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 OVERVIEW - An on-line survey of young people undertaken by the Association for Young People's Health (AYPH), for the Children and Young People's Health Outcomes Forum (an independent advisory group of professionals and representatives from the children's sector) - The aim of the survey was to collect young people's views on how they like to be involved in service development or improvement, and how they feel about giving feedback or making complaints - 98 respondents were as follows: 10-14 years old, n= 15; 15-19 years old, n= 52; 20-24 years old, n=31. 69 were female; 37 had long-term conditions.	**SURVEY OVERVIEW** - Third national survey sent to children and young people, and their parent or carer - Children and young people aged 15 days to 15 years, admitted to hospital as an inpatient (planned or as an emergency) or as a day case - Questionnaire completed solely by the parent/carer of children aged 0-7 years; children aged 8-11 or 12-15 received a questionnaire of two halves, one for themselves to complete, and one for their parent/carer - Sampled 129 NHS acute trusts - 33, 170 questionnaires were competed (response rate of 25%)	**SURVEY OVERVIEW** - Data related to outcomes and experiences of children and young people (0-25 years) seen across 75 mental health services in England taking part in the service transformation 'Children and Young People's Improving Access to Psychological Therapies' (CYP IAPT) from April 2011 to June 2015 - 96, 325 case records, representing 91,502 children and young people, mean age = 12 years; 52% female; 82% white; 155 young people (0.2%) aged 20 or over and 3,213 (3.3%) aged 0-4 years; remainder aged 5-19 years (96.65%) - Experience of service questionnaire (ESQ) used to explore satisfaction with services.	**SURVEY OVERVIEW** - A survey carried out every 10 years since 1973 to provide information on the dental health of children - Includes questions on access to dental treatment services, perceptions of care and anxiety about treatment which were included in this analysis - Children aged 5, 8, 12 and 15 years were sampled to take part in the survey, which was conducted in conjunction with a dental examination - Children undergoing the dental examination aged 12 or 15 were asked to complete a questionnaire and 99.6% completed it. - Parents of all children undergoing a dental examination	**SURVEY OVERVIEW** - An analysis of 12-18 year olds perceptions of their experiences in secure training centres and young offender institutes An independent report commissioned by the Youth Justice Board. Includes surveys of detained children (under 18 years) at secure training centres (n=3) and young offender institutes (n= 5) and a specialist unit site (n=1) within one of the young offender institutes. The questionnaires included a section on healthcare. - 720 surveys were completed (response rate of 85%). -In STCs 91% were boys, and 36% were under 16 - in YOIs 100% were boys and 6% were under 16	**SURVEY OVERVIEW** - A survey carried out in England in November to December 2018 on behalf of the CQC (by the organisation 'Opinion Matters') - Focus of the survey was on reporting concerns relating to care - Respondents were 2,002 people in England who have had some sort of health service (NHS and private care) or social care experience in the last 5 years, either as a patient or a carer - Data was split into age groups, and included 128 12-15 year olds, whose results are analysed here.	**SURVEY OVERVIEW** - This review comprised a literature review (not analysed here) and views of children and young people from 46 consultations conducted with children and young people by a number of organisations across England (analysed below) - Children and young people were defined as those up to the age of 18, or 25 in the case of young people with a disability, a long term health problem, care leavers and young people in custody. Where possible, responses only from children and young people under 18 are included in the analysis	**SURVEY OVERVIEW** - A survey of views from children, young people and their parents or carers in England during hospital visits, conducted by Picker Institute. Data from this survey feeds in the CQC report but is included here because the Picker summary contains some details not reported in the CQC version.	**SURVEY OVERVIEW** - The emergency department survey was conducted in 5 NHS trusts in 2015; 650 parents (of children aged 0-16) responded and 387 children aged 8-16 responded. - The outpatient survey was conducted in 9 trusts in 2015; - 1,039 parents (of children aged 0-16) responded and 916 children aged 8-16 responded. - Only children's responses were analysed for both surveys	**SURVEY OVERVIEW** - A survey of parents' experiences of neonatal care - Surveyed parents from 88 hospital neonatal units in 2 waves: • Wave 1: babies discharged from neonatal care between October 2013 and March 2014 • Wave 2: babies discharged from neonatal care between April 2014 and September 2014 - A sample of 100 consecutive parents (aged 16 or over) per neonatal unit (in each wave) whose baby (or babies) has received neonatal care for more than 24 hours and who had been discharged home - 15,944 eligible parents were sent a questionnaire. Responses were received from 6000 parents, (response rate of 37.6%)	**SURVEY OVERVIEW** - A report of a study to explore different methods of obtaining feedback relating to the experiences of children and young people with cancer - Commissioned by NHS England to fulfil need of national cancer strategy to collect patient experience data for under 16s - Study had 3 parts: a literature review; interviews with healthcare professionals; interviews with children and young people, parents and carers (the analysis below only relates to the interviews with children and young people) - 13 children and young people who had received cancer treatment aged 7 to 17 years took part (3 were 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 yourself.' (M16)
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% **UNDERSTANDING:**	**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	**COMMUNICATION 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	**UNDERSTANDING (EMERGENCY DEPARTMENT):** - 70% children and young people aged 8-16 said doctors and nurses explained what was wrong in a way they could understand	**COMMUNICATION WITH STAFF ON NEONATAL UNIT:** - When you visited the unit did the staff caring for your baby introduce themselves to you? Score = 79	**BEING INFORMED ABOUT TREATMENT:** **-** Young people aged 13 to 17 reported a good experience of how the diagnosis and treatment plan

