

EUROPEAN AWARENESS OF RARE DISEASES



EU27  Number of interviews:
26,574

LU  Number of interviews:
501

Fieldwork:
25/11-14/12/2010

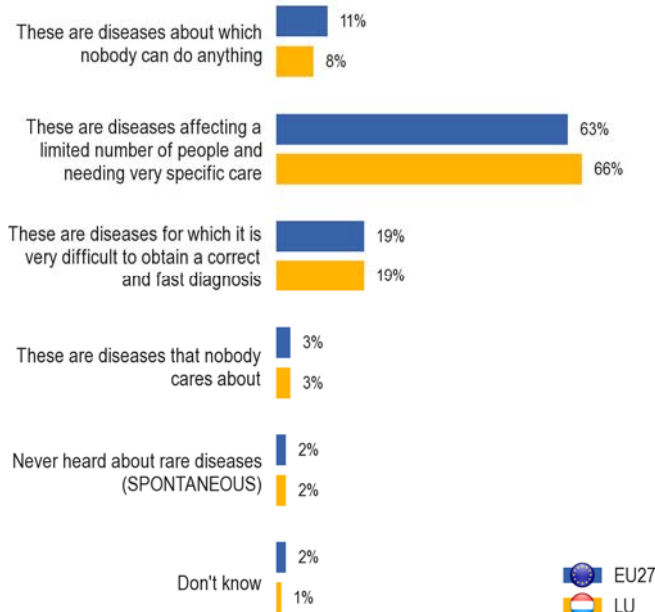
Fieldwork:
26/11-15/12/2010

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?

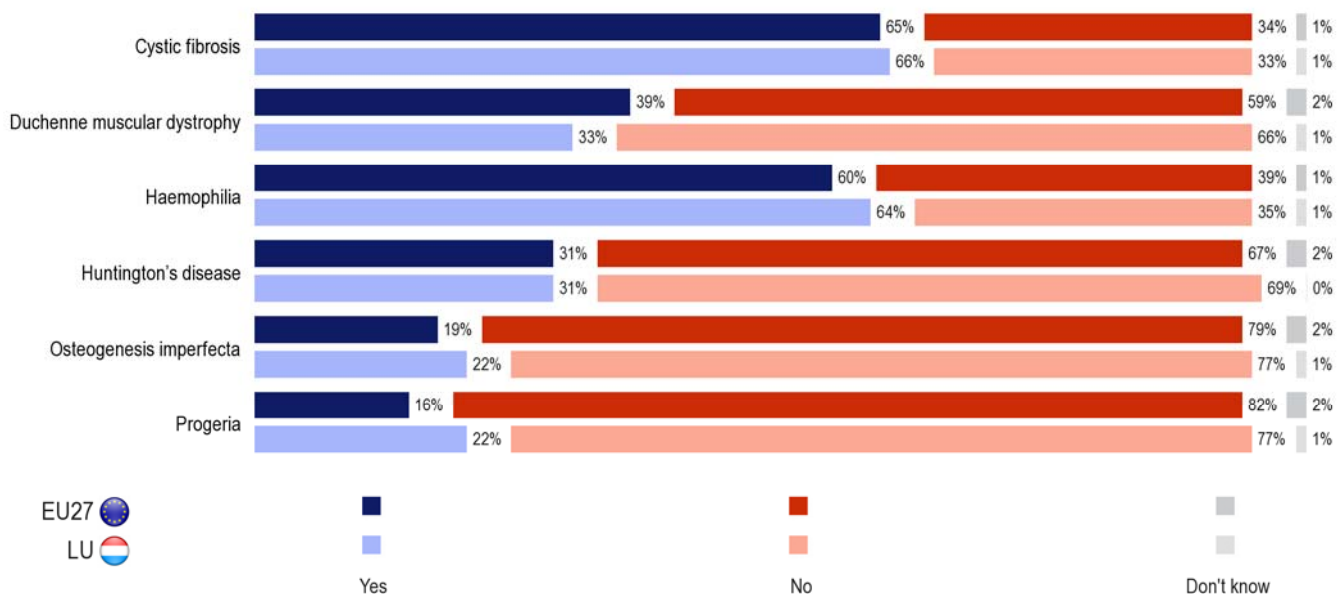


QD1. When talking about rare diseases, which of the following is, in your opinion, the statement that best describes what "rare diseases" are?

