

# EARLS 2018-19 RLS Patient Survey

## - FINAL OUTCOMES -

Munich, 13-14 December 2019



# Context



- Launched 23rd September 2018, to co-incide with International RLS Day.
- Europe-focus: interest from Australia, Argentina, USA, Canada, Costa Rica, and others.
- Open to Austria, Finland, France, Germany, Ireland, Netherlands, Norway, Spain, Sweden and UK.
- Available in 8 languages
- Responses as at close, 22/09/2019, 4087
- Online survey: did not include digitally excluded patients (who are likely to be older).
- Not a scientific-based study, but provides strong indicators and inferences from a large RLS community cohort.
- Promoted through social media channels. RLS patients using these channels are likely to be on more severe end of RLS spectrum.



# Response Rates: Overview



	UK	1369	87%	1575
	Ireland	100	6%	
	Other	106	7%	

	Finland	100	97%	103
	Other	3	3%	

	Germany	531	95%	561
	Austria	14	2%	
	Other	16	3%	

	Norway	98	100%	98
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	France	786	96%	822
	Other	36	4%	

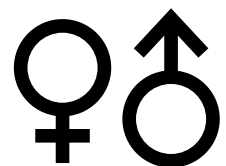
	Netherlands	268	69%	286
	Other	18	6%	

	Spain	227	40%	252
	Other	25	4%	

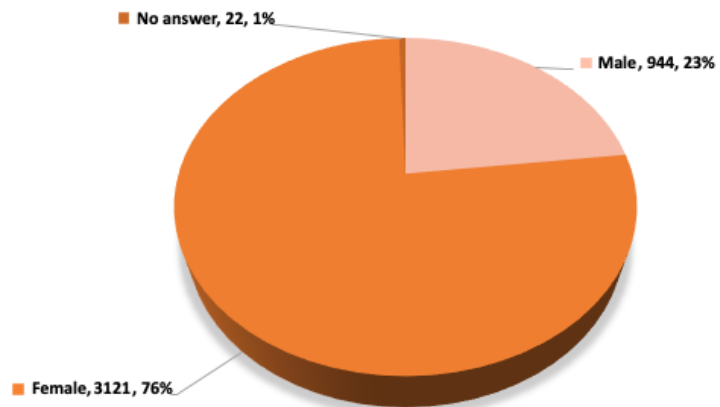
	Sweden	334	86%	390
	Other	56	14%	



# Gender - Overview

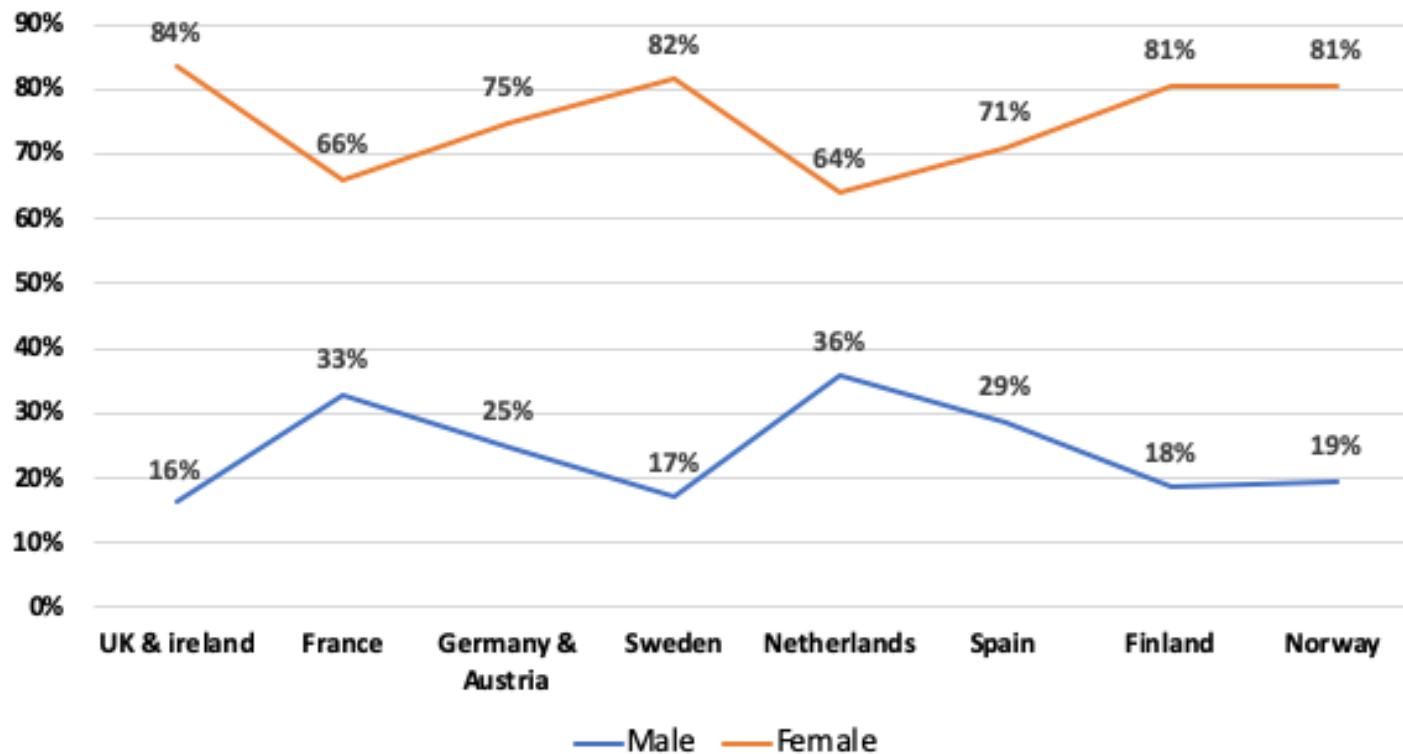


Gender - All Respondents

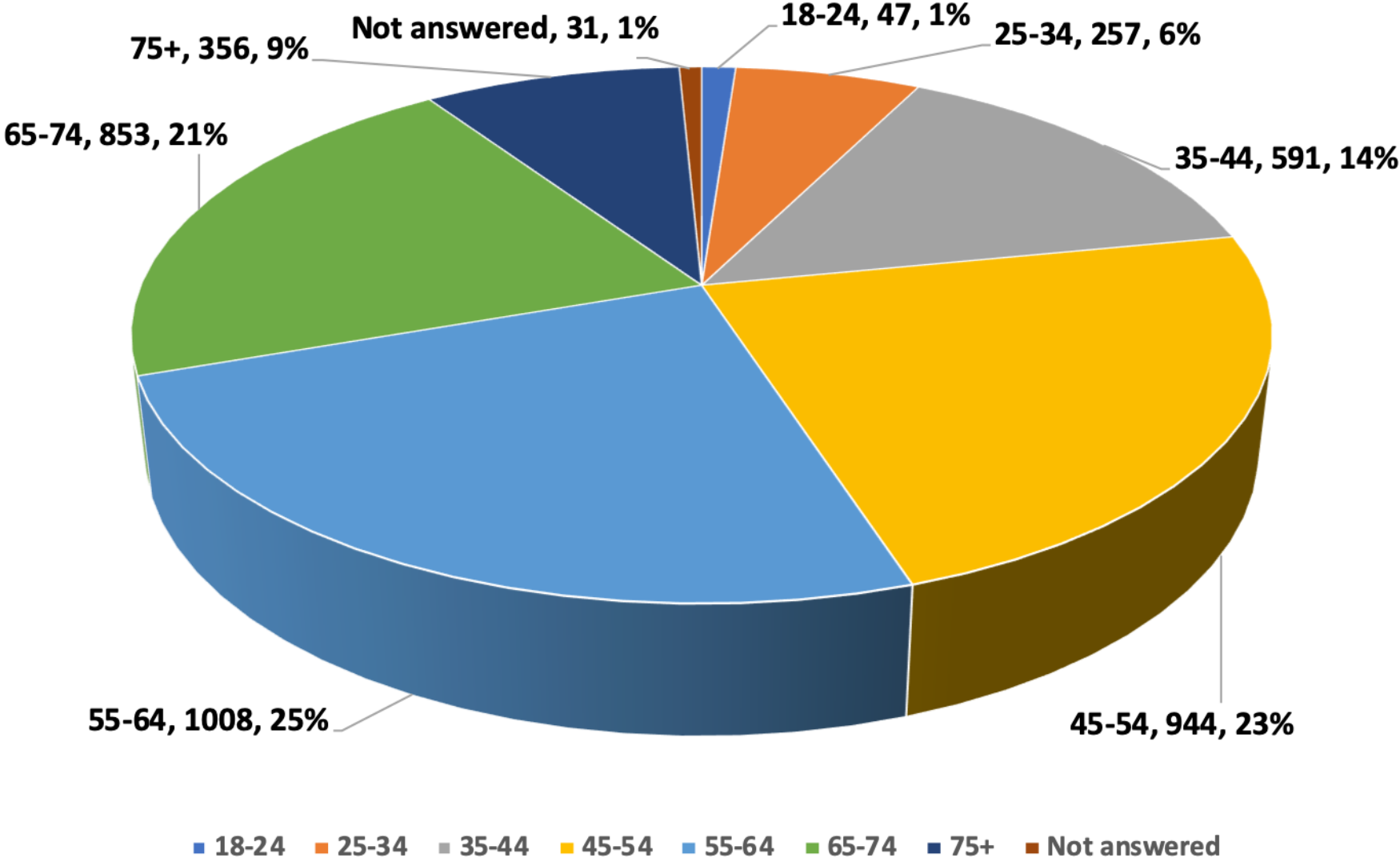


Responses	Total
UK & Ireland	1575
France	822
Germany & Austria	561
Sweden	390
Netherlands	286
Spain	252
Finland	103
Norway	98
<b>All</b>	<b>4087</b>

