Why is it important to have a national strategy?

And how can Nordic collaboration help?

Stephanie Juran, Rare Diseases Sweden

Guðrún Helga Harðardóttir, Einstok börn / Unique Children in Iceland

SBONN Nordic co-operation for people living with rare diseases

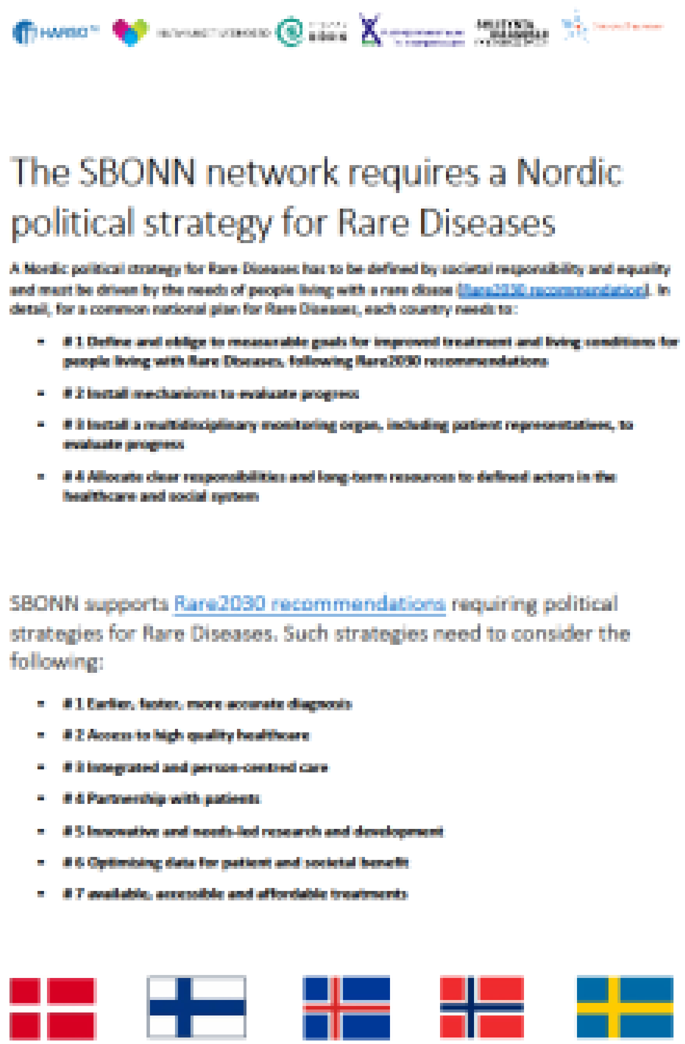
Minimum requirements for national strategies

 # 1 Define and oblige to measurable goals for improved treatment and living conditions for people living with Rare Diseases, following Rare2030 recommendations

 # 2 Install mechanisms to evaluate progress

 # 3 Install a multidisciplinary monitoring organ, including people living with rare diseases, to evaluate progress

 # 4 Allocate clear responsibilities and long-term resources to defined actors in the healthcare and social system



The SBONN network requires a Nordic political strategy for Rare Diseases

A Nordic political strategy for Rare Diseases has to be defined by societal responsibility and equality and must be driven by the needs of people living with a rare disease (Rare2030 recommendations). In detail, for a common national plan for Rare Diseases, each country needs to:

- **# 1 Define and oblige to measurable goals for improved treatment and living conditions for people living with Rare Diseases, following Rare2030 recommendations**
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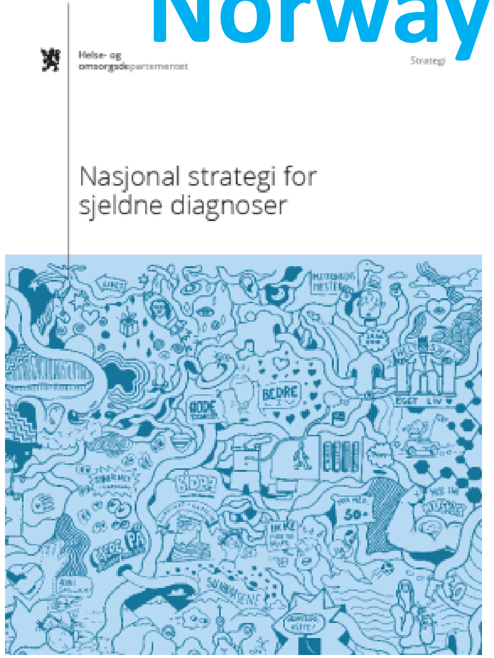
SBONN supports Rare2030 recommendations requiring political strategies for Rare Diseases. Such strategies need to consider the following:

