SUBJECT: Dying Baby in NICU-Care of

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PERSON RESPONSIBLE FOR MONITORING AND REVIEW:
Jennifer Ormsby CNC for Newborn Services (Relieving)

COMMITTEE RESPONSIBLE FOR RATIFICATION AND REVIEW:
NICU Executive Management Committee

KEYWORDS: Autopsy, Dying baby, Coronial, Grieving process, Mortuary, Palliative.

Disclaimer:
It should be noted that this document reflects what is currently regarded as a safe and appropriate approach to care. However, as in any clinical situation there may be factors that cannot be covered by a single set of guidelines, this document should be used as a guide, rather than as a complete authoritative statement of procedures to be followed in respect of each individual presentation. It does not replace the need for the application of clinical judgment to each individual presentation.
Rationale

The care of the dying baby and family is important in assisting the family to come to terms with the death of their child and to assist them at the start of the grieving process. Care and support of the baby and family can help with the long-term outcome for the family.

Outcomes

- The baby is cared for in a supportive environment
- End of life care is peaceful and comfortable
- Parents and families can be as actively involved as they wish and spend as much time with their baby as they need.
- The family and their friends will be able to spend as much time with their baby with the maximum amount of physical comfort and privacy available.
- The family is able to participate as much as they want to, in the care of their baby prior to and following death.
- Parents, family & staff are supported
- The baby is transported to the mortuary and all the appropriate documentation is completed.
- Alternatively the family is supported to take their baby home for palliative care.

Care of the Dying Baby in NICU

In the event of critical deterioration in a Babies’ clinical condition or the decision to withdraw treatment has been made Nursing or Medical staff will;

- Contact the parents (if they are not already present).
- Contact the Neonatologist (if after hours).
- Notify the Social Worker for support and follow-up.
- Notify postnatal ward if mother is still an inpatient.
- Discuss Baptism options with parents, Contact preferred Chaplain at parents request, can be either the Hospitals’ chaplain (via switch) or a celebrant of the families’ faith. (Located in the X-ray room behind level 3 desk in the labelled cupboard, is the box containing all the equipment required for Baptism/Naming/Christening), the Chaplain may also like a small clean trolley to set-up on.
- At this time staff should ask if they would like other relatives contacted, in a quiet private setting either by the parents or by staff if parents desire.
• Ensure privacy for family by offering the Xstrata room ensuring outer doors are closed and “do not enter” signs are in place to reduce traffic outside this room.
• In the event the parents request to stay in NICU3, set-up the privacy screen.
• Discuss with the family if they would like to use the services of Heartfelt Photography.
• SIDS & Kids plaster casting can be discussed with parents before or after the baby has died. SIDS and Kids can only do casts from 28 weeks gestation, and success is dependent on baby’s skin integrity. Casting is only done after a baby has died. Check with the Social Worker before offering, as service may be limited due to SIDS and Kids staffing/policy at the time.
• Ensure parents’ wishes are fulfilled as much as possible – for example: if the parents wish to take the baby for a walk in the hospital grounds they are supported in doing so. The family does not require any supporting documentation unless they leave the hospital, in which case a letter should accompany the family stating the baby is in the care of NICU.
• Parents may wish to bathe their baby when he/she is alive. This can also be offered.
• At an appropriate time attend baby hand and footprint with an ink card. Ask parents if they would like a lock of hair to be collected for keepsake.
• Collect Newborn Screening Test (if not already done).
• Consider what other tests may need to be collected such as muscle biopsy and blood and what teams may need to be involved e.g. Surgeons.
• Remember; Care of the baby should be guided by the parents’ requests.

(All documentation and ink cards required are kept in the x-ray room behind L3 desk, in the filing cabinet).

Paediatric Palliative Care Service Consultation

If appropriate the Paediatric Palliative Care Service should be consulted for advice and involvement in end of life care for the neonate. The Paediatric Palliative Care Staff Specialist can be contacted for advice 24hours via JHH Switch. The Neonatologist on duty in NICU must make the referral to the Paediatric Palliative Care staff specialist. The Paediatric Palliative Care Service offer services that will assist in end of life care for the neonate, ensuring both infant and family are supported throughout the process.

