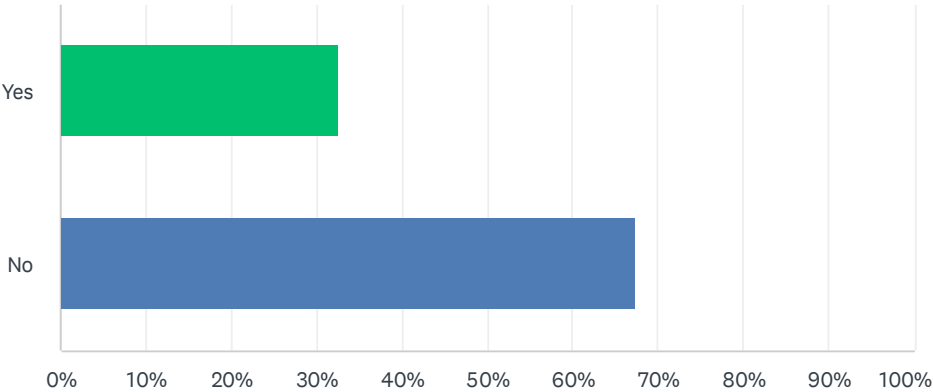


Q1 Before receiving this survey, had you heard of the Industry Pharmacogenomics Working Group (I-PWG)?

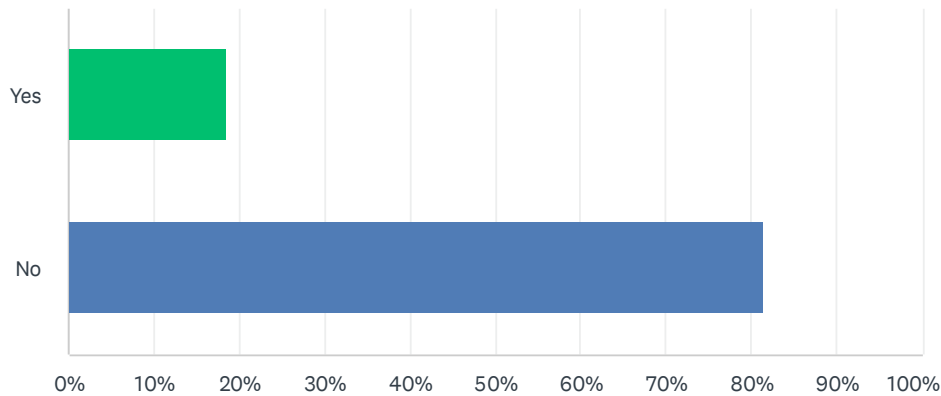
Answered: 43 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	32.56%	14
No	67.44%	29
TOTAL		43

Q2 Have you read the Biomarker brochure produced by the I-PWG (www.i-pwg.org)?

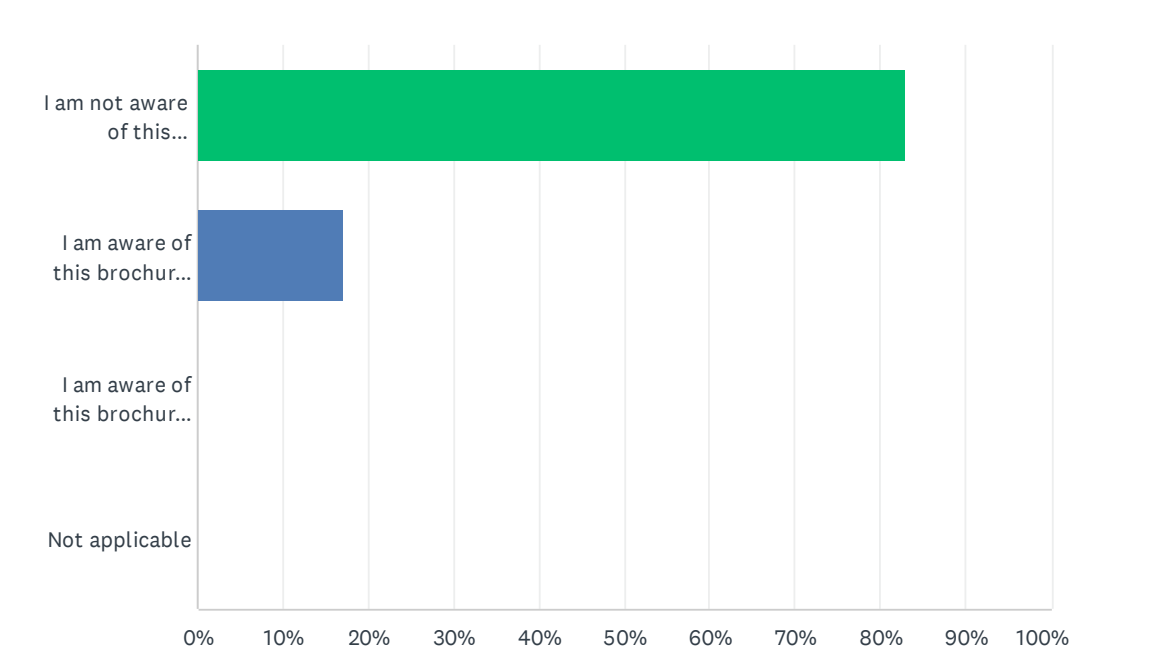
Answered: 43 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	18.60%	8
No	81.40%	35
TOTAL		43

Q3 If you have not read the biomarker brochure is it because:

Answered: 35 Skipped: 8



ANSWER CHOICES	RESPONSES	
I am not aware of this brochure	82.86%	29
I am aware of this brochure, but do not know where to find it	17.14%	6
I am aware of this brochure but have not read it	0.00%	0
Not applicable	0.00%	0
TOTAL		35

