

eNAP European Patient Survey 2025 on Narcolepsy and Idiopathic Hypersomnia

1,667 respondents from 15 countries
Public report with all 59 questions



eNAP
European Narcolepsy
Alliance for Patients



■ Index

Preface	page 3
About respondents	page 9
Overall take-aways	page 10
01 Diagnosis and demographics (Q1-9)	page 14
02 Diagnosis Journey (Q10-25)	page 31
03 Treatment and medication (Q26-36)	page 80
04 Support: Financial, communication wise and from N/IH patient organisations (Q37-49)	page 103
05 Everyday life with N/IH (Q50-59)	page 133

■ Preface: Aims

eNAP is very proud to present this report. It contains the results of a patient survey, created and completed by patients. We sincerely hope that the content will contribute in various ways to a better understanding and guidance for people living with Narcolepsy/Idiopathic hypersomnia (N/IH).

eNAP survey

The European Narcolepsy Alliance for Patients (eNAP) is a collaboration between patient support groups for those with Narcolepsy and Idiopathic Hypersomnia across Europe. **It is dedicated to raising awareness and improving understanding, treatment, and quality of life for people with Narcolepsy (N) and Idiopathic Hypersomnia (IH) in Europe.**

In line with the goals of eNAP, a European-level survey was created to investigate the needs of those living with N/IH and the differences between European countries for provided support. The information gathered from this survey will form a shared European knowledge base to support patient organisations' work, influence healthcare policy, and increase awareness of narcolepsy and idiopathic hypersomnia. It was important to eNAP that the collected information was regarding issues relevant to the individual with N/IH.

Aims

This survey aimed to gain information of the patient's journey, from onset of symptoms to diagnosis and treatment of patients with N/IH as well as information on the level of access to care and treatment that individuals have across Europe. Cross-country comparisons of the barriers and issues that individuals experience can help to identify the most useful and impactful support and guidance to inform best practices for future N/IH care.

The aim of this project was to collect data on patients' experiences and needs within four main areas:

- 1) Financial and Independence Insight of people with N/IH.
- 2) Patient journey: From the first symptoms to diagnosis and treatment.
- 3) Level and sources of information: How and where patients obtain knowledge about their condition.
- 4) Activities of Daily Living: Suggestions for support, treatment, and changes that could improve life quality with N/IH.

■ Preface: Methods

Survey development

The development of survey questions underwent multiple iterations to incorporate feedback from these groups to develop relevant questions that would be most beneficial and prominent in chronicling the stories of individuals with N/IH living in today's Europe.

A result of an eNAP member meeting (September 2024) was the formation of a European Survey Working Group. The group consisted of Leontien Sickenga (Netherlands), Connie Landstedt (Denmark), and Aisling Martin (Ireland). Kompas Kommunikation © supported eNAP in the creation of this survey. Dr. Denise Bijlenga (SEIN Sleep-Wake Center, Netherlands) who has scientific experience with questionnaire development and the N/IH patient group, consulted throughout the development process.

The first step was asking eNAP representatives to discuss with their national organisation the type of questions that they would like answered regarding people living with N/IH in Europe. The working group defined the final aims of the survey and organised the submitted questions from the patient organisations into a first draft of questions for the survey, in English. It was important that all country members felt represented by the questions in the survey and that the answers to these questions would be beneficial both at a country and European level.

After a 2nd draft was completed by Kompas, it was reviewed and adjusted by the Survey Working Group. The resulting 3rd draft was brought back to Kompas who created the survey again with additional small changes were made. This 4th draft was then shared with eNAP representatives, to ensure that the questions made sense to them. For each of the 14 national languages represented by eNAP, a translation of the survey was made using AI. The AI translations were shared with national representatives to check and correct the translations of the survey.

■ Preface: Methods

Procedure

The online survey was hosted by Kompas Kommunikation. A link to the survey was shared by email with patient organisations. They were asked to share the survey link with their members (and non-members) through email lists and social media, and to share the link on (social media) discussion groups/platforms for patients with N/IH. Individuals of age 18 or older with Narcolepsy or Idiopathic Hypersomnia were invited to take part in the survey between June 1 and August 11, 2025.

Participants were informed that their responses to the survey were anonymous. No names, IP addresses or other identifying information were collected, and the data handling and storage was compliant with GDPR. Continuation to and completion of the survey was taken as understanding and agreement/consent to these terms. Participation was voluntary and there was no monetary compensation given for participating in the survey.

Survey overview

The survey took 20-30 minutes to complete and consisted of 59 questions. These questions were grouped into five sections:

1. Diagnosis and demographics (9 questions): Questions about diagnosis, gender, age, country, level of education completed, employment status, relationship/partnership status, living status.
2. Diagnosis Journey (16 questions): Questions about age of diagnosis, age of onset of symptoms, time before first consultation, any previous diagnoses, consulted healthcare professionals, waiting list durations, feelings after receiving diagnosis, comorbidities, family members with diagnosis of N/IH, support from national patient organisations.
3. Treatment and medicine (11 questions): Questions about current treatment, number of appointments in a year, type of follow-up appointments, treatment satisfaction, use of medication, non-pharmacological management strategies.
4. Support: Financial support, getting around, and N/IH patient organisations (13 questions): Questions regarding financial compensation due to N/IH, governmental or public healthcare compensation for N/IH-related expenses, level of independence, access to public transport, driving capabilities, sources of N/IH information, membership of patient organisations, satisfaction with support from national patient organisation, suggestions for support after receiving a N/IH diagnosis.
5. Everyday life with N/IH (10 questions): Questions regarding the impact of N/IH on relationships, work and education, any provided work and educational adjustments, daily life activities, use of mobile applications or trackers, impact of symptoms of N/IH, quality of life.

■ Preface: Methods

Current report

In this report, we are proud to present the general results of the eNAP patient survey. In a relatively short time, an impressive number of **1,667 respondents from 15 European countries** have filled out the survey. A few respondents were from other countries than these. All patient groups Narcolepsy Types 1 and 2, and Idiopathic Hypersomnia (which will be referred to as N/IH from here on), gender and age groups were represented.

In each section of this report, the results are shown as frequencies and percentages for the total group, within diagnostic groups, gender groups, age groups, and countries. The current report and the collected data will be used for scientific, advocacy, and awareness activities of eNAP and its member organisations.

Important considerations

Some considerations should be kept in mind when interpreting the results. First of all, the survey link was distributed through emails and social media, and no personal identification data was collected. Therefore, we cannot confirm the authenticity of the responses. All data, including diagnoses, were self-reported, which may have introduced some response bias.

Also, there were several imbalances. Three in four respondents were women (76%), and almost a quarter of respondents came from France (23%). This was a 10% higher response than the next highest country response (Germany, Italy, and Norway with 11% each). France also had a higher proportion of IH diagnoses. The reasons for a higher proportion of IH in France is unknown. The respondent group does not likely represent the N/IH population. Results are not generalizable and thus not be interpreted as prevalence rates.

The current report shows unadjusted results. Further scientific activities will aim to dive deeper into the numbers, in order to look at associations between responses. Also, free text responses, which are not shown in this report, may give new insights or may influence the currently reported response outcomes.

■ Preface: Disclaimer

The results are based on eNAP's European Patient Survey 2025 and reflect respondents' views at the time of the survey. Findings may not be representative of all patient populations. Any use of data or figures must cite this report. All rights are reserved by eNAP. The information is provided for informational purposes only.

For referencing, please use the following citation format: "*Leontien Sickenga, Connie Landstedt & Aisling Martin for eNAP. eNAP European Patient Survey 2025 on Narcolepsy and Idiopathic Hypersomnia. Kompas Kommunikation, Denmark, January 2026.*"

Data sharing

The current report is freely available.

Collected survey data are available upon request for researchers after review of project proposal. Besides the reported frequency/numeric outcomes of the survey, also the free text responses are available for a qualitative investigation. There is also a report for a subsequent survey held among national N/IH patient organisations. Please email eNAP for more information or a request.

Visit www.narcolepsy.eu for more information.

Email: enap@narcolepsy.eu

■ Preface: Acknowledgements

The survey is an initiative by the European Narcolepsy Alliance for Patients (eNAP) – made possible with the help and support from the national patient organisations, representing the patients in their country. Financial support for this survey was granted by Takeda Pharmaceuticals © and Centessa Pharmaceuticals ©. Thanks to our corporate partner: Alkermes ©. The project was led by Leontien Sickenga, Connie Landstedt, and Aisling Martin, with help from Dr. Denise Bijlenga. Created and hosted by Kompas Kommunikation. Illustrations were made by Henriëtte Treurniet.

Many thanks to all the members organisations of eNAP:

Belgium:	Association Belge de Narcolepsie A.B.N,
Bulgaria:	Bulgarian Association of Narcolepsy Patients
Denmark:	Dansk Narkolepsiforening
Finland:	Tatu and Suomen narkolepsiyhdistys
France:	Association Française de Narcolepsie-Cataplexie et d'hypersomnie (ANC)
Germany:	Narkolepsie Netzwerk e.V.
Greece:	ΕΛΛΗΝΙΚΟ ΣΩΜΑΤΕΙΟ ΑΣΘΕΝΩΝ ΜΕ ΝΑΡΚΟΛΗΨΙΑ ΚΑΙ ΙΔΙΟΠΑΘΗΣ ΥΠΕΡΥΠΝΙΑ
Ireland:	Narcolepsy Ireland and Sufferers of Unique Narcolepsy Disorder (SOUND),
Italy:	Associazione italiana narcolettici e ipersonni (AIN)
Netherlands:	Nederlandse Vereniging voor Narcolepsie (NVN)
Norway:	Sovnforeningen
Poland:	Polskie Stowarzyszenie Narkolepsji
Spain:	Asociación española de Narcolepsia e Hipersomnias Centrales
Sweden:	Narkolepsiföreningen i Sverige
Switzerland:	Schweizerische Narkolepsie Gesellschaft (SNaG)

And last but not least we'd like to thank all respondents for their participation!

About respondents

The survey was conducted in 15 countries (Belgium, Bulgaria, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Netherlands, Norway, Poland, Spain, Sweden, Switzerland)) and answered by 1,667 respondents between June 1st and August 11th 2025, with 91% answering all 58 questions and 9% completing at least half.

Most respondents came from France (23%), followed by Germany, Italy, and Norway (11% each). Denmark, the Netherlands, and Sweden each accounted for 7% of the respondents. For countries with fewer than 50 respondents (especially Belgium, Bulgaria, Greece, and Switzerland and in some questions further countries), no conclusions can be drawn in the report. However, the results from these countries are still included in the tables, marked in grey for reference.

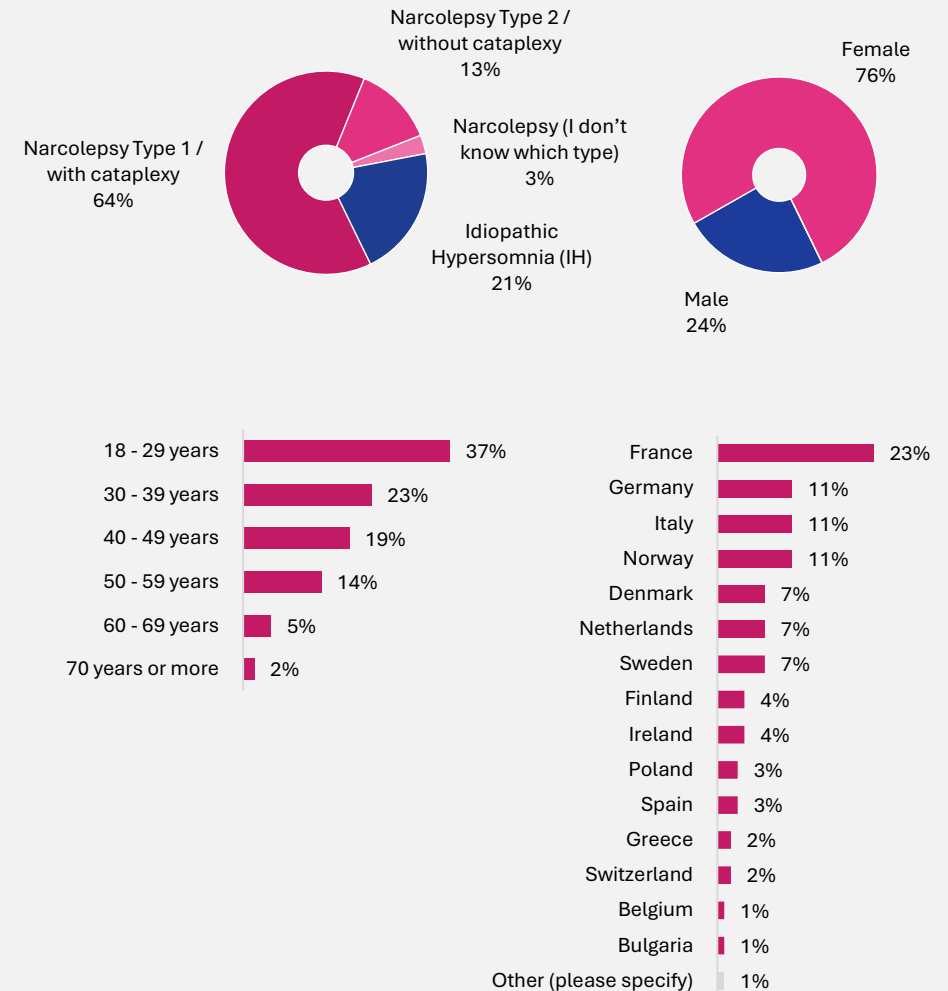
Other countries – specified as “other” – are Austria (7 respondents), Canada (6), United States (4) and New Zealand, Canada (Quebec), Martinique, and Northern Ireland (each 1 respondent).

64% of respondents were diagnosed with Narcolepsy Type 1 (with cataplexy), 13% had Narcolepsy Type 2 (without cataplexy) and 3% did not know their type. 21% were diagnosed with Idiopathic Hypersomnia (IH).

Most respondents (37%) were aged 18–29, followed by 23% aged 30–39, 19% aged 40–49 and 14% aged 50–59 years. Only 5% were 60–69 and 2% were aged 70+.

Three in four respondents were women (76%), while 24% were men.

15% are unable to work due to their N/IH.



Overall take-aways

01 Diagnosis and demographics (Q1-9)

- See demographics on diagnosis gender, age and country in prior page.
- 33% have completed higher education, 25% secondary education, 18% vocational training, 18% postgraduate degrees and 3% only primary education.
- Half of respondents are employed or self-employed (51%), while 15% are students and 15% unable to work due to N/IH.
- 33% work less than 30 hours weekly, 42% work 30–39 hours, and 25% work 40+ hours.
- 56% are married, in a domestic partnership, or in a relationship, while 36% are single, 8% are separated, divorced or widowed.
- 23% live with a partner without children, 23% with a partner and children, 22% live alone, and 22% with parents or in a shared household.

02 Diagnosis Journey (Q10-25)

- Most respondents were diagnosed at ages 18–29 (40%) or 10–17 (23%). Fewer were diagnosed at 30–39 (17%), 40–49 (11%), and very few after 50 (5%).
- Diagnosis often came after long delays: 28% waited more than 10 years, while only 11% were diagnosed within the first year.
- The average time until contacting a general practitioner about N/IH symptoms was 5 years. 28% consulted their GP within the first year, while 17% waited more than 10 years.
- On average 14% state that their N/IH was caused by the Pandemrix vaccination. 62% said no and 24% don't know.
- 72% got another diagnosis / cause for their symptoms before their N/IH diagnosis. The most frequent were lack of sleep or poor sleep habits (33%), depression or anxiety (32%), stress (24%), and lifestyle factors such as diet or exercise (23%).
- Most had to see several healthcare professionals before getting their diagnosis, with an average of four. 49% of respondents saw 1–3 healthcare professionals before receiving their N/IH diagnosis, 38% saw 4–10, and 6% saw more than 10.
- Most were diagnosed by a neurologist (57%), while one third (33%) were diagnosed by a sleep specialist. Only 2% by a respiratory specialist, 2% by a psychiatrist or other mental health professional and 2% by a child doctor/pediatrician.
- 33% were seen within 2 months, 22% after 3–5 months, 17% after 6–12 months, 6% more than 1 year, while 22% do not remember.
- 65% were satisfied or very satisfied with the diagnostic procedure, while 14% were (very) dissatisfied and 20% were neutral or uncertain.
- 50% reported having undergone a lumbar puncture (spinal tap), while 49% had not. 1% were unsure.
- With their own words describing their feelings after having received the N/IH diagnosis mostly concentrated about 3 themes: Relief, fatigue and frustration.
- 48% have changed healthcare professional or treatment centre since their diagnosis. 13% because their doctor retired or moved, 13% were referred to another specialist, 12% because of dissatisfaction with care. Still 36% reported being satisfied and had stayed with the same professional.

Overall take-aways

- 82% had not received any previous sleep diagnosis before being diagnosed with N/IH. 18% reported an earlier sleep-related diagnosis, most often another unspecified sleep disorder (8%) or Idiopathic Hypersomnia (4%).
- 64% reported at least one additional diagnosis besides N/IH. The most common were depression (20%), allergy (18%), anxiety (17%) and sleep apnoea (14%). Asthma or other lung diseases were reported by 10%, ADHD/ADD by 8%, and chronic pain by 9%.
- 25% reported having family members who also have or may have N/IH. 6% said they knew at least one relative with a diagnosis, while 17% suspected family members but without a confirmed diagnosis – plus 2% suspecting so, but not knowing, if the family members received a diagnosis.
- Satisfaction with support varied considerably across groups. 74% were satisfied or very satisfied with the support from partners or children, 57% with friends, 54% with healthcare professionals, 53% with national patient organisations, 27% with work and 29% with support from school / education.

03 Treatment and medicine (Q26-36)

- 95% are treated by a healthcare professional. Neurologists were the most common providers (54%), followed by sleep specialists (30%) and general practitioners (6%).
- 53% have up to one yearly appointment, and 41% at least two appointments per year. 6% do not have follow-ups.
- Most follow-ups take place in person (76%) followed by phone consultations (32%), communication via online video consultations (13%) and communication via email or online patient portals (12%).
- 63% find their follow-ups useful or very useful. 18% are neutral, while 15% rated follow-ups as not very or not at all useful.
- Among the small group without follow-up, the main reasons were that healthcare professionals had not offered it (33%) or that patients did not consider it necessary (32%). Another 20% cited lack of specialists nearby, and 6% mentioned financial barriers.
- 48% prefer their current number of follow-ups, while 33% would prefer more. Only 4% wants fewer.
- Among those diagnosed before 18 years, 57% said their support from healthcare professionals continued unchanged after turning 18 years, while 19% said it worsened and 11% said it improved.
- 58% reported that their medical treatment continued unchanged after turning 18, while 29% gained access to new types of medication and 1% lost access.
- The vast majority (91%) use medication. The most common are stimulants (61%), followed by sodium oxybate (27%) and antidepressants (26%).
- 57% are satisfied or very satisfied with their treatment, 20% (very) dissatisfied and 23% neutral.
- The most common self-management strategy is taking naps during the day (73%), followed by daily routines (50%), keeping regular bedtimes at night (48%), exercise (39%) and diet or food management (29%).

Overall take-aways

04 Support: Financial, communication wise and from N/IH patient organisations (Q37-49)

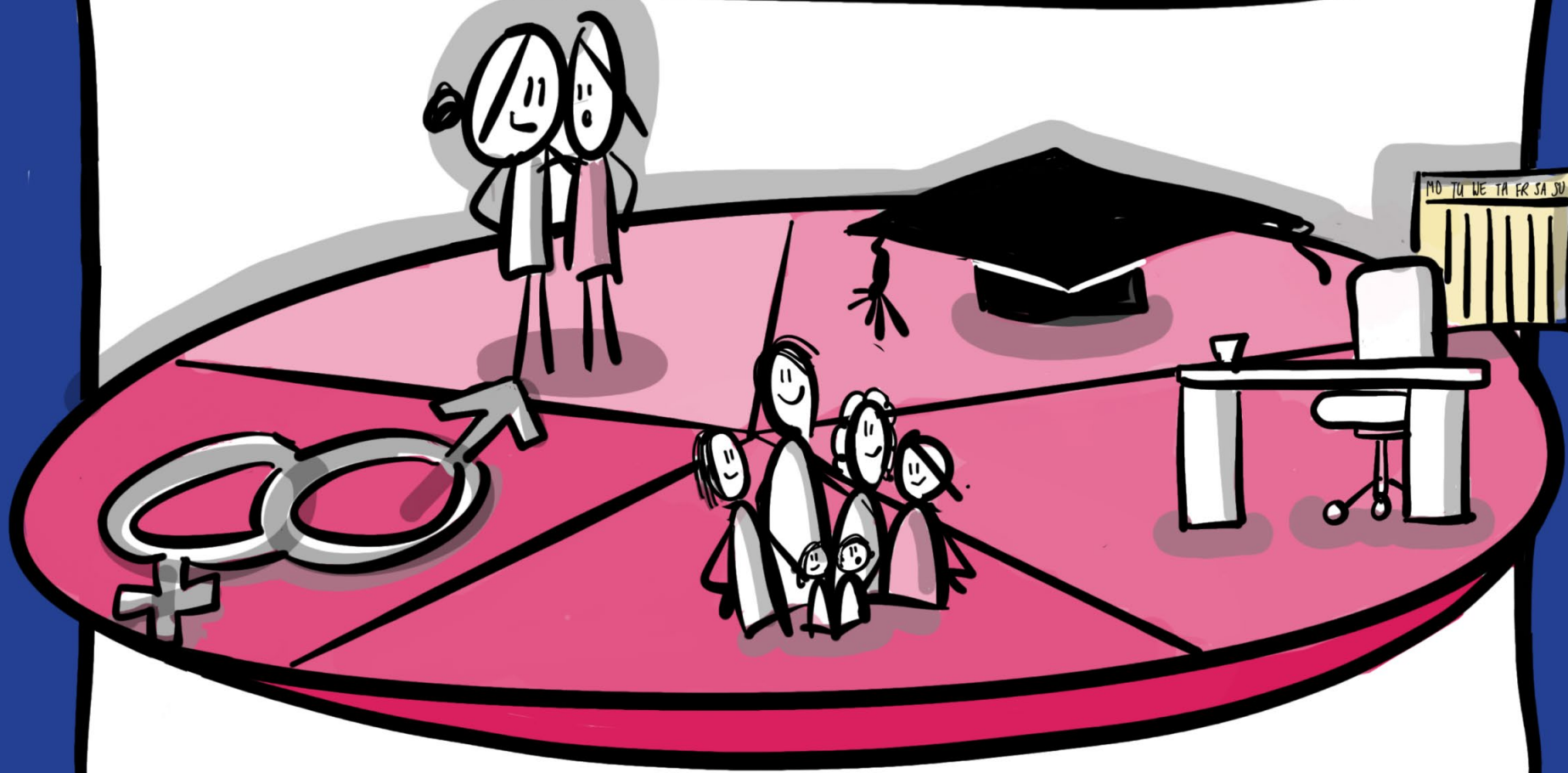
- 79% receive some form of financial compensation for N/IH. The most common is full (43%) or partial (34%) coverage of medication costs. Lost income due to inability to work is compensated for 16%, while only small shares receive support for other expenses.
- Government or public healthcare is the primary source of financial compensation for N/IH-related expenses, reported by 67%. Followed by 16% private health insurance and 12% disability / social welfare, 5% Pandemrix compensation and 3% employer support.
- 72% are satisfied with at least one of the mentioned N/IH support options. The most frequent is access to medication (49%), followed by access to specialized healthcare (40%), information (20%), patient organisations (18%), economic support (13%) and psychological support (9%).
- 47% are independent for managing daily activities, while 2% is completely dependent on others.
- 68% can use public transport independently, 60% can drive a car, while 8% need help with transport.
- In total, 72% are limited or prevented by their N/IH to drive a car. 49% have a driving license but drive less than they would like due to their condition.
- 51% get N/IH information from a specialist, 47% from a patient organisation, 42% from websites, 42% from social media, 38% from online patient communities, 35% from research papers, 10% from traditional media, 10% from books / printed materials and 6% from family/friends.
- 59% are satisfied or very satisfied with the N/IH information available, while 11% are (very) dissatisfied. 31% are neutral / don't know.
- 50% are paying members of a national N/IH patient organisation, while 13% are non-paying members.
- 84% feel supported by their N/IH patient organisation. The most common type of is information and resources about the condition (59%), followed by social events and community building (52%), access to (online) support groups and peer networking (39%), educational workshops (28%), guidance on treatment options (27%), legal/advocacy support (21%) and received emotional/psychological support (18%).
- 58% are satisfied or very satisfied with the offerings and support from their N/IH patient organisation. 8% are (very) dissatisfied. 34% are neutral / don't know.
- 56% miss offerings or supports from their N/IH patient organisation. The most frequently is legal/financial advice and advocacy (28%), emotional and psychological support (25%) and guidance on treatment options and healthcare navigation (25%) followed by information and resources (18%), educational workshops and seminars (17%), support groups and networking (14%) and social events and community building (14%).
- 87% were missing offerings or supports when they got their N/IH diagnosis. The top need was more advice for managing daily life with the condition (57%) followed by clearer guidance on treatment options, such as medication and lifestyle adjustments (49%), more information about their condition (47%), counselling or mental health support (47%), support from family and friends (34%) and support from patient organisations (25%).

Overall take-aways

05 Everyday life with N/IH (Q50-59)

- For 65% N/IH impacts their work or education to a high or very high degree, while for 34% it has some or a minor impact. 1% feels no impact.
- 36% had to reduce their working or study hours due to N/IH, 14% had to change work or study, 16% can no longer work or study. 22% specified other impacts, while N/IH had no impact on work / education for 9%.
- In total, 64% reports, that their workplace or educational institution (who're told about N/H) provides accommodations. 33% do not, while 16% haven't told their workplace or educational about their N/IH. The most common accommodations were flexible work or study hours (20%) followed by designated rooms or places for rest (18%), adjusted timetables or schedules (17%), remote work or study options (12%) and subsidized travel (1%).
- Most with N/IH are still able to do housekeeping (70%), watch TV/streaming (68%), be with friends/relatives (65%) and shop for food/household supplies (64%). The least common activities with N/IH are playing computer games (24%), volunteer work (17%) and creative hobbies in a club / centre (11%).
- Amongst respondents currently in in a sexual / intimate relationship, 42% experienced that N/IH affects their sex life and/or intimacy to a high or very high degree. 47% answered to some or minor degree, while 12% reported not at all.
- 18% use sleep-, health- or wellness apps.
- With their own words describing the most difficult or bothersome thing about having N/IH mostly concentrated about 4 themes: Fatigue, unpredictability, isolation and limitations.
- The average quality of life score is 5,6 on a 0–10 scale. 59% rated their quality of life as a 6 or higher, 24% gave a 4 or 5, while 15% rated their quality of life as a 4 or less.
- 65% reported that their N/IH impacts their quality of life to a high or very high degree, 34% to some or minor degree, while 1% not at all.
- The most frequently reported symptoms / challenges to a high or very high degree are a lack of feeling refreshed in the morning (64%), concentration and attention problems (64%), daytime sleepiness (62%), lack of physical energy (61%), bad night sleep (54%) and memory problems (48%). Other challenges include weight gain (37%), feelings of sadness or depression (36%), lucid dreaming (35%), automatic behaviour (35%), social isolation (34%), dream reality confusion (33%), pain in joints and muscles (30%), and headaches or migraines (25%).

1. DIAGNOSIS & DEMOGRAPHICS

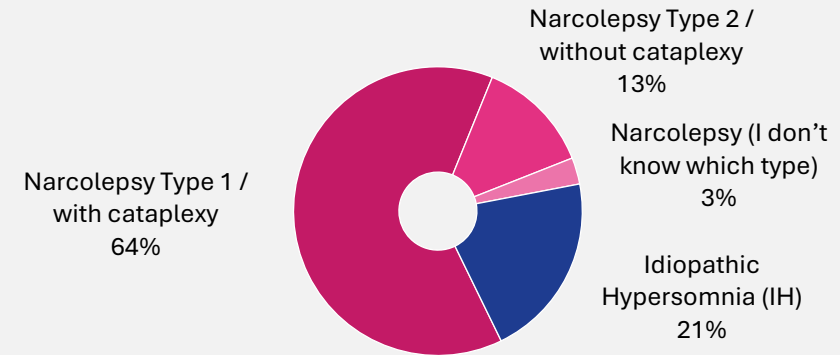


Q1 What sleep disorder are you diagnosed with? (choose 1 answer)

64% of respondents reported to have been diagnosed with NT1 (with cataplexy, NT1), while 13% reported to have NT2 (without cataplexy, NT2). 21% reported to being diagnosed with IH. 3% reported to have Narcolepsy but did not know their type; **these respondents have been left out of the reported results for the diagnosis groups throughout this report.**

Age group 18-39 was most represented, followed by the 40-59 age group. Across all age groups, NT1 was most represented among respondents.

Three times as many women participated compared to men. Compared to men, women had a lower percentage of NT1 and a higher percentage of IH. There were 8 respondents did not fill out to be either male or female; their results are not represented in the Gender outcomes throughout this report.



1. What sleep disorder are you diagnosed with? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Narcolepsy Type 1 / with cataplexy	64%	100%	0%	0%	67%	58%	64%	73%	61%
Narcolepsy Type 2 / without cataplexy	13%	0%	100%	0%	12%	13%	15%	14%	12%
Narcolepsy (I don't know which type)	3%	0%	0%	0%	2%	4%	4%	3%	3%
Idiopathic Hypersomnia (IH)	21%	0%	0%	100%	19%	25%	17%	11%	24%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259

Q1 What sleep disorder are you diagnosed with? (choose 1 answer)

NT1 was the most represented diagnosis in all countries, ranging from 39% in France to 93% in Finland.

IH was most common in France (46%) and Norway (42%), compared with the overall 21%.

NT2 varied between 4% in Finland and 21% in Italy.

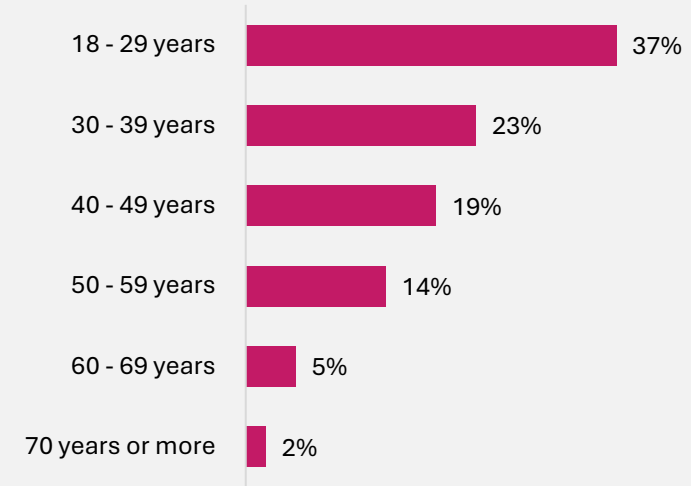
Country

1. What sleep disorder are you diagnosed with? (choose 1 answer)	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Narcolepsy Type 1 / with cataplexy	64%	59%	61%	71%	93%	39%	73%	76%	78%	71%	73%	49%	84%	82%	88%	67%
Narcolepsy Type 2 / without cataplexy	13%	24%	22%	10%	4%	13%	18%	12%	14%	21%	10%	8%	10%	11%	5%	17%
Narcolepsy (I don't know which type)	3%	0%	17%	3%	1%	3%	3%	2%	4%	2%	6%	1%	2%	4%	2%	0%
Idiopathic Hypersomnia (IH)	21%	18%	0%	17%	1%	46%	6%	10%	4%	6%	11%	42%	4%	4%	5%	17%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36

■ Q2 What is your age?

Most respondents (37%) were aged 18–29, followed by 23% aged 30–39, 19% aged 40–49 and 14% aged 50–59 years. Only 5% were 60–69 and 2% were 70+.

NT1 and NT2 were most frequent in the youngest age group (41% and 33%), while IH was more evenly distributed across the 18–49 age groups (26–29%).



2. What is your age?	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
18 - 29 years	37%	41%	33%	29%	62%	0%	0%	43%	35%
30 - 39 years	23%	21%	25%	26%	38%	0%	0%	17%	24%
40 - 49 years	19%	17%	19%	26%	0%	57%	0%	18%	19%
50 - 59 years	14%	14%	16%	14%	0%	43%	0%	13%	15%
60 - 69 years	5%	4%	6%	4%	0%	0%	67%	6%	4%
70 years or more	2%	2%	2%	1%	0%	0%	33%	3%	2%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259

■ Q2 What is your age?

In most countries, most respondents were 18–29 years, with particularly high levels in Ireland (45%), Sweden (45%) and Italy (46%).

Poland (34%) and Sweden (37%) stood out with higher shares in the 30–39 years group, while Spain had a relatively large group of 40–49 years (38%).

Older age groups (60+) were small across all countries.

2. What is your age?	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
18 - 29 years	37%	41%	50%	29%	43%	41%	37%	29%	45%	46%	41%	25%	42%	18%	45%	11%
30 - 39 years	23%	24%	11%	28%	31%	22%	21%	15%	22%	17%	17%	22%	34%	14%	37%	28%
40 - 49 years	19%	24%	33%	18%	9%	22%	22%	17%	18%	17%	11%	19%	22%	38%	9%	19%
50 - 59 years	14%	6%	6%	14%	13%	11%	17%	37%	14%	15%	18%	22%	2%	18%	5%	11%
60 - 69 years	5%	6%	0%	6%	3%	2%	3%	2%	1%	4%	9%	8%	0%	13%	4%	17%
70 years or more	2%	0%	0%	6%	0%	2%	1%	0%	1%	1%	5%	4%	0%	0%	1%	14%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36

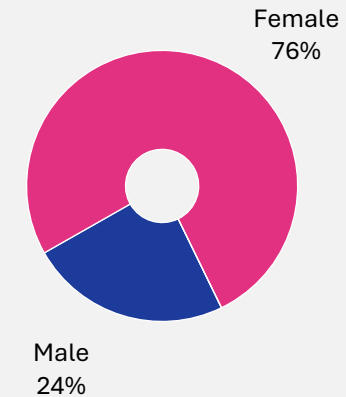
■ Q3 What is your gender? (choose 1 answer)

Three in four respondents were women (76%), while 24% were men.

In the IH group, female respondents are even higher (86%) than in the narcolepsy groups (73-74%). In the 60+ age group men are slightly more represented (31%) than in the younger age groups (23-24%).

France (82%), Finland (84%) and Norway (82%) had a few more female respondents, while Italy (60%) and Spain (63%) had fewer compared to the general results.

There were 8 respondents who filled out to have 'other' gender; their results are not represented in the binary Gender outcomes throughout this report.



3. What is your gender? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Male	24%	27%	26%	12%	24%	23%	31%	100%	0%
Female	76%	73%	74%	86%	75%	77%	69%	0%	100%
Other	0%	0%	0%	1%	1%	0%	0%	0%	0%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259

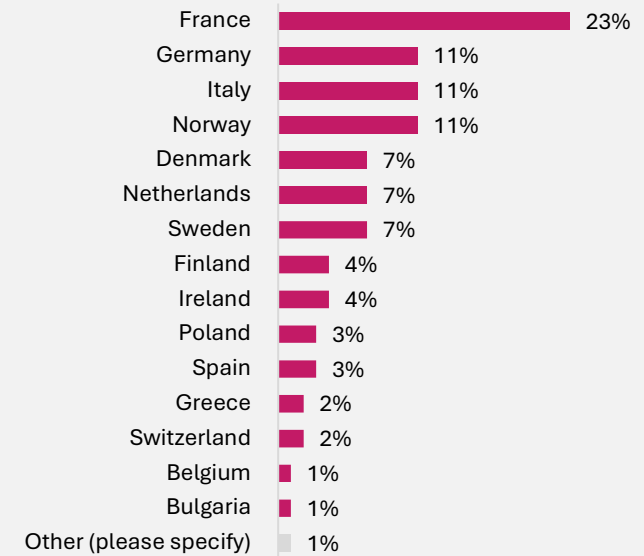
3. What is your gender? (choose 1 answer)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Male	24%	6%	22%	24%	13%	17%	26%	22%	27%	40%	29%	18%	32%	38%	26%	31%
Female	76%	94%	78%	76%	84%	82%	74%	78%	73%	60%	71%	82%	68%	63%	74%	67%
Other	0%	0%	0%	0%	3%	1%	1%	0%	0%	0%	0%	0%	0%	0%	0%	3%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36

■ Q4 What country do you live in? (choose 1 answer)

Almost a quarter of the respondents were from France (23%), followed by Germany, Italy, and Norway (11% each). Denmark, the Netherlands, and Sweden each accounted for 7% of the respondents.

Other countries – specified as “other” – are Austria (7 respondents), Canada (6), United States (4) and New Zealand, Canada, Martinique, and Northern Ireland (each 1 respondent).

In the IH group, as much as 50% were from France and 23% from Norway.

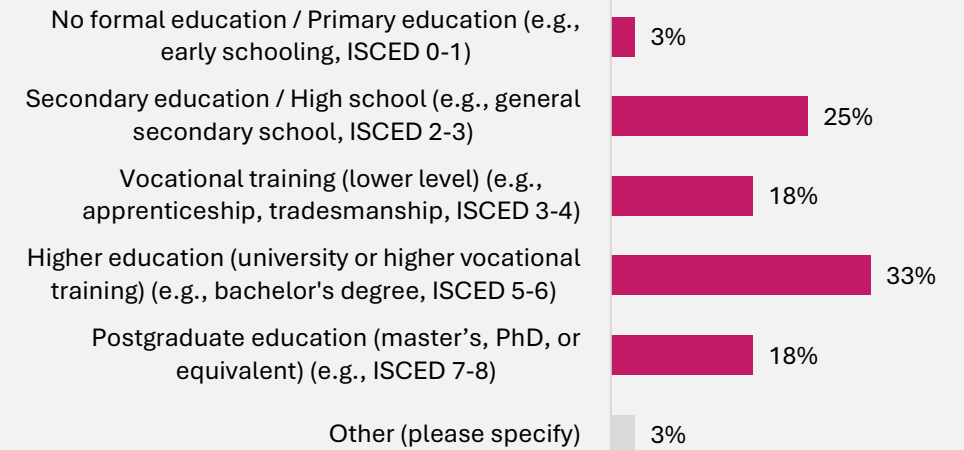


4. What country do you live in? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
France	23%	14%	23%	50%	24%	22%	14%	17%	25%
Germany	11%	13%	16%	3%	11%	13%	5%	12%	11%
Italy	11%	12%	18%	3%	11%	10%	7%	18%	8%
Norway	11%	9%	7%	23%	9%	14%	20%	8%	12%
Denmark	7%	8%	6%	6%	7%	7%	12%	7%	7%
Netherlands	7%	8%	5%	3%	7%	6%	14%	8%	6%
Sweden	7%	9%	3%	1%	9%	3%	4%	7%	7%
Finland	4%	6%	1%	0%	5%	3%	2%	2%	4%
Ireland	4%	5%	5%	1%	5%	4%	2%	5%	4%
Poland	3%	4%	2%	1%	4%	2%	0%	4%	3%
Spain	3%	4%	3%	1%	2%	6%	6%	5%	3%
Greece	2%	3%	2%	1%	2%	4%	1%	2%	3%
Switzerland	2%	2%	3%	2%	1%	2%	10%	3%	2%
Belgium	1%	1%	2%	1%	1%	1%	1%	0%	1%
Bulgaria	1%	1%	2%	0%	1%	1%	0%	1%	1%
Other (please specify)	1%	1%	1%	3%	1%	1%	1%	0%	2%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259

Q5 What is the highest level of education you have completed? (choose 1 answer)

One third of respondents had completed higher education (33%), while 25% reported secondary education and 18% vocational training. Another 18% had postgraduate degrees, while 3% had only primary education. Other highest levels of education (3%), specified as “other”, include: High school, university, various vocational diplomas and certificates, bachelor’s and master’s degrees, preparatory and commercial exams, ongoing higher education, and mixed qualifications combining vocational training with professional practice.

In the IH group, higher education was more frequent (45%) compared to NT1 (30%) and NT2 (31%). By age, higher education was most common among 40–59-year-olds (35%), while postgraduate education was relatively more frequent among younger respondents aged 18–39 (19%). By gender, men more often reported secondary education (34% vs. 23%), while women were more likely to have higher education (35% vs. 26%).



5. What is the highest level of education you have completed? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
No formal education / Primary education (e.g., early schooling, ISCED 0-1)	3%	3%	3%	2%	2%	2%	7%	3%	2%
Secondary education / High school (e.g., general secondary school, ISCED 2-3)	25%	30%	24%	14%	27%	23%	22%	34%	23%
Vocational training (lower level) (e.g., apprenticeship, tradesmanship, ISCED 3-4)	18%	20%	14%	15%	17%	20%	21%	21%	17%
Higher education (university or higher vocational training) (e.g., bachelor's degree, ISCED 5-6)	33%	30%	31%	45%	33%	35%	28%	26%	35%
Postgraduate education (master's, PhD, or equivalent) (e.g., ISCED 7-8)	18%	15%	25%	21%	19%	16%	13%	13%	19%
Other (please specify)	3%	3%	3%	3%	3%	3%	8%	3%	3%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259

Q5 What is the highest level of education you have completed? (choose 1 answer)

Country differences were notable: Postgraduate education was especially frequent in France (33%) and Sweden (25%), while secondary education dominated in Italy (56%) and Germany (41%).

Vocational training stood out in the Netherlands (42%) and Finland (27%). Poland (56%) and France (41%) also had relatively high shares with higher education.

5. What is the highest level of education you have completed? (choose 1 answer)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
No formal education / Primary education (e.g., early schooling, ISCED 0-1)	3%	0%	0%	5%	6%	0%	0%	0%	1%	3%	3%	7%	2%	0%	6%	0%
Secondary education / High school (e.g., general secondary school, ISCED 2-3)	25%	18%	44%	23%	15%	5%	41%	34%	19%	56%	21%	27%	36%	14%	37%	8%
Vocational training (lower level) (e.g., apprenticeship, tradesmanship, ISCED 3-4)	18%	12%	6%	18%	27%	19%	21%	22%	16%	5%	42%	11%	4%	34%	7%	42%
Higher education (university or higher vocational training) (e.g., bachelor's degree, ISCED 5-6)	33%	47%	28%	31%	40%	41%	24%	41%	30%	25%	27%	39%	56%	34%	16%	22%
Postgraduate education (master's, PhD, or equivalent) (e.g., ISCED 7-8)	18%	18%	17%	17%	12%	33%	9%	2%	31%	8%	6%	11%	2%	18%	25%	22%
Other (please specify)	3%	6%	6%	7%	0%	2%	5%	0%	3%	2%	1%	5%	0%	0%	8%	6%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36

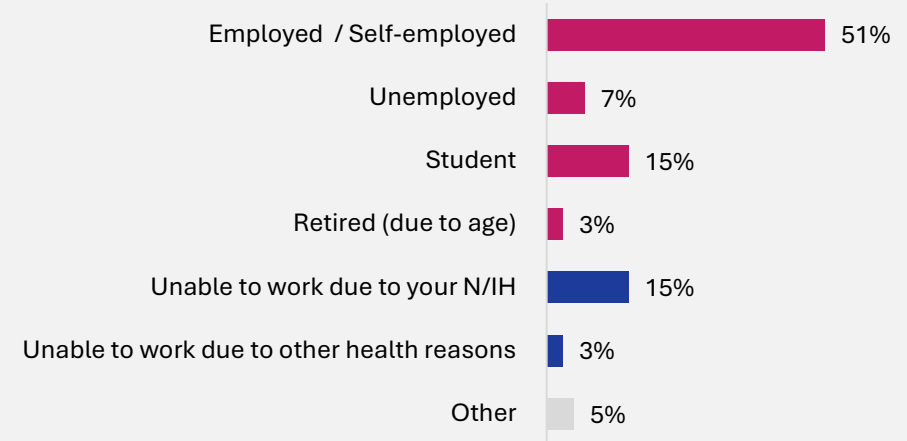
Q6 What is your employment status? (choose 1 answer)

Half of respondents were employed or self-employed (51%), while 15% were students and 15% unable to work due to N/IH.

IH respondents were more often unable to work (22%) compared to those with narcolepsy (12–14%).

Employment was most frequent among 40–59-year-olds (60%), compared to 50% of 18–39-year-olds, while half of respondents aged 60+ were retired.

Gender differences were minimal.



6. What is your employment status? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Employed / Self-employed	51%	50%	53%	52%	50%	60%	19%	51%	52%
Unemployed	7%	8%	6%	4%	8%	7%	1%	10%	7%
Student	15%	17%	16%	11%	26%	0%	0%	17%	15%
Retired (due to age)	3%	4%	3%	2%	0%	0%	50%	4%	3%
Unable to work due to your N/IH	15%	14%	12%	22%	9%	25%	19%	15%	15%
Unable to work due to other health reasons	3%	2%	6%	4%	1%	4%	7%	2%	3%
Other	5%	5%	4%	5%	5%	4%	4%	2%	5%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259

Q6 What is your employment status? (choose 1 answer)

Employment was highest in Sweden (65%), Poland (64%) and Italy (57%), while it was lowest in Spain (30%).

Being unable to work due to N/IH was most frequent in Spain (39%), Norway (27%) and Ireland (22%) compared to 15% overall.

The number of students were notably higher in Italy (27%) and Finland (19%) than the total average (15%).

6. What is your employment status? (choose 1 answer)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Employed / Self-employed	51%	41%	61%	45%	55%	54%	50%	49%	41%	57%	50%	45%	64%	30%	65%	58%
Unemployed	7%	0%	11%	8%	7%	7%	6%	15%	15%	10%	7%	2%	12%	7%	10%	3%
Student	15%	35%	11%	13%	19%	17%	14%	10%	16%	27%	17%	9%	14%	7%	11%	6%
Retired (due to age)	3%	6%	0%	6%	3%	3%	2%	0%	1%	1%	6%	4%	0%	9%	4%	17%
Unable to work due to your N/IH	15%	12%	0%	17%	7%	13%	21%	20%	22%	2%	12%	27%	8%	39%	8%	3%
Unable to work due to other health reasons	3%	0%	0%	5%	4%	2%	3%	0%	4%	3%	2%	4%	0%	4%	1%	3%
Other	5%	6%	17%	7%	3%	4%	5%	7%	1%	2%	7%	9%	2%	4%	2%	11%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36

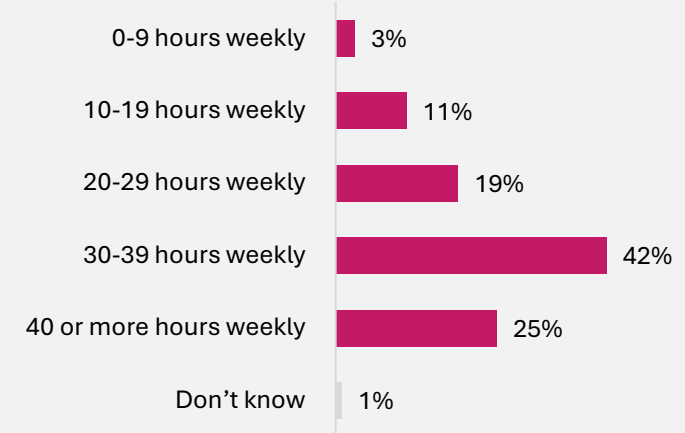
Q7 How many hours per week do you typically work (paid work only)? (choose 1 answer)

Among employed respondents, most reported working 30–39 hours weekly (42%), while one in four (25%) worked 40+ hours. Smaller groups worked 20–29 hours (19%) or 10–19 hours (11%), and only 3% worked less than 10 hours.

In the IH group, half (50%) worked 30–39 hours compared to 38% with NT1 and 43% with NT2.

By age, 45% of 18–39-year-olds and 37% of 40–59-year-olds worked 30–39 hours, while 48% of those aged 60+ worked 30-39 hours.

Men were more likely to work 40+ hours (35% vs. 22% of women), while women more often reported 30–39 hours (43% vs. 36%).



7. How many hours per week do you typically work (paid work only)? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
0-9 hours weekly	3%	4%	3%	1%	3%	3%	0%	2%	3%
10-19 hours weekly	11%	11%	12%	12%	9%	13%	19%	8%	11%
20-29 hours weekly	19%	21%	15%	18%	18%	19%	33%	18%	19%
30-39 hours weekly	42%	38%	43%	50%	45%	37%	48%	36%	43%
40 or more hours weekly	25%	26%	26%	19%	25%	27%	0%	35%	22%
Don't know	1%	1%	2%	1%	1%	2%	0%	0%	1%
Number of respondents: Employed with N/IH diagnosis	856	536	113	180	504	331	21	203	651

Q7 How many hours per week do you typically work (paid work only)? (choose 1 answer)

By country, Poland (50%) and Italy (40%) stood out with higher shares in the 40+ hours group.

