



Rijksinstituut voor Volksgezondheid
en Milieu
*Ministerie van Volksgezondheid,
Welzijn en Sport*

The facts are coming! 25 years public health reporting in The Netherlands

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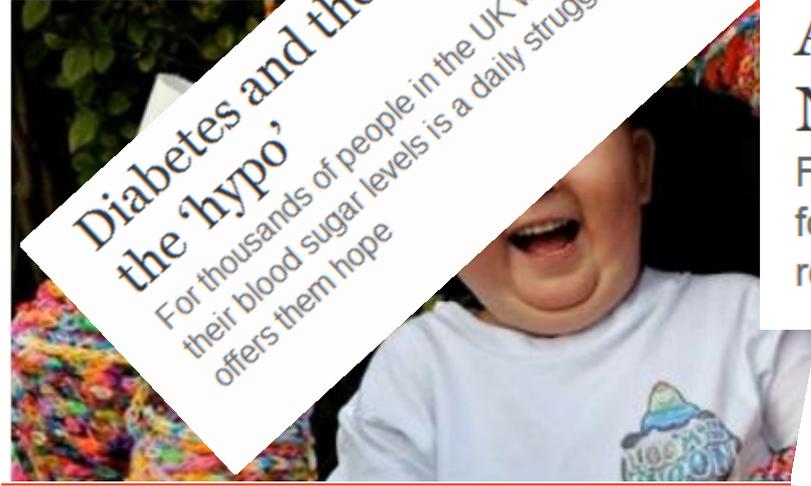


The facts are coming! The facts are coming!

Parents of boy who died from effects of cancer treatment call for more funding

Doctors say more research into child cancer is needed after death of Skye Hall, who had same kind of brain tumour as Ashya King

Sarah Boseley, Health editor
The Guardian, Thursday 18 September



Diabetes and the gadget that could end the 'hypo'

For thousands of people in the UK with type 1 diabetes, controlling their blood sugar levels is a daily struggle. Now a new monitor offers them hope

Diabetes and the gadget that could end the 'hypo'

Ambulance queue death blamed on NHS cuts

Family of Sonia Powell, who died in an ambulance after waiting for more than half an hour outside hospital, criticise care she received

'Angelina effect' more than doubled breast cancer tests in UK, study finds

Angelina Jolie's double mastectomy to avoid cancer 'had bigger impact because of her image as a glamorous and strong woman'



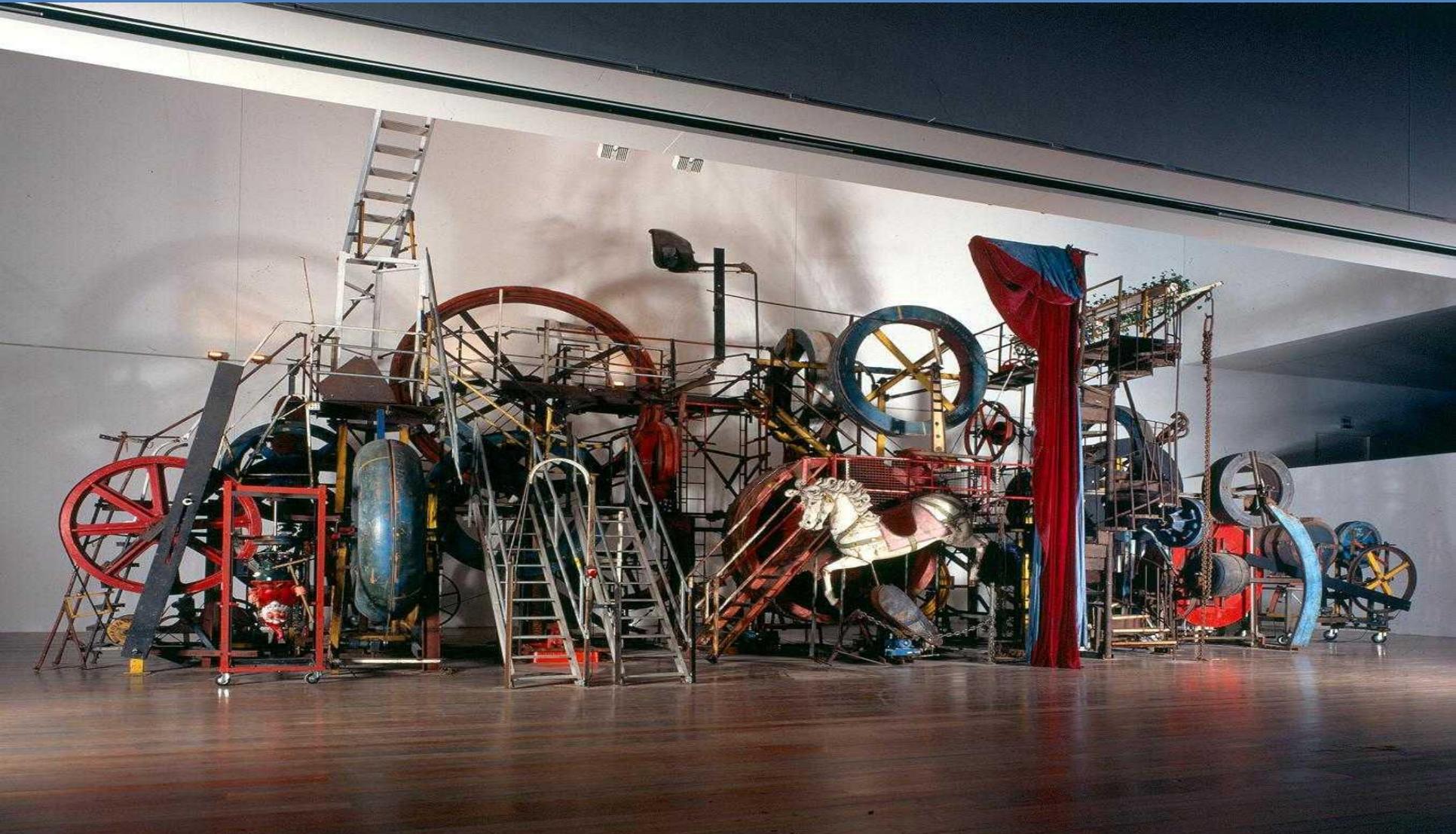
Cannabis use in teens, suicide and school dropout: the jury is still out

A recent study found associations between cannabis use and later poor educational achievement and suicide attempts. But was the cannabis really to blame?

Should we be worried about drinking milk?
Study linked drinking more than a glass a day with higher rates of breast cancer in women and a rise in the risk for men of prostate disease



The Dutch Public Health Information System





Situation 25 years ago

- Every day new (public) health problems on the political agenda, leading to public health information needs
- Fragmented availability of public health information
- No systematic analysis of the public health challenges
- Changing policy-focus from health care policy to public health policy



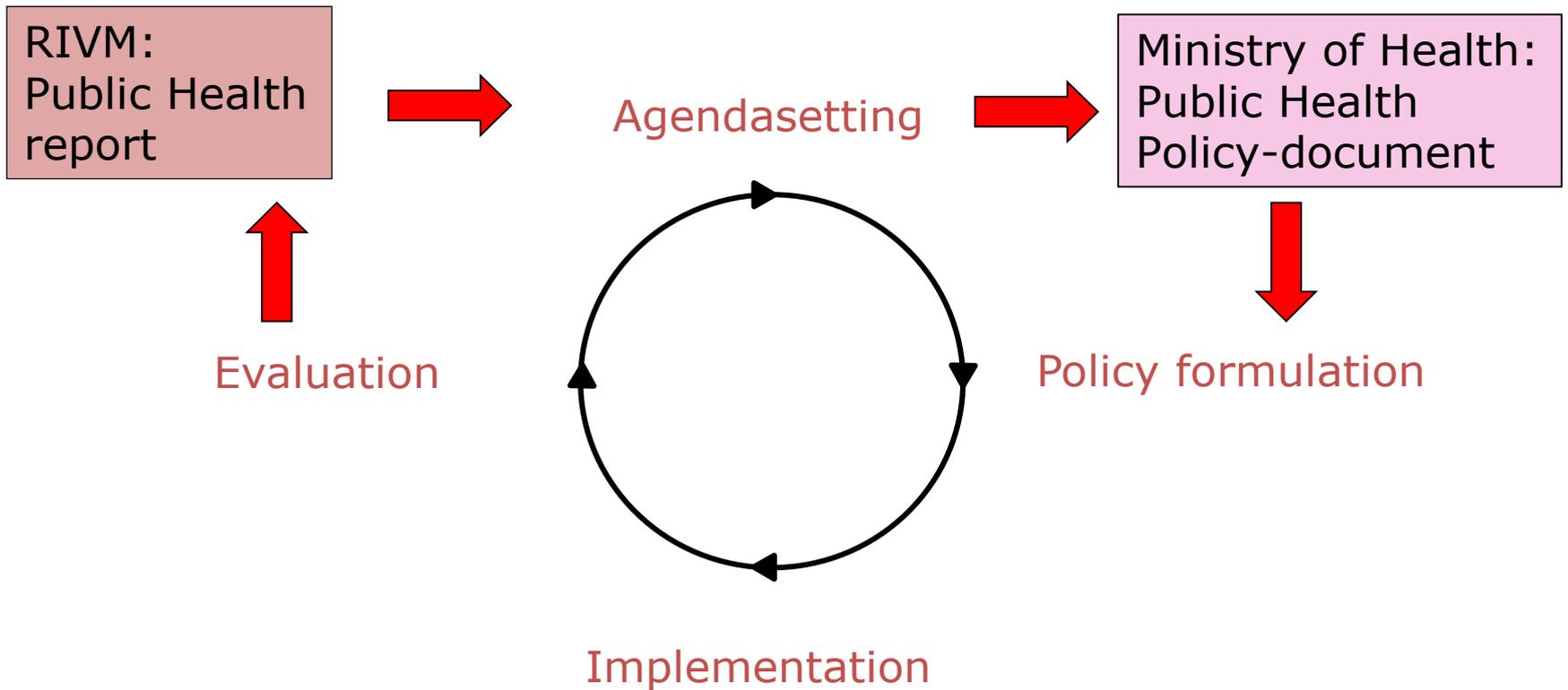
A brief history of Dutch Public Health reporting

