Soon we will all be patients

Overdiagnosis in medical and social sciences perspectives

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Centre of General Practices, University of Copenhagen
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Chair of EUROPREV

Both: Research Unit for General Practice, Department of Community Medicine,
Faculty of Health Sciences, UiT The Arctic University of Norway, Tromsø

Conflicts of interest

We have written a textbook targeting primarily university students at medical and social sciences faculties, but also clinicians, researchers, PhD students, healthcare administrators, authorities and other healthcare professionals and other stakeholders in healthcare.

If the book sells more than 750 pieces we will get royalty.

Jønsson & Brodersen. “Snart er vi alle patienter. Overdiagnostik i medicinske og samfundsfaglige perspektiver”, 2022

EUROPREV

National Representative

European Network for Prevention and Health Promotion in Family Medicine and General Practice

www.europrev.eu

Content of presentation

- Setting the scene
- Overdiagnosis: What it is and isn’t
- Health culture and drivers to overdiagnosis
- Big Data, Personalised Medicine, AI & ML

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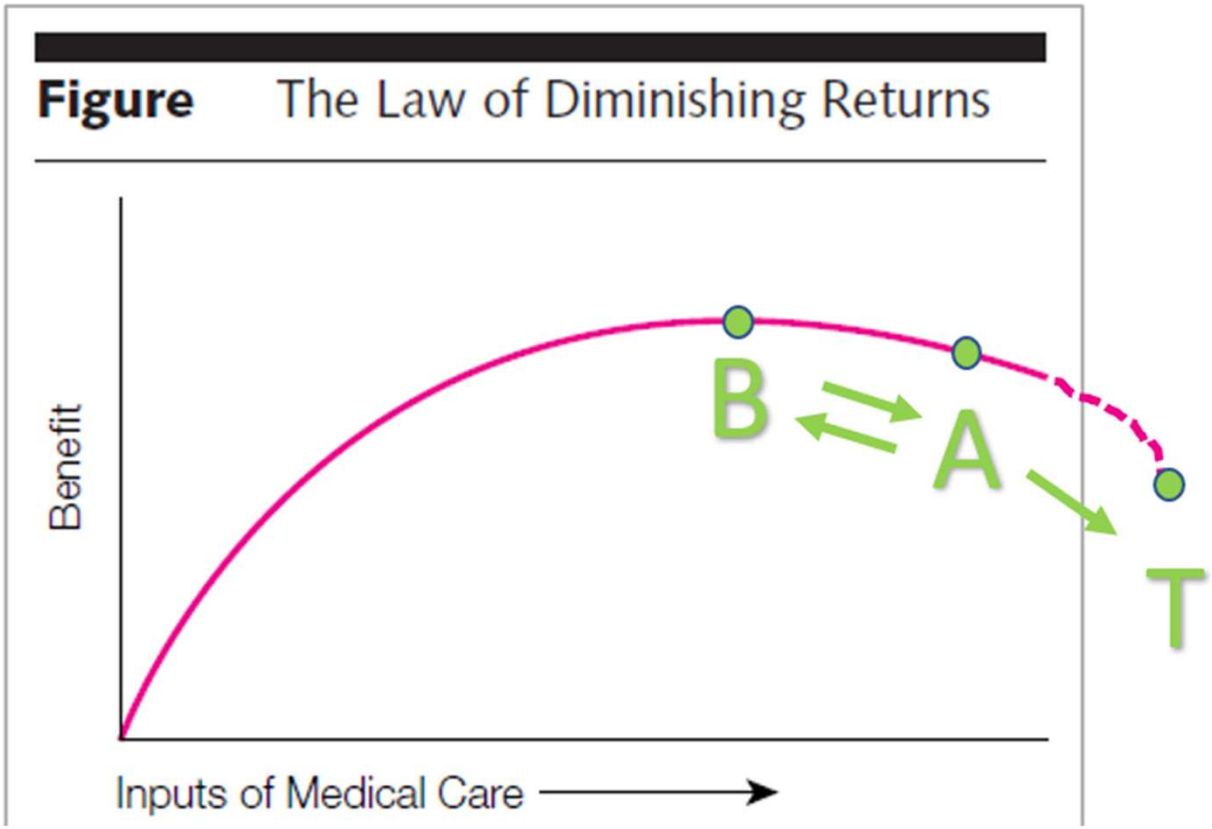
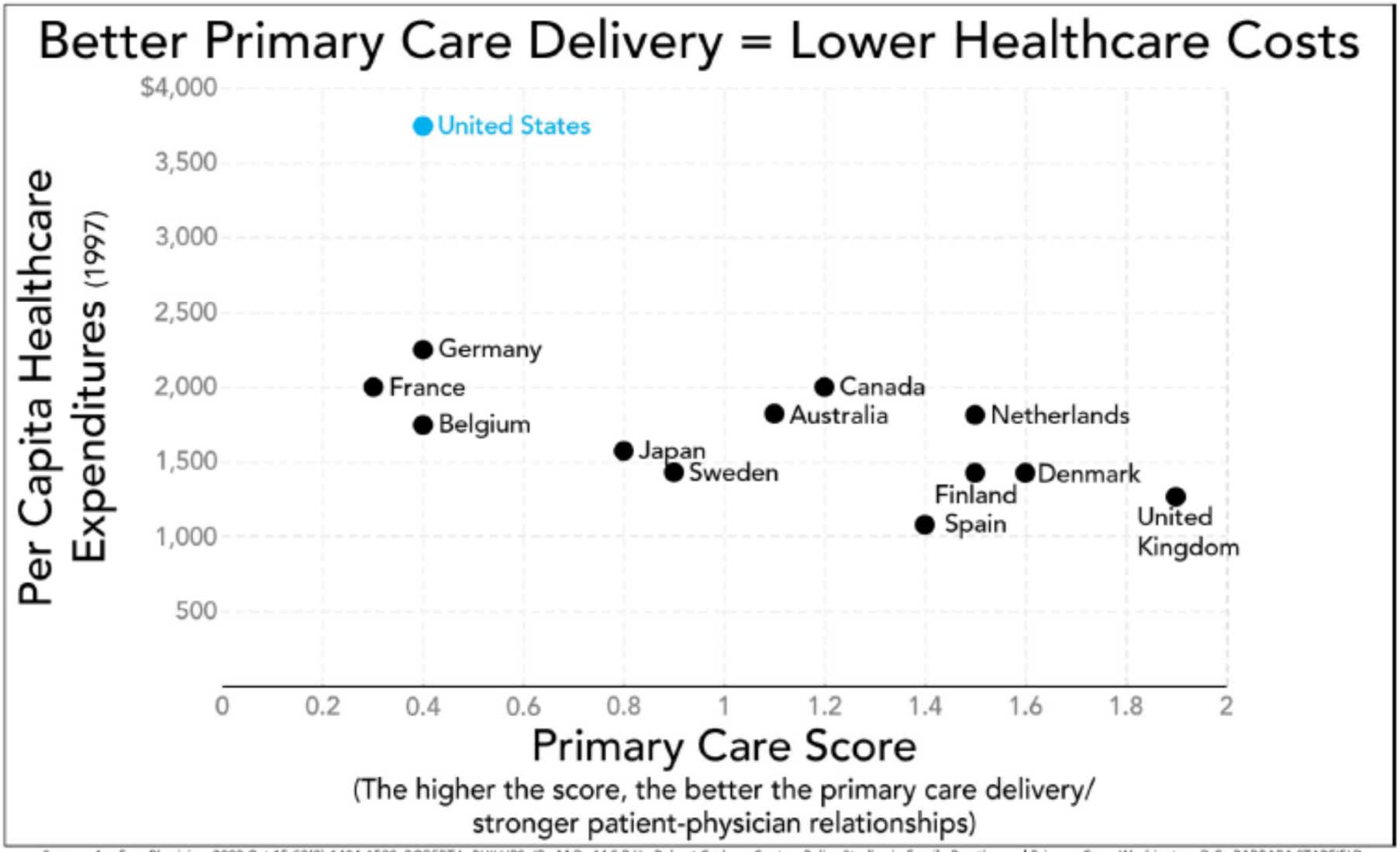
How Might More be Worse?



Fisher & Welch. Avoiding the Unintended Consequences of Growth in Medical Care. JAMA 1999

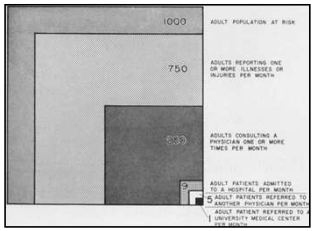


Source: *Am Fam Physician*. 2003 Oct 15;68(8):1494-1500. ROBERT L. PHILLIPS, JR., M.D., M.S.P.H., Robert Graham Center: Policy Studies in Family Practice and Primary Care, Washington, D.C., BARBARA STARFIELD, M.D., M.P.H., Johns Hopkins University Bloomberg School of Public Health, Baltimore, Maryland. http://www.aafp.org/afp/2003/1015/p1494.html and Starfield B, Shi L. Policy relevant determinants of health: an international perspective. Health Policy. 2002;60:201–18. http://www.jhsph.edu/research/centers-and-institutes/johns-hopkins-primary-care-policy-center/Publications_PDFs/2002_HP_Starfield.pdf

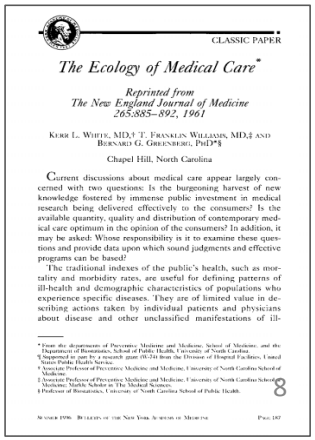
Citizens

Expectations and interpretations of symptoms and sensations

Decides to go to the GP: open access



The GP is gatekeeper for referral to secondary healthcare


CLASSIC PAPER

*The Ecology of Medical Care**

Reprinted from
The New England Journal of Medicine
265:885–892, 1961

KERR L. WHITE, M.D.,† T. FRANKLIN WILLIAMS, M.D.,‡ AND BERNARD G. GREENBERG, PH.D.*§

Chapel Hill, North Carolina

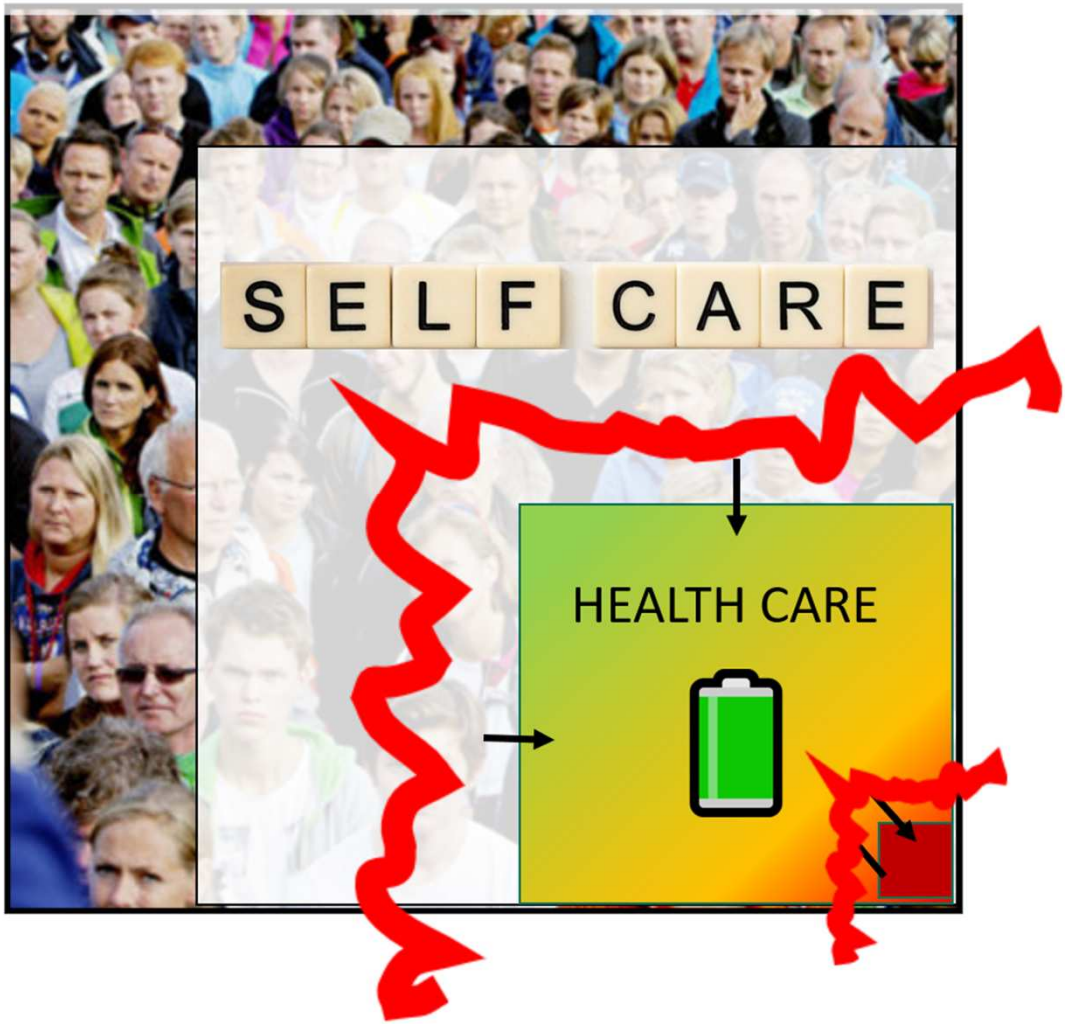
Current discussions about medical care appear largely concerned with two questions: Is the burgeoning harvest of new knowledge fostered by immense public investment in medical research being delivered effectively to the consumers? Is the available quantity, quality and distribution of contemporary medical care optimum in the opinion of the consumers? In addition, it may be asked: Whose responsibility is it to examine these questions and provide data upon which sound judgments and effective programs can be based?

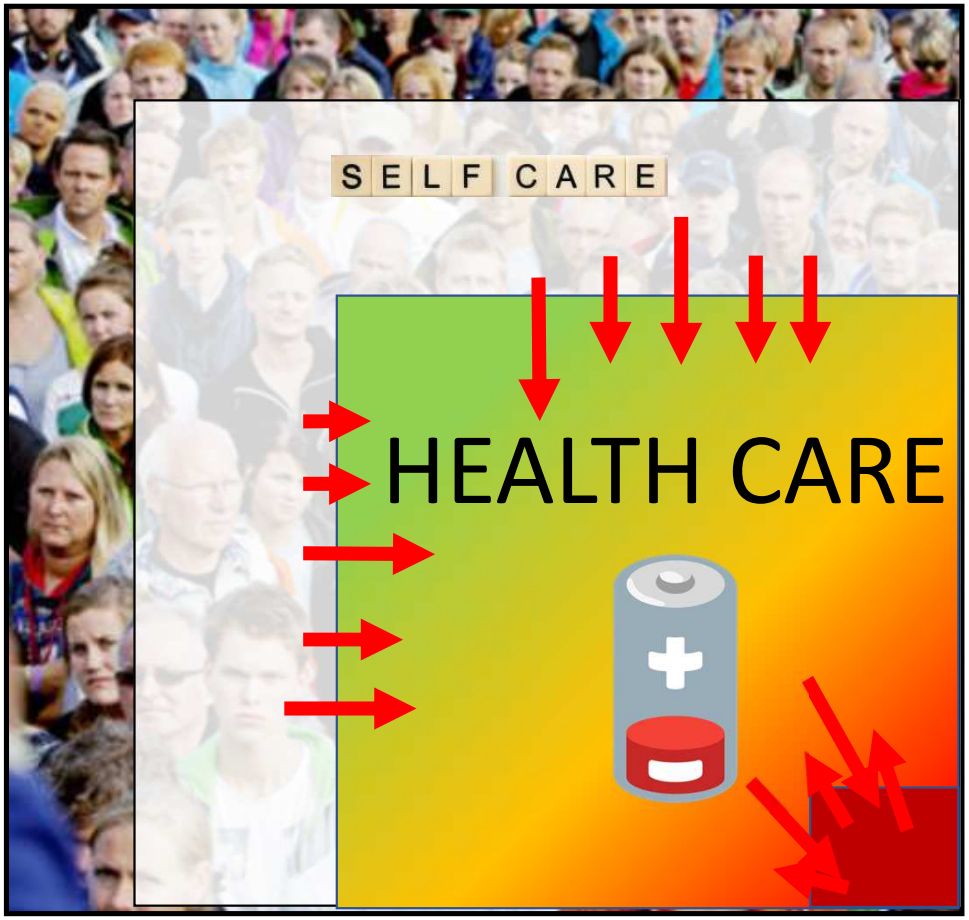
The traditional indexes of the public's health, such as mortality and morbidity rates, are useful for defining patterns of ill-health and demographic characteristics of populations who experience specific diseases. They are of limited value in describing actions taken by individual patients and physicians about disease and other unclassified manifestations of ill-

8

White et al. The ecology of medical care. NEJM, 1961. Classic Paper in Bull N Y Acad Med, 1996


SELF CARE
HEALTH CARE





«The new normal?»

