



BEREAVED FAMILY MEMBER INTERVIEW FORM

© National Review of Asthma Deaths (NRAD)

Assessing quality of care is essential for quality improvement, and a family member's perspective is important for judging quality of care. These interviews will allow the NRAD team to include these views in their report.

INSTRUCTIONS FOR THE INTERVIEWER

- When conducting this interview (starting with the section titled 'Introduction and Screening'), read all lower-case text aloud to the interviewee.
- Instructions for the interviewers are provided throughout in capital letters. Words appearing in CAPITAL LETTERS are meant to guide the interviewer and should not be read aloud.
- Read instructions in lower-case letters aloud to the interviewee to guide him/her in answering.
- The questions have been designed to allow you to understand the specific information we would like to obtain from a question. If you find that some questions are not working, please let the NRAD team know.
- You may find that the participant may have answered one of your questions during the time when they are telling you what happened. If this happens, and you are confident that you do not need clarification of the answer, you may skip asking that question, but please ensure that you have made an entry in one of the answer categories for that question and ensure that all questions are completed, even if the answer is 'not known' or if it is felt that the question is 'not applicable' (with written justification as to why the question is 'not known').
- It is also important to try and read questions in the order in which they appear in the questionnaire – this is to ensure that all the questions get answered. If a question is not applicable, simply select that option and move on to the next.
- Some questions are followed by round brackets (...); these are a signpost for the interviewer who should read the answer choices aloud to the interviewee. Read all the answer choices before pausing for a response. For 'yes/no' questions, the answer categories should not be read aloud.
- The interviewer will often be expected to insert personal information into questions. For example, the patient's name is often inserted into questions. The interviewer will know to substitute specific information when a word written in [CAPITAL LETTERS ENCLOSED IN PARENTHESIS]: Please read through the interview questions before phoning the interviewee so that you can insert the deceased person's name in those places on the form where this is appropriate.

Example: Was [PATIENT] asthma worse at any particular time of day or night? Read as: Was Jessica's asthma worse at any particular time of day or night?

When words with options appear in parentheses, the interviewer should choose the appropriate word:

Example: Did [PATIENT] know what to do when [HE/SHE] felt [HIS/HER] asthma was bad?

Read as: Did Jessica know what to do when she felt her asthma was bad?

Tick the box of the answer chosen by the interviewee.

• For fill-in or free-text answers, write in the appropriate information as stated by the interviewee as accurately as possible. Additions can be made following transcription of the interview from the recording.

- Based on the answers to certain questions, it is sometimes logical to skip subsequent questions.
 Instructions for skipping questions are provided within parentheses after a specific answer. If this answer is selected, move on to the question number indicated after that answer choice.
- Please be familiar with the interview questionnaire before conducting the interviews. At times, for example, it is necessary to refer back to previous answers to determine whether a question or a group of questions should be skipped.
- Terminating the interview please refer to your guidance notes from the training on how and when to terminate the call if necessary.
- Once you have completed the interview, please take time to go back over the questionnaire and ensure that all the questions have been answered (even if the answer is 'not known' or 'not applicable')
- Please also ensure that the questionnaire and interview tape are stored in line with the operational procedures outlined in your guidance pack (ie secure cabinet in a locked office/or hand over immediately to a member of the NRAD team).

Finally, it is important to refrain from offering any opinion on behalf of Asthma UK or the RCP in response to a question from the interviewee. If the interviewee asks a question that deviates from the questions below, please respond by saying that the question is beyond the scope of the interview but that you would be happy to arrange a time after the interview for an Asthma UK advice line nurse specialist to answer any additional questions they may have.

