

A two round survey to identify data sources capable of taking part in rapid vaccine benefit-risk studies in Europe

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BACKGROUND

ADVANCE project (Accelerated development of vaccine benefit-risk collaboration in Europe)

- Unique public-private collaboration with 19 European countries
- Aims to establish a prototype of a sustainable and compelling system that rapidly provides best available scientific evidence on vaccination benefits and risks for well informed decisions

ADVANCE International Research Readiness (AIRR) Survey

- Developed to collect metadata from potential databases for vaccine benefit-risk studies
- Captures information such as data custodian details, database overview, population, geographical coverage, publications, data access/ethics, Vaccines
- Dissemination of the AIRR survey was carried out in 2 phases
- Survey results from 105 databases have been shared on the EMIF platform

Synergies with other European initiatives

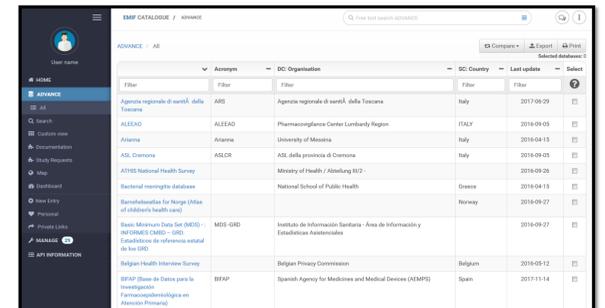
- Models of Child Health Appraised (MOCHA): Due to the overlap of the metadata collected by the MOCHA project, we were able to exchange relevant metadata profiles between the repositories
- European Medical Information Framework (EMIF): The metadata catalogue platform for created by the EMIF project was used to host the metadata collected by the AIRR survey

OBJECTIVES

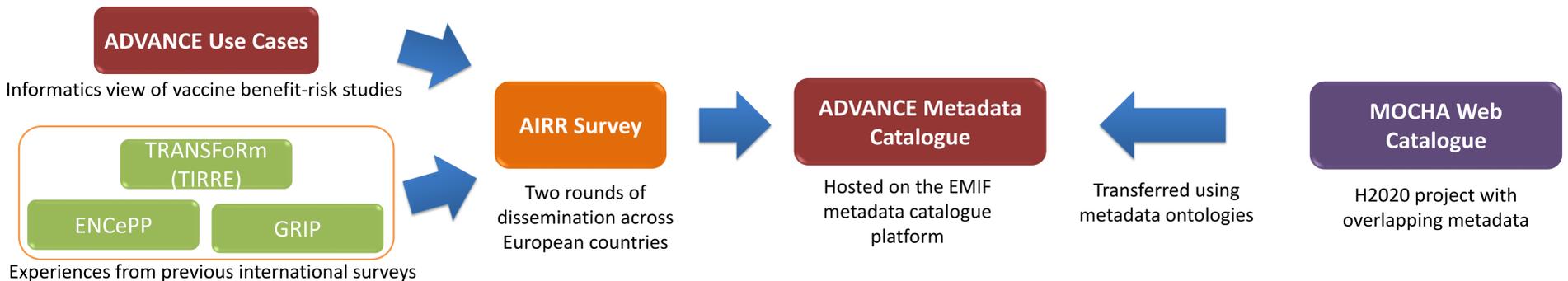
To identify data sources capable of contributing to proof-of-concept studies conducted by ADVANCE

AIRR Web Catalogue

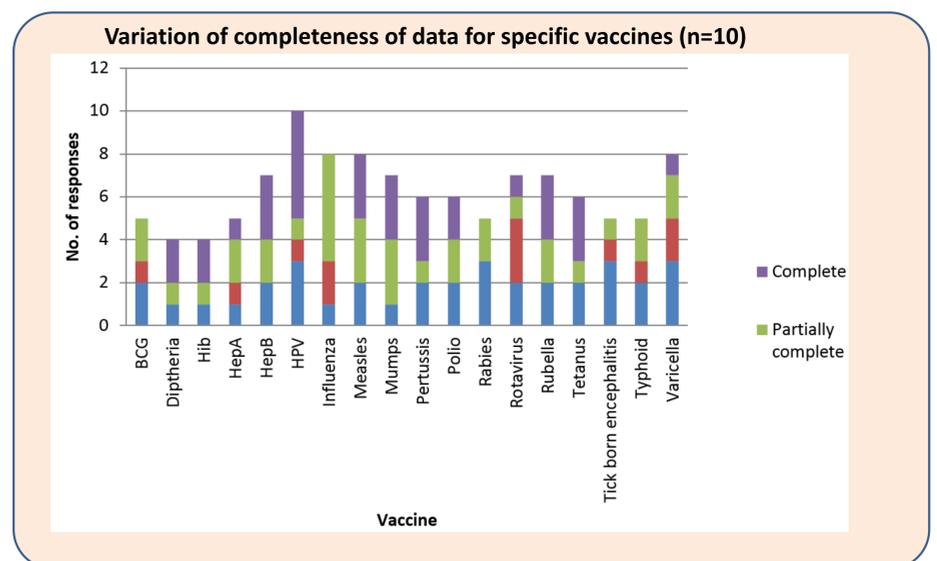
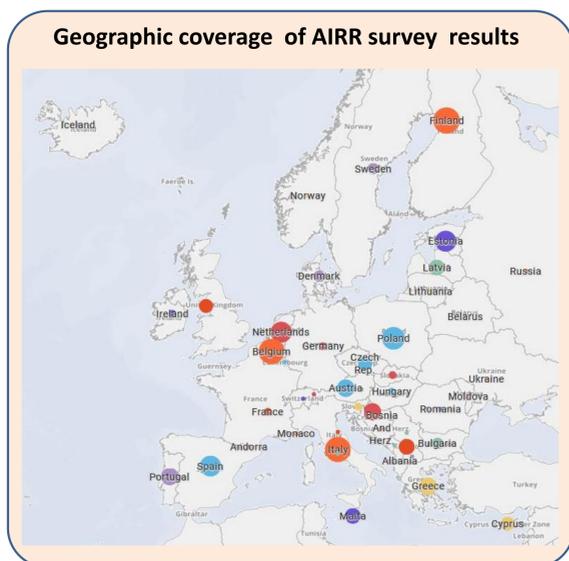
Visit <https://emif-catalogue.eu/> and join the ADVANCE community



METHODS



RESULTS



| | Vaccine coverage | Vaccine effectiveness | Vaccine safety | Burden of disease |
|-------------------------------|------------------|-----------------------|----------------|-------------------|
| Primary data sources | 26(25%) | 25(24%) | 26(25%) | 25(24%) |
| Supporting data source | 5(5%) | 7(7%) | 13(12%) | 4(4%) |
| Total | 31(30%) | 32(30%) | 39(37%) | 29(28%) |

Primary data sources: directly contribute data to studies
Supporting data sources: provide a subset of data required for some studies (e.g. prescription databases for vaccine coverage or mortality databases for deaths due to adverse events)



SUMMARY AND RECOMMENDATIONS

- Need sustainable solutions to ensure that metadata catalogues continue beyond the life time of a project
- Need a mechanism to allow database meta-profiles to be updated by database custodians beyond the lifetime of the project
- Need systematic development of survey instruments for collecting metadata (e.g. use cases) that accurately model the information used for studies
- Use incentive-driven strategies for disseminating metadata surveys to maximise response rates
- Minimise the number of questions in survey to maximise response rates
- Use ontological approaches for mapping between databases to promote networks and data sharing among EU projects (accessibility and exchange of metadata within the EU)

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