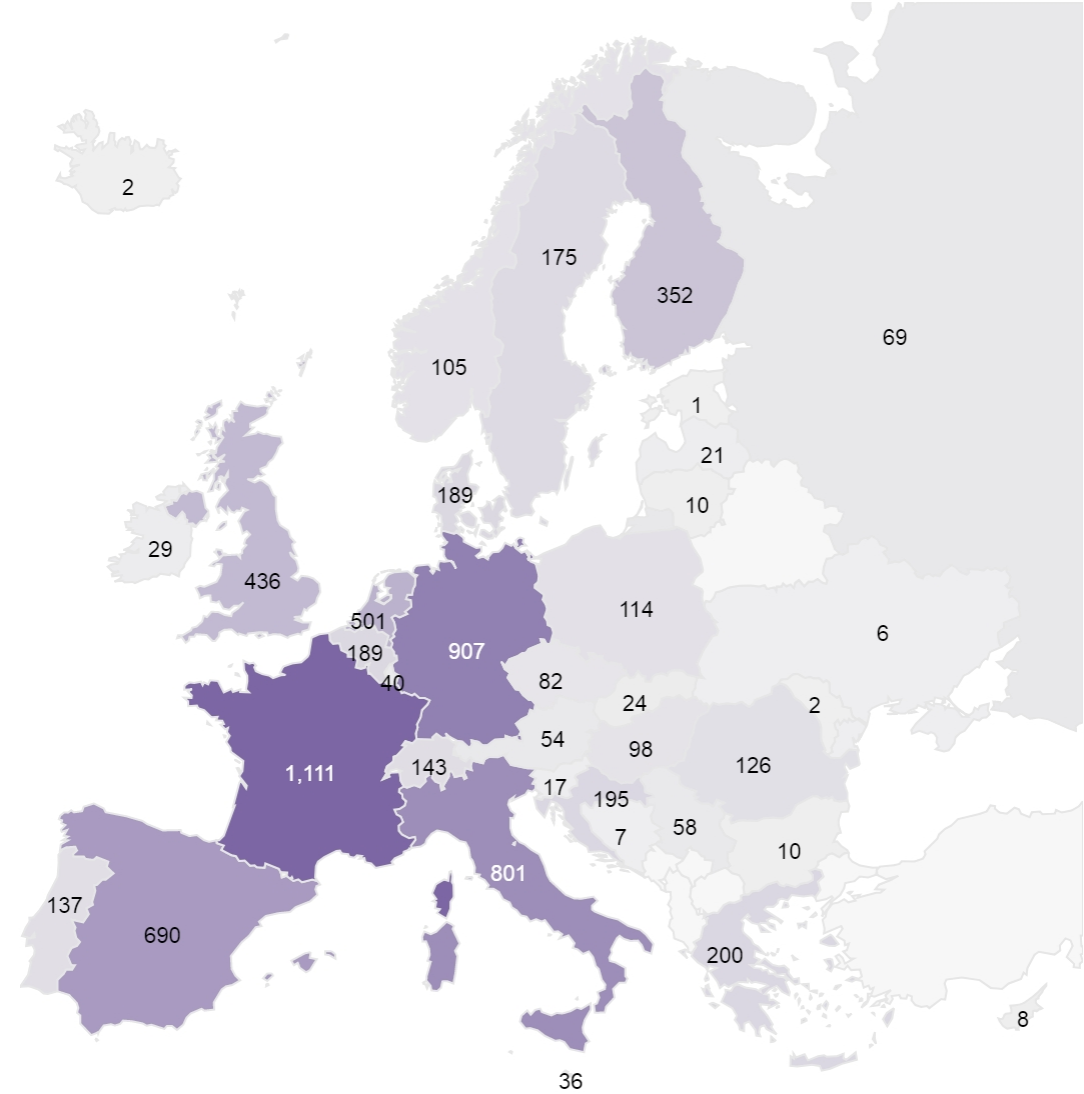




Rare disease patients' experience of COVID-19

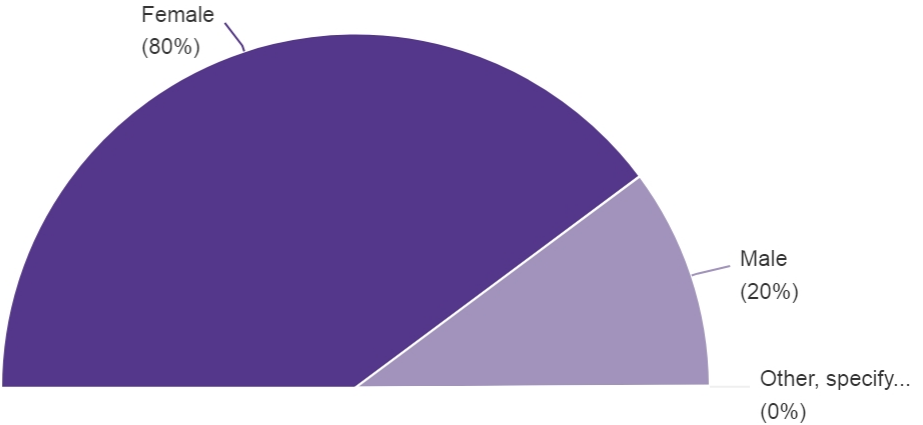
In which country do you live?



1. Status

	N	%
Patient	4,343	64%
Patient representative	138	2%
Parent of a child or adult with a rare di...	2,145	31%
Grandparent of a person living with a r...	24	0%
Spouse of a person living with a rare d...	136	2%
Uncle/aunt of a person living with a rar...	11	0%
Sibling of a child or adult with a rare di...	31	0%
TOTAL	6,828	100%

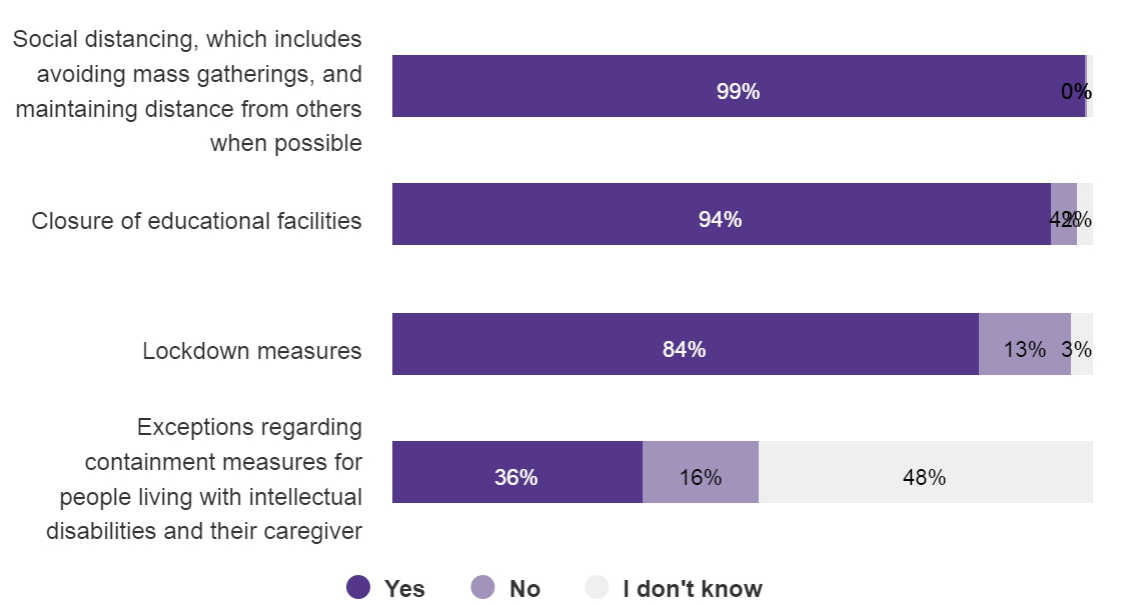
Are you :



Are the following measures currently in place in your country/region/state in order to fight against the COVID-19 pandemic?

