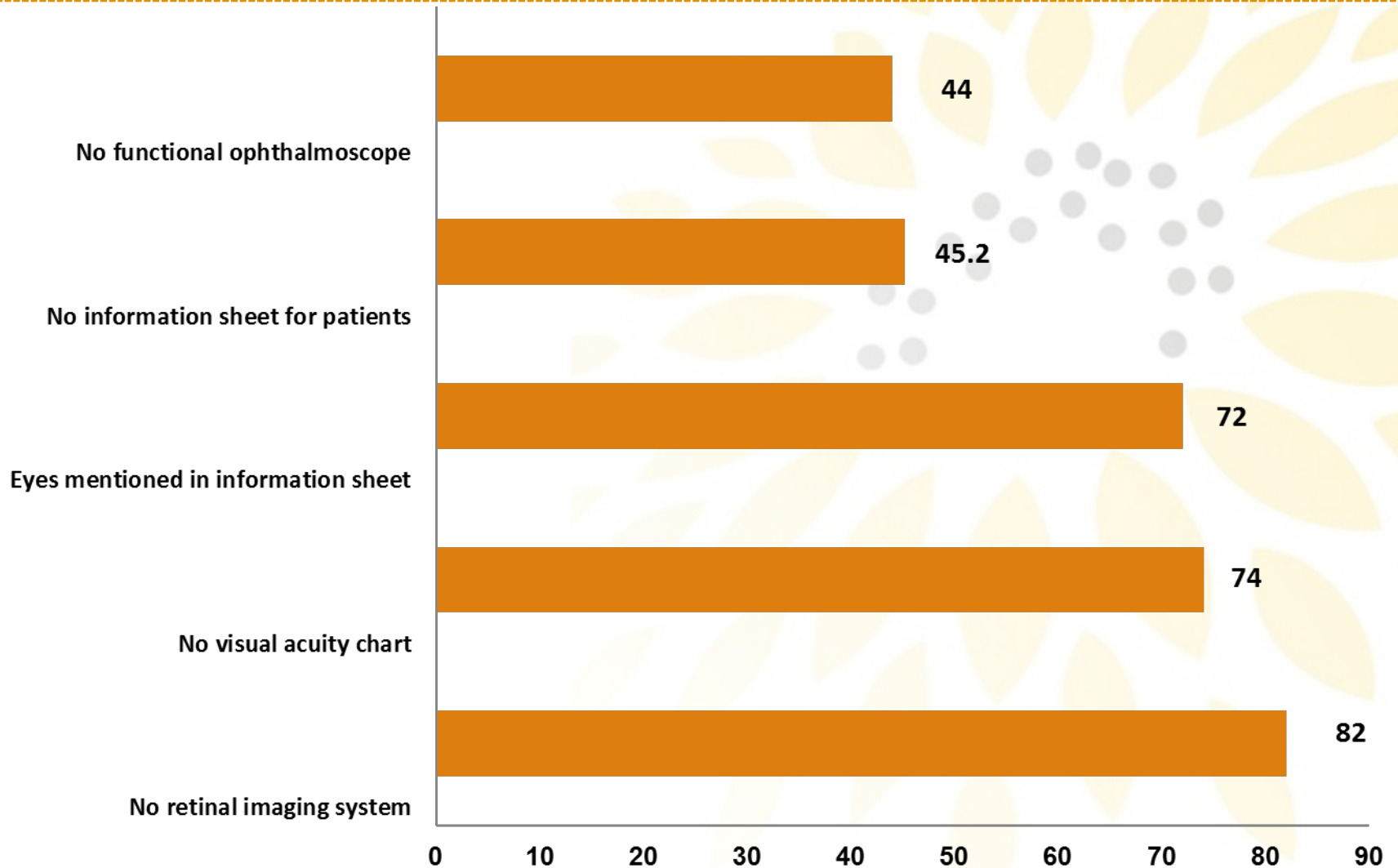
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