	and young children.		~70% children and young people understood what staff said **ASKING QUESTIONS:** - 95% 8-15 year olds felt able to ask questions and 92% said their questions were answered.					language they use is confusing'. **COMMUNICATION WITH DISABLED YOUNG PEOPLE:** - Disabled young people aged 15-21 recommended that there should be an NHS e-learning module on communicating with young people with learning difficulties and communication impairments, resources in hospitals to address communication with disabled young people, and systems for setting up appointments which would support preparation for the consultation.		- 27% children and young people said doctors and nurses did not talk to them about their questions or worries **LISTENING (OUTPATIENTS):** - 76% children and young people aged 8-16 years thought they were listened to by hospital staff	- Were you told which nurse was responsible for your baby's care each day he/she was in the neonatal unit? Score = 90 - Were you able to talk to staff on the unit about your worries and concerns? Score = 88 - Were you able to speak to a doctor about your baby as much as you wanted? Score = 66 - Were the nurses on the unit sensitive to your emotions and feelings? Score = 85 - Were the doctors on the unit sensitive to your emotions and feelings? Score = 83 - Did staff refer to your baby by his/her first name? Score = 90	was communicated and discussed with them and none felt excluded from this process. All felt that the manner in which doctors had spoken with them (and with their parents at the same time) had been unproblematic. None felt that that medical staff had spoken about them but not to them, nor that they were made to feel that their views were not important. **Quotes:** 'When they were deciding the treatment, I felt I was fully involved. I was always asked before they were doing anything. They always had me and my 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 recommendations 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 or carers of babies and young children, prefer to access healthcare information?’	children and young people, and the parents or carers of babies and young children, prefer to access healthcare information.	identified for this question	- 93% of children 8 to 15 years old said that staff explained pre-operative information - 76% said that they were informed how the procedure had gone - 90% of parents said staff explained the procedure in a way they could understand	**HEALTH HELP AVAILABLE:** **-** 74.4% of children and young people said they were given enough explanation about the help available	identified for this question	identified for this question	- Of young people who had raised a concern or made a complaint, in 48% the subject had been lack of information about a health condition or treatment options not being well explained.	identified for this question	identified for this question	**OUTPATIENT VISIT:** **-** 55% of children and young people aged 8-16 years did not know before their visit to hospital what was going to happen to them while they were there	- Before your baby was born did a member of staff from the neonatal unit talk to you about what to expect after the birth? Score = 54 **INFORMATION ABOUT THE NEONATAL UNIT:** - Were you given enough 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	identified for this question

											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	
RQ 2.2 'What are 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?'	The aim of this 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.	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	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	No relevant 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	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	**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

decisions about their care?	people, want their parents or carers to be involved in their care and decisions about their care.							that as the young person reaches adolescence, the clinician should explore with the family the formal handing over to the young person of their own diagnosis.				her parents' involvement when she was younger. **Quotes:** 'I think it's really important that you can influence 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 doctor I didn't know.' (F15)
RQ 3.2 'How do children and young people want healthcare staff to support them?'	To establish how children and young people want healthcare staff to support them to be involved in, and making decisions about, their own healthcare.	No relevant findings were identified for this question	**EMOTIONAL SUPPORT:** - 92% of 8-15 year olds who had worries said that staff talked with them about them	**VIEWS AND WORRIES:** - 84.1% of children and young people said their views and worries were taken seriously	No relevant findings were identified for this question	No relevant findings were identified for this question	**LACK OF 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 patient care	**BEING TAKEN 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' - Disabled young people aged 15 to 21 recommended that performance assessments for staff working with disabled young people and	No relevant findings were identified for this question	No relevant findings were identified for this question	**EMOTIONAL 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 your baby? Score = 92	No relevant findings were identified for this question

								those with long-term conditions should include a focus on the extent to which they are fostering self-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 aged 16-25 consulted about mental health professionals had mixed views and said: ‘Last time I went to counselling...she 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 … 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 on.’ ‘You can speak to them and				

