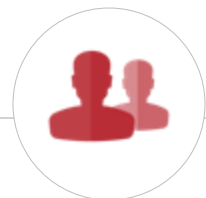


# THE EUROPEAN RARE DISEASES OBSERVATORY

Third wave - 2024

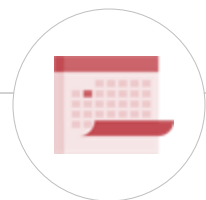


# METHODOLOGY



## SAMPLE

11,413 Europeans aged 16 and over



## FIELD DATES

From February 19 to March 19, 2024.



## METHOD

Sample surveyed online via Ipsos' Online Access Panel.  
Quota method: Gender, age, occupation of the respondent, market size and region

Number of respondents	
Total	11,413
France	2,413
Germany	1,000
Spain	1,000
Great Britain	1,000
Italy	1,000
Sweden	1,000
Greece	1,000
Poland	1,000
Netherlands	1,000



NB / the previous survey was carried out from 5 to 31 March 2022.

# 1 – RARE DISEASES CONCERN MANY EUROPEANS

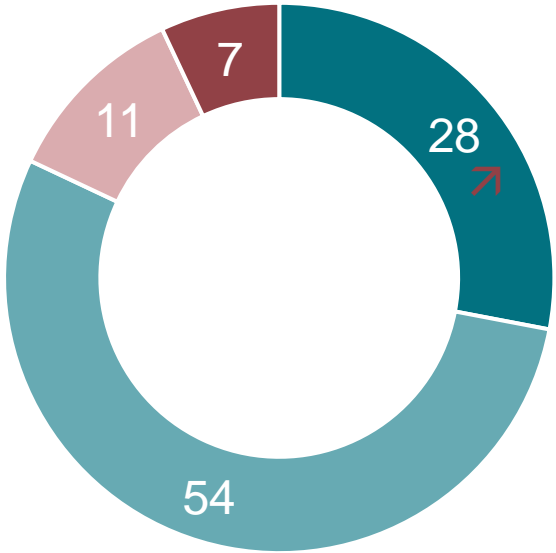
The level of knowledge of Europeans about rare diseases is increasing slightly

1 in 25 Europeans say they have a rare disease

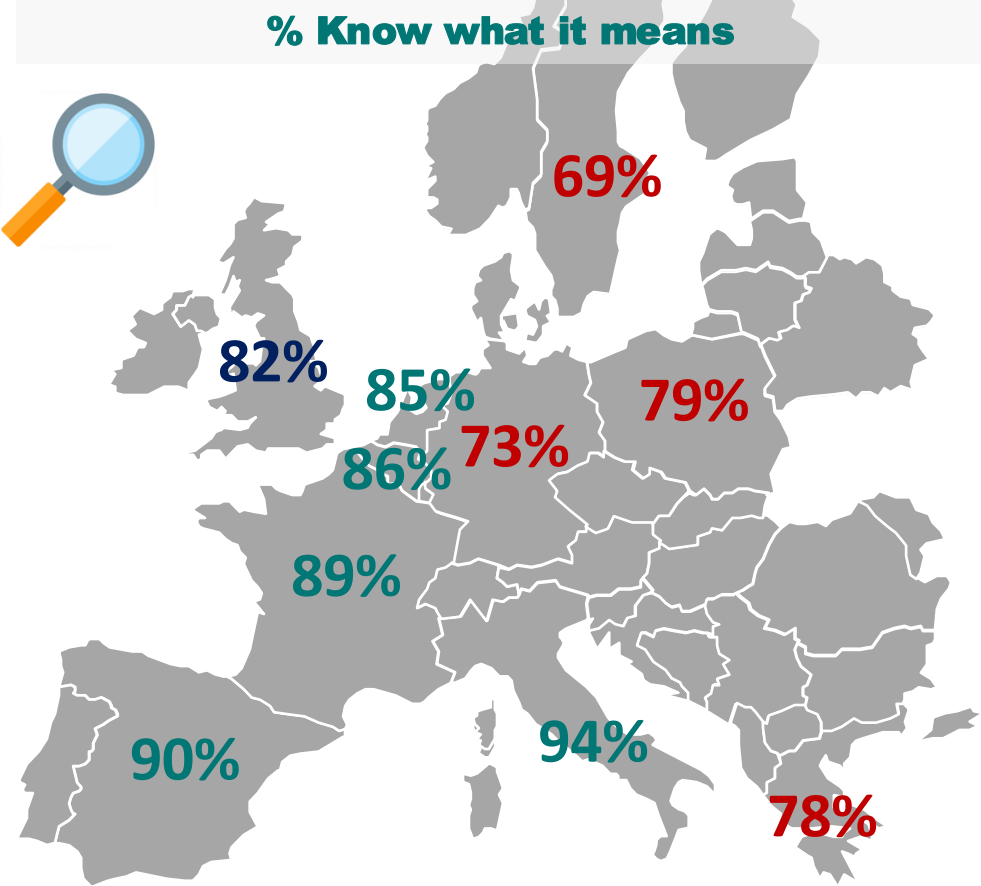
Almost 1 in 3 suffers directly or indirectly from it

# ONLY A LITTLE MORE THAN 1 IN 4 EUROPEANS KNOW PRECISELY WHAT A RARE DISEASE IS: KNOWLEDGE IS INCREASING SLIGHTLY.

Do you know what is meant by the term "rare disease"?  
 Base: Europeans, n = 11413



