RAIRDA Survey 2024

Table 1

Q1 Have you been diagnosed with any of the following rare autoimmune diseases?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE))	**398**	320	17	5	21	5	9	3	18	44	66	6	38	5	11	108	22
	29%CDFGH	**100%ACDEFGHI**	**11%FGH**	**6%F**	**27%CDFGH**	*2%*	*3%*	*3%*	**22%CDFGH**	**100%AKMOPQ**	**57%AOP**	*38%*	**90%AKOPQ**	*63%*	*22%*	*28%*	**44%AOP**
Sjogren's disease	**366**	105	151	11	8	12	58	7	14	18	116	5	15	2	12	97	16
	27%DEFGHI	**33%ADEFGHI**	**100%ABDEFGHI**	**14%F**	*10%*	*5%*	**21%EFH**	*6%*	**17%FH**	**41%AP**	**100%AJMOPQ**	*31%*	*36%*	*25%*	*24%*	*25%*	*32%*
Myositis/inflammatory muscle disease	**116**	7	5	77	1	3	16	2	5	2	7	16	4	1	11	28	9
	9%BCEFH	*2%*	*3%*	**100%ABCEFGHI**	*1%*	*1%*	**6%BF**	*2%*	**6%F**	*5%*	*6%*	*100%*	*10%*	*13%*	**22%AJKP**	*7%*	**18%AJKP**
Antiphospholipid syndrome (APS)	**151**	62	1	2	77	3	2	-	4	15	6	-	42	1	2	27	10
	11%CDFGHKP	**19%ACDFGHI**	*1%*	*3%*	**100%ABCDFGHI**	*1%*	*1%*	-	**5%CFGH**	**34%AKOP**	*5%*	-	**100%AJKOPQ**	*13%*	*4%*	*7%*	**20%AKOP**
Form of systemic vasculitis (including Behcet's)	**287**	15	3	1	1	260	5	-	2	3	17	2	1	8	3	26	4
	21%BCDEGHIJM OPQ	**5%H**	*2%*	*1%*	*1%*	**100%ABCDEGHI**	*2%*	-	*2%*	*7%*	**15%MP**	*13%*	*2%*	*100%*	*6%*	*7%*	*8%*
Form of systemic sclerosis or scleroderma	**350**	15	13	11	1	3	270	29	8	4	31	7	2	2	50	199	10
	26%BCDEFIJM	**5%F**	**9%EF**	**14%BEF**	*1%*	*1%*	**100%ABCDEFHI**	**25%BCEFI**	**10%EF**	*9%*	**27%JM**	*44%*	*5%*	*25%*	**100%AJKMPQ**	**52%AJKMQ**	**20%M**
Raynaud's disease	**649**	150	52	32	16	24	216	115	44	20	61	8	19	5	45	383	32
	48%CEF	**47%CEF**	**34%EF**	**42%EF**	**21%F**	*9%*	**80%ABCDEFI**	**100%ABCDEFGI**	**54%CEF**	*45%*	*53%*	*50%*	*45%*	*63%*	**90%AJKMQ**	**100%AJKMOQ**	**64%A**
Undifferentiated or mixed connective tissue disease	**193**	42	13	11	9	5	24	7	82	13	17	3	7	4	13	56	50
	14%CFGH	**13%FH**	**9%F**	**14%F**	**12%F**	*2%*	**9%F**	**6%F**	**100%ABCDEFGH**	**30%AKP**	*15%*	*19%*	*17%*	*50%*	**26%AP**	*15%*	**100%AJKMOP**
None of these rare autoimmune diseases	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 2

Q1 Have you been diagnosed with any of the following rare autoimmune diseases?

Base: all participants

	Total (A)	Combined diagnoses: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE))	**398** **29%DFG**	398 **100%ACDEFGHI**	141 **39%ADFGH**	16 *14%*	90 **60%ACDFGHI**	23 *8%*	32 *9%*	199 **31%DFG**	75 **39%ADFGH**
Sjogren's disease	**366** **27%F**	141 **35%ADEFG**	366 **100%ABDEFGHI**	27 **23%F**	33 **22%F**	28 *10%*	88 **25%F**	202 **31%AEFG**	59 **31%F**
Myositis/inflammatory muscle disease	**116** **9%BF**	16 *4%*	27 **7%BF**	116 **100%ABCEFGHI**	8 *5%*	6 *2%*	33 **9%BF**	60 **9%BF**	26 **13%ABCEFH**
Antiphospholipid syndrome (APS)	**151** **11%FG**	90 **23%ACDFGHI**	33 **9%FG**	8 **7%FG**	151 **100%ABCDFGHI**	6 *2%*	6 *2%*	63 **10%FG**	26 **13%FG**
Form of systemic vasculitis (including Behcet's)	**287** **21%BCDEGHI**	23 *6%*	28 **8%G**	6 *5%*	6 *4%*	287 **100%ABCDEGHI**	15 *4%*	44 **7%G**	15 *8%*
Form of systemic sclerosis or scleroderma	**350** **26%BEF**	32 **8%E**	88 **24%BEF**	33 **28%BEF**	6 *4%*	15 *5%*	350 **100%ABCDEFHI**	290 **45%ABCDEFI**	52 **27%BEF**
Raynaud's disease	**649** **48%F**	199 **50%EF**	202 **55%AEF**	60 **52%F**	63 **42%F**	44 *15%*	290 **83%ABCDEFI**	649 **100%ABCDEFGI**	131 **68%ABCDEF**
Undifferentiated or mixed connective tissue disease	**193** **14%F**	75 **19%AF**	59 **16%F**	26 **22%AFG**	26 **17%F**	15 *5%*	52 **15%F**	131 **20%ACFG**	193 **100%ABCDEFGH**
None of these rare autoimmune diseases	**-** **-**	- -	- -	- -	- -	- -	- -	- -	- -
Don't know/no answer	**-** **-**	- -	- -	- -	- -	- -	- -	- -	- -

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 3

Q1 Have you been diagnosed with any of the following rare autoimmune diseases?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE))	**398**	14	30	56	86	129	63	16	4	20	374	2	-
	29%GHJ	*61%*	**39%AGH**	**37%AGH**	**32%GH**	**31%GH**	*22%*	*14%*	*40%*	*17%*	**30%AJ**	*100%*	-
Sjogren's disease	**366**	-	14	22	64	119	103	41	3	11	354	-	-
	27%DJ	-	*18%*	*15%*	**24%D**	**28%D**	**35%ACDE**	**37%ACDE**	*30%*	*9%*	**29%AJ**	-	-
Myositis/inflammatory muscle disease	**116**	-	8	14	29	28	30	7	-	12	104	-	-
	9%	-	*11%*	*9%*	*11%*	*7%*	*10%*	*6%*	-	*10%*	*8%*	-	-
Antiphospholipid syndrome (APS)	**151**	6	4	27	49	44	18	3	-	14	136	1	-
	11%GH	*26%*	*5%*	**18%ACFGH**	**18%ACFGH**	**11%GH**	*6%*	*3%*	-	*12%*	*11%*	*50%*	-
Form of systemic vasculitis (including Behcet's)	**287**	3	19	30	53	110	55	17	-	43	244	-	-
	21%K	*13%*	*25%*	*20%*	*20%*	**26%AEGH**	*19%*	*15%*	-	**36%AK**	*20%*	-	-
Form of systemic sclerosis or scleroderma	**350**	3	9	29	67	102	98	39	3	20	330	-	-
	26%CJ	*13%*	*12%*	*19%*	**25%C**	**24%C**	**34%ACDEF**	**35%ACDEF**	*30%*	*17%*	**27%AJ**	-	-
Raynaud's disease	**649**	6	23	84	135	176	153	66	6	56	591	1	-
	48%CF	*26%*	*30%*	**56%ACF**	**50%CF**	*42%*	**52%CF**	**59%ACF**	*60%*	*47%*	*48%*	*50%*	-
Undifferentiated or mixed connective tissue disease	**193**	1	12	29	58	59	28	5	1	6	185	1	-
	14%GHJ	*4%*	**16%H**	**19%GH**	**21%AFGH**	**14%H**	*10%*	*4%*	*10%*	*5%*	**15%AJ**	*50%*	-
None of these rare autoimmune diseases	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 4

Q2 Thinking about the diagnoses you selected, which of the following best describes your primary rare autoimmune diagnosis?

Base: participants with 2 or more rare autoimmune rheumatic diseases

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**709**	222	66*	39*	29**	37*	225	39*	52*	44*	116	16**	42*	8**	50*	383	50*
Form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE))	**216**	216	-	-	-	-	-	-	-	-	60	3	35	3	6	95	14
	30%CDFGHIJOP	**97%ACDFGHI**	-	-	-	-	-	-	-	-	**52%AJOPQ**	*19%*	**83%AJKOPQ**	*38%*	**12%J**	**25%JO**	**28%JO**
Sjogren's disease	**56**	-	56	-	-	-	-	-	-	10	-	1	1	-	6	35	3
	8%BGIK	-	**85%ABDFGHI**	-	-	-	-	-	-	**23%AKMPQ**	-	*6%*	*2%*	-	**12%K**	**9%K**	**6%K**
Myositis/inflammatory muscle disease	**38**	-	-	38	-	-	-	-	-	2	6	-	-	-	8	17	5
	5%BG	-	-	**97%ABCFGHI**	-	-	-	-	-	*5%*	*5%*	-	-	-	**16%AKMP**	*4%*	**10%M**
Antiphospholipid syndrome (APS)	**26**	-	-	-	26	-	-	-	-	11	2	-	-	1	1	6	5
	4%BGP	-	-	-	*90%*	-	-	-	-	**25%AKMOP**	*2%*	-	-	*13%*	*2%*	*2%*	**10%AKMP**
Form of systemic vasculitis (including Behcet's)	**36**	-	-	-	-	36	-	-	-	3	9	2	-	-	1	17	4
	5%BG	-	-	-	-	**97%ABCDGHI**	-	-	-	*7%*	*8%*	*13%*	-	-	*2%*	*4%*	*8%*
Form of systemic sclerosis or scleroderma	**221**	-	-	-	-	-	221	-	-	1	24	5	1	2	-	181	7
	31%BCDFHIJKMOQ	-	-	-	-	-	**98%ABCDFHI**	-	-	*2%*	**21%JMO**	*31%*	*2%*	*25%*	-	**47%AJKMOQ**	**14%JO**
Raynaud's disease	**34**	-	-	-	-	-	-	34	-	3	4	1	-	-	21	-	5
	5%BGP	-	-	-	-	-	-	**87%ABCDFGI**	-	**7%P**	**3%P**	*6%*	-	-	**42%AJKMPQ**	-	**10%MP**
Undifferentiated or mixed connective tissue disease	**49**	-	-	-	-	-	-	-	49	9	9	2	3	2	2	22	-
	7%BCG	-	-	-	-	-	-	-	**94%ABCDFGH**	**20%AKOPQ**	**8%Q**	*13%*	*7%*	*25%*	*4%*	*6%*	-
I don't know	**33**	6	10	1	3	1	4	5	3	5	2	2	2	-	5	10	7
	5%GP	*3%*	**15%ABDG**	*3%*	*10%*	*3%*	*2%*	**13%ABG**	*6%*	**11%AKP**	*2%*	*13%*	*5%*	-	**10%KP**	*3%*	**14%AKP**
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 5

Q2 Thinking about the diagnoses you selected, which of the following best describes your primary rare autoimmune diagnosis?

Base: participants with 2 or more rare autoimmune rheumatic diseases

	Total (A)	Combined diagnoses: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**709**	300	281	78*	103	64*	305	573	163
Form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE))	**216** **30%DGHI**	216 **72%ACDEFGHI**	103 **37%ADFGHI**	7 *9%*	60 **58%ACDFGHI**	15 **23%DG**	14 *5%*	147 **26%DG**	39 **24%DG**
Sjogren's disease	**56** **8%BEG**	12 *4%*	56 **20%ABDEFGHI**	4 *5%*	1 *1%*	2 *3%*	9 *3%*	43 **8%BEG**	9 *6%*
Myositis/inflammatory muscle disease	**38** **5%B**	5 *2%*	11 **4%B**	38 **49%ABCEFGHI**	2 *2%*	1 *2%*	11 *4%*	32 **6%BG**	10 **6%B**
Antiphospholipid syndrome (APS)	**26** **4%CGH**	18 **6%ACGH**	5 **2%G**	1 *1%*	26 **25%ABCDFGHI**	1 *2%*	1 *	13 **2%G**	6 **4%G**
Form of systemic vasculitis (including Behcet's)	**36** **5%BGH**	5 *2%*	11 **4%BG**	3 **4%G**	3 *3%*	36 **56%ABCDEGHI**	2 *1%*	23 **4%BG**	5 **3%G**
Form of systemic sclerosis or scleroderma	**221** **31%BCDEFI**	8 *3%*	58 **21%BEF**	15 **19%BEF**	2 *2%*	5 **8%B**	221 **72%ABCDEFHI**	212 **37%ABCDEFI**	24 **15%BE**
Raynaud's disease	**34** **5%BCE**	3 *1%*	6 *2%*	1 *1%*	- -	- -	27 **9%ABCDEFHI**	34 **6%ABCEF**	5 *3%*
Undifferentiated or mixed connective tissue disease	**49** **7%G**	16 **5%G**	14 **5%G**	5 **6%G**	4 *4%*	2 *3%*	7 *2%*	41 **7%G**	49 **30%ABCDEFGH**
I don't know	**33** ***5%***	17 *6%*	17 *6%*	4 *5%*	5 *5%*	2 *3%*	13 *4%*	28 *5%*	16 **10%ABGH**
Don't know/no answer	**-** -	- -	- -	- -	- -	- -	- -	- -	- -

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used. * small base

RAIRDA Survey 2024

Table 6

Q2 Thinking about the diagnoses you selected, which of the following best describes your primary rare autoimmune diagnosis?

Base: participants with 2 or more rare autoimmune rheumatic diseases

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**709**	8**	28**	85*	153	206	163	61*	5**	42*	663	2**	-**
Form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE))	**216**	5	11	32	54	65	39	8	2	14	200	-	-
	30%GH	*63%*	*39%*	**38%GH**	**35%GH**	**32%H**	*24%*	*13%*	*40%*	*33%*	*30%*	-	-
Sjogren's disease	**56**	-	1	2	5	13	17	16	2	1	55	-	-
	8%DE	-	*4%*	*2%*	*3%*	*6%*	**10%DE**	**26%ADEFG**	*40%*	*2%*	*8%*	-	-
Myositis/inflammatory muscle disease	**38**	-	1	6	7	12	9	3	-	5	33	-	-
	5%	-	*4%*	*7%*	*5%*	*6%*	*6%*	*5%*	-	*12%*	*5%*	-	-
Antiphospholipid syndrome (APS)	**26**	-	1	4	9	8	3	1	-	2	23	1	-
	4%	-	*4%*	*5%*	*6%*	*4%*	*2%*	*2%*	-	*5%*	*3%*	*50%*	-
Form of systemic vasculitis (including Behcet's)	**36**	-	1	6	5	16	8	-	-	2	34	-	-
	5%	-	*4%*	**7%H**	*3%*	**8%AH**	*5%*	-	-	*5%*	*5%*	-	-
Form of systemic sclerosis or scleroderma	**221**	2	6	15	38	65	70	24	1	14	207	-	-
	31%D	*25%*	*21%*	*18%*	*25%*	**32%D**	**43%ADEF**	**39%DE**	*20%*	*33%*	*31%*	-	-
Raynaud's disease	**34**	-	2	8	7	7	4	6	-	1	33	-	-
	5%	-	*7%*	**9%AFG**	*5%*	*3%*	*2%*	**10%FG**	-	*2%*	*5%*	-	-
Undifferentiated or mixed connective tissue disease	**49**	1	5	7	22	9	3	2	-	-	48	1	-
	7%G	*13%*	*18%*	**8%G**	**14%AFGH**	*4%*	*2%*	*3%*	-	-	*7%*	*50%*	-
I don't know	**33**	-	-	5	6	11	10	1	-	3	30	-	-
	5%	-	-	*6%*	*4%*	*5%*	*6%*	*2%*	-	*7%*	*5%*	-	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 7

Q3 Thinking about all of your rare autoimmune disease(s), in the last 12 months, which of the following specialties have you received care from?

Base: all participants

	Total (A)	Primary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Primary diagnosis: Sjogren's disease (C)	Primary diagnosis: Myositis/ inflammatory muscle disease (D)	Primary diagnosis: Antiphospholipid syndrome (APS) (E)	Primary diagnosis: A form of systemic vasculitis (including Behcet's) (F)	Primary diagnosis: A form of systemic sclerosis or scleroderma (G)	Primary diagnosis: Raynaud's disease (H)	Primary diagnosis: Undifferentiated or mixed connective tissue disease (I)	Secondary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Secondary diagnosis: Sjogren's disease (K)	Secondary diagnosis: Myositis/ inflammatory muscle disease (L)	Secondary diagnosis: Antiphospholipid syndrome (APS) (M)	Secondary diagnosis: A form of systemic vasculitis (including Behcet's) (N)	Secondary diagnosis: A form of systemic sclerosis or scleroderma (O)	Secondary diagnosis: Raynaud's disease (P)	Secondary diagnosis: Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Rheumatology	**1046**	261	121	70	32	186	240	64	72	35	95	14	35	7	43	327	44
	77%EFH	**82%AEFH**	**80%EH**	**91%ABCEFH**	*42%*	**72%EH**	**89%ABCEFH**	*56%*	**88%AEFH**	*80%*	*82%*	*88%*	*83%*	*88%*	*86%*	**85%A**	*88%*
Ophthalmology	**354**	101	70	12	13	71	49	15	23	14	41	9	14	3	13	96	13
	26%DGH	**32%ADEGH**	**46%ABDEFGHI**	*16%*	*17%*	**27%DGH**	*18%*	*13%*	**28%H**	*32%*	**35%AP**	*56%*	*33%*	*38%*	*26%*	*25%*	*26%*
Respiratory	**346**	46	27	27	5	70	128	22	21	7	28	9	8	2	23	133	17
	26%BCE	*14%*	**18%E**	**35%BCEH**	*6%*	**27%BCE**	**47%ABCEFHI**	**19%E**	**26%BE**	*16%*	*24%*	*56%*	*19%*	*25%*	**46%AJKM**	**35%AJKM**	**34%J**
Cardiology	**280**	54	22	20	10	39	103	14	18	8	26	5	10	-	15	119	13
	21%BCFH	*17%*	*15%*	**26%CEFH**	*13%*	*15%*	**38%ABCDEFHI**	*12%*	*22%*	*18%*	*22%*	*31%*	*24%*	-	*30%*	**31%A**	*26%*
Gastroenterology	**244**	45	32	14	10	35	78	14	16	8	19	1	10	2	17	102	12
	18%BF	*14%*	**21%F**	*18%*	*13%*	*13%*	**29%ABEFH**	*12%*	*20%*	*18%*	*16%*	*6%*	*24%*	*25%*	**34%AK**	**27%AK**	*24%*
Dermatology	**220**	77	20	17	7	34	46	11	8	9	25	5	6	2	10	66	10
	16%H	**24%ACEFGHI**	*13%*	**22%EHI**	*9%*	*13%*	*17%*	*10%*	*10%*	*20%*	*22%*	*31%*	*14%*	*25%*	*20%*	*17%*	*20%*
Renal	**193**	52	5	6	8	97	16	2	7	5	14	-	6	1	4	40	9
	14%CGHP	**16%CGH**	*3%*	**8%H**	**10%CH**	**37%ABCDEGHI**	*6%*	*2%*	**9%H**	*11%*	*12%*	-	*14%*	*13%*	*8%*	*10%*	*18%*
ENT	**165**	26	18	7	1	80	18	7	8	1	12	3	6	1	5	40	2
	12%BEGHJ	**8%E**	**12%E**	**9%E**	*1%*	**31%ABCDEGHI**	*7%*	*6%*	**10%E**	*2%*	*10%*	*19%*	**14%J**	*13%*	*10%*	*10%*	*4%*
Oral medicine	**161**	30	34	9	6	21	39	9	13	5	17	3	3	3	9	60	5
	12%F	*9%*	**23%ABDEFGH**	*12%*	*8%*	*8%*	**14%F**	*8%*	**16%F**	*11%*	*15%*	*19%*	*7%*	*38%*	*18%*	**16%A**	*10%*
Neurology	**143**	39	14	15	14	31	19	7	4	8	17	2	5	3	2	38	10
	11%G	**12%G**	*9%*	**19%ACGHI**	**18%AGHI**	*12%*	*7%*	*6%*	*5%*	**18%O**	*15%*	*13%*	*12%*	*38%*	*4%*	*10%*	**20%AOP**
Haematology	**32**	6	2	1	19	-	1	1	2	5	1	-	3	-	1	3	1
	2%FGP	**2%F**	*1%*	*1%*	**25%ABCDFGHI**	-	*	*1%*	**2%F**	**11%AKP**	*1%*	-	**7%AKP**	-	*2%*	*1%*	*2%*
Physiotherapy	**17**	8	1	4	-	2	-	1	1	-	3	-	2	-	2	5	2
	1%	**3%AG**	*1%*	**5%ACEFG**	-	*1%*	-	*1%*	*1%*	-	*3%*	-	**5%A**	-	*4%*	*1%*	*4%*

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

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RAIRDA Survey 2024

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		Primary diagnosis								Secondary diagnosis							
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Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Endocrinology	**15**	5	-	-	-	6	1	2	1	-	-	-	-	-	-	5	1
	1%	*2%*	-	-	-	*2%*	*	*2%*	*1%*	-	-	-	-	-	-	*1%*	*2%*
Orthopaedics	**14**	8	1	-	-	3	2	-	-	-	-	-	1	-	-	5	1
	1%	**3%A**	*1%*	-	-	*1%*	*1%*	-	-	-	-	-	*2%*	-	-	*1%*	*2%*
Pain management	**11**	2	2	2	1	4	-	-	-	-	2	-	1	-	-	4	-
	1%	*1%*	*1%*	**3%G**	*1%*	**2%G**	-	-	-	-	*2%*	-	*2%*	-	-	*1%*	-
GP	**10**	2	1	-	-	3	1	3	-	1	-	-	-	-	-	2	-
	1%	*1%*	*1%*	-	-	*1%*	*	**3%AG**	-	*2%*	-	-	-	-	-	*1%*	-
Immunology	**9**	2	-	1	-	5	-	-	1	-	1	-	-	-	-	2	-
	1%	*1%*	-	*1%*	-	**2%AG**	-	-	*1%*	-	*1%*	-	-	-	-	*1%*	-
Vascular	**9**	1	-	-	-	4	2	-	2	1	1	-	-	-	-	2	1
	1%	*	-	-	-	*2%*	*1%*	-	**2%B**	*2%*	*1%*	-	-	-	-	*1%*	*2%*
Urology	**8**	2	2	-	-	3	1	-	-	-	-	-	-	-	-	2	2
	1%	*1%*	*1%*	-	-	*1%*	*	-	-	-	-	-	-	-	-	*1%*	**4%AKP**
Podiatry	**6**	2	1	1	-	-	2	-	-	-	1	-	-	-	-	3	1
	*	*1%*	*1%*	*1%*	-	-	*1%*	-	-	-	*1%*	-	-	-	-	*1%*	*2%*
Dental	**6**	-	2	-	-	1	2	1	-	-	2	-	-	-	-	-	1
	*	-	**1%B**	-	-	*	*1%*	*1%*	-	-	**2%P**	-	-	-	-	-	**2%P**
Plastics	**6**	-	-	-	-	1	4	1	-	-	-	1	-	-	1	3	-
	*	-	-	-	-	*	**1%AB**	*1%*	-	-	-	*6%*	-	-	*2%*	*1%*	-
Gynaecology	**5**	2	-	-	1	1	1	-	-	-	1	2	-	-	-	-	-
	*	*1%*	-	-	*1%*	*	*	-	-	-	*1%*	*13%*	-	-	-	-	-
Pulmonary hypertension	**4**	-	-	-	-	1	1	-	2	-	-	-	-	-	-	2	-
	*	-	-	-	-	*	*	-	**2%AB**	-	-	-	-	-	-	*1%*	-

Fieldwork dates: 22nd April - 31st May 2024
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Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Colorectal	**3**	-	-	1	-	1	1	-	-	-	-	-	-	-	-	1	1
	*	-	-	**1%B**	-	*	*	-	-	-	-	-	-	-	-	*	**2%A**
Hepatology	**3**	1	-	-	-	-	1	-	1	-	-	-	-	-	-	-	-
	*	*	-	-	-	-	*	-	*1%*	-	-	-	-	-	-	-	-
Psychology	**3**	1	-	-	-	1	1	-	-	-	-	-	-	-	-	1	-
	*	*	-	-	-	*	*	-	-	-	-	-	-	-	-	*	-
Oncology	**2**	-	1	-	-	-	1	-	-	-	-	-	-	-	-	-	-
	*	-	*1%*	-	-	-	*	-	-	-	-	-	-	-	-	-	-
Dietician	**2**	1	-	-	-	-	1	-	-	-	-	-	-	-	-	1	1
	*	*	-	-	-	-	*	-	-	-	-	-	-	-	-	*	**2%A**
Stroke clinic	**2**	1	-	-	1	-	-	-	-	-	1	-	-	-	-	-	-
	*	*	-	-	**1%A**	-	-	-	-	-	*1%*	-	-	-	-	-	-
Thrombosis	**2**	-	-	-	2	-	-	-	-	1	-	-	-	-	-	-	-
	*	-	-	-	**3%ABCFG**	-	-	-	-	**2%AP**	-	-	-	-	-	-	-
Nephrology	**2**	-	-	-	-	2	-	-	-	-	-	-	-	-	-	-	-
	*	-	-	-	-	**1%A**	-	-	-	-	-	-	-	-	-	-	-
Psychiatry	**2**	2	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	*	**1%A**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Other	**44**	13	2	2	2	12	8	5	-	2	5	1	1	-	1	12	2
	3%	*4%*	*1%*	*3%*	*3%*	**5%I**	*3%*	*4%*	-	*5%*	*4%*	*6%*	*2%*	-	*2%*	*3%*	*4%*
None of these	**102**	18	7	-	22	7	13	31	4	2	8	-	2	1	2	17	1
	8%DFP	**6%D**	*5%*	-	**29%ABCDFGI**	*3%*	*5%*	**27%ABCDFGI**	*5%*	*5%*	*7%*	-	*5%*	*13%*	*4%*	*4%*	*2%*
I don't know	**1**	-	-	-	-	-	-	1	-	-	-	-	-	-	-	-	-
	*	-	-	-	-	-	-	**1%A**	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
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Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
1 specialist	**349**	92	43	22	25	59	51	37	20	11	30	1	10	1	14	83	11
	26%GP	**29%G**	**28%G**	*29%*	**32%G**	*23%*	*19%*	**32%G**	*24%*	*25%*	*26%*	*6%*	*24%*	*13%*	*28%*	*22%*	*22%*
2 specialists	**313**	82	38	19	8	66	62	19	19	9	25	4	10	1	3	90	11
	23%EO	**26%EH**	**25%E**	**25%E**	*10%*	**25%E**	**23%E**	*17%*	**23%E**	**20%O**	**22%O**	*25%*	**24%O**	*13%*	*6%*	**23%O**	**22%O**
3 specialists	**247**	52	29	12	10	53	55	13	23	11	19	3	10	2	13	74	9
	18%H	*16%*	*19%*	*16%*	*13%*	**20%H**	**20%H**	*11%*	**28%ABEH**	*25%*	*16%*	*19%*	*24%*	*25%*	*26%*	*19%*	*18%*
4 specialists	**183**	35	16	15	5	40	54	8	10	8	16	5	3	-	8	64	10
	14%H	*11%*	*11%*	**19%BEH**	*6%*	**15%EH**	**20%ABCEH**	*7%*	*12%*	*18%*	*14%*	*31%*	*7%*	-	*16%*	**17%A**	*20%*
5 specialists	**83**	26	8	4	4	17	16	4	4	2	7	2	5	3	5	25	5
	6%	*8%*	*5%*	*5%*	*5%*	*7%*	*6%*	*3%*	*5%*	*5%*	*6%*	*13%*	*12%*	*38%*	*10%*	*7%*	*10%*
6 specialists	**38**	8	6	3	1	10	8	1	1	1	6	-	1	-	5	14	1
	3%	*3%*	*4%*	*4%*	*1%*	*4%*	*3%*	*1%*	*1%*	*2%*	*5%*	-	*2%*	-	**10%AP**	*4%*	*2%*
7 specialists	**23**	2	3	1	1	6	8	1	1	-	2	1	-	-	-	11	1
	2%	*1%*	*2%*	*1%*	*1%*	*2%*	**3%B**	*1%*	*1%*	-	*2%*	*6%*	-	-	-	*3%*	*2%*
8 specialists	**6**	2	-	1	1	1	1	-	-	-	2	-	1	-	-	1	-
	*****	*1%*	-	*1%*	*1%*	*	*	-	-	-	*2%*	-	*2%*	-	-	*	-
9 specialists	**3**	1	-	-	-	1	1	-	-	-	-	-	-	-	-	2	-
	*****	*	-	-	-	*	*	-	-	-	-	-	-	-	-	*1%*	-
10 or more specialists	**4**	2	1	-	-	-	1	-	-	-	1	-	-	-	-	2	1
	*****	*1%*	*1%*	-	-	-	*	-	-	-	*1%*	-	-	-	-	*1%*	**2%A**
Average number of codes selected, not including `None of these', `I don't know', 'Not stated'	**2.5EH**	**2.5EH**	**2.5EH**	**2.7EH**	**1.7**	**2.7AEH**	**2.8ABEH**	**1.6**	**2.4EH**	**2.5**	**2.7**	**3.4**	**2.6**	**3.0**	**2.9**	**2.8A**	**3.0A**

Fieldwork dates: 22nd April - 31st May 2024
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Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Standard deviation	**1.7**	**1.7**	**1.7**	**1.6**	**1.8**	**1.6**	**1.7**	**1.5**	**1.4**	**1.4**	**1.9**	**1.5**	**1.7**	**1.9**	**1.7**	**1.8**	**1.9**
Standard error	**0.05**	**0.10**	**0.14**	**0.18**	**0.21**	**0.10**	**0.11**	**0.14**	**0.16**	**0.21**	**0.18**	**0.38**	**0.26**	**0.68**	**0.25**	**0.09**	**0.27**

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RAIRDA Survey 2024

Table 8

Q3 Thinking about all of your rare autoimmune disease(s), in the last 12 months, which of the following specialties have you received care from?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Rheumatology	**1046**	327	302	105	95	210	309	525	173
	77%E	**82%AEF**	**83%AEF**	**91%ABCEFH**	*63%*	**73%E**	**88%ABCEFH**	**81%AEF**	**90%ABCEFH**
Ophthalmology	**354**	128	154	26	39	82	67	162	58
	26%G	**32%ADGH**	**42%ABDEFGHI**	*22%*	*26%*	**29%G**	*19%*	**25%G**	**30%G**
Respiratory	**346**	69	95	48	19	78	164	202	62
	26%BE	*17%*	**26%BE**	**41%ABCEFH**	*13%*	**27%BE**	**47%ABCEFHI**	**31%ABCE**	**32%ABE**
Cardiology	**280**	75	79	32	26	41	130	171	51
	21%F	*19%*	**22%F**	**28%BEF**	*17%*	*14%*	**37%ABCDEFHI**	**26%ABCEF**	**26%ABEF**
Gastroenterology	**244**	62	79	24	28	41	105	153	54
	18%	*16%*	**22%ABF**	*21%*	*19%*	*14%*	**30%ABCDEFH**	**24%ABF**	**28%ABEF**
Dermatology	**220**	94	67	26	19	41	61	110	33
	16%	**24%ACEFGHI**	*18%*	**22%EF**	*13%*	*14%*	*17%*	*17%*	*17%*
Renal	**193**	63	29	7	19	105	24	61	26
	14%CDGH	**16%CDGH**	*8%*	*6%*	**13%G**	**37%ABCDEGHI**	*7%*	**9%G**	**13%CDGH**
ENT	**165**	35	44	15	11	85	27	61	19
	12%BEGH	*9%*	**12%G**	*13%*	*7%*	**30%ABCDEGHI**	*8%*	*9%*	*10%*
Oral medicine	**161**	44	72	16	12	25	51	94	33
	12%	*11%*	**20%ABEFGH**	*14%*	*8%*	*9%*	**15%EF**	**14%ABEF**	**17%ABEF**
Neurology	**143**	52	50	20	22	38	24	67	28
	11%G	**13%G**	**14%AGH**	**17%AGH**	**15%G**	**13%G**	*7%*	**10%G**	**15%G**
Haematology	**32**	12	5	1	23	-	2	7	4
	2%FGH	**3%FGH**	**1%F**	*1%*	**15%ABCDFGHI**	-	*1%*	*1%*	**2%F**
Physiotherapy	**17**	9	6	4	2	2	2	10	6
	1%	**2%A**	*2%*	**3%AFG**	*1%*	*1%*	*1%*	**2%G**	**3%AFG**
Endocrinology	**15**	6	2	-	-	6	2	7	3
	1%	*2%*	*1%*	-	-	*2%*	*1%*	*1%*	*2%*

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 8

Q3 Thinking about all of your rare autoimmune disease(s), in the last 12 months, which of the following specialties have you received care from?

Base: all participants

	Total (A)	Combined diagnoses							
		A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Orthopaedics	**14**	9	1	-	2	4	2	7	1
	1%	**2%AC**	*	-	*1%*	*1%*	*1%*	*1%*	*1%*
Pain management	**11**	3	6	2	2	5	-	6	2
	1%	*1%*	**2%G**	**2%G**	**1%G**	**2%G**	-	*1%*	*1%*
GP	**10**	3	2	-	1	3	2	6	-
	1%	*1%*	*1%*	-	*1%*	*1%*	*1%*	*1%*	-
Immunology	**9**	2	2	1	-	6	1	3	1
	1%	*1%*	*1%*	*1%*	-	**2%ABGH**	*	*	*1%*
Vascular	**9**	3	2	-	-	4	2	5	3
	1%	*1%*	*1%*	-	-	*1%*	*1%*	*1%*	*2%*
Urology	**8**	3	3	-	1	3	1	4	2
	1%	*1%*	*1%*	-	*1%*	*1%*	*	*1%*	*1%*
Podiatry	**6**	2	2	1	1	-	2	3	2
	*	*1%*	*1%*	*1%*	*1%*	-	*1%*	*	*1%*
Dental	**6**	-	4	-	-	2	2	3	1
	*	-	**1%B**	-	-	*1%*	*1%*	*	*1%*
Plastics	**6**	-	1	1	-	1	5	4	1
	*	-	*	*1%*	-	*	**1%ABH**	*1%*	*1%*
Gynaecology	**5**	2	3	2	2	1	1	1	-
	*	*1%*	**1%H**	**2%AH**	**1%H**	*	*	*	-
Pulmonary hypertension	**4**	-	1	1	-	1	2	2	3
	*	-	*	*1%*	-	*	*1%*	*	**2%ABH**
Colorectal	**3**	-	-	1	-	1	1	1	1
	*	-	-	*1%*	-	*	*	*	*1%*
Hepatology	**3**	1	-	-	-	-	1	-	1
	*	*	-	-	-	-	*	-	*1%*
Psychology	**3**	1	1	-	-	1	1	1	1
	*	*	*	-	-	*	*	*	*1%*

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 8

Q3 Thinking about all of your rare autoimmune disease(s), in the last 12 months, which of the following specialties have you received care from?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Oncology	**2**	-	1	-	-	-	1	-	-
	*	-	*	-	-	-	*	-	-
Dietician	**2**	1	2	-	-	-	1	2	1
	*	*	*1%*	-	-	-	*	*	*1%*
Stroke clinic	**2**	1	1	-	1	1	-	1	-
	*	*	*	-	*1%*	*	-	*	-
Thrombosis	**2**	1	-	-	2	-	-	-	-
	*	*	-	-	**1%ACGH**	-	-	-	-
Nephrology	**2**	-	-	-	-	2	-	-	-
	*	-	-	-	-	**1%AH**	-	-	-
Psychiatry	**2**	2	-	-	-	-	-	-	-
	*	*1%*	-	-	-	-	-	-	-
Other	**44**	16	12	3	3	13	10	23	6
	3%	*4%*	*3%*	*3%*	*2%*	*5%*	*3%*	*4%*	*3%*
None of these	**102**	22	18	-	25	9	15	55	7
	8%CDFGI	**6%D**	**5%D**	-	**17%ABCDFGHI**	*3%*	**4%D**	**8%BCDFGI**	**4%D**
I don't know	**1**	-	-	-	-	-	-	1	-
	*	-	-	-	-	-	-	*	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
1 specialist	**349**	107	92	27	44	63	75	150	36
	26%GHI	**27%I**	*25%*	*23%*	**29%I**	*22%*	*21%*	*23%*	*19%*
2 specialists	**313**	93	80	25	26	69	69	136	40
	23%	*23%*	*22%*	*22%*	*17%*	*24%*	*20%*	*21%*	*21%*
3 specialists	**247**	70	63	26	24	59	72	123	47
	18%	*18%*	*17%*	*22%*	*16%*	*21%*	*21%*	*19%*	**24%ABCEH**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Q3 Thinking about all of your rare autoimmune disease(s), in the last 12 months, which of the following specialties have you received care from?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
4 specialists	**183**	52	54	21	15	44	67	94	33
	14%	*13%*	*15%*	***18%E***	*10%*	*15%*	***19%ABEH***	*14%*	***17%E***
5 specialists	**83**	31	24	9	9	22	24	45	13
	6%	*8%*	*7%*	*8%*	*6%*	*8%*	*7%*	*7%*	*7%*
6 specialists	**38**	13	16	5	4	12	16	23	9
	3%	*3%*	***4%A***	*4%*	*3%*	*4%*	***5%A***	*4%*	*5%*
7 specialists	**23**	4	9	2	1	7	9	14	3
	2%	*1%*	*2%*	*2%*	*1%*	*2%*	*3%*	*2%*	*2%*
8 specialists	**6**	3	4	1	2	1	1	3	2
	*	*1%*	*1%*	*1%*	*1%*	*	*	*	*1%*
9 specialists	**3**	1	2	-	-	1	1	2	1
	*	*	*1%*	-	-	*	*	*	*1%*
10 or more specialists	**4**	2	4	-	1	-	1	3	2
	*	*1%*	***1%A***	-	*1%*	-	*	*	*1%*
Average number of codes selected, not including `None of these', `I don't know', 'Not stated'	**2.5E**	**2.6E**	**2.8ABE**	**2.9AE**	**2.2**	**2.8AE**	**2.9ABEH**	**2.6AE**	**3.0ABEH**
Standard deviation	**1.7**	**1.8**	**2.0**	**1.6**	**1.9**	**1.7**	**1.7**	**1.8**	**1.9**
Standard error	**0.05**	**0.09**	**0.10**	**0.15**	**0.15**	**0.10**	**0.09**	**0.07**	**0.13**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
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RAIRDA Survey 2024

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Q3 Thinking about all of your rare autoimmune disease(s), in the last 12 months, which of the following specialties have you received care from?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Rheumatology	**1046**	18	65	120	213	322	223	77	8	75	969	-	-
	77%HJ	*78%*	**86%H**	**80%H**	**79%H**	*77%*	*76%*	*69%*	*80%*	*63%*	**79%AJ**	-	-
Ophthalmology	**354**	5	17	42	58	115	91	24	2	23	331	-	-
	26%E	*22%*	*22%*	*28%*	*21%*	*28%*	**31%AE**	*21%*	*20%*	*19%*	**27%A**	-	-
Respiratory	**346**	4	17	40	65	104	87	27	2	29	317	-	-
	26%	*17%*	*22%*	*27%*	*24%*	*25%*	*30%*	*24%*	*20%*	*24%*	*26%*	-	-
Cardiology	**280**	4	15	36	55	78	62	28	2	21	259	-	-
	21%	*17%*	*20%*	*24%*	*20%*	*19%*	*21%*	*25%*	*20%*	*18%*	*21%*	-	-
Gastroenterology	**244**	3	10	29	52	78	50	22	-	12	231	1	-
	18%J	*13%*	*13%*	*19%*	*19%*	*19%*	*17%*	*20%*	-	*10%*	**19%AJ**	*50%*	-
Dermatology	**220**	7	17	24	43	73	36	19	1	11	208	-	-
	16%GJ	*30%*	**22%G**	*16%*	*16%*	*17%*	*12%*	*17%*	*10%*	*9%*	**17%AJ**	-	-
Renal	**193**	3	15	19	42	62	39	13	-	30	162	1	-
	14%K	*13%*	*20%*	*13%*	*15%*	*15%*	*13%*	*12%*	-	**25%AK**	*13%*	*50%*	-
ENT	**165**	3	9	26	34	56	30	7	-	16	149	-	-
	12%H	*13%*	*12%*	**17%AGH**	*13%*	**13%H**	*10%*	*6%*	-	*13%*	*12%*	-	-
Oral medicine	**161**	3	11	16	37	49	32	11	2	7	154	-	-
	12%J	*13%*	*14%*	*11%*	*14%*	*12%*	*11%*	*10%*	*20%*	*6%*	**13%AJ**	-	-
Neurology	**143**	2	6	20	29	49	29	8	-	12	130	1	-
	11%	*9%*	*8%*	*13%*	*11%*	*12%*	*10%*	*7%*	-	*10%*	*11%*	*50%*	-
Haematology	**32**	3	4	5	8	6	4	2	-	1	30	1	-
	2%	*13%*	**5%FG**	*3%*	*3%*	*1%*	*1%*	*2%*	-	*1%*	*2%*	*50%*	-
Physiotherapy	**17**	-	-	2	6	6	3	-	-	1	16	-	-
	1%	-	-	*1%*	*2%*	*1%*	*1%*	-	-	*1%*	*1%*	-	-
Endocrinology	**15**	-	3	2	5	1	2	2	-	-	15	-	-
	1%F	-	**4%AFG**	*1%*	**2%F**	*	*1%*	*2%*	-	-	*1%*	-	-
Orthopaedics	**14**	-	1	-	-	6	4	2	1	1	13	-	-
	1%	-	*1%*	-	-	**1%E**	*1%*	**2%E**	*10%*	*1%*	*1%*	-	-
Pain management	**11**	-	-	2	5	4	-	-	-	1	10	-	-
	1%	-	-	**1%G**	**2%G**	*1%*	-	-	-	*1%*	*1%*	-	-
GP	**10**	-	-	1	-	3	3	3	-	1	9	-	-
	1%	-	-	*1%*	-	*1%*	*1%*	**3%AE**	-	*1%*	*1%*	-	-
Immunology	**9**	-	1	-	2	2	4	-	-	-	9	-	-
	1%	-	*1%*	-	*1%*	*	*1%*	-	-	-	*1%*	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 9

Q3 Thinking about all of your rare autoimmune disease(s), in the last 12 months, which of the following specialties have you received care from?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Vascular	**9**	-	-	-	4	1	3	1	-	1	7	1	-
	1%	-	-	-	*1%*	*	*1%*	*1%*	-	*1%*	*1%*	*50%*	-
Urology	**8**	-	1	-	-	4	1	2	-	-	8	-	-
	1%	-	*1%*	-	-	*1%*	*	**2%E**	-	-	*1%*	-	-
Podiatry	**6**	-	-	1	1	2	2	-	-	-	6	-	-
	*	-	-	*1%*	*	*	*1%*	-	-	-	*	-	-
Dental	**6**	-	-	-	-	1	5	-	-	-	6	-	-
	*	-	-	-	-	*	**2%AEF**	-	-	-	*	-	-
Plastics	**6**	-	1	1	1	1	1	1	-	-	6	-	-
	*	-	*1%*	*1%*	*	*	*	*1%*	-	-	*	-	-
Gynaecology	**5**	-	1	-	2	1	1	-	-	-	5	-	-
	*	-	*1%*	-	*1%*	*	*	-	-	-	*	-	-
Pulmonary hypertension	**4**	-	1	-	1	1	1	-	-	1	3	-	-
	*	-	*1%*	-	*	*	*	-	-	*1%*	*	-	-
Colorectal	**3**	-	1	-	-	-	1	1	-	-	3	-	-
	*	-	**1%F**	-	-	-	*	*1%*	-	-	*	-	-
Hepatology	**3**	-	1	1	-	-	-	1	-	-	3	-	-
	*	-	**1%F**	*1%*	-	-	-	*1%*	-	-	*	-	-
Psychology	**3**	-	1	1	-	-	1	-	-	-	3	-	-
	*	-	**1%F**	*1%*	-	-	*	-	-	-	*	-	-
Oncology	**2**	-	-	-	-	1	1	-	-	1	1	-	-
	***K**	-	-	-	-	*	*	-	-	**1%K**	*	-	-
Dietician	**2**	-	-	-	-	1	1	-	-	1	1	-	-
	***K**	-	-	-	-	*	*	-	-	**1%K**	*	-	-
Stroke clinic	**2**	-	-	-	-	2	-	-	-	-	2	-	-
	*	-	-	-	-	*	-	-	-	-	*	-	-
Thrombosis	**2**	-	-	-	1	1	-	-	-	-	2	-	-
	*	-	-	-	*	*	-	-	-	-	*	-	-
Nephrology	**2**	-	-	-	1	-	1	-	-	-	2	-	-
	*	-	-	-	*	-	*	-	-	-	*	-	-
Psychiatry	**2**	-	-	2	-	-	-	-	-	-	2	-	-
	*	-	-	**1%AFG**	-	-	-	-	-	-	*	-	-
Other	**44**	1	3	3	2	19	13	3	-	6	38	-	-
	3%E	*4%*	**4%E**	*2%*	*1%*	**5%E**	**4%E**	*3%*	-	*5%*	*3%*	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
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RAIRDA Survey 2024

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Q3 Thinking about all of your rare autoimmune disease(s), in the last 12 months, which of the following specialties have you received care from?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
None of these	**102**	1	3	11	23	31	17	15	1	13	89	-	-
	8%	*4%*	*4%*	*7%*	*8%*	*7%*	*6%*	**13%ACFG**	*10%*	*11%*	*7%*	-	-
I don't know	**1**	-	-	-	1	-	-	-	-	-	1	-	-
	*	-	-	-	*	-	-	-	-	-	*	-	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
1 specialist	**349**	7	17	31	71	115	74	29	5	43	305	-	-
	26%K	*30%*	*22%*	*21%*	*26%*	*28%*	*25%*	*26%*	*50%*	**36%AK**	*25%*	-	-
2 specialists	**313**	6	21	31	56	99	76	22	2	28	283	1	-
	23%	*26%*	*28%*	*21%*	*21%*	*24%*	*26%*	*20%*	*20%*	*23%*	*23%*	*50%*	-
3 specialists	**247**	3	15	37	53	70	50	18	1	14	232	1	-
	18%J	*13%*	*20%*	**25%AF**	*20%*	*17%*	*17%*	*16%*	*10%*	*12%*	*19%*	*50%*	-
4 specialists	**183**	3	9	22	40	50	42	17	-	12	171	-	-
	14%	*13%*	*12%*	*15%*	*15%*	*12%*	*14%*	*15%*	-	*10%*	*14%*	-	-
5 specialists	**83**	2	7	10	11	23	22	8	-	5	78	-	-
	6%	*9%*	*9%*	*7%*	*4%*	*6%*	*8%*	*7%*	-	*4%*	*6%*	-	-
6 specialists	**38**	1	2	5	5	16	6	2	1	2	36	-	-
	3%	*4%*	*3%*	*3%*	*2%*	*4%*	*2%*	*2%*	*10%*	*2%*	*3%*	-	-
7 specialists	**23**	-	2	3	8	6	3	1	-	2	21	-	-
	2%	-	*3%*	*2%*	*3%*	*1%*	*1%*	*1%*	-	*2%*	*2%*	-	-
8 specialists	**6**	-	-	-	3	3	-	-	-	-	6	-	-
	*	-	-	-	*1%*	*1%*	-	-	-	-	*	-	-
9 specialists	**3**	-	-	-	-	2	1	-	-	-	3	-	-
	*	-	-	-	-	*	*	-	-	-	*	-	-
10 or more specialists	**4**	-	-	-	-	3	1	-	-	1	3	-	-
	*	-	-	-	-	*1%*	*	-	-	*1%*	*	-	-
Average number of codes selected, not including `None of these', `I don't know', 'Not stated'	**2.5J**	**2.4**	**2.6**	**2.6**	**2.5**	**2.5**	**2.5**	**2.3**	**1.8**	**2.1**	**2.5AJ**	**2.5**	**-**
Standard deviation	**1.7**	**1.6**	**1.6**	**1.6**	**1.7**	**1.9**	**1.6**	**1.6**	**1.7**	**1.7**	**1.7**	**0.7**	**-**
Standard error	**0.05**	**0.33**	**0.18**	**0.13**	**0.11**	**0.09**	**0.10**	**0.15**	**0.53**	**0.16**	**0.05**	**0.50**	**-**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 10

Q4 Thinking about all of your rare autoimmune disease(s), currently how many different hospital sites do you visit for your treatment or monitoring?

Base: all participants

		Total (A)	Primary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Primary diagnosis: Sjogren's disease (C)	Primary diagnosis: Myositis/ inflammatory muscle disease (D)	Primary diagnosis: Antiphospholipid syndrome (APS) (E)	Primary diagnosis: A form of systemic vasculitis (including Behcet's) (F)	Primary diagnosis: A form of systemic sclerosis or scleroderma (G)	Primary diagnosis: Raynaud's disease (H)	Primary diagnosis: Undifferentiated or mixed connective tissue disease (I)	Secondary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Secondary diagnosis: Sjogren's disease (K)	Secondary diagnosis: Myositis/ inflammatory muscle disease (L)	Secondary diagnosis: Antiphospholipid syndrome (APS) (M)	Secondary diagnosis: A form of systemic vasculitis (including Behcet's) (N)	Secondary diagnosis: A form of systemic sclerosis or scleroderma (O)	Secondary diagnosis: Raynaud's disease (P)	Secondary diagnosis: Undifferentiated or mixed connective tissue disease (Q)
Total		**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
1	(1)	**585**	148	71	33	43	110	92	55	33	18	48	8	17	1	22	139	21
		43%GP	**46%G**	**47%G**	*43%*	**56%AFG**	*42%*	*34%*	**48%G**	*40%*	*41%*	*41%*	*50%*	*40%*	*13%*	*44%*	*36%*	*42%*
2	(2)	**428**	101	39	28	15	100	98	22	25	15	29	4	17	2	14	144	16
		32%EH	**32%EH**	*26%*	**36%EH**	*19%*	**38%ACEH**	**36%CEH**	*19%*	*30%*	*34%*	*25%*	*25%*	*40%*	*25%*	*28%*	**38%AK**	*32%*
3	(3)	**210**	50	27	8	10	32	53	12	18	7	26	3	3	4	11	67	9
		16%	*16%*	*18%*	*10%*	*13%*	*12%*	**20%AFH**	*10%*	**22%FH**	*16%*	**22%AM**	*19%*	*7%*	*50%*	*22%*	*17%*	*18%*
4	(4)	**65**	12	7	6	2	15	15	5	3	2	8	-	5	-	3	20	3
		5%	*4%*	*5%*	*8%*	*3%*	*6%*	*6%*	*4%*	*4%*	*5%*	*7%*	-	**12%A**	-	*6%*	*5%*	*6%*
5	(5)	**18**	4	3	1	1	-	6	-	3	2	2	1	-	1	-	7	-
		1%	*1%*	**2%F**	*1%*	*1%*	-	**2%F**	-	**4%FH**	*5%*	*2%*	*6%*	-	*13%*	-	*2%*	-
6 or more	(6)	**15**	4	3	1	1	2	4	-	-	-	3	-	-	-	-	3	1
		1%	*1%*	*2%*	*1%*	*1%*	*1%*	*1%*	-	-	-	*3%*	-	-	-	-	*1%*	*2%*
I can't remember		**31**	1	1	-	5	1	2	21	-	-	-	-	-	-	-	3	-
		2%BFGP	*	*1%*	-	**6%ABCDFGI**	*	*1%*	**18%ABCDEFGI**	-	-	-	-	-	-	-	*1%*	-
Don't know/no answer		-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Average number of hospital sites		**1.9H**	**1.9**	**1.9H**	**1.9**	**1.7**	**1.8**	**2.1ABEFH**	**1.6**	**2.0H**	**2.0**	**2.1A**	**1.9**	**1.9**	**2.8**	**1.9**	**2.0A**	**2.0**
Standard deviation		**1.0**	**1.0**	**1.2**	**1.1**	**1.1**	**0.9**	**1.1**	**0.9**	**1.1**	**1.1**	**1.2**	**1.1**	**1.0**	**1.2**	**1.0**	**1.0**	**1.1**
Standard error		**0.03**	**0.06**	**0.09**	**0.12**	**0.12**	**0.06**	**0.07**	**0.09**	**0.12**	**0.16**	**0.11**	**0.29**	**0.15**	**0.41**	**0.13**	**0.05**	**0.15**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 11

Q4 Thinking about all of your rare autoimmune disease(s), currently how many different hospital sites do you visit for your treatment or monitoring?

