

Nordic collaboration

Merging of registry data

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Nordic collaboration - Purposes

- Statistical power
- Comparisons between countries
- Generalisability

Nordic collaboration - Opportunities

- Similar registries – key variables
- Personal identity numbers – linkages and follow-up
- Similar populations - demography
- Similar healthcare structure - public

Nordic collaboration - Issues

- Many permissions in different languages and different agencies
 - Ethical review committees
 - Data inspectorates
 - Registry holders
- Many registries, each with its pros and cons
- Danish data cannot leave the country
 - Time-consuming to get the remote access to Statistics Denmark
 - The remote access is not well-functioning
- Hard work
- Time-consuming
- Expensive

Nordic collaboration - Work plan

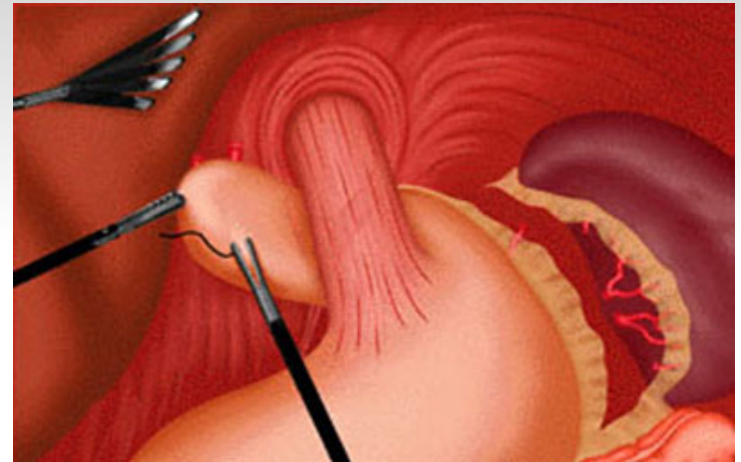
1. Collaborate with experienced researcher(s) in each country
2. Detailed study protocol
3. Personal meetings
4. Apply for permissions from all relevant parties
5. Ask Statistics Denmark for storage of data and remote access
6. Data retrieval from the registries
7. Data check-up in each country separately
8. Additional data retrievals
9. Data sent to Statistics Denmark
10. Check-up of all data
11. Additional data retrievals
12. Data merging
13. Data management
14. Statistical analyses
15. Manuscript writing

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Example: Nordic Antireflux Surgery Cohort (NordASCo)

- Research question
 - Does risk of oesophageal adenocarcinoma decrease after antireflux surgery?

- Background
 - Contradictory findings (mainly no effect) although reflux is a strong risk factor
 - Short follow-up
 - Loss to follow-up
 - ➔ Poor statistical power in the long-term follow-up categories
 - ➔ Need for a large-scale study with long and complete follow-up



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Example: NordASCo, cont.

- Design
 - Nordic register-based (retrospective) cohort study
- Countries
 - Denmark, Finland, Iceland, Norway, Sweden
- Data sources
 - Patient registries – antireflux surgery
 - Cancer registries – cancer incidence
 - Death registries – censoring

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Example: NordASCo, cont.

Risk of oesophageal adenocarcinoma over time after antireflux surgery (n=48,414):

SIRs comparing antireflux surgery with the background population

HRs comparing antireflux surgery with medicated reflux patients (n=894,492)

<u>Years after surgery</u>	<u>SIR (95% CI)</u>	<u>HR (95% CI)</u>
5-9	7.6 (5.4-10.4)	2.0 (1.4-2.8)
10-14	3.6 (2.7-4.8)	2.0 (1.4-2.7)
≥15	1.3 (1.0-1.8)	1.8 (1.3-2.5)

➔ Antireflux surgery prevents oesophageal adenocarcinoma

Nordic studies - Success factors

- Collaboration with experienced researchers
- Thorough check-up of all data
- Experienced statisticians
- Patience – from all involved

Nordic collaboration - Wish list

- Facilitate and speed up the procedure for approvals
 - Centrally organised from one country
 - English language
- Detailed descriptions of the registries and all variables
 - English language
 - Documentation of issues related to each of the registries
 - Documentation of issues related to each of the variables
- Improve the remote access to Statistics Denmark
- Keep the key codes to the participants longer

Nordic collaboration - Conclusions

- Merging of registry data between the Nordic countries:
 - Possible
 - Rewarding if used for the right purpose
- But:
 - Many obstacles ($x > 5$)
- Future:
 - Facilitate Nordic collaboration based on registry data!



Thank you