Review question	Aim of question	Association for Young People's Health. Young people's views on involvement and feedback in healthcare 2014	Care Quality Commission. Children and young people's inpatient and day case survey 2018	Child Outcomes Research Consortium. Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011-2015	Health and Social Care Information Centre. Children's Dental Health Survey 2013. (Country specific report for England, published 2015)	HM Inspectorate of Prisons. Children in Custody 2016- 2017.	Opinion Matters. Declare your care survey 2018.	National Children's Bureau. Listening to children's views on health provision 2012	Picker Institute. Children and Young People's Patient Experience Survey 2018.	Picker Institute. Paediatric Emergency Department Survey 2015 and Children and Young People's Outpatient Survey 2015	Picker Institute/ NHS England / BLISS. Neonatal Survey 2014	Word of Mouth Research and Point of Care Foundation. An options appraisal for obtaining feedback on the experiences of children and young people with cancer 2018
		SURVEY	SURVEY	SURVEY	SURVEY	SURVEY	SURVEY	SURVEY	SURVEY	SURVEY	SURVEY	SURVEY
		OVERVIEW	OVERVIEW	OVERVIEW	OVERVIEW	OVERVIEW	OVERVIEW	OVERVIEW	OVERVIEW	OVERVIEW	OVERVIEW	OVERVIEW
		- An on-line	- Third national	- Data related to	- A survey carried	- An analysis of	- A survey carried	- This review	- A survey of	- The emergency	- A survey of	- A report of a
		survey of young	survey sent to	outcomes and	out every 10	12-18 year olds	out in England in	comprised a	views from	department	parents'	study to explore
		people	children and	experiences of	years since 1973	perceptions of	November to	literature review	children, young	survey was	experiences of	different
		undertaken by the Association	young people, and their parent	children and young people (0-	to provide information on	their experiences in secure training	December 2018 on behalf of the	(not analysed here) and views	people and their parents or carers	conducted in 5 NHS trusts in	neonatal care - Surveyed	methods of obtaining
		for Young	or carer	25 years) seen	the dental health	centres and	CQC (by the	of children and	in England during	2015; 650	parents from 88	feedback relating
		People's Health	- Children and	across 75 mental	of children	young offender	organisation	young people	hospital visits,	parents (of	hospital neonatal	to the
		(AYPH), for the	young people	health services in	- Includes	institutes	'Opinion	from 46	conducted by	children aged 0-	units in 2 waves:	experiences of
		Children and	aged 15 days to	England taking	questions on	An independent	Matters')	consultations	Picker Institute.	16) responded	Wave 1: babies	children and
		Young People's	15 years,	part in the	access to dental	report	- Focus of the	conducted with	Data from this	and 387 children	discharged from	young people
		Health Outcomes	admitted to	service	treatment	commissioned by	survey was on	children and	survey feeds in	aged 8-16	neonatal care	with cancer
		Forum (an	hospital as an	transformation	services,	the Youth Justice	reporting	young people by	the CQC report	responded.	between October	- Commissioned
		independent	inpatient	'Children and	perceptions of	Board. Includes	concerns relating	a number of	but is included	- The outpatient	2013 and March	by NHS England
		advisory group of	(planned or as an	Young People's	care and anxiety	surveys of	to care	organisations	here because the	survey was	2014	to fulfil need of
		professionals and	emergency) or as	Improving Access	about treatment	detained children	- Respondents	across England	Picker summary	conducted in 9	Wave 2: babies	national cancer
		representatives from the	a day case - Questionnaire	to Psychological Therapies' (CYP	which were included in this	(under 18 years) at secure training	were 2,002 people in	(analysed below) - Children and	contains some details not	trusts in 2015; - 1,039 parents	discharged from neonatal care	strategy to collect patient
		children's sector)	completed solely	IAPT) from April	analysis	centres (n=3) and	England who	young people	reported in the	(of children aged	between April	experience data
		- The aim of the	by the	2011 to June	- Children aged 5,	young offender	have had some	were defined as	CQC version.	0-16) responded	2014 and	for under 16s
		survey was to	parent/carer of	2015	8, 12 and 15	institutes (n= 5)	sort of health	those up to the	000 101010111	and 916 children	September 2014	- Study had 3
		collect young	children aged 0-7	- 96, 325 case	years were	and a specialist	service (NHS and	age of 18, or 25		aged 8-16	- A sample of	parts: a literature
		people's views	years; children	records,	sampled to take	unit site (n=1)	private care) or	in the case of		responded.	100 consecutive	review;
		on how they like	aged 8-11 or 12-	representing	part in the	within one of the	social care	young people		- Only children's	parents (aged 16	interviews with
		to be involved in	15 received a	91,502 children	survey, which	young offender	experience in the	with a disability,		responses were	or over) per	healthcare
		service	questionnaire of	and young	was conducted in	institutes. The	last 5 years,	a long term		analysed for both	neonatal unit (in	professionals;
		development or	two halves, one	people, mean	conjunction with	questionnaires	either as a	health problem,		surveys	each wave)	interviews with
		improvement,	for themselves to	age = 12 years;	a dental	included a	patient or a carer	care leavers and			whose baby (or	children and
		and how they feel about giving	complete, and one for their	52% female; 82% white; 155 young	examination - Children	section on healthcare.	- Data was split into age groups,	young people in custody. Where			babies) has received	young people, parents and
		feedback or	parent/carer	people (0.2%)	undergoing the	- 720 surveys	and included 128	possible,			neonatal care for	carers (the
		making	- Sampled 129	aged 20 or over	dental	were completed	12-15 year olds,	responses only			more than 24	analysis below
		complaints	NHS acute trusts	and 3,213 (3.3%)	examination	(response rate of	whose results are	from children			hours and who	only relates to
		- 98 respondents	- 33, 170	aged 0-4 years;	aged 12 or 15	85%).	analysed here.	and young			had been	the interviews
		were as follows:	questionnaires	remainder aged	were asked to	-In STCs 91%		people under 18			discharged home	with children and
		10-14 years old,	were competed	5-19 years	complete a	were boys, and		are included in			- 15,944 eligible	young people)
		n= 15; 15-19	(response rate of	(96.65%)	questionnaire	36% were under		the analysis			parents were	- 13 children and
		years old, n= 52;	25%)	- Experience of	and 99.6%	16					sent a	young people
		20-24 years old,		service	completed it.	- in YOIs 100%					questionnaire.	who had
		n=31. 69 were female; 37 had		questionnaire	- Parents of all children	were boys and 6% were under					Responses were received from	received cancer
		long-term		(ESQ) used to explore	undergoing a	16 were under					6000 parents,	treatment aged 7 to 17 years took
		conditions.		satisfaction with	dental	10					(response rate of	part (3 were
		331141111131		services.	examination						37.6%)	under 11 years

		- Where possible analysis was based on the 10- 19 year olds only		3,196 ESQs were completed by children (mean age 13.8 years) and 2,698 ESQs were completed by parents (mean age 11.1 years). Only children's reports are analysed here.	were also invited to complete a questionnaire, and 43% completed it Exact numbers of included children or parents differ for each question but results from approximately 700 parents of 5 year olds 600 parents of 8 year olds, 1,400 12 year olds, and 1,300 15 year olds were included						- Results for individual questions were converted into scores on a scale of 1 to 100, with 100 representing the best possible outcome (the scores are not percentages)	and 10 Young people aged 13 to 17) Interviews were conducted in small groups or individually over the phone
RQ 1.1 How do children and young people, and the parents and carers of babies and young children, prefer to be involved and support in planning their healthcare and making informed, shared decisions about their health?	The aim of this review is to establish how children and young people, and the parents and carers of babies and young people, prefer to be involved in planning their own healthcare and making informed, shared decisions about their health.	No relevant findings were identified for this question	INVOLVEMENT IN CARE: - 46% 8-15 year olds felt very involved in their care; 15% said they had not been involved -74% parents of 0-7 year olds said they were given enough information to be involved in decisions about their child's care	No relevant findings were identified for this question	No relevant findings were identified for this question	No relevant the findings were identified for this question	No relevant findings were identified for this question	INVOLVEMENT IN DECISIONS ABOUT CARE: - Disabled young people aged 15 to 21 recommended that consultations with all health professionals must place the young person at the centre. Every effort should be made to enable children to make a contribution to the consultation and any decisions made should take into account any preferences expressed by the young person.	No relevant findings were identified for this question	INVOLVEMENT IN CARE (OUTPATIENTS): - 55% children and young people aged 8-16 (for whom it was needed) said they did not have a say in what would happen to them in hospital	INVOLVEMENT IN DECISIONS ABOUT BABY'S CARE: - Did the neonatal staff include you in discussions about your baby's care and treatment? Score = 78 - Were you told about changes in your baby's condition or care? Score = 89 - When a ward round was taking place, were you allowed to be present when your baby was being discussed? Score = 80	INVOLVEMENT IN DECISIONS ABOUT CARE: - 3 Young people aged 13 to 17 reported that the presumption that children and young people with cancer would be especially concerned to ensure that they were fully involved in all aspects of their treatment and care was not so clear cut. 2 said that they had been too ill to even consider the notion of wanting control over decision making. Instead, they reported that they had been very willing to entrust all matters to do with their medical condition to their parents and the medical staff.

