EUROPEAN BAROMETER ON RARE DISEASES

Your Ipsos contacts (France)

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GAME CHANGERS



Methodology







11,400 Europeans aged 16 and over.



February, 28th to March 24th 2020.

Online interviews via Ipsos Access Panel.

Quota method applied to gender, age, occupation, market size and region.



This report has been produced in accordance with international standard ISO 20252 "Market, opinion and social research". This report has been proofread by Etienne Mercier, PA Health Department Director





Countries surveyed

SAMPLES

Total



FRANCE



GERMANY



BELGIUM



SPAIN



GREAT BRITAIN



ITALY



SWEDEN



GREECE



POLAND



NETHERLANDS

11,400 respondents

2,400 respondents

1,000 respondents









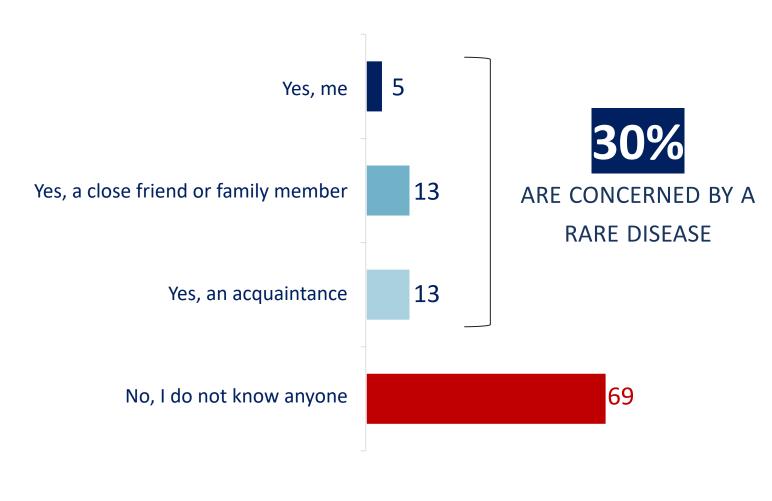
In Europe, rare diseases are not so rare:

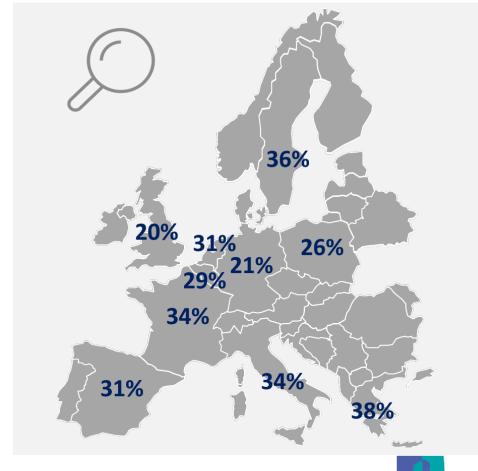
→ 1 person in 20 declares to be affected
and 3 out of 10 people are concerned by

... and 3 out of 10 people are concerned by this problem

Question: « Do you know someone with a rare disease?»







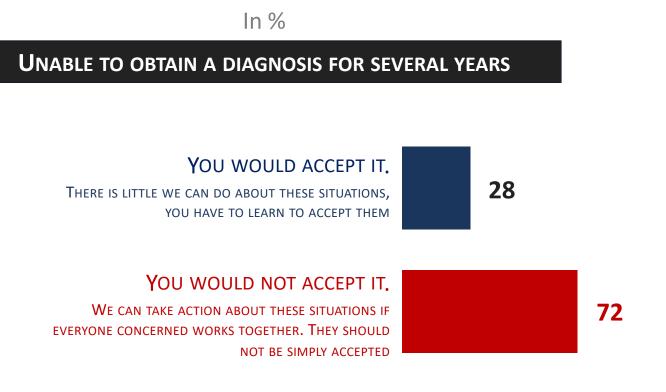


The impossibility of obtaining a diagnosis for several years for a patient suffering from a rare disease: an unacceptable situation for 7 out of 10 Europeans.



Question: « If someone close to you had a rare disease and was faced with the following situations, what would be your most likely

response? »





Real expectations when it comes to the implementation of measures deemed essential by a majority of Europeans: training, systematic screening at birth when there are effective treatments, etc.

Europeans (n=11 400)

Question: « 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? »

%
ESSENTIAL
OR IMPORTANT

Conduct **systematic screening at birth** for rare diseases for which there is an effective treatment



Develop a "culture of doubt" by encouraging health professionals to take more account of symptoms described by parents, in order to reduce diagnostic errors and misdiagnosis in children.



