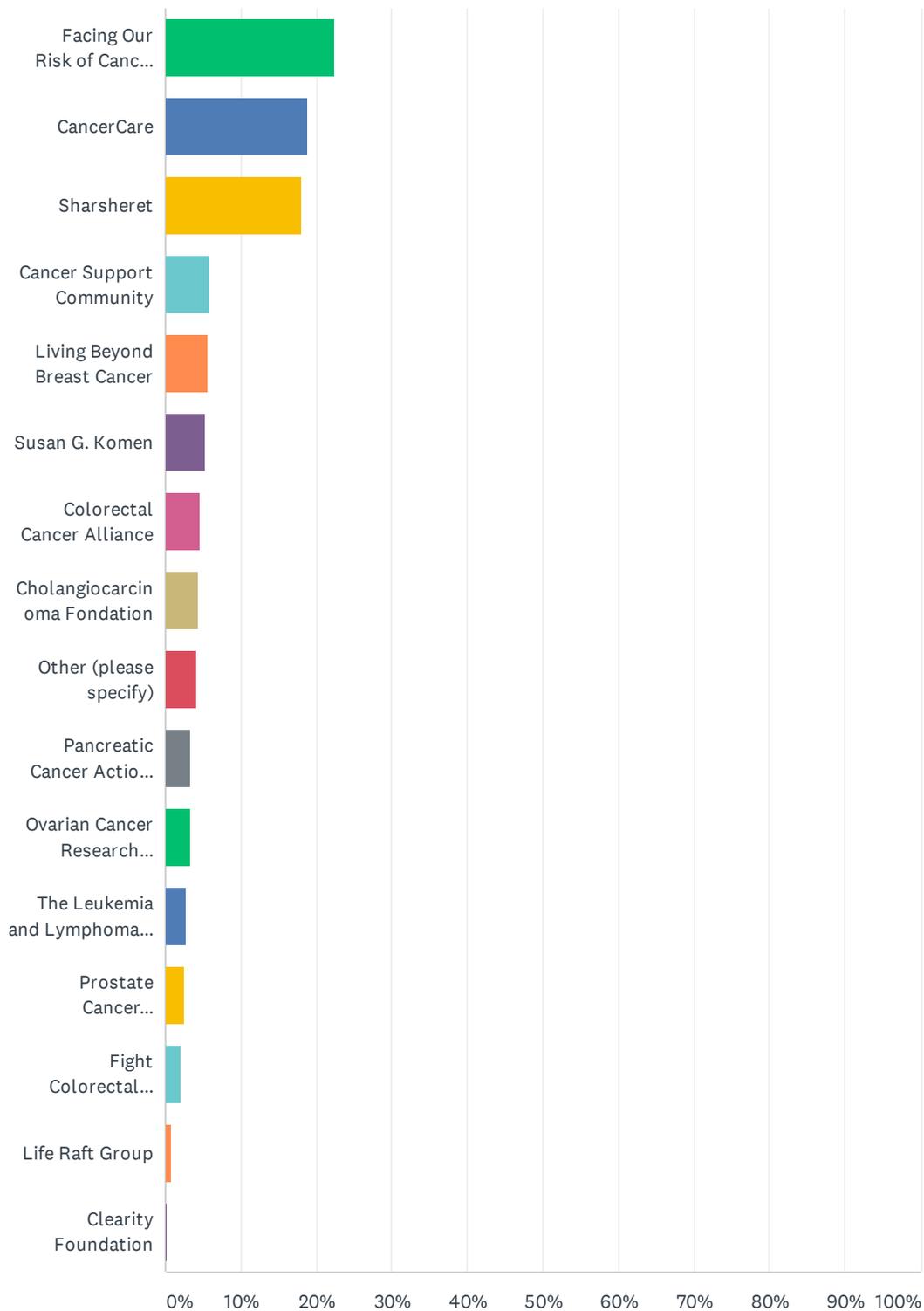


Q1 Did you learn about this survey through any of the organizations below? (please select all that apply)

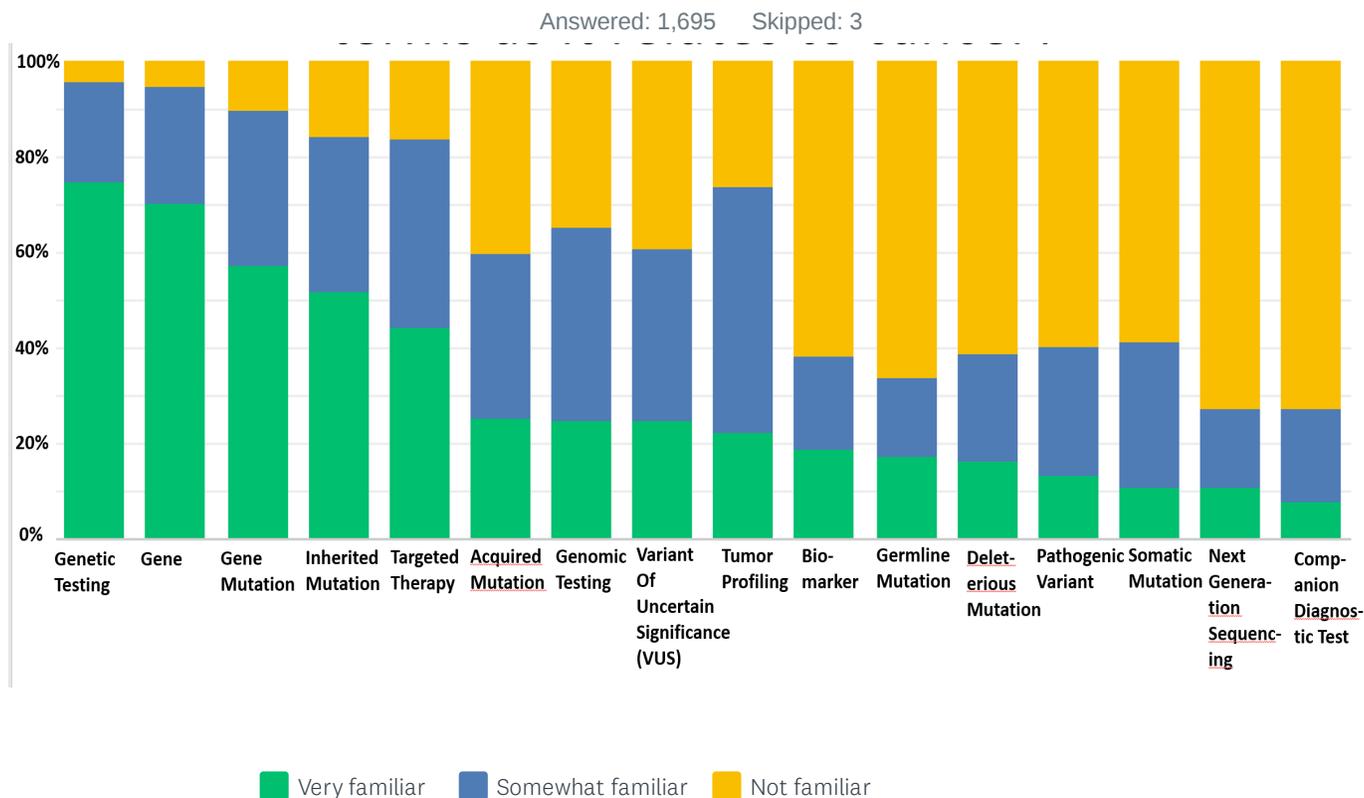
Answered: 1,690 Skipped: 8



Survey on terms used for "genetic testing"

ANSWER CHOICES	RESPONSES	
Facing Our Risk of Cancer Empowered (FORCE)	22.31%	377
CancerCare	18.76%	317
Sharsheret	17.99%	304
Cancer Support Community	5.86%	99
Living Beyond Breast Cancer	5.62%	95
Susan G. Komen	5.15%	87
Colorectal Cancer Alliance	4.67%	79
Cholangiocarcinoma Fondation	4.38%	74
Other (please specify)	4.14%	70
Pancreatic Cancer Action Network (PanCAN)	3.31%	56
Ovarian Cancer Research Alliance	3.31%	56
The Leukemia and Lymphoma Society	2.66%	45
Prostate Cancer Foundation	2.49%	42
Fight Colorectal Cancer	2.07%	35
Life Raft Group	0.89%	15
Clarity Foundation	0.12%	2
Total Respondents: 1,690		

Q2 How familiar are you with each of the following terms as it relates to cancer?

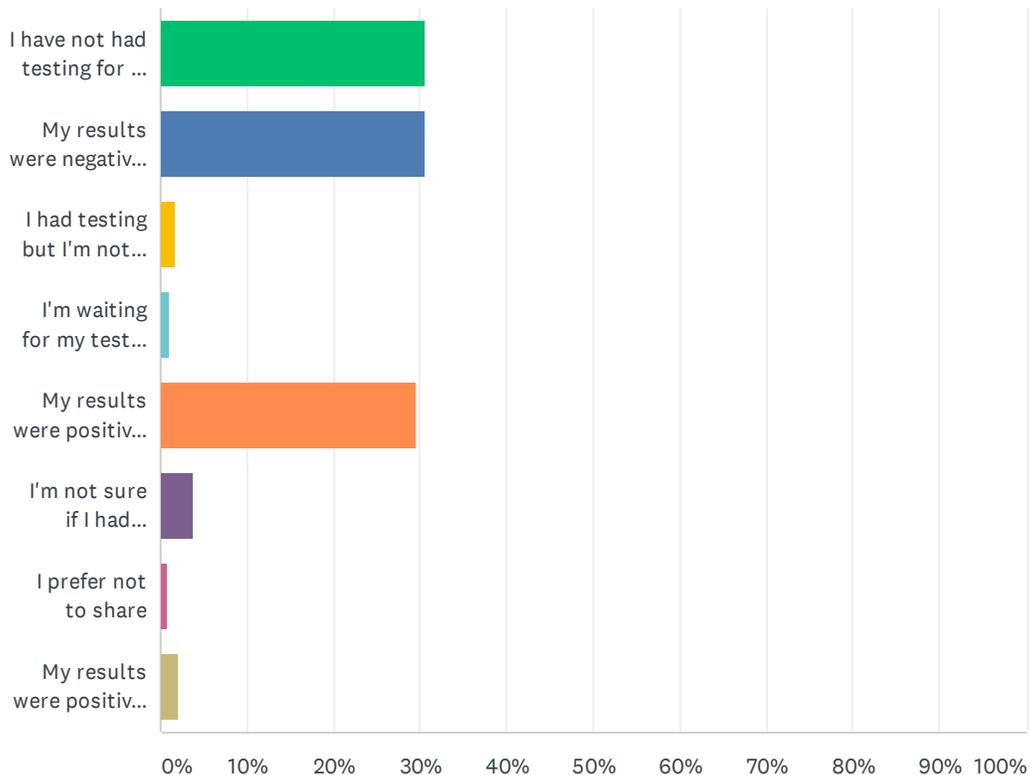


Survey on terms used for "genetic testing"

	VERY FAMILIAR	SOMEWHAT FAMILIAR	NOT FAMILIAR	TOTAL
Genetic testing	74.79% 1,261	21.23% 358	3.97% 67	1,686
Gene	70.69% 1,184	24.42% 409	4.90% 82	1,675
Gene mutation	57.43% 966	32.40% 545	10.17% 171	1,682
Inherited mutation	52.11% 877	32.56% 548	15.33% 258	1,683
Targeted therapy	44.45% 749	39.64% 668	15.91% 268	1,685
Acquired mutation	25.66% 429	34.45% 576	39.89% 667	1,672
Tumor profiling	24.84% 416	40.72% 682	34.45% 577	1,675
Genomic testing	24.78% 415	36.06% 604	39.16% 656	1,675
Biomarker	22.72% 374	51.40% 846	25.88% 426	1,646
Variant of Uncertain Significance (VUS)	19.19% 321	19.55% 327	61.27% 1,025	1,673
Deleterious mutation	17.31% 290	16.66% 279	66.03% 1,106	1,675
Germline mutation	16.37% 273	22.60% 377	61.03% 1,018	1,668
Pathogenic variant	13.75% 229	26.89% 448	59.36% 989	1,666
Next generation sequencing	11.13% 185	30.45% 506	58.42% 971	1,662
Somatic mutation	11.04% 185	16.24% 272	72.72% 1,218	1,675
Companion diagnostic test	8.00% 134	19.51% 327	72.49% 1,215	1,676

Q3 Tests can find gene changes (called mutations) that a person may be born with. These changes are called "germline" or "inherited" gene mutations. They can be passed from fathers or mothers to their sons and daughters. Some inherited gene changes increase risk for cancer, and can cause cancer to run in families. Have you had testing for an inherited gene mutation linked to cancer? If so, what were your test results?

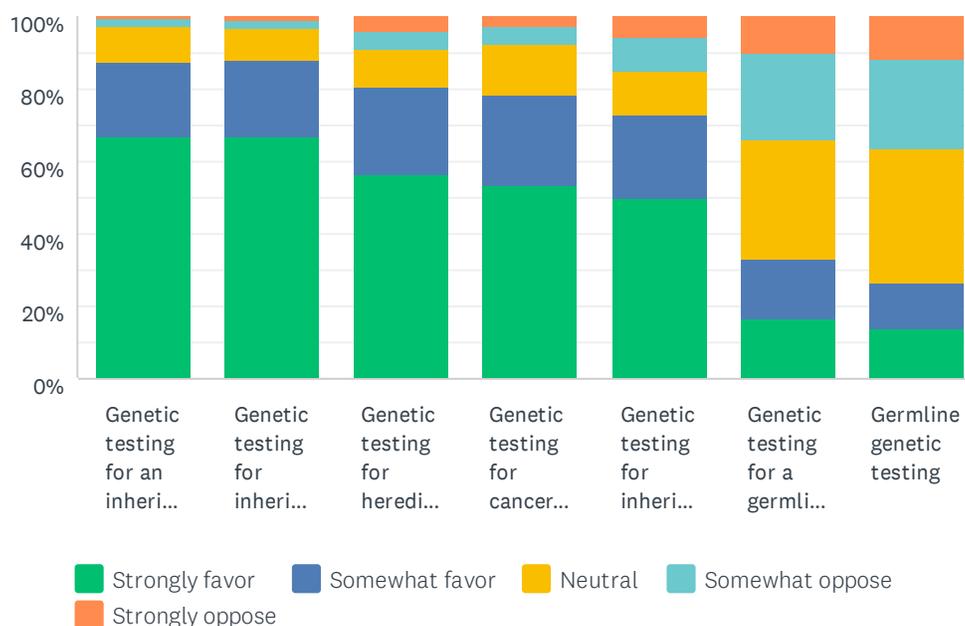
Answered: 1,688 Skipped: 10



ANSWER CHOICES	RESPONSES	
I have not had testing for an inherited mutation	30.63%	517
My results were negative for any inherited mutation	30.63%	517
I had testing but I'm not sure what my test results were	1.66%	28
I'm waiting for my test results	0.95%	16
My results were positive for an inherited mutation	29.56%	499
I'm not sure if I had genetic testing for an inherited mutation	3.67%	62
I prefer not to share	0.77%	13
My results were positive for an inherited mutation and a variant of uncertain significance (VUS)	2.13%	36
TOTAL		1,688

Q4 The term "genetic testing" is very general and can be used to describe different types of tests. This can lead to confusion among patients and their health care providers. Adding terms like "germline" or "inherited" may help distinguish tests used to learn if a person has an inherited gene mutation that is linked to cancer risk. If organizations can agree to use one term for the same test, this may reduce confusion. The groups that developed this survey want to help patients communicate with their doctors to get the right tests and treatments for them. In order to find a common term we can use, we are exploring which terms most people find more or less acceptable and clear. Please rate your feelings about the following terms used to describe genetic testing for an inherited mutation on a scale from "strongly favor" to "strongly oppose."

Answered: 1,687 Skipped: 11



Survey on terms used for "genetic testing"

	STRONGLY FAVOR	SOMEWHAT FAVOR	NEUTRAL	SOMEWHAT OPPOSE	STRONGLY OPPOSE	TOTAL
Genetic testing for an inherited mutation	67.07% 1,122	20.56% 344	9.92% 166	1.85% 31	0.60% 10	1,673
Genetic testing for inherited cancer risk	66.93% 1,115	21.01% 350	9.00% 150	2.04% 34	1.02% 17	1,666
Genetic testing for hereditary cancer	56.68% 946	23.85% 398	10.25% 171	5.27% 88	3.95% 66	1,669
Genetic testing for cancer risk	53.57% 893	24.96% 416	13.86% 231	5.34% 89	2.28% 38	1,667
Genetic testing for inherited cancer	50.00% 834	22.84% 381	12.29% 205	9.35% 156	5.52% 92	1,668
Genetic testing for a germline mutation	16.43% 273	16.67% 277	32.79% 545	23.95% 398	10.17% 169	1,662
Germline genetic testing	14.04% 233	12.60% 209	36.65% 608	25.32% 420	11.39% 189	1,659

Q5 Please share with us if you have a preferred term and why you prefer it (either one of the terms above or a different term not listed).

Answered: 883 Skipped: 815

Survey on terms used for "genetic testing"

#	RESPONSES	DATE
1	No objections to terminology ! "If you disagree with the logic, correct the grammar". Why would anyone question established terminology ?!	3/2/2020 12:50 AM
2	N/A	3/2/2020 12:49 AM
3	n/a	2/25/2020 7:18 PM
4	Genetic testing	2/25/2020 7:17 PM
5	Like including "inherited" and "risk." Hate germline. No average person will know what that means without a definition.	2/25/2020 7:14 PM
6	I like to keep things simple and clear. The easy to understand words. "Keep it Simple"	2/25/2020 7:13 PM
7	Inherited risk is easily understood	2/25/2020 7:12 PM
8	Don't have	2/25/2020 7:11 PM
9	Simpler is better.	2/25/2020 7:05 PM
10	Genetik testing For inherited mutation	2/25/2020 7:01 PM
11	I am a genetic counselor, so germline makes sense to me, but isn't a patient-friendly term	2/22/2020 12:40 AM
12	Genetic testing for cancer risk. Simple and to the point.....	2/21/2020 8:59 PM
13	I prefer "Genetic testing for inherited cancer risk" because it is clear and less threatening.	2/21/2020 7:59 PM
14	Better keep it simple, and not convey the false - and scary - impression that cancer is a certainty if mutation is present.	2/21/2020 7:02 PM
15	no	2/21/2020 4:13 PM
16	Genetic testing for cancer risk	2/21/2020 3:57 PM
17	Genetic testing is the most straight forward with the word risk since you don't know if you will get the cancer	2/21/2020 2:54 PM
18	No	2/21/2020 2:25 PM
19	inherited is my preference because it is the easiest term to understand and explain.	2/21/2020 2:21 PM
20	I think genetic testing for an inherited mutation is a more understandable, intuitive phrase that germline testing. Testing for "cancer risk" is less scary than testing for "inherited cancer," and, ultimately, if I am correct, the results indicate risk and not a definitive response as to whether or not one will be diagnosed with cancer.	2/21/2020 1:03 PM
21	none	2/21/2020 11:52 AM
22	Genetic testing for inherited cancer risk	2/21/2020 11:27 AM
23	na	2/21/2020 11:11 AM
24	I have none at this time.	2/21/2020 11:09 AM
25	Blank	2/21/2020 10:32 AM
26	I had the brca testing and I was negative	2/21/2020 10:28 AM
27	as noted above, the terms that contain everyday understandable words are preferable.	2/21/2020 10:24 AM
28	Genetic testing for hereditary cancer	2/21/2020 10:14 AM
29	Na	2/21/2020 9:52 AM
30	Genetic testing for inherited cancer risk	2/21/2020 9:24 AM
31	none	2/21/2020 8:58 AM
32	Adding "risk"	2/21/2020 8:23 AM
33	I like the incorporation of the word "risk" as it clarifies that you don't have the cancer, per se, but	2/20/2020 9:37 PM

Survey on terms used for "genetic testing"

	that the testing is for RISK of cancer as it relates to genetic inheritance.	
34	Generic testing for inherited cancer risk seems to be the least jargony term and doesn't suggest that the test is actually a test for cancer.	2/20/2020 9:27 PM
35	None	2/20/2020 9:18 PM
36	Genetic testing for an inherited cancer risk	2/20/2020 9:16 PM
37	Germline sounds as if it's related to a germ or pathology versus an inherited gene	2/20/2020 9:00 PM
38	clarity of meaning	2/20/2020 9:00 PM
39	n/a	2/20/2020 8:41 PM
40	inherited mutation	2/20/2020 8:33 PM
41	Genetic tessting	2/20/2020 8:29 PM
42	Genetic testing for an inherited mutation	2/20/2020 8:25 PM
43	None preferred	2/20/2020 8:24 PM
44	Cancer risk	2/20/2020 8:24 PM
45	Trying to keep terms as simple as possible so there is the most understanding as many people read at a 6th grade level	2/20/2020 8:23 PM
46	None	2/20/2020 8:15 PM
47	No preference on terms	2/20/2020 8:13 PM
48	Not really	2/20/2020 8:06 PM
49	Testing for an inherited gene mutation; to me that's what the testing is for	2/20/2020 8:02 PM
50	genetic testing for an inherited mutation -- keeps the stigma/fear factor out	2/20/2020 8:02 PM
51	Something with inherited in it cause it's clear that this is something outside my control and something I need to look for in my future generations	2/20/2020 7:54 PM
52	I like the wording that says "Genetic testing for..." It just seems like a more comprehensive name.	2/20/2020 7:45 PM
53	I think more people are going to understand the terms "genetic" and "inherited" than the term "germline."	2/20/2020 7:41 PM
54	Most people understand words like genetic or inherited not germline	2/20/2020 7:33 PM
55	The term Germline means nothing to me and I have a bs in chemistry. It isn't inherited cancer or hereditary cancer because often people have the mutation but don't get cancer - it isn't 100 percent chance.	2/20/2020 7:28 PM
56	I do genealogy, which has become very popular, as has the testing. Genetic testing for health risks needs to be clearly differentiated from "genetic testing" Further, the genetic testing for health reasons detects the genetic marker or defect, but only determines the risk of cancer. It is important that patients understand this, as well as the fact that the current testing may not give the entire picture. Words are very important - the reason for your survey. I have been encouraging people to get free BRCA testing from the BFOR study, and finding that there is a lack of information.	2/20/2020 7:21 PM
57	I have no idea none of these terms were mentioned to me.	2/20/2020 7:10 PM
58	Genetic testing for cancer risk is preferred. Clear and simple	2/20/2020 7:03 PM
59	Genetic testing	2/20/2020 7:00 PM
60	Genetic testing for inherited mutation or risk	2/20/2020 6:57 PM
61	it needs to be straight forward and simple	2/20/2020 6:53 PM
62	None	2/20/2020 6:45 PM
63	None, tell it like it is	2/20/2020 6:44 PM

Survey on terms used for "genetic testing"

