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#### Routine data in skin cancer epidemiology



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#### Structure



- Definition
- My story using routine databases in practice
- Highlights and challenges
- My tips for anyone considering this type of research

## **Routine data**



- Data obtained from routine data-collection systems
- Not specifically collected for your research question







# Diagnostic process of AK patients in primary care

- Limitations of GP database
- GP diagnosis only (no gold standard)
- No information on how certain the GP considers the diagnosis (differential diagnosis)
- No data on what is not recorded/missed



#### Lentigo Maligna (LM)



#### Lentigo Maligna Melanoma (LMM)



### Incidence rates?



#### Lentigo Maligna (LM)

#### Lentigo Maligna Melanoma (LMM)





#### **Risk of Progression**



British Journal of Dermatology (1987) 116, 303-310.

## The risk of progression of lentigo maligna to lentigo maligna melanoma

#### M.A.WEINSTOCK AND A.J.SOBER

Department of Dermatology, Massachusetts General Hospital and Harvard Medical School, Boston, MA, U.S.A.

Accepted for publication 16 September 1986

Lifetime risk < 5%

#### **Databases**

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#### **Methods**



Netherlands Cancer Registry

Primary LM and LMM

**1989 – 2013** 

Incidence rates per 100.000 person years

Age-standardized

Incidence trends over time

Joinpoint regression analyses

#### **Results - LM and LMM incidence between 1989** and 2013 in the Netherlands





N = 10,545

**58%** ♀

Median age: 70 years

Head and neck region: 74%



N = 2,898

**57%** ♀

Median age: 72 years

Head and neck region: 69%

#### Lentigo Maligna - Incidence Rates





#### Lentigo Maligna - Incidence Rates





#### Lentigo Maligna - Incidence Rates





#### Lentigo Maligna Melanoma - Incidence Rates



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#### Lentigo Maligna Melanoma - Incidence Rates



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### Lentigo Maligna Melanoma - Incidence Rates



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#### **Trends in Incidence LM/LMM - Discussion**

True increase (UV exposure)

Increased awareness

Underreporting











#### Cumulative Incidence Curve: LM $\rightarrow$ LMM

 



#### Cumulative Incidence Curve: LM $\rightarrow$ LMM





25-year risk:

**∂ 2.0%** 

♀ **2.6%** 

(95% Cl, 1.2 – 2.8)

(95% CI, 1.9 – 3.3)

#### **Risk of Progression - Discussion**



Overestimation?

Non histologically confirmed LM

**Underestimation?** 

- LMM without previous diagnosis of LM
- LM with unrecognized component of invasive melanoma

#### Conclusion



To assess trends in LM and LMM incidence between 1989 and 2013 in the Netherlands

Incidence rates have increased

To estimate the risk of a subsequent LMM after a (histologically confirmed) LM

Low (2-3% after 25-years)

#### **Databases**

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#### **Claims data – mostly medical specialist care**

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#### Limitations



- Not very detailed (e.g. disease severity) vs large datasource.
- Incorrect coding (misclassification)
- Inkage with pharmacy data?



## HIGHLIGHTS AND CHALLENGES

## Highlights



- Less time intensive
- Large sample size
- Relatively inexpensive
- Less susceptible to selection bias
- No opportunity for interviewer or recall bias

## Challenges



- Routine data
- Lack information on disease severity
- Possible misclassification
- Lack information on some confounders
- Don't include "over the counter" drugs
- Statistical knowledge



## My tips for anyone considering this type of research

## **Two questions**



# Are the data adequate to answer your research question?

Are the data sufficiently accurate?

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# My top tips for anyone considering this type of research



- Find a great mentor....or three!
- Join a team with experience using these data sources
- Learn how to write code in SPSS, STATA, SAS, R
- Be prepared for frustrating weeks and lots of challenges

#### **Acknowledgements**

Dr. Karin Grevelingen Drs. Sven van Egmond Drs. Eline Noels

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Rotterdam Study

INTEGRATED PRIMARY CARE INFORM





Thank you



Any questions?

If you are interested....

Chat at one of the breaks or this evening

Or

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