

# **CORD Rare Disease Patient Survey**

7 March 2015

**491 Eng + 61 Fr = 552**

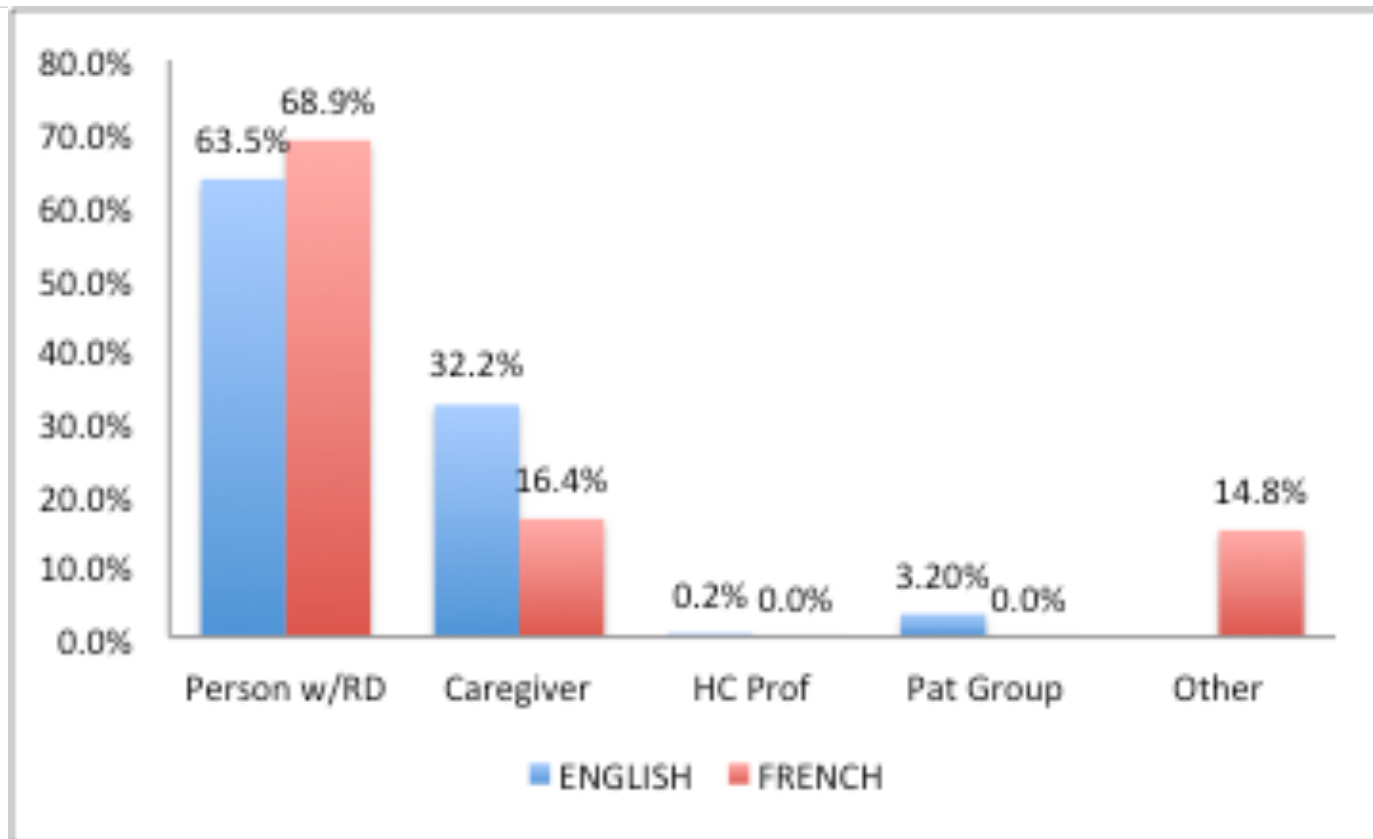
Total Responses

March 3, 2015

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