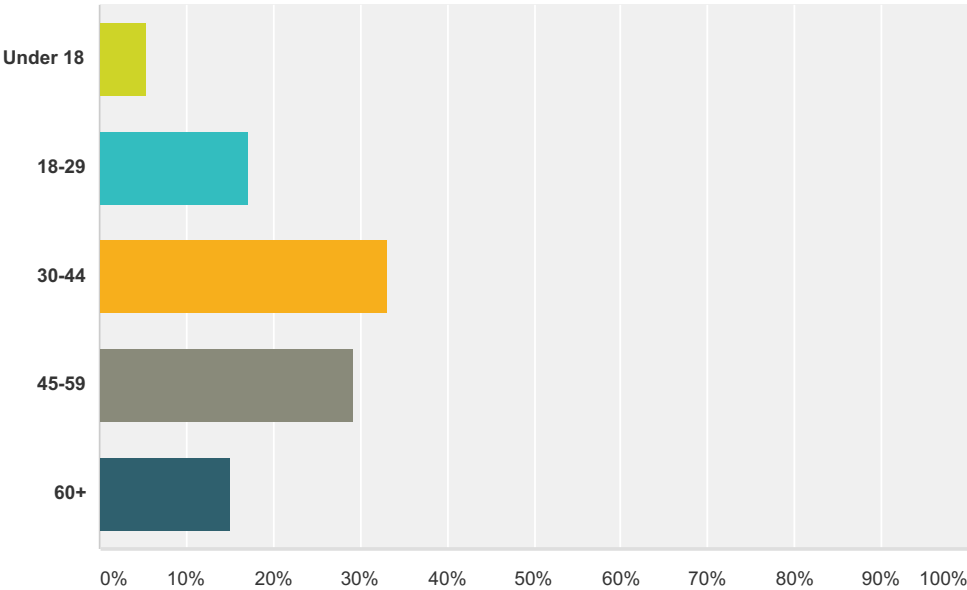


Q1 What is your age?

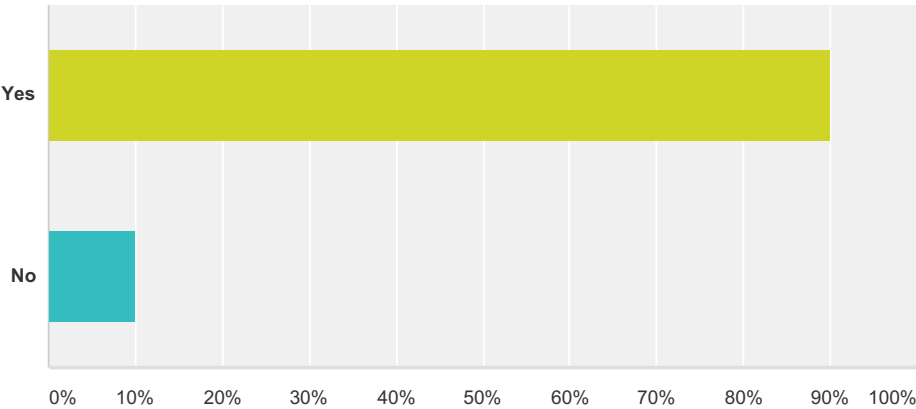
Answered: 326 Skipped: 0



Answer Choices	Responses	
Under 18	5.52%	18
18-29	17.18%	56
30-44	33.13%	108
45-59	29.14%	95
60+	15.03%	49
Total		326

Q2 Do you live in the United States?

Answered: 326 Skipped: 0



Answer Choices	Responses	
Yes	89.88%	293
No	10.12%	33
Total		326

Q3 What are the first two numbers of your zip code?

Answered: 301 Skipped: 25

#	Responses	Date
1	22	6/7/2017 3:35 PM
2	10	6/7/2017 3:31 PM
3	97	6/7/2017 3:30 PM
4	87	6/7/2017 3:25 PM
5	35	6/7/2017 3:23 PM
6	47	6/7/2017 2:38 PM
7	32	6/7/2017 2:22 PM
8	48	6/7/2017 2:21 PM
9	20	6/7/2017 1:54 PM
10	22	6/7/2017 1:50 PM
11	22	6/7/2017 1:47 PM
12	22	6/7/2017 1:47 PM
13	20	6/7/2017 1:17 PM
14	20	6/7/2017 1:11 PM
15	01	6/7/2017 12:57 PM
16	91	6/7/2017 12:53 PM
17	94	6/7/2017 12:50 PM
18	15	6/7/2017 12:45 PM
19	01	6/7/2017 12:43 PM
20	85	6/7/2017 12:30 PM
21	02	6/7/2017 12:19 PM
22	02	6/7/2017 11:44 AM
23	02	6/6/2017 7:28 PM
24	21	6/6/2017 7:11 PM
25	30	6/6/2017 5:43 PM
26	Tw	6/6/2017 5:20 PM
27	90	6/6/2017 4:58 PM
28	30	6/6/2017 2:19 PM
29	44	6/6/2017 12:33 PM
30	30	6/6/2017 12:23 PM
31	01	6/6/2017 10:16 AM
32	20	6/6/2017 10:07 AM
33	20	6/6/2017 8:23 AM
34	19	6/6/2017 8:10 AM
35	58	6/6/2017 12:28 AM

36	20	6/5/2017 11:37 PM
37	47	6/5/2017 10:36 PM
38	80	6/5/2017 9:14 PM
39	20	6/5/2017 9:11 PM
40	20	6/5/2017 8:31 PM
41	29	6/5/2017 6:51 PM
42	30	6/5/2017 6:38 PM
43	02	6/5/2017 5:34 PM
44	01	6/5/2017 4:39 PM
45	98	6/5/2017 4:20 PM
46	30	6/5/2017 4:11 PM
47	22	6/5/2017 4:05 PM
48	10	6/5/2017 3:36 PM
49	29	6/5/2017 3:28 PM
50	36	6/5/2017 3:08 PM
51	22	6/5/2017 2:45 PM
52	94	6/5/2017 2:36 PM
53	06	6/5/2017 2:32 PM
54	20	6/5/2017 1:59 PM
55	21	6/5/2017 1:41 PM
56	20	6/5/2017 1:39 PM
57	22	6/5/2017 1:34 PM
58	20	6/5/2017 1:29 PM
59	20	6/5/2017 1:29 PM
60	01	6/5/2017 1:12 PM
61	02	6/5/2017 1:07 PM
62	20	6/5/2017 1:05 PM
63	32	6/5/2017 12:46 PM
64	98	6/5/2017 12:39 PM
65	14	6/5/2017 11:42 AM
66	14	6/5/2017 11:41 AM
67	05	6/5/2017 11:32 AM
68	13	6/5/2017 11:09 AM
69	53	6/4/2017 9:46 PM
70	94	6/4/2017 1:35 PM
71	98	6/3/2017 5:31 PM
72	15	6/3/2017 2:10 PM
73	06	6/3/2017 7:41 AM
74	03	6/2/2017 8:33 PM
75	04	6/2/2017 8:32 PM

76	02	6/2/2017 7:26 PM
77	94	6/2/2017 6:01 PM
78	85	6/2/2017 5:17 PM
79	85	6/2/2017 4:10 PM
80	27	6/2/2017 3:51 PM
81	20	6/2/2017 3:32 PM
82	01	6/2/2017 3:24 PM
83	78	6/2/2017 1:35 PM
84	20	6/2/2017 1:21 PM
85	20	6/2/2017 1:21 PM
86	02	6/2/2017 1:10 PM
87	85	6/2/2017 1:05 PM
88	19	6/2/2017 1:02 PM
89	02	6/2/2017 1:01 PM
90	02	6/2/2017 1:01 PM
91	02	6/2/2017 12:59 PM
92	02	6/2/2017 12:52 PM
93	10	6/2/2017 12:36 PM
94	97	6/2/2017 11:55 AM
95	60	6/2/2017 11:54 AM
96	60	6/2/2017 11:54 AM
97	06	6/2/2017 11:31 AM
98	22	6/2/2017 10:47 AM
99	22	6/2/2017 10:28 AM
100	30	6/2/2017 9:23 AM
101	19	6/1/2017 4:01 PM
102	20	6/1/2017 3:56 PM
103	20	6/1/2017 3:34 PM
104	21	5/31/2017 2:28 PM
105	80	5/31/2017 2:14 PM
106	30	5/31/2017 1:26 PM
107	21	5/31/2017 8:03 AM
108	07	5/30/2017 11:15 PM
109	80	5/30/2017 11:06 PM
110	80	5/30/2017 11:00 PM
111	80	5/30/2017 10:59 PM
112	53	5/30/2017 9:31 PM
113	04	5/30/2017 9:23 PM
114	24	5/30/2017 7:26 PM
115	94	5/30/2017 7:19 PM
116	28	5/30/2017 7:16 PM

117	20	5/30/2017 6:23 PM
118	24	5/30/2017 5:29 PM
119	84	5/30/2017 5:08 PM
120	82	5/30/2017 3:41 PM
121	97	5/30/2017 12:48 PM
122	94	5/30/2017 11:13 AM
123	94	5/30/2017 9:57 AM
124	46	5/30/2017 8:02 AM
125	27	5/30/2017 7:32 AM
126	85	5/30/2017 12:57 AM
127	95	5/30/2017 12:23 AM
128	85	5/30/2017 12:23 AM
129	64	5/30/2017 12:13 AM
130	80	5/29/2017 10:39 PM
131	20	5/29/2017 9:52 PM
132	20	5/29/2017 9:51 PM
133	47	5/29/2017 9:41 PM
134	95	5/29/2017 9:41 PM
135	80	5/29/2017 9:41 PM
136	20	5/29/2017 9:40 PM
137	90	5/29/2017 9:38 PM
138	96	5/29/2017 9:37 PM
139	18	5/29/2017 9:28 PM
140	97	5/29/2017 9:28 PM
141	27	5/29/2017 9:09 PM
142	60	5/29/2017 9:01 PM
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144	20	5/29/2017 8:46 PM
145	20	5/29/2017 8:41 PM
146	02	5/29/2017 8:25 PM
147	95	5/29/2017 8:23 PM
148	88	5/29/2017 8:17 PM
149	77	5/29/2017 8:09 PM
150	73	5/29/2017 4:45 AM
151	80	5/27/2017 5:39 PM
152	29	5/27/2017 11:14 AM
153	28	5/26/2017 1:52 PM
154	96	5/26/2017 12:16 AM
155	33	5/25/2017 8:41 PM
156	56	5/25/2017 8:00 PM
157	92	5/25/2017 7:46 PM

158	51	5/25/2017 7:42 PM
159	93	5/25/2017 7:23 PM
160	92	5/25/2017 7:19 PM
161	14	5/25/2017 4:25 AM
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163	02	5/24/2017 11:04 PM
164	06	5/24/2017 1:32 PM
165	55	5/24/2017 11:40 AM
166	92	5/24/2017 9:40 AM
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168	21	5/23/2017 9:34 PM
169	06	5/23/2017 7:31 PM
170	20	5/23/2017 7:29 PM
171	03	5/23/2017 5:23 PM
172	28	5/23/2017 4:49 PM
173	90	5/23/2017 4:39 PM
174	61	5/23/2017 4:25 PM
175	60	5/23/2017 4:00 PM
176	19	5/23/2017 3:47 PM
177	20	5/23/2017 3:33 PM
178	t4	5/23/2017 3:05 PM
179	20	5/23/2017 3:53 AM
180	75	5/22/2017 8:44 PM
181	85	5/22/2017 5:51 PM
182	55	5/22/2017 5:09 PM
183	15	5/22/2017 5:07 PM
184	89	5/22/2017 4:50 PM
185	32	5/22/2017 4:40 PM
186	50	5/22/2017 4:35 PM
187	94	5/22/2017 12:35 PM
188	45	5/22/2017 7:59 AM
189	95	5/21/2017 11:21 PM
190	48	5/21/2017 1:55 PM
191	85	5/21/2017 1:03 PM
192	64	5/20/2017 3:49 PM
193	64	5/20/2017 3:44 PM
194	46	5/20/2017 10:01 AM
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196	90	5/19/2017 2:26 PM
197	30	5/18/2017 3:37 PM
198	30	5/18/2017 3:24 PM

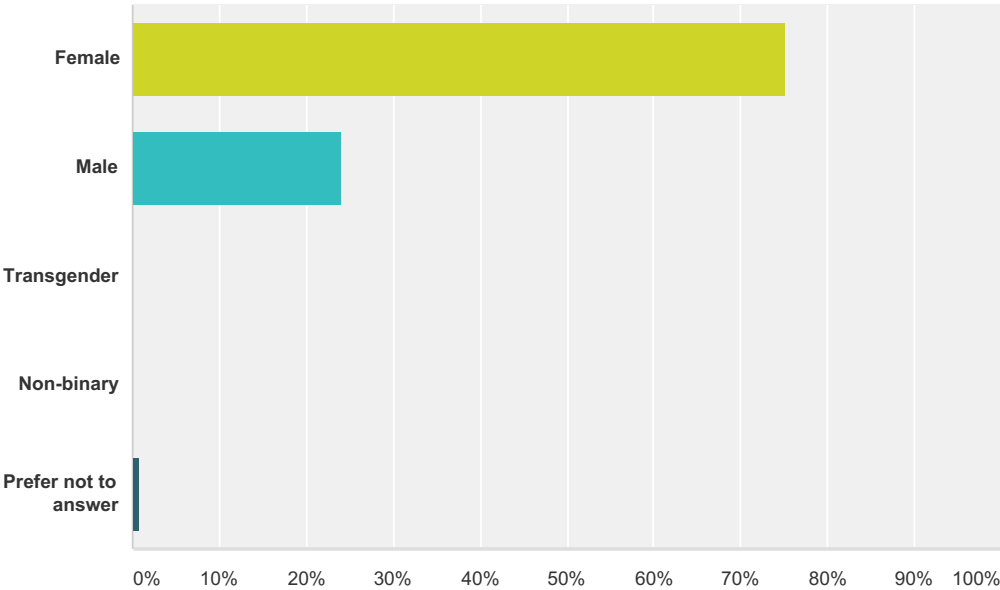
199	20	5/18/2017 3:12 PM
200	BT	5/17/2017 5:55 PM
201	33	5/16/2017 9:25 PM
202	74	5/16/2017 3:37 PM
203	92	5/16/2017 1:50 PM
204	84	5/16/2017 8:35 AM
205	75	5/15/2017 11:36 PM
206	44	5/15/2017 10:40 PM
207	78	5/15/2017 8:59 PM
208	30	5/15/2017 7:04 PM
209	76	5/15/2017 6:56 PM
210	89	5/15/2017 6:35 PM
211	91	5/15/2017 6:27 PM
212	53	5/15/2017 4:17 PM
213	94	5/12/2017 1:42 PM
214	08	5/12/2017 6:48 AM
215	32	5/11/2017 11:22 PM
216	61	5/11/2017 10:05 PM
217	23	5/11/2017 9:37 PM
218	64	5/11/2017 3:37 PM
219	76	5/11/2017 3:05 PM
220	11	5/11/2017 2:22 PM
221	22	5/11/2017 12:35 PM
222	56	5/11/2017 11:41 AM
223	95	5/11/2017 2:13 AM
224	93	5/10/2017 10:49 PM
225	11	5/10/2017 10:40 PM
226	98	5/10/2017 10:14 PM
227	02	5/10/2017 9:41 PM
228	08	5/10/2017 9:21 PM
229	34	5/10/2017 9:20 PM
230	52	5/10/2017 8:49 PM
231	51	5/10/2017 8:33 PM
232	72	5/10/2017 8:18 PM
233	55	5/10/2017 8:04 PM
234	07	5/10/2017 7:54 PM
235	45	5/10/2017 7:39 PM
236	64	5/10/2017 7:36 PM
237	29	5/10/2017 7:25 PM
238	65	5/10/2017 7:24 PM
239	76	5/10/2017 7:10 PM