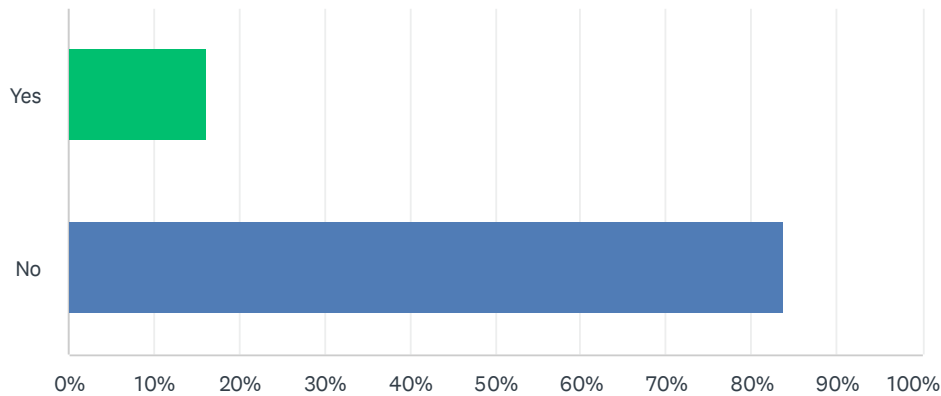
Q4 Please explain why you did not read the biomarker brochure

Answered: 0 Skipped: 43

#	RESPONSES	DATE
	There are no responses.	

Q5 Have you read the Pharmacogenomic (PGx) brochure produced by the Industry Pharmacogenomics Working Group?

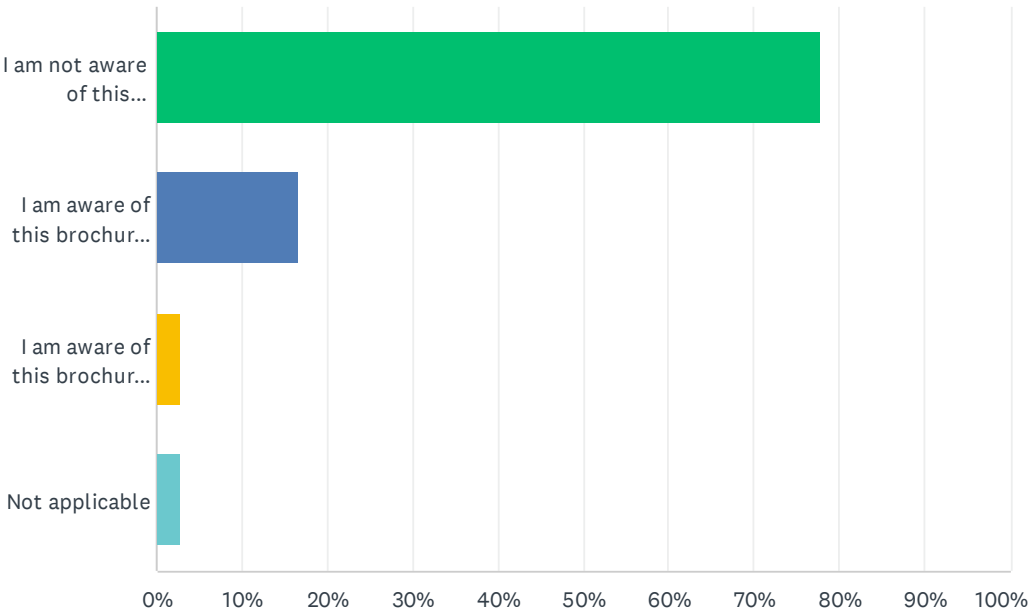
Answered: 43 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	16.28%	7
No	83.72%	36
TOTAL		43

Q6 If you have not read the PGx brochure is it because:

Answered: 36 Skipped: 7



ANSWER CHOICES	RESPONSES	
I am not aware of this brochure	77.78%	28
I am aware of this brochure, but do not know where to find it	16.67%	6
I am aware of this brochure but have not read it	2.78%	1
Not applicable	2.78%	1
TOTAL		36

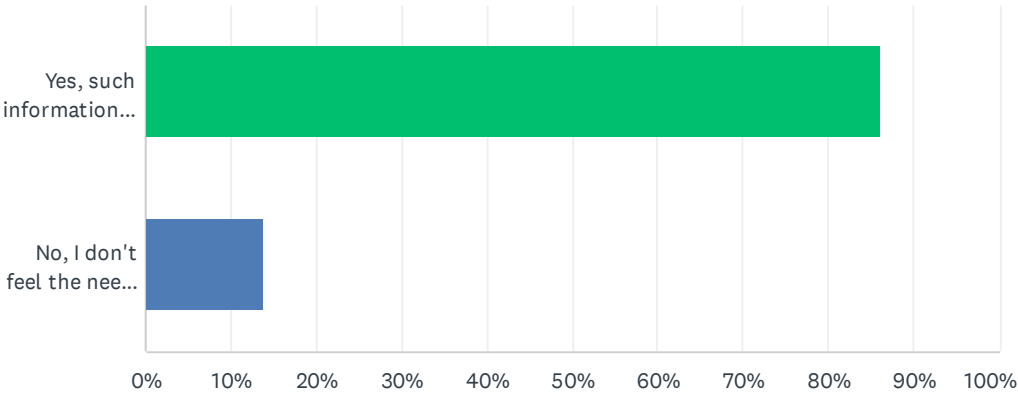
Q7 Please explain why you did not read the PGx brochure

Answered: 1 Skipped: 42

#	RESPONSES	DATE
1	Have not had time	5/30/2014 11:40 PM

Q8 Whether or not you have viewed the I-PWG brochure(s) in the past, would you find information about biomarker and pharmacogenomic research helpful for your review of protocols that involve research of this nature?