% "YES"  
**82** ↗  
 2022 : 79%





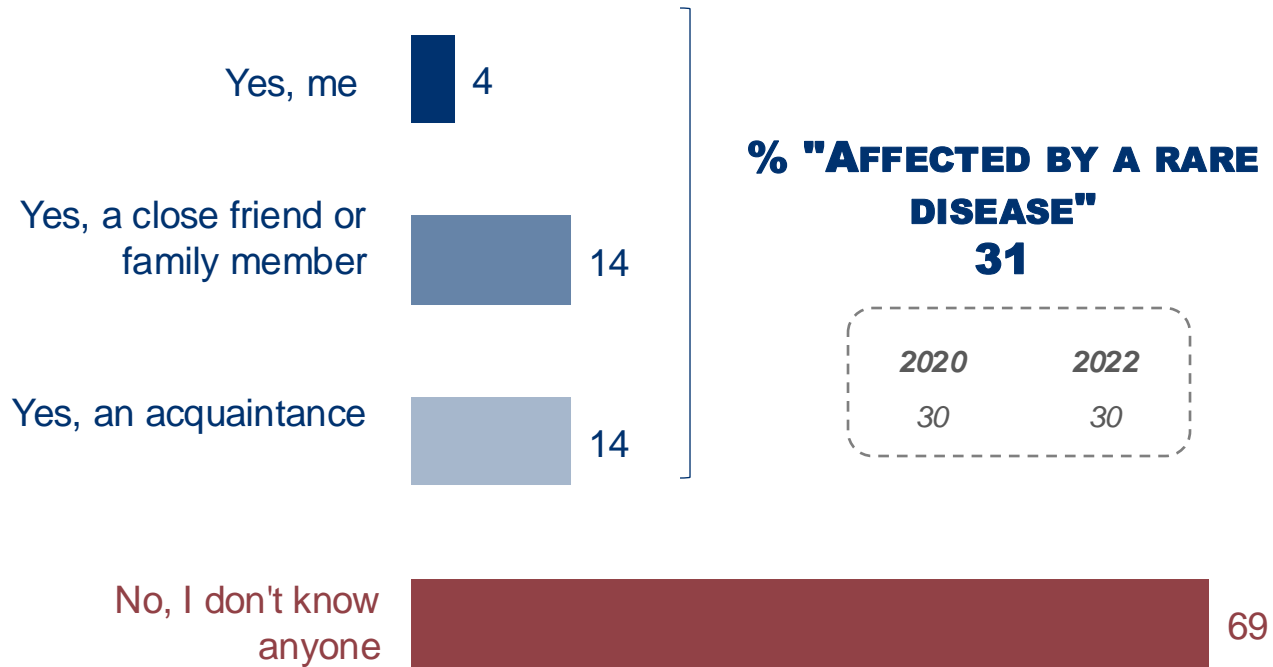
*A rare disease is a disease that affects fewer than 5 in 10,000 people. About 80% of them have a genetic cause.*

*Within the European Union, about 30 million citizens are affected by more than 6,000 different rare diseases.*

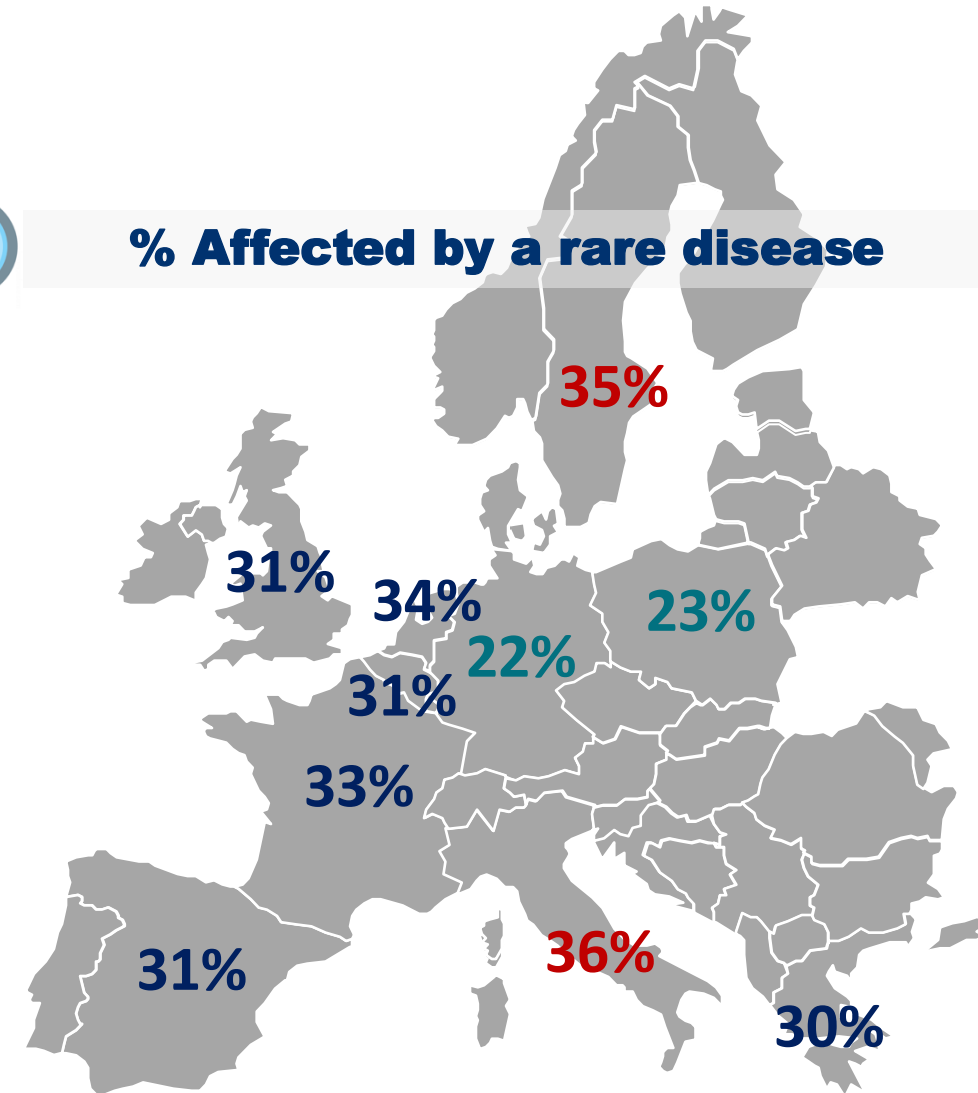
*These include, for example, cystic fibrosis, brittle bone disease, Crohn's disease or Duchenne muscular dystrophy.*