	EU27	LU
These are diseases affecting a limited number of people and needing very specific care		
TOTAL	63%	66%
Education (End of)		
15-	49%	60%
16-19	63%	63%
20+	73%	71%
Still studying	68%	68%
Respondent occupation scale		
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%
Self-positioning on the social scale		
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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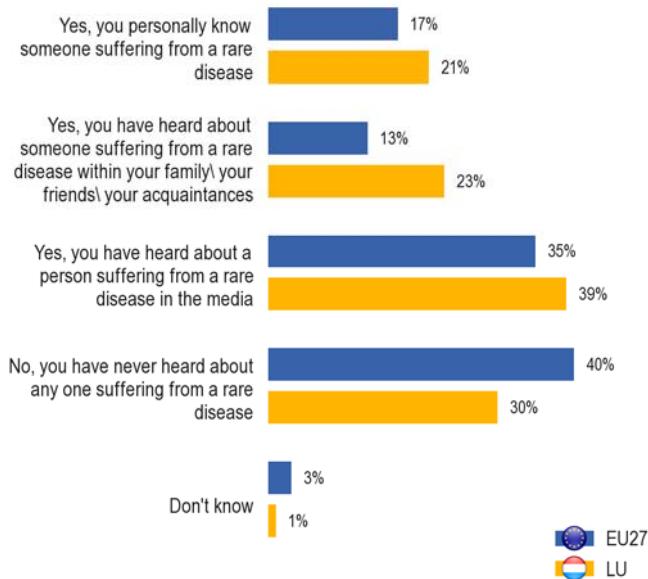
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2. Personal experience with rare diseases

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



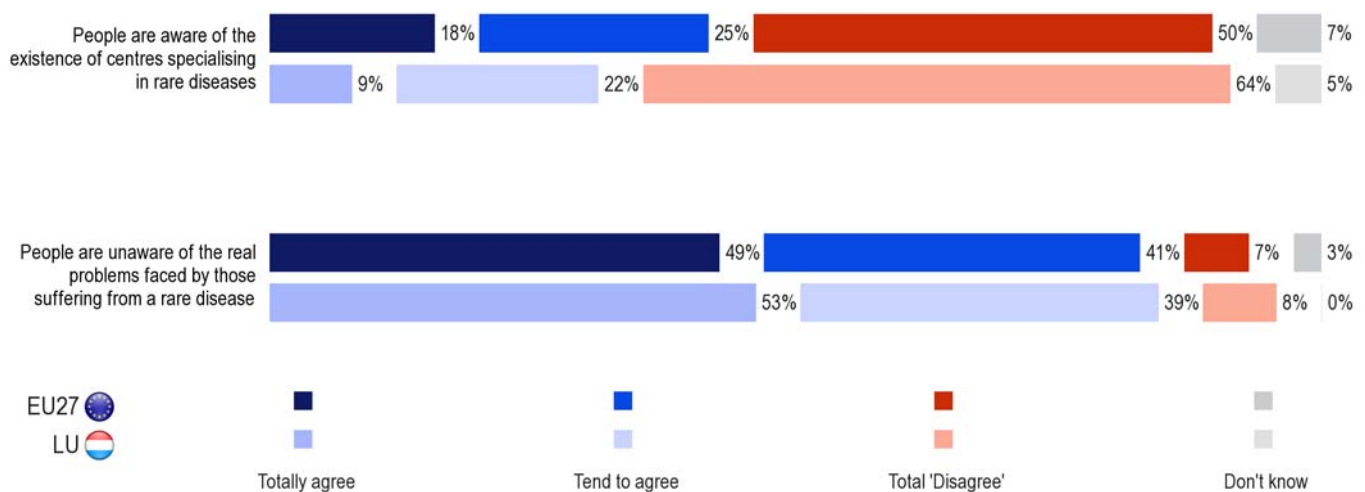
QD2. Do you personally know or have you heard about a person suffering from a rare disease?

Total 'yes'	EU27	LU
TOTAL	57%	69%
Age		
15-24	54%	49%
25-39	60%	72%
40-54	61%	80%
55 +	54%	65%
Education (End of)		
15-	49%	60%
16-19	56%	70%
20+	67%	79%
Still studying	56%	52%
Self-positioning on the social scale		
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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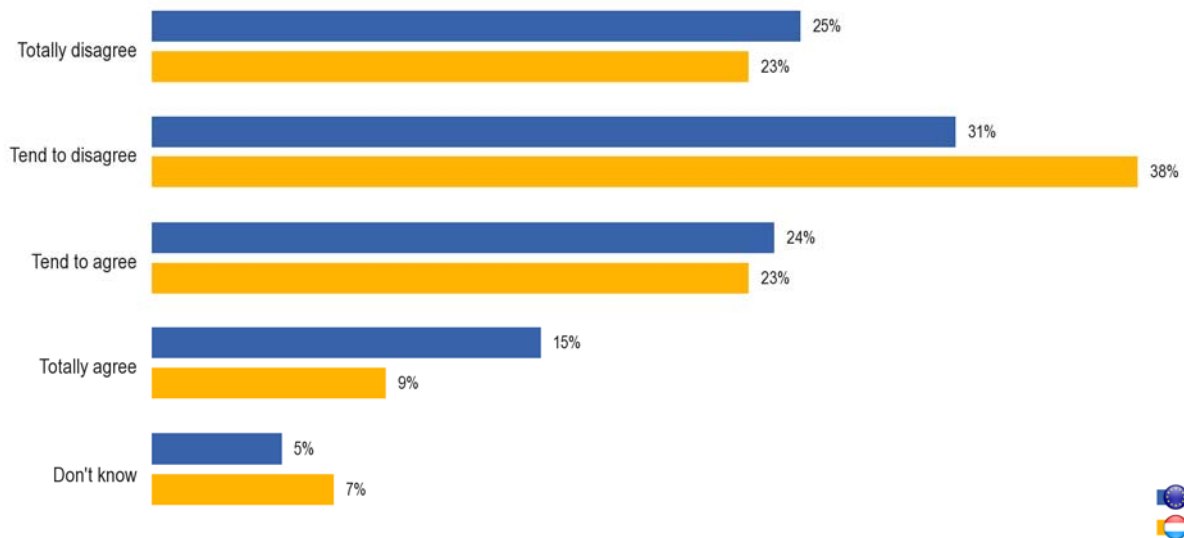