The Nicholas Trust palliative care rooms are available for NICU infants and their families, allowing the opportunity to spend some private time together. The rooms are located on ward J1 and H1. To organise the use of this room please contact the NUM or Nurse in Charge on 13310 in J1 or 13260 in H1, to see if the room is available. If the families are not local there is palliative care rooms located in Maitland and Taree if this would be more suitable. This can be discussed with the treating team.
Non Coronial Death

When the baby has died

- A medical officer pronounces the baby dead. The date and time are recorded and a medical certificate is completed.
- Autopsy is discussed and offered to the family. If possible consideration should be given to the designated officer (see page 6) being present for this discussion so the designated officer doesn’t have to repeat to the family later.
- Heartfelt photography is offered to the parents and arrangements made at parents request. This is a free service. If Heartfelt Photography service is not available, nursing staff to offer to take photos.
- The family is encouraged to spend as much time as they want with the baby, and can bathe or dress him/her as they desire.
- The family may wish to dress the baby in clothes they have supplied or clothing can be supplied from the NICU store (kept in Xstrata room in packs according to gestation). Clothing and wraps can be given to parents as a memento or sent with the baby.
- Parents are informed that they can return later to see the baby again.
- Memory Box – this box is prepared as a memento for the family. Kept in the locked cupboard near the smart room. This box contains; a memorial card to display a lock of the infants hair (with parents’ permission), a hand and footprint card (with parents’ permission), identity band, name card, and any other memento the parents want from the baby’s care in NICU. For example; CPAP prongs, chord clamp. Additional memorial cards can be collected if required for separated parents or grandparents.
- Funeral arrangements – The Social Worker will discuss and assist the family with this. The Social Worker will give parents a package of information, (LIGHT Package), which is kept in the top left hand cupboard in the X Strata Room. In this package is a Centrelink Bereavement Payment Claim Form, the back page of which needs to be completed by a medical officer before giving to parents.

Please note-tissue removal or blood collection (for example, a muscle biopsy) from the baby’s body requires the presence and consent of a designated officer
Designated Officers

Ring the JHH Switchboard operator to contact the Designated Officer on duty. There are several in NICU but they cannot participate in NICU matters.

- A Designated Officer is the person identified as such for the purposes of the “Care of Deceased: Designated Officer” Procedure relating to removal of tissue from a deceased person for the purposes of transplant, medical/therapeutic purposes or post mortem examinations. The Designated Officer should be notified prior to the next of kin (parents, siblings >18 years or Guardian) leaving the Hospital, to meet and obtain consent for post mortem examination and before tissue removal or organ donation occurs. The Designated Officer must authorise all non-coronial post-mortems and donations of bodies to science and or science programs as well as organ and tissue donation. The Medical Officer can only collect tissue samples required for genetic testing following consent from the next of kin.

Preparing to take the body to the Mortuary ¹

- The baby’s weight, length and head circumference are recorded in the medical records and the Personal Health Record (blue book)
- Two identity bands clearly stating the baby’s name, DOB and MRN are placed on the baby’s limbs
- The baby is dressed in the clothing the parents have requested.
- ‘Body Labels’ x 2 completed, (kept in the X-Ray room behind Level 3 desk)- 1 of which is placed on the baby’s clothing and the other on the blanket or sheet the baby will be wrapped in.
- The baby is wrapped in a blanket or sheet and placed in the body bag (kept in the Xstrata room)
- The papoose stored in Delivery Suite, is to be used to transport the baby to the mortuary.
- Medical Records including a death certificate need to be completed and collated to be taken with the baby to the mortuary.
- All medical records need to be photocopied or put onto Digital Medical Records (DMR) prior to original notes going to the mortuary.
- A wards person is notified to identify the baby and accompany the nurse to the mortuary with the baby and paperwork.
- The Personal Health Record book (blue book) is to be placed in the memorial box for the parents.