- **# 1 Earlier, faster, more accurate diagnosis**
- **# 2 Access to high quality healthcare**
- **# 3 Integrated and person-centred care**
- **# 4 Partnership with patients**
- **# 5 Innovative and needs-led research and development**
- **# 6 Optimising data for patient and societal benefit**
- **# 7 available, accessible and affordable treatments**

National RD strategies in the nordics

Norway



Helse- og omsorgsdepartementet

Strategi

Nasjonal strategi for
sjeldne diagnoser

Denmark

Sundhedsstyrelsen

NATIONAL STRA
SJÆLDNE SYGD

SUNDHEDSSTYRELSEN

2018

National
sjældne

Evaluering af den

Finland

Rapport av arbetsgruppen för sällsynta sjukdomar

Nationella programmet för sällsynta
sjukdomar 2019–2023

SOCIAL- OCH HÄLSOVÅRDSMINISTERIETS RAPPORTER OCH PROMEMORIOR 2020:10

Need analysis → 5 prioritized areas
Clear goals
Clear orders and responsibilities
System with RD perspective

Need analysis → 8 prioritized themes
Clear goals
Clear orders, responsibilities, some BUDGET
EVALUATION!

Need analysis
Legal & structural ADAPTATION
Evaluation
Clear recommendation
COST ANALYSIS

National strategies in the nordics show:

- ✓Clear (longterm) goals
- ✓Clear prioritization of areas and efforts
- ✓Involving all relevant actors
- ✓Clear responsibilities
- ✓(Resources)
- ✓Follow-up and evaluation

But there are still a lot of needs to be met!

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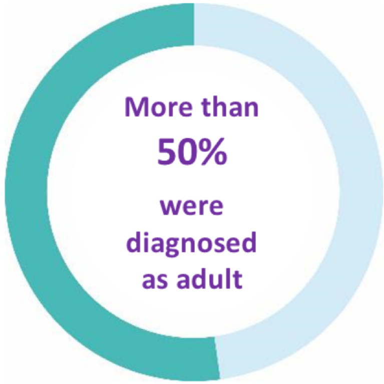
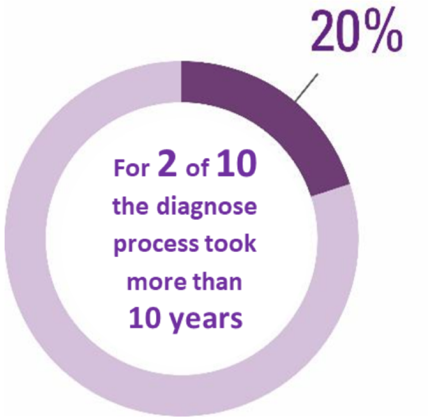
Results from RD Sweden’s member survey 2022

