

Public perception and
attitudes to biobanks and
biotechnology:
What do we know?
Of impact for REC?

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Overview

- I. Attitudes towards biobanks
- II. Expectations to bio- and gentechnology
- III. A warning
- IV. Four patterns in applied “public” ethics
- V. Three discussions

I. Attitudes towards biobanks

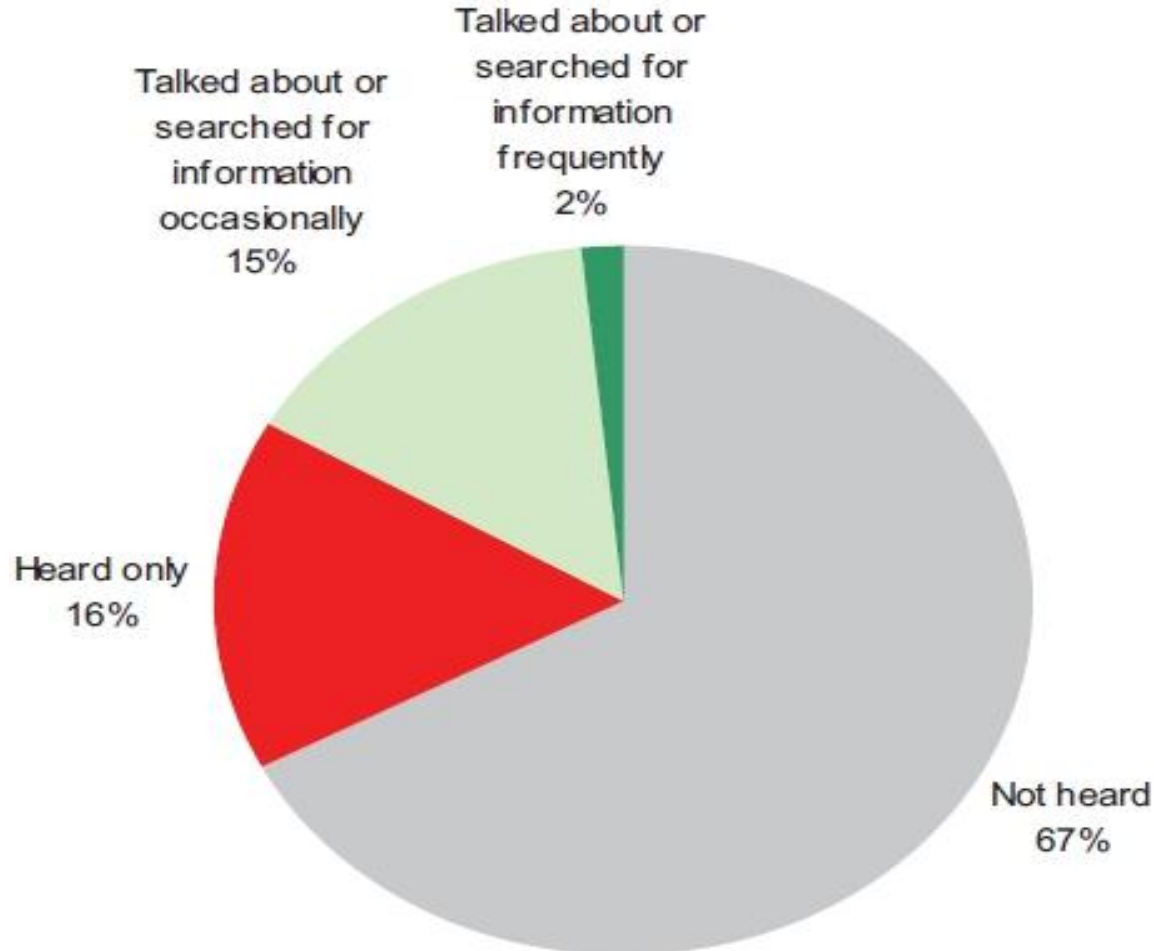
- a. Very low awareness
- b. Low willingness to provide information
- c. Mixed/miscellaneous concern
- d. Demand for specific consent
- e. Strict regulation: external - internal

Data:

- «Biotechnology». Special Eurobarometer 73.1 (2010).
- European Commission: European and Biotechnology in 2010. «Winds of change?»

