

# EUROPEAN AWARENESS OF RARE DISEASES



EU27  Number of interviews: 26,574

LU  Number of interviews: 501

Fieldwork: 25/11-14/12/2010

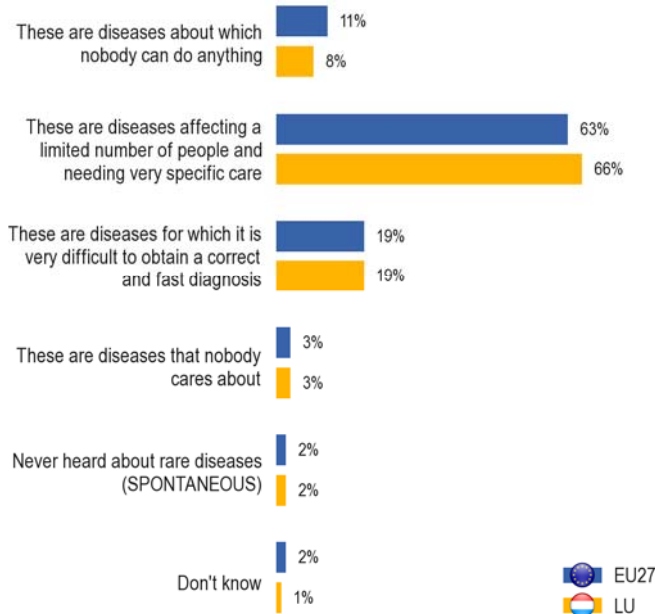
Fieldwork: 26/11-15/12/2010



Methodology: face-to-face

## 1. Understanding and knowledge of 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?

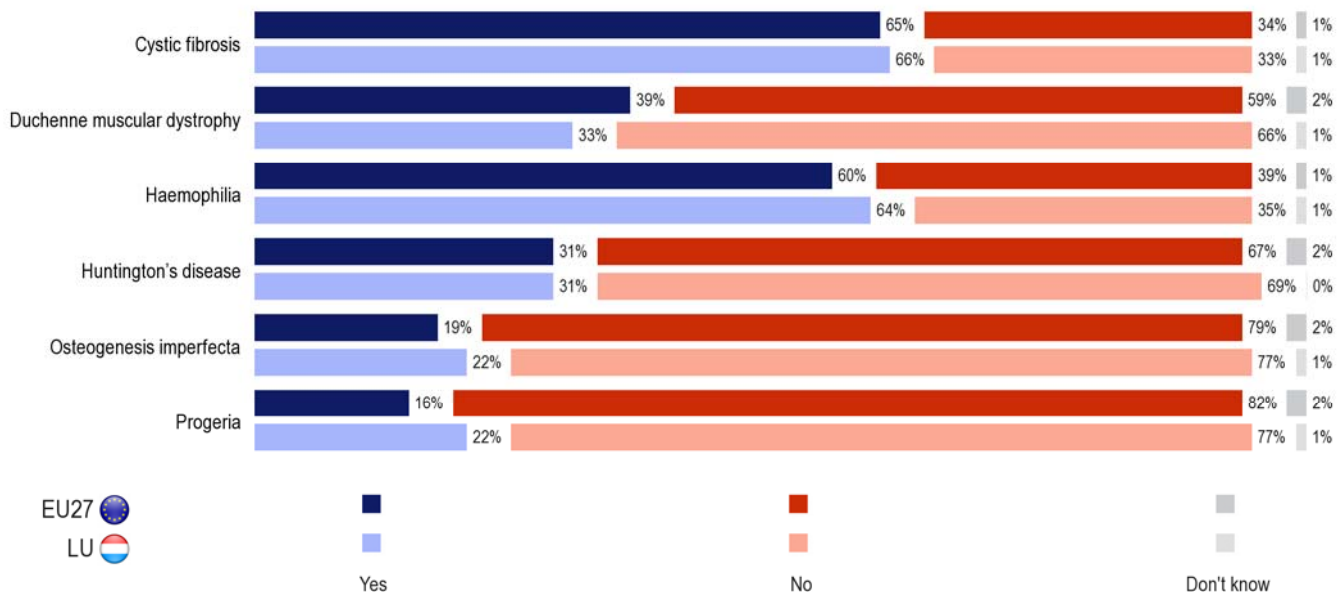


QD1. When talking about rare diseases, which of the following is, in your opinion, the statement that best describes what "rare diseases" are?

