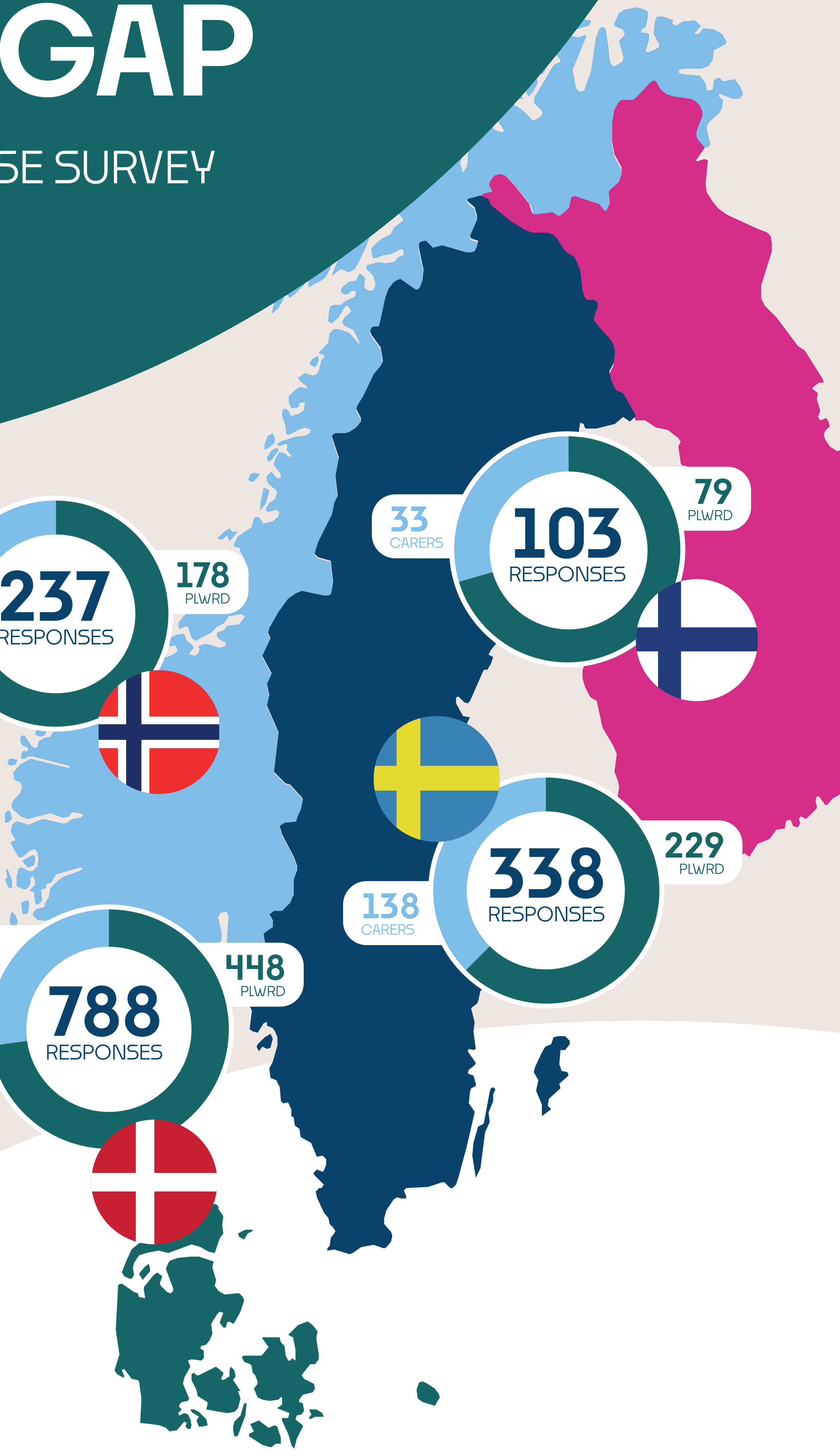
THE PATIENT EMPOWERMENT GAP

NORDIC
RARE DISEASE
SUMMIT 2025

THE PATIENT EMPOWERMENT GAP

THE LARGEST NORDIC RARE DISEASE SURVEY

1607 TOTAL RESPONSES



123 RESPONSES
121 CARERS
7 PLWRD

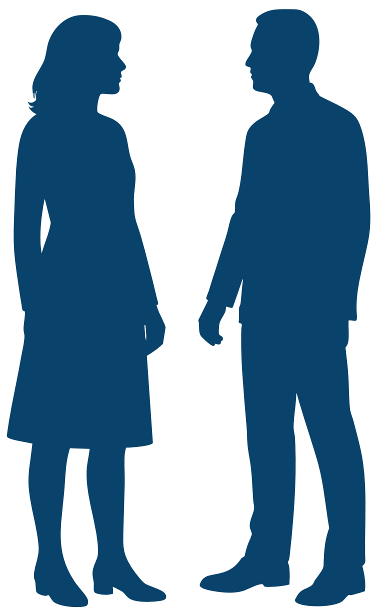
237 RESPONSES
67 CARERS
178 PLWRD

103 RESPONSES
33 CARERS
79 PLWRD

338 RESPONSES
138 CARERS
229 PLWRD

788 RESPONSES
384 CARERS
448 PLWRD

963 CARERS



89% FEMALES
11% MALES

81% FEMALES
18% MALES

761 PLWRD*

Avg. age: **52**

* People Living With Rare Disease

THE PATIENT EMPOWERMENT GAP

Empowerment refers to the process by which people gain control over the factors and decisions that shape their lives.

The WHO describes empowerment as **"a prerequisite for health"**

The Nordic Rare Disease Roadmap published after the last summit called for **the expertise of people living with rare diseases to be recognised as a resource on all levels of the Nordic healthcare systems.**

Nordic rare disease patients urgently need better coordinated care and psychological support, with

95% calling for improved collaboration between healthcare professionals.

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A CALL FOR CHANGE IN THE TREATMENT FOR RARE DISEASES

"To have regular contact with healthcare, even if there's no cure. Psychological support should be available even if the patient doesn't ask, e.g., in family groups."

"Access to a correct diagnosis within a reasonable timeframe - kept in 'suspected diagnosis' for years and can't access help to get diagnosis formally and the rights that go along with the diagnosis. So tired and can't access help that I know is essential to stop further damage to health"

