Norfolk and Norwich University Hospitals Itel Services Text Service Services Text Serv	identifier lebel	
	Name	
Sudden	Date of Birth	D
Unexpected	Sex	
Death in	Address	
Childhood	General Practitioner	
(SUDIC)		
		Introductory Notes
child. This documentat Review (CDR) Process	ion should be used in conju	ork through the process of responding to the sudden unexpected de unction with Clinical Guideline <u>Trustdocs Id: 1228</u> and The Child Dea ogether to Safeguard Children 2018 ('A child is defined in the Act o ensure that:
Bereaved familie	s are offered optimal suppo	ort during a traumatic time.
A thorough inqui	ry into child's death is perfo	rmed, with emphasis on history, examination and investigations.
 Pathologists and of death. 	the Coroner have access t	o information which will assist them in accurate determination of the
The welfare of si	blings and subsequent child	dren is safeguarded, whatever the cause of death.
		General Principles
• This documentation applies		be dealt with in a sensitive manner with early involvement of Senior N Acute General Paediatrician).
to all children and young people dying suddenly and	 Careful recording and de underpins the process. 	ocumentation of the history, examination and appropriate investigation
unexpectedly <u>prior</u> to their 18th birthday.		ed death in childhood should prompt a multi-disciplinary investigation ce, and Children's Services, the Coroner and others, as appropriate.
• In some circumstances, a child is revived by resuscitation efforts, but subsequently dies. In these cases, it is still appropriate to use the SUDIC documentation.		ted death, it is good practice for the responsible Consultant to write to bossible, giving details of the death and follow-up arrangements.
• Following the sudden unexpected death of a child the responsible named consultant will be the Children's Assessment Unit (CAU) consultant		

Informing the Family of Death

The management of sudden unexpected deathin infancy and childhood (SUDIC)Author/s: Dr Ravi Alanoor, Dr Barbara WatlingAuthor/s title: Paediatric Consultant'sDate approved: 08/04/2022Review date: 08/04/2025

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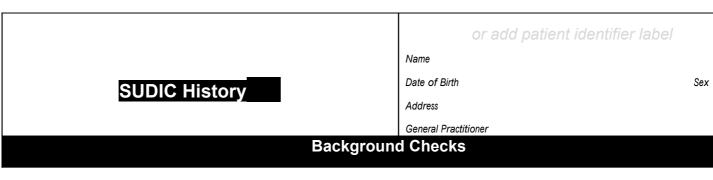
 When death has been pronounced, an experienced Paediatrician, preferably a Consultant should break the news to the parents, having first reviewed all available information. The interview should be in the privacy of an appropriate room A 	 conjunction with t with information fr Explain that we w This will include p Explain that the P 	he police. The rom investigatio rill also liaise wi professionals in Pathologist, will	CDRT) will usually also visit the Coroner's Officer and/or CDRT v ons and the post mortem examin ith other professionals to best un Health and Children's Services. need to know everything about t th problems in other family mem	vill keep the family u ation. derstand the cause o he baby's previous n
	or add patient identifier label			
	Name		D	
SUDIC	Date of Birth			
Sex				
	C	ircumstance	es of Death	
Record where, when an Record the subsequent	d by whom the child was fo course of events.	ound.	Date ^{dd/mm/} yyyy Time	Time of Death 24hour clock
•	s, and the time of discontir	nuation.	24hour clock	
Note names of key profe	,	Responsible		
Make a copy of Acciden	t Assetssmenget ncy (A&E) ar he main hospital notes and	nd		

Page 2

Print Name

Signature

Date dd/mmm/yyyy /



The management of sudden unexpected death in infancy and childhood (SUDIC)Author/s: Dr Ravi Alanoor, Dr Barbara WatlingAuthor/s title: Paediatric Consultant'sDate approved: 08/04/2022Review date: 08/04/2025

Approved by: CGAP chair Trust Docs Id: 8798 Page 3 of 23 Ascertain if the child or family was/is known to Social Services, and if the child had a Child Protection Plan. Social Serv accessible out of hours via the Hospital Switchboard.

Obtain A&E records and details of admissions/A&E attendances to other hospitals, if known.

Detailed Account of Events Prior to Death

Use this section to record further information about the circumstances of death, if necessary. Record a detailed account of events leading up to death. This will include at least the last 48 hours prior to death. Include details of any signs of illness, sleeping and waking, oral intake, including when last fed/eaten. Note use of any medication (including non-prescribed medication), drugs, alcohol.

