Results

- Two ways of ORPHAcoding implemented at CRDT and University Hospital Tübingen: (i) custom-made ORPHAcode lists for CRDT subunits and (ii) all ORPHAcodes via the diagnostic coding software ID DIACOS
- ORPHAcode lists were implemented for 14 CRDT subunits
- Total numbers of ORPHAcodes contained at CRDT subunit lists: 931 (by 31.12.2019)
- Counting RD patients using ORHPAcodes and QlikView

Discussion

To our knowledge, the CRDT is the first Rare Disease Centre (RDC) that has implemented an expertise reflecting ORPHAcoding. In particular, for rare disease care it is important that an expertise claim is confirmed by a number of ORPHAcodes for disorders that have yet not been given an ORPHAcode.

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