1486 participants

Diagnose

Access to healthcare

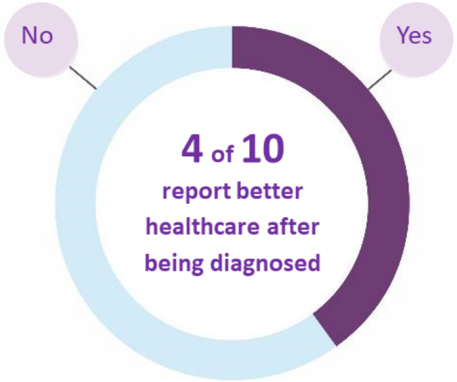

More than
50%
were
diagnosed
as adult



For 2 of 10
the diagnose
process took
more than
10 years


4 of 10
Received
genetic
testing

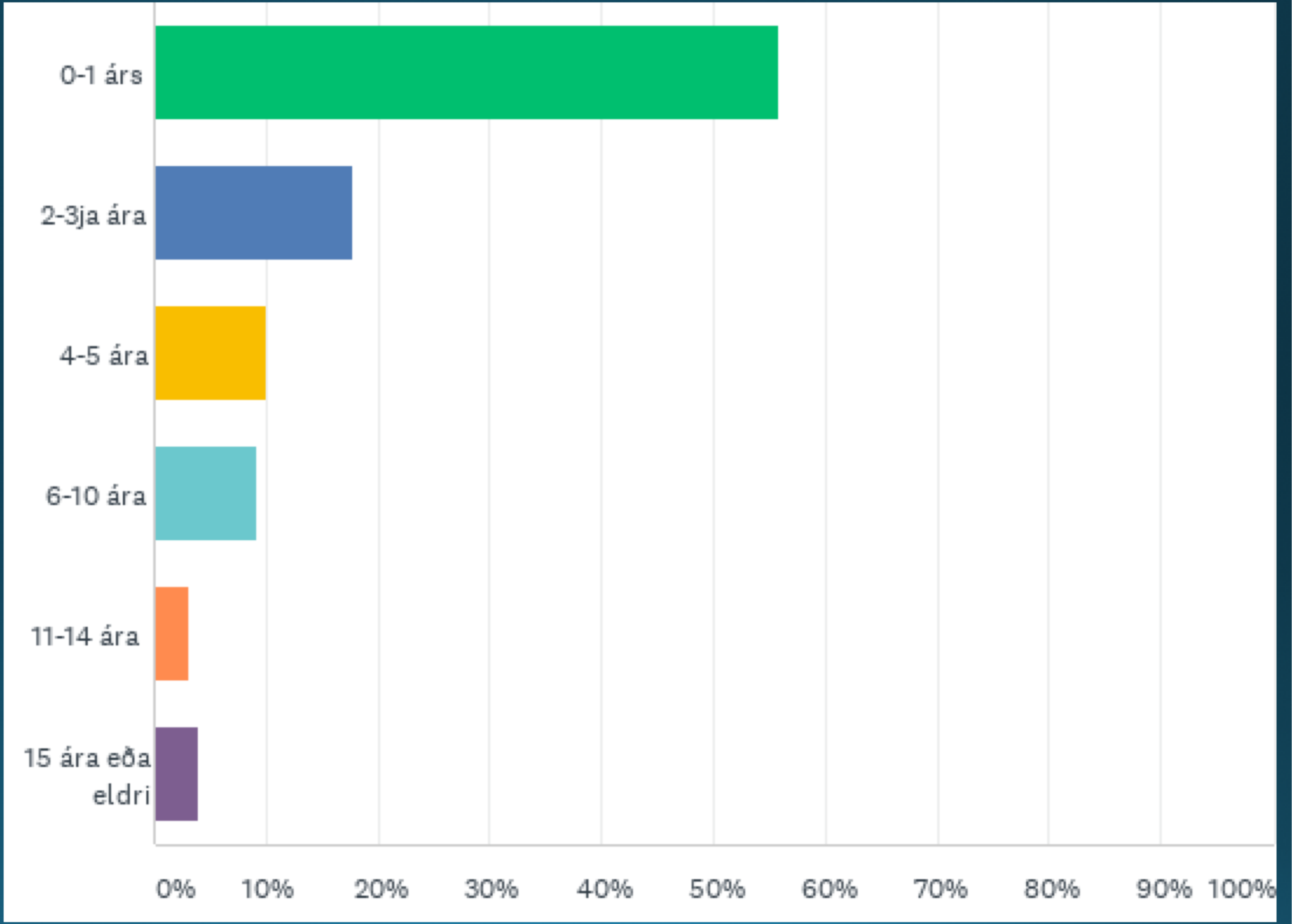

3 of 10
Were denied healthcare
due to their rare disease

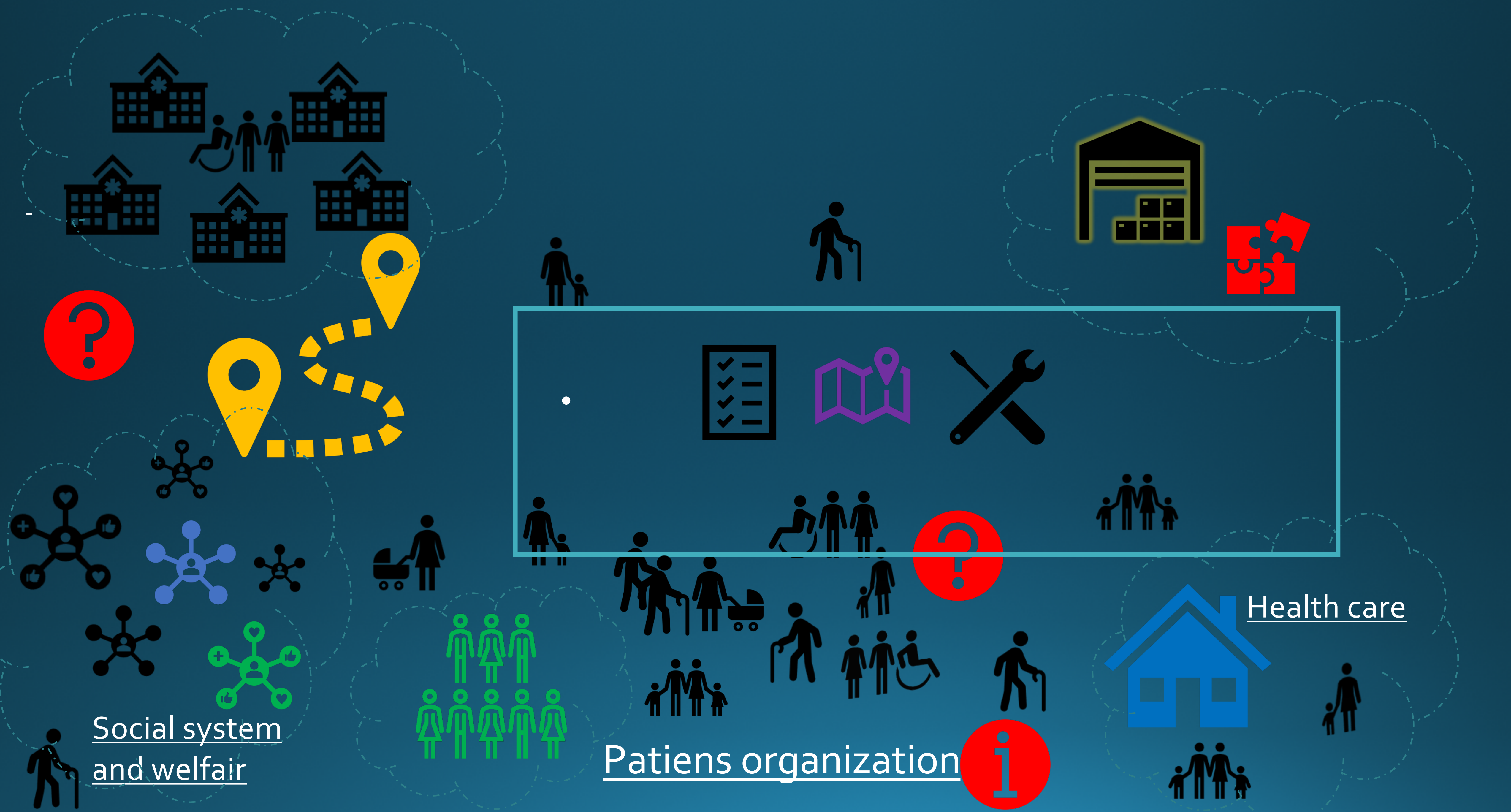


4 of 10
report better
healthcare after
being diagnosed

- ➢ *Large needs, complex challenges, planning is needed!*

Reality in Iceland – Early diagnoses are going well



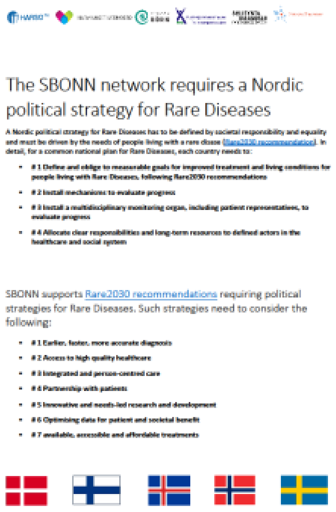


Health care

Social system
and welfair

Patiens organization

Take home message



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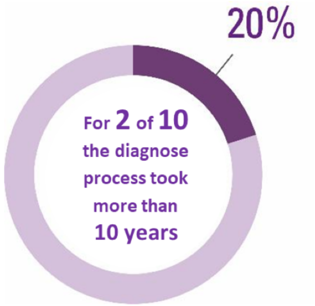
With a minimum of requirements we can reach a lot

Our neighbours are on a good way

Needs in the RD community are huge



Let’s collaborate and learn from each other!

SBONN

Thank you for your attention!

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