

Electronic Supplement:

Mortality Analysis: Patients on the PDOC programme who died in the RHRU or soon after discharge: 2007/2016 – in no particular order

	PDOC state admission / death	Medical conditions	CANH withdrawal	Mode of death
Patients who died whilst on the RHRU				
1	VS/VS	Severe stroke with haemorrhagic transformation. Prolonged ventilatory support. Tracheostomy – eventually decannulated. Chronic aspiration. Neuro-palliative care following BI decision	No	Aspiration Pneumonia
2	MCS/MCS	Severe brainstem stroke with bilateral basilar artery occlusion. One week into admission deterioration. Cardiopulmonary arrest. Extended stroke with reduced responsiveness. Cheyne Stokes breathing. Sepsis. Neuro-palliative care following BI decision	No	Hypostatic Pneumonia
3	MCS/emerged	Severe hypoglycaemic BI. Brittle diabetic. Ischaemic heart disease Initially in MCS. Emerged but profound physical/cognitive disability Tracheostomy. Tracheal stenosis. Sudden hypoxic cardiac arrest	No	Cardiac arrest
4	VS/VS	Severe sub-arachnoid haemorrhage from AVM. External ventricular drain with subsequent ventriculitis. Tracheostomy – weaning and decannulation Advanced liver disease and cardiac valvular disease. Hypotensive episodes. Apnoea, bradycardia. Aspiration pneumonia Neuro-palliative care following BI decision	No	Aspiration Pneumonia
5	VS/MCS	Severe TBI. Admitted in VS. Pyrexial and unwell soon after admission	No	Acute Sepsis
6	VS/MCS-	Hypoxic brain injury following cardiac arrest shortly after aortic valve replacement. Severe ischaemic heart disease, with previous myocardial infarction and cardiac surgery. Intractable seizures. In fast atrial fibrillation and cardiac failure. Neuro-palliative care following BI decision	No	Cardiac failure
7	MCS-/MCS-	Hypoxic BI following out of hospital cardiac arrest. Storming, desaturation. Overwhelming sepsis – IV antibiotics. Pulmonary haemorrhage. Neuro-palliative care following BI decision	No	Sepsis and aspiration pneumonia
8	VS/VS	Elective admission for withdrawal of CANH Neuro-palliative care following Court Approval	Yes	Dehydration. Multi-organ failure

9	VS/VS	Hypoxic BI following catastrophic haemorrhage. Chronic abdominal sepsis. Total small bowel obstruction with multiple level adhesions and ileus. Vomiting back all feed. Surgical review: inoperable - low likelihood of success and the high operative/anaesthetic risk. Confirmed by an independent surgeon. Neuro-palliative care following BI decision	Yes	Dehydration. Multi-organ failure Abdominal sepsis
10	VS/VS	Hypoglycaemic BI. Brittle diabetic – ischaemic heart disease with previous surgery. Severe diabetic complications including peripheral vascular disease, chronic renal impairment, peripheral neuropathy, hypertension, chronic osteomyelitis and partial amputation. BI decision-making – paperwork in preparation for Court application for withdrawal of CANH, but developed respiratory sepsis. Neuro-palliative care following BI decision	No	Broncho-pneumonia
11	MCS-/VS	Traumatic brain injury and multiple trauma, with thoracic injury. Peritonitis following with bowel leak. GI surgery only partially successful. Prolonged stay on intensive care. Hypotensive, inotropic support. CPAP. Multiple courses of antibiotics. Total ileus. Sepsis and desaturation continued. Neuro-palliative care following BI decision	Yes	Pneumonia
12	MCS / emerged	Multiple brainstem and cortical strokes due to atrial fibrillation. Insulin dependent diabetes. Ischaemic heart disease with previous cardiac surgery. Ischaemic cardiomyopathy and chronic heart failure. Tracheostomy Hypotensive, desaturation. Cheyne-stokes breathing. Sepsis	No	Broncho-pneumonia
13	Locked in/VS	Severe TBI and high spinal cord injury following RTA. Tracheostomy / on ventilator. Initially conscious. Repeated chest infections with mucous plugging Developed seizures and non-convulsive status epilepticus with deteriorating consciousness. CT demonstrated major new intracranial event leading to vegetative state. Neuro-palliative care following BI decision	No	Cardiac arrest Broncho-pneumonia
14	Coma/Coma	Severe TBI with extensive contusion and haemorrhage. Hypoxia secondary to mucous plugging, Hydrocephalus, VP shunt. Further intracranial bleeding. cranial sepsis. Referred for PDOC diagnosis and second opinion on BI. Found to be in coma Neuro-palliative care following BI decision. Withdrawal of CANH and tracheostomy	Yes	Broncho-pneumonia