	YES	NO	I DON'T KNOW	TOTAL
Social distancing, which includes avoiding mass gatherings, and maintaining distance from others when possible	6,879	34	32	6,945
Closure of educational facilities	6,540	263	142	6,945
Lockdown measures	5,841	911	193	6,945
Exceptions regarding containment measures for people living with intellectual disabilities and their caregiver	2,108	955	2,778	5,841

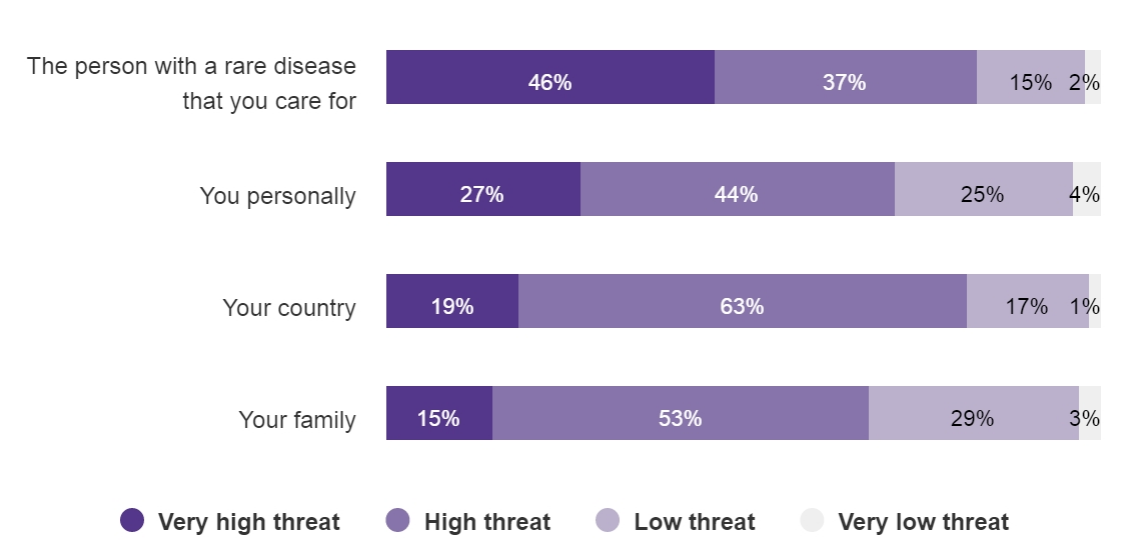
Are the following measures currently in place in your country/region/state in order to fight against the COVID-19 pandemic?



What level of threat do you think the coronavirus poses to each of the following?

	VERY HIGH THREAT	HIGH THREAT	LOW THREAT	VERY LOW THREAT	TOTAL
You personally	1,904	3,056	1,730	255	6,945
Your country	1,312	4,356	1,184	93	6,945
The person with a rare disease that you care for	1,083	860	360	44	2,347
Your family	1,054	3,659	2,029	203	6,945

What level of threat do you think the coronavirus poses to each of the following?



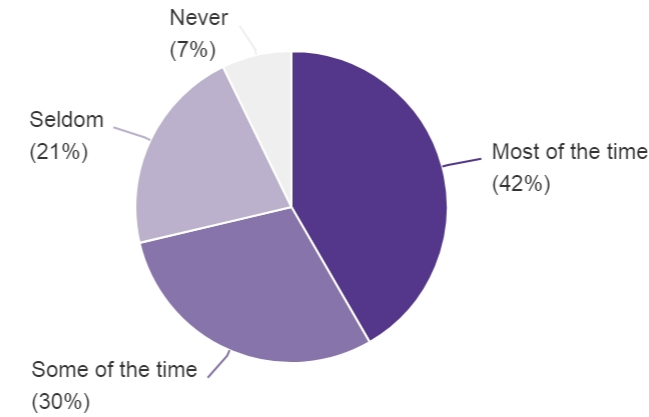
Sample information : **Europe among "Europe"**

Sample size : 6945 responses

With regard to COVID-19 and in relation to the rare disease you or your family member is affected with, do you feel that you have access to all the information you need?

	N
Most of the time	2,893
Some of the time	2,060
Seldom	1,491
Never	501
TOTAL	6,945

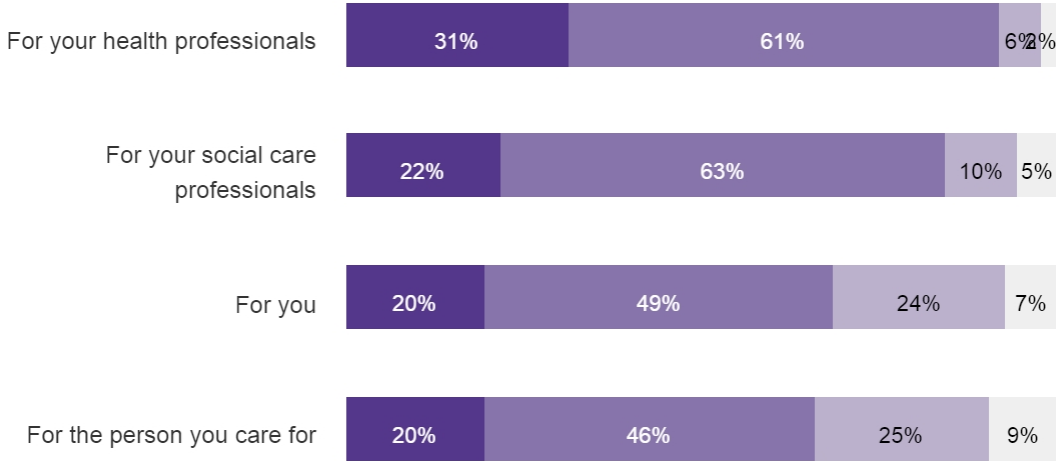
With regard to COVID-19 and in relation to the rare disease you or your family member is affected with, do you feel that you have access to all the information you need?



Are protective equipment such as face masks and plastic gloves...

	... AVAILABLE AND EASILY ACCESSIBLE	... DIFFICULT TO FIND, SOMETIMES NOT AVAILABLE	... IMPOSSIBLE TO FIND, NOT AVAILABLE	... NOT NEEDED	TOTAL
For your health professionals	1,938	3,736	372	118	6,164
For you	1,335	3,310	1,617	484	6,746
For your social care professionals	1,090	3,129	506	266	4,991
For the person you care for	445	1,043	556	208	2,252

Are protective equipment such as face masks and plastic gloves...



