

# Healthcare needs in Sweden, a rich western country with high social welfare standards

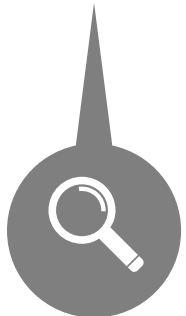
Results from Rare Diseases Swedens' member survey 2022



# Our member survey in a nutshell

## Problem

Modern Healthcare systems are badly adjusted to the needs of people living with rare diseases. **Lack of knowledge** about the disease meets lack of collaboration and coordination between highly specialized healthcare professionals. Besides individual storytelling, **data is needed to raise awareness** for the complex but highly needed system change. But data is scarce because **no registries exist** and disease codes for the more than 7000 rare diseases known today are not being used consequently. Instead, **patient organizations** via their member registries offer the only access to the target group: people living with rare diseases.



## Method

Rare Diseases Sweden performed a digital member survey with over 100 questions in winter 2021 with 1483 participants.



## Results

show that being **diagnosed as adult is common** and that the diagnose process **can take more than 30 years**. Getting diagnosed however improves healthcare encounters according to four in ten participants. Open comments clarify repeatedly that access to **diagnose, and expertise is crucial for perceiving good care**. However, three in ten participants have never met an expert for their diagnose and four in ten report that the best knowledge about the rare disease is available at patient organizations. Although a majority of seven in ten live with a syndrome diagnose with effects on multiple organ systems, only two in ten have an individual care plan and half of the participants would like to have an individual contact person helping them with coordination of care which can take between six and over 21 hours per week.



## Conclusion

Healthcare systems need to adjust better to the needs of people living with rare diseases, even in countries with high social welfare standards. Statistics showing the large challenges are scarce and we strongly suggest more research collaboration to utilize the valuable sources available in patient organizations.

# Summary of our main results

reported by our 1.483 members

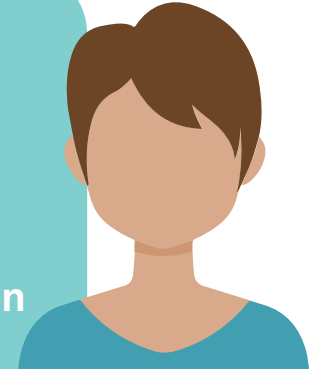
## Diagnose

Often given **late in life**  
Prerequisite for **good healthcare**  
Often needs **genetic testing**  
**Late diagnose** results in **lifelong challenges** in access to healthcare



## Expertise

Prerequisite for **good healthcare**  
Lack of expertise can lead to **denied healthcare**  
**Patient organisations** are a neglected **source for knowledge and collaboration**



## Coordinating structures

Are needed in healthcare to **ease administrative and care- burden** from individuals and next of kin



## Medical treatment

Is available more **often** than expected  
But is **not always reimbursed**



## Dental care

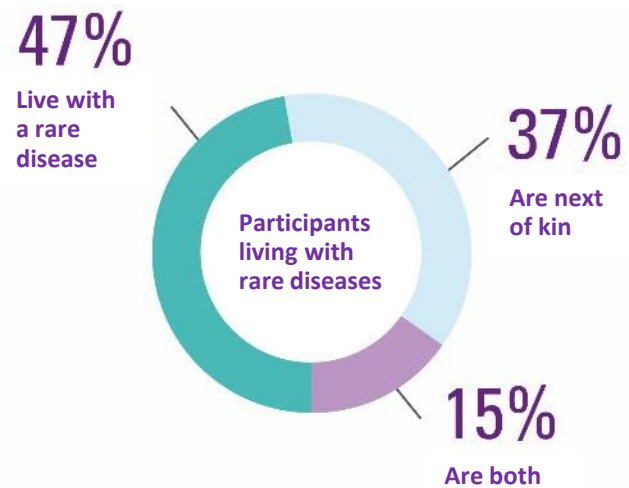
Rare diseases often affect the **dental system**  
Lack of **expertise and reimbursement**