1991: Request of the Ministry of Health

- Give an overview and systematic analysis of available information on health of the Dutch population
- With explicit identification of any gaps in the information supply
- To judge the current Dutch public health status
- To support development of new health policy
(not: judge current health policy!)
- For policymakers at Ministry of Health, Regional Public Health Services, healthcare professionals

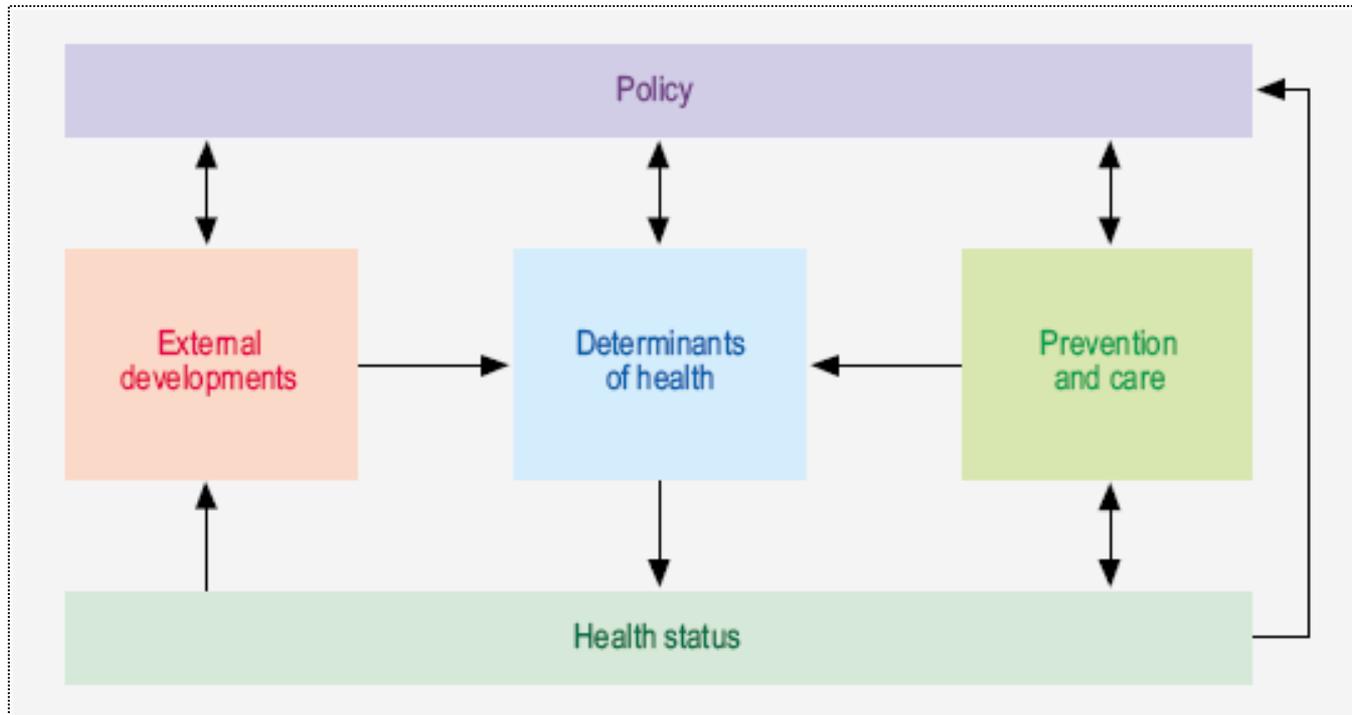


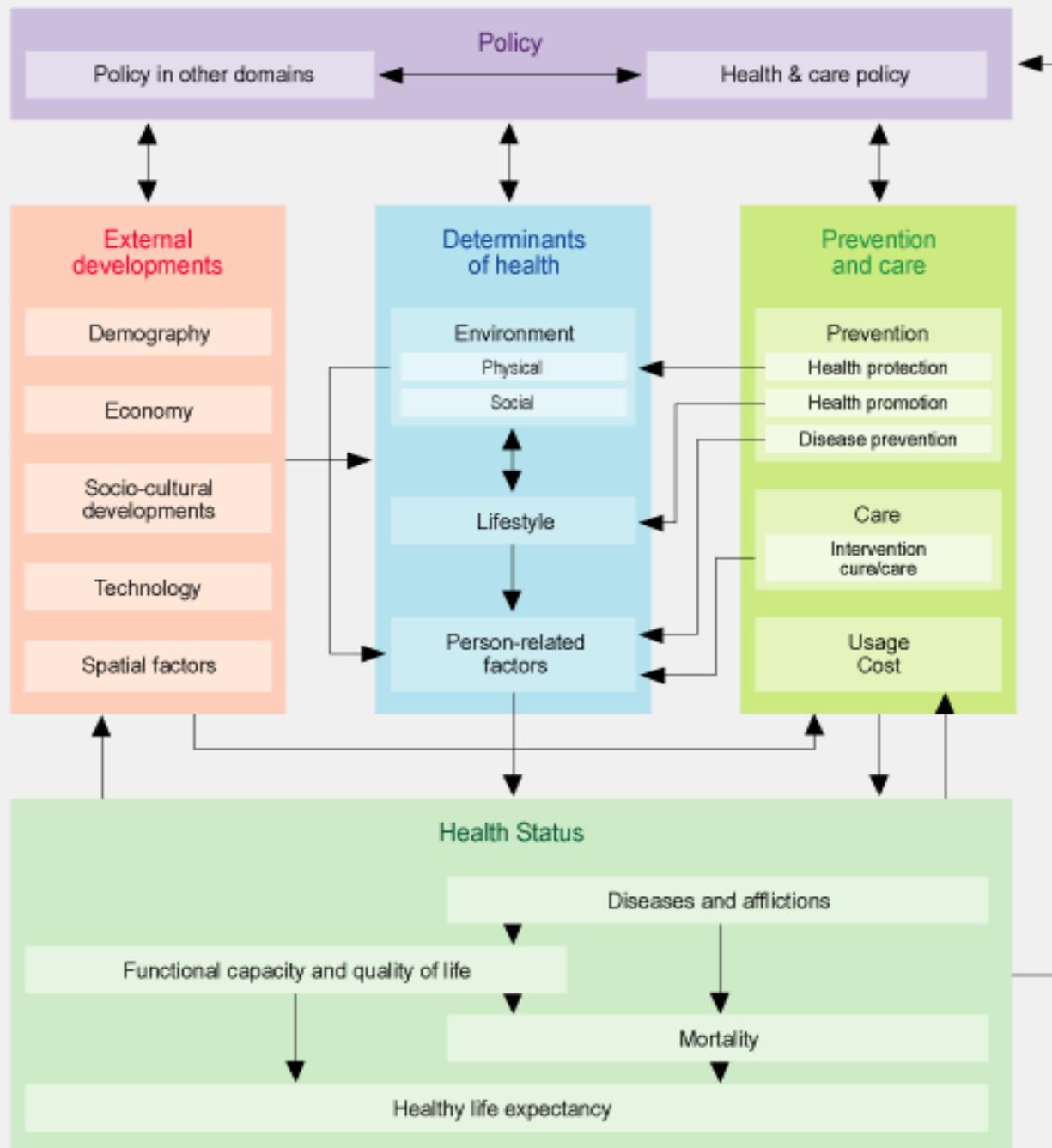
Position in the policy cycle





Underlying model of the Public Health report







1993: First Public Health report



- One book was published, *800 pages*
- Conceptual model of Lalonde, to define the health system, ordering data and information
- Model was operationalised by a set of quantitative indicators
- Enormous job, strong cooperation (250 experts) inside and outside the RIVM
- Report is presented to Minister of Health (Hans Simons)



Response MoH:

- **No follow-up in a health policy document**
- Interesting overview of facts and figures
- Doubts about usability for policymaking, too scientific
- Nevertheless a 2nd edition is requested



1997: Second Public Health report

- Eight books, *2500 pages*
- What is health? How do you measure health?
- Composite measures? Health-inequalities?
- Effectiveness of prevention and healthcare? Healthcare-costs?
- The word 'policy' was systematically removed in drafts by the MoH
- Summarizing report with key-messages (very few policy-recommendations)
- Report is presented to Minister Els Borst



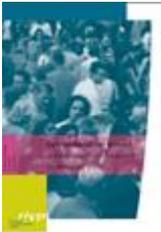
Response MoH

- **No follow-up in a health policy document (except tobacco)**
- Low usability for policymaking, too much pages
- A 3rd edition requested (after much discussion inside MoH))





2002: Third report 'Health on course?'