Denmark (55%), Finland (59%), France (52%), Ireland (50%) and Norway (53%) had particularly many in the 30–39 hours group.

7. How many hours per week do you typically work(paid work only)? (choose 1 answer)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
0-9 hours weekly	3%	0%	9%	2%	0%	2%	2%	10%	3%	3%	2%	5%	3%	6%	3%	5%
10-19 hours weekly	11%	0%	0%	15%	5%	9%	12%	5%	13%	9%	18%	12%	9%	12%	11%	10%
20-29 hours weekly	19%	29%	9%	15%	11%	16%	19%	10%	27%	17%	30%	20%	9%	12%	29%	33%
30-39 hours weekly	42%	57%	18%	55%	59%	52%	37%	5%	50%	32%	36%	53%	25%	35%	29%	19%
40 or more hours weekly	25%	14%	55%	9%	24%	19%	30%	70%	7%	40%	14%	10%	50%	35%	28%	29%
Don't know	1%	0%	9%	4%	0%	2%	0%	0%	0%	0%	0%	0%	3%	0%	0%	5%
Number of respondents: Employed with N/IH diagnosis	856	7	11	53	37	204	94	20	30	101	56	83	32	17	72	21

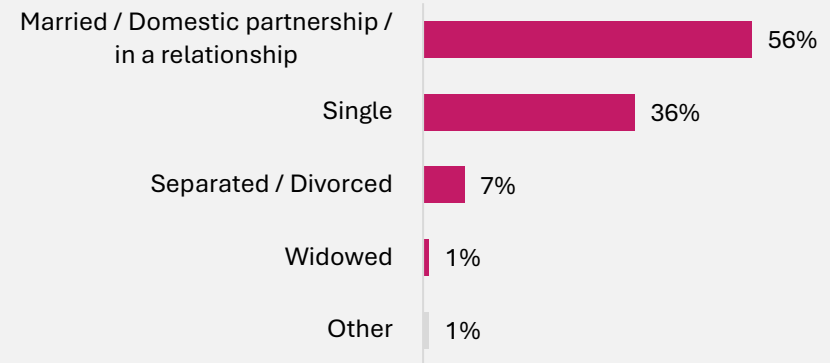
Q8 What is your current marital/relationship status? (choose 1 answer)

In total, 56% of respondents were married, in a domestic partnership, or in a relationship, while 36% were single.

In the IH group, more were partnered (68%) compared to NT1 (51%) and NT2 (60%).

By age, partnership rates were higher among respondents aged 40–59 (65%) and 60+ (66%), compared to 49% among 18–39-year-olds.

Men were more often single (48% vs. 32% of women), while women more often reported being in a relationship (59% vs. 46%).



8. What is your current marital/relationship status? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Married / Domestic partnership / in a relationship	56%	51%	60%	68%	49%	65%	66%	46%	59%
Single	36%	42%	27%	25%	49%	20%	10%	48%	32%
Separated / Divorced	7%	6%	9%	7%	2%	14%	12%	4%	7%
Widowed	1%	1%	1%	0%	0%	1%	11%	1%	1%
Other	1%	1%	1%	0%	1%	0%	1%	1%	0%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259

Q8 What is your current marital/relationship status? (choose 1 answer)

Across most countries, the majority of respondents were married, in a domestic partnership, or in a relationship (43–69%).

Norway had most partnered respondents (69%), while Spain and Poland had fewest (43% and 46%).

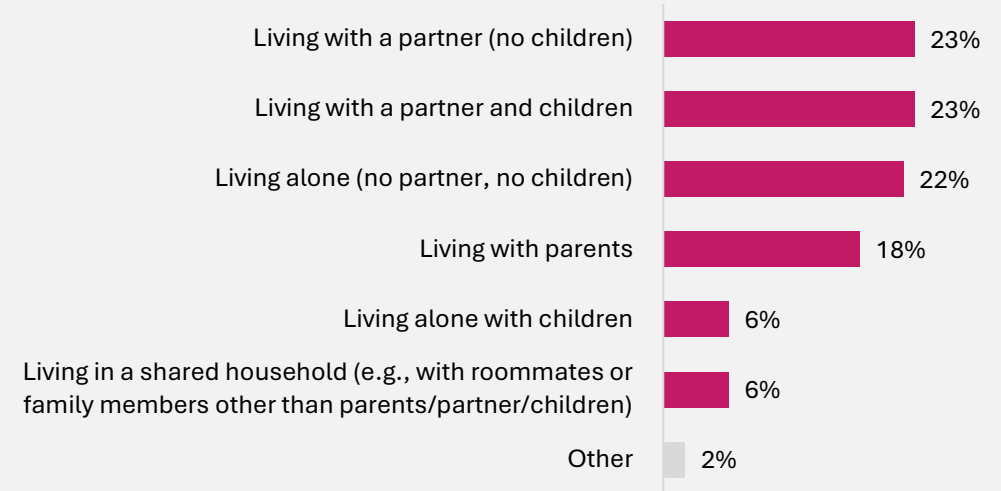
Single status was more common in Italy (44%) and Spain (43%). Rates of separation/divorce were relatively high in Spain (13%).

8. What is your current marital/relationship status? (choose 1 answer)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Married / Domestic partnership / in a relationship	56%	59%	28%	55%	61%	56%	52%	37%	58%	47%	58%	69%	46%	43%	59%	75%
Single	36%	35%	56%	40%	33%	37%	40%	37%	34%	44%	37%	23%	42%	43%	34%	22%
Separated / Divorced	7%	0%	11%	2%	6%	7%	7%	27%	7%	7%	1%	6%	6%	13%	5%	3%
Widowed	1%	6%	6%	3%	0%	0%	1%	0%	1%	2%	2%	1%	0%	0%	1%	0%
Other	1%	0%	0%	0%	0%	0%	0%	0%	0%	1%	2%	1%	6%	2%	1%	0%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36

Q9 What is your current living situation? (choose 1 answer)

Living situations were evenly distributed, with 23% living with a partner without children, 23% with a partner and children, 22% living alone and 18% living with parents.

By diagnosis, respondents with IH were more often living with a partner (29%), while those with NT1 were more often living with parents (21%). By age, living with parents was most common among 18–39-year-olds (29%), while living with a partner and children peaked among 40–59-year-olds (42%). More than half of respondents aged 60+ lived with a partner without children (53%). By gender, men more often lived with parents than women (31% vs. 14%), while women were more likely to live with a partner (25% vs. 18%)



9. What is your current living situation? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Living with a partner (no children)	23%	21%	27%	29%	21%	22%	53%	18%	25%
Living with a partner and children	23%	21%	24%	29%	15%	42%	9%	21%	24%
Living alone (no partner, no children)	22%	23%	17%	21%	23%	19%	27%	22%	22%
Living with parents	18%	21%	18%	9%	29%	3%	1%	31%	14%
Living alone with children	6%	5%	8%	7%	2%	12%	3%	2%	7%
Living in a shared household (e.g., with roommates or family members other than parents/partner/children)	6%	7%	4%	4%	9%	1%	1%	4%	6%
Other	2%	1%	2%	2%	1%	1%	6%	2%	2%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259

Q9 What is your current living situation? (choose 1 answer)

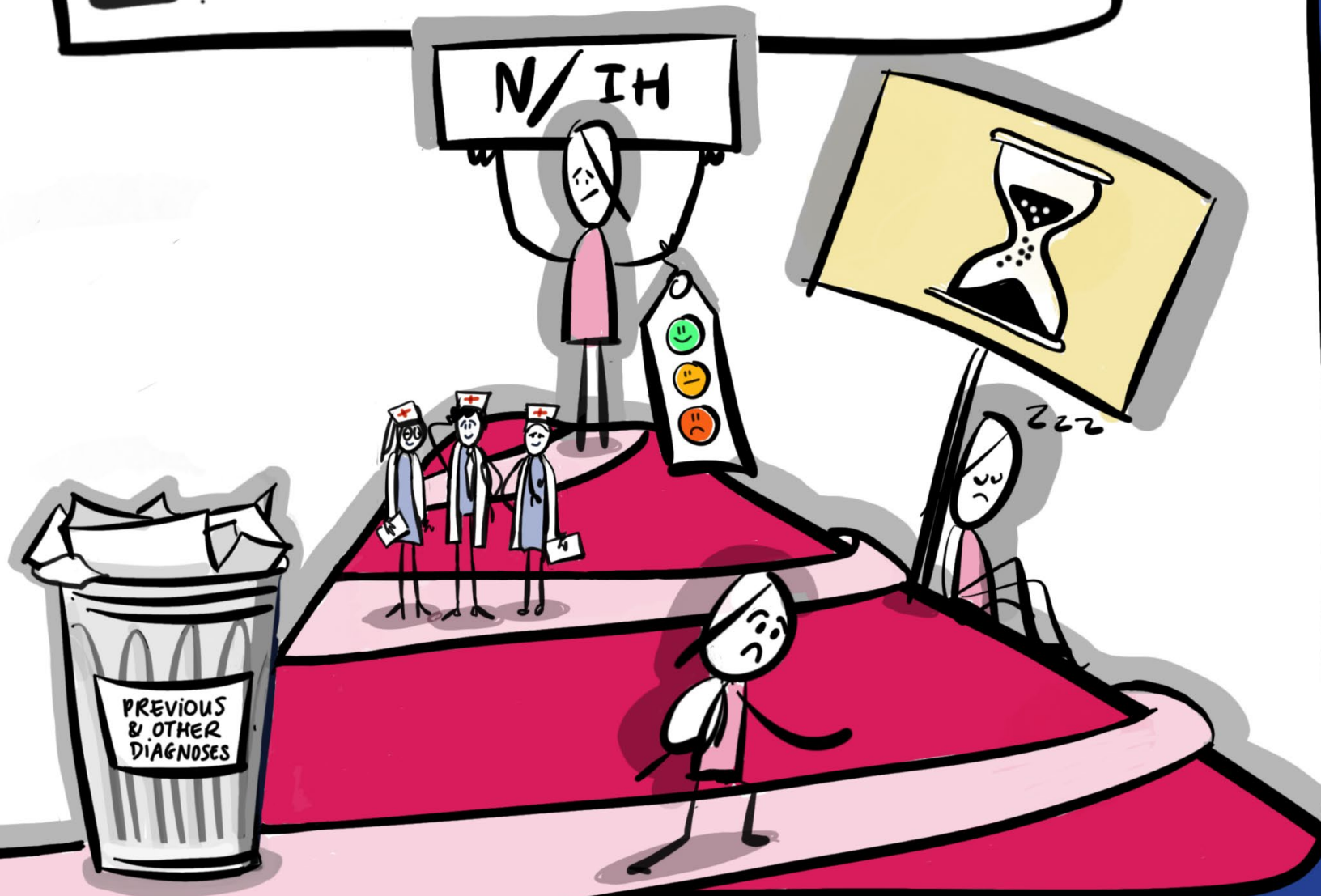
Living situations varied somewhat by country. Respondents in Italy (40%) and Poland (36%) more often lived with parents compared to the overall 18%.

By contrast, Sweden (34%) had more respondents living alone without partner/children than the overall 22%.

Living with a partner without children was particularly frequent in Finland (39%) and Norway (30%) compared to the total of 23%.

9. What is your current living situation? (choose 1 answer)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Living with a partner (no children)	23%	29%	0%	23%	39%	23%	24%	7%	14%	19%	24%	30%	26%	14%	21%	44%
Living with a partner and children	23%	24%	22%	24%	21%	24%	20%	29%	26%	15%	22%	31%	12%	30%	27%	22%
Living alone (no partner, no children)	22%	0%	6%	29%	25%	25%	25%	20%	8%	15%	17%	20%	18%	23%	34%	17%
Living with parents	18%	47%	44%	8%	1%	12%	14%	27%	34%	40%	28%	8%	36%	23%	14%	6%
Living alone with children	6%	0%	17%	5%	9%	8%	3%	12%	8%	6%	2%	4%	4%	4%	2%	3%
Living in a shared household (e.g., with roommates or family members other than parents/partner/children)	6%	0%	6%	9%	3%	6%	12%	0%	11%	4%	6%	4%	2%	4%	0%	6%
Other	2%	0%	6%	3%	1%	1%	2%	5%	0%	1%	1%	3%	2%	2%	2%	3%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36

2. DIAGNOSIS JOURNEY

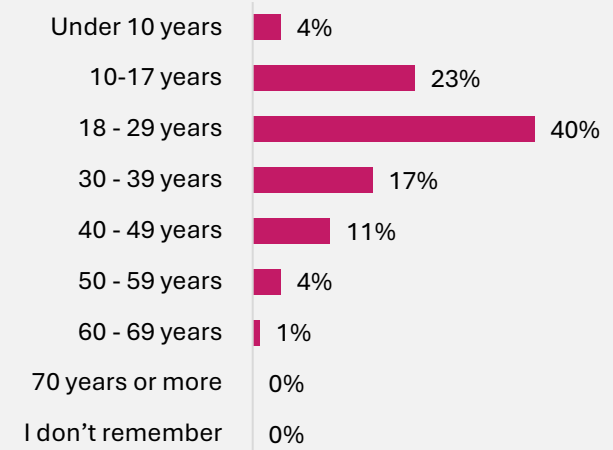


Q10 At what age were you diagnosed with N/IH? (choose 1 answer)

Most respondents were diagnosed at ages 18–29 (40%) or 10–17 (23%). Fewer were diagnosed at 30–39 (17%), 40–49 (11%), and very few after 50 (5% in total).

27% of respondents were diagnosed under 18 years of age. This was 38% for men and 24% for women.

In general NT1 was diagnosed earlier than NT2 and IH.



10. At what age were you diagnosed with N/IH? (choose 1 answer)	N/IH diagnosis				Age			Gender	
	Total	NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Under 10 years	4%	6%	1%	1%	7%	1%	0%	9%	3%
10-17 years	23%	29%	16%	8%	34%	6%	4%	29%	21%
18 - 29 years	40%	36%	43%	50%	49%	29%	10%	33%	42%
30 - 39 years	17%	15%	19%	21%	9%	29%	23%	16%	17%
40 - 49 years	11%	9%	14%	15%	0%	28%	28%	9%	12%
50 - 59 years	4%	3%	6%	4%	0%	7%	24%	4%	4%
60 - 69 years	1%	1%	0%	0%	0%	0%	9%	0%	1%
70 years or more	0%	0%	0%	0%	0%	0%	1%	0%	0%
I don't remember	0%	0%	0%	0%	0%	0%	1%	1%	0%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259

Q10 At what age were you diagnosed with N/IH? (choose 1 answer)

The average age of diagnosis was 26 years overall, but with notable variation across countries.

Respondents in Norway (29 years), Spain (29 years), and Denmark (28 years) reported the latest diagnoses.

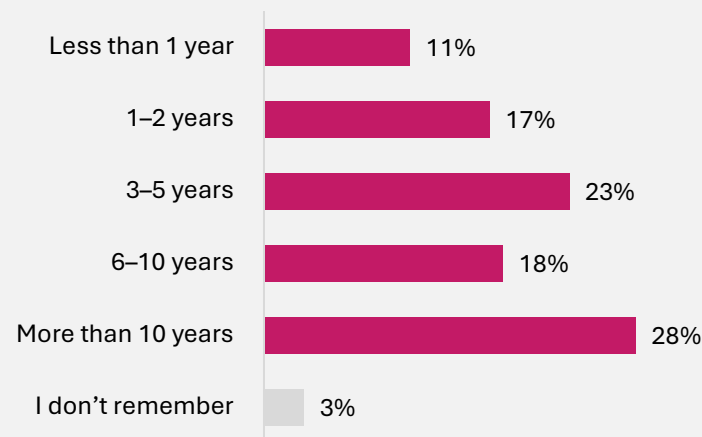
Sweden (22 years), Finland (23 years) and Poland (23 years) reported the youngest diagnosis age.

10. At what age were you diagnosed with N/IH? (choose 1 answer)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Under 10 years	4%	6%	0%	3%	0%	3%	3%	0%	5%	9%	5%	3%	2%	13%	14%	0%
10-17 years	23%	29%	33%	18%	40%	21%	23%	29%	30%	23%	29%	10%	34%	14%	30%	25%
18 - 29 years	40%	35%	17%	45%	40%	47%	39%	20%	41%	35%	39%	45%	38%	18%	37%	28%
30 - 39 years	17%	0%	33%	13%	12%	16%	16%	24%	14%	14%	14%	23%	22%	36%	12%	19%
40 - 49 years	11%	29%	11%	13%	6%	11%	12%	12%	8%	11%	8%	15%	4%	16%	5%	17%
50 - 59 years	4%	0%	6%	5%	0%	2%	6%	15%	3%	6%	4%	4%	0%	4%	3%	8%
60 - 69 years	1%	0%	0%	2%	1%	0%	1%	0%	0%	1%	0%	1%	0%	0%	1%	0%
70 years or more	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	3%
I don't remember	0%	0%	0%	0%	0%	0%	0%	0%	0%	1%	1%	0%	0%	0%	0%	0%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36
Estimated average diagnosis age	26	26	28	28	23	26	27	31	24	26	24	29	23	29	22	29

Q11 How long did it take from your first symptoms until you got a N/IH diagnose? (choose 1 answer)

Diagnosis often came after a long time: 28% waited more than 10 years, while only 11% were diagnosed within the first year.

By diagnosis, more patients with NT2 or IH reported 10+ years time between first symptoms and diagnosis (34-38%) compared to patients with NT1.



11. How long did it take from your first symptoms until you got a N/IH diagnose? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Less than 1 year	11%	15%	5%	3%	12%	9%	12%	14%	10%
1–2 years	17%	19%	14%	11%	20%	13%	11%	18%	16%
3–5 years	23%	22%	26%	23%	26%	19%	16%	24%	23%
6–10 years	18%	18%	17%	19%	21%	13%	14%	16%	19%
More than 10 years	28%	24%	34%	38%	19%	43%	41%	26%	29%
I don't remember	3%	2%	3%	6%	2%	3%	7%	2%	3%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259

Q11 How long did it take from your first symptoms until you got a N/IH diagnose? (choose 1 answer)

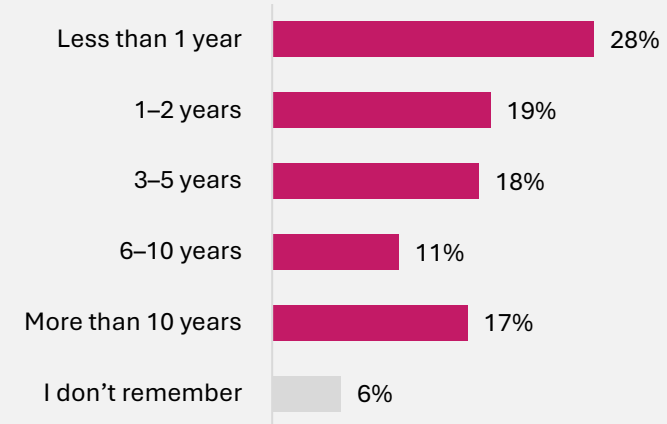
A large number of patients (28%) waited more than 10 years, especially in Denmark (39%), Norway (40%) and Spain (41%). In contrast, only 11% were diagnosed within the first year, most often in Sweden (21%), Italy (19%) and Finland (19%).

11. How long did it take from your first symptoms until you got a N/IH diagnose? (choose 1 answer)	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Less than 1 year	11%	0%	17%	11%	19%	7%	13%	10%	9%	19%	14%	4%	6%	9%	21%	14%
1–2 years	17%	24%	6%	14%	24%	19%	17%	10%	11%	16%	19%	7%	16%	20%	25%	25%
3–5 years	23%	18%	17%	18%	16%	25%	20%	29%	26%	15%	27%	24%	34%	25%	28%	22%
6–10 years	18%	12%	22%	15%	19%	19%	21%	20%	22%	19%	18%	22%	22%	5%	13%	11%
More than 10 years	28%	47%	39%	39%	19%	26%	26%	32%	30%	29%	20%	40%	20%	41%	13%	25%
I don't remember	3%	0%	0%	2%	1%	4%	3%	0%	3%	2%	3%	4%	2%	0%	1%	3%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36

Q12 How long did it take from your first N/IH symptoms until you talked to your general practitioner about them? (choose 1 answer)

28% consulted their GP within the first year, while 17% waited more than 10 years.

More with NT1 (35%) than NT2 (20%) and IH (13%) consulted their GP within 1 year.



12. How long did it take from your first N/IH symptoms until you talked to your general practitioner about them? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Less than 1 year	28%	35%	20%	13%	31%	23%	27%	33%	27%
1–2 years	19%	19%	22%	18%	22%	16%	12%	21%	19%
3–5 years	18%	18%	19%	18%	20%	15%	14%	17%	18%
6–10 years	11%	10%	11%	15%	12%	9%	9%	7%	12%
More than 10 years	17%	13%	21%	29%	9%	30%	28%	17%	18%
I don't remember	6%	5%	8%	6%	5%	7%	10%	6%	6%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259

Q12 How long did it take from your first N/IH symptoms until you talked to your general practitioner about them? (choose 1 answer)

Most in Sweden (53%), Finland (48%) and Ireland (47%) consulted their GP within 1 year.

12. How long did it take from your first N/IH symptoms until you talked to your general practitioner about them? (choose 1 answer)	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Less than 1 year	28%	29%	22%	30%	48%	9%	30%	15%	47%	37%	41%	21%	38%	21%	53%	28%
1–2 years	19%	12%	17%	19%	16%	20%	18%	10%	20%	16%	23%	21%	24%	25%	22%	17%
3–5 years	18%	18%	22%	16%	16%	24%	17%	27%	12%	14%	15%	18%	16%	18%	11%	11%
6–10 years	11%	6%	17%	8%	10%	18%	12%	17%	9%	6%	6%	12%	8%	2%	5%	17%
More than 10 years	17%	35%	22%	18%	6%	25%	17%	32%	8%	19%	10%	17%	4%	27%	3%	22%
I don't remember	6%	0%	0%	8%	3%	4%	6%	0%	3%	8%	5%	11%	10%	7%	6%	6%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36

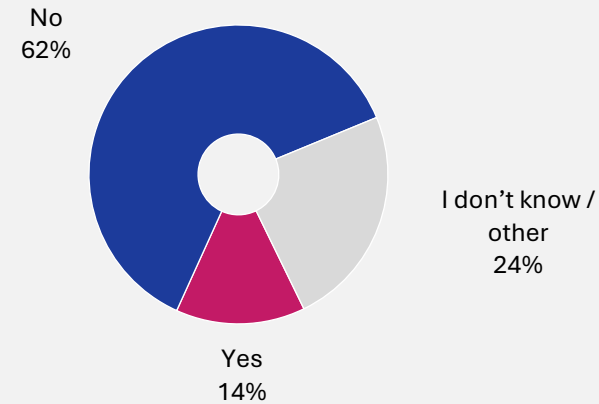
Q13 Is your N/IH due to the Pandemrix vaccination? (choose 1 answer)

14% responded that their narcolepsy or IH was caused by the Pandemrix vaccination, while 62% said no and 24% answered 'I don't know / other.'

NT1 respondents were most likely to attribute their condition to Pandemrix (19%), compared to 7% of NT2 and 3% of IH.

By age, 'Yes' was most common among 18–39-year-olds (19%) and least common among those aged 40–59 (6%) and 60+ (4%).

Men and women reported similar levels, with 14% in both groups linking their diagnosis to the vaccination.



13. Is your N/IH due to the Pandemrix vaccination? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Yes	14%	19%	7%	3%	19%	6%	4%	14%	14%
No	62%	61%	59%	67%	55%	71%	83%	59%	63%
I don't know / other	24%	20%	34%	30%	26%	22%	12%	27%	23%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259

Q13 Is your N/IH due to the Pandemrix vaccination? (choose 1 answer)

Respondents in Finland (43%), Ireland (42%), Norway (22%), and especially Sweden (81%) were far more likely to attribute their condition to Pandemrix. These were the countries where Pandemrix was widely administered during the 2009 N1H1 (swine flu) epidemic.

By contrast, 'No' was most common in Denmark (80%), Germany (76%) and the Netherlands (74%). Levels of uncertainty were relatively high in Italy (31%) and Poland (32%).

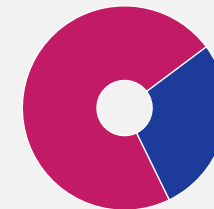
13. Is your N/IH due to the Pandemrix vaccination? (choose 1 answer)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Yes	14%	6%	0%	1%	43%	5%	3%	0%	42%	1%	5%	22%	2%	0%	81%	8%
No	62%	82%	56%	80%	37%	65%	76%	59%	46%	68%	74%	58%	66%	71%	8%	81%
I don't know / other	24%	12%	44%	19%	19%	30%	21%	41%	12%	31%	20%	20%	32%	29%	11%	11%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36

Q14 Before your N/IH diagnosis, were you given a different diagnosis / cause for the symptoms? (you can choose several answers)

72% reported having been given another explanation for their symptoms before their N/IH diagnosis, while 28% had not.

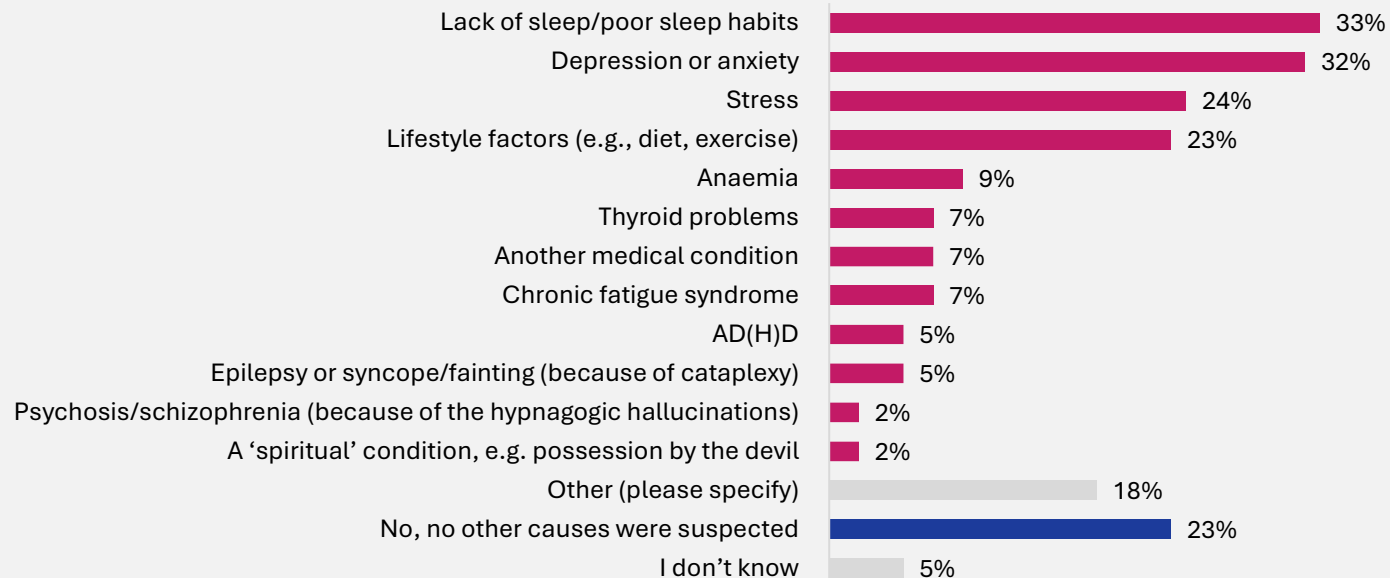
The most frequent were lack of sleep or poor sleep habits (33%), depression or anxiety (32%), stress (24%), and lifestyle factors such as diet or exercise (23%).

We're given a different
diagnose / cause before
their N/IH diagnosis
72%



No prior diagnosis /
Don't know
28%

Excl. "I don't know"



Q14 Before your N/IH diagnosis, were you given a different diagnosis / cause for the symptoms? (you can choose several answers)

NT2 respondents were more often told their symptoms were due to poor sleep habits (42% vs. 31% with NT1 and IH), while IH respondents were more often linked to depression or anxiety (48% vs. 26–35% with narcolepsy).

By age, younger respondents (18–39) were more often told their symptoms were due to sleep habits (35%), while middle-aged respondents were more likely to be told depression or anxiety was the cause.

Women were more likely than men to have been given an alternative explanation (75% vs. 64%).

14. Before your N/IH diagnosis, were you given a different diagnosis / cause for the symptoms? (you can choose several answers)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Lack of sleep/poor sleep habits	33%	31%	42%	31%	35%	30%	27%	34%	32%
Depression or anxiety	32%	26%	35%	48%	31%	34%	31%	25%	34%
Stress	24%	22%	27%	29%	25%	22%	26%	20%	26%
Lifestyle factors (e.g., diet, exercise)	23%	22%	24%	22%	26%	20%	12%	21%	23%
Anaemia	9%	7%	12%	12%	11%	7%	3%	4%	10%
Thyroid problems	7%	6%	9%	9%	7%	8%	4%	4%	8%
Another medical condition	7%	6%	11%	7%	6%	9%	11%	9%	7%
Chronic fatigue syndrome	7%	4%	11%	10%	6%	8%	11%	8%	7%
AD(H)D	5%	4%	8%	5%	6%	3%	3%	9%	4%
Epilepsy or syncope/fainting (because of cataplexy)	5%	8%	1%	1%	5%	6%	4%	6%	5%
Psychosis/schizophrenia (because of the hypnagogic hallucinations)	2%	3%	1%	1%	2%	2%	3%	3%	2%
A 'spiritual' condition, e.g. possession by the devil	2%	2%	2%	1%	2%	2%	2%	3%	2%
Other (please specify)	18%	20%	14%	16%	20%	16%	12%	16%	19%
No, no other causes were suspected	23%	25%	21%	21%	23%	24%	24%	29%	21%
I don't know	5%	5%	4%	3%	5%	4%	7%	7%	4%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259
We're given a different diagnose / cause before their N/IH diagnosis	72%	70%	75%	76%	72%	72%	69%	64%	75%

(excl. I don't know)

Q14 Before your N/IH diagnosis, were you given a different diagnosis / cause for the symptoms? (you can choose several answers)

Across countries, many respondents reported receiving a different diagnosis before their N/IH. The most common were lack of sleep/poor sleep habits, especially in Ireland (46%) and Poland (38%), and depression or anxiety, with high shares in France (44%) and Ireland (43%). Stress was also a frequent misdiagnosis, particularly in Poland (30%) and Spain (29%). Lifestyle factors such as diet or exercise were often cited in Ireland (46%) and Poland (34%).

Other causes such as anaemia, thyroid problems, or chronic fatigue syndrome were less common, though thyroid issues stood out in Poland (18%). Overall, 72% had received an alternative diagnosis before their N/IH was identified.

14. Before your N/IH diagnosis, were you given a different diagnosis / cause for the symptoms? (you can choose several answers)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Lack of sleep/poor sleep habits	33%	59%	28%	27%	30%	35%	36%	27%	46%	28%	29%	26%	32%	38%	34%	36%
Depression or anxiety	32%	18%	0%	17%	33%	44%	34%	49%	43%	27%	17%	24%	30%	30%	26%	36%
Stress	24%	24%	17%	15%	18%	24%	27%	34%	28%	27%	28%	17%	30%	29%	27%	17%
Lifestyle factors (e.g., diet, exercise)	23%	29%	17%	18%	21%	22%	23%	10%	46%	18%	21%	17%	34%	18%	30%	31%
Anaemia	9%	12%	6%	3%	10%	16%	5%	2%	14%	8%	12%	4%	6%	5%	4%	6%
Thyroid problems	7%	29%	17%	5%	10%	4%	14%	2%	9%	5%	1%	5%	18%	9%	7%	6%
Another medical condition	7%	0%	6%	3%	3%	3%	11%	5%	22%	5%	12%	10%	8%	2%	5%	19%
Chronic fatigue syndrome	7%	0%	6%	3%	1%	8%	10%	22%	5%	5%	7%	6%	4%	4%	5%	8%
AD(H)D	5%	12%	0%	3%	1%	3%	6%	7%	5%	3%	9%	6%	4%	7%	6%	6%
Epilepsy or syncope/fainting (because of cataplexy)	5%	6%	17%	4%	1%	3%	4%	20%	8%	10%	3%	2%	22%	9%	2%	8%
Psychosis/schizophrenia (because of the hypnagogic hallucinations)	2%	6%	11%	2%	0%	1%	1%	15%	4%	3%	4%	1%	2%	4%	0%	0%
A 'spiritual' condition, e.g. possession by the devil	2%	0%	6%	2%	0%	1%	1%	5%	0%	6%	3%	0%	2%	4%	0%	3%
Other (please specify)	18%	47%	22%	38%	24%	15%	13%	7%	19%	11%	26%	18%	14%	13%	25%	14%
No, no other causes were suspected	23%	6%	28%	23%	22%	23%	24%	17%	15%	29%	25%	30%	18%	14%	24%	25%
I don't know	5%	0%	6%	3%	4%	4%	7%	0%	5%	6%	7%	4%	0%	14%	4%	0%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36
We're given a different diagnose / cause before their N/IH diagnosis	72%	94%	66%	74%	74%	73%	69%	83%	80%	65%	68%	66%	82%	72%	72%	75%

(excl. I don't know)

Q14 Before your N/IH diagnosis, were you given a different diagnosis / cause for the symptoms? (you can choose several answers)

The free-text responses of other frequent diagnoses reveal a strong tendency for patients' symptoms to be attributed to common, benign, or psychosocial explanations before their N/IH diagnosis. This suggests a diagnostic pathway often beginning with non-specialist, broad explanations—frequently delaying recognition of N/IH.

Most frequent other prior diagnoses described with free-text:

- 1) Teenage tiredness/puberty – Many respondents said their symptoms were dismissed as normal adolescence, teenage laziness, or part of a growth phase. Variants included “teenager tired,” “normal for a teenager,” “part of puberty,” “growth spurt,” and “adolescent crisis.”
- 2) Sleep apnoea – Frequently mentioned as an initial suspected diagnosis, including obstructive sleep apnoea, apnoea due to obesity, sleep apnoea with CPAP, and combinations with restless legs syndrome.
- 3) Vitamin/mineral deficiencies – Commonly cited were vitamin D deficiency, iron deficiency, vitamin B12 deficiency, and combinations (e.g., vitamin D + iron, iron + pernicious anemia).
- 4) Psychological/psychiatric explanations – Respondents often reported being told their symptoms were psychological, due to depression, laziness, burnout, overwork, adjustment disorder, borderline personality disorder, bipolar disorder, psychosomatic disorder, or “it’s in your head.”
- 5) Viral or infectious illnesses – Mononucleosis/Epstein-Barr virus was the most common, alongside flu, post-H1N1 encephalitis, COVID-19, and suspected viral infections.

Other Recurring Themes:

- Hormonal/life-stage factors – Menopause, menstruation, pregnancy, breastfeeding, and postpartum changes were often blamed.
- Neurological conditions – Migraine, epilepsy, brain tumor, MS, Kleine-Levin syndrome, functional neurological disorder, acquired brain injury.
- Allergies/asthma – Dust, pollen, animal hair, asthma, food allergies.
- Autoimmune/inflammatory diseases – Endometriosis, autoimmune disease, hypothyroidism, Bechterew’s disease, myasthenia gravis.
- Lifestyle and external factors – Overtraining, demanding jobs, irregular working hours, childcare responsibilities, poor sleep habits, overwork.

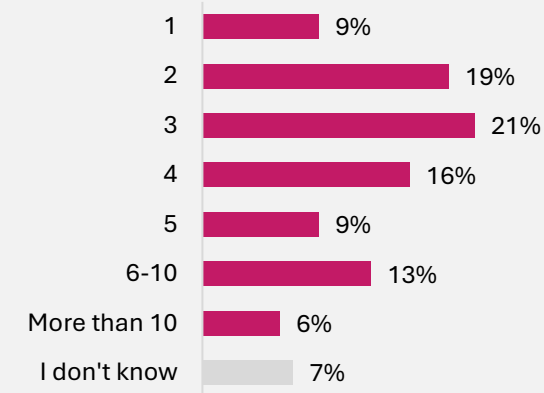
Less Frequent/Isolated Mentions

- Rare diseases (e.g., thymoma, vasovagal syncope).
- Structural issues (e.g., adenoids, enlarged tonsils).
- Cardiovascular/metabolic issues (e.g., diabetes, low blood pressure, obesity).
- Environmental factors (e.g., poor indoor air quality at school).
- Trauma (childhood abuse, major illness, near-death experience).

Q15 How many healthcare professionals incl. your general practitioner did you see for your N/IH symptoms before getting the diagnosis of N/IH? (choose 1 answer)

Most respondents had to see several healthcare professionals before getting their diagnosis. 49% of respondents saw 1–3 healthcare professionals before receiving their N/IH diagnosis, 38% saw 4–10, and 6% saw more than 10.

Across diagnoses, age groups, and genders, there were no substantial demographic differences.



15. How many healthcare professionals incl. your general practitioner did you see for your N/IH symptoms before getting the diagnosis of N/IH? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
1	9%	9%	9%	7%	7%	11%	15%	8%	9%
2	19%	19%	20%	16%	18%	19%	23%	19%	19%
3	21%	21%	23%	23%	22%	21%	23%	17%	23%
4	16%	16%	14%	17%	19%	12%	8%	17%	15%
5	9%	9%	8%	7%	9%	9%	8%	10%	9%
6-10	13%	13%	13%	15%	13%	14%	16%	17%	12%
More than 10	6%	5%	7%	7%	5%	8%	4%	6%	6%
I don't know	7%	8%	6%	7%	8%	7%	3%	7%	8%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259

(excl. I don't know)

Q15 How many healthcare professionals incl. your general practitioner did you see for your N/IH symptoms before getting the diagnosis of N/IH? (choose 1 answer)

The number of healthcare professionals consulted before diagnosis, suggest relatively consistent patterns across most countries.

15. How many healthcare professionals incl. your general practitioner did you see for your N/IH symptoms before getting the diagnosis of N/IH? (choose 1 answer)	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
1	9%	0%	17%	12%	10%	8%	6%	5%	4%	16%	9%	11%	2%	13%	2%	14%
2	19%	18%	6%	24%	12%	20%	13%	15%	20%	17%	26%	21%	4%	34%	13%	31%
3	21%	24%	6%	23%	16%	26%	20%	22%	20%	18%	22%	24%	12%	20%	20%	19%
4	16%	18%	6%	13%	13%	17%	19%	12%	15%	13%	13%	10%	16%	16%	21%	22%
5	9%	0%	6%	8%	9%	7%	10%	24%	12%	10%	5%	8%	18%	5%	10%	3%
6-10	13%	18%	33%	9%	12%	11%	18%	12%	14%	12%	12%	14%	32%	9%	17%	8%
More than 10	6%	6%	11%	1%	7%	4%	10%	10%	5%	6%	6%	5%	12%	0%	10%	0%
I don't know	7%	18%	17%	11%	19%	7%	4%	0%	9%	7%	7%	6%	4%	4%	8%	3%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36

(excl. I don't know)

Q16 What kind of healthcare professional finally diagnosed you for N/IH? (choose 1 answer)

Most respondents were diagnosed by a neurologist (57%), while one third (33%) were diagnosed by a sleep specialist (who may or may not have been a neurologist as well). Much smaller shares reported being diagnosed by a pulmonologist (2%), a psychiatrist or other mental health professional (2%), or a child doctor/pediatrician (2%).

By diagnosis, neurologists were most frequently involved for NT1 (60%) and IH (57%), whereas NT2 was more often diagnosed by a sleep specialist (45%). By age, neurologists were the diagnosing doctors for the majority across groups (55–65%). By gender, men and women showed almost identical patterns, with neurologists as the primary diagnosing professional in both groups (54% vs. 58%).



16. What kind of healthcare professional finally diagnosed you for N/IH? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Neurologist	57%	60%	46%	57%	58%	55%	65%	54%	58%
Sleep specialist (discipline unknown)	33%	29%	45%	38%	32%	38%	27%	34%	33%
Respiratory Specialist / pulmonologist	2%	2%	3%	3%	3%	3%	2%	2%	3%
Psychiatrist, psychologist or other mental healthcare professional	2%	2%	2%	1%	3%	1%	3%	3%	2%
Child doctor / paediatrician	2%	2%	1%	0%	3%	0%	1%	3%	1%
Other	1%	1%	2%	1%	1%	2%	2%	1%	2%
I don't remember	1%	2%	0%	0%	2%	1%	0%	3%	1%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259

Q16 What kind of healthcare professional finally diagnosed you for N/IH? (choose 1 answer)

Across countries, neurologists were generally the most common professionals diagnosing Narcolepsy or IH, although the extent varied considerably. Finland (84%), Norway (77%), and Sweden (72%) stood out with particularly high proportions diagnosed by neurologists, while Germany (40%) and Italy (42%) reported the lowest share.

Sleep specialists were the second most frequent group, ranging from 10% in Finland to 53% in Germany and Italy. Other healthcare professionals (such as psychiatrists, pulmonologists, or paediatricians) played only minor roles in most countries, though Poland (22%) had relatively many respondents diagnosed by psychiatrists or other mental health professionals.

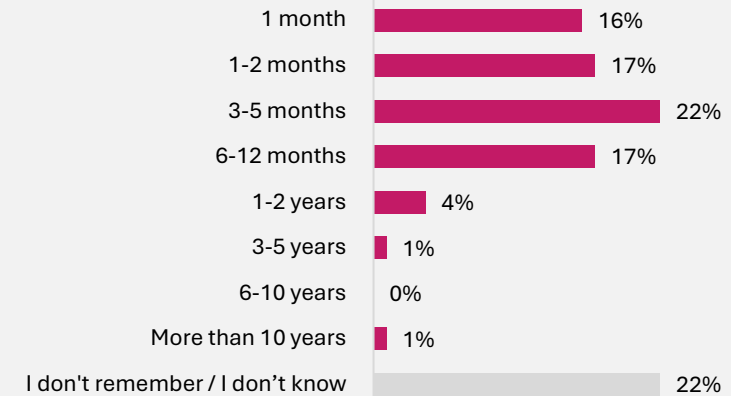
16. What kind of healthcare professional finally diagnosed you for N/IH? (choose 1 answer)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Neurologist	57%	47%	33%	68%	84%	54%	40%	93%	35%	42%	71%	77%	48%	50%	72%	50%
Sleep specialist (discipline unknown)	33%	35%	61%	21%	10%	39%	53%	7%	50%	53%	22%	16%	26%	41%	11%	42%
Respiratory Specialist / pulmonologist	2%	18%	0%	1%	0%	3%	1%	0%	12%	1%	1%	1%	2%	0%	0%	6%
Psychiatrist, psychologist or other mental healthcare professional	2%	0%	0%	1%	0%	3%	2%	0%	0%	3%	0%	1%	22%	2%	0%	3%
Child doctor / paediatrician	2%	0%	0%	4%	0%	0%	2%	0%	0%	1%	3%	2%	0%	0%	9%	0%
Other	1%	0%	6%	2%	0%	1%	2%	0%	3%	0%	2%	2%	0%	7%	1%	0%
I don't remember	1%	0%	0%	3%	6%	0%	1%	0%	0%	1%	2%	1%	2%	0%	7%	0%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36

Q17 How long were you on the waiting list for the first appointment with the specialist who diagnosed you with N/IH? (choose 1 answer)

Waiting times for the first specialist appointment varied considerably. While 33% were seen within 2 months, many reported delays of 3–5 months (22%) or 6–12 months (17%). 6% waited more than 1 year, while 22% could not recall their waiting time.

57% of those with NT1 reported being seen by a specialist within 6 months. This was 55% for NT2 and 49% for IH.

Gender differences were minimal.



17. How long were you on the waiting list for the first appointment with the specialist who diagnosed you with N/IH? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
1 month	16%	18%	18%	9%	14%	17%	27%	21%	14%
1-2 months	17%	18%	17%	11%	18%	15%	19%	17%	17%
3-5 months	22%	21%	20%	29%	23%	23%	17%	19%	24%
6-12 months	17%	13%	23%	26%	17%	17%	15%	13%	18%
1-2 years	4%	4%	4%	7%	4%	7%	2%	4%	5%
3-5 years	1%	1%	1%	0%	1%	0%	1%	1%	0%
6-10 years	0%	0%	0%	1%	1%	0%	1%	1%	0%
More than 10 years	1%	0%	0%	1%	0%	1%	3%	0%	1%
I don't remember / I don't know	22%	25%	17%	16%	24%	18%	16%	24%	21%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259

(excl. I don't know)

Q17 How long were you on the waiting list for the first appointment with the specialist who diagnosed you with N/IH? (choose 1 answer)

Across countries, the number of months spent on the waiting list before the first specialist appointment varied considerably.

17. How long were you on the waiting list for the first appointment with the specialist who diagnosed you with N/IH? (choose 1 answer)	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
1 month	16%	6%	61%	9%	13%	10%	12%	41%	7%	38%	19%	9%	10%	21%	12%	25%
1-2 months	17%	18%	17%	25%	18%	13%	20%	27%	15%	19%	19%	10%	10%	20%	19%	22%
3-5 months	22%	41%	0%	20%	25%	29%	27%	17%	19%	18%	16%	25%	20%	16%	14%	17%
6-12 months	17%	6%	0%	10%	9%	25%	22%	2%	19%	8%	5%	26%	28%	9%	11%	11%
1-2 years	4%	0%	0%	8%	4%	4%	2%	0%	14%	1%	1%	5%	14%	13%	5%	0%
3-5 years	1%	0%	0%	1%	1%	1%	0%	0%	1%	1%	1%	1%	2%	0%	0%	0%
6-10 years	0%	0%	0%	0%	0%	1%	0%	5%	0%	0%	0%	1%	2%	0%	0%	0%
More than 10 years	1%	0%	0%	0%	3%	1%	0%	0%	0%	0%	0%	1%	0%	0%	1%	0%
I don't remember / I don't know	22%	29%	22%	26%	25%	16%	17%	7%	26%	15%	39%	23%	14%	21%	40%	25%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36

(excl. I don't know)

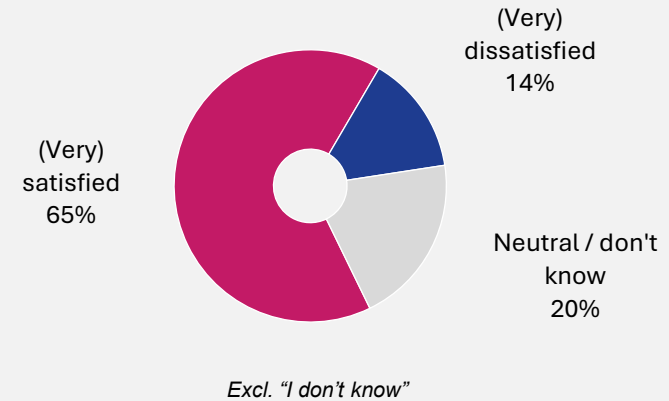
Q18 How satisfied were you with the diagnostic procedure in general, including all the tests needed to get your N/IH diagnosis? (choose 1 answer)

Overall 65% were satisfied with the diagnostic procedure, while 14% were dissatisfied and 20% were neutral or uncertain.

By diagnosis, dissatisfaction was a bit higher among IH (19%) compared with NT1 (13%).

By age, older respondents were more positive, with 75% of those aged 60+ satisfied compared to 64% of respondents aged 18–39 years.

By gender, no demographic differences is worth mentioning.



18. How satisfied were you with the diagnostic procedure in general, including all the tests needed to get your N/IH diagnosis? (choose 1 answer)	N/IH diagnosis				Age			Gender	
	Total	NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Very satisfied	28%	29%	32%	22%	27%	29%	35%	30%	28%
Satisfied	37%	38%	34%	34%	37%	37%	40%	36%	38%
Neutral	18%	18%	17%	23%	20%	16%	13%	17%	18%
Dissatisfied	9%	8%	8%	13%	9%	9%	8%	10%	9%
Very dissatisfied	5%	5%	8%	6%	5%	6%	3%	6%	5%
I don't know	2%	2%	1%	2%	2%	3%	1%	2%	2%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259
(Very) satisfied	65%	67%	66%	56%	64%	66%	75%	66%	66%
(Very) dissatisfied	14%	13%	16%	19%	14%	15%	11%	16%	14%
Neutral / don't know	20%	20%	18%	25%	22%	19%	14%	19%	20%

(excl. I don't know)

Q18 How satisfied were you with the diagnostic procedure in general, including all the tests needed to get your N/IH diagnosis? (choose 1 answer)

Satisfaction with the diagnostic procedure was highest in Denmark (80%) and Italy (86%), while Norway (52%), Sweden (52%) and Poland (48%) reported the lowest.