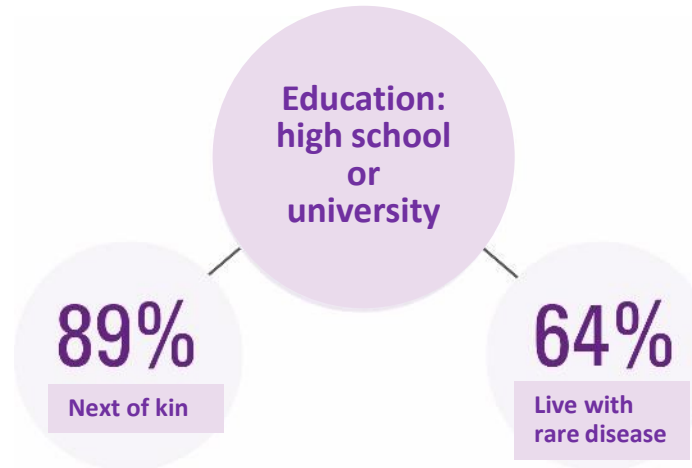
# Rare Diseases Swedens' member survey 2022

## Background of our 1.483 participants

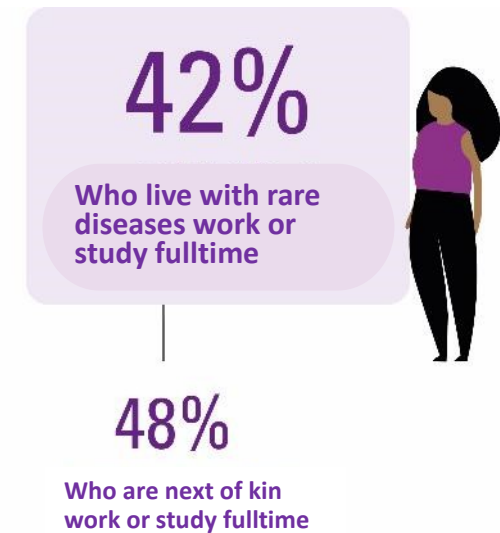
About **half** live with a rare disease **themselves**



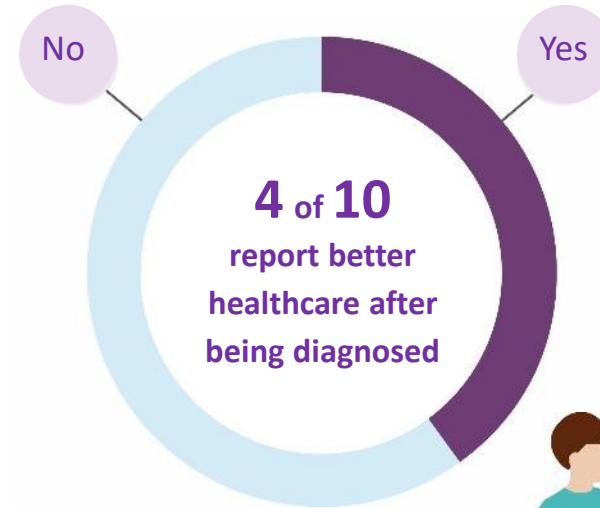
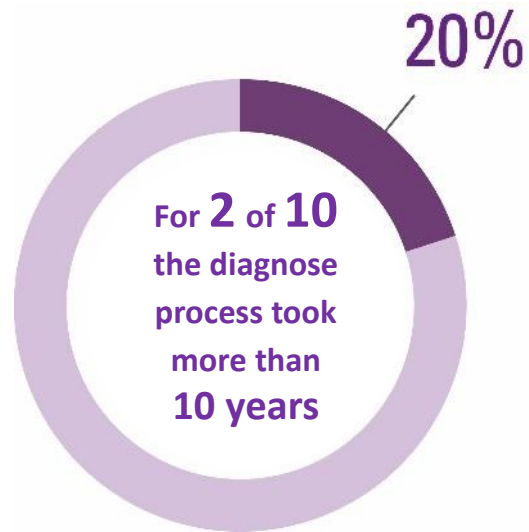
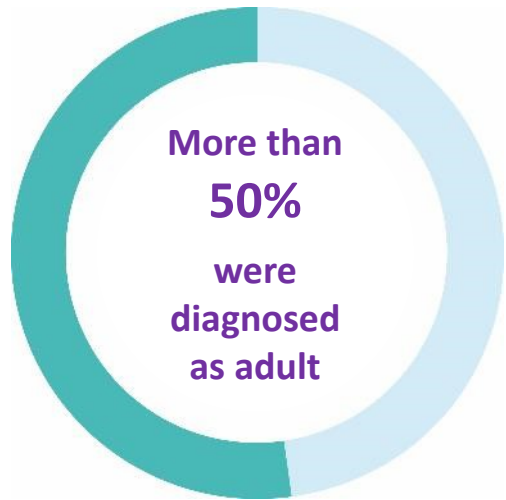
High amount is **well educated**