240	85	5/10/2017 6:35 PM
241	92	5/10/2017 5:41 PM
242	92	5/10/2017 5:17 PM
243	02	5/10/2017 5:03 PM
244	83	5/10/2017 4:16 PM
245	34	5/10/2017 4:15 PM
246	01	5/10/2017 4:05 PM
247	50	5/10/2017 4:03 PM
248	53	5/10/2017 3:55 PM
249	33	5/10/2017 3:44 PM
250	22	5/10/2017 3:43 PM
251	16	5/10/2017 8:43 AM
252	85	5/9/2017 5:53 PM
253	22	5/9/2017 3:43 PM
254	01	5/9/2017 3:41 PM
255	02	5/9/2017 1:15 PM
256	01	5/9/2017 12:33 PM
257	95	5/9/2017 10:59 AM
258	29	5/9/2017 10:51 AM
259	02	5/9/2017 10:45 AM
260	02	5/9/2017 9:21 AM
261	46	5/9/2017 6:03 AM
262	46	5/9/2017 6:02 AM
263	02	5/8/2017 10:29 PM
264	80	5/8/2017 9:48 PM
265	98	5/8/2017 7:55 PM
266	01	5/8/2017 7:48 PM
267	13	5/8/2017 7:31 PM
268	48	5/8/2017 6:10 PM
269	89	5/8/2017 5:50 PM
270	WA	5/8/2017 4:30 PM
271	JE	5/8/2017 4:29 PM
272	10	5/8/2017 4:27 PM
273	74	5/8/2017 3:26 PM
274	98	5/8/2017 3:21 PM
275	52	5/8/2017 3:18 PM
276	10	5/8/2017 3:18 PM
277	84	5/8/2017 3:08 PM
278	22	5/8/2017 3:02 PM
279	97	5/5/2017 6:45 PM
280	20	5/5/2017 3:12 PM

281	02	5/2/2017 4:19 PM
282	02	5/2/2017 3:28 PM
283	02	5/2/2017 2:38 PM
284	22	5/2/2017 2:09 PM
285	02	5/2/2017 11:38 AM
286	02	5/2/2017 11:00 AM
287	22	5/2/2017 10:08 AM
288	06	4/26/2017 9:41 PM
289	06	4/26/2017 8:54 PM
290	20	4/26/2017 5:42 PM
291	20	4/26/2017 5:39 PM
292	22	4/26/2017 3:39 PM
293	22	4/26/2017 3:05 PM
294	20	4/26/2017 3:04 PM
295	02	4/26/2017 2:16 PM
296	22	4/26/2017 2:16 PM
297	20	4/26/2017 2:09 PM
298	20	4/26/2017 1:55 PM
299	20	4/26/2017 1:42 PM
300	20	4/26/2017 1:42 PM
301	22	4/26/2017 1:41 PM

Q4 Which gender do you identify as?

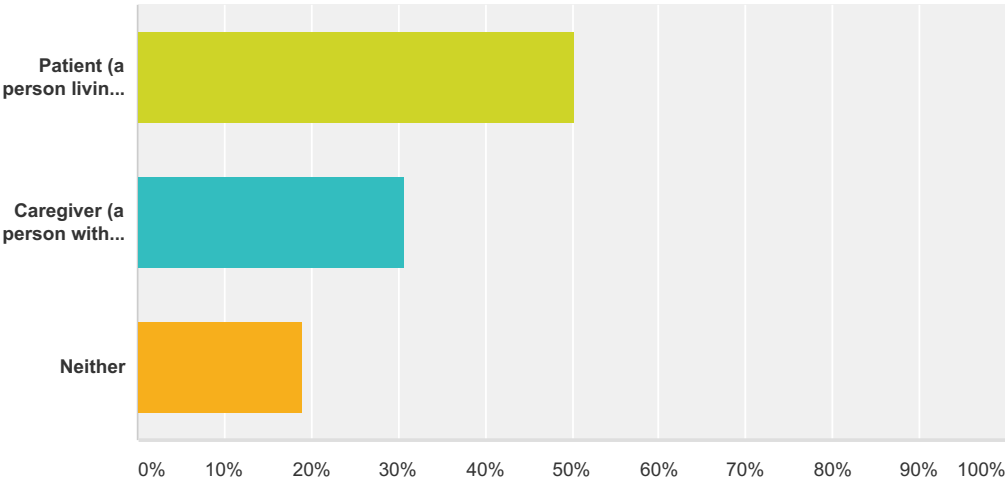
Answered: 321 Skipped: 5



Answer Choices	Responses	
Female	75.08%	241
Male	23.99%	77
Transgender	0.00%	0
Non-binary	0.00%	0
Prefer not to answer	0.93%	3
Total		321

Q5 Do you identify yourself primarily as a patient or caregiver?

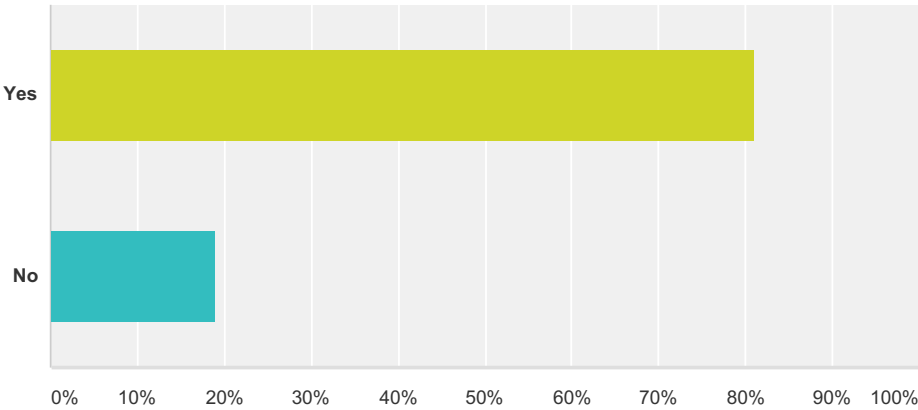
Answered: 326 Skipped: 0



Answer Choices	Responses	
Patient (a person living with one or more health conditions that requires ongoing medical attention or support from healthcare professionals)	50.31%	164
Caregiver (a person with caregiving responsibilities for another person with a health condition)	30.67%	100
Neither	19.02%	62
Total		326

Q6 Have you ever tried to get and/or look at your medical record(s) or other health data?

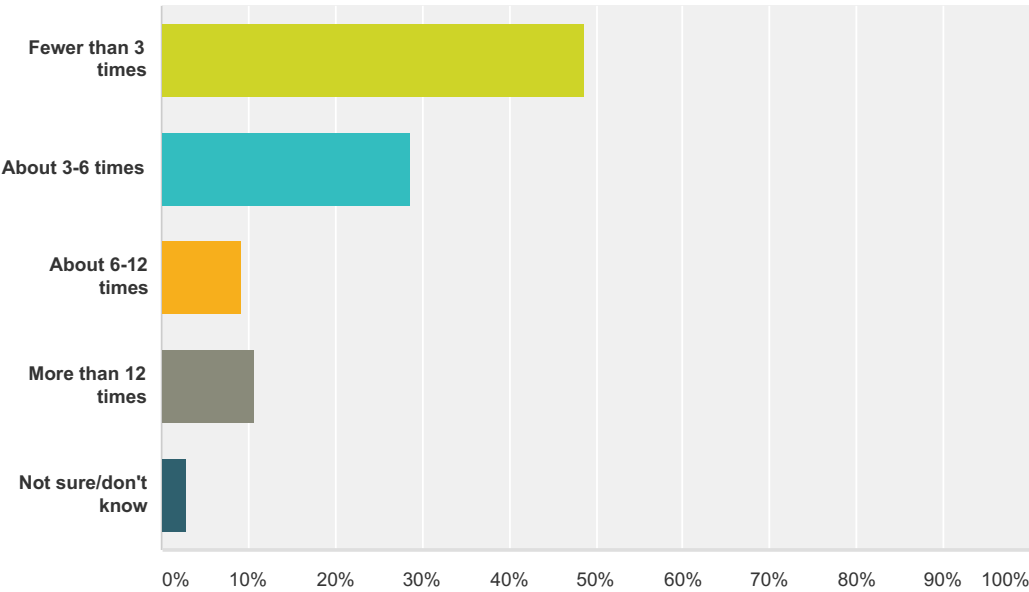
Answered: 189 Skipped: 137



Answer Choices	Responses	
Yes	80.95%	153
No	19.05%	36
Total		189

Q7 How many times did you get copies of or look at your health data over the last 12 months?

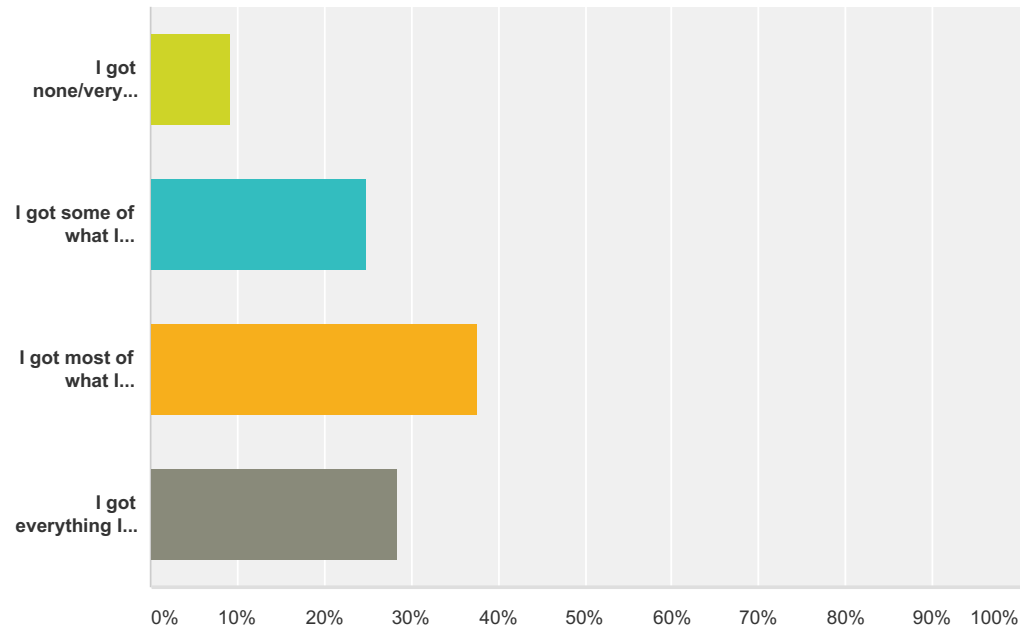
Answered: 140 Skipped: 186



Answer Choices	Responses	
Fewer than 3 times	48.57%	68
About 3-6 times	28.57%	40
About 6-12 times	9.29%	13
More than 12 times	10.71%	15
Not sure/don't know	2.86%	4
Total		140

Q8 How successful were you?

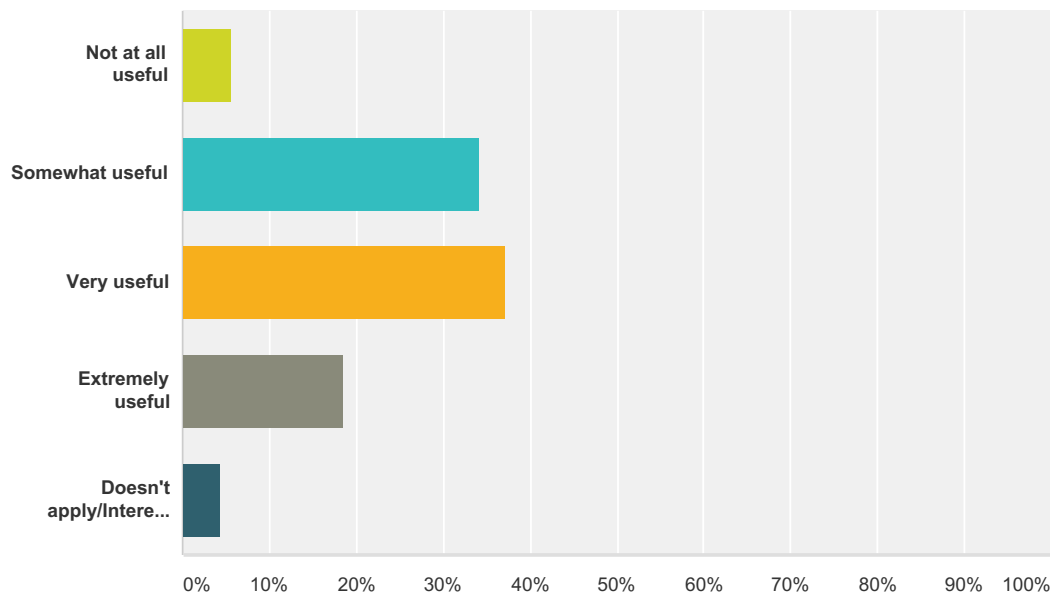
Answered: 141 Skipped: 185



Answer Choices	Responses	
I got none/very little of what I needed/hoped	9.22%	13
I got some of what I needed/hoped	24.82%	35
I got most of what I needed/hoped	37.59%	53
I got everything I needed/hoped	28.37%	40
Total		141

Q9 How useful did you find the health data that you accessed?

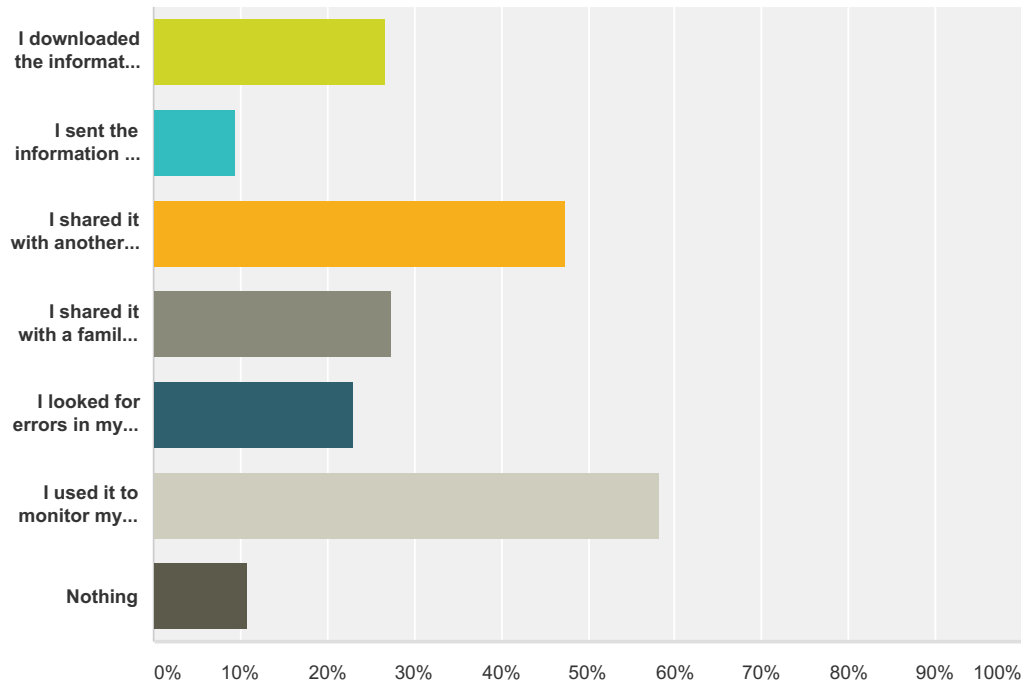
Answered: 140 Skipped: 186



Answer Choices	Responses	
Not at all useful	5.71%	8
Somewhat useful	34.29%	48
Very useful	37.14%	52
Extremely useful	18.57%	26
Doesn't apply/Interesting, but not useful	4.29%	6
Total		140

Q10 What did you do with your health data?
Check all that apply.