Print Name
Page 3

Signature

Date dd/mmm/yyyy / Time 24 hour clock

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	or add patient identifier label	
	Name	
SUDIC History	Date of Birth	Sex
	Address	
	General Practitioner	
Detailed Account of Events	Prior to Death (continued)	

Page 4

Print Name

Signature

Date dd/mmm/yyyy / Time 24 hour c

The management of sudden unexpected deathin infancy and childhood (SUDIC)Author/s: Dr Ravi Alanoor, Dr Barbara WatlingAuthor/s title: Paediatric Consultant'sDate approved: 08/04/2022Review date: 08/04/2025

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	or add patient identifier label	
	Name	
SIDIC History	Date of Birth	Sex
	Address	
	General Practitioner	
Detailed Account of Events I	Prior to Death (continued)	

Pad		5
гач	-	J

Print Name

Signature

Insert continuation paper at this point if ne

Date dd/mmm/yyyy / Time 24 /

The management of sudden unexpected death in infancy and childhood (SUDIC) Author/s: Dr Ravi Alanoor, Dr Barbara Watling Author/s title: Paediatric Consultant's Date approved: 08/04/2022 Review date: 08/04/2025

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Date of Birth

Name

Address

Sex

General Practitioner **Previous Medical History**

Record appropriate details of previous medical history, including:

Where relevant, details of birth history, antenatal problems, and admission to neonatal unit

- Immunisations •
- **Development and Behaviour**
- School/Nursery/Child Minder attended. Any problems/concerns?
- Illnesses, operations, accidents, particularly noting outpatient and inpatient Hospital and A&E attendances. When has been admitted to hospital determine where, when and why.
- Medication
- Allergies

Page 6

Print Name

Signature

Date dd/mmm/yyyy / Time 24 /

			or add patient identifier la	bel	
			Name		D
	C Social and Famil	v History	Date of Birth	Sex	
<u>30DI</u>	C Social and Famil	y history	Address		
			General Practitioner		
First Name	ousenoid and Family	Date of Birth	Address and Telephone number	Relationship Child	to
Surname		Gender		Parental Responsibility	y
First Name		Date of Birth	Address and Telephone number	Relationship Child	to
Surname		Gender		Parental Responsibility	ý
First Name		Date of Birth	Address and Telephone number	Relationship Child	to
Surname		Gender		Parental Responsibility	y
First Name		Date of Birth	Address and Telephone number	Relationship Child	to
Surname		Gender		Parental Responsibility	
First Name		Date of Birth	Address and Telephone number	Relationship Child	ło
Surname		Gender		Parental Responsibility	ý
First Name		Date of Birth	Address and Telephone number	Relationship Child	to
Surname		Gender		Parental Responsibility	ý
First Name		Date of Birth	Address and Telephone number	Relationship Child	to
Surname		Gender		Parental Responsibility	ý
		Other Relevant Famil	y History/Information		
Record all fractures.	salient information. It is use	eful to include a family tree	e. If appropriate, note any family history of eas	sy bruising or	
Page 7	Print Name	Signature	Date dd/mmm/yyyy /	Time 24 hour clo	[,] ck

SUDIC Examination

or add patient identifier label

D

Sex

Name

Date of Birth

Address

		General Practitioner		
	Examina	ation		
The examination must be thorough and of It should be performed as soon as possil declared. Skin and Rectal temperature should be r General appearance (including nutrition, condition of clothing). Dysmorphic features. Growth (height, weight and head circumf Any evidence of rashes, external injuries details on body diagrams overleaf.	ble after death has been recorded (note time). cleanliness, ference)	injury to genitalia/ Specifically note f investigation (brol marks, cannulas e Keep all clothing a	eatures relating to resuscitation / ken ribs from cardiac massage, punctu	ire
Height/Centile	Weight/Centile		Head Circumference/Centile	

Page 8

Print Name

Signature

Date dd/mmm/yyyy / Time 24 hour clock

or add patient identifier label

SUDIC Examination

Date of Birth

Name

Address

General Practitioner

Examination (continued)

