

### The 22 Week Study (IRAS 346626) - Single Form Data Collection Variables

Variable / Field Name	Form Name	Data Type	Field Label	Choices	Required Field?
unit_surgical	unit questionnaire	categorical	Are you a surgical or non-surgical tertiary neonatal unit?	1, surgical   2, non-surgical	y
surgery_site	unit questionnaire	categorical	If a surgical unit, are there general paediatric surgeons and surgical facilities on-site or do you need to transfer (transport by ambulance) a baby to a separate location?	1, On-site   2, Off-site (transport by road/air required)	
unit_environment	unit questionnaire	categorical	How is your unit generally set out?	1, All single (family) rooms   2, Bays or rooms of patients with some isolation rooms   3, Bays or rooms of patients only (cotspace isolation only)   4, Other	y
rooms_other	unit questionnaire	text	If other please describe		
consultant_cover_wd	unit questionnaire	categorical	What are your arrangements for consultant cover during the week Monday - Friday?	1, 24hr on-site cover   2, 12hr day on-site/ nights off-site   3, < 12 hrs on-site   4, Other	y
consultant_cover_we	unit questionnaire	categorical	What are your arrangement for consultant cover during the weekend?	1, 24hr on-site cover   2, 12hr on-site/ nights off-site   3, < 12 hrs on-site   4, Other	y
consultant_cover_other	unit questionnaire	text	If other, please describe		
ahp	unit questionnaire	categorical	Which Allied Health Professionals do you have access to on your unit	1, Dietetics 2, Lactation consultant 3, Physiotherapy 4, Occupational Therapy 5, Speech and language therapy 6, Neonatal pharmacist 7, Psychology 8, Music/ play therapy 9, Tissue Viability Team 10, NCOT (neonatal community outreach) team 11, Other	y
other_ahp	unit questionnaire	text	If other please describe		
palliative_care_unit	unit questionnaire	categorical	Do you have a dedicated paediatric/ neonatal palliative care team available for advice for involvement in neonatal cases?	1, Yes   2, No	y

### The 22 Week Study (IRAS 346626) - Single Form Data Collection Variables

parallel_plan_describe	unit questionnaire	text	Please describe		
prem_guideline	unit questionnaire	categorical	Do you have a unit (or network) guideline or practice document specifically for the care of babies born at 22 weeks gestation?	1, Yes   2, No	y
guidanceupload	unit questionnaire		If yes and willing to share, please upload		
unit_consensus	unit questionnaire	categorical	Do you have any agreed departmental consensus on babies at 22 weeks gestation e.g. universal stabilisation or decided on an individual case basis?	1, Yes   2, No	y
unit_consensus2	unit questionnaire	text	If yes, please describe		
counselling_tier	unit questionnaire	categorical	Who is generally expected to provide antenatal counselling for a 22 week gestation pregnancy?	1, Consultant/ associate specialist level 2, Minimum registrar level with direct consultant supervision 3, Senior trainee (>ST6/ GRID) or equivalent independently 4, Senior ANNP independently 5, Registrar (>ST3)-level independently 6, Most senior person available at the time counselling requested 7, No explicit guidance or expectation for this within department	y
bedside_trolley	unit questionnaire	categorical	Do you routinely use a bedside resuscitation trolley for stabilisation with cord-intact?	1, Yes   2, No	y
dr_transport	unit questionnaire	categorical	How do you transfer babies from delivery suite to NICU?	1, Transport incubator/pod   2, Open resuscitaire   3, Other	y
vent_transfer	unit questionnaire	categorical	Can you deliver volume ventilation during transfer from delivery room to NICU or only pressure ventilation for intubated babies?	1, Volume (or pressure)   2, Pressure only	y
laryngoscope_blade	unit questionnaire	categorical	What is the smallest laryngoscope blade size on the unit?	0, 0   00, 00   000, 000	y

### The 22 Week Study (IRAS 346626) - Single Form Data Collection Variables

suction_catheter_size_unit	unit questionnaire	categorical	Size of smallest ETT suction catheters available on unit		y
vl_preterms	unit questionnaire	categorical	Do you have a video laryngoscope used regularly in extreme preterm babies?	1, Yes   3, Yes but not often used in those < 24 weeks   2, No	y
xray_surfactant	unit questionnaire	categorical	Do you routinely x-ray to confirm ETT placement before delivering surfactant in extreme preterms intubated after birth?	1, Yes   2, No	y
caffeine_load_dose	unit questionnaire	numeric	What is your standard loading dose of caffeine in mg/kg for extreme preterm babies?		y
caffeine_maintenance	unit questionnaire	numeric	What is your standard maintenance dose of caffeine (mg/kg) in extreme preterm babies?		y
hnfc_intub	unit questionnaire	categorical	Do you use high flow nasal cannulae routinely during intubation attempts?	1, Yes   2, No   3, Case by case	
echo	unit questionnaire	categorical	Is regular echocardiography (not POCUS) routinely performed in extreme preterm infants in your unit?	1, Yes   2, No	y
nirs	unit questionnaire	categorical	Does your unit use cerebral near-infrared spectroscopy (NIRS)?	1, Yes   2, No but starting/ will be starting to use it   3, No	y
iv_access	unit questionnaire	categorical	Would your guidelines or general departmental practice be to attempt insertion of central umbilical lines in a 22 week admission or to attempt an IV cannula first?	1, Attempt central umbilical access as primary access   2, Attempt peripheral cannula before central access   3, Varies depending on clinician and situation	y
uac_size	unit questionnaire	categorical	What is the smallest available umbilical arterial catheter (UAC) size?	1, 2.5Fr   2, 3.5Fr   3, 4Fr   4, 4.5Fr   5, 5Fr	y

