

The 22 Week Study (IRAS 346626) - Single/ Optional Repeated Forms

Variable / Field Name	Form Name	Data Type	Field Label	Choices	Required Field?
counselling1	counselling	categorical	Was antenatal counselling completed?	1, Yes 2, No 3, Unknown	y
counselling2	counselling	categorical	Why was counselling not undertaken?	1, Delivered out of hospital 2, Imminent delivery on arrival to hospital 3, Imminent delivery on ward before counselled 4, Language barrier 5, Other 6, Don't know/ unclear	y
counselling2a	counselling	text	Other		
not_counselled_risk	counselling	categorical	What parameters were known by the delivery team before/ when attending birth? (even if not counselled)	1, Gestational age 2, Plurality 3, Fetal sex 4, Estimated fetal weight 5, Antenatal steroid status 6, Rupture of membrane status 7, If any suspicion of chorioamnionitis	
counselling3	counselling	categorical	Location of this counselling episode	1, NICU 2, LNU 3, SCU	
counselling4	counselling	categorical	If LNU or SCU a) was case discussed with NICU before counselling b) was remote neonatal counselling undertaken or considered?	1, Case not discussed 2, Case discussed but no remote counselling 3, Case discussed and remote counselling utilised 4, Not clear/ not documented	
teams_counselling	counselling	categorical	Which teams were involved with counselling?	1, NICU 2, LNU/SCU3, Obstetrics4, Regional neonatal transport team5, Palliative care/ bereavement team	y
counselling5	counselling	categorical	Was counselling joint or done separately?	1, Yes - joint 2, No - separate 3, Unknown/ not documented	
counselling5a	counselling	text	Why was counselling not joint?		
counselling_interpreter	counselling	categorical	Was an interpreter used for counselling?	1, Yes 2, No 3, N/a or unknown	
counselling6	counselling	categorical	Grade of neonatal counsellor	1, Consultant 2, Senior Tier 2 (Registrar ST6 and above, equivalent staff grade/ fellow/associate, senior ANNP) 3, Junior Tier 2 (Registrar ST4-5 or equivalent staff grade/fellow, ANNP) 4, Other	y
other_counsellor	counselling	text	Other		
congenital_anomaly_counsel	counselling	categorical	Any congenital anomaly known?	1, Yes 2, No	y
congen_anomaly_counsel	counselling	text	What congenital abnormality was suspected?		
counselling7	counselling	text	Gestational age at counselling		y

The 22 Week Study (IRAS 346626) - Single/ Optional Repeated Forms

counselling8	counselling	categorical	Plurality known	1, Known 2, Unknown	y
counselling8a	counselling	categorical	Fetal sex	1, Male 2, Female 3, Unknown	y
counselling8b	counselling	categorical	EFW	1, Known 2, Unknown	y
counselling8g	counselling	numeric	Estimated fetal weight in grams		y
counselling8c	counselling	categorical	Steroids at time of counselling	1, Yes - full course 2, Yes - 1st dose given 3, No - awaiting plan for intended neonatal care 4, No - declined 5, Not clear/ not documented	y
counselling8d	counselling	categorical	Rupture of membranes (at time of counselling)	1, Not occurred 2, < 18 hours 3, >18 hours 4, Unknown status	y
counselling8e	counselling	categorical	Suspected chorioamnionitis at counselling	1, No concern 2, Suspected chorioamnionitis 3, Diagnosed (clinical) chorioamnionitis 4, Unknown	y
counselling_8aa	counselling	categorical	GA informed counselling	1, Yes 2, No	
counselling_8ab	counselling	categorical	Plurality informed counselling	1, Yes 2, No	
counselling_8ac	counselling	categorical	Sex informed counselling	1, Yes 2, No	
counselling_8ad	counselling	categorical	EFW informed counselling	1, Yes 2, No	
counselling_8ae	counselling	categorical	Steroids informed counselling	1, Yes 2, No 3, N/a	
counselling_8af	counselling	categorical	ROM informed counselling	1, Yes 2, No	
counselling_8ag	counselling	categorical	Chorio informed counselling	1, Yes 2, No	
counselling_recommendation	counselling	categorical	Was a recommendation made by the medical team(s) regarding care?	1, Comfort care 2, Survival focused care 3, Assess at delivery 4, No recommendation given	y
counselling9	counselling	categorical	Plan made with parents for primary intention of care at delivery?	1, Comfort care 2, Survival focused care (SFC) 3, Assess at delivery to decide 4, Unknown or no clear plan 5, To provide second counselling to make decision	y
sfc_limitation	counselling	categorical	If survival focused care (SFC) or assessment at delivery planned, was any limitation to stabilisation discussed?	1, SFC/ assess at delivery with limitation to ventilation (no compressions or drugs) 2, SFC/ assess at delivery with limitation to cardiac compressions (no drugs) 3, No limitation 4, Not discussed	
counselling10	counselling	categorical	If plan for SFC made in a LNU or SCU, was a plan to aim for in-utero transfer made?	1, Yes 2, No 3, Not clear 4, N/a (in NICU)	y
counselling11	counselling	categorical	Was any palliative care specialist (nurse or medic) or bereavement midwife involved antenatally?	1, Yes 2, No - not available 3, No - not asked 4, No - no time before delivery 5, Not clear	

