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# BMJ Open

## How do children and adolescents experience healthcare professionals? Scoping review and interpretive synthesis

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5 1 **TITLE PAGE**  
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7 2 **How do children and adolescents experience healthcare professionals? Scoping review and**  
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9 3 **interpretive synthesis**  
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11  
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5 30 **ABSTRACT**

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7 31 **Objective**

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9  
10 32 Explore children's and adolescents' (CADs') lived experiences of healthcare professionals (HCPs).

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13 33 **Design**

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16 34 Scoping review methodology provided a six-step framework to, first, identify and organise  
17  
18 35 existing evidence. Interpretive phenomenology provided methodological principles for, second,  
19  
20 36 an interpretive synthesis of the life-worlds of CADs receiving healthcare, as represented by  
21  
22 37 verbatim accounts of their experiences.

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25 38 **Data Sources**

26  
27  
28 39 Five key databases (Ovid MEDLINE, Embase, Scopus, CINAHL Plus, and Web of Science), from  
29  
30 40 inception through to January 2019, reference lists, and opportunistically identified publications.

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33 41 **Eligibility criteria**

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36 42 Research articles containing direct first-person quotations by CADs (aged 0-18 years inclusive)  
37  
38 43 describing how they experienced HCPs.

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41 44 **Data extraction and synthesis**

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43  
44 45 Tabulation of study characteristics, contextual information, and verbatim extraction of all  
45  
46 46 'relevant' (as defined above) direct quotations. Analysis of basic scope of the evidence-base. The  
47  
48 47 research team worked reflexively and collaboratively to interpret the qualitative data and  
49  
50 48 construct a synthesis of children's experiences. To consolidate and elaborate the interpretation,  
51  
52 49 we held two focus groups with CAD inpatients in a children's hospital.

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55 50 **Results**

1  
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4  
5 51 669 quotations from 99 studies described CADs' experiences of HCPs. Favourable experiences  
6  
7 52 were of forming trusting relationships and being involved in healthcare discussions and  
8  
9 53 decisions; less favourable experiences were of not relating to or being unable to trust HCPs  
10  
11 54 and/or being excluded from conversations about them. HCPs fostered trusting relationships by  
12  
13 55 being personable, wise, sincere, and relatable. HCPs made CADs feel involved by including them  
14  
15 56 in conversations, explaining medical information, and listening to CADs' wider needs and  
16  
17 57 preferences.  
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## 21 58 **Conclusion**

22  
23  
24 59 These findings strengthen the case for making CADs partners in healthcare despite their youth.  
25  
26 60 We propose that a criterion for high-quality child-centred healthcare should be that HCPs  
27  
28 61 communicate in ways that engender trust and involvement.  
29  
30

## 31 62 **STRENGTHS AND LIMITATIONS OF THIS STUDY**

- 32  
33  
34 63 • Our findings have advanced current evidence by providing a comprehensive overview of  
35  
36 64 CADs' experiences of HCPs, while providing a blueprint for the child-centred care  
37  
38 65 conceptual model.  
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40  
41 66 • In addition to completing a scoping review in line with a published protocol, this article  
42  
43 67 reports an interpretive phenomenological synthesis of the evidence-base  
44  
45 68 • Restricting included articles to the English language limited the scope of our review  
46  
47  
48 69 • Limitations in the metadata provided by primary researchers prevented subgroup  
49  
50 70 analyses  
51  
52 71 • The subjectivity of interpretive synthesis is both a limitation and a strength: a limitation,  
53  
54 72 because it does not meet quantitative, experimental standards of proof; and a strength  
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56 73 because we used our subject position as clinicians to help fellow clinicians earn the trust  
57  
58 74 of CADs.  
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## 75 **BACKGROUND**

76 Children's experiences, like patients' experiences in general, are of fundamental importance in  
77 healthcare.[1–3] Research consistently shows that favourable experiences are associated with a  
78 wide range of positive health outcomes, including adherence to recommended treatments,  
79 uptake of preventive care, and utilisation of healthcare resources.[3] Exploring, understanding,  
80 and adapting to patients' experiences, particularly those concerning interpersonal  
81 communication, is the hallmark of patient-centred care (PCC), which is what patients 'strongly  
82 want'. [4,5] Accordingly, PCC has become the dominant ideology in healthcare design and  
83 delivery.[6]

84 In the case of children, however, it has proven more difficult to establish a model of PCC.  
85 Children and adolescents (CADs) are distinct from adults; they are developing physically,  
86 intellectually, and emotionally, and they occupy different positions in society and by law.[7]  
87 CADs, therefore, typically experience healthcare as part of a family unit, accompanied by  
88 parents or guardians who often act on their behalf. These factors affect the roles that CADs  
89 occupy within healthcare settings – how they interact and communicate with others – and  
90 predispose them to asymmetric relationships with adults. To address this, two specific  
91 theoretical models of care – family-centred care (FCC) and child-centred care (CCC) – have been  
92 developed for use in paediatric practice, based on the principles of PCC but incorporating  
93 modified conceptualisations of centredness.[8]

94 In FCC, the family is the central unit of care, with the aspiration of an equal partnership between  
95 healthcare professionals (HCPs) and families. FCC, which first originated in the 1950s, was an  
96 important conceptual advance because, up to this point, no framework existed to involve  
97 parents in their children's care.[7] Recent research shows, however, that even within the FCC  
98 framework, parents and professionals tend to predominate and CADs struggle to be true  
99 participants.[9] In contrast, the newer concept of CCC situates CADs at the centre of healthcare



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5 100 practice, giving primacy to their voices and experiences. Rather than being guided by outsider  
6  
7 101 perspectives of children's best interests, CCC compels HCPs to consciously perceive and  
8  
9 102 understand children's conditions, experiences, and priorities, as viewed through their  
10  
11 103 eyes:[8,10,11]

14 104 "[CCC] requires providers to critically consider the child's  
15  
16 105 perspective in every situation while ensuring collaboration  
17  
18 106 with the family who the [child] is part of." [8]

21 107 While aspects of FCC and CCC may be pertinent in different clinical contexts,[12] experts now  
22  
23 108 advocate a move towards CCC,[13] arguing that it better upholds values laid down by the UN  
24  
25 109 Convention on the Rights of the Child and governing bodies (such as the General Medical  
26  
27 110 Council),[14,15] and could improve how CADs experience healthcare.[8,13]

31 111 Adopting the CCC approach, however, requires a major shift in thinking and practice. Research  
32  
33 112 suggests that HCPs' realities are incompatible with CADs', with HCPs focused on prioritizing  
34  
35 113 tasks, 'getting the job done', and mitigating, rather than engaging with, CADs' demands.[16]  
36  
37 114 Furthermore, HCPs' communication strategies adopted for consulting CADs are largely  
38  
39 115 underpinned and conceptualized by biomedical or psychosocial models, from the clinical  
40  
41 116 gaze,[17] with little or no input from CADs.[18,19] And while CADs' healthcare experiences  
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43 117 overall are generally positive, large-scale studies have identified shortcomings in how HCPs  
44  
45 118 interact and communicate,[20–22] impacting on CADs' ability to manage their conditions and  
46  
47 119 participate in decision-making.[23] HCPs, too, continue to find communicating with CADs  
48  
49 120 challenging, supporting a change in thinking and practice.[19]

54 121 To achieve the vision of CCC, then, HCPs need greater insight into the experiences of sick  
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56 122 children.[11] This reflects a wider drive towards co-production (providers and service users  
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58 123 working in equal partnership to effect change) in children's healthcare;[24,25] and also

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5 124 complements the present impetus to acknowledge and examine CADs' *own* experiences,  
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7 125 opinions, and priorities, within research,[26,27] quality improvement,[28–30] and standard  
8  
9 126 setting.[31] To date, however, most research and surveys examining experiences in paediatric  
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11 127 settings have relied on parents' accounts, while CADs have participated less, if at all.[32]  
12  
13 128 Nevertheless, the few studies that have explored CADs' own experiential accounts have found  
14  
15 129 them to be informative and distinct from parents'.[23,33] At present, these accounts are widely  
16  
17 130 dispersed, yet if compiled, synthesised, and interpreted, these could provide a rich account of  
18  
19 131 CADs' lived experiences of how they encounter HCPs.  
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23 132 This study aimed to explore how CADs experience HCPs within interpersonal interactions, in  
24  
25 133 order to provide practitioners, organisations, and policymakers with evidence that could  
26  
27 134 promote child-centred communication. First, we conducted a scoping literature review to  
28  
29 135 systematically gather evidence on CADs' experiences of HCPs. Second, we interpreted CADs'  
30  
31 136 extracted quotations from the perspective of phenomenology. This well-established  
32  
33 137 methodological tradition, grounded in philosophy, enables researchers to produce valid  
34  
35 138 interpretations by examining and interpreting participants' verbatim accounts of their lived  
36  
37 139 experience.[34] Finally, we organised the interpretation into a synthetic account of how CADs  
38  
39 140 experience their interactions with HCPs.  
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## 44 141 **METHODS**

### 45 142 **Methodological orientation**

46 143 Scoping review methodology has a pragmatic orientation in the sense that it sets out to map  
47  
48 144 existing published evidence on a topic but it is adaptable in the sense that the usefulness of its  
49  
50 145 procedures is not tied to any one specific epistemology (theory of the nature of knowledge).[35–  
51  
52 146 37] As in our previously published research,[38] this review augments scoping review  
53  
54 147 procedures with interpretive phenomenology. The latter has an ontology (theory of the nature  
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56 148 of being) derived from the philosophy of Husserl, according to which the lived experience of  
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5 149 research participants is a legitimate topic of qualitative inquiry.[34] Interpretive phenomenology  
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7 150 helps researchers respond reflexively to spoken or written words and arrive at valid, subjective  
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9 151 interpretations. Phenomenologists typically take a reflexive stance that consciously sets aside  
10  
11 152 strong a priori preconceptions whilst allowing their own experiences (such as, in our case, having  
12  
13 153 experience of caring for sick children) to help them construct an informative interpretation. The  
14  
15 154 quality of a constructivist interpretation is to be judged by its trustworthiness, authenticity, and  
16  
17 155 ability to catalyse action – which, in this case, would be to improve future children’s healthcare  
18  
19 156 experiences.[39]

### 23 157 **Study procedures**

25 158 The research followed a published protocol (accessible at <https://rdcu.be/b2FFk>),[40] which  
26  
27 159 proposed to supplement traditional scoping review procedures with an interpretive synthesis,  
28  
29 160 the distinction between which is explained in the previous paragraph. The scoping component  
30  
31 161 followed the 6-step framework outlined by Arksey & O’Malley,[35] Levac et al.,[36] and  
32  
33 162 Colquhoun et al.,[37] adhering to PRISMA-ScR reporting guidance (included in online  
34  
35 163 supplementary file 1).[41]

### 39 164 **Step 1: Defining the research question**

42 165 This was: *‘What is known about children’s and adolescents’ experiences of healthcare*  
43  
44 166 *professionals, from their present perspective?’*, the final phrase emphasizing our commitment to  
45  
46 167 CADs’ contemporaneous accounts of their experiences expressed in their own words, rather  
47  
48 168 than parents’ descriptions or adults describing childhood memories.

### 51 169 **Step 2: Identifying relevant articles**

54 170 We designed a STARLITE search strategy (summarised in table 1) to identify all published articles  
55  
56 171 containing CADs’ experiences of HCPs expressed as first-person direct quotations.[42] A subject  
57  
58 172 librarian constructed a database search (included in online supplementary file 2), using the

173 population, context, and concept framework,[43] combining the terms ‘children’ or  
 174 ‘adolescents’, ‘healthcare’, and ‘experience’ (and synonyms), limiting it to English language  
 175 articles, ‘qualitative research’, and ‘0 to 18 years’, and then running it on Ovid MEDLINE,  
 176 Embase, Scopus, CINAHL Plus, and Web of Science from inception to 11<sup>th</sup> January 2019. We  
 177 included other articles found by searching relevant reference lists or found opportunistically.

**Table 1 STARLITE summary of search strategy[42]**

Sampling strategy	Comprehensive: attempting to identify all published materials
Types of studies	Any published study contributing to the research question: qualitative (with or without other methodologies (i.e., mixed method)); primary or secondary sources
Approaches	Electronic database searching; manual searching of reference lists; articles found opportunistically
Range of years	From database inception until 11 <sup>th</sup> January 2019
Limits	Articles published in English language; ‘qualitative research’; children aged 0-18 years (inclusive)
Inclusion and exclusion criteria	See table 2 and Step 3: Study selection
Terms used	See online supplementary file 2
Electronic databases	Ovid MEDLINE; Embase; Scopus; CINAHL Plus; Web of Science

178 **Step 3: Study selection**

179 Refinement of selection criteria

180 As is customary in scoping review, the process iterated between searching, selecting, extracting  
 181 data, and refining the research question. To enhance the rigour of this process, and in keeping  
 182 with our interpretive stance, we responded reflexively to the accumulating evidence, discussing  
 183 our interpretations, and articulating a clear rationale for each refinement. All records were  
 184 imported to Mendeley Reference Manager, duplicates removed, titles and abstracts screened  
 185 against five screening questions (Box 1), and full texts of those that screened positive reviewed  
 186 against eligibility criteria.

**Box 1 Screening questions**

1. Are the participants CADs ( $\leq$  18 years)?
2. Is the study examining an aspect of health, illness, or healthcare?
3. Are CADs participating as recipients of healthcare?
4. Are participants aged > 18 years excluded from the study?
5. Do children or adolescents describe experiences?

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5 187 These criteria, at first provisional (table 2A), were progressively refined in response to the  
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7 188 heterogeneity of evidence. Table 2B shows final criteria. GD led the process of first-screening,  
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9 189 annotating, sorting, and collating articles. MK & TD supported her by second-screening 10% of  
10  
11 190 records, discussing results, assessing articles whose eligibility was in doubt, and responding to  
12  
13 191 the often-imprecise details given by researchers. Any ambiguities (i.e., lack of age ranges) during  
14  
15 192 screening led to full-text review and a final decision about eligibility against criteria. To optimise  
16  
17 193 validity of the selection process, GD rescreened all records and annotations after each  
18  
19 194 refinement and, finally, after definitive criteria had been set.