"Co-operation between different hospitals/units, and between physical and mental health - the experience is that no one sees the big picture, and all units push the responsibility onto someone else!"

WHAT NOW?

As policy expands to include increasing references to patient empowerment in national rare disease strategies, it is important to ensure that people living with rare diseases themselves are the ones shaping the meanings and uses of this term. So that it may be used correctly, reflect the needs of the people it relates to, and most importantly become measurable so that it might be improved.

1

BASIC HEALTH NEEDS

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1 BASIC HEALTH NEEDS

Access to medical specialists for your/the patient's disease

While 95% of rare disease patients need specialist access and coordinated care, more than one in three lack holistic long-term treatment plans and face significant barriers accessing medical expertise, highlighting a **critical gap between essential care needs and current healthcare delivery.**

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1

BASIC HEALTH NEEDS

Access to medical specialists for your/the patient's disease

> **"Norway includes rare diagnoses in its diagnostic system... I received my diagnosis from a professor at the national hospital, but the diagnosis code doesn't exist in the Norwegian system. That made it very difficult to access medication"**

38% of respondents classed the development of a long-term treatment plan as the most unmet basic health need

84% of respondents agree that there should be easier access to medical expertise or treatment in neighbouring Nordic countries for people living with rare diseases

90% of respondents identified timely and accurate diagnosis as critical, with 22% saying this need remains unmet