a. Awareness of biobanks

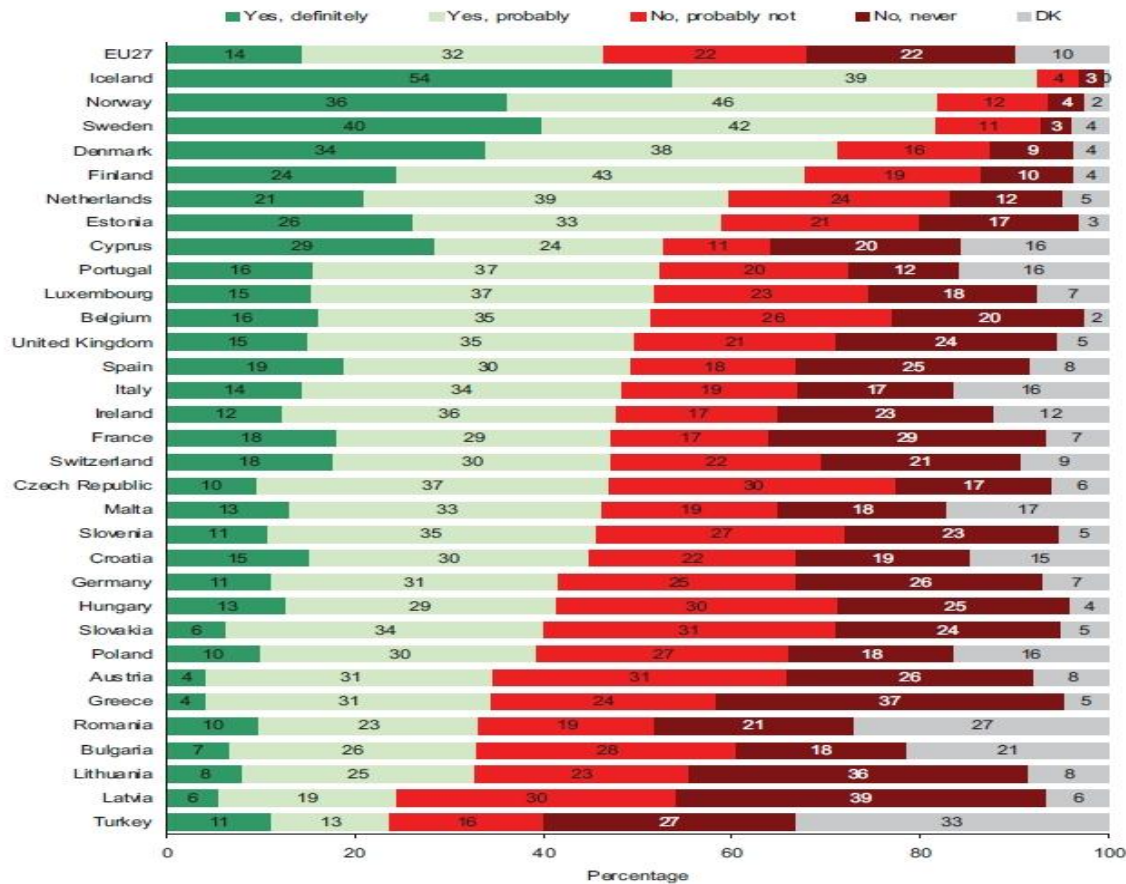
Figure 25: Awareness of biobanks, EU27



Winds of change?: 60

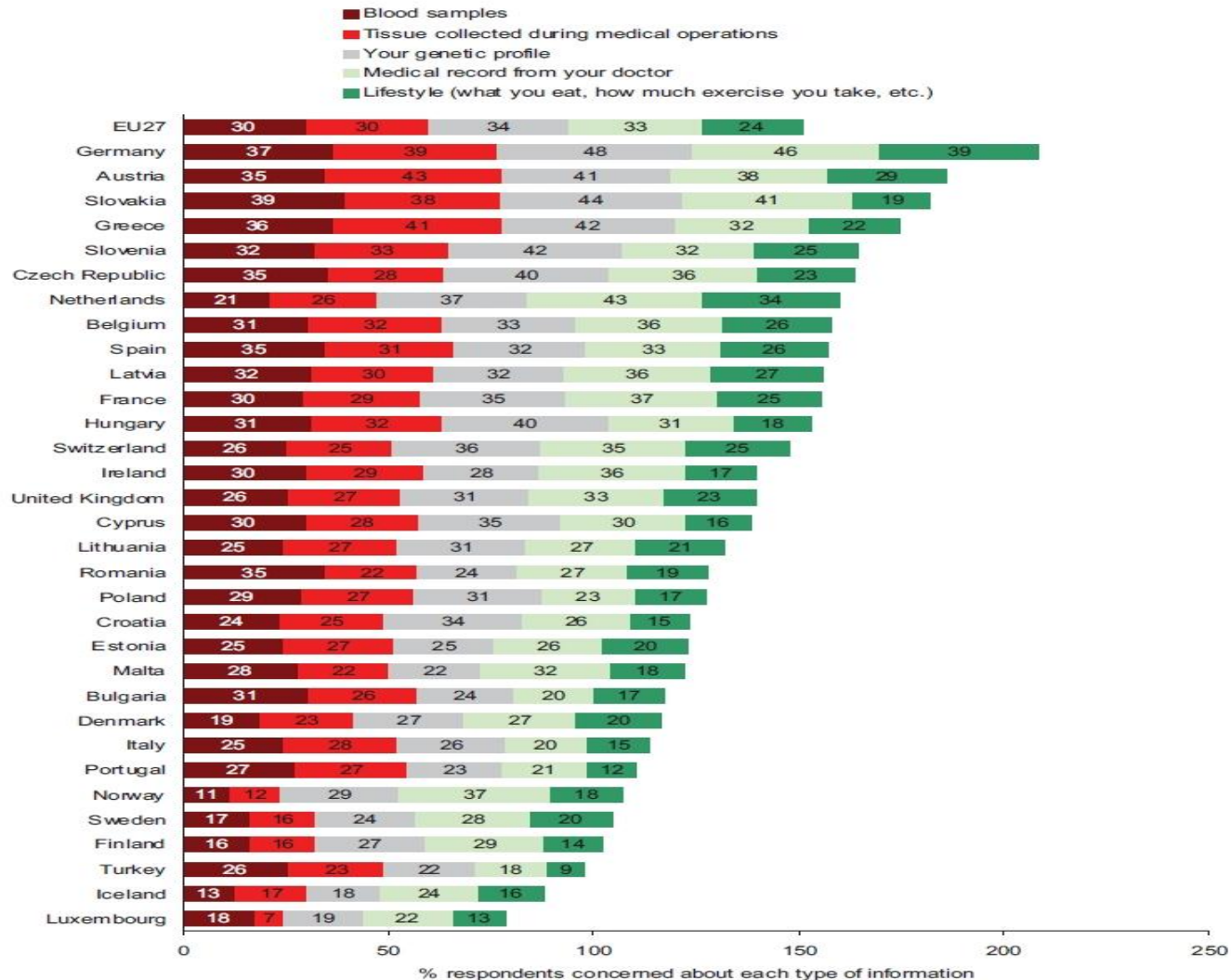
b. Willingness to provide information

Figure 26: Would you be willing to provide information about yourself to a biobank?