#### 22 195 Rationale for criteria

23  
24 196 We included children up to and including 18 years because late adolescents are increasingly  
25  
26 197 cared for in paediatric settings.[44,45] Our age range conforms, also, with the United Nations'  
27  
28 198 influential definition of adolescence.[46] We included articles that contained verbatim  
29  
30 199 quotations irrespective of methodology. Judgement of methodological quality was not a  
31  
32 200 criterion for three reasons: it is not standard practice in scoping reviews; it is notoriously difficult  
33  
34 201 to judge qualitative research categorically;[46] and the interpretive synthesis used verbatim  
35  
36 202 quotations, whose validity does not depend on what the primary researchers did with CADs'  
37  
38 203 words. Because authors often failed to report the exact age of patient participants they quoted,  
39  
40 204 we excluded any study that included patient participants aged > 18 years (see, for example,  
41  
42 205 Tjaden et al. [47]).  
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<b>Table 2 Eligibility criteria for article selection</b>	
<b>A. Provisional</b>	<b>B. Definitive</b>
Inclusion criteria:	
<ol style="list-style-type: none"> <li>CADs speaking about HCPs, through first-person direct quotations.</li> <li>HCP defined as a member of a healthcare team.</li> <li>CADs defined as <math>\leq 18</math> years old, regardless of health status or illness type.</li> </ol>	<ol style="list-style-type: none"> <li>CADs speaking about one or more HCPs, on one or more instances, from any experience, through first-person direct quotation(s), where there had been direct contact between the two parties, and where CADs were the persons receiving healthcare.</li> <li>An HCP defined as a member of a healthcare team with professional qualifications and training, such as a qualified doctor, nurse, therapist, psychologist, or social workers, regardless of grade.</li> <li>CADs defined as <math>\leq 18</math> years, regardless of health status or illness type.</li> </ol>
Exclusion criteria:	
<ol style="list-style-type: none"> <li>Adults aged <math>&gt;18</math> years included in the study.</li> <li>Non-English language publications.</li> </ol>	<ol style="list-style-type: none"> <li>Adult <u>patients</u> aged <math>&gt;18</math> years included in the study with or without CADs as defined above.</li> <li>Non-English language publications.</li> <li>CADs speaking about HCP(s) not from memory of personal experience as a patient; for example, third-party description (e.g., parent).</li> <li>Age range of CAD participants unclear.</li> <li>No full-text manuscript available; only an abstract available, or unobtainable by searching online, directly emailing authors, or by university librarians requesting inter-library loans.</li> </ol>

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5 207 **Step 4: Charting the data**

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7 208 GD and MK piloted a spreadsheet to chart study characteristics, contextual information, and all  
8  
9 209 CADs' verbatim quotations on 10 articles; this resulted in the final dataset shown in box 2, which  
10  
11  
12 210 GD then used to extract data on the remaining articles.

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14  
15 **Box 2 Data extracted**

16  
17 Study characteristics:

- 18 - First author
- 19 - Year published
- 20 - Country of origin
- 21 - No. CAD participants
- 22 - Age range of CAD participants
- 23 - Male to female (or non-binary) ratio
- 24 - Other participants (e.g., parents)
- 25 - Methods
- 26 - Methodology (or analytical approach)

27  
28  
29 Contextual information:

- 30 - Study focus (the experience being explored)
- 31 - Health setting
- 32 - Health condition
- 33 - Length of healthcare encounter being explored

34  
35  
36 CADs' quotations:

- 37 - All first-person direct quotations, where CADs are talking about HCPs
- 38 - Age and gender referenced to each quotation

39  
40 211 When key information was missing or unclear, we sought clarification from primary authors. All  
41  
42 212 authors independently reviewed the extracted information for its fitness to address the aims  
43  
44 213 and purpose of the study, subsequently conferring to optimise the validity of the dataset.

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47 214 **Step 5: Collating, summarising, and reporting the results**

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50 215 We first analysed the basic characteristics of included studies. We then identified themes in the  
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52 216 verbatim quotations following Braun and Clarke's method of thematic analysis as defined by  
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54 217 their checklist (included in online supplementary file 3).[48,49] GD immersed herself in the data,  
55  
56 218 reviewing all quotations on Microsoft Excel, using NVivo 12 qualitative analysis software to  
57  
58 219 support generation of codes and construction of themes.[50] Other team members supported

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5 220 her interpretation, by reviewing quotations first individually, and then collectively. We  
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7 221 systematically interrogated the data for themes that had meaning in relation to the research  
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9 222 question, revising candidate themes periodically (with the aid of a visual thematic map) to  
10  
11 223 ensure these were coherent, distinctive, complementary, and relevant. The ensuing thematic  
12  
13 224 structure had central concepts, which we used to organise subordinate themes and their  
14  
15 225 associated codes. Throughout this process, we constantly compared our evolving interpretation  
16  
17 226 against the original data, including a final 'quality control' check of the synthesis against all  
18  
19 227 quotations.[49]

20  
21  
22  
23 228 In keeping with our interpretive stance, we used our different subject positions as  
24  
25 229 paediatricians, a family doctor, and an adult internist to interpret CADs' words reflexively and  
26  
27 230 arrive at 'beyond-surface insights', so that the themes were amenable to an additional stage of  
28  
29 231 phenomenological synthesis.[48,49] As we did this, the gamut of emotional content in CADs'  
30  
31 232 words became an increasingly compelling influence on our interpretation. CADs' emotional  
32  
33 233 expressions tended to have quite distinct 'valence' (defined as the attractiveness [positive  
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35 234 valence] or averseness [negative valence] of the emotions described) which linked in recurring  
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37 235 ways to HCPs' reported behaviours.[51,52] So, for example, a HCP who related well to a child  
38  
39 236 might engender trust, while an HCP who related poorly might engender mistrust.

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44 237 Whilst crude dichotomies between positive/negative emotions and behaviours do not reflect  
45  
46 238 the subtlety of interpretive research, links between these contrasting behaviours were so clearly  
47  
48 239 present that they offered a parsimonious way of presenting our results. The Results section uses  
49  
50 240 the terms 'favourable' and 'unfavourable' to specify what are, in reality, nuanced polarities. To  
51  
52 241 epitomize these important themes in ways that could encourage HCPs to emulate favourable  
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54 242 behaviours, we present predominantly favourable behaviours, but provide negative counter-  
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56 243 examples to emphasize the breadth of CADs' experiences. As in previous research,[53] we used  
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58 244 CADs' own words, as far as possible, to construct a narrative of findings that was as true as  
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5 245 possible to the phenomena experienced and narrated by children. We use the wording 'HCPs did  
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7 246 X' as a shorthand for the more correct wording, 'CADs experienced HCPs as doing X'.  
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#### 10 247 **Step 6: Stakeholder consultations**

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12 248 As recommended by Levac et al.,[36] GD, AT, and RC (with research ethics and governance  
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14 249 approvals) recruited CADs aged 8-16 from inpatient wards in the Royal Belfast Hospital for Sick  
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16 250 Children (RBHSC) to two focus groups whose aim was to consolidate and elaborate on findings.  
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18 251 Participants and parents chose whether parents should attend. We presented candidate themes  
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20 252 along with exemplar quotations and facilitated discussions, asking participants to comment on  
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22 253 provisional findings and provide suggestions for practice. We audio-recorded sessions and  
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24 254 transcribed recordings verbatim. We reviewed transcripts alongside the provisional findings to  
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26 255 authenticate, build upon, and summarise a final narrative of results. Participants' identities are  
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28 256 pseudonymised in the results section.  
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#### 33 257 **Patient and public involvement**

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36 258 The essence of this research was to involve children, albeit as expressed verbatim by other  
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38 259 researchers. The stakeholder consultation further fulfilled the patient and public involvement  
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40 260 component of the research by ensuring findings disseminated were intelligible and relevant.  
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## 44 261 **RESULTS**

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46 262 We identified 1,359 articles, excluding 1,015 by screening and 245 by reviewing full texts, and  
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48 263 categorised reasons for exclusion on a PRISMA flow diagram (shown in figure 1).  
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#### 51 264 **Overview of included studies**

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54 265 Table 3 presents an overview of included studies (n=99), published between 1992 and 2018. In  
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56 266 total, 4,448 CADs, aged 11 months to 18 years, participated. Most studies included 8 to 50  
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58 267 participants (n=73), aged 7 or older (n=70), and used interviews only (n=64). Studies commonly  
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5 268 included CADs with chronic and potentially debilitating or life-threatening conditions (such as  
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7 269 asthma and cancers), explored long-term experiences (over months to years), and focused on  
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9 270 hospital care. Further descriptive findings and figures are presented in online supplementary file  
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For peer review only

Table 3 Study characteristics

Study details		CAD participants			Design		Contextual information				Data
First author, year	Country	n	Age (yrs)	M:F	Methods	Methodology/analytical approach	Study focus (experience of)	Health setting	Health condition	Length of encounter	Quotes (n)
Aalsma <i>et al.</i> , 2014[54]	US	19	11-17	12:7	INT	Qualitative	CAMHS	Non-specific	Mental health illness	Long-term	5
Alex MR, 1992[55]	Canada	24	7-11	13:11	INT, Q	Content analysis	Pain	Hospital	Surgical (post-op)	Short-term	4
Anderson <i>et al.</i> , 2017[56]	England	6	15-18	3:3	INT	Interpretative phenomenological analysis	Lung transplantation	Hospital	Post-lung transplantation	Long-term	6
Ångström-Brännström <i>et al.</i> , 2008[57]	Sweden	7	4-10	3:4	INT (PT)	Thematic analysis	Being comforted	Hospital	Chronic	Short-term	6
Ångström-Brännström <i>et al.</i> , 2014[58]	Sweden	9	3-9	5:4	INT	Content analysis	Comfort during cancer treatment	Hospital	Cancer	Long-term	3
Beresford <i>et al.</i> , 2003[59]	England	63	11-16	27:36	INT, FG (PT)	Framework method	Communicating	Hospital	Chronic	Long-term	14
Boyd <i>et al.</i> , 1998[60]	Canada	6	10-13	2:4	INT (PT), WT	Grounded theory	Hospital and coping strategies	Hospital	Surgical (chronic)	Long-term	3
Brown <i>et al.</i> , 2014[61]	US	19	11-17	12:7	INT	Grounded theory	Therapeutic alliances	Hospital	Mental health illness	~	16
Carney <i>et al.</i> , 2003[62]	Scotland	213	4-17	115:98	INT, FTQ	Thematic analysis	Healthcare	Hospital	Non-specific	Non-specific	9
Cheng <i>et al.</i> , 2003[63]	Taiwan	90	5-14	45:45	INT	Content analysis	Pain	Hospital	Non-specific	Non-specific	1
Cheng <i>et al.</i> , 2016[64]	Taiwan	11	12-18	7:4	INT	Content analysis	Cancer recovery	Hospital	Cancer	Long-term	1
Christofides <i>et al.</i> , 2016[65]	Canada	19	8-18	7:12	INT	Thematic analysis	Research participation	Hospital	Cystic fibrosis	Long-term	3
Clift <i>et al.</i> , 2007[66]	Wales	6	11-15	3:3	INT	Qualitative	Emergency admission	Hospital	Non-specific	Short-term	7
Colver <i>et al.</i> , 2018[67]	England	374	14-18	219:155	INT, Q, OBS	Constant comparison	Transition	Hospital	Medical	Long-term	2
Corsano <i>et al.</i> , 2015[68]	Italy	27	6-15	12:15	INT	Qualitative	Emotional events	Hospital	Cancer/ blood disorders	Long-term	4
Coyne, 2006[69]	Ireland	55	7-18	30:25	INT, FG	Constant comparison analysis	Participating/ decision-making	Hospital	Non-specific	Non-specific	52
Coyne, 2006a[70]	Ireland	11	7-14	~	INT	Grounded theory	Hospitalisation	Hospital	Non-specific	~	1
Coyne, 2006b[71]	Ireland	11	9-14	~	INT (PT), FTQ, OBS	Grounded theory	Participating	Hospital	Non-specific	~	4
Coyne <i>et al.</i> , 2007[72]	Ireland	17	7-16	~	INT	Qualitative	Hospitalisation	Hospital	Non-specific	Non-specific	8

Study details		CAD participants			Design		Contextual information				Data
First author, year	Country	n	Age (yrs)	M:F	Methods	Methodology/analytical approach	Study focus (experience of)	Health setting	Health condition	Length of encounter	Quotes (n)
Coyne, 2011[73]	Ireland	55	7-18	31:24	INT, FG	Qualitative	Communicating/ decision-making	Hospital	Non-specific	Non-specific	20
Coyne, 2012[74]	Ireland	38	7-18	~	INT (PT)	Content analysis	Hospital and HCPs	Hospital	~	~	24
Coyne, 2014[75]	Ireland	20	7-16	11:9	INT (PT)	Constant comparison analysis	Participating/ decision-making	Hospital	Cancer	Long-term	2
Coyne <i>et al.</i> , 2015[76]	Ireland	15	12-18	6:9	INT, FG	Thematic analysis	CAMHS	Non-specific	Mental health illness	Long-term	6
Coyne <i>et al.</i> , 2016[77]	Ireland	20	7-16	11:9	INT	Grounded theory	Communicating	Hospital	Cancer	Long-term	6
Curtis <i>et al.</i> , 2017[78]	England	17	5-16	~	INT (PT), OBS	Ethnographic	Single/ shared rooms	Hospital	~	~	3
Das <i>et al.</i> , 2017[79]	India	14	8-15	~	FG	Qualitative	Living with HIV	Non-specific	HIV	Long-term	1
Day <i>et al.</i> , 2006[80]	England	11	9-14	5:6	FG	Thematic Analysis	CAMHS	Non-specific	Mental health illness	Long-term	13
Dell'Api <i>et al.</i> , 2007[81]	Canada	5	10-17	2:3	INT	Qualitative	Interacting with HCPs	Hospital	Non-specific	Long-term	19
Dixon-Woods <i>et al.</i> , 2002[82]	England	20	8-16	9:11	INT	Constant comparison analysis	Asthma services	Community	Asthma	Long-term	12
Edgecombe <i>et al.</i> , 2010[83]	England	22	11-18	16:6	INT	Thematic analysis	Asthma services	Hospital	Asthma	Long-term	5
Ekra <i>et al.</i> , 2012[84]	Norway	9	7-12	5:4	INT, OBS (PT)	Hermeneutic phenomenology	Hospitalisation	Hospital	TIDM	Long-term	2
Engvall <i>et al.</i> , 2016[85]	Sweden	13	5-15	6:7	INT (PT)	Content Analysis	Radiotherapy	Hospital	Cancer	Long-term	2
Forsner <i>et al.</i> , 2005[86]	Sweden	7	7-10	4:3	INT	Thematic analysis	Illness	Hospital	~	Short-term	4
Forsner <i>et al.</i> , 2009[87]	Sweden	9	7-11	2:7	INT, OBS	Hermeneutic phenomenology	Fear	Hospital	Non-specific	Short-term	4
Garth <i>et al.</i> , 2009[88]	Australia	10	8-12	3:7	INT	Grounded theory	Participating	Non-specific	Cerebral palsy	Long-term	3
Gill <i>et al.</i> , 2016[89]	England	12	14-17	2:10	INT	Thematic analysis	CAMHS inpatient ward	Non-specific	Mental health illness	Long-term	2
Griffiths <i>et al.</i> , 2011[90]	Australia	9	8-16	~	INT	Interpretative phenomenological analysis	Living with cancer	Non-specific	Cancer	Long-term	3
Haase <i>et al.</i> , 1994[91]	US	7	5-18	3:4	INT (PT)	Colaizzi's method of phenomenological analysis	Completing cancer treatment	Non-specific	Cancer	Long-term	6
Hall <i>et al.</i> , 2013[92]	England	17	8-17	~	INT	Thematic analysis	Life with repaired cleft lip/ palate	Non-specific	Cleft lip/ palate	Long-term	1