												- 7 other Young people aged 13 to 17 took a different view and very keen that the views and wishes of young people like themselves should be sought and acted upon.
												Quotes: 'To be honest, I was so out of it, physically and things, really sick all the time, that I wasn't thinking like that I just went with what they (parents/medical staff) decided' (M17)
												'It was really important to me that I was involved fully in the decisions about treatment. I was made very aware of everything that was going on. At the end of the day it's your body, your life and once you reach a certain age you should be able to make decisions for
RQ 1.2 'How should healthcare staff communicate with babies, children and young people, and the parents or carers of babies and young children?'	The aim of this review is to identify the best way for healthcare staff to communicate with babies, children and young people, and the parents or carer of babies	No relevant findings were identified for this question	HOSPITAL STAFF: - 87% 12-15 year olds said staff talked to them about their care; for 8-11 year olds this was 83% UNDERSTANDIN G:	LISTENING: - 84.6% children and young people said they were listened to - 70.8% said the staff were easy to talk to	No relevant findings were identified for this question	No relevant the findings were identified for this question	No relevant findings were identified for this question	COMMUNICATIO N BY DOCTORS: - Children and young people aged 12-19 years reported 'doctors don't explain things and they speak to your parents, the	No relevant findings were identified for this question	UNDERSTANDIN G (EMERGENCY DEPARTMENT): - 70% children and young people aged 8-16 said doctors and nurses explained what was wrong in a way they could understand	COMMUNICATIO N WITH STAFF ON NEONATAL UNIT: - When you visited the unit did the staff caring for your baby introduce themselves to you? Score = 79	yourself.' (M16) BEING INFORMED ABOUT TREATMENT: - Young people aged 13 to 17 reported a good experience of how the diagnosis and treatment plan

г		1			1		1			
	nd young		~70% children and			language they		- 27% children	- Were you told	was
ch	nildren.		young people			use is confusing'.		and young	which nurse was	communicated
			understood what					people said	responsible for	and discussed
			staff said			COMMUNICATIO		doctors and	your baby's care	with them and
						N WITH		nurses did not	each day he/she	none felt
			ASKING			DISABLED		talk to them	was in the	excluded from
		1	QUESTIONS:			YOUNG PEOPLE:		about their	neonatal unit?	this process. All
			- 95% 8-15 year			- Disabled young		questions or	Score = 90	felt that the
			olds felt able to			people aged 15-		worries	- Were you able	manner in which
			ask questions			21 recommended		Wornes	to talk to staff on	doctors had
			and 92% said			that there should		LISTENING	the unit about	spoken with
		1				be an NHS e-		(OUTPATIENTS):	your worries and	
			their questions						-	them (and with
			were answered.			learning module		- 76% children	concerns? Score	their parents at
						on		and young	= 88	the same time)
						communicating		people aged 8-16	- Were you able	had been
						with young		years thought	to speak to a	unproblematic.
						people with		they were	doctor about	None felt that
						learning		listened to by	your baby as	that medical staff
						difficulties and		hospital staff	much as you	had spoken
						communication			wanted? Score =	about them but
						impairments,			66	not to them, nor
						resources in			- Were the	that they were
						hospitals to			nurses on the	made to feel that
						address			unit sensitive to	their views were
						communication			your emotions	not important.
						with disabled			and feelings?	P
						young people,			Score = 85	Quotes:
						and systems for			- Were the	'When they were
						setting up			doctors on the	deciding the
						appointments			unit sensitive to	treatment, I felt I
						which would			your emotions	was fully
										involved. I was
						support			and feelings?	
						preparation for			Score = 83	always asked
						the consultation.			- Did staff refer	before they were
									to your baby by	doing anything.
									his/her first	They always had
									name? Score =	me and my
									90	parents there
										and they talked
										to us all,
										explaining it all
										to me and them.'
										(M16)
										'I've always been
										told that they
										would never do
										anything without
										talking to me
										first. They said
										I'm old enough
										to make my own
										decisions and I
										have been heard
										at all times. They
										have always
										talked to me and

my mum and dad
at the same time.
I've never felt
excluded.' (F13)
'Everything I
asked, I got an
answer to. I was
definitely
listened to. And
that was true the
whole way
through. With the surgeon, I
wanted to see
the CT scans and
she was fine
about it. At every
shift change the
nurse would
come in and
introduce themselves and
say, 'just push
the buzzer if you
want anything'.
The diagnosis
was as positive
as it can be. First
and foremost,
they were talking
to me. My mum was there too.
But it was at the
point where I
could make my
own decisions, so
they were talking
to me.' (M16)
'They listened to
me most of the
time and my
voice was heard.
There weren't
any times when I
was treated in ways that were
bad. I was
diagnosed and
the doctor
explained things
quite well. I felt
that they were
speaking to me.
They always asked me if I had

												any questions or needed anything. My oncologist would always ask me if I had any questions.' (F15)
RQ 1.3 'How should issues about consent, privacy and confidentiality be addressed with babies, children and young people?'	The aim of this review was to provide recommendation s for the NHS on the best way to ensure these rights are respected in the delivery of healthcare	No relevant findings were identified for this question	PRIVACY: - 80% 0-15 year olds reported they were always given enough privacy - 90% of 12-15 year olds were able to talk to a doctor or nurse without their parent or carer being there if they wanted to.	No relevant findings were identified for this question	No relevant findings were identified for this question	No relevant findings were identified for this question	No relevant findings were identified for this question	CONCERNS OF ETHNIC MINORITIES REGARDING MENTAL HEALTH SUPPORT: - A consultation with young people aged 12- 24 from a range of ethnic backgrounds and including some for whom English was a second language, refugees and asylum seekers, found that few mainstream public services were mentioned as sources of support by these young people, who were more likely to rely on family, social networks and community organisations. Influences on the decision to seek help (and from whom) were: • Knowing that confidentiality will be respected • Trust in the person • A good relationship • Feeling at ease, understood and feeling safe with that person.	No relevant findings were identified for this question	No relevant findings were identified for this question	PRIVACY FOR CONVERSATIONS: - Were you given enough privacy when discussing your baby's care on the neonatal unit with staff? Score = 84 PRIVACY FOR BREASTFEEDING: - Were you given enough privacy in the neonatal unit for expressing milk and/or breastfeeding your baby? Score = 88	No relevant findings were identified for this question
RQ 2.1 'How do children and young people,	The aim of this review is to determine how	No relevant findings were	INFORMATION AROUND SURGERY:	INFORMATION ABOUT MENTAL	No relevant findings were	No relevant findings were	LACK OF INFORMATION:	No relevant findings were	No relevant findings were	INFORMATION ABOUT	INFORMATION BEFORE BIRTH:	No relevant findings were

and the parents	children and	identified for this	- 93% of children	HEALTH HELP	identified for this	identified for this	- Of young	identified for this	identified for this	OUTPATIENT	- Before your	identified for this
or carers of	young people,	question	8 to 15 years old	AVAILABLE:	question	question	people who had	question	question	VISIT:	baby was born	question
babies and young	and the parents	question	said that staff	- 74.4% of	question	question	raised a concern	question	question	- 55% of children	did a member of	question
children, prefer	or carers of		explained pre-	children and			or made a			and young	staff from the	
to access	babies and young		operative	young people			complaint, in			people aged 8-16	neonatal unit	
healthcare	children, prefer		information	said they were			48% the subject			years did not	talk to you about	
information?'	to access		- 76% said that	given enough			had been lack of			know before	what to expect	
IIIIOIIIIatioii	healthcare						information			their visit to		
	information.		they were	explanation							after the birth?	
	information.		informed how	about the help			about a health			hospital what	Score = 54	
			the procedure	available			condition or			was going to		
			had gone				treatment			happen to them	INFORMATION	
			- 90% of parents				options not being			while they were	ABOUT THE	
			said staff				well explained.			there	NEONATAL	
			explained the								UNIT:	
			procedure in a								- Were you given	
			way they could								enough	
			understand								information	
											about the	
											neonatal unit	
											(such as rules,	
											procedures,	
											facilities for	
											parents)? Score =	
											76	
											- Was the	
											purpose of the	
											machines,	
											monitors and	
											alarms used in	
											the neonatal unit	
											clearly explained	
											to you? Score =	
											73	
											- Were infection	
											control practices	
											•	
											explained to you, such as hand	
											washing and	
											procedures for	
											visitors? Score =	
											85	
											INFORMATION	
											ABOUT YOUR	
											BABY:	
											- If you asked	
											questions about	
											your baby's	
											condition and	
											treatment, did	
											you get answers	
											you could	
											understand?	
											Score = 88	
											- Were you given	
											enough written	
											information to	
	1				1					1	ן וווטווומנוטוו נט	1