- ... available and easily accessible
- ... difficult to find, sometimes not available
- ... impossible to find, not available
- ... not needed

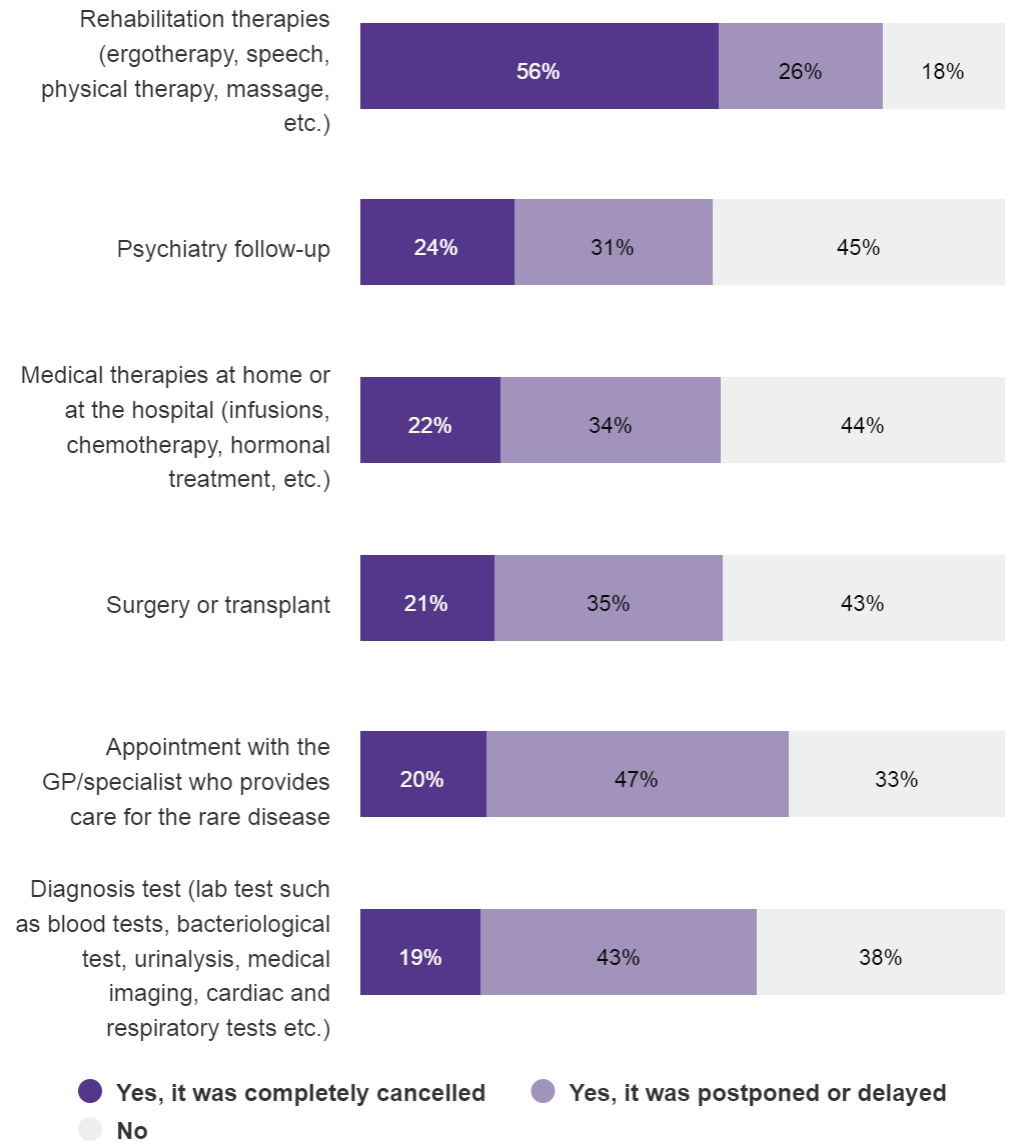
Sample information : **Europe among "Europe"**

Sample size : 6945 responses

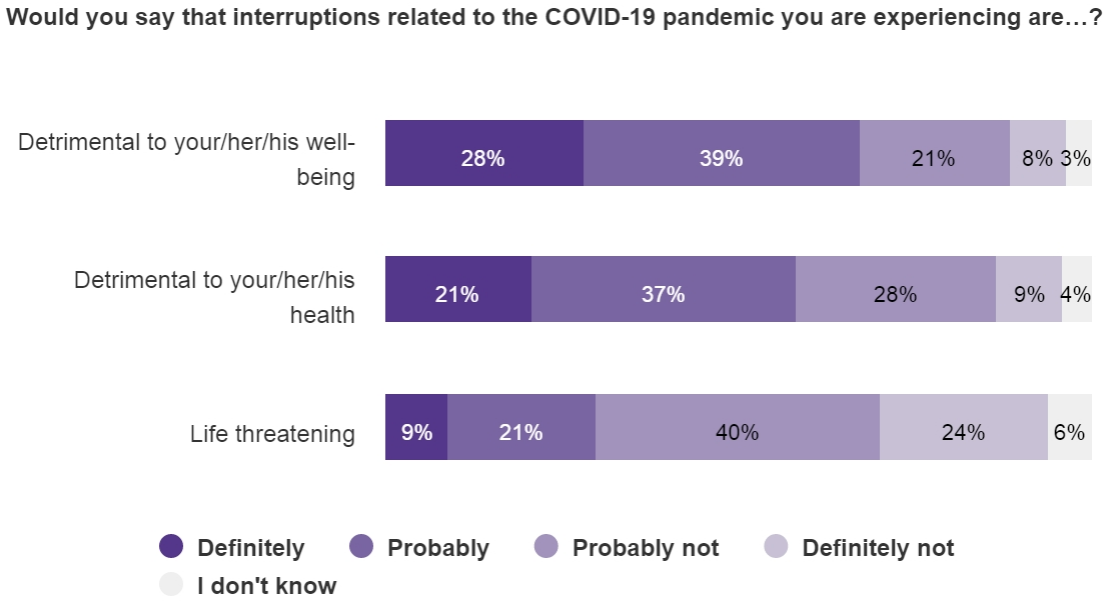
Since the beginning of the COVID-19 pandemic, have you or the person you care for experienced an interruption in the following aspects of the care provided by healthcare professionals for the rare disease ...

	YES, IT WAS COMPLETELY CANCELLED	YES, IT WAS POSTPONED OR DELAYED	NO	TOTAL
Rehabilitation therapies (ergotherapy, speech, physical therapy, massage, etc.)	2,933	1,341	969	5,243
Appointment with the GP/specialist who provides care for the rare disease	1,135	2,681	1,890	5,706
Diagnosis test (lab test such as blood tests, bacteriological test, urinalysis, medical imaging, cardiac and respiratory tests etc.)	959	2,179	1,937	5,075
Medical therapies at home or at the hospital (infusions, chemotherapy, hormonal treatment, etc.)	904	1,393	1,780	4,077
Psychiatry follow-up	573	724	1,066	2,363
Surgery or transplant	451	757	929	2,137