The 22 Week Study (IRAS 346626) - Single/ Optional Repeated Forms

counselling12	counselling	text	Any additional information regarding counselling?		
---------------	-------------	------	---	--	--

The 22 Week Study (IRAS 346626) - Single/ Optional Repeated Forms

Variable / Field Name	Form Name	Data Type	Field Label	Choices	Required Field?
surg_consult	surgery form	categorical	Has this baby had a surgical consultation or operation today (or this week if >7 days old)?	1, Consultation only 2, Consultation and Operation	y
surg_date	surgery form	numeric	Day of Life		y
surgicalform1	surgery form	categorical	Corrected gestational age (in completed weeks)	22, 22 23, 23 24, 24 25, 25 26, 26 27, 27 28, 28 29, 29 30, 30 31, 31 32, 32 33, 33 34, 34 35, 35 36, 36 37, 37 38, 38 39, 39 40, 40 41, 41 42, 42 43, 43 44, 44	
cga_surg_days	surgery form	categorical	Corrected gestational age (days)	0, 0 1, 1 2, 2 3, 3 4, 4 5, 5 6, 6	
surgicalform2	surgery form	categorical	Has the baby been transported in ambulance between hospitals in order to have surgery or consultation?	1, Yes 2, No	
surgical_consult2	surgery form	categorical	Indication for surgical consultation	1, Abdominal distension 2, Abdominal discoloration 3, Abdominal mass 4, Bilious aspirates/ vomiting 5, Perforation found on xray 6, PDA 7, Vascular access 8, Neurosurgical - head circumference and/or VIs increasing 9, Neurosurgical - symptomatic hydrocephalus 10, Neurosurgical - unable to do LP/tap 11, Post-operative review 12, Hernia 13, Other	y
surgical_consult2a	surgery form	text	Indication for surgical consultation (other)		
surgical_consult3	surgery form	categorical	Outcome of surgical consultation	1, Reassurance 2, Further review planned 3, Transfer to surgical unit for ongoing management (e.g. if reviewed at a non-surgical site by visiting surgeon) 4, Contrast study/ imaging recommended 5, Surgery 6, Other	y
surgical_consult3a	surgery form	text	Outcome of surgical consultation (other)		
surgicalform3	surgery form	numeric	Weight at time of surgery (grams)		
surgicalform5	surgery form	categorical	Emergency or elective surgery?	1, Emergency 2, Elective	
op_location	surgery form	categorical	Place of surgery	1, NICU 2, PICU 3, Theatre 4, Other	