RQ 2.2 'What are the best ways to help children and	review is to determine the	No relevant findings were identified for this	No relevant findings were identified for this	No relevant findings were identified for this	No relevant findings were identified for this	No relevant findings were identified for this	No relevant findings were identified for this	No relevant findings were identified for this	No relevant findings were identified for this	No relevant findings were identified for this	help you understand your baby's condition and treatment? Score = 53 INFORMATION ABOUT OTHER SUPPORT: - Were you given enough information about help you could get with expenses related to your baby's stay in the neonatal unit (such as travelling/ parking expenses, hardship fund or food vouchers)? Score = 41 - Did staff give you any information about parent support groups such as Bliss or other local groups? Score = 53 No relevant findings were identified for this	No relevant findings were identified for this
the best ways to help children and young people and the parents and carers of babies and young children understand the risks and benefits of healthcare decisions?'	review is to determine the best way to help children and young people and the parents and carers of babies and young children understand the risks and benefits of healthcare decisions.	findings were identified for this question	findings were identified for this question	findings were identified for this question	No relevant findings were identified for this question	findings were identified for this question						
RQ 3.1 'How do children and young people want their parents or carers to be involved in their care and	The aim of this review is to establish how children and young people, and the parents and carers of babies and young	No relevant findings were identified for this question	HANDOVER OF CARE FOR ADOLESCENT DISABLED YOUNG PEOPLE: - Disabled young people aged 15- 21 recommended	No relevant findings were identified for this question	No relevant findings were identified for this question	No relevant findings were identified for this question	AGE DIFFERENCE IN RELATION TO PARENTAL INVOLVEMENT: - 1 teenager reported that she would have felt differently about					

al a state or a laborate								41-441				h
decisions about	people, want							that as the young				her parents'
their care?	their parents or							person reaches				involvement
	carers to be							adolescence, the				when she was
	involved in their							clinician should				younger.
	care and							explore with the				
	decisions about							family the formal				Quotes:
	their care.							handing over to				'I think it's really
								the young person				important that
								of their own				you can influence
								diagnosis.				things that affect
												your care,
												because some
												things affect you
												but not others. I
												think it's
												important to
												take into
												consideration
												what each
												person wants. I
												feel that maybe
												if I'd been
												younger I would
												have preferred
												my parents to
												talk to me (about
												the diagnosis),
												rather than some
												1 1 1 1 1 1 1 1
												doctor I didn't
												doctor I didn't know.' (F15)
												know.' (F15)
RQ 3.2 'How do	To establish how	No relevant	EMOTIONAL	VIEWS AND	No relevant	No relevant	LACK OF	BEING TAKEN	No relevant	No relevant	EMOTIONAL	know.' (F15) No relevant
RQ 3.2 'How do children and	To establish how children and	No relevant findings were	EMOTIONAL SUPPORT:	VIEWS AND WORRIES:	No relevant findings were	No relevant findings were	LACK OF RESPECT:	BEING TAKEN SERIOUSLY:	No relevant findings were	findings were	EMOTIONAL SUPPORT:	know.' (F15) No relevant findings were
children and	children and		I			I .	RESPECT:	1				know.' (F15) No relevant
children and young people	children and young people	findings were identified for this	SUPPORT: - 92% of 8-15	WORRIES: - 84.1% of	findings were identified for this	findings were identified for this	RESPECT: - Of young	SERIOUSLY: - Children and	findings were identified for this	findings were identified for this	SUPPORT: - Were you	know.' (F15) No relevant findings were identified for this
children and young people want healthcare	children and young people want healthcare	findings were	SUPPORT: - 92% of 8-15 year olds who	WORRIES: - 84.1% of children and	findings were	findings were	RESPECT: - Of young people who had	SERIOUSLY: - Children and young people	findings were	findings were	SUPPORT: - Were you offered	know.' (F15) No relevant findings were
children and young people want healthcare staff to support	children and young people want healthcare staff to support	findings were identified for this	SUPPORT: - 92% of 8-15 year olds who had worries said	WORRIES: - 84.1% of children and young people	findings were identified for this	findings were identified for this	RESPECT: - Of young people who had raised a concern	SERIOUSLY: - Children and young people aged 12 to 19	findings were identified for this	findings were identified for this	SUPPORT: - Were you offered emotional	know.' (F15) No relevant findings were identified for this
children and young people want healthcare	children and young people want healthcare staff to support them to be	findings were identified for this	SUPPORT: - 92% of 8-15 year olds who had worries said that staff talked	worries: - 84.1% of children and young people said their views	findings were identified for this	findings were identified for this	RESPECT: - Of young people who had raised a concern or made a	SERIOUSLY: - Children and young people aged 12 to 19 reported that	findings were identified for this	findings were identified for this	SUPPORT: - Were you offered emotional support or	know.' (F15) No relevant findings were identified for this
children and young people want healthcare staff to support	children and young people want healthcare staff to support them to be involved in, and	findings were identified for this	SUPPORT: - 92% of 8-15 year olds who had worries said that staff talked with them about	worries - 84.1% of children and young people said their views and worries were	findings were identified for this	findings were identified for this	RESPECT: - Of young people who had raised a concern or made a complaint, in	SERIOUSLY: - Children and young people aged 12 to 19 reported that 'Staff don't	findings were identified for this	findings were identified for this	SUPPORT: - Were you offered emotional support or counselling	know.' (F15) No relevant findings were identified for this
children and young people want healthcare staff to support	children and young people want healthcare staff to support them to be involved in, and making decisions	findings were identified for this	SUPPORT: - 92% of 8-15 year olds who had worries said that staff talked	worries: - 84.1% of children and young people said their views	findings were identified for this	findings were identified for this	RESPECT: - Of young people who had raised a concern or made a complaint, in 65% the subject	SERIOUSLY: - Children and young people aged 12 to 19 reported that 'Staff don't always take you	findings were identified for this	findings were identified for this	SUPPORT: - Were you offered emotional support or counselling services from	know.' (F15) No relevant findings were identified for this
children and young people want healthcare staff to support	children and young people want healthcare staff to support them to be involved in, and making decisions about, their own	findings were identified for this	SUPPORT: - 92% of 8-15 year olds who had worries said that staff talked with them about	worries - 84.1% of children and young people said their views and worries were	findings were identified for this	findings were identified for this	RESPECT: - Of young people who had raised a concern or made a complaint, in 65% the subject had been lack of	SERIOUSLY: - Children and young people aged 12 to 19 reported that 'Staff don't always take you seriously or pay	findings were identified for this	findings were identified for this	SUPPORT: - Were you offered emotional support or counselling services from neonatal unit	know.' (F15) No relevant findings were identified for this
children and young people want healthcare staff to support	children and young people want healthcare staff to support them to be involved in, and making decisions	findings were identified for this	SUPPORT: - 92% of 8-15 year olds who had worries said that staff talked with them about	worries - 84.1% of children and young people said their views and worries were	findings were identified for this	findings were identified for this	RESPECT: - Of young people who had raised a concern or made a complaint, in 65% the subject had been lack of respect from	SERIOUSLY: - Children and young people aged 12 to 19 reported that 'Staff don't always take you seriously or pay attention to you'	findings were identified for this	findings were identified for this	SUPPORT: - Were you offered emotional support or counselling services from	know.' (F15) No relevant findings were identified for this
children and young people want healthcare staff to support	children and young people want healthcare staff to support them to be involved in, and making decisions about, their own	findings were identified for this	SUPPORT: - 92% of 8-15 year olds who had worries said that staff talked with them about	worries - 84.1% of children and young people said their views and worries were	findings were identified for this	findings were identified for this	RESPECT: - Of young people who had raised a concern or made a complaint, in 65% the subject had been lack of respect from staff or poor	SERIOUSLY: - Children and young people aged 12 to 19 reported that 'Staff don't always take you seriously or pay attention to you' and 'It's scary	findings were identified for this	findings were identified for this	SUPPORT: - Were you offered emotional support or counselling services from neonatal unit staff? Score = 57	know.' (F15) No relevant findings were identified for this
children and young people want healthcare staff to support	children and young people want healthcare staff to support them to be involved in, and making decisions about, their own	findings were identified for this	SUPPORT: - 92% of 8-15 year olds who had worries said that staff talked with them about	worries - 84.1% of children and young people said their views and worries were	findings were identified for this	findings were identified for this	RESPECT: - Of young people who had raised a concern or made a complaint, in 65% the subject had been lack of respect from	SERIOUSLY: - Children and young people aged 12 to 19 reported that 'Staff don't always take you seriously or pay attention to you'	findings were identified for this	findings were identified for this	SUPPORT: - Were you offered emotional support or counselling services from neonatal unit	know.' (F15) No relevant findings were identified for this
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children and young people want healthcare staff to support	children and young people want healthcare staff to support them to be involved in, and making decisions about, their own	findings were identified for this	SUPPORT: - 92% of 8-15 year olds who had worries said that staff talked with them about	worries - 84.1% of children and young people said their views and worries were	findings were identified for this	findings were identified for this	RESPECT: - Of young people who had raised a concern or made a complaint, in 65% the subject had been lack of respect from staff or poor	SERIOUSLY: - Children and young people aged 12 to 19 reported that 'Staff don't always take you seriously or pay attention to you' and 'It's scary [going into hospital] because you don't know	findings were identified for this	findings were identified for this	SUPPORT: - Were you offered emotional support or counselling services from neonatal unit staff? Score = 57 TRUST: -Overall, did you have confidence	know.' (F15) No relevant findings were identified for this
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children and young people want healthcare staff to support	children and young people want healthcare staff to support them to be involved in, and making decisions about, their own	findings were identified for this	SUPPORT: - 92% of 8-15 year olds who had worries said that staff talked with them about	worries - 84.1% of children and young people said their views and worries were	findings were identified for this	findings were identified for this	RESPECT: - Of young people who had raised a concern or made a complaint, in 65% the subject had been lack of respect from staff or poor	SERIOUSLY: - Children and young people aged 12 to 19 reported that 'Staff don't always take you seriously or pay attention to you' and 'It's scary [going into hospital] because you don't know what's going to happen'	findings were identified for this	findings were identified for this	SUPPORT: - Were you offered emotional support or counselling services from neonatal unit staff? Score = 57 TRUST: -Overall, did you have confidence and trust in the staff caring for	know.' (F15) No relevant findings were identified for this
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DRAFT FOR CONSULTATION
Grey literature mapping to questions