Dissatisfaction was highest in Poland (24%) and Norway (23%), while Italy (6%) were lowest.

18. How satisfied were you with the diagnostic procedure in general, including all the tests needed to get your N/IH diagnosis? (choose 1 answer)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Very satisfied	28%	6%	56%	32%	16%	21%	28%	20%	28%	55%	22%	28%	28%	34%	23%	25%
Satisfied	37%	47%	33%	48%	52%	41%	38%	49%	32%	31%	46%	24%	20%	38%	29%	44%
Neutral	18%	29%	0%	9%	12%	21%	21%	27%	15%	7%	14%	23%	26%	11%	32%	19%
Dissatisfied	9%	12%	11%	5%	13%	12%	5%	0%	12%	4%	12%	13%	10%	5%	6%	8%
Very dissatisfied	5%	6%	0%	5%	6%	2%	5%	2%	9%	2%	4%	10%	14%	5%	6%	3%
I don't know	2%	0%	0%	1%	0%	2%	4%	2%	3%	2%	2%	2%	7%	4%	0%	
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36
(Very) satisfied	65%	53%	89%	80%	68%	62%	66%	69%	60%	86%	68%	52%	48%	72%	52%	69%
(Very) dissatisfied	14%	18%	11%	10%	19%	14%	10%	2%	21%	6%	16%	23%	24%	10%	12%	11%
Neutral / don't know	20%	29%	0%	10%	12%	23%	25%	29%	18%	9%	16%	25%	28%	18%	36%	19%

(excl. I don't know)

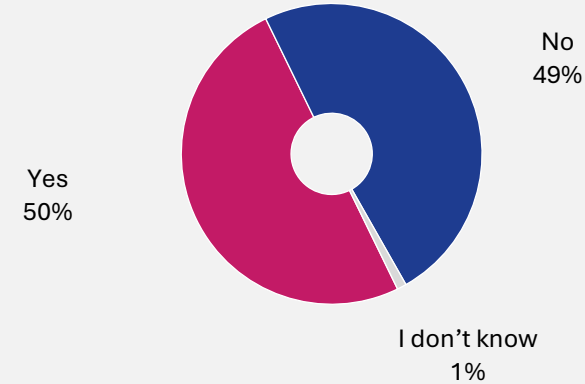
Q19 Did you ever get a lumbar puncture / spinal tap (a needle inserted into the spinal cord to remove fluid for diagnostic testing)?

Half of respondents (50%) reported having undergone a lumbar puncture / spinal tap, while 49% had not and 1% were unsure.

The procedure was most common among NT1 (57%) and NT2 (51%), but far less frequent in IH (28%).

52% of those aged 18–39 had a lumbar puncture, while 48% of 40–59-year-olds and 41% of those aged 60+ had undergone the procedure.

Men reported the procedure more often than women (58% vs. 47%).



19. Did you ever get a lumbar puncture / spinal tap (a needle inserted into the spinal cord to remove fluid for diagnostic testing)?	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Yes	50%	57%	51%	28%	52%	48%	41%	58%	47%
No	49%	42%	49%	71%	47%	50%	58%	41%	52%
I don't know	1%	1%	0%	1%	1%	2%	1%	2%	1%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259

Q19 Did you ever get a lumbar puncture / spinal tap (a needle inserted into the spinal cord to remove fluid for diagnostic testing)?

Lumbar puncture was most frequently reported in Denmark (72%), Italy (82%) and Sweden (80%), followed closely by Finland (66%) and Norway (62%).

Fewest were observed in Poland (18%), France (28%) and the Netherlands (32%).

19. Did you ever get a lumbar puncture / spinal tap (a needle inserted into the spinal cord to remove fluid for diagnostic testing)?	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Yes	50%	24%	39%	72%	66%	28%	44%	83%	43%	82%	32%	62%	18%	36%	80%	39%
No	49%	76%	56%	28%	33%	71%	55%	17%	55%	18%	67%	38%	78%	61%	20%	58%
I don't know	1%	0%	6%	0%	1%	2%	2%	0%	1%	0%	1%	0%	4%	4%	0%	3%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36

■ Q20 What was the feeling you had after receiving the diagnosis?

This question was answered by 1.667 respondents via free-text. Here are the main conclusions starting with the most dominant themes:

Relief after Diagnosis

Many respondents mention feelings of relief — often immediate — upon receiving a correct diagnosis, starting an effective treatment, or having their symptoms validated. This relief is described as both emotional (reduced anxiety, a sense of being believed) and physical (improved symptom management). For some, relief was short-lived as challenges remained, but the moment of recognition or improvement was deeply significant. This relief often stands in sharp contrast to the ongoing fatigue and frustration, acting as a rare but powerful reminder that improvement and validation are possible.

Overwhelming Fatigue

The most frequently repeated challenge across responses is constant, debilitating tiredness. People describe never feeling rested, struggling to stay awake in daily life, and having their energy disappear unpredictably. Many mentioned needing frequent naps, planning their entire day around rest periods, and waking up still exhausted.

Frustration

Frustration is a recurring emotion in many responses, often linked to the limitations the condition imposes and the lack of understanding from others, including healthcare professionals. It arises in work settings where accommodations are denied or opportunities lost, and in social situations where symptoms lead to cancelled plans or reduced participation. For many, frustration is a constant presence, reflecting both the daily obstacles and the ongoing struggle for recognition and support. For many, frustration is a daily companion, driven not only by the limitations of the condition but also by the repeated need to justify their symptoms to others, often without receiving adequate understanding or support.

"I was incredibly relieved and cried because my almost 5-year odyssey from doctor to doctor was finally over and I had a name for my condition. I celebrated like it was birthday and Christmas together. The previous years before diagnosis were incredibly bad."

Male, 18-29 years, Germany, IH, ID 176

"It was a great relief: at last, I understood why I kept falling asleep during an important meeting, while watching a film or reading a fascinating book. It was an illness that could be named and a treatment existed. It was like going from darkness to light."

Female, 60-69 years, France, Narcolepsy (unknown type), ID 558

"The thought that I would never again wake up feeling rested dominated my mind for a long time."

Male, 50-59 years, Norway, IH, ID 651

"I cried because I thought I'd have to be tired for the rest of my life along with frequent cataplexy."

Female, 30-39 years, Germany, NT1 / with cataplexy, ID 748

"A brief relief that it wasn't 'just in my head,' and a lot of frustration that there was nothing more to do than deal with it myself. Not being truly supported. Having to research my own condition and spending time not fully understanding my symptoms, which led me to masking and which was deeply harmful to my overall health, both physical and mental"

Female, 30-39 years, France, IH, ID 769

"Relief and joy to know what my problems were caused by. At the same time: anger, frustration, and despair at having had to fight so hard and so long for the right help and assessment. Joy at finally being seen, heard, and believed."

Female, 40-49 years, Norway, Narcolepsy (unknown type), ID 1605

■ Q20 What was the feeling you had after receiving the diagnosis?

Impact on Social Life

Many respondents report a significant reduction in social participation due to their condition. They describe cancelling plans at the last minute because of fatigue, leaving events early, and being unable to enjoy evenings out. Spontaneous activities are often avoided entirely, as daily life must be carefully aligned with planned rest periods. Over time, this pattern contributes to feelings of isolation, loneliness, and missing out, which in turn can worsen mental health and overall wellbeing. Beyond practical barriers, many describe a sense of lost identity — having to abandon career ambitions, withdraw from valued relationships, and adapt to a smaller, more constrained social world.

Employment and Career Limitations

Work and career opportunities are also heavily affected. Many are unable to work full-time or take on demanding jobs, while others face difficulty finding employment due to the condition itself or employer prejudice. Even when employed, respondents often need accommodations such as nap rooms or flexible schedules, which are rarely available. In some cases, individuals have had to abandon their studies or chosen career paths because their symptoms made it impossible to continue.

Lack of Understanding and Awareness

A lack of understanding and awareness is a persistent challenge. Many note that people—including healthcare professionals—tend to equate their illness with “just being tired,” which underestimates its seriousness. The invisible nature of narcolepsy and IH means that symptoms are often overlooked or misunderstood. This lack of awareness can lead to hurtful comments, discrimination, and a lack of empathy, compounding the daily struggles of living with the condition.

Commonly Mentioned Specific Issues

- Cataplexy: Particularly disruptive in social or public situations; can cause embarrassment and safety concerns.
- Cognitive problems: Memory lapses, brain fog, difficulty concentrating, and losing words mid-sentence.
- Medication side effects: Many note that treatments bring their own challenges (e.g., mood changes, physical symptoms).
- Loss of independence: Inability to drive safely is a major limitation in multiple countries, affecting both work and personal life.
- Life planning restrictions: Everything must be scheduled around symptoms, leaving little room for spontaneity.
- Emotional impact: Depression, anxiety, frustration, and loss of self-esteem are frequently reported consequences — sometimes balanced by relief when effective treatment or recognition is achieved.
- Physical pain: Muscle aches and other body pains are sometimes attributed to constant fatigue or medication.

■ Q20 What was the feeling you had after receiving the diagnosis?

Less Common but Notable Mentions

While not as frequent, several unique points emerged:

- Financial strain from inability to work full-time or at all.
- Impact on parenting, e.g., difficulty caring for children, fear of falling asleep during activities.
- Restrictions in hobbies such as sports, travel, and creative pursuits.
- Geographic healthcare inequality — some must travel long distances for specialist care.
- Comparison to other illnesses: Frustration that IH/N is less recognized than similar neurological disorders.

Summarizing all Statements

The free-text responses depict a condition that permeates every aspect of daily life, from work to relationships to self-image. Fatigue is the most persistent and overwhelming feature — described as constant, debilitating, and unpredictable — shaping how respondents structure their days and limiting participation in both social and professional life. This fatigue is compounded by frustration, which emerges repeatedly in accounts of misunderstood symptoms, lack of medical and public awareness, and the practical barriers to securing appropriate support or accommodations. Fatigue and frustration are deeply intertwined, with the relentless tiredness often fuelling emotional strain. Moments of relief — whether from treatment, diagnosis, or recognition — can temporarily break this cycle, offering both physical and emotional respite.

Amid these challenges, moments of relief stand out as deeply significant. Many respondents describe profound emotional and physical release when finally receiving a correct diagnosis, starting an effective treatment, or having their symptoms validated. These moments, while sometimes short-lived, offer a sense of recognition and hope that contrasts sharply with the daily grind of managing an invisible, relentless condition.

Overall, the illness is not just about managing sleepiness — it is about navigating an entire life constrained by invisible limitations, marked by cycles of fatigue and frustration, yet punctuated by powerful, transformative episodes of relief when understanding and effective care are achieved.

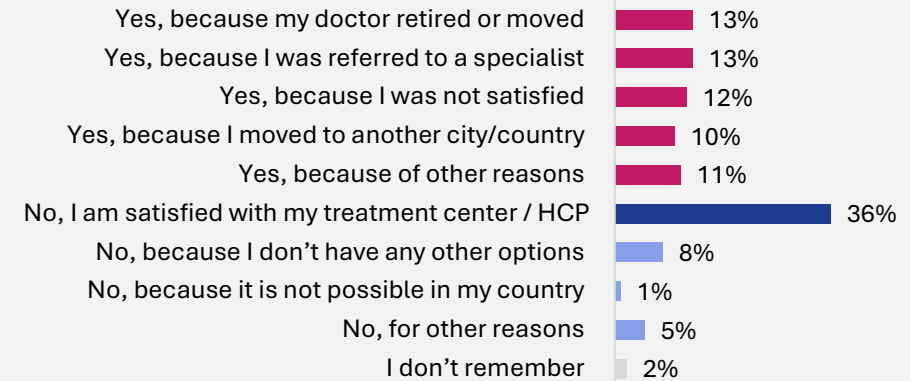
“When I was first diagnosed with narcolepsy, I felt relieved — even happy — because I’d spent 8 or 9 years being misdiagnosed, with symptoms that never fully made sense under other labels. Finally, something fit. But once the medication started working and my symptoms improved, that relief quickly turned into anger. I couldn’t stop thinking about how much of my life I’d lost — opportunities missed, relationships strained, energy wasted — because it took so long to get the right diagnosis. It was a strange mix of validation and grief for the years I spent struggling in the dark without proper support.”
Male, 18-29 years, Ireland, NT1 / with cataplexy, ID 314

“Relief at finally getting an answer, because I had met so much resistance along the way and almost felt crazy, but there was a real cause for my tiredness. At the same time, a huge grief over a chronic condition and not getting a “normal” life.”
Female, 18-29 years, Denmark, NT1 / with cataplexy, ID 347

Q21 Have you changed healthcare professionals and / or place of treatment since you got your diagnosis? (you can choose several answers)

Nearly half of respondents (48%) had changed healthcare professional or treatment centre since their diagnosis. The most common reasons were that their doctor retired or moved (13%), being referred to another specialist (13%), or dissatisfaction with care (12%). Still, over one third (36%) reported being satisfied and had stayed with the same professional.

By diagnosis, changes were more frequent among NT1 (52%) compared to NT2 (40%) and IH (43%). By age, switching was slightly more common among respondents aged 60+ (51%) compared to those aged 18–39 (47%) and 40–59 (50%). By gender, no notable demographic differences were observed.



21. Have you changed healthcare professionals and/or place of treatment since you got your diagnosis? (you can choose several answers)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Yes, because my doctor/specialist retired or moved to another city/country	13%	14%	10%	15%	11%	16%	20%	13%	13%
Yes, because I was referred to a specialist	13%	16%	12%	6%	13%	14%	17%	16%	13%
Yes, because I was not satisfied	12%	13%	10%	11%	12%	12%	8%	11%	12%
Yes, because I moved to another city/country	10%	10%	11%	10%	12%	8%	7%	9%	11%
Yes, because of other reasons	11%	12%	7%	10%	12%	11%	6%	11%	11%
No, I am satisfied with my treatment centre/healthcare professional	36%	36%	45%	35%	37%	36%	37%	38%	36%
No, because I don't have any other options	8%	6%	7%	14%	9%	8%	4%	7%	8%
No, because it is not possible in my country	1%	0%	2%	1%	1%	0%	1%	1%	1%
No, for other reasons	5%	5%	4%	7%	6%	5%	6%	5%	6%
I don't remember	2%	2%	3%	1%	2%	2%	2%	3%	2%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259
Have changed HCP / place of treatment since diagnosis	48%	52%	40%	43%	47%	50%	51%	48%	48%

Q21 Have you changed healthcare professionals and / or place of treatment since you got your diagnosis? (you can choose several answers)

Among countries, changes of healthcare professional or treatment centre since diagnosis were most frequent in Sweden (74%) and Norway (68%), followed by Finland (61%).

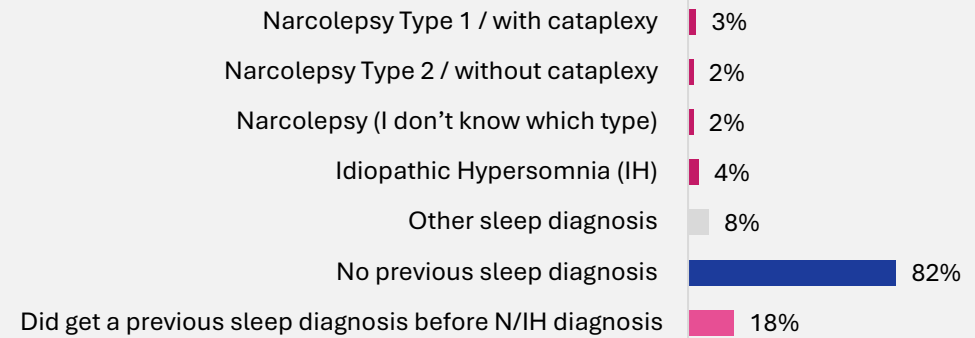
The lowest rates were observed in Poland (14%) and Italy (32%).

21. Have you changed healthcare professionals and/or place of treatment since you got your diagnosis? (you can choose several answers)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Yes, because my doctor/specialist retired or moved to another city/country	13%	6%	0%	8%	13%	9%	10%	0%	24%	3%	12%	28%	2%	21%	41%	6%
Yes, because I was referred to a specialist	13%	18%	6%	13%	9%	7%	21%	17%	14%	10%	23%	15%	10%	13%	19%	14%
Yes, because I was not satisfied	12%	24%	6%	11%	16%	11%	14%	15%	8%	12%	12%	18%	2%	5%	10%	11%
Yes, because I moved to another city/country	10%	0%	0%	13%	13%	10%	12%	0%	12%	4%	3%	17%	6%	4%	17%	14%
Yes, because of other reasons	11%	12%	11%	8%	30%	7%	15%	7%	9%	6%	11%	13%	4%	16%	21%	0%
No, I am satisfied with my treatment centre/healthcare professional	36%	35%	44%	43%	27%	45%	26%	49%	30%	58%	33%	18%	46%	34%	17%	50%
No, because I don't have any other options	8%	6%	0%	3%	7%	11%	9%	12%	11%	2%	2%	11%	24%	7%	5%	8%
No, because it is not possible in my country	1%	0%	6%	1%	0%	0%	0%	0%	1%	1%	0%	1%	6%	0%	1%	0%
No, for other reasons	5%	0%	22%	8%	3%	5%	6%	7%	4%	7%	11%	3%	0%	5%	1%	8%
I don't remember	2%	0%	6%	3%	3%	2%	3%	0%	0%	2%	4%	1%	10%	0%	3%	0%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36
Have changed HCP / place of treatment since diagnosis	48%	59%	22%	45%	61%	38%	57%	37%	57%	32%	52%	68%	14%	54%	74%	36%

Q22 Before your current N/IH diagnosis: Did you get any previous sleep diagnosis? (you can choose several answers)

Most respondents (82%) had not received any previous sleep diagnosis before being diagnosed with Narcolepsy or IH. 18% reported an earlier sleep-related diagnosis, most often another unspecified sleep disorder (8%) or IH (4%).

NT2 respondents more often reported a prior diagnosis (28%) compared to NT1 (14%) and IH (22%). By age, previous diagnoses were more common among respondents aged 40–59 (22%) than among the youngest group (15%). Men also reported prior sleep diagnoses more often than women (23% vs. 16%).



22. Before your current N/IH diagnosis: Did you get any previous sleep diagnosis? (you can choose several answers)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Narcolepsy Type 1 / with cataplexy	3%	4%	1%	2%	2%	4%	4%	5%	2%
Narcolepsy Type 2 / without cataplexy	2%	1%	5%	3%	2%	3%	4%	2%	2%
Narcolepsy (I don't know which type)	2%	1%	2%	1%	2%	2%	2%	3%	1%
Idiopathic Hypersomnia (IH)	4%	2%	13%	5%	4%	6%	2%	3%	5%
Other sleep diagnosis	8%	6%	9%	13%	6%	10%	11%	12%	7%
No previous sleep diagnosis	82%	86%	72%	78%	85%	78%	80%	77%	84%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259
Did get a previous sleep diagnosis before N/IH diagnosis	18%	14%	28%	22%	15%	22%	20%	23%	16%

Q22 Before your current N/IH diagnosis: Did you get any previous sleep diagnosis? (you can choose several answers)

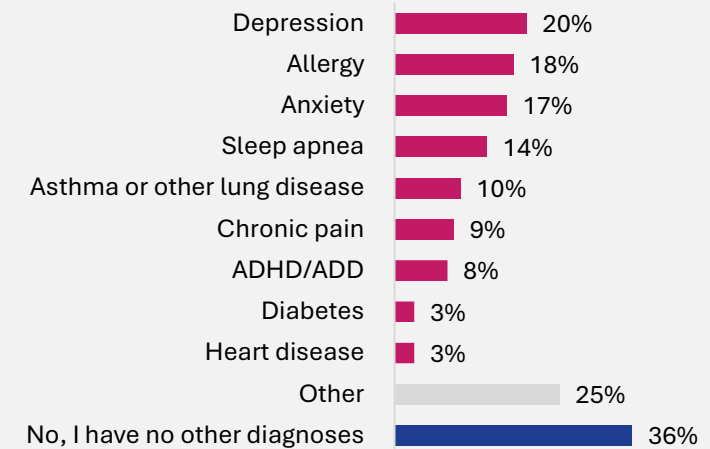
Most respondents in France (26%) and Spain (23%) reported a previous sleep diagnosis before N/IH – fewest in Finland (6%) and the Netherlands (8%).

22. Before your current N/IH diagnosis: Did you get any previous sleep diagnosis? (you can choose several answers)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Narcolepsy Type 1 / with cataplexy	3%	6%	6%	0%	0%	3%	1%	12%	0%	8%	2%	2%	4%	5%	3%	3%
Narcolepsy Type 2 / without cataplexy	2%	0%	0%	3%	0%	2%	2%	2%	5%	1%	4%	3%	0%	2%	2%	3%
Narcolepsy (I don't know which type)	2%	0%	0%	1%	1%	3%	1%	2%	0%	3%	1%	0%	4%	5%	1%	3%
Idiopathic Hypersomnia (IH)	4%	12%	0%	2%	0%	8%	4%	5%	4%	3%	1%	2%	4%	7%	2%	0%
Other sleep diagnosis	8%	6%	11%	7%	4%	11%	9%	20%	16%	6%	2%	8%	2%	4%	4%	8%
No previous sleep diagnosis	82%	76%	83%	90%	94%	74%	84%	68%	81%	79%	92%	87%	86%	77%	90%	83%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36
Did get a previous sleep diagnosis before N/IH diagnosis	18%	24%	17%	10%	6%	26%	16%	32%	19%	21%	8%	13%	14%	23%	10%	17%

Q23 Do you have any other diagnoses besides your N/IH? (you can choose several answers)

Almost two thirds of respondents (64%) reported at least one other diagnosis besides Narcolepsy or IH. The most common were depression (20%), allergy (18%), anxiety (17%) and sleep apnoea (14%). Asthma or other lung diseases were reported by 10%, chronic pain by 9% and ADHD/ADD by 8%.

Other diagnoses were most frequent among IH respondents (76%) and NT2 (74%), compared with 59% of NT1. By age, comorbidities increased with age: 59% among 18–39, 71% among 40–59 and 77% among 60+. Men and women showed nearly similar overall patterns (61% vs. 65%), with large gender differences for Sleep apnoea and Other diagnoses..



23. Do you have any other diagnoses besides your N/IH? (you can choose several answers)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Depression	20%	18%	20%	29%	19%	23%	16%	18%	21%
Allergy	18%	16%	18%	24%	17%	20%	10%	13%	19%
Anxiety	17%	13%	17%	28%	19%	14%	11%	13%	18%
Sleep apnoea	14%	14%	16%	15%	8%	21%	37%	23%	11%
Asthma or other lung disease	10%	9%	14%	14%	10%	11%	13%	10%	11%
Chronic pain	9%	6%	12%	15%	7%	14%	10%	3%	11%
ADHD/ADD	8%	6%	11%	13%	9%	7%	3%	9%	8%
Diabetes	3%	3%	5%	1%	1%	3%	10%	4%	2%
Heart disease	3%	3%	3%	3%	2%	4%	12%	4%	3%
Other	25%	22%	29%	30%	20%	32%	27%	16%	27%
No, I have no other diagnoses	36%	41%	26%	24%	41%	29%	23%	39%	35%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259
Have other diagnoses besides N/IH	64%	59%	74%	76%	59%	71%	77%	61%	65%

Q23 Do you have any other diagnoses besides your N/IH? (you can choose several answers)

Among countries respondents having other diagnoses besides N/IH was highest in Poland (76%), Ireland (73%) and Germany (73%).

Denmark (55%), Italy (55%) and Sweden (55%) were lowest.

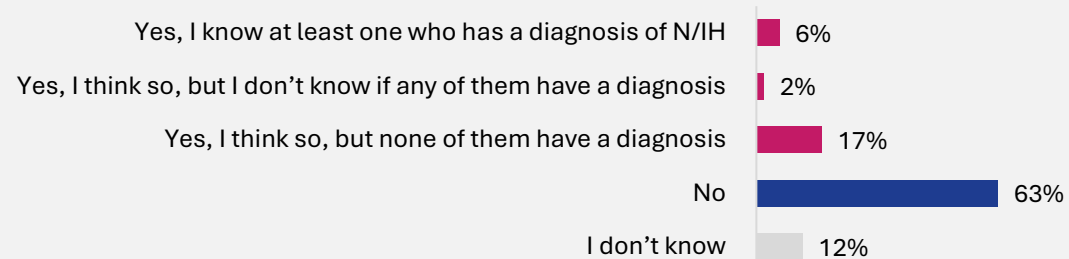
23. Do you have any other diagnoses besides your N/IH? (you can choose several answers)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Depression	20%	6%	11%	12%	18%	21%	32%	39%	23%	12%	12%	17%	22%	32%	16%	17%
Allergy	18%	18%	11%	18%	18%	16%	22%	15%	14%	19%	18%	23%	8%	11%	14%	33%
Anxiety	17%	6%	17%	13%	15%	25%	9%	32%	24%	14%	10%	12%	14%	14%	14%	11%
Sleep apnoea	14%	12%	0%	8%	10%	18%	14%	29%	16%	8%	10%	11%	28%	18%	7%	22%
Asthma or other lung disease	10%	12%	11%	13%	9%	11%	13%	10%	14%	8%	7%	11%	6%	5%	11%	19%
Chronic pain	9%	18%	6%	9%	4%	12%	11%	10%	5%	5%	5%	13%	2%	11%	6%	14%
ADHD/ADD	8%	12%	6%	8%	7%	12%	8%	0%	7%	2%	8%	10%	6%	5%	7%	14%
Diabetes	3%	6%	0%	3%	1%	2%	3%	7%	3%	3%	5%	1%	0%	4%	2%	0%
Heart disease	3%	0%	11%	2%	3%	3%	3%	2%	3%	2%	3%	5%	6%	2%	1%	6%
Other	25%	35%	28%	24%	30%	24%	29%	17%	35%	20%	27%	21%	32%	32%	15%	17%
No, I have no other diagnoses	36%	47%	50%	45%	37%	35%	27%	22%	27%	45%	41%	34%	24%	39%	45%	31%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36
Have other diagnoses besides N/IH	64%	53%	50%	55%	63%	65%	73%	78%	73%	55%	59%	66%	76%	61%	55%	69%

Q24 Do you have any family members (parents, siblings, children or grandparents) who also have or seem to have N/IH? (choose 1 answer)

One in four respondents (25%) reported having family members who also have or may have Narcolepsy or IH. 6% said they knew at least one relative with a diagnosis, while 17% suspected family members but without a confirmed diagnosis.

This goes for more respondents with NT2 (37%) and IH (36%) compared with NT1 (20%). Family history appeared more common among older respondents, with 32% of those aged 40–59 and 35% of those 60+ reporting affected relatives, versus 20% of 18–39-year-olds.

Women were also somewhat more likely than men to report family members with possible symptoms (27% vs. 20%).



24. Do you have any family members (parents, siblings, children or grandparents) who also have or seem to have N/IH? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Yes, I know at least one who has a diagnosis of N/IH	6%	5%	8%	8%	5%	8%	9%	5%	6%
Yes, I think so, but I don't know if any of them have a diagnosis	2%	1%	6%	3%	2%	3%	5%	4%	2%
Yes, I think so, but none of them have a diagnosis	17%	13%	24%	26%	14%	22%	21%	11%	19%
No	63%	68%	52%	53%	69%	53%	55%	67%	61%
I don't know	12%	12%	11%	11%	11%	15%	10%	13%	12%
Number of respondents: All with N/IH diagnosis	1,667	1,067	212	343	999	555	113	400	1,259
Have other family members with (possible) N/IH	25%	20%	37%	36%	20%	32%	35%	20%	27%

(excl. I don't know)

Q24 Do you have any family members (parents, siblings, children or grandparents) who also have or seem to have N/IH? (choose 1 answer)

Most respondents in Denmark (34%) and France (32%) had family members also (possibly) affected by N/IH
- fewest in Sweden (9%) and Finland (15%).

24. Do you have any family members (parents, siblings, children or grandparents) who also have or seem to have N/IH? (choose 1 answer)	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Yes, I know at least one who has a diagnosis of N/IH	6%	6%	0%	12%	0%	8%	4%	5%	4%	9%	6%	6%	0%	11%	1%	3%
Yes, I think so, but I don't know if any of them have a diagnosis	2%	0%	0%	2%	1%	2%	1%	5%	1%	2%	4%	3%	2%	5%	1%	6%
Yes, I think so, but none of them have a diagnosis	17%	24%	22%	20%	13%	22%	20%	12%	12%	15%	12%	17%	16%	14%	7%	19%
No	63%	59%	39%	58%	70%	57%	62%	56%	73%	57%	72%	62%	58%	59%	88%	61%
I don't know	12%	12%	39%	8%	15%	11%	13%	22%	9%	17%	6%	12%	24%	11%	3%	11%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36
Have other family members with (possible) N/IH (excl. I don't know)	25%	29%	22%	34%	15%	32%	25%	22%	18%	26%	22%	26%	18%	30%	9%	28%

Q25 In general, how satisfied are you currently with the support (social / emotional / practical) from the following groups regarding your N/IH? (choose 1 answer for each group)

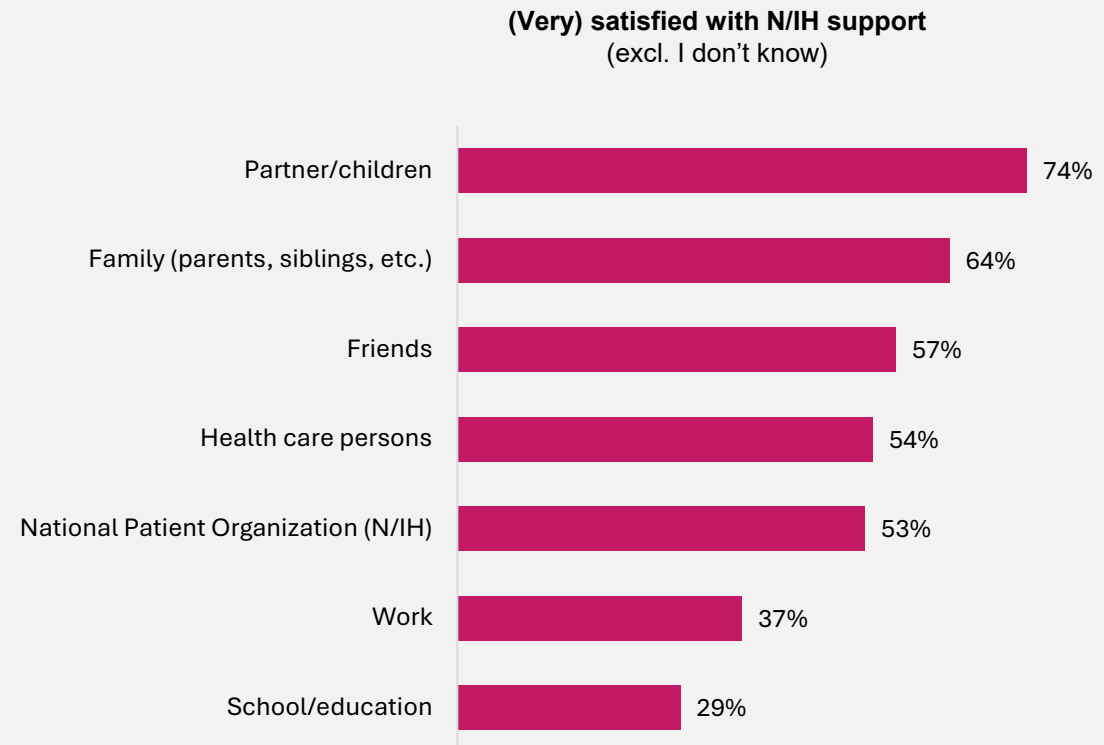
Satisfaction with support varied considerably across groups.

The highest levels of satisfaction to a high or very high degree were reported with support from partners or children (74%) and family (64%).

Friends (57%), healthcare professionals (54%), and national patient organisations (53%) also provided substantial support.

Satisfaction was lower with support from work (37%) and school/education (29%).

See many more details on the following 14 slides.

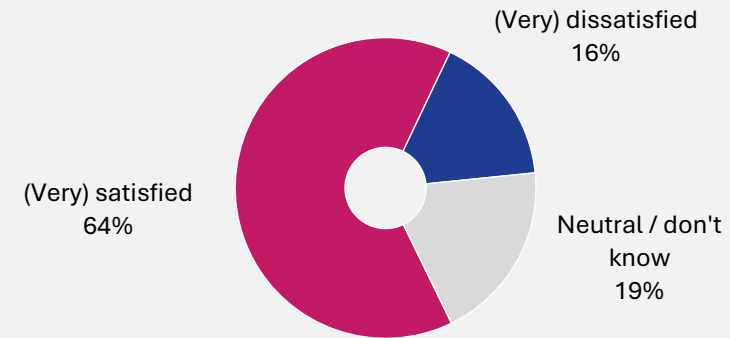


In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer)

■ Q25a Family (parents, siblings, etc.)

Nearly two thirds of respondents (64%) were satisfied with the support they received from family members regarding their Narcolepsy or IH, while 16% were dissatisfied and 19% were neutral. Satisfaction was highest among NT1 and Narcolepsy 2 respondents (68% and 64%), compared to 50% of IH.

Younger respondents tended to be most positive, with 70% of those aged 18–39 satisfied, compared with 55% of 40–59 and 60% of those 60+. Men were more likely than women to feel well supported by family (72% vs. 61%).



25a. In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer for each group) - Family (parents, siblings, etc.)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Very satisfied	32%	37%	30%	18%	36%	23%	27%	39%	30%
Satisfied	33%	32%	35%	32%	33%	32%	33%	34%	32%
Neutral	19%	19%	17%	22%	17%	24%	27%	16%	21%
Dissatisfied	11%	8%	16%	19%	10%	14%	11%	8%	12%
Very dissatisfied	5%	4%	2%	8%	5%	5%	3%	3%	5%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.259
(Very) satisfied	64%	68%	64%	50%	70%	55%	60%	72%	61%
(Very) dissatisfied	16%	12%	18%	28%	15%	19%	15%	11%	17%
Neutral / don't know	19%	19%	17%	22%	17%	24%	27%	16%	21%
Not relevant	2%	2%	2%	2%	1%	2%	11%	2%	2%

In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer)

■ Q25a Family (parents, siblings, etc.)

Most respondents in Sweden (84%) and Denmark (78%) were (very) satisfied with family support – fewest in France (53%) and Norway (55%).

25a. In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer for each group) - <u>Family (parents, siblings, etc.)</u>	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Very satisfied	32%	24%	44%	50%	30%	23%	29%	35%	38%	34%	36%	24%	24%	39%	45%	38%
Satisfied	33%	41%	44%	28%	42%	30%	35%	28%	23%	37%	37%	31%	34%	28%	38%	27%
Neutral	19%	6%	11%	16%	24%	23%	21%	28%	16%	10%	15%	28%	22%	21%	10%	20%
Dissatisfied	11%	29%	0%	4%	3%	15%	9%	7%	16%	16%	12%	13%	10%	7%	5%	3%
Very dissatisfied	5%	0%	0%	2%	1%	8%	6%	2%	7%	3%	0%	4%	10%	5%	2%	12%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36
(Very) satisfied	64%	65%	88%	78%	72%	53%	63%	62%	61%	70%	72%	55%	58%	66%	84%	65%
(Very) dissatisfied	16%	29%	0%	6%	4%	23%	15%	9%	23%	19%	12%	17%	20%	12%	7%	15%
Neutral / don't know	19%	6%	11%	16%	24%	23%	21%	28%	16%	10%	15%	28%	22%	21%	10%	20%
Not relevant	2%	0%	0%	4%	0%	2%	2%	2%	0%	2%	2%	2%	0%	2%	1%	6%

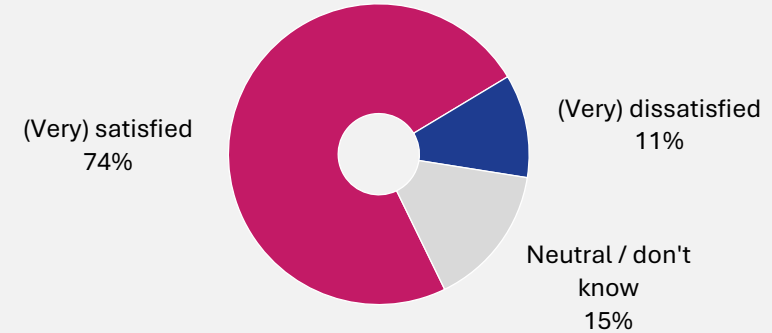
In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer)

■ Q25b Partner/children

Nearly three quarters of respondents (74%) were satisfied with the support they received from their partner or children, including 42% who were very satisfied.

Dissatisfaction was relatively low (11%). Dissatisfaction was slightly higher among IH respondents (15%) compared to NT1 (9%) and NT2 (13%).

Support was rated most positively by older respondents, with 83% of those aged 60+ satisfied. Men and women reported identical satisfaction levels (73%).



25b. In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer for each group) - Partner/children	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Very satisfied	42%	43%	42%	38%	40%	43%	44%	42%	41%
Satisfied	32%	30%	33%	34%	32%	30%	39%	31%	32%
Neutral	15%	16%	12%	12%	16%	15%	9%	18%	15%
Dissatisfied	8%	6%	10%	12%	8%	9%	6%	10%	8%
Very dissatisfied	3%	3%	3%	2%	3%	3%	3%	3%	3%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.258
(Very) satisfied	74%	73%	76%	72%	73%	72%	83%	73%	73%
(Very) dissatisfied	11%	9%	13%	15%	11%	13%	9%	13%	11%
Neutral / don't know	15%	16%	12%	12%	16%	15%	9%	18%	15%
Not relevant	28%	33%	22%	18%	38%	13%	13%	38%	25%

In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer)

Q25b Partner/children

Most respondents in the Netherlands (91%) and Denmark (85%) were (very) satisfied with support from partner/children – fewest in Poland (63%), France (69%) and Italy (69%).

25b. In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer for each group) - Partner/children	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Very satisfied	42%	60%	18%	57%	33%	35%	44%	30%	45%	34%	55%	40%	25%	60%	54%	54%
Satisfied	32%	20%	28%	28%	41%	35%	25%	34%	28%	34%	36%	31%	38%	24%	26%	35%
Neutral	15%	14%	46%	10%	16%	16%	17%	25%	14%	19%	6%	15%	19%	10%	12%	4%
Dissatisfied	8%	7%	10%	4%	8%	11%	11%	9%	5%	12%	2%	10%	3%	6%	3%	4%
Very dissatisfied	3%	0%	0%	0%	1%	4%	3%	3%	9%	1%	2%	2%	16%	0%	7%	4%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	73	177	113	186	50	56	111	36
(Very) satisfied	74%	81%	46%	85%	74%	69%	70%	64%	73%	69%	91%	71%	63%	84%	80%	89%
(Very) dissatisfied	11%	7%	10%	4%	10%	15%	14%	11%	15%	13%	3%	12%	19%	6%	10%	7%
Neutral / don't know	15%	14%	46%	10%	16%	16%	17%	25%	14%	19%	6%	15%	19%	10%	12%	4%
Not relevant	28%	12%	39%	33%	27%	25%	37%	20%	26%	33%	34%	16%	36%	32%	31%	19%

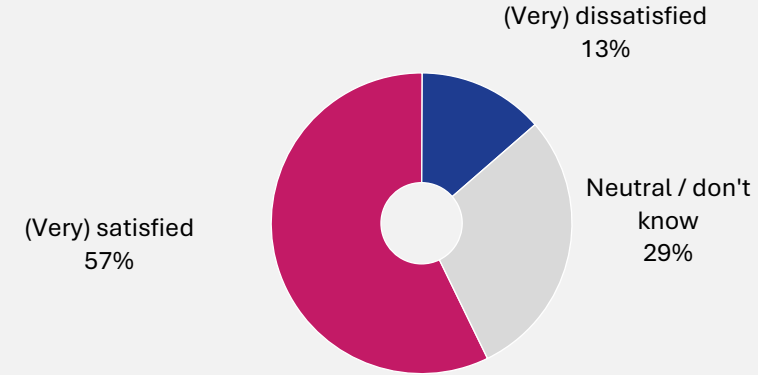
In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer)

Q25c Friends

Support from friends received more mixed ratings. Just over half (57%) were satisfied, while almost one in three (29%) were neutral and 13% were dissatisfied.

NT1 respondents were more positive (61% satisfied) compared to IH (45%).

Younger respondents tended to rate friend support higher (62% satisfied among 18–39), while only 52% of those 40–59 agreed. Men and women reported nearly identical satisfaction levels (55–58%).



25c. In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer for each group) - Friends	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Very satisfied	21%	24%	21%	13%	24%	18%	21%	22%	21%
Satisfied	36%	37%	37%	32%	38%	34%	36%	33%	37%
Neutral	29%	28%	33%	33%	27%	33%	35%	33%	28%
Dissatisfied	9%	7%	7%	16%	9%	10%	7%	6%	10%
Very dissatisfied	4%	4%	2%	5%	3%	6%	1%	5%	3%
Number of respondents: All with N/IH diagnosis	1.666	1.066	212	343	999	555	112	400	1.258
(Very) satisfied	57%	61%	58%	45%	62%	52%	57%	55%	58%
(Very) dissatisfied	13%	11%	9%	22%	12%	16%	8%	11%	13%
Neutral / don't know	29%	28%	33%	33%	27%	33%	35%	33%	28%
Not relevant	3%	3%	5%	3%	3%	3%	11%	4%	3%

In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer)

■ Q25c Friends

Most respondents in Denmark (68%) and Finland (68%) were (very) satisfied with support from friends – fewest in Poland (43%) and Spain (49%).

25c. In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer for each group) - <u>Friends</u>	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Very satisfied	21%	26%	23%	29%	13%	19%	19%	30%	17%	21%	24%	19%	20%	14%	27%	35%
Satisfied	36%	26%	65%	39%	55%	32%	40%	24%	35%	40%	43%	32%	22%	35%	34%	41%
Neutral	29%	44%	6%	27%	24%	30%	28%	24%	26%	30%	25%	35%	45%	28%	28%	15%
Dissatisfied	9%	6%	6%	5%	4%	14%	9%	15%	12%	8%	6%	9%	4%	11%	7%	9%
Very dissatisfied	4%	0%	0%	0%	3%	4%	4%	5%	11%	2%	3%	4%	8%	13%	4%	0%
Number of respondents: All with N/IH diagnosis	1.666	17	18	119	67	379	188	41	73	177	113	186	50	56	111	36
(Very) satisfied	57%	51%	88%	68%	68%	51%	59%	54%	52%	60%	67%	51%	43%	49%	61%	77%
(Very) dissatisfied	13%	6%	6%	5%	7%	18%	13%	20%	22%	10%	9%	14%	12%	24%	11%	9%
Neutral / don't know	29%	44%	6%	27%	24%	30%	28%	24%	26%	30%	25%	35%	45%	28%	28%	15%
Not relevant	3%	6%	6%	4%	1%	4%	2%	2%	5%	4%	4%	4%	2%	2%	0%	6%

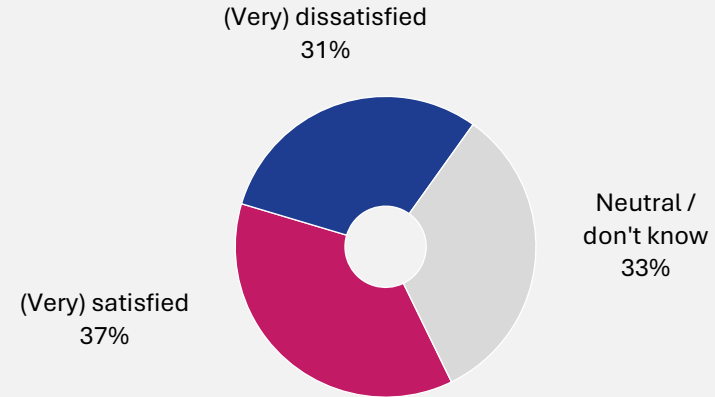
In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer)

Q25d Work

Workplace support was one of the most critically rated. Only 37% felt satisfied, while almost one in three (31%) were dissatisfied and another third (33%) were neutral.

IH respondents were least positive, with only 26% satisfied and close to half (41%) dissatisfied. Satisfaction was higher among those aged 60+ (48%), but otherwise similar across age groups.

Men and women reported comparable experiences (37–38% satisfied, 28–31% dissatisfied).



25d. In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer for each group) - Work	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Very satisfied	12%	14%	11%	6%	12%	11%	20%	14%	11%
Satisfied	25%	27%	26%	19%	27%	23%	28%	24%	27%
Neutral	33%	32%	34%	33%	32%	34%	27%	36%	32%
Dissatisfied	16%	15%	16%	17%	16%	16%	12%	14%	16%
Very dissatisfied	15%	12%	13%	24%	13%	18%	13%	13%	15%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.258
(Very) satisfied	37%	41%	37%	26%	39%	34%	48%	38%	37%
(Very) dissatisfied	31%	27%	29%	41%	29%	34%	25%	28%	31%
Neutral / don't know	33%	32%	34%	33%	32%	34%	27%	36%	32%
Not relevant	25%	26%	24%	22%	25%	20%	40%	24%	25%

In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer)

Q25d Work

Most respondents in Sweden (59%) and the Netherlands (52%) were (very) satisfied with support from work – fewest in Spain (17%) and France (26%).

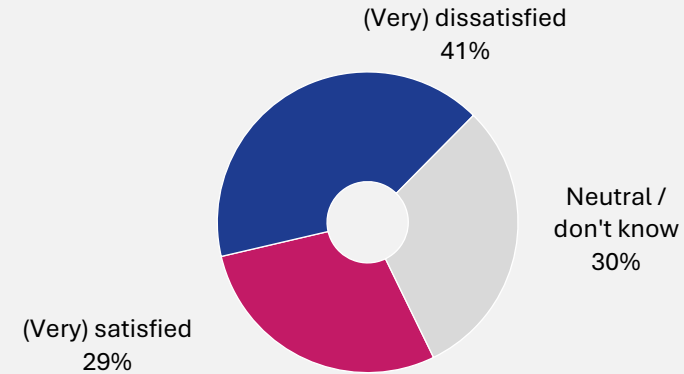
25d. In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer for each group) - Work	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Very satisfied	12%	0%	11%	21%	7%	5%	12%	6%	14%	13%	15%	9%	17%	5%	21%	33%
Satisfied	25%	10%	39%	31%	41%	21%	25%	8%	31%	18%	37%	32%	20%	12%	38%	29%
Neutral	33%	49%	20%	34%	35%	34%	34%	32%	24%	40%	31%	32%	27%	28%	23%	22%
Dissatisfied	16%	31%	11%	10%	12%	18%	13%	24%	14%	15%	13%	16%	17%	36%	11%	13%
Very dissatisfied	15%	10%	20%	4%	4%	21%	18%	32%	17%	14%	6%	13%	20%	19%	8%	3%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	73	177	113	186	50	56	111	36
(Very) satisfied	37%	10%	50%	51%	48%	26%	36%	14%	45%	31%	52%	41%	37%	17%	59%	62%
(Very) dissatisfied	31%	41%	30%	15%	16%	39%	31%	55%	31%	29%	18%	29%	37%	55%	19%	16%
Neutral / don't know	33%	49%	20%	34%	35%	34%	34%	32%	24%	40%	31%	32%	27%	28%	23%	22%
Not relevant	25%	41%	44%	32%	19%	20%	23%	15%	42%	22%	29%	31%	18%	25%	20%	14%

In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer)

Q25e School/education

Support within school or education was also rated low. Fewer than one in three respondents (29%) were satisfied, while 21% were dissatisfied, and 20% were very dissatisfied.

IH respondents again rated the lowest, with only 10% satisfied and 46% dissatisfied. By age, both negative and positive experiences were most common among younger respondents (41% dissatisfied and 33% satisfied among 18–39), while neutrality was more common among older respondents. Men and women reported broadly similar experiences.