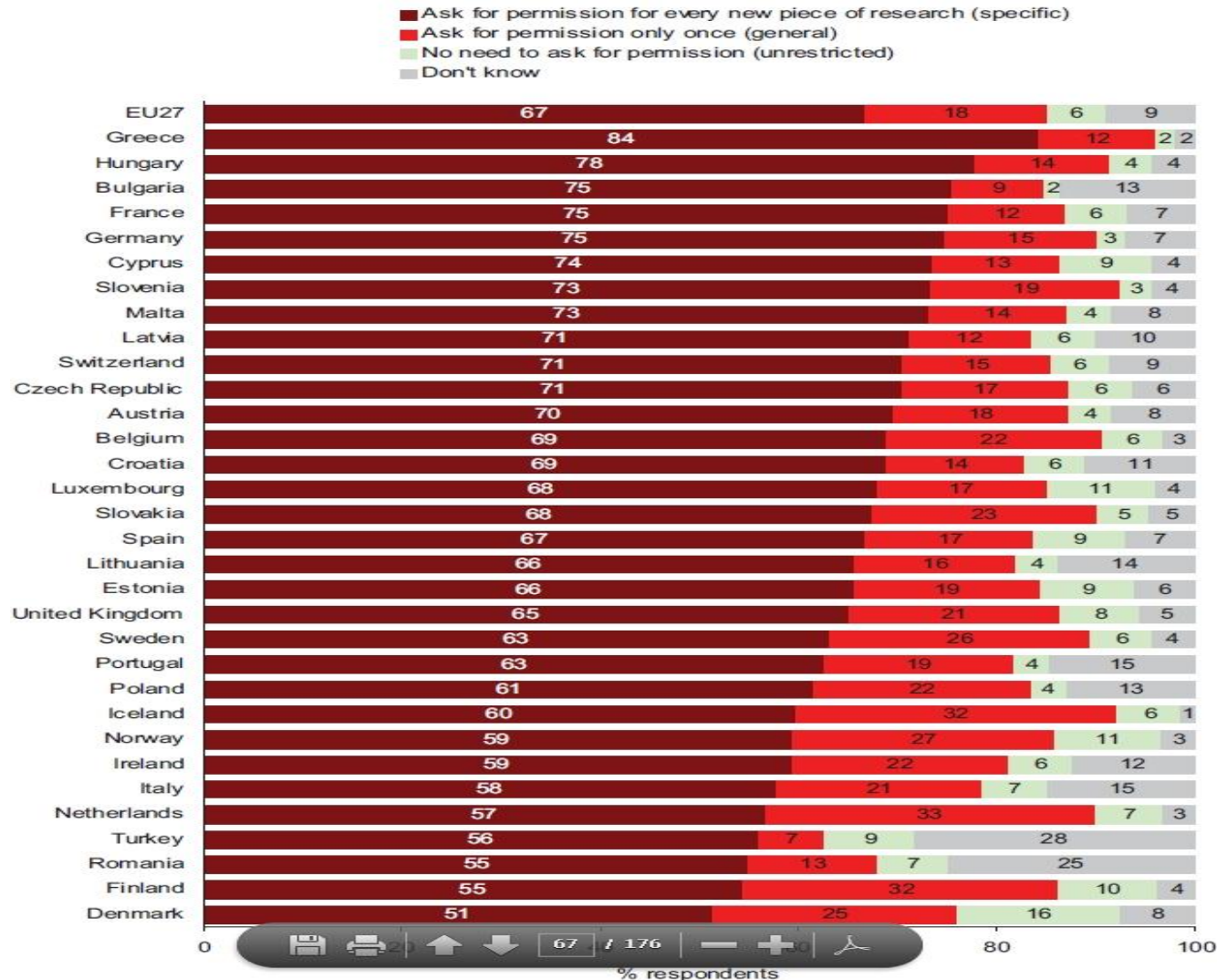
c. Types and level of concern

Figure 27: Levels of concern about giving different types of information to a biobank



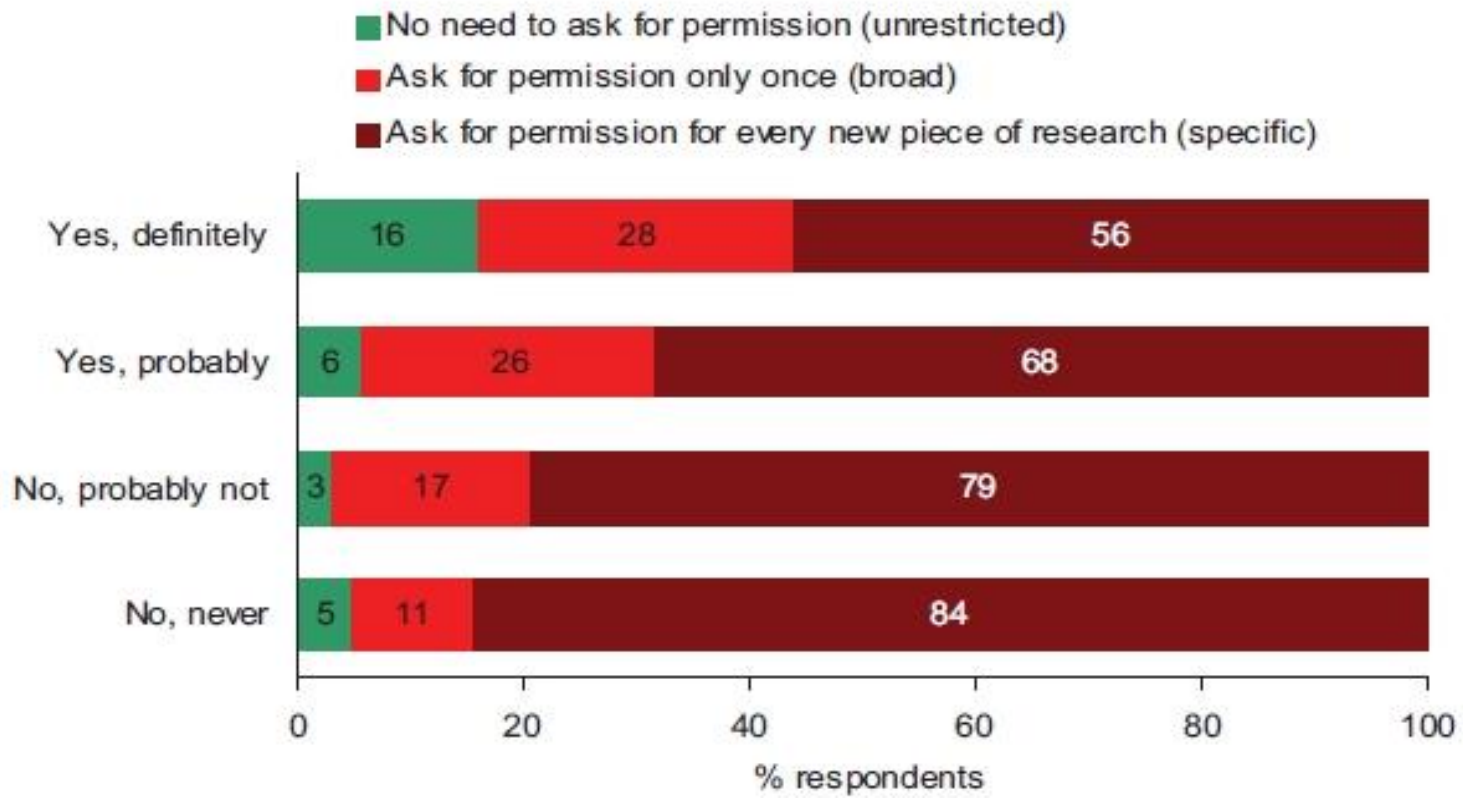
d. Form of consent

Figure 28: Form of consent for biobank research



d. Consent for biobank research

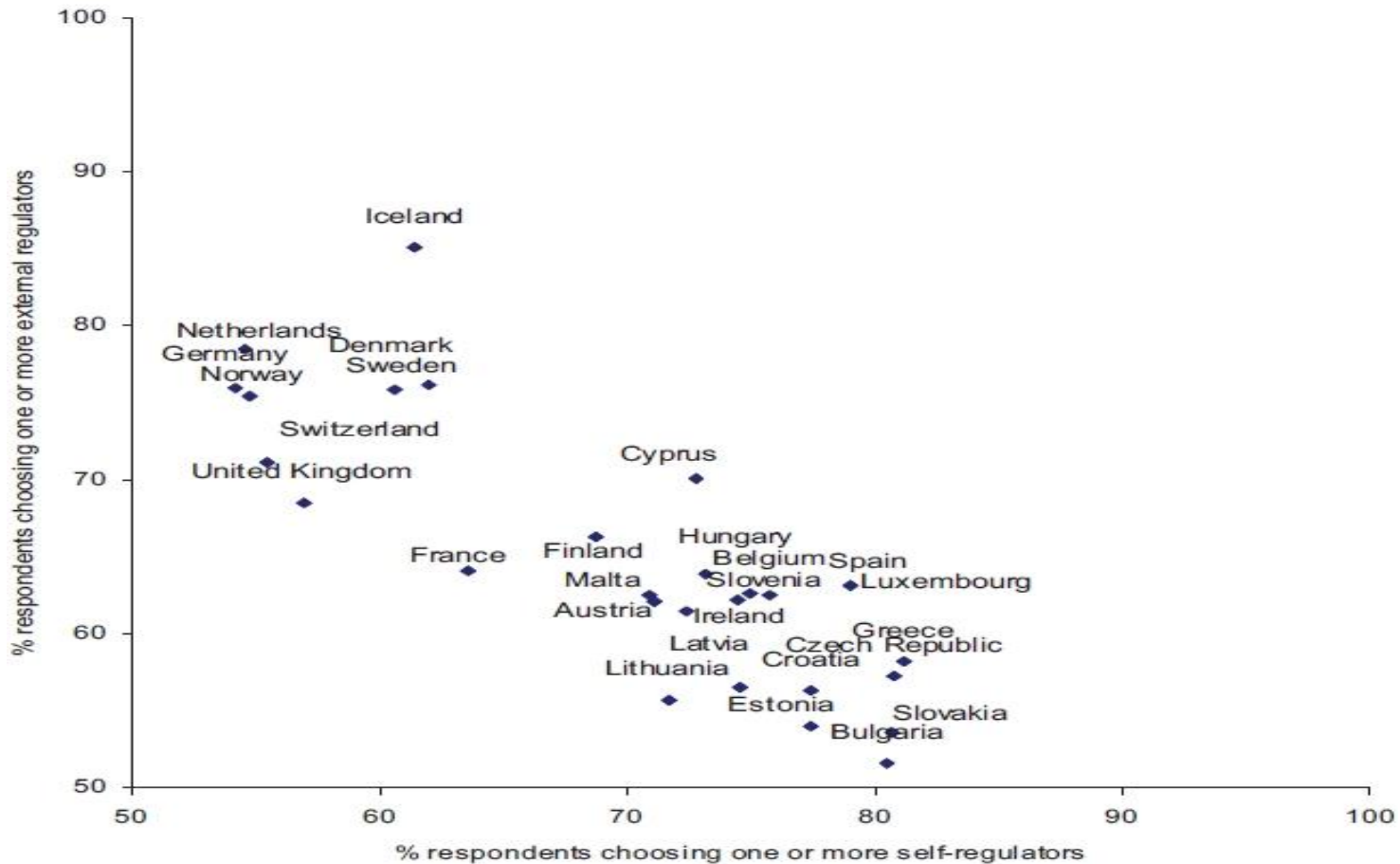
Figure 29: Probability of participation and preferred form of consent (excluding DKs)