- Executive summary, *15 pages*
- Summarising report 'Health on course?', *250 pages*
- Websites with information for shortterm policy-support
- Focus on lifestyle, health-inequalities, healthcare costs, international and regional comparisons
- League-table on cost-effectiveness interventions in prevention/cure
- Clear key-messages: 'findings' and 'recommendations'
- Minister informed about key-messages shortly before publication
- Report is presented to resigned Minister Aart-Jan de Geus



Response MoH:



- **Followed by policy document 'Living longer healthy' in 2003, first public health document in 25 years**
- A lot of money for so few pages
- Again discussion about next edition



2006: Fourth report 'Care for health'



- Summarising report 'Care for health'
- Websites with information for shortterm policy-support
- Focus on lifestyle in social and physical context, health-inequallities, healthcare performance, healthcare costs
- Key-messages presented with a clear storyline, with 'findings' and 'consequences of these findings for policy'
- Big point of discussion: Minister did not want the word SEHD in the publication
- Report is presented to resigned Minister Hans Hoogervorst



Response MoH:

- Followed by policy document 'Choosing for healthy living' in 2006
- Followed by new policy document 'Prevention and health' in 2007
- No discussion about next edition



2010: Fifth report 'Towards better health'



- Summarising report 'Towards better health', written as eight essays
- Websites and several background reports
- Focus on lifestyle, health-inequalities, societal costs and benefits of care and prevention
- Report is presented to resigned Minister Ab Klink

Response MoH:



- Followed by policy document 'Health nearby' in 2011
- Policy cycle included in the new Public Health Act
- MoH 'not amused' of an article written by RIVM in Dutch scientific journal about the report





2014: Sixth report 'A healthier Netherlands'

- Small booklet with key-messages and infographics, *20 pages*
- Summarising report 'A healthier Netherlands' online available, with supportive short video
- Websites
- Focus on participation, societal costs and benefits, prevention in cure and care
- Policy-free future trends and four normative future scenarios
- Policy game to explore policy options
- Report is presented to Minister Edith Schippers

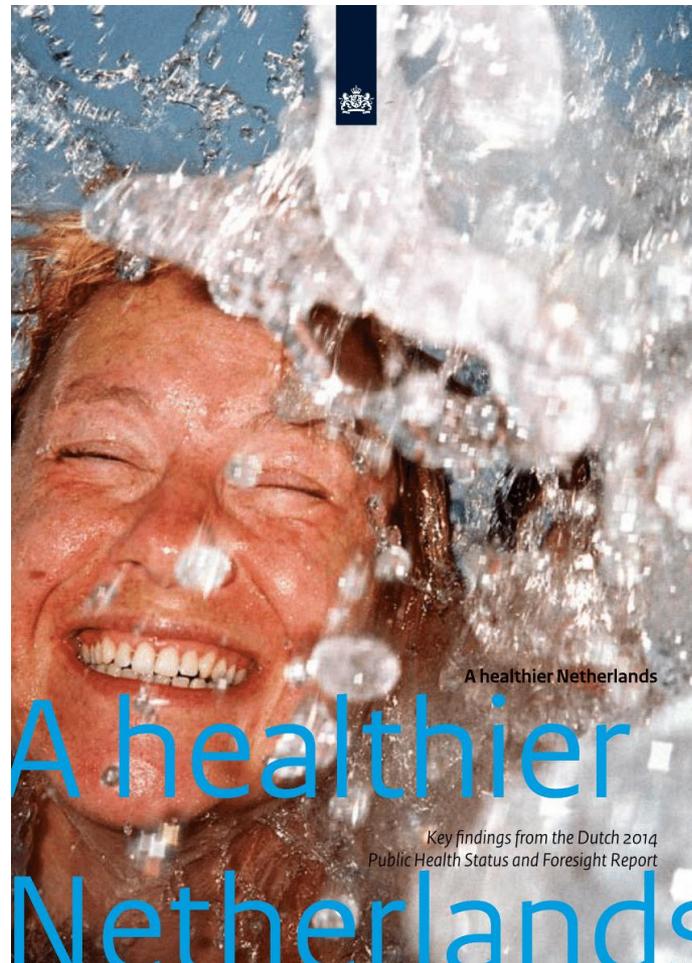
Response MoH:

- Followed by policy document in 2016
- Continuation of prevention program 'All about Health...' (Responsibility deal)
- Strong interest in policy game at local level





A few examples from latest Public Health report



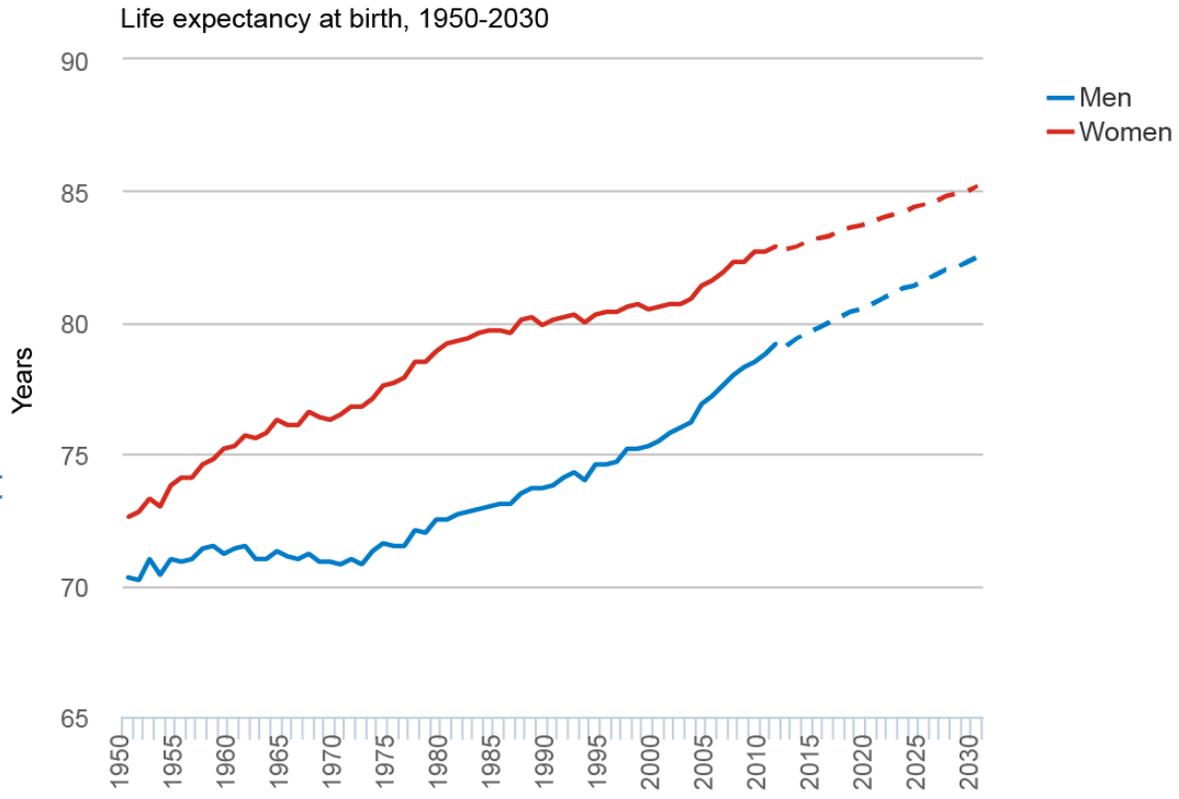


Life expectancy continues to increase

From 2000-2011 a 3 years increase:

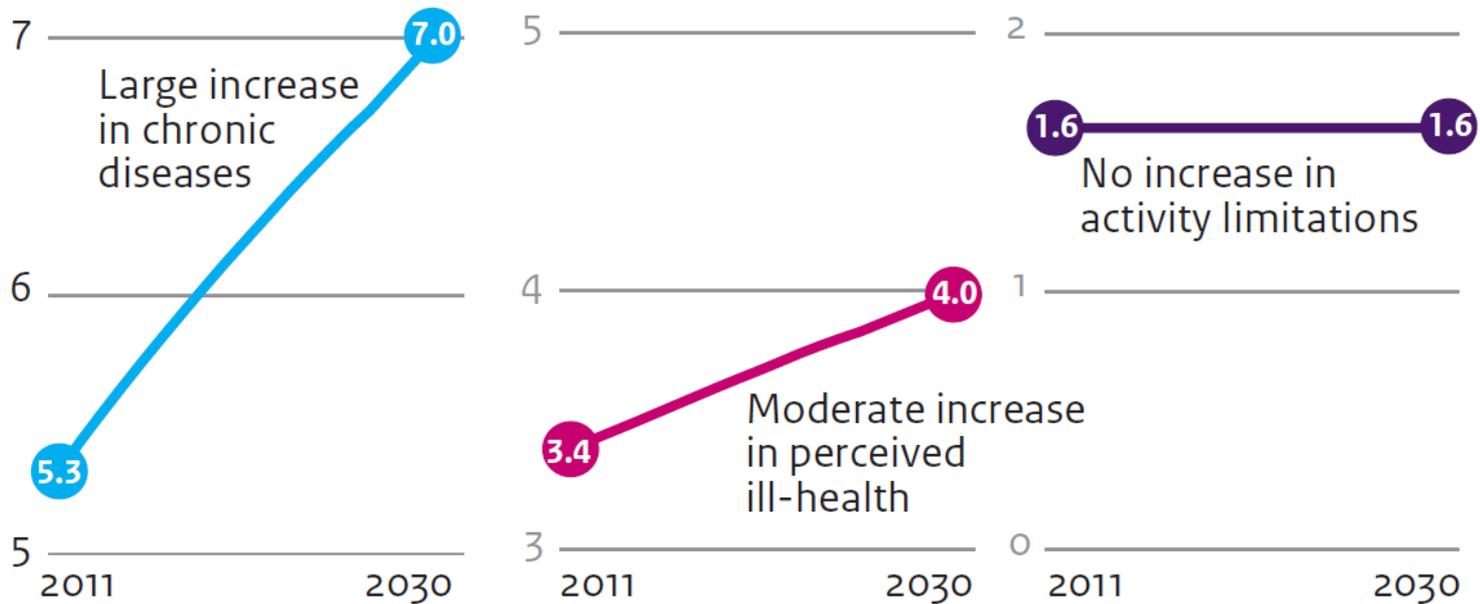
- each week an additional weekend!
- prevention & cure

Till 2030 further increase is expected, less steep than last decade





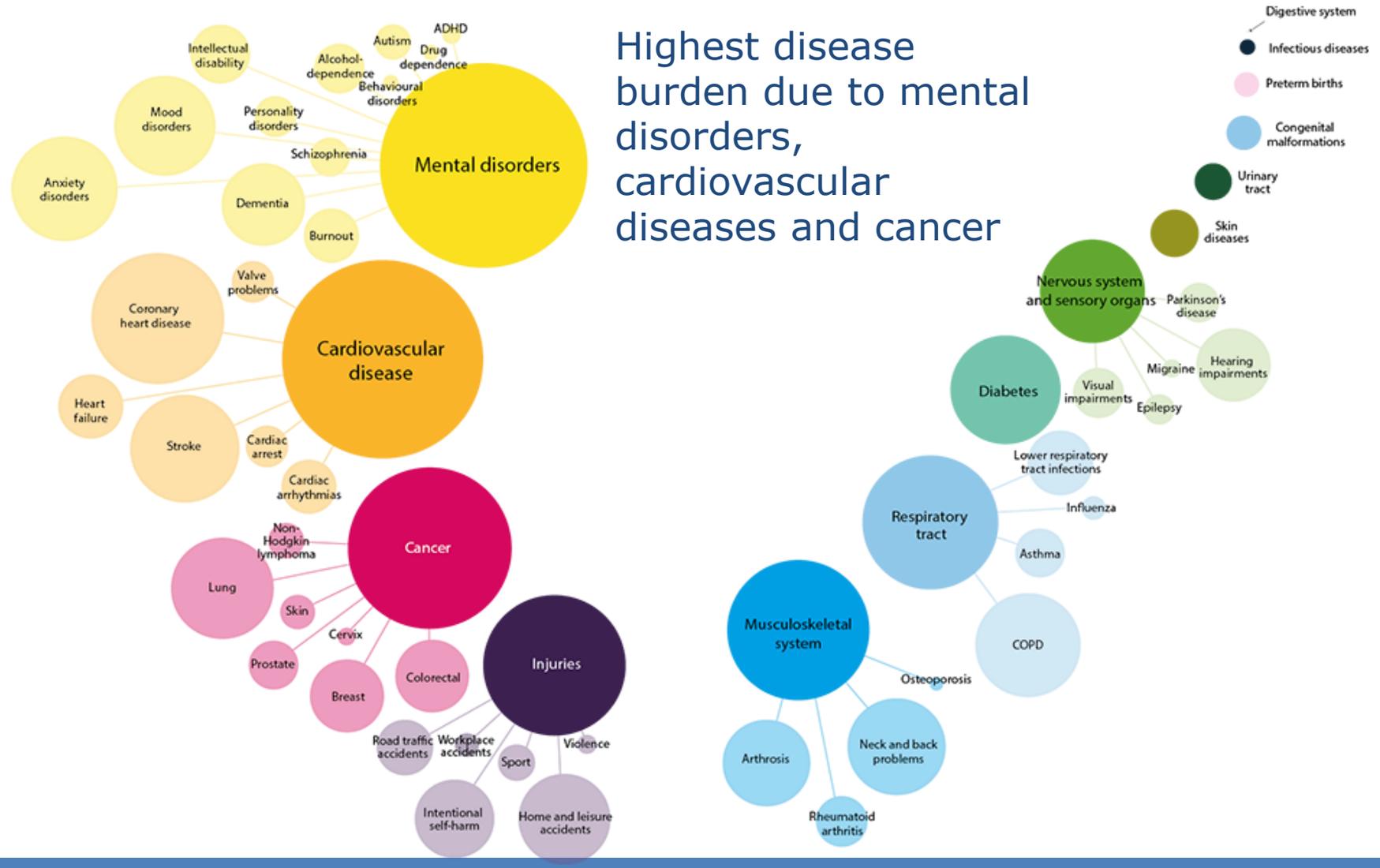
Continued increase in chronic diseases



Moderate effect on perceived health
No effect on participation

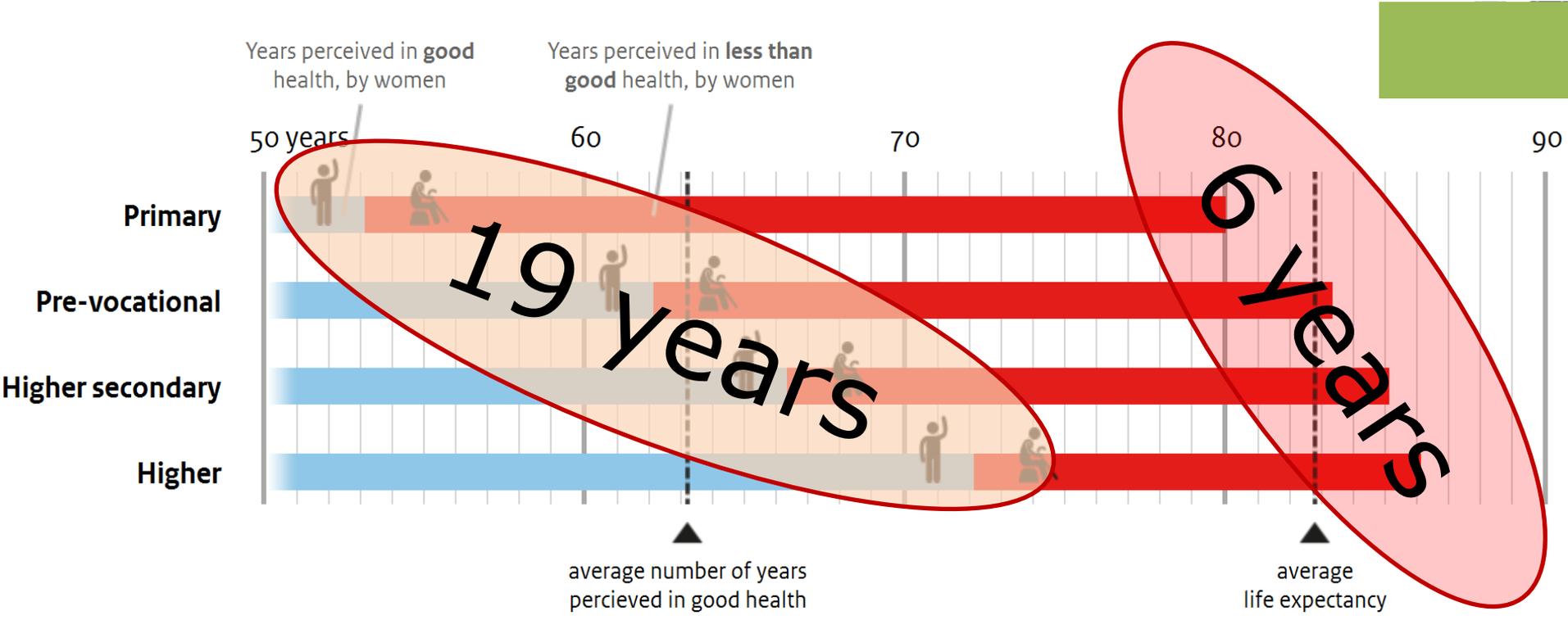


Highest disease burden due to mental disorders, cardiovascular diseases and cancer





