

**Objectives of workpackage 6**

To evaluate the accuracy and the quality of the ICD coding of congenital anomalies in health care databases compared to EUROCAT data - UMCG

To develop algorithms for use of health care data in the surveillance of congenital anomalies to improve the quality of the data - UNIFE

To evaluate the accuracy and the quality of data on terminations of pregnancy for fetal anomalies from health care databases and provide advice on coding to improve it - RSD

**Replies to questions for WP6 – Autumn 2017**

**WP6 registries:**

Wales (PHW NHS), Northern Netherlands (UMCG), Finland (THL), Funen DK (RSD), IMER (UNIFE),

S Portugal (INSA), Zagreb (KDB), Valencia Region (FISABIO), Basque Country (BIOEF),

BINOCAR\_NORCAS, BINOCAR\_EMSYCAR, BINOCAR\_CAROBB, BINOCAR\_SWCAR, BINOCAR\_WANDA

**Questions:**

1. Please confirm your interest and contribution to the WP6 validation studies

Yes: Wales, Funen DK, Northern Netherlands, Basque, Valencia Region, Finland, Zagreb, Emilia Romagna, South Portugal, BINOCAR\_NORCAS, BINOCAR\_EMSYCAR, BINOCAR\_CAROBB, BINOCAR\_SWCAR, BINOCAR\_WANDA

No:

1. Is it possible for you to link your TOPFA data in EUROCAT to health care databases with discharge diagnosis and outpatient diagnosis based on the maternal ID?

Yes: Wales, Basque, Northern Netherlands, Funen DK, Finland, BINOCAR\_NORCAS, BINOCAR\_EMSYCAR, BINOCAR\_CAROBB, BINOCAR\_SWCAR, BINOCAR\_WANDA

No: Valencia Region, Zagreb, EMILIA ROMAGNA due to privacy, South Portugal

1. Do you forsee any problems in this linkage? Can you get access to all maternal codes related to these pregnancies including those TOPFA that are fetal reductions?

Yes: Wales (very little info except the procedure code),

Basque (fetal reductions not liable),

Northern Netherlands (TOPFA in private clinics also not available, not all maternal codes might be available)

BINOCAR\_NORCAS, BINOCAR\_EMSYCAR, BINOCAR\_CAROBB, BINOCAR\_SWCAR, BINOCAR\_WANDA (TOPFA in private clinics not available, uncertain how much information is available)

No: Funen DK, Finland

1. Do you prefer to apply for ethics for this TOPFA linkage together with the linkage of livebirths for the morbidity studies in WP4 or to apply for ethics for WP6 after month 24?

Yes, now: Basque (not a big issue)

No: Finland (no ethical review is required, but permission to use the confidential health register data is required),

BINOCAR\_NORCAS, BINOCAR\_EMSYCAR, BINOCAR\_CAROBB, BINOCAR\_SWCAR, BINOCAR\_WANDA (separate process than linking livebirths)

No ethical approval needed: Northern Netherlands, Wales, DK

1. Can you contribute with all years planned for you to contribute to EUROlinkCAT? Or do you prefer to focus on a more recent time period, could be 5 years?

All years: Wales, Valencia Region (data are available from 2007 onwards), Finland (data are available from 1993 onwards), Zagreb, BINOCAR\_NORCAS, BINOCAR\_EMSYCAR, BINOCAR\_CAROBB, BINOCAR\_SWCAR, BINOCAR\_WANDA

Prefer recent years: Basque, Northern Netherlands, Funen DK

Emilia Romagna: We are limited to the years since the creation of the databases so from 2004

South Portugal: more accurate data in recent years (2010), but we would like to contribute since 2000

1. Fetal deaths from 20 weeks are only a very small proportion of all congenital anomalies, but still important. Can you include these in the validation studies?

Yes: Wales, Valencia Region, Basque, Northern Netherlands, Funen DK, Finland (yes until 24+0 weeks, which is the upper limit in Finland), Zagreb Emilia Romagna, South Portugal, BINOCAR\_NORCAS, BINOCAR\_EMSYCAR, BINOCAR\_CAROBB, BINOCAR\_SWCAR, BINOCAR\_WANDA

No: