

# Diabetic Retinopathy Barometer Project

*Global perspectives*

Dr Jane Barratt  
Secretary General, International Federation on Ageing  
25-26<sup>th</sup> July 2016

[jbarratt@ifa-fiv.org](mailto:jbarratt@ifa-fiv.org)  
[www.ifa-fiv.org](http://www.ifa-fiv.org)









International  
Diabetes  
Federation



INTERNATIONAL FEDERATION ON AGEING  
Global Connections



*“To preserve healthy vision through awareness,  
improved access to treatments and education  
of patients with diabetes and  
health care professionals”*



Bayer Pharma AG has funded and facilitated this research, acted as an advisor to the participating organizations and will assist in the dissemination of the research findings.

Why?



29.1  
million

1/4

1/3

## PREDIABETES

86  
MILLION



86 million people —  
more than 1 out of 3 adults  
— have prediabetes



9 **OUT OF** 10 do not know they  
have prediabetes



Without weight  
loss and moderate  
physical activity

15–30% of people with  
**prediabetes** will develop  
type 2 diabetes within 5 years



## COST



\$245  
BILLION

Total medical costs and lost  
work and wages for people  
with diagnosed diabetes

Risk of death  
for adults with  
diabetes is



50%  
**HIGHER**



than for  
adults without  
diabetes



Medical costs for  
people with diabetes  
are **twice as high**  
as for people  
without diabetes

People who have diabetes are at higher risk of serious health complications:



BLINDNESS



KIDNEY  
FAILURE



HEART  
DISEASE



STROKE



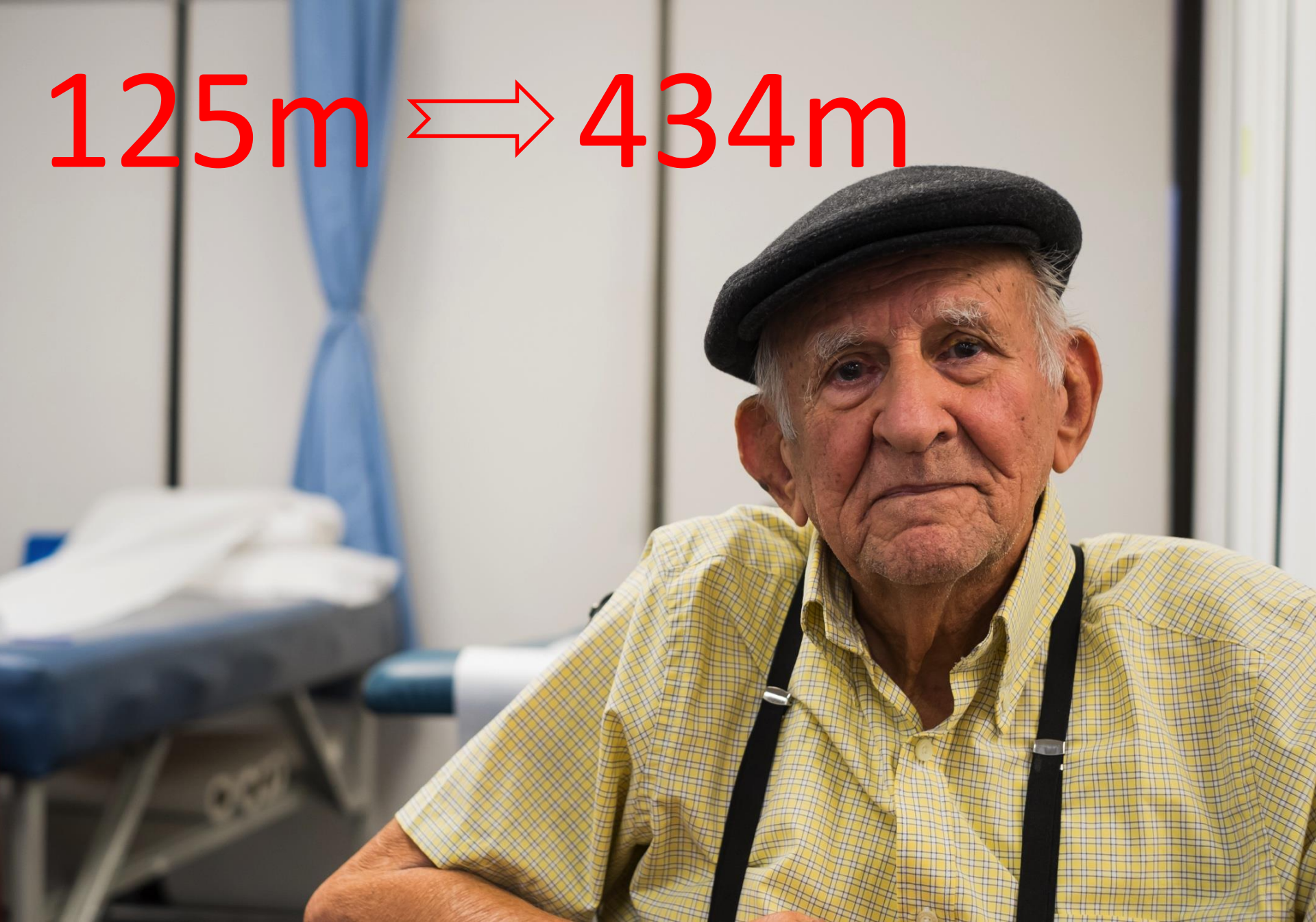
LOSS OF TOES,  
FEET, OR LEGS



2b



125m  $\Rightarrow$  434m





# Diabetic Retinopathy Barometer Study provides

*Insight on the experience of  
people with diabetes and the  
health professionals who care  
for them as they face the threat  
and impact of vision  
impairment and loss.*



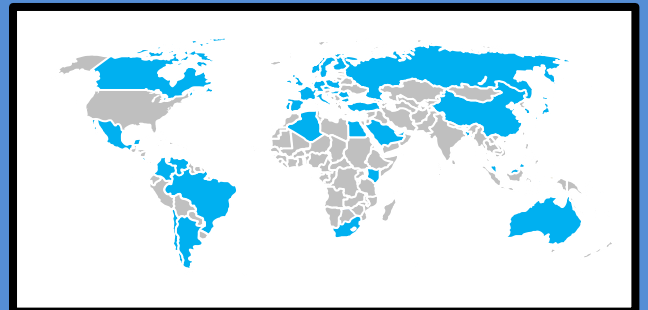
# Qualitative Study

- Eight countries: Argentina, Bangladesh, Germany, Japan, Mexico, Romania, Saudi Arabia and Uganda
- Interviews to examine the experience of people with diabetes (n=73) and providers (n=48)

