IMPLEMENTING CONSENT FOR RECORD LINKAGE IN A CROSS-NATIONAL SURVEY
A PRACTICAL EXAMPLE FROM SHARE WAVE 8

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Short Overview of SHARE

• **SHARE – „Survey of Health, Ageing and Retirement in Europe“**
  
  • Multidisciplinary and cross-national panel study
  
  • Wave 1 (2004) - wave 8 (2018/19)
  
  • 28 countries (EU, CH, Israel)
  
  • Micro data on health, socio-economic status & social and family networks of individuals aged 50 or older
  
  • Computer assisted personal interviews (CAPI)
  
  • Data made available for scientific research (SHARE RDC)
Short Overview of Organisational Structure

- **International coordination of the study**: SHARE Central in Munich, Germany

- **National scientific partner institutions**
  - SHARE Country Team DE
  - SHARE Country Team DK
  - SHARE Country Team ...

- **National Survey Agencies (processors)**
  - Survey Agency DE
  - Survey Agency DK
  - Survey Agency ...

- Basic structure for the data collection with regard to the questionnaire modules that are implemented in all countries
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**National providers of administrative data**

- German Pension Insurance
- Statistics Denmark & Danish Health Data Authority
- Nat. providers in SHARE wave 8: AT, FI, HU, IL, IT, SE

- “Record linkage module” = optional & country-specific
- IF LINKAGE (8 countries in wave 8):
Obtaining Consent in SHARE Wave 8

• **GDPR = applicable law**
  – GDPR applies in relation to personal data
  → Entire SHARE data collection is subject to the GDPR

• **Consent = legal basis for data processing in SHARE**
  – Consent procedure developed together with SHARE-ERIC DPO
    • Documented oral consent in the CAPI software
    – General template of the SHARE data protection statement in English for all countries:
      • Includes required information for data subjects needed for consent
      • Fulfills information duties when collecting personal data from data subjects
    – Translated in national languages by the Country Teams
    – Procedure and document reviewed by ethics committee

  + Explicit consent for the purpose of Record Linkage projects
Consent for Record Linkage in Wave 8

• **Different approach**
  - No template, but information, instructions and **checklist** for Country Teams

• **Why?**
  - Different institutions involved: controllers & processors
  - Different variables, in some cases special categories of data
  - Purpose of the data processing varies in accordance with the data that is linked
  - Procedure of processing and recipients of data vary depending on requirements of administrative data providers
  - Access to data depends on requirements of providers
  - Form of consent varies: written vs oral

→ Various differences regarding information that has to be provided to the data subjects, etc.
Preparation of Consent for Record Linkage

• Responsibilities

– SHARE Country Teams:
  • Ensure compliance with national legal, ethical and administrative requirements
  • Responsibility for the production of the national consent documents & translation into English

– Central SHARE coordination:
  • Provides supporting information
  • Provides clauses regarding the rights of the data subjects for consent documents
  • Wording regarding period of storage of personal data
  • Responsible for central documentation of procedure
Preparation of Consent for Record Linkage

• Supporting information & instructions
  – Legal definitions & explanations
    • E.g. „consent“ (freely given, specific, informed and unambiguous) and conditions for withdrawal
  – Clarify options (no explicit consent = no option)
    • Written or documented oral consent in CAPI software
  – Instruction: when to ask for consent
    • At the time when personal data are obtained: during interview
    • Ask for consent separately during the linkage module and not combine it with the general consent for participation
  – Presentation of the consent information
    • In a written form (documentation duties)
    • To be provided in a concise, transparent and easily accessible form, using clear and plain language
Preparation of Consent for Record Linkage

• Checklist for national consent documents (1)
  – Mention that consent is voluntary (and independent from participation in the study)
  – Identity and contact details of controllers and the DPO
  – If special categories of personal data are linked to the survey data this has to be explicitly mentioned
  – Purpose of data processing (e.g. research projects in the area of the linked data)
  – Procedure of storing and processing data:
    • Contact data, other identifying variables, research data
    • Information about data separation and coding list
    • Recipients of data that is processed during the linkage process
Preparation of Consent for Record Linkage

• Checklist for national consent documents (2)
  – Mention consent as the legal basis of the processing
  – Period for which the personal data will be stored, or if not possible, criteria used to determine that period → use wording of general consent template
  – If applicable: details of intended transfers of personal data into third countries (outside EU/EEA)
  – Comments on all rights of the data subject → use clauses of general consent template
    • revocation of consent; right of access; right of correction; right of deletion; right to complain to the supervisory authority responsible for SHARE-ERIC (DPA of Bavaria) and the responsible authority in respective country
THANK YOU!

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Questions, Feedback