

ATTITUDES TOWARDS PERTINENT AND INCIDENTAL FINDINGS IN WHOLE GENOME RESEARCH

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BACKGROUND

In 2007 the first individual genome was sequenced for research purposes and whole genome sequencing (WGS) are rapidly emerging as important tools in human genetics research. The development of WGS has made it possible to identify genetic variations associated with increased risk for many disorders. WGS produce large volumes of genetic data on each research subject. Some of this data are pertinent to the study, while others will be incidental and unrelated to the primary focus of the study.

A small survey was conducted (6 items) at the iPSYCH Annual Meeting (<http://ipsych.au.dk>) to evaluate members of the iPSYCH's projects attitudes towards pertinent and incidental findings from whole genome studies. Members of the iPSYCH project are individuals who are actively involved in genetic research on human subjects.

AIM

Characterize members of the iPSYCH's projects attitudes towards pertinent and incidental findings from whole genome studies.

METHODS

A survey was designed and conducted using Lenovo tablets at the iPSYCH Annual Meeting 2014. The objectives were to explore attitudes towards: i) Sharing of pertinent findings from whole genome studies, (ii) sharing of incidental findings from whole genome studies. Sociodemographic information was recorded as well. The survey did not include questions concerning the way research subject should be informed.

RESULTS

Sample characteristics

41 completed the questionnaire. Sample characteristics are shown in Table 1. Fifty-one percent of the respondents were women. Age ranged from 24 to 71 years, with mean age of 38.6 years.

17 % were Research Years Students, 19 % were Ph.D. students, 22 % were Postdocs, 24 % were Senior Researchers, 12 % were Professors and 5 % were Technical Administrative staff.

Pertinent findings

The majority (n=28) of the respondents agreed that pertinent findings from genome studies should be made available to research subjects (table 2 and 3).

Incidental findings

A majority (n=25) of the respondents agreed that incidental findings from genome studies should be made available to research subjects. Research Year Students, Ph.D. Students and Postdocs agreed and Senior researchers and Professors disagreed that incidental findings should be made available (table 4 and 5).

Respondents rated how long incidental findings should be available (scale as follows: For the length of the initial research project; 10 years; forever). A small majority (n=15) of all the respondents wanted incidental findings to be available for the research subjects forever. 12 respondents agreed that incidental findings should be available for the length of the initial research project. There was only a slight difference among professions groups with regard to this question (table 6 and 7).

Don't know responses

We also found that the lowest level of profession was associated with a higher proportion of "don't know" responses to the attitude statements (table 2, 4 and 6). Sex was also associated with "don't know" responses, as women was more prone to choose the "don't know" option than men (table 3 and 5).

CONCLUSION

These results show that a majority of the members of the iPSYCH project generally approved that pertinent and incidental findings from genome studies should be made available to research subject. A small majority wanted incidental findings to be available for the research subjects forever.

However, respondents with a higher profession (Senior Researcher and Professors) were more against feedback of incidental findings than those with a lower profession level (Research Year Students, Ph.D. Students and Postdocs). This finding suggests that there is an association between profession and attitudes. The relationship between attitudes toward feedback of pertinent and incidental findings in whole genome studies is complex, and a higher level of profession is linked with being more reluctant towards feedback of particularly incidental findings.

Gender	n		%	
	Female	Male		
Female	21		51.2 %	
Male		20		48.8 %
Profession	Research Year Student	7	17.1 %	
	Ph.D. Student	8	19.5 %	
	Postdoc	9	22.0 %	
	Senior Researcher	10	24.4 %	
	Professor	5	12.2 %	
	Technical Administrative Staff	2	4.9 %	
Mean Age	38,6			
Age	24-30	12	29.3 %	
	31-40	16	39.0 %	
	41-50	5	12.2 %	
	51-60	5	12.2 %	
	61-71	3	7.3 %	

Table 1

Should pertinent findings from genome studies be made available to research subjects?	Profession						Total
	Research Year Student	Ph.D. Student	Postdoc	Senior Researcher	Professor	Technical Administrative Staff	
Research subjects should be able to receive pertinent findings if they want them	4	7	8	5	2	2	28
I don't think pertinent findings from research projects should be available	14,3%	25,0%	28,6%	17,9%	7,1%	7,1%	8
I don't know	0	0	0	5	3	0	5
	0,0%	0,0%	0,0%	62,5%	37,5%	0,0%	
	3	1	1	0	0	0	5
	60,0%	20,0%	20,0%	0,0%	0,0%	0,0%	
Total	7	8	9	10	5	2	41

Table 2

Should pertinent findings from genome studies be made available to research subjects?	Gender		
	Female	Male	Total
Research subjects should be able to receive pertinent findings if they want them	16	12	28
	57,1%	42,9%	
I don't think pertinent findings from research projects should be available	2	6	8
	25,0%	75,0%	
I don't know	3	2	5
	60,0%	40,0%	
Total	21	20	41

Table 3

Should incidental findings from genome studies be made available to research subjects?	Profession						Total
	Research Year Student	Ph.D. Student	Postdoc	Senior Researcher	Professor	Technical Administrative Staff	
Research subjects should be able to receive incidental findings if they want them	5	8	7	4	0	1	25
I don't think incidental findings from research projects should be available	20,0%	32,0%	28,0%	16,0%	0,0%	4,0%	14
I don't know	0	0	2	6	5	1	2
	0,0%	0,0%	14,3%	42,9%	35,70%	7,1%	
I don't know	2	0	0	0	0	0	2
	100,0%	0,0%	0,0%	0,0%	0,0%	0,0%	
Total	7	8	9	10	5	2	41

Table 4

Should incidental findings from genome studies be made available to research subjects?	Gender		
	Female	Male	Total
Research subjects should be able to receive incidental findings if they want them	14	11	25
	56,0%	44,0%	
I don't think incidental findings from research projects should be available	5	9	14
	35,7%	64,3%	
I don't know	2	0	2
	100 %	0,0%	
Total	21	20	41

Table 5

If there was a duty to provide incidental findings from WGS, how long should this be available?	Profession						Total
	Research Year Student	Ph.D. Student	Postdoc	Senior Researcher	Professor	Technical Administrative Staff	
For the length of the initial research project	2	6	0	2	2	0	12
	16,7%	50,0%	0,0%	16,7%	16,7%	0,0%	
10 years	1	1	1	1	0	0	4
	25,0%	25,0%	25,0%	25,0%	0,0%	0,0%	
Forever	1	1	6	4	1	2	15
	6,7%	6,7%	40,0%	26,7%	6,7%	13,3%	
Don't know	3	0	2	3	2	0	10
	30,0%	0,0%	20,0%	16,7%	20,0%	0,0%	
Total	7	8	9	10	5	2	41

Table 6

If there was a duty to provide incidental findings from WGS, how long should this be available?	Gender		
	Female	Male	Total
For the length of the initial research project	7	5	12
	58,3%	41,7%	
10 years	1	3	4
	25,0%	75,0%	
Forever	8	7	15
	53,3%	46,7%	
Don't know	5	5	10
	50,0%	50,0%	
Total	21	20	41

Table 7