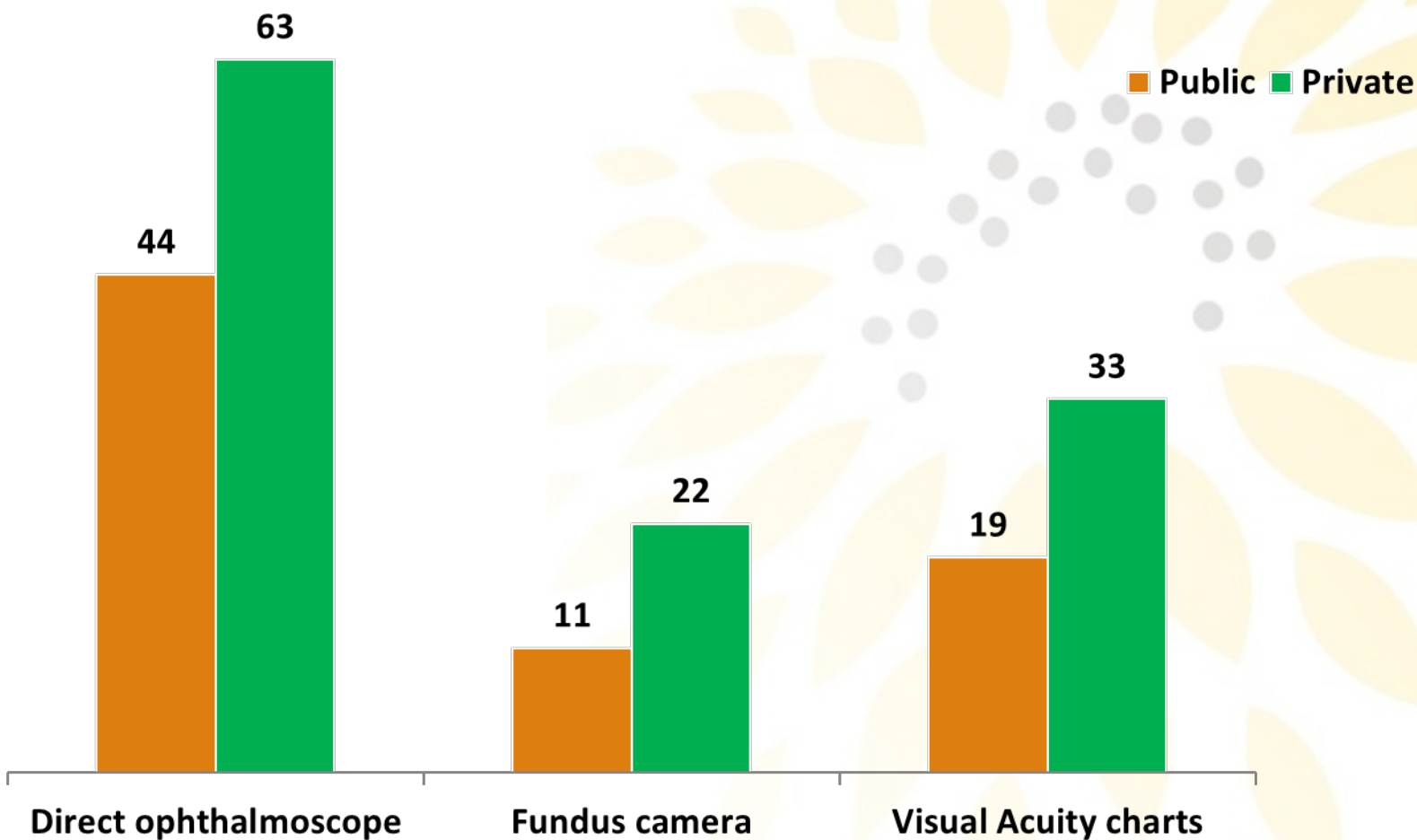


