

METHODOLOGY



SAMPLE

11,413 Europeans aged 16 and over



FIELD DATES

From February 19 to March 19, 2024.

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			



METHOD

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

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







1 - RARE DISEASES CONCERN MANY EUROPEANS

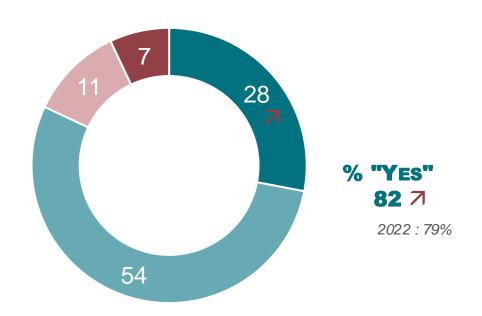
The level of knowledge of Europeans about rare diseases is increasing slightly
1 in 25 Europeans say they have a rare disease
Almost 1 in 3 suffers directly or indirectly from it

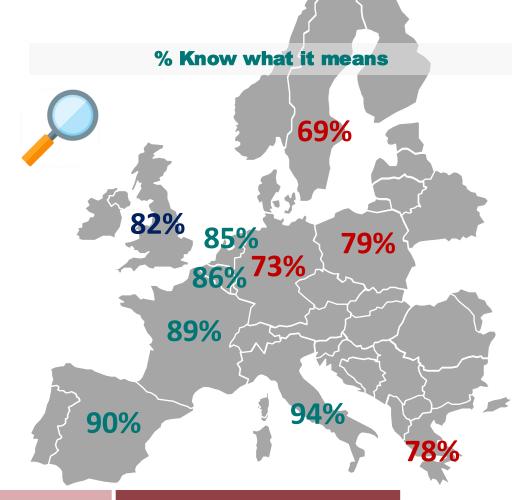


ONLY A LITTLE MORE THAN 1 IN 4 EUROPEANS KNOW PRECISELY WHAT A RARE DISEASE IS:

KNOWLEDGE IS INCREASING SLIGHTLY.

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





YES, I KNOW EXACTLY WHAT IT MEANS

YES, I KNOW ROUGHLY WHAT IT MEANS

NO, I DON'T KNOW WHAT IT MEANS

NO, I HAD NEVER HEARD OF THIS TERM







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.

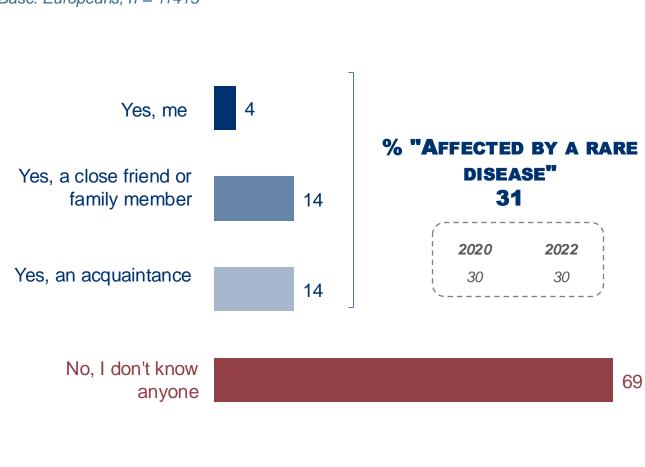
These include, for example, cystic fibrosis, brittle bone disease, Crohn's disease or Duchenne muscular dystrophy.