HEARTFELT PHOTOGRAPHY:
Heartfelt offer complimentary portrait sessions for families who have an infant in Neonatal Intensive Care who meet the heartfelt criteria. More information on criteria can be found in the heartfelt resource folder located in X-Ray room located in Level 3. The folder also contains contact details for Heartfelt. This service is available 24 hours
**Documentation**

- Medical records- nursing and medical notes are completed prior to the medical records leaving the unit
- All progress/ clinical notes to be photocopied prior to hard copy leaving the unit to mortuary
- The date and time of death are recorded into the notes, admission book and entered on the database.
- Parents to be informed that they will need to complete Birth Registration Statement; this form is given to them in Delivery Suite and may have already been completed by them. Social Worker can assist if required.
- Autopsy form- the Neonatologist will discuss with parents their wishes and will obtain consent where appropriate and fill out the request for autopsy.
- Medical Certificate of Cause of Death should only be completed after consultation with a neonatologist, unless it is not within 28 days. (Form B)
- Attending Practitioner’s Cremation Certificate

**Communication**

The Nurse in charge or the Nurse caring for the baby will notify the following people of the baby’s death:

- Post natal ward or the ward caring for the mother of the baby. This should occur if the mother has been discharged as well.
- SWISH hearing screeners
- Child and Family Health Centre
- Referring Hospital (if mother or baby has been referred to John Hunter Hospital)
- Ward Clerk or Bed Allocation’s if after hours
- Afterhours resource person if applicable

The medical staff will notify:

- Pediatrician involved in the baby’s care if the baby had been retrieved
- G.P.
- Obstetrician/s or Registrar involved in the antenatal care and delivery of the baby.
Non Coronial Autopsy\textsuperscript{1, 2}

Complete the following documents:

1. Authority for Post Mortem Examination - signed permission form by parent(s).
2. Authority for Post Mortem Examination – Requires authorisation by Designated Officer.
3. Autopsy Request Form
4. Medical Certificate of Cause of Death
5. Attending Practitioner’s Cremation Certificate

Coronial Death

A reportable death to the Coroner includes if

- The baby died in circumstances where the death was not the reasonably expected outcome of a health related procedure.
- The cause of death is unknown and the medical officer is unable to complete a death certificate.

In relation to section 24 of the Coroners Act, for some circumstances previous reports to Family and Community Services (FaCS) might influence the decision to assign a death as a coronial death. However following consultation between the Medical Practitioners, Police Officers and the Coroner, the Coroner may make a decision to dispense with a post mortem if the reports are not related to the current death.

An example of this is when DOCS reports have been made on a 24week gestation infant with Intra Uterine Growth Restricted (IUGR) due to placental insufficiency and subsequently dies of respiratory failure which appears unrelated to the reports.

*Parental consent is not required for a coronial post mortem. However, agreement of the next of kin should be obtained in relation to retention of body parts for purposes other than the post mortem examination and disposal of body parts.

**Note:** When suspected Coronial death the following must be adhered to.

1. Do not remove any medical devices or equipment from the body.
2. Contact Waratah Police station. Notify them of coronial death.
3. Await arrival of officers.
4. Identification of Deceased Person. Medical Officer must be present when NSW Police arrives to identify deceased to the Police.
5. When Police have identified the baby the family can follow the non-coronial death pathway (bath the baby etc.)
6. A death certificate **MUST NOT** be issued.
7. Report of Death of a Patient to the Coroner - Form A (refer to appendix 1)
8. Medical Record is photocopied and a copy is sent to Clinical Information Department
9. The original Medical Record document must accompany the patient to the Coroner.

**Parents Returning to NICU to Visit Their Deceased Baby**

Parents are asked to notify the nurse in charge of their impending visit to allow time to retrieve the infant and have it prepared for parental viewing. The longest time a body can be left unrefrigerated is 8 hours. The baby can be brought to NICU several times but must have a period of refrigeration between those times if the stay is of a long duration. To organise a baby to return to NICU you must call a wardsman to escort you to the mortuary as they need to sign the body in and out within the 8 hour period.

**Taking the Baby Home after Death**

There may be several reasons why the family would request to leave the hospital with the baby after death. For example they may want to travel to the beach and show the baby the sea or they may want to take the baby home. It is acceptable for the family to take the baby out of the hospital after death if the death was less than five days previously and the journey is less than 8 hours. In this case the body will not be embalmed for transport. A letter from the medical officer must accompany the baby’s body to state date and time of death and that the hospital is aware of the body being moved. This has to go through the mortuary staff.