COVERSHEET (To be completed by NRAD)

NRAD reference number:	
Participant number:	
Interviewer:	
Interview date:	
Interview start time:	
Interview finish time:	
PATIENT DETAILS	
Name:	
Gender:	Male Female
Age patient died:	years
Date of death: If no full date of death is known, enter month and year	/ / (DD/MM/YYYY)
Diagnosis at death: (on death certificate)	1a
	1b
	1c
	2
Marital status:	Not known
Ethnicity	Not known
INTERVIEWEE/PARTICIPANT DETAILS	
Surname/family name:	
First name:	
Gender:	☐ Male ☐ Female ☐ Other
Contact details:	

INTRODUCTION AND SCREENING

[NOTE FOR INTERVIEWER] KEY INFORMATION REQUIRED FROM THIS SECTION:

Is now the most convenient time to talk?

- is now the most convenient time to tak:					
- Interviewee's relationship to the person who died					
- If they are not the person who would be able to answer the most about the person who died,					
then to obtain the contact details of the person who would be					
Hello, may I speak to [INTERVIEWEE NAME]?					
My name is [INTERVIEWER NAME] and I am calling from Asthma UK on behalf of the National					
Review of Asthma Deaths.					
Review of Astrilla Deaths.					
0 I II (1-1-1-1-1-1-1-1-1-1-1-1-1-1-1-1-1-1-1-					
Can I call you [INTERVIEWEE NAME]?					
You were recently invited to participate in an interview for the project and said that it would be OK to					
talk with you - it may take an hour.					
Is now a good time for us to talk?					
Yes [CONTINUE]					
No We will call you another time. When is usually a good time for you to talk?					
[CONFIRM THAT INTERVIEWEE WILL BE CALLED AGAIN AND TERMINATE INTERVIEW – PASS					
•					
INFORMATION ON TO THE NRAD TEAM]					
If yes,					
Before we start then, I'd like to thank you for your time in talking with me today, and I'm sorry about					
the circumstances under which we have contacted you.					
The things we talk about today, together with information from interviews with other families, will be					
used to write a final report and to make recommendations so that the care of people with asthma can					
be improved.					
Could I just ask how you would like [PATIENT] to be referred to during the interview?					
i. Please could you tell me how you knew [PATIENT]?					
Spouse Daughter/son-in-law Parent of person who died Friend					
Partner Child Sibling Other, specify					
ii. Would you say you are one of the people who knows the most about [PATIENT] and their asthma					
in the last few months of life?					
Yes (SKIP QUESTIONS iii, iv and v AND GO TO INFORMED CONSENT STATEMENT)					
□ No – GO TO iii.					
iii. Who would know more about [PATIENT] asthma in the last few months of their life?					
iv. How did [ALTERNATIVE PERSON] know [PATIENT]?					
Spouse Daughter/son-in-law Parent of person who died Friend					
Partner Child Sibling Other, specify					
We may want to interview [ALTERNATIVE PERSON], do you happen to have [HIS/HER] full name and					
address and telephone number so that they can be contacted by the project team?					
[ADD ALTERNATIVE PERSON'S CONTACT DETAILS HERE]					
INTERVIEWER: CONFIRM THAT THE ALTERNATIVE PERSON KNOWS MORE THAN THE INTERVIEWEE					

NTERVIEWER: CONFIRM THAT THE ALTERNATIVE PERSON KNOWS MORE THAN THE INTERVIEWER ABOUT THE PATIENT'S ASTHMA – THANK INTERVIEWEE AND TERMINATE THE INTERVIEW

INFORMED CONSENT STATEMENT

I am going to read you a few, quite formal, sentences to make sure you have all the information about the study, and to ensure you are happy to continue:

- Your participation in this interview is voluntary, so if you decide at any point not to participate that is OK.
- I'd like to reassure you that this is a confidential conversation. The information from your interview with me will not be presented or published in any way that would allow anybody to know who you are; your answers will be combined with those of other people for writing the final report.
- There are five key sections in the interview that I will ask questions about:
 - ✓ what happened to [PATIENT]
 - ✓ [PATIENT]'s asthma
 - ✓ [PATIENT]'s household and living environment
 - √ how asthma impacted on [PATIENT]'s life
 - ✓ [PATIENT]'s asthma care and management
- You will be able to take a break or stop before or after any section.
- Please take your time and answer as honestly and as accurately as you can. If there is any question you would rather not answer, just say so and we will move on.
- If you have any questions related to the [PATIENT]'s care beyond the scope of the interview, I will provide you with an opportunity to receive a call back from an Asthma UK Advice Line Nurse Specialist after the interview.