Open access Research

BMJ Open

Continuity of care with doctors—a matter of life and death? A systematic review of continuity of care and mortality

2018

Denis J Pereira Gray,[1] Kate Sidaway-Lee,[1] Eleanor White,[1,2] Angus Thorne,[1,3] Philip H Evans[1,2]

Research

British Journal of General Practice, September 2020

Richard Baker, George K Freeman, Jeannie L Haggerty, M John Bankart and Keith H Nockels

Primary medical care continuity and patient mortality:

a systematic review

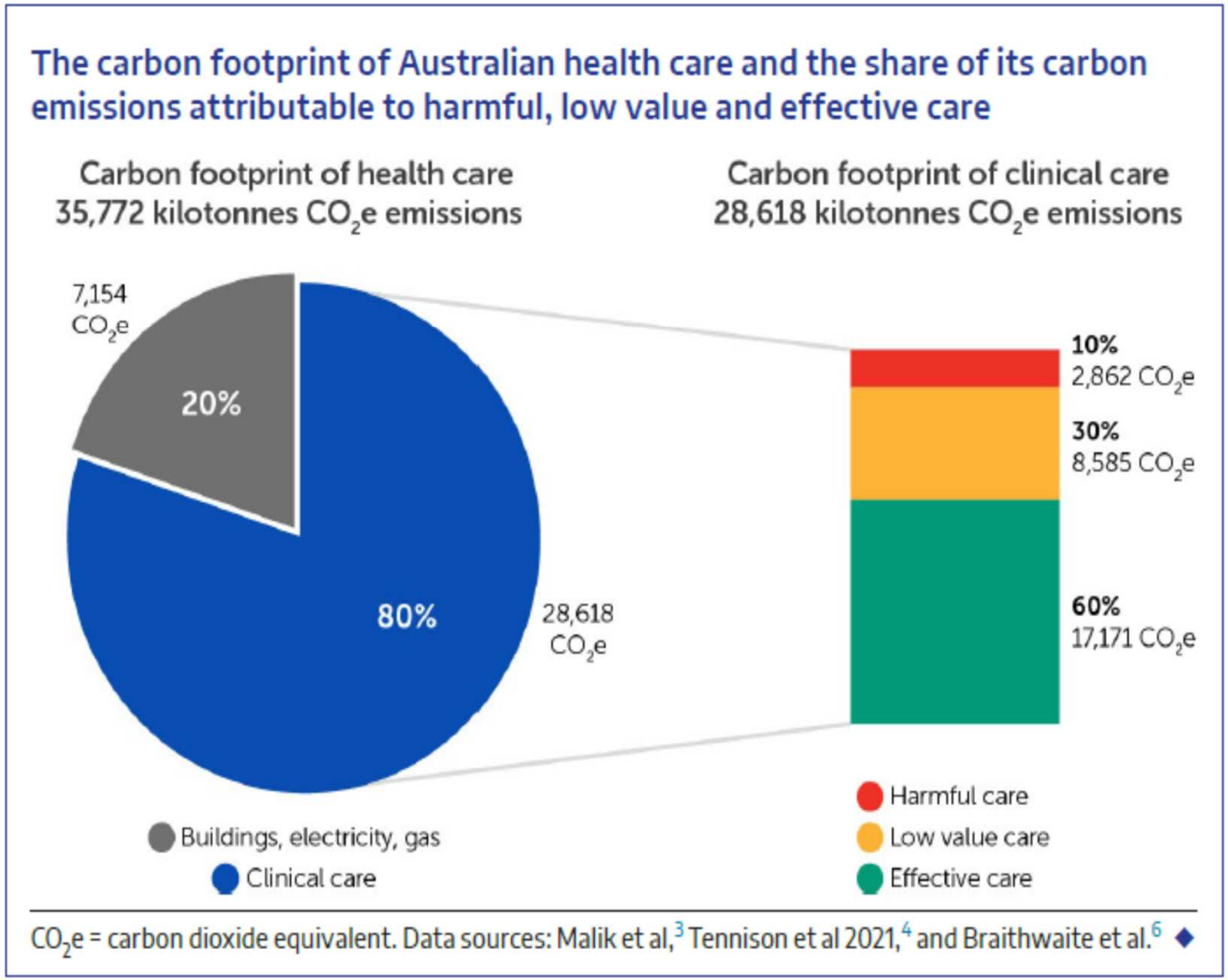
Research

British Journal of General Practice, February 2022

Hogne Sandvik, Øystein Hetlevik, Jesper Blinkenberg and Steinar Hunskaar

Continuity in general practice as predictor of mortality, acute hospitalisation, and use of out-of-hours care:

a registry-based observational study in Norway



Barratt et al (2022). "High value health care is low carbon health care." Med J Aust 216(2): 67-68.

Core Values and Principles of General Practice/Family Medicine

WHO considers primary health care to be a cornerstone of sustainable health care systems. The General Practice/Family Doctor (GP/FD) is a key provider of primary health care.

WONCA Europe has defined General Practice/Family Medicine as both a clinical specialty and a discipline in its own right, with its own curriculum and research base.

GP/FM may be practiced in different contexts according to the characteristics of each health system, country or community. However, the foundation of GP/FM is based on the core values listed below. They are the essential elements of good quality of GP/FM, and should provide a frame of reference for our professional identity.

PERSON-CENTERED CARE

GPs/FDs practice person-centered medicine, emphasizing dialogue, context, and the best evidence available.

GPs/FDs always take the impact of biological, psychosocial and cultural determinants on individuals' health into consideration.

GPs/FDs engage professionally with their patients' current life situations, biographical stories, beliefs, worries, and hopes. This helps to recognize the links between social factors and sickness and to deepen the understanding of how life and life events leave their imprint on the human body and mind. GPs/FDs promote patients' capacity to make use of their individual and communal resources.

CONTINUITY OF CARE

GPs/FDs promote continuity of doctor-patient relationships as a central organizing principle

The doctor-patient relationship is based on personal involvement and confidentiality. Continuity of care helps build mutual trust and enable high-quality, person-centered care.

GPs/FDs seek to maintain this continuity of care when organizing their practices, regardless the size, composition and nature of the primary care team.

COOPERATION IN CARE

GPs/FDs collaborate across professions and disciplines while also taking care not to blur the lines of responsibility.

GPs/FDs integrate different programs and services and engage actively in developing and adapting effective ways to cooperate with other health and social workers.

GPs/FDs help patients navigate the health system and facilitate communication with other health professionals

COMMUNITY ORIENTED CARE

GPs/FDs remain committed to education, research, and quality development.

GPs/FDs community orientation and social accountability aim at influencing the health policies addressing health disparities by integrating clinical care, public health and social services on community level.

EQUITY OF CARE

General practitioners/Family doctors prioritize those whose needs for healthcare are greatest.

GPs/FDs provide equitable health care. Equity is an essential dimension of the quality of health care. The aim is to minimize inequalities in health service delivery. We organize our practices to allocate time and effort to those whose needs for treatment and support are greatest.

GPs/FDs perceive it their duty to speak out publicly about societal factors impacting access to health care and inequalities in health outcomes. GPs/FDs are especially aware of the health challenges facing certain groups in relation to age, gender, sexual orientation, ethnicity, socio-economic status and religious orientation.

SCIENCE ORIENTED CARE

GPs/FDs provide care based on the best available evidence, respecting patients' values and preferences.

Overexamination, overdiagnosis, and overtreatment can harm patients, consume resources and indirectly lead to harmful underdiagnosis and undertreatment. When equally effective interventions are available, GPs/FDs choose the interventions on the basis of cost-effectiveness and patient safety.

PROFESSIONALISM IN CARE

GPs/FDs provide medical care to individuals and promote health on the community level. GPs/FDs engage in political and social aspects impacting health outcomes in community-oriented advocacy.

GPs/FDs engage actively in the training of future colleagues and facilitate inclusion of young doctors in organizational and fundamental decisions regarding the under and postgraduate medical education.

GPs/FDs implement and promote research relevant to the needs of GP/FM, and assess knowledge and guidelines critically with a constructive and academic approach.

Core Values and Principles of General Practice/Family Medicine

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Overdiagnosis in medical and social sciences perspectives

A textbook for college/university students

1. Overdiagnosis: What it is and what it isn't
2. Health culture and the pursuit of eternal life
3. Diagnostics: sick, healthy – or in-between?
4. Medical screening and overdiagnosis
5. Risk, prevention and self monitoring
6. Big Data, Personalised Medicine and Artificial Intelligence
7. Is it always good to know?
8. Causes, drivers, mechanisms and incitements to overdiagnosis

Jønsson & Brodersen. "Snart er vi alle patienter. Overdiagnostik I medicinske og samfundsfaglige perspektiver", August, 2022

Overdiagnosis: definition & operationalising

Broadly, overdiagnosis means making people patients unnecessarily, by identifying problems that were never going to cause harm or by medicalising ordinary life experiences through expanded definitions of diseases.

Overdiagnosis is the diagnosis of deviations, abnormalities, risk factors, and pathologies that in themselves would never cause symptoms (this applies only to risk factors and pathology), would never lead to morbidity, and would never be the cause of death.

Brodersen. How to conduct research on overdiagnosis. The European Journal of General Practice, 2017
Brodersen et al. Overdiagnosis: what it is and what it isn't." BMJ Evidence-Based Medicine, 2018

Overdiagnosis: What it isn’t

- False positive
- Overtreatment
- Overtesting (overuse)
- Misdiagnosis
- Incidental findings (incidentalomas)
- The opposite of underdiagnosis
- Unwarranted (clinical) variation

Brodersen et al. Overdiagnosis: what it is and what it isn’t." BMJ Evidence-Based Medicine, 2018
Jønsson & Brodersen. “Snart er vi alle patienter. Overdiagnostik i medicinske og samfundsfaglige perspektiver”, 2022