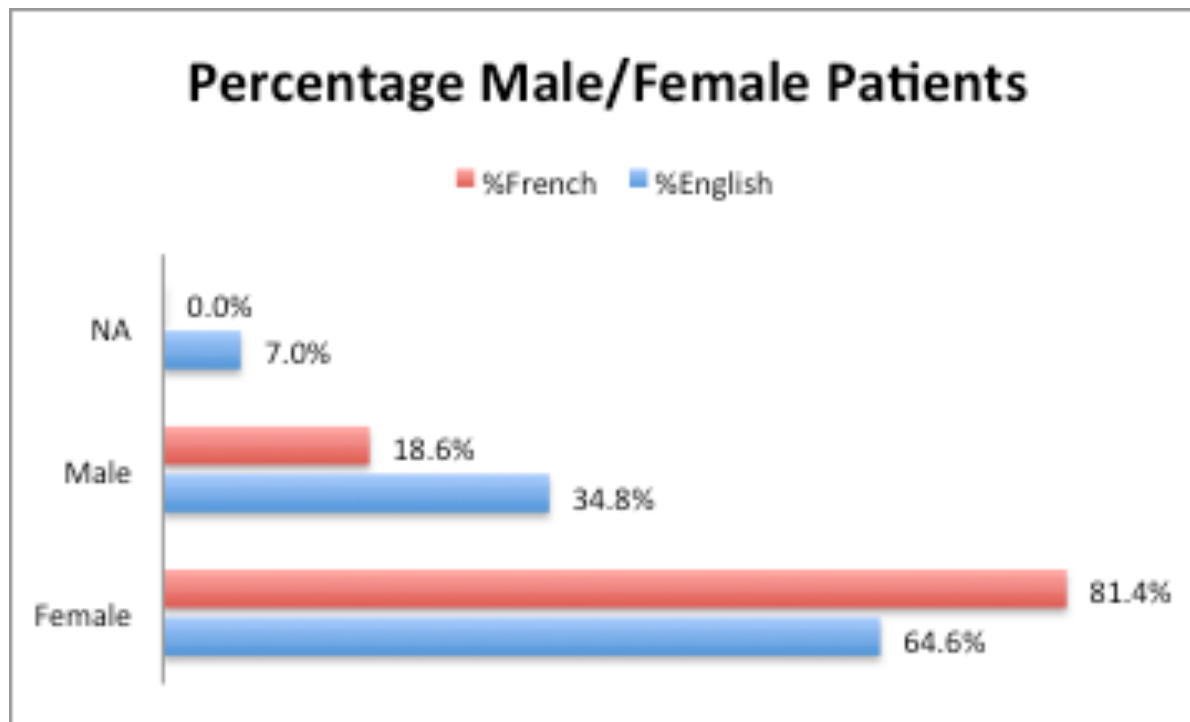
## Q1: Who is answering this questionnaire?

534 Responses



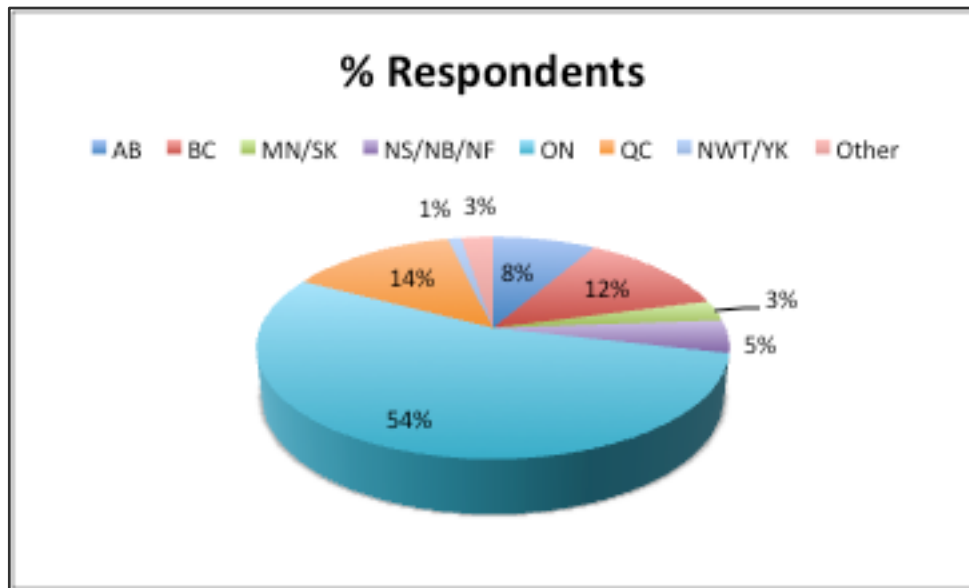
### Q3: What is gender of person with rare disease?

