

Utilizing Cancer Registry Data

Giske Ursin, MD, PhD

Director

Cancer Registry of Norway

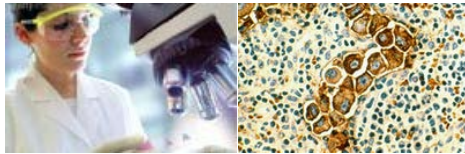
Cancer Registry of Norway

- Population-based, national coverage
- Compulsory reporting of cancer since 1952
- Personal identification number
 - Correct coding of multiple primary tumours
 - Follow up of patients for survival analysis
 - Correct assessment of the population (denominators for cancer rates)
 - Linkage with other sources/registries

31 651 incident cancer cases in 2014



Cancer registration in Norway



Pathology reports



Clinical reports



Death certificates



Hospital patient administrative systems/
Norwegian Patient Registry

Legislation

- The Cancer Registry may without consent contain data relating to persons who have or have had cancer, precancerous conditions, or benign tumours in the central nervous system:
 - name and personal identity number
 - address and municipality of residence
 - the site of origin of the cancer
 - morphological diagnosis
 - spread at the time of diagnosis
 - metastases
 - relapses
 - basis for diagnosis (imaging diagnostics, histopathological examination, cytological material, other type of examination)
 - cancer treatment received by the data subject (patient), indications and contra-indications for treatment, method of treatment, as well as any complications or side-effects
 - date and cause of death

Core variables

- Administrative information
- Site and morphology
- Date of diagnosis
- Basis of diagnosis
- Stage at time of diagnosis
- Some information about treatment

Cancer registry data:

Great for studies where the endpoint is cancer.

Can these registry data help us understand who benefits from their diagnosis and treatment?

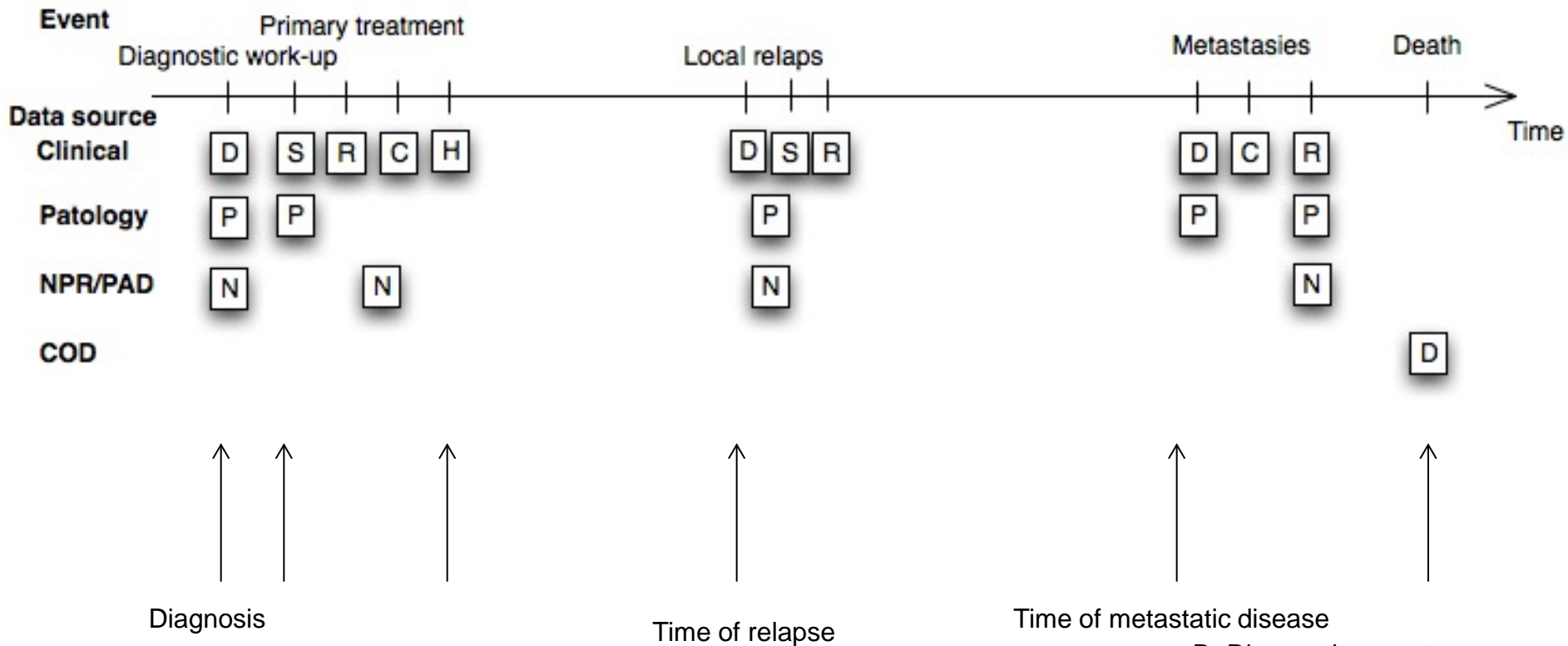
- **REQUIRES** more data than what most cancer registries collect...