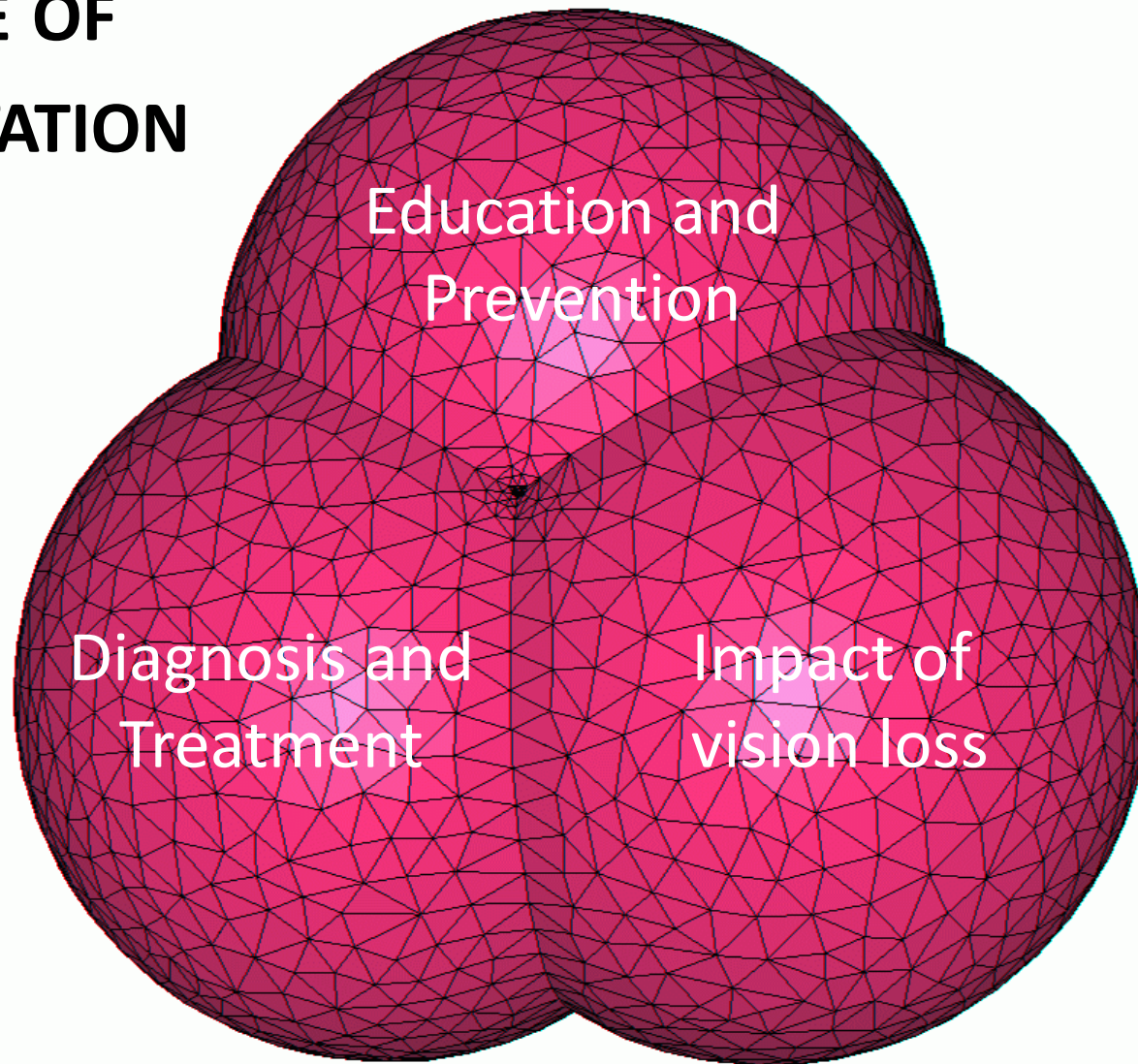


## Quantitative Study

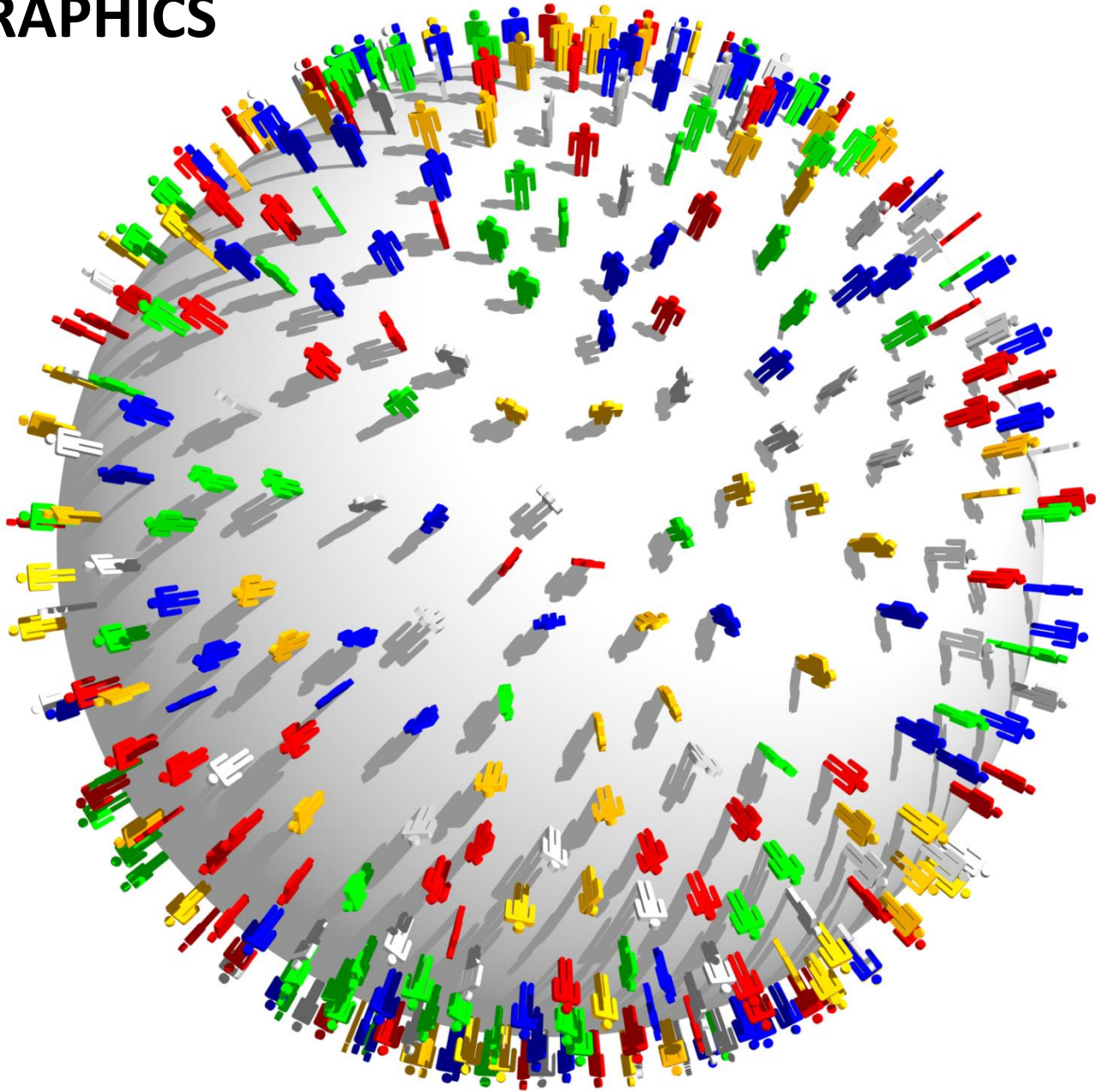
- Forty-one countries across Europe, the Americas, Africa, Middle East, Asia and Australia
- Purposeful sample of people with diabetes (n=4,340) and healthcare professionals (n=2,329)



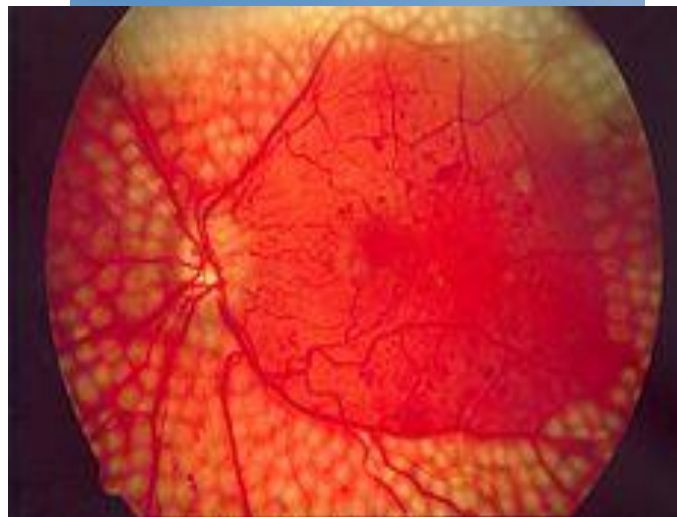
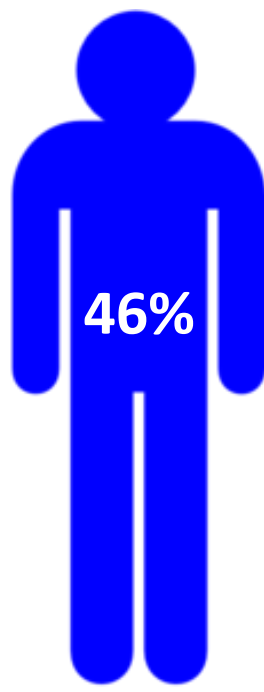
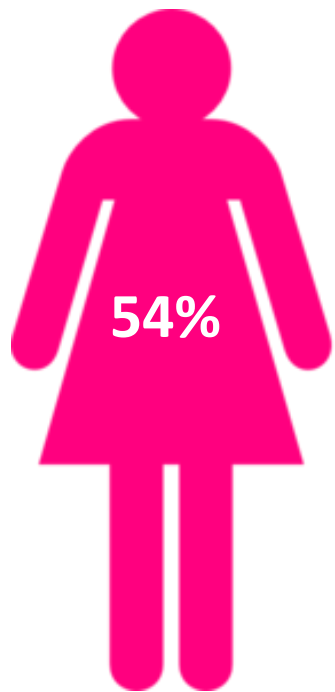
# OUTLINE OF PRESENTATION



# DEMOGRAPHICS







## Time since diabetes diagnosis

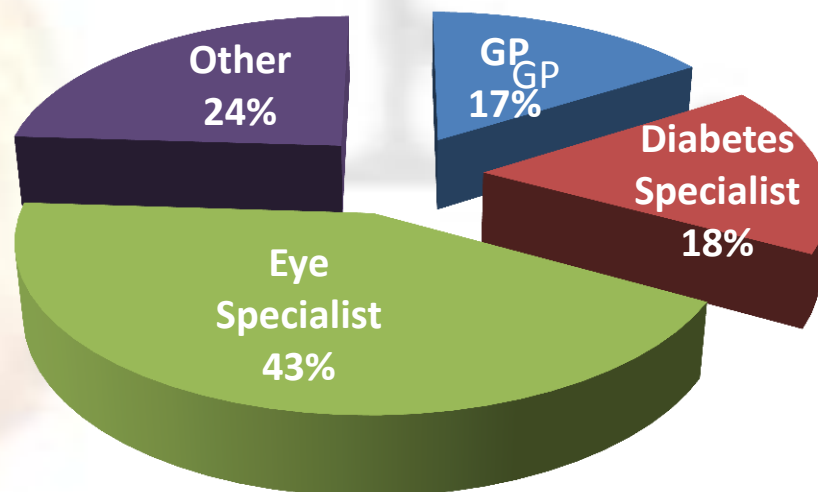
Time	%
11+ years	24%
6-10 years	38%
1-5 years	23%
Within the past year	12%