Nurse Specialist after the interview.
Do you have any questions at this point about anything I have just said? Yes [ANSWER QUESTIONS] No May we proceed with the interview? Yes [CONTINUE THE INTERVIEW – GO TO Informed consent to record interview] No [THANK INTERVIEWEE AND TERMINATE THE INTERVIEW]
INFORMED CONSENT TO RECORD INTERVIEW
I need to remind you that our conversation is being confidentially recorded. This is so that I can ensure I have written down your answers correctly. The recording will be kept in a secure place where no one else can hear it and will be deleted after we have finished writing our reports. Is this OK? Yes [CONTINUE WITH INTERVIEW – GO TO QUESTION 1] No OK, I will switch off the recording machine. Is it OK for us to continue now? Yes [CONTINUE WITH INTERVIEW – GO TO QUESTION 1] No [THANK INTERVIEWEE AND TERMINATE THE INTERVIEW]

SECTION 1: WHAT HAPPENED

[NOTE FOR INTERVIEWER] KEY INFORMATION REQUIRED FROM THIS SECTION:

	- Details of what led to the death, ie was there a final attack? Any triggers?							
	- How was the patient's asthma leading up to death?							
	_	Details of what happened						
Lar	n go	• • • • • • • • • • • • • • • • • • • •	about the time	leading up to v	vhen [PATIENT] died. I'll start w	/ith		
	_							
	ome specific questions, but you will get a chance later to tell me about things that I haven't asked. Thank you. In the next few minutes could you please tell me in as much detail as possible what							
Τ.	happened							
	-							
	(US	e bullet points here)						
2.	Wł	nen did the final attack that le	d to the death b	egin?				
3.	Но	w quickly did the final attack	come on?					
		☐ IN MINUTES	O	VER A FEW WE	EKS			
		OVER A FEW HOURS	D(ON'T KNOW				
		OVER A FEW DAYS						
		_						
4.	Do	you think anything particular	set off the final	attack, such a	s exposure to pollution, a pet,			
	typ	pe of food, stress or a bad cold	?					
	•		lo [GO TO Q5]	☐ Don't k	now [GO TO Q5]			
		If yes,			()			
		4.1 Please tell me what you t	hink might have	e been the caus	se·			
		4.11 lease tell lile What you	illing in gire inde	e been the caa				
5.	ľm	now going to read a list of ot	her conditions t	hat [PATIENT]	may have had in addition to th	neir		
٥.					I with a yes, no or don't know:			
	a.	COPD	Yes	No	Don't know	•		
	b.	Eczema	=	□ No	Don't know			
			∐ Yes					
	С.	Hay fever	∐ Yes	∐ No	Don't know			
	a.	Allergic rhinitis (runny or	Yes	∐ No	Don't know			
		sneezy nose all year round)		□				
	e.	Food allergies	Yes	No	Don't know			
		(eg nuts, fish, dairy)						
	f.	Drug allergies	∐ Yes	∐ No	Don't know			
		(eg aspirin, ibuprofen)	Yes	■ No	Don't know			
	g.	Anaphylaxis	Yes	☐ No	Don't know			
	h.	Other allergies, specify	Yes	☐ No	☐ Don't know			
		(eg animals, dust, latex)						
		, , ,						
6.	We	ere any of these present durin	g the final attac	k?				
6.		ere any of these present durin	· —		Don't know			
6.	a.	COPD	Yes	☐ No	☐ Don't know			
6.		-	· —		Don't know Don't know Don't know			