Response Rate by Gender (%) - Per Country



# Respondent Age - Overview

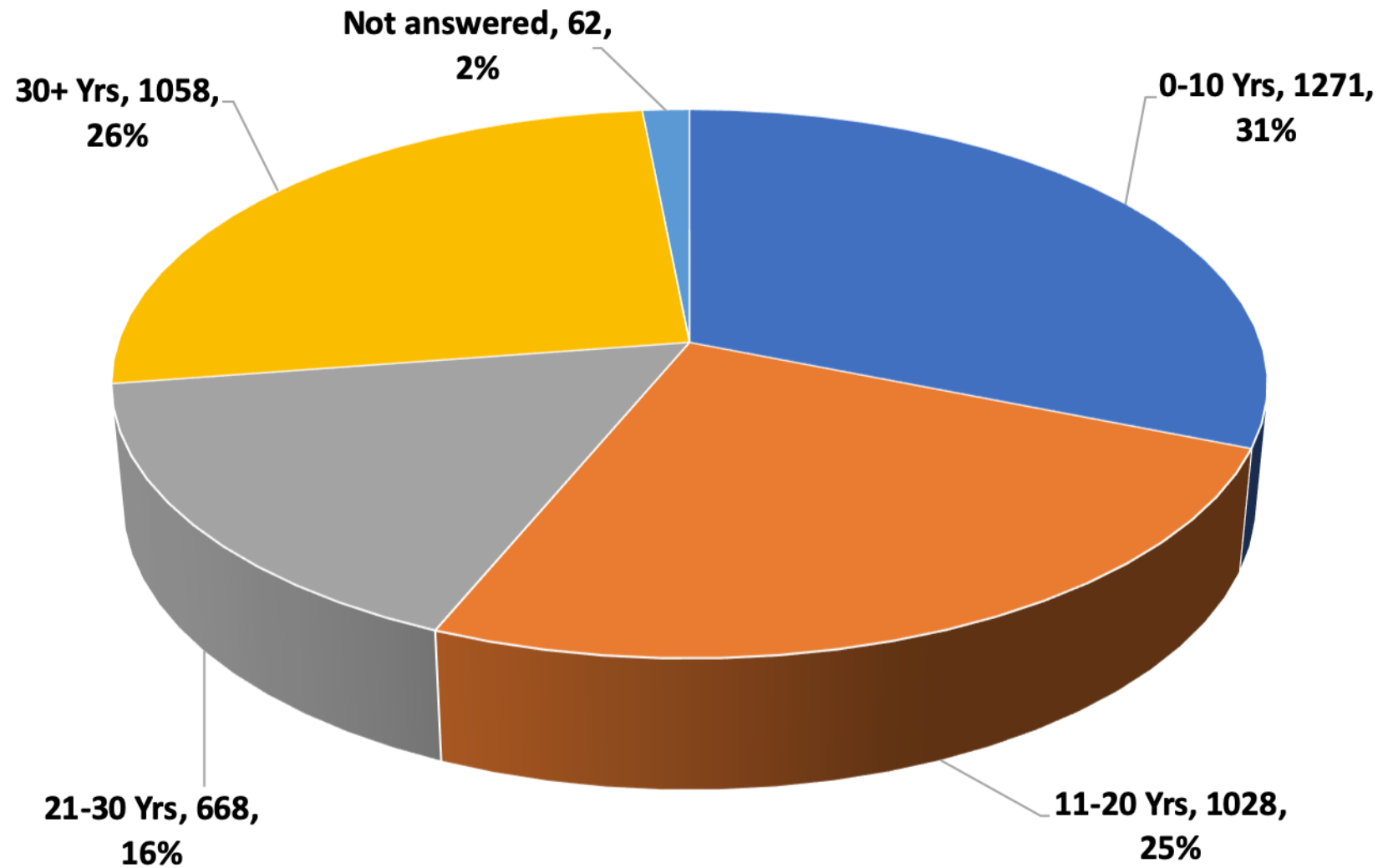


# Respondent Age - By Country



Country	18-24 #	%	25-34 #	%	35-44 #	%	45-54 #	%	55-64 #	%	65-74 #	%	75+ #	%	No Answer #	%	Total
UK & Ireland	19	1%	127	8%	315	20%	450	29%	375	24%	235	15%	47	3%	7	0%	1575
Finland	2	2%	11	11%	27	26%	21	20%	28	27%	8	8%	5	5%	1	1%	103
Germany & Austria	9	2%	42	7%	78	14%	144	26%	166	30%	82	15%	27	5%	13	2%	561
Norway	0	0%	4	4%	9	9%	24	24%	26	27%	22	22%	12	12%	1	1%	98
France	8	1%	29	4%	60	7%	119	14%	171	21%	258	31%	173	21%	4	0%	822
Netherlands	1	0%	6	2%	14	5%	39	14%	74	26%	102	36%	50	17%	0	0%	286
Sweden	4	1%	20	5%	32	8%	93	24%	96	25%	105	27%	37	9%	3	1%	390
Spain	4	2%	18	7%	56	22%	54	21%	72	29%	41	16%	5	2%	2	1%	252
Total	47	1%	257	6%	591	14%	944	23%	1008	25%	853	21%	356	9%	31	1%	4087

