

## Babies, children and young people's experience of healthcare

### Supplement 5: Grey literature review of national surveys

*NICE guideline NG204*

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## Contents

<b>Evidence from national surveys.....</b>	<b>5</b>
Introduction .....	5
Inclusion criteria .....	5
Search strategy .....	5
Sources searched .....	6
Surveys identified .....	7
Surveys included .....	7
Quality assessment .....	9
References.....	20
Surveys excluded .....	21
Evidence mapping to review questions.....	21

# Evidence from national surveys

## Introduction

During the scoping for this guideline, a number of national surveys of children and young people's experience of healthcare were identified. Some of these surveys were conducted by or on behalf of the NHS, or by national charities and they provided a snapshot of children's and young people's views on different aspects of healthcare provision. The surveys were not published in peer-reviewed literature and so would not be identified by the systematic literature searches. However, the results of these surveys provided a wealth of information, both quantitative and qualitative, and the committee agreed that a grey literature review of national surveys should be undertaken in parallel to the systematic reviews to provide additional evidence. Use of grey literature is in accordance with the recommendations on sources of evidence in [Developing NICE guidelines: the manual \(2014, updated 2020\)](#).

## Inclusion criteria

A number of criteria were agreed with the committee to define the surveys that would be included in the grey literature review. These were:

- Surveys must collect information from children or young people on their experience of healthcare, or from the parents or carers of babies or young children.
  - As with the systematic literature review, the views of parents and carers were only included if they are acting as a proxy for a baby or child under 5 years, or there is a clear rationale provided as to why the study is using parents' or carers' views on and experiences of healthcare as proxies for their child.
- Surveys must be conducted nationally across England, the UK or contain samples of data from a variety of geographical locations across the UK, so that the results could be interpreted as applicable to babies, children and young people across England.
- Surveys must have been conducted during or after 2014. This cut-off date was selected as a number of surveys are conducted on a regular basis (for example every 2 or 3 years) and it was only necessary to capture the most recent version, and for pragmatic reasons to limit the size of the search.
- Surveys must provide quantitative or qualitative data that is relevant to at least one of the review questions under consideration for this guideline. The committee agreed that qualitative data would supplement the main systematic qualitative literature reviews conducted for the guideline, but the committee were aware that a number of large national surveys may contain a mixture of qualitative and quantitative data, or just quantitative data, and that this might also provide useful insights.

## Search strategy

The search terms used were:

((child or children or adolescent or adolescents or teenage or youth or paediatric or baby or babies or neonate) and (health\*) and (survey or surveys))

## **Sources searched**

The following sources were searched for surveys. In addition to these sources the committee members were asked to identify any national surveys that they were aware of for consideration.

### ***Catalogues and databases***

- OpenGrey
- Greylit
- EThOS
- Patient Experience Library

### ***NHS and other organisations***

- NHS England Scotland Wales and Northern Ireland
- NHS Digital
- NHSsurveys.org
- King's Fund
- Youthhealthtalk.org
- CQC
- Nationalvoices.org.uk
- Royal College of Paediatric and Child Health
- Picker Institute
- Joseph Rowntree
- National Children's Bureau
- NHS Youth Forum
- Patient participation groups

### ***National charities***

- NSPCC
- Together For Short Lives
- Rainbow Trust
- Save The Children
- Children With Cancer
- Children's Society
- Barnado's
- Honey Pot
- Action for children
- Starlight
- Child Autism
- National Deaf Children's Society
- Family Fund
- Young Minds
- Mermaids

- The Children’s Hospital Charity
- Support Evelina
- The Grand Appeal
- GOSH
- Bliss
- Childline
- Girlguiding
- Scouts

### **Google Search**

Searching was limited to the first 10 pages when results exceeded 10 pages.

### **Surveys identified**

Eighteen surveys were identified from the search and were checked to ensure they met the inclusion criteria.

### **Surveys included**

Twelve surveys met the inclusion criteria and were therefore included in the grey literature review. They are summarised in Table 1.