### The 22 Week Study (IRAS 346626) - Single Form Data Collection Variables

uvc_size	unit questionnaire	categorical	What is the smallest available umbilical venous catheter (UVC) size?	1, 2.5Fr   2, 3.5Fr   3, 4Fr   4, 4.5Fr   5, 5Fr	y
cannula_size	unit questionnaire	categorical	What is the smallest size of cannula available in the unit?	1, 26G   2, 24G	y
starterfluids	unit questionnaire	categorical	Do you have a standard fluid volume in mls/kg/day to start on for extreme preterms?	1, Yes   2, No	y
starterfluids2	unit questionnaire	text	If yes, describe		y
pn1	unit questionnaire	categorical	What types of parenteral nutrition (PN) are available on your unit?	1, Standard (pre-made bags) 2, Bespoke 3, Other	y
pn2	unit questionnaire	categorical	Is acetate included in standard PN or do you need to add it/ choose a specific bag	1, Included   2, Choose specific bag for it/ ask for bespoke   3, Don't know	y
peripheral_pn	unit questionnaire	categorical	How does your unit routinely administer PN in extreme preterms?	1, Central access only   2, Peripheral access while waiting or if any issue with central line placement   3, Variable - clinician dependent	y
pn_consituents	unit questionnaire	file	Please attach unit PN guideline		
pn_consituents_written	unit questionnaire	text	Or document names of PN bags and any relevant sections here to demonstrate main constituents eg kcal, glucose/dextrose g/100ml (or %), carbohydrate (g/100ml), and protein/amino acids (g/100ml), in different PN bags used and if there are electrolytes (sodium, potassium, phosphate) added to starter and standard bags		
d1_electrolyte_pn	unit questionnaire	categorical	Does your day 1 / starter bag of PN contain electrolytes (sodium, phosphate)?	1, Yes   2, No   3, Don't know	y
unit_lipid_start	unit questionnaire	numeric	When do you start lipids in extreme preterm babies? (age in days)		y
unit_lipid_type	unit questionnaire	categorical	Type of lipid chosen to start	1, Intralipid   2, SMOF lipid   3, Other	y
unit_lipid_other	unit questionnaire	text	Other		
routine_trigs	unit questionnaire	categorical	Does your unit routinely measure triglyceride levels for babies on lipids?	1, Yes   2, No   3, Only in certain circumstances   4, Don't know	y

### The 22 Week Study (IRAS 346626) - Single Form Data Collection Variables

gravity_feed	unit questionnaire	categorical	When starting on enteral feeds, are nasogastric bolus feeds given routinely by gravity feeding or by pump feed for extreme preterms?	1, Gravity feed   2, Pump feed   3, Use continuous feeds as standard (via pump)   4, Clinician or nurse dependent   5, Don't know	
probiotic1	unit questionnaire	categorical	Does your unit routinely use probiotics in preterms?	1, Yes   2, No	y
probiotic2	unit questionnaire	categorical	Which probiotic is used in your unit?		y
probiotic3	unit questionnaire	categorical	When does unit guidance state probiotic should start		y
insulguidance	unit questionnaire	categorical	What parameters does your unit guidance state for starting insulin?		y
home_ngfeeding	unit questionnaire	categorical	Are you able to send babies home on nasogastric feeds (community/NCOT support available)?	1, Yes   2, No	y
admission_screen	unit questionnaire	categorical	Does your unit do any routine screening on admission (not including standard Guthrie/neonatal screening or COVID)?	1, Microbiology/colonisation swabs 2, CMV (cytomegalovirus) salivary swab 3, Swab for mitochondrial (gentamicin sensitivity) 4, Other 5, Ureaplasma endotracheal secretions (soon after birth/ admission as available)	y
screening_other	unit questionnaire	text	If 'Other' please describe		
ivh_bundle	unit questionnaire	categorical	Do you have a IVH care bundle for preterms in first 72 hours?	1, Yes   2, No	y
ivh_bundle2	unit questionnaire	text	What does the bundle consist of?		
unit_pain_tool1	unit questionnaire	categorical	Does your unit have a pain tool that is consistently implemented?	1, Yes   2, No	y
pain_tool2	unit questionnaire	text	Which pain tool is used?		
dev_assessment	unit questionnaire	categorical	Does your unit perform a structured developmental assessment prior to discharge?	1, Yes   2, No   3, Don't know	y
dev_assessment_type	unit questionnaire	text	If yes, which one do you use?		

