



Democracy of patient advocacy

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Politeia of Plato

Aristocracy

Timocracy

Oligarchy

Democracy

Dictatorship

Athens 400 BC

Politeia of Plato

Aristocracy : the bests

Timocracy : the ambitious ones

Oligarchy : the few (ambitious men)

Democracy : the people

Dictatorship : the one and only

Athens 400 BC

Who are the bests?

Patient – doctor relationship

is in the

PRIVATE DOMAIN





Who are the bests?

Getting all relevant information

Handling all relevant information

Communication between the bests

(relevant is not : available)



Who are the bests?

There is evidence in medicine

but no

evidence based medicine







Goals

Primary:

To design and execute prospective clinical trials for hematological malignancies in the Netherlands and Belgium

Secondary :

To design guidelines and to implement quality programs

Participation

Every of the about 95 hospitals in the Netherlands participates in one of the 9 Integral Cancer Centers (IKC)

10 transplantation centers act as consultants and coordinators within the IKC's



Monitoring

- Site specific monitoring
 - Site evaluation visits
 - Once a year
- Study specific monitoring
 - Initiation visits
 - Follow-up visits
 - Close-out visit

Assessment of Quality

1. Allogeneic transplantation centers: 8 UMC
(JACIE; DoH license)
2. Autological transplantation centers: 5
(JACIE; DoH license)
3. Hematological intensive care centers: 10 ?
(HOVON rules)
4. Outpatient centers: ? of remaining 70 hospitals
(HOVON rules)

Assessment of Quality

The grading of centra in the HOVON organisation is made by only “one of the bests” and only so for participation in clinical trials

but

the “rules” are easily to be supplemented by criteria proposed by the other “the best”

but

such a more complete grading system is a care oriented system and should be presented by both “the bests”



Guidelines are there to bridge the gap between
science / experience
and
individualized medicine

Who are the bests?

Health economy

is in the

PUBLIC DOMAIN









Expenditure

2003 : 63.4 10>9 euro's

2005 : 68.5 10>9 euro's

QALY

infectious diseases : 2000 - 5000

cardiovascular diseases: 2000 - 5000

cancers :16000 – 18000

in euro's

Life expectancy

1950 -2007 : > 7 years

of which in infections, cardiovascularly
and in cancers:

men : 3 years

women : 4.5 years



Increase in life expectancy

Total increase : 7.8 years

Infections 1.4

Cancer 0.6

Cardiovascular 2.0 (22%)

Other than health care : 2.1

Effects in other diseases : 1.7 (78%)



Guidelines are increasingly used in the public domain and , thereby, frozen into solid rules of engagement and financial constraint

Costs or health care economy?