Page 9

Print Name

Signature

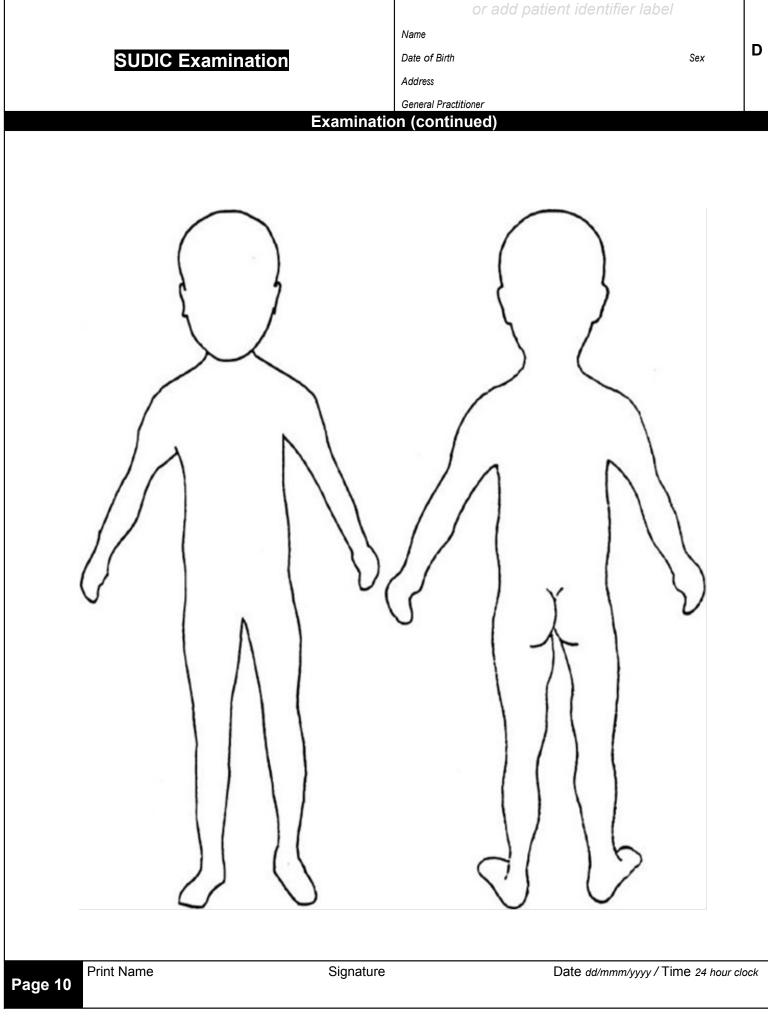
Date dd/mmm/yyyy / Time 24 hour clock

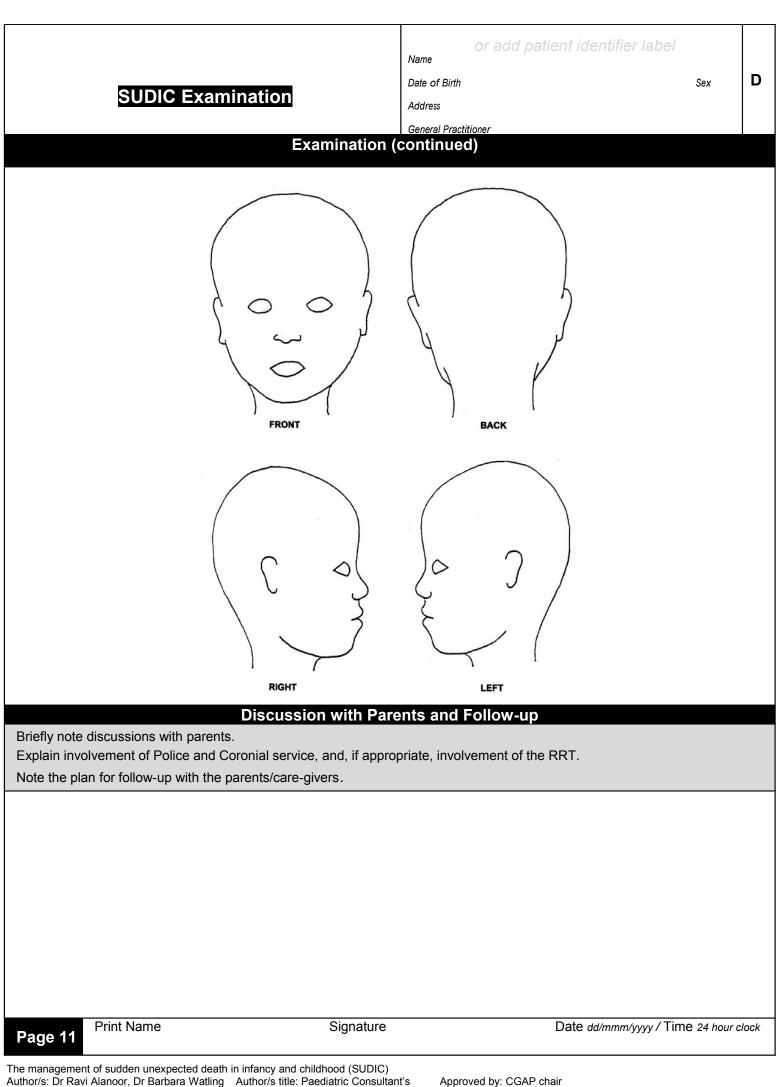
The management of sudden unexpected death in infancy and childhood (SUDIC)Author/s: Dr Ravi Alanoor, Dr Barbara WatlingAuthor/s title: Paediatric Consultant'sDate approved: 08/04/2022Review date: 08/04/2025

