Genetic testing and 'biosociality' revisited

Comparing attitudes towards genetic testing between 2002-2010

Eric Vermeulen
Lidewij Henneman, Carla G. van El, Martina C. Cornel

Netherlands Cancer Institute/Antoni van Leeuwenhoek Hospital
VU University Medical Center
Amsterdam

VU medisch centrum

Society & GENOMICS
Centre for Society and Genomics

EMGO+
Institute for Health and Care Research

Introduction

Increasing attention-availability of genetic tests

Prevention – health inequalities

Cross-sectional questionnaire survey of a representative consumer panel

Goals: Experiences with, expectations of and attitudes towards genetic testing.

Changes since 2002?

Social lives of genes

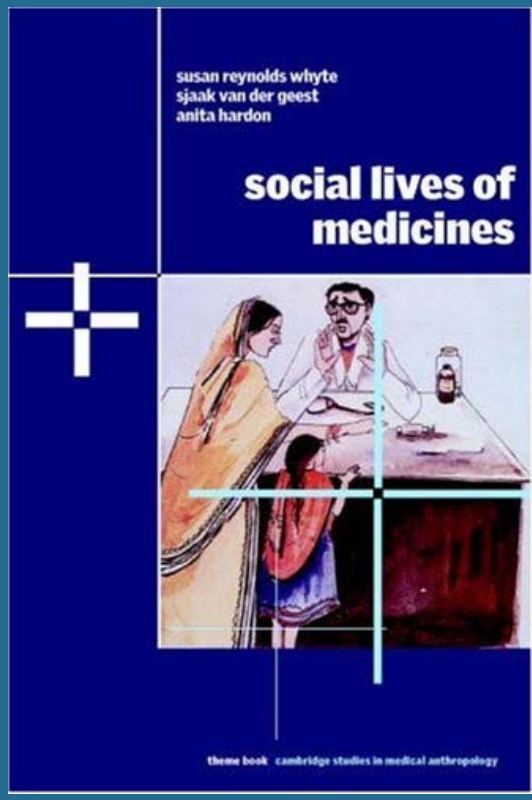
‘Production’, ‘research’, ‘marketing’

(Everett 2003: The social **life** of genes)

Perspectives on genetic tests

‘*Biosociality*’

Biology is no longer ‘blind destiny’ but subject to the personal responsibility.



Capable and inclined to consider genetic factors for disease?

Other attitude towards risk?

