

# SPECIAL EUROBAROMETER 361

## European awareness of Rare Diseases

### REPORT

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Day

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## **Eurobarometer 74.3**

### **European awareness of Rare Diseases**

Conducted by TNS Opinion & Social at the request of  
Directorate General for Health and Consumers

Survey co-ordinated by Directorate General  
Communication

TNS Opinion & Social  
Avenue Herrmann Debroux, 40  
1160 Brussels  
Belgium



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## INTRODUCTION

It is estimated that between 6,000 and 8,000 distinct rare diseases exist today (currently around 5,860 are described in the Orphanet database), affecting between 6% and 8% of the population in total. In other words, between 27 and 36 million people in the European Union are affected by a rare disease. A disease or disorder is defined as rare in the European Union when it affects fewer than 5 per 10,000 citizens<sup>1</sup>. Rare diseases are typically chronic, progressive, degenerative, and often life threatening. Due to their nature, rare diseases tend to be highly disabling and seriously affect the quality of life of patients and those close to them.

The specific characteristics which typify rare diseases - limited number of patients and scarcity of relevant resources and expertise - make them a unique opportunity for a European approach. There is probably no other area in health where collaboration between 27 different national approaches can be as efficient and effective. Coordination at EU level is probably the best way of pooling the very limited resources available.

Due to the low prevalence of rare diseases, patients face many problems. These include delays in correct diagnosis, a lack of sufficient information, insufficient medical knowledge, effort and difficulties in accessing the right treatment. These challenges call for joint effort, as currently scarce resources are limited within individual EU Member States.

The European Commission promotes joint actions which will help patients and professionals share expertise and information across borders with the objective of reducing the number of people suffering these type of diseases, preventing newborns and young children dying from them and improving the patients' quality of life.

Specific measures have been adopted by the Commission, including<sup>2</sup>:

- improving recognition and visibility of rare diseases;
- supporting national plans for rare diseases in EU member countries;
- strengthening European-level cooperation and coordination;
- creating European reference networks, linking centres of expertise and professionals in different countries to share knowledge and identify where patients should go when expertise is unavailable in their home country;
- encouraging more research into rare diseases.

To this end, the Commission has taken a number of actions that together form the legal basis of EU policy on rare diseases. The Regulation (EC) No 141/2000 of 16 December 1999 on orphan medicinal products was extended to the public health field by the

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<sup>1</sup> Orphan Drug Regulation 141/2000 and Council Recommendation, of 8 June 2009, on an action in the field of rare diseases

<sup>2</sup> [http://ec.europa.eu/health/rare\\_diseases/policy/index\\_en.htm](http://ec.europa.eu/health/rare_diseases/policy/index_en.htm)

Community action programme on rare diseases including genetic diseases, 1 January 1999 to 31 December 2003<sup>2</sup>, and most recently by the Commission Communication COM(2008) 679 final on Rare Diseases: Europe's challenges<sup>3</sup> of 11 November 2008 and by the Council Recommendation, of 8 June 2009, on an Action in the Field of Rare Diseases<sup>3</sup>. All these initiatives aimed to improve the coordination and coherence of national, regional and local initiatives addressing rare diseases. In addition, the European Union Committee of Experts on Rare Diseases<sup>4</sup> was established via Commission Decision in 2009<sup>5</sup>.

Within this context of raising awareness of rare diseases in Europe, the European Commission launched this Eurobarometer survey – published today, 28 February 2011, on the 4<sup>th</sup> World Rare Disease Day<sup>6</sup>. This report examines Europeans' awareness and knowledge of rare diseases and their support for policy initiatives actions taken at national and European level.

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<sup>3</sup> The Council Recommendation on an Action in the Field of Rare Diseases (2009/C 151/02) <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2009:151:0007:0010:EN:PDF>

<sup>4</sup> The European Union Committee of Experts on Rare Diseases <http://www.eucerd.eu/>

<sup>5</sup> <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2009:315:0018:0021:EN:PDF>

<sup>6</sup> <http://www.rarediseaseday.org/>

### Note

In this report, countries are referred to by their official abbreviation. The abbreviations used in this report correspond to:

#### ABBREVIATIONS

EU27	European Union - 27 Member States
BE	Belgium
CZ	Czech Republic
BG	Bulgaria
DK	Denmark
DE	Germany
EE	Estonia
EL	Greece
ES	Spain
FR	France
IE	Ireland
IT	Italy
CY	Republic of Cyprus
LT	Lithuania
LV	Latvia
LU	Luxembourg
HU	Hungary
MT	Malta
NL	The Netherlands
AT	Austria
PL	Poland
PT	Portugal
RO	Romania
SI	Slovenia
SK	Slovakia
FI	Finland
SE	Sweden
UK	The United Kingdom



## Executive Summary

The following conclusions can be drawn from the results of the Special Eurobarometer on Rare Diseases:

### **Europeans have a relatively accurate understanding of what rare diseases are but detailed knowledge and awareness remain low.**

- 63% of Europeans correctly define rare diseases as diseases affecting a limited number of people and requiring very specific care. However, some misconceptions exist with 14% who believe that these are conditions which nobody can do anything about or that nobody cares about.
- The level of familiarity with specific cases of rare diseases varies considerably: while around three respondents in five claim to recognise Cystic Fibrosis and Haemophilia, awareness of Osteogenesis imperfecta and Progeria is much lower (around one in five Europeans);
- This lack of knowledge and awareness of rare diseases is also perceived by the European public to be a wider issue: 90% think that Europeans are unaware of the real problems faced by people suffering from rare diseases;
- Almost one in six European citizens is personally affected (17%) or through knowing somebody who is suffering from a rare disease (13%). However, 40% of Europeans have never heard of anyone who suffers from a rare disease.

### **The European public expresses strong support for policy initiatives linked to rare diseases at both national and European level.**

- Almost all agree that national health authorities should provide specific support to people suffering from rare diseases (96%) and fully reimburse their medication even if it is very expensive (93%).
- Similarly, there is widespread support for policy initiatives aiming at increasing cooperation at European level, granting full access to care for patients in other Member States and introducing national strategies for rare diseases.
- The only statement that divides the European public opinion concerns the prioritisation of the treatment of rare diseases at national level: 56% of respondents disagree that there are too many other national health issues to make rare diseases a priority while 39% agree.

### **Europeans see the actions of allocating resources to improve research, to ensure access to care and to raise awareness as highly justified.**

- An overwhelming majority of respondents in every Member State – in many cases 90% or more – supports resource allocation to various actions which tackle rare diseases in various areas, such as strengthening research cooperation, easing access to drugs and laboratory tests and giving support to families and patient organisations.

## 1. Understanding and awareness of rare diseases

This chapter examines Europeans' awareness of what rare diseases are, the level of familiarity with specific rare diseases and the extent and impact of personal experience.

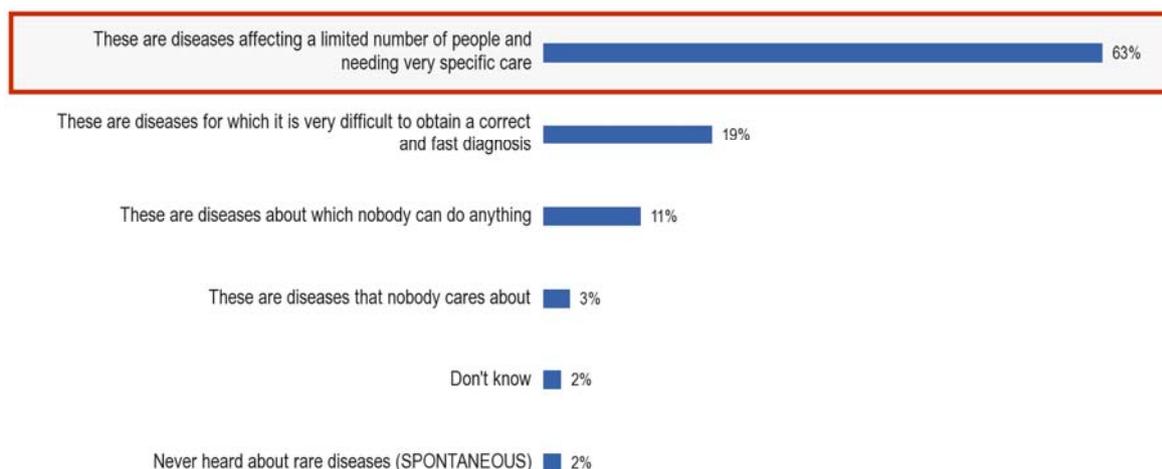
### 1.1 Knowledge about what rare diseases are

*- Europeans have a relatively good understanding of what rare diseases are -*

In the EU countries, any disease affecting fewer than 5 people in 10 000 is considered to be rare. Rare diseases are often life-threatening or chronically debilitating and thus call for specific care.

The respondents were asked how they would best describe what rare diseases are. Using the definition above, nearly two-thirds (63%) of Europeans correctly describe them as diseases which affect a limited number of people and need very specific care, indicating that the general level of understanding of what rare diseases are is relatively high.

QD1. When talking about rare diseases, which of the following is, in your opinion, the statement that best describes what "rare diseases" are?



EU27

A further one in five (19%) think that rare diseases are diseases for which it is very difficult to obtain a correct and fast diagnosis – although not strictly correct as it is not always the case, this statement does characterise the treatment of many rare diseases.

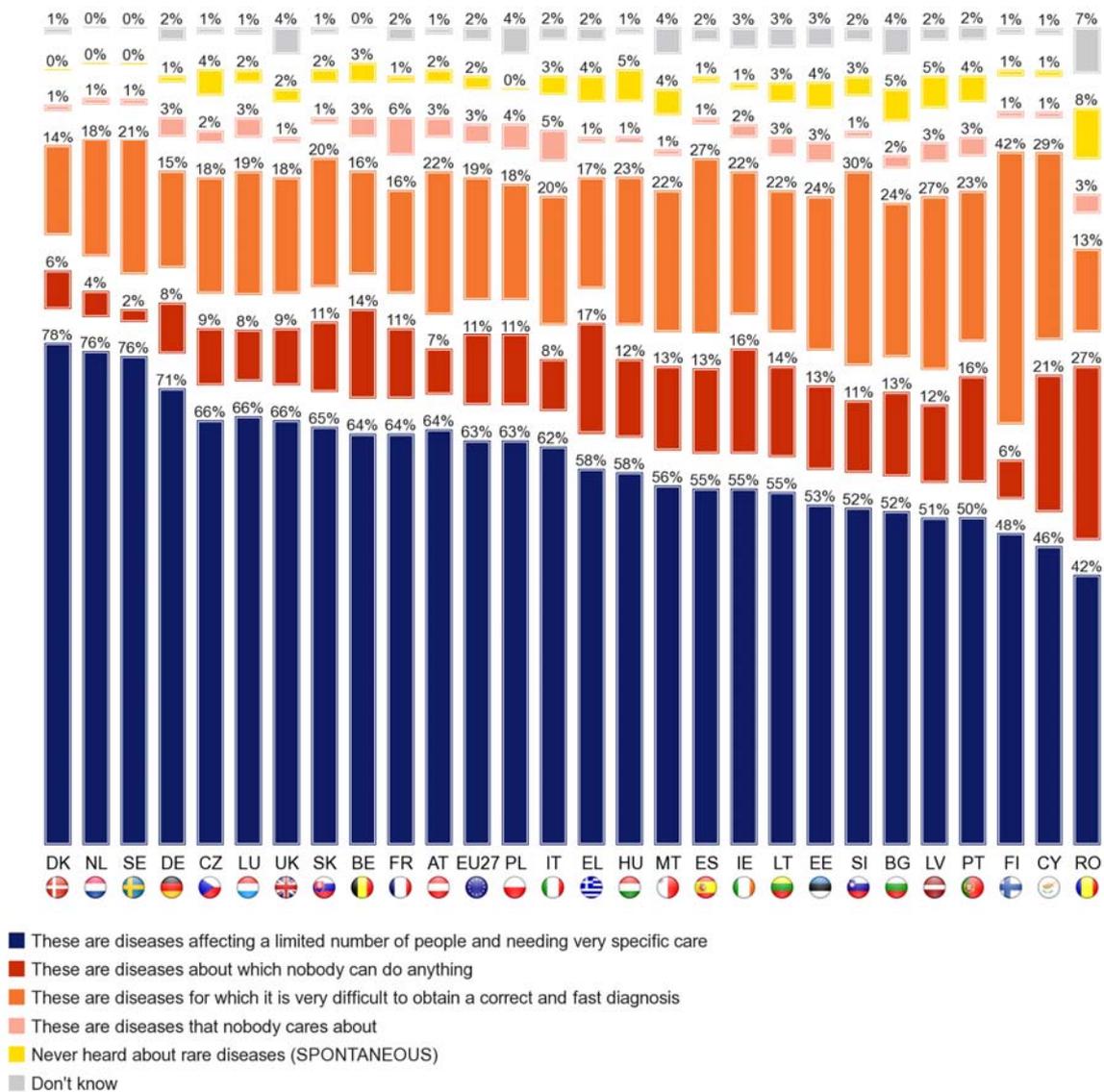
However, one in ten (11%) incorrectly believe that rare diseases are diseases which nobody can do anything about. A minority (3%) believe that these are diseases which nobody cares about.

### A) Differences between Member States

In every Member State, the majority defines rare diseases as diseases affecting a limited number of people and requiring specific care. However, large differences can be observed between Member States: while over 70% of respondents in Denmark, the Netherlands, Sweden and Germany agree with this definition, the proportion falls to under 50% in Finland, Cyprus and Romania.

In this latter group of countries, Finnish respondents are the most likely of all to say that rare diseases are diseases for which it is very hard to obtain a diagnosis (42%) while relatively high proportions of Romanians and Cypriots hold the negative view that rare diseases are diseases which nobody can do anything about.

QD1. When talking about rare diseases, which of the following is, in your opinion, the statement that best describes what "rare diseases" are?



The graph above shows that while in all Member States the majority of population correctly understands what rare diseases are, at least a fifth of the population in every country incorrectly understand what rare diseases are.

## B) Socio-demographic analysis

Respondents with a higher socio-economic status – whether in terms of level of education, occupation or self-positioning on the social staircase – are the most likely to correctly describe rare diseases. Older respondents with a low level of education tend to have the lowest level of awareness. Not surprisingly, respondents who know or have heard about somebody suffering from a rare disease are significantly more knowledgeable than those who have no personal experience.

**QD1** When talking about rare diseases, which of the following is, in your opinion, the statement that best describes what "rare diseases" are?

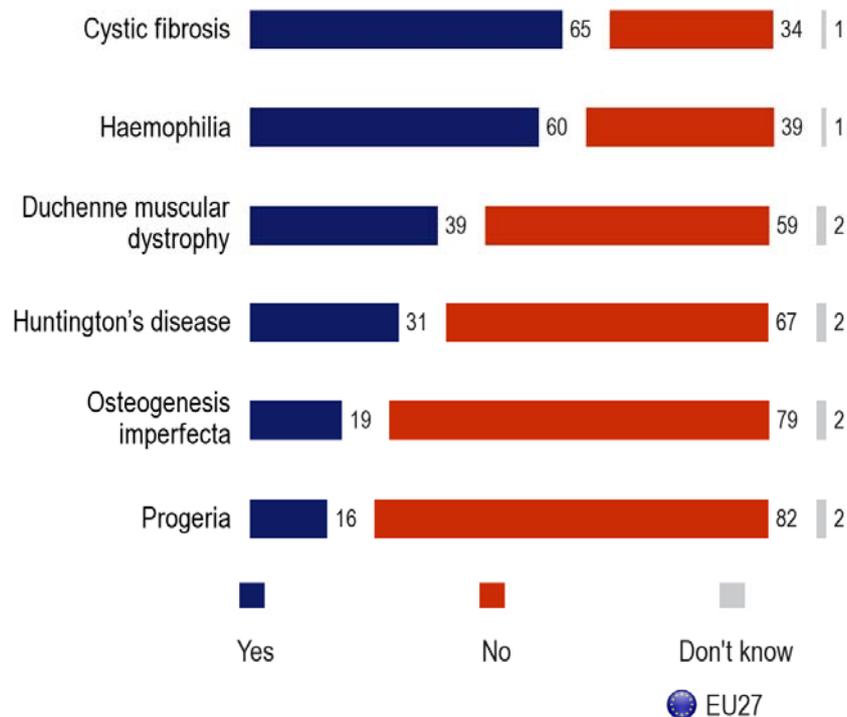
	These are diseases about which nobody can do anything	These are diseases affecting a limited number of people and needing very specific care	These are diseases for which it is very difficult to obtain a correct and fast diagnosis	These are diseases that nobody cares about	Never heard about rare diseases/DK
EU27	11%	63%	19%	3%	4%
 <b>Age</b>					
15-24	10%	66%	17%	3%	4%
25-39	9%	66%	18%	3%	4%
40-54	10%	66%	19%	3%	2%
55 +	13%	57%	21%	3%	6%
 <b>Education (End of)</b>					
15-	15%	49%	23%	4%	8%
16-19	11%	63%	19%	3%	4%
20+	6%	73%	17%	2%	2%
Still studying	10%	68%	16%	2%	4%
 <b>Respondent occupation scale</b>					
Self-employed	7%	71%	16%	3%	3%
Managers	5%	76%	16%	1%	2%
Other white collars	7%	70%	18%	3%	2%
Manual workers	10%	63%	20%	3%	4%
House persons	13%	57%	21%	3%	6%
Unemployed	15%	57%	21%	3%	4%
Retired	13%	55%	21%	4%	7%
Students	10%	68%	16%	2%	4%
 <b>Self-positioning on the social staircase</b>					
Low (1-4)	14%	54%	22%	4%	5%
Medium (5-6)	10%	65%	18%	3%	4%
High (7-10)	9%	68%	19%	2%	2%
<b>Knows or have heard about a case of rare disease</b>					
Yes	9%	69%	19%	2%	1%
No	13%	56%	20%	4%	7%

## 1.2 Knowledge about specific rare diseases

### - Familiarity with specific rare diseases varies considerably -

Respondents were presented with a list of different rare diseases and asked for each one whether they had ever heard of them. Overall, awareness of specific rare diseases tends to be rather low, although familiarity with different types of rare diseases varies significantly. Cystic fibrosis (65%) and Haemophilia (60%) are known by the majority of respondents, while fewer than one in five has heard of Osteogenesis imperfecta and Progeria. Around four in ten (39%) claim to have heard of Duchenne muscular dystrophy and 31% of Huntington's disease.

QD5. Have you ever heard of each of the following diseases?



## A) Differences between Member States

Major differences can be seen between countries in the level of claimed familiarity of different types of rare diseases:

QD5. Have you ever heard of each of the following diseases?

		Cystic fibrosis: "Yes"	Duchenne muscular dystrophy: "Yes"	Haemophilia: "Yes"	Huntington's disease: "Yes"	Osteogenesis imperfecta: "Yes"	Progeria: "Yes"
 EU27		65%	39%	60%	31%	19%	16%
 BE		79%	32%	62%	33%	15%	41%
 BG		8%	22%	30%	7%	4%	2%
 CZ		45%	25%	52%	12%	8%	38%
 DK		76%	21%	40%	63%	15%	33%
 DE		58%	17%	26%	25%	9%	9%
 EE		15%	21%	44%	22%	25%	8%
 IE		97%	56%	85%	69%	15%	6%
 EL		11%	14%	42%	11%	19%	30%
 ES		52%	37%	59%	14%	8%	9%
 FR		96%	57%	85%	32%	21%	25%
 IT		78%	61%	62%	16%	15%	11%
 CY		11%	66%	60%	21%	29%	47%
 LV		13%	21%	40%	10%	7%	5%
 LT		25%	39%	40%	5%	6%	4%
 LU		66%	33%	64%	31%	22%	22%
 HU		27%	34%	77%	19%	11%	69%
 MT		32%	35%	37%	25%	8%	4%
 NL		49%	73%	83%	66%	18%	29%
 AT		37%	13%	24%	18%	9%	12%
 PL		74%	26%	75%	21%	75%	13%
 PT		26%	24%	61%	7%	8%	10%
 RO		31%	32%	41%	8%	11%	5%
 SI		32%	50%	51%	10%	8%	6%
 SK		55%	38%	58%	14%	7%	10%
 FI		33%	22%	84%	31%	53%	11%
 SE		75%	24%	33%	57%	10%	18%
 UK		90%	55%	81%	82%	18%	15%
		<b>Highest percentage per country</b>			<i>Lowest percentage per country</i>		
		Highest percentage per item			Lowest percentage per item		

- **Cystic fibrosis** was the most well-known with just under two-thirds aware of this disease. There are considerable differences in awareness by Member State: while 90% or more of Irish, French and British respondents are familiar with the condition, the figure falls under 20% in Estonia, Latvia, Greece, Cyprus and Bulgaria. This corresponds to a large difference in awareness between the EU15 (70%) and NMS12 (47%).

- Nearly three-quarters (73%) of respondents in the Netherlands say they have heard of **Duchenne muscular dystrophy** which contrasts sharply with the low levels of awareness seen in Germany, Greece and Austria where awareness is less than 20%. Respondents in the EU15 countries (42%) are significantly more likely to recognise the condition than respondents in the NMS12 countries (30%).
- Over 80% of respondents in Ireland, France, Finland, the Netherlands and the UK have heard of **Haemophilia**. The level of familiarity is lowest in Austria and Germany where only around a quarter have heard of the condition. No significant difference is observed between the EU15 and NMS12.
- **Huntington's disease** is widely known in the UK with 82% of respondents aware of this disease. Relatively high proportions of respondents – between 57% and 69% - in Ireland, the Netherlands, Denmark and Sweden have also heard of this condition. However, awareness is much lower in the remainder of Member States where under a third of citizens are aware of the disease.
- In most Member States, awareness of **Osteogenesis imperfecta** is low, only known by up to three in ten respondents. The level of awareness is as low as 4% in Bulgaria. At the same time, there are high levels of claimed awareness in Poland (75%) and Finland (53%) although this can be assumed to be due to the translated name in these countries which is more descriptive and more easily confused with more common diseases such as osteoporosis.
- Familiarity with **Progeria** differs significantly between the Member States: while 69% of Hungarians say they have heard of it, less than 5% of respondents in Malta, Lithuania and Bulgaria are aware of the condition.
- Overall, respondents in the EU15 countries – particularly in Ireland, the UK, France and the Netherlands tend to be more familiar with the rare diseases listed here than respondents in the NMS12 countries.

When it comes to socio-demographic factors, women, those with a high level of education and those who personally know or have heard of somebody suffering from a rare disease are the most likely to be aware of specific rare diseases. Younger citizens tended to be less aware.

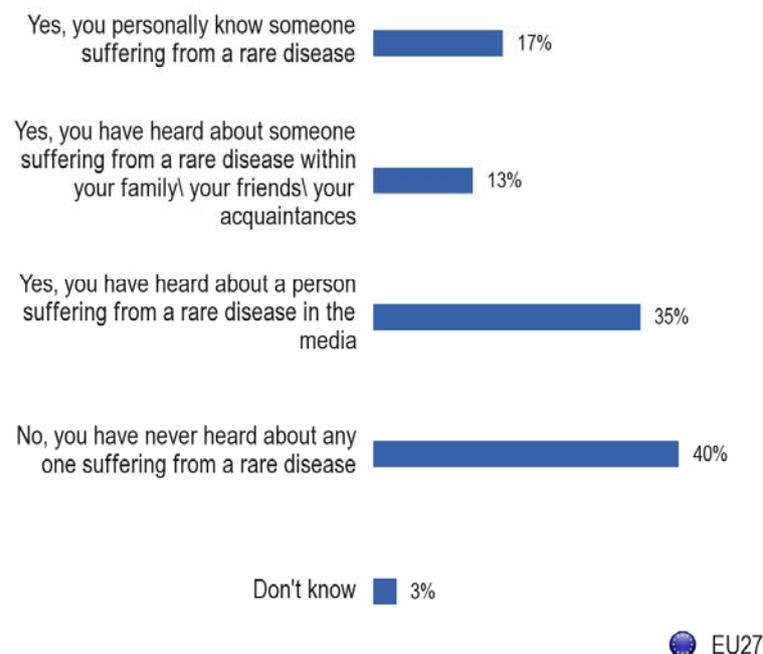
### 1.3 Personal experience with rare diseases

#### **- The majority of Europeans know or have heard about a person suffering from a rare disease -**

In order to measure the extent of personal experience of rare diseases, citizens were asked whether they personally know or have heard about a person suffering from a rare disease. While 40% of respondents say that they have never heard of a person suffering from a rare disease, 57% have – at least to some extent – some personal experience of rare diseases.

