

Results of RD-Action WP5: Steering, maintaining and promoting the adoption of Orphacodes across MS

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This presentation is part of the project / joint action '677024 / RD-ACTION' which has received funding from the European Union's Health Programme (2014-2020).

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Objectives of the WP5

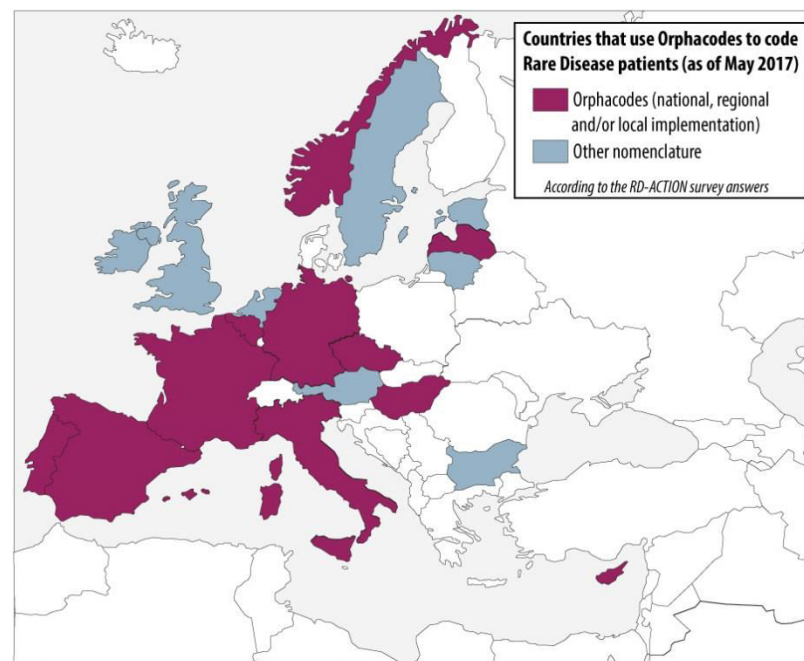
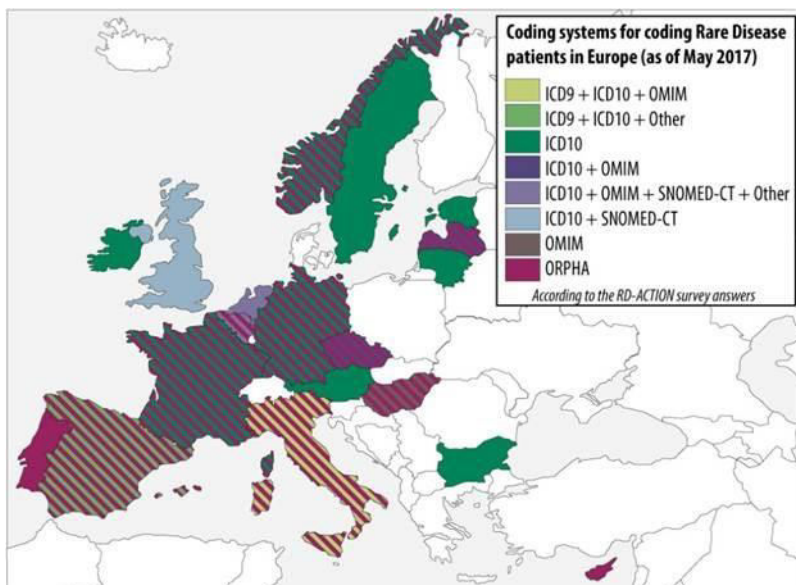
Main aim: to develop a toolset to assist Member States (MS) in implementing the Orphacodes in their health system

- Define common objectives for coding RD
- Provide guidance and common standards
- Create consistency across MS
- Tune the codification resource



Implementation of RD patient coding across MS

- Introduction of a new coding system without guidelines may not be sufficient to succeed.
- Classification use depends on the use case
- Balance between national system requirements and international demand for data on RD is required.
- Strict rules for RD-coding could restrict the national possibilities but will enhance the international comparability.



