



SYNERGIES FOR COHORTS IN HEALTH: INTEGRATING THE ROLE OF ALL STAKEHOLDERS



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**A European Initiative to Foster Research Across
Clinical and Population Cohorts**



SYNCHROS?

THE PROJECT IN A NUTSHELL

- A European project funded under the Research Programme Horizon 2020 (2019-2021)
- Goal: Coordination and support for synchronising cohorts and population surveys in Europe and worldwide
- Focus on practical, methodological, ethical and legal challenges to facilitate research towards the development of stratified and personalised medicine as well as better health policies
- Initiated by institutions and experts representing epidemiological and clinical research, patients, legal/ethical competencies and European infrastructures



CHALLENGE

Health research using data from different cohort studies is a challenge because the studies use different protocols and are conducted in different organisation and legal systems. Often variables and data available in one cohort study is missing or differently defined in another.



APPROACH

- Map of cohort study landscape
- Collect information on legal and organisational standards
- Compile information on variables
- Propose algorithms for the detection of systematic errors and approximating true and missing values
- Recommendations for standardisation
- Implementation by stakeholder dialogue and consensus building



STAKEHOLDERS

- Cohort study leaders
- International research organizations
- Alliances for standardisation
- Patient organisations
- Funding organisations
- Health administrations
- WHO
- Editors of peer-reviewed journals



SYNCHROS-BACKGROUND

A cohort represents a group of people followed over time. In cohort studies, medical, health and contextual information is collected systematically. Cohort studies include patient and population cohorts, and intervention studies.

The relevance and statistical reliability of findings depend both on the size of the cohorts and the quality of the data. Often results are not transferable to other populations or

regions. Harmonising data over several cohorts, however, can greatly extend the significance of the results.

In particular, research on rare diseases, or research supporting personalised medicine, requires large cohorts in order to find a statistically representative number of individuals who share rare characteristics.

SYNCHROS-PROJECT

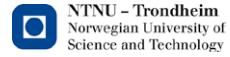
We collaborate with relevant initiatives worldwide. The cohort mapping exercise and the compilation of methodological, legal and ethical issues will provide the basis for strategic briefs for stakeholder dialogues. We also aim to make sustainable recommendations on standards to improve the compatibility of future data collection, e.g. for data sharing methods towards an international strategic agenda to improve the coordination of cohorts globally.

A scientific advisory board and an ethics committee composed of key stakeholders guide the research.

The broader community of interested stakeholders is invited to get involved and to share results and comment via various communication channels such as email, blogs, Twitter and LinkedIn – all accessible via our website www.synchros.eu.



PARTNERS



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