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Sex

D





or add patient identifier label

SUDIC Contact Checklist

Date of Birth Address

Name

Sex

D

General Practitioner

The checklist must be completed for all cases. This ensures that key individuals are notified of the death, and are provided with relevant information. Urgent contacts should be called without delay.

Note name and contact details of individual spoken to.

	Urgent Contacts		
Agency	Contact Information	Person	Date/Time
Medical Examiner at NNUH	medicalexamineroffice@nnuh.nhs.uk		
Coroner	Telephone 01603 663302 in office hours, via switchboard out of hours.		
Norfolk Police	Dial 101 Child Abuse Investigation Unit		
Children's Services	0344 800 8021 (8am-8pm Mon-Fri) Or EDT (out of hours) 0344 800 8020		
Child Death Review Team	07866059486 (8am to 6pm) Out-of-hours, leave message on extension 3201 (direct dial 287201)		
Designated Safeguarding/CDR team	Telephone 01603 257164		
	Other Contacts		
	act any Health Professionals who have had recent inv peak to the child's school, or schools attended by sibl		
	child deaths may lead to significant media interest an n the Trust's Communications Department on extension	• •	•

Page 12 Print Name

Signature

SUDIC Final C	or add patient identifier label Name Date of Birth Sex Address General Practitioner Final Checklist	D
Complete Patient Episode on PAS.	This ensures all future appointments are cancelled.	
Complete Electronic Discharge Letter (EDL) (this should be followed by a letter from the responsible Consultant).	This ensures the GP receives timely information.	
Complete the Chain of Evidence form (page13) and photocopy it.	The photocopied form should accompany all laboratory specimens to Pathology Reception, and be signed by the person taking the samples and laboratory staff. The form must remain in the laboratory.	
Photocopy the complete SUDIC paperwork, Ambulance record and A&E notes for the RRT	The RRT needs full information to assist in gathering evidence at the Home Visit.	
Put the SUDIC paperwork and photocopy of Ambulance & A&E record in main hospital notes.	It may be helpful for the responsible Consultant to retain a copy for their own information.	
Print Name	Signature Date dd/mmm/yyyy/Time 24 hour clock	

