

ARCHANGELS + Susannah Fox Rare Disease Survey

OVERVIEW

This study was conducted by SSRS on its Opinion Panel Omnibus platform. The SSRS Opinion Panel Omnibus is a national, twice-per-month, probability-based survey. Data collection was conducted on two waves of the omnibus, from January 17 to January 21, 2025 and from February 7 to February 10, 2025, among a total sample of $N = 2,012$ respondents. The survey was conducted via web ($n = 1,952$) and telephone ($n = 60$) and administered in English ($n = 2,012$). More information about the SSRS Opinion Panel can be found at www.ssrs.com.

All SSRS Opinion Panel Omnibus data are weighted to represent the target population of U.S. adults ages 18 or older. The margin of error for total respondents is +/- 2.6 percentage points at the 95% confidence level.

NOTES ABOUT RESULTS

Because percentages are rounded, they may not total 100%. An asterisk (*) indicates less than 0.5%.

Data collection was conducted via web and telephone. Verbiage in this topline reflects web wording. Telephone wording may differ slightly due to interviewer-administered data collection.

CARE3. Now thinking about your own healthcare, in the past 12 months, how many times, if any, have you...?
 [ITEMS ASKED IN RANDOM ORDER]

	Have not done this in the past 12 months	1-2 times	3-6 times	7 or more times	DK/Ref	Total have done this in past 12 months
a. Seen a doctor or other health care provider, such as a specialist, in their office or health care clinic						
Total (2012)	22	40	29	10	0	78
Rare Disease HH (180)	21	32	28	19	0	79
b. Seen a mental health professional or therapist in their office or health care clinic						
Total	80	10	6	4	*	20
Rare Disease HH	72	16	7	4	0	28
c. Seen a doctor or other health care provider, such as a specialist, online or via a telehealth appointment						
Total	54	31	11	4	*	46
Rare Disease HH	37	41	15	7	0	63
d. Seen a mental health professional or therapist online or via a telehealth appointment						
Total	81	9	5	4	0	19
Rare Disease HH	71	14	8	7	0	29
e. Used an AI tool such as ChatGPT or Gemini to learn about a health condition or treatment options						
Total	77	14	5	4	*	23
Rare Disease HH	62	24	7	7	0	38
f. Gone online to find other people who might have health concerns similar to yours						
Total	62	22	11	6	0	38
Rare Disease HH	50	24	18	9	0	50

(People who went online to find others with similar health concerns, n=770)

CARE4. Were you successful in finding people online with health concerns similar to yours?

Total		Rare Disease HH
83	Yes	80
17	No	20
0	Dk/Ref	0
(770)		(90)

CARE3f/CARE4 COMBO TABLE

Total		Rare Disease HH
38	Total looked online for someone with similar health concerns in past 12 months	50
32	Successful	40
7	Not successful	11
62	Total did not look online for someone with similar health concerns	50
0	Dk/Ref	0
(2012)		(180)

CARE5. Have you, or has anyone in your household, ever been told by a doctor or other health professional that you (or they) have a rare disease? A rare disease is one that affects fewer than 200,000 people in the U.S..

Total	
8	Yes
92	No
*	Dk/Ref
(2012)	

(No one in HH diagnosed with rare disease, n=1832)

CARE6. Are you, or is anyone in your household, currently experiencing an illness that doctors or other health care professionals have not been able to diagnose?

Total	
8	Yes
92	No
0	Dk/Ref
(1832)	

CARE5/CARE6 COMBO TABLE

Total	
15	Total rare disease or undiagnosed HH
85	Total not rare disease or undiagnosed HH
(2012)	