Overdiagnosis – 2 types

- Overdetection – especially at screening
- Overdefinition: lowering thresholds for treatment or expanding disease definitions
  - Invent new ”diseases”
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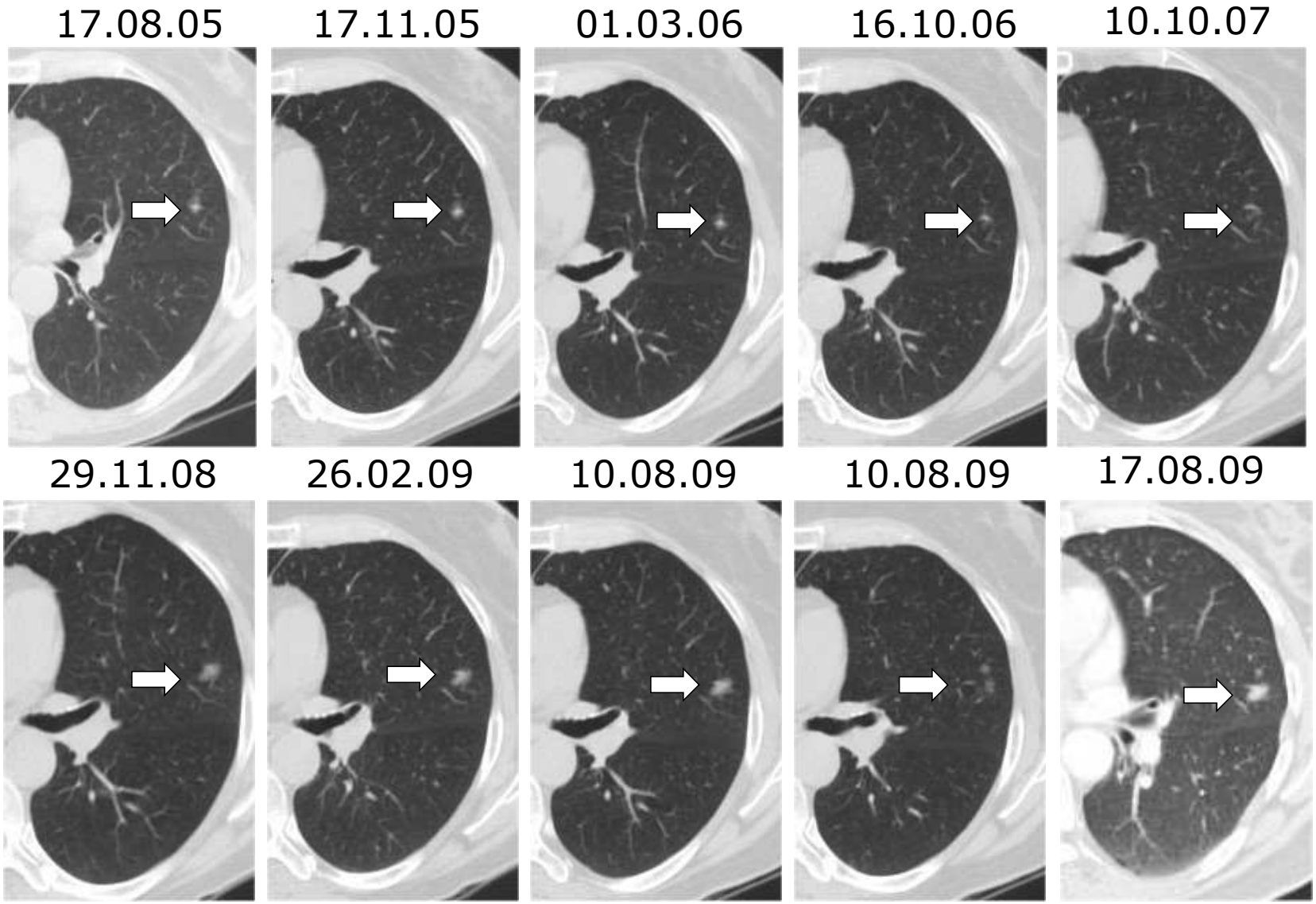
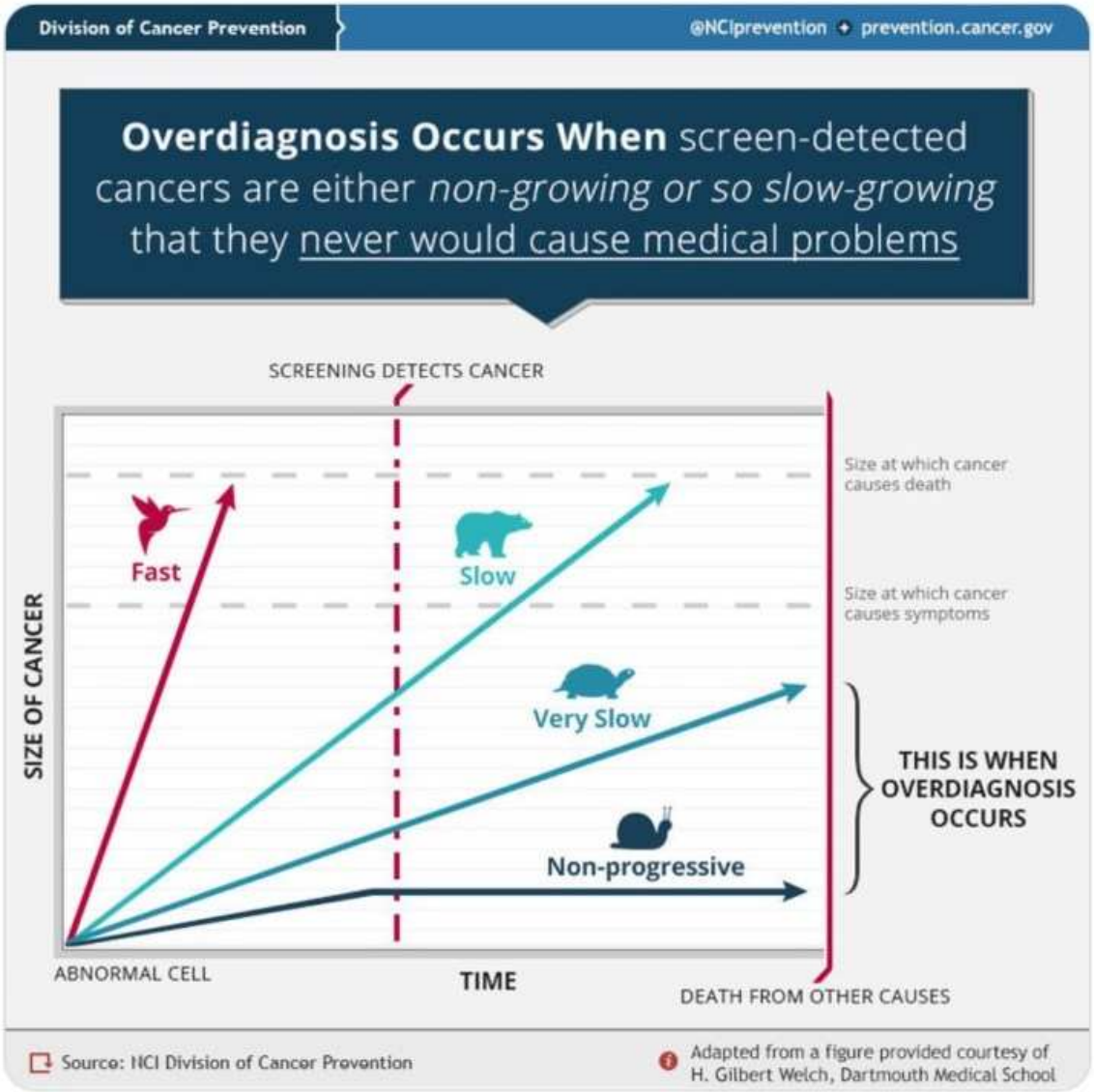
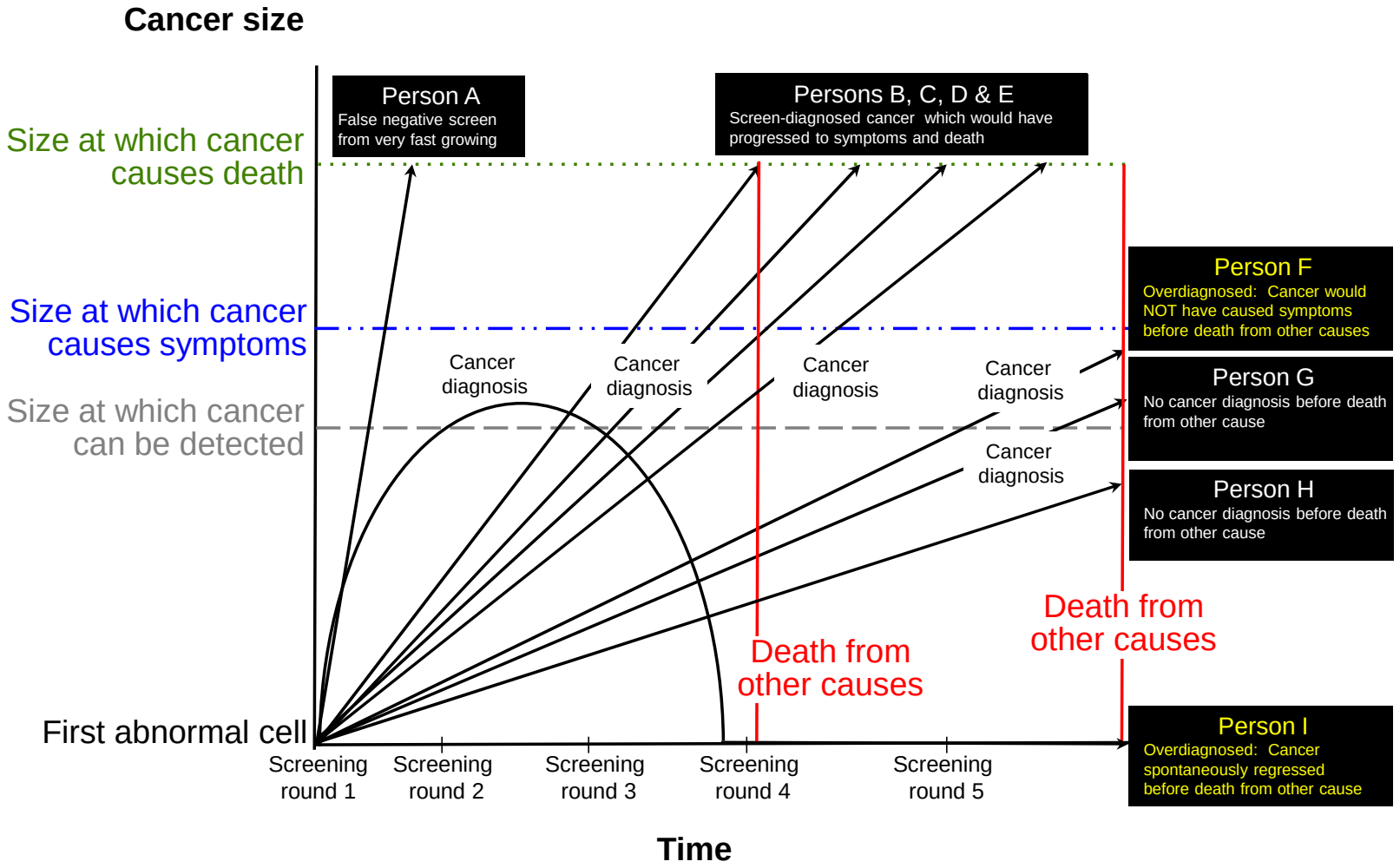
Jønsson & Brodersen. “Snart er vi alle patienter. Overdiagnostik i medicinske og samfundsfaglige perspektiver”, 2022

Screening with low-dose CT for lung cancer




Division of Cancer Prevention
@NCIprevention
prevention.cancer.gov
Overdiagnosis Occurs When screen-detected cancers are either non-growing or so slow-growing that they never would cause medical problems
SCREENING DETECTS CANCER
Size at which cancer causes death
Size at which cancer causes symptoms
Fast
Slow
Very Slow
Non-progressive
THIS IS WHEN OVERDIAGNOSIS OCCURS
SIZE OF CANCER
ABNORMAL CELL
TIME
DEATH FROM OTHER CAUSES
Source: NCI Division of Cancer Prevention
Adapted from a figure provided courtesy of H. Gilbert Welch, Dartmouth Medical School

Model: What happens when screening for cancer?



Brodersen, J., et al. (2014). "Overdiagnosis: how cancer screening can turn indolent pathology into illness." APMIS **122**(8): 683-689.

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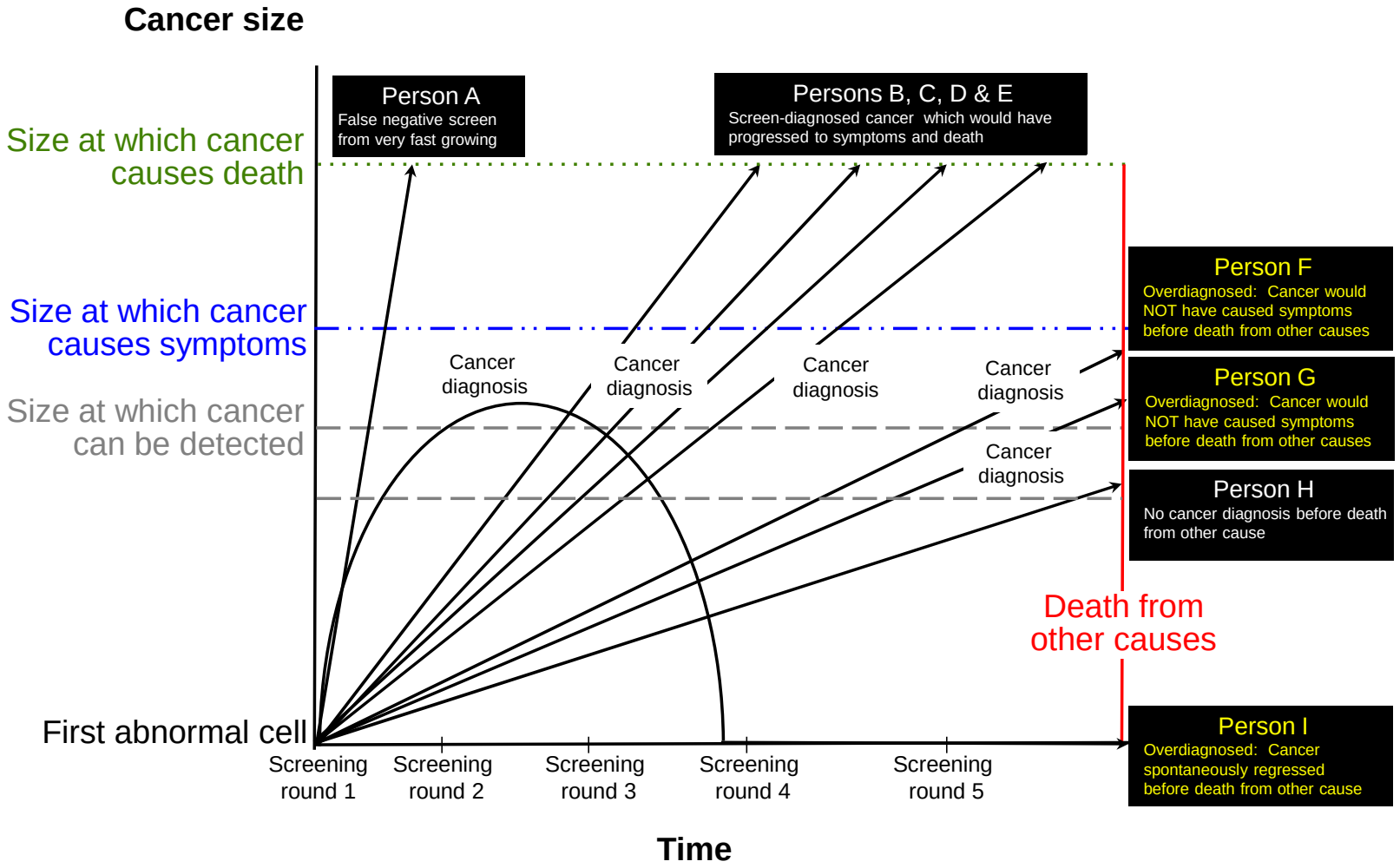

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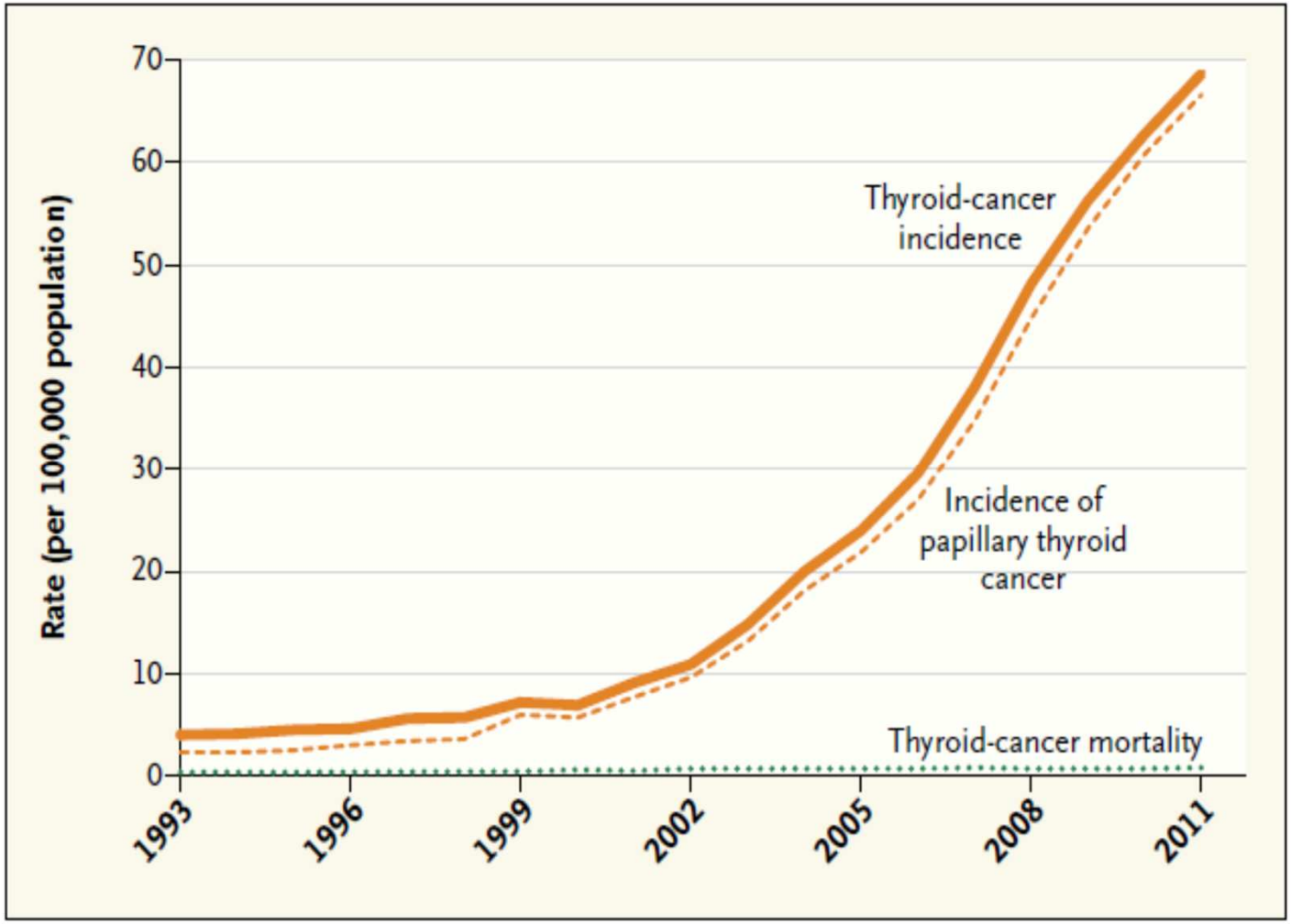
Thyroid cancer in South Korea