522 Responses



# PROVINCIAL REPRESENTATION OF Respondents

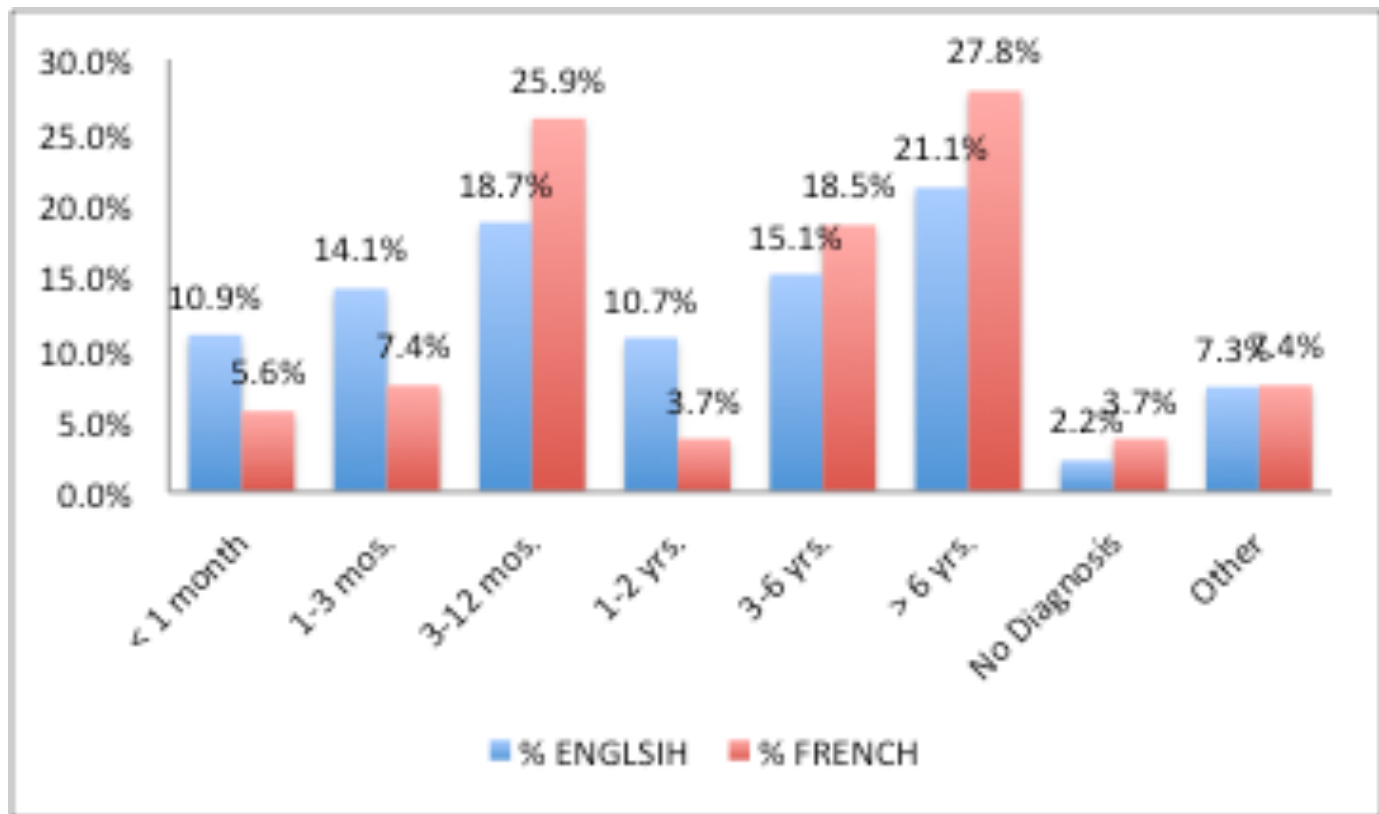
561 respondents



Alberta	8.4%
British Columbia	12.5%
Manitoba	1.5%
New Brunswick	0.4%
Newfnd//Lab	2.2%
NW Territories	0.7%
Nova Scotia	2.2%
Nunavik	0.0%
Ontario	54.2%
PEI	0.0%
Quebec	13.6%
Saskatchewan	1.5%
Yukon	0.4%
Other	2.6%

