IKNL (Netherlands Integral Cancer Institute)

NKR+ : updating of the Netherlands Cancer Registration
Data in oncology

MDO (1) : 100,000 patients/year
MDO (2) : ??? patients/year

Uniform in hospital presentation of patient data
Digitalising of guidelines
Uniform documentation of MDO’s
National database with expert defined datasets
Palliative care

NKR+
- tumorspecifiek
- minimale dataset
- repal
- prado

richtlijnen
- onco/niet-onco
- normen
- transmurale
- zorgpaden

publiek domein
ziekenhuizen
- thuis
v&v huizen
- hospices

zorgdomein
politiek domein

MTA
- kwaliteit
- van leven
- kwaliteit
- van sterven

verbeteren:
deskundigheid ↑
samenwerken
gedragsverandering
benchmarking
Facts and figures IKNL

• by:
  140 NKR datamanagers, 70 study datamanagers,
  50 advisors, 40 researchers, 20 guidelines developers

• with:
  400 consultants for clinical oncology
  200 consultants for palliative care
  10,000 professionals in networks and working parties
Audits and population based registry

Audits according to DICA:
- registration by medical specialist of specific medical intervention
- short cycling reports to individualised specialist and hospital
Population based registry NKR:
- registration by datamanagers of all relevant data from diagnosis to death or apparently sustained cure
- yearly reports to individualised hospitals and comprehensive cancer networks
Challenges

simplifying presentation of MDO data in order to handle the really ‘gray’ issue of decision making and to accept more data

relating diagnosis data to treatment decisions

relating clinical data to tissue banks and research programs