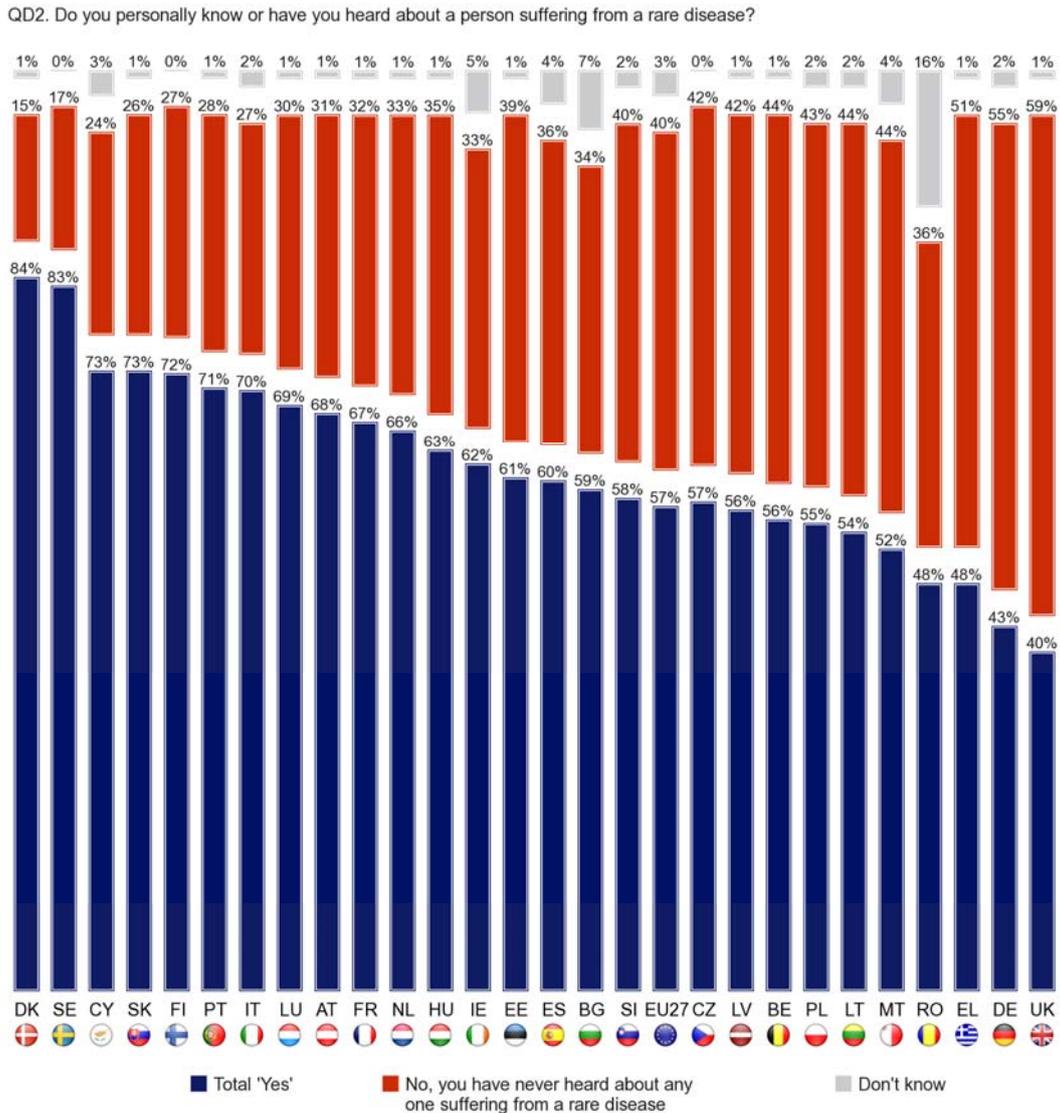
Around one in six (17%) personally know somebody suffering from a rare disease and a further 13% have heard of somebody within their wider social circle who suffer from such a condition. However, media remains the main source of information for Europeans with 35% saying that they have only heard of anyone who suffers from a rare disease through the media.

QD2. Do you personally know or have you heard about a person suffering from a rare disease?



### A) Differences between Member States

Looking at the overall figures, it can be seen that over half the population in the UK, Germany and Greece indicate that they have never heard of a person suffering from a rare disease, followed by over 40% of respondents in Malta, Lithuania, Belgium, Poland, the Czech Republic and Latvia.



At the other end of the scale, more than four respondents in five in Denmark and Sweden claim to have some awareness of a person suffering from a rare disease. High levels of personal experience (70% and higher) are also seen in Cyprus, Slovakia, Finland, Portugal and Italy.

QD2 Do you personally know or have you heard about a person suffering from a rare disease?

		Yes, you personally know someone suffering from a rare disease	Yes, you have heard about someone suffering from a rare disease within your family, your friends, your acquaintances	Yes, you have heard about a person suffering from a rare disease in the media	No, you have never heard about any one suffering from a rare disease	Don't know
 EU27		17%	13%	35%	40%	3%
 EL		6%	16%	30%	51%	1%
 BG		7%	6%	48%	34%	7%
 CZ		7%	10%	43%	42%	0%
 RO		7%	8%	36%	36%	16%
 PT		10%	12%	54%	28%	1%
 IE		11%	22%	35%	33%	5%
 ES		11%	11%	43%	36%	4%
 IT		12%	20%	43%	27%	2%
 LV		12%	10%	39%	42%	1%
 AT		13%	14%	48%	31%	1%
 PL		13%	9%	37%	43%	2%
 HU		14%	10%	40%	35%	1%
 SI		14%	11%	40%	40%	2%
 DE		15%	8%	27%	55%	2%
 MT		15%	20%	28%	44%	4%
 LT		16%	9%	33%	44%	2%
 EE		17%	12%	41%	39%	1%
 SK		17%	16%	47%	26%	1%
 UK		18%	9%	16%	59%	1%
 LU		21%	23%	39%	30%	1%
 BE		23%	15%	24%	44%	1%
 FI		26%	20%	42%	27%	0%
 FR		28%	16%	36%	32%	1%
 CY		29%	22%	36%	24%	3%
 NL		33%	17%	26%	33%	1%
 SE		38%	27%	51%	17%	0%
 DK		42%	24%	49%	15%	1%

When analysing the results in more detail, it is clear that for most, their experience of rare diseases is limited to the media. This is the case in every Member State with the exception of the UK where, of those who have some experience, more report that they personally know a person suffering from such disease.

In terms of those who personally know somebody suffering from a rare disease, there are major differences by Member State. A third or more of Danish, Swedish and Dutch respondents know somebody who suffers from a rare disease compared with fewer than one in ten respondents in the Czech Republic, Romania, Bulgaria and Greece. Similarly, the proportion of respondents who have heard of somebody within their own family or among friends and acquaintances who suffers from a rare disease varies significantly between countries, ranging from 27% in Sweden to only 6% in Bulgaria.

## B) Socio-demographic analysis

Some differences linked to the socio-demographic profile of respondents can be seen:

- Respondents in the youngest and oldest age groups and those who have a low level of education are more likely to say that they have never heard of anyone who suffers from a rare disease.
- Those who spent longer in education or with a high self-perceived socio-economic status are the most likely to personally know somebody suffering from a rare disease.

QD2 Do you personally know or have you heard about a person suffering from a rare disease? (MULTIPLE ANSWERS POSSIBLE)

	Yes, you personally know someone suffering from a rare disease	Yes, you have heard about someone suffering from a rare disease within your family/ your friends/ your acquaintances	Yes, you have heard about a person suffering from a rare disease in the media	No, you have never heard about any one suffering from a rare disease	DK	Total 'Yes'
EU27	17%	13%	35%	40%	3%	57%
 <b>Age</b>						
15-24	15%	12%	32%	44%	3%	54%
25-39	16%	14%	37%	38%	2%	60%
40-54	18%	14%	37%	37%	2%	61%
55 +	16%	12%	33%	43%	3%	54%
 <b>Education (End of)</b>						
15-	11%	10%	32%	48%	3%	49%
16-19	16%	11%	35%	42%	2%	56%
20+	24%	17%	38%	30%	2%	67%
Still studying	16%	13%	33%	42%	3%	56%
 <b>Self-positioning on the social staircase</b>						
Low (1-4)	15%	11%	34%	42%	3%	55%
Medium (5-6)	16%	12%	36%	41%	2%	57%
High (7-10)	21%	15%	34%	37%	2%	61%

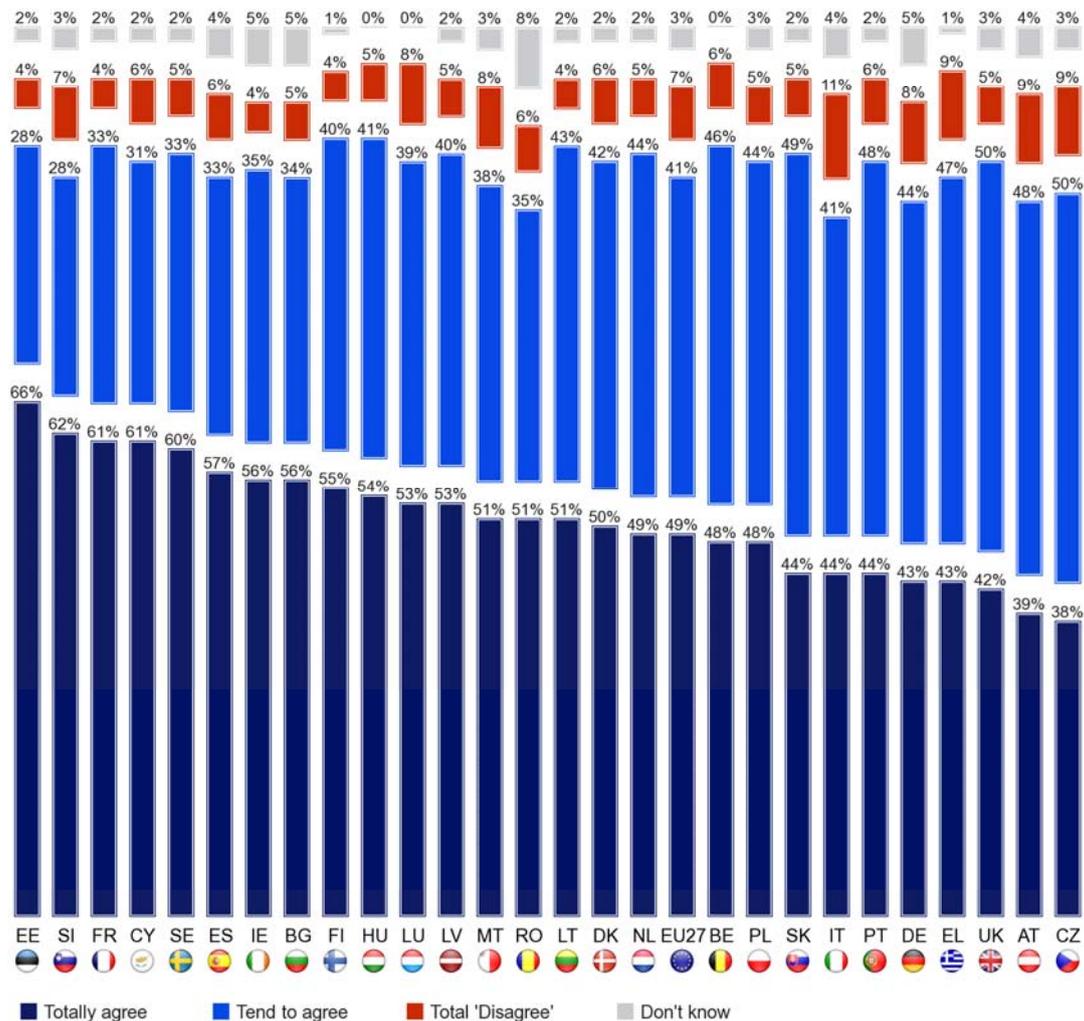
### 1.4 Perceived awareness of real problems faced by those suffering from a rare disease

**- Awareness of real problems faced by people suffering from rare diseases is felt to be very low -**

An overwhelming majority of Europeans agree that people are unaware of the real problems faced by those suffering from a rare disease with only 7% who disagree.

QD3.8. For each of the following statements, please tell me whether you totally agree, tend to agree, tend to disagree or totally disagree.

People are unaware of the real problems faced by those suffering from a rare disease



This widely-felt perception that people are generally not aware of the problems of those suffering from a rare disease is seen across all of the Member States with the level of overall agreement with the statement ranging from 95% in Hungary and Finland to 85% in Italy. The only differences between countries is in the strength of agreement, i.e. between the proportions of those who *totally agree* and *tend to agree*.

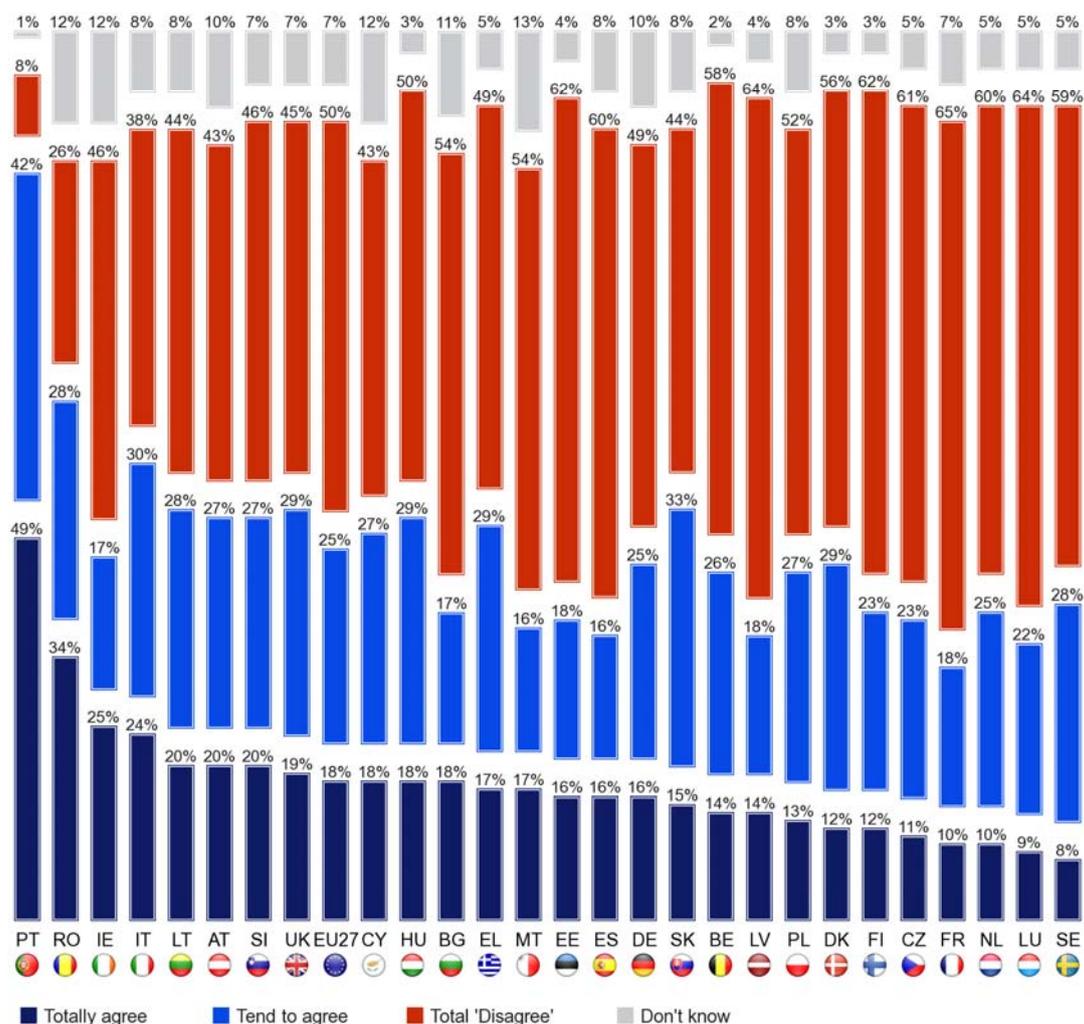
### 1.5 Awareness of the existence of centres specialising in rare diseases

**- Most Europeans think that people are not aware of the existence of centres specialising in rare diseases -**

When it comes to a more specific awareness of the existence of centres which specialise in rare diseases, European public opinion is relatively divided: half (50%) disagree that people are aware of the existence of such centres while 43% agree.

QD3.4. For each of the following statements, please tell me whether you totally agree, tend to agree, tend to disagree or totally disagree.

People are aware of the existence of centres specialising in rare diseases

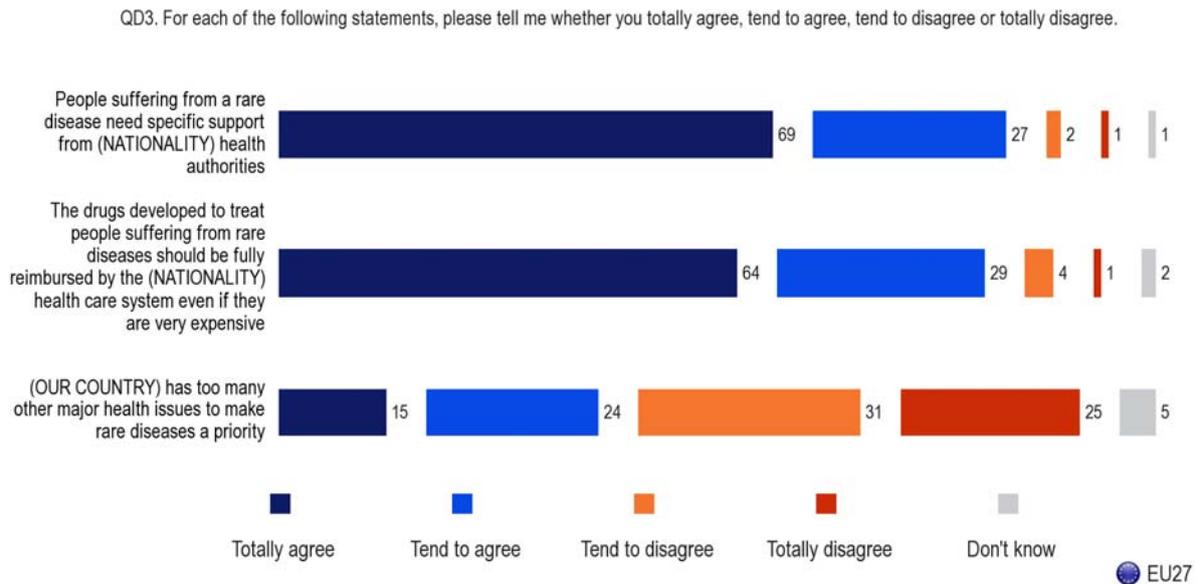


Some differences can be observed across the Member States:

- In the majority of Member States (15 in total), the majority disagree that people are aware of the existence of research centres, with highest levels of disagreement seen in France, Luxembourg and Latvia;
- In five countries – Hungary, Greece, Slovenia, Cyprus and the UK – opinion is more evenly divided with broadly equal shares of respondents agree and disagree with the statement.

## 2. Views on actions taken at national level

This chapter examines European attitudes toward policy initiatives which deal with rare diseases at national level. Three statements regarding the role of national health authorities and the prioritisation of rare diseases in relation to other health issues were presented to respondents.

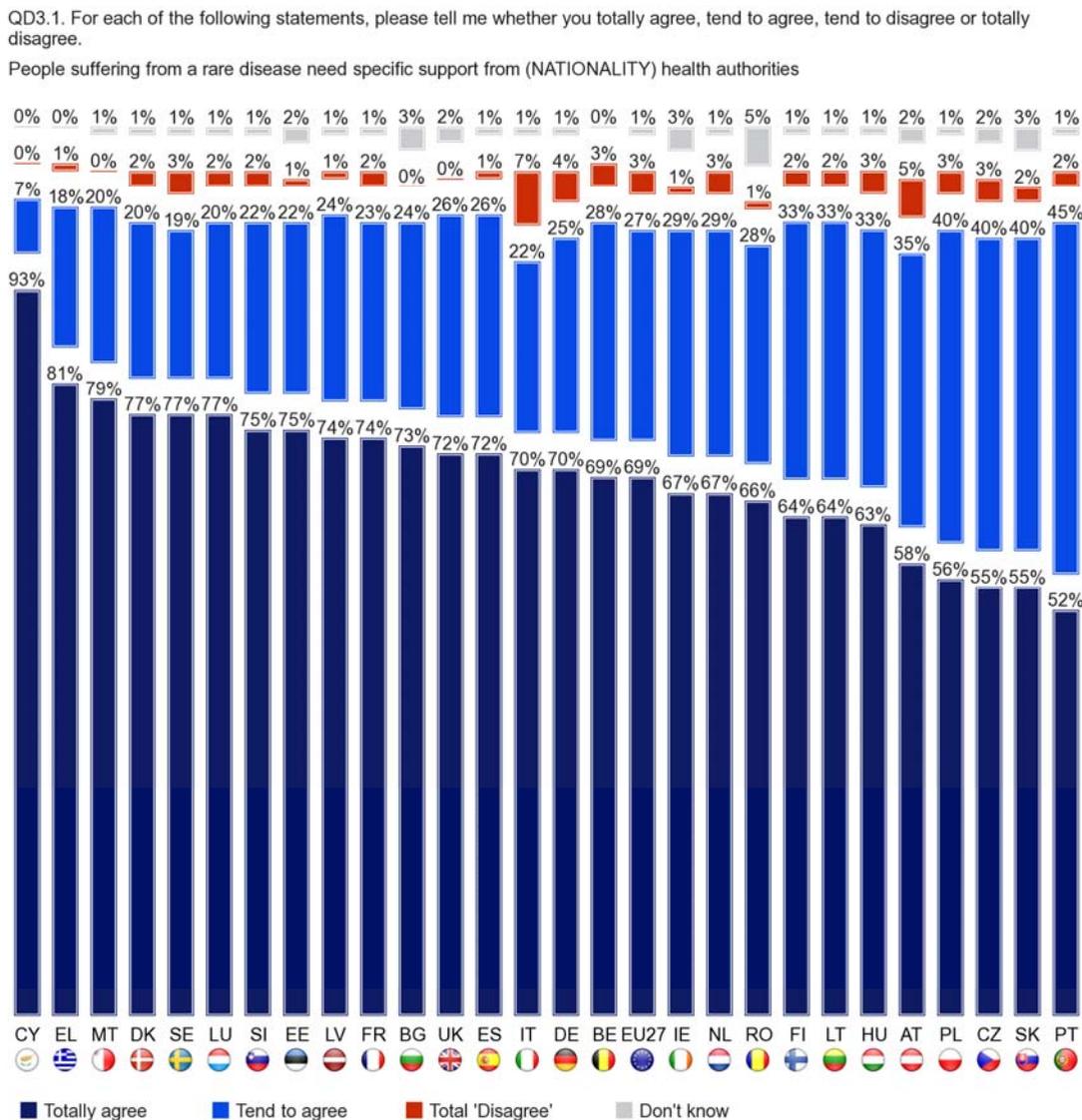


The graph above depicts the levels of agreement and disagreement with the three statements at an overall EU level. An overwhelming majority of Europeans support the idea that national health authorities should give specific support to people suffering from rare diseases and that they should fully reimburse the cost of medication developed to treat such patients. However, the European public is divided on whether rare diseases should be made a priority at national level when considering other major health issues which exist.

### 2.1 Specific support from the national health authorities

**- Europeans strongly agree that national health authorities should give specific support to people suffering from rare diseases -**

Almost all (96%) agree that people suffering from a rare disease need specific support from national health authorities. Seven in ten (69%) of European citizens *totally agree* with the statement while 27% *tend to agree*, confirming a strong support for such policy action.

