

Nordic Infrastructure: Researcher perspective

'The Nordic Twin Cancer Study'

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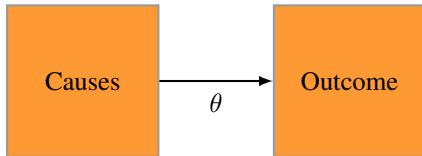
May 15th 2019

Overview

- 1 Past
- 2 NorTwinCan Data Management
- 3 Perspectives

'research to improve human health.'

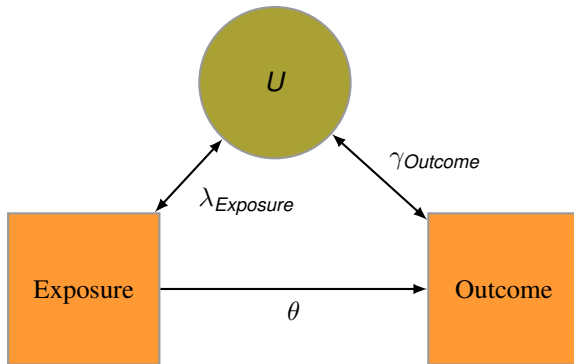
Health Sciences



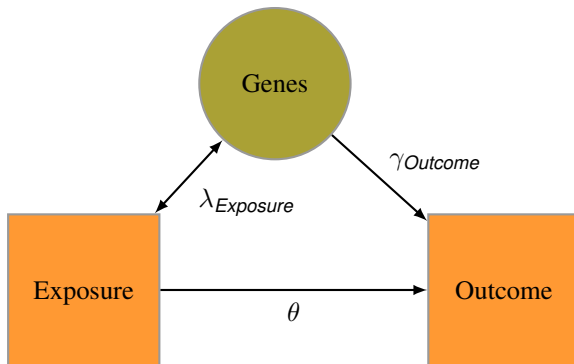
'You're talking be yes, when it's yes, no when it's no' (Matthew 5, 37)



The problem



The problem



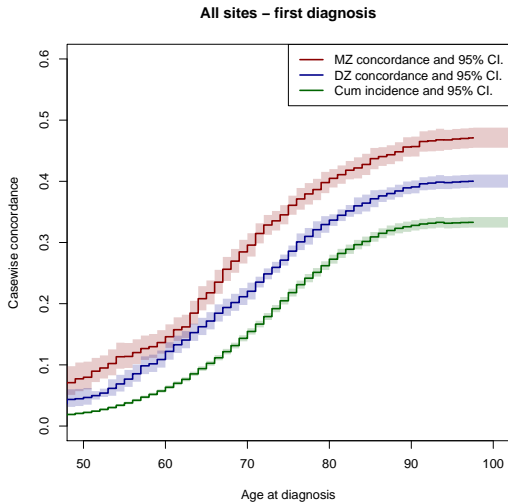
Dependence?



Studies with Twins: Causes of Cancer

- **1918:** Biometrical Genetics landmark papers.
- **1943:** The first Cancer Registry is founded.
- **1953:** The first Twin Registry is founded.
- **1963:** ~15.000 Danish twins, first study, less to conclude (JAMA).
- **2000:** ~90.000 Nordic twins, but wrong methodology (NEJM).
- **2016:** ~300.000 Most comprehensive of familial risks ever (JAMA).
- **2020:** ~350.000 Most comprehensive of cross cancer familial risks ever.





L. Mucci, J. Hjelmborg, T. Scheike, K. Holst, A. Skytthe, H. Adami, N. Holm, K. Christensen, J. Harris, J. Kaprio et al. JAMA (2016)

Politiken and US media January 2016

Kræftisiko for ...


