



Leading cancer research. **Together.**

Dear Colleagues,

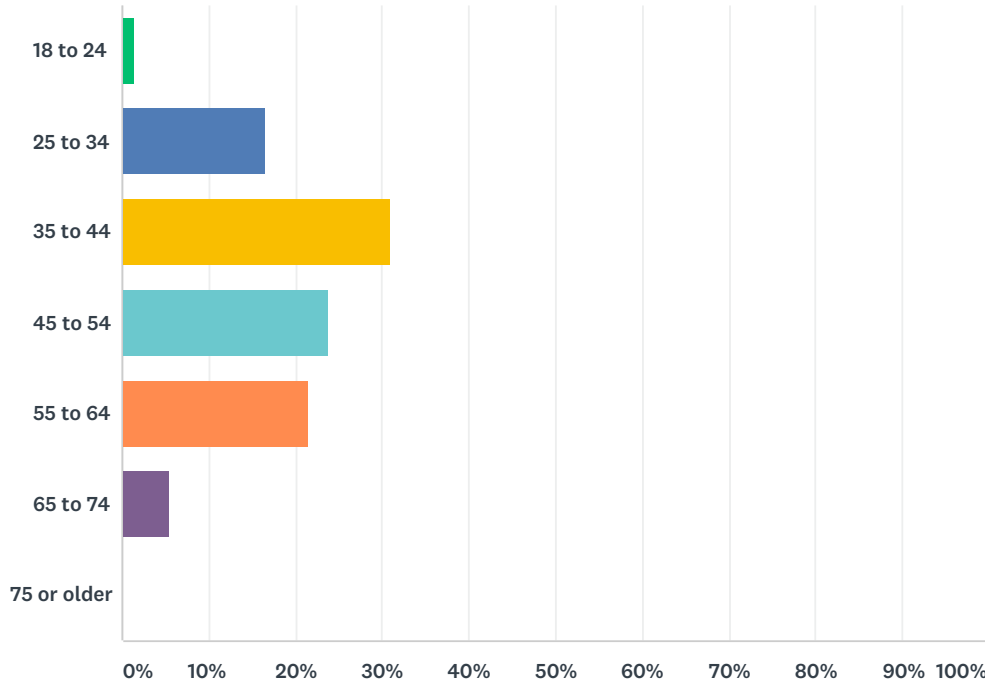
Before we established the Palliative and End of Life Care Committee in development, it became clear that there were many different opinions regarding how this process should occur. Therefore, in addition to extensive conversations about the topic, a formal members' survey was prepared, with the assistance and advice of Matt Hudson and Dana Sparks. The information sought by the survey spanned opinions about education and research. Thirty-three questions were prepared and distributed via Survey Monkey, to more than 5000 individual members of SWOG. On average, 500+ individuals answered each question, and results were analyzed by Statistician Catherine Guthrie.

If you are interested in analyzed the data in more detail or using the information for a presentation please contact Dr. Frank Meyskens.

Sincerely,
Charles D. Blanke, MD, FACP, FASCO
Chair, SWOG

Q1 What is your age?

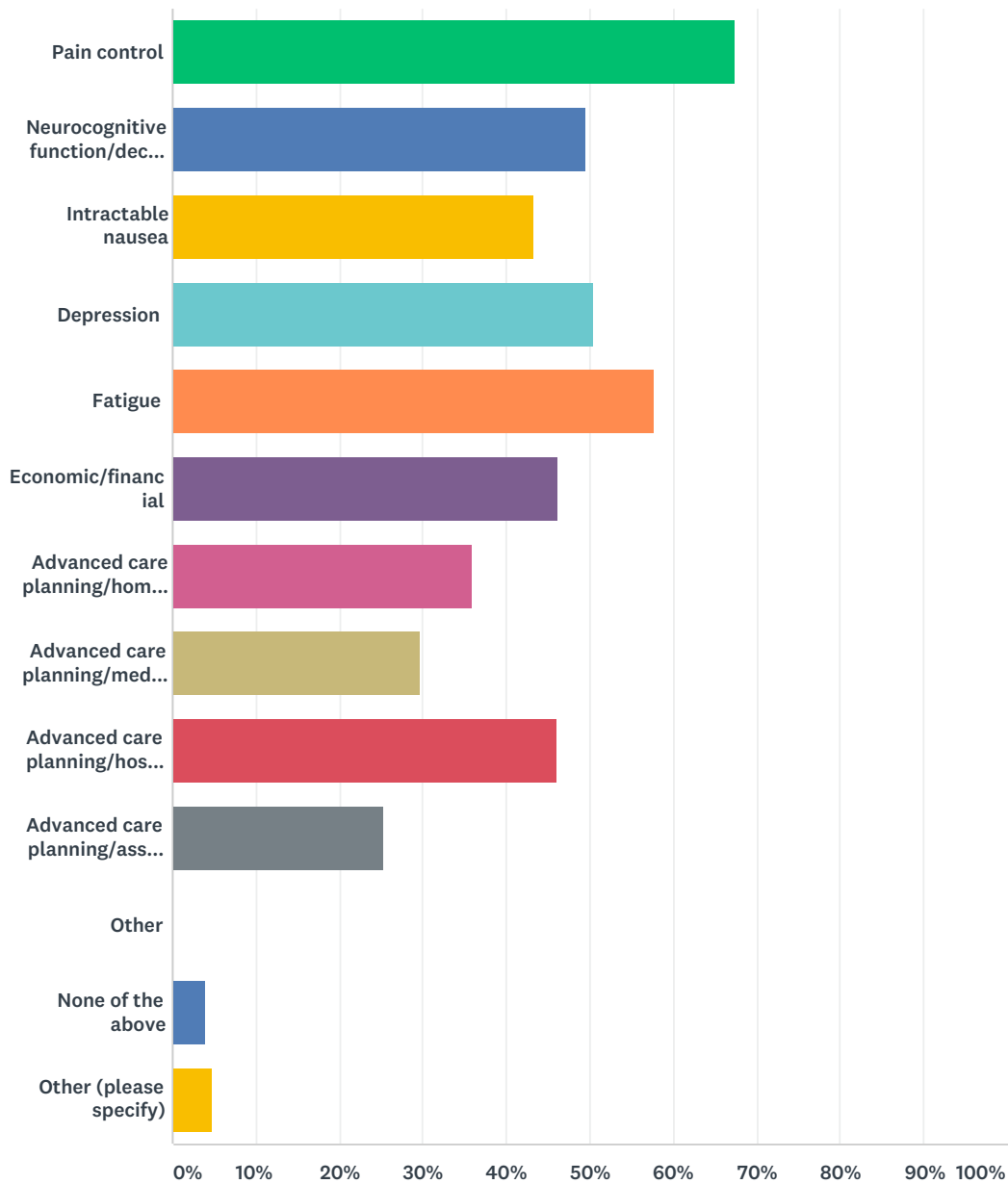
Answered: 582 Skipped: 2



ANSWER CHOICES	RESPONSES	
18 to 24	1.37%	8
25 to 34	16.49%	96
35 to 44	30.93%	180
45 to 54	23.88%	139
55 to 64	21.65%	126
65 to 74	5.50%	32
75 or older	0.17%	1
TOTAL		582

Q2 In your opinion, in which of these areas could SWOG contribute effectively (feel free to mark multiple responses)?

Answered: 574 Skipped: 10



ANSWER CHOICES	RESPONSES
Pain control	67.42% 387
Neurocognitive function/decision making	49.65% 285
Intractable nausea	43.21% 248
Depression	50.52% 290
Fatigue	57.67% 331

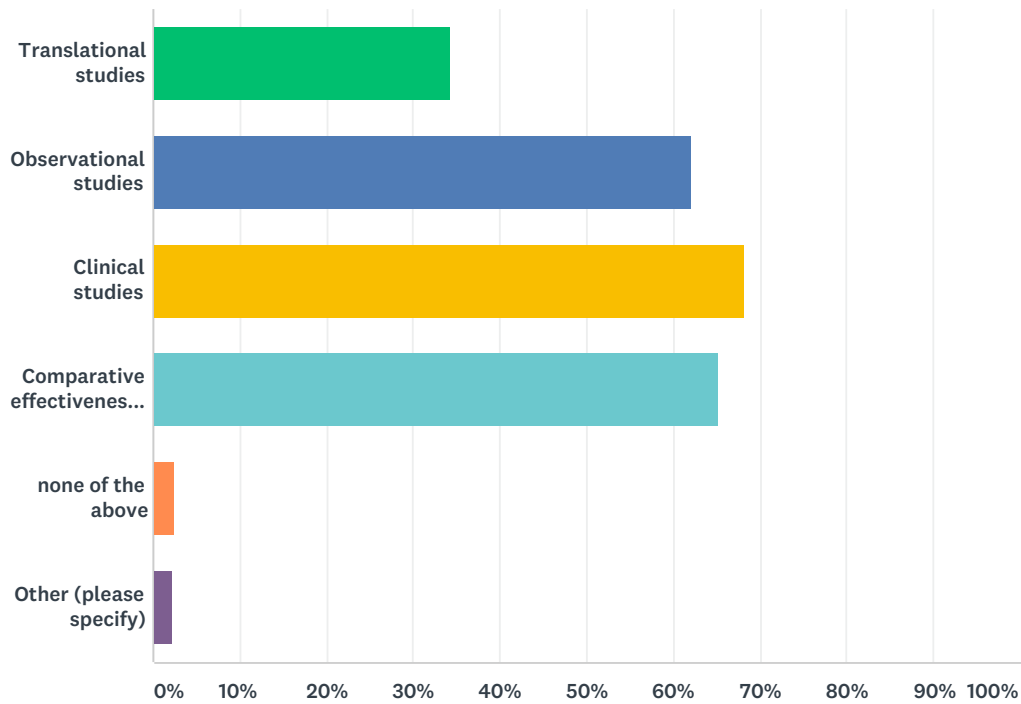
Palliative Care

SurveyMonkey

Economic/financial	46.17%	265
Advanced care planning/home care	36.06%	207
Advanced care planning/medical home	29.62%	170
Advanced care planning/hospice	45.99%	264
Advanced care planning/assisted living	25.26%	145
Other	0.00%	0
None of the above	4.01%	23
Other (please specify)	4.88%	28
Total Respondents: 574		

Q3 In your opinion, how could SWOG effectively contribute in these areas (feel free to mark more than one answer)?

Answered: 569 Skipped: 15



ANSWER CHOICES	RESPONSES
Translational studies	34.27% 195
Observational studies	62.04% 353
Clinical studies	68.19% 388
Comparative effectiveness studies	65.20% 371
none of the above	2.46% 14
Other (please specify)	2.28% 13
Total Respondents: 569	

Q4 In what country do you live?