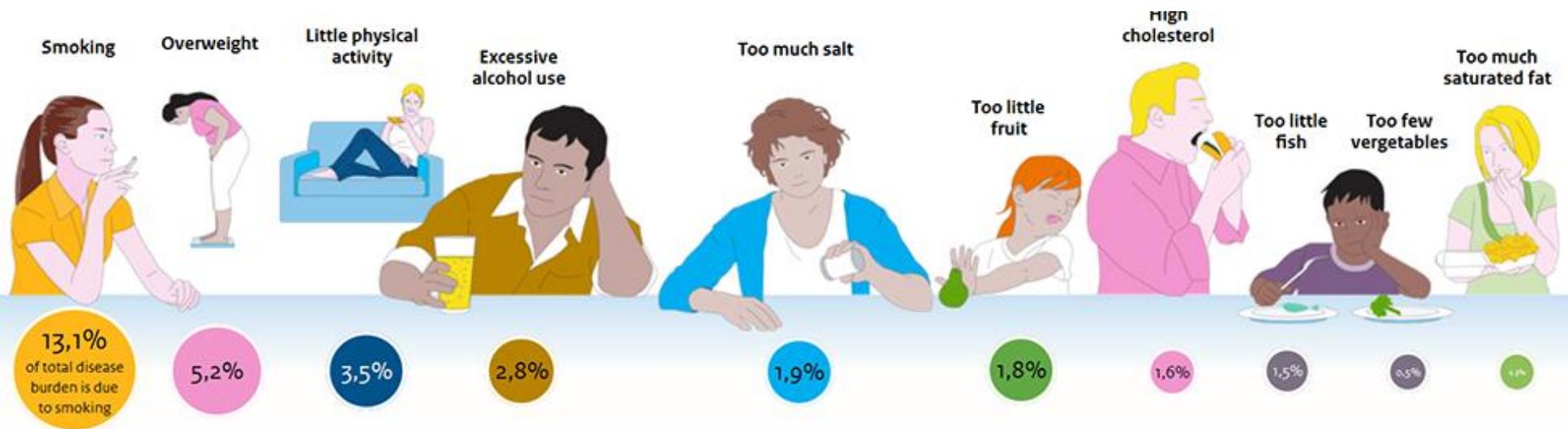
Socio-economic differences remain large





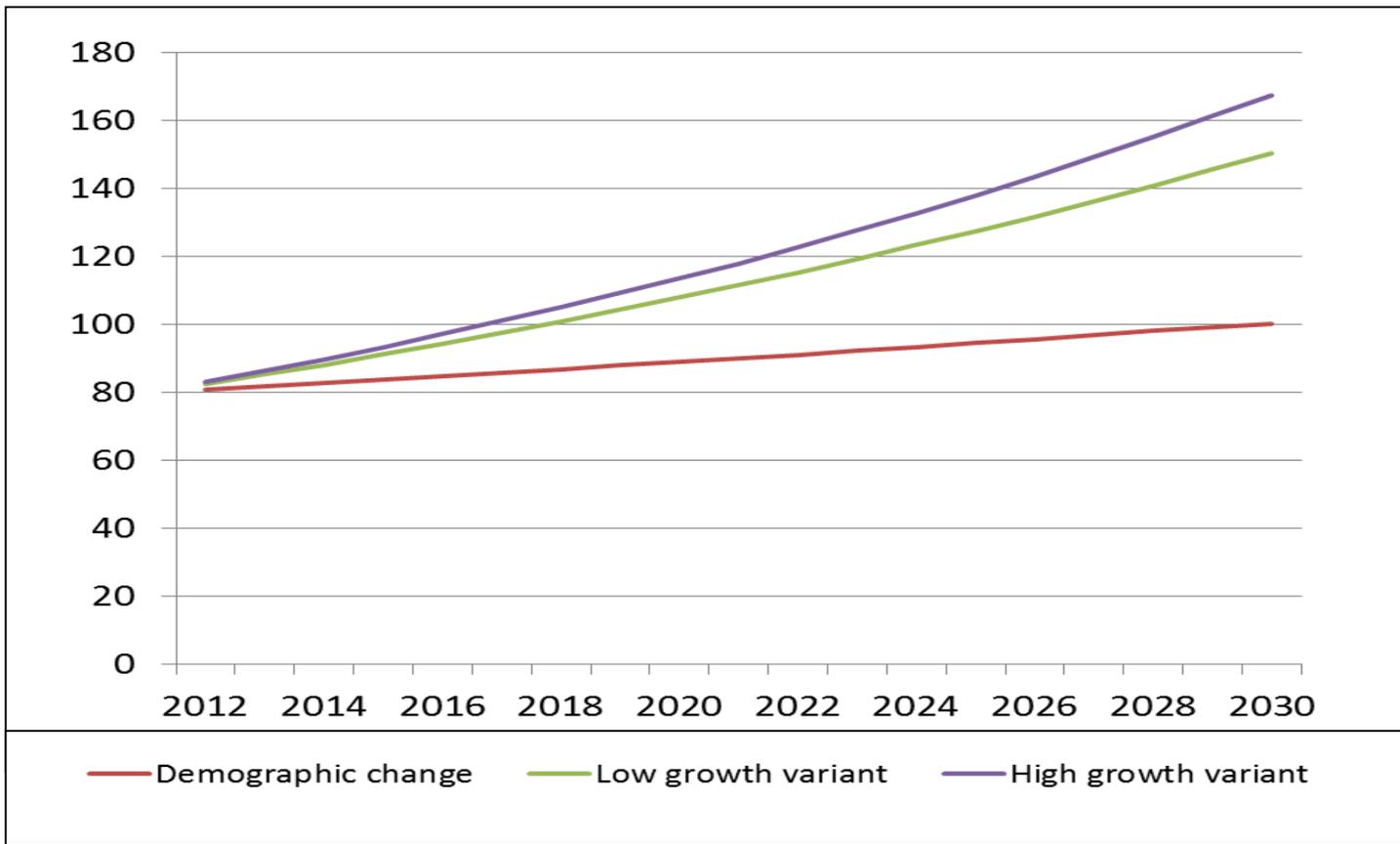
Life style and social/physical environment

- Smoking responsible for 13% of the disease burden
- Followed by overweight, inactivity and food consumption
- Trends: smoking declines, other risks stable
- Workplace-related 5%
- Physical environment 5%





Health care expenditures on the rise ...



... but highly uncertain at what pace



Lessons learned





What makes a good public health report?

Definition of Public Health Reporting:

"... a system of different products and measures aiming at creating knowledge and awareness of important Public Health problems and their determinants (in different population groups) among policy makers and others involved in organisations that can influence the health of a population."

