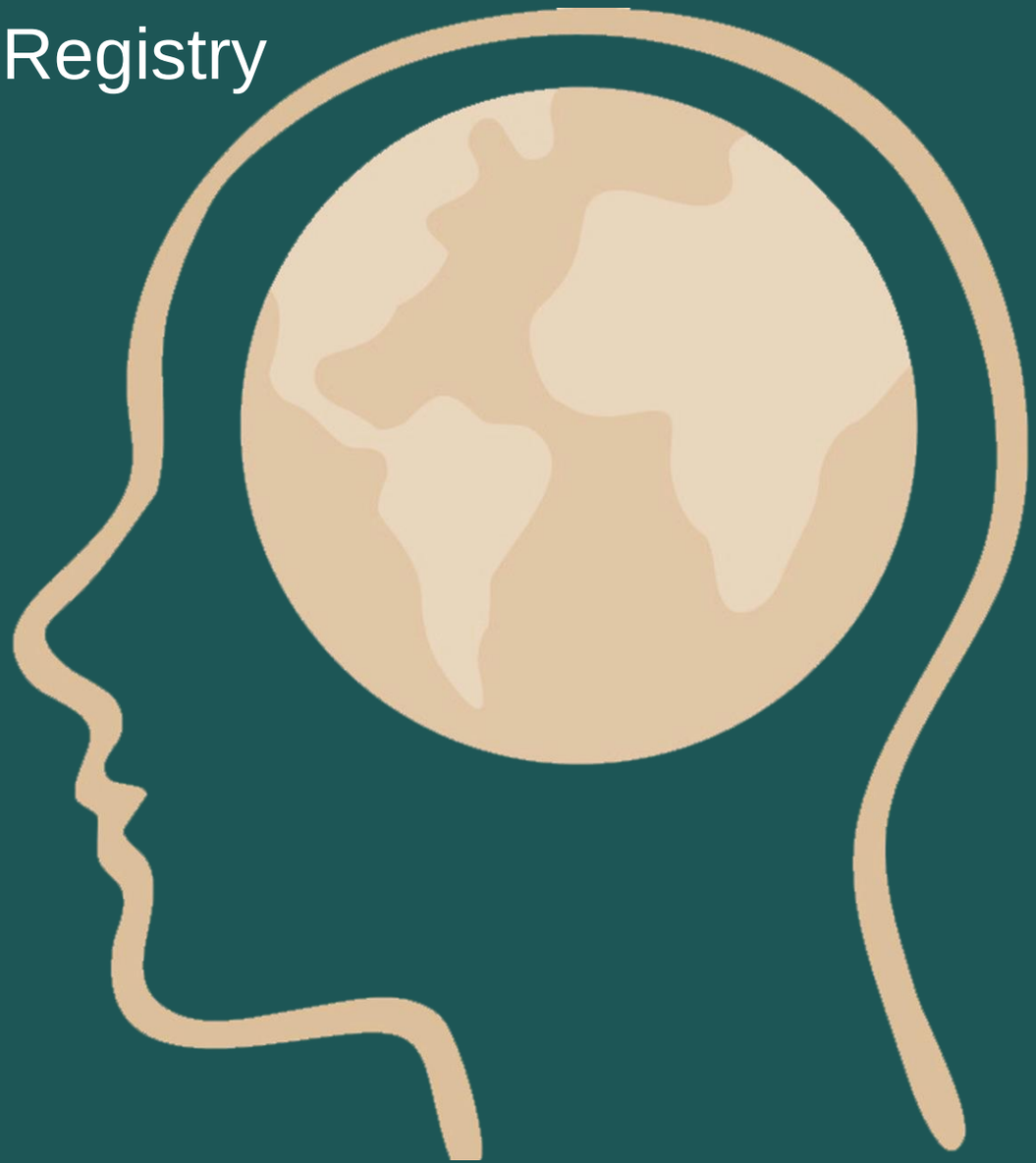
MAX PLANCK INSTITUTE
FOR HUMAN DEVELOPMENT

Adding Relations to the German Twin Registry

Extended Twin Family Designs
and what we did to support them in Castellum



Castellum Community Meeting

Speaker: Kathi Schmalen

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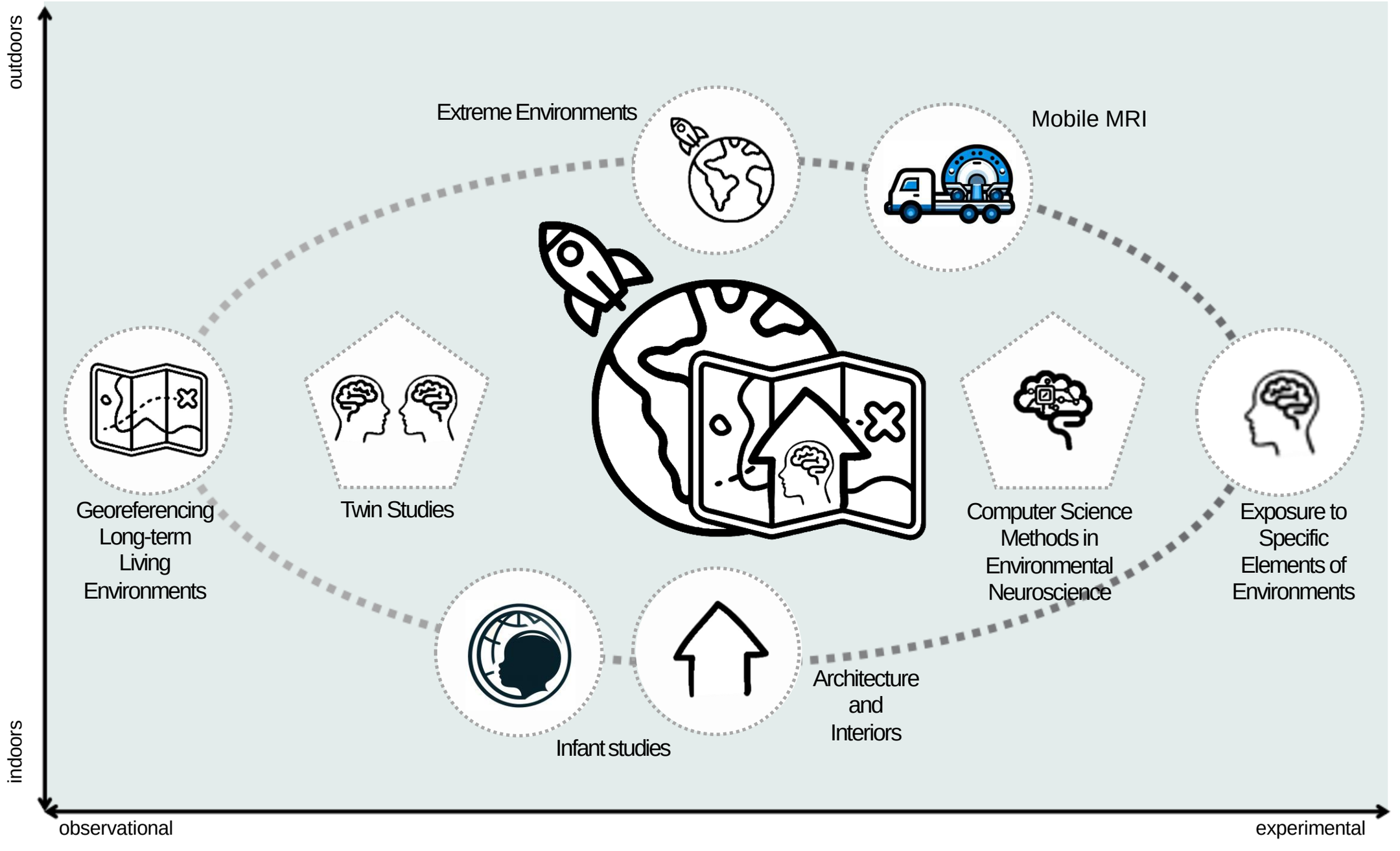
Agenda

- Introduction to the Center for Environmental Neuroscience (CEN)
- Twin Studies - Historical Context and Benefits
- Previously on GERTRUD
- GERTRUD 2.0
- Extended Twin Family Design
- Implementation in Castellum - Approaches, Feature Overview and Open Questions