30 % of scientific output from UMC's

Jobs : 1. 10^{>6} people

Gain in life years

Increase in quality of life

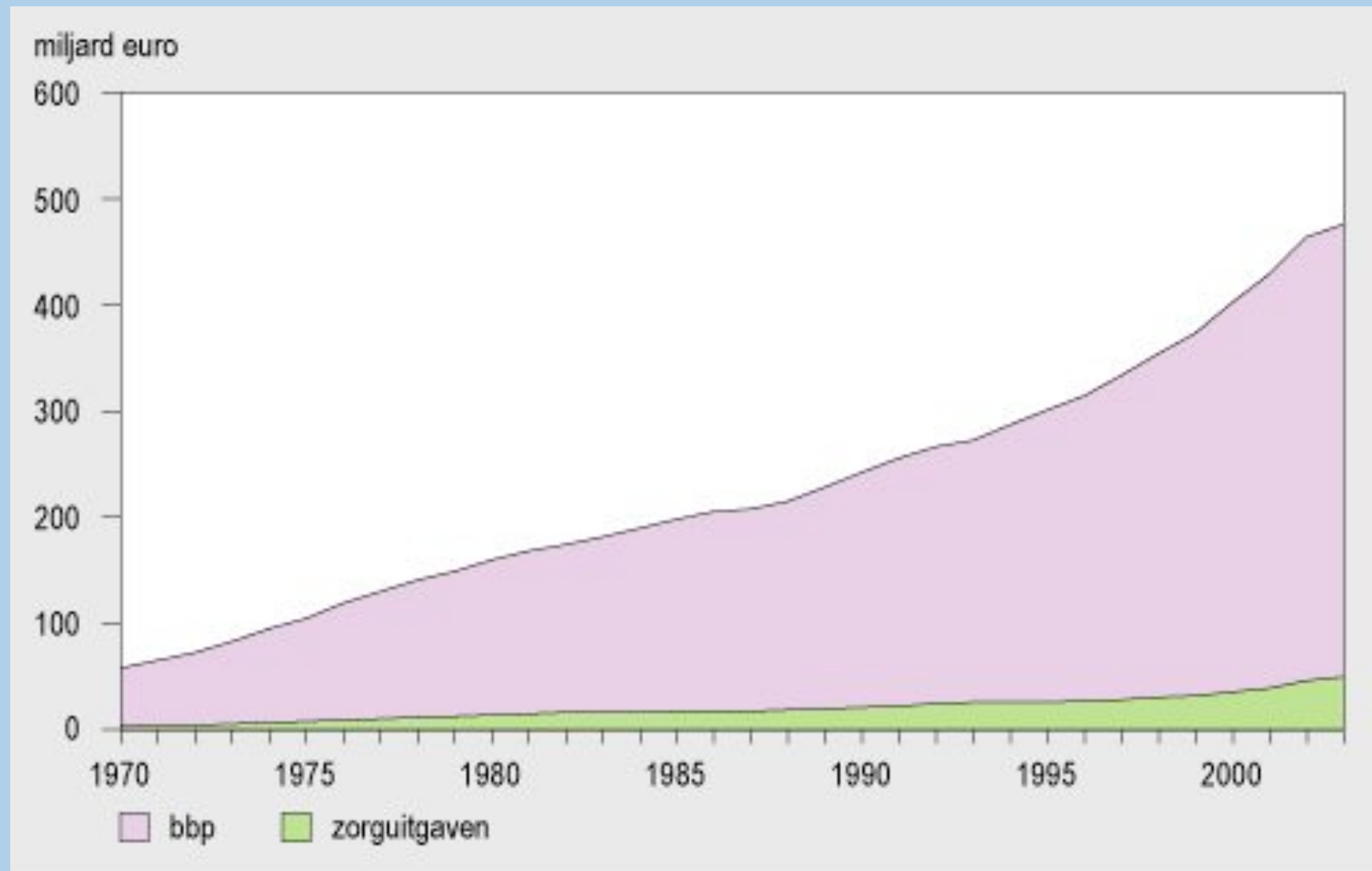


Health care in 2006

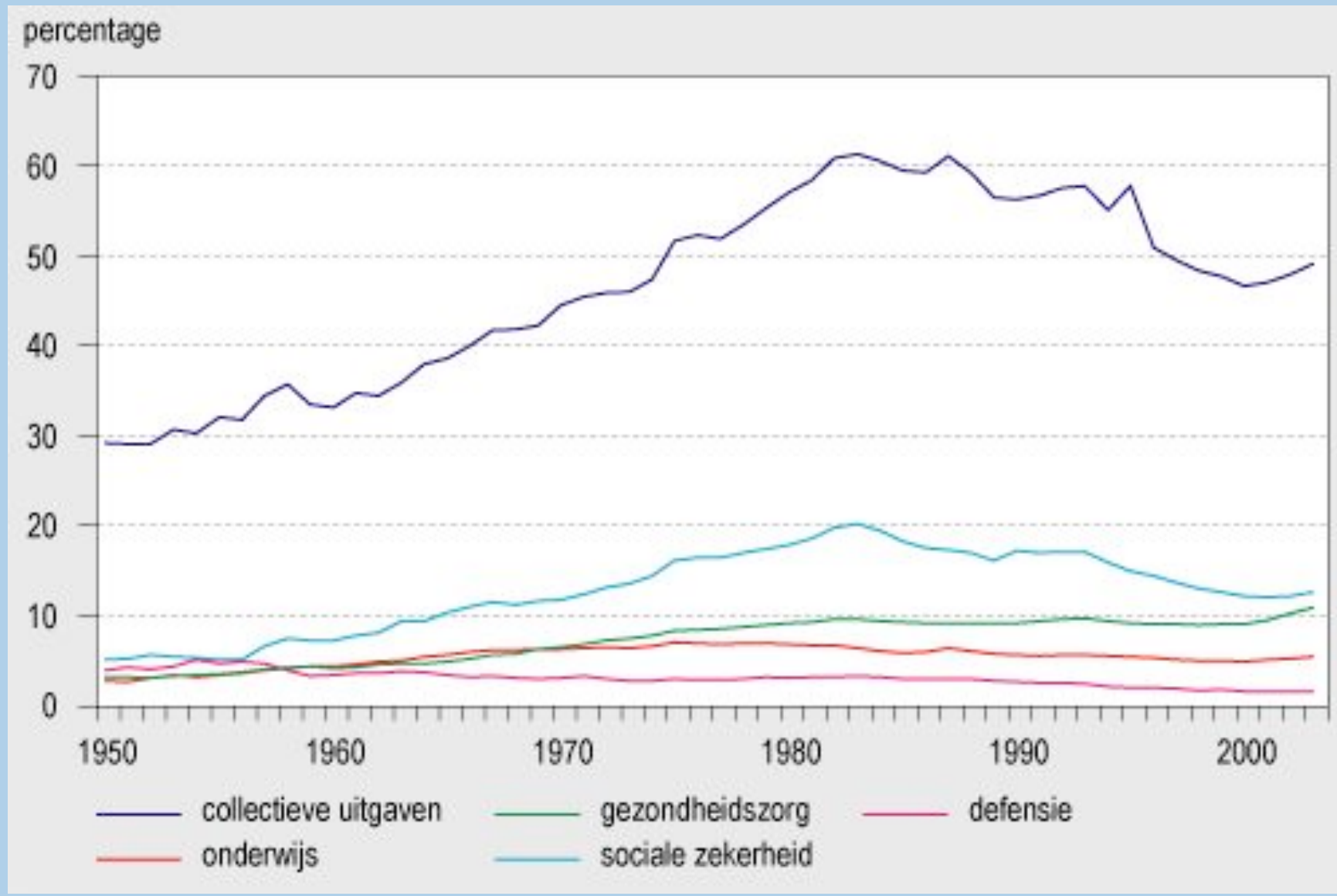
Jobs in the Netherlands: 7.589.000

Jobs in health care : 1.179.000

i.e.: 15.5%



RIVM 2006



RIVM 2006



Bruto National Product

Includes air pollution, advertizing, cigarettes, prisons;

Increases by producing napalm and nuclear bombs;

Does not measure the health of our families, nor the quality of our educational system.

Bruto National Product

It measures everything but
does not take into account
all what makes life valuable

Robert Kennedy



PATIENT ADVOCACY

private vs public

grading of hospitals for quality

guidelines for quality

costs vs health care economy