64	Genetic testing for inherited cancer risk feels like the most accurate and clearest terminology.	2/20/2020 6:41 PM
65	I think using the terminology that most women are familiar with will cause less confusion	2/20/2020 6:37 PM
66	Genetic testing for inherited risk. Germ line is a dumb term that most people will not understand-I have a lot of experience with genetics and it is still confusing	2/20/2020 6:33 PM
67	None	2/20/2020 6:28 PM
68	None	2/20/2020 6:27 PM
69	Some of the terms seem more clear or obvious in their meaning.	2/20/2020 6:27 PM
70	I like adding the word "risk" at the end because the test does not determine if the person has the cancer. Genetic testing for cancer risk seems simple and clear as long as ppl understand what genetic means and that the test doesn't cover other risk factors for cancer.	2/20/2020 6:26 PM
71	Inherited genetic risk	2/20/2020 6:13 PM
72	Keep it very simple - testing for cancer risk makes sense because just because you have the mutation doesn't mean you'll develop the cancer	2/20/2020 6:09 PM
73	Genetic testing for inherited cancer risks. I think that terminology is more appropriate giving the fact that some cancer may be inherited, and thus pose an additional threat to a person's health.	2/20/2020 6:08 PM
74	Cancer risk is more correct. Having the gene does not his guarantee cancer	2/20/2020 6:05 PM
75	I most strongly prefer Germline Genetic Testing because it is a concise term and it does not infer that the presence of a particular gene mutation absolutely indicates the likelihood of developing a certain type of cancer. In my case, I was BRCA1/2 negative, but developed breast cancer at a young age and many people who didn't know any better asked me, "then what did you do to develop cancer so young?" And I would have to explain what these genes actually "mean" and that testing positive doesn't necessarily mean you will develop cancer, and testing negative doesn't necessarily mean that you won't.	2/20/2020 6:04 PM
76	No preference	2/20/2020 6:00 PM
77	genetic testing, because it says that you are testing the genes for cancer	2/20/2020 5:56 PM
78	Inherited mutation seems more specific and accurate than value- or emotion-laden terms such as inherited cancer or inherited risk	2/20/2020 5:43 PM
79	Needs to be short, succinct, and clear.	2/20/2020 5:39 PM
80	I don't really have a preference	2/20/2020 5:35 PM
81	Genetic testing	2/20/2020 5:32 PM
82	Na	2/20/2020 5:32 PM
83	Genetic testing has always been the norm	2/20/2020 5:30 PM
84	genetic testing for inherited diseases	2/20/2020 5:29 PM
85	Genetic testing for health risks	2/20/2020 5:27 PM
86	"genetic testing for an inherited mutation." Preferred as it does not use the word "cancer" and not all mutations necessarily lead to cancer.	2/20/2020 5:26 PM
87	Genetic testing is a familiar term so it is my preference.	2/20/2020 5:26 PM
88	Makes simpler to understand	2/20/2020 5:20 PM
89	I like genetic testing because it is a term that most people are familiar with and it doesn't sound scary like the other terms. I like cancer risk because even though mutation is scientifically accurate is sounds really bad and many are already afraid to take test. The terminology needs to be geared toward lay people who may already be nervous about taking the test.	2/20/2020 5:18 PM
90	None	2/20/2020 5:16 PM
91	Any of the terms that use layman's language are fine.	2/20/2020 5:15 PM
92	GENETIC TESTING	2/20/2020 5:04 PM

Survey on terms used for "genetic testing"

93	I would not favor the terms germline and mutation because they are not generally understood by the public.	2/20/2020 5:03 PM
94	no	2/20/2020 5:01 PM
95	Genetic testing.	2/20/2020 4:58 PM
96	Genetic testing for hereditary cancer risk. Leaving off the word "risk" makes it sound like you already have cancer. Prefer "hereditary" to "inherited"...blame attached to inherited	2/20/2020 4:58 PM
97	Not sure.	2/20/2020 4:57 PM
98	Simplest terms as possible	2/20/2020 4:52 PM
99	inherited cancer gene	2/20/2020 4:50 PM
100	I understand Genetic testing. Germline is very confusing. Makes me think germ, like the flu germ	2/20/2020 4:45 PM
101	No preference	2/20/2020 4:43 PM
102	Genetic Testing for Inherited Cancer Risk I like this term because even if you test positive you're only at risk	2/20/2020 4:41 PM
103	germline is not a word i have heard before	2/20/2020 4:40 PM
104	Na	2/20/2020 4:38 PM
105	All tests for possible cancers.	2/20/2020 4:36 PM
106	Germline is not a known term to me. When my genetic counselor explained what we were testing for, she said to see if I had inherited any cancer mutations that would increase my risk of other cancers.	2/20/2020 4:36 PM
107	I prefer the word hereditary over inherited. Inherited sounds like someone chose to gift it to you	2/20/2020 4:35 PM
108	Sorry, Chemo Brain/Migraine/Fibro. Fog. Issues understanding.	2/20/2020 4:34 PM
109	genetic testing for hereditary cancer risk, easier to understand	2/20/2020 4:33 PM
110	N/A	2/20/2020 4:28 PM
111	Genetic Testing for Cancer Risk: I prefer this term because it encompasses both testing for inherited and spontaneous mutations that confer an increased risk (not certainty) for cancer.	2/20/2020 4:28 PM
112	Genetic testing for Cancer Risk	2/20/2020 4:27 PM
113	None	2/20/2020 4:24 PM
114	I like inherited mutation or inherited cancer risk--"inherited is more common vocabulary with clearer meaning than "germline," which can sound a bit scary or highly technical.	2/20/2020 4:23 PM
115	Genetic testing for hereditary cancer	2/20/2020 4:21 PM
116	I like what is listed	2/20/2020 4:19 PM
117	I would prefer the term to include "risk"	2/20/2020 4:19 PM
118	I prefer using cancer risk. Just because you carry the gene does not mean that you will get cancer, just that your risk MAY be higher.	2/20/2020 4:17 PM
119	Genetic testing for inherited cancer risk	2/20/2020 4:17 PM
120	I think genetic testing for an inherited cancer risk is straightforward and understandable.	2/20/2020 4:16 PM
121	No preference	2/20/2020 4:14 PM
122	Preference for clarity as well as neutral/ not scary.	2/20/2020 4:12 PM
123	I prefer a term with the word "risk" in it, because having a gene does not guarantee that you will actually get cancer	2/20/2020 4:12 PM
124	I find germline a bit offensive for some reason.	2/20/2020 4:11 PM

Survey on terms used for "genetic testing"

125	detail is helpful	2/20/2020 4:11 PM
126	no preference	2/20/2020 4:11 PM
127	No preference	2/20/2020 4:09 PM
128	Genetic testing for inherited cancer risk - "inherited" makes it clear that it runs in the family, cancer risk makes it clear that having the mutation does not guarantee you will get the cancer - something a lot of people don't understand	2/20/2020 4:08 PM
129	Simple wording that most people have heard and understand. It is already a stressful tense time. The easier the language the better. Too much new info and terms at once is difficult. You may understand when MD discussing and then later be confused.	2/20/2020 4:07 PM
130	Genetic Testing for inherited mutation- describes clearly (to me at least) what is being tested	2/20/2020 4:05 PM
131	Not opposed to any of those terms	2/20/2020 4:05 PM
132	cancer risk is more accurate than cancer	2/20/2020 4:03 PM
133	Hereditary cancer testing	2/20/2020 4:02 PM
134	Not germline - the word germ has too many unrelated associations in commonvernacular	2/20/2020 4:01 PM
135	Based on the perceived connotation	2/20/2020 4:00 PM
136	Genetic testing for inherited mutations	2/20/2020 4:00 PM
137	genetic testing for a gene mutation. I think most people are familiar with this term and it's simple to understand. The last thing someone having genetic testing needs is a euphemism. Use plain, simple language that people can understand	2/20/2020 4:00 PM
138	No	2/20/2020 3:59 PM
139	Genetic testing for cancer risk seems to explain in truly laymen's terms	2/20/2020 3:58 PM
140	genetic mutation just makes more sense to me	2/20/2020 3:57 PM
141	None	2/20/2020 3:57 PM
142	Genetic testing for hereditary cancer	2/20/2020 3:57 PM
143	Genetic testing for inherited markers	2/20/2020 3:56 PM
144	Of the terms offered, I prefer "genetic testing for inherited mutation" because I think it's the most accurate and understandable definition. You're not really testing for inherited cancer, just inherited risk for cancer.	2/20/2020 3:56 PM
145	genetic testing for inherited mutation	2/20/2020 3:56 PM
146	Genetic testing for an inherited mutation is accurate and easy to understand.	2/20/2020 3:55 PM
147	Inherited because it is clearer where a cancer most likely comes from	2/20/2020 3:55 PM
148	Genetic testing for inherited cancer	2/20/2020 3:53 PM
149	I favor the terms that are most self explanatory	2/20/2020 3:53 PM
150	Genetic testing for inherited mutation Seems most accurate and easy to understand. Having aN inherited mutation does not guarantee cancer	2/20/2020 3:53 PM
151	N/A	2/20/2020 3:53 PM
152	Genetic testing for cancer risk	2/20/2020 3:52 PM
153	Xxx	2/20/2020 3:52 PM
154	Genetic testing for cancer risk	2/20/2020 3:52 PM
155	I prefer genetic testing for inherited cancer risk, as just having the gene mutation doesn't necessarily mean you will (or not having it doesn't mean you won't) get cancer; just increased/decreased risk	2/20/2020 3:51 PM
156	braca testing	2/20/2020 3:51 PM

Survey on terms used for "genetic testing"

157	Genetic testing for cancer risk	2/20/2020 3:50 PM
158	Genetic testing to determine hereditary cancer risk	2/20/2020 3:50 PM
159	Simpler the better, most people diagnosed with cancer have to learn a whole new language besides dealing with the shock of being newly diagnosed.	2/20/2020 3:49 PM
160	"genetic testing for an inherited....," is most descriptive and clear.	2/20/2020 3:49 PM
161	I am an MD myself, but have a strong family hx of Ca I have had 2 bouts of genetic testing	2/20/2020 3:49 PM
162	"genetic testing for an inherited mutation" because to me it seems the most easily understandable to the broadest audience	2/20/2020 3:49 PM
163	genetic testing for inherited cancer risk	2/20/2020 3:49 PM
164	I prefer "genetic testing for an inherited mutation" because i believe it most accurately describes the nature of the test in terms most can understand.	2/20/2020 3:49 PM
165	genetic testing for cancer risk	2/20/2020 3:49 PM
166	No lay person knows what "germline" means.	2/20/2020 3:48 PM
167	Genetic testing for inherited risk sounds the most self explanatory.	2/20/2020 3:48 PM
168	Genetic testing for inherited cancer risk.	2/20/2020 3:48 PM
169	Inherited makes sense to me. Germline doesn't without me learning a new term.	2/20/2020 3:47 PM
170	No specifics	2/20/2020 3:47 PM
171	no preference	2/20/2020 3:47 PM
172	My bachelor of science focused on genetics and human development.	2/20/2020 3:46 PM
173	Germline makes sense only to those in medicine. The alternative terminology is appropriate for non-medical persons.	2/18/2020 3:11 PM
174	I understand just what "genetic testing for cancer risk" means. I'm a well-educated writer and I'm not 100% clear on exactly what those other terms mean so I don't see how I could say them to my doctor. I could say, "There's a lot of breast cancer in my family so what should I get tested for?" but I'm not able to get more specific.	2/18/2020 11:35 AM
175	N/a	2/17/2020 11:28 PM
176	Genetic testing for a heredity mutation lets people know the md is looking for some that may be in your family	2/17/2020 11:04 PM
177	genetic testing	2/17/2020 9:43 PM
178	Genetic testing for inherited cancer	2/17/2020 7:27 PM
179	Genetic testing for susceptibility to cancer	2/17/2020 2:51 PM
180	Inherited genetic testing	2/16/2020 10:01 AM
181	How the mutated genetic cancer gene passes to which possiblity of the sex or how it broken down to be determined to ratios	2/16/2020 12:58 AM
182	Genetic testing for an inherited mutation	2/15/2020 11:37 PM
183	I prefer the phrase "genetic testing for an inherited mutation" because including "cancer" in the phrase might be alarming where it doesn't need to be. I understand that inherited mutations increase your risk of cancer, but don't automatically mean you will get cancer.	2/15/2020 9:45 PM
184	Genetic testing for inherited cancer risk. Easy to understand by most people. Would make sure whatever term(s) are selected, they are at the 6th grade reading level	2/15/2020 5:33 PM
185	Genetic testing for inherited cancer gene.you are implying looking for a gene..the other terms seem to state the cancer is present..it's not	2/15/2020 1:40 PM
186	Genetic testing for inherited gene mutation	2/15/2020 1:23 PM
187	Genetic testing for inherited mutation - this seems to me to summarize most accurately what is	2/15/2020 1:02 PM

Survey on terms used for "genetic testing"

being tested for. I was turned off by the ones including cancer as I feel they can be misleading as mutations don't always result in cancer.

188	genetic testing for inherited cancer risk	2/15/2020 11:04 AM
189	Genetic testing for an inherited cancer risk - Germline is too scientific and not using the the word risk makes it feel like you have a 100% chance of a cancer diagnosis	2/15/2020 9:46 AM
190	Genetic testing for an inherited mutation may be a term many patients could understand if used by most testing providers	2/15/2020 6:56 AM
191	Genetic testing for hereditary cancer: it names the test in lay terms	2/14/2020 10:46 PM
192	Genetic testing for cancer risk	2/14/2020 12:16 PM
193	Genetic testing for inherited or hereditary cancer	2/14/2020 12:05 PM
194	I believe a majority of folks understand the term genetic. I had never heard the term "germline" prior to taking this survey.	2/14/2020 7:49 AM
195	I think I prefer the term inherited because it would help distinguish testing.	2/13/2020 8:57 PM
196	I lost my mom to PC. She did genetic testing at MD Anderson, and I have since done Genetic testing myself and we have Ashkenazi Jewish heritage and known biomarkers and genetic mutations. I am a big proponent of simplifying the language JUST so people at least get tested. The confusing language, the technical terms just create further barriers to entry, confusion, and thus inaction. If my mom had been tested earlier, it just may have saved her life.	2/13/2020 8:46 PM
197	I think the term should be easy for anyone to understand	2/13/2020 2:58 PM
198	I think inherited is important along with cancer and risk	2/13/2020 11:53 AM
199	I think most of us would like to know what caused our cancer so genetic testing for inherited cancer would eliminate, or not, that cause. Inherited cancer risk would not be that helpful unless you have something like lung cancer where a significant cause, that could be avoided, is widely known.	2/12/2020 10:12 PM
200	No preferred term.	2/12/2020 10:00 PM
201	No	2/12/2020 9:13 PM
202	Family Risk Profile	2/12/2020 5:19 PM
203	The term Genetic Testing for Inherited Cancer is clearly understood and concise. If asked to do this test, I know it's to determine whether I've inherited any gene from family members that may cause/has caused my cancer.	2/12/2020 1:32 PM
204	Genetic testing for inherited cancer is the phrase I like best. The word riskbseems unnecessary.....we all know the testing holds outcomes that could have risks for us and our loved ones . The word Germaine is positively nasty and doesn't at all describe the meaning of the testing at all	2/12/2020 1:18 PM
205	Genetic testing for inherited cancer risk because it is easy to understand and expresses the point without using the word mutation which some may not know	2/12/2020 1:12 PM
206	I like the word "hereditary" because most people are familiar with that term due to all of the family tree research.	2/12/2020 1:06 PM
207	Genetic testing for an inherited mutation. It is very clear.	2/12/2020 12:45 PM
208	Nothing	2/12/2020 10:07 AM
209	Prefer "genetic testing for inherited cancer risk". No one understands "germline" (germs?). And we must be clear we are talking about inherited RISK of cancer, not looking to detect cancer.	2/12/2020 9:50 AM
210	Inherited is a familiar word to the general population	2/12/2020 12:08 AM
211	a few more words in the title make it more understandable - more description = more understanding	2/11/2020 11:41 PM
212	Genetic testing for interited cancer.	2/11/2020 11:27 PM

Survey on terms used for "genetic testing"

213	genetic testing for cancer risk	2/11/2020 10:26 PM
214	Genetic testing for inherited cancer risk seems most clear to me, conveying a concept most people understand	2/11/2020 10:23 PM
215	I prefer the term "genetic testing for inherited cancer risk" because it is easily understood by the general population.	2/11/2020 9:46 PM
216	Risk is important in naming!	2/11/2020 9:42 PM
217	Genetic testing for hereditary cancer	2/11/2020 7:15 PM
218	I think more people will recognize the terms "inherited" or "hereditary" over "germline".	2/11/2020 7:06 PM
219	The distinction between "Germline" and "Inherited" is important as it relates to the mutated gene. In my genetic testing I was most concerned if I have the mutated gene to pass on to my children. Which I did not.	2/11/2020 7:06 PM
220	"Genetic testing for an inherited mutation" because it describes exactly what it is. I dislike terms like "Genetic testing for inherited cancer" because it sounds like you are being tested for the cancer itself, not a mutation.	2/11/2020 6:15 PM
221	genetic testing	2/11/2020 6:06 PM
222	genetic testing for cancer risk	2/11/2020 5:55 PM
223	No preferred term	2/11/2020 5:49 PM
224	I have none at this moment	2/11/2020 5:39 PM
225	Genetic testing for inherited cancer risk, this tells you what cancers you have the most risk of getting based on your genetic makeup.	2/11/2020 5:28 PM
226	N/A	2/11/2020 5:03 PM
227	Zzzz	2/11/2020 4:56 PM
228	no - I would want a thorough explanation when the terms were used regarding me	2/11/2020 4:55 PM
229	Hardly any gene that is related to hereditary cancer gives a person anywhere near 100% risk. Genetic testing for inherited cancer risk makes the most sense.	2/11/2020 4:41 PM
230	Genetic testing for an inherited genetic mutation explains the test in the simplest terms according to me. But then I am a nurse and understand terms probably more than the public	2/11/2020 4:20 PM
231	Not sure	2/11/2020 4:20 PM
232	Genetic testing for cancer risk -- the words in themselves describe your chance of developing cancer.	2/11/2020 4:17 PM
233	Prefer labels that use the terms inherited or hereditary because those words are commonly used. Germline is not commonly used and isn't a meaningful word.	2/11/2020 3:48 PM
234	Genetic testing for inherited cancer risk - risk explains that you are at risk of developing cancer, rather than actually having cancer. Inherited explains in plain English how this risk is transmitted.	2/11/2020 3:29 PM
235	genetic testing for inherited cancer..... I think this is terminology most everyone can understand	2/11/2020 1:43 PM
236	I think easy plain words work bested. People don't know or understand germline etc. Speak in terms the average person understands. Genetic mutation or inherited genetic mutation	2/11/2020 9:56 AM
237	Strongly prefer using the term " inherited" as believe it is more commonly understood by greater number of people. Ditto for "germline" - if I don't know what it is, there will be large populations who will not.	2/11/2020 9:23 AM
238	No	2/11/2020 8:23 AM
239	Genetic testing for hereditary cancer- It's sounds and explains what kind of test it is with understanding. This was the way it was presented to me and I knew without doubt what it meant.	2/11/2020 1:18 AM

Survey on terms used for "genetic testing"

240	Genetic testing for inherited cancer risk	2/10/2020 6:00 PM
241	The word "germline" sounds too much like "germs" a negative connotation. I favor "genetic testing for inherited cancer risk" as it is most accurate.	2/10/2020 5:36 PM
242	Genetic testing for cancer risk This term seems broad a enough to appeal to patients of various education levels.	2/10/2020 4:24 PM
243	Also - define the difference between inherited and hereditary	2/10/2020 3:33 PM
244	for inherited risk	2/10/2020 2:44 PM
245	Just keep the term simple and straight forward... genetic mutation for cancer	2/10/2020 2:29 PM
246	It just seems logical	2/10/2020 12:49 PM
247	Genetic testing for inherited cancer risk is preferred. I like including the word 'risk', since the person is not necessarily inheriting the actual cancer.	2/10/2020 10:52 AM
248	Gene site testing	2/10/2020 9:52 AM
249	Bracket to in ovarian cancer is a very dangerous game	2/10/2020 8:58 AM
250	I prefer genetic testing vs use of the word germline because it is easier to understand.	2/10/2020 8:38 AM
251	genetic testing for inherited cancer risk (understandable)	2/10/2020 8:31 AM
252	Risk test is preferred to cancer test. Avoids assumption that cancer is a "given." Germline and mutation may be too technical for some people.	2/9/2020 10:14 PM
253	Na	2/9/2020 9:58 PM
254	Genetic testing for inherited cancer risk	2/9/2020 9:01 PM
255	genetic testing for inherited cancer risk. easy to understand!	2/9/2020 7:35 PM
256	Genetic testing	2/9/2020 6:45 PM
257	Genetic testing for inherited cancer.	2/9/2020 6:26 PM
258	Genetic testing for hereditary cancer. Because this may be the most clear for people with no background in medical/genetic terminology	2/9/2020 3:32 PM
259	Genetic testing for inherited mutation -- prefer it because it seems to be the most clear.	2/9/2020 2:45 PM
260	I prefer the terms that clear and understandable.	2/9/2020 2:31 PM
261	"Genetic testing for an inherited mutation". Seems to be a good compromise for mutual understanding between a lay person, scientists, and clinicians	2/9/2020 12:39 PM
262	Na	2/9/2020 9:56 AM
263	Genetic testing for inherited cancer risk is my preferred term. I like this because it is clearer with use of genetic testing and inherited. The use of cancer risk is less jarring because there might be an increased risk of cancer rather than a definite diagnosis of cancer.	2/9/2020 7:22 AM
264	i dont know	2/9/2020 4:13 AM
265	Germlin	2/9/2020 2:37 AM
266	genetic testing	2/9/2020 1:46 AM
267	Genetic testing for hereditary cancer	2/8/2020 11:09 PM
268	Inherited risk.	2/8/2020 9:53 PM
269	I don't	2/8/2020 9:05 PM
270	Genetic testing for inherited cancer risk, I think it best summarizes what the testing is about	2/8/2020 8:20 PM
271	Na	2/8/2020 6:59 PM
272	I am not very familiar with the term germline. I have looked into the term; however, I am simply less familiar with it and prefer such as genetic or inherited.	2/8/2020 5:12 PM

Survey on terms used for "genetic testing"

273	Genetic testing for family cancer risk. Plan n simple - "MISS - make it simple stupid" think common sense who the customer base is - patient- unmedical verbiage.	2/8/2020 3:46 PM
274	Genetic testing for hereditary cancer	2/8/2020 3:36 PM
275	Inherited	2/8/2020 3:29 PM
276	For me, adding the word "cancer" to the term might scare people off from having this important test. It also leads to misunderstandings that if you're "positive," you have cancer. (Which is something I'm noticing get elided in pop-culture/media)	2/8/2020 1:37 PM
277	Simpler, most descriptive	2/8/2020 1:32 PM
278	Germline Genetic testing seems like pretty simple wording that gets across what type of genetic testing you are getting	2/8/2020 12:45 PM
279	Inherited is my absolute preference! Everyone knows that term in everyday language and NOT germline	2/8/2020 12:40 PM
280	Genetic Testing for Inherited cancer risk	2/8/2020 11:06 AM
281	No	2/8/2020 10:07 AM
282	I have no real opposition to the terms as I am still trying to understand what some of these are.	2/8/2020 9:55 AM
283	Yes it's good to know if u have a mutation	2/8/2020 9:35 AM
284	Might there be a different term for environmentally caused cancers as with nicotine or chemicals?	2/8/2020 9:11 AM
285	Germline testing	2/8/2020 8:12 AM
286	Genetic tests for inherited mutation Like to keep the word "mutation" in the name since it is factual.	2/8/2020 7:59 AM
287	Genetic testing for inherited cancer risk. Easier to understand and addresses risk. Even if someone tests negative they should be aware of their risk	2/8/2020 7:42 AM
288	I prefer genetic testing for inherited cancer risk or genetic mutation.	2/8/2020 4:25 AM
289	Prefer Genetic testing for inherited cancer risk because it's in layman's terms and it clearly states it as a risk, there is no guarantee that you will develop cancer.	2/8/2020 3:08 AM
290	None	2/8/2020 1:50 AM
291	Genetic test for cancer risk. It's the easiest one to understand.	2/8/2020 12:57 AM
292	Genetic testing. For cancer	2/7/2020 11:51 PM
293	None	2/7/2020 11:23 PM
294	N/a	2/7/2020 11:07 PM
295	Genetic testing	2/7/2020 10:57 PM
296	It is more specific to me, but in addition to an ovca survivor of 30 years, I am also an RN-BSN.	2/7/2020 10:57 PM
297	Na	2/7/2020 9:52 PM
298	I prefer the word inherited over germline. I feel that more of the general population knows what inherited and/or hereditary means over germline.	2/7/2020 9:27 PM
299	Prefer genetic testing	2/7/2020 9:11 PM
300	Genetic mutation (not specific), brca2+ (specific)	2/7/2020 8:49 PM
301	Lay language over scientific is always easier to relate with.	2/7/2020 7:45 PM
302	No preferences	2/7/2020 7:38 PM
303	Cannot answer that except I feel strongly about genetic testing and should be covered by insurance!!!	2/7/2020 7:02 PM
304	None	2/7/2020 7:00 PM

Survey on terms used for "genetic testing"

305	Genetic teating for hereditary cancer	2/7/2020 6:01 PM
306	Genetic testing for inherited cancer	2/7/2020 5:44 PM
307	genetic testing seems clearer than germline and is more commonly used	2/7/2020 5:35 PM
308	Genetic	2/7/2020 5:29 PM
309	Genetic testing for an inherited mutation or for an inherited cancer risk is tells what the test does in the most understandable language. Germline is not a common term until you are getting genetic tests. And the tests do not test for cancer; they test for the mutation or risk.	2/7/2020 5:26 PM
310	I think any mention of "germ" sounds negative as most people think of germs as bacteria or other disease causing agent, not having to do with inherited. "Inherited" has one definition and is a neutral term.	2/7/2020 4:45 PM
311	Just because a person is found to have a germline mutation does not mean they will get cancer--hence I do not like the term "genetic testing for hereditary or inherited cancer."	2/7/2020 4:38 PM
312	Genetic testing for hereditary cancer. I prefer this term because I think the general public understands these words for testing.	2/7/2020 4:37 PM
313	No preferred term but getting tested depends if person can live with result and faith in accuracy	2/7/2020 4:29 PM
314	genetic testing for an inherited cancer risk	2/7/2020 4:09 PM
315	I think people mostly understand what the word inherited means vs something like germ line. I took genetics classes but most people haven't. It's very confusing to get a cancer diagnosis so the easier it is to understand for the patient, the better. There is so much information thrown at you when you get a cancer diagnosis not to mention the shock factor and it's so hard to process all the information:	2/7/2020 3:45 PM
316	Genetic testing, because it deals with the family.	2/7/2020 3:21 PM
317	It's scary enough to know you might have a genes for cancer. The less I hear the word "cancer" the better	2/7/2020 3:20 PM
318	Genetic testing for cancer risk	2/7/2020 3:15 PM
319	Genetic testing for inherited cancer . I am a clinical dietitian and this choice makes the most sense to me and I think would be easy for anyone to understand. I guess I just do not like the work "germline." :)	2/7/2020 3:12 PM
320	Genetic Testing/genetic mutation	2/7/2020 2:56 PM
321	I prefer genetic mutation over inherited mutation because it makes me think of a tree diagram (other branches could have it and we can discuss it). Inherited mutation makes me think that I'm alone.	2/7/2020 2:46 PM
322	Genetic testing for inherited cancer risk.	2/7/2020 2:44 PM
323	None	2/7/2020 2:36 PM
324	Need to be clear	2/7/2020 2:25 PM
325	genetic testing for inherited or hereditary cancer.. Many people do not know what germline means	2/7/2020 2:25 PM
326	NA	2/7/2020 2:11 PM
327	Genetic testing for cancer	2/7/2020 2:08 PM
328	Genetic	2/7/2020 2:04 PM
329	makes more sense and is understandable IN my perception of many more people	2/7/2020 1:55 PM
330	Test for inherited risk. I think it needs to be simply explained and not imply disease is a given	2/7/2020 1:52 PM
331	No	2/7/2020 1:49 PM
332	Inherited -- I think more people will understand that term,over "germline"	2/7/2020 1:45 PM
333	Inherited it's easier to remember	2/7/2020 1:22 PM

Survey on terms used for "genetic testing"

334	Gentic testing for streamline. Seems to be specific and easy to understand.	2/7/2020 1:18 PM
335	I don't know	2/7/2020 1:14 PM
336	Don't have any family to know if there is cancer in it	2/7/2020 12:13 PM
337	unk	2/7/2020 10:59 AM
338	I work in biomedical research, so there's no confusion for me, but a lot of people have very little understanding of genetics/genomics and it would be best to speak in plain language. "Inherited/hereditary cancer risk," for example, makes immediate sense to a lot more people than "germline mutation." I also think that "inherited cancer risk" is more accurate than "inherited cancer" as very few mutations give a 100% chance of cancer, and people could also think that they were born with cancer when that's rarely the case. People generally understand the term "risk" more than statistics and probability.	2/7/2020 10:15 AM
339	Genetic testing for cancer risk. A simple term for layman people.	2/7/2020 10:02 AM
340	germline genetic testing is probably the more technical term and what I would prefer as a genetic counselor. This term might not be as friendly for healthcare providers and patients who do not work in genetics everyday.	2/7/2020 9:21 AM
341	the terms cancer risk, mutation and inherited are easy to understand	2/7/2020 9:21 AM
342	You need to have it in the simplest terms for people to understand. Genetic testing for inherited cancer and Genetic testing for inherited cancer risk are clear and simple to the point.	2/7/2020 9:10 AM
343	I think plain simple language makes sense. Also, saying "cancer risk" vs. "cancer" is less scary for the person being tested.	2/7/2020 8:58 AM
344	I prefer inherited over germline. It is a clearer concept.	2/7/2020 8:54 AM
345	No discussion on issue	2/7/2020 8:52 AM
346	Not all people with a mutation are going to get cancer (hence opposed to test for hereditary cancer). Your getting tested to see if you have a mutation which increase your risk of cancer.	2/7/2020 5:55 AM
347	none	2/6/2020 11:22 PM
348	Inherited mutation is better than Defect	2/6/2020 11:14 PM
349	Genetic testing for inherited cancer risk	2/6/2020 10:40 PM
350	Hereditary	2/6/2020 10:38 PM
351	Prefer hereditary. It is a term that is commonly used in language and helps the patient to understand better the results of what is being tested.	2/6/2020 10:34 PM
352	DNA testing for cancer risk	2/6/2020 9:37 PM
353	Inherited cancers or diseases is a very important to learn more about I found out that I have an inherited anemia that comes from Asian or Southeastern Mediterranean descent this was something that I had no idea about as my ancestors was always from United States that we thought so to find out that I have so to find out that I have a rare inherited anemia I found this part of the world was very shocking to me all right. I have all the right to learn more about it and willing to learn as much as I can.	2/6/2020 8:47 PM
354	I prefer the terms that are more descriptive and less jargon. Genetic testing for an inherited mutation, or genetic testing for inherited cancer risk feel more accessible and self explanatory.	2/6/2020 8:22 PM
355	Genetic testing for inherited cancer risk. It's very clear what that means and are words that I believe most people are familiar with.	2/6/2020 7:21 PM
356	I just think they should explain and give it written down too so you can look over it with questions.	2/6/2020 7:17 PM
357	Using terms more commonly understood by laypeople is best. Genetic testing and inherited or hereditary are preferred over a term like germline.	2/6/2020 7:12 PM
358	Genetic testing for cancer risk. I would like this type of testing because I had pancreatic cancer but breast cancer also runs in my family.	2/6/2020 7:08 PM

Survey on terms used for "genetic testing"

359	Genetic testing	2/6/2020 6:43 PM
360	Once you have cancer why is not important	2/6/2020 6:41 PM
361	i think it is best to keep it simple.	2/6/2020 6:41 PM
362	Maybe use family risk in description	2/6/2020 6:40 PM
363	Genetic testing for cancer risk	2/6/2020 6:39 PM
364	Germline makes it sound like I have a cold or something I might catch. I really like would like it to be specific to what you are searching for in your testing for the individual or group. Origin might be a good word and is understandable in layman terms.	2/6/2020 6:28 PM
365	Genetic mutation	2/6/2020 6:22 PM
366	Genetic testing for inherited cancer risk	2/6/2020 6:19 PM
367	Genetic testing for inherited cancer risk - I think it just says it simply/in an easily understood way	2/6/2020 6:13 PM
368	Genetic testing for inherited cancer risk - because it is clear and simple, and adding "risk" conveys that having the mutation does not inexorably lead to cancer	2/6/2020 6:11 PM
369	genetic testing for an inherited mutation	2/6/2020 5:42 PM
370	Some are very vague, using the correct medical term would be helpful	2/6/2020 5:32 PM
371	Genetic mutation gene	2/6/2020 5:30 PM
372	Any of the options that don't involve "germline." I wouldn't have known what that was if I didn't read the paragraph before. The others all made sense to me.	2/6/2020 5:16 PM
373	NA	2/6/2020 4:59 PM
374	I like inherited vs Germline , which says nothing to me.	2/6/2020 4:34 PM
375	I prefer Genetic testing for cancer risk as it is plain speak that most people would understand.	2/6/2020 4:29 PM
376	Genetic testing for an inherited cancer risk. I like the word risk because the existence of a mutation does not necessarily mean the cancer diagnosis is inevitable.	2/6/2020 4:19 PM
377	Going for clarity without jargon	2/6/2020 4:17 PM
378	I think it terms with cancer have quite a negative conotation and perhaps even guilt associated with it for parents	2/6/2020 4:09 PM
379	Na	2/6/2020 4:08 PM
380	Genetic testing for inherited cancer risk.	2/6/2020 4:07 PM
381	Germline genetric testing. Simplicity.	2/6/2020 3:56 PM
382	I have no clue	2/6/2020 3:48 PM
383	Genetic, inherited,	2/6/2020 3:39 PM
384	I might like to have genetic testing for cancer	2/6/2020 3:38 PM
385	GERMline sounds like germs. Sounds contagious! Inherited cancer sounds like 100%. Inherited cancer risk seems more accurate and less scary.	2/6/2020 3:04 PM
386	As in most things medical, if you keep the language as non-clinical as possible, more people will understand.	2/6/2020 3:04 PM
387	I don't understand none of this	2/6/2020 2:49 PM
388	I do not like germaine. Sounds like a germ ... something that is contagious.	2/6/2020 2:38 PM
389	Just use "Genetic testing for an inherited mutation." I understand that they want to be as scientifically correct as possible, but it's every day people who are struggling with this information, and usually at a time of already increased stress. Make it as easy as possible for people to get right and understand correctly.	2/6/2020 2:32 PM

Survey on terms used for "genetic testing"

390	Genetic testing for inherited cancer is easy to define in it's name	2/6/2020 2:25 PM
391	Genetics testing	2/6/2020 2:11 PM
392	Inherited Genetic Test	2/6/2020 1:39 PM
393	never had any of this done	2/6/2020 1:26 PM
394	No preference	2/6/2020 1:20 PM
395	None	2/6/2020 1:18 PM
396	None	2/6/2020 1:07 PM
397	Simple is best	2/6/2020 12:07 PM
398	Germ line implies germination which can be confused with the cancer cells germinating — as in, the cancer cells' own progress of mutations over time. So I think this term should not be used, as the tumor genes are also tested. It gets confusing.	2/6/2020 11:49 AM
399	I prefer Gentetic testing for inherited cancer or inherited cancer risk. It is straight forward and easy to understand.	2/6/2020 11:48 AM
400	"Genetic testing for inherited cancer" - it is clear in what it is.	2/6/2020 11:46 AM
401	I prefer any term that doesn't implicitly say "You have cancer." Saying something like testing for inherited/genetic cancer implies the person will get cancer if they test positive, which of course isn't the case, but I feel could increase misinformation and emotional distress.	2/6/2020 11:24 AM
402	Genetic testing for inherited cancer or cancer risk. Because most lay people will understand and remember it.	2/6/2020 11:18 AM
403	Genetic testing for cancer risk.	2/6/2020 10:58 AM
404	Genetic testing for a germline mutation	2/6/2020 10:49 AM
405	Genetic testing for inherited cancer risk is most clear and at the lowest reading level. The term should incorporate the work "risk" since cancer is not 100. Inherited should be included because its accurate and conveys how the risk got there which is impartant to patients.	2/6/2020 10:41 AM
406	genetic testing for inherited cancer risk. It is plan and less scary	2/6/2020 10:40 AM
407	The more familiar the words used to describe the test might be easier for everyone to understand	2/6/2020 10:09 AM
408	No answer	2/6/2020 10:08 AM
409	Common language	2/6/2020 10:01 AM
410	I feel that using "inherited" may, in some minds, assign blame to family members.	2/6/2020 9:55 AM
411	Genetic testing for an inherited mutation -straight forward term	2/6/2020 9:53 AM
412	Genetic or inherited risk is preferable for use with patients over "germline", as those are more widely accessible terms for a non medical professional. Cancer risk is more preferable to cancer alone, as it clarifies the results only indicate a risk, not an actual cancer diagnosis.	2/6/2020 9:28 AM
413	Genetic testing for inherited cancer risk	2/6/2020 9:20 AM
414	make as simple as possible	2/6/2020 9:19 AM
415	Genetic testing for inherited cancer risk	2/6/2020 8:53 AM
416	No	2/6/2020 8:48 AM
417	Genetic testing for inherited cancer risk - because having a mutation doesn't mean you will get cancer, but your risk is higher	2/6/2020 8:46 AM
418	No preference--just thorough explanation, when asked (Plain English)	2/6/2020 8:03 AM
419	Genetic testing	2/6/2020 7:20 AM
420	I prefer the term germ-line because it reflects where exactly in the development as a human this mutation stems.	2/6/2020 7:10 AM

Survey on terms used for "genetic testing"

421	genetic testing for hereditary cancer - because it is understandable to all	2/6/2020 6:51 AM
422	Genetic Testing for an Inherited Mutation is easy to understand	2/6/2020 6:18 AM
423	Genetic testing for cancer risk	2/6/2020 4:25 AM
424	No clue	2/6/2020 1:03 AM
425	GENETIC TESTING-it is just plain	2/6/2020 12:26 AM
426	Genetic testing for inherited mutation , I chose this because most lay persons will understand this terminology	2/6/2020 12:10 AM
427	Genetic testing for an inherited mutation. It is clear (genes are tested) and it states that it is a part of the DNA that you got at birth, or will give to your children at their birth.	2/5/2020 11:16 PM
428	I like the one I chose because it explains it clearly.	2/5/2020 11:13 PM
429	N/a	2/5/2020 10:56 PM
430	Genetic testing	2/5/2020 10:50 PM
431	Genetic testing for cancer risk - fewest and simplest words most likely what I will have available in my brain when I'm stressed out at the doctors office	2/5/2020 10:43 PM
432	No	2/5/2020 10:32 PM
433	I do not have a preference	2/5/2020 10:28 PM
434	Inherited cancer risk	2/5/2020 10:25 PM
435	Because the term "germ" is commonplace, the term "germline" could easily be misinterpreted as something related to an infectious agent. That is a dangerous return to the ideas about cancer in the 1800s.	2/5/2020 10:24 PM
436	Genetic testing	2/5/2020 10:22 PM
437	I do not have a preferred term.	2/5/2020 10:14 PM
438	I had never heard "germline" before and suspect it is not commonly understood by non-medical people.	2/5/2020 10:08 PM
439	Genetic testing for inherited cancer or Genetic testing for cancer risk just sounds self explanatory and easy to grasp.	2/5/2020 10:05 PM
440	Genetic testing for hereditary cancer risk is what I prefer and should be done on all cancer patients and patients with possible risks.	2/5/2020 9:36 PM
441	I prefer inherited or hereditary because they are words I'm familiar with and make sense to me.	2/5/2020 9:31 PM
442	Because my children can get tested earlier	2/5/2020 9:31 PM
443	Inherited is more related to a cancer that runs in the family	2/5/2020 9:29 PM
444	Genetic testing for hereditary cancer . I think if they all mean the same thing this is the simplest way to relate.	2/5/2020 9:19 PM
445	I would like testing	2/5/2020 9:14 PM
446	"Inherited cancer risk" seems both most accurate and clearest to laypeople	2/5/2020 8:47 PM
447	Genetic testing for hereditary cancer	2/5/2020 8:45 PM
448	Inherited gene mutation is my preferred term. Germline sounds so dirty and unpleasant to me	2/5/2020 8:42 PM
449	Genetic testing for inherited cancer risk- doesn't sound terrifying, uses common language. I am a non-native speaker and even after 30 years in this country, most of the medical terms in the cancer field are mumble-jumble	2/5/2020 8:33 PM
450	The layperson's definition of "inherited" is consistent with its use. The term "germline" has no meaning to the layperson. In the phrase "Genetic testing for inherited cancer risk," the "inherited" is redundant given "genetic." This causes one to wonder if "inherited" is adding extra meaning, which can cause confusion. (To my knowledge, it isn't). I think hereditary and	2/5/2020 8:28 PM

Survey on terms used for "genetic testing"

inherited are roughly equally favorable, though I believe I've come across the term "inherited" more frequently in the research papers I've scoured.

451	I favor the terms that are easy to understand	2/5/2020 8:12 PM
452	Genetic testing for an inherited mutation - comprehensive	2/5/2020 8:11 PM
453	Germline just doesn't sound like a term we should attach to cancer heredity. Just call it what it is—inherited.	2/5/2020 8:11 PM
454	Genetic testing	2/5/2020 8:05 PM
455	Genetic testing for inherited mutation bc that's what it is In my mind A mutation I'm not educated enough to understand why Germline bothers me. Maybe bc I confuse it with the word 'germ'	2/5/2020 8:04 PM
456	Inherited to learn if my parents had it or past generations	2/5/2020 7:42 PM
457	don't have a preferred term.	2/5/2020 7:13 PM
458	Genetic testing to assess hereditary risk	2/5/2020 7:02 PM
459	just do not completely understand what those terms mean so I cannot prefer them without understanding	2/5/2020 7:00 PM
460	None	2/5/2020 6:57 PM
461	No preference	2/5/2020 6:50 PM
462	The more straightforward terminology the easier it is to intuit what is being tested. Inherited has a basic meaning that can be inferred from context, whereas Germline has to be explained and then recalled among other overwhelming terms. I'm surprised this even has to be examined and surveyed.	2/5/2020 6:47 PM
463	No preference.	2/5/2020 6:45 PM
464	no preference	2/5/2020 6:42 PM
465	Inherited is something most people already understand. So I like this term over terms like genetic or familial.	2/5/2020 6:34 PM
466	I like inherited because I'm familiar with what that means.	2/5/2020 6:32 PM
467	Genetic testing for inherited cancer	2/5/2020 6:26 PM
468	This whole situation was overwhelming. I think that was the biggest issue	2/5/2020 6:18 PM
469	Genetic Testing for Cancer Risk..clear and tells you what the test is for.	2/5/2020 6:17 PM
470	Inherited is easier.	2/5/2020 6:14 PM
471	Genetic testing for inherited cancer risk	2/5/2020 6:13 PM
472	Genetic testing for inherited mutation	2/5/2020 6:04 PM
473	Bracca test	2/5/2020 6:00 PM
474	None	2/5/2020 5:55 PM
475	I'm not familiar with all terms	2/5/2020 5:55 PM
476	I like the word hereditary as it shows that it comes from your families bloodline.	2/5/2020 5:51 PM
477	no	2/5/2020 5:36 PM
478	Genetic Testing for inherited cancer risk seems to be the most accurate description in lay terms. That was how it was described to me and I think the simple direct approach is the best.	2/5/2020 5:32 PM
479	Want the term to be simple and details can be provided by report or a visit with the physician. My senior aged friends cannot understand any of the above terms except for the last one and I have them in mind with this reply.	2/5/2020 5:20 PM
480	I'm not sure what the two Gene's that were found in my test that they couldn't find out what they were.	2/5/2020 5:17 PM

Survey on terms used for "genetic testing"

481	Inherited gene because more people are familiar with what inherited means and they would have a better understanding if they tested positive for the gene.	2/5/2020 5:15 PM
482	If we are born with cancer and not know it. That is very bad. People can get saved so young and never worry about it again. So I believe that the testing is very important for are well being	2/5/2020 5:15 PM
483	Easy to understand what is being referred to.	2/5/2020 5:15 PM
484	nO PREFERRED TERM	2/5/2020 5:08 PM
485	Cancer similarities meaning a similar gene of cancer that can be the same gene as mom or dad, which display cancerous connections.	2/5/2020 5:00 PM
486	Genetic inherited cancer risk	2/5/2020 4:57 PM
487	Inherited Cancer because you than know exactly what they mean about where it comes from	2/5/2020 4:55 PM
488	None	2/5/2020 4:55 PM
489	No opinion	2/5/2020 4:54 PM
490	None	2/5/2020 4:53 PM
491	Genetic testing for inherited cancer risk is simple and clear. When one is trying to process any information regarding their health and cancer, stress dampens this ability. Simple lay language will help.	2/5/2020 4:51 PM
492	How I got my cancer	2/5/2020 4:43 PM
493	I think most people understand the term Genetic Testing refers to tests that determine if certain diseases run in your family, even if someone isn't familiar with medical terminology there would still likely be able to interpret "Genetic Testing"	2/5/2020 4:40 PM
494	na	2/5/2020 4:39 PM
495	N/A	2/5/2020 4:38 PM
496	Sorry I do not have a preferred term.	2/5/2020 4:37 PM
497	Will my grand daughter be at risk for breast cancer	2/5/2020 4:36 PM
498	I dont like the term germline, I think it could be interpreted as a germ you may have.	2/5/2020 4:33 PM
499	.	2/5/2020 4:32 PM
500	N/A	2/5/2020 4:31 PM
501	Germaine genetic testing	2/5/2020 4:28 PM
502	Inherited cancer risk	2/5/2020 4:26 PM
503	I prefer "Genetic testing for inherited cancer risk" as I feel it covers each term (genetic, inherited, risk) that embodies what the test is for and is the most simple and understandable one.	2/5/2020 4:24 PM
504	Genetic. It refers to genes.	2/5/2020 4:21 PM
505	i think the term germline is difficult to understand for non-medical people. I like the term genetic testing for inherited cancer risk, because it is a risk factor, no 100% guarantee that someone will get cancer.	2/5/2020 4:19 PM
506	No preference	2/5/2020 4:19 PM
507	Genetic testing for cancer risk, this terms is more favorable because many can understand the reason for this type of testing which clearly explain it will be searching for risk factors that may be the cause of getting cancer...and it can provide information and data on how to prevent cancer before it happens if you are aware of your risk of getting it. Whether it is a high or low risk base on your genes makeup.	2/5/2020 4:19 PM
508	Genetic testing for cancer risk	2/5/2020 4:17 PM
509	N/a	2/5/2020 4:16 PM

Survey on terms used for "genetic testing"

510	Genetic Testing For Inherited Cancer Risk - I prefer this because it is clear and is honest about it being about calculating risk	2/5/2020 4:14 PM
511	NA	2/5/2020 4:14 PM
512	Genetic testing	2/5/2020 4:12 PM
513	Had the Barca test for breast cancer thank god it was available	2/5/2020 4:11 PM
514	n/a	2/5/2020 4:11 PM
515	Terms above	2/5/2020 4:11 PM
516	I prefer the word risk be added as it conveys that testing positive is not a guarantee you will get cancer. If the test is for cancer risk then it should state that in the name. If it includes other mutations then the term should indicate that.	2/5/2020 12:59 PM
517	Genetic testing for hereditary/inherited cancer still sounds ambiguous to me.	2/5/2020 12:59 PM
518	I prefer using inherited cancer risk or inherited mutation, as "inherited cancer" sounds like you will definitely get cancer.	2/5/2020 9:53 AM
519	I most prefer "Genetic testing for cancer risk", since so many people confuse "Risk" with "Cancer" itself. Clarifying the name could really help dispel the myth that you can actually "inherit cancer", thank you!	2/5/2020 9:35 AM
520	Genetic testing for inherited cancer	2/5/2020 8:20 AM
521	hereditary cancer genetic testing	2/5/2020 8:18 AM
522	Genetic testing for inherited mutation makes clear the test is for a specific thing, not just vague risk. It's easier to understand than "germline" but still indicates that it is hereditary.	2/5/2020 7:40 AM
523	I don't like the term germline. It reminds me of germs, infectious diseases and something dirty. Like the line between washing your hands or having dirty germs hands. To me the term germ has negative connotations	2/5/2020 4:45 AM
524	Genetic Testing for Inherited Cancer Gene Mutation....Seems easy to understand and straight forward.	2/5/2020 1:38 AM
525	Genetic testing for inherited cancer risk	2/5/2020 12:52 AM
526	Genetic testing for inherited cancer risk seems the most clear	2/4/2020 11:39 PM
527	Genetic testing for inherited cancer risk (Germline sounds like germs). And "risk" sounds more clear than inherited mutation (guaranteed cancer probability)	2/4/2020 11:39 PM
528	Genetic testing for inherited mutation. Clear and easy to understand.	2/4/2020 9:04 PM
529	NA	2/4/2020 8:51 PM
530	no preferred term	2/4/2020 8:20 PM
531	Genetic testing for inherited cancer risk. It has clear wording and makes sense	2/4/2020 8:16 PM
532	Genetic testing for at risk cancer	2/4/2020 7:48 PM
533	I don't think people know what "germline" means, so why confuse people? "Inherited mutation" or "inherited cancer risk" is clearer. Also it's important to say it's testing for *risk* or a *mutation,* but not testing for actual cancer, because that's not what it is.	2/4/2020 7:14 PM
534	no one preference	2/4/2020 7:11 PM
535	I prefer "risk" as opposed to "cancer" because cancer may not be present.	2/4/2020 6:39 PM
536	I don't know to much about inherited cancer risk.	2/4/2020 6:24 PM
537	Keep it simple and basic and easy for the "lay" person.	2/4/2020 6:23 PM
538	I think "inherited" is clearer for laypersons than "germline", which is more technical.	2/4/2020 6:09 PM
539	Genetic testing for inherited gene mutation and or cancer risk	2/4/2020 6:01 PM
540	It is the mutations that are hereditary, not the cancer. So I prefer use of language around	2/4/2020 5:57 PM