25e. In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer for each group) - School/education	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Very satisfied	7%	9%	9%	2%	9%	5%	0%	10%	7%
Satisfied	21%	26%	18%	8%	24%	14%	16%	23%	20%
Neutral	30%	29%	29%	42%	27%	41%	52%	32%	31%
Dissatisfied	21%	22%	21%	20%	23%	19%	16%	23%	20%
Very dissatisfied	20%	17%	21%	26%	19%	22%	16%	16%	20%
Number of respondents: All with N/IH diagnosis	1,667	1,067	212	343	999	555	113	400	1,258
(Very) satisfied	29%	34%	27%	10%	33%	19%	16%	32%	28%
(Very) dissatisfied	41%	40%	43%	46%	41%	41%	32%	39%	41%
Neutral / don't know	30%	29%	29%	42%	27%	41%	52%	32%	31%
Not relevant	44%	42%	44%	50%	30%	63%	75%	38%	46%

In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer)

Q25e School/education

Most respondents in Finland (48%) and Ireland (47%) were (very) satisfied with support from school/education – fewest in Poland (13%) and France (19%).

25e. In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer for each group) - School/education	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Very satisfied	7%	0%	16%	13%	10%	5%	8%	3%	12%	7%	12%	7%	3%	0%	8%	8%
Satisfied	21%	34%	33%	30%	37%	14%	13%	0%	35%	26%	26%	20%	10%	24%	32%	15%
Neutral	30%	34%	25%	17%	37%	29%	25%	30%	32%	36%	38%	35%	23%	31%	29%	49%
Dissatisfied	21%	34%	16%	24%	10%	22%	33%	21%	18%	18%	14%	22%	39%	24%	15%	28%
Very dissatisfied	20%	0%	9%	15%	1%	29%	21%	47%	5%	13%	10%	20%	26%	22%	15%	0%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	73	177	113	186	50	56	111	36
(Very) satisfied	29%	34%	49%	43%	48%	19%	21%	3%	47%	33%	38%	26%	13%	24%	41%	23%
(Very) dissatisfied	41%	34%	25%	39%	12%	52%	54%	67%	23%	32%	24%	41%	65%	46%	31%	28%
Neutral / don't know	30%	34%	25%	17%	37%	29%	25%	30%	32%	36%	38%	35%	23%	31%	29%	49%
Not relevant	44%	47%	33%	54%	33%	42%	52%	27%	40%	24%	58%	54%	38%	41%	41%	61%

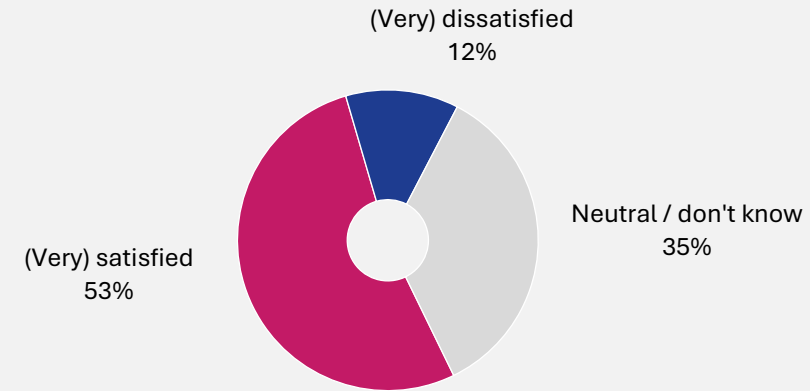
In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer)

■ Q25f National Patient Organisation (N/IH)

Just over half of respondents (53%) were satisfied with the support from their national patient organisation, while 12% were dissatisfied and over a third (35%) neutral.

Satisfaction was highest among NT1 respondents (57%) compared with NT2 (49%) and IH (41%).

Older respondents (60+) were more positive (70% satisfied), while younger respondents were more likely to be neutral. Gender differences were small.



25f. In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer for each group) - National Patient Organisation (N/IH)	N/IH diagnosis				Age			Gender	
	Total	NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Very satisfied	22%	23%	28%	13%	21%	21%	31%	26%	21%
Satisfied	31%	35%	21%	28%	31%	31%	39%	27%	33%
Neutral	35%	32%	38%	42%	37%	35%	24%	36%	35%
Dissatisfied	8%	8%	8%	10%	10%	8%	2%	10%	7%
Very dissatisfied	4%	4%	5%	6%	3%	6%	3%	2%	4%
Number of respondents: All with N/IH diagnosis	1,666	1,066	212	343	999	555	112	400	1,258
(Very) satisfied	53%	57%	49%	41%	52%	52%	70%	53%	54%
(Very) dissatisfied	12%	12%	13%	16%	13%	14%	6%	12%	11%
Neutral / don't know	35%	32%	38%	42%	37%	35%	24%	36%	35%
Not relevant	26%	25%	24%	31%	29%	23%	13%	19%	28%

In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer)

Q25f National Patient Organisation (N/IH)

Most respondents in Italy (78%), the Netherlands (76%) and Denmark (76%) were (very) satisfied with support from their national patient organisation – fewest in France (33%) and Germany (31%).

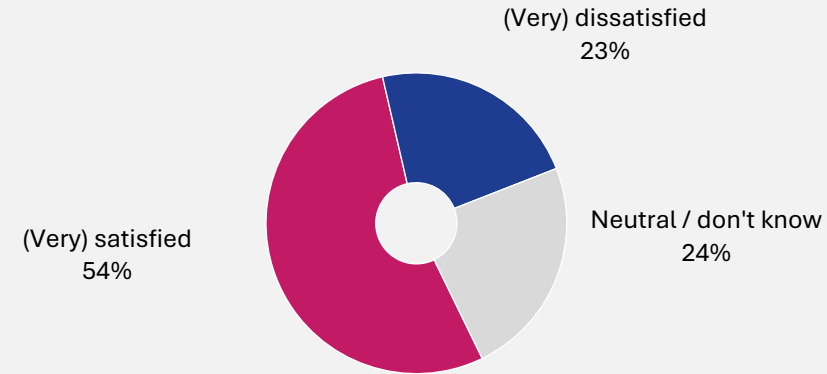
25f. In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer for each group) - <u>National Patient Organisation (N/IH)</u>	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Very satisfied	22%	9%	34%	36%	1%	11%	15%	24%	18%	43%	30%	14%	40%	14%	20%	40%
Satisfied	31%	37%	27%	40%	49%	23%	16%	46%	32%	35%	46%	31%	30%	34%	28%	28%
Neutral	35%	37%	34%	21%	42%	48%	51%	26%	27%	18%	22%	41%	28%	29%	39%	24%
Dissatisfied	8%	9%	0%	1%	6%	12%	13%	2%	13%	2%	1%	10%	3%	16%	10%	4%
Very dissatisfied	4%	9%	7%	1%	0%	6%	5%	2%	10%	1%	1%	5%	0%	9%	3%	4%
Number of respondents: All with N/IH diagnosis	1.666	17	18	119	67	379	188	41	73	177	113	186	50	56	111	36
(Very) satisfied	53%	46%	60%	76%	51%	33%	31%	69%	51%	78%	76%	45%	70%	48%	48%	68%
(Very) dissatisfied	12%	18%	7%	2%	6%	18%	18%	5%	23%	3%	2%	15%	3%	25%	13%	8%
Neutral / don't know	35%	37%	34%	21%	42%	48%	51%	26%	27%	18%	22%	41%	28%	29%	39%	24%
Not relevant	26%	35%	17%	16%	33%	34%	45%	15%	23%	8%	13%	22%	20%	20%	29%	22%

In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer)

■ Q25g Healthcare persons

Satisfaction with support from healthcare professionals was moderate: 54% were satisfied, 23% dissatisfied and 24% neutral. NT1 respondents were most positive (58%), while IH respondents were least satisfied (42%).

Satisfaction rose with age, from 52% among 18–39 to 67% among those 60+. Men tended to be more positive than women (60% vs. 52%).



25g. In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer for each group) - Healthcare persons	N/IH diagnosis				Age			Gender	
	Total	NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Very satisfied	16%	19%	18%	10%	18%	14%	22%	22%	15%
Satisfied	37%	39%	35%	32%	34%	39%	46%	38%	36%
Neutral	24%	24%	26%	24%	26%	23%	16%	23%	25%
Dissatisfied	16%	14%	15%	24%	16%	18%	14%	12%	18%
Very dissatisfied	6%	5%	6%	9%	6%	7%	2%	5%	6%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.258
(Very) satisfied	54%	58%	53%	42%	52%	54%	67%	60%	52%
(Very) dissatisfied	23%	20%	22%	33%	23%	25%	16%	18%	24%
Neutral / don't know	24%	24%	26%	24%	26%	23%	16%	23%	25%
Not relevant	3%	3%	3%	1%	3%	3%	8%	3%	3%

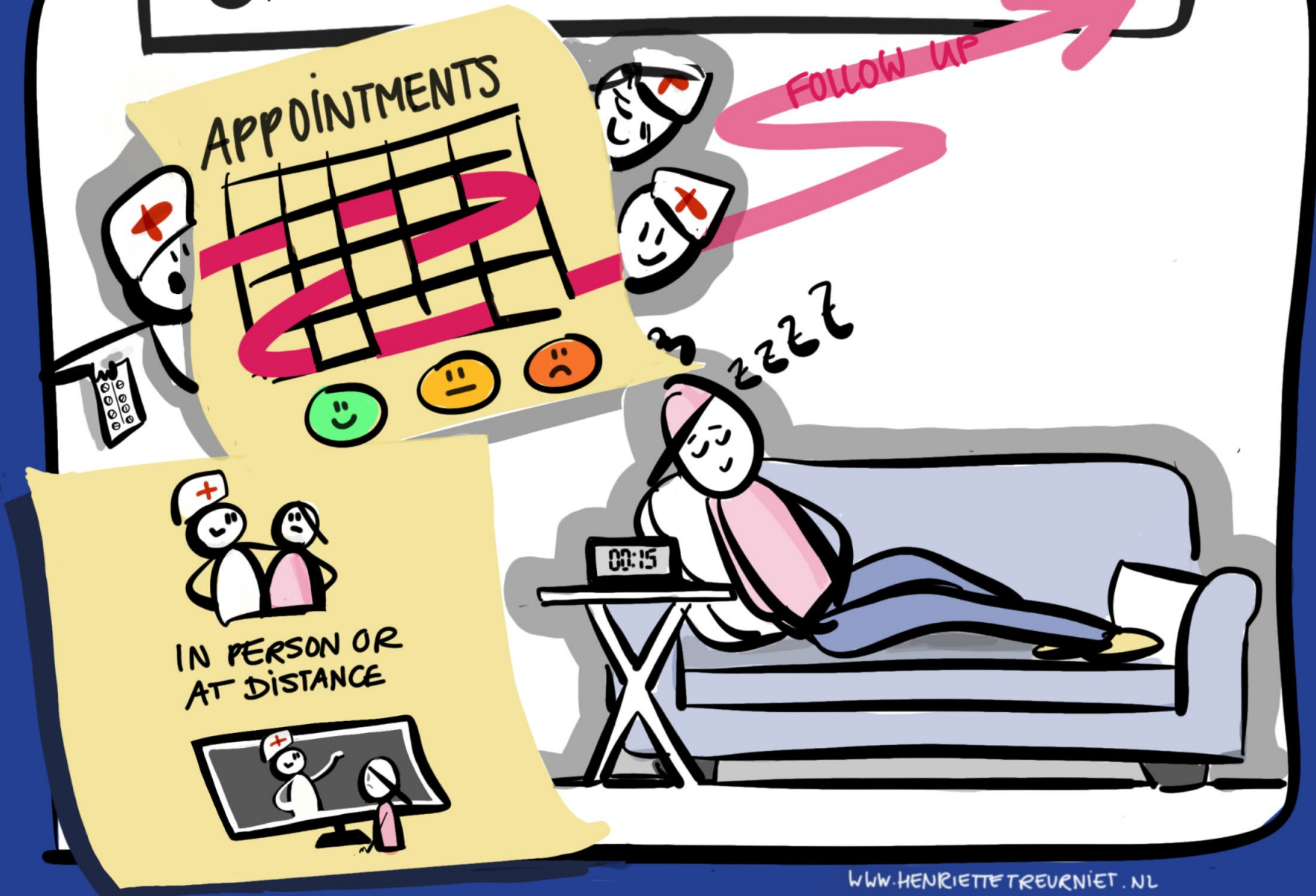
In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer)

■ Q25g Healthcare persons

Most respondents in Italy (76%) and Spain (74%) were (very) satisfied with support from healthcare persons - fewest in Norway (36%) and Poland (33%).

25g. In general, how satisfied are you currently with the support (social/emotional/practical) from the following groups regarding your N/IH? (choose 1 answer for each group) - Healthcare persons	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Very satisfied	16%	12%	41%	23%	6%	15%	8%	7%	19%	36%	23%	10%	10%	17%	11%	30%
Satisfied	37%	18%	12%	36%	39%	37%	32%	39%	39%	40%	47%	26%	22%	57%	44%	45%
Neutral	24%	59%	30%	25%	28%	21%	29%	37%	22%	16%	18%	25%	35%	19%	29%	15%
Dissatisfied	16%	12%	12%	13%	24%	20%	21%	10%	17%	7%	7%	26%	22%	7%	12%	6%
Very dissatisfied	6%	0%	6%	3%	3%	7%	9%	7%	4%	2%	4%	12%	10%	0%	5%	6%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	73	177	113	186	50	56	111	36
(Very) satisfied	54%	30%	53%	59%	45%	52%	40%	46%	57%	76%	71%	36%	33%	74%	55%	74%
(Very) dissatisfied	23%	12%	18%	16%	27%	28%	31%	17%	21%	9%	12%	38%	33%	7%	17%	13%
Neutral / don't know	24%	59%	30%	25%	28%	21%	29%	37%	22%	16%	18%	25%	35%	19%	29%	15%
Not relevant	3%	0%	6%	3%	0%	2%	5%	0%	4%	5%	5%	1%	2%	4%	2%	6%

3. TREATMENT AND MEDICATION



Q26 Who is mainly treating your N/IH currently with follow-ups? (choose 1 answer)

95% of respondents reported being treated by a healthcare professional. Neurologists were the most common providers (54%), followed by sleep specialists (30%) and general practitioners (6%).

Note: Sleep specialists are medically educated professionals specialised in somnology; including neurologists, pulmonologist, ear-nose-throat (ENT) doctors and other medical professions.

Neurologists were most frequently reported by people with Narcolepsy Type 1 (59%), while Narcolepsy Type 2 (38%) and Idiopathic Hypersomnia (32%) more often reported sleep specialists. Younger respondents were more likely to have follow-ups by a neurologist (57% among 18–39 years) compared to those aged 60+ (41%), who more often reported follow-up by a general practitioner (15%). By gender, no notable demographic differences were observed



26. Who is mainly treating your N/IH currently with follow-ups? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Neurologist	54%	59%	44%	45%	57%	50%	41%	51%	54%
Sleep specialist	30%	28%	38%	32%	30%	33%	26%	34%	30%
General Practitioner	6%	5%	9%	8%	5%	6%	15%	5%	6%
Respiratory Specialist / pulmonologist	2%	2%	4%	3%	2%	2%	5%	2%	2%
Psychiatrist, psychologist or other mental healthcare professional	2%	1%	2%	4%	2%	1%	1%	2%	2%
Child doctor / paediatrician	0%	0%	0%	0%	0%	0%	0%	0%	0%
Other	1%	1%	0%	1%	1%	1%	2%	1%	1%
I don't get treated by a healthcare professional	5%	4%	3%	8%	4%	7%	11%	6%	5%
Number of respondents: All with N/IH diagnosis	1.667	1.067	212	343	999	555	113	400	1.258
Treated by HCP	95%	96%	97%	92%	96%	93%	89%	94%	95%

Q26 Who is mainly treating your N/IH currently with follow-ups? (choose 1 answer)

Follow-up care by a healthcare professional was reported by nearly all respondents, with the highest shares in Ireland (100%) and Italy (100%) while Norway (88%) and Poland (90%) reported the lowest.

Neurologists were the main treating specialists in most countries, with particularly high shares in Sweden (95%) and Finland (88%). Sleep specialists dominated in Italy (61%) and Ireland (45%).

26. Who is mainly treating your N/IH currently with follow-ups? (choose 1 answer)	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Neurologist	54%	47%	0%	67%	88%	41%	51%	93%	36%	37%	44%	73%	40%	54%	95%	36%
Sleep specialist	30%	18%	61%	21%	6%	41%	31%	5%	45%	61%	36%	3%	32%	38%	0%	36%
General Practitioner	6%	6%	0%	6%	3%	6%	6%	0%	9%	2%	4%	13%	0%	2%	4%	11%
Respiratory Specialist / pulmonologist	2%	18%	6%	0%	0%	3%	1%	0%	9%	0%	0%	0%	0%	0%	0%	6%
Psychiatrist, psychologist or other mental healthcare professional	2%	0%	0%	1%	0%	3%	3%	0%	0%	0%	1%	0%	18%	0%	0%	3%
Child doctor / paediatrician	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
Other	1%	0%	0%	2%	1%	0%	0%	0%	0%	0%	2%	2%	4%	0%	0%	0%
I don't get treated by a healthcare professional	5%	12%	33%	3%	1%	3%	8%	2%	0%	0%	12%	10%	6%	7%	2%	8%
Number of respondents: All with N/IH diagnosis	1.667	17	18	119	67	379	188	41	74	177	113	186	50	56	111	36
Treated by HCP	95%	88%	67%	97%	99%	97%	92%	98%	100%	100%	88%	90%	94%	93%	98%	92%

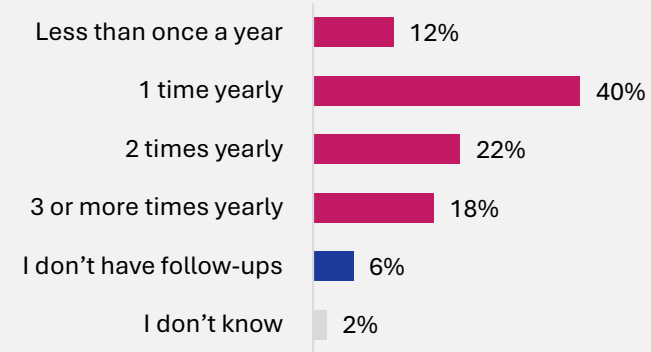
Q27 How often do you have follow-up appointments with this healthcare professional about your N/IH? (choose 1 answer)

Overall, 6% reported having no follow-ups, 53% had up to one yearly appointment, and 41% had at least two appointments per year.

By diagnosis, NT2 respondents more often reported at least two yearly follow-ups (46%) compared with NT1 (41%) and IH (39%).

By age, younger respondents (18–39 years) more often reported at least two yearly follow-ups (43%) than those aged 60+ (28%).

By gender, no demographic differences are relevant.



27. How often do you have follow-up appointments with this healthcare professional about your N/IH? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Less than once a year	12%	13%	11%	10%	12%	12%	13%	10%	13%
1 time yearly	40%	40%	40%	42%	40%	40%	46%	44%	39%
2 times yearly	22%	22%	26%	19%	23%	21%	14%	23%	21%
3 or more times yearly	18%	18%	20%	19%	19%	18%	14%	18%	18%
I don't have follow-ups	6%	5%	3%	8%	4%	7%	13%	4%	6%
I don't know	2%	2%	1%	2%	2%	2%	1%	1%	2%
Number of respondents: N/IH diagnosed and treated by HCP	1.581	1.023	205	317	962	518	101	379	1.194
No follow ups	6%	5%	3%	8%	4%	7%	13%	4%	6%
Up to 1 time yearly	53%	54%	51%	53%	53%	53%	59%	55%	54%
At least 2 times yearly	41%	41%	46%	39%	43%	40%	28%	41%	40%

(excl. I don't know)

Q27 How often do you have follow-up appointments with this healthcare professional about your N/IH? (choose 1 answer)

At least two yearly follow-ups were highest in Germany (69%) and Ireland (58%), while Finland (16%) and Sweden (23%) were lowest.

Up to one yearly follow-up was highest in Finland (79%) and Sweden (74%), while Germany (25%) and Spain (39%) were lowest.

No follow-ups were most frequent in the Netherlands (16%) and Norway (13%).

27. How often do you have follow-up appointments with this healthcare professional about your N/IH? (choose 1 answer)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Less than once a year	12%	13%	8%	10%	20%	7%	8%	10%	7%	8%	12%	25%	17%	6%	26%	18%
1 time yearly	40%	60%	8%	50%	61%	50%	16%	8%	34%	50%	31%	42%	19%	33%	49%	30%
2 times yearly	22%	13%	33%	20%	11%	23%	25%	23%	46%	21%	23%	11%	19%	27%	17%	30%
3 or more times yearly	18%	13%	25%	15%	5%	17%	42%	45%	12%	19%	18%	7%	17%	29%	6%	15%
I don't have follow-ups	6%	0%	0%	3%	5%	2%	6%	13%	1%	1%	16%	13%	21%	6%	3%	3%
I don't know	2%	0%	25%	2%	0%	1%	2%	3%	0%	1%	0%	2%	8%	0%	1%	3%
Number of respondents: N/IH diagnosed and treated by HCP	1,581	15	12	115	66	366	173	40	74	177	100	168	48	52	109	33
No follow ups	6%	0%	0%	3%	5%	2%	6%	13%	1%	1%	16%	13%	23%	6%	3%	3%
Up to 1 time yearly	53%	74%	22%	61%	79%	58%	25%	18%	41%	59%	43%	68%	39%	39%	74%	50%
At least 2 times yearly	41%	26%	78%	36%	16%	40%	69%	69%	58%	40%	41%	18%	39%	55%	23%	47%

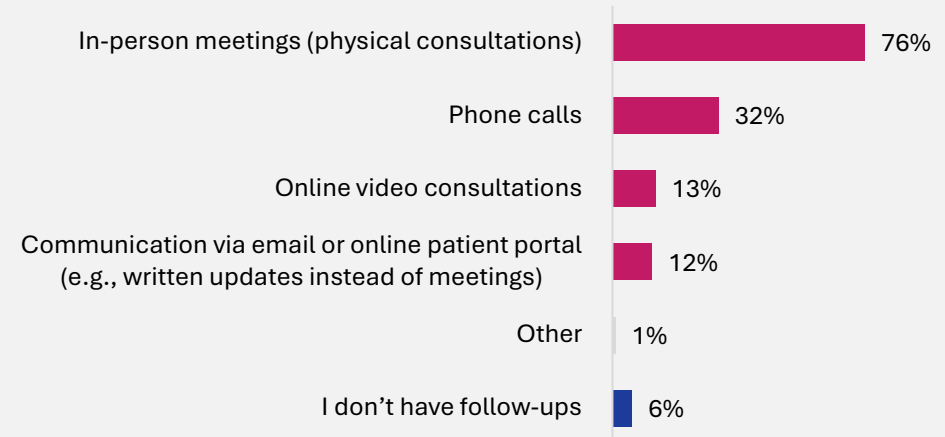
(excl. I don't know)

Q28 How do you have these follow-ups about your N/IH? (you can choose several answers)

Most follow-ups took place in person (76%), but phone consultations (32%) were also common. 13% mentioned communication via online video consultations and 12% communication via email or portals.

NT2 respondents were most likely to have in-person meetings (81%), while phone calls were frequent among NT1 (37%).

By age, younger and middle-aged respondents relied most on physical consultations (76%), whereas older respondents (60+) were less likely to meet in person (66%). Men were more likely than women to have in-person consultations (83% vs. 73%).



28. How do you have these follow-ups about your N/IH? (you can choose several answers)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
In-person meetings (physical consultations)	76%	74%	81%	77%	76%	76%	66%	83%	73%
Phone calls	32%	37%	28%	22%	36%	27%	24%	29%	33%
Online video consultations	13%	13%	12%	15%	14%	11%	7%	13%	13%
Communication via email or online patient portal (e.g., written updates instead of meetings)	12%	13%	12%	9%	13%	12%	10%	12%	12%
Other	1%	1%	1%	2%	1%	1%	2%	1%	1%
I don't have follow-ups	6%	5%	4%	7%	4%	6%	15%	4%	6%
Number of respondents: N/IH diagnosed and treated by HCP	1.581	1.022	205	317	962	518	101	379	1.194

Q28 How do you have these follow-ups about your N/IH? (you can choose several answers)

In-person consultations were the most common type of follow-up across countries, ranging from 37% in Denmark to 95% in Italy. Phone calls were most frequent in Denmark (70%) and the Netherlands (66%), while France (15%) and Italy (6%) reported the lowest levels.

Online video consultations stood out in Ireland (51%), but were rare in Spain (0%), Denmark (3%) and Italy (4%). Communication via email or patient portals was most common in Sweden (17%) and Germany (17%), while nearly absent in Finland (3%), and Spain (4%).

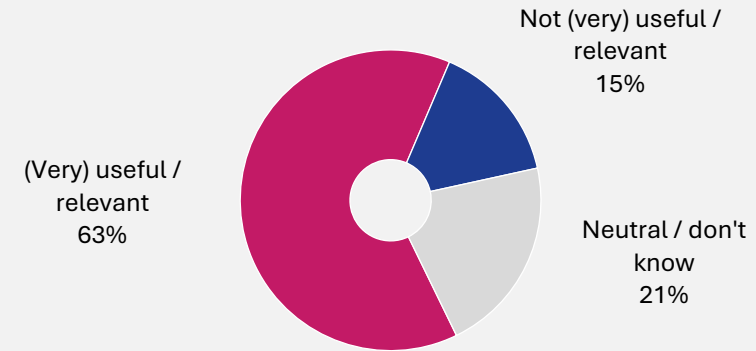
Most respondents in the Netherlands (14%) had follow-ups – fewest in Italy (1%) and Ireland (1%).

28. How do you have these follow-ups about your N/IH? (you can choose several answers)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
In-person meetings (physical consultations)	76%	93%	75%	37%	74%	90%	68%	83%	77%	95%	63%	73%	40%	83%	75%	88%
Phone calls	32%	27%	42%	70%	64%	15%	23%	35%	27%	6%	66%	28%	56%	21%	60%	27%
Online video consultations	13%	7%	0%	3%	6%	16%	21%	8%	51%	4%	22%	7%	2%	0%	12%	3%
Communication via email or online patient portal (e.g., written updates instead of meetings)	12%	7%	33%	10%	3%	13%	17%	5%	12%	12%	15%	5%	17%	4%	17%	21%
Other	1%	0%	17%	4%	0%	1%	1%	0%	0%	0%	0%	2%	2%	0%	1%	3%
I don't have follow-ups	6%	0%	8%	3%	8%	2%	9%	10%	1%	1%	14%	12%	21%	4%	2%	0%
Number of respondents: N/IH diagnosed and treated by HCP	1.581	15	12	115	66	366	173	40	73	177	100	168	48	52	109	33

Q29 How useful / relevant do you find the follow-ups with your healthcare professional about your N/IH? (choose 1 answer)

Almost two thirds (63%) found their follow-ups useful, including 28% who found them very useful. Around one in five (18%) were neutral, while 15% rated follow-ups as not very or not at all useful.

Satisfaction levels were similar across diagnoses, though IH respondents were slightly less positive (56%). Age differences and gender differences were limited, but the oldest group found the follow-ups slightly more useful, while the younger groups found them quite more not (very) useful/relevant (6% vs. 15-17%).



29. How useful / relevant do you find the follow-ups with your healthcare professional about your N/IH? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Very useful / relevant	28%	28%	31%	23%	26%	31%	29%	26%	28%
Useful / relevant	35%	37%	32%	33%	37%	32%	37%	36%	35%
Neutral	18%	19%	16%	17%	18%	17%	23%	23%	16%
Not very useful / relevant	11%	10%	13%	16%	13%	10%	4%	9%	12%
Not useful / relevant at all	4%	3%	3%	7%	4%	5%	2%	4%	4%
I don't know	3%	3%	5%	3%	3%	3%	5%	1%	4%
Number of respondents: N/IH diagnosed and treated by HCP	1.579	1.021	205	317	961	518	100	379	1.192
(Very) useful / relevant	63%	65%	63%	56%	63%	63%	66%	62%	63%
Not (very) useful / relevant	15%	13%	16%	23%	17%	15%	6%	13%	16%
Neutral / don't know	21%	22%	21%	20%	21%	20%	28%	24%	20%

Q29 How useful / relevant do you find the follow-ups with your healthcare professional about your N/IH? (choose 1 answer)

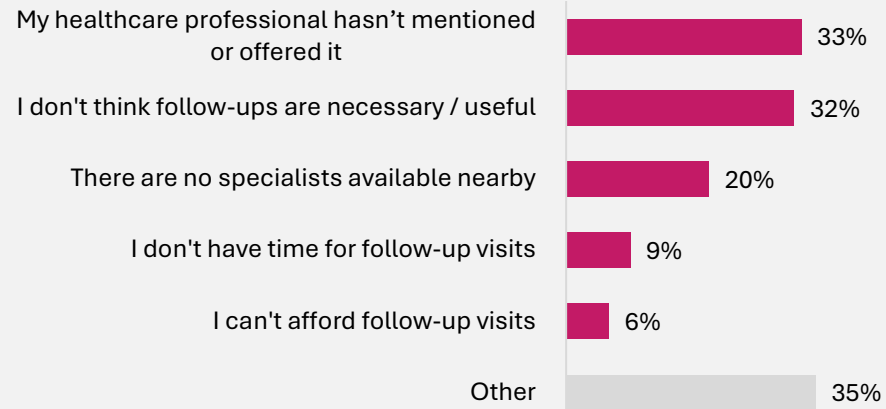
Most respondents in Italy (77%), Finland (71%) and the Netherlands (70%) found follow-ups useful or very useful – fewest in Norway (45%) and Spain (46%).

29. How useful / relevant do you find the follow-ups with your healthcare professional about your N/IH? (choose 1 answer)	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Very useful / relevant	28%	13%	50%	28%	26%	32%	23%	40%	29%	41%	28%	20%	23%	13%	18%	30%
Useful / relevant	35%	47%	33%	37%	45%	37%	37%	33%	25%	36%	42%	25%	28%	33%	39%	48%
Neutral	18%	20%	8%	21%	15%	13%	17%	18%	27%	16%	18%	18%	23%	37%	24%	15%
Not very useful / relevant	11%	13%	0%	10%	8%	12%	11%	5%	15%	6%	6%	21%	4%	8%	16%	6%
Not useful / relevant at all	4%	7%	0%	2%	2%	5%	5%	3%	4%	1%	1%	11%	4%	6%	2%	0%
I don't know	3%	0%	8%	2%	5%	2%	7%	3%	0%	0%	5%	4%	17%	4%	2%	0%
Number of respondents: N/IH diagnosed and treated by HCP	1.579	15	12	115	66	366	173	40	73	177	100	168	47	52	109	33
(Very) useful / relevant	63%	60%	83%	65%	71%	69%	60%	73%	54%	77%	70%	45%	51%	46%	57%	78%
Not (very) useful / relevant	15%	20%	0%	12%	10%	17%	16%	8%	19%	7%	7%	32%	8%	14%	18%	6%
Neutral / don't know	21%	20%	16%	23%	20%	15%	24%	21%	27%	16%	23%	22%	40%	41%	26%	15%

Q30 Why don't you have follow-ups with a healthcare professional about your N/IH? (you can choose several answers)

Only 88 respondents (5%) reported not having follow-ups.

The main reasons for not having follow-ups were that healthcare professionals had not offered it (33%) or patients did not consider it necessary (32%). Additionally, 20% reported no specialists nearby, 9% lacked time, and 6% cited financial barriers.



30. Why don't you have follow-ups with a healthcare professional about your N/IH? (you can choose several answers)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
My healthcare professional hasn't mentioned or offered it	33%	22%	14%	65%	36%	27%	42%	18%	38%
I don't think follow-ups are necessary / useful	32%	41%	57%	4%	33%	30%	33%	41%	29%
There are no specialists available nearby	20%	15%	14%	31%	36%	8%	8%	27%	18%
I don't have time for follow-up visits	9%	9%	0%	12%	10%	11%	0%	14%	8%
I can't afford follow-up visits	6%	4%	0%	4%	5%	8%	0%	9%	5%
Other	35%	37%	43%	31%	31%	43%	25%	32%	36%
Number of respondents: N/IH diagnosed and not treated by HCP	88	46	7	26	39	37	12	22	66

Q30 Why don't you have follow-ups with a healthcare professional about your N/IH? (you can choose several answers)

Not enough respondents answered on country level to conclude trustworthy.

30. Why don't you have follow-ups with a healthcare professional about your N/IH? (you can choose several answers)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
My healthcare professional hasn't mentioned or offered it	33%	0%	17%	0%	0%	46%	13%	0%	0%	0%	43%	56%	33%	0%	50%	33%
I don't think follow-ups are necessary / useful	32%	100%	33%	50%	100%	15%	47%	100%	0%	0%	21%	11%	67%	50%	50%	33%
There are no specialists available nearby	20%	0%	17%	0%	0%	15%	40%	0%	0%	0%	7%	28%	67%	0%	50%	0%
I don't have time for follow-up visits	9%	0%	17%	0%	0%	15%	13%	0%	0%	0%	0%	11%	33%	0%	0%	0%
I can't afford follow-up visits	6%	0%	17%	0%	0%	0%	7%	100%	0%	0%	0%	6%	33%	0%	0%	0%
Other	35%	50%	50%	50%	0%	23%	20%	0%	0%	0%	43%	44%	0%	50%	50%	33%
Number of respondents: N/IH diagnosed and not treated by HCP	88	2	6	4	1	13	15	1	0	0	14	18	3	4	2	3

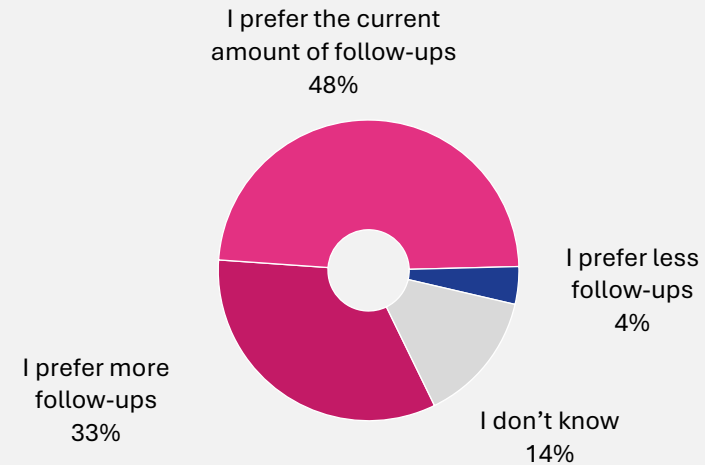
Q31 Would it be useful / relevant for you to have more or less follow-ups with a healthcare professional about your N/IH? (choose 1 answer)

Nearly half (48%) prefer their current number of follow-ups, while 33% would prefer more. Only 4% wanted fewer.

The wish for more follow-ups was particularly high among IH respondents (52% vs. 29%).

By age, demand for more follow-ups was strongest among the two youngest age groups (34%) and the least among those 60+ (22%), who more often preferred the current level (58% vs. 46-49%).

By gender women were more likely than men to want more follow-ups (36% vs. 25%).



31. Would it be useful / relevant for you to have more or less follow-ups with a healthcare professional about your N/IH? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
I prefer more follow-ups	33%	29%	29%	52%	34%	34%	22%	25%	36%
I prefer the current amount of follow-ups	48%	52%	47%	36%	49%	46%	58%	54%	47%
I prefer less follow-ups	4%	4%	6%	3%	4%	4%	3%	6%	3%
I don't know	14%	15%	18%	10%	13%	16%	18%	16%	14%
Number of respondents: All with N/IH diagnosis	1.658	1.061	211	341	992	553	113	400	1.250

Q31 Would it be useful / relevant for you to have more or less follow-ups with a healthcare professional about your N/IH? (choose 1 answer)

A wish for more follow-ups were most preferred in Norway (57%), while the Netherlands (16%) and Italy (19%) were lowest.

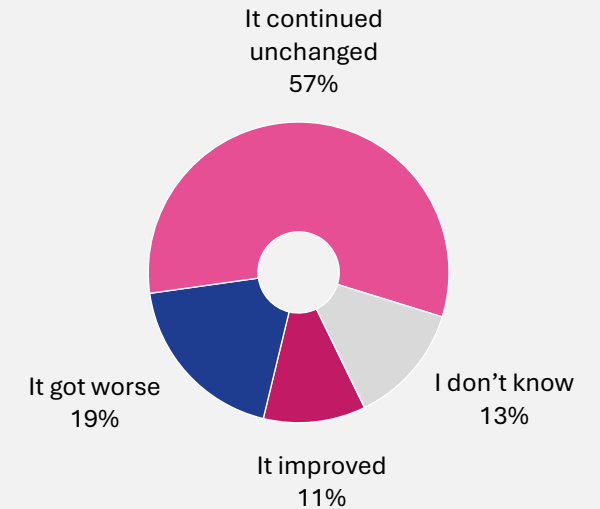
Keeping the current amount was highest in the Netherlands (68%) and Finland (67%), and lowest in Norway (31%).

31. Would it be useful / relevant for you to have more or less follow-ups with a healthcare professional about your N/IH? (choose 1 answer)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
I prefer more follow-ups	33%	6%	39%	25%	22%	40%	23%	39%	42%	19%	16%	57%	41%	33%	43%	8%
I prefer the current amount of follow-ups	48%	59%	22%	63%	67%	44%	53%	39%	45%	57%	68%	31%	31%	38%	42%	72%
I prefer less follow-ups	4%	6%	0%	3%	1%	3%	4%	5%	1%	10%	3%	2%	4%	7%	3%	11%
I don't know	14%	29%	39%	9%	9%	13%	20%	17%	11%	14%	13%	10%	24%	22%	13%	8%
Number of respondents: All with N/IH diagnosis	1.658	17	18	119	67	378	188	41	73	175	113	185	49	55	110	36

Q32 How did your support and follow-ups from healthcare professionals change after you turned 18 years old? (choose 1 answer)

Among those diagnosed before 18 years, over half (57%) said their support continued unchanged after turning 18 years, while 19% said it worsened and 11% said it improved.

By gender, women a bit more often reported worsened support than men (21% vs. 14%).



32. How did your support and follow-ups from healthcare professionals change after you turned 18 years old? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
It improved	11%	12%	6%	3%	10%	13%	20%	14%	9%
It got worse	19%	20%	14%	10%	19%	18%	0%	14%	21%
It continued unchanged	57%	55%	67%	77%	58%	53%	60%	62%	55%
I don't know	13%	13%	14%	10%	13%	16%	20%	10%	14%
Number of respondents: N/IH diagnosis under 18 years	446	366	36	30	403	38	5	146	298

Q32 How did your support and follow-ups from healthcare professionals change after you turned 18 years old? (choose 1 answer)

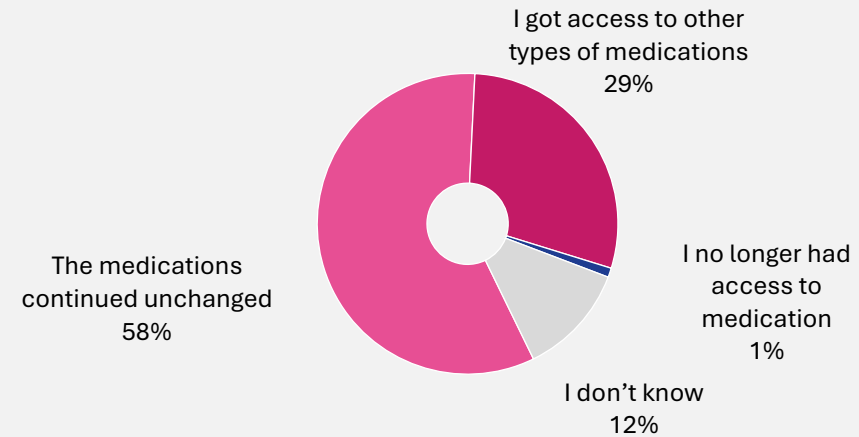
Among countries with more than 50 respondents, follow-ups after turning 18 years most often continued unchanged, reported by 69% in Italy and 65% in France.

Improvements were reported only by a minority, ranging from 6% in France to 11% in Italy.

32. How did your support and follow-ups from healthcare professionals change after you turned 18 years old? (choose 1 answer)	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
It improved	11%	17%	0%	13%	4%	6%	15%	25%	19%	11%	16%	13%	6%	21%	8%	0%
It got worse	19%	0%	0%	13%	50%	16%	15%	8%	19%	11%	3%	46%	0%	14%	42%	0%
It continued unchanged	57%	67%	83%	65%	31%	65%	50%	67%	46%	69%	66%	21%	88%	64%	42%	89%
I don't know	13%	17%	17%	9%	15%	14%	21%	0%	15%	9%	16%	21%	6%	0%	8%	11%
Number of respondents: N/IH diagnosis under 18 years	446	6	6	23	26	88	48	12	26	55	38	24	16	14	48	9

Q33 How did your medical treatment change after you turned 18 years old? (choose 1 answer)

Among those diagnosed before 18 years, 58% reported that their medical treatment continued unchanged after turning 18, while 29% gained access to new types of medication and 1% lost access.



33. How did your medical treatment change after you turned 18 years old? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
The medications continued unchanged	58%	58%	44%	70%	59%	42%	60%	55%	59%
I got access to other types of medications	29%	30%	39%	17%	28%	42%	20%	34%	28%
I no longer had access to medication	1%	1%	6%	0%	1%	3%	20%	1%	1%
I don't know	12%	12%	11%	13%	12%	13%	0%	10%	13%
Number of respondents: N/IH diagnosis under 18 years	446	366	36	30	403	38	5	146	298

Q33 How did your medical treatment change after you turned 18 years old? (choose 1 answer)

In both France and Italy, most respondents reported that their medications continued unchanged after turning 18 (61% and 55%, respectively).

Access to other types of medications was also common, with 26% in France and 35% in Italy.

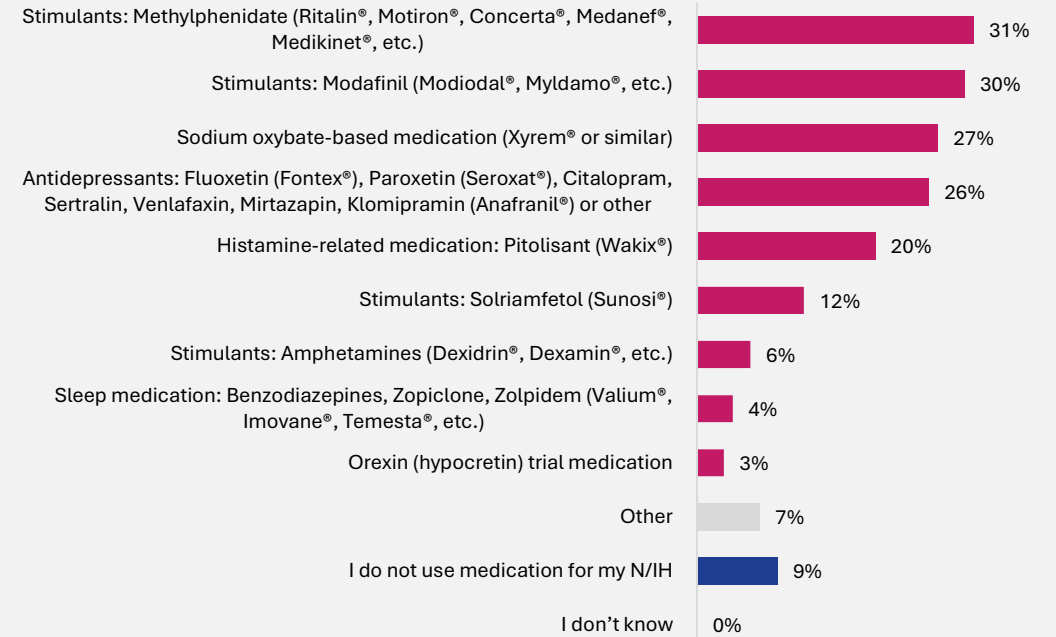
33. How did your medical treatment change after you turned 18 years old? (choose 1 answer)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
The medications continued unchanged	58%	83%	67%	74%	58%	61%	46%	17%	65%	55%	55%	63%	50%	64%	65%	33%
I got access to other types of medications	29%	0%	0%	22%	19%	26%	31%	75%	23%	35%	32%	25%	44%	36%	27%	67%
I no longer had access to medication	1%	0%	17%	0%	0%	1%	2%	0%	0%	2%	0%	4%	0%	0%	0%	0%
I don't know	12%	17%	17%	4%	23%	11%	21%	8%	12%	9%	13%	8%	6%	0%	8%	0%
Number of respondents: N/IH diagnosis under 18 years	446	6	6	23	26	88	48	12	26	55	38	24	16	14	48	9

Q34 What type of medication do you use regularly for your N/IH? (you can choose several answers)

The vast majority (91%) used medication. The most common were stimulants such as methylphenidate (31%) and modafinil (30%), followed by sodium oxybate (27%) and antidepressants (26%).

By diagnosis, NT1 and IH respondents relied more on methylphenidate (32% and 34%) than NT2 (24%).

By age, younger respondents (18–39) most often used methylphenidate (35%), while antidepressants were more frequent among older patients (31% in 60+). Gender differences were small: women slightly more often used methylphenidate (33% vs. 27%), while men more often used sodium oxybate (32% vs. 25%).



34. What type of medication do you use regularly for your N/IH? (you can choose several answers)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Stimulants: Methylphenidate (Ritalin®, Motiron®, Concerta®, Medanef®, Medikinet®, etc.)	31%	32%	24%	34%	35%	27%	20%	27%	33%
Stimulants: Modafinil (Modiodal®, Myldamo®, etc.)	30%	29%	32%	33%	29%	33%	29%	36%	28%
Sodium oxybate-based medication (Xyrem® or similar)	27%	38%	12%	4%	27%	26%	29%	32%	25%
Antidepressants: Fluoxetine (Fontex®), Paroxetine (Seroxat®), Citalopram, Sertraline, Venlafaxin, Mirtazapin, Klomipramin (Anafranil®) or other	26%	33%	14%	14%	24%	28%	31%	23%	27%
Histamine-related medication: Pitolisant (Wakix®)	20%	20%	29%	15%	23%	17%	7%	24%	19%
Stimulants: Solriamfetol (Sunosi®)	12%	11%	18%	14%	13%	12%	10%	11%	13%
Stimulants: Amphetamines (Dexidrin®, Dexamin®, etc.)	6%	6%	4%	7%	6%	6%	5%	6%	6%
Sleep medication: Benzodiazepines, Zopiclone, Zolpidem (Valium®, Imovane®, Temesta®, etc.)	4%	4%	6%	4%	3%	5%	7%	5%	3%
Orexin (hypocretin) trial medication	3%	4%	0%	0%	3%	2%	1%	4%	2%
Other	7%	8%	6%	8%	7%	8%	8%	7%	7%
I do not use medication for my N/IH	9%	6%	12%	12%	7%	11%	16%	7%	9%
I don't know	0%	0%	0%	1%	0%	1%	1%	1%	0%
Number of respondents: All with N/IH diagnosis	1,635	1,042	211	338	976	547	112	392	1,235
Use medication for N/IH	91%	94%	88%	87%	93%	88%	83%	92%	91%

Q34 What type of medication do you use regularly for your N/IH? (you can choose several answers)

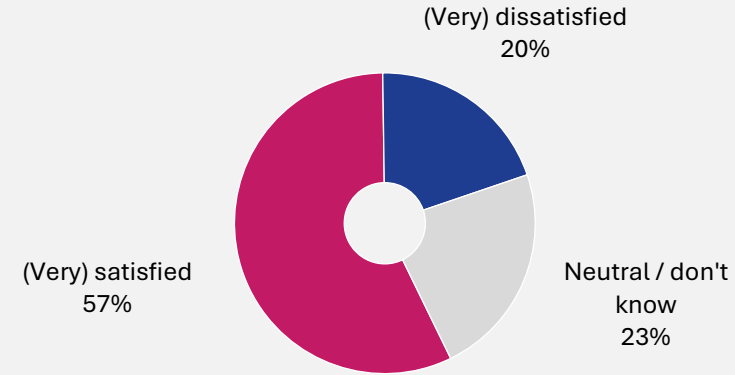
Stimulants (methylphenidate, etc.) were especially common in Denmark (68%) and Ireland (59%) but rarely used in Italy (1%) and Spain (17%). Modafinil was widely used in France (41%), while Denmark stood out with only 14% use. Sodium oxybate was most common in Italy (45%), the Netherlands (48%) and Finland (42%). Antidepressants were frequently reported in Ireland (42%) and Sweden (41%), but low in Italy (10%).