Winds of change?: 66

e. Regulation of biobanks

Figure 30: External regulation versus self-regulation of biobanks



Winds of change?: 67

II. Expectations to bio/gentechnology in general

a. Medium among new technologies

b. Time series

- Declining in the 90's
- Increasing in the 00's
- New decline?

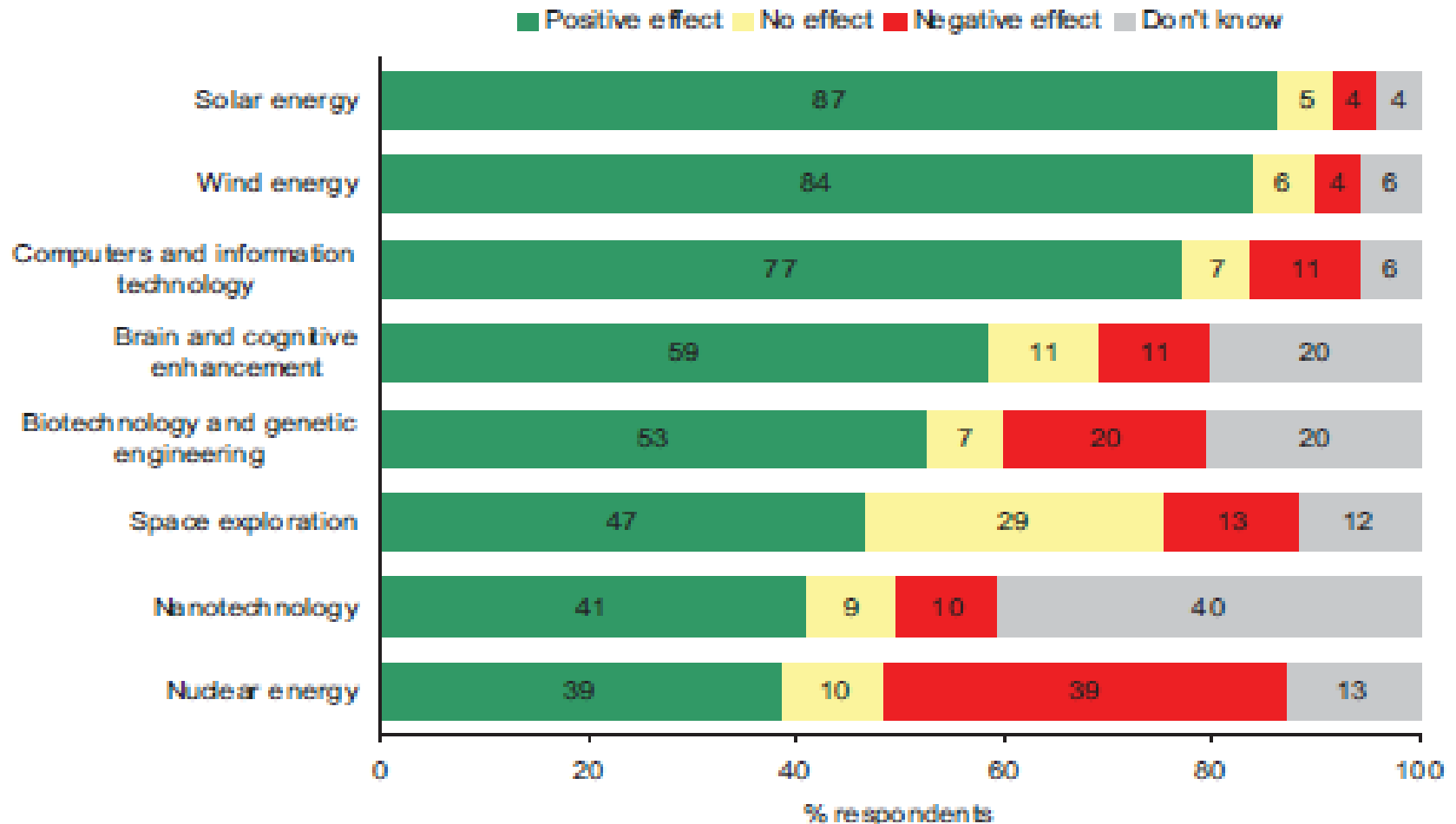
c. High expectations to medical applications, low to food

Data:

