

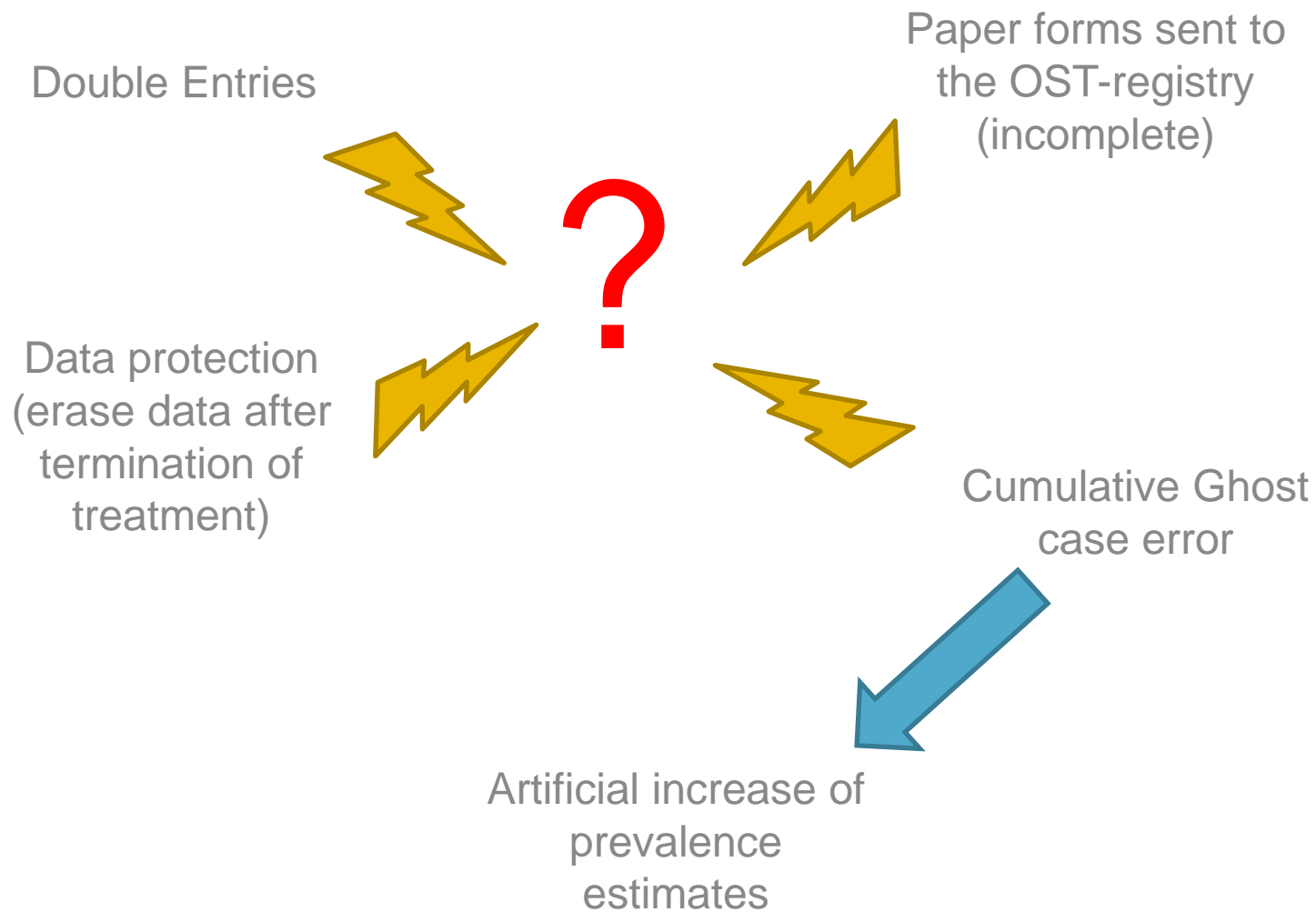
# The Austrian mortality cohort study – fruit of more than one decade of work and future perspectives