**Table 1: Surveys included**

<b>Survey title</b>	<b>Population</b>	<b>Notes</b>
<b>Association for Young People’s Health. Young people’s views on involvement and feedback in healthcare 2014</b>	<ul style="list-style-type: none"> <li>• Children and young people aged 10-24 years who completed an on-line survey</li> <li>• N=67 aged 10-19</li> </ul>	<ul style="list-style-type: none"> <li>• Aim of 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</li> <li>• 98 respondents in total, which included young people aged 20-24, but data analysed only for cohort aged 10-19 where possible</li> </ul>
<b>Care Quality Commission. Children and young people’s inpatient and day case survey 2018 (conducted by the Picker Institute)</b>	<ul style="list-style-type: none"> <li>• Babies, 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</li> <li>• Children aged 8-11 or 12-15 received a questionnaire of two halves, one for themselves to complete, and one for their parent/carer</li> <li>• Questionnaire completed solely by the parent/carer of children aged 0-7 years</li> </ul>	

Babies, children and young people’s experience of healthcare: Supplement 5. Grey literature review of national surveys FINAL (August 2021)

Survey title	Population	Notes
	<ul style="list-style-type: none"> <li>• Sampled 129 NHS acute trusts</li> <li>• N=33,170 completed surveys</li> </ul>	
<b>Child Outcomes Research Consortium. Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011-2015</b>	<ul style="list-style-type: none"> <li>• Babies children and young people aged 0-25 years</li> <li>• Sampled 75 mental health services in England taking part in the service transformation 'Children and Young People's Improving Access to Psychological Therapies'</li> <li>• N=3,196 children, mean age 13.8 years</li> </ul>	Used an experience of service questionnaire (ESQ) to explore satisfaction with services
<b>Health and Social Care Information Centre. Children's Dental Health Survey 2013. (Country specific report for England, published 2015</b>	<ul style="list-style-type: none"> <li>• Children and young people aged 5, 8, 12 and 15 years undergoing a dental examination, were invited to complete a survey</li> <li>• Parents completed surveys for 5 and 8 year olds; 12 and 15 years olds completed survey themselves</li> <li>• n=approx. 700 aged 5</li> <li>• n=approx. 600 aged 8</li> <li>• n=approx. 1,400 aged 12</li> <li>• n=approx. 1,300 aged 15</li> </ul>	<ul style="list-style-type: none"> <li>• Focus of survey was access to treatment, perceptions and anxiety about treatment</li> <li>• Exact numbers for each group not available as results were reported separately for each question, in terms of the number who answered that question</li> </ul>
<b>HM Inspectorate of Prisons. Children in Custody 2016-2017</b>	<ul style="list-style-type: none"> <li>• Young people aged 12-18 years in 3 secure training centres, 5 young offender institutions and 1 specialist unit</li> <li>• N= 720 completed questionnaires</li> </ul>	Section on health care (from a larger questionnaire on experiences in general) was analysed
<b>National Children's Bureau. Listening to children's views on health provision 2012</b>	<ul style="list-style-type: none"> <li>• A narrative review of findings from 46 consultations conducted with children and young people by a number of organisations across England</li> <li>• 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.</li> </ul>	Where possible, responses only from children and young people under 18 are included in the analysis, but for some of the findings it was not possible to determine the age of the respondents so data from young adults may have been included.
<b>Opinion Matters. Declare your care survey 2018</b>	<ul style="list-style-type: none"> <li>• Children and young people in England who had received some sort of health service (NHS and private care) or social care experience in the</li> </ul>	<ul style="list-style-type: none"> <li>• Questionnaire focused on reporting concerns</li> <li>• 2002 respondents in total, which included adults, but data analysed only for cohort aged 12-15</li> </ul>

Babies, children and young people's experience of healthcare: Supplement 5. Grey literature review of national surveys FINAL (August 2021)