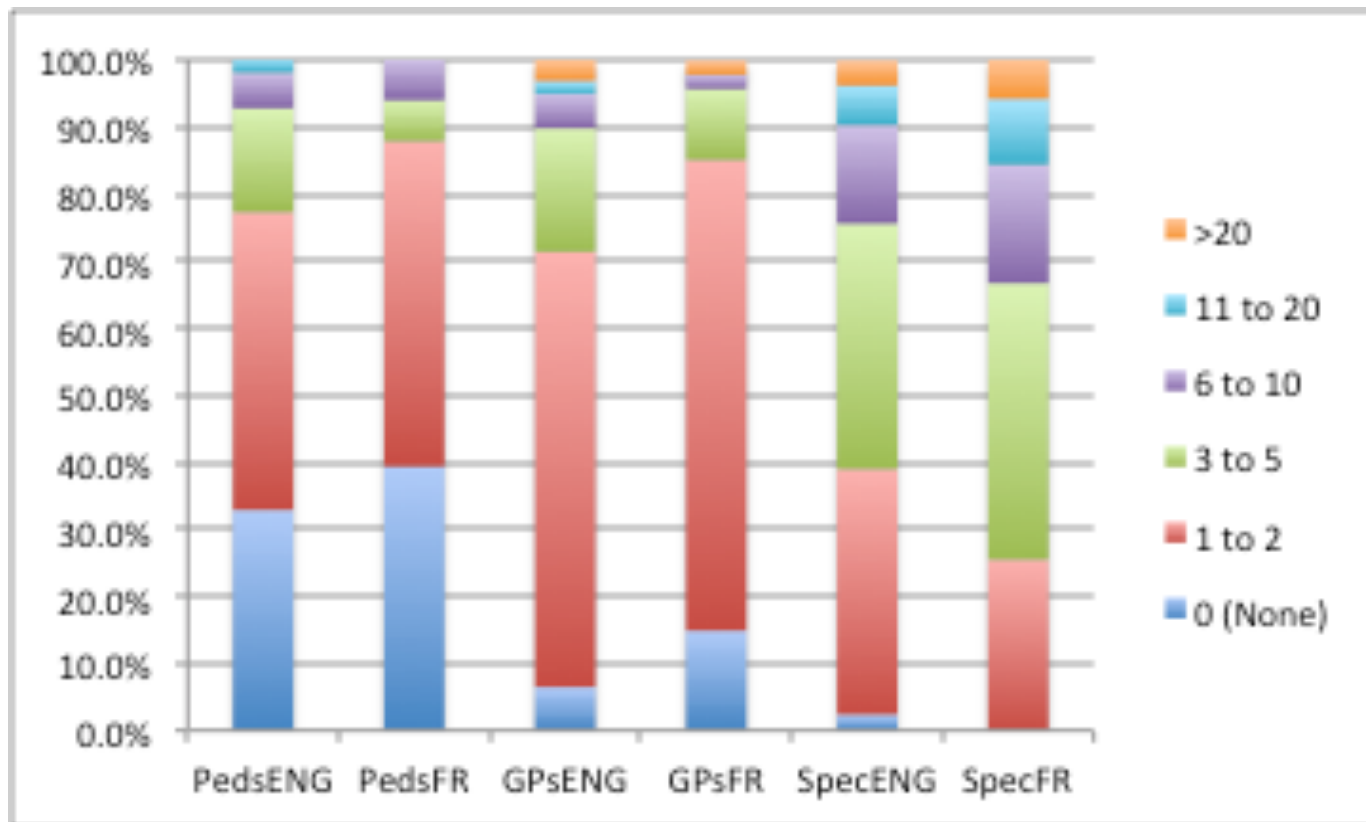
## Q6: How long after the first symptoms or suspicion of disease did it take to get an accurate diagnosis?