**Cultural & Religious Considerations**

Grief is universal and crosses all cultures and religions. Spiritual, religious and cultural beliefs play a significant role in the lives of families whose babies are seriously ill or dying. Showing consideration for cultural, religious and spiritual beliefs helps families cope with the death of a loved one. Failing to carry out expected cultural rituals can lead to unresolved feeling of loss for family members. Religious and spiritual beliefs are in some cases a source of comfort for families as they face end of life decisions.
The term religion reflects an organised faith system of beliefs. Spirituality reflects a person’s life experiences and beliefs - and can change over a person’s life. Religious and spiritual beliefs can influence decision making about active treatment as well as end of life decisions.

Assessment of religious and spiritual needs:
- Requires an interdisciplinary team including doctors, nurses, chaplains, social workers, and members of the community or parish.

Management of religious and spiritual needs:
- Provide supportive listening and dialogue to help families express their religious or spiritual needs and desires.
- Be sensitive to the individuals practices and customs

Bereavement Follow Up

NICU Social Workers keep a bereavement register and provide telephone follow up with parents over the initial days and months, after their baby has died. A bereavement interview with the Neonatologist and the Social Worker is offered to parents at around 6 weeks after their baby has died. The Social Worker also provides families with a list of counseling/support services in the “LIGHT” Package, and makes referrals as required.

Staff Support

Staff involved in end-of-life care will inevitably share in the family’s grief and loss and feelings of sorrow and helplessness can be felt. These emotions are normal human responses but in the workplace can lead to emotional fatigue and disenfranchised grief, the hidden grief often downplayed in the clinical setting. In recognition of this possible outcome there needs to be opportunity for staff to work through their feelings in a safe environment. Support services should be offered to all members of the health care team. Facilitated debriefing after all difficult deaths is essential. Ways that staff should be offered support should include (but not be limited to):
- Formal case reviews e.g. Mortality and Morbidity Meeting, Team debriefings
- Mentorship and collegial support particularly from more experienced and professionally mature staff.
- Private debriefing by senior colleague, social work or the referral to EAP if required.

It is important to note, for long term cases where death of the patient is anticipated, the debriefing and support process should be introduced well before the death occurs, during the palliative care or treatment process.
References

6. *Advances in Neonatal Care* • Vol. 10, No. 6 • pp. 287-293 NANN Position Statement 3051

Resources

National Cancer Institute (Website) Grief, Bereavement, and Coping with Loss

DEVELOPED BY: S. Prince 1994
UPDATED BY: N. Butchard, 2001;
CNS Group 2012

Approved by: NICU Executive Group Feb 2013
Ratified by Kaleidoscope Quality Committee Feb 2013
Appendix 1  Report of Death of a Patient to the Coroner (Form A)

REPORT OF DEATH OF A PATIENT TO THE CORONER

PATIENT'S DETAILS
Patient's Surname: ___________________________ Given Names: ___________________________
Sex: Male ☐ Female ☐ Age: ________ Marital Status: ________
Address: ___________________________

NEXT OF KIN DETAILS
Next of Kin: ___________________________ Relationship: ___________________________
Address: ___________________________
Telephone contact details: V: ___________________________ H: ___________________________ M: ___________________________

SYNOPSE OF CLINICAL NOTES
Date admitted: __/__/____ Time of admittance (24 hour clock): __:__
Date of death: __/__/____ Time of death (24 hour clock): __:__
History (including all relevant pre-existing conditions)
Examination on admission (including evidence of any injuries, consumption of drugs or other relevant clinical findings)
Treatment and subsequent progress:
Opinions as to cause of death (include whether the cause of death is a result of natural causes or other factors)
Why has the case been referred to the Coroner?: ___________________________
Have any ante-mortem specimens been taken and/or stored that you are aware of? (If so, please provide details): ___________________________
Are there any specific issues which need addressing at autopsy?: ___________________________
List results of any discussion with Next of Kin (e.g., was the Next of Kin informed that this is a Coroner's case? Is the Next of Kin satisfied with the treatment? Does the Next of Kin object to an autopsy?): ___________________________
Are the results of any potentially relevant tests awaited? If so, please specify: ___________________________

Additional comments: ___________________________

I (print name) ___________________________, a registered Medical Practitioner or a registered Nurse/Midwife, in the state of New South Wales hereby certify that at ________ time (24 hour clock) on ________ date (day, month and year), I examined the body of the above named patient and pronounced him/her dead.
Your relationship to the deceased, e.g., treating practitioner or nurse unit manager of ward:

CONTACT DETAILS OF CLINICIAN COMPLETING FORM
Please print
Work Address: ___________________________
Work telephone number: ___________________________, Mobile telephone number: ___________________________, Pager number: ___________________________

Signature: ___________________________, Qualifications: ___________________________, Date: __/__/____

"Only to be completed by an RN in circumstances outlined in PD2065.466 Death - Extinction of Life and the Certification - Assessment TO THE CORONER"
CORONIAL CHECKLIST

Deaths Reportable to the Coroner – check list

This checklist is to be used to determine if a death should be reported to the coroner. It is to be completed by the officer determining the cause of death for all patients (PD 2005_468). The form is filed in the front of the medical record.

This checklist is to be used in conjunction with NSW Health Policy Directive *Coroner’s Cases and the Coroners Act* http://www.health.nsw.gov.au/policies/pd2012_054

Coronial Flags

1. Did the person die a violent or unnatural death?
2. Did the person die a sudden death, the cause of which is unknown?
3. Did the person die under suspicious or unusual circumstances?
4. Did the person die in circumstances where the person had NOT been attended by a medical practitioner during the period of six months immediately before the person’s death?
5. Did the person die in circumstances where death was not the reasonably expected outcome of a health-related procedure carried out in relation to that person? (see point 1 over page for further guidance)
6. Did the person die whilst in or temporarily absent from a declared mental health facility and while the person was a resident at the facility for the purpose of receiving care, treatment or assistance? (includes admission to acute care facility whilst a patient of a Mental Health Facility)
7. Did the person die whilst in the custody of a police officer or in other lawful custody? (see point 5 over page for further guidance related to deaths in custody)
8. Did the person die whilst escaping or attempting to escape from the custody of a police officer or other lawful custody?
9. Did the person die as a result of, or in the course of police operations?
10. Did the person die whilst temporarily absent from an institution or place where the person was an inmate?
11. Was the person a child in care, or a child whose death is or may be due to abuse or neglect or that occurred in suspicious circumstances? (see point 3 over page for definitions and guidance related to death of a child)
12. Was the person (child or adult) living in or temporarily absent from, residential care provided by a service provider and authorised or funded under the Disability Services Act 1993 or a residential centre for disabled persons? (see point 3 (b) over page for definitions and guidance)
13. Was the person disabled within the meaning of the Disability Services Act 1993 and receiving from a service provider assistance to enable them to live independently in the community? (see over page point 3 (f) for definitions and guidance)

If answers to ALL of the questions are NO, the death is NOT required to be referred to the Coroner and a death certificate MAY be issued. Where doubt exists as to whether a death should be reported, telephone the Duty Pathologist. Glove: Business Hours (02) 6584 7621, After Hours (02) 6584 7621. Northern Forensic Hub, Newcastle: Business Hours (02) 4622 3700, After Hours (02) 49290922) for clarification. The State Coroner’s Court may also be contacted for advice on (02) 8584 7777.

If the answer is YES to ANY question the death must be referred to the Coroner using SMRO10.510 – Reporting of Death of a Patient to the Coroner and a death certificate MUST NOT be issued.

The exception to this rule is that under S38 (2) of the Act, medical practitioners can issue a death certificate if they are of the opinion that the person:
(a) was aged 72 years or older, and
(b) died in circumstances other than in any of the circumstances referred to above, and
(c) died after sustaining an injury from an accident, being an accident that was attributable to the age of the person, contributed substantially to the cause of death and was not caused by an act or omission by any other person (this applies to accidents at home or in institutions).

However the medical practitioner must state on the certificate that it is given in pursuance of s38(2) of the Coroners Act 2009. A medical practitioner cannot certify the cause of death in accordance with this section if the certificate is given a relative of the deceased person indicates to the medical practitioner that the object is giving the certificate. If an objection by a relative occurs the death must be reported to a police officer who is then required to report the death to a coroner or assistant coroner as soon as possible after the report is made.

