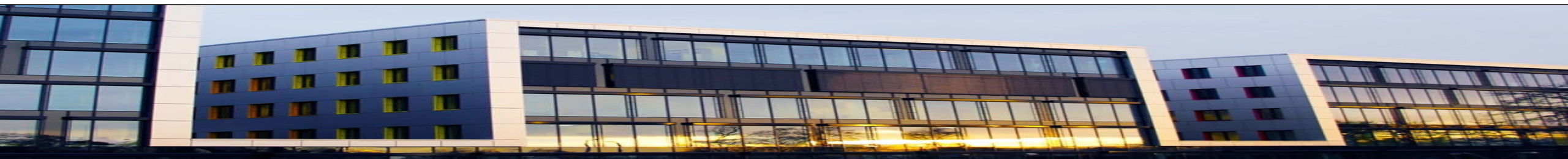


# Real World Data – Pilotprosjekt mellom LMI og Kreftregisteret

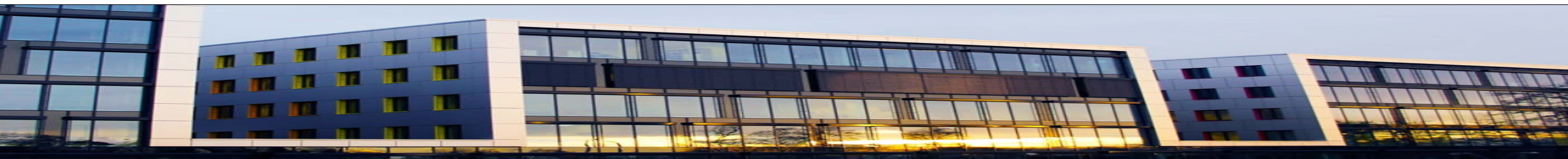
*Espen Enerly, Researcher,  
HPV-related Epidemiological Research Unit,  
Norwegian Cancer Registry*

2017 Regulatorisk høstmøte, Felix konferansesenter, Aker Brygge



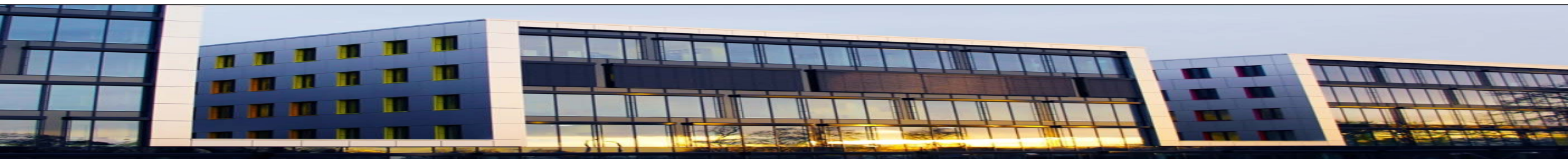
# Disclosure

- Funding
  - Researcher on projects where the Cancer Registry has received funding from MSD/Merck and AstraZeneca.
- Conflict of interest
  - No conflict of interest