Clinical registries

Clinical registries

- More detailed information
- Information that is specific for each site
- Linked to the national guidelines for diagnostics and treatment
- More information about metastasis
- Information about recurrence

Clinical registries - data



D: Diagnostic report
 S: Surgery report
 R: Radiotherapy
 C: Chemotherapy report
 H: Hormone therapy report
 P: Pathology report
 D: Death certificate
 N: Patient registry report

Clinical registries – Norway:

8 with national status

Cancer cases per year:

Prostate: 4900

Colorectal: 4200

Breast: 3300

Lung: 3000

Malignant melanoma: 2000

Lymphoma/lymphatic leukemia: 1500

Gynecologic cancer (subset): 600

Childhood cancer: 150



Use of clinical registries

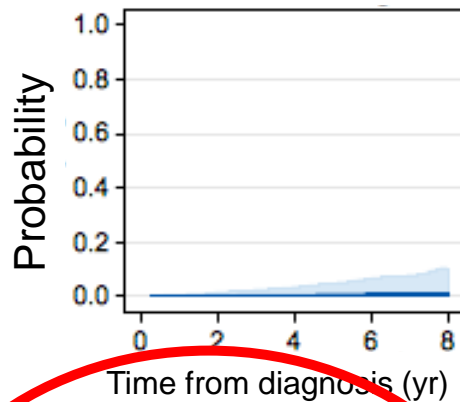
Example 1:

- Prostate cancer: Is active surveillance safe?

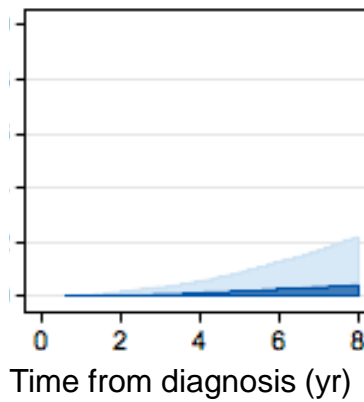
Active surveillance of prostate cancer

low prostate cancer mortality

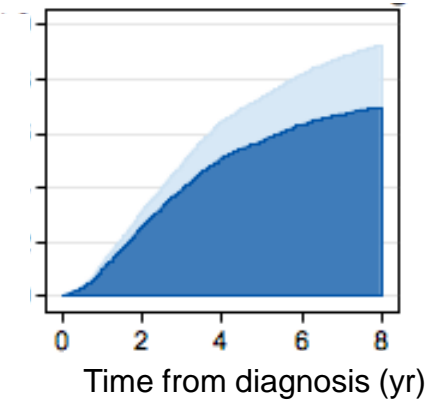
Radical surgery



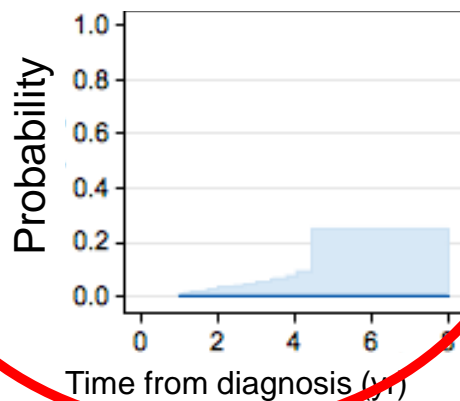
Curative radiation



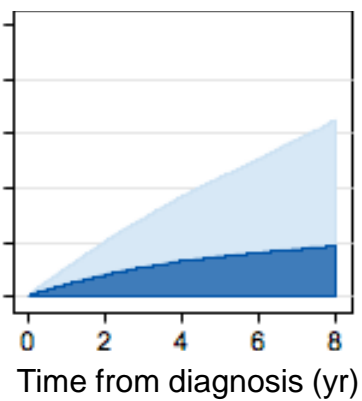
Palliative radiation



Active surveillance



Not treated



■ P (Death from prostate cancer) ■ P (Death from other causes)