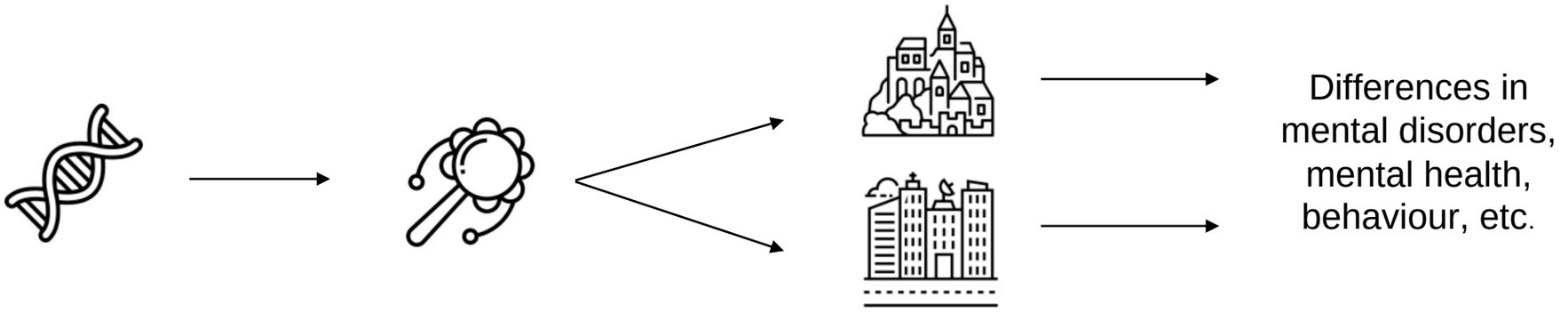

outdoors
indoors
observational
experimental
Extreme Environments
Mobile MRI
Georeferencing Long-term Living Environments
Twin Studies
Computer Science Methods in Environmental Neuroscience
Exposure to Specific Elements of Environments
Infant studies
Architecture and Interiors

Twin Studies - Historical Context and Benefits

- The Max Planck Society emerged from the Kaiser Wilhelm Society.
- During the Nazi era: at the KWI for Anthropology, Human Genetics, and Eugenics, twins, among others, were subjected to unethical, inhumane studies.
- Today: Commit to care, transparency, and participant welfare.
- Goal of GERTRUD to serve human dignity and the public good.

Why Twin Research?

Twin studies enable unique investigations into genetic and environmental factors.



Twin Studies - Historical Context and Benefits

- GERTRUD stands for German Twin Registry.
- Currently the only twin registry in Germany.
- GERTRUD offers twins of all ages the opportunity to participate in a series of scientific studies.

Previously on GERTRUD

- GERTRUD recruited twins.
- The actual study was executed by individual research groups (both at MPIB and externally).
  - No responsibility regarding data of external studies.

- We therefore did not use a lot of Castellum functions like:
  - Saving which participant participated in which study.
  - No execution was needed.
  - …

