Quality Registers in Finland – The Importance to Measure Fertility Treatments

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National, mandatory data collections on reproductive health maintained by THL

- Register on Congenital Malformations since 1963
- Register on induced abortions and sterilisations since 1983 (statistics since 1950/1939)
- Medical Birth Register since 1987
  - More detailed data on very premature children since 2005 (< 1501 grams or < 32 gestational weeks)
- Statistics on IVF/IUI since 1992/2005
- Drug and pregnancy – research database on use of medication during pregnancy and its consequences since 1996
National, mandatory registers on reproductive health maintained by THL

- Information on hospital care related to reproduction is available in the Hospital Discharge Register
  - Hospital inpatient care since 1967
  - Hospital day surgery since 1994
  - Social institutions since 1995
  - Hospital outpatient visits since 1998
  - Primary health care visits since 2011
Total fertility rate decreases in Finland
Total fertility rate in the Nordic countries
Fertility rate per 1000 women by age
The mean age of parturients, years
The number of ART treatments
The number of ART treatments per 1000 women aged 15-49 years
Total fertility rate by the age at first birth

The number of ART treatments per 1000 women aged 15-49 years, 2015
The proportion of IVF+ICSI and FET, 2015
The number of donations
Started treatments by age
The number of newborns born after ART
The number of newborns and the effect of ART
How to measure quality in ART?
The mean number of transferred embryos
The proportion of single embryo transfers
The number of multiple deliveries after ART
The proportion of multiple deliveries after ART, %
The proportion of treatments ending to a live birth
Success rates by the number of transferred embryos in 2016

[Bar chart showing success rates for different embryo transfer methods (IVF, ICSI, FET) with clinical pregnancies and births.]
IVF/ICSI success rates by clinic in 2016
Proportion of IVF/ICSI single embryo transfers by clinic in 2016
The proportion of premature births (<37 gw) and low birth weight children (<2500 g), %
The mean number of embryos per a live born child
Need for better data

- Current data collection is based on aggregated data.

- The ART legislation (2007)
  - National statistics are based on aggregated data.
  - Each clinic has to keep a register.
  - For research purposes clinical data can be combined.

- Monitoring of quality in ART services is limited.
  - Benchmarking between clinics cannot be done by using case-mix.
  - No information on the number of treatments per woman/couple.
  - No information on cumulative success rate.
  - No information on the effectiveness of ART services, e.g. the high use of FET.
Need for better data

- Possibilities:
  - To start a new quality register: informed consent is required as well as more funding.
  - To collect cycle-based data for research: no informed consent is required, but there are limitation how the data can be used.
  - The parliament has received a proposal for a new legislation on secondary use of health care information (2019?). In the background document, the request to initiate an IVF-register has been mentioned.