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***CURE/NexCura Health Literacy Survey***  
August 2009

<b>Are you a patient or a caregiver? (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
I am a patient	538	100
I am a family member or friend of a patient	0	0
None of the above	0	0

<b>What is your age? (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
Under 18	0	0
18 - 29	2	0
30 - 39	15	3
40 - 49	102	19
50 - 59	218	41
60 - 69	164	30
70 - 79	34	6
80 or older	3	1

<b>What is your gender? (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
Male	165	31
Female	373	69

<b>Which of the following best describes you? (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
I am currently undergoing treatment for cancer	202	38
I completed cancer treatment within the past 12 months	192	36
I completed cancer treatment more than 1 year ago, but less than 2 years ago	113	21
I completed cancer treatment 2 or more years ago, but less than 3 years ago	31	6
I completed cancer treatment 3 or more years ago	0	0

<b>With which cancer(s) were you diagnosed? (check all that apply) (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
Breast	306	57
Colorectal	32	6
Lung	46	9
Melanoma	15	3
Ovarian	17	3
Prostate	128	24
Other (please specify)	23	4
<b>When were you initially diagnosed with cancer? (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
Less than 1 month ago	3	1
1 - 5 months ago	54	10
6 - 11 months ago	137	25
1 - 2 years ago	259	48
More than 2 years ago, up to 3 years ago	85	16
More than 3 years ago	0	0

<b>When you were first diagnosed, did your doctor explain the type of cancer you had in a clear and understandable way? (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
Yes	476	88
No	52	10
I don't remember	10	2

<b>Following the initial meeting when you were given your diagnosis, which of the following best represents your understanding? (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
I understood my diagnosis clearly enough to explain it to others	388	72
I understood my diagnosis a little, but not enough to feel comfortable explaining it to others	95	18
I did not understand my diagnosis	5	1
I thought I understood my diagnosis, but over time I realized that I did not	50	9

<b>Did your doctor give you a copy of your pathology report and explain what each section meant? (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
Yes	293	54
No	221	41
I don't remember	24	4

<b>Did your doctor give you additional information, resources, and/or a referral to a patient educator or navigator to help you understand your diagnosis? (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
Yes	297	55
No	228	42
I don't remember	13	2

**What type of information and/or resources were you given? Please indicate how helpful each information or resource was.**

<b>Written materials (educational brochures and drawings) (N = 297)</b>	<b>Count</b>	<b>Percentage</b>
Very helpful	190	64
Somewhat helpful	86	29
Not helpful	5	2
Didn't use	16	5

<b>Video/DVD (N = 297)</b>	<b>Count</b>	<b>Percentage</b>
Very helpful	31	10
Somewhat helpful	21	7
Not helpful	6	2
Didn't use	239	80

<b>Internet sites (N = 297)</b>	<b>Count</b>	<b>Percentage</b>
Very helpful	174	59
Somewhat helpful	74	25
Not helpful	2	1
Didn't use	47	16

<b>Referral to a person, such as a patient educator or navigator (N = 297)</b>	<b>Count</b>	<b>Percentage</b>
Very helpful	92	31
Somewhat helpful	48	16
Not helpful	12	4
Didn't use	145	49

<b>Did your doctor explain your options for treatment using language you understood? (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
Yes	490	91
No	42	8
I don't remember	6	1

<b>Did your doctor inform you about the possible side effects of a specific treatment? (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
Yes	442	82
No	84	16
I don't remember	12	2

<b>Did your doctor clearly explain the possible risks and the possible benefits of a specific treatment? (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
Yes, and I understood the information clearly	300	56
Yes, and I somewhat understood the information	154	29
Yes, but I still did not understand the information	22	4
No, my doctor did not clearly explain the risks and benefits of treatment	57	11
I don't remember	5	1

<b>Did you ask questions when/if your doctor used words or phrases that were difficult to understand? (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
Yes	499	93
No	28	5
I don't remember	11	2

<b>Did your medical team offer you options for how you wanted them to communicate and deliver information to you regarding your diagnosis and treatment plan? Options may have included verbal information, written materials, and audio or video? (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
Yes	211	39
No	285	53
I don't remember	42	8

<b>Did you seek information regarding your diagnosis from a source other than your doctor? (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
Yes	511	95
No	26	5
I don't remember	1	0

**Which sources did you utilize to further understand your diagnosis and treatment?  
Please indicate how helpful each source was.**

<b>Internet (N = 511)</b>	<b>Count</b>	<b>Percentage</b>
Very helpful	378	74
Somewhat helpful	127	25
Not helpful	0	0
Didn't use	6	1

<b>Nonprofit groups (N = 511)</b>	<b>Count</b>	<b>Percentage</b>
Very helpful	151	30
Somewhat helpful	132	26
Not helpful	14	3
Didn't use	214	42

<b>Government organizations (N = 511)</b>	<b>Count</b>	<b>Percentage</b>
Very helpful	62	12
Somewhat helpful	104	20
Not helpful	30	6
Didn't use	315	62

<b>Patient educator / navigator (N = 511)</b>	<b>Count</b>	<b>Percentage</b>
Very helpful	78	15
Somewhat helpful	88	17
Not helpful	18	4
Didn't use	327	64

<b>Family / friends (N = 511)</b>	<b>Count</b>	<b>Percentage</b>
Very helpful	154	30
Somewhat helpful	192	38
Not helpful	62	12
Didn't use	103	20

<b>Support group (N = 511)</b>	<b>Count</b>	<b>Percentage</b>
Very helpful	53	10
Somewhat helpful	70	14
Not helpful	22	4
Didn't use	366	72

<b>Books / magazines / brochures (N = 511)</b>	<b>Count</b>	<b>Percentage</b>
Very helpful	221	43
Somewhat helpful	223	44
Not helpful	9	2
Didn't use	58	11

<b>At the time you were initially diagnosed, could you have explained to a friend or family member why your treatment plan was right for you? (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
Yes	360	67
No	147	27
I don't know	31	6

<b>Were you given the option to participate in a clinical trial? (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
Yes	141	26
No	386	72
I don't remember	11	2

<b>Did your doctor explain the purpose of clinical trials? (N = 141)</b>	<b>Count</b>	<b>Percentage</b>
Yes	125	89
No	10	7
I don't remember	6	4

<b>Did you understand what the clinical trial meant to you and your treatment plan? (N = 141)</b>	<b>Count</b>	<b>Percentage</b>
Yes	125	89
No	12	9
I don't know	4	3

<b>Did you participate in a clinical trial? (N = 141)</b>	<b>Count</b>	<b>Percentage</b>
Yes	63	45
No	78	55

<b>How well did you understand the risks of participating in the trial <i>before</i> you enrolled? (N = 63)</b>	<b>Count</b>	<b>Percentage</b>
I clearly understood the risks	46	73
I somewhat understood the risks	16	25
I did not understand the risks	1	2

<b>What is the highest level of education you have completed? (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
Less than high school	2	0
High school / GED	146	27
Associate degree	97	18
Bachelor's degree	157	29
Master's degree	107	20
Doctorate	29	5

<b>What is your native language? (N = 538)</b>	<b>Count</b>	<b>Percentage</b>
Chinese	0	0
English	527	98
French	1	0
Spanish	5	1
Tagalog	1	0
Other (please specify)	4	1