Base: all participants

		Total (A)	Combined diagnoses: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total		**1352**	398	366	116	151	287	350	649	193
1	(1)	**585**	176	152	46	71	117	130	256	72
		43%GH	**44%G**	*42%*	*40%*	**47%G**	*41%*	*37%*	*39%*	*37%*
2	(2)	**428**	124	99	38	45	105	118	203	59
		32%C	*31%*	*27%*	*33%*	*30%*	**37%AC**	**34%C**	*31%*	*31%*
3	(3)	**210**	69	75	18	19	42	70	116	43
		16%	*17%*	**20%AEF**	*16%*	*13%*	*15%*	**20%AE**	**18%A**	**22%AEF**
4	(4)	**65**	16	23	11	9	19	20	34	13
		5%	*4%*	*6%*	**9%AB**	*6%*	*7%*	*6%*	*5%*	*7%*
5	(5)	**18**	7	7	2	1	1	6	10	3
		1%	*2%*	*2%*	*2%*	*1%*	*	*2%*	*2%*	*2%*
6 or more	(6)	**15**	5	8	1	1	2	4	6	3
		1%	*1%*	**2%AH**	*1%*	*1%*	*1%*	*1%*	*1%*	*2%*
I can't remember		**31**	1	2	-	5	1	2	24	-
		2%BCFGI	*	*1%*	-	**3%BCDFGI**	*	*1%*	**4%ABCDFGI**	-
Don't know/no answer		**-**	-	-	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-
Average number of hospital sites		**1.9**	**1.9**	**2.1ABE**	**2.0**	**1.8**	**1.9**	**2.0AE**	**2.0A**	**2.1ABEF**
Standard deviation		**1.0**	**1.1**	**1.2**	**1.1**	**1.0**	**1.0**	**1.1**	**1.1**	**1.1**
Standard error		**0.03**	**0.05**	**0.06**	**0.10**	**0.08**	**0.06**	**0.06**	**0.04**	**0.08**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 12

Q4 Thinking about all of your rare autoimmune disease(s), currently how many different hospital sites do you visit for your treatment or monitoring?

Base: all participants

		Total (A)	Age								Gender			
			16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total		**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
1	(1)	**585**	10	33	59	108	186	130	54	5	64	520	-	-
		43%K	*43%*	*43%*	*39%*	*40%*	*44%*	*45%*	*48%*	*50%*	**53%AK**	*42%*	-	-
2	(2)	**428**	5	23	55	94	131	87	29	4	25	401	1	-
		32%J	*22%*	*30%*	*37%*	*35%*	*31%*	*30%*	*26%*	*40%*	*21%*	**33%AJ**	*50%*	-
3	(3)	**210**	8	16	18	46	61	49	12	-	19	191	-	-
		16%	*35%*	*21%*	*12%*	*17%*	*15%*	*17%*	*11%*	-	*16%*	*16%*	-	-
4	(4)	**65**	-	2	14	10	23	10	6	-	3	62	-	-
		5%	-	*3%*	**9%AEG**	*4%*	*6%*	*3%*	*5%*	-	*3%*	*5%*	-	-
5	(5)	**18**	-	-	-	7	4	5	2	-	1	16	1	-
		1%	-	-	-	**3%D**	*1%*	*2%*	*2%*	-	*1%*	*1%*	*50%*	-
6 or more	(6)	**15**	-	2	2	3	2	3	3	-	1	14	-	-
		1%	-	*3%*	*1%*	*1%*	*	*1%*	**3%F**	-	*1%*	*1%*	-	-
I can't remember		**31**	-	-	2	3	11	8	6	1	7	24	-	-
		2%K	-	-	*1%*	*1%*	*3%*	*3%*	**5%ACE**	*10%*	**6%AK**	*2%*	-	-
Don't know/no answer		**-**	-	-	-	-	-	-	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-	-	-	-	-
Average number of hospital sites		**1.9J**	**1.9**	**1.9**	**2.0**	**2.0**	**1.9**	**1.9**	**1.9**	**1.4**	**1.7**	**1.9**	**3.5**	**-**
Standard deviation		**1.0**	**0.9**	**1.1**	**1.1**	**1.1**	**1.0**	**1.0**	**1.2**	**0.5**	**1.0**	**1.0**	**2.1**	**-**
Standard error		**0.03**	**0.19**	**0.12**	**0.09**	**0.07**	**0.05**	**0.06**	**0.12**	**0.18**	**0.09**	**0.03**	**1.50**	**-**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 13

Q5 Still thinking about all your rare autoimmune disease(s), how long do you need to travel to get to appointments with your specialist?

Base: all participants

		Total (A)	Primary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	Secondary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total		**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Under 30 mins	(15)	**401**	99	46	33	24	71	84	18	26	15	34	2	10	2	16	118	16
		30%H	**31%H**	**30%H**	**43%ABFH**	**31%H**	**27%H**	**31%H**	*16%*	**32%H**	*34%*	*29%*	*13%*	*24%*	*25%*	*32%*	*31%*	*32%*
31 mins up to 60 minutes	(45)	**540**	136	56	28	17	116	113	38	36	18	51	9	14	1	19	161	17
		40%E	**43%E**	**37%E**	*36%*	*22%*	**45%EH**	**42%E**	*33%*	**44%E**	*41%*	*44%*	*56%*	*33%*	*13%*	*38%*	*42%*	*34%*
61 minutes up to 90 minutes	(75)	**169**	37	16	9	7	46	37	10	7	3	17	2	5	4	8	51	9
		13%	*12%*	*11%*	*12%*	*9%*	**18%ABHI**	*14%*	*9%*	*9%*	*7%*	*15%*	*13%*	*12%*	*50%*	*16%*	*13%*	*18%*
91 minutes up to 2 hours	(105)	**61**	15	14	3	2	9	12	2	4	1	4	2	5	-	1	20	5
		5%	*5%*	**9%AFGH**	*4%*	*3%*	*3%*	*4%*	*2%*	*5%*	*2%*	*3%*	*13%*	**12%AK**	-	*2%*	*5%*	*10%*
Over 2 hours, up to 3 hours	(150)	**36**	4	7	2	3	3	9	3	5	5	2	-	1	-	1	8	1
		3%	*1%*	**5%BF**	*3%*	*4%*	*1%*	*3%*	*3%*	**6%BF**	**11%AKP**	*2%*	-	*2%*	-	*2%*	*2%*	*2%*
Over 3 hours	(180)	**39**	8	5	2	2	9	7	4	2	1	4	1	2	1	1	10	1
		3%	*3%*	*3%*	*3%*	*3%*	*3%*	*3%*	*3%*	*2%*	*2%*	*3%*	*6%*	*5%*	*13%*	*2%*	*3%*	*2%*
My appointments take place virtually (over the phone or via video call)		**21**	9	2	-	1	2	3	2	2	-	2	-	2	-	-	5	-
		2%	*3%*	*1%*	-	*1%*	*1%*	*1%*	*2%*	*2%*	-	*2%*	-	*5%*	-	-	*1%*	-
I do not see a specialist		**82**	11	5	-	21	4	4	37	-	1	2	-	3	-	4	10	1
		6%BDFGIKP	*3%*	*3%*	-	**27%ABCDFGI**	*2%*	*1%*	**32%ABCDFGI**	-	*2%*	*2%*	-	*7%*	-	**8%KP**	*3%*	*2%*
I can't remember		**3**	1	-	-	-	-	1	1	-	-	-	-	-	-	-	-	-
		*	*	-	-	-	-	*	*1%*	-	-	-	-	-	-	-	-	-
Don't know/no answer		-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Average time to appointment (minutes)		**49.6**	**46.8**	**54.4B**	**44.2**	**48.5**	**50.2**	**49.6**	**54.8**	**50.8**	**53.4**	**49.3**	**60.9**	**59.2**	**69.4**	**46.3**	**48.8**	**51.7**
Standard deviation (minutes)		**38.2**	**35.0**	**42.8**	**37.5**	**43.9**	**36.0**	**37.8**	**42.1**	**41.0**	**46.3**	**37.1**	**40.8**	**44.6**	**51.9**	**34.8**	**36.5**	**37.5**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 13

Q5 Still thinking about all your rare autoimmune disease(s), how long do you need to travel to get to appointments with your specialist?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Standard error (minutes)	**1.08**	**2.02**	**3.57**	**4.28**	**5.92**	**2.26**	**2.34**	**4.86**	**4.59**	**7.06**	**3.51**	**10.20**	**7.33**	**18.36**	**5.13**	**1.90**	**5.36**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 14

Q5 Still thinking about all your rare autoimmune disease(s), how long do you need to travel to get to appointments with your specialist?

Base: all participants

		Total (A)	Combined diagnoses							
			A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total		**1352**	398	366	116	151	287	350	649	193
Under 30 mins	(15)	**401**	124	104	45	45	77	108	182	69
		30%	*31%*	*28%*	**39%ACFH**	*30%*	*27%*	*31%*	*28%*	**36%ACFH**
31 mins up to 60 minutes	(45)	**540**	165	150	47	41	124	147	256	77
		40%E	**41%E**	**41%E**	**41%E**	*27%*	**43%E**	**42%E**	**39%E**	**40%E**
61 minutes up to 90 minutes	(75)	**169**	49	51	14	17	54	48	88	23
		13%	*12%*	*14%*	*12%*	*11%*	**19%ABEHI**	*14%*	*14%*	*12%*
91 minutes up to 2 hours	(105)	**61**	19	23	5	9	10	15	31	11
		5%	*5%*	*6%*	*4%*	*6%*	*3%*	*4%*	*5%*	*6%*
Over 2 hours, up to 3 hours	(150)	**36**	9	10	2	5	3	10	16	6
		3%F	*2%*	*3%*	*2%*	*3%*	*1%*	*3%*	*2%*	*3%*
Over 3 hours	(180)	**39**	9	12	3	7	11	9	18	4
		3%	*2%*	*3%*	*3%*	*5%*	*4%*	*3%*	*3%*	*2%*
My appointments take place virtually (over the phone or via video call)		**21**	10	5	-	3	3	3	8	2
		2%	**3%H**	*1%*	-	*2%*	*1%*	*1%*	*1%*	*1%*
I do not see a specialist		**82**	12	11	-	24	5	9	49	1
		6%BCDFGI	*3%*	**3%I**	-	**16%ABCDFGHI**	*2%*	*3%*	**8%ABCDFGI**	*1%*
I can't remember		**3**	1	-	-	-	-	1	1	-
		*	*	-	-	-	-	*	*	-
Don't know/no answer		-	-	-	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-
Average time to appointment (minutes)		**49.6**	**47.8**	**52.0**	**44.9**	**54.4B**	**51.1**	**49.1**	**50.3**	**47.4**
Standard deviation (minutes)		**38.2**	**36.0**	**39.1**	**35.9**	**46.0**	**36.8**	**37.1**	**37.8**	**37.1**
Standard error (minutes)		**1.08**	**1.86**	**2.09**	**3.33**	**4.13**	**2.20**	**2.02**	**1.55**	**2.69**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 15

Q5 Still thinking about all your rare autoimmune disease(s), how long do you need to travel to get to appointments with your specialist?

Base: all participants

		Total (A)	Age								Gender			
			16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total		**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Under 30 mins	(15)	**401**	6	24	50	89	129	77	24	2	34	367	-	-
		30%H	*26%*	*32%*	**33%H**	**33%H**	*31%*	*26%*	*21%*	*20%*	*28%*	*30%*	-	-
31 mins up to 60 minutes	(45)	**540**	11	31	57	103	169	117	49	3	45	493	1	-
		40%	*48%*	*41%*	*38%*	*38%*	*40%*	*40%*	*44%*	*30%*	*38%*	*40%*	*50%*	-
61 minutes up to 90 minutes	(75)	**169**	2	15	21	34	44	40	13	-	14	154	-	-
		13%	*9%*	**20%F**	*14%*	*13%*	*11%*	*14%*	*12%*	-	*12%*	*13%*	-	-
91 minutes up to 2 hours	(105)	**61**	2	1	6	13	18	13	8	-	4	57	-	-
		5%	*9%*	*1%*	*4%*	*5%*	*4%*	*4%*	*7%*	-	*3%*	*5%*	-	-
Over 2 hours, up to 3 hours	(150)	**36**	-	-	3	3	16	8	5	1	4	32	-	-
		3%	-	-	*2%*	*1%*	**4%E**	*3%*	**4%E**	*10%*	*3%*	*3%*	-	-
Over 3 hours	(180)	**39**	1	3	2	10	11	11	1	-	3	35	1	-
		3%	*4%*	*4%*	*1%*	*4%*	*3%*	*4%*	*1%*	-	*3%*	*3%*	*50%*	-
My appointments take place virtually (over the phone or via video call)		**21**	-	-	2	3	6	6	2	2	4	17	-	-
		2%	-	-	*1%*	*1%*	*1%*	*2%*	*2%*	*20%*	*3%*	*1%*	-	-
I do not see a specialist		**82**	1	2	9	15	24	19	10	2	12	70	-	-
		6%	*4%*	*3%*	*6%*	*6%*	*6%*	*7%*	*9%*	*20%*	*10%*	*6%*	-	-
I can't remember		**3**	-	-	-	1	1	1	-	-	-	3	-	-
		*	-	-	-	*	*	*	-	-	-	*	-	-
Don't know/no answer		**-**	-	-	-	-	-	-	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-	-	-	-	-
Average time to appointment (minutes)		**49.6**	**51.1**	**47.6**	**45.5**	**48.2**	**49.4**	**52.5**	**53.1**	**52.5**	**49.5**	**49.5**	**112.5**	**-**
Standard deviation (minutes)		**38.2**	**38.9**	**35.7**	**33.5**	**38.4**	**39.1**	**40.1**	**36.1**	**50.0**	**38.7**	**38.0**	**95.5**	**-**
Standard error (minutes)		**1.08**	**8.30**	**4.15**	**2.84**	**2.42**	**1.99**	**2.46**	**3.61**	**20.40**	**3.80**	**1.13**	**67.50**	**-**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 16

Q6 Have you ever used private healthcare for your rare autoimmune disease(s) for any of the following reasons?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Yes - to get a diagnosis	**254**	65	48	17	4	37	47	9	27	9	23	5	12	-	10	79	8
	19%EFH	**20%EH**	**32%ABEFGH**	**22%EH**	*5%*	**14%E**	**17%EH**	*8%*	**33%ABEFGH**	*20%*	*20%*	*31%*	*29%*	-	*20%*	*21%*	*16%*
Yes - to see a specific doctor/ consultant	**167**	37	48	11	4	22	27	6	12	7	16	2	7	-	7	53	7
	12%EFH	*12%*	**32%ABDEFGHI**	**14%H**	*5%*	*8%*	*10%*	*5%*	**15%H**	*16%*	*14%*	*13%*	*17%*	-	*14%*	*14%*	*14%*
Yes - the service I needed wasn't available in my area	**32**	5	11	3	1	1	6	3	2	1	6	2	2	-	3	8	-
	2%F	*2%*	**7%ABFG**	**4%F**	*1%*	*	*2%*	*3%*	*2%*	*2%*	**5%A**	*13%*	*5%*	-	*6%*	*2%*	-
Yes - the waiting time in my area for appointments was too long	**131**	39	21	9	8	17	22	6	9	2	14	3	7	-	8	36	4
	10%	**12%FH**	**14%FH**	*12%*	*10%*	*7%*	*8%*	*5%*	*11%*	*5%*	*12%*	*19%*	*17%*	-	*16%*	*9%*	*8%*
Yes - I always use private healthcare	**14**	6	1	1	-	-	2	1	3	3	4	-	-	-	1	2	1
	1%	**2%F**	*1%*	*1%*	-	-	*1%*	*1%*	**4%AF**	**7%AP**	**3%AP**	-	-	-	*2%*	*1%*	*2%*
No - I have not used private healthcare for my rare autoimmune disease(s)	**958**	222	76	51	63	199	206	94	47	26	82	10	26	8	33	262	33
	71%CI	**69%CI**	*50%*	**66%C**	**82%ABCDI**	**77%ACI**	**76%ACI**	**82%ABCDI**	*57%*	*59%*	*71%*	*63%*	*62%*	*100%*	*66%*	*68%*	*66%*
I don't know	**3**	-	-	-	-	1	-	2	-	-	-	-	-	-	-	-	-
	*	-	-	-	-	*	-	**2%ABG**	-	-	-	-	-	-	-	-	-
Prefer not to say	**8**	2	1	1	-	3	1	-	-	2	-	-	-	-	-	1	1
	1%	*1%*	*1%*	*1%*	-	*1%*	*	-	-	**5%AKP**	-	-	-	-	-	*	*2%*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Yes	**383**	96	74	25	14	57	63	19	35	16	34	6	16	-	17	120	16
	28%EFGH	**30%EFH**	**49%ABDEFGH**	**32%EH**	***18%***	***22%***	***23%***	***17%***	**43%ABEFGH**	***36%***	***29%***	***38%***	***38%***	-	***34%***	***31%***	***32%***
No	**958**	222	76	51	63	199	206	94	47	26	82	10	26	8	33	262	33
	71%CI	**69%CI**	***50%***	**66%C**	**82%ABCDI**	**77%ACI**	**76%ACI**	**82%ABCDI**	***57%***	***59%***	***71%***	***63%***	***62%***	***100%***	***66%***	***68%***	***66%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 17

Q6 Have you ever used private healthcare for your rare autoimmune disease(s) for any of the following reasons?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Yes - to get a diagnosis	**254** **19%F**	81 **20%F**	91 **25%AEFGH**	28 **24%EF**	22 *15%*	40 *14%*	67 *19%*	122 *19%*	49 **25%AEFH**
Yes - to see a specific doctor/ consultant	**167** **12%F**	48 *12%*	83 **23%ABEFGHI**	20 **17%EFG**	13 *9%*	25 *9%*	37 *11%*	83 *13%*	30 **16%EF**
Yes - the service I needed wasn't available in my area	**32** **2%F**	7 *2%*	19 **5%ABFHI**	7 **6%ABFI**	3 *2%*	2 *1%*	11 **3%F**	19 **3%F**	3 *2%*
Yes - the waiting time in my area for appointments was too long	**131** **10%F**	46 **12%F**	44 **12%F**	17 **15%F**	17 *11%*	19 *7%*	32 *9%*	63 *10%*	22 *11%*
Yes - I always use private healthcare	**14** ***1%***	9 **2%AF**	6 *2%*	1 *1%*	- -	1 *	3 *1%*	10 *2%*	5 **3%AEF**
No - I have not used private healthcare for my rare autoimmune disease(s)	**958** **71%CI**	270 **68%C**	223 *61%*	74 *64%*	111 **74%CI**	222 **77%ABCDHI**	257 **73%CDI**	452 **70%CI**	121 *63%*
I don't know	**3** *	- -	- -	- -	- -	1 *	- -	2 *	- -
Prefer not to say	**8** ***1%***	4 *1%*	2 *1%*	1 *1%*	1 *1%*	3 *1%*	2 *1%*	3 *	1 *1%*
Don't know/no answer	**-** -	- -	- -	- -	- -	- -	- -	- -	- -
Yes	**383** **28%F**	**124** **31%F**	**141** **39%ABEFGH**	**41** **35%FG**	**39** ***26%***	**61** ***21%***	**91** ***26%***	**192** **30%F**	**71** **37%AEFGH**
No	**958** **71%CI**	**270** **68%C**	**223** ***61%***	**74** ***64%***	**111** **74%CI**	**222** **77%ABCDHI**	**257** **73%CDI**	**452** **70%CI**	**121** ***63%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 18

Q6 Have you ever used private healthcare for your rare autoimmune disease(s) for any of the following reasons?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Yes - to get a diagnosis	**254**	3	12	24	61	82	51	20	1	21	232	1	-
	19%	*13%*	*16%*	*16%*	*23%*	*20%*	*17%*	*18%*	*10%*	*18%*	*19%*	*50%*	-
Yes - to see a specific doctor/ consultant	**167**	2	10	17	31	49	38	19	1	7	159	1	-
	12%J	*9%*	*13%*	*11%*	*11%*	*12%*	*13%*	*17%*	*10%*	*6%*	**13%AJ**	*50%*	-
Yes - the service I needed wasn't available in my area	**32**	1	-	1	7	11	9	3	-	-	31	1	-
	2%	*4%*	-	*1%*	*3%*	*3%*	*3%*	*3%*	-	-	*3%*	*50%*	-
Yes - the waiting time in my area for appointments was too long	**131**	4	10	16	33	32	23	13	-	10	120	1	-
	10%	*17%*	*13%*	*11%*	**12%F**	*8%*	*8%*	*12%*	-	*8%*	*10%*	*50%*	-
Yes - I always use private healthcare	**14**	-	-	3	3	3	2	3	-	-	13	1	-
	1%	-	-	*2%*	*1%*	*1%*	*1%*	*3%*	-	-	*1%*	*50%*	-
No - I have not used private healthcare for my rare autoimmune disease(s)	**958**	17	51	113	183	297	211	78	8	93	862	1	-
	71%	*74%*	*67%*	*75%*	*68%*	*71%*	*72%*	*70%*	*80%*	*78%*	*70%*	*50%*	-
I don't know	**3**	-	-	-	2	1	-	-	-	-	3	-	-
	*	-	-	-	*1%*	*	-	-	-	-	*	-	-
Prefer not to say	**8**	-	2	-	2	3	-	1	-	-	8	-	-
	1%	-	**3%ADG**	-	*1%*	*1%*	-	*1%*	-	-	*1%*	-	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Yes	**383**	**6**	**23**	**37**	**84**	**117**	**81**	**33**	**2**	**27**	**355**	**1**	**-**
	28%	***26%***	***30%***	***25%***	***31%***	***28%***	***28%***	***29%***	***20%***	***23%***	***29%***	***50%***	**-**
No	**958**	**17**	**51**	**113**	**183**	**297**	**211**	**78**	**8**	**93**	**862**	**1**	**-**
	71%	***74%***	***67%***	***75%***	***68%***	***71%***	***72%***	***70%***	***80%***	***78%***	***70%***	***50%***	**-**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 19

Q7 In the last 12 months, where have you accessed most of your care for your rare autoimmune disease(s)?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
England	**1115**	270	127	66	60	210	228	88	66	40	100	14	35	7	41	315	45
	82%	*84%*	*84%*	*86%*	*78%*	*81%*	*84%*	*77%*	*80%*	*91%*	*86%*	*88%*	*83%*	*88%*	*82%*	*82%*	*90%*
Scotland	**116**	28	13	9	8	26	18	5	9	1	9	-	5	1	3	38	2
	9%	*9%*	*9%*	*12%*	*10%*	*10%*	*7%*	*4%*	*11%*	*2%*	*8%*	-	*12%*	*13%*	*6%*	*10%*	*4%*
Wales	**62**	8	10	2	5	18	12	5	2	1	3	-	2	-	1	16	3
	5%B	*3%*	**7%B**	*3%*	*6%*	**7%B**	*4%*	*4%*	*2%*	*2%*	*3%*	-	*5%*	-	*2%*	*4%*	*6%*
Northern Ireland	**27**	8	1	-	1	4	7	4	2	1	2	1	-	-	3	9	-
	2%	*3%*	*1%*	-	*1%*	*2%*	*3%*	*3%*	*2%*	*2%*	*2%*	*6%*	-	-	**6%A**	*2%*	-
I can't remember	**32**	6	-	-	3	2	5	13	3	1	2	1	-	-	2	5	-
	2%F	*2%*	-	-	**4%CF**	*1%*	*2%*	**11%ABCDFG**	**4%C**	*2%*	*2%*	*6%*	-	-	*4%*	*1%*	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 20

Q7 In the last 12 months, where have you accessed most of your care for your rare autoimmune disease(s)?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
England	**1115**	338	307	94	123	233	294	533	163
	82%	*85%*	*84%*	*81%*	*81%*	*81%*	*84%*	*82%*	*84%*
Scotland	**116**	32	35	15	15	29	24	56	19
	9%	*8%*	*10%*	**13%G**	*10%*	*10%*	*7%*	*9%*	*10%*
Wales	**62**	10	18	4	8	18	14	23	5
	5%B	*3%*	**5%B**	*3%*	**5%B**	**6%BH**	*4%*	*4%*	*3%*
Northern Ireland	**27**	10	4	2	2	4	10	16	3
	2%	*3%*	*1%*	*2%*	*1%*	*1%*	*3%*	*2%*	*2%*
I can't remember	**32**	8	2	1	3	3	8	21	3
	2%C	**2%C**	*1%*	*1%*	*2%*	*1%*	**2%C**	**3%CF**	*2%*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 21

Q7 In the last 12 months, where have you accessed most of your care for your rare autoimmune disease(s)?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
England	**1115**	21	63	124	211	346	247	94	9	98	1015	1	-
	82%E	*91%*	*83%*	*83%*	*78%*	*83%*	***85%E***	*84%*	*90%*	*82%*	*83%*	*50%*	-
Scotland	**116**	1	7	13	31	38	19	6	1	10	105	-	-
	9%	*4%*	*9%*	*9%*	***11%G***	*9%*	*7%*	*5%*	*10%*	*8%*	*9%*	-	-
Wales	**62**	-	2	4	11	22	18	5	-	6	56	-	-
	5%	-	*3%*	*3%*	*4%*	*5%*	*6%*	*4%*	-	*5%*	*5%*	-	-
Northern Ireland	**27**	-	3	4	10	6	3	1	-	1	26	-	-
	2%	-	*4%*	*3%*	***4%AG***	*1%*	*1%*	*1%*	-	*1%*	*2%*	-	-
I can't remember	**32**	1	1	5	8	6	5	6	-	5	26	1	-
	2%	*4%*	*1%*	*3%*	*3%*	*1%*	*2%*	***5%AFG***	-	*4%*	*2%*	*50%*	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 22

Q9 PRIMARY - how long before this diagnosis were you experiencing symptoms, if at all?

Base: all participants

		Total (A)	Primary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	Secondary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total		**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Under 3 months	(1.5)	**96**	20	2	16	5	36	13	3	1	2	8	3	1	-	3	16	2
		7%CHIP	**6%C**	*1%*	**21%ABCEGHI**	**6%C**	**14%ABCGHI**	*5%*	*3%*	*1%*	*5%*	*7%*	*19%*	*2%*	-	*6%*	*4%*	*4%*
3 months up to 6 months	(4.5)	**145**	25	9	17	5	52	25	6	6	5	10	2	4	1	5	30	4
		11%BCHP	*8%*	*6%*	**22%ABCEGHI**	*6%*	**20%ABCEGHI**	*9%*	*5%*	*7%*	*11%*	*9%*	*13%*	*10%*	*13%*	*10%*	*8%*	*8%*
6 months up to 1 year	(9)	**210**	41	16	15	11	51	46	15	15	5	11	1	4	1	13	58	4
		16%	*13%*	*11%*	*19%*	*14%*	**20%ABC**	*17%*	*13%*	*18%*	*11%*	*9%*	*6%*	*10%*	*13%*	**26%AKMQ**	*15%*	*8%*
1 year up to 2 years	(18)	**199**	38	14	8	9	46	55	16	13	6	14	3	5	1	6	68	5
		15%C	*12%*	*9%*	*10%*	*12%*	**18%BC**	**20%ABCD**	*14%*	*16%*	*14%*	*12%*	*19%*	*12%*	*13%*	*12%*	*18%*	*10%*
2 years up to 3 years	(30)	**132**	36	23	5	8	23	23	10	4	4	10	2	4	-	3	37	7
		10%	*11%*	**15%AFGI**	*6%*	*10%*	*9%*	*9%*	*9%*	*5%*	*9%*	*9%*	*13%*	*10%*	-	*6%*	*10%*	*14%*
3 years up to 4 years	(42)	**64**	15	7	2	-	11	13	12	4	2	7	1	2	1	6	17	2
		5%	*5%*	*5%*	*3%*	-	*4%*	*5%*	**10%ABDEFG**	*5%*	*5%*	*6%*	*6%*	*5%*	*13%*	**12%AP**	*4%*	*4%*
4 years up to 5 years	(54)	**52**	13	11	3	2	6	7	5	5	1	9	-	1	-	1	11	4
		4%	*4%*	**7%AFG**	*4%*	*3%*	*2%*	*3%*	*4%*	*6%*	*2%*	**8%AP**	-	*2%*	-	*2%*	*3%*	*8%*
More than 5 years	(61)	**401**	124	64	10	29	29	78	36	31	18	43	4	19	4	9	134	18
		30%DF	**39%ADFG**	**42%ADFG**	*13%*	**38%DF**	*11%*	**29%DF**	**31%DF**	**38%DF**	**41%O**	**37%O**	*25%*	**45%AO**	*50%*	*18%*	**35%AO**	**36%O**
I did not experience any symptoms		**27**	4	3	-	6	5	7	2	-	1	-	-	-	-	2	7	1
		2%	*1%*	*2%*	-	**8%ABCDFGHI**	*2%*	*3%*	*2%*	-	*2%*	-	-	-	-	**4%K**	*2%*	*2%*
I can't remember		**26**	4	2	1	2	1	3	10	3	-	4	-	2	-	2	5	3
		2%F	*1%*	*1%*	*1%*	*3%*	*	*1%*	**9%ABCDFG**	**4%F**	-	*3%*	-	*5%*	-	*4%*	*1%*	**6%AP**
Don't know/no answer		-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Average time experiencing symptoms before diagnosis (months)		**30.9DF**	**35.8ADFG**	**40.6ABDFG**	**18.2**	**34.9DF**	**19.0**	**30.4DF**	**36.2ADFG**	**36.0ADF**	**35.7**	**36.7AO**	**26.4**	**39.1AO**	**39.7**	**26.0**	**33.7AO**	**38.2AO**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 22

Q9 PRIMARY - how long before this diagnosis were you experiencing symptoms, if at all?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Standard deviation (months)	**23.5**	**23.7**	**21.8**	**20.9**	**24.5**	**19.3**	**22.9**	**22.3**	**23.6**	**24.3**	**23.7**	**23.7**	**23.6**	**25.3**	**21.9**	**23.3**	**22.9**
Standard error (months)	**0.65**	**1.34**	**1.81**	**2.40**	**2.95**	**1.21**	**1.42**	**2.19**	**2.66**	**3.70**	**2.24**	**5.91**	**3.73**	**8.94**	**3.23**	**1.21**	**3.37**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 23

Q9 PRIMARY - how long before this diagnosis were you experiencing symptoms, if at all?

Base: all participants

			Combined diagnoses								
		Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total		**1352**	398	366	116	151	287	350	649	193
Under 3 months	(1.5)	**96**	24	14	20	6	39	21	27	5
		7%CHI	**6%I**	*4%*	**17%ABCEGHI**	*4%*	**14%ABCEGHI**	**6%HI**	*4%*	*3%*
3 months up to 6 months	(4.5)	**145**	33	28	20	11	56	33	53	15
		11%CH	*8%*	*8%*	**17%ABCEGHI**	*7%*	**20%ABCEGHI**	*9%*	*8%*	*8%*
6 months up to 1 year	(9)	**210**	51	40	22	18	52	65	90	29
		16%C	*13%*	*11%*	**19%C**	*12%*	**18%BC**	**19%BCH**	*14%*	*15%*
1 year up to 2 years	(18)	**199**	47	44	16	18	48	63	102	31
		15%B	*12%*	*12%*	*14%*	*12%*	*17%*	**18%ABC**	**16%BC**	*16%*
2 years up to 3 years	(30)	**132**	42	45	9	16	26	29	58	18
		10%	*11%*	**12%GH**	*8%*	*11%*	*9%*	*8%*	*9%*	*9%*
3 years up to 4 years	(42)	**64**	18	19	4	3	14	20	38	9
		5%	*5%*	*5%*	*3%*	*2%*	*5%*	*6%*	**6%E**	*5%*
4 years up to 5 years	(54)	**52**	14	20	5	5	6	9	28	10
		4%	*4%*	**5%FG**	*4%*	*3%*	*2%*	*3%*	**4%G**	*5%*
More than 5 years	(61)	**401**	157	142	19	64	39	94	220	66
		30%DF	**39%ADFGH**	**39%ADFGH**	*16%*	**42%ADFGH**	*14%*	**27%DF**	**34%ADFG**	**34%DFG**
I did not experience any symptoms		**27**	6	5	-	6	5	9	12	2
		2%	*2%*	*1%*	-	**4%D**	*2%*	*3%*	*2%*	*1%*
I can't remember		**26**	6	9	1	4	2	7	21	8
		2%	*2%*	*2%*	*1%*	*3%*	*1%*	*2%*	**3%ABF**	**4%ABF**
Don't know/no answer		**-**	-	-	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-
Average time experiencing symptoms before diagnosis (months)		**30.9DF**	**35.9ADFG**	**37.5ADFGH**	**21.5**	**37.8ADFG**	**20.4**	**29.4DF**	**34.4ADFG**	**34.9ADFG**
Standard deviation (months)		**23.5**	**23.8**	**22.9**	**21.9**	**23.7**	**20.3**	**22.9**	**23.2**	**23.1**
Standard error (months)		**0.65**	**1.21**	**1.22**	**2.04**	**2.00**	**1.21**	**1.25**	**0.94**	**1.71**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 24

Q9 PRIMARY - how long before this diagnosis were you experiencing symptoms, if at all?

Base: all participants

		Total (A)	Age								Gender			
			16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total		**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Under 3 months	(1.5)	**96**	2	9	5	25	24	25	4	2	16	80	-	-
		7%K	*9%*	**12%DH**	*3%*	**9%D**	*6%*	**9%D**	*4%*	*20%*	**13%AK**	*7%*	-	-
3 months up to 6 months	(4.5)	**145**	3	8	12	29	49	35	8	1	24	121	-	-
		11%K	*13%*	*11%*	*8%*	*11%*	*12%*	*12%*	*7%*	*10%*	**20%AK**	*10%*	-	-
6 months up to 1 year	(9)	**210**	3	14	29	52	64	29	17	2	23	187	-	-
		16%G	*13%*	**18%G**	**19%G**	**19%G**	**15%G**	*10%*	*15%*	*20%*	*19%*	*15%*	-	-
1 year up to 2 years	(18)	**199**	2	14	27	37	63	40	16	-	12	187	-	-
		15%	*9%*	*18%*	*18%*	*14%*	*15%*	*14%*	*14%*	-	*10%*	*15%*	-	-
2 years up to 3 years	(30)	**132**	5	7	19	20	43	27	10	1	7	125	-	-
		10%	*22%*	*9%*	*13%*	*7%*	*10%*	*9%*	*9%*	*10%*	*6%*	*10%*	-	-
3 years up to 4 years	(42)	**64**	2	2	8	13	22	12	5	-	4	60	-	-
		5%	*9%*	*3%*	*5%*	*5%*	*5%*	*4%*	*4%*	-	*3%*	*5%*	-	-
4 years up to 5 years	(54)	**52**	-	1	4	13	14	13	6	1	2	50	-	-
		4%	-	*1%*	*3%*	*5%*	*3%*	*4%*	*5%*	*10%*	*2%*	*4%*	-	-
More than 5 years	(61)	**401**	4	17	38	74	124	102	39	3	26	371	2	-
		30%J	*17%*	*22%*	*25%*	*27%*	*30%*	**35%ACD**	*35%*	*30%*	*22%*	*30%*	*100%*	-
I did not experience any symptoms		**27**	2	1	5	4	5	6	4	-	4	23	-	-
		2%	*9%*	*1%*	*3%*	*1%*	*1%*	*2%*	*4%*	-	*3%*	*2%*	-	-
I can't remember		**26**	-	3	3	4	10	3	3	-	2	24	-	-
		2%	-	*4%*	*2%*	*1%*	*2%*	*1%*	*3%*	-	*2%*	*2%*	-	-
Don't know/no answer		**-**	-	-	-	-	-	-	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-	-	-	-	-
Average time experiencing symptoms before diagnosis (months)		**30.9CJ**	**26.5**	**25.2**	**29.9**	**29.1**	**31.0C**	**33.3CE**	**35.2CE**	**29.3**	**23.0**	**31.6AJ**	**61.0**	**-**
Standard deviation (months)		**23.5**	**21.3**	**22.6**	**22.0**	**23.7**	**23.3**	**24.3**	**23.4**	**27.1**	**23.4**	**23.4**	**0.0**	**-**
Standard error (months)		**0.65**	**4.65**	**2.66**	**1.85**	**1.46**	**1.16**	**1.44**	**2.29**	**8.57**	**2.19**	**0.68**	**0.00**	**-**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 25

Q10 PRIMARY - how long did you have to wait to see a specialist for this diagnosis from the time of referral?

Base: all participants

			Primary diagnosis								Secondary diagnosis							
		Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total		**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Under 2 weeks	(0.2)	**146**	21	4	13	2	78	20	5	3	2	10	2	1	1	3	30	3
		11%BCEGHIP	*7%*	*3%*	**17%BCEGHI**	*3%*	**30%ABCDEGHI**	**7%C**	*4%*	*4%*	*5%*	*9%*	*13%*	*2%*	*13%*	*6%*	*8%*	*6%*
2 weeks up to 1 month	(0.7)	**155**	34	12	11	1	48	38	4	7	4	14	2	5	-	11	36	3
		11%EH	**11%EH**	**8%E**	**14%EH**	*1%*	**18%ABCEHI**	**14%EH**	*3%*	**9%E**	*9%*	*12%*	*13%*	*12%*	-	**22%APQ**	*9%*	*6%*
1 month up to 2 months	(1.5)	**151**	41	21	14	7	22	37	3	6	4	14	1	4	1	2	48	5
		11%H	**13%H**	**14%H**	**18%AFHI**	**9%H**	**8%H**	**14%H**	*3%*	*7%*	*9%*	*12%*	*6%*	*10%*	*13%*	*4%*	*13%*	*10%*
2 months up to 3 months	(2.5)	**123**	39	13	4	6	15	31	6	9	4	15	1	3	-	4	40	8
		9%F	**12%AFH**	*9%*	*5%*	*8%*	*6%*	**11%F**	*5%*	*11%*	*9%*	*13%*	*6%*	*7%*	-	*8%*	*10%*	*16%*
3 months up to 6 months	(4.5)	**187**	43	29	8	6	26	49	8	18	5	15	-	5	2	1	72	7
		14%FHO	*13%*	**19%AEFH**	*10%*	*8%*	*10%*	**18%AEFH**	*7%*	**22%AEFH**	*11%*	**13%O**	-	*12%*	*25%*	*2%*	**19%AO**	**14%O**
6 months up to 1 year	(9)	**172**	43	22	12	12	19	31	16	17	8	22	4	4	-	8	43	4
		13%F	**13%F**	**15%F**	**16%F**	**16%F**	*7%*	*11%*	**14%F**	**21%AFG**	*18%*	**19%AP**	*25%*	*10%*	-	*16%*	*11%*	*8%*
1 year up to 18 months	(15)	**52**	21	6	-	3	4	6	8	4	1	5	-	4	1	5	18	5
		4%F	**7%ADFG**	*4%*	-	*4%*	*2%*	*2%*	**7%DFG**	*5%*	*2%*	*4%*	-	*10%*	*13%*	**10%A**	*5%*	**10%A**
18 months up to 2 years	(21)	**18**	6	4	-	3	-	1	3	1	1	3	-	1	-	1	3	2
		1%	**2%F**	**3%FG**	-	**4%FG**	-	*	**3%FG**	*1%*	*2%*	*3%*	-	*2%*	-	*2%*	*1%*	**4%P**
2 years or more	(25)	**51**	7	6	3	3	6	9	11	6	3	4	1	3	-	1	15	3
		4%	*2%*	*4%*	*4%*	*4%*	*2%*	*3%*	**10%ABFG**	**7%BF**	*7%*	*3%*	*6%*	*7%*	-	*2%*	*4%*	*6%*
I did not receive a referral to a specialist as I was diagnosed through an emergency route or another route		**130**	28	14	8	27	31	5	15	2	5	5	3	8	2	1	22	4
		10%GIKP	**9%G**	**9%G**	**10%GI**	**35%ABCDFGHI**	**12%GI**	*2%*	**13%GI**	*2%*	*11%*	*4%*	*19%*	**19%AKOP**	*25%*	*2%*	*6%*	*8%*
I can't remember		**167**	37	20	4	7	11	43	36	9	7	9	2	4	1	13	56	6
		12%DF	**12%F**	**13%F**	*5%*	*9%*	*4%*	**16%DF**	**31%ABCDEFGI**	**11%F**	*16%*	*8%*	*13%*	*10%*	*13%*	**26%AKMP**	*15%*	*12%*

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 25

Q10 PRIMARY - how long did you have to wait to see a specialist for this diagnosis from the time of referral?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Average wait time (months)	**5.2F**	**5.4F**	**6.2DFG**	**4.0**	**8.0ABDFG**	**2.8**	**4.5F**	**10.3ABCDFGI**	**7.1ABDFG**	**7.0**	**5.6**	**6.1**	**7.7AP**	**5.1**	**6.1**	**5.3**	**7.2A**
Standard deviation (months)	**6.3**	**5.9**	**6.5**	**5.6**	**7.3**	**4.9**	**5.5**	**8.6**	**6.9**	**7.5**	**6.2**	**7.4**	**8.1**	**5.8**	**6.7**	**6.1**	**7.7**
Standard error (months)	**0.19**	**0.37**	**0.60**	**0.70**	**1.12**	**0.33**	**0.37**	**1.08**	**0.82**	**1.33**	**0.62**	**2.24**	**1.47**	**2.60**	**1.11**	**0.35**	**1.22**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Q10 PRIMARY - how long did you have to wait to see a specialist for this diagnosis from the time of referral?

Base: all participants

			Combined diagnoses								
		Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total		**1352**	398	366	116	151	287	350	649	193
Under 2 weeks	(0.2)	**146**	27	23	17	7	80	27	49	10
		11%BCEGHI	*7%*	*6%*	**15%BCEGHI**	*5%*	**28%ABCDEGHI**	*8%*	*8%*	*5%*
2 weeks up to 1 month	(0.7)	**155**	41	36	16	8	49	51	64	17
		11%E	**10%E**	*10%*	**14%E**	*5%*	**17%ABCEHI**	**15%ACEHI**	*10%*	*9%*
1 month up to 2 months	(1.5)	**151**	49	46	17	14	24	43	66	18
		11%	*12%*	*13%*	*15%*	*9%*	*8%*	*12%*	*10%*	*9%*
2 months up to 3 months	(2.5)	**123**	45	35	9	13	19	37	61	24
		9%	**11%F**	*10%*	*8%*	*9%*	*7%*	*11%*	*9%*	**12%F**
3 months up to 6 months	(4.5)	**187**	50	56	12	16	30	54	93	29
		14%	*13%*	*15%*	*10%*	*11%*	*10%*	*15%*	*14%*	*15%*
6 months up to 1 year	(9)	**172**	55	51	21	19	21	42	80	31
		13%F	**14%F**	**14%F**	**18%F**	*13%*	*7%*	**12%F**	**12%F**	**16%F**
1 year up to 18 months	(15)	**52**	24	20	1	10	6	11	35	13
		4%	**6%ADF**	**5%DF**	*1%*	**7%DF**	*2%*	*3%*	**5%ADFG**	**7%ADFG**
18 months up to 2 years	(21)	**18**	7	8	-	4	2	3	12	3
		1%	*2%*	*2%*	-	*3%*	*1%*	*1%*	*2%*	*2%*
2 years or more	(25)	**51**	12	14	5	8	7	13	34	11
		4%	*3%*	*4%*	*4%*	*5%*	*2%*	*4%*	**5%ABF**	*6%*
I did not receive a referral to a specialist as I was diagnosed through an emergency route or another route		**130**	41	28	12	37	34	7	48	12
		10%GH	**10%GH**	**8%G**	**10%G**	**25%ABCDFGHI**	**12%GHI**	*2%*	**7%G**	**6%G**
I can't remember		**167**	47	49	6	15	15	62	107	25
		12%DF	**12%DF**	**13%DF**	*5%*	*10%*	*5%*	**18%ABDEF**	**16%ABDEF**	**13%DF**
Don't know/no answer		**-**	-	-	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-
Average wait time (months)		**5.2F**	**5.6F**	**5.9ADFG**	**4.5F**	**7.4ABCDFG**	**3.2**	**4.9F**	**6.2ADFG**	**6.7ADFG**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Q10 PRIMARY - how long did you have to wait to see a specialist for this diagnosis from the time of referral?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Standard deviation (months)	**6.3**	**6.2**	**6.5**	**5.9**	**7.5**	**5.3**	**6.0**	**7.0**	**6.9**
Standard error (months)	**0.19**	**0.35**	**0.38**	**0.60**	**0.75**	**0.34**	**0.36**	**0.32**	**0.55**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 27

Q10 PRIMARY - how long did you have to wait to see a specialist for this diagnosis from the time of referral?

Base: all participants

		Total (A)	Age								Gender			
			16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total		**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Under 2 weeks	(0.2)	**146**	4	6	11	27	55	33	10	-	29	117	-	-
		11%K	*17%*	*8%*	*7%*	*10%*	*13%*	*11%*	*9%*	-	**24%AK**	*10%*	-	-
2 weeks up to 1 month	(0.7)	**155**	3	6	12	37	43	40	13	1	16	139	-	-
		11%	*13%*	*8%*	*8%*	*14%*	*10%*	*14%*	*12%*	*10%*	*13%*	*11%*	-	-
1 month up to 2 months	(1.5)	**151**	2	8	17	29	44	38	12	1	16	134	-	-
		11%	*9%*	*11%*	*11%*	*11%*	*11%*	*13%*	*11%*	*10%*	*13%*	*11%*	-	-
2 months up to 3 months	(2.5)	**123**	1	9	13	17	41	30	11	1	8	115	-	-
		9%	*4%*	*12%*	*9%*	*6%*	*10%*	*10%*	*10%*	*10%*	*7%*	*9%*	-	-
3 months up to 6 months	(4.5)	**187**	1	10	21	40	56	41	17	1	10	177	-	-
		14%	*4%*	*13%*	*14%*	*15%*	*13%*	*14%*	*15%*	*10%*	*8%*	*14%*	-	-
6 months up to 1 year	(9)	**172**	1	13	22	42	53	29	11	1	9	162	1	-
		13%	*4%*	*17%*	*15%*	**15%G**	*13%*	*10%*	*10%*	*10%*	*8%*	*13%*	*50%*	-
1 year up to 18 months	(15)	**52**	1	2	8	10	18	10	3	-	3	49	-	-
		4%	*4%*	*3%*	*5%*	*4%*	*4%*	*3%*	*3%*	-	*3%*	*4%*	-	-
18 months up to 2 years	(21)	**18**	2	-	2	7	2	2	3	-	-	17	1	-
		1%F	*9%*	-	*1%*	**3%F**	*	*1%*	**3%F**	-	-	*1%*	*50%*	-
2 years or more	(25)	**51**	1	2	4	12	19	8	5	-	3	48	-	-
		4%	*4%*	*3%*	*3%*	*4%*	*5%*	*3%*	*4%*	-	*3%*	*4%*	-	-
I did not receive a referral to a specialist as I was diagnosed through an emergency route or another route		**130**	3	9	15	24	43	24	9	3	12	117	-	-
		10%	*13%*	*12%*	*10%*	*9%*	*10%*	*8%*	*8%*	*30%*	*10%*	*10%*	-	-
I can't remember		**167**	4	11	25	26	44	37	18	2	14	153	-	-
		12%	*17%*	*14%*	**17%EF**	*10%*	*11%*	*13%*	*16%*	*20%*	*12%*	*12%*	-	-
Don't know/no answer		**-**	-	-	-	-	-	-	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-	-	-	-	-
Average wait time (months)		**5.2GJ**	**6.5**	**5.0**	**5.7G**	**5.8G**	**5.2**	**4.3**	**5.5**	**3.6**	**3.3**	**5.4AJ**	**15.0**	**-**
Standard deviation (months)		**6.3**	**8.8**	**5.4**	**6.0**	**6.7**	**6.4**	**5.6**	**6.8**	**3.3**	**5.3**	**6.3**	**8.5**	**-**
Standard error (months)		**0.19**	**2.21**	**0.72**	**0.58**	**0.45**	**0.35**	**0.37**	**0.74**	**1.48**	**0.54**	**0.21**	**6.00**	**-**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 28

Q9 SECONDARY - how long before this diagnosis were you experiencing symptoms, if at all?