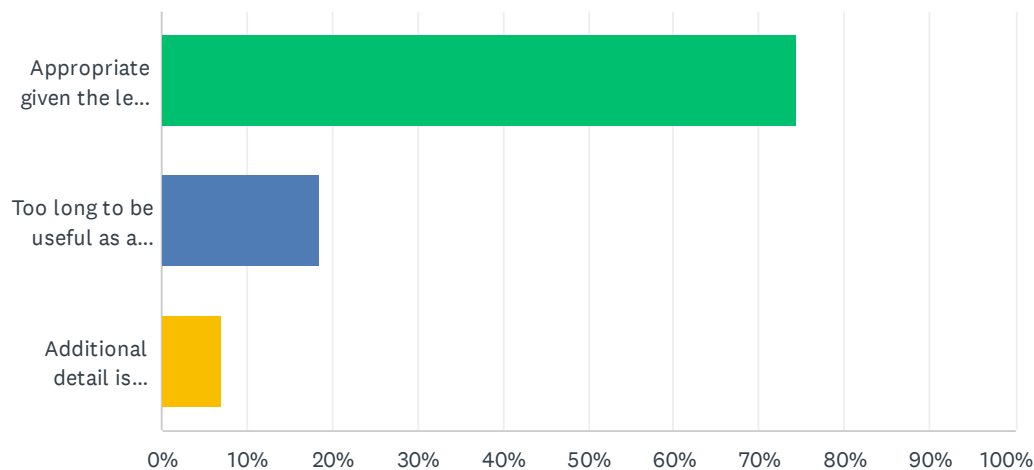
Answered: 43 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes, such information would be a helpful resource	86.05%	37
No, I don't feel the need to have additional information	13.95%	6
TOTAL		43

Q9 Currently the I-PWG biomarker brochure is a 10 page resource and the I-PWG Pharmacogenomics brochure is a 9 page resource. In order for these to be useful educational resources, do you feel this length is:

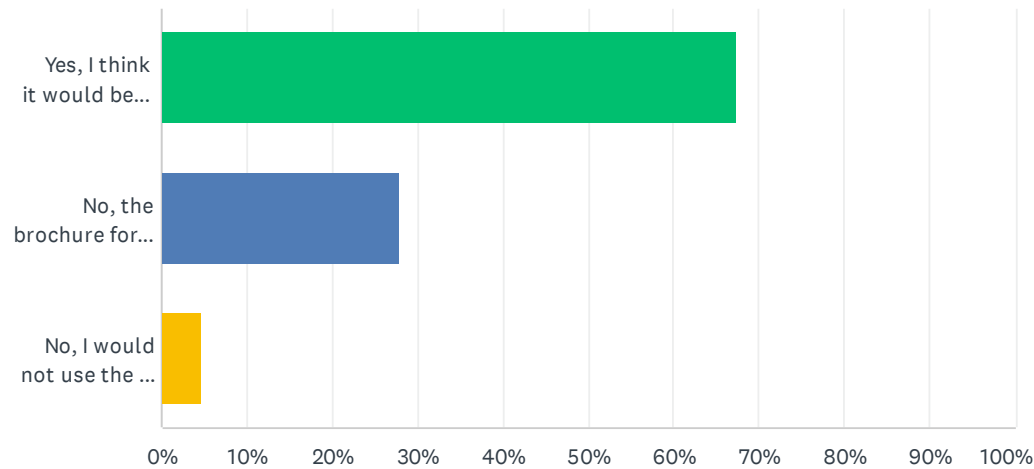
Answered: 43 Skipped: 0



ANSWER CHOICES	RESPONSES	
Appropriate given the level of detail needed to understand biomarker and PGx research	74.42%	32
Too long to be useful as a resource	18.60%	8
Additional detail is needed to help the audience better understand biomarker and PGx research	6.98%	3
TOTAL		43

Q10 Would it be helpful to have information about biomarker and PGx research summarized in a one page document?

Answered: 43 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes, I think it would be helpful to have this one page resource available	67.44%	29
No, the brochure format currently available is preferable	27.91%	12
No, I would not use the one page document or the current brochure	4.65%	2
TOTAL		43

Q11 Please explain why you would not use either the current brochure or a shorter one page document

Answered: 2 Skipped: 41

#	RESPONSES	DATE
1	I have not viewed the current brochure. I do believe that a one page document will not be doing anyone reading the information any favors or help with insight or understanding.	6/20/2014 7:40 PM
2	I can educate myself and do not want the biases of your group influencing my thinking. We do not need more self promotion interestgroups	5/12/2014 6:08 AM

Q12 What information do you think would be most important and helpful to communicate regarding biomarker research?