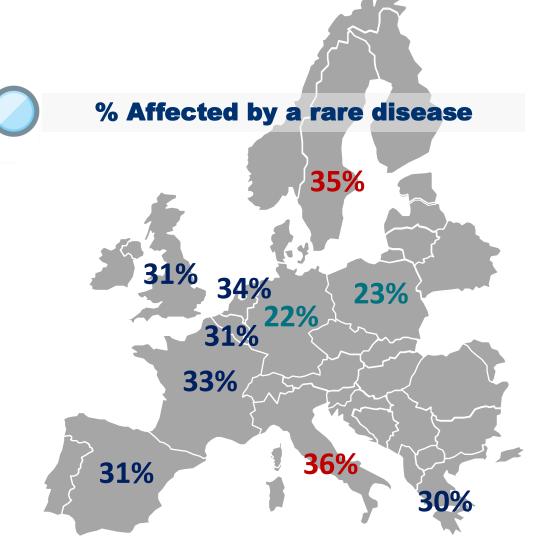




4% OF EUROPEANS SAY THEY HAVE A RARE DISEASE AND ALMOST 1 IN 3 PEOPLE KNOW SOMEONE WHO DOES

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







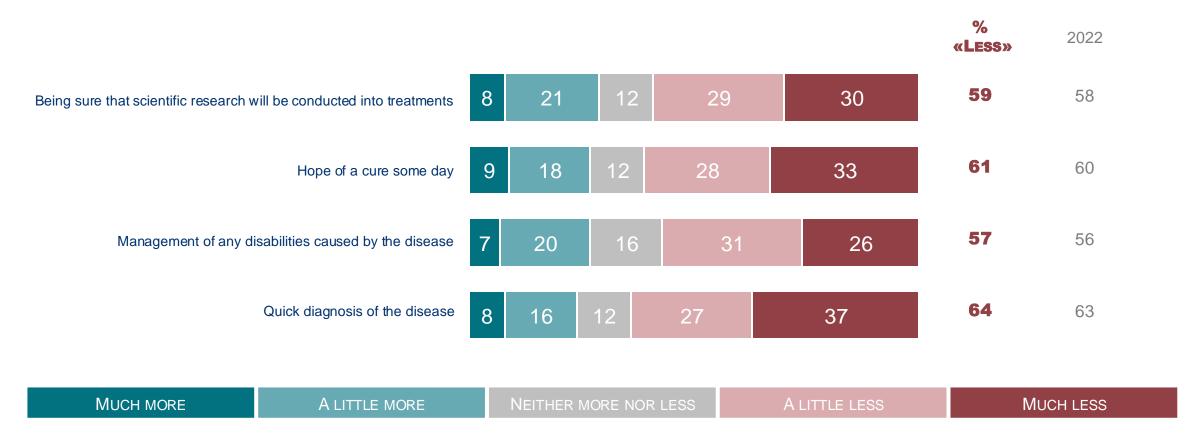


2 - EUROPEANS INCREASINGLY FIND THE SUFFERING EXPERIENCED BY PATIENTS UNACCEPTABLE



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

					% «SATISFACTORY»	«Unsatisfactory »	2022
Psychological care for patients, especially children and their families when the diagnosis of a rare disease is announced	5	29	45	21	34	66	64
The development of new treatments for rare diseases	4	27	49	20	31	69	68
Aid granted to caregivers who take care of a person with a rare disease (financial aid, flexible working hours, etc.)	4	26	47	23	30	70	69
The level of reimbursement of care and the remaining out-of-pocket expenses for the families of patients suffering from rare diseases	5	24	45	26	29	71	71
The time between when a patient begins to suffer from a rare disease and when it is correctly diagnosed	4	23	51	22	27	73	71
The financial and human resources currently invested in research against rare diseases	4	23	49	24	27	73	72

VERY SATISFACTORY

QUITE SATISFACTORY

RATHER UNSATISFACTORY

NOT AT ALL SATISFACTORY





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: «BAD» «GOOD» Base: People with a rare disease or having a very close person affected. n = 3536Medical monitoring by healthcare professionals throughout the disease Information on the progression of the disease over time and its different stages The consultation to announce the diagnosis Information on therapeutic solutions, whether feasible or not Management of disabilities caused by the disease Services tailored to the life of the patient (transport, adapted school, home help, medical equipment, etc.) The time between the first symptoms and the time of diagnosis of the disease Psychological support for the patient and their relatives (parents, brothers and sisters, etc.) **VERY GOOD** SOMEWHAT BAD **FAIRLY GOOD VERY POOR**





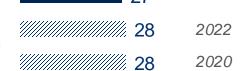
THE SITUATIONS EXPERIENCED BY PATIENTS WITH RARE DISEASES ARE OVERWHELMINGLY CONSIDERED UNACCEPTABLE: NEARLY 3 OUT OF 4 EUROPEANS WOULD NOT ACCEPT NOT BEING ABLE TO GET A DIAGNOSIS FOR SEVERAL YEARS IF A LOVED ONE SUFFERED FROM A RARE DISEASE.

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 would accept it.
There is little we can do about these situations,
you have to learn to accept them



You would not accept it.

We can take action about these situations if everyone concerned works together. They should not be simply accepted.