Base: participants with 2 or more rare autoimmune rheumatic diseases

		Total (A)	Primary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Primary diagnosis: Sjogren's disease (C)	Primary diagnosis: Myositis/ inflammatory muscle disease (D)	Primary diagnosis: Antiphospholipid syndrome (APS) (E)	Primary diagnosis: A form of systemic vasculitis (including Behcet's) (F)	Primary diagnosis: A form of systemic sclerosis or scleroderma (G)	Primary diagnosis: Raynaud's disease (H)	Primary diagnosis: Undifferentiated or mixed connective tissue disease (I)	Secondary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Secondary diagnosis: Sjogren's disease (K)	Secondary diagnosis: Myositis/ inflammatory muscle disease (L)	Secondary diagnosis: Antiphospholipid syndrome (APS) (M)	Secondary diagnosis: A form of systemic vasculitis (including Behcet's) (N)	Secondary diagnosis: A form of systemic sclerosis or scleroderma (O)	Secondary diagnosis: Raynaud's disease (P)	Secondary diagnosis: Undifferentiated or mixed connective tissue disease (Q)
Total		**709**	222	66*	39*	29**	37*	225	39*	52*	44*	116	16**	42*	8**	50*	383	50*
Under 3 months	(1.5)	**60**	19	3	5	1	4	23	3	2	1	8	4	7	2	7	30	1
		8%	*9%*	*5%*	*13%*	*3%*	*11%*	*10%*	*8%*	*4%*	*2%*	*7%*	*25%*	**17%JQ**	*25%*	**14%JQ**	*8%*	*2%*
3 months up to 6 months	(4.5)	**62**	11	6	7	1	5	22	4	6	4	6	2	3	-	9	33	5
		9%B	*5%*	*9%*	**18%AB**	*3%*	**14%B**	*10%*	*10%*	*12%*	*9%*	*5%*	*13%*	*7%*	-	**18%AKP**	*9%*	*10%*
6 months up to 1 year	(9)	**85**	22	12	5	3	4	26	5	8	8	17	1	2	-	7	47	3
		12%	*10%*	*18%*	*13%*	*10%*	*11%*	*12%*	*13%*	*15%*	*18%*	*15%*	*6%*	*5%*	-	*14%*	*12%*	*6%*
1 year up to 2 years	(18)	**95**	27	7	7	3	5	35	4	7	6	18	3	5	1	4	50	8
		13%	*12%*	*11%*	*18%*	*10%*	*14%*	*16%*	*10%*	*13%*	*14%*	*16%*	*19%*	*12%*	*13%*	*8%*	*13%*	*16%*
2 years up to 3 years	(30)	**58**	21	4	3	2	3	18	3	4	2	9	2	3	-	3	32	7
		8%	*9%*	*6%*	*8%*	*7%*	*8%*	*8%*	*8%*	*8%*	*5%*	*8%*	*13%*	*7%*	-	*6%*	*8%*	*14%*
3 years up to 4 years	(42)	**40**	11	6	-	5	1	11	1	5	3	9	-	3	1	2	22	-
		6%	*5%*	*9%*	-	*17%*	*3%*	*5%*	*3%*	*10%*	*7%*	**8%Q**	-	*7%*	*13%*	*4%*	*6%*	-
4 years up to 5 years	(54)	**30**	11	1	1	2	2	8	2	3	4	7	2	1	-	3	9	4
		4%P	*5%*	*2%*	*3%*	*7%*	*5%*	*4%*	*5%*	*6%*	**9%P**	**6%P**	*13%*	*2%*	-	*6%*	*2%*	**8%P**
More than 5 years	(61)	**202**	66	22	6	11	9	65	9	14	12	31	2	8	2	6	122	19
		28%O	*30%*	**33%D**	*15%*	*38%*	*24%*	*29%*	*23%*	*27%*	*27%*	**27%O**	*13%*	*19%*	*25%*	*12%*	**32%AO**	**38%O**
I did not experience any symptoms		**20**	11	1	-	1	-	3	4	-	2	3	-	6	1	3	4	1
		3%P	**5%AG**	*2%*	-	*3%*	-	*1%*	**10%ACDGI**	-	*5%*	*3%*	-	**14%AKPQ**	*13%*	**6%P**	*1%*	*2%*
I can't remember		**57**	23	4	5	-	4	14	4	3	2	8	-	4	1	6	34	2
		8%	*10%*	*6%*	*13%*	-	*11%*	*6%*	*10%*	*6%*	*5%*	*7%*	-	*10%*	*13%*	*12%*	*9%*	*4%*
Don't know/no answer		**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Average time experiencing symptoms before diagnosis (months)		**32.0DO**	**34.4D**	**33.3D**	**21.2**	**40.6**	**28.6**	**30.8D**	**30.0**	**32.1D**	**33.3O**	**32.7O**	**23.0**	**27.8**	**30.8**	**21.7**	**32.8O**	**37.9O**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 28

Q9 SECONDARY - how long before this diagnosis were you experiencing symptoms, if at all?

Base: participants with 2 or more rare autoimmune rheumatic diseases

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**709**	222	66*	39*	29**	37*	225	39*	52*	44*	116	16**	42*	8**	50*	383	50*
Standard deviation (months)	**23.7**	**23.6**	**24.0**	**21.7**	**21.5**	**24.3**	**23.9**	**24.3**	**23.2**	**23.5**	**23.0**	**22.7**	**23.9**	**27.7**	**22.4**	**23.9**	**22.9**
Standard error (months)	**0.94**	**1.72**	**3.07**	**3.72**	**4.07**	**4.23**	**1.66**	**4.37**	**3.31**	**3.72**	**2.24**	**5.67**	**4.23**	**11.30**	**3.50**	**1.29**	**3.34**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Q9 SECONDARY - how long before this diagnosis were you experiencing symptoms, if at all?

Base: participants with 2 or more rare autoimmune rheumatic diseases

			Combined diagnoses								
		Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total		**709**	300	281	78*	103	64*	305	573	163
Under 3 months	(1.5)	**60**	23	22	12	10	8	32	49	11
		8%	*8%*	*8%*	**15%ABCHI**	*10%*	*13%*	*10%*	*9%*	*7%*
3 months up to 6 months	(4.5)	**62**	19	16	12	4	5	35	55	15
		9%BC	*6%*	*6%*	**15%ABCE**	*4%*	*8%*	**11%ABCE**	**10%BCE**	*9%*
6 months up to 1 year	(9)	**85**	34	41	9	7	5	40	68	19
		12%	*11%*	**15%E**	*12%*	*7%*	*8%*	*13%*	*12%*	*12%*
1 year up to 2 years	(18)	**95**	37	33	11	14	7	41	75	22
		13%	*12%*	*12%*	*14%*	*14%*	*11%*	*13%*	*13%*	*13%*
2 years up to 3 years	(30)	**58**	27	20	9	8	6	24	44	18
		8%	*9%*	*7%*	*12%*	*8%*	*9%*	*8%*	*8%*	*11%*
3 years up to 4 years	(42)	**40**	16	19	1	8	2	14	31	6
		6%	*5%*	**7%D**	*1%*	**8%D**	*3%*	*5%*	*5%*	*4%*
4 years up to 5 years	(54)	**30**	16	12	6	3	3	13	21	12
		4%	*5%*	*4%*	*8%*	*3%*	*5%*	*4%*	*4%*	**7%AH**
More than 5 years	(61)	**202**	89	85	11	32	18	78	169	52
		28%D	**30%D**	**30%D**	*14%*	**31%D**	**28%D**	**26%D**	**29%DG**	**32%D**
I did not experience any symptoms		**20**	14	10	-	8	2	6	11	1
		3%HI	**5%AHI**	**4%H**	-	**8%ADGHI**	*3%*	*2%*	*2%*	*1%*
I can't remember		**57**	25	23	7	9	8	22	50	7
		8%I	**8%I**	*8%*	*9%*	*9%*	**13%I**	*7%*	**9%I**	*4%*
Don't know/no answer		**-**	-	-	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-
Average time experiencing symptoms before diagnosis (months)		**32.0DG**	**34.0DG**	**33.5DG**	**23.4**	**35.3DG**	**32.0D**	**29.1D**	**31.9DG**	**34.0DG**
Standard deviation (months)		**23.7**	**23.6**	**23.8**	**22.1**	**23.5**	**24.6**	**23.8**	**24.0**	**23.6**
Standard error (months)		**0.94**	**1.46**	**1.51**	**2.62**	**2.54**	**3.35**	**1.43**	**1.06**	**1.89**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used. * small base

RAIRDA Survey 2024

Table 30

Q9 SECONDARY - how long before this diagnosis were you experiencing symptoms, if at all?

Base: participants with 2 or more rare autoimmune rheumatic diseases

		Total (A)	Age								Gender			
			16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total		**709**	8**	28**	85*	153	206	163	61*	5**	42*	663	2**	-**
Under 3 months	(1.5)	**60**	2	2	3	22	12	13	6	-	5	55	-	-
		8%	*25%*	*7%*	*4%*	**14%ADF**	*6%*	*8%*	*10%*	-	*12%*	*8%*	-	-
3 months up to 6 months	(4.5)	**62**	-	5	13	14	12	14	3	1	4	58	-	-
		9%	-	*18%*	**15%AF**	*9%*	*6%*	*9%*	*5%*	*20%*	*10%*	*9%*	-	-
6 months up to 1 year	(9)	**85**	-	2	5	22	25	23	8	-	5	80	-	-
		12%	-	*7%*	*6%*	**14%D**	*12%*	*14%*	*13%*	-	*12%*	*12%*	-	-
1 year up to 2 years	(18)	**95**	3	5	9	17	31	21	7	2	6	87	1	-
		13%	*38%*	*18%*	*11%*	*11%*	*15%*	*13%*	*11%*	*40%*	*14%*	*13%*	*50%*	-
2 years up to 3 years	(30)	**58**	-	1	9	9	19	13	6	1	2	56	-	-
		8%	-	*4%*	*11%*	*6%*	*9%*	*8%*	*10%*	*20%*	*5%*	*8%*	-	-
3 years up to 4 years	(42)	**40**	1	1	5	12	8	6	7	-	1	39	-	-
		6%	*13%*	*4%*	*6%*	*8%*	*4%*	*4%*	**11%AFG**	-	*2%*	*6%*	-	-
4 years up to 5 years	(54)	**30**	-	1	5	8	8	8	-	-	3	27	-	-
		4%	-	*4%*	*6%*	*5%*	*4%*	*5%*	-	-	*7%*	*4%*	-	-
More than 5 years	(61)	**202**	2	8	23	32	72	48	17	-	9	191	1	-
		28%E	*25%*	*29%*	*27%*	*21%*	**35%AE**	*29%*	*28%*	-	*21%*	*29%*	*50%*	-
I did not experience any symptoms		**20**	-	1	3	3	6	5	2	-	2	18	-	-
		3%	-	*4%*	*4%*	*2%*	*3%*	*3%*	*3%*	-	*5%*	*3%*	-	-
I can't remember		**57**	-	2	10	14	13	12	5	1	5	52	-	-
		8%	-	*7%*	*12%*	*9%*	*6%*	*7%*	*8%*	*20%*	*12%*	*8%*	-	-
Don't know/no answer		**-**	-	-	-	-	-	-	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-	-	-	-	-
Average time experiencing symptoms before diagnosis (months)		**32.0E**	**27.6**	**29.9**	**33.7**	**27.6**	**35.2AE**	**32.0**	**32.1**	**17.6**	**28.3**	**32.1**	**39.5**	**-**
Standard deviation (months)		**23.7**	**24.1**	**24.9**	**23.5**	**23.6**	**23.5**	**24.0**	**23.2**	**10.4**	**24.3**	**23.7**	**30.4**	**-**
Standard error (months)		**0.94**	**8.53**	**4.98**	**2.77**	**2.03**	**1.72**	**1.99**	**3.15**	**5.21**	**4.12**	**0.97**	**21.50**	**-**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 31

Q10 SECONDARY - how long did you have to wait to see a specialist for this diagnosis from the time of referral?

Base: participants with 2 or more rare autoimmune rheumatic diseases

		Total (A)	Primary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Primary diagnosis: Sjogren's disease (C)	Primary diagnosis: Myositis/ inflammatory muscle disease (D)	Primary diagnosis: Antiphospholipid syndrome (APS) (E)	Primary diagnosis: A form of systemic vasculitis (including Behcet's) (F)	Primary diagnosis: A form of systemic sclerosis or scleroderma (G)	Primary diagnosis: Raynaud's disease (H)	Primary diagnosis: Undifferentiated or mixed connective tissue disease (I)	Secondary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Secondary diagnosis: Sjogren's disease (K)	Secondary diagnosis: Myositis/ inflammatory muscle disease (L)	Secondary diagnosis: Antiphospholipid syndrome (APS) (M)	Secondary diagnosis: A form of systemic vasculitis (including Behcet's) (N)	Secondary diagnosis: A form of systemic sclerosis or scleroderma (O)	Secondary diagnosis: Raynaud's disease (P)	Secondary diagnosis: Undifferentiated or mixed connective tissue disease (Q)
Total		**709**	222	66*	39*	29**	37*	225	39*	52*	44*	116	16**	42*	8**	50*	383	50*
Under 2 weeks	(0.2)	**44**	13	-	4	1	5	15	3	3	5	4	3	5	-	6	19	2
		6%C	**6%C**	-	**10%C**	*3%*	**14%C**	**7%C**	**8%C**	*6%*	*11%*	*3%*	*19%*	**12%K**	-	**12%KP**	*5%*	*4%*
2 weeks up to 1 month	(0.7)	**56**	20	6	6	-	3	18	1	2	2	8	2	4	-	7	29	4
		8%	*9%*	*9%*	*15%*	-	*8%*	*8%*	*3%*	*4%*	*5%*	*7%*	*13%*	*10%*	-	*14%*	*8%*	*8%*
1 month up to 2 months	(1.5)	**63**	19	4	2	3	2	27	1	5	4	14	1	2	3	2	32	5
		9%	*9%*	*6%*	*5%*	*10%*	*5%*	*12%*	*3%*	*10%*	*9%*	*12%*	*6%*	*5%*	*38%*	*4%*	*8%*	*10%*
2 months up to 3 months	(2.5)	**63**	21	2	5	-	3	23	5	4	2	14	-	3	1	5	32	6
		9%	*9%*	*3%*	*13%*	-	*8%*	*10%*	*13%*	*8%*	*5%*	*12%*	-	*7%*	*13%*	*10%*	*8%*	*12%*
3 months up to 6 months	(4.5)	**81**	19	5	2	6	2	33	4	10	5	17	1	4	-	4	41	9
		11%	*9%*	*8%*	*5%*	*21%*	*5%*	**15%B**	*10%*	**19%B**	*11%*	*15%*	*6%*	*10%*	-	*8%*	*11%*	*18%*
6 months up to 1 year	(9)	**84**	25	9	5	2	6	21	9	7	8	20	4	1	-	9	36	6
		12%MP	*11%*	*14%*	*13%*	*7%*	*16%*	*9%*	**23%ABG**	*13%*	**18%M**	**17%MP**	*25%*	*2%*	-	**18%M**	*9%*	*12%*
1 year up to 18 months	(15)	**36**	14	3	1	2	1	8	5	2	2	4	-	3	2	6	15	4
		5%	*6%*	*5%*	*3%*	*7%*	*3%*	*4%*	**13%AG**	*4%*	*5%*	*3%*	-	*7%*	*25%*	**12%AKP**	*4%*	*8%*
18 months up to 2 years	(21)	**14**	2	2	-	1	1	4	4	-	1	3	-	1	-	2	4	3
		2%P	*1%*	*3%*	-	*3%*	*3%*	*2%*	**10%ABDGI**	-	*2%*	*3%*	-	*2%*	-	*4%*	*1%*	**6%AP**
2 years or more	(25)	**30**	9	2	2	2	2	11	1	1	2	3	-	3	-	1	18	3
		4%	*4%*	*3%*	*5%*	*7%*	*5%*	*5%*	*3%*	*2%*	*5%*	*3%*	-	*7%*	-	*2%*	*5%*	*6%*
I did not receive a referral to a specialist as I was diagnosed through an emergency route or another route		**119**	52	16	6	10	3	19	3	10	6	16	2	12	2	3	76	2
		17%GOQ	**23%AFGH**	**24%FGH**	*15%*	*34%*	*8%*	*8%*	*8%*	**19%G**	*14%*	*14%*	*13%*	**29%AKOQ**	*25%*	*6%*	**20%AOQ**	*4%*
I can't remember		**119**	28	17	6	2	9	46	3	8	7	13	3	4	-	5	81	6
		17%B	*13%*	**26%ABH**	*15%*	*7%*	*24%*	**20%B**	*8%*	*15%*	*16%*	*11%*	*19%*	*10%*	-	*10%*	**21%AK**	*12%*

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 31

Q10 SECONDARY - how long did you have to wait to see a specialist for this diagnosis from the time of referral?

Base: participants with 2 or more rare autoimmune rheumatic diseases

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**709**	222	66*	39*	29**	37*	225	39*	52*	44*	116	16**	42*	8**	50*	383	50*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Average wait time (months)	**6.4**	**6.2**	**7.7**	**5.2**	**8.9**	**6.5**	**5.8**	**9.0ABGI**	**5.4**	**6.7**	**5.9**	**4.0**	**7.0**	**6.2**	**6.6**	**6.3**	**7.6**
Standard deviation (months)	**7.0**	**6.9**	**7.2**	**6.9**	**8.3**	**7.7**	**6.9**	**7.2**	**5.2**	**7.1**	**6.0**	**4.1**	**8.7**	**6.9**	**6.8**	**7.2**	**7.7**
Standard error (months)	**0.32**	**0.58**	**1.26**	**1.33**	**2.01**	**1.53**	**0.55**	**1.25**	**0.90**	**1.27**	**0.65**	**1.25**	**1.71**	**2.80**	**1.04**	**0.48**	**1.18**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Q10 SECONDARY - how long did you have to wait to see a specialist for this diagnosis from the time of referral?

Base: participants with 2 or more rare autoimmune rheumatic diseases

		Total (A)	Combined diagnoses: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total		**709**	300	281	78*	103	64*	305	573	163
Under 2 weeks	(0.2)	**44**	22	13	9	7	5	22	35	9
		6%	*7%*	*5%*	**12%ACH**	*7%*	*8%*	*7%*	*6%*	*6%*
2 weeks up to 1 month	(0.7)	**56**	24	21	10	7	3	29	46	12
		8%	*8%*	*7%*	*13%*	*7%*	*5%*	*10%*	*8%*	*7%*
1 month up to 2 months	(1.5)	**63**	26	29	6	7	5	33	52	16
		9%	*9%*	*10%*	*8%*	*7%*	*8%*	*11%*	*9%*	*10%*
2 months up to 3 months	(2.5)	**63**	25	20	8	5	5	30	49	15
		9%	*8%*	*7%*	*10%*	*5%*	*8%*	*10%*	*9%*	*9%*
3 months up to 6 months	(4.5)	**81**	28	34	7	13	4	40	59	24
		11%H	*9%*	*12%*	*9%*	*13%*	*6%*	**13%H**	*10%*	**15%B**
6 months up to 1 year	(9)	**84**	38	31	11	8	10	34	67	20
		12%	*13%*	*11%*	*14%*	*8%*	*16%*	*11%*	*12%*	*12%*
1 year up to 18 months	(15)	**36**	18	11	3	7	4	15	28	13
		5%	*6%*	*4%*	*4%*	*7%*	*6%*	*5%*	*5%*	**8%C**
18 months up to 2 years	(21)	**14**	3	7	1	2	1	7	11	4
		2%	*1%*	*2%*	*1%*	*2%*	*2%*	*2%*	*2%*	*2%*
2 years or more	(25)	**30**	12	10	3	7	4	15	26	5
		4%	*4%*	*4%*	*4%*	*7%*	*6%*	*5%*	*5%*	*3%*
I did not receive a referral to a specialist as I was diagnosed through an emergency route or another route		**119**	67	51	10	27	9	25	97	18
		17%GI	**22%AGHI**	**18%GI**	*13%*	**26%ADGHI**	*14%*	*8%*	**17%GI**	*11%*
I can't remember		**119**	37	54	10	13	14	55	103	27
		17%B	*12%*	**19%B**	*13%*	*13%*	**22%B**	**18%B**	**18%B**	*17%*
Don't know/no answer		**-**	-	-	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-
Average wait time (months)		**6.4**	**6.2**	**6.3**	**5.3**	**7.6**	**7.6**	**6.1**	**6.5**	**6.5**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used. * small base

RAIRDA Survey 2024

Q10 SECONDARY - how long did you have to wait to see a specialist for this diagnosis from the time of referral?

Base: participants with 2 or more rare autoimmune rheumatic diseases

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**709**	300	281	78*	103	64*	305	573	163
Standard deviation (months)	**7.0**	**6.8**	**6.9**	**6.5**	**8.1**	**7.7**	**7.1**	**7.1**	**6.6**
Standard error (months)	**0.32**	**0.49**	**0.52**	**0.86**	**1.03**	**1.21**	**0.47**	**0.37**	**0.61**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used. * small base

RAIRDA Survey 2024

Table 33

Q10 SECONDARY - how long did you have to wait to see a specialist for this diagnosis from the time of referral?

Base: participants with 2 or more rare autoimmune rheumatic diseases

		Total (A)	Age								Gender			
			16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total		**709**	8**	28**	85*	153	206	163	61*	5**	42*	663	2**	-**
Under 2 weeks	(0.2)	**44**	1	1	5	10	12	10	5	-	7	37	-	-
		6%K	*13%*	*4%*	*6%*	*7%*	*6%*	*6%*	*8%*	-	**17%AK**	*6%*	-	-
2 weeks up to 1 month	(0.7)	**56**	1	1	5	11	18	18	2	-	7	49	-	-
		8%	*13%*	*4%*	*6%*	*7%*	*9%*	*11%*	*3%*	-	**17%AK**	*7%*	-	-
1 month up to 2 months	(1.5)	**63**	-	1	8	14	15	19	6	-	3	59	-	-
		9%	-	*4%*	*9%*	*9%*	*7%*	*12%*	*10%*	-	*7%*	*9%*	-	-
2 months up to 3 months	(2.5)	**63**	2	3	5	10	27	12	4	-	3	60	-	-
		9%	*25%*	*11%*	*6%*	*7%*	**13%AE**	*7%*	*7%*	-	*7%*	*9%*	-	-
3 months up to 6 months	(4.5)	**81**	-	4	12	23	19	17	6	-	2	79	-	-
		11%	-	*14%*	*14%*	*15%*	*9%*	*10%*	*10%*	-	*5%*	*12%*	-	-
6 months up to 1 year	(9)	**84**	1	6	12	19	26	14	5	1	-	83	1	-
		12%J	*13%*	*21%*	*14%*	*12%*	*13%*	*9%*	*8%*	*20%*	-	**13%AJ**	*50%*	-
1 year up to 18 months	(15)	**36**	-	1	7	9	11	6	2	-	1	34	1	-
		5%	-	*4%*	*8%*	*6%*	*5%*	*4%*	*3%*	-	*2%*	*5%*	*50%*	-
18 months up to 2 years	(21)	**14**	-	-	4	4	3	2	1	-	2	12	-	-
		2%	-	-	*5%*	*3%*	*1%*	*1%*	*2%*	-	*5%*	*2%*	-	-
2 years or more	(25)	**30**	1	1	1	5	12	7	3	-	2	28	-	-
		4%	*13%*	*4%*	*1%*	*3%*	*6%*	*4%*	*5%*	-	*5%*	*4%*	-	-
I did not receive a referral to a specialist as I was diagnosed through an emergency route or another route		**119**	2	3	13	28	29	29	12	3	11	107	-	-
		17%	*25%*	*11%*	*15%*	*18%*	*14%*	*18%*	*20%*	*60%*	*26%*	*16%*	-	-
I can't remember		**119**	-	7	13	20	34	29	15	1	4	115	-	-
		17%	-	*25%*	*15%*	*13%*	*17%*	*18%*	**25%E**	*20%*	*10%*	*17%*	-	-
Don't know/no answer		**-**	-	-	-	-	-	-	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-	-	-	-	-
Average wait time (months)		**6.4**	**6.7**	**6.8**	**6.9**	**6.4**	**6.7**	**5.5**	**6.5**	**9.0**	**5.0**	**6.5**	**12.0**	**-**
Standard deviation (months)		**7.0**	**9.5**	**6.0**	**6.5**	**6.7**	**7.3**	**6.9**	**7.6**	**-**	**8.2**	**6.9**	**4.2**	**-**
Standard error (months)		**0.32**	**3.89**	**1.42**	**0.85**	**0.66**	**0.61**	**0.68**	**1.31**	**-**	**1.58**	**0.33**	**3.00**	**-**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 34

Q11 PRIMARY - still thinking about your primary diagnosis, from your understanding, which service or team is mainly responsible for the care of your disease?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
My GP	**95**	16	15	2	14	3	9	32	4	4	4	2	3	-	3	18	3
	7%FGP	**5%F**	**10%BDFG**	*3%*	**18%ABDFGI**	*1%*	*3%*	**28%ABCDFGI**	**5%F**	*9%*	*3%*	*13%*	*7%*	-	*6%*	*5%*	*6%*
My local hospital's rheumatology department (secondary care)	**648**	175	65	44	14	113	152	35	50	20	67	9	20	1	31	206	22
	48%EH	**55%ACEFH**	**43%EH**	**57%CEFH**	*18%*	**43%EH**	**56%ACEFH**	*30%*	**61%ACEFH**	*45%*	**58%A**	*56%*	*48%*	*13%*	**62%A**	**54%A**	*44%*
A specialised service or centre	**69**	11	3	5	3	21	23	2	1	1	1	1	-	2	1	26	2
	5%K	*3%*	*2%*	*6%*	*4%*	**8%ABCHI**	**9%ABCHI**	*2%*	*1%*	*2%*	*1%*	*6%*	-	*25%*	*2%*	**7%K**	*4%*
Another hospital department (such as nephrology, cardiology, respiratory)	**126**	26	3	4	13	64	11	2	3	2	9	-	3	1	3	17	3
	9%CGHP	**8%CGH**	*2%*	*5%*	**17%ABCDGHI**	**25%ABCDGHI**	*4%*	*2%*	*4%*	*5%*	*8%*	-	*7%*	*13%*	*6%*	*4%*	*6%*
A regional specialised rheumatology service, or tertiary centre, in a hospital	**141**	34	22	18	1	20	27	8	11	6	16	1	10	1	5	47	8
	10%E	**11%E**	**15%EF**	**23%ABEFGH**	*1%*	**8%E**	**10%E**	*7%*	**13%E**	*14%*	*14%*	*6%*	**24%AP**	*13%*	*10%*	*12%*	*16%*
A multi-disciplinary clinic where you can see doctors from multiple specialties (e. g. rheumatology and nephrology) in one visit	**60**	9	2	2	7	20	14	2	4	-	4	-	1	-	2	16	3
	4%C	*3%*	*1%*	*3%*	**9%ABCH**	**8%ABCH**	**5%C**	*2%*	*5%*	-	*3%*	-	*2%*	-	*4%*	*4%*	*6%*
Consultant	**4**	1	-	-	-	2	1	-	-	-	-	-	-	-	-	1	-
	*	*	-	-	-	*1%*	*	-	-	-	-	-	-	-	-	*	-
Dental	**2**	-	2	-	-	-	-	-	-	1	-	-	-	-	-	-	-
	*	-	**1%AB**	-	-	-	-	-	-	**2%AP**	-	-	-	-	-	-	-
Guy's Hospital	**2**	-	-	-	1	1	-	-	-	-	-	-	-	-	-	-	-
	*	-	-	-	**1%AB**	*	-	-	-	-	-	-	-	-	-	-	-
Private rheumatologist	**10**	2	4	-	-	1	1	-	2	2	-	-	-	-	-	3	-
	1%	*1%*	**3%AFG**	-	-	*	*	-	*2%*	**5%AKP**	-	-	-	-	-	*1%*	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 34

Q11 PRIMARY - still thinking about your primary diagnosis, from your understanding, which service or team is mainly responsible for the care of your disease?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Royal Free Hospital	**2**	-	-	-	-	-	2	-	-	-	-	-	-	-	-	2	-
	*	-	-	-	-	-	**1%A**	-	-	-	-	-	-	-	-	*1%*	-
Other	**6**	1	1	-	1	-	2	1	-	-	-	-	1	-	-	1	-
	*	*	*1%*	-	*1%*	-	*1%*	*1%*	-	-	-	-	*2%*	-	-	*	-
I am responsible for coordinating my care	**70**	17	15	2	6	6	8	16	-	1	6	2	1	1	2	15	1
	5%FI	**5%I**	**10%ADFGI**	*3%*	**8%FI**	*2%*	*3%*	**14%ABDFGI**	-	*2%*	*5%*	*13%*	*2%*	*13%*	*4%*	*4%*	*2%*
It is unclear to me who is responsible for coordinating my care	**117**	28	19	-	17	9	20	17	7	7	9	1	3	2	3	31	8
	9%DF	**9%DF**	**13%DF**	-	**22%ABDFGI**	*3%*	**7%DF**	**15%ADFG**	**9%D**	*16%*	*8%*	*6%*	*7%*	*25%*	*6%*	*8%*	*16%*
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Q11 PRIMARY - still thinking about your primary diagnosis, from your understanding, which service or team is mainly responsible for the care of your disease?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
My GP	**95** **7%FG**	21 **5%F**	27 **7%FG**	4 *3%*	18 **12%ABDFGI**	4 *1%*	15 **4%F**	58 **9%ABDFGI**	10 **5%F**
My local hospital's rheumatology department (secondary care)	**648** **48%E**	213 **54%AEFH**	180 **49%E**	65 **56%EF**	52 *34%*	124 *43%*	198 **57%ACEFH**	315 **49%E**	107 **55%AEFH**
A specialised service or centre	**69** ***5%***	14 *4%*	13 *4%*	9 **8%CI**	5 *3%*	24 **8%ABCEHI**	25 **7%BCHI**	33 *5%*	6 *3%*
Another hospital department (such as nephrology, cardiology, respiratory)	**126** **9%CDGHI**	32 **8%CGH**	15 *4%*	4 *3%*	17 **11%CDGHI**	66 **23%ABCDEGHI**	16 *5%*	26 *4%*	10 *5%*
A regional specialised rheumatology service, or tertiary centre, in a hospital	**141** ***10%***	44 *11%*	49 **13%A**	21 **18%ABFG**	16 *11%*	25 *9%*	37 *11%*	81 **12%A**	26 *13%*
A multi-disciplinary clinic where you can see doctors from multiple specialties (e. g. rheumatology and nephrology) in one visit	**60** **4%BC**	10 *3%*	7 *2%*	4 *3%*	9 **6%BC**	20 **7%ABCH**	18 **5%BC**	24 **4%C**	9 **5%C**
Consultant	**4** *	1 *	- -	- -	- -	2 *1%*	1 *	1 *	- -
Dental	**2** *	1 *	2 *1%*	- -	- -	- -	- -	- -	- -
Guy's Hospital	**2** *	- -	- -	- -	1 **1%H**	1 *	- -	- -	- -
Private rheumatologist	**10** ***1%***	4 *1%*	4 *1%*	1 *1%*	1 *1%*	1 *	1 *	3 *	2 *1%*
Royal Free Hospital	**2** *	- -	- -	- -	- -	- -	2 *1%*	2 *	- -
Other	**6** *	1 *	1 *	- -	2 *1%*	- -	2 *1%*	2 *	- -

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 35

Q11 PRIMARY - still thinking about your primary diagnosis, from your understanding, which service or team is mainly responsible for the care of your disease?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
I am responsible for coordinating my care	**70** **5%FGI**	19 **5%I**	28 **8%ABFGI**	4 *3%*	9 **6%I**	8 *3%*	11 *3%*	38 **6%FGI**	2 *1%*
It is unclear to me who is responsible for coordinating my care	**117** **9%DF**	38 **10%DF**	40 **11%DFG**	4 *3%*	21 **14%ADFG**	12 *4%*	24 *7%*	66 **10%DFG**	21 **11%DF**
Don't know/no answer	- -	- -	- -	- -	- -	- -	- -	- -	- -

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 36

Q11 PRIMARY - still thinking about your primary diagnosis, from your understanding, which service or team is mainly responsible for the care of your disease?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
My GP	**95**	2	1	7	20	34	15	14	2	13	82	-	-
	7%C	*9%*	*1%*	*5%*	*7%*	***8%C***	*5%*	***13%ACDG***	*20%*	*11%*	*7%*	-	-
My local hospital's rheumatology department (secondary care)	**648**	9	41	74	137	205	137	40	5	50	596	-	-
	48%H	*39%*	***54%H***	***49%H***	***51%H***	***49%H***	***47%H***	*36%*	*50%*	*42%*	*49%*	-	-
A specialised service or centre	**69**	1	5	6	13	21	17	6	-	5	63	1	-
	5%	*4%*	*7%*	*4%*	*5%*	*5%*	*6%*	*5%*	-	*4%*	*5%*	*50%*	-
Another hospital department (such as nephrology, cardiology, respiratory)	**126**	1	7	19	24	44	26	5	-	15	111	-	-
	9%	*4%*	*9%*	***13%H***	*9%*	***11%H***	*9%*	*4%*	-	*13%*	*9%*	-	-
A regional specialised rheumatology service, or tertiary centre, in a hospital	**141**	3	11	13	28	39	37	9	1	13	128	-	-
	10%	*13%*	*14%*	*9%*	*10%*	*9%*	*13%*	*8%*	*10%*	*11%*	*10%*	-	-
A multi-disciplinary clinic where you can see doctors from multiple specialties (e. g. rheumatology and nephrology) in one visit	**60**	1	8	10	13	15	11	2	-	5	55	-	-
	4%	*4%*	***11%AFGH***	*7%*	*5%*	*4%*	*4%*	*2%*	-	*4%*	*4%*	-	-
Consultant	**4**	1	-	-	-	2	1	-	-	-	4	-	-
	*	*4%*	-	-	-	*	*	-	-	-	*	-	-
Dental	**2**	-	-	-	-	-	1	1	-	-	2	-	-
	*	-	-	-	-	-	*	*1%*	-	-	*	-	-
Guy's Hospital	**2**	-	-	-	-	2	-	-	-	1	1	-	-
	***K**	-	-	-	-	*	-	-	-	***1%K***	*	-	-
Private rheumatologist	**10**	-	-	1	-	1	4	4	-	-	10	-	-
	1%	-	-	*1%*	-	*	*1%*	***4%AEF***	-	-	*1%*	-	-
Royal Free Hospital	**2**	-	-	-	-	1	-	1	-	-	2	-	-
	*	-	-	-	-	*	-	*1%*	-	-	*	-	-
Other	**6**	-	-	1	-	1	1	3	-	1	5	-	-
	*	-	-	*1%*	-	*	*	***3%AEFG***	-	*1%*	*	-	-
I am responsible for coordinating my care	**70**	2	1	9	14	17	18	9	-	6	64	-	-
	5%	*9%*	*1%*	*6%*	*5%*	*4%*	*6%*	***8%C***	-	*5%*	*5%*	-	-
It is unclear to me who is responsible for coordinating my care	**117**	3	2	10	22	36	24	18	2	11	105	1	-
	9%	*13%*	*3%*	*7%*	*8%*	*9%*	*8%*	***16%ACDEFG***	*20%*	*9%*	*9%*	*50%*	-
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 37

Q12 PRIMARY - how confident or not are you that your GP understands your primary diagnosis and your needs for this diagnosis?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Very confident	**76**	20	11	6	7	13	10	6	3	4	7	1	3	-	6	17	5
	6%	*6%*	*7%*	*8%*	*9%*	*5%*	*4%*	*5%*	*4%*	*9%*	*6%*	*6%*	*7%*	-	**12%P**	*4%*	*10%*
Fairly confident	**264**	76	31	20	12	42	47	23	13	6	26	3	7	3	10	75	8
	20%	**24%AF**	*21%*	*26%*	*16%*	*16%*	*17%*	*20%*	*16%*	*14%*	*22%*	*19%*	*17%*	*38%*	*20%*	*20%*	*16%*
Not very confident	**434**	107	43	29	18	87	88	34	28	14	34	5	13	2	16	130	14
	32%	*33%*	*28%*	*38%*	*23%*	*33%*	*33%*	*30%*	*34%*	*32%*	*29%*	*31%*	*31%*	*25%*	*32%*	*34%*	*28%*
Not at all confident	**395**	77	41	18	35	85	82	32	25	17	31	6	13	2	11	107	18
	29%B	*24%*	*27%*	*23%*	**45%ABCDFGH**	**33%B**	*30%*	*28%*	*30%*	*39%*	*27%*	*38%*	*31%*	*25%*	*22%*	*28%*	*36%*
I don't have/see a specific GP	**140**	33	22	3	3	17	36	17	9	2	16	1	4	1	5	46	4
	10%F	*10%*	**15%DEF**	*4%*	*4%*	*7%*	**13%DEF**	**15%DEF**	*11%*	*5%*	*14%*	*6%*	*10%*	*13%*	*10%*	*12%*	*8%*
I don't know or it doesn't apply	**43**	7	3	1	2	16	7	3	4	1	2	-	2	-	2	8	1
	3%	*2%*	*2%*	*1%*	*3%*	**6%ABG**	*3%*	*3%*	*5%*	*2%*	*2%*	-	*5%*	-	*4%*	*2%*	*2%*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Confident	**340**	**96**	**42**	**26**	**19**	**55**	**57**	**29**	**16**	**10**	**33**	**4**	**10**	**3**	**16**	**92**	**13**
	25%	**30%AFG**	***28%***	**34%FGI**	***25%***	***21%***	***21%***	***25%***	***20%***	***23%***	***28%***	***25%***	***24%***	***38%***	***32%***	***24%***	***26%***
Not confident	**829**	**184**	**84**	**47**	**53**	**172**	**170**	**66**	**53**	**31**	**65**	**11**	**26**	**4**	**27**	**237**	**32**
	61%	***58%***	***56%***	***61%***	***69%***	**66%BC**	***63%***	***57%***	***65%***	***70%***	***56%***	***69%***	***62%***	***50%***	***54%***	***62%***	***64%***
Net confident	**-489**	**-88**	**-42**	**-21**	**-34**	**-117**	**-113**	**-37**	**-37**	**-21**	**-32**	**-7**	**-16**	**-1**	**-11**	**-145**	**-19**
	-36%	***-28%***	***-28%***	***-27%***	***-44%***	***-45%***	***-42%***	***-32%***	***-45%***	***-48%***	***-28%***	***-44%***	***-38%***	***-13%***	***-22%***	***-38%***	***-38%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Q12 PRIMARY - how confident or not are you that your GP understands your primary diagnosis and your needs for this diagnosis?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Very confident	**76**	28	28	7	10	14	18	40	12
	6%	*7%*	*8%*	*6%*	*7%*	*5%*	*5%*	*6%*	*6%*
Fairly confident	**264**	84	80	27	26	50	65	125	32
	20%	*21%*	*22%*	*23%*	*17%*	*17%*	*19%*	*19%*	*17%*
Not very confident	**434**	134	111	42	43	94	115	204	66
	32%	*34%*	*30%*	*36%*	*28%*	*33%*	*33%*	*31%*	*34%*
Not at all confident	**395**	105	92	31	59	93	102	186	60
	29%C	*26%*	*25%*	*27%*	**39%ABCDGH**	**32%C**	*29%*	*29%*	*31%*
I don't have/see a specific GP	**140**	38	46	7	9	19	41	77	16
	10%F	*10%*	**13%DEF**	*6%*	*6%*	*7%*	**12%EF**	**12%DEF**	*8%*
I don't know or it doesn't apply	**43**	9	9	2	4	17	9	17	7
	3%	*2%*	*2%*	*2%*	*3%*	**6%ABCGH**	*3%*	*3%*	*4%*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
Confident	**340**	**112**	**108**	**34**	**36**	**64**	**83**	**165**	**44**
	25%	***28%***	**30%AFG**	***29%***	***24%***	***22%***	***24%***	***25%***	***23%***
Not confident	**829**	**239**	**203**	**73**	**102**	**187**	**217**	**390**	**126**
	61%C	***60%***	***55%***	***63%***	**68%BC**	**65%C**	**62%C**	***60%***	**65%C**
Net confident	**-489**	**-127**	**-95**	**-39**	**-66**	**-123**	**-134**	**-225**	**-82**
	-36%	***-32%***	***-26%***	***-34%***	***-44%***	***-43%***	***-38%***	***-35%***	***-42%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 39

Q12 PRIMARY - how confident or not are you that your GP understands your primary diagnosis and your needs for this diagnosis?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Very confident	**76**	-	2	8	17	20	19	9	1	7	68	-	-
	6%	-	*3%*	*5%*	*6%*	*5%*	*7%*	*8%*	*10%*	*6%*	*6%*	-	-
Fairly confident	**264**	4	14	31	56	72	70	15	2	27	237	-	-
	20%	*17%*	*18%*	*21%*	*21%*	*17%*	**24%AFH**	*13%*	*20%*	*23%*	*19%*	-	-
Not very confident	**434**	8	25	35	90	149	86	36	5	38	396	-	-
	32%D	*35%*	*33%*	*23%*	**33%D**	**36%D**	*29%*	*32%*	*50%*	*32%*	*32%*	-	-
Not at all confident	**395**	8	23	56	81	123	76	27	1	25	368	2	-
	29%J	*35%*	*30%*	**37%AGH**	*30%*	*29%*	*26%*	*24%*	*10%*	*21%*	**30%J**	*100%*	-
I don't have/see a specific GP	**140**	2	7	14	19	44	34	19	1	17	122	-	-
	10%E	*9%*	*9%*	*9%*	*7%*	*11%*	*12%*	**17%AE**	*10%*	*14%*	*10%*	-	-
I don't know or it doesn't apply	**43**	1	5	6	8	10	7	6	-	6	37	-	-
	3%	*4%*	*7%*	*4%*	*3%*	*2%*	*2%*	*5%*	-	*5%*	*3%*	-	-
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Confident	**340**	**4**	**16**	**39**	**73**	**92**	**89**	**24**	**3**	**34**	**305**	**-**	**-**
	25%	***17%***	***21%***	***26%***	***27%***	***22%***	**30%AF**	***21%***	***30%***	***28%***	***25%***	**-**	**-**
Not confident	**829**	**16**	**48**	**91**	**171**	**272**	**162**	**63**	**6**	**63**	**764**	**2**	**-**
	61%GJ	***70%***	***63%***	***61%***	***63%***	**65%G**	***55%***	***56%***	***60%***	***53%***	**62%AJ**	***100%***	**-**
Net confident	**-489**	**-12**	**-32**	**-52**	**-98**	**-180**	**-73**	**-39**	**-3**	**-29**	**-459**	**-2**	**0**
	-36%	***-52%***	***-42%***	***-35%***	***-36%***	***-43%***	***-25%***	***-35%***	***-30%***	***-24%***	***-37%***	***-100%***	***0%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 40

Q13 PRIMARY - thinking more generally about your primary diagnosis, how confident or not are you that the specialist healthcare professionals you engage with understand your disease and needs?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Very confident	**461**	95	60	41	17	120	95	17	16	12	39	4	13	2	20	134	10
	34%EHIQ	**30%H**	**40%BEHI**	**53%ABEGHI**	*22%*	**46%ABEGHI**	**35%EHI**	*15%*	*20%*	*27%*	*34%*	*25%*	*31%*	*25%*	**40%Q**	**35%Q**	*20%*
Fairly confident	**475**	125	42	22	17	89	100	40	40	16	41	8	14	4	21	138	20
	35%CE	**39%CE**	*28%*	*29%*	*22%*	**34%E**	**37%E**	*35%*	**49%ACDEF**	*36%*	*35%*	*50%*	*33%*	*50%*	*42%*	*36%*	*40%*
Not very confident	**244**	68	29	9	25	34	42	20	17	10	25	4	9	2	3	71	11
	18%FO	**21%F**	*19%*	*12%*	**32%ABCDFGH**	*13%*	*16%*	*17%*	*21%*	**23%O**	**22%O**	*25%*	**21%O**	*25%*	*6%*	**19%O**	**22%O**
Not at all confident	**144**	28	18	5	12	16	32	25	8	6	10	-	6	-	5	37	9
	11%F	*9%*	**12%F**	*6%*	**16%F**	*6%*	**12%F**	**22%ABCDFGI**	*10%*	*14%*	*9%*	-	*14%*	-	*10%*	*10%*	*18%*
I don't know or it doesn't apply	**28**	4	2	-	6	1	1	13	1	-	1	-	-	-	1	3	-
	2%FGP	*1%*	*1%*	-	**8%ABCDFGI**	*	*	**11%ABCDFGI**	*1%*	-	*1%*	-	-	-	*2%*	*1%*	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Confident	**936**	**220**	**102**	**63**	**34**	**209**	**195**	**57**	**56**	**28**	**80**	**12**	**27**	**6**	**41**	**272**	**30**
	69%EH	**69%EH**	**68%EH**	**82%ABCEH**	***44%***	**80%ABCEGHI**	**72%EH**	***50%***	**68%EH**	***64%***	***69%***	***75%***	***64%***	***75%***	**82%AJQ**	***71%***	***60%***
Not confident	**388**	**96**	**47**	**14**	**37**	**50**	**74**	**45**	**25**	**16**	**35**	**4**	**15**	**2**	**8**	**108**	**20**
	29%DFO	**30%DF**	**31%DF**	***18%***	**48%ABCDFGI**	***19%***	**27%F**	**39%ADFG**	**30%F**	**36%O**	***30%***	***25%***	**36%O**	***25%***	***16%***	***28%***	**40%O**
Net confident	**548**	**124**	**55**	**49**	**-3**	**159**	**121**	**12**	**31**	**12**	**45**	**8**	**12**	**4**	**33**	**164**	**10**
	41%	***39%***	***36%***	***64%***	***-4%***	***61%***	***45%***	***10%***	***38%***	***27%***	***39%***	***50%***	***29%***	***50%***	***66%***	***43%***	***20%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 41

Q13 PRIMARY - thinking more generally about your primary diagnosis, how confident or not are you that the specialist healthcare professionals you engage with understand your disease and needs?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Very confident	**461**	119	129	50	40	127	124	200	50
	34%BEHI	*30%*	**35%BEI**	**43%ABEHI**	*26%*	**44%ABCEGHI**	**35%EHI**	*31%*	*26%*
Fairly confident	**475**	153	115	41	45	101	134	233	78
	35%	**38%CE**	*31%*	*35%*	*30%*	*35%*	**38%C**	*36%*	**40%CE**
Not very confident	**244**	85	80	16	42	39	47	118	42
	18%FG	**21%AFG**	**22%ADFG**	*14%*	**28%ADFGH**	*14%*	*13%*	**18%G**	**22%FG**
Not at all confident	**144**	36	39	9	18	19	43	81	21
	11%F	*9%*	*11%*	*8%*	*12%*	*7%*	**12%F**	**12%ABF**	*11%*
I don't know or it doesn't apply	**28**	5	3	-	6	1	2	17	2
	2%CFG	*1%*	*1%*	-	**4%BCDFG**	*	*1%*	**3%CFG**	*1%*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
Confident	**936**	**272**	**244**	**91**	**85**	**228**	**258**	**433**	**128**
	69%E	**68%E**	**67%E**	**78%ABCEHI**	***56%***	**79%ABCEHI**	**74%ACEHI**	**67%E**	**66%E**
Not confident	**388**	**121**	**119**	**25**	**60**	**58**	**90**	**199**	**63**
	29%F	**30%F**	**33%DFG**	***22%***	**40%ABDFGH**	***20%***	***26%***	**31%DFG**	**33%DF**
Net confident	**548**	**151**	**125**	**66**	**25**	**170**	**168**	**234**	**65**
	41%	***38%***	***34%***	***57%***	***17%***	***59%***	***48%***	***36%***	***34%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 42

Q13 PRIMARY - thinking more generally about your primary diagnosis, how confident or not are you that the specialist healthcare professionals you engage with understand your disease and needs?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Very confident	**461**	7	30	41	80	149	112	38	4	62	399	-	-
	34%K	*30%*	*39%*	*27%*	*30%*	*36%*	**38%DE**	*34%*	*40%*	**52%AK**	*32%*	-	-
Fairly confident	**475**	9	25	63	97	137	106	36	2	31	442	1	-
	35%J	*39%*	*33%*	**42%F**	*36%*	*33%*	*36%*	*32%*	*20%*	*26%*	**36%AJ**	*50%*	-
Not very confident	**244**	4	16	24	58	72	47	20	3	15	228	-	-
	18%	*17%*	*21%*	*16%*	*21%*	*17%*	*16%*	*18%*	*30%*	*13%*	*19%*	-	-
Not at all confident	**144**	3	4	18	33	51	22	12	1	8	135	1	-
	11%G	*13%*	*5%*	*12%*	*12%*	**12%G**	*8%*	*11%*	*10%*	*7%*	*11%*	*50%*	-
I don't know or it doesn't apply	**28**	-	1	4	3	9	5	6	-	4	24	-	-
	2%	-	*1%*	*3%*	*1%*	*2%*	*2%*	**5%AEG**	-	*3%*	*2%*	-	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Confident	**936**	**16**	**55**	**104**	**177**	**286**	**218**	**74**	**6**	**93**	**841**	**1**	**-**
	69%	***70%***	***72%***	***69%***	***65%***	***68%***	**75%AE**	***66%***	***60%***	**78%AK**	***68%***	***50%***	**-**
Not confident	**388**	**7**	**20**	**42**	**91**	**123**	**69**	**32**	**4**	**23**	**363**	**1**	**-**
	29%GJ	***30%***	***26%***	***28%***	**34%AG**	***29%***	***24%***	***29%***	***40%***	***19%***	**30%AJ**	***50%***	**-**
Net confident	**548**	**9**	**35**	**62**	**86**	**163**	**149**	**42**	**2**	**70**	**478**	**0**	**0**
	41%	***39%***	***46%***	***41%***	***32%***	***39%***	***51%***	***38%***	***20%***	***58%***	***39%***	***0%***	***0%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 43

Q14 PRIMARY - to what extent do the specialist healthcare professionals you engage with for this diagnosis involve you in agreeing a plan for your care and treatment?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
A great deal	**391**	80	56	35	9	101	75	19	16	10	34	6	10	2	15	105	11
	29%EH	**25%E**	**37%ABEGHI**	**45%ABEGHI**	*12%*	**39%ABEGHI**	**28%EH**	*17%*	*20%*	*23%*	*29%*	*38%*	*24%*	*25%*	*30%*	*27%*	*22%*
A fair amount	**473**	116	40	29	26	99	98	27	38	16	42	4	15	2	21	141	14
	35%CH	**36%CH**	*26%*	**38%H**	*34%*	**38%CH**	**36%CH**	*23%*	**46%ACH**	*36%*	*36%*	*25%*	*36%*	*25%*	*42%*	*37%*	*28%*
Not very much	**275**	77	30	9	17	39	56	28	19	11	22	2	11	2	7	89	15
	20%F	**24%DF**	*20%*	*12%*	*22%*	*15%*	*21%*	**24%DF**	*23%*	*25%*	*19%*	*13%*	*26%*	*25%*	*14%*	*23%*	*30%*
Not at all	**185**	44	24	4	20	18	37	30	8	7	18	1	6	2	7	44	10
	14%DF	**14%DF**	**16%DF**	*5%*	**26%ABDFGI**	*7%*	**14%DF**	**26%ABCDFGI**	*10%*	*16%*	*16%*	*6%*	*14%*	*25%*	*14%*	*11%*	*20%*
I was not able to be involved	**25**	3	-	-	5	3	4	9	1	-	-	3	-	-	-	3	-
	2%	*1%*	-	-	**6%ABCDFG**	*1%*	*1%*	**8%ABCDFGI**	*1%*	-	-	*19%*	-	-	-	*1%*	-
I did not want to be involved	**3**	-	1	-	-	-	-	2	-	-	-	-	-	-	-	1	-
	*	-	*1%*	-	-	-	-	**2%ABFG**	-	-	-	-	-	-	-	*	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Involved in care	**864**	196	96	64	35	200	173	46	54	26	76	10	25	4	36	246	25
	64%EHQ	**61%EH**	**64%EH**	**83%ABCEGHI**	***45%***	**77%ABCEGHI**	**64%EH**	***40%***	**66%EH**	***59%***	***66%***	***63%***	***60%***	***50%***	**72%Q**	***64%***	***50%***
Not involved in care	**460**	121	54	13	37	57	93	58	27	18	40	3	17	4	14	133	25
	34%DF	**38%DF**	**36%DF**	***17%***	**48%ADFG**	***22%***	**34%DF**	**50%ABCDFGI**	**33%DF**	***41%***	***34%***	***19%***	***40%***	***50%***	***28%***	***35%***	**50%AOP**
Net involved in care	**404**	75	42	51	-2	143	80	-12	27	8	36	7	8	0	22	113	0
	30%	***23%***	***28%***	***66%***	***-3%***	***55%***	***30%***	***-10%***	***33%***	***18%***	***31%***	***44%***	***19%***	***0%***	***44%***	***30%***	***0%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 44