## Patients

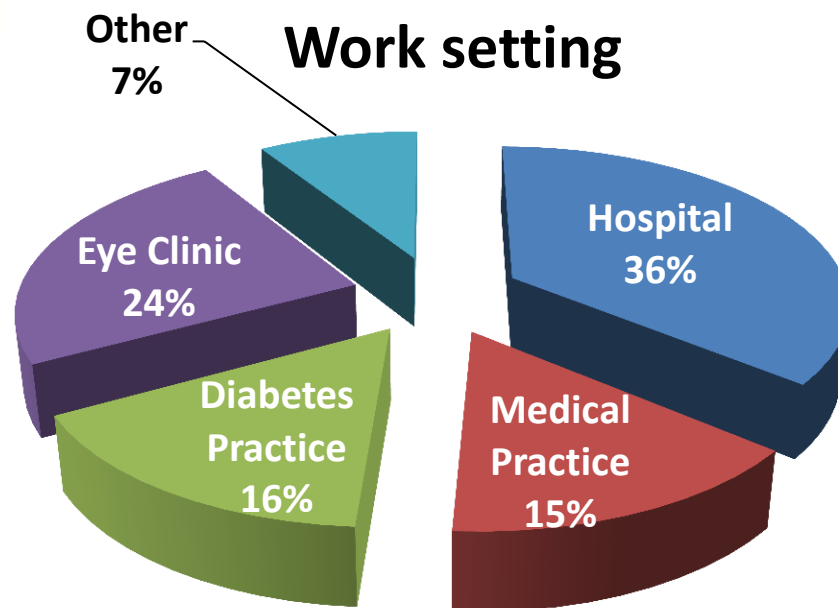
Prevalence	%
Neither	74%
DR	26%
DME	8%
Not sure	17%

# Providers

## Specialty

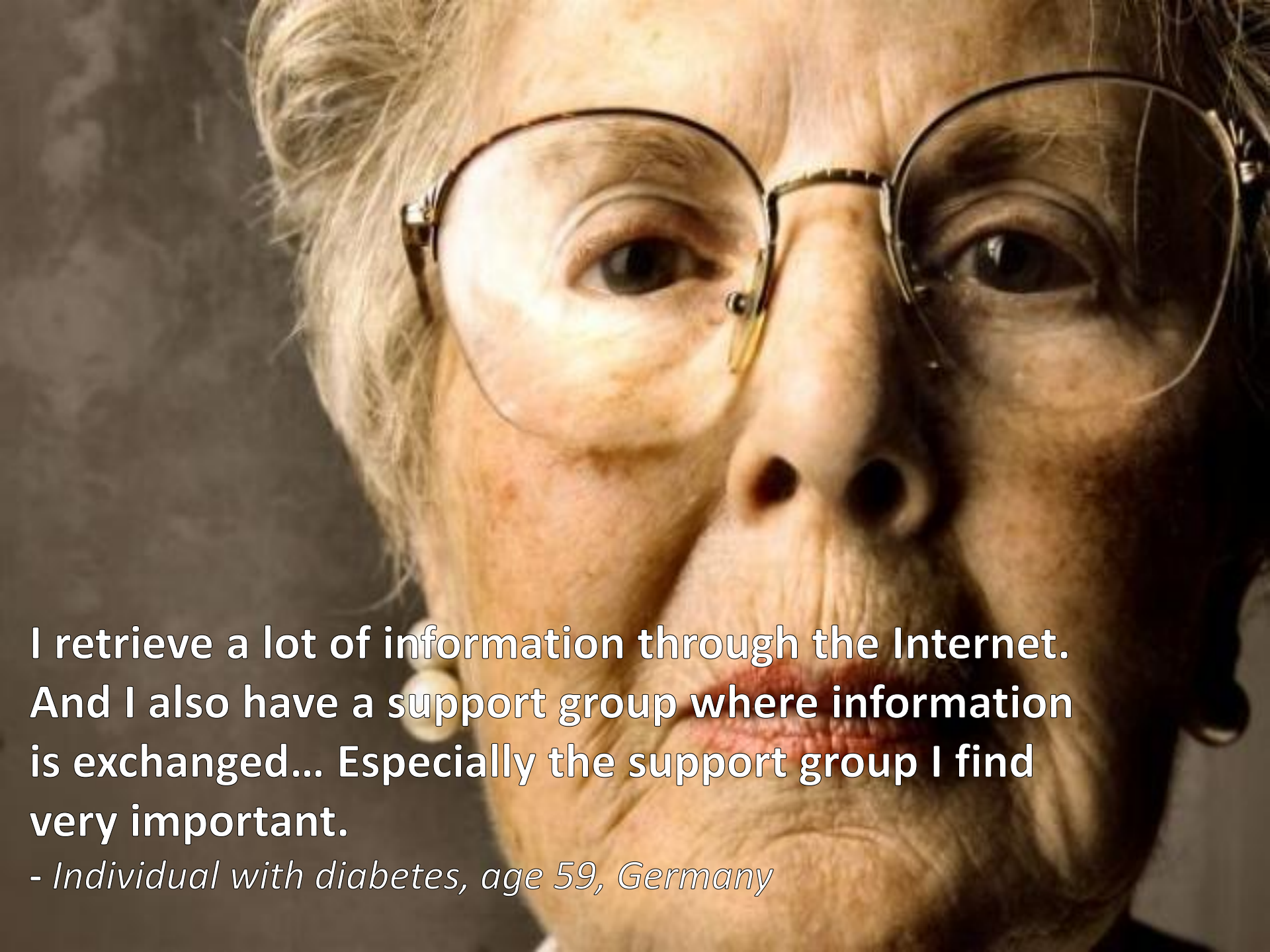


## Work setting







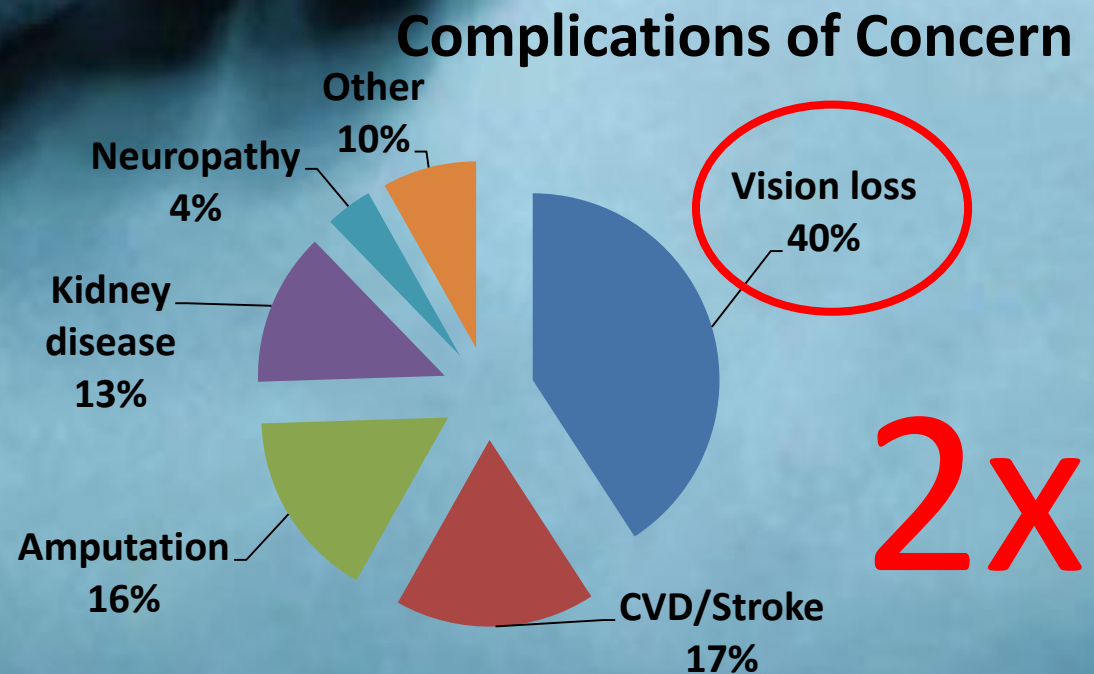
A close-up, high-resolution portrait of an elderly woman with short, light-colored hair. She is wearing round, dark-rimmed glasses. Her expression is neutral as she looks directly at the camera. The lighting is soft, highlighting the texture of her skin and the details of her facial features. The background is a dark, out-of-focus grey.

I retrieve a lot of information through the Internet.  
And I also have a support group where information  
is exchanged... Especially the support group I find  
very important.

*- Individual with diabetes, age 59, Germany*

# Diabetes

## Complications





A close-up, high-contrast photograph of an elderly man's face. He is wearing a dark beret. His skin is wrinkled, and his eyes are looking slightly to the side. The lighting is dramatic, with strong highlights and deep shadows.