Eurobarometer 39.1,
46.1, 52.1, 64.3, 73.1

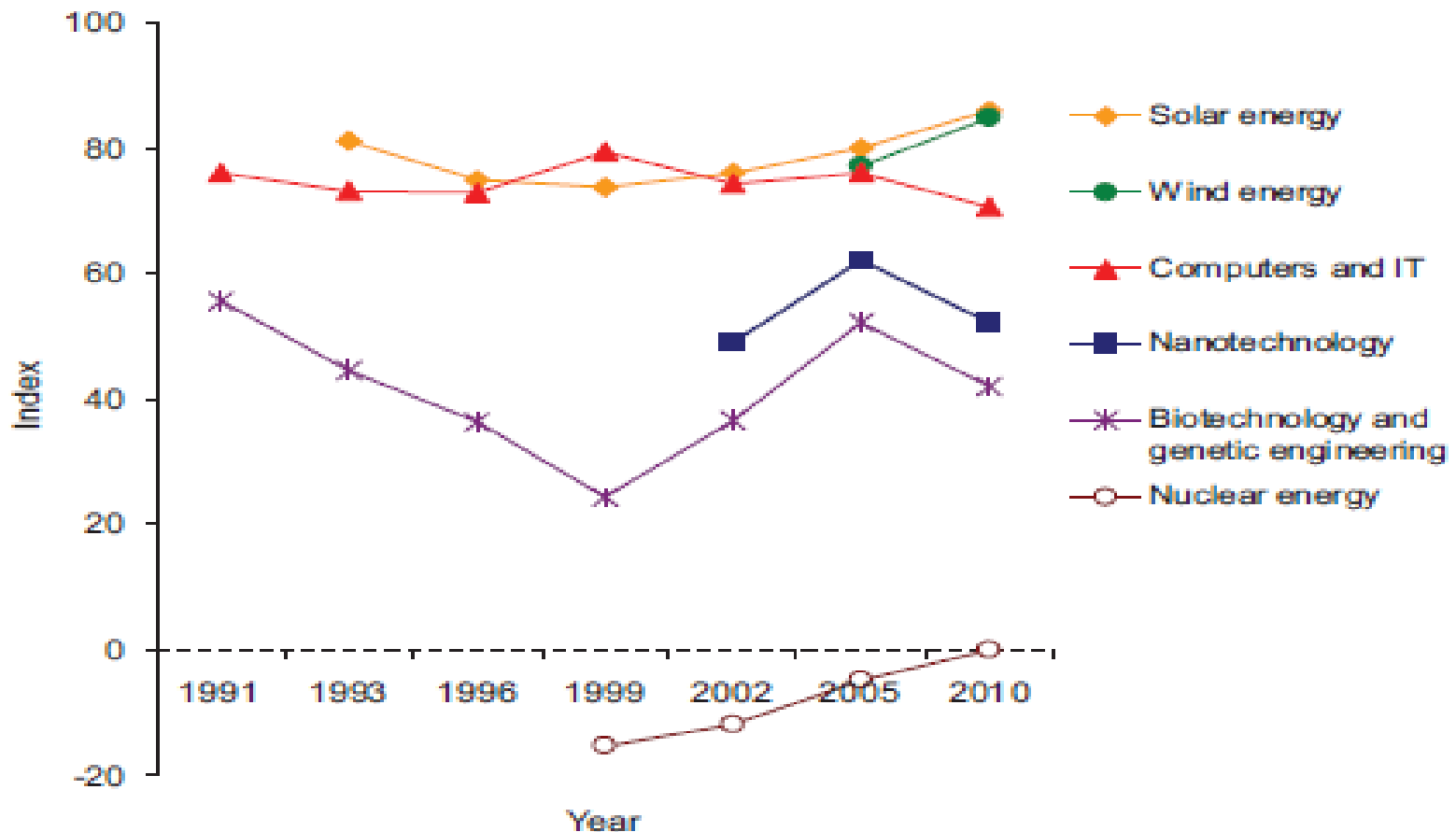
a. Expectations to new Technologies, EU 2010