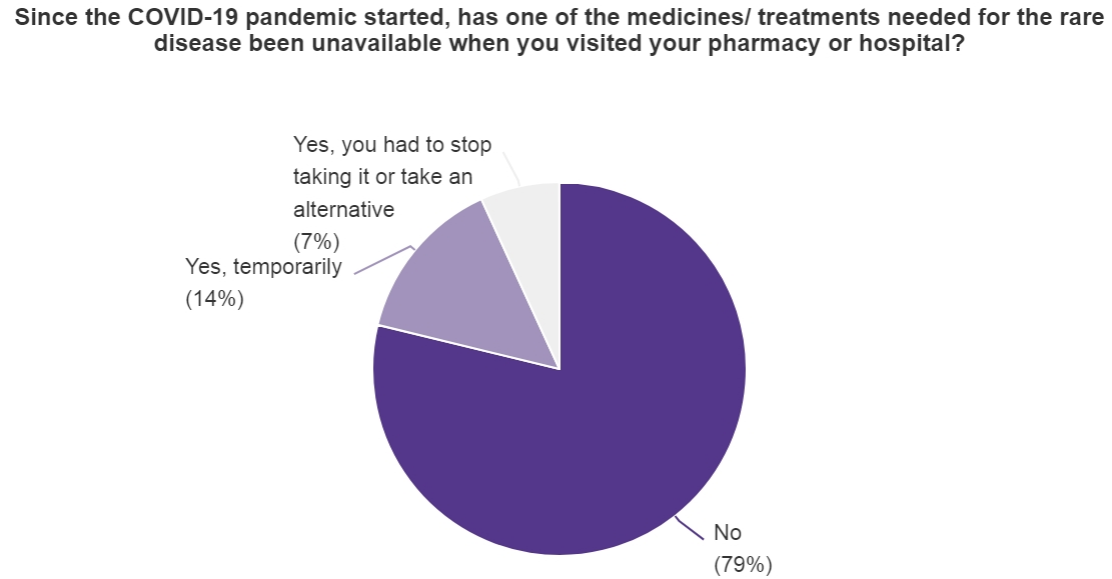
Since the beginning of the COVID-19 pandemic, have you or the person you care for experienced an interruption in the following aspects of the care provided by healthcare professionals for the rare disease ...



Would you say that interruptions related to the COVID-19 pandemic you are experiencing are...?						
	DEFI...	PRO...	PRO... NOT	DEFI... NOT	I DON'T KNOW	TOTAL
Detrimental to your/her/his well-being	1,612	2,222	1,223	453	187	5,697
Detrimental to your/her/his health	1,191	2,132	1,621	521	232	5,697
Life threatening	514	1,203	2,280	1,366	335	5,698



Since the COVID-19 pandemic started, has one of the medicines/ treatments needed for the rare disease been unavailable when you visited your pharmacy or hospital?	
	N
No	5,472
Yes, temporarily	997
Yes, you had to stop taking it or take an alternative	476
TOTAL	6,945

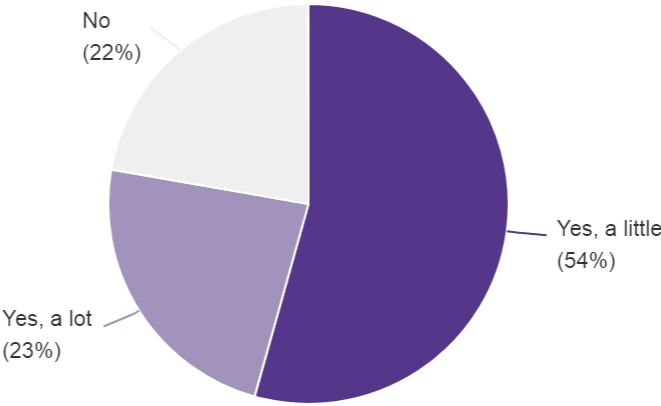


Sample information : **Europe among "Europe"**

Sample size : 6945 responses

And are you afraid that this might happen in the future if the pandemic continues?	
	N
Yes, a little	2,977
Yes, a lot	1,282
No	1,218
TOTAL	5,477

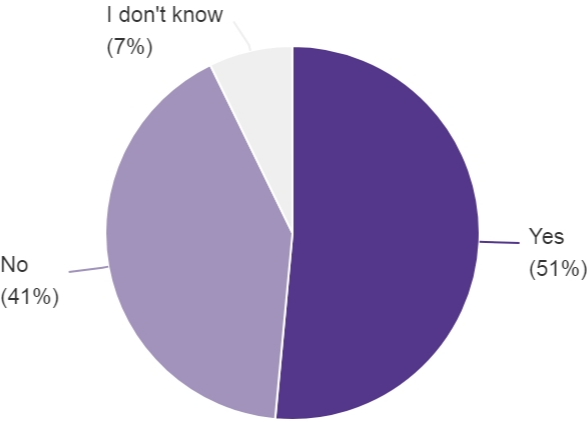
And are you afraid that this might happen in the future if the pandemic continues?



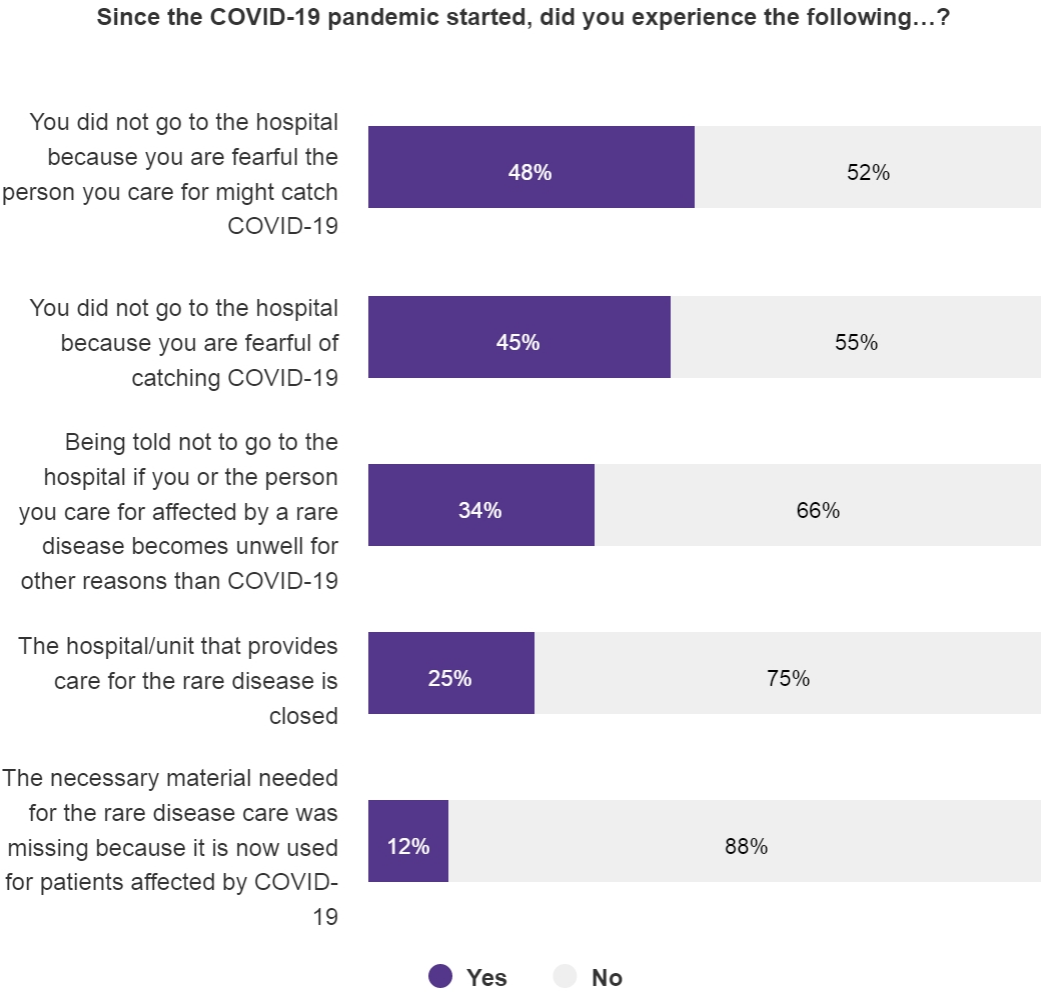
Do you or the person you care for receive/s at least part of the care for the rare disease through a hospital?