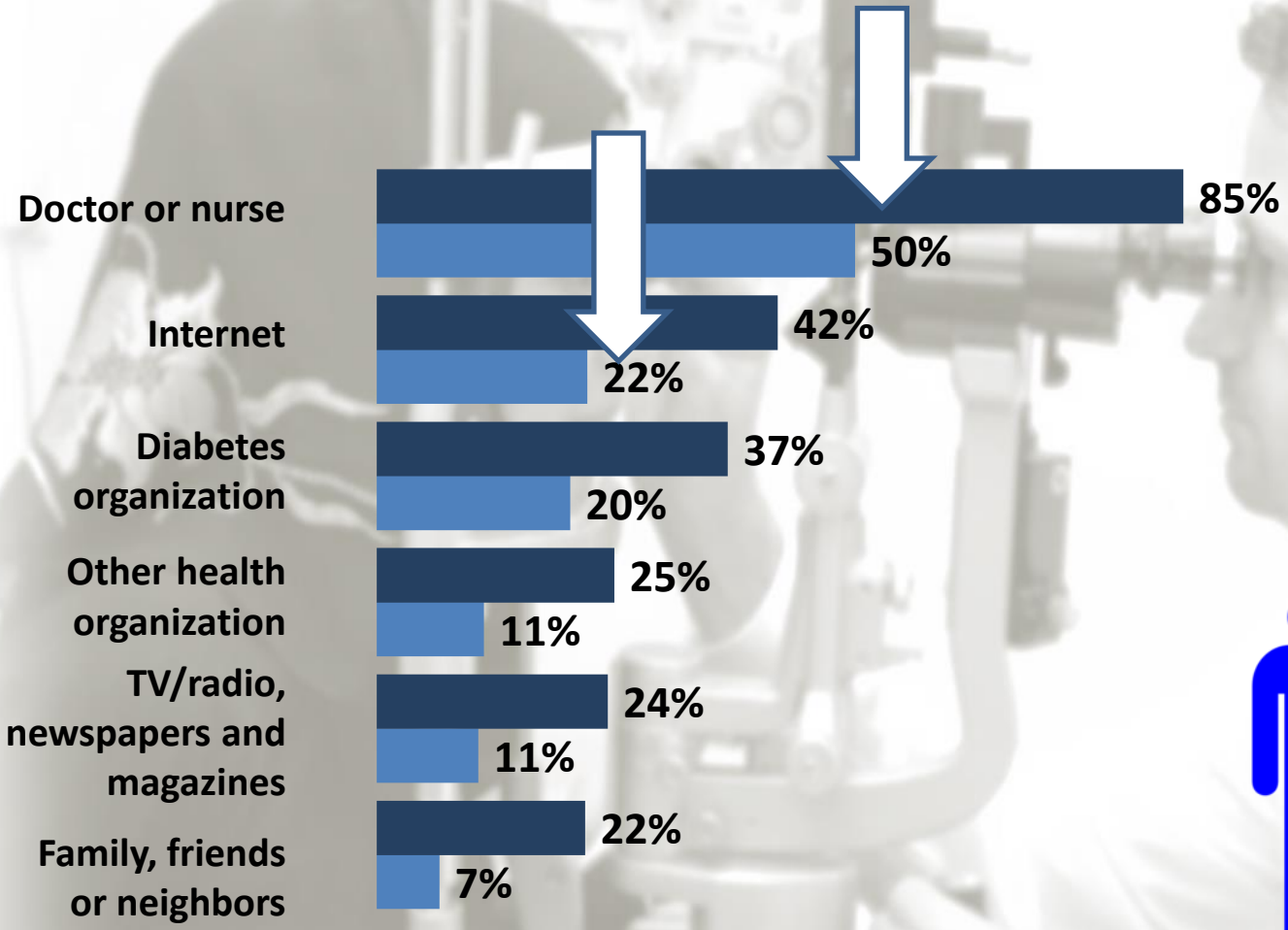
Knowledge impacts  
attitudes (and decisions)

14%

Do not do all that they can to  
Associated vision loss with ageing  
prevent vision loss

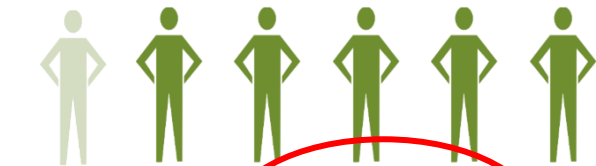


# Sources of information about Diabetes and DR / DME impacts on action

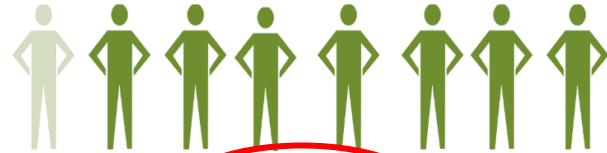


**NO** information about DR / DME

# Patient knowledge impacts the nature of discussions



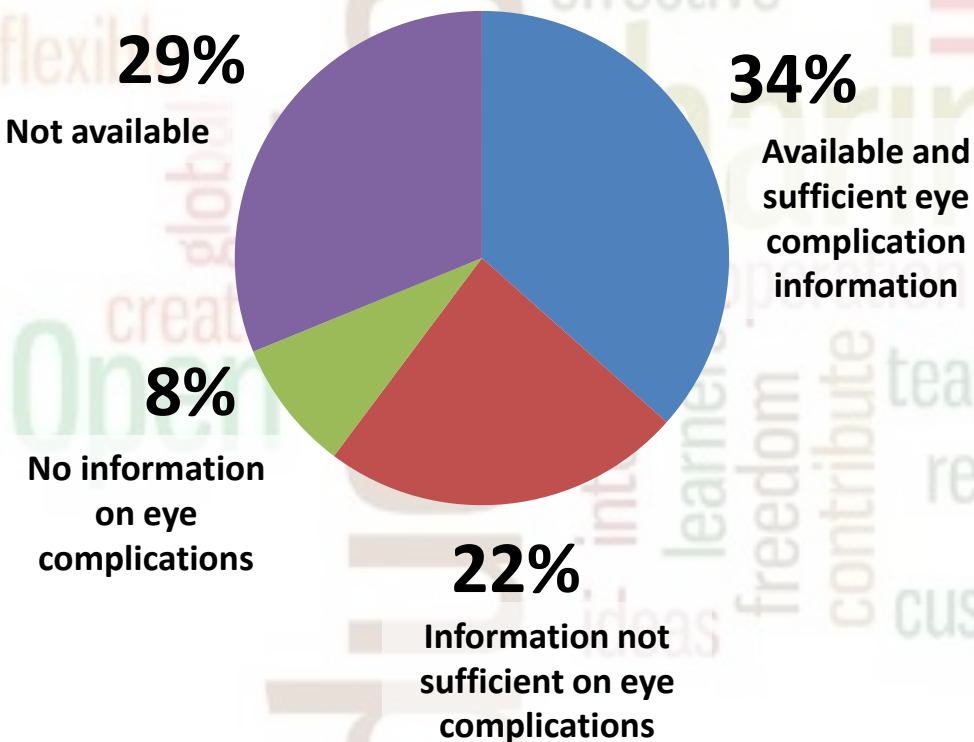
Around **1 in 6** patients  
discuss symptoms **only** when  
they arise



Nearly **1 in 8** **never** discuss  
eye complications with their  
physicians

1 in 4

# Two out of every three providers Reported insufficient educational information on diabetes and eye complications



Of the **patients** currently enrolled on a patient-support program **only 1 in 6** reported having education on eye complications



# Summary

1

## Management

Patients are:

- Concerned about vision loss
- Not managing their diabetes well
- Not doing everything they can to prevent vision loss



2

## Communication

- Many patients do not discuss eye complications with HCP
- Many do not see HCPs as early or regularly as they should