# Number of years living with RLS - Overview



# Number of years living with RLS: by Country

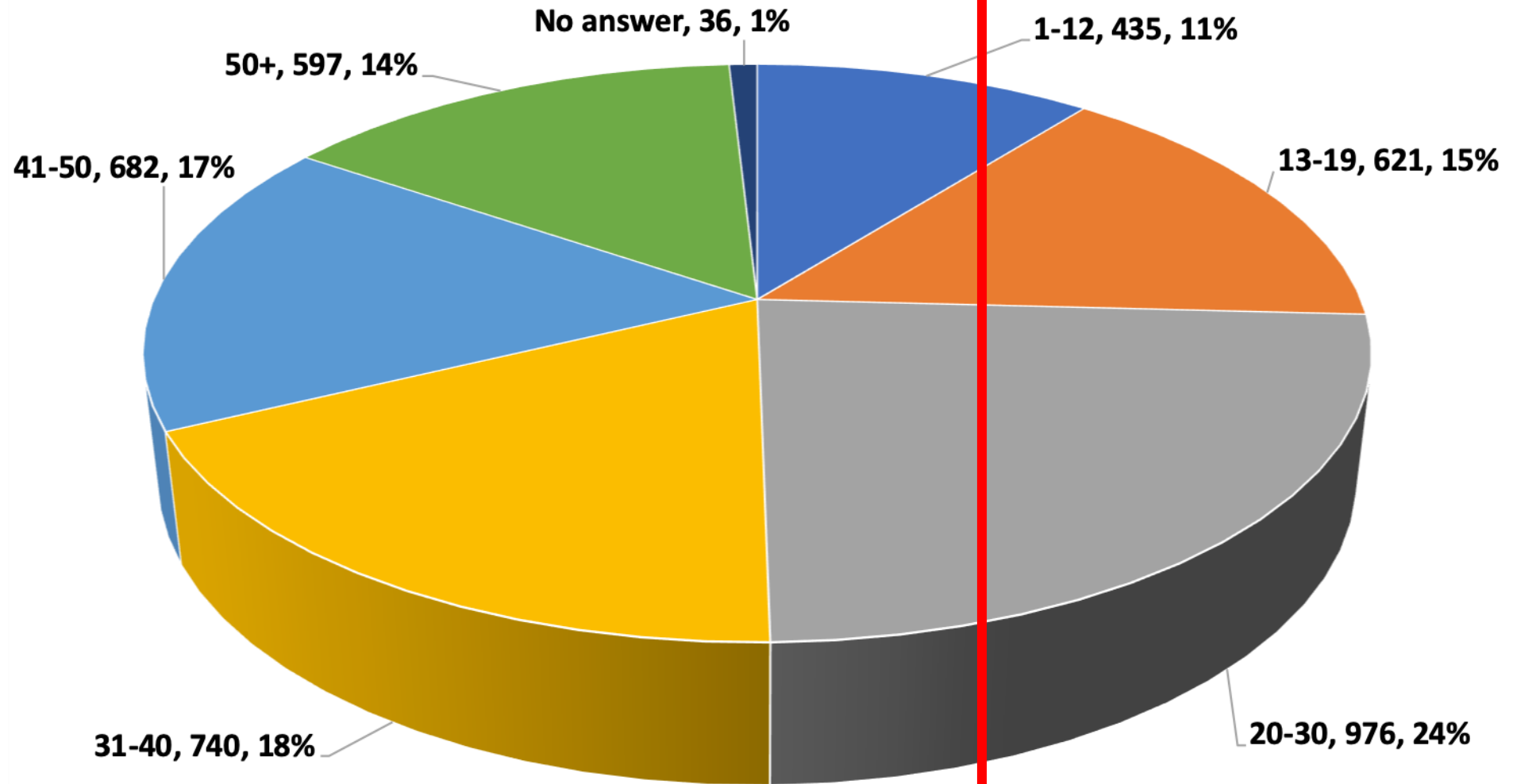


Country	0-10 Yrs	%	11-20 Yrs	%	21-30 Yrs	%	30+ Yrs	%	Not Answered #	%	Total
UK & Ireland	600	38%	355	23%	221	14%	390	25%	9	1%	1575
Finland	33	32%	25	24%	18	17%	27	26%	0	0%	103
Germany & Austria	213	38%	149	27%	101	18%	92	16%	6	1%	561
Norway	18	18%	19	19%	15	15%	45	46%	1	1%	98
France	186	23%	271	33%	145	18%	205	25%	15	2%	822
Netherlands	48	17%	74	26%	52	18%	112	39%	0	0%	286
Sweden	82	21%	89	23%	83	21%	131	34%	5	1%	390
Spain	91	36%	46	18%	33	13%	56	22%	26	10%	252
Overall	1271	31%	1028	25%	668	16%	1058	26%	62	2%	4087