34. What type of medication do you use regularly for your N/IH? (you can choose several answers)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Stimulants: Methylphenidate (Ritalin®, Motiron®, Concerta®, Medanef®, Medikinet®, etc.)	31%	47%	0%	68%	47%	30%	25%	27%	59%	1%	20%	41%	22%	17%	41%	36%
Stimulants: Modafinil (Modiodal®, Myldamo®, etc.)	30%	47%	28%	14%	41%	32%	32%	68%	30%	22%	25%	34%	39%	30%	25%	33%
Sodium oxybate-based medication (Xyrem® or similar)	27%	18%	17%	26%	42%	9%	27%	20%	41%	45%	48%	26%	0%	31%	36%	36%
Antidepressants: Fluoxetin (Fontex®), Paroxetin (Seroxat®), Citalopram, Sertralin, Venlafaxin, Mirtazapin, Klomipramin (Anafranil®) or other	26%	18%	17%	23%	31%	25%	24%	80%	42%	10%	21%	17%	37%	39%	41%	11%
Histamine-related medication: Pitolisant (Wakix®)	20%	0%	22%	3%	14%	19%	20%	29%	30%	36%	27%	14%	41%	19%	11%	8%
Stimulants: Solriamfetol (Sunosi®)	12%	0%	0%	3%	13%	21%	26%	0%	0%	29%	2%	1%	0%	6%	1%	0%
Stimulants: Amphetamines (Dexidrin®, Dexamin®, etc.)	6%	0%	0%	5%	0%	1%	6%	2%	0%	0%	17%	17%	2%	2%	17%	3%
Sleep medication: Benzodiazepines, Zopiclone, Zolpidem (Valium®, Imovane®, Temesta®, etc.)	4%	6%	0%	3%	3%	2%	7%	5%	1%	4%	1%	3%	7%	11%	7%	0%
Orexin (hypocretin) trial medication	3%	0%	0%	0%	3%	1%	0%	0%	0%	13%	2%	1%	13%	11%	0%	6%
Other	7%	0%	6%	9%	16%	5%	14%	5%	7%	5%	5%	5%	9%	2%	11%	14%
I do not use medication for my N/IH	9%	12%	33%	8%	6%	9%	9%	2%	0%	4%	12%	12%	11%	9%	6%	17%
I don't know	0%	0%	6%	0%	0%	1%	0%	0%	0%	0%	1%	1%	0%	0%	0%	0%
Number of respondents: All with N/IH diagnosis	1.635	17	18	117	64	374	186	41	73	171	110	185	46	54	109	36
Use medication for N/IH	91%	88%	61%	92%	94%	90%	91%	98%	100%	96%	87%	87%	89%	91%	94%	83%

Q35 How satisfied are you with your current medical treatment for your N/IH? (choose 1 answer)

A majority (57%) were satisfied with their treatment, 20% dissatisfied and 23% neutral.

By diagnosis, NT2 respondents were most satisfied (61%), while IH were less so (47%). Satisfaction was highest among older respondents (62% of 60+), while younger respondents (18–39 and 40-59) were slightly lower (56-57%).



35. How satisfied are you with your current medical treatment for your N/IH? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Very satisfied	13%	13%	17%	10%	12%	13%	22%	12%	13%
Satisfied	44%	46%	44%	37%	45%	43%	40%	47%	43%
Neutral	22%	23%	14%	22%	23%	20%	18%	20%	22%
Dissatisfied	15%	12%	18%	20%	14%	17%	15%	14%	15%
Very dissatisfied	5%	5%	5%	9%	5%	6%	5%	6%	5%
Don't know	1%	1%	1%	2%	1%	1%	0%	1%	1%
Number of respondents: N/IH diagnosed in medical treatment	1.486	977	185	293	909	484	93	362	1.117
(Very) satisfied	57%	59%	61%	47%	57%	56%	62%	59%	56%
(Very) dissatisfied	20%	17%	23%	29%	19%	23%	20%	20%	20%
Neutral / don't know	23%	24%	15%	24%	24%	21%	18%	21%	23%

Q35 How satisfied are you with your current medical treatment for your N/IH? (choose 1 answer)

Satisfaction (very satisfied + satisfied) was highest in Finland (80%), Italy (76%), and the Netherlands (66%).

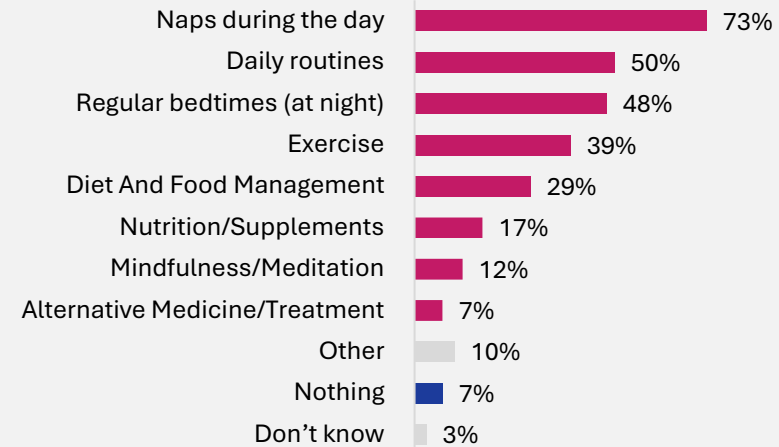
Dissatisfaction (dissatisfied + very dissatisfied) peaked in France (27%) and Germany (26%).

35. How satisfied are you with your current medical treatment for your N/IH? (choose 1 answer)	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Very satisfied	13%	13%	27%	17%	15%	11%	14%	0%	7%	20%	10%	15%	10%	12%	7%	30%
Satisfied	44%	53%	55%	45%	65%	41%	41%	20%	45%	56%	56%	40%	37%	37%	39%	33%
Neutral	22%	20%	0%	20%	12%	20%	19%	43%	27%	10%	24%	26%	24%	24%	37%	23%
Dissatisfied	15%	13%	9%	14%	7%	20%	16%	33%	14%	10%	5%	14%	22%	16%	12%	7%
Very dissatisfied	5%	0%	9%	2%	2%	7%	10%	5%	5%	2%	3%	6%	5%	8%	3%	3%
Don't know	1%	0%	0%	2%	0%	1%	0%	0%	1%	1%	1%	0%	2%	2%	2%	3%
Number of respondents: N/IH diagnosed in medical treatment	1.486	15	11	108	60	337	169	40	73	164	96	162	41	49	102	30
(Very) satisfied	57%	66%	82%	62%	80%	52%	55%	20%	52%	76%	66%	55%	47%	49%	46%	63%
(Very) dissatisfied	20%	13%	18%	16%	9%	27%	26%	38%	19%	12%	8%	20%	27%	24%	15%	10%
Neutral / don't know	23%	20%	0%	22%	12%	21%	19%	43%	28%	11%	25%	26%	26%	26%	39%	26%

Q36 What else is helping you manage your N/IH? (you can choose several answers)

The most common self-management strategy was taking naps during the day (73%), followed by daily routines (50%) and keeping regular bedtimes at night (48%). Exercise (39%) and diet or food management (29%) were also widely used.

By diagnosis, naps were especially common among NT1 respondents (81%), compared with 70% in NT2 and only 48% in IH.



36. What else is helping you manage your N/IH? (you can choose several answers)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Naps during the day	73%	81%	70%	48%	72%	74%	76%	73%	73%
Daily routines	50%	50%	53%	47%	52%	46%	50%	49%	50%
Regular bedtimes (at night)	48%	49%	48%	42%	49%	48%	43%	48%	48%
Exercise	39%	41%	42%	29%	42%	34%	37%	43%	37%
Diet And Food Management	29%	33%	27%	20%	31%	28%	22%	30%	29%
Nutrition/Supplements	17%	18%	15%	15%	19%	14%	15%	17%	17%
Mindfulness/Meditation	12%	12%	14%	9%	11%	13%	11%	10%	12%
Alternative Medicine/Treatment	7%	7%	7%	8%	7%	9%	7%	7%	7%
Other	10%	9%	9%	13%	11%	10%	3%	8%	10%
Nothing	7%	4%	6%	15%	7%	7%	5%	6%	7%
Don't know	3%	2%	3%	7%	4%	3%	1%	3%	3%
Number of respondents: All with N/IH diagnosis	1.639	1.047	211	337	981	547	111	391	1.240

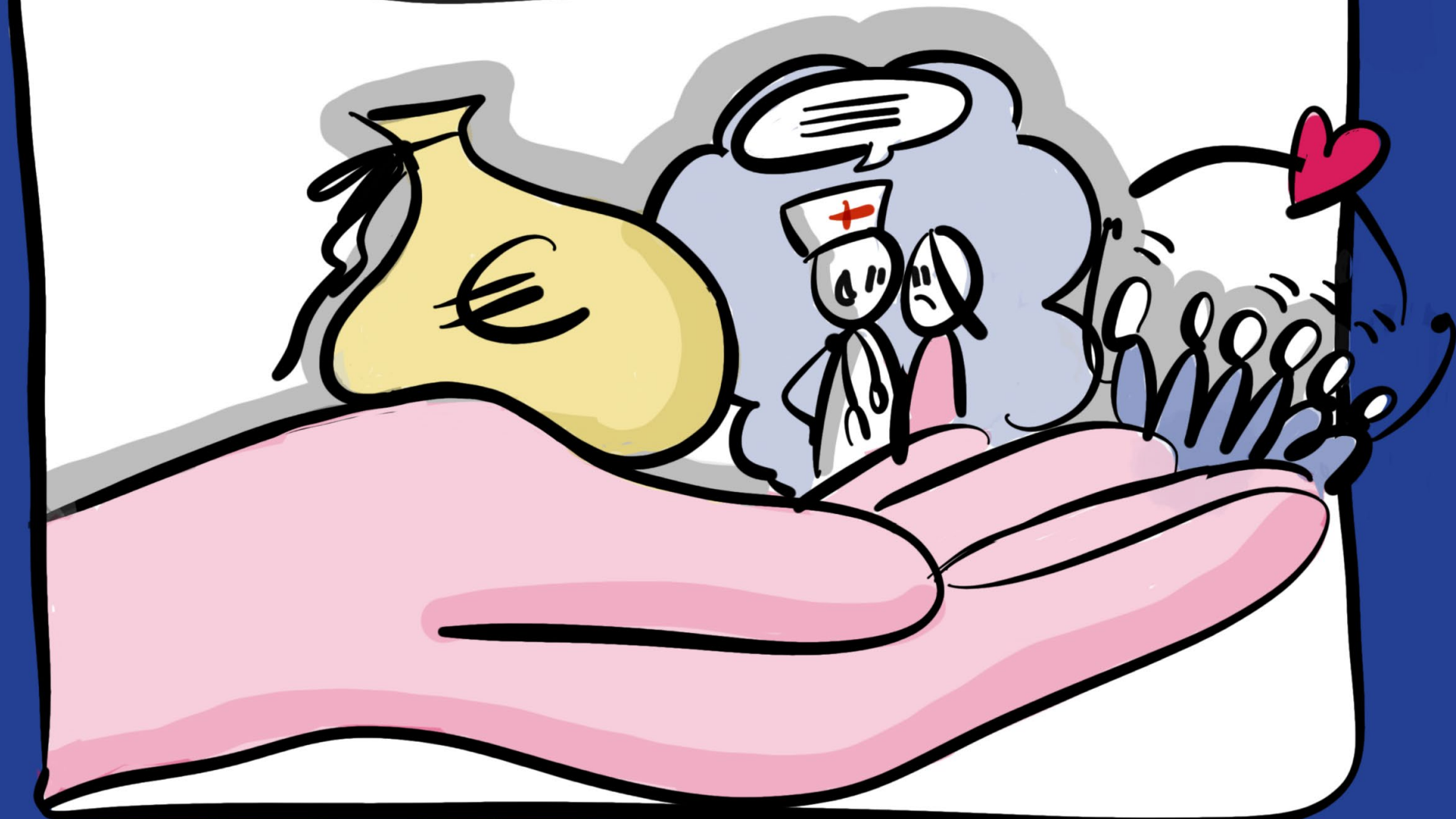
Q36 What else is helping you manage your N/IH? (you can choose several answers)

France stands out with notably fewer respondents relying on naps (61%) and diet/food management (13%) compared to most other countries. Finland shows the highest use of diet/food management (62%).

Sweden has more respondents using daily routines (68%) than other countries, while Italy is lower (35%). Germany reports higher levels of exercise (53%) compared to France (26%) and Italy (29%).

36. What else is helping you manage your N/IH? (you can choose several answers)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Naps during the day	73%	94%	78%	69%	83%	61%	82%	61%	78%	69%	84%	68%	83%	89%	84%	81%
Daily routines	50%	41%	11%	58%	63%	42%	55%	37%	60%	39%	61%	50%	36%	56%	68%	36%
Regular bedtimes (at night)	48%	65%	39%	60%	57%	39%	56%	29%	52%	35%	61%	52%	43%	52%	51%	47%
Exercise	39%	24%	22%	44%	51%	26%	53%	29%	42%	29%	45%	46%	36%	39%	51%	39%
Diet And Food Management	29%	6%	28%	43%	62%	13%	32%	29%	40%	27%	40%	34%	28%	35%	35%	19%
Nutrition/Supplements	17%	6%	11%	21%	18%	15%	22%	15%	32%	10%	15%	19%	17%	15%	19%	19%
Mindfulness/Meditation	12%	12%	11%	9%	11%	9%	16%	20%	18%	8%	12%	16%	4%	13%	13%	17%
Alternative Medicine/Treatment	7%	0%	6%	3%	9%	9%	6%	17%	11%	3%	4%	7%	2%	17%	11%	8%
Other	10%	12%	33%	10%	14%	12%	10%	2%	5%	3%	6%	12%	11%	15%	13%	3%
Nothing	7%	0%	6%	7%	3%	11%	4%	10%	7%	7%	5%	6%	4%	2%	3%	6%
Don't know	3%	0%	6%	3%	2%	6%	0%	2%	4%	2%	1%	3%	9%	0%	5%	3%
Number of respondents: All with N/IH diagnosis	1.639	17	18	117	65	374	187	41	73	172	110	185	47	54	109	36

4. SUPPORT

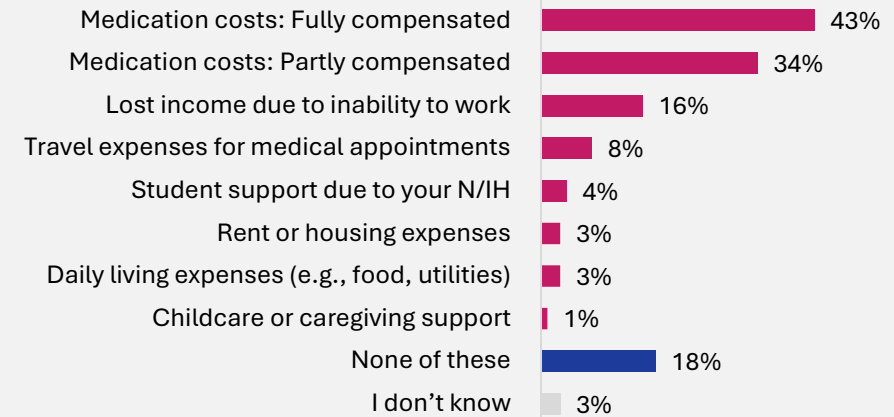


Q37 Which of the following aspects are financially compensated for you? (You can choose several answers)

Most respondents (79%) received some form of financial compensation. The most common was full coverage of medication costs (43%) or partial coverage (34%). Lost income due to inability to work was compensated for 16%, while only small shares received support for travel expenses (8%), student support (4%) or housing costs (3%).

By diagnosis, IH respondents were slightly more often compensated (81%), mainly through full medication coverage (49%).

By age, younger respondents (18–39) most often had medication fully covered (46%), while 40-59-year-olds, were least compensated in total (75% vs. 81-84%). Men and women were nearly identical (80% vs. 79%).



37. Which of the following aspects are financially compensated for you? (You can choose several answers)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Medication costs: Fully compensated	43%	41%	46%	49%	46%	36%	42%	44%	42%
Medication costs: Partly compensated	34%	37%	26%	29%	34%	33%	35%	35%	33%
Lost income due to inability to work	16%	16%	11%	19%	12%	21%	20%	15%	16%
Travel expenses for medical appointments	8%	9%	5%	7%	9%	7%	3%	11%	7%
Student support due to your N/IH	4%	5%	4%	3%	6%	1%	0%	5%	4%
Rent or housing expenses	3%	3%	3%	3%	4%	4%	1%	4%	3%
Daily living expenses (e.g., food, utilities)	3%	3%	3%	3%	3%	3%	4%	3%	3%
Childcare or caregiving support	1%	1%	2%	1%	2%	1%	1%	1%	2%
None of these	18%	17%	22%	17%	16%	22%	16%	15%	19%
I don't know	3%	3%	1%	2%	3%	3%	0%	5%	2%
Number of respondents: All with N/IH diagnosis	1.620	1.034	209	334	969	540	111	388	1.224
Are financial compensated (by mentioned aspects)	79%	80%	77%	81%	81%	75%	84%	80%	79%

Q37 Which of the following aspects are financially compensated for you? (You can choose several answers)

France (73%) and Italy (72%) stood out with the highest shares reporting full compensation, while Denmark (73%) and Finland (52%) had relatively high levels of partial compensation. Compensation for lost income due to inability to work was reported by 16%, with Norway (33%) and Sweden (25%) standing out.

Overall, most respondents across countries reported some form of financial compensation, with particularly high levels in France (89%), Ireland (89%), and Italy (85%).

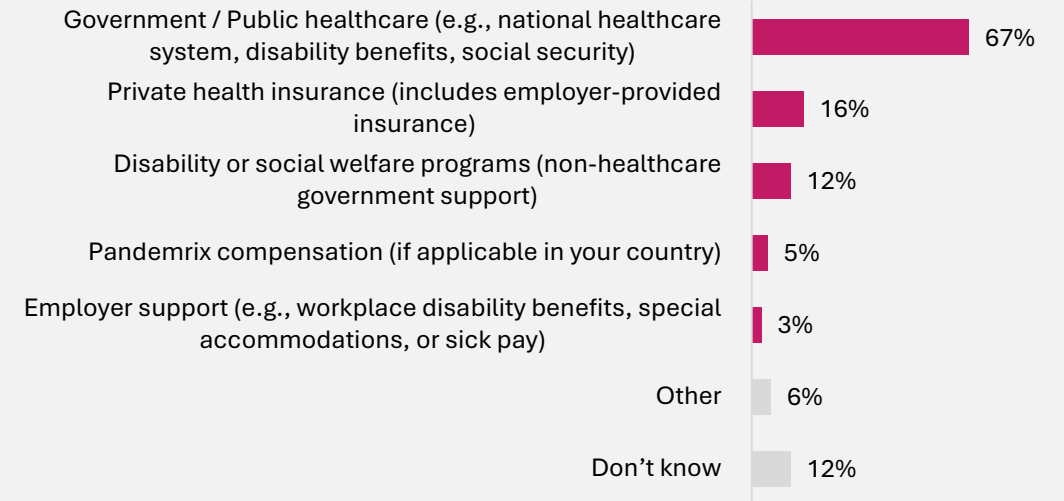
37. Which of the following aspects are financially compensated for you? (You can choose several answers)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Medication costs: Fully compensated	43%	0%	28%	8%	25%	73%	22%	23%	40%	72%	54%	33%	6%	36%	28%	17%
Medication costs: Partly compensated	34%	53%	6%	73%	52%	17%	31%	63%	48%	9%	27%	46%	40%	42%	34%	61%
Lost income due to inability to work	16%	6%	6%	12%	9%	14%	13%	8%	16%	1%	17%	33%	9%	21%	25%	36%
Travel expenses for medical appointments	8%	0%	6%	3%	9%	8%	2%	0%	33%	8%	4%	11%	6%	8%	11%	8%
Student support due to your N/IH	4%	0%	6%	11%	6%	2%	2%	0%	16%	3%	5%	3%	6%	2%	2%	0%
Rent or housing expenses	3%	0%	11%	4%	3%	3%	5%	0%	7%	1%	3%	2%	0%	0%	7%	3%
Daily living expenses (e.g., food, utilities)	3%	0%	6%	1%	3%	3%	3%	8%	7%	2%	1%	3%	4%	4%	1%	6%
Childcare or caregiving support	1%	0%	0%	0%	0%	1%	3%	3%	10%	1%	1%	1%	2%	2%	1%	6%
None of these	18%	47%	56%	14%	20%	10%	36%	8%	8%	9%	17%	15%	36%	15%	28%	17%
I don't know	3%	0%	6%	2%	3%	1%	3%	3%	3%	6%	3%	2%	9%	6%	4%	0%
Number of respondents: All with N/IH diagnosis	1.620	17	18	117	64	367	185	40	73	170	109	185	47	53	106	36
Are financial compensated (by mentioned aspects)	79%	53%	38%	84%	77%	89%	61%	89%	89%	85%	80%	83%	55%	79%	68%	83%

Q38 Who is providing financial compensation for your N/IH-related expenses? (you can choose several answers)

Government or public healthcare was the primary source of financial compensation for N/IH-related expenses, reported by 67% overall. This was particularly high among respondents with IH (73%).

Private health insurance accounted for 16% overall, while 12% received support through disability or social welfare programs. Employer support was limited (3%), and 5% reported receiving compensation related to Pandemrix.

By age, government or public healthcare compensation was relatively consistent across groups (66–70%). By gender, no notable differences were observed.



38. Who is providing financial compensation for your N/IH-related expenses? (you can choose several answers)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Government / Public healthcare (e.g., national healthcare system, disability benefits, social security)	67%	65%	67%	73%	66%	69%	70%	69%	66%
Private health insurance (includes employer-provided insurance)	16%	15%	18%	18%	17%	14%	18%	16%	16%
Disability or social welfare programs (non-healthcare government support)	12%	14%	8%	8%	10%	15%	13%	13%	12%
Pandemrix compensation (if applicable in your country)	5%	8%	2%	0%	7%	2%	1%	6%	5%
Employer support (e.g., workplace disability benefits, special accommodations, or sick pay)	3%	3%	4%	4%	3%	4%	6%	3%	3%
Other	6%	7%	4%	5%	6%	6%	2%	7%	6%
Don't know	12%	11%	13%	14%	12%	11%	10%	10%	12%
Number of respondents: N/IH diagnosed and financial compensated	1.281	821	159	272	787	401	93	310	964

Q38 Who is providing financial compensation for your N/IH-related expenses? (you can choose several answers)

Government or public healthcare was by far the main source of financial compensation in most countries. The highest shares were seen in Italy (83%) and Denmark (76%). By contrast, much lower reliance on public systems was reported in the Netherlands (29%) and Sweden (36%).

Private health insurance was most common in the Netherlands (56%), but only marginally present in Italy (1%) and Norway (6%). Disability or social welfare programs outside healthcare played a notable role in Sweden (35%), compared to very low levels in Denmark (2%) and Germany (4%).

Unique country-specific differences included Sweden (38%) and Ireland (26%) reported compensation from Pandemrix, while other countries were at 5% or lower.

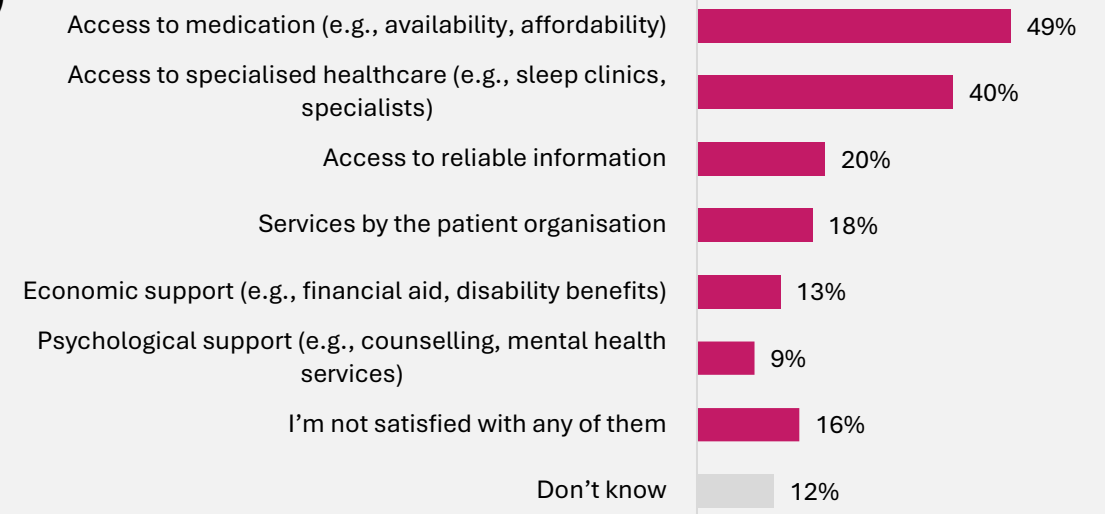
38. Who is providing financial compensation for your N/IH-related expenses? (you can choose several answers)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Government / Public healthcare (e.g., national healthcare system, disability benefits, social security)	67%	56%	86%	76%	67%	71%	65%	69%	72%	83%	29%	75%	44%	83%	36%	67%
Private health insurance (includes employer-provided insurance)	16%	44%	0%	27%	6%	21%	9%	3%	11%	1%	56%	6%	4%	2%	14%	37%
Disability or social welfare programs (non-healthcare government support)	12%	0%	0%	2%	2%	6%	4%	14%	20%	3%	18%	24%	44%	10%	35%	17%
Pandemrix compensation (if applicable in your country)	5%	0%	0%	0%	22%	1%	2%	0%	26%	1%	0%	5%	0%	0%	38%	0%
Employer support (e.g., workplace disability benefits, special accommodations, or sick pay)	3%	0%	0%	1%	2%	1%	3%	0%	2%	0%	3%	5%	12%	10%	10%	10%
Other	6%	0%	14%	6%	2%	5%	11%	8%	3%	7%	2%	3%	24%	10%	11%	0%
Don't know	12%	11%	14%	5%	16%	18%	13%	17%	0%	7%	16%	9%	8%	5%	11%	0%
Number of respondents: N/IH diagnosed and financial compensated	1,281	9	7	99	49	327	114	36	65	143	87	154	25	41	72	30

Q39 Which of the following supports for managing your N/IH are you satisfied with? (you can choose several questions)

Nearly three in four (72%) were satisfied with at least one of the mentioned support options. The most frequent was access to medication (49%), followed by access to specialized healthcare (40%). Fewer were satisfied with information (20%), patient organisations (18%) or economic support (13%), while only 9% mentioned psychological support.

By diagnosis, NT1 respondents were slightly more satisfied (73%) than NT2 (72%) and IH (71%).

By age, satisfaction peaked among 60+ (83%). Men were slightly more satisfied than women (74% vs. 72%).



39. Which of the following supports for managing your N/IH are you satisfied with? (you can choose several questions)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Access to medication (e.g., availability, affordability)	49%	52%	45%	46%	50%	47%	47%	52%	48%
Access to specialised healthcare (e.g., sleep clinics, specialists)	40%	41%	42%	37%	39%	39%	48%	44%	39%
Access to reliable information	20%	23%	18%	14%	19%	20%	36%	20%	20%
Services by the patient organisation	18%	19%	14%	15%	16%	20%	26%	21%	17%
Economic support (e.g., financial aid, disability benefits)	13%	14%	8%	10%	12%	13%	13%	13%	12%
Psychological support (e.g., counselling, mental health services)	9%	9%	11%	10%	11%	7%	7%	8%	10%
I'm not satisfied with any of them	16%	15%	16%	18%	16%	17%	7%	14%	16%
Don't know	12%	12%	12%	11%	12%	12%	10%	12%	12%
Number of respondents: All with N/IH diagnosis	1.614	1.030	209	332	965	538	111	387	1.219
Satisfied with mentioned supports	72%	73%	72%	71%	72%	71%	83%	74%	72%

Q39 Which of the following supports for managing your N/IH are you satisfied with? (you can choose several questions)

Overall satisfaction was highest in Italy (91%) and the Netherlands (87%), while lower shares were seen in Germany (61%) and Norway (61%).

Access to medication stood out as the area of highest satisfaction, particularly in Italy (69%) and the Netherlands (61%). Access to specialised healthcare was also frequently mentioned, with Italy and the Netherlands (both 65%), in contrast to much lower shares in Germany (23%) and Norway (22%). By contrast, satisfaction with psychological support and economic aid was generally low across all countries, though Ireland (15% for psychological support) and Norway (24% for economic support) reported slightly higher levels than others.

Notably, dissatisfaction was highest in Sweden (27%) and Norway (27%).

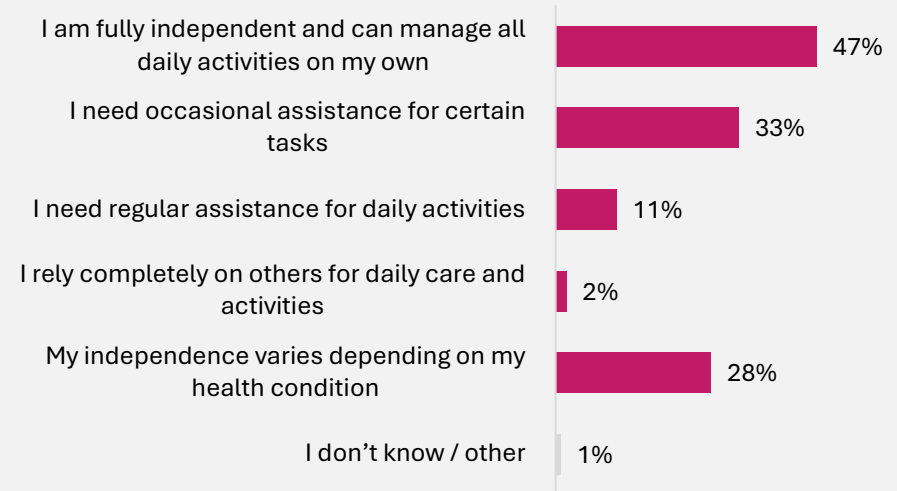
39. Which of the following supports for managing your N/IH are you satisfied with? (you can choose several questions)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Access to medication (e.g., availability, affordability)	49%	47%	17%	59%	44%	48%	45%	26%	53%	69%	61%	42%	28%	54%	41%	69%
Access to specialised healthcare (e.g., sleep clinics, specialists)	40%	35%	28%	43%	39%	45%	23%	13%	40%	65%	65%	22%	22%	54%	24%	69%
Access to reliable information	20%	12%	39%	36%	19%	14%	19%	28%	15%	24%	32%	21%	9%	12%	13%	51%
Services by the patient organisation	18%	0%	17%	28%	17%	15%	6%	18%	14%	27%	37%	20%	24%	8%	14%	20%
Economic support (e.g., financial aid, disability benefits)	13%	6%	6%	19%	13%	11%	5%	13%	23%	5%	8%	24%	11%	15%	11%	14%
Psychological support (e.g., counselling, mental health services)	9%	12%	6%	5%	3%	10%	11%	21%	15%	4%	15%	2%	15%	12%	9%	23%
I'm not satisfied with any of them	16%	29%	17%	6%	9%	14%	22%	36%	18%	4%	1%	27%	35%	13%	27%	3%
Don't know	12%	6%	28%	9%	16%	14%	17%	3%	10%	5%	12%	12%	9%	12%	9%	0%
Number of respondents: All with N/IH diagnosis	1,614	17	18	117	64	366	185	39	73	170	109	184	46	52	106	35
Satisfied with mentioned supports	72%	65%	55%	85%	75%	72%	61%	61%	72%	91%	87%	61%	56%	75%	64%	97%

Q40 Considering your N/IH: How independent are you at managing your daily activities? (you can choose several answers)

Just under half (47%) said they were fully independent, while one third (33%) needed occasional help and 11% needed regular help. A further 28% reported that their independence varied depending on their health.

IH respondents were least independent (only 38% fully independent, 37% varying by condition). By age, independence was highest among 60+ (57%) and lowest among middle-aged respondents (46%).

Men more often reported being fully independent (54% vs. 45%), while women more often said they needed occasional or regular help.



40. Considering your N/IH: How independent are you at managing your daily activities? (you can choose several answers)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
I am fully independent and can manage all daily activities on my own	47%	49%	51%	38%	47%	46%	57%	54%	45%
I need occasional assistance for certain tasks	33%	34%	32%	33%	36%	29%	31%	30%	34%
I need regular assistance for daily activities	11%	11%	7%	14%	12%	9%	5%	7%	12%
I rely completely on others for daily care and activities	2%	2%	0%	2%	2%	2%	1%	3%	1%
My independence varies depending on my health condition	28%	26%	26%	37%	26%	34%	18%	22%	30%
I don't know / other	1%	1%	1%	1%	1%	1%	0%	2%	1%
Number of respondents: All with N/IH diagnosis	1.599	1.019	208	330	952	536	111	381	1.210

Q40 Considering your N/IH: How independent are you at managing your daily activities? (you can choose several answers)

Finland (72%) and Italy (64%) had the highest shares of respondents reporting being fully independent, while Germany (35%) and Sweden (35%) reported the lowest.

Occasional assistance for certain tasks was most frequently noted in Sweden (48%) and Germany (39%), but much less in Finland (22%). Regular assistance was relatively uncommon overall, though Ireland (18%) and Spain (16%) reported higher shares than other countries.

28% of all European respondents acknowledged that their level of independence depended on their health condition.

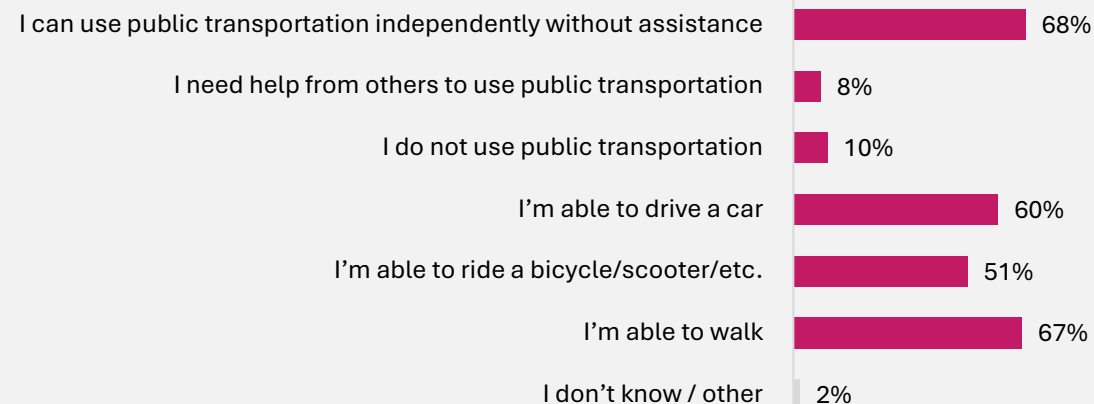
40. Considering your N/IH: How independent are you at managing your daily activities? (you can choose several answers)	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
I am fully independent and can manage all daily activities on my own	47%	29%	59%	52%	72%	43%	35%	15%	44%	64%	50%	58%	39%	39%	35%	77%
I need occasional assistance for certain tasks	33%	59%	35%	26%	22%	35%	39%	33%	38%	25%	34%	27%	45%	35%	48%	14%
I need regular assistance for daily activities	11%	18%	6%	13%	9%	9%	15%	13%	18%	4%	15%	4%	7%	16%	15%	6%
I rely completely on others for daily care and activities	2%	0%	0%	2%	3%	1%	3%	8%	0%	0%	0%	4%	0%	4%	2%	0%
My independence varies depending on my health condition	28%	35%	18%	17%	11%	36%	35%	41%	27%	20%	17%	28%	25%	41%	31%	11%
I don't know / other	1%	0%	6%	3%	0%	1%	1%	0%	0%	1%	4%	1%	2%	0%	2%	3%
Number of respondents: All with N/IH diagnosis	1.599	17	17	117	64	364	182	39	71	169	108	184	44	51	106	35

Q41 Considering your N/IH: How independent are you in getting from location a to b? (you can choose several answers)

Most respondents (68%) could use public transport independently, and 67% said they were able to walk. 60% could drive a car, and half (51%) could ride a bike, scooter or similar. About 8% needed help with transport, and 10% did not use public transport at all.

NT2 respondents reported slightly higher independence (71% public transport, 66% car use) than NT1 (69% public transport, 56% car use).

By age, car use was highest among 40–59 (69%), while bike/scooter use declined with age (56% in 18–39 vs. 43% in 60+). Women were more likely able to drive cars (61% vs. 57%) and able to walk independently (68% vs. 64%), while men were more often able to cycle (53% vs. 50%).



41. Considering your N/IH: How independent are you in getting from location a to b? (you can choose several answers)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
I can use public transportation independently without assistance	68%	69%	71%	65%	73%	61%	65%	71%	67%
I need help from others to use public transportation	8%	9%	6%	4%	8%	8%	8%	7%	8%
I do not use public transportation	10%	10%	4%	14%	9%	12%	7%	10%	10%
I'm able to drive a car	60%	56%	66%	66%	54%	69%	64%	57%	61%
I'm able to ride a bicycle/scooter/etc.	51%	53%	50%	44%	56%	44%	43%	53%	50%
I'm able to walk	67%	70%	66%	60%	70%	62%	74%	64%	68%
I don't know / other	2%	2%	1%	3%	2%	3%	1%	2%	2%
Number of respondents: All with N/IH diagnosis	1.596	1.017	208	329	951	535	110	379	1.209

Q41 Considering your N/IH: How independent are you in getting from location a to b? (you can choose several answers)

The ability to use public transportation independently was especially high in Finland (77%) and Denmark (75%). Being able to walk was also common, with the highest shares in the Netherlands (79%) and Sweden (78%).

Being able to drive a car was most frequently reported in Norway (74%) and the Netherlands (69%) – with fewest in Spain (47%).

Needing help to use public transport was relatively uncommon, but more frequent in Germany (16%).

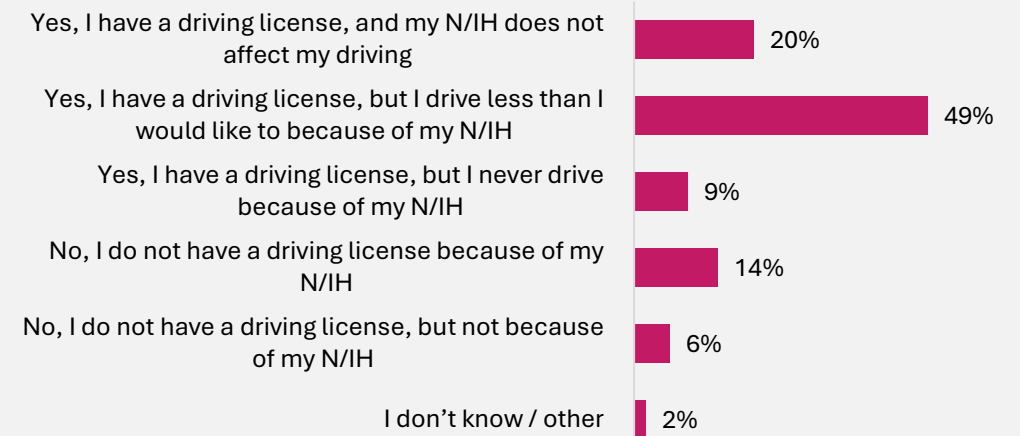
41. Considering your N/IH: How independent are you in getting from location a to b? (you can choose several answers)	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
I can use public transportation independently without assistance	68%	71%	71%	75%	77%	70%	68%	46%	55%	67%	70%	64%	77%	65%	69%	97%
I need help from others to use public transportation	8%	24%	12%	2%	5%	5%	16%	18%	14%	5%	6%	5%	5%	14%	7%	6%
I do not use public transportation	10%	0%	6%	5%	8%	12%	13%	15%	6%	6%	15%	9%	7%	8%	17%	0%
I'm able to drive a car	60%	53%	35%	64%	67%	60%	52%	41%	54%	66%	69%	74%	36%	47%	55%	60%
I'm able to ride a bicycle/scooter/etc.	51%	65%	59%	56%	53%	48%	54%	13%	27%	48%	77%	49%	36%	35%	66%	71%
I'm able to walk	67%	76%	65%	68%	66%	70%	73%	51%	52%	64%	79%	58%	59%	71%	78%	77%
I don't know / other	2%	0%	6%	3%	2%	2%	2%	8%	0%	3%	2%	1%	5%	6%	4%	0%
Number of respondents: All with N/IH diagnosis	1.596	17	17	117	64	362	182	39	71	169	108	183	44	51	106	35

Q42 Do you have a driving license, and do you currently drive? (choose 1 answer)

In total, 72% said Narcolepsy or IH limited or prevented their driving. Almost half (49%) had a driving license but drove less than they would like due to their condition, while 20% said their driving was unaffected. 14% did not have a license because of their condition, and 9% had one but never drove.

By diagnosis, NT1 respondents were most affected (77%), while IH somewhat less (65%).

By age, restrictions were most frequent among older respondents (77% of 60+). Women were more affected than men (73% vs. 66%).



42. Do you have a driving license, and do you currently drive? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Yes, I have a driving license, and my N/IH does not affect my driving	20%	15%	25%	29%	18%	23%	20%	24%	19%
Yes, I have a driving license, but I drive less than I would like to because of my N/IH	49%	50%	50%	51%	45%	57%	49%	41%	52%
Yes, I have a driving license, but I never drive because of my N/IH	9%	9%	9%	8%	7%	10%	15%	9%	8%
No, I do not have a driving license because of my N/IH	14%	18%	10%	6%	19%	7%	13%	16%	13%
No, I do not have a driving license, but not because of my N/IH	6%	7%	5%	4%	9%	2%	2%	7%	6%
I don't know / other	2%	2%	1%	2%	2%	1%	2%	1%	2%
Number of respondents: All with N/IH diagnosis	1.595	1.016	208	329	951	534	110	380	1.207
N/IH affects or prevents driving license	72%	77%	69%	65%	71%	74%	77%	66%	73%

Q42 Do you have a driving license, and do you currently drive? (choose 1 answer)

Across most countries the majority reported having a driving license but driving less than they would like due to their N/IH, with the highest shares in France (57%) and Germany (53%).

A smaller proportion stated that they have a license but never drive because of their N/IH, most notably in Germany (19%). Looking at the overall impact, most respondents in Spain (86%) and Germany (83%) reporting that N/IH affects or prevents their ability to drive.

42. Do you have a driving license, and do you currently drive? (choose 1 answer)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Yes, I have a driving license, and my N/IH does not affect my driving	20%	0%	12%	28%	25%	13%	13%	15%	21%	25%	26%	36%	5%	10%	19%	14%
Yes, I have a driving license, but I drive less than I would like to because of my N/IH	49%	76%	18%	44%	52%	57%	53%	41%	39%	49%	44%	49%	45%	47%	46%	54%
Yes, I have a driving license, but I never drive because of my N/IH	9%	0%	24%	8%	8%	11%	19%	15%	3%	5%	6%	3%	5%	14%	6%	3%
No, I do not have a driving license because of my N/IH	14%	12%	29%	10%	13%	10%	11%	18%	25%	10%	11%	9%	41%	25%	22%	26%
No, I do not have a driving license, but not because of my N/IH	6%	12%	18%	9%	3%	7%	3%	10%	8%	9%	8%	2%	2%	2%	8%	0%
I don't know / other	2%	0%	0%	1%	0%	2%	2%	0%	3%	2%	5%	1%	2%	2%	0%	3%
Number of respondents: All with N/IH diagnosis	1.595	17	17	117	64	362	182	39	71	168	108	183	44	51	106	35
N/IH affects or prevents driving license	72%	88%	71%	62%	73%	78%	83%	74%	67%	64%	61%	61%	91%	86%	74%	83%

Q43 Now you have the diagnosis, where do you get information regarding your N/IH? (you can choose several answers)

Half (51%) got N/IH information from a specialist, 47% from a patient organisation, 42% from websites, and 42% from social media. A notable 38% used online patient communities, and 35% relied on research papers. Only small shares turned to traditional media (10%), books / prints (10%) or family/friends (6%).

By diagnosis, NT1 respondents were more likely to get their information from specialists (54%), while IH respondents relied less on specialists (43%). Younger respondents (18–39) leaned heavily on social media (46%) and websites (46%), while 60+ relied more on patient organisations (66%).



43. Now you have the diagnosis, where do you get information regarding your N/IH? (you can choose several answers)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Specialist in N/IH	51%	54%	51%	43%	55%	47%	43%	54%	50%
A patient organisation	47%	51%	42%	38%	43%	50%	66%	51%	46%
General websites (Google, Wikipedia, medical sites, etc.)	42%	42%	41%	42%	46%	38%	28%	37%	44%
Social media groups (Facebook, Reddit, Discord, etc.)	42%	42%	42%	44%	46%	41%	19%	34%	45%
Online patient communities or forums (e.g., dedicated websites for N/IH patients)	38%	39%	38%	34%	39%	36%	33%	35%	39%
Scientific research papers or medical journals	35%	36%	31%	34%	37%	31%	31%	31%	36%
TV, radio, podcasts or YouTube	10%	11%	11%	7%	13%	7%	7%	9%	10%
Books or printed materials	10%	10%	11%	10%	10%	10%	12%	8%	11%
Friends or family	6%	7%	3%	5%	9%	2%	3%	9%	5%
General Practitioner	6%	5%	8%	5%	6%	4%	9%	9%	5%
Other	2%	2%	3%	2%	2%	3%	1%	2%	2%
I don't get information regarding my N/IH	6%	5%	4%	11%	6%	7%	4%	5%	6%
Number of respondents: All with N/IH diagnosis	1.588	1.011	208	328	946	533	109	379	1.201

Q43 Now you have the diagnosis, where do you get information regarding your N/IH? (you can choose several answers)

Specialists in N/IH were the most frequently mentioned in several countries, with particularly high shares in the Netherlands (69%) and Italy (61%).

Participants from the Netherlands (82%) and Denmark (65%) indicated that patient organisations were an important source of information, while this was a less reported source of information in Germany (28%). Use of general websites (e.g., Google, Wikipedia, medical sites) as a source of narcolepsy information was especially common in Finland (56%) and Ireland (52%), whereas only 22% in Italy used them. Social media groups were highly used in Finland (61%) and Sweden (55%), compared to just 18% in Spain.

The least used sources of information were friends or family, books or printed materials, and TV, radio, podcasts, or YouTube.

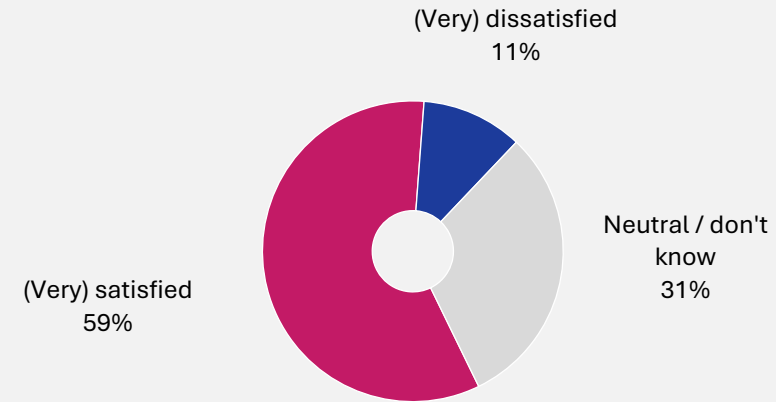
43. Now you have the diagnosis, where do you get information regarding your N/IH? (you can choose several answers)	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Specialist in N/IH	51%	53%	47%	56%	45%	52%	53%	37%	58%	61%	69%	37%	52%	39%	38%	69%
A patient organisation	47%	29%	24%	65%	33%	34%	28%	50%	31%	60%	82%	59%	68%	45%	41%	69%
General websites (Google, Wikipedia, medical sites, etc.)	42%	59%	35%	44%	56%	40%	42%	47%	52%	22%	43%	49%	57%	43%	43%	34%
Social media groups (Facebook, Reddit, Discord, etc.)	42%	47%	41%	38%	61%	32%	48%	68%	45%	40%	43%	47%	41%	18%	55%	20%
Online patient communities or forums (e.g., dedicated websites for N/IH patients)	38%	35%	35%	43%	42%	30%	41%	71%	44%	44%	25%	41%	48%	31%	37%	26%
Scientific research papers or medical journals	35%	65%	6%	46%	52%	37%	27%	13%	35%	23%	34%	33%	34%	39%	35%	40%
TV, radio, podcasts or YouTube	10%	6%	12%	4%	13%	13%	12%	13%	11%	3%	10%	7%	9%	12%	18%	11%
Books or printed materials	10%	6%	6%	13%	3%	10%	14%	13%	15%	5%	12%	13%	2%	12%	6%	6%
Friends or family	6%	0%	12%	7%	8%	5%	8%	3%	1%	2%	2%	6%	0%	10%	22%	3%
General Practitioner	6%	24%	0%	6%	5%	8%	3%	3%	11%	3%	3%	7%	2%	2%	5%	6%
Other	2%	0%	0%	1%	0%	3%	4%	3%	1%	1%	3%	2%	2%	4%	2%	0%
I don't get information regarding my N/IH	6%	6%	18%	2%	5%	13%	4%	3%	7%	2%	0%	5%	2%	12%	4%	3%
Number of respondents: All with N/IH diagnosis	1.588	17	17	117	64	361	180	38	71	167	108	182	44	51	105	35

Q44 How satisfied are you in general with this information about N/IH? (choose 1 answer)

Overall, 59% were (very) satisfied with the N/IH information available, while 31% were neutral and 11% dissatisfied.