The Provider Perspective

Overview of Diabetic Clinics (%)



Availability of functional equipment at diabetic clinics (%)



Physician Practices at Clinics (%)

- Only in 10% clients the eye is examined by a physician
- 20% advise retina examination routinely at first visit
- 45% stated that they could not access eye data of patients from eye clinics

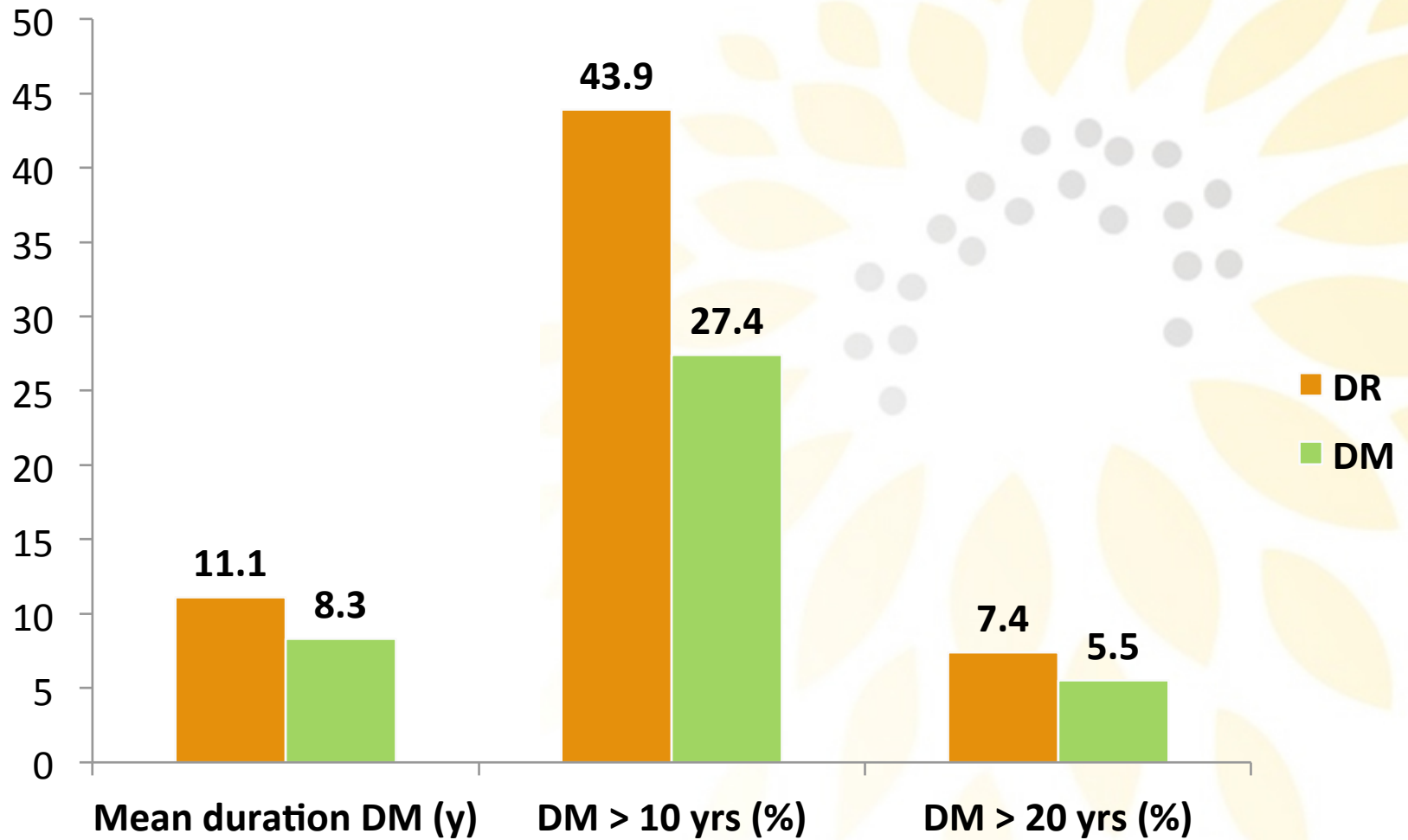
Perceptions of Counselors/Dietitians

- Commonest complications known to counselors/dietitians are renal and eye complications
- Only 27% talk to their patients about having an eye examination
- Only 41% knew that diabetes results in vision loss