Statement	EU27 (%)	LU (%)
These are diseases affecting a limited number of people and needing very specific care	63%	66%
<b>Education (End of)</b>		
15-	49%	60%
16-19	63%	63%
20+	73%	71%
Still studying	68%	68%
<b>Respondent occupation scale</b>		
Self-employed	71%	90%
Managers	76%	77%
Other white collars	70%	82%
Manual workers	63%	60%
House persons	57%	54%
Unemployed	57%	44%
Retired	55%	63%
Students	68%	68%
<b>Self-positioning on the social scale</b>		
Low (1-4)	54%	64%
Medium (5-6)	65%	66%
High (7-10)	68%	69%

Socio-demographic breakdown

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



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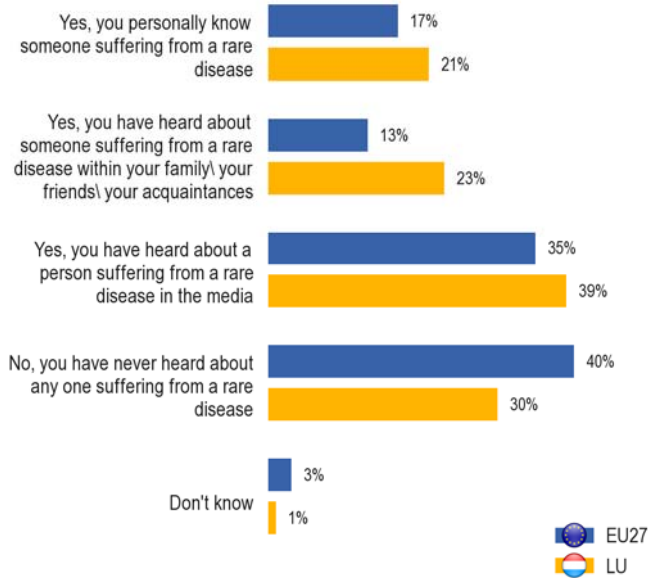
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Methodology: face-to-face

## 2. Personal experience with rare diseases

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



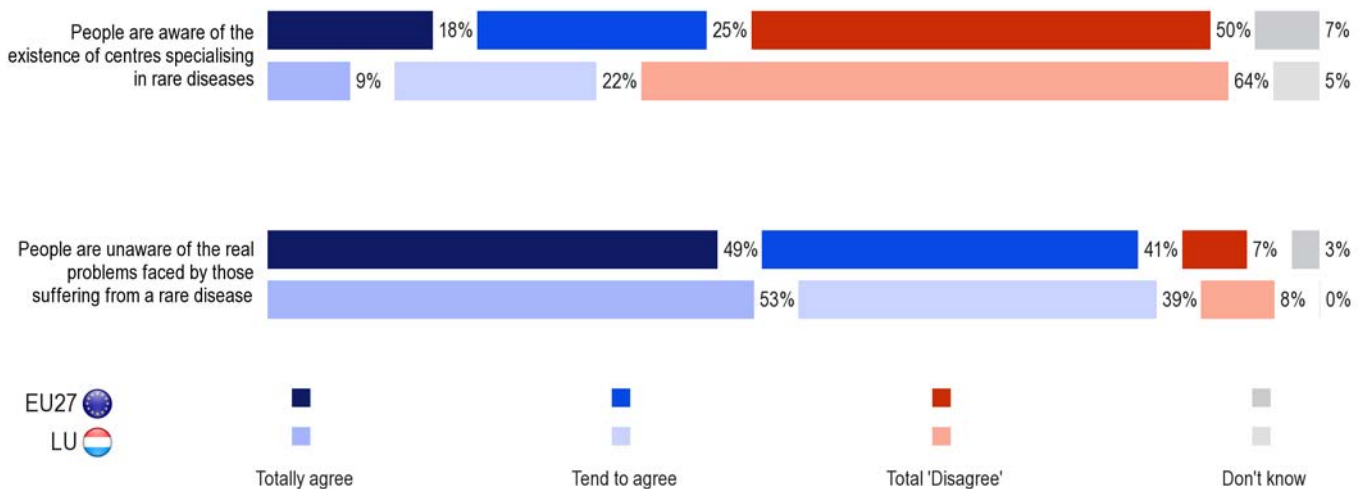
QD2. Do you personally know or have you heard about a person suffering from a rare disease?