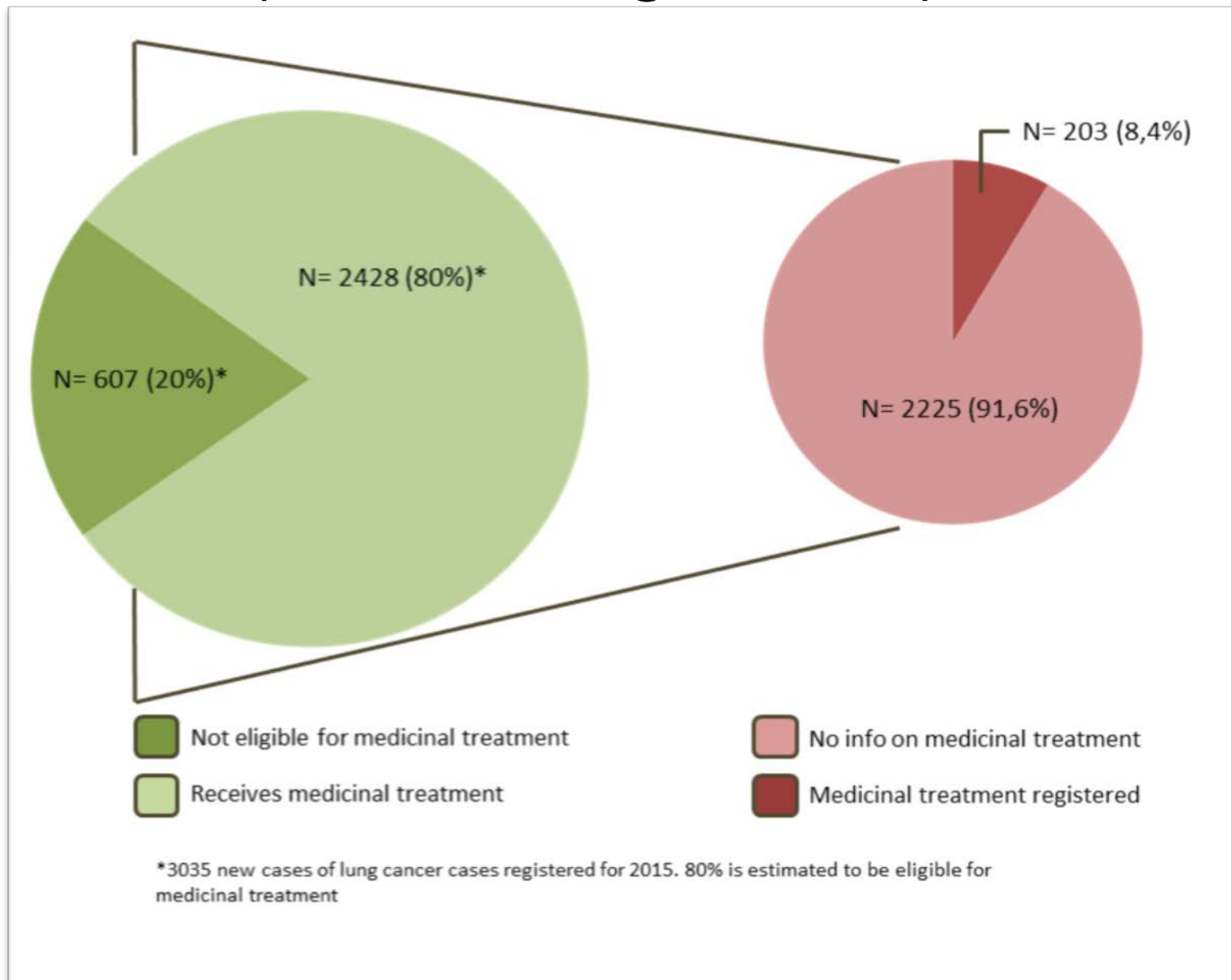


# Background

- Establishment of Clinical registries
- Increasing interest in RWD from industry
- Dec 2016: Workshop - Real world data – Lungekreft (er vi klare?)



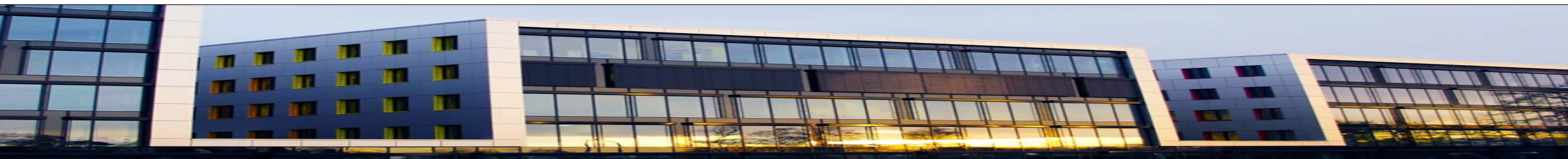
# Status (2015 – lung cancer)