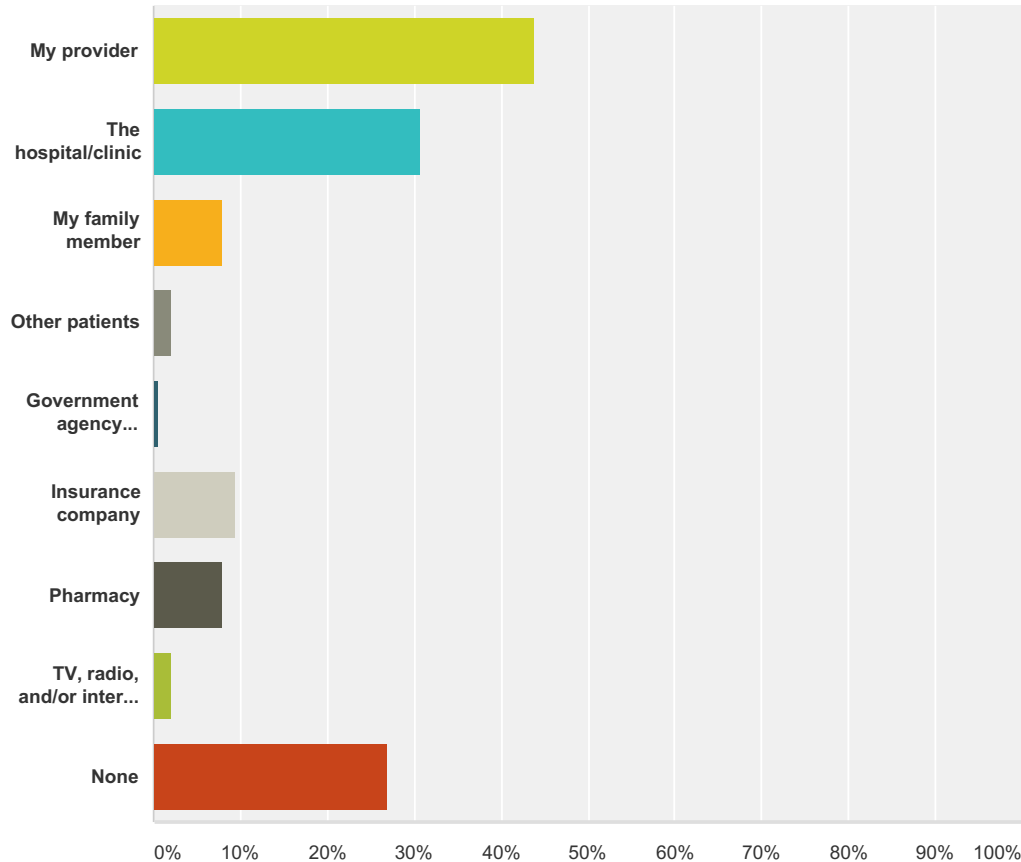
Answered: 139 Skipped: 187



Answer Choices	Responses
I downloaded the information to a computer or other electronic device (cellphone, tablet, USB/portable memory stick)	26.62% 37
I sent the information to a personal health record app or website (A personal health record, or PHR, is an electronic application that allows you to access, enter, and manage some of your health information.)	9.35% 13
I shared it with another health care provider treating me	47.48% 66
I shared it with a family member or someone else involved in my care	27.34% 38
I looked for errors in my health data and offered corrections/updates	23.02% 32
I used it to monitor my health (check my meds, date of last test, etc.)	58.27% 81
Nothing	10.79% 15
Total Respondents: 139	

Q11 Did any of these sources help you figure out how to access your health data?
Check all that apply.

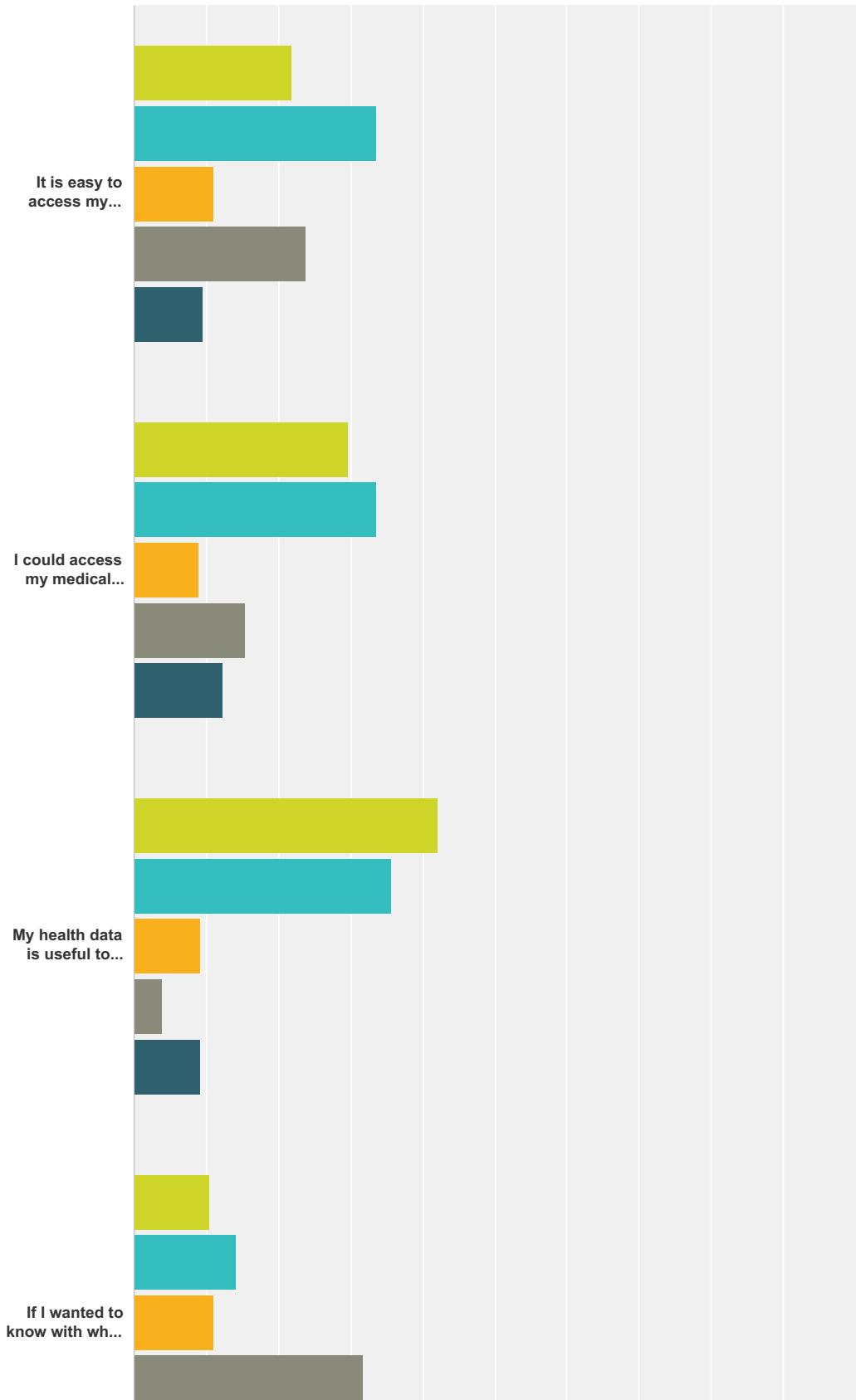
Answered: 137 Skipped: 189

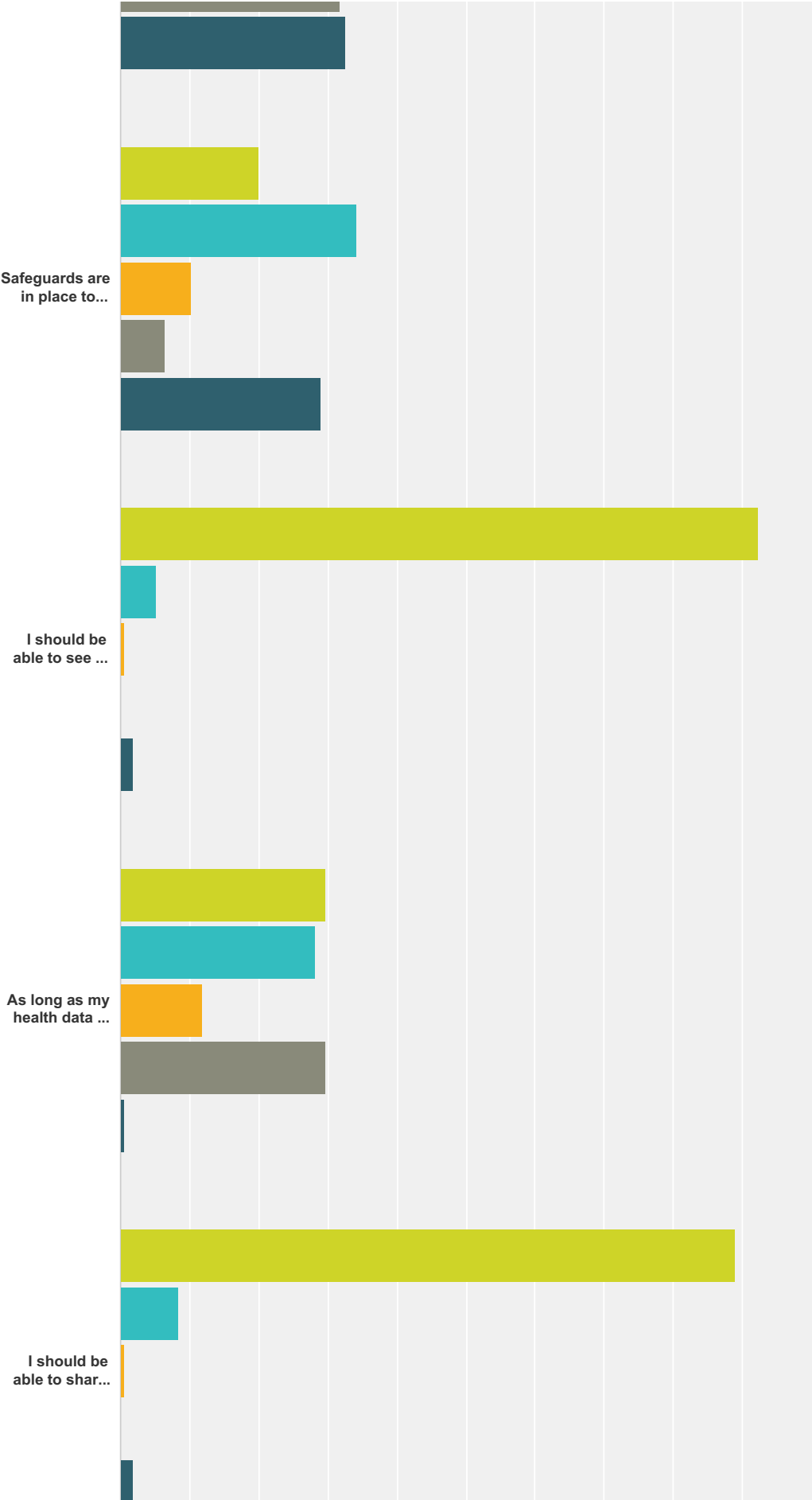


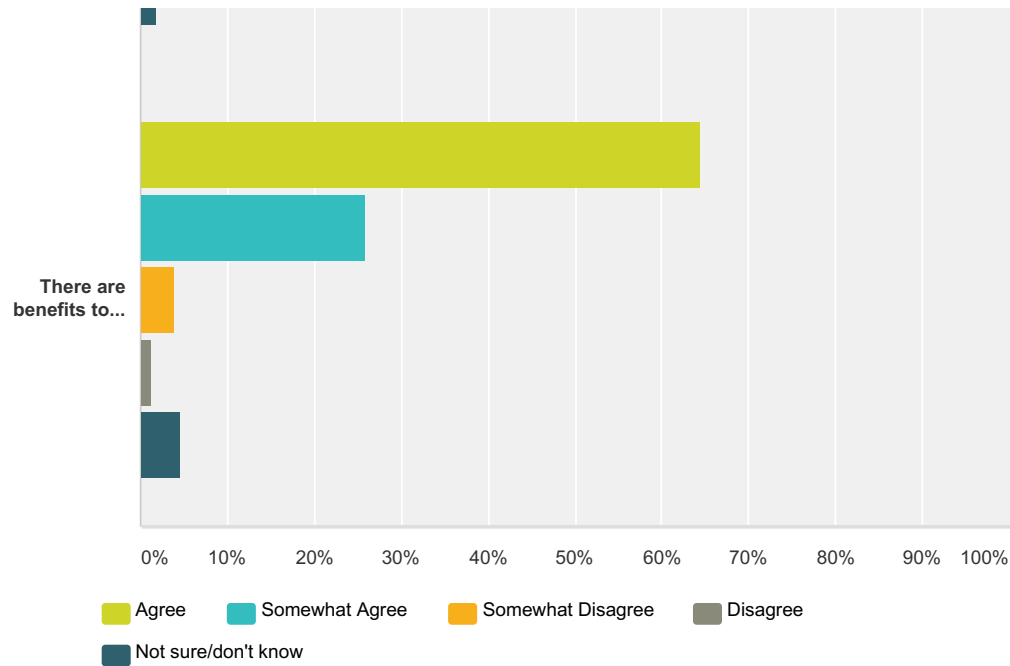
Answer Choices	Responses	
My provider	43.80%	60
The hospital/clinic	30.66%	42
My family member	8.03%	11
Other patients	2.19%	3
Government agency (HealthIT, public health department)	0.73%	1
Insurance company	9.49%	13
Pharmacy	8.03%	11
TV, radio, and/or internet Ad	2.19%	3
None	27.01%	37
Total Respondents: 137		

Q12 How much do you agree with the following statements?

Answered: 155 Skipped: 171



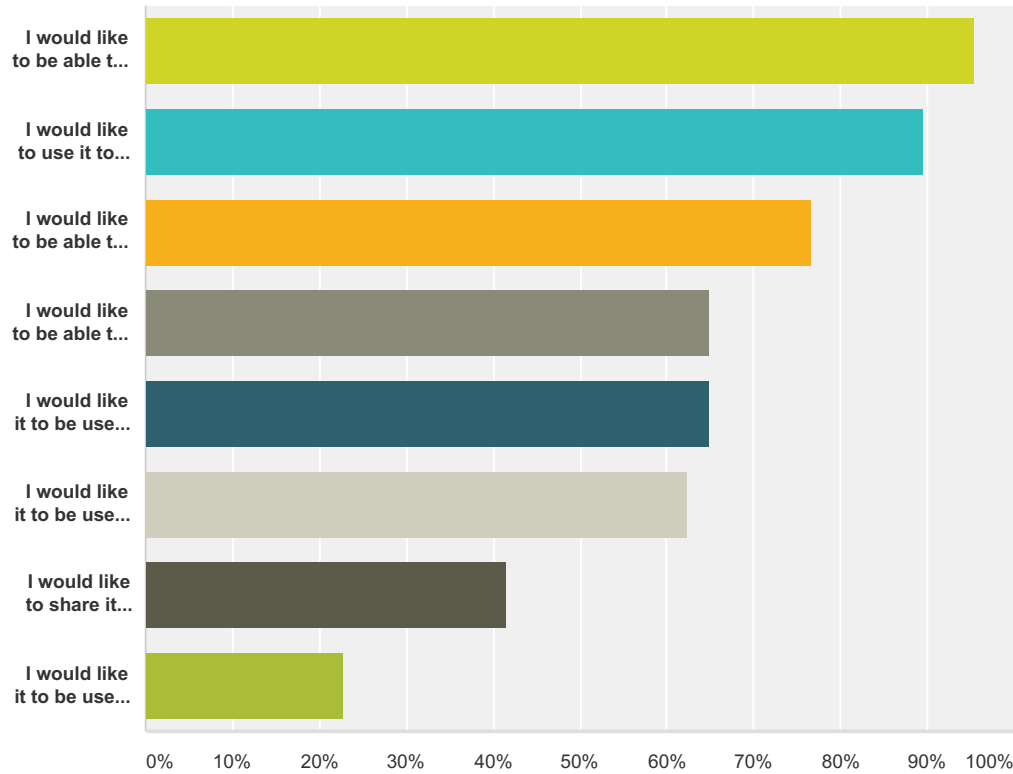




	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Not sure/don't know	Total
It is easy to access my health data online	21.94% 34	33.55% 52	10.97% 17	23.87% 37	9.68% 15	155
I could access my medical record if I wanted to	29.68% 46	33.55% 52	9.03% 14	15.48% 24	12.26% 19	155
My health data is useful to me even if it is incomplete	42.21% 65	35.71% 55	9.09% 14	3.90% 6	9.09% 14	154
If I wanted to know with whom my health data had been shared, I would be able to find out	10.39% 16	14.29% 22	11.04% 17	31.82% 49	32.47% 50	154
Safeguards are in place to protect my health data from being misused	20.00% 31	34.19% 53	10.32% 16	6.45% 10	29.03% 45	155
I should be able to see all of my health data, including everything in my medical records.	92.26% 143	5.16% 8	0.65% 1	0.00% 0	1.94% 3	155
As long as my health data is anonymized (can't be tracked back to me) I would be okay with it being shared without my permission	29.58% 42	28.17% 40	11.97% 17	29.58% 42	0.70% 1	142
I should be able to share my health data, including my medical records, with any of my providers (or other members of my care team/people caring for me)	89.03% 138	8.39% 13	0.65% 1	0.00% 0	1.94% 3	155
There are benefits to people/public health when organizations involved in health care share health data about individuals, including me.	64.52% 100	25.81% 40	3.87% 6	1.29% 2	4.52% 7	155

Q13 If you had access to all of your health data and it was complete and accurate, how would you prefer to use it? Check all that apply.