3

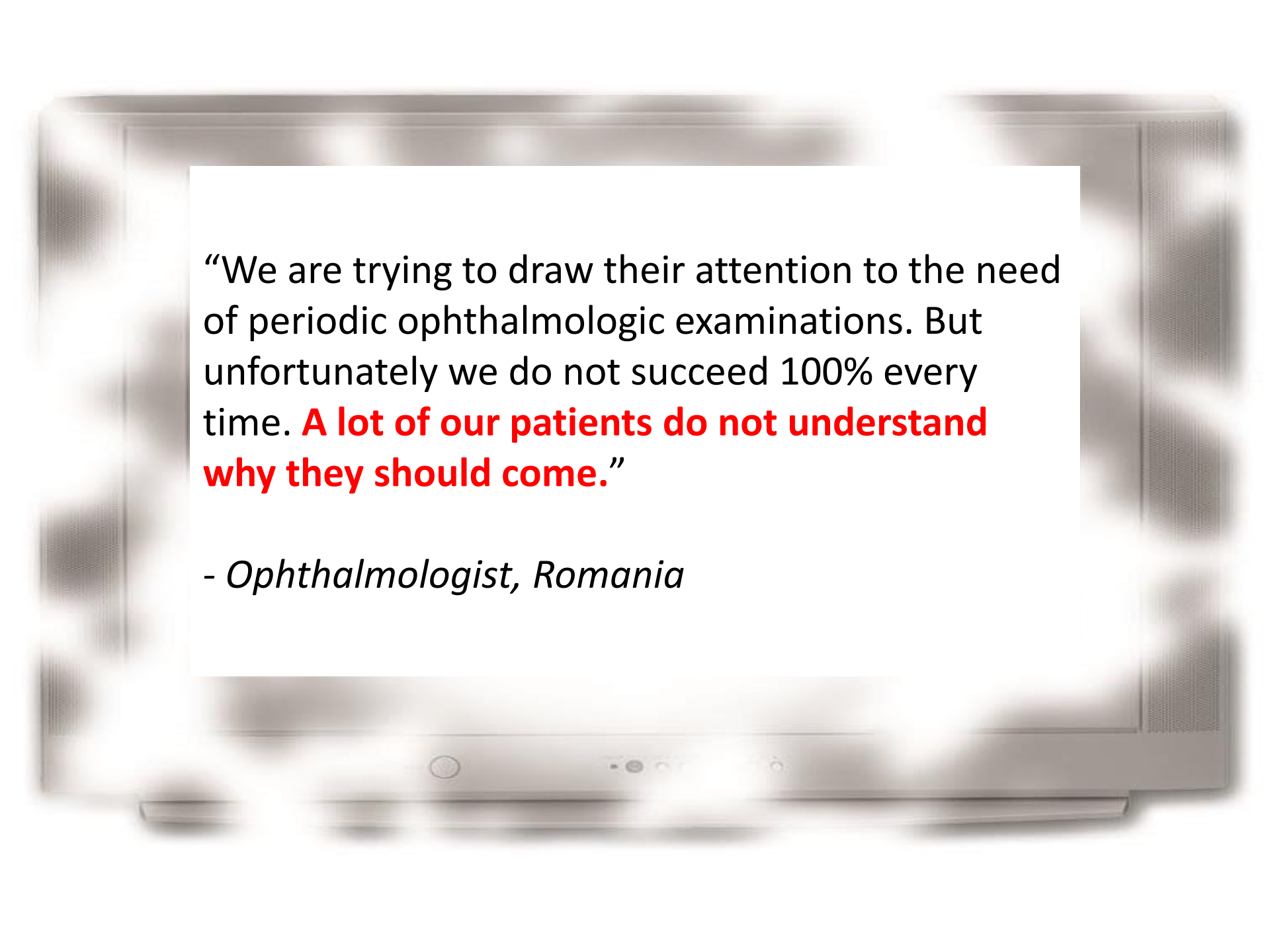
## Education Resources

There is lack of meaningful educational resources that supports prevention and early diagnosis



# DIAGNOSIS AND TREATMENT

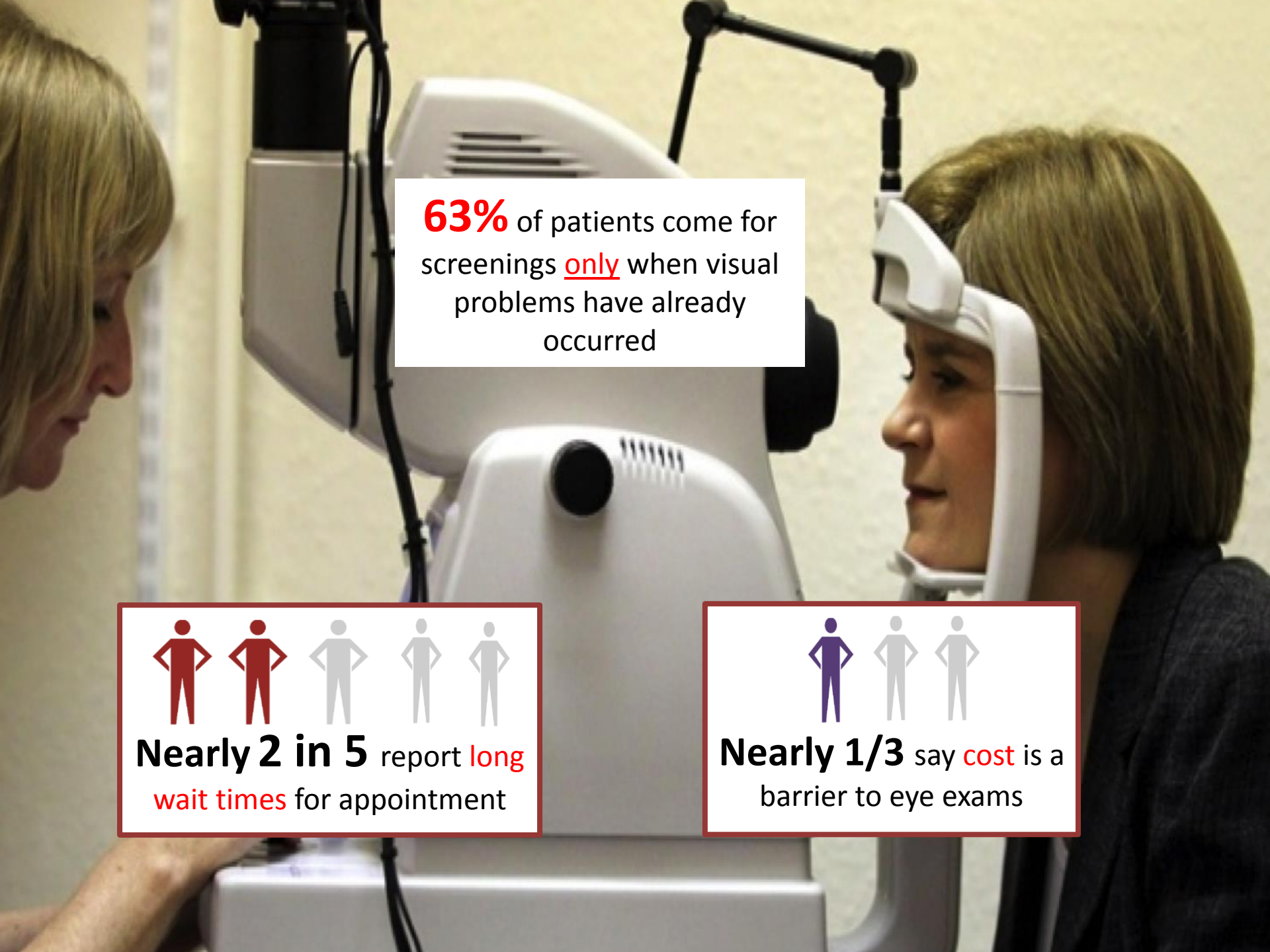




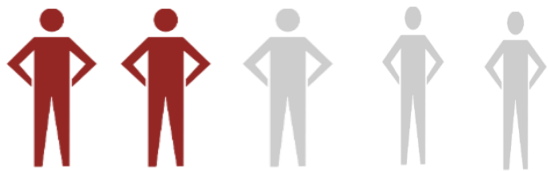
“We are trying to draw their attention to the need of periodic ophthalmologic examinations. But unfortunately we do not succeed 100% every time. **A lot of our patients do not understand why they should come.**”