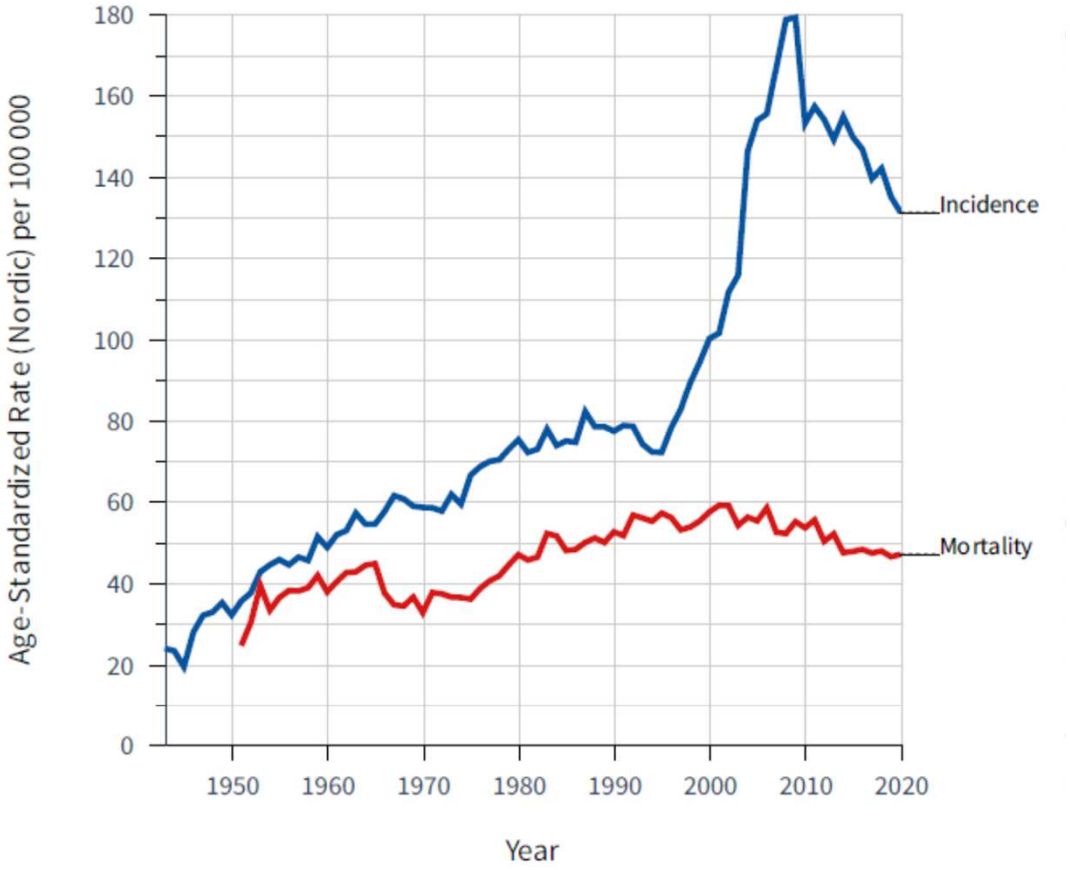


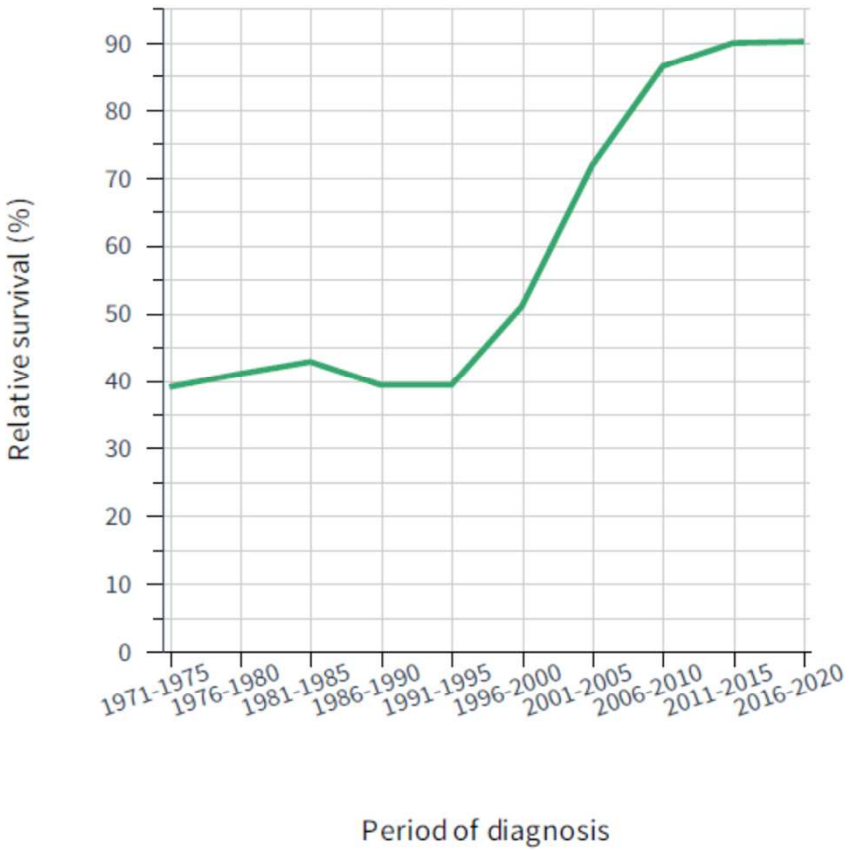
Ahn et al. Korea's thyroid-cancer "epidemic"--screening and overdiagnosis. N. Engl. J Med 2014

Age-Standardized Rate (Nordic) per 100 000 , Incidence and Mortality, Males

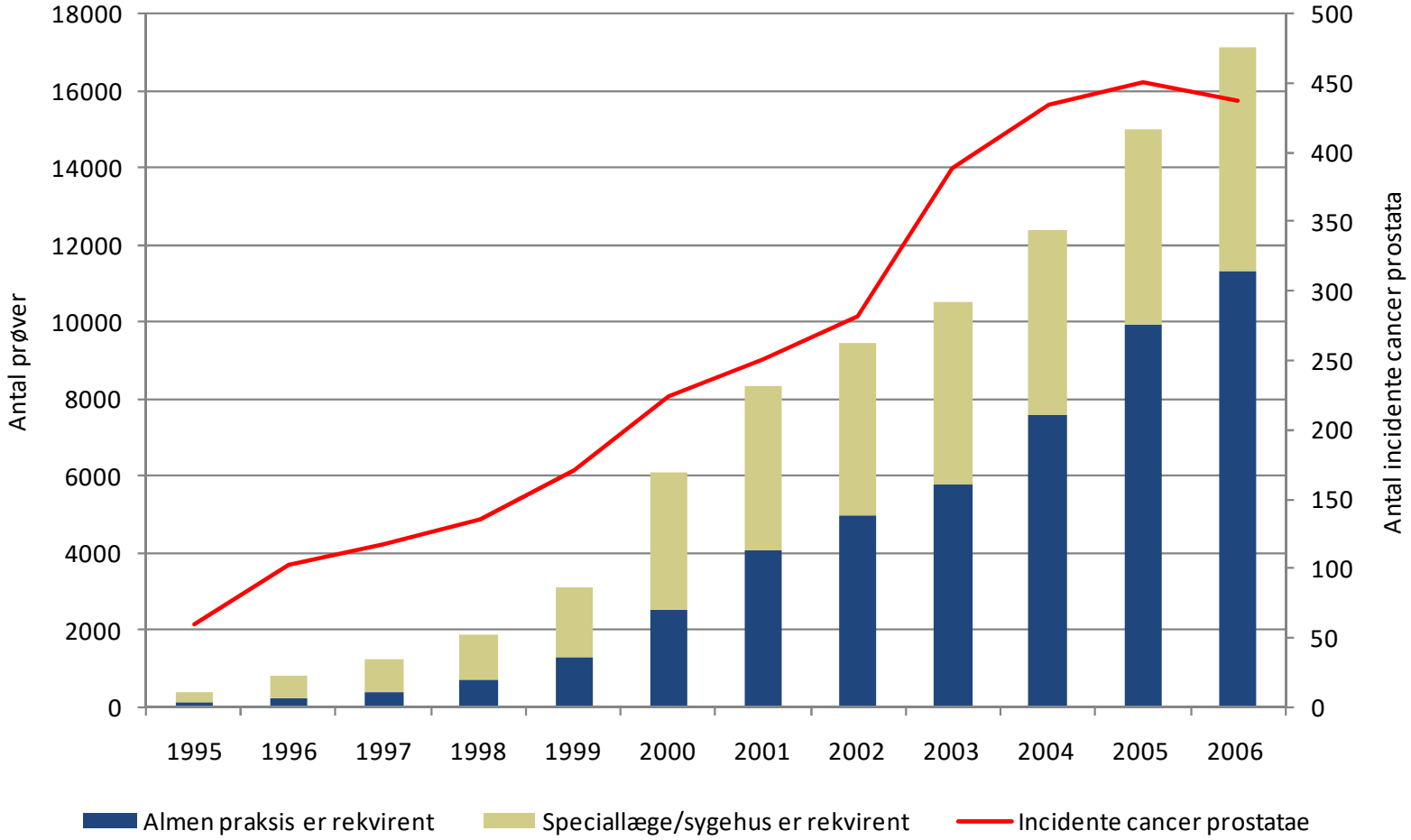
Denmark

Prostate





PSA-test and prostate cancer in DK



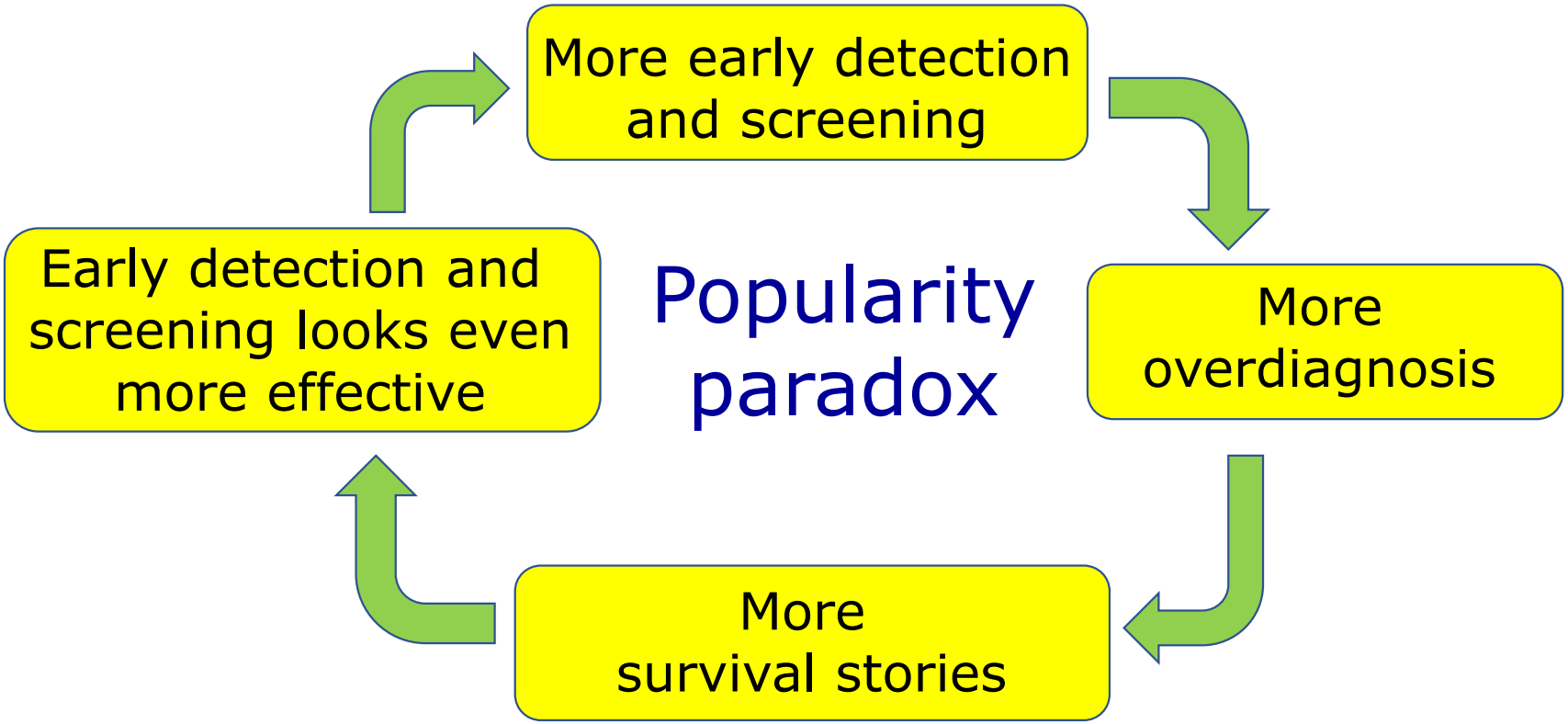
Mukai, Bro, Pedersen, Vedsted. Brug af undersøgelse for prostataspecifikt antigen . Ugeskr.Laeger 172 (9):696-700, 2010.

Men in the **highest testing quartile** of practices compared to men in the **lowest quartile**

Event	incidence rate ratio	95% confidence interval
Trans-rectal ultrasound	1.20	0.95–1.51
Biopsy	1.76	1.54–2.02
prostate cancer diagnosis	1.37	1.23–1.52
local stage	1.61	1.37–1.89
Prostatectomy	2.25	1.72–2.94
Radiotherapy	1.28	1.02–1.62
Mortality of prostate cancer	1.11	0.92–1.33
Mortality, all causes	1.01	0.97–1.05
Survival	83.4 (relative)	79.3–86.7 (relative)

Hjertholm et al. Variation in general practice prostate-specific antigen testing and prostate cancer outcomes: an ecological study. Int J Cancer, 2015.

Survival stories are drivers to more overdiagnosis



Raffle, A. and M. Gray (2007). Screening: Evidence and Practice. Oxford, Oxford University Press.

“It doesn’t matter if I don’t live longer, as long as I get saved from dying [from breast cancer]”

(Mary, 72 in Gram et al 2023)

Screening as a citizen's duty

- "Breast cancer screening is something that you should be proud to have participated in, because now we can save thousands of women from getting breast cancer" (Anny, 73 years old, Gram et al. 2023)

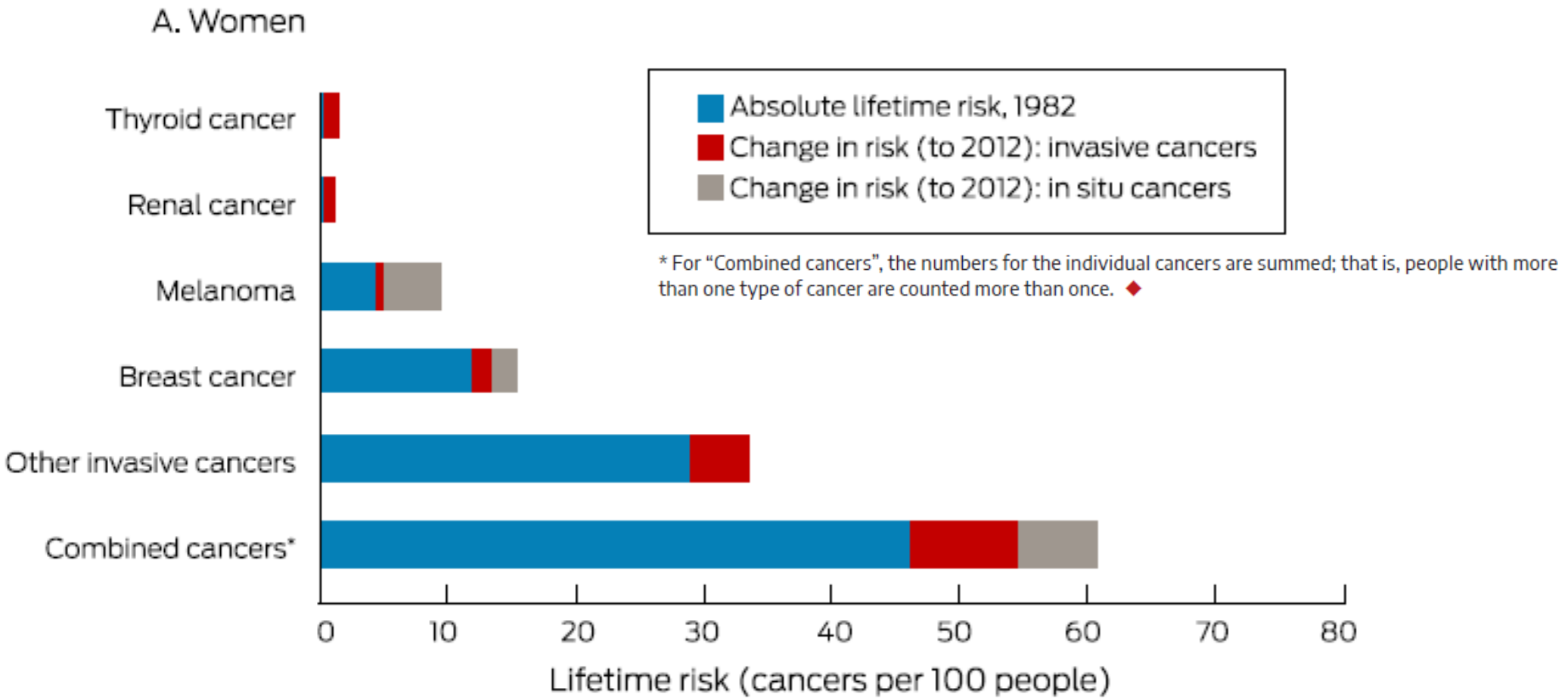
Rather too much than too little

- "I'd say better treat too much. Maybe this isn't a cancer-cell, maybe it's just a regular change in the cell (…) but still, rather treat one time too much than too little" (Jette, 71 years old, Gram et al. 2023).