	N
Yes	3,575
No	2,868
I don't know	502
TOTAL	6,945

Do you or the person you care for receive/s at least part of the care for the rare disease through a hospital?



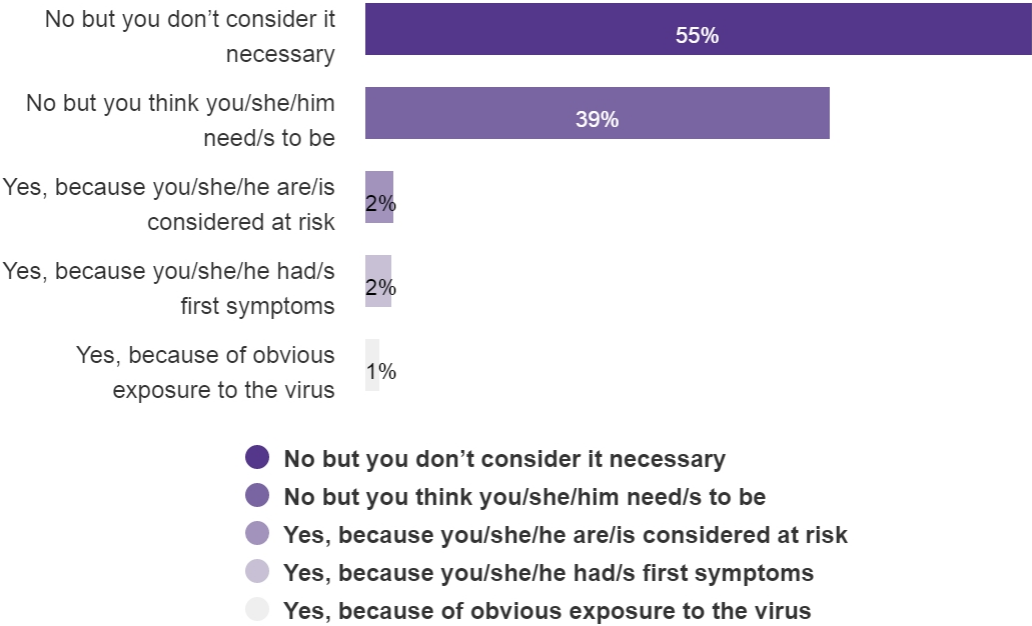
Since the COVID-19 pandemic started, did you experience the following...?	YES	NO	TOTAL
Being told not to go to the hospital if you or the person you care for affected by a rare disease becomes unwell for other reasons than COVID-19	1,206	2,372	3,578
You did not go to the hospital because you are fearful of catching COVID-19	1,036	1,269	2,305
The hospital/unit that provides care for the rare disease is closed	896	2,690	3,586
You did not go to the hospital because you are fearful the person you care for might catch COVID-19	597	636	1,233
The necessary material needed for the rare disease care was missing because it is now used for patients affected by COVID-19	437	3,146	3,583



Have you been tested for COVID-19?

	N
No but you don't consider it necessary	3,844
No but you think you/she/him need/s to be	2,687
Yes, because you/she/he are/is considered at risk	169
Yes, because you/she/he had/s first symptoms	158
Yes, because of obvious exposure to the virus	87
TOTAL	6,945

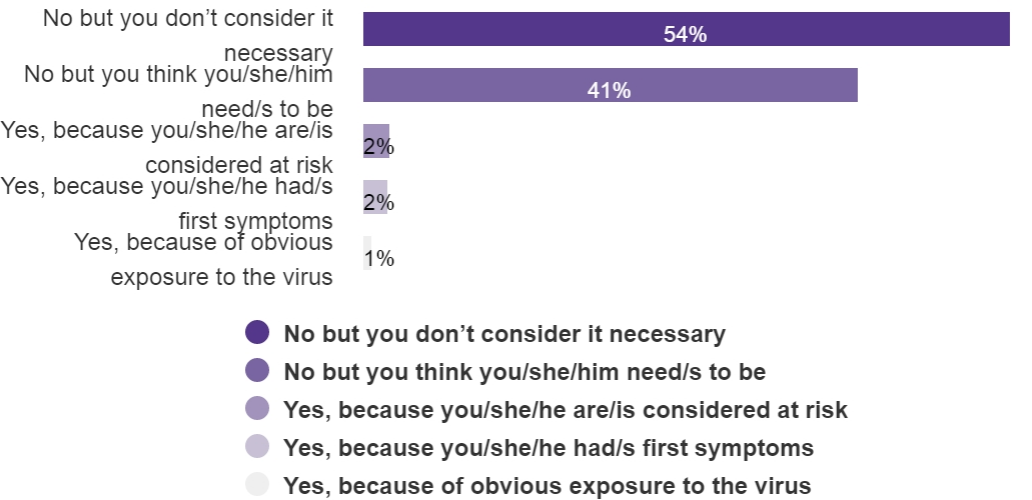
Have you been tested for COVID-19?



Has the person you care for been tested for COVID-19?

	N
No but you don't consider it necessary	1,259
No but you think you/she/him need/s to be	964
Yes, because you/she/he are/is considered at risk	54
Yes, because you/she/he had/s first symptoms	51
Yes, because of obvious exposure to the virus	20
TOTAL	3,348

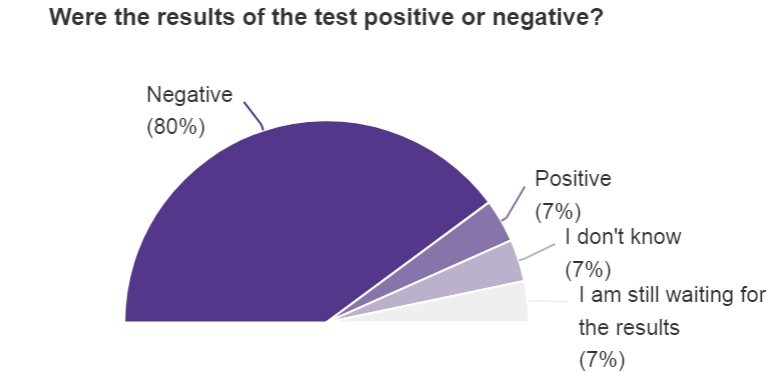
Has the person you care for been tested for COVID-19?



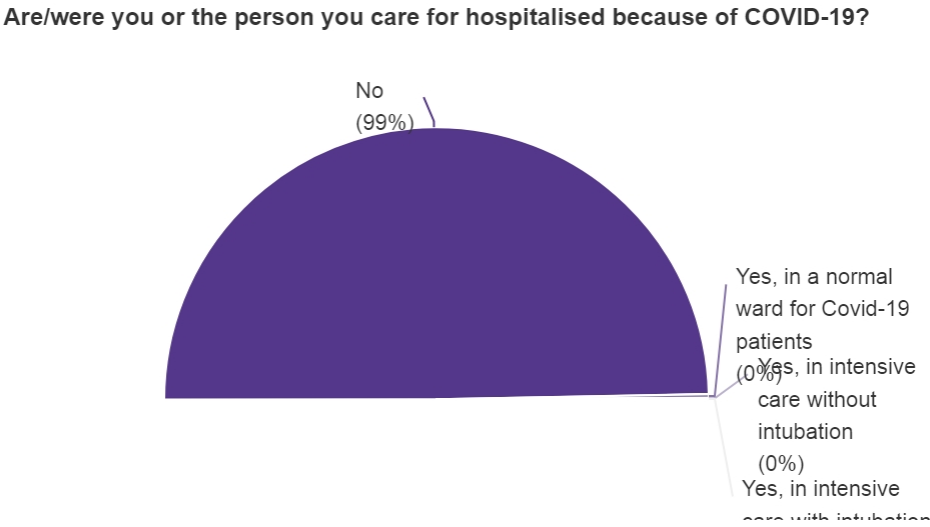
Sample information : **Europe among "Europe"**