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term_mri	unit questionnaire	categorical	Do you perform an MRI at term-corrected age for extreme preterms on your unit?	1, Yes   2, No   3, Depends on clinical picture	y
skin_management1	unit questionnaire	categorical	Does your unit use any of these measures to support skin integrity in 22 week babies?	1, Pressure-relieving mattresses (gel, air) 2, Positioning equipment 3, Silk bedding or specific sheets 4, Other 5, None	y
skin_management2	unit questionnaire	text	Please describe measures to support skin integrity		
skin_ax	unit questionnaire	categorical	Do you use a standardised skin assessment tool on the unit?	1, Yes   2, No	y
skin_tool	unit questionnaire	text	Name of tool		
incubator_guideline	unit questionnaire	categorical	Do you have a guideline for humidity +/- temperature control of incubator for extreme preterm babies?	1, Yes   2, No	y
skin2skin2	unit questionnaire	categorical	In general, does your unit support babies on a ventilator to come out for skin to skin?	1, Yes - on ventilator and with umbilical lines   2, Yes - on ventilator but must have umbilical lines out   3, No - only non-invasive ventilation   4, Variable - depends on nurse/ medical team/ case-by-case	y
parallel_plan	unit questionnaire	categorical	Is there any unit guidance for discussing parallel planning or an advanced care plan early in the admission of a 22 week baby?	1, No guidance   2, Guidance - Routinely discussed with parents   3, Guidance - Only discussed when concerns about baby's clinical condition   4, Other   5, Not known	y
parallel_plan_other	unit questionnaire	text	Other		
equipment_challenge1	unit questionnaire	categorical	Have you, your colleagues or the unit had any issues with availability or sizes of equipment for 22 week babies that you are aware of?	1, Yes   2, No	y
equipment_challenges2	unit questionnaire	text	If yes, please describe		
questionnaire_extra	unit questionnaire	text	If there are any details not included above or you would like to comment more on, please record here		

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ga_at_birth	demographics	categorical	Gestational age at birth	0, 22+0   1, 22+1   2, 22+2   3, 22+3   4, 22+4   5, 22+5   6, 22+6	y
birthweight	demographics	numeric	Birth Weight in grams		y
sex	demographics	categorical	Sex	1, Male   2, Female   3, Indeterminate	y
plurality	demographics	categorical	Plurality	1, Singleton   2, Twin   3, Triplet   4, More than triplet (>3)	y
dcda	demographics	categorical	If twins or triplets, describe chorion and amnion eg MCDA/ DCDA/ TCTA		
ethnicity	demographics	categorical	Ethnic group	As, Asian or Asian British   Bl, Black, Black British, Caribbean, African   M, Mixed or multiple ethnic groups   W, White   O, Other   1, Unknown/ not documented	y
language	demographics	categorical	English spoken by parents as a first language?	1, Yes   2, No   3, Unknown/ not documented	y
language2	demographics	categorical	Is an interpreter required?	1, Yes   2, No   3, Unknown/ not documented	y
region	demographics	categorical	Region/ ODN at Birth		y
annual_quartile	demographics	categorical	When were they born? (month of year)	1, January-March   2, April-June   3, July-September   4, October-December	y
birthday	demographics	categorical	Day of Birth	WD, Weekday (Mon-Fri)   WE, Weekend (Sat-Sun or Bank Holiday)	y
birthtime	demographics	categorical	Time of Birth	1, Day (9am-9pm)   2, Night (9pm-9am)	y
inborn	demographics	categorical	Inborn at NICU	1, Yes   2, No	y
outborn	demographics	categorical	Outborn	LNU, LNU   SCU, SCU   OOH, Out of hospital	y
outborn_transfer_time	demographics	numeric	If outborn, how old in hours was baby when they arrived at your unit?		

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Variable / Field Name	Form Name	Data Type	Field Label	Choices	Required Field?
maternal_age	perinatal_information	numeric	Maternal age in years		
mat_ethnicity	perinatal_information	categorical	Maternal ethnicity	As, Asian or Asian British   Bl, Black, Black British, Caribbean, African   M, Mixed or multiple ethnic groups   W, White   O, Other   1, Unknown/ not documented	
dating_scan	perinatal_information	categorical	Method of confirming gestational age in pregnancy	1, Dating scan (done before 14 weeks)   2, Dating scan (late, after 14 weeks)   3, Last menstrual period   4, Other   5, Unknown	y
an_steroids	perinatal_information	categorical	Received any antenatal steroids?	1, Yes - full course   2, Yes - 1st dose given   3, No - delivered before could be given   4, No - declined   5, Unknown/ not documented	y
an_steroids_ga	perinatal_information	categorical	Gestation when steroids given (first dose)	0.5, < 22+0   0, 22+0   1, 22+1   2, 22+2   3, 22+3   4, 22+4   5, 22+5   6, 22+6	y
time_btw_steroids_birth	perinatal_information	numeric	Time elapsed between first dose of steroids and birth (in hours)		
an_steroid_timing	perinatal_information	categorical	Timing of steroid doses (if received 2 doses)	1, 12 hours apart   2, 24 hours apart   3, Unknown	
mgso4	perinatal_information	categorical	Magnesium sulphate given	1, Loading dose   2, Loading and maintenance   3, Contraindicated for maternal reasons   4, None   5, Unknown	y
rom	perinatal_information	categorical	Rupture of Membranes Prior to Delivery	1, None (ruptured at delivery)   2, Under 18 hours   3, 18-24 hours   4, 24-48 hours   5, 48-72 hours   6, 4 -7 days   7, 7-14 days   8, Over 14 days   9, Unknown	y
maternal_abx	perinatal_information	categorical	Maternal antibiotics given?	1, Yes   2, No	y
maternal_abx_type__1	perinatal_information	categorical	Antibiotics detail	1, Oral antibiotics e.g. for prolonged preterm rupture of membranes	
maternal_abx_type__2	perinatal_information			2, < 4 hrs before birth (IV)	
maternal_abx_type__3	perinatal_information			3, >4 hrs before birth (IV)	
maternal_abx_type__4	perinatal_information			4, Other	
maternal_abx_type__5	perinatal_information			5, Unknown	



