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IMPLEMENTING CONSENT FOR RECORD LINKAGE IN A CROSS- NATIONAL SURVEY

A PRACTICAL EXAMPLE FROM SHARE WAVE 8

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MAX PLANCK INSTITUTE FOR
SOCIAL LAW AND SOCIAL POLICY
Munich Center for the Economics of Aging



1. A very short overview

- SHARE & its organisational structure

2. Consent procedures in SHARE wave 8

- General consent procedure in SHARE
- Different approach re consent for record linkage

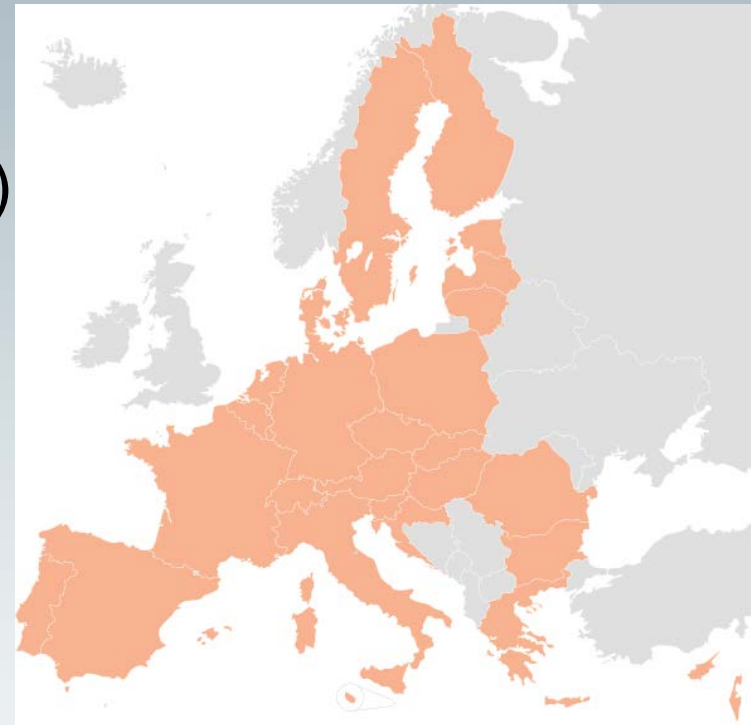
3. Preparation of consent for record linkage

- Checklist for national consent documents

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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**SHARE Country
Team DE**

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**SHARE Country
Team ...**

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

**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**

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

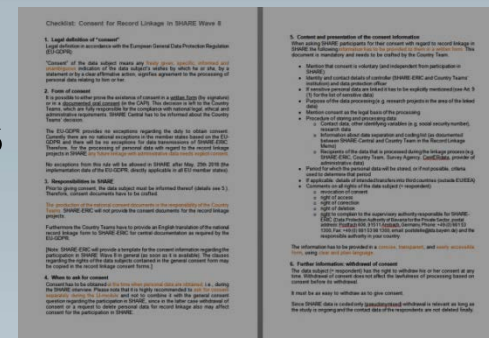
- **Different approach**

- 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.**



- **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

- **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

- **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

- **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