	Name		or add patient i	dentifier label			
	Date of Birth		Sex				D
DIC			Sex				U
	Address						
	General Practition	er					
Complete this page	and then photocor	w it. The conv. needs	SUDIC investigation		vidual taking the specimens to the la	aboratory The for	m
should remain with	the laboratory for si	ubsequent signing by	microbiology. Any blood or other sample	es obtained prior to de	ath must also be retained for potent	tial future analysis.	Notif
Notes	ne need for such sam	ples to be kept.		nvestigations During	Resuscitation		
Notes	В	Urine and		Other			
	0	Other samples					
	0						
	d	10					
Note which investigations	Blood Gas						
were done during (or prior) to							
resuscitation,							
particularly urinalysis,				Chest X-ray			
capillary blood glucose and			Urinalysis	Chest X-ray			
ketones, and				ECG			
blood gas analyses. Ensure							
the blood gas result is copied							
into the notes as							
	Blood Glucose						
	Blood Glucose ¹ Blood ketones ^{1,2}	1 □ 2 □					
	Blood Glucose Blood ketones ^{1,2} Other (specify):	1 0 2 0					
the printout fades with time.	Blood ketones ^{1,2}	1 □ 2 □					
	Blood ketones ^{1,2}	10	Standard Investiga	tions Following De	ath		
with time. Samples should	Blood ketones ^{1,2} Other (specify):	2	Standard Investiga				
with time. Samples should be taken as soon as possible after	Blood ketones ^{1,2} Other (specify): B I	Urine and Other samples	Standard Investiga		ath Dther		
with time. Samples should be taken as soon as possible after	Blood ketones ^{1,2} Other (specify): B I o o	Urine and Other	Standard Investiga				
with time. Samples should be taken as soon as possible after death.	Blood ketones ^{1,2} Other (specify): B I o o d	2⊔ Urine and Other samples		(Dther	ne unless clearly	/
with time. Samples should be taken as soon as possible after death. Blood samples	Blood ketones ^{1,2} Other (specify): B I o o d	2⊔ Urine and Other samples	Standard Investiga	(ne unless clearly	,
with time. Samples should be taken as soon as possible after death. Blood samples may be taken	Blood ketones ^{1,2} Other (specify): B I o o d	2⊔ Urine and Other samples		All standard invest	Dther	ne unless clearly	,
Samples should be taken as soon as possible after death. Blood samples may be taken from the heart (insert syringe	Blood ketones ^{1,2} Other (specify): B I o o d	2⊔ Urine and Other samples		All standard invest	Dther	ne unless clearly	,
Samples should be taken as soon as possible after death. Blood samples may be taken from the heart (insert syringe and needle at 90° in the 4th	Blood ketones ^{1,2} Other (specify): B I o o d	2⊔ Urine and Other samples		All standard invest	Dther	ne unless clearly	[
Samples should be taken as soon as possible after death. Blood samples may be taken from the heart (insert syringe and needle at 90° in the 4th intercostal space	Blood ketones ^{1,2} Other (specify): B I o o d	2⊔ Urine and Other samples		All standard invest	Dther	ne unless clearly	[
Samples should be taken as soon as possible after death. Blood samples may be taken from the heart (insert syringe and needle at 90° in the 4th intercostal space at the LEFT sternal edge. If	Blood ketones ^{1,2} Other (specify): B I o o d	2⊔ Urine and Other samples		All standard invest	Dther	ne unless clearly	[
Samples should be taken as soon as possible after death. Blood samples may be taken from the heart (insert syringe and needle at 90° in the 4th intercostal space at the LEFT sternal edge. If blood is not	Blood ketones ^{1,2} Other (specify): B I o o d	2⊔ Urine and Other samples		All standard invest	Dther	ne unless clearly	ſ
Samples should be taken as soon as possible after death. Blood samples may be taken from the heart (insert syringe and needle at 90° in the 4th intercostal space at the LEFT sternal edge. If blood is not obtained easily, attempt to obtain	Blood ketones ^{1,2} Other (specify): B I o o d	2⊔ Urine and Other samples		All standard invest	Dther	ne unless clearly	[
Samples should be taken as soon as possible after death. Blood samples may be taken from the heart (insert syringe and needle at 90° in the 4th intercostal space at the LEFT sternal edge. If blood is not obtained easily, attempt to obtain blood from the 4th intercostal	Blood ketones ^{1,2} Other (specify): B I o o d	2⊔ Urine and Other samples		All standard invest	Dther	ne unless clearly	[