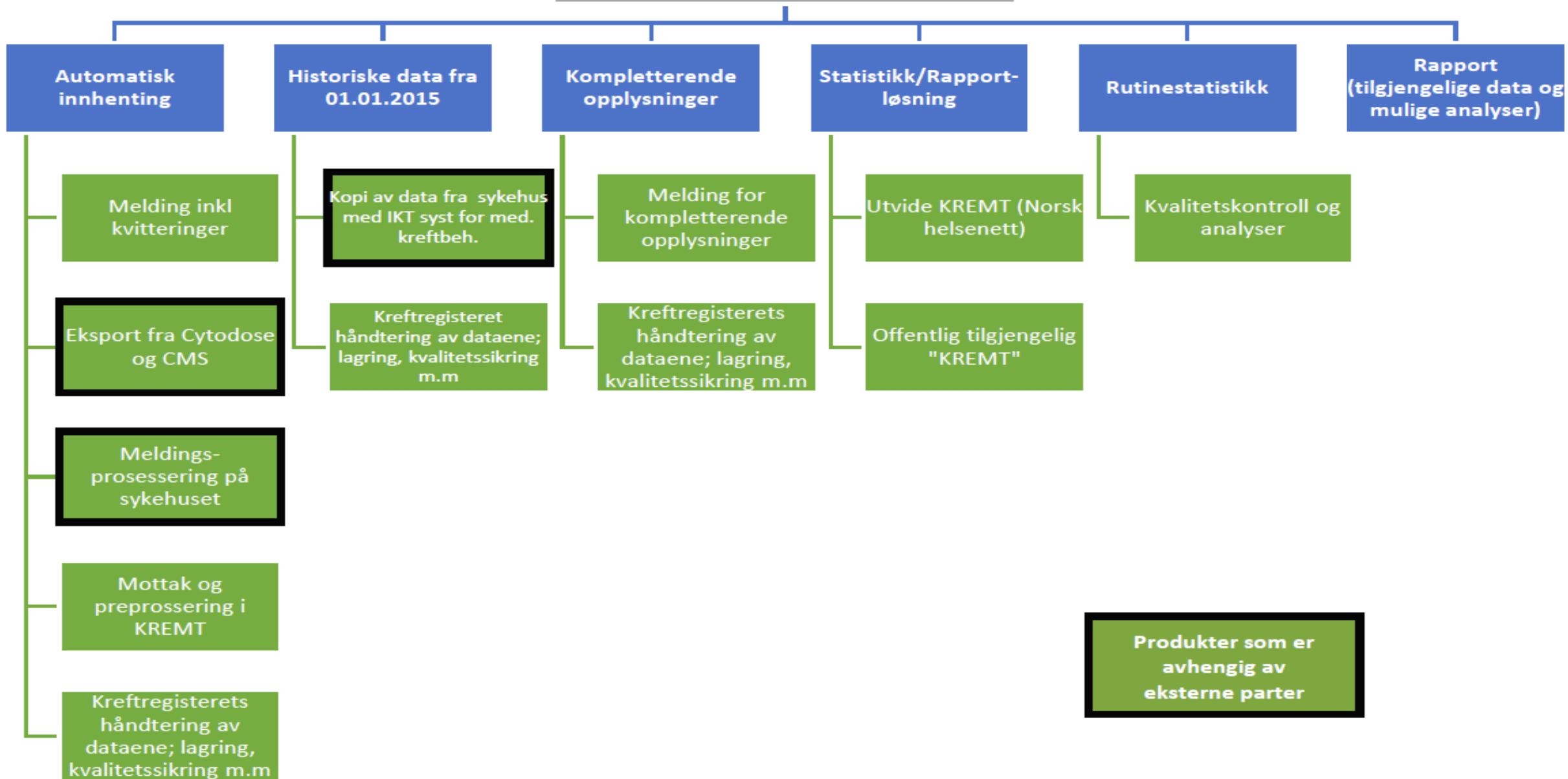
# «INSPIRE»