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EMCDDA–Workshop on Mortality Cohort Studies  
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## Let us go back to the year 2007 – OST-Registry

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## 2007 to 2011 – construction and implementation of eSuchtmittel

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Double Entries  
Identification via  
population registry



Paper forms sent to  
the registry  
(incomplete)  
Online system with  
quality checks

Data protection  
(erase data after  
termination of  
treatment)  
See next slide

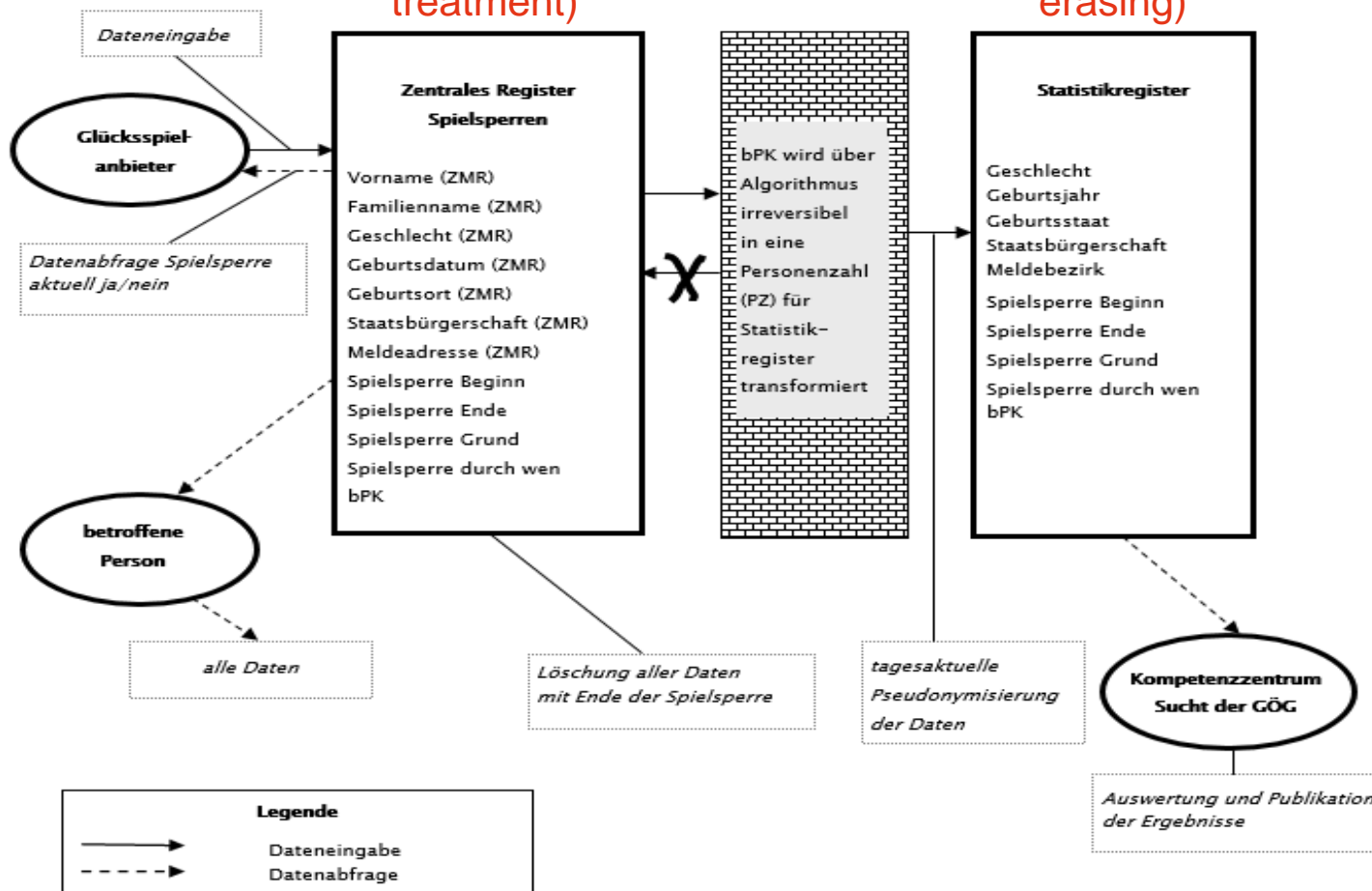


Cumulative Ghost  
case error  
Quality check of  
open cases

# 2007 to 2011 – construction and implementation of eSuchtmittel

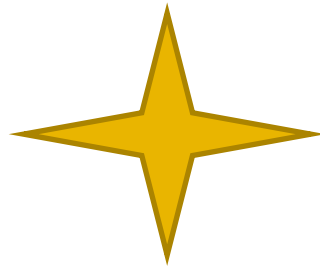
OST Registry with full personal data (erasing after termination of treatment)

Statistic Registry with one-way encrypted pseudonym (no erasing)



## Idea for future possibilities (very simplified)

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If you manage to encrypt any other data based on identification via population registry the same way as the OST–statistic registry you can merge the data

## Preconditions for the Austrian mortality cohort based on OST

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- » Everyone undergoing opioid substitution therapy (OST) in Austria has to be notified by the medical officer supervising OST to the OST-registry.
- » The notification is possible by unique identification of the patient in the population registry only.
- » In Austria there is a system of bPKs which are unique identifiers for persons in different area e.g. bPK health, bPK statistics...
- » The OST-data are pseudonymised (encryption of the bPK-health) and stored in the OST-Statistic Register without other personal data than sex and year of birth.
