'I am not alone'

A qualitative survey of the impact of patient support groups using corpus linguistics

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Corpus Linguistics: computer-assisted analysis of large bodies of text

- Suitable for the analysis of **large collections of text**

- Corpus methods can provide **fast and informative insights** by:

  - Facilitating analysis of collections of (transcribed) spoken and written language, typically using specialist software to extract common patterns in the use of words, grammar and meaning

  - Offering a mixed methods approach (qualitative and quantitative)
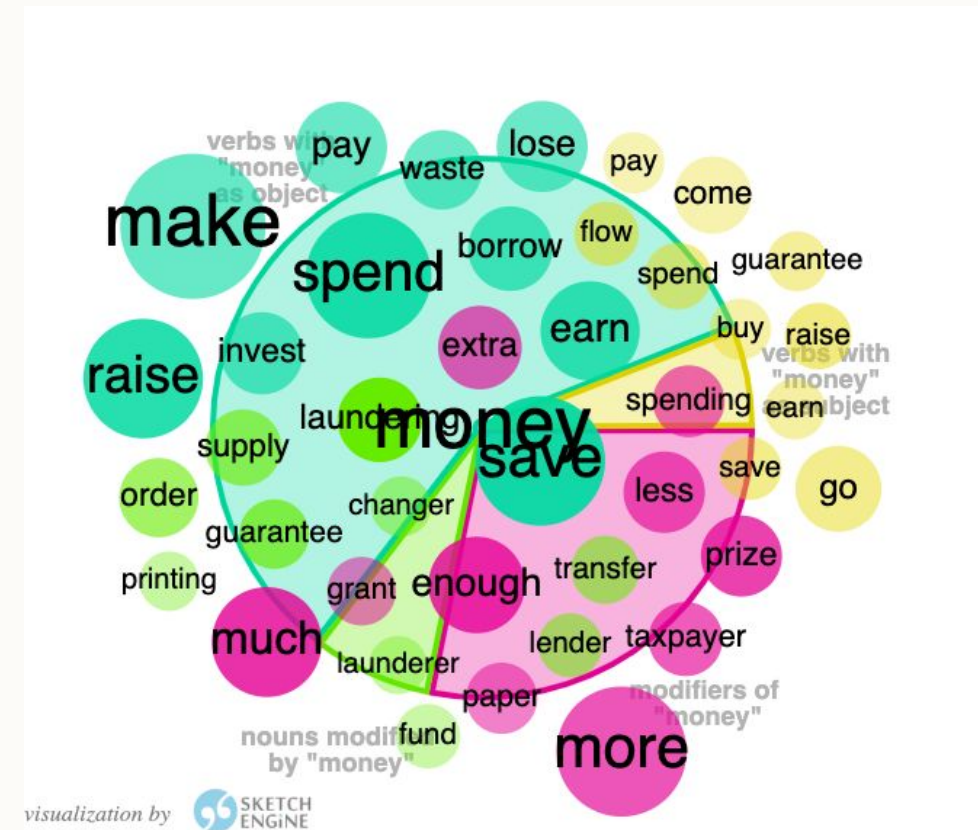
Survey questions open text

Q3.   Do you agree with this statement: Having access to trustworthy information from this organisation helps me manage my health? Tell us more about your answer.

Q4.   What difference has access to this organisation's health information made to you personally?

Q6.   What type of health information do you prefer? Please select up to three options. Tell us more about your answer.

Q7.   Tell us more about the sources of health information you find most useful.

Q8.   Have you been able to get a GP or hospital appointment in an acceptable time? Tell us more about your answer.

Q9.   Have you tried to find information before making an appointment with a GP or waiting for a hospital appointment?

Q10. Has a health professional such as doctor, nurse or pharmacist given you health information? Tell us more about your answer.

Q11. To what extent do you agree or disagree with each of the following statements about your relationship with most healthcare professionals? Tell us more about your answer.

Q13. How would seeing trust or credibility marks affect your trust in a source of information? Examples are PIF TICK, Orcha and YouTube HealthShelf. Tell us more about your answer.

Q14. To what extent do you agree or disagree with each of the following statements about online health misinformation? Please think about health information you may find on social media as well as websites. Tell us more about your answers.

Q15. Do you think you have been harmed by misinformation about your health?