Gram EG, Jønsson ABR, Brodersen JB, Damhus CS. Questioning 'Informed Choice' in Medical Screening: The Role of Neoliberal Rhetoric, Culture, and Social Context. *Healthcare*. 2023; 11(9):1230. https://doi.org/10.3390/healthcare11091230

Illustration: Getty Images

The magnitude of overdiagnosis of cancer in Australia



Glasziou et al. Estimating the magnitude of cancer overdiagnosis in Australia. The Medical journal of Australia. 2019.

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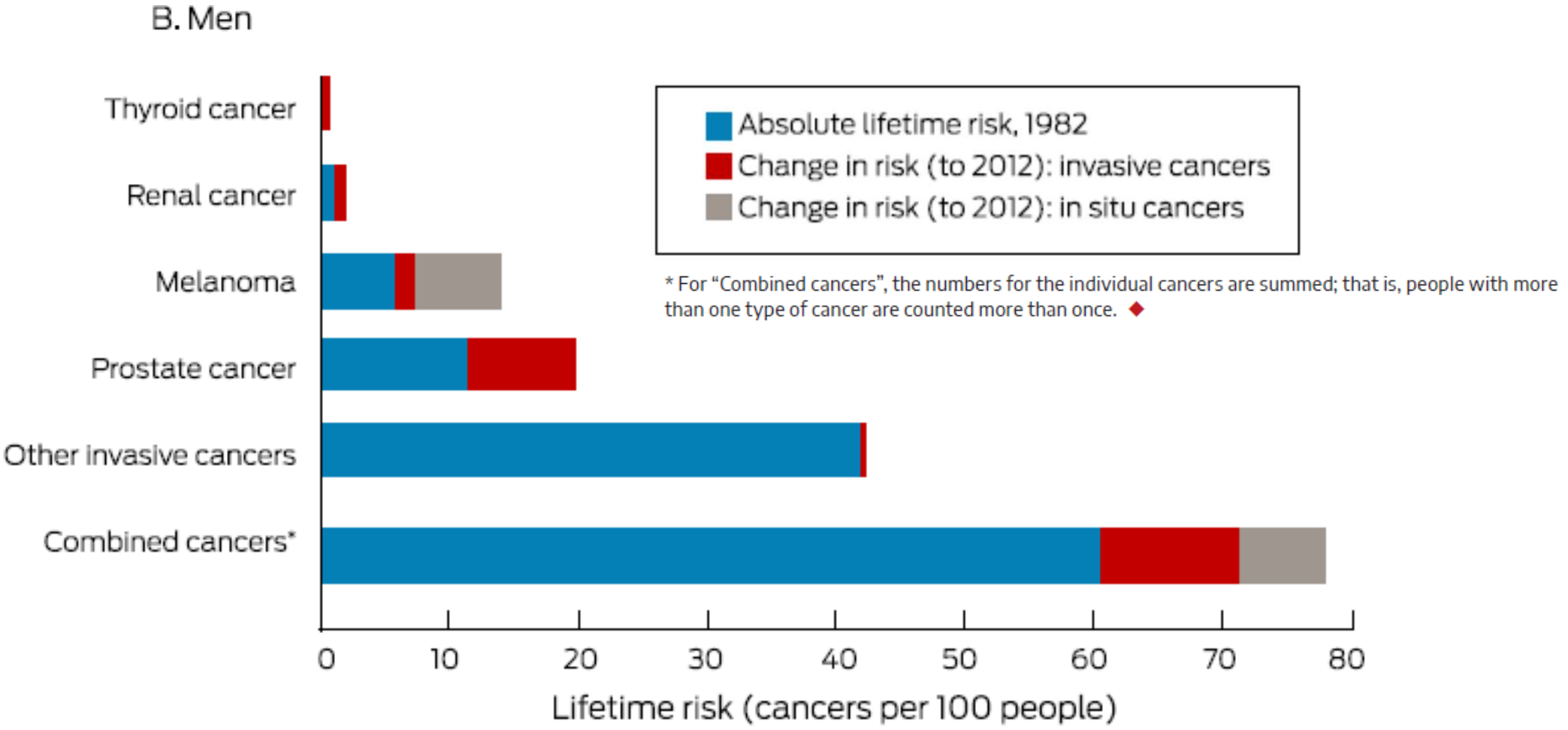

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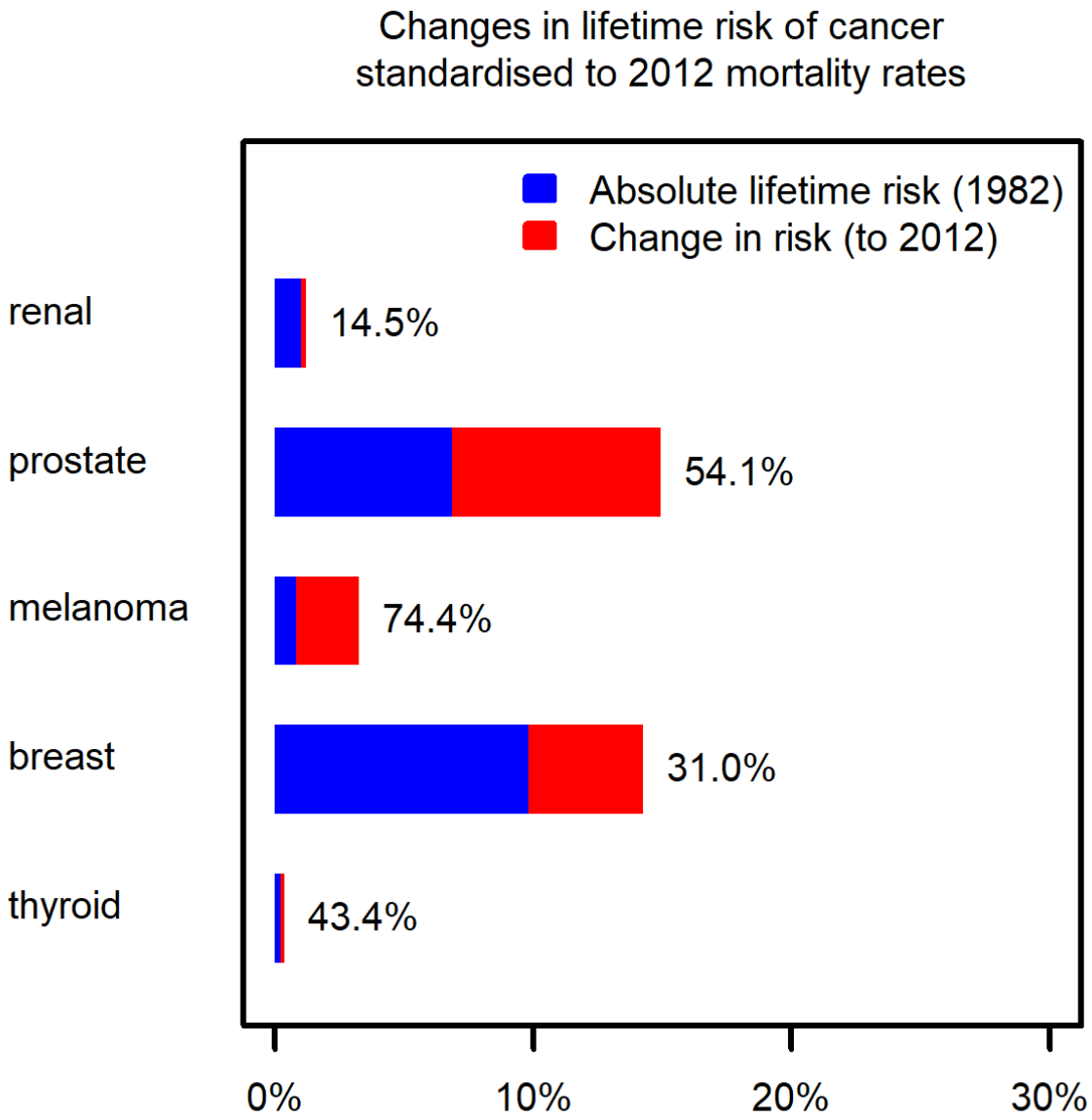
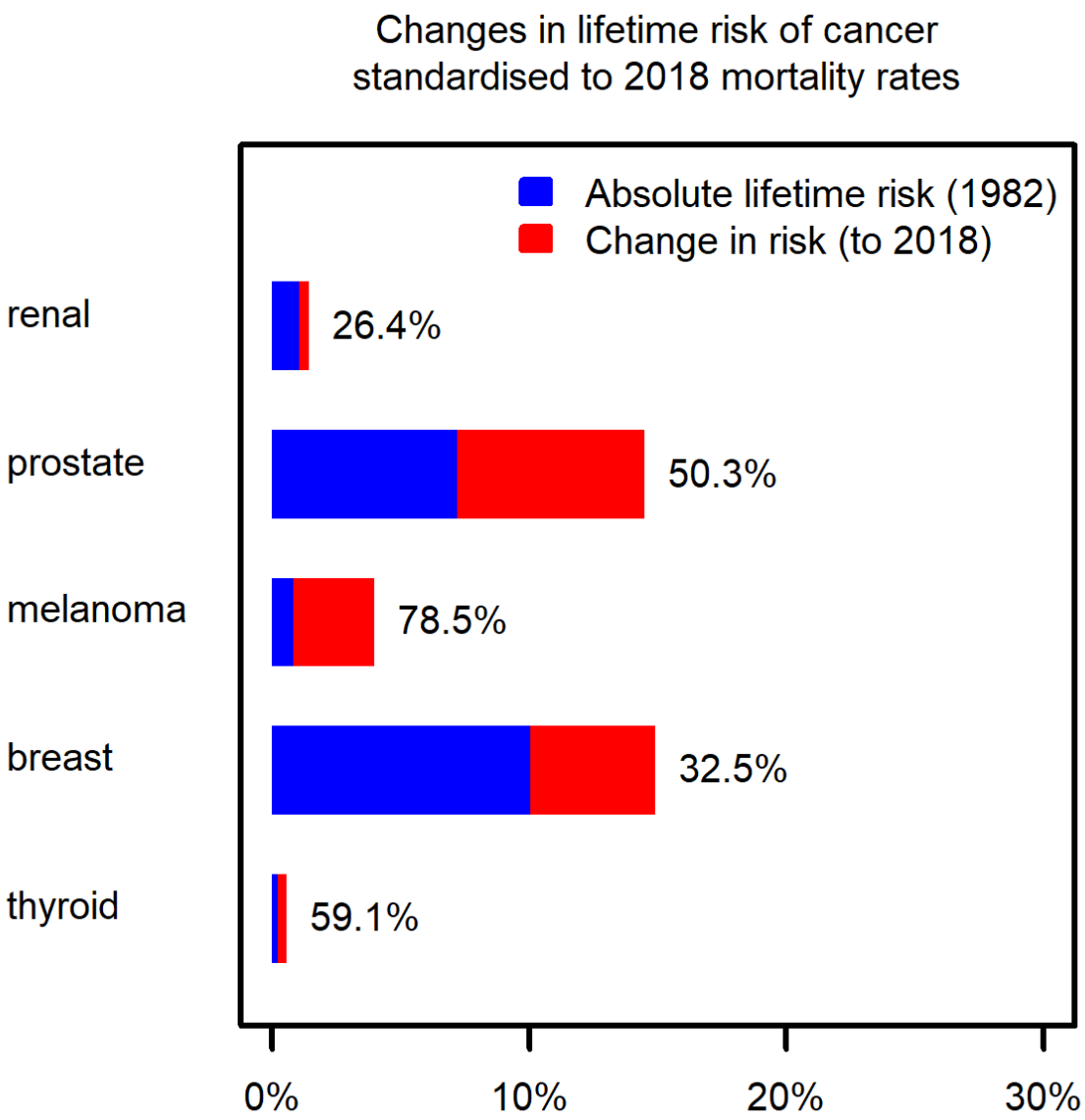

Changes in lifetime risk of cancer
standardised to 2012 mortality rates
Absolute lifetime risk (1982)
Change in risk (to 2012)
renal
14.5%
prostate
54.1%
melanoma
74.4%
breast
31.0%
thyroid
43.4%
0%
10%
20%
30%


Changes in lifetime risk of cancer
standardised to 2018 mortality rates
Absolute lifetime risk (1982)
Change in risk (to 2018)
renal
26.4%
prostate
50.3%
melanoma
78.5%
breast
32.5%
thyroid
59.1%
0%
10%
20%
30%

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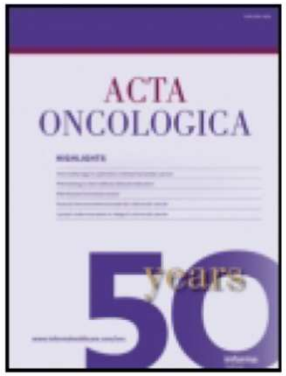

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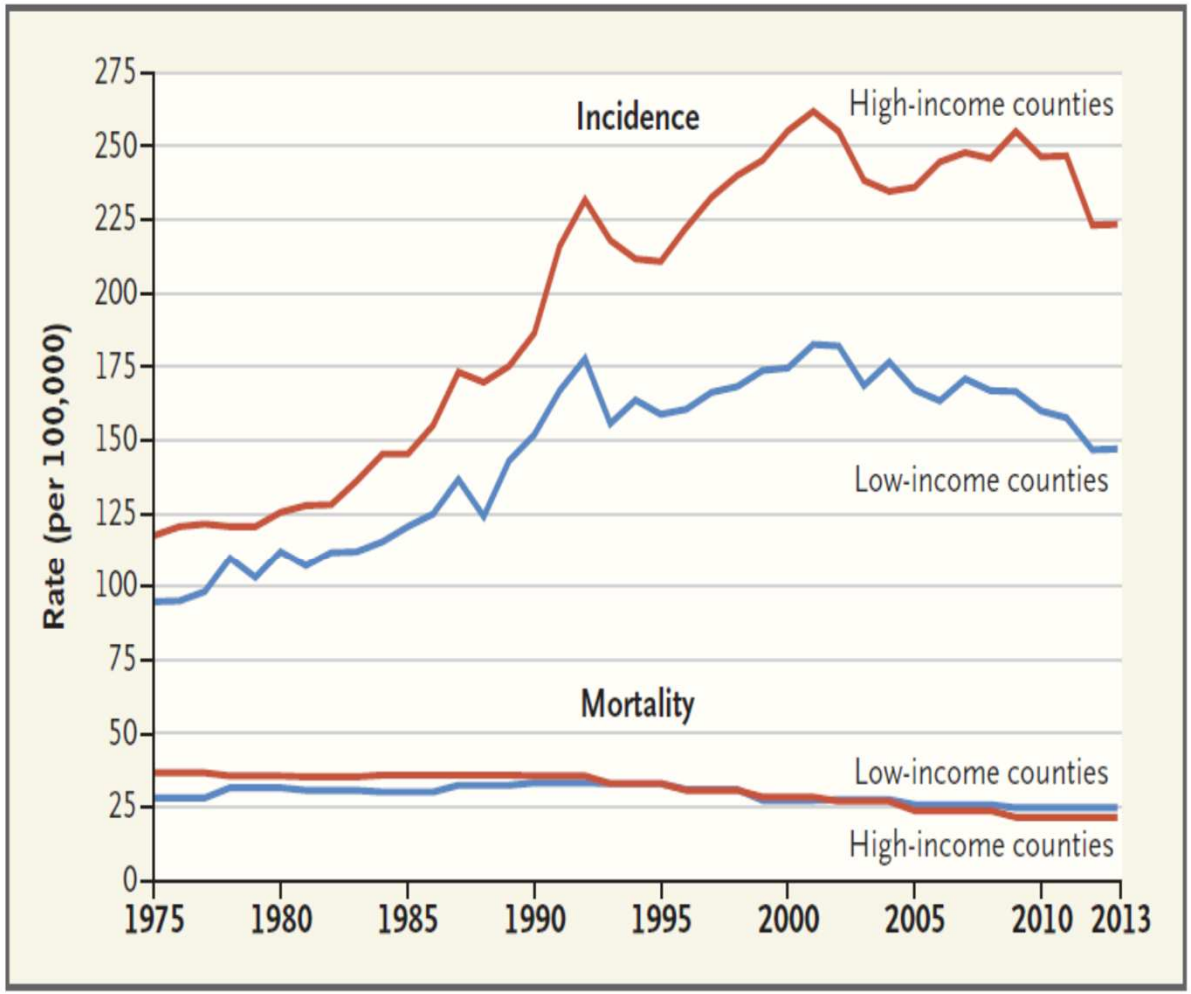
Acta Oncologica

ISSN: 0284-186X (Print) 1651-226X (Online) Journal homepage: https://www.tandfonline.com/loi/ionc20

PSA testing without clinical indication for prostate cancer in relation to socio-demographic and clinical characteristics in the Danish Diet, Cancer and Health Study

Randi V. Karlsen, Signe B. Larsen, Jane Christensen, Klaus Brasso, Søren Friis, Anne Tjønneland & Susanne Oksbjerg Dalton

Conclusions. PSA testing without clinical indication was associated with higher educational level.