Survey on terms used for "genetic testing"

	inherited mutations, or inherited cancer risk.	
541	genetic testing for an inherited mutation	2/4/2020 5:08 PM
542	genetic testing for inherited cancer risk--very clear meaning	2/4/2020 5:06 PM
543	Genetic testing for cancer risk	2/4/2020 4:58 PM
544	na	2/4/2020 4:38 PM
545	More people understand "inherited" than gremlin	2/4/2020 4:32 PM
546	Genetic testing for inherited mutation.	2/4/2020 4:11 PM
547	I feel like the terminology used should be more specific to what is actually being tested for. The word "germline" is NOT specific enough, and the general public is unfamiliar with this word.	2/4/2020 4:06 PM
548	Genetic testing for an inherited mutation Seems most clear as not all mutations increase cancer risk	2/4/2020 3:58 PM
549	I'm less familiar with the term Germline As a non-geneticist I find inherited or hereditary clearer however if there were reasons that germline should be used I wouldn't be opposed to re-educating myself.	2/4/2020 3:54 PM
550	Genetic testing for inherited cancer risk because it does not give the assumption that you have cancer with a positive result it just gives the knowledge of the reason for testing.	2/4/2020 3:41 PM
551	Genetic testing for hereditary cancer or inherited cancer. The simpler the terminology the better.	2/4/2020 3:36 PM
552	"Genetic profile" to replace genetic mutations. "Our Family Health History indicates that we may have a genetic profile that increases our risk of some inherited medical conditions."	2/4/2020 3:33 PM
553	No other term	2/4/2020 3:25 PM
554	'Genetic testing for an inherited mutation' because I have an irrational recoil about the word 'germ' and a mutation does not equate to cancer, so I think keeping the word 'cancer' out of the title will help some people think calmly and clearly about their situation.	2/4/2020 3:09 PM
555	I prefer not to use/see the word "cancer" if possible.	2/4/2020 3:08 PM
556	Genetic testing for inherited cancer risk seems most clear about the fact that it's inherited from a family member and is about cancer risk (that you may be more likely to develop the disease), not cancer (that you have the disease)	2/4/2020 3:03 PM
557	These are tests for risk, not tests for cancer. Some of these options are misleading, and the idea that they are being tested to see if they have cancer may scare some people away from being tested - or may lead them to misinterpret their results, or decline other needed testing, etc. Germline is a less broadly familiar term than inherited, I suspect - and the 'germ' part may seem unappealing or confusing to some.	2/4/2020 2:52 PM
558	Inherited genetic testing	2/4/2020 2:50 PM
559	Genetic testing	2/4/2020 2:39 PM
560	None	2/4/2020 2:36 PM
561	Inherited/hereditary risk are both easy to understand and broad enough to clarify for a stressed out applicant	2/4/2020 2:26 PM
562	Genetic testing for an inherited mutation I believe this specifically communicates what's being done	2/4/2020 2:24 PM
563	Genetic Testing for Inherited Cancer Risk, I like this term because it most accurately describes that it is an inherited RISK, not an actual cancer.	2/4/2020 2:22 PM
564	Genetic testing for an inherited mutation. It's a lamens term but I think what it needs to be to clarify what the test is for. I knew I was getting a "genetic test" but had no idea why, and had I known I was testing for an inherited mutation I could have prepared better or researched more so that when I got a positive result, maybe I wouldn't have been so shocked or confused.	2/4/2020 2:10 PM
565	I didn't know what germline meant until you told me. You are not testing for cancer. I have a son with the gene, but no cancer. So I want something that says it is testing for a genetic risk	2/4/2020 2:07 PM

Survey on terms used for "genetic testing"

566	I like the phrases with the word "risk" in them since you are not doomed to actually be diagnosed with cancer if you are just bring tested for, or test positive for, a genetic mutation.	2/4/2020 2:06 PM
567	genetic testing for cancer risk	2/4/2020 2:03 PM
568	Genetic testing for an Inherited mutation is descriptive without being too "medical lingo" sounding.	2/4/2020 1:58 PM
569	N/A	2/4/2020 1:56 PM
570	Genetic testing for an inherited mutation. To me this sounds like the easiest to understand and doesn't allow people to draw incorrect conclusions about what the test is for.	2/4/2020 1:44 PM
571	I voted against the word drumline because I didn't know the definition and I consider myself to be pretty well-informed. Inherited will be much easier to understand.	2/4/2020 1:39 PM
572	Genetic testing for an inherited mutation states clearly what it is without dumbing it down or making it too scientific	2/4/2020 1:33 PM
573	Genetic testing for an inherited mutation - it feels most accurate to me.	2/4/2020 1:26 PM
574	Genetic testing for an inherited cancer risk. I like this term because it makes clear that it is the "risk" that is inherited and not necessarily the cancer itself. I believe this more accurately describes what the test is for and what the results mean.	2/4/2020 1:25 PM
575	terms I preferred above	2/4/2020 1:23 PM
576	I think the word inherited is important.	2/4/2020 1:23 PM
577	inherited genetic testing or genetic testing for inherited risk for cancer	2/4/2020 1:20 PM
578	I think adding the word risk is important.	2/4/2020 1:16 PM
579	I think the general public does not understand the germ "germline" so "inherited" is preferable. Also, I think the concept of "risk" is not well understood so that should be emphasized and that there should be a lot of educational emphasis on what risk means in the setting of cancer.	2/4/2020 1:16 PM
580	Easier to understand, "germline" connotes images of a germ. Inherited implies parents fault, vs hereditary sounds more passive.	2/4/2020 1:15 PM
581	You're being tested to an inherited mutation, which doesn't necessarily mean you'll get cancer, although I understand you are at a very increased risk if testing positive.	2/4/2020 1:05 PM
582	Genetic testing	2/4/2020 1:01 PM
583	Na	2/4/2020 1:00 PM
584	Genetic testing for an inherited mutation	2/4/2020 12:58 PM
585	Genetic Testing for an inherited cancer or anything similar. It seems like it would be most clear to the average person. I wouldn't have been familiar with the word germline.	2/4/2020 12:56 PM
586	Genetic testing for an inherited mutation.	2/4/2020 11:04 AM
587	Inherited is a more familiar word than germline.	2/4/2020 12:10 AM
588	Germline is less informative to me than inherited which is a more familiar term.	2/3/2020 8:58 PM
589	Genetic testing for cancer risk is my choice. It's simple and clear.	2/3/2020 7:52 PM
590	Genetic profiling	2/3/2020 6:26 PM
591	Not sure	2/3/2020 6:15 PM
592	Genetic testing for inherited or risk of cancer	2/3/2020 5:24 PM
593	I do not have a preferred term	2/3/2020 2:51 PM
594	I think the terms I have highlighted should be as clear as possible for what is being tested.	2/3/2020 2:22 PM
595	No preferred term.	2/3/2020 2:07 PM
596	Cholangiocarcinoma	2/3/2020 1:11 PM

Survey on terms used for "genetic testing"

597	Not qualified to answer. Too many unknowns for me.	2/3/2020 12:54 PM
598	Unless I misunderstand, it is clearest.	2/3/2020 8:16 AM
599	Genetic testing for treatments options	2/2/2020 8:12 AM
600	Most confusing terminology that I have heard	2/1/2020 4:18 PM
601	NA	2/1/2020 1:32 PM
602	Genetic testing for cancer risk says a lot and is very easy to understand what the test is for.	2/1/2020 1:23 AM
603	None	1/31/2020 10:45 PM
604	Genetic testing for inherited cancer	1/31/2020 7:46 PM
605	genetic testing for inherited cancer risk	1/31/2020 5:49 PM
606	Testing for inherited genetic mutations Very clear meaning	1/31/2020 5:14 PM
607	Genetic testing for INHERITED mutation	1/31/2020 3:41 PM
608	No preference	1/31/2020 3:36 PM
609	None	1/31/2020 3:25 PM
610	Genetic testing for inherited mutation is vaguely specific enough that it points the patient in the right direction for testing without explicitly implying that the results are a definite cause of their cancer. The doctors should already understand what the testing intention and meaning is.	1/31/2020 2:40 PM
611	Genetic tested for inherited mutation	1/31/2020 2:17 PM
612	I think the term 'inherited' is very commonly used in the community and will be easier for people newly diagnosed to understand.	1/31/2020 2:08 PM
613	genetic testing for an inherited mutation. In lay terms, I think more people understand inherited versus germline.	1/31/2020 1:55 PM
614	Genetic testing for inherited cancer. People understand what inheriting means.	1/31/2020 1:55 PM
615	simple universal terms work	1/31/2020 1:45 PM
616	Genetic testing for inherited cancer risk.	1/31/2020 5:48 AM
617	Genetic testing for an inherited cancer ... Terminology that's is clear and easy to understand.	1/31/2020 1:51 AM
618	Do not know enough to appreciate the differences in usage of the terms. Within my team I get different responses based on the focus of their medical practice. Have learned to say nothing until I have time to research the terms and come to my own understanding. Most of the team have cheat-sheets, boxes to check or bullet-points they need to/want to cover; any questions are usually are not responded to unless I am very forceful. I do not believe that the medical practice understands the cause of cancer, how to identify the fundamentals of the disease and certainly lack the communication skills to effectively and compassionly transmit this information to the patient. In one recent PCF article they are proud of spending over \$750M over a 25 year period and advance the expected life increase by 18 months; consider this a sad joke on the patients. There is little consistency within a organization, facility, authors in what the research data means; sometimes even within the same article there are inconsistencies. Who, what... are the patients to believe. If the numbers go up I have maybe 3 months to live; if they go down maybe 3 to 6 months to live; is a way to live?	1/30/2020 11:05 PM
619	"Genetic testing for inherited cancer risk" This term seems self-explanatory and easily understandable	1/30/2020 10:48 PM
620	na	1/30/2020 9:39 PM
621	I prefer non medical speak & explanations. Thanks you, Too many medical terms, jargon and stats for the non-medical like me.	1/30/2020 8:58 PM
622	None	1/30/2020 5:54 PM
623	I don't like the word germ. I like it to be clear what it is for. Like inherited etc.	1/30/2020 5:36 PM
624	Genetic testing for cancer risk	1/30/2020 3:25 PM

Survey on terms used for "genetic testing"

625	Hereditary I understand. Genetic Testing also. Have no Idea what gremline means	1/30/2020 2:45 PM
626	Too much medical jargon . Terminology needs to be simplified and standardized.	1/30/2020 2:28 PM
627	Clear speech. Do not need dictionary to figure out what it means. We have to learn an new language as it is.	1/30/2020 1:36 PM
628	Genetic testing for inherited cancer risk	1/30/2020 1:08 PM
629	No prefrence	1/30/2020 12:49 PM
630	Genetic testing fir inherited mutations	1/30/2020 12:22 PM
631	Genetic testing for inherited mutations	1/30/2020 12:00 PM
632	Keep it as simple as possible	1/30/2020 11:59 AM
633	The terms "genetic" and "inherited" are very common and easily understood by patients like me. STANDARDIZE!	1/30/2020 11:47 AM
634	No preference	1/30/2020 11:40 AM
635	Inherited mutation - you can quickly understand exactly what the subject is and why it is being tested.	1/30/2020 11:02 AM
636	Genetic Testing For Hereditary Cancer Risk. Easy to understand that it is not a somatic genetic test, or a test to determine whether an inherited gene has mutated during the person's lifetime, and it accurately describes how to use the test results: it only measures a "risk" for cancer, not "if gene is inherited, then definitely cancer".	1/30/2020 10:57 AM
637	Genetic testing for hereditary cancer. It gives the best description for specific gene testing.	1/30/2020 10:43 AM
638	Genetic testing for cancer risk	1/30/2020 10:43 AM
639	I don't think a lot of people understand what "germline" means.	1/30/2020 10:34 AM
640	genetic testing for inherited cancer risk. Because it explains it in simple to understand language	1/30/2020 8:20 AM
641	No preference	1/30/2020 7:37 AM
642	Genetic testing for inherited cancer	1/30/2020 7:17 AM
643	I don't really have a preferred term and not sure if these are different kinds of testing or all the same type of testing just worded in different ways. I know when I went it was explained to me as genetic testing for inherited cancer risk and that was very clear to me what services I was receiving and why.	1/30/2020 6:23 AM
644	Inhereted seems to most telegraphically represent the definition that you provided	1/30/2020 3:07 AM
645	None	1/30/2020 12:30 AM
646	Genetic testing for inherited risk of certain cancers	1/29/2020 11:24 PM
647	I had never heard of germline before. I don't care for "germ" - it makes me think of what makes people sick, not necessarily inherited or genetic.	1/29/2020 11:13 PM
648	Genetic testing for risk	1/29/2020 8:52 PM
649	Genetic testing for cancer risk	1/29/2020 6:28 PM
650	Words like "inherited" are much more self explanatory of what the test is for. "germline mutation" is a harder term for the brain. I like inherited better as we know that means it came from an ancestor/parent.	1/29/2020 5:22 PM
651	No preference	1/29/2020 4:51 PM
652	genetic testing for inherited cancer risk - clearly indicates testing for an inherited risk	1/29/2020 4:19 PM
653	The term should imply that it's only to assess risk, and where that risk comes from.	1/29/2020 4:17 PM
654	Genetic testing	1/29/2020 3:22 PM
655	The last 4 are simplistic and easy to understand	1/29/2020 2:35 PM

Survey on terms used for "genetic testing"

656	None	1/29/2020 2:09 PM
657	genetic testing for inherited cancer risk because it's not saying you have or not, but saying that if we see these markers your higher level of possibly having something in the future.	1/29/2020 2:00 PM
658	Gene testing can be beneficial for treating a particular cancer or know if you could pass it to your children or their children or aid in mot having children at all	1/29/2020 1:08 PM
659	none	1/29/2020 1:04 PM
660	n/a	1/29/2020 12:33 PM
661	The more simple the better when referring to testing. When discussing results and talking to my doctors I like hearing and learning the more scientific terms but simple is more accessible.	1/29/2020 12:24 PM
662	No preferred term.	1/28/2020 7:11 PM
663	Not got a clue what you are asking	1/28/2020 6:07 PM
664	-	1/28/2020 2:58 PM
665	Genetic testing for inherited cancer risk Seems simple and descriptive	1/28/2020 2:51 PM
666	I believe it would be preferable to not use either the word inherited or risk to describe the test	1/28/2020 12:46 PM
667	I think including the idea that it is inherited and does increase cancer risk would help.	1/28/2020 12:31 PM
668	Clearer	1/27/2020 9:43 PM
669	genetic profiling	1/27/2020 12:50 AM
670	Genetic testing for inherited cancer risk	1/26/2020 10:49 PM
671	Genetic testing for inherited cancer risk - because "risk" is the key term	1/26/2020 9:20 PM
672	Genetic testing for inherited risk of developing illness (not just cancer)	1/26/2020 7:51 PM
673	I prefer genetic testing for an inherited mutation Because it is the most clear and most accurate of the options while still being simple enough for someone not familiar with the terminology to understand its meaning	1/26/2020 6:27 PM
674	Genetic testing for an inherited mutation	1/26/2020 5:36 PM
675	I prefer "inherited" to "germline" because it communicates better to laypeople. The genetic tests don't test for cancer, but for cancer risk; that distinction is important.	1/26/2020 5:35 PM
676	no, I don;t have a preferred term I am a healthcare professional, so I can navigate thru terms pretty easily, but others may not be able to	1/26/2020 5:10 PM
677	Genetic testing for an inherited mutation of a gene related to cancer. .	1/26/2020 2:38 PM
678	Genetic testing for an inherited mutation seems to accurately describe the test and what it is looking for in simple terms.	1/25/2020 11:18 PM
679	I don't like the descriptor "germline" bc I think there is misunderstanding in what that is. I like "inherited" and "risk" to be in the title	1/25/2020 9:54 PM
680	Genetic testing for inherited mutation	1/25/2020 6:42 PM
681	I prefer terms that I'm familiar with and understand	1/25/2020 12:51 PM
682	Risk Genetic testing for cancer risk - I think this is the simplest layman term and when confronting so much medical terminology on the midst of health concerns the easier it can be for the majority to comprehend is best.	1/25/2020 10:24 AM
683	I think it needs to be clear that the testing is for pathogenic mutations or VUS which contribute to cancer risk. Positive or VUS results do not indicate presence of cancer or certainty of cancer (like the 4th and 5th options might imply), but an increased risk.	1/25/2020 10:00 AM
684	inherited cancer risk Risk I really like "genetically tested for inherited cancer risk" because it explains 1) it's genetic (which people recognize) and 2) there is an increased RISK of getting cancer. When you say genetic mutation for inherited cancer(not saying the word risk), it sounds like I have cancer, not that I have a gene which increases my risk. I think there is a very	1/25/2020 9:49 AM

Survey on terms used for "genetic testing"

important distinction between being tested for inherited cancer and being tested for an inherited risk of cancer. Risk is an important word to use. Thank you for doing this survey, this is very important to have similar language! I appreciate it.

685	inherited cancer risk Risk Inherited cancer risk.	1/25/2020 9:38 AM
686	inherited cancer risk Risk Inherited cancer risk.	1/25/2020 9:37 AM
687	I think whatever you use (inherited or germline) it needs to include the term risk. Leaving that out implies that cancer is assumed - not just a risk. I don't have a problem with the term germline if you do a lot of education first - inherited is more familiar to more (non-professional) people.	1/24/2020 9:17 PM
688	inherited cancer risk Risk I prefer the terms with clearer language for a non-expert (eg inherited cancer risk)	1/24/2020 12:34 AM
689	don't have one	1/23/2020 12:15 PM
690	I have none.	1/23/2020 12:10 PM
691	None	1/23/2020 10:58 AM
692	NA	1/23/2020 9:31 AM
693	No	1/23/2020 8:09 AM
694	Testing for inherited genetic mutations that increase cancer risk. Common words generally understood, 2 short phrases, one leading to another.	1/23/2020 7:15 AM
695	inherited cancer risk Genetic testing for inherited cancer risk because it's easy to understand and clear. You don't have to know anything about cancer to know what it means.	1/23/2020 2:55 AM
696	inherited cancer risk Genetic testing for inherited cancer risk seems to express the meaning of what the testing is for in ways most people would understand.	1/22/2020 9:43 PM
697	I prefer inherited to hereditary, hate the tens Germaine & mutations.	1/22/2020 9:40 PM
698	Genetic testing for hereditary cancer. This clearly states what it is.	1/22/2020 7:37 PM
699	Genetic testing for cancer risk- straightforward and simple	1/22/2020 6:50 PM
700	inherited cancer risk Genetic testing for inherited cancer risk as it seems to me to be the most self-explanatory term	1/22/2020 6:25 PM
701	Genetic testing for an inherited mutation. I think it is most accurate and clearest. I think the term germline is not a familiar term and the use of hereditary or inherited cancer whilst clear possibly overstates the likelihood of someone getting cancer on a hereditary basis. As my understanding is the mutation might be inherited but it does not necessarily mean someone will get cancer?	1/22/2020 6:03 PM
702	n/a	1/22/2020 5:55 PM
703	Genetic testing for inherited cancer. It makes the most sense to me.	1/22/2020 5:28 PM
704	ease of understanding with inherited term vs germline	1/22/2020 3:40 PM
705	labeling something as "inherited" or "hereditary" is farm more self-explanatory than "germline"	1/22/2020 3:40 PM
706	Genetic molecular profiling	1/22/2020 2:53 PM
707	Genetic testing	1/22/2020 2:53 PM
708	Preference for general audience: inherited vs spontaneous; inherited vs tumor Preference for audience w/ the slightest bit of biology literacy: germline vs somatic.	1/22/2020 2:31 PM
709	I think genetic testing for inherited cancer risk may be understood the best by most people although genetic testing for an inherited mutation seems a more accurate way to describe it.	1/21/2020 10:07 PM
710	Genetic testing for cancer risk sounds like it might have the widest appeal.	1/21/2020 8:53 PM
711	You are not testing for hereditary cancer. Instead, you are testing for the risk or predisposition to hereditary cancer.	1/21/2020 4:19 PM
712	I prefer terms and phrasing that is most like phrasing patients are used to hearing in their every	1/21/2020 11:52 AM

Survey on terms used for "genetic testing"

	day lives.	
713	Any universal term is preferred at the lowest common denominator.	1/21/2020 12:06 AM
714	"Genetic testing for an inherited mutation" is my preferred term. "Germline" is not a term I'm familiar with, and I think is less self explanatory than "inherited." I don't like the terms that mention cancer as much, because I think they would scare people off from being tested.	1/20/2020 10:46 PM
715	Inherited cancer makes it sound like there is cancer present from birth. That is not the case as genetic testing can inform you of risk for cancer I prefer genetic testing for germline mutations	1/20/2020 6:38 PM
716	Genetic testing for potential inherited cancer risk. Not everyone with the mutations gets cancer and sadly when you are told you have this, they automatically treat you as though you will get it.	1/20/2020 5:12 PM
717	I have the RAD51D gene and a breast cancer survivor	1/20/2020 12:20 PM
718	Genetic testing for cancer risk. A risk may be inherited or develop overtime. Would like to know both. Genetic seems to be a more common term.	1/20/2020 12:07 PM
719	Genetic testing for an inherited mutation.	1/20/2020 9:28 AM
720	Germ line is confusing to many people. When you are doing genetic testing, you are not testing for cancer itself but the risk associated with the gene, hence the terminology should reflect that.	1/20/2020 8:36 AM
721	Germline testing as patients are confused especially in the beginning of a cancer diagnosis	1/20/2020 8:24 AM
722	No	1/20/2020 6:43 AM
723	Na	1/20/2020 2:09 AM
724	inherited cancer risk "Genetic testing for inherited cancer risk" is my favorite although its a mouthful. But I like it bc it says exactly what it is.	1/19/2020 11:06 PM
725	Germline just sounds bad like germs Inherited makes me feel bad as a daughter that my children may inherit this from me. Heredity seems broader like it was in our genetic make up as an entire family. Cousins aunts uncles etc. links the family together in a supporting way. My cousins, brother and I are positive and heredity to me seems like best way to describe it. Thank you for asking for opinions.	1/19/2020 11:02 PM
726	Inherited mutation feels the most clear	1/19/2020 11:01 PM
727	Genetic testing for an inherited (fill in cancer risk, trait, mutation here) I think this is the easiest to understand with little confusion for an average person.	1/19/2020 10:56 PM
728	Genetic testing for inherited cancer risk. It clearly defined the purpose of the test.	1/19/2020 10:29 PM
729	Personally, I like germline but I think inherited cancer risk is more immediately understandable by a broader group of people.	1/19/2020 9:42 PM
730	Genetic testing for inherited cancer	1/19/2020 9:20 PM
731	Genetic testing for inherited cancer risk	1/19/2020 8:00 PM
732	Something that says risk at the end because we know that having a genetic gene doesn't guarantee you'll get cancer. I also don't like germline	1/19/2020 6:55 PM
733	Genetic testing for cancer risk	1/19/2020 6:45 PM
734	Genetic testing	1/19/2020 6:31 PM
735	Do not have a preferred term.	1/19/2020 6:24 PM
736	N/A	1/19/2020 6:19 PM
737	N/A	1/19/2020 6:16 PM
738	inherited mutation Genetic testing for inherited mutation is simple, and makes sense. I'm a scientist and took biology but germline is not a common term in the real world, and can be confusing as it has "germ" in it, but that is related to something you catch (germs), rather than inherit. I prefer mutation because it is the most accurate - risk is variable. Hereditary cancer makes me think that people will assume having the mutation means you already have cancer.	1/19/2020 5:56 PM
739	inherited mutation I think the clearer you can be with the terminology - and appealing to the	1/19/2020 12:40 PM

Survey on terms used for "genetic testing"

broadest possible base of people - the better. I think the concept of a "germline" mutation is beyond the wheelhouse of the common American public. So I really prefer "genetic testing for an inherited mutation" or similar terms because I think they are the most clear.

