

Att utnyttja andras data – och att själv bli utnyttjad

The Swedish Twin Registry

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The Swedish Twin Registry

- Started 1961
 - All 200,000 twins born in Sweden since 1886
 - (Inter)national resource
 - \approx 30 ongoing project
 - \approx 20 new projects per year
 - $>$ 40 publications per year

 - Long term vision:
 - Collect phenotypic data on all twins

 - Collect DNA from all twins
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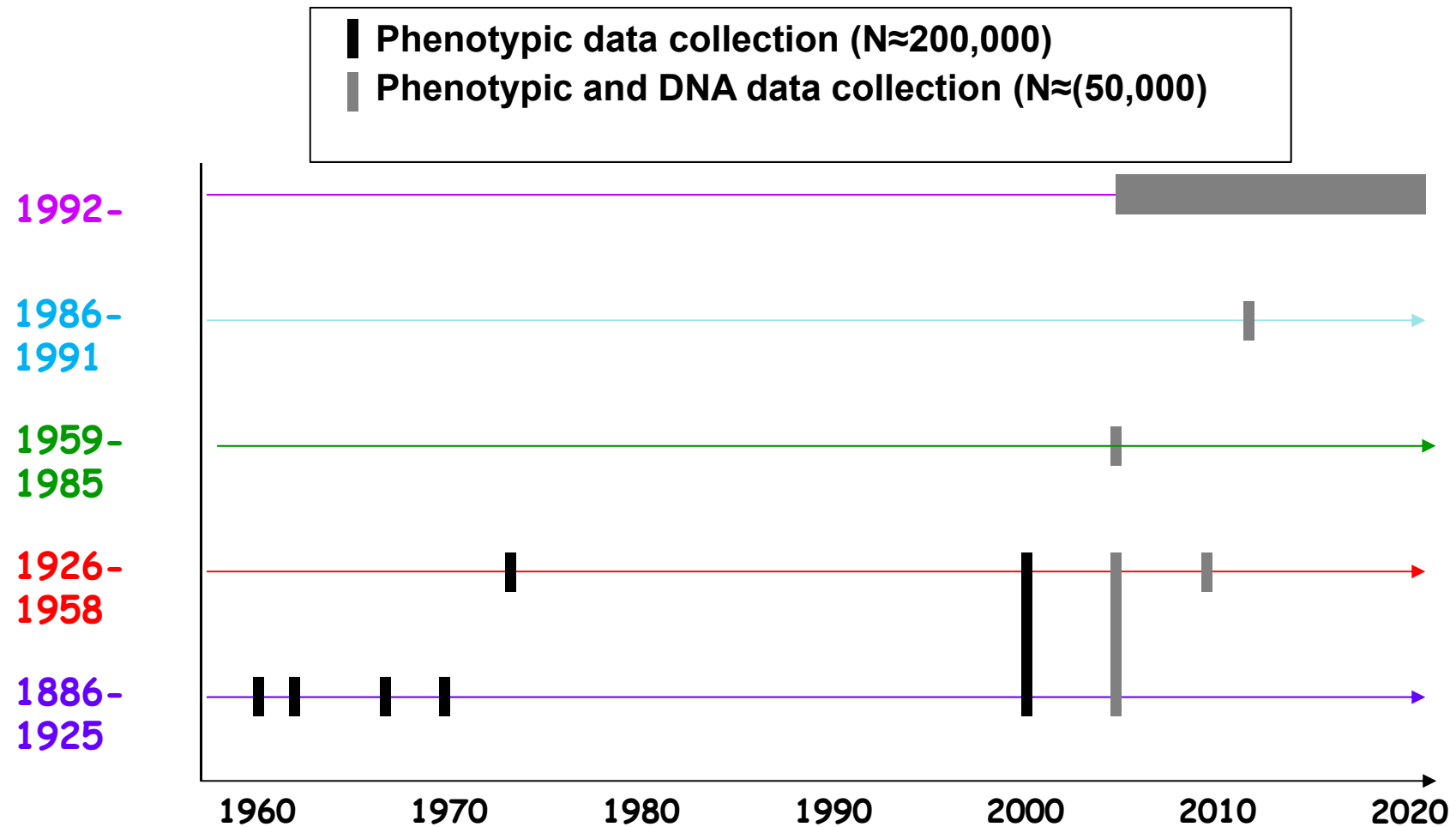
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The Swedish Twin Registry: The data



The Steering group

- 10 Members
 - 4 meeting per year
 - Approve projects
 - Oversee contacts with twins
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Utnyttja oss

- Tvillingarna har deltagit med tid och diverse kroppsdelar
- Data ska användas till bästa tänkbara forskning



Policy och ansökan

- www.tvillingregistret.se
 - Click “for researchers”
 - Scanned questionnaires
 - Meta-data
 - Instructions for applications
 - Policy
 - Kräver forskare vid svenskt universitet
 - Svenskt etikillstånd
 - Inga krav på medförfattarskap
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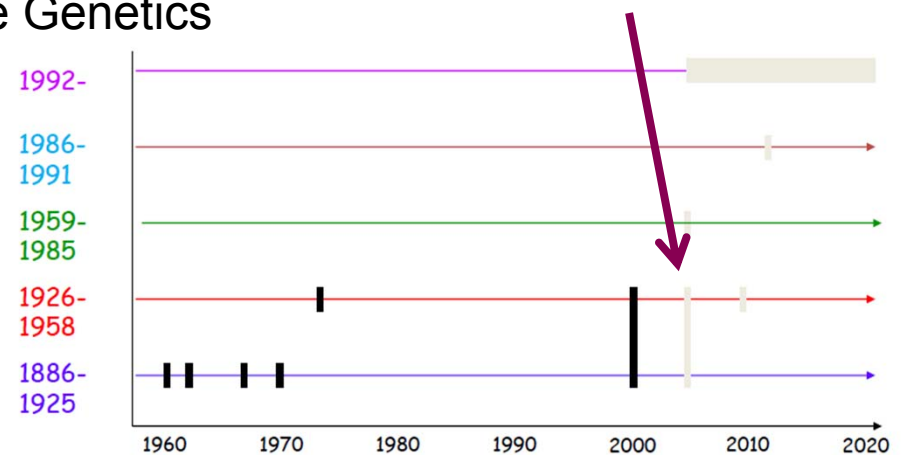
Kostnad?

- “Gamla” data (>5 år)
 - Billigt
 - Nya data
 - Dyrare
 - Antagligen bäst att samarbeta med de som har samlat in data
 - Samarbete inget krav!
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Exempel

The Swedish Twin Registry: GWAS

- TwinGene (N≈14,000)
- GWAS (OmniExpress)
 - Used by 15+ Swedish research groups
 - Contribute in several (all?) consortia
 - Included in at least 30 publications in high profile journals like Science, Nature, Cell and Nature Genetics



Utnyttja oss

..... vi utnyttjar andra

- Samarbetar med flera kvalitetsregister
- Varje gång vi använder data frågar vi dem och får tillstånd
- Nästan alltid blir de medförfattare

Everything is twice as fun with twins