But less than **half** work **fulltime**



# Diagnose is important but challenging



Those who were diagnosed after 10 years or more, report more challenges in access to healthcare

**Diagnose** is given **late** in life

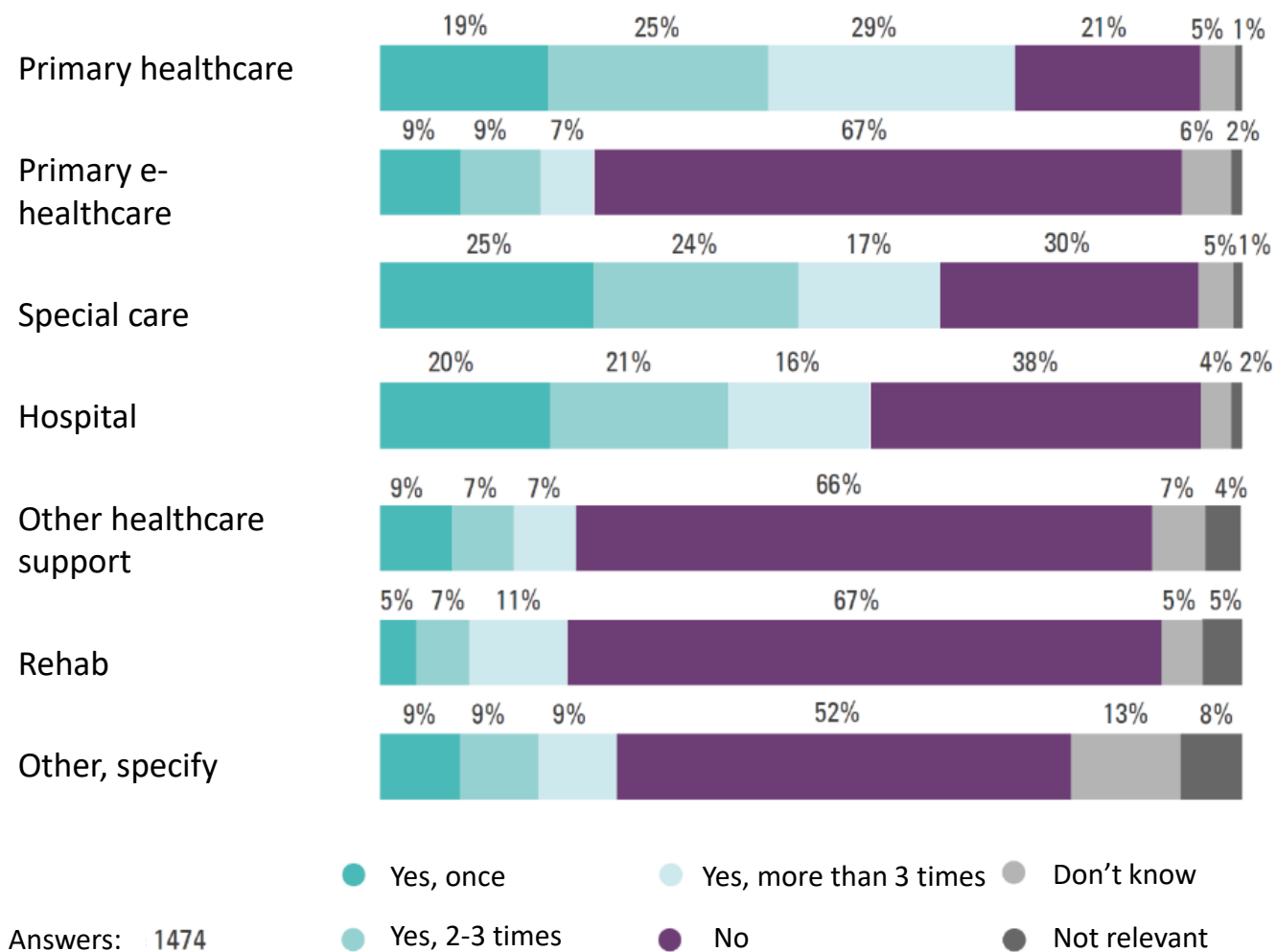
**Diagnose** facilitates **access to healthcare**

Those who are diagnosed **late** report largest challenges in **access to healthcare**