Q14 PRIMARY - to what extent do the specialist healthcare professionals you engage with for this diagnosis involve you in agreeing a plan for your care and treatment?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
A great deal	**391**	102	112	44	24	108	99	167	48
	29%EH	**26%E**	**31%EH**	**38%ABEGHI**	*16%*	**38%ABCEGHI**	**28%E**	**26%E**	**25%E**
A fair amount	**473**	144	116	39	56	109	127	225	72
	35%	*36%*	*32%*	*34%*	*37%*	*38%*	*36%*	*35%*	*37%*
Not very much	**275**	93	77	20	36	46	72	143	43
	20%F	**23%F**	*21%*	*17%*	**24%F**	*16%*	*21%*	**22%F**	*22%*
Not at all	**185**	55	58	10	30	21	47	99	29
	14%F	**14%F**	**16%DF**	*9%*	**20%ABDF**	*7%*	**13%F**	**15%DF**	**15%F**
I was not able to be involved	**25**	4	2	3	5	3	4	12	1
	2%C	*1%*	*1%*	**3%C**	**3%C**	*1%*	*1%*	**2%C**	*1%*
I did not want to be involved	**3**	-	1	-	-	-	1	3	-
	*	-	*	-	-	-	*	*	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
Involved in care	**864**	**246**	**228**	**83**	**80**	**217**	**226**	**392**	**120**
	64%EH	**62%E**	**62%E**	**72%BEH**	***53%***	**76%ABCEGHI**	**65%EH**	***60%***	***62%***
Not involved in care	**460**	**148**	**135**	**30**	**66**	**67**	**119**	**242**	**72**
	34%F	**37%DF**	**37%DF**	***26%***	**44%ADFG**	***23%***	**34%F**	**37%ADF**	**37%DF**
Net involved in care	**404**	**98**	**93**	**53**	**14**	**150**	**107**	**150**	**48**
	30%	***25%***	***25%***	***46%***	***9%***	***52%***	***31%***	***23%***	***25%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Q14 PRIMARY - to what extent do the specialist healthcare professionals you engage with for this diagnosis involve you in agreeing a plan for your care and treatment?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
A great deal	**391**	7	20	40	72	122	93	34	3	47	344	-	-
	29%K	*30%*	*26%*	*27%*	*27%*	*29%*	*32%*	*30%*	*30%*	**39%AK**	*28%*	-	-
A fair amount	**473**	10	38	63	93	138	105	22	4	34	437	1	-
	35%H	*43%*	**50%AEFGH**	**42%FH**	**34%H**	**33%H**	**36%H**	*20%*	*40%*	*28%*	*36%*	*50%*	-
Not very much	**275**	2	11	27	61	94	46	34	-	22	252	-	-
	20%G	*9%*	*14%*	*18%*	**23%G**	**22%G**	*16%*	**30%ACDG**	-	*18%*	*21%*	-	-
Not at all	**185**	3	4	15	39	57	45	19	3	16	168	1	-
	14%C	*13%*	*5%*	*10%*	**14%C**	**14%C**	**15%C**	**17%C**	*30%*	*13%*	*14%*	*50%*	-
I was not able to be involved	**25**	1	3	5	6	5	2	3	-	1	24	-	-
	2%	*4%*	**4%G**	**3%G**	*2%*	*1%*	*1%*	*3%*	-	*1%*	*2%*	-	-
I did not want to be involved	**3**	-	-	-	-	2	1	-	-	-	3	-	-
	*	-	-	-	-	*	*	-	-	-	*	-	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Involved in care	**864**	**17**	**58**	**103**	**165**	**260**	**198**	**56**	**7**	**81**	**781**	**1**	**-**
	64%H	***74%***	**76%AEFH**	**69%H**	***61%***	**62%H**	**68%H**	***50%***	***70%***	***68%***	***64%***	***50%***	**-**
Not involved in care	**460**	**5**	**15**	**42**	**100**	**151**	**91**	**53**	**3**	**38**	**420**	**1**	**-**
	34%C	***22%***	***20%***	***28%***	**37%C**	**36%C**	***31%***	**47%ACDFG**	***30%***	***32%***	***34%***	***50%***	**-**
Net involved in care	**404**	**12**	**43**	**61**	**65**	**109**	**107**	**3**	**4**	**43**	**361**	**0**	**0**
	30%	***52%***	***57%***	***41%***	***24%***	***26%***	***37%***	***3%***	***40%***	***36%***	***29%***	***0%***	***0%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 46

Q14a PRIMARY - are you involved as much as you want to be in decisions about your care and treatment for this diagnosis?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Yes, definitely	**483**	111	59	37	16	124	97	20	19	12	44	6	13	2	19	144	10
	36%EHIQ	**35%EHI**	**39%EHI**	**48%ABEHI**	*21%*	**48%ABEGHI**	**36%EHI**	*17%*	*23%*	*27%*	**38%Q**	*38%*	*31%*	*25%*	*38%*	**38%Q**	*20%*
Yes, to some extent	**534**	133	59	29	23	100	110	38	42	20	43	5	18	5	18	151	24
	39%	*42%*	*39%*	*38%*	*30%*	*38%*	*41%*	*33%*	**51%AEFH**	*45%*	*37%*	*31%*	*43%*	*63%*	*36%*	*39%*	*48%*
No, not at all	**276**	64	29	11	29	30	57	38	18	9	26	5	10	1	11	79	16
	20%F	**20%F**	**19%F**	*14%*	**38%ABCDFGI**	*12%*	**21%F**	**33%ABCDFG**	**22%F**	*20%*	*22%*	*31%*	*24%*	*13%*	*22%*	*21%*	**32%A**
I don't know or it doesn't apply	**59**	12	4	-	9	6	6	19	3	3	3	-	1	-	2	9	-
	4%GP	*4%*	*3%*	-	**12%ABCDFG**	*2%*	*2%*	**17%ABCDFGI**	*4%*	*7%*	*3%*	-	*2%*	-	*4%*	*2%*	-
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Yes	**1017**	**244**	**118**	**66**	**39**	**224**	**207**	**58**	**61**	**32**	**87**	**11**	**31**	**7**	**37**	**295**	**34**
	75%EH	**76%EH**	**78%EH**	**86%AEH**	***51%***	**86%ABCEGHI**	**77%EH**	***50%***	**74%EH**	***73%***	***75%***	***69%***	***74%***	***88%***	***74%***	***77%***	***68%***
No	**276**	**64**	**29**	**11**	**29**	**30**	**57**	**38**	**18**	**9**	**26**	**5**	**10**	**1**	**11**	**79**	**16**
	20%F	**20%F**	**19%F**	***14%***	**38%ABCDFGI**	***12%***	**21%F**	**33%ABCDFG**	**22%F**	***20%***	***22%***	***31%***	***24%***	***13%***	***22%***	***21%***	**32%A**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Q14a PRIMARY - are you involved as much as you want to be in decisions about your care and treatment for this diagnosis?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Yes, definitely	**483**	133	133	49	39	131	124	216	54
	36%EI	**33%E**	**36%EI**	**42%EHI**	*26%*	**46%ABCEGHI**	**35%EI**	*33%*	*28%*
Yes, to some extent	**534**	171	139	44	55	114	142	248	91
	39%	*43%*	*38%*	*38%*	*36%*	*40%*	*41%*	*38%*	**47%ACEH**
No, not at all	**276**	79	84	23	47	36	74	154	45
	20%F	**20%F**	**23%F**	*20%*	**31%ABCDFGH**	*13%*	**21%F**	**24%AF**	**23%F**
I don't know or it doesn't apply	**59**	15	10	-	10	6	10	31	3
	4%DFI	**4%D**	*3%*	-	**7%CDFGI**	*2%*	*3%*	**5%CDGI**	*2%*
Don't know/no answer	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
Yes	**1017**	**304**	**272**	**93**	**94**	**245**	**266**	**464**	**145**
	75%EH	**76%EH**	**74%E**	**80%EH**	***62%***	**85%ABCEGHI**	**76%EH**	**71%E**	**75%E**
No	**276**	**79**	**84**	**23**	**47**	**36**	**74**	**154**	**45**
	20%F	**20%F**	**23%F**	***20%***	**31%ABCDFGH**	***13%***	**21%F**	**24%AF**	**23%F**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 48

Q14a PRIMARY - are you involved as much as you want to be in decisions about your care and treatment for this diagnosis?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Yes, definitely	**483**	8	33	65	90	149	101	35	2	51	431	-	-
	36%	*35%*	*43%*	**43%AEH**	*33%*	*36%*	*35%*	*31%*	*20%*	*43%*	*35%*	-	-
Yes, to some extent	**534**	10	31	52	112	162	118	44	5	37	496	1	-
	39%J	*43%*	*41%*	*35%*	*41%*	*39%*	*40%*	*39%*	*50%*	*31%*	**40%AJ**	*50%*	-
No, not at all	**276**	3	9	27	63	81	62	29	2	30	245	-	-
	20%	*13%*	*12%*	*18%*	**23%C**	*19%*	*21%*	**26%C**	*20%*	*25%*	*20%*	-	-
I don't know or it doesn't apply	**59**	2	3	6	6	26	11	4	1	2	56	1	-
	4%E	*9%*	*4%*	*4%*	*2%*	**6%AE**	*4%*	*4%*	*10%*	*2%*	*5%*	*50%*	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Yes	**1017**	**18**	**64**	**117**	**202**	**311**	**219**	**79**	**7**	**88**	**927**	**1**	**-**
	75%	***78%***	**84%H**	***78%***	***75%***	***74%***	***75%***	***71%***	***70%***	***73%***	***75%***	***50%***	**-**
No	**276**	**3**	**9**	**27**	**63**	**81**	**62**	**29**	**2**	**30**	**245**	**-**	**-**
	20%	***13%***	***12%***	***18%***	**23%C**	***19%***	***21%***	**26%C**	***20%***	***25%***	***20%***	**-**	**-**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 49

Q15 PRIMARY - do all the different health professionals caring for you work well together to give you the best possible care and support for this diagnosis?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Yes, definitely	**240**	47	25	24	8	62	52	14	8	5	22	2	6	-	16	67	5
	18%I	*15%*	*17%*	**31%ABCEGHI**	*10%*	**24%ABEHI**	**19%I**	*12%*	*10%*	*11%*	*19%*	*13%*	*14%*	-	**32%AJPQ**	*17%*	*10%*
Yes, to some extent	**512**	126	48	33	20	113	105	29	38	17	43	7	8	2	18	156	20
	38%EHM	**39%EH**	*32%*	**43%EH**	*26%*	**43%ACEH**	**39%EH**	*25%*	**46%CEH**	*39%*	**37%M**	*44%*	*19%*	*25%*	*36%*	**41%M**	**40%M**
No, not at all	**465**	119	60	16	34	64	94	47	31	16	40	6	26	6	14	129	24
	34%DF	**37%DF**	**40%DF**	*21%*	**44%DF**	*25%*	**35%DF**	**41%DF**	**38%DF**	*36%*	*34%*	*38%*	**62%AJKOP**	*75%*	*28%*	*34%*	**48%AOP**
I don't know or it doesn't apply	**135**	28	18	4	15	21	19	25	5	6	11	1	2	-	2	31	1
	10%	*9%*	*12%*	*5%*	**19%ABDFGI**	*8%*	*7%*	**22%ABCDFGI**	*6%*	**14%Q**	*9%*	*6%*	*5%*	-	*4%*	*8%*	*2%*
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Yes	**752**	**173**	**73**	**57**	**28**	**175**	**157**	**43**	**46**	**22**	**65**	**9**	**14**	**2**	**34**	**223**	**25**
	56%EHM	**54%EH**	***48%***	**74%ABCEGHI**	***36%***	**67%ABCEGH**	**58%EH**	***37%***	**56%EH**	***50%***	**56%M**	***56%***	***33%***	***25%***	**68%M**	**58%M**	***50%***
No	**465**	**119**	**60**	**16**	**34**	**64**	**94**	**47**	**31**	**16**	**40**	**6**	**26**	**6**	**14**	**129**	**24**
	34%DF	**37%DF**	**40%DF**	***21%***	**44%DF**	***25%***	**35%DF**	**41%DF**	**38%DF**	***36%***	***34%***	***38%***	**62%AJKOP**	***75%***	***28%***	***34%***	**48%AOP**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 50

Q15 PRIMARY - do all the different health professionals caring for you work well together to give you the best possible care and support for this diagnosis?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Yes, definitely	**240**	61	60	31	16	64	75	108	26
	18%E	*15%*	*16%*	**27%ABCEHI**	*11%*	**22%ABCEHI**	**21%ABCEHI**	**17%E**	*13%*
Yes, to some extent	**512**	156	126	48	46	126	134	243	79
	38%E	**39%E**	*34%*	*41%*	*30%*	**44%ACE**	*38%*	*37%*	**41%E**
No, not at all	**465**	146	143	31	69	76	116	234	79
	34%F	**37%DF**	**39%ADF**	*27%*	**46%ABDFGH**	*26%*	*33%*	**36%DF**	**41%ADFG**
I don't know or it doesn't apply	**135**	35	37	6	20	21	25	64	9
	10%GI	**9%I**	**10%I**	*5%*	**13%DFGI**	*7%*	*7%*	**10%GI**	*5%*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
Yes	**752**	**217**	**186**	**79**	**62**	**190**	**209**	**351**	**105**
	56%CE	**55%E**	**51%E**	**68%ABCEHI**	***41%***	**66%ABCEHI**	**60%CEH**	**54%E**	**54%E**
No	**465**	**146**	**143**	**31**	**69**	**76**	**116**	**234**	**79**
	34%F	**37%DF**	**39%ADF**	***27%***	**46%ABDFGH**	***26%***	***33%***	**36%DF**	**41%ADFG**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 51

Q15 PRIMARY - do all the different health professionals caring for you work well together to give you the best possible care and support for this diagnosis?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Yes, definitely	**240**	5	15	28	48	65	57	22	-	35	205	-	-
	18%K	*22%*	*20%*	*19%*	*18%*	*16%*	*20%*	*20%*	-	**29%AK**	*17%*	-	-
Yes, to some extent	**512**	7	32	55	100	168	113	33	4	40	471	-	-
	38%	*30%*	*42%*	*37%*	*37%*	**40%H**	*39%*	*29%*	*40%*	*33%*	*38%*	-	-
No, not at all	**465**	11	21	52	97	144	97	40	3	33	429	2	-
	34%	*48%*	*28%*	*35%*	*36%*	*34%*	*33%*	*36%*	*30%*	*28%*	*35%*	*100%*	-
I don't know or it doesn't apply	**135**	-	8	15	26	41	25	17	3	12	123	-	-
	10%	-	*11%*	*10%*	*10%*	*10%*	*9%*	*15%*	*30%*	*10%*	*10%*	-	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Yes	**752**	**12**	**47**	**83**	**148**	**233**	**170**	**55**	**4**	**75**	**676**	**-**	**-**
	56%	***52%***	***62%***	***55%***	***55%***	***56%***	***58%***	***49%***	***40%***	***63%***	***55%***	**-**	**-**
No	**465**	**11**	**21**	**52**	**97**	**144**	**97**	**40**	**3**	**33**	**429**	**2**	**-**
	34%	***48%***	***28%***	***35%***	***36%***	***34%***	***33%***	***36%***	***30%***	***28%***	***35%***	***100%***	**-**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 52

Q16 Which, if any, of the following drugs are you taking for your rare autoimmune disease(s)?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Hydroxychloroquine/Plaquenil	**285**	133	56	5	8	7	38	8	30	15	32	5	13	3	9	87	11
	21%DEFGH	**42%ADEFGH**	**37%ADEFGH**	*6%*	**10%F**	*3%*	**14%FH**	*7%*	**37%ADEFGH**	**34%A**	*28%*	*31%*	*31%*	*38%*	*18%*	*23%*	*22%*
Mycophenolate/Mycophenolate Mofetil/MMF/CellCept	**180**	48	6	19	2	31	64	2	8	4	17	6	4	3	4	67	5
	13%CEH	**15%CEH**	*4%*	**25%ABCEFHI**	*3%*	**12%CEH**	**24%ABCEFHI**	*2%*	**10%H**	*9%*	*15%*	*38%*	*10%*	*38%*	*8%*	**17%A**	*10%*
Prednisolone	**129**	42	4	16	1	51	8	2	5	2	7	5	4	1	1	25	8
	10%CEGHP	**13%ACEGH**	*3%*	**21%ACEGHI**	*1%*	**20%ABCEGHI**	*3%*	*2%*	*6%*	*5%*	*6%*	*31%*	*10%*	*13%*	*2%*	*7%*	**16%KOP**
Methotrexate/MTX	**119**	34	8	16	2	24	26	2	7	3	17	1	-	2	1	32	7
	9%EHM	**11%EH**	*5%*	**21%ABCEFGHI**	*3%*	**9%H**	**10%EH**	*2%*	**9%H**	*7%*	**15%AMOP**	*6%*	-	*25%*	*2%*	*8%*	**14%MO**
Rituximab/Rituxan	**95**	16	4	12	-	55	3	1	4	1	10	2	1	-	4	14	4
	7%CEGHP	**5%EG**	*3%*	**16%ABCEGHI**	-	**21%ABCEGHI**	*1%*	*1%*	**5%G**	*2%*	**9%P**	*13%*	*2%*	-	*8%*	*4%*	*8%*
Sildenafil	**94**	7	2	5	-	2	55	20	3	1	10	2	-	2	12	49	1
	7%BCEF	*2%*	*1%*	**6%BCEF**	-	*1%*	**20%ABCDEFI**	**17%ABCDEFI**	*4%*	*2%*	*9%*	*13%*	-	*25%*	**24%AJKMPQ**	**13%AJMQ**	*2%*
Azathioprine/Imuran	**73**	22	4	7	3	30	3	-	4	3	2	-	3	1	3	15	6
	5%GH	**7%GH**	*3%*	**9%CGH**	**4%H**	**12%ACEGH**	*1%*	-	**5%GH**	*7%*	*2%*	-	*7%*	*13%*	*6%*	*4%*	**12%AKP**
Nifedipine/Adalat/Adipine/Coracten/ Fortipine/Nifedipress	**53**	4	2	1	1	-	21	22	2	2	2	1	1	1	6	24	2
	4%BF	*1%*	*1%*	*1%*	*1%*	-	**8%ABCDEF**	**19%ABCDEFGI**	**2%F**	*5%*	*2%*	*6%*	*2%*	*13%*	**12%AK**	**6%A**	*4%*
Pilocarpine	**27**	-	23	-	-	-	4	-	-	-	-	1	-	-	-	12	-
	2%BF	-	**15%ABDEFGHI**	-	-	-	**1%BF**	-	-	-	-	*6%*	-	-	-	*3%*	-
Warfarin	**27**	4	-	1	22	-	-	-	-	5	1	-	3	-	-	5	-
	2%FG	*1%*	-	*1%*	**29%ABCDFGHI**	-	-	-	-	**11%AKOPQ**	*1%*	-	**7%AKP**	-	-	*1%*	-
Tocilizumab	**26**	2	1	-	-	15	7	-	1	-	-	-	-	-	2	8	1
	2%B	*1%*	*1%*	-	-	**6%ABCDEH**	*3%*	-	*1%*	-	-	-	-	-	**4%K**	*2%*	*2%*
Omeprazole/Prilosec/Losec	**23**	1	-	2	-	-	15	4	1	-	2	1	-	-	4	13	1
	2%BF	*	-	**3%BCF**	-	-	**6%ABCEF**	**3%BCF**	*1%*	-	*2%*	*6%*	-	-	**8%AK**	**3%A**	*2%*

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 52

Q16 Which, if any, of the following drugs are you taking for your rare autoimmune disease(s)?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Tadalafil	**20**	-	1	-	-	-	17	-	2	-	2	-	-	-	1	13	2
	1%BF	-	*1%*	-	-	-	**6%ABCDEFH**	-	**2%BF**	-	*2%*	-	-	-	*2%*	**3%A**	*4%*
Steroids	**19**	6	1	1	2	7	1	-	1	3	2	-	-	2	-	4	1
	1%	*2%*	*1%*	*1%*	*3%*	**3%G**	*	-	*1%*	**7%AP**	*2%*	-	-	*25%*	-	*1%*	*2%*
Losartan/Cozaar	**17**	1	-	1	-	1	10	2	2	-	2	-	-	1	2	8	-
	1%	*	-	*1%*	-	*	**4%ABCF**	*2%*	**2%B**	-	*2%*	-	-	*13%*	*4%*	*2%*	-
Nintedanib	**14**	-	1	-	-	-	12	-	1	-	1	-	-	1	-	8	-
	1%	-	*1%*	-	-	-	**4%ABCFH**	-	**1%B**	-	*1%*	-	-	*13%*	-	**2%A**	-
Avacopan	**13**	-	-	-	-	12	-	1	-	-	-	-	-	-	-	1	-
	1%	-	-	-	-	**5%ABCGI**	-	*1%*	-	-	-	-	-	-	-	*	-
Iloprost/Ventavis	**13**	-	-	2	-	-	8	2	1	-	1	-	-	-	2	7	-
	1%	-	-	**3%BCF**	-	-	**3%ABCF**	**2%BF**	**1%B**	-	*1%*	-	-	-	**4%A**	*2%*	-
Asprin	**12**	4	-	-	6	-	2	-	-	-	1	-	-	-	-	4	1
	1%	*1%*	-	-	**8%ABCDFGHI**	-	*1%*	-	-	-	*1%*	-	-	-	-	*1%*	*2%*
Belimumab	**12**	12	-	-	-	-	-	-	-	-	1	-	1	-	1	2	-
	1%	**4%ACFGH**	-	-	-	-	-	-	-	-	*1%*	-	*2%*	-	*2%*	*1%*	-
Folic acid	**9**	1	1	-	-	2	5	-	-	-	-	1	-	1	-	2	1
	1%	*	*1%*	-	-	*1%*	**2%A**	-	-	-	-	*6%*	-	*13%*	-	*1%*	*2%*
Lansoprazole/Prevacid	**9**	-	-	-	1	-	7	1	-	-	2	-	-	1	1	2	-
	1%	-	-	-	**1%B**	-	**3%ABCF**	*1%*	-	-	*2%*	-	-	*13%*	*2%*	*1%*	-
Benralizumab/Fasenra	**8**	1	-	-	-	7	-	-	-	-	-	-	-	1	-	-	-
	1%	*	-	-	-	**3%ABCG**	-	-	-	-	-	-	-	*13%*	-	-	-
Eye drops (various)	**7**	1	2	-	-	-	4	-	-	-	1	1	-	1	-	2	-
	1%	*	*1%*	-	-	-	**1%AF**	-	-	-	*1%*	*6%*	-	*13%*	-	*1%*	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 52

Q16 Which, if any, of the following drugs are you taking for your rare autoimmune disease(s)?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Leflunomide/Arava	**7**	1	2	-	-	2	1	-	1	2	1	-	-	-	-	-	-
	1%	*	*1%*	-	-	*1%*	*	-	*1%*	**5%AP**	*1%*	-	-	-	-	-	-
Apixaban/Eliquis	**7**	2	-	-	4	-	1	-	-	-	1	-	-	-	-	1	1
	1%	*1%*	-	-	**5%ABCDFGHI**	-	*	-	-	-	*1%*	-	-	-	-	*	*2%*
Gabapentin/Neurontin	**7**	1	2	-	-	1	2	1	-	-	-	-	-	1	-	2	-
	1%	*	*1%*	-	-	*	*1%*	*1%*	-	-	-	-	-	*13%*	-	*1%*	-
Bosentan/Tracleer	**7**	-	-	-	-	-	7	-	-	-	-	-	1	-	-	6	-
	1%	-	-	-	-	-	**3%ABCF**	-	-	-	-	-	*2%*	-	-	**2%A**	-
Ciclosporin/Cyclosporine	**7**	3	3	1	-	-	-	-	-	1	-	-	2	-	-	2	-
	1%	*1%*	**2%AFG**	*1%*	-	-	-	-	-	*2%*	-	-	**5%AKP**	-	-	*1%*	-
Myfortic/Mycophenolic acid	**6**	1	-	3	-	1	1	-	-	-	-	-	-	-	1	1	1
	*****	*	-	**4%ABCFGH**	-	*	*	-	-	-	-	-	-	-	*2%*	*	*2%*
Tacrolimus/Prograf	**6**	-	-	6	-	-	-	-	-	-	1	-	-	-	-	3	-
	*****	-	-	**8%ABCEFGHI**	-	-	-	-	-	-	*1%*	-	-	-	-	*1%*	-
Cyclophosphamide/Cytophosphane	**6**	1	-	-	-	4	1	-	-	-	1	1	-	-	-	-	-
	*****	*	-	-	-	**2%A**	*	-	-	-	*1%*	*6%*	-	-	-	-	-
Adcal	**5**	-	-	1	-	2	1	1	-	-	-	-	-	-	-	1	-
	*****	-	-	**1%B**	-	*1%*	*	*1%*	-	-	-	-	-	-	-	*	-
Amlodipine/Norvasc	**5**	-	-	-	-	1	2	-	2	-	2	-	-	-	-	3	-
	*****	-	-	-	-	*	*1%*	-	**2%AB**	-	**2%A**	-	-	-	-	*1%*	-
Amitriptyline/Elavil	**5**	1	2	-	-	-	2	-	-	-	-	-	-	-	-	3	1
	*****	*	*1%*	-	-	-	*1%*	-	-	-	-	-	-	-	-	*1%*	*2%*
Ursodeoxycholic acid/Ursodiol	**5**	2	-	-	-	1	2	-	-	-	2	1	-	-	-	1	-
	*****	*1%*	-	-	-	*	*1%*	-	-	-	**2%A**	*6%*	-	-	-	*	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 52

Q16 Which, if any, of the following drugs are you taking for your rare autoimmune disease(s)?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
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Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Colchicine	**5**	3	-	-	-	-	1	-	1	-	1	-	-	-	-	2	-
	*	*1%*	-	-	-	-	*	-	*1%*	-	*1%*	-	-	-	-	*1%*	-
Ramipril	**4**	1	-	-	-	1	2	-	-	-	-	-	-	-	-	2	-
	*	*	-	-	-	*	*1%*	-	-	-	-	-	-	-	-	*1%*	-
Adalimumab/Amgevita/Hyrimoz/Idacio/ Imraldi/Yuflyma/Humira	**4**	-	1	-	-	2	-	1	-	-	-	-	-	-	-	-	-
	*	-	*1%*	-	-	*1%*	-	*1%*	-	-	-	-	-	-	-	-	-
Levothyroxine/L-thyroxine	**4**	-	1	-	-	2	1	-	-	-	-	-	-	-	-	1	-
	*	-	*1%*	-	-	*1%*	*	-	-	-	-	-	-	-	-	*	-
Atorvastatin	**4**	-	1	-	2	-	1	-	-	-	-	-	-	-	-	1	-
	*	-	*1%*	-	**3%ABF**	-	*	-	-	-	-	-	-	-	-	*	-
Upadacitinib/Rinvoq	**4**	-	-	-	-	3	-	1	-	-	1	-	-	-	-	-	-
	*	-	-	-	-	**1%A**	-	*1%*	-	-	*1%*	-	-	-	-	-	-
Intravenous Immunoglobulin/IVIg	**4**	-	-	4	-	-	-	-	-	-	-	-	-	-	1	2	-
	*	-	-	**5%ABCEFGHI**	-	-	-	-	-	-	-	-	-	-	**2%A**	*1%*	-
Vitamins (various)	**4**	1	-	-	-	-	2	1	-	-	1	-	-	1	-	1	1
	*	*	-	-	-	-	*1%*	*1%*	-	-	*1%*	-	-	*13%*	-	*	**2%A**
Duloxetine/Cymbalta	**4**	-	2	-	-	-	2	-	-	-	-	-	-	-	-	2	-
	*	-	**1%AB**	-	-	-	*1%*	-	-	-	-	-	-	-	-	*1%*	-
Loperamide/Imodium	**3**	-	-	-	-	-	3	-	-	-	-	1	-	1	-	1	-
	*	-	-	-	-	-	**1%A**	-	-	-	-	*6%*	-	*13%*	-	*	-
Pregabalin/Lyrica	**3**	1	1	-	-	-	1	-	-	-	-	-	-	-	-	2	-
	*	*	*1%*	-	-	-	*	-	-	-	-	-	-	-	-	*1%*	-
Alendronic acid/Fosamax	**3**	-	-	1	-	-	1	1	-	-	-	-	-	-	-	1	-
	*	-	-	**1%B**	-	-	*	*1%*	-	-	-	-	-	-	-	*	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
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RAIRDA Survey 2024

Table 52

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Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Tramadol/Ultram	**3**	1	-	-	-	-	2	-	-	-	-	-	-	1	-	1	1
	*	*	-	-	-	-	*1%*	-	-	-	-	-	-	*13%*	-	*	**2%A**
Remsima	**2**	-	-	-	-	2	-	-	-	-	-	-	-	-	-	-	-
	*	-	-	-	-	**1%A**	-	-	-	-	-	-	-	-	-	-	-
Naproxen/Aleve	**2**	-	-	-	-	-	1	1	-	1	-	-	-	-	-	1	-
	*	-	-	-	-	-	*	*1%*	-	**2%A**	-	-	-	-	-	*	-
Secukinumab	**2**	-	-	-	-	2	-	-	-	-	1	-	-	-	-	1	-
	*	-	-	-	-	**1%A**	-	-	-	-	*1%*	-	-	-	-	*	-
Selaxipag	**2**	-	-	-	-	-	2	-	-	-	1	-	-	-	-	1	-
	*	-	-	-	-	-	**1%A**	-	-	-	*1%*	-	-	-	-	*	-
Doxazosin/Cardura	**2**	1	-	-	-	-	1	-	-	-	-	-	-	-	-	1	-
	*	*	-	-	-	-	*	-	-	-	-	-	-	-	-	*	-
Sulfadiazine	**2**	-	-	-	-	-	2	-	-	-	1	-	-	-	-	-	1
	*	-	-	-	-	-	**1%A**	-	-	-	*1%*	-	-	-	-	-	**2%AP**
Omalizumab/Xolair	**2**	2	-	-	-	-	-	-	-	-	-	-	-	1	-	-	-
	*	**1%A**	-	-	-	-	-	-	-	-	-	-	-	*13%*	-	-	-
Clopidogrel/Plavix	**2**	-	-	-	2	-	-	-	-	-	-	-	-	-	-	-	-
	*	-	-	-	**3%ABCFG**	-	-	-	-	-	-	-	-	-	-	-	-
Co-trimoxazole (trimethoprim and sulfamethoxazole)/Bactrim	**2**	-	-	-	-	2	-	-	-	-	-	-	-	-	-	-	-
	*	-	-	-	-	**1%A**	-	-	-	-	-	-	-	-	-	-	-
Famotidine/Pepcid	**2**	-	-	-	-	-	1	1	-	-	-	-	-	-	1	1	-
	*	-	-	-	-	-	*	*1%*	-	-	-	-	-	-	**2%A**	*	-
Fexofenadine/Allegra	**2**	2	-	-	-	-	-	-	-	-	-	-	-	1	-	-	-
	*	**1%A**	-	-	-	-	-	-	-	-	-	-	-	*13%*	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
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RAIRDA Survey 2024

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Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Co-Codamol	**2**	-	-	-	-	1	-	1	-	1	-	-	-	-	-	1	-
	*	-	-	-	-	*	-	*1%*	-	**2%A**	-	-	-	-	-	*	-
Coedine	**1**	-	-	-	-	-	-	-	1	1	-	-	-	-	-	-	-
	*	-	-	-	-	-	-	-	**1%AB**	**2%AP**	-	-	-	-	-	-	-
Morphine	**1**	-	-	-	-	-	-	-	1	1	-	-	-	-	-	-	-
	*	-	-	-	-	-	-	-	**1%AB**	**2%AP**	-	-	-	-	-	-	-
Alemtuzumab/Campath/Lemtrada	**1**	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-	-
	*	-	-	-	-	*	-	-	-	-	-	-	-	-	-	-	-
Voclosporin	**1**	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	*	-	**1%A**	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Ambresantan Mylan/Letairis	**1**	-	-	-	-	-	1	-	-	-	-	-	-	-	-	1	-
	*	-	-	-	-	-	*	-	-	-	-	-	-	-	-	*	-
Meloxicam/Mobic	**1**	-	1	-	-	-	-	-	-	-	-	-	-	-	-	1	-
	*	-	**1%A**	-	-	-	-	-	-	-	-	-	-	-	-	*	-
Other	**106**	30	13	1	6	15	23	12	6	1	5	3	7	2	4	31	7
	8%D	**9%D**	**9%D**	*1%*	*8%*	*6%*	**9%D**	**10%D**	*7%*	*2%*	*4%*	*19%*	**17%AJK**	*25%*	*8%*	*8%*	**14%JK**
None of these	**438**	91	63	18	34	69	79	59	25	15	33	6	15	2	18	120	15
	32%F	*28%*	**42%ABDFG**	*23%*	**44%ABDFG**	*27%*	*29%*	**51%ABDFGI**	*30%*	*34%*	*28%*	*38%*	*36%*	*25%*	*36%*	*31%*	*30%*
Don't know/prefer not to say	**18**	5	5	-	-	1	3	2	2	2	-	-	1	-	1	5	1
	1%	*2%*	**3%AF**	-	-	*	*1%*	*2%*	*2%*	**5%K**	-	-	*2%*	-	*2%*	*1%*	*2%*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
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RAIRDA Survey 2024

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Total	**1352**	398	366	116	151	287	350	649	193
Hydroxychloroquine/Plaquenil	**285**	157	111	18	34	11	52	139	55
	21%FG	**39%ACDEFGHI**	**30%ADFGH**	**16%F**	**23%FG**	*4%*	**15%F**	**21%FG**	**28%ADFGH**
Mycophenolate/Mycophenolate Mofetil/MMF/CellCept	**180**	61	38	30	9	40	73	93	25
	13%CE	**15%CE**	*10%*	**26%ABCEFHI**	*6%*	**14%E**	**21%ABCEFHI**	**14%CE**	**13%E**
Prednisolone	**129**	50	20	23	9	53	12	37	20
	10%CGH	**13%ACEGH**	*5%*	**20%ABCEGHI**	*6%*	**18%ABCEGHI**	*3%*	**6%G**	**10%CGH**
Methotrexate/MTX	**119**	42	34	20	7	29	30	54	24
	9%	**11%E**	*9%*	**17%ACEFGH**	*5%*	**10%E**	*9%*	*8%*	**12%EH**
Rituximab/Rituxan	**95**	18	20	15	3	57	7	25	12
	7%BEGH	**5%G**	**5%G**	**13%ABCEGHI**	*2%*	**20%ABCEGHI**	*2%*	**4%G**	**6%G**
Sildenafil	**94**	11	18	10	2	5	73	84	14
	7%BEF	*3%*	**5%F**	**9%BEF**	*1%*	*2%*	**21%ABCDEFHI**	**13%ABCEFI**	**7%BEF**
Azathioprine/Imuran	**73**	26	9	8	9	31	7	22	11
	5%CGH	**7%CGH**	*2%*	**7%CG**	**6%CG**	**11%ABCGHI**	*2%*	*3%*	**6%CG**
Nifedipine/Adalat/Adipine/Coracten/ Fortipine/Nifedipress	**53**	6	6	6	2	1	30	50	5
	4%BCF	*2%*	*2%*	**5%BCF**	*1%*	*	**9%ABCEFI**	**8%ABCEFI**	**3%F**
Pilocarpine	**27**	-	24	1	-	-	5	13	1
	2%BF	-	**7%ABDEFGHI**	*1%*	-	-	**1%BF**	**2%BF**	*1%*
Warfarin	**27**	12	2	1	26	-	-	7	-
	2%CFGHI	**3%CFGHI**	*1%*	*1%*	**17%ABCDFGHI**	-	-	*1%*	-
Tocilizumab	**26**	3	1	2	1	16	9	10	4
	2%BC	*1%*	*	*2%*	*1%*	**6%ABCEH**	**3%BC**	**2%C**	**2%C**
Omeprazole/Prilosec/Losec	**23**	1	3	4	1	-	20	21	4
	2%BF	*	*1%*	**3%BCF**	*1%*	-	**6%ABCEFHI**	**3%ABCF**	**2%BF**
Tadalafil	**20**	1	6	2	-	3	19	16	6
	1%B	*	**2%B**	*2%*	-	*1%*	**5%ABCEFH**	**2%AB**	**3%BE**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: All Columns Tested (5% risk level)
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RAIRDA Survey 2024

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Total	**1352**	398	366	116	151	287	350	649	193
Steroids	**19**	9	7	3	3	12	2	10	5
	1%	**2%G**	*2%*	**3%G**	*2%*	**4%AGH**	*1%*	**2%G**	**3%G**
Losartan/Cozaar	**17**	2	5	2	-	3	14	14	5
	1%	*1%*	*1%*	*2%*	-	*1%*	**4%ABCEFH**	**2%AB**	**3%BE**
Nintedanib	**14**	2	3	-	-	1	12	10	1
	1%	*1%*	*1%*	-	-	*	**3%ABCDEFHI**	*2%*	*1%*
Avacopan	**13**	-	-	-	-	12	-	2	-
	1%BH	-	-	-	-	**4%ABCDEGHI**	-	*	-
Iloprost/Ventavis	**13**	-	2	3	-	-	10	11	2
	1%B	-	*1%*	**3%BEF**	-	-	**3%ABCEF**	**2%ABCF**	**1%B**
Asprin	**12**	5	2	-	9	-	2	5	1
	1%	*1%*	*1%*	-	**6%ABCDFGHI**	-	*1%*	*1%*	*1%*
Belimumab	**12**	12	2	-	2	-	1	4	1
	1%	**3%ACFGHI**	*1%*	-	*1%*	-	*	*1%*	*1%*
Folic acid	**9**	1	3	3	1	3	5	4	2
	1%	*	*1%*	**3%ABH**	*1%*	*1%*	**1%H**	*1%*	*1%*
Lansoprazole/Prevacid	**9**	-	3	1	1	1	8	6	1
	1%	-	*1%*	*1%*	*1%*	*	**2%ABFH**	*1%*	*1%*
Benralizumab/Fasenra	**8**	1	-	-	-	8	-	-	-
	1%H	*	-	-	-	**3%ABCEGHI**	-	-	-
Eye drops (various)	**7**	1	6	2	1	1	4	5	1
	1%	*	**2%AB**	*2%*	*1%*	*	*1%*	*1%*	*1%*
Leflunomide/Arava	**7**	3	4	-	-	2	1	-	1
	1%	**1%H**	**1%H**	-	-	**1%H**	*	-	*1%*
Apixaban/Eliquis	**7**	2	1	1	5	-	1	3	1
	1%	*1%*	*	*1%*	**3%ABCFGHI**	-	*	*	*1%*
Gabapentin/Neurontin	**7**	1	3	1	-	2	2	4	1
	1%	*	*1%*	*1%*	-	*1%*	*1%*	*1%*	*1%*

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
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Total	**1352**	398	366	116	151	287	350	649	193
Bosentan/Tracleer	**7**	1	1	1	1	-	7	7	-
	1%	*	*	*1%*	*1%*	-	**2%ABCFI**	**1%A**	-
Ciclosporin/Cyclosporine	**7**	4	5	1	2	-	1	3	2
	1%	*1%*	**1%AFH**	*1%*	*1%*	-	*	*	*1%*
Myfortic/Mycophenolic acid	**6**	1	-	3	-	1	2	2	2
	*	*	-	**3%ABCEFGH**	-	*	*1%*	*	*1%*
Tacrolimus/Prograf	**6**	-	1	6	-	-	-	4	1
	*	-	*	**5%ABCEFGHI**	-	-	-	*1%*	*1%*
Cyclophosphamide/Cytophosphane	**6**	1	1	1	-	4	1	2	1
	*	*	*	*1%*	-	**1%A**	*	*	*1%*
Adcal	**5**	-	-	2	-	2	1	2	-
	*	-	-	**2%ABCH**	-	*1%*	*	*	-
Amlodipine/Norvasc	**5**	-	2	-	-	1	3	5	2
	*	-	*1%*	-	-	*	*1%*	**1%A**	**1%B**
Amitriptyline/Elavil	**5**	1	2	-	1	-	2	3	1
	*	*	*1%*	-	*1%*	-	*1%*	*	*1%*
Ursodeoxycholic acid/Ursodiol	**5**	2	3	1	1	1	2	2	1
	*	*1%*	*1%*	*1%*	*1%*	*	*1%*	*	*1%*
Colchicine	**5**	3	1	-	-	1	1	3	1
	*	*1%*	*	-	-	*	*	*	*1%*
Ramipril	**4**	1	-	-	-	1	2	2	-
	*	*	-	-	-	*	*1%*	*	-
Adalimumab/Amgevita/Hyrimoz/Idacio/ Imraldi/Yuflyma/Humira	**4**	-	1	-	-	2	-	1	-
	*	-	*	-	-	*1%*	-	*	-
Levothyroxine/L-thyroxine	**4**	-	1	-	-	2	1	1	-
	*	-	*	-	-	*1%*	*	*	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 53

Q16 Which, if any, of the following drugs are you taking for your rare autoimmune disease(s)?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Atorvastatin	**4**	1	1	-	2	-	1	1	-
	*	*	*	-	**1%AH**	-	*	*	-
Upadacitinib/Rinvoq	**4**	-	1	-	-	3	1	2	-
	*	-	*	-	-	**1%AB**	*	*	-
Intravenous Immunoglobulin/IVIg	**4**	-	-	4	-	-	1	3	1
	*	-	-	**3%ABCEFGHI**	-	-	*	*	*1%*
Vitamins (various)	**4**	1	2	1	1	1	2	4	2
	*	*	*1%*	*1%*	*1%*	*	*1%*	*1%*	*1%*
Duloxetine/Cymbalta	**4**	-	3	-	-	-	2	2	-
	*	-	*1%*	-	-	-	*1%*	*	-
Loperamide/Imodium	**3**	-	2	2	-	1	3	3	1
	*	-	*1%*	**2%AB**	-	*	**1%A**	*	*1%*
Pregabalin/Lyrica	**3**	1	2	-	1	-	1	2	-
	*	*	*1%*	-	*1%*	-	*	*	-
Alendronic acid/Fosamax	**3**	-	-	2	-	-	1	2	-
	*	-	-	**2%ABCFH**	-	-	*	*	-
Tramadol/Ultram	**3**	1	2	1	-	1	2	3	2
	*	*	*1%*	*1%*	-	*	*1%*	*	**1%A**
Remsima	**2**	-	-	-	-	2	-	-	-
	*	-	-	-	-	**1%AH**	-	-	-
Naproxen/Aleve	**2**	1	-	-	-	-	1	2	-
	*	*	-	-	-	-	*	*	-
Secukinumab	**2**	1	1	-	-	2	-	1	1
	*	*	*	-	-	**1%A**	-	*	*1%*
Selaxipag	**2**	-	1	-	-	-	2	2	-
	*	-	*	-	-	-	*1%*	*	-
Doxazosin/Cardura	**2**	1	-	-	-	-	1	1	-
	*	*	-	-	-	-	*	*	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 53

Q16 Which, if any, of the following drugs are you taking for your rare autoimmune disease(s)?