Free text survey data

- Scleroderma and Raynaud's UK (SRUK) **only**: 12,345 words free text

Which organisation shared this survey?		
Answer Choices	Responses	
Anthony Nolan	1.91%	4
Asthma + Lung UK	16.27%	34
Cognitant (healthinote)	0.48%	1
CoppaFeel!	2.39%	5
EIDO Healthcare	0.00%	0
Macmillan	0.48%	1
National Rheumatoid Arthritis Society (NRAS)	6.22%	13
Patient Information Forum (PIF)	5.74%	12
Royal College of Anaesthetists	0.00%	0
Scleroderma & Raynaud's UK (SRUK)	**65.55%**	**137**
Tommy's	0.96%	2
	Answered	209
	Skipped	2

Which organisation shared this survey?
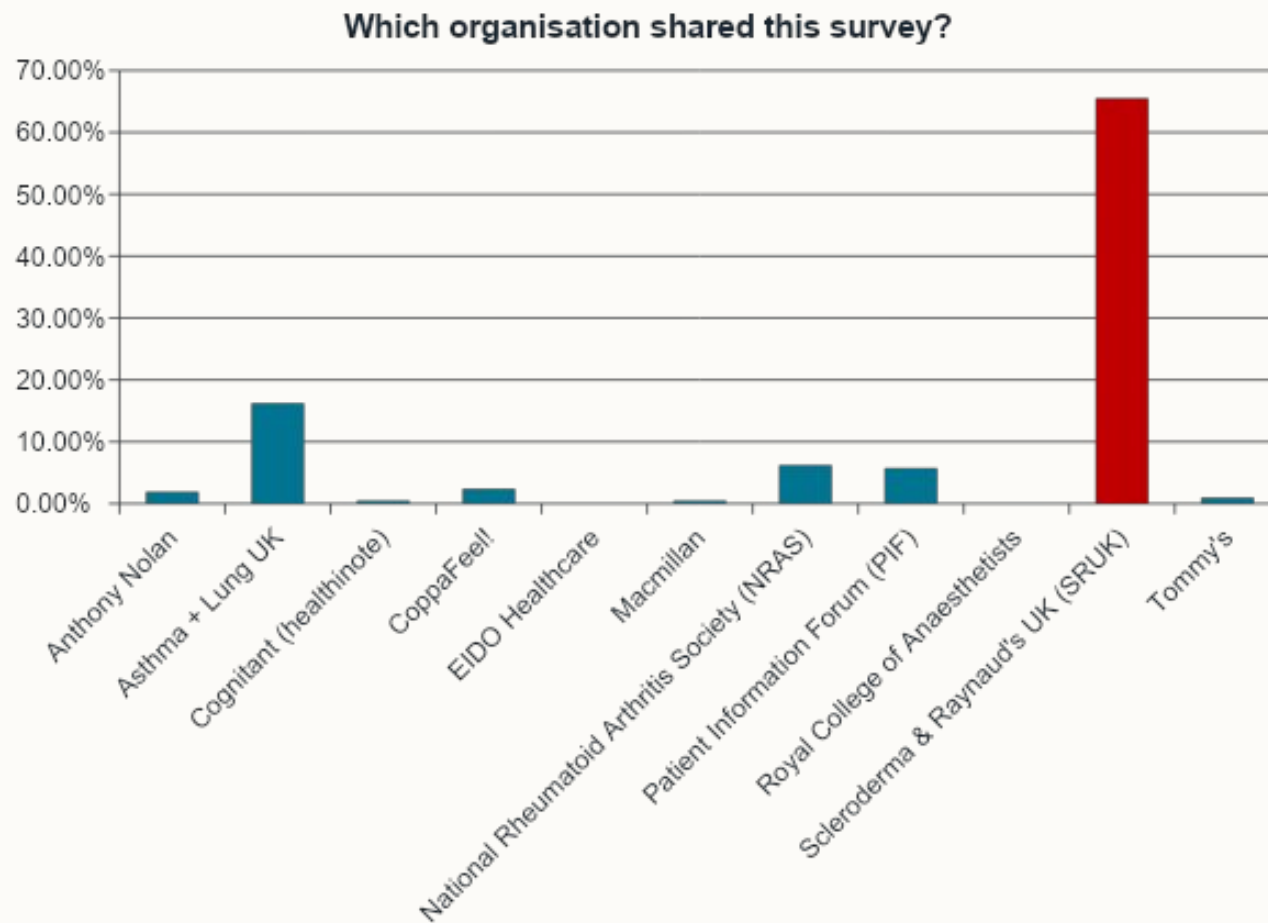
Most frequent words in the responses