740	test for an inherited genetic fault which causes high risk of certain cancers	1/19/2020 12:29 PM
741	inherited cancer risk inherited mutation I like "genetic testing for an inherited mutation" or "genetic Testing For inherited cancer risk" be cause they seem to be the most accurate but still understandable to the average patient.	1/19/2020 12:39 AM
742	No preferred terms	1/18/2020 3:35 PM
743	I prefer "inherited" when using the term Mutation, if talking about testing, or cancer risk. Such as: A test to evaluate the cancer risk due to an inherited gene mutation. Or a test on inherited gene mutations. Germline to me means nothing. Don't remember seeing this in biology. For me it leads to confusion. Germs ? Line of germ ? This may be quite used in the scientific world related to microbiology and genetics but there is no link to what the common person would know. I think.	1/18/2020 2:01 PM
744	Risk Genetic testing for inherited risk	1/18/2020 12:06 PM
745	Genetic testing for genetic mutation	1/18/2020 11:29 AM
746	inherited cancer risk genetic testing for inherited cancer risk or genetic testing for cancer risk. Both are easily understood.	1/18/2020 12:30 AM
747	Inherited genetic cancer - simple and easy to understand.	1/17/2020 10:51 PM
748	Genetic testing for gene mutation I prefer this because it just easier to understand for most people.	1/17/2020 7:29 PM
749	inherited mutation Genetic testing for an inherited mutation	1/17/2020 3:35 PM
750	inherited cancer risk Genetic testing for inherited cancer risk. I feel this term is the most understandable. Anyone, regardless of educational background , would be able to understand the significance of this term.	1/17/2020 1:54 PM
751	inherited mutation Genetic Testing for Inherited mutation	1/17/2020 10:41 AM
752	Genetic testing for hereditary gene mutation	1/17/2020 10:20 AM
753	It is scary enough to test positive for a generic mutation and find out you have an increased risk, and using the terms "genetic testing for... cancer" will scare people into even stronger thinking that cancer is inevitable	1/17/2020 8:06 AM
754	None	1/17/2020 12:36 AM
755	I think germline is too confusing. Inherited is much more understandable.	1/16/2020 11:11 PM
756	None	1/16/2020 5:51 PM
757	I	1/16/2020 1:49 PM
758	I prefer Genetic testing for inherited cancer risk because I think this most clearly states in plain English the purpose of the test.	1/16/2020 1:32 PM
759	inherited mutation genetic testing for inherited mutation is easiest and most specific for widest audience to understand	1/16/2020 1:31 PM
760	inherited cancer risk "Genetic Testing for inherited cancer risk " is probably the term that uses the words that are the easiest for people to understand while not simplifying so much that it is no longer accurate	1/16/2020 1:19 PM
761	I don't have a preference	1/16/2020 1:17 PM
762	inherited cancer risk inherited mutation Genetic testing for an inherited cancer risk or testing for inherited mutation are two terms I think are very clear	1/16/2020 1:16 PM
763	Inherited or hereditary - it seems the majority of the population understands both terms with ease.	1/16/2020 1:10 PM
764	Hereditary	1/16/2020 11:24 AM

Survey on terms used for "genetic testing"

765	"germline" is not standard everyday terminology" "inherited" is commonly understood	1/16/2020 10:05 AM
766	inherited cancer risk genetic testing for inherited cancer risk. I prefer this because it is very clear that they are looking for familial risks of cancer.	1/16/2020 10:00 AM
767	Genetic is the preferred term. More relatable and understood	1/16/2020 9:30 AM
768	I like your word inherited to explain what you are talking about. I don't like inherited cancer without using risk. It's not a certainty.	1/16/2020 9:04 AM
769	genetic testing for inherited cancer risk. a few reasons: the test tells us not about the certainty of cancer but about the *risk* of getting it; inherited is a more common word than hereditary; the word 'germline' is too technical	1/16/2020 8:33 AM
770	Genetic family history	1/16/2020 7:36 AM
771	inherited cancer risk Genetic testing for inherited cancer risk is the most clear for a non-expert	1/16/2020 6:36 AM
772	Using the word "inherited" means something to most people while "germline" does not.	1/16/2020 4:30 AM
773	Connotation of "germ" is negative. People cannot understand "germline" if they can't see past "germ".	1/16/2020 12:56 AM
774	The simpler, the better - and "genetic testing for cancer risk" is about as simple as it gets.	1/16/2020 12:45 AM
775	I think that genetic testing for cancer risk is clear. The other terms are redundant e.g. genetic=inherited=germline	1/16/2020 12:22 AM
776	Inherited	1/15/2020 11:46 PM
777	Germ line testing	1/15/2020 11:41 PM
778	Clearest to me	1/15/2020 11:31 PM
779	Genetic testing for hereditary cancer risk	1/15/2020 11:30 PM
780	inherited cancer risk I prefer genetic testing for inherited cancer risk because it uses terms that are generally understood (as opposed to germline testing)and it also gets across the fact that they're not testing for cancer or for a mutation that is not inherited.	1/15/2020 11:23 PM
781	I think germline is a confusing term to the general public. Including the word "risk" clarifies that these tests don't mean cancer is the certain outcome.	1/15/2020 11:16 PM
782	Genetic testing	1/15/2020 11:05 PM
783	don't have a preferred term, depends on who I'm talking to which terms I use	1/15/2020 10:40 PM
784	Genetic inherited gene	1/15/2020 10:33 PM
785	Just say "inherited" And "cancer" — much clearer. I didn't understand what my doctor said to me so never relayed the information to family. Then my sister diagnosed with ovarian cancer. Doctors need to be clear and direct as if explaining to a second grader.	1/15/2020 10:23 PM
786	I think that the risk is inherited, not the cancer. Germline is not a commin term. I agree that genetic testing is very broad	1/15/2020 10:05 PM
787	Lets see what u dont have,than what u might have genetically	1/15/2020 9:58 PM
788	inherited cancer risk Genetic testing for inherited cancer rock	1/15/2020 9:47 PM
789	Simpler words used the better for all to understand .	1/15/2020 8:45 PM
790	Genetic testing for cancer risk	1/15/2020 8:41 PM
791	inherited cancer risk Genetic testing for inherited cancer risk is o.k. as it's easily understood by most people and is fairly accurate.	1/15/2020 8:35 PM
792	N/a	1/15/2020 8:31 PM
793	inherited cancer risk Genetic testing for inherited cancer risk takes away the confusion with 23&me like tests and with genomic testing. "Genetic testing for inherited cancer" or "genetic testing for hereditary cancer" is TERRIBLE because it makes it sounds like you're testing	1/15/2020 8:17 PM

Survey on terms used for "genetic testing"

whether the person has cancer and that's not it. It's a test for mutations that change the RISK of cancer.

794	i understand the word inherited...but not germline	1/15/2020 7:22 PM
795	inherited cancer risk Genetic testing for inherited cancer risk is the clearest way to express it. If you don't have the cancer then it's just a risk. I would also be ok with Genetic testing for hereditary cancer risk.	1/15/2020 7:13 PM
796	inherited mutation Genetic testing for an inherited mutation seems to be the most accurate term and gets rid of "germline" that may not be understood. Genetic testing can identify a mutation. However, it can not quantify increased risk (that gets into statistics and a separate tool). So, to imply the link is a bit disingenuous.	1/15/2020 6:16 PM
797	Patients may not know what germline testing is. Using more familiar language will make it easier on the patients.	1/15/2020 6:08 PM
798	I'm not really well versed in genetic testing so I don't know that I have a preference.	1/15/2020 6:02 PM
799	inherited mutation Inherited Mutation because it sounds like what it is	1/15/2020 5:58 PM
800	inherited cancer risk inherited mutation Oppose "germline", as it is not well-understood. Support "inherited cancer risk" and "inherited mutation". Makes it clear that it is about familial risk.	1/15/2020 5:38 PM
801	genetic testing....just a little more simpler.	1/15/2020 5:28 PM
802	inherited cancer risk Genetic Testing for inherited cancer risk	1/15/2020 5:26 PM
803	Genetic testing for potential risk	1/15/2020 5:21 PM
804	Genetic test for Hereditary Cancer Risk	1/15/2020 5:16 PM
805	I prefer the ones that are self explanatory or that tell you exactly what you are doing or why. Adding in words such as "germline" tells me nothing of substance.	1/15/2020 5:16 PM
806	Doctors tend to do well in terminology. Most people run from doctors and BIG WORDS. Break it down, Tell the Truth. Keep it simple. Hell...make a youtube video!	1/15/2020 5:14 PM
807	Genetic testing for hereditary cancer or genetic testing for inherited cancer. I've worked for public health for the last 11 years, I believe everything needs to be at a sixth grade reading level.	1/15/2020 5:07 PM
808	inherited cancer risk Genetic Testing for inherited cancer/cancer risk because this term is clear. As the patient I understand I am being tested for something I could have inherited from someone as well potentially pass onto someone else (son, daughter etc.)	1/15/2020 5:02 PM
809	Inherited mutation or risk. Clean and simple to understand	1/15/2020 4:46 PM
810	inherited mutation genetic testing for an inherited mutation	1/15/2020 4:44 PM
811	Genetic Testing for Cancer Risk - Keep it simple, tell people what you're doing and what this information will do for them.	1/15/2020 4:35 PM
812	Genetic	1/15/2020 4:34 PM
813	I prefer using inherited, as I think that is more commonly understood than gremlin.	1/15/2020 4:32 PM
814	Genetic testing for an inherited mutation- seems very clear and concise.	1/15/2020 4:31 PM
815	Don't like germline term. Sounds like bacteria. Hereditary or unherited to me is more descriptive	1/15/2020 4:21 PM
816	Hereditary genetic testing	1/15/2020 4:06 PM
817	Genetic testing for inherited genetic mutation	1/15/2020 4:00 PM
818	Prefer using terms that bring science, clinical care and the lay community into alignment. Prefer terms that do NOT use words like mutation or cancer with negative connotations. Instead prefer words like variant or cancer risk	1/15/2020 4:00 PM
819	Genetic testing for cancer it's just plain and simple	1/15/2020 3:53 PM
820	Genetic testing for inherited cancer - because it uses the simplest terms that more of the	1/15/2020 3:51 PM

Survey on terms used for "genetic testing"

population would understand; some might not know what hereditary means even.

821	Honestly, as a layman, "germline" will take too much explanation and makes me think of a virus or something contagious.	1/15/2020 3:49 PM
822	The terms that I support in my answers are easily understood	1/15/2020 3:49 PM
823	Clear language is essential; use words that most people will know and comfortably understand.	1/15/2020 3:47 PM
824	Genetic testing for an inherited cancer risk seems self explanatory especially early on in discussions	1/15/2020 2:25 PM
825	inherited cancer risk "Genetic testing for an inherited mutation" is the simplest and most accurate term.	1/15/2020 2:00 PM
826	I don't like the term Germline.	1/15/2020 1:24 PM
827	inherited cancer risk Genetic Testing for Inherited Cancer Risk	1/15/2020 1:21 PM
828	Genetic testing for inherited cancer risks. It just sounds exactly like what it is	1/15/2020 1:10 PM
829	inherited cancer risk Genetic testing, this is the only term I have heard.	1/15/2020 12:55 PM
830	inherited mutation Genetic Testing for an Inherited Mutation - it's clear for those who aren't familiar with other terms	1/15/2020 10:54 AM
831	Easy to understand	1/15/2020 10:44 AM
832	inherited - a word we all already use and understand	1/15/2020 9:43 AM
833	inherited cancer risk I think "genetic testing for inherited cancer risk" is the clearest choice among those presented. "Genetic testing for cancer risk" is vague. "Genetic testing for an inherited mutation" is also clear, but does not mention cancer risk. "Genetic testing for hereditary cancer" or "inherited cancer" imply that cancer is being diagnosed at the time of testing. "Germline" is not a term that I knew before learning that I have a genetic mutation.	1/15/2020 8:53 AM
834	Gene mutation	1/15/2020 2:17 AM
835	I prefer the "cancer risk" given it is only a risk factor not a guarantee	1/15/2020 2:03 AM
836	Your average person understands what inherited or hereditary means in general. The word mutation is another word most people understand as something not right or wrong with something.	1/15/2020 12:11 AM
837	Anything without the word "Germline"...sounds contagious, not inherited.	1/14/2020 11:52 PM
838	None	1/14/2020 10:08 PM
839	No real preference	1/14/2020 9:57 PM
840	Mutation. I think it's easy to understand	1/14/2020 9:56 PM
841	Genetic testing for an inherited mutation- straight forward without jargon. I don't like the word cancer in the description	1/14/2020 9:17 PM
842	Genetic testing for cancer risk assessment	1/14/2020 9:12 PM
843	inherited cancer risk Genetic testing for inherited cancer risk - the thing that is inherited is risk, not cancer. And, the language of mutation sounds extremely negative.	1/14/2020 9:07 PM
844	Genetic inheritance testing	1/14/2020 8:53 PM
845	inherited mutation genetic testing for an inherited mutation	1/14/2020 8:43 PM
846	inherited mutation genetic testing for an inherited mutation	1/14/2020 8:43 PM
847	inherited mutation Genetic testing for inherited mutation sounds the most accurate and easiest to understand if you have no prior knowledge of the different term definitions.	1/14/2020 8:37 PM
848	inherited cancer risk inherited mutation I prefer genetic testing for an inherited mutation or genetic testing for cancer risk because they're easy to understand and don't make it sound like you definitely have/or will have cancer.	1/14/2020 7:35 PM

Survey on terms used for "genetic testing"

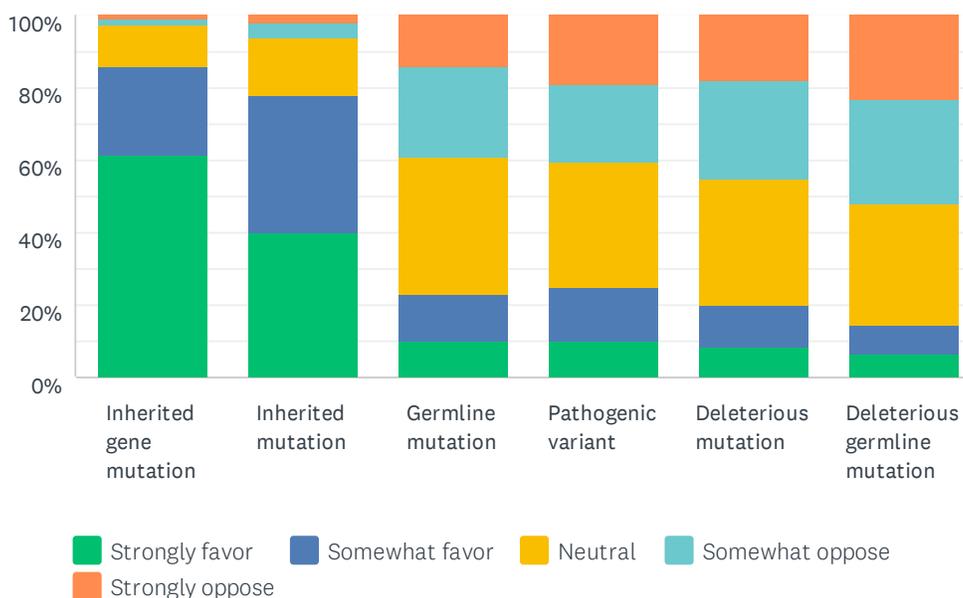
849	inherited mutation Genetic testing for an inherited mutation. I feel that this is the most descriptive term and does not indicate that cancer is eminent.	1/14/2020 7:22 PM
850	Inherited genetic testing. Easily understood	1/14/2020 7:22 PM
851	Genetic testing for an inherited cancer causing gene mutation. I think this describes what the test is.	1/14/2020 7:18 PM
852	inherited cancer risk Genetic testing for Inherited cancer risk - seems to be most layman terms for the test that majority of people can understand	1/14/2020 7:15 PM
853	I prefer the terms germline and somatic. Once you learn the terms, they're easily remembered.	1/14/2020 7:09 PM
854	Genetic testing - straight forward term that states that your Gene's are being tested.	1/14/2020 6:57 PM
855	consistency in terms	1/14/2020 6:52 PM
856	None	1/14/2020 6:21 PM
857	inherited cancer risk Putting the word inherited in the title makes it clearer to people. A biologist understands Germaine, most ordinary folks do not.	1/14/2020 6:11 PM
858	No	1/14/2020 6:03 PM
859	I understand that you're trying to make the language "germline mutation" more accessible and plain English, but the terminology also needs to be _accurate_.	1/14/2020 5:46 PM
860	Genetic Hereditary Cancer is more preferable, as it more self-explanatory	1/14/2020 5:36 PM
861	inherited cancer risk Genetic testing for inherited cancer risk -because these are already terms that most people understand	1/14/2020 5:25 PM
862	N/A	1/14/2020 5:23 PM
863	n/a	1/14/2020 5:23 PM
864	i think get like mutation sounds too scientific and is more likely to be confused with the genetic testing done on tumors.	1/14/2020 5:14 PM
865	I like the terms that are plain English. Genetic testing for inherited disease. All common words that my 6 year old kid or my 96 year old grandmother can understand.	1/14/2020 5:06 PM
866	inherited cancer risk The simpler the terms, the better. That's why I would choose "Genetic testing for inherited cancer risk." Adding the word "inherited" makes it more specific.	1/14/2020 5:00 PM
867	I think germline is a niche term for scientists, so something that says inherited would be better. Also associating it with risk of cancer, but not cancer, is a good idea.	1/14/2020 4:57 PM
868	n/a	1/14/2020 4:47 PM
869	I prefer referring to inherited risk for cancer. Making it clear that one inherits a risk for cancer, not the cancer itself, is important. I've heard from a number of women getting very upset because they think that testing positive for a BRCA (or other cancer-related) mutation means they are 100% going to get cancer. While we're at it... at least in the ovarian cancer community, women often refer to themselves as "BRCA positive" when they are referring not to an inherited mutation, but a somatic mutation found in genomic testing. I've heard women say they hope they have a BRCA mutation, when what they mean is they hope their tumor has a mutation associated with HRD, so they can get a PARP inhibitor!	1/14/2020 4:26 PM
870	Inherited. Term just seems more familiar. Never heard of germline.	1/14/2020 4:18 PM
871	inherited mutation "Genetic testing for inherited mutation" best describes the test, to me. Whenever I use the term "germline" to patients online, I always have to add "(inherited)" to clarify. I also think the 'inherited risk' is more than the mere presence or absence of the mutation, including the actual location and type of mutation as well as gene expression or the environment shared with the family - which, in a way, are also inherited from the family. Risk is not just the genes.	1/14/2020 4:17 PM
872	Genetic testing for cancer risk. I like its simplicity.	1/14/2020 4:02 PM
873	inherited mutation Genetic testing for an inherited mutation -- I think this is most clear as to what is being tested. It's not for the cancer itself or really for risk. It's for the mutation that then	1/14/2020 3:44 PM

Survey on terms used for "genetic testing"

	carries the risk or is the root of the cancer.	
874	Genetic testing for cancer risk	1/14/2020 3:29 PM
875	I don't have one, I just wouldn't have known what germline testing was.	1/14/2020 3:28 PM
876	The term germline seems confusing	1/14/2020 3:18 PM
877	No	1/14/2020 3:16 PM
878	.	1/14/2020 2:57 PM
879	Genetic testing for an inherited mutation - simpler than germline which many may not know term and does not sound as though inevitable to get cancer.	1/14/2020 2:56 PM
880	DNA testing for a mutation that puts the patient at higher risk of getting cancer or DNA test for inherited mutation	1/14/2020 2:56 PM
881	I prefer the word inherited or hereditary...rather than germline. I think people would have a better understanding with those words rather than germline mutation.	1/14/2020 2:50 PM
882	inherited mutation Genetic testing for an inherited mutation -- clearest.	1/14/2020 2:37 PM
883	Germline seems confusing	1/14/2020 2:33 PM

Q6 Health care professionals and laboratories may also use different terms for inherited gene mutations. The common term "gene mutation" is used broadly, which can lead to confusion. The groups that developed this survey are exploring which terms are more or less acceptable and clear to most people. Please rate your feelings about the following terms used to describe inherited gene mutations on a scale from "strongly favor" to "strongly oppose."

Answered: 1,653 Skipped: 45



	STRONGLY FAVOR	SOMEWHAT FAVOR	NEUTRAL	SOMEWHAT OPPOSE	STRONGLY OPPOSE	TOTAL
Inherited gene mutation	61.62% 1,013	24.15% 397	11.92% 196	1.28% 21	1.03% 17	1,644
Inherited mutation	40.11% 649	38.01% 615	16.07% 260	3.96% 64	1.85% 30	1,618
Germline mutation	10.00% 163	12.88% 210	38.28% 624	24.91% 406	13.93% 227	1,630
Pathogenic variant	9.78% 159	15.44% 251	34.26% 557	21.59% 351	18.94% 308	1,626
Deleterious mutation	8.39% 136	11.60% 188	34.79% 564	27.02% 438	18.20% 295	1,621
Deleterious germline mutation	6.51% 106	8.10% 132	33.46% 545	28.73% 468	23.20% 378	1,629

Q7 Please share with us if you have a preferred term and why you prefer it (either one of the terms above or a different term not listed).