- *Ophthalmologist, Romania*





**63%** of patients come for screenings only when visual problems have already occurred

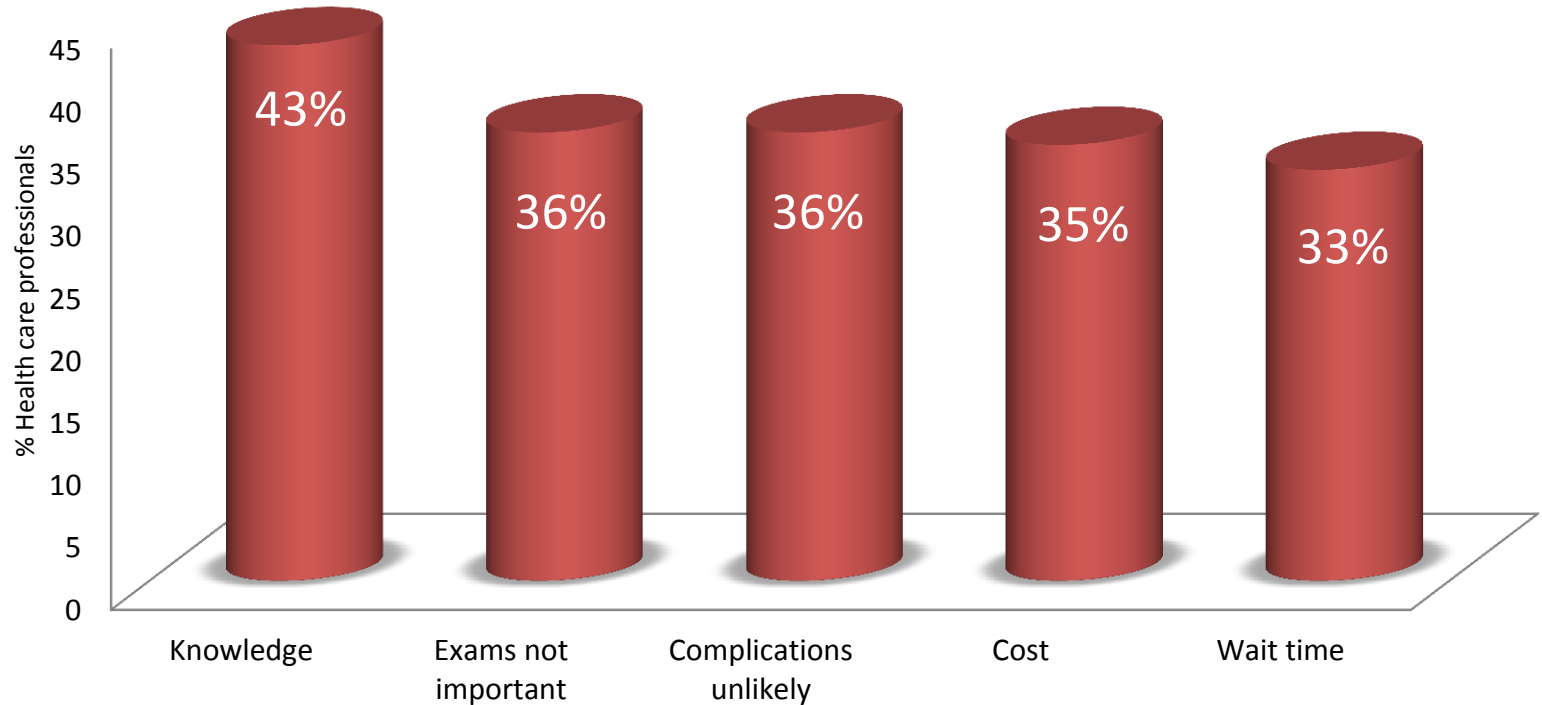


**Nearly 2 in 5** report **long wait times** for appointment






**Nearly 1/3** say **cost** is a barrier to eye exams

# Barriers to eye examinations as perceived by health care professionals



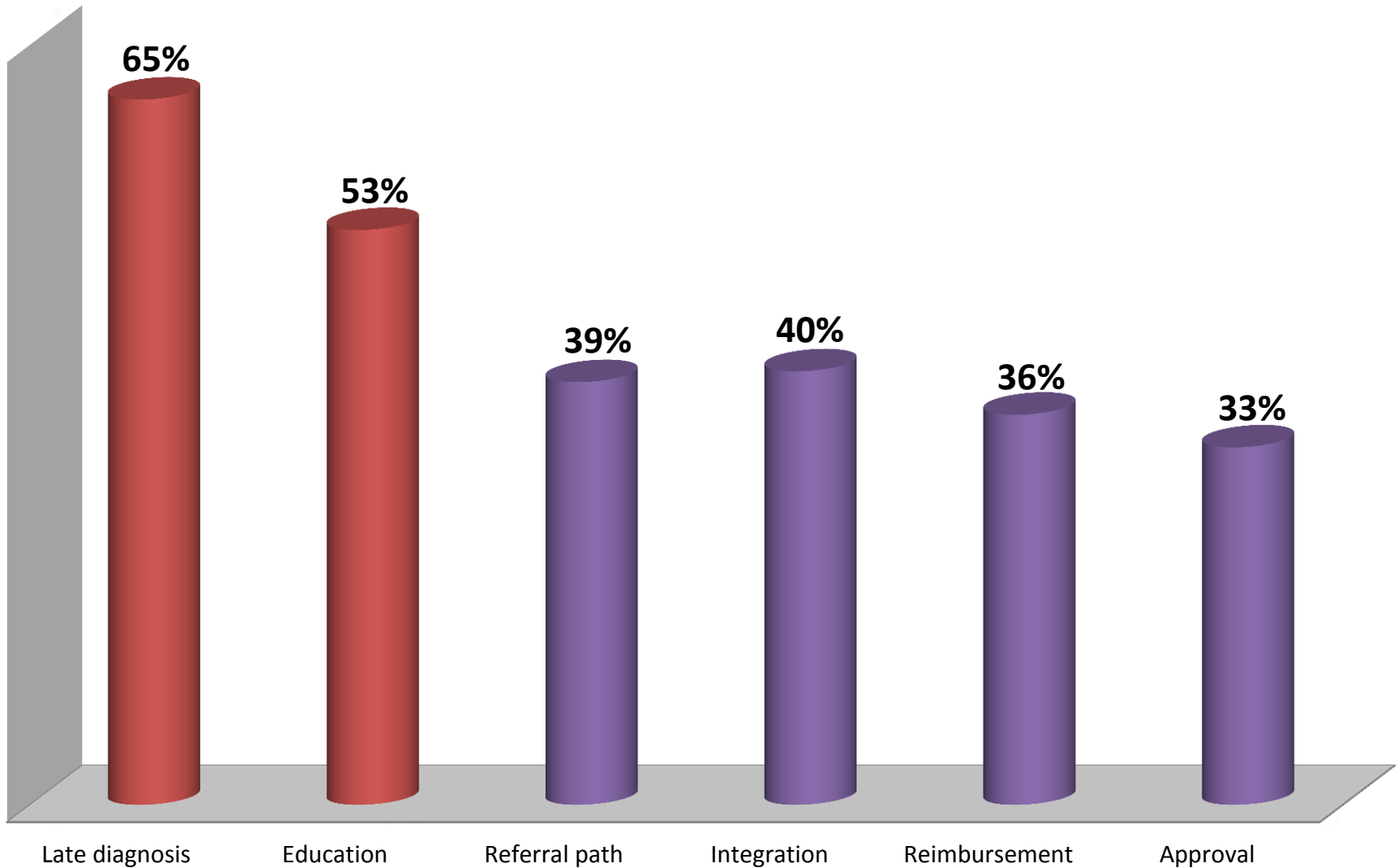
# Cost is a barrier

-  Part of out of pocket
-  No out of pocket costs
-  Do not use service

More than **4 in 10**  
people are paying for  
screening,  
counselling,  
medical visits,  
procedures and  
treatments



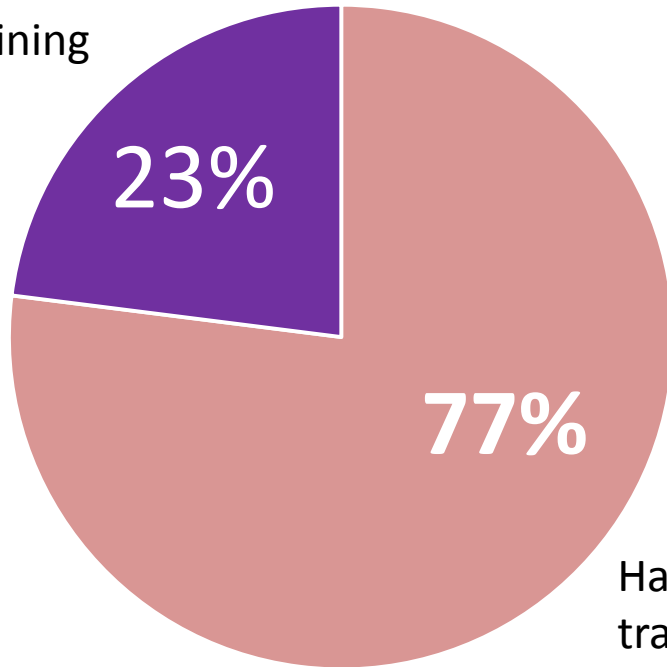
# Late diagnosis and limited access to patient education materials are barriers



# Lack of training is a barrier

Almost 1 in 4 specialists report  
**no specific training** in diagnosis  
and treatment of DME/DR

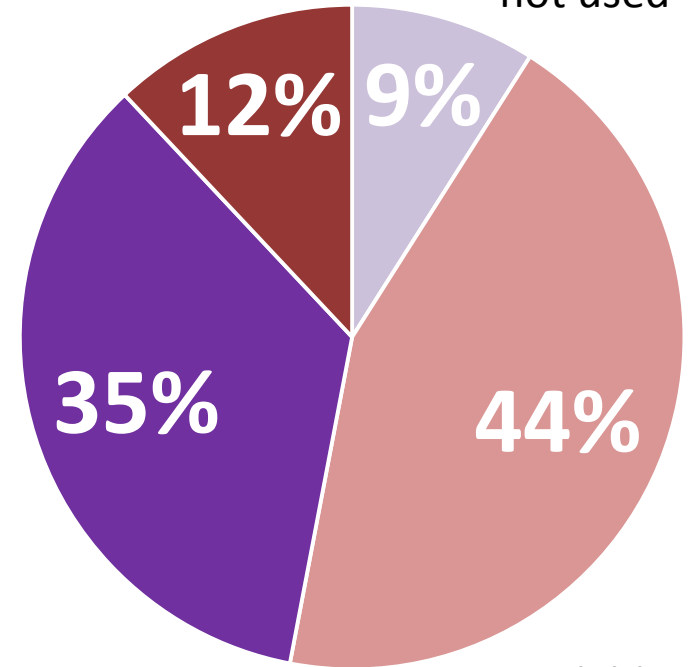
Have had no  
training



Protocols and guidelines for  
detection and  
management of DR

Did not Report

Available but  
not used



Not available

Available and  
used

# Summary

1

## Patient knowledge

Most patients present for screening after vision loss has already occurred



2

## Timely Screening

Impact by:

- Lack of understanding of diabetes-related eye complications
- Long wait times
- High costs



3

## Late diagnosis

Occurs as a consequence of:

- Poor referral pathways
- Lack of multidisciplinary integration
- Insufficient resources for patients and providers