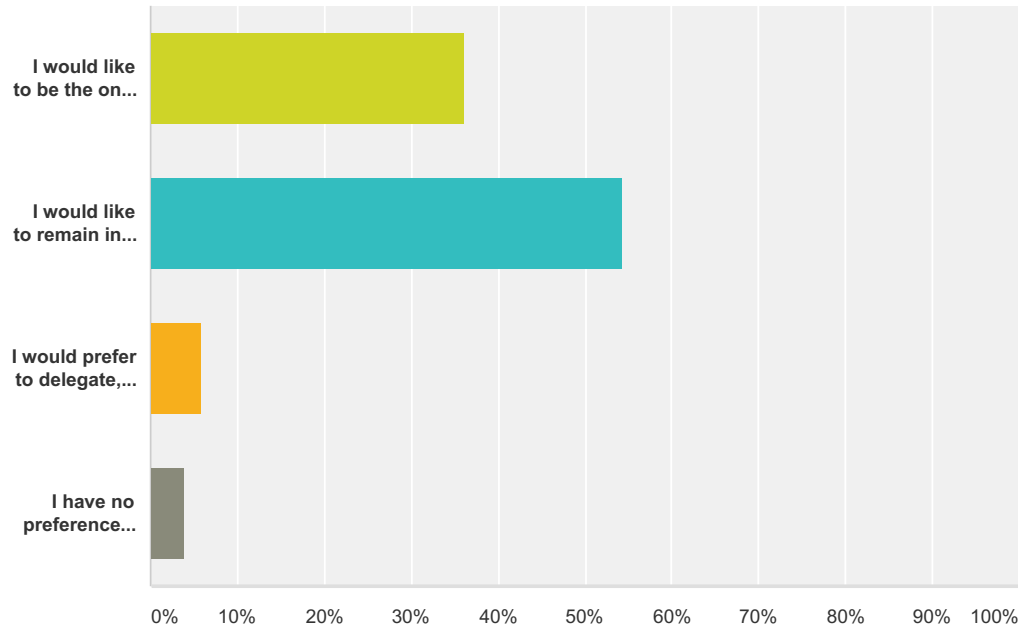
Answered: 154 Skipped: 172



Answer Choices	Responses	
I would like to be able to share it with any of the providers involved in my care.	95.45%	147
I would like to use it to help me better understand my health condition and/or care for myself and/or follow treatment recommendations.	89.61%	138
I would like to be able to share it with researchers or give it to a research study.	76.62%	118
I would like to be able to share it with my family or other non-health professionals in my care.	64.94%	100
I would like it to be used to help other patients.	64.94%	100
I would like it to be used by hospitals and clinics to understand the quality of the care they provide to others.	62.34%	96
I would like to share it with medical product developers (pharmaceutical and device companies).	41.56%	64
I would like it to be used by insurance companies to decide on what medical care they will provide coverage for..	22.73%	35
Total Respondents: 154		

Q14 How would you prefer to make decisions about how your health data is shared?

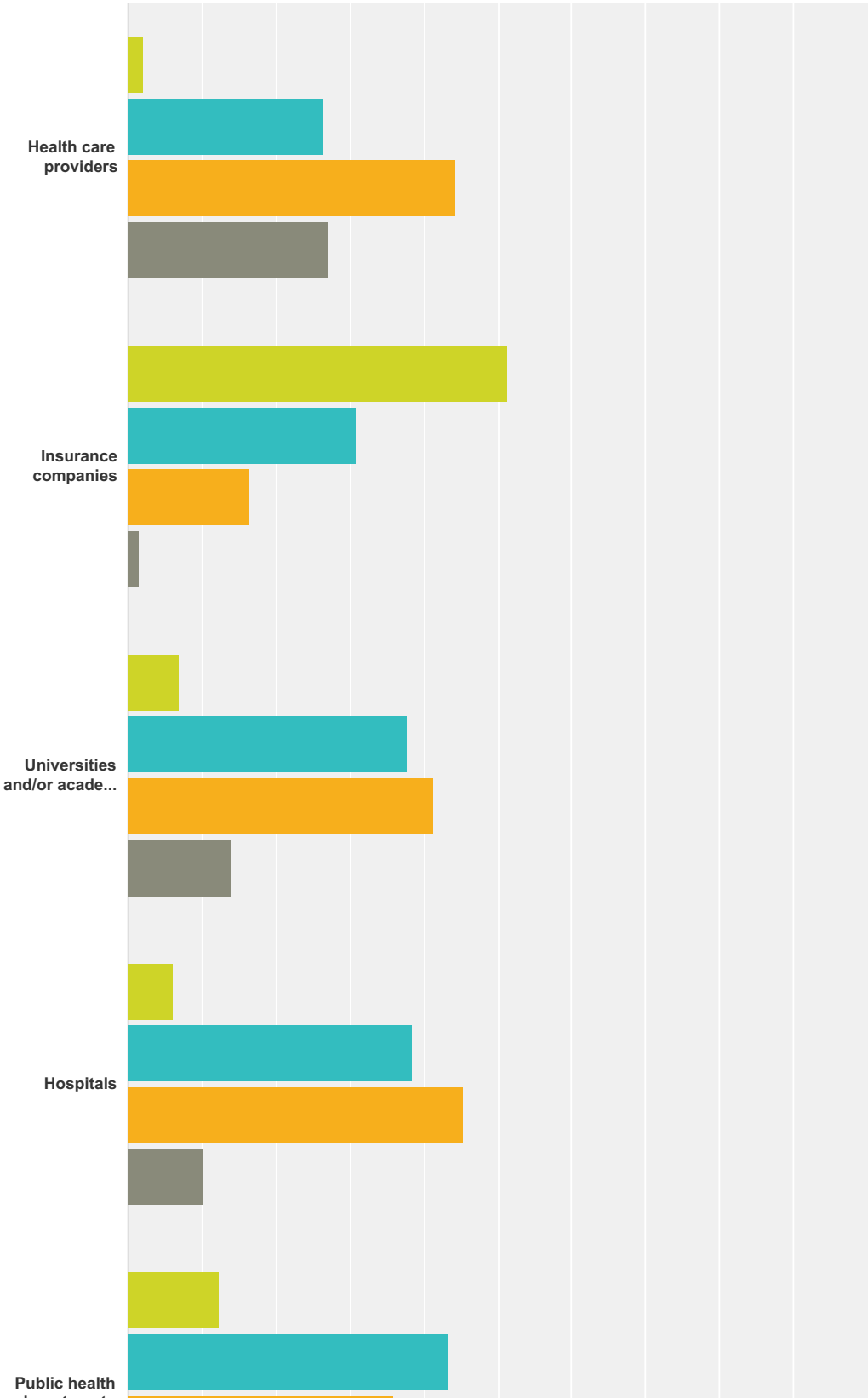
Answered: 155 Skipped: 171

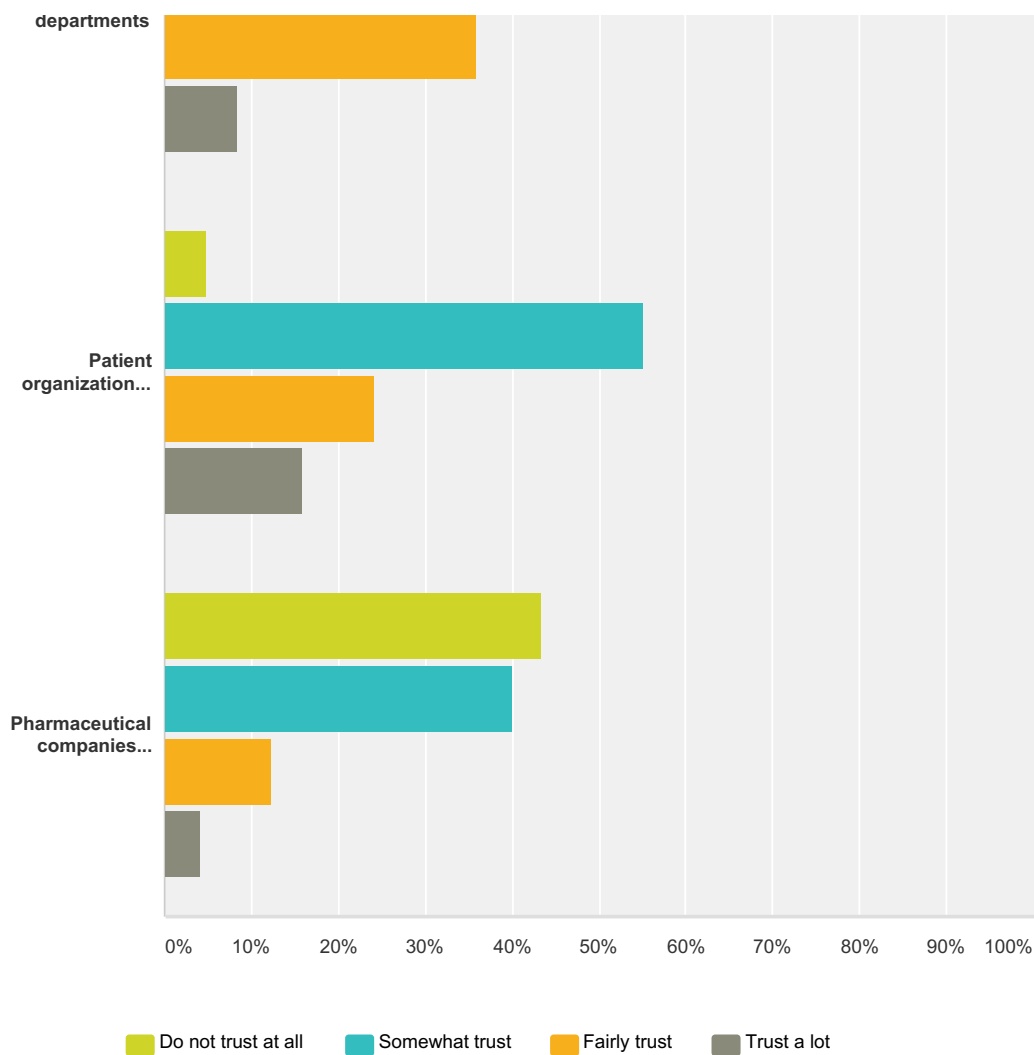


Answer Choices	Responses
I would like to be the only person making decisions about how my health data is shared	36.13% 56
I would like to remain in charge of decision making, but consult with a health care professional, or other person I choose, to help me make decisions about how my data is shared	54.19% 84
I would prefer to delegate, or give over, decision making about how my health data is shared to someone I trust	5.81% 9
I have no preference about how decisions are made about sharing my health data	3.87% 6
Total	155

Q15 How much do you trust the following organizations to manage how your health data is shared within the system?

Answered: 148 Skipped: 178

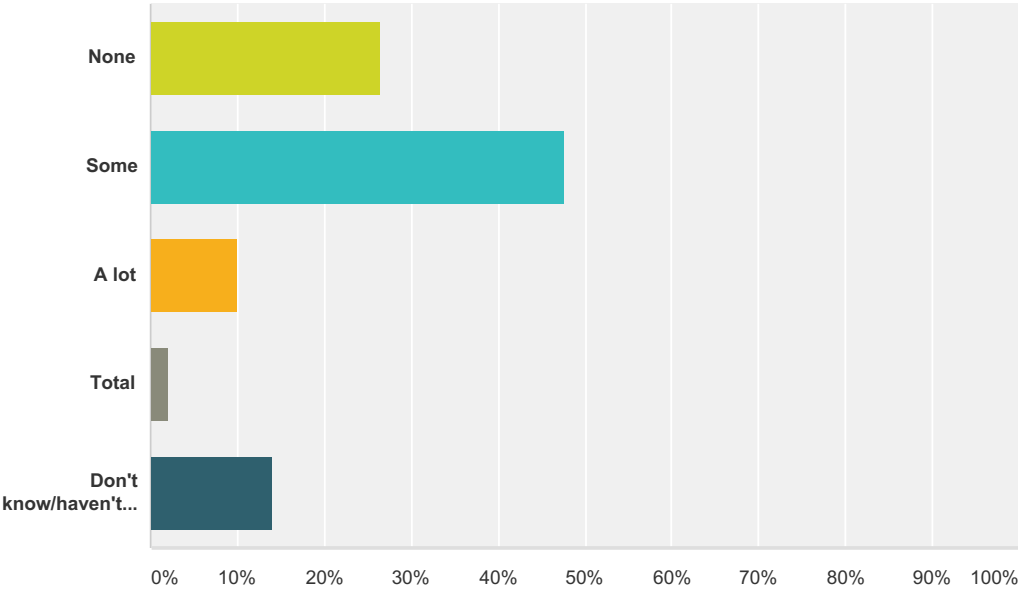




	Do not trust at all	Somewhat trust	Fairly trust	Trust a lot	Total
Health care providers	2.04% 3	26.53% 39	44.22% 65	27.21% 40	147
Insurance companies	51.37% 75	30.82% 45	16.44% 24	1.37% 2	146
Universities and/or academic medical centers	6.99% 10	37.76% 54	41.26% 59	13.99% 20	143
Hospitals	6.08% 9	38.51% 57	45.27% 67	10.14% 15	148
Public health departments	12.41% 18	43.45% 63	35.86% 52	8.28% 12	145
Patient organizations, patient registries	4.83% 7	55.17% 80	24.14% 35	15.86% 23	145
Pharmaceutical companies and/or medical device manufacturers	43.45% 63	40.00% 58	12.41% 18	4.14% 6	145

Q16 How much control do you feel you have over whether or not your health data is shared?