(Måns Rosén, Sweden)

'products' 'activities' 'policy impact'

Måns Rosén in: Achterberg, P.W., Kramers, P.G.N. Health Reporting in the European Union. Bilthoven: RIVM, Report No.: 432504004, 1998



Public Health Reporting Activities

- `a system for collecting, organizing, analysing, reporting, and disseminating data and information on health, diseases and their determinants in a defined population`
- can include annual statistical reports, websites, summaries and reports on the health status of population, conferences on public health issues, health impact assessments, etc.
- focus on the involvement of politicians and policymakers

*H. Brand et al. Evaluation of National and Regional Public Health Reports in Europe.
<http://www.pia-phr.nrw.de>, 2009*



Content: quality aspects

- Conceptual approach: starting from a clear conceptual model, not just from available data
- Integrative approach: relations between health status, health determinants, care and costs, effectiveness information,
- Prospective approach: looking towards the future, trend models, scenario-studies
- Comprehensive, yet with focus on main problems
- Scientific standards: neutral and independent, clear methodology, reliable and timely data, valid indicators, evidence based information

Based on: Brand, 2009; van Bon et al, 2011; Rosenkötter et al, 2016



Content: challenges



Uncertainty:

- Following scientific standards can mean to mention limits of certainty and knowledge.
- Uncertainty has negative effects on the political will to do something and the possibilities to develop and implement policies.
- Challenge to maximize reliability and minimize uncertainty

Finding and attracting interest:

- Often reports provide information and knowledge which are not surprising for policy makers
- Challenge to attract interest by:
 - Benchmarking, league tables
 - Timetrends
 - Regional or international comparisons
 - Future projections

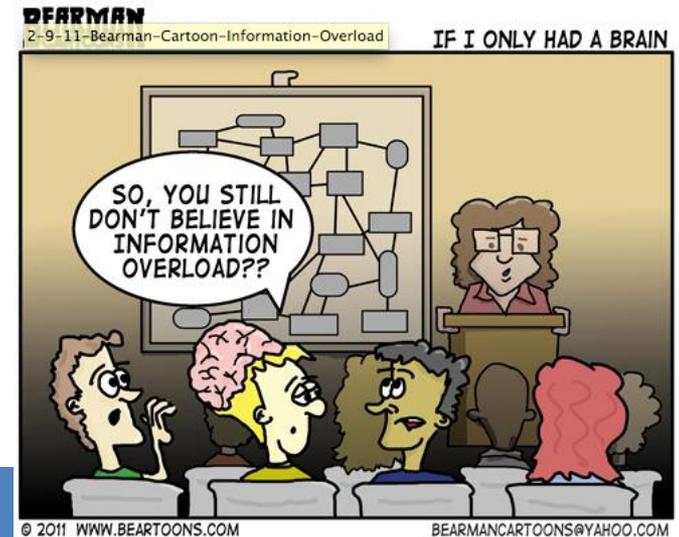




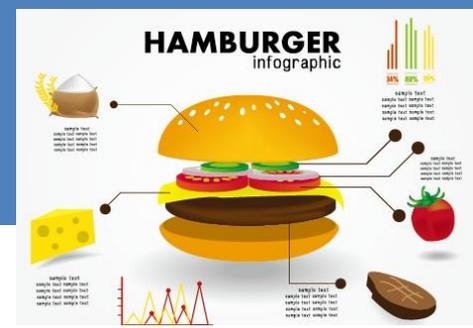
Form: quality aspects

Present relevant information in an attractive way, in a style adapted to the audience, has to be an eye catcher (information overload):

- Traditional report
- Short presentation of key findings e.g. in fact sheet, executive summary, short report, linked with further information
- Narrative
- Infographic
- Newsletter
- Debate
- Website
- App
- Video



Based on: Brand, 2009; van Bon et al, 2011; Rosenkötter et al, 2016



Form: challenges

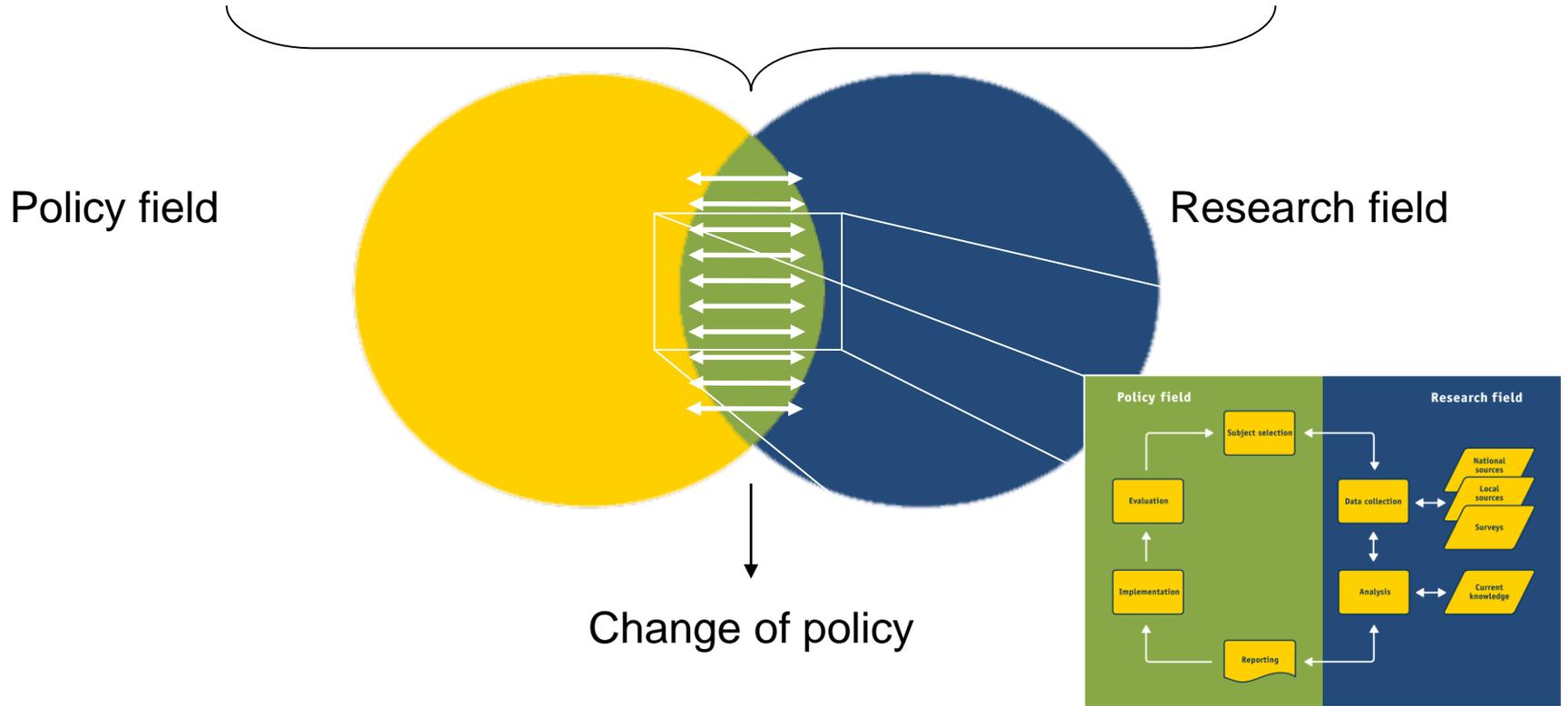
- The media are helpful for the dissemination of results from public health reports, but they:
 - follow their own concept of „news value“;
 - jump from headline to headline;
 - not always follow public health professionals perceptions and perspectives

- Public health professionals have to invest in:
 - professionalising public relations
 - qualifying journalists
 - active corrections of information by media if necessary



Process: organising interaction

Expectations, transfer, adoption and interpretation



de Goede et al. Knowledge in process. Health Research Policy and Systems, 2010

van Bon et al. Towards quality criteria for regional public health reporting. EJPH, 2011



Process: organising interaction

Kok and Schuit developed the Contribution Mapping model

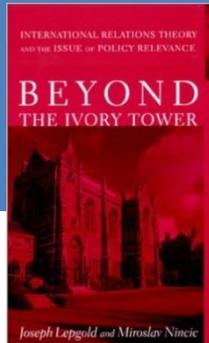
- Formulation Phase
 - 'knowledge question' from commissioner
 - research proposal from PH-institute
 - formal procedure (front stage), informal interaction (backstage)
- Production Phase
 - evidence production according to proposal
 - production of knowledge products: reports, website, factsheet
 - interaction during production process with commissioner (backstage)
- Extension Phase
 - formal transfer of knowledge products (front stage)
 - further dissemination of knowledge products
 - evaluation of research process