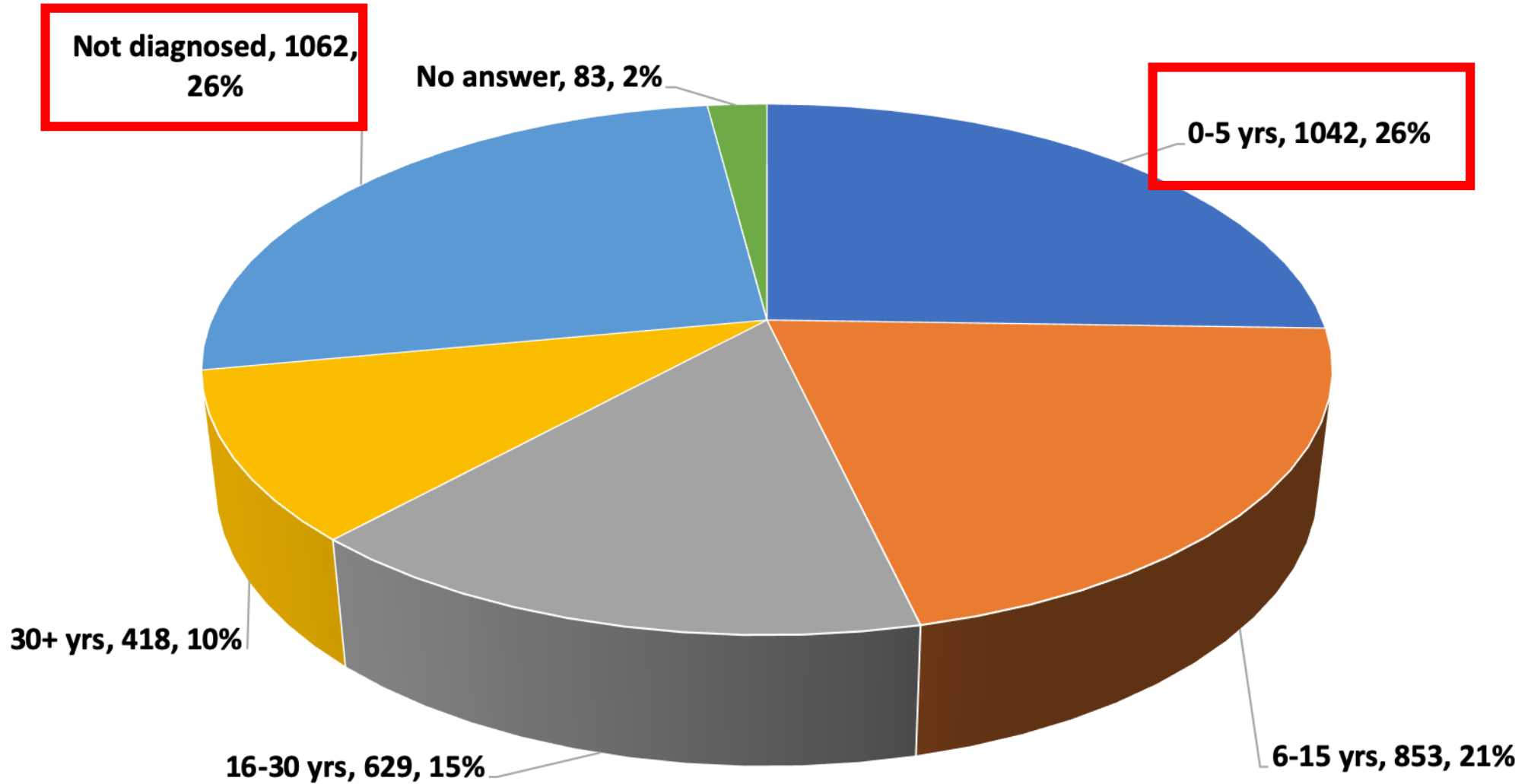




# Age at First Symptoms: Overview



# First symptoms to diagnosis: Overview

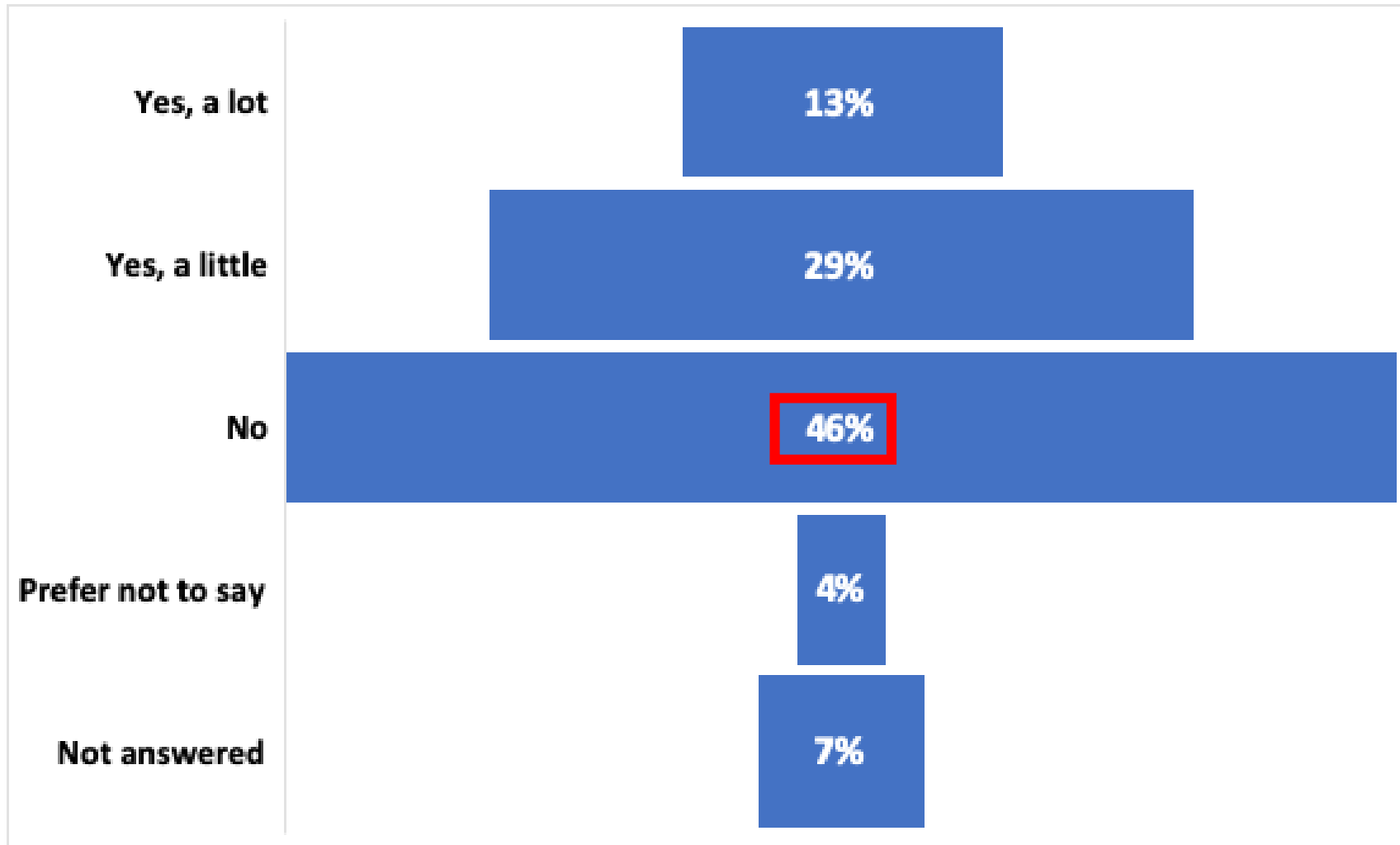


# First symptoms to diagnosis: By Country

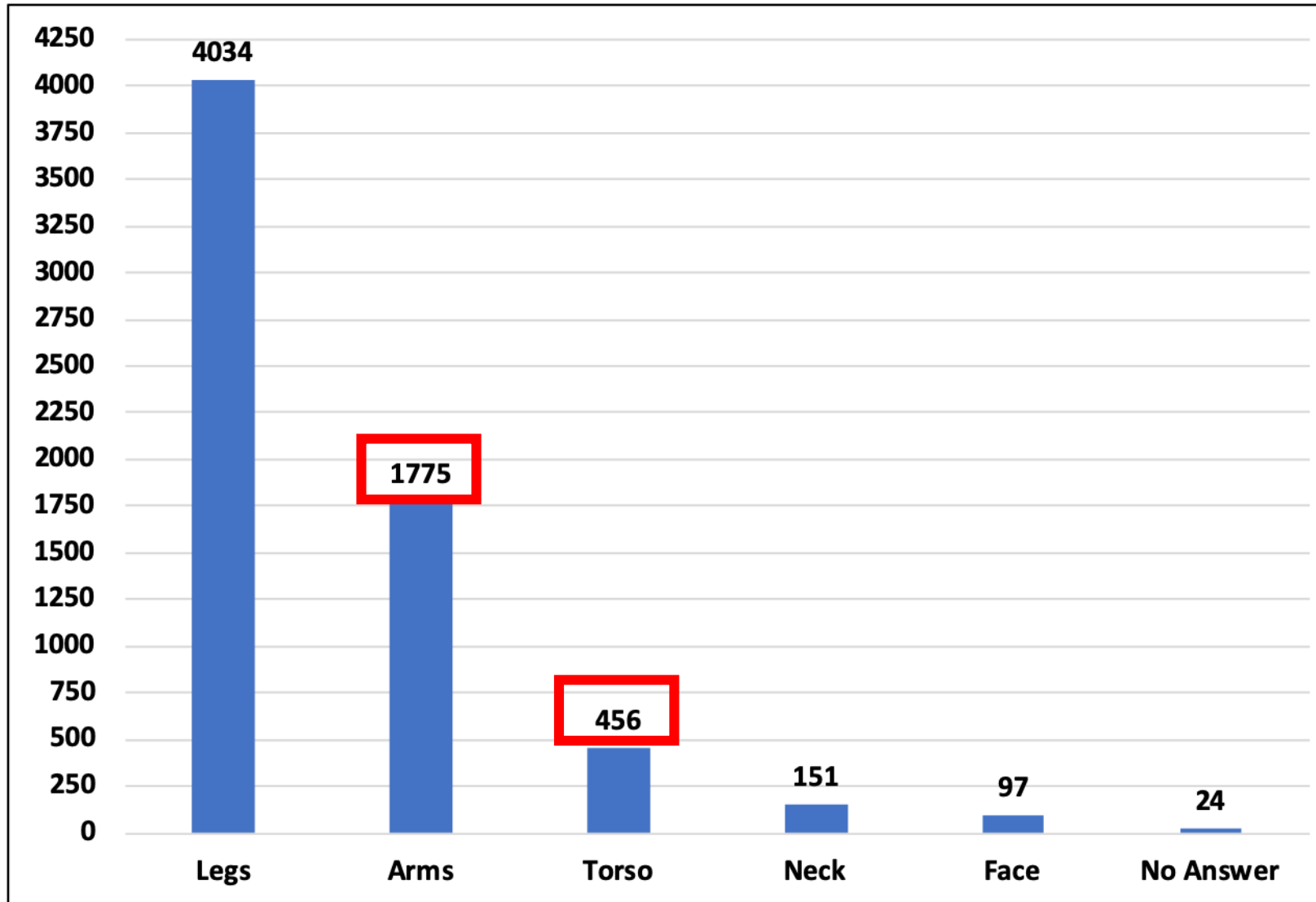
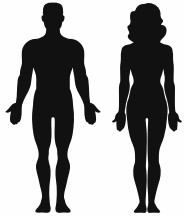
Country	0-5 Yrs #	%	6-15 Yrs #	%	16-30 Yrs #	%	30+ Yrs #	%	Not diagnosed	%	No answer	%	Total
UK & Ireland	353	22%	260	17%	204	13%	123	8%	598	38%	37	2%	1575
Finland	15	15%	14	14%	20	19%	11	11%	43	42%	0	0%	103
Germany & Austria	192	34%	149	27%	99	18%	62	11%	46	8%	13	2%	561
Norway	19	19%	20	20%	26	27%	17	17%	15	15%	1	1%	98
France	267	32%	226	27%	115	14%	94	11%	106	13%	14	2%	822
Netherlands	72	25%	61	21%	48	17%	40	14%	61	21%	4	1%	286
Sweden	66	17%	80	21%	88	23%	49	13%	99	25%	8	2%	390
Spain	58	23%	43	17%	29	12%	22	9%	94	37%	6	2%	252
Overall	1042	25%	853	21%	629	15%	418	10%	1062	26%	83	2%	4087