Base: all participants

	Total (A)	Combined diagnoses							
		A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Sulfadiazine	**2**	1	1	-	-	-	2	2	1
	*	*	*	-	-	-	*1%*	*	*1%*
Omalizumab/Xolair	**2**	2	1	-	-	1	-	1	-
	*	*1%*	*	-	-	*	-	*	-
Clopidogrel/Plavix	**2**	-	-	-	2	-	-	-	-
	*	-	-	-	**1%ABCGH**	-	-	-	-
Co-trimoxazole (trimethoprim and sulfamethoxazole)/Bactrim	**2**	-	-	-	-	2	-	-	-
	*	-	-	-	-	**1%AH**	-	-	-
Famotidine/Pepcid	**2**	-	-	-	-	-	2	2	-
	*	-	-	-	-	-	*1%*	*	-
Fexofenadine/Allegra	**2**	2	1	-	-	1	-	1	-
	*	*1%*	*	-	-	*	-	*	-
Co-Codamol	**2**	1	-	-	-	1	-	2	-
	*	*	-	-	-	*	-	*	-
Coedine	**1**	1	-	-	-	-	-	1	1
	*	*	-	-	-	-	-	*	*1%*
Morphine	**1**	1	-	-	-	-	-	1	1
	*	*	-	-	-	-	-	*	*1%*
Alemtuzumab/Campath/Lemtrada	**1**	-	-	-	-	1	-	-	-
	*	-	-	-	-	*	-	-	-
Voclosporin	**1**	-	1	-	-	-	-	-	-
	*	-	*	-	-	-	-	-	-
Ambresantan Mylan/Letairis	**1**	-	-	-	-	-	1	1	-
	*	-	-	-	-	-	*	*	-
Meloxicam/Mobic	**1**	-	1	-	-	-	-	1	-
	*	-	*	-	-	-	-	*	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 53

Q16 Which, if any, of the following drugs are you taking for your rare autoimmune disease(s)?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Other	**106**	32	30	6	18	18	29	59	20
	8%	*8%*	*8%*	*5%*	**12%F**	*6%*	*8%*	*9%*	*10%*
None of these	**438**	117	135	31	56	75	108	221	59
	32%F	*29%*	**37%ABDF**	*27%*	**37%BF**	*26%*	*31%*	**34%BF**	*31%*
Don't know/prefer not to say	**18**	7	7	-	3	1	5	11	4
	1%	*2%*	*2%*	-	*2%*	*	*1%*	*2%*	*2%*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 54

Q16 Which, if any, of the following drugs are you taking for your rare autoimmune disease(s)?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Hydroxychloroquine/Plaquenil	**285**	10	24	31	54	88	62	15	1	10	275	-	-
	21%HJ	*43%*	**32%AEFH**	*21%*	*20%*	*21%*	*21%*	*13%*	*10%*	*8%*	**22%AJ**	-	-
Mycophenolate/Mycophenolate Mofetil/MMF/CellCept	**180**	3	11	23	33	64	35	10	1	16	164	-	-
	13%	*13%*	*14%*	*15%*	*12%*	*15%*	*12%*	*9%*	*10%*	*13%*	*13%*	-	-
Prednisolone	**129**	2	11	14	16	47	28	9	2	12	117	-	-
	10%E	*9%*	**14%E**	*9%*	*6%*	**11%E**	*10%*	*8%*	*20%*	*10%*	*10%*	-	-
Methotrexate/MTX	**119**	3	9	11	24	39	29	4	-	11	108	-	-
	9%H	*13%*	**12%H**	*7%*	*9%*	**9%H**	**10%H**	*4%*	-	*9%*	*9%*	-	-
Rituximab/Rituxan	**95**	3	9	15	24	31	9	4	-	12	82	-	-
	7%G	*13%*	**12%GH**	**10%GH**	**9%G**	**7%G**	*3%*	*4%*	-	*10%*	*7%*	-	-
Sildenafil	**94**	-	3	12	19	26	28	5	1	15	79	-	-
	7%K	-	*4%*	*8%*	*7%*	*6%*	*10%*	*4%*	*10%*	**13%AK**	*6%*	-	-
Azathioprine/Imuran	**73**	5	7	11	14	24	9	3	-	10	63	-	-
	5%G	*22%*	**9%G**	**7%G**	*5%*	*6%*	*3%*	*3%*	-	*8%*	*5%*	-	-
Nifedipine/Adalat/Adipine/Coracten/ Fortipine/Nifedipress	**53**	-	3	4	13	15	14	3	1	4	49	-	-
	4%	-	*4%*	*3%*	*5%*	*4%*	*5%*	*3%*	*10%*	*3%*	*4%*	-	-
Pilocarpine	**27**	-	2	-	4	7	11	3	-	2	25	-	-
	2%	-	**3%D**	-	*1%*	*2%*	**4%AD**	**3%D**	-	*2%*	*2%*	-	-
Warfarin	**27**	1	1	4	9	7	3	1	1	2	25	-	-
	2%	*4%*	*1%*	*3%*	*3%*	*2%*	*1%*	*1%*	*10%*	*2%*	*2%*	-	-
Tocilizumab	**26**	-	3	6	4	6	5	2	-	3	23	-	-
	2%	-	*4%*	*4%*	*1%*	*1%*	*2%*	*2%*	-	*3%*	*2%*	-	-
Omeprazole/Prilosec/Losec	**23**	-	2	3	2	7	7	2	-	1	22	-	-
	2%	-	*3%*	*2%*	*1%*	*2%*	*2%*	*2%*	-	*1%*	*2%*	-	-
Tadalafil	**20**	-	1	3	5	2	6	3	-	-	20	-	-
	1%F	-	*1%*	*2%*	*2%*	*	*2%*	**3%F**	-	-	*2%*	-	-
Steroids	**19**	-	2	2	4	5	4	1	1	1	18	-	-
	1%	-	*3%*	*1%*	*1%*	*1%*	*1%*	*1%*	*10%*	*1%*	*1%*	-	-
Losartan/Cozaar	**17**	-	1	2	2	4	6	2	-	3	14	-	-
	1%	-	*1%*	*1%*	*1%*	*1%*	*2%*	*2%*	-	*3%*	*1%*	-	-
Nintedanib	**14**	-	-	1	3	5	5	-	-	3	11	-	-
	1%	-	-	*1%*	*1%*	*1%*	*2%*	-	-	*3%*	*1%*	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 54

Q16 Which, if any, of the following drugs are you taking for your rare autoimmune disease(s)?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Avacopan	**13**	-	4	4	3	1	1	-	-	2	11	-	-
	1%F	-	**5%AEFGH**	**3%AFG**	*1%*	*	*	-	-	*2%*	*1%*	-	-
Iloprost/Ventavis	**13**	-	-	2	2	4	5	-	-	2	11	-	-
	1%	-	-	*1%*	*1%*	*1%*	*2%*	-	-	*2%*	*1%*	-	-
Asprin	**12**	1	-	3	3	3	2	-	-	1	11	-	-
	1%	*4%*	-	*2%*	*1%*	*1%*	*1%*	-	-	*1%*	*1%*	-	-
Belimumab	**12**	1	3	2	4	-	2	-	-	-	12	-	-
	1%	*4%*	**4%AFGH**	**1%F**	**1%F**	-	*1%*	-	-	-	*1%*	-	-
Folic acid	**9**	-	1	-	2	3	3	-	-	1	8	-	-
	1%	-	*1%*	-	*1%*	*1%*	*1%*	-	-	*1%*	*1%*	-	-
Lansoprazole/Prevacid	**9**	-	-	-	1	4	1	3	-	1	8	-	-
	1%	-	-	-	*	*1%*	*	**3%ADEG**	-	*1%*	*1%*	-	-
Benralizumab/Fasenra	**8**	-	1	3	1	2	1	-	-	2	6	-	-
	1%	-	*1%*	**2%A**	*	*	*	-	-	*2%*	*	-	-
Eye drops (various)	**7**	-	1	-	1	1	2	2	-	-	7	-	-
	1%	-	*1%*	-	*	*	*1%*	*2%*	-	-	*1%*	-	-
Leflunomide/Arava	**7**	-	1	-	-	3	3	-	-	3	4	-	-
	1%K	-	*1%*	-	-	*1%*	*1%*	-	-	**3%AK**	*	-	-
Apixaban/Eliquis	**7**	-	-	-	2	2	3	-	-	-	7	-	-
	1%	-	-	-	*1%*	*	*1%*	-	-	-	*1%*	-	-
Gabapentin/Neurontin	**7**	-	1	-	1	4	1	-	-	-	7	-	-
	1%	-	*1%*	-	*	*1%*	*	-	-	-	*1%*	-	-
Bosentan/Tracleer	**7**	-	-	1	4	1	-	1	-	1	6	-	-
	1%	-	-	*1%*	**1%AG**	*	-	*1%*	-	*1%*	*	-	-
Ciclosporin/Cyclosporine	**7**	-	-	-	2	3	-	2	-	1	6	-	-
	1%	-	-	-	*1%*	*1%*	-	**2%G**	-	*1%*	*	-	-
Myfortic/Mycophenolic acid	**6**	-	-	-	-	5	1	-	-	-	6	-	-
	*	-	-	-	-	**1%A**	*	-	-	-	*	-	-
Tacrolimus/Prograf	**6**	-	-	-	3	3	-	-	-	1	5	-	-
	*	-	-	-	*1%*	*1%*	-	-	-	*1%*	*	-	-
Cyclophosphamide/Cytophosphane	**6**	-	-	-	-	3	3	-	-	-	6	-	-
	*	-	-	-	-	*1%*	*1%*	-	-	-	*	-	-
Adcal	**5**	-	-	1	-	1	2	1	-	-	5	-	-
	*	-	-	*1%*	-	*	*1%*	*1%*	-	-	*	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 54

Q16 Which, if any, of the following drugs are you taking for your rare autoimmune disease(s)?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Amlodipine/Norvasc	**5**	-	-	-	1	1	2	1	-	-	5	-	-
	*	-	-	-	*	*	*1%*	*1%*	-	-	*	-	-
Amitriptyline/Elavil	**5**	1	-	1	-	1	2	-	-	-	5	-	-
	*	*4%*	-	*1%*	-	*	*1%*	-	-	-	*	-	-
Ursodeoxycholic acid/Ursodiol	**5**	-	-	-	-	2	2	-	1	-	5	-	-
	*	-	-	-	-	*	*1%*	-	*10%*	-	*	-	-
Colchicine	**5**	1	-	1	-	1	2	-	-	-	5	-	-
	*	*4%*	-	*1%*	-	*	*1%*	-	-	-	*	-	-
Ramipril	**4**	-	1	1	-	2	-	-	-	-	4	-	-
	*	-	*1%*	*1%*	-	*	-	-	-	-	*	-	-
Adalimumab/Amgevita/Hyrimoz/Idacio/ Imraldi/Yuflyma/Humira	**4**	-	-	1	-	-	3	-	-	1	3	-	-
	*	-	-	*1%*	-	-	**1%AF**	-	-	*1%*	*	-	-
Levothyroxine/L-thyroxine	**4**	-	-	1	-	2	1	-	-	-	4	-	-
	*	-	-	*1%*	-	*	*	-	-	-	*	-	-
Atorvastatin	**4**	-	-	-	1	2	1	-	-	2	2	-	-
	***K**	-	-	-	*	*	*	-	-	**2%AK**	*	-	-
Upadacitinib/Rinvoq	**4**	-	-	1	1	1	1	-	-	-	4	-	-
	*	-	-	*1%*	*	*	*	-	-	-	*	-	-
Intravenous Immunoglobulin/IVIg	**4**	-	-	1	1	2	-	-	-	1	3	-	-
	*	-	-	*1%*	*	*	-	-	-	*1%*	*	-	-
Vitamins (various)	**4**	-	-	-	2	-	2	-	-	1	3	-	-
	*	-	-	-	*1%*	-	*1%*	-	-	*1%*	*	-	-
Duloxetine/Cymbalta	**4**	-	-	-	-	1	2	1	-	1	3	-	-
	*	-	-	-	-	*	*1%*	*1%*	-	*1%*	*	-	-
Loperamide/Imodium	**3**	-	1	-	1	-	1	-	-	-	3	-	-
	*	-	**1%F**	-	*	-	*	-	-	-	*	-	-
Pregabalin/Lyrica	**3**	-	-	-	-	-	1	2	-	-	3	-	-
	*	-	-	-	-	-	*	**2%AEF**	-	-	*	-	-
Alendronic acid/Fosamax	**3**	-	-	1	-	1	1	-	-	-	3	-	-
	*	-	-	*1%*	-	*	*	-	-	-	*	-	-
Tramadol/Ultram	**3**	-	-	-	2	-	1	-	-	1	2	-	-
	*	-	-	-	*1%*	-	*	-	-	*1%*	*	-	-
Remsima	**2**	-	-	-	2	-	-	-	-	-	2	-	-
	*	-	-	-	**1%A**	-	-	-	-	-	*	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 54

Q16 Which, if any, of the following drugs are you taking for your rare autoimmune disease(s)?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Naproxen/Aleve	**2**	1	-	-	-	1	-	-	-	-	2	-	-
	*	*4%*	-	-	-	*	-	-	-	-	*	-	-
Secukinumab	**2**	-	-	-	-	2	-	-	-	-	2	-	-
	*	-	-	-	-	*	-	-	-	-	*	-	-
Selaxipag	**2**	-	-	-	-	-	2	-	-	-	2	-	-
	*	-	-	-	-	-	**1%A**	-	-	-	*	-	-
Doxazosin/Cardura	**2**	-	-	-	-	1	-	1	-	-	2	-	-
	*	-	-	-	-	*	-	*1%*	-	-	*	-	-
Sulfadiazine	**2**	-	-	-	-	2	-	-	-	-	2	-	-
	*	-	-	-	-	*	-	-	-	-	*	-	-
Omalizumab/Xolair	**2**	-	-	-	-	2	-	-	-	-	2	-	-
	*	-	-	-	-	*	-	-	-	-	*	-	-
Clopidogrel/Plavix	**2**	-	-	-	1	1	-	-	-	1	1	-	-
	***K**	-	-	-	*	*	-	-	-	**1%K**	*	-	-
Co-trimoxazole (trimethoprim and sulfamethoxazole)/Bactrim	**2**	-	1	-	-	1	-	-	-	1	1	-	-
	***K**	-	**1%A**	-	-	*	-	-	-	**1%K**	*	-	-
Famotidine/Pepcid	**2**	-	-	-	1	1	-	-	-	-	2	-	-
	*	-	-	-	*	*	-	-	-	-	*	-	-
Fexofenadine/Allegra	**2**	-	-	-	-	2	-	-	-	-	2	-	-
	*	-	-	-	-	*	-	-	-	-	*	-	-
Co-Codamol	**2**	-	-	-	-	1	1	-	-	-	2	-	-
	*	-	-	-	-	*	*	-	-	-	*	-	-
Coedine	**1**	-	-	-	1	-	-	-	-	-	-	1	-
	*	-	-	-	*	-	-	-	-	-	-	*50%*	-
Morphine	**1**	-	-	-	1	-	-	-	-	-	-	1	-
	*	-	-	-	*	-	-	-	-	-	-	*50%*	-
Alemtuzumab/Campath/Lemtrada	**1**	-	-	-	1	-	-	-	-	-	1	-	-
	*	-	-	-	*	-	-	-	-	-	*	-	-
Voclosporin	**1**	-	-	-	-	1	-	-	-	-	1	-	-
	*	-	-	-	-	*	-	-	-	-	*	-	-
Ambresantan Mylan/Letairis	**1**	-	-	-	-	-	1	-	-	-	1	-	-
	*	-	-	-	-	-	*	-	-	-	*	-	-
Meloxicam/Mobic	**1**	-	-	-	-	1	-	-	-	-	1	-	-
	*	-	-	-	-	*	-	-	-	-	*	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 54

Q16 Which, if any, of the following drugs are you taking for your rare autoimmune disease(s)?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Other	**106**	1	4	9	19	33	31	7	2	10	96	-	-
	8%	*4%*	*5%*	*6%*	*7%*	*8%*	*11%*	*6%*	*20%*	*8%*	*8%*	-	-
None of these	**438**	5	16	48	89	121	100	55	4	35	401	1	-
	32%C	*22%*	*21%*	*32%*	**33%C**	*29%*	**34%C**	**49%ACDEFG**	*40%*	*29%*	*33%*	*50%*	-
Don't know/prefer not to say	**18**	-	2	4	2	7	2	1	-	3	15	-	-
	1%	-	*3%*	*3%*	*1%*	*2%*	*1%*	*1%*	-	*3%*	*1%*	-	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 55

Q17 How easy or not do you find it to access blood tests to monitor your drug safety?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Very easy	**319**	65	23	36	17	88	61	16	13	9	23	4	5	1	18	85	5
	24%CHQ	*20%*	*15%*	**47%ABCEFGHI**	*22%*	**34%ABCGHI**	*23%*	*14%*	*16%*	*20%*	*20%*	*25%*	*12%*	*13%*	**36%AKMPQ**	**22%Q**	*10%*
Fairly easy	**374**	101	34	20	18	86	76	15	24	13	39	5	16	4	10	105	17
	28%H	**32%CH**	**23%H**	**26%H**	*23%*	**33%ACH**	**28%H**	*13%*	**29%H**	*30%*	*34%*	*31%*	*38%*	*50%*	*20%*	*27%*	*34%*
Neither easy nor difficult	**127**	40	12	5	8	22	22	8	10	6	8	-	5	2	3	34	5
	9%	**13%A**	*8%*	*6%*	*10%*	*8%*	*8%*	*7%*	*12%*	*14%*	*7%*	-	*12%*	*25%*	*6%*	*9%*	*10%*
Not very easy	**155**	48	24	9	11	22	23	7	11	6	12	5	8	1	3	51	9
	11%	**15%AFGH**	**16%FGH**	*12%*	*14%*	*8%*	*9%*	*6%*	*13%*	*14%*	*10%*	*31%*	*19%*	*13%*	*6%*	*13%*	*18%*
Not at all easy	**74**	15	5	3	6	12	16	9	8	1	10	1	3	-	4	17	6
	5%	*5%*	*3%*	*4%*	*8%*	*5%*	*6%*	*8%*	**10%C**	*2%*	*9%*	*6%*	*7%*	-	*8%*	*4%*	**12%AP**
I don't have blood tests to monitor drug safety	**215**	32	41	3	13	19	49	48	10	6	17	1	2	-	7	60	3
	16%BDFMQ	*10%*	**27%ABDFGI**	*4%*	**17%DF**	*7%*	**18%BDF**	**42%ABCDEFGI**	*12%*	*14%*	*15%*	*6%*	*5%*	-	*14%*	*16%*	*6%*
I don't know if I have blood tests to monitor drug safety	**88**	19	12	1	4	11	23	12	6	3	7	-	3	-	5	31	5
	7%	*6%*	**8%D**	*1%*	*5%*	*4%*	**9%DF**	**10%DF**	*7%*	*7%*	*6%*	-	*7%*	-	*10%*	*8%*	*10%*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Easy	**693**	**166**	**57**	**56**	**35**	**174**	**137**	**31**	**37**	**22**	**62**	**9**	**21**	**5**	**28**	**190**	**22**
	51%CH	**52%CH**	***38%***	**73%ABCEGHI**	**45%H**	**67%ABCEGHI**	**51%CH**	***27%***	**45%H**	***50%***	***53%***	***56%***	***50%***	***63%***	***56%***	***50%***	***44%***
Not easy	**229**	**63**	**29**	**12**	**17**	**34**	**39**	**16**	**19**	**7**	**22**	**6**	**11**	**1**	**7**	**68**	**15**
	17%	**20%F**	***19%***	***16%***	***22%***	***13%***	***14%***	***14%***	**23%F**	***16%***	***19%***	***38%***	***26%***	***13%***	***14%***	***18%***	**30%AP**
Net easy	**464**	**103**	**28**	**44**	**18**	**140**	**98**	**15**	**18**	**15**	**40**	**3**	**10**	**4**	**21**	**122**	**7**
	34%	***32%***	***19%***	***57%***	***23%***	***54%***	***36%***	***13%***	***22%***	***34%***	***34%***	***19%***	***24%***	***50%***	***42%***	***32%***	***14%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 56

Q17 How easy or not do you find it to access blood tests to monitor your drug safety?

Base: all participants

	Total (A)	Combined diagnoses: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Very easy	**319**	82	68	47	28	93	83	134	35
	24%CH	*21%*	*19%*	**41%ABCEGHI**	*19%*	**32%ABCEGHI**	*24%*	*21%*	*18%*
Fairly easy	**374**	124	103	29	47	97	96	176	61
	28%	*31%*	*28%*	*25%*	*31%*	**34%AH**	*27%*	*27%*	*32%*
Neither easy nor difficult	**127**	48	29	10	16	26	28	53	19
	9%	**12%ACH**	*8%*	*9%*	*11%*	*9%*	*8%*	*8%*	*10%*
Not very easy	**155**	61	54	18	24	27	32	73	30
	11%	**15%AFGH**	**15%AFGH**	**16%G**	**16%FG**	*9%*	*9%*	*11%*	**16%FG**
Not at all easy	**74**	22	18	4	9	13	23	38	18
	5%	*6%*	*5%*	*3%*	*6%*	*5%*	*7%*	*6%*	**9%ABCDFH**
I don't have blood tests to monitor drug safety	**215**	39	67	6	18	19	60	122	16
	16%BDFI	*10%*	**18%BDFI**	*5%*	*12%*	*7%*	**17%BDFI**	**19%ABDEFI**	*8%*
I don't know if I have blood tests to monitor drug safety	**88**	22	27	2	9	12	28	53	14
	7%D	*6%*	**7%D**	*2%*	*6%*	*4%*	**8%DF**	**8%ABDF**	**7%D**
Don't know/no answer	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
Easy	**693**	**206**	**171**	**76**	**75**	**190**	**179**	**310**	**96**
	51%CH	***52%***	***47%***	**66%ABCEGHI**	***50%***	**66%ABCEGHI**	***51%***	***48%***	***50%***
Not easy	**229**	**83**	**72**	**22**	**33**	**40**	**55**	**111**	**48**
	17%	**21%AF**	**20%F**	***19%***	**22%F**	***14%***	***16%***	***17%***	**25%AFGH**
Net easy	**464**	**123**	**99**	**54**	**42**	**150**	**124**	**199**	**48**
	34%	***31%***	***27%***	***47%***	***28%***	***52%***	***35%***	***31%***	***25%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 57

Q17 How easy or not do you find it to access blood tests to monitor your drug safety?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Very easy	**319**	6	14	32	66	97	72	32	-	39	280	-	-
	24%K	*26%*	*18%*	*21%*	*24%*	*23%*	*25%*	*29%*	-	**33%AK**	*23%*	-	-
Fairly easy	**374**	7	25	41	85	118	77	16	5	34	339	-	-
	28%H	*30%*	**33%H**	**27%H**	**31%H**	**28%H**	**26%H**	*14%*	*50%*	*28%*	*28%*	-	-
Neither easy nor difficult	**127**	4	7	17	26	38	27	8	-	4	123	-	-
	9%J	*17%*	*9%*	*11%*	*10%*	*9%*	*9%*	*7%*	-	*3%*	**10%AJ**	-	-
Not very easy	**155**	1	11	20	29	52	31	11	-	15	139	-	-
	11%	*4%*	*14%*	*13%*	*11%*	*12%*	*11%*	*10%*	-	*13%*	*11%*	-	-
Not at all easy	**74**	2	5	8	16	25	13	5	-	7	66	1	-
	5%	*9%*	*7%*	*5%*	*6%*	*6%*	*4%*	*4%*	-	*6%*	*5%*	*50%*	-
I don't have blood tests to monitor drug safety	**215**	2	9	22	32	66	45	35	4	18	196	1	-
	16%E	*9%*	*12%*	*15%*	*12%*	*16%*	*15%*	**31%ACDEFG**	*40%*	*15%*	*16%*	*50%*	-
I don't know if I have blood tests to monitor drug safety	**88**	1	5	10	17	22	27	5	1	3	85	-	-
	7%	*4%*	*7%*	*7%*	*6%*	*5%*	**9%AF**	*4%*	*10%*	*3%*	*7%*	-	-
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Easy	**693**	**13**	**39**	**73**	**151**	**215**	**149**	**48**	**5**	**73**	**619**	**-**	**-**
	51%K	***57%***	***51%***	***49%***	**56%H**	***51%***	***51%***	***43%***	***50%***	**61%AK**	***50%***	**-**	**-**
Not easy	**229**	**3**	**16**	**28**	**45**	**77**	**44**	**16**	**-**	**22**	**205**	**1**	**-**
	17%	***13%***	***21%***	***19%***	***17%***	***18%***	***15%***	***14%***	**-**	***18%***	***17%***	***50%***	**-**
Net easy	**464**	**10**	**23**	**45**	**106**	**138**	**105**	**32**	**5**	**51**	**414**	**-1**	**0**
	34%	***43%***	***30%***	***30%***	***39%***	***33%***	***36%***	***29%***	***50%***	***43%***	***34%***	***-50%***	***0%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 58

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: all participants

	Total (A)	Primary diagnosis								Secondary diagnosis							
		A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Internet search	**910**	211	108	47	44	179	181	81	59	30	76	13	28	6	36	257	36
	67%	*66%*	**72%E**	*61%*	*57%*	*69%*	*67%*	*70%*	*72%*	*68%*	*66%*	*81%*	*67%*	*75%*	*72%*	*67%*	*72%*
Consultant during appointment	**870**	211	104	58	33	186	183	38	57	21	83	12	30	5	34	262	28
	64%EHJ	**66%EH**	**69%EH**	**75%AEH**	*43%*	**72%AEH**	**68%EH**	*33%*	**70%EH**	*48%*	**72%J**	*75%*	**71%J**	*63%*	*68%*	**68%AJ**	*56%*
Through social media, e. g. Facebook forums	**674**	150	41	57	56	175	110	40	45	25	51	11	29	6	26	172	27
	50%CGHP	**47%CH**	*27%*	**74%ABCGHI**	**73%ABCGHI**	**67%ABCGHI**	**41%C**	*35%*	**55%CGH**	*57%*	*44%*	*69%*	**69%AKP**	*75%*	*52%*	*45%*	*54%*
Patient organisations, e. g. charity helplines or support groups	**642**	150	111	36	30	135	102	42	36	18	63	7	23	3	22	170	23
	47%GH	**47%G**	**74%ABDEFGHI**	*47%*	*39%*	**52%EGH**	*38%*	*37%*	*44%*	*41%*	*54%*	*44%*	*55%*	*38%*	*44%*	*44%*	*46%*
Online support and discussion groups	**446**	101	56	27	23	97	83	23	36	16	45	6	17	2	13	126	18
	33%H	**32%H**	**37%H**	**35%H**	*30%*	**37%H**	**31%H**	*20%*	**44%ABGH**	*36%*	*39%*	*38%*	*40%*	*25%*	*26%*	*33%*	*36%*
Specialist nurse	**379**	112	24	27	14	77	83	10	32	14	31	4	15	3	16	127	17
	28%CEH	**35%ACEH**	*16%*	**35%CEH**	*18%*	**30%CEH**	**31%CEH**	*9%*	**39%ACEH**	*32%*	*27%*	*25%*	*36%*	*38%*	*32%*	**33%A**	*34%*
Hospital-based advice lines	**308**	90	22	20	10	61	64	18	23	10	29	4	14	1	16	97	19
	23%CE	**28%ACEH**	*15%*	**26%CE**	*13%*	**23%CE**	**24%CE**	*16%*	**28%CEH**	*23%*	*25%*	*25%*	*33%*	*13%*	*32%*	*25%*	**38%A**
Psychological support	**96**	32	8	7	5	18	14	3	9	2	14	4	4	3	3	24	4
	7%H	**10%AGH**	*5%*	**9%H**	*6%*	*7%*	*5%*	*3%*	**11%H**	*5%*	**12%AP**	*25%*	*10%*	*38%*	*6%*	*6%*	*8%*
Library	**40**	16	6	2	2	3	5	4	2	1	6	-	3	-	1	10	1
	3%F	**5%AFG**	*4%*	*3%*	*3%*	*1%*	*2%*	*3%*	*2%*	*2%*	*5%*	-	*7%*	-	*2%*	*3%*	*2%*
Healthcare professionals, i. e. GP/ consultant etc.	**18**	5	3	3	1	1	2	3	-	1	4	-	-	-	-	4	1
	1%	*2%*	*2%*	**4%FG**	*1%*	*	*1%*	*3%*	-	*2%*	**3%A**	-	-	-	-	*1%*	*2%*
Journals/books/leaflets (printed material)	**11**	3	2	-	1	2	2	-	1	-	1	1	-	-	1	3	1
	1%	*1%*	*1%*	-	*1%*	*1%*	*1%*	-	*1%*	-	*1%*	*6%*	-	-	*2%*	*1%*	*2%*
SRUK/Scleroderma & Raynaud's UK	**10**	-	-	-	-	-	7	3	-	-	-	-	-	-	-	7	1
	1%	-	-	-	-	-	**3%ABCF**	**3%ABCF**	-	-	-	-	-	-	-	**2%A**	*2%*

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 58

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
BSSA/British Sjorgens Syndrome	**7**	1	4	1	-	-	-	1	-	-	-	1	-	-	-	2	1
Association	***1%***	*	**3%ABFG**	*1%*	-	-	-	*1%*	-	-	-	*6%*	-	-	-	*1%*	*2%*
Conducted my own research	**6**	2	1	-	1	1	1	-	-	-	1	1	-	-	-	2	-
	*	*1%*	*1%*	-	*1%*	*	*	-	-	-	*1%*	*6%*	-	-	-	*1%*	-
Private healthcare channels	**5**	1	2	2	-	-	-	-	-	1	1	-	-	-	1	1	-
	*	*	*1%*	**3%ABFG**	-	-	-	-	-	*2%*	*1%*	-	-	-	*2%*	*	-
Lupus UK	**5**	5	-	-	-	-	-	-	-	-	1	-	1	-	-	1	1
	*	**2%AFG**	-	-	-	-	-	-	-	-	*1%*	-	**2%A**	-	-	*	*2%*
Websites /online (various)	**5**	4	-	-	-	1	-	-	-	-	-	1	1	-	-	-	1
	*	**1%A**	-	-	-	*	-	-	-	-	-	*6%*	**2%AP**	-	-	-	**2%P**
Word of mouth/networking/friends/ family/other patients	**5**	-	-	1	-	1	2	-	1	-	-	-	-	-	1	2	-
	*	-	-	**1%B**	-	*	*1%*	-	**1%B**	-	-	-	-	-	*2%*	*1%*	-
Videos	**4**	1	-	-	-	2	-	1	-	-	-	1	-	-	-	-	-
	*	*	-	-	-	*1%*	-	*1%*	-	-	-	*6%*	-	-	-	-	-
Downloaded an app	**4**	-	-	2	1	-	1	-	-	1	-	-	-	-	2	1	-
	*	-	-	**3%ABCF**	**1%B**	-	*	-	-	**2%A**	-	-	-	-	**4%AKP**	*	-
USA/American organisations	**4**	2	1	-	-	-	1	-	-	-	1	-	-	-	-	2	-
	*	*1%*	*1%*	-	-	-	*	-	-	-	*1%*	-	-	-	-	*1%*	-
Vasculitis UK	**3**	-	-	-	-	3	-	-	-	1	-	-	-	-	-	-	-
	*	-	-	-	-	**1%A**	-	-	-	**2%AP**	-	-	-	-	-	-	-
Books/leaflets/printed material	**3**	1	-	-	-	-	1	1	-	-	-	-	-	-	-	1	1
	*	*	-	-	-	-	*	*1%*	-	-	-	-	-	-	-	*	**2%A**
My own background in healthcare	**2**	1	-	-	-	-	-	1	-	-	-	-	-	-	-	1	-
	*	*	-	-	-	-	-	*1%*	-	-	-	-	-	-	-	*	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 58

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: all participants

	Total (A)	Primary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Primary diagnosis: Sjogren's disease (C)	Primary diagnosis: Myositis/ inflammatory muscle disease (D)	Primary diagnosis: Antiphospholipid syndrome (APS) (E)	Primary diagnosis: A form of systemic vasculitis (including Behcet's) (F)	Primary diagnosis: A form of systemic sclerosis or scleroderma (G)	Primary diagnosis: Raynaud's disease (H)	Primary diagnosis: Undifferentiated or mixed connective tissue disease (I)	Secondary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Secondary diagnosis: Sjogren's disease (K)	Secondary diagnosis: Myositis/ inflammatory muscle disease (L)	Secondary diagnosis: Antiphospholipid syndrome (APS) (M)	Secondary diagnosis: A form of systemic vasculitis (including Behcet's) (N)	Secondary diagnosis: A form of systemic sclerosis or scleroderma (O)	Secondary diagnosis: Raynaud's disease (P)	Secondary diagnosis: Undifferentiated or mixed connective tissue disease (Q)
Total	1352	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Events/conferences/seminars/ webinars	2	-	-	-	-	1	1	-	-	-	-	1	-	-	-	-	-
	*	-	-	-	-	*	*	-	-	-	-	*6%*	-	-	-	-	-
Other	5	2	1	-	-	1	1	-	-	-	1	-	-	-	-	1	-
	*	*1%*	*1%*	-	-	*	*	-	-	-	*1%*	-	-	-	-	*	-
I have not accessed any information or support	28	3	3	-	3	1	9	7	2	1	1	1	-	-	2	8	1
	2%F	*1%*	*2%*	-	4%F	*	3%BF	6%ABDF	*2%*	*2%*	*1%*	*6%*	-	-	*4%*	*2%*	*2%*
Prefer not to say	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
1 type of support accessed	175	44	9	6	11	20	45	30	10	6	14	-	3	-	7	49	5
	13%CF	14%CF	*6%*	*8%*	14%C	*8%*	17%ACF	26%ABCDFGI	*12%*	*14%*	*12%*	-	*7%*	-	*14%*	*13%*	*10%*
2 types of support accessed	253	58	28	13	23	43	50	29	9	6	24	2	5	2	6	72	9
	19%	*18%*	*19%*	*17%*	30%ABFGI	*17%*	*19%*	25%I	*11%*	*14%*	*21%*	*13%*	*12%*	*25%*	*12%*	*19%*	*18%*
3 types of support accessed	336	71	54	21	18	71	61	25	15	15	25	3	10	-	10	99	11
	25%	*22%*	36%ABGHI	*27%*	*23%*	*27%*	*23%*	*22%*	*18%*	*34%*	*22%*	*19%*	*24%*	-	*20%*	*26%*	*22%*
4 types of support accessed	246	55	28	14	11	52	50	17	19	7	18	3	8	5	11	64	8
	18%	*17%*	*19%*	*18%*	*14%*	*20%*	*19%*	*15%*	*23%*	*16%*	*16%*	*19%*	*19%*	*63%*	*22%*	*17%*	*16%*
5 types of support accessed	173	52	21	10	5	38	28	5	14	6	14	5	8	1	9	43	9
	13%H	16%AEGH	14%H	13%H	*6%*	15%H	*10%*	*4%*	17%EH	*14%*	*12%*	*31%*	*19%*	*13%*	*18%*	*11%*	*18%*
6 types of support accessed	85	20	6	7	3	22	17	1	9	1	14	-	6	-	3	30	4
	6%H	6%H	*4%*	9%H	*4%*	8%H	6%H	*1%*	11%CH	*2%*	12%A	-	14%AJ	-	*6%*	*8%*	*8%*
7 types of support accessed	39	10	2	2	2	10	8	1	4	2	4	1	2	-	1	13	1
	3%	*3%*	*1%*	*3%*	*3%*	*4%*	*3%*	*1%*	*5%*	*5%*	*3%*	*6%*	*5%*	-	*2%*	*3%*	*2%*

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 58

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: all participants

	Total (A)	Primary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Primary diagnosis: Sjogren's disease (C)	Primary diagnosis: Myositis/ inflammatory muscle disease (D)	Primary diagnosis: Antiphospholipid syndrome (APS) (E)	Primary diagnosis: A form of systemic vasculitis (including Behcet's) (F)	Primary diagnosis: A form of systemic sclerosis or scleroderma (G)	Primary diagnosis: Raynaud's disease (H)	Primary diagnosis: Undifferentiated or mixed connective tissue disease (I)	Secondary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Secondary diagnosis: Sjogren's disease (K)	Secondary diagnosis: Myositis/ inflammatory muscle disease (L)	Secondary diagnosis: Antiphospholipid syndrome (APS) (M)	Secondary diagnosis: A form of systemic vasculitis (including Behcet's) (N)	Secondary diagnosis: A form of systemic sclerosis or scleroderma (O)	Secondary diagnosis: Raynaud's disease (P)	Secondary diagnosis: Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
8 types of support accessed	**11**	**5**	**-**	**3**	**-**	**2**	**1**	**-**	**-**	**-**	**1**	**-**	**-**	**-**	**-**	**4**	**2**
	1%	*2%*	-	**4%ACFGH**	-	*1%*	*	-	-	-	*1%*	-	-	-	-	*1%*	**4%A**
9 types of support accessed	**5**	**2**	**-**	**1**	**1**	**1**	**-**	**-**	**-**	**-**	**1**	**-**	**-**	**-**	**1**	**1**	**-**
	*	*1%*	-	*1%*	*1%*	*	-	-	-	-	*1%*	-	-	-	*2%*	*	-
10 types of support accessed	**1**	**-**	**-**	**-**	**-**	**-**	**1**	**-**	**-**	**-**	**-**	**1**	**-**	**-**	**-**	**-**	**-**
	*	-	-	-	-	-	*	-	-	-	-	*6%*	-	-	-	-	-
11+ types of support accessed	**-**	**-**	**-**	**-**	**-**	**-**	**-**	**-**	**-**	**-**	**-**	**-**	**-**	**-**	**-**	**-**	**-**
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Average number of types of support accessed	**3.3EH**	**3.4EGH**	**3.3H**	**3.8ACEGH**	**2.9H**	**3.6ACEGH**	**3.1H**	**2.3**	**3.7AEGH**	**3.2**	**3.5**	**4.2**	**3.9AJP**	**3.6**	**3.4**	**3.3**	**3.6**
Standard deviation	**1.7**	**1.8**	**1.4**	**1.8**	**1.7**	**1.6**	**1.7**	**1.4**	**1.8**	**1.6**	**1.8**	**2.3**	**1.6**	**1.1**	**1.9**	**1.7**	**1.8**
Standard error	**0.05**	**0.10**	**0.11**	**0.21**	**0.19**	**0.10**	**0.11**	**0.13**	**0.19**	**0.24**	**0.17**	**0.56**	**0.25**	**0.38**	**0.26**	**0.09**	**0.26**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 59

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: all participants

	Total (A)	Combined diagnoses: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Internet search	**910**	260	251	81	89	198	239	440	139
	67%E	*65%*	**69%E**	*70%*	*59%*	**69%E**	**68%E**	**68%E**	**72%E**
Consultant during appointment	**870**	257	258	87	84	206	233	400	133
	64%EH	**65%E**	**70%ABEH**	**75%ABEH**	*56%*	**72%ABEH**	**67%EH**	*62%*	**69%EH**
Through social media, e. g. Facebook forums	**674**	192	137	80	96	191	150	297	106
	50%CGH	**48%C**	*37%*	**69%ABCGHI**	**64%ABCGH**	**67%ABCGHI**	*43%*	**46%C**	**55%CGH**
Patient organisations, e. g. charity helplines or support groups	**642**	181	218	53	65	147	145	288	92
	47%GH	*45%*	**60%ABDEFGHI**	*46%*	*43%*	**51%GH**	*41%*	*44%*	*48%*
Online support and discussion groups	**446**	132	140	45	54	107	109	211	78
	33%	*33%*	**38%AGH**	*39%*	*36%*	*37%*	*31%*	*33%*	**40%ABGH**
Specialist nurse	**379**	142	95	42	43	85	107	189	78
	28%	**36%ACH**	*26%*	**36%AC**	*28%*	*30%*	*31%*	*29%*	**40%ACEFGH**
Hospital-based advice lines	**308**	111	80	33	34	66	85	164	58
	23%	**28%AC**	*22%*	*28%*	*23%*	*23%*	*24%*	**25%A**	**30%AC**
Psychological support	**96**	36	31	15	12	24	18	45	21
	7%	**9%G**	**8%G**	**13%AGH**	*8%*	*8%*	*5%*	*7%*	**11%AGH**
Library	**40**	19	18	2	7	3	7	21	7
	3%F	**5%AFG**	**5%AFG**	*2%*	**5%F**	*1%*	*2%*	*3%*	*4%*
Healthcare professionals, i. e. GP/ consultant etc.	**18**	6	7	4	1	2	2	9	2
	1%	*2%*	*2%*	**3%AFG**	*1%*	*1%*	*1%*	*1%*	*1%*
Journals/books/leaflets (printed material)	**11**	4	5	1	2	2	3	6	3
	1%	*1%*	*1%*	*1%*	*1%*	*1%*	*1%*	*1%*	*2%*
SRUK/Scleroderma & Raynaud's UK	**10**	-	-	-	-	-	7	10	1
	1%	-	-	-	-	-	**2%ABCF**	**2%ABCF**	*1%*
BSSA/British Sjorgens Syndrome Association	**7**	1	7	2	-	-	-	4	1
	1%	*	**2%ABFGH**	**2%FG**	-	-	-	*1%*	*1%*

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 59

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: all participants

	Total (A)	Combined diagnoses							
		A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Conducted my own research	**6**	2	3	1	1	2	1	3	-
	*	*1%*	*1%*	*1%*	*1%*	*1%*	*	*	-
Private healthcare channels	**5**	2	3	2	-	-	1	2	1
	*	*1%*	*1%*	**2%AFH**	-	-	*	*	*1%*
Lupus UK	**5**	5	2	-	1	-	1	3	1
	*	**1%A**	*1%*	-	*1%*	-	*	*	*1%*
Websites /online (various)	**5**	4	2	1	1	1	-	2	1
	*	**1%A**	*1%*	*1%*	*1%*	*	-	*	*1%*
Word of mouth/networking/friends/ family/other patients	**5**	-	-	1	-	1	3	3	2
	*	-	-	*1%*	-	*	*1%*	*	**1%B**
Videos	**4**	1	1	1	-	2	-	1	-
	*	*	*	*1%*	-	*1%*	-	*	-
Downloaded an app	**4**	1	-	2	1	-	3	3	-
	*	*	-	**2%ACF**	*1%*	-	*1%*	*	-
USA/American organisations	**4**	2	2	-	-	-	1	2	-
	*	*1%*	*1%*	-	-	-	*	*	-
Vasculitis UK	**3**	1	-	-	-	3	-	-	-
	*	*	-	-	-	**1%AH**	-	-	-
Books/leaflets/printed material	**3**	1	1	-	-	-	1	3	1
	*	*	*	-	-	-	*	*	*1%*
My own background in healthcare	**2**	1	1	-	1	-	-	2	-
	*	*	*	-	*1%*	-	-	*	-
Events/conferences/seminars/ webinars	**2**	-	1	1	-	1	1	1	-
	*	-	*	*1%*	-	*	*	*	-
Other	**5**	2	2	-	-	1	1	1	1
	*	*1%*	*1%*	-	-	*	*	*	*1%*

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 59

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: all participants

	Total (A)	Combined diagnoses							
		A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	1352	398	366	116	151	287	350	649	193
I have not accessed any information or support	28 2%F	5 *1%*	6 *2%*	1 *1%*	3 *2%*	1 *	12 3%BF	16 2%F	4 *2%*
Prefer not to say	- -	- -	- -	- -	- -	- -	- -	- -	- -
Don't know/no answer	- -	- -	- -	- -	- -	- -	- -	- -	- -
1 type of support accessed	175 13%CDF	55 14%CDF	33 *9%*	7 *6%*	17 *11%*	23 *8%*	56 16%CDFI	94 14%CDF	20 *10%*
2 types of support accessed	253 19%	71 *18%*	65 *18%*	18 *16%*	35 23%I	48 *17%*	61 *17%*	123 *19%*	27 *14%*
3 types of support accessed	336 25%I	90 *23%*	104 28%BGI	26 *22%*	39 *26%*	74 *26%*	78 *22%*	158 *24%*	37 *19%*
4 types of support accessed	246 18%	69 *17%*	66 *18%*	26 *22%*	23 *15%*	62 22%H	66 *19%*	106 *16%*	40 *21%*
5 types of support accessed	173 13%	61 *15%*	50 *14%*	18 *16%*	17 *11%*	40 *14%*	40 *11%*	80 *12%*	32 *17%*
6 types of support accessed	85 6%	25 *6%*	28 *8%*	10 *9%*	11 *7%*	24 *8%*	23 *7%*	45 *7%*	18 *9%*
7 types of support accessed	39 3%	14 *4%*	8 *2%*	4 *3%*	4 *3%*	12 *4%*	11 *3%*	18 *3%*	9 *5%*
8 types of support accessed	11 *1%*	5 *1%*	3 *1%*	4 3%ACFGH	1 *1%*	2 *1%*	1 *	6 *1%*	4 2%G
9 types of support accessed	5 *	3 *1%*	2 *1%*	1 *1%*	1 *1%*	1 *	1 *	2 *	2 *1%*
10 types of support accessed	1 *	- -	1 *	1 1%A	- -	- -	1 *	1 *	- -
11+ types of support accessed	- -	- -	- -	- -	- -	- -	- -	- -	- -

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Average number of types of support accessed	**3.3**	**3.4**	**3.5AGH**	**3.9ABCEGH**	**3.3**	**3.6AEGH**	**3.2**	**3.3**	**3.8ABCEGH**
Standard deviation	**1.7**	**1.8**	**1.7**	**1.9**	**1.7**	**1.6**	**1.8**	**1.8**	**1.9**
Standard error	**0.05**	**0.09**	**0.09**	**0.17**	**0.14**	**0.10**	**0.09**	**0.07**	**0.14**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 60

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Internet search	**910**	19	48	93	185	284	204	72	5	82	826	1	-
	67%	*83%*	*63%*	*62%*	*68%*	*68%*	*70%*	*64%*	*50%*	*68%*	*67%*	*50%*	-
Consultant during appointment	**870**	15	48	89	164	272	205	71	6	84	785	-	-
	64%	*65%*	*63%*	*59%*	*61%*	*65%*	**70%ADE**	*63%*	*60%*	*70%*	*64%*	-	-
Through social media, e. g. Facebook forums	**674**	11	44	94	178	207	114	24	2	55	616	2	-
	50%GH	*48%*	**58%GH**	**63%AFGH**	**66%AFGH**	**50%GH**	**39%H**	*21%*	*20%*	*46%*	*50%*	*100%*	-
Patient organisations, e. g. charity helplines or support groups	**642**	11	29	61	127	200	150	61	3	54	587	1	-
	47%	*48%*	*38%*	*41%*	*47%*	*48%*	**51%CD**	**54%CD**	*30%*	*45%*	*48%*	*50%*	-
Online support and discussion groups	**446**	4	34	49	101	143	86	27	2	34	411	-	-
	33%H	*17%*	**45%AGH**	*33%*	**37%GH**	**34%H**	*29%*	*24%*	*20%*	*28%*	*33%*	-	-
Specialist nurse	**379**	7	20	46	86	121	77	19	3	33	345	-	-
	28%H	*30%*	*26%*	**31%H**	**32%H**	**29%H**	**26%H**	*17%*	*30%*	*28%*	*28%*	-	-
Hospital-based advice lines	**308**	7	24	49	63	90	54	19	2	26	281	-	-
	23%G	*30%*	**32%GH**	**33%AEFGH**	*23%*	*22%*	*18%*	*17%*	*20%*	*22%*	*23%*	-	-
Psychological support	**96**	1	12	18	28	27	9	1	-	6	90	-	-
	7%GH	*4%*	**16%AFGH**	**12%AFGH**	**10%AGH**	**6%GH**	*3%*	*1%*	-	*5%*	*7%*	-	-
Library	**40**	1	2	6	9	8	12	2	-	4	36	-	-
	3%	*4%*	*3%*	*4%*	*3%*	*2%*	*4%*	*2%*	-	*3%*	*3%*	-	-
Healthcare professionals, i. e. GP/ consultant etc.	**18**	-	2	-	3	7	2	4	-	1	17	-	-
	1%	-	**3%D**	-	*1%*	*2%*	*1%*	**4%ADG**	-	*1%*	*1%*	-	-
Journals/books/leaflets (printed material)	**11**	1	2	2	1	1	2	1	1	3	8	-	-
	1%K	*4%*	**3%F**	*1%*	*	*	*1%*	*1%*	*10%*	**3%AK**	*1%*	-	-
SRUK/Scleroderma & Raynaud's UK	**10**	-	-	-	1	4	3	2	-	2	8	-	-
	1%	-	-	-	*	*1%*	*1%*	*2%*	-	*2%*	*1%*	-	-
BSSA/British Sjorgens Syndrome Association	**7**	-	-	-	-	-	5	2	-	1	6	-	-
	1%	-	-	-	-	-	**2%AEF**	**2%EF**	-	*1%*	*	-	-
Conducted my own research	**6**	-	1	-	1	-	2	1	1	1	5	-	-
	*	-	**1%F**	-	*	-	*1%*	*1%*	*10%*	*1%*	*	-	-
Private healthcare channels	**5**	-	-	-	2	3	-	-	-	-	5	-	-
	*	-	-	-	*1%*	*1%*	-	-	-	-	*	-	-
Lupus UK	**5**	-	-	1	-	1	2	-	1	1	4	-	-
	*	-	-	*1%*	-	*	*1%*	-	*10%*	*1%*	*	-	-
Websites /online (various)	**5**	-	-	1	2	1	1	-	-	1	4	-	-
	*	-	-	*1%*	*1%*	*	*	-	-	*1%*	*	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 60

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	1352	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Word of mouth/networking/friends/ family/other patients	5	-	-	1	-	-	3	1	-	1	4	-	-
	*	-	-	*1%*	-	-	**1%F**	*1%*	-	*1%*	*	-	-
Videos	4	-	-	-	2	-	2	-	-	-	4	-	-
	*	-	-	-	*1%*	-	*1%*	-	-	-	*	-	-
Downloaded an app	4	-	-	-	-	2	2	-	-	3	1	-	-
	***K**	-	-	-	-	*	*1%*	-	-	**3%AK**	*	-	-
USA/American organisations	4	-	-	-	-	1	2	1	-	2	2	-	-
	***K**	-	-	-	-	*	*1%*	*1%*	-	**2%AK**	*	-	-
Vasculitis UK	3	-	-	-	1	2	-	-	-	1	2	-	-
	*	-	-	-	*	*	-	-	-	*1%*	*	-	-
Books/leaflets/printed material	3	-	-	-	-	1	2	-	-	1	2	-	-
	*	-	-	-	-	*	*1%*	-	-	*1%*	*	-	-
My own background in healthcare	2	-	-	-	-	1	-	1	-	-	2	-	-
	*	-	-	-	-	*	-	*1%*	-	-	*	-	-
Events/conferences/seminars/ webinars	2	-	1	-	-	-	1	-	-	-	2	-	-
	*	-	**1%AF**	-	-	-	*	-	-	-	*	-	-
Other	5	-	-	-	1	3	-	1	-	-	5	-	-
	*	-	-	-	*	*1%*	-	*1%*	-	-	*	-	-
I have not accessed any information or support	28	-	2	3	6	10	2	5	-	1	27	-	-
	2%G	-	*3%*	*2%*	*2%*	*2%*	*1%*	**4%G**	-	*1%*	*2%*	-	-
Prefer not to say	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
1 type of support accessed	175	2	7	22	26	59	35	20	4	16	158	1	-
	13%	*9%*	*9%*	*15%*	*10%*	*14%*	*12%*	18%E	*40%*	*13%*	*13%*	*50%*	-
2 types of support accessed	253	5	19	27	52	70	57	22	1	25	228	-	-
	19%	*22%*	*25%*	*18%*	*19%*	*17%*	*20%*	*20%*	*10%*	*21%*	*19%*	-	-
3 types of support accessed	336	4	18	37	50	111	84	30	2	33	300	1	-
	25%E	*17%*	*24%*	*25%*	*18%*	27%E	29%E	*27%*	*20%*	*28%*	*24%*	*50%*	-
4 types of support accessed	246	7	12	16	59	69	59	23	1	19	227	-	-
	18%D	*30%*	*16%*	*11%*	22%D	*17%*	20%D	21%D	*10%*	*16%*	*18%*	-	-
5 types of support accessed	173	5	5	26	43	50	33	9	2	12	161	-	-
	13%	*22%*	*7%*	17%CH	16%CH	*12%*	*11%*	*8%*	*20%*	*10%*	*13%*	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 60

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	1352	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
6 types of support accessed	85	-	4	10	23	30	16	2	-	6	79	-	-
	6%H	-	*5%*	*7%*	8%H	7%H	*5%*	*2%*	-	*5%*	*6%*	-	-
7 types of support accessed	39	-	4	5	10	13	6	1	-	5	34	-	-
	3%	-	*5%*	*3%*	*4%*	*3%*	*2%*	*1%*	-	*4%*	*3%*	-	-
8 types of support accessed	11	-	3	2	2	4	-	-	-	3	8	-	-
	1%K	-	4%AEFGH	1%G	*1%*	*1%*	-	-	-	3%AK	*1%*	-	-
9 types of support accessed	5	-	1	2	-	2	-	-	-	-	5	-	-
	*	-	*1%*	1%G	-	*	-	-	-	-	*	-	-
10 types of support accessed	1	-	1	-	-	-	-	-	-	-	1	-	-
	*	-	1%AF	-	-	-	-	-	-	-	*	-	-
11+ types of support accessed	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Average number of types of support accessed	3.3H	3.3	3.5H	3.4H	3.5AGH	3.3H	3.2H	2.8	2.6	3.3	3.3	2.0	-
Standard deviation	1.7	1.3	2.1	1.9	1.7	1.8	1.5	1.5	1.6	1.7	1.7	1.4	-
Standard error	0.05	0.27	0.24	0.15	0.10	0.09	0.09	0.14	0.52	0.16	0.05	1.00	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 61

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: accessed support from specialist nurse

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**379**	112	24**	27**	14**	77*	83*	10**	32*	14**	31*	4**	15**	3**	16**	127	17**
Specialist nurse	**379**	112	24	27	14	77	83	10	32	14	31	4	15	3	16	127	17
	100%	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*
Consultant during appointment	**319**	99	19	24	11	65	71	4	26	8	30	4	14	3	15	112	11
	84%	*88%*	*79%*	*89%*	*79%*	*84%*	*86%*	*40%*	*81%*	*57%*	**97%A**	*100%*	*93%*	*100%*	*94%*	*88%*	*65%*
Internet search	**250**	67	17	19	7	56	62	2	20	8	19	4	7	2	13	93	11
	66%	*60%*	*71%*	*70%*	*50%*	*73%*	**75%B**	*20%*	*63%*	*57%*	*61%*	*100%*	*47%*	*67%*	*81%*	**73%A**	*65%*
Through social media, e. g. Facebook forums	**220**	60	9	25	10	55	41	2	18	7	17	3	11	1	9	68	11
	58%	*54%*	*38%*	*93%*	*71%*	**71%ABG**	*49%*	*20%*	*56%*	*50%*	*55%*	*75%*	*73%*	*33%*	*56%*	*54%*	*65%*
Patient organisations, e. g. charity helplines or support groups	**207**	63	16	14	7	45	41	4	17	7	22	1	8	2	8	64	10
	55%	*56%*	*67%*	*52%*	*50%*	*58%*	*49%*	*40%*	*53%*	*50%*	**71%P**	*25%*	*53%*	*67%*	*50%*	*50%*	*59%*
Hospital-based advice lines	**170**	56	10	11	7	30	35	5	16	8	17	1	8	1	8	59	11
	45%	*50%*	*42%*	*41%*	*50%*	*39%*	*42%*	*50%*	*50%*	*57%*	*55%*	*25%*	*53%*	*33%*	*50%*	*46%*	*65%*
Online support and discussion groups	**145**	40	7	10	6	33	32	1	16	4	13	1	7	-	5	53	5
	38%	*36%*	*29%*	*37%*	*43%*	*43%*	*39%*	*10%*	*50%*	*29%*	*42%*	*25%*	*47%*	-	*31%*	*42%*	*29%*
Psychological support	**48**	16	1	7	3	8	7	1	5	1	4	1	2	1	2	17	2
	13%	*14%*	*4%*	*26%*	*21%*	*10%*	*8%*	*10%*	*16%*	*7%*	*13%*	*25%*	*13%*	*33%*	*13%*	*13%*	*12%*
Library	**8**	2	1	-	1	1	2	-	1	-	-	-	-	-	-	4	-
	2%	*2%*	*4%*	-	*7%*	*1%*	*2%*	-	*3%*	-	-	-	-	-	-	*3%*	-
Healthcare professionals, i. e. GP/ consultant etc.	**5**	-	1	1	1	1	1	-	-	1	1	-	-	-	-	2	-
	1%	-	*4%*	*4%*	*7%*	*1%*	*1%*	-	-	*7%*	*3%*	-	-	-	-	*2%*	-
Journals/books/leaflets (printed material)	**3**	1	-	-	-	1	1	-	-	-	-	-	-	-	-	1	1
	1%	*1%*	-	-	-	*1%*	*1%*	-	-	-	-	-	-	-	-	*1%*	*6%*
Lupus UK	**3**	3	-	-	-	-	-	-	-	-	1	-	-	-	-	1	-
	1%	**3%A**	-	-	-	-	-	-	-	-	*3%*	-	-	-	-	*1%*	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 61

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: accessed support from specialist nurse

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**379**	112	24**	27**	14**	77*	83*	10**	32*	14**	31*	4**	15**	3**	16**	127	17**
Downloaded an app	**2**	-	-	1	1	-	-	-	-	1	-	-	-	-	1	-	-
	1%	-	-	*4%*	*7%*	-	-	-	-	*7%*	-	-	-	-	*6%*	-	-
Word of mouth/networking/friends/ family/other patients	**2**	-	-	1	-	-	-	-	1	-	-	-	-	-	1	-	-
	1%	-	-	*4%*	-	-	-	-	*3%*	-	-	-	-	-	*6%*	-	-
Private healthcare channels	**1**	1	-	-	-	-	-	-	-	-	1	-	-	-	-	-	-
	*	*1%*	-	-	-	-	-	-	-	-	**3%AP**	-	-	-	-	-	-
SRUK/Scleroderma & Raynaud's UK	**1**	-	-	-	-	-	1	-	-	-	-	-	-	-	-	1	-
	*	-	-	-	-	-	*1%*	-	-	-	-	-	-	-	-	*1%*	-
USA/American organisations	**1**	-	-	-	-	-	1	-	-	-	-	-	-	-	-	1	-
	*	-	-	-	-	-	*1%*	-	-	-	-	-	-	-	-	*1%*	-
Websites /online (various)	**1**	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	*	*1%*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Conducted my own research	**1**	1	-	-	-	-	-	-	-	-	1	-	-	-	-	-	-
	*	*1%*	-	-	-	-	-	-	-	-	**3%AP**	-	-	-	-	-	-
BSSA/British Sjorgens Syndrome Association	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Events/conferences/seminars/ webinars	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Vasculitis UK	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Videos	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
My own background in healthcare	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 61

