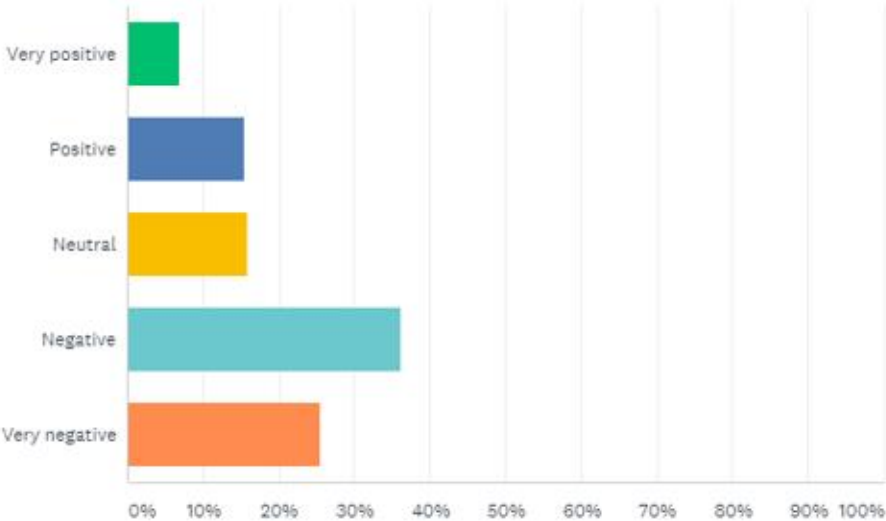


# “My Medical Insurance Story” – survey results

This story is about an experience that is

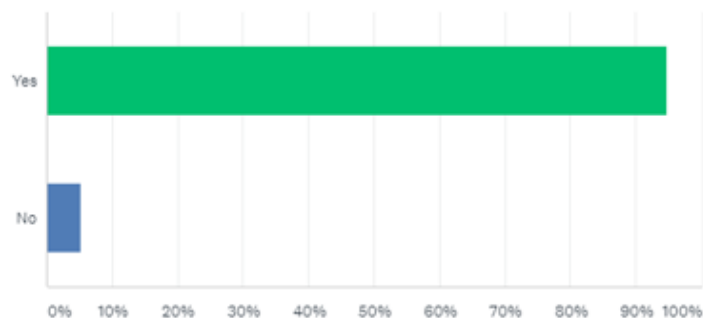
Answered: 188 Skipped: 0



ANSWER CHOICES	RESPONSES
Very positive	6.91% 13
Positive	15.43% 29
Neutral	15.96% 30
Negative	36.17% 68
Very negative	25.53% 48
<b>TOTAL</b>	<b>188</b>

## Do you have a diagnosis of either ME or CFS?

Answered: 188 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	94.68%	178
No	5.32%	10
<b>TOTAL</b>		<b>188</b>

### Key Issues

Responses could include more than one factor, so percentages add to more than 100%.

Survey Results (N=185)	N	%	Comments
<b>ACCESS TO CARE</b>			
No Access to ME/CFS providers	37	20.0%	"I have not found a provider who says ME/CFS is real and they will not treat it." "The specialist who covers ME/CFS is a psychiatrist who treats it as a psychosomatic illness."
No coverage for ME/CFS specialists	38	20.5%	"They refuse an outside referral, there is nothing that can be done for you." "The doctors who know anything about ME/CFS are out of network and my insurance pays zero for them."
No coverage for diagnostic tests	22	11.9%	"None of the costs for diagnosis were covered." "They refuse to schedule testing my specialist ordered." "Insurance doesn't cover recommended tests by my doctor."
Stigma ME/CFS affected my care	52	28.1%	"I have been traumatized by the way doctors have treated me." "The only referral I could get was to a psychiatrist."

			“Insurance concluded that ME/CFS does not exist so I was denied coverage.”
None/limited coverage for drugs MD prescribed	50	26.5%	“Medicines are denied.” “They do not cover any compounded drugs.” “Insurance refuses to pay any drugs if it is coded for ME/CFS.”
Drugs are too expensive	16	8.1%	“Cannot afford my medicines.” “The cost for one drug after insurance is \$2000/month.” “I had to pay for my medications myself so I stopped taking them.”
<b>CARE COSTS</b>			
Insurance is very expensive	13	7.0%	“Unaffordable premiums.” “I could no longer afford it.”
Out of pocket costs are too high	29	15.7%	“High deductible, I did not seek medical care I needed.” “They have raised the deductible higher and higher.” “Over half of my husband’s gross income goes to medical care for me.”
Out of network costs are too expensive	9	4.9%	“They have raised the out-of-network deductible higher and higher that we never hit it. “
No coverage for alternative care or supplements	12	6.5%	“I have spent many thousands of dollars for CFS/ME specialists or alternative treatments that aren't covered by conventional insurance, even when proven to work.” “I take close to \$300 a month in supplements to be able to function a few hours a day and none of these are covered by insurance.”
Insurance is generally OK	59	31.9%	“I have pretty good coverage but the premiums are very high.”
Work-related disability insurance coverage stopped/ threatened	10	5.4%	“Numerous times they have stopped my benefits without justification.” “I was warned if there was anything psychiatric about my condition I would not receive benefits.”