Survey title	Population	Notes
	<p>last 5 years, either as a patient or a carer</p> <ul style="list-style-type: none"> <li>• n=128 children aged 12-15</li> </ul>	
<b>Picker Institute. Children and Young People's Patient Experience Survey 2018</b>	<ul style="list-style-type: none"> <li>• Same survey as: Care Quality Commission. Children and young people's inpatient and day case survey 2018 (see above)</li> </ul>	Data from the Picker Institute report of this survey is included separately as it contains some details not included in the CQC report
<b>Picker Institute. Paediatric Emergency Department Survey 2015</b>	<ul style="list-style-type: none"> <li>• Babies children and young people aged 0 to 16 years attending an emergency department</li> <li>• Sampled 5 NHS emergency departments</li> <li>• n=387 children aged 8-16</li> <li>• n=650 parents of children aged 0-16</li> </ul>	Only children's responses were analysed
<b>Picker Institute. Children and Young People's Outpatient Survey 2015</b>	<ul style="list-style-type: none"> <li>• Babies children and young people aged 0 to 16 years attending an outpatient appointment</li> <li>• Sampled 9 NHS trusts</li> <li>• n=916 children aged 8-16</li> <li>• n=1,039 parents of children aged 0-16</li> </ul>	Only children's responses were analysed
<b>Picker Institute/ NHS England / BLISS. Neonatal Survey 2014</b>	<ul style="list-style-type: none"> <li>• Parents whose babies had been in a neonatal care unit for at least 24 hours and then discharged</li> <li>• Sampled sequentially from 88 neonatal units across England</li> <li>• N=6000 completed questionnaires</li> </ul>	
<b>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</b>	<ul style="list-style-type: none"> <li>• Children aged 7-17 years who had received cancer treatment</li> <li>• N=13 (3 aged under 11, 10 aged 13-17)</li> </ul>	<ul style="list-style-type: none"> <li>• Qualitative study with interviews conducted in small groups or over the phone</li> </ul>

## Quality assessment

The quality of the evidence of the surveys included as part of the grey literature is summarised in Table 2.

**Table 2: Quality assessment**

Survey title	Limitations
<p><b>Association for Young People’s Health. Young people’s views on involvement and feedback in healthcare 2014</b></p>	<p><u>The quality of the evidence was assessed with the Center for Evidence-Based Management (CEBM) checklist for survey questionnaire studies</u></p> <ol style="list-style-type: none"> <li>1. Did the study assess a clearly focused question / issue? Yes</li> <li>2. Is the research method (study design) appropriate for answering the research question? Yes</li> <li>3. Is the method of selection of the subjects (employees, teams, divisions, organizations) clearly described? Yes</li> <li>4. Could the way the sample was obtained introduce (selection) bias? Yes</li> <li>5. Was the sample of subjects representative with regard to the population to which the findings will be referred? No</li> <li>6. Was the sample size based on pre-study considerations of statistical power? No</li> <li>7. Was a satisfactory response rate achieved? Unclear (total number of surveys sent was not reported)</li> <li>8. Are the measurements (questionnaires) likely to be valid and reliable? No</li> <li>9. Was the statistical significance assessed? No</li> <li>10. Are confidence intervals given for the main results? No</li> <li>11. Could there be confounding factors that haven’t been accounted for? No</li> <li>12. Can the results be applied to your organization? Yes</li> </ol> <p>Overall quality of the evidence: Low</p>
<p><b>Care Quality Commission. Children and young people’s inpatient and day case survey 2018 (conducted by the Picker Institute) &amp; Picker Institute. Children and Young People’s Patient Experience Survey 2018</b></p>	<p><u>The quality of the evidence was assessed with the Center for Evidence-Based Management (CEBM) checklist for survey questionnaire studies</u></p> <ol style="list-style-type: none"> <li>1. Did the study assess a clearly focused question / issue? Yes</li> <li>2. Is the research method (study design) appropriate for answering the research question? Yes</li> <li>3. Is the method of selection of the subjects (employees, teams,</li> </ol>