Din kræftisiko stiger,
hvis du har en kræftramt
tvillingebror eller -søster

... almindelig person

... person med kræftsyg enægget tvilling

... person med kræftsyg tveægget tvilling

Kræft generelt



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| | 32,4 % |
| Hoved- og hals | 0,8 % |
| Mave | 1,1 % |
| Tarm | 2,9 % |
| Endetarm | 1,9 % |
| Bugspytkirtel | 1,1 % |
| Strubehoved | 0,2 % |
| Lunge | 3,2 % |
| Modermærke | 1,2 % |
| Hud | 1,9 % |
| Bryst | 9,4 % |
| Livmoder | 2,0 % |
| Æggestok | 1,6 % |
| Prostata | 10,5 % |
| Testikel | 0,5 % |
| Nyre | 0,8 % |
| Blære | 2,2 % |
| Hjerne | 0,9 % |
| Blod | 0,6 % |

45,8 %



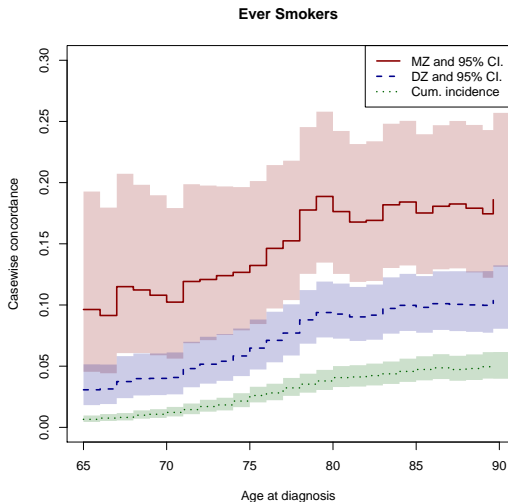
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37,1 %



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| | 5,1 % |
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| | 5,5 % |
| | 1,8 % |
| | 4,1 % |

Time-varying genetic influence? Lung Cancer



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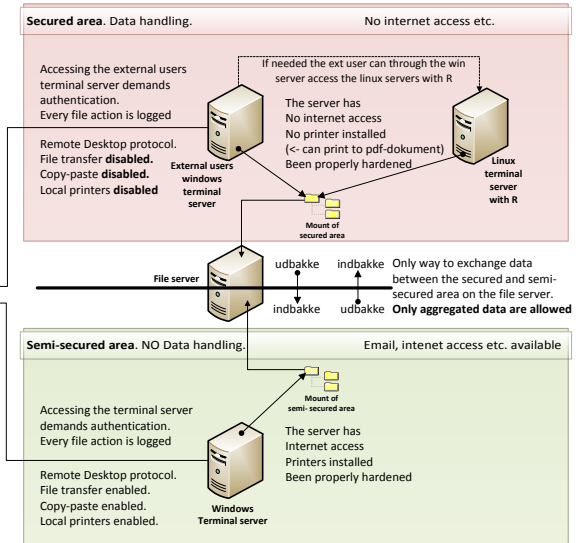
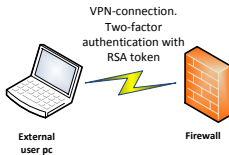
Data is person specific pseudo-anonymous.

- **Storage:** Secured server
- **Access:** Remote analysis
- **EU Legislation:** General Data Protection Regulation compliant.
- **Approval:** It took two years!



External users Access to EBBs Secure Server System

To get access
the external user
has to sign a
Data Access Agreement



Data is person specific pseudo-anonymous.

- **Data**: resides in all participating countries.
- **Access**: available from a single point for computation.
- **Storage**: no copy is stored.

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Bridging biomedical data

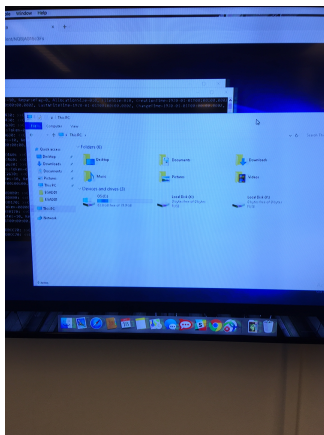
'data moves but is not stored outside from home'

Infrastructure for computing and collaboration.

- **Storage:** Secure cloud from secure servers in all participating countries
- **Access:** Secure remote access

Computing with distributed data

It's alive!



Antti Pursula and Jaakko Leinonen,
NeIC, CSC - IT Center for Science, Finland

'research to improve human health'

- The Nordic Twin Registries - the world's oldest and largest.
- A Nordic Health Data Cohort. . .
- Combining registries principle: Integrating or Bridging?
- Facilitate that 'data moves but is not stored outside from home' (bridging).
- Computing with distributed data.
- Modelling integration and development.