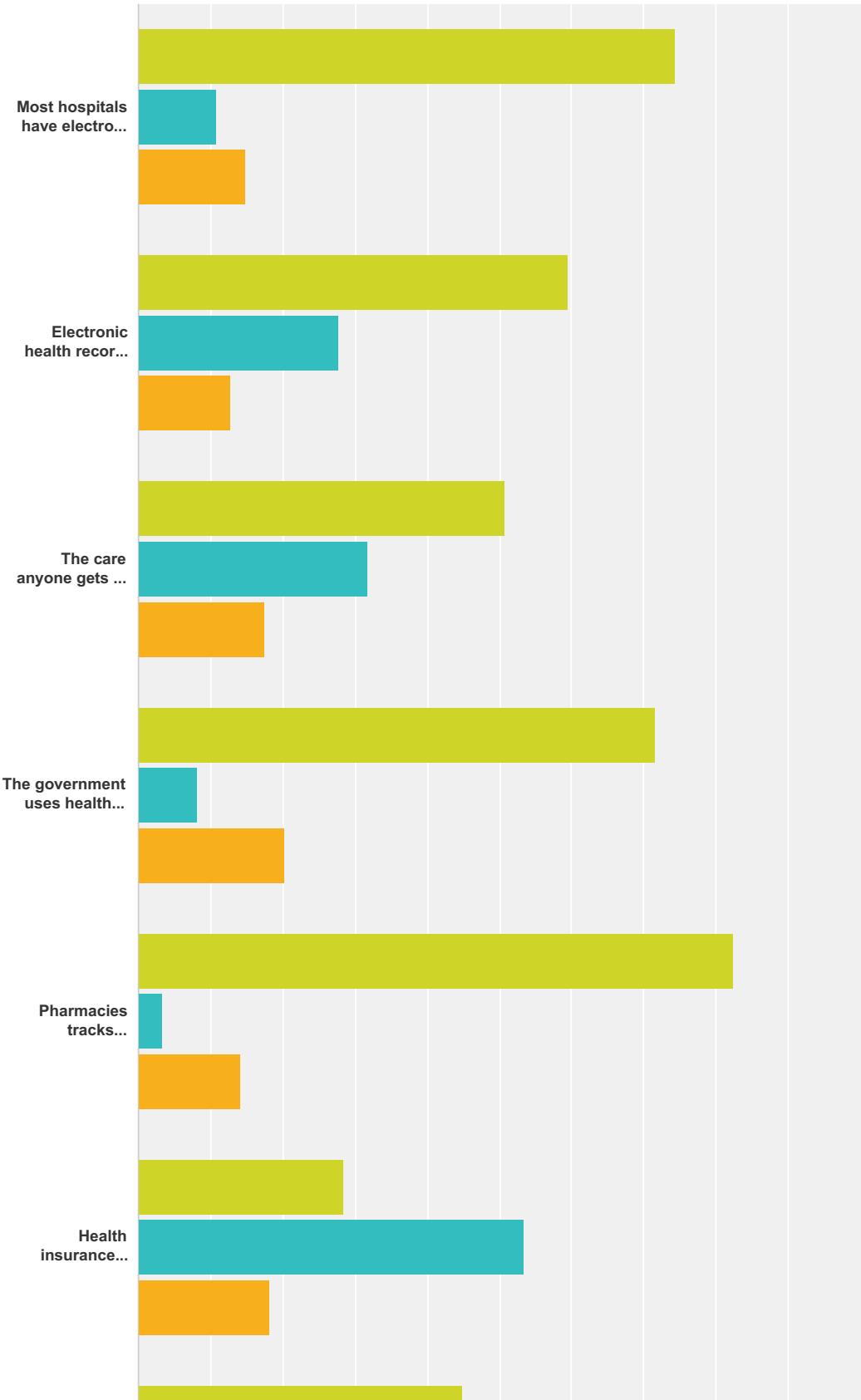
Answered: 151 Skipped: 175

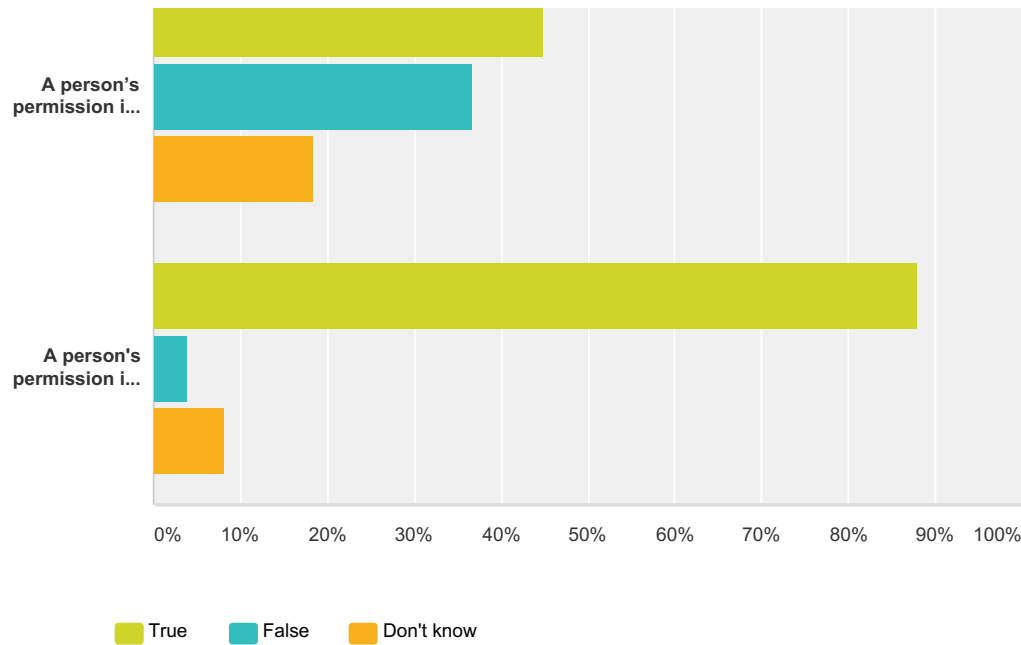


Answer Choices	Responses	
None	26.49%	40
Some	47.68%	72
A lot	9.93%	15
Total	1.99%	3
Don't know/haven't considered	13.91%	21
Total		151

Q17 What do you think of the following statements?

Answered: 148 Skipped: 178

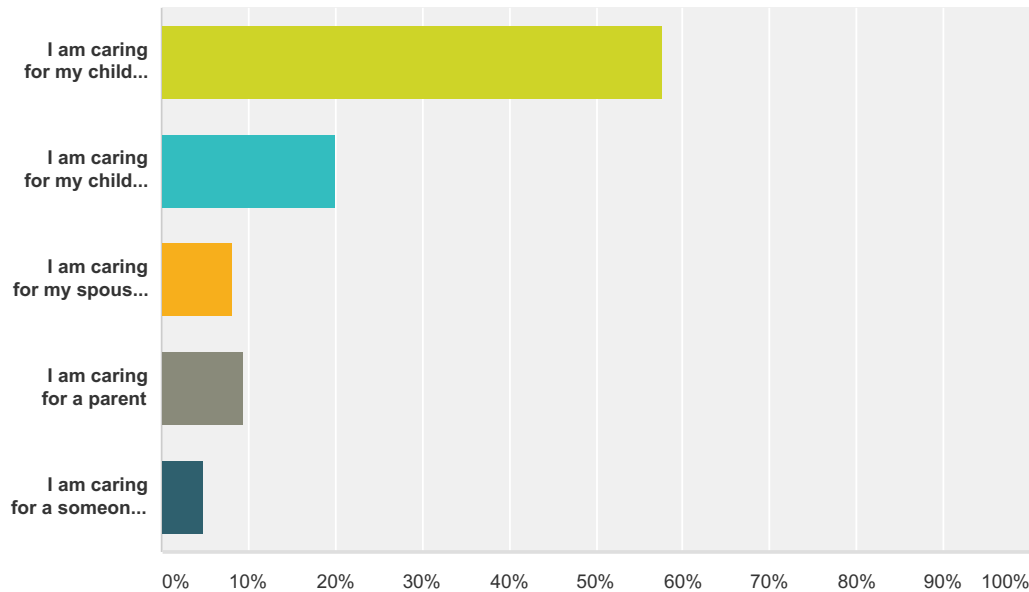




	True	False	Don't know	Total
Most hospitals have electronic health records	74.32% 110	10.81% 16	14.86% 22	148
Electronic health records are shared among providers (physicians, specialists, hospital systems)	59.46% 88	27.70% 41	12.84% 19	148
The care anyone gets is tracked	50.68% 75	31.76% 47	17.57% 26	148
The government uses health data provided by hospitals and clinics to track diseases	71.62% 106	8.11% 12	20.27% 30	148
Pharmacies tracks purchases, including medical products and other things people buy from them	82.43% 122	3.38% 5	14.19% 21	148
Health insurance companies cannot use health data to deny people coverage	28.38% 42	53.38% 79	18.24% 27	148
A person's permission is required for their health data to be used in any type of health research	44.90% 66	36.73% 54	18.37% 27	147
A person's permission is required for their health data to be shared with a loved one or caregiver	87.84% 130	4.05% 6	8.11% 12	148

Q18 As a caregiver, you may care for more than one person. For this survey, please select one category that best describes your current situation.

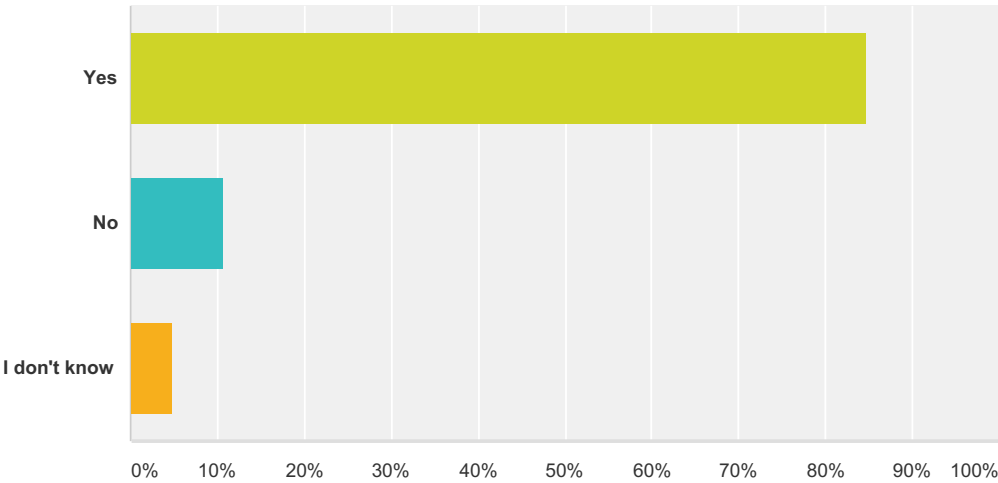
Answered: 85 Skipped: 241



Answer Choices	Responses	
I am caring for my child or a child in my custody (under the age of 18)	57.65%	49
I am caring for my child or a child in my custody (over the age of 18)	20.00%	17
I am caring for my spouse or partner	8.24%	7
I am caring for a parent	9.41%	8
I am caring for a someone other than the above	4.71%	4
Total		85

Q19 As a caregiver, do you have the necessary permissions (medical power of attorney and/or HIPAA authorization) to access the health data of the person you are caring for?

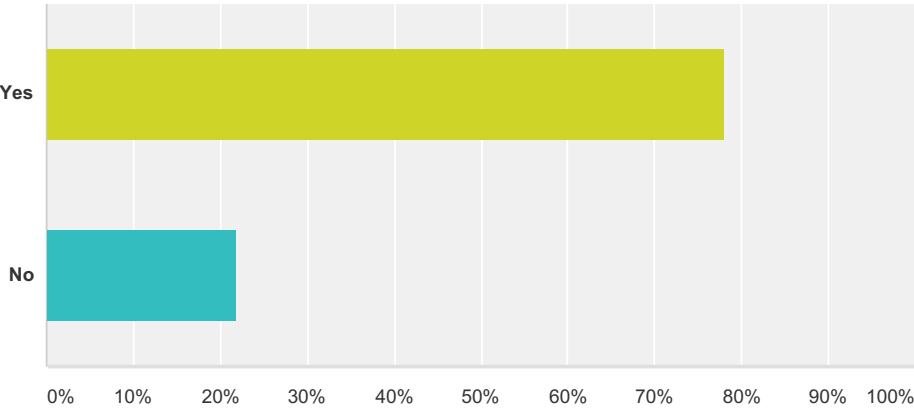
Answered: 85 Skipped: 241



Answer Choices	Responses	
Yes	84.71%	72
No	10.59%	9
I don't know	4.71%	4
Total		85

Q20 Have you ever tried to get copies of or look at the medical record(s) or other health data of the person you are caring for?

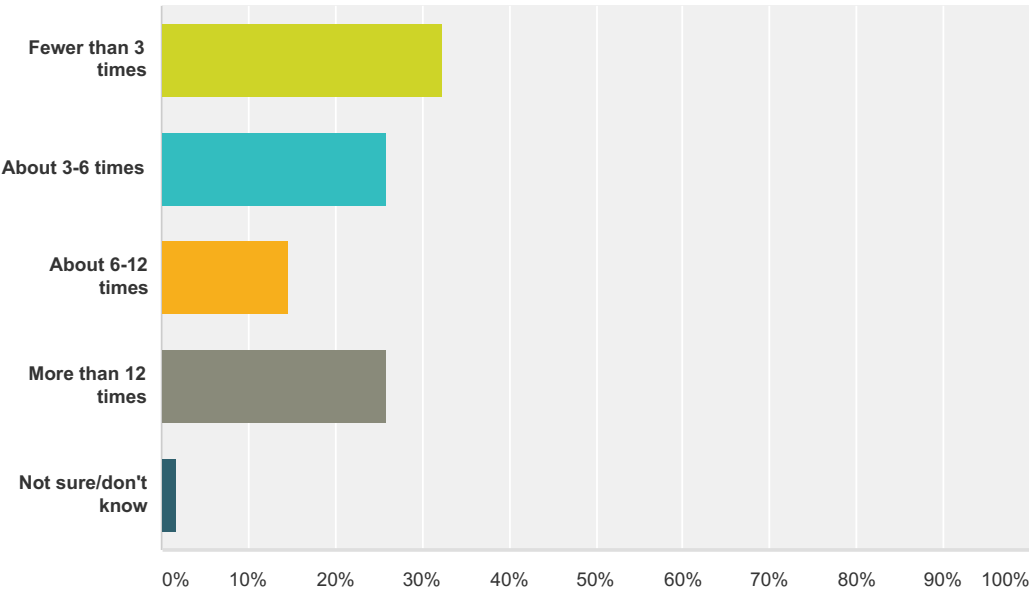
Answered: 87 Skipped: 239



Answer Choices	Responses	
Yes	78.16%	68
No	21.84%	19
Total		87

Q21 How many times did you get and/or look at their health data over the last 12 months?

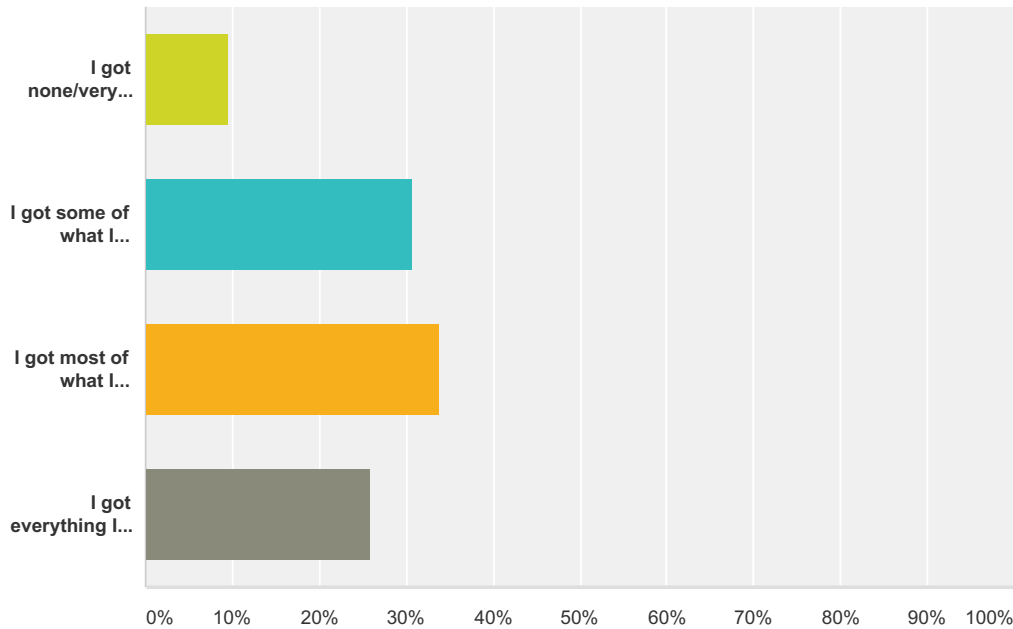
Answered: 62 Skipped: 264



Answer Choices	Responses
Fewer than 3 times	32.26%20
About 3-6 times	25.81%16
About 6-12 times	14.52%9
More than 12 times	25.81%16
Not sure/don't know	1.61%1
Total	62

Q22 How successful were you?