Samples should be taken as soon as possible after death. Blood samples may be taken from the heart (insert syringe and needle at 90° in the 4th intercostal space at the LEFT sternal edge. If blood is not obtained easily, attempt to obtain blood from the 4th intercostal space at the	Blood ketones ^{1,2} Other (specify): B I o o d	2⊔ Urine and Other samples		All standard invest	Dther	ne unless clearly	[
Samples should be taken as soon as possible after death. Blood samples may be taken from the heart (insert syringe and needle at 90° in the 4th intercostal space at the LEFT sternal edge. If blood is not obtained easily, attempt to obtain blood from the 4th intercostal space at the RIGHT sternal	Blood ketones ^{1,2} Other (specify): B I o o d	2⊔ Urine and Other samples		All standard invest	Dther	ne unless clearly	[
Samples should be taken as soon as possible after death. Blood samples may be taken from the heart (insert syringe and needle at 90° in the 4th intercostal space at the LEFT sternal edge. If blood is not obtained easily, attempt to obtain blood from the	Blood ketones ^{1,2} Other (specify): B I o o d	2⊔ Urine and Other samples		All standard invest	Dther	ne unless clearly	[
Samples should be taken as soon as possible after death. Blood samples may be taken from the heart (insert syringe and needle at 90° in the 4th intercostal space at the LEFT sternal edge. If blood is not obtained easily, attempt to obtain blood from the 4th intercostal space at the RIGHT sternal edge.	Blood ketones ^{1,2} Other (specify): B I o o d	2⊔ Urine and Other samples		All standard invest	Dther	ne unless clearly	[
Samples should be taken as soon as possible after death. Blood samples may be taken from the heart (insert syringe and needle at 90° in the 4th intercostal space at the LEFT sternal edge. If blood is not obtained easily, attempt to obtain blood from the 4th intercostal space at the RIGHT sternal edge. Urine samples can be taken by	Blood ketones ^{1,2} Other (specify): B I o o d	2⊔ Urine and Other samples		All standard invest	Dther	ne unless clearly	[
Samples should be taken as soon as possible after death. Blood samples may be taken from the heart (insert syringe and needle at 90° in the 4th intercostal space at the LEFT sternal edge. If blood is not obtained easily, attempt to obtain blood from the 4th intercostal space at the RIGHT sternal edge. Urine samples can be taken by using a catheter/feeding	Blood ketones ^{1,2} Other (specify): B I o o d	2⊔ Urine and Other samples		All standard invest	Dther	ne unless clearly	[
Samples should be taken as soon as possible after death. Blood samples may be taken from the heart (insert syringe and needle at 90° in the 4th intercostal space at the LEFT sternal edge. If blood is not obtained easily, attempt to obtain blood from the 4th intercostal space at the RIGHT sternal edge. Urine samples can be taken by using a catheter/feeding tube, or by	Blood ketones ^{1,2} Other (specify): B I o o d	2⊔ Urine and Other samples		All standard invest	Dther	ne unless clearly	[
Samples should be taken as soon as possible after death. Blood samples may be taken from the heart (insert syringe and needle at 90° in the 4th intercostal space at the LEFT sternal edge. If blood is not obtained easily, attempt to obtain blood from the 4th intercostal space at the RIGHT sternal edge. Urine samples can be taken by using a catheter/feeding	Blood ketones ^{1,2} Other (specify): B I o o d	2⊔ Urine and Other samples		All standard invest	Dther	ne unless clearly	[
with time. Samples should be taken as soon as possible after death. Blood samples may be taken from the heart (insert syringe and needle at 90° in the 4th intercostal space at the LEFT sternal edge. If blood is not obtained easily, attempt to obtain blood from the 4th intercostal space at the RIGHT sternal edge. Urine samples can be taken by using a catheter/feeding tube, or by suprapubic	Blood ketones ^{1,2} Other (specify): B I o o d	2⊔ Urine and Other samples		All standard invest	Dther	ne unless clearly	, , ,