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pregnancy_conditions__1	perinatal_information	categorical	Any documented pregnancy complications	1, Antepartum Haemorrhage (APH) / Bleeding	y
pregnancy_conditions__2	perinatal_information			2, Cholestasis	
pregnancy_conditions__3	perinatal_information			3, Chorioamnionitis (suspected or confirmed)	
pregnancy_conditions__4	perinatal_information			4, Gestational diabetes	
pregnancy_conditions__5	perinatal_information			5, Pre-eclampsia	
pregnancy_conditions__6	perinatal_information			6, Pregnancy induced hypertension	
pregnancy_conditions__7	perinatal_information			7, Maternal pyrexia (2 temps over 37.5oC or 1 over 38oC)	
pregnancy_conditions__8	perinatal_information			8, Maternal sepsis (suspected or confirmed)	
pregnancy_conditions__9	perinatal_information			9, Maternal illness requiring ITU or HDU admission 48 hours pre or post-delivery	
pregnancy_conditions__10	perinatal_information			10, Twin-to-Twin transfusion (TTT or TAPS/TRAPS) condition	
pregnancy_conditions__11	perinatal_information			11, Other	
pregnancy_conditions__12	perinatal_information			12, None	
mat_med_hx__1	perinatal_information	categorical	Pre-existing maternal health conditions	1, Type 1 or 2 diabetes	
mat_med_hx__2	perinatal_information			2, Hypertension	
mat_med_hx__3	perinatal_information			3, Obesity (Booking BMI >30kg/m2)	
mat_med_hx__4	perinatal_information			4, Autoimmune condition	
mat_med_hx__5	perinatal_information			5, Cardiac condition	
mat_med_hx__6	perinatal_information			6, Other requiring medication or ongoing management	
mat_med_hx__7	perinatal_information			7, None	
mat_insulin	perinatal_information	categorical	On insulin for diabetes?	1, Yes   2, No	
maternal_info	perinatal_information	text	If 'other' in maternal conditions please describe		
delivery_reason	perinatal_information	categorical	Indication for delivery	1, Spontaneous preterm labour/ delivery   2, Fetal wellbeing concern   3, Maternal indication	y
maternal_indication__1	perinatal_information	categorical	If maternal indication	1, Pre-eclampsia	

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maternal_indication__2	perinatal_information			2, Haemorrhage (vaginal bleeding, suspected abruption)	
maternal_indication__3	perinatal_information			3, Sepsis	
maternal_indication__4	perinatal_information			4, In labour (previous c-section)	
maternal_indication__5	perinatal_information			5, Other	
maternal_indication_other	perinatal_information	text	If 'other' in maternal indication please describe		
fetal_indication1__1	perinatal_information	categorical	If fetal wellbeing concern please select	1, Concern with intermittent heartbeat auscultation	
fetal_indication1__2	perinatal_information			2, Concern with CTG	
fetal_indication1__3	perinatal_information			3, Concern during scan	
fetal_indication1__4	perinatal_information			4, Documented as fetal distress	
fetal_indication1__5	perinatal_information			5, IUGR on scan	
fetal_indication1__6	perinatal_information			6, Other	
fetal_indication2	perinatal_information	text	If other or additional information, please describe		
mode	perinatal_information	categorical	Mode of delivery	1, Cephalic vaginal   2, Breech vaginal   3, Instrumental   4, C-section	y
en_caul	perinatal_information	categorical	If born by C-section, was the baby delivered 'en caul' (ie inside the amniotic sac which is kept intact until removal from uterus)	1, Yes   2, No   3, Unknown	
delivery_complications__1	perinatal_information	categorical	Delivery complications	1, Cord prolapse	y
delivery_complications__2	perinatal_information			2, Uterine rupture	
delivery_complications__3	perinatal_information			3, Baby entrapment (eg head when breech)	
delivery_complications__4	perinatal_information			4, Nuchal/bandolier cord (cord around the neck)	
delivery_complications__5	perinatal_information			5, Maternal haemorrhage	
delivery_complications__6	perinatal_information			6, Other	
delivery_complications__7	perinatal_information			7, None of above	

### The 22 Week Study (IRAS 346626) - Single Form Data Collection Variables

dcc	perinatal_information	categorical	Delayed cord clamping	1, None (clamped immediately)   2, Less than 60 seconds   3, Equal to or more than 60 seconds   4, Not documented	y
dcc_length	perinatal_information	numeric	If longer than 60 seconds, please document length of DCC in minutes		
dcc_resp__1	perinatal_information	categorical	Any respiratory support provided during delayed cord clamping?	1, None	
dcc_resp__2	perinatal_information			2, PEEP	
dcc_resp__3	perinatal_information			3, IPPV	
dcc_resp__4	perinatal_information			4, Intubated	
cord_milking	perinatal_information	categorical	Cord milking?	1, Yes   2, No   3, Unknown	