# High frequency of healthcare contacts

Among people living with rare diseases

Question: What were your healthcare contacts during the last 6 months? i.e. during autumn 2022 & covid-19



# Access to healthcare

Can be **denied completely**

Is **especially challenging** for those who are diagnosed late

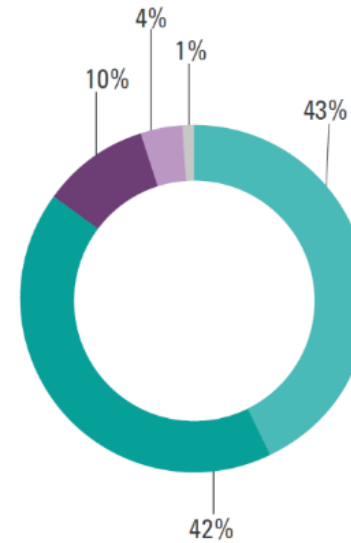
**3 of 10**

Were denied healthcare due to their rare disease



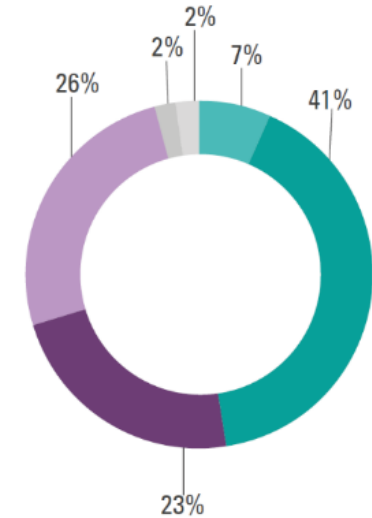
Question: Did you have access to healthcare when needed?

Diagnose within 6 months



Answers: 366

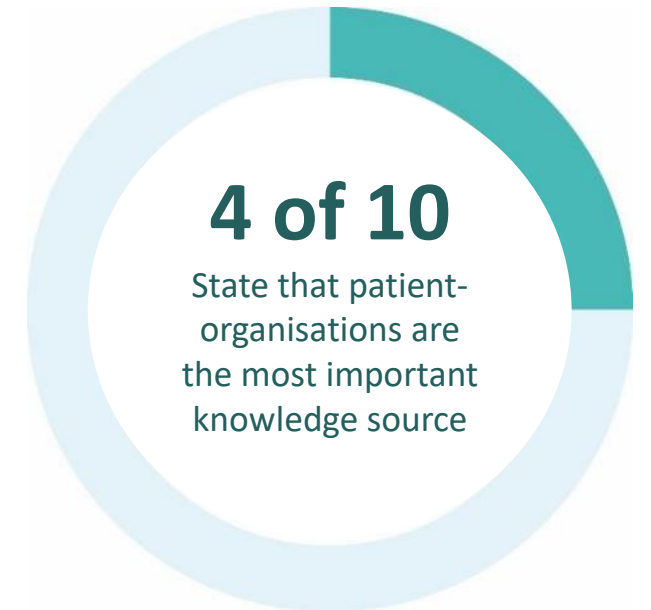
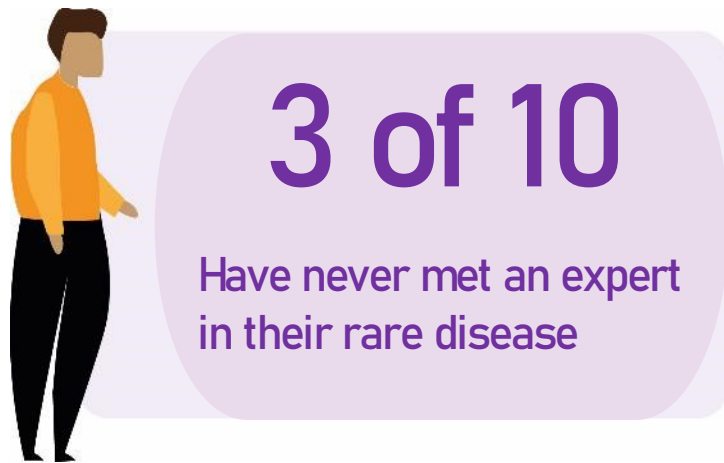
Diagnose after > 10 years



Answers: = 247

- Yes, always
- Yes, most of times
- No, sometimes not
- No, regularly not
- Don't know
- Don't want to answer