those with long-term conditions should include a focus on the extent to which they are fostering self-care and care and	
term conditions should include a focus on the extent to which they are fostering self- care and	
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extent to which they are fostering self- care and	
which they are fostering self-care and	
fostering self-care and	
fostering self-care and	
care and	
care and	
independence,	
and that	
protocols for the	
safe	
management of	
medicine	
maximise young	
people's	
independence	
and control	
around self-	
medication.	
MENTAL HEALTH	
SERVICES FOR	
YOUNG PEOPLE:	
- Young people	
- Tourig people	
aged 16-25	
consulted about	
mental health	
professionals had	
mixed views and	
said:	
'Last time I went	
to	
counsellingshe	
Courseilingsite	
judged me. She	
judged me from	
every angle, you	
don't know	
nothing, you're	
this you're that,	
it's your fault'	
'If you have mild	
a bad mantal	
or bad mental	
health problems,	
they are there to	
help you, to	
give you a name	
for what you	
have got as	
well as for	
whatever is going	
whatever is going on '	
whatever is going on.'	
whatever is going on.'	
on.'	
on.' 'You can speak to	
on.'	

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RQ 3.3 'How can	This review aims	No relevant	No relevant	No relevant	No relevant	No relevant	No relevant	like talk to them and tell them things that you haven't told no one else, and it's all confidential isn't it, and you know it's not going out of that room.' 'I was sitting in this little room and it was like it's all my fault, like I was the naughty one.'	No relevant	No relevant	No relevant	No relevant
children and young people be empowered to advocate for themselves?'	to establish how children and young people want their parents and carers of babies and young people, to be empowered to advocate for themselves.	findings were identified for this question	findings were identified for this question	findings were identified for this question	findings were identified for this question	findings were identified for this question	findings were identified for this question	findings were identified for this question	findings were identified for this question	findings were identified for this question	findings were identified for this question	findings were identified for this question
RQ 3.4 'How can the views of babies, children and young people be best represented by independent advocates?'	The aim of this review is to determine how children and young people can be best represented by independent advocates. This may include ease of accessing independent advocacy services, and how the services can be helpful, supportive and useful.	No relevant findings were identified for this question	No relevant findings were identified for this question	No relevant findings were identified for this question	No relevant findings were identified for this question	No relevant findings were identified for this question	ENCOURAGEME NT TO RAISE CONCERNS: - 19% of young people aged 12- to 15 reported that having an advocate or third party who could raise concerns, would encourage them to express concerns about healthcare.	No relevant findings were identified for this question	No relevant findings were identified for this question	No relevant findings were identified for this question	No relevant findings were identified for this question	No relevant findings were identified for this question
RQ 4.1a/b 'What factors are important to babies, children and young people to	To investigate which factors are important to babies, children and young people to	No relevant findings were identified for this question	FOOD AND DRINK: ~50% 8-15 year olds said they liked hospital food; in a sub-	No relevant findings were identified for this question	No relevant findings were identified for this question	No relevant findings were identified for this question	No relevant findings were identified for this question	FEEDING: - If you wanted to express breast milk for your baby, were you given the	FOOD: - Several Young people aged 13 to 17 discussed that the quality of food in			

	T	6 1 21	 		1			1 1
improve their	improve their	group of children					support you	hospital was a
experience of	experience of	who had had					needed from	major concern.
healthcare	healthcare	cancer in last 5					neonatal staff?	
services?'	services	years this was					Score = 86	Quotes:
		lower					- When you were	'The only
		-35% parents of 0					in the neonatal	problem (at
		to 7 year olds					unit, were you	hospital 1) was
		said they liked					given the feeding	the food. That
		hospital food					equipment you	was also the case
		- 17% of parents					needed for	in (hospital 2).
		of 0-15 year olds					expressing, such	But there, my
		said they did not					as breast pump	mum could buy
		have access to					and sterilisation	better food
		hot drink					equipment?	outside and bring
		facilities					Score = 87	it to me.' (M16)
		- 36% of parents					- If you wanted	,
		were unable to					to breastfeed	'In (hospital 1)
		prepare food in					your baby, were	the food was
		hospital					you given	dire. It was
		ospitai					enough support	micro-waved and
		PAIN:					to do this from	really hard, but I
		- 79% of children					neonatal staff?	didn't know what
		aged 8 to 15					Score = 84	to say. It's not
		years old who					= If you fed your	like they're going
		had pain felt that					baby formula	to change it
		staff did						
							milk, were you	overnight. In
		everything they					given enough	(hospital 2) the
		could to help					support to do	food was very
							this from	good.' (F15)
							neonatal staff?	
							Score = 85	
							4 DA 415 SI ON TO	
							ADMISSION TO	
							NEONATAL	
							CARE:	
							- After you gave	
							birth were you	
							offered a	
							photograph of	
							your baby? Score	
							= 63	
							- After you gave	
							birth, were you	
							ever cared for in	
							the same ward as	
							mothers who	
							had their baby	
							with them? Score	
							= 55	
							- After your baby	
							was admitted to	
							the neonatal	
							unit, were you	
							able to see your	
							baby as soon as	
							you wanted?	
							Score = 91	
L				 <u> </u>	<u> </u>	l	550.5 51	