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sfc	delivery_stabilisation	categorical	Was stabilisation attempted/ provided?	1, Yes   2, No	y
cons_present	delivery_stabilisation	categorical	Consultant present at time of delivery	1, Yes   2, No	
age_at_arrival	delivery_stabilisation	numeric	If not, age of baby when arrived in minutes		
dr_weight	delivery_stabilisation	categorical	Was baby weighed in delivery room/theatre?	1, Yes   2, No	
dr_wt	delivery_stabilisation	text	Weight in grams		
cc_primary_mx	delivery_stabilisation	categorical	Was comfort care provided as primary management	1, Yes   2, No	
dr_cc_role	delivery_stabilisation	text	Please describe neonatal team role in provision of comfort care or any further details		
apgar1	delivery_stabilisation	numeric	APGAR score at 1 minute (total)		
apgar5	delivery_stabilisation	numeric	APGAR score at 5 minutes (total)		
apgar10	delivery_stabilisation	numeric	APGAR score at 10 minutes (total)		
dr_intubation	delivery_stabilisation	categorical	Was intubation attempted?	1, Yes   2, No	y
dr_niv	delivery_stabilisation	categorical	Was non-invasive ventilation used?	1, Yes   2, No	
ippv	delivery_stabilisation	categorical	Intermittent positive pressure ventilation (IPPV) or positive end expiratory pressure (PEEP) (facemask or nasal) given initially prior to any intubation?	1, Yes - facemask interface   3, Yes - nasal interface   2, No   4, Don't know	y
pip	delivery_stabilisation	numeric	Maximum peak pressure of IPPV		
peep	delivery_stabilisation	numeric	Maximum PEEP		
resus_oxygen	delivery_stabilisation	numeric	Starting Inspired oxygen (in %)		y
resus_oxygen_max	delivery_stabilisation	numeric	Maximum inspired oxygen during stabilisation (in %)		

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dr_diff_air	delivery_stabilisation	categorical	Was a videolaryngoscope used for any attempts?	1, Yes   2, No	
dr_ett_stylet	delivery_stabilisation	categorical	ETT stylet used?	1, Yes   2, No	
intubation_check__1	delivery_stabilisation	categorical	Method(s) of checking intubation success	1, CO2 detector (ETCO2/ colorimeter)	
intubation_check__2	delivery_stabilisation			2, Auscultation	
intubation_check__3	delivery_stabilisation			3, Chest rise	
dr_intubation_attempts	delivery_stabilisation	categorical	Number of intubation attempts	1, 1   2, 2   3, 3   4, 4   5, 5   6, 6   7, 7   8, 8   9, >8	y
drage1 (repeated 1-8 max)	delivery_stabilisation	numeric	Age at first DR intubation		
drintubator1 (repeated 1-8 max)	delivery_stabilisation	categorical	DR Intubator 1	1, NICU consultant   2, LNU/SCU consultant   3, GRID trainee/ Senior ANNP level   4, ST6-8 non-GRID   5, ST4-5/CF equivalent   6, ST1-3/ Cf/ Junior ANNP level	
drett1 (repeated 1-8 max)	delivery_stabilisation	categorical	DR Size of ETT 1	1, 2mm   2, 2.5mm   3, 3mm	
drettlength1 (repeated 1-8 max)	delivery_stabilisation	categorical	DR ETT Length 1	1, 5cm   2, 5.5cm   3, 6cm   4, 6.5cm	
drsucceed1 (repeated 1-8 max)	delivery_stabilisation	categorical	Intubation 1 Successful	1, Yes   2, No	
dr_intub_attempt_other	delivery_stabilisation	text	Please document any additional information here e.g. if accidental extubation. If >8 attempts, document the total number of attempts and the above parameters for the successful attempt if there was one.		
dr_surfactant	delivery_stabilisation	categorical	Surfactant given in delivery room?	1, Yes   2, No	y
surfactant_dose	delivery_stabilisation	numeric	Dose of surfactant (mg)		
age_at_surfactant	delivery_stabilisation	numeric	Age at first dose of surfactant (minutes)		
surfactant_cxr	delivery_stabilisation	categorical	Chest xray for ETT position done before surfactant given?	1, Yes   2, No	y
transfer_vent	delivery_stabilisation	categorical	Volume ventilation used in delivery room or transfer?	1, Yes   2, No	