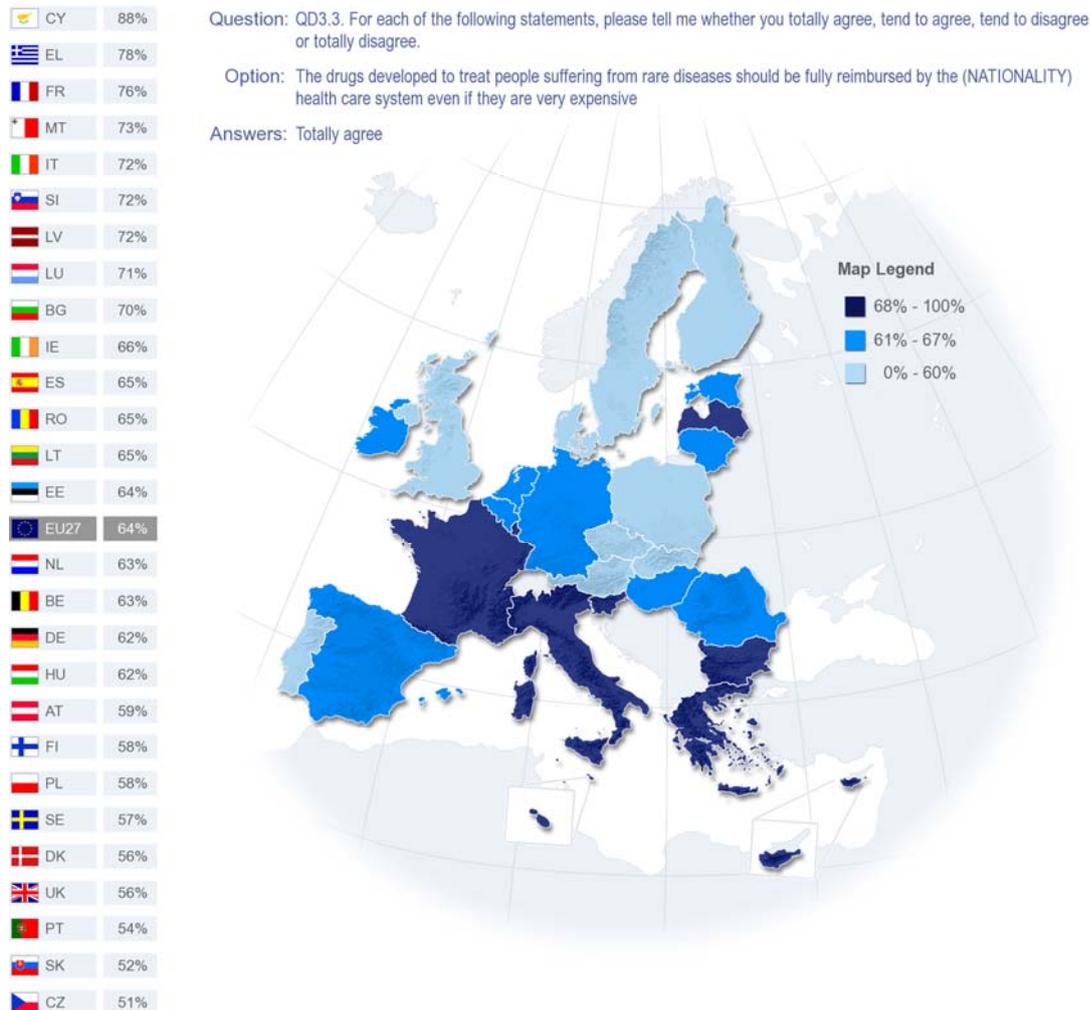


Differences between countries are minimal due to the nearly universal support for specific help given by national health authorities. In every Member State, the majority *totally agrees* with the statement, with the highest level of agreement seen in Cyprus (93%) and the lowest in Portugal (52%).

## 2.2 Full reimbursement

### - Europeans unanimously support full reimbursement of the cost of developing drugs

More than nine in ten Europeans (93%) agree with the statement that the cost of developing drugs to treat people suffering from rare diseases should be fully reimbursed by the national health care system even if they are expensive. Nearly two-thirds (64%) *totally* agree with the statement.



Agreement with the idea of fully reimbursing the cost of drugs is universal across the Member States, and differences can only be observed in the strength of agreement. The majority of citizens in every Member State *totally agree* with the statement, although the proportions vary considerably from 88% in Cyprus to 51% in the Czech Republic.

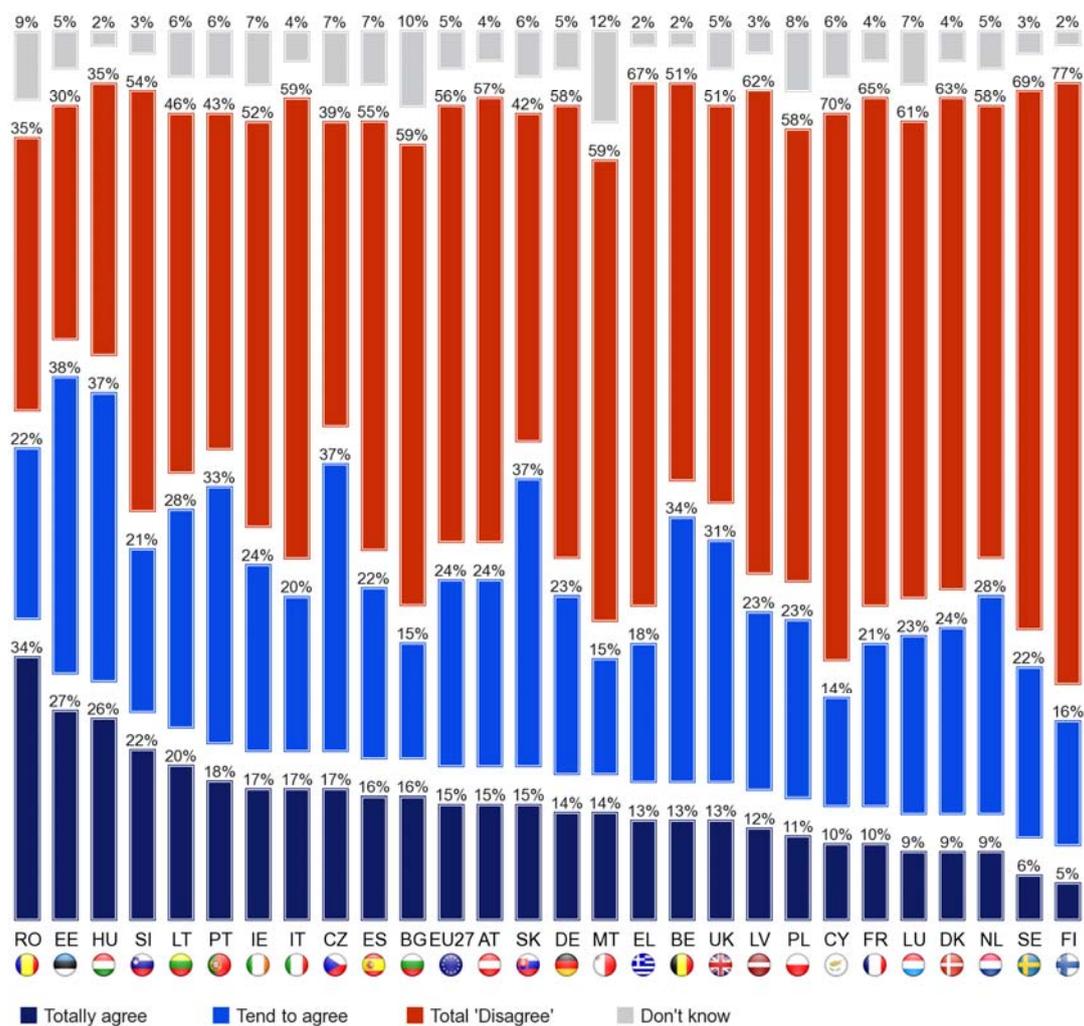
### 2.3 Prioritisation of rare diseases

**- European public opinion is divided about the prioritisation of rare diseases when other health issues are also taken into account -**

The prioritisation of rare diseases within the context of other major health issues sharply divides European public opinion. While four in ten (39%) agree that their respective countries have too many other major health issues to make rare diseases a priority, over half (56%) disagree that this should affect the prioritisation of rare diseases.

QD3.6. For each of the following statements, please tell me whether you totally agree, tend to agree, tend to disagree or totally disagree.

(OUR COUNTRY) has too many other major health issues to make rare diseases a priority



In most countries, the majority are still willing to make rare diseases a priority even when taking other major health issues into account, especially in Finland, Cyprus, Sweden, Greece and France. However, in six countries (mostly eastern European) the majority agrees that there are other health issues which are more important - Estonia, Hungary, Romania, the Czech Republic, Slovakia and Portugal. These results reflect a

difference between the EU15 and NMS12 countries, with 58% of the first group and 48% of the latter group disagreeing with the statement.

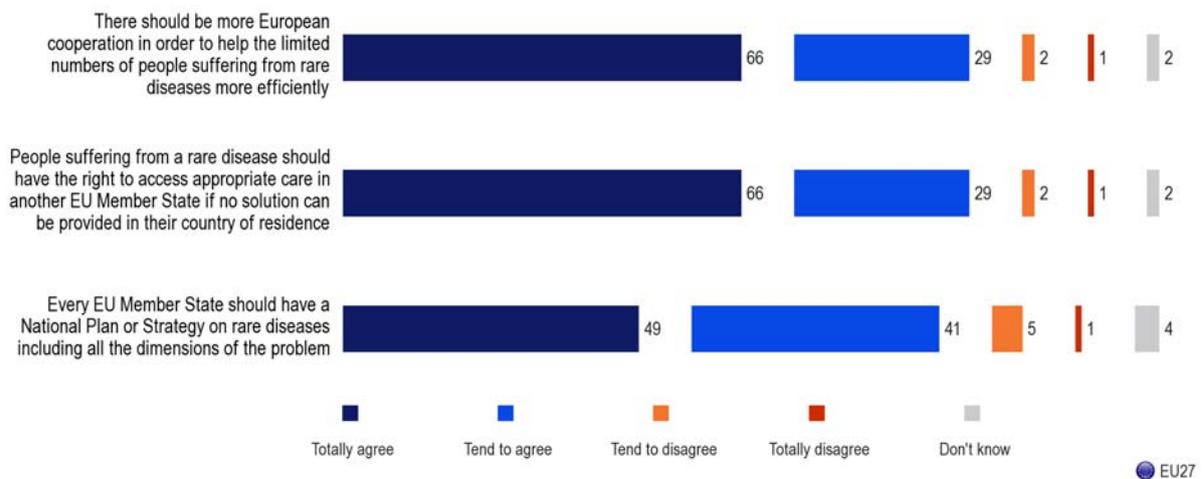
A socio-demographic analysis shows that respondents who have spent the longest period in education and respondents with a higher occupational status are the most likely to say that rare diseases should be made a priority regardless of other major health issues.

### 3. Views on actions taken at European level

#### - Widespread support for actions at European level -

This chapter examines the views of European public on policy actions taken at the European level regarding cooperation, access to care in other Member States and national plans for dealing with rare diseases.

QD3. For each of the following statements, please tell me whether you totally agree, tend to agree, tend to disagree or totally disagree.

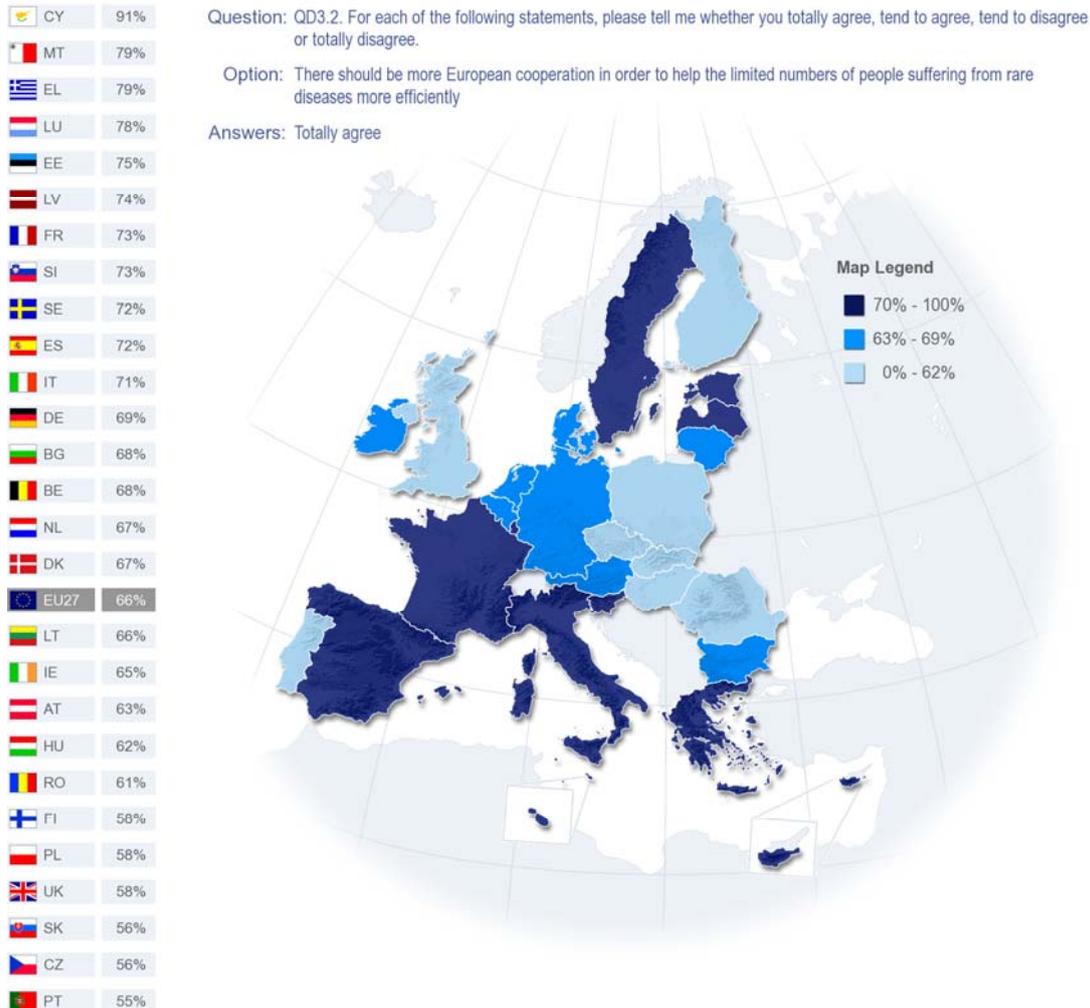


As the graph above shows, the vast majority of the European public supports actions at European level: 95% agree that there should be more European cooperation and the same proportion believe that people suffering from a rare disease should have the right to access appropriate care in another EU Member State. In addition, nine in ten citizens (90%) agree that every EU Member State should have a National Plan or Strategy on rare diseases.

### 3.1 Strengthening EU cooperation

#### - Strong support for improving European cooperation -

An overwhelming majority (95%) of Europeans agree that there should be more European cooperation in order to help the limited number of people suffering from rare diseases more efficiently. Two-thirds (66%) *totally agree* and 29% tend to agree with the statement. Only 3% of Europeans think that increasing such cooperation is not necessary.



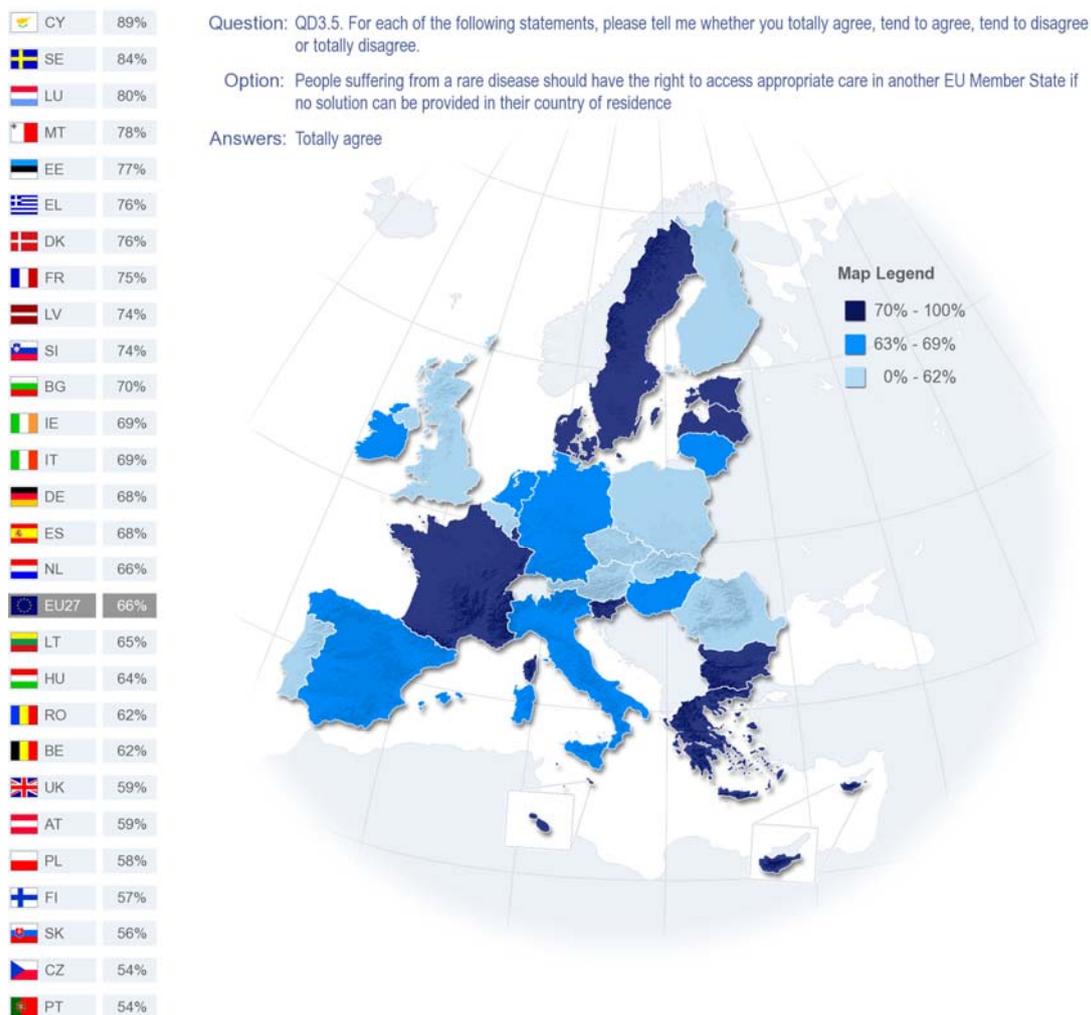
In every Member State, the level of overall agreement (*totally* and *tend to agree*) is above 90%. Therefore, the only difference between countries is in the strength of agreement. As shown in the map above, in every country the majority *totally agrees* that there should be more European cooperation. However, this majority ranges from 91% in Cyprus and 79% in Malta and Greece down to 56% in Slovakia and the Czech Republic and 55% in Portugal. Overall, the support seems to be the strongest in Southern European countries whereas respondents in many eastern countries are less emphatic in their agreement.

Due to the strong overall support, there are no considerable differences between the socio-demographic groups.

### 3.2 Right to access appropriate care in other EU member states

#### - Access to care in other Member States is widely accepted -

Support for people suffering from a rare disease to have the right to access appropriate care in another EU Member State if not available in their country of residence is very strong among EU citizens: 95% agree with this idea while only 3% oppose such a policy. Two-thirds (66%) *totally agree* while 29% *tend to agree* with cross-border access to treatment.



Once again, the differences between Member States remain minimal in terms of the overall level of agreement. However, as seen in the map above, when analysing the strength of support, considerable differences can be seen in the proportion of those of *totally agree* that people suffering from a rare disease should have the right to access appropriate care in another EU Member State. The proportions range from 89% in Cyprus and 84% in Sweden to 54% in the Czech Republic and Portugal.

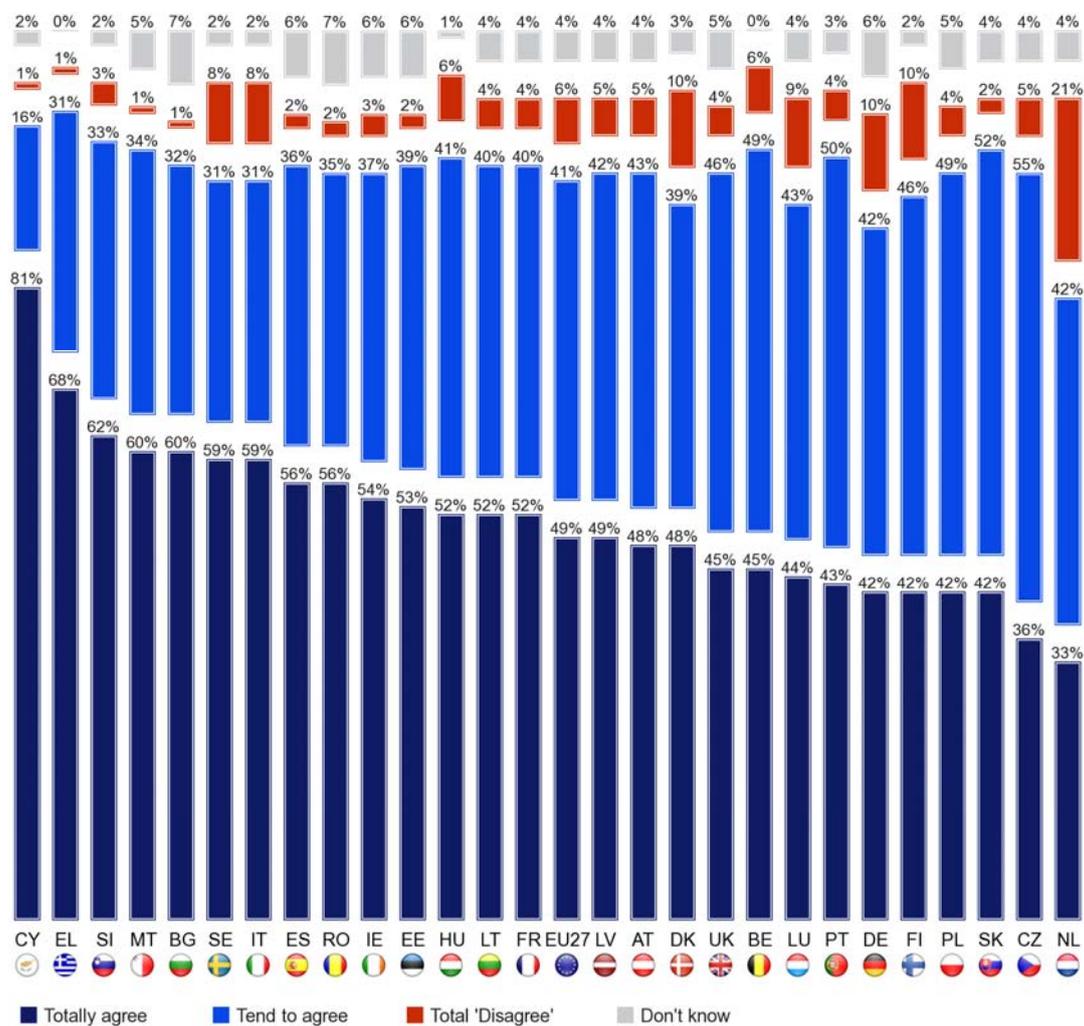
### 3.3 National Plans or Strategies for rare diseases

**- National Plans or Strategies are supported by most Europeans -**

Opinions on the need for National Plans/Strategies on rare diseases are slightly more divided than those on other issues, although an overwhelming majority of respondents in each Member State agree that such plans should be introduced in every Member State. 49% *totally agree* while 41% *tend to agree* compared with only 6% who oppose such a policy.

QD3.7. For each of the following statements, please tell me whether you totally agree, tend to agree, tend to disagree or totally disagree.

Every EU Member State should have a National Plan or Strategy on rare diseases including all the dimensions of the problem



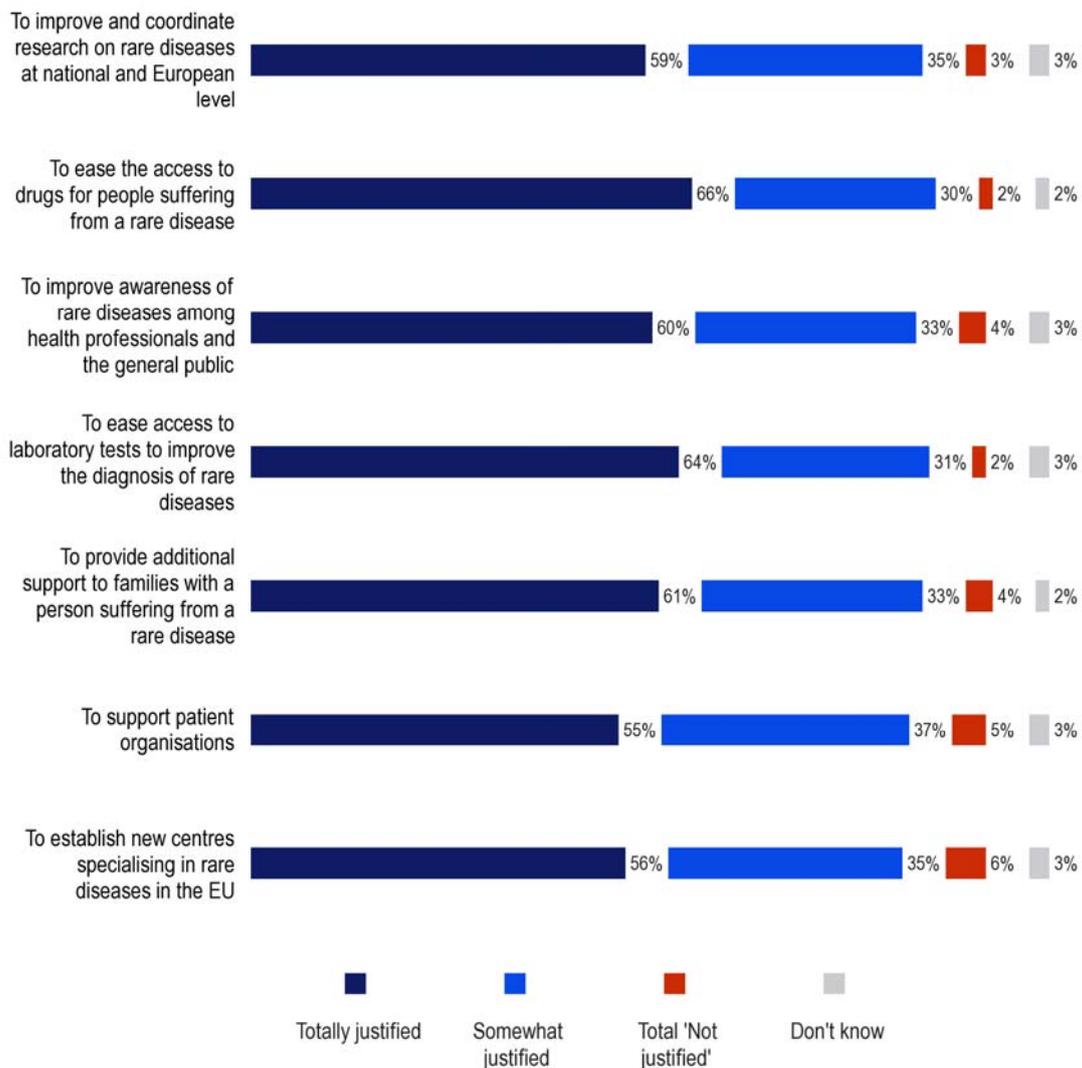
The level of overall agreement with the statement is high in every Member State but significant differences are again observed in the strength of agreement: while 81% of respondents in Cyprus *totally* support the introduction of national plans or strategies in every Member State, only around a third of respondents in the Czech Republic and the Netherlands share this view. In the Netherlands, one in five respondents (21%) is opposed to their introduction.