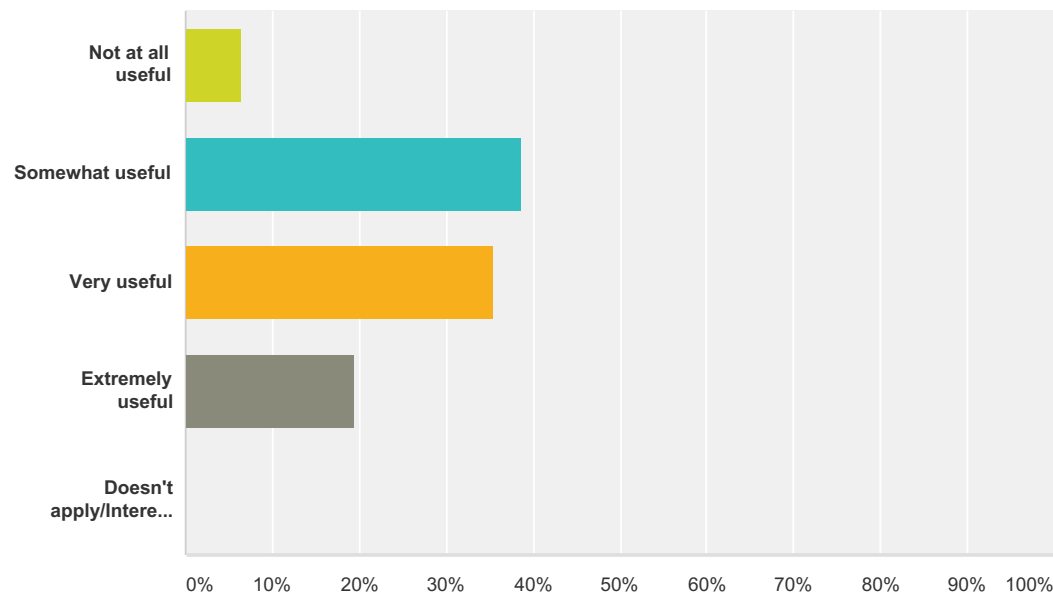
Answered: 62 Skipped: 264



Answer Choices	Responses	
I got none/very little of what I needed/hoped	9.68%	6
I got some of what I needed/hoped	30.65%	19
I got most of what I needed/hoped	33.87%	21
I got everything I needed/hoped	25.81%	16
Total		62

Q23 How useful did you find the health data that you accessed?

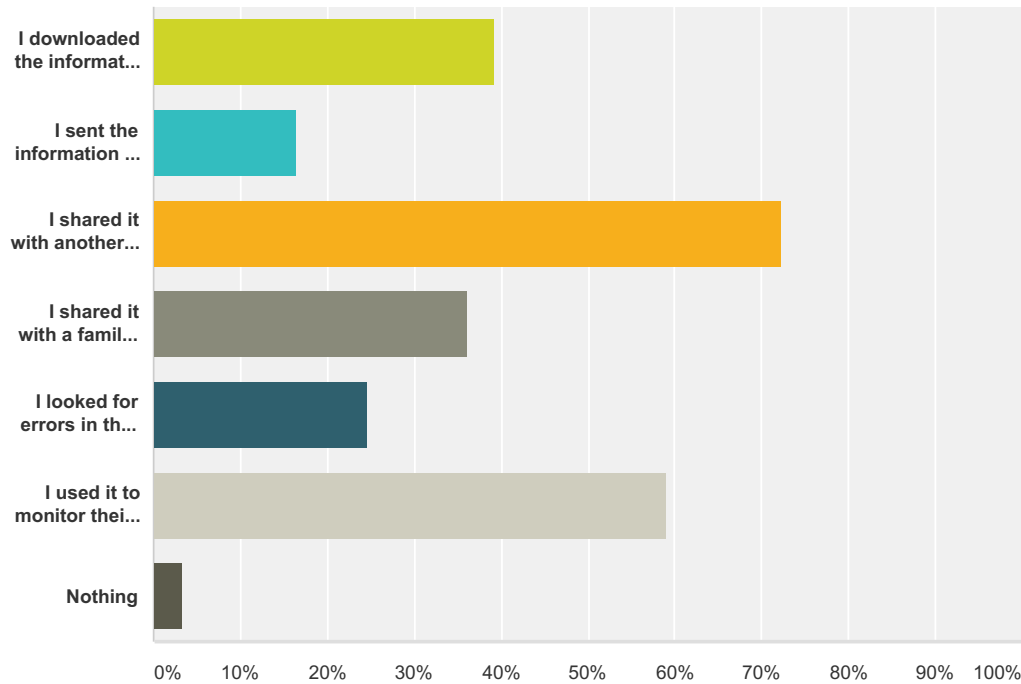
Answered: 62 Skipped: 264



Answer Choices	Responses	
Not at all useful	6.45%	4
Somewhat useful	38.71%	24
Very useful	35.48%	22
Extremely useful	19.35%	12
Doesn't apply/Interesting but not useful	0.00%	0
Total		62

Q24 What did you do with their health data?
Check all that apply.

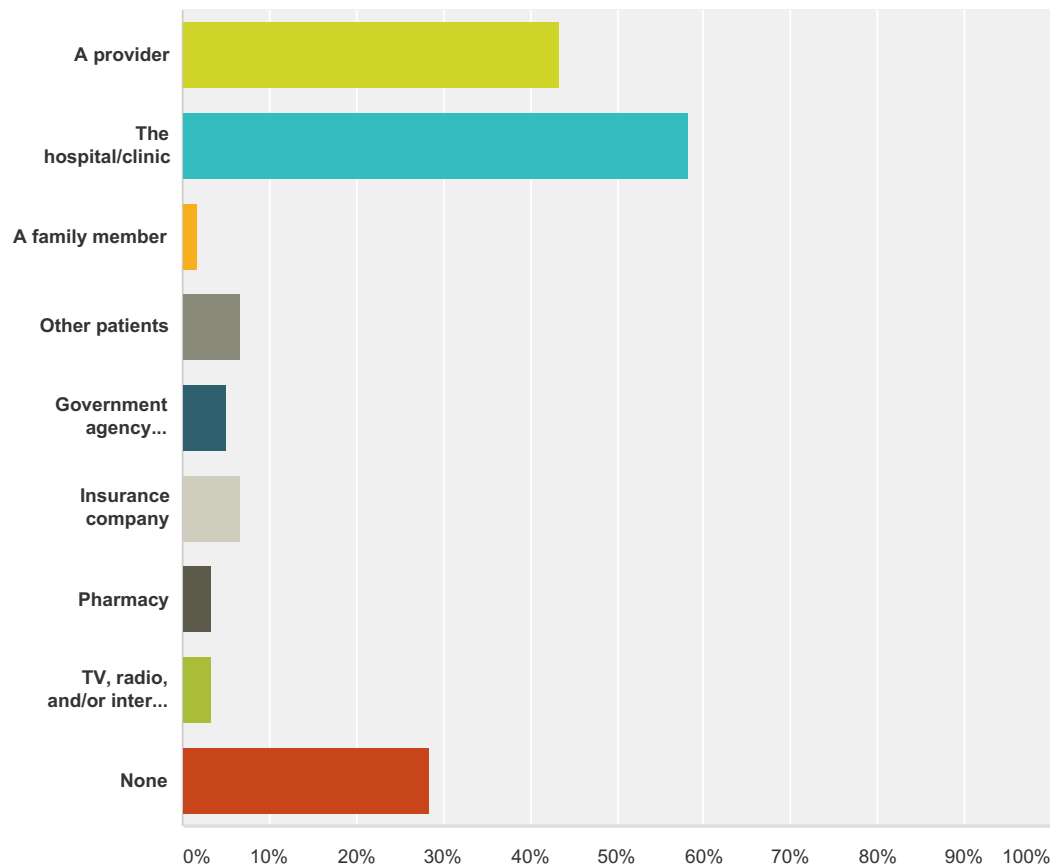
Answered: 61 Skipped: 265



Answer Choices	Responses
I downloaded the information to a computer or other electronic device (cellphone, tablet, USB/portable memory stick)	39.34% 24
I sent the information to a personal health record app or website (A personal health record, or PHR, is an electronic application that allows you to access, enter, and manage some of your health information.)	16.39% 10
I shared it with another health care provider who is taking care of them	72.13% 44
I shared it with a family member or someone else involved in helping me provide care	36.07% 22
I looked for errors in their health data and offered corrections/updates	24.59% 15
I used it to monitor their health (check their meds, date of last test, etc.)	59.02% 36
Nothing	3.28% 2
Total Respondents: 61	

Q25 Did any of these sources help you figure out how to access the health data of the person you are caring for? Check all that apply.

