

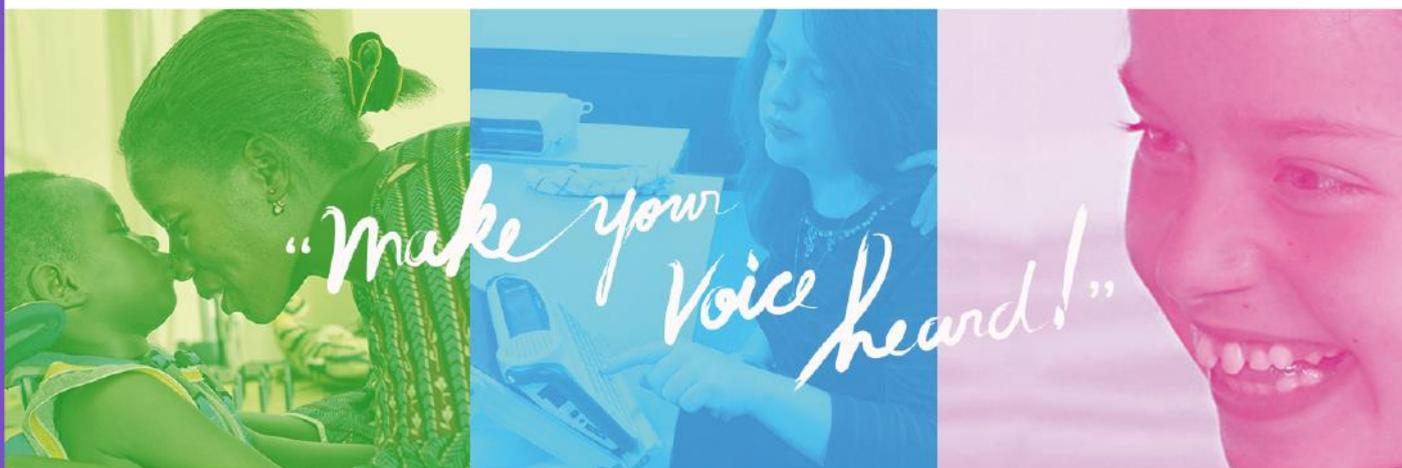


Juggling care and daily life

The balancing act of the rare disease
community

A Rare Barometer survey

May 2017



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The survey '*Juggling care and daily life: The balancing act of the rare disease community*' was conducted by EURORDIS-Rare Disease Europe via [Rare Barometer Voices](#) and in the scope of the EU-funded project [INNOVCare](#).

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 700 rare disease patient organisations from more than 60 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services.

Rare Barometer Voices is a [EURORDIS-Rare Diseases Europe](#) initiative and part of the wider [Rare Barometer Programme](#), created to systematically collect patients' opinions on transversal topics and introduce them into the policy and decision-making process. The objective is to transform patients' and families' opinions and experiences into facts and figures that can be shared with a wider public and policymakers.

The EU-funded project [INNOVCare](#) gives a voice to the social and everyday needs of people living with a rare disease and addresses the need for person-centred care in European countries. The project is developing and testing an innovative care pathway that links health and social services, using case management.

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- Native English-speaking proof-readers who gave their feedback on the survey questionnaire: Suzy Cooper, Polly Moyer.

Objective of the survey

The overall objective of the survey was to explore the social needs of people living with a rare disease and their carers, specifically by:

- Assessing the impact of rare diseases on mental, social and physical functions, household budget, employment and job careers, family life and well-being;
- Evaluating rare disease patients access to social and healthcare services and exploring the challenges surrounding coordination of care.

Executive summary

- For **52% of the patients and families surveyed, the rare disease has a severe (30%) or very severe (22%) impact** on everyday life (e.g. capacity to carry out daily tasks, motor and sensorial functioning, personal care). **The diseases are complex and symptoms can change across time;**
- **The time burden is substantial for a majority of people living with a rare disease and their carers, especially because of daily care and care coordination. This time burden falls heavily on women, often the main carers;**
- The majority of people living with a rare disease need to **visit different health, social and local support services in a short space of time, and find that hard to manage;**
- Most people living with a rare disease and their carers consider that **professionals from social services are poorly prepared to support them** and that there is a **clear lack of communication between service providers;**
- There is a **preference for services supporting autonomy of patients and carers** (e.g. psychological support, rehabilitation services) and significant number of respondents express unmet needs in this regard. For **very complex cases, specialised services are required and often not accessible;**
- **Work-life balance is a major challenge** for people living with a rare disease and their carers: **flexibility and adaptation are required** to allow for quality of employment (e.g. reorganisation of tasks or working hours);
- **Absence from work due to health-related problems is a serious challenge** for people living with a rare disease and their carers and the **possibility of obtaining special leave is the highest unmet employment need;**
- The disease has serious effects on social and family life, **thus triggering isolation** and feelings of being neglected for some members of the family;
- **Mental health of people living with a rare disease often deteriorates** and is worse in comparison with the general population.

1. Methodology

1.1. Questionnaire design and translation

For the purpose of shaping and prioritising areas to be studied through the survey, a volunteer-based focus group was organised in October 2015 with 5 members of the [EURORDIS Council of National Alliances](#).

The questionnaire was also designed in collaboration with:

- Partners of the INNOVCare project (ZSI, Zentrum für Soziale Innovation, Karolinska Institutet and NoRo Resource Centre, Asociatia Prader Willi, Romania);
- Academics and corporate partners involved in the Rare Barometer Programme (University of Rouen, Social Science department and MAPI, Patient-Centered Research company) also participated in shaping the methodology of the survey;
- EURORDIS members involved in the Rare Barometer Programme who previously carried out surveys on the social impact of rare diseases (Rare Diseases Denmark and FEDER, Spanish Alliance for Rare Diseases).

The questionnaire was translated in 23 languages¹ and the languages were selected for being the most used within each of the EU countries.

MAPI, partner of the Rare Barometer Programme and expert in medical translation and linguistic validation, provided the translation in kind. The translation was also checked by volunteer patient organisations to ensure that questions and wording were relevant to the different national contexts.

1.2. Timing and organisation

The study comprised two stages with the aim of reducing the length of the questionnaire and limiting participants dropout:

- The first stage dealt with care needs, access to care services, coordination of care and the cost of the disease;
- The second stage dealt with employment, schooling, family and social life and well-being.

The first stage of the survey was opened from 2nd August 2016 to 28th of February 2017. The second stage from 10th November 2016 to 28th of February 2017.

The stage 1 sample received 3450 answers, including 3071 valid questionnaires and stage 2 received 2117 answers, including 1953 valid questionnaires.

¹ Bulgarian, Croatian, Czech, Danish, Dutch, English, Estonian, Finnish, French, German, Greek, Hungarian, Italian, Latvian, Lithuanian, Polish, Portuguese, Romanian, Russian, Slovak, Slovenian, Spanish, Swedish

1.3. Survey sample

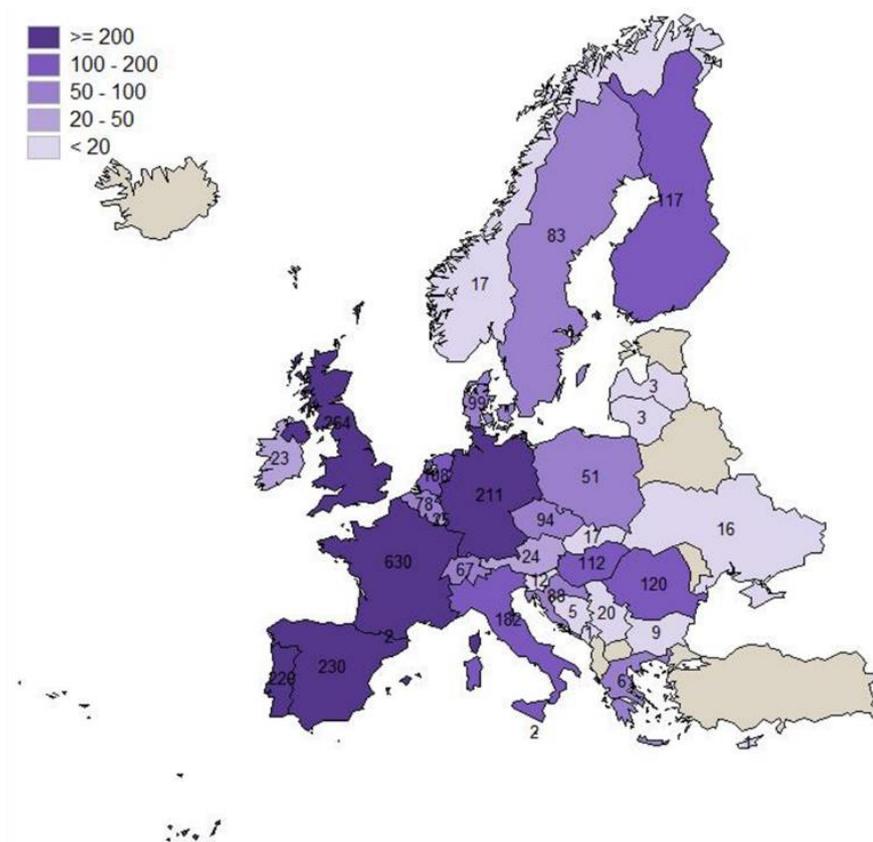
1.3.1. Rare Barometer Voices

Patients who participated in this survey are part of the [Rare Barometer Voices](#) database. [Rare Barometer Voices](#) is a tool to carry out EURORDIS quantitative surveys on issues affecting people living with a rare disease. It is made up of a community of over 5,000 people living with a rare disease who commit to regularly participate in surveys and studies. The Rare Barometer Voices survey software enables high-quality, secure data collection and analysis. Rare Barometer Voices covers 48 countries and all surveys are conducted in 23 languages. This database has been approved by the French data protection authority (CNIL).



