




Project Title

**Cross-border Patient
Registries Initiative**

Work Package 5 PARENT Common Data Set

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1. ABBREVIATIONS

| | |
|-----------|-----------------------------------------------------------------------------------------------|
| PARENT | cross-border PATient REGistries iNITiative |
| EU | European Union |
| EC | European Commission |
| CDS | Common Data Set |
| EPIRARE | EPIRARE (European Platform for Rare Disease Registries) |
| EAR | European Arthroplasty Register |
| EFFORT | European Federation of National Associations of Orthopaedics and Traumatology |
| epSOS | European Patients - Smart open Services |
| ENCR | The European Network of Cancer Registries |
| CARDS | Cardiology Audit and Registration Data Standards |
| B.I.R.O. | Best Information through Regional Outcomes |
| TREAT-NMD | Translational Research in Europe – Assessment & Treatment of Neuromuscular Diseases |
| EUReMS | European Register for Multiple Sclerosis |
| RES | The National Arthroplasty Registry of Slovenia (in Slovene: Register endoprotetike Slovenije) |
| NIJZ | National Institute of Public Health (in Slovene: Nacionalni inštitut za javno zdravje) |
| HJZJ | Hrvatski Zavod za Javno Zdravstvo |

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2. Introductions

The document describes Common Data Set for registries included in Parent.

There are many different registries in the EU. Some of them we analysed in the project Parent. We liked to find the data elements, which are same or similar in all registries we deal with. We called them Common Data Set (CDS).

We started this activity in February 2014. We find out that there are only few common data elements.


In April 2015 we started this activity again.

We included following registries: EPIRARE, EFFORT-EAR, epSOS, ENCR, CARDS, B.I.R.O., TREAT-NMD, EUREMS, Parent RES.

3. Methodology

Researchers from HJZJ and NIJZ analysed following registries:

| Area | Author | Common data set | Link to the dataset |
|----------------------------------------------------|----------------------------|--------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Rare diseases | EPIRARE | EPIRARE common data set | http://www.epirare.eu/_down/del/D9.3_ProposalforCDE_FINAL.pdf |
| Arthroplasty | EFFORT-EAR | EFORT EAR Minimal datasets | http://www.ear.efort.org/ |
| Patient summary | epSOS | epSOS Patient Summary | http://ec.europa.eu/health/ehealth/docs/guidelines_patient_summary_en.pdf |
| Cancer | ENCR | ENCR Standard dataset | http://www.enccr.eu/images/docs/recommendations/recommendations.pdf |
| Cardiology | CARDS | CARDS Data Standards | http://www.escardio.org/Policy/Pages/data-standard-cards.aspx |
| Diabetes | B.I.R.O. | BIRO Common Dataset Summary | http://www.biro-project.eu/documents/downloads/D3_1_Common_Dataset_v1_7.pdf |
| Neuromuscular disorder | TREAT-NMD | FSHD Core Dataset | http://www.treat-nmd.eu/downloads/file/registries_toolkit/FSH_core_dataset.pdf |
| Multiple Sclerosis | EUREMS | EUREMS Core data set | http://eurems.eu/attachments/article/93/EUREMS%20Data%20Mask_August2014.pdf |
| RES-The National Arthroplasty Registry of Slovenia | Parent | RES-data model for primary operation | |

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For starting point we select EpSOS Patient Summary. All other data sets we compared with this. All our analyses we merged in one table (see enclosure CDS-final table.xlsx).

4. Results and Discussion

Our analyse shows that common data set of observed registries are very small. For more results please see enclosure CDS-final table.xlsx.

Only Gender and Date of Birth are present in all registries, in most of them are: Primary Patient Identifier, Healthcare Facility's identifier, Problem/diagnosis description.

5. Conclusion

Registries in the EU are very different structured, so common data set is very small and not usable.