



# Medical Home Family Index UK Version

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The Medical Home Family Index questionnaire was developed by the Center for Medical Home Improvement in the USA. Its purpose is to ask about families' experiences of using services for children with special health care needs. As part of the TraCCS Study, we have adapted this questionnaire. We want to know how useful the adapted questionnaire is for understanding families' experiences of using Children's Community Nursing (CCN) teams in England.

We are inviting you to complete this questionnaire about your experiences of using the [name of team] for your child's care.

Before continuing, please note the following:

- **Completion of this questionnaire is voluntary.**
- **If there are any questions that you do not want to answer, please leave them blank.**
- **All information you provide in this questionnaire will be confidential and used for research purposes only.**
- **By completing this questionnaire, the care you receive for your child will not be affected in any way.**

If you would like to complete the questionnaire, please sign below and then turn to **page 2** to begin.

Name: \_\_\_\_\_ Signature: \_\_\_\_\_

Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Contact ID: 

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**Thank you for your help with this research.**



Contact ID:

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Before you begin, please tell us if you have a **key worker** for your child? (please tick one)

Yes     No

If **yes**, is your key worker a member of the **[name of team]**? (please tick one)

Yes     No

Please tick one box on each line.		Never	Sometimes	Often	Always	Not Sure
1.	The children's community nursing (CCN) team provides the support that my child needs when we need it (including evenings, weekends and holidays).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	When we come into contact with the CCN team: <div style="text-align: right;"> <b>a)</b> Staff know who we are;  <b>b)</b> Staff respect our needs and requests;  <b>c)</b> Staff remember any special needs or support that we have asked for;  <b>d)</b> We are asked if we have any new needs.         </div>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	The CCN communicates well (e.g. explaining terms clearly, helping us prepare for visits, email, or encouraging our questions): <div style="text-align: right;"> <b>a)</b> With me;    <b>b)</b> With my child where applicable (tick here if not applicable ____).         </div>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	The CCN team ask for my knowledge and expertise as the parent or caregiver of a child with special health care needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Please tick one box on each line.		Never	Sometimes	Often	Always	Not Sure

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5.	The CCN team asks how my child's condition affects our family (e.g. the impact on siblings, the time my child's care takes, lost sleep, extra expenses, etc.).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	The CCN team listen to my concerns and questions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	When the CCN team plan care for my child, these things happen: <b>a)</b> Writing down key information (e.g. recommendations, treatments, telephone numbers); <b>b)</b> Setting short-term goals (e.g. for the next three months); <b>c)</b> Setting long-term goals (e.g. for the next year or more); <b>d)</b> Checking to make sure the plan is put into action.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
8.	The CCN team work jointly with our family to create a care plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	I receive a copy of my child's care plan with all updates and changes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	The CCN team: <b>a)</b> Use care plans they have created and deliver the care as planned; <b>b)</b> Use a care plan to help follow my child's progress; <b>c)</b> Review and update the care plan with me regularly.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<b>Please tick one box on each line.</b>		<b>Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>	<b>Not Sure</b>
11.	My Children's Community Nurse, or someone else in the CCN team, will: <b>a)</b> Help me with difficult referrals, and follow-up activities;	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