Staff Name:  Signature:  Designation:  Date:  

NO WRITING
### Appendix 2 – Coronial Checklist page 2

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**CORONIAL CHECKLIST**

COMPLETE ALL DETAILS OR AFFIX PATIENT LABEL HERE

The following are extracts from NSW Health Policy Directive ' Coroners Cases and the Coroners Act 2009 - P2019_064

1. **NSW Health Guidelines Regarding Whether a Death is a Reasonably Expected Outcome of a Health-Related Procedure**

   - The NSW Coroner’s Act does not define the term ‘reasonably expected outcome’. This is a matter for medical practitioners to decide based upon the facts of the case. ‘Health-related procedure’ is defined in the Act. Guidelines to assist the medical practitioner determine whether or not the death should be reported to the coroner are below.

   - **(i)** Is there a reportable death? Consider:
     - Did the health-related procedure cause the death?
     - Was the death an unexpected outcome?
     - If the answer to both of these questions is yes, then the death is reportable.

   - **(ii)** Did the health-related procedure cause the death? Consider:
     - Was the health-related procedure necessary to improve the patient’s medical condition, rather than an elective or optional procedure?
     - Was the health-related procedure performed in a manner, which at the time of the death, would be considered by your peers as competent professional practice?
     - If the answer to both of these questions is yes, then the death may not be reportable.

   - **(iii)** Was the death an unexpected outcome of the health-related procedure? Consider:
     - Whether the patient’s condition (including their age and comorbidities) at the time they underwent the health-related procedure was such that death was likely to occur if they did not undergo the procedure?
     - Whether the potential benefits of the procedure outweighed the risk.
     - Whether the health-related procedure was performed in a manner which at the time of the death, would be considered by your peers as competent professional practice?
     - If the answer to each of these questions is yes, then the death may not be reportable.

   - The factors to consider in each particular case will be different and doctors should use their professional judgement to determine whether the death is reportable. If the medical practitioner is uncertain about whether the death is reportable then she/he should contact the NSW State Coroner’s Office on (02) 9364 7701 or the Duty Pathologist (Gladesville: Business Hours) (02) 9364 7621, After Hours (02) 9364 7621. Northern Forensic Hub, Newcastle: Business Hours (02) 4922 3100, After Hours (02) 40519207.

2. **Deaths in Custody**

   - A senior coroner has jurisdiction to hold an inquest concerning the death or suspected death of a person if it appears to the coroner that the person has died:
     - (a) while in the custody of a police officer or in other lawful custody; or
     - (b) while escaping, or attempting to escape, from the custody of a police officer or other lawful custody; or
     - (c) as a result of, or in the course of, police operations; or
     - (d) while in, or temporarily absent from, any of the following institutions or places of which the person was an inmate:
       - (i) a detention centre within the meaning of the Children (Detention Centres) Act 1987;
       - (ii) a correctional centre within the meaning of the Crimes (Administration of Sentences) Act 1999;
     - (e) while proceeding to an institution or place referred to in paragraph (d), for the purpose of being admitted as an inmate of the institution or place and while in the company of a police officer or other official charged with the person’s care or custody.

3. **Death of a Child and/or a Disabled Person**

   - A senior coroner has jurisdiction to hold an inquest concerning the death or suspected death of a person if it appears to the coroner that the person was (or that there is reasonable cause to suspect that the person was):
     - (a) a child in care, or
     - (b) a child in respect of whom a report was made under Part 2 of Chapter 3 of the Children and Young Persons (Care and Protection) Act 1990 within the period of 3 years immediately preceding the child’s death; or
     - (c) a child who is a sibling of a child in respect of whom a report was made under Part 2 of Chapter 3 of the Children and Young Persons (Care and Protection) Act 1990 within the period of 3 years immediately preceding the child’s death; or
     - (d) a child whose death is, or may be due to abuse or neglect or that occurs in suspicious circumstances, or
     - (e) a person (whether or not a child) who, at the time of the person’s death, was living in, or was temporarily absent from, residential care provided by a service provider and authorised or funded under the Disability Services Act 1983 or a residential service for disabled persons, or
     - (f) a person (other than a child in care) who is in a target group within the meaning of the Disability Services Act 1983 who receives a service provider for assistance (as defined by the regulations) to enable the person to live independently in the community.
Appendix 3

List of Reportable Infectious Diseases

LIST A infectious diseases
- Creutzfeldt- Jakob Disease
- Hepatitis C
- Human Immunodeficiency Virus Infection (HIV)

LIST B infectious Diseases
- Diphtheria
- Plague
- Anthrax
- Small Pox
- Tuberculosis
- Viral Haemorrhagic Fever