# Lack of rare disease expertise in healthcare



Without **expertise** it is difficult to offer good healthcare  
**Diagnose organisations** are an important resource



# Care coordination is important in rare diseases

**7 of 10**

Live with a syndrome affecting multiple organs



20%

**2 of 10**

Have an individual care plan

**6 of 10**

Have a fix healthcare contact

Yes

No

But

**1 in 4**

Don't think that helps

**1 in 7**

spend more than

**11h / week**

on administration and care



Lack of **coordinating structures** to match **complex healthcare needs**

**Responsibility** ends up on individual and next of kin

# Access to and success of genetic testing

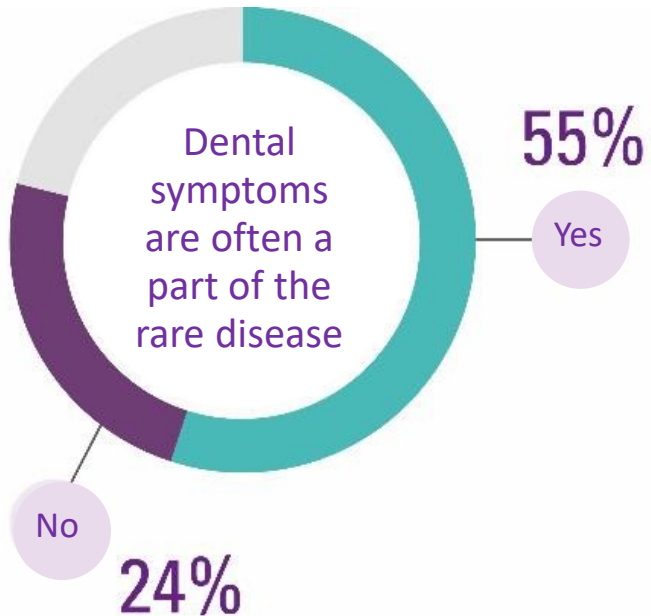


- Genetic testing    ➤ Diagnose    ➤ Better healthcare

## Quotes from participants

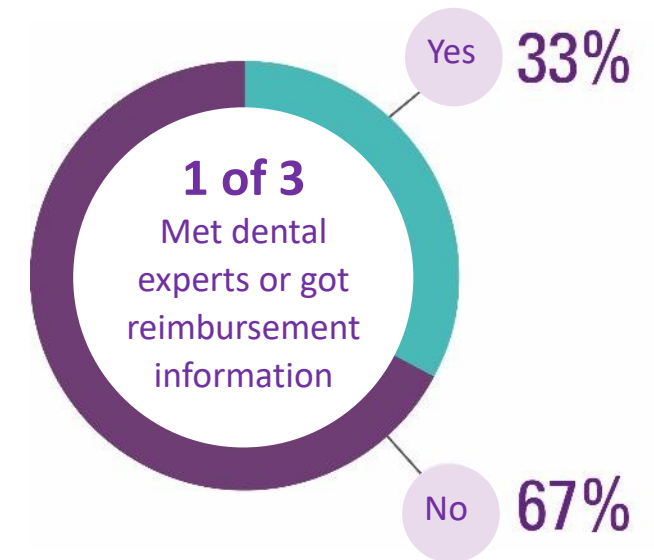
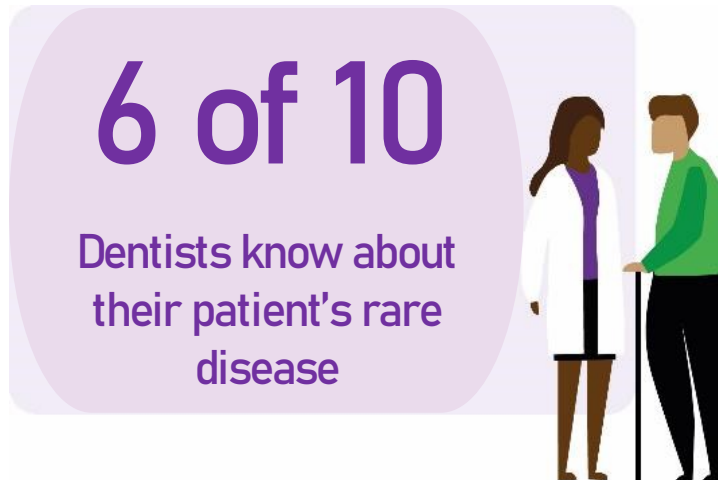
- *It became better, with a diagnose, most doctors understand...*
- **Higher interest** from healthcare professionals