Survey title	Limitations
	<p>divisions, organizations) clearly described? Yes</p> <ol style="list-style-type: none"> <li>4. Could the way the sample was obtained introduce (selection) bias? No</li> <li>5. Was the sample of subjects representative with regard to the population to which the findings will be referred? Yes</li> <li>6. Was the sample size based on pre-study considerations of statistical power? No</li> <li>7. Was a satisfactory response rate achieved? No</li> <li>8. Are the measurements (questionnaires) likely to be valid and reliable? No</li> <li>9. Was the statistical significance assessed? No</li> <li>10. Are confidence intervals given for the main results? No</li> <li>11. Could there be confounding factors that haven't been accounted for? No</li> <li>12. Can the results be applied to your organization? Yes</li> </ol> <p>Overall quality of the evidence: Low</p>
<p><b>Child Outcomes Research Consortium. Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011-2015</b></p>	<p><u>The quality of the evidence was assessed with the Center for Evidence-Based Management (CEBM) checklist for survey questionnaire studies</u></p> <ol style="list-style-type: none"> <li>1. Did the study assess a clearly focused question / issue? Yes</li> <li>2. Is the research method (study design) appropriate for answering the research question? Yes</li> <li>3. Is the method of selection of the subjects (employees, teams, divisions, organizations) clearly described? Yes</li> <li>4. Could the way the sample was obtained introduce (selection) bias? No</li> <li>5. Was the sample of subjects representative with regard to the population to which the findings will be referred? Yes</li> <li>6. Was the sample size based on pre-study considerations of statistical power? No</li> <li>7. Was a satisfactory response rate achieved? Yes</li> </ol>

Survey title	Limitations
	8. Are the measurements (questionnaires) likely to be valid and reliable? Yes 9. Was the statistical significance assessed? No 10. Are confidence intervals given for the main results? No 11. Could there be confounding factors that haven't been accounted for? No 12. Can the results be applied to your organization? Yes Overall quality of the evidence: Moderate
<b>Health and Social Care Information Centre. Children's Dental Health Survey 2013. (Country specific report for England, published 2015)</b>	<u>The quality of the evidence was assessed with the Center for Evidence-Based Management (CEBM) checklist for survey questionnaire studies</u> 1. Did the study assess a clearly focused question / issue? Yes 2. Is the research method (study design) appropriate for answering the research question? Yes 3. Is the method of selection of the subjects (employees, teams, divisions, organizations) clearly described? Yes 4. Could the way the sample was obtained introduce (selection) bias? No 5. Was the sample of subjects representative with regard to the population to which the findings will be referred? No 6. Was the sample size based on pre-study considerations of statistical power? No 7. Was a satisfactory response rate achieved? Yes 8. Are the measurements (questionnaires) likely to be valid and reliable? Yes 9. Was the statistical significance assessed? No 10. Are confidence intervals given for the main results? No 11. Could there be confounding factors that haven't been accounted for? no 12. Can the results be applied to your organization? Yes Overall quality of the evidence: Moderate

Survey title	Limitations
<p><b>HM Inspectorate of Prisons.            Children in Custody 2016-2017</b></p>	<p><u>The quality of the evidence was assessed with the Center for Evidence-Based Management (CEBM) checklist for survey questionnaire studies</u></p> <ol style="list-style-type: none"> <li>1. Did the study assess a clearly focused question / issue? Yes</li> <li>2. Is the research method (study design) appropriate for answering the research question? Yes</li> <li>3. Is the method of selection of the subjects (employees, teams, divisions, organizations) clearly described? Yes</li> <li>4. Could the way the sample was obtained introduce (selection) bias? No</li> <li>5. Was the sample of subjects representative with regard to the population to which the findings will be referred? Yes</li> <li>6. Was the sample size based on pre-study considerations of statistical power? No</li> <li>7. Was a satisfactory response rate achieved? Yes</li> <li>8. Are the measurements (questionnaires) likely to be valid and reliable? No</li> <li>9. Was the statistical significance assessed? No</li> <li>10. Are confidence intervals given for the main results? No</li> <li>11. Could there be confounding factors that haven't been accounted for? No</li> <li>12. Can the results be applied to your organization? Yes</li> </ol> <p>Overall quality of the evidence:            Moderate</p>
<p><b>National Children's Bureau.            Listening to children's views on health provision 2012</b></p>	<p><u>The quality of the evidence was assessed with the Center for Evidence-Based Management (CEBM) checklist for survey questionnaire studies</u></p> <ol style="list-style-type: none"> <li>1. Did the study assess a clearly focused question / issue? Yes</li> <li>2. Is the research method (study design) appropriate for answering the research question? Yes, routinely collected data</li> <li>3. Is the method of selection of the subjects (employees, teams, divisions, organizations) clearly described? Yes</li> </ol>