								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.'				
RQ 3.3 'How can children and young people be empowered to advocate for themselves?'	This review aims to establish how children and young people want their parents and carers of babies and young people, to be empowered to advocate for themselves.	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	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	No relevant 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	**ENCOURAGEMENT 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	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

improve their experience of healthcare services?’	improve their experience of healthcare services		group of children who had had cancer in last 5 years this was lower -35% parents of 0 to 7 year olds said they liked hospital food - 17% of parents of 0-15 year olds said they did not have access to hot drink facilities - 36% of parents were unable to prepare food in hospital **PAIN:** - 79% of children aged 8 to 15 years old who had pain felt that staff did everything they could to help								support you needed from neonatal staff? Score = 86 - When you were in the neonatal unit, were you given the feeding equipment you needed for expressing, such as breast pump and sterilisation equipment? Score = 87 - If you wanted to breastfeed your baby, were you given enough support to do this from neonatal staff? Score = 84 = If you fed your baby formula milk, were you given enough support to do this from neonatal staff? Score = 85 **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	hospital was a major concern. **Quotes:** ‘The only problem (at hospital 1) was the food. That was also the case in (hospital 2). But there, my mum could buy better food outside and bring it to me.’ (M16) ‘In (hospital 1) the food was dire. It was micro-waved and really hard, but I didn’t know what to say. It’s not like they’re going to change it overnight. In (hospital 2) the food was very good.’ (F15)

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

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

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

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

		who actually would or have used the service being in positions to make changes and take complaints, rather than someone who is just guessing what is actually needed"; "Most people won't speak up because they don't' want to make a fuss, it isn't worth it. There needs to be a mass change. A change in the way we read and interpret opinions. Not seeing the individual as someone who just wants to complain. But someone who would like to see genuine, positive change."					standards of care (34%) - A more open culture encouraging feedback (34%) - Receiving regular feedback on actions taken (37%) - Having an advocate or third party who could raise concerns (19%) - Being able to report concerns anonymously (34%) - Knowing which staff (36%) or services (24%) to raise concerns with					online survey as easy to administer, cheap and simple to complete, and would like to receive the invitation by email not by text. **Quotes:** 'I feel that a group would be good for support rather than to give information. If I was invited to one now, I wouldn't mind going to it. But when I was ill I wouldn't have done it. I would prefer a survey. And I think that for me, when I was in hospital, for a lot of the time I was just too ill to engage with a group discussion or anything like 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

												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)

												‘‘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 them

												- 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 their room/ environment.

												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 nice they 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)
RQ 6.1 ‘What features of the	To determine what features of	No relevant findings were	**WARD SUITABLE:**	**FACILITIES /WAITING AREA:**	No relevant findings were	No relevant findings were	No relevant findings were	**HOSPITAL ENVIRONMENT:**	No relevant findings were	No relevant findings were	**WARD FACILITIES:**	No relevant findings were

environment in which healthcare is provided are important to babies, children and young people to improve their experience of care?'	the environment in which healthcare is provided are important to babies, children and young people to improve their experience of care.	identified for this question	~ 70% of 12-15 year olds said ward was suitable for someone their age - Of those who stayed on a teenage or adolescent ward this rose to 80% - Of those who stayed on a children's or adult ward this fell to ~66% **EQUIPMENT:** - 73% 0-15 year olds had appropriate equipment or adaptations to meet their needs - Poorer experience was reported by parents of children with developmental disability, mental health conditions, neurological conditions or other long term condition **SLEEP:** - 40% 8-15 year olds said it was quiet enough to sleep **CLEANLINESS:** - 67% parents reported that hospital room or ward was very clean	- 63.5% of children and young people said the facilities were comfortable	identified for this question	identified for this question	identified for this question	- Children and young people aged 12-19 reported: 'Depressing and boring because you have to wait long hours and there's nothing to do'; 'Horrible, the smell makes you nervous' and 'The beds are old and uncomfortable, toys don't work and parts are missing'.	identified for this question	identified for this question	- Was there enough space for you to sit alongside your baby's cot in the unit? Score = 82 - In your opinion was there adequate security on the neonatal unit? Score = 88 **OVERNIGHT STAYS:** - If you wanted to stay overnight to be close to your baby, did the hospital offer you accommodation? Score = 70	identified for this question
RQ 7.1 'How can health services support babies, children, and young people to participate in	To determine how health services can support babies, children, and young people to	No relevant findings were identified for this question	**WIFI:** - 41% 8-15 year olds who used hospital Wi-Fi said that it was 'always' good	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	**WIFI:** - 36% parents of 0-7 year olds said Wi-Fi was good enough for children to do	**ACTIVITIES (OUTPATIENTS):** - 26% of children and young people aged 8 to 16 thought there	**INVOLVEMENT IN CARING FOR THEIR BABY:** - Were you involved as much as you wanted in	**LIAISION WITH SCHOOL:** - 1 teenager suggested it would have been helpful if the