Answered: 772 Skipped: 926

Survey on terms used for "genetic testing"

#	RESPONSES	DATE
1	==== see above comment ==== Terminology doesn't matter as much as effective treatment modes !	3/2/2020 12:50 AM
2	n/a	3/2/2020 12:49 AM
3	n/a	2/25/2020 7:18 PM
4	Inherited gene mutation	2/25/2020 7:17 PM
5	Again, please please please don't use germline	2/25/2020 7:14 PM
6	Just simple words that most people know. Almost everyone understands inherited and gene	2/25/2020 7:13 PM
7	No	2/25/2020 7:11 PM
8	The words deleterious or pathogenic have negative connotations.	2/25/2020 7:05 PM
9	Inherited Gene mutation	2/25/2020 7:01 PM
10	Inherited gene mutation. Simple and to the point...	2/21/2020 8:59 PM
11	"Inherited gene mutation" is a clear laymen's term. While it is redundant, it help people who have no familiarity with mutation	2/21/2020 7:59 PM
12	no	2/21/2020 4:13 PM
13	Inherited gene mutation	2/21/2020 3:57 PM
14	I personally have not heard or understand the term gremlin so any use of that I would oppose	2/21/2020 2:54 PM
15	No	2/21/2020 2:25 PM
16	n/a	2/21/2020 2:21 PM
17	The shorter the term, as long as it captures the meaning, the better. For the purpose of patients, the more common the language, the better.	2/21/2020 1:03 PM
18	none	2/21/2020 11:52 AM
19	Inherited mutation	2/21/2020 11:27 AM
20	na	2/21/2020 11:11 AM
21	I have none at this time.	2/21/2020 11:09 AM
22	Blamk	2/21/2020 10:32 AM
23	unsure	2/21/2020 10:28 AM
24	easy to understand - Inherited gene mutation	2/21/2020 10:24 AM
25	Inherited gene mutation	2/21/2020 10:14 AM
26	none	2/21/2020 8:58 AM
27	If the goal is to increase understanding of terms and Increasing communication then we need to use the most simple terms. Using verbiage that is technical and more in line with practitioners than patients increases the likelihood of misunderstanding from a patient's perspective.	2/20/2020 9:37 PM
28	The tests generally are not looking for mutations that are positive, so it seems unnecessary to say "deleterious." "Inherited gene mutation" best sums it up.	2/20/2020 9:27 PM
29	No	2/20/2020 9:18 PM
30	Inherited gene mutation. It's very clear.	2/20/2020 9:16 PM
31	Inherited gene mutations is simple and descriptive. Neutral sounding	2/20/2020 9:00 PM
32	inherited (gene) mutation for clarity	2/20/2020 9:00 PM
33	inherited gene mutation	2/20/2020 8:41 PM
34	inherited gene mutation	2/20/2020 8:33 PM

Survey on terms used for "genetic testing"

35	None preferred	2/20/2020 8:24 PM
36	Inherited mutation	2/20/2020 8:24 PM
37	Same as above	2/20/2020 8:23 PM
38	None	2/20/2020 8:15 PM
39	No preference	2/20/2020 8:13 PM
40	Not really	2/20/2020 8:06 PM
41	I listed it above.	2/20/2020 8:02 PM
42	inherited mutation/gene mutation -- keep it neutral	2/20/2020 8:02 PM
43	Again clear wording is key	2/20/2020 7:54 PM
44	I prefer "inherited." Keep it simple. When people are worried about cancer, they don't also want to have to learn a new set of five-dollar words to go with it!	2/20/2020 7:41 PM
45	Deleterious and germline don't mean anything to me and I have a science background. Pathogenic variant is only somewhat better. Just say inherited gene mutation which plain English.	2/20/2020 7:28 PM
46	It is easy to understand	2/20/2020 7:26 PM
47	"Deleterious" and "pathogenic" can be confusing. Deleterious is very negative and infers that the individual will get the disease. Pathogen is confusing - I think of a pathogen as bacteria or another organism.	2/20/2020 7:21 PM
48	I understood BrCa 1, 2 and 3	2/20/2020 7:10 PM
49	Inherited gene mutation I understand	2/20/2020 7:03 PM
50	No	2/20/2020 7:00 PM
51	Inherited gene mutation is the most specific. Germline suggests contamination.	2/20/2020 6:57 PM
52	DO NOT CARE	2/20/2020 6:57 PM
53	simple and straight forward	2/20/2020 6:53 PM
54	None	2/20/2020 6:45 PM
55	Noi	2/20/2020 6:44 PM
56	Inherited gene mutation - common clear terminology.	2/20/2020 6:41 PM
57	None	2/20/2020 6:28 PM
58	Nope	2/20/2020 6:27 PM
59	Same reason as before- some terms are more clear to average people (non-science/ non-medical).	2/20/2020 6:27 PM
60	I think Inherited gene mutation is self-explanatory for most people. I have done a lot of research on this topic and haven't heard of many of the other phrases and they sound scarier.	2/20/2020 6:26 PM
61	No preference	2/20/2020 6:13 PM
62	No	2/20/2020 6:09 PM
63	Some terms I have stated being opposed to, are often not understood by many, and should be limited to the most simple language, so as to be understood by all concerned.	2/20/2020 6:08 PM
64	Reduce confusion	2/20/2020 6:05 PM
65	Germline mutation is the most concise and informative term to me.	2/20/2020 6:04 PM
66	None	2/20/2020 6:00 PM
67	mutation	2/20/2020 5:56 PM

Survey on terms used for "genetic testing"

68	Inherited gene mutation seems more clear, specific and accurate	2/20/2020 5:43 PM
69	I just understand what inherited mutation means, as opposed to the other terms.	2/20/2020 5:35 PM
70	Na	2/20/2020 5:32 PM
71	Not sure	2/20/2020 5:30 PM
72	Inherited gene mutation	2/20/2020 5:29 PM
73	Don't like any above	2/20/2020 5:27 PM
74	"Inherited gene mutation". Preferred as it says what it means and patient does not need a medical dictionary.	2/20/2020 5:26 PM
75	Simplistic to understand	2/20/2020 5:20 PM
76	I don't like of them. They all sound scarier than cancer.	2/20/2020 5:18 PM
77	None	2/20/2020 5:16 PM
78	Layman's terms are easiest	2/20/2020 5:15 PM
79	INHERITED MUTATION	2/20/2020 5:04 PM
80	more understandable by the general public	2/20/2020 5:03 PM
81	no	2/20/2020 5:01 PM
82	Deleterious gene mutation. Appears most accurate to me. Do not favor the term "inherited."	2/20/2020 4:58 PM
83	Simplest label	2/20/2020 4:52 PM
84	inherited gene mutation is clear to me. more than half of my female cousins had early onset breast cancer and many were tested for the bracha gene. My mother did not have it My mothers 2 sisters had ovarian cancer and one lived for 18 years after diagnosis.	2/20/2020 4:50 PM
85	Stay away from germline. Yuck.	2/20/2020 4:45 PM
86	Deleterious Mutation- term I'm most familiar with	2/20/2020 4:41 PM
87	Na	2/20/2020 4:38 PM
88	Genetic Family History.	2/20/2020 4:36 PM
89	I prefer inherited gene mutation so I know what was mutated.	2/20/2020 4:36 PM
90	Hereditary deleterious mutation. Clear that it's passed on, clear that it has a bad effect, clear its not normal	2/20/2020 4:35 PM
91	none.	2/20/2020 4:34 PM
92	inherited mutation	2/20/2020 4:33 PM
93	N/A	2/20/2020 4:28 PM
94	Inherited mutation: It does not have a negative connotation — just states what the test is specifically for	2/20/2020 4:28 PM
95	Inherited gene mutation	2/20/2020 4:27 PM
96	Genetic inherited mutation.	2/20/2020 4:24 PM
97	Inherited gene mutation; meaning is clearer for non-health professionals than "germline mutation."	2/20/2020 4:23 PM
98	na	2/20/2020 4:19 PM
99	Inherited gene mutation	2/20/2020 4:19 PM
100	Germline and deleterious sound ominous as does pathogenic variant. I believe using more positive terms sound better.	2/20/2020 4:17 PM
101	Inherited gene mutation	2/20/2020 4:17 PM

Survey on terms used for "genetic testing"

102	No preference	2/20/2020 4:14 PM
103	Inherited gene mutation	2/20/2020 4:12 PM
104	Inherited gene mutation seems the clearest.	2/20/2020 4:12 PM
105	Inherited gene mutation, in my opinion, seems the most direct and simply stated without causing confusion	2/20/2020 4:12 PM
106	Inherited mutation	2/20/2020 4:11 PM
107	same as above	2/20/2020 4:11 PM
108	no preference	2/20/2020 4:11 PM
109	I have never heard of Germline mutations and would not know what it meant	2/20/2020 4:09 PM
110	Inherited gene mutation - easily understandable by laypeople	2/20/2020 4:08 PM
111	Inherited (gene) mutation sounds less negative and is simpler terminology than the others.	2/20/2020 4:07 PM
112	n/a	2/20/2020 4:05 PM
113	All are ok	2/20/2020 4:05 PM
114	the geneticists prefer Pathogenic Variant to get away from the word "mutation" which has negative connotations. I worry that it is too unfamiliar	2/20/2020 4:03 PM
115	Gene carrier	2/20/2020 4:02 PM
116	Need to choose term that does not sound frightening or too obscurely scientific. One that has an intuitive unemotional meaning	2/20/2020 4:01 PM
117	Again, the perceived connotation	2/20/2020 4:00 PM
118	Inherited gene mutation	2/20/2020 4:00 PM
119	Inherited Mutation I think again this is something most people can understand. It is scary to people to be in the situation of genetic testing and using esoteric scientific language confuses people and makes for more anxiety.	2/20/2020 4:00 PM
120	I don't like "germline" because it can be thought of as contagious. I don't know what deleterious means.	2/20/2020 3:59 PM
121	Inherited gene mutation is clearer in laymen's terms	2/20/2020 3:58 PM
122	inherited or genetic mutation just makes more sense	2/20/2020 3:57 PM
123	Na	2/20/2020 3:57 PM
124	The word germline is poorly understood by non-medical personnel	2/20/2020 3:57 PM
125	Inherited gene mutation	2/20/2020 3:56 PM
126	Just keep them accurate and easy to understand (e.g., what's a germline?)	2/20/2020 3:56 PM
127	Vocabulary is not defined, therefore it is meaningless.	2/20/2020 3:56 PM
128	inherited gene mutation	2/20/2020 3:56 PM
129	Inherited gene mutation is descriptive and accurate.	2/20/2020 3:55 PM
130	inherited mutation - term understood by most people	2/20/2020 3:53 PM
131	As a healthcare professional I am familiar with most/all of these terms. However, from speaking with friends, most do not know what these terms mean. In fact, I have met people who do not understand the difference between genetic cancer screening and a mammogram.	2/20/2020 3:53 PM
132	Again, the term whose meaning is most apparent to the general public is best.	2/20/2020 3:53 PM
133	N/A	2/20/2020 3:53 PM
134	Inherited gene mutation	2/20/2020 3:52 PM
135	Xxx	2/20/2020 3:52 PM

Survey on terms used for "genetic testing"

136	Inherited gene mutation	2/20/2020 3:52 PM
137	I don't really like any of these very much	2/20/2020 3:51 PM
138	inherited mutation - simple and easy to comprehend	2/20/2020 3:51 PM
139	Inherited gene mutation. I think everyone can understand this term, even if you are not familiar with DNA testing.	2/20/2020 3:50 PM
140	Inherited mutation	2/20/2020 3:50 PM
141	Keep it simple	2/20/2020 3:49 PM
142	Clear simple language with more common terms is easier for people who are newcomers to learning about the disease.	2/20/2020 3:49 PM
143	The above has to be carefully explained to the patient	2/20/2020 3:49 PM
144	no preference	2/20/2020 3:49 PM
145	inherited gene mutation	2/20/2020 3:49 PM
146	I believe "inherited gene mutation" most accurately describes the mutation in terms most can understand.	2/20/2020 3:49 PM
147	inherited mutation	2/20/2020 3:49 PM
148	n/a	2/20/2020 3:48 PM
149	Inherited gene mutation sounds the most clear	2/20/2020 3:48 PM
150	Inherited gene mutation, simple, doesn't necessarily mean that it's a dangerous mutation.	2/20/2020 3:48 PM
151	Inherited gene mutation - it says exactly what you mean	2/20/2020 3:47 PM
152	No specifics	2/20/2020 3:47 PM
153	no preference	2/20/2020 3:47 PM
154	See above	2/20/2020 3:46 PM
155	none	2/20/2020 3:45 PM
156	Inhereted gene	2/18/2020 4:13 PM
157	The physician or genetic counselor will have to explain the terminology and that doesn't always happen. When you are discussing this with health care persons you are stressed and scared. Later when you are calm and look at the medical terminology it makes no sense.	2/18/2020 3:11 PM
158	the only ones I understand are the two I checked. If someone hands out definitions before using the others, okay. Otherwise they're too unclear.	2/18/2020 11:35 AM
159	N/a	2/17/2020 11:28 PM
160	Don't really like any of them	2/17/2020 11:04 PM
161	inhereted gene mutation	2/17/2020 7:27 PM
162	Pathogenic means it could express (in various ways), and a person is more susceptible Deleterious sounds like cancer is inevitable.	2/17/2020 2:51 PM
163	Inherited gene mutation	2/16/2020 10:01 AM
164	Inherited mutation	2/15/2020 11:37 PM
165	Inherited gene mutation (as above)	2/15/2020 5:33 PM
166	This is accurate	2/15/2020 1:40 PM
167	Inherited gene mutation	2/15/2020 1:23 PM
168	Inherited mutation or inherited gene mutation. They use "simple" terms that aren't too complex.	2/15/2020 1:02 PM
169	inherited mutation is more descriptive.	2/15/2020 11:04 AM

Survey on terms used for "genetic testing"

170	Inherited gene mutation- easy to understand	2/15/2020 9:46 AM
171	Inherited gene mutation: it uses common verbage	2/14/2020 10:46 PM
172	Inherited gene mutation	2/14/2020 12:16 PM
173	Inherited gene mutation	2/14/2020 12:05 PM
174	Again, "genetic" is a term used much more often as well as "inherited" and more readily recognized.	2/14/2020 7:49 AM
175	I think I prefer the inherited gene mutation term because it sounds clear.	2/13/2020 8:57 PM
176	nothing to add here	2/13/2020 8:46 PM
177	I think terms used should be easy for anyone to understand	2/13/2020 2:58 PM
178	keep the vocab basic so that all can understand and not necessarily have to learn new medical vocab	2/13/2020 11:53 AM
179	Inherited gene mutation at least tells us something concrete. You inherited something that could cause cancer. Germline mutation? Is that bad? I have no idea. I guess mutation is but what's a germline?	2/12/2020 10:12 PM
180	No preferred term.	2/12/2020 10:00 PM
181	None	2/12/2020 9:13 PM
182	Inherited Gene Mutation is the clearest & simplest term in my opinion and I think clear and simple is always better.	2/12/2020 2:47 PM
183	Definitely want the word inherited. Definitely want the word gene and definitely want the word mutation. This says it all.	2/12/2020 1:18 PM
184	Inherited gene mutation uses the word inherited which is well understood. But some may not understand the word mutation.	2/12/2020 1:12 PM
185	n/a	2/12/2020 1:06 PM
186	Inherited gene mutation. It is easy to understand	2/12/2020 12:45 PM
187	No preferred term	2/12/2020 10:07 AM
188	We need to remember health literacy levels! Most of those terms are not understood at the reading grade level we need. "Inherited" is probably the only term most would understand	2/12/2020 9:50 AM
189	same reason as above	2/11/2020 11:41 PM
190	Inherited gene mutation	2/11/2020 11:27 PM
191	inherited gene mutation	2/11/2020 10:26 PM
192	Inherited mutation or inherited gene mutation is the simplest terminology	2/11/2020 10:23 PM
193	"Inherited gene mutation", again because it is easily understood by the general public.	2/11/2020 9:46 PM
194	Germline	2/11/2020 9:42 PM
195	Inherited mutation; because it is what I'm used to.	2/11/2020 7:15 PM
196	I have no preferred term. I just look for consistant and explained terms.	2/11/2020 7:06 PM
197	inherited gene mutation	2/11/2020 6:06 PM
198	not sure	2/11/2020 5:55 PM
199	No preferred term, but the clearer/less jargon-y, the term, the better. Those that are labeled in very plain language would seem to resonate and make sense to the broadest swath of people.	2/11/2020 5:49 PM
200	None	2/11/2020 5:39 PM
201	Inherited gene mutation.	2/11/2020 5:28 PM
202	N/A	2/11/2020 5:03 PM

Survey on terms used for "genetic testing"

203	Zzz	2/11/2020 4:56 PM
204	again just a thorough explanation of terms; none preferred	2/11/2020 4:55 PM
205	Mutation has too many connotations (de novo mutation, mutant, DNA damage, etc). We all have a good number of variations in our DNA because we are not all identical. Calling one that may cause a problem or increase risk for a problem a pathogenic variant makes most sense and is what the ACMG recommends.	2/11/2020 4:41 PM
206	I am not familiar with most of the terms so I am not sure how I feel about the terminology.	2/11/2020 4:38 PM
207	Inherited mutation tells me that I inherited a likely hood of genetic mutations.	2/11/2020 4:20 PM
208	Not sure	2/11/2020 4:20 PM
209	Inherited gene mutation -- the words simply say that its a gene that a child inherits from a parent.	2/11/2020 4:17 PM
210	Prefer using words that are commonly understood - like inherited.	2/11/2020 3:48 PM
211	Deleterious and pathogenic are too difficult to understand. Same for germline.	2/11/2020 3:29 PM
212	most of these terms will not be meaningful to the general public	2/11/2020 1:43 PM
213	Inherited genetic mutation	2/11/2020 9:56 AM
214	I believe the terms ' Inherited" and "gene" are commonly understood, while "deleterious", "germline" and "pathogenic variant" are definitely not. Am surprised to see suggestion that "gene mutation" is confusing!	2/11/2020 9:23 AM
215	No	2/11/2020 8:23 AM
216	Inherited gene mutation is more understanding to me because it uses common words that are easily understood.	2/11/2020 1:18 AM
217	Still confusing. . I liked inhertd gene mutations The rest seem like subcategories .	2/10/2020 9:52 PM
218	Inherited gene mutation	2/10/2020 6:00 PM
219	Inherited gene mutation is easier to understand by lay public.	2/10/2020 5:36 PM
220	Pathogenic variant, because it seems more accurate.	2/10/2020 4:24 PM
221	Inherited gene mutation more clearly understood by lay people	2/10/2020 2:44 PM
222	Its just my choice	2/10/2020 12:49 PM
223	Genetic review	2/10/2020 9:52 AM
224	Yes	2/10/2020 8:58 AM
225	no one except a medical researcher can understand the term deleterious	2/10/2020 8:38 AM
226	genetic inherited	2/10/2020 8:31 AM
227	Seems easy to understand by broader populations. Not as technical.	2/9/2020 10:14 PM
228	Genetic mutation	2/9/2020 9:58 PM
229	don't know but I'm not familiar with germline as a term and I would prefer the terms that sound less terrifying, though also not euphemistic, that sound more neutral.	2/9/2020 9:10 PM
230	inherited gene mutation. easy to understand	2/9/2020 7:35 PM
231	No I don't think so. These are good	2/9/2020 7:23 PM
232	Inherited gene mutation	2/9/2020 6:26 PM
233	Inherited mutation. Inherited gene mutation. Because these also may be the most clear for people with no background in medical/genetic terminology	2/9/2020 3:32 PM
234	I like the terms I can clearly understand. I'm not familiar with the other terms.	2/9/2020 2:31 PM
235	F	2/9/2020 12:39 PM

Survey on terms used for "genetic testing"

236	Na	2/9/2020 9:56 AM
237	Inherited gene mutation is the clearest term to me.	2/9/2020 7:22 AM
238	idk	2/9/2020 4:13 AM
239	None	2/8/2020 11:09 PM
240	Inherited mutation.	2/8/2020 9:53 PM
241	Inherited gene mutation, it is plain English and easy to understand	2/8/2020 8:20 PM
242	Na	2/8/2020 6:59 PM
243	I prefer terms such as inherited mutation.	2/8/2020 5:12 PM
244	Inherited gene mutation- again, for this customer base we are patients who know virtually NO MEDICAL BASED VERBIAGE. "MISS make it simple stupid"	2/8/2020 3:46 PM
245	Inherited mutation	2/8/2020 3:36 PM
246	Inherited gene mutation seems like a gem that non scientific people would still understand.	2/8/2020 3:29 PM
247	Again, I prefer the word inherited, and the specifics of gene with the word mutation.	2/8/2020 12:40 PM
248	No	2/8/2020 10:07 AM
249	Genetic mutation	2/8/2020 9:11 AM
250	Anything with word germline	2/8/2020 8:12 AM
251	My preference is inherited gene mutation.	2/8/2020 4:25 AM
252	Prefer Inherited gene mutation because it's in layman's terms.	2/8/2020 3:08 AM
253	Hereditary cancer	2/8/2020 1:50 AM
254	Pathogenic variant and inherited mutation .	2/8/2020 12:57 AM
255	Inherited mutation	2/7/2020 11:51 PM
256	None	2/7/2020 11:23 PM
257	N/A	2/7/2020 11:07 PM
258	Inherited mutation - I think it describes what the test will show.	2/7/2020 10:57 PM
259	Na	2/7/2020 9:52 PM
260	Inherited mutation. More people probably understand what that means as opposed to pathogenic variant.	2/7/2020 9:27 PM
261	Inherited mutations	2/7/2020 9:11 PM
262	The terms gene,germline,deleterious, pathogenic, and mutation are non relatable...the only terminology there that is relatable to lay language is inherited	2/7/2020 7:45 PM
263	Cannot decide this.	2/7/2020 7:02 PM
264	None	2/7/2020 7:00 PM
265	Inherited gene mutation because it is the easiest terminology to understand	2/7/2020 5:44 PM
266	Genetic seems most clear and germline adds nothing to the definition	2/7/2020 5:35 PM
267	Mutations	2/7/2020 5:29 PM
268	Inherited gene mutation is the clearest/easiest to understand.	2/7/2020 5:26 PM
269	"Germ" I explained my opposition above. and "deleterious" just seems like a long, academic word that can be better explained by a simpler word.	2/7/2020 4:45 PM
270	Inherited gene mutation is my preferred term. It clearly implies the gene mutation came from your parents, yet it does not state that you will absolutely have the cancer with which the gene mutation is associated.	2/7/2020 4:38 PM

Survey on terms used for "genetic testing"

271	Inherited gene mutation. I feel the general public can understand this term.	2/7/2020 4:37 PM
272	No preference	2/7/2020 4:29 PM
273	I think people who haven't taken genetics won't really understand deleterious mutations, germline or pathogenic variant.	2/7/2020 3:45 PM
274	Have none at this time	2/7/2020 3:21 PM
275	Inherited mutation.	2/7/2020 3:15 PM
276	Inherited mutation and inherited gene mutation would be understandable/familiar to more individuals.	2/7/2020 3:12 PM
277	Not sure	2/7/2020 2:46 PM
278	Inherited gene mutation	2/7/2020 2:44 PM
279	Don't know what some of the words mean	2/7/2020 2:36 PM
280	To be clear to all	2/7/2020 2:25 PM
281	inherited mutation or inherited gene mutation is easy to understand	2/7/2020 2:25 PM
282	NA	2/7/2020 2:11 PM
283	Inherited Gene mutated	2/7/2020 2:08 PM
284	like any other - car repairs one may want to know what size bolt failed and is the replacement better while others want o "when ready" do both simple first, details follow or reference to add'l	2/7/2020 1:55 PM
285	No	2/7/2020 1:49 PM
286	Deleterious is a word that will make people tune out. Or they'll get "stuck" on that word and not listen to the words that follow.	2/7/2020 1:45 PM
287	Inherited gene mutation. Easier to remember and understand	2/7/2020 1:22 PM
288	Inherited germ line mutation. It isn't confusing. And easier to understand	2/7/2020 1:18 PM
289	i don't know	2/7/2020 1:14 PM
290	unk	2/7/2020 10:59 AM
291	I prefer to not speak in jargon for the general public and think that "inherited" is more easily understood than "germline." People who are freshly diagnosed with cancer are often anxious, scared, and traumatized - their memories are impaired and any term that sounds unfamiliar will be lost or demonized.	2/7/2020 10:15 AM
292	Inherited gene mutation is easy and understandable to the mine set of under educated people	2/7/2020 10:02 AM
293	pathogenic variant is the current term that has been "agreed" upon. I think it is the most descriptive, but potentially confusing for non-genetics providers.	2/7/2020 9:21 AM
294	mutation and inherited are easy terms to understand	2/7/2020 9:21 AM
295	Inherited mutation and inherited gene mutation speak right to the point. easy to understand.	2/7/2020 9:10 AM
296	I think plain simple language makes sense for the average person who doesn't understand scientific terms.	2/7/2020 8:58 AM
297	No discussion on issue	2/7/2020 8:52 AM
298	In my mind inherited Gene mutation more accurately describes the issue	2/7/2020 5:55 AM
299	none	2/6/2020 11:22 PM
300	Inherited gene mutation	2/6/2020 10:40 PM
301	Germline suggests disease is germ based	2/6/2020 10:38 PM
302	When my mother had pancreatic cancer, my father taped the conversations with the oncologist and surgeon and would go home and look specific terms up in a medical dictionary that he	2/6/2020 10:34 PM

Survey on terms used for "genetic testing"

hadn't understood. What a waste of his valuable time that could be better spent with my mother or just resting up to support her. Common terms always work better.