	d.	Allergic rhinitis (runny or	Yes	No	☐ Don't know	
	e.	sneezy nose all year round) Food allergies	Yes	No	Don't know	
	С.	(eg nuts, fish, dairy)				
	a.	Drug allergies	Yes	☐ No	☐ Don't know	
		(eg aspirin, ibuprofen)	Yes	☐ No	Don't know	
	f.	Anaphylaxis	Yes	No No	Don't know	
	g.	Other allergies, specify	Yes	No	Don't know	
		(eg animals, dust, latex)				
7.	Dic	I anyone try to get help?				
			No [GO TO 7.2]	☐ Don't kr	now [GO TO 8]	
		If yes,				
		7.1 Who was contacted and	in which order?			
		GP practice		IS Direct	☐ Don't know	
		999 or 111		cal pharmacist	_	
		Hospital directly	∐ So	meone else, pl	ease specify	
		7.2 Were there any problem	ns with getting he	eln or going to	hospital?	
		Yes	No (GO T		Don't know	
		If no,		,	_	
		7.3 What prevented someon	ne from seeking l	nelp?		
SF.	CTIO	N 1: ADDITIONAL NOTES				
		illet points or a flow diagram	of events here)			
(ω.	JC 50	met points of a now alagram	or events here,			

SECTION 2: ABOUT THE PATIENT AND THEIR ASTHMA [NOTE FOR INTERVIEWER] KEY INFORMATION REQUIRED FROM THIS SECTION: Education/employment information ie what did they do and did this impact on their asthma/did the asthma impact on their work Was there a formal diagnosis of asthma made? Asthma triggers READ: Thank you for sharing that information with me. I'm now going to ask you some more questions about [PATIENT] and [HIS/HER] asthma. 8. Was [PATIENT] employed or in education, for example did they work full time, part time, studying or were they retired at the time of their death? (tick all that apply) Full-time work [GO TO Q8.1] School/college [GO TO Q10] Higher education/university [GO TO Q10] Part-time work [GO TO Q8.1] Unemployed [GO TO Q8.2] Pre-school child [GO TO Q10] Retired [GO TO Q8.2] Other, specify [GO TO Q10] Homemaker [GO TO Q8.2] Don't know [GO TO 10] If [PATIENT] was employed full or part time: 8.1 What was [HIS/HER] main work and what did this involve [PATIENT] doing from day to day? [Go to Q11 after answering this question] If [PATIENT] was unemployed or retired: 8.2 What was their previous employment/education status at the time of death? (Select all that may apply) ☐ Full-time work School/college Part-time work Higher education/university Unemployed Pre-school child Retired Other, specify Don't know Homemaker 8.2.1 What was [PATIENT]'s work before [HE/SHE] stopped working and what did this involve [PATIENT] doing from day to day? 8.2.2 Were there any medical reasons for [PATIENT] stopping work? Yes No Don't know If yes, 8.2.2.1 What were they? 8.2.3 How old was [PATIENT] when [HE/SHE] stopped working? _____ years 9. Was [PATIENT]'s asthma caused or made worse by any work they ever did? Yes No Don't know NA – Patient didn't ever work If yes, 9.1 What was the work?