Deliverable D5.1 (Review document of existing technical implementations for RD coding of MS) and the **Surveys on current codification situations** can be found on the RD-Action website

How to make RD data exploitable at EU level?

Data should be collected in a unified way by using:

- ✓ An agreed list of Orphacodes (Masterfile)
- ✓ Coding guidelines that do not interfere with national regulations (as much as possible) but standardize the data collection so that it serves the international use case

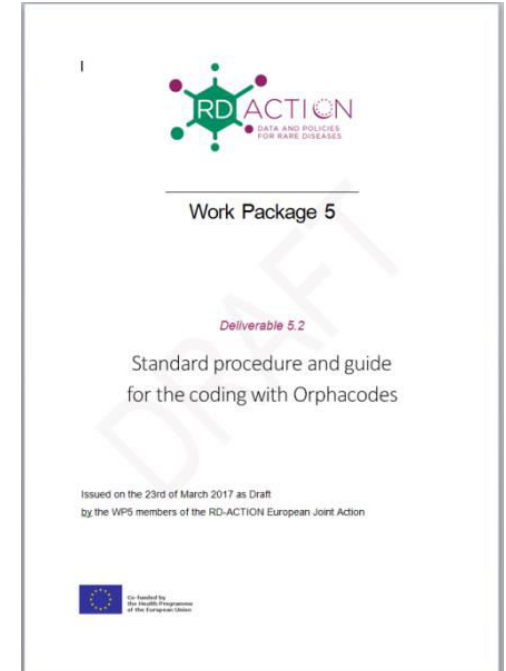


International rules and guidelines for coding RD

Guideline 1 - Several tools and strategies could be set at MS level to produce data or statistics for RD, nevertheless each country should set this **strategy** accordingly to a standard principle of **maximizing exhaustiveness** as well as possible **re-use of existing data** collections

Guideline 2 - Code the data in a way that **the reporting can compile to the granularity of the international recommended list of Orphacodes** (“master file”-granularity). If no further national needs for reporting are necessary, use the codes from the “master file” directly.

Guideline 3 - **Whenever possible** capture the information of the **diagnostic assertion** for all RD cases. Use the Options “Suspected rare disease”, “Confirmed rare disease” and “Undetermined diagnosis”. Additional options might be helpful.



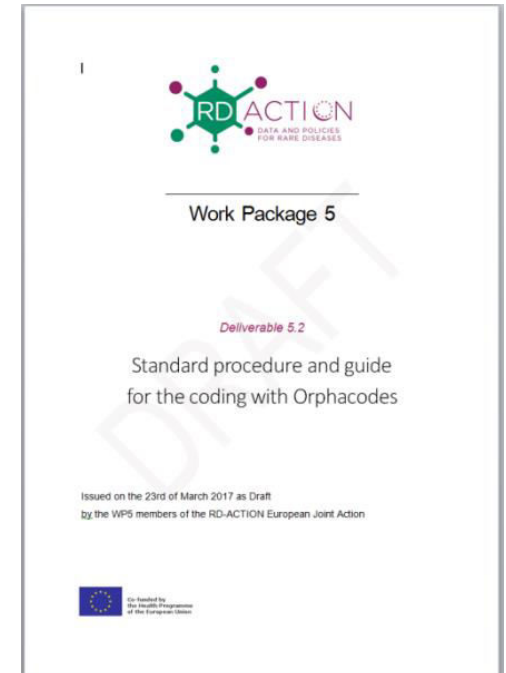
International rules and guidelines for coding RD

Guideline 4 – Although **rare disease registries** (disease, population or patient based) should promote the use of data standards to increase interoperability of their data, they should **not be the only instruments** upon which the EU strategy to produce health statistics for RD at population level relies.

Guideline 5 - **Update your coding resource** according to the internationally agreed cycle in order to have the most recent coding file and to ensure comparability.

Guideline 6 - If Orphacodes are used together with another national **coding** system for morbidity coding, the two **systems should be linked in a standardized way** to ensure that code combinations are standardized and the coding effort for the user is minimized.

➤ Information about the Guidelines can also be found on
Poster no. 78



The specification and implementation Manual of the Master file



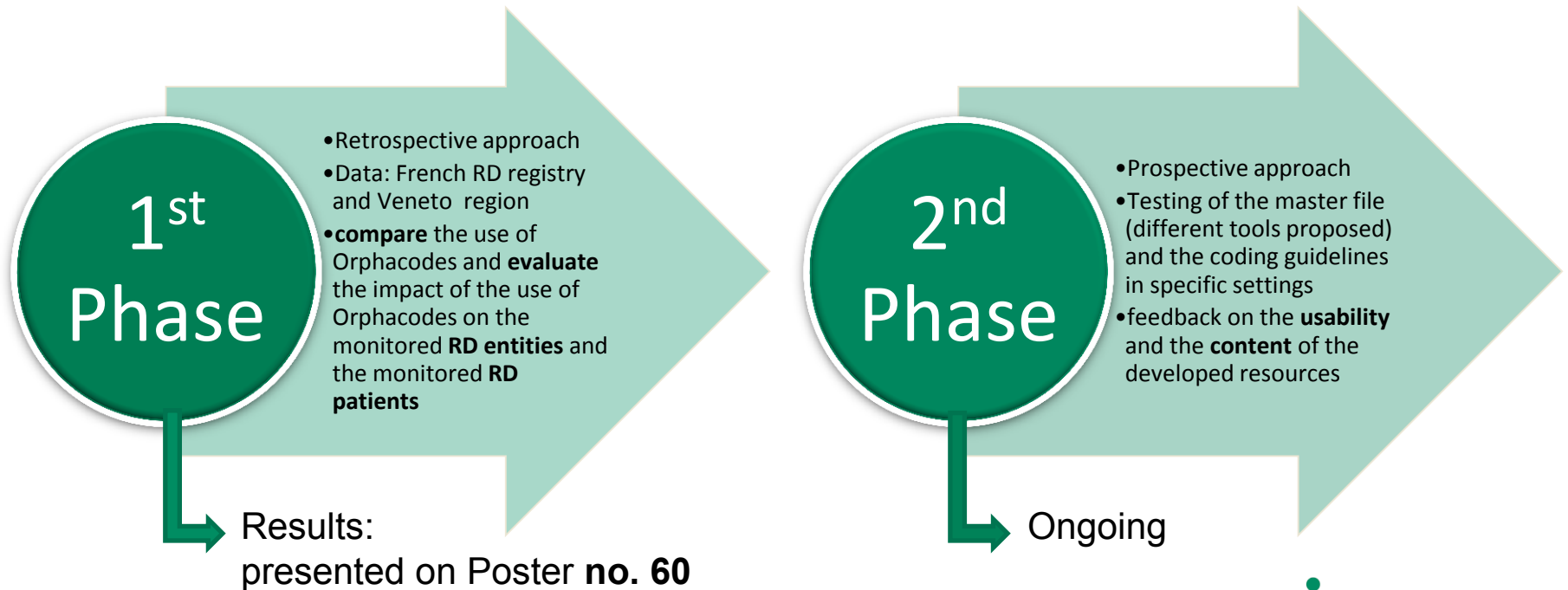
The Manual provides an overview of:

- The benefits of using the Master file
- The Master file concept
- The content definition of the Master file
- How to use the Master file
- The release schedule
- A detailed description of the Master file

➤ More information about the Master file and the Manual can also be found on Poster no. 78

Testing phase

“In the last year of this WP the developed products will be tested in the countries and results will be collected through **two different tools**, as to share developments conducted in Italy and in France. The results will be used for fine-tuning and adapting of coding rules and content. **In order to test the new file and the guidelines previous coding exercises can be repeated and the results can be checked for proof of concept”.**