Incidence and Mortality Trends for Breast Cancer, Prostate Cancer, Thyroid Cancer, and Melanoma in High- and Low-Income Counties in the United States, 1975–2013.

Welch & Fisher. "Income and Cancer Overdiagnosis - When Too Much Care Is Harmful. N Engl J Med 376(23): 2208-2209, 2017

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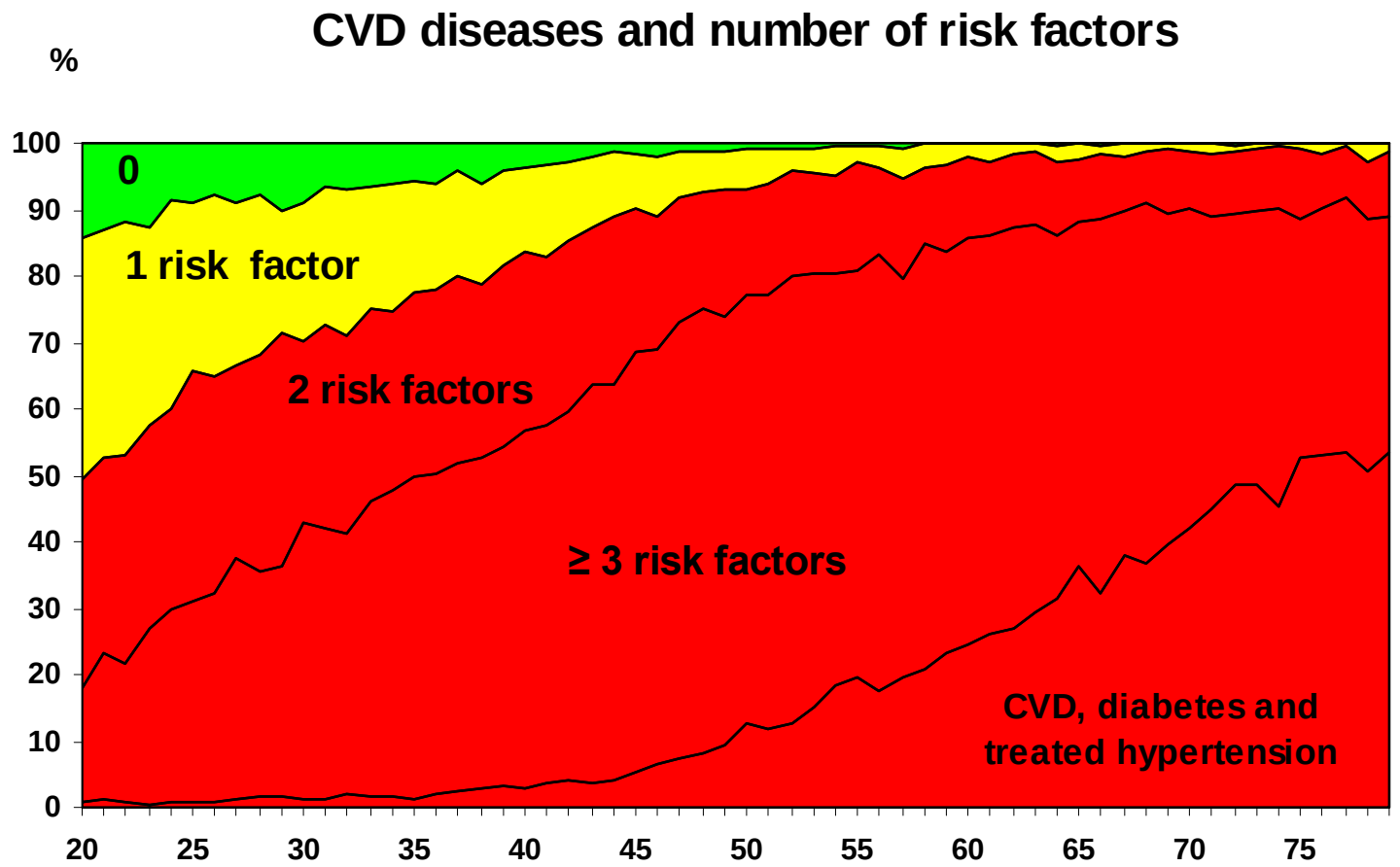
Jønsson & Brodersen. “Snart er vi alle patienter. Overdiagnostik i medicinske og samfundsfaglige perspektiver”, 2022

Overdiagnosis of cardiovascular risk factors



Petursson et al. Can individuals with a significant risk for cardiovascular disease be adequately identified by combination of several risk factors? *J.Eval.Clin.Pract. 15 (1):103-109, 2009.*

Expanding disease definitions
- (measuring) on a mental continuum

A colonisation of life's mild symptoms and suffering – an illusion of zero risk:

- Scared – anxiety
- Sad – depression
- Misthrive – ADHD
- Autism spectrum expanded
- Shy – social phobia
- Grief – prolonged grief disorder

ELSEVIER

Patient Education and Counseling 60 (2006) 267–271

Patient Education and Counseling

www.elsevier.com/locate/pateducou

The Zero-vision: Potential side effects of communicating health perfection and zero risk☆

Per Fugelli *

Department of General Practice and Community Medicine, University of Oslo, P.B. 1130 Blindern, 0318 Oslo, Norway

Received 8 November 2005; accepted 8 November 2005

Overdiagnosis – 2 types

- Overdetection – especially at screening
- Overdefinition: lowering thresholds for treatment or expanding disease definitions
  - Invent new ”diseases” (disease mongering)

Brodersen et al. Overdiagnosis: what it is and what it isn’t." BMJ Evidence-Based Medicine, 2018
Jønsson & Brodersen. “Snart er vi alle patienter. Overdiagnostik i medicinske og samfundsfaglige perspektiver”, 2022

Diasease mongering

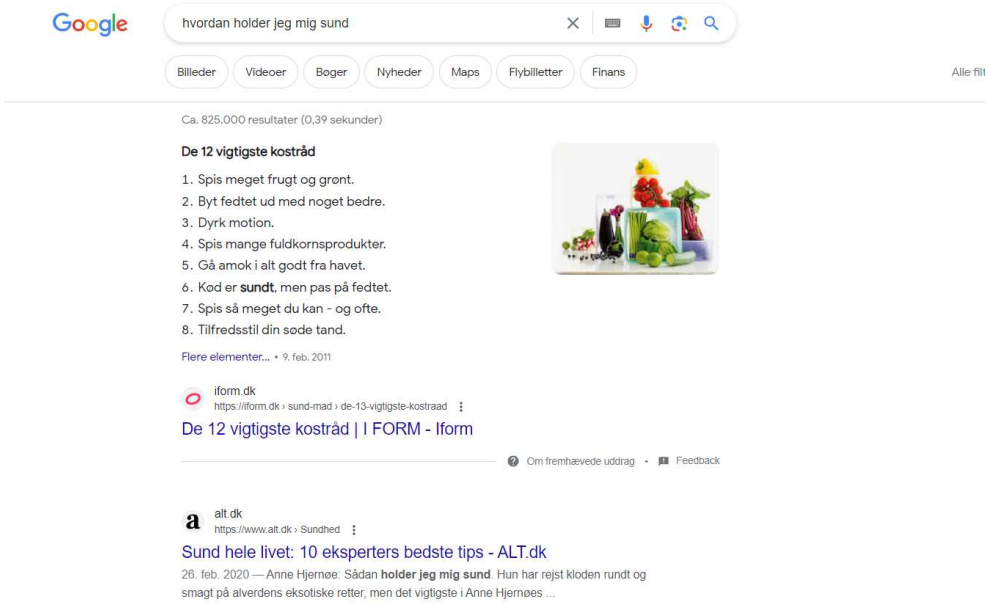
- Restless leg syndrom
- Baldness
- Low T
- Dry eye syndrome
- Road rage disorder
- Short eyelashes
- Prolonged grief disorder
- Sarcopenia

Content of presentation

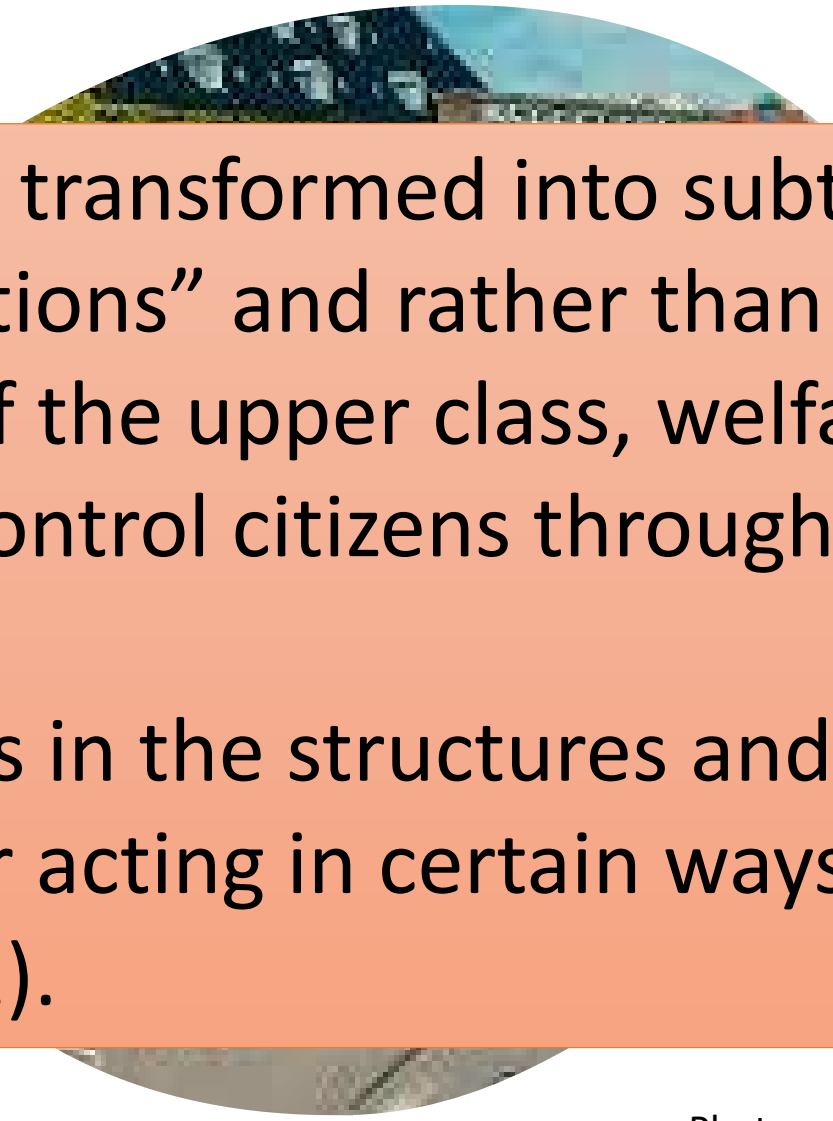
- Setting the scene
- Overdiagnosis: What it is and isn't
- Health culture and drivers to overdiagnosis
- Big Data, Personalised Medicine, AI & ML

Healthism

=When health is elevated to a form of meta-value and becomes a goal in itself, resulting in an ideology built upon a lifestyle where health and exercise are prioritized above all else.



(Crawford 1980:368)



The power has transformed into subtle ”recommendations” and rather than nurturing the interests of the upper class, welfare democracies control citizens through self-discipline.

Power then lies in the structures and incitaments for acting in certain ways (Foucault 1982).

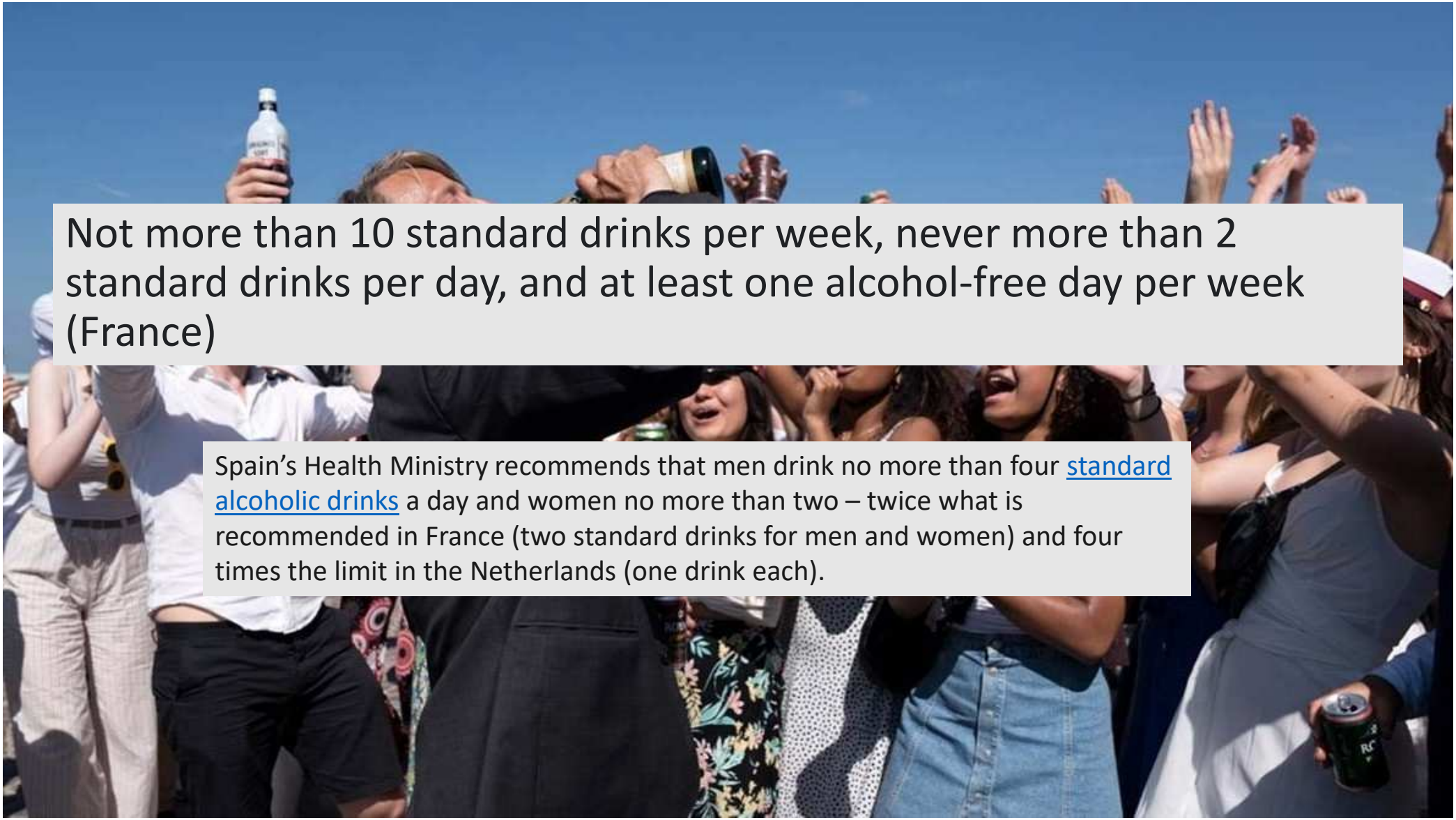
Photo credit: Wonderful Copenhagen

Neoliberal governmentality

The"**entrepreneurial self**." Individuals are encouraged to view themselves as entrepreneurs of their own lives, constantly seeking to optimize their human capital, skills, and marketability.