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: accessed support from specialist nurse

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**379**	112	24**	27**	14**	77*	83*	10**	32*	14**	31*	4**	15**	3**	16**	127	17**
Books/leaflets/printed material	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Other	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
I have not accessed any information or support	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Prefer not to say	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
1 type of support accessed	**4**	**3**	-	-	-	-	-	**1**	-	-	-	-	-	-	-	-	**1**
	1%	***3%***	-	-	-	-	-	***10%***	-	-	-	-	-	-	-	-	***6%***
2 types of support accessed	**21**	**8**	-	-	-	**6**	**4**	**2**	**1**	**1**	**1**	-	-	-	-	**6**	**1**
	6%	***7%***	-	-	-	***8%***	***5%***	***20%***	***3%***	***7%***	***3%***	-	-	-	-	***5%***	***6%***
3 types of support accessed	**71**	**20**	**7**	**5**	**4**	**11**	**15**	**4**	**5**	**5**	**6**	-	**3**	-	**2**	**26**	**2**
	19%	***18%***	***29%***	***19%***	***29%***	***14%***	***18%***	***40%***	***16%***	***36%***	***19%***	-	***20%***	-	***13%***	***20%***	***12%***
4 types of support accessed	**86**	**18**	**6**	**5**	**4**	**16**	**26**	**3**	**8**	**3**	**3**	**1**	**4**	**2**	**5**	**27**	**3**
	23%B	***16%***	***25%***	***19%***	***29%***	***21%***	**31%AB**	***30%***	***25%***	***21%***	***10%***	***25%***	***27%***	***67%***	***31%***	***21%***	***18%***
5 types of support accessed	**89**	**32**	**7**	**7**	**1**	**17**	**16**	-	**9**	**2**	**9**	**3**	**3**	**1**	**5**	**27**	**6**
	23%	***29%***	***29%***	***26%***	***7%***	***22%***	***19%***	-	***28%***	***14%***	***29%***	***75%***	***20%***	***33%***	***31%***	***21%***	***35%***
6 types of support accessed	**59**	**15**	**3**	**5**	**2**	**15**	**14**	-	**5**	**1**	**7**	-	**3**	-	**3**	**23**	**2**
	16%	***13%***	***13%***	***19%***	***14%***	***19%***	***17%***	-	***16%***	***7%***	***23%***	-	***20%***	-	***19%***	***18%***	***12%***
7 types of support accessed	**33**	**9**	**1**	**1**	**2**	**9**	**7**	-	**4**	**2**	**3**	-	**2**	-	-	**13**	-
	9%	***8%***	***4%***	***4%***	***14%***	***12%***	***8%***	-	***13%***	***14%***	***10%***	-	***13%***	-	-	***10%***	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 61

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: accessed support from specialist nurse

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**379**	112	24**	27**	14**	77*	83*	10**	32*	14**	31*	4**	15**	3**	16**	127	17**
8 types of support accessed	**11**	**5**	-	**3**	-	**2**	**1**	-	-	-	**1**	-	-	-	-	**4**	**2**
	3%	***4%***	-	***11%***	-	***3%***	***1%***	-	-	-	***3%***	-	-	-	-	***3%***	***12%***
9 types of support accessed	**5**	**2**	-	**1**	**1**	**1**	-	-	-	-	**1**	-	-	-	**1**	**1**	-
	1%	***2%***	-	***4%***	***7%***	***1%***	-	-	-	-	***3%***	-	-	-	***6%***	***1%***	-
10 types of support accessed	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
11+ types of support accessed	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Average number of types of support accessed	**4.7**	**4.7**	**4.4**	**5.2**	**4.9**	**4.8**	**4.6**	**2.9**	**4.8**	**4.2**	**5.1**	**4.8**	**4.8**	**4.3**	**4.9**	**4.7**	**4.6**
Standard deviation	**1.6**	**1.7**	**1.2**	**1.7**	**1.9**	**1.6**	**1.4**	**1.0**	**1.3**	**1.6**	**1.6**	**0.5**	**1.4**	**0.6**	**1.5**	**1.6**	**1.8**
Standard error	**0.08**	**0.16**	**0.24**	**0.33**	**0.50**	**0.18**	**0.15**	**0.31**	**0.24**	**0.42**	**0.29**	**0.25**	**0.35**	**0.33**	**0.36**	**0.14**	**0.45**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 62

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: accessed support from specialist nurse

	Total (A)	Combined diagnoses							
		A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**379**	142	95*	42*	43*	85*	107	189	78*
Specialist nurse	**379**	142	95	42	43	85	107	189	78
	100%	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*
Consultant during appointment	**319**	122	85	36	36	73	94	161	66
	84%	*86%*	*89%*	*86%*	*84%*	*86%*	*88%*	*85%*	*85%*
Internet search	**250**	87	62	32	18	62	82	127	53
	66%E	**61%E**	**65%E**	**76%E**	*42%*	**73%E**	**77%ABCEH**	**67%E**	**68%E**
Through social media, e. g. Facebook forums	**220**	76	45	36	26	61	55	101	47
	58%C	*54%*	*47%*	**86%ABCEGHI**	*60%*	**72%ABCGH**	*51%*	*53%*	*60%*
Patient organisations, e. g. charity helplines or support groups	**207**	77	61	21	22	51	56	100	43
	55%	*54%*	**64%ABGH**	*50%*	*51%*	*60%*	*52%*	*53%*	*55%*
Hospital-based advice lines	**170**	75	45	18	23	34	47	92	39
	45%	**53%A**	*47%*	*43%*	*53%*	*40%*	*44%*	*49%*	*50%*
Online support and discussion groups	**145**	51	36	16	17	37	42	72	35
	38%	*36%*	*38%*	*38%*	*40%*	*44%*	*39%*	*38%*	*45%*
Psychological support	**48**	19	11	11	7	9	9	25	14
	13%	*13%*	*12%*	**26%ABCFGH**	*16%*	*11%*	*8%*	**13%G**	**18%G**
Library	**8**	3	2	-	2	1	2	4	2
	2%	*2%*	*2%*	-	*5%*	*1%*	*2%*	*2%*	*3%*
Healthcare professionals, i. e. GP/ consultant etc.	**5**	1	2	2	1	1	1	3	1
	1%	*1%*	*2%*	*5%*	*2%*	*1%*	*1%*	*2%*	*1%*
Journals/books/leaflets (printed material)	**3**	1	1	-	-	1	1	2	1
	1%	*1%*	*1%*	-	-	*1%*	*1%*	*1%*	*1%*
Lupus UK	**3**	3	1	-	-	-	1	1	-
	1%	*2%*	*1%*	-	-	-	*1%*	*1%*	-
Downloaded an app	**2**	1	-	1	1	-	1	1	-
	1%	*1%*	-	*2%*	*2%*	-	*1%*	*1%*	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used. * small base

RAIRDA Survey 2024

Table 62

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: accessed support from specialist nurse

	Total (A)	Combined diagnoses							
		A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**379**	142	95*	42*	43*	85*	107	189	78*
Word of mouth/networking/friends/ family/other patients	**2**	-	-	1	-	-	1	1	2
	1%	-	-	*2%*	-	-	*1%*	*1%*	**3%A**
Private healthcare channels	**1**	1	1	-	-	-	-	-	-
	*	*1%*	*1%*	-	-	-	-	-	-
SRUK/Scleroderma & Raynaud's UK	**1**	-	-	-	-	-	1	1	-
	*	-	-	-	-	-	*1%*	*1%*	-
USA/American organisations	**1**	-	-	-	-	-	1	1	-
	*	-	-	-	-	-	*1%*	*1%*	-
Websites /online (various)	**1**	1	-	-	-	-	-	-	-
	*	*1%*	-	-	-	-	-	-	-
Conducted my own research	**1**	1	1	-	-	-	-	-	-
	*	*1%*	*1%*	-	-	-	-	-	-
BSSA/British Sjorgens Syndrome Association	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
Events/conferences/seminars/ webinars	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
Vasculitis UK	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
Videos	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
My own background in healthcare	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
Books/leaflets/printed material	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
Other	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
I have not accessed any information or support	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used. * small base

RAIRDA Survey 2024

Table 62

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: accessed support from specialist nurse

	Total (A)	Combined diagnoses							
		A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**379**	142	95*	42*	43*	85*	107	189	78*
Prefer not to say	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
Don't know/no answer	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
1 type of support accessed	**4**	**3**	**-**	**-**	**1**	**-**	**-**	**2**	**1**
	1%	***2%***	-	-	***2%***	-	-	***1%***	***1%***
2 types of support accessed	**21**	**9**	**3**	**-**	**1**	**6**	**4**	**8**	**4**
	6%	***6%***	***3%***	-	***2%***	***7%***	***4%***	***4%***	***5%***
3 types of support accessed	**71**	**28**	**21**	**5**	**11**	**11**	**17**	**39**	**11**
	19%	***20%***	***22%***	***12%***	***26%***	***13%***	***16%***	***21%***	***14%***
4 types of support accessed	**86**	**25**	**20**	**11**	**11**	**19**	**32**	**41**	**16**
	23%	***18%***	***21%***	***26%***	***26%***	***22%***	**30%ABH**	***22%***	***21%***
5 types of support accessed	**89**	**37**	**24**	**12**	**7**	**18**	**24**	**45**	**22**
	23%	***26%***	***25%***	***29%***	***16%***	***21%***	***22%***	***24%***	***28%***
6 types of support accessed	**59**	**20**	**17**	**7**	**6**	**17**	**19**	**31**	**11**
	16%	***14%***	***18%***	***17%***	***14%***	***20%***	***18%***	***16%***	***14%***
7 types of support accessed	**33**	**12**	**5**	**2**	**4**	**11**	**9**	**15**	**7**
	9%	***8%***	***5%***	***5%***	***9%***	***13%***	***8%***	***8%***	***9%***
8 types of support accessed	**11**	**5**	**3**	**4**	**1**	**2**	**1**	**6**	**4**
	3%	***4%***	***3%***	**10%AGH**	***2%***	***2%***	***1%***	***3%***	***5%***
9 types of support accessed	**5**	**3**	**2**	**1**	**1**	**1**	**1**	**2**	**2**
	1%	***2%***	***2%***	***2%***	***2%***	***1%***	***1%***	***1%***	***3%***
10 types of support accessed	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
11+ types of support accessed	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
Average number of types of support accessed	**4.7**	**4.7**	**4.7**	**5.1AH**	**4.6**	**4.9**	**4.7**	**4.7**	**4.9**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used. * small base

RAIRDA Survey 2024

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: accessed support from specialist nurse

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**379**	142	95*	42*	43*	85*	107	189	78*
Standard deviation	**1.6**	**1.7**	**1.5**	**1.5**	**1.7**	**1.6**	**1.4**	**1.6**	**1.7**
Standard error	**0.08**	**0.14**	**0.16**	**0.24**	**0.26**	**0.17**	**0.13**	**0.11**	**0.19**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used. * small base

RAIRDA Survey 2024

Table 63

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: accessed support from specialist nurse

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**379**	7**	20**	46*	86*	121	77*	19**	3**	33*	345	-**	-**
Specialist nurse	**379**	7	20	46	86	121	77	19	3	33	345	-	-
	100%	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*	-	-
Consultant during appointment	**319**	7	14	38	75	103	62	18	2	29	290	-	-
	84%	*100%*	*70%*	*83%*	*87%*	*85%*	*81%*	*95%*	*67%*	*88%*	*84%*	-	-
Internet search	**250**	5	11	25	60	83	51	14	1	21	229	-	-
	66%	*71%*	*55%*	*54%*	*70%*	*69%*	*66%*	*74%*	*33%*	*64%*	*66%*	-	-
Through social media, e. g. Facebook forums	**220**	4	13	33	51	74	36	8	1	18	201	-	-
	58%G	*57%*	*65%*	**72%AG**	*59%*	**61%G**	*47%*	*42%*	*33%*	*55%*	*58%*	-	-
Patient organisations, e. g. charity helplines or support groups	**207**	2	10	20	46	70	46	12	1	16	191	-	-
	55%	*29%*	*50%*	*43%*	*53%*	*58%*	*60%*	*63%*	*33%*	*48%*	*55%*	-	-
Hospital-based advice lines	**170**	3	12	28	39	55	24	8	1	15	154	-	-
	45%G	*43%*	*60%*	**61%AG**	*45%*	**45%G**	*31%*	*42%*	*33%*	*45%*	*45%*	-	-
Online support and discussion groups	**145**	1	10	19	33	49	27	6	-	11	134	-	-
	38%	*14%*	*50%*	*41%*	*38%*	*40%*	*35%*	*32%*	-	*33%*	*39%*	-	-
Psychological support	**48**	-	8	10	13	13	3	1	-	6	42	-	-
	13%G	-	*40%*	**22%G**	**15%G**	*11%*	*4%*	*5%*	-	*18%*	*12%*	-	-
Library	**8**	-	1	1	2	3	1	-	-	-	8	-	-
	2%	-	*5%*	*2%*	*2%*	*2%*	*1%*	-	-	-	*2%*	-	-
Healthcare professionals, i. e. GP/ consultant etc.	**5**	-	-	-	1	3	1	-	-	-	5	-	-
	1%	-	-	-	*1%*	*2%*	*1%*	-	-	-	*1%*	-	-
Journals/books/leaflets (printed material)	**3**	-	1	1	-	-	1	-	-	2	1	-	-
	1%K	-	*5%*	*2%*	-	-	*1%*	-	-	**6%AK**	*	-	-
Lupus UK	**3**	-	-	-	-	1	1	-	1	-	3	-	-
	1%	-	-	-	-	*1%*	*1%*	-	*33%*	-	*1%*	-	-
Downloaded an app	**2**	-	-	-	-	1	1	-	-	1	1	-	-
	1%K	-	-	-	-	*1%*	*1%*	-	-	**3%K**	*	-	-
Word of mouth/networking/friends/ family/other patients	**2**	-	-	1	-	-	1	-	-	1	1	-	-
	1%K	-	-	*2%*	-	-	*1%*	-	-	**3%K**	*	-	-
Private healthcare channels	**1**	-	-	-	-	1	-	-	-	-	1	-	-
	*	-	-	-	-	*1%*	-	-	-	-	*	-	-
SRUK/Scleroderma & Raynaud's UK	**1**	-	-	-	-	1	-	-	-	-	1	-	-
	*	-	-	-	-	*1%*	-	-	-	-	*	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 63

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: accessed support from specialist nurse

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**379**	7**	20**	46*	86*	121	77*	19**	3**	33*	345	-**	-**
USA/American organisations	**1**	-	-	-	-	-	1	-	-	1	-	-	-
	*	-	-	-	-	-	*1%*	-	-	**3%AK**	-	-	-
Websites /online (various)	**1**	-	-	-	-	1	-	-	-	-	1	-	-
	*	-	-	-	-	*1%*	-	-	-	-	*	-	-
Conducted my own research	**1**	-	-	-	-	-	1	-	-	-	1	-	-
	*	-	-	-	-	-	*1%*	-	-	-	*	-	-
BSSA/British Sjorgens Syndrome	-	-	-	-	-	-	-	-	-	-	-	-	-
Association	-	-	-	-	-	-	-	-	-	-	-	-	-
Events/conferences/seminars/	-	-	-	-	-	-	-	-	-	-	-	-	-
webinars	-	-	-	-	-	-	-	-	-	-	-	-	-
Vasculitis UK	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Videos	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
My own background in healthcare	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Books/leaflets/printed material	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Other	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
I have not accessed any information	-	-	-	-	-	-	-	-	-	-	-	-	-
or support	-	-	-	-	-	-	-	-	-	-	-	-	-
Prefer not to say	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
1 type of support accessed	**4**	-	-	**1**	**1**	-	**1**	-	**1**	-	**4**	-	-
	1%	-	-	***2%***	***1%***	-	***1%***	-	***33%***	-	***1%***	-	-
2 types of support accessed	**21**	-	**5**	**4**	**2**	**5**	**5**	-	-	**3**	**18**	-	-
	6%	-	***25%***	***9%***	***2%***	***4%***	***6%***	-	-	***9%***	***5%***	-	-
3 types of support accessed	**71**	**3**	**3**	**8**	**15**	**23**	**15**	**4**	-	**7**	**63**	-	-
	19%	***43%***	***15%***	***17%***	***17%***	***19%***	***19%***	***21%***	-	***21%***	***18%***	-	-
4 types of support accessed	**86**	-	**1**	**6**	**23**	**29**	**21**	**5**	**1**	**7**	**79**	-	-
	23%	-	***5%***	***13%***	***27%***	***24%***	***27%***	***26%***	***33%***	***21%***	***23%***	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 63

Q18 Which of the following ways, if any, have you accessed information or support? Please include formal and informal support you may have accessed.

Base: accessed support from specialist nurse

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	379	7**	20**	46*	86*	121	77*	19**	3**	33*	345	-**	-**
5 types of support accessed	89	4	2	11	18	26	20	7	1	6	83	-	-
	23%	*57%*	*10%*	*24%*	*21%*	*21%*	*26%*	*37%*	*33%*	*18%*	*24%*	-	-
6 types of support accessed	59	-	1	8	17	20	11	2	-	4	55	-	-
	16%	-	*5%*	*17%*	*20%*	*17%*	*14%*	*11%*	-	*12%*	*16%*	-	-
7 types of support accessed	33	-	4	4	8	12	4	1	-	3	30	-	-
	9%	-	*20%*	*9%*	*9%*	*10%*	*5%*	*5%*	-	*9%*	*9%*	-	-
8 types of support accessed	11	-	3	2	2	4	-	-	-	3	8	-	-
	3%K	-	*15%*	*4%*	*2%*	*3%*	-	-	-	9%AK	*2%*	-	-
9 types of support accessed	5	-	1	2	-	2	-	-	-	-	5	-	-
	1%	-	*5%*	*4%*	-	*2%*	-	-	-	-	*1%*	-	-
10 types of support accessed	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
11+ types of support accessed	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Average number of types of support accessed	4.7G	4.1	5.0	4.8	4.7	4.8G	4.3	4.5	3.3	4.7	4.7	-	-
Standard deviation	1.6	1.1	2.5	1.9	1.4	1.6	1.3	1.1	2.1	1.8	1.6	-	-
Standard error	0.08	0.40	0.56	0.28	0.16	0.14	0.15	0.26	1.20	0.31	0.08	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 64

Q19 Generally, how easy or difficult is it to contact your specialist nurse?

Base: accessed support from specialist nurse

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**379**	112	24**	27**	14**	77*	83*	10**	32*	14**	31*	4**	15**	3**	16**	127	17**
Very easy	**62**	12	3	7	3	20	13	1	3	4	2	-	1	-	1	23	1
	16%B	*11%*	*13%*	*26%*	*21%*	**26%AB**	*16%*	*10%*	*9%*	*29%*	*6%*	-	*7%*	-	*6%*	*18%*	*6%*
Fairly easy	**179**	55	11	11	3	38	40	6	15	5	19	1	9	2	9	60	6
	47%	*49%*	*46%*	*41%*	*21%*	*49%*	*48%*	*60%*	*47%*	*36%*	*61%*	*25%*	*60%*	*67%*	*56%*	*47%*	*35%*
Neither easy nor difficult	**46**	16	3	5	3	4	9	1	5	1	2	1	1	-	3	14	4
	12%F	**14%F**	*13%*	*19%*	*21%*	*5%*	*11%*	*10%*	*16%*	*7%*	*6%*	*25%*	*7%*	-	*19%*	*11%*	*24%*
Fairly difficult	**62**	17	5	4	4	11	13	1	7	3	3	1	2	-	2	21	6
	16%	*15%*	*21%*	*15%*	*29%*	*14%*	*16%*	*10%*	*22%*	*21%*	*10%*	*25%*	*13%*	-	*13%*	*17%*	*35%*
Very difficult	**17**	7	-	-	-	2	6	1	1	-	3	-	1	-	-	7	-
	4%	*6%*	-	-	-	*3%*	*7%*	*10%*	*3%*	-	*10%*	-	*7%*	-	-	*6%*	-
I haven't tried	**7**	4	1	-	-	1	1	-	-	1	2	1	1	-	-	-	-
	2%	*4%*	*4%*	-	-	*1%*	*1%*	-	-	*7%*	**6%P**	*25%*	*7%*	-	-	-	-
I do not have access to a specialist nurse	**3**	1	-	-	1	1	-	-	-	-	-	-	-	1	1	-	-
	1%	*1%*	-	-	*7%*	*1%*	-	-	-	-	-	-	-	*33%*	*6%*	-	-
Don't know/no answer	**3**	-	1	-	-	-	1	-	1	-	-	-	-	-	-	2	-
	1%	-	*4%*	-	-	-	*1%*	-	*3%*	-	-	-	-	-	-	*2%*	-
Easy	**241**	**67**	**14**	**18**	**6**	**58**	**53**	**7**	**18**	**9**	**21**	**1**	**10**	**2**	**10**	**83**	**7**
	64%	***60%***	***58%***	***67%***	***43%***	**75%AB**	***64%***	***70%***	***56%***	***64%***	***68%***	***25%***	***67%***	***67%***	***63%***	***65%***	***41%***
Not easy	**79**	**24**	**5**	**4**	**4**	**13**	**19**	**2**	**8**	**3**	**6**	**1**	**3**	**-**	**2**	**28**	**6**
	21%	***21%***	***21%***	***15%***	***29%***	***17%***	***23%***	***20%***	***25%***	***21%***	***19%***	***25%***	***20%***	**-**	***13%***	***22%***	***35%***
Net easy	**162**	**43**	**9**	**14**	**2**	**45**	**34**	**5**	**10**	**6**	**15**	**0**	**7**	**2**	**8**	**55**	**1**
	43%	***38%***	***38%***	***52%***	***14%***	***58%***	***41%***	***50%***	***31%***	***43%***	***48%***	***0%***	***47%***	***67%***	***50%***	***43%***	***6%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 65

Q19 Generally, how easy or difficult is it to contact your specialist nurse?

Base: accessed support from specialist nurse

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**379**	142	95*	42*	43*	85*	107	189	78*
Very easy	**62**	18	11	7	5	20	14	28	9
	16%	*13%*	*12%*	*17%*	*12%*	**24%BCI**	*13%*	*15%*	*12%*
Fairly easy	**179**	65	48	15	18	43	52	88	38
	47%	*46%*	*51%*	*36%*	*42%*	*51%*	*49%*	*47%*	*49%*
Neither easy nor difficult	**46**	20	11	9	6	6	15	23	13
	12%	*14%*	*12%*	**21%F**	*14%*	*7%*	*14%*	*12%*	*17%*
Fairly difficult	**62**	24	13	8	10	11	17	35	15
	16%	*17%*	*14%*	*19%*	*23%*	*13%*	*16%*	*19%*	*19%*
Very difficult	**17**	8	6	1	2	2	6	10	2
	4%	*6%*	*6%*	*2%*	*5%*	*2%*	*6%*	*5%*	*3%*
I haven't tried	**7**	5	3	1	1	1	1	1	-
	2%H	**4%H**	*3%*	*2%*	*2%*	*1%*	*1%*	*1%*	-
I do not have access to a specialist nurse	**3**	2	2	-	1	2	1	2	-
	1%	*1%*	*2%*	-	*2%*	*2%*	*1%*	*1%*	-
Don't know/no answer	**3**	-	1	1	-	-	1	2	1
	1%	-	*1%*	*2%*	-	-	*1%*	*1%*	*1%*
Easy	**241**	**83**	**59**	**22**	**23**	**63**	**66**	**116**	**47**
	64%	***58%***	***62%***	***52%***	***53%***	**74%ABDEH**	***62%***	***61%***	***60%***
Not easy	**79**	**32**	**19**	**9**	**12**	**13**	**23**	**45**	**17**
	21%	***23%***	***20%***	***21%***	***28%***	***15%***	***21%***	***24%***	***22%***
Net easy	**162**	**51**	**40**	**13**	**11**	**50**	**43**	**71**	**30**
	43%	***36%***	***42%***	***31%***	***26%***	***59%***	***40%***	***38%***	***38%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used. * small base

RAIRDA Survey 2024

Table 66

Q19 Generally, how easy or difficult is it to contact your specialist nurse?

Base: accessed support from specialist nurse

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**379**	7**	20**	46*	86*	121	77*	19**	3**	33*	345	-**	-**
Very easy	**62**	2	4	7	9	21	16	3	-	10	52	-	-
	16%K	*29%*	*20%*	*15%*	*10%*	*17%*	*21%*	*16%*	-	**30%AK**	*15%*	-	-
Fairly easy	**179**	1	11	24	45	49	36	12	1	14	164	-	-
	47%	*14%*	*55%*	*52%*	*52%*	*40%*	*47%*	*63%*	*33%*	*42%*	*48%*	-	-
Neither easy nor difficult	**46**	1	2	6	10	21	4	-	2	2	44	-	-
	12%G	*14%*	*10%*	*13%*	*12%*	**17%AG**	*5%*	-	*67%*	*6%*	*13%*	-	-
Fairly difficult	**62**	3	3	6	15	19	14	2	-	4	58	-	-
	16%	*43%*	*15%*	*13%*	*17%*	*16%*	*18%*	*11%*	-	*12%*	*17%*	-	-
Very difficult	**17**	-	-	2	5	4	4	2	-	1	16	-	-
	4%	-	-	*4%*	*6%*	*3%*	*5%*	*11%*	-	*3%*	*5%*	-	-
I haven't tried	**7**	-	-	1	-	5	1	-	-	1	6	-	-
	2%	-	-	*2%*	-	**4%A**	*1%*	-	-	*3%*	*2%*	-	-
I do not have access to a specialist nurse	**3**	-	-	-	2	1	-	-	-	-	3	-	-
	1%	-	-	-	*2%*	*1%*	-	-	-	-	*1%*	-	-
Don't know/no answer	**3**	-	-	-	-	1	2	-	-	1	2	-	-
	1%	-	-	-	-	*1%*	*3%*	-	-	*3%*	*1%*	-	-
Easy	**241**	**3**	**15**	**31**	**54**	**70**	**52**	**15**	**1**	**24**	**216**	**-**	**-**
	64%	***43%***	***75%***	***67%***	***63%***	***58%***	***68%***	***79%***	***33%***	***73%***	***63%***	**-**	**-**
Not easy	**79**	**3**	**3**	**8**	**20**	**23**	**18**	**4**	**-**	**5**	**74**	**-**	**-**
	21%	***43%***	***15%***	***17%***	***23%***	***19%***	***23%***	***21%***	**-**	***15%***	***21%***	**-**	**-**
Net easy	**162**	**0**	**12**	**23**	**34**	**47**	**34**	**11**	**1**	**19**	**142**	**0**	**0**
	43%	***0%***	***60%***	***50%***	***40%***	***39%***	***44%***	***58%***	***33%***	***58%***	***41%***	***0%***	***0%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 67

Q20 How often are you able to get advice within 48 hours from your hospital when you experience issues with your disease(s) or treatment between appointments?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Always or almost always	**198**	43	17	16	7	60	37	8	10	6	20	-	5	-	7	53	4
	15%H	*13%*	*11%*	**21%EH**	*9%*	**23%ABCEGHI**	*14%*	*7%*	*12%*	*14%*	*17%*	-	*12%*	-	*14%*	*14%*	*8%*
A lot of the time	**210**	50	12	15	12	58	41	9	13	7	20	2	9	1	10	55	9
	16%CH	**16%CH**	*8%*	**19%CH**	*16%*	**22%ABCGH**	**15%C**	*8%*	*16%*	*16%*	*17%*	*13%*	*21%*	*13%*	*20%*	*14%*	*18%*
Sometimes	**313**	87	30	19	7	61	64	17	28	8	27	4	7	4	14	103	13
	23%EH	**27%EH**	**20%E**	**25%E**	*9%*	**23%E**	**24%E**	*15%*	**34%ACEH**	*18%*	*23%*	*25%*	*17%*	*50%*	*28%*	**27%A**	*26%*
Never or almost never	**318**	92	31	16	22	43	55	33	26	12	32	6	17	3	9	87	20
	24%F	**29%AFG**	*21%*	*21%*	**29%F**	*17%*	*20%*	**29%F**	**32%FG**	*27%*	*28%*	*38%*	**40%AOP**	*38%*	*18%*	*23%*	**40%AOP**
I haven't tried	**313**	48	61	11	29	38	73	48	5	11	17	4	4	-	10	85	4
	23%BFIKMQ	**15%I**	**40%ABDFGI**	*14%*	**38%ABDFI**	**15%I**	**27%BDFI**	**42%ABDFGI**	*6%*	**25%Q**	*15%*	*25%*	*10%*	-	*20%*	**22%Q**	*8%*
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Always or almost always/a lot of the time	**408**	**93**	**29**	**31**	**19**	**118**	**78**	**17**	**23**	**13**	**40**	**2**	**14**	**1**	**17**	**108**	**13**
	30%CH	**29%CH**	*19%*	**40%ACEH**	*25%*	**45%ABCEGHI**	**29%CH**	*15%*	**28%H**	*30%*	*34%*	*13%*	*33%*	*13%*	*34%*	*28%*	*26%*
Sometimes/never or almost never	**631**	**179**	**61**	**35**	**29**	**104**	**119**	**50**	**54**	**20**	**59**	**10**	**24**	**7**	**23**	**190**	**33**
	47%F	**56%ACEFGH**	*40%*	*45%*	*38%*	*40%*	*44%*	*43%*	**66%ACDEFGH**	*45%*	*51%*	*63%*	*57%*	*88%*	*46%*	*50%*	**66%AJOP**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 68

Q20 How often are you able to get advice within 48 hours from your hospital when you experience issues with your disease(s) or treatment between appointments?

Base: all participants

	Total (A)	Combined diagnoses							
		A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Always or almost always	**198**	54	50	18	15	62	47	80	22
	15%H	*14%*	*14%*	*16%*	*10%*	**22%ABCEGHI**	*13%*	*12%*	*11%*
A lot of the time	**210**	63	50	19	26	62	54	92	35
	16%	*16%*	*14%*	*16%*	*17%*	**22%ABCGH**	*15%*	*14%*	*18%*
Sometimes	**313**	106	85	32	24	74	90	163	65
	23%E	**27%E**	**23%E**	**28%E**	*16%*	**26%E**	**26%E**	**25%E**	**34%ABCEGH**
Never or almost never	**318**	115	92	30	50	50	69	167	56
	24%FG	**29%AFG**	**25%FG**	*26%*	**33%ACFGH**	*17%*	*20%*	**26%FG**	**29%FG**
I haven't tried	**313**	60	89	17	36	39	90	147	15
	23%BDFI	**15%I**	**24%BDFI**	**15%I**	**24%BFI**	**14%I**	**26%BDFI**	**23%BDFI**	*8%*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
Always or almost always/a lot of the time	**408**	**117**	**100**	**37**	**41**	**124**	**101**	**172**	**57**
	30%H	***29%***	***27%***	***32%***	***27%***	**43%ABCDEGHI**	***29%***	***27%***	***30%***
Sometimes/never or almost never	**631**	**221**	**177**	**62**	**74**	**124**	**159**	**330**	**121**
	47%	**56%ACFG**	***48%***	***53%***	***49%***	***43%***	***45%***	**51%AFG**	**63%ACEFGH**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 69

Q20 How often are you able to get advice within 48 hours from your hospital when you experience issues with your disease(s) or treatment between appointments?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Always or almost always	**198**	5	8	22	34	57	49	21	2	27	171	-	-
	15%K	*22%*	*11%*	*15%*	*13%*	*14%*	*17%*	*19%*	*20%*	**23%AK**	*14%*	-	-
A lot of the time	**210**	3	15	30	43	69	39	11	-	18	191	-	-
	16%	*13%*	*20%*	**20%H**	*16%*	*17%*	*13%*	*10%*	-	*15%*	*16%*	-	-
Sometimes	**313**	6	26	29	82	87	68	11	4	18	295	-	-
	23%HJ	*26%*	**34%ADFH**	**19%H**	**30%ADFH**	**21%H**	**23%H**	*10%*	*40%*	*15%*	**24%AJ**	-	-
Never or almost never	**318**	7	13	43	66	99	65	25	-	19	296	2	-
	24%J	*30%*	*17%*	*29%*	*24%*	*24%*	*22%*	*22%*	-	*16%*	**24%J**	*100%*	-
I haven't tried	**313**	2	14	26	46	106	71	44	4	38	275	-	-
	23%EK	*9%*	*18%*	*17%*	*17%*	**25%DE**	**24%E**	**39%ACDEFG**	*40%*	**32%AK**	*22%*	-	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Always or almost always/a lot of the time	**408**	**8**	**23**	**52**	**77**	**126**	**88**	**32**	**2**	**45**	**362**	**-**	**-**
	30%	***35%***	***30%***	***35%***	***28%***	***30%***	***30%***	***29%***	***20%***	***38%***	***29%***	**-**	**-**
Sometimes/never or almost never	**631**	**13**	**39**	**72**	**148**	**186**	**133**	**36**	**4**	**37**	**591**	**2**	**-**
	47%HJ	***57%***	**51%H**	**48%H**	**55%AFGH**	**44%H**	**46%H**	***32%***	***40%***	***31%***	**48%AJ**	***100%***	**-**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 70

Q21 Do you feel you currently have access to enough information and support about your disease(s)?

Base: all participants

	Total (A)	Primary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Primary diagnosis: Sjogren's disease (C)	Primary diagnosis: Myositis/ inflammatory muscle disease (D)	Primary diagnosis: Antiphospholipid syndrome (APS) (E)	Primary diagnosis: A form of systemic vasculitis (including Behcet's) (F)	Primary diagnosis: A form of systemic sclerosis or scleroderma (G)	Primary diagnosis: Raynaud's disease (H)	Primary diagnosis: Undifferentiated or mixed connective tissue disease (I)	Secondary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Secondary diagnosis: Sjogren's disease (K)	Secondary diagnosis: Myositis/ inflammatory muscle disease (L)	Secondary diagnosis: Antiphospholipid syndrome (APS) (M)	Secondary diagnosis: A form of systemic vasculitis (including Behcet's) (N)	Secondary diagnosis: A form of systemic sclerosis or scleroderma (O)	Secondary diagnosis: Raynaud's disease (P)	Secondary diagnosis: Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Yes, definitely	**213**	42	31	15	6	69	36	9	5	8	17	2	6	-	3	54	6
	16%EHI	*13%*	**21%BEHI**	**19%EHI**	*8%*	**27%ABEGHI**	*13%*	*8%*	*6%*	*18%*	*15%*	*13%*	*14%*	-	*6%*	*14%*	*12%*
Yes, to some extent	**645**	161	68	43	22	129	140	45	37	17	60	6	18	3	30	190	20
	48%E	**50%EH**	**45%E**	**56%EH**	*29%*	**50%E**	**52%EH**	*39%*	**45%E**	*39%*	*52%*	*38%*	*43%*	*38%*	**60%JQ**	*50%*	*40%*
No, not at all	**477**	113	47	19	48	62	92	56	40	19	38	8	18	5	16	133	24
	35%DF	**35%F**	*31%*	*25%*	**62%ABCDFG**	*24%*	**34%F**	**49%ABCDFG**	**49%ABCDFG**	*43%*	*33%*	*50%*	*43%*	*63%*	*32%*	*35%*	*48%*
I don't know or it doesn't apply	**17**	4	5	-	1	-	2	5	-	-	1	-	-	-	1	6	-
	1%	*1%*	**3%AFG**	-	*1%*	-	*1%*	**4%ABFG**	-	-	*1%*	-	-	-	*2%*	*2%*	-
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Yes	**858**	**203**	**99**	**58**	**28**	**198**	**176**	**54**	**42**	**25**	**77**	**8**	**24**	**3**	**33**	**244**	**26**
	63%EHI	**63%EHI**	**66%EHI**	**75%ABEHI**	***36%***	**76%ABCEGHI**	**65%EHI**	***47%***	***51%***	***57%***	***66%***	***50%***	***57%***	***38%***	***66%***	***64%***	***52%***
No	**477**	**113**	**47**	**19**	**48**	**62**	**92**	**56**	**40**	**19**	**38**	**8**	**18**	**5**	**16**	**133**	**24**
	35%DF	**35%F**	***31%***	***25%***	**62%ABCDFG**	***24%***	**34%F**	**49%ABCDFG**	**49%ABCDFG**	***43%***	***33%***	***50%***	***43%***	***63%***	***32%***	***35%***	***48%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Q21 Do you feel you currently have access to enough information and support about your disease(s)?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Yes, definitely	**213** **16%EGHI**	55 **14%E**	65 **18%EGHI**	19 *16%*	13 *9%*	70 **24%ABCEGHI**	40 *11%*	87 *13%*	19 *10%*
Yes, to some extent	**645** ***48%***	194 **49%E**	169 *46%*	60 *52%*	61 *40%*	144 **50%E**	187 **53%ACEH**	303 *47%*	93 *48%*
No, not at all	**477** **35%F**	145 **36%F**	124 **34%F**	37 *32%*	76 **50%ABCDFGH**	72 *25%*	120 **34%F**	248 **38%AF**	81 **42%ACFG**
I don't know or it doesn't apply	**17** ***1%***	4 *1%*	8 **2%FI**	- -	1 *1%*	1 *	3 *1%*	11 *2%*	- -
Don't know/no answer	- -	- -	- -	- -	- -	- -	- -	- -	- -
Yes	**858** **63%EH**	**249** **63%E**	**234** **64%E**	**79** **68%E**	**74** ***49%***	**214** **75%ABCEGHI**	**227** **65%EH**	**390** **60%E**	**112** ***58%***
No	**477** **35%F**	**145** **36%F**	**124** **34%F**	**37** ***32%***	**76** **50%ABCDFGH**	**72** ***25%***	**120** **34%F**	**248** **38%AF**	**81** **42%ACFG**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 72

Q21 Do you feel you currently have access to enough information and support about your disease(s)?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Yes, definitely	**213**	3	16	18	35	61	55	24	1	36	177	-	-
	16%K	*13%*	*21%*	*12%*	*13%*	*15%*	*19%*	**21%DE**	*10%*	**30%AK**	*14%*	-	-
Yes, to some extent	**645**	12	36	71	125	199	146	50	6	44	600	-	-
	48%J	*52%*	*47%*	*47%*	*46%*	*48%*	*50%*	*45%*	*60%*	*37%*	**49%AJ**	-	-
No, not at all	**477**	8	22	61	110	152	85	36	3	37	437	2	-
	35%G	*35%*	*29%*	**41%G**	**41%AG**	**36%G**	*29%*	*32%*	*30%*	*31%*	*36%*	*100%*	-
I don't know or it doesn't apply	**17**	-	2	-	1	6	6	2	-	3	14	-	-
	1%	-	**3%D**	-	*	*1%*	*2%*	*2%*	-	*3%*	*1%*	-	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Yes	**858**	**15**	**52**	**89**	**160**	**260**	**201**	**74**	**7**	**80**	**777**	**-**	**-**
	63%	***65%***	***68%***	***59%***	***59%***	***62%***	**69%ADE**	***66%***	***70%***	***67%***	***63%***	**-**	**-**
No	**477**	**8**	**22**	**61**	**110**	**152**	**85**	**36**	**3**	**37**	**437**	**2**	**-**
	35%G	***35%***	***29%***	**41%G**	**41%AG**	**36%G**	***29%***	***32%***	***30%***	***31%***	***36%***	***100%***	**-**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 73

Q22 Have you received any support on exercising, or nutrition and diet management, with your disease?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Yes, I have received support on exercising	**112** **8%EF**	24 **8%EF**	15 **10%EF**	27 **35%ABCEFGHI**	- -	1 *	24 **9%EF**	9 **8%EF**	12 **15%ABEF**	1 *2%*	15 **13%J**	3 *19%*	4 *10%*	2 *25%*	7 **14%J**	34 *9%*	7 **14%J**
Yes, I have received support on nutrition and diet management	**85** ***6%***	14 *4%*	12 *8%*	3 *4%*	2 *3%*	15 *6%*	32 **12%ABDEFHI**	5 *4%*	2 *2%*	4 *9%*	7 *6%*	- -	2 *5%*	- -	1 *2%*	28 *7%*	2 *4%*
Yes, I have received support on both exercising and diet and nutrition management	**94** ***7%***	24 *8%*	12 *8%*	6 *8%*	4 *5%*	15 *6%*	21 *8%*	8 *7%*	4 *5%*	2 *5%*	8 *7%*	2 *13%*	2 *5%*	1 *13%*	8 **16%A**	37 **10%A**	3 *6%*
No, I have not received this type of support	**1036** **77%DG**	251 **78%DG**	109 **72%D**	40 *52%*	69 **90%ABCDG**	224 **86%ABCDG**	188 **70%D**	91 **79%D**	64 **78%D**	37 *84%*	86 *74%*	10 *63%*	33 *79%*	4 *50%*	34 *68%*	280 *73%*	38 *76%*
I can't remember	**25** ***2%***	7 *2%*	3 *2%*	1 *1%*	2 *3%*	5 *2%*	5 *2%*	2 *2%*	- -	- -	- -	1 *6%*	1 *2%*	1 *13%*	- -	4 *1%*	- -
Don't know/no answer	**-** -	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 74

Q22 Have you received any support on exercising, or nutrition and diet management, with your disease?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Yes, I have received support on exercising	**112** **8%EF**	28 **7%EF**	43 **12%ABEF**	32 **28%ABCEFGHI**	4 *3%*	5 *2%*	35 **10%EF**	64 **10%ABEF**	29 **15%ABEFH**
Yes, I have received support on nutrition and diet management	**85** ***6%***	20 *5%*	26 *7%*	4 *3%*	7 *5%*	15 *5%*	34 **10%ABDFHI**	42 *6%*	10 *5%*
Yes, I have received support on both exercising and diet and nutrition management	**94** ***7%***	31 *8%*	31 *8%*	12 *10%*	9 *6%*	20 *7%*	31 *9%*	57 **9%A**	12 *6%*
No, I have not received this type of support	**1036** **77%CDGH**	310 **78%CDG**	262 **72%D**	66 *57%*	128 **85%ABCDGHI**	241 **84%ABCDGHI**	245 **70%D**	478 **74%D**	142 **74%D**
I can't remember	**25** ***2%***	9 **2%I**	4 *1%*	2 *2%*	3 *2%*	6 **2%I**	5 *1%*	8 *1%*	- -
Don't know/no answer	**-** -	- -	- -	- -	- -	- -	- -	- -	- -

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 75

Q22 Have you received any support on exercising, or nutrition and diet management, with your disease?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Yes, I have received support on exercising	**112**	2	3	13	24	29	27	13	1	5	107	-	-
	8%	*9%*	*4%*	*9%*	*9%*	*7%*	*9%*	*12%*	*10%*	*4%*	*9%*	-	-
Yes, I have received support on nutrition and diet management	**85**	1	5	11	10	22	25	8	3	11	73	1	-
	6%E	*4%*	*7%*	*7%*	*4%*	*5%*	**9%E**	*7%*	*30%*	*9%*	*6%*	*50%*	-
Yes, I have received support on both exercising and diet and nutrition management	**94**	2	7	8	13	22	30	11	1	13	81	-	-
	7%	*9%*	*9%*	*5%*	*5%*	*5%*	**10%AEF**	*10%*	*10%*	*11%*	*7%*	-	-
No, I have not received this type of support	**1036**	17	60	115	218	337	205	79	5	87	946	1	-
	77%G	*74%*	*79%*	*77%*	**80%GH**	**81%AGH**	*70%*	*71%*	*50%*	*73%*	*77%*	*50%*	-
I can't remember	**25**	1	1	3	6	8	5	1	-	4	21	-	-
	2%	*4%*	*1%*	*2%*	*2%*	*2%*	*2%*	*1%*	-	*3%*	*2%*	-	-
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 76

Q23 Which of the following, if any, have you experienced in the last 12 months as a result of your rare autoimmune disease(s)?