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Study details		CAD participants			Design		Contextual information				Data
First author, year	Country	n	Age (yrs)	M:F	Methods	Methodology/analytical approach	Study focus (experience of)	Health setting	Health condition	Length of encounter	Quotes (n)
Han <i>et al.</i> , 2011[93]	China	29	7-14	16:13	INT	Content analysis	Cancer	Hospital	Cancer	Long-term	2
Hanson <i>et al.</i> , 2017[94]	US	30	4-14	16:14	INT	Narrative analysis	Pain	Hospital	Fractured arm	Short-term	5
Harper <i>et al.</i> , 2013[95]	England	10	16-18	3:7	INT	Interpretative phenomenological analysis	CAMHS	Non-specific	Mental health illness	Long-term	8
Hart <i>et al.</i> , 2018[96]	England	14	14-16	~	INT	Thematic analysis	CAMHS	Non-specific	Mental health illness	Long-term	2
Hawthorne <i>et al.</i> , 2011[97]	England	21	7-16	12:9	FG	Thematic analysis	Diabetes services	Hospital	T1DM	Long-term	8
Hinton <i>et al.</i> , 2015[98]	England	21	8-17	6:15	INT (PT)	Constant comparison analysis	A multiple sclerosis diagnosis	Non-specific	Multiple sclerosis	Long-term	3
Hodgins <i>et al.</i> , 1997[99]	Canada	85	5-13	38:41	INT, Q	Mixed-method	Venepuncture	Hospital	Non-specific	Short-term	3
Hutton, 2005[100]	Australia	7	13-18	3:4	INT (PT)	Qualitative	Adolescent wards	Hospital	Cystic fibrosis/asthma	Long-term	3
Jachyra <i>et al.</i> , 2018a[101]†	Canada	8	11-17	4:4	INT	Interpretative phenomenological analysis	Talking about weight	Non-specific	ASD	Long-term	6
Jachyra <i>et al.</i> , 2018b[102]†	Canada	8	11-17	4:4	INT	Interpretative phenomenological analysis	Talking about weight	Non-specific	ASD	Long-term	4
Jensen <i>et al.</i> , 2012[103]	Denmark	8	8-10	5:3	INT (PT)	Thematic analysis	Acute hospitalisation	Hospital	Medical	Short-term	6
Jongudomkarn <i>et al.</i> , 2006[104]	Thailand	49	4-18	31:18	INT, FG, OBS, PT	Content analysis	Pain	Non-specific	Non-specific	Long-term	1
Kluthe <i>et al.</i> , 2018[105]	Canada	18	6-17	11:7	INT	Content analysis	IBD diagnosis	Hospital	IBD	Long-term	1
Koller <i>et al.</i> , 2010[106]	Canada	21	5-18	12:9	INT (PT)	Grounded theory	Hospitalisation during SARS	Hospital	Non-specific	Long-term	2
Koller, 2017[107]	Canada	26	5-18	11:15	INT (PT)	Thematic analysis	Medical education/participating	Hospital	Chronic	Long-term	10
Kortesluoma <i>et al.</i> , 2006[108]†	Finland	44	4-11	~	INT	Content analysis	Pain	Hospital	Non-specific	Non-specific	1
Kortesluoma <i>et al.</i> , 2008[109]†	Finland	44	4-11	27:17	INT	Content analysis	Pain	Hospital	Non-specific	Non-specific	7
Lewis <i>et al.</i> , 2007[110]	Australia	9	8-16	5:4	INT	Cognitive mapping	Receiving care	Hospital	~	~	5
Livesley <i>et al.</i> , 2013[16]	England	15	5-15	3:2	INT (PT), OBS	Critical ethnography, constant comparison analysis	Hospitalisation	Hospital	Surgical	Long-term	4
Lowes <i>et al.</i> , 2015[23]	Wales	518	7-15	~	FTQ	Qualitative descriptive analysis	Life with T1DM and services	Hospital	T1DM	Long-term	8

Study details		CAD participants			Design		Contextual information				Data
First author, year	Country	n	Age (yrs)	M:F	Methods	Methodology/analytical approach	Study focus (experience of)	Health setting	Health condition	Length of encounter	Quotes (n)
Macartney <i>et al.</i> , 2014[111]	Canada	12	9-18	6:6	INT	Content analysis	Life after a brain tumour	Non-specific	Brain tumour	Long-term	1
Manookian <i>et al.</i> , 2014[112]	Iran	6	6-17	3:3	INT	Interpretative phenomenological analysis	Stem cell transplantation	Hospital	Cancer & blood disorders	Long-term	4
Marcinowicz <i>et al.</i> , 2016[113]	Poland	22	10-16	8:14	INT	Content analysis	Nurse relationships and wards	Hospital	~	~	7
Marshman <i>et al.</i> , 2010[114]	England	10	12-14	5:5	INT, Q	Framework analysis	Malocclusion treatment	Non-specific	Malocclusion	Long-term	1
McNelis <i>et al.</i> , 2007[115]	India	11	7-15	6:5	FG	Thematic analysis	Living with epilepsy	Non-specific	Epilepsy	Long-term	2
McPherson <i>et al.</i> , 2017[116]	Canada	17	6-18	8:9	INT	Phenomenology, thematic analysis	Talking about weight	Hospital	Spina Bifida	Long-term	3
McPherson <i>et al.</i> , 2018[117]	Canada	18	10-17	9:9	INT, FG	Thematic analysis	Talking about weight	Hospital	Non-specific	Long-term	3
Moules, 2009[118]	England	138	9-14	82:56	INT (PT)	Framework analysis	Hospital care	Hospital	~	~	3
Nguyen <i>et al.</i> , 2010[119]	Sweden	40	7-12	~	INT, Q, vital signs	Content analysis	Music therapy for lumbar puncture	Hospital	Cancer	Short-term	1
Nilsson <i>et al.</i> , 2011[120]	Sweden	39	5-10	32:7	INT	Content analysis	Pain	Hospital	Skin trauma	Short-term	4
Noreña Peña AL <i>et al.</i> , 2011[121] <sup>†</sup>	Spain	30	8-14	13:17	INT, OBS	Critical incident technique	Communicating with nurses	Hospital	Surgical	~	24
Noreña Peña AL <i>et al.</i> , 2014[122] <sup>†</sup>	Spain	30	8-14	13:17	INT, OBS	Critical incident technique	Communicating with nurses	Hospital	Surgical	~	22
Olausson <i>et al.</i> , 2006[123]	Sweden	18	4-18	8:10	INT	Hermeneutic phenomenology	Life after transplantation	Non-specific	Post- transplant	Long-term	6
Pelander <i>et al.</i> , 2004[124]	Finland	40	4-11	28:12	INT	Content analysis	Nursing care	Hospital	Chronic (T1DM & other)	Long-term	3
Pelander <i>et al.</i> , 2010[125]	Finland	388	7-11	198:188 *	FTQ	Content analysis	Hospitalisation	Hospital	Non-specific	Non-specific	2
Pölkki <i>et al.</i> , 1999[126]	Finland	20	7-11	~	INT, WT	Content analysis	Pain	Hospital	Non-specific	~	1
Pope <i>et al.</i> , 2018[127]	Australia	15	4-8	11:4	INT (PT)	Thematic analysis	Pain and nurses' roles	Hospital	Trauma	Short-term	1
Randall, 2012[128]	England	21	0.9-17	8:12 *	INT, FG (PT), PTD	Colaizzi's method of phenomenological analysis	Community children's nursing	Community	Non-specific	Long-term	4
Rankin <i>et al.</i> , 2018[129]	Scotland	24	9-12	13:11	INT (PT)	Thematic analysis	Managing T1DM	Non-specific	T1DM	Long-term	1
Roper <i>et al.</i> , 2018[27]	England	16	7-15	9:7	INT	Qualitative	Research participation/ consent	Hospital	Asthma or anaphylaxis	Short-term	7

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Study details		CAD participants			Design		Contextual information				Data
First author, year	Country	n	Age (yrs)	M:F	Methods	Methodology/analytical approach	Study focus (experience of)	Health setting	Health condition	Length of encounter	Quotes (n)
Ruhe <i>et al.</i> , 2016[130]	Switzerland	17	9-17	11:6	INT	Thematic analysis	Participating	Hospital	Cancer	Long-term	1
Ryals, 2011[131]	US	8	13-17	6:2	INT	Phenomenology	Therapeutic relationships	Non-specific	Mental health illness	Long-term	59
Saarikoski <i>et al.</i> , 2018[132]	Finland	19	6-12	7:12	FG	Content analysis	Therapeutic intervention	Community (school)	Enuresis	Long-term	1
Salmela <i>et al.</i> , 2010[133]	Finland	90	4-6	~	INT	Colaizzi's method of phenomenological analysis	Hospital related fears	Hospital	~	~	4
Schalkers <i>et al.</i> , 2014[134]	The Netherlands	63	6-18	31:32	INT (PT), WT	Action research	Hospital care	Hospital	Non-specific	~	8
Schmidt <i>et al.</i> , 2007[135]	US	65	5-18	34:31	INT, FTQ	Thematic analysis	Nurses in hospital	Hospital	Non-specific	Non-specific	45
Spalding <i>et al.</i> , 2016[136]	England	7	8-14	2:5	WS (PT)	Action research, thematic analysis	Good doctors	Hospice	Palliative	Long-term	3
Stevens <i>et al.</i> , 2006[137]	Canada	14	7-16	9:5	INT	Content analysis	Home chemotherapy	Community (home)	Cancer	Long-term	1
Taylor <i>et al.</i> , 2010[138]	England	14	12-18	~	INT	Framework analysis	Life after transplantation	Non-specific	Liver transplant	Long-term	6
Vejzovic <i>et al.</i> , 2014[139]	Sweden	17	10-17	5:12	INT	Content analysis	Preparing for colonoscopy	Hospital	Suspected IBD	Short-term	4
Vindrola-Padros, 2012[140]	Argentina	10	8-16	5:5	INT (PT)	Narrative analysis	Living with cancer	Non-specific	Cancer	Long-term	4
Wangmo <i>et al.</i> , 2016[141]	Switzerland	17	9-17	11:6	INT	Qualitative	Cancer services and treatment	Hospital	Cancer	Long-term	5
Watson <i>et al.</i> , 2009[142]	US	9	14-18	7:1:1#	INT	Grounded theory	Assessing CAMHS & mental illness	Non-specific	Mental health illness	Long-term	1
Wen <i>et al.</i> , 2013[143]§	Singapore	203	4-18	~	INT, OBS	Thematic analysis	Pain	Non-specific	Surgical (post-op)	Non-specific	15
Wise, 2002[144]	US	9	7-15	~	INT (PT)	Hermeneutic phenomenology	Transplantation	Non-specific	Liver transplant	Long-term	7
Wong <i>et al.</i> , 2012[145]	China	79	10-13	54:25	FG	Qualitative	Weight-loss program	Community (school)	Obesity	Long-term	1
Woodgate, 2008[146]	Canada	13	9-17	7:6	INT	Constant comparison analysis	Cancer symptoms	Non-specific	Cancer	Long-term	1
Wray <i>et al.</i> , 2018[147]	England	543	8-16	~	INT, FG, Q	Framework Analysis	Healthcare	Hospital	~	~	5
Xie <i>et al.</i> , 2016[148]	China	21	7-12	12:9	INT	Content Analysis	Lumbar puncture	Hospital	ALL	Short-term	15
Young <i>et al.</i> , 2003[149]	England	13	8-17	8:5	INT	Constant comparison analysis	Communicating	Hospital	Cancer	Long-term	7

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Note:

Non-specific, not focusing on a certain type or area; ALL, acute lymphoblastic leukaemia; ASD, autism spectrum disorder; CAMHS, child and adolescent mental health service; HIV, human immunodeficiency virus; IDB, inflammatory bowel disease; SARS, severe acute respiratory syndrome; T1DM, type 1 diabetes mellitus. FG, focus groups; FTQ, free-text questionnaires; INT, interviews; OBS, observations; PT, participatory techniques employed; PTD, photo talk diaries; Q, quantitative questionnaires; WS, workshops; WT, writings; ~, unable to ascertain; \*, numerical inconsistency detected in source article; †, same study with different quotations presented; §, qualitative systematic review; #, non-binary gender.



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5 **279 Children's and adolescents' experiences**  
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8 280 Six-hundred and sixty-nine quotations referred to CADs' experiences of HCPs, most of whom  
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10 281 were doctors or nurses. CADs also spoke about their experiences with counsellors,  
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12 282 psychologists, social workers, and dentists. CADs' ages (available for 397 quotations), ranged  
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14 283 from 5-18 years (average 13); male and female participants were equally represented (see  
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16 284 supplementary file 5). All quotations extracted are available at doi:10.5061/dryad.z08kprrc2;  
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18 285 quotations presented below are cited in online supplementary file 6.  
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22 286 CADs' favourable experiences were of HCPs forming trusting relationships and involving them in  
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24 287 healthcare discussions and decisions and their unfavourable experiences were generally towards  
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26 288 the opposite pole.  
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29 289 Forming trusting relationships  
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32 290 *Their nature*  
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35 291 Being in a trusting relationship was feeling a 'bond', having an 'emotional attachment', or having  
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37 292 a 'best friend'. CADs and HCPs knew each other, could 'relate to' each other, and really  
38  
39 293 understood each other. There was openness, transparency, and there was trust. CADs trusted in  
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41 294 HCPs to provide 'good care', knowing they would do everything necessary, and do it right.  
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45 295 *Their origins*  
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48 296 At first, HCPs were 'strangers'; CADs did not know the HCPs, who they were, and how they were.  
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50 297 HCPs, likewise, did not know CADs, their histories, or their personalities. Repeated contact and  
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52 298 dialogue built and reinforced relationships: 'As time passed, [...] we created that bond.'  
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55 299 HCPs engendered trusting relationships by demonstrating positive attributes, including being  
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57 300 able to empathise. CADs trusted in HCPs who were 'very smart', 'experienced', '[knew] what to  
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5 301 do', '[took] care', and did 'everything the best they [could]'. They trusted HCPs who were  
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7 302 'truthful', '100% with you', and 'just [told] you straight up.' Such HCPs did 'not tell children any  
8  
9 303 lies'; 'nothing [was] hidden'. CADs built trusting relationships with HCPs who were 'really nice',  
10  
11 304 'nurturing, caring, and helpful people who [were] there for you', and had a 'good sense of  
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13  
14 305 [humour]'.  
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17 306 HCPs related to CADs by understanding them: 'she knew what I was talking about, she knew  
18  
19 307 what I was feeling, she knew how I was feeling.' HCPs 'took time to get to know' CADs and had  
20  
21 308 'real conversations, not just [HCP]-patient discussions', in which they shared experiences and  
22  
23 309 got to know each other personally. CADs could better relate to HCPs who were 'down to earth'  
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25  
26 310 and had 'a lot in common'.  
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### 29 311 *Their effects*

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31  
32 312 Trust was vital: 'you gotta have trust.' Trusting relationships improved CADs' healthcare  
33  
34 313 experiences by promoting positive emotions. CADs felt 'satisfied' and 'happy'. They enjoyed  
35  
36 314 their time with HCPs and had 'good memories'. CADs were more able to 'open up' or 'tell  
37  
38 315 anything' to HCPs whom they trusted. Trusting relationships gave CADs hope that HCPs could  
39  
40 316 'cure [the] illness' or help lessen the pain. CADs who trusted HCPs submitted themselves more  
41  
42 317 willingly to recommended treatments: 'whatever happens I let them [HCPs] do what they have  
43  
44 318 to do to help me get better.' And they consciously chose to remain with or seek out HCPs they  
45  
46 319 trusted. CADs admired trustworthy HCPs: 'individually [they're] all heroes.' And they aspired to  
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49 320 be like them: 'Because you can save people [...] I'm going to be a children's doctor.'

