Routine data in skin cancer epidemiology

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No conflict of interest
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

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%
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

Incidence per 100,000 person years

Year of diagnosis

Males
Joinpoint Regression Line Males
Females
Joinpoint Regression Line Females

Incidence per 100,000 person years has increased by 5x.
Lentigo Maligna - Incidence Rates

Incidence per 100,000 person years

Year of diagnosis

Males
Joinpoint Regression Line Males
Females
Joinpoint Regression Line Females

♂ 24% ↑
♀ 19% ↑
Lentigo Maligna - Incidence Rates

Incidence per 100,000 person years

Year of diagnosis

Males

Joinpoint Regression Line Males

Females

Joinpoint Regression Line Females

♂ 7% ↑
♀ 9% ↑
Lentigo Maligna Melanoma - Incidence Rates

![Graph showing the incidence rates of Lentigo Maligna Melanoma from 1989 to 2013 for males and females. The incidence rate increases over time, with a significant upward trend after 2005. The graph includes a joinpoint regression line for both males and females, showing a 5x increase in incidence over the period.]
Lentigo Maligna Melanoma - Incidence Rates

Incidence per 100,000 person years

Year of diagnosis

Joinpoint Regression Line Males
Joinpoint Regression Line Females

♂ 14% ↑
♀ 14% ↑
Trends in Incidence LM/LMM - Discussion

- True increase (UV exposure)
- Increased awareness
- Underreporting
True increase
- Ultraviolet exposure
Cumulative Incidence Curve: LM → LMM

Number at Risk

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<th>Females</th>
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Cumulative Incidence Curve: LM → LMM

25-year risk:

♂ 2.0%  
(95% CI, 1.2 – 2.8)

♀ 2.6%  
(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)
Claims data – mostly medical specialist care
Limitations

- Not very detailed (e.g. disease severity) vs large datasource.
- Incorrect coding (misclassification)
- Linkage 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?
ISPOR International Digest of Databases

Browse by country (Total databases found: 402)
- Netherlands (8 databases)
- New Zealand (5 databases)
- Nigeria (4 databases)
- Norway (2 databases)
- Poland (1 database)
- Portugal (1 database)
- Puerto Rico (1 database)
- Russia (2 databases)
- Singapore (1 database)
- Slovak (1 database)
- South Africa (3 databases)
- Spain (10 databases)
- Sweden (1 databases)
- Switzerland (3 databases)
- Taiwan (2 databases)
- Turkey (3 databases)
- United Kingdom (26 databases)
- United States (153 databases)
- Uruguay (1 database)
- Vietnam (1 database)

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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

Dr. Loes Hollestein
Prof. Tamar Nijsten
Thank you

Any questions?

If you are interested....
Chat at one of the breaks or this evening
Or
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