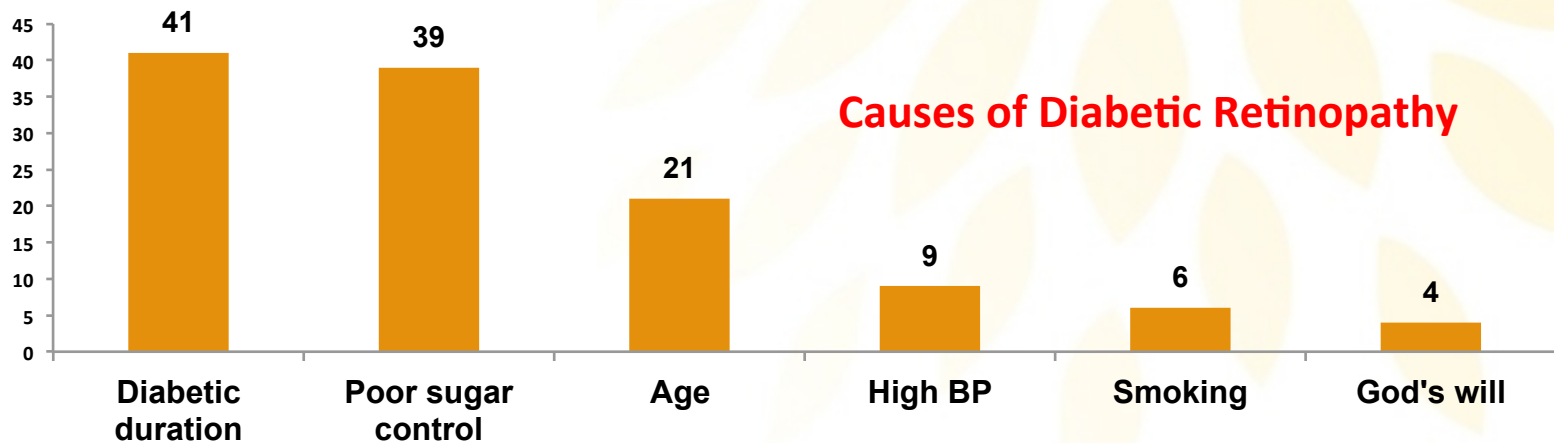
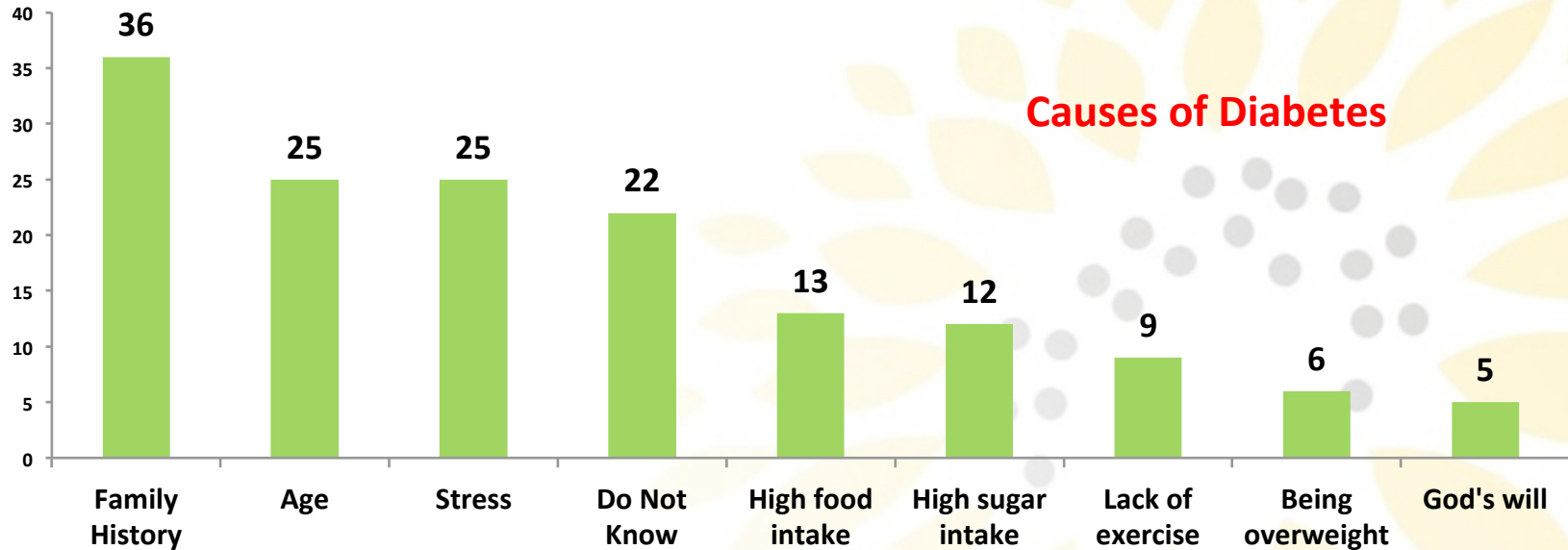