9.2 What specifically made [PATIENT] asthma worse?					
9.3 Was [PATIENT] ever diagnosed with occupational asthma?					
Yes No Don't know					
9.4 Was [PATIENT]'s asthma better when they were away from the workplace?					
	know				
10. Did [PATIENT] know they had asthma?					
Yes	☐ Don't know				
☐ No	Other				
If yes,					
10.1 How old was [PATIENT] when [HE/SI	HE/YOU] was told for the first time by a doctor or				
other health professional that they had a	sthma? years 🔲 Don't know				
11. Did [PATIENT]'s asthma ever come on sudder					
Yes	Didn't have a problem before				
∐ No	Don't know				
12. Was [DATIENTIA sathura was at an arrival	alon time of record (tick all the stars to)				
12. Was [PATIENT]'s asthma worse at any particu					
Yes – spring Yes – summer	Yes – change of seasons Not noticeably seasonal				
Yes – autumn	Don't know				
Yes – winter	Other, please specify:				
res winter	Other, please specify.				
13. Was [PATIENT]'s asthma worse at any particu	llar time of day or night? (tick all that apply)				
Yes - early morning (6am – 9am)	Yes – night time (10pm – 6am)				
Yes - evening (5pm – 10pm)	Not noticeably				
Yes - day time (9am-5pm)	☐ Don't know				
14. Was [PATIENT]'s asthma worse during or after					
☐ Yes – during	☐ No				
☐ Yes — after	Don't know				
Yes – both					
15. [Use the space to ask about asthma at school	– if applicable				
	approace,				
16. I'd be interested to hear if there were any otl	her things that you think may have made				
[PATIENT]'s asthma worse.	So that you think may have made				

17. W	ere any allergies confirmed by	an allergy spe	cialist in hospit	al, a GP or by a	practice nurse?		
Yes Don't know							
If yes,							
17.1 Who confirmed the allergy? (allergy specialist in hospital, a GP or a practice nurse)							
	17.1 Who committee the anergy: (anergy specialist in hospital, a Gr of a practice hurse)						
10 Di	d [DATIENT] think thou had an	. allawaisa +ha+	thay falt ware				
18. DI	d [PATIENT] think they had any		-	never address	ear		
		0	Don't know				
	If yes,						
	18.1 What were these allergi	es?					
19. Di	d [PATIENT] have an adrenalin	e injection for	emergency use	? (eg Epipen, Jo	ext, Anapen)		
	Yes No	☐ Don't k	now				
	If yes,						
	19.1 Did they use it just before	re they died?	Yes	□No	Don't know		
		o and, and an					
20 Di	d any of [PATIENT]'s family (eg	narents hrot	har sistars chil	dren) have:			
a.		Yes	No	· —	t know		
b.	Eczema	Yes	□ No		t know		
_		=	=	=			
C.	Hay fever	∐ Yes	∐ No	=	t know		
d.	• ,	Yes	∐ No	∐ Don′	t know		
	sneezy nose all year around)						
e.	O .	Yes	No	Don'	t know		
	(eg nuts, fish, dairy)						
a.	Drug allergies	Yes	☐ No	☐ Don'	t know		
	(eg aspirin, ibuprofen)	Yes	☐ No	☐ Don'	t know		
f.	Anaphylaxis	Yes	☐ No	Don'	t know		
g.	Other allergies, specify	Yes	☐ No	☐ Don'	t know		
	(eg animals, dust, latex)						
	(19						
SECTIO	ON 2: ADDITIONAL NOTES						
SECTIO	DN 2. ADDITIONAL NOTES						

SECTION 3: ABOUT THE PATIENT'S HOUSEHOLD AND LIVING ENVIRONMENT
READ: The following questions are about [PATIENT]'s household and living environment.
21. Were there any indoor pets (such as dogs, cats, hamsters, birds or other feathered or furry pets)
that were kept inside [PATIENT]'s home?
Yes No Don't know
22. Was the place where [PATIENT] was living prior to death noticeably damp?
☐ Yes ☐ No ☐ Don't know
23. Did [PATIENT] ever smoke?
Yes, smoker No Don't know Ex-smoker (stopped in last 12 months)
Ex-smoker (stopped more than 12 months ago)
24. Was [PATIENT] exposed to cigarette smoke at all, for example at home or work?
Exposed to tobacco smoke in the home Exposed to tobacco smoke at work
☐ Don't know
25. Did a health professional ever advise [PATIENT] to change things in the home, at school or at
work to improve their asthma? ie carpets, stop smoking indoors etc
☐ Yes ☐ No ☐ Don't know
If yes,
25.1 Please explain what these changes were:
SECTION 3: ADDITIONAL NOTES