Answered: 31 Skipped: 12

#	RESPONSES	DATE
1	costs, potential applications, confidentiality issues	7/21/2014 7:00 PM
2	Differences vs genomic research.	7/18/2014 7:31 PM
3	Discovery of new and potentially useful biomarkers.	7/18/2014 3:45 PM
4	Discussion of how useful are they without being able to go back and identify subject	7/13/2014 11:59 PM
5	developing technology for future testing experienced labs to discuss testing availability of certified labs for various testing, including costs.	7/13/2014 6:34 PM
6	Pictures and graphics are an extremely effective way to communicate this information. Long winded articles are less useful to many, and the information is frequently not communicated well.	7/11/2014 4:00 PM
7	definitions of terms - biomarker, etc. A very broad term that is interpreted differently in different clinical and non-clinical groups	6/25/2014 12:10 AM
8	specificity and sensitivity	6/21/2014 7:04 AM
9	Recent examples (especially from Australia)	6/21/2014 6:04 AM
10	Basic definitions, functions, and examples of use.	6/20/2014 7:41 PM
11	What the goals are and timelines	6/20/2014 6:51 PM
12	Whenever information is presented, it should be done in a clear and easily understood manner.	6/20/2014 6:49 PM
13	Directions/trends of overall research	6/11/2014 8:07 PM
14	What is being done and why and the risks and potential benefits to participants and others.	6/11/2014 7:05 PM
15	no comment	6/11/2014 6:43 PM
16	You have it -- medicine of a greater efficacy.	6/11/2014 6:41 PM
17	Your current brochures do a good job for the layperson - more advanced readers will be able to find the information they require elsewhere.	6/1/2014 4:15 PM
18	The main issue our IRB has with this type of research is that there is no immediate benefit to the study subjects, while there is a clear benefit for the pharmaceutical companies.	5/30/2014 11:43 PM
19	x	5/29/2014 6:49 PM
20	State of the art, potential risks, limitations.	5/28/2014 3:50 PM
21	Findings in the pharmacogenetics area. Details about methodology included in the studies.	5/27/2014 11:01 PM
22	gene testing	5/27/2014 9:42 PM
23	no comment	5/27/2014 9:36 PM
24	What is the impact on an individual human subject? What is the impact of this research on communities from which subjects are drawn (geographic areas, small isolated populations, extended families, ethnic groups)?	5/27/2014 8:53 PM
25	how am I protected from a breach of data	5/27/2014 8:37 PM
26	value of increased use of biomarkers in research.	5/27/2014 8:04 PM
27	I am satisfied with what has been provided	5/16/2014 1:45 AM

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28	A clear statement of the risks of participating in this biomarker research.	5/13/2014 12:29 AM
29	Implications for subject - privacy protection, considerations for return of findings	5/12/2014 3:37 PM
30	Risk of reidentification in case of whole genome sequencing or analysis of many alleles.	5/12/2014 10:14 AM
31	None - stop trying to bias the regulators.	5/12/2014 6:09 AM

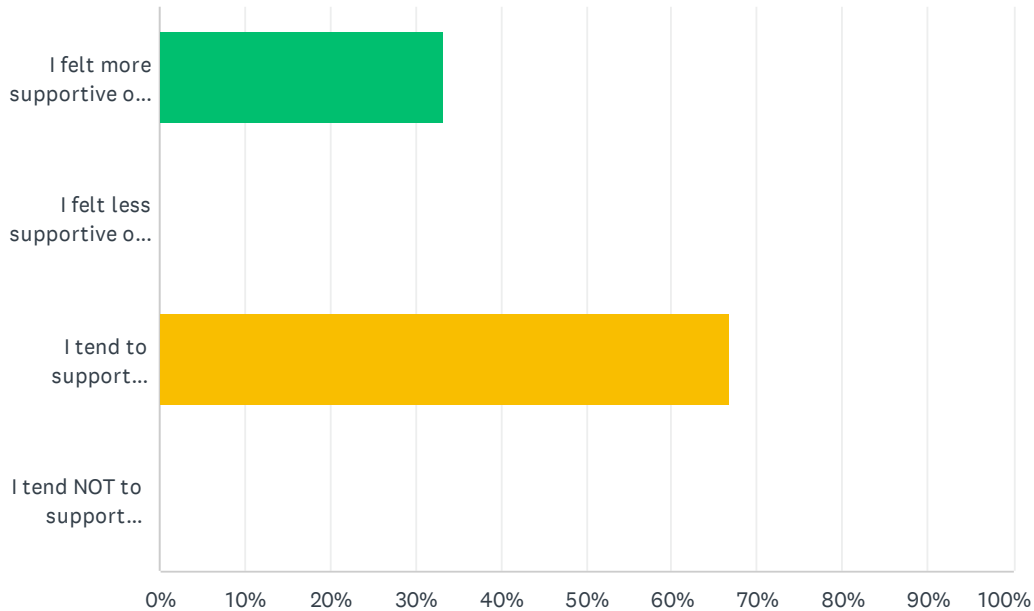
Q13 What information do you think would be most important and helpful to communicate regarding pharmacogenomics research?