The Client Perspective

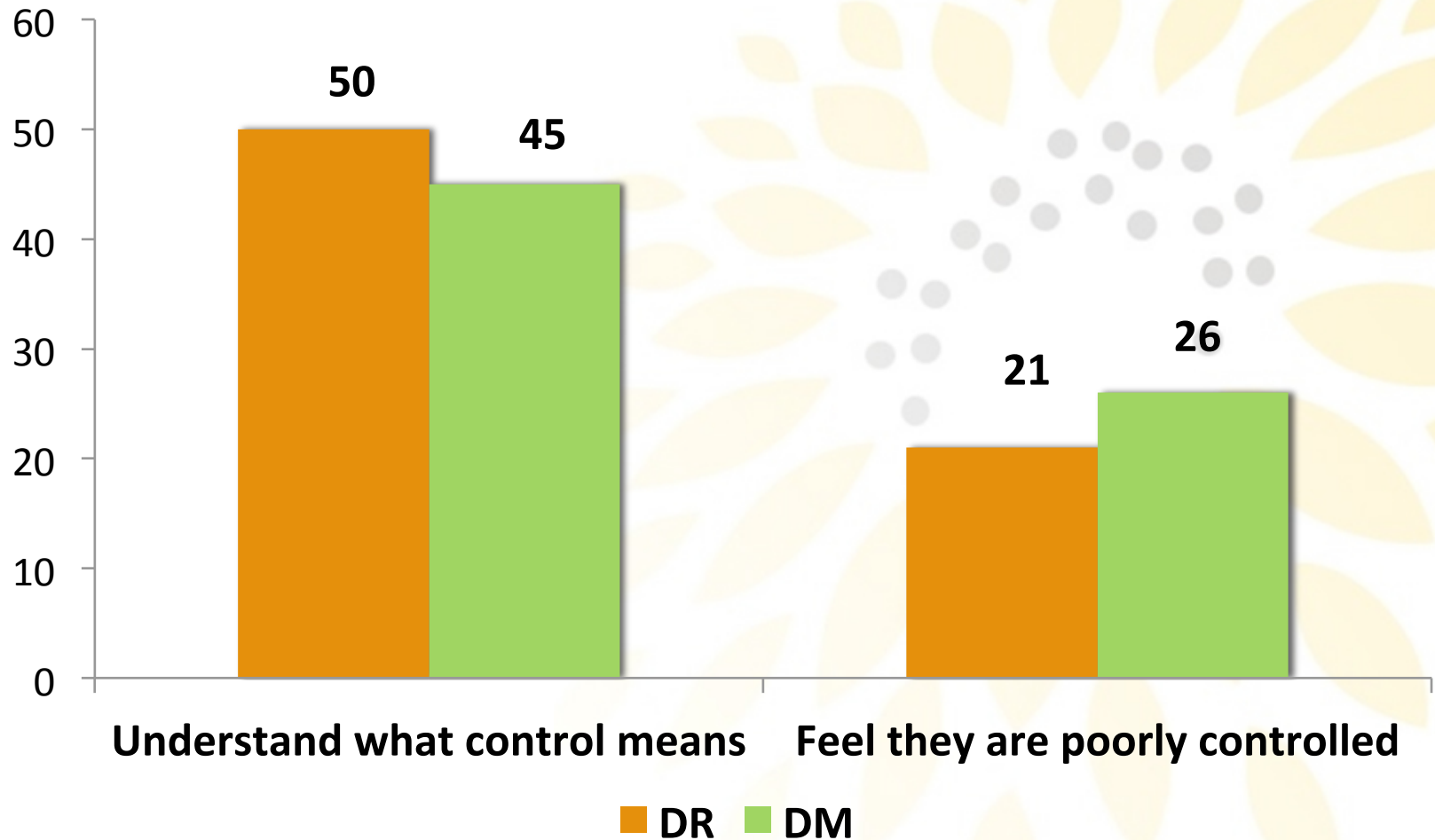
Client characteristics at Diabetic & eye clinics



Client perceptions on causes of DM & DR (%)



Perceptions on Diabetes Control (%)