Sample size : 6945 responses

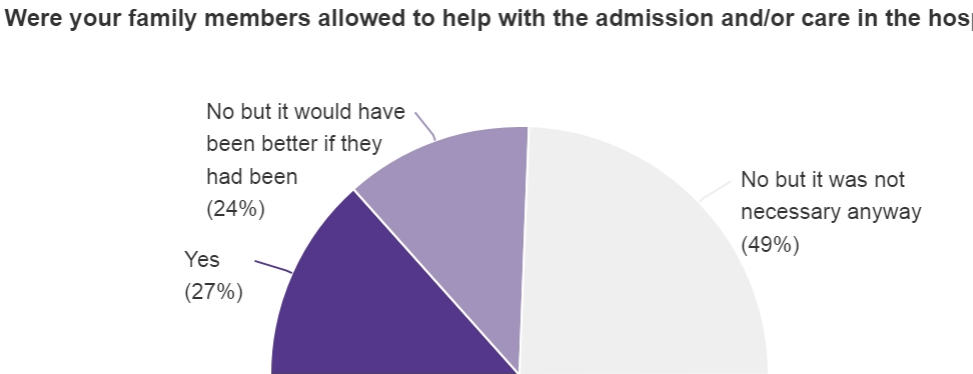
Were the results of the test positive or negative?	
	N
Negative	402
Positive	35
I don't know	34
I am still waiting for the results	33
TOTAL	504



Are/were you or the person you care for hospitalised because of COVID-19?	
	N
No	6,904
Yes, in a normal ward for Covid-19 patients	30
Yes, in intensive care without intubation	6
Yes, in intensive care with intubation	5
TOTAL	6,945

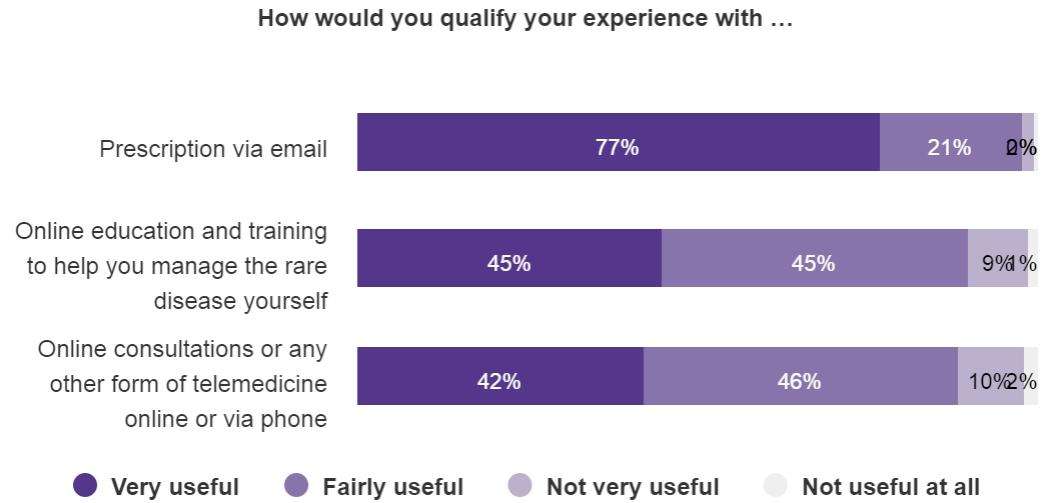
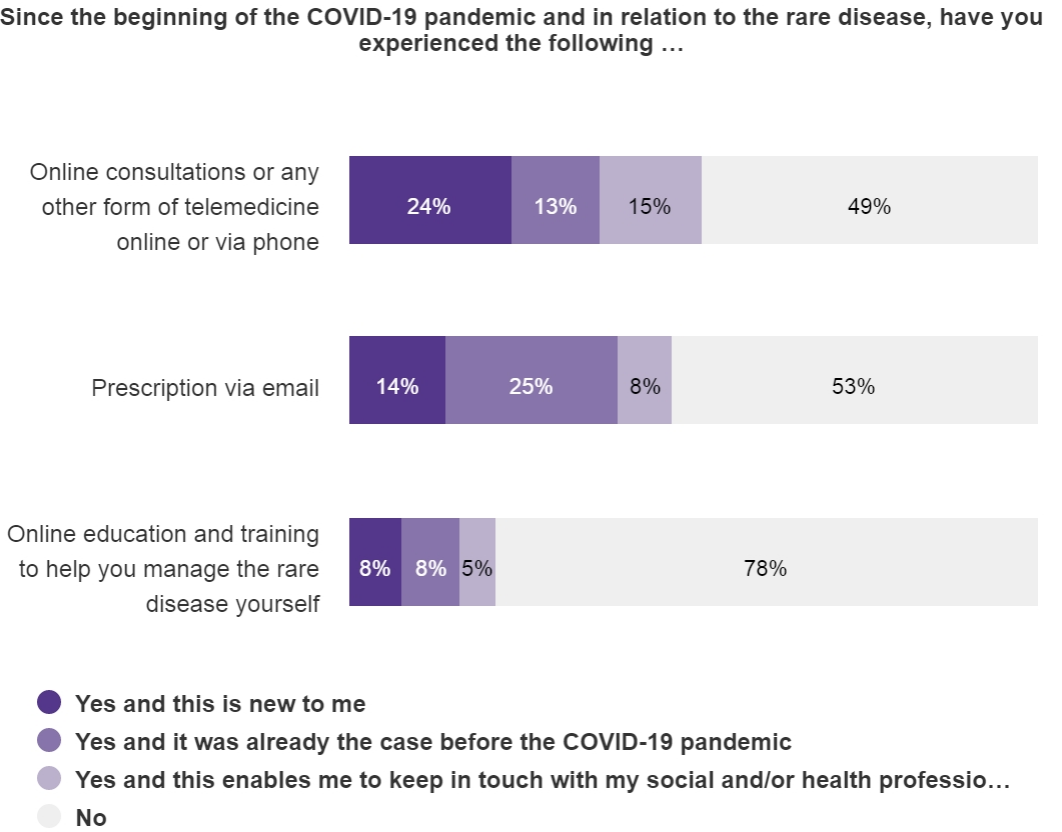


Were your family members allowed to help with the admission and/or care in the hospital?	
	N
Yes	11
No but it would have been better if they had been	10
No but it was not necessary anyway	20
TOTAL	41



Since the beginning of the COVID-19 pandemic and in relation to the rare disease, have you experienced the following ...					
	YES AND THIS IS NEW TO ME	YES AND IT WAS ALREADY THE CASE BEFORE THE COVID-19 PANDE...	YES AND THIS ENABLES ME TO KEEP IN TOUCH WITH MY SOCIAL AND/OR HEALTH PROFE...	NO	TOTAL
Online consultations or any other form of telemedicine online or via phone	1,646	889	1,031	3,379	6,945
Prescription via email	993	1,740	542	3,670	6,945
Online education and training to help you manage the rare disease yourself	544	585	368	5,448	6,945