# Rare diseases require knowledgeable dental care

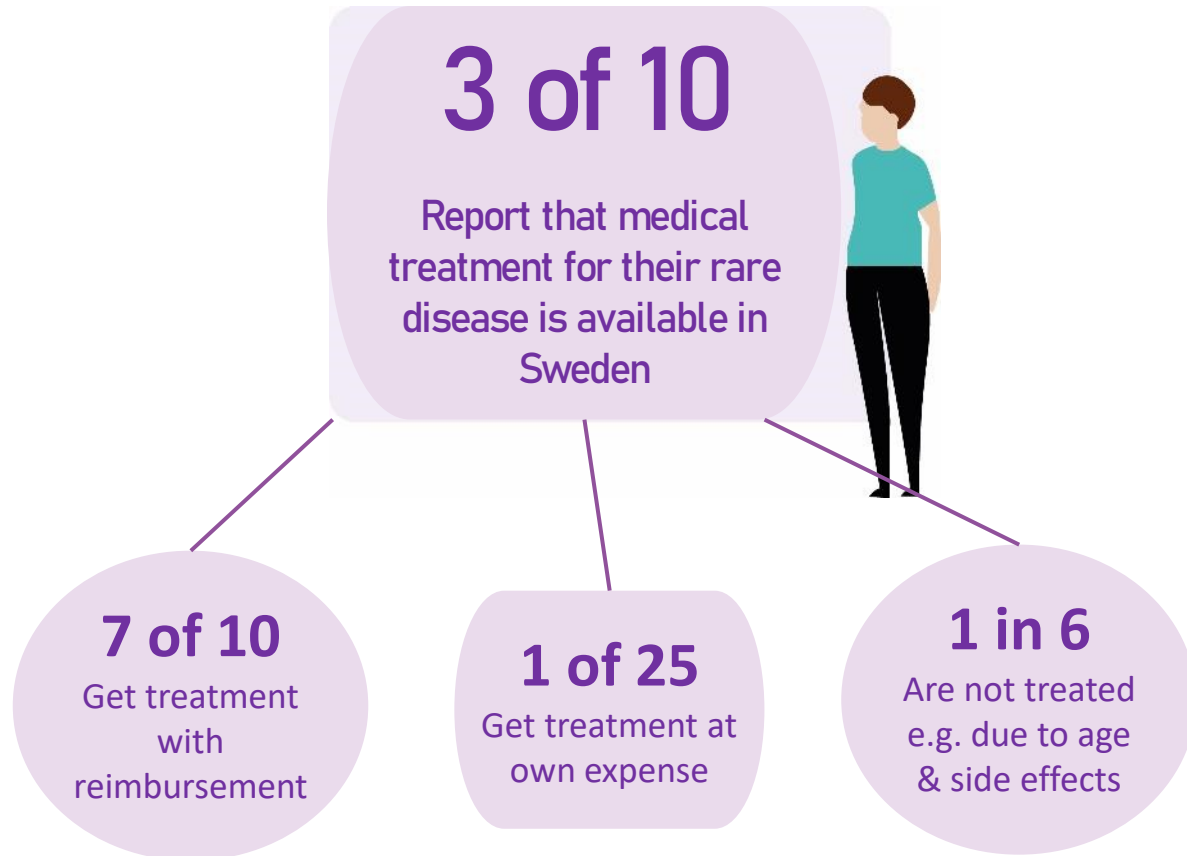


Teeth are a **part of the body**

Lack of access to **expertise** and **financial support**



# Medical treatment for rare diseases



More participants than expected report **access to medical treatment**

Medical treatment is **not always reimbursed**

Mainly **medical reasons** for not being treated

# Rare Diseases Swedens' member survey 2022

## Survey background

### **Webbased survey**

unique survey link

Sent in **December 2021**

answered by **1 483 members**

In **upper age**,

mainly **women**,

mainly **Swedish**

well **educated**

### **Questions focused on access to:**

- expertise
- diagnose
- healthcare
- genetic testing
- dental care
- medical treatment



# Thank you!

[stephanie.juran@sallsyntadiagnoser.se](mailto:stephanie.juran@sallsyntadiagnoser.se)

**SALLSYNTA  
"DIAGNOSER**  
RARE DISEASES SWEDEN