RQ 5.1 'How can,	The aim of this	GIVING VIEWS	No relevant	No relevant	No relevant	No relevant	No relevant	SUCCESSFUL	No relevant	No relevant	No relevant	IMPORTANCE OF
and how should,	review is to	ABOUT HEALTH						PARTICIPATION:	findings were	findings were		USING PATIENT
· · · · · · · · · · · · · · · · · · ·			findings were identified for this	findings were identified for this	findings were	findings were identified for this	findings were		identified for this	1	findings were	
the perspective	determine how	AND			identified for this		identified for this	- At a stakeholder		identified for this	identified for this	EXPERIENCE
of children and	the views and	WELLBEING:	question	question	question	question	question	event looking at	question	question	question	INFORMATION:
young people,	perspective of	- Young people						NHS white				- Young people
and of the	babies, children	preferred						papers and				(13 to 17 years)
parents or carers	and young	providing their						strategy the				were very keen
of babies inform	people can and	views using						young people				that the views
the design of	should be taken	questionnaires,						(age not				and wishes of
healthcare	into	or small focus						specified)				young people
services?	consideration	groups (fewer						recommended				like themselves
	when designing	than 10 people),						that:				should be sought
	healthcare	and their least						- Service user				and acted upon
	services.	preferred						involvement and				both 'in the
		method was						active feedback				moment', in
		large focus						should be sought				relation to care
		groups (more						and acted				and treatment
		than 10 people)						upon				affecting
		or meetings/						- Participation				patients, and
		activities led by						should be seen as				more generally,
		adults						a fundamental				to improve the
		- Young people						aspect of service				quality of service
		thought it was						evaluation				provision.
		useful for them						and service				- Young people
		to be involved in						improvement				(13 to 17 years)
		most areas of						- Progress should				felt that a survey
		service design,						be fed back to				should be carried
		especially						the young				out that should
		identifying needs						people.				be uniform
		or problems,										across the
		designing										country and that
		physical space,										it should be used
		designing										to assess services
		publicity										and to improve
		materials. Other										the quality of
		areas were										care provided. It
		reviewing										was important to
		services (mystery										know that the
		shopping), having										information
		a say on how										provided would
		budgets are										be used to
		spent,										address both
		developing										individual and
		policies and										local service level
		recruiting staff.										concerns, and to
		0.00										improve the
		Relevant quotes:										quality of cancer
		"take us										services for
		seriously. Get										children and
		more young										young people
		people involved										overall.
		in roles in these										Jvc. ull.
		services. Ask for										INCENTIVES:
		regular feedback,										- Young people
		_										
		and make it easy										(13 to 17 years) said that the
	1	and quick to give.	i	I	1	I	I	1	i	1	1	i saiu that the

		Don't be invasive										invitation to
		(especially										complete a
1		through sexual										survey should
		health services)."										include clear
		ileaith services).										information
												about the value
												and purpose of
												the survey and
1												that answers
1												would be used to
1												help the NHS to
1												improve care for
												other young
												people with
												cancer, and that
												a small financial
												incentive (£5-10)
1												would help to
1												ensure
1												completion and
												return of the
1												
1												questionnaire.
1												
												Quotes:
												'For the survey,
1												online would be
1												easiest. By email.
Į.												A reward would
Į.												motivate people
1												to do it. I think
!												about £10.' (F15)
Į.												
!												AGE-
1												APPROPRIATE
1												METHODS:
1												- Young people
1												(13 to 17 years)
1												said that
1												questionnaires
1												should be age-
1												
1												appropriate with
												a simple one for
												children aged 7-
												11 and another
												version for
												secondary school
												age children.
1												Younger children
1												should be
												interviewed, or
1												their parents
1												could complete a
1												survey on their
'												behalf.
	1	l										
RQ 5.2 'How can	To establish how	COMPLAINTS:	CONCERNS:	No relevant	No relevant	No relevant	CONCERNS/	No relevant	No relevant	No relevant	No relevant	IMPORTANCE OF
RQ 5.2 'How can the experience of	To establish how the experience of	COMPLAINTS:	CONCERNS:	No relevant findings were	No relevant findings were	No relevant findings were	CONCERNS/ COMPLAINTS:	No relevant findings were	IMPORTANCE OF USING PATIENT			

babies, children	babies, children	- 60% of young	- 64% of parents	identified for this	identified for this	identified for this	-34% of young	identified for this	identified for this	identified for this	identified for this	EXPERIENCE
and young	and young	people wanted	of 0-15 year olds	question	question	question	people had	question	question	question	question	INFORMATION: -
people be	people can be	to make a	said they could	'	'	'	voiced concerns	'	'	'	'	- Young people
measured so as	measured, in	complaint or a	have told				or made an					(13-17 years)
to improve their	order to improve	suggestion but	hospital staff if				official complaint					were very keen
experience of	their experience	had not done so	they had a				- 15% had					that the views
healthcare?'	of healthcare.	- 19% had made	concern				wanted to					and wishes of
nearmeare.	or meanineare.	a complaint but	Concern				complain but					young people
		over 50% of					didn't					like themselves
		these reported					- the remaining					should be sought
		that nothing					52% had never					and acted upon
		happened as a					felt the need to					both 'in the
		result.					raise a concern					moment', in
		- 3 young people					or make a					relation to care
		had had positive					complaint					and treatment
		experiences of					Complaint					affecting
		making a					REASONS FOR					patients, and
		complaint: in 1					NOT RAISING					more generally,
		case the service					CONCERN /					to improve the
		had explained					MAKING					quality of service
		how they					COMPLAINT:					provision.
		planned to					- Of 19 young					- Young people
		address the					people who did					(13 – 17 years)
		complaint; in 1					not raise					felt that it was
		case the service					concerns the					important for the
		had explained					reasons that					local services to
		that changes had					prevented them					collect
		been made as a					from doing this					information
		result; in 1 case					were:					about the
		the young person					Didn't know how					experiences of
		could see that					(21%)					patients they
		obvious changes					Didn't know who					treated through
		had been made					is best person to					a series of
		to improve the					raise it with					regular
		service.					(42%)					qualitative
		Sci vice.					Didn't want to be					approaches
		REASONS FOR					seen as a					(group
		NOT MAKING A					trouble-maker					discussions
		COMPLAINT:					(42%)					and/or individual
		- The most					Didn't think it					interviews with
		common reasons					would be taken					children and
		given for not					seriously (21%)					young people
		making a					Didn't think it					with cancer), and
		complaint was					would make any					that these should
		that nothing					difference (26%)					be supplemented
		would change,					Staff are busy					with a survey
		thinking nobody					and it doesn't					that was sent to
		will listen, fear of					help (5%)					all patients (over
		repercussions, or					Worried care					a certain age).
		not knowing how					would get worse					- 55. tall 450/
		to complain.					if I complained					Quotes:
		lo complain.					(21%)					'I think it's really
		Relevant quotes:					I have					important that
		"I've already					complained					you can influence
		been treated like					before and it					things that affect
		rubbish by					didn't make any					your care,
		people in power					difference (5%)					because some
		heobie ili howei					uniterence (3/0)			1	1	necause sume

			1	
of the service I've		The issue was		things affect you
complained		resolved without		but not others. I
about"; "I think I		me needing to		think it's
will be		make a		important to
stereotyped as a		complaint (11%)		take into
complainer and				consideration
that they think I		RESULT OF		what each
don't appreciate		RAISING		person wants.'
the NHS and my		CONCERN/		(F15)
care"; "Raised		MAKING		"I think it's
concern and told		COMPLAINT:		important to ask
if raised another		Of 43 young		about all the
concern wouldn't		people who had		places where
be allowed to use		raised a concern		people are seen.
service again".		or made a		Personally, I've
However, one		complaint, 65%		had good
respondent said		wanted it to		experiences
"Nothing would		improve their		everywhere, but
stop me giving		care; 65%		I know some
feedback".		wanted it to		people haven't
MANUNC IT		improve the		and I think it's
MAKING IT		service for		important to ask
EASIER TO GIVE		everyone and		about all the
FEEDBACK OR		37% wanted an		places where we
MAKE A		apology or an		are seen.' (M16)
COMPLAINT:		explanation.		METHODS TO
- Being able to		33% said the		GATHER
complain anonymously,		issue was		FEEDBACK:
clear information		resolved quickly;		Under 11 years:
about the right		19% were happy		- Prefer handheld
to complain and		with the		electronic device,
how to complain,		outcome; 42%		iPad or tablet
belief that		had to complain		- prefer symbols
feedback and		multiple times,		(smiley/sad
responses will be		didn't feel like		faces) rather
received about		they were taken		than text
complaints, and		seriously, or no		Young people
assurance that		action was taken		(13-17 years):
they won't be		as a result of		- Liked both
treated		their concern/		surveys and
differently for		complaint		interviews
making a		Complaint		(individual face
complaint were		ENCOURAGEME		to face or
all given as		NT TO RAISE		groups), but
factors that		CONCERNS:		thought surveys
would make it		Of 128 young		would be easier
easier for young		people, factors		if you were very
people to make a		that would		ill.
complaint.		encourage them		- 2 young people
		to express		preferred pen
Relevant quotes:		concerns would		and paper
"Having people		be:		surveys sent to
actually read and		- More		their home
take complaints		information		address, but all
seriously!";		about expected		the others
"Having people				preferred an
 Urr-	_ l			I Processes and