Base: all participants

	Total (A)	Primary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	Secondary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Extreme tiredness/fatigue	**1173**	300	131	68	71	220	231	75	77	40	103	16	39	8	42	343	49
	87%H	**94%ACFGH**	**87%H**	**88%H**	**92%H**	**85%H**	**86%H**	*65%*	**94%AFGH**	*91%*	*89%*	*100%*	*93%*	*100%*	*84%*	*90%*	**98%AO**
A negative impact on my ability to do day-to-day tasks	**1074**	259	116	63	55	192	229	84	76	37	95	15	35	8	41	321	45
	79%F	**81%F**	*77%*	*82%*	*71%*	*74%*	**85%ACEFH**	*73%*	**93%ABCDEFH**	*84%*	*82%*	*94%*	*83%*	*100%*	*82%*	**84%A**	*90%*
A negative impact on my leisure activities, sports or hobbies	**1061**	258	120	66	56	199	213	80	69	35	93	15	36	7	38	313	45
	78%H	**81%H**	*79%*	**86%EH**	*73%*	*77%*	*79%*	*70%*	**84%H**	*80%*	*80%*	*94%*	*86%*	*88%*	*76%*	*82%*	**90%A**
A negative impact on my relationship with my friends and family	**628**	168	68	37	34	124	110	32	55	19	51	8	29	7	19	192	33
	46%GH	**53%AGH**	**45%H**	**48%H**	**44%H**	**48%H**	**41%H**	*28%*	**67%ABCDEFGH**	*43%*	*44%*	*50%*	**69%AJKOP**	*88%*	*38%*	*50%*	**66%AJKOP**
A negative impact on my ability to do my day-to-day job	**573**	139	42	34	38	126	101	45	48	17	43	9	20	4	22	163	30
	42%C	**43%C**	*28%*	**44%C**	**49%C**	**48%ACG**	**37%C**	*39%*	**59%ABCGH**	*39%*	*37%*	*56%*	*48%*	*50%*	*44%*	*43%*	**60%AJKP**
Changes to my working hours	**317**	83	20	21	18	85	56	12	22	9	24	3	10	2	10	91	20
	23%CH	**26%CH**	*13%*	**27%CH**	**23%H**	**33%ACGH**	**21%H**	*10%*	**27%CH**	*20%*	*21%*	*19%*	*24%*	*25%*	*20%*	*24%*	**40%AJKOP**
A carer or family member has had to change their working or education pattern	**184**	51	12	17	13	43	29	6	13	6	16	4	9	3	4	54	12
	14%CH	**16%CH**	*8%*	**22%ACGH**	**17%CH**	**17%CH**	*11%*	*5%*	**16%H**	*14%*	*14%*	*25%*	*21%*	*38%*	*8%*	*14%*	**24%AO**
A negative impact on my education	**73**	27	5	3	5	16	7	3	7	2	9	2	2	1	2	16	4
	5%G	**8%ACGH**	*3%*	*4%*	*6%*	**6%G**	*3%*	*3%*	**9%G**	*5%*	*8%*	*13%*	*5%*	*13%*	*4%*	*4%*	*8%*
Changes to my education pattern	**32**	13	1	1	3	8	3	1	2	-	1	-	1	-	2	11	2
	2%	**4%ACG**	*1%*	*1%*	*4%*	*3%*	*1%*	*1%*	*2%*	-	*1%*	-	*2%*	-	*4%*	*3%*	*4%*
A negative impact on my mental health/mood/self-esteem	**32**	10	5	2	-	5	5	4	1	-	5	1	1	1	2	6	3
	2%	*3%*	*3%*	*3%*	-	*2%*	*2%*	*3%*	*1%*	-	*4%*	*6%*	*2%*	*13%*	*4%*	*2%*	**6%P**
A negative impact on the quality of life/living in pain	**26**	4	6	1	1	3	6	4	1	1	1	-	2	-	1	5	2
	2%	*1%*	*4%*	*1%*	*1%*	*1%*	*2%*	*3%*	*1%*	*2%*	*1%*	-	*5%*	-	*2%*	*1%*	*4%*

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 76

Q23 Which of the following, if any, have you experienced in the last 12 months as a result of your rare autoimmune disease(s)?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
A negative impact on my physical health	**20** ***1%***	6 *2%*	4 **3%F**	- -	- -	1 *	5 *2%*	4 **3%F**	- -	1 *2%*	2 *2%*	1 *6%*	- -	1 *13%*	1 *2%*	5 *1%*	2 *4%*
A negative impact on my ability to do my day-to-day job - had to retire	**19** **1%B**	- -	4 **3%B**	2 **3%B**	1 **1%B**	6 **2%B**	4 **1%B**	- -	2 **2%B**	- -	3 *3%*	- -	- -	- -	- -	5 *1%*	- -
Lack of understanding of the condition/impacts on the sufferers	**8** ***1%***	2 *1%*	2 *1%*	1 *1%*	1 *1%*	- -	2 *1%*	- -	- -	1 *2%*	1 *1%*	- -	- -	- -	- -	4 *1%*	- -
A negative impact on my mobility/ ability to leave the home/get out and about	**7** ***1%***	4 *1%*	- -	- -	- -	- -	2 *1%*	1 *1%*	- -	- -	1 *1%*	- -	- -	- -	1 *2%*	2 *1%*	1 *2%*
A negative impact on my ability to take care of myself/others	**6** *	3 *1%*	1 *1%*	- -	1 *1%*	1 *	- -	- -	- -	- -	1 *1%*	- -	1 *2%*	1 *13%*	- -	2 *1%*	- -
A negative impact on my sight/eye problem	**5** *	1 *	2 *1%*	- -	- -	- -	2 *1%*	- -	- -	- -	- -	- -	- -	- -	- -	- -	2 **4%AKP**
A negative impact on my diet/ weight/food I can eat	**4** *	- -	2 **1%AB**	- -	- -	1 *	1 *	- -	- -	- -	- -	- -	- -	- -	- -	3 *1%*	- -
A negative impact on my ability to think/use my brain/mind	**3** *	2 *1%*	- -	- -	- -	1 *	- -	- -	- -	- -	- -	- -	- -	1 *13%*	- -	1 *	- -
A negative impact on my sleep/ sleeping pattern	**3** *	1 *	2 **1%A**	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -	1 **2%AP**
A negative impact on my body temperature/I always feel cold	**3** *	- -	- -	- -	- -	- -	1 *	2 **2%ABF**	- -	- -	- -	- -	- -	- -	- -	1 *	- -
A negative impact on my ability to do my day-to-day job - impact on income	**3** *	- -	- -	1 **1%B**	- -	- -	- -	1 *1%*	1 **1%B**	- -	1 *1%*	- -	- -	- -	1 **2%AP**	- -	1 **2%AP**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 76

Q23 Which of the following, if any, have you experienced in the last 12 months as a result of your rare autoimmune disease(s)?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
A negative impact on my mouth/teeth	**2**	-	2	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	*	-	**1%AB**	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Other	**15**	5	-	1	1	2	2	2	2	1	2	-	-	-	1	5	2
	1%	*2%*	-	*1%*	*1%*	*1%*	*1%*	*2%*	*2%*	*2%*	*2%*	-	-	-	*2%*	*1%*	*4%*
None of the above	**62**	9	4	3	3	19	14	9	1	2	7	-	3	-	2	15	1
	5%	*3%*	*3%*	*4%*	*4%*	**7%ABCI**	*5%*	**8%BI**	*1%*	*5%*	*6%*	-	*7%*	-	*4%*	*4%*	*2%*
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
1 code selected, excluding `None of the above', 'Not stated'	**80**	**12**	**13**	**4**	**8**	**16**	**12**	**13**	**2**	**2**	**5**	-	-	-	**3**	**15**	-
	6%P	*4%*	**9%B**	*5%*	**10%BGI**	*6%*	*4%*	**11%ABGI**	*2%*	*5%*	*4%*	-	-	-	*6%*	*4%*	-
2 codes selected, excluding `None of the above', 'Not stated'	**125**	**28**	**14**	**3**	**7**	**23**	**28**	**18**	**4**	**4**	**12**	**1**	-	-	**6**	**29**	**1**
	9%M	*9%*	*9%*	*4%*	*9%*	*9%*	*10%*	**16%ABDI**	*5%*	**9%M**	**10%M**	*6%*	-	-	**12%M**	*8%*	*2%*
3 codes selected, excluding `None of the above', 'Not stated'	**303**	**58**	**43**	**19**	**15**	**52**	**76**	**31**	**9**	**8**	**27**	**5**	**5**	**1**	**13**	**89**	**9**
	22%BI	*18%*	**28%BI**	**25%I**	*19%*	*20%*	**28%ABFI**	**27%BI**	*11%*	*18%*	*23%*	*31%*	*12%*	*13%*	*26%*	*23%*	*18%*
4 codes selected, excluding `None of the above', 'Not stated'	**288**	**79**	**37**	**16**	**18**	**34**	**57**	**24**	**23**	**12**	**23**	**2**	**12**	**1**	**11**	**90**	**9**
	21%F	**25%F**	**25%F**	*21%*	**23%F**	*13%*	**21%F**	*21%*	**28%F**	*27%*	*20%*	*13%*	*29%*	*13%*	*22%*	*23%*	*18%*
5 codes selected, excluding `None of the above', 'Not stated'	**237**	**67**	**20**	**17**	**9**	**56**	**36**	**11**	**21**	**11**	**16**	**3**	**13**	**2**	**8**	**70**	**10**
	18%GH	**21%CGH**	*13%*	**22%H**	*12%*	**22%CGH**	*13%*	*10%*	**26%ACEGH**	*25%*	*14%*	*19%*	**31%AK**	*25%*	*16%*	*18%*	*20%*
6 codes selected, excluding `None of the above', 'Not stated'	**159**	**39**	**16**	**9**	**9**	**37**	**31**	**3**	**15**	**4**	**17**	**2**	**6**	**3**	**3**	**43**	**12**
	12%H	**12%H**	**11%H**	**12%H**	**12%H**	**14%H**	**11%H**	*3%*	**18%H**	*9%*	*15%*	*13%*	*14%*	*38%*	*6%*	*11%*	**24%AOP**
7 codes selected, excluding `None of the above', 'Not stated'	**64**	**20**	**2**	**2**	**6**	**13**	**12**	**4**	**5**	-	**5**	**2**	**3**	-	**2**	**25**	**3**
	5%C	**6%C**	*1%*	*3%*	**8%C**	*5%*	*4%*	*3%*	**6%C**	-	*4%*	*13%*	*7%*	-	*4%*	*7%*	*6%*
8 codes selected, excluding `None of the above', 'Not stated'	**17**	**4**	**1**	**2**	**1**	**6**	**1**	**1**	**1**	**1**	**3**	**1**	-	-	**1**	**3**	**1**
	1%	*1%*	*1%*	*3%*	*1%*	*2%*	*	*1%*	*1%*	*2%*	*3%*	*6%*	-	-	*2%*	*1%*	*2%*

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 76

Q23 Which of the following, if any, have you experienced in the last 12 months as a result of your rare autoimmune disease(s)?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
9 codes selected, excluding `None of the above', 'Not stated'	**13**	**3**	**1**	**2**	**-**	**2**	**3**	**1**	**1**	**-**	**1**	**-**	**-**	**1**	**1**	**4**	**2**
	1%	***1%***	***1%***	***3%***	**-**	***1%***	***1%***	***1%***	***1%***	**-**	***1%***	**-**	**-**	***13%***	***2%***	***1%***	**4%A**
10 codes selected, excluding `None of the above', 'Not stated'	**4**	**1**	**-**	**-**	**1**	**2**	**-**	**-**	**-**	**-**	**-**	**-**	**-**	**-**	**-**	**-**	**2**
	*	*	-	-	***1%***	***1%***	-	-	-	-	-	-	-	-	-	-	**4%AKP**
11+ codes selected, excluding `None of the above', 'Not stated'	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Average number of codes selected, excluding `None of the above', `Not stated'	**3.9CH**	**4.2ACGH**	**3.6H**	**4.1CH**	**3.9H**	**4.0H**	**3.7H**	**3.1**	**4.6ACEFGH**	**3.8**	**3.9**	**4.6**	**4.4**	**5.5**	**3.7**	**4.0**	**5.1AJKOP**
Standard deviation	**1.9**	**1.8**	**1.6**	**1.9**	**2.0**	**2.1**	**1.8**	**1.8**	**1.6**	**1.6**	**1.9**	**1.8**	**1.6**	**1.8**	**1.9**	**1.8**	**2.0**
Standard error	**0.05**	**0.10**	**0.13**	**0.21**	**0.23**	**0.13**	**0.11**	**0.17**	**0.17**	**0.25**	**0.18**	**0.45**	**0.25**	**0.63**	**0.26**	**0.09**	**0.28**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Q23 Which of the following, if any, have you experienced in the last 12 months as a result of your rare autoimmune disease(s)?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Extreme tiredness/fatigue	**1173**	373	325	107	142	247	301	560	183
	87%	**94%ACFGH**	*89%*	*92%*	**94%AFGH**	*86%*	*86%*	*86%*	**95%ACFGH**
A negative impact on my ability to do day-to-day tasks	**1074**	328	296	99	117	217	296	543	175
	79%	**82%F**	*81%*	**85%F**	*77%*	*76%*	**85%AF**	**84%AF**	**91%ABCEFGH**
A negative impact on my leisure activities, sports or hobbies	**1061**	322	299	103	121	223	277	525	169
	78%	*81%*	*82%*	**89%ABFGH**	*80%*	*78%*	*79%*	**81%A**	**88%ABCEFGH**
A negative impact on my relationship with my friends and family	**628**	209	177	57	84	145	148	306	122
	46%	**53%AGH**	*48%*	*49%*	**56%AGH**	**51%G**	*42%*	**47%G**	**63%ABCDFGH**
A negative impact on my ability to do my day-to-day job	**573**	172	129	52	73	135	135	280	103
	42%C	**43%C**	*35%*	**45%C**	**48%CG**	**47%CG**	*39%*	**43%CG**	**53%ABCGH**
Changes to my working hours	**317**	103	71	31	36	90	70	144	57
	23%C	**26%CG**	*19%*	*27%*	*24%*	**31%ACGH**	*20%*	*22%*	**30%ACGH**
A carer or family member has had to change their working or education pattern	**184**	62	48	27	32	50	40	88	43
	14%	*16%*	*13%*	**23%ABCGH**	**21%ACGH**	**17%AG**	*11%*	*14%*	**22%ABCGH**
A negative impact on my education	**73**	30	17	6	10	17	11	30	15
	5%G	**8%ACGH**	*5%*	*5%*	*7%*	*6%*	*3%*	*5%*	**8%GH**
Changes to my education pattern	**32**	15	5	1	5	8	5	16	6
	2%	**4%ACG**	*1%*	*1%*	*3%*	*3%*	*1%*	*2%*	*3%*
A negative impact on my mental health/mood/self-esteem	**32**	10	14	3	1	9	8	18	6
	2%	*3%*	**4%AE**	*3%*	*1%*	*3%*	*2%*	*3%*	*3%*
A negative impact on the quality of life/living in pain	**26**	5	10	2	3	3	7	11	4
	2%	*1%*	*3%*	*2%*	*2%*	*1%*	*2%*	*2%*	*2%*
A negative impact on my physical health	**20**	7	8	1	-	2	7	12	3
	1%	*2%*	*2%*	*1%*	-	*1%*	*2%*	*2%*	*2%*

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Q23 Which of the following, if any, have you experienced in the last 12 months as a result of your rare autoimmune disease(s)?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
A negative impact on my ability to do my day-to-day job - had to retire	**19** **1%B**	2 *1%*	9 **2%BH**	2 *2%*	1 *1%*	6 *2%*	4 *1%*	7 *1%*	3 *2%*
Lack of understanding of the condition/impacts on the sufferers	**8** ***1%***	3 *1%*	4 *1%*	1 *1%*	1 *1%*	1 *	2 *1%*	5 *1%*	- -
A negative impact on my mobility/ ability to leave the home/get out and about	**7** ***1%***	4 *1%*	2 *1%*	- -	- -	- -	3 *1%*	5 *1%*	1 *1%*
A negative impact on my ability to take care of myself/others	**6** *	3 *1%*	3 *1%*	- -	2 **1%G**	2 *1%*	- -	3 *	- -
A negative impact on my sight/eye problem	**5** *	1 *	3 **1%H**	- -	- -	- -	2 *1%*	1 *	2 **1%H**
A negative impact on my diet/ weight/food I can eat	**4** *	- -	2 *1%*	- -	- -	1 *	1 *	3 *	- -
A negative impact on my ability to think/use my brain/mind	**3** *	2 *1%*	1 *	- -	- -	2 *1%*	- -	2 *	- -
A negative impact on my sleep/ sleeping pattern	**3** *	1 *	3 **1%AH**	- -	- -	- -	- -	1 *	1 *1%*
A negative impact on my body temperature/I always feel cold	**3** *	- -	- -	- -	- -	- -	1 *	3 *	- -
A negative impact on my ability to do my day-to-day job - impact on income	**3** *	- -	2 *1%*	2 **2%ABF**	- -	- -	1 *	3 *	3 **2%ABF**
A negative impact on my mouth/teeth	**2** *	- -	2 *1%*	- -	- -	- -	- -	- -	- -
Other	**15** ***1%***	7 *2%*	4 *1%*	1 *1%*	1 *1%*	2 *1%*	3 *1%*	9 *1%*	5 **3%A**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 77

Q23 Which of the following, if any, have you experienced in the last 12 months as a result of your rare autoimmune disease(s)?

Base: all participants

	Total (A)	Combined diagnoses								
		A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	1352	398	366	116	151	287	350	649	193
None of the above	62	11	14	3	6	19	17	29	2
	5%BI	*3%*	4%I	*3%*	*4%*	7%BI	5%I	4%I	*1%*
Don't know/no answer	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
1 code selected, excluding `None of the above', 'Not stated'	80	16	20	5	8	17	15	30	4
	6%BHI	*4%*	5%I	*4%*	*5%*	6%I	*4%*	*5%*	*2%*
2 codes selected, excluding `None of the above', 'Not stated'	125	32	33	4	10	23	37	53	11
	9%D	*8%*	*9%*	*3%*	*7%*	*8%*	11%DI	*8%*	*6%*
3 codes selected, excluding `None of the above', 'Not stated'	303	74	86	28	25	56	93	153	26
	22%BI	*19%*	23%BI	24%I	*17%*	*20%*	27%ABEFI	24%BEI	*13%*
4 codes selected, excluding `None of the above', 'Not stated'	288	97	85	26	37	42	76	142	48
	21%F	24%F	23%F	*22%*	25%F	*15%*	22%F	22%F	25%F
5 codes selected, excluding `None of the above', 'Not stated'	237	84	57	24	30	62	54	121	47
	18%	21%ACG	*16%*	*21%*	*20%*	22%ACG	*15%*	19%G	24%ACGH
6 codes selected, excluding `None of the above', 'Not stated'	159	53	47	15	21	43	37	67	33
	12%	*13%*	*13%*	*13%*	*14%*	15%H	*11%*	*10%*	17%AGH
7 codes selected, excluding `None of the above', 'Not stated'	64	22	15	6	12	14	14	37	13
	5%	*6%*	*4%*	*5%*	*8%*	*5%*	*4%*	*6%*	*7%*
8 codes selected, excluding `None of the above', 'Not stated'	17	5	4	3	1	6	3	8	2
	1%	*1%*	*1%*	*3%*	*1%*	*2%*	*1%*	*1%*	*1%*
9 codes selected, excluding `None of the above', 'Not stated'	13	3	4	2	-	3	4	8	5
	1%	*1%*	*1%*	*2%*	-	*1%*	*1%*	*1%*	3%AE
10 codes selected, excluding `None of the above', 'Not stated'	4	1	1	-	1	2	-	1	2
	*	*	*	-	*1%*	*1%*	-	*	1%H
11+ codes selected, excluding `None of the above', 'Not stated'	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Q23 Which of the following, if any, have you experienced in the last 12 months as a result of your rare autoimmune disease(s)?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Average number of codes selected, excluding `None of the above', `Not stated'	**3.9**	**4.2ACGH**	**3.9**	**4.3AG**	**4.2G**	**4.0**	**3.8**	**4.0G**	**4.7ABCDEFGH**
Standard deviation	**1.9**	**1.7**	**1.8**	**1.8**	**1.8**	**2.1**	**1.8**	**1.8**	**1.7**
Standard error	**0.05**	**0.09**	**0.09**	**0.17**	**0.15**	**0.12**	**0.10**	**0.07**	**0.12**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 78

Q23 Which of the following, if any, have you experienced in the last 12 months as a result of your rare autoimmune disease(s)?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Extreme tiredness/fatigue	**1173**	21	67	133	248	373	238	84	9	86	1083	2	-
	87%GHJ	*91%*	**88%H**	**89%H**	**92%AGH**	**89%GH**	*82%*	*75%*	*90%*	*72%*	**88%AJ**	*100%*	-
A negative impact on my ability to do day-to-day tasks	**1074**	17	56	127	227	332	221	86	8	80	990	2	-
	79%J	*74%*	*74%*	**85%CG**	**84%ACG**	*79%*	*76%*	*77%*	*80%*	*67%*	**81%AJ**	*100%*	-
A negative impact on my leisure activities, sports or hobbies	**1061**	15	56	123	229	337	224	70	7	88	969	2	-
	78%H	*65%*	*74%*	**82%H**	**85%ACGH**	**81%H**	**77%H**	*63%*	*70%*	*73%*	*79%*	*100%*	-
A negative impact on my relationship with my friends and family	**628**	11	36	82	156	198	109	32	4	47	577	2	-
	46%GH	*48%*	**47%H**	**55%AGH**	**58%AFGH**	**47%GH**	*37%*	*29%*	*40%*	*39%*	*47%*	*100%*	-
A negative impact on my ability to do my day-to-day job	**573**	7	47	97	169	203	40	9	1	50	519	2	-
	42%GH	*30%*	**62%AFGH**	**65%AFGH**	**62%AFGH**	**49%AGH**	*14%*	*8%*	*10%*	*42%*	*42%*	*100%*	-
Changes to my working hours	**317**	5	31	56	90	117	17	1	-	24	290	1	-
	23%GH	*22%*	**41%AFGH**	**37%AFGH**	**33%AGH**	**28%AGH**	**6%H**	*1%*	-	*20%*	*24%*	*50%*	-
A carer or family member has had to change their working or education pattern	**184**	6	20	32	37	52	27	9	1	13	170	1	-
	14%G	*26%*	**26%AEFGH**	**21%AEFGH**	*14%*	*12%*	*9%*	*8%*	*10%*	*11%*	*14%*	*50%*	-
A negative impact on my education	**73**	14	12	14	19	10	4	-	-	5	67	1	-
	5%FGH	*61%*	**16%AEFGH**	**9%AFGH**	**7%FGH**	*2%*	*1%*	-	-	*4%*	*5%*	*50%*	-
Changes to my education pattern	**32**	5	4	13	6	4	-	-	-	1	31	-	-
	2%FG	*22%*	**5%FGH**	**9%AEFGH**	**2%G**	*1%*	-	-	-	*1%*	*3%*	-	-
A negative impact on my mental health/mood/self-esteem	**32**	-	1	6	6	9	9	1	-	3	29	-	-
	2%	-	*1%*	*4%*	*2%*	*2%*	*3%*	*1%*	-	*3%*	*2%*	-	-
A negative impact on the quality of life/living in pain	**26**	-	-	5	2	5	7	7	-	5	21	-	-
	2%	-	-	**3%E**	*1%*	*1%*	*2%*	**6%ACEF**	-	*4%*	*2%*	-	-
A negative impact on my physical health	**20**	-	1	1	-	7	8	2	1	2	18	-	-
	1%E	-	*1%*	*1%*	-	**2%E**	**3%E**	**2%E**	*10%*	*2%*	*1%*	-	-
A negative impact on my ability to do my day-to-day job - had to retire	**19**	-	-	-	-	8	8	3	-	3	16	-	-
	1%E	-	-	-	-	**2%E**	**3%ADE**	**3%DE**	-	*3%*	*1%*	-	-
Lack of understanding of the condition/impacts on the sufferers	**8**	-	-	1	-	2	3	2	-	1	7	-	-
	1%	-	-	*1%*	-	*	*1%*	**2%E**	-	*1%*	*1%*	-	-
A negative impact on my mobility/ ability to leave the home/get out and about	**7**	-	1	-	-	-	5	1	-	2	5	-	-
	1%	-	**1%F**	-	-	-	**2%AEF**	*1%*	-	*2%*	*	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 78

Q23 Which of the following, if any, have you experienced in the last 12 months as a result of your rare autoimmune disease(s)?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	1352	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
A negative impact on my ability to take care of myself/others	6	-	-	1	2	1	2	-	-	1	5	-	-
	*	-	-	*1%*	*1%*	*	*1%*	-	-	*1%*	*	-	-
A negative impact on my sight/eye problem	5	-	-	-	-	-	4	1	-	1	4	-	-
	*	-	-	-	-	-	**1%AF**	*1%*	-	*1%*	*	-	-
A negative impact on my diet/ weight/food I can eat	4	-	-	-	-	2	1	1	-	1	3	-	-
	*	-	-	-	-	*	*	*1%*	-	*1%*	*	-	-
A negative impact on my ability to think/use my brain/mind	3	-	-	-	-	1	2	-	-	1	2	-	-
	*	-	-	-	-	*	*1%*	-	-	*1%*	*	-	-
A negative impact on my sleep/ sleeping pattern	3	-	-	-	-	-	3	-	-	1	2	-	-
	*	-	-	-	-	-	**1%AF**	-	-	*1%*	*	-	-
A negative impact on my body temperature/I always feel cold	3	-	-	-	-	-	2	-	1	1	2	-	-
	*	-	-	-	-	-	*1%*	-	*10%*	*1%*	*	-	-
A negative impact on my ability to do my day-to-day job - impact on income	3	-	-	-	3	-	-	-	-	1	2	-	-
	*	-	-	-	**1%AF**	-	-	-	-	*1%*	*	-	-
A negative impact on my mouth/teeth	2	-	-	-	-	-	2	-	-	-	2	-	-
	*	-	-	-	-	-	**1%A**	-	-	-	*	-	-
Other	15	-	2	-	2	4	5	2	-	3	12	-	-
	1%	-	**3%D**	-	*1%*	*1%*	*2%*	*2%*	-	*3%*	*1%*	-	-
None of the above	62	1	6	5	7	11	18	14	-	13	49	-	-
	5%FK	*4%*	**8%EF**	*3%*	*3%*	*3%*	**6%EF**	**13%ADEFG**	-	**11%AK**	*4%*	-	-
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
1 code selected, excluding `None of the above', 'Not stated'	80	-	5	6	9	27	25	6	2	9	71	-	-
	6%E	-	*7%*	*4%*	*3%*	*6%*	9%AE	*5%*	*20%*	*8%*	*6%*	-	-
2 codes selected, excluding `None of the above', 'Not stated'	125	3	3	11	13	37	39	19	-	16	109	-	-
	9%E	*13%*	*4%*	*7%*	*5%*	9%E	13%ACE	17%ACDEF	-	*13%*	*9%*	-	-
3 codes selected, excluding `None of the above', 'Not stated'	303	6	14	17	50	89	85	40	2	25	278	-	-
	22%D	*26%*	*18%*	*11%*	*18%*	21%D	29%ADEF	36%ACDEF	*20%*	*21%*	*23%*	-	-
4 codes selected, excluding `None of the above', 'Not stated'	288	3	7	30	58	93	71	20	6	17	271	-	-
	21%CJ	*13%*	*9%*	20%C	21%C	22%C	24%C	*18%*	*60%*	*14%*	22%AJ	-	-
5 codes selected, excluding `None of the above', 'Not stated'	237	2	14	33	63	79	35	11	-	20	216	1	-
	18%GH	*9%*	*18%*	22%GH	23%AGH	19%GH	*12%*	*10%*	-	*17%*	*18%*	*50%*	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 78

Q23 Which of the following, if any, have you experienced in the last 12 months as a result of your rare autoimmune disease(s)?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	1352	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
6 codes selected, excluding `None of the above', 'Not stated'	159	3	13	25	47	55	14	2	-	12	145	-	-
	12%GH	*13%*	17%GH	17%GH	17%AGH	13%GH	*5%*	*2%*	-	*10%*	*12%*	-	-
7 codes selected, excluding `None of the above', 'Not stated'	64	3	9	14	16	19	3	-	-	4	60	-	-
	5%GH	*13%*	12%AFGH	9%AFGH	6%GH	5%GH	*1%*	-	-	*3%*	*5%*	-	-
8 codes selected, excluding `None of the above', 'Not stated'	17	2	3	4	3	5	-	-	-	1	15	1	-
	1%	*9%*	4%AGH	3%G	*1%*	*1%*	-	-	-	*1%*	*1%*	*50%*	-
9 codes selected, excluding `None of the above', 'Not stated'	13	-	2	3	4	3	1	-	-	2	11	-	-
	1%	-	3%G	*2%*	*1%*	*1%*	*	-	-	*2%*	*1%*	-	-
10 codes selected, excluding `None of the above', 'Not stated'	4	-	-	2	1	-	1	-	-	1	3	-	-
	*	-	-	1%AF	*	-	*	-	-	*1%*	*	-	-
11+ codes selected, excluding `None of the above', 'Not stated'	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Average number of codes selected, excluding `None of the above', `Not stated'	3.9GHJ	4.4	4.4AGH	4.6AFGH	4.4AFGH	4.0GH	3.2H	2.8	3.2	3.5	3.9AJ	6.5	-
Standard deviation	1.9	2.2	2.3	2.0	1.8	1.8	1.6	1.5	1.2	2.2	1.8	2.1	-
Standard error	0.05	0.45	0.26	0.17	0.11	0.09	0.09	0.14	0.39	0.20	0.05	1.50	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 79

Q24 Thinking specifically about all of your rare autoimmune disease(s), how many unplanned hospital visits have you made in the last year? Please do not include any regular appointments or routine tests and treatment.

Base: all participants

		Total (A)	Primary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Primary diagnosis: Sjogren's disease (C)	Primary diagnosis: Myositis/ inflammatory muscle disease (D)	Primary diagnosis: Antiphospholipid syndrome (APS) (E)	Primary diagnosis: A form of systemic vasculitis (including Behcet's) (F)	Primary diagnosis: A form of systemic sclerosis or scleroderma (G)	Primary diagnosis: Raynaud's disease (H)	Primary diagnosis: Undifferentiated or mixed connective tissue disease (I)	Secondary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Secondary diagnosis: Sjogren's disease (K)	Secondary diagnosis: Myositis/ inflammatory muscle disease (L)	Secondary diagnosis: Antiphospholipid syndrome (APS) (M)	Secondary diagnosis: A form of systemic vasculitis (including Behcet's) (N)	Secondary diagnosis: A form of systemic sclerosis or scleroderma (O)	Secondary diagnosis: Raynaud's disease (P)	Secondary diagnosis: Undifferentiated or mixed connective tissue disease (Q)
Total		**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
None	(0)	**800**	173	108	46	40	129	176	87	41	22	68	9	20	2	34	233	25
		59%BF	*54%*	**72%ABEFI**	*60%*	*52%*	*50%*	**65%ABEFI**	**76%ABDEFGI**	*50%*	*50%*	*59%*	*56%*	*48%*	*25%*	*68%*	*61%*	*50%*
One	(1)	**194**	51	23	8	10	43	32	8	19	6	13	2	7	1	6	50	7
		14%H	**16%H**	**15%H**	*10%*	*13%*	**17%H**	*12%*	*7%*	**23%ADGH**	*14%*	*11%*	*13%*	*17%*	*13%*	*12%*	*13%*	*14%*
Two	(2)	**152**	36	12	9	13	44	23	6	9	4	13	-	7	2	3	44	5
		11%H	*11%*	*8%*	*12%*	**17%CGH**	**17%ABCGH**	*9%*	*5%*	*11%*	*9%*	*11%*	-	*17%*	*25%*	*6%*	*11%*	*10%*
Three	(3)	**88**	30	5	7	4	13	17	4	8	6	11	4	3	1	2	22	5
		7%	**9%ACFH**	*3%*	*9%*	*5%*	*5%*	*6%*	*3%*	**10%C**	**14%P**	*9%*	*25%*	*7%*	*13%*	*4%*	*6%*	*10%*
Four	(4)	**41**	10	-	1	9	9	7	3	2	4	4	-	3	1	1	11	2
		3%C	**3%C**	-	*1%*	**12%ABCDFGHI**	**3%C**	**3%C**	**3%C**	*2%*	**9%AP**	*3%*	-	*7%*	*13%*	*2%*	*3%*	*4%*
Five or more	(5)	**57**	15	3	6	1	17	10	4	1	1	6	1	2	1	4	17	5
		4%	*5%*	*2%*	**8%CI**	*1%*	**7%AC**	*4%*	*3%*	*1%*	*2%*	*5%*	*6%*	*5%*	*13%*	*8%*	*4%*	**10%A**
I can't remember		**20**	5	-	-	-	5	5	3	2	1	1	-	-	-	-	6	1
		1%	*2%*	-	-	-	*2%*	*2%*	**3%C**	*2%*	*2%*	*1%*	-	-	-	-	*2%*	*2%*
Don't know/no answer		**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
One		**194**	**51**	**23**	**8**	**10**	**43**	**32**	**8**	**19**	**6**	**13**	**2**	**7**	**1**	**6**	**50**	**7**
		14%H	**16%H**	**15%H**	***10%***	***13%***	**17%H**	***12%***	***7%***	**23%ADGH**	***14%***	***11%***	***13%***	***17%***	***13%***	***12%***	***13%***	***14%***
Two or three		**240**	**66**	**17**	**16**	**17**	**57**	**40**	**10**	**17**	**10**	**24**	**4**	**10**	**3**	**5**	**66**	**10**
		18%CH	**21%CH**	***11%***	**21%H**	**22%CH**	**22%CGH**	***15%***	***9%***	**21%H**	***23%***	***21%***	***25%***	***24%***	***38%***	***10%***	***17%***	***20%***
Four or more		**98**	**25**	**3**	**7**	**10**	**26**	**17**	**7**	**3**	**5**	**10**	**1**	**5**	**2**	**5**	**28**	**7**
		7%C	**8%C**	***2%***	**9%C**	**13%CI**	**10%C**	**6%C**	***6%***	***4%***	***11%***	***9%***	***6%***	***12%***	***25%***	***10%***	***7%***	***14%***
Average number of unplanned hospital visits		**0.9CH**	**1.0CGH**	**0.5**	**1.1CH**	**1.2CGH**	**1.1ACGH**	**0.8C**	**0.6**	**0.9C**	**1.2**	**1.0**	**1.2**	**1.2**	**2.1**	**0.8**	**0.9**	**1.3AP**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Q24 Thinking specifically about all of your rare autoimmune disease(s), how many unplanned hospital visits have you made in the last year? Please do not include any regular appointments or routine tests and treatment.

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Standard deviation	**1.4**	**1.4**	**1.0**	**1.6**	**1.5**	**1.5**	**1.3**	**1.3**	**1.2**	**1.5**	**1.5**	**1.6**	**1.5**	**1.8**	**1.5**	**1.4**	**1.7**
Standard error	**0.04**	**0.08**	**0.08**	**0.18**	**0.17**	**0.09**	**0.08**	**0.12**	**0.14**	**0.23**	**0.14**	**0.41**	**0.24**	**0.64**	**0.22**	**0.07**	**0.25**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 80

Q24 Thinking specifically about all of your rare autoimmune disease(s), how many unplanned hospital visits have you made in the last year? Please do not include any regular appointments or routine tests and treatment.

Base: all participants

		Total (A)	Combined diagnoses							
			A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total		**1352**	398	366	116	151	287	350	649	193
None	(0)	**800**	208	223	68	69	139	229	394	96
		59%BEFI	*52%*	**61%BEFI**	**59%E**	*46%*	*48%*	**65%ABEFHI**	**61%BEFI**	*50%*
One	(1)	**194**	61	51	13	24	45	42	82	34
		14%	*15%*	*14%*	*11%*	*16%*	*16%*	*12%*	*13%*	**18%GH**
Two	(2)	**152**	45	37	10	27	54	30	64	21
		11%	*11%*	*10%*	*9%*	**18%ABCDGHI**	**19%ABCDGHI**	*9%*	*10%*	*11%*
Three	(3)	**88**	42	27	13	10	14	20	43	16
		7%	**11%AFGH**	*7%*	**11%AFG**	*7%*	*5%*	*6%*	*7%*	*8%*
Four	(4)	**41**	17	9	3	13	11	8	20	8
		3%	*4%*	*2%*	*3%*	**9%ABCDFGH**	*4%*	*2%*	*3%*	*4%*
Five or more	(5)	**57**	19	15	9	7	19	14	34	12
		4%	*5%*	*4%*	*8%*	*5%*	**7%A**	*4%*	*5%*	*6%*
I can't remember		**20**	6	4	-	1	5	7	12	6
		1%	*2%*	*1%*	-	*1%*	*2%*	*2%*	*2%*	*3%*
Don't know/no answer		-	-	-	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-
One		**194**	**61**	**51**	**13**	**24**	**45**	**42**	**82**	**34**
		14%	***15%***	***14%***	***11%***	***16%***	***16%***	***12%***	***13%***	**18%GH**
Two or three		**240**	**87**	**64**	**23**	**37**	**68**	**50**	**107**	**37**
		18%G	**22%AGH**	***17%***	***20%***	**25%AGH**	**24%ACGH**	***14%***	***16%***	***19%***
Four or more		**98**	**36**	**24**	**12**	**20**	**30**	**22**	**54**	**20**
		7%	***9%***	***7%***	***10%***	**13%ACGH**	**10%A**	***6%***	***8%***	***10%***
Average number of unplanned hospital visits		**0.9G**	**1.1ACGH**	**0.9**	**1.1G**	**1.3ACGH**	**1.2ACGH**	**0.8**	**0.9G**	**1.2ACGH**
Standard deviation		**1.4**	**1.5**	**1.4**	**1.6**	**1.5**	**1.5**	**1.3**	**1.5**	**1.5**
Standard error		**0.04**	**0.08**	**0.07**	**0.15**	**0.13**	**0.09**	**0.07**	**0.06**	**0.11**

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 81

Q24 Thinking specifically about all of your rare autoimmune disease(s), how many unplanned hospital visits have you made in the last year? Please do not include any regular appointments or routine tests and treatment.

Base: all participants

		Total (A)	Age								Gender			
			16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total		1352	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
None	(0)	800	10	34	69	145	254	195	86	7	78	721	-	-
		59%CDE	*43%*	*45%*	*46%*	*54%*	61%CD	67%ACDE	77%ACDEF	*70%*	*65%*	*59%*	-	-
One	(1)	194	3	13	17	42	67	38	11	3	13	180	-	-
		14%	*13%*	*17%*	*11%*	*15%*	*16%*	*13%*	*10%*	*30%*	*11%*	*15%*	-	-
Two	(2)	152	2	7	22	33	46	35	7	-	12	140	-	-
		11%	*9%*	*9%*	15%H	*12%*	*11%*	*12%*	*6%*	-	*10%*	*11%*	-	-
Three	(3)	88	4	10	15	23	20	13	3	-	5	82	1	-
		7%	*17%*	13%AFGH	10%FGH	8%H	*5%*	*4%*	*3%*	-	*4%*	*7%*	*50%*	-
Four	(4)	41	3	2	8	11	9	5	3	-	3	37	1	-
		3%	*13%*	*3%*	5%G	*4%*	*2%*	*2%*	*3%*	-	*3%*	*3%*	*50%*	-
Five or more	(5)	57	1	6	16	13	17	3	1	-	7	50	-	-
		4%G	*4%*	8%GH	11%AEFGH	5%G	4%G	*1%*	*1%*	-	*6%*	*4%*	-	-
I can't remember		20	-	4	3	4	5	3	1	-	2	18	-	-
		1%	-	5%AFG	*2%*	*1%*	*1%*	*1%*	*1%*	-	*2%*	*1%*	-	-
Don't know/no answer		-	-	-	-	-	-	-	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-	-	-	-	-
One		194	3	13	17	42	67	38	11	3	13	180	-	-
		14%	*13%*	*17%*	*11%*	*15%*	*16%*	*13%*	*10%*	*30%*	*11%*	*15%*	-	-
Two or three		240	6	17	37	56	66	48	10	-	17	222	1	-
		18%H	*26%*	22%H	25%AFGH	21%H	*16%*	*16%*	*9%*	-	*14%*	*18%*	*50%*	-
Four or more		98	4	8	24	24	26	8	4	-	10	87	1	-
		7%G	*17%*	11%G	16%AEFGH	9%G	6%G	*3%*	*4%*	-	*8%*	*7%*	*50%*	-
Average number of unplanned hospital visits		0.9GH	1.6	1.3AFGH	1.5AEFGH	1.1AFGH	0.8GH	0.6	0.5	0.3	0.8	0.9	3.5	-
Standard deviation		1.4	1.7	1.6	1.7	1.5	1.3	1.1	1.0	0.5	1.4	1.4	0.7	-
Standard error		0.04	0.35	0.19	0.14	0.09	0.07	0.06	0.10	0.15	0.13	0.04	0.50	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 82

Q25 To what extent have all of your rare autoimmune disease(s) had a positive or negative impact on your emotional and mental well-being?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Very positive	**24**	6	3	1	-	5	6	3	-	-	3	-	2	-	4	7	1
	2%	*2%*	*2%*	*1%*	-	*2%*	*2%*	*3%*	-	-	*3%*	-	*5%*	-	**8%AP**	*2%*	*2%*
Fairly positive	**64**	17	9	6	3	7	15	7	-	2	3	-	-	-	2	24	3
	5%I	**5%I**	**6%I**	**8%FI**	*4%*	*3%*	**6%I**	**6%I**	-	*5%*	*3%*	-	-	-	*4%*	*6%*	*6%*
Neither positive nor negative	**264**	57	28	16	17	53	52	29	12	10	22	3	6	1	16	77	8
	20%	*18%*	*19%*	*21%*	*22%*	*20%*	*19%*	*25%*	*15%*	*23%*	*19%*	*19%*	*14%*	*13%*	**32%A**	*20%*	*16%*
Fairly negative	**565**	125	64	25	30	119	117	45	40	18	46	6	19	-	11	150	14
	42%OQ	*39%*	*42%*	*32%*	*39%*	**46%D**	*43%*	*39%*	**49%D**	*41%*	**40%O**	*38%*	**45%O**	-	*22%*	**39%O**	*28%*
Very negative	**417**	109	45	29	26	74	77	27	30	14	42	7	13	7	17	119	24
	31%	**34%H**	*30%*	**38%H**	*34%*	*28%*	*29%*	*23%*	**37%H**	*32%*	*36%*	*44%*	*31%*	*88%*	*34%*	*31%*	**48%AP**
Don't know/prefer not to say	**18**	6	2	-	1	2	3	4	-	-	-	-	2	-	-	6	-
	1%	*2%*	*1%*	-	*1%*	*1%*	*1%*	**3%A**	-	-	-	-	**5%K**	-	-	*2%*	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Positive	**88**	**23**	**12**	**7**	**3**	**12**	**21**	**10**	**-**	**2**	**6**	**-**	**2**	**-**	**6**	**31**	**4**
	7%I	**7%I**	**8%I**	**9%I**	***4%***	**5%I**	**8%I**	**9%I**	-	***5%***	***5%***	-	***5%***	-	***12%***	***8%***	***8%***
Negative	**982**	**234**	**109**	**54**	**56**	**193**	**194**	**72**	**70**	**32**	**88**	**13**	**32**	**7**	**28**	**269**	**38**
	73%HO	**73%H**	***72%***	***70%***	***73%***	**74%H**	***72%***	***63%***	**85%ABCDFGH**	***73%***	**76%O**	***81%***	**76%O**	***88%***	***56%***	**70%O**	**76%O**
Net positive	**-894**	**-211**	**-97**	**-47**	**-53**	**-181**	**-173**	**-62**	**-70**	**-30**	**-82**	**-13**	**-30**	**-7**	**-22**	**-238**	**-34**
	-66%	***-66%***	***-64%***	***-61%***	***-69%***	***-70%***	***-64%***	***-54%***	***-85%***	***-68%***	***-71%***	***-81%***	***-71%***	***-88%***	***-44%***	***-62%***	***-68%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 83

Q25 To what extent have all of your rare autoimmune disease(s) had a positive or negative impact on your emotional and mental well-being?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Very positive	**24**	7	11	1	2	7	11	15	3
	2%	*2%*	*3%*	*1%*	*1%*	*2%*	**3%A**	*2%*	*2%*
Fairly positive	**64**	22	20	8	6	9	17	38	11
	5%	*6%*	*5%*	*7%*	*4%*	*3%*	*5%*	*6%*	*6%*
Neither positive nor negative	**264**	70	63	23	27	58	71	134	32
	20%	*18%*	*17%*	*20%*	*18%*	*20%*	*20%*	*21%*	*17%*
Fairly negative	**565**	152	150	40	63	122	141	245	69
	42%H	*38%*	*41%*	*34%*	*42%*	*43%*	*40%*	*38%*	*36%*
Very negative	**417**	141	117	44	49	88	106	206	76
	31%	**35%A**	*32%*	*38%*	*32%*	*31%*	*30%*	*32%*	**39%ACFGH**
Don't know/prefer not to say	**18**	6	5	-	4	3	4	11	2
	1%	*2%*	*1%*	-	*3%*	*1%*	*1%*	*2%*	*1%*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
Positive	**88**	**29**	**31**	**9**	**8**	**16**	**28**	**53**	**14**
	7%	***7%***	***8%***	***8%***	***5%***	***6%***	***8%***	**8%A**	***7%***
Negative	**982**	**293**	**267**	**84**	**112**	**210**	**247**	**451**	**145**
	73%H	***74%***	***73%***	***72%***	***74%***	***73%***	***71%***	***69%***	***75%***
Net positive	**-894**	**-264**	**-236**	**-75**	**-104**	**-194**	**-219**	**-398**	**-131**
	-66%	***-66%***	***-64%***	***-65%***	***-69%***	***-68%***	***-63%***	***-61%***	***-68%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 84

Q25 To what extent have all of your rare autoimmune disease(s) had a positive or negative impact on your emotional and mental well-being?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Very positive	**24**	-	-	1	4	8	7	4	-	1	23	-	-
	2%	-	-	*1%*	*1%*	*2%*	*2%*	*4%*	-	*1%*	*2%*	-	-
Fairly positive	**64**	-	2	4	7	18	18	13	2	5	59	-	-
	5%	-	*3%*	*3%*	*3%*	*4%*	**6%E**	**12%ACDEF**	*20%*	*4%*	*5%*	-	-
Neither positive nor negative	**264**	1	10	26	37	84	69	34	3	33	230	-	-
	20%EK	*4%*	*13%*	*17%*	*14%*	**20%E**	**24%ACE**	**30%ACDEF**	*30%*	**28%AK**	*19%*	-	-
Fairly negative	**565**	11	34	56	124	179	119	38	4	37	527	1	-
	42%J	*48%*	*45%*	*37%*	**46%H**	*43%*	*41%*	*34%*	*40%*	*31%*	**43%AJ**	*50%*	-
Very negative	**417**	9	29	61	96	126	74	21	1	41	374	1	-
	31%GH	*39%*	**38%GH**	**41%AFGH**	**35%GH**	**30%H**	*25%*	*19%*	*10%*	*34%*	*30%*	*50%*	-
Don't know/prefer not to say	**18**	2	1	2	3	3	5	2	-	3	15	-	-
	1%	*9%*	*1%*	*1%*	*1%*	*1%*	*2%*	*2%*	-	*3%*	*1%*	-	-
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Positive	**88**	-	**2**	**5**	**11**	**26**	**25**	**17**	**2**	**6**	**82**	-	-
	7%	-	***3%***	***3%***	***4%***	***6%***	**9%DE**	**15%ACDEF**	***20%***	***5%***	***7%***	-	-
Negative	**982**	**20**	**63**	**117**	**220**	**305**	**193**	**59**	**5**	**78**	**901**	**2**	-
	73%GH	***87%***	**83%AGH**	**78%GH**	**81%AFGH**	**73%GH**	**66%H**	***53%***	***50%***	***65%***	**73%J**	***100%***	-
Net positive	**-894**	**-20**	**-61**	**-112**	**-209**	**-279**	**-168**	**-42**	**-3**	**-72**	**-819**	**-2**	**0**
	-66%	***-87%***	***-80%***	***-75%***	***-77%***	***-67%***	***-58%***	***-38%***	***-30%***	***-60%***	***-67%***	***-100%***	***0%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 85

Q26 Over the last 12 months, how well, if at all, do you feel you have been managing day to day with all of your rare autoimmune disease(s)?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Very well	**97**	13	10	7	3	38	19	7	-	1	5	-	3	-	5	22	1
	7%BI	*4%*	**7%I**	**9%I**	*4%*	**15%ABCEGHI**	**7%I**	**6%I**	-	*2%*	*4%*	-	*7%*	-	*10%*	*6%*	*2%*
Fairly well	**669**	147	65	43	34	146	141	58	35	20	57	9	13	1	29	197	18
	49%M	*46%*	*43%*	*56%*	*44%*	**56%ABCI**	*52%*	*50%*	*43%*	*45%*	**49%M**	*56%*	*31%*	*13%*	**58%MQ**	**51%MQ**	*36%*
Not very well	**440**	121	58	22	27	55	83	37	37	16	41	7	19	6	14	114	24
	33%F	**38%AF**	**38%F**	*29%*	**35%F**	*21%*	**31%F**	**32%F**	**45%ADFG**	*36%*	*35%*	*44%*	**45%P**	*75%*	*28%*	*30%*	**48%AOP**
Not at all well	**136**	37	17	5	10	20	27	10	10	7	13	-	7	1	2	48	6
	10%	*12%*	*11%*	*6%*	*13%*	*8%*	*10%*	*9%*	*12%*	*16%*	*11%*	-	**17%O**	*13%*	*4%*	*13%*	*12%*
I don't know	**10**	2	1	-	3	1	-	3	-	-	-	-	-	-	-	2	1
	1%	*1%*	*1%*	-	**4%ABFG**	*	-	**3%AG**	-	-	-	-	-	-	-	*1%*	*2%*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Well	**766**	**160**	**75**	**50**	**37**	**184**	**160**	**65**	**35**	**21**	**62**	**9**	**16**	**1**	**34**	**219**	**19**
	57%BIMQ	***50%***	***50%***	**65%BCEI**	***48%***	**71%ABCEGHI**	**59%BI**	***57%***	***43%***	***48%***	***53%***	***56%***	***38%***	***13%***	**68%MQ**	**57%MQ**	***38%***
Not well	**576**	**158**	**75**	**27**	**37**	**75**	**110**	**47**	**47**	**23**	**54**	**7**	**26**	**7**	**16**	**162**	**30**
	43%F	**49%ADFG**	**50%DF**	***35%***	**48%F**	***29%***	**41%F**	**41%F**	**57%ADFGH**	***52%***	***47%***	***44%***	**62%AOP**	***88%***	***32%***	***42%***	**60%AOP**
Net well	**190**	**2**	**0**	**23**	**0**	**109**	**50**	**18**	**-12**	**-2**	**8**	**2**	**-10**	**-6**	**18**	**57**	**-11**
	14%	***1%***	***0%***	***30%***	***0%***	***42%***	***19%***	***16%***	***-15%***	***-5%***	***7%***	***13%***	***-24%***	***-75%***	***36%***	***15%***	***-22%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 86

Q26 Over the last 12 months, how well, if at all, do you feel you have been managing day to day with all of your rare autoimmune disease(s)?

Base: all participants

		Combined diagnoses							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Very well	**97**	15	20	8	6	38	25	38	3
	7%BI	*4%*	**5%I**	**7%I**	*4%*	**13%ABCEGHI**	**7%BI**	**6%I**	*2%*
Fairly well	**669**	180	167	59	58	156	183	310	79
	49%BEI	*45%*	*46%*	**51%E**	*38%*	**54%BCEI**	**52%BCEHI**	**48%EI**	*41%*
Not very well	**440**	154	136	41	59	67	106	218	86
	33%F	**39%AFGH**	**37%AFG**	**35%F**	**39%F**	*23%*	**30%F**	**34%F**	**45%AFGH**
Not at all well	**136**	46	41	8	25	25	36	78	23
	10%	*12%*	*11%*	*7%*	**17%ADFG**	*9%*	*10%*	**12%A**	*12%*
I don't know	**10**	3	2	-	3	1	-	5	2
	1%	*1%*	*1%*	-	**2%G**	*	-	*1%*	*1%*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
Well	**766**	**195**	**187**	**67**	**64**	**194**	**208**	**348**	**82**
	57%BCEHI	***49%***	**51%I**	**58%EI**	***42%***	**68%ABCEGHI**	**59%BCEHI**	**54%EI**	***42%***
Not well	**576**	**200**	**177**	**49**	**84**	**92**	**142**	**296**	**109**
	43%F	**50%AFG**	**48%AFG**	**42%F**	**56%ADFGH**	***32%***	**41%F**	**46%AFG**	**56%ACDFGH**
Net well	**190**	**-5**	**10**	**18**	**-20**	**102**	**66**	**52**	**-27**
	14%	***-1%***	***3%***	***16%***	***-13%***	***36%***	***19%***	***8%***	***-14%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 87

Q26 Over the last 12 months, how well, if at all, do you feel you have been managing day to day with all of your rare autoimmune disease(s)?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Very well	**97**	1	4	9	9	35	27	12	-	17	80	-	-
	7%EK	*4%*	*5%*	*6%*	*3%*	**8%E**	**9%E**	**11%E**	-	**14%AK**	*7%*	-	-
Fairly well	**669**	11	41	64	136	208	148	55	6	62	607	-	-
	49%	*48%*	*54%*	*43%*	*50%*	*50%*	*51%*	*49%*	*60%*	*52%*	*49%*	-	-
Not very well	**440**	9	28	55	90	129	96	29	4	27	410	1	-
	33%J	*39%*	*37%*	*37%*	*33%*	*31%*	*33%*	*26%*	*40%*	*23%*	**33%AJ**	*50%*	-
Not at all well	**136**	1	3	20	35	43	19	15	-	11	124	1	-
	10%G	*4%*	*4%*	**13%CG**	**13%CG**	*10%*	*7%*	**13%CG**	-	*9%*	*10%*	*50%*	-
I don't know	**10**	1	-	2	1	3	2	1	-	3	7	-	-
	1%K	*4%*	-	*1%*	*	*1%*	*1%*	*1%*	-	**3%AK**	*1%*	-	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Well	**766**	**12**	**45**	**73**	**145**	**243**	**175**	**67**	**6**	**79**	**687**	**-**	**-**
	57%D	***52%***	***59%***	***49%***	***54%***	**58%D**	**60%D**	***60%***	***60%***	**66%AK**	***56%***	**-**	**-**
Not well	**576**	**10**	**31**	**75**	**125**	**172**	**115**	**44**	**4**	**38**	**534**	**2**	**-**
	43%J	***43%***	***41%***	**50%G**	***46%***	***41%***	***39%***	***39%***	***40%***	***32%***	**43%AJ**	***100%***	**-**
Net well	**190**	**2**	**14**	**-2**	**20**	**71**	**60**	**23**	**2**	**41**	**153**	**-2**	**0**
	14%	***9%***	***18%***	***-1%***	***7%***	***17%***	***21%***	***21%***	***20%***	***34%***	***12%***	***-100%***	***0%***

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 88

Q27 Which of the following best describes your gender?

Base: all participants

	Total (A)	Primary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Primary diagnosis: Sjogren's disease (C)	Primary diagnosis: Myositis/ inflammatory muscle disease (D)	Primary diagnosis: Antiphospholipid syndrome (APS) (E)	Primary diagnosis: A form of systemic vasculitis (including Behcet's) (F)	Primary diagnosis: A form of systemic sclerosis or scleroderma (G)	Primary diagnosis: Raynaud's disease (H)	Primary diagnosis: Undifferentiated or mixed connective tissue disease (I)	Secondary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Secondary diagnosis: Sjogren's disease (K)	Secondary diagnosis: Myositis/ inflammatory muscle disease (L)	Secondary diagnosis: Antiphospholipid syndrome (APS) (M)	Secondary diagnosis: A form of systemic vasculitis (including Behcet's) (N)	Secondary diagnosis: A form of systemic sclerosis or scleroderma (O)	Secondary diagnosis: Raynaud's disease (P)	Secondary diagnosis: Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Man	**120**	18	6	9	6	42	18	20	1	-	1	2	4	1	2	28	4
	9%BCIJK	*6%*	*4%*	**12%CI**	**8%I**	**16%ABCGI**	*7%*	**17%ABCGI**	*1%*	-	*1%*	*13%*	**10%JK**	*13%*	*4%*	**7%K**	**8%K**
Woman	**1228**	300	145	68	70	218	252	95	80	42	115	14	38	7	48	354	45
	91%FH	**94%AFH**	**96%ADFH**	*88%*	*91%*	*84%*	**93%FH**	*83%*	**98%ADFH**	*95%*	**99%AMPQ**	*88%*	*90%*	*88%*	*96%*	*92%*	*90%*
Non-binary	**2**	-	-	-	1	-	-	-	1	2	-	-	-	-	-	-	-
	*	-	-	-	**1%AB**	-	-	-	**1%AB**	**5%AKP**	-	-	-	-	-	-	-
My gender is not listed	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Prefer not to say	**2**	2	-	-	-	-	-	-	-	-	-	-	-	-	-	1	1
	*	**1%A**	-	-	-	-	-	-	-	-	-	-	-	-	-	*	**2%A**
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 89

Q27 Which of the following best describes your gender?