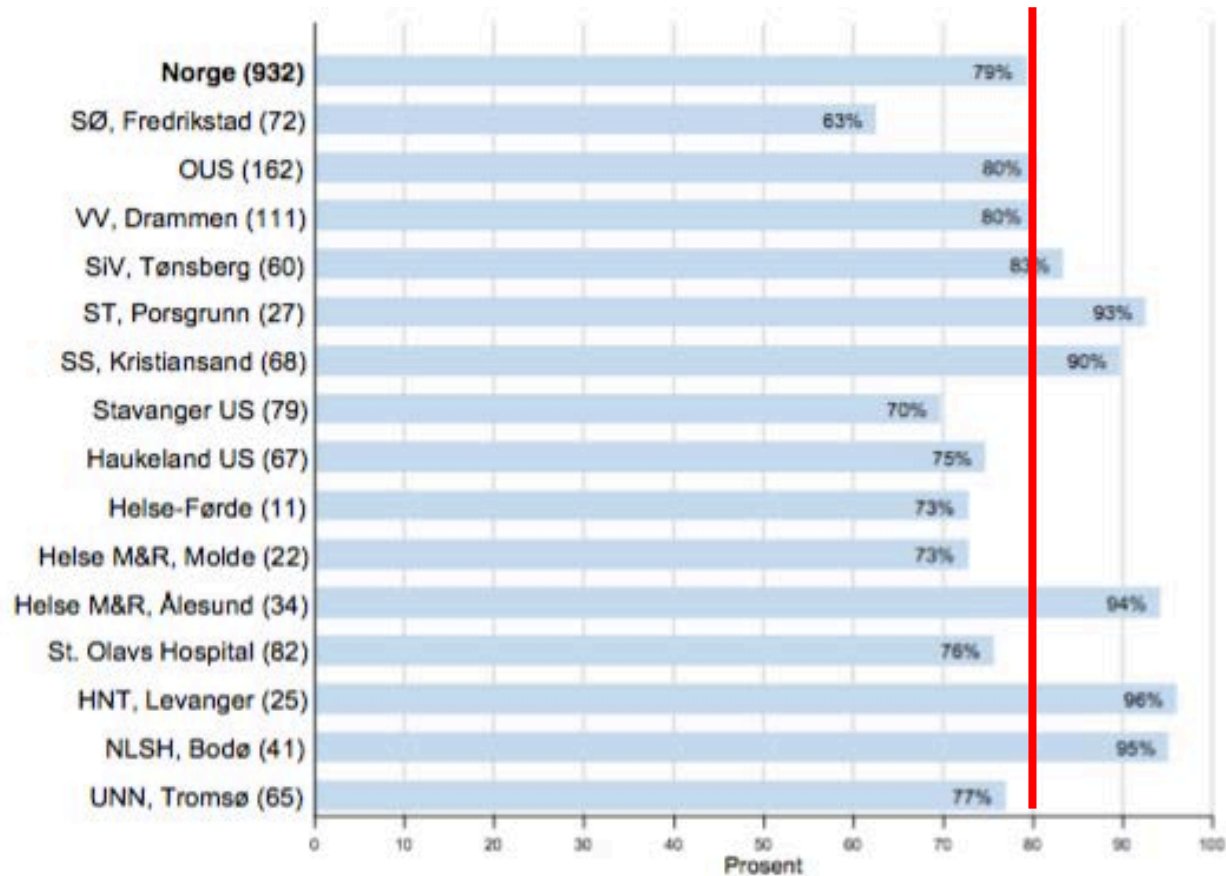


Use of clinical registries

Example 2:

- Breast cancer: do all Norwegian hospitals follow national guidelines?

Breast conserving therapy: for small ($pT1$ – 0-20 mm) tumors



Use of clinical registries

Example 3:

- Lung cancer surgery

Lung cancer surgery – who gets it?

- Lung cancer clinical registry data linked with socioeconomic data:



IJC

International Journal of Cancer

Lung cancer treatment is influenced by income, education, age and place of residence in a country with universal health coverage

Yngvar Nilssen¹, Trond-Eirik Strand¹, Lars Fjellbirkeland^{2,3}, Kristian Bartnes^{4,5}, Odd Terje Brustugun⁶, Dianne L O'Connell^{7,8}, Xue Qin Yu^{7,8} and Bjørn Møller¹

What about real world oncology studies?

Useful for phase III studies?

- Recruitment of eligible patients for clinical trials?
- Use clinical registries ? - already system in place for collecting follow-up data in clinical trials

Example – could registries have been used?

Can registries be used in phase III trials?