Answered: 495 Skipped: 89



- Benin
- Bhutan
- Bolivia
(Plurinational...)
- Bosnia and
Herzegovina
- Botswana
- Brazil
- Brunei
Darussalam
- Bulgaria
- Burkina Faso
- Burundi
- Cabo Verde
- Cambodia
- Cameroon
- Canada
- Central
African...
- Chad
- Chile
- China
- Colombia
- Comoros

Congo									
Costa Rica									
Côte D'Ivoire									
Croatia									
Cuba									
Cyprus									
Czech Republic									
Democratic People's...									
Democratic Republic of ...									
Denmark									
Djibouti									
Dominica									
Dominican Republic									
Ecuador									
Egypt									
El Salvador									
Equatorial Guinea									
Eritrea									
Estonia									
Ethiopia									
Fiji									

Finland									
France									
Gabon									
Gambia									
Georgia									
Germany									
Ghana									
Greece									
Grenada									
Guatemala									
Guinea									
Guinea Bissau									
Guyana									
Haiti									
Holy See									
Honduras									
Hungary									
Iceland									
India									
Indonesia									
Iran (Islamic Republic of)									

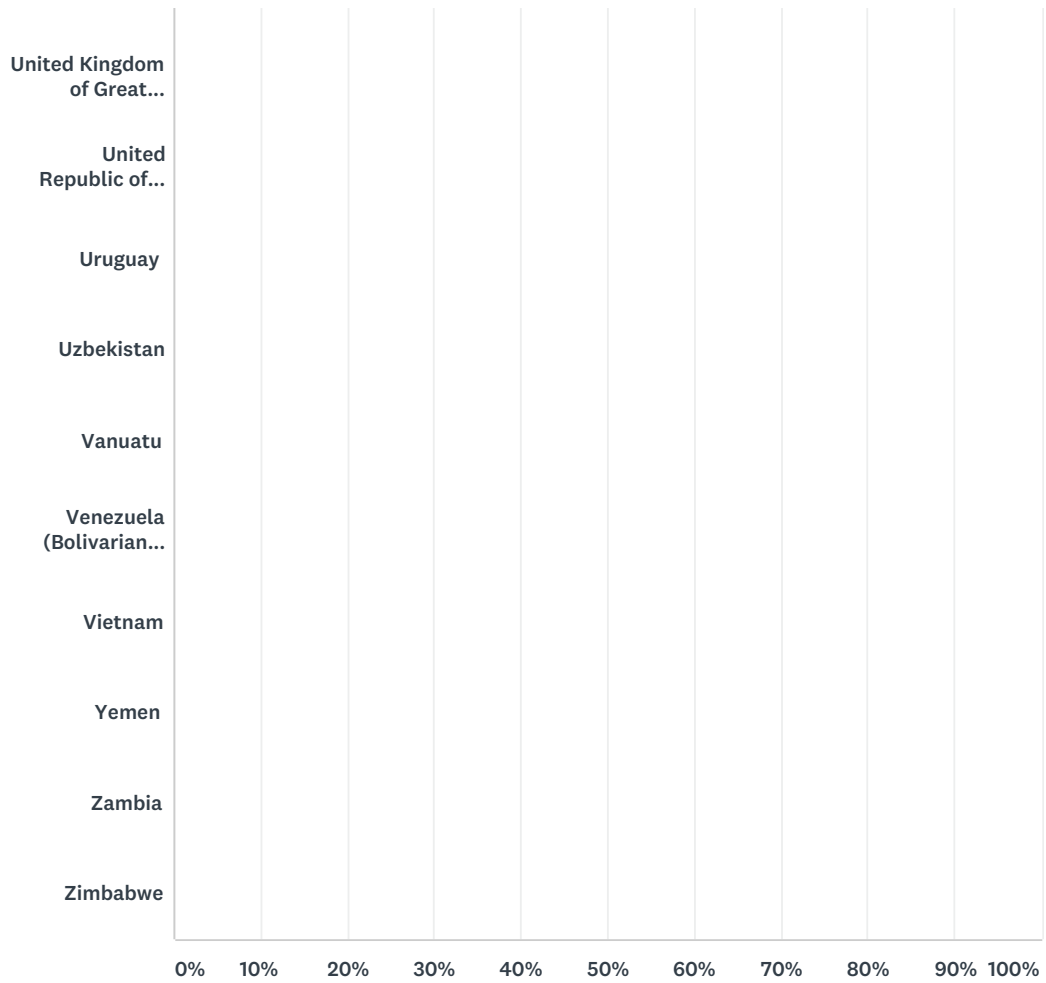
Iraq									
Ireland									
Israel									
Italy									
Jamaica									
Japan									
Jordan									
Kazakhstan									
Kenya									
Kiribati									
Kuwait									
Kyrgyzstan									
Lao People's Democratic...									
Latvia									
Lebanon									
Lesotho									
Liberia									
Libya									
Liechtenstein									
Lithuania									
Luxembourg									

Madagascar									
Malawi									
Malaysia									
Maldives									
Mali									
Malta									
Marshall Islands									
Mauritania									
Mauritius									
Mexico									
Micronesia (Federated...)									
Monaco									
Mongolia									
Montenegro									
Morocco									
Mozambique									
Myanmar									
Namibia									
Nauru									
Nepal									
Netherlands									

Netherlands									
New Zealand									
Nicaragua									
Niger									
Nigeria									
Norway									
Oman									
Pakistan									
Palau									
Panama									
Papua New Guinea									
Paraguay									
Peru									
Philippines									
Poland									
Portugal									
Qatar									
Republic of Korea									
Republic of Moldova									
Romania									
Russian Federation									

Rwanda									
Saint Kitts and Nevis									
Saint Lucia									
Saint Vincent and the...									
Samoa									
San Marino									
Sao Tome and Principe									
Saudi Arabia									
Senegal									
Serbia									
Seychelles									
Sierra Leone									
Singapore									
Slovakia									
Slovenia									
Solomon Islands									
Somalia									
South Africa									
South Sudan									
Spain									
Sri Lanka									

State of Palestine									
Sudan									
Suriname									
Swaziland									
Sweden									
Switzerland									
Syrian Arab Republic									
Tajikistan									
Thailand									
The former Yugoslav...									
Timor-Leste									
Togo									
Tonga									
Trinidad and Tobago									
Tunisia									
Turkey									
Turkmenistan									
Tuvalu									
Uganda									
Ukraine									
United Arab Emirates									



ANSWER CHOICES	RESPONSES	
United States of America	98.99%	490
Afghanistan	0.00%	0
Albania	0.00%	0
Algeria	0.00%	0
Andorra	0.00%	0
Angola	0.00%	0
Antigua and Barbuda	0.00%	0
Argentina	0.00%	0
Armenia	0.00%	0
Australia	0.00%	0
Austria	0.00%	0
Azerbaijan	0.00%	0
Bahamas	0.00%	0
Bahrain	0.00%	0
Bangladesh	0.00%	0

Barbados	0.00%	0
Belarus	0.00%	0
Belgium	0.00%	0
Belize	0.00%	0
Benin	0.00%	0
Bhutan	0.00%	0
Bolivia (Plurinational State of)	0.00%	0
Bosnia and Herzegovina	0.00%	0
Botswana	0.00%	0
Brazil	0.00%	0
Brunei Darussalam	0.00%	0
Bulgaria	0.00%	0
Burkina Faso	0.00%	0
Burundi	0.00%	0
Cabo Verde	0.00%	0
Cambodia	0.00%	0
Cameroon	0.00%	0
Canada	0.00%	0
Central African Republic	0.00%	0
Chad	0.00%	0
Chile	0.00%	0
China	0.00%	0
Colombia	0.00%	0
Comoros	0.00%	0
Congo	0.00%	0
Costa Rica	0.00%	0
Côte D'Ivoire	0.00%	0
Croatia	0.00%	0
Cuba	0.00%	0
Cyprus	0.00%	0
Czech Republic	0.00%	0
Democratic People's Republic of Korea	0.00%	0
Democratic Republic of the Congo	0.00%	0
Denmark	0.00%	0

Djibouti	0.00%	0
Dominica	0.00%	0
Dominican Republic	0.00%	0
Ecuador	0.00%	0
Egypt	0.00%	0
El Salvador	0.00%	0
Equatorial Guinea	0.00%	0
Eritrea	0.00%	0
Estonia	0.00%	0
Ethiopia	0.00%	0
Fiji	0.00%	0
Finland	0.00%	0
France	0.00%	0
Gabon	0.00%	0
Gambia	0.00%	0
Georgia	0.00%	0
Germany	0.00%	0
Ghana	0.00%	0
Greece	0.00%	0
Grenada	0.00%	0
Guatemala	0.00%	0
Guinea	0.00%	0
Guinea Bissau	0.00%	0
Guyana	0.00%	0
Haiti	0.00%	0
Holy See	0.00%	0
Honduras	0.00%	0
Hungary	0.00%	0
Iceland	0.00%	0
India	0.00%	0
Indonesia	0.00%	0
Iran (Islamic Republic of)	0.00%	0
Iraq	0.00%	0
Ireland	0.00%	0
Israel	0.00%	0

Italy	0.00%	0
Jamaica	0.00%	0
Japan	0.00%	0
Jordan	0.00%	0
Kazakhstan	0.00%	0
Kenya	0.00%	0
Kiribati	0.00%	0
Kuwait	0.00%	0
Kyrgyzstan	0.00%	0
Lao People's Democratic Republic	0.00%	0
Latvia	0.00%	0
Lebanon	0.00%	0
Lesotho	0.00%	0
Liberia	0.00%	0
Libya	0.00%	0
Liechtenstein	0.00%	0
Lithuania	0.00%	0
Luxembourg	0.00%	0
Madagascar	0.00%	0
Malawi	0.00%	0
Malaysia	0.00%	0
Maldives	0.00%	0
Mali	0.00%	0
Malta	0.00%	0
Marshall Islands	0.00%	0
Mauritania	0.00%	0
Mauritius	0.00%	0
Mexico	0.20%	1
Micronesia (Federated States of)	0.00%	0
Monaco	0.00%	0
Mongolia	0.00%	0
Montenegro	0.00%	0
Morocco	0.00%	0
Mozambique	0.00%	0
Myanmar	0.00%	0

Palliative Care

SurveyMonkey

Namibia	0.00%	0
Nauru	0.00%	0
Nepal	0.00%	0
Netherlands	0.00%	0
New Zealand	0.00%	0
Nicaragua	0.00%	0
Niger	0.00%	0
Nigeria	0.00%	0
Norway	0.00%	0
Oman	0.00%	0
Pakistan	0.00%	0
Palau	0.00%	0
Panama	0.00%	0
Papua New Guinea	0.00%	0
Paraguay	0.00%	0
Peru	0.61%	3
Philippines	0.00%	0
Poland	0.00%	0
Portugal	0.00%	0
Qatar	0.00%	0
Republic of Korea	0.00%	0
Republic of Moldova	0.00%	0
Romania	0.00%	0
Russian Federation	0.00%	0
Rwanda	0.00%	0
Saint Kitts and Nevis	0.00%	0
Saint Lucia	0.00%	0
Saint Vincent and the Grenadines	0.00%	0
Samoa	0.00%	0
San Marino	0.00%	0
Sao Tome and Principe	0.00%	0
Saudi Arabia	0.20%	1
Senegal	0.00%	0
Serbia	0.00%	0
Seychelles	0.00%	0

Palliative Care

SurveyMonkey

Sierra Leone	0.00%	0
Singapore	0.00%	0
Slovakia	0.00%	0
Slovenia	0.00%	0
Solomon Islands	0.00%	0
Somalia	0.00%	0
South Africa	0.00%	0
South Sudan	0.00%	0
Spain	0.00%	0
Sri Lanka	0.00%	0
State of Palestine	0.00%	0
Sudan	0.00%	0
Suriname	0.00%	0
Swaziland	0.00%	0
Sweden	0.00%	0
Switzerland	0.00%	0
Syrian Arab Republic	0.00%	0
Tajikistan	0.00%	0
Thailand	0.00%	0
The former Yugoslav Republic of Macedonia	0.00%	0
Timor-Leste	0.00%	0
Togo	0.00%	0
Tonga	0.00%	0
Trinidad and Tobago	0.00%	0
Tunisia	0.00%	0
Turkey	0.00%	0
Turkmenistan	0.00%	0
Tuvalu	0.00%	0
Uganda	0.00%	0
Ukraine	0.00%	0
United Arab Emirates	0.00%	0
United Kingdom of Great Britain and Northern Ireland	0.00%	0
United Republic of Tanzania	0.00%	0
Uruguay	0.00%	0