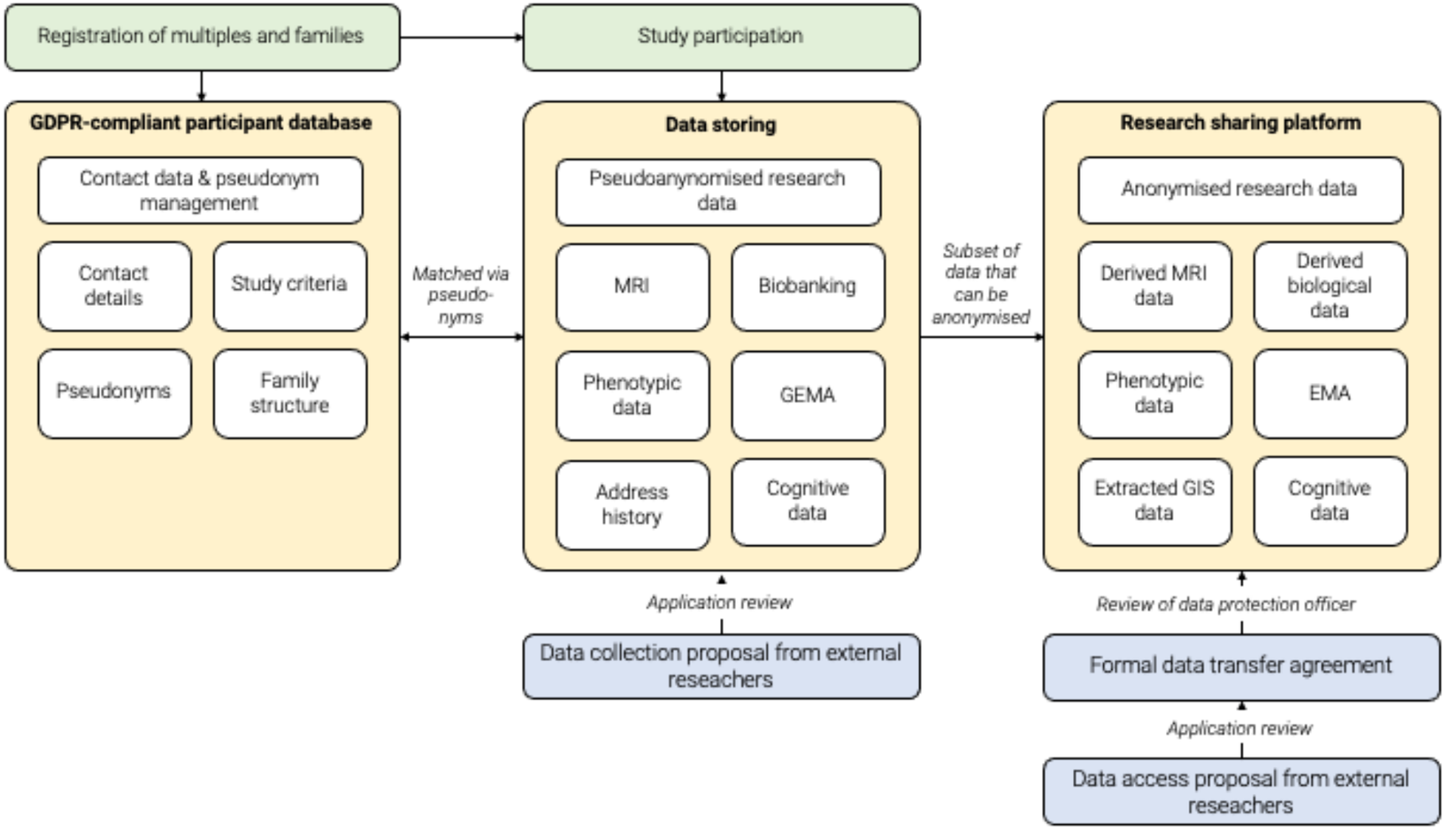
GERTRUD 2.0

Old:

- No control what other institutes are doing with GERTRUD participants.
- Confusing for participants who we are and what we are doing with their data.
- No linkage between datasets of participants.

New:

- Therefore: all studies are applying to a committee. After decision the study is conducted by the GERTRUD-Team.
- Recruitment, execution and overview of participants' study enrollments in Castellum.
- Now: Linkage between all datasets.


Registration of multiples and families
Study participation
GDPR-compliant participant database
Contact data & pseudonym management
Contact details
Study criteria
Pseudonyms
Family structure
Matched via pseudo-nyms
Data storing
Pseudoanynomised research data
MRI
Biobanking
Phenotypic data
GEMA
Address history
Cognitive data
Application review
Data collection proposal from external reseachers
Subset of data that can be anonymised
Research sharing platform
Anonymised research data
Derived MRI data
Derived biological data
Phenotypic data
EMA
Extracted GIS data
Cognitive data
Review of data protection officer
Formal data transfer agreement
Application review
Data access proposal from external reseachers