- » Data on OST in Austria are available in this form from 1987 onwards.
- » In Austria there exists a General Mortality Register (GMR) with full personal information of all death cases and underlying cause of death.

Since some years there was the idea to link the GMR to the OST-Statistic Register to calculate mortality rates!

## ...now it becomes very complicated

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- » In 2016 the legal framework for this linkage was included in a change of the narcotic substance law.
- » In a first step all death cases from 2002 to 2016 stored in the General Mortality Register (GMR) were identified in the Population Registry.
- » In a second step a list of all bPKs–health of the death cases from 2002 to 2016 were sent to the Ministry of Health. The list included the bPK–health and a second code (run number).
- » At the Ministry of Health the list of bPKs–health were encrypted the same way as the OST–Statistic Register and linked to the OST–Statistic Register.
- » A list of all second codes and encrypted bPKs–health of persons found in the OST Statistic Register was sent back to the GMR.
- » Based on the second code date and cause of death were integrated in this list and the list was sent back to the Ministry of Health again.
- » The Ministry of Health sent the list to the Addiction Competence Center where the list of dates and causes of death was linked to the OST–Statistic Register

## Fruit of more than one decade of work I

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- » Sample: all 24,892 persons who started opioid substitution treatment in Austria from 1.1.2002 to 31.12.2016.
- » These persons supply a total of 197,739 person-years. 126,469 of these years (64%) they were in opioid substitution treatment.
- » 1,526 of the 24,892 persons (6.1%) died during the observation period from 1.1.2002 to 31.12.2016.