303	Germline mutation it's something new to me I'm not really sure if I understand it but if it is if it is what I think it is this what I think it is yes I would like to learn more. if it is what I think it is then yes there should be booklet about it and this would really help to educate people	2/6/2020 8:47 PM
304	Fewer syllables, more common words that are understood by most people are favorable compared to medical terms that aren't as accessible to patients and their families.	2/6/2020 8:22 PM
305	inherited gene mutation. easy.	2/6/2020 7:21 PM
306	The most easily understood words should be used	2/6/2020 7:17 PM
307	Same reasoning as previously noted. Pathogenic over deleterious. Inherited over germline.	2/6/2020 7:12 PM
308	Inherited mutation seems like the easiest term to understand if your cancer is likely to be passed on to your children.	2/6/2020 7:08 PM
309	NA	2/6/2020 6:43 PM
310	?	2/6/2020 6:41 PM
311	Genetic mutations	2/6/2020 6:39 PM
312	Deleterious mutation sounds like something that can be wiped away with no problems. Poof and it is gone whatever it was. It was something to fear but now you see it and it is gone. If it is harmful to the body then say it. I do not what would be a kinder word or words. You can always keep it and put a parenthesis around the simpler term.	2/6/2020 6:28 PM
313	Genetic mutation	2/6/2020 6:22 PM
314	Inherited gene mutation. It is precise.	2/6/2020 6:19 PM
315	Inherited gene mutation - easily understood	2/6/2020 6:13 PM
316	inherited gene mutation seems most clear; some of these terms I've never heard of	2/6/2020 6:11 PM
317	inherited gene mutation	2/6/2020 5:42 PM
318	The more correct the description is as opposed to vague	2/6/2020 5:32 PM
319	Isn't deleterious a type of mutation but inherited is more general? I like either inherited or inherited gene mutation.	2/6/2020 5:16 PM
320	NA	2/6/2020 4:59 PM
321	Deleterious inherited gene mutation--it should be most clear to most people	2/6/2020 4:37 PM
322	Inherited gene mutation as it is understandable to most people. The others are words most people might not understand. When you are diagnosed or having test so much is thrown at you that the simpler the terms the easier it is to comprehend and less you have to research.	2/6/2020 4:29 PM
323	Inherited mutation, easier to understand and less threatening.	2/6/2020 4:19 PM
324	Clarity without jargon/technical terms not widely understood	2/6/2020 4:17 PM
325	Na	2/6/2020 4:08 PM
326	Inherited gene mutation	2/6/2020 4:07 PM
327	Germline mutation.	2/6/2020 3:56 PM
328	no opinion. whatever	2/6/2020 3:48 PM
329	genetic mutation, Inherited mutation, pathogenic variant	2/6/2020 3:39 PM
330	Inherited	2/6/2020 3:38 PM
331	Most people don't know what pathogenic or deleterious mean. When we get our results, we want words like we see on informed consent forms... Rare, Unlikely, Frequent, Likely, Very Likely. Better still if chances are also put in percentages.	2/6/2020 3:04 PM
332	I don't understand none of it.	2/6/2020 2:49 PM

Survey on terms used for "genetic testing"

333	As above I don't like germaine. Keep words simple for the layperson.	2/6/2020 2:38 PM
334	Inherited gene mutation seems to spell it out without big words	2/6/2020 2:25 PM
335	Neutral	2/6/2020 2:11 PM
336	Inherited gene mutation...because it doesn't sound intimidating.	2/6/2020 1:39 PM
337	never had any of this done	2/6/2020 1:26 PM
338	No preference	2/6/2020 1:20 PM
339	None	2/6/2020 1:18 PM
340	None	2/6/2020 1:07 PM
341	mutation is an unsettling word	2/6/2020 12:46 PM
342	Use words that are familiar to average non medical person.	2/6/2020 12:07 PM
343	Same issues with confusing germline of cancer gene mutation progression versus inherited genes from parents.	2/6/2020 11:49 AM
344	I tend to lean toward Inherited gene mutation because it is easier to understand than most of the others.	2/6/2020 11:48 AM
345	"Inherited gene mutation" - again, it is self explanatory.	2/6/2020 11:46 AM
346	They are all fine.	2/6/2020 11:24 AM
347	Inherited gene mutation is good. Because most lay people may understand and remember it.	2/6/2020 11:18 AM
348	Germline mutation	2/6/2020 10:49 AM
349	The terms I prefer have the lowest reading level and would require the least additional information in order for most people too understand it	2/6/2020 10:41 AM
350	inherited gene mutation. germline sounds condemning, like my family isn't clean	2/6/2020 10:40 AM
351	N:/A	2/6/2020 10:08 AM
352	Inherited mutation	2/6/2020 9:53 AM
353	Inherited gene mutation	2/6/2020 9:20 AM
354	simple is better	2/6/2020 9:19 AM
355	inherited gene mutation	2/6/2020 8:53 AM
356	No	2/6/2020 8:48 AM
357	Inherited gene mutation - just seems to be the most clear	2/6/2020 8:46 AM
358	no preference (plain English)	2/6/2020 8:03 AM
359	Genetic mutation	2/6/2020 7:20 AM
360	n/a	2/6/2020 7:10 AM
361	inherited gene mutation - understandable to lay person	2/6/2020 6:51 AM
362	Inherited Mutation is easiest to understand.	2/6/2020 6:18 AM
363	Inherited mutation	2/6/2020 4:25 AM
364	?	2/6/2020 1:03 AM
365	Inherited gene mutation - because alit of family has had cancer	2/6/2020 12:33 AM
366	Inherited gene mutation	2/6/2020 12:10 AM
367	Inherited gene mutation seems the clearest.	2/5/2020 11:16 PM
368	Gene mutation, it's clear	2/5/2020 11:13 PM

Survey on terms used for "genetic testing"

369	N/a	2/5/2020 10:56 PM
370	Inherited gene mutation - I understand each word in the term, and I think it's better to specify inherited GENE mutation, as simply "inherited mutation" could be received as anything. Also I consider myself to be somewhat educated, and while I could deduce what "deleterious" "germline" and "pathogenic" mean I have never heard any of these terms ... so maybe I'm not that educated haha but I'm thinking if I'm not familiar with them I don't think any one else in my family would be either.	2/5/2020 10:43 PM
371	No	2/5/2020 10:32 PM
372	I do not have a preference	2/5/2020 10:28 PM
373	The simpler the language, the better for everyone. Please be sure that the words you choose don't contribute to stigmatizing of people who have cancer. Terms like germline, pathogenic, deleterious could lead to misunderstanding and stigmatization.	2/5/2020 10:24 PM
374	Na	2/5/2020 10:22 PM
375	I do not preferred term.	2/5/2020 10:14 PM
376	Inherited gene mutation seems the clearest and simplest to understand.	2/5/2020 10:08 PM
377	Inherited gene mutation again is a general layman's term and sounds self explanatory	2/5/2020 10:05 PM
378	What is wrong with gene mutation., why confuse and add more. That term tells alot	2/5/2020 9:36 PM
379	I prefer inherited gene mutation because I understand what they are looking for.	2/5/2020 9:31 PM
380	No preferences	2/5/2020 9:31 PM
381	Inherited gene mutation still sounds like family gene	2/5/2020 9:29 PM
382	Inherited gene mutation . It is the simplest ,relatable term	2/5/2020 9:19 PM
383	I would like testing	2/5/2020 9:14 PM
384	The term "Germline" doesn't mean anything to me.	2/5/2020 8:47 PM
385	Inherited gene mutation	2/5/2020 8:45 PM
386	Inherited mutation is preferable	2/5/2020 8:42 PM
387	Inherited mutation	2/5/2020 8:33 PM
388	I'm familiar with the English word "deleterious," but it confuses me in this context. We are talking about cell mutations in the context of cancer, so what is the alternative to them being deleterious? This implies that there's some other type of mutation. Is there? With "pathogenic," again, I know what the word means in English. But unless its used to differentiate between options, why use it? (Maybe there is some alternative and I'm just ignorant about it.) As with the earlier question, the term "germline" sounds absurd to me. I know what a "germ" is and I know what a "line" is. I'm familiar with "line" in other domains in which I'm a subject matter expert, but I've never come across "germline" to me so its gibberish. Adding to the confusion is that I (think I) know that "germs," as a layperson would usually use the word, has nothing to do with how cancer operates. Further, the layperson understanding of the word pathogen more commonly refers to "traditional" illnesses. Like the bacteria that gives you the flu is a pathogen. It feels like the word "pathogen" is being overburdened when used to refer to cancer. Cancer operates so differently from many other diseases that it can be confusing when using such terms.	2/5/2020 8:28 PM
389	I only like the terms that are easy to understand	2/5/2020 8:12 PM
390	Inherited gene mutation - most clear	2/5/2020 8:11 PM
391	Again, call it what it is—inherited.	2/5/2020 8:11 PM
392	None	2/5/2020 8:05 PM
393	Inherited gene mutation bc it's straight forward	2/5/2020 8:04 PM
394	Inherited	2/5/2020 7:42 PM
395	Genetic testing	2/5/2020 7:14 PM

Survey on terms used for "genetic testing"

396	No preferred term.	2/5/2020 7:13 PM
397	Inherited gene mutation	2/5/2020 7:02 PM
398	just do not completely understand what those terms mean so I cannot prefer them without understanding	2/5/2020 7:00 PM
399	None	2/5/2020 6:57 PM
400	No preference	2/5/2020 6:50 PM
401	Simpler is better. Though I know what the word deleterious means, it's possible the average person would t. Also, it's more frightening to hear that a mutation has an automatic negative connotation. Even if it is accurate, it may unnecessarily predispose the patient's anxiety levels.	2/5/2020 6:47 PM
402	None	2/5/2020 6:45 PM
403	Always	2/5/2020 6:43 PM
404	no preference	2/5/2020 6:42 PM
405	I prefer inherited to some terms appear to have a negative tone or connotation that implies disease or even seems to blame the person for an inherited mutation.	2/5/2020 6:34 PM
406	Again, I understand inherited.	2/5/2020 6:32 PM
407	Inherited mutation	2/5/2020 6:26 PM
408	As I preciously said this was a lot of information given to someone that just found out she has triple negative breast cancer	2/5/2020 6:18 PM
409	n/a	2/5/2020 6:17 PM
410	Inherited	2/5/2020 6:14 PM
411	Inherited gene mutation	2/5/2020 6:13 PM
412	Inherited mutation	2/5/2020 6:04 PM
413	Can't think if anything right now	2/5/2020 6:00 PM
414	I don't have a clear understanding of any of these terms to replace a term with my vocabulary	2/5/2020 5:55 PM
415	What I'm familiar with	2/5/2020 5:55 PM
416	Again, inherited is a simple term that most people will understand.	2/5/2020 5:51 PM
417	no	2/5/2020 5:36 PM
418	Inherited Gene variant again seem to be a more layman understandable terminology. Mutation just sounds so negative and bad, as a cancer patient I hear ENOUGH bad terms. Since this testing seems to be a good thing for everyone in the family lets not use scary terms like mutation.	2/5/2020 5:32 PM
419	Inherited mutation	2/5/2020 5:29 PM
420	I'm not sure what to think.	2/5/2020 5:17 PM
421	I prefer inherited because that is something that is pasted down from one parent to a child. Mutation seems more like a deformity with a person's limbs.	2/5/2020 5:15 PM
422	I see something that makes sense not does not make sense. Understand	2/5/2020 5:15 PM
423	Easy to understand what is being referred to.	2/5/2020 5:15 PM
424	No preferred term	2/5/2020 5:08 PM
425	Inherited gene mutation because again you clearly know what it is and where it came from	2/5/2020 4:55 PM
426	None	2/5/2020 4:55 PM
427	No opinion	2/5/2020 4:54 PM
428	None	2/5/2020 4:53 PM

Survey on terms used for "genetic testing"

429	Na	2/5/2020 4:48 PM
430	Germline	2/5/2020 4:43 PM
431	Genetic Testing Genetic/Hereditary Mutation Unknown Pathogen are kind of self explanatory	2/5/2020 4:40 PM
432	na	2/5/2020 4:39 PM
433	N/A	2/5/2020 4:38 PM
434	Ive did the genetic testing not sure what all the covers.	2/5/2020 4:37 PM
435	Too clinical - not sure what they mean	2/5/2020 4:36 PM
436	.	2/5/2020 4:32 PM
437	Dont know	2/5/2020 4:30 PM
438	None	2/5/2020 4:28 PM
439	Don't have a preference	2/5/2020 4:26 PM
440	Using all the terms "inherited gene mutation" is much more explanatory for those who do not understand words like germline and deleterious.	2/5/2020 4:24 PM
441	No.	2/5/2020 4:21 PM
442	how about inherited deleterious mutation	2/5/2020 4:19 PM
443	No preference	2/5/2020 4:19 PM
444	Pathogenic variant - relates to pathology testing and variant mean many different types....which makes a lot of since. I just don't like the word "mutation" just sounds cruel and scary.	2/5/2020 4:19 PM
445	N/a	2/5/2020 4:16 PM
446	I think Inherited Gene Mutation is clear about what is being talked about.	2/5/2020 4:14 PM
447	NA	2/5/2020 4:14 PM
448	No comment	2/5/2020 4:11 PM
449	n/a	2/5/2020 4:11 PM
450	Term listed	2/5/2020 4:11 PM
451	Words such as deleterious and germline are not commonly understood until after you get positive results or are diagnosed with cancer and start to Google.	2/5/2020 12:59 PM
452	No	2/5/2020 12:32 PM
453	Inherited gene mutation	2/5/2020 8:20 AM
454	germline mutation or germline pathogenic variant seem straightforward that these are changes in the DNA that can be passed on to offspring. I think that most people generally believe that the term "mutation" means the same as "pathogenic variant" as opposed to simply a variant. But "pathogenic variant" is more accurate so maybe there should be more of push to use that term over "mutation," which can mean different things in different situations.	2/5/2020 8:18 AM
455	I like inherited gene mutation for the patient community because it's easiest to understand without being misleading. But I think different terms are appropriate at different stages of discussion. "Deleterious" for example wouldn't be a term I'd open a patient discussion with but might be useful at some point in discussing results.	2/5/2020 7:40 AM
456	I was tested for a possible inherited gene mutation or I thought, to see if I have genes that cause breast cancer It wasn't Exactly clear to me when I did the testing or when I talked with others who had genetic testing Did we have the same tests or not since, as you stated, we were given different terminology Please don't use "germline". Bad associations (testing how clean we are)	2/5/2020 4:45 AM
457	Inherited gene mutation is easy to understand.	2/5/2020 1:38 AM
458	Inherited gene mutation	2/5/2020 12:52 AM

Survey on terms used for "genetic testing"

459	Inherited gene mutation for clarity	2/4/2020 11:39 PM
460	Inherited gene mutation	2/4/2020 11:39 PM
461	Inherited genetic mutation	2/4/2020 9:04 PM
462	More education on this to the patient	2/4/2020 8:36 PM
463	none	2/4/2020 8:20 PM
464	Genetic mutation	2/4/2020 7:48 PM
465	"Pathogenic variant" is scary; so is "deleterious mutation." "Inherited gene mutation" is easy to understand, accurate and less scary. "Deleterious mutation" and "Inherited mutation" are both accurate, but why not specify gene to be more clear?	2/4/2020 7:14 PM
466	no one preference	2/4/2020 7:11 PM
467	how my genetist described it	2/4/2020 6:51 PM
468	I don't understand.	2/4/2020 6:24 PM
469	"Inherited gene mutation" seems clearer for laypersons than deleterious or pathogenic, which are not commonly used outside of science	2/4/2020 6:09 PM
470	NA	2/4/2020 6:07 PM
471	inherited gene mutation, because it sounds more specific	2/4/2020 5:08 PM
472	Inherited gene mutation	2/4/2020 4:58 PM
473	na	2/4/2020 4:38 PM
474	"Inherited mutation" is very understandable for most people; "pathogenic variant" sounds like a criminal	2/4/2020 4:32 PM
475	As above	2/4/2020 4:11 PM
476	Inherited gene mutation speaks to exactly what being BRCA 1 positive means. I don't feel the general public understands "deleterious" or "germline".	2/4/2020 4:06 PM
477	Inherited gene mutation Easily understood	2/4/2020 3:58 PM
478	Aforementioned reasons	2/4/2020 3:54 PM
479	Inherited gene mutation is easier to understand and seems less abrasive.	2/4/2020 3:41 PM
480	Keep it in simple terms. Too many words can be confusing, especially when they are words people are unfamiliar with. Inherited gene mutation speaks for itself.	2/4/2020 3:36 PM
481	Genetic profile	2/4/2020 3:33 PM
482	No other term	2/4/2020 3:25 PM
483	'Inherited gene mutation' because 'deleterious', 'germline' and 'pathogenic' all repulse me and, without the word 'gene', 'mutation' sounds like a physical deformity.	2/4/2020 3:09 PM
484	Seems most straightforward	2/4/2020 3:08 PM
485	Inherited gene mutation - inherited reinforces the family genetic link, gene mutation makes clear exactly what it is	2/4/2020 3:03 PM
486	deleterious and germline are words I have not heard before.	2/4/2020 2:59 PM
487	Inherited gene mutation-I think this clarifies the terminology for most people. When using other terminology, it is not familiar for most people.	2/4/2020 2:50 PM
488	None	2/4/2020 2:36 PM
489	Again inherited/genetic mutation are terms most familiar with average people; terms like Germline are more obtuse and stressful to the average test taker , even pathological terms are stressful	2/4/2020 2:26 PM
490	Inherited gene mutation More understandable	2/4/2020 2:24 PM

Survey on terms used for "genetic testing"

491	Inherited Mutation	2/4/2020 2:22 PM
492	Inherited gene mutation. It's simple.	2/4/2020 2:10 PM
493	I like the idea of deleterious mutation. We can have good mutations, but I think many people won't know the word deleterious. Why not use a bad, dangerous, or negative mutation. Those are the words that I as a lay person know. By the way I have a Master's Degree in education, so I have a good vocabulary. Teaching taught me that it is better to use simple straight forward word with 8th and 10th grade students. There is enough for them to learn. Don't make a lesson more difficult than necessary. The same applies in medicine. You are already giving me bad news, and I will have lots of questions. Dont make it harder for me to understand.	2/4/2020 2:07 PM
494	Inherited gene mutation. Everyone knows what the word inherited" means just from basic usage in the English language.	2/4/2020 2:06 PM
495	Na	2/4/2020 1:56 PM
496	Inherited gene mutation. It sounds like the best way to describe it without adding confusion.	2/4/2020 1:44 PM
497	most common lay terminology	2/4/2020 1:34 PM
498	again, says what it is vs. too generic or overly scientific	2/4/2020 1:33 PM
499	Inherited (gene) mutation just seems straightforward to me.	2/4/2020 1:26 PM
500	Inherited mutation appeals to me because it more clearly and plainly describes exactly what the result may be.	2/4/2020 1:25 PM
501	inherited pathogenic mutation	2/4/2020 1:23 PM
502	It's important to use words that people already know the meaning of	2/4/2020 1:23 PM
503	pathogenic variant or inherited mutation- pathogenic variant is specific to what the gene change is doing which can help when comparing to a VUS	2/4/2020 1:20 PM
504	A less scary term	2/4/2020 1:16 PM
505	I think the terms "germline" and "deleterious" are not well understood by the public. Personally I have no problem with pathogenic variant but again the public does not understand it and it sounds extremely scary.	2/4/2020 1:16 PM
506	Some are not intuitively understood.	2/4/2020 1:15 PM
507	N/A	2/4/2020 1:07 PM
508	Most easily understandable	2/4/2020 1:05 PM
509	gene mutation	2/4/2020 1:01 PM
510	Na	2/4/2020 1:00 PM
511	Inherited genetic mutation	2/4/2020 12:58 PM
512	I like anything using inherited mutation or something similar. I don't think the average person knows what deleterious, germline or pathogenic means.	2/4/2020 12:56 PM
513	Inherited gene mutation. I also think that familial could work or hereditary but I think gene mutation should be included in the term.	2/4/2020 11:04 AM
514	See above.	2/4/2020 12:10 AM
515	Mutation sounds negative but not as strong as pathogenic. I like pathogenic because it denotes illness. Deleterious is good because it doesn't sound as deadly as pathogenic.	2/3/2020 8:58 PM
516	Inherited mutation. It's simple and clear.	2/3/2020 7:52 PM
517	None	2/3/2020 6:15 PM
518	Inherited mutation	2/3/2020 5:24 PM
519	These are all pretty bad. Of these, I'd prefer Inherited gene mutation as the words are familiar to people and the meaning is clear	2/3/2020 4:19 PM

Survey on terms used for "genetic testing"

520	N/a	2/3/2020 2:51 PM
521	As specific as possible as to what is being looked for.	2/3/2020 2:22 PM
522	No preference	2/3/2020 2:07 PM
523	Chemo	2/3/2020 1:11 PM
524	Not qualified.	2/3/2020 12:54 PM
525	simple, everyday words	2/3/2020 8:16 AM
526	none	2/1/2020 4:18 PM
527	na	2/1/2020 1:32 PM
528	Inherited gene mutation sounds more explanatory.	2/1/2020 1:23 AM
529	None	1/31/2020 10:45 PM
530	Said Neutral if I had no idea what it meant.	1/31/2020 9:34 PM
531	Inherited mutation	1/31/2020 7:46 PM
532	Inherited genetic mutation Very clear meaning	1/31/2020 5:14 PM
533	INHERITED mutation	1/31/2020 3:41 PM
534	No preference	1/31/2020 3:36 PM
535	None	1/31/2020 3:25 PM
536	It is consistent with my answer in question 4	1/31/2020 2:40 PM
537	Inherited gene mutation	1/31/2020 2:17 PM
538	I prefer the term inherited. I think if you look quickly "Deleterious" could be misread as "Delirious"	1/31/2020 2:08 PM
539	inherited mutation or inherited gene mutation. I think an emphasis needs to be on mutation-so many say, "I have the gene" when everyone has the genes, but they mean a mutation.	1/31/2020 1:55 PM
540	Inherited gene mutation	1/31/2020 1:55 PM
541	simple	1/31/2020 1:45 PM
542	Inherited gene mutation	1/31/2020 5:48 AM
543	Inherited mutation ... again, it's clear and simple to understand.	1/31/2020 1:51 AM
544	Suggest you learn to communicate with the patients in clear , plain English; not laboratory or academic jargon.	1/30/2020 11:05 PM
545	"Inherited gene mutation" This is the most easily understood term of the set of options presented	1/30/2020 10:48 PM
546	na	1/30/2020 9:39 PM
547	See 5, supra	1/30/2020 8:58 PM
548	None	1/30/2020 5:54 PM
549	Don't make the words too difficult that the patient is intimidated.	1/30/2020 5:36 PM
550	Inherited mutation	1/30/2020 3:25 PM
551	Deleterious I understand, also Pathogenic. Variant of what? Germline means nothing to me.	1/30/2020 2:45 PM
552	Clear speech.	1/30/2020 1:36 PM
553	Inherited gene mutation	1/30/2020 1:08 PM
554	No preferrence	1/30/2020 12:49 PM
555	genetic testing for inherited mutations	1/30/2020 12:22 PM

Survey on terms used for "genetic testing"

556	Inherited gene mutation	1/30/2020 12:00 PM
557	Obvious what it is	1/30/2020 11:59 AM
558	Pathogenic, Deleterious, and germline all sound really bad.	1/30/2020 11:59 AM
559	Most common words	1/30/2020 11:47 AM
560	Inherited gene mutation - you can quickly understand exactly what the subject is and why it is being tested.	1/30/2020 11:02 AM
561	Inherited Gene Mutation. Very simple and avoids scientific jargon, and clearly describes it as a genetic mutation, not some other type of mutation.	1/30/2020 10:57 AM
562	Inherited gene mutation	1/30/2020 10:43 AM
563	It should be clearly explained that having a genetic mutation, or not, is only part of the risk scenario.	1/30/2020 10:34 AM
564	inherited gene mutation. Because it's easy to understand	1/30/2020 8:20 AM
565	No preference	1/30/2020 7:37 AM
566	Inherited gene mutation	1/30/2020 7:17 AM
567	Inherited mutation and inherited gene mutation are very clear. I have never heard of a deleterious or pathogenic variant. The pathogenic variant sounds like I caused this mutation by smoking or some other pathogen when I didn't, I was just born with it.	1/30/2020 6:23 AM
568	They are the least "medical speak" ish.	1/30/2020 3:51 AM
569	Same response as before	1/30/2020 3:07 AM
570	None	1/30/2020 12:30 AM
571	Inherited gene mutation. Easy for most folks to understand. I have Lynch Syndrome, and have to keep it simple for people, many in the medical field.	1/29/2020 11:24 PM
572	I prefer inherited over germline - "germ" makes me think of what makes people sick and not necessarily something inherited.	1/29/2020 11:13 PM
573	Inherited gene mutation	1/29/2020 6:28 PM
574	Easier to understand the word inherited.	1/29/2020 5:22 PM
575	No preference	1/29/2020 4:51 PM
576	inherited gene mutation - clearly states the mutation is inherited and involves a specific gene	1/29/2020 4:19 PM
577	The term should state what the mutation is in a broader term that is easier for the layman to understand.	1/29/2020 4:17 PM
578	Genetic mutations	1/29/2020 3:22 PM
579	Inherited mutation or gene mutation seems clear	1/29/2020 2:35 PM
580	Inherited mutation since it is more descriptive	1/29/2020 2:09 PM
581	inherited gene mutation because it was the best of the options.	1/29/2020 2:00 PM
582	Knowledge of any kind is better than not knowing	1/29/2020 1:08 PM
583	none	1/29/2020 1:04 PM
584	n/a	1/29/2020 12:33 PM
585	Simple and less scientific is better!	1/29/2020 12:24 PM
586	No preferred term.	1/28/2020 7:11 PM
587	Still don't have a clue	1/28/2020 6:07 PM
588	-	1/28/2020 2:58 PM
589	Inherited gene mutation Descriptive	1/28/2020 2:51 PM