### 50 51 52 321 Being involved in healthcare discussions and decisions

### 53 54 55 322 *The nature of involvement*

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5 323 CADs who were fully involved in healthcare discussions felt they knew everything; 'everything  
6  
7 324 [was] always clear' to them. They had a seat at the table to discuss issues that affected them and  
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9  
10 325 felt acknowledged as key stakeholders. CADs worked 'together' with HCPs and parents; they felt  
11  
12 326 as though they were respected, taken 'seriously', and treated 'as an equal'.

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15 327 *Its origins*

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17 328 HCPs involved CADs by including them in conversations, sharing information, providing  
18  
19 329 opportunities to ask questions, taking time to answer, and listening to their wider needs and  
20  
21 330 preferences. HCPs who promoted involvement used simple words, communicated in a timely  
22  
23 331 way, gave accurate information at the right pace, and explained things so that CADs understood.  
24  
25 332 These HCPs brought CADs 'into all the conversations' by talking to CADs 'as much as they [talked  
26  
27 333 to the] parents'. Parents facilitated CADs' involvement in the presence of HCPs or afterwards by  
28  
29 334 '[breaking] the words down in an easier explanation'. HCPs promoted participation by 'listening'  
30  
31 335 to and respecting CADs' requests: 'I tell them I don't want this and they ... understand'. For more  
32  
33 336 complex decisions, CADs took a joint approach: 'me because I know my own body, my parents  
34  
35 337 because they know what's best for me [...] and the paediatrician because they are qualified.'

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41 338 *Its effects*

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43 339 CADs viewed involvement as 'most important, as in the end it is about [them]'. CADs enjoyed  
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45 340 being involved; it was 'brilliant', and they looked forward to their next visit. CADs were more  
46  
47 341 satisfied with healthcare; they found it 'interesting and informational'. Getting to 'learn  
48  
49 342 something new' made them feel 'comfortable and confident'. CADs could 'make better  
50  
51 343 decisions' because they were 'fully informed'. This promoted self-advocacy and self-efficacy:  
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53 344 'I'm asking the doctor more questions myself than having my Dad do it.'

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57 345 Not forming trusting relationships or being involved

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5 346 CADs described unfavourable experiences, which broadly *mirrored* favourable ones. For  
6  
7 347 instance, trust was undermined by HCPs getting things wrong, being 'nasty', and not '[seeming]  
8  
9 348 that concerned'. HCPs being unfamiliar to CADs because they were 'too busy' or because HCPs  
10  
11 349 or CADs moved to other services prevented trusting relationships forming. HCPs excluded CADs  
12  
13 350 by using 'big words', speaking too fast, or telling them nothing, so that CADs could not  
14  
15 351 understand. HCPs neglecting to ask CADs or asking in a tokenistic way prevented them 'having a  
16  
17 352 say': 'they [HCPs] might ask me "is that ok" [...] in such a way that I kind of feel like I don't have  
18  
19 353 any other option but [to] agree with them'. HCPs and parents side-lined CADs by talking behind  
20  
21 354 the curtains so CADs could not hear or sticking them 'in the middle' of a conversation where  
22  
23 355 they could not interrupt. Some parents told CADs to keep quiet or dominated conversations:  
24  
25 356 'you try to say something but then your parents just say shhhhh! [...] They come out and say, [...]  
26  
27 357 did you understand that, you say no, they say, you should have asked them, and then you say,  
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29 358 oh you didn't let me, they say rubbish!'  
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34  
35 359 Not trusting people or understanding what was happening made CADs fearful. HCPs who made  
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37 360 CADs feel 'rejected' and objectified, 'like a piece of machinery', enraged them. CADs found it  
38  
39 361 'hard to talk', disengaged in conversations, and left the talking to their parents. Not trusting in  
40  
41 362 HCPs or being uninvolved meant some CADs hated hospital or clinic, they objected to attending,  
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43 363 and sought information or guidance from other sources.  
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#### 364 Stakeholder consultations

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49 365 Two CAD inpatients participated in each of two focus groups (3 females and 1 male, aged 11-15  
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51 366 years) lasting 67 and 93 minutes respectively. Their medical conditions included type 1 diabetes,  
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53 367 coeliac disease, spina bifida, and spinal/brain surgery. No parents attended. Three authors (GD,  
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55 368 AT, & RC) attended both consultations and a hospital play specialist attended the first  
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57 369 consultation. Participants identified with the provisional findings and elaborated on them (table  
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370 4). All wanted some degree of involvement in their own care though the amount of information  
371 and level of participation they wanted depended on their age, what was being discussed, and  
372 individual preferences. Box 3 offers take-home messages for HCPs.

For peer review only

373 **Table 4 Stakeholder findings: Focus group participants' experiences mapped to overarching themes**

Overarching themes	Forming trusting relationships	Being involved in healthcare discussions and decisions
Favourable experiences	<p>Rachel, a young girl with diabetes, described having a very good relationship with the diabetic team and ward staff: <i>'Hm, it's just the nurses really like nice. Like, the first night I was staying over they were staying it's a sleepover and stuff.'</i> (Rachel, FG1, line 746 &amp; 747) She acknowledged how continuity of care helped her become more familiar with the staff: <i>'they're always in the clinic when I am there.'</i> (Rachel, FG1, line 678) She commented on how the diabetic team got to know her, by chatting casually and taking an interest in her wider life: <i>'they like asked me what school I'm going to this year' and about 'my baby sister and stuff.'</i> (Rachel, FG1, line 815-819)</p> <p>Participants experienced some HCPs as being easier to talk to than others. Rachel felt that she could talk to the diabetic team: <i>'[...] I can talk to them more 'cos you know them.'</i> (Rachel, FG1, line 621) From the perspective of Laura, a young girl with a recent diagnosis of diabetes, a caring nature was an important factor: <i>'[HCPs who] make you feel as if they care [were easier to talk to].'</i> (Laura, FG2, line 432)</p>	<p>Laura was well informed by her hospital consultant, who had seen her when she was first diagnosed with diabetes: <i>'My consultant like came the day before [...] and he explained the whole thing in detail.'</i> (Laura, FG2, line) Laura's experience of being well informed resembled Rachel's: <i>'The doctor like normally tells me everything that I need to know anyway and they put it in like ways that I like, know.'</i> (Rachel, FG1, line 657 &amp; 658)</p> <p>Sarah, an adolescent with spina bifida and scoliosis, felt she had some control over her treatment: <i>'Uhm, I might have to get the surgery on my back, because I've got scoliosis, em, so if it gets like really, it's not too bad but if it gets worse I have to have surgery so I feel as if I have like a choice because I don't have to have it, and I don't want it. [...] I don't want to have it.'</i> (Sarah, FG2, line 743-748)</p> <p>Although all participants wanted to be informed, the oldest participant, Darren, a young boy with spina bifida and epilepsy, preferred his parents to ask and answer questions, and doctors to make decisions on his behalf:  <i>'GD: Do you ever have any questions [Darren]?'                  Darren: Ah...don't think so.                  AT: Are you happy for your parents to ask the questions?                  Darren: Yeah.                  AT: And you just listen?                  Darren: Yeah [smiling and laughing].'</i> (Verbatim excerpt, FG1, line 555-560)</p>
Unfavourable experiences	<p>Sarah found it difficult to trust HCPs who were uncaring: <i>'Well yesterday I had to get a line [cannula] in and there was four different doctors that tried [...] and I thought like the doctors didn't really care, they were just gonna get it in, they didn't really care what I was thinking. [...] Well I know they needed to do it. But they didn't care, [...] they didn't care if they hurt me.'</i> (Sarah, FG2, line 438-441 &amp; 512)</p>	<p>During her cannulation experience, Sarah felt angry because HCPs failed to grant her wishes: <i>'I always tell them to put it, try my feet first because I don't have any feeling in my feet [...] I told the doctor not to put it in there and they still did it. [...] I was really cross after it because I thought all that pain.'</i> (Sarah, FG2, line 460-465)</p> <p>Sarah spoke about feeling excluded when a doctor spoke discretely to her mother: <i>'No but it does happen to people like they feel they're left out. [...] Today, [...] a doctor was explaining something to me and he was just about to leave and when he was just about to leave he said to my mum, "If you want to ask a question I can come back" so I kind of thought is he doing that because he doesn't want me to hear my mother asking the question.'</i> (Sarah, FG2, line 612 &amp; 619-622)</p>

374 Note: Rachel, Laura, Sarah, and Darren are pseudonyms (participants aged 11-15 years)

375

376 **Box 3 Take-home messages for HCPs**

Focus group participants provided take-home messages about how HCPs, could deliver high-quality child-centred care:

1. *'Explain.'* (Laura, FG2, line 409) *'Explain it in a child friendly way.'* (Sarah, FG2, line 411) *'Because if the child is really young it has to be explained in a different way. At an age you're able to understand [or HCPs will] scare them.'* (Sarah, FG2, line 658-663)
2. *'They should explain what they are going to do before they do it, and like [...] always say who they are and what they're gonna do [...] [and at] what time [...], and explain what was gonna happen and why [...].'* (Rachel, FG1, line 498-510)
3. *'I think just tell everyone together. [...] Because like telling your mum and dad first you'll see the expression on their face and then you're already gonna know.'* (Laura, FG2, line 651-654)
4. *'Always like ask [children] do you have any questions [...] ask [to check understanding].'* (Sarah, FG2, line 388 & 416-417)
5. *'Whenever [children] come in, try and treat them like nicer, em.'* (Darren, FG1, line 992) *'Like treat them the same as everybody else so they all feel the same.'* (Rachel, FG1, line 993)

377 Note: Rachel, Laura, Sarah, and Darren are pseudonyms (participants aged 11-15 years)

378 **DISCUSSION**

379 CADs' experiences were influenced by HCPs forming relationships and involving them:

380 engendering trust and involving CADs satisfied them, made them happier when undergoing  
 381 procedures and treatments, and better able to confide. HCPs did this by being personable, wise,  
 382 and sincere, relating at a personal level, bringing CADs into conversations and decisions, and  
 383 speaking in child-friendly ways. Conversely, not relating to or involving CADs, communicating  
 384 ineffectively by using inappropriately technical language or positioning CADs as 'piggy-in-the-  
 385 middle' between HCPs and parents resulted in CADs being fearful, angry, resistant, and  
 386 disengaged.

387 These findings add to earlier studies, which identified intimate relationships,[77,110,150]  
 388 trust,[77] and involvement,[47,151] as important ingredients of caring well for CADs. They  
 389 corroborate a recent systematic review of decision-making experiences, which found that HCPs  
 390 (and parents) made adolescents feel fearful, anxious, and depersonalised when they withheld

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5 391 information or denied involvement.[151] Parents had a significant influence on HCPs'  
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7 392 experiences in our study too, by facilitating or impeding communication. Overcoming parental  
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9 393 primacy, over-involvement, over-protectiveness,[47,77,151] and wish to withhold information  
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11  
12 394 remains a substantial challenge for HCPs.[77]  
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### 15 395 **Strengths and limitations**

16  
17 396 Our synthesis advances understanding of CADs' experiences of HCPs because of its  
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19 397 comprehensiveness, analysis of interrelationships between the nature, origins, and effects of  
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21 398 trust and involvement, and its advocacy for CADs' autonomy. It provides a blueprint for CCC,  
22  
23 399 which has, until now, largely depended on theory and expert consensus rather than empirical  
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25 400 evidence.[8] Our findings endorse the concept and importance of CCC, whilst showing how  
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27 401 much work is needed to put this principle into practice. Our review was innovative in the way it  
28  
29 402 used phenomenology, a theory that is highly relevant to the topic, to inform a rigorous  
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31 403 interpretive synthesis. This allows us to go beyond cataloguing publications and draw empirically  
32  
33 404 supported conclusions about how HCPs could care more effectively for CADs. This, we suggest, is  
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35 405 a significant contribution to the scholarship of evidence synthesis.  
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41 406 As with most qualitative syntheses, we present a broad overview, whose findings are potentially  
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43 407 transferable across a range of clinical contexts. We took an iterative approach to article  
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45 408 selection and ensured adequate time for rigorous interpretive analysis; while some evidence  
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47 409 may have been published since we searched the databases, this is an inherent limitation in  
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49 410 research that goes to such lengths to analyse a huge evidence-base and synthesise information.  
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51 411 We doubt that this materially affects our conclusions since the nature of human relationships  
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53 412 are unlikely to change in 12 months. Consulting with stakeholders, whilst obviously desirable, is  
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55 413 often omitted from scoping reviews.[152] Our consultation sample was admittedly small and  
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5 414 relatively homogenous, but participants spoke informatively about their experiences, which  
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7 415 helped consolidate and authenticate the findings.  
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10 416 Our conclusions are susceptible to both publication and interpretation bias because more  
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12 417 emotive material tends to attract greater attention. This limitation is partially offset by our  
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14 418 rigorous adherence to methodological standards. Another limitation, imposed by the non-  
15  
16 419 specific nature of studies and inexplicit reporting of metadata by primary authors, is that we  
17  
18 420 could not analyse how different types of HCP, or participants' ages or illnesses, affected CADs'  
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20 421 experiences. Restricting the scope to English language publications excluded non-English  
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22 422 speaking children from distinct cultural groups.[40] This is an important topic for future study.  
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### 26 423 **Implications for policy, research, and practice**

