



ORPHAcodes coding overview of training programs

Czech Republic

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Czech training course (3 hours)

- **Introduction, RD case definition, why collect RD data, why ICD-10 coding is not enough**
- **Introduction to Orphanet – where to go, what to search for**
- **Excercise on ORPHAcode Search on Orpha.net/SLG website, terminology examples, comparison with ICD-10 coding**
- **National Registry of Reproductive Health, Module of Congenital Malformations (NRVV) – why, how and what to report**
- **Guide on filling the NRVV Case Form**
- **Case study – example of filling the NRVV form, 2 excercises**
- **RD-CODE project (web and tools), ERNs, reporting of ORPHAcodes to Health Insurance Funds**

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Lessons learned

- **Not all clinicians (even in the ERN hospitals) are aware about Orphanet and ORPHAcodes (!) – start from the beginning**
- **It is hard to push clinicians to play with the examples/exercises**
- **Our Czech course is focused only on one use case = NRVV**
- **More general courses are needed:**
 - **One short (one presentation) for clinicians**
 - **One more complex on Orphanet nomenclature and classifications**
- **Completely e-learning version needed**
- **Future update about Health Insurance Funds reporting**

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Other countries - discussion

RD-CODE Implementing countries

- **Spain**
- **Romania**
- **Malta**

Other countries

- **Norway**
- **Poland**
- **Italy**

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Greetings from on site participants