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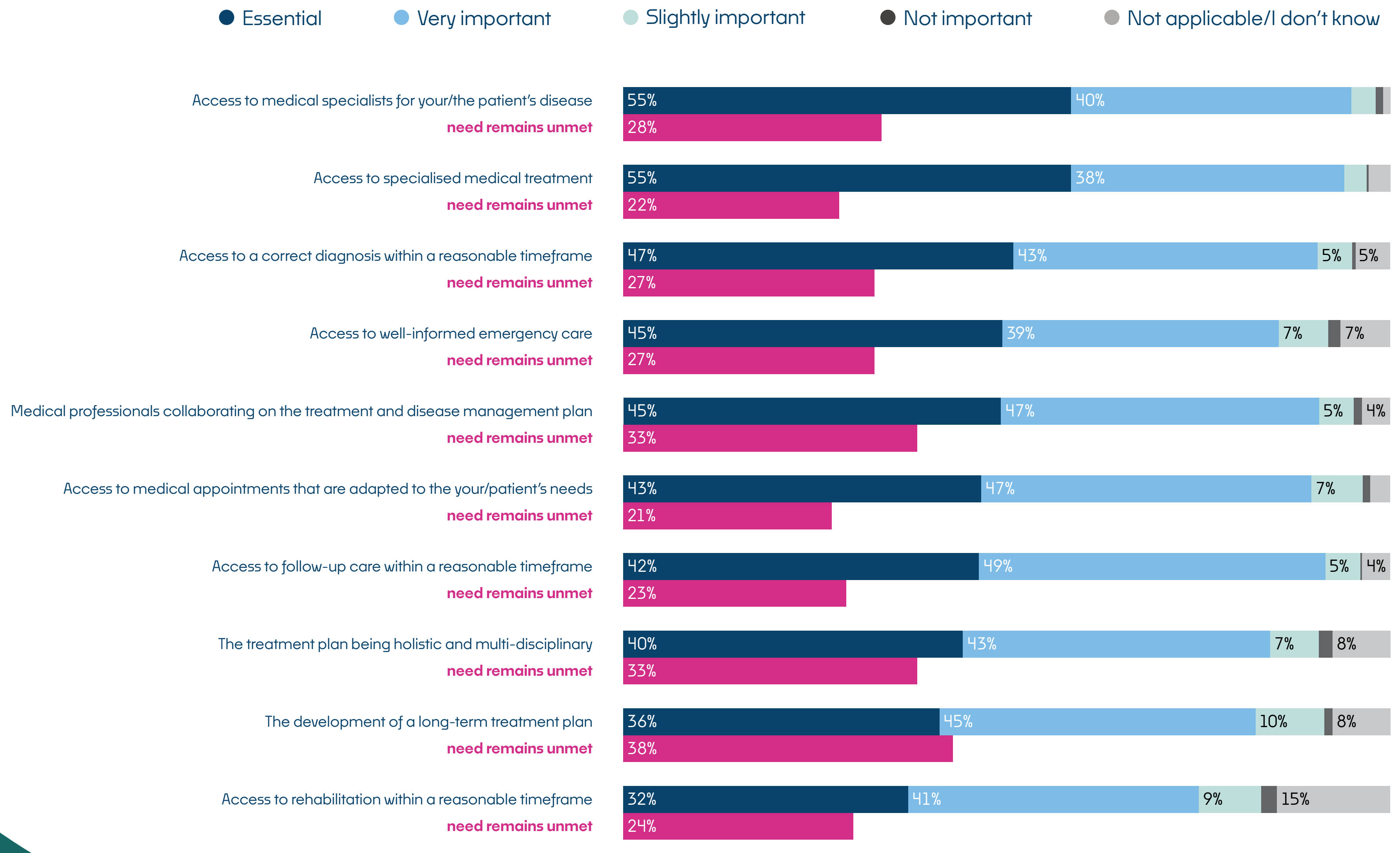

BASIC HEALTH NEEDS:

What Respondents consider Important and Whether Needs are Unmet

2 SAFETY AND SECURITY

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2 SAFETY AND SECURITY

Consistent and easy access to treatment

Despite 96% of patients prioritising trust in healthcare systems, one in four lack consistent treatment access and nearly one in three struggle with inadequate financial support, **revealing fundamental gaps in healthcare security and trust for rare disease patients.**

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2

SAFETY AND SECURITY

Consistent and easy access to treatment

> **“Ideally there is one coordinator [of specialists]. I feel like I run from pillar to post with no coherence… You need to be healthy to navigate the Danish healthcare system”**

96% say trust in the healthcare system is important, of which 52% deem it essential, yet 22% say they do not feel that this trust is there.