Author/s: Dr Ravi Alanoor, Dr Barbara Watling Author/s title: Paediatric Consultant's Date approved: 08/04/2022 Review date: 08/04/2025

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						-			
puncture in the									
usual way.									
It may be easier									
to use a									
hypodermic									
needle rather									
than a standard									
LP needle. If									
there is									
significant blood									
staining of CSF,									
this may indicate									
intra-cerebral									
haemorrhage / closed head									
cioseu neau									
trauma. Ensure									
the Police and									
Coroner are									
notified of this									
finding.									
initianity.									
Record puncture									
sites for									
investigations on									
the body									
diagrams									
	[B] Blood			_					
	Glucose1		Urine toxicology						
	Blood ketones1,2		Urine metabolic						
			screen5						
			Urine MC&S						
	[C] U&Es, LFTs,	_	Urine for	_					
	Ca, Mg, CRP		storage6 (spin			1			
			and freeze at						
			-20°C)				-		
	• •							<u>,, , , , , , , , , , , , , , , , , , ,</u>	
			CSF glucose7			2	they must be don	ot done prior to de	eath. If after death,
	[B] Blood alcohol					6	they must be don	e inimediately to i	be of any value
			CSF Protein7			3	-		
	[H] Tryptase3 [F] Neonatal	<u> </u>					-		
	Screening Card3								
	(for		CSF MC&S7			4	If suspected infect	tion in children ol	der than 2 months
	Acylcarnitines)						laboratory analysi		
			CSF for storage6				Laboratory analys	s nocrequited	
			7(spin and freeze	, !					
	[G] Blood Culture		at -20°C) Gastric			5			
			aspirate (for	-					
			culture)						
	[H] Viral serology						If anaphylaxis, un	explained shock of	or suspected
	[H]						cardiac cause		
	Descussors	-			_		_		Stored samples
	HiB and Tetanus		NPA: Virol.			MC&S		6	are discarded
	Antibodies4								after 6 months
	[D] Low		Threat Owner						
	r •	п	Throat Swab Virol.			MC&S		7	
	resolution micro-		IVIFOI.				Infants, or older c		f learning
	array5							· · · · · · · · · · · · · · · · · · ·	
	array5 [complete						difficulties or dysr	norphic features	
	array5 [complete Molecular						difficulties or dysr	norphic teatures	
	array5 [complete Molecular Genetics Request						difficulties or dysr	norphic features	
	array5 [complete Molecular Genetics Request form]						difficulties or dysr	horphic features	If there is
	array5 [complete Molecular Genetics Request form] [C] Green Top					9	for suspected me		
	array5 [complete Molecular Genetics Request form] [C] Green Top bottle for		Nasal Swab			8			significant blood usually done at staining, this may
	array5 [complete Molecular Genetics Request form] [C] Green Top bottle for storage6		Nasal Swab			8	for suspected me		significant blood ustrally done at staining, this may indicate
	array5 [complete Molecular Genetics Request form] [C] Green Top bottle for storage6 [D] Purple Top		Nasal Swab Surface swabs			8	for suspected me		significant blood staining, this may indicate intracerebral
	array5 [complete Molecular Genetics Request form] [C] Green Top bottle for storage6 [D] Purple Top bottle for		Nasal Swab Surface swabs from any skin	0		8	for suspected me		significant blood staining, this may indicate intracerebral haemorrhage or
	array5 [complete Molecular Genetics Request form] [C] Green Top bottle for storage6 [D] Purple Top bottle for storage6		Nasal Swab Surface swabs from any skin lesions			8	for suspected me		significant blood staining, this may indicate intracerebral
	array5 [complete Molecular Genetics Request form] [C] Green Top bottle for storage6 [D] Purple Top bottle for storage6 [H] Red Top		Nasal Swab Surface swabs from any skin lesions COVID-19 T/N			8	for suspected me		significant blood staining, this may indicate intracerebral haemorrhage or
	array5 [complete Molecular Genetics Request form] [C] Green Top bottle for storage6 [D] Purple Top bottle for storage6 [H] Red Top		Nasal Swab Surface swabs from any skin lesions COVID-19 T/N Swabs			8	for suspected me		significant blood staining, this may indicate intracerebral haemorrhage or
	array5 [complete Molecular Genetics Request form] [C] Green Top bottle for storage6 [D] Purple Top bottle for storage6 [H] Red Top bottle for storage6		Nasal Swab Surface swabs from any skin lesions COVID-19 T/N Swabs Skin biopsy			8	for suspected me		significant blood staining, this may indicate intracerebral haemorrhage or
	array5 [complete Molecular Genetics Request form] [C] Green Top bottle for storage6 [D] Purple Top bottle for storage6 [H] Red Top bottle for		Nasal Swab Surface swabs from any skin lesions COVID-19 T/N Swabs			8 Required	for suspected me		significant blood staining, this may indicate intracerebral haemorrhage or

