

Linkage of HBM studies and administrative health registers

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Former experience

An introduction

Former experience I

- Linkage to registers is important in many cases:
 - Clinical research
 - long-term follow up of intervention- and control-arm
 - long term survival (e.g. after cancer therapy)
 - Cohort studies in occupational and environmental health
 - Extend a cross-sectional study (e.g. HBM-study) into a cohort study
- Own previous experiences with follow up of occupational cohorts
 - In the “old days” not much fluctuation among citizens. Workers usually stayed in the same region or district. Citizens’ register was kept at the districts’ level until 2000 (paper register usually). Seek a death entry. Then approach local hospitals for cause of death information. No longer feasible now.

Moshammer H, Neuberger M (2004): Lung cancer and dust exposure: Results of a prospective cohort study following 3260 workers for 50 years. Brit J Occup Environ Med 61: 157-162

Former experience II

- Follow-up of an occupational asbestos cohort
 - Names and birth-dates (and social security number) available
 - Linkage to the national Cause of Death Register was possible

Moshhammer H, Neuberger M (2009): Lung function predicts survival in a cohort of asbestos cement workers. Int Arch Occup Environ Health (2009) 82:199–207.

- Follow up of an occupational cohort in the hard-metal industry
 - Names and birth-dates again, follow-up would have been possible initially
 - Occupational health officer at plant was afraid of consequences and asked for approval by ethics committee first. EC declined: “data privacy is not an ethical issue”
 - When data were finally available, follow up blocked for legal reasons
 - Amendment of university law allowed follow-up provided a positive EC vote

Wallner P, Kundi M, Moshhammer H, Zimmerman SD, Buchanich JM, Marsh GM. (2017): Mortality Among Hardmetal Production Workers: A Retrospective Cohort Study in the Austrian Hardmetal Industry. Journal of Occupational and Environmental Medicine. 59(12):e282-e287.

Former experience III

- The hard-metal study:
 - Access to the Cause of Death Register was possible because of a positive vote from the EC of the Medical University of Innsbruck (plant is situated in the Tyrol)
 - Incomplete coverage (name change, workers moved to Germany)
 - Cross-check of CoD-Register data based on Citizens' Register: no Cause of Death, no exact date of death, but information on life status and approximate date when moved out of Austria
 - Problem: national Citizens' register only established in 2000
- General problem: linkage only by name and birthdate (subject to change, spelling error)

The Austrian Statistical Institute (Statistik Austria, StatAT) now use a personal identifier that enables StatAT linkages across registers ("bereichsspezifisches Personenkennzeichen Amtliche Statistik" bPK-AS). But as researchers we have no direct access to that personal identifier.

Linkage of HBM data

A pilot study

Pilot study I

- Cross-sectional data from 2 HBM studies (synthetic musks):
 - The first study (Hutter et al., 2005, 2009) was conducted in 2002 among students mostly from the Medical Faculty of the University of Vienna. Blood samples of 100 healthy students (55 female, average age 25 years) were collected and analyzed.
 - A second study (Hutter et al., 2010) was conducted in 2005 among female patients of the department of angiology of a Viennese hospital and samples from 53 elderly women (aged more than 50 years) were analyzed.
 - Assumption: suspicion of adverse health effect (e.g. cancer) warrants follow-up analysis.

Hutter, H.-P., Wallner, P., Moshhammer, H., et al. (2005): Blood concentrations of polycyclic musks in healthy young adults. *Chemosphere* 59(4):487-492

Hutter, H.-P., Wallner, P., Moshhammer, H., et al. (2009): Synthetic musks in blood of healthy young adults: Relationship to cosmetics use. *Science of the Total Environment* 407(17):4821-4825

Hutter, H.-P., Wallner, P., Hartl, W., et al. (2010): Higher blood concentrations of synthetic musks in women above fifty years than in younger women. *International Journal of Hygiene and Environmental Health* 213(2):124-130.

Pilot study II

- Problem:
 - Follow-up not covered in original EC application
 - Follow-up not granted by study participants
- A note aside:
 - Observation period too short and cohort members too young for meaningful investigation of cancer risk. But as a starting-point for a feasibility study the material seemed well suited.
 - We obtained information on costs and procedures for data linkage from StatAT
 - Approval from EC (this time EC of the Medical University of Vienna) necessary

Pilot study III

- Communication with EC
 - Applied for register-based prospective cohort study
 - Explained that it is a feasibility study in the HBM4EU framework
- Preliminary check by EC secretariat:
 - “This is not a prospective but a retrospective study because we use old data”
 - Old EC votes had to be provided
 - PI from old studies had to sign the application
- Final vote by EC:
 - Insufficient data! Who is HBM4EU?
 - No sound research proposal (study participants too young or follow-up too short)
 - Therefore, no positive vote possible

I gave up! Really, there are better and more important tasks I can spend my time on!

HBM record linkage

Conclusion

Conclusion I

- **Ethics committees**
 - Mixed experiences
 - EC of MUI was very helpful, supportive, and friendly
 - EC of MUW was distrustful and very critical
 - ECs not well prepared for that kind of question
 - Personal data protection not their primary or original task
 - Focus on clinical studies. Even data protection issues set aside: not much experience with observational studies that are the dominant type in environmental and occupational epidemiology.
 - Even the forms to be filled when submitting a project do not well fit our study types

“What is the intervention?” “How long will it take?” “How dangerous is it?” “What is the gain for the patients?”
Even power calculations are often not meaningful in observational studies: you only get the data that you get!

Conclusion II

- **Technical challenges**

- Linkage by name and birthdate prone to errors
- Cross-validation by Citizens' register as a possible option
- Access to CoD register at least legally possible
 - After considerable lobbying with parliamentarians
 - Vote by EC as a legal requirement
 - Procedures at ECs are poorly harmonised across Austria

- Record linkage is possible in Austria and has been done successfully. It is challenging for several reasons.
- We envy the colleagues from Scandinavia and other regions where this task seems to be much easier!
- Lack of harmonisation across Europe might pose another problem for European multi-centre studies.

Thank you for your interest!

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