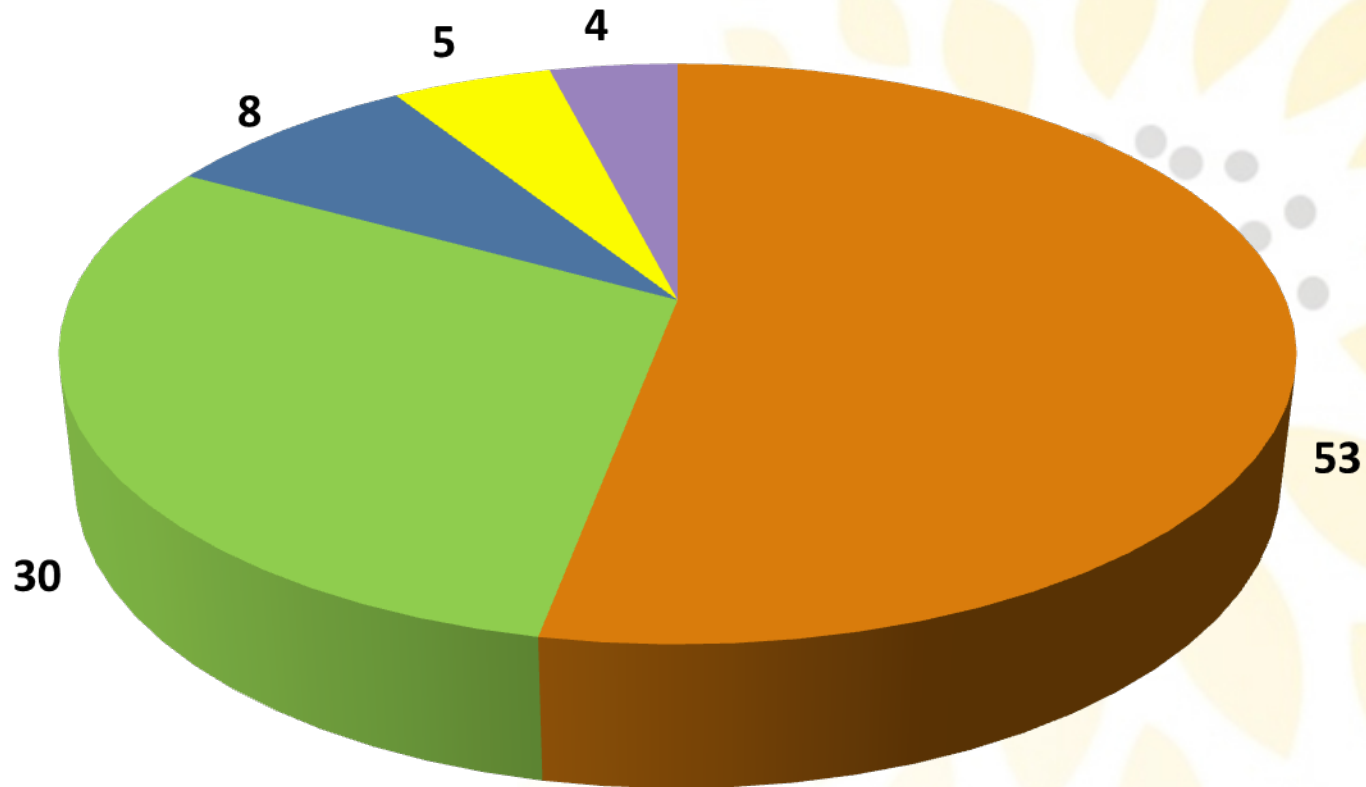
Challenges in controlling diabetes (%)

| | Challenges | % |
|------------------------|------------------------|-----|
| Life style factors | Changing diet | 45% |
| | Exercise | 18% |
| Costs | Cost of Investigation | 10% |
| | Cost of Medication | 13% |
| | Loss of wages | 6% |
| Difficulty remembering | Clinic appointment | 8% |
| | Remembering medication | 14% |
| Other reasons | Lack of time | 9% |
| | Distance to the clinic | 9% |
| | Accept being diabetic | 4% |
| | Other | 10% |