European
Commission

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

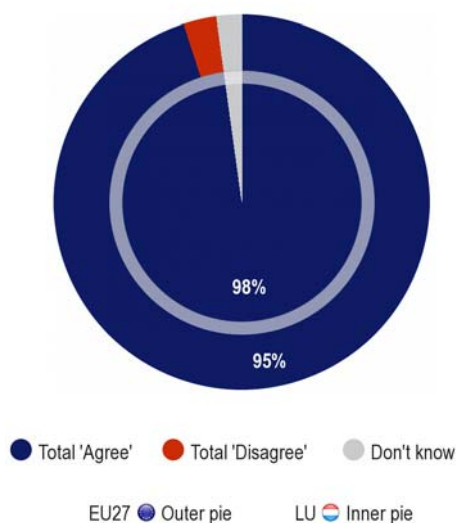


EU27
LU

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

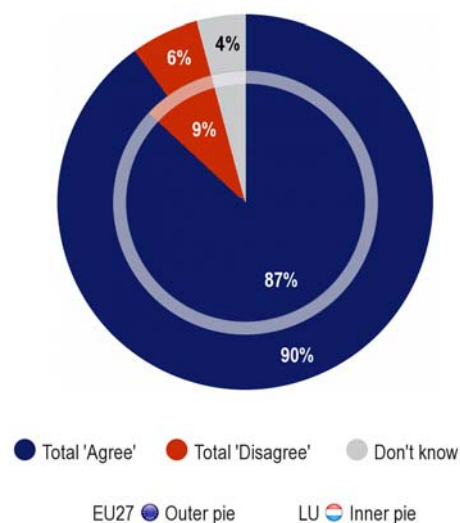


Total 'Agree' Total 'Disagree' Don't know

EU27 LU

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



Total 'Agree' Total 'Disagree' Don't know

EU27 LU

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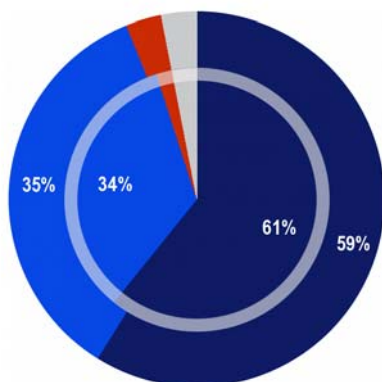
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6. Perceptions of initiatives being undertaken concerning rare diseases

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

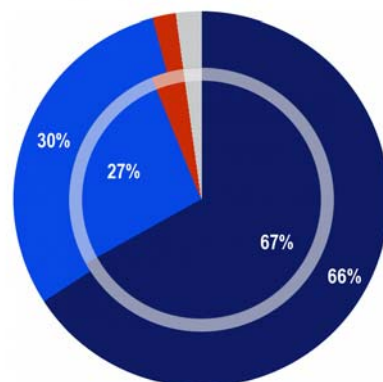


Legend: Totally justified Somewhat justified Total 'Not justified' Don't know

EU27  Outer pie LU  Inner pie

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

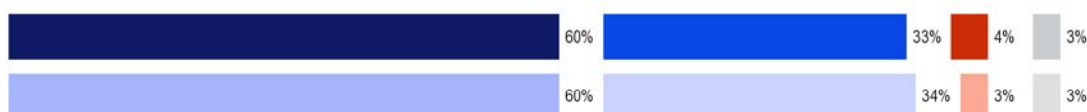


Legend: Totally justified Somewhat justified Total 'Not justified' Don't know

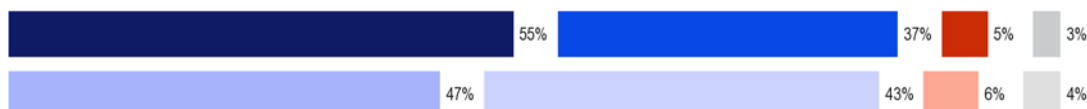
EU27  Outer pie LU  Inner pie

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



EU27 
LU 

Totally justified

Somewhat justified

Total 'Not justified'

Don't know

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