It limits specialists' ability to improve patient outcomes





# IMPACT OF VISION IMPAIRMENT AND LOSS



**I am unemployed...**

*I trained as an electrician  
and worked for 10 years  
in this job.*

**I stopped working at 31**  
*because of the progressing  
loss of vision, because of  
diabetes the loss of vision  
happened.*

- Individual with diabetes,  
age 59, Germany

**Normal Vision**



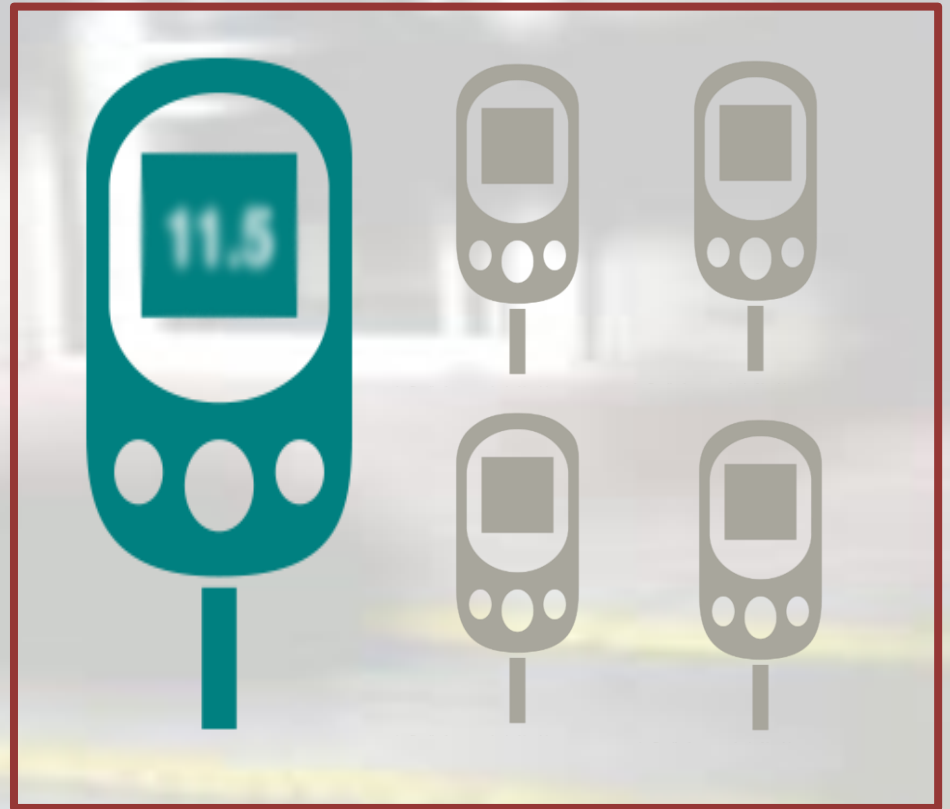
**With Diabetic Retinopathy**



# Self management of diabetes

~1 in 5 people  
with diabetes

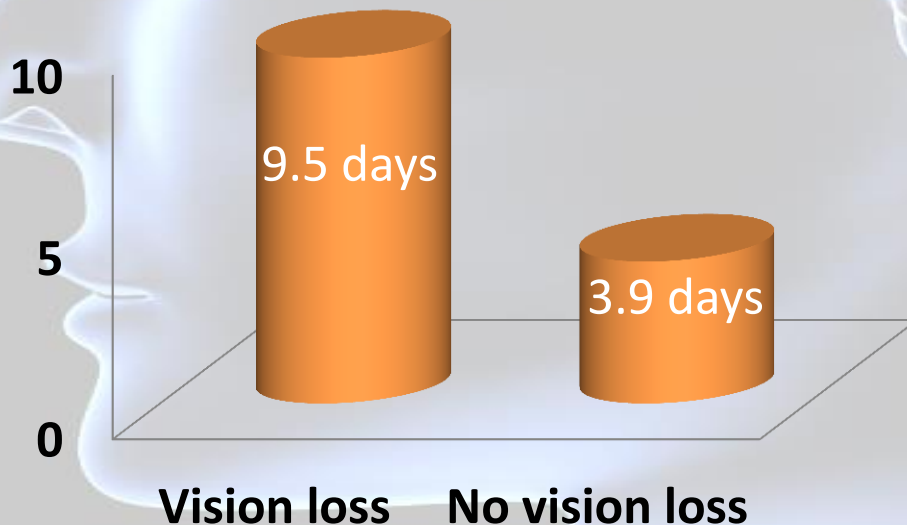
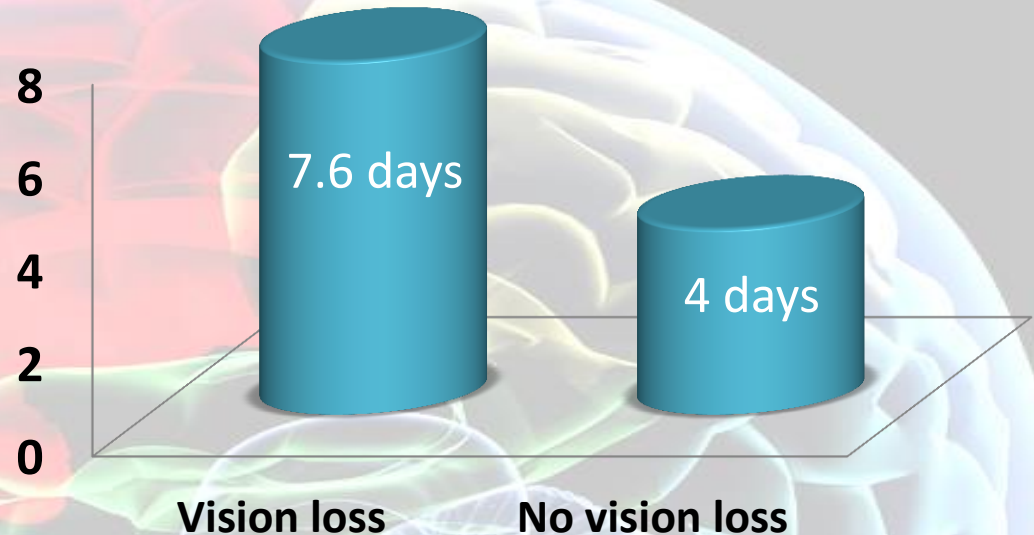
and vision loss report  
difficulties in managing  
their condition



# Vision loss impacts health

## Mental health

People with diabetes who have vision loss have nearly double the number of poor mental health days as people with diabetes without vision loss



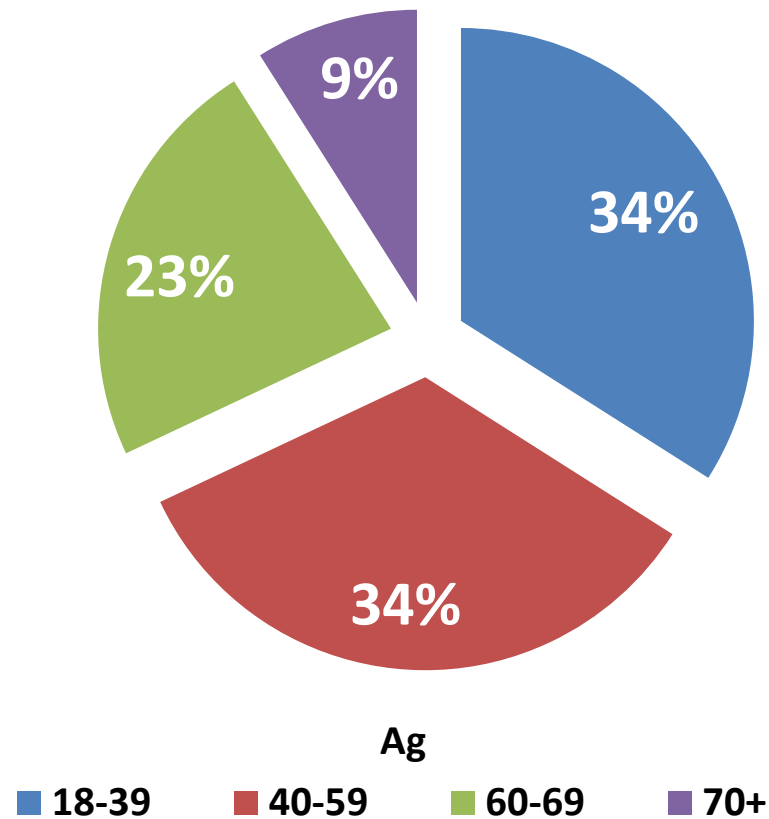
## Physical health

People with diabetes who have vision loss have double the number of poor physical health days as people with diabetes without vision loss

