

2.2.4 Local Variables

In addition to the variables listed in Chapter 2.2.1, EUROCAT registries may collect other variables for use locally (not for transmission to the Central Registry).

The list below includes variables that previously have been included in the standard set of variables for EUROCAT, but are no longer collected in the Central Database.

Place of birth	A code for each maternity unit and for home delivery. Selective referral of case to registry population. This variable is particularly important for those registries which are classified as Population-based II or III (see Chapter 5.1 for definition). This variable should identify cases for exclusion which were referred to a hospital within the registry area in order to receive specialist services after prenatal diagnosis of malformation outside the registry hospitals.
Prenatal diagnostic techniques	Prenatal diagnostic tests and their results. A possible coding scheme can be found in EUROCAT Guide 1.2. It is important to distinguish whether the result of the test was positive or negative for malformation. Some registries may wish to identify which of multiple malformations were identified by any particular test.
Previous pregnancies	Record number of previous spontaneous abortions, induced abortions, stillbirths and live births separately. Remember that this should refer to the baby/fetus, not the pregnancy (e.g. in the variable "previous pregnancies" in the main dataset, a twin pregnancy is counted once only. Here you would count a twin delivery twice i.e. two live births, one live and one stillbirth).
Maternal smoking	Code smoking during first trimester e. g. Number of cigarettes per day. Make sure that the code you use can distinguish high levels of smoking from yes/no.
Maternal alcohol use	Code alcohol intake during first trimester, making sure that alcoholism and high alcohol intake can be distinguished. If the child has Fetal alcohol syndrome, code under malformation using ICD code (Q860).
Age of father at delivery	Age of father in completed years at the time of delivery. If only the year of birth is available, assume that the father was born on 30 June.
Sources of information (spontaneous)	This is an important variable for the management and quality assessment of your registry. You should record which sources of information notified the case (e.g. maternity unit, paediatric surgery, cytogenetic laboratory, ultrasound department), devising a code for the different sources of information used by your registry (see Chapter 5.2 for more examples in the Registry Description Questionnaire). For example, if the co-ordinator at a maternity unit gives you a list of recent malformed births including this case, or if you consult the entire maternity records to obtain a list of cases including this case, then code the maternity unit as a source of information. If the same case is also found on a list from the paediatric surgery department, then code paediatric surgery as another source of ascertainment. It should be possible to calculate the proportion of cases ascertained from more than one source of notification each year. Generally, a high proportion of "multiply ascertained" cases are an indicator of high data quality.
Source of information (confirmatory)	Use the same code as above, but code here the sources which confirmed the case or gave you extra information on request. For example, if the maternity unit notified a case and told you that he/she had died and you then request a post mortem report for this specific child, then the autopsy department should be coded as a confirmatory, not a spontaneous, source of information.