				T
who actu			standards of care	online survey as
would or			(34%)	easy to
used the			- A more open	administer,
	positions		culture	cheap and simple
to make			encouraging	to complete, and
and take			feedback (34%)	would like to
complain	nts,		- Receiving	receive the
rather th	nan		regular feedback	invitation by
someone	e who is		on actions taken	email not by text.
just gues	ssing		(37%)	
what is a			- Having an	Quotes:
needed"			advocate or third	'I feel that a
people w		I I	party who could	group would be
speak up			raise concerns	good for support
because			(19%)	rather than to
don't' wa			- Being able to	give information.
make a fi			report concerns	If I was invited to
isn't wor			anonymously	one now, I
There ne			(34%)	wouldn't mind
	1 1			
be a mas			- Knowing which	going to it. But
	A change		staff (36%) or	when I was ill I wouldn't have
in the wa	· I		services (24%) to	
read and			raise concerns	done it. I would
interpret			with	prefer a survey.
opinions				And I think that
seeing th				for me, when I
individua				was in hospital,
someone				for a lot of the
just want				time I was just
complain				too ill to engage
someone				with a group
would lik				discussion or
genuine,				anything like
change."	,			that. The
				advantage of a
				survey is that you
				can look at it
				when you want
				and fill it in when
				you feel you can.
				And it should
				have open
				questions as well
				so that you can
				write in your
				feelings about
				questions.' (F15)
				'I guess it's most
				convenient to do
				it online really.
				And then you
				just send it off to
				them. I definitely
				think most
				people nowadays
				have a tablet or a
				phone or a
				

Grey literat	ure mapping to q	uestions					
							computer. I think it should be sent by email. Because knowing myself, I reckon I would ignore random texts, and email is a bit more official.' (F15)
							WHEN TO GATHER FEEDBACK: - Young people (13-17 years) thought surveys were best conducted after the end of treatment, but qualitative data should be collected at different points in the journey.
							Quotes: 'My experience has been very long (from August 2015 to January 2018) so I think it should be done at regular intervals. I think patients would be happy with that, every few of months or so. If I'd been asked say 3 months into it,
							I'd have been able to comment on the diagnosis part and the early part of the treatment. But then a few months later, things were different, and it would be best if I'd been asked again at that point.' (F15)

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Grey literature mapping to q	luestions							
								"I think the
								group discussion
								would be a good
								idea – both at
								the end but also
								half way
								through.' (F13)
								. ,
								WHAT
								QUESTIONS TO
								ASK:
								 Young people
								(13-17 years)
								said the
								questions should
								include:
								- Whether you
								felt you were
								treated with
								respect
								- Quality of
								communication
								with medical and
								other staff
								- Friendliness of
								staff
								- Whether you
								felt fully
								informed about
								your care and
								treatment,
								including side
								effects of
								medications
								- Whether you
								felt you were
								fully involved in
								decision making
								- Whether the
								environment was
								clean and
								hygienic
								- Whether young
								people felt they
								were treated as
								an autonomous
								and independent
								person, or
								whether medical
								staff spoke about
								them (with
								parents etc or
								other healthcare
								professionals)
								rather than to
		1	I	I	1	1		them

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Grey literat	ure mapping to q	uestions							
									- Whether young
									people were able
									to see family and
									friends whenever
									they wanted
									- Whether there
									were other
									children/young
									people of a
									similar age (and
									opportunities for
									socialising and
									making friends)
									- Whether there
									were adequate
									facilities to
									alleviate the
									boredom/tedium
									of being on
									treatment,
									including
									electronic
									gaming/devices
									and WIFI etc as
									well as
									DVDs/books and
									traditional games
									- Views on the
									school hospital
									service and on
									the support
									provided by the
									hospital with
									education more
									broadly
									(including
									working with
									respondents'
									schools to
									address
									uninformed
									'teasing' and
									bullying related
									to cancer)
									- Views on the
									quality of food
									provided
									- Whether there
									was sufficient
									privacy (including
									noise)
									- Whether they
									were able to
									regulate the
									temperature of
1		I	I	I	I	1	I	1	their room/

environment.

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RQ 6.1 'What	To determine	No relevant	WARD SUITABLE:	FACILITIES	No relevant	No relevant	No relevant	HOSPITAL	No relevant	No relevant	WARD	RAISING CONCERNS OR MAKING COMPLIMENTS: Quotes: 'Now when I go as an outpatient I see comments cards, but at the time when I was inpatient, I never really did any of that – I wasn't really well enough to do anything like that. I don't remember anyone saying, 'if things aren't good, here's how you can let us know.' (F15) "I filled in the cards on the ward quite a few times. If you had a good experience. There's a box for any room for improvement. You write what ward you're on. I wrote how helpful and cheerful the staff were and how much they do to cheer you up. You can write about a particular member of staff and put their name down and the message gets passed on and then the hospital praises them I think.' (F13) No relevant
		findings were	WARD SUITABLE:	/WAITING AREA:	findings were	findings were	findings were	ENVIRONMENT:	findings were	findings were	FACILITIES:	findings were

identified for this question identified for t	his - Children and young people aged 12-19 reported: 'Depressing and boring because you have to wait long hours and identified for this question	identified for this question - Was there enough space you to sit alongside yo baby's cot in unit? Score = - In your opin	ur the
	aged 12-19 reported: 'Depressing and boring because you have to wait	you to sit alongside yo baby's cot in unit? Score =	ur the
	reported: 'Depressing and boring because you have to wait	alongside yo baby's cot in unit? Score =	the
	'Depressing and boring because you have to wait	baby's cot in unit? Score =	the
	you have to wait		: 82
	1 *	- In your opi	
	long hours and		nion
		was there	
	there's nothing	adequate	
	to do'; 'Horrible,	security on t	he
	the smell makes	neonatal uni	t?
	you nervous' and	Score = 88	
	l l		
	· I		
	1 '	1 -	
	missing'.		
		I I	
			offer
			4:2
		I I	lon?
		Score = 70	
No relevant	No relevant WIEL	ACTIVITIES INVOLVENCE	NIT HAISION WITH
I I	l l		
		1 · 1	
_ I			_
question question	question WI-FI Was 8000	Tana young T- Welle VOU	suggested it
	enough for	people aged 8 to involved as r	
	No relevant findings were identified for this question No relevant findings were identified for the question	No relevant findings were identified for this No relevant findings were identified for this No relevant findings were identified for this No relevant findings were identified for this	The beds are old and uncomfortable, toys don't work and parts are missing". No relevant findings were identified for this in the findings were in the findings were identified for this in the findings were in the findings were identified for this in the findings were in the findings were identified for this in the findings were in the findings were in the findings were in the findings were in the findin

usual activities	participate in	enough to do			what they	was enough age-	the day-to-day	hospital could
(for example	usual activities.	what they			wanted to do	appropriate	care of your	have done more
family		wanted.				things to do in	baby, such as	to tackle
relationships,						the waiting room	nappy changing	misunderstandin
schooling, peer		PLAY:					and feeding?	g and ignorance
friendships,		- Of those					Score = 89	about cancer and
social activities)?'		children aged 8-					- Did you have as	treatment for
		11 who wanted					much skin-to-	cancer at his
		to play: 23% -					skin contact with	school. - Other young
		happened a lot 38% - happened					your baby as you wanted? Score =	people reported
		a little					72	that the school
		39% - did not					- Where possible,	hospital service
		happen.					did staff arrange	was not well
		appe					your baby's care	connected to the
		73% of parents of					(such as	local school and
		children aged 0-7					weighing,	that work was
		said yes, staff					bathing) to fit in	set that was
		played with them					with your usual	inappropriate for
							visiting times?	the age group.
		ACTIVITIES:					Score = 74	
		- Approximately					- Overall, did	Quotes:
		half of all					staff help you	'My friends were
		children and					feel confident in	really good with
		young people (8					caring for your	me and treated
		to 15) said there					baby? Score = 89	me like a normal
		were enough						person, but not
		things for them						everybody knew
		to do.						about my cancer.
		- 63% of parents						I imagine that it's
		of 0 to 7 year						worse in a bigger
		olds said there						school. The
		was enough for						hospital could
		them to do						send someone out to talk at the
								school to explain
								what's going on.
								Because
								everyone asked
								me, and it's not
								something I
								really want to
								talk about. If
								they could
								explain what I
								could and
								couldn't do, that
								would have
								helped big time.'
								(M16)
								'They had
								someone come
								in but she could
								only do work
								that was for the
								year below me. It