post-mortem specimens MUST be taken to the Pathology Laboratory in person, and not sent by the Vacuum tube system. <u>Microbiology</u> <u>samples</u> <u>MUST also be</u> taken to the <u>Pathology</u> Laboratory, and not sent	Blood (Use Adult Blood Tubes): A Blood Gas Syringe or Cap. tube x 1 B Grey Top (Fluoride Oxalate) x 2 C Green Top (Lithium Heparin) x 2 D Purple Top (EDTA) x 3 E Blue Top (Citrate) x 1 F Neonatal Screening Card x 1 G Blood Culture Bottle x1 H Red Top (Serum) x 2	Urine: Universal bottle x2 Boric acid x1 (red top) CSF: Universal bottle x4 (10-20 drops in each) Grev Top bottle		
				Investigations
This is to				
ensure the				
chain of			Rec	ord any additional investigations performed
evidence is				
maintained				
	Print name	Signature	Date dd/mm/yyy	Time 24 hour clock
Samples taken				
by: Chain of				
Evidence Form				
completed by:				
Samples taken to Main Lab by:				
Samples received				
in Main Lab by:				
Samples received				
in Microbiology Lab by:				
	To assist	Date of Death	Time of Death	
	laboratory			
	staff in			
	interpretati			
Page 14	on of			
	results,			

Appendix 1

Skin Fibroblast Sampling in cases of Sudden Unexplained Death in Childhood (SUDIC)

Background

Skin biopsy for fibroblast culture is recommended within the Kennedy Sampling Guidelines in cases of sudden child death where there is possibility of an underlying chromosomal anomaly or metabolic disorder.

Not all cases of sudden death will require this investigation, however it should be considered at the time of examination and sampling and appropriate consent sought.

Fibroblasts from skin biopsy are used to extract DNA which can be stored indefinitely. This allows future further DNA extraction and metabolic testing.

It is important to note that fibroblast culture from skin biopsy is not always successful. Postmortem skin biopsy should be obtained ideally within 24 hours of death. Samples taken after 48 hours post-mortem are extremely unlikely to successfully culture fibroblasts.

Identifying need for fibroblast culture

This investigation is recommended in the RCPCH guidance in all cases of sudden unexplained death where metabolic disease is suspected.

In practice an obvious cause of death may not be apparent, hence particular suspicion of metabolic disease should be raised in cases of:

- Sudden death in babies and children under 2 years
- Family history of metabolic disorders or SUDIC
- Children with complex medical/developmental needs without clear unifying diagnosis.

- Any other cases where the lead consultant feels there is clinical suspicion of metabolic disease.

Consent

The collection of Kennedy samples in cases of SUDIC is a mandatory legal requirement, hence written consent is not formally required. However, the process should be explained to the parents including the rationale for testing and all investigations needed. Skin biopsy and fibroblast culture should be included in this discussion if indicated.

In all cases, explanation should include both the process itself and the need for DNA and skin fibroblast storage to enable future genetic or metabolic investigation should this be needed.

The conversation with parents including verbally obtained consent should be documented.

Long term/indefinite storage of DNA extracted from fibroblast culture requires specific consent.

Organising biopsy and culture

The skin biopsy request page in the SUDIC paperwork should be completed, documenting clinical reason for the request and confirming parents are aware of need for the investigation.

Consent for indefinite DNA storage, if obtained, should be documented.

Copies of all SUDIC paperwork, including skin biopsy request and agreement should be delivered to the mortuary with the child.

Mortuary staff should be informed of the request for skin biopsy and the necessary time frame. For deaths outside of normal working hours, biopsy would be performed during the next working day.

On the rare occasion of the mandatory time frame ending before the next working day, an oncall mortuary staff member may be requested to attend to ensure sampling is completed within the necessary window.

The biopsy will be performed by an appropriately trained member of mortuary staff. The date, time and location of the biopsy will be documented within the skin biopsy page of the SUDIC paperwork.

Samples will be sent to the Addenbrookes Genetics laboratory for fibroblast culture and DNA extraction. Results should be recorded as part of the final post-mortem report.

Consent for skin fibroblast testing

In cases of sudden, unexplained death where there is a possibility of underlying metabolic disorder, RCPCH guidance advises a skin biopsy is taken for fibroblast culture to identify any metabolic pathologies.

Skin biopsy will be undertaken <u>only when it has been agreed that this is needed by the</u> overseeing paediatrician, and where the family have been informed of the need to take these samples as part of the Kennedy sampling process.

Has the need for skin biopsy been discussed with parents? Yes / No

Comments

.....

Do parents consent for indefinite DNA storage in case of need for future testing? Yes / No

Comments.....

Testing Record for Mortuary staff

Date and time skin biopsy takenam / pm.

Location of biopsy site

(usually taken from thigh)

left / right.

Taken by:

(Name)

(Signature)

Date and time sent to laboratory

.....

.....am / pm.