## INcreaSe Pharmaceutical REporting

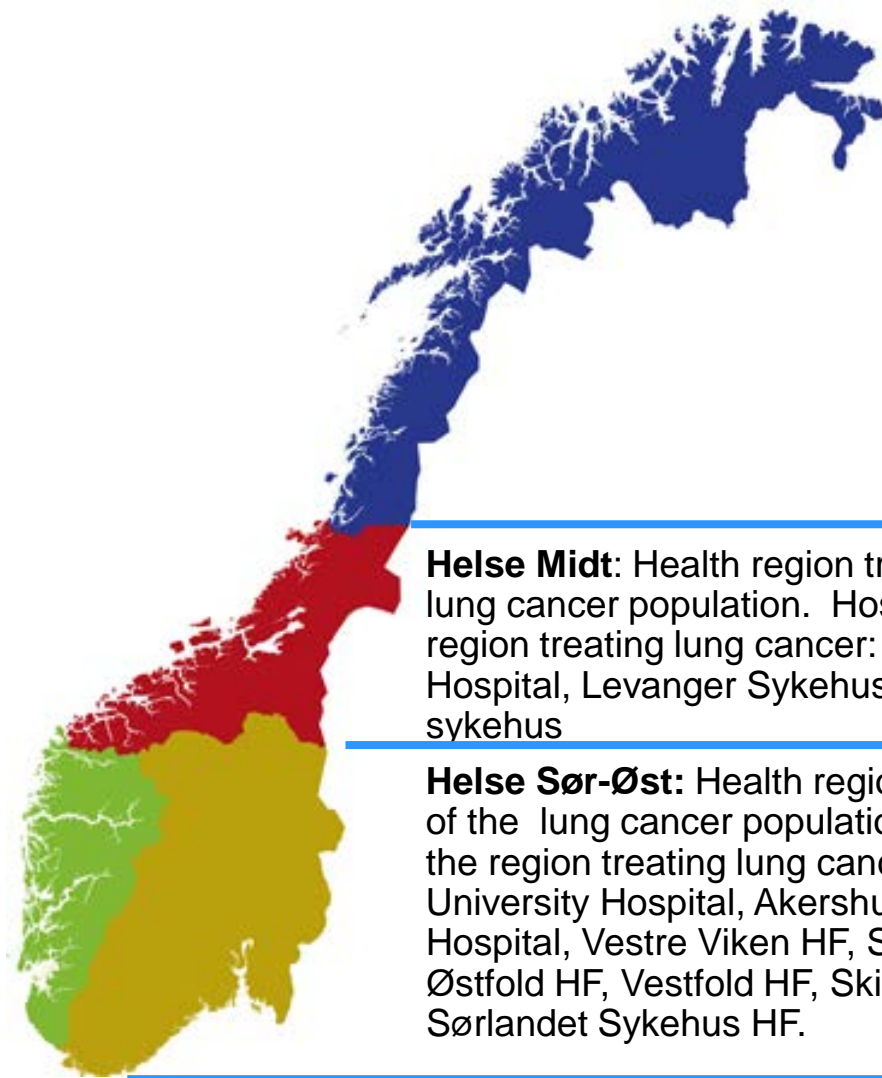
A joint pilot project between LMI, opt-in LMI-members, and the Cancer Registry



# Informasjon om medikamentell behandling på lungekreftpasienter







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**Helse Midt:** Health region treating 13% of the lung cancer population. Hospitals in the region treating lung cancer: St. Olavs Hospital, Levanger Sykehus, Ålesund sykehus

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**Helse Sør-Øst:** Health region treating 55% of the lung cancer population. Hospitals in the region treating lung cancer: Oslo University Hospital, Akershus University Hospital, Vestre Viken HF, Sykehuset i Østfold HF, Vestfold HF, Skien Hospital, Sørlandet Sykehus HF.

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Total population coverage: 68% of the annual diagnosed lung cancer population will potentially be covered by the pilot project.

# Budget and timeline

## Timeline

- Goal: Agreement signed before the end of the year
- Project 18 months

## Budget

- LMI (members) ~5,6 mill
  - Hiring: Data manager and system developers.
  - Allocating existing people (Inc. project leader)
- KRG ~2,4 mill
  - Support from MD, statistician, IT-support etc.