462 Responses



## Q7: How many doctors did you see between the time of first manifestations or symptoms and the final diagnosis?

465 Responses

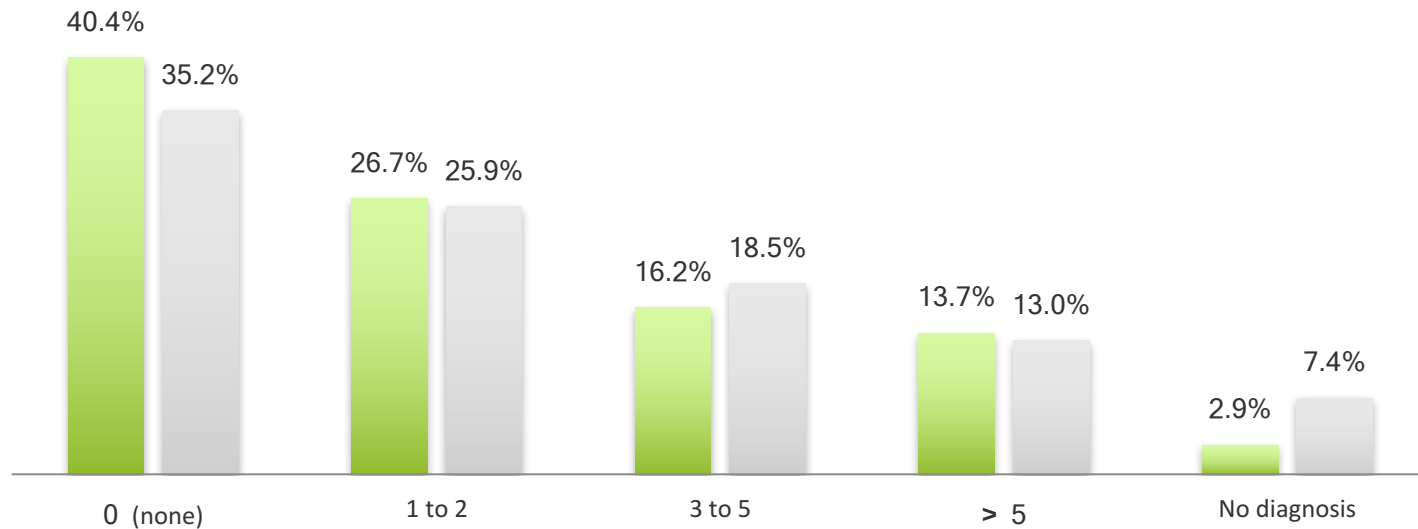


# Q9: How many "wrong" or inaccurate diagnoses did you receive before the final "right" diagnosis?

462 Responses

## # Wrong Diagnoses

%English %French





**Q.10 To what degree do you agree with the following statements about the information you have received about the rare disease.**

	Agree English	Agree French	Disagree English	Disagree French
Right amount information at time of diagnosis	40.1%	25.5%	43.7%	48.9%
Understand information from HCP	50.8%	68.1%	21.1%	17.0%
Found rare disease information on Internet	71.6%	89.5%	10.7%	5.4%
Given contact person or number	19.1%	10.6%	66.3%	80.8%
Given patient organization or support group	20.5%	4.3%	68.1%	91.5%
Know where to get info to deal with disease	53.7%	38.3%	29.5%	38.0%
Have access to needed info at this time	57.3%	31.9%	36.4%	42.6%

**Q11: To what degree do you agree with the following statements about information about rare diseases overall?**

	Agree English	Agree French	Disagree English	Disagree French
GPS are aware & informed about rare diseases	5.2%	4.2%	81.0%	55.3%
Paediatricians aware & informed about RDs	3.8%	17.0%	49.2%	31.9%
Specialists have knowledge & expertise in RDs	26.0%	25.5%	53.0%	42.6%
Researchers interested & engaged in RDs	28.8%	21.9%	36.4%	44.7%
Educational services aware/informed re: RDs	20.5%	4.3%	68.1%	91.5%
Employment services aware/informed re: RDs	1.3%	4.6%	80.6%	66.0%
Disability services aware/informed re: RDs	7.9%	17.4%	66.4%	60.9%

**Q12: To what degree do you agree with the following statements about the access to treatment and support you have received for the rare disease.**