BEQ.S. What are to the foliations of the base is a subscription of the same to										was because
ROSE 1 What was find a finding were for she hashbase the shear of the sales and base s										they're not
EQ. 8.1 What start The determine the USE OF The desiration										_
RG E I What are the formation of the standard in a room asky from other than the public and the										
8.8.1 "What are the Buillators of a consideration of the Buillators of a consideration of										(hospital).' (F14)
but they only came one the bast day was there? (1913) SOCIAL ACTIVITIES - Some young to 19 years they solded in a room away from outbor pumphs. Real 19th at the sold and they were responded that they were good the solded in a room away from outbor pumphs. Real 19th at the sold and they were responded that they were good they were good that t										'The school
ACCES TO NATE Facilitators of of an arrivers of the control of the										
RG 8.1 "What are the facilitators of of and barriers to services food by basic children and young poople?" BO 8.5 "What are the facilitators of and barriers to the ballows the barriers food by barriers f										
APPOINTMENTS To determine the Not all determine the Services for Serv										
SOCIAL ACTIVITIES - Some young and 7.7 years reported that the feet toolsted for notice years of the carrier patients are put in a side room, 30 young begin and young people? RD 8.1 "What are If determine the facilitators of, and barriers to, accessing Seaves for bubbles, children and young people? RD 8.2 "What are If determine the facilitators of, and barriers to, accessing Seaves for bubbles, children and young people said the bubbles, children and young people. RD 8.2 "What are If determine the facilitators of, and barriers to, accessing Seaves for bubbles, children and young people said the population of the appointment was a children and young people said the population of the people said the people said the population of the people said the people										1 .
SQ.8.1 "What are the facilitations of, and barriers, to, accessing healthcare services for bubbles, children and bursers, to, accessing people, accessing people, accessing people, accessing people who had bubbles, children and pharmacise and hospital health were people. Colored and some people who had become the concentration of the appointment was a short through a said the location of the appointment was a legislated from the appointment was a legislated from the propried of the appointment was a legislated from the propried of the appointment was a legislated from the propried and through a services such as the location of the appointment was a legislated from the propried and through a services such as the location of the appointment was a legislated from the propried and through a services such as a formation of the appointment motion of appointment was a legislated from the appointment motion or nurse if they feel that was 78% where deliticate was a legislated from the appointment motion or nurse if they feel that was 78% where deliticate was a legislated from the appointment motion or nurse if they feel that was 78% where deliticate was a legislated from the appointment motion or nurse if they feel that was 78% where deliticate was a legislated from the appointment motion or nurse if they feel that was 78% where deliticate of 5 year olds.										
RQ 8.1 "What are the Facilitators of, and barriers to, accessing healthcare to, excessing people, specified in a form key people." APPOINTMENTS: 6.28 A PPOINTMENTS: 6.28 A PROINTMENTS: 6.28 A PPOINTMENTS:										
\$0.5.1 What are to determine the facilitators of, and barriers of battles, children and young people had used General young people h										
FO.B.1.What are to find barriers to, accressing healthcare services facely and young people?"										
RQ.8.1.*What are the facilitations of, accessing heathcare services for bables, children and young people. Propose Pr										
RQ 8.1 'What are the facilitators of of abserters that was not so good. Because in (hospital) at the cancer patients of possible, children and young people? RQ 8.1 'What are the facilitators of of abserters to facilitators of of a section of the timing of their timing										
RQ.8.1-What are the facilitators of, of, and barriers to, accessing healthcare services for bables, children and young people. No relevant findings were least the services faced by bables, children and young people.										1
RQ 8.1 'What are the facilitators of o, and barriers to, saccessing heathcare salves continued young people." RQ 8.1 'What are the facilitators of o, and barriers to, saccessing heathcare salves continued young people. Body on the people will be about how all these services, and were positive about how all these services and the services, and were positive about how all these services met their needs - 70% had used accident and emergency, but the way and the services where the interest of the continued and the services where their needs - 70% had used accident and emergency, but this was ranked will be accessing a service of the continued of the continued and the services where their needs - 70% had used accident and emergency, but this was ranked will be served to this was ranked will be accessed to the things of parents appointment or services which were eligible for access to the health services which were none to the services with the was 78% of parents which were none to the services with the was 78% of parents which were none to the services of the poople. The social asspects: thet was not so good. No relevant findings were identified for this question. RQ 8.1 'What are the facilitators of a large was and poople and the services and proposition of the poople will be accessed to the proposition of the poople will be accessed to the proposition of the health services where the interested the services where the interested the poople will be accessed to the proposition of the health services where the interested the services which were eligible for a control of the proposition of the health services which were eligible for a control of the proposition of the proposition of the health services which were eligible for a control of the proposition o										-
RQ 8.1 'What are the facilitators of, of, and barriers to, accessing healthcare services for bables, children and young people?' RQ 8.1 'What are the facilitators of, and barriers to, accessing healthcare services for bables, children and young people?' RQ 8.1 'What are the facilitators of, and barriers to, accessing healthcare services for bables, children and young people." RQ 8.1 'What are the facilitators of, and barriers to, accessing healthcare services for bables, children and young people." RQ 8.1 'What are the facilitators of, and barriers to, accessing healthcare services for plants in the services of services for and used deneral and young people." ACCESS TO HEALTHCARE IN SERVICES: over training of their appointment was convenient to the popplement of the services, and were positive about how all these services ment their needs or the popplement of the services of services for ment their needs or the popplement of the services of services for fire school meals and emergency, but this was rained with the were eligible for fire school meals access the same their needs or the popplement of the services of Syear olds of the popplement of the services of Syear olds of the popplement of the services of Syear olds of the popplement of the popplement of the services of Syear olds of the popplement of their needs of the popplement of the popp										
RQ 8.1 'What are the facilitators of, of, and barriers to, accessing healthcare services for bables, children and young people?' RQ 8.1 'What are the facilitators of, and barriers to, accessing healthcare services for bables, children and young people?' RQ 8.1 'What are the facilitators of, and barriers to, accessing healthcare services for bables, children and young people." RQ 8.1 'What are the facilitators of, and barriers to, accessing healthcare services for bables, children and young people." RQ 8.1 'What are the facilitators of, and barriers to, accessing healthcare services for bables, children and young people will be services, and were positive about how all these services met their needs and pointment was easy to get to where children were eligible for access health and emergency, but this was ranked 1 - 6.6% and the conton of the exponents of fire school meals and emergency, but this was ranked 1 - 2.0% for pointment to the conton of the exponents of fire school meals and emergency, but this was ranked 1 - 2.0% for pointment to the conton of the co										Quotes:
RQ 8.1 'What are the facilitators of, and barriers to, accessing healthcare services from bables, children and young people. Popele. No relevant findings were identified for this accessing healthcare services for bables, children and young people. popele?' Popele. Pope										
RQ 8.1 'What are the facilitators of, and barriers to, accessing healthcare services for bables, children and young people.' BRO 8.1 'What are the facilitators of, and barriers to, accessing healthcare services for bables, children and young people.' BRO 8.1 'What are the facilitators of, and barriers to, accessing healthcare services for bables, children and young people.' BRO 8.1 'What are the facilitators of, and barriers to, accessing healthcare services for bables, children and young people.' BRO 8.1 'What are the facilitators of, and barriers to, accessing healthcare services for bables, children and young people.' BRO 8.1 'What are the facilitators of, and barriers to, accessing healthcare services for bables, children and young people.' BRO 8.1 'What are the facilitators of, and barriers to, accessing healthcare services safed by abole, children and young people.' BRO 8.1 'What are the facilitators of, and barriers to, accessing healthcare services, faced by abole, children and young people.' BRO 8.1 'What are the facilitators of, and barriers to, accessing healthcare services, faced by abole, children and young people.' BRO 8.1 'What are the facilitators of, and barriers to, accessing healthcare services, and were positive about how all these services met their needs -70% had used accident and emergency, but this was ranked the the face shool means. BRO 8.1 'What are the findings were of thindings were in the findings were of the dentified for this question.' BRACTESS TO NHS DEATH ACCESS TO NHS FRACTES. DENTAL SERVICES: -0.2% of children and young people said the they needed they were able to side they accident and emergency, but this was ranked the findings were in findings were timeling for this question.' BRACTESS TO NHS DEATH ACCESS TO NHS PRODUCTS.' CACCESS TO NHS DEATH ACCESS TO NHS PRODUCTS.' BRACTICARE IN BALTH ACCES TO NHS CHILDRENTS: Care creating exposite the findings were timely over the										-
RQ.8.1 'What are the facilitators of, and barriers to, accessing healthcare services for bables, children and young people.' Bellikare and young people said the didner and hospital health services, and were positive about how all these services for and young people.' Bellikare and poung people.' Bellikare and poung people.' Bellikare and poung people said the didner and poung people said the didner and poung people.' Bellikare and poung people.' Bellikare and poung people said the didner and poung p										
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babies, children and young people. babies, children and young people said that they were able to see a doctor or ourse if they felt unwell about how all these services met their needs - 70% had used accident and emergency, but this was ranked babies, children and young people. convenient - 66.4% of problems finding people said that they were able to see a doctor or ourse if they felt unwell - 64% said the being cancelled babies, children and young people said that they were able to see a doctor or ourse if they felt unwell - 64% said the being cancelled being cancelled specified) reported that they were edbet to see a doctor or ourse if they felt unwell - 64% said the services were 'good' where children and young people said that they were able to see a doctor or ourse if they felt unwell - 64% said the services were 'good' where children and young people said that they were able to see a doctor or ourse if they felt unwell - 64% said the services were 'good' where children and young people said that they were able to see a doctor or ourse if they felt unwell - 64% said the services were 'good' where children and young people said that they were able to see a doctor or ourse if they felt unwell - 64% said the services were 'good' where children and health services were 'good' where children and young people said that they were able to see a doctor or ourse if they felt unwell - 64% said the services were 'good' where 'good' where 'good' and Young people said that they were able to see a doctor or ourse if they felt unwell - 64% said the yer or ourse if they felt unwell se			_	l '						
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about how all these services these services met their needs -70% had used accident and emergency, but this was ranked easy to get to easy to get to that this was 78% where children were eligible for for 5 year olds easy to get to that this was 78% where children were 'good' every six months, more money for dental and NHS more convenient, but they just refused the services such as regular check-ups every six months, more money for dental and NHS more convenient, but they just refused the services such as regular check-ups every six months, more money for dental and NHS more convenient, but they just refused the services such as regular check-ups every six months, more money for dental and NHS more convenient, but they just refused they is someone to the services such as regular check-ups every six months, were 'good' every six months, more money for dental and NHS more convenient, but they just refused they is someone to the services such as regular check-ups every six months, were 'good' every six months, more money for dental and NHS more convenient, but they just refused they is someone to the services and the belief to services such as regular check-ups every six months, were 'good' every six months, and the latth is was ranked to services such as regular check-ups every six months, and the latth is was refused to services such as regular check-ups every six months, and the latth is was refused to severy six months, and the latth is was refused to severy six months, and the latth is was refused to severy six months, and the latth is was refused to severy six months, and the latth is was refused to severy six months, and the latth is was refused to severy six months, and the latth is was refused to severy six months, and the latth is was refused to severy six months, and the latth is was refused to severy six months, and the latth is was refused to severy six months, and the latth is was refused to severy six months, and the latth is was refused to severy six months, and the latth is was refused to severy six		· ·			1		1 ' '			journey.
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met their needs - 70% had used accident and emergency, but this was ranked met their needs - 70% had used accident and emergency, but this was ranked met their needs where children were 'good' - 24% said they had health needs which were not being met more good' - 24% said they had health needs which were not being met stay at (hospital 1) because it was more dental and NHS doctor care, someone to stay at (hospital 1) because it was more convenient, but they just refused										
- 70% had used accident and emergency, but this was ranked			322, 10 800 00		I .					
emergency, but this was ranked - 76% of parents which were not they just refused convenient, but they just refused				_	1		-			1) because it was
this was ranked of 5 year olds being met someone to they just refused					I .					
		1		1			-			
1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1		lowest of 7		were satisfied	Jenig IIIet		make sure that			and said, 'no,