## 4. Support for initiatives being undertaken concerning rare diseases

### - Overwhelming support for allocating resources to initiatives in the areas of research, access to treatment, communication and support -

The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. When asked whether such support is justified, the European public express their strong agreement. Over 90% of respondents consider that it is justified to allocate resources to each of the actions in the areas of research, access to treatment, communication and patient support discussed in this chapter.

QD4. The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. In your opinion, is it justified or not to allocate resources to initiatives in the following



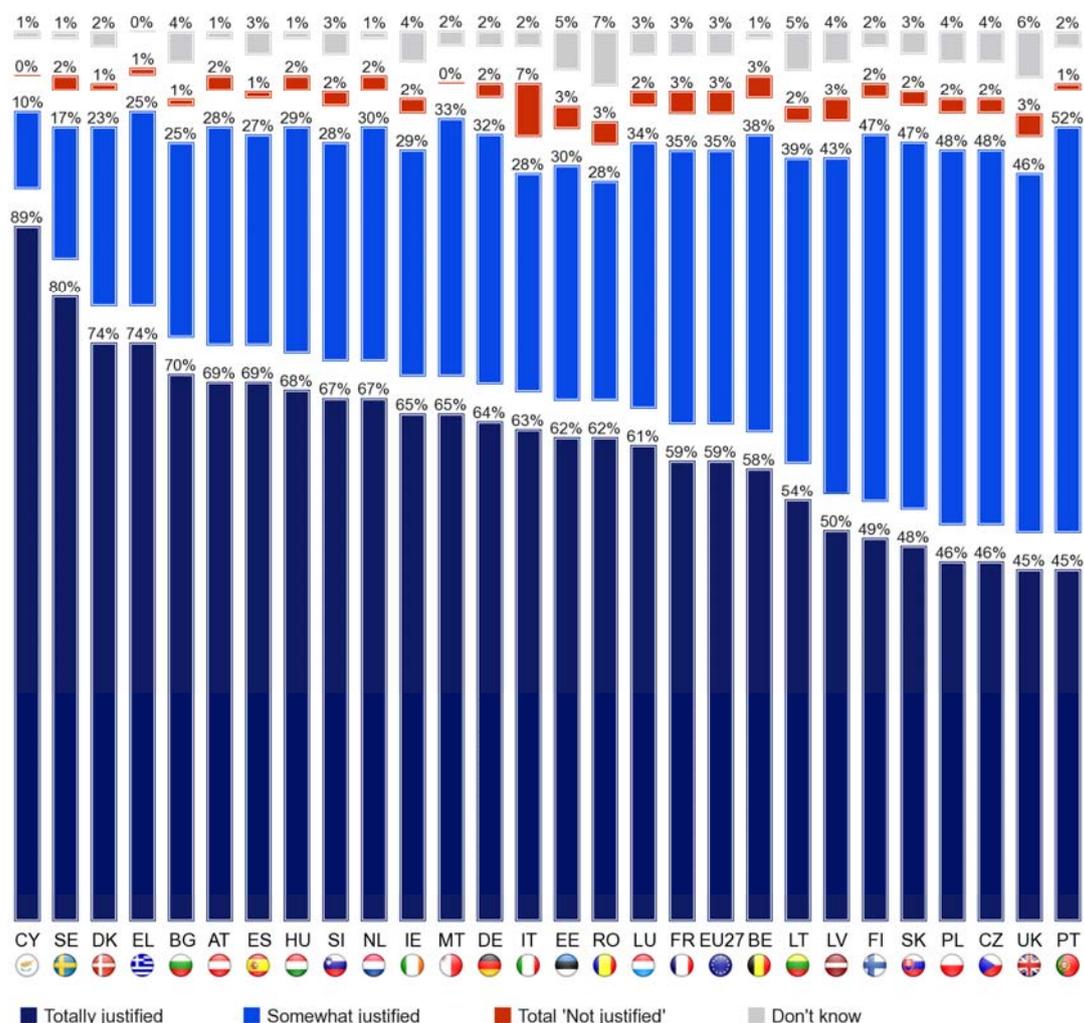
### 4.1 Initiatives in the area of research

#### 4.1.1. Improvement and coordination of research at national level and EU level

**- Strong support for improving and coordinating national and cross-national research on rare diseases -**

Almost all European citizens (94%) think it is justified to allocate resources in order to improve and coordinate research on rare diseases at national and European level – indeed in most Member States the majority finds such initiative *totally justified*. Only 3% of respondents do not support resource allocation for the development of research.

QD4.1. The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. In your opinion, is it justified or not to allocate resources to initiatives in the following  
To improve and coordinate research on rare diseases at national and European level



Strongest levels of support (in terms of those who think the allocation of resources would be totally justified) can be seen in Cyprus, Sweden, Denmark and Greece. There is somewhat more opposition in Italy although again the proportion is low at only 7%.

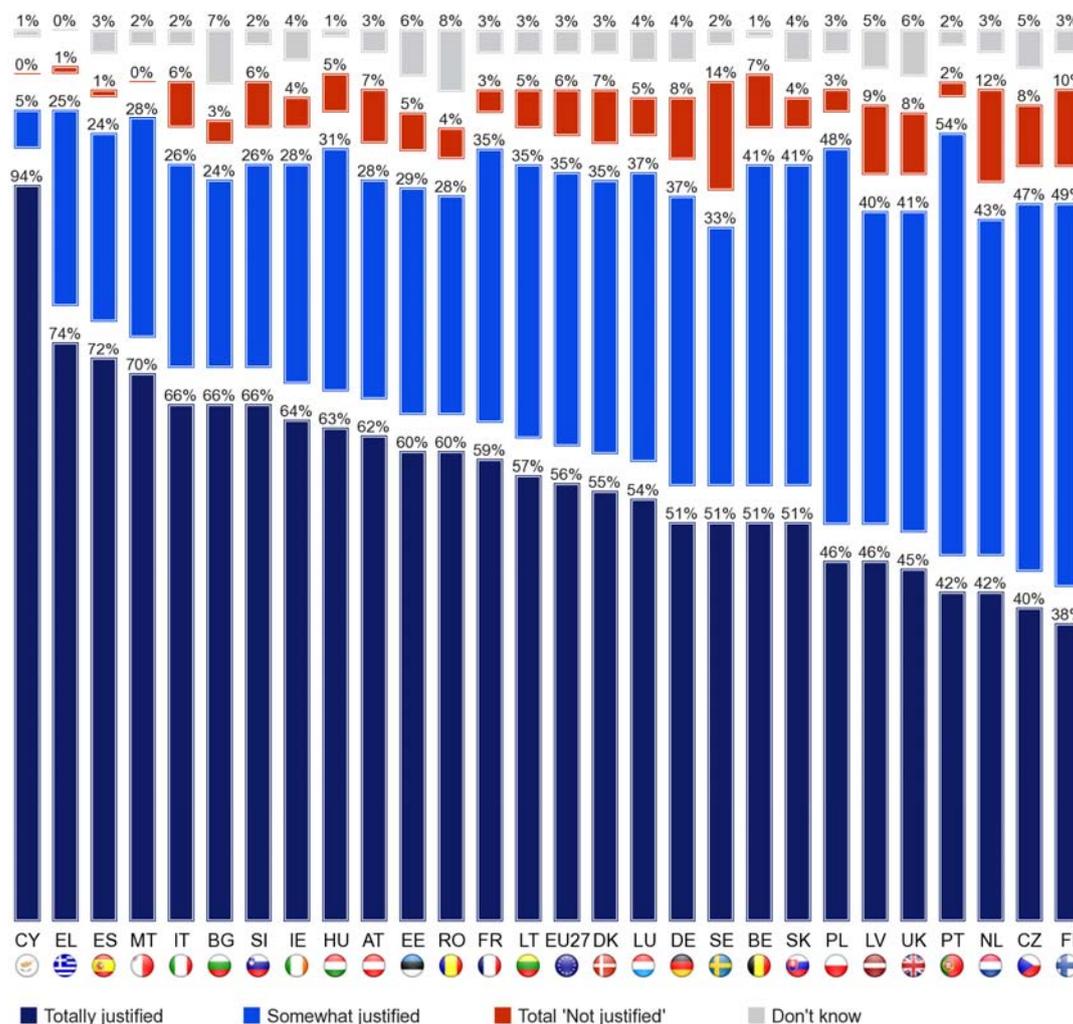
4.1.2. Establishing new centres specialising in rare diseases in the EU

**- Establishment of new centres specialising in rare diseases in the EU see as highly justified -**

Nine in ten Europeans (91%) support the allocation of resources to establishing new centres specialising in rare diseases in the EU, with only 6% against the idea.

QD4.7. The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. In your opinion, is it justified or not to allocate resources to initiatives in the following

To establish new centres specialising in rare diseases in the EU



In every Member State, 84% or more respondents feel it is justified to allocate resources for establishing new centres specialising in rare diseases. The support is strong as in 20 Member States where the majority think it is *totally justified*, most notably in Cyprus, Greece and Spain. Opposition was higher in certain countries with 14% of Swedes, 12% of the Dutch and 10% of Finns against the initiative.

## 4.2 Initiatives in the area of access to treatment

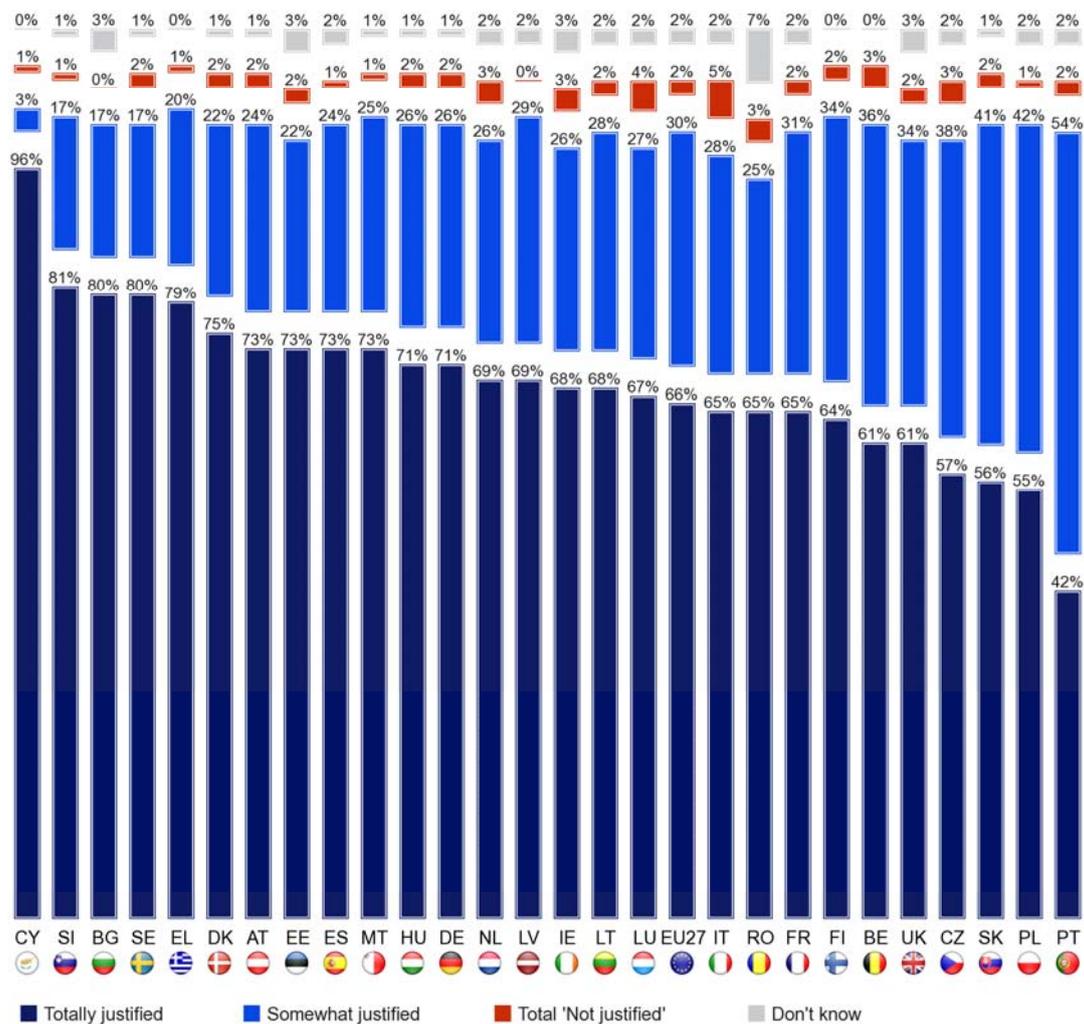
### 4.2.1. Ease of access to drugs for people suffering from a rare disease

**- Undivided support for allocating resources to ease access to drugs -**

Almost all Europeans (96%) agree that resources should be allocated to ease the access to drugs for people suffering from a rare disease with only 2% opposed

QD4.2. The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. In your opinion, is it justified or not to allocate resources to initiatives in the following

To ease the access to drugs for people suffering from a rare disease



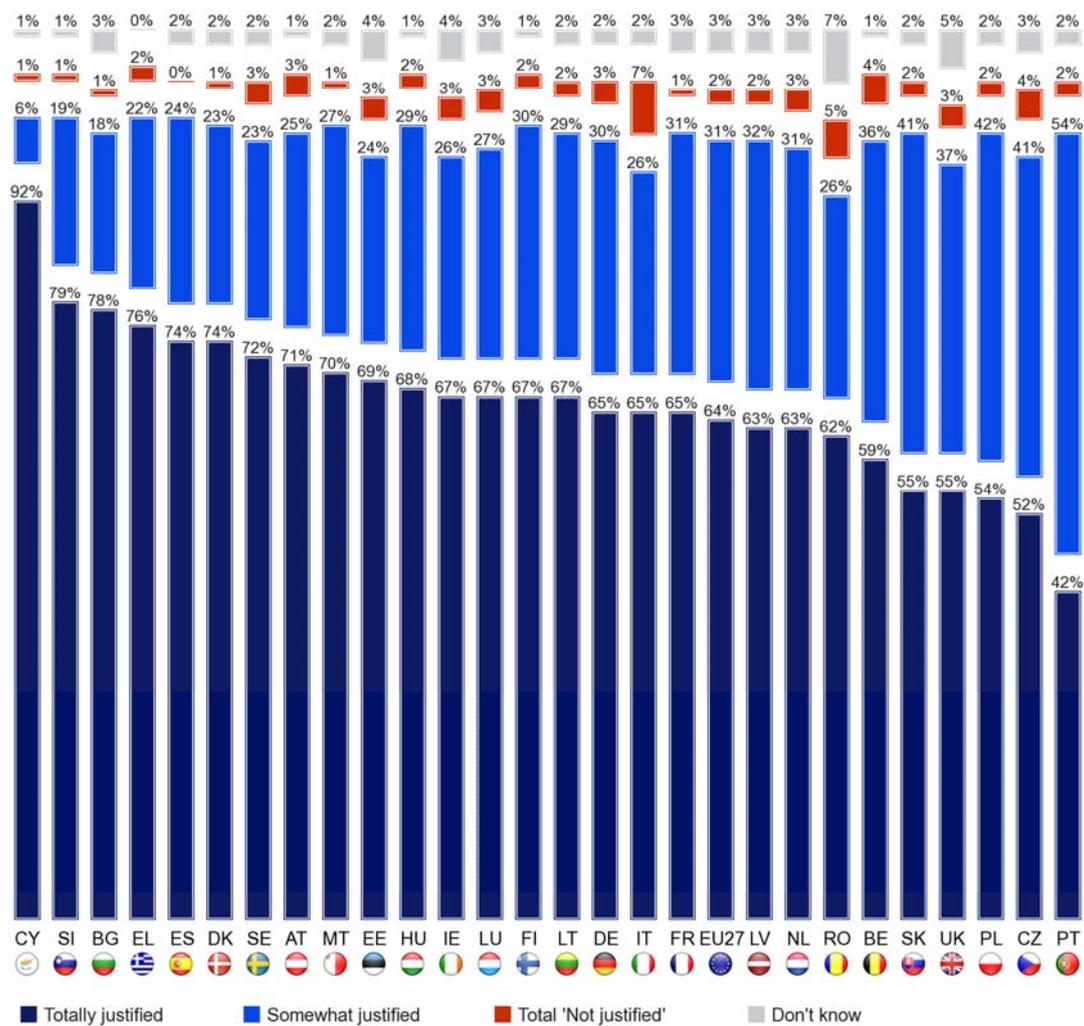
At least nine in ten respondents in every Member State find it justified to allocate resources to ease the access to drugs, and in nearly all Member States (with the exception of Portugal) the majority of the poll think this is *totally justified*.

4.2.2. Ease of access to laboratory tests to improve the diagnosis of rare diseases

**- Allocating resources to ease access to laboratory tests found to be highly justified -**

There is almost universal support for allocating resources to ease access to laboratory tests to improve the diagnosis of rare diseases: 95% of respondents find it justified to allocate resources to improve accessibility with only 2% opposed.

QD4.4. The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. In your opinion, is it justified or not to allocate resources to initiatives in the following  
To ease access to laboratory tests to improve the diagnosis of rare diseases



In every Member State with the exception of Portugal, the majority feel it is *totally justified* to allocate resources to initiatives that ease access to laboratory tests - most notably Cyprus where 92% of respondents *totally* support such action.

### 4.3 Initiatives in the area of support and education

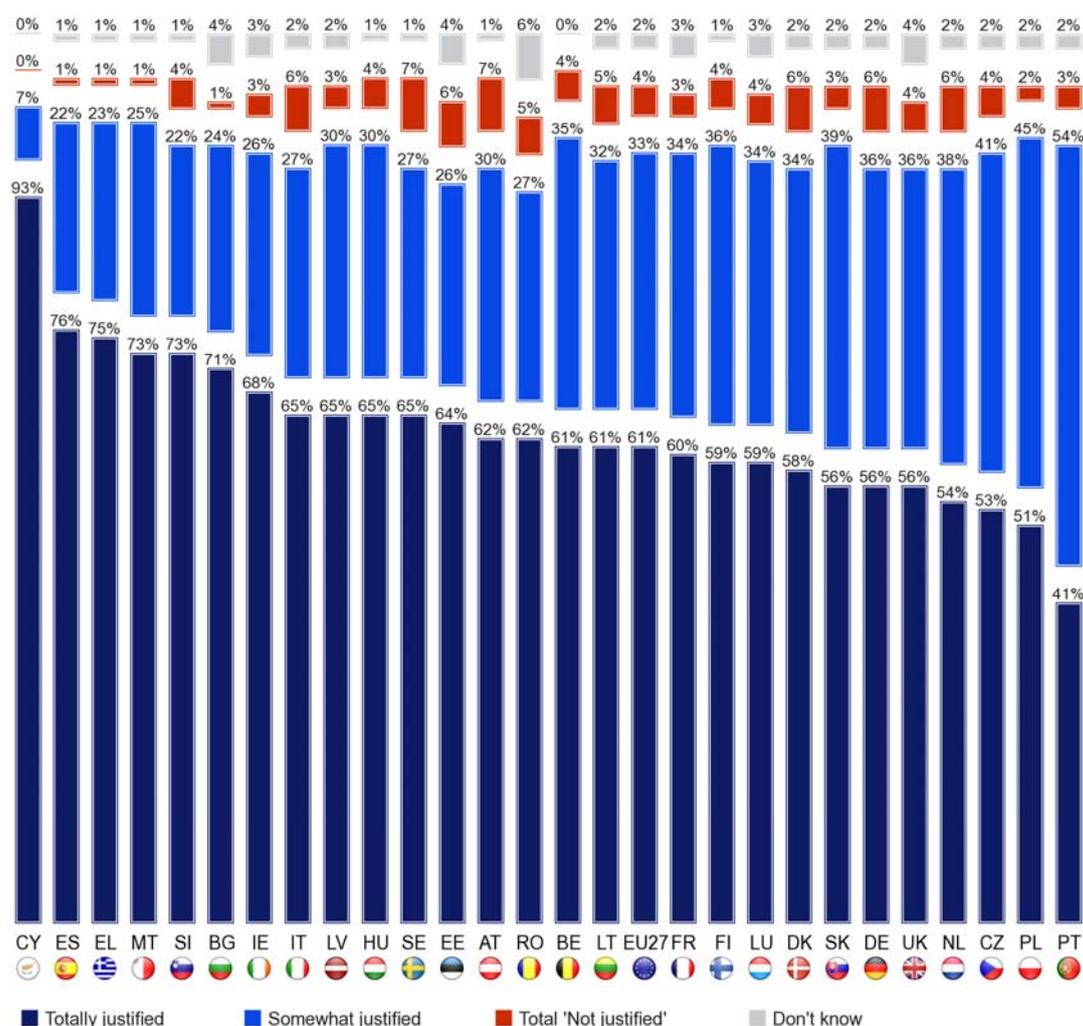
#### 4.3.1. Support to families with a person suffering from a rare disease

##### - Unconditional support for initiatives aiming at providing additional support to families with a person suffering from a rare disease -

There is strong EU-wide support for the allocation of resources to provide additional support to families with a person suffering from rare diseases: 94% of respondents support such initiative with only 4% of respondents who feel it to be unjustified.

QD4.5. The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. In your opinion, is it justified or not to allocate resources to initiatives in the following

To provide additional support to families with a person suffering from a rare disease



The majority of respondents in every Member State with the exception of Portugal find it *totally justified* to allocate resources to provide additional support for families with a member suffering a rare disease. Respondents in Cyprus, Spain Greece, Malta, Slovenia and Bulgaria are particularly supportive in this respect. A small minority in each country find allocating resources to support families unjustified, the highest level of opposition (7%) being seen in Austria and in Sweden.