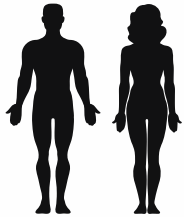
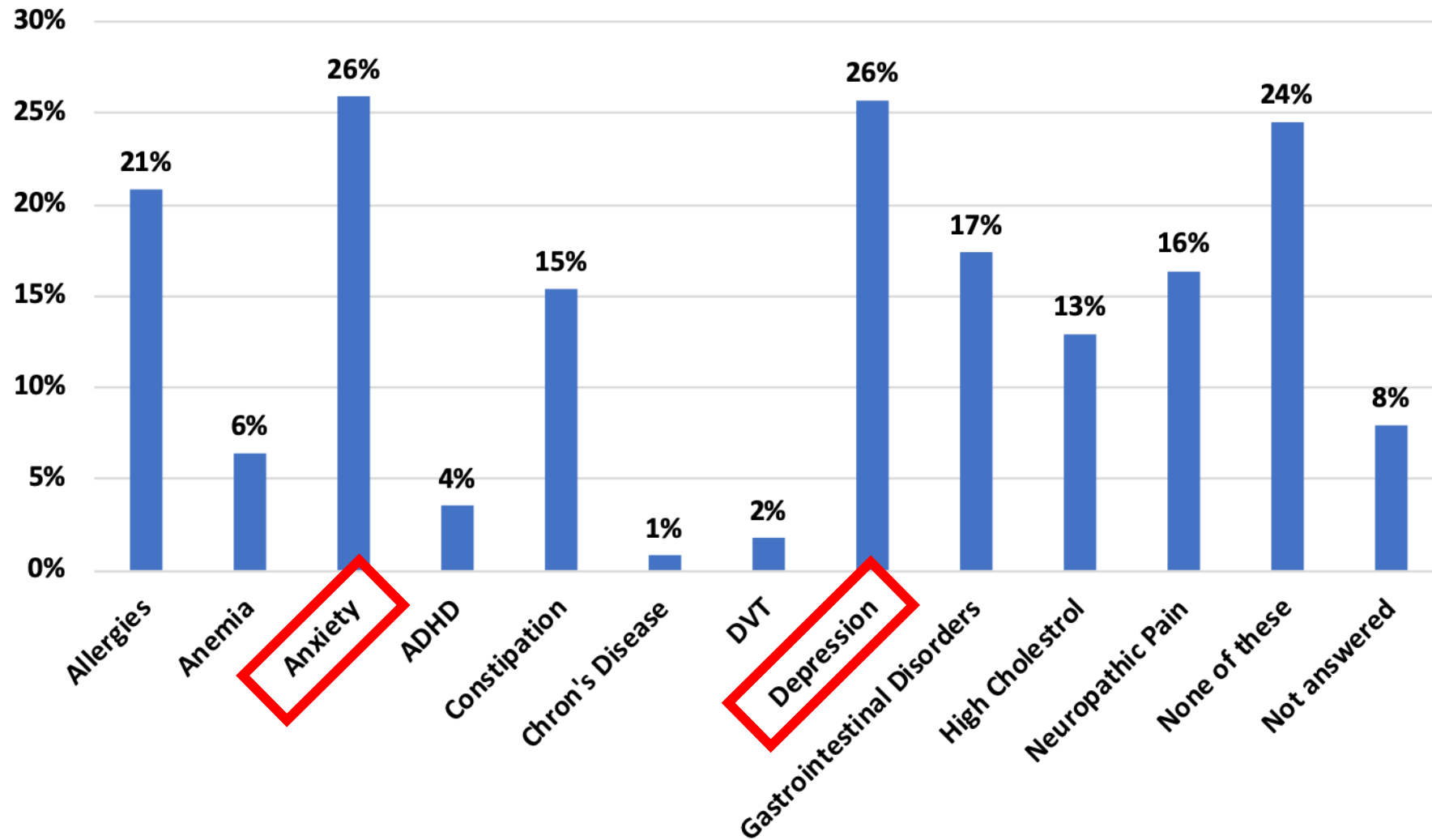
# My Doctor works with me to find ways to manage my RLS



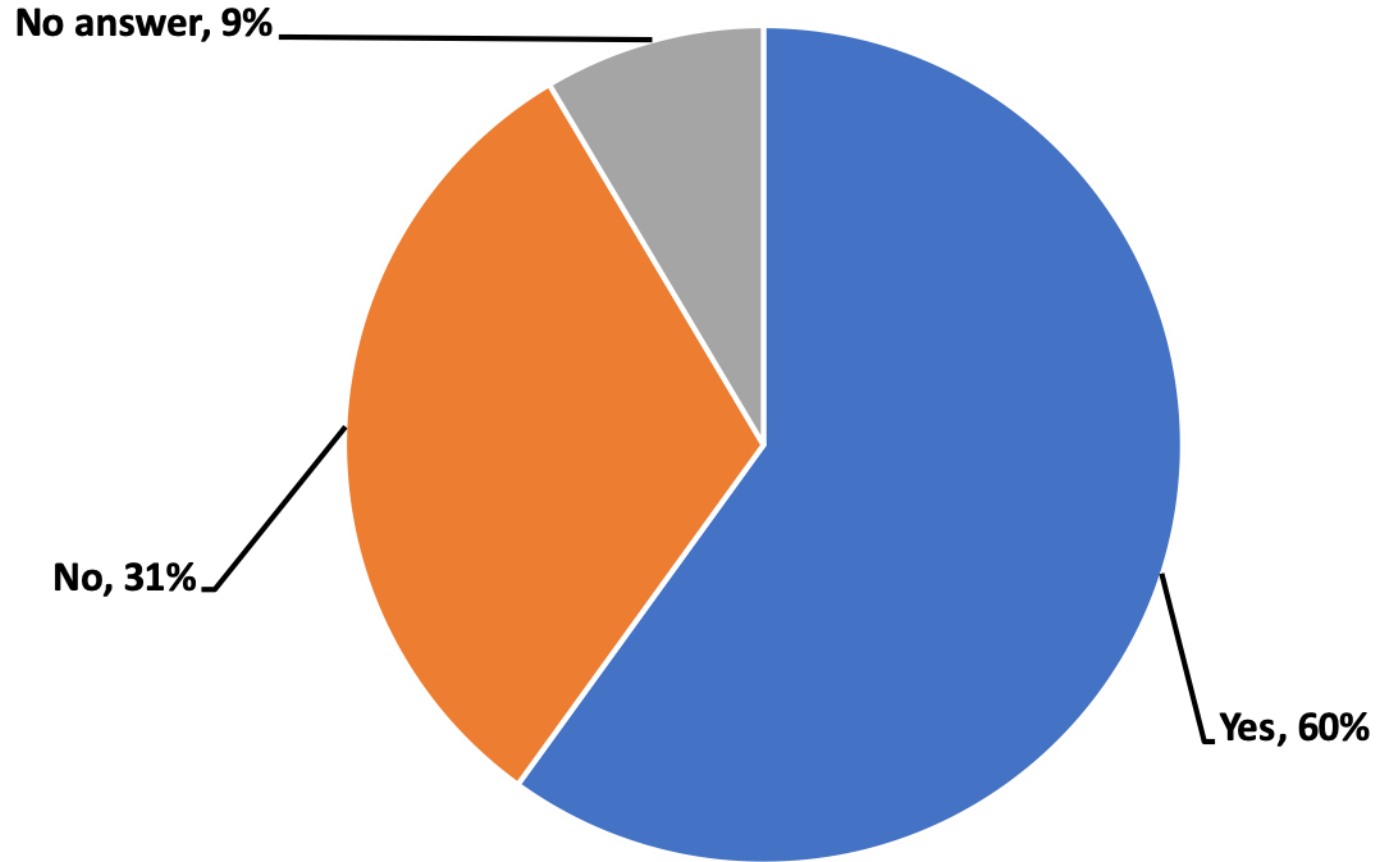
# Parts of Body affected by RLS: Overview



