

PROFESSIONAL AND FAMILY ATTITUDES REGARDING LARGE SCALE GENETIC INFORMATION GENERATED THROUGH NEXT GENERATION SEQUENCING IN RESEARCH

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OUTLINE

▶ Introduction

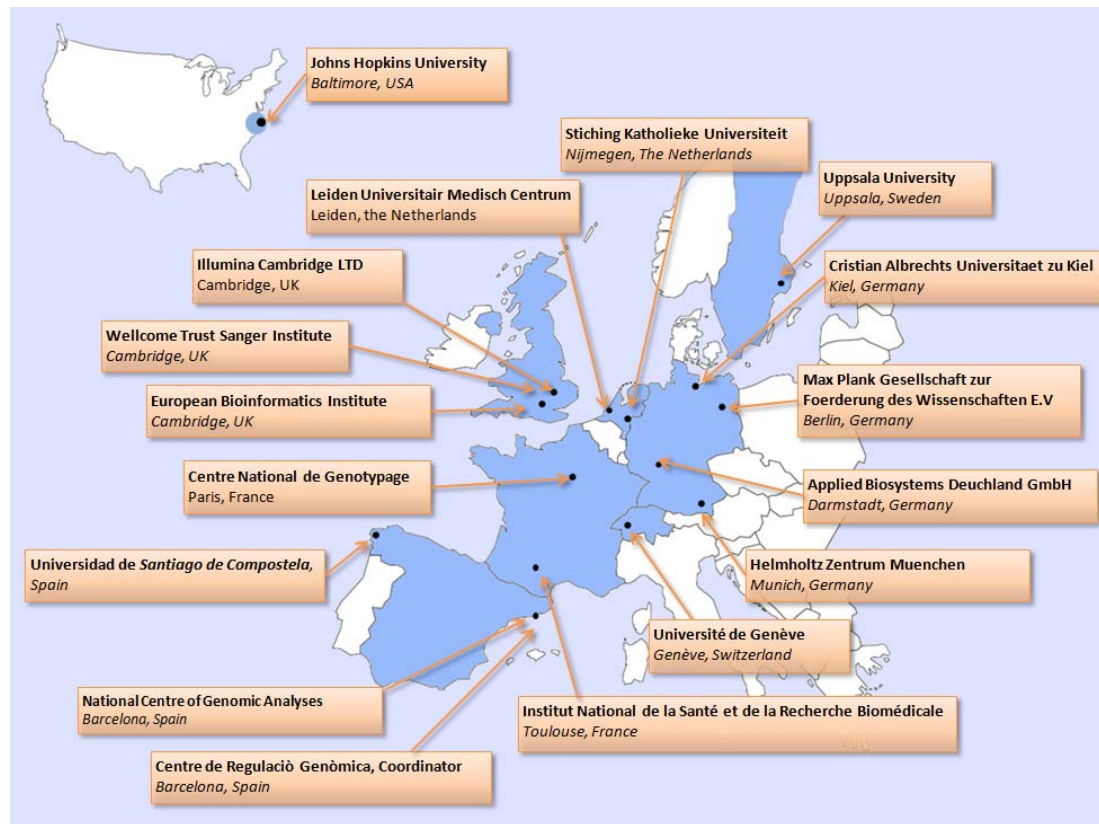
1. GEUVADIS: The big project's little story
2. Our study: 2 objectives, 2 approaches
3. Main findings
4. Involving scientists in an ethical reflection
5. Suggestion for future research

▶ Conclusion

INTRODUCTION



- ▶ Speaker
- ▶ The GEUVADIS project



GEUVADIS

Genetic European Variation
in Disease

*Sharing capacity across
Europe in high-throughput
sequencing technology to
explore genetic variation in
health and disease*

Funded by: EC - FP7

Scheme: Coordination Action

start date: 1st October 2010

Duration: 3 years

Coordinator: X. Estivill

Center for Genomic
Regulation, Barcelona

1. THE BIG PROJECT'S LITTLE STORY



WP1: Communication and Coordination

WP2: Quality control of sequence data

WP3: Data storage, access and exchange

WP4: RNA Sequencing

WP5: Medical sequencing

WP6: Ethical, Legal and Social Issues

WP7: Dissemination and training

2. OUR STUDY: 2 OBJECTIVES

- ▶ A space for discussion
 - ▶ *Team members*
 - ▶ *Individuals*
 - ▶ *Family members*
- ▶ An exploration
 - ▶ *Attitudes*
 - ▶ *Opinions*



2. OUR STUDY: 2 COMPLEMENTARY APPROACHES

- ▶ **Group discussion**
 - ▶ *TOTAL: 5 discussions, 82 participants*
 - ▶ *2 hours*
 - ▶ *Script distributed*
 - ▶ *Leaders send feedback*
- ▶ **Individual questionnaires**
 - ▶ *TOTAL: 79 questionnaires*
 - ▶ *Anonymity possible*
 - ▶ *Demographics*
 - ▶ *Same sections as discussion*
 - ▶ *Mix open/closed questions*



Discussion Indicative Outline ***Am I fine with having my genome sequenced and put in a database?***

The aim of this discussion is to get the participants' personal opinion on the question raised.