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

												was because they're not working with the local secondary school in (hospital).' (F14) 'The school service was ok but they only came on the last day I was there.' (F15) **SOCIAL ACTIVITIES:** - Some young people aged 13 to 17 years reported that they felt isolated in a room away from other people. **Quotes:** 'The social aspects: that was not so good. Because in (hospital) all the cancer patients are put in a side room, so you don't see people.' (F14)
RQ 8.1 'What are the facilitators of, and barriers to, accessing healthcare services for babies, children and young people?'	To determine the facilitators of, and barriers to, accessing healthcare services faced by babies, children and young people.	**USE OF DIFFERENT HEALTH SERVICES:** - Over 80% of young people had used General practice, pharmacies and hospital health services, and were positive about how all these services met their needs - 70% had used accident and emergency, but this was ranked lowest of 7	No relevant findings were identified for this question	**APPOINTMENTS:** - 62% of children and young people said the timing of their appointment was convenient - 66.4% of children and young people said the location of the appointment was easy to get to	**ACCESS TO NHS DENTAL SERVICES:** - 83% of parents (of children of all ages) said they did not have problems finding an NHS dentist, although a breakdown by free school meal eligibility found that this was 78% where children were eligible for free school meals - 76% of parents of 5 year olds were satisfied	**ACCESS TO HEALTHCARE IN CUSTODY**: Secure training centres: - 82% of children and young people said that they were able to see a doctor or nurse if they felt unwell -64% said the health services were 'good' - 24% said they had health needs which were not being met	**APPOINTMENTS:** - Of young people who had raised a concern or made a complaint, in 63% the subject had been delays in getting an appointment or the appointment being cancelled	**ACCESS TO HEALTHCARE FOR CARE-LEAVERS:** - Care leavers (age not specified) reported that they needed increased levels of support to access health services such as regular check-ups every six months, more money for dental and NHS doctor care, someone to make sure that	No relevant findings were identified for this question	No relevant findings were identified for this question	No relevant findings were identified for this question	**CHOICE OF HOSPITAL:** - 1 teenager reported not being treated at a hospital of her (and her parents') choice, resulting in a more difficult journey. **Quotes:** 'We asked to stay at (hospital 1) because it was more convenient, but they just refused and said, 'no,

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

					not for routine check-ups			• Where and how to find local health services, 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 factors promote, or present barriers to, continuity of care for babies, children and young people?'	To determine the factors which promote or present barriers to continuity of healthcare for babies, children and young people.	No relevant findings were identified for this question	**KNOWLEDGE OF MEDICAL HISTORY:** - 58% parents of 0-15 year olds said staff were aware of their child's medical history **DISCHARGE FROM HOSPITAL:**	No relevant findings were identified for this question	No relevant findings were identified for this question	No relevant findings were identified for this question	**ADMISSION/ DISCHARGE/ TRANSFER:** - Of young people who had raised a concern or made a complaint, in 31% the subject had related to admission, discharge or transfer, or a lack	**DISCHARGE FROM TERTIARY CARE:** - Disabled young people aged 15-21 recommended that at the stage of discharge from tertiary care after diagnosis, thought must be given to the way in which	**DISCHARGE FROM HOSPITAL:** 71% of parents of 0-7 years old knew what was going to happen next, and 79% knew who to talk to if they were worried about their child	No relevant findings were identified for this question	**KNOWLEDGE OF MEDICAL HISTORY:** - In your opinion, was important information about your baby passed from one member of staff to another? Score = 84 - Did the staff give you	No relevant findings were identified for this question

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