SECTION 4: HOW ASTHMA IMPACTED ON LIFE
[NOTE FOR INTERVIEWER] KEY INFORMATION REQUIRED FROM THIS SECTION: - How asthma impacted on life, eg did it stop them from going to school/work, sleeping?
READ: Thank you. I would now like to ask you some questions on how asthma affected [PATIENT]'s life 26. In their last 12 months, were there times when the asthma stopped [PATIENT] from sleeping through the night? Yes If yes, 26.1 How regularly did this happen Don't know
27. In their last 12 months, were there times when the asthma stopped [PATIENT] from (going to school/going to work/undertaking normal activities)? (as applicable) Yes If yes, 27.1 How often? Don't know
28. Looking back over their last 12 months, how would you describe the overall control of asthma? Well controlled Fairly well controlled Poorly controlled Don't know
29. In their last month, did [PATIENT] have asthma symptoms: Every day Most days Some days No days Don't know
30. In their <u>last month</u> , how many days did [PATIENT]'s asthma stop [HIM/HER] (going to school/going to work/undertaking normal activities)? Every day Most days Some days No days Don't know
31. In their last month, how many nights did [PATIENT'S] asthma stop [HIM/HER] sleeping through the night? Every night Most nights Some nights No nights Don't know
32. In their <u>last month</u> , did [PATIENT] need to use [HIS/HER] asthma reliever inhaler (this is normally blue): Every day Most days Some days No days Don't know N/A - DIDN'T HAVE AN INHALER
33. Looking back over the last month, how would you describe the overall control of [HIS/HER] asthma? Well controlled Fairly well controlled Poorly controlled Don't know
SECTION 4: ADDITIONAL NOTES

SECTION 5: ASTHMA CARE AND MANAGEMENT					
READ: Thank you. I'm now going to ask you some questions about the care [PATIENT] received for [HIS/HER] asthma and about how [HE/SHE] managed [HIS/HER] asthma. For example, we will talk about inhalers and medications used.					
34. Had [PATIENT] been treated for an episode/attack at hospital or at the GP in the past? Yes Don't know If yes,					
34.1 Did a health professional ever talk with [PATIENT or YOU] about how to control [HIS/HER] asthma to prevent serious episodes or attacks and hospital admissions in the future?					
Yes No Don't know					
35. Did [PATIENT or YOU] know how to recognise the early signs or symptoms of an asthma attack? Yes Don't know If yes,					
35.1 Who taught [PATIENT] these? (tick all that apply)					
Self-taught Hospital doctor Don't know Hospital nurse Other, please detail Practice nurse Parent					
36. Did [PATIENT or YOU] know what to do when [HE/SHE] had early signs or symptoms of an asthma attack? Yes Don't know If yes, 36.1 Who taught [PATIENT] what to do during an asthma attack? (tick all that apply) Self-taught Hospital doctor Don't know					
GP Hospital nurse Other, please detail Practice nurse Parent					
READ: An asthma self-management plan or personal asthma action plan is usually a printed leaflet or form that tells you how to recognise a worsening of your asthma, when to change the amount or type of medicine (inhalers) taken, when to call the doctor for advice, and when to go to the emergency department or urgent care centre or call 999.					
37. Did [PATIENT] have a written asthma self-management plan/asthma action plan?					
☐ Yes [GO TO 37.1] ☐ No [GO TO Q38] ☐ Don't know [GO TO Q38] If yes,					
37.1 Did it explain which medication to use? Yes No Don't know					
37.2 Did it explain how to know when the asthma was getting worse? Yes Don't know					
37.3 Did it explain when to ask for medical help? Yes Don't know					
37.4 Did [PATIENT or YOU] find the plan useful/helpful?					