- Total ~8 mill NOK



# Final notes

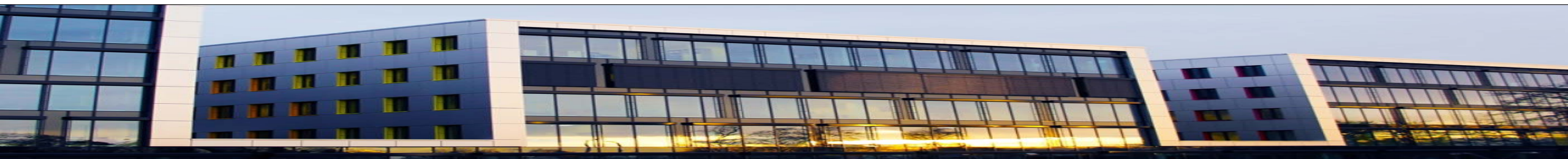
- Data accessible for all
- Lung is the pilot, then we expand
- The more opt-in members the better
- Aligning with other initiatives
- Other: Kreftforeningen, NFR, SLV
- Inven2

Win - Hospitals

Win - CRN

Win - Industry

Win – Regulator authorities





# Project goals

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Establish automatic transfer of drug treatment data



Consider access to non-automatic information



(a) Report describing the data, (b) web-portal, and (c) expanding drug reporting in the annual lung cancer report

# Mål og utbytte av prosjektet

Overordnet mål: Komplette behandlingsprofil for lungekreftpasienter tilbake til 01.01.2015 fra deltagende sykehus.

- **For Kreftregisteret**

- Økt mengde data for kvalitetssikring av utredning, behandling og oppfølging av lungekreft pasienter (årsrapport kvalitetsregisteret)
- Tilby mer fullstendig data tilgjengelig for forskning på pasientforløp

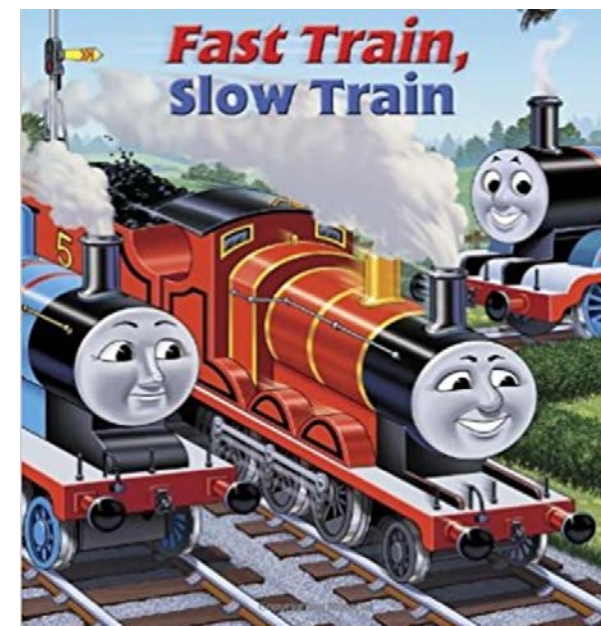
- **For legemiddelindustrien**

- Tilgang til (via DUE) økt informasjon om legemiddelbruk/pasientforløp
- Oppgradert web-portal for statistikk
- For partnere: Prosjektspesifikke kunnskap

- **For lungekreftpasientene**

- Bidra til at deres helsedata utnyttes til det beste for fremtidige pasienter

- Kvalitetssikring
- Forskning
- Legemiddelutvikling, regulatoriske prosesser, HEOR



# Cancer registration in Norway



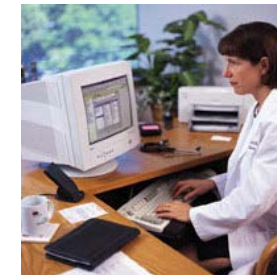
Pathology reports



Clinical reports



Death certificates



Hospital patient  
administrative systems/  
Norwegian Patient Registry