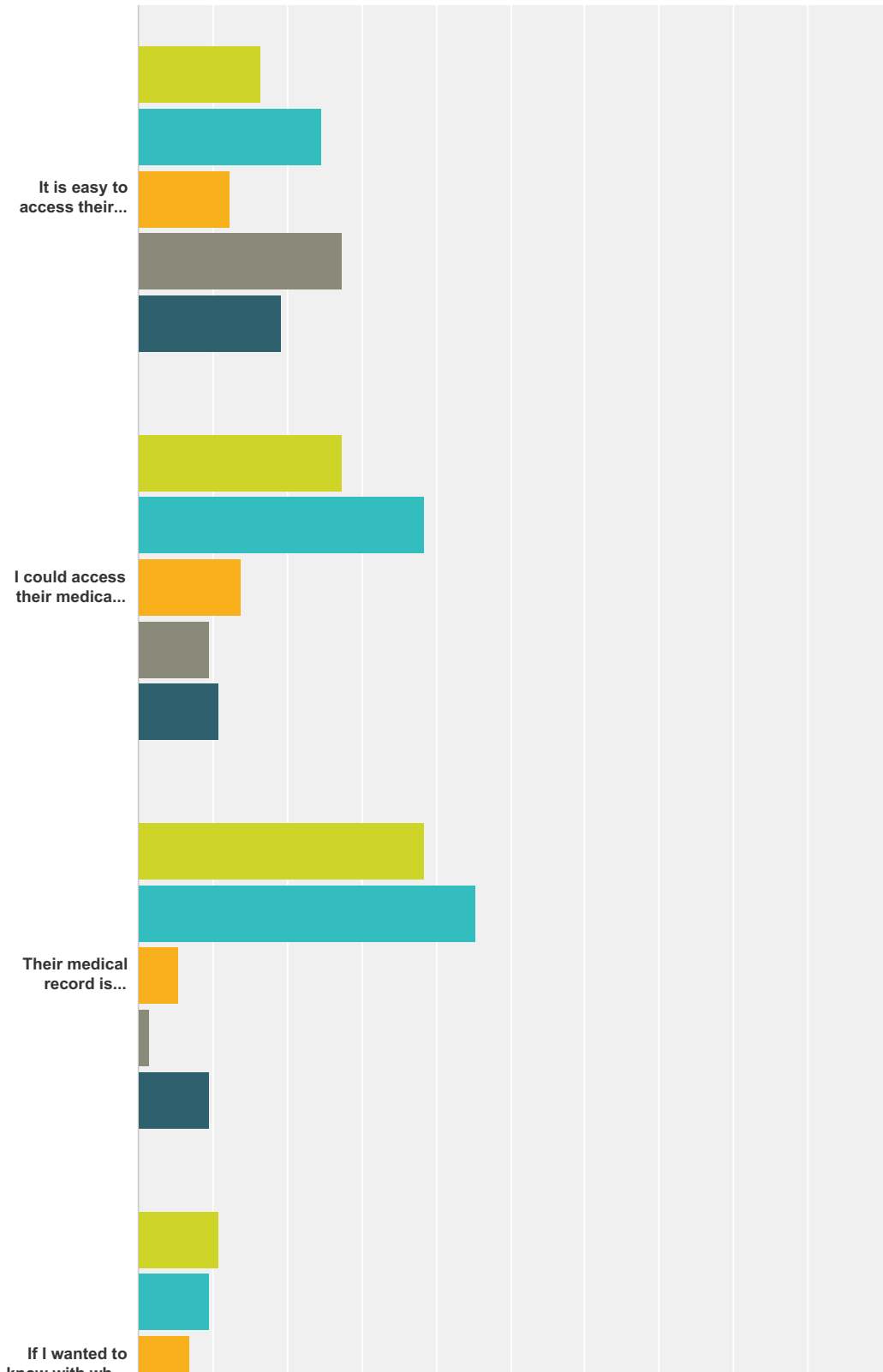
Answered: 60 Skipped: 266

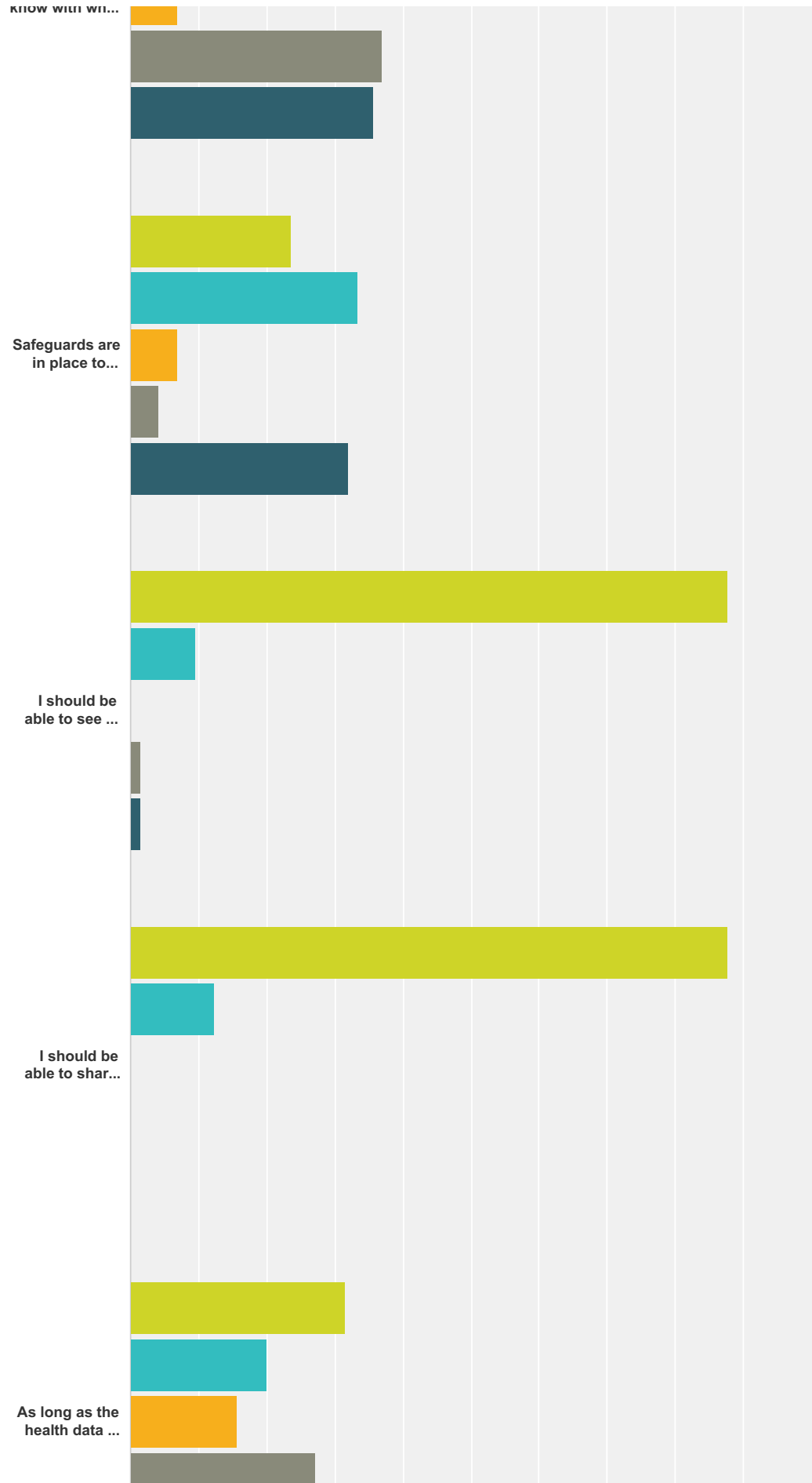


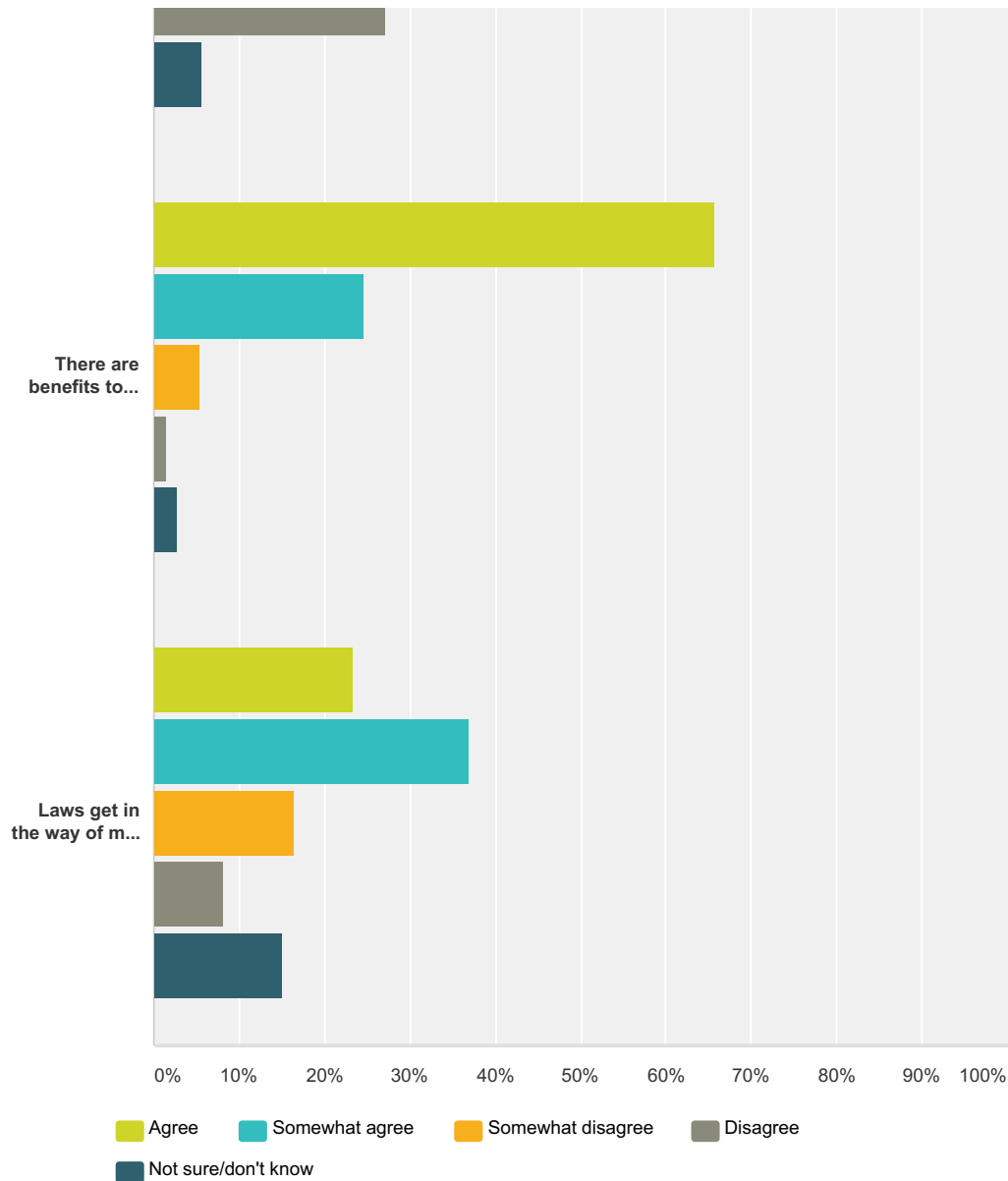
Answer Choices	Responses	
A provider	43.33%	26
The hospital/clinic	58.33%	35
A family member	1.67%	1
Other patients	6.67%	4
Government agency (HealthIT, public health department)	5.00%	3
Insurance company	6.67%	4
Pharmacy	3.33%	2
TV, radio, and/or internet Ad	3.33%	2
None	28.33%	17
Total Respondents: 60		

Q26 Assuming you have permission to access the health data of the person you are caring for, how much do you agree with the following statements?

Answered: 73 Skipped: 253





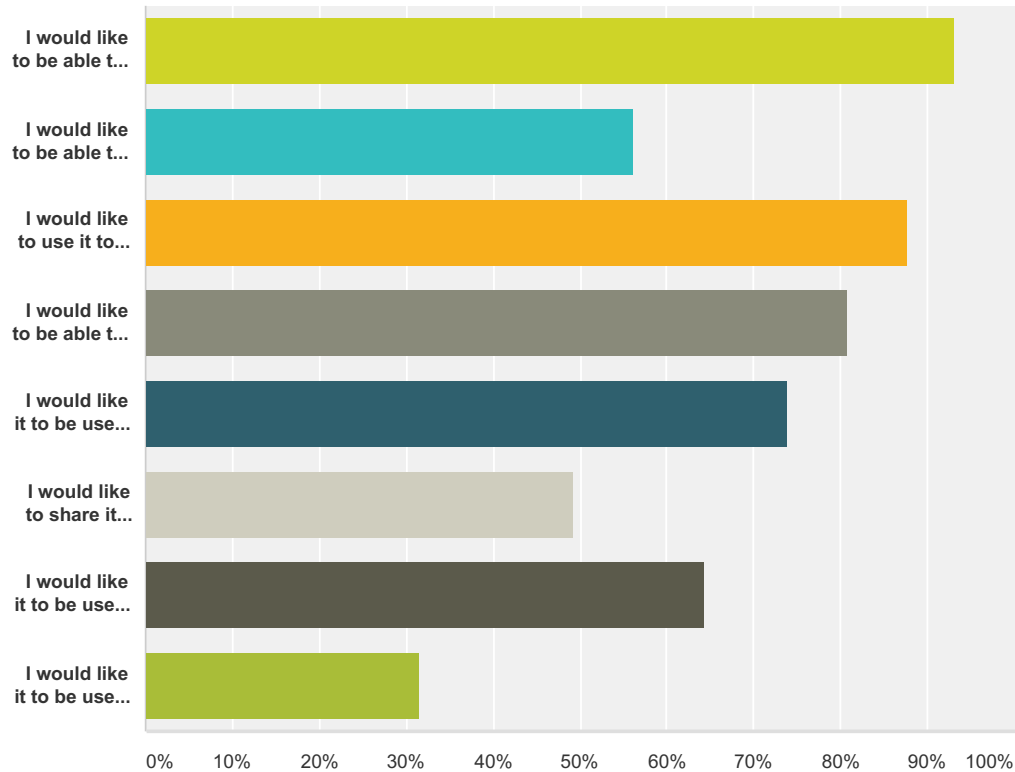


	Agree	Somewhat agree	Somewhat disagree	Disagree	Not sure/don't know	Total
It is easy to access their health data on their behalf online	16.44% 12	24.66% 18	12.33% 9	27.40% 20	19.18% 14	73
I could access their medical record if I needed to	27.40% 20	38.36% 28	13.70% 10	9.59% 7	10.96% 8	73
Their medical record is useful even if it is incomplete	38.36% 28	45.21% 33	5.48% 4	1.37% 1	9.59% 7	73
If I wanted to know with whom their health data had been shared, I would be able to find out	10.96% 8	9.59% 7	6.85% 5	36.99% 27	35.62% 26	73
Safeguards are in place to protect their health data from being misused	23.61% 17	33.33% 24	6.94% 5	4.17% 3	31.94% 23	72
I should be able to see all of their health data, including everything in their medical records.	87.67% 64	9.59% 7	0.00% 0	1.37% 1	1.37% 1	73
I should be able to share their health data, including their medical records, with any of their providers (or other members of their care team/others caring for them).	87.67% 64	12.33% 9	0.00% 0	0.00% 0	0.00% 0	73

As long as the health data is anonymized (can't be traced back to the person in my care), I would be okay with it being shared without my permission	31.43% 22	20.00% 14	15.71% 11	27.14% 19	5.71% 4	70
There are benefits to people/public health when organizations involved in health care share health data about individuals, including the person I care for.	65.75% 48	24.66% 18	5.48% 4	1.37% 1	2.74% 2	73
Laws get in the way of my having access to their health data to help them with their care.	23.29% 17	36.99% 27	16.44% 12	8.22% 6	15.07% 11	73

Q27 If you had access to all of the health data of the person you are caring for and it was complete and accurate, how would you prefer to use it? Check all that apply.

Answered: 73 Skipped: 253

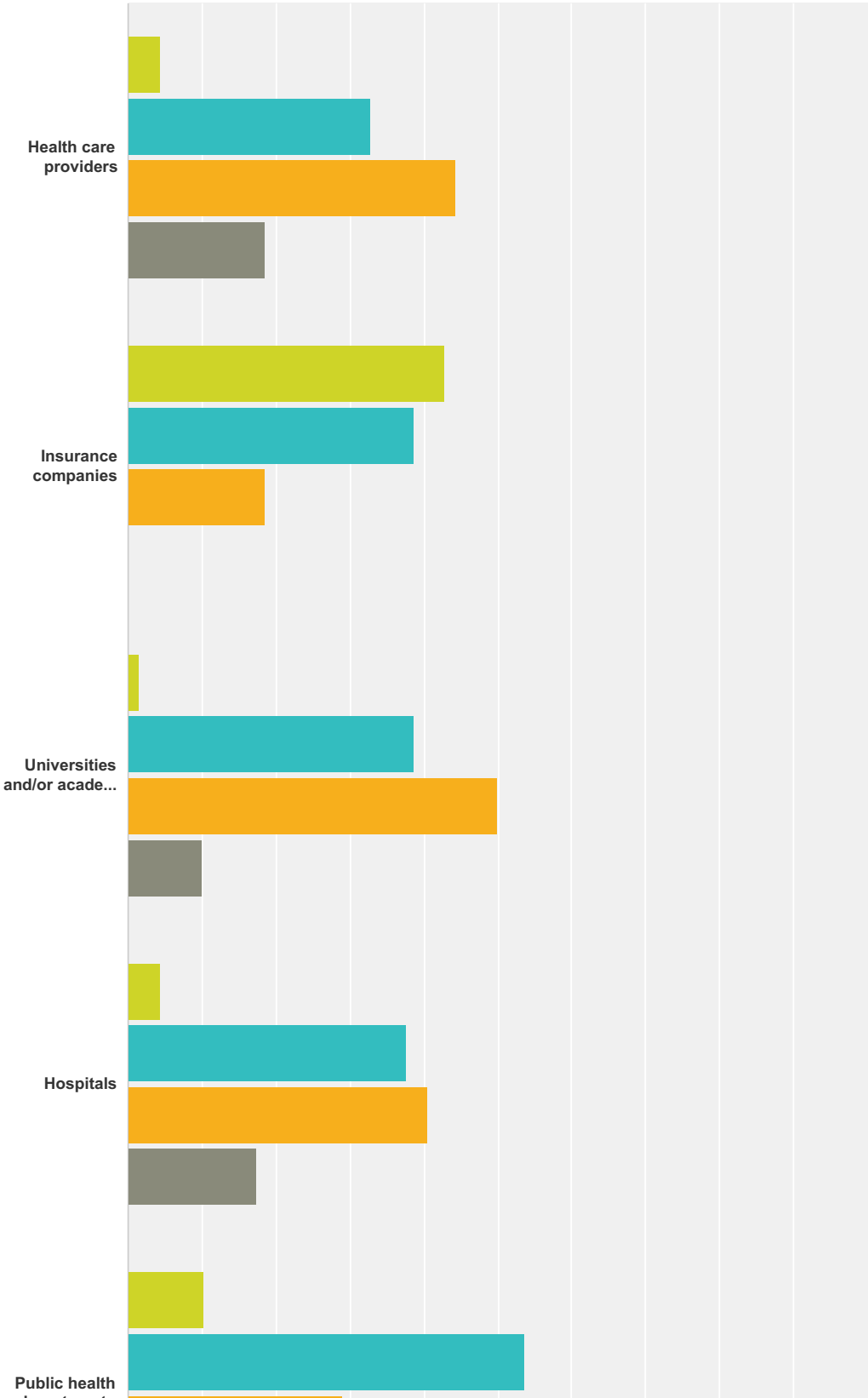


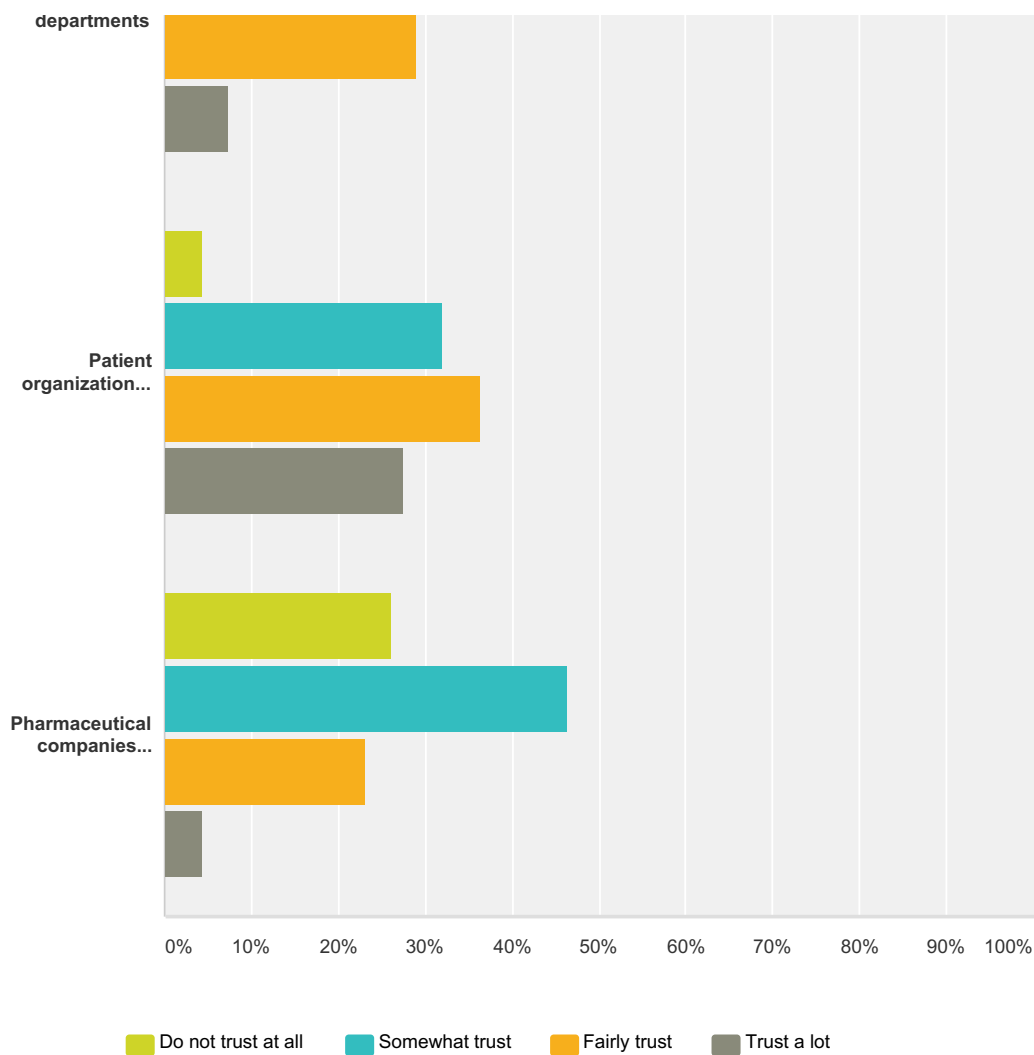
Answer Choices	Responses
I would like to be able to share it with any of the providers involved in their care.	93.15% 68
I would like to be able to share it with family or other non-health professionals in their care.	56.16% 41
I would like to use it to help me better understand the heath condition of the person I am caring for and/or care for them better and/or help them follow treatment recommendations.	87.67% 64
I would like to be able to share it with researchers or give it to a research study.	80.82% 59
I would like it to be used to help other patients.	73.97% 54
I would like to share it with medical product developers (pharmaceutical and device companies).	49.32% 36
I would like it to be used by hospitals and clinics to understand the quality of the care they provide to others.	64.38% 47

I would like it to be used by insurance companies to decide on what medical care they will provide coverage for.	31.51% 23
Total Respondents: 73	

Q28 How much do you trust the following organizations to manage how their health data is shared within the system?

