

NEXT GENERATION DNA SEQUENCING AND INCIDENTAL FINDINGS

Consultant's opinion about the impact of being informed

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INTRODUCTION

The implantation of Next generation DNA sequencing has brought ethical and psychological concerns to geneticists and psychoanalysts regarding the potential advantages and disadvantages of communicating unexpected mutations / variants not related to the specific patient disorder and / or of an uncertain prognosis.

OBJECTIVE

To question whether it is reasonable to impose to geneticists the responsibility to inform to people seeking a specific diagnosis incidental unrelated findings potentially associated to increased genetic risks.

METHODS

Directed and opened questions.

SUBJECTS

POPULATION



Aged from 17 to 25	114	55%
Aged from 26 to 45	46	22%
Aged from 46 to 65	47	22%
Aged over 66	1	1%

POPULATION'S EDUCATION

Uneducated	6	3%
High school studies	88	42%
Undergraduate studies	68	33%
Post-graduation studies	46	22%

EXPERTISE

General public	127	61%
Medical area	65	31%
Affected patients	16	8%

RESULT

YES - 85% replied they wanted to be informed

Ex. of statements:

- Although it's hard to know the truth, one cannot get rid from life.
- It's important to know what happens in one's own body.
- My chances of treatment will increase and I'll be able to cope with possible limitations.

YES
85%



NO
15%

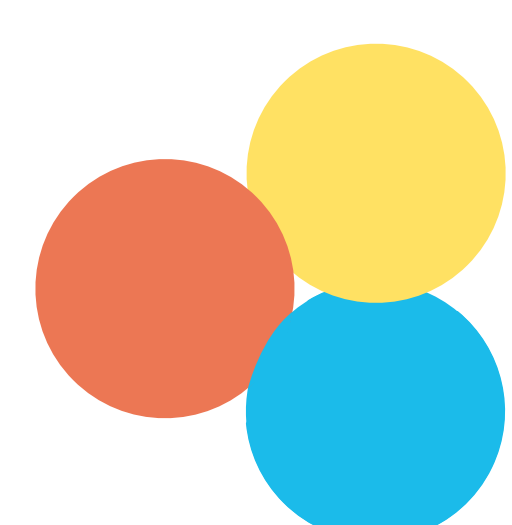
NO - 15% replied they did not want to be informed

Ex. of arguments:

- A diagnosis is not definitive.
- There is no guarantee that a person will develop a disease.
- If there's no treatment, there's no reason to be informed. Life will go on the same way.
- I'd like to live without the anxiety of knowing I will soon be dead.

CONCLUSION

For people that declare they would like to know about incidental findings, the first question for the genetic counseling team is to ensure they understand correctly what is the meaning of these findings. Then, the next questions are when, how and who should deliver such information.



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