Access to financial support was the least well met safety need assessed, with 28% listing it as an unmet need. In Finland, this went up to 37% of respondents.

Consistent and easy access to treatment is basic for patients to feel secure, agreed by 48% as essential, but for 25% of respondents they didn’t feel this need was met.

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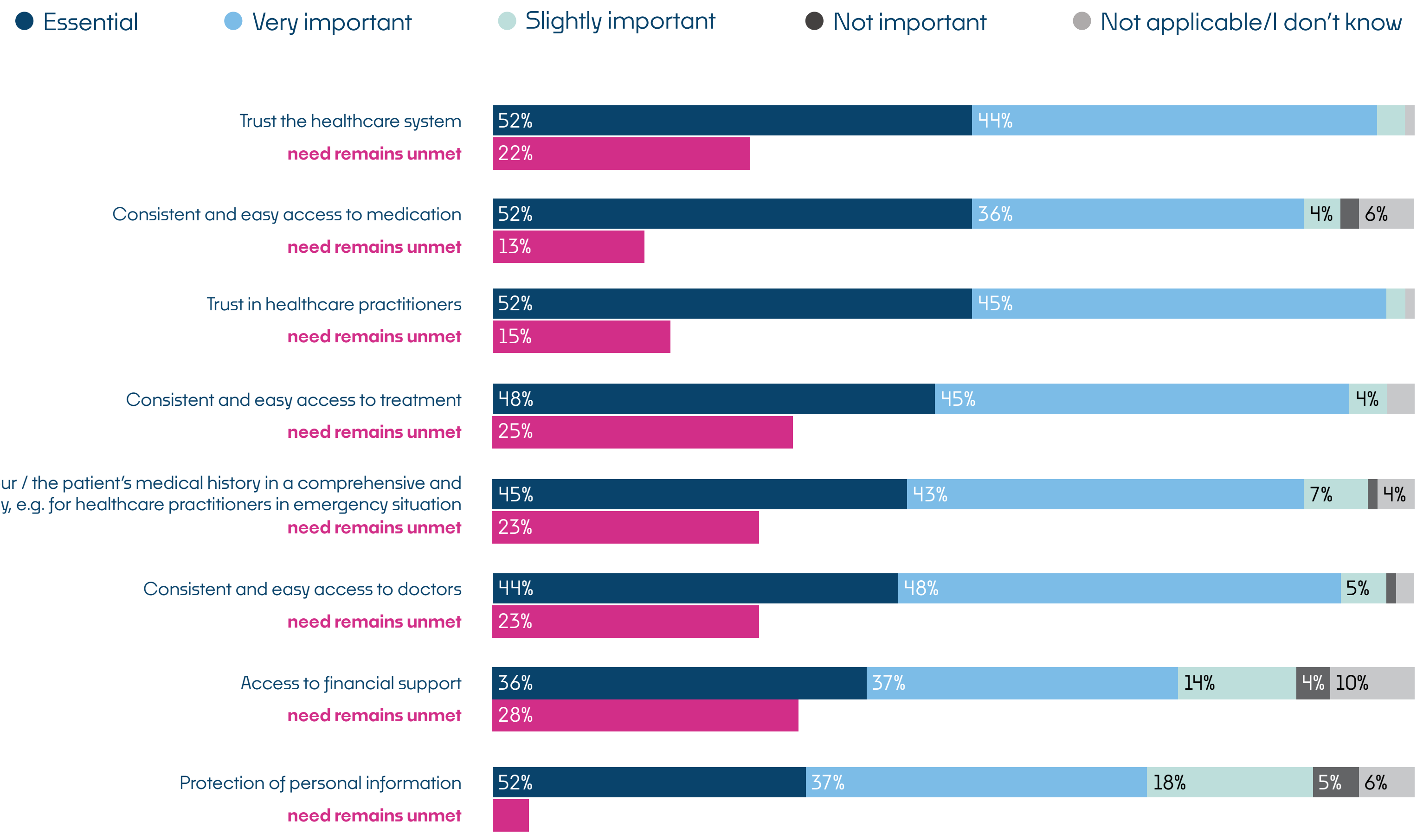
SAFETY AND SECURITY:

What Respondents consider Important and Whether Needs are Unmet



3 INFORMATION AND KNOWLEDGE

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3 INFORMATION AND KNOWLEDGE

Existence of medical specialists or researchers who are knowledgeable about the disease

While 96% of patients consider knowledgeable medical specialists vital, nearly one in three face an information vacuum about their conditions and treatment options, **with many discovering support networks years after diagnosis.**

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3

INFORMATION AND KNOWLEDGE

Existence of medical specialists or researchers who are knowledgeable about the disease

“I think doctors should inform people about rare diagnoses and rare disease networks when they know they are dealing with such patients. Or make it visible in the hospital environment. I’ve lived with my illness my whole life, and only at age 24 did I discover a small network of people with the same disease”

Across the Nordics, 58% of respondents deemed the existence of medical specialists or researchers who are knowledgeable about the disease as essential, rising to 96% who considered it very important. And for 29% of respondents, this key need is not met, highlighting the need for continued research and medical learning.

This is compounded by the ongoing lack of basic information about rare disease at 19% and information about treatment options faring even worse with 29% of respondents considering this need unmet.

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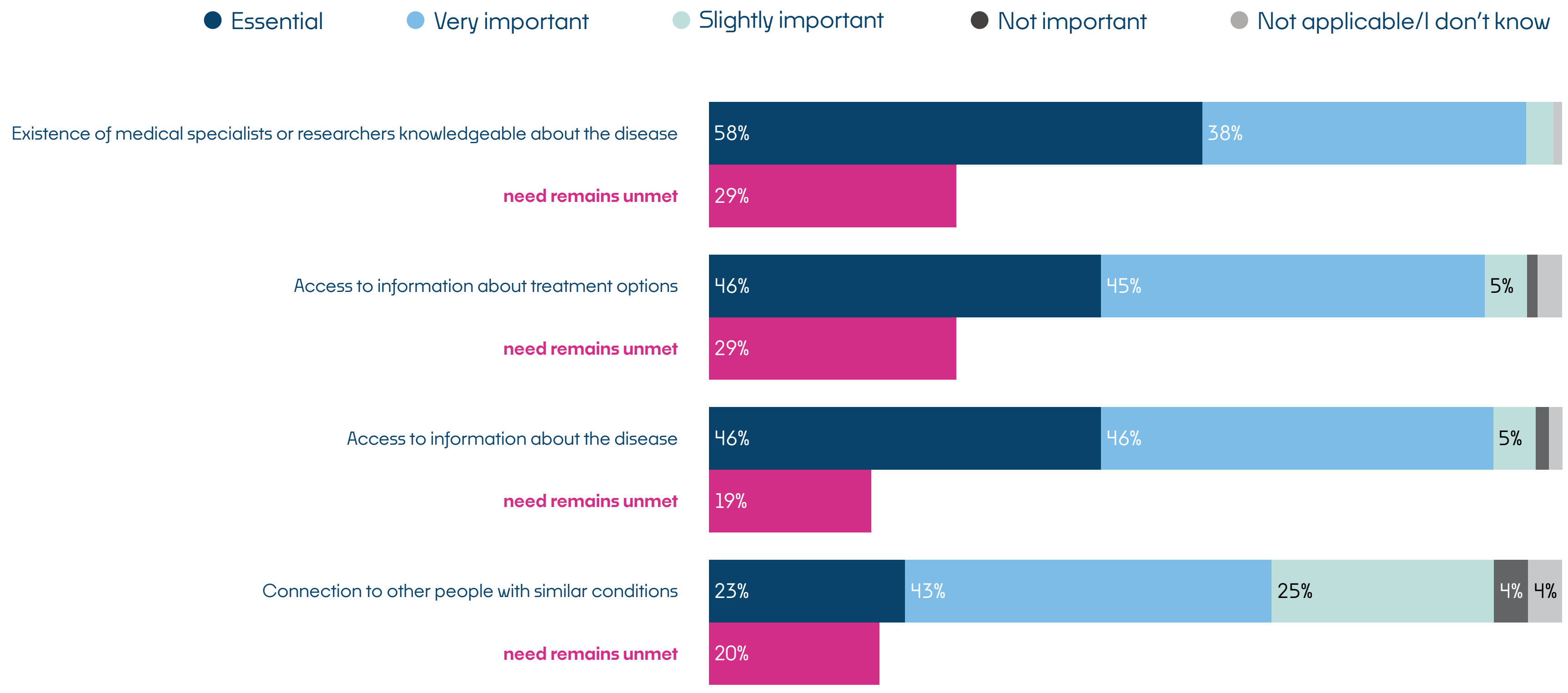
INFORMATION AND KNOWLEDGE:

What Respondents consider Important and Whether Needs are Unmet

4

SUPPORT AND BELONGING

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4 SUPPORT AND BELONGING

Feeling fully included in society

While 87% of rare disease patients consider social inclusion vital, critical gaps persist in psychological support (unmet for 41%) and community connection (unmet for 11%),

with many patients facing isolation and lacking access to specialised mental health care that understands their unique challenges.

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SUPPORT AND BELONGING

Feeling fully included in society

“I think psychiatry could be better, and that there should be more choices and follow-ups by good psychologists who understand that many of those with rare diagnoses have been severely exposed to bullying and exclusion during their childhood/adolescence, and that they live with scars — lifelong scars — that affect their quality of life every day”

“I wish there was a register where you can sign up to, for example, get information about new treatments or have the opportunity to meet others with the same rare diagnosis”

An overwhelming 41% of respondents deemed their need for professional psychological support unmet

Clearly top of mind for respondents was the attitude of society at large, with 41% considering feeling fully included in society essential, rising to 87% considering it at least very important. And for 25% this remains unmet

69% of respondents called out the importance of access to communities, networks or organisations of other people living with rare diseases

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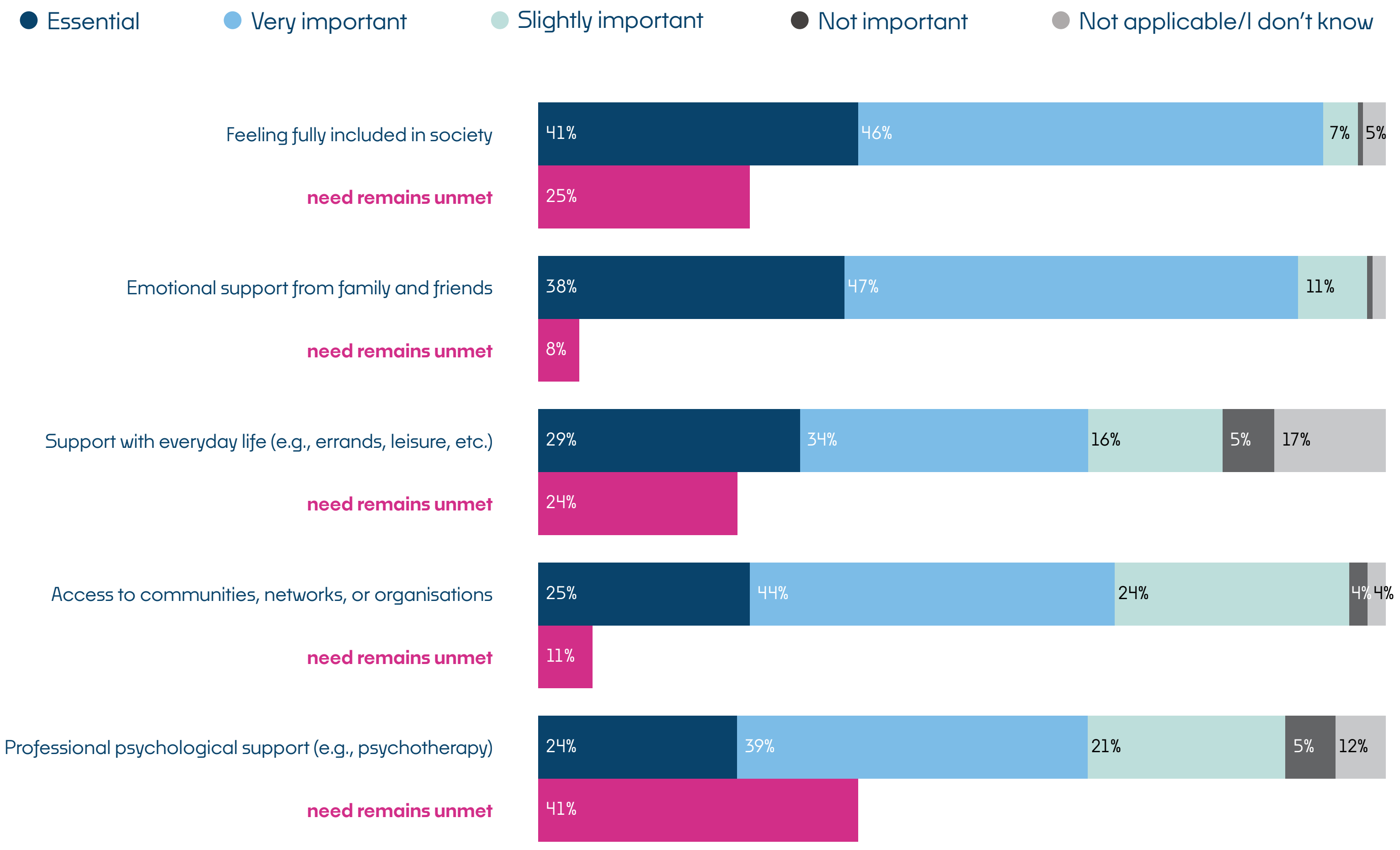
SUPPORT AND BELONGING

