

Appendix 3

Glossary and Acronyms

Acute Services - health care and treatment provided mainly in hospitals.

Acute Trusts - Health & Social Services Trusts which provide acute hospital care (also **Health & Social Services Trusts**).

Alder Hey Inquiry – Royal Liverpool Children’s Inquiry.

Anonymisation - the removal of information that would identify babies, family members, professionals and institutions.

Antenatal – before birth.

Biopsy – the removal of a small piece of tissue from an organ or part of the body for microscopic examination to discover the presence, cause, or extent of a disease.

Blocks - small pieces of organs removed and imbedded in small, usually wax, blocks. These are normally about 20mm (less than one inch) square and about 5mm (under one quarter of an inch) thick. Even so, substantial parts of small organs from very small babies – even whole organs in exceptional cases – may be contained within a block. The tissue is chemically treated to remove water, which is replaced with wax. These tissue blocks become hard, so that thin sections can be cut with a sharp knife. These sections are very thin – ten times thinner than a hair (also **Slides**).

CESDI – the Confidential Enquiry into Stillbirths and Deaths in Infancy was established in 1992 to improve understanding of how the risks of death in the late fetal period or within the first year of life might be reduced. CESDI is organised on a regional basis throughout England. Wales and Northern Ireland participate as regional entities. There are in the participating regions some 10,000 deaths annually between 20 weeks’ gestation and one year of life.

Clinical audit – a quality improvement process that seeks to improve patient care and outcomes through systematic review of care against explicit criteria and the implementation of change. Aspects of the structure, processes and outcome of care are selected and systematically evaluated against explicit criteria. Where indicated, changes are implemented at an individual, team or service level and further monitoring is used to confirm improvement in health-care delivery.

Clinical governance – the means by which organisations ensure the provision of quality clinical care by making individuals accountable for setting, maintaining and monitoring performance standards.

Clinician – a doctor having direct contact with and responsibility for treating patients (including pathologists who contribute directly to the care of patients) rather than one involved with theoretical or laboratory studies.

CMO – the Chief Medical Officer is the Government’s most senior medical adviser. Separate posts exist in England, Scotland, Wales and Northern Ireland.

Community Trusts - Trusts which provide community health and social services, but not acute hospital services (also **Health & Social Services Trusts**).

Congenital – describing a condition that is recognised at birth or that is believed to have been present since birth. Congenital malformations include all disorders present at birth whether they are inherited or caused by an environmental factor.

Congenital abnormality - A physical malformation, chromosomal disorder or metabolic abnormality which is present at birth.

Consultant – a fully trained specialist in a branch of medicine who accepts total responsibility for patient care. In the United Kingdom consultants are usually responsible for the care of patients in hospital wards but they are allowed to opt for some sessions in private practice in addition to any National Health Service commitments. After registration, doctors continuing in hospital service are appointed as ‘senior house officers’ and then obtain ‘specialist registrar’ posts (which replaces the older registrar and senior registrar posts) in their chosen specialty.

Coroner – the official who presides at an Inquest. He must be either a medical practitioner or a lawyer of at least five years’ experience.

Coroner’s post mortem – not dependent upon relatives’ consent but required by law when death is due to unnatural, suspicious or unknown causes. Relatives’ attendance at an inquest is necessary in only a minority of cases.

Cot death – the death of a baby, often occurring overnight while it is in its cot, from an unidentifiable cause, also known as Sudden Infant Death Syndrome (SIDS).

DHSSPS – the Department of Health, Social Services and Public Safety is the Government Department responsible for health and social services in Northern Ireland.

Early neonatal death - death of a liveborn infant occurring less than seven completed days (168 hours) from the time of birth.

Fetus – an unborn child from its eighth week of development.

Fixing – before organs or tissues can be examined in detail, particularly under a microscope, they have to be hardened by immersion in a chemical, usually formaldehyde. This is known as ‘fixing’. The complete process may take several weeks.