Survey title	Limitations
	<ol style="list-style-type: none"> <li>4. Could the way the sample was obtained introduce (selection) bias? No</li> <li>5. Was the sample of subjects representative with regard to the population to which the findings will be referred? Yes</li> <li>6. Was the sample size based on pre-study considerations of statistical power? No</li> <li>7. Was a satisfactory response rate achieved? Yes</li> <li>8. Are the measurements (questionnaires) likely to be valid and reliable? Yes</li> <li>9. Was the statistical significance assessed? No</li> <li>10. Are confidence intervals given for the main results? No</li> <li>11. Could there be confounding factors that haven't been accounted for? No</li> <li>12. Can the results be applied to your organization? Yes</li> </ol> <p>Overall quality of the evidence: Moderate</p>
<p><b>Opinion Matters.</b>  <b>Declare your care survey 2018</b></p>	<p><u>The quality of the evidence was assessed with the Center for Evidence-Based Management (CEBM) checklist for survey questionnaire studies</u></p> <ol style="list-style-type: none"> <li>1. Did the study assess a clearly focused question / issue? Yes</li> <li>2. Is the research method (study design) appropriate for answering the research question? Unclear, not enough information was provided</li> <li>3. Is the method of selection of the subjects (employees, teams, divisions, organizations) clearly described? Unclear, not enough information was provided</li> <li>4. Could the way the sample was obtained introduce (selection) bias? Unclear, not enough information was provided</li> <li>5. Was the sample of subjects representative with regard to the population to which the findings will be referred? Unclear, not enough information was provided</li> <li>6. Was the sample size based on pre-study considerations of statistical power? Unclear, not enough information was provided</li> </ol>

Survey title	Limitations
	<ol style="list-style-type: none"> <li>7. Was a satisfactory response rate achieved? Unclear, not enough information was provided</li> <li>8. Are the measurements (questionnaires) likely to be valid and reliable? Unclear, not enough information was provided</li> <li>9. Was the statistical significance assessed? Unclear, not enough information was provided</li> <li>10. Are confidence intervals given for the main results? Unclear, not enough information was provided</li> <li>11. Could there be confounding factors that haven't been accounted for? Unclear, not enough information was provided</li> <li>12. Can the results be applied to your organization? Unclear, not enough information was provided</li> </ol> <p>Overall quality of the evidence: Low</p>
<p><b>Picker Institute.            Paediatric Emergency Department Survey            2015</b></p>	<p><u>The quality of the evidence was assessed with the Center for Evidence-Based Management (CEBM) checklist for survey questionnaire studies</u></p> <ol style="list-style-type: none"> <li>1. Did the study assess a clearly focused question / issue? Yes</li> <li>2. Is the research method (study design) appropriate for answering the research question? Unclear, not enough information was provided</li> <li>3. Is the method of selection of the subjects (employees, teams, divisions, organizations) clearly described? Unclear, not enough information was provided</li> <li>4. Could the way the sample was obtained introduce (selection) bias? Unclear, not enough information was provided</li> <li>5. Was the sample of subjects representative with regard to the population to which the findings will be referred? Unclear, not enough information was provided</li> <li>6. Was the sample size based on pre-study considerations of statistical power? Unclear, not enough information was provided</li> <li>7. Was a satisfactory response rate achieved? Unclear, not enough information was provided</li> </ol>

Survey title	Limitations
	<p>8. Are the measurements (questionnaires) likely to be valid and reliable? Unclear, not enough information was provided</p> <p>9. Was the statistical significance assessed? Unclear, not enough information was provided</p> <p>10. Are confidence intervals given for the main results? Unclear, not enough information was provided</p> <p>11. Could there be confounding factors that haven't been accounted for? Unclear, not enough information was provided</p> <p>12. Can the results be applied to your organization? Unclear, not enough information was provided</p> <p>Overall quality of the evidence: Low</p>
<p><b>Picker Institute.</b>  <b>Children and Young People's Outpatient Survey 2015</b></p>	<p><u>The quality of the evidence was assessed with the Center for Evidence-Based Management (CEBM) checklist for survey questionnaire studies</u></p> <ol style="list-style-type: none"> <li>1. Did the study assess a clearly focused question / issue? Yes</li> <li>2. Is the research method (study design) appropriate for answering the research question? Unclear, not enough information was provided</li> <li>3. Is the method of selection of the subjects (employees, teams, divisions, organizations) clearly described? Unclear, not enough information was provided</li> <li>4. Could the way the sample was obtained introduce (selection) bias? Unclear, not enough information was provided</li> <li>5. Was the sample of subjects representative with regard to the population to which the findings will be referred? Unclear, not enough information was provided</li> <li>6. Was the sample size based on pre-study considerations of statistical power? Unclear, not enough information was provided</li> <li>7. Was a satisfactory response rate achieved? Unclear, not enough information was provided</li> <li>8. Are the measurements (questionnaires) likely to be valid and reliable? Unclear, not enough information was provided</li> </ol>