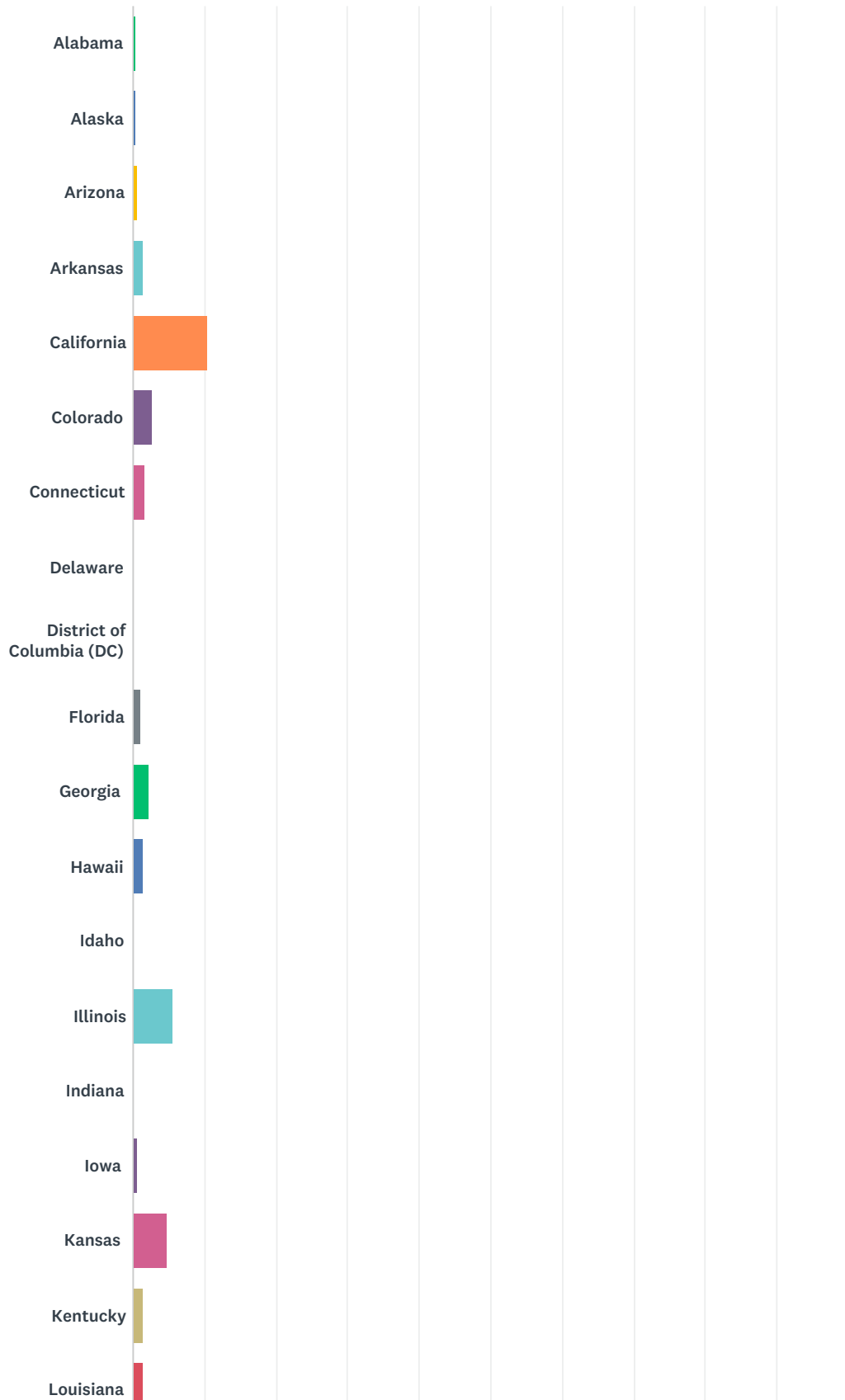
Palliative Care

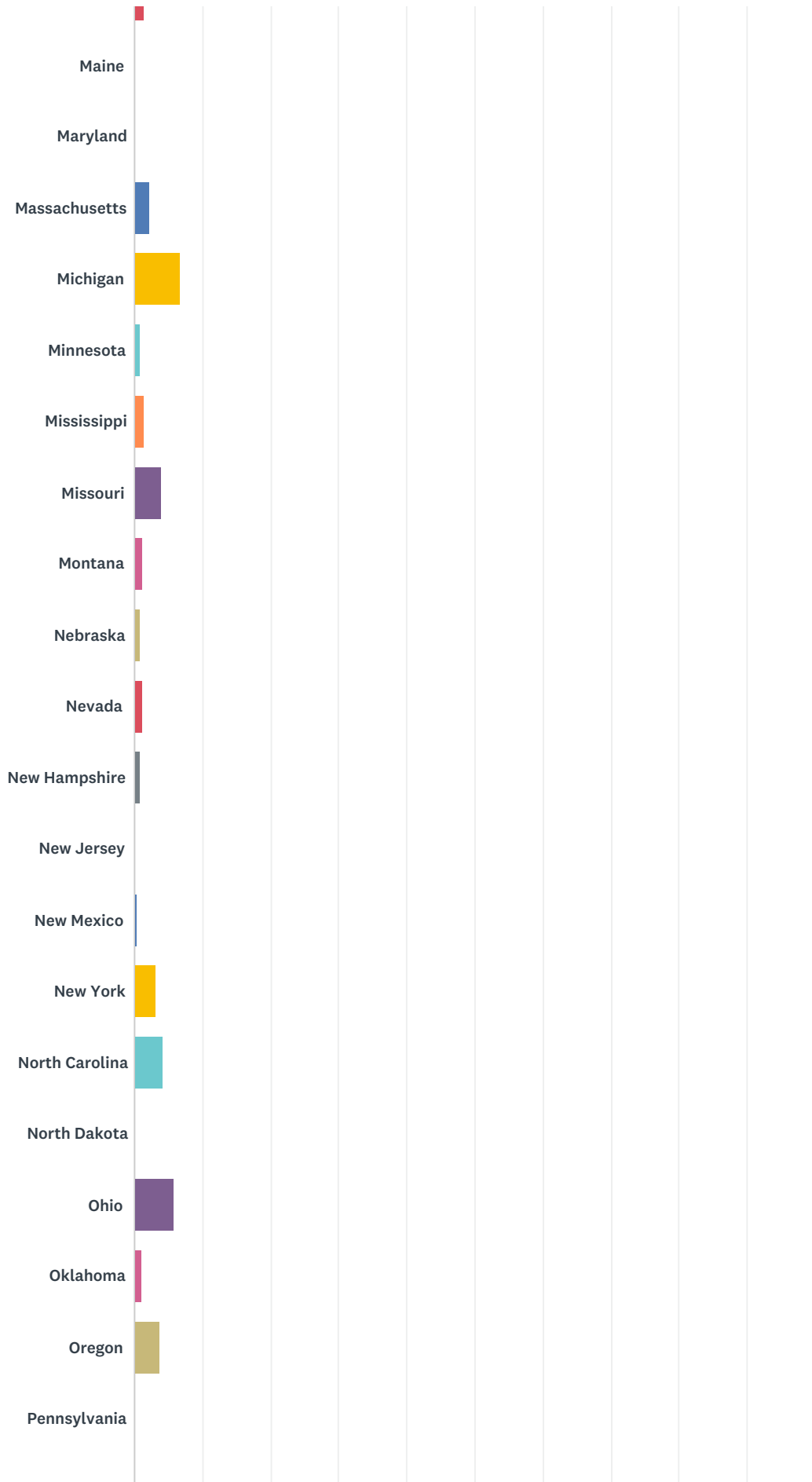
SurveyMonkey

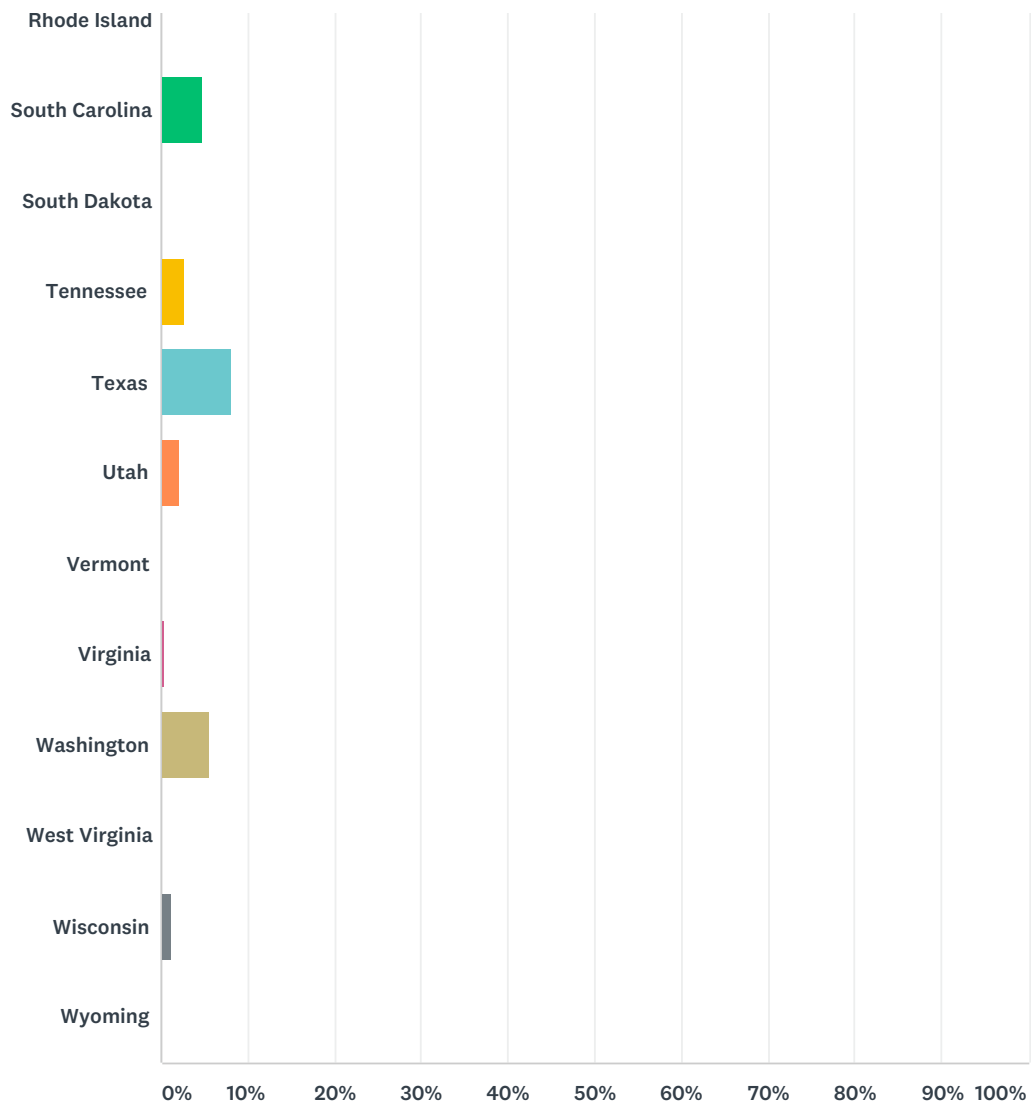
Uzbekistan	0.00%	0
Vanuatu	0.00%	0
Venezuela (Bolivarian Republic of)	0.00%	0
Vietnam	0.00%	0
Yemen	0.00%	0
Zambia	0.00%	0
Zimbabwe	0.00%	0
TOTAL		495

Q5 If you live in the United States, what state do you reside in?