Figure 2: Optimism and pessimism regarding eight technologies, EU27

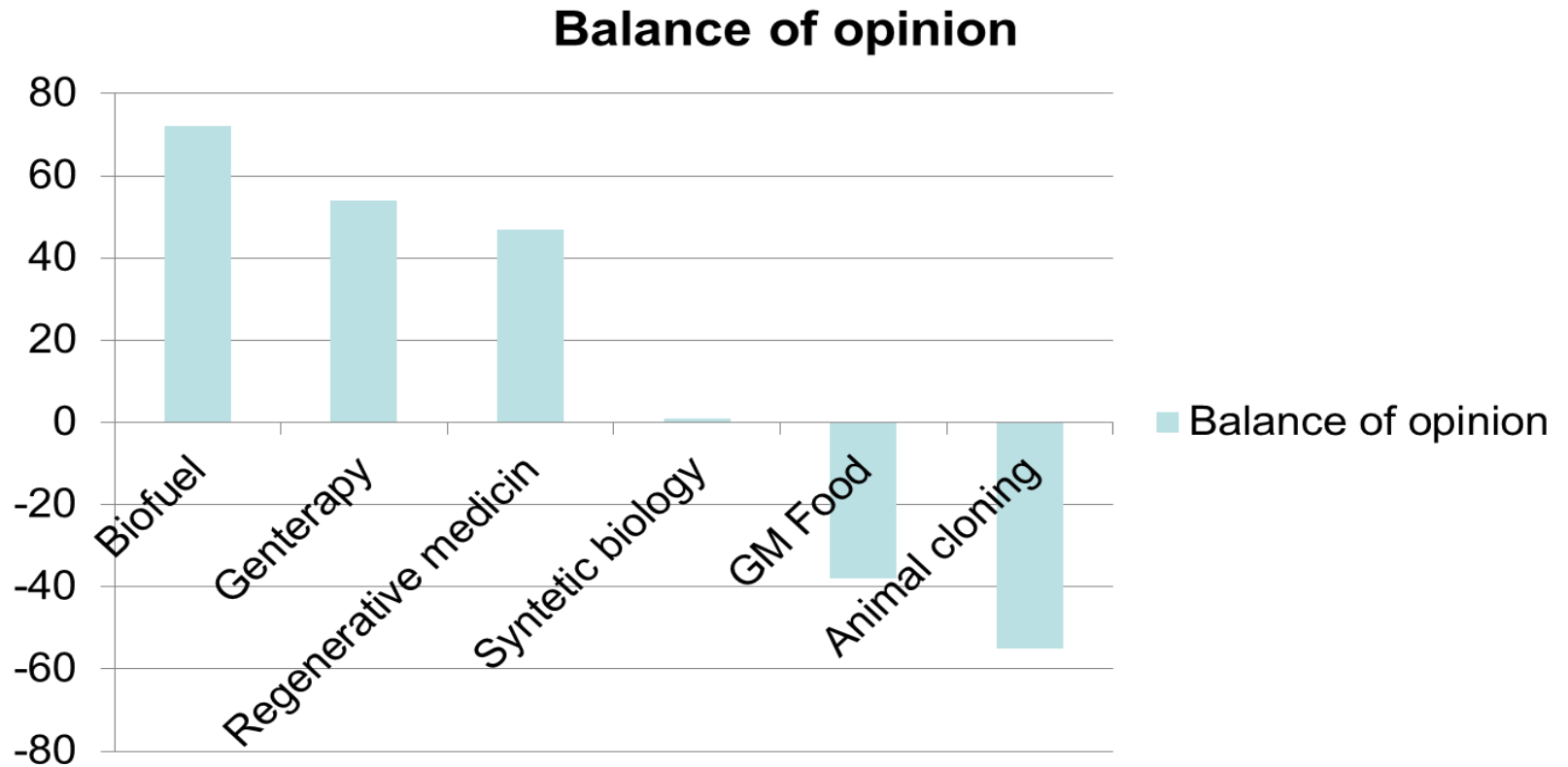


b. Expectations to new Technologies, EU 1991-2010

Figure 3: Index of optimism about six technologies²



c. «Applications» of bio- and gencechnology. EU27, 2010



d. «New» Technologies and Expectations. The Agenda. EU. 1978 & 2010

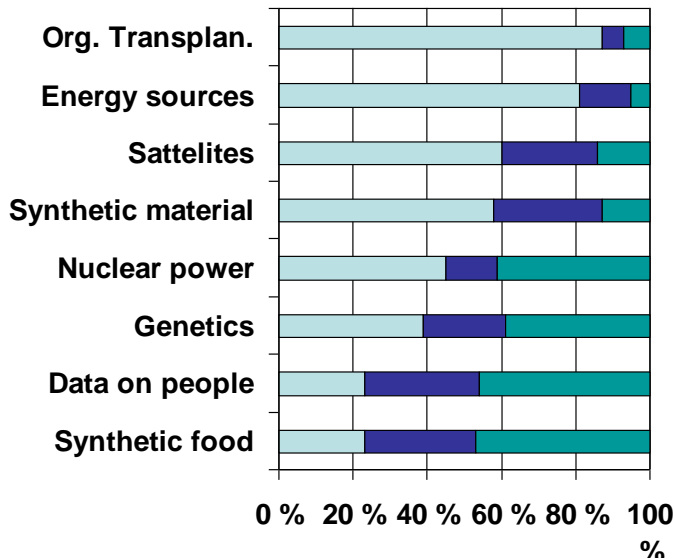
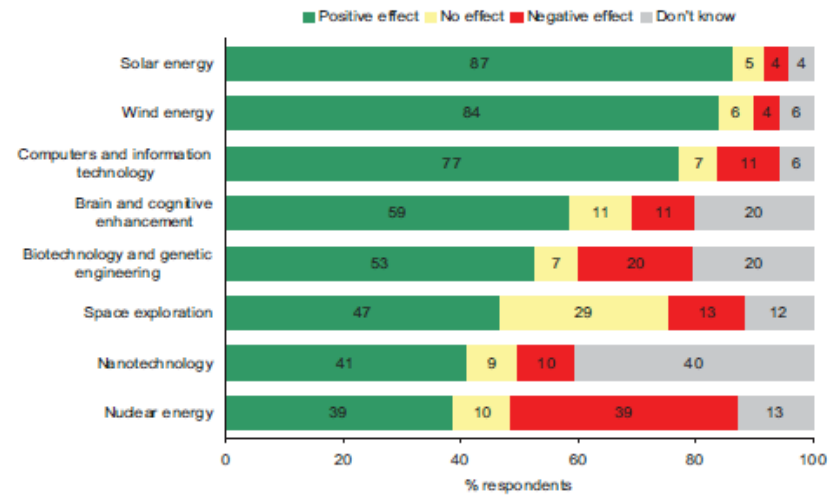
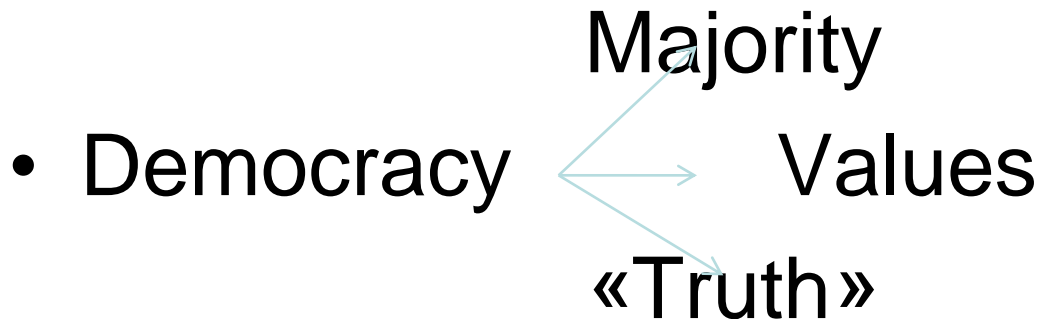


Figure 2: Optimism and pessimism regarding eight technologies, EU27



III. A warning

- Survey as a poor measurement of public opinion
- «Gallup-democracy» and representative democracy

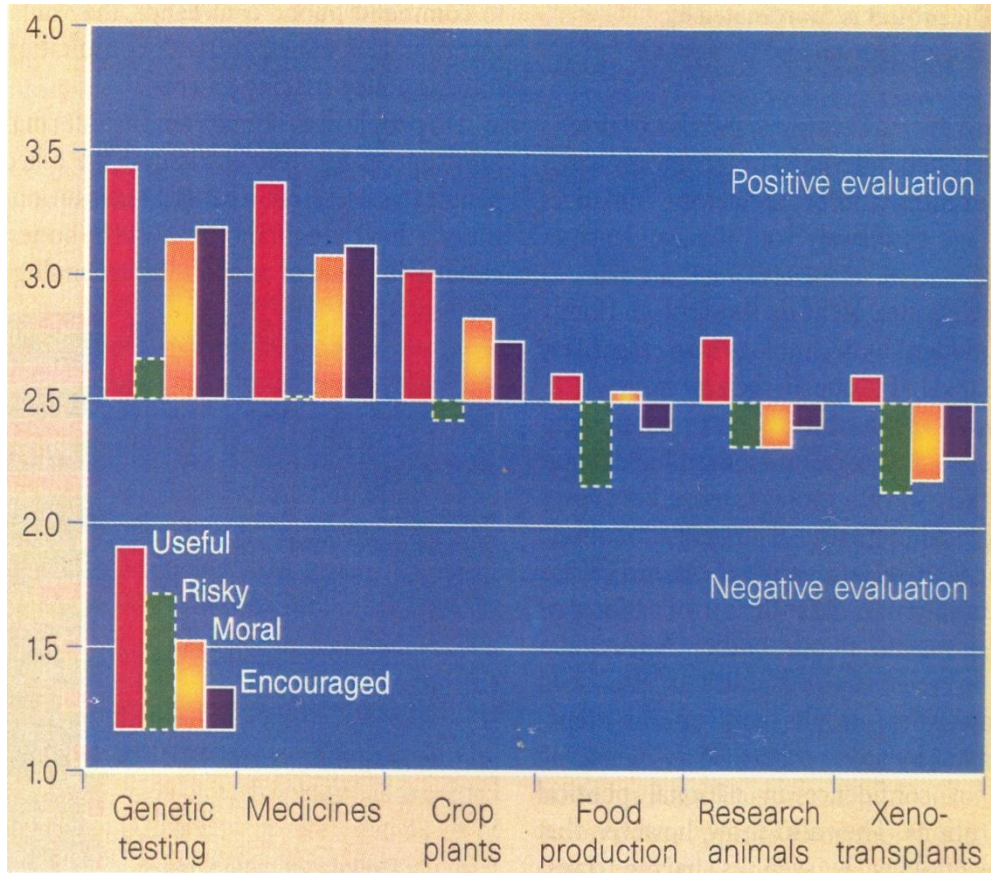


- Is / ought, «the naturalist fallacy»

IV. Four patterns in applied “public” ethics

- a. Ethics as veto
- b. Dignity versus utility
- c. Black and green scepticism
- d. Trust and experts: “evaluating the evaluator”

a. Ethics as veto: Perception of Usefulness, Risk and Ethics as Determinant of Encouragement.