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

You would accept it.
There is little we can do about these situations,
you have to learn to accept them

You would not accept it.

We can take action about these situations if everyone concerned works together. They should not be simply accepted.





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.

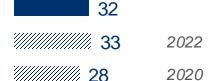
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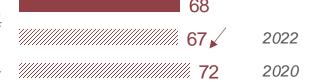
The discovery that no research is being carried out to develop a treatment



You would accept it. There is little we can do about these situations, you have to learn to accept them



You would not accept it. We can take action about these situations if everyone concerned works together. They should not be simply accepted.









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

				"YES»	2022
Advance research for diseases other than rare diseases	26	53	17 4	79	80
To care for and save many lives of people with rare diseases	27	51	18 4	78 🛚	80
To position your country's research at the forefront in this field	22	50	23 5	72	73
To create many jobs	17	47	31 5	64	65
To have significant economic benefits from this research	17	47	30 6	64	65

YES, DEFINITELY	YES, SOMEWHAT	NO, NOT REALLY	N O, NOT AT ALL





2022

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

						«ESSENTIAL / IMPORTANT »	2022	
En	suring each patient a faster diagnosis, reducing the diagnostic time with a goal reduced to month		64	2	5 8 3	89	90	
	Train health professionals in delivering diagnose	es	59	30	8 3	89	89	
Mal	ke it systematic to share the entire medical file so that it is accessible to the patient and to a the health professionals who follow his		54	33	9 4	87	88	
	Develop a "culture of doubt" by encouraging health professionals to take more account of the mptoms described to them by parents, in order to reduce diagnosis errors or misdiagnosis childre	in	51	36	10 3	87	87	
	etting up working groups bringing together health professionals, patients and their families are awareness among healthcare staff of the difficulties and experiences of patients and the caregive	eir ei r	48	39	10 3	87	87	
;	Speed up the procedures for providing innovative treatments when there is a life-threatening emergency, even if it means greater risks for the patie		50	36	11 3	86	86	
Cor	nduct systematic screening at birth for rare diseases for which there is an effective treatme	ent	52	33	11 4	85	85	
Sy	stematically include patients without diagnosis in a comprehensive diagnostic and research progra		45	38	13 4	83	84	
	T IS ESSENTIAL TO SERVICE TO THE SECOND SECOND SERVICE TO THE SECOND SE		IT DOESN'T HELP M	MUCH	lT's	POINTLESS		



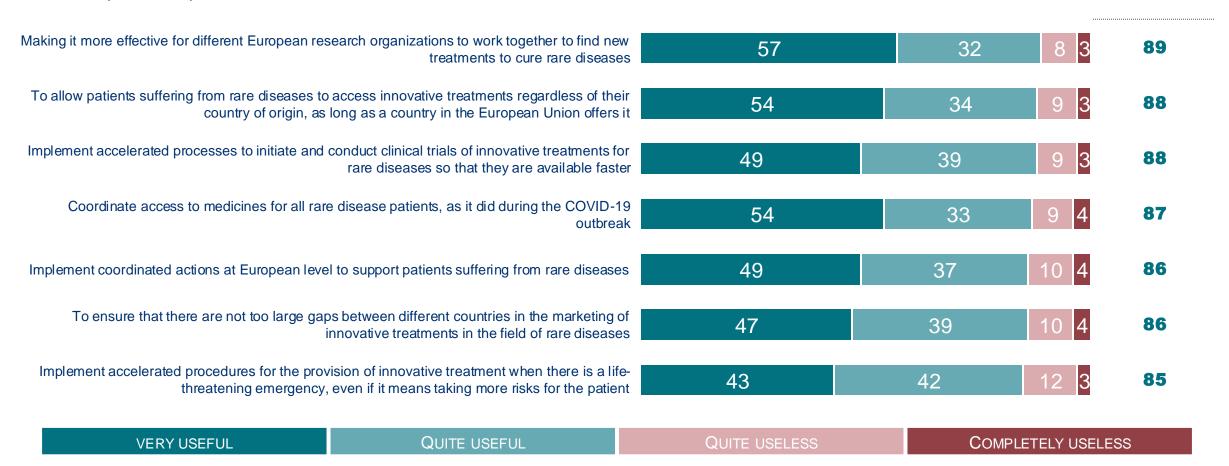
"ECCENTIAL /



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

% **«USEFUL»**





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