1.3.2. Sample composition

The geographical repartition of the sample (stage 1) is as follow:



The rare disease population is very diverse: there are over 6,000 distinct rare diseases and a range of disease group, including metabolic, neuro-muscular, autoimmune, developmental anomalies, bleeding disorders, cardiovascular, respiratory, skin diseases and rare cancers. The sample of this survey represents this diversity and is **composed of 802 diseases**. It is also composed as follows:

Type	Frequency
Gender	
Male	21 %
Female	79 %
Other	<0,5%
Diagnosis Status	
Diagnosed	92 %
Undiagnosed	8 %
Respondent Status (Several answers possible)	
Patient	62 %
Parent of a child living with a rare disease	37 %
Grandparent of a person living with a rare disease	1 %
Spouse of a person living with a rare disease	2%
Uncle/Aunt of a person living with a rare disease	1 %
Sibling of a person living with a rare disease	4 %
Other	3 %

The female proportion is high (79/21) compared to the general population (52/48). These figures reflect several aspects:

- the fact that the primary carer role for people living with rare diseases is primarily assumed by the mother has been proven by the ENSERIO² study. It is confirmed by the results of the survey carried out within the INNOVCare project, as 71% of parents living with a rare disease identify the mother as the main carer in the household;
- the usual tendencies of woman to be more interested in health-related subjects and medicine (Pew Research Center, 2015³);
- the fact that woman contribute disproportionately to online panel surveys (Smith, 2008⁴);

² FEDER : Huete García, A and Díaz Velázquez, E. Situación y Necesidades Sociosanitarias de las personas con Enfermedades Raras en España, <http://www.enfermedades-raras.org/index.php/actualidad/publicaciones/1281-estudio-enserio>, Madrid, 2009

³ Kennedy, B, Funk, C, Public interest in science, health and other topics, p. 3, Pew research Center, 2015

⁴ Smith, W.G, Does Gender Influence Online Survey Participation? p.9 University Faculty Online Survey Response Behavior, 2008

2. Survey results

Reading note:

- Sentences in italics mean that the wording of the sentence is the exact the same wording as the question asked during the survey;
- Patients were asked to answer concerning their personal situation and relatives with the situation of the patient;
- Respondents were asked to evaluate the impact of the rare disease on the state of their household situation as a whole;
- Paragraphs on a purple background mention results that impact the reading of the rest of the report.

2.1. Impact of rare diseases on patients and related needs

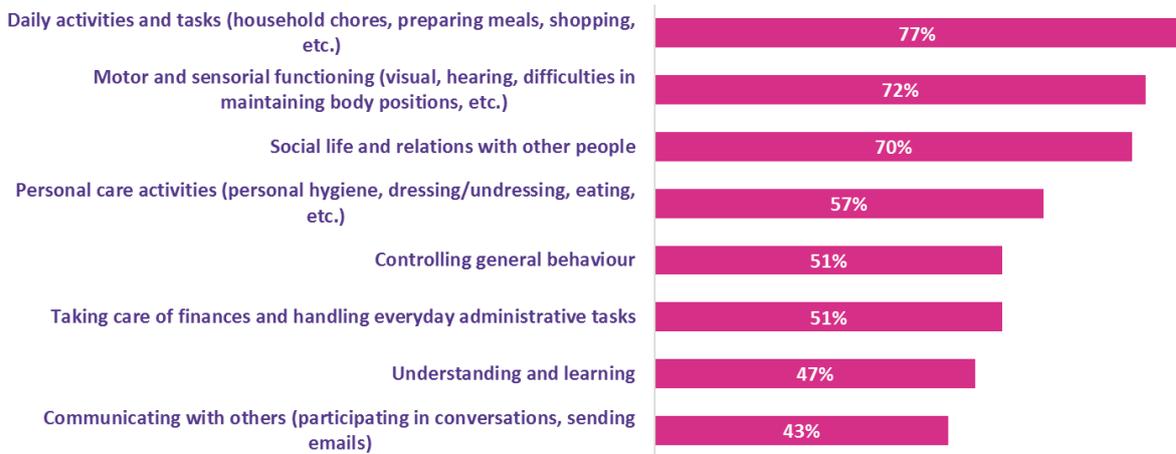
2.1.1. Most rare diseases have a serious impact on patients' everyday life

Rare diseases are characterised by a wide range of symptoms and signs that vary not only from disease to disease but also between patients suffering from the same disease. Most rare diseases are genetic, often chronic and life-threatening. They are present throughout a person's entire life, even if symptoms do not immediately appear.

Without distinguishing between diseases, the results show that a large percentage of rare diseases have a serious impact on patients' everyday life and **prevent them from carrying out the most basics and essential daily tasks** (see graph. 1):

- **More than 70% consider that they have difficulty with daily activities and tasks** and that the disease impacts their motor and sensorial functioning;
- More than 50% mention that their social life and their ability to cope with personal care activities is impacted by the disease, as well as their ability to control general behaviour and to take care of their finances;
- More than 40% also have difficulty with understanding, learning and communicating with others.

Graph. 1. To what extent does the person living with a rare disease have difficulties with... (Subtotal difficulty) (n=2689)

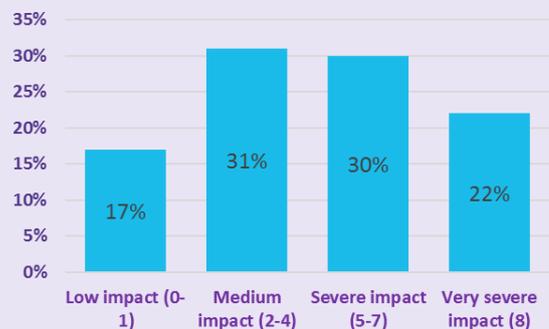


Some modalities have been grouped:
 Difficulty=Completely unable + A lot of difficulty + Some difficulty

The question from graph. 1 can be analysed by considering the number of affirmative answers given by each respondent. For instance, in graph. 2, the category "medium impact" represents respondents who gave 2 to 3 affirmative answers to the question or in other words, respondents who expressed 2 to 3 difficulties.

This table shows that **most rare diseases have an impact on several aspect of the patients' everyday lives**. It also demonstrates **the diversity of the diseases represented in terms of impact**, with two significant cases: a proportion of the sample (17%) composed of diseases that are less complex and another significant part of the sample (22%) made up of diseases for which any basic functions and capacities are affected.

Graph. 2. To what extent does the person living with a rare disease have difficulties with... Combined variable Number of difficulties expressed (n=2689)



2.1.2. Most rare diseases are complex

Despite this diversity, many characteristics are common to rare diseases and the complexity of these diseases, as shown in graph. 2, is one of these common features. This is confirmed by the fact that **85% of respondents says that the disease impacts upon several aspects of the health and everyday life** (against 15%) and by patient testimonies in the survey open questions:

“ I cannot lift anything weighing more than 10k on medical advice, I tire easily and have to be very careful with diet. If I overexert myself I get considerable abdominal discomfort.»

Male, United Kingdom

Another characteristic of rare diseases is that symptoms can considerably vary across time and may not always be visible:

“ The difficulty lies in the impossibility of carrying a routine. When you do not have episodes you can do a normal life, but when episodes occur, it often interrupts what the person is doing. The problem arises when one day you appear completely healthy, the next day you are sick, and two days later you appear completely normal again. Many people find it difficult to understand the disease and the process, and the absenteeism that entails.»

Female, Spain

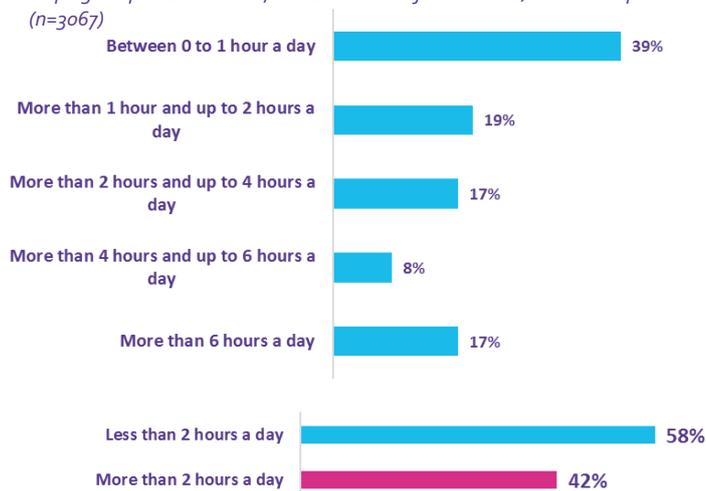
2.2. A heavy time burden on daily life, especially for carers

2.2.1. Caring represents a heavy time burden

A substantial care burden

The time spent in an average day on illness-related tasks has a serious impact on the everyday life of people living with a rare disease: **42% spend more than 2 hours a day on care-related tasks**. Among them, 25% are spending more than 6 hours a day, which can be considered as almost all of their “active” part of the day.