In each phase alignment efforts are needed

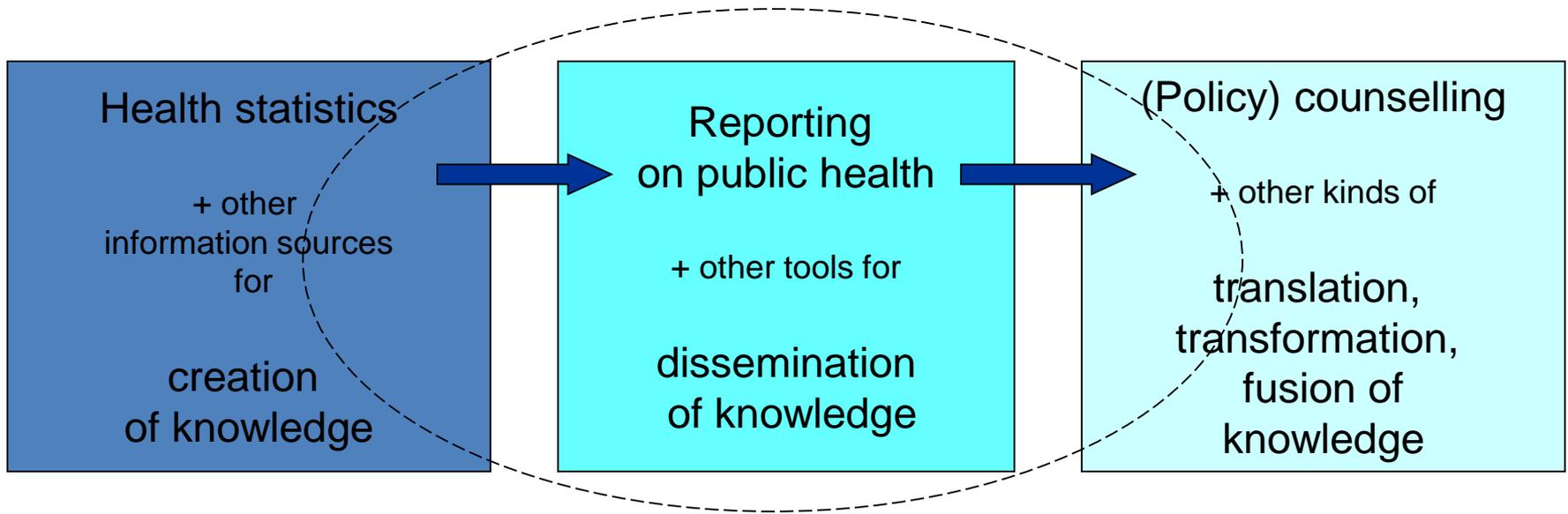


Process: alignment efforts

Goal	The formulation of the knowledge question; exploration of its origin, the question behind the knowledge question and the underlying need for the knowledge products
Tasks and authority	The input of all involved actors (both researchers and policymakers); their responsibilities, knowledge and data exchange by actors during the process and the final authority over the knowledge products
Quality	The research method; conceptual framework, methods and data used in the research project
Consultative structure	The consultative structure of the project; the sharing of relevant information and the relationship between actors
Vertical alignment	Interaction within the own organization; interaction between hierarchical levels and the embedding of the project in the organization
Organizational environment	The environment of the research project; awareness of relevant conditions outside the research project influencing the relationship between investigators and linked actors and /or the research project; incidents, media-events, relationship with other organizations, changing priorities and changing actors
Relevance and timing	The formulation and wording of the research results and timing of the delivery and presentation of the knowledge products
Presentation	The design and structure of knowledge products and the tools for the extension strategy

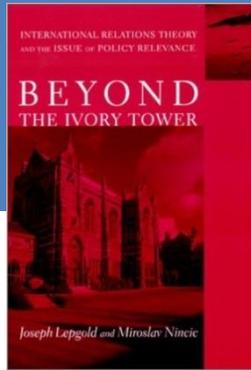


Relevance: position of public health reporting



Public health reporting is at the interface between scientific knowledge creation and policy making, in a more or less 'political' environment

H. Brand et al, 2009



Relevance: quality aspects

- providing timely
- enlightening, e.g. showing relation between health, determinants, care, costs
- giving orientation in a world of competing statistics and positions
- comparing by international/regional benchmarking and trend analysis
- helping to detect issues of major importance/main problems
- meeting the policy maker's expectations and relating to topical policy issues
- describing what the policy options are



Developments in 25 years (1)

Content: adhered to scientific quality criteria

- Accepted by policymakers and scientists as best available evidence
 - just another evidence source → highly relevant evidence source
- Identifying knowledge gaps helped policymakers
 - new large population studies were funded to fill information gaps
- Focus of content changed: closer to political and societal issues
 - started with presenting diseases and LE → diseased (with multimorbidity)
 - health and HLE → ability to participate

 - started with focus on lifestyle → lifestyle in social and physical context
 - cost-effectiveness of prevention → intersectoral policy

 - started with cost of illness → healthcare costs and projections
 - societal costs and benefits



Developments in 25 years (2)

Form: the way of reporting has changed dramatically

- started with 1 report
- series of 8 reports
- executive summary with keymessages and recommendations
- summary report with storyline
- summary report with short essays
- executive summary linked to online report, videos and serious game

Alignment with policymakers during whole process



Developments in 25 years (3)

Process: backstage and frontstage

- RIVM and MoH are at 'close distance', with both formal (frontstage) and informal (backstage) relations (van Egmond et al, 2011)
 - frontstage: formal relationship through role of reports in the policy cycle
 - backstage: a safe interaction and negotiation space
 - RIVM has become 'trusted advisor'
 - alignment efforts are crucial
-
- started as linear process, distinction between scientist and policymakers
 - interaction process, involving scientists and policymakers MoH
 - cocreation process, involving other stakeholders and general public



Developments in 25 years (4)

Policy relevance: getting closer to policymaking process

- started with facts and figures → integration and interpretation
- enlightenment → policy recommendations →
- policy game, to explore effect of different policy measures

- nice to know → need to know → major building block for public health policy document and priority setting → included in Public Health-act

- one stakeholder (MoH)
- multiple stakeholders (MoH, regional health services, municipalities, healthcare providers)

Three times cabinet has resigned shortly before publication of PH-report

These reports were followed by good health policy documents

Policymaking process continues without politicians in charge



**KEEP
CALM
AND
ALIGN
ON TIME**



fuse

The Centre for Translational
Research in Public Health

www.fuse.ac.uk

One (very big) myth, several metaphors, and some conceptual challenges for translational research in public health

Rosemary Rushmer

Teesside University, UK r.rushmer@tees.ac.uk

There is something about....

- The nature of public health issues
- The way we produce evidence
- The metaphors we use to show how evidence is shared
- The ontological differences between research (understanding, knowing) and practice (doing)

That make the creation, sharing and using of evidence tricky....

all

Once upon a time...

Public health evidence...
intervention... RCT trial...



That would
never work
here...

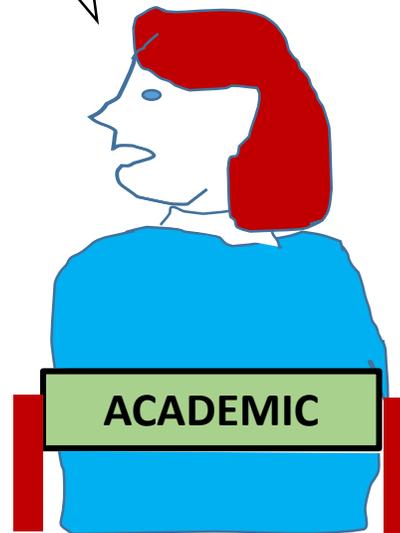
PRACTITIONER

ACADEMIC

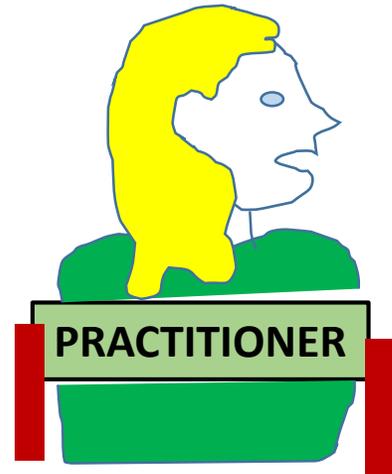
WHAT!!

**...but things are
different here...**

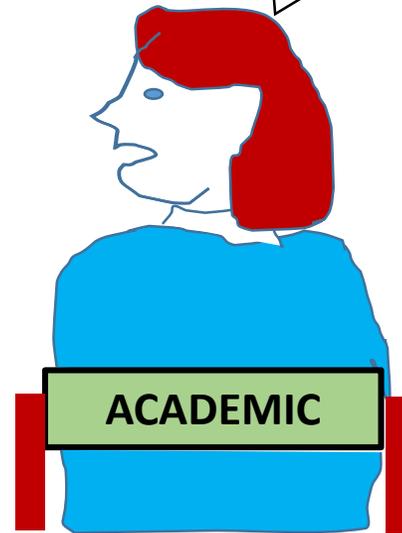
**...this is RCT evidence...
that's the gold standard...**



No I mean... our set-up is different, our services... our people too - different traditions and what people want...



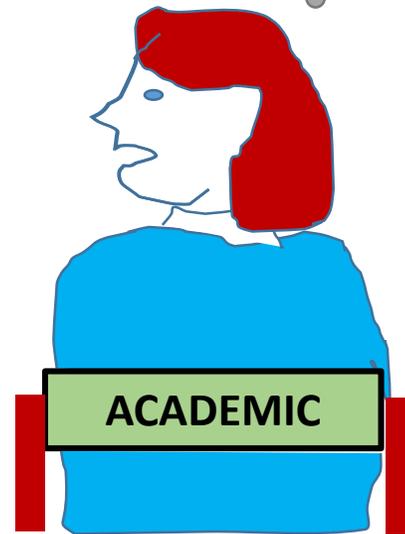
...no you don't understand RCT evidence is generalisable – that means it will work anywhere



She thinks I'm stupid...