Responsibilization: Neoliberal governmentality emphasizes personal responsibility and self-regulation. Individuals are expected to take responsibility for their own well-being and health.

Michel Foucault 1977. Discipline and punish: The birth of the prison. London: Allen Lane. 1979. The history of sexuality. Vol. 1, An introduction. London: Allen Lane. 1980. Power/Knowledge: Selected interviews and other writings 1972–1977, ed. C. Gordon. Brighton: Harvester. 1988. Technologies of the self: A seminar with Michel Foucault, ed. L. H. Martin, H. Gutman, P. H. Hutton. Amherst: University of Massachusetts Press



Not more than 10 standard drinks per week, never more than 2 standard drinks per day, and at least one alcohol-free day per week (France)

Spain's Health Ministry recommends that men drink no more than four standard alcoholic drinks a day and women no more than two – twice what is recommended in France (two standard drinks for men and women) and four times the limit in the Netherlands (one drink each).

“That’s just the way I am. I do what I have to do and what I can do in relation to my body and my health. So, that’s just what you do. When you receive that letter, you just do it.”

(Charlotte, 57 in Gram et al. 2023)

The role of technology

- Technology alters patients embodied experiences
- Patients seek and expects technology as a symbol of high quality
- Technology has done much good, but may not be the golden solution to all problems

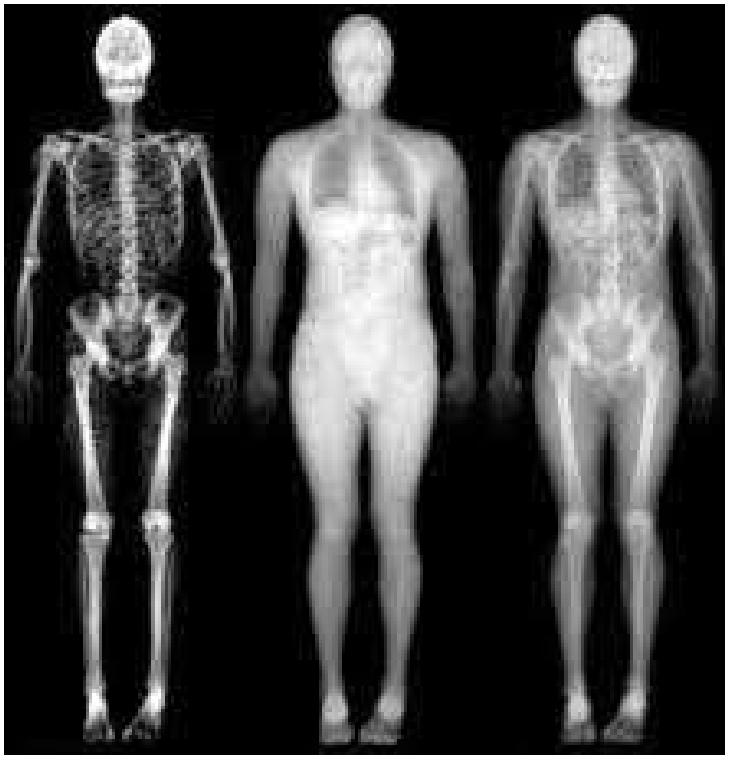
Technology becomes the ‘truth’

Women appeared to take the scan literally and planned their lives accordingly; the 'pictures' revealed some truth in themselves.

The information supplied by the scan fostered a new body image; a bodily fragility which they incorporated into their bodily perception.

New bodies: technology triggered a reconstruction of the body self as weak with reduced capacity.

Women's interpretation of the bone scan reorganized their lived space and time, and their relations with others and themselves. Technological information about osteoporosis appeared to leave most affected women more uncertain and restricted rather than empowered.



MAT Medicine Anthropology Theory

RESEARCH ARTICLES

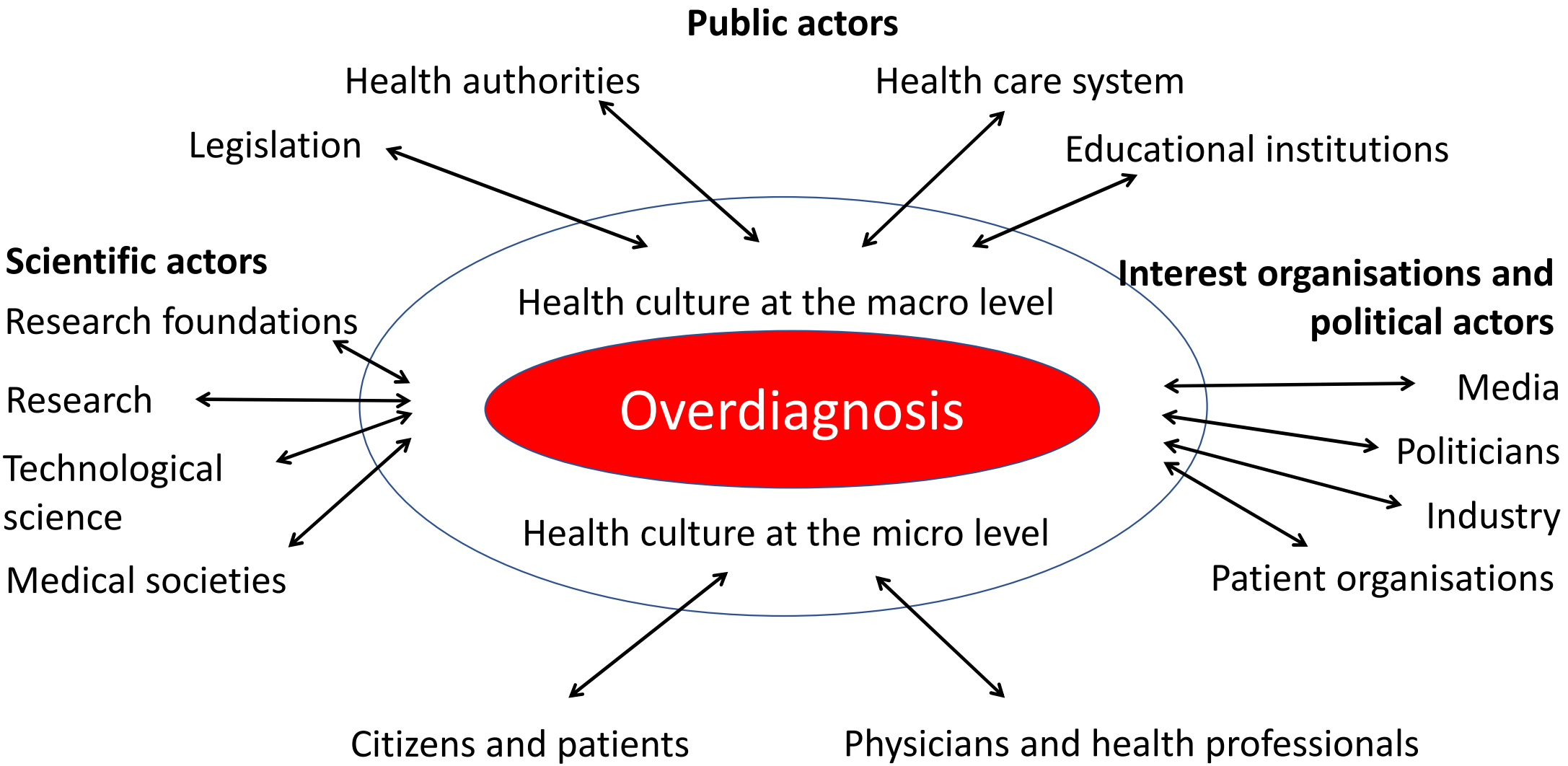
The Tyranny of Numbers

How e-Health Record Transparency Affects Patients' Health Perceptions and Conversations with Physicians

Benedikte Møller Kristensen, John Brandt Brodersen, and Alexandra Brandt Ryborg Jønsson

Received: 05 April 2021; Accepted: 27 August 2021; Published: 28 April 2022

- Epistemological errors
- Runaway processes


Public actors
Health authorities
Health care system
Legislation
Educational institutions
Scientific actors
Interest organisations and political actors
Health culture at the macro level
Research foundations
Research
Overdiagnosis
Media
Politicians
Technological science
Industry
Health culture at the micro level
Medical societies
Patient organisations
Citizens and patients
Physicians and health professionals

Content of presentation

- Setting the scene
- Overdiagnosis: What it is and isn't
- Health culture and drivers to overdiagnosis
- Big Data, Personalised Medicine, AI & ML

Secondary prevention - screening

Traditional medical screening	Screening with Big Data
Screening for one variable	Screening for many variables
Screening once or several time in life	Continuously screening throughout life
Screening with physical attendance	Screening without physical attendance
Eligible participants are invited to screening, and are encourage to make an informed choice whether to participate or not	Screening happens with an informed choice

Personalised Medicine and Big Data

- Spectrum bias
- Prognosis and diagnosis
- Measurement error

Personalised Medicine and Big Data

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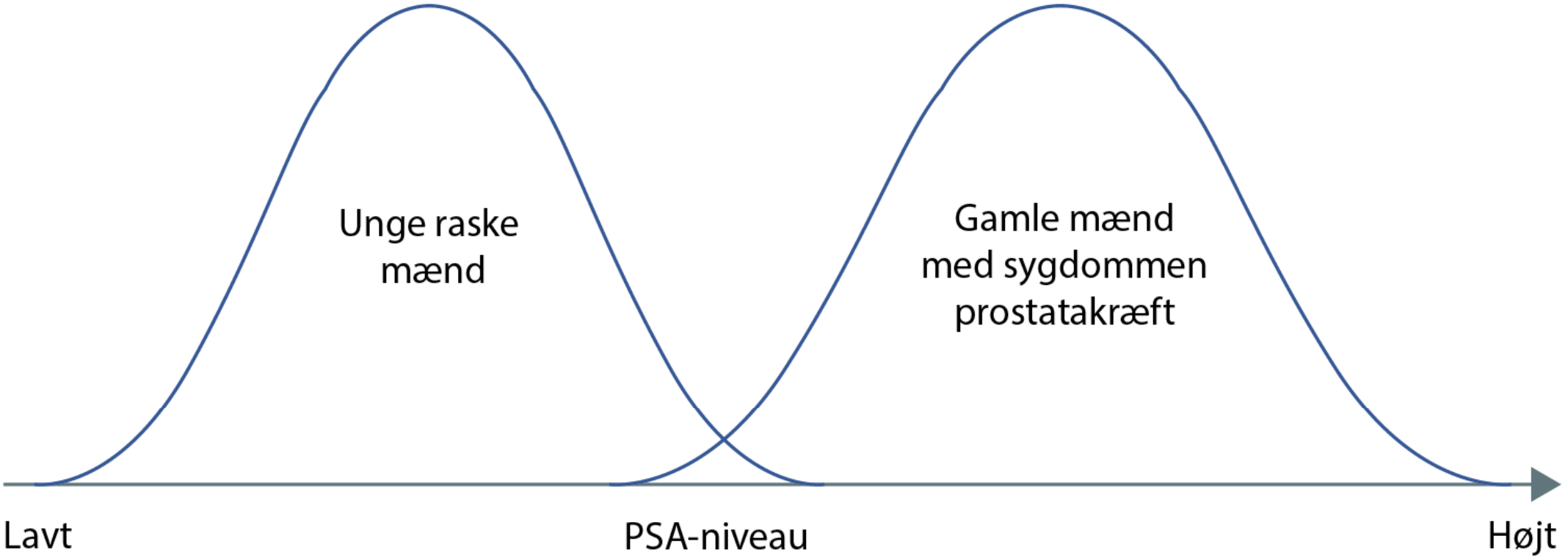
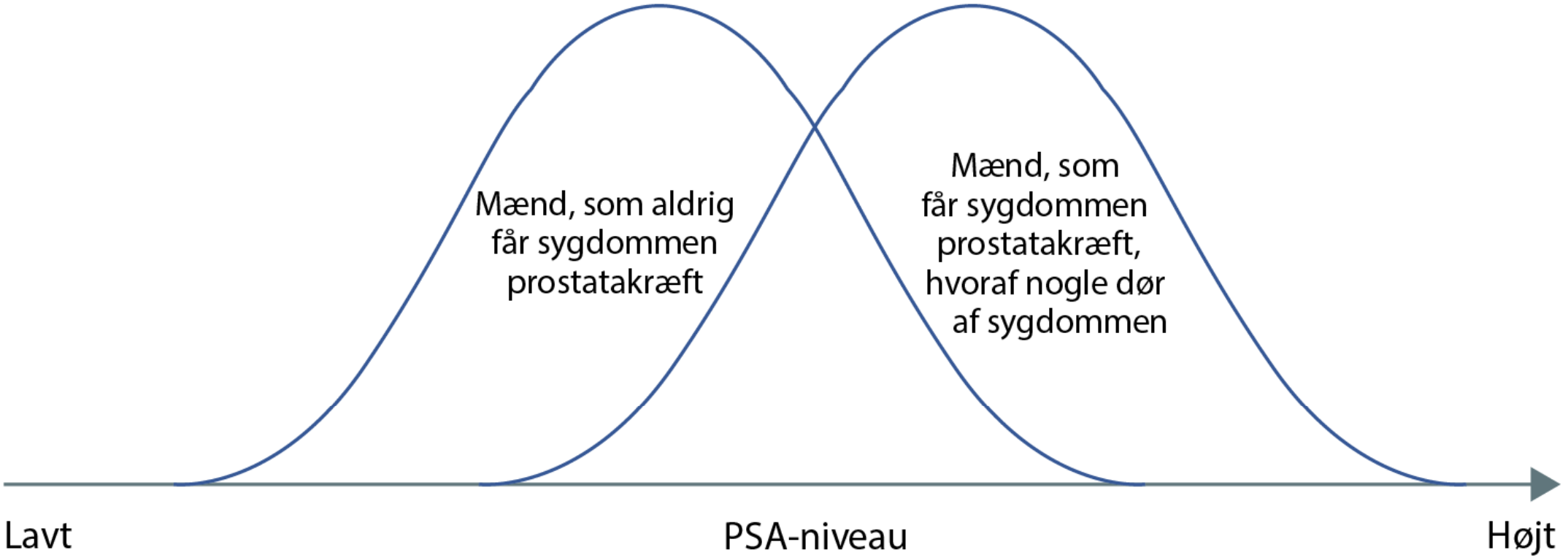
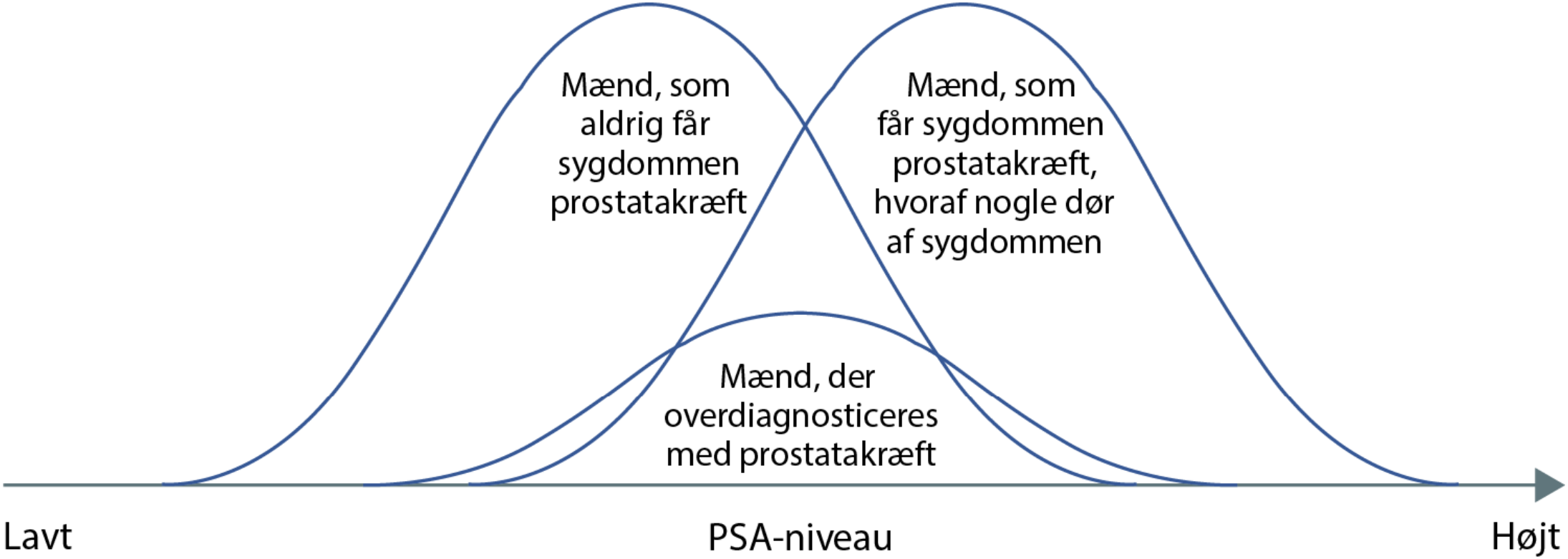