Formalin – a water solution containing 40% formaldehyde. In pathology laboratories it is used to preserve human organs and tissue.

Full post-mortem examination – the full post mortem involves external examination followed by an examination of the contents of the skull, chest and abdomen. It includes the retention of tissue blocks and slides as part of the medical record.

Gestation – the period during which a fertilized egg cell develops into a baby that is ready to be delivered. In humans gestation averages 266 days.

Gynaecology – the study of diseases of women and girls, particularly those affecting the female reproductive system.

Histopathology – the branch of medicine concerned with the changes in tissues caused by disease.

Health & Social Services Board – an organisation responsible for commissioning health and social services for the population resident within its area. There are four Health & Social Services Boards in Northern Ireland.

Health & Social Services Council – an organisation responsible for representing the views of health and social services users, and for providing an independent oversight of the activities of Health & Social Services Boards. Members are nominated by District Councils, voluntary organisations and other interested bodies and individuals. There are four Health & Social Services Councils in Northern Ireland, one for each Health & Social Services Board area.

Health & Social Services Trust – an organisation responsible for providing health and social services, and for exercising certain statutory functions on behalf of Health & Social Services Boards. A Trust may include a hospital(s) or other unit which, whilst remaining fully in the Health & Personal Social Services, is run by its own Board of Directors and has a wide range of freedoms which were not available to the former directly managed units. There are 19 Trusts in Northern Ireland. They provide acute services, community services or a combination of both (also **Acute Trusts** and **Community Trusts**).

Hospital post mortem – under the terms of the Human Tissue Act (NI) 1962 a clinician who wishes to have a hospital post mortem examination performed must satisfy himself, 'having made such reasonable enquiry as may be practicable', that the surviving relatives have no objection to the post mortem examination. The purpose of the hospital post mortem examination is to enable clinicians to tell surviving relatives more about the likely cause of death, counsel them appropriately and learn appropriate lessons in relation to the future treatment of others.

HPSS – the Health & Personal Social Services include hospital services, community health services, personal social services and general medical services.

Infant death - death in the first year following live birth.

Inquest – an official judicial enquiry into the cause of a person's death, which is carried out when the death is sudden or takes place under suspicious circumstances.

Late fetal loss – CESDI defines a late fetal loss as a death occurring between 20 weeks + 0 days and 23 weeks + 6 days

Limited post-mortem examination – a post mortem can be limited, in consented post-mortem examinations and if relatives so wish, to one body cavity (for example, the chest). This may not provide all possible information about the cause of death.

Live birth - delivery of an infant which, after complete separation from its mother, shows any signs of life. There is no recognised gestation or weight qualifier in UK law on birth registration, so that any birth at any gestation or birthweight, which fulfils these criteria, should be registered as a live birth.

Locum – a doctor who stands in temporarily for a colleague who is absent or ill.

MLA – Medical Laboratory Assistant.

MLSO – Medical Laboratory Scientific Officer.

Mortality rates

Infant mortality rate - the number of deaths under the age of one year following live birth, per 1000 live births per annum.

Perinatal mortality rate - the number of stillbirths and early neonatal deaths (those occurring in the first week of life) per 1000 live and stillbirths per annum.

Neonatal death rate - the number of neonatal deaths (those occurring within the first 28 days of life) per 1000 live births per annum.

Postneonatal mortality rate - the number of infants who die between 28 completed days and less than one year following live birth, per 1000 live births per annum.

Stillbirth rate - the number of stillbirths per 1000 live births and stillbirths per annum.

Late fetal loss rate - the number of late fetal losses per 1000 live births and stillbirths per annum.

Mortuary –a group of rooms, usually in a hospital (those outside hospitals are called public mortuaries), where bodies are kept in refrigerators before collection by the undertakers. The mortuary also includes the post-mortem room where the post-mortem examination is performed.

Mortuary Technical Officers – these technicians have undergone specialist training and acquired certification in post-mortem examination techniques, including the identification of bodies, the external examination of bodies, the procedures involved in removal of organs for post-mortem examination and the return of organs to, and restoring of the body after, post-mortem examination. In this work, they co-operate with the ward staff, pathologists and funeral directors.

