

ESFRI Exchange of Experience Workshop
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Managing ethical issues *in* **SHARE**



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SHARE-ERIC



Ethics is a **topic**....

that **you will come across** sooner or later as researcher or research manager

- on **EU, national and international level**
- with possible effects on:
 - Operations of the research infrastructure
 - Grants
 - Publications
- to which extent, might vary **depending** on the respective **scientific domain**.

Survey of Health, Ageing and Retirement in Europe

- **Social science** project from ESFRI Roadmap 2006
- Set up as an **ERIC** in **2011**
- **Survey in 28 European countries (+ Israel)**
- Our **respondents (aged 50+)** are asked **repeatedly every two years** for **personal information** on topics of **health, ageing and retirement**.
- The survey is conducted as **face-to-face interview** (by commissioned survey agencies).
- Released data are provided **free of charge** to the **scientific community (no commercial use!)/ for evidence-based policies**.

Why do we have ethical issues in SHARE?

SHARE´s research is focused on **human beings**.

=> Respondents **entrust** us for scientific purposes with their very **personal circumstances and life decisions**.

That imposes a **special responsibility** on us, including **mental** and **physical integrity** and **protection of personal data of the respondents**.



Implementing these requirements means to actually *live* this responsibility day by day:

In concrete, we consider **protecting health, identities and personal data of our respondents** and **keeping our promises** to them (= no commercial use of the data) as **main duty** and **backbone of the whole project!**

- Continuous review by the Ethics Council of the Max Planck Society (current home institution of SHARE-ERIC).
- In addition: in some countries (e.g. SE, CH) ethical approval for social science surveys is required by law.

M A X - P L A N C K - G E S E L L S C H A F T

Ethikrat – Kommission des Präsidenten



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To
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Opinion of the Ethics Council of the Max Planck Society on the "SHARE" Project

The SHARE project has been running since 2002. It was originally established at the Mannheim Research Institute for the Economics of Aging (MEA) of the University of Mannheim. Since 2011, it is being operated under the umbrella of the Max Planck Society at the Max Planck Institute for Social Law and Social Policy and is centrally coordinated by the Munich Center for the Economics of Aging. As a result, the research-ethical assessments of the project, which were previously carried out by the University of Mannheim (see ethics committee decisions dated 13.12.2004, 16.12.2008 and 28.6.2010), were taken over by the Ethics Council of the Max Planck Society. The Council first dealt with parts of the project at its meeting on 19.10.2011 – not conclusively – and later at its meetings on 15.2.2012, 13.6.2012, 19.2.2014, 23.2.2016, 14.6.2018, and 29.5.2020 (Waves 4-8) in detail. In the process, the overall concept with its interdisciplinary and international approach was also scrutinized in an appropriate scope. The Ethics Council came to the unanimous conclusion that the overall project design as well as the subprojects it assessed – e.g., the SHARE Corona Survey (SCS), the SHARELIFE questionnaire or the sampling and analysis of dried blood spots since Wave 4 – did not raise any research-ethical concerns as regards design and foreseen practical implementation. Upon recommendation of the Ethics Council, data protection concerns were clarified with the Data Protection Officer of the Max Planck Society.

Numerous approvals and votes by other ethics committees in the participating SHARE countries – in particular, with regard to the international sampling and analysis of dried blood spots in Wave 6 – have confirmed the project to be compliant with relevant legal, especially statutory norms, as well as with research-ethical guidelines, e.g., the set of ethical principles regarding human experimentation developed for the medical community by the World Medical Association (Declaration of Helsinki, last revised at the 64th WMA Meeting held in Fortaleza/Brazil in October 2013).

The Ethics Council of the Max Planck Society extends its best wishes to the persons responsible for the continued success of the project.



Prof. Dr. Rüdiger Wolfrum
Chairman

Every “survey wave” has different **focus/ challenges**:

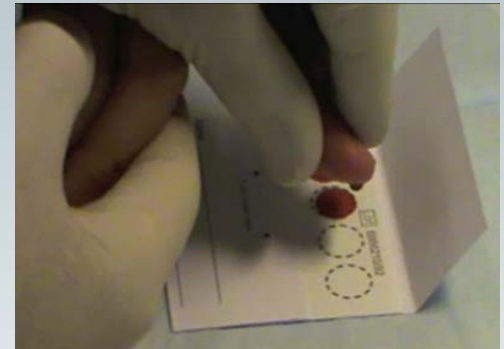
⇒ **new ethical requirements**

- Wave 6: collection of biomarker: Dried blood spots

⇒ **Ethical approval in every country**

⇒ Involvement of **new ethics committees**
due to “**medical dimension**”

⇒ **more efforts** to explain research



- Wave 9: **pandemic** required **suspension of face-to-face interviews** and **switch to telephone interviews** to **protect our respondents**.



Respect Code of Practice for Socio-Economic Research

= professional and ethical guidelines for the conduct of socio-economic research

Declaration of Helsinki

= *a set of ethical principles regarding human experimentation developed for the medical community by the World Medical Association*

SHARE applies these principles and also obliges its users to comply with them in the SHARE conditions of use.

Legal background:

Art. 19 HE regulation “Ethical principles“

“Actions carried out under the Programme shall comply with ethic principles....”

Stages:

1. Ethics Self Assessment (during application phase)
2. Ethics Review (before finalisation of GA)
3. Possibly: Ongoing assessment during project.

Possible fields:

- human (embryonic stem cells, embryos, participants, cells/ tissues); personal data;
- animals;
- dual use;
- non EU countries;
- environment & health and safety;
- artificial intelligence.

- Journals more frequently ask for evidence and proof that data has been collected in compliance with ethical principles.

Lessons learned (1)

Managing the infrastructure:

- The **relevance of ethics** should be a **matter of course for researchers/managers**.
- It has effects in **all scientific domains**, possibly with varying degrees of intensity.
- **Conscientious and thorough work pays off** and is required in different situation on **international, European and national level**.
- Ethics is an **ongoing issue**: new research topics require new ethical considerations.

Lessons learned (2)

Managing EU proposals/ grants:

- Ethics should be considered **right from the beginning** of a proposal and checked for issues. **Necessary new applications may be very time-consuming** with respect to preparation and waiting for approval.
- Allowing **sufficient time** for the **ethics part also** during the implementation is essential.



SHARE IS THE LARGEST PAN-EUROPEAN SOCIAL SCIENCE PANEL STUDY.

SINCE 2004 MORE THAN 140.000 PEOPLE PARTICIPATED IN 480.000 INTERVIEWS.

How we age in Europe.

SHARE
SURVEY OF HEALTH, AGEING
AND RETIREMENT IN EUROPE

SHARE PROVIDES MICRO DATA ON HEALTH, SOCIO-ECONOMIC STATUS AND SOCIAL & FAMILY NETWORKS.

Thank you for your attention!