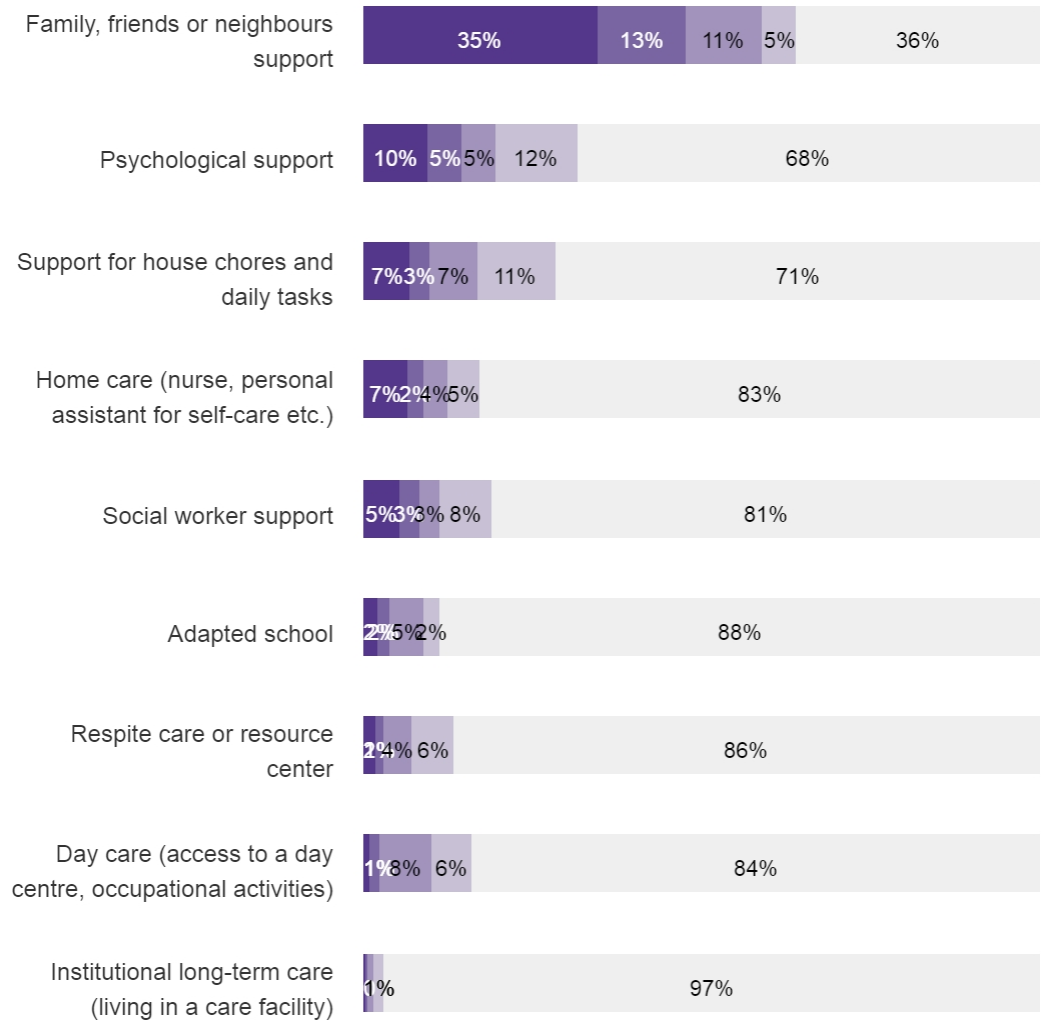
How would you qualify your experience with ...					
	VERY USEFUL	FAIRLY USEFUL	NOT VERY USEFUL	NOT USEFUL AT ALL	TOTAL
Prescription via email	2,527	684	53	14	3,278
Online consultations or any other form of telemedicine online or via phone	1,514	1,649	343	63	3,569
Online education and training to help you manage the rare disease yourself	676	675	131	18	1,500



Do you need the following support and do you still have access to them since the COVID-19 pandemic started?

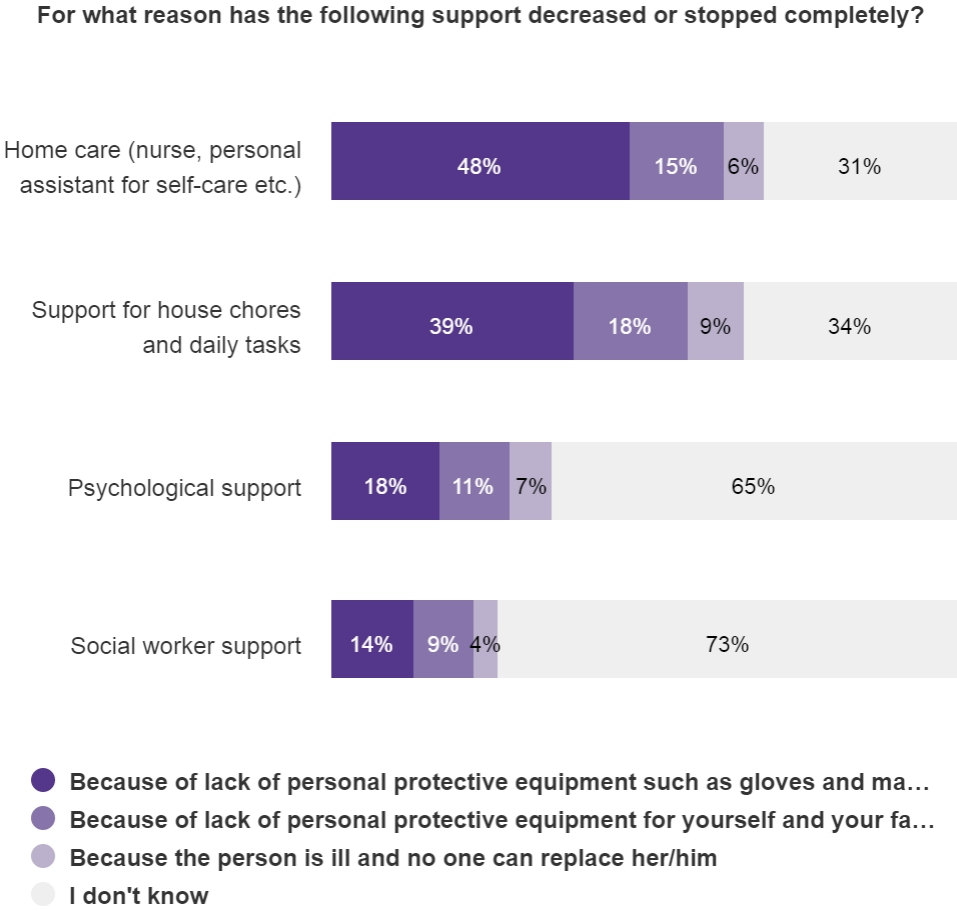
	YES I NEED THIS SUPP... AND I CAN STILL ACCE... TO IT	YES I NEED THIS SUPP... BUT I RECEI... LESS SUPP... SINCE THE PAND... STAR...	YES I NEED THIS SUPP... BUT IT STOP... COMP... SINCE THE PAND... STAR...	I NEED THIS SUPP... BUT HAVE NOT RECEI... IT BEFO... OR DURING THE PAND...	NO I DON'T NEED THIS SUPP...	TOTAL
Family, friends or neighbours support	2,072	768	654	313	2,112	5,919
Psychological support	618	304	324	740	4,258	6,244
Support for house chores and daily tasks	442	186	437	707	4,389	6,161
Home care (nurse, personal assistant for self-care etc.)	408	151	219	286	5,020	6,084
Social worker support	375	207	203	534	5,506	6,825
Adapted school	142	104	295	147	5,241	5,929
Respite care or resource center	120	73	240	381	5,139	5,953
Day care (access to a day centre, occupational activities)	76	83	462	369	5,043	6,033
Institutional long-term care (living in a care facility)	44	11	44	89	5,793	5,981

Do you need the following support and do you still have access to them since the COVID-19 pandemic started?