Total 'yes'	EU27	LU
<b>TOTAL</b>	<b>57%</b>	<b>69%</b>
<b>Age</b>		
15-24	54%	49%
25-39	60%	72%
40-54	61%	80%
55+	54%	65%
<b>Education (End of)</b>		
15-	49%	60%
16-19	56%	70%
20+	67%	79%
Still studying	56%	52%
<b>Self-positioning on the social scale</b>		
Low (1-4)	55%	77%
Medium (5-6)	57%	66%
High (7-10)	61%	68%

Socio-demographic breakdown

## 3. Awareness of 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.



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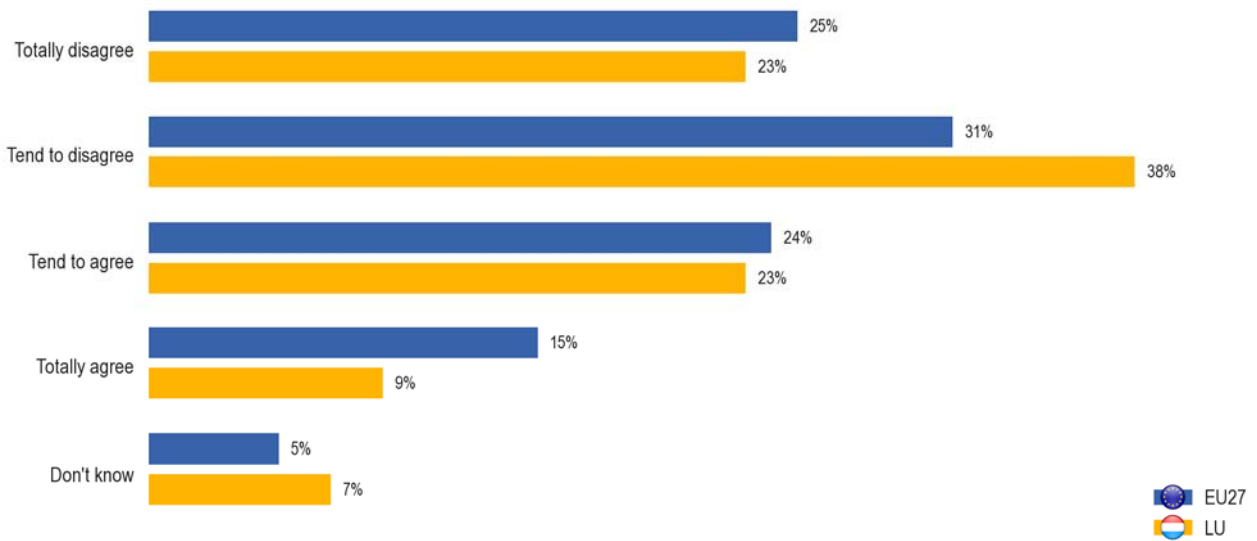


Methodology: face-to-face

## 4. Views about rare disease treatment at national level

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

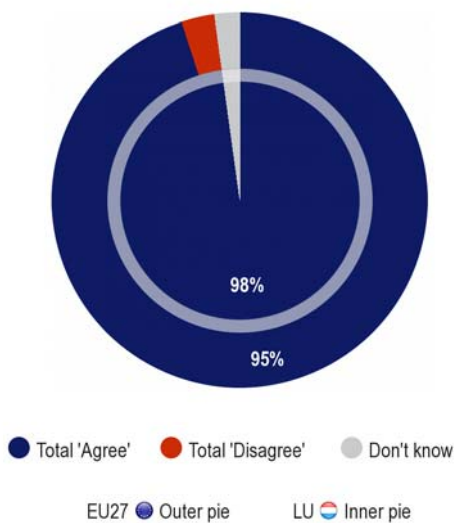
(OUR COUNTRY) has too many other major health issues to make rare diseases a priority



