

2 Terms and definitions

For the purpose of this document, the following terms and definitions apply.

2.1

assisted feeding

use of a soft, squeezable, bottle and/or adjusted teat and/or sipper spout to allow delivery of milk to the infant who is unable to generate suction to extract fluid independently

Note 1 to entry: It enables the infant to feed, effectively and safely, the required volume within an acceptable time frame.

Note 2 to entry: For further information on types of bottles and teats used for assisted feeding of babies born with clefts see Annex C.

2.2

cleft centre

hospital with a designated cleft team and paediatric facilities

2.3

cleft surgeon

surgeon trained in cleft surgery with a major commitment to cleft care and who practices cleft surgery on a regular and frequent basis

2.4

cleft team

multidisciplinary team which comprises the following members with proven competence in their field of expertise, paediatric experience and a major commitment to cleft care: A care coordinator/manager of the service; a surgeon trained in primary cleft surgery; a surgeon specialising in secondary cleft surgery such as bone grafting and orthognathic surgery; an orthodontist; a speech and language therapist; a nurse specialising in cleft care; a psychologist with recognised clinical training; an audiologist; an ENT surgeon; a geneticist; a restorative dentist; a paediatric dentist; a dental technician

Note 1 to entry: Whilst not all specialities will be required for every patient, access to all these practitioners is available when needed.

Note 2 to entry: If patients receive some aspects of care nearer home (e.g orthodontics, speech and language therapy) they receive care by trained specialists working in collaboration with the cleft team.

2.5

Eurocleft

Eurocleft Project 1996 – 2000 funded by the European Commission having the aim to improve management and understanding of cleft lip and palate and create a network of European researchers and clinicians to facilitate information exchange

2.6

cleft support organization

non-medical group with paid staff and/or volunteers offering advice and support to families affected by cleft

2.7

nurse specialising in cleft care

specialist responsible for planning and coordination of early cleft care, including feeding assessment, development of a feeding plan, providing support to the family and liaising with other health care professionals

Note 1 to entry: In the absence of a nurse, these services are provided by another trained professional with similar skills.

Note 2 to entry: An illustrative role of a nurse specialising in cleft care is provided in Annex D.

2.8

palatal plate

presurgical orthopaedics

intraoral appliance which can be used in the treatment of infants with cleft palate

Note 1 to entry: It can help with feeding and can be used to influence the maxillary growth and therefore to create better conditions for surgery.

Note 2 to entry: In newborns with Pierre-Robin-Sequence a plate with velar extension can be helpful to treat upper airway obstruction and avoid tracheostomy.

2.9

Pierre Robin Sequence

sequence of symptoms present in a newborn; micrognathia (small lower jaw), cleft palate, and glossoptosis (posteriorly placed tongue) that combine to cause airway obstruction

Note to entry: The back of the tongue falls back , particularly when the baby is supine, and occludes the airway.