Train health professionals in delivering diagnoses



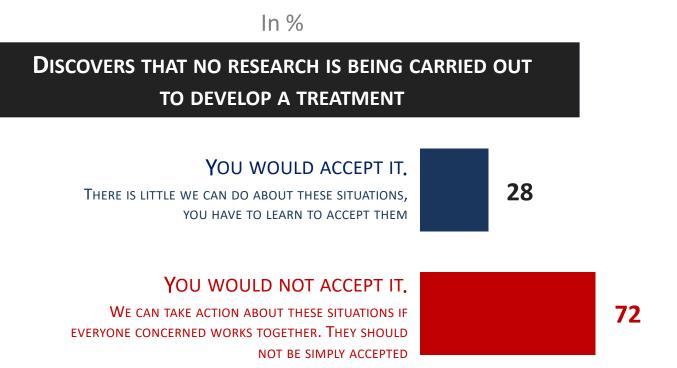
IT IS ESSENTIAL IT IS IMPORTANT, BUT NOT ESSENTIAL IT DOES NOT HELP MUCH

To learn that no research is being carried out against a loved one's rare disease is also an unacceptable discovery for nearly ¾ of the interviewees.



Question: « If someone close to you had a rare disease and was faced with the following situations, what would be your most likely response? »

(n=11 400)





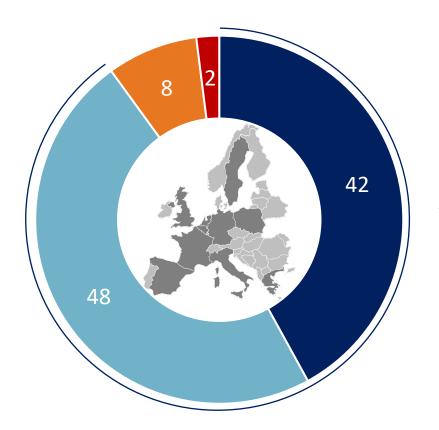
GAME CHANGERS



Europeans are convinced that funding research projects on innovative treatments for rare diseases will help advance research for other diseases.



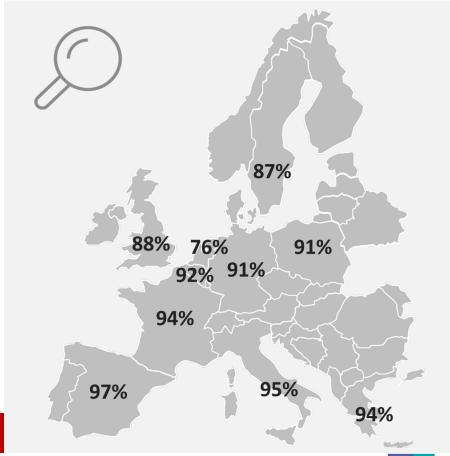
Question: « In your opinion, does funding research projects on innovative treatments (such as gene therapy or immunotherapy) within research institutions make it possible to advance research for diseases other than rare diseases?»



« YES »

Funding research projects on innovative treatments make it possible to advance research for diseases other than rare diseases

90 %



YES, DEFINITELY
YES, RATHER
NO, RATHER NOT

NO, CERTAINLY NOT



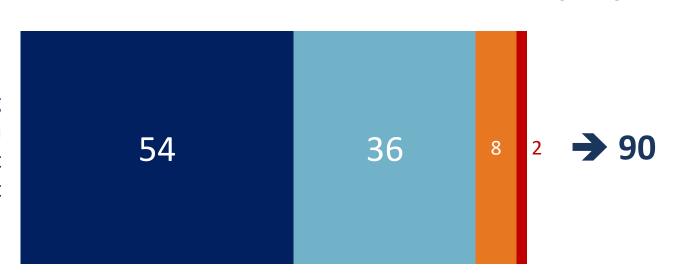
They are also extremely favorable to speeding up procedures for making innovative treatments available whenever there is a vital emergency, and for most of them this is even essential.



Question: « 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? »

> % **ESSENTIAL OR IMPORTANT**

Speed up the procedures for providing innovative treatments when there is a life-threatening emergency, even if it means greater risk for the patient



IT IS ESSENTIAL IT IS IMPORTANT BUT NOT ESSENTIAL IT DOES NOT HELP MUCH IT IS POINTLESS



Thanks!