Answered: 491 Skipped: 93







ANSWER CHOICES	RESPONSES
Alabama	0.41% 2
Alaska	0.41% 2
Arizona	0.61% 3
Arkansas	1.43% 7
California	10.39% 51
Colorado	2.65% 13
Connecticut	1.63% 8
Delaware	0.00% 0
District of Columbia (DC)	0.00% 0
Florida	1.02% 5
Georgia	2.24% 11
Hawaii	1.43% 7

Palliative Care

SurveyMonkey

Idaho	0.20%	1
Illinois	5.70%	28
Indiana	0.00%	0
Iowa	0.61%	3
Kansas	4.89%	24
Kentucky	1.43%	7
Louisiana	1.43%	7
Maine	0.00%	0
Maryland	0.20%	1
Massachusetts	2.24%	11
Michigan	6.72%	33
Minnesota	0.81%	4
Mississippi	1.43%	7
Missouri	4.07%	20
Montana	1.22%	6
Nebraska	0.81%	4
Nevada	1.22%	6
New Hampshire	0.81%	4
New Jersey	0.00%	0
New Mexico	0.41%	2
New York	3.05%	15
North Carolina	4.28%	21
North Dakota	0.00%	0
Ohio	5.91%	29
Oklahoma	1.02%	5
Oregon	3.87%	19
Pennsylvania	0.00%	0
Rhode Island	0.20%	1
South Carolina	4.89%	24
South Dakota	0.00%	0
Tennessee	2.65%	13
Texas	8.15%	40
Utah	2.04%	10
Vermont	0.00%	0

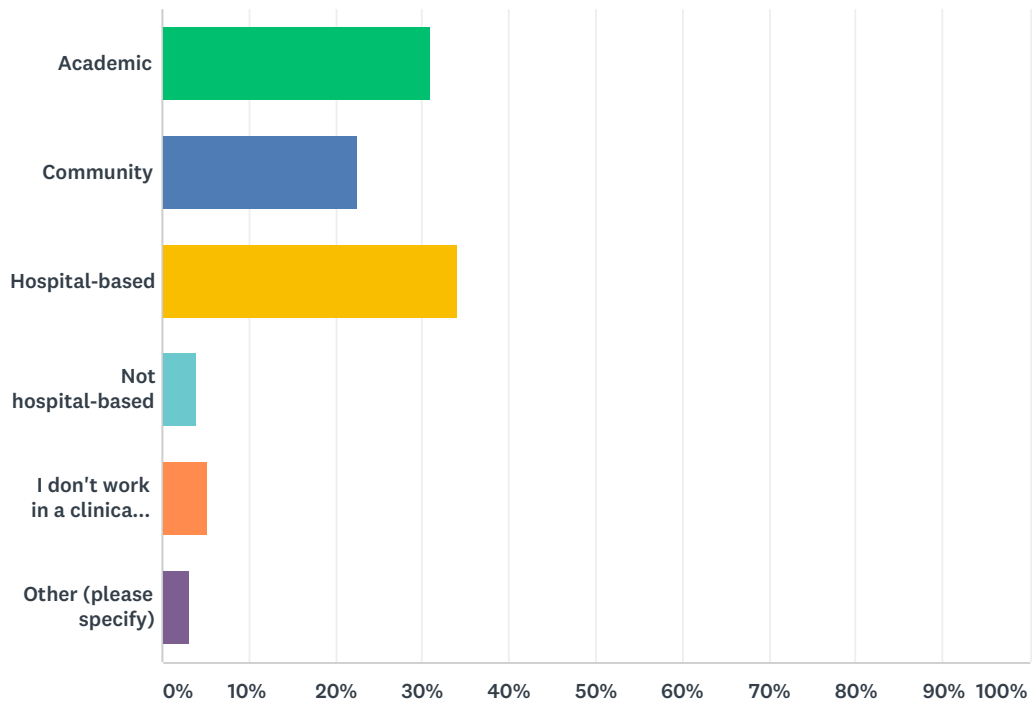
Palliative Care

SurveyMonkey

Virginia	0.41%	2
Washington	5.70%	28
West Virginia	0.00%	0
Wisconsin	1.22%	6
Wyoming	0.20%	1
TOTAL		491

Q6 Select the Practice Site type you think best describes your practice site:

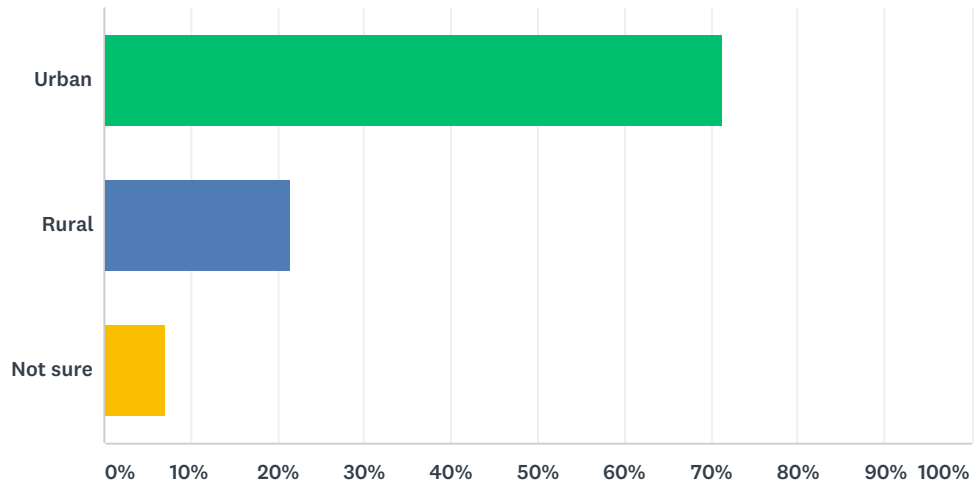
Answered: 499 Skipped: 85



ANSWER CHOICES	RESPONSES	
Academic	30.86%	154
Community	22.65%	113
Hospital-based	34.07%	170
Not hospital-based	4.01%	20
I don't work in a clinical site	5.21%	26
Other (please specify)	3.21%	16
TOTAL		499

Q7 How do you classify the location of your practice site?

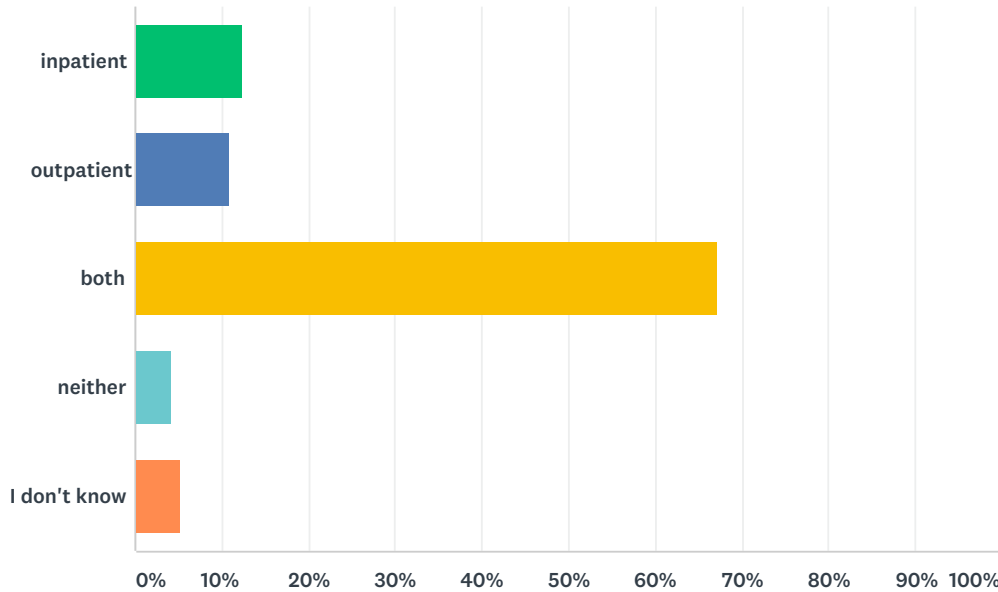
Answered: 493 Skipped: 91



ANSWER CHOICES	RESPONSES	
Urban	71.40%	352
Rural	21.50%	106
Not sure	7.10%	35
TOTAL		493

Q8 Palliative care improves the quality of life of patients with a serious or life-threatening cancer. Palliative care prevents or treats symptom, disease, and treatment side effects. Palliative care also addresses psychological, social, and spiritual problems. Please consider this definition when answering the following two questions. Please note the Palliative Care consultation type in your institution.

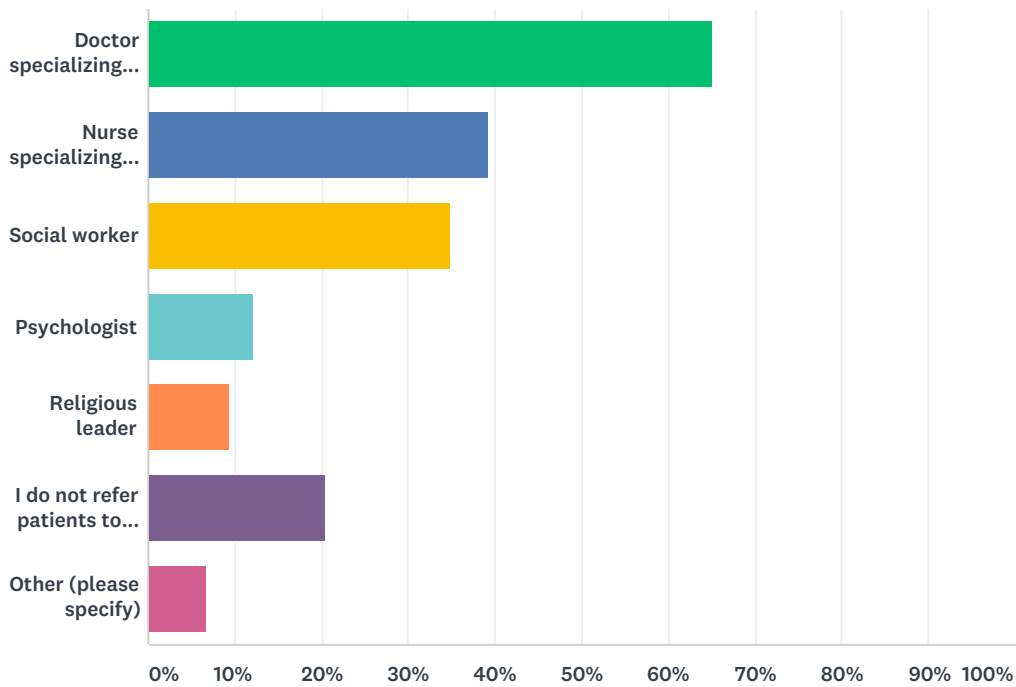
Answered: 492 Skipped: 92



ANSWER CHOICES	RESPONSES	
inpatient	12.40%	61
outpatient	10.98%	54
both	67.07%	330
neither	4.27%	21
I don't know	5.28%	26
TOTAL		492

Q9 Where do you refer patients for palliative care consultation? (check all that apply)

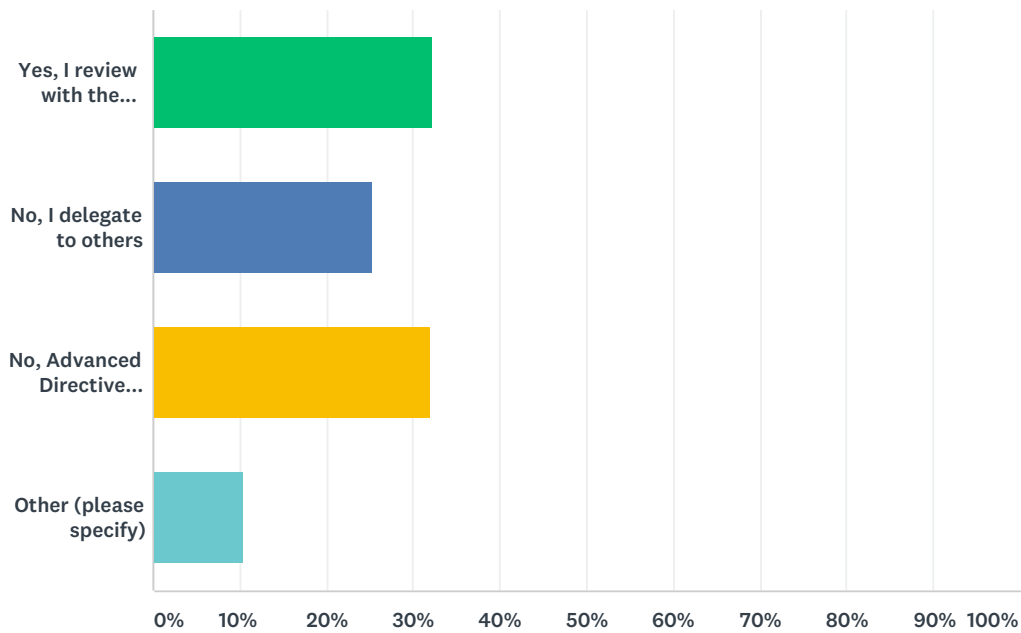
Answered: 497 Skipped: 87



ANSWER CHOICES	RESPONSES	
Doctor specializing in palliative care	64.99%	323
Nurse specializing in palliative care	39.24%	195
Social worker	35.01%	174
Psychologist	12.07%	60
Religious leader	9.46%	47
I do not refer patients to palliative care	20.52%	102
Other (please specify)	6.64%	33
Total Respondents: 497		

Q10 Advanced Directives (ADs) are legal papers that tell a patient’s loved ones and doctors the patient’s preference for medical care if the patient cannot inform care teams themselves. Please consider this definition when answering the next seven questions. Do you engage in Advanced Directive discussion with patients in your practice?