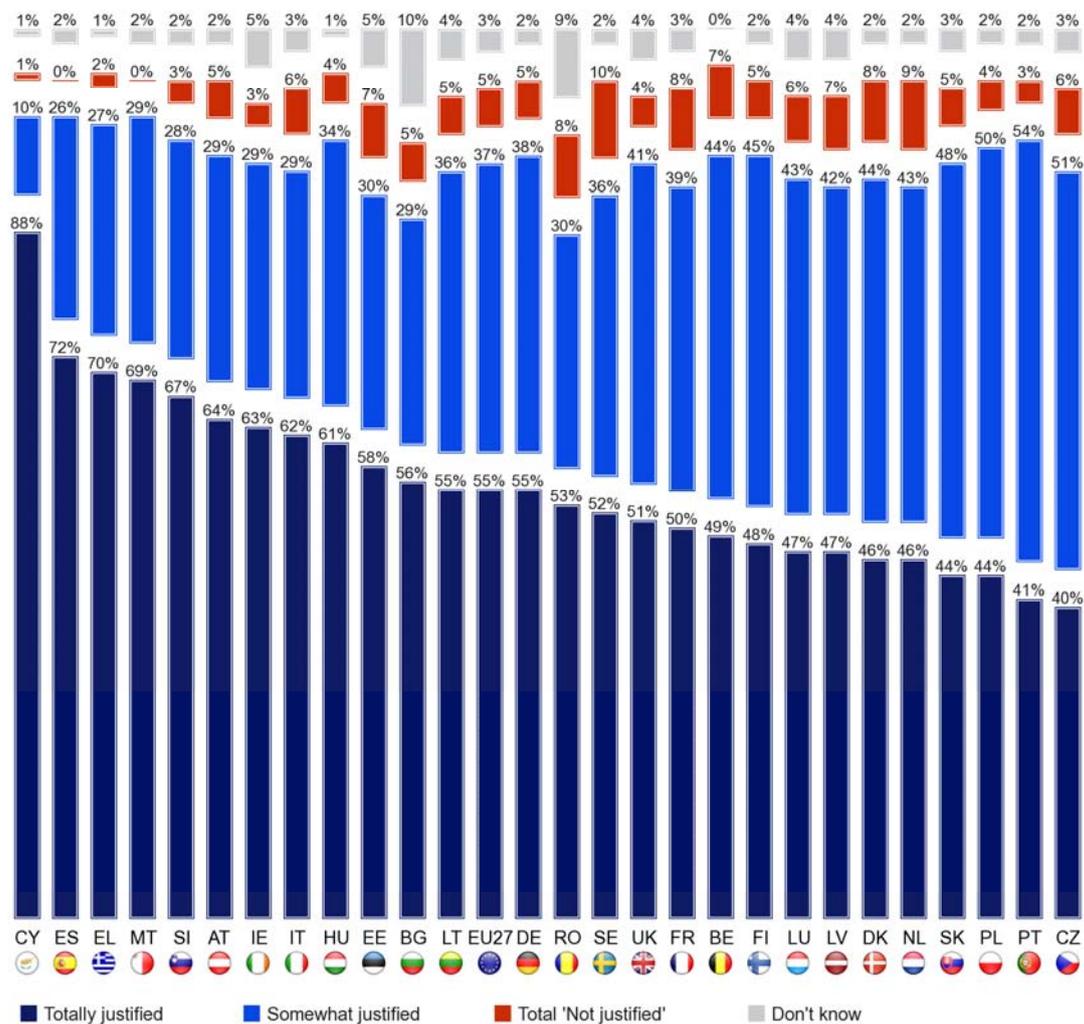
4.3.2. Support of patient organisations

**- The European public willing to allocate resources to support patient organisations -**

Nine in ten European citizens (92%) believe it is justified to allocate resources to support patient organisations with 5% of respondents opposed.

QD4.6. The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. In your opinion, is it justified or not to allocate resources to initiatives in the following

To support patient organisations



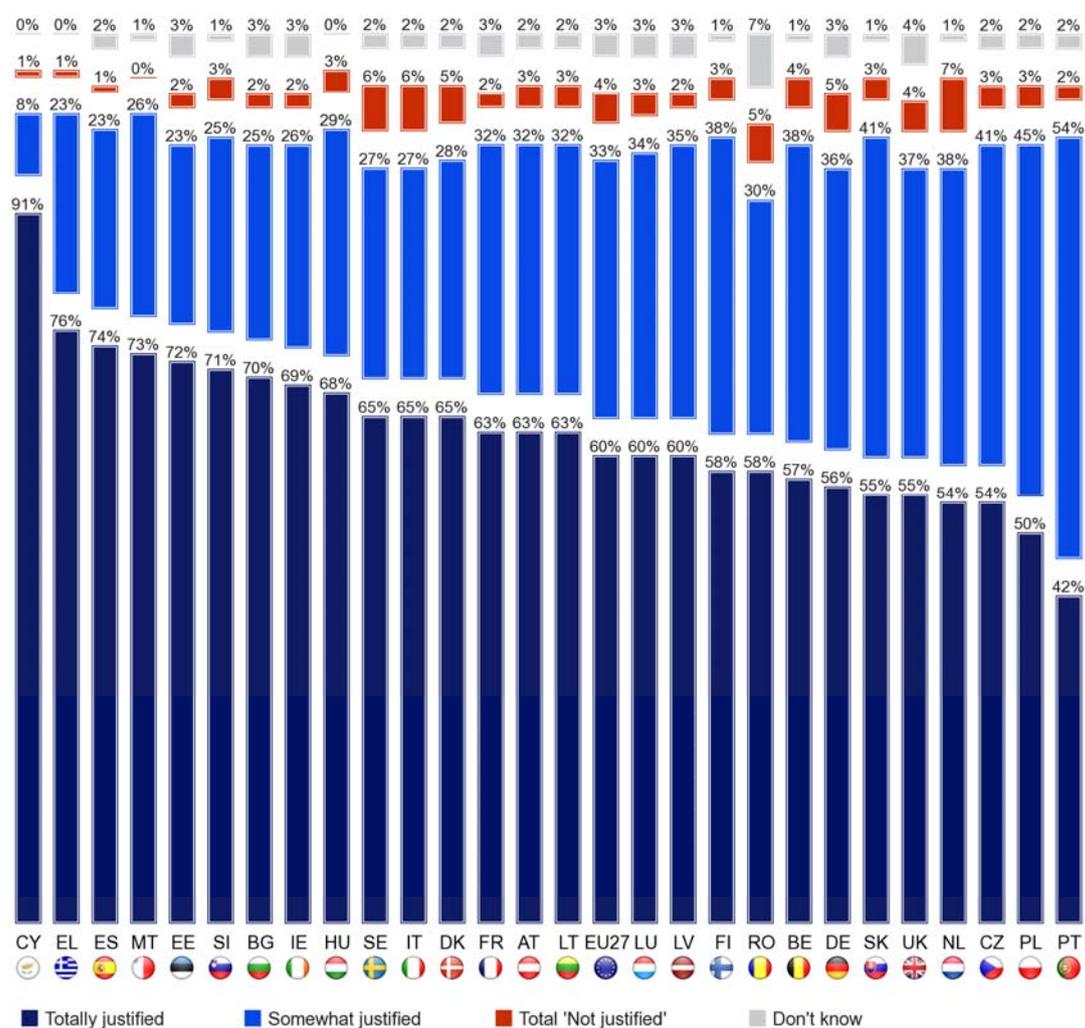
In most Member States, the majority think it is *totally justified* to allocate resources to support patient organisations, with around seven in ten in Cyprus, Spain, Greece and Malta expressing support. Around one in ten citizens were opposed to the financial support of patient organisations in Sweden, the Netherlands, Romania, France and Denmark.

4.3.3. Improving awareness of rare diseases

**- Initiatives improving awareness of rare diseases receive unconditional support of the European public -**

European citizens show strong support for allocating resources to improve awareness of rare diseases among health professionals and the general public: 93% think it is justified to allocate resources for such an initiative. Six in ten (60%) find such action *totally justified* and 33% *somewhat justified* with only 4% against the initiative.

QD4.3. The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. In your opinion, is it justified or not to allocate resources to initiatives in the following  
To improve awareness of rare diseases among health professionals and the general public



In all Member States with the exception of Portugal, the majority think it is *totally justified* to allocate resources to raise awareness of rare diseases, most notably in Cyprus. Very few find such an initiative unjustified – at the highest level opposition reaches only as high as 7% of respondents in the Netherlands.



## CONCLUSION

The key finding of this survey is that the European public almost unanimously supports a coordinated EU strategy for improving the treatment of people suffering from rare diseases. It is only within the context of other major national health issues that respondents are slightly less supportive although even here the majority of Europeans are still willing to make rare diseases a priority.

The results also show that the general understanding of what rare diseases are is relatively good although it differs significantly between the Member States. However, basic awareness of specific rare diseases is low, in part due to a lack of direct or indirect personal experience. Two Europeans in five have never heard of a person suffering from a rare disease.

However, despite the lack of any personal experience for most, the European public expresses a strong support for policy initiatives which relate to rare diseases at both a national and European level. There is clear support for a coordinated and collaborative European effort to tackle rare diseases, both in terms of treatment, care and awareness building, with high levels of support for access to treatment in other Member States. The introduction of national strategies for rare diseases is also welcomed although, despite strong support, opinion is more divided on the prioritisation of the treatment of rare diseases at national level.

The main message of this survey for EU policy makers is that amongst the European public there is a widespread willingness to improve the treatment of rare diseases. However this willingness is instinctive and empathetic rather than based on actual knowledge. It also has to be remembered that questions were asked without the requirement for respondents to consider the resources needed or potential financial consequences of any change in policy.

Future policy needs to be accompanied by education and awareness-building to increase the general recognition and visibility of rare diseases which in terms of real knowledge is very low amongst the general public. This in turn will lead to stronger support – stronger because real and better-informed.

# **ANNEXES**



# **TECHNICAL SPECIFICATIONS**



## SPECIAL EUROBAROMETER 361

“Rare diseases”

### TECHNICAL SPECIFICATIONS

Between the 25th of November and the 17th of December 2010, TNS Opinion & Social, a consortium created between TNS plc and TNS opinion, carried out the wave 74.3 of the EUROBAROMETER, on request of the EUROPEAN COMMISSION, Directorate-General for Communication, “Research and Speechwriting”.

The SPECIAL EUROBAROMETER 361 is part of wave 74.3 and covers the population of the respective nationalities of the European Union Member States, resident in each of the Member States and aged 15 years and over. The basic sample design applied in all states is a multi-stage, random (probability) one. In each country, a number of sampling points was drawn with probability proportional to population size (for a total coverage of the country) and to population density.

In order to do so, the sampling points were drawn systematically from each of the “administrative regional units”, after stratification by individual unit and type of area. They thus represent the whole territory of the countries surveyed according to the EUROSTAT NUTS II (or equivalent) and according to the distribution of the resident population of the respective nationalities in terms of metropolitan, urban and rural areas. In each of the selected sampling points, a starting address was drawn, at random. Further addresses (every Nth address) were selected by standard “random route” procedures, from the initial address. In each household, the respondent was drawn, at random (following the “closest birthday rule”). All interviews were conducted face-to-face in people’s homes and in the appropriate national language. As far as the data capture is concerned, CAPI (*Computer Assisted Personal Interview*) was used in those countries where this technique was available.

**Table 1**

<b>ABBREVIATIONS</b>	<b>COUNTRIES</b>	<b>INSTITUTES</b>	<b>N° INTERVIEWS</b>	<b>FIELDWORK DATES</b>		<b>POPULATION 15+</b>
BE	Belgium	TNS Dimarso	1020	25/11/2010	14/12/2010	8.866.411
BG	Bulgaria	TNS BBSS	1000	26/11/2010	08/12/2010	6.584.957
CZ	Czech Rep.	TNS Aisa	1015	26/11/2010	13/12/2010	8.987.535
DK	Denmark	TNS Gallup DK	1007	26/11/2010	15/12/2010	4.533.420
DE	Germany	TNS Infratest	1519	25/11/2010	12/12/2010	64.545.601
EE	Estonia	Emor	1000	26/11/2010	13/12/2010	916.000
IE	Ireland	MRBI	975	26/11/2010	17/12/2010	3.375.399
EL	Greece	TNS ICAP	1000	26/11/2010	13/12/2010	8.693.566
ES	Spain	TNS Demoscopia	1006	26/11/2010	14/12/2010	39.035.867
FR	France	TNS Sofres	1000	26/11/2010	14/12/2010	47.620.942
IT	Italy	TNS Infratest	1039	26/11/2010	13/12/2010	51.252.247
CY	Rep. of Cyprus	Synovate	501	26/11/2010	12/12/2010	651.400
LV	Latvia	TNS Latvia	1000	26/11/2010	13/12/2010	1.448.719
LT	Lithuania	TNS Gallup Lithuania	1026	26/11/2010	13/12/2010	2.849.359
LU	Luxembourg	TNS ILReS	501	26/11/2010	15/12/2010	404.907
HU	Hungary	TNS Hungary	1014	26/11/2010	13/12/2010	8.320.614
MT	Malta	MISCO	500	26/11/2010	12/12/2010	335.476
NL	Netherlands	TNS NIPO	1024	26/11/2010	14/12/2010	13.288.200
AT	Austria	Österreichisches Gallup-Institut	1010	26/11/2010	12/12/2010	6.973.277
PL	Poland	TNS OBOP	1000	26/11/2010	13/12/2010	32.306.436
PT	Portugal	TNS EUROTESTE	1046	26/11/2010	13/12/2010	8.080.915
RO	Romania	TNS CSOP	1013	26/11/2010	10/12/2010	18.246.731
SI	Slovenia	RM PLUS	1020	26/11/2010	13/12/2010	1.748.308
SK	Slovakia	TNS AISA SK	1034	26/11/2010	13/12/2010	4.549.954
FI	Finland	TNS Gallup Oy	1003	26/11/2010	16/12/2010	4.412.321
SE	Sweden	TNS GALLUP	1010	26/11/2010	15/12/2010	7.723.931
UK	United Kingdom	TNS UK	1291	26/11/2010	14/12/2010	51.081.866
<b>TOTAL EU27</b>			<b>26.574</b>	<b>25/11/2010</b>	<b>17/12/2010</b>	<b>406.834.359</b>

For each country a comparison between the sample and the universe was carried out. The Universe description was derived from Eurostat population data or from national statistics offices. For all countries surveyed, a national weighting procedure, using marginal and intercellular weighting, was carried out based on this Universe description. In all countries, gender, age, region and size of locality were introduced in the iteration procedure. For international weighting (i.e. EU averages), TNS Opinion & Social applies the official population figures as provided by EUROSTAT or national statistic offices. The total population figures for input in this post-weighting procedure are listed above.

Readers are reminded that survey results are estimations, the accuracy of which, everything being equal, rests upon the sample size and upon the observed percentage. With samples of about 1,000 interviews, the real percentages vary within the following confidence limits:

<b>Observed percentages</b>	10% or 90%	20% or 80%	30% or 70%	40% or 60%	50%
<b>Confidence limits</b>	± 1.9 points	± 2.5 points	± 2.7 points	± 3.0 points	± 3.1 points



# **QUESTIONNAIRE**

D. RARE DISEASES

QD1 When talking about rare diseases, which of the following is, in your opinion, the statement that best describes what "rare diseases" are?

(SHOW CARD – READ OUT – ONE ANSWER ONLY)

	(627)
These are diseases about which nobody can do anything	1
These are diseases affecting a limited number of people and needing very specific care	2
These are diseases for which it is very difficult to obtain a correct and fast diagnosis	3
These are diseases that nobody cares about	4
Other (SPONTANEOUS)	5
Never heard about rare diseases (SPONTANEOUS)	6
DK	7

NEW

A rare disease is a disease affecting fewer than 1 people in 2.000

QD2 Do you personally know or have you heard about a person suffering from a rare disease?

(SHOW CARD – READ OUT – MULTIPLE ANSWERS POSSIBLE)

	(628-632)
Yes, you personally know someone suffering from a rare disease	1,
Yes, you have heard about someone suffering from a rare disease within your family\ your friends\ your acquaintances	2,
Yes, you have heard about a person suffering from a rare disease in the media	3,
No, you have never heard about any one suffering from a rare disease	4,
DK	5,

NEW

D. LES MALADIES RARES

QD1 Lorsque l'on parle de maladies rares, selon vous, laquelle des propositions suivantes décrit le mieux ce que sont les "maladies rares" ?

(MONTRER CARTE – LIRE – UNE SEULE REPONSE)

	(627)
Ce sont des maladies contre lesquelles personne ne peut rien faire	1
Ce sont des maladies qui touchent un nombre limité de personnes et qui exigent des soins très spécifiques	2
Ce sont des maladies pour lesquelles il est très difficile d'obtenir un diagnostic correct et rapide	3
Ce sont des maladies dont personne ne se soucie	4
Autre (SPONTANE)	5
Jamais entendu parler de maladies rares (SPONTANE)	6
NSP	7

NEW

Une maladie rare est une maladie qui touche moins d'1 personne sur 2.000

QD2 Connaissez-vous personnellement ou avez-vous entendu parler d'une personne atteinte d'une maladie rare ?

(MONTRER CARTE – LIRE – PLUSIEURS REPONSES POSSIBLES)

	(628-632)
Oui, vous connaissez personnellement quelqu'un atteint d'une maladie rare	1,
Oui, vous avez entendu parler de quelqu'un atteint d'une maladie rare dans votre famille\ vos amis \ vos connaissances	2,
Oui, vous avez entendu parler de quelqu'un atteint d'une maladie rare dans les médias	3,
Non, vous n'avez jamais entendu parler d'une personne atteinte d'une maladie rare	4,
NSP	5,

NEW

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QD3 For each of the following statements, please tell me whether you totally agree, tend to agree, tend to disagree or totally disagree.

QD3 Pour chacune des propositions suivantes, veuillez me dire si vous êtes tout à fait d'accord, plutôt d'accord, plutôt pas d'accord ou pas du tout d'accord.

(SHOW CARD WITH SCALE – ONE ANSWER PER LINE)

(MONTRER CARTE AVEC ECHELLE – UNE REPONSE PAR LIGNE)

	(READ OUT)	Totally agree	Tend to agree	Tend to disagree	Totally disagree	DK
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	(LIRE)	Tout à fait d'accord	Plutôt d'accord	Plutôt pas d'accord	Pas du tout d'accord	NSP
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(633)	1	People suffering from a rare disease need specific support from (NATIONALITY) health authorities	1	2	3	4	5
(634)	2	There should be more European cooperation in order to help the limited numbers of people suffering from rare diseases more efficiently	1	2	3	4	5
(635)	3	The drugs developed to treat people suffering from rare diseases should be fully reimbursed by the (NATIONALITY) health care system even if they are very expensive	1	2	3	4	5
(636)	4	People are aware of the existence of centres specialising in rare diseases	1	2	3	4	5

(633)	1	Les personnes atteintes d'une maladie rare ont besoin d'un soutien spécifique de la part des autorités (NATIONALITE) de la santé	1	2	3	4	5
(634)	2	Il devrait y avoir plus de coopération européenne pour aider plus efficacement le nombre limité de personnes atteintes d'une maladie rare	1	2	3	4	5
(635)	3	Les médicaments développés pour le traitement des personnes atteintes d'une maladie rare devraient être remboursés intégralement par le système de santé (NATIONALITE) même s'ils coûtent très cher	1	2	3	4	5
(636)	4	Les gens connaissent l'existence de centres spécialisés dans les maladies rares	1	2	3	4	5

(637)	5	People suffering from a rare disease should have the right to access appropriate care in another EU Member State if no solution can be provided in their country of residence	1	2	3	4	5	(637)
(638)	6	(OUR COUNTRY) has too many other major health issues to make rare diseases a priority	1	2	3	4	5	(638)
(639)	7	Every EU Member State should have a National Plan or Strategy on rare diseases including all the dimensions of the problem	1	2	3	4	5	(639)
(640)	8	People are unaware of the real problems faced by those suffering from a rare disease	1	2	3	4	5	(640)

NEW

(637)	5	Les personnes atteintes d'une maladie rare devraient avoir le droit d'accéder à des soins appropriés dans un autre Etat membre de l'UE si aucune solution ne peut leur être fournie dans leur pays de résidence	1	2	3	4	5	(637)
(638)	6	(NOTRE PAYS) a trop d'autres problèmes de santé importants avant de faire des maladies rares une priorité	1	2	3	4	5	(638)
(639)	7	Chaque Etat membre de l'UE devrait avoir un programme ou une stratégie nationale sur les maladies rares intégrant toutes les dimensions du problème	1	2	3	4	5	(639)
(640)	8	Les gens n'ont pas conscience des réels problèmes auxquels sont confrontées les personnes atteintes d'une maladie rare	1	2	3	4	5	(640)

NEW

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QD4 The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. In your opinion, is it justified or not to allocate resources to initiatives in the following areas?

QD4 La Commission européenne et les autorités nationales de santé des Etats membres de l'UE ont adopté plusieurs initiatives pour aider les personnes atteintes de maladies rares. Selon vous, est-il justifié ou non d'allouer des ressources aux initiatives prises dans les domaines suivants ?

(SHOW CARD WITH SCALE – ONE ANSWER PER LINE)

(MONTRER CARTE AVEC ECHELLE – UNE REPOSE PAR LIGNE)

	(READ OUT)	Totally justified	Somewhat justified	Not very justified	Not at all justified	DK
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	(LIRE)	Tout à fait justifié	Plutôt justifié	Pas très justifié	Pas du tout justifié	NSP
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(641)	1	To improve and coordinate research on rare diseases at national and European level	1	2	3	4	5
(642)	2	To ease the access to drugs for people suffering from a rare disease	1	2	3	4	5
(643)	3	To improve awareness of rare diseases among health professionals and the general public	1	2	3	4	5
(644)	4	To ease access to laboratory tests to improve the diagnosis of rare diseases	1	2	3	4	5
(645)	5	To provide additional support to families with a person suffering from a rare disease	1	2	3	4	5
(646)	6	To support patient organisations	1	2	3	4	5
(647)	7	To establish new centres specialising in rare diseases in the EU	1	2	3	4	5

(641)	1	Pour améliorer et coordonner la recherche sur les maladies rares aux niveaux national et européen	1	2	3	4	5
(642)	2	Pour faciliter l'accès aux médicaments pour les personnes atteintes d'une maladie rare	1	2	3	4	5
(643)	3	Pour améliorer la connaissance des maladies rares auprès des professionnels de la santé et du grand public	1	2	3	4	5
(644)	4	Pour faciliter l'accès aux tests de laboratoire afin d'améliorer le diagnostic des maladies rares	1	2	3	4	5
(645)	5	Pour fournir une aide supplémentaire aux familles dont l'un des membres est atteint d'une maladie rare	1	2	3	4	5
(646)	6	Pour soutenir les associations de patients	1	2	3	4	5
(647)	7	Pour créer de nouveaux centres spécialisés dans les maladies rares dans l'UE	1	2	3	4	5

NEW \_\_\_\_\_

NEW \_\_\_\_\_

QD5 Have you ever heard of each of the following diseases?

QD5 Avez-vous déjà entendu parler de chacune des maladies suivantes ?

(ONE ANSWER PER LINE)

(UNE REPOSE PAR LIGNE)

	(READ OUT)	Yes	No	DK
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	(LIRE)	Oui	Non	NSP
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(648)	1	Cystic fibrosis	1	2	3
(649)	2	Duchenne muscular dystrophy	1	2	3
(650)	3	Haemophilia	1	2	3
(651)	4	Huntington's disease	1	2	3
(652)	5	Osteogenesis imperfecta	1	2	3
(653)	6	Progeria	1	2	3

(648)	1	La mucoviscidose	1	2	3
(649)	2	La myopathie de Duchenne	1	2	3
(650)	3	L'hémophilie	1	2	3
(651)	4	La maladie de Huntington	1	2	3
(652)	5	L'ostéogénèse imparfaite	1	2	3
(653)	6	La progeria	1	2	3

NEW

NEW



# **TABLES**



QD1 Lorsque l'on parle de maladies rares, selon vous, laquelle des propositions suivantes décrit le mieux ce que sont les "maladies rares" ?

QD1 When talking about rare diseases, which of the following is, in your opinion, the statement that best describes what "rare diseases" are?

QD1 Wenn es um das Thema seltene Krankheiten geht, welche der folgenden Aussagen beschreibt da Ihrer Meinung nach am besten, was "seltene Krankheiten" sind?