What Respondents consider Important and Whether Needs are Unmet



5 SUPPORT AND BELONGING

5 AUTONOMY AND ADVOCACY

Feeling listened to and believed when communicating the condition to community support services

While nearly all patients (97%) emphasize the critical importance of being heard and believed by healthcare providers, significant gaps remain in shared decision-making, with one in three lacking access to second opinions and a quarter excluded from their own treatment planning,

highlighting a persistent disconnect between patient expertise and healthcare delivery.

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5

AUTONOMY AND ADVOCACY

Feeling listened to and believed when communicating the condition to community support services

> **“One care unit includes me in all discussion and planning, while other care units make decisions without me, even though I repeatedly point out that I want to participate. Decisions are often made above my head, and when I am informed about the decisions, I have to point out why my specific illness does not work in relation to their decisions.”**

97% of respondents stressed the importance of doctors becoming better listeners to patient concerns and experiences, and believing them, with 19% feeling this was an unmet need today.

89% agree that doctors and other healthcare professionals need to better listen to people living with rare diseases who have better knowledge and expertise on their disease.

92% considered patient and/or carer inclusion in treatment decisions and the development of treatment plans (86%) to be at least very important, with 11% and 25% respectively considering this not to be the case currently.

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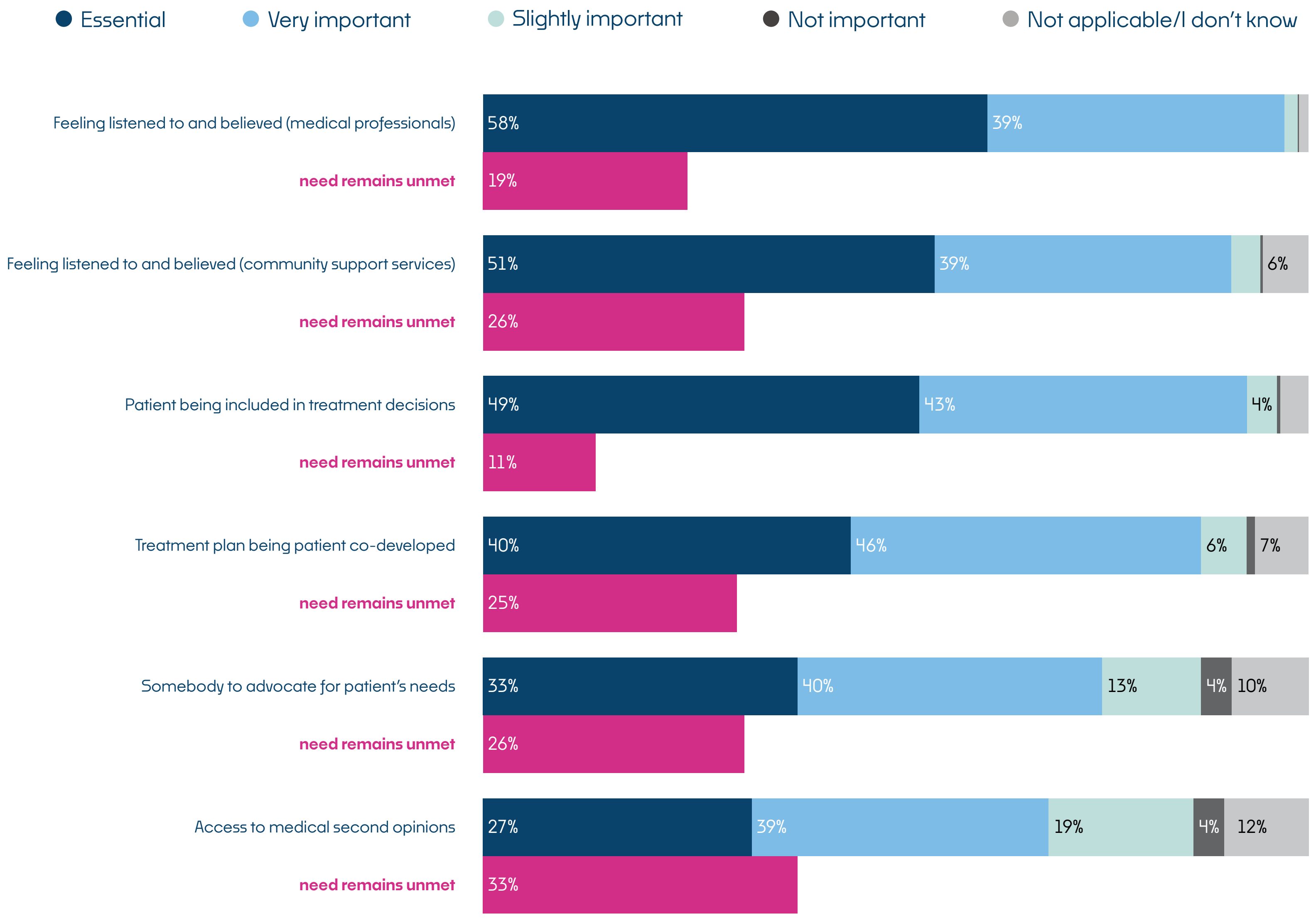