The pattern of results across the six applications in Fig. 1 suggests that perceptions of usefulness, riskiness and moral acceptability could be combined to shape overall support in the following way. First, usefulness is a precondition of support; second, people seem prepared to accept some risk as long as there is a perception of usefulness and no moral concern; but third, and crucially, moral doubts act as a veto irrespective of people's views on use and risk.

b. Dignity and utility

Two ethical / legal principles:

Recital 16: Dignity

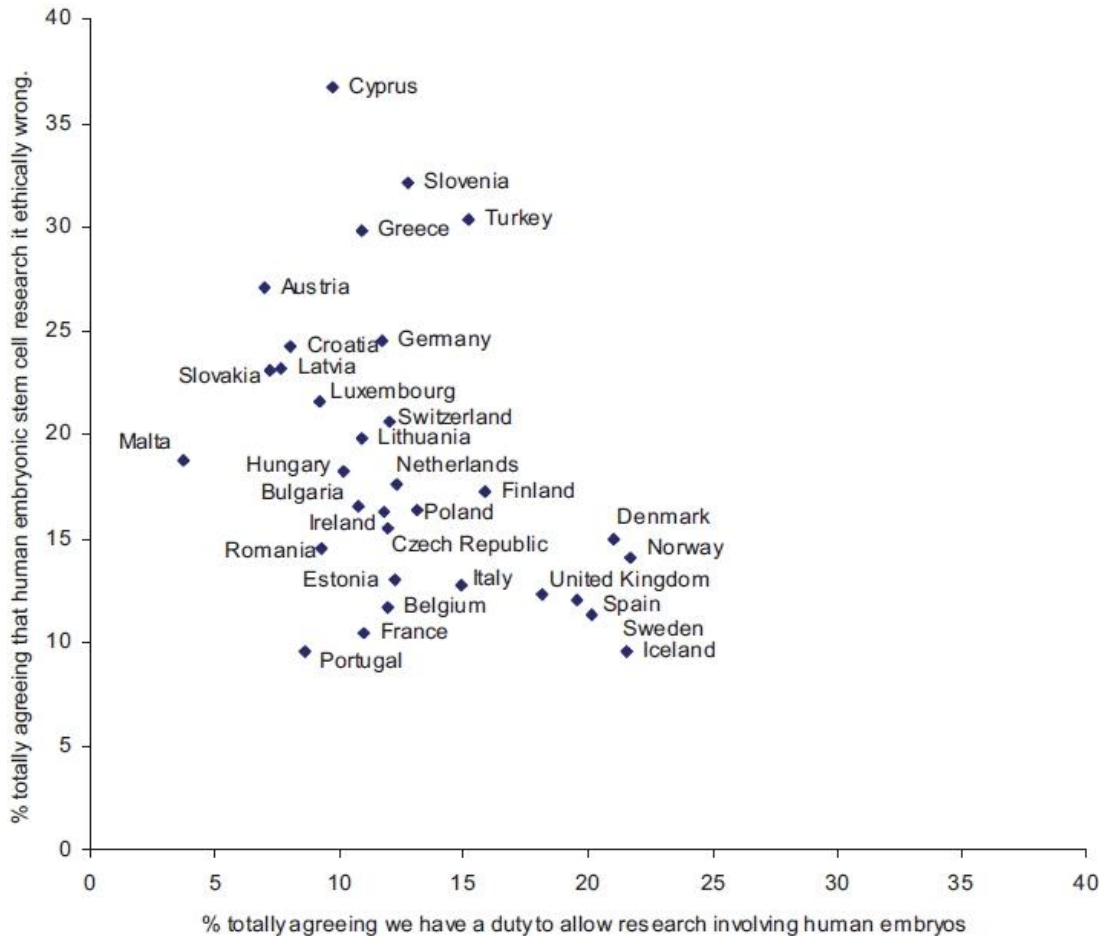
Affirms «fundamental principles safeguarding the dignity and integrity of the person»

Recital 17: Utility

The patent system should encourage the production of medicines «derived from elements isolated from the human body»

b. «Dignity» versus «utility»

Figure 24: Sanctity of human life versus utilitarian positions



«Europe's Ethical Divide».

Gaskell et.al. Nature, Biotechnology. Vol 30, no. 5, may 2012: 392-94.

α

Split or divide?

Within or among nations?