NT1 and 2 respondents were more positive (63% and 57%), while IH were less satisfied (45%).

Satisfaction increased with age: 56% in 18–39, 60% in 40–59 and 74% in 60+. Men were more likely to be satisfied than women (63% vs. 57%).



44. How satisfied are you in general with this information about N/IH? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Very satisfied	14%	13%	18%	13%	13%	14%	21%	17%	13%
Satisfied	45%	50%	39%	32%	43%	46%	53%	46%	44%
Neutral	30%	28%	32%	33%	31%	30%	19%	26%	31%
Dissatisfied	9%	6%	9%	16%	10%	7%	5%	8%	9%
Very dissatisfied	2%	1%	2%	5%	2%	2%	2%	1%	2%
I don't know	1%	2%	0%	1%	2%	1%	0%	3%	1%
Number of respondents: N/IH diagnosed getting information	1,494	965	200	293	892	497	105	360	1,128
(Very) satisfied	59%	63%	57%	45%	56%	60%	74%	63%	57%
(Very) dissatisfied	11%	7%	11%	21%	12%	9%	7%	9%	11%
Neutral / don't know	31%	30%	32%	34%	33%	31%	19%	29%	32%

Q44 How satisfied are you in general with this information about N/IH? (choose 1 answer)

The highest shares of respondents who were (very) satisfied were found in Italy (82%), and the Netherlands (75%).

Dissatisfaction was particularly notable in Norway (19%) and France (18%), while most other countries reported single-digit shares in this category.

Overall, a majority reported being satisfied, but the degree of satisfaction varied.

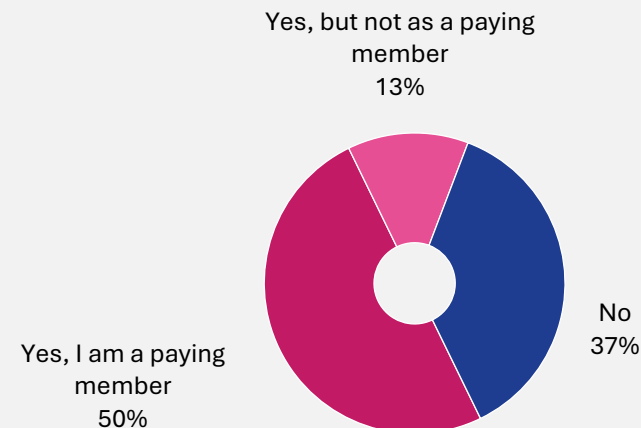
44. How satisfied are you in general with this information about N/IH? (choose 1 answer)	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Very satisfied	14%	13%	29%	19%	5%	13%	10%	8%	11%	31%	11%	10%	12%	16%	6%	24%
Satisfied	45%	25%	36%	48%	56%	37%	44%	62%	33%	51%	64%	33%	51%	47%	47%	68%
Neutral	30%	50%	29%	25%	36%	31%	36%	24%	42%	13%	19%	35%	33%	31%	37%	6%
Dissatisfied	9%	13%	7%	4%	3%	15%	8%	5%	11%	4%	5%	15%	5%	2%	5%	3%
Very dissatisfied	2%	0%	0%	2%	0%	3%	2%	0%	0%	0%	1%	4%	0%	2%	1%	0%
I don't know	1%	0%	0%	2%	0%	2%	0%	0%	3%	1%	0%	2%	0%	2%	5%	0%
Number of respondents: N/IH diagnosed getting information	1.494	16	14	115	61	315	173	37	66	163	108	172	43	45	101	34
(Very) satisfied	59%	38%	65%	67%	61%	50%	54%	70%	44%	82%	75%	43%	63%	63%	53%	92%
(Very) dissatisfied	11%	13%	7%	6%	3%	18%	10%	5%	11%	4%	6%	19%	5%	4%	6%	3%
Neutral / don't know	31%	50%	29%	27%	36%	33%	36%	24%	45%	14%	19%	37%	33%	33%	42%	6%

Q45 Are you a member of a national N/IH patient organisation? (choose 1 answer)

In total 63% reported being a member of a national N/IH patient organisation.

By diagnosis, 67% of NT1 respondents reported being a member while 62% of NT2 and 49% of IH reported being members.

By age, membership was highest among older respondents (88%). Men were more likely than women to be members (72% vs. 60%).



45. Are you a member of a national N/IH patient organisation? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Yes, I am a paying member	50%	54%	45%	40%	44%	53%	80%	60%	47%
Yes, but not as a paying member	13%	13%	17%	9%	13%	13%	8%	12%	13%
No	37%	33%	38%	51%	42%	34%	12%	28%	40%
Number of respondents: All with N/IH diagnosis	1.588	1.011	208	328	946	533	109	379	1.201

Q45 Are you a member of a national N/IH patient organisation? (choose 1 answer)

Italy had the highest membership rate (90%). Norway, the Netherlands, Spain, Denmark and Sweden reported membership rates between 81% and 85%.

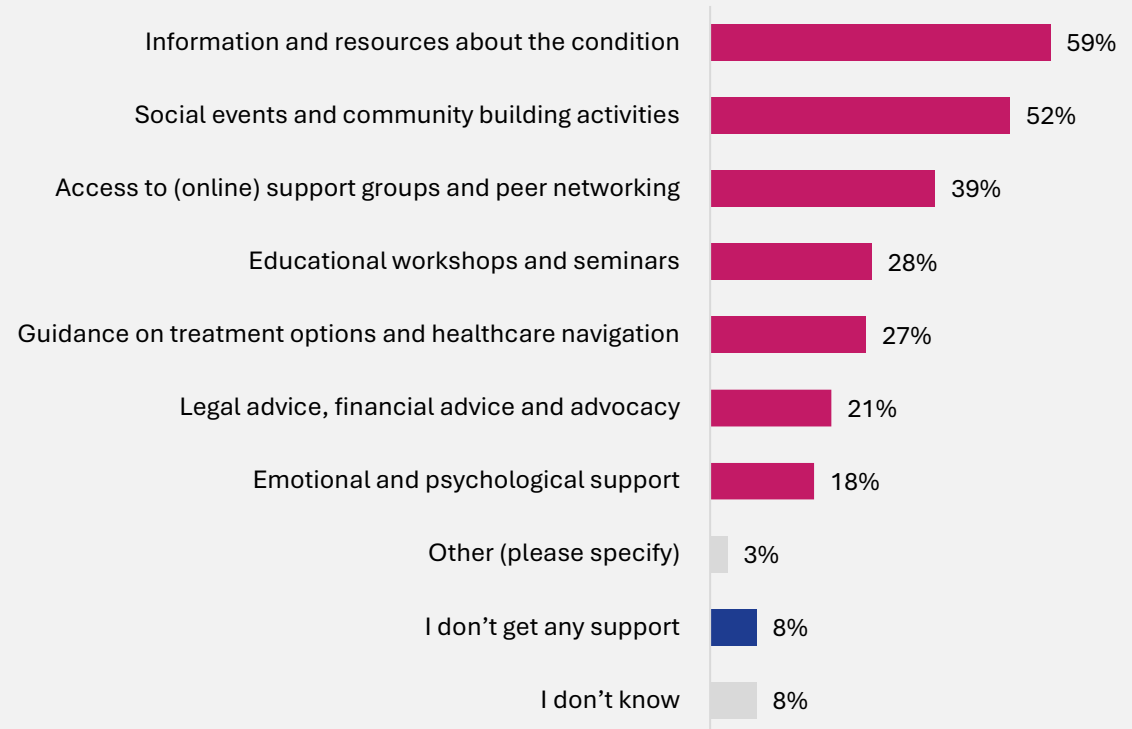
Germany reported lowest membership rates (28%) followed by France (40%).

45. Are you a member of a national N/IH patient organisation? (choose 1 answer)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Yes, I am a paying member	50%	24%	0%	76%	39%	24%	11%	47%	1%	81%	80%	81%	52%	75%	79%	80%
Yes, but not as a paying member	13%	6%	41%	6%	16%	16%	17%	32%	56%	9%	4%	4%	5%	8%	2%	3%
No	37%	71%	59%	18%	45%	60%	72%	21%	42%	10%	17%	15%	43%	18%	19%	17%
Number of respondents: All with N/IH diagnosis	1.588	17	17	117	64	361	180	38	71	167	108	182	44	51	105	35

Q46 What types of support do you get from your N/IH patient organisation (you can choose several answers)

Overall, 84% reported feeling supported by their N/IH patient organisation.

The most common type of support was information and resources about the condition (59%), followed by social events and community building activities (52%).



Q46 What types of support do you get from your N/IH patient organisation (you can choose several answers)

By diagnosis, support was reported most often among those with NT1 (84%), while slightly fewer with NT2 (81%) and IH (80%) felt supported. Most respondents aged 60+ years (88%) reported support, compared to those aged 18–39 years (84%) and 40–59 years (81%). By gender, no notable differences were observed

Across ‘Other (please specify)’ answers, the most cited support from N/IH patient organisations is peer and emotional connection, e.g. support groups (online/offline), sharing experiences, and mutual empathy — especially valuable for newly diagnosed.

Second most common is information sharing, such as research updates, study participation, and annual seminars, though some find IH-specific information lacking. Less frequent mentions include legal help, general neurological patient activities, and motivational follow-up.

Several respondents state they do not currently use the support due to low personal need, recent membership, or practical constraints, but still value the organisation’s work for others.

46. What types of support do you get from your N/IH patient organisation (you can choose several answers)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Information and resources about the condition	59%	59%	59%	57%	60%	58%	59%	63%	58%
Social events and community building activities	52%	56%	45%	40%	56%	48%	44%	53%	52%
Access to (online) support groups and peer networking	39%	41%	36%	29%	43%	34%	32%	41%	38%
Educational workshops and seminars	28%	28%	23%	29%	28%	28%	27%	28%	28%
Guidance on treatment options and healthcare navigation	27%	28%	31%	22%	26%	30%	25%	31%	26%
Legal advice, financial advice and advocacy	21%	23%	14%	19%	25%	18%	12%	25%	20%
Emotional and psychological support	18%	19%	19%	15%	19%	19%	11%	16%	19%
Other (please specify)	3%	3%	2%	4%	3%	4%	3%	3%	3%
I don't get any support	8%	8%	10%	10%	8%	11%	5%	7%	9%
I don't know	8%	8%	9%	10%	8%	8%	7%	7%	8%
Number of respondents: N/IH diagnosed and member	984	673	128	158	540	349	95	270	710
Members feeling supported from their N/IH patient organisation	84%	84%	81%	80%	84%	81%	88%	86%	83%

Q46 What types of support do you get from your N/IH patient organisation (you can choose several answers)

Italy (96%) and Germany (88%) stood out with the highest shares of respondents feeling supported. By contrast, France (68%) reported the lowest levels.

Looking at specific types of support, information and resources about the condition was especially high in Italy (80%). Social events and community-building activities were most common in Italy (72%) and Denmark (66%), whereas France reported a much lower share (30%). Access to (online) support groups and peer networking was strongest in Germany (62%) and Italy (62%), but far less frequent in France (19%).

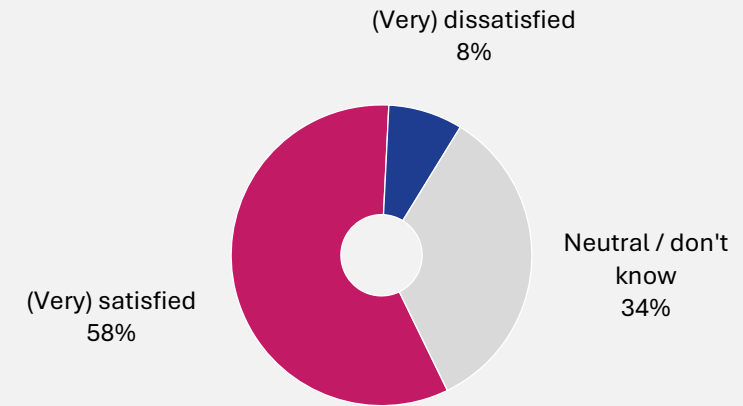
In contrast, emotional and psychological support appeared relatively limited overall, with notable peaks in Italy (33%) and Germany (32%), while being much lower in other countries.

46. What types of support do you get from your N/IH patient organisation (you can choose several answers)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Information and resources about the condition	59%	40%	43%	66%	53%	46%	48%	40%	56%	80%	66%	58%	68%	45%	47%	79%
Social events and community building activities	52%	60%	71%	66%	67%	30%	42%	13%	59%	72%	60%	44%	64%	29%	51%	76%
Access to (online) support groups and peer networking	39%	60%	14%	41%	42%	19%	62%	23%	41%	62%	38%	27%	68%	24%	33%	59%
Educational workshops and seminars	28%	20%	0%	27%	14%	12%	24%	0%	7%	35%	38%	42%	44%	19%	34%	31%
Guidance on treatment options and healthcare navigation	27%	0%	43%	28%	8%	15%	32%	43%	27%	51%	3%	27%	28%	21%	29%	45%
Legal advice, financial advice and advocacy	21%	0%	0%	17%	0%	8%	14%	17%	7%	31%	4%	29%	8%	24%	69%	10%
Emotional and psychological support	18%	0%	29%	15%	11%	12%	32%	47%	22%	33%	8%	8%	44%	14%	11%	21%
Other (please specify)	3%	20%	14%	6%	3%	7%	2%	0%	0%	1%	6%	0%	0%	2%	2%	3%
I don't get any support	8%	0%	29%	6%	6%	21%	10%	3%	15%	1%	7%	7%	16%	17%	4%	0%
I don't know	8%	0%	0%	8%	14%	11%	2%	7%	5%	3%	8%	14%	0%	5%	12%	0%
Number of respondents: N/IH diagnosed and member	984	5	7	95	36	140	50	30	41	147	90	153	25	42	83	29
Members feeling supported from their N/IH patient organisation	84%	100%	71%	86%	80%	68%	88%	90%	80%	96%	85%	79%	84%	78%	84%	100%

Q47 How satisfied are you with the offerings and support from your N/IH patient organisation? (choose 1 answer)

Overall, 58% reported being (very) satisfied with the offerings and support from their N/IH patient organisation, while 34% were neutral or did not know, and 8% reported being (very) dissatisfied.

Most respondents with NT2 were satisfied (62%), followed by NT1 (59%) and IH (46%). By age, satisfaction was highest among respondents aged 60+ years (71%), compared to those aged 40–59 years (54%) and 18–39 years (58%). By gender, men showed more satisfaction (63% vs. 56%).



47. How satisfied are you with the offerings and support from your N/IH patient organisation? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Very satisfied	21%	21%	27%	15%	22%	17%	29%	25%	19%
Satisfied	37%	38%	35%	31%	36%	37%	42%	38%	37%
Neutral	26%	26%	21%	33%	26%	29%	22%	24%	28%
Dissatisfied	5%	6%	4%	8%	6%	6%	1%	5%	6%
Very dissatisfied	3%	2%	4%	5%	2%	4%	1%	2%	3%
Don't know	8%	7%	9%	8%	8%	8%	4%	7%	8%
Number of respondents: N/IH diagnosed and member	982	671	128	158	538	349	95	269	709
(Very) satisfied	58%	59%	62%	46%	58%	54%	71%	63%	56%
(Very) dissatisfied	8%	8%	8%	13%	8%	10%	2%	7%	9%
Neutral / don't know	34%	33%	30%	41%	34%	37%	26%	31%	36%

Q47 How satisfied are you with the offerings and support from your N/IH patient organisation? (choose 1 answer)

Most respondents in Italy (85%) and Denmark (66%) were (very) satisfied – fewest in France (37%) and Norway (46%).

For dissatisfaction, France (16%) stood out with the highest shares, while Italy (1%) and Denmark (3%) were in the lower end.

47. How satisfied are you with the offerings and support from your N/IH patient organisation? (choose 1 answer)	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Very satisfied	21%	0%	43%	25%	6%	12%	20%	17%	17%	38%	19%	13%	24%	17%	23%	38%
Satisfied	37%	60%	29%	41%	34%	25%	30%	43%	27%	47%	43%	33%	36%	33%	41%	45%
Neutral	26%	20%	14%	22%	43%	36%	28%	20%	29%	11%	26%	36%	28%	29%	19%	17%
Dissatisfied	5%	20%	0%	3%	9%	10%	8%	7%	17%	1%	4%	5%	4%	12%	1%	0%
Very dissatisfied	3%	0%	0%	0%	0%	6%	0%	7%	5%	0%	1%	3%	4%	7%	5%	0%
Don't know	8%	0%	14%	8%	9%	11%	14%	7%	5%	3%	7%	10%	4%	2%	11%	0%
Number of respondents: N/IH diagnosed and member	982	5	7	95	35	140	50	30	41	147	89	153	25	42	83	29
(Very) satisfied	58%	60%	72%	66%	40%	37%	50%	60%	44%	85%	62%	46%	60%	50%	64%	83%
(Very) dissatisfied	8%	20%	0%	3%	9%	16%	8%	14%	22%	1%	5%	8%	8%	19%	6%	0%
Neutral / don't know	34%	20%	28%	30%	52%	47%	42%	27%	34%	14%	33%	46%	32%	31%	30%	17%

Q48 Do you miss any of the following offerings / support from your N/IH patient organisation? (you can choose several answers)

Overall, 56% reported missing offerings or supports from their N/IH patient organisation, while 29% stated they did not miss any and 15% responded 'Don't know'.

The most frequently missed support types were legal/financial advice and advocacy (28%), emotional and psychological support (25%), and guidance on treatment options and healthcare navigation (25%).

Around one in five highlighted missing information and resources (18%) or educational workshops and seminars (17%).

Smaller but notable shares pointed to support groups and networking (14%) and social events and community building (14%).



Q48 Do you miss any of the following offerings / support from your N/IH patient organisation? (you can choose several answers)

Most respondents with IH (69%) missed offerings, compared to NT1 (52%) and NT2 (55%). By age, respondents aged 18–39 years (57%) and 40–59 years (55%) more often reported missing offerings compared to those aged 60+ years (39%). By gender, females (58%) were more likely than males (47%) to report missing offerings or supports.

In the ‘Other: Please specify’ free-texts several respondents ask for more accessible and targeted support, including online participation in events, age-specific groups, and more frequent social gatherings.

Many highlight the need for greater focus on IH rather than primarily narcolepsy, as well as increased awareness among healthcare professionals.

Common requests include more information on research, treatments (including dietary approaches), and practical guidance such as energy management, help with disability applications, and finding neurologists.

Some call for psychological support, mentoring for younger patients, and improved representation. Criticism is directed at inactive associations or those perceived to focus only on “living with” the condition rather than working toward a cure.

48. Do you miss any of the following offerings / support from your N/IH patient organisation? (you can choose several answers)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Legal advice, financial advice and advocacy	28%	27%	28%	35%	30%	29%	9%	23%	30%
Emotional and psychological support	25%	24%	24%	30%	29%	22%	14%	17%	28%
Guidance on treatment options and healthcare navigation	25%	21%	26%	41%	25%	26%	19%	19%	27%
Information and resources about the condition	18%	15%	17%	30%	17%	22%	7%	12%	20%
Educational workshops and seminars	17%	16%	16%	24%	18%	19%	8%	10%	20%
Access to (online) support groups and peer networking	14%	12%	19%	23%	14%	15%	11%	6%	17%
Social events and community building activities	14%	14%	14%	17%	16%	13%	8%	8%	16%
Other (please specify)	4%	3%	2%	8%	3%	5%	4%	3%	4%
I don't miss offerings or support from my patient organisation	29%	32%	30%	17%	26%	29%	53%	34%	28%
Don't know	15%	16%	15%	14%	17%	16%	8%	19%	14%
Number of respondents: N/IH diagnosed and member	982	671	128	158	538	349	95	269	709
Members missing offerings / supports from their N/IH patient organisation	56%	52%	55%	69%	57%	55%	39%	47%	58%

Q48 Do you miss any of the following offerings / support from your N/IH patient organisation? (you can choose several answers)

Among countries France (70%), Germany (62%) and Norway (62%) reported the highest shares missing offerings, while Italy (38%) and the Netherlands (38%) reported the lowest.

Legal advice, financial advice and advocacy was especially high in Germany (44%) and France (41%). Emotional and psychological support stood out in France (35%) and Germany (30%). Meanwhile, guidance on treatment options and healthcare navigation was most often highlighted in France (39%) and Norway (37%).

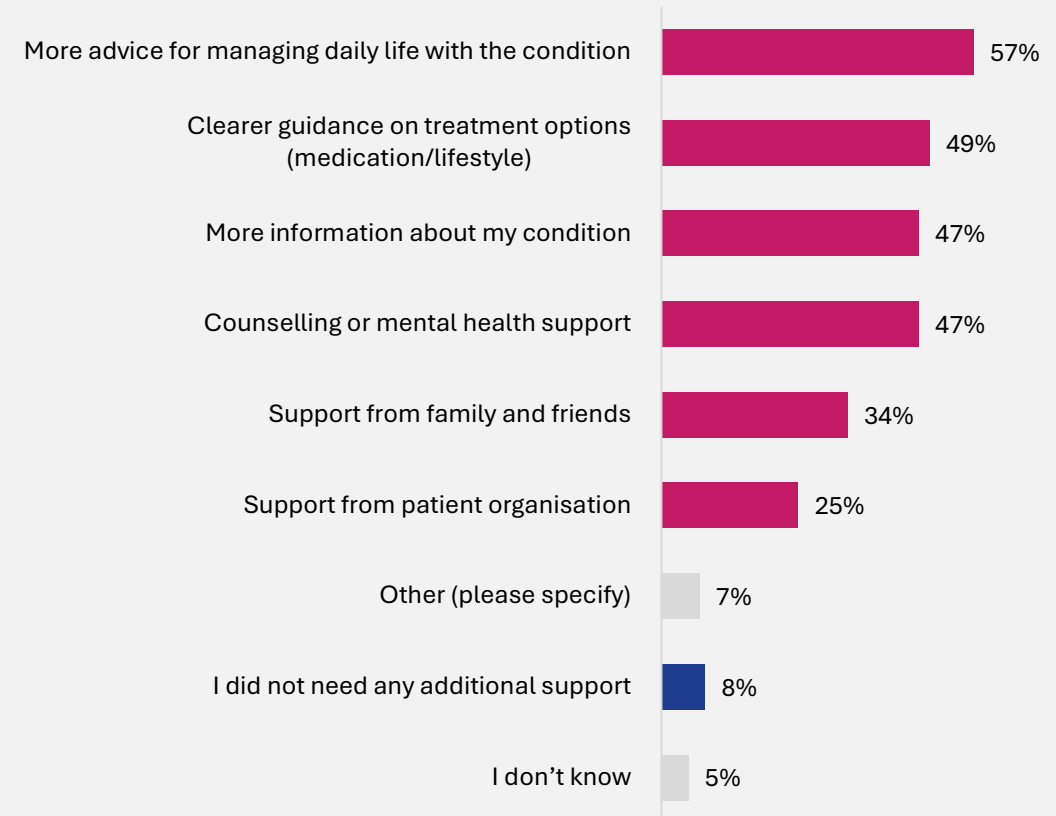
48. Do you miss any of the following offerings / support from your N/IH patient organisation? (you can choose several answers)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Legal advice, financial advice and advocacy	28%	60%	14%	19%	29%	41%	44%	43%	41%	9%	25%	31%	60%	38%	17%	17%
Emotional and psychological support	25%	0%	0%	19%	29%	35%	30%	43%	27%	28%	11%	26%	20%	36%	22%	3%
Guidance on treatment options and healthcare navigation	25%	20%	29%	18%	31%	39%	22%	33%	22%	12%	15%	37%	28%	31%	20%	10%
Information and resources about the condition	18%	40%	0%	13%	23%	30%	14%	47%	24%	6%	8%	20%	20%	29%	14%	7%
Educational workshops and seminars	17%	20%	14%	7%	17%	28%	20%	27%	34%	7%	7%	21%	20%	33%	16%	3%
Access to (online) support groups and peer networking	14%	0%	14%	8%	6%	27%	8%	23%	29%	7%	6%	18%	12%	24%	13%	3%
Social events and community building activities	14%	0%	0%	8%	17%	21%	16%	40%	34%	5%	2%	15%	12%	21%	16%	3%
Other (please specify)	4%	20%	0%	4%	3%	5%	2%	0%	0%	1%	4%	5%	4%	5%	5%	3%
I don't miss offerings or support from my patient organisation	29%	20%	43%	41%	23%	16%	18%	20%	20%	42%	43%	21%	20%	29%	27%	66%
Don't know	15%	0%	14%	15%	14%	14%	20%	0%	10%	20%	19%	17%	4%	7%	23%	7%
Number of respondents: N/IH diagnosed and member	982	5	7	95	35	140	50	30	41	147	89	153	25	42	83	29
Members missing offerings / supports from their N/IH patient organisation	56%	80%	43%	44%	63%	70%	62%	80%	70%	38%	38%	62%	76%	64%	50%	27%

Q49 Looking back on the time when you got diagnosed: What would have helped you the most in accepting the diagnosis and managing your N/IH? (you can choose several answers)

Overall, 87% reported that they were missing offerings or supports when they got their N/IH diagnosis.

The most cited need was more advice for managing daily life with the condition (57%). Nearly half of respondents pointed to receiving clearer guidance on treatment options, such as medication and lifestyle adjustments (49%), as well as more information about their condition (47%).

47% also emphasised the importance of counselling or mental health support. Around one-third (34%) would have valued more support from family and friends, while one in four (25%) mentioned support from patient organisations.



Q49 Looking back on the time when you got diagnosed: What would have helped you the most in accepting the diagnosis and managing your N/IH? (you can choose several answers)

Most respondents with IH (95%) missed offerings / support, when they got their N/IH diagnosis - compared to NT1 (84%) and NT2 (86%). By age, respondents aged 18–39 years (86%) and 40–59 years (89%) more often reported missing supports compared to those aged 60+ years (81%). By gender, women (88%) were more likely than men (80%) to report missing supports.

Free-text answers in ‘Other: Please specify’ highlight needs for better practical and legal support (e.g., disability applications, workplace adaptations, school accommodations, driving license rights, and financial aid), plus access to knowledgeable healthcare providers who listen, believe patients, and give clear, comprehensive information on diagnosis, treatment, and daily management.

Many stress the importance of peer support and meeting others with N/IH early to reduce isolation, as well as psychological support and mentoring. Respondents also want specific guidance on nutrition, energy management, medication use, and ways to explain the illness, so it’s taken seriously. A recurring frustration is having to find information and resources themselves due to low awareness among doctors, schools, and institutions, leaving patients to navigate medical, administrative, and social challenges largely alone.

49. Looking back on the time when you got diagnosed: What would have helped you the most in accepting the diagnosis and managing your N/IH? (you can choose several answers)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
More advice for managing daily life with the condition	57%	54%	56%	68%	60%	55%	46%	52%	59%
Clearer guidance on treatment options (medication/lifestyle)	49%	45%	50%	61%	50%	49%	40%	45%	50%
More information about my condition	47%	42%	45%	63%	46%	51%	36%	38%	49%
Counselling or mental health support	47%	48%	39%	49%	51%	43%	23%	37%	50%
Support from family and friends	34%	32%	38%	37%	33%	37%	26%	26%	37%
Support from patient organisation	25%	23%	25%	29%	24%	26%	20%	21%	25%
Other (please specify)	7%	7%	6%	7%	6%	7%	10%	6%	7%
I did not need any additional support	8%	9%	9%	3%	8%	6%	13%	12%	7%
I don't know	5%	7%	5%	2%	6%	5%	6%	8%	5%
Number of respondents: All with N/IH diagnosis	1.565	994	208	323	930	528	107	374	1.183

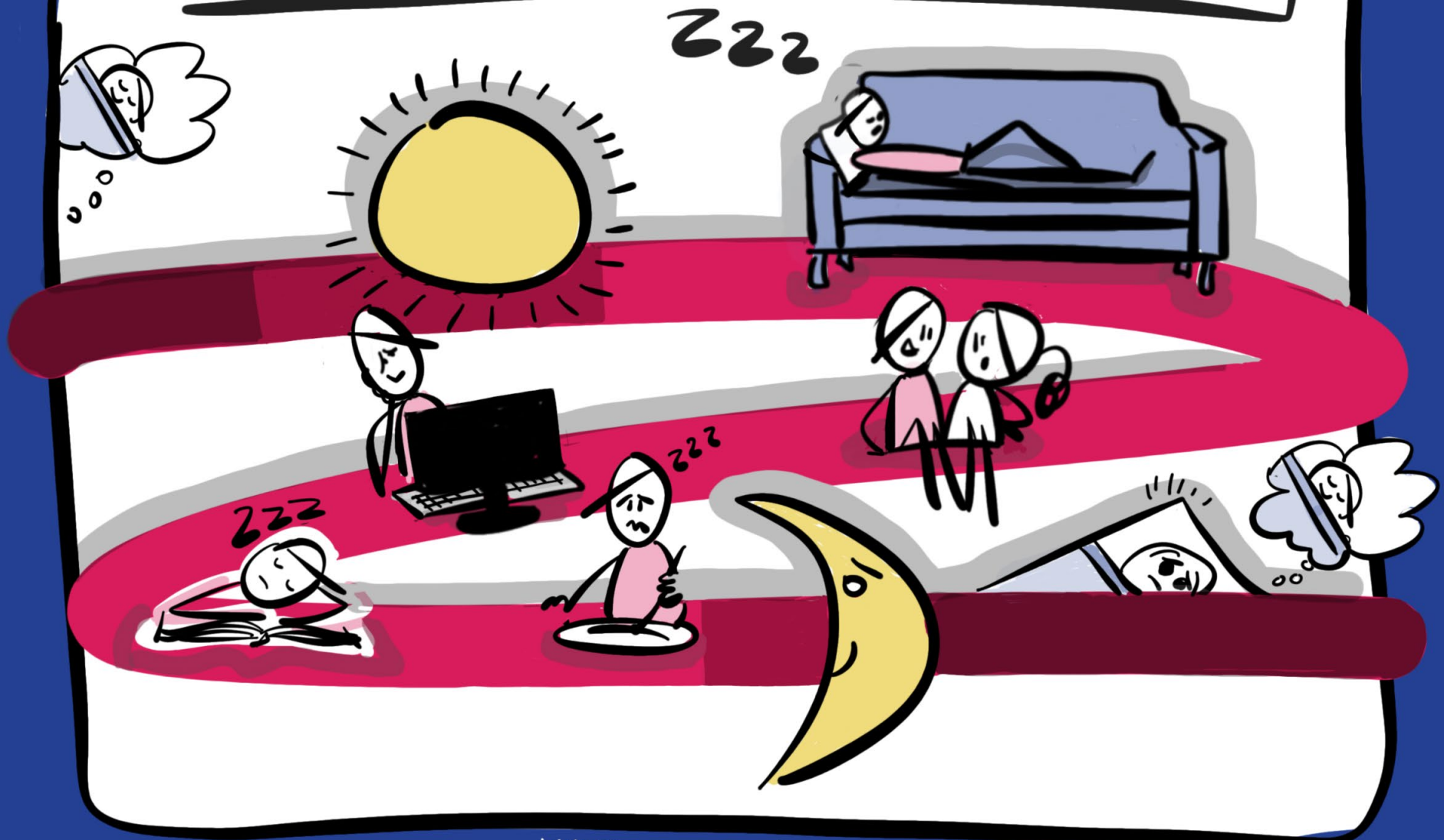
Q49 Looking back on the time when you got diagnosed: What would have helped you the most in accepting the diagnosis and managing your N/IH? (you can choose several answers)

Among the specific types of support, 'More advice for managing daily life' stood out particularly in Denmark (70%) and Sweden (65%). 'Clearer guidance on treatment options' was especially emphasised in Norway (62%) and Sweden (59%), whereas Italy (27%) and the Netherlands (39%) reported the lowest shares.

Finally, counselling or mental health support was most frequently highlighted in Denmark (58%) and Ireland (55%), compared with notably lower shares in Italy (31%).

49. Looking back on the time when you got diagnosed: What would have helped you the most in accepting the diagnosis and managing your N/IH? (you can choose several answers)	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
More advice for managing daily life with the condition	57%	59%	41%	70%	48%	61%	61%	61%	63%	39%	54%	59%	64%	47%	65%	43%
Clearer guidance on treatment options (medication/lifestyle)	49%	65%	59%	51%	47%	49%	52%	53%	56%	27%	39%	62%	52%	49%	59%	23%
More information about my condition	47%	47%	47%	57%	42%	49%	49%	58%	58%	18%	33%	63%	55%	31%	49%	34%
Counselling or mental health support	47%	35%	53%	58%	50%	52%	42%	50%	55%	31%	40%	42%	66%	53%	51%	29%
Support from family and friends	34%	18%	24%	25%	31%	39%	37%	37%	54%	36%	29%	32%	45%	37%	13%	29%
Support from patient organisation	25%	35%	29%	15%	27%	34%	25%	32%	37%	16%	13%	24%	16%	33%	13%	20%
Other (please specify)	7%	12%	6%	9%	6%	8%	8%	0%	7%	4%	4%	5%	9%	2%	9%	11%
I did not need any additional support	8%	12%	24%	9%	13%	5%	4%	5%	1%	17%	13%	8%	0%	4%	6%	20%
I don't know	5%	6%	6%	3%	5%	4%	4%	3%	7%	12%	8%	3%	5%	8%	11%	3%
Number of respondents: All with N/IH diagnosis	1.565	17	17	115	64	356	179	38	71	163	106	180	44	49	102	35

5. EVERYDAY LIFE WITH N/IH

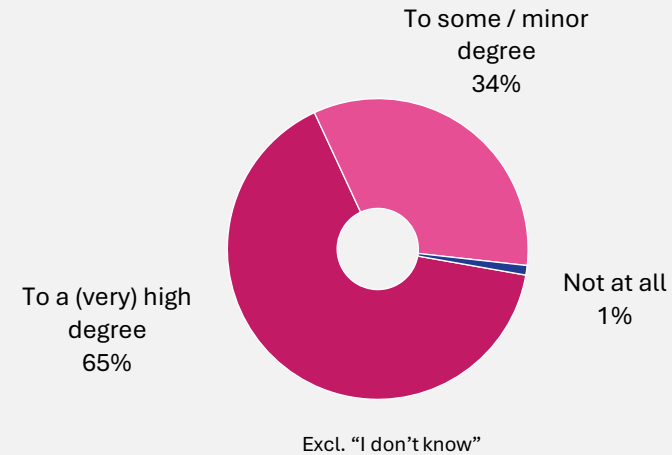


Q50 To what degree does your N/IH impact your work or education? (choose 1 answer)

Overall, 65% reported that their N/IH impacts their work or education to a (very) high degree, while 34% reported some or minor impact and only 1% reported no impact.

Most respondents with IH (77%) reported a (very) high degree of impact, compared to NT1 (63%) and NT2 (61%).

By age, respondents aged 40–59 years (68%) more often reported a (very) high degree of impact compared to those aged 18–39 years (64%) and 60+ years (65%). By gender, no notable differences were observed.



50. To what degree does your N/IH impact your work or education? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	34%	32%	31%	46%	30%	42%	36%	33%	35%
To a high degree	30%	30%	29%	31%	33%	25%	26%	27%	30%
To some degree	25%	26%	27%	19%	27%	21%	19%	26%	25%
To a minor degree	8%	10%	9%	3%	8%	8%	11%	10%	8%
Not at all	1%	1%	2%	1%	1%	2%	3%	2%	1%
I don't know	2%	2%	1%	1%	1%	2%	5%	2%	2%
Number of respondents: All with N/IH diagnosis	1.561	991	208	322	926	528	107	374	1.179
To a (very) high degree	65%	63%	61%	77%	64%	68%	65%	61%	66%
To some / minor degree	34%	36%	37%	22%	35%	30%	32%	37%	33%
Not at all	1%	1%	2%	1%	1%	2%	3%	2%	1%

(excl. I don't know)

Q50 To what degree does your N/IH impact your work or education? (choose 1 answer)

Most respondents in Ireland (74%), France (72%) and Sweden (72%) experienced an impact on work or education to a (very) high degree – fewest in Italy (37%) and the Netherlands (50%).

50. To what degree does your N/IH impact your work or education? (choose 1 answer)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
To a very high degree	34%	41%	41%	29%	25%	42%	31%	39%	39%	19%	31%	39%	50%	41%	29%	17%
To a high degree	30%	47%	12%	26%	32%	30%	33%	45%	34%	18%	17%	29%	41%	27%	42%	31%
To some degree	25%	12%	47%	25%	29%	22%	25%	13%	21%	40%	31%	22%	5%	29%	22%	26%
To a minor degree	8%	0%	0%	14%	13%	5%	8%	3%	4%	16%	16%	4%	2%	4%	6%	20%
Not at all	1%	0%	0%	1%	0%	1%	1%	0%	1%	6%	1%	2%	0%	0%	0%	6%
I don't know	2%	0%	0%	5%	2%	0%	1%	0%	0%	1%	3%	4%	2%	0%	1%	0%
Number of respondents: All with N/IH diagnosis	1,561	17	17	114	63	355	179	38	71	163	105	180	44	49	102	35
To a (very) high degree	65%	88%	53%	58%	58%	72%	65%	84%	74%	37%	50%	71%	93%	67%	72%	48%
To some / minor degree	34%	12%	47%	41%	42%	27%	34%	16%	25%	57%	49%	27%	7%	33%	28%	46%
Not at all	1%	0%	0%	1%	0%	1%	1%	0%	1%	6%	1%	2%	0%	0%	0%	6%

(excl. I don't know)

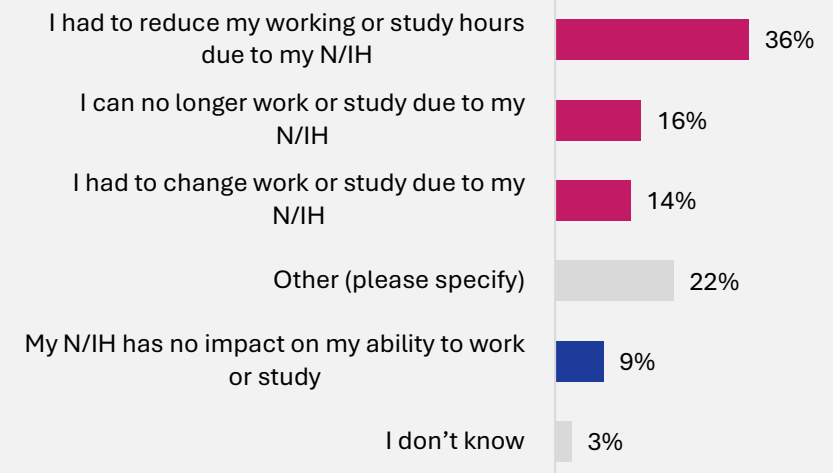
Q51 How does your N/IH impact your work or education? (choose 1 answer)

Overall, 36% reported that they had to reduce their working or study hours due to N/IH, 14% had to change work or study, and 16% could no longer work or study. 22% specified other impacts, while N/IH had no impact on work / education for 9%.

Most respondents with IH (21%) were unable to work or study - compared to NT1 (14%) and NT2 (14%).

By age, those aged 60+ reported the highest share unable to work or study (25%), while younger respondents aged 18–39 reported the lowest (10%).

By gender, for the response option 'My N/IH has no impact on my ability to work or study', men (13%) reported this more often than women (7%).



51. How does your N/IH impact your work or education? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
My N/IH has no impact on my ability to work or study	9%	9%	10%	6%	9%	8%	11%	13%	7%
I had to reduce my working or study hours due to my N/IH	36%	39%	36%	31%	41%	31%	29%	33%	38%
I had to change work or study due to my N/IH	14%	15%	13%	14%	14%	14%	10%	13%	14%
I can no longer work or study due to my N/IH	16%	14%	14%	21%	10%	24%	25%	18%	15%
Other (please specify)	22%	20%	21%	27%	23%	21%	22%	18%	23%
I don't know	3%	3%	5%	2%	4%	3%	2%	6%	2%
Number of respondents: N/IH diagnosed with impact	1.514	958	201	316	908	507	99	360	1.146

■ Q51 How does your N/IH impact your work or education? (choose 1 answer)

Free-text in “Other: Please specify” shows that N/IH impacts work and education in several recurring ways, with some patterns more common than others.

Most Common Impacts (most frequently mentioned):

- Reduced capacity to work or study — Many report having to reduce hours, change careers, or completely stop working/studying due to fatigue, unpredictable energy, and concentration problems.
- Need for flexible schedules and planned naps — A frequent theme is the need for flexible working/study hours, avoiding night/evening shifts, and scheduling regular naps to maintain performance.
- Cognitive challenges — Memory lapses, difficulty focusing, and slower work pace were widely reported, often leading to missed material, delayed studies, and repeated classes/exams.

Other Notable Themes:

- Lack of support and understanding — Reports of discrimination, lack of accommodations, or minimal awareness from employers, colleagues, and educational staff.
- Impact on personal and social life — Many said work/study demands leave little or no energy for social activities or family, leading to isolation.
- Self-management and coping strategies — Individuals adapt by choosing jobs/studies with more variation, using medication effectively, and structuring tasks to align with their energy peaks.

Overall, the most widespread issues are reduced working/study capacity and the need for flexible hours and nap breaks, followed by cognitive difficulties. Social impact and lack of institutional support are also significant but mentioned slightly less often.

Q51 How does your N/IH impact your work or education? (choose 1 answer)

Most respondents in Italy (48%) and Sweden (47%) reduced their working or study hours due to N/IH – fewest in France (30%), Ireland (34%) and the Netherlands (34%).

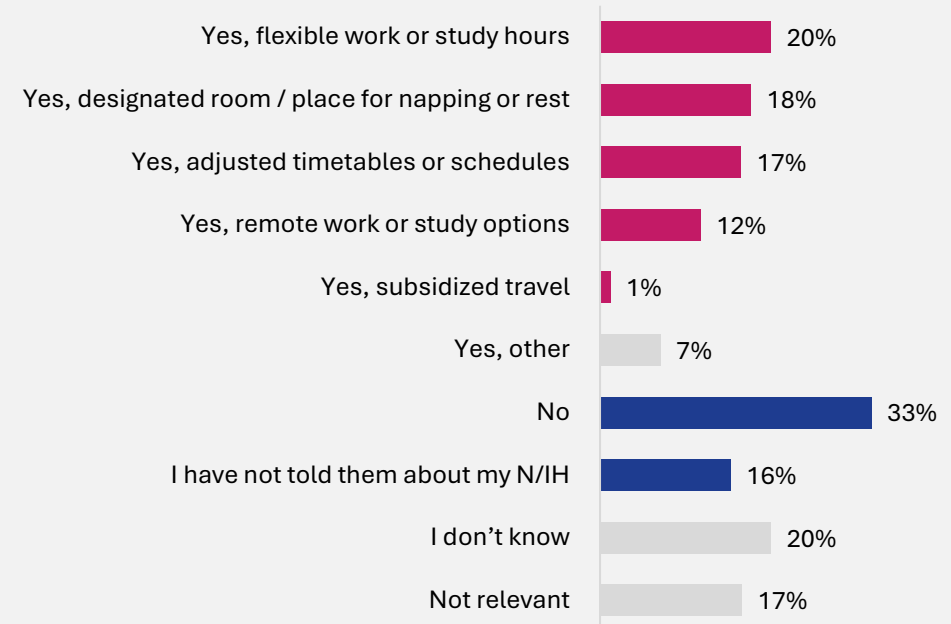
Most respondents in Norway (28%) were no longer able to work or study due to N/IH – fewest in Italy (3%).

51. How does your N/IH impact your work or education? (choose 1 answer)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
My N/IH has no impact on my ability to work or study	9%	6%	0%	8%	11%	7%	9%	3%	7%	18%	13%	4%	2%	8%	7%	21%
I had to reduce my working or study hours due to my N/IH	36%	53%	29%	38%	39%	30%	35%	37%	34%	48%	34%	36%	47%	18%	47%	45%
I had to change work or study due to my N/IH	14%	0%	24%	8%	10%	15%	12%	32%	20%	11%	19%	10%	16%	18%	15%	9%
I can no longer work or study due to my N/IH	16%	18%	6%	18%	11%	13%	18%	18%	21%	3%	18%	28%	9%	31%	8%	3%
Other (please specify)	22%	24%	24%	24%	27%	30%	22%	11%	14%	14%	16%	20%	23%	20%	20%	21%
I don't know	3%	0%	18%	3%	2%	3%	5%	0%	3%	5%	1%	2%	2%	4%	4%	0%
Number of respondents: N/IH diagnosed with impact	1,514	17	17	107	62	351	175	38	70	152	101	170	43	49	101	33

Q52 Does your workplace or educational institution provide accommodations for your N/IH? (you can choose several answers)

Overall, 64% reported that their workplace or educational institution (who're told about N/IH) provides accommodations. 33% do not, while 16% haven't told their workplace or educational about their N/IH.

The most common accommodations were flexible work or study hours (20%), designated rooms or places for rest (18%), and adjusted timetables or schedules (17%). Remote work or study options were mentioned by 12%, while only 1% received subsidized travel.



Q52 Does your workplace or educational institution provide accommodations for your N/IH? (you can choose several answers)

By diagnosis, accommodations were most often reported among NT1 (66%) compared to NT2 (62%) and IH (59%).

By age, younger respondents (18–39 years: 72%) were much more likely to report accommodations compared to those aged 40–59 years (53%) and especially those 60+ (27%).

By gender, men were more likely to report accommodations compared to women (67% vs. 61%).

52. Does your workplace or educational institution provide accommodations for your N/IH? (you can choose several answers)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Yes, flexible work or study hours	20%	23%	19%	17%	22%	21%	25%	21%	21%
Yes, subsidized travel	1%	1%	0%	1%	0%	1%	3%	1%	1%
Yes, designated room / place for napping or rest	18%	22%	19%	6%	22%	12%	22%	21%	17%
Yes, adjusted timetables or schedules	17%	18%	14%	17%	19%	14%	12%	17%	17%
Yes, remote work or study options	12%	13%	8%	10%	11%	13%	10%	10%	12%
Yes, other	7%	8%	5%	7%	10%	4%	5%	7%	7%
No	33%	29%	37%	40%	30%	37%	37%	31%	33%
I have not told them about my N/IH	16%	13%	19%	20%	15%	19%	7%	14%	17%
I don't know	20%	20%	19%	22%	14%	28%	67%	19%	22%
Number of respondents: All with N/IH diagnosis	1,559	990	207	322	924	528	107	374	1,177
Workplace / education (who're told about N/H) provide accommodation	64%	66%	62%	59%	72%	53%	27%	67%	61%
Not relevant	17%	17%	16%	18%	12%	22%	40%	16%	18%

Q52 Does your workplace or educational institution provide accommodations for your N/IH? (you can choose several answers)

Sweden (74%), Ireland (70%) and Italy (70%) reported the highest shares stating that workplace or education provides accommodations, while Norway (47%) reported the lowest.