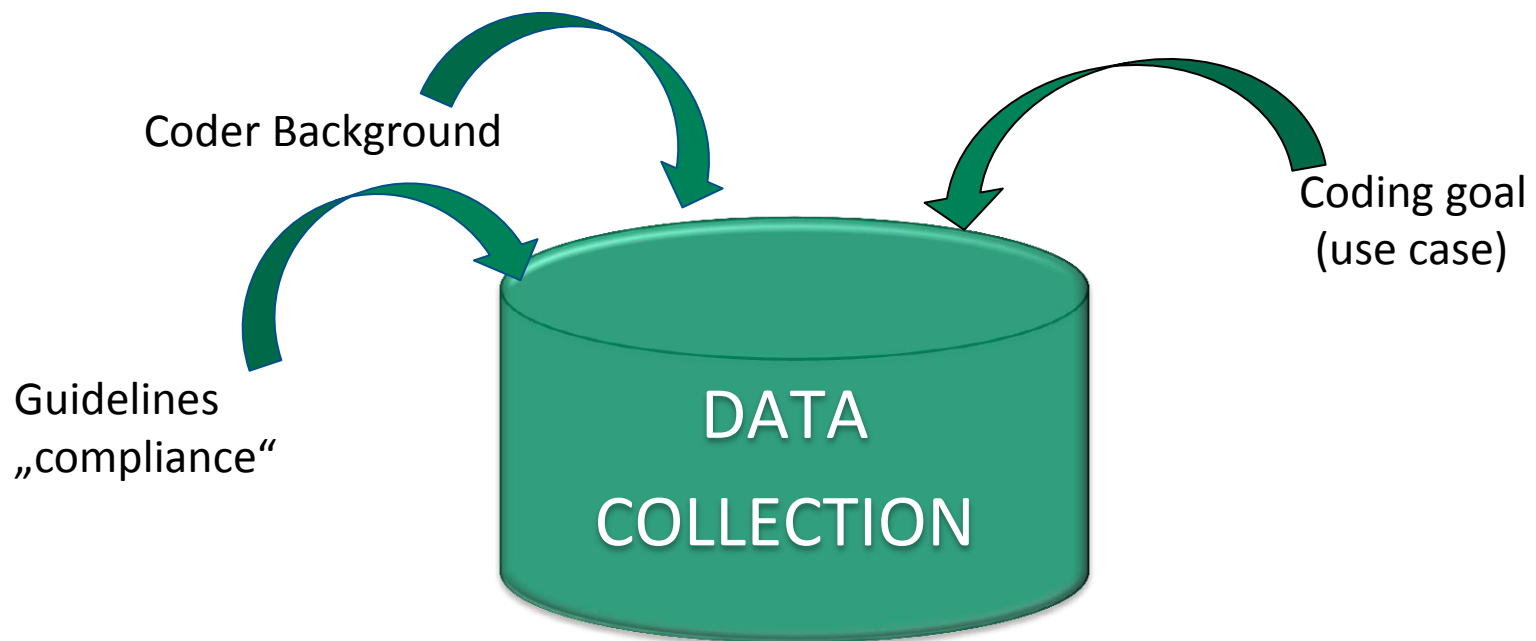
How could ERN's support interoperability at EU level?

- By using a system that:
 - enables international statistical retrieval and aggregation. (Common denominator: use of Orphacodes at master file granularity and coding guidelines (especially 2 and 5))
 - allows different national or field specific coding practices but recognises the need for standardisation for international comparison and interoperability of data. (Not exclusive, see coding guideline 6)
- ✓ Master file, standard procedures, data formats, coding guidelines, recommendation



Influence of coding environment on standardization

- Standardized coding → homogeneous data collection
- Inter-observer Variability





THANK YOU!

Comments and feedback on the works of the WP5 could be directed to:

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