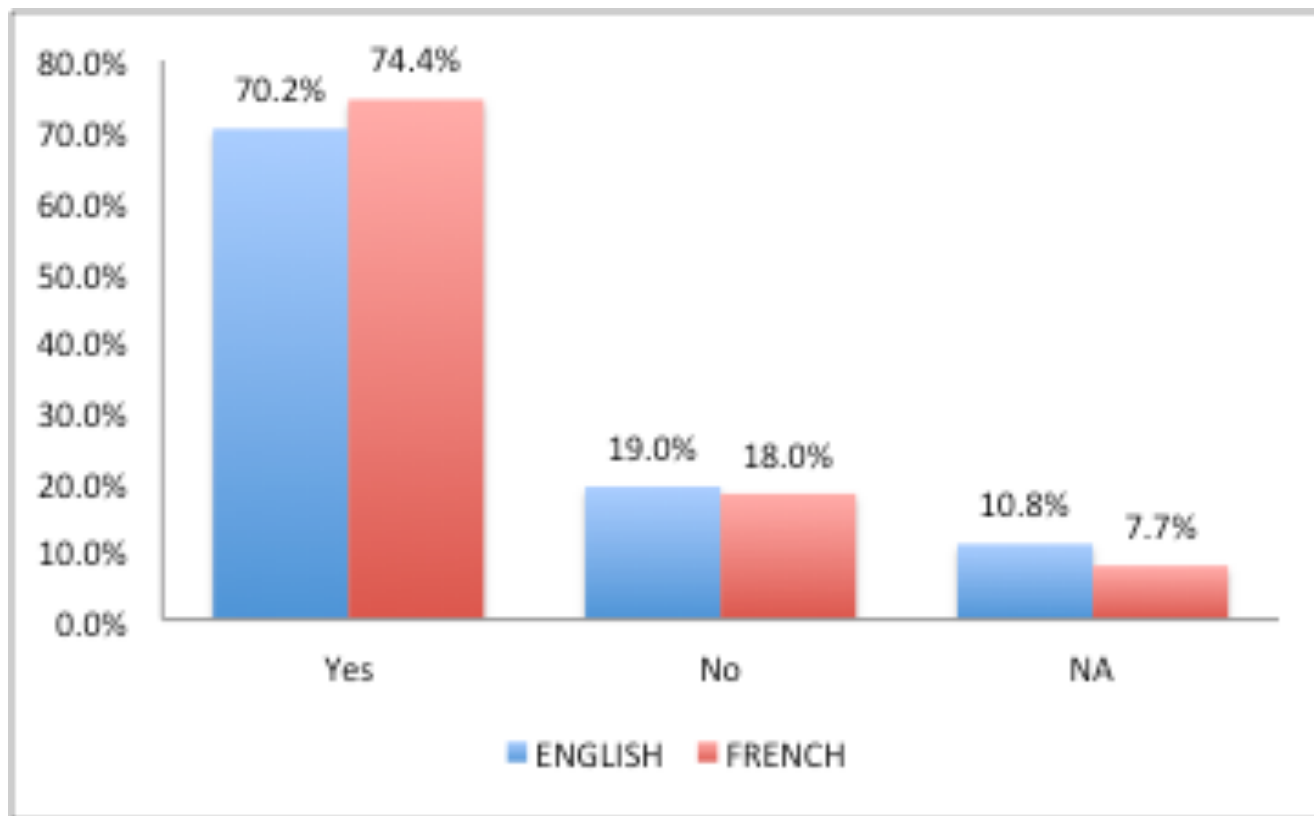
	Agree English	Agree French	Disagree English	Disagree French
Appropriate assessment & testing following diagnosis	59.9%	53.7%	28.1%	31.7%
Access specialists & clinics for RD	37.0%	20.0%	50.4%	65.5%
Access coordinator for clinics & specialists	24.8%	40.0%	53.0%	59.7%
Access to appropriate drug treatments	40.1%	47.5%	35.7%	40.0%
Access to non-drug treatments	31.4%	40.0%	33.7%	30.0%
Received counselling with diagnosis	14.6%	10.0%	73.4%	80.0%
Access to financial resources to deal with RD	21.0%	15.4%	58.8%	74.4%
Access to palliative care, if needed	24.0%	15.4%	35.2%	33.4%

## Q13: To what degree do you agree with the following statements about medicines for your rare disease?

	Agree English	Agree French	Disagree English	Disagree French
Aware of approved drugs for my rare disease	38.7%	42.1%	39.7%	34.2%
Can access prescription drugs for my rare disease	35.8%	54.1%	46.2%	35.1%
Aware of off-label drugs for my rare disease	31.5%	42.1%	33.8%	15.8%
Can access off-label drugs for my rare disease	10.5%	29.4%	52.6%	40.0%
Difficult or stressful to access drugs for my rare disease	44.0%	28.9%	28.3%	39.4%
Have private drug plan for prescription drugs	37.7%	47.4%	41.0%	36.9%
Drug plan does not cover some of my prescription drugs	29.0%	23.7%	36.9%	50.0%
Unable to access drugs because costs or co-pay too high	28.5%	16.2%	39.3%	56.7%