Survey on terms used for "genetic testing"

590	Using the term, "germ," in any phrase is confusing. It sounds like a communicable disease.	1/27/2020 10:45 PM
591	Less clinical	1/27/2020 9:43 PM
592	Not sure	1/26/2020 9:20 PM
593	The inherited gene mutation is the easiest to understand.	1/26/2020 7:51 PM
594	Use terms that don't sound scary medical. Deleterious sounds scary.	1/26/2020 5:35 PM
595	it is clearer for the general public	1/26/2020 5:10 PM
596	Inherited gene mutation	1/26/2020 2:38 PM
597	inherited gene mutaion	1/25/2020 11:18 PM
598	Again, don't like "germline" in the terminology. Pathogenic variant doesn't help with understanding	1/25/2020 9:54 PM
599	Inherited gene mutation is better description of why it actually is in layman's terms.	1/25/2020 8:51 PM
600	Inherited gene mutation	1/25/2020 6:42 PM
601	.	1/25/2020 12:51 PM
602	Keep it simple	1/25/2020 10:24 AM
603	None	1/25/2020 10:00 AM
604	I don't know what deleterious or germline means. Not very comprehensive for the general public, myself included.	1/25/2020 9:49 AM
605	Again - moving away from "mutation" is ok as long as there is a LOT of education beforehand because most of us are used to mutation - however, we are educable!!	1/24/2020 9:17 PM
606	Again, as clear as possible. Most people would interpret all cancer mutations as 'deleterious' if they don't understand.	1/24/2020 12:34 AM
607	dont have one	1/23/2020 12:15 PM
608	I think germ has negative connotations and some people may struggle to understand the term	1/23/2020 12:10 PM
609	None	1/23/2020 10:58 AM
610	NA	1/23/2020 9:31 AM
611	No	1/23/2020 8:09 AM
612	Words to explain something can't themselves need specialized understanding. Use commonly understood language.	1/23/2020 7:15 AM
613	Inherited genetic mutation. However, I still don't know if this applies to me or the tumor. I am confused that there are different mutation tests for the tumor that are "biomarkers" but not necessarily inherited???	1/23/2020 2:55 AM
614	Inherited gene mutation. Its simple.	1/22/2020 7:37 PM
615	Inherited gene mutation, as it is the most understandable term without adding further scary terms	1/22/2020 6:25 PM
616	n/a	1/22/2020 5:55 PM
617	I think inherited mutation is short and to the point.	1/22/2020 5:28 PM
618	ease of understanding	1/22/2020 3:40 PM
619	Acquired Mutations	1/22/2020 2:53 PM
620	My preference for "pathogenic" is somewhat paradoxical. Pathogen, to me, usually refers to infectious disease whereas "deleterious" is neutral in it's reference to the source of where harm originates from & makes more sense in oncology discussions. Perhaps it's just an odd, linguistic aesthetic preference.	1/22/2020 2:31 PM

Survey on terms used for "genetic testing"

621	Inherited gene mutation sounds clear	1/21/2020 8:53 PM
622	People have different levels of education. Inherited gene mutation seems like the most understandable term.	1/21/2020 4:19 PM
623	I believe medical terms should be avoided, if possible.	1/21/2020 11:52 AM
624	As I already understand inherited gene mutation, it is at its most basic level.	1/21/2020 12:06 AM
625	"inherited mutation" -- I think "deleterious" may be confusing to people who are just getting their results	1/20/2020 10:46 PM
626	Inherited gene mutation	1/20/2020 5:12 PM
627	BC survivor	1/20/2020 12:20 PM
628	Inherited gene mutation	1/20/2020 9:28 AM
629	It is important to differentiate these mutations from what you see in commercial genetic tests as potential problems. It should also be consistent with medical literature. However, we should also recognize that sometimes something that is negative may carry some positive attributes as well, for example sickle cell carriers, so important the term allows for that as well.	1/20/2020 8:36 AM
630	Germline and deleterious are my preferred terms. I feel like germline is better understanding of what is being tested over tumor testing.	1/20/2020 8:24 AM
631	No	1/20/2020 6:43 AM
632	Na	1/20/2020 2:09 AM
633	Again, I like the one that says exactly what it is. "Inherited gene mutation."	1/19/2020 11:06 PM
634	I have an unknown pathogenic variant, this has been extremely confusing	1/19/2020 11:02 PM
635	Inherited gene mutation	1/19/2020 11:01 PM
636	Inherited gene mutation. It clearly defines the purpose of the test using words most people can understand	1/19/2020 10:29 PM
637	Inherited gene mutation	1/19/2020 9:20 PM
638	Inherited gene mutation	1/19/2020 8:00 PM
639	I feel the word "mutation" is important—everyone may have a particular genes but not everyone has a mutation of it.	1/19/2020 7:05 PM
640	Inherited gene mutation	1/19/2020 6:45 PM
641	Pathogenic variant. Pathogen seems more descriptive than 'germline'.	1/19/2020 6:24 PM
642	N/a	1/19/2020 6:19 PM
643	N/A	1/19/2020 6:16 PM
644	pathogenic variant is not common language and makes me think of a disease. Mutation is accurate and I am in favor of any of the accurate descriptors of type of mutation.	1/19/2020 5:56 PM
645	My mutation is a duplication not a deletion! But either way, the effect is the same. Neither term is useful for someone at the initial stages of testing.	1/19/2020 12:29 PM
646	Inherited Gene mutation would be the most preferred because it is accurate and understandable by the average population.	1/19/2020 12:39 AM
647	No preferred	1/18/2020 3:35 PM
648	Again, I would prefer to start with GENE and MUTATION. To that, add "inherited"if it was passed from parents. And to that can be added adjectives to describe the Inherited gene mutation (of unknown variant, non-specific, etc.).	1/18/2020 2:01 PM
649	Inherited gene mutation. This seems to explain how someone would have the condition or mutation.	1/18/2020 12:06 PM
650	Pathogenic variant	1/18/2020 11:29 AM

Survey on terms used for "genetic testing"

651	No preference	1/18/2020 12:30 AM
652	Inherited gene mitigation - again it is easy to understand.	1/17/2020 10:51 PM
653	Inherited mutatiom	1/17/2020 3:35 PM
654	Inherited gene mutation. Break the term down and each word down is understandable. Not so with "germline" or "deleterious" for the average person.	1/17/2020 1:54 PM
655	Inherited mutation is easiest to understand	1/17/2020 10:41 AM
656	Inherited gene mutation	1/17/2020 10:20 AM
657	Described above	1/17/2020 8:06 AM
658	Making things simple and straightforward is best.	1/16/2020 11:11 PM
659	Inherited gene mutation is my preferred term. In my experience, many people do not understand the basics of genetics and things need to be spelled out in simple, yet accurate terms. I believe this term does that best. (On a related note, it is one of my pet peeves when people say, "I have the BRCA gene.")	1/16/2020 8:55 PM
660	Pathogenic mutation seems to sum up the risk and issue for me.	1/16/2020 7:48 PM
661	None	1/16/2020 5:51 PM
662	genetic testing for inherited cancer risk	1/16/2020 5:28 PM
663	I prefer inherited gene mutation because it says in plain English what it is.	1/16/2020 1:32 PM
664	"Inherited mutation" is the simplest term and I'm not sure that adding the word "gene" is necessary	1/16/2020 1:19 PM
665	Easier to understand	1/16/2020 1:17 PM
666	Inherited gene mutation	1/16/2020 1:16 PM
667	Inherited or hereditary - it seems the majority of the population understands both terms with ease.	1/16/2020 1:10 PM
668	Hereditary	1/16/2020 11:24 AM
669	should use common, everyday words... "deleterious, Pathological variant are not common, need explanation to many	1/16/2020 10:05 AM
670	Inherited gene mutation. This wording makes it very clear what we are talking about	1/16/2020 10:00 AM
671	Inherited mutation and gene are better understood words	1/16/2020 9:30 AM
672	I wish there was a word that helped "germline"	1/16/2020 9:04 AM
673	it is the most plain language example provided; the others are too technical/medical jargon	1/16/2020 8:33 AM
674	\$7. Not all mutations are deleterious	1/16/2020 7:36 AM
675	Inherited gene mutation is both clear for professionals and patients.	1/16/2020 6:36 AM
676	The word "germline" would likely confuse people, so I definitely would steer away from that term.	1/16/2020 12:45 AM
677	deleterious mutation is clear	1/16/2020 12:22 AM
678	No	1/15/2020 11:46 PM
679	Inherited germline mutations	1/15/2020 11:41 PM
680	Clearest to me	1/15/2020 11:31 PM
681	Inherited gene mutation	1/15/2020 11:30 PM
682	Mainly because I am familiar with the term deleterious due to my end. Not familiar with the terms germline or pathogenic.	1/15/2020 11:23 PM
683	I think "inherited gene mutation" is the simplest, least esoteric phrase used above.	1/15/2020 11:16 PM

Survey on terms used for "genetic testing"

684	Sounds more familiar	1/15/2020 11:05 PM
685	people understand "inherited" more than germline. Not sure of a better term for "deleterious"	1/15/2020 10:40 PM
686	None	1/15/2020 10:33 PM
687	Call it Cancer - call it inherited- needs to be understood by everyone.	1/15/2020 10:23 PM
688	It's the only one that I think many people would understand	1/15/2020 10:05 PM
689	Deleterious genetic mutation	1/15/2020 9:47 PM
690	Simply stated terms without requiring medical knowledge or a dictionary are best !	1/15/2020 8:45 PM
691	Inherited gene mutation	1/15/2020 8:41 PM
692	Including the term "pathogenic" or "deleterious" adds useful information - the mutation has significance whereas a VUS does not. Other terms such as "inherited gene mutation" don't tell either a provider or the client whether the mutation presents any concern. Anything including the term "germline" is likely not going to be understood by the majority of the public, unfortunately.	1/15/2020 8:35 PM
693	N-A	1/15/2020 8:31 PM
694	really dont understand any of those terms other than inherited	1/15/2020 7:22 PM
695	Lay people do not know "germline" or "deleterious". Inherited gene variant isn't bad either. However variants could be good or bad so it depends on what context you're using it in.	1/15/2020 7:13 PM
696	Germline mutation is accurate and can be googled if someone doesn't understand it. Inherited is immediately understood. Deleterious just adds extra unnecessary verbage. Pathogenic variant is unnecessary tech speak and convoluted.	1/15/2020 6:16 PM
697	Familiar language again	1/15/2020 6:08 PM
698	No preference	1/15/2020 6:02 PM
699	Inherited again because it sounds like what it is	1/15/2020 5:58 PM
700	Others are not familiar and I am well educated	1/15/2020 5:49 PM
701	Germline, deleterious and pathologic variant are not patient-friendly. "Inherited" is clear.	1/15/2020 5:38 PM
702	none not sure	1/15/2020 5:28 PM
703	inherited gene mutation	1/15/2020 5:26 PM
704	Inherited genetic variant	1/15/2020 5:21 PM
705	Inherited Gene Mutation because the terms are easily understood and no derogatory descriptions.	1/15/2020 5:16 PM
706	Same as prior response...I like the term to be self explanatory on what we are doing and why.	1/15/2020 5:16 PM
707	Inherited gene mutation	1/15/2020 5:14 PM
708	Inherited mutation, because it's the most basic term that anyone could probably understand.	1/15/2020 5:07 PM
709	I chose Inherited gene mutation because the term is simple and easy to understand. Less confusion is always better. Patients have so much to think about; trying to define/decipher terminology should not be one of them.	1/15/2020 5:02 PM
710	Inherited mutation or inherited gene mutation	1/15/2020 4:46 PM
711	inherited gene mutation	1/15/2020 4:44 PM
712	Again, keep it simple. Inherited Mutation...the average person does not walk around talking about their pathogenic variant.	1/15/2020 4:35 PM
713	None	1/15/2020 4:34 PM
714	I prefer inherited mutation or deleterious mutation - although I think there could be an more easily understood term than "deleterious".	1/15/2020 4:32 PM

Survey on terms used for "genetic testing"

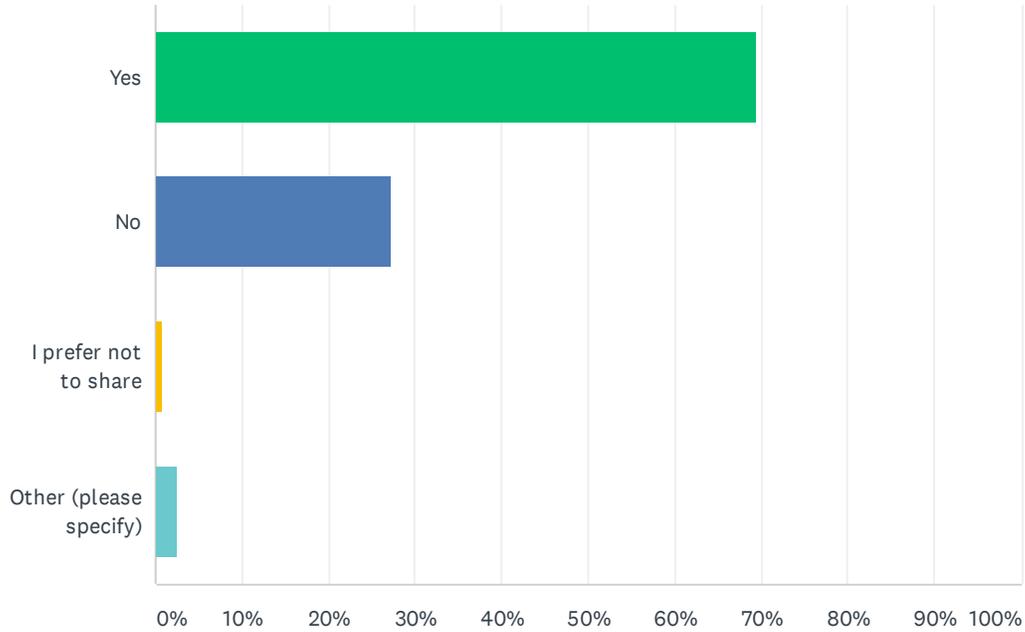
715	Inherited gene mutation seems the most descriptive	1/15/2020 4:31 PM
716	Make terms easier for all to understand. Nix the unfamiliar words.	1/15/2020 4:21 PM
717	I believe some terms are too scientific it will confuse people that do not have a background in genetics or medicine	1/15/2020 4:16 PM
718	I prefer Genetic testing for inherited cancer or cancer risk, whichever is more correct. If you are only testing for a possible risk that should be the term used	1/15/2020 4:12 PM
719	I would prefer something like 'germline variant'	1/15/2020 4:00 PM
720	na	1/15/2020 3:53 PM
721	inherited gene mutation because it expresses what it is in the simplest terms that more of the population would understand	1/15/2020 3:51 PM
722	Once again, germline is going to need too much explanation. "inherited" will need less explanation.	1/15/2020 3:49 PM
723	Easily Understood	1/15/2020 3:49 PM
724	See previous comment; same logic applies here.	1/15/2020 3:47 PM
725	Early in diagnosis and consultation inherited gene mutation seems easier to understand. Using several terms for same thing can be confusing	1/15/2020 2:25 PM
726	Inherited Gene Mutation	1/15/2020 1:21 PM
727	Inherited gene mutation. Because it is the least confusing	1/15/2020 1:10 PM
728	Inherited gene mutation. Seems more easily understandable. Closest to a lay term.	1/15/2020 1:05 PM
729	It's the only one I have heard of	1/15/2020 12:55 PM
730	Inherited Gene mutation - it states clearly what it is without sounding scary	1/15/2020 10:54 AM
731	Says what it is plainly	1/15/2020 10:44 AM
732	I think more people would understand the term "inherited gene mutation" than the other choices presented. It makes it clear what is being tested without using technical jargon.	1/15/2020 8:53 AM
733	Gene mutation testing	1/15/2020 2:17 AM
734	Hereditary. The majority of people understand the term without looking it up in the dictionary or googling the meaning.	1/15/2020 12:11 AM
735	Inherited gene mutation. Explains exactly what it is!	1/14/2020 11:52 PM
736	None	1/14/2020 10:08 PM
737	When discussing a gene mutation, referring to it as deleterious leads one right into an explanation in as simple terms as possible.	1/14/2020 10:06 PM
738	No preference	1/14/2020 9:57 PM
739	No	1/14/2020 9:56 PM
740	None	1/14/2020 8:53 PM
741	I prefer inherited gene mutation or inherited mutation since I think it's the easiest to understand.	1/14/2020 7:35 PM
742	Inherited gene mutation. It is the most descriptive without complicated medical terms.	1/14/2020 7:22 PM
743	Inherited mutation	1/14/2020 7:22 PM
744	I really don't have a preferred term	1/14/2020 7:18 PM
745	Inherited gene mutation - describes in common language that most will understand	1/14/2020 7:15 PM
746	Same as my comment in #5. Plus the "neutral" items I checked because I have no clue what the terms means.	1/14/2020 7:09 PM
747	i like genetics and genomics with simple explanation...genetics are gens passed genomics are	1/14/2020 6:52 PM

Survey on terms used for "genetic testing"

	tumor make up	
748	None	1/14/2020 6:21 PM
749	Inherited gene mutation - it's clear...it's a mutation in a gene which you inherited. He other terms would need additional explanation for most people.	1/14/2020 6:11 PM
750	No	1/14/2020 6:03 PM
751	Deleterious germline mutation is the most accurate, specific phrase, once you know the meaning of the words.	1/14/2020 5:46 PM
752	Inherited Mutation - explains where the mutation is driven from	1/14/2020 5:36 PM
753	N/A	1/14/2020 5:23 PM
754	n/a	1/14/2020 5:23 PM
755	Once again simple English - inherited gene mutation	1/14/2020 5:06 PM
756	I believe the term "germline" will not be familiar to most people, and also sounds like a turn-off. The same goes for Pathogenic Variant. Neither are commonly-known terms.	1/14/2020 5:00 PM
757	I think mutation should be good, with or without the term gene. Not all mutations are known to be deleterious if you consider VUS or pathogenic.	1/14/2020 4:57 PM
758	None of those have a clear meaning to patients	1/14/2020 4:47 PM
759	It's important to get across that not all "inherited mutations" are harmful—some are of unknown significance, some harmless (benign). In talking about mutations associated with cancer risk, you want to get across that the mutation (variant sounds less threatening) is inherited (not acquired) and that it is potentially harmful (pathogenic).	1/14/2020 4:26 PM
760	I think the terms 'deleterious' and 'pathogenic' are overloaded with meanings that are too close to the desired usage.	1/14/2020 4:17 PM
761	I think Pathogenic Mutation would make the most sense to me as a lay person. We get that pathogenic vs. benign so if the goal is to set that apart from a VUS, then it should be in the name (vs. inherited mutation, which could be a nothing mutation)	1/14/2020 3:44 PM
762	Inherited gene mutation	1/14/2020 3:29 PM
763	I don't have one.	1/14/2020 3:28 PM
764	Inherited gene mutation seems simple for lay people and includes complete description	1/14/2020 3:18 PM
765	No	1/14/2020 3:16 PM
766	.	1/14/2020 2:57 PM
767	none. Just very opposed to terms that lead people to believe that having a gene = 100% chance of cancer	1/14/2020 2:56 PM
768	Germline Mutation It is the simpliest	1/14/2020 2:56 PM
769	n/a	1/14/2020 2:55 PM
770	I don't like the word germline, and deleterious makes it sounds very detrimental. Pathogenic sounds too scientific. Inherited gene mutation is much more straight forward.	1/14/2020 2:50 PM
771	no preference	1/14/2020 2:37 PM
772	If words are too difficult people will become confused	1/14/2020 2:33 PM

Q8 Have you ever been diagnosed with cancer?

Answered: 1,675 Skipped: 23



ANSWER CHOICES	RESPONSES	
Yes	69.55%	1,165
No	27.10%	454
I prefer not to share	0.84%	14
Other (please specify)	2.51%	42
TOTAL		1,675

Survey on terms used for "genetic testing"

#	OTHER (PLEASE SPECIFY)	DATE
1	Lung and breast	2/25/2020 7:11 PM
2	ovarian	2/25/2020 7:02 PM
3	family members have inherited genetic mutation	2/21/2020 9:15 AM
4	I have not been diagnosed, but I have persistent symptoms that are constantly being watched, and I have a family history.	2/20/2020 7:41 PM
5	I have never had cancer, but both of my parents died of cancer, as well as many family members.	2/20/2020 7:21 PM
6	Squamous cell	2/20/2020 6:27 PM
7	I've had a cancerous thyroid nodule	2/20/2020 5:05 PM
8	My mother had genetic testing for the BRCA gene, so I didn't have testing.	2/20/2020 3:55 PM
9	Two types of breast, one metastatic and also ovarian cancer. All three without gene mutation	2/15/2020 6:56 AM
10	Both parents	2/14/2020 10:52 PM
11	My husband, CLL	2/12/2020 1:18 PM
12	Multiple myeloma	2/11/2020 8:23 AM
13	No but pathology after pbm abnormal cells, etc both side that would have turned cancerous per oncologist.	2/8/2020 7:59 AM
14	Had Whipple for a pancreatic IPMN to prevent cancer	2/7/2020 4:37 PM
15	I'm a kidney cancer survivor. My husband passed from pancreatic cancer.	2/7/2020 6:32 AM
16	Squamous cell skin cancer.	2/6/2020 7:16 PM
17	Basal and Squamous	2/6/2020 6:42 PM
18	i had cancer in 2014	2/6/2020 6:41 PM
19	My husband has S II pancreatic cancer	2/6/2020 11:18 AM
20	Wife has pancreatic cancer	2/5/2020 10:32 PM
21	Breast	2/5/2020 8:37 PM
22	Multiple myeloma	2/5/2020 7:42 PM
23	Carcinoma of the Lymph Node	2/5/2020 6:31 PM
24	Breast cancer	2/5/2020 4:31 PM
25	Yes, two separate diagnoses.	2/4/2020 1:16 PM
26	My mother was diagnosed in 2018	2/3/2020 6:59 PM
27	MDS	2/3/2020 6:15 PM
28	Answering for my husband who has cancer	2/3/2020 7:03 AM
29	Waiting on results	2/1/2020 4:48 AM
30	Child and husband with cancer	1/31/2020 3:05 PM
31	husband	1/30/2020 9:39 PM
32	My father had cancer	1/30/2020 5:55 PM
33	Husband has	1/30/2020 12:51 PM
34	I have been diagnosed. I have it, but it does not have me. I have made lifestyle changes to keep it in check. I will probably die with it, but it will not be the cause of death. If people in medicine actually wanted to improve human health, they would put 95% of their funding and efforts towards prevention, and very little towards treatment. Everyone that I know diagnosed	1/30/2020 11:59 AM

Survey on terms used for "genetic testing"

with cancer that went down the conventional medical, industrial recommended treatment path, either died or had severe permanent impacts on their lives. All cancers are not fast growing requiring heroic, costly life altering treatments. Why can't researches concentrate on getting people the absolute best information about lifestyle choices that prevent cancers in the first place. Prevent angiogenesis, and boost the immune system before any cancers are established. Focusing on treatment, with for profit companies, absolutely guarantees cancer will never be beaten. No for profit company will put itself out of business. Our whole approach to cancer is like trying to prevent a birth 7 months after conception. The place to attack the problem is BEFORE conception. You can do much more in prevention than you can with treatment. Our approach to cancer, almost all treatment, and no prevention is why Americans have such high healthcare costs and such dismal results.

35	My husband was diagnosed with extrahepatic CC	1/30/2020 5:37 AM
36	A GIST but it was low reoccurrence	1/28/2020 9:03 PM
37	Skin cancer pre-cells, precancerous breast cells, breast tumors	1/25/2020 9:38 AM
38	My husband has stage IV colon	1/15/2020 10:44 AM
39	Thankfully have only had skin cancers to date. I have had conditions that were medically referred to as pre-cancerous.	1/14/2020 10:06 PM
40	Prior caregiver	1/14/2020 6:03 PM
41	Skin cancer only	1/14/2020 5:00 PM
42	Skin only	1/14/2020 4:04 PM