AUTONOMY AND ADVOCACY

What Respondents consider Important and Whether Needs are Unmet



6 SELF-ACTUALISATION

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6

SELF-ACTUALISATION

The ability and freedom to pursue hobbies and interests

While over 80% of rare disease patients prioritize pursuing personal goals and interests, they face significant barriers in accessibility and support systems, from educational and workplace inclusion to basic infrastructure needs,

with the constant burden of advocating for essential aids across different jurisdictions.

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6

SELF-ACTUALISATION

The ability and freedom to pursue hobbies and interests

“I am worried that my new municipality (and region) will not accept my needs and need for aids. It is very exhausting to have to start all over again every time you have to apply for renewal of assistive devices.”

“Benches/chairs etc could be set up in several places so that those of us who cannot stand and walk for long periods could get a rest. I think in the pedestrian streets and in the shops. It would help me enormously and would allow me to get out more and for longer.”

82% of respondents consider the ability and freedom to pursue personal goals as at least very important, and 37% the ability to pursue hobbies and interests as essential to their wellbeing. Both of these needs were unmet for over 17% of respondents.

In education and in the workplace, empowerment remains out of reach as well for many. 29% deem accessibility and inclusivity measures in education as essential, unmet for 14% and 25% deem it essential in the workplace, unmet for 11%.

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SELF-ACTUALISATION:

What Respondents consider Important and Whether Needs are Unmet