Answered: 30 Skipped: 13

#	RESPONSES	DATE
1	confidentiality issues primarily	7/21/2014 7:00 PM
2	Problems related to whole genome probing and privacy of the patient.	7/18/2014 7:31 PM
3	Patient protections as related to genetic research.	7/18/2014 3:45 PM
4	Ways of making findings unidentified	7/13/2014 11:59 PM
5	available, experienced labs to test various agents, including costs.	7/13/2014 6:34 PM
6	Examples of what has happened, and what could happen...	7/11/2014 4:00 PM
7	likely clinical utility, relevance in 'routine' practice, relative impact of variability in genomic/phenotypic expression- when many variables may impact on overall clinical variability in response	6/25/2014 12:10 AM
8	Recent examples (especially from Australia)	6/21/2014 6:04 AM
9	Basic definitions, functions, and examples of use.	6/20/2014 7:41 PM
10	Benefits and risk mitigation	6/20/2014 6:51 PM
11	Whenever information is presented, it should be done in a clear and easily understood manner.	6/20/2014 6:49 PM
12	Areas that are garnering the most interest and research dollars	6/11/2014 8:07 PM
13	What is being done and why and the risks and potential benefits to participants and others.	6/11/2014 7:05 PM
14	no comment	6/11/2014 6:43 PM
15	This research is leading edge and the future of clinical care. Do it now!	6/11/2014 6:41 PM
16	ditto	6/1/2014 4:15 PM
17	The scientific basis for pharmacogenomics research is clear for most IRB members.	5/30/2014 11:43 PM
18	x	5/29/2014 6:49 PM
19	State of the art, potential risks, limitations.	5/28/2014 3:50 PM
20	Findings and research groups.	5/27/2014 11:01 PM
21	na	5/27/2014 9:42 PM
22	no comment	5/27/2014 9:36 PM
23	What are the issues or concerns that make this different than any other research?	5/27/2014 8:53 PM
24	how it can help you to get better medical care	5/27/2014 8:37 PM
25	no specific answer	5/27/2014 8:04 PM
26	I am satisfied with what has been provided	5/16/2014 1:45 AM
27	A clear statement of the risks of participating in pharmacogenomics research.	5/13/2014 12:29 AM
28	See above	5/12/2014 3:37 PM
29	cf. above	5/12/2014 10:14 AM
30	List of publications	5/12/2014 6:09 AM

Q14 Upon reviewing the biomarker and/or PGx brochure(s) which of the following statements reflect your view of this type of research?

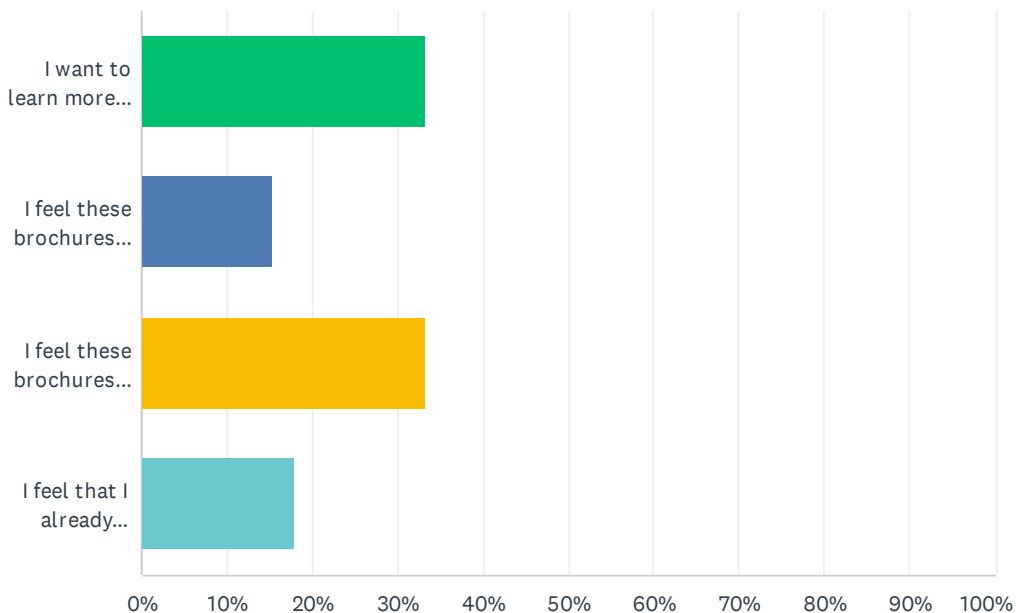
Answered: 12 Skipped: 31



ANSWER CHOICES	RESPONSES	
I felt more supportive of biomarker and PGx research after reading one or both of these brochures	33.33%	4
I felt less supportive of biomarker and PGx research after reading one or both of these brochures	0.00%	0
I tend to support biomarker and PGx research, and these views didn't change after reading one or both of these brochures	66.67%	8
I tend NOT to support biomarker and PGx research, and these views did not change after reading one or both of these brochures	0.00%	0
TOTAL		12

Q15 How helpful did you find these brochures in explaining biomarker and PGx research?

Answered: 39 Skipped: 4



ANSWER CHOICES	RESPONSES	
I want to learn more about biomarker and PGx research. However, these brochures did not do a good job of helping me understand these concepts	33.33%	13
I feel these brochures helped me better understand biomarker and/or PGx research but there is room for improvement	15.38%	6
I feel these brochures helped me better understand biomarker and/or PGx research	33.33%	13
I feel that I already understood biomarker and PGx research, and there is nothing new in these brochures that I did not already know	17.95%	7
TOTAL		39

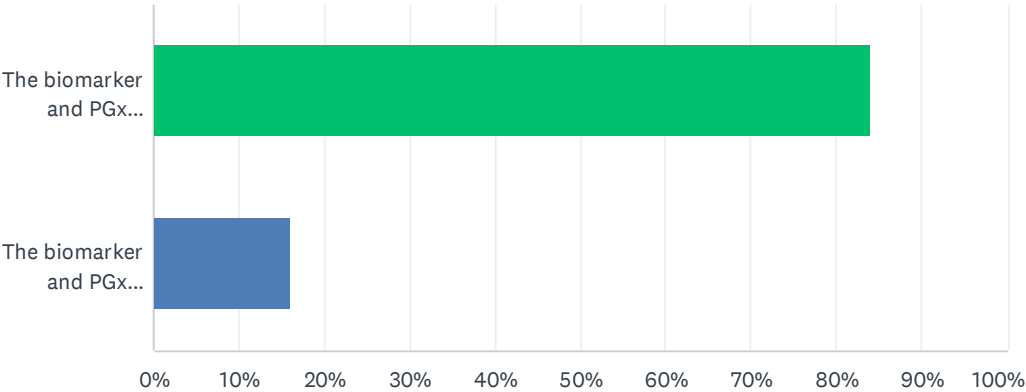
Q16 In the previous question if you responded that the brochures could use improvement, please explain what could have been done differently to help you better understand biomarker and PGx research (e.g. these concepts need clearer explanation):

