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

Results from Rare Diseases Swedens' member survey 2022 with 1.483 participants

SÄLLSYNTA DIAGNOSER
RARE DISEASES SWEDEN

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.

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.

Results

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

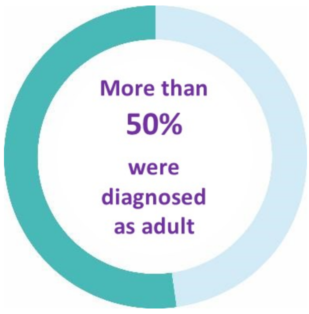
Are needed in healthcare to **ease administrative and care- burden** from individuals and next of kin

Dental care

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

Medical treatment

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



More than **50%** were diagnosed as adult

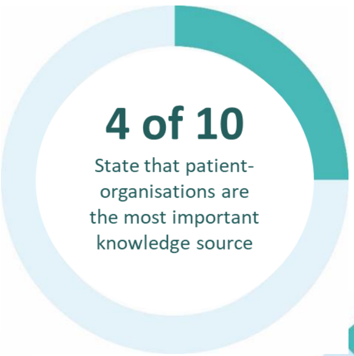
7 of 10

Received a diagnose after genetic testing

4 of 10 report better healthcare after being diagnosed

6 of 10

Report that knowledge in the healthcare system does not suffice to offer good care



4 of 10

State that patient-organisations are the most important knowledge source

3 of 10

Were denied healthcare due to their rare disease

1 in 7

spend more than

11h / week

on administration and care

6 of 10

Have a fix healthcare contact

But

1 in 4

Don't think that helps

3 of 10

Report that medical treatment for their rare disease is available in Sweden

7 of 10

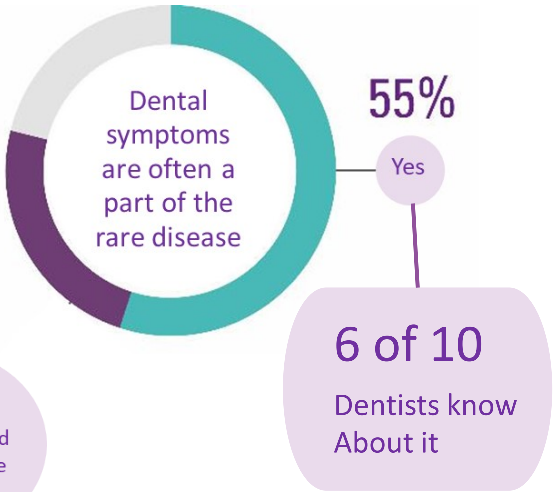
Get treatment with reimbursement

1 of 25

Get treatment at own expense

1 in 6

Are not treated e.g. due to age & side effects



Dental symptoms are often a part of the rare disease

55%

6 of 10

Dentists know About it

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