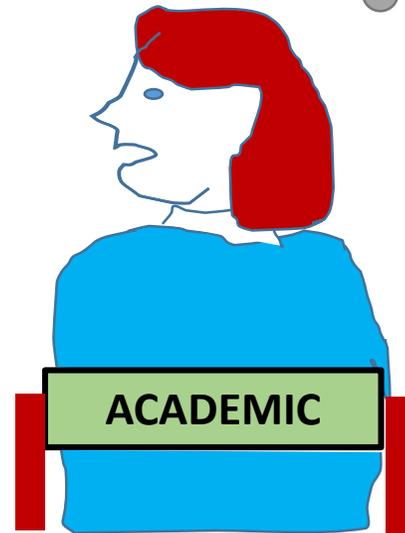


Oh dear, she thinks that I think she's stupid



...I don't...
but there are some training needs...

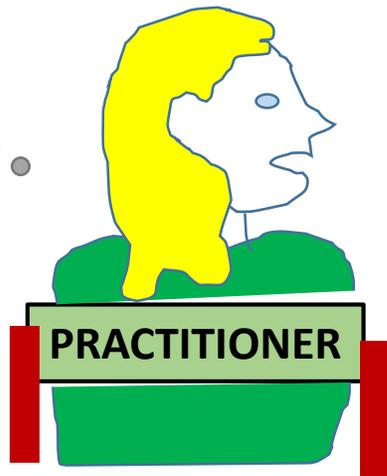
...it just doesn't fit



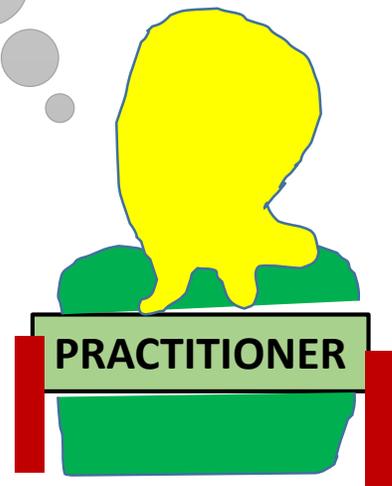
**Sounds like
an excuse
to me...**

She's not listening...

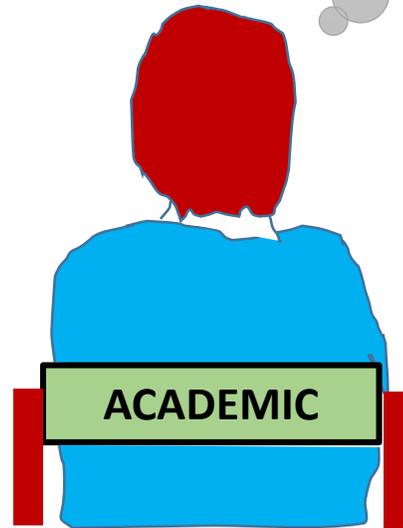
You too!



No good – too ivory tower... doesn't understand the real world..



No point talking any more she'll never try it...



Question:

Is the evidence from Randomised Controlled Trials (RCTs) generalizable - meaning that the findings apply, and 'work' anywhere?

X

RCTs:

- Have high internal validity but low external validity
- Establishes *proof of concept*
- Field trials will look at field barriers... but even then *fields differ*

The Evidence Ecosystem – one of many metaphors

Evidence use as a petro-chemical production line

- Assumptions that the metaphor makes
- Other hidden metaphors...
- Opportunities for seeing things differently
- New challenges and new roles



evaluation funders

e.g. government,
NGOs, charities,
research councils



storage

e.g. journal,
libraries, online



Intermediaries

evidence producers

evidence pumps

evidence synthesisers

evidence end users



drilling, mining and
creating evidence

e.g. Universities,
National Statistics,
private sector



deal with the targeting
and flow of evidence

e.g. Royal Colleges



mix and blend the 'raw
ingredients'

e.g. Cochrane, Campbell, JBI
reviews, Practice guidelines



Consumers

e.g. Policy-makers,
commissioners, managers,
social workers, doctors,
nurses, AHPs, Police, the
public.



evaluation funders



storage



Intermediaries

...arrows need to go both ways

evidence producers



evidence pumps



evidence synthesisers



evidence end users



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evaluation funders



storage



Intermediaries

evidence producers



evidence pumps



evidence synthesisers



evidence end users



What counts as 'evidence'? ...multiple types of knowledge



evaluation funders



storage



Intermediaries

evidence producers



evidence pumps



evidence synthesisers



evidence end users



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...open, leaky, political complex system

...end-users are not compliant machine parts



evaluation funders



storage



Intermediaries

...evidence is stored in hearts
as well as minds

evidence producers



evidence pumps



evidence synthesisers



evidence end users

Conceptual not physical 'products'



...we don't use evidence as a product
but as ideas and new understandings



evaluation funders



storage



Intermediaries

...more active role
for intermediaries

...funders need to fund a
different type of research

evidence producers



evidence pumps



evidence synthesisers



evidence end users



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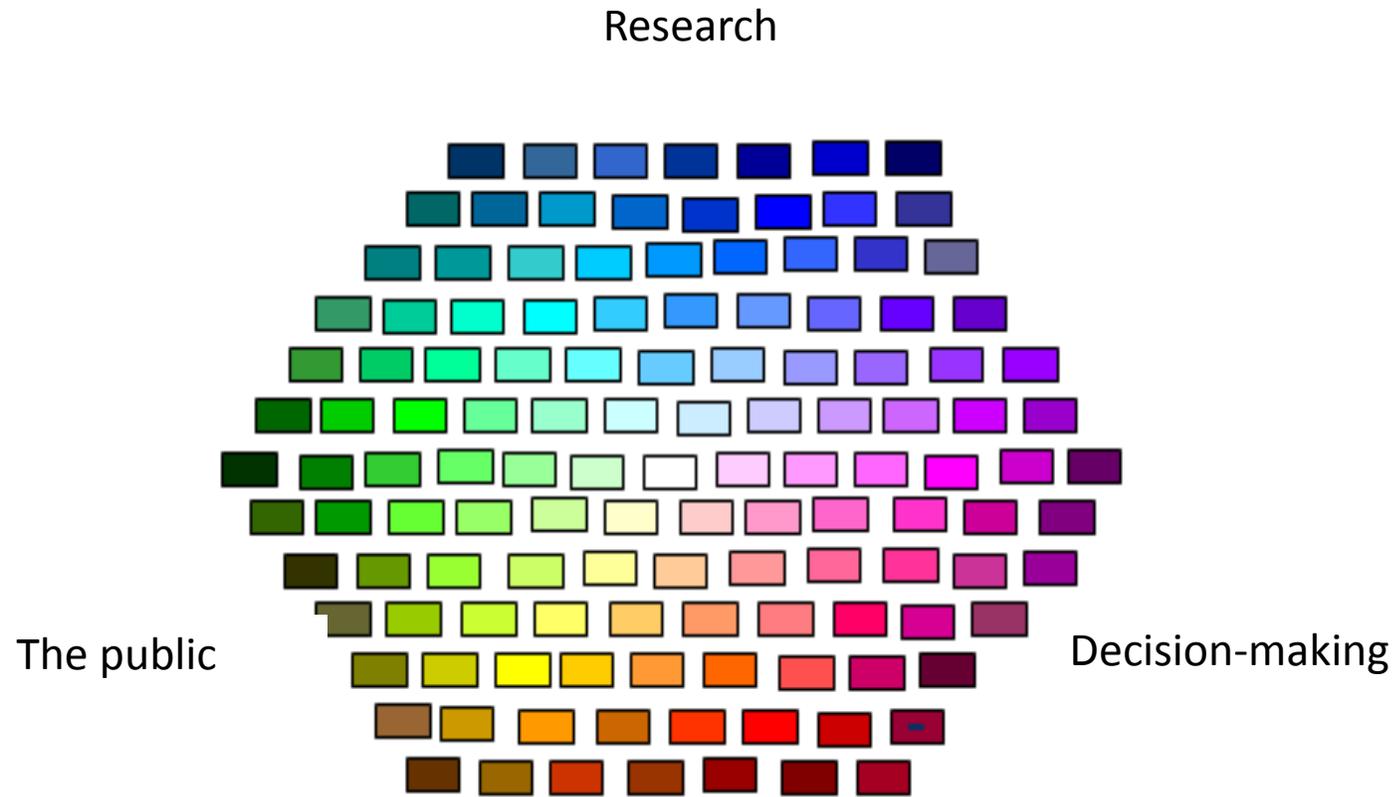


Challenges for translational researchers

- Many ways of knowing – why privilege research evidence?
- How do we understand how evidence is blended?



Blending evidence



New opportunities....

- If using evidence is about creating new understanding then...
- Look at the complexity don't 'control-it-out'
- Doing research with end-users not doing research on them? (co-creation, embedded research)
- Look at what is working and identify why (the active ingredients that could be repeated in other places)
- New conversational spaces to share knowledge (two-way) to inform decision-making



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