Answered: 10 Skipped: 33

#	RESPONSES	DATE
1	It don't work...I can't answer questions 11/12, since I've not seen the brochure, and it will not let me advance without an answer. So, this data is pretty useless, and I just wasted my time. Sorry.	7/11/2014 4:02 PM
2	Note- I have not read the brochure=- this questionnaire did not allow me to skip the last question	6/25/2014 12:11 AM
3	I have not seen the brochures.	6/20/2014 6:50 PM
4	no comment	6/11/2014 6:44 PM
5	x	5/29/2014 6:50 PM
6	n/a	5/28/2014 3:52 PM
7	na	5/27/2014 9:43 PM
8	no comment	5/27/2014 9:37 PM
9	shorter	5/27/2014 8:37 PM
10	Even though I had NOT read the brochures, and was not supposed to answer either question, I could NOT proceed without providing an answer here.	5/13/2014 12:31 AM

Q17 Do the brochures seem to provide an unbiased explanation of biomarker and PGx research?

Answered: 25 Skipped: 18



ANSWER CHOICES	RESPONSES	
The biomarker and PGx brochures provide unbiased content	84.00%	21
The biomarker and PGx brochures provide biased content	16.00%	4
TOTAL		25

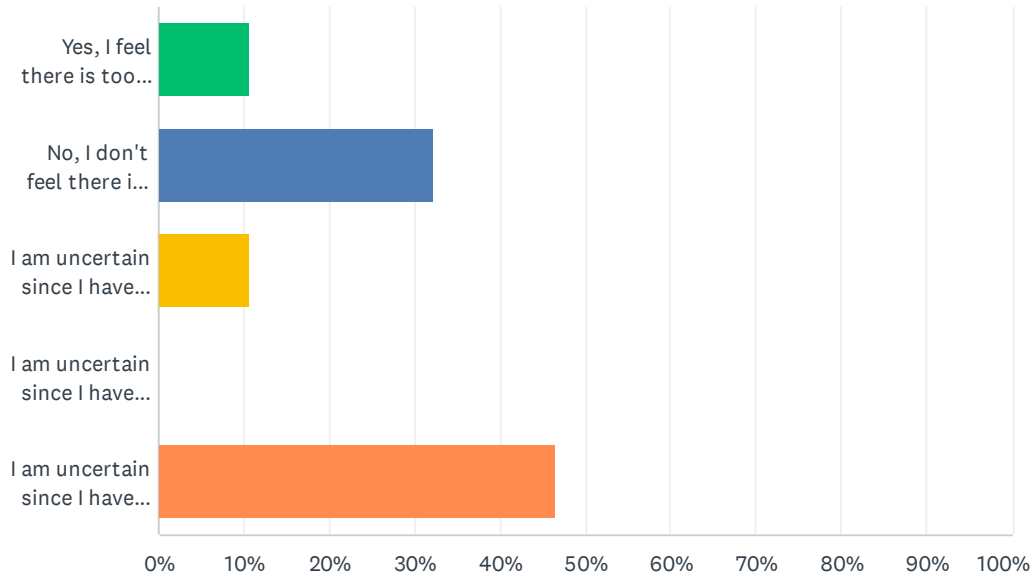
Q18 If you feel the biomarker and PGx brochures provide biased content please explain what lead you to this conclusion

Answered: 7 Skipped: 36

#	RESPONSES	DATE
1	I did not read the brochure	6/25/2014 12:11 AM
2	I have not seen the brochures.	6/20/2014 6:50 PM
3	no comment	6/11/2014 6:44 PM
4	Pharmaceutical companies have clear economic benefit; subjects donating the blood have no clear benefits (either economic, personal health or even for the good of their community).	5/30/2014 11:45 PM
5	n/a	5/28/2014 3:52 PM
6	Did not read brochures but this survey will not let me continue without answering questions that it specifically tells me not to answer if I have not read survey. Therefore last two answers are wrong.	5/27/2014 9:13 PM
7	I am skipping this question	5/27/2014 8:54 PM

Q19 Do you feel there is too much overlap in content between the biomarker and PGx brochures?


































Answered: 28 Skipped: 15



ANSWER CHOICES	RESPONSES	
Yes, I feel there is too much overlap	10.71%	3
No, I don't feel there is too much overlap	32.14%	9
I am uncertain since I have only read the biomarker brochure	10.71%	3
I am uncertain since I have only read the PGx brochure	0.00%	0
I am uncertain since I have not read either brochure	46.43%	13
TOTAL		28

Q20 In what country do you serve as an IRB or IEC member?