Perception of Persons with diabetes

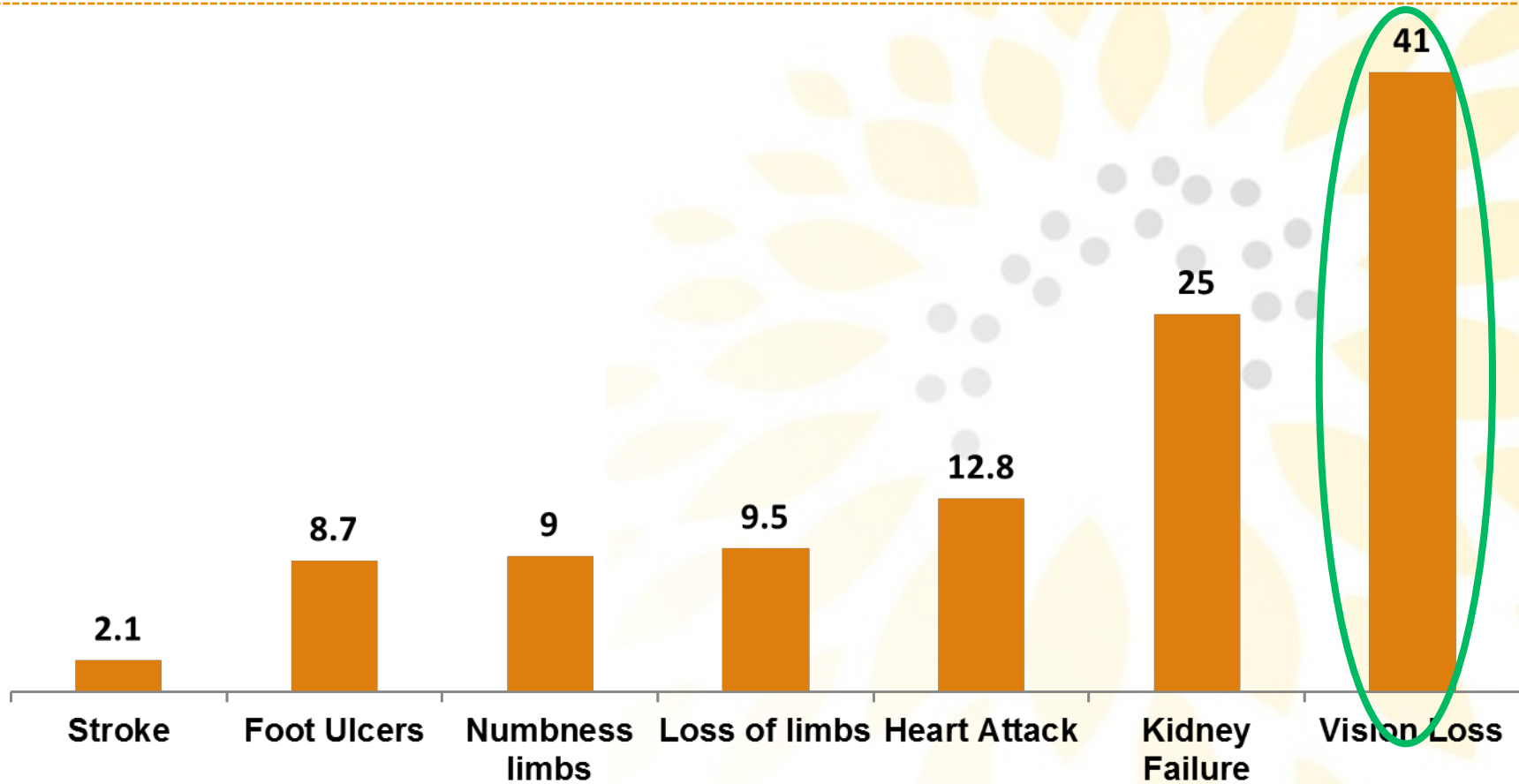
- Mean time of consultant interaction: 12.2 minutes
- 26% interact with dietician at OPD visit
- 15% interact with counselor at OPD visit
- 10% meet optometrist/vision technician
- 29% never had a dilated eye examination
- 21% knew retina is affected in diabetes
- 9% said that there is no need for eye examination
- 16% would get eyes examined only if there is a problem

Barriers in accessing Eye Clinics for DR patients (%)