# 4% OF EUROPEANS SAY THEY HAVE A RARE DISEASE AND ALMOST 1 IN 3 PEOPLE KNOW SOMEONE WHO DOES

Do you know someone with a rare disease?  
Base: Europeans, n = 11413



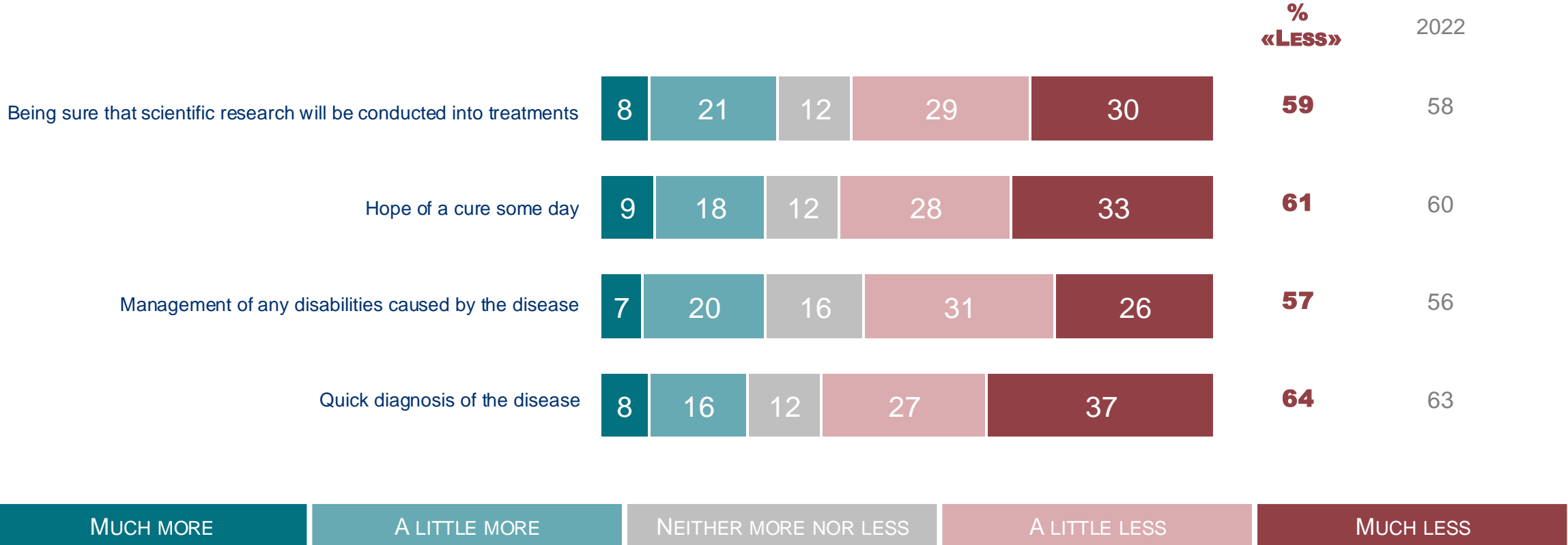
## % Affected by a rare disease



# 2 - EUROPEANS INCREASINGLY FIND THE SUFFERING EXPERIENCED BY PATIENTS UNACCEPTABLE

# THE FEELING THAT PEOPLE WITH RARE DISEASES HAVE POORER OUTCOME OPTIONS THAN OTHER PATIENTS NOT ONLY REMAINS IN THE MAJORITY, BUT ALSO INCREASES SLIGHTLY COMPARED TO 2022

Personally, do you think that people with rare diseases have more, less or the same chance as other patients with serious illnesses with regard to ...?  
 Base: Europeans, n = 11400