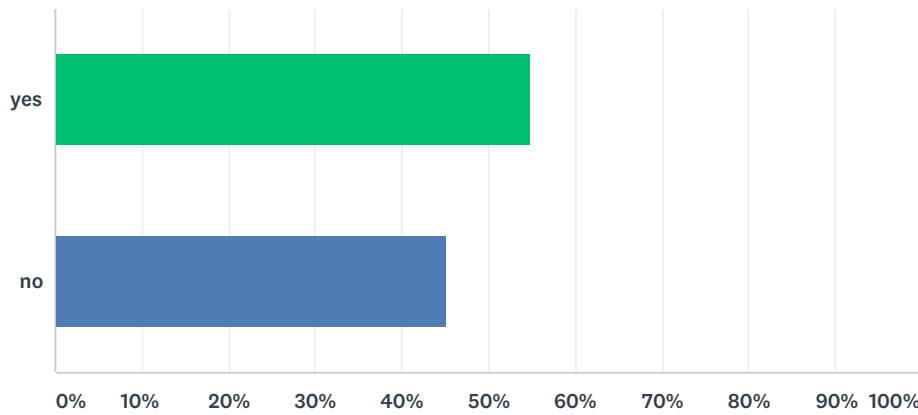
Answered: 494 Skipped: 90



ANSWER CHOICES	RESPONSES	
Yes, I review with the patient	32.19%	159
No, I delegate to others	25.30%	125
No, Advanced Directive discussion are not a part of my practice/profession	31.98%	158
Other (please specify)	10.53%	52
TOTAL		494

Q11 Do you consider yourself qualified to review an Advanced Directive with patients?

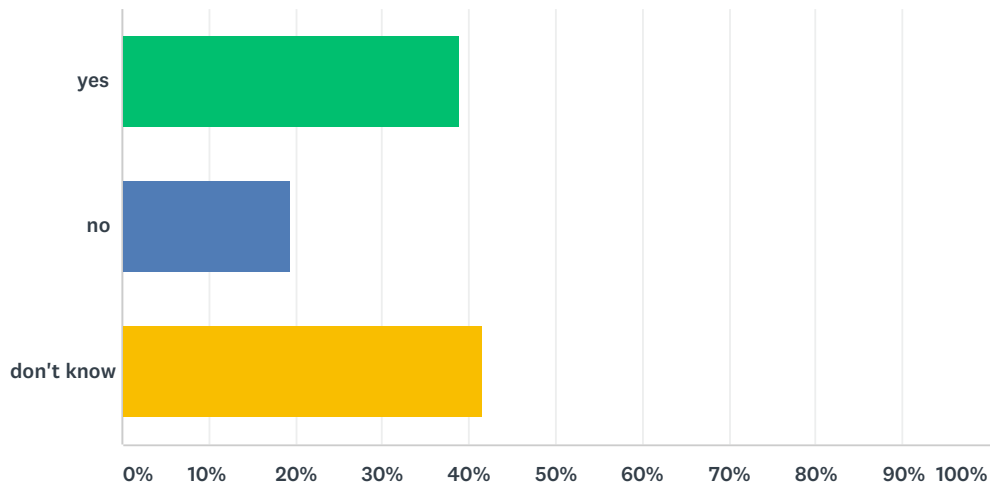
Answered: 479 Skipped: 105



ANSWER CHOICES	RESPONSES	
yes	54.91%	263
no	45.09%	216
TOTAL		479

Q12 Does your institution's practice policy permit you to make medical decisions guided exclusively by a patient's Advanced Directives?

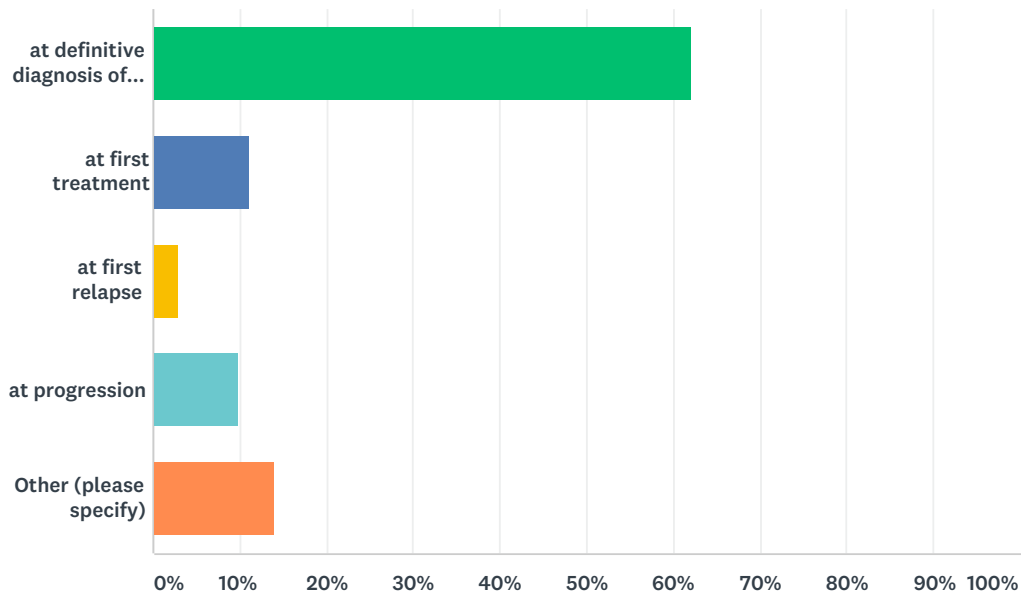
Answered: 483 Skipped: 101



ANSWER CHOICES	RESPONSES	
yes	38.92%	188
no	19.46%	94
don't know	41.61%	201
TOTAL		483

Q13 At what care point do you believe it best for patients with advanced cancer to consider preparing an Advanced Directive?

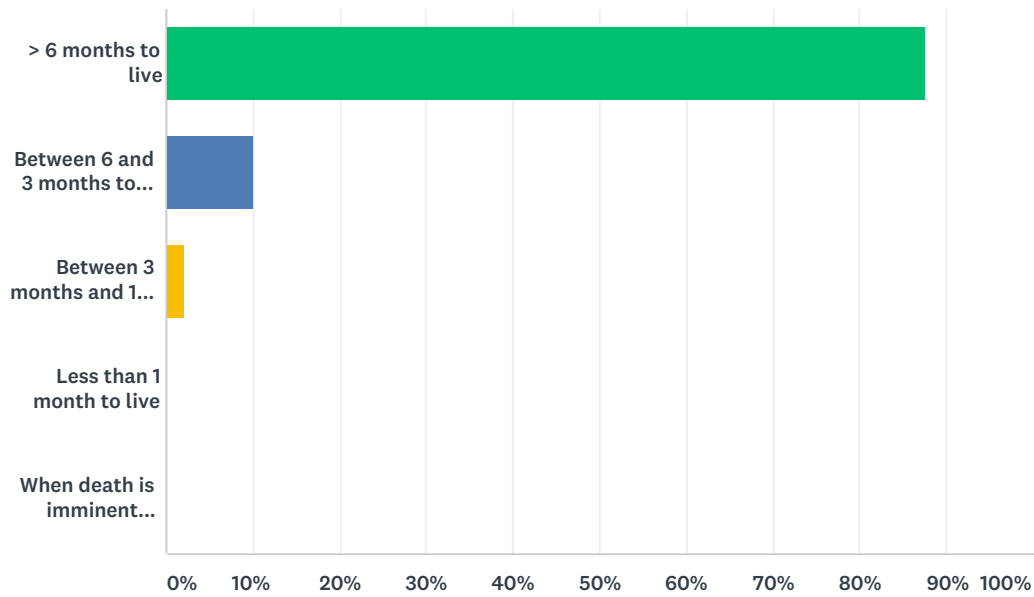
Answered: 486 Skipped: 98



ANSWER CHOICES	RESPONSES	
at definitive diagnosis of advanced cancer	62.14%	302
at first treatment	11.11%	54
at first relapse	2.88%	14
at progression	9.88%	48
Other (please specify)	13.99%	68
TOTAL		486

Q14 At what time point is it best to encourage your patients with advanced cancer to consider preparing Advanced Directives?

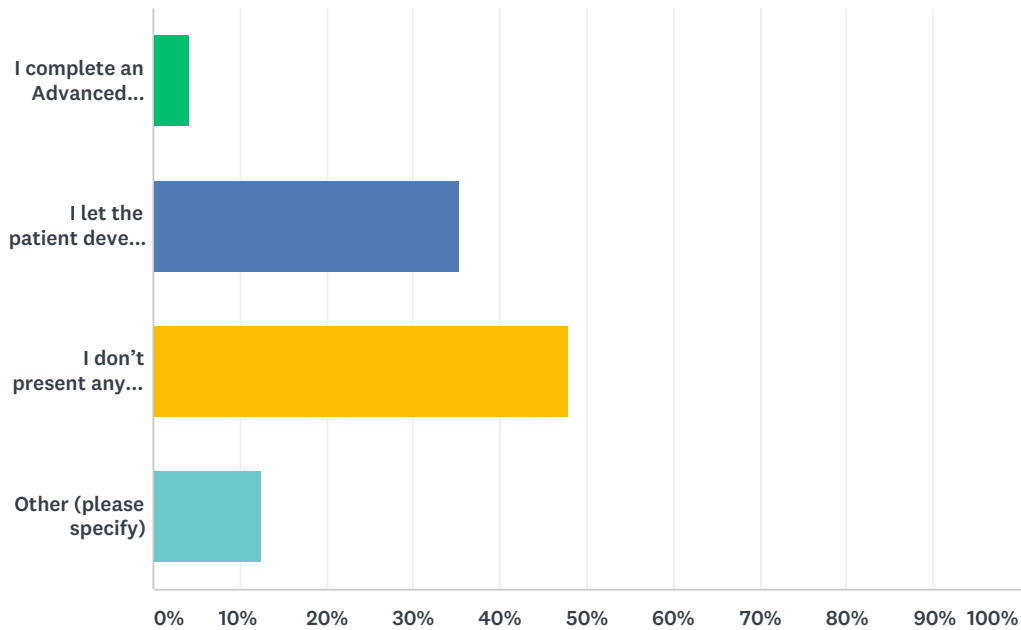
Answered: 476 Skipped: 108



ANSWER CHOICES	RESPONSES	
> 6 months to live	87.61%	417
Between 6 and 3 months to live	10.08%	48
Between 3 months and 1 month to live	2.10%	10
Less than 1 month to live	0.00%	0
When death is imminent (prognosis of days)	0.21%	1
TOTAL		476

Q15 Advanced Directives (ADs) are legal papers that tell a patient’s loved ones and doctors the patient’s preference for medical care if the patient cannot inform care teams themselves. How do you typically address Advanced Directives with patients?

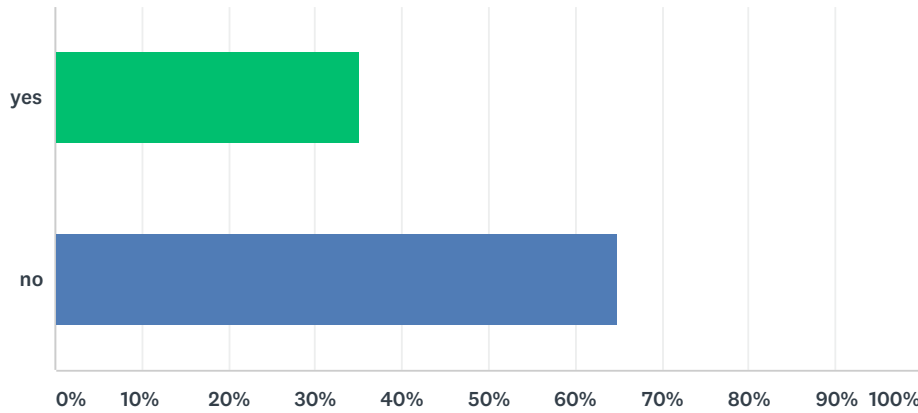
Answered: 486 Skipped: 98



ANSWER CHOICES	RESPONSES	
I complete an Advanced Directive plan that's best for the patient	4.12%	20
I let the patient develop an Advanced Directive plan, based on the information I provide	35.39%	172
I don't present any Advanced Directives information	47.94%	233
Other (please specify)	12.55%	61
TOTAL		486

Q16 Does your practice have a designated Advanced Directives provider team ?