■ No barrier ■ Distance ■ Cost/Wage loss ■ Too much time ■ No escort

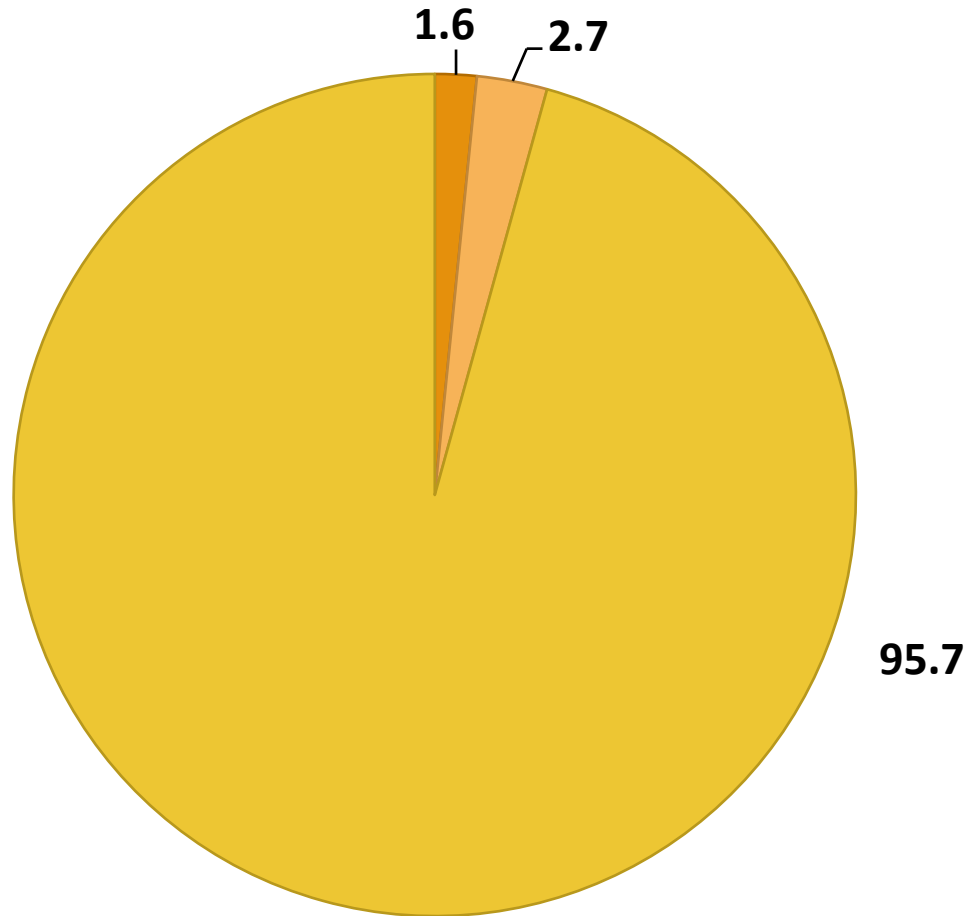
Complications of Diabetes of concern to clients (%)



Reality Check!

- 85% of persons with Diabetic Retinopathy were aware of complications of diabetes
- 63% of persons with diabetic retinopathy were worried about blindness/visual loss
- **YET** 45% of persons with Diabetic Retinopathy presented to an eye clinic with visual loss!
- This shows that too little is done too late!

Location where patient's retinopathy detected (%)



■ Diabetic clinic ■ Optician ■ Eye Hospital/Clinic/Camp

Optimal Outcome of a DR Program

Early detection of eye complications and
comprehensive management of risk factors
for DR

Queen Elizabeth Diamond Jubilee Trust supported program

- Pan India program
- Will cover 8-10 districts in India to develop integrated models of diabetic care at district level
- Modalities to support capacity building for physicians, eye care providers and persons with diabetes to reduce the risk of vision loss in DR
- Operational / implementation / health economics research embedded in the proposed district models
- Develop advocacy and communication strategy
- Create national guidelines for early detection and management of DR

Overall Goal of the Trust

Reducing avoidable blindness across
the Commonwealth

Lasting Legacy that Trust support should lead to

The control of blindness due to DR in India becomes fully integrated into national and State level health systems, supported by professional bodies of ophthalmologists, physicians and diabetologists, and is, therefore, sustainable and scalable

A One Stop Shop!

A significant proportion of physicians, ophthalmologists and persons with diabetes favored an integrated care package where diabetes and its complications are managed under one roof

What Needs to be done

- Sensitizing physicians to their critical role in treating risk factors for vision loss in diabetic retinopathy
- Empowering and partnering persons with diabetes and their family carers to control diabetes
- Integrated comprehensive district level care for early detection and management of DR
- Encouraging physicians to invest time for early detection of vision problems
- Newer imaging systems that can be used by non-ophthalmologists

Unleashing the power of technology to make a difference!



Opportunities for collaborations/ internships

- Help in developing advocacy & communication material
- Piloting ideas for enhancing participation of persons with diabetes
- Technical partnerships with media, other INGO/NGOs
- Collaborative on integration at district and State level
- Inputs for Integration with NCD surveillance
- Developing guidelines/ protocols for health professionals
- Participate in monitoring of program components
- Identifying and piloting new imaging methods
- Assessment of costs/effectiveness & implementation



If you have the **INTEREST**, We have
the **TIME** to listen & Work
Together!!

WELCOME ABOARD!