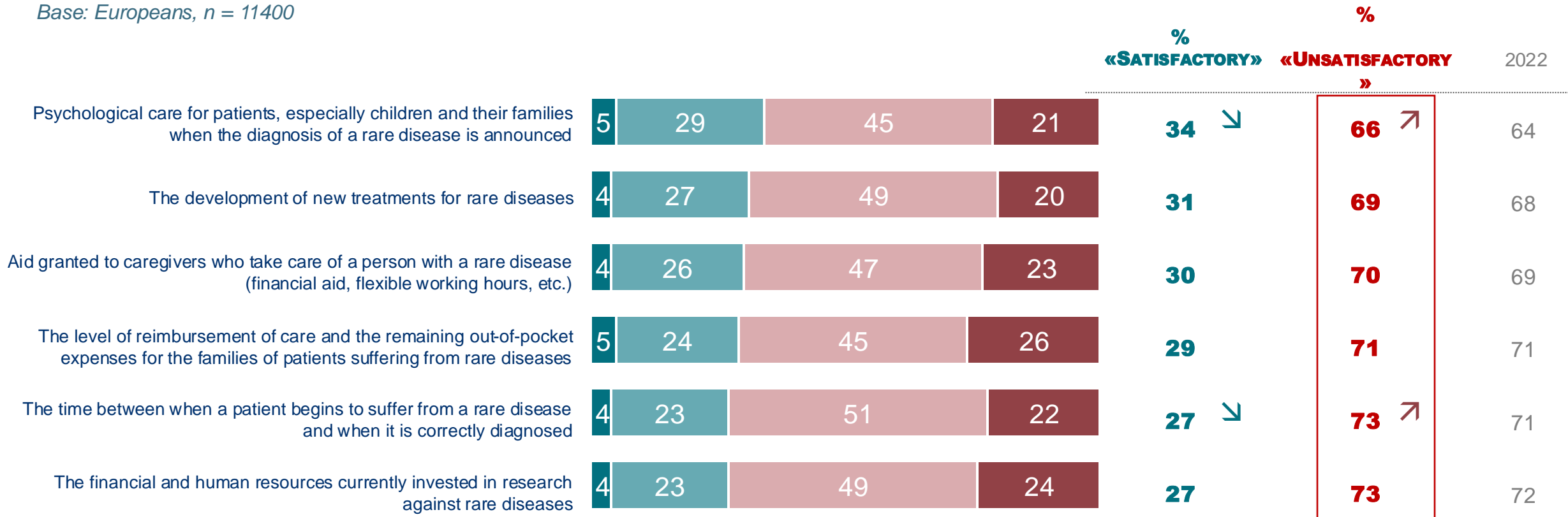




# THE VAST MAJORITY OF EUROPEANS CONSIDER THE CARE OF PATIENTS SUFFERING FROM RARE DISEASES AND THE FINANCIAL RESOURCES DEDICATED TO RESEARCH TO BE INCREASINGLY UNSATISFACTORY

From what you know, is the situation in your country satisfactory or not today with regard to each of the following points?

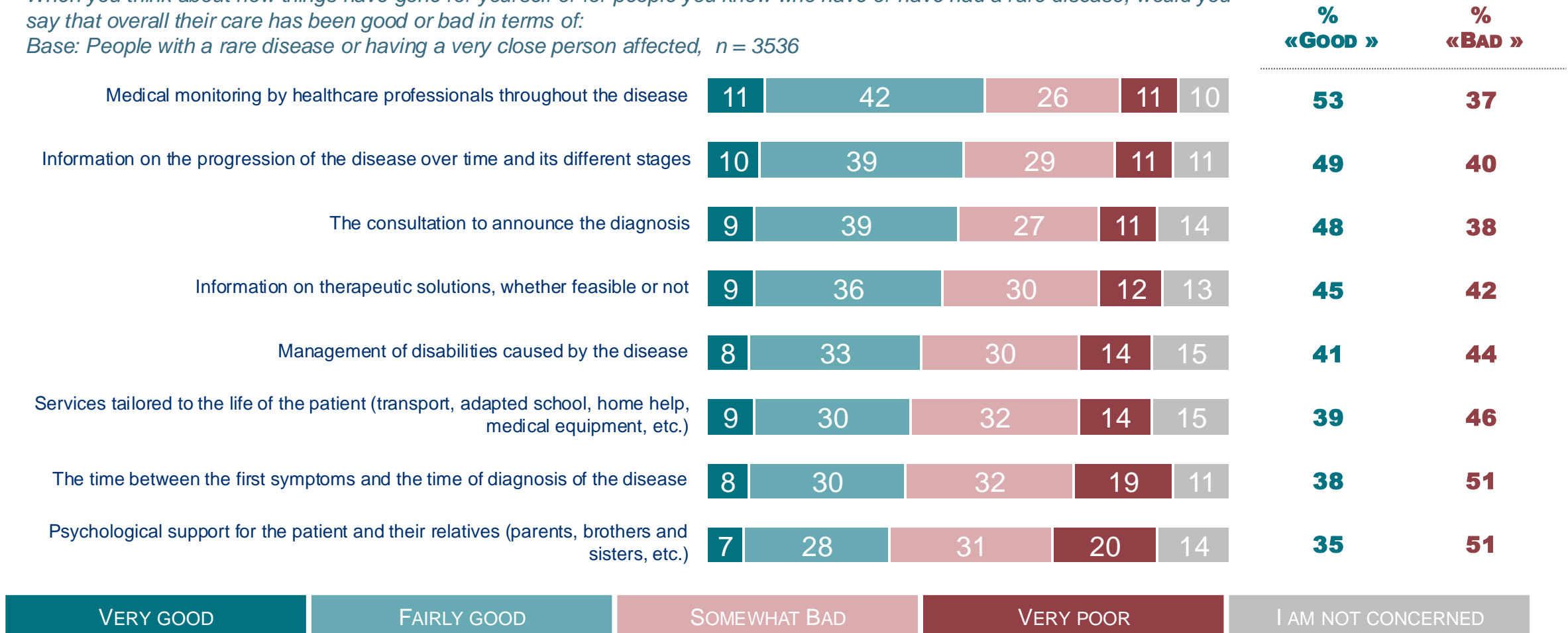
Base: Europeans, n = 11400



# AMONG PEOPLE AFFECTED BY RARE DISEASES, A MAJORITY ARE DISSATISFIED WITH THE PSYCHOLOGICAL SUPPORT OFFERED, THE TIME SPENT ON GETTING A DIAGNOSIS OR THE SERVICES AVAILABLE

When you think about how things have gone for yourself or for people you know who have or have had a rare disease, would you say that overall their care has been good or bad in terms of:

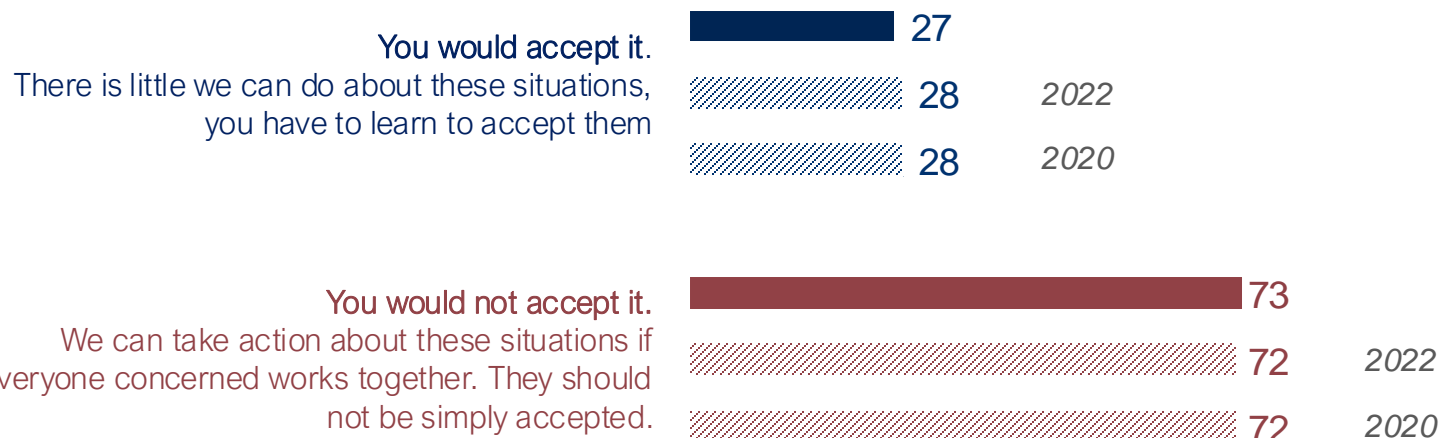
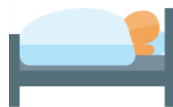
Base: People with a rare disease or having a very close person affected, n = 3536



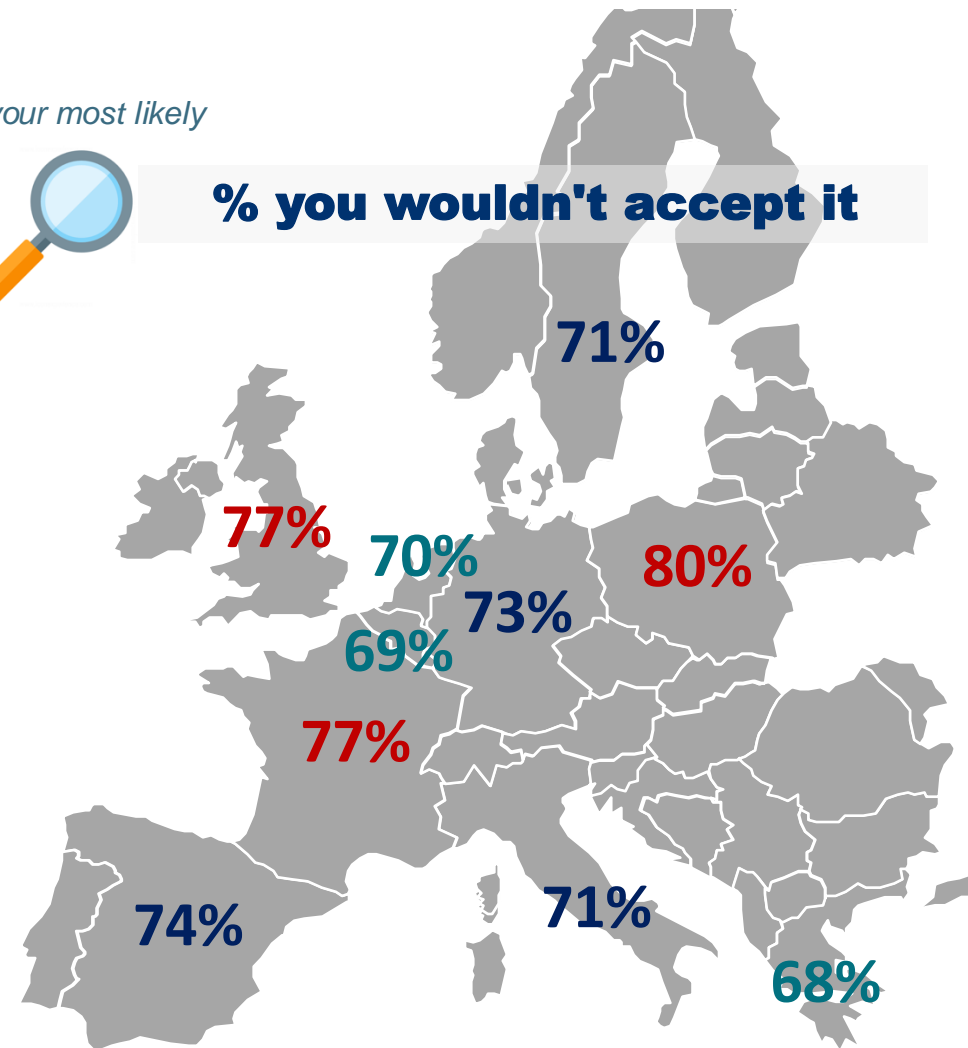
# THE SITUATIONS EXPERIENCED BY PATIENTS WITH RARE DISEASES ARE OVERWHELMINGLY CONSIDERED UNACCEPTABLE: NEARLY 3 OUT OF 4 EUROPEANS WOULD NOT ACCEPT NOT BEING ABLE TO GET A DIAGNOSIS FOR SEVERAL YEARS IF A LOVED ONE SUFFERED FROM A RARE DISEASE.

If someone close to you had a rare disease and was faced with the following situations, what would be your most likely response? (base: Europeans, n= 11413)