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29 424 Our findings add impetus to the movement to design, deliver, and further characterise child-  
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31 425 centred healthcare which has important implications for HCPs, educators, researchers, and  
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33 426 policymakers.[153] Our empirical augmentation of this conceptual model supports these  
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35 427 initiatives. To achieve the vision of CCC, there is a need for communication strategies, training,  
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37 428 assessments, and feedback (from CADs, specifically) at both the undergraduate and  
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39 429 postgraduate levels of health professions education. Further research will be needed to address  
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41 430 the long-term sustainability and effectiveness of CCC. Evidence on how healthcare policy,  
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43 431 practice, and legislation can influence child-centred approaches is long overdue. Further  
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45 432 research could also examine how age, illness, gender, and the cultures of different professions  
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47 433 influence the drive for CCC. Further implications for practice include the need for HCPs to  
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49 434 examine how professional boundaries between themselves and CADs are characterized, and  
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51 435 consider how best to respect CADs' preferences when it goes against 'best practice'.  
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### 56 436 **ABBREVIATIONS**

1  
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5 437 CADs- Children and adolescents  
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8 438 CCC- Child-centred care  
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11 439 CINAHL- Cumulative Index to Nursing and Allied Health Literature  
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14 440 FCC- Family-centred care  
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17 441 HCPs- Healthcare professionals  
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20 442 PCC- Patient-centred care  
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23 443 RBHSC- Royal Belfast Hospital for Sick Children  
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25  
26 444 **DECLARATIONS**  
27

28 445 **Ethics approval and consent to participate**  
29

30  
31 446 Ethical approval for focus groups was obtained from the Office for Research Ethics Committees  
32

33 447 Northern Ireland (reference: 19/NI/0070), while research governance was obtained from the  
34

35  
36 448 Belfast Health and Social Care Trust, Northern Ireland.  
37

38  
39 449 **Consent for publication**  
40

41  
42 450 Consent for publication was gained.  
43

44  
45 451 **Availability of data and materials**  
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47 452 All data are available in this article, or supplementary materials and open access repositories.  
48  
49

50 453 **Supplementary materials**  
51

52  
53 454 The content has been supplied by the authors.  
54

55  
56 455 **Competing interests**  
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58  
59 456 None declared.  
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14  
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16

17  
18 **462 Authors' contributions**  
19

20 463 GD conceived the review, sought approvals, secured funding, led the execution, and led the  
21  
22  
23 464 write-up. GD, AT & RC completed the focus groups. MK, RC, AT & TD assisted with data  
24  
25 465 selection, analyses, and manuscript revision. All authors read and approved the final manuscript.  
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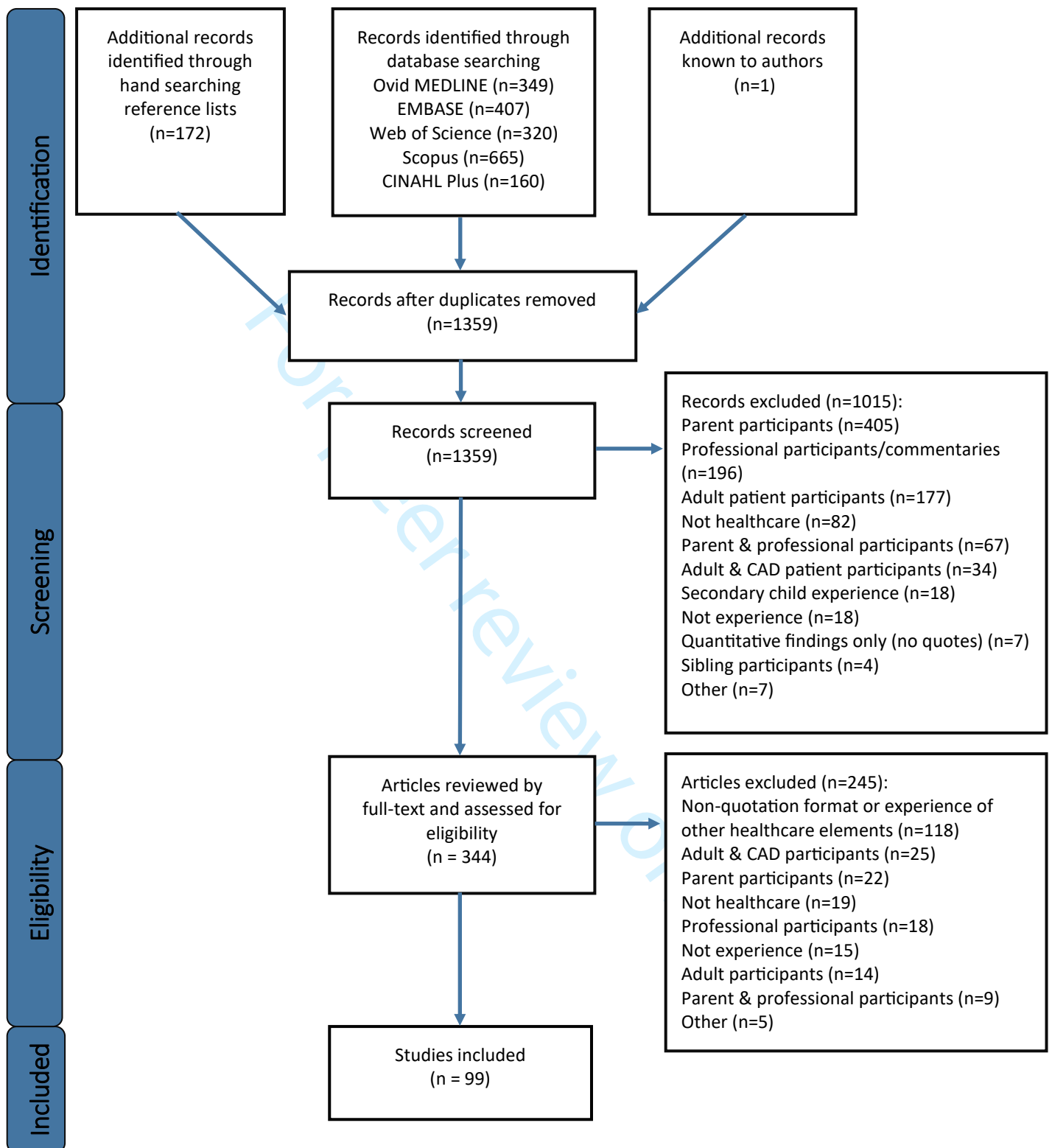
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43 **FIGURE CAPTIONS**

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46 871 Figure 1 PRISMA flow diagram  
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Note 'Other' (n=12) reasons for excluding records/articles included: participants' ages unclear (n=4); no full-text available or unobtainable in English (n=7); same study as included article (n=1).

### PRISMA-ScR Checklist

This supplementary information includes the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist (1).

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE # (untracked version)
<b>TITLE</b>			
Title	1	Identify the report as a scoping review.	p.1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	p.3-4, background not required in abstract as per journal guidance
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	p.6-8
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	p.8 & 9
<b>METHODS</b>			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	p.9 and reference list. Not registered.
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	p.9-12 (Table 2)
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	p. 9 & 10 (Table 1)
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	p. 9 & 10, Supp file 2
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	p. 10 & 11
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	p. 13 (box 2)
Data items	11	List and define all variables for which data were	p. 13



SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE # (untracked version)
		sought and any assumptions and simplifications made.	
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Critical appraisal not done. Rationale on p.11
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	p. 13-15
<b>RESULTS</b>			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	p. 15 (Figure 1)
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	p. 15 (Table 2)
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	p. 15 (Table 2) & Dryad data
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	p. 15, 16, 23-26, & supp file 4.
<b>DISCUSSION</b>			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	p. 29-30
Limitations	20	Discuss the limitations of the scoping review process.	P. 30-31
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	p. 31
<b>FUNDING</b>			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	p. 32

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

\* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable





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3 to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used  
4 in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).  
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7 REFERENCE:

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9 1. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for scoping reviews (PRISMA-  
10 ScR): Checklist and explanation. *Ann Intern Med.* 2018;169(7):467–73. doi: [10.7326/M18-0850](https://doi.org/10.7326/M18-0850).  
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For peer review only



MEDLINE search	
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3.	Community Mental Health Services/ or Mental Health Services/ or Community Health Services/ or Community Health Nursing/
4.	School Health Services/
5.	1 or 2 or 3 or 4
6.	Stress, Psychological/
7.	Emotions/
8.	emotion*.mp.
9.	experienc*.mp.
10.	6 or 7 or 8 or 9
11.	5 and 10
12.	limit 11 to "all child (0 to 18 years)"
13.	((child* or infant* or adolescen* or teen?age* or boy* or girl* or toddler*) adj5 (view* or opinion* or feeling* or emotion* or experience* or perception* or first?hand* or their* or say?in or decision* or choice* or choos* or autonomon* or interview* or art or "art* therap*")).mp.
14.	12 and 13
15.	Qualitative Research/
16.	14 and 15

key: mp, multi-purpose search; adj5, search within adjacent 5 words.

## Braun &amp; Clarke 15-point Thematic Analysis Checklist

Process	No.	Criteria	Response
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'	Both focus group transcripts transcribed to an appropriate level of detail and checked against tapes.
Coding	2	Each data item has been given equal attention in the coding process	We reviewed all quotations to generate coding.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive	Themes, and the findings described herein, were developed from a complete coding process of the entire dataset. The coding process was thorough, inclusive and comprehensive, as all quotations were used to generate codes, and develop themes. Each theme was developed based on numerous codes gathered across a range of articles and participants quotations.
	4	All relevant extracts for all each theme have been collated	Yes.
	5	Themes have been checked against each other and back to the original data set	Yes.
	6	Themes are internally coherent, consistent, and distinctive	Yes.
Analysis	7	Data have been analysed- interpreted, made sense of- rather than just paraphrased or described	Yes, evident from the results.
	8	Analysis and data match each other- the extracts illustrate the analytic claims	The analysis and findings from it closely match the data set.
	9	Analysis tells a convincing and well-organised story about the data and topic	Yes.
	10	A good balance between analytical narrative and illustrative extracts is provided	Yes. Illustrative extracts have been used within the results section.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly	Yes.
Written report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated	Yes, stated in the methods section.
	13	There is good fit between what you claim you do, and what you show you have done- i.e. described method and reported analysis are consistent	Yes.

	14	The language and concepts used in the report are consistent with the epistemological position of the analysis	Yes.
	15	The researcher is positioned as <i>active</i> in the research process; themes do not just 'emerge'	Yes.

## REFERENCE:

1. Braun V, Clarke V. Successful qualitative research: a practical guide for beginners. London: SAGE Publications Ltd; 2013.

### **Additional Scoping Review Results: Basic numerical analysis and figures**

This supplementary information includes additional findings and graphical illustrations from basic numerical analysis.

#### *Trend in study publications over time*

On average, four studies were published each year and the rate of publication rose progressively, increasing to 11 per year in 2018 (as shown in Figure 1).

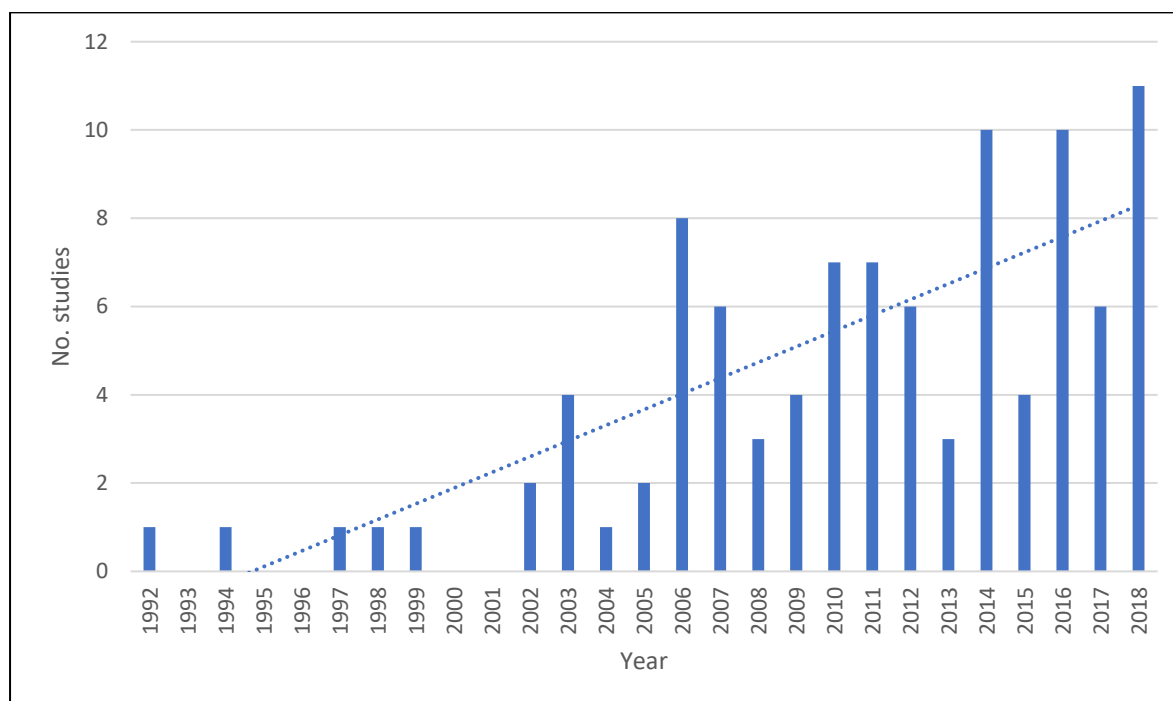


Figure 1 Years of publications

#### *Countries of origin*

Figure 2 illustrates the geographical distribution of included studies on the world map and figure 3 lists countries of origin (n=21) including the number of studies pertaining to each country. Eighty-eight studies originated in western or more developed countries of which the UK (n=26), Canada (n=15), Ireland (n=9), Sweden (n=9), and the United States (n=9) were most common.