Graph. 3. How much time do you invest in an average day for illness-related daily tasks (hygiene, helping the patient with house chores, helping the patient to move, administration of treatments)? Total sample (n=3067)



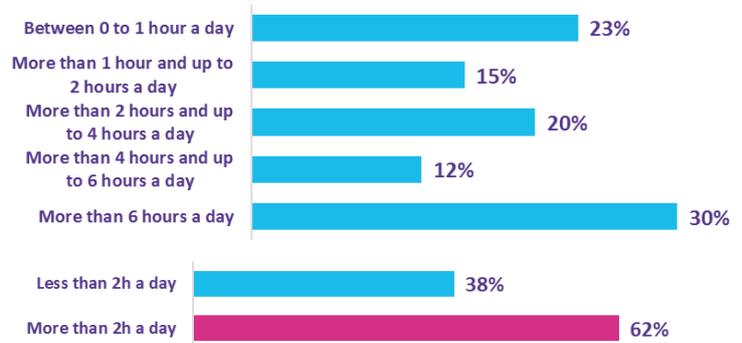
Some modalities have been grouped:
 Less than 2h a day= Between 0 to 1 hour a day + More than 1 hour and up to 2 hours a day
 More than 2h a day = More than 2 hours and up to 4 hours a day + More than 4 hours and up to 6 hours a day + More than 6 hours a day

The heavy time burden on carers, in particular for very severe conditions

Looking at the result for carers only, the time burden, is reported as being substantial: 62% spend more than 2 hours per day on illness-related daily tasks (against 38% who spend less than two hours).

Specifically, results show that a significant percentage of carers are providing intense caring: 30% spend more than 6 hours a day helping the patient, meaning that they dedicate almost all of their active part of the day to care for another person. In comparison, OECD figures also show that 50% of carers (for patients suffering from any type of disease or dependent conditions) provide less than 1.4 hours a day. Consequently, rare disease patient carers seem to be clearly above the OECD carers average.

Graph. 4. How much time do you invest in an average day for illness-related daily tasks (hygiene, helping the patient with house chores, helping the patient to move, administration of treatments)? [For carers] (n=1147)



Some modalities have been grouped:

Less than 2h a day = Between 0 to 1 hour a day + More than 1 hour and up to 2 hours a day

More than 2h a day = More than 2 hours and up to 4 hours a day + More than 4 hours and up to 6 hours a day + More than 6 hours a day

The time spent for disease-related tasks varies depending on the severity of the disease (see graph. 2.). With regard to diseases with very severe impact, 47% of respondents who care for severely affected people have to spend more than 6 hours a day on illness-related tasks.

Graph. 5. How much time do you invest in an average day for illness-related daily tasks (hygiene, helping the patient with house chores, helping the patient to move, administration of treatments)? [For carers] (n=1147)

Carer	Between 0 to 1 hour a day	More than 1 hour and up to 2 hours a day	More than 2 hours and up to 4 hours a day	More than 4 hours and up to 6 hours a day	More than 6 hours a day
Low impact	58%	18%	13%	3%	8%
Medium impact	39%	20%	21%	7%	13%
Severe impact	23%	17%	23%	9%	28%
Very severe impact	5%	11%	19%	18%	47%

2.2.2. Organising care increases patients' care related time burden

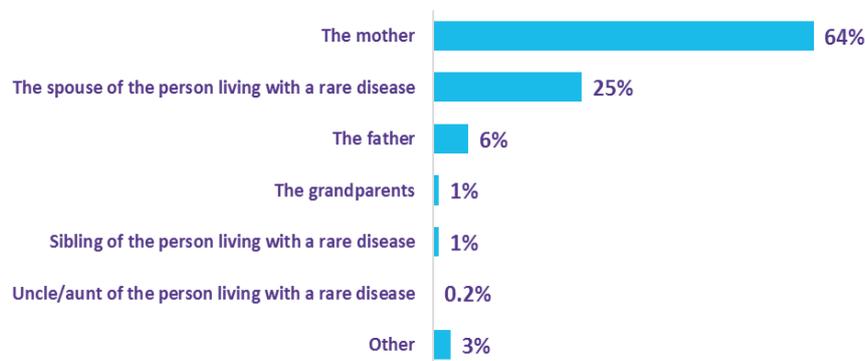
As described earlier, care-related activities represent a huge time burden on patients and carers. In addition to these essential tasks, people living with a rare disease have to deal with the coordination of care. When it comes to finding the necessary information on the disease, finding the right professionals, arranging and attending appointments with different service providers and traveling to and from appointments, 75% of the respondents declare that it is time-consuming (against 25% not time consuming). If 36% of the participants declare that they can manage this time, 64% consider that it is, on the contrary, difficult to manage.

The time dedicated to coordination of care increases with the severity of the disease. Among patients affected by severely disabling diseases, 88% declare that coordinating care is time consuming and 81% that it is difficult to manage.

2.2.3. A burden that heavily relies on woman

The role of primary carer for people living with rare diseases is primarily assumed by women. The results show for example that the overwhelming majority (64%) of rare disease patient carers are mothers.

Graph. 6. Who is the main carer in your household ? [For carers] (n=1712)



2.3. The challenge of coordination of care

2.3.1. Professionals from social services are poorly prepared to support rare disease patients

Among social workers, teachers and care givers, because the diseases are rare and the situations very specific and complex, the level of knowledge regarding the diseases and their consequences is most of the time very low. Therefore, **75% of the respondents consider that this level of knowledge is deficient**. Beyond being aware of a specific disease, professionals do not seem sensitised to general issues that surround rare diseases, such as the difficulty to get a diagnosis or the number of care providers that can be involved in the management of a single disease: **71% of the participants consider that they are not sufficiently prepared to support them**.

As a result, the time spent explaining the disease over the phone to different services and experts is time consuming for 74% of the respondents and for a majority among them, this amount of time is hard to manage (59%).

2.3.2. A clear lack of communication between the different service providers

Navigating the system between these different service providers is even more complicated as communication between them is poor: **67% of the respondents say that they communicate the disease-related information badly** and among them, 33% very badly.

“ We face an absence of communication and coordination between the health teams and, on a broader scale, between therapists. We, the parents, undertake the role of coordinators and researchers of potential therapies, support and strategies. »

Female, Portugal

This lack of communication is enhanced by the complexity and the unknown aspect of the disease, that does not fit with pre-existing processes:

“ Interprofessional communication works only through the good intentions and efforts of particular professional individuals, but not as a course of action. This is one of the main difficulties in the lives of families with disabilities. Today, departments such as neurology, pulmonology, nutrition, rehabilitation, orthopedics and orthoptists communicate with each other primarily through patients themselves or their parents however this only works for very dedicated people. Not everyone is able or willing to carry this out. »

Male, Czech Republic

2.3.3. The lack of coordination and communication has a serious impact on patients' situation

This lack of coordination and communication has a serious impact on patients' situation and can delay help they could have benefited from:

“ It took two years to obtain social care support...departments don't talk to one another so records weren't passed on. They heard from me and my mum but didn't have my medical records to confirm so I was discharged without help...this isn't the first time...it's a constant battle. »

Female, United Kingdom

These delays can have a major impact on the financial and more general situation of the families as it can delay social help they could be entitled to:

“ Everyone becomes self-involved in their own tasks and forgets about the bigger picture of the disabled person's life. The disabled person has to deal with several different services to receive help and benefits in France, such as the regional council, the benefits office and the regional offices dealing with a disabled person's enquiries. There are therefore often waiting times of around 6 months, whilst dealing with each service or waiting for service A to send your paperwork to service B. During this time, you have not had time to employ someone and you are still not working.»

Female, France

2.3.4. Patients are badly informed about their rights

In this context, more than 70% do not feel well informed about their social rights or help they could be entitled to: they have poor knowledge about their rights related to the consequences of the disease (73% not well informed), financial help (73%) and the relevant social services that can help them (71%). However, respondents feel better informed about medical services for their disease with 47% feeling not well informed and 53% well informed.

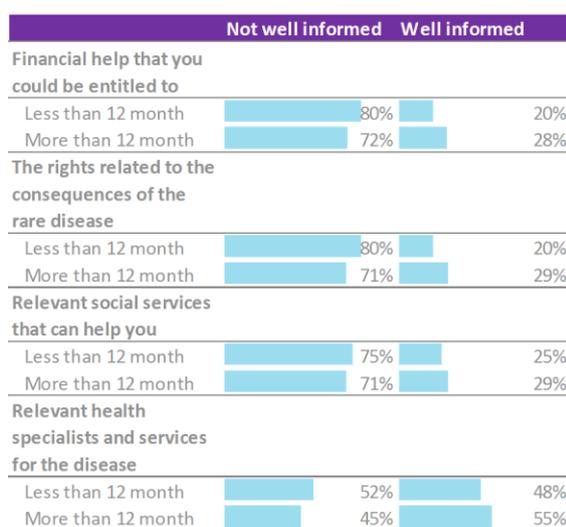
In situations concerning rare diseases where, due to the low prevalence of the diseases and the lack of expertise around the disease, the patient is forced to become knowledgeable about his own disease state.

“ In the last two years from the time of diagnosis all that has helped me is my own research and my internet experience over time to better manage my health has been a gradual improvement.»

Female, Greece

The level of information varies with the amount of time which has elapsed since diagnosis was received, which shows that patients' knowledge evolve over time as they become more familiar with the disease and the administrative system. With regard to those who feel well informed, the difference between respondents recently diagnosed and diagnosed more than 1 year ago ranges between 4 to 9 percentage points depending on the nature of the information.

Graph. 7. How well informed do you feel about... (crossed with when was the rare disease diagnosis given) (n=3067)



2.3.5. The difficulty involved in visiting various social and healthcare care providers in a short space of time

The complex nature of most rare diseases requires that patients receive assistance from a number of different social care providers: 65% of the respondents declare that they have to visit different health, social and local support services in a short space of time. This feeling is confirmed by other studies carried out among rare disease patients, such as Only Strong Survive carried out by Rare Disease Denmark which shows that patients mention between 10 to 30 social and healthcare professionals as contact points.