Answered: 43 Skipped: 0

#	RESPONSES	DATE
1	 US	7/21/2014 7:01 PM
2	 Italy	7/18/2014 7:32 PM
3	 USA	7/18/2014 3:45 PM
4	 USA	7/18/2014 2:25 PM
5	 us	7/14/2014 12:01 AM
6	 USA	7/13/2014 6:36 PM
7	 USA	7/12/2014 1:43 PM
8	 Canada	7/11/2014 5:52 PM
9	 us	7/11/2014 4:03 PM
10	 USA	7/11/2014 3:55 PM
11	 Australia	6/25/2014 12:12 AM
12	 USA	6/23/2014 10:31 PM
13	 Poland	6/21/2014 7:07 AM
14	 Australia	6/21/2014 6:05 AM
15	 United States	6/20/2014 7:43 PM
16	 USA	6/20/2014 6:52 PM
17	 United States	6/20/2014 6:51 PM
18	 Georgia	6/12/2014 12:48 PM
19	 U.S.A.	6/11/2014 9:21 PM
20	 US	6/11/2014 8:08 PM
21	 USA	6/11/2014 7:07 PM
22	 United States	6/11/2014 6:46 PM
23	 USA	6/11/2014 6:43 PM
24	 Canada	6/1/2014 4:16 PM
25	 Mexico	5/30/2014 11:46 PM
26	 US	5/29/2014 6:51 PM
27	 USA	5/28/2014 3:53 PM
28	 usa	5/28/2014 3:24 AM
29	 Mexico	5/27/2014 11:05 PM
30	 usaa	5/27/2014 9:43 PM
31	 usa	5/27/2014 9:38 PM
32	 US	5/27/2014 9:14 PM
33	 USA	5/27/2014 8:54 PM

IRB/IEC views of I-PWG Educational Brochures

34	 usa	5/27/2014 8:38 PM
35	 USA	5/27/2014 8:19 PM
36	 USA	5/27/2014 8:06 PM
37	 Australia	5/16/2014 1:46 AM
38	 united states	5/14/2014 5:27 PM
39	 U.S.A.	5/13/2014 12:32 AM
40	 US (but consult in Thailand)	5/12/2014 3:39 PM
41	 GERMANY	5/12/2014 10:15 AM
42	 USA	5/12/2014 6:10 AM
43	 USA	4/29/2014 9:45 PM

Q21 How long have you been a member of an IRB or IEC?

Answered: 42 Skipped: 1

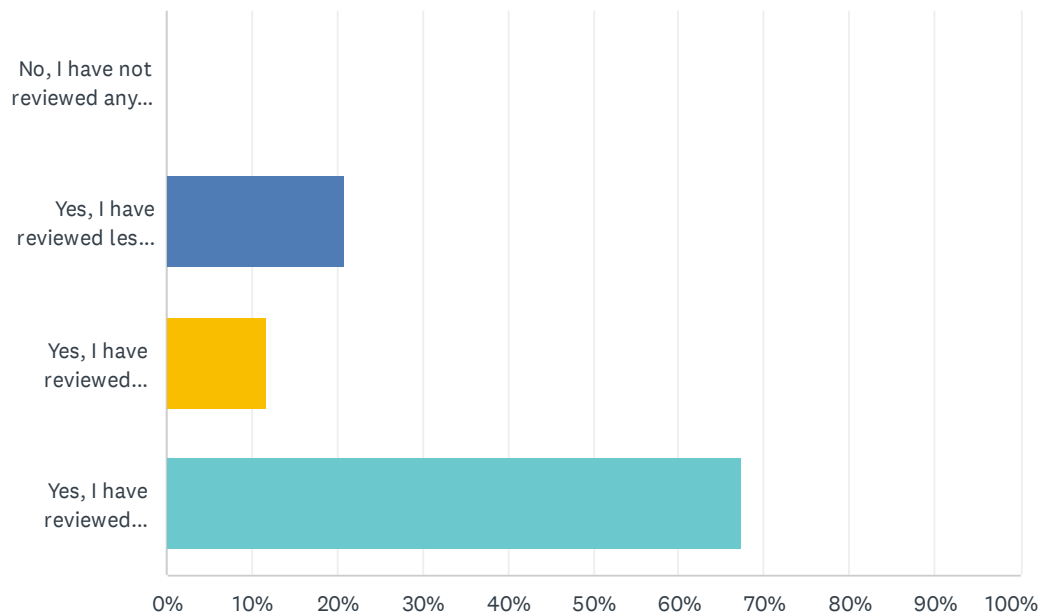
#	RESPONSES	DATE
1	10-20 years 12 years	7/21/2014 7:01 PM
2	10-20 years >10 yrs.	7/18/2014 7:32 PM
3	More than 20 years 31 years	7/18/2014 3:45 PM
4	10-20 years 10 yrs	7/18/2014 2:25 PM
5	10-20 years 10 years	7/14/2014 12:01 AM
6	5-10 years 9 years	7/13/2014 6:36 PM
7	10-20 years 15 yr	7/12/2014 1:43 PM
8	10-20 years 10 years	7/11/2014 5:52 PM
9	More than 20 years 26 years	7/11/2014 4:03 PM
10	10-20 years 15 years	7/11/2014 3:55 PM
11	10-20 years 12 years	6/25/2014 12:12 AM
12	Former member I am no longer a member, 7 years	6/23/2014 10:31 PM
13	10-20 years 12 years	6/21/2014 7:07 AM
14	More than 20 years 25 years	6/21/2014 6:05 AM
15	10-20 years 12 years	6/20/2014 7:43 PM
16	10-20 years 15 years	6/20/2014 6:52 PM
17	10-20 years 17 years	6/20/2014 6:51 PM
18	5-10 years 7 years	6/12/2014 12:48 PM
19	More than 20 years 20 years	6/11/2014 9:21 PM
20	10-20 years 15 years	6/11/2014 8:08 PM
21	10-20 years 18 years	6/11/2014 7:07 PM
22	5-10 years > 5 years	6/11/2014 6:46 PM
23	More than 20 years 20+ yrs	6/11/2014 6:43 PM
24	10-20 years 10 years	6/1/2014 4:16 PM
25	10-20 years Since 2004	5/30/2014 11:46 PM
26	10-20 years 12 yrs	5/29/2014 6:51 PM
27	10-20 years 10 yr	5/28/2014 3:53 PM
28	More than 20 years 25 years	5/28/2014 3:24 AM
29	10-20 years 15 years	5/27/2014 11:05 PM
30	5-10 years 5	5/27/2014 9:43 PM
31	More than 20 years 40 years	5/27/2014 9:38 PM
32	5-10 years ?5 yrs	5/27/2014 9:14 PM
33	10-20 years 15 years	5/27/2014 8:54 PM