ASCO 2016:

Adding Capecitabine chemotherapy to Gemcitabine extends survival after pancreatic cancer surgery

- European Study Group for Pancreatic Cancer (ESPAC4)
- Early stage pancreatic ductal adenocarcinoma
- Within 12 weeks of surgery – randomly assigned to:
 - gemcitabine alone (G) or
 - **gemcitabine with capecitabine (GC)** for 24 weeks.
- **Results:**
 - 732 patients
 - median overall survival was **28.0 months with GC**, vs 25.5 months with G
 - 5-year survival rates: **28.8% with GC** vs 16.3% with G


Main information may already be collected in registry.....


Primærsykdom - avansert sykdom (fjernspredning)
 Tilbakefall - lokal/lokalavansert sykdom inkludert spredning til regionale lymfeknuter
 Tilbakefall - avansert sykdom (fjernspredning)

Siktemål for behandlingen *


Kurativ Palliativ Ukjent

Medikamentell behandling

Oppstart behandling (dd.mm.åååå) * 


Avsluttet behandling (dd.mm.åååå) * 

Type medikamentell behandling *

Velg... 

- Velg...
- IntronA (Interferon alfa 2b)
- DTIC (Dakarbazin)
- Temodal (Temozolomid)
- CCNU (Lomustin)
- Velbe (Vinblastin)
- Karboplatin/Paklitaxel
- Karboplatin/Docetaxel
- Zelboraf (Vemurafenib)
- Yervoy (Ipilimumab)
- Tafinlar (Dabrafenib)
- Pembrolizumab
- Nivolumab
- Annet

Oppfølging/tiltak

Tiltak *
Velg... 

KOMMENTAR

Kommentarer til utførelse av meldingen

The ipilimumab example



But – the current challenge....



Manual reporting – not yet automatic retrieval from patient records...

KREFT registeret
INSTITUTT FOR POPULASJONS-BASERT KREFTFORSKNING

Krefregisterets Meldetjeneste Logg ut

Registrere ny melding

- Manglende kreftmeldinger
- Våre kvitteringer
- Administrativ statistikk
- Klinisk statistikk
- Hjelp

i bruk

- Barnekreft
- CIN
- Colorectal
- Lunge
- LymfomKLL
- Mammae
- Melanom**
- NonSolideSvulster
- OsofagusVentrickel
- Ovarier
- Patologi
- Prostata
- SolideSvulster

i test

- Lymfom KLL
- Patologimaleksempel

Pasient/behandlingsinstitusjon

Fødselsnummer: 01010000000 Ikke norsk personnummer

Navn: Kari Nordmann

Hvor er pasienten behandlet*
Velg...

Primærtumors lokalisasjon ?

Velg organ: Hud

Velg lokalisasjon: Ansikt

Klinisk sikker kreft ?
 Ja Usikker

Behandling rettet mot

Primærtumor Metastase i primærsituasjon Både primærtumor og metastase

Siktemål for behandlingen

Kurativ Palliativ Ukjent

Behandlingsmetode

- Velg...
- Plastisk kirurgisk
- Hud
- Kirurgisk
- Øye
- Medisinsk
- Onkologisk
- Annen
- Ikke relevant

BUT – quickly completed!

Useful for phase IV studies?

- Investigate effects of cancer treatment in population
 - Who benefits?
- Link Cancer Registry and Cause of Death Registry with:
 - Prescription Registry – details on all prescriptions
 - National Patient Registry – details on comorbidities
 - Hospital pharmacy databases?

Example:

- Linked cancer registry with prescription registry
- Glioblastoma multiforme

Results:

Two-year survival 25% in radiotherapy + TMZ group
= *comparable results to that from randomized clinical trials.*

Neuro-Oncology 14(9):1178–1184, 2012.
doi:10.1093/neuonc/nos153

NEURO-ONCOLOGY

A population-based study on the effect of temozolomide in the treatment of glioblastoma multiforme

Pål A. Rønning, Eirik Helseth, Torstein R. Meling, and Tom B. Johannesen

Department of Neurosurgery, Oslo University Hospital, Oslo, Norway (P.A.R., E.H., T.R.M.); The Cancer Registry of Norway, Oslo, Norway (T.B.J.)

The effect of temozolomide (TMZ) and radiotherapy (RT) in the treatment of glioblastoma multiforme (GBM) has been well documented in randomized controlled trials. Here we present our findings on the

glioblastoma multiforme (GBM) is the most common primary brain tumor and also has the poorest outcome, with median overall survival (OS) often < 1 year.^{1,2} It is well documented that both

Conclusion:

Real World Use of clinical registries

- Large unused potential in oncology - for phase III and IV trials
- Can identify patients
- System in place for follow-up
- Can link with other registries
- Potential will increase with time