Given this level of complexity, the coordination of care between multiple and often independent providers becomes a challenge for the majority of respondents: 51% declare that having to visit different care providers is hard to manage (against 49% not hard to manage).

“The appointments should be multidisciplinary and allowing for the various specialists to see the patient on the same day and the same place. Besides facilitating communication and the definition of adequate treatment it would also avoid that the patient has to travel to different appointments and places, being absent from work (losing income and facing discrimination at the workplace) and spending a lot in travel. »

Female, Portugal

2.4. Access to services: a preference for services that strengthen autonomy

2.4.1. A preference for services that strengthen autonomy

Most rare diseases do not have available treatment and existing treatments are not always able to minimise all the complex impairments and disabilities triggered by the disease, as a result, support services are essential to patients to help them manage the everyday challenges of the disease:

“5 years since my diagnosis and now aware of the problems, I am now selling my home with a view to being able to utilise some funds to enable me to live a fuller and more independent life. There is nothing I can do about the disease, but I can lessen the impact myself when I have access to services or treatments which may improve my life. »

Female, United Kingdom

The main organisation who support families in dealing with the everyday consequences of the diseases is the hospital (40%). It is also noticeable that patient organisations are the second support provider for patients (14%).

The complexity and severity of rare diseases lead to significant requirements in terms of services. The results show that these needs remain largely unmet (see graph. 7):

- In a situation where **the cost related to the disease is considered high by 73% of the respondents** and difficult to manage by 63%, when participants were asked to describe their needs and corresponding access to these services, economic issues, including fee reimbursement (56% of “uncovered needs”), disability benefits (50%) and tax exemption (45%) were mentioned as the least met needs - something often observed in surveys asking about people’s top concerns.

“We have to pay expensive parking fees at hospitals, and have no financial relief, even though paying for child care is very demanding. We are waiting for care allowance but approval takes longer than 8 months (for the first round!). We pay for all the rehab, because it is not provided by health insurance (hippo-therapy, swimming, body workout (...) rehabilitation). Because we are so focused on the baby, he is doing relatively well, so officials reject our applications for support. We pay for everything from our savings and have no support from society.»

Female, Czech Republic

- Looking at the results in more detail (see graph. 9), with regard to fee reimbursement and tax exemption, among people whose needs are not covered, **respectively 34% and 30% do not have access to these financial help related to the disease but think it would be necessary** and 21% and 15% have already access to these financial aids but consider that the help received is insufficient. Regarding disability benefits, among people whose needs are not covered, part of the respondents (28%) already benefit from this type of financial help but consider that they would need more, and 22% do not have access to disability benefit and consider that they would need to.
- The second highest need expressed is the request for services that help patients to maintain their autonomy and help self-management of the disease, including rehabilitation services and therapies (48%), psychological support (47%), support to adapt house to the needs (30%), medical devices (28%) and adapted transports (23%). Autonomy is particularly at risk in cases in which the person needs help with their most basic and private needs or when the impairment affects his/her ability to communicate. Services supporting patients and carers on daily life needs were mentioned as being very helpful when it comes to remaining employed:

“ Housekeeping to compensate for my willingness to work 100% and parking card.»

Female, France

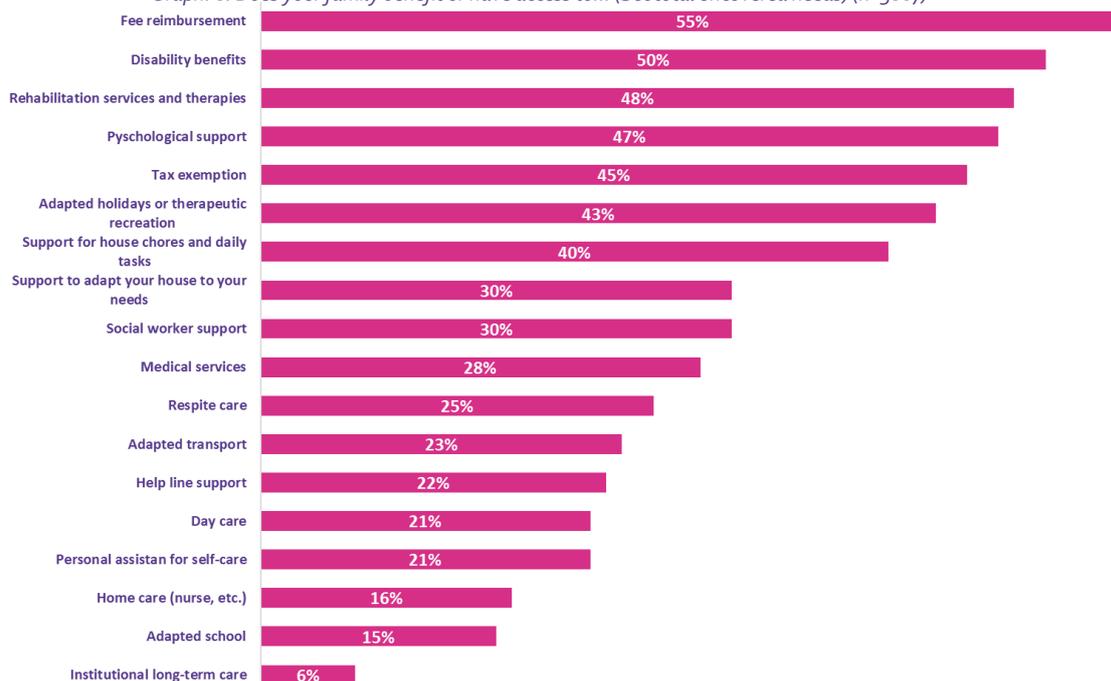
However, results show that most of the people who request this kind of help do not have any access to the services, this is especially true for psychological support (38% say that they do not have access but they would need it) and the support to adapt their house to their needs (24%):

“ However the psychological effects it has on daily life are huge. I do not 'look ill' therefore I am treated as though I have no health problems. The GP will give me drugs for depression but this is not what I want. I need help with strategies to help me manage the psychological side of living with a rare disease for which there is no treatment..»

Female, United Kingdom

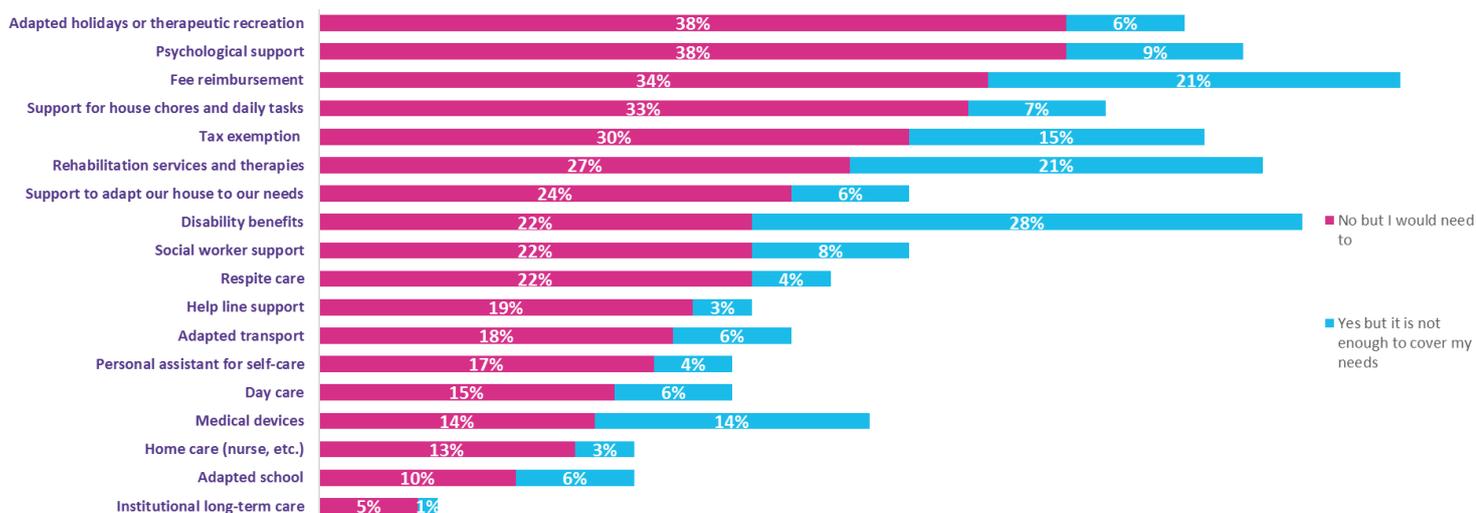
- External help from benefactors who can assist with care management and daily tasks, including help with house chores and daily tasks and social worker support is also needed for a significant percentage of the respondents. Among those who need this kind of support, the majority do not have access to this type of help (with respectively 33% and 22%) and very few are satisfied with the level of support provided (7% and 8%).

Graph. 8. Does your family benefit or have access to... (Subtotal uncovered needs) (n=3067)



Some modalities have been grouped:
Uncovered needs: Yes but it is not enough to cover my needs + No but I would need

Graph. 9. Does your family benefit or have access to... (n=3067)



Some modalities have been grouped:
Covered needs: Yes and it covers my needs + Yes but I don't need to + No but I don't need to

2.4.2. Specialised services requested for severe cases

Other services seem to be less of a priority for the majority of people affected by a rare disease (see graph. 8):

- The need for services that could disturb people's privacy, including a personal assistant for self care, home care and day care are requested by 20% or less of the respondents. However, it is noticeable that patients who need this type of services do not have access to what they need, with respectively 17%, 13% and 5% saying that they have need of these services but they do not have access to them.