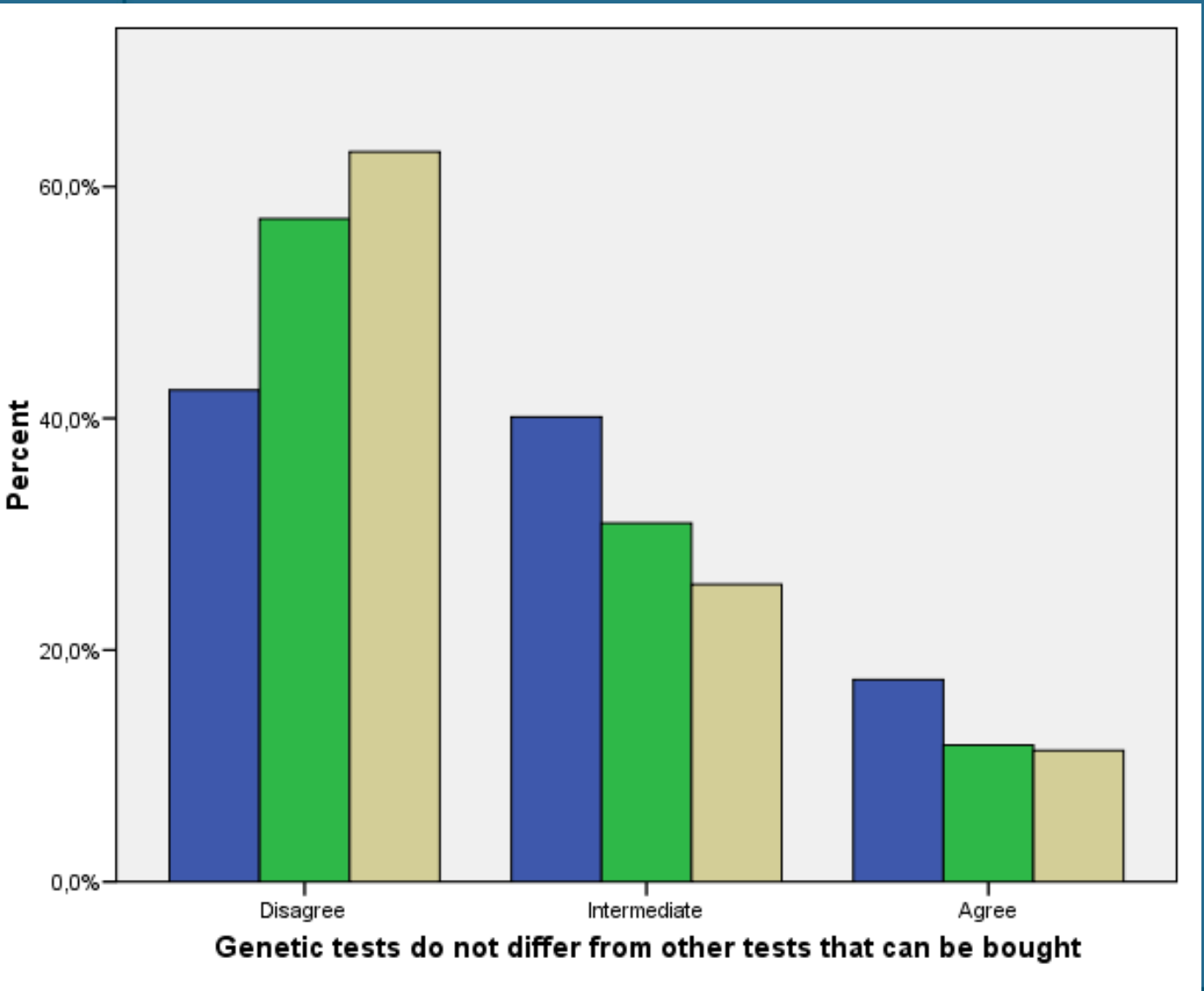
Method

Respons 70% (964/1385)

	Respondents (2010) n = 964		Respondents (2002) n = 811 *	
	%	n	%	n
Gender, female	57	546	57	346
Age				
20-39 years	9	82	20	165
40-64 years	56	539	52	423
≥ 65 years	36	343	28	223
Level of education				
Low	19	179	44	352
Medium	49	459	34	275
High	33	307	22	179

* Henneman et al. *Public attitudes towards genetic testing*. Community Genetics 2004
Henneman et al. *Public experiences, knowledge and expectations about medical genetics*. Genetic Testing 2006

Genetic tests are different….



Blue:
Low educational level

Green:
Intermediate

Grey:
High educational level

2010 Questionnaire

Common to test - educational level *
- experience test *

Expectations (health) - educational level *

Negative consequences and educational level
- Dichotomy *
- Insurers demand genetic testing *
- Employers demand genetic testing *

Interest in specific tests (CVD, Cancer, Alzheimer, Diabetes)
Lower educational level > high educational level

Availability of genetic tests:
- In health care
- Preventable and curable

Experiences and expectations

	2002 %	2002 n	2010 %	2010 n
Has heard about genetic testing	**60**	461	**55**	528
Is familiar with a genetic test	**8**	67	**10**	96
Is familiar with a genetic test for themselves	**52**	35	**58**	56

Constant: 'To prevent disease I would want to know my risk of getting diseases'

	2002	2010
Knowledge about the genetic background of disease will help people to live longer		*
(Completely) disagree	20	12
Not agree / not disagree	37	24
(Completely) agree	**43**	**64**
I am curious about my genetic make-up		*
(Completely) disagree	36	31
Not agree / not disagree	30	26
(Completely) agree	**34**	**44**
The use of genetic tests among people should be promoted		*
(Completely) disagree	44	37
Not agree / not disagree	45	38
(Completely) agree	**11**	**26**

Expectations

	2002 %	2010 %
It will become common to have a genetic test		*
(Very) unlikely	19	18
Not unlikely / not likely	36	25
(Very) likely	**45**	**57**
There will be a dichotomy in society: 'good' and 'bad' predispositions		*
(Very) unlikely	44	34
Not unlikely / not likely	36	28
(Very) likely	**20**	**38**
Insurance companies will ask for a genetic test (height of premium)		*
(Very) unlikely	29	40
Not unlikely / not likely	29	26
(Very) likely	**42**	**34**
Future employees will have to do a genetic test before they are hired		*
(Very) unlikely	63	56
Not unlikely / not likely	24	23
(Very) likely	**13**	**21**

Summary

Higher educated respondents expect more advantages
Lower educated respondents more interested in specific tests

2002-2010
Constant: experience with genetic testing

Increased: expectations of benefits, potential use
impact on society (and worries on inequity)

Decreased: worries genetic testing and health insurance

2010: Different environment

‘Genes’, knowledge. DTC - genetic testing and common/complex disease

Trends in attitudes towards genetic testing

Gaskell et al 2000

Longitudinal studies:
Calsbeek et al 2007: attitudes did not differ much: more genetic knowledge = more reserved attitude towards genetic testing

Singer et al (2008): change in perceptions
More good than harm: 47%-49%-62%

Interpretation

No more interest in knowing about disease risk
More curiosity about genetic make-up:

Interpretation?

Biosociality: emergent phenomenon with increasing importance of genetic factors. ‘Gensociality’?

Different ‘biosocialities’: educational levels

Quantified selves

Different way of dealing with risk?
Individualizing. Knowing your risk as public duty.

Liminality: patients in waiting.

Conclusions

2002-2010

Constant: Experience with genetic testing
Increased: Expectations of benefit to health
Expectations of impact on society

Educational level: worries and benefits

2010

Access unequal as is perception of genetic testing
Genetic tests offered in the context of health care
Directed at preventable and curable diseases

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