

# Different types and purposes for cancer registries

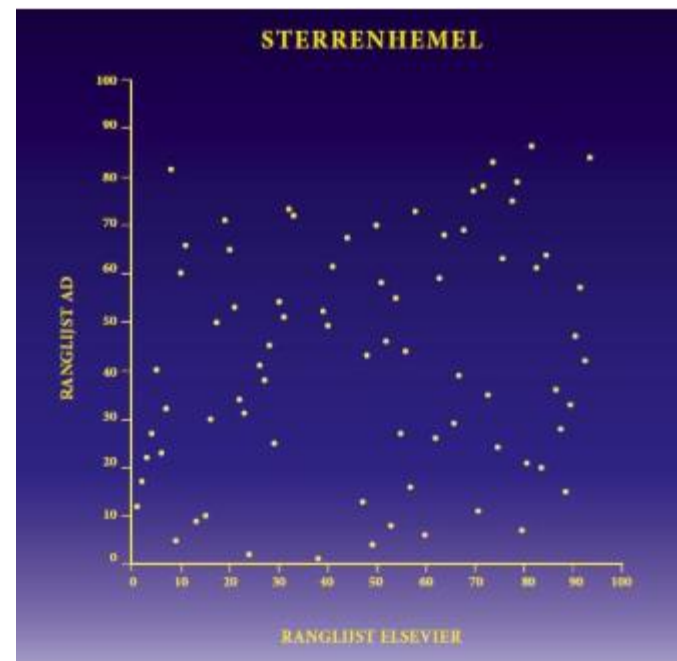
- Prof dr Hans Gelderblom, medical oncologist Leiden University Medical Center, The Netherlands

# Different registries

- For quality control
- For outcomes research
- For clinical research
  
- Examples from The Netherlands

# Why registries for quality

- To get rid of useless ranking lists
- To see how you are doing compared to others
- To measure improvements over time



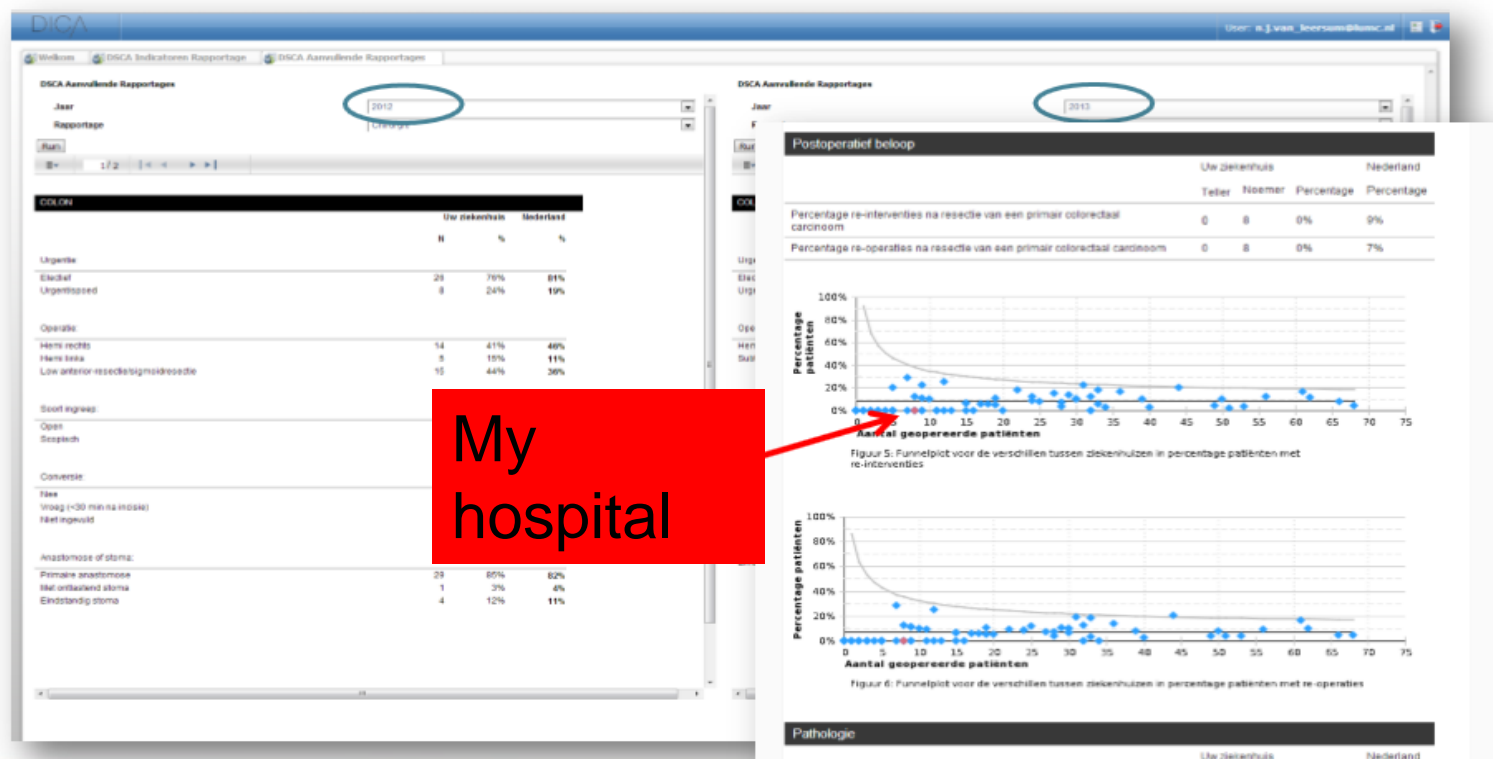
## Dutch Institute for Clinical Auditing