	Lemma	Frequency		Lemma	Frequency		Lemma	Frequency		Lemma	Frequency		Lemma	Frequency
1	i	634	11	it	163	21	that	99	31	from	65	41	only	49
2	be	574	12	information	159	22	condition	85	32	very	63	42	give	49
3	to	466	13	for	137	23	about	83	33	feel	62	43	so	48
4	and	339	14	with	120	24	can	83	34	consultant	60	44	this	48
5	the	297	15	in	116	25	appointment	83	35	by	54	45	find	48
6	have	288	16	as	112	26	but	82	36	more	53	46	time	47
7	a	283	17	gp	112	27	get	79	37	see	52	47	no	47
8	my	260	18	me	110	28	or	75	38	other	52	48	website	46
9	not	199	19	do	103	29	know	70	39	up	51	49	nhs	45
10	of	188	20	on	103	30	help	69	40	trust	50	50	at	44

⬜ **'trust', 'feel', 'information'**

Collocates of 'trust' 3L-3R

	Lemma	Cooccurrences ?	Candidates ?	T-score	MI	LogDice ↓	
1	☐ source	8	27	2.79	6.32	11.73	⋯
2	☐ can	11	83	3.22	5.16	11.40	⋯
3	☐ site	5	26	2.19	5.69	11.07	⋯
4	☐ would	4	32	1.94	5.07	10.64	⋯
5	☐ I	31	601	5.17	3.79	10.61	⋯
6	☐ that	7	99	2.51	4.25	10.59	⋯
7	☐ medium	3	18	1.69	5.49	10.50	⋯
8	☐ information	9	157	2.81	3.95	10.48	⋯
9	☐ social	3	20	1.69	5.33	10.46	⋯
10	☐ you	4	44	1.92	4.61	10.45	⋯

	Lemma	Cooccurrences ?	Candidates ?	T-score	MI	LogDice ↓	
11	☐ website	4	45	1.92	4.58	10.43	⋯
12	☐ any	3	24	1.68	5.07	10.38	⋯
13	☐ use	3	42	1.64	4.26	10.06	⋯
14	☐ only	3	49	1.63	4.04	9.96	⋯
15	☐ on	4	103	1.81	3.39	9.74	⋯
16	☐ do	4	103	1.81	3.39	9.74	⋯
17	☐ from	3	65	1.59	3.63	9.74	⋯
18	☐ the	9	297	2.63	3.03	9.73	⋯
19	☐ of	6	188	2.16	3.10	9.69	⋯
20	☐ .	13	475	3.12	2.88	9.66	⋯

Rows per page: 20 ▾ 1–20 of 29 |< < 1 /2 > >|

☐ **'source'** (8), **'can'** (10), **'site'** (5), **'would'** (3), **'information'** (9), **'social'** (3), **'website'** (4)

trust+

Importance of trusted sources recognised

- 'I think knowing you **can trust** a **source** of info is only a good thing as you will go back to that source and use it to be informed about your health'

- 'Therefore it's extremely helpful to have as much information as possible from a **source** you can **trust**'

- 'There's so much false information out there is good to know I **can trust** any **information** that is posted'

- 'I look for **information** I **can trust** that comes from a good [source] and I can research at home'

- 'it's extremely helpful to have as much information as possible from a **source** you **can trust**'

- 'There is a lot of scaremonger article out there I prefer to go to **sites** I **can trust**'

- 'I like that the information I get is from a **trusted source**'

Difficulties finding trusted sources

- 'Again, the rarity of the disease limits **trusted sources**'

- 'It's not easy to get **information** you can **trust**'

trust+

Charity and NHS are trusted sources

- 'I need to be able to **trust** the **information** I'm reading, so tend to limit my sources of information to those linked to the NHS or my own GP practice'

- 'Again **trusted websites** I like to be able to listen to varied sources of information and then make a decision on a factual basis ie SRUK'

- 'I follow SRUK, SRF, WHO and other organisations I **trust** on **social** media as they often give me the most up to date information'

- 'I usually go via SRUK or NHS' wouldn't ever go to a patient website, but on the whole **would trust** a charity **website**'

- 'Useful **source** of **trusted information** and advice to supplement the info provided by rheumatologist'

- 'Usually check **trusted sources** eg SRUK as I know that most GPs know little about scleroderma'