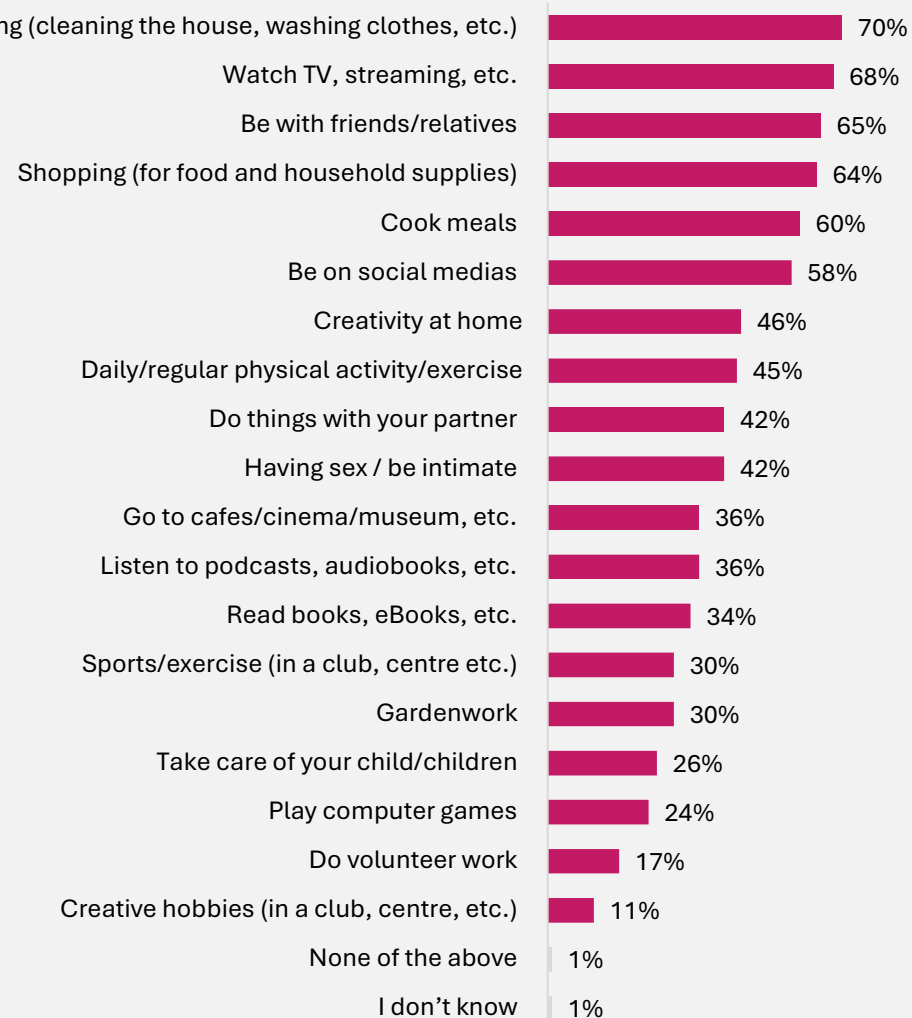
Regarding specific accommodations, flexible work or study hours were most common in Sweden (33%) and Finland (32%), and least common in Italy (11%). Designated rooms for napping or rest were highest in Sweden (44%) and the Netherlands (40%), and least common Italy again (5%).

52. Does your workplace or educational institution provide accommodations for your N/IH? (you can choose several answers)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Yes, flexible work or study hours	20%	14%	0%	30%	32%	15%	31%	3%	22%	11%	24%	24%	29%	8%	33%	30%
Yes, subsidized travel	1%	0%	0%	0%	3%	0%	0%	0%	5%	1%	4%	0%	0%	0%	0%	3%
Yes, designated room / place for napping or rest	18%	14%	14%	23%	20%	11%	19%	0%	34%	5%	40%	18%	14%	5%	44%	34%
Yes, adjusted timetables or schedules	17%	27%	0%	22%	27%	19%	13%	0%	13%	13%	28%	17%	3%	15%	31%	7%
Yes, remote work or study options	12%	7%	7%	15%	22%	11%	13%	3%	19%	3%	16%	13%	9%	3%	19%	27%
Yes, other	7%	14%	0%	8%	6%	7%	8%	0%	9%	8%	7%	10%	3%	5%	8%	10%
No	33%	27%	53%	30%	30%	31%	27%	81%	30%	43%	22%	29%	43%	49%	19%	23%
I have not told them about my N/IH	16%	20%	14%	8%	6%	21%	18%	5%	4%	23%	12%	14%	25%	13%	7%	23%
I don't know	20%	14%	14%	37%	27%	18%	18%	3%	27%	8%	20%	39%	25%	25%	19%	16%
Number of respondents: All with N/IH diagnosis	1.559	17	17	113	63	354	179	38	71	163	105	180	44	49	102	35
Workplace / education (who're told about N/H) provide accomodation	64%	66%	73%	55%	67%	61%	65%	92%	70%	70%	67%	47%	50%	63%	74%	60%
Not relevant	17%	12%	12%	27%	21%	15%	15%	3%	21%	7%	17%	28%	20%	20%	16%	14%

Q53 Which of the following do you do on a regular basis having N/IH? (You can choose several answers)

Most with N/IH are still able to housekeep (70%), watch TV / streaming (68%), be with friends/relatives (65%) and shop for food/household supplies (64%).

The least common activities with N/IH are playing computer games (24%), volunteer work (17%) and creative hobbies in a club / centre (11%).



Q53 Which of the following do you do on a regular basis having N/IH? (You can choose several answers)

By diagnosis, responses were broadly similar. By age, younger respondents (18–39 years) were more active on social media (68%) compared to the 40-59-year-olds (47%) and the 60+-year-olds (32%). In sports/exercise the 18-39-year-olds were also more active (35%) compared to the 40-59-year-olds (20%). The oldest group reported more frequent gardening (50%) than younger respondents (23%). By gender, women reported higher engagement in housekeeping (75% vs. 53%) and cooking (63% vs. 48%), while men reported higher engagement in playing computer games (41% vs. 18%).

53. Which of the following do you do on a regular basis having N/IH? (You can choose several answers)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Housekeeping (cleaning the house, washing clothes, etc.)	70%	69%	71%	69%	69%	72%	66%	53%	75%
Watch TV, streaming, etc.	68%	69%	64%	69%	72%	62%	70%	64%	70%
Be with friends/relatives	65%	66%	65%	60%	71%	55%	66%	59%	67%
Shopping (for food and household supplies)	64%	66%	63%	59%	63%	65%	70%	53%	68%
Cook meals	60%	60%	61%	57%	59%	60%	63%	48%	63%
Be on social medias	58%	58%	57%	59%	68%	47%	32%	46%	62%
Creativity at home (e.g. painting, knitting, photography, Lego, handcraft)	46%	49%	35%	46%	46%	45%	47%	31%	51%
Daily/regular physical activity/exercise (e.g. walking, jogging, ride a bike, do yoga at home)	45%	47%	43%	40%	49%	39%	46%	46%	45%
Do things with your partner	42%	40%	43%	44%	42%	42%	41%	35%	44%
Having sex / be intimate	42%	41%	45%	42%	47%	36%	24%	35%	44%
Go to cafes/cinema/museum, etc.	36%	39%	36%	28%	42%	27%	34%	30%	38%
Listen to podcasts, audiobooks, etc.	36%	36%	34%	36%	41%	29%	18%	29%	37%
Read books, eBooks, etc.	34%	32%	38%	35%	36%	30%	38%	25%	36%
Sports/exercise (in a club, centre etc.)	30%	31%	33%	21%	35%	20%	32%	34%	29%
Gardenwork	30%	30%	36%	26%	23%	39%	50%	27%	31%
Take care of your child/children	26%	23%	27%	30%	16%	43%	18%	20%	27%
Play computer games	24%	26%	17%	22%	31%	13%	14%	41%	18%
Do volunteer work	17%	17%	18%	18%	13%	23%	26%	16%	17%
Creative hobbies (in a club, centre, etc.)	11%	12%	9%	7%	9%	14%	13%	12%	11%
None of the above	1%	1%	1%	1%	1%	1%	0%	1%	1%
I don't know	1%	1%	1%	1%	1%	2%	3%	2%	1%
Number of respondents: All with N/IH diagnosis	1.545	981	207	318	918	522	105	371	1.166

■ Q53 Which of the following do you do on a regular basis having N/IH? (You can choose several answers)

Housekeeping was most common in Finland (89%) and Denmark (77%), while Ireland (59%) and Italy (59%) reported the lowest. Watching TV/streaming was most frequent in the Netherlands (86%) and Denmark (82%), while Italy (60%) and France (65%) reported the lowest.

Being with friends/relatives was most common in Denmark (79%) and the Netherlands (78%), while Ireland (51%) and France (60%) reported the lowest. Shopping was highest in Finland (85%) and the Netherlands (77%), while Ireland (53%) and Italy (53%) reported the lowest.

Cooking meals was highest in Finland (73%) and Denmark (71%), while Ireland (44%) and Italy (52%) reported the lowest. Being on social medias was highest in Denmark (79%) and Finland (79%), while Italy (47%) and Germany (48%) reported the lowest.

Creative hobbies (in a club, centre, etc.) were reported by very few overall (11%), with the highest in Finland (19%) and the Netherlands (15%). Volunteer work was also low (17%), with the Netherlands (31%) at the high end and Sweden (4%) at the low end.

Playing computer games was also uncommon (24%), most frequent in Italy (33%) and Germany (28%), while Finland (16%) reported the lowest.

Q53 Which of the following do you do on a regular basis having N/IH? (You can choose several answers)

53. Which of the following do you do on a regular basis having N/IH? (You can choose several answers)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Housekeeping (cleaning the house, washing clothes, etc.)	70%	76%	63%	77%	89%	69%	71%	42%	59%	59%	74%	72%	73%	71%	71%	77%
Watch TV, streaming, etc.	68%	59%	31%	82%	77%	65%	74%	39%	66%	60%	86%	71%	50%	63%	76%	63%
Be with friends/relatives	65%	65%	63%	79%	76%	60%	69%	50%	51%	68%	78%	62%	55%	58%	62%	86%
Shopping (for food and household supplies)	64%	53%	63%	71%	85%	61%	69%	50%	53%	53%	77%	66%	61%	65%	62%	80%
Cook meals	60%	53%	31%	71%	73%	58%	64%	47%	44%	52%	62%	68%	64%	58%	54%	63%
Be on social medias	58%	59%	38%	79%	79%	58%	48%	58%	59%	47%	54%	58%	70%	48%	67%	40%
Creativity at home (e.g. painting, knitting, photography, Lego, handcraft)	46%	41%	44%	59%	68%	46%	48%	18%	41%	41%	39%	53%	20%	33%	49%	46%
Daily/regular physical activity/exercise (e.g. walking, jogging, ride a bike, do yoga at home)	45%	53%	31%	54%	52%	43%	48%	16%	40%	36%	58%	51%	30%	38%	52%	49%
Do things with your partner	42%	71%	19%	43%	60%	37%	34%	34%	49%	36%	59%	42%	39%	31%	42%	66%
Having sex / be intimate	42%	47%	19%	44%	55%	43%	32%	18%	34%	45%	43%	45%	48%	27%	44%	54%
Go to cafes/cinema/museum, etc.	36%	35%	38%	39%	42%	39%	30%	21%	39%	42%	54%	23%	36%	35%	32%	31%
Listen to podcasts, audiobooks, etc.	36%	41%	19%	47%	47%	33%	40%	16%	41%	23%	30%	40%	23%	27%	51%	26%
Read books, eBooks, etc.	34%	35%	25%	36%	37%	38%	31%	21%	29%	39%	42%	31%	16%	35%	24%	40%
Sports/exercise (in a club, centre etc.)	30%	24%	6%	40%	32%	27%	30%	26%	31%	33%	46%	25%	20%	27%	25%	46%
Gardenwork	30%	35%	25%	42%	39%	27%	32%	11%	26%	24%	38%	34%	30%	13%	25%	46%
Take care of your child/children	26%	24%	25%	30%	32%	25%	19%	26%	26%	16%	24%	35%	18%	29%	28%	23%
Play computer games	24%	29%	19%	24%	16%	24%	28%	5%	23%	33%	26%	20%	27%	17%	26%	26%
Do volunteer work	17%	35%	6%	18%	18%	17%	20%	18%	16%	16%	31%	16%	5%	2%	4%	37%
Creative hobbies (in a club, centre, etc.)	11%	6%	0%	8%	19%	9%	9%	21%	11%	14%	15%	12%	0%	19%	5%	17%
None of the above	1%	6%	0%	0%	0%	2%	1%	5%	1%	2%	0%	1%	2%	0%	1%	0%
I don't know	1%	0%	6%	0%	0%	1%	1%	0%	0%	3%	1%	1%	2%	2%	3%	0%
Number of respondents: All with N/IH diagnosis	1.545	17	16	112	62	353	178	38	70	161	104	177	44	48	102	35

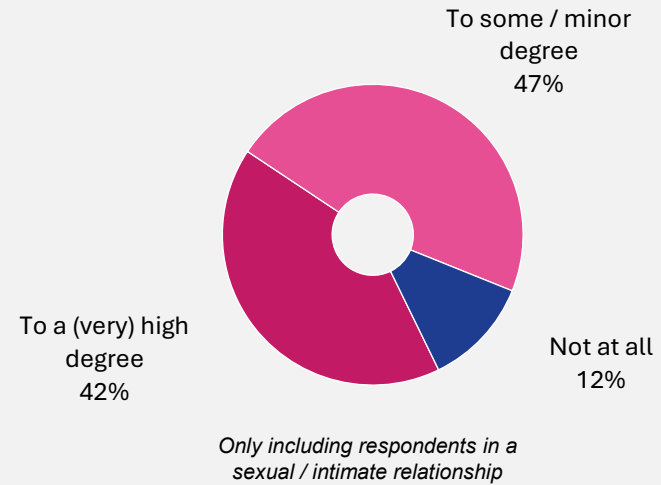
Q54 How do you experience that your N/IH affects your sex life and/or intimacy? (choose 1 answer)

Amongst respondents currently in a sexual / intimate relationship, 42% experienced that N/IH affects their sex life and/or intimacy to a (very) high degree. 47% answered to some or minor degree, while 12% reported not at all.

By diagnosis, IH reported the highest prevalence (41%) compared to NT1 (29%) and NT2 (28%).

By age, the 40–59 years group (40%) reported higher impact than the youngest group aged 18–39 years (27%) and the 60+ group (31%).

By gender, no notable differences were observed.



54. How do you experience that your N/IH affects your sex life and/or intimacy? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	18%	12%	12%	20%	11%	18%	15%	12%	14%
To a high degree	24%	17%	16%	21%	16%	22%	16%	18%	18%
To some degree	30%	23%	19%	27%	24%	23%	13%	22%	24%
To a minor degree	17%	12%	18%	11%	15%	9%	10%	12%	13%
Not at all	12%	10%	12%	5%	9%	9%	10%	9%	9%
Number of respondents: All with N/IH diagnosis	1.545	982	207	317	917	523	105	371	1.166
To a (very) high degree	42%	29%	28%	41%	27%	40%	31%	30%	32%
To some / minor degree	47%	35%	37%	38%	39%	32%	23%	34%	37%
Not at all	12%	10%	12%	5%	9%	9%	10%	9%	9%
I am not currently in a sexual or intimate relationship	19%	21%	18%	13%	20%	15%	27%	21%	18%
I don't know / prefer not to answer	5%	5%	6%	3%	5%	4%	9%	6%	4%

Q54 How do you experience that your N/IH affects your sex life and/or intimacy? (choose 1 answer)

Most respondents in Germany (41%) and France (40%) experienced that N/IH affects their sex life and/or intimacy to a (very) high degree – fewest in Italy (14%) and Finland (18%).

54. How do you experience that your N/IH affects your sex life and/or intimacy? (choose 1 answer)	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
To a very high degree	18%	6%	6%	13%	8%	17%	22%	21%	11%	4%	8%	12%	9%	17%	19%	0%
To a high degree	24%	24%	13%	13%	10%	23%	19%	29%	21%	10%	14%	18%	9%	19%	18%	20%
To some degree	30%	29%	25%	19%	32%	24%	19%	18%	20%	27%	20%	23%	32%	21%	24%	31%
To a minor degree	17%	18%	0%	18%	16%	10%	10%	8%	9%	18%	15%	15%	14%	6%	12%	31%
Not at all	12%	6%	0%	9%	18%	7%	8%	3%	7%	16%	11%	7%	7%	15%	5%	11%
Number of respondents: All with N/IH diagnosis	1.545	17	16	113	62	352	178	38	70	161	104	177	44	48	102	35
To a (very) high degree	42%	30%	19%	26%	18%	40%	41%	50%	32%	14%	22%	30%	18%	36%	37%	20%
To some / minor degree	47%	47%	25%	37%	48%	34%	29%	26%	29%	45%	35%	38%	46%	27%	36%	62%
Not at all	12%	6%	0%	9%	18%	7%	8%	3%	7%	16%	11%	7%	7%	15%	5%	11%
I am not currently in a sexual or intimate relationship	19%	18%	38%	22%	15%	16%	19%	21%	23%	17%	27%	19%	25%	17%	21%	6%
I don't know / prefer not to answer	5%	0%	19%	6%	2%	3%	3%	0%	9%	8%	5%	7%	5%	6%	3%	0%

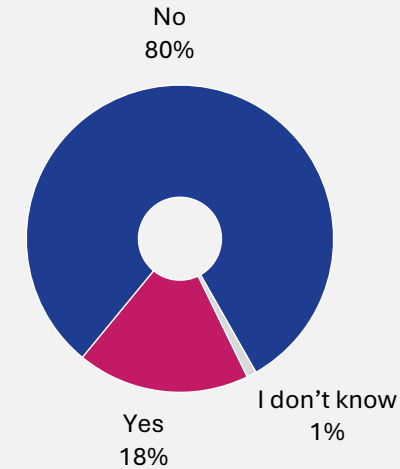
Q55 Do you use any sleep-, health- or wellness apps to monitor your progress in N/IH or in general? (choose 1 answer)

Overall, 18% reported using sleep-, health- or wellness apps.

By diagnosis, respondents with IH reported the highest use (21%) compared to NT1 (18%) and NT2 (16%).

By age, usage decreased with age, from 20% among 18–39 years to 12% among those 60+.

By gender, no notable differences were observed.



55. Do you use any sleep-, health- or wellness apps to monitor your progress in N/IH or in general? (choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Yes	18%	18%	16%	21%	20%	17%	12%	17%	19%
No	80%	81%	83%	77%	79%	81%	88%	82%	80%
I don't know	1%	1%	1%	2%	1%	2%	0%	1%	2%
Number of respondents: All with N/IH diagnosis	1.544	981	207	317	916	523	105	370	1.166

Q55 Do you use any sleep-, health- or wellness apps to monitor your progress in N/IH or in general? (choose 1 answer)

Finland (26%) and Sweden (25%) reported the highest use of sleep-, health- or wellness apps, while Italy (9%) and Denmark (10%) reported the lowest.

55. Do you use any sleep-, health- or wellness apps to monitor your progress in N/IH or in general? (choose 1 answer)	Total	Country														
		Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Yes	18%	18%	19%	10%	26%	19%	24%	21%	20%	9%	13%	21%	14%	19%	25%	9%
No	80%	82%	81%	89%	69%	81%	75%	71%	77%	89%	87%	77%	84%	81%	74%	91%
I don't know	1%	0%	0%	1%	5%	1%	1%	8%	3%	2%	1%	2%	2%	0%	1%	0%
Number of respondents: All with N/IH diagnosis	1.544	17	16	113	62	352	178	38	70	160	104	177	44	48	102	35

■ Q56 What do you think is the most difficult or bothersome thing about having N/IH?

This question was answered by 1.512 respondents via free-text.
Here are the main conclusions:

The free-text responses revealed a consistent set of experiences that patients considered most important in their daily lives with narcolepsy and idiopathic hypersomnia. Across countries and diagnoses, seven main themes emerged: constant fatigue and brain fog, the unpredictability of symptoms, social isolation and lack of understanding, major limitations in daily life, gaps in healthcare and treatment, the emotional burden of living with a chronic condition, and, for a smaller group, coping strategies and resilience. Together, these themes provide a deeper understanding of the challenges and adaptations shaping patients' quality of life.

Fatigue / Brain fog

Many patients described overwhelming fatigue and cognitive problems as the most burdensome aspect of their condition. Even after long periods of sleep, they never felt rested and struggled with memory, concentration, and mental clarity. This constant exhaustion left them unable to keep up with studies, work, social life, or even basic daily tasks.

Unpredictability / Lack of control

Respondents emphasised the unpredictability of their symptoms as a major challenge. Sudden sleep attacks or cataplexy made it impossible to plan ahead, while daily fluctuations in energy levels created constant uncertainty. The lack of control over their own bodies caused frustration and anxiety, undermining both social and professional life.

Limitations
Unpredictability
Fatigue
Isolation

“Living in a chronic fog, never really being fully awake, not being in control of my own body, and not being able to do as I wish.”
Female, 40-49 years, Denmark, , IH, ID 721

“Dark thoughts because spending a life sleeping and in waking phases of exhaustion is not a life.”
Female, 30-39 years, France, IH, ID 643

“The most difficult part of having narcolepsy is the relentless, unpredictable tiredness that hits every single day. It's not like normal fatigue—it's sudden, overpowering, and impossible to push through.”
Male, 18-29 years, Ireland, NT1 / with cataplexy, ID 314

“Never knowing when I will have to sleep or be out of commission. Not really being able to plan or planning very little to be sure I can manage.”
Female, 18-29 years, France, IH, ID 660

■ Q56 What do you think is the most difficult or bothersome thing about having N/IH?

Social isolation / Lack of understanding

Patients often felt isolated and misunderstood because their condition is invisible to others. Many explained that friends, colleagues, and even healthcare professionals underestimated the severity of narcolepsy or hypersomnia, leading to stigma and a lack of support. This lack of understanding reinforced feelings of loneliness and frustration.

Limitations in daily life

Respondents described a profound loss of independence and opportunities. They struggled to maintain education, employment, and social activities, with many unable to drive, pursue careers, or sustain family life as they wished. Daily tasks felt overwhelming, and the condition often dictated what was possible rather than personal choice.

Healthcare experience / treatment gaps

Many patients described insufficient treatment and side effects that limited their quality of life. Several reported frustration with doctors' lack of knowledge, forcing them to explain their own condition. Others highlighted bureaucratic barriers and long delays in receiving the correct diagnosis or gaining access to appropriate medication.

"Friends and family don't understand how disabling it is, because from the outside you look normal."

Female, 50-59 years, France, IH, ID 835

"Nobody really understands unless they live with it themselves."

Female, 30-39 years, France, IH, ID 624

"It affects everything in my life—work, relationships, hobbies, even being able to drive."

Female, 50-59 years, Greece, NT1 / with cataplexy, ID 279

"Having to say no to things I want to do, because I know my body won't let me."

Female, 60-69 years, Italy, NT1 / with cataplexy, ID 2064

"Doctors don't know enough, and you have to explain your own condition to them."

Female, 18-29 years, Norway, IH, ID 378

"Medication helps a little but never enough, and the side effects are often worse."

Female, 18-29 years, Norway, IH, ID 897

■ Q56 What do you think is the most difficult or bothersome thing about having N/IH?

Emotional burden / mental health

Respondents often spoke about the emotional toll of living with a chronic, invisible, and incurable disorder. Feelings of depression, hopelessness, and low self-worth were common, driven both by the limitations of the condition and the lack of understanding from others. Some described “dark thoughts” and despair at the prospect of spending a lifetime between exhaustion and sleep.

Coping and resilience

A smaller group of respondents emphasised coping strategies that helped them manage daily life. They described how strict routines, planned naps, and flexible work arrangements provided some stability. Support from partners, family, or colleagues was mentioned as a key factor in maintaining quality of life. Although less frequent, these accounts highlighted resilience and adaptation in contrast to the dominant experiences of burden and limitation.

Overall, the free-text responses show that life with narcolepsy and idiopathic hypersomnia is dominated by constant fatigue, unpredictability, social isolation, and major limitations in daily life. Frustration with insufficient healthcare and the emotional toll of living with an invisible condition further intensify the burden. Yet, alongside these challenges, some respondents described coping strategies and resilience, underlining the importance of support, structure, and recognition in making daily life more manageable.

To accept myself that I am not as alert and enduring as a healthy person. Sometimes it is difficult to remember to take naps, but without them the day ends too soon.”

Female, 40-49 years, Finland, NT1 / with cataplexy, ID 1467

“Negative impact on professional life (loss of job), on self-esteem and confidence, on morale, on family life (high mental load for the partner).”

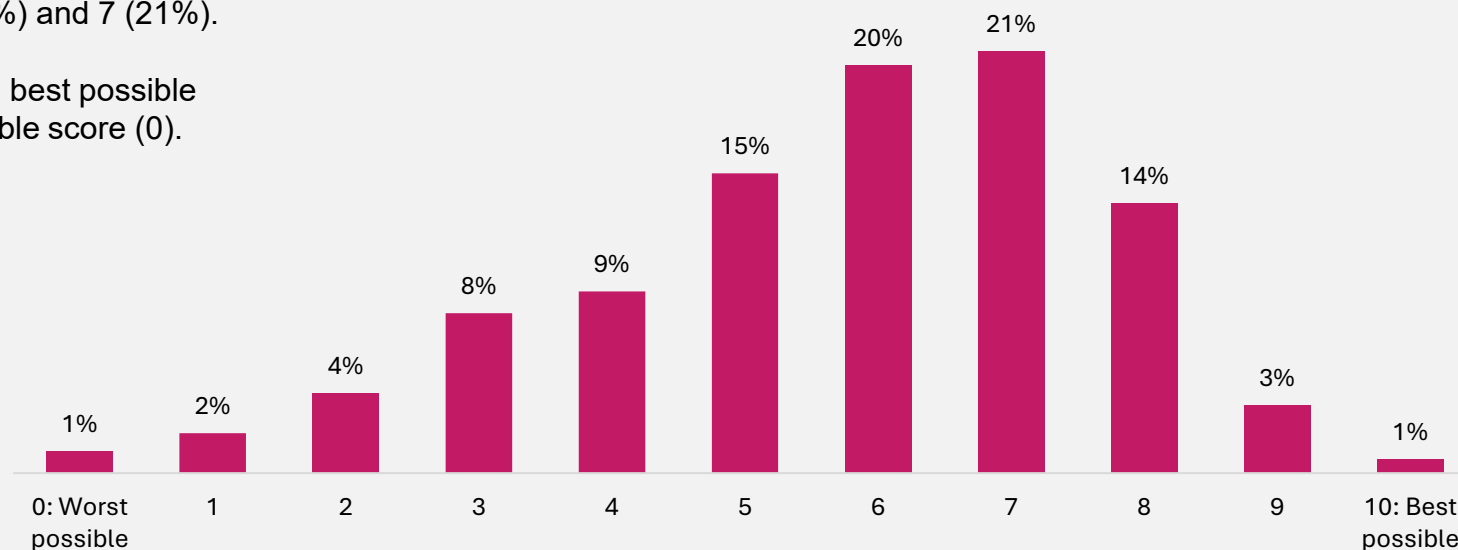
Female, 50-59 years, France, IH, ID 2296

Q57 On a scale from 0 to 10: How would you rate your overall quality of life? (choose 1 answer)

The average quality of life score was 5,6 on a 0–10 scale. This is -1,7 lower than the 7,3 in EU in general in 2023*.

Most respondents rated their quality of life in the mid-range, with the highest shares at 6 (20%) and 7 (21%).

Only 1% rated their quality of life as the best possible (10), while 1% reported the worst possible score (0).



avg. **5,6**

avg in EU populations
in 2023*. **7,3**

* Source: Eurostat: [“EU quality-of-life indicators – Statistics Explained, EU-SILC survey data, 2023”](#)

Q57 On a scale from 0 to 10: How would you rate your overall quality of life? (choose 1 answer)

By diagnosis, respondents with NT1 reported the highest average score (5,8), followed by NT2 (5,5), while IH was lowest (5,1).

By age, younger respondents aged 18–39 and those aged 60+ both reported higher averages (5,8) compared to respondents aged 40–59 (5,3).

By gender, women reported a slightly higher average (5,7) than men (5,5).

The highest average quality of life was reported in Finland (6,6), the Netherlands (6,5) and Denmark (6,2).

The lowest averages were observed in Germany (5,3), Norway (5,3), Ireland (5,3), France (5,4) and Sweden (5,4).

57. On a scale from 0 to 10: How would you rate your overall quality of life? (choose 1 answer) 0 = Worst possible quality of life, 10 = Best possible quality of life	N/IH diagnosis				Age			Gender	
	Total	NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
Average quality of life	5,6	5,8	5,5	5,1	5,8	5,3	5,8	5,5	5,7
Number of respondents: All with N/IH diagnosis	1.515	956	206	314	897	513	105	366	1.141
Quality of Life in general in EU 2023 *	7,3								
Difference between N/IH patients and general EU	-1,7								

57. On a scale from 0 to 10: How would you rate your overall quality of life? (choose 1 answer) 0 = Worst possible quality of life, 10 = Best possible quality of life	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
Average quality of life	5,6	6,1	5,0	6,2	6,6	5,4	5,3	4,6	5,3	6,1	6,5	5,3	4,8	5,3	5,4	6,8
Number of respondents: All with N/IH diagnosis	1.515	15	16	111	60	345	174	37	68	158	102	176	44	47	100	35
Quality of Life in general in EU 2023 *	7,3	7,7	5,9	7,5	7,8	7,1	7,0	6,9	7,6	7,2	7,6	7,6	7,6	7,2	7,5	7,8
Difference between N/IH patients and general EU	-1,7	-1,6	-0,9	-1,3	-1,2	-1,7	-1,7	-2,3	-2,3	-1,1	-1,1	-2,3	-2,8	-1,9	-2,1	-1,0

* Source: Eurostat: [“EU quality-of-life indicators – Statistics Explained, EU-SILC survey data, 2023”](#)

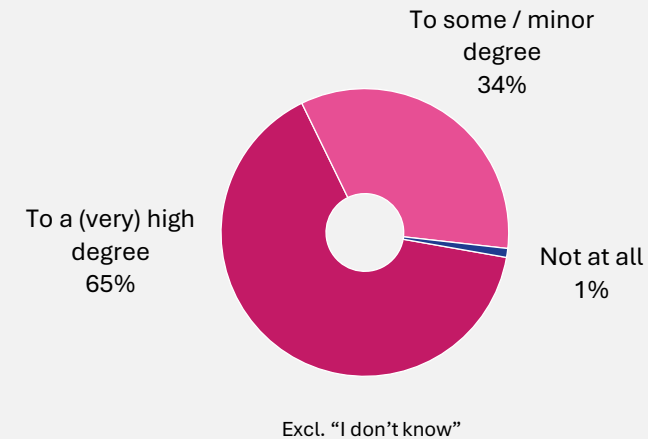
Q58 To what degree does your N/IH impact your quality of life in general? (Choose 1 answer)

Overall, 65% reported that their N/IH impacts their quality of life to a (very) high degree, 34% to some or minor degree, while 1% not at all.

Most respondents with IH (74%) reported this to a (very) high degree - compared to NT2 (66%) and NT1 (63%).

By age, respondents aged 40–59 years (69%) and those aged 18–39 years (64%) were more likely to report a (very) high degree than those aged 60+ years (53%)

By gender, no notable differences were observed.



58. To what degree does your N/IH impact your quality of life in general? (Choose 1 answer)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	27%	26%	24%	34%	26%	31%	21%	28%	27%
To a high degree	38%	36%	42%	41%	38%	38%	32%	37%	38%
To some degree	27%	28%	25%	24%	28%	25%	36%	26%	28%
To a minor degree	7%	8%	8%	2%	7%	5%	11%	7%	6%
Not at all	1%	1%	1%	0%	1%	1%	0%	1%	1%
I don't know	1%	1%	0%	0%	1%	0%	1%	1%	0%
Number of respondents: All with N/IH diagnosis	1.515	956	206	314	897	514	104	366	1.141
To a (very) high degree	65%	63%	66%	74%	64%	69%	53%	66%	65%
To some / minor degree	34%	36%	33%	26%	35%	30%	47%	33%	34%
Not at all	1%	1%	1%	0%	1%	1%	0%	1%	1%

(excl. I don't know)

Q58 To what degree does your N/IH impact your quality of life in general? (Choose 1 answer)

Most respondents in Sweden (81%) and Ireland (73%) experienced an impact on quality of life to a (very) high degree – fewest in Italy (39%) and the Netherlands (52%).

58. To what degree does your N/IH impact your quality of life in general? (Choose 1 answer)	Country															
	Total	Belgium	Bulgaria	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Netherlands	Norway	Poland	Spain	Sweden	Switzerland
To a very high degree	27%	25%	25%	19%	23%	31%	26%	38%	35%	13%	21%	33%	45%	26%	37%	11%
To a high degree	38%	50%	44%	37%	30%	42%	42%	49%	38%	26%	30%	38%	39%	45%	44%	26%
To some degree	27%	25%	25%	29%	35%	24%	24%	11%	24%	43%	35%	26%	11%	26%	17%	43%
To a minor degree	7%	0%	0%	14%	10%	4%	7%	3%	3%	15%	10%	2%	2%	2%	2%	20%
Not at all	1%	0%	6%	1%	2%	0%	1%	0%	0%	2%	3%	1%	0%	0%	0%	0%
I don't know	1%	0%	0%	0%	0%	0%	1%	0%	0%	2%	1%	0%	2%	2%	0%	0%
Number of respondents: All with N/IH diagnosis	1.515	16	16	111	60	344	174	37	68	158	102	176	44	47	100	35
To a (very) high degree	65%	75%	69%	56%	53%	72%	68%	86%	73%	39%	52%	71%	87%	72%	81%	37%
To some / minor degree	34%	25%	25%	43%	45%	28%	31%	14%	27%	59%	45%	28%	13%	28%	19%	63%
Not at all	1%	0%	6%	1%	2%	0%	1%	0%	0%	2%	3%	1%	0%	0%	0%	0%

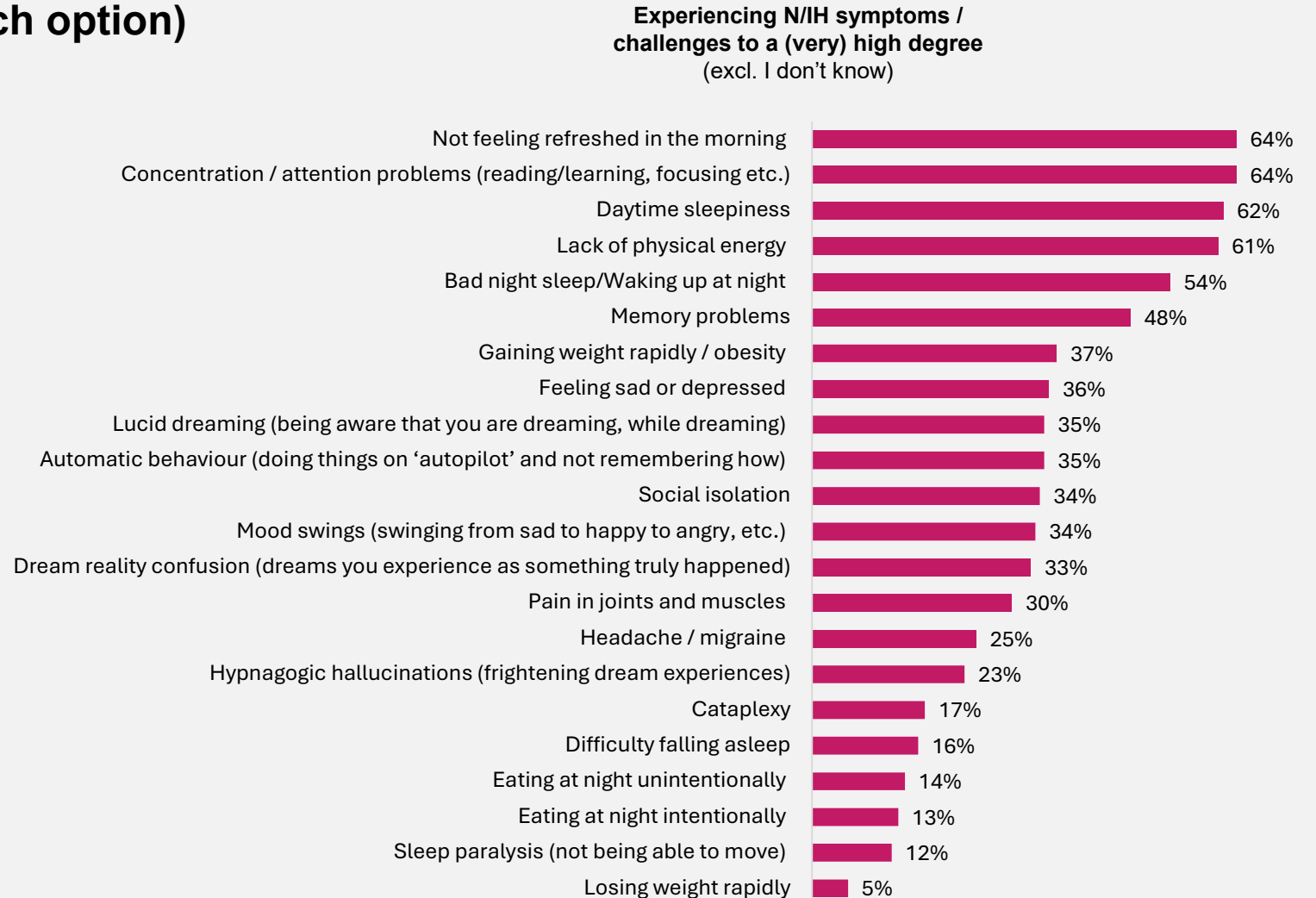
(excl. I don't know)

■ **Q59 To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)**

The most frequently reported symptoms / challenges to a high or very high degree were lack of feeling refreshed in the morning (64%), concentration and attention problems (64%), daytime sleepiness (62%), lack of physical energy (61%), bad night sleep (54%) and memory problems (48%).

Other challenges included weight gain (37%), feelings of sadness or depression (36%), lucid dreaming (35%), automatic behaviour (35%), social isolation (34%), dream reality confusion (33%), pain in joints and muscles (30%), and headaches or migraines (25%).

For question 59 the breakdown of symptoms is only reported by diagnosis, age and gender. Country specific breakdowns of symptoms can be obtained on request of the data from eNAP.



To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

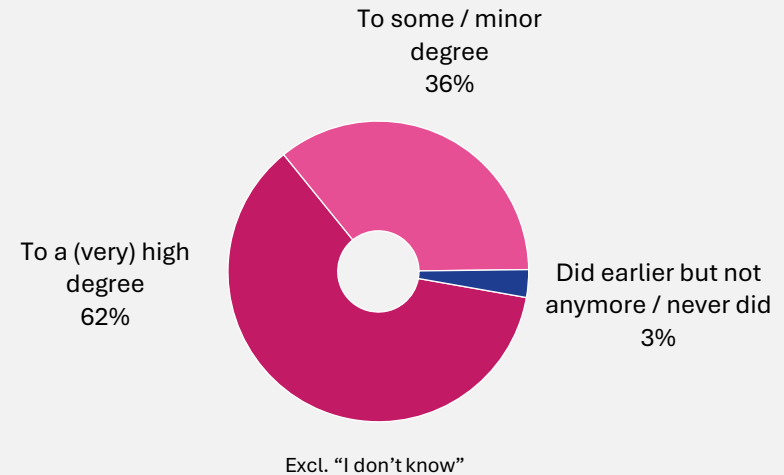
Q59a Daytime sleepiness

Overall, 62% experienced daytime sleepiness to a (very) high degree, 36% to some or minor degree, while 3% did earlier or never did.

By diagnosis, IH reported the highest prevalence (72%) compared to NT2 (64%) and NT1 (58%).

By age, the middle-aged group (40–59 years: 66%) reported the highest prevalence, followed by younger respondents (18–39 years: 60%) and older respondents (60+: 56%).

By gender, females (64%) reported a higher prevalence than males (56%).



59a. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - Daytime sleepiness	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	27%	23%	26%	39%	25%	30%	24%	24%	28%
To a high degree	35%	35%	38%	33%	35%	36%	32%	32%	36%
To some degree	27%	29%	24%	21%	28%	24%	28%	27%	26%
To a minor degree	9%	9%	9%	5%	9%	8%	9%	12%	8%
I did earlier but not anymore	3%	3%	2%	2%	3%	2%	6%	4%	2%
I never did	0%	0%	1%	0%	0%	0%	1%	1%	0%
I don't know	0%	0%	0%	0%	0%	0%	0%	0%	0%
Number of respondents: All with N/IH diagnosis	1.502	946	204	313	895	505	102	364	1.130
To a (very) high degree	62%	58%	64%	72%	60%	66%	56%	56%	64%
To some / minor degree	36%	38%	33%	26%	37%	32%	37%	39%	34%
Did earlier but not anymore / never did	3%	3%	3%	2%	3%	2%	7%	5%	2%

(excl. I don't know)

To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

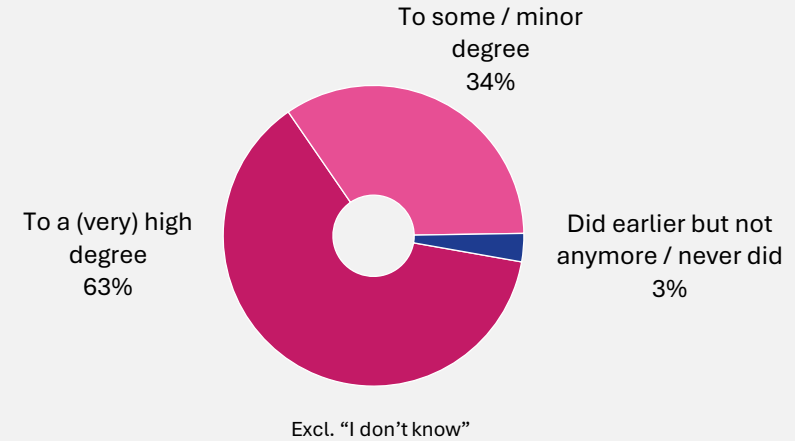
Q59b Concentration / attention problems (reading/learning, focusing etc.)

Overall, 63% experienced concentration or attention problems to a (very) high degree, 34% to some or minor degree, and 3% did earlier or never did.

By diagnosis, IH reported the highest prevalence (73%) compared to NT2 (66%) and NT1 (58%).

By age, respondents aged 40–59 years (66%) reported the highest share, while those aged 60+ (54%) reported the lowest.

By gender, results were similar, with men (61%) and women (63%) reporting to a (very) high degree.



59b. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - Concentration / attention problems (reading/learning, focusing etc.)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	28%	23%	31%	40%	26%	31%	22%	28%	27%
To a high degree	34%	34%	34%	33%	35%	34%	30%	32%	35%
To some degree	24%	26%	21%	21%	24%	23%	26%	23%	24%
To a minor degree	10%	12%	9%	4%	10%	8%	17%	10%	10%
I did earlier but not anymore	2%	3%	1%	2%	3%	2%	1%	3%	2%
I never did	1%	1%	2%	0%	2%	1%	1%	3%	1%
I don't know	1%	1%	0%	0%	1%	0%	2%	1%	0%
Number of respondents: All with N/IH diagnosis	1.504	948	204	313	895	506	103	364	1.132
To a (very) high degree	63%	58%	66%	73%	61%	66%	54%	61%	63%
To some / minor degree	34%	38%	31%	25%	34%	31%	44%	33%	34%
Did earlier but not anymore / never did	3%	4%	3%	2%	5%	3%	2%	6%	3%

(excl. I don't know)

To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

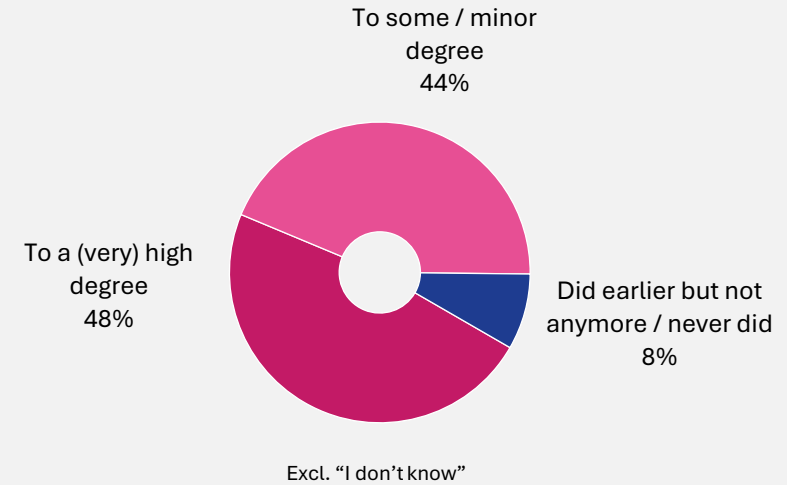
Q59c Memory problems

Overall, 48% experienced memory problems to a (very) high degree, 44% to some or minor degree, while 8% did earlier or never did.

By diagnosis, IH reported the highest prevalence (59%), followed by NT2 (57%) and NT1 (43%).

By age, those aged 40–59 years were highest (56%) compared with 18–39 years (44%) and 60+ years (44%).

By gender, females were higher (49%) than males (45%).



59c. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - Memory problems	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	21%	17%	25%	31%	19%	25%	17%	16%	23%
To a high degree	26%	24%	30%	27%	24%	30%	24%	27%	26%
To some degree	30%	30%	25%	30%	30%	29%	24%	28%	30%
To a minor degree	13%	15%	12%	9%	15%	10%	20%	14%	13%
I did earlier but not anymore	1%	2%	0%	0%	1%	2%	1%	2%	1%
I never did	7%	8%	5%	2%	9%	3%	7%	9%	6%
I don't know	2%	3%	3%	1%	2%	2%	6%	4%	2%
Number of respondents: All with N/IH diagnosis	1.504	948	204	313	895	506	103	364	1.132
To a (very) high degree	48%	43%	57%	59%	44%	56%	44%	45%	49%
To some / minor degree	44%	47%	38%	39%	46%	39%	47%	44%	43%
Did earlier but not anymore / never did	8%	10%	5%	2%	10%	5%	9%	11%	7%

(excl. I don't know)

To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

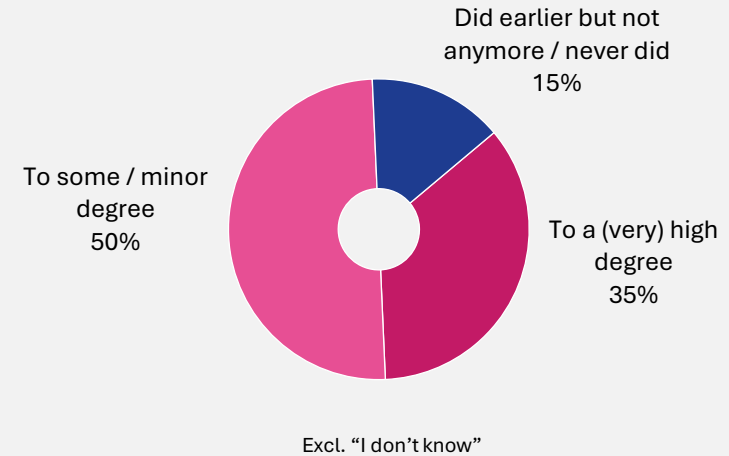
Q59d Automatic behaviour (doing things on 'autopilot' and not remembering how)

Overall, 35% experienced automatic behaviour to a (very) high degree, 50% to some or minor degree, while 15% did earlier or never did.

By diagnosis, IH reported the highest prevalence (48%) compared to NT2 (38%) and NT1 (32%).

By age, respondents aged 40–59 years (38%) and 18–39 years (36%) were more affected than those aged 60+ years (24%).

By gender, women (37%) reported slightly higher prevalence than men (32%).



59d. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - Automatic behaviour (doing things on 'autopilot' and not remembering how)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	13%	10%	12%	23%	14%	13%	9%	9%	14%
To a high degree	21%	20%	24%	24%	20%	24%	14%	20%	22%
To some degree	27%	27%	27%	27%	25%	29%	35%	26%	27%
To a minor degree	21%	23%	19%	18%	22%	20%	19%	22%	21%
I did earlier but not anymore	7%	9%	3%	2%	8%	5%	8%	6%	7%
I never did	7%	6%	10%	4%	6%	6%	12%	9%	6%
I don't know	4%	5%	4%	3%	5%	4%	4%	7%	4%
Number of respondents: All with N/IH diagnosis	1.504	948	204	313	895	506	103	364	1.132
To a (very) high degree	35%	32%	38%	48%	36%	38%	24%	32%	37%
To some / minor degree	50%	53%	48%	46%	49%	51%	56%	52%	49%
Did earlier but not anymore / never did	15%	16%	14%	6%	15%	11%	21%	16%	13%

(excl. I don't know)

To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

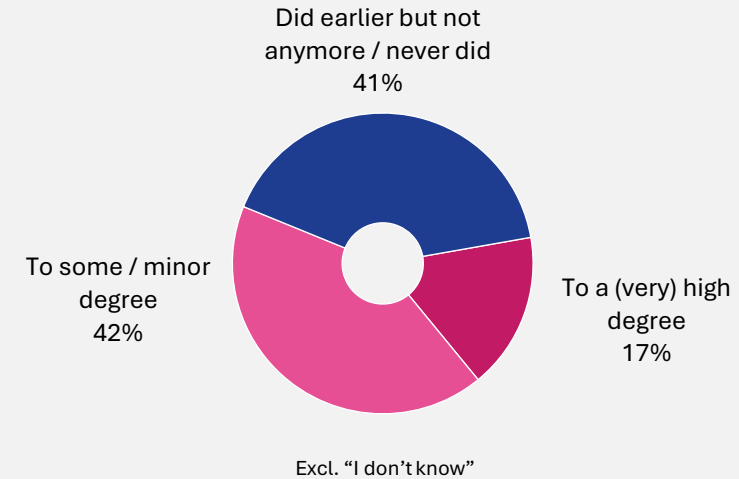
Q59e Cataplexy

Overall, 17% experienced cataplexy to a (very) high degree, 42% to some or minor degree, while 41% did earlier or never did.