- Facilitating organisation
- Bottom-up, professionals driven
- Webbased datacollection system
- Online dashboards
- Linking careprocess – outcomes – costs
- Patient portal
- Annual Quality Conference
- Transparency

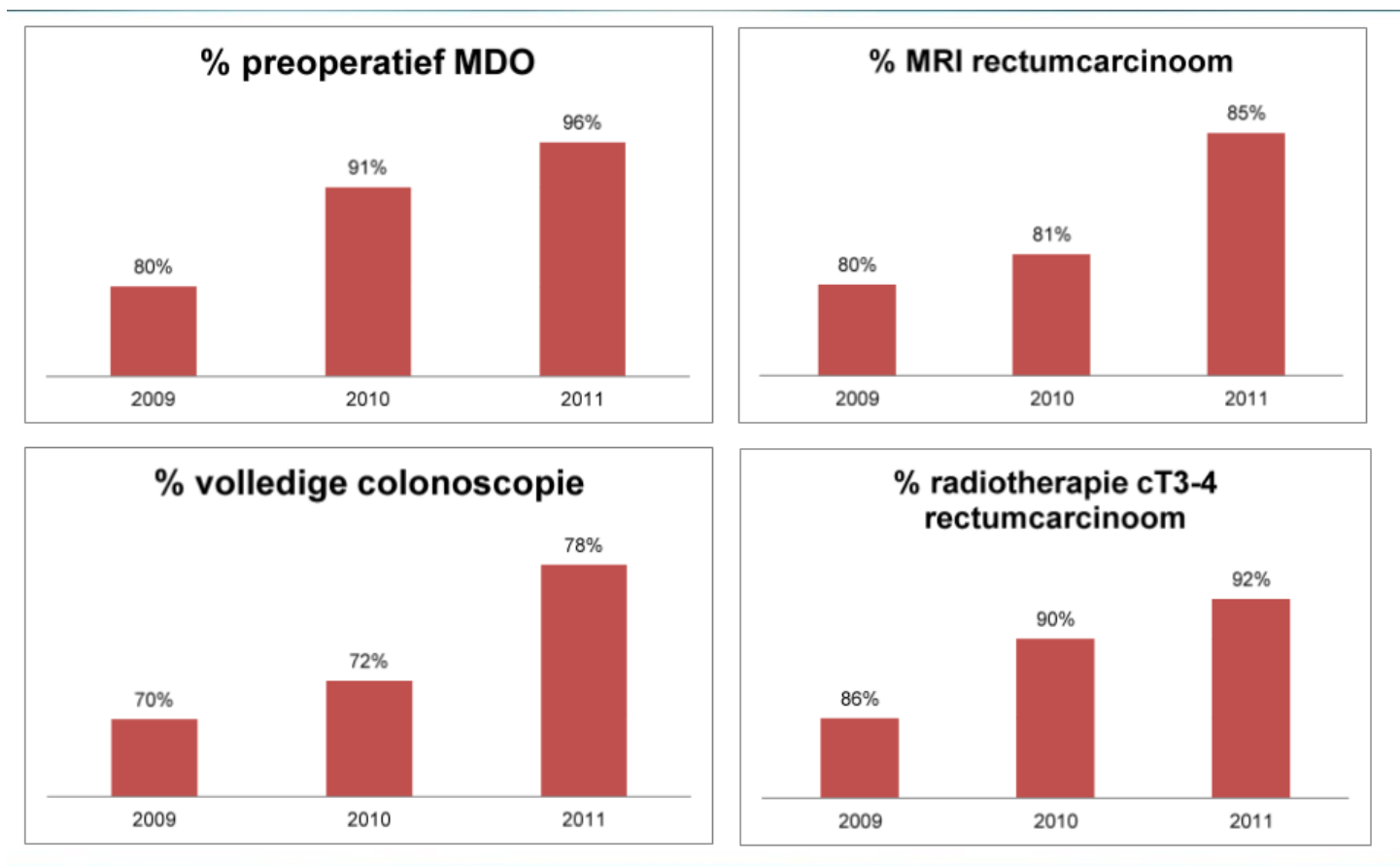


# Dutch example: Dutch Institute for Clinical Auditing

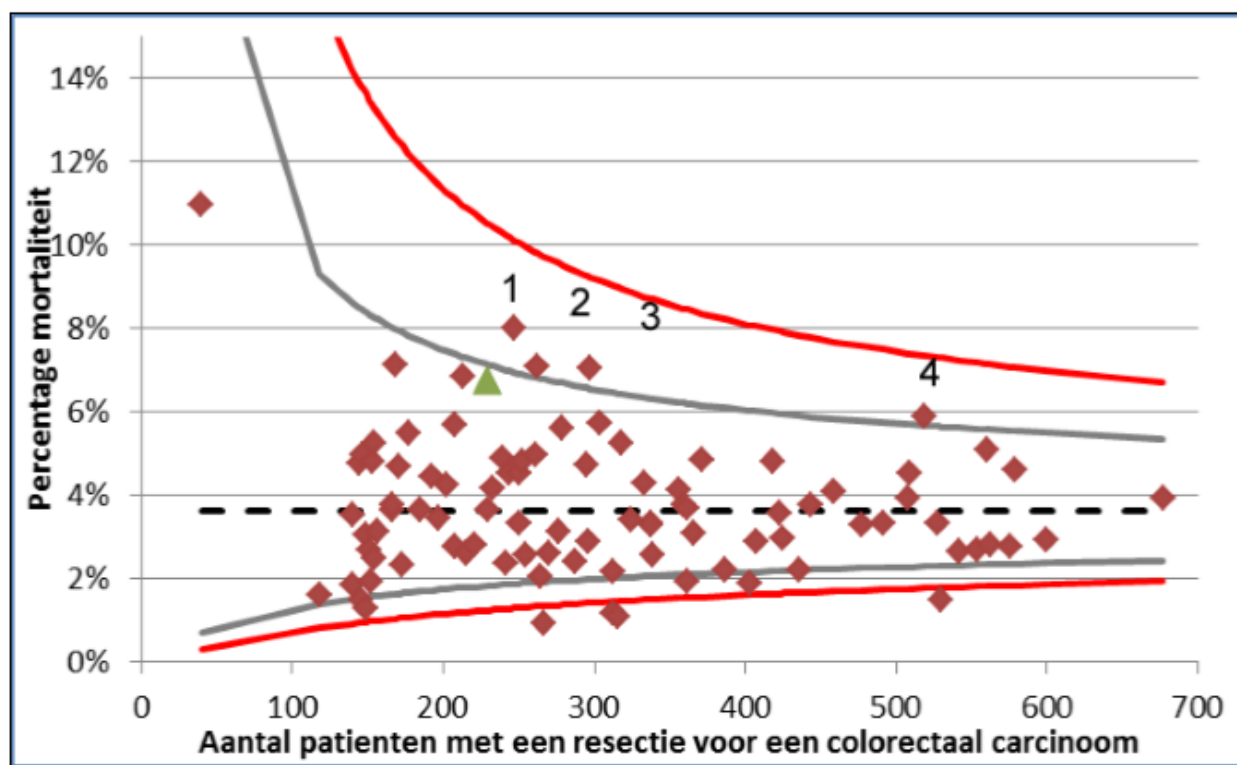
## *MijnDSCA*: web-based feedback



# Measuring improvement over time



# Naming and shaming: it's not just a game!!



# Points of attention for Quality Registries

- Patients and physicians in the lead
- Proper case mix corrections
- Avoid cherry picking medicine
- Improvement of EPD interface saves money
- Open data versus your own feedback
- Governance important!



# Next step: example melanoma

2012 introduction new expensive drugs for melanoma

Dutch answer: centralisation and DMTR



# DMTR

- Jointly payed by health authorities and pharma
- Independent datamangement
- Goals
  - Quality control
  - Health outcomes research
  - Patient reported outcomes
  - Platform for research

# Research in registries

- Link to quality registries avoids double work
- Link to (virtual) biological databank
- Informed consent needed?
- Platform for studies in rare subtypes
- Alternative to prospective trials in rare tumours
- Governance important!

# Examples of EU research registries

- CONTICANET
- EUROBONET
- SPECTA platform
- Chordoma Registry

# Take home message

- Registries are hard work and costly – but they pay-off
- As they improve quality
- As they can monitor rightful use of expenses
- As they can be linked to PROMS
- As they can serve as a basis for research- and thus innovation