

KORA-gen: 3 years of biobanking experience in Germany

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- Institute of Epidemiology

Content

- The KORA study and its use for genetic research
- KORA-gen – a population based biobank from Southern Germany
- Other epidemiological cohorts in Germany
- Ethics and biobanking
- Possible perspectives

KORA Augsburg

An ongoing epidemiological study

- **KORA**
 - = **K**ooperative Gesundheitsforschung in der **R**egion **A**ugsburg
 - = Cooperative Health Research in the Region of Augsburg
- Population based cohort study (18 000 individuals)
- Age range 25-74 years at recruitment
- Follow up investigations in regular intervals
- Study center open whole year

KORA Augsburg

An ongoing epidemiological study

1985 KORA Myocardial Infarction Registry → 2007

1984/85 (S1)
n= 4022

open

open (F1)

1989/90 (S2)
n= 4940

open

open (F2)

1994/95 (S3)
n= 4856

10 years

2004/05 (F3)

1999/01 (S4)
n= 4261

7 years

2006/07 (F4)

1985 → Biological Specimen Banking → 2007



GSF KORA Studienzentrum
Viktoriastr. 3, 86150 Augsburg



KORA Augsburg

- Information on multiple parameters available for
 - Sociodemography
 - Environmental factors, nutrition, smoking
 - General medical history : diseases, medication
 - Laboratory values of relevance to the disease fields
- Phenotyping of health related parameters for
 - Cardiovascular diseases
 - Metabolic disease, type 2 diabetes
 - Allergies
 - Cancer

KORA Augsburg

Available phenotypic information

● Availability	n	K/S	S1	S2	S3	S4
- Core Information	18 000	K	x	x	x	x
- ECG	13 000	K	x	x	-	x
- ECHO	1 600	S	x	-	x	-
- Glucose tolerance	1 700	K	-	-	-	x
- Sonography	1 400	S	-	x	-	-
- Atopy (spec. IgE)	8 000	K	-	-	x	x
- Lipid parameters	18 000	K	x	x	x	x
- Hemostaseology	13 000	S	x	-	x	x

K : KORA Core **S** : Participation of topic related specialists

KORA Augsburg

Population-based genetic resource

- **Population based prevalences of**
 - **Diseases**
 - **Binary traits / dichotomous phenotypes**
- **Population based reference values for**
 - **Quantitative traits**
- **Available resources for molecular genetics**
 - **DNA and serum samples from n = 18 000**
 - **Lymphoblastoid cell lines from n = 1 600**

KORA Augsburg population-based genetic resource

Advantages

- **Prospective accumulation of genetic and phenotypic information from the same individuals**
- **Platform design for multiple use and multiple contributions by different collaborators**
- **Anonymized database easily accessible**

KORA used as control population (examples)

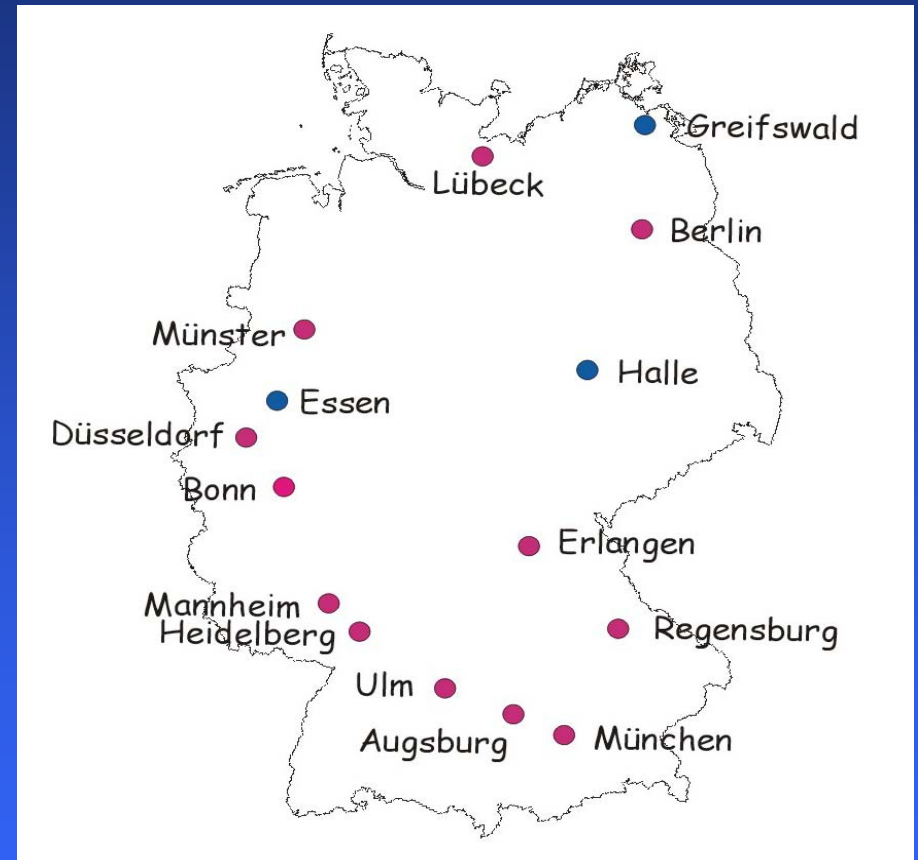
- Bipolar affective disorders, Bonn
- Myocardial infarction, Ulm
- Chronic inflammatory diseases, Ulm
- Diabetic nephropathy, Regensburg
- Sporadic CJD, Munich
- Atrial arrhythmia, Munich
- Asthma, Munich