				Yes		No	☐ Do	n't know
	3	37.5	_	ATIENT or YO	U] recei	ve enough in	formation/tra	ining on the plan and how to
			use it?	Yes		No		on't know
				res		NO		THE KITOW
38.	How	many	times p	er week, on	average,	did [PATIEN]	T] use their 're	eliever' or 'rescue' inhalers?
		-				be red if on 'S	Symbico <u>rt</u> SMA	ART regime')
						Don't know	∐ NA	A – not on inhalers
39.					_		ore than 2 or 3	times a week could indicate
	_	conτι ′es	roi and ir	ncreased risk	or an at		t know	NA – not on inhalers
	ш.							
40	Thinl	ving a	hout the	medicines t	hat [DAT	TENT1 took in	the week he	fore they died, please say yes
40.		_		ving that the		izivi j took iii	tile week be	iore they died, please say yes
		Aspirir				Yes	☐ No	Don't know
			painkille matory t	rs or anti-		Yes	No	Don't know
			ofen, ibu					
				ontaining a pa	ainkiller	Yes	☐ No	☐ Don't know
	-	•	n, ibupro ar preven	fen) ter inhalers (usually	Yes	□No	☐ Don't know
		_	twice dai	-	asaany		NO	Don't know
41.	(a) D	oid [P	ATIENT]	take any med	dication	for other con	ditions?	
		Yes	5	☐ No		Don't knov	v	
41.	(b) [Did [P	ATIENT]	have a home	e nebulis	er?		
	[Ye	S	☐ No		Don't knov	V	
41.	If yes		ften did	they use the	ir home	nebuliser?		
	[Da		Weekly	_	Monthly	Never	Don't know
REA	AD: A I	peak i	flow met	er is a device	that me	asures how m	nuch air you co	an blow out of your lungs
42.	Did [PATIE		e a peak flow	meter a		_	
43.	∐ Y	'es		∐ No [GO 1	ΓΟ 45]		Don't know	[GO TO 45]
44.			NT] mea	·	eak flow	during the fi	_	
	∐ Y	'es		∐ No		Don't know	∐ Didi	n't have a peak flow meter
45.	Did a	doct	or or oth	er healthcar	e profes		=) how to use a peak flow
	mete	er?	Yes		No	Don	't know	

46.	Had [PATIE	ENT or YOU] ever been told by a healthcare professional about how serious asthma	is	
	and that at	t worse you can die because of it?		
	Yes	☐ No ☐ Don't know		
47.	Do you fee	el that [PATIENT or YOU] understood how to manage their asthma?		
	Yes	☐ No ☐ Don't know		
48.	shortness o	did [PATIENT] have asthma symptoms? (symptoms may include cough, wheeze or of breath) MPTOMS ON MOST DAYS		
	SYI	MPTOMS SEVERAL TIMES A WEEK MPTOMS SEVERAL TIMES MONTH D SYMPTOMS DN'T KNOW		
49.	Was [PATII	ENT] made aware of how well their asthma should be controlled?		
	Ye	es No Don't know		
	If yes,			
	46.1 W	Vhat were they told?		
	Did [DATIE	The table of an arthur and in the 42 weather before full (upple death)		
50.		INT] attend an asthma review in the 12 months before [HIS/HER] death? IS [GO TO 50.1]		
	If yes,			
	50.1	Who was this with?		
		☐ GP ☐ Hospital doctor ☐ Don't know		
		Practice nurse Hospital nurse Other, please detail		
	50.2	Did the review include a discussion about the asthma medicines? No Don't know		
		Yes Don't know		
	50.3	Did the review include a check of inhaler technique?		
		Yes No Don't know		
		If yes,		
		50.3.1 Was [PATIENT] shown how to use it?		
		Yes Don't know 50.3.2 Did [PATIENT] show the doctor or nurse how they use it?		
		Yes No Don't know		
	50.4	Was the review, in your opinion: Very helpful Unhelpful		
		Fairly helpful Neither helpful or unhelpful		
51. We know that people find it difficult sometimes to attend asthma appointments and we are				
	interested to know what stops people from attending. If [PATIENT] was unable to attend an			
	appointment, what do you think the reasons for this might be?			
	i.			