Answered: 71 Skipped: 255

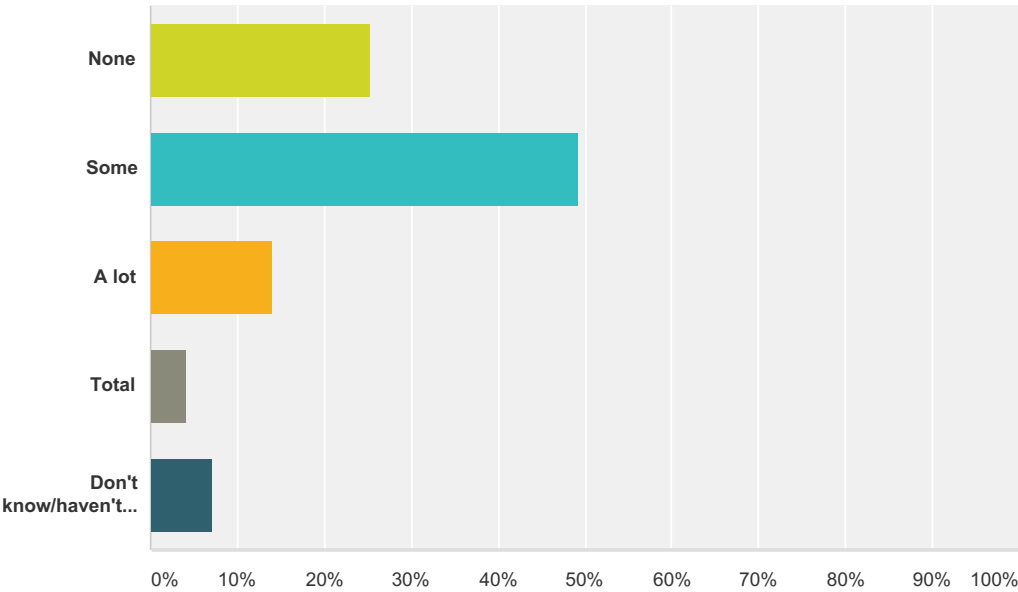




	Do not trust at all	Somewhat trust	Fairly trust	Trust a lot	Total
Health care providers	4.29% 3	32.86% 23	44.29% 31	18.57% 13	70
Insurance companies	42.86% 30	38.57% 27	18.57% 13	0.00% 0	70
Universities and/or academic medical centers	1.43% 1	38.57% 27	50.00% 35	10.00% 7	70
Hospitals	4.35% 3	37.68% 26	40.58% 28	17.39% 12	69
Public health departments	10.14% 7	53.62% 37	28.99% 20	7.25% 5	69
Patient organizations and/or patient registries	4.35% 3	31.88% 22	36.23% 25	27.54% 19	69
Pharmaceutical companies and/or medical device manufacturers	26.09% 18	46.38% 32	23.19% 16	4.35% 3	69

Q29 How much control do you feel you have over whether or not their health data is shared?

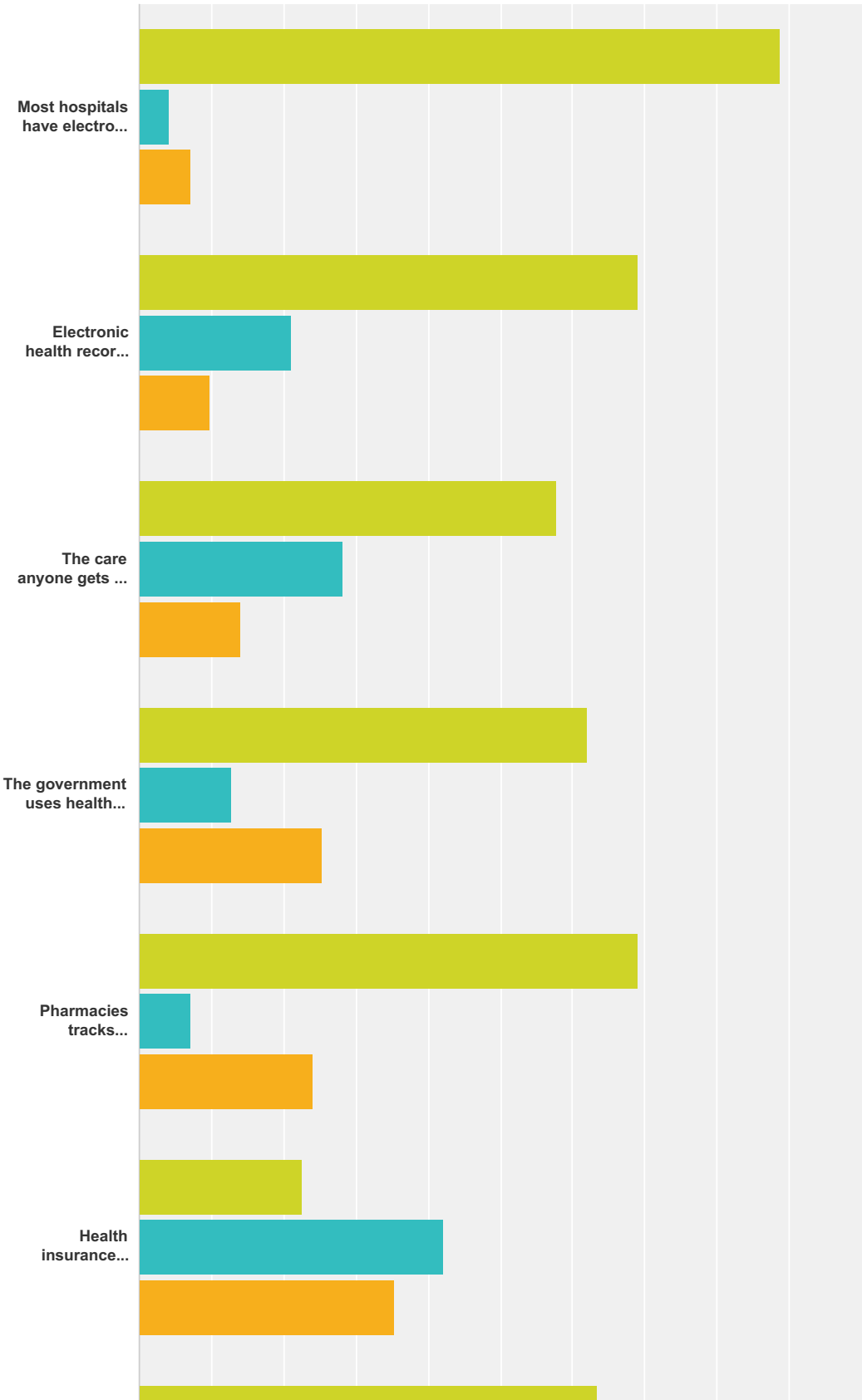
Answered: 71 Skipped: 255

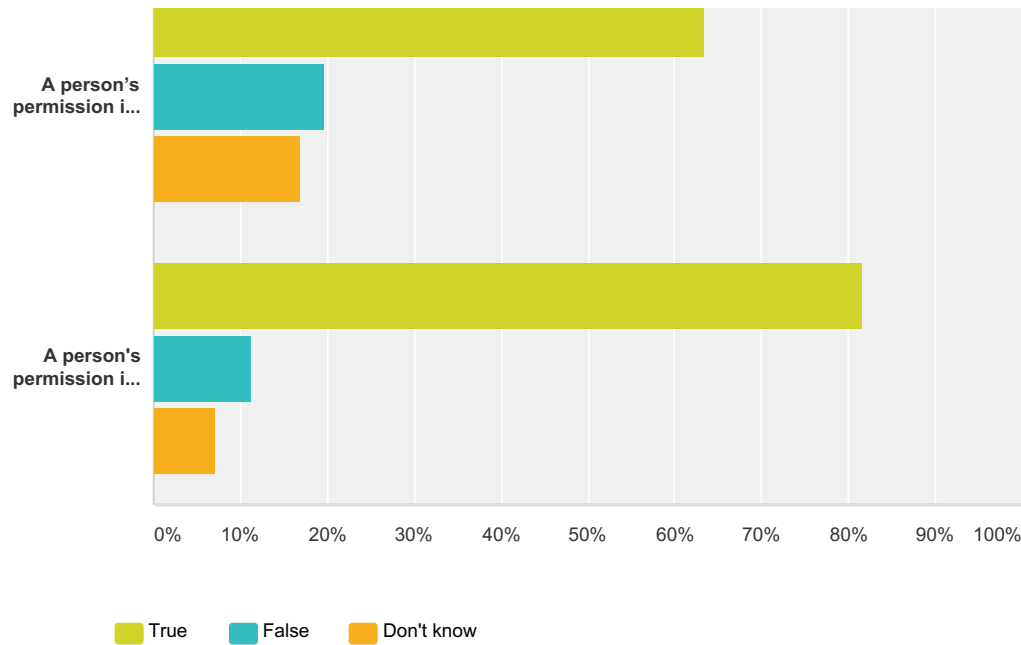


Answer Choices	Responses	
None	25.35%	18
Some	49.30%	35
A lot	14.08%	10
Total	4.23%	3
Don't know/haven't considered	7.04%	5
Total		71

Q30 What do you think of the following statements?

Answered: 71 Skipped: 255





	True	False	Don't know	Total
Most hospitals have electronic health records.	88.73% 63	4.23% 3	7.04% 5	71
Electronic health records are shared among providers (physicians, specialists, hospital systems).	69.01% 49	21.13% 15	9.86% 7	71
The care anyone gets is tracked.	57.75% 41	28.17% 20	14.08% 10	71
The government uses health data provided by hospitals and clinics to track diseases.	61.97% 44	12.68% 9	25.35% 18	71
Pharmacies tracks purchases, including medical products and other things people buy from them.	69.01% 49	7.04% 5	23.94% 17	71
Health insurance companies cannot use health data to deny people coverage.	22.54% 16	42.25% 30	35.21% 25	71
A person's permission is required for their information to be used in any type of health research.	63.38% 45	19.72% 14	16.90% 12	71
A person's permission is required for their health data to be shared with a loved one or caregiver.	81.69% 58	11.27% 8	7.04% 5	71

Q31 Thank you for taking the survey!
Please let us know if you have any feedback
on the questions, answers, or process.

Answered: 25 Skipped: 301

#	Responses	Date
1	I did not answer all the questions because the print was so light it was too difficult to read, Too bad. I would have liked to participate.	6/7/2017 1:05 PM
2	Data analytics is useful and necessary to move treatments and research positively, however as an IT professional safeguards must be in place. With turmoil in the federal government in 2017 on health care I would be wary of sharing	6/7/2017 12:52 PM
3	I marked that I disagree that health data is safe because of all the hacking taking place and it does not see that any changes are being made to prevent these activities	6/6/2017 12:28 PM
4	Please consider adding a "NOT APPLICABLE" option (on page 3) to "How much do you trust the following organizations to manage how your health data is shared within the system?" I did not respond to some options because I have no experience with them.	6/6/2017 8:29 AM
5	The process was easy, questions were interesting. Only comment, is that the font size was hard to read.	6/6/2017 8:17 AM
6	I can get my health records from my primary doctor online, but only the very recent records. I didn't understand the exact meaning of the question about trust so that's why I didn't fill it in.	6/5/2017 5:41 PM
7	EHR systems are so disjointed that even if my health data were complete (and not spread out over multiple doctors in different states), it would not be accurate. It's gotten better but the fact that I can't (or maybe don't know how to) transfer my records from doctors in different networks using different EHR systems is disconcerting. I had to transfer OB-GYNs after getting an IUD because my insurance changed and I had no way to transfer the information from the doctor I had seen for the past two years! I'm all for sharing data but someone needs to ensure it's actually going to be useful and not just full of missing data, duplicated in many systems, or unable to be aggregated, stored, and made available to patients.	6/5/2017 12:52 PM
8	This is a very good survey. How will the results be shared with people who take the survey? How will you provide transparency of data collected (as the survey itself is about transparency). Here is my email jensenchr@aol.com, so who will contact me with answers (has this even be considered!?). Thank you.	6/2/2017 3:56 PM
9	I think the HIPPA law blocks family members from getting accurate access to family members in crisis and blocking patients from getting safe and adequate care.	6/2/2017 11:42 AM
10	(1) It has been difficult (I am dissatisfied) to access my health data online. Hassles with passwords and security questions. Also hassle with ADOBE FLASH and other plugins or add-on software to use some data systems. Incessant software update messages with FLASH and update process is confusing and frustrating. (2) For my primary care Patient Portal, I was invited to use FACEBOOK login, then share my records with my "friends". This added to my feeling very dissatisfied with FACEBOOK due to their privacy abuses. I have de-activated my account with FACEBOOK. (3) I also would like to be able to make appointments fully online. Submitting appointment request but having to wait to be called back is unsatisfactory and actually more inconvenient. I am not a "telephone person" and calling health care offices to make appointment is hassle including limited hours, unable to review appointment time later date, and phone menus. In contrast I am happy with appointment making with several massage therapists. 3 places I have gone for massage in scenic and recreational locations use same websystem, works great and easy to use, shows schedule blocks calendar that lets me directly choose time/date online. No telephone calls needed. These locations: Boulder CO, Breckenridge CO, Glenwood Springs CO. Also easy to make appointments with 3 other massage practitioners: Email in Lafayette CO, texting in Denver CO, and walk up at hot tub spa area part of ski/snowboard resort in Keystone CO.	5/31/2017 2:41 PM
11	Please use the two step method for gender. It was painful to have to choose between being transgender and being male or female.	5/31/2017 8:09 AM
12	It is my understanding that insurance companies cannot currently deny based on health records, but that could change if the ACA is overturned.	5/30/2017 12:55 PM

13	Some of the answers in last section are not strictly true/false; e.g., sharing of data by providers is very dependent upon the systems that are in place. EHRs vary widely from provider to provider, hospital to hospital, and most do not link to one another. Therefore, while yes, providers within an organization and within one EHR system can share info, providers across systems (or esp across state lines) cannot. Also an extra period exists on one of the questions toward the end. :)	5/29/2017 8:53 PM
14	I had a problem answering the 2nd question on page 2. I am happy to share my data with all of scenarios listed but I would want to be the one giving the permission -- I do not agree with any if they are taking it and using it for any of those purposes without my permission.	5/24/2017 1:42 PM
15	On the question about being able to access my medical records- many health organizations charge for copies of medical records. This has deterred me in the past from obtaining them and I imagine this is a barrier for others, as well	5/23/2017 5:31 PM
16	Would like to know the results.	5/20/2017 3:49 PM
17	I was not sure if the questions concerned my individual health records or my records after anonymization. I was not clear about the meaning of trust: a) I do not trust any organization to properly manage the sharing of my health records due to cyber theft which is exceptionally high for medical records. Cyber theft is a form of sharing. b) I do not trust the organizations listed to share health records in a way that is optimal for the advancement of health research or health care unless required by specific laws and regulations. c) I trust the organizations listed to comply with specific law and regulations regarding sharing of health records.	5/19/2017 3:05 PM
18	As of right now, insurers can't use personal medical data to determine if they will provide coverage to an individual, but I worry that will change if the "trump care" bill passes, and I will be denied coverage or it will become unaffordable to me because I have so many pre existing conditions.	5/16/2017 1:57 PM
19	Some of these questions mask the true answers because of key phrases (e.g. used by/shared with). Simply put, I want access to all of the data (including Genetic), I want to choose who I share it with, and I want all of the caregivers to have access to the data they need, easily.	5/11/2017 12:43 PM
20	I do not know if the questions might change with the new administration. Also, I have concerns with the insurance companies. I am tired of their need of a Prior Auth! If a Doctor prescribes a medication we should be able to get it! This is a major issue! I am tired of them dictating, and playing games with my daughters health and well being! I am so frustrated!!!!	5/11/2017 12:08 PM
21	We us CareSync to track our sons records and I follow it very closely.	5/10/2017 7:47 PM
22	Felt long. Who owns my healthcare data? Does the hospital that took my blood pressure, that owns the BP cuff, own my reading?	5/9/2017 9:27 AM
23	I think there is a current grey area about the question of whether insurance providers ca deny claims based on your health data. That grey area is because of what is happening right now with the possible dismantling of the ACA. If, when this survey is evaluated, the ACA has indeed by dismantled, then I would definitely think insurance providers would deny you coverage based on your existing medical data.	5/8/2017 3:28 PM
24	It's Louise Perkins so happy to have a call re my comments if that's helpful	4/26/2017 9:05 PM
25	Great survey! Perfect amount of time, few open response questions, clear and direct questions.	4/26/2017 2:20 PM