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ptx_dr	delivery_stabilisation	categorical	Pneumothorax diagnosed during stabilisation?	1, Yes   2, No	
needle_decomp	delivery_stabilisation	categorical	Needle thoracocentesis	1, Yes   2, No	
dr_chest_drain	delivery_stabilisation	categorical	Chest drain	1, Yes   2, No	
type_of_icd	delivery_stabilisation	categorical	Type of chest drain	1, Pigtail (?size)   2, Surgical	
dr_compressions	delivery_stabilisation	categorical	Chest compressions received?	1, Yes   2, No	y
dr_access	delivery_stabilisation	categorical	Central venous access obtained in delivery room?	1, Yes   2, No	y
dr_drugs__1	delivery_stabilisation	categorical	Emergency Drugs or Bolus Given?	1, Adrenaline	y
dr_drugs__2	delivery_stabilisation			2, Sodium bicarbonate	
dr_drugs__3	delivery_stabilisation			3, Glucose	
dr_drugs__4	delivery_stabilisation			4, 0.9% sodium chloride bolus	
dr_drugs__5	delivery_stabilisation			5, Blood transfusion	
dr_drugs__6	delivery_stabilisation			6, None	
dr_thermal__1	delivery_stabilisation	categorical	Temperature control in delivery room	1, Plastic bag	y
dr_thermal__2	delivery_stabilisation			2, Hat	
dr_thermal__3	delivery_stabilisation			3, Resuscitaire/ radiant heat	
dr_thermal__4	delivery_stabilisation			4, Lifestart/bedside resuscitation trolley	
dr_thermal__5	delivery_stabilisation			5, Transwarmer	
dr_thermal__6	delivery_stabilisation			6, Other	
dr_temp	delivery_stabilisation	categorical	Were there any concerns or difficulties with temperature control during stabilisation	1, Yes   2, No   3, Temperature not monitored in delivery room	
dr_temp2	delivery_stabilisation	text	If yes please describe		
dr_cuddles	delivery_stabilisation	categorical	Delivery room cuddles?	1, Yes   2, No	y
dr_cc	delivery_stabilisation	categorical	Any discussion with parents about re-direction to comfort care	1, Yes   2, No	
dr_discussion	delivery_stabilisation	text	If discussion about redirecting to comfort care in delivery room,		

### The 22 Week Study (IRAS 346626) - Single Form Data Collection Variables

			please briefly describe (including approximate age of baby in minutes when this occurred)		
dr_admission	delivery_stabilisation	categorical	Was baby admitted to the neonatal unit?	1, Yes   2, No	y
end_of_stabilisation	delivery_stabilisation	numeric	Age of baby in minutes when attempts at stabilisation ceased		
reason_for_resus_stopping	delivery_stabilisation	text	Description of reason(s) for either not commencing or discontinuing stabilisation/ re-orientation to comfort care in delivery room		
adm_temp	delivery_stabilisation	numeric	Admission temperature		y

### The 22 Week Study (IRAS 346626) - Single Form Data Collection Variables

Variable / Field Name	Form Name	Data Type	Field Label	Choices	Required Field?
dr_comfort_care1__1	delivery death outcome	categorical	Comfort care and memory making components offered to family	1, Cuddles with parent(s)   2, Time for extended family to visit   3, Photos   4, Handprint/ footprint casts   5, Religious support or service   6, Cold cot   7, Financial/social support   8, Psychology or counselling input   9, Other	y
dr_comfort_care_2	delivery death outcome	text	If other please describe		
dr_bereavement1	delivery death outcome	categorical	Was bereavement midwife or nurse available to support?	1, Yes   2, No   3, Unknown   4, Not available at this trust	y
settings_of_care__1	delivery death outcome	categorical	Setting(s) of care	1, Private/ single room on labour ward/ postnatal ward 2, Private/single room away from labour ward used for bereavement or stillbirth 3, Room in a specialist bereavement suite 4, Bed in bay on ward 5, Other	
dr_sb1	delivery death outcome	categorical	Classified as stillbirth or neonatal death?	1, Stillbirth   2, Neonatal death	
dr_cc3	delivery death outcome	text	If neonatal death, cause(s) of death on certificate		y
dr_pm1	delivery death outcome	categorical	Post-mortem offered?	1, Yes   2, No   3, Unknown   4, Coroner/ Procurator Fiscal decision	y
dr_pm2	delivery death outcome	categorical	Post-mortem consented to?	1, Yes   2, No   3, Unknown or n/a (if coroner/PF)	
dr_pm3	delivery death outcome	text	Post-mortem findings		



### The 22 Week Study (IRAS 346626) - Single Form Data Collection Variables

Variable / Field Name	Form Name	Data Type	Field Label	Choices	Required Field?
death1	Died after admission outcome	numeric	Corrected gestational age at death		y
day_death	Died after admission outcome	categorical	Day of death	1, Weekday (Mon-Fri)   2, Weekend (Sat-Sun or Bank Holiday)	
time_death	Died after admission outcome	categorical	Time of death	1, Day (9am-9pm)   2, Night (9pm-9am)	
death_cert	Died after admission outcome	text	Cause(s) of death as per certificate		y
death_re_orient	Died after admission outcome	categorical	Was care re-orientated to comfort care prior to death?	1, Yes   2, No   3, Other e.g. suggested/ discussed but not agreed upon prior to death	y
re_direction_reason	Died after admission outcome	categorical	Reason(s) for re-direction	1, Hypoxia despite maximal neonatal intensive care   2, Refractory hypotension   3, Unilateral grade 4 IVH   4, Bilateral grade 3-4 IVH   5, Periventricular leucomalacia (PVL)   6, NEC   7, Congenital anomaly   8, Parental request   9, Other	y
re_direction_other	Died after admission outcome	text	If 'other' selected or any difficulties/ challenges around re-direction please describe		
death_resus	Died after admission outcome	categorical	Did the baby receive active acute resuscitation immediately prior to death?	1, Yes   2, No	y
death_resus_note	Died after admission outcome	text	Please describe acute resuscitation reasons with some more detail around events leading to death.		
death_pall_care	Died after admission outcome	categorical	Was a neonatal/ paediatric palliative care team involved in this baby's care at any point?	1, Yes   2, No	
palliative_care	Died after admission outcome	categorical	Elements of comfort or palliative care offered to family	1, Cuddles with parent(s) 2, Time for extended family to visit 3, Photos 4, Handprint/ footprint casts 5, Religious support or service 6, Cold cot 7, Financial/social support 8, Psychology or	