	ii.
	iii.
52.	One of the aims of the NRAD project is to improve care. We would be grateful if you could take some time to think and give me three examples of good care and three examples of where you think care could have been improved? Three examples of good care: i.
	ii.
	iii.
	Three examples of where you think care could have been improved: i.
	ii.
	iii.
SEC	TION 5: ADDITIONAL NOTES

SECTION 6: FINAL COMMENTS AND CLOSE OF INTERVIEW
Read: Thank you. Before we end the interview, I would like to give you the opportunity to tell us
anything else about [PATIENT]'s asthma that you think is important.
In particular, is there anything that you think is an important learning point for health professionals or
others in your position?
Thank you so much for your time in answering these questions. The information you have provided,
together with information from other interviews, will be used to write a final report, of which we
will send you a copy.
will selle you a copy.
Your information is confidential and the report will not identify you in any way.
Your information is confidential and the report will not identify you in any way.
We hope that sharing the information from these interviews will enable us to improve care and
support for others in the future.
Are you still happy for the information you have given me today to be used in our report?
☐ Yes ☐ No
Thank you. I understand that talking with me today about this may have been difficult. If you would
like to talk to an asthma nurse specialist at Asthma UK or someone from a bereavement support
charity, I have contact details for you. Is this something you'd be interested in?
Yes (Provide relevant information using the following options):
Offer a call back from an Asthma UK Advice Line Nurse Specialist (Provide AUK advice line details so they say adl when it is convenient for them)
(Provide AUK advice line details so they can call when it is convenient for them)
0800 121 6244 and <u>www.asthma.org.uk</u>
Signpost to CRUSE Bereavement Care or to the Child Bereavement UK (as applicable)
CRUSE: 0844 477 9400 and <u>www.cruse.org.uk</u>
CB UK: 01494 568900 and www.childbereavement.org.uk
No (Thank interviewee and terminate the interview)

After the interview Do you, the interviewer, have any concerns regarding the wellbeing of the interviewee? (ie has the interview affected the interviewee and they may need post-interview support etc) Yes Provide relevant information below and follow safeguarding procedure flowchart | No Do you, the interviewer, have any concerns regarding safeguarding of children or vulnerable adults related to the deceased? (ie related or unrelated to asthma, eg withholding medication/overmedicating, physical abuse or neglect) Yes – Provide relevant information below and follow safeguarding procedure flowchart Do you, the interviewer, have any concerns regarding the safeguarding of other children? (ie related or unrelated to asthma, eq withholding medication/overmedicating, physical abuse or neglect) Yes – Provide relevant information below and follow safeguarding procedure flowchart No Has the interview affected you as the interviewer? Yes – Please debrief with your assigned 'interview buddy' Flow chart to support safeguarding disclosures or concerns during an NRAD call INTERVIEW CONDUCTED Disclosure* of abuse of the child/adult at Concerns* involving abuse of the child/adult at risk who died and/or other child/adult at risk risk who died and/or other child/adult at Listen, assure and record (as per guidance in section 2, below) Signpost interviewee to appropriate services (as per guidance in section 3, below) 1 End call Asthma UK interviewer to inform NRAD of any safeguarding disclosure/concerns and the procedures to be followed

*NB. A safeguarding disclosure or concern can be related or unrelated to asthma, e.g. withholding medication/over medicating, physical abuse or neglect etc.

SO to speak with Hackney safeguarding board for advice

If appropriate, SO to refer disclosure/concern to interviewee's local safeguarding board

Asthma UK interviewer Report to Safeguarding Officer (SO) at Asthma UK