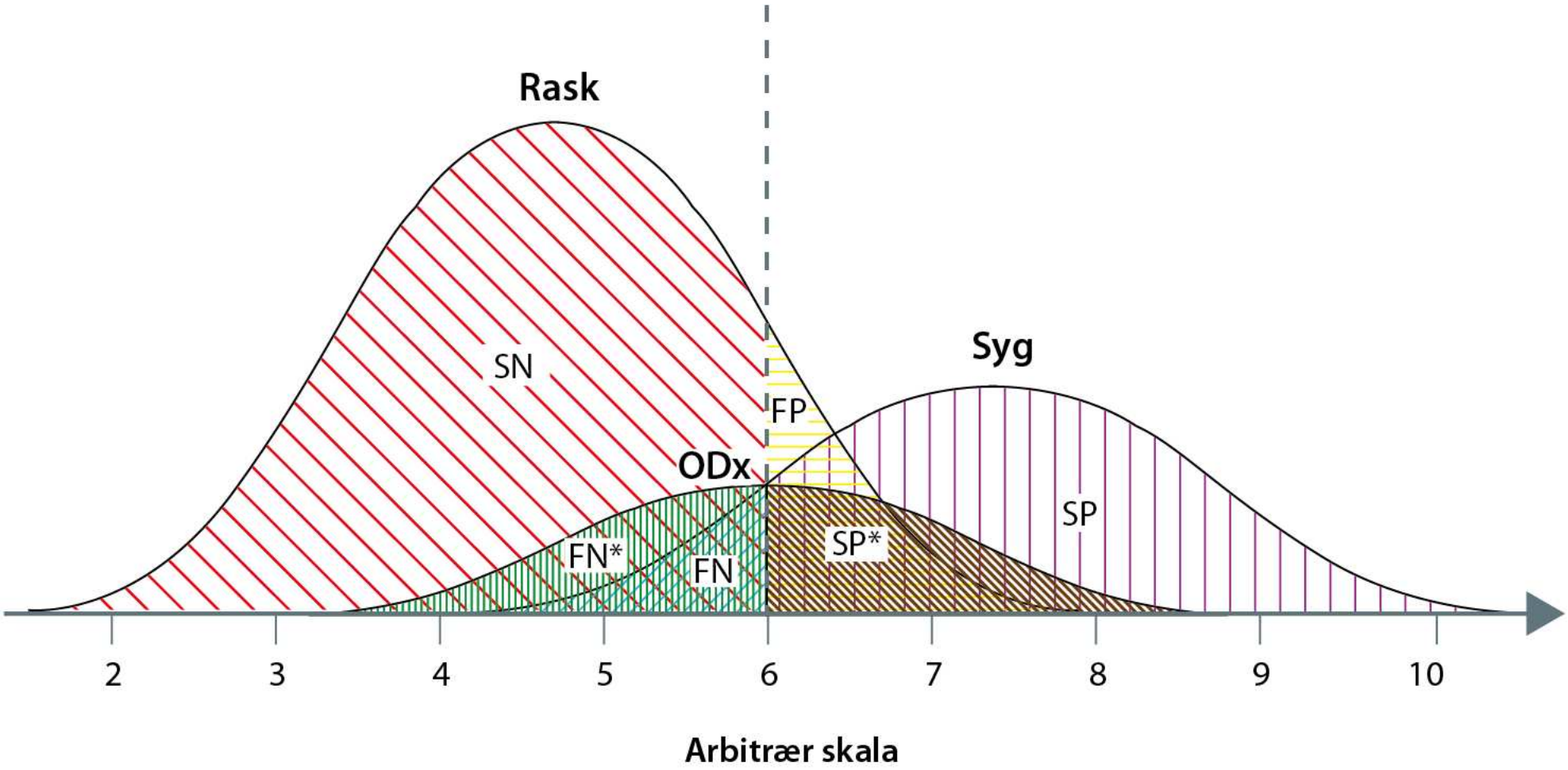
Figur 6.2. PSA-niveauet hos forskellige grupper af mænd: unge raske mænd og ældre mænd med sygdommen prostatakræft.
Fra: Alexandra Brandt Ryborg Jønsson og John Brandt Brodersen: *Snart er vi alle patienter. Overdiagnostik i medicinske og samfundsfaglige perspektiver*.



Figur 6.3. PSA-niveau hos mænd, som aldrig får sygdommen prostatakræft, og mænd, som får sygdommen prostatakræft, hvoraf nogle dør af sygdommen.
Fra: Alexandra Brandt Ryborg Jønsson og John Brandt Brodersen: *Snart er vi alle patienter. Overdiagnostik i medicinske og samfundsfaglige perspektiver*.



Figur 6.4. Spektrum bias og overdiagnostik. Her illustreres den gruppe af mænd, som overdiagnosticeres med prostatakræft.
Fra: Alexandra Brandt Ryborg Jønsson og John Brandt Brodersen: *Snart er vi alle patienter. Overdiagnostik i medicinske og samfundsfaglige perspektiver*. © Forfatterne og Samfundslitteratur 2022



Figur 4.4. Fordelinger af henholdsvis en "Rask" population, en population, som i deres kroppe har harmløse patologiske forandringer, som kan overdiagnosticeres "ODx", og en "Syg" population.
Fra: Alexandra Brandt Ryborg Jønsson og John Brandt Brodersen: *Snart er vi alle patienter. Overdiagnostik i medicinske og samfundsfaglige perspektiver*. © Forfatterne og Samfundslitteratur 2022

		Opdeling af en population i syge, overdiagnosticerede og raske i forhold til en referencestandard og prognose/dødsårsag			
		Syge	**Overdiagnosticerede**	**Ikke syge**	
Diagnostisk test	**Positiv test**	Sandt positivt svar (a)	"Sandt" positivt svar (a*)	Falsk positivt svar (b)	a + b
	Negativ test	Falsk negativt svar (c)	"Falsk" negativt svar (c*)	Sandt negativt svar (d)	c + d
		a + c	a* + c*	b + d	N = a + a* + b + c + c* + d

Figur 3.4. Det diagnostiske paradigme inkluderende overdiagnostik.
Fra: Alexandra Brandt Ryborg Jønsson og John Brandt Brodersen: *Snart er vi alle patienter. Overdiagnostik i medicinske og samfundsfaglige perspektiver*.

Personalised Medicine and Big Data

- Spectrum bias
- Prognosis and diagnosis
- Measurement error

Søren Kierkegaard, 1813-55
Danish theologian, philosopher, poet and social critic

'Life can only be understood backwards; but must be lived forwards'

- BMI
- Cholesterol

Personalised Medicine and Big Data

- Spectrum bias
- Prognosis and diagnosis
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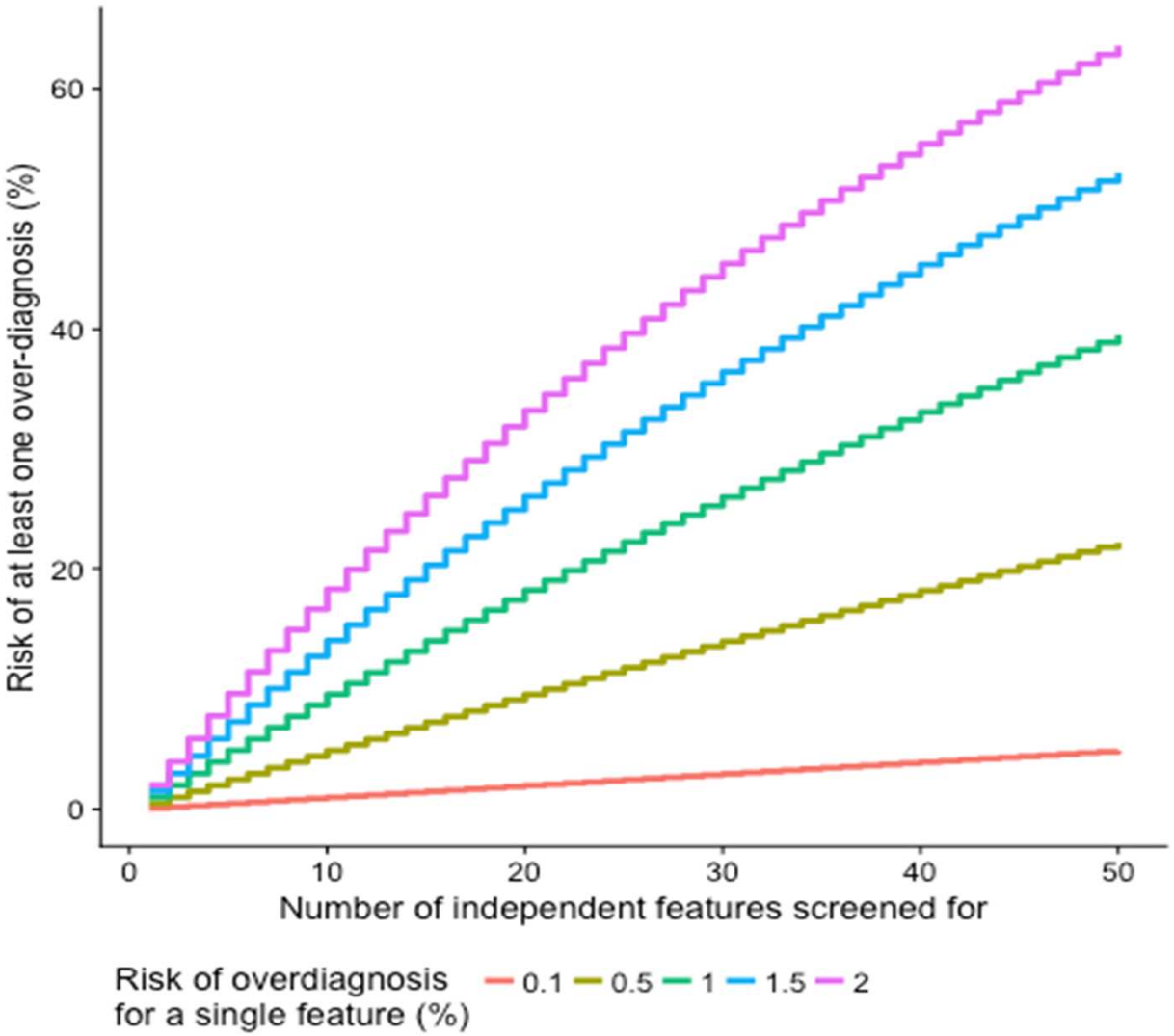

thebmj

BMJ 2019;366:l5270 doi: 10.1136/bmj.l5270 (Published 13 September 2019) Page 1 of 4

ANALYSIS

How precision medicine and screening with big data could increase overdiagnosis

Precision medicine based on big data promises to revolutionise disease prevention but increases the challenge of determining which abnormalities will be clinically important, argue **Henrik Vogt and colleagues**

Henrik Vogt *postdoctoral fellow*[1 2 3], Sara Green *assistant professor*[4 5], Claus Thorn Ekstrøm *professor*[6], John Brodersen *professor*[7 8]

Jønsson & Brodersen. "Snart er vi alle patienter. Overdiagnostik i medicinske og samfundsfaglige perspektiver", 2022

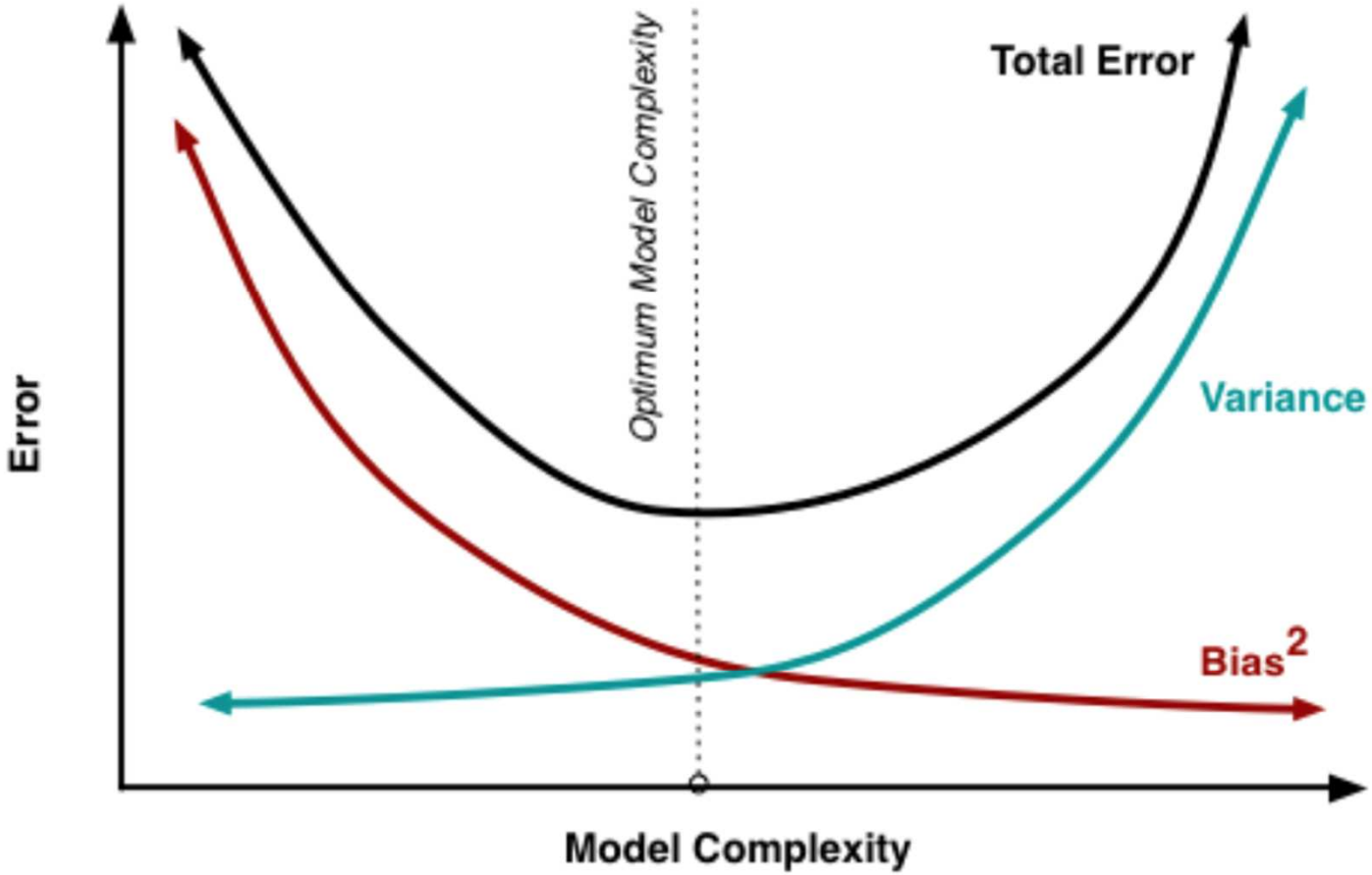

Fig. 6 Bias and variance contributing to total error.

Fortmann-Roe S. Understanding the bias-variance tradeoff. 2012. http://scott.fortmann-roe.com/docs/BiasVariance.html

Thanks for you attention!