- Finally, services which exclude patients from the mainstream system, both adults and children, such as adapted school and institutional long term care, are needed by a few people only. Here again, these specific needs are not satisfied for the majority of people who need them, respectively 10% and 5%.

However, patients affected by conditions that severely impact their every-day lives (see p. 9 show a greater need for this category of services. Moreover, it seems that a large percentage of them do not have access to these necessary services. For instance, 31% have need of a personal assistant for self care and do not have access to it, 26% for day care and 20% for adapted school. It should also be noted that 26% do have access to day care, but consider that they need more in order to fully cover their needs.

Graph. 10. Does your family benefit or have access to... (n=3067)

	No but I would need to	Yes but it is not enough to cover my needs	Other modalities
Personal assistant for self-care	17%	3%	80%
Low impact	4%	1%	95%
Medium impact	10%	2%	88%
Severe impact	21%	4%	75%
Very severe impact	31%	7%	62%
Day care	15%	6%	79%
Low impact	5%	1%	94%
Medium impact	9%	1%	89%
Severe impact	19%	5%	76%
Very severe impact	26%	16%	58%
Institutional long-term care	5%	1%	94%
Low impact	1%	0%	98%
Medium impact	2%	0%	98%
Severe impact	6%	1%	93%
Very severe impact	9%	2%	89%
Adapted school	10%	6%	85%
Low impact	3%	1%	97%
Medium impact	5%	2%	94%
Severe impact	10%	5%	84%
Very severe impact	20%	15%	65%
Home care (nurse, etc.)	22%	8%	70%
Low impact	4%	2%	94%
Medium impact	8%	1%	91%
Severe impact	14%	4%	82%
Very severe impact	23%	6%	71%

2.5. The work-life balance challenge

Reading note: Even though carers and patients are not impacted in the same way by the disease, there is very low variation in the results between these two populations. Furthermore 8% of the sample is composed of participants who are both patients and relatives (parents, grandparents or uncle) of someone affected by a rare disease. Therefore, results are presented as a single sample.

2.5.1. The difficulty of combining rare diseases and work life

When voicing their experience on employment-related issues, patients and carers express problems including fatigue due to the disease itself or as a side-effect of treatment, memory issues, difficulty to travel from and to the workplace, etc.

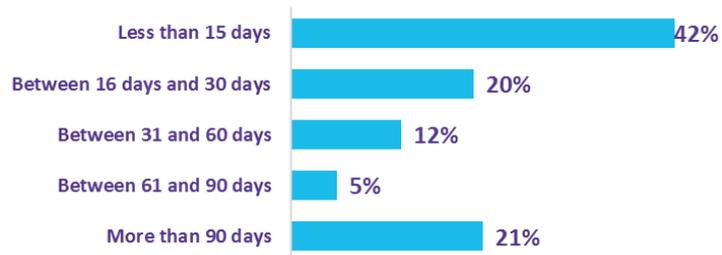
“With hyperacusis, tinnitus, hearing loss and dizziness, I had to stop working as a teacher and reinvent myself. I currently work in an office and the dizziness and hearing loss make my job very difficult.»

Female, Spain

Respondents talked a lot about their difficulties balancing work life and organisation of care. As a result, being affected by a rare disease can trigger several issues such as:

- high absence rate at work, for instance to attend medical appointments: **21% of the respondents declare that they were absent from work more than 90 days in the last 12 months**, or a quarter of the year:

Graph. 11. In the past 12 months, how many days in total were you absent from work for health-related problems? (n=1095)



- having to make the decision to leave or reduce employment because of their commitment to providing care or more care: 13% have decided to look after their child or children full time:

“My son has a rare disease. He is now 28 years old and is completely dependent on the support of his father and mother since he was 5 years old. Because of this, the mother had to leave her job and take care of the child fulltime. Our biggest challenge is to keep him alive.»

Female, Portugal

- facing the fact that the child is starting school later than average: **23% of the parents caring for a child living with a rare disease report this issue;**
- difficulty in accessing higher education: 19% declare that it prevented them from studying according to their wishes.

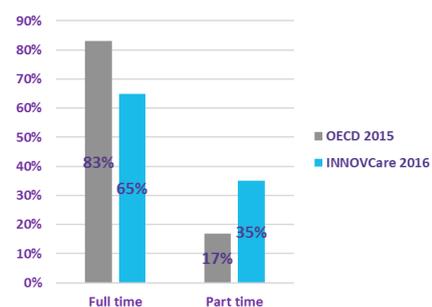
With regard to these issues, most of the time, they experience lack of understanding from employers or school, mainly due to a lack of knowledge about the disease – for example patients are often suspected of making up symptoms – that leads to a lack of adaptation of the workplace.

2.5.2. Most rare disease patients remain employed but the disease decreases employment quality

Working whilst caring or when affected by a rare disease represents a major challenge. People affected by a rare disease remain employed (46%) in similar proportions compared to the general population (47%) which also includes carers and people affected by chronic diseases (ISSP, EU 28 results, 2011). These figures have to be considered with caution as the rare disease patient sample is more educated than the general population and, as a result, better protected against the possibility of becoming unemployed, but the trend remains valid.

However, rare diseases have a specific impact on **employment and career quality**:

Graph. 12. What type of contract do you have? (n=913)



- People living with a rare disease often need to stop working during challenging times:

“The worse time, was the time we were looking for a diagnosis (which took roughly 6 years). It was also the time I had two young children. By asking a year "non paid break "(to pursue my diagnosis journey and to take care of my children, one of them also having similar symptoms) I received a refusal from the employer. So I decided to give up my job and stayed unemployed for 4 years. At least I had the time to find out exactly what disease I had enough energy to take care of my children. Strangely, feeling stronger after the diagnosis and the information about the disease (which my husband I and I sought by ourselves), I decided to pick up work again. One year: part-time and thus earning half as much as before. Later on and until now: working less then a part time and earning even less; but the job is my dream job and I still have a husband who is the main "breadwinner". That's how we manage to make ends meet.»

Female, Luxembourg

- Or to reduce working hours: the proportion of part-time jobs among the rare disease sample (35%, see graph. 12) is considerably higher than in the general population (17%), which is also due to the fact that woman are more numerous in the sample:

“I am a wheelchair user and I am not able to work fulltime. I was a researcher but can not compete with colleagues that work fulltime. I had a limited time contract as a post doctoral researcher and could not get funding after that probably partially due to my diagnose. Even fieldwork for research for consulting reason became impossible, I could not get as many consulting jobs as most of my former colleagues. I felt that employers are "afraid" to employ me, but this was officially never the reason. It took me 8 years to get a new part-time job.»

Male, Poland

2.5.3. Less fulfilling job careers for rare disease patients

In the end, all the problems described earlier lead to less fulfilling job careers, and less responsibilities:

- 76% of the respondents declare that the fact they are affected by a rare disease has limited their professional choices;
- 67% also declare that the disease has limited them in being promoted, many report that they had to find a job with lower employment prospects in the end:

“My previous job role had prospects to go higher within the company. Due to the onset of my rare disease my mobility was compromised meaning that I was unable to fulfil the current role. This lead to me having to search for a new job with less prospects.»

Female, United Kingdom

This lack of professional opportunities is linked to the difficulty in accessing higher education: 94% of the respondents who report difficulties in accessing higher education declare that the disease has limited their professional choices, 92% their opportunities to get a job and 67% their promotions.

In the open questions, it is frequently mentioned that many people affected by a rare disease fail to realise their full potential at work, work below their skill capacities and fail to take up training opportunities.

“ I am mother/carer of 2 children (now young adults) who both have serious but different health issues related to the genetic, neurological disability Neurofibromatosis Type 1. My daughter had her first bone operation aged 2 years and each and every year until her last operation in 2000. My son showed challenging behaviour and extreme anxiety resulting in verbal & physical aggression from the age of 4 years old. Both of my offspring had effects of disability which made it impossible for me to continue with my Higher Education or a part or full time job. I have had a full time job of supporting them in daily tasks, accessing social educational and leisure activities, training them for many independent living tasks etc.»

Female, United Kingdom

“ I was studying for a degree in software engineering, and spent a year in industry after the first two years at university. By the end of that year, my mental and physical health both had collapsed and I had no choice but to suspend my studies and move back to my parents' because I wasn't well enough to work or cope on my own. I spent three years applying for every job I thought I had any chance of doing, and over that time went from ambulatory, to a stick, to crutches, and then to a manual and then a powered wheelchair. Every time my disability got more obvious, the look of "oh, you're wasting my time" when I went to an interview got more obvious.»

Other gender, United Kingdom

2.5.4. An unsatisfied request for flexible employment practices

There is a clear need for understanding and flexibility from employers that is poorly met. Whether it be in terms of reorganisation of tasks or working hours (31%), assistance in travelling to work (26%), equipment and accessibility such as lift and specific chair or desk (29%), a relative majority of the respondents say that their current or last job was not specially adapted for them while they actually needed it. **Possibility of special leave being the highest unmet need for rare disease patients with 41%** who would need it and could not obtain it.