Survey title	Limitations
	9. Was the statistical significance assessed? Unclear, not enough information was provided 10. Are confidence intervals given for the main results? Unclear, not enough information was provided 11. Could there be confounding factors that haven't been accounted for? Unclear, not enough information was provided 12. Can the results be applied to your organization? Unclear, not enough information was provided Overall quality of the evidence: Low
<b>Picker Institute/ NHS England / BLISS. Neonatal Survey 2014</b>	<u>The quality of the evidence was assessed with the Center for Evidence-Based Management (CEBM) checklist for survey questionnaire studies</u> 1. Did the study assess a clearly focused question / issue? Yes 2. Is the research method (study design) appropriate for answering the research question? Yes 3. Is the method of selection of the subjects (employees, teams, divisions, organizations) clearly described? Yes, consecutive sampling 4. Could the way the sample was obtained introduce (selection) bias? No 5. Was the sample of subjects representative with regard to the population to which the findings will be referred? Yes 6. Was the sample size based on pre-study considerations of statistical power? No 7. Was a satisfactory response rate achieved? No 8. Are the measurements (questionnaires) likely to be valid and reliable? No 9. Was the statistical significance assessed? No 10. Are confidence intervals given for the main results? Yes 11. Could there be confounding factors that haven't been accounted for? No 12. Can the results be applied to your organization? Yes Overall quality of the evidence: Moderate

Survey title	Limitations
<p><b>Word of Mouth Research and Point of Care Foundation.</b>  <b>An options appraisal for obtaining feedback on the experiences of children and young people with cancer 2018</b></p>	<p><u>The quality of the quantitative evidence was assessed with the Center for Evidence-Based Management (CEBM) checklist for survey questionnaire studies</u></p> <ol style="list-style-type: none"> <li>1. Did the study assess a clearly focused question / issue? Yes</li> <li>2. Is the research method (study design) appropriate for answering the research question? Yes</li> <li>3. Is the method of selection of the subjects (employees, teams, divisions, organizations) clearly described? Yes</li> <li>4. Could the way the sample was obtained introduce (selection) bias? Yes</li> <li>5. Was the sample of subjects representative with regard to the population to which the findings will be referred? No</li> <li>6. Was the sample size based on pre-study considerations of statistical power? No</li> <li>7. Was a satisfactory response rate achieved? Yes</li> <li>8. Are the measurements (questionnaires) likely to be valid and reliable? No</li> <li>9. Was the statistical significance assessed? No</li> <li>10. Are confidence intervals given for the main results? No</li> <li>11. Could there be confounding factors that haven't been accounted for? No</li> <li>12. Can the results be applied to your organization? Yes</li> </ol> <p>Overall quality of the evidence: Low</p> <p><u>The quality of the qualitative evidence was assessed using the CASP checklist for qualitative studies</u></p> <ol style="list-style-type: none"> <li>1: Was there a clear statement of the aims of the research? Yes</li> <li>2: Was a qualitative methodology appropriate? Yes</li> <li>3 Was the research design appropriate to address the aims of the research? Yes</li> <li>4: Was the recruitment strategy appropriate to the aims of the</li> </ol>