IRB/IEC views of I-PWG Educational Brochures

34	More than 20 years	20 yrs	5/27/2014 8:38 PM
35	More than 20 years	20 years	5/27/2014 8:19 PM
36	More than 20 years	20 years +	5/27/2014 8:06 PM
37	10-20 years	12 years	5/16/2014 1:46 AM
38	More than 20 years	20+ years	5/14/2014 5:27 PM
39	More than 20 years	26 YEARS	5/13/2014 12:32 AM
40	More than 20 years	22 years	5/12/2014 3:39 PM
41	5-10 years	8 years	5/12/2014 10:15 AM
42	10-20 years	10 years	5/12/2014 6:10 AM

Q22 Have you reviewed many clinical protocols with biomarker and/or PGx research?

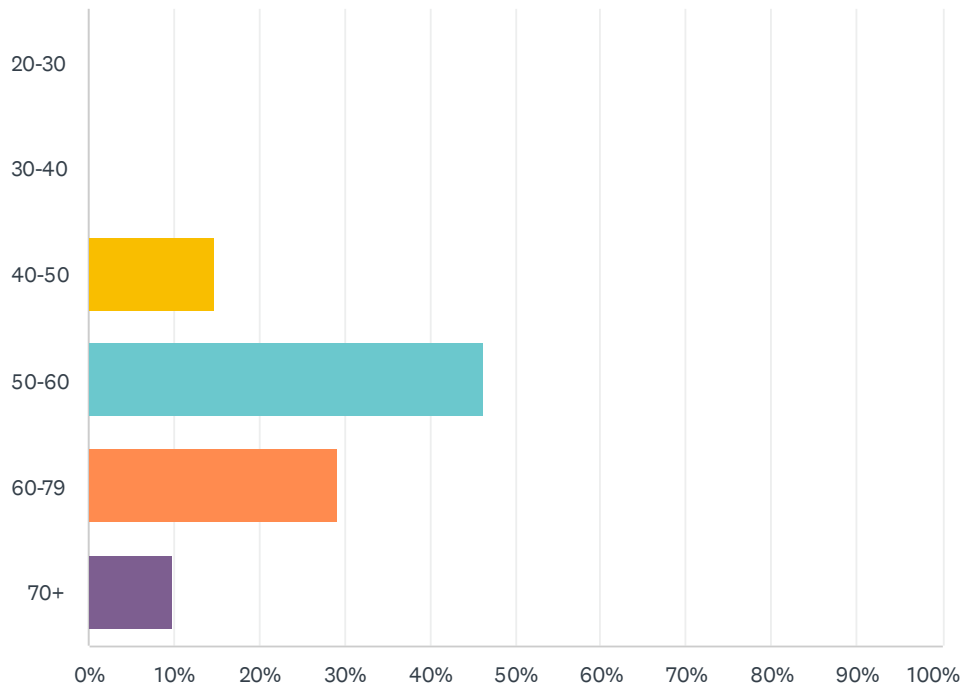
Answered: 43 Skipped: 0



ANSWER CHOICES	RESPONSES	
No, I have not reviewed any clinical protocols with biomarker and/or PGx research	0.00%	0
Yes, I have reviewed less then 5 protocols with biomarker and/or PGx research	20.93%	9
Yes, I have reviewed between 5 and 10 protocols with biomarker and/or PGx research	11.63%	5
Yes, I have reviewed greater than 10 protocols with biomarker and/or PGx research	67.44%	29
TOTAL		43

Q23 What is your age?

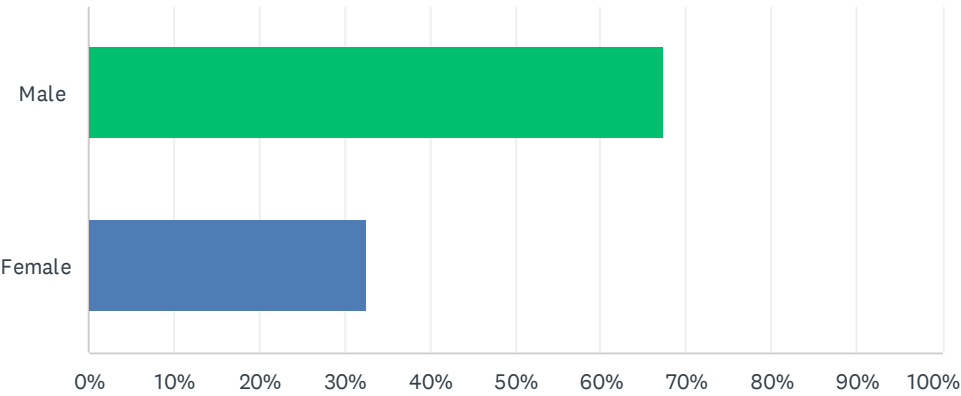
Answered: 41 Skipped: 2



ANSWER CHOICES	RESPONSES	
20-30	0.00%	0
30-40	0.00%	0
40-50	14.63%	6
50-60	46.34%	19
60-79	29.27%	12
70+	9.76%	4
TOTAL		41

Q24 What is your gender?

Answered: 43 Skipped: 0



ANSWER CHOICES	RESPONSES	
Male	67.44%	29
Female	32.56%	14
TOTAL		43