### The 22 Week Study (IRAS 346626) - Single Form Data Collection Variables

				counselling input 9, Time in/ use of specialist bereavement suite 10, Other	
pall_care_other	Died after admission outcome	text	If other please describe		
nicu_bereavement1	Died after admission outcome	categorical	Was bereavement midwife or nurse available to support (during/after/followup)?	1, Yes   2, No   3, Unknown   4, Not available at this trust	
nicu_pm1	Died after admission outcome	categorical	Post-mortem offered?	1, Yes   2, No	y
nicu_pm2	Died after admission outcome	categorical	Post-mortem accepted by parents?	1, Yes   2, No   3, Coroner/PF PM	
nicu_pm3	Died after admission outcome	text	Post-mortem findings		

### The 22 Week Study (IRAS 346626) - Single Form Data Collection Variables

Variable / Field Name	Form Name	Data Type	Field Label	Choices	Required Field?
final_outcome3	Final Outcome	categorical	Corrected gestational age at outcome (in completed weeks)		y
final_outcome1	Final Outcome	categorical	Outcome	1, Died   2, Discharged home/ foster care   3, Discharged to PICU   4, Discharged to a paediatric ward (including HDU)   5, Other	y
reason_hospital_outcome	Final Outcome	text	Main reason why still in hospital (or other)		
congenital_anomaly	Final Outcome	categorical	Any congenital anomaly identified during stay?	1, Yes   2, No	y
congenital_anomaly_2	Final Outcome	text	If yes please give diagnosis		
final_outcome2	Final Outcome	numeric	Total length of stay in hospital (in days)		y
ic_days	Final Outcome	numeric	Total number of IC (intensive care) days		y
hdu_days	Final Outcome	numeric	Total number of HDU (high dependency) days		y
scu_days	Final Outcome	numeric	Total number of SC (special care) days		y
total_ventilation_days	Final Outcome	numeric	Total number of (mechanical) ventilation days		y
cpap_days	Final Outcome	numeric	Total number of CPAP days		
hf_days	Final Outcome	numeric	Total number of HF (high flow) days		
cld1	Final Outcome	categorical	Chronic lung disease (CLD)/ BPD at 36 weeks CGA	1, Yes   2, No   3, Died before 36 weeks CGA	y
cld2	Final Outcome	categorical	Stage of CLD (what support baby is on at 36 weeks CGA)	1, Nasal cannula oxygen < 2L/min   2, Nasal cannula oxygen >2L/min   3, Non-invasive ventilation (CPAP, high flow)   4, Invasive mechanical ventilation	y
home_o2	Final Outcome	categorical	Discharged home on oxygen	1, Yes   2, No   3, Remains in hospital	y
cld3	Final Outcome	categorical	Tracheostomy in situ?	1, Yes   2, No	

### The 22 Week Study (IRAS 346626) - Single Form Data Collection Variables

postnatal_steroid_courses	Final Outcome	numeric	Total number of postnatal steroid courses given		y
steroids_course_day	Final Outcome	numeric	Day of life when first course of steroids for respiratory purpose received?		
azithromycin	Final Outcome	categorical	Has one or more courses of azithromycin (or erythromycin) been given since birth for a respiratory reason (not for gut motility)?	1, Yes   2, No	
pulmonary_hypertension	Final Outcome	categorical	Any diagnosis of pulmonary hypertension during stay?	1, Yes   2, No	
pulmonary_vasodilators	Final Outcome	categorical	Have any pulmonary vasodilators been given during neonatal admission?	1, Inhaled nitric oxide 2, Sildenafil 3, Other 4, None	
pda_outcome	Final Outcome	categorical	Any patent ductus arteriosus (PDA) management received?	1, None 2, Medical 3, Surgical	y
pda_mx_start	Final Outcome	numeric	Day of life when first course of medical management (ibuprofen or paracetamol) started		y
cardiac_diagnosis	Final Outcome	categorical	Any other cardiac diagnosis?	1, Yes   2, No	
cardiac_diagnosis2	Final Outcome	text	Describe cardiac diagnosis		
nec_outcome1	Final Outcome	categorical	Diagnosed with NEC at any time during neonatal period?	1, Yes - clinical signs (clinical and radiological) only 2, Yes - surgical confirmation 3, Yes - post-mortem confirmation 4, No	y
final_outcome_surg	Final Outcome	categorical	Abdominal surgical input during neonatal period?	1, NEC (surgical management) 2, SIP (surgical management) 3, Stoma in-situ 4, Stoma closed 5, Hernia awaiting surgery 6, Hernia already repaired 7, Other 8, None	y
feeding_outcome3	Final Outcome	categorical	Is this baby receiving any parenteral nutrition?	1, Yes   2, No	y
feeding_outcome1	Final Outcome	categorical	Is this baby currently having any enteral feeds?	1, Yes   2, No	y