KORA used as control population continued

- **Breast cancer, Bonn/Heidelberg**
- **Lung cancer, Munich/Göttingen**
- **Parkinson's disease, Munich**
- **Alzheimer's disease, Munich**
- **Affective disorders, Munich**

KORA Partners in Germany

- Universities and Research Centers
- Cooperation with other population-based studies



Databases in KORA

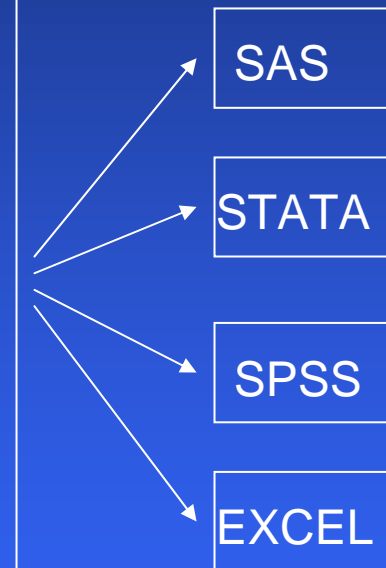
data sources



INGRES-DB



data for analysis



KORA: Data storage

- Separation of raw data and data for analysis
- Uniform concept for names of tables and variables
- Clearly defined access of users
- Comprehensive electronic documentation (Intranet)
- Study manuals and SOPs
- Comprehensive back-up system

KORA: Genetic Resource

- KORA-Biobank
- resource for genetic analyses
 - DNA, serum n = 18 000
 - cell lines n = 1 600
- SNP-Analysis in Genome Analysis Center possible



KORA probands with risk factors (4 surveys)

hypertension (RR > 140/90 mm Hg)	6 000
obesity (BMI ≥ 30 kg/m²)	3 500
hypercholesterinemia (Chol. ≥ 250)	5 600
active smokers	4 800
ex-smokers	5 100

KORA phenotypes (4 surveys)

alive	16 000
dead	1 600
Diabetes	1 800
Cancer	1 500
Myocardial infarction < 75 years	800

KORA-gen: Biobank from Southern Germany

- expanding from S4 survey to earlier surveys
- rules for use of the resource
- rights of „old“ data owners
- how to avoid conflict when research interests overlap
- ethics and confidentiality for the old surveys (without explicit consent for genetic research)

KORA-gen: study population

n = 18 000

	S1	S2	S3	S4
males	2023	2482	2405	2090
females	1999	2458	2451	2171

KORA-gen: possibilities and limitations

- **Data (phenotypes, environmental parameters etc)**
 - Selected set of variables available for everybody
 - Other variables only with agreement of the data owners
- **Biosamples (D N A, serum, plasma, urine)**
 - available for everybody as long as enough is available
 - restrictions if samples are limited
- **Genotypes**
 - in a common data base
 - after few months available for everybody

KORA-gen: Organisation

Team

- Scientific head
- Documentalist
- Additional expertise available for epidemiology, biostatistics, medical informatics, molecular biology



KORA-gen: How to use it

- Application (research question, variables and biosamples needed, genotyping, ethics, collaborators, coauthors for publication)
- Pre-evaluation/counseling by KORA team leader
- Evaluation by advisory board
- After acceptance: data/material transfer agreement
- Agreement of user, to provide the genotypes for the common pool

Epidemiologic population cohorts in Germany (with public funding)

		n	follow-up
● KORA Augsburg		18 000	5-20y
● SHIP Greifswald		7 000	5y
● RECALL Essen		7 000	
● EPIC Potsdam		25 000	8y
● EPIC Heidelberg		25 000	3y 8y
Sum		> 80 000	
● POPGEN Schleswig	patients	15 000	
●	controls	10 000	
			2y

Collections of patients in Germany (with public funding)

National competence networks (number of diseases)

cardiovascular (3)

infections (4)

neurological/ psychiatric (5)

cancer (3)

others (2)

Sum 17 diseases

Most have DNA banks



National German Ethics Board

Recommendation of 17 March 2004:

- Unlimited storage
- Consent without specification of research question
- Scientific use of 'old' samples
- Use of anonymized data and biological samples without informed consent

is possible under reasonable conditions

Biobanking

– possible perspectives for Germany

- **Big new biobank with public money: probably not**
- **Network of existing epidemiologic cohorts: possible**
- **Network of existing patient collections: possible**
- **New local activities: probable**

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KORA team Augsburg

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KORA-gen team