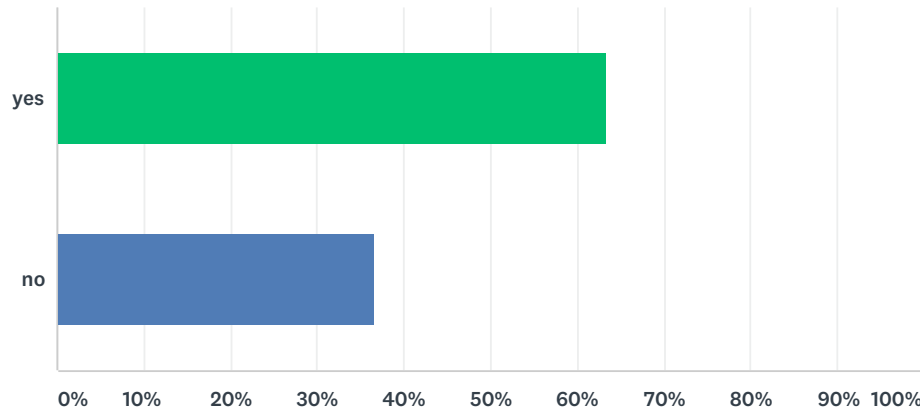
Answered: 472 Skipped: 112



ANSWER CHOICES	RESPONSES	
yes	35.17%	166
no	64.83%	306
TOTAL		472

Q17 Do you refer patients to this team?

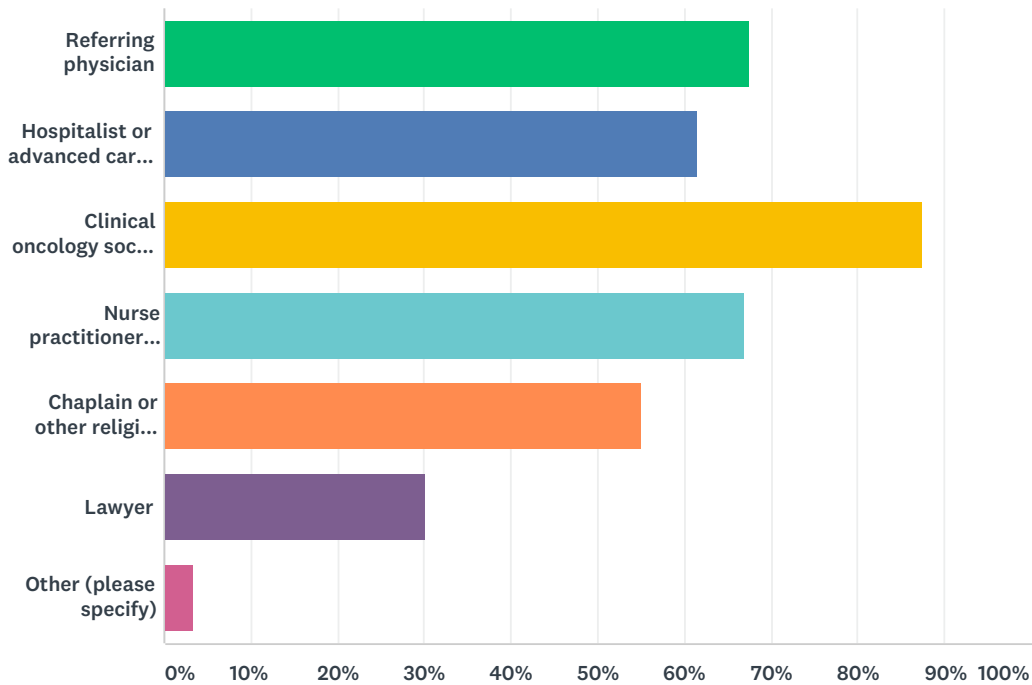
Answered: 161 Skipped: 423



ANSWER CHOICES	RESPONSES	
yes	63.35%	102
no	36.65%	59
TOTAL		161

Q18 Which of these personnel do you think should be an essential individual for an Advanced Care Planning team (Assume that all are interested in or trained in oncology). Mark as many as you consider necessary/

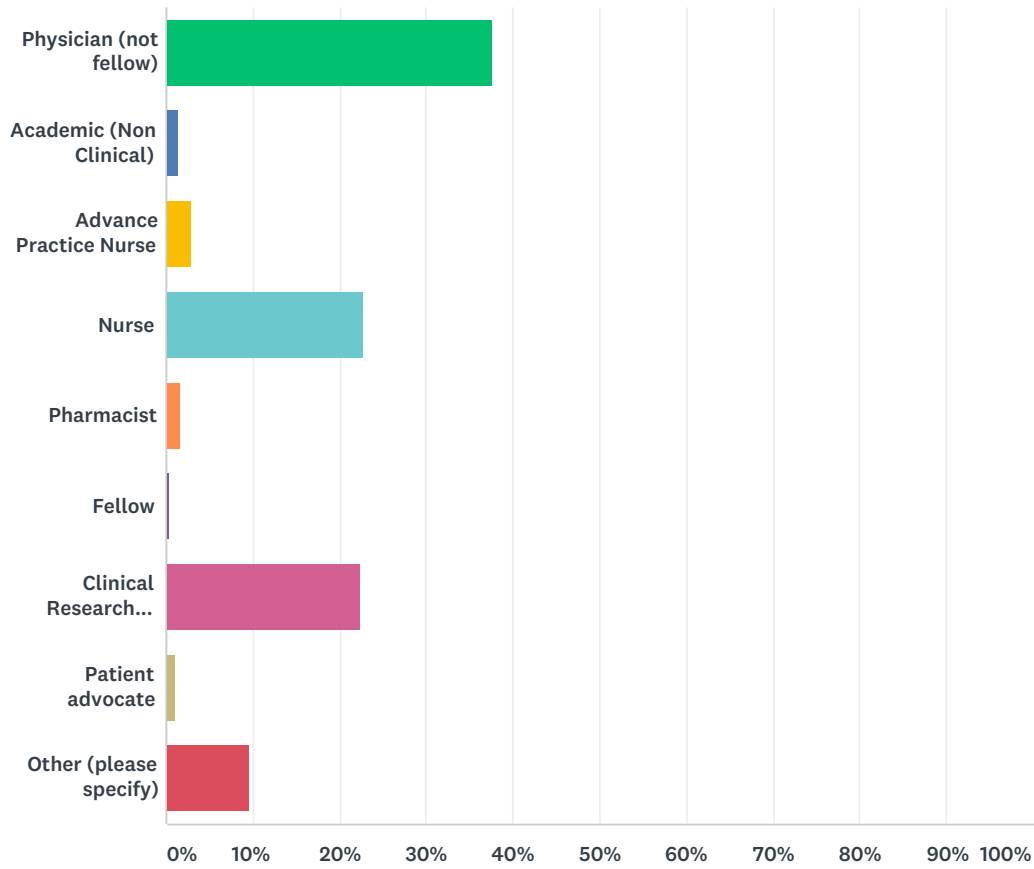
Answered: 182 Skipped: 402



ANSWER CHOICES	RESPONSES	
Referring physician	67.58%	123
Hospitalist or advanced care physician specialist	61.54%	112
Clinical oncology social worker	87.36%	159
Nurse practitioner or RN	67.03%	122
Chaplain or other religious representative	54.95%	100
Lawyer	30.22%	55
Other (please specify)	3.30%	6
Total Respondents: 182		

Q19 What is your profession?

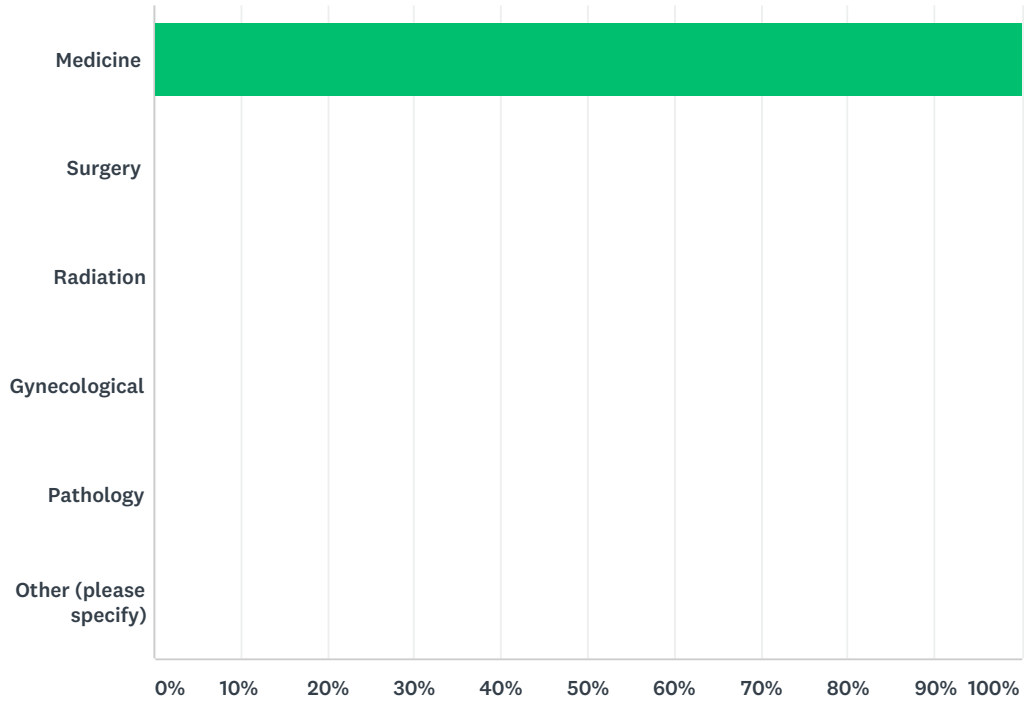
Answered: 486 Skipped: 98



ANSWER CHOICES	RESPONSES	
Physician (not fellow)	37.65%	183
Academic (Non Clinical)	1.44%	7
Advance Practice Nurse	2.88%	14
Nurse	22.84%	111
Pharmacist	1.65%	8
Fellow	0.41%	2
Clinical Research Associate	22.43%	109
Patient advocate	1.03%	5
Other (please specify)	9.67%	47
TOTAL		486

Q20 Fellowship discipline

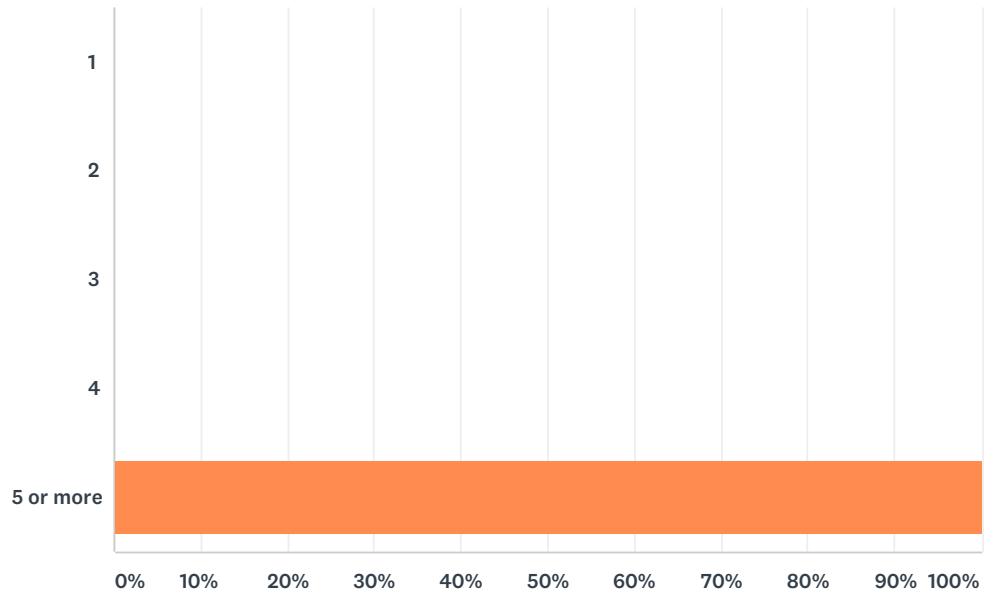
Answered: 2 Skipped: 582



ANSWER CHOICES	RESPONSES	
Medicine	100.00%	2
Surgery	0.00%	0
Radiation	0.00%	0
Gynecological	0.00%	0
Pathology	0.00%	0
Other (please specify)	0.00%	0
TOTAL		2

Q21 What is your current year of training?