The discussion organiser/chair should provide as little input as possible, and let the discussion be shaped by the participants. The timeline shown below is **indicative**.

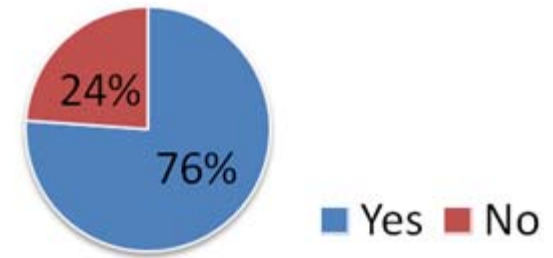
In the personal/familial context, bear in mind that the participants might ask you many questions and shape their opinion according to your answers, which would lower the relevance of the discussion results. Try to avoid the debate to derive on technical issues, and keep the focus on the participants opinion on the **consequences of genomic sequencing**. Generic answers like "By studying the genetics of a specific disease, a research team can draw important conclusions that will have an impact on the general interest and on public health" can be a way to keep the focus right. Recording the discussion might be a good way to give a more detailed feedback.

	Themes to discuss	Actions from Moderator	Indicative Timeline
	General introduction: why are we here? Geuvadis, WP6 (5 mins). Aim of the discussion: get personal views, as detailed and argued as possible. 2nd part: Questionnaire.	Scheme in p2: to draw at this moment or to distribute after the discussion.	10min
	If relevant: Rapid tour de table: Name, lab, research subject and position		10min
	All ideas, word that come to your mind when thinking of ethical issues of research including whole genome sequencing	Write words on board and split between 4 categories: source of samples, type of consent, privacy, return of results	5min
1	Sources of samples: anyone, only in medical context, in the general population, children, developing countries...	Identify agreements/disagreements	10min
2	Type of consent: Very general, very detailed, what exact details, duration and scope of studies, what teams, private/public funds, academic/industrial, National/European/International teams	Identify agreements/disagreements	10min
3	Privacy: Who should have access to our information data, links biological/ID data, recontact patients for more data, what type of anonymity	Identify agreements/disagreements	10min
4	Return of results: Be informed about medical outcomes, person/his family, about the general results of the study	Identify agreements/disagreements	10min
	Other questions, debates	Identify agreements/disagreements	5min
	Questionnaire		20 min
7	TOTAL		1h30

3. MAIN FINDINGS

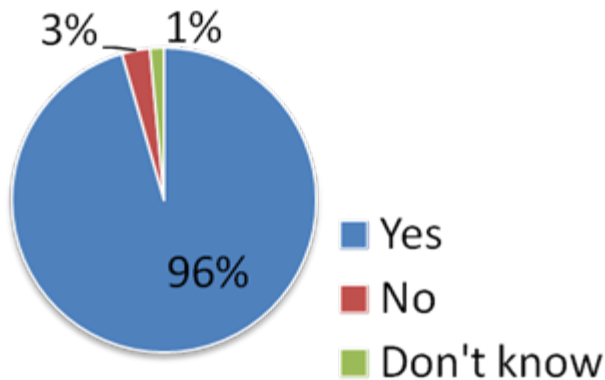
(1)

- ▶ Would you accept the sequencing of your genome ?

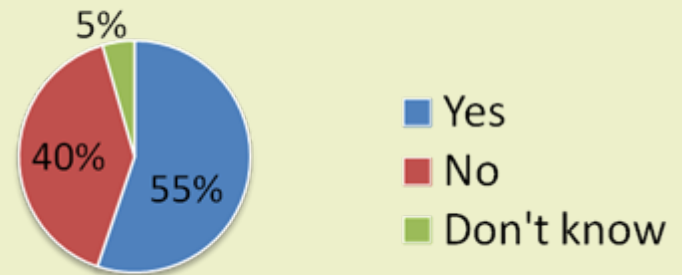


- ▶ Involvement of the family

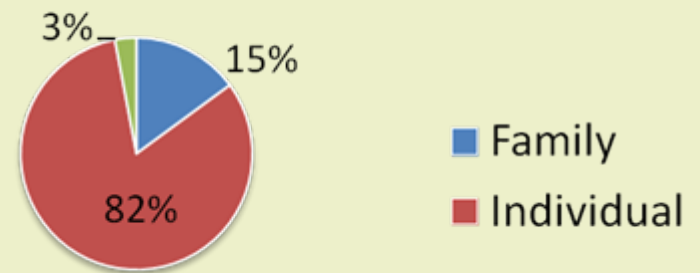
- ▶ Right to withdraw



Should I consult my family?



