

Import & Export of Datasets: two examples



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Preliminaries

The principles of **General Data Protection Regulation** (GDPR) cover the scope, security, and retention of data, with exemptions; for example, journalism, disclosure of harm, law enforcement.

For **UK research**, GDPR requires that participants are **informed** on how their personal data will be used in research.

The “simple” case of secondary use

Observe any **limits** placed on the consent of the data provider

Obtain consent from the original participants for any research using **personal data** that would affect them or be likely to cause damage or distress to anyone.

Seek ethical advice where reuse of data (even anonymised) may affect an **identifiable community, group or category of people**

For projects taking place entirely **overseas**, ethical review should be sought in that country, assuming rigorous processes and standards.

Import

Surveillance data obtained by a commercial organization for an overseas local authority to monitor traffic flow is imported for studies of urban pollution

No consent

Contains personal data (faces, car registrations)

Processed data could be reused in a way that (potentially negatively) affects individuals



Import

Local ethical review

Assurance of adherence to local laws, regulations, and guidelines for collection and export

Justification for the use of identifiable data

Explain how the data would be stored, accessed and protected to fulfil data protection obligations

Evidence of mitigations for protecting processed datasets that safeguards individuals and communities

Export

“Investigate the genetic and environmental factors that contribute to autism and related physical and mental health conditions to better understand wellbeing in autistic people and their families”



Collecting DNA, survey data and consent to access medical records.

Data may be shared within the academic community and/or commercial partners

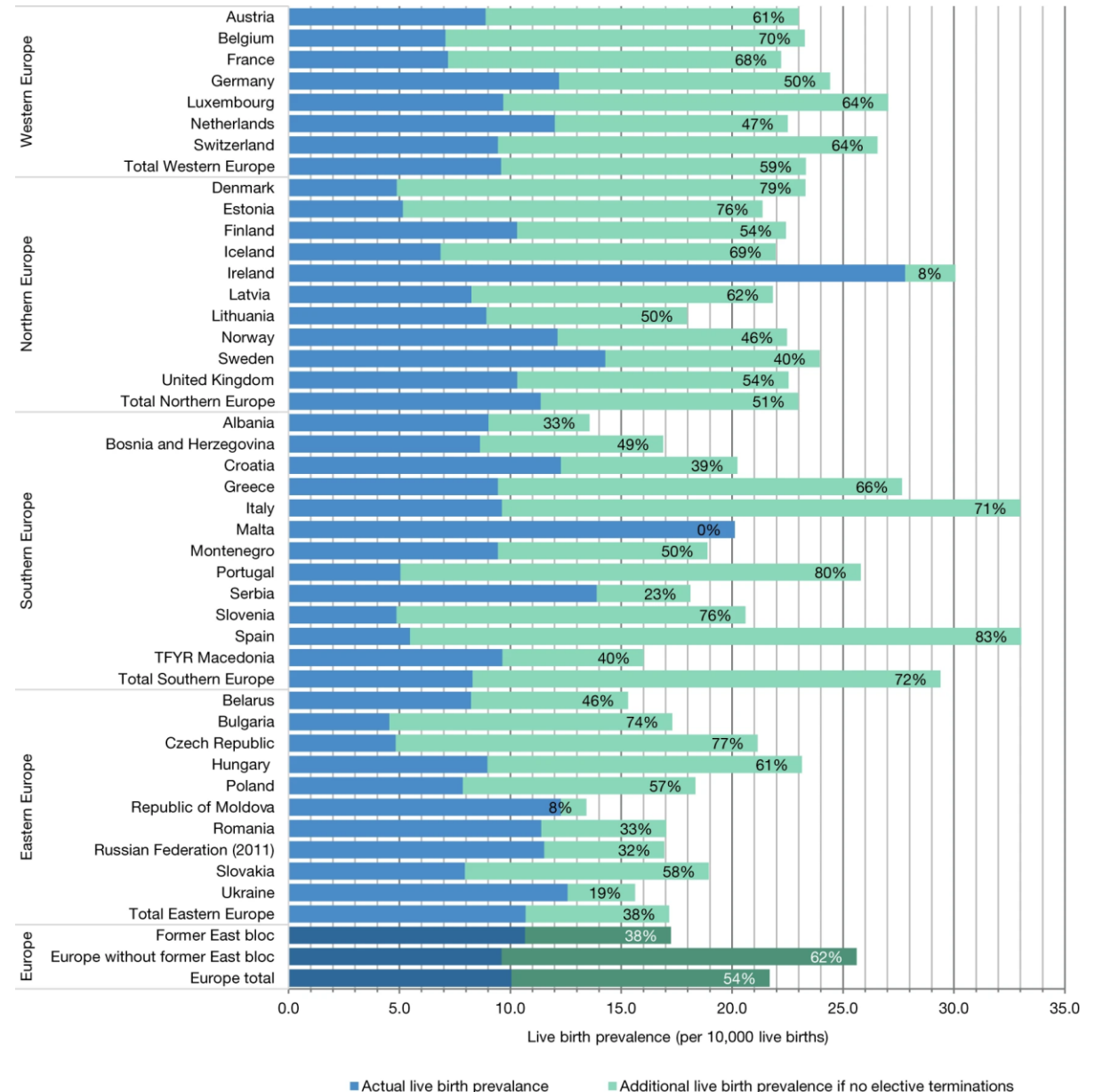
Export

Secondary use has unspecified consent

Future use of DNA data for prenatal testing (eugenics)

What is research for in the context of a particular community?

Live birth prevalence of Down syndrome (2011–2015) and the effect of elective terminations (de Graf et al, 2020)



Resources

Ethical review of studies taking place overseas: <https://www.research-integrity.admin.cam.ac.uk/research-ethics/ethics-application-guidance/ethical-review-overseas-research>

Secondary data use: <https://www.medschl.cam.ac.uk/wp-content/uploads/2016/01/UREC-Good-Practice-Guidelines-on-Secondary-Data-Research.pdf>

Data/Material Transfer Agreements: <https://researchgovernance.medschl.cam.ac.uk/information-governance-storage-of-research-participant-data/data-transfer-agreements/>; <https://www.research-operations.admin.cam.ac.uk/research-contracts/types-contracts/material-transfer-agreement-mta>

List of resources from institutions: <https://www.research-integrity.admin.cam.ac.uk/guidance-0>