**Inability to get a diagnosis for several years**



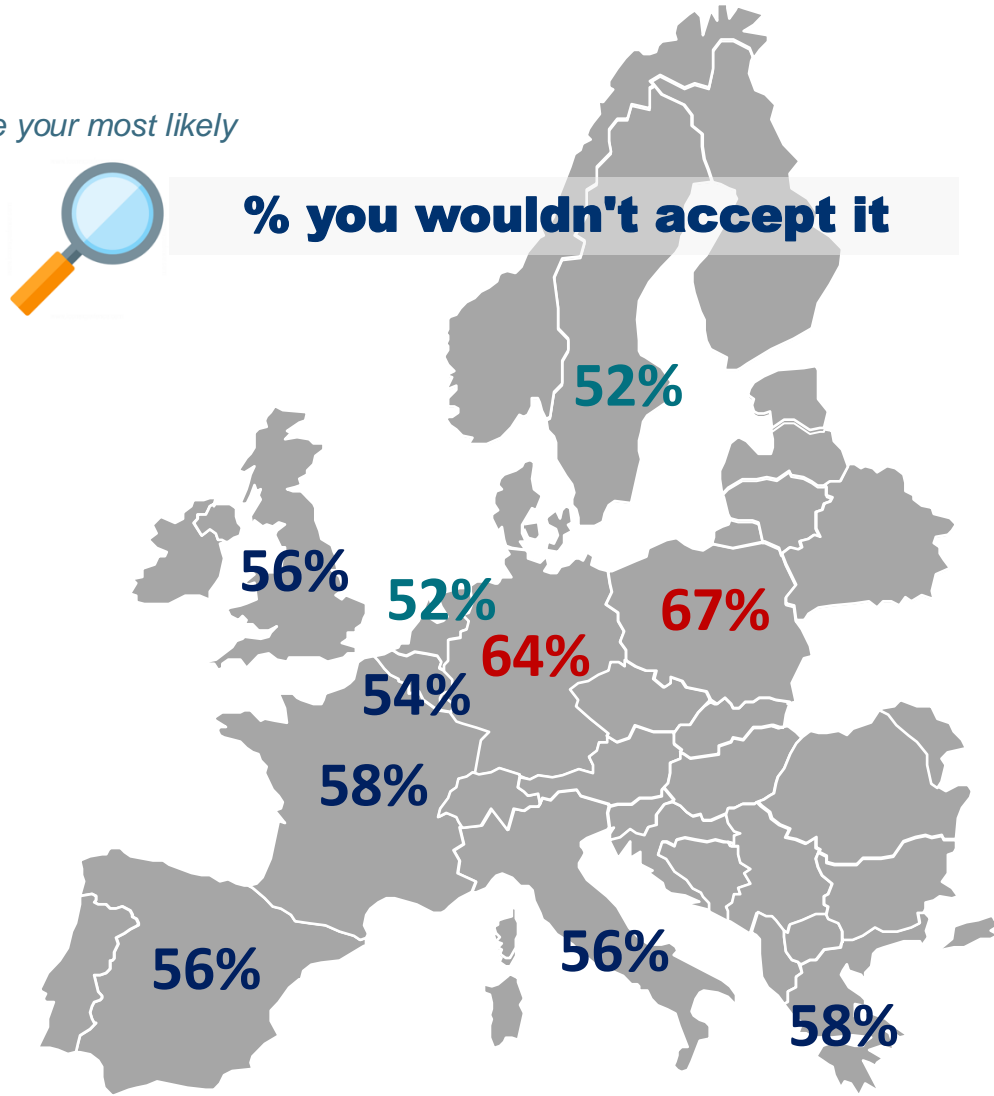
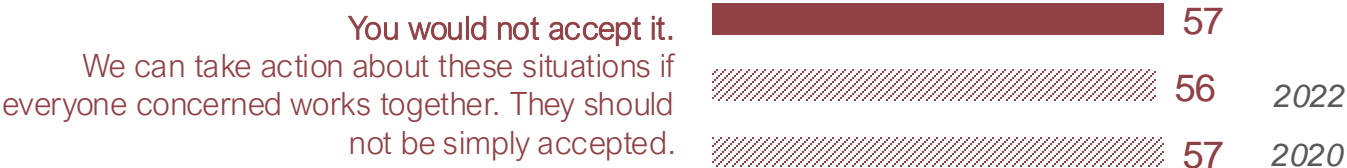
**% you wouldn't accept it**



# THE ANNOUNCEMENT THAT NO EFFECTIVE TREATMENT EXISTS REMAINS UNACCEPTABLE: 6 OUT OF 10 FRENCH PEOPLE COULD NOT BRING THEMSELVES TO ACCEPT IT.

If someone close to you had a rare disease and was faced with the following situations, what would be your most likely response? (base: Europeans, n= 11413)

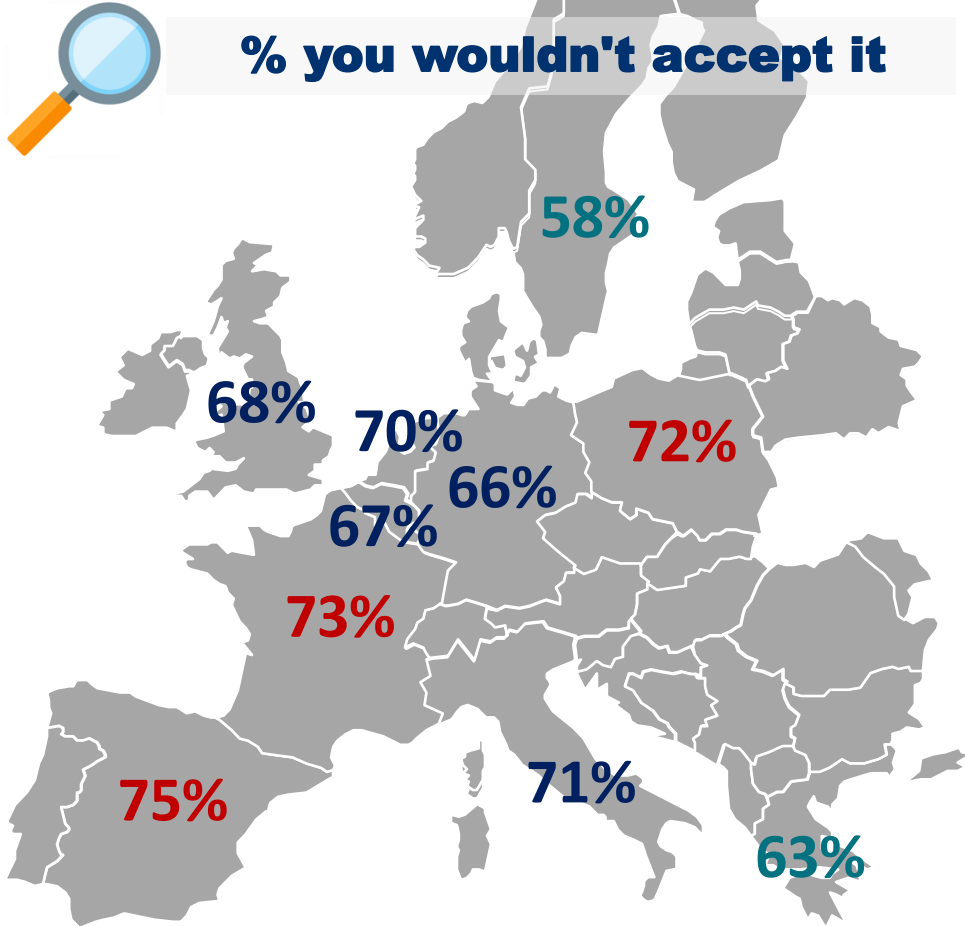
**The announcement that there is no effective treatment at this time**