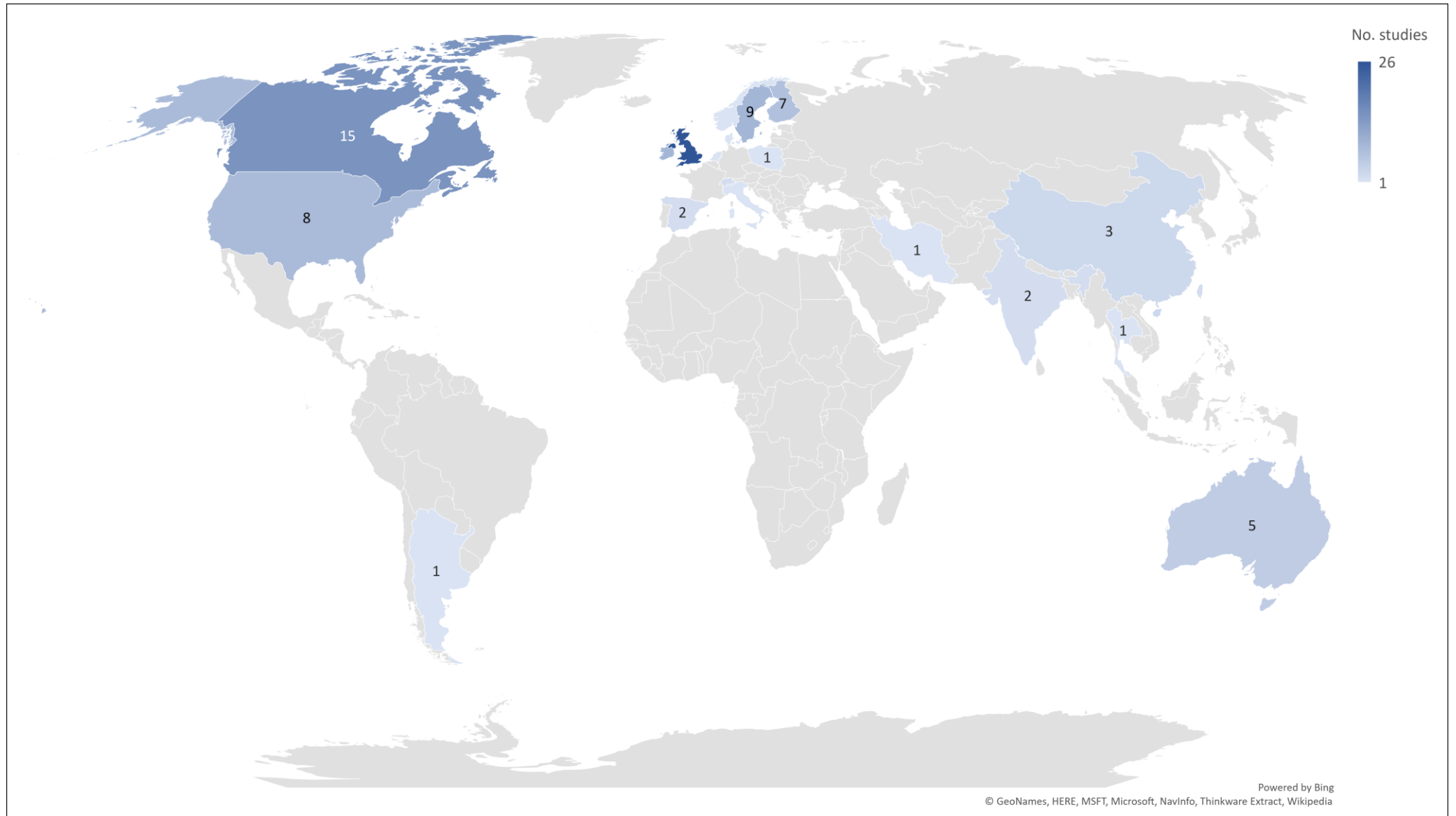


Figure 2 Map of geographical distribution of studies

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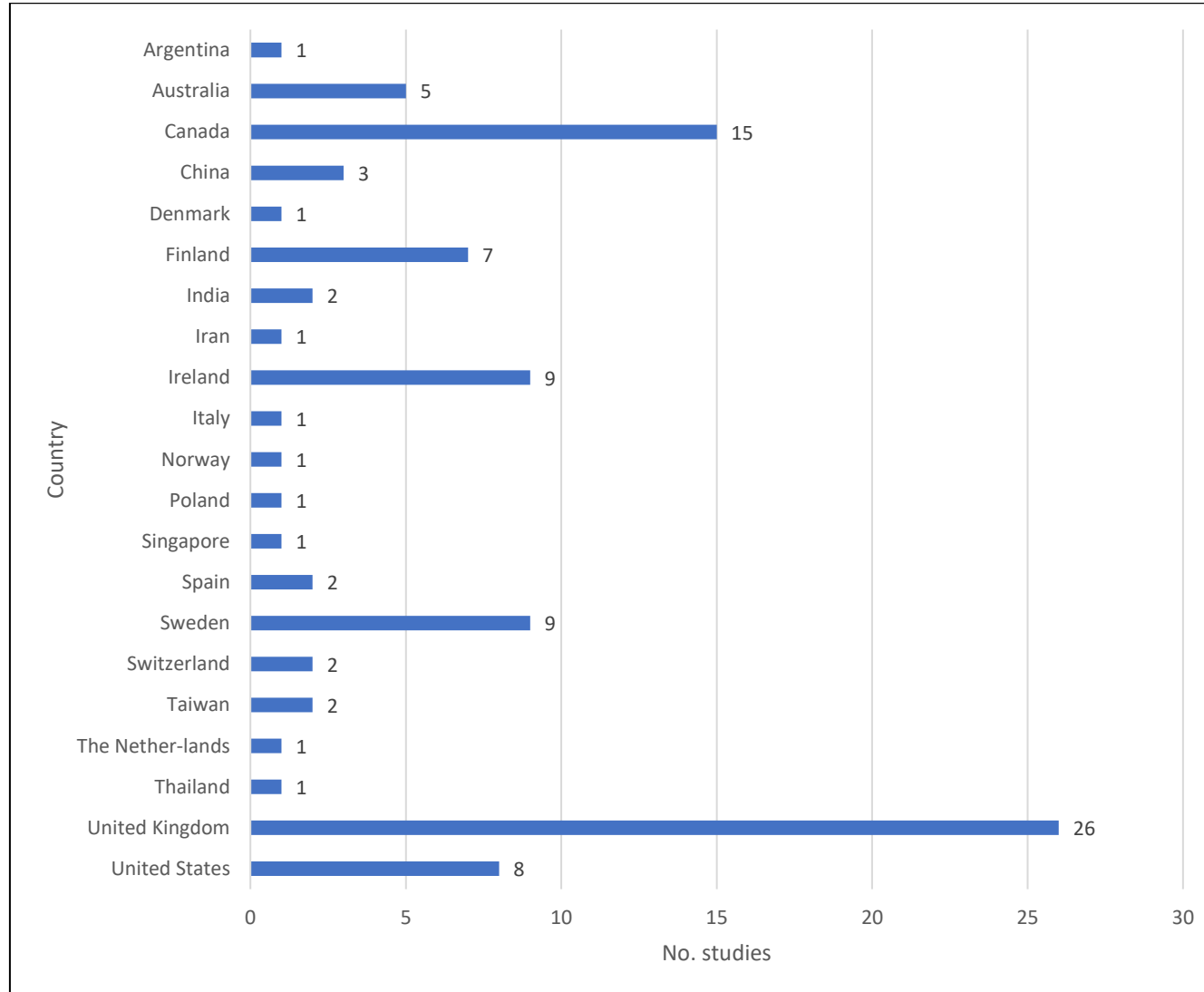


Figure 3 Number of studies per country

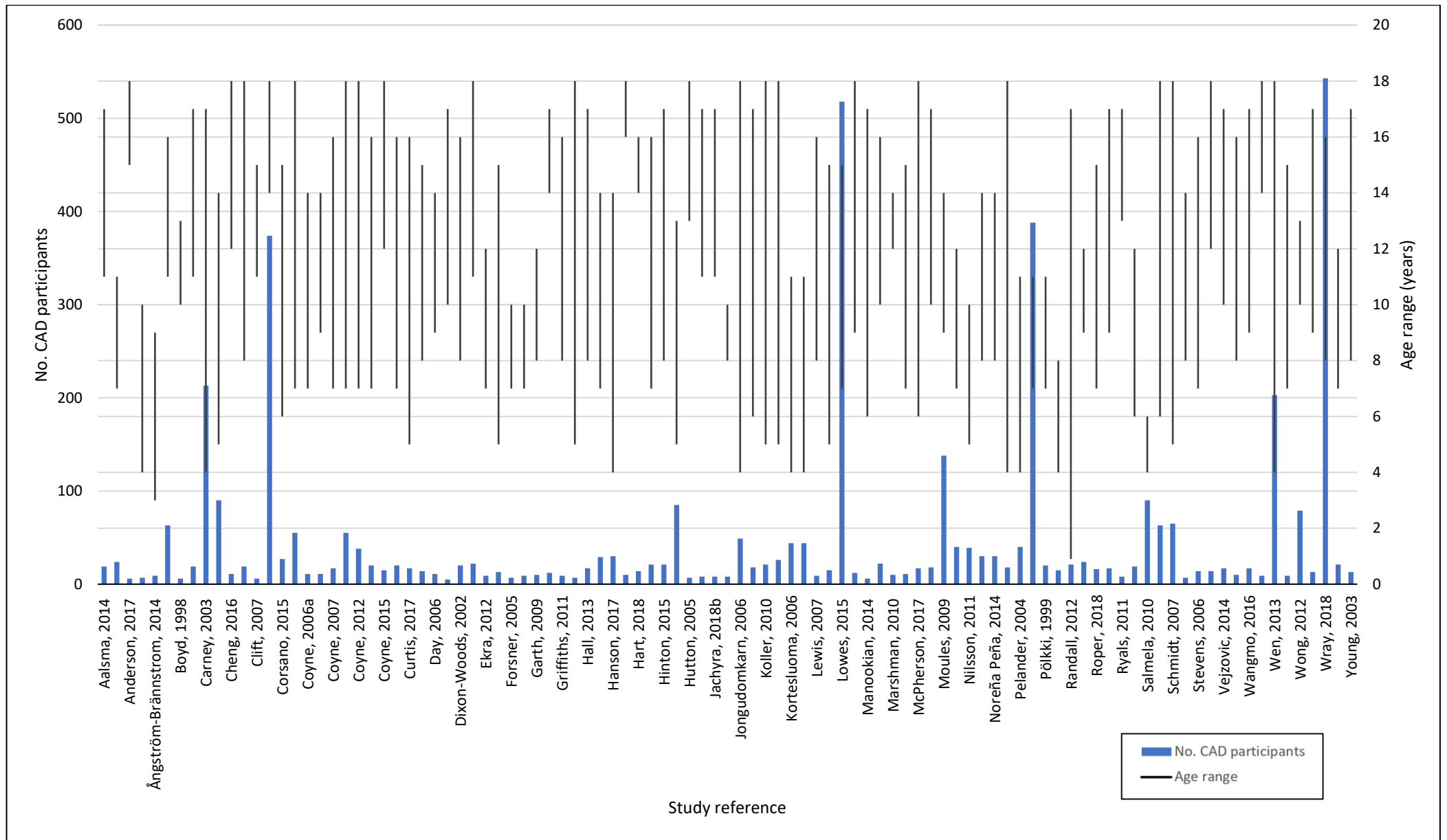


Figure 4 Number of CAD participants per study and age ranges



### *CAD participants*

The number of CAD participants per study and age ranges are illustrated in figure 4. Age ranges varied, however, most studies recruited CAD participants aged 6-17 years. Studies tended to recruit between 8 to 50 participants; seven studies recruited over 100.

### *Additional participants*

Most studies recruited CADs only (n=72). Some studies recruited other participants (n=27); who were parents, HCPs, and teachers (figure 5).

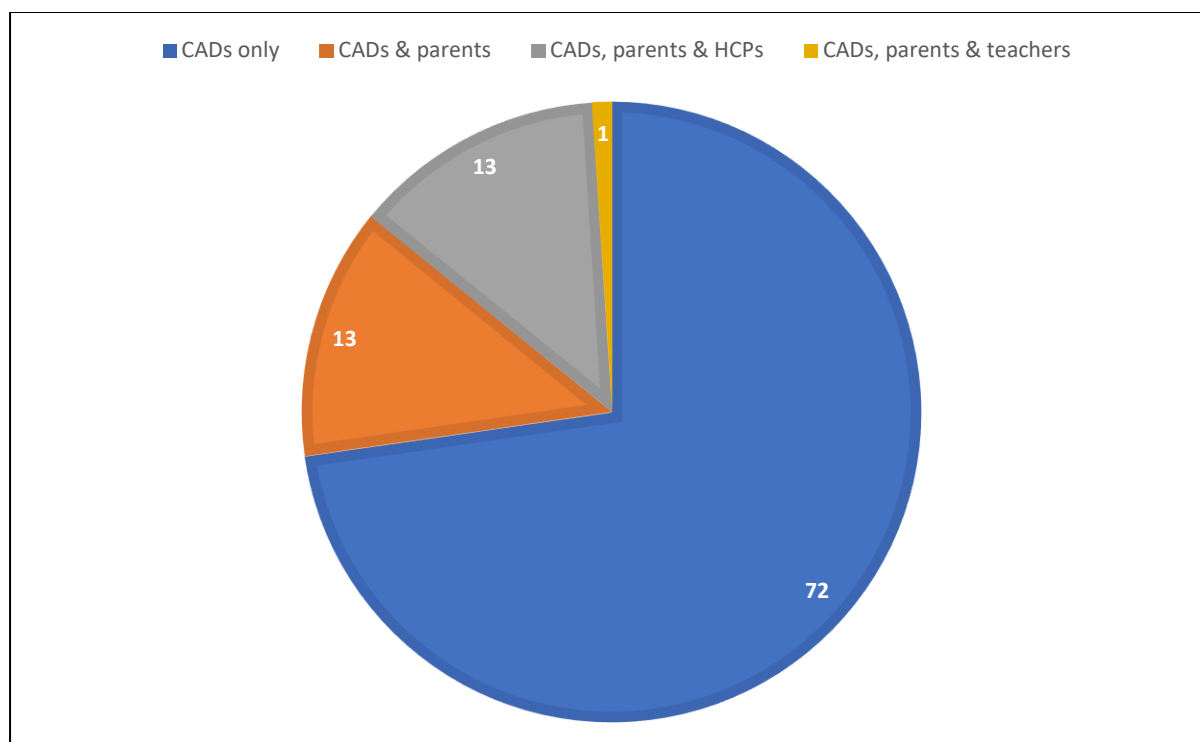


Figure 5 Study participants

### *Study methods*

Most studies used a single method; interviews were most prevalent, followed by focus groups, free-text questionnaires, and workshops (figure 6). Twenty-nine studies used 2 or 3 methods; commonly, interviews combined with observation or focus groups (figure 7).