2.6. The impact of rare diseases on well-being and mental health

2.6.1. A decline in social and family life

Overall, the impact of rare diseases on families is important:

- The most important problem faced by families is the **isolation from friends and family: 54% declare that it was caused or amplified by the rare disease**. Some patients report the fact that an unknown disease can generate fear and misunderstanding among friends and employers, and they sometimes described how they are tired to explain their diseases to their friends or colleagues and prefer not to socialise in the end. The time burden described earlier is also a major obstacle to socialisation;
- More than half of the participants (**52%**) report that the disease triggered tensions between family members;
- Another aspect of family problems is the fact that members of the family can feel neglected, this often happens for siblings of a child affected by a rare disease for instance.

Despite these problems, the disease can also have a positive impact on some families with 45% declaring that it has strengthened the family unit.

2.6.2. Deteriorated mental health for people living with a rare disease

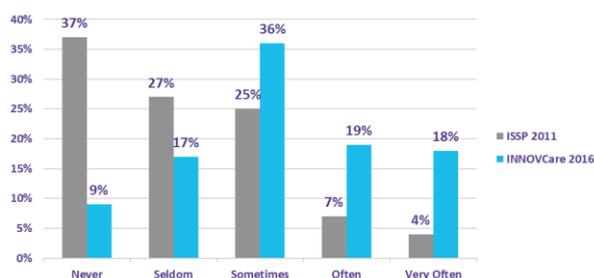
Being affected by a rare disease has a huge impact on mental health. With regard to patients, the fact that they feel misunderstood, that the disease is unknown by medical and social professionals or that they can remain undiagnosed for a long time, generates a lot of stress and sometimes can lead to serious mental health problems. Concerning carers, many studies on the effects of providing care over the long term show that it is characterised by anxiety, stress, loss of confidence and self esteem. The comparison with the general population (ISSP, International Social Survey Programme, 2011) on these issues is striking:

- In total, 37% of the respondents declare that they feel often (19%) or very often (18%) unhappy and depressed, compare to 11% of the general population.
- 34% also say that felt they could not overcome their problems often (17%) or very often (17%) in the past 4 weeks, when only 8% of the general population feel the same.

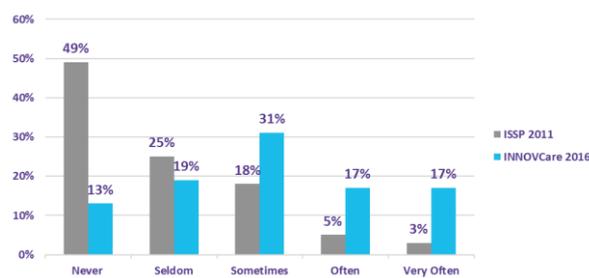
“ People believe I am making up symptoms, contributing to my poor mental health and making me able to cope less »

Female, United Kingdom

Graph. 13. In the past 4 weeks, how often have you felt unhappy and/or depressed?



Graph. 14. In the past 4 weeks, how often have you felt you could not overcome your problems?



My fatigue symptoms mean I am virtually unable to work and spend a lot of time resting. My life is very very limited: I am only 51 but able to do much less than many 75 year olds, but I would not qualify for any help from government benefits because the questions they ask don't capture the impact of my condition. I feel abandoned to this betrayed by my government it's awful if I didn't have such a good husband I really don't know how I could go on. I don't look ill but am very ill with a condition which no one understands or has heard of so get no sympathy. There's no cure or any hope of improvement it's depressing and I feel alone. People with well known conditions or who have acute conditions get sympathy but people with chronic conditions like mine »

Female, United Kingdom

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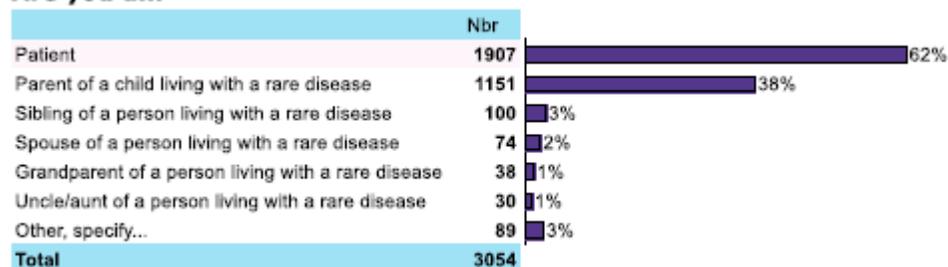
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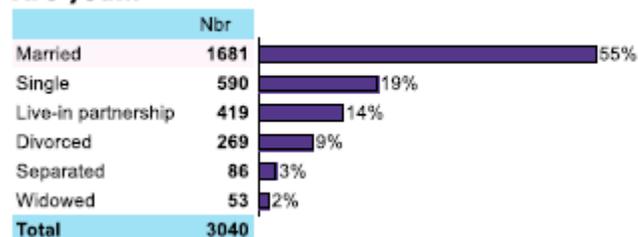
3. Annex: Survey Results

Sociodemographic information

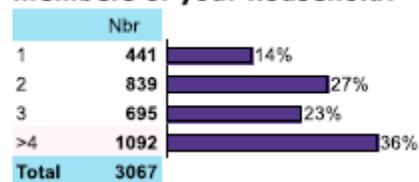
Are you a...



Are you...



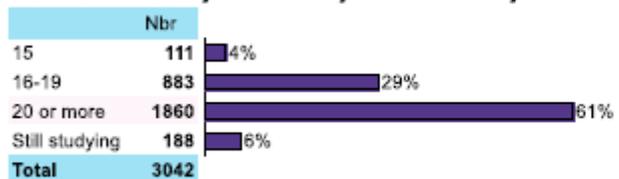
Including yourself, how many people – including children – live regularly as members of your household?



Including yourself, how many people live with a rare disease in your household?

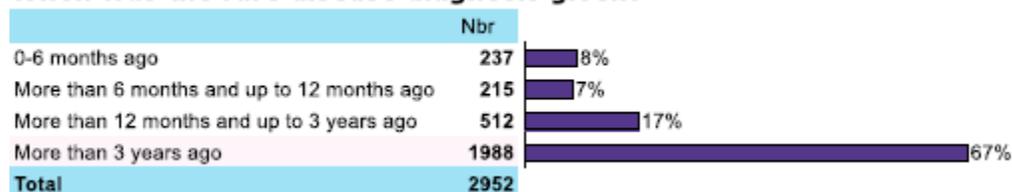


How old were you when you finished your full-time education?



CARE PROFILE

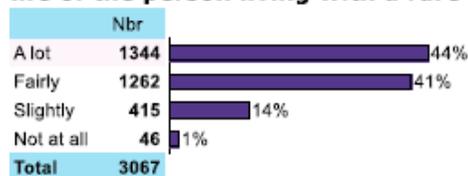
When was the rare disease diagnosis given?



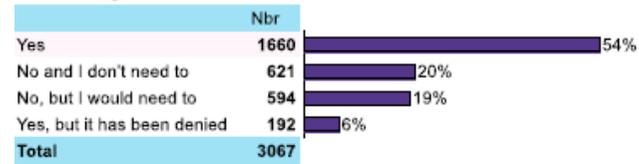
To what extent does the person living with a rare disease have difficulties with:

	No difficulty		Some difficulty		A lot of difficulty		Completely unable	
	N	% cit.	N	% cit.	N	% cit.	N	% cit.
Communicating with others (participating in conversations, sending emails)	1528	57%	658	24%	303	11%	200	7%
Understanding and learning	1423	53%	708	26%	479	18%	79	3%
Taking care of finances and handling everyday administrative tasks	1318	49%	604	22%	311	12%	456	17%
Controlling general behaviour	1310	49%	934	35%	360	13%	85	3%
Personal care activities (personal hygiene, dressing/undressing, eating, etc.)	1164	43%	887	33%	394	15%	244	9%
Social life and relations with other people	819	30%	1118	42%	666	25%	86	3%
Motor and sensorial functioning (visual, hearing, difficulties in maintaining body positions, etc.)	757	28%	1141	42%	713	27%	78	3%
Daily activities and tasks (household chores, preparing meals, shopping, etc.)	631	23%	910	34%	722	27%	426	16%

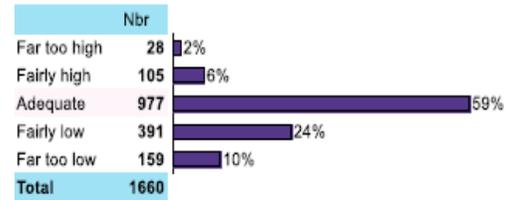
To what extent would you say that the disease impacts upon several aspects of health and everyday life of the person living with a rare disease?



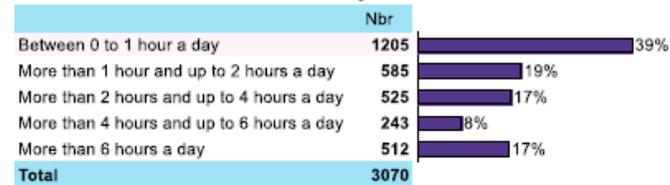
Has the person living with a rare disease been submitted to an official assessment of the level of disability?



In your opinion, do you think that the percentage of disability officially assigned to the person living with a rare disease is...?



How much time do you invest in a average day for illness-related daily tasks (hygiene, helping the patient with house chores, helping the patient to move, administration of treatments)?