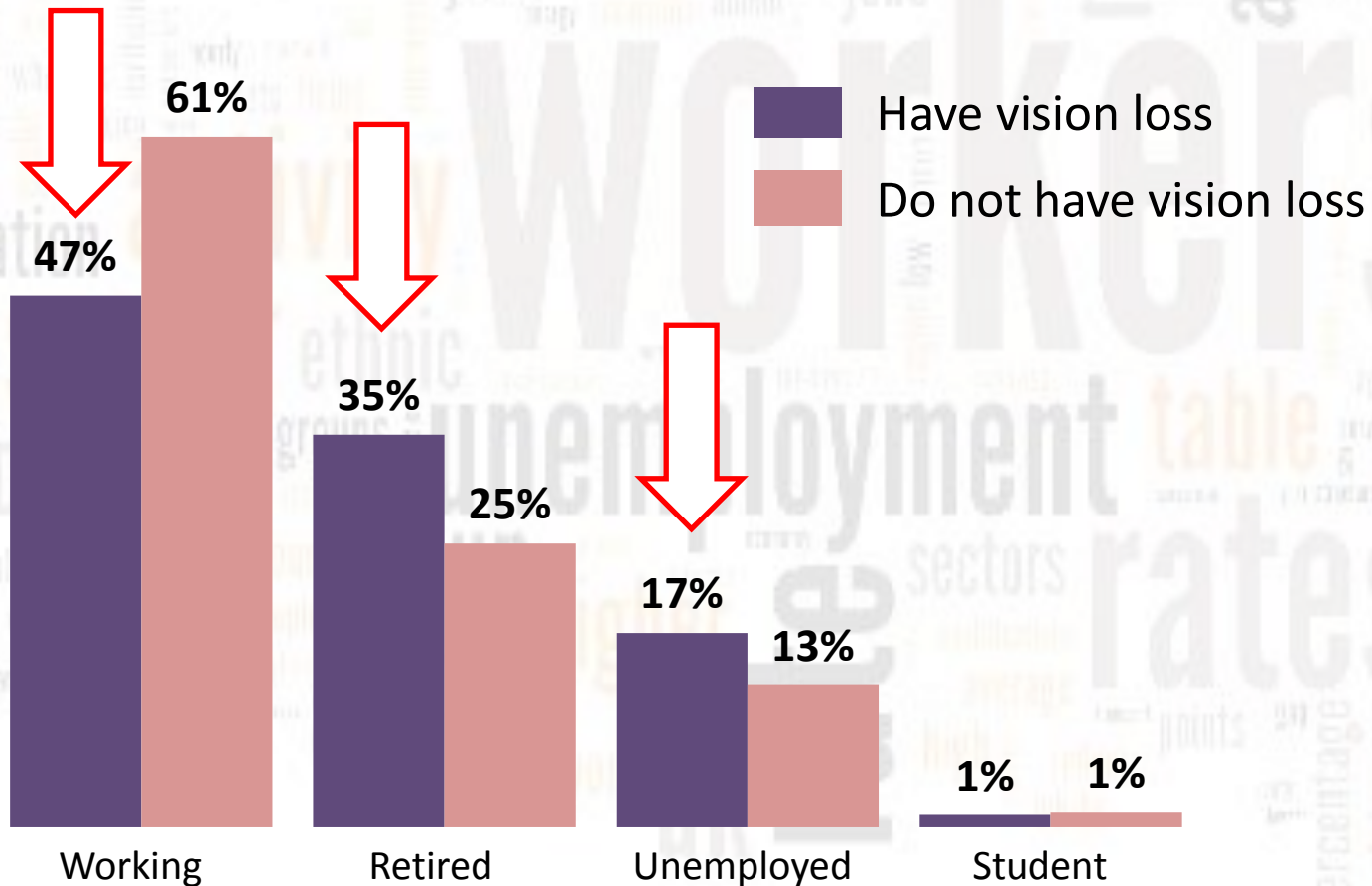


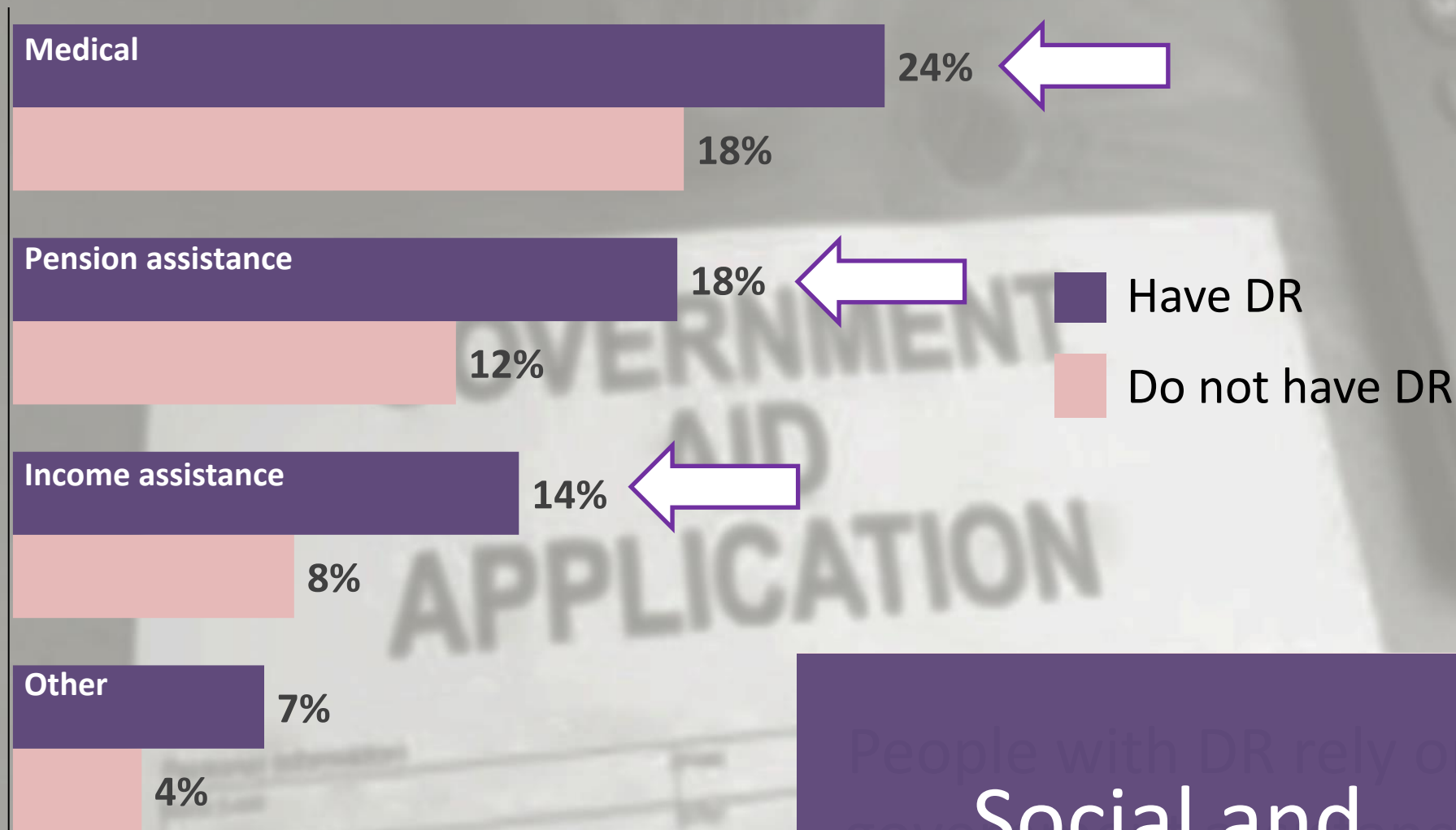
Vision loss impacts being able to work or even keep a job

**THINK**  
**OF THE**  
**CONSEQUENCES**  
**IF YOU DO**  
**NOTHING**



# Vision loss affects employment status



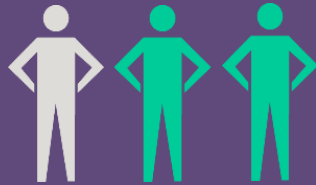


People with DR rely on  
government assistance  
more than those  
without DR

## Social and Economic Burden

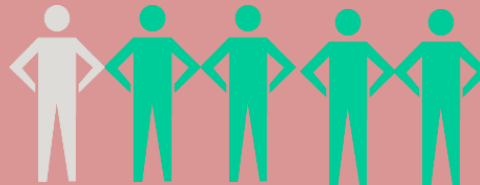
# Vision loss affects daily life

## Driving



More than 1 in 3  
affected (40%)

## Social activities



**1 in 5** affected (20%)

## Leisure and household activities



Around **1 in 4** affected (27%)



# Summary

1

## Patient management

Eye complications impact a person's ability to:

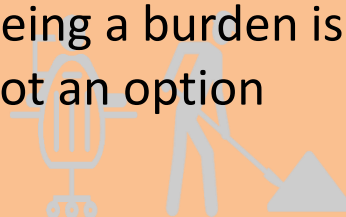
manage diabetes and its complications



2

## Work life

- Our ability to be in paid employment is impacted by vision loss
- Our contribution to family resources is then limited
- Being a burden is not an option



3

## Home life

Our role and responsibilities in family, community and society are impacted with DR and vision loss





Shifting  
DR the  
Barometer Needle

A stylized needle gauge graphic. It features a circular dial with a needle pointing towards the top. The dial has markings for "Good", "Fair", and "Change". The needle is positioned between "Good" and "Fair". The gauge is surrounded by a green, leaf-like border.