### The 22 Week Study (IRAS 346626) - Single Form Data Collection Variables

enteral_milk_at_discharge	Final Outcome	categorical	Enteral milk at discharge	1, Exclusively mother's own milk (no fortifier)   2, Exclusively mother's own milk (with fortifier)   3, Combination mother's own milk and formula   4, All formula	
day_of_life_100mls_kg	Final Outcome	numeric	Day of life when first reached 120ml/kg/day enteral feeds		y
feeding_outcome_2	Final Outcome	categorical	Method of enteral feeding at discharge (or 44 weeks)	1, All nasogastric/nasojejunal/gastrostomy   2, Mixed tube and oral   3, All oral (breast or bottle)	
po_feed	Final Outcome	numeric	Day of life when baby reached all oral feeds (no NG)		
pn_day	Final Outcome	numeric	Day of life when last central line for PN was removed		y
pn_days	Final Outcome	numeric	Total number of PN days (if known)		
short_gut	Final Outcome	categorical	Has this baby been diagnosed with short gut syndrome?	1, Yes   2, No   3, Unknown	
wt_at_discharge	Final Outcome	numeric	Weight at final outcome (death/discharge/44 weeks) (in grams)		y
hc_discharge	Final Outcome	numeric	Head circumference at final outcome (death/discharge/44 weeks)		y
length_discharge	Final Outcome	numeric	Length at final outcome (death/discharge/44 weeks)		
neuro_outcome	Final Outcome	categorical	Brain injury - any of the following present during admission	1, Unilateral - IVH grade 3 or 4 2, Bilateral - IVH grade 3 or 4 3, Unilateral cystic periventricular leucomalacia (cPVL) 4, Bilateral cystic periventricular leucomalacia (cPVL) 5, Unilateral porencephalic cyst(s) 6, Bilateral porencephalic cyst(s) 7, Post-ventricular haemorrhage dilatation with surgical intervention 8, Meningitis 9, Kernicterus 10, Seizures 11, Other 12, None	y
meningitis	Final Outcome	categorical	Meningitis details	1, Bacterial meningitis 2, Viral meningitis 3, Candida meningitis 4, Herpes simplex meningitis	

### The 22 Week Study (IRAS 346626) - Single Form Data Collection Variables

hydrocephalus_intervention	Final Outcome	categorical	Type of intervention	1, Reservoir   2, Subgaleal shunt   3, VP shunt   4, Other	
mriatterm	Final Outcome	categorical	Has this baby had a term-corrected MRI?	1, Yes   2, No   3, Not term	y
mri_report	Final Outcome	text	MRI report summary findings		
neurodev_assessment1	Final Outcome	categorical	Has this baby had a formal neurodevelopmental assessment prior to discharge?	1, Yes   2, No	y
neurodev_assessment2	Final Outcome	categorical	If yes, which one has been used?	1, Hammersmith Neonate/ Infant Neurological Examination (HINE/HHNE)   2, General movements assessment (GMA)   3, Other	
dev_assess_other	Final Outcome	text	If other please describe		
dev_assess3	Final Outcome	text	Outcome of Assessment		
ropno_treatment	Final Outcome	categorical	Any retinopathy of prematurity noted on screening?	1, None   2, Grade 1   3, Grade 2   4, Grade 3   5, Grade 4   6, Unilateral   7, Bilateral   8, Too young - never screened	y
rop2	Final Outcome	categorical	Treatment received for ROP	1, Anti-VEGF Injection 2, Laser Therapy 3, Unilateral 4, Bilateral 5, None	y
laser_vent	Final Outcome	categorical	If treated, did baby require intubation and ventilation for treatment?	1, Yes   2, No	
final_outcome_sepsis	Final Outcome	categorical	Treated for culture-positive late onset sepsis (>72 hours of age)	1, Yes   2, No	y
pn_cmv	Final Outcome	categorical	Postnatal CMV infection?	1, Yes   2, No   3, Uncertain results   4, Not tested	
creat_discharge	Final Outcome	numeric	Most recent serum (lab) creatinine level (prior to death/discharge/44 weeks)		
bone_fracture	Final Outcome	categorical	Any bone fractures noted (at more than 3 days of life)?	1, Yes   2, No	
discharge_meds	Final Outcome	text	List medications at discharge (name only, not doses)		
placenta_histology	Final Outcome	categorical	Was placenta sent for histology?	1, Yes   2, No   3, Unknown	

### The 22 Week Study (IRAS 346626) - Single Form Data Collection Variables

placenta_histology2	Final Outcome	text	Placenta histology summary report (ensure no identifiable details)		
surgical_histology	Final Outcome	text	Please also ensure any surgical histology has been recorded either in the surgical form or put here with the operation related to.		
discharge_diagnoses	Final Outcome	text	Any other outcome details that are not covered above in terms of significant systems or diagnoses on discharge		