Neonatal death – death before the age of 28 completed days following live birth.

Neonate – an infant at any time during the first four weeks of life. This word is particularly applied to infants just born or in the first week of life.

Obstetrics – the branch of medical science concerned with the care of women during pregnancy, childbirth, and the period of about six weeks following the birth, when the reproductive organs are recovering.

Organ(s) – a part of the body, composed of more than one tissue that forms a structural unit responsible for a particular function (or functions). Examples are the brain, heart, lungs and liver.

Paediatrics – the branch of medicine dealing with children and their diseases.

Pathology – the study of disease processes with the aim of understanding their nature and causes. This is achieved by observing samples of blood, urine, faeces, and diseased tissue obtained from the living patient or at post mortem, by the use of X-rays and many other techniques.

Pathologist – a doctor who has undertaken a number of years of postgraduate study and professional examinations to become qualified in the specialty of **pathology**.

Perinatal – relating to the period from 16 weeks before birth to one week after birth.

Perinatal Mortality Rate – see **Mortality Rates**.

Postneonatal Infant Death – death occurring after 28 completed days up to one year following live birth.

Postneonatal mortality rate – see **Mortality Rates**.

Placenta – an **organ** within the uterus (womb) by means of which the embryo is attached to the wall of the uterus. Its primary function is to provide the embryo with nourishment, eliminate its wastes and exchange respiratory gases. It also functions as a gland secreting hormones, which regulate the maintenance of pregnancy.

Post mortem – examination of a body after death, usually involving dissection, in order to determine the cause of death or presence of disease processes. Also known as autopsy.

Post -mortem report – the report compiled from information obtained as a result of post-mortem examination.

Post natal – following birth.

Regional centre for specialist post mortem – sometimes it is necessary for a body to be moved to another place for the post-mortem examination where there are special facilities and pathologists skilled in dealing with examination of particular cases (for example, deaths in infancy and childhood).

RRG – the Relatives' Reference Group was set up by the Minister for Health, Social Services and Public Safety to act as a resource, both for families affected and to hospitals, providing them with the advice and information that they need. The RRG also act as a resource to the Department of Health, Social Services and Public Safety, in assisting it to develop necessary guidance.

Research Ethics Committees – these committees, of which there are four in Northern Ireland, are intended to protect the interests of patients and other subjects of research and to give advice to the researchers. Committees consider the ethical issues arising from submissions involving investigative projects in humans and will give or withhold approval for such projects and, where necessary, make appropriate suggestions.

Retained Organs Commission – organisation set up by the Secretary of State for Health, as recommended by the Chief Medical Officer in England in his advice to the Government on the taking and retention of organs and tissue at post-mortem examinations. It is a Special Health Authority for England and Wales.

Section – in microscopy a section is a thin slice of the specimen to be examined under a microscope.

SHO – Senior House Officer.

Slides – sections cut from a tissue block. The glass slides are stained with special dyes to enable the cells to be examined under a microscope. More than one slide may be cut from a block (also **Blocks**).

State Pathologist – a consultant pathologist appointed by the Secretary of State for NI to carry out post-mortem examinations ordered by HM Coroner in cases of sudden, unexpected or unnatural death.

Stillbirth

Legal definition: England and Wales

A child which has issued forth from its mother after the 24th week of pregnancy and which did not at any time after being completely expelled from its mother breathe or show any other signs of life.

Legal definition: Northern Ireland

A stillbirth 'means the complete expulsion from its mother after the 24th week of pregnancy of a child which did not at any time after being completely expelled or extracted breathe or show any other evidence of life'.

Tissue – organs contain tissue ie collections of cells which give organs their special functions. For example, the heart contains muscle tissue composed of cells which contract to pump the blood. Samples of tissue (typically small slices about a quarter of an inch thick) are usually taken during a post mortem.