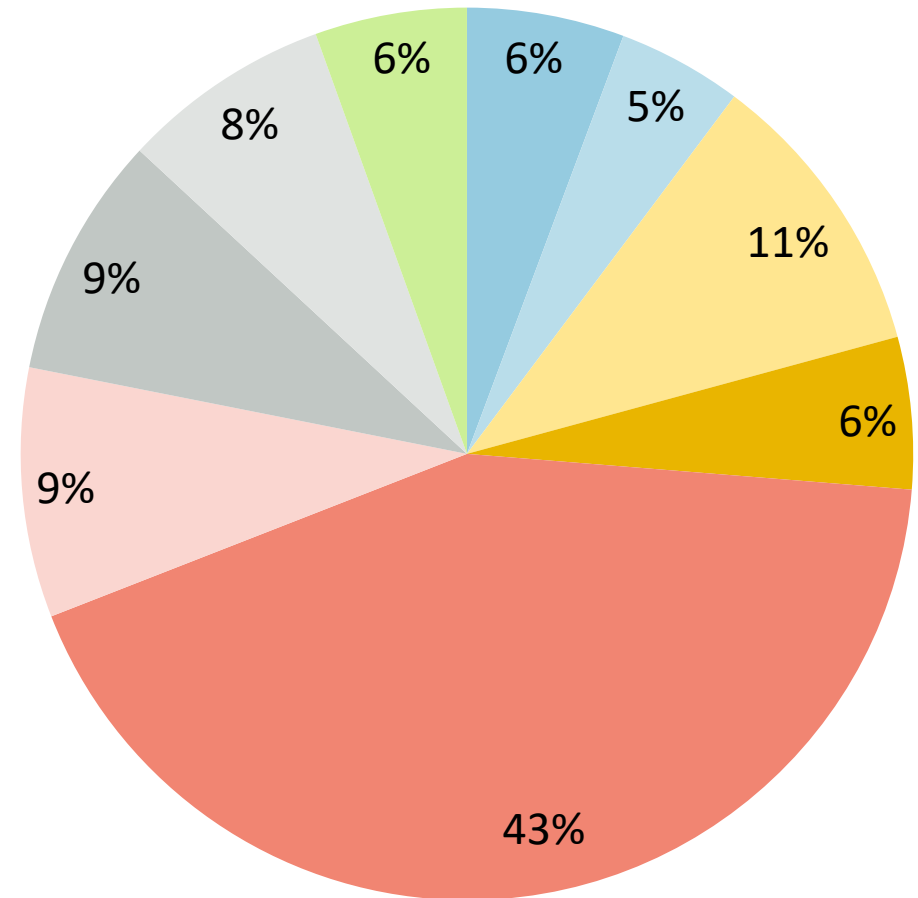
## Fruit of more than one decade of work II

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Sex	Crude Mortality Rate	Mortality Rate in the Austrian population (same gender and age distribution)	Standard Mortality Ratio
Men	8,4 (7,9–8,8)	2,0	4,2 (3,9–4,4)
Women	6,3 (5,7–7,0)	0,8	7,9 (7,1–8,8)
<b>All</b>	<b>7,7 (7,3–8,0)</b>	<b>1,7</b>	<b>4,5 (4,3–4,7)</b>

## Fruit of more than one decade of work III

- neoplasms (cancer)
- diseases of the circulatory system
- hepatitis / liver diseases
- HIV/AIDS
- mental and behavioural disorders due to psychoactive substance use
- poisoning by drugs / medicaments
- suicide
- other external causes (e.g. accidents)
- others



## Future possibilities

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- » The first mortality cohort study in 2018 can be repeated any time we want (and we have the resources) – many things can be reused (e. g. SPSS syntax)
- » A joined analysis together with other countries might increase comparability and usefulness (and probability to get resources) – I will come back to this later on
  
- » Another plan besides mortality: merge OST data with data on COVID-19 infections

## ...Lessons learned

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- » Use possibilities and take care that methodical knowledge is used when anything is changed in data collection.
- » To have a pseudonymized statistic register behind a registry with personal data is a very good idea and allows epidemiological analysis AND full data protection.
- » Put all these things on a legal base written in the law (you need good connections to policy makers, they have to be convinced that your efforts make sense).
- » Once a way has been found – try to include mortality cohort data merging into routine data collection and your data treasury will increase every year – you need resources for analysis only.

## Next steps (in the mortality cohort project)

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- » Fill in the EXCEL for data collection and send it to the NFPs for control and filling in (April)
- » Select some countries for more detailed country profiles (May)
- » Finalisation of the European Overview (June)
- » Finalisation of the whole base for the website, Technical report including revision of ST18 (November)
  
- » What´s about the idea of joint analysis of mortality cohort data?