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	services for	with the wait for	Young offender	all care leavers		because it's
	meeting needs.	an urgent	institutions:	have a doctor,		closer to you,
	- Specialist	appointment,	- 71% of children	dentist and		you have to go
	services for long-	and 82% were	and young	health visitor,		there' (to
	term conditions,	satisfied with the	people said it	and help to		hospital 2). But it
	counselling	wait for a routine	was easy to see a	ensure they are		was difficult for
	services, and	appointment	nurse	able to cope		us to get there
	sexual health		- 57% said it was	managing their		and it's along
	services were	DENTAL	easy to see a	own care.		country roads
	each used by less	ANXIETY:	doctor	- Care leavers		and things. They
	than 40% of	- Parents of 5	- 35% said it was	(age not		just really
	young people	year olds	easy to see a	specified) also		refused. I would
	, and people	reported how	dentist53% said	said they need		have liked them
		anxious their	health services	more		to have listened
		children were	were good	information such		to me and let me
		about attending	-27% reported	as advice and		stay at (hospital
		the dentist with	having an	support on		1), not (hospital
		50% stating their	emotional or	health issues,		2). But they said
		children were	mental health	particularly sex		'no'. (F15)
			problem, and of	education,		110 . (F13)
		not anxious, 26%	1 -			
		reported low	these 54% were	making health services better		
		anxiety and 22%	being helped by			
		reported	someone.	known and easier		
		moderate to		to get involved		
		extreme anxiety		with, including		
		- Self-report of		sexual health		
		anxiety by 12		clinics. They also		
		year olds were as		needed more		
		follows:		information on		
		23% low/no		how to register		
		anxiety		with doctors and		
		63% moderate		dentists (the		
		anxiety		social		
		14% extreme		workers need to		
		anxiety		take them and		
		Self-report of		show them), and		
		anxiety by 15		an education		
		year olds were as		pack, newsletter		
		follows:		or video on		
		36% low/no		leaving care, so		
		anxiety		care leavers		
		54% moderate		know how to use		
		anxiety		different health		
		10% extreme		services.		
		anxiety		- Another		
		- 21% of 12 year		consultation with		
		olds with		young people in		
		extreme anxiety		care and care		
		and 31% of 15		leavers (age not		
		year olds with		specified) led to		
		extreme anxiety		recommendation		
		reported they		that they needed		
		would only		a guide to local		
		attend the		health services.		
		dentist if they		This should		
		had trouble with		include:		
		their teeth, and				
<u> </u>				<u>l</u>		

					not for routine			Where and				
					check-ups			how to find local				
					check-ups			health services,				
								l .				
								and how often				
								young people				
								should go to				
								them (e.g.				
								dentist)				
								 Information on 				
								health services				
								needs to be clear				
								about young				
								people's				
								entitlements (e.g.				
								free prescriptions				
								and dental care)				
								How to get help				
								if you have				
								emotional				
								problems				
								 Information on 				
								different types of				
								contraception				
								and where you				
								can access				
								them				
								• Information				
								and services on				
								giving up				
								smoking, drugs				
								and alcohol				
								Information on				
								how to eat				
								healthily (e.g.				
								what is a healthy				
								'five a day' diet				
								and what is a bad				
								diet and why)				
								• Information on				
								free leisure				
								passes, leisure				
								facilities for				
								children in care.				
RQ 8.2 'What	To determine the	No relevant	KNOWLEDGE OF	No relevant	No relevant	No relevant	ADMISSION/	DISCHARGE	DISCHARGE	No relevant	KNOWLEDGE OF	No relevant
factors promote,	factors which	findings were	MEDICAL	findings were	findings were	findings were	DISCHARGE/	FROM TERTIARY	FROM	findings were	MEDICAL	findings were
or present	promote or	identified for this	HISTORY:	identified for this	identified for this	identified for this	TRANSFER:	CARE:	HOSPITAL:	identified for this	HISTORY:	identified for this
barriers to,	present barriers	question	- 58% parents of	question	question	question	- Of young	- Disabled young	71% of parents	question	- In your opinion,	question
continuity of care	to continuity of	4 -	0-15 year olds	1	1	4	people who had	people aged 15-	of 0-7 years old	4	was important	4 -
for babies,	healthcare for		said staff were				raised a concern	21 recommended	knew what was		information	
			aware of their									
children and	babies, children		1				or made a	that at the stage	going to happen		about your baby	
young people?'	and young		child's medical				complaint, in	of discharge from	next, and 79%		passed from one	
	people.		history				31% the subject	tertiary care after	knew who to talk		member of staff	
							had related to	diagnosis,	to if they were		to another?	
			DISCHARGE				admission,	thought must	worried about		Score = 84	
			FROM HOSPITAL:				discharge or	be given to the	their child		- Did the staff	
							transfer, or a lack				give you	
			l						l		·	

T			T T	
	- 79% of children	of	care packages	conflicting
	8-15 years old	communication	impact on family	information
	were given	between service	l l	about your
	information on	such as their GP,		baby's condition
	how to look after	hospital, or care	do not dis-	or care? Score =
	themselves at	services	empower	67
	home; 69% knew		families or young	
	what was going		people.	DISCHARGE
	to happen next,			FROM THE
	and 72% knew		CONTINUITY OF	NEONATAL
	who to talk to if		CARE FOR CARE	UNIT:
	they were		LEAVERS:	- Were you
	worried		- A consultation	offered overnight
			with young	accommodation
			people in care	with your baby at
			and care leavers	the hospital
			(age not	before they left
			specified)	the neonatal
			recommended	unit? Score = 95
			that they should	- Did you feel
			have twice a year	prepared for
			check-ups (even	your baby's
			when they leave	discharge from
			care) and these	neonatal care?
			should	Score = 86
			be up to 18 years	- Were you given
			of age and not	enough
			stop at 16; carers	information on
			should have	what to expect in
			more training on	terms of your
			health and the	baby's progress
			young people	and recovery?
			should have the	Score = 76
			same health	
			worker for health	
			assessments,	
			and a health	
			folder that has all	
			young people's	
			health	
			information in it.	
			IIIIOIIIIatioii III It.	