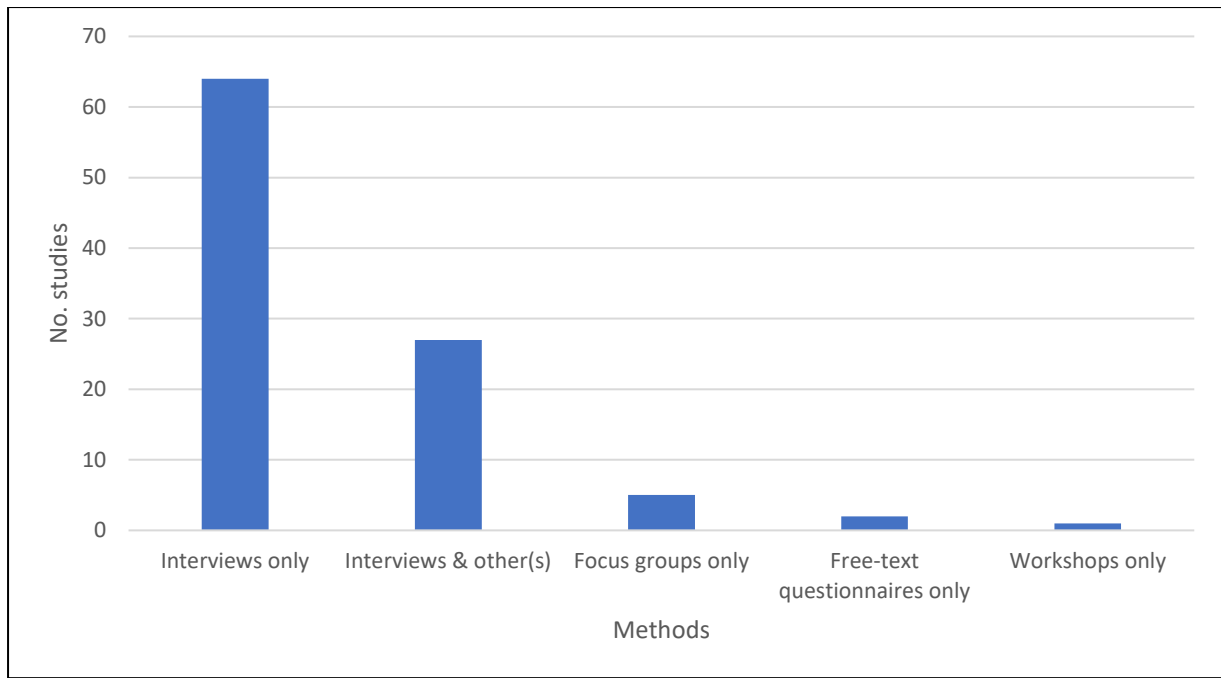


Figure 6 Methods classification

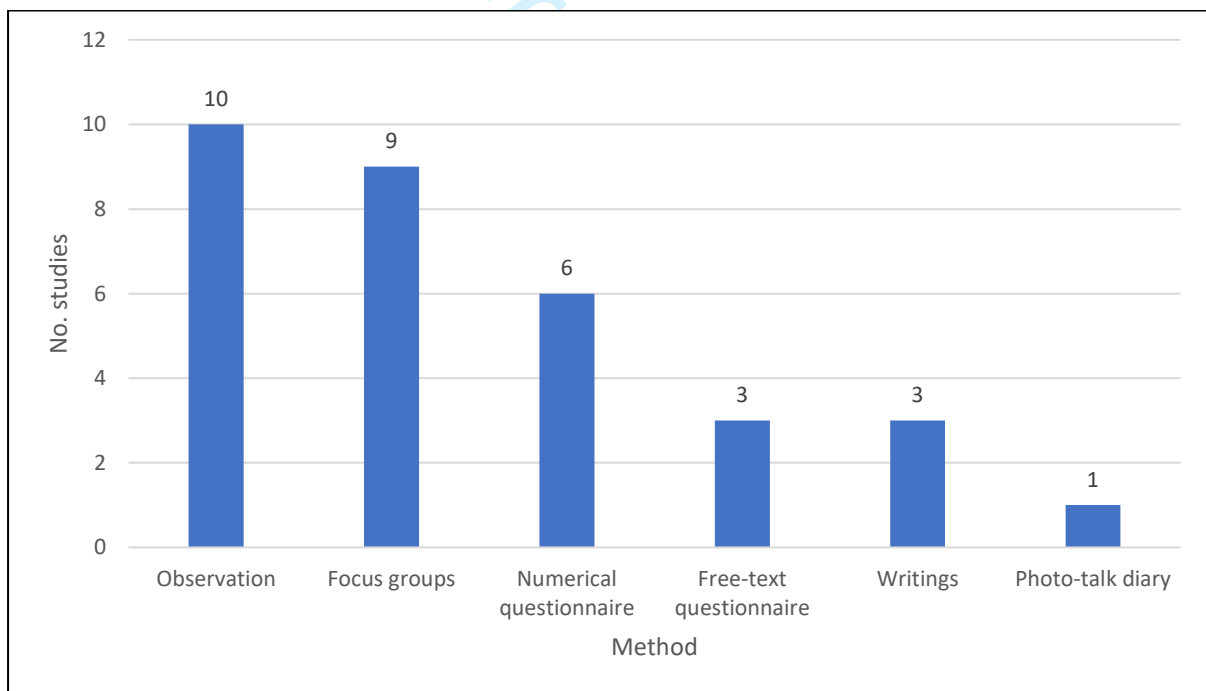


Figure 7 Methods conducted with interviews

### CADs' ages and genders from extracted quotes

Figure 1 illustrates the age distribution of quotations extracted. CADs aged 11-14 were more commonly quoted, while those aged 5-8 years were quoted less. Many quotations referenced CADs' ages (n=379, 56.7%) and genders (n=390, 58.3%); of which 52% were female.

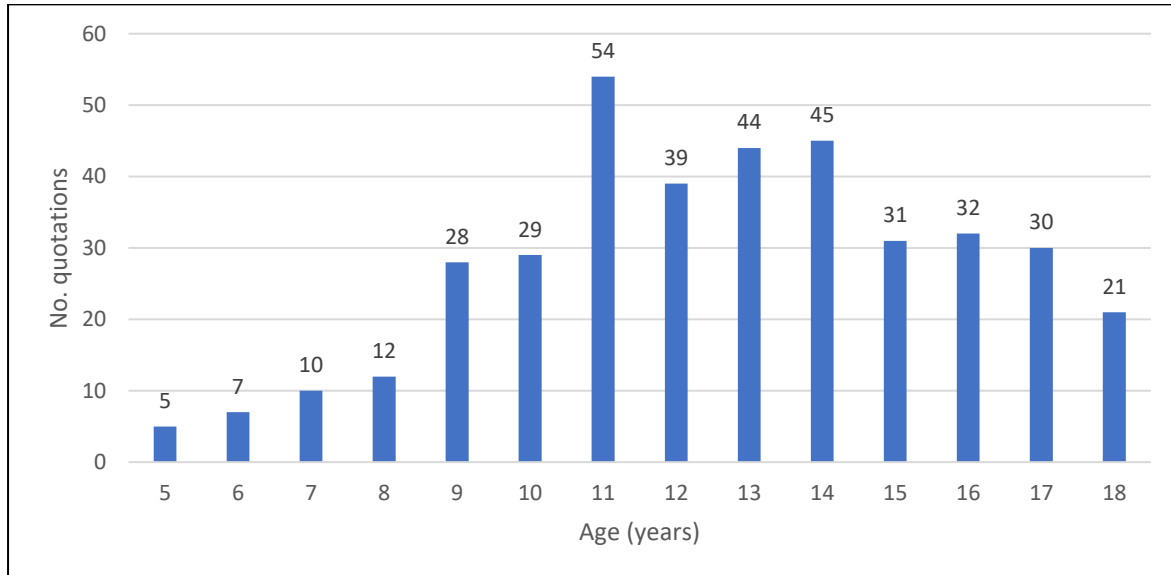


Figure 1 CAD participant ages, from extracted quotes

Quotations presented in results section

The full quotations extracted from articles are accessible using the Dryad unique identifier

<https://doi.org/10.5061/dryad.z08kprrc2>

Quote no.	Quote as written in results section	Quote reference (first author, year, quote no.)
1	'bond'	Ryals, 2011(49)
2	'emotional attachment'	Brown et al., 2014(04)
3	'best friend'	Ryals, 2011(33)
4	'relate to'	Ryals, 2011(32)
5	'good care'	Ångström-Brännström et al., 2008(05)
6	'strangers'	Coyne et al., 2015(02)
7	'As time passed, [...] we created that bond.'	Ryals, 2011(29)
8	'very smart'	Coyne et al., 2014(02)
9	'experienced'	Hodgins et al., 1997(02)
10	'[knew] what to do'	Day et al., 2006(04)
11	'[took] care'	Noreña Peña, 2011(21)
12	'everything the best they [could]'	Boyd, 1998(03)
13	'truthful'	Brown et al., 2014(15)
14	100% with you'	Brown et al., 2014(15)
15	'just [told] you straight up.'	Brown et al., 2014(15)
16	'not tell children any lies'	Koller et al., 2010(02)
17	'nothing [was] hidden'	Coyne et al., 2016(01)
18	'really nice'	Clift et al., 2007(06)
19	'nurturing, caring and helpful people who [were] there for you'	Schmidt et al., 2007(01)
20	'good sense of [humour]'	Schmidt et al., 2007(15)
21	'she knew what I was talking about, she knew what I was feeling, she knew how I was feeling.'	Ryals, 2011(20)
22	'took time to get to know'	Brown et al., 2014(06)
23	'real conversations, not just [HCP]-patient discussions'	Schmidt et al., 2007(31)
24	'down to earth'	Ryals, 2011(45)
25	'a lot in common'	Ryals, 2011(22)
26	'you gotta have trust.'	Ryals, 2011(42)
27	'satisfied'	Wangmo et al. 2016(05)
28	'happy'	Corsano et al. 2015(04)
29	'good memories'	Manookian et al, 2014(03)
30	'open up'	Ryals, 2011(42)
31	'tell anything'	Beresford et al, 2003(06)
32	'cure [the] illness'	Han et al, 2011(01)
33	'whatever happens I let them [HCPs] do what they have to do to help me get better.'	Boyd & Hunsberger, 1998(01)
34	'individually [they're] all heroes.'	Anderson et al., 2017(04)
35	'Because you can save people [...] I'm going to be a children's doctor.'	Olausson et al., 2006(01)
36	'everything [was] always clear'	Schalkers et al., 2014(04)
37	'together'	Dell'Api et al., 2007(07)
38	'seriously'	Clift et al., 2007(05)
39	'as an equal'	Clift et al., 2007(05)

40	'into all the conversations'	Coyne et al., 2011(15)
41	'as much as they [talked to the] parents'	Edgecombe et al., 2010(03)
42	'[breaking] the words down in an easier explanation'	Coyne et al., 2006(13)
43	'listening'	Coyne et al., 2006(03)
44	'I tell them I don't want this and they ... understand'	Coyne et al., 2006(03)
45	'me because I know my own body, my parents because they know what's best for me [...] and the paediatrician because they are qualified.'	Garth et al., 2009(02)
46	'most important, as in the end it is about [them]'	Schalkers et al., 2014(04)
47	'brilliant'	Moules, 2009(01)
48	'interesting and informational'	Lowes et al., 2015(02)
49	'learn something new'	Lowes et al., 2015(03)
50	'comfortable and confident'	Lowes et al., 2015(02)
51	'make better decisions'	Coyne & Kirwan, 2012(23)
52	'fully informed'	Coyne & Kirwan, 2012(23)
53	'I'm asking the doctor more questions myself than having my Dad do it.'	Coyne et al., 2006(15)
54	'nasty'	McPherson et al., 2018(03)
55	'[seeming] that concerned'	Coyne, 2006b(02)
56	'too busy'	Coyne et al., 2006(28)
57	'big words'	Coyne et al., 2006(16)
58	'they [HCPs] might ask me "is that ok" and they ask me in such a way that I kind of feel like I don't have any other option but [to] agree with them'	Coyne et al., 2015(01)
59	'behind the curtains'	Coyne et al., 2011(20)
60	'in the middle'	Coyne et al., 2006(18)
61	'you try to say something but then your parents just say shhhh! [...] They come out and say, [...] did you understand that, you say no, they say, you should have asked them, and then you say, oh you didn't let me, they say rubbish!'	Hawthorne et al., 2011(04)
62	'rejected'	Coyne et al., 2006(17)
63	'like a piece of machinery'	Coyne, 2006b(04)
64	'hard to talk'	Anderson et al., 2017(01)

# BMJ Open

## How do children and adolescents experience healthcare professionals? Scoping review and interpretive synthesis

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5 1 **TITLE PAGE**

6  
7 2 **How do children and adolescents experience healthcare professionals? Scoping review and**  
8  
9 3 **interpretive synthesis**

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5 29 **ABSTRACT**

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7 30 **Objective**

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10 31 Explore children's and adolescents' (CADs') lived experiences of healthcare professionals (HCPs).

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13 32 **Design**

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15  
16 33 Scoping review methodology provided a six-step framework to, first, identify and organise  
17  
18 34 existing evidence. Interpretive phenomenology provided methodological principles for, second,  
19  
20 35 an interpretive synthesis of the life-worlds of CADs receiving healthcare, as represented by  
21  
22 36 verbatim accounts of their experiences.

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26 37 **Data Sources**

27  
28  
29 38 Five key databases (Ovid MEDLINE, Embase, Scopus, CINAHL Plus, and Web of Science), from  
30  
31 39 inception through to January 2019, reference lists, and opportunistically identified publications.

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34 40 **Eligibility criteria**

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37 41 Research articles containing direct first-person quotations by CADs (aged 0-18 years inclusive)  
38  
39 42 describing how they experienced HCPs.

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41  
42 43 **Data extraction and synthesis**

43  
44 44 Tabulation of study characteristics, contextual information, and verbatim extraction of all  
45  
46 45 'relevant' (as defined above) direct quotations. Analysis of basic scope of the evidence-base. The  
47  
48 46 research team worked reflexively and collaboratively to interpret the qualitative data and  
49  
50 47 construct a synthesis of children's experiences. To consolidate and elaborate the interpretation,  
51  
52 48 we held two focus groups with CAD inpatients in a children's hospital.