Base: all participants

	Total (A)	Combined diagnoses: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Man	**120**	20	11	12	14	43	20	56	6
	9%BCGI	*5%*	*3%*	**10%BCI**	**9%BCI**	**15%ABCGHI**	**6%C**	**9%BCGI**	*3%*
Woman	**1228**	374	354	104	136	244	330	591	185
	91%F	**94%AFH**	**97%ABDEFH**	*90%*	*90%*	*85%*	**94%AFH**	**91%F**	**96%ADEFH**
Non-binary	**2**	2	-	-	1	-	-	1	1
	*	*1%*	-	-	*1%*	-	-	*	*1%*
My gender is not listed	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
Prefer not to say	**2**	2	1	-	-	-	-	1	1
	*	*1%*	*	-	-	-	-	*	*1%*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 90

Q27 Which of the following best describes your gender?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Man	**120**	2	5	9	14	39	40	10	1	120	-	-	-
	9%EK	*9%*	*7%*	*6%*	*5%*	**9%E**	**14%ADE**	*9%*	*10%*	**100%AK**	-	-	-
Woman	**1228**	21	70	140	256	378	252	102	9	-	1228	-	-
	91%GJ	*91%*	*92%*	**93%G**	**94%AG**	*90%*	*86%*	*91%*	*90%*	-	**100%AJ**	-	-
Non-binary	**2**	-	1	-	1	-	-	-	-	-	-	2	-
	*	-	**1%AF**	-	*	-	-	-	-	-	-	*100%*	-
My gender is not listed	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Prefer not to say	**2**	-	-	1	-	1	-	-	-	-	-	-	-
	*	-	-	*1%*	-	*	-	-	-	-	-	-	-
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 91

Q28 How old are you?

Base: all participants

	Total (A)	Primary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Primary diagnosis: Sjogren's disease (C)	Primary diagnosis: Myositis/ inflammatory muscle disease (D)	Primary diagnosis: Antiphospholipid syndrome (APS) (E)	Primary diagnosis: A form of systemic vasculitis (including Behcet's) (F)	Primary diagnosis: A form of systemic sclerosis or scleroderma (G)	Primary diagnosis: Raynaud's disease (H)	Primary diagnosis: Undifferentiated or mixed connective tissue disease (I)	Secondary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Secondary diagnosis: Sjogren's disease (K)	Secondary diagnosis: Myositis/ inflammatory muscle disease (L)	Secondary diagnosis: Antiphospholipid syndrome (APS) (M)	Secondary diagnosis: A form of systemic vasculitis (including Behcet's) (N)	Secondary diagnosis: A form of systemic sclerosis or scleroderma (O)	Secondary diagnosis: Raynaud's disease (P)	Secondary diagnosis: Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
16 to 24	**23**	14	-	-	3	2	3	-	1	-	-	-	2	1	-	5	-
	2%	***4%ACFGH***	-	-	***4%CFH***	*1%*	*1%*	-	*1%*	-	-	-	***5%K***	*13%*	-	*1%*	-
25 to 34	**76**	25	6	4	3	19	9	3	7	3	6	3	1	-	-	11	4
	6%P	**8%G**	*4%*	*5%*	*4%*	**7%G**	*3%*	*3%*	**9%G**	*7%*	*5%*	*19%*	*2%*	-	-	*3%*	**8%O**
35 to 44	**150**	49	6	8	14	28	16	17	12	4	8	-	6	1	11	47	8
	11%CG	**15%ACG**	*4%*	*10%*	**18%ACG**	**11%CG**	*6%*	**15%CG**	**15%CG**	*9%*	*7%*	-	*14%*	*13%*	**22%AK**	*12%*	*16%*
45 to 54	**271**	71	16	19	25	46	46	19	29	6	22	3	16	5	11	76	14
	20%C	**22%C**	*11%*	**25%C**	**32%ACFGH**	*18%*	*17%*	*17%*	**35%ABCFGH**	*14%*	*19%*	*19%*	**38%AJKP**	*63%*	*22%*	*20%*	*28%*
55 to 64	**418**	95	45	22	23	100	82	29	22	20	42	2	12	1	11	103	15
	31%P	*30%*	*30%*	*29%*	*30%*	**38%ABH**	*30%*	*25%*	*27%*	**45%AOP**	*36%*	*13%*	*29%*	*13%*	*22%*	*27%*	*30%*
65 to 74	**292**	52	47	17	8	50	83	27	8	6	29	8	5	-	10	96	9
	22%BEI	*16%*	**31%ABEFI**	**22%I**	*10%*	**19%I**	**31%ABEFI**	**23%EI**	*10%*	*14%*	*25%*	*50%*	*12%*	-	*20%*	*25%*	*18%*
75 to 84	**112**	11	29	7	1	15	30	17	2	4	8	-	-	-	6	43	-
	8%BEIQ	*3%*	**19%ABDEFGI**	**9%BE**	*1%*	*6%*	**11%BEFI**	**15%ABEFI**	*2%*	**9%MQ**	*7%*	-	-	-	**12%MQ**	**11%AMQ**	-
85 or over	**10**	3	2	-	-	-	1	3	1	1	1	-	-	-	1	2	-
	1%	*1%*	*1%*	-	-	-	*	**3%AFG**	*1%*	*2%*	*1%*	-	-	-	*2%*	*1%*	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 92

Q28 How old are you?

Base: all participants

	Total (A)	Combined diagnoses: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
16 to 24	**23**	14	-	-	6	3	3	6	1
	2%CH	**4%ACDFGHI**	-	-	**4%ACDFGHI**	*1%*	*1%*	*1%*	*1%*
25 to 34	**76**	30	14	8	4	19	9	23	12
	6%GH	**8%CEGH**	*4%*	**7%G**	*3%*	**7%GH**	*3%*	*4%*	**6%GH**
35 to 44	**150**	56	22	14	27	30	29	84	29
	11%CG	**14%ACG**	*6%*	**12%C**	**18%ACFG**	**10%C**	*8%*	**13%ACG**	**15%CG**
45 to 54	**271**	86	64	29	49	53	67	135	58
	20%	*22%*	*17%*	*25%*	**32%ABCFGH**	*18%*	*19%*	*21%*	**30%ABCFGH**
55 to 64	**418**	129	119	28	44	110	102	176	59
	31%H	**32%H**	**33%H**	*24%*	*29%*	**38%ADGH**	*29%*	*27%*	*31%*
65 to 74	**292**	63	103	30	18	55	98	153	28
	22%BEI	*16%*	**28%ABEFHI**	**26%BEI**	*12%*	*19%*	**28%ABEFHI**	**24%BEI**	*15%*
75 to 84	**112**	16	41	7	3	17	39	66	5
	8%BEI	*4%*	**11%ABEFI**	*6%*	*2%*	*6%*	**11%ABEFI**	**10%ABEFI**	*3%*
85 or over	**10**	4	3	-	-	-	3	6	1
	1%	*1%*	*1%*	-	-	-	*1%*	*1%*	*1%*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 93

Q28 How old are you?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
16 to 24	**23**	23	-	-	-	-	-	-	-	2	21	-	-
	2%EFG	*100%*	-	-	-	-	-	-	-	*2%*	*2%*	-	-
25 to 34	**76**	-	76	-	-	-	-	-	-	5	70	1	-
	6%DEFGH	-	**100%ADEFGH**	-	-	-	-	-	-	*4%*	*6%*	*50%*	-
35 to 44	**150**	-	-	150	-	-	-	-	-	9	140	-	-
	11%CEFGH	-	-	**100%ACEFGH**	-	-	-	-	-	*8%*	*11%*	-	-
45 to 54	**271**	-	-	-	271	-	-	-	-	14	256	1	-
	20%CDFGHJ	-	-	-	**100%ACDFGH**	-	-	-	-	*12%*	**21%AJ**	*50%*	-
55 to 64	**418**	-	-	-	-	418	-	-	-	39	378	-	-
	31%CDEGH	-	-	-	-	**100%ACDEGH**	-	-	-	*33%*	*31%*	-	-
65 to 74	**292**	-	-	-	-	-	292	-	-	40	252	-	-
	22%CDEFHK	-	-	-	-	-	**100%ACDEFH**	-	-	**33%AK**	*21%*	-	-
75 to 84	**112**	-	-	-	-	-	-	112	-	10	102	-	-
	8%CDEFG	-	-	-	-	-	-	**100%ACDEFG**	-	*8%*	*8%*	-	-
85 or over	**10**	-	-	-	-	-	-	-	10	1	9	-	-
	1%	-	-	-	-	-	-	-	*100%*	*1%*	*1%*	-	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 94

Q29 Which of the following best describes what you are doing at present?

Base: all participants

	Total (A)	Primary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	Secondary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
In full-time paid work (30 hours or more each week) including self-employment	**322**	83	22	20	23	74	52	28	20	7	19	2	15	-	12	80	15
	24%CGK	***26%C***	*15%*	***26%C***	***30%CG***	***28%CG***	*19%*	***24%C***	*24%*	*16%*	*16%*	*13%*	***36%JKP***	-	*24%*	*21%*	***30%K***
In part-time paid work (under 30 hours each week) including self-employment	**228**	57	20	13	15	46	42	19	16	8	17	-	3	1	10	58	7
	17%	*18%*	*13%*	*17%*	*19%*	*18%*	*16%*	*17%*	*20%*	*18%*	*15%*	-	*7%*	*13%*	*20%*	*15%*	*14%*
In full-time education at school, college or university	**17**	8	1	-	1	2	3	-	2	-	-	-	1	1	-	2	-
	1%	***3%A***	*1%*	-	*1%*	*1%*	*1%*	-	*2%*	-	-	-	*2%*	*13%*	-	*1%*	-
Unemployed	**13**	2	-	-	1	4	2	3	1	-	-	-	1	-	1	2	-
	1%	*1%*	-	-	*1%*	*2%*	*1%*	***3%C***	*1%*	-	-	-	*2%*	-	*2%*	*1%*	-
Unable to work due to long-term sickness or disability	**272**	82	19	7	24	53	49	14	24	12	27	6	13	6	8	83	17
	20%CDH	***26%ACDGH***	*13%*	*9%*	***31%ACDFGH***	***20%CD***	*18%*	*12%*	***29%ACDGH***	*27%*	*23%*	*38%*	*31%*	*75%*	*16%*	*22%*	***34%AO***
Fully retired from work	**431**	68	82	31	10	74	112	41	13	14	41	8	7	-	16	141	9
	32%BEIMQ	*21%*	***54%ABDEFGHI***	***40%BEI***	*13%*	***28%BEI***	***41%ABEFI***	***36%BEI***	*16%*	*32%*	***35%MQ***	*50%*	*17%*	-	*32%*	***37%AMQ***	*18%*
Looking after the family or home	**42**	11	5	4	3	4	5	7	3	-	7	-	1	-	1	7	2
	3%	*3%*	*3%*	*5%*	*4%*	*2%*	*2%*	***6%FG***	*4%*	-	***6%P***	-	*2%*	-	*2%*	*2%*	*4%*
Other	**27**	9	2	2	-	3	5	3	3	3	5	-	1	-	2	10	-
	2%	*3%*	*1%*	*3%*	-	*1%*	*2%*	*3%*	*4%*	***7%A***	*4%*	-	*2%*	-	*4%*	*3%*	-
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 95

Q29 Which of the following best describes what you are doing at present?

Base: all participants

	Total (A)	Combined diagnoses: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
In full-time paid work (30 hours or more each week) including self-employment	**322** **24%CGH**	94 **24%C**	54 *15%*	26 **22%C**	48 **32%ABCGHI**	76 **26%CG**	70 **20%C**	138 **21%C**	43 **22%C**
In part-time paid work (under 30 hours each week) including self-employment	**228** ***17%***	70 *18%*	50 *14%*	15 *13%*	24 *16%*	48 *17%*	53 *15%*	97 *15%*	31 *16%*
In full-time education at school, college or university	**17** **1%CH**	8 **2%CH**	1 *	- -	3 **2%CH**	3 *1%*	3 *1%*	3 *	2 *1%*
Unemployed	**13** ***1%***	3 *1%*	- -	- -	2 **1%C**	4 **1%C**	3 *1%*	6 *1%*	1 *1%*
Unable to work due to long-term sickness or disability	**272** ***20%***	107 **27%AGH**	84 *23%*	25 *22%*	44 **29%AG**	67 *23%*	66 *19%*	147 **23%AG**	65 **34%ABCDFGH**
Fully retired from work	**431** **32%BEI**	91 **23%E**	151 **41%ABEFHI**	44 **38%BEI**	24 *16%*	81 **28%E**	139 **40%ABEFHI**	224 **35%ABEFI**	41 *21%*
Looking after the family or home	**42** **3%F**	12 *3%*	13 *4%*	4 *3%*	4 *3%*	4 *1%*	8 *2%*	15 *2%*	5 *3%*
Other	**27** ***2%***	13 **3%A**	13 **4%A**	2 *2%*	2 *1%*	4 *1%*	8 *2%*	19 **3%A**	5 *3%*
Don't know/no answer	- -	- -	- -	- -	- -	- -	- -	- -	- -

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 96

Q29 Which of the following best describes what you are doing at present?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
In full-time paid work (30 hours or more each week) including self-employment	**322**	7	39	63	108	100	5	-	-	39	283	-	-
	24%GHK	*30%*	**51%AFGH**	**42%AFGH**	**40%AFGH**	**24%GH**	*2%*	-	-	**33%AK**	*23%*	-	-
In part-time paid work (under 30 hours each week) including self-employment	**228**	3	12	35	63	90	22	3	-	11	215	-	-
	17%GHJ	*13%*	**16%GH**	**23%AGH**	**23%AGH**	**22%AGH**	*8%*	*3%*	-	*9%*	**18%AJ**	-	-
In full-time education at school, college or university	**17**	11	1	1	4	-	-	-	-	1	16	-	-
	1%F	*48%*	**1%F**	*1%*	**1%FG**	-	-	-	-	*1%*	*1%*	-	-
Unemployed	**13**	1	-	3	3	5	1	-	-	3	10	-	-
	1%	*4%*	-	*2%*	*1%*	*1%*	*	-	-	*3%*	*1%*	-	-
Unable to work due to long-term sickness or disability	**272**	-	21	39	76	119	16	1	-	15	256	1	-
	20%GHJ	-	**28%GH**	**26%GH**	**28%AGH**	**28%AGH**	**5%H**	*1%*	-	*13%*	**21%AJ**	*50%*	-
Fully retired from work	**431**	-	-	1	2	80	236	102	10	50	381	-	-
	32%CDEFK	-	-	*1%*	*1%*	**19%CDE**	**81%ACDEF**	**91%ACDEFG**	*100%*	**42%AK**	*31%*	-	-
Looking after the family or home	**42**	1	1	7	11	15	4	3	-	-	42	-	-
	3%G	*4%*	*1%*	**5%G**	**4%G**	*4%*	*1%*	*3%*	-	-	**3%AJ**	-	-
Other	**27**	-	2	1	4	9	8	3	-	1	25	1	-
	2%	-	*3%*	*1%*	*1%*	*2%*	*3%*	*3%*	-	*1%*	*2%*	*50%*	-
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 97

Q30 Which one of the following best describes your ethnic group or background?

Base: all participants

	Total (A)	Primary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Primary diagnosis: Sjogren's disease (C)	Primary diagnosis: Myositis/ inflammatory muscle disease (D)	Primary diagnosis: Antiphospholipid syndrome (APS) (E)	Primary diagnosis: A form of systemic vasculitis (including Behcet's) (F)	Primary diagnosis: A form of systemic sclerosis or scleroderma (G)	Primary diagnosis: Raynaud's disease (H)	Primary diagnosis: Undifferentiated or mixed connective tissue disease (I)	Secondary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Secondary diagnosis: Sjogren's disease (K)	Secondary diagnosis: Myositis/ inflammatory muscle disease (L)	Secondary diagnosis: Antiphospholipid syndrome (APS) (M)	Secondary diagnosis: A form of systemic vasculitis (including Behcet's) (N)	Secondary diagnosis: A form of systemic sclerosis or scleroderma (O)	Secondary diagnosis: Raynaud's disease (P)	Secondary diagnosis: Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
White	**1230**	**269**	**143**	**69**	**72**	**243**	**252**	**106**	**76**	**41**	**106**	**14**	**38**	**8**	**42**	**356**	**45**
	91%B	***84%***	**95%B**	***90%***	**94%B**	**93%B**	**93%B**	**92%B**	**93%B**	***93%***	***91%***	***88%***	***90%***	***100%***	***84%***	**93%O**	***90%***
English/Welsh/Scottish/Northern Irish/British	**1196**	256	142	68	70	239	248	101	72	40	101	14	33	8	41	349	45
	88%BM	*80%*	**94%AB**	*88%*	**91%B**	**92%AB**	**92%AB**	*88%*	*88%*	*91%*	*87%*	*88%*	*79%*	*100%*	*82%*	**91%AMO**	*90%*
Irish	**23**	7	-	-	1	4	3	4	4	1	3	-	3	-	1	5	-
	2%	*2%*	-	-	*1%*	*2%*	*1%*	**3%C**	**5%ACG**	*2%*	*3%*	-	**7%AP**	-	*2%*	*1%*	-
Gypsy or Irish traveller	**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Any other white background	**11**	6	1	1	1	-	1	1	-	-	2	-	2	-	-	2	-
	1%	**2%AF**	*1%*	*1%*	*1%*	-	*	*1%*	-	-	*2%*	-	**5%AP**	-	-	*1%*	-
Mixed/multiple ethnic groups	**22**	**10**	**2**	**1**	**-**	**1**	**6**	**-**	**2**	**-**	**4**	**-**	**1**	**-**	**2**	**8**	**-**
	2%	**3%AF**	*1%*	*1%*	-	*	*2%*	-	*2%*	-	*3%*	-	*2%*	-	*4%*	*2%*	-
White and black Caribbean	**7**	2	-	1	-	1	2	-	1	-	1	-	1	-	-	4	-
	1%	*1%*	-	*1%*	-	*	*1%*	-	*1%*	-	*1%*	-	*2%*	-	-	*1%*	-
White and black African	**3**	-	1	-	-	-	1	-	1	-	-	-	-	-	-	1	-
	*	-	*1%*	-	-	-	*	-	**1%B**	-	-	-	-	-	-	*	-
White and Asian	**6**	6	-	-	-	-	-	-	-	-	2	-	-	-	1	-	-
	*	**2%AFG**	-	-	-	-	-	-	-	-	**2%P**	-	-	-	**2%P**	-	-
Any other mixed/multiple ethnic background	**6**	2	1	-	-	-	3	-	-	-	1	-	-	-	1	3	-
	*	*1%*	*1%*	-	-	-	*1%*	-	-	-	*1%*	-	-	-	*2%*	*1%*	-
Asian/Asian British	**34**	**17**	**2**	**3**	**2**	**6**	**1**	**2**	**1**	**1**	**3**	**-**	**2**	**-**	**4**	**7**	**1**
	3%G	**5%ACG**	*1%*	**4%G**	*3%*	*2%*	*	*2%*	*1%*	*2%*	*3%*	-	*5%*	-	**8%AP**	*2%*	*2%*
Indian	**18**	9	2	1	1	3	1	1	-	-	-	-	2	-	1	2	1
	1%	**3%AG**	*1%*	*1%*	*1%*	*1%*	*	*1%*	-	-	-	-	**5%KP**	-	*2%*	*1%*	*2%*

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 97

Q30 Which one of the following best describes your ethnic group or background?

Base: all participants

	Total (A)	Primary diagnosis								Secondary diagnosis							
		A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Pakistani	**4**	1	-	1	-	2	-	-	-	-	1	-	-	-	1	2	-
	*	*	-	*1%*	-	*1%*	-	-	-	-	*1%*	-	-	-	**2%A**	*1%*	-
Bangladeshi	**2**	1	-	-	-	-	-	1	-	-	-	-	-	-	1	1	-
	*	*	-	-	-	-	-	*1%*	-	-	-	-	-	-	**2%A**	*	-
Chinese	**4**	3	-	-	-	-	-	-	1	-	2	-	-	-	-	-	-
	*	**1%A**	-	-	-	-	-	-	*1%*	-	**2%AP**	-	-	-	-	-	-
Any other Asian background	**6**	3	-	1	1	1	-	-	-	1	-	-	-	-	1	2	-
	*	*1%*	-	*1%*	*1%*	*	-	-	-	*2%*	-	-	-	-	*2%*	*1%*	-
Black/African/Caribbean/black British	**18**	**9**	**1**	**2**	**1**	**1**	**3**	**-**	**1**	**-**	**-**	**1**	**1**	**-**	**-**	**4**	**-**
	1%	**3%AF**	***1%***	***3%***	***1%***	*	***1%***	**-**	***1%***	**-**	**-**	***6%***	***2%***	**-**	**-**	***1%***	**-**
African	**11**	4	1	1	1	1	3	-	-	-	-	-	-	-	-	3	-
	1%	*1%*	*1%*	*1%*	*1%*	*	*1%*	-	-	-	-	-	-	-	-	*1%*	-
Caribbean	**7**	5	-	1	-	-	-	-	1	-	-	1	1	-	-	1	-
	1%	**2%AFG**	-	*1%*	-	-	-	-	*1%*	-	-	*6%*	*2%*	-	-	*	-
Any other black/African/Caribbean background	**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Other ethnic group	**40**	**15**	**2**	**2**	**1**	**8**	**7**	**3**	**2**	**2**	**3**	**1**	**-**	**-**	**2**	**7**	**2**
	3%	**5%A**	***1%***	***3%***	***1%***	***3%***	***3%***	***3%***	***2%***	***5%***	***3%***	***6%***	**-**	**-**	***4%***	***2%***	***4%***
Arab	**2**	1	1	-	-	-	-	-	-	1	-	-	-	-	-	-	-
	*	*	*1%*	-	-	-	-	-	-	**2%AP**	-	-	-	-	-	-	-
Any other ethnic group	**38**	14	1	2	1	8	7	3	2	1	3	1	-	-	2	7	2
	3%	**4%C**	*1%*	*3%*	*1%*	*3%*	*3%*	*3%*	*2%*	*2%*	*3%*	*6%*	-	-	*4%*	*2%*	*4%*
Don't know	**2**	-	-	-	1	1	-	-	-	-	-	-	-	-	-	1	-
	*	-	-	-	**1%AB**	*	-	-	-	-	-	-	-	-	-	*	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 97

Q30 Which one of the following best describes your ethnic group or background?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
I would prefer not to say	**6**	-	1	-	-	-	1	4	-	-	-	-	-	-	-	-	2
	*	-	*1%*	-	-	-	*	**3%ABFG**	-	-	-	-	-	-	-	-	**4%AKP**
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 98

Q30 Which one of the following best describes your ethnic group or background?

Base: all participants

	Total (A)	Combined diagnoses: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
White	**1230**	**343**	**341**	**105**	**138**	**270**	**321**	**594**	**172**
	91%B	***86%***	**93%B**	***91%***	**91%B**	**94%ABI**	**92%B**	**92%B**	***89%***
English/Welsh/Scottish/Northern Irish/British	**1196**	328	332	103	131	265	315	575	167
	88%B	*82%*	**91%B**	*89%*	*87%*	**92%ABI**	**90%B**	**89%B**	*87%*
Irish	**23**	9	5	1	4	5	5	14	5
	2%	*2%*	*1%*	*1%*	*3%*	*2%*	*1%*	*2%*	*3%*
Gypsy or Irish traveller	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
Any other white background	**11**	6	4	1	3	-	1	5	-
	1%	**2%F**	*1%*	*1%*	**2%F**	-	*	*1%*	-
Mixed/multiple ethnic groups	**22**	**10**	**7**	**1**	**2**	**1**	**8**	**14**	**4**
	2%F	**3%F**	*2%*	*1%*	*1%*	*	**2%F**	**2%F**	*2%*
White and black Caribbean	**7**	2	2	1	1	1	2	5	1
	1%	*1%*	*1%*	*1%*	*1%*	*	*1%*	*1%*	*1%*
White and black African	**3**	-	1	-	-	-	1	1	1
	*	-	*	-	-	-	*	*	*1%*
White and Asian	**6**	6	2	-	1	-	1	3	1
	*	**2%AFH**	*1%*	-	*1%*	-	*	*	*1%*
Any other mixed/multiple ethnic background	**6**	2	2	-	-	-	4	5	1
	*	*1%*	*1%*	-	-	-	**1%A**	*1%*	*1%*
Asian/Asian British	**34**	**19**	**7**	**3**	**6**	**6**	**7**	**15**	**7**
	3%	**5%ACGH**	***2%***	***3%***	***4%***	***2%***	***2%***	***2%***	***4%***
Indian	**18**	9	3	1	4	3	2	3	2
	1%H	**2%CH**	*1%*	*1%*	**3%H**	*1%*	*1%*	*	*1%*
Pakistani	**4**	1	1	1	-	2	1	4	2
	*	*	*	*1%*	-	*1%*	*	*1%*	*1%*

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 98

Q30 Which one of the following best describes your ethnic group or background?

Base: all participants

	Total (A)	Combined diagnoses							
		A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Bangladeshi	**2**	1	-	-	-	-	1	2	-
	*	*	-	-	-	-	*	*	-
Chinese	**4**	3	2	-	-	-	1	2	2
	*	*1%*	*1%*	-	-	-	*	*	*1%*
Any other Asian background	**6**	5	1	1	2	1	2	4	1
	*	**1%A**	*	*1%*	*1%*	*	*1%*	*1%*	*1%*
Black/African/Caribbean/black British	**18**	**9**	**2**	**4**	**2**	**1**	**3**	**5**	**2**
	1%	**2%CFH**	***1%***	**3%ACFGH**	***1%***	*	***1%***	***1%***	***1%***
African	**11**	4	1	2	1	1	3	3	1
	1%	*1%*	*	*2%*	*1%*	*	*1%*	*	*1%*
Caribbean	**7**	5	1	2	1	-	-	2	1
	1%	**1%AGH**	*	**2%FG**	*1%*	-	-	*	*1%*
Any other black/African/Caribbean background	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-
Other ethnic group	**40**	**17**	**8**	**3**	**2**	**8**	**10**	**16**	**6**
	3%	**4%CEH**	***2%***	***3%***	***1%***	***3%***	***3%***	***2%***	***3%***
Arab	**2**	2	1	-	-	-	-	1	-
	*	*1%*	*	-	-	-	-	*	-
Any other ethnic group	**38**	15	7	3	2	8	10	15	6
	3%	*4%*	*2%*	*3%*	*1%*	*3%*	*3%*	*2%*	*3%*
Don't know	**2**	-	-	-	1	1	-	1	-
	*	-	-	-	*1%*	*	-	*	-
I would prefer not to say	**6**	-	1	-	-	-	1	4	2
	*	-	*	-	-	-	*	*1%*	**1%B**
Don't know/no answer	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 99

Q30 Which one of the following best describes your ethnic group or background?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
White	**1230**	**13**	**61**	**119**	**244**	**393**	**282**	**109**	**9**	**109**	**1119**	**1**	**-**
	91%CD	***57%***	***80%***	***79%***	**90%CD**	**94%ACD**	**97%ACDE**	**97%ACDE**	***90%***	***91%***	***91%***	***50%***	**-**
English/Welsh/Scottish/Northern Irish/British	**1196**	12	60	110	238	383	275	109	9	106	1088	1	-
	88%CD	*52%*	*79%*	*73%*	**88%D**	**92%ACD**	**94%ACDE**	**97%ACDEF**	*90%*	*88%*	*89%*	*50%*	-
Irish	**23**	-	1	6	5	7	4	-	-	3	20	-	-
	2%	-	*1%*	**4%AH**	*2%*	*2%*	*1%*	-	-	*3%*	*2%*	-	-
Gypsy or Irish traveller	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Any other white background	**11**	1	-	3	1	3	3	-	-	-	11	-	-
	1%	*4%*	-	*2%*	*	*1%*	*1%*	-	-	-	*1%*	-	-
Mixed/multiple ethnic groups	**22**	**2**	**1**	**3**	**6**	**6**	**4**	**-**	**-**	**1**	**21**	**-**	**-**
	2%	***9%***	***1%***	***2%***	***2%***	***1%***	***1%***	**-**	**-**	***1%***	***2%***	**-**	**-**
White and black Caribbean	**7**	-	-	2	1	2	2	-	-	1	6	-	-
	1%	-	-	*1%*	*	*	*1%*	-	-	*1%*	*	-	-
White and black African	**3**	-	-	-	2	1	-	-	-	-	3	-	-
	*	-	-	-	*1%*	*	-	-	-	-	*	-	-
White and Asian	**6**	2	-	1	2	-	1	-	-	-	6	-	-
	*	*9%*	-	*1%*	*1%*	-	*	-	-	-	*	-	-
Any other mixed/multiple ethnic background	**6**	-	1	-	1	3	1	-	-	-	6	-	-
	*	-	*1%*	-	*	*1%*	*	-	-	-	*	-	-
Asian/Asian British	**34**	**4**	**4**	**13**	**7**	**5**	**1**	**-**	**-**	**4**	**30**	**-**	**-**
	3%FG	*17%*	**5%FGH**	**9%AEFGH**	**3%G**	*1%*	*	-	-	*3%*	*2%*	-	-
Indian	**18**	2	2	7	3	3	1	-	-	4	14	-	-
	1%K	*9%*	**3%G**	**5%AEFGH**	*1%*	*1%*	*	-	-	**3%K**	*1%*	-	-
Pakistani	**4**	-	-	3	1	-	-	-	-	-	4	-	-
	*	-	-	**2%AFG**	*	-	-	-	-	-	*	-	-
Bangladeshi	**2**	-	-	2	-	-	-	-	-	-	2	-	-
	*	-	-	**1%AFG**	-	-	-	-	-	-	*	-	-
Chinese	**4**	-	1	-	2	1	-	-	-	-	4	-	-
	*	-	*1%*	-	*1%*	*	-	-	-	-	*	-	-
Any other Asian background	**6**	2	1	1	1	1	-	-	-	-	6	-	-
	*	*9%*	*1%*	*1%*	*	*	-	-	-	-	*	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 99

Q30 Which one of the following best describes your ethnic group or background?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Black/African/Caribbean/black British	**18**	**1**	**3**	**6**	**4**	**3**	**1**	**-**	**-**	**2**	**16**	**-**	**-**
	1%	***4%***	**4%FGH**	**4%AFGH**	***1%***	***1%***	*	**-**	**-**	***2%***	***1%***	**-**	**-**
African	**11**	1	2	4	3	-	1	-	-	2	9	-	-
	1%	*4%*	**3%FG**	**3%AFG**	**1%F**	-	*	-	-	*2%*	*1%*	-	-
Caribbean	**7**	-	1	2	1	3	-	-	-	-	7	-	-
	1%	-	*1%*	**1%G**	*	*1%*	-	-	-	-	*1%*	-	-
Any other black/African/Caribbean background	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-
Other ethnic group	**40**	**3**	**7**	**8**	**7**	**9**	**3**	**3**	**-**	**1**	**37**	**1**	**-**
	3%G	***13%***	**9%AEFG**	**5%G**	***3%***	***2%***	***1%***	***3%***	**-**	***1%***	***3%***	***50%***	**-**
Arab	**2**	-	-	2	-	-	-	-	-	-	2	-	-
	*	-	-	**1%AFG**	-	-	-	-	-	-	*	-	-
Any other ethnic group	**38**	3	7	6	7	9	3	3	-	1	35	1	-
	3%G	*13%*	**9%AEFG**	**4%G**	*3%*	*2%*	*1%*	*3%*	-	*1%*	*3%*	*50%*	-
Don't know	**2**	-	-	-	1	-	1	-	-	2	-	-	-
	*	-	-	-	*	-	*	-	-	**2%AK**	-	-	-
I would prefer not to say	**6**	-	-	1	2	2	-	-	1	1	5	-	-
	*	-	-	*1%*	*1%*	*	-	-	*10%*	*1%*	*	-	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 100

Q31 Which country do you live in?

Base: all participants

	Total (A)	Primary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	Secondary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
England	**1112**	271	121	66	61	210	226	92	65	40	99	14	35	7	39	312	44
	82%	*85%*	*80%*	*86%*	*79%*	*81%*	*84%*	*80%*	*79%*	*91%*	*85%*	*88%*	*83%*	*88%*	*78%*	*81%*	*88%*
Wales	**71**	8	13	2	5	19	14	7	3	1	4	-	2	-	3	18	4
	5%B	*3%*	**9%B**	*3%*	*6%*	**7%B**	*5%*	*6%*	*4%*	*2%*	*3%*	-	*5%*	-	*6%*	*5%*	*8%*
Scotland	**117**	28	14	9	8	26	18	5	9	1	9	-	5	1	3	38	2
	9%	*9%*	*9%*	*12%*	*10%*	*10%*	*7%*	*4%*	*11%*	*2%*	*8%*	-	*12%*	*13%*	*6%*	*10%*	*4%*
Northern Ireland	**29**	8	3	-	1	4	7	4	2	1	2	1	-	-	3	10	-
	2%	*3%*	*2%*	-	*1%*	*2%*	*3%*	*3%*	*2%*	*2%*	*2%*	*6%*	-	-	*6%*	*3%*	-
Prefer not to say	**23**	5	-	-	2	1	5	7	3	1	2	1	-	-	2	5	-
	2%	*2%*	-	-	**3%C**	*	*2%*	**6%ABCDFG**	**4%CF**	*2%*	*2%*	*6%*	-	-	*4%*	*1%*	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 101

Q31 Which country do you live in?

Base: all participants

	Total (A)	Combined diagnoses							
		A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
England	**1112**	339	299	92	124	233	290	532	160
	82%	*85%*	*82%*	*79%*	*82%*	*81%*	*83%*	*82%*	*83%*
Wales	**71**	10	23	6	8	19	18	29	8
	5%B	*3%*	**6%B**	*5%*	**5%B**	**7%B**	*5%*	**4%B**	*4%*
Scotland	**117**	32	36	15	15	29	24	56	19
	9%	*8%*	*10%*	**13%G**	*10%*	*10%*	*7%*	*9%*	*10%*
Northern Ireland	**29**	10	6	2	2	4	10	17	3
	2%	*3%*	*2%*	*2%*	*1%*	*1%*	*3%*	*3%*	*2%*
Prefer not to say	**23**	7	2	1	2	2	8	15	3
	2%C	*2%*	*1%*	*1%*	*1%*	*1%*	**2%C**	**2%C**	*2%*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 102

Q31 Which country do you live in?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
England	**1112**	21	62	123	211	344	247	95	9	101	1009	1	-
	82%E	*91%*	*82%*	*82%*	*78%*	*82%*	***85%E***	*85%*	*90%*	*84%*	*82%*	*50%*	-
Wales	**71**	-	2	5	12	26	20	6	-	6	65	-	-
	5%	-	*3%*	*3%*	*4%*	*6%*	*7%*	*5%*	-	*5%*	*5%*	-	-
Scotland	**117**	1	8	13	31	38	19	6	1	10	106	-	-
	9%	*4%*	*11%*	*9%*	***11%G***	*9%*	*7%*	*5%*	*10%*	*8%*	*9%*	-	-
Northern Ireland	**29**	-	3	4	11	6	3	2	-	1	28	-	-
	2%	-	*4%*	*3%*	***4%AFG***	*1%*	*1%*	*2%*	-	*1%*	*2%*	-	-
Prefer not to say	**23**	1	1	5	6	4	3	3	-	2	20	1	-
	2%	*4%*	*1%*	***3%F***	*2%*	*1%*	*1%*	*3%*	-	*2%*	*2%*	*50%*	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 103

Q32 Who do you live with?

Base: all participants

	Total (A)	Primary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	Secondary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
By myself	**301**	70	31	22	13	50	61	35	19	5	30	7	6	-	11	102	8
	22%	*22%*	*21%*	*29%*	*17%*	*19%*	*23%*	**30%AEF**	*23%*	*11%*	*26%*	*44%*	*14%*	*-*	*22%*	**27%AJ**	*16%*
With my partner/spouse	**627**	128	96	34	33	125	133	46	32	29	59	6	17	2	19	168	30
	46%B	*40%*	**64%ABDEFGHI**	*44%*	*43%*	*48%*	**49%B**	*40%*	*39%*	**66%AMOP**	*51%*	*38%*	*40%*	*25%*	*38%*	*44%*	**60%AOP**
With my partner/spouse and children	**279**	74	14	17	21	65	48	19	21	7	18	2	11	4	14	76	9
	21%C	**23%C**	*9%*	**22%C**	**27%C**	**25%CG**	**18%C**	*17%*	**26%C**	*16%*	*16%*	*13%*	*26%*	*50%*	*28%*	*20%*	*18%*
With family	**125**	37	9	4	9	17	25	14	10	2	9	1	7	2	5	32	1
	9%	**12%F**	*6%*	*5%*	*12%*	*7%*	*9%*	*12%*	*12%*	*5%*	*8%*	*6%*	**17%Q**	*25%*	*10%*	*8%*	*2%*
With friends	**8**	4	1	-	-	1	2	-	-	-	-	-	1	-	1	1	-
	1%	*1%*	*1%*	*-*	*-*	*	*1%*	*-*	*-*	*-*	*-*	*-*	*2%*	*-*	*2%*	*	*-*
Prefer not to say	**12**	7	-	-	1	2	1	1	-	1	-	-	-	-	-	4	2
	1%	**2%A**	*-*	*-*	*1%*	*1%*	*	*1%*	*-*	*2%*	*-*	*-*	*-*	*-*	*-*	*1%*	**4%AK**
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 104

Q32 Who do you live with?

Base: all participants

	Total (A)	Combined diagnoses							
		A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
By myself	**301**	83	85	33	30	54	79	163	42
	22%	*21%*	*23%*	**28%F**	*20%*	*19%*	*23%*	**25%ABF**	*22%*
With my partner/spouse	**627**	173	199	51	61	135	167	293	90
	46%	*43%*	**54%ABDEGH**	*44%*	*40%*	*47%*	*48%*	*45%*	*47%*
With my partner/spouse and children	**279**	87	52	26	37	70	66	120	39
	21%C	**22%C**	*14%*	**22%C**	**25%C**	**24%CH**	*19%*	**18%C**	**20%C**
With family	**125**	42	27	6	19	25	33	64	19
	9%	*11%*	*7%*	*5%*	**13%CD**	*9%*	*9%*	*10%*	*10%*
With friends	**8**	5	1	-	1	1	3	2	1
	1%	**1%H**	*	-	*1%*	*	*1%*	*	*1%*
Prefer not to say	**12**	8	2	-	3	2	2	7	2
	1%	**2%AC**	*1%*	-	*2%*	*1%*	*1%*	*1%*	*1%*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 105

Q32 Who do you live with?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
By myself	**301**	-	15	23	47	88	79	46	3	26	274	1	-
	22%DE	-	*20%*	*15%*	*17%*	*21%*	**27%ADE**	**41%ACDEFG**	*30%*	*22%*	*22%*	*50%*	-
With my partner/spouse	**627**	3	25	36	76	240	186	56	5	62	564	-	-
	46%CDE	*13%*	*33%*	*24%*	*28%*	**57%ACDE**	**64%ACDEH**	**50%CDE**	*50%*	*52%*	*46%*	-	-
With my partner/spouse and children	**279**	1	13	67	122	64	9	2	1	17	260	1	-
	21%FGH	*4%*	**17%GH**	**45%ACFGH**	**45%ACFGH**	**15%GH**	*3%*	*2%*	*10%*	*14%*	*21%*	*50%*	-
With family	**125**	14	22	22	22	21	17	6	1	12	113	-	-
	9%FG	*61%*	**29%ADEFGH**	**15%AEFGH**	*8%*	*5%*	*6%*	*5%*	*10%*	*10%*	*9%*	-	-
With friends	**8**	4	1	1	-	1	-	1	-	-	8	-	-
	1%	*17%*	*1%*	*1%*	-	*	-	*1%*	-	-	*1%*	-	-
Prefer not to say	**12**	1	-	1	4	4	1	1	-	3	9	-	-
	1%K	*4%*	-	*1%*	*1%*	*1%*	*	*1%*	-	**3%K**	*1%*	-	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 106

Q33 Are you a carer for someone over the age of 16 in your household?

Base: all participants

		Primary diagnosis								Secondary diagnosis							
	Total (A)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)	A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Sjogren's disease (K)	Myositis/ inflammatory muscle disease (L)	Antiphospholipid syndrome (APS) (M)	A form of systemic vasculitis (including Behcet's) (N)	A form of systemic sclerosis or scleroderma (O)	Raynaud's disease (P)	Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
Yes	**114**	24	17	7	4	16	24	15	7	2	13	1	4	2	3	28	3
	8%	*8%*	*11%*	*9%*	*5%*	*6%*	*9%*	**13%F**	*9%*	*5%*	*11%*	*6%*	*10%*	*25%*	*6%*	*7%*	*6%*
No	**1222**	290	133	70	70	242	244	99	74	42	103	15	38	6	47	351	45
	90%	*91%*	*88%*	*91%*	*91%*	**93%H**	*90%*	*86%*	*90%*	*95%*	*89%*	*94%*	*90%*	*75%*	*94%*	*92%*	*90%*
Prefer not to say	**16**	6	1	-	3	2	2	1	1	-	-	-	-	-	-	4	2
	1%	*2%*	*1%*	-	**4%AFG**	*1%*	*1%*	*1%*	*1%*	-	-	-	-	-	-	*1%*	**4%K**
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 107

Q33 Are you a carer for someone over the age of 16 in your household?

Base: all participants

	Total (A)	Combined diagnoses							
		A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
Yes	**114**	29	43	11	8	22	28	60	15
	8%	*7%*	**12%ABE**	*9%*	*5%*	*8%*	*8%*	*9%*	*8%*
No	**1222**	363	321	105	140	263	320	583	175
	90%C	**91%C**	*88%*	*91%*	*93%*	*92%*	*91%*	*90%*	*91%*
Prefer not to say	**16**	6	2	-	3	2	2	6	3
	1%	*2%*	*1%*	-	*2%*	*1%*	*1%*	*1%*	*2%*
Don't know/no answer	**-**	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 108

Q33 Are you a carer for someone over the age of 16 in your household?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
Yes	**114**	-	4	11	33	37	19	8	2	5	107	1	-
	8%	-	*5%*	*7%*	**12%AG**	*9%*	*7%*	*7%*	*20%*	*4%*	*9%*	*50%*	-
No	**1222**	22	71	138	235	375	272	101	8	114	1107	1	-
	90%E	*96%*	*93%*	*92%*	*87%*	*90%*	**93%E**	*90%*	*80%*	*95%*	*90%*	*50%*	-
Prefer not to say	**16**	1	1	1	3	6	1	3	-	1	14	-	-
	1%	*4%*	*1%*	*1%*	*1%*	*1%*	*	**3%G**	-	*1%*	*1%*	-	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 109

Q34 What is the highest level of education you completed?

Base: all participants

	Total (A)	Primary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Primary diagnosis: Sjogren's disease (C)	Primary diagnosis: Myositis/ inflammatory muscle disease (D)	Primary diagnosis: Antiphospholipid syndrome (APS) (E)	Primary diagnosis: A form of systemic vasculitis (including Behcet's) (F)	Primary diagnosis: A form of systemic sclerosis or scleroderma (G)	Primary diagnosis: Raynaud's disease (H)	Primary diagnosis: Undifferentiated or mixed connective tissue disease (I)	Secondary diagnosis: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (J)	Secondary diagnosis: Sjogren's disease (K)	Secondary diagnosis: Myositis/ inflammatory muscle disease (L)	Secondary diagnosis: Antiphospholipid syndrome (APS) (M)	Secondary diagnosis: A form of systemic vasculitis (including Behcet's) (N)	Secondary diagnosis: A form of systemic sclerosis or scleroderma (O)	Secondary diagnosis: Raynaud's disease (P)	Secondary diagnosis: Undifferentiated or mixed connective tissue disease (Q)
Total	**1352**	320	151	77*	77*	260	270	115	82*	44*	116	16**	42*	8**	50*	383	50*
University degree (completed a bachelor/master's/PhD degree or equivalent)	**592**	144	65	34	24	127	109	41	48	19	55	9	16	3	16	168	18
	44%E	**45%E**	*43%*	*44%*	*31%*	**49%EH**	*40%*	*36%*	**59%ABCEGH**	*43%*	*47%*	*56%*	*38%*	*38%*	*32%*	*44%*	*36%*
Vocational qualification specific to a particular occupation or trade (below degree level)	**334**	68	39	20	21	66	70	31	19	8	32	3	11	2	15	92	16
	25%	*21%*	*26%*	*26%*	*27%*	*25%*	*26%*	*27%*	*23%*	*18%*	*28%*	*19%*	*26%*	*25%*	*30%*	*24%*	*32%*
Upper secondary that allows access to university	**223**	58	32	18	16	38	39	14	8	9	15	3	11	2	5	64	7
	16%	*18%*	**21%I**	**23%HI**	*21%*	*15%*	*14%*	*12%*	*10%*	*20%*	*13%*	*19%*	**26%KO**	*25%*	*10%*	*17%*	*14%*
Lower secondary education (schooling approximately until the age of 15)	**148**	31	10	2	14	25	38	23	5	5	12	-	3	1	8	43	5
	11%D	**10%D**	*7%*	*3%*	**18%ABCDFI**	**10%D**	**14%CD**	**20%ABCDFI**	*6%*	*11%*	*10%*	-	*7%*	*13%*	*16%*	*11%*	*10%*
Primary education (schooling approximately until the age of 11)	**2**	2	-	-	-	-	-	-	-	-	1	-	-	-	-	-	-
	*	**1%A**	-	-	-	-	-	-	-	-	*1%*	-	-	-	-	-	-
No primary education completed	**5**	1	-	1	1	-	1	1	-	-	-	1	-	-	2	1	-
	*	*	-	*1%*	*1%*	-	*	*1%*	-	-	-	*6%*	-	-	**4%AKP**	*	-
Never been in formal education	**4**	-	1	1	-	-	2	-	-	1	-	-	-	-	1	-	1
	*	-	*1%*	**1%B**	-	-	*1%*	-	-	**2%AP**	-	-	-	-	**2%AP**	-	**2%AP**
Prefer not to say	**44**	16	4	1	1	4	11	5	2	2	1	-	1	-	3	15	3
	3%	**5%F**	*3%*	*1%*	*1%*	*2%*	*4%*	*4%*	*2%*	*5%*	*1%*	-	*2%*	-	**6%K**	*4%*	**6%K**
Don't know/no answer	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212

Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M/N/O/P/Q
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing

RAIRDA Survey 2024

Table 110

Q34 What is the highest level of education you completed?

Base: all participants

	Total (A)	Combined diagnoses: A form of lupus (such as systemic lupus erythematosus (SLE), cutaneous lupus (skin lupus), drug-induced lupus or juvenile-onset lupus (JSLE)) (B)	Sjogren's disease (C)	Myositis/ inflammatory muscle disease (D)	Antiphospholipid syndrome (APS) (E)	A form of systemic vasculitis (including Behcet's) (F)	A form of systemic sclerosis or scleroderma (G)	Raynaud's disease (H)	Undifferentiated or mixed connective tissue disease (I)
Total	**1352**	398	366	116	151	287	350	649	193
University degree (completed a bachelor/master's/PhD degree or equivalent)	**592** **44%EG**	173 **43%E**	163 **45%E**	54 *47%*	54 *36%*	134 **47%E**	137 *39%*	278 *43%*	96 **50%EGH**
Vocational qualification specific to a particular occupation or trade (below degree level)	**334** ***25%***	85 *21%*	94 *26%*	31 *27%*	41 *27%*	73 *25%*	89 *25%*	160 *25%*	47 *24%*
Upper secondary that allows access to university	**223** ***16%***	77 **19%I**	64 *17%*	23 *20%*	31 **21%I**	45 *16%*	54 *15%*	102 *16%*	25 *13%*
Lower secondary education (schooling approximately until the age of 15)	**148** **11%D**	39 **10%D**	31 *8%*	4 *3%*	19 **13%D**	29 **10%D**	49 **14%ACDI**	80 **12%CD**	17 *9%*
Primary education (schooling approximately until the age of 11)	**2** *	2 *1%*	1 *	- -	- -	- -	- -	- -	- -
No primary education completed	**5** *	1 *	1 *	2 **2%AF**	1 *1%*	- -	3 *1%*	4 *1%*	- -
Never been in formal education	**4** *	1 *	2 *1%*	1 *1%*	- -	- -	3 *1%*	2 *	1 *1%*
Prefer not to say	**44** ***3%***	20 **5%ACDF**	10 *3%*	1 *1%*	5 *3%*	6 *2%*	15 *4%*	23 *4%*	7 *4%*
Don't know/no answer	**-** -	- -	- -	- -	- -	- -	- -	- -	- -

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: All Columns Tested (5% risk level)
Overlap formulae used.

RAIRDA Survey 2024

Table 111

Q34 What is the highest level of education you completed?

Base: all participants

	Total (A)	Age								Gender			
		16 to 24 (B)	25 to 34 (C)	35 to 44 (D)	45 to 54 (E)	55 to 64 (F)	65 to 74 (G)	75 to 84 (H)	85 or over (I)	Man (J)	Woman (K)	Non-binary (L)	Not listed (M)
Total	**1352**	23**	76*	150	271	418	292	112	10**	120	1228	2**	-**
University degree (completed a bachelor/master's/PhD degree or equivalent)	**592**	8	53	75	129	177	104	41	5	47	542	2	-
	44%G	*35%*	**70%ADEFGH**	**50%GH**	**48%GH**	*42%*	*36%*	*37%*	*50%*	*39%*	*44%*	*100%*	-
Vocational qualification specific to a particular occupation or trade (below degree level)	**334**	2	7	38	67	105	93	19	3	38	296	-	-
	25%CH	*9%*	*9%*	**25%C**	**25%C**	**25%C**	**32%ACFH**	*17%*	*30%*	*32%*	*24%*	-	-
Upper secondary that allows access to university	**223**	5	8	18	42	68	50	31	1	16	207	-	-
	16%	*22%*	*11%*	*12%*	*15%*	*16%*	*17%*	**28%ACDEFG**	*10%*	*13%*	*17%*	-	-
Lower secondary education (schooling approximately until the age of 15)	**148**	7	7	12	22	48	34	18	-	14	134	-	-
	11%	*30%*	*9%*	*8%*	*8%*	*11%*	*12%*	**16%DE**	-	*12%*	*11%*	-	-
Primary education (schooling approximately until the age of 11)	**2**	-	-	-	-	2	-	-	-	-	2	-	-
	*	-	-	-	-	*	-	-	-	-	*	-	-
No primary education completed	**5**	-	-	1	2	-	2	-	-	2	3	-	-
	***K**	-	-	*1%*	*1%*	-	*1%*	-	-	**2%AK**	*	-	-
Never been in formal education	**4**	-	1	-	-	-	3	-	-	1	3	-	-
	*	-	**1%F**	-	-	-	**1%AF**	-	-	*1%*	*	-	-
Prefer not to say	**44**	1	-	6	9	18	6	3	1	2	41	-	-
	3%	*4%*	-	*4%*	*3%*	*4%*	*2%*	*3%*	*10%*	*2%*	*3%*	-	-
Don't know/no answer	**-**	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-

Fieldwork dates: 22nd April - 31st May 2024
Participant type: People 16+ with rare autoimmune rheumatic diseases
Source: Ipsos (JN 23-069657-01)
File name: 23-069657-RAIRDA-condensed-V1-Public241212
Proportions/Means: Columns Tested (5% risk level) - A/B/C/D/E/F/G/H/I - A/J/K/L/M
Overlap formulae used. * small base; ** very small base (under 30) ineligible for sig testing