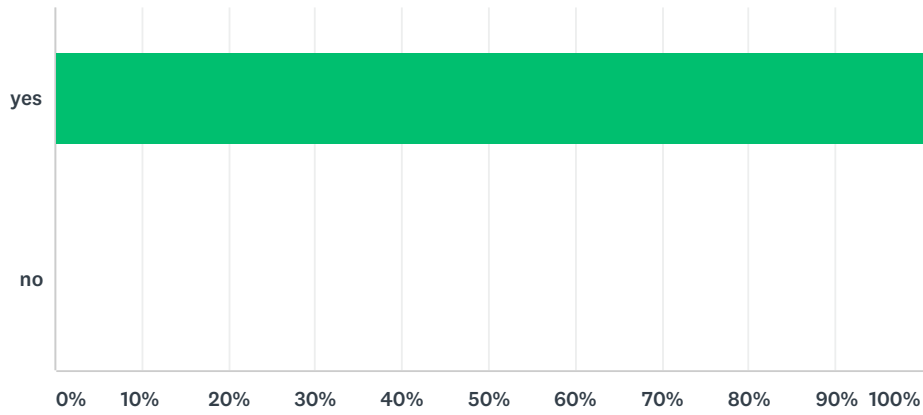
Answered: 2 Skipped: 582



ANSWER CHOICES	RESPONSES
1	0.00% 0
2	0.00% 0
3	0.00% 0
4	0.00% 0
5 or more	100.00% 2
TOTAL	2

Q22 To date, have you received training in Advanced Care Directives?

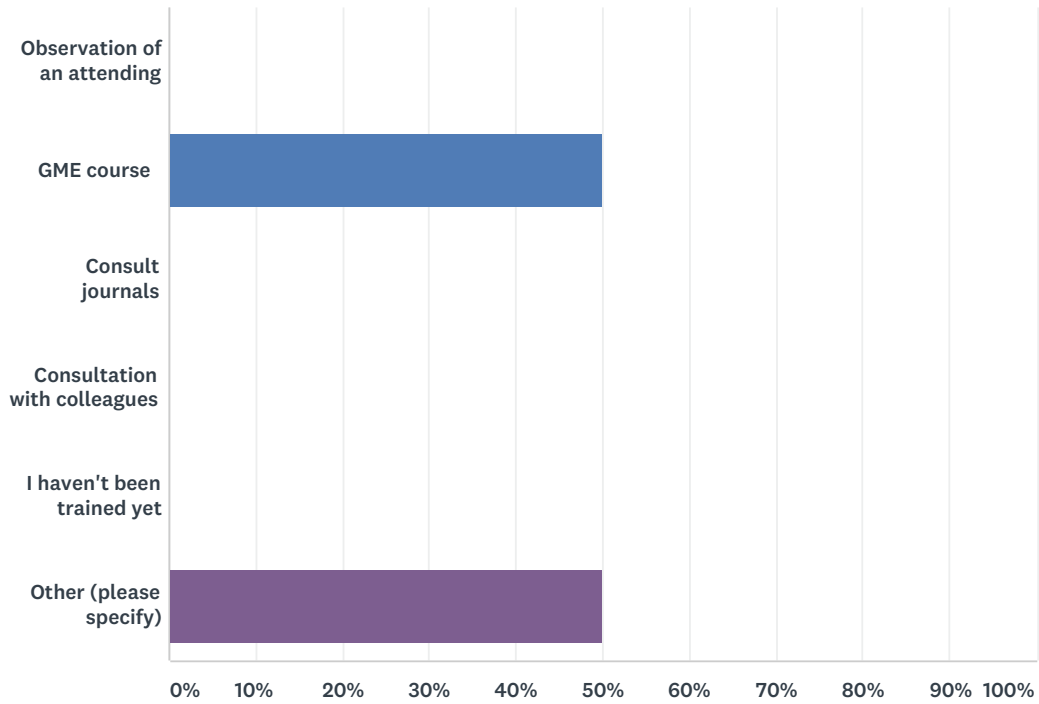
Answered: 2 Skipped: 582



ANSWER CHOICES	RESPONSES	
yes	100.00%	2
no	0.00%	0
TOTAL		2

Q23 How were you trained in Advanced Care Directives?

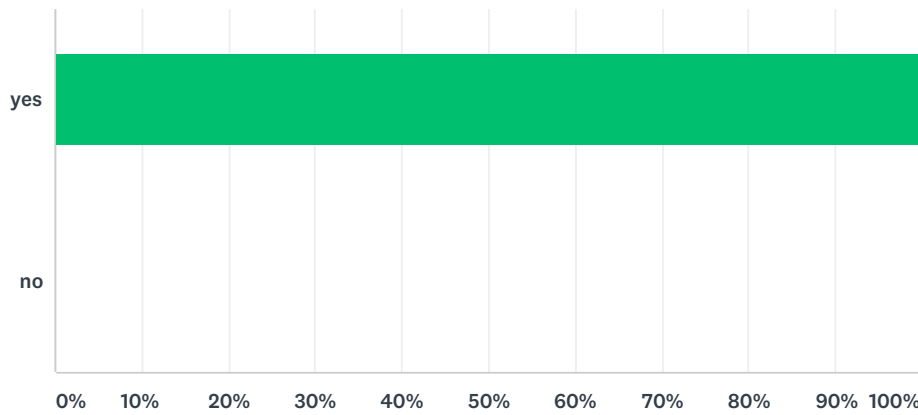
Answered: 2 Skipped: 582



ANSWER CHOICES	RESPONSES	
Observation of an attending	0.00%	0
GME course	50.00%	1
Consult journals	0.00%	0
Consultation with colleagues	0.00%	0
I haven't been trained yet	0.00%	0
Other (please specify)	50.00%	1
TOTAL		2

Q24 To date, have you received training in Participating in Advanced Care Planning/End-of-Life Activities?

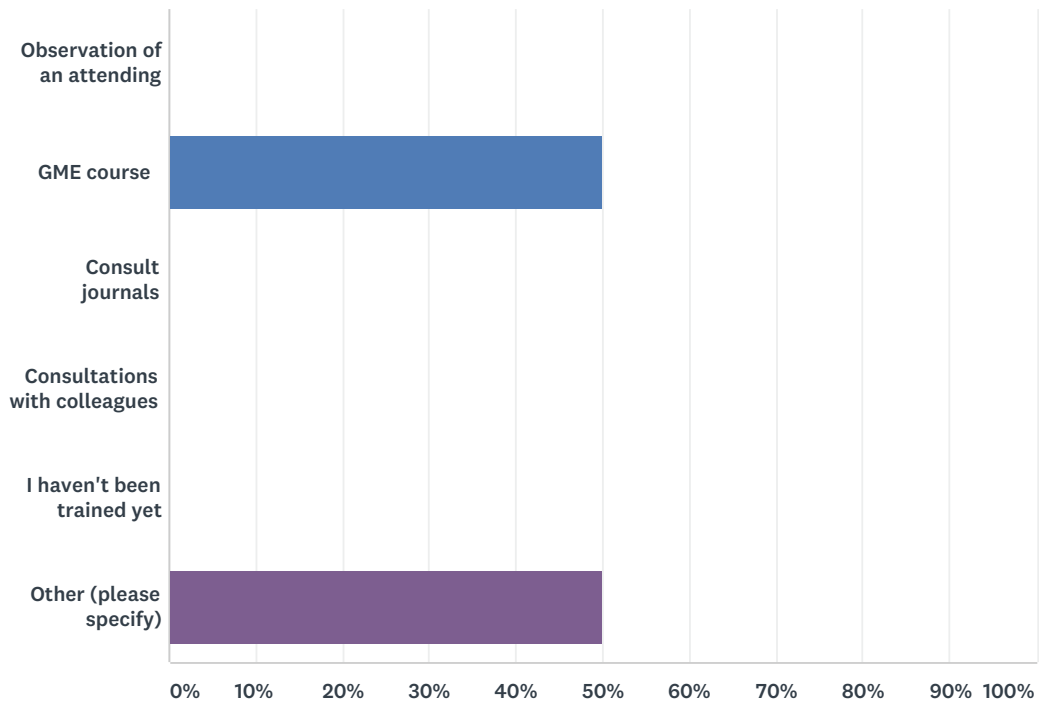
Answered: 2 Skipped: 582



ANSWER CHOICES	RESPONSES	
yes	100.00%	2
no	0.00%	0
TOTAL		2

Q25 How were you trained in Participating in Advanced Care Planning/End-of-Life Activities?

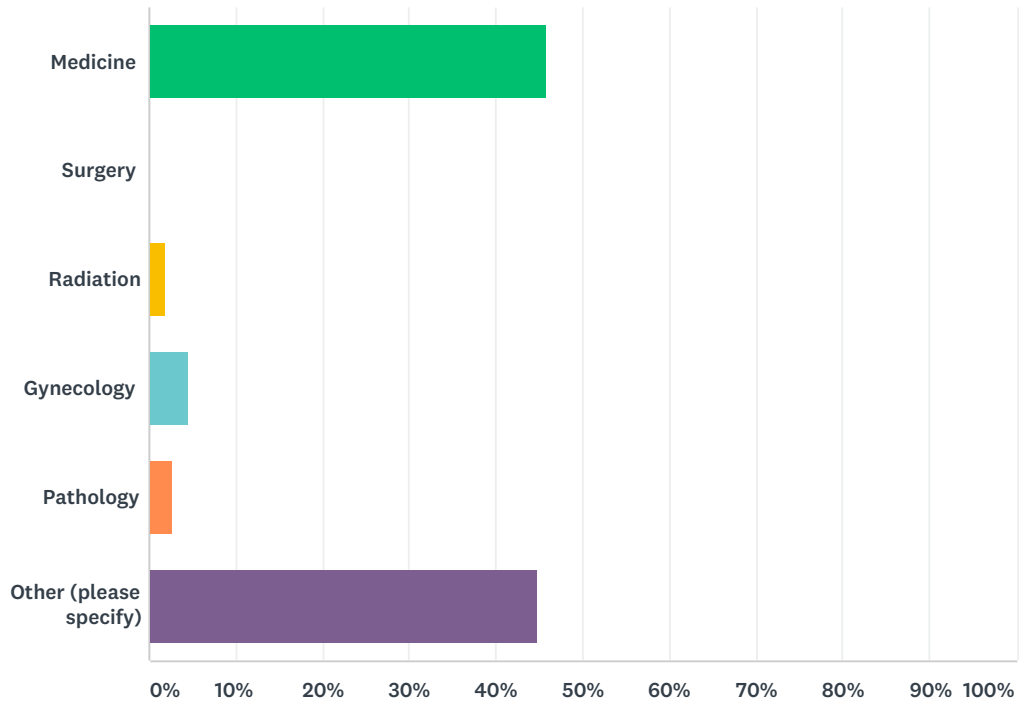
Answered: 2 Skipped: 582



ANSWER CHOICES	RESPONSES	
Observation of an attending	0.00%	0
GME course	50.00%	1
Consult journals	0.00%	0
Consultations with colleagues	0.00%	0
I haven't been trained yet	0.00%	0
Other (please specify)	50.00%	1
TOTAL		2

Q26 Clinical Research Associate (CRA) - discipline

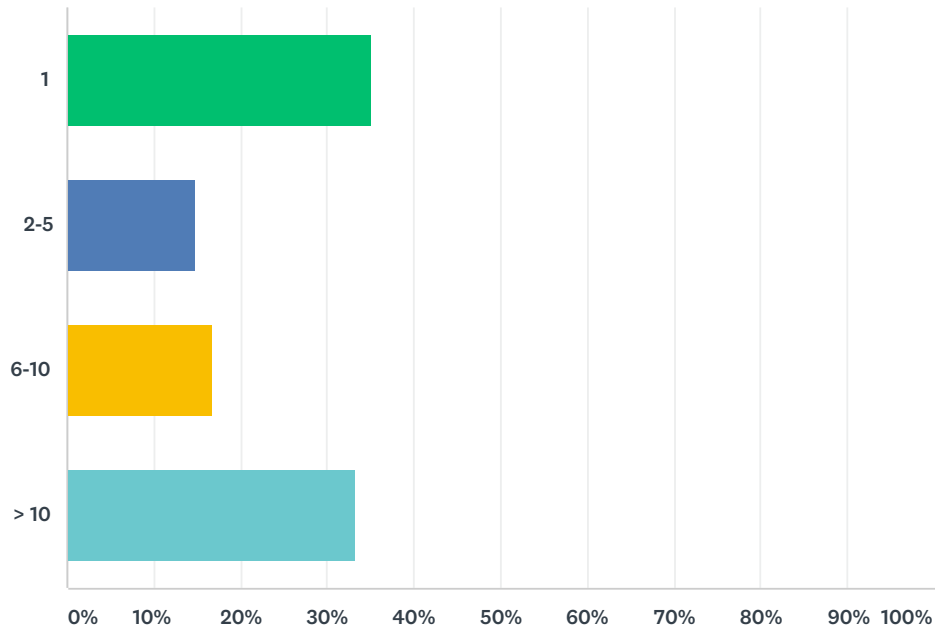
Answered: 107 Skipped: 477



ANSWER CHOICES	RESPONSES	
Medicine	45.79%	49
Surgery	0.00%	0
Radiation	1.87%	2
Gynecology	4.67%	5
Pathology	2.80%	3
Other (please specify)	44.86%	48
TOTAL		107

Q27 How many years have you been a CRA?