		Ce sont des maladies contre lesquelles personne ne peut rien faire	Ce sont des maladies qui touchent un nombre limité de personnes et qui exigent des soins très spécifiques	Ce sont des maladies pour lesquelles il est très difficile d'obtenir un diagnostic correct et rapide	Ce sont des maladies dont personne ne se soucie	Autre (SPONTANE)	Jamais entendu parler de maladies rares (SPONTANE)	NSP
		These are diseases about which nobody can do anything	These are diseases affecting a limited number of people and needing very specific care	These are diseases for which it is very difficult to obtain a correct and fast diagnosis	These are diseases that nobody cares about	Other (SPONTANEOUS)	Never heard about rare diseases (SPONTANEOUS)	DK
		Das sind Krankheiten, gegen die niemand etwas tun kann	Das sind Krankheiten, von denen eine begrenzte Zahl von Menschen betroffen ist und die eine ganz besondere Behandlung benötigen	Das sind Krankheiten, bei denen es sehr schwierig ist, eine richtige und schnelle Diagnose zu erhalten	Das sind Krankheiten, für die sich niemand interessiert	Andere (SPONTAN)	Noch nie von seltenen Krankheiten gehört (SPONTAN)	WN
%		EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3
 EU 27		11	63	19	3	0	2	2
 BE		14	64	16	3	0	3	0
 BG		13	52	24	2	0	5	4
 CZ		9	66	18	2	0	4	1
 DK		6	78	14	1	0	0	1
 D-W		8	70	16	3	0	1	2
 DE		8	71	15	3	0	1	2
 D-E		7	75	14	2	0	1	1
 EE		13	53	24	3	0	4	3
 IE		16	55	22	2	1	1	3
 EL		17	58	17	1	1	4	2
 ES		13	55	27	1	1	1	2
 FR		11	64	16	6	0	1	2
 IT		8	62	20	5	0	3	2
 CY		21	46	29	1	1	1	1
 LV		12	51	27	3	0	5	2
 LT		14	55	22	3	0	3	3
 LU		8	66	19	3	1	2	1
 HU		12	58	23	1	0	5	1
 MT		13	56	22	1	0	4	4
 NL		4	76	18	1	1	0	0
 AT		7	64	22	3	1	2	1
 PL		11	63	18	4	0	0	4
 PT		16	50	23	3	2	4	2
 RO		27	42	13	3	0	8	7
 SI		11	52	30	1	1	3	2
 SK		11	65	20	1	0	2	1
 FI		6	48	42	1	1	1	1
 SE		2	76	21	1	0	0	0
 UK		9	66	18	1	0	2	4

QD2 Connaissez-vous personnellement ou avez-vous entendu parler d'une personne atteinte d'une maladie rare ? (PLUSIEURS REPONSES POSSIBLES)

QD2 Do you personally know or have you heard about a person suffering from a rare disease? (MULTIPLE ANSWERS POSSIBLE)

QD2 Kennen Sie persönlich jemanden oder haben Sie von jemandem gehört, der an einer seltenen Krankheit leidet? (MEHRFACHNENNUNGEN MÖGLICH)

		Oui, vous connaissez personnellement quelqu'un atteint d'une maladie rare	Oui, vous avez entendu parler de quelqu'un atteint d'une maladie rare dans votre famille/ vos amis / vos connaissances	Oui, vous avez entendu parler de quelqu'un atteint d'une maladie rare dans les médias	Non, vous n'avez jamais entendu parler d'une personne atteinte d'une maladie rare	NSP	Total 'Oui'
		Yes, you personally know someone suffering from a rare disease	Yes, you have heard about someone suffering from a rare disease within your family/ your friends/ your acquaintances	Yes, you have heard about a person suffering from a rare disease in the media	No, you have never heard about any one suffering from a rare disease	DK	Total 'Yes'
		Ja, Sie kennen persönlich jemanden, der an einer seltenen Krankheit leidet	Ja, Sie haben in Ihrem Familien-/ Freundes-/ Bekanntenkreis von jemandem gehört, der an einer seltenen Krankheit leidet	Ja, Sie haben in den Medien von jemandem gehört, der an einer seltenen Krankheit leidet	Nein, Sie haben noch nie von jemandem gehört, der an einer seltenen Krankheit leidet	WN	Gesamt 'Ja'
	%	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3
	EU 27	17	13	35	40	3	57
	BE	23	15	24	44	1	56
	BG	7	6	48	34	7	59
	CZ	7	10	43	42	0	57
	DK	42	24	49	15	1	84
	D-W	16	9	27	53	3	44
	DE	15	8	27	55	2	43
	D-E	12	5	24	60	1	39
	EE	17	12	41	39	1	61
	IE	11	22	35	33	5	62
	EL	6	16	30	51	1	48
	ES	11	11	43	36	4	60
	FR	28	16	36	32	1	67
	IT	12	20	43	27	2	70
	CY	29	22	36	24	3	73
	LV	12	10	39	42	1	56
	LT	16	9	33	44	2	54
	LU	21	23	39	30	1	69
	HU	14	10	40	35	1	63
	MT	15	20	28	44	4	52
	NL	33	17	26	33	1	66
	AT	13	14	48	31	1	68
	PL	13	9	37	43	2	55
	PT	10	12	54	28	1	71
	RO	7	8	36	36	16	48
	SI	14	11	40	40	2	58
	SK	17	16	47	26	1	73
	FI	26	20	42	27	0	72
	SE	38	27	51	17	0	83
	UK	18	9	16	59	1	40

QD3.1 Pour chacune des propositions suivantes, veuillez me dire si vous êtes tout à fait d'accord, plutôt d'accord, plutôt pas d'accord ou pas du tout d'accord.

Les personnes atteintes d'une maladie rare ont besoin d'un soutien spécifique de la part des autorités (NATIONALITE) de la santé

QD3.1 For each of the following statements, please tell me whether you totally agree, tend to agree, tend to disagree or totally disagree.

People suffering from a rare disease need specific support from (NATIONALITY) health authorities

QD3.1 Bitte sagen Sie mir für jede der folgenden Aussagen, ob Sie ihr voll und ganz zustimmen, eher zustimmen, eher nicht zustimmen oder überhaupt nicht zustimmen.

Menschen, die an einer seltenen Krankheit leiden, benötigen besondere Unterstützung von den (NATIONALEN) Gesundheitsbehörden

		Tout à fait d'accord	Plutôt d'accord	Plutôt pas d'accord	Pas du tout d'accord	NSP	Total 'D'accord'	Total 'Pas d'accord'
		Totally agree	Tend to agree	Tend to disagree	Totally disagree	DK	Total 'Agree'	Total 'Disagree'
		Stimme voll und ganz zu	Stimme eher zu	Stimme eher nicht zu	Stimme überhaupt nicht zu	WN	Gesamt 'Stimme zu'	Gesamt 'Stimme nicht zu'
%		EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3
	EU 27	<b>69</b>	<b>27</b>	<b>2</b>	<b>1</b>	<b>1</b>	<b>96</b>	<b>3</b>
	BE	<b>69</b>	<b>28</b>	<b>2</b>	<b>1</b>	<b>0</b>	<b>97</b>	<b>3</b>
	BG	<b>73</b>	<b>24</b>	<b>0</b>	<b>0</b>	<b>3</b>	<b>97</b>	<b>0</b>
	CZ	<b>55</b>	<b>40</b>	<b>2</b>	<b>1</b>	<b>2</b>	<b>95</b>	<b>3</b>
	DK	<b>77</b>	<b>20</b>	<b>2</b>	<b>0</b>	<b>1</b>	<b>97</b>	<b>2</b>
	D-W	<b>70</b>	<b>26</b>	<b>2</b>	<b>0</b>	<b>2</b>	<b>96</b>	<b>2</b>
	DE	<b>70</b>	<b>25</b>	<b>3</b>	<b>1</b>	<b>1</b>	<b>95</b>	<b>4</b>
	D-E	<b>71</b>	<b>24</b>	<b>4</b>	<b>1</b>	<b>0</b>	<b>95</b>	<b>5</b>
	EE	<b>75</b>	<b>22</b>	<b>1</b>	<b>0</b>	<b>2</b>	<b>97</b>	<b>1</b>
	IE	<b>67</b>	<b>29</b>	<b>1</b>	<b>0</b>	<b>3</b>	<b>96</b>	<b>1</b>
	EL	<b>81</b>	<b>18</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>99</b>	<b>1</b>
	ES	<b>72</b>	<b>26</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>98</b>	<b>1</b>
	FR	<b>74</b>	<b>23</b>	<b>2</b>	<b>0</b>	<b>1</b>	<b>97</b>	<b>2</b>
	IT	<b>70</b>	<b>22</b>	<b>5</b>	<b>2</b>	<b>1</b>	<b>92</b>	<b>7</b>
	CY	<b>93</b>	<b>7</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>100</b>	<b>0</b>
	LV	<b>74</b>	<b>24</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>98</b>	<b>1</b>
	LT	<b>64</b>	<b>33</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>97</b>	<b>2</b>
	LU	<b>77</b>	<b>20</b>	<b>2</b>	<b>0</b>	<b>1</b>	<b>97</b>	<b>2</b>
	HU	<b>63</b>	<b>33</b>	<b>3</b>	<b>0</b>	<b>1</b>	<b>96</b>	<b>3</b>
	MT	<b>79</b>	<b>20</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>99</b>	<b>0</b>
	NL	<b>67</b>	<b>29</b>	<b>3</b>	<b>0</b>	<b>1</b>	<b>96</b>	<b>3</b>
	AT	<b>58</b>	<b>35</b>	<b>4</b>	<b>1</b>	<b>2</b>	<b>93</b>	<b>5</b>
	PL	<b>56</b>	<b>40</b>	<b>2</b>	<b>1</b>	<b>1</b>	<b>96</b>	<b>3</b>
	PT	<b>52</b>	<b>45</b>	<b>2</b>	<b>0</b>	<b>1</b>	<b>97</b>	<b>2</b>
	RO	<b>66</b>	<b>28</b>	<b>1</b>	<b>0</b>	<b>5</b>	<b>94</b>	<b>1</b>
	SI	<b>75</b>	<b>22</b>	<b>2</b>	<b>0</b>	<b>1</b>	<b>97</b>	<b>2</b>
	SK	<b>55</b>	<b>40</b>	<b>2</b>	<b>0</b>	<b>3</b>	<b>95</b>	<b>2</b>
	FI	<b>64</b>	<b>33</b>	<b>2</b>	<b>0</b>	<b>1</b>	<b>97</b>	<b>2</b>
	SE	<b>77</b>	<b>19</b>	<b>3</b>	<b>0</b>	<b>1</b>	<b>96</b>	<b>3</b>
	UK	<b>72</b>	<b>26</b>	<b>0</b>	<b>0</b>	<b>2</b>	<b>98</b>	<b>0</b>

QD3.2 Pour chacune des propositions suivantes, veuillez me dire si vous êtes tout à fait d'accord, plutôt d'accord, plutôt pas d'accord ou pas du tout d'accord.

Il devrait y avoir plus de coopération européenne pour aider plus efficacement le nombre limité de personnes atteintes d'une maladie rare

QD3.2 For each of the following statements, please tell me whether you totally agree, tend to agree, tend to disagree or totally disagree.

There should be more European cooperation in order to help the limited numbers of people suffering from rare diseases more efficiently

QD3.2 Bitte sagen Sie mir für jede der folgenden Aussagen, ob Sie ihr voll und ganz zustimmen, eher zustimmen, eher nicht zustimmen oder überhaupt nicht zustimmen.

Es sollte eine stärkere europäische Zusammenarbeit geben, um der begrenzten Anzahl an Menschen, die an einer seltenen Krankheit leiden, wirksamer zu helfen

		Tout à fait d'accord	Plutôt d'accord	Plutôt pas d'accord	Pas du tout d'accord	NSP	Total 'D'accord'	Total 'Pas d'accord'
		Totally agree	Tend to agree	Tend to disagree	Totally disagree	DK	Total 'Agree'	Total 'Disagree'
		Stimme voll und ganz zu	Stimme eher zu	Stimme eher nicht zu	Stimme überhaupt nicht zu	WN	Gesamt 'Stimme zu'	Gesamt 'Stimme nicht zu'
%		EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3
	EU 27	<b>66</b>	<b>29</b>	<b>2</b>	<b>1</b>	<b>2</b>	<b>95</b>	<b>3</b>
	BE	<b>68</b>	<b>28</b>	<b>2</b>	<b>1</b>	<b>1</b>	<b>96</b>	<b>3</b>
	BG	<b>68</b>	<b>27</b>	<b>1</b>	<b>0</b>	<b>4</b>	<b>95</b>	<b>1</b>
	CZ	<b>56</b>	<b>39</b>	<b>3</b>	<b>0</b>	<b>2</b>	<b>95</b>	<b>3</b>
	DK	<b>67</b>	<b>27</b>	<b>3</b>	<b>1</b>	<b>2</b>	<b>94</b>	<b>4</b>
	D-W	<b>69</b>	<b>26</b>	<b>2</b>	<b>1</b>	<b>2</b>	<b>95</b>	<b>3</b>
	DE	<b>69</b>	<b>26</b>	<b>2</b>	<b>1</b>	<b>2</b>	<b>95</b>	<b>3</b>
	D-E	<b>70</b>	<b>27</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>97</b>	<b>2</b>
	EE	<b>75</b>	<b>20</b>	<b>2</b>	<b>0</b>	<b>3</b>	<b>95</b>	<b>2</b>
	IE	<b>65</b>	<b>29</b>	<b>2</b>	<b>0</b>	<b>4</b>	<b>94</b>	<b>2</b>
	EL	<b>79</b>	<b>20</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>99</b>	<b>0</b>
	ES	<b>72</b>	<b>27</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>99</b>	<b>0</b>
	FR	<b>73</b>	<b>24</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>97</b>	<b>2</b>
	IT	<b>71</b>	<b>21</b>	<b>5</b>	<b>2</b>	<b>1</b>	<b>92</b>	<b>7</b>
	CY	<b>91</b>	<b>8</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>99</b>	<b>0</b>
	LV	<b>74</b>	<b>24</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>98</b>	<b>1</b>
	LT	<b>66</b>	<b>31</b>	<b>1</b>	<b>0</b>	<b>2</b>	<b>97</b>	<b>1</b>
	LU	<b>78</b>	<b>20</b>	<b>0</b>	<b>0</b>	<b>2</b>	<b>98</b>	<b>0</b>
	HU	<b>62</b>	<b>34</b>	<b>3</b>	<b>0</b>	<b>1</b>	<b>96</b>	<b>3</b>
	MT	<b>79</b>	<b>20</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>99</b>	<b>0</b>
	NL	<b>67</b>	<b>24</b>	<b>6</b>	<b>1</b>	<b>2</b>	<b>91</b>	<b>7</b>
	AT	<b>63</b>	<b>31</b>	<b>3</b>	<b>1</b>	<b>2</b>	<b>94</b>	<b>4</b>
	PL	<b>58</b>	<b>39</b>	<b>1</b>	<b>0</b>	<b>2</b>	<b>97</b>	<b>1</b>
	PT	<b>55</b>	<b>40</b>	<b>4</b>	<b>0</b>	<b>1</b>	<b>95</b>	<b>4</b>
	RO	<b>61</b>	<b>32</b>	<b>1</b>	<b>0</b>	<b>6</b>	<b>93</b>	<b>1</b>
	SI	<b>73</b>	<b>23</b>	<b>2</b>	<b>0</b>	<b>2</b>	<b>96</b>	<b>2</b>
	SK	<b>56</b>	<b>39</b>	<b>2</b>	<b>0</b>	<b>3</b>	<b>95</b>	<b>2</b>
	FI	<b>58</b>	<b>36</b>	<b>5</b>	<b>0</b>	<b>1</b>	<b>94</b>	<b>5</b>
	SE	<b>72</b>	<b>21</b>	<b>4</b>	<b>1</b>	<b>2</b>	<b>93</b>	<b>5</b>
	UK	<b>58</b>	<b>34</b>	<b>4</b>	<b>1</b>	<b>3</b>	<b>92</b>	<b>5</b>

QD3.3 Pour chacune des propositions suivantes, veuillez me dire si vous êtes tout à fait d'accord, plutôt d'accord, plutôt pas d'accord ou pas du tout d'accord.

Les médicaments développés pour le traitement des personnes atteintes d'une maladie rare devraient être remboursés intégralement par le système de santé (NATIONALITE) même s'ils coûtent très cher

QD3.3 For each of the following statements, please tell me whether you totally agree, tend to agree, tend to disagree or totally disagree.

The drugs developed to treat people suffering from rare diseases should be fully reimbursed by the (NATIONALITY) health care system even if they are very expensive

QD3.3 Bitte sagen Sie mir für jede der folgenden Aussagen, ob Sie ihr voll und ganz zustimmen, eher zustimmen, eher nicht zustimmen oder überhaupt nicht zustimmen.

Die Medikamente, die zur Behandlung von Personen entwickelt wurden, die eine seltene Krankheit haben, sollten vom (NATIONALEN) Gesundheitssystem vollständig erstattet werden, selbst wenn diese sehr teuer sind

		Tout à fait d'accord	Plutôt d'accord	Plutôt pas d'accord	Pas du tout d'accord	NSP	Total 'D'accord'	Total 'Pas d'accord'
		Totally agree	Tend to agree	Tend to disagree	Totally disagree	DK	Total 'Agree'	Total 'Disagree'
		Stimme voll und ganz zu	Stimme eher zu	Stimme eher nicht zu	Stimme überhaupt nicht zu	WN	Gesamt 'Stimme zu'	Gesamt 'Stimme nicht zu'
%		EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3
	EU 27	<b>64</b>	<b>29</b>	<b>4</b>	<b>1</b>	<b>2</b>	<b>93</b>	<b>5</b>
	BE	<b>63</b>	<b>32</b>	<b>4</b>	<b>1</b>	<b>0</b>	<b>95</b>	<b>5</b>
	BG	<b>70</b>	<b>24</b>	<b>2</b>	<b>0</b>	<b>4</b>	<b>94</b>	<b>2</b>
	CZ	<b>51</b>	<b>40</b>	<b>5</b>	<b>1</b>	<b>3</b>	<b>91</b>	<b>6</b>
	DK	<b>56</b>	<b>36</b>	<b>6</b>	<b>1</b>	<b>1</b>	<b>92</b>	<b>7</b>
	D-W	<b>62</b>	<b>29</b>	<b>6</b>	<b>0</b>	<b>3</b>	<b>91</b>	<b>6</b>
	DE	<b>62</b>	<b>29</b>	<b>6</b>	<b>0</b>	<b>3</b>	<b>91</b>	<b>6</b>
	D-E	<b>62</b>	<b>29</b>	<b>7</b>	<b>1</b>	<b>1</b>	<b>91</b>	<b>8</b>
	EE	<b>64</b>	<b>30</b>	<b>3</b>	<b>0</b>	<b>3</b>	<b>94</b>	<b>3</b>
	IE	<b>66</b>	<b>26</b>	<b>3</b>	<b>1</b>	<b>4</b>	<b>92</b>	<b>4</b>
	EL	<b>78</b>	<b>21</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>99</b>	<b>1</b>
	ES	<b>65</b>	<b>26</b>	<b>5</b>	<b>2</b>	<b>2</b>	<b>91</b>	<b>7</b>
	FR	<b>76</b>	<b>21</b>	<b>2</b>	<b>0</b>	<b>1</b>	<b>97</b>	<b>2</b>
	IT	<b>72</b>	<b>21</b>	<b>4</b>	<b>2</b>	<b>1</b>	<b>93</b>	<b>6</b>
	CY	<b>88</b>	<b>10</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>98</b>	<b>1</b>
	LV	<b>72</b>	<b>24</b>	<b>3</b>	<b>0</b>	<b>1</b>	<b>96</b>	<b>3</b>
	LT	<b>65</b>	<b>31</b>	<b>2</b>	<b>1</b>	<b>1</b>	<b>96</b>	<b>3</b>
	LU	<b>71</b>	<b>26</b>	<b>2</b>	<b>0</b>	<b>1</b>	<b>97</b>	<b>2</b>
	HU	<b>62</b>	<b>30</b>	<b>5</b>	<b>2</b>	<b>1</b>	<b>92</b>	<b>7</b>
	MT	<b>73</b>	<b>21</b>	<b>3</b>	<b>0</b>	<b>3</b>	<b>94</b>	<b>3</b>
	NL	<b>63</b>	<b>28</b>	<b>6</b>	<b>1</b>	<b>2</b>	<b>91</b>	<b>7</b>
	AT	<b>59</b>	<b>33</b>	<b>5</b>	<b>1</b>	<b>2</b>	<b>92</b>	<b>6</b>
	PL	<b>58</b>	<b>38</b>	<b>2</b>	<b>0</b>	<b>2</b>	<b>96</b>	<b>2</b>
	PT	<b>54</b>	<b>41</b>	<b>4</b>	<b>0</b>	<b>1</b>	<b>95</b>	<b>4</b>
	RO	<b>65</b>	<b>27</b>	<b>3</b>	<b>0</b>	<b>5</b>	<b>92</b>	<b>3</b>
	SI	<b>72</b>	<b>22</b>	<b>3</b>	<b>1</b>	<b>2</b>	<b>94</b>	<b>4</b>
	SK	<b>52</b>	<b>39</b>	<b>5</b>	<b>1</b>	<b>3</b>	<b>91</b>	<b>6</b>
	FI	<b>58</b>	<b>38</b>	<b>3</b>	<b>0</b>	<b>1</b>	<b>96</b>	<b>3</b>
	SE	<b>57</b>	<b>33</b>	<b>6</b>	<b>3</b>	<b>1</b>	<b>90</b>	<b>9</b>
	UK	<b>56</b>	<b>34</b>	<b>6</b>	<b>1</b>	<b>3</b>	<b>90</b>	<b>7</b>

QD3.4 Pour chacune des propositions suivantes, veuillez me dire si vous êtes tout à fait d'accord, plutôt d'accord, plutôt pas d'accord ou pas du tout d'accord.

Les gens connaissent l'existence de centres spécialisés dans les maladies rares

QD3.4 For each of the following statements, please tell me whether you totally agree, tend to agree, tend to disagree or totally disagree.

People are aware of the existence of centres specialising in rare diseases

QD3.4 Bitte sagen Sie mir für jede der folgenden Aussagen, ob Sie ihr voll und ganz zustimmen, eher zustimmen, eher nicht zustimmen oder überhaupt nicht zustimmen.

Den Menschen ist die Existenz von Zentren, die sich auf seltene Krankheiten spezialisiert haben, bekannt

		Tout à fait d'accord	Plutôt d'accord	Plutôt pas d'accord	Pas du tout d'accord	NSP	Total 'D'accord'	Total 'Pas d'accord'
		Totally agree	Tend to agree	Tend to disagree	Totally disagree	DK	Total 'Agree'	Total 'Disagree'
		Stimme voll und ganz zu	Stimme eher zu	Stimme eher nicht zu	Stimme überhaupt nicht zu	WN	Gesamt 'Stimme zu'	Gesamt 'Stimme nicht zu'
%		EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3
	EU 27	18	25	34	16	7	43	50
	BE	14	26	42	16	2	40	58
	BG	18	17	32	22	11	35	54
	CZ	11	23	41	20	5	34	61
	DK	12	29	43	13	3	41	56
	D-W	14	26	37	12	11	40	49
	DE	16	25	37	12	10	41	49
	D-E	19	21	38	14	8	40	52
	EE	16	18	39	23	4	34	62
	IE	25	17	27	19	12	42	46
	EL	17	29	32	17	5	46	49
	ES	16	16	26	34	8	32	60
	FR	10	18	43	22	7	28	65
	IT	24	30	31	7	8	54	38
	CY	18	27	30	13	12	45	43
	LV	14	18	39	25	4	32	64
	LT	20	28	28	16	8	48	44
	LU	9	22	40	24	5	31	64
	HU	18	29	31	19	3	47	50
	MT	17	16	33	21	13	33	54
	NL	10	25	47	13	5	35	60
	AT	20	27	31	12	10	47	43
	PL	13	27	38	14	8	40	52
	PT	49	42	6	2	1	91	8
	RO	34	28	16	10	12	62	26
	SI	20	27	30	16	7	47	46
	SK	15	33	33	11	8	48	44
	FI	12	23	44	18	3	35	62
	SE	8	28	35	24	5	36	59
	UK	19	29	33	12	7	48	45

QD3.5 Pour chacune des propositions suivantes, veuillez me dire si vous êtes tout à fait d'accord, plutôt d'accord, plutôt pas d'accord ou pas du tout d'accord.

Les personnes atteintes d'une maladie rare devraient avoir le droit d'accéder à des soins appropriés dans un autre Etat membre de l'UE si aucune solution ne peut leur être fournie dans leur pays de résidence

QD3.5 For each of the following statements, please tell me whether you totally agree, tend to agree, tend to disagree or totally disagree.

People suffering from a rare disease should have the right to access appropriate care in another EU Member State if no solution can be provided in their country of residence

QD3.5 Bitte sagen Sie mir für jede der folgenden Aussagen, ob Sie ihr voll und ganz zustimmen, eher zustimmen, eher nicht zustimmen oder überhaupt nicht zustimmen.