By diagnosis, NT1 reported the highest prevalence (25%), compared to NT2 (1%) and IH (2%).

By age, respondents aged 60+ years reported the highest prevalence (28%) compared to those aged 40–59 years (18%) and 18–39 years (15%).

By gender, females (16%) reported slightly lower prevalence than males (21%).



59e. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - <u>Cataplexy</u>	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	6%	9%	0%	1%	5%	6%	11%	8%	5%
To a high degree	10%	16%	1%	1%	9%	11%	15%	12%	10%
To some degree	17%	24%	3%	4%	19%	14%	11%	16%	17%
To a minor degree	23%	32%	13%	4%	24%	21%	24%	24%	23%
I did earlier but not anymore	14%	18%	7%	4%	14%	13%	13%	17%	13%
I never did	25%	1%	64%	72%	24%	28%	20%	18%	27%
I don't know	5%	0%	12%	15%	4%	6%	7%	5%	5%
Number of respondents: All with N/IH diagnosis	1.504	948	204	313	895	506	103	364	1.132
To a (very) high degree	17%	25%	1%	2%	15%	18%	28%	21%	16%
To some / minor degree	42%	56%	18%	9%	45%	38%	37%	42%	42%
Did earlier but not anymore / never did	41%	19%	81%	88%	40%	44%	35%	37%	42%

(excl. I don't know)

To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

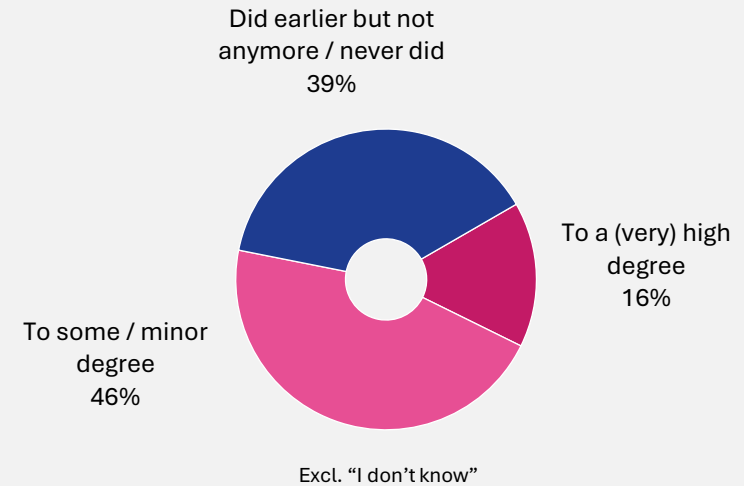
■ Q59f Difficulty falling asleep

Overall, 16% experienced difficulty falling asleep to a (very) high degree, 46% to some or minor degree, while 39% did earlier or never did.

By diagnosis, NT2 reported the highest prevalence (20%) compared to NT1 (16%) and IH (13%).

By age, the youngest group (18–39 years: 14%) was slightly less affected than those aged 40-59 years (20%) and 60+ (20%).

By gender, no notable differences were observed.



59f. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - Difficulty falling asleep	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	6%	6%	9%	6%	6%	8%	8%	6%	6%
To a high degree	9%	10%	10%	6%	8%	11%	11%	8%	10%
To some degree	18%	19%	21%	16%	20%	17%	16%	20%	18%
To a minor degree	26%	27%	21%	27%	26%	26%	21%	25%	26%
I did earlier but not anymore	7%	9%	4%	4%	8%	5%	14%	9%	7%
I never did	30%	27%	32%	37%	30%	29%	24%	28%	30%
I don't know	3%	3%	3%	4%	3%	3%	7%	4%	3%
Number of respondents: All with N/IH diagnosis	1.503	947	204	313	894	506	103	363	1.132
To a (very) high degree	16%	16%	20%	13%	14%	20%	20%	15%	16%
To some / minor degree	46%	47%	43%	45%	47%	45%	39%	47%	45%
Did earlier but not anymore / never did	39%	37%	37%	43%	39%	35%	40%	39%	38%

(excl. I don't know)

To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

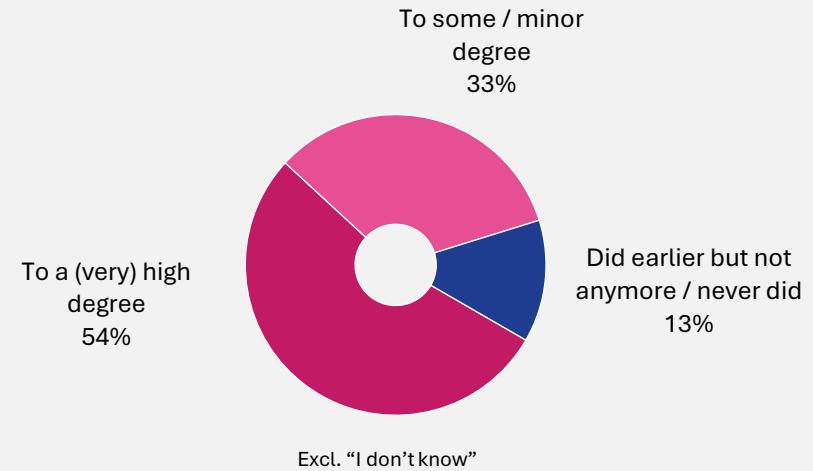
■ Q59g Bad night sleep/Waking up at night

Overall, more than half (54%) reported experiencing bad night sleep or waking up at night to a (very) high degree, while 33% reported it to some or a minor degree and 13% had experienced it earlier but not anymore or never did.

By diagnosis, those with NT1 (60%) reported the highest levels, while IH was lowest (32%).

By age, respondents aged 40–59 (56%) and 60+ (54%) were more affected compared to those aged 18–39 (52%).

By gender, no notable differences were observed.



59g. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - <u>Bad night sleep/Waking up at night</u>	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	29%	34%	28%	16%	29%	30%	21%	29%	29%
To a high degree	24%	27%	24%	15%	22%	26%	32%	24%	24%
To some degree	18%	18%	21%	20%	17%	20%	20%	19%	18%
To a minor degree	15%	13%	16%	21%	16%	14%	14%	15%	15%
I did earlier but not anymore	6%	7%	6%	3%	6%	5%	7%	8%	5%
I never did	7%	2%	6%	23%	8%	5%	5%	5%	7%
I don't know	1%	1%	0%	2%	1%	1%	1%	1%	1%
Number of respondents: All with N/IH diagnosis	1.502	946	204	313	894	505	103	363	1.131
To a (very) high degree	54%	60%	51%	32%	52%	56%	54%	53%	54%
To some / minor degree	33%	31%	37%	42%	34%	34%	34%	34%	34%
Did earlier but not anymore / never did (excl. I don't know)	13%	9%	12%	27%	14%	10%	12%	13%	12%

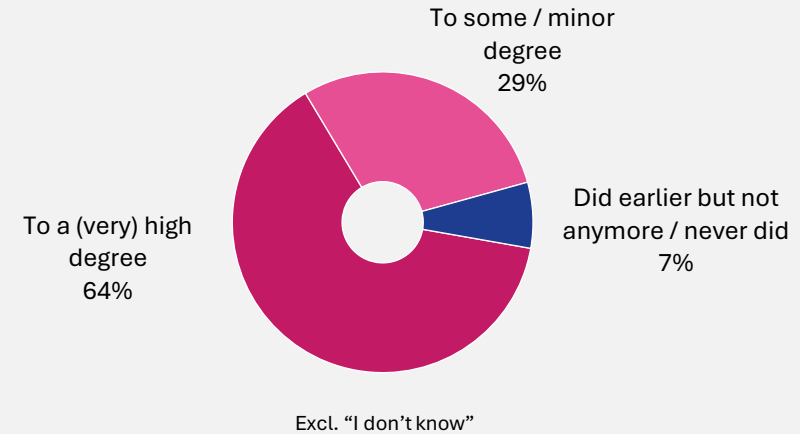
To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

Q59h Not feeling refreshed in the morning

Overall, 64% reported not feeling refreshed in the morning to a (very) high degree, 29% to some or a minor degree, while 7% had never experienced it or did so only in the past.

By diagnosis, the share reporting to a (very) high degree was highest among IH (87%) compared with NT2 (71%) and NT1 (54%).

By age, 66% of respondents aged 40–59 years reported not feeling refreshed in the morning to a (very) high degree, compared to 64% of those aged 18–39 years and 45% of those aged 60+ years. By gender, 66% of females reported not feeling refreshed in the morning to a (very) high degree compared with 55% of males.



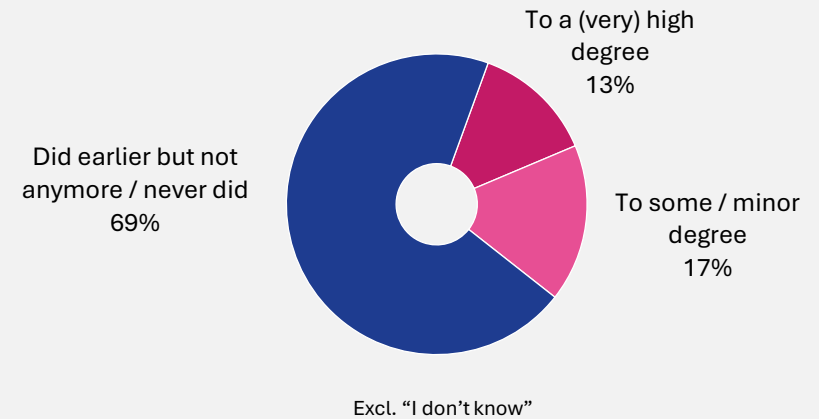
59h. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - <u>Not feeling refreshed in the morning</u>	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	41%	30%	43%	71%	42%	41%	26%	32%	43%
To a high degree	22%	23%	27%	16%	21%	25%	17%	22%	22%
To some degree	17%	21%	14%	7%	17%	16%	20%	20%	16%
To a minor degree	12%	16%	8%	4%	12%	11%	21%	15%	11%
I did earlier but not anymore	5%	6%	4%	1%	4%	4%	10%	7%	4%
I never did	2%	3%	3%	1%	2%	3%	1%	3%	2%
I don't know	1%	1%	1%	0%	1%	0%	4%	1%	1%
Number of respondents: All with N/IH diagnosis	1.503	947	204	313	894	506	103	363	1.132
To a (very) high degree	64%	54%	71%	87%	64%	66%	45%	55%	66%
To some / minor degree	29%	37%	22%	11%	30%	27%	43%	35%	28%
Did earlier but not anymore / never did (excl. I don't know)	7%	9%	7%	2%	6%	7%	12%	10%	6%

To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

Q59i Eating at night unintentionally

13% reported eating at night unintentionally to a (very) high degree, while 17% experienced it to some or a minor degree. The majority (69%) stated they had experienced it earlier but no longer did, or that they had never experienced it.

IH patients reported this symptom most rarely, with 85% saying they had never or no longer experienced it. By age, the share reporting no or no longer experiencing this symptom was highest among those aged 60+ (72%) and lowest among those aged 18–39 (66%). Women were more likely than men to report never or no longer experiencing it (73% vs. 59%).



59i. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - Eating at night unintentionally	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	6%	8%	3%	3%	7%	6%	1%	7%	6%
To a high degree	7%	9%	6%	3%	7%	8%	3%	8%	7%
To some degree	7%	8%	9%	3%	6%	9%	12%	10%	6%
To a minor degree	9%	9%	11%	6%	8%	10%	11%	13%	7%
I did earlier but not anymore	7%	10%	2%	3%	9%	6%	6%	6%	8%
I never did	59%	51%	63%	79%	59%	58%	62%	48%	62%
I don't know	4%	4%	5%	4%	5%	3%	6%	8%	3%
Number of respondents: All with N/IH diagnosis	1.503	947	204	313	894	506	103	363	1.132
To a (very) high degree	13%	18%	10%	6%	15%	14%	4%	16%	14%
To some / minor degree	17%	18%	21%	9%	15%	20%	24%	25%	14%
Did earlier but not anymore / never did	69%	64%	69%	85%	71%	66%	72%	59%	73%

(excl. I don't know)

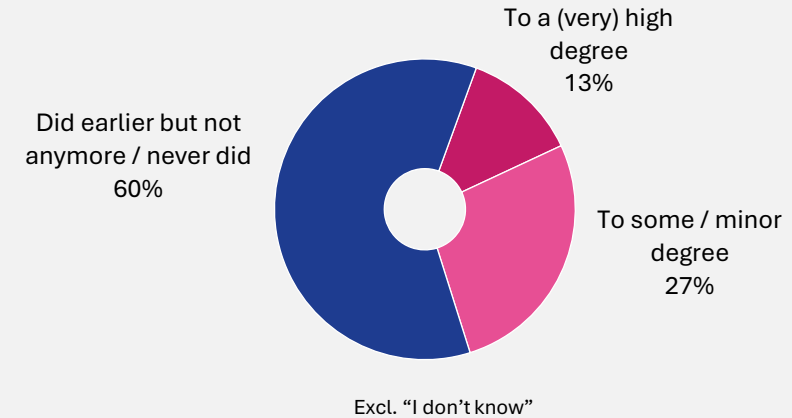
To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

Q59j Eating at night intentionally

Overall, 13% reported eating at night intentionally to a (very) high degree, 27% to some or a minor degree, while 60% had never experienced it or did so only in the past.

By diagnosis, 14% of respondents with NT1 reported eating at night intentionally to a (very) high degree, compared to 12% with NT2 and 4% with IH.

By age, 13% of respondents aged 18–39 years reported eating at night intentionally to a (very) high degree, compared to 11% of those aged 40–59 years and 10% of those aged 60+ years.



59j. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - Eating at night intentionally	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	5%	6%	4%	2%	6%	5%	2%	7%	5%
To a high degree	7%	8%	7%	2%	7%	6%	7%	7%	7%
To some degree	11%	13%	11%	7%	11%	13%	9%	13%	10%
To a minor degree	15%	16%	10%	17%	14%	16%	18%	19%	13%
I did earlier but not anymore	11%	14%	5%	8%	13%	10%	8%	10%	11%
I never did	47%	40%	56%	61%	47%	48%	50%	38%	50%
I don't know	3%	3%	7%	4%	3%	3%	6%	6%	3%
Number of respondents: All with N/IH diagnosis	1.502	947	203	313	894	505	103	362	1.132
To a (very) high degree	13%	14%	12%	4%	13%	11%	10%	15%	13%
To some / minor degree	27%	30%	23%	25%	26%	30%	29%	34%	24%
Did earlier but not anymore / never did	60%	56%	66%	71%	61%	59%	62%	51%	64%

(excl. I don't know)

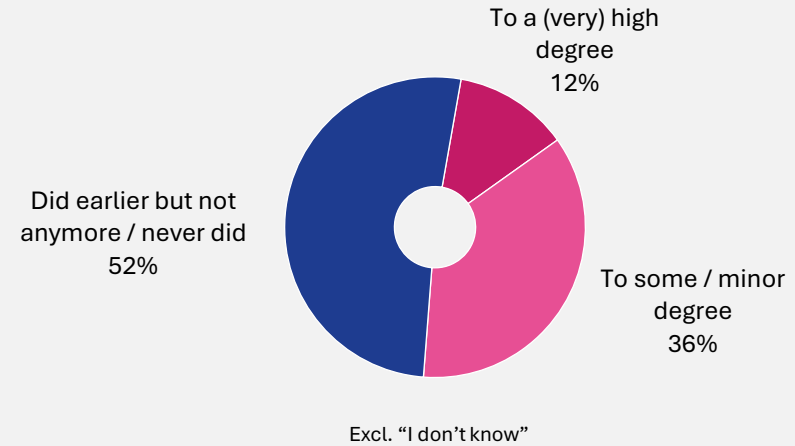
To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

Q59k Sleep paralysis (not being able to move)

Overall, 12% reported sleep paralysis to a (very) high degree, 36% to some or a minor degree, while 52% had never experienced it or did so only in the past.

By diagnosis, 15% of respondents with NT1 reported sleep paralysis to a (very) high degree, compared to 10% with NT2 and 7% with IH.

By age, 16% of respondents aged 40–59 years reported sleep paralysis to a (very) high degree, compared to 11% of those aged 18–39 years and 8% of those aged 60+ years.



59k. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - Sleep paralysis (not being able to move)	N/IH diagnosis				Age			Gender	
	Total	NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	4%	5%	2%	2%	4%	6%	1%	5%	4%
To a high degree	8%	10%	8%	5%	7%	10%	6%	8%	8%
To some degree	15%	16%	14%	11%	14%	17%	8%	15%	15%
To a minor degree	20%	20%	20%	18%	20%	18%	22%	17%	20%
I did earlier but not anymore	23%	27%	18%	15%	23%	23%	23%	24%	23%
I never did	27%	20%	34%	43%	28%	23%	33%	27%	27%
I don't know	4%	3%	5%	6%	3%	4%	8%	4%	4%
Number of respondents: All with N/IH diagnosis	1.502	946	204	313	894	506	102	363	1.131
To a (very) high degree	12%	15%	10%	7%	11%	16%	8%	14%	12%
To some / minor degree	36%	37%	35%	31%	35%	36%	32%	33%	36%
Did earlier but not anymore / never did (excl. I don't know)	52%	48%	54%	62%	53%	47%	60%	53%	52%

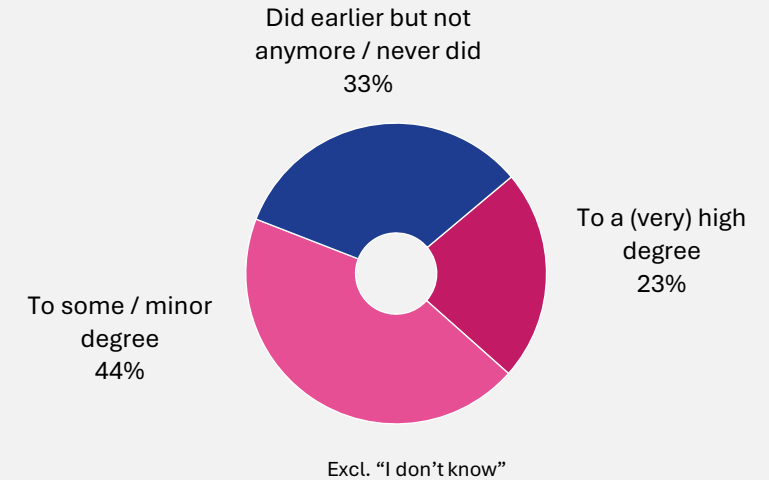
To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

Q59I Hypnagogic hallucinations (frightening dream experiences)

Overall, 23% reported hypnagogic hallucinations to a (very) high degree, 44% to some or a minor degree, while 33% had never experienced them or did so only in the past.

By diagnosis, 24% of respondents with NT1 reported hypnagogic hallucinations to a (very) high degree, compared to 22% with NT2 and 17% with IH.

By age, 24% of respondents aged 18–39 years reported hypnagogic hallucinations to a (very) high degree, compared to 21% of those aged 40–59 years and 19% of those aged 60+ years. By gender, 24% of females reported hypnagogic hallucinations to a (very) high degree compared to 20% of males.



59I. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - Hypnagogic hallucinations (frightening dream experiences)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	10%	11%	10%	6%	11%	10%	5%	7%	11%
To a high degree	12%	13%	11%	10%	13%	11%	13%	12%	12%
To some degree	21%	21%	28%	19%	20%	24%	21%	20%	22%
To a minor degree	22%	22%	22%	23%	23%	21%	17%	23%	21%
I did earlier but not anymore	18%	22%	9%	9%	17%	20%	18%	17%	18%
I never did	14%	9%	15%	27%	14%	12%	21%	17%	13%
I don't know	3%	2%	5%	5%	3%	3%	4%	3%	3%
Number of respondents: All with N/IH diagnosis	1.503	946	205	313	895	505	103	363	1.132
To a (very) high degree	23%	24%	22%	17%	24%	21%	19%	20%	24%
To some / minor degree	44%	44%	53%	45%	44%	46%	40%	45%	44%
Did earlier but not anymore / never did	33%	32%	25%	38%	32%	33%	41%	35%	32%

(excl. I don't know)

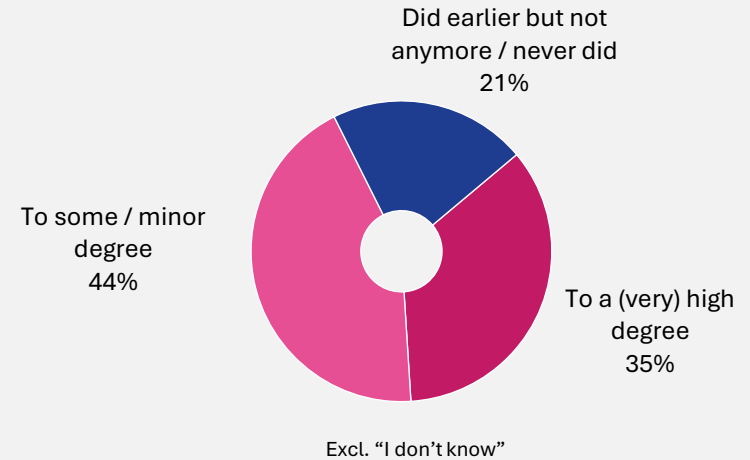
To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

■ Q59m Lucid dreaming (being aware that you are dreaming, while dreaming)

Overall, 35% reported lucid dreaming to a (very) high degree, 44% to some or a minor degree, while 21% had never experienced it or did so only in the past.

By diagnosis, 38% of respondents with NT1 reported lucid dreaming to a (very) high degree, compared to 36% with NT2 and 25% with IH.

By age, 37% of respondents aged 18–39 years reported lucid dreaming to a (very) high degree, compared to 36% of those aged 40–59 years and 23% of those aged 60+ years. By gender, 37% of females reported lucid dreaming to a (very) high degree compared to 30% of males.



59m. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - Lucid dreaming (being aware that you are dreaming, while dreaming)	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	15%	17%	16%	9%	17%	14%	6%	12%	16%
To a high degree	18%	19%	18%	14%	18%	19%	14%	16%	18%
To some degree	22%	22%	22%	21%	21%	22%	24%	25%	20%
To a minor degree	19%	19%	20%	17%	18%	19%	22%	20%	18%
I did earlier but not anymore	10%	12%	6%	8%	11%	9%	5%	10%	10%
I never did	10%	6%	13%	22%	10%	9%	16%	10%	10%
I don't know	7%	5%	5%	9%	5%	8%	14%	6%	7%
Number of respondents: All with N/IH diagnosis	1.504	947	205	313	895	506	103	363	1.133
To a (very) high degree	35%	38%	36%	25%	37%	36%	23%	30%	37%
To some / minor degree	44%	43%	44%	42%	41%	45%	53%	48%	41%
Did earlier but not anymore / never did	21%	19%	20%	33%	22%	20%	24%	22%	22%

(excl. I don't know)

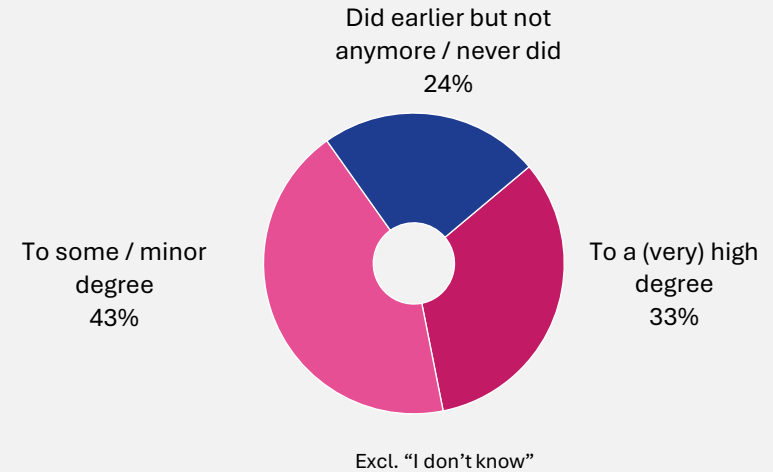
To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

Q59n Dream reality confusion (dreams you experience as something truly happened)

Overall, 33% reported dream reality confusion to a (very) high degree, 43% to some or a minor degree, while 24% had never experienced it or did so only in the past.

By diagnosis, 36% of respondents with NT2 reported dream reality confusion to a (very) high degree, compared to 33% with NT1 and 31% with IH.

By age, 33% of respondents aged 40–59 years reported dream reality confusion to a (very) high degree, compared to 32% of those aged 18–39 years and 26% of those aged 60+ years. By gender, 35% of females reported dream reality confusion to a (very) high degree compared to 25% of males.



59n. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - <u>Dream reality confusion (dreams you experience as something truly happened)</u>	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	13%	13%	16%	12%	14%	12%	10%	10%	14%
To a high degree	19%	19%	20%	18%	18%	20%	14%	14%	20%
To some degree	22%	24%	21%	19%	23%	21%	25%	24%	22%
To a minor degree	20%	19%	25%	22%	21%	19%	21%	22%	20%
I did earlier but not anymore	13%	16%	5%	8%	13%	13%	12%	12%	13%
I never did	10%	7%	12%	17%	10%	11%	10%	13%	9%
I don't know	3%	3%	1%	4%	2%	4%	9%	6%	3%
Number of respondents: All with N/IH diagnosis	1.504	947	205	313	895	506	103	363	1.133
To a (very) high degree	33%	33%	36%	31%	32%	33%	26%	25%	35%
To some / minor degree	43%	44%	46%	43%	44%	42%	50%	48%	43%
Did earlier but not anymore / never did	24%	23%	17%	26%	23%	25%	24%	26%	22%

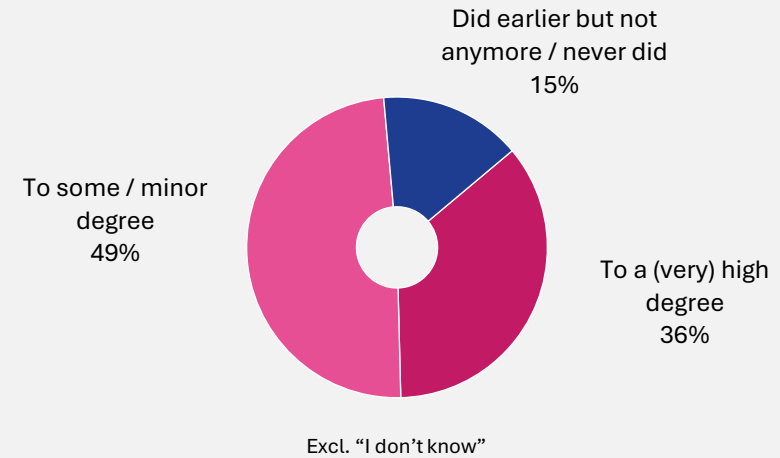
(excl. I don't know)

To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

Q59o Feeling sad or depressed

Overall, 36% reported feeling sad or depressed to a (very) high degree, 49% to some or a minor degree, while 15% had never experienced it or did so only in the past. By diagnosis, 44% of respondents with IH reported feeling sad or depressed to a (very) high degree, compared to 43% with NT2 and 31% with NT1.

By age, 37% of respondents aged 40–59 years reported feeling sad or depressed to a (very) high degree, compared to 36% of those aged 18–39 years and 25% of those aged 60+ years. By gender, 51% of females reported feeling sad or depressed to some or a minor degree compared to 45% of males, while reports to a (very) high degree were similar (35% each).



59o. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - <u>Feeling sad or depressed</u>	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	14%	11%	16%	22%	14%	15%	6%	15%	13%
To a high degree	21%	19%	25%	21%	21%	21%	17%	18%	21%
To some degree	27%	28%	24%	27%	27%	28%	19%	25%	28%
To a minor degree	21%	22%	17%	17%	22%	18%	27%	18%	22%
I did earlier but not anymore	6%	7%	5%	6%	6%	6%	6%	6%	7%
I never did	9%	10%	9%	5%	7%	10%	16%	13%	7%
I don't know	3%	3%	4%	1%	3%	2%	9%	4%	2%
Number of respondents: All with N/IH diagnosis	1.504	947	205	313	895	506	103	363	1.133
To a (very) high degree	36%	31%	43%	44%	36%	37%	25%	35%	35%
To some / minor degree	49%	52%	43%	45%	51%	47%	51%	45%	51%
Did earlier but not anymore / never did	15%	18%	15%	11%	13%	16%	24%	20%	14%

(excl. I don't know)

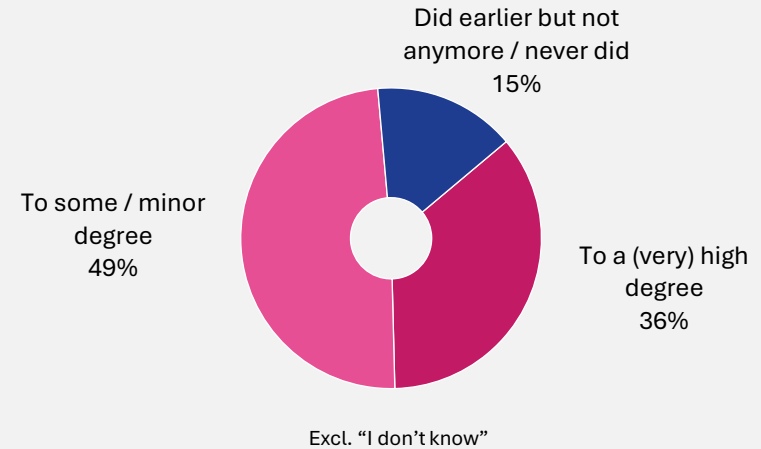
To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

■ Q59p Mood swings (swinging from sad to happy to angry, etc.)

Overall, 34% reported mood swings to a (very) high degree, 50% to some or a minor degree, while 16% had never experienced them or did so only in the past.

By diagnosis, 40% of respondents with NT2 reported mood swings to a (very) high degree, compared to 35% with IH and 32% with NT1.

By age, 37% of respondents aged 18–39 years reported mood swings to a (very) high degree, compared to 32% of those aged 40–59 years and 17% of those aged 60+ years. By gender, 35% of females reported mood swings to a (very) high degree, compared to 29% of males.



59p. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - <u>Mood swings (swinging from sad to happy to angry, etc.)</u>	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	12%	10%	17%	16%	14%	10%	2%	9%	13%
To a high degree	21%	21%	21%	19%	22%	21%	14%	19%	22%
To some degree	27%	27%	24%	27%	27%	27%	21%	27%	27%
To a minor degree	22%	22%	17%	23%	20%	23%	31%	20%	23%
I did earlier but not anymore	5%	6%	2%	4%	5%	4%	4%	7%	4%
I never did	11%	11%	14%	10%	9%	12%	21%	15%	10%
I don't know	3%	4%	4%	2%	3%	3%	8%	4%	3%
Number of respondents: All with N/IH diagnosis	1.501	945	205	312	894	505	102	363	1.130
To a (very) high degree	34%	32%	40%	35%	37%	32%	17%	29%	35%
To some / minor degree	50%	51%	43%	51%	48%	52%	56%	48%	51%
Did earlier but not anymore / never did	16%	18%	17%	14%	14%	16%	27%	23%	14%

(excl. I don't know)

To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

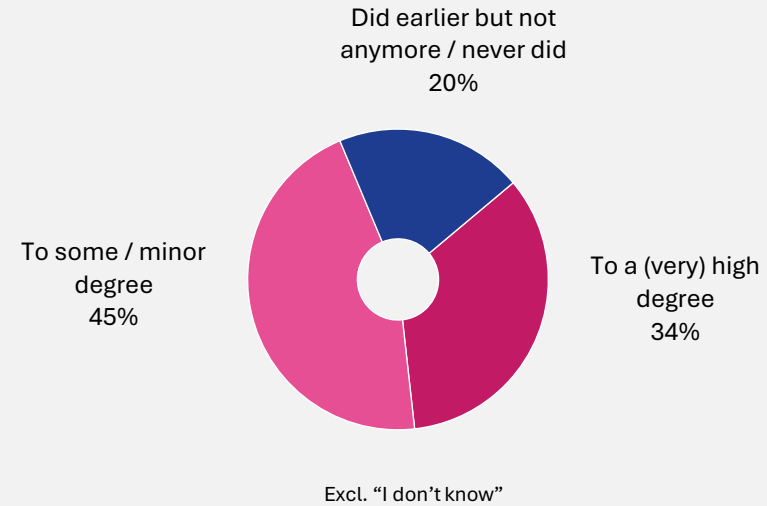
Q59q Social isolation

Overall, 34% reported social isolation to a (very) high degree, 45% to some or a minor degree, while 20% had never experienced it or did so only in the past.

By diagnosis, 44% of respondents with IH reported social isolation to a (very) high degree, compared to 33% with NT2 and 32% with NT1.

By age, 38% of respondents aged 40–59 years reported social isolation to a (very) high degree, compared to 34% of those aged 18–39 years and 23% of those aged 60+ years.

By gender, no notable demographic differences were observed.



59q. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - Social isolation	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	14%	13%	8%	21%	13%	17%	8%	14%	14%
To a high degree	20%	18%	25%	22%	20%	21%	14%	23%	19%
To some degree	27%	25%	29%	29%	26%	28%	30%	24%	28%
To a minor degree	18%	19%	18%	13%	18%	18%	17%	18%	18%
I did earlier but not anymore	6%	7%	2%	5%	7%	3%	3%	5%	6%
I never did	14%	15%	17%	8%	13%	12%	24%	15%	13%
I don't know	2%	2%	2%	2%	3%	1%	5%	2%	2%
Number of respondents: All with N/IH diagnosis	1.499	944	204	312	894	503	102	362	1.129
To a (very) high degree	34%	32%	33%	44%	34%	38%	23%	37%	34%
To some / minor degree	45%	45%	47%	43%	45%	46%	49%	42%	47%
Did earlier but not anymore / never did	20%	23%	19%	13%	21%	15%	28%	20%	19%

(excl. I don't know)

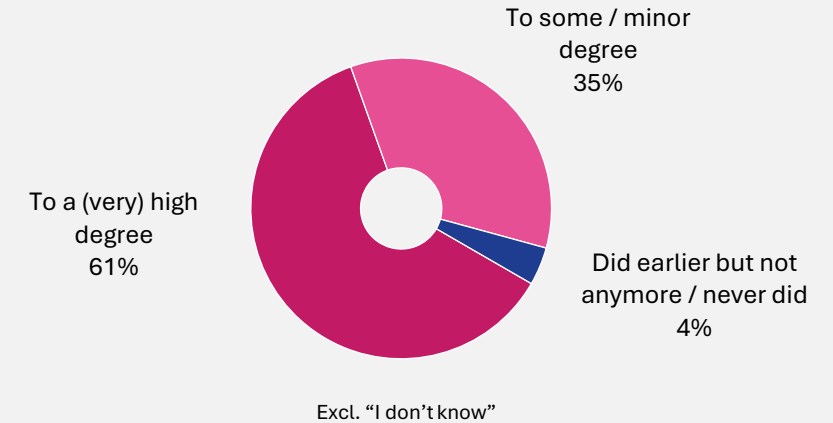
To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

Q59r Lack of physical energy

Overall, 61% reported lack of physical energy to a (very) high degree, 35% to some or a minor degree, while 4% had never experienced it or did so only in the past.

By diagnosis, 81% of respondents with IH reported lack of physical energy to a (very) high degree, compared to 59% with NT2 and 56% with NT1.

By age, 69% of respondents aged 40–59 years reported lack of physical energy to a (very) high degree, compared to 58% of those aged 18–39 years and 44% of those aged 60+ years. By gender, 65% of females reported lack of physical energy to a (very) high degree, compared to 51% of males.



59r. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - Lack of physical energy	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	32%	25%	35%	53%	30%	39%	18%	24%	35%
To a high degree	28%	30%	23%	28%	28%	30%	25%	26%	29%
To some degree	21%	23%	24%	13%	22%	19%	22%	23%	20%
To a minor degree	13%	15%	14%	5%	15%	9%	23%	18%	12%
I did earlier but not anymore	2%	3%	2%	0%	3%	2%	3%	4%	2%
I never did	2%	2%	1%	1%	2%	1%	6%	3%	1%
I don't know	1%	2%	0%	0%	1%	1%	4%	2%	1%
Number of respondents: All with N/IH diagnosis	1.501	945	205	312	894	505	102	363	1.130
To a (very) high degree	61%	56%	59%	81%	58%	69%	44%	51%	65%
To some / minor degree	35%	39%	38%	18%	37%	28%	46%	42%	32%
Did earlier but not anymore / never did	4%	5%	3%	1%	5%	3%	9%	7%	3%

(excl. I don't know)

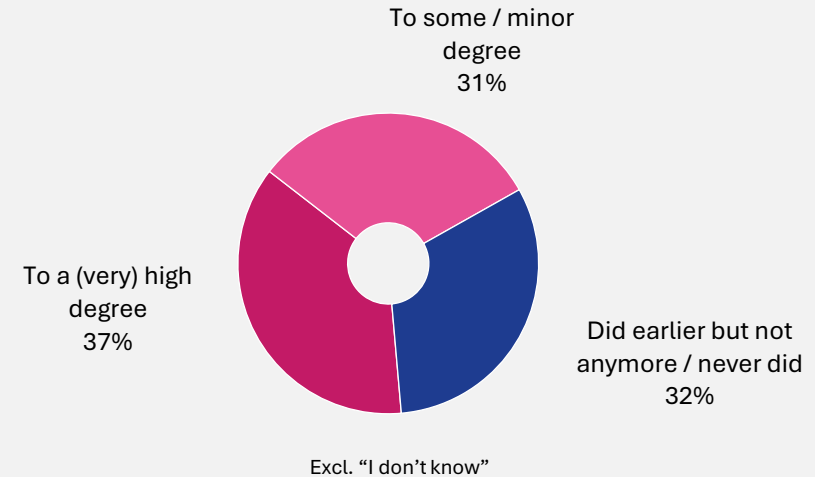
To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

Q59s Gaining weight rapidly / obesity

Overall, 37% reported weight gain/obesity to a (very) high degree, 31% to some or a minor degree, while 32% had never experienced it or did so only in the past.

By diagnosis, 39% of respondents with NT1 reported weight gain/obesity to a (very) high degree, compared to 31% with NT2 and 33% with IH.

By age, 43% of respondents aged 40–59 years reported weight gain/obesity to a (very) high degree, compared to 34% of those aged 18–39 years and 33% of those aged 60+ years. By gender, 39% of females reported weight gain/obesity to a (very) high degree, compared to 32% of males.



59s. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - <u>Gaining weight rapidly / obesity</u>	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	18%	20%	12%	15%	17%	21%	12%	13%	20%
To a high degree	18%	18%	17%	16%	16%	20%	19%	18%	18%
To some degree	18%	18%	14%	19%	17%	20%	14%	20%	17%
To a minor degree	12%	12%	16%	14%	11%	13%	19%	13%	12%
I did earlier but not anymore	11%	12%	6%	8%	12%	8%	11%	13%	10%
I never did	20%	17%	29%	23%	24%	14%	19%	19%	20%
I don't know	4%	3%	6%	4%	3%	4%	8%	4%	4%
Number of respondents: All with N/IH diagnosis	1.501	944	204	312	893	504	102	361	1.130
To a (very) high degree	37%	39%	31%	33%	34%	43%	33%	32%	39%
To some / minor degree	31%	31%	32%	35%	29%	34%	35%	34%	30%
Did earlier but not anymore / never did (excl. I don't know)	32%	30%	37%	33%	37%	23%	32%	33%	31%

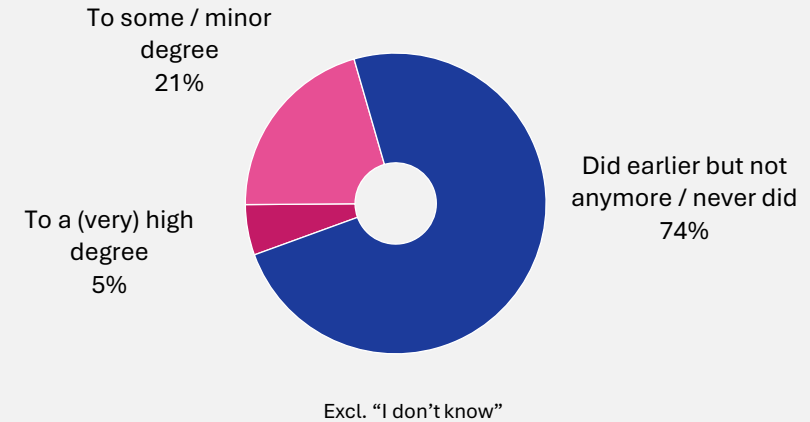
To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

Q59t Losing weight rapidly

Overall, 5% reported losing weight rapidly to a (very) high degree, 21% to some or a minor degree, while 74% had never experienced it or did so only in the past.

By diagnosis, respondents with NT2 (9%) and IH (7%) reported slightly higher prevalence to a (very) high degree compared to NT1 (5%).

By age, younger respondents aged 18–39 years (7%) reported more often losing weight rapidly to a (very) high degree compared to those aged 40–59 years (4%) and 60+ years (2%). By gender, females (6%) reported a slightly higher prevalence to a (very) high degree compared to males (2%).



59t. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - Losing weight rapidly	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	2%	2%	5%	3%	3%	2%	0%	1%	3%
To a high degree	3%	3%	3%	4%	4%	2%	2%	1%	3%
To some degree	6%	7%	7%	6%	6%	7%	4%	8%	6%
To a minor degree	13%	12%	11%	14%	12%	14%	15%	16%	12%
I did earlier but not anymore	12%	14%	8%	12%	15%	10%	4%	8%	14%
I never did	56%	56%	57%	55%	54%	59%	62%	56%	57%
I don't know	7%	7%	8%	6%	6%	6%	14%	9%	6%
Number of respondents: All with N/IH diagnosis	1.501	945	205	312	894	505	102	363	1.130
To a (very) high degree	5%	5%	9%	7%	7%	4%	2%	2%	6%
To some / minor degree	21%	20%	20%	21%	19%	22%	22%	27%	19%
Did earlier but not anymore / never did	74%	74%	71%	71%	73%	73%	76%	71%	75%

(excl. I don't know)

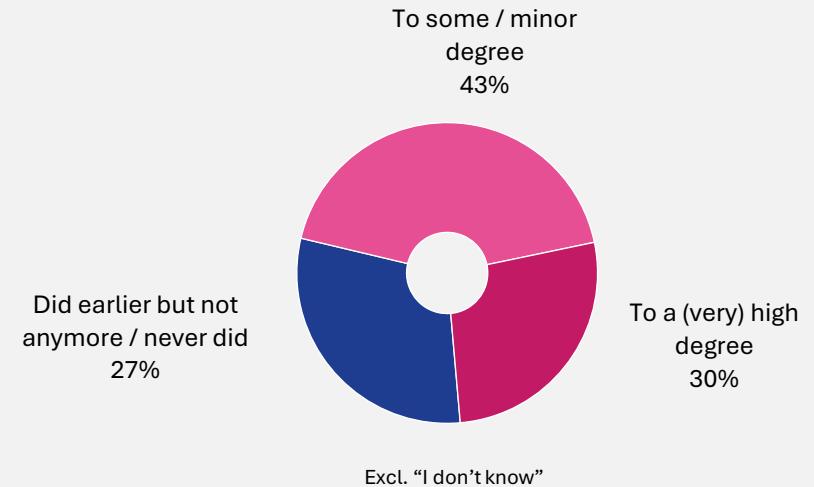
To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option)

Q59u Pain in joints and muscles

Overall, 30% of respondents reported experiencing pain in joints and muscles to a (very) high degree, 43% to some or a minor degree, while 27% had never experienced it or did so only in the past.

By diagnosis, pain to a (very) high degree was more common among IH (39%) compared to NT2 (33%) and NT1 (27%).

By age, respondents aged 40–59 years (40%) reported more pain to a (very) high degree compared to 18–39 years (25%) and 60+ years (27%). By gender, females (33%) reported a higher prevalence of pain to a (very) high degree compared to males (23%).



59u. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - Pain in joints and muscles	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	11%	9%	12%	18%	9%	16%	12%	8%	13%
To a high degree	17%	16%	19%	19%	14%	23%	14%	13%	18%
To some degree	21%	21%	20%	23%	18%	26%	29%	20%	22%
To a minor degree	19%	19%	18%	19%	19%	18%	22%	20%	18%
I did earlier but not anymore	1%	1%	0%	2%	2%	1%	0%	1%	1%
I never did	24%	27%	24%	14%	30%	13%	18%	29%	22%
I don't know	7%	7%	7%	5%	8%	4%	5%	9%	6%
Number of respondents: All with N/IH diagnosis	1.499	943	205	312	894	505	100	363	1.128
To a (very) high degree	30%	27%	33%	39%	25%	40%	27%	23%	33%
To some / minor degree	43%	43%	41%	44%	40%	45%	54%	44%	43%
Did earlier but not anymore / never did	27%	30%	26%	17%	35%	14%	19%	33%	24%

(excl. I don't know)

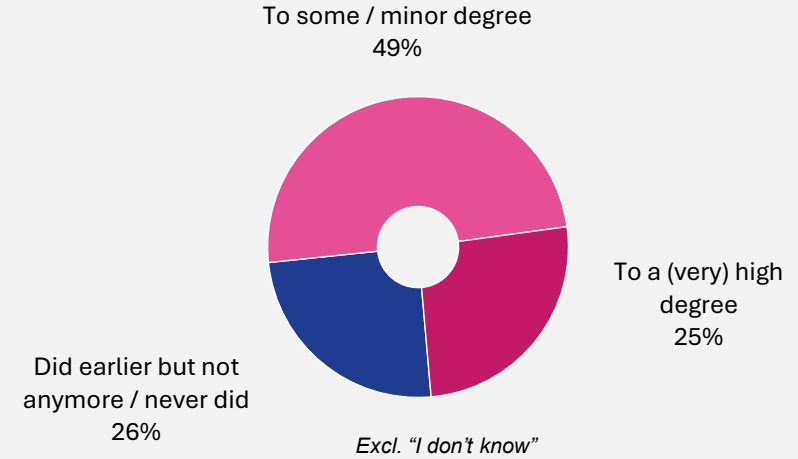
To what degree do you currently experience the following symptoms / challenges due to your N/IH? (choose 1 answer for each option)

Q59v Headache / migraine

25% reported experiencing headaches or migraines to a (very) high degree. Roughly half (49%) to some or a minor degree, and 26% stated they had experienced headaches or migraines earlier but no longer did, or that they had never experienced them at all.

By diagnosis, IH patients reported headaches or migraines to a (very) high degree more often (36%) than those with NT1 (20%) or NT2 (29%).

By age, younger groups (18–39 and 40–59 years) reported headaches to a (very) high degree more frequently (26% each) compared to those aged 60+ (12%). By gender: Women reported headaches or migraines to a (very) high degree more often than men (28% vs. 17%).



59v. To what degree do you currently experience the following symptoms/challenges due to your N/IH? (choose 1 answer for each option) - Headache / migraine	Total	N/IH diagnosis			Age			Gender	
		NT1 / with cataplexy	NT2 / without cataplexy	IH	18-39 years	40-59 years	60+ years	Male	Female
To a very high degree	10%	7%	12%	15%	10%	11%	5%	6%	11%
To a high degree	14%	12%	16%	20%	15%	14%	6%	10%	16%
To some degree	23%	23%	24%	21%	23%	24%	12%	21%	23%
To a minor degree	25%	25%	23%	26%	26%	25%	24%	23%	26%
I did earlier but not anymore	5%	6%	4%	4%	4%	6%	9%	5%	5%
I never did	20%	22%	18%	12%	19%	17%	36%	31%	16%
I don't know	4%	4%	2%	2%	3%	3%	9%	6%	3%
Number of respondents: All with N/IH diagnosis	1.500	944	205	312	894	505	101	363	1.129
To a (very) high degree	25%	20%	29%	36%	26%	26%	12%	17%	28%
To some / minor degree	49%	51%	48%	48%	51%	51%	39%	46%	51%
Did earlier but not anymore / never did	26%	29%	23%	16%	24%	24%	49%	38%	22%

(excl. I don't know)

Thank you for reading



eNAP
European Narcolepsy
Alliance for Patients