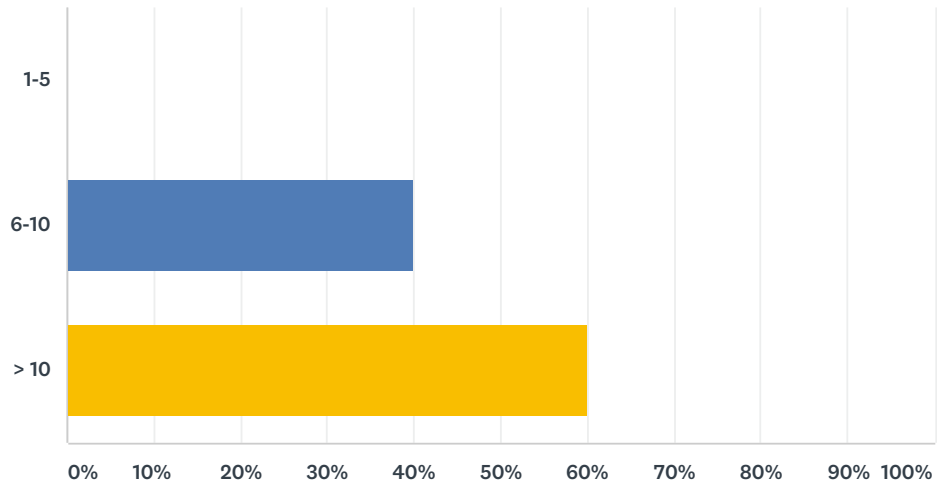
Answered: 108 Skipped: 476



ANSWER CHOICES	RESPONSES	
1	35.19%	38
2-5	14.81%	16
6-10	16.67%	18
> 10	33.33%	36
TOTAL		108

Q28 How many years have you been involved in advocacy?

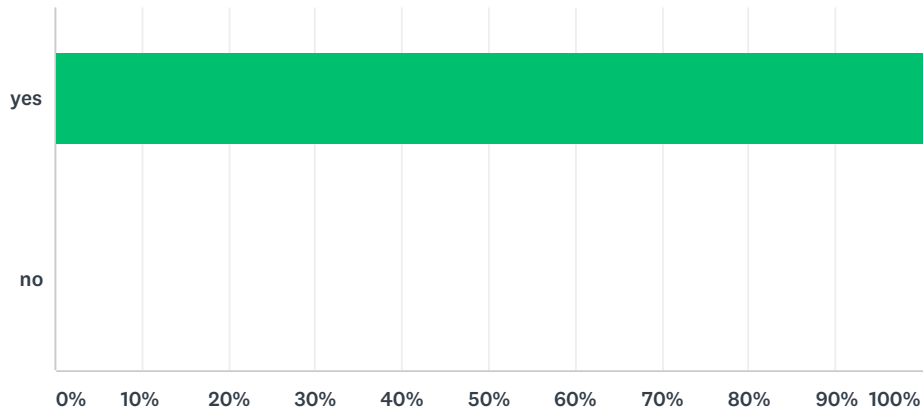
Answered: 5 Skipped: 579



ANSWER CHOICES	RESPONSES
1-5	0.00% 0
6-10	40.00% 2
> 10	60.00% 3
TOTAL	5

Q29 Are you a member of SWOG's Patient Advocacy Committee?

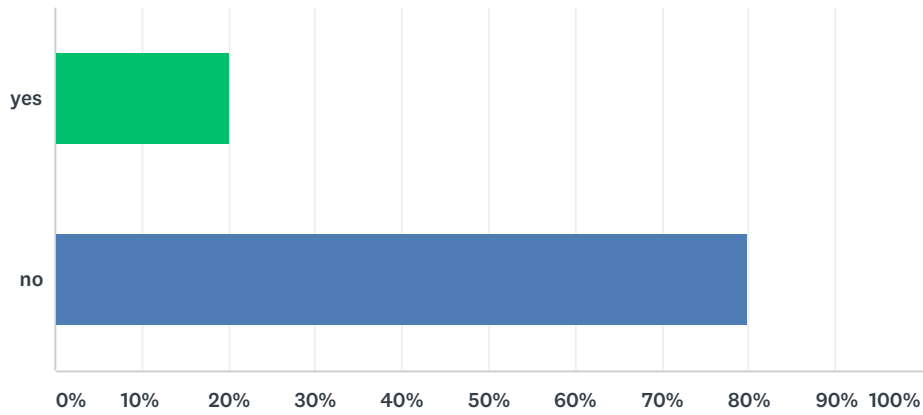
Answered: 5 Skipped: 579



ANSWER CHOICES	RESPONSES	
yes	100.00%	5
no	0.00%	0
TOTAL		5

Q30 Do you believe the Advocacy Committee substantively informs Palliative Care practice and policy in a manner consistent with patients' values and preferences?

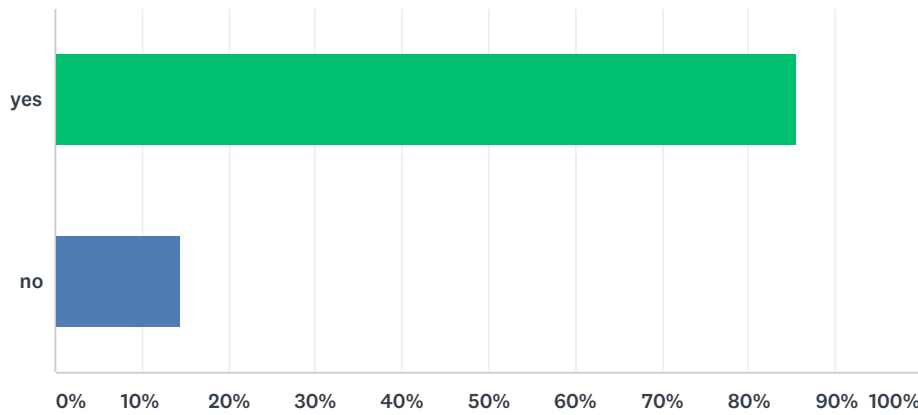
Answered: 5 Skipped: 579



ANSWER CHOICES	RESPONSES	
yes	20.00%	1
no	80.00%	4
TOTAL		5

Q31 Do you think SWOG should establish Palliative Care Subcommittee embedded in a currently existing committee?

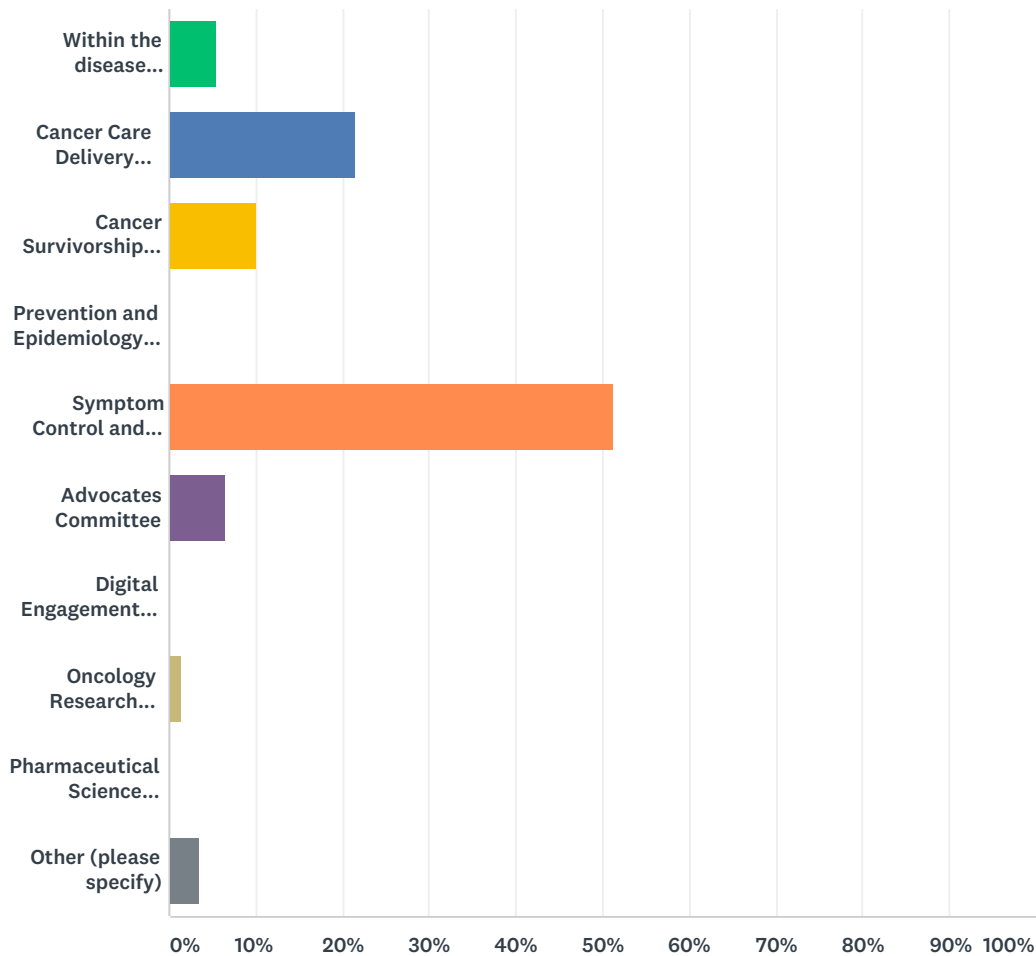
Answered: 467 Skipped: 117



ANSWER CHOICES	RESPONSES	
yes	85.65%	400
no	14.35%	67
TOTAL		467

Q32 Please check the committee you think is best positioned to inform Palliative Care practice and policy

Answered: 467 Skipped: 117



ANSWER CHOICES	RESPONSES	
Within the disease specific committees	5.35%	25
Cancer Care Delivery Committee	21.63%	101
Cancer Survivorship Committee	10.06%	47
Prevention and Epidemiology Committee	0.00%	0
Symptom Control and Quality of Life Committee	51.18%	239
Advocates Committee	6.42%	30
Digital Engagement Committee	0.00%	0
Oncology Research Professionals Committee	1.50%	7
Pharmaceutical Science Committee	0.21%	1
Other (please specify)	3.64%	17

TOTAL	467
-------	-----

Q33 Please provide suggestions about how to improve future Advanced Care Planning/End of Life - related questionnaires

Answered: 73 Skipped: 511