The Danish Trophoblast Database

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Objectives
The Danish Trophoblast Database (DTD) was established in 2013 as part of Danish Gynecological Cancer Database (DGCD). The purpose of DGCD is to monitor the quality of diagnostics and treatment of Danish patients with gynecological neoplasias and to generate data for scientific purposes. Registration is mandatory in case of any gynaecological cancer or gestational trophoblastic disease. Registration in DTD: When a hydatidiform mole or a neoplastic trophoblastic disease woman is suspected, the woman is registered with her Danish identification number. The gynaecologist enters data on: • Demography, history of previous pregnancies, symptoms and ultrasound scans • The genetic constitution of the hydatidiform mole/the trophoblastic neoplasm • Initial hCG value, and the following hCG values

The pathologist enters data on: • Morphology and ancillary test results of the evacuated tissue

For patients with persistent trophoblastic disease or neoplastic trophoblastic disease, the gynaecologist enters data on: • MRI or PET/CT scans • Surgery • hCG values

Quality indicators: For monitoring quality of diagnostics and treatment, Danish health authorities request that one or more indicator(s) are analysed. As the first indicator of the quality of diagnostics of hydatidiform moles, the frequency of genetic analysis performed on fresh tissue was chosen. The standard for good quality was set to ≥ 75 %.

Methods
Data were retrieved from DTD. To estimate the completeness of DTD, data registered in The Danish National Patients Registry were used.

Results
For the first three years of registration, the completeness of DTD was app. 50 %. Genetic analyses of fresh tissue had been performed in app. 50 % of the registered cases; i.e. the standard of ≥ 75 % was not met.

Conclusions
Nation wide registration of data on patients with trophoblastic disease allows focusing improvements on diagnostics and treatments of patients not meeting the standards. In order to improve the completeness of DTD, the entry of data will be centralised to the Danish Trophoblast Centre. With improved completeness, data from DTD can also be used for research. The free access to public health care in Denmark and the unique person number assigned to all Danish citizens allow comprehensive statistics and research by linkage of data from DTD with data in other Danish public registers, such as: • The Danish Pathology Register • The Danish National Patients Register • The Danish Cancer Register • The Danish Register of Causes of Death International collaborations on the data registered are welcomed.