GERTRUD 2.0 - Current Status

2205 registered twins

821 twin pairs

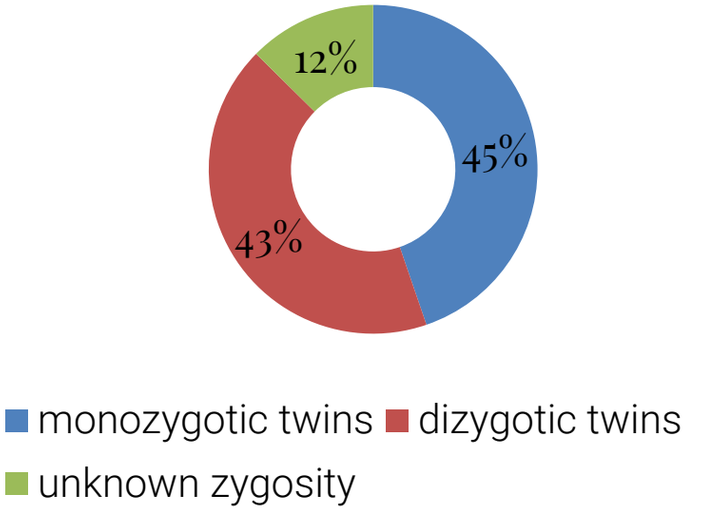
541 unmatched twins

2 triplets

1 quadruplet

585 adult twin pairs

231 non-adult twin pairs



GERTRUD 2.0 - Finding Twins

Existing twin studies

Registration offices

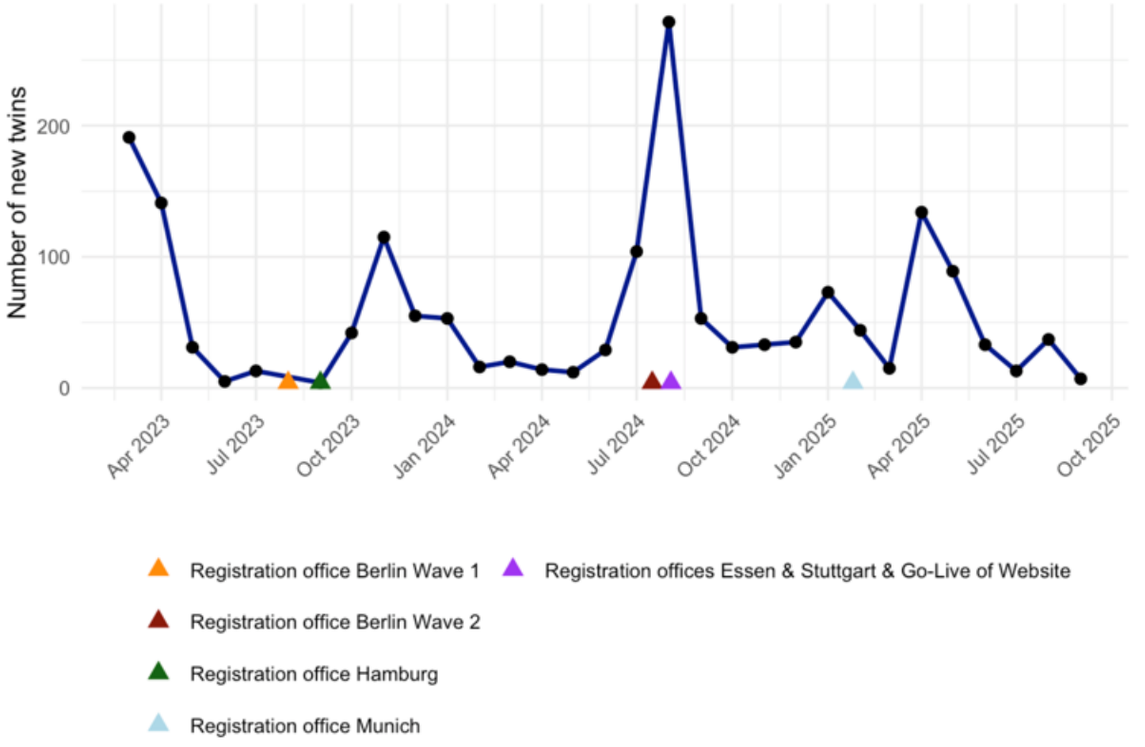
Website

Events, e.g. open campus days

Social media

Birth registries

GERTRUD 2.0 - Finding Twins



Extended Twin Family Design (ETFD)

- Registration of twins, parents, siblings, partners, and children of twins.
- More and more twin registries and studies are using ETFDs.
- More comprehensively disentangles genetic and environmental influences.
- Estimation capabilities:
  - Simultaneous estimation of shared and non-shared environmental effects.
  - Additive and non-additive (dominant) genetic influences.
  - Parental environmental transmission.

Implementation in Castellum - Approaches, Feature Overview and Open Questions

Challenges and requirements:

- Implementing ETFD in Castellum.
- It needs to be clear which relation goes to which twin/person.
- It needs to be possible to invite subgroups of the family.
- It needs to be possible to save contact infos and attributes of each family member.

Implementation in Castellum - Approach “Groups”

Instead of family members the whole family is primary object.

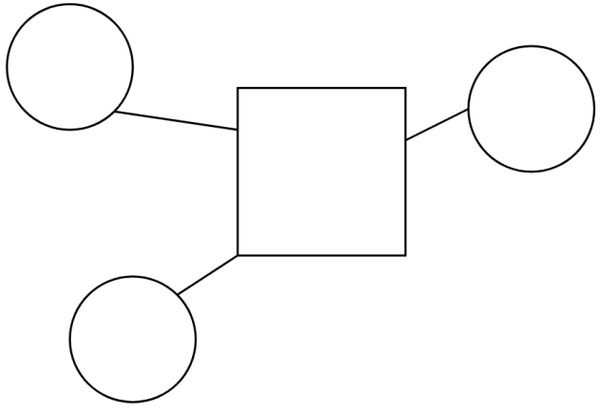
Advantage:

- This approach has been in use so far, so no changes needed.
- Very generic.

Disadvantage:

- No information on internal structure of the family.
- Any information must be saved in attributes such as "is any of the group members male“.
- Unclear legal situation: which right has individual of data of the group.
- Prone to errors.

Implementation in Castellum - Approach “Twins at the center”



The twin pair is the center and defines other family members by the role they have in relation to that pair.

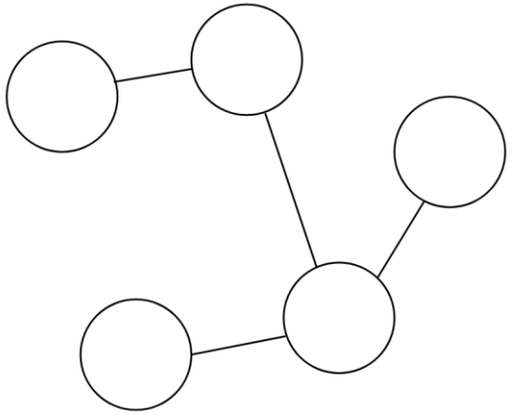
Advantage:

- All roles can be implemented.
- Individuals can have roles in relation to different pairs.

Disadvantage:

- Not possible to link child and partner to specific twin.

Implementation in Castellum - Approach “Relations”



All participants form a flexible network of inter-personal relations.

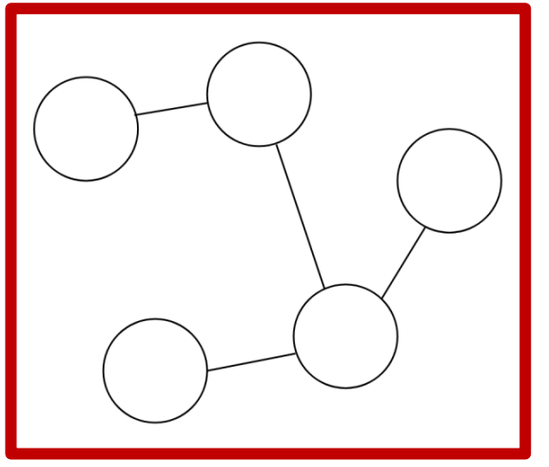
Advantage:

- All roles can be implemented.
- Flexible.
- Individuals can have roles in relation to different pairs.
- It is clear which Twin has which relation to other members of the family.

Disadvantage:

- Creating new entries manually can be complex and slow: You need to implement every relation to every member.
- No way to store data about the family as a whole.

Implementation in Castellum - Approach “Relations”



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Implementation in Castellum - Feature Overview

- Relations is now implemented in Castellum (release version: 25.10).

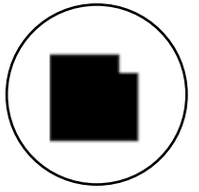
Implementation in Castellum – Open Questions

- How do we deal with uncertainty regarding attributes (e.g. zygosity)?
- How do we know that Twin A and Twin B are from the same family?
- Are there other use cases outside the ETFD?
- Should we use Prolific to find twins?

GERTRUD is a Cooperation

Max Planck Institute for Human Development

Medical School Hamburg



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