- 'It's **information** I can **trust** and rely on' | 'It **can** be **trusted**'

- 'I **trust** the **information** I get from this organisation'

- 'These are more **trusted sources** of **information**'

- 'If it's the NHS I **would trust** that & patient forum'

- 'I only use **trusted** web **sites**'

trust+

Difficulties trusting social media

- 'I prefer **trusted sites** for **information** and take **social** media references with a pinch of salt although that are useful for conversations'

- 'Social media posts are a definite no because they **can** not be **trusted** and I've no wish to know what other patients think or do'

- 'Not that interested in finding info from social media, as I don't feel I **can trust** it'

- 'I don't think I **would trust** anything on YouTube as I've seen some "doubtful" items on it'

- 'I don't **trust** any **social** media with regard to health information'

- 'On the whole, I don't **trust social** media'

Importance of trusted websites recognised

- 'There is a lot of scaremonger articles out there I prefer to go on **sites** I can **trust** and have more in depth resources and research that I can trust as my condition is seem[ing]ly rare'

- 'There's a lot of information online but it's good to have a **trusted** UK **site**'

- 'Always inform myself as good as I can and I use **trusted** web **sites**'

- '**Trusted** online UK **websites** and SRUK magazine'

- 'Always look at my **trusted websites**'

Collocates of 'feel' (3L-3R)

	Lemma	Cooccurrences ?	Candidates ?	T-score	MI	LogDice ↓	
1	alone	8	18	2.80	6.59	11.68	...
2	I	45	601	6.30	4.02	11.12	...
3	less	5	12	2.21	6.50	11.11	...
4	do	11	103	3.17	4.53	11.09	...
5	that	10	99	3.02	4.45	10.99	...
6	me	10	110	3.00	4.30	10.90	...
7	they	6	42	2.37	4.95	10.88	...
8	make	5	29	2.18	5.23	10.81	...
9	isolate	3	4	1.72	7.35	10.54	...
10	longer	3	7	1.71	6.54	10.48	...

	Lemma	Cooccurrences ?	Candidates ?	T-score	MI	LogDice ↓	
11	listen	3	15	1.69	5.44	10.32	...
12	not	10	199	2.87	3.45	10.29	...
13	sometimes	3	17	1.69	5.26	10.28	...
14	no	4	47	1.89	4.21	10.23	...
15	.	19	475	3.86	3.12	10.18	...
16	like	3	25	1.67	4.70	10.14	...
17	very	4	61	1.86	3.83	10.06	...
18	and	13	339	3.17	3.06	10.05	...
19	be	18	574	3.62	2.77	9.86	...
20	more	3	53	1.59	3.62	9.74	...

Rows per page: 20 ▼   1–20 of 31 |<   <   1 / 2   >   >|

☐ **'alone'** (8), **'isolate'** (3), **'listen'** (3)

feel +listen (3) +alone (8) +isolate (3)

Feeling let down by medical professionals

- 'Don't **feel listened** to or respected, especially if I ask about what they've said, they seem to to feel I'm arguing with them'

- 'The whole process is long-winded, I don't **feel listened** to or have satisfactory answers & end up giving up'

- '…I didn't have a consultant as mine retired after 1st meeting so I **feel** very **alone**'

- cf.: 'I definitely **feel listened** to by my consultant'

Charity helped them to feel less alone

- 'Realising that lots of people suffer with my condition and lots of them are worse than me do not **feel alone** with this condition, and get the latest research'

- 'Made me **feel** less **alone**' x2; 'Makes you **feel** less **alone**'

- 'I no longer **feel isolated** having and official source for information'

- 'I no longer **feel isolated**, and know I can contact them if I need to'

- 'I don't **feel alone**, and the affect (sic) on my life is recognised'

- 'their emails help me **feel** less **alone**'

- 'Not **feeling alone**'

- 'I **feel** less **isolated**'

Collocates of 'information' 3L-3R

	Lemma	Cooccurrences	Candidates	T-score	MI	LogDice
1	from	17	65	3.94	4.47	11.28 ···
2	the	30	297	4.84	3.10	11.07 ···
3	and	32	339	4.95	3.00	11.04 ···
4	give	13	49	3.44	4.49	11.00 ···
5	I	46	601	5.73	2.69	10.95 ···
6	.	37	475	5.16	2.72	10.90 ···
7	of	20	188	3.98	3.17	10.88 ···
8	get	13	79	3.35	3.80	10.81 ···
9	on	14	103	3.42	3.52	10.77 ···
10	to	33	466	4.79	2.58	10.76 ···