# Other Health Conditions: % of Respondents



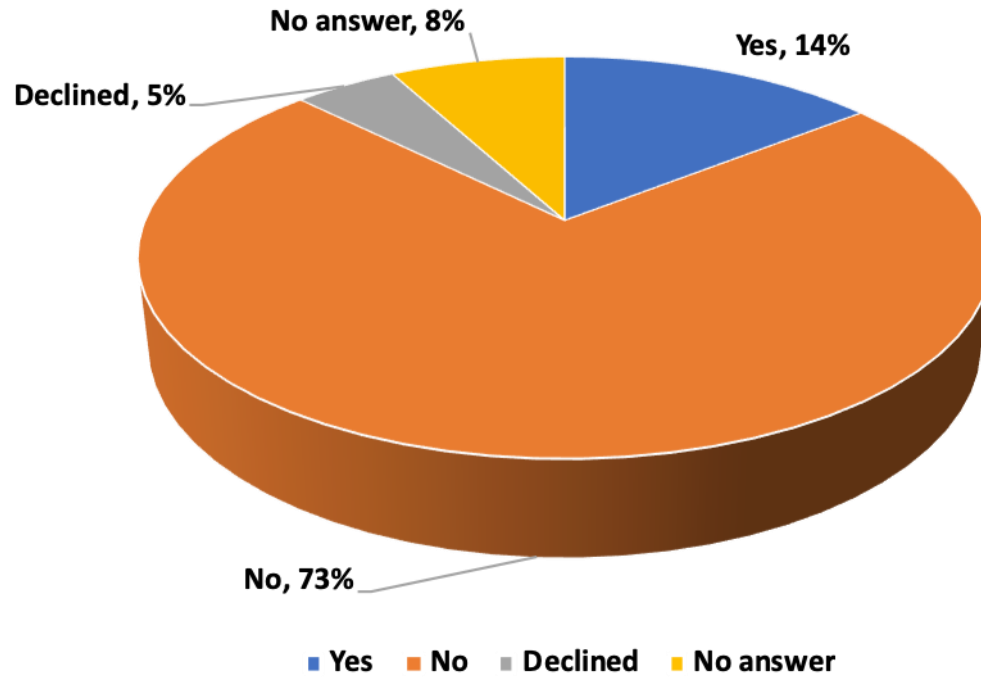
# I understand the term 'Augmentation': Overview



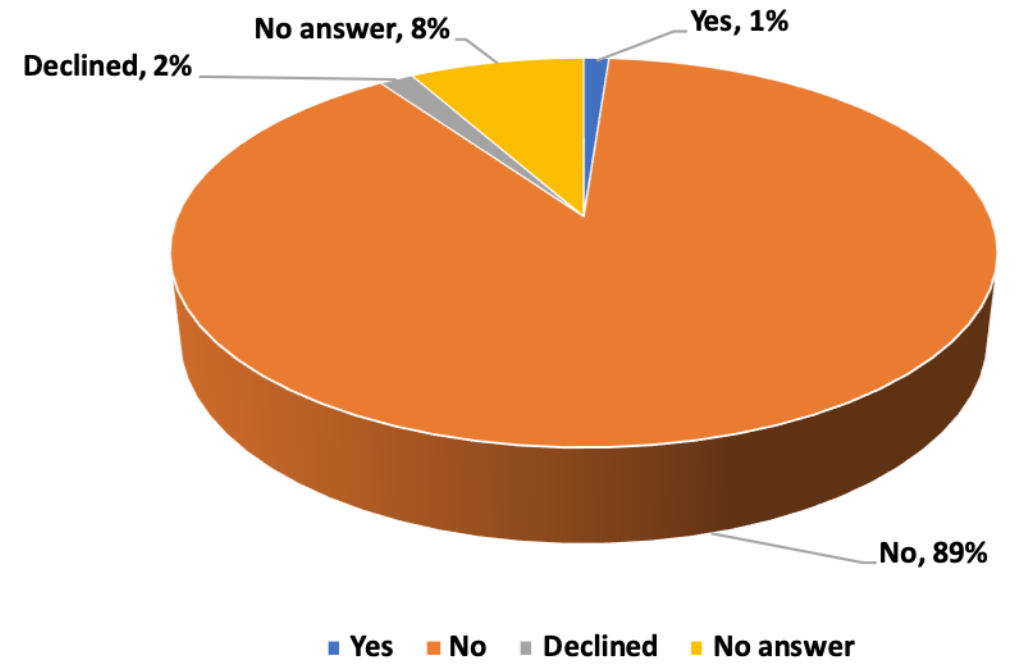
# Suicide



## Considered



## Attempted





# Awareness of RLS is increasing