Menschen, die an einer seltenen Krankheit leiden, sollten das Recht haben, Zugang zu einer geeigneten Behandlung in einem anderen EU-Mitgliedstaat zu bekommen, wenn ihnen in dem Land, in dem sie wohnen, keine Lösung angeboten werden kann

		Tout à fait d'accord	Plutôt d'accord	Plutôt pas d'accord	Pas du tout d'accord	NSP	Total 'D'accord'	Total 'Pas d'accord'
		Totally agree	Tend to agree	Tend to disagree	Totally disagree	DK	Total 'Agree'	Total 'Disagree'
		Stimme voll und ganz zu	Stimme eher zu	Stimme eher nicht zu	Stimme überhaupt nicht zu	WN	Gesamt 'Stimme zu'	Gesamt 'Stimme nicht zu'
%		EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3
 EU 27		<b>66</b>	<b>29</b>	<b>2</b>	<b>1</b>	<b>2</b>	<b>95</b>	<b>3</b>
 BE		<b>62</b>	<b>31</b>	<b>5</b>	<b>1</b>	<b>1</b>	<b>93</b>	<b>6</b>
 BG		<b>70</b>	<b>26</b>	<b>1</b>	<b>0</b>	<b>3</b>	<b>96</b>	<b>1</b>
 CZ		<b>54</b>	<b>42</b>	<b>2</b>	<b>0</b>	<b>2</b>	<b>96</b>	<b>2</b>
 DK		<b>76</b>	<b>20</b>	<b>2</b>	<b>0</b>	<b>2</b>	<b>96</b>	<b>2</b>
 D-W		<b>67</b>	<b>27</b>	<b>2</b>	<b>1</b>	<b>3</b>	<b>94</b>	<b>3</b>
 DE		<b>68</b>	<b>27</b>	<b>2</b>	<b>1</b>	<b>2</b>	<b>95</b>	<b>3</b>
 D-E		<b>74</b>	<b>24</b>	<b>1</b>	<b>1</b>	<b>0</b>	<b>98</b>	<b>2</b>
 EE		<b>77</b>	<b>19</b>	<b>1</b>	<b>0</b>	<b>3</b>	<b>96</b>	<b>1</b>
 IE		<b>69</b>	<b>26</b>	<b>2</b>	<b>0</b>	<b>3</b>	<b>95</b>	<b>2</b>
 EL		<b>76</b>	<b>23</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>99</b>	<b>1</b>
 ES		<b>68</b>	<b>29</b>	<b>1</b>	<b>0</b>	<b>2</b>	<b>97</b>	<b>1</b>
 FR		<b>75</b>	<b>22</b>	<b>1</b>	<b>0</b>	<b>2</b>	<b>97</b>	<b>1</b>
 IT		<b>69</b>	<b>24</b>	<b>4</b>	<b>2</b>	<b>1</b>	<b>93</b>	<b>6</b>
 CY		<b>89</b>	<b>10</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>99</b>	<b>1</b>
 LV		<b>74</b>	<b>24</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>98</b>	<b>1</b>
 LT		<b>65</b>	<b>32</b>	<b>1</b>	<b>0</b>	<b>2</b>	<b>97</b>	<b>1</b>
 LU		<b>80</b>	<b>18</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>98</b>	<b>1</b>
 HU		<b>64</b>	<b>32</b>	<b>3</b>	<b>0</b>	<b>1</b>	<b>96</b>	<b>3</b>
 MT		<b>78</b>	<b>21</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>99</b>	<b>0</b>
 NL		<b>66</b>	<b>29</b>	<b>3</b>	<b>1</b>	<b>1</b>	<b>95</b>	<b>4</b>
 AT		<b>59</b>	<b>36</b>	<b>3</b>	<b>1</b>	<b>1</b>	<b>95</b>	<b>4</b>
 PL		<b>58</b>	<b>37</b>	<b>2</b>	<b>1</b>	<b>2</b>	<b>95</b>	<b>3</b>
 PT		<b>54</b>	<b>43</b>	<b>2</b>	<b>0</b>	<b>1</b>	<b>97</b>	<b>2</b>
 RO		<b>62</b>	<b>30</b>	<b>2</b>	<b>0</b>	<b>6</b>	<b>92</b>	<b>2</b>
 SI		<b>74</b>	<b>23</b>	<b>1</b>	<b>0</b>	<b>2</b>	<b>97</b>	<b>1</b>
 SK		<b>56</b>	<b>40</b>	<b>2</b>	<b>0</b>	<b>2</b>	<b>96</b>	<b>2</b>
 FI		<b>57</b>	<b>36</b>	<b>4</b>	<b>1</b>	<b>2</b>	<b>93</b>	<b>5</b>
 SE		<b>84</b>	<b>14</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>98</b>	<b>1</b>
 UK		<b>59</b>	<b>33</b>	<b>4</b>	<b>1</b>	<b>3</b>	<b>92</b>	<b>5</b>

QD3.6 Pour chacune des propositions suivantes, veuillez me dire si vous êtes tout à fait d'accord, plutôt d'accord, plutôt pas d'accord ou pas du tout d'accord.

(NOTRE PAYS) a trop d'autres problèmes de santé importants avant de faire des maladies rares une priorité

QD3.6 For each of the following statements, please tell me whether you totally agree, tend to agree, tend to disagree or totally disagree.

(OUR COUNTRY) has too many other major health issues to make rare diseases a priority

QD3.6 Bitte sagen Sie mir für jede der folgenden Aussagen, ob Sie ihr voll und ganz zustimmen, eher zustimmen, eher nicht zustimmen oder überhaupt nicht zustimmen.

(UNSER LAND) hat zu viele andere wichtige Angelegenheiten im Bereich Gesundheit, als dass seltenen Krankheiten Vorrang eingeräumt werden sollte

		Tout à fait d'accord	Plutôt d'accord	Plutôt pas d'accord	Pas du tout d'accord	NSP	Total 'D'accord'	Total 'Pas d'accord'
		Totally agree	Tend to agree	Tend to disagree	Totally disagree	DK	Total 'Agree'	Total 'Disagree'
		Stimme voll und ganz zu	Stimme eher zu	Stimme eher nicht zu	Stimme überhaupt nicht zu	WN	Gesamt 'Stimme zu'	Gesamt 'Stimme nicht zu'
%		EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3
	EU 27	15	24	31	25	5	39	56
	BE	13	34	35	16	2	47	51
	BG	16	15	32	27	10	31	59
	CZ	17	37	29	10	7	54	39
	DK	9	24	31	32	4	33	63
	D-W	13	23	28	31	5	36	59
	DE	14	23	28	30	5	37	58
	D-E	19	22	28	27	4	41	55
	EE	27	38	22	8	5	65	30
	IE	17	24	26	26	7	41	52
	EL	13	18	30	37	2	31	67
	ES	16	22	31	24	7	38	55
	FR	10	21	35	30	4	31	65
	IT	17	20	25	34	4	37	59
	CY	10	14	27	43	6	24	70
	LV	12	23	37	25	3	35	62
	LT	20	28	30	16	6	48	46
	LU	9	23	38	23	7	32	61
	HU	26	37	23	12	2	63	35
	MT	14	15	34	25	12	29	59
	NL	9	28	38	20	5	37	58
	AT	15	24	37	20	4	39	57
	PL	11	23	37	21	8	34	58
	PT	18	33	26	17	6	51	43
	RO	34	22	20	15	9	56	35
	SI	22	21	30	24	3	43	54
	SK	15	37	33	9	6	52	42
	FI	5	16	33	44	2	21	77
	SE	6	22	29	40	3	28	69
	UK	13	31	35	16	5	44	51

QD3.7 Pour chacune des propositions suivantes, veuillez me dire si vous êtes tout à fait d'accord, plutôt d'accord, plutôt pas d'accord ou pas du tout d'accord.

Chaque Etat membre de l'UE devrait avoir un programme ou une stratégie nationale sur les maladies rares intégrant toutes les dimensions du problème

QD3.7 For each of the following statements, please tell me whether you totally agree, tend to agree, tend to disagree or totally disagree.

Every EU Member State should have a National Plan or Strategy on rare diseases including all the dimensions of the problem

QD3.7 Bitte sagen Sie mir für jede der folgenden Aussagen, ob Sie ihr voll und ganz zustimmen, eher zustimmen, eher nicht zustimmen oder überhaupt nicht zustimmen.

Jeder EU-Mitgliedstaat sollte einen nationalen Plan oder eine nationale Strategie für seltene Krankheiten haben, in dem/ in der alle Dimensionen des Problems berücksichtigt werden

		Tout à fait d'accord	Plutôt d'accord	Plutôt pas d'accord	Pas du tout d'accord	NSP	Total 'D'accord'	Total 'Pas d'accord'
		Totally agree	Tend to agree	Tend to disagree	Totally disagree	DK	Total 'Agree'	Total 'Disagree'
		Stimme voll und ganz zu	Stimme eher zu	Stimme eher nicht zu	Stimme überhaupt nicht zu	WN	Gesamt 'Stimme zu'	Gesamt 'Stimme nicht zu'
%		EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3
	EU 27	49	41	5	1	4	90	6
	BE	45	49	5	1	0	94	6
	BG	60	32	1	0	7	92	1
	CZ	36	55	5	0	4	91	5
	DK	48	39	9	1	3	87	10
	D-W	41	42	8	2	7	83	10
	DE	42	42	8	2	6	84	10
	D-E	45	41	9	2	3	86	11
	EE	53	39	2	0	6	92	2
	IE	54	37	2	1	6	91	3
	EL	68	31	1	0	0	99	1
	ES	56	36	2	0	6	92	2
	FR	52	40	3	1	4	92	4
	IT	59	31	6	2	2	90	8
	CY	81	16	1	0	2	97	1
	LV	49	42	4	1	4	91	5
	LT	52	40	3	1	4	92	4
	LU	44	43	7	2	4	87	9
	HU	52	41	6	0	1	93	6
	MT	60	34	1	0	5	94	1
	NL	33	42	17	4	4	75	21
	AT	48	43	4	1	4	91	5
	PL	42	49	3	1	5	91	4
	PT	43	50	4	0	3	93	4
	RO	56	35	2	0	7	91	2
	SI	62	33	2	1	2	95	3
	SK	42	52	2	0	4	94	2
	FI	42	46	8	2	2	88	10
	SE	59	31	7	1	2	90	8
	UK	45	46	3	1	5	91	4

QD3.8 Pour chacune des propositions suivantes, veuillez me dire si vous êtes tout à fait d'accord, plutôt d'accord, plutôt pas d'accord ou pas du tout d'accord.

Les gens n'ont pas conscience des réels problèmes auxquels sont confrontées les personnes atteintes d'une maladie rare

QD3.8 For each of the following statements, please tell me whether you totally agree, tend to agree, tend to disagree or totally disagree.

People are unaware of the real problems faced by those suffering from a rare disease

QD3.8 Bitte sagen Sie mir für jede der folgenden Aussagen, ob Sie ihr voll und ganz zustimmen, eher zustimmen, eher nicht zustimmen oder überhaupt nicht zustimmen.

Die Menschen sind sich der tatsächlichen Probleme derjenigen, die an einer seltenen Krankheit leiden, nicht bewusst

		Tout à fait d'accord	Plutôt d'accord	Plutôt pas d'accord	Pas du tout d'accord	NSP	Total 'D'accord'	Total 'Pas d'accord'
		Totally agree	Tend to agree	Tend to disagree	Totally disagree	DK	Total 'Agree'	Total 'Disagree'
		Stimme voll und ganz zu	Stimme eher zu	Stimme eher nicht zu	Stimme überhaupt nicht zu	WN	Gesamt 'Stimme zu'	Gesamt 'Stimme nicht zu'
%		EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3
	EU 27	49	41	6	1	3	90	7
	BE	48	46	5	1	0	94	6
	BG	56	34	4	1	5	90	5
	CZ	38	50	8	1	3	88	9
	DK	50	42	5	1	2	92	6
	D-W	43	44	7	1	5	87	8
	DE	43	44	7	1	5	87	8
	D-E	43	43	7	2	5	86	9
	EE	66	28	3	1	2	94	4
	IE	56	35	3	1	5	91	4
	EL	43	47	8	1	1	90	9
	ES	57	33	5	1	4	90	6
	FR	61	33	3	1	2	94	4
	IT	44	41	9	2	4	85	11
	CY	61	31	5	1	2	92	6
	LV	53	40	3	2	2	93	5
	LT	51	43	3	1	2	94	4
	LU	53	39	7	1	0	92	8
	HU	54	41	4	1	0	95	5
	MT	51	38	5	3	3	89	8
	NL	49	44	4	1	2	93	5
	AT	39	48	8	1	4	87	9
	PL	48	44	5	0	3	92	5
	PT	44	48	6	0	2	92	6
	RO	51	35	4	2	8	86	6
	SI	62	28	5	2	3	90	7
	SK	44	49	5	0	2	93	5
	FI	55	40	3	1	1	95	4
	SE	60	33	3	2	2	93	5
	UK	42	50	4	1	3	92	5

QD4.1 La Commission européenne et les autorités nationales de santé des Etats membres de l'UE ont adopté plusieurs initiatives pour aider les personnes atteintes de maladies rares. Selon vous, est-il justifié ou non d'allouer des ressources aux initiatives prises dans les domaines suivants ?  
 Pour améliorer et coordonner la recherche sur les maladies rares aux niveaux national et européen

QD4.1 The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. In your opinion, is it justified or not to allocate resources to initiatives in the following areas?  
 To improve and coordinate research on rare diseases at national and European level

QD4.1 Die Europäische Kommission und die nationalen Gesundheitsbehörden der EU-Mitgliedstaaten haben mehrere Initiativen eingeführt, um Menschen zu helfen, die an einer seltenen Krankheit leiden. Ist es Ihrer Meinung nach gerechtfertigt oder nicht gerechtfertigt, Mittel für Initiativen in den folgenden Bereichen zur Verfügung zu stellen?  
 Forschung zu seltenen Krankheiten auf nationaler und europäischer Ebene zu verbessern und zu koordinieren

		Tout à fait justifié	Plutôt justifié	Pas très justifié	Pas du tout justifié	NSP	Total 'Justifié'	Total 'Pas justifié'
		Totally justified	Somewhat justified	Not very justified	Not at all justified	DK	Total 'Justified'	Total 'Not justified'
		Voll und ganz gerechtfertigt	Eher gerechtfertigt	Nicht besonders	Überhaupt nicht	WN	Gesamt 'Gerechtfertigt'	Gesamt 'Nicht gerechtfertigt'
%		EB	EB	EB	EB	EB	EB	EB
		74.3	74.3	74.3	74.3	74.3	74.3	74.3
	EU 27	59	35	2	1	3	94	3
	BE	58	38	2	1	1	96	3
	BG	70	25	1	0	4	95	1
	CZ	46	48	2	0	4	94	2
	DK	74	23	1	0	2	97	1
	D-W	63	33	2	0	2	96	2
	DE	64	32	2	0	2	96	2
	D-E	66	30	3	0	1	96	3
	EE	62	30	3	0	5	92	3
	IE	65	29	1	1	4	94	2
	EL	74	25	1	0	0	99	1
	ES	69	27	1	0	3	96	1
	FR	59	35	2	1	3	94	3
	IT	63	28	5	2	2	91	7
	CY	89	10	0	0	1	99	0
	LV	50	43	3	0	4	93	3
	LT	54	39	2	0	5	93	2
	LU	61	34	1	1	3	95	2
	HU	68	29	2	0	1	97	2
	MT	65	33	0	0	2	98	0
	NL	67	30	2	0	1	97	2
	AT	69	28	2	0	1	97	2
	PL	46	48	2	0	4	94	2
	PT	45	52	1	0	2	97	1
	RO	62	28	2	1	7	90	3
	SI	67	28	2	0	3	95	2
	SK	48	47	2	0	3	95	2
	FI	49	47	2	0	2	96	2
	SE	80	17	2	0	1	97	2
	UK	45	46	3	0	6	91	3

QD4.2 La Commission européenne et les autorités nationales de santé des Etats membres de l'UE ont adopté plusieurs initiatives pour aider les personnes atteintes de maladies rares. Selon vous, est-il justifié ou non d'allouer des ressources aux initiatives prises dans les domaines suivants ?

Pour faciliter l'accès aux médicaments pour les personnes atteintes d'une maladie rare

QD4.2 The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. In your opinion, is it justified or not to allocate resources to initiatives in the following areas?

To ease the access to drugs for people suffering from a rare disease

QD4.2 Die Europäische Kommission und die nationalen Gesundheitsbehörden der EU-Mitgliedstaaten haben mehrere Initiativen eingeführt, um Menschen zu helfen, die an einer seltenen Krankheit leiden. Ist es Ihrer Meinung nach gerechtfertigt oder nicht gerechtfertigt, Mittel für Initiativen in den folgenden Bereichen zur Verfügung zu stellen?

Menschen, die an einer seltenen Krankheit leiden, den Zugang zu Medikamenten erleichtern

		Tout à fait justifié	Plutôt justifié	Pas très justifié	Pas du tout justifié	NSP	Total 'Justifié'	Total 'Pas justifié'
		Totally justified	Somewhat justified	Not very justified	Not at all justified	DK	Total 'Justified'	Total 'Not justified'
		Voll und ganz gerechtfertigt	Eher gerechtfertigt	Nicht besonders	Überhaupt nicht	WN	Gesamt 'Gerechtfertigt'	Gesamt 'Nicht gerechtfertigt'
%		EB	EB	EB	EB	EB	EB	EB
		74.3	74.3	74.3	74.3	74.3	74.3	74.3
	EU 27	66	30	2	0	2	96	2
	BE	61	36	3	0	0	97	3
	BG	80	17	0	0	3	97	0
	CZ	57	38	3	0	2	95	3
	DK	75	22	2	0	1	97	2
	D-W	71	26	2	0	1	97	2
	DE	71	26	2	0	1	97	2
	D-E	72	25	1	1	1	97	2
	EE	73	22	2	0	3	95	2
	IE	68	26	3	0	3	94	3
	EL	79	20	1	0	0	99	1
	ES	73	24	1	0	2	97	1
	FR	65	31	2	0	2	96	2
	IT	65	28	4	1	2	93	5
	CY	96	3	1	0	0	99	1
	LV	69	29	0	0	2	98	0
	LT	68	28	2	0	2	96	2
	LU	67	27	4	0	2	94	4
	HU	71	26	2	0	1	97	2
	MT	73	25	0	1	1	98	1
	NL	69	26	3	0	2	95	3
	AT	73	24	2	0	1	97	2
	PL	55	42	1	0	2	97	1
	PT	42	54	2	0	2	96	2
	RO	65	25	2	1	7	90	3
	SI	81	17	1	0	1	98	1
	SK	56	41	1	1	1	97	2
	FI	64	34	2	0	0	98	2
	SE	80	17	2	0	1	97	2
	UK	61	34	2	0	3	95	2

QD4.3 La Commission européenne et les autorités nationales de santé des Etats membres de l'UE ont adopté plusieurs initiatives pour aider les personnes atteintes de maladies rares. Selon vous, est-il justifié ou non d'allouer des ressources aux initiatives prises dans les domaines suivants ?

Pour améliorer la connaissance des maladies rares auprès des professionnels de la santé et du grand public

QD4.3 The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. In your opinion, is it justified or not to allocate resources to initiatives in the following areas?

To improve awareness of rare diseases among health professionals and the general public

QD4.3 Die Europäische Kommission und die nationalen Gesundheitsbehörden der EU-Mitgliedstaaten haben mehrere Initiativen eingeführt, um Menschen zu helfen, die an einer seltenen Krankheit leiden. Ist es Ihrer Meinung nach gerechtfertigt oder nicht gerechtfertigt, Mittel für Initiativen in den folgenden Bereichen zur Verfügung zu stellen?

Das Bewusstsein für das Thema seltene Krankheiten unter Gesundheitsfachleuten und in der allgemeinen Öffentlichkeit zu fördern

		Tout à fait justifié	Plutôt justifié	Pas très justifié	Pas du tout justifié	NSP	Total 'Justifié'	Total 'Pas justifié'
		Totally justified	Somewhat justified	Not very justified	Not at all justified	DK	Total 'Justified'	Total 'Not justified'
		Voll und ganz gerechtfertigt	Eher gerechtfertigt	Nicht besonders	Überhaupt nicht	WN	Gesamt 'Gerechtfertigt'	Gesamt 'Nicht gerechtfertigt'
%		EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3	EB 74.3
	EU 27	60	33	3	1	3	93	4
	BE	57	38	4	0	1	95	4
	BG	70	25	2	0	3	95	2
	CZ	54	41	3	0	2	95	3
	DK	65	28	5	0	2	93	5
	D-W	56	36	5	0	3	92	5
	DE	56	36	5	0	3	92	5
	D-E	57	37	4	1	1	94	5
	EE	72	23	2	0	3	95	2
	IE	69	26	2	0	3	95	2
	EL	76	23	1	0	0	99	1
	ES	74	23	1	0	2	97	1
	FR	63	32	2	0	3	95	2
	IT	65	27	5	1	2	92	6
	CY	91	8	1	0	0	99	1
	LV	60	35	2	0	3	95	2
	LT	63	32	3	0	2	95	3
	LU	60	34	3	0	3	94	3
	HU	68	29	3	0	0	97	3
	MT	73	26	0	0	1	99	0
	NL	54	38	6	1	1	92	7
	AT	63	32	3	0	2	95	3
	PL	50	45	2	1	2	95	3
	PT	42	54	2	0	2	96	2
	RO	58	30	4	1	7	88	5
	SI	71	25	3	0	1	96	3
	SK	55	41	3	0	1	96	3
	FI	58	38	3	0	1	96	3
	SE	65	27	5	1	2	92	6
	UK	55	37	3	1	4	92	4

QD4.4 La Commission européenne et les autorités nationales de santé des Etats membres de l'UE ont adopté plusieurs initiatives pour aider les personnes atteintes de maladies rares. Selon vous, est-il justifié ou non d'allouer des ressources aux initiatives prises dans les domaines suivants ?

Pour faciliter l'accès aux tests de laboratoire afin d'améliorer le diagnostic des maladies rares

QD4.4 The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. In your opinion, is it justified or not to allocate resources to initiatives in the following areas?

To ease access to laboratory tests to improve the diagnosis of rare diseases

QD4.4 Die Europäische Kommission und die nationalen Gesundheitsbehörden der EU-Mitgliedstaaten haben mehrere Initiativen eingeführt, um Menschen zu helfen, die an einer seltenen Krankheit leiden. Ist es Ihrer Meinung nach gerechtfertigt oder nicht gerechtfertigt, Mittel für Initiativen in den folgenden Bereichen zur Verfügung zu stellen?

Den Zugang zu Laboruntersuchungen zu erleichtern, um die Diagnose seltener Krankheiten zu verbessern

		Tout à fait justifié	Plutôt justifié	Pas très justifié	Pas du tout justifié	NSP	Total 'Justifié'	Total 'Pas justifié'
		Totally justified	Somewhat justified	Not very justified	Not at all justified	DK	Total 'Justified'	Total 'Not justified'
		Voll und ganz gerechtfertigt	Eher gerechtfertigt	Nicht besonders	Überhaupt nicht	WN	Gesamt 'Gerechtfertigt'	Gesamt 'Nicht gerechtfertigt'
%		EB	EB	EB	EB	EB	EB	EB
		74.3	74.3	74.3	74.3	74.3	74.3	74.3
	EU 27	64	31	2	0	3	95	2
	BE	59	36	4	0	1	95	4
	BG	78	18	1	0	3	96	1
	CZ	52	41	3	1	3	93	4
	DK	74	23	1	0	2	97	1
	D-W	65	30	2	1	2	95	3
	DE	65	30	2	1	2	95	3
	D-E	65	27	5	1	2	92	6
	EE	69	24	3	0	4	93	3
	IE	67	26	3	0	4	93	3
	EL	76	22	2	0	0	98	2
	ES	74	24	0	0	2	98	0
	FR	65	31	1	0	3	96	1
	IT	65	26	6	1	2	91	7
	CY	92	6	1	0	1	98	1
	LV	63	32	2	0	3	95	2
	LT	67	29	2	0	2	96	2
	LU	67	27	2	1	3	94	3
	HU	68	29	2	0	1	97	2
	MT	70	27	1	0	2	97	1
	NL	63	31	3	0	3	94	3
	AT	71	25	3	0	1	96	3
	PL	54	42	2	0	2	96	2
	PT	42	54	2	0	2	96	2
	RO	62	26	3	2	7	88	5
	SI	79	19	1	0	1	98	1
	SK	55	41	2	0	2	96	2
	FI	67	30	2	0	1	97	2
	SE	72	23	3	0	2	95	3
	UK	55	37	3	0	5	92	3

QD4.5 La Commission européenne et les autorités nationales de santé des Etats membres de l'UE ont adopté plusieurs initiatives pour aider les personnes atteintes de maladies rares. Selon vous, est-il justifié ou non d'allouer des ressources aux initiatives prises dans les domaines suivants ?

Pour fournir une aide supplémentaire aux familles dont l'un des membres est atteint d'une maladie rare

QD4.5 The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. In your opinion, is it justified or not to allocate resources to initiatives in the following areas?

To provide additional support to families with a person suffering from a rare disease

QD4.5 Die Europäische Kommission und die nationalen Gesundheitsbehörden der EU-Mitgliedstaaten haben mehrere Initiativen eingeführt, um Menschen zu helfen, die an einer seltenen Krankheit leiden. Ist es Ihrer Meinung nach gerechtfertigt oder nicht gerechtfertigt, Mittel für Initiativen in den folgenden Bereichen zur Verfügung zu stellen?