	Lemma	Cooccurrences	Candidates	T-score	MI	LogDice
11	about	12	83	3.18	3.61	10.67 ···
12	trust	10	50	2.98	4.08	10.61 ···
13	it	15	163	3.38	2.96	10.58 ···
14	be	34	574	4.67	2.33	10.57 ···
15	can	11	83	3.02	3.49	10.54 ···
16	provide	8	20	2.74	5.08	10.52 ···
17	in	12	116	3.07	3.13	10.48 ···
18	source	8	27	2.72	4.65	10.46 ···
19	online	8	27	2.72	4.65	10.46 ···
20	health	8	34	2.69	4.32	10.41 ···

Rows per page: 20 ▾   1–20 of 74 |< < 1 /4 > >|

☐ **'give'** (12), **'get'** (13), **'trust'** (9), **'provide'** (6), **'source'** (8), **'online'** (7), **'health'** (7)

Information+

Professionals did not give (reliable) information

- 'None of these professionals seem to be able to **give information**'
- 'Having worked in the NHS for 40 years, I do not trust any of them or their knowledge or **information** they **give**'
- 'I was diagnosed with two conditions I know nothing about and **given** no **information** about them'
- 'Sometimes doctors **give** incorrect **information** or don't know about the illness so nothing is that reliable'
- 'I was told for several years to "deal with it" instead of **giving** my **information** and treatment'
- 'Doctor useless in **providing information**'
- 'No **information given**'

Cannot access medical appointments / medical care and support

- 'I work in the hospital environment as an Ambulance ICA and can **get information** from Dr's (sic), however I find it almost impossible to talk to my GP as I can never get an appointment, or the doctors are locums'
- 'The **information** I **get** is very helpful, but I am still lacking help from my medical professional, as my GP's (sic) do not understand it'
- 'I can **get information** about symptoms and management but unable to get GP support...'
- 'I never **get** any **information** back and I don't get much support or follow ups'

Information+

NHS and charities are trusted sources providing quality, detailed information

- 'I need to be able to trust the information I'm reading, so tend to limit my **sources** of **information** to those linked to the NHS or my own GP practice'
- 'SRUK **provide** very helpful **information** which means I am and I feel very knowledgeable about my current symptoms and the likely development'
- 'I now have a **source** of **information** about Ryanair's (sic) which I didn't have before as I haven't officially been diagnosed with it'
- 'It was great to speak to someone in the first instance and get advice that isn't always covered by medical **information online**'
- 'It has **given** me more **information** and also makes you realise that there are other people out there with similar problems'
- 'I would not rely on any **source** of **information** other than the NHS or recognised charities supporting conditions'
- 'Especially the seminars that SRUK organise which **give** more indepth (sic) **information** on specific topics'
- 'I used **online information** from the nhs but that's how I learned about my disease'
- 'These are more trusted **sources** of **information**'

Importance of getting reliable, trustworthy information recognised

- 'I **get information** I can use now and later when my regards [sic] gets worse, which it is doing'
- 'It's the content of the **health information** rather than the format that I find important'
- '**Getting** the right **information** allows me to know what will help me'
- 'I like that the **information** I **get** is from a trusted source'
- 'it is good being able to **get** reliable factual **information**'
- 'I'm careful who and where I **get** my **information** from'

information+

Information does not help to 'manage health' even if useful/trustworthy

- 'I feel the **information** they **give** is trustworthy but I don't think it assists me to manage my health as I rely on my GP and consultant to do that'
- 'I agree it **provides information** which is useful, but it doesn't affect how I manage my health'

Relevance of information

- 'I trust the **information** I **get** from this organisation, but it isn't always relevant to my situation, therefore only helps to a degree'
- 'Scleroderma is a broad spectrum disease so I **get** my **information** from a variety of resources'

Varied sources of information preferred

- I like to be able to listen to varied **sources** of **information** and then make a decision on a factual basis ie SRUK
- There's a lot of **information online** but it's good to have a trusted UK site
- Many medical **information sources**

Difficulties finding information online

- It's sometimes hard to find the right **information online**
- There's a lot of **information online** regarding health

Reluctance to search online for information

- I would NEVER search for health **information online**
- I probably don't indulge enough in health **information online** to be helpful here with my answers

Thank you

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