# NEARLY 7 OUT OF 10 EUROPEANS CONSIDER IT UNACCEPTABLE THAT NO RESEARCH IS CARRIED OUT TO DEVELOP TREATMENTS FOR RARE DISEASES: THE FRENCH FEEL THE MOST STRONGLY ALONG WITH THE SPANISH AND THE POLES.

If someone close to you had a rare disease and was faced with the following situations, what would be your most likely response? (base: Europeans, n= 11413)

**The discovery that no research is being carried out to develop a treatment**



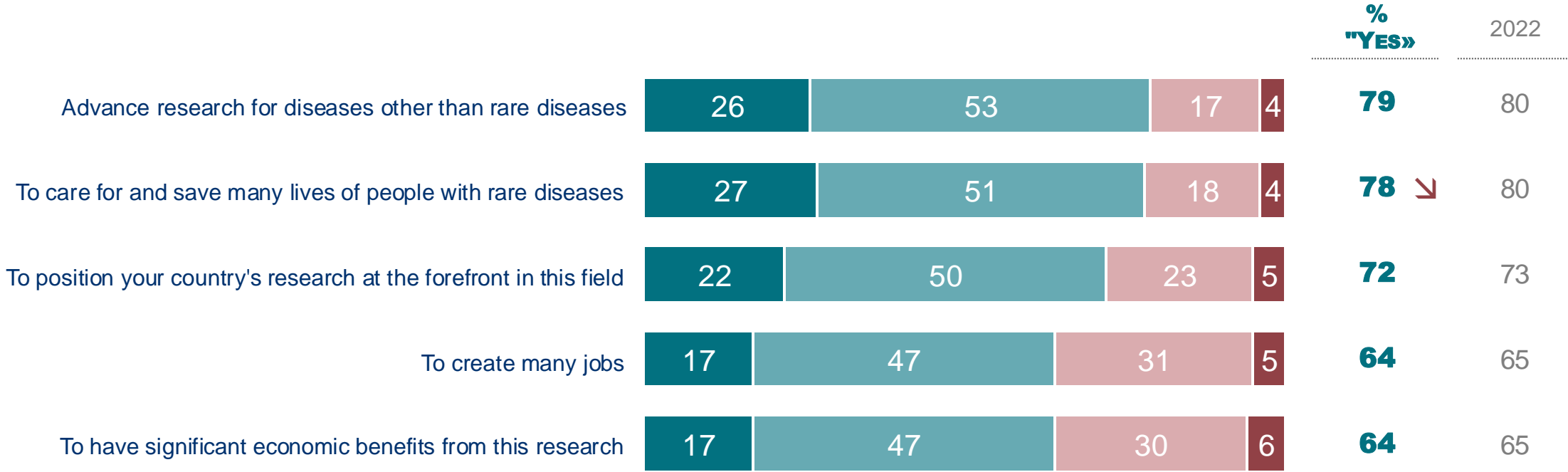
# 3 - EXPECTATIONS IN THE FORM OF DEMANDS

Many measures are still supported by a majority of Europeans, both within their own country and the European Union

# THE VAST MAJORITY OF EUROPEANS REMAIN CONVINCED THAT FUNDING RESEARCH ON RARE DISEASES WOULD BENEFIT EVERYONE: A VERY STRONG MEMBERSHIP THAT REMAINS STABLE IN 2024.