Abbreviations:

AVM=Arterio-Venous Malformation; BI=Best Interests; CPAP= Continuous Positive Airways Pressure ventilatory support; CT=Computerised tomography;
CVA= Cerebrovascular Accident; MRI=Magnetic Resonance Imaging; MCS= Minimally Conscious State; PDOC=Prolonged Disorder of Consciousness;
RRU=Regional Hyperacute Regional Rehabilitation Unit at Northwick Park; RHRU – Regional Hyper-acute Rehabilitation Unit a Northwick Park Hospital; RTA=Road Traffic Accident; SAH= Subarachnoid Haemorrhage; SCI= Spinal Cord Injury; SDH = Subdural Haematoma; TBI =Traumatic Brain Injury; TPN: Total parenteral nutrition; VF=Ventricular Fibrillation;
VP=Ventriculo=peritoneal; VS= Vegetative State.

Patients who died soon after discharge (exact mode of death unknown)				
15	MCS-/MCS-	Cerebral haemorrhage due to aneurysmal rupture. Severe sickle cell disease with chronic anaemia. Chronic hydronephrosis. Tracheostomy. Recurrent pyrexia. Discharged to specialist nursing home. Died 2 days later	No	
16	MCS/ emerged	Subarachnoid haemorrhage with ventricular extension and obstructive hydrocephalus. Ventriculitis, seizures. Tracheostomy with CPAP. Recurrent chest and urinary sepsis with resistant organisms. BI decision – palliative care only. Discharged to specialist nursing home with ceiling of care	No	
17	VS/Coma	Chronic subdural haematoma with midline shift and uncal herniation. Failed to regain consciousness after evacuation. Initially in VS but deteriorated to coma Severe chronic liver disease. BI decision – palliative care only. Discharged to specialist nursing home with ceiling of care	No	
18	MCS/MCS-	Multiple cerebral infarction secondary to bacterial pneumonia Further progression with new infarction and reduced responsiveness BI decision – palliative care only. Discharged to specialist nursing home with ceiling of care	No	
19	VS/VS	Long term neurological condition. Hypoxic brain injury following cardiac arrest shortly following major surgery. Down time 15-30 minutes. BI decision – palliative care only. Discharged to nursing home with ceiling of care	No	
20	VS/MCS	Traumatic brain injury with diffuse axonal injury. Recurrent hydrocephalus, VP shunt. Ventriculitis. Recurrent sepsis Discharged to specialist nursing home.	No	
21	MCS+/MCS+	Extensive subdural haematoma with coning. On anticoagulation for cardiomyopathy. Implanted cardiac device with cardiac re-synchronisation therapy. Congestive heart failure. Cheyne-Stokes breathing BI decision – palliative care only. De-fibrillator de-activated Discharged to nursing home with ceiling of care.	No	
22	VS/MCS	Hypoxic cardiac arrest with prolonged down time. Severe neutropaenic sepsis following chemotherapy. Late onset seizures Discharged to specialist nursing home	No	
23	VS/VS	Traumatic brain injury with severe intra cranial bleeding requiring decompressive craniectomy. Cardiac arrest with hypoxic BI. Tracheostomy. Recurrent chest and urinary sepsis Discharged to specialist nursing home with ceiling of care. Hypoxic cardiac arrest.	No	