CONGENITAL MALFORMATIONS REQUIRING SURGICAL CORRECTION IN CHILDREN UNDER 1 YEAR OF AGE

GENERAL CONSIDERATIONS	
Issues	Perinatal diseases
Type of indicator	Health outcome
Rationale	The foetus is especially vulnerable to exposures to radiation, hazardous or toxic chemicals, and infections in the environment. Maternal exposures during pregnancy thus constitute an important source of risk for young children. These exposures may derive from a wide range of sources, including the home (e.g. domestic chemicals, furnishings, garden pesticides), the workplace (e.g. industrial or agricultural chemicals), drinking water, food and the ambient environment (e.g. hazardous wastes). Infections (e.g. due to rubella) are also recognized as important risk factors. This indicator is therefore designed to provide a measure of the incidence of congenital anomalies in new-born children, as a result of exposures to these environmental hazards.
Issues in indicator design	Congenital malformations take a wide range of different forms, from minor (and often unseen) anomalies to severe disfigurement and abnormality, possibly resulting in death. ICD-9 categories 740-759 (and ICD-10 categories Q00-Q99) comprise the general category of all congenital anomalies, including major forms such as neural tube defects, cardiovascular defects, abdominal wall defects, hypospadias and epispadias: this category thus provides a relatively clearly defined basis for this indicator. The indicator may thus be expressed as the rate of all congenital anomalies per thousand live births. Many issues, nevertheless, need to be recognized in designing and using this indicator. These include problems in diagnosing and reporting anomalies – especially in areas with less well developed health services. Care is also needed to ensure that pre-term terminations and stillbirths are treated consistently in the reported data. The wide range of congenital anomalies may also result from different exposures, so in some cases it may also be more appropriate to devise separate indicators for different anomalies. An age limit of 1 year is used in the indicator because congenital malformations are usually reported and treated (if possible) within that time period – though in poorer areas treatment of non-life threatening malformations (e.g. cleft palette) may not occur until much later in life.
SPECIFICATION	
Definition	Incidence of congenital malformations requiring surgical correction in children under 1 year of age.
Terms and concepts	***Congenital malformation requiring surgical correction in children under 1 year of age***: a bodily or functional abnormality, evident at birth, due to malformation of the foetus during pregnancy sufficiently severe to require surgical treatment or correction during the first year after birth. Malformations are defined to include all congenital anomalies (ICD-9 categories 740-59; ICD-10 categories Q00-Q99). ***Live birth****:* birth of a living and viable child.
Data needs	Number of congenital malformations requiring surgical correction during the first year after birth.

	Number of live births
Data sources, availability and quality	Data on congenital malformations may be obtained from a number of sources, including national or regional registers, hospitals and special surveys. Hospitals probably provide the main source of data on malformations requiring surgical correction or treatment. Marked variations in reporting may occur, however, depending on the effectiveness of, and levels of access to, the health service. Registers also exist for certain types of malformation, especially more severe and rarer anomalies such as hypospadias and gastroschisis. These usually provide data on the number of children born with the specific anomaly within the register area, but may not specify whether surgical correction was required (though this can often be assumed). Again, marked variations in reporting rates may occur between registers, and between areas with and without formal registry systems. Where routine data are not available, information can be gathered by special surveys. In all cases, care is needed to ensure that the data are consistent, for example in terms of the classification of congenital anomalies, treatment of stillbirths and terminations, and reporting of multiple anomalies. Data on the number of live births can usually be obtained from vital registration systems, sample registration systems, surveillance systems and censuses and demographic surveys (such as the demographic and health surveys of world fertility surveys). Information is also collated by the UN on a regular basis. These data are generally of sound quality. In some developing countries, however, registration procedures may be incomplete or inconsistent, especially in remote rural areas. Definitions of live births may also vary between countries.
Level of spatial aggregation	Health district or registry area
Averaging period	Annual
Computation	The indicator can be computed as: 1000 * *Canom / Blive* where: *Canom* = the number of newborn children with congenital anomalies during the survey period; *Blive* is the total number of live births over the same period.
Units of measurement	Number per thousand live births
Worked example	Assume that an area has 1 420 cases of congenital anomalies requiring surgical correction, from a total of 44 560 live births. In this case, the value of the indicator would be: 1 000 * (1 420 / 44 560) = 31.8
Interpretation	This indicator provides a measure of the risk to children from congenital malformations. As such it gives some indication of the possible effects from maternal exposures during pregnancy to hazardous chemicals, radiation and other risk factors in the home, workplace or ambient environment. Like almost all health outcome indicators, however, it needs to be interpreted with caution, since specific environmental exposures are far from the only cause of congenital malformation, and indeed in most cases are likely to be only a minor cause. Variations in rates of congenital malformation, therefore, cannot directly be attributed to changes in levels of exposure. Many different exposure pathways may also be involved, so attribution of cause is invariably difficult.

	Care is also needed because of possible inconsistencies in the data on both malformations and births. Particular reasons for inconsistency include differences in the definition and classification of malformations, differences in diagnosis and reporting, treatment in the data of stillbirths and terminations and differences in the effectiveness of vital registration systems and other sources of births data.
Variations and alternatives	This indicator can alternatively be defined in terms of specific types of anomaly. This may be more appropriate where specific risk factors or exposures are of interest.
Examples	None known
Useful references	IPCS 1984 *Environmental health criteria 46. Guidelines for the study of genetic effects in human populations.* Geneva: World Health Organization.