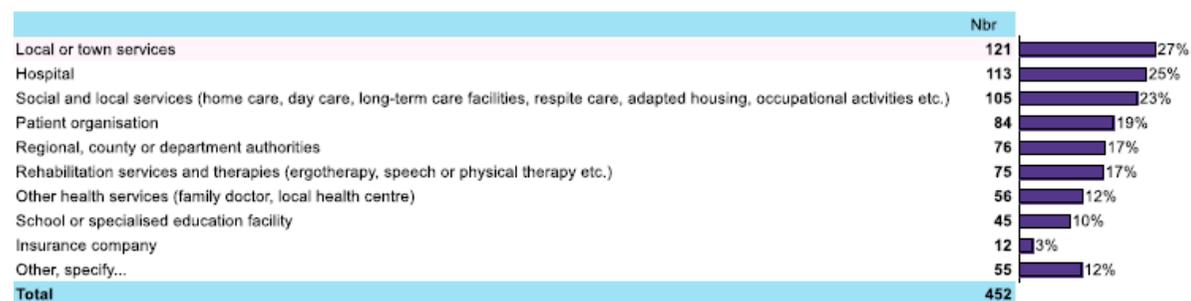


Does your family currently benefit or have access to ...

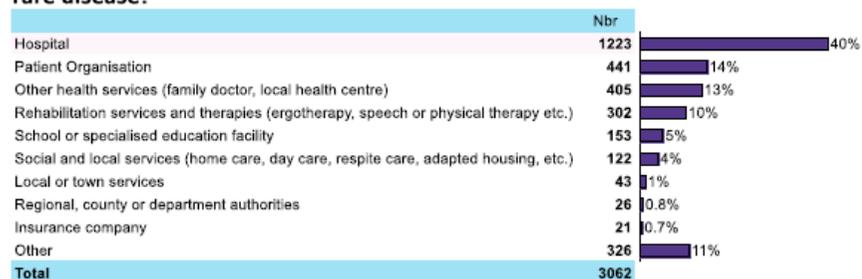
	Yes and it covers my needs		Yes but it is not enough to cover my needs		Yes but I don't need to		No but I would need to		No but I don't need to		Don't know	
	N	% cit.	N	% cit.	N	% cit.	N	% cit.	N	% cit.	N	% cit.
Social worker support	193	6%	259	8%	92	3%	672	22%	1694	55%	160	5%
Psychological support	371	12%	283	9%	107	3%	1159	38%	1015	33%	135	4%
Help line support	201	7%	100	3%	90	3%	581	19%	1820	59%	278	9%
Personal assistant for self-care	166	5%	116	4%	47	2%	520	17%	2065	67%	156	5%
Support for house chores and daily tasks	255	8%	203	7%	55	2%	1028	33%	1427	46%	102	3%
Home care (nurse, etc.)	176	6%	101	3%	75	2%	393	13%	2207	72%	118	4%
Rehabilitation services and therapies (ergotherapy, speech or physical therapy etc.)	570	19%	645	21%	53	2%	835	27%	873	28%	94	3%
Medical devices	729	24%	426	14%	61	2%	445	14%	1258	41%	151	5%
Day care (access to a day centre, occupational activities)	234	8%	187	6%	53	2%	471	15%	1963	64%	162	5%

	Yes and it covers my needs		Yes but it is not enough to cover my needs		Yes but I don't need to		No but I would need to		No but I don't need to		Don't know	
	N	% cit.	N	% cit.	N	% cit.	N	% cit.	N	% cit.	N	% cit.
Adapted holidays or therapeutic recreation	110	4%	172	6%	53	2%	1161	38%	1332	43%	242	8%
Support to adapt your house to your needs	168	5%	198	6%	67	2%	737	24%	1723	56%	177	6%
Adapted school	242	8%	183	6%	58	2%	297	10%	2088	68%	202	7%
Adapted transport	280	9%	178	6%	74	2%	538	18%	1838	60%	162	5%
Institutional long-term care (living in a care facility)	56	2%	35	1%	53	2%	145	5%	2548	83%	233	8%
Tax exemption	360	12%	464	15%	40	1%	915	30%	811	26%	480	16%
Disability benefits	464	15%	847	28%	32	1%	688	22%	837	27%	202	7%
Fee reimbursement (for medical supplies, treatments, transports for consultations, etc.)	537	17%	645	21%	44	1%	1033	34%	624	20%	187	6%
Respite care	88	3%	113	4%	58	2%	662	22%	1762	57%	387	13%

And which authority provides you with your social worker's services? (Several answers possible)

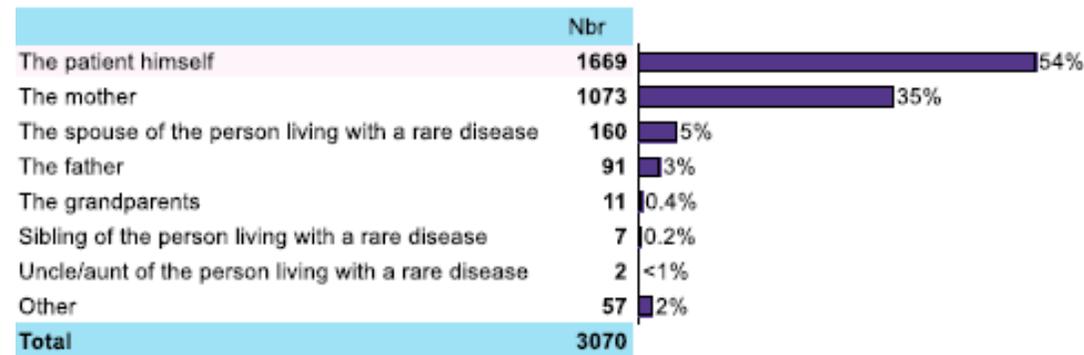


Which is the main organisation or institution supporting your family to deal with the daily life consequences of the rare disease?



COORDINATION OF CARE

Who organises and coordinates care in your household?

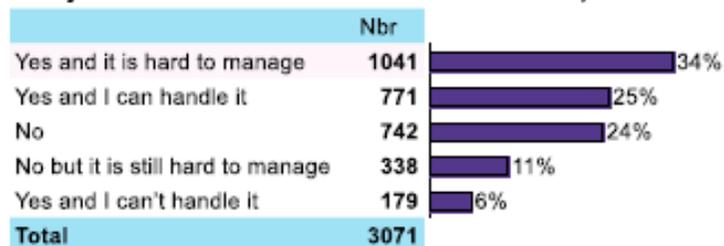


Do you spend time organising care, which includes:

- finding the needed information on your disease, your rights and the administrative procedures;
- finding the right professionals;
- arranging and attending appointments with different people who support you in health, social or local services;
- travel to and from appointments etc. ?



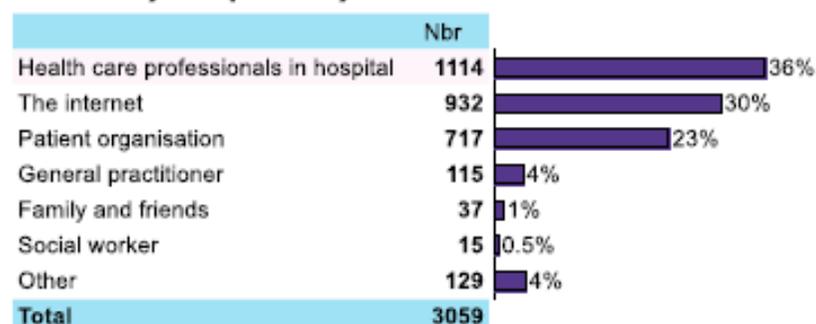
Do you have to visit different health, social and local support services and specialists in a short space of time?



And in general, do you feel that these different service providers communicate and exchange between each other about the person living with a rare disease, treatments, the consequences of the disease and other relevant information...?



What is your primary source of information about your disease, treatment and care?



Would you say that professionals from social, local and support services who support you ...



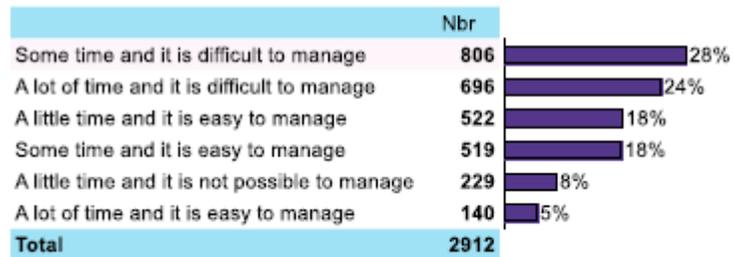
How well informed do you feel about ...

	Very well informed		Fairly well informed		Fairly not well informed		Not informed at all	
	N	% cit.	N	% cit.	N	% cit.	N	% cit.
Relevant health specialists and services for the disease	411	13%	1215	40%	966	32%	461	15%
Relevant social services that can help you	160	5%	717	23%	1275	42%	900	29%
The rights related to the consequences of the rare disease	150	5%	672	22%	1279	42%	951	31%
Financial help that you could be entitled to	127	4%	706	23%	1166	38%	1053	35%

The time you spend in health related administrative procedures represents...



The time you spend explaining (on the phone or face to face) the disease to different services/experts represents...

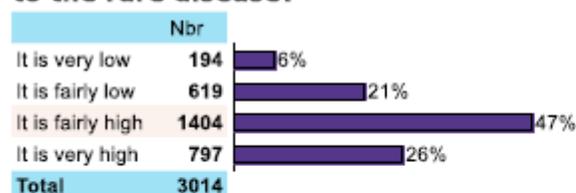


COST OF CARE

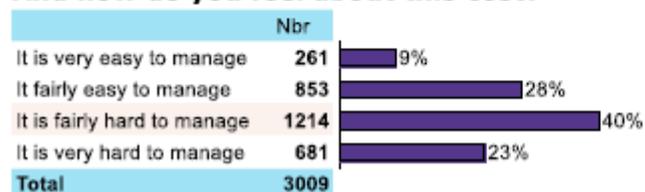
Among the following costs resulting from the rare disease, please indicate if they are at least partly covered by yourself or your family?