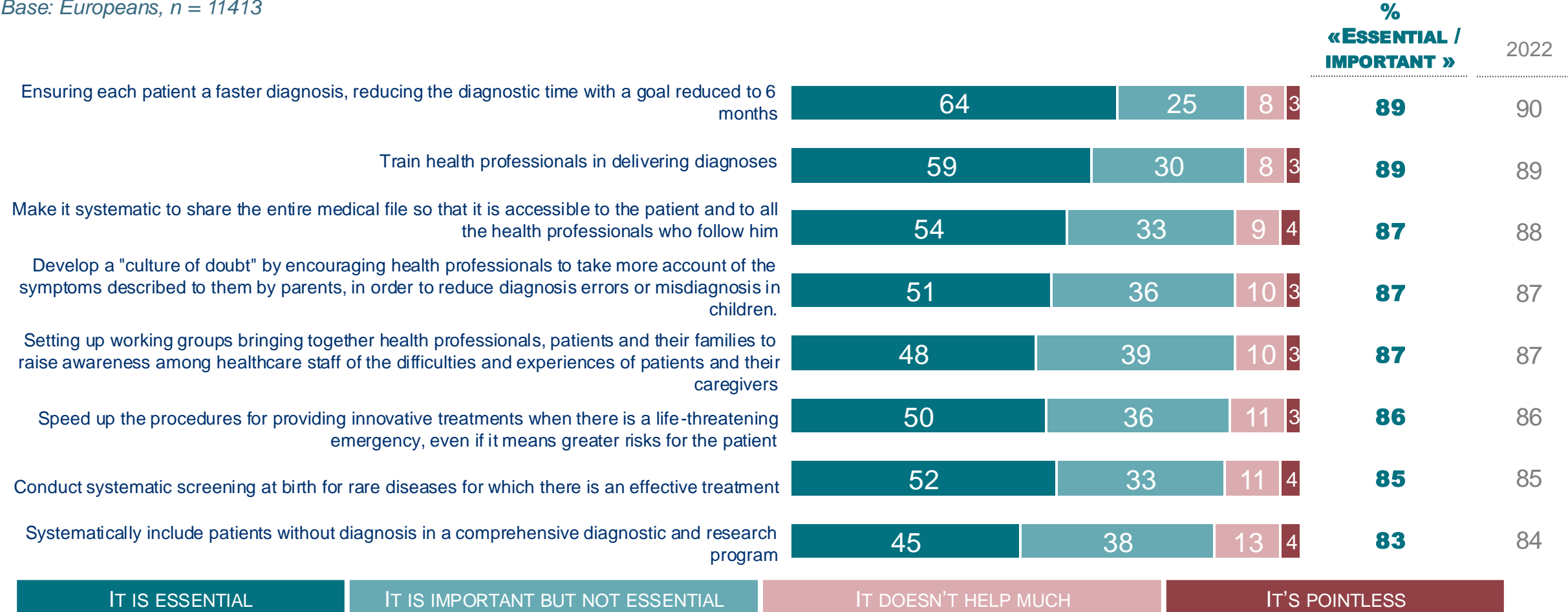
In your opinion, does funding research projects on innovative treatments (such as gene therapy or immunotherapy) within your country's research institutions make it possible to advance research for diseases other than rare diseases?

Base: Europeans, n = 11413



# EUROPEANS EXPRESS EXPECTATIONS THAT THEY ALMOST ALL CONSIDER TO BE "ESSENTIAL" TO IMPROVE THE FIGHT AGAINST RARE DISEASES

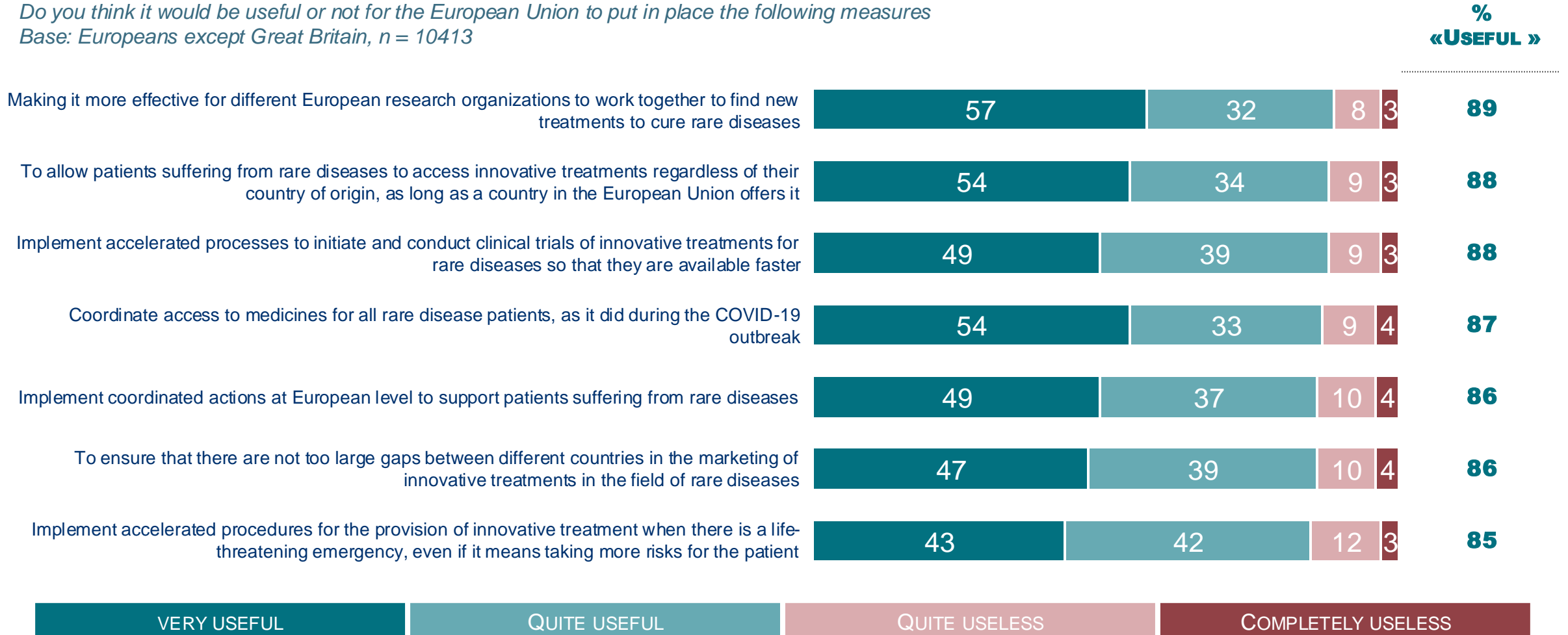
What is your personal opinion regarding the following measures that could be put in place to improve the fight against rare diseases and patient care?  
 Base: Europeans, n = 11413





## EUROPEANS ALSO STRESS THE USEFULNESS OF IMPLEMENTING MEASURES WITHIN THE EUROPEAN UNION TO PROMOTE AND COORDINATE ACCESS TO TREATMENTS FOR PATIENTS SUFFERING FROM RARE DISEASES

Do you think it would be useful or not for the European Union to put in place the following measures  
Base: Europeans except Great Britain, n = 10413



# ABOUT IPSOS

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