Survey title	Limitations
	<p>research? No. Details on recruitment strategy were not provided, suitable volunteers were identified, suggesting selection bias</p> <p>5: Were the data collected in a way that addressed the research issue? Yes. Semi-structured interviews and focus groups were used, but no detailed information on interview guides</p> <p>6: Has the relationship between the researcher and participants been adequately considered? No. Descriptions of potential bias/influence between researcher and participants were not described</p> <p>7: Have ethical issues been taken into consideration? No details were provided</p> <p>Q8: Was the data analysis sufficiently rigorous? Can't tell, no enough details were reported</p> <p>9: Is there a clear statement of findings? No, no explanation of findings was reported</p> <p>10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) yes. 1. No, it does not contextualise findings in the literature. 2. Probably not. Small population size and sample had a limited age range</p> <p>Overall judgement of quality: serious concerns.</p>

*CASP: Critical Appraisal Skills Programme; CEBM: Center for Evidence Based Management*

## References

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Association for Young People's Health (2014) Young people's views on involvement and feedback in healthcare: Report of a brief on-line survey of young people. London: AYPH

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La Valle, I., Payne, L., Gibb, J., & Jelacic, H. (2012). Listening to children's views on health provision: A rapid review of the evidence. London: National Children's Bureau Research Centre

### **Opinion Matters. Declare your care survey 2018**

Declare Your Care: Children and young people (2018) Survey results data

### **Picker Institute. Children and Young People's Patient Experience Survey 2018**

Picker for the Care Quality Commission (2018) Children and Young People's Patient Experience Survey

### **Picker Institute. Paediatric Emergency Department Survey 2015**

Picker for the Care Quality Commission (2015) Paediatric Emergency survey

### **Picker Institute. Children and Young People's Outpatient Survey 2015**

Picker for the Care Quality Commission (2015) Children and Young People's Outpatient Survey

### **Picker Institute/ NHS England / BLISS. Neonatal Survey 2014**

Picker for the Care Quality Commission, NHS England, BLISS (2014) Neonatal survey

Babies, children and young people's experience of healthcare: Supplement 5. Grey literature review of national surveys FINAL (August 2021)

## Word of Mouth Research and Point of Care Foundation 2018

Word of Mouth Research and Point of Care Foundation (2018) An Options Appraisal for obtaining feedback on the experiences of children and young people with cancer. Final report to NHS England

### Surveys excluded

Six surveys were excluded and reasons for their exclusion are provided in Table 3.

**Table 3: Surveys excluded**

Survey title	Reason for exclusion
<b>Hargreaves, D. S., Sizmur, S., Pitchforth, J., Tallett, A., Toomey, S. L., Hopwood, B., ... &amp; Viner, R. M. (2018). Children and young people's versus parents' responses in an English national inpatient survey. Archives of disease in childhood, 103(5), 486-491.</b>	Reports on correlations between children and parents' responses. The paper is a secondary analysis of the data, it does not report the views of the children.
<b>Healthwatch. Young Healthwatch survey results. 2019</b>	Not a national survey – conducted by the Wakefield branch of Healthwatch and relates to experiences in Wakefield only
<b>National Children's Bureau. Delivering mental health transformation for all children. Findings from engagement with the children and young people's voluntary sector in autumn 2016</b>	The report is based on views of professionals working with children and young people
<b>NHS Digital. Mental Health of Children and Young People in England, 2017</b>	Data were collected from parents and carers of young people aged 5-16 years, and not from young people themselves, and related to demographics and treatments and not experience of healthcare.
<b>Patient Experience Network and NHS England. Celebrating the Best of Children's and Young People's Experience of Care. Report of Survey Findings 2013</b>	It is unclear who provides the information included; however, it appears to be based on the views of health professionals working in NHS England, commissioners, providers, specialist children services, charities, networks, councils, local authorities, universities, custody service – not from children themselves.
<b>Picker Institute Young outpatients survey 2015</b>	Not a national survey – conducted on behalf of Sheffield children's NHS trust and relates to experiences in Sheffield only

### Evidence mapping to review questions

The content and results reported in each survey were read and the quantitative results, qualitative findings and, if present, supporting quotes were extracted and mapped to the most appropriate individual review question. This evidence was then included as part of the overall evidence for each review question, and as such was considered by the committee and used as part of the evidence when making recommendations for each question. The evidence mapped to each question can be found in appendix N of each evidence review, and is summarized and discussed as part of the committee's discussion of the evidence for each review.