- Yes I need this support and I can still access to it
- Yes I need this support but I receive less support since the pandemic started
- Yes I need this support but it stopped completely since the pandemic started
- I need this support but have not received it before or during the pandemic
- No I don't need this support

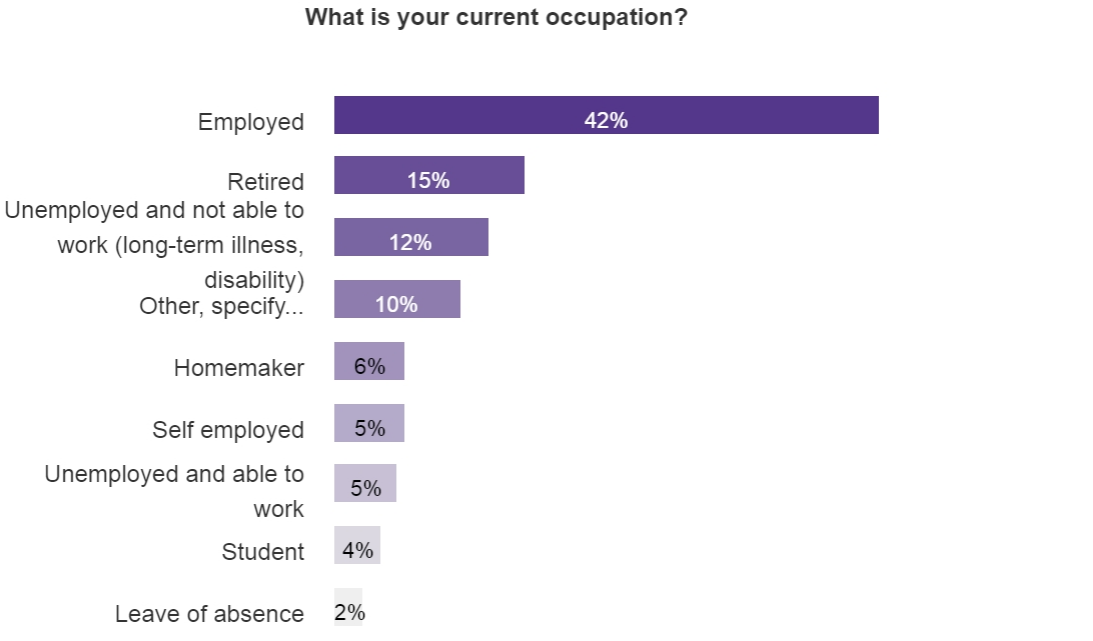
For what reason has the following support decreased or stopped completely?					
	BECAUSE OF LACK OF PERSONAL PROTEC... EQUIPME... SUCH AS GLOVES AND MASKS AVAILABLE FOR THE PERSON PROVIDING THE SUPPORT	BECAUSE OF LACK OF PERSONAL PROTEC... EQUIPME... FOR YOURSELF AND YOUR FAMILY	BECAUSE THE PERSON IS ILL AND NO ONE CAN REPLACE HER/HIM	I DON'T KNOW	TOTAL
Support for house chores and daily tasks	120	56	27	104	307
Home care (nurse, personal assistant for self-care etc.)	101	32	13	65	211
Psychological support	57	36	21	208	322
Social worker support	39	27	11	211	288



Sample information : **Europe among "Europe"**

Sample size : 6945 responses

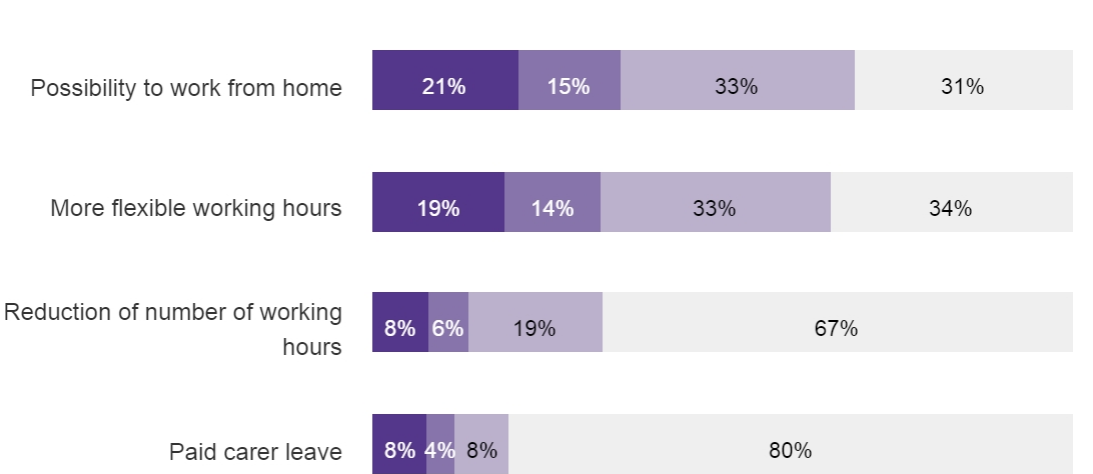
What is your current occupation?	
	N
Employed	2,889
Retired	1,018
Unemployed and not able to work (lon...	823
Other, specify...	677
Homemaker	381
Self employed	378
Unemployed and able to work	343
Student	251
Leave of absence	159
TOTAL	6,919



In order to adapt to the COVID-19 pandemic, does your employer allow the following...

	YES AND THIS WAS ALR... IMPO... BY PUB... AUT...	YES AND THIS WAS ADVI... BY PUB... AUT...	YES AND THIS IS AN INITI... FROM MY EMP...	NO	TOTAL
Possibility to work from home	647	448	1,016	943	3,054
More flexible working hours	583	426	1,001	1,055	3,065
Reduction of number of working hours	256	170	591	2,041	3,058
Paid carer leave	242	126	230	2,455	3,053

In order to adapt to the COVID-19 pandemic, does your employer allow the following...



- Yes and this was already imposed by public authorities
- Yes and this was advised by public authorities
- Yes and this is an initiative from my employers
- No

Sample information : **Europe among "Europe"**

Sample size : 6945 responses

Please choose the sentence that best describes your situation since the COVID-19 pandemic started.

	N
I work from home	1,638
I had to stop working	576
I continue to work normally	557
I had to significantly reduce my number of working hours	272
TOTAL	3,043

Since the COVID-19 pandemic started, how often...	NEVER	SELD...	SOM...	OFTEN	VERY OFTEN	TOTAL
Have you felt you could not overcome your problems?	1,714	1,717	2,001	713	547	6,692
Have you felt tensions between family members?	1,477	1,750	2,200	753	434	6,614
Have you felt isolated?	1,229	1,246	1,946	1,212	1,155	6,788
Have you felt unhappy and/or depressed?	1,088	1,621	2,371	935	783	6,798
Have you felt a strengthening of the family unit?	343	722	1,834	2,085	1,541	6,525

Please choose the sentence that best describes your situation since the COVID-19 pandemic started.



● I work from home ● I had to stop working ● I continue to work normally
● I had to significantly reduce my number of working hours