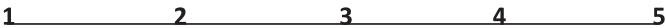
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	<p><b>b)</b> Help to find needed services (e.g. transportation, durable equipment);</p> <p><b>c)</b> Make sure that the planning of care meets my child and my family's needs;</p> <p><b>d)</b> Help all people involved in my child's care to communicate with each other (with my consent).</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>12.</b>	<p>If I ask them to, the CCN team help me to:</p> <p><b>a)</b> Explain my child's needs to other health professionals;</p> <p><b>b)</b> Explain my child's needs to his/her school/nursery (tick here if not applicable ____).</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>13.</b>	Someone in the CCN team is available to review my child's medical record with me when or if I ask to see it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>14.</b>	Other members of the CCN team who are involved with my child's care know about his or her condition, history, and our concerns and priorities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>15.</b>	The CCN team have set-up or are able to direct me to other activities to support my family (e.g. support groups, parent skill building and activities, care skills)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>16.</b>	The CCN team help me to connect with family support organisations and other sources of information locally.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Please tick one box on each line.</b>		<b>Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>	<b>Not Sure</b>
<b>17.</b>	The CCN team show strong support for the rights and services important to children with special health care needs and their families.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>18.</b>	The CCN team helps me find adult health care services for my child (tick here if not applicable ____).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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<b>19.</b>	The CCN team organise and attend team meetings about my child's plan of care that include us and other agencies/staff when needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>20.</b>	The CCN team organise and attend events to talk about concerns and needs common to all children with special health care needs (CSHCN) and their families.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>21.</b>	My experience of the CCN team is that they are committed to providing the quality of care and family support that we need.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>22.</b>	How satisfied are you with the care provided by the CCN team? Please rate your answer on a scale of 1 to 5 (please circle one) (1 = <i>not at all satisfied</i> , 5 = <i>very satisfied</i> ).	<p>1                      2                      3                      4                      5</p> 				

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Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

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Before you begin, please tell us if you have a **key worker** for your child? (please tick one)

 Yes

 No

If yes, is your key worker a member of the [name of team]?

 Yes

 No

Please tick one box on each line.		Never	Sometimes	Often	Always	Not Sure
1.	The children's community nursing (CCN) team provides the support that my child needs when we need it (including evenings, weekends and holidays).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	When we come into contact with the CCN team: a) Staff know who we are; b) Staff respect our needs and requests; c) Staff remember any special needs or support that we have asked for; d) We are asked if we have any new needs.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
3.	The CCN communicates well (e.g. explaining terms clearly, helping us prepare for visits, email, or encouraging our questions): a) With me; b) With my child where applicable (tick here if not applicable ____).	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>



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4.	The CCN team ask for my knowledge and expertise as the parent or caregiver of a child with special health care needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Please tick one box on each line.</b>		<b>Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>	<b>Not Sure</b>
5.	The CCN team asks how my child's condition affects our family (e.g. the impact on siblings, the time my child's care takes, lost sleep, extra expenses, etc.).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	The CCN team listen to my concerns and questions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	When the CCN team plan care for my child, these things happen:					
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	<b>b)</b> Setting short-term goals (e.g. for the next three months);	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<b>c)</b> Setting long-term goals (e.g. for the next year or more);	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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10.	The CCN team:					
	<b>a)</b> Use care plans they have created and deliver the care as planned;	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<b>b)</b> Use a care plan to help follow my child's progress;	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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	c) Review and update the care plan with me regularly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Please tick one box on each line.</b>		<b>Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>	<b>Not Sure</b>
<b>11.</b>	My Children’s Community Nurse, or someone else in the CCN team, will:					
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	<b>b)</b> Help to find needed services (e.g. transportation, durable equipment);	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<b>c)</b> Make sure that the planning of care meets my child and my family’s needs;	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<b>d)</b> Help all people involved in my child’s care to communicate with each other (with my consent).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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	<b>b)</b> Explain my child’s needs to his/her school/nursery (tick here if not applicable ____).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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16.	The CCN team help me to connect with family support organisations and other sources of information locally.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Please tick one box on each line.</b>		<b>Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>	<b>Not Sure</b>
17.	The CCN team show strong support for the rights and services important to children with special health care needs and their families.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18.	The CCN team helps me find adult health care services for my child (tick here if not applicable ____).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19.	The CCN team organise and attend team meetings about my child's plan of care that include us and other agencies/staff when needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20.	The CCN team organise and attend events to talk about concerns and needs common to all children with special health care needs (CSHCN) and their families.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21.	I have seen changes made to the CCN service as a result of my suggestions or those made by other families.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22.	The CCN team have conducted surveys of families' views or had discussions with families (in the last two years) to see if they are satisfied with their children's care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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<b>23.</b>	My experience of the CCN team is that they are committed to providing the quality of care and family support that we need.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>24.</b>	How satisfied are you with the care provided by the CCN team? Please rate your answer on a scale of 1 to 5 (1 = <i>not at all satisfied</i> , 5 = <i>very satisfied</i> ).	1 ————— 2 ————— 3 ————— 4 ————— 5				