## 5. Views on EU Co-operation in treatment of rare diseases

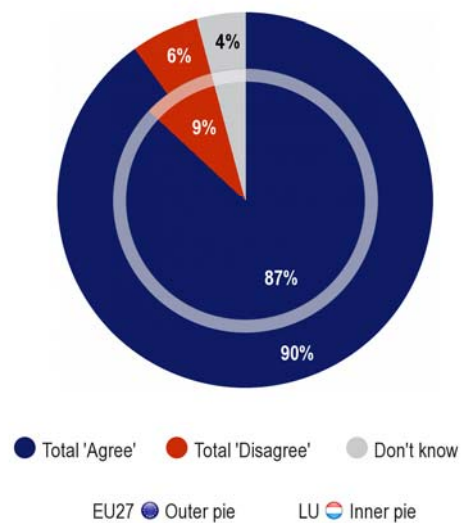
QD3.2. For each of the following statements, please tell me whether you totally agree, tend to agree, tend to disagree or totally disagree.

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



QD3.7. 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



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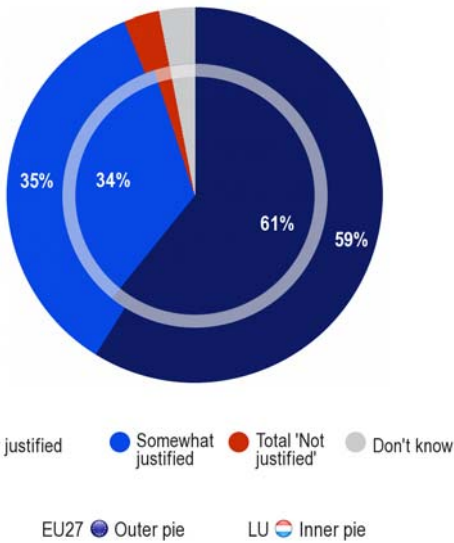


Methodology: face-to-face

## 6. Perceptions of initiatives being undertaken concerning rare diseases

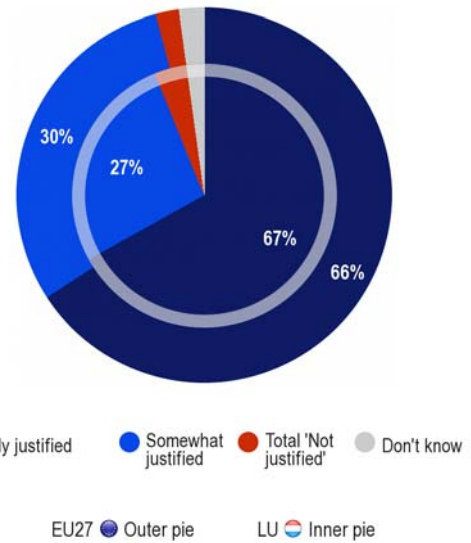
QD4.1. The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. In your opinion, is it justified or not to allocate resources to initiatives in the following areas?

To improve and coordinate research on rare diseases at national and European level



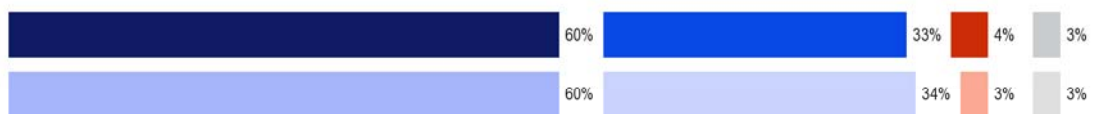
QD4.2. The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. In your opinion, is it justified or not to allocate resources to initiatives in the following areas?

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

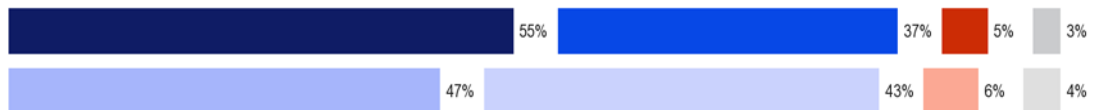



QD4. The European Commission and the national health authorities of the EU Member States have adopted several initiatives to help people suffering from rare diseases. In your opinion, is it justified or not to allocate resources to initiatives in the following areas?

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



To support patient organisations



     
     
 Totally justified      Somewhat justified      Total 'Not justified'      Don't know