	Yes but I can handle it		Yes and it's hard to manage		Yes and I can't afford it		No it is covered by the health system or by a patient organisation		No, I am not concerned	
	N	% cit.	N	% cit.	N	% cit.	N	% cit.	N	% cit.
Treatments and medications	703	24%	747	25%	218	7%	1046	35%	264	9%
Transportation services	593	20%	549	19%	272	9%	324	11%	1191	41%
Hospital admissions	573	19%	424	14%	129	4%	1405	47%	463	15%
Tests and assessments	525	18%	540	18%	219	7%	1145	39%	524	18%
Special diet	514	18%	544	19%	223	8%	208	7%	1433	49%
Appointments with health care professionals	496	28%	403	23%	132	8%	593	34%	120	7%
Rehabilitation therapies	390	13%	544	19%	364	12%	807	28%	819	28%
Home care services (home help, personal assistants, nannies)	247	9%	339	12%	402	14%	253	9%	1646	57%
Devices and investments (wheelchair, housing adaptation, etc.)	239	8%	469	16%	381	13%	312	11%	1508	52%
Respite care	166	6%	263	9%	289	10%	218	8%	1928	67%

All things considered, how would you judge the costs associated to the rare disease?



And how do you feel about this cost?

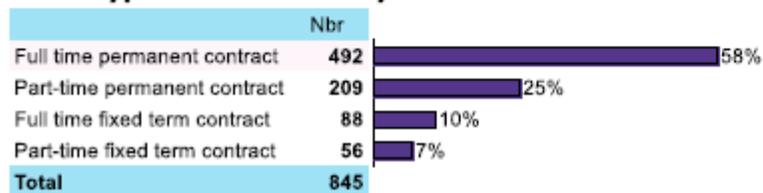


Employment

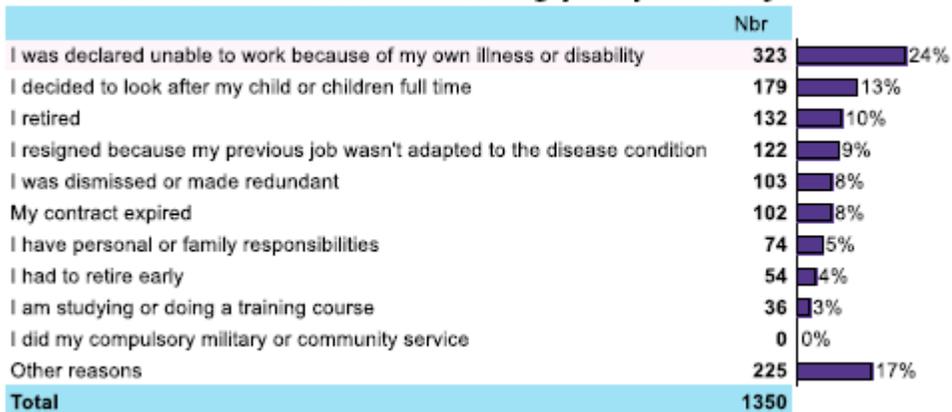
What is your current occupation?



What type of contract do you have?



What was the main reason for leaving your previous job?



Has the fact that your life is affected by a rare disease...

	Yes		No	
	N	% cit.	N	% cit.
Limited your professional choices	1227	75%	401	25%
Led you to reduce or stop professional activity	1179	70%	507	30%
Caused a decrease in your income	1145	69%	515	31%
Limited your opportunities to get a job	1016	67%	505	33%
Limited you from being promoted	840	60%	560	40%
Prevented you from accessing higher education	369	27%	979	73%
Led you to more fulfilling professional opportunities	278	19%	1198	81%

Ideally, if your work environment was totally adapted (for example in terms of an adaptable timetable, easy access to the workplace, no discrimination...) to the rare disease you are affected by, would you like...

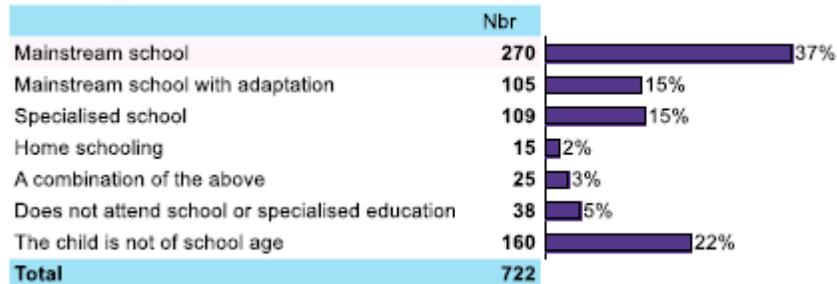
	Increase		Decrease		Remain similar	
	N	% cit.	N	% cit.	N	% cit.
Your working hours to...	113	14%	263	33%	412	52%
Your responsibilities to...	182	22%	138	17%	490	60%

Is/was your current/last work environment specially adapted for you, in terms of:

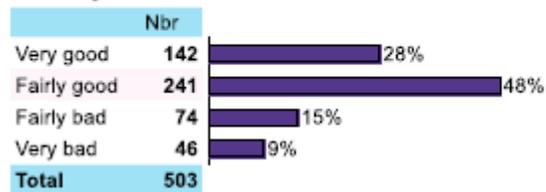
	Yes and it covers/covered my needs		Yes but it is/was not enough to cover my needs		Yes but I don't/didn't need it		No but I need/needed it		No but I don't/didn't need it		Adaptation is/was in process	
	N	% cit.	N	% cit.	N	% cit.	N	% cit.	N	% cit.	N	% cit.
Reorganisation of tasks or working-hours (more flexibility, changes in responsibility)	272	22%	250	20%	57	5%	388	31%	206	16%	80	6%
Possibility of special leave in relation to the rare disease	282	22%	171	13%	59	5%	524	41%	196	15%	37	3%
Assistance in travelling to work	161	16%	101	10%	60	6%	271	26%	416	40%	20	2%
Equipment and accessibility such as lift and specific chair or desk	162	17%	92	10%	52	6%	268	29%	310	33%	53	6%

School

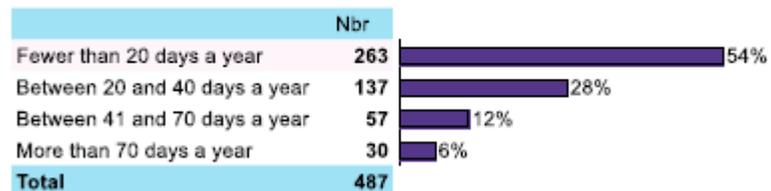
What type of school does the child you care for attend?



In terms of support and adaptation, how would you rate the integration of the child you care for at school?



How many days per year is the child you care for absent from school?



Family and social life, stress and well-being

Do the following people or services help you care for your child?

	Yes and it helps me a lot		Yes and it helps me a little		Yes but I don't need to		No but I would need to		No but I don't need to	
	N	% cit.	N	% cit.	N	% cit.	N	% cit.	N	% cit.
Family members	343	50%	164	24%	11	2%	114	17%	53	8%
Private child care services at your own cost	80	15%	94	17%	8	1%	126	23%	240	44%
Child care services (baby-sitting, respite or day centre) provided by social and community services	71	12%	70	12%	17	3%	223	38%	207	35%
Friends	70	11%	128	20%	29	5%	216	34%	191	30%
Child care services provided by patient organisations	22	4%	46	8%	13	2%	217	40%	247	45%

On average, how many hours of support per week do you receive...

	1 to 2 hours		3 to 4 hours		5 to 8 hours		9 to 12 hours		More than 12 hours	
	N	% cit.	N	% cit.	N	% cit.	N	% cit.	N	% cit.
For support of house chores and daily tasks	252	34%	178	24%	113	15%	58	8%	149	20%
For rehabilitation services and therapies (for example ergotherapy, speech or physical therapy, etc.)	498	60%	204	24%	83	10%	26	3%	24	3%

On average, how many days per year do you take of adapted holidays therapeutic recreation or respite care?

	Nbr	% cit.
1 to 7 days	215	46%
8 to 14 days	102	22%
15 to 30 days	96	21%
More than 30 days	51	11%
Total	464	

Since the symptoms of the disease started, have you experienced the following within your family?

	Yes and it was caused by the rare disease		Yes and it was amplified by the rare disease		Yes but the rare disease was not the cause		No		Not applicable	
	N	% cit.	N	% cit.	N	% cit.	N	% cit.	N	% cit.
Isolation from friends or family	582	32%	403	22%	74	4%	767	42%	0	0%
Members of the family feeling neglected	505	29%	300	17%	43	2%	907	52%	0	0%
Tensions between family members	487	27%	460	25%	157	9%	711	39%	0	0%
Strengthening of the family unit	311	18%	480	27%	168	10%	791	45%	0	0%
Divorce or separation	100	6%	146	9%	98	6%	1336	80%	0	0%

During the past 4 weeks, how often...

	Never		Seldom		Sometimes		Often		Very often		Can't choose	
	N	% cit.	N	% cit.	N	% cit.	N	% cit.	N	% cit.	N	% cit.
Have you felt unhappy and/or depressed	185	10%	324	17%	676	35%	376	19%	342	18%	44	2%
Have you felt you could not overcome your problems?	250	13%	345	18%	627	32%	364	19%	316	16%	45	2%



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Thank you to all Rare Barometer partners:



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