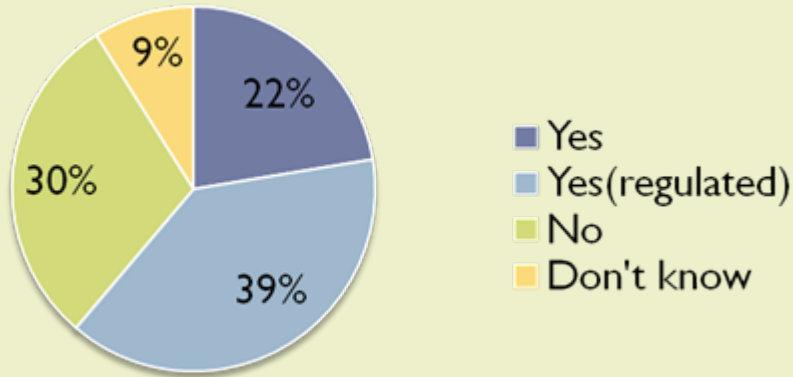
Family or individual decision?



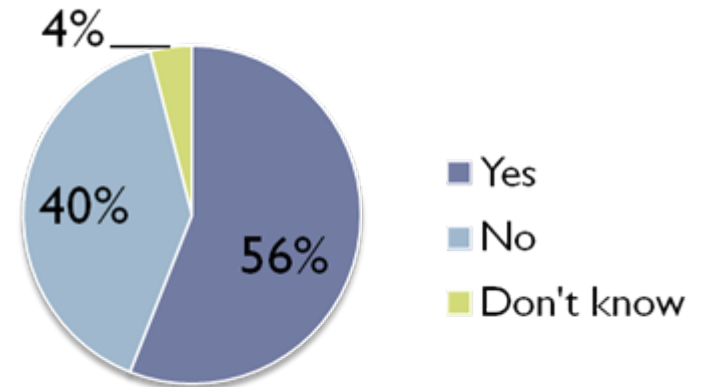
3. MAIN FINDINGS

(2)

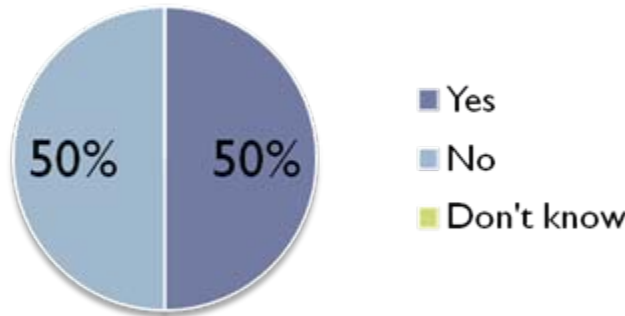
Should genetic testing via the internet be allowed, and if yes, should it be regulated by law?



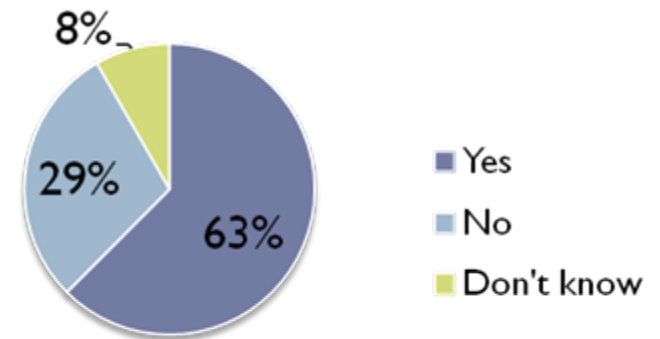
Should my sequence be considered as identifying information?



Female respondents



Male respondents



INVOLVING SCIENTISTS IN AN ETHICAL REFLECTION

- ▶ 1. Labs participation in the discussions was a success
 - ▶ Animated debates
 - ▶ Motivated and opinionated groups
 - ▶ High questionnaires response rate
- ▶ 2. Failure in reaching researchers families
 - ▶ Only 2 familial discussions, few questionnaire
 - ▶ Reasons why:
 - ▶ Time
 - ▶ Topic
 - ▶ Other

SUGGESTIONS FOR FUTURE RESEARCH

- ▶ Potential extension of the research to other projects



- ▶ What would we change?

- ▶ Familial dimension: objectives and reality
- ▶ Discussion groups
- ▶ Questionnaires

CONCLUSION

- ▶ A space for discussion of topics of interest for society
- ▶ Preparation of researchers for public debates
- ▶ A novel practice of ELSI in European projects

- ▶ Any suggestion ... ?

ACKNOWLEDGEMENTS



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- ▶ *Xavier Estivill*
- ▶ *Rodric Guigó*
- ▶ *Their labs*



Genetic European Variation
in health and Disease
GA. N* 261123



Cancer Genomics of the Kidney
GA. N* 241669



European Sequencing and
Genotyping infrastructure
GA N* 262055.