Zusätzliche Unterstützung für Familien mit Personen, die an einer seltenen Krankheit leiden, bereitzustellen

		Tout à fait justifié	Plutôt justifié	Pas très justifié	Pas du tout justifié	NSP	Total 'Justifié'	Total 'Pas justifié'
		Totally justified	Somewhat justified	Not very justified	Not at all justified	DK	Total 'Justified'	Total 'Not justified'
		Voll und ganz gerechtfertigt	Eher gerechtfertigt	Nicht besonders	Überhaupt nicht	WN	Gesamt 'Gerechtfertigt'	Gesamt 'Nicht gerechtfertigt'
%		EB	EB	EB	EB	EB	EB	EB
		74.3	74.3	74.3	74.3	74.3	74.3	74.3
	EU 27	<b>61</b>	<b>33</b>	<b>3</b>	<b>1</b>	<b>2</b>	<b>94</b>	<b>4</b>
	BE	<b>61</b>	<b>35</b>	<b>4</b>	<b>0</b>	<b>0</b>	<b>96</b>	<b>4</b>
	BG	<b>71</b>	<b>24</b>	<b>1</b>	<b>0</b>	<b>4</b>	<b>95</b>	<b>1</b>
	CZ	<b>53</b>	<b>41</b>	<b>3</b>	<b>1</b>	<b>2</b>	<b>94</b>	<b>4</b>
	DK	<b>58</b>	<b>34</b>	<b>5</b>	<b>1</b>	<b>2</b>	<b>92</b>	<b>6</b>
	D-W	<b>56</b>	<b>36</b>	<b>5</b>	<b>1</b>	<b>2</b>	<b>92</b>	<b>6</b>
	DE	<b>56</b>	<b>36</b>	<b>5</b>	<b>1</b>	<b>2</b>	<b>92</b>	<b>6</b>
	D-E	<b>56</b>	<b>36</b>	<b>6</b>	<b>1</b>	<b>1</b>	<b>92</b>	<b>7</b>
	EE	<b>64</b>	<b>26</b>	<b>6</b>	<b>0</b>	<b>4</b>	<b>90</b>	<b>6</b>
	IE	<b>68</b>	<b>26</b>	<b>3</b>	<b>0</b>	<b>3</b>	<b>94</b>	<b>3</b>
	EL	<b>75</b>	<b>23</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>98</b>	<b>1</b>
	ES	<b>76</b>	<b>22</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>98</b>	<b>1</b>
	FR	<b>60</b>	<b>34</b>	<b>3</b>	<b>0</b>	<b>3</b>	<b>94</b>	<b>3</b>
	IT	<b>65</b>	<b>27</b>	<b>5</b>	<b>1</b>	<b>2</b>	<b>92</b>	<b>6</b>
	CY	<b>93</b>	<b>7</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>100</b>	<b>0</b>
	LV	<b>65</b>	<b>30</b>	<b>3</b>	<b>0</b>	<b>2</b>	<b>95</b>	<b>3</b>
	LT	<b>61</b>	<b>32</b>	<b>4</b>	<b>1</b>	<b>2</b>	<b>93</b>	<b>5</b>
	LU	<b>59</b>	<b>34</b>	<b>3</b>	<b>1</b>	<b>3</b>	<b>93</b>	<b>4</b>
	HU	<b>65</b>	<b>30</b>	<b>4</b>	<b>0</b>	<b>1</b>	<b>95</b>	<b>4</b>
	MT	<b>73</b>	<b>25</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>98</b>	<b>1</b>
	NL	<b>54</b>	<b>38</b>	<b>6</b>	<b>0</b>	<b>2</b>	<b>92</b>	<b>6</b>
	AT	<b>62</b>	<b>30</b>	<b>7</b>	<b>0</b>	<b>1</b>	<b>92</b>	<b>7</b>
	PL	<b>51</b>	<b>45</b>	<b>2</b>	<b>0</b>	<b>2</b>	<b>96</b>	<b>2</b>
	PT	<b>41</b>	<b>54</b>	<b>3</b>	<b>0</b>	<b>2</b>	<b>95</b>	<b>3</b>
	RO	<b>62</b>	<b>27</b>	<b>4</b>	<b>1</b>	<b>6</b>	<b>89</b>	<b>5</b>
	SI	<b>73</b>	<b>22</b>	<b>4</b>	<b>0</b>	<b>1</b>	<b>95</b>	<b>4</b>
	SK	<b>56</b>	<b>39</b>	<b>3</b>	<b>0</b>	<b>2</b>	<b>95</b>	<b>3</b>
	FI	<b>59</b>	<b>36</b>	<b>4</b>	<b>0</b>	<b>1</b>	<b>95</b>	<b>4</b>
	SE	<b>65</b>	<b>27</b>	<b>6</b>	<b>1</b>	<b>1</b>	<b>92</b>	<b>7</b>
	UK	<b>56</b>	<b>36</b>	<b>4</b>	<b>0</b>	<b>4</b>	<b>92</b>	<b>4</b>

QD4.6 La Commission européenne et les autorités nationales de santé des Etats membres de l'UE ont adopté plusieurs initiatives pour aider les personnes atteintes de maladies rares. Selon vous, est-il justifié ou non d'allouer des ressources aux initiatives prises dans les domaines suivants ?  
Pour soutenir les associations de patients

QD4.6 The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. In your opinion, is it justified or not to allocate resources to initiatives in the following areas?  
To support patient organisations

QD4.6 Die Europäische Kommission und die nationalen Gesundheitsbehörden der EU-Mitgliedstaaten haben mehrere Initiativen eingeführt, um Menschen zu helfen, die an einer seltenen Krankheit leiden. Ist es Ihrer Meinung nach gerechtfertigt oder nicht gerechtfertigt, Mittel für Initiativen in den folgenden Bereichen zur Verfügung zu stellen?  
Patientenorganisationen zu unterstützen

		Tout à fait justifié	Plutôt justifié	Pas très justifié	Pas du tout justifié	NSP	Total 'Justifié'	Total 'Pas justifié'
		Totally justified	Somewhat justified	Not very justified	Not at all justified	DK	Total 'Justified'	Total 'Not justified'
		Voll und ganz gerechtfertigt	Eher gerechtfertigt	Nicht besonders	Überhaupt nicht	WN	Gesamt 'Gerechtfertigt'	Gesamt 'Nicht gerechtfertigt'
%		EB	EB	EB	EB	EB	EB	EB
		74.3	74.3	74.3	74.3	74.3	74.3	74.3
	EU 27	55	37	4	1	3	92	5
	BE	49	44	6	1	0	93	7
	BG	56	29	5	0	10	85	5
	CZ	40	51	5	1	3	91	6
	DK	46	44	7	1	2	90	8
	D-W	55	38	4	1	2	93	5
	DE	55	38	5	0	2	93	5
	D-E	54	37	6	1	2	91	7
	EE	58	30	6	1	5	88	7
	IE	63	29	3	0	5	92	3
	EL	70	27	2	0	1	97	2
	ES	72	26	0	0	2	98	0
	FR	50	39	6	2	3	89	8
	IT	62	29	5	1	3	91	6
	CY	88	10	1	0	1	98	1
	LV	47	42	6	1	4	89	7
	LT	55	36	4	1	4	91	5
	LU	47	43	6	0	4	90	6
	HU	61	34	4	0	1	95	4
	MT	69	29	0	0	2	98	0
	NL	46	43	8	1	2	89	9
	AT	64	29	5	0	2	93	5
	PL	44	50	3	1	2	94	4
	PT	41	54	3	0	2	95	3
	RO	53	30	7	1	9	83	8
	SI	67	28	2	1	2	95	3
	SK	44	48	5	0	3	92	5
	FI	48	45	5	0	2	93	5
	SE	52	36	9	1	2	88	10
	UK	51	41	4	0	4	92	4

QD4.7 La Commission européenne et les autorités nationales de santé des Etats membres de l'UE ont adopté plusieurs initiatives pour aider les personnes atteintes de maladies rares. Selon vous, est-il justifié ou non d'allouer des ressources aux initiatives prises dans les domaines suivants ?

Pour créer de nouveaux centres spécialisés dans les maladies rares dans l'UE

QD4.7 The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. In your opinion, is it justified or not to allocate resources to initiatives in the following areas?

To establish new centres specialising in rare diseases in the EU

QD4.7 Die Europäische Kommission und die nationalen Gesundheitsbehörden der EU-Mitgliedstaaten haben mehrere Initiativen eingeführt, um Menschen zu helfen, die an einer seltenen Krankheit leiden. Ist es Ihrer Meinung nach gerechtfertigt oder nicht gerechtfertigt, Mittel für Initiativen in den folgenden Bereichen zur Verfügung zu stellen?

Neue Zentren in der EU einzurichten, die sich auf seltene Krankheiten spezialisieren

		Tout à fait justifié	Plutôt justifié	Pas très justifié	Pas du tout justifié	NSP	Total 'Justifié'	Total 'Pas justifié'
		Totally justified	Somewhat justified	Not very justified	Not at all justified	DK	Total 'Justified'	Total 'Not justified'
		Voll und ganz gerechtfertigt	Eher gerechtfertigt	Nicht besonders	Überhaupt nicht	WN	Gesamt 'Gerechtfertigt'	Gesamt 'Nicht gerechtfertigt'
%		EB	EB	EB	EB	EB	EB	EB
		74.3	74.3	74.3	74.3	74.3	74.3	74.3
	EU 27	56	35	5	1	3	91	6
	BE	51	41	6	1	1	92	7
	BG	66	24	3	0	7	90	3
	CZ	40	47	7	1	5	87	8
	DK	55	35	6	1	3	90	7
	D-W	51	37	6	1	5	88	7
	DE	51	37	7	1	4	88	8
	D-E	53	33	9	2	3	86	11
	EE	60	29	5	0	6	89	5
	IE	64	28	3	1	4	92	4
	EL	74	25	1	0	0	99	1
	ES	72	24	1	0	3	96	1
	FR	59	35	3	0	3	94	3
	IT	66	26	5	1	2	92	6
	CY	94	5	0	0	1	99	0
	LV	46	40	8	1	5	86	9
	LT	57	35	5	0	3	92	5
	LU	54	37	4	1	4	91	5
	HU	63	31	5	0	1	94	5
	MT	70	28	0	0	2	98	0
	NL	42	43	10	2	3	85	12
	AT	62	28	6	1	3	90	7
	PL	46	48	3	0	3	94	3
	PT	42	54	2	0	2	96	2
	RO	60	28	3	1	8	88	4
	SI	66	26	5	1	2	92	6
	SK	51	41	4	0	4	92	4
	FI	38	49	9	1	3	87	10
	SE	51	33	11	3	2	84	14
	UK	45	41	7	1	6	86	8

QD5.1 Avez-vous déjà entendu parler de chacune des maladies suivantes ?

La mucoviscidose

QD5.1 Have you ever heard of each of the following diseases?

Cystic fibrosis

QD5.1 Haben Sie jemals von den folgenden Krankheiten gehört?

Mukoviszidose

		Oui Yes Ja	Non No Nein	NSP DK WN
%		EB 74.3	EB 74.3	EB 74.3
	EU 27	<b>65</b>	<b>34</b>	<b>1</b>
	BE	<b>79</b>	<b>21</b>	<b>0</b>
	BG	<b>8</b>	<b>89</b>	<b>3</b>
	CZ	<b>45</b>	<b>55</b>	<b>0</b>
	DK	<b>76</b>	<b>23</b>	<b>1</b>
	D-W	<b>59</b>	<b>39</b>	<b>2</b>
	DE	<b>58</b>	<b>40</b>	<b>2</b>
	D-E	<b>57</b>	<b>42</b>	<b>1</b>
	EE	<b>15</b>	<b>84</b>	<b>1</b>
	IE	<b>97</b>	<b>3</b>	<b>0</b>
	EL	<b>11</b>	<b>86</b>	<b>3</b>
	ES	<b>52</b>	<b>47</b>	<b>1</b>
	FR	<b>96</b>	<b>4</b>	<b>0</b>
	IT	<b>78</b>	<b>19</b>	<b>3</b>
	CY	<b>11</b>	<b>89</b>	<b>0</b>
	LV	<b>13</b>	<b>87</b>	<b>0</b>
	LT	<b>25</b>	<b>73</b>	<b>2</b>
	LU	<b>66</b>	<b>33</b>	<b>1</b>
	HU	<b>27</b>	<b>72</b>	<b>1</b>
	MT	<b>32</b>	<b>64</b>	<b>4</b>
	NL	<b>49</b>	<b>50</b>	<b>1</b>
	AT	<b>37</b>	<b>61</b>	<b>2</b>
	PL	<b>74</b>	<b>25</b>	<b>1</b>
	PT	<b>26</b>	<b>73</b>	<b>1</b>
	RO	<b>31</b>	<b>64</b>	<b>5</b>
	SI	<b>32</b>	<b>67</b>	<b>1</b>
	SK	<b>55</b>	<b>44</b>	<b>1</b>
	FI	<b>33</b>	<b>66</b>	<b>1</b>
	SE	<b>75</b>	<b>24</b>	<b>1</b>
	UK	<b>90</b>	<b>10</b>	<b>0</b>

QD5.2 Avez-vous déjà entendu parler de chacune des maladies suivantes ?

La myopathie de Duchenne

QD5.2 Have you ever heard of each of the following diseases?

Duchenne muscular dystrophy

QD5.2 Haben Sie jemals von den folgenden Krankheiten gehört?

Duchenne-Muskeldystrophie

		Oui Yes Ja	Non No Nein	NSP DK WN
%		EB 74.3	EB 74.3	EB 74.3
	EU 27	<b>39</b>	<b>59</b>	<b>2</b>
	BE	<b>32</b>	<b>68</b>	<b>0</b>
	BG	<b>22</b>	<b>75</b>	<b>3</b>
	CZ	<b>25</b>	<b>74</b>	<b>1</b>
	DK	<b>21</b>	<b>78</b>	<b>1</b>
	D-W	<b>18</b>	<b>80</b>	<b>2</b>
	DE	<b>17</b>	<b>81</b>	<b>2</b>
	D-E	<b>16</b>	<b>83</b>	<b>1</b>
	EE	<b>21</b>	<b>78</b>	<b>1</b>
	IE	<b>56</b>	<b>42</b>	<b>2</b>
	EL	<b>14</b>	<b>84</b>	<b>2</b>
	ES	<b>37</b>	<b>62</b>	<b>1</b>
	FR	<b>57</b>	<b>42</b>	<b>1</b>
	IT	<b>61</b>	<b>36</b>	<b>3</b>
	CY	<b>66</b>	<b>33</b>	<b>1</b>
	LV	<b>21</b>	<b>78</b>	<b>1</b>
	LT	<b>39</b>	<b>59</b>	<b>2</b>
	LU	<b>33</b>	<b>66</b>	<b>1</b>
	HU	<b>34</b>	<b>65</b>	<b>1</b>
	MT	<b>35</b>	<b>61</b>	<b>4</b>
	NL	<b>73</b>	<b>27</b>	<b>0</b>
	AT	<b>13</b>	<b>85</b>	<b>2</b>
	PL	<b>26</b>	<b>72</b>	<b>2</b>
	PT	<b>24</b>	<b>75</b>	<b>1</b>
	RO	<b>32</b>	<b>63</b>	<b>5</b>
	SI	<b>50</b>	<b>49</b>	<b>1</b>
	SK	<b>38</b>	<b>61</b>	<b>1</b>
	FI	<b>22</b>	<b>77</b>	<b>1</b>
	SE	<b>24</b>	<b>76</b>	<b>0</b>
	UK	<b>55</b>	<b>43</b>	<b>2</b>

QD5.3 Avez-vous déjà entendu parler de chacune des maladies suivantes ?

L'hémophilie

QD5.3 Have you ever heard of each of the following diseases?

Haemophilia

QD5.3 Haben Sie jemals von den folgenden Krankheiten gehört?

Hämophilie

		Oui Yes Ja	Non No Nein	NSP DK WN
%		EB 74.3	EB 74.3	EB 74.3
	EU 27	<b>60</b>	<b>39</b>	<b>1</b>
	BE	<b>62</b>	<b>38</b>	<b>0</b>
	BG	<b>30</b>	<b>67</b>	<b>3</b>
	CZ	<b>52</b>	<b>47</b>	<b>1</b>
	DK	<b>40</b>	<b>59</b>	<b>1</b>
	D-W	<b>26</b>	<b>71</b>	<b>3</b>
	DE	<b>26</b>	<b>71</b>	<b>3</b>
	D-E	<b>24</b>	<b>74</b>	<b>2</b>
	EE	<b>44</b>	<b>56</b>	<b>0</b>
	IE	<b>85</b>	<b>14</b>	<b>1</b>
	EL	<b>42</b>	<b>56</b>	<b>2</b>
	ES	<b>59</b>	<b>40</b>	<b>1</b>
	FR	<b>85</b>	<b>14</b>	<b>1</b>
	IT	<b>62</b>	<b>36</b>	<b>2</b>
	CY	<b>60</b>	<b>39</b>	<b>1</b>
	LV	<b>40</b>	<b>60</b>	<b>0</b>
	LT	<b>40</b>	<b>59</b>	<b>1</b>
	LU	<b>64</b>	<b>35</b>	<b>1</b>
	HU	<b>77</b>	<b>23</b>	<b>0</b>
	MT	<b>37</b>	<b>59</b>	<b>4</b>
	NL	<b>83</b>	<b>16</b>	<b>1</b>
	AT	<b>24</b>	<b>74</b>	<b>2</b>
	PL	<b>75</b>	<b>24</b>	<b>1</b>
	PT	<b>61</b>	<b>38</b>	<b>1</b>
	RO	<b>41</b>	<b>54</b>	<b>5</b>
	SI	<b>51</b>	<b>48</b>	<b>1</b>
	SK	<b>58</b>	<b>41</b>	<b>1</b>
	FI	<b>84</b>	<b>15</b>	<b>1</b>
	SE	<b>33</b>	<b>66</b>	<b>1</b>
	UK	<b>81</b>	<b>18</b>	<b>1</b>

QD5.4 Avez-vous déjà entendu parler de chacune des maladies suivantes ?

La maladie de Huntington

QD5.4 Have you ever heard of each of the following diseases?

Huntington's disease

QD5.4 Haben Sie jemals von den folgenden Krankheiten gehört?

Chorea Huntington

		Oui Yes Ja	Non No Nein	NSP DK WN
%		EB 74.3	EB 74.3	EB 74.3
	EU 27	<b>31</b>	<b>67</b>	<b>2</b>
	BE	<b>33</b>	<b>67</b>	<b>0</b>
	BG	<b>7</b>	<b>89</b>	<b>4</b>
	CZ	<b>12</b>	<b>87</b>	<b>1</b>
	DK	<b>63</b>	<b>36</b>	<b>1</b>
	D-W	<b>26</b>	<b>72</b>	<b>2</b>
	DE	<b>25</b>	<b>73</b>	<b>2</b>
	D-E	<b>22</b>	<b>76</b>	<b>2</b>
	EE	<b>22</b>	<b>78</b>	<b>0</b>
	IE	<b>69</b>	<b>29</b>	<b>2</b>
	EL	<b>11</b>	<b>87</b>	<b>2</b>
	ES	<b>14</b>	<b>85</b>	<b>1</b>
	FR	<b>32</b>	<b>67</b>	<b>1</b>
	IT	<b>16</b>	<b>80</b>	<b>4</b>
	CY	<b>21</b>	<b>77</b>	<b>2</b>
	LV	<b>10</b>	<b>90</b>	<b>0</b>
	LT	<b>5</b>	<b>94</b>	<b>1</b>
	LU	<b>31</b>	<b>69</b>	<b>0</b>
	HU	<b>19</b>	<b>79</b>	<b>2</b>
	MT	<b>25</b>	<b>72</b>	<b>3</b>
	NL	<b>66</b>	<b>33</b>	<b>1</b>
	AT	<b>18</b>	<b>80</b>	<b>2</b>
	PL	<b>21</b>	<b>78</b>	<b>1</b>
	PT	<b>7</b>	<b>92</b>	<b>1</b>
	RO	<b>8</b>	<b>85</b>	<b>7</b>
	SI	<b>10</b>	<b>89</b>	<b>1</b>
	SK	<b>14</b>	<b>86</b>	<b>0</b>
	FI	<b>31</b>	<b>68</b>	<b>1</b>
	SE	<b>57</b>	<b>43</b>	<b>0</b>
	UK	<b>82</b>	<b>17</b>	<b>1</b>

QD5.5 Avez-vous déjà entendu parler de chacune des maladies suivantes ?

L'ostéogénèse imparfaite

QD5.5 Have you ever heard of each of the following diseases?

Osteogenesis imperfecta

QD5.5 Haben Sie jemals von den folgenden Krankheiten gehört?

Osteogenesis imperfecta

		Oui Yes Ja	Non No Nein	NSP DK WN
%		EB 74.3	EB 74.3	EB 74.3
	EU 27	<b>19</b>	<b>79</b>	<b>2</b>
	BE	<b>15</b>	<b>84</b>	<b>1</b>
	BG	<b>4</b>	<b>92</b>	<b>4</b>
	CZ	<b>8</b>	<b>92</b>	<b>0</b>
	DK	<b>15</b>	<b>84</b>	<b>1</b>
	D-W	<b>10</b>	<b>88</b>	<b>2</b>
	DE	<b>9</b>	<b>89</b>	<b>2</b>
	D-E	<b>8</b>	<b>90</b>	<b>2</b>
	EE	<b>25</b>	<b>74</b>	<b>1</b>
	IE	<b>15</b>	<b>81</b>	<b>4</b>
	EL	<b>19</b>	<b>79</b>	<b>2</b>
	ES	<b>8</b>	<b>91</b>	<b>1</b>
	FR	<b>21</b>	<b>78</b>	<b>1</b>
	IT	<b>15</b>	<b>81</b>	<b>4</b>
	CY	<b>29</b>	<b>70</b>	<b>1</b>
	LV	<b>7</b>	<b>93</b>	<b>0</b>
	LT	<b>6</b>	<b>93</b>	<b>1</b>
	LU	<b>22</b>	<b>77</b>	<b>1</b>
	HU	<b>11</b>	<b>86</b>	<b>3</b>
	MT	<b>8</b>	<b>88</b>	<b>4</b>
	NL	<b>18</b>	<b>82</b>	<b>0</b>
	AT	<b>9</b>	<b>89</b>	<b>2</b>
	PL	<b>75</b>	<b>23</b>	<b>2</b>
	PT	<b>8</b>	<b>91</b>	<b>1</b>
	RO	<b>11</b>	<b>82</b>	<b>7</b>
	SI	<b>8</b>	<b>91</b>	<b>1</b>
	SK	<b>7</b>	<b>93</b>	<b>0</b>
	FI	<b>53</b>	<b>45</b>	<b>2</b>
	SE	<b>10</b>	<b>90</b>	<b>0</b>
	UK	<b>18</b>	<b>81</b>	<b>1</b>

QD5.6 Avez-vous déjà entendu parler de chacune des maladies suivantes ?

La progeria

QD5.6 Have you ever heard of each of the following diseases?

Progeria

QD5.6 Haben Sie jemals von den folgenden Krankheiten gehört?

Progeria

		Oui Yes Ja	Non No Nein	NSP DK WN
%		EB 74.3	EB 74.3	EB 74.3
	EU 27	<b>16</b>	<b>82</b>	<b>2</b>
	BE	<b>41</b>	<b>59</b>	<b>0</b>
	BG	<b>2</b>	<b>94</b>	<b>4</b>
	CZ	<b>38</b>	<b>61</b>	<b>1</b>
	DK	<b>33</b>	<b>66</b>	<b>1</b>
	D-W	<b>10</b>	<b>88</b>	<b>2</b>
	DE	<b>9</b>	<b>89</b>	<b>2</b>
	D-E	<b>8</b>	<b>89</b>	<b>3</b>
	EE	<b>8</b>	<b>92</b>	<b>0</b>
	IE	<b>6</b>	<b>89</b>	<b>5</b>
	EL	<b>30</b>	<b>68</b>	<b>2</b>
	ES	<b>9</b>	<b>90</b>	<b>1</b>
	FR	<b>25</b>	<b>74</b>	<b>1</b>
	IT	<b>11</b>	<b>85</b>	<b>4</b>
	CY	<b>47</b>	<b>53</b>	<b>0</b>
	LV	<b>5</b>	<b>95</b>	<b>0</b>
	LT	<b>4</b>	<b>96</b>	<b>0</b>
	LU	<b>22</b>	<b>77</b>	<b>1</b>
	HU	<b>69</b>	<b>30</b>	<b>1</b>
	MT	<b>4</b>	<b>92</b>	<b>4</b>
	NL	<b>29</b>	<b>71</b>	<b>0</b>
	AT	<b>12</b>	<b>87</b>	<b>1</b>
	PL	<b>13</b>	<b>86</b>	<b>1</b>
	PT	<b>10</b>	<b>89</b>	<b>1</b>
	RO	<b>5</b>	<b>87</b>	<b>8</b>
	SI	<b>6</b>	<b>93</b>	<b>1</b>
	SK	<b>10</b>	<b>89</b>	<b>1</b>
	FI	<b>11</b>	<b>88</b>	<b>1</b>
	SE	<b>18</b>	<b>81</b>	<b>1</b>
	UK	<b>15</b>	<b>84</b>	<b>1</b>