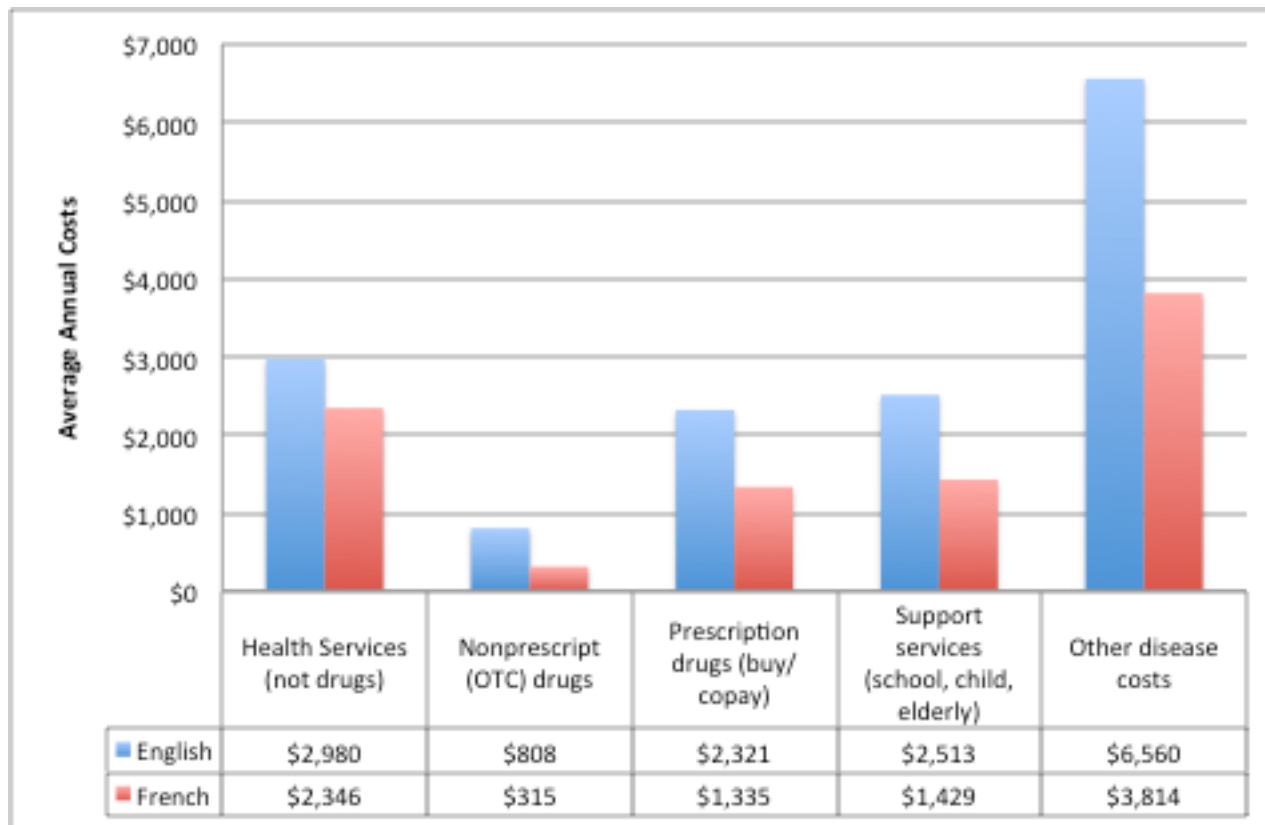
## Q14: Do you and your family incur personal costs related to care for your rare disease?