The 22 Week Study (IRAS 346626) - Single/ Optional Repeated Forms

surgicalform6	surgery form	categorical	Indication for surgery	1, Abdominal - suspected perforation 2, Abdominal - suspected NEC (no perforation) 3, Abdominal - suspected obstruction 4, Abdominal - stoma closure 5, Neurosurgical 6, PDA ligation 7, Vascular access 8, Hernia 9, Other	y
surgicalform7	surgery form	text	Additional/ Other information for indication for surgery		
surgicalform8	surgery form	categorical	Procedure(s) undertaken at this operation	1, Abdominal (drain, laparotomy, laparoscopy 2, Neurosurgical (reservoir, shunt)) 3, PDA closure 4, Central venous access 5, Hernia repair 6, Other	y
surgicalform8a	surgery form	categorical	Abdominal diagnosis at surgery	1, NEC with perforation 2, NEC without perforation 3, SIP 4, Meconium inspissation 5, Volvulus 6, Malrotation 7, Oesophageal or gastric perforation 8, Obstruction 9, Atresia 10, Stricture 11, Other	
surgical_form8b	surgery form	categorical	Abdominal operation performed	1, Peritoneal drain 2, Laparotomy 3, Second-look laparotomy (e.g. after clip and drop) 4, Laparoscopy	
surgicalform8ba	surgery form	categorical	Operation detail	1, Intestinal resection 2, Primary anastomosis 3, Stoma formation 4, Clip and Drop 5, Closed for palliation 6, Stoma closure 7, Other	
surgical_form_8ba	surgery form	categorical	Location of perforation(s) or atresia(s) or stricture(s) or area affected by NEC if found	1, Duodenal 2, Jejunal 3, Ileal 4, Colonic 5, Pan-NEC 6, Other	
stoma_site	surgery form	categorical	Stoma site/ type	1, Jejunostomy 2, Ileostomy 3, Colostomy 4, Other	
other_abdo_diagnosis	surgery form	text	If 'other' selected in above questions, document here		
histology_description	surgery form	text	Histology description if available		
surgical_form_8c	surgery form	categorical	Neurosurgical diagnosis	1, PHVD 2, Other	
surgical_form_8d	surgery form	categorical	Neurosurgical management	1, Reservoir 2, Subgaleal shunt 3, VP shunt 4, Other	
pda_closure	surgery form	categorical	PDA closure method	1, Surgical ligation 2, Device closure	
surgical_form_8f	surgery form	categorical	Type of vascular access inserted	1, PICC 2, Broviac3, Other4, Cut down5, Percutaneous	

The 22 Week Study (IRAS 346626) - Single/ Optional Repeated Forms

surgical_form_8e	surgery form	categorical	Hernia repair details	1, Incarcerated 2, Elective repair 3, Unilateral 4, Bilateral	
surgical_form_8g	surgery form	text	If 'other' selected for any additional comments, please document here		
surgical_form_8h	surgery form	text	Any patient-related surgical difficulties or complications experienced by the surgeon?		y

The 22 Week Study (IRAS 346626) - Single/ Optional Repeated Forms

Variable / Field Name	Form Name	Data Type	Field Label	Choices	Required Field?
transfer_duration	transfer form	categorical	Will this baby stay at the hospital they are transferred to, or have they/will they return within 48 hours?	1, Yes (stay) 2, No (return)	
transfer_dol	transfer form	numeric	Day of life at transfer		y
cgatransfer	transfer form	numeric	Corrected gestational age at transfer (in weeks)		y
transferlocation3	transfer form	categorical	Type of transfer	1, Upward Transfer (NICU to a surgical NICU or PICU) 2, Horizontal Transfer (NICU to NICU or LNU to other LNU) 3, Step-down Transfer (NICU to LNU, LNU to SCU etc) 4, Not sure	y
transferreason	transfer form	categorical	Reason for Transfer	1, Surgical opinion or operation 2, Imaging or tests e.g. MRI, GI contrast 3, Repatriation 4, Palliation closer to home/ in other location 5, Parental request 6, Other	y
transfer_other	transfer form	text	Other		