c. The blue and the green scepticisms. The arguments

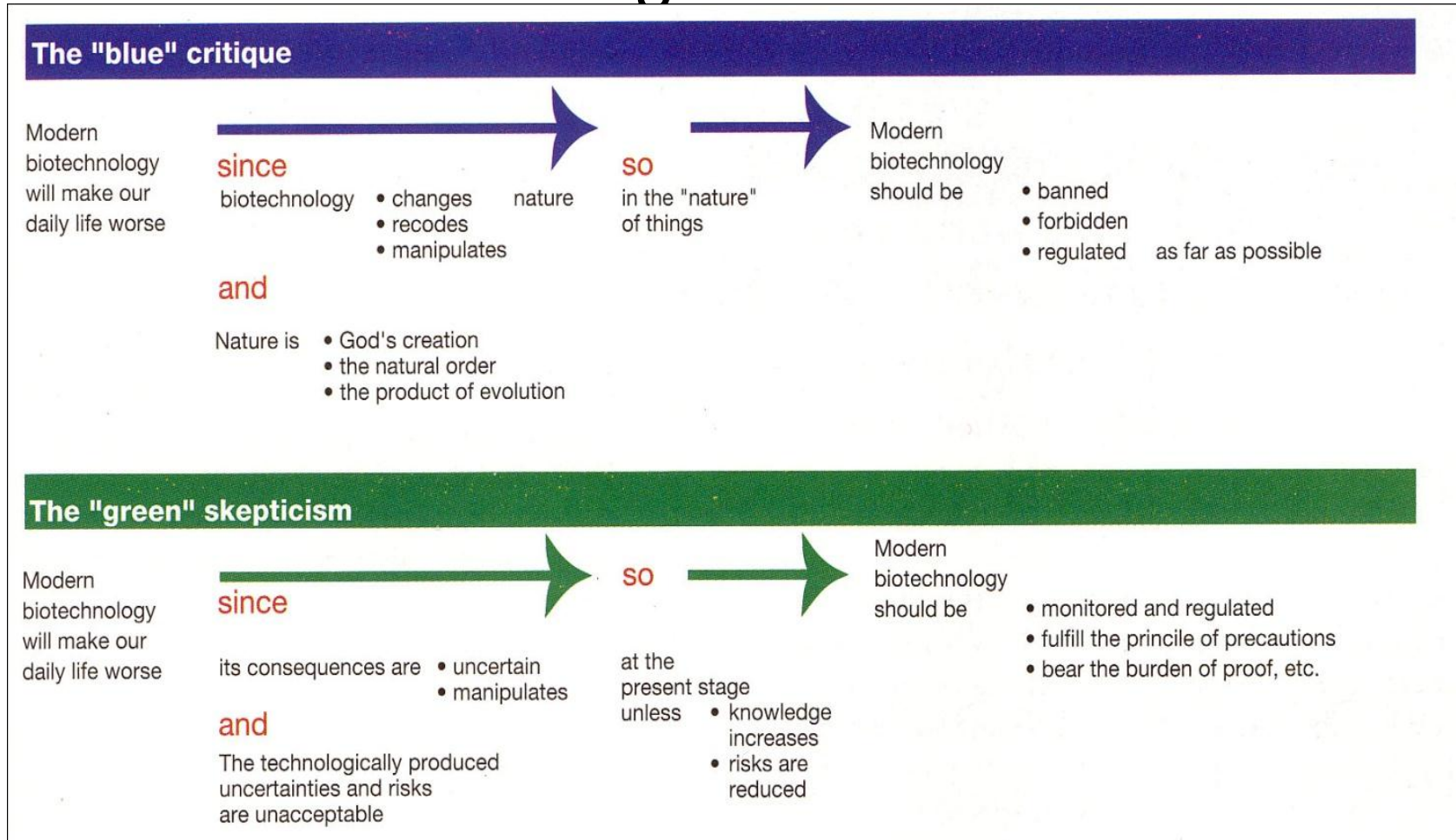


Figure 2. Breaking down the arguments of biotechnology's opponents. The analysis follows Stephen Toulmin's pragmatic T-model^{7,8}.

c. The blue and the green scepticisms. The segments.

Table 1. Profiles of biotechnology optimists, “blues” and “greens” in Norway, 1996*.

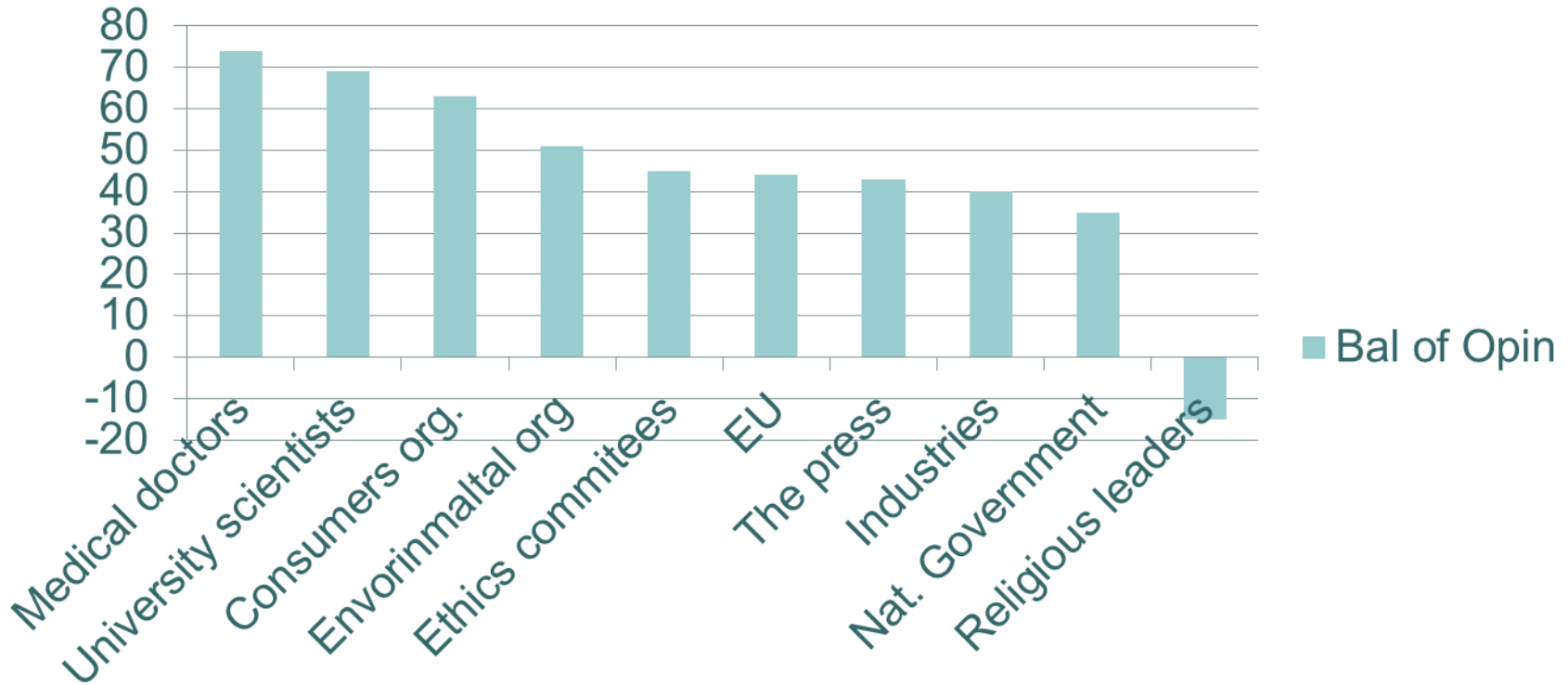
Optimists (n=345)	The pessimists (n=272)	
	The “blue” critique(n=112)	The “green” scepticism (n=160)
Male (11%)	Female (9%)	Female (15%)
15–25 years (18%)	56–91 years (107%)	26–40 years (60%)
Secondary school (20%)	Primary school (16%)	University (27%)
City and town (14%)	Countryside (23%)	
Low perceived risk (10%)	Low perceived risk (15%)	High perceived risk (87%)
High knowledge of biotechnology (28%)	Low knowledge of biotechnology (27%)	High knowledge of biotechnology (49%)
Political right (32%)	Political right (29%)	Political left (53%)
Some religious (9%)	Very religious (54%)	Non-religious (35%)
	Materialist (60%)	Post-materialist (33%)

*Percentage over-representation compared to the total population (n=966) including the “undecided”

d. Trust and experts

«The evaluation of the evaluator»

Bal of Opin





V. Three discussions

- a. Ethics as a bag full
- b. Ethics as / in Law
- c. Autonomy versus pluralism: The state-liberal dilemma

a. Ethics as a bag full

Ethics	Focus	Horizon
Arete / Duty (Aristotle / Kant)	Absolute limits	Religion
Utilitarian (Bentham / Mill)	Cost-benefit	Economy
Discourse (Habermas)	Deliberative democracy, consensus	Politics



b. Ethics as / in Law

„Recht und Moral standen bisher in einem Ergänzungsverhältnis zu Wissenschaft, Technik und Wirtschaft als den Schrittmacher der Modernisierung. Aber welche Seite wird sich an die andere anpassen, wenn bestimmte, durch gentechnische Fortschritte möglich gewordene Praktiken unser Selbstverständnis als moralisch handelnde Personen einmal ein terminieren sollten?



c. Autonomy versus pluralism: The state-liberal dilemma

Freedom

«The only freedom which deserves the name, is that of pursuing our own good in our own way, so long as we do not attempt to deprive others of theirs, or impede their efforts to obtain it»

Society's jurisdiction

«As soon as any part of a person's conduct affects prejudicially the interests of others, society has jurisdiction over it, and the question whether the general welfare will or will not be promoted by interfering with it, becomes open to discussion»