391 Responses



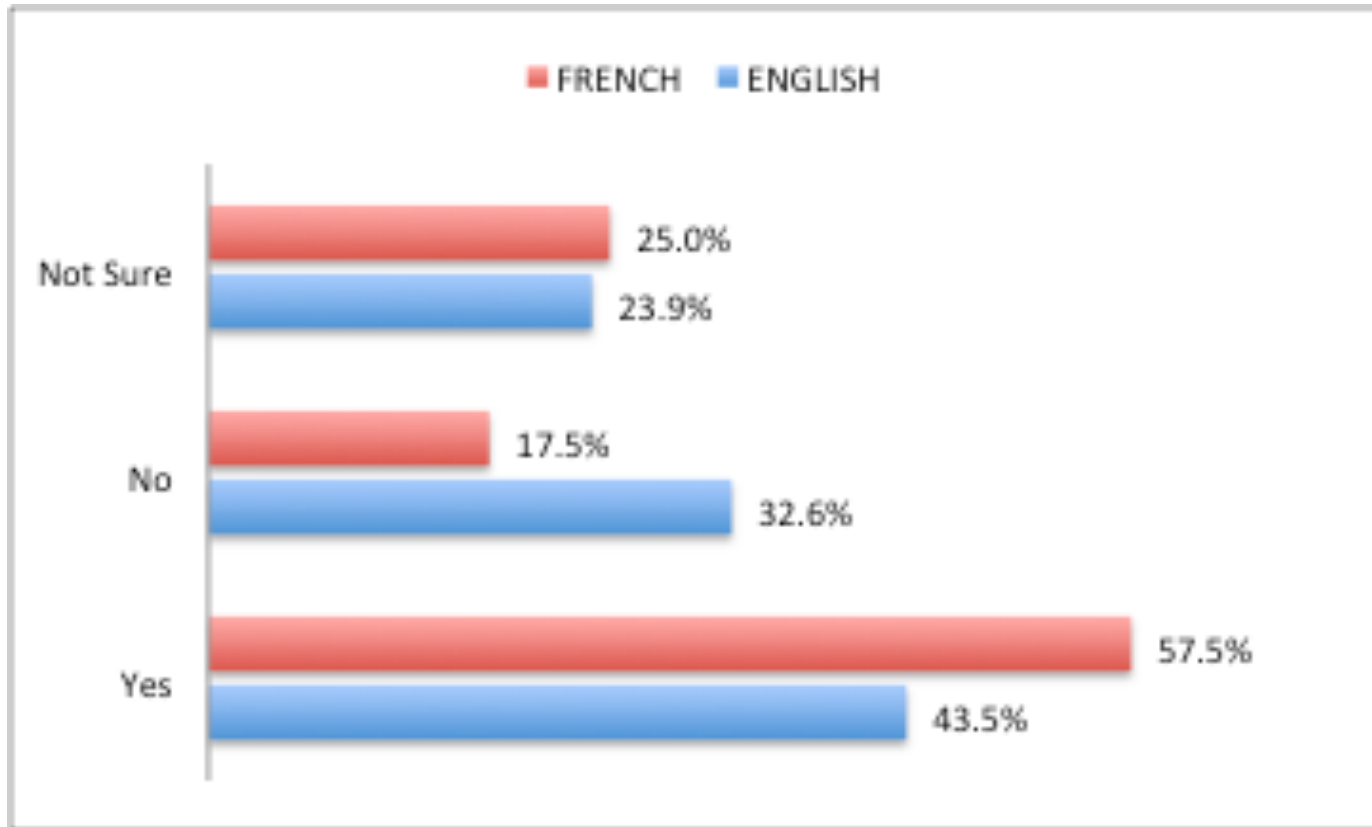
# Q15: What is the amount your family spends annually related to care for your rare disease?

392 Responses



## Q16: Is your rare disease a genetic (or inherited) condition?

447 Responses



**Q17: To what degree do you agree with the following statements about genetic services for rare diseases.**

	Agree English	Agree French	Disagree English	Disagree French
Received pre-natal counselling about genetic RD	8.0%	13.6%	47.3%	68.2%
Received pre-natal screening for genetic RD	6.4%	4.8%	43.2%	71.4%
Received newborn screening for genetic RD	5.9%	0%	46.3%	76.2%
Received diagnosis, info & support for my RD	19.1%	10.6%	66.3%	52.7%
Family got screening, testing, counselling for RD	17.9%	27.3%	49.3%	68.2%
Family got post-natal support for RD	13.2%	31.9%	40.0%	78.2%



# CORD Patient Survey—Summary Findings

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## • Getting to Diagnosis

- Median time to diagnosis: 3 to 6 years
  - 21% over 6 years
- Median number of specialists consulted: 3 to 5
  - 10% over 11 specialists; 5% over 20 specialists
- Median number of “wrong” diagnosis: 1 to 2
  - 40% more than 3 misdiagnoses; 15% more than 5 misdiagnoses

## • Information at Diagnosis

- Only 40% got right amount of information at diagnosis
- Only 50% understood information from Healthcare professional
- Only 50% know where to get information needed
- Only 5% feel GPs and/or pediatricians have knowledge of rare diseases
- Only 25% feel specialists are knowledgeable about rare diseases

# CORD Patient Survey—Summary Findings

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## • Access to Treatment and Support

- Less than 40% have access to rare disease specialist or clinic
- Less than 40% have access to drug treatments
- Less than 30% have access to non-drug treatments

## Personal expenses to deal with rare disease

- 70% incur personal costs related to rare disease
- Personal costs for non-Quebeckers about 60% more than for Quebeckers
- Average personal health services cost: \$3,000
- Average personal prescription drug costs: \$2,300
- Average OTC drug costs: \$800
- Average support services costs: \$2,500
- Average other costs: \$6,500
- Average total personal costs: \$14,400 outside Quebec; \$9,000 Quebec

***THANK YOU!***

**For More information please contact:**

Canadian Organization for Rare Disorders

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