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56 49 **Results**

1  
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4  
5 50 669 quotations from 99 studies described CADs' experiences of HCPs. Favourable experiences  
6  
7 51 were of forming trusting relationships and being involved in healthcare discussions and  
8  
9 52 decisions; less favourable experiences were of not relating to or being unable to trust HCPs  
10  
11 53 and/or being excluded from conversations about them. HCPs fostered trusting relationships by  
12  
13 54 being personable, wise, sincere, and relatable. HCPs made CADs feel involved by including them  
14  
15 55 in conversations, explaining medical information, and listening to CADs' wider needs and  
16  
17 56 preferences.  
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20

## 21 57 **Conclusion**

22  
23  
24 58 These findings strengthen the case for making CADs partners in healthcare despite their youth.  
25  
26 59 We propose that a criterion for high-quality child-centred healthcare should be that HCPs  
27  
28 60 communicate in ways that engender trust and involvement.  
29  
30

## 31 61 **STRENGTHS AND LIMITATIONS OF THIS STUDY**

- 32  
33  
34 62 • Our findings have advanced current evidence by providing a comprehensive overview of  
35  
36 63 CADs' experiences of HCPs, while providing a blueprint for the child-centred care  
37  
38 64 conceptual model.  
39  
40  
41 65 • In addition to completing a scoping review in line with a published protocol, this article  
42  
43 66 reports an interpretive phenomenological synthesis of the evidence-base  
44  
45 67 • Restricting included articles to the English language limited the scope of our review  
46  
47  
48 68 • Limitations in the metadata provided by primary researchers prevented subgroup  
49  
50 69 analyses  
51  
52 70 • The subjectivity of interpretive synthesis is both a limitation and a strength: a limitation,  
53  
54 71 because it does not meet quantitative, experimental standards of proof; and a strength  
55  
56 72 because we used our subject position as clinicians to help fellow clinicians earn the trust  
57  
58 73 of CADs.  
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60

## 74 BACKGROUND

75 Children's experiences, like patients' experiences in general, are of fundamental importance in  
76 healthcare.[1–3] Research consistently shows that favourable experiences are associated with a  
77 wide range of positive health outcomes, including adherence to recommended treatments,  
78 uptake of preventive care, and utilisation of healthcare resources.[3] Exploring, understanding,  
79 and adapting to patients' experiences, particularly those concerning interpersonal  
80 communication, is the hallmark of patient-centred care (PCC), which is what patients 'strongly  
81 want'. [4,5] Accordingly, PCC has become the dominant ideology in healthcare design and  
82 delivery.[6]

83 In the case of children, however, it has proven more difficult to establish a model of PCC.  
84 Children and adolescents (CADs) are distinct from adults; they are developing physically,  
85 intellectually, and emotionally, and they occupy different positions in society and by law.[7]  
86 CADs, therefore, typically experience healthcare as part of a family unit, accompanied by  
87 parents or guardians who often act on their behalf. These factors affect the roles that CADs  
88 occupy within healthcare settings – how they interact and communicate with others – and  
89 predispose them to asymmetric relationships with adults. To address this, two specific  
90 theoretical models of care – family-centred care (FCC) and child-centred care (CCC) – have been  
91 developed for use in paediatric practice, based on the principles of PCC but incorporating  
92 modified conceptualisations of centredness.[8]

93 In FCC, the family is the central unit of care, with the aspiration of an equal partnership between  
94 healthcare professionals (HCPs) and families. FCC, which first originated in the 1950s, was an  
95 important conceptual advance because, up to this point, no framework existed to involve  
96 parents in their children's care.[7] Recent research shows, however, that even within the FCC  
97 framework, parents and professionals tend to predominate and CADs struggle to be true  
98 participants.[9] In contrast, the newer concept of CCC situates CADs at the centre of healthcare

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5 99 practice, giving primacy to their voices and experiences. Rather than being guided by outsider  
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7 100 perspectives of children's best interests, CCC compels HCPs to consciously perceive and  
8  
9 101 understand children's conditions, experiences, and priorities, as viewed through their  
10  
11 102 eyes:[8,10,11]

13  
14 103 "[CCC] requires providers to critically consider the child's  
15  
16 104 perspective in every situation while ensuring collaboration  
17  
18 105 with the family who the [child] is part of." [8]

19  
20  
21 106 While aspects of FCC and CCC may be pertinent in different clinical contexts,[12] experts now  
22  
23 107 advocate a move towards CCC,[13] arguing that it better upholds values laid down by the UN  
24  
25 108 Convention on the Rights of the Child and governing bodies (such as the General Medical  
26  
27 109 Council),[14,15] and could improve how CADs experience healthcare.[8,13]

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31 110 Adopting the CCC approach, however, requires a major shift in thinking and practice. Research  
32  
33 111 suggests that HCPs' realities are incompatible with CADs', with HCPs focused on prioritizing  
34  
35 112 tasks, 'getting the job done', and mitigating, rather than engaging with, CADs' demands.[16]  
36  
37 113 Furthermore, HCPs' communication strategies adopted for consulting CADs are largely  
38  
39 114 underpinned and conceptualized by biomedical or psychosocial models, from the clinical  
40  
41 115 gaze,[17] with little or no input from CADs.[18,19] And while CADs' healthcare experiences  
42  
43 116 overall are generally positive, large-scale studies have identified shortcomings in how HCPs  
44  
45 117 interact and communicate,[20–22] impacting on CADs' ability to manage their conditions and  
46  
47 118 participate in decision-making.[23] HCPs, too, continue to find communicating with CADs  
48  
49 119 challenging, supporting a change in thinking and practice.[19]

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54 120 To achieve the vision of CCC, then, HCPs need greater insight into the experiences of sick  
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56 121 children.[11] This reflects a wider drive towards co-production (providers and service users  
57  
58 122 working in equal partnership to effect change) in children's healthcare;[24,25] and also

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5 123 complements the present impetus to acknowledge and examine CADs' *own* experiences,  
6  
7 124 opinions, and priorities, within research,[26,27] quality improvement,[28–30] and standard  
8  
9 125 setting.[31] To date, however, most research and surveys examining experiences in paediatric  
10  
11 126 settings have relied on parents' accounts, while CADs have participated less, if at all.[32]  
12  
13 127 Nevertheless, the few studies that have explored CADs' own experiential accounts have found  
14  
15 128 them to be informative and distinct from parents'.[23,33] At present, these accounts are widely  
16  
17 129 dispersed, yet if compiled, synthesised, and interpreted, these could provide a rich account of  
18  
19  
20 130 CADs' lived experiences of how they encounter HCPs.  
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22

23 131 This study aimed to explore how CADs experience HCPs within interpersonal interactions, in  
24  
25 132 order to provide practitioners, organisations, and policymakers with evidence that could  
26  
27 133 promote child-centred communication. First, we conducted a scoping literature review to  
28  
29 134 systematically gather evidence on CADs' experiences of HCPs. Second, we interpreted CADs'  
30  
31 135 extracted quotations from the perspective of phenomenology. This well-established  
32  
33 136 methodological tradition, grounded in philosophy, enables researchers to produce valid  
34  
35 137 interpretations by examining and interpreting participants' verbatim accounts of their lived  
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37 138 experience.[34] Finally, we organised the interpretation into a synthetic account of how CADs  
38  
39 139 experience their interactions with HCPs.  
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## 44 140 **METHODS**

### 45 141 **Methodological orientation**

46 142 Scoping review methodology has a pragmatic orientation in the sense that it sets out to map  
47  
48 143 existing published evidence on a topic but it is adaptable in the sense that the usefulness of its  
49  
50 144 procedures is not tied to any one specific epistemology (theory of the nature of knowledge).[35–  
51  
52 145 37] As in our previously published research,[38] this review augments scoping review  
53  
54 146 procedures with interpretive phenomenology. The latter has an ontology (theory of the nature  
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56 147 of being) derived from the philosophy of Husserl, according to which the lived experience of  
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5 148 research participants is a legitimate topic of qualitative inquiry. Interpretive phenomenology  
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7 149 helps researchers respond reflexively to spoken or written words and arrive at valid, subjective  
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9 150 interpretations. Phenomenologists typically take a reflexive stance that consciously sets aside  
10  
11 151 strong a priori preconceptions whilst allowing their own experiences (such as, in our case, having  
12  
13 152 experience of caring for sick children) to help them construct an informative interpretation.[34]  
14  
15  
16 153 The quality of a constructivist interpretation is to be judged by its trustworthiness, authenticity,  
17  
18 154 and ability to catalyse action – which, in this case, would be to improve future children’s  
19  
20 155 healthcare experiences.[39]  
21  
22

### 23 156 **Study procedures**

24  
25 157 The research followed a published protocol (accessible at <https://rdcu.be/b2FFk>),[40] which  
26  
27 158 proposed to supplement traditional scoping review procedures with an interpretive synthesis,  
28  
29 159 the distinction between which is explained in the previous paragraph. The scoping component  
30  
31 160 followed the 6-step framework outlined by Arksey & O’Malley,[35] Levac et al.,[36] and  
32  
33 161 Colquhoun et al.,[37] adhering to PRISMA-ScR reporting guidance (included in online  
34  
35 162 supplementary file 1).[41]  
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### 39 163 **Step 1: Defining the research question**

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42 164 This was: *‘What is known about children’s and adolescents’ experiences of healthcare*  
43  
44 165 *professionals, from their present perspective?’*, the final phrase emphasizing our commitment to  
45  
46 166 CADs’ contemporaneous accounts of their experiences expressed in their own words, rather  
47  
48 167 than parents’ descriptions or adults describing childhood memories.  
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### 51 168 **Step 2: Identifying relevant articles**

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54 169 We designed a STARLITE search strategy (summarised in table 1) to identify all published articles  
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56 170 containing CADs’ experiences of HCPs expressed as first-person direct quotations.[42] A subject  
57  
58 171 librarian constructed a database search (included in online supplementary file 2), using the  
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60

172 population, context, and concept framework,[43] combining the terms ‘children’ or  
 173 ‘adolescents’, ‘healthcare’, and ‘experience’ (and synonyms), limiting it to English language  
 174 articles, ‘qualitative research’, and ‘0 to 18 years’, and then running it on Ovid MEDLINE,  
 175 Embase, Scopus, CINAHL Plus, and Web of Science from inception to 11<sup>th</sup> January 2019. We  
 176 included other articles found by searching relevant reference lists or found opportunistically.

**Table 1 STARLITE summary of search strategy[42]**

Sampling strategy	Comprehensive: attempting to identify all published materials
Types of studies	Any published study contributing to the research question: qualitative (with or without other methodologies (i.e., mixed method)); primary or secondary sources
Approaches	Electronic database searching; manual searching of reference lists; articles found opportunistically
Range of years	From database inception until 11 <sup>th</sup> January 2019
Limits	Articles published in English language; ‘qualitative research’; children aged 0-18 years (inclusive)
Inclusion and exclusion criteria	See table 2 and Step 3: Study selection
Terms used	See online supplementary file 2
Electronic databases	Ovid MEDLINE; Embase; Scopus; CINAHL Plus; Web of Science

### 177 **Step 3: Study selection**

178 Refinement of selection criteria

179 As is customary in scoping review, the process iterated between searching, selecting, extracting  
 180 data, and refining the research question. To enhance the rigour of this process, and in keeping  
 181 with our interpretive stance, we responded reflexively to the accumulating evidence, discussing  
 182 our interpretations, and articulating a clear rationale for each refinement. All records were  
 183 imported to Mendeley Reference Manager, duplicates removed, titles and abstracts screened  
 184 against five screening questions (Box 1), and full texts of those that screened positive reviewed  
 185 against eligibility criteria.

#### **Box 1 Screening questions**

1. Are the participants CADs ( $\leq$  18 years)?
2. Is the study examining an aspect of health, illness, or healthcare?
3. Are CADs participating as recipients of healthcare?
4. Are participants aged > 18 years excluded from the study?
5. Do children or adolescents describe experiences?



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5 186 These criteria, at first provisional (table 2A), were progressively refined in response to the  
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7 187 heterogeneity of evidence. Table 2B shows final criteria. GD led the process of first-screening,  
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9 188 annotating, sorting, and collating articles. MK & TD supported her by second-screening 10% of  
10  
11 189 records, discussing results, assessing articles whose eligibility was in doubt, and responding to  
12  
13 190 the often-imprecise details given by researchers. Any ambiguities (i.e., lack of age ranges) during  
14  
15 191 screening led to full-text review and a final decision about eligibility against criteria. To optimise  
16  
17 192 validity of the selection process, GD rescreened all records and annotations after each  
18  
19 193 refinement and, finally, after definitive criteria had been set.

#### 22 194 Rationale for criteria

25 195 We included children up to and including 18 years because late adolescents are increasingly  
26  
27 196 cared for in paediatric settings.[44,45] Our age range conforms, also, with the United Nations'  
28  
29 197 influential definition of adolescence.[46] We included articles that contained verbatim  
30  
31 198 quotations irrespective of methodology. Judgement of methodological quality was not a  
32  
33 199 criterion for three reasons: it is not standard practice in scoping reviews; it is notoriously difficult  
34  
35 200 to judge qualitative research categorically;[47] and the interpretive synthesis used verbatim  
36  
37 201 quotations, whose validity does not depend on what the primary researchers did with CADs'  
38  
39 202 words. Because authors often failed to report the exact age of patient participants they quoted,  
40  
41 203 we excluded any study that included patient participants aged > 18 years (see, for example,  
42  
43 204 Tjaden et al. [48]).

<b>Table 2 Eligibility criteria for article selection</b>	
<b>A. Provisional</b>	<b>B. Definitive</b>
Inclusion criteria:	
<ol style="list-style-type: none"> <li>1. CADs speaking about HCPs, through first-person direct quotations.</li> <li>2. HCP defined as a member of a healthcare team.</li> <li>3. CADs defined as <math>\leq 18</math> years old, regardless of health status or illness type.</li> </ol>	<ol style="list-style-type: none"> <li>1. CADs speaking about one or more HCPs, on one or more instances, from any experience, through first-person direct quotation(s), where there had been direct contact between the two parties, and where CADs were the persons receiving healthcare.</li> <li>2. An HCP defined as a member of a healthcare team with professional qualifications and training, such as a qualified doctor, nurse, therapist, psychologist, or social workers, regardless of grade.</li> <li>3. CADs defined as <math>\leq 18</math> years, regardless of health status or illness type.</li> </ol>
Exclusion criteria:	
<ol style="list-style-type: none"> <li>1. Adults aged <math>&gt;18</math> years included in the study.</li> <li>2. Non-English language publications.</li> </ol>	<ol style="list-style-type: none"> <li>1. Adult <u>patients</u> aged <math>&gt;18</math> years included in the study with or without CADs as defined above.</li> <li>2. Non-English language publications.</li> <li>3. CADs speaking about HCP(s) not from memory of personal experience as a patient; for example, third-party description (e.g., parent).</li> <li>4. Age range of CAD participants unclear.</li> <li>5. No full-text manuscript available; only an abstract available, or unobtainable by searching online, directly emailing authors, or by university librarians requesting inter-library loans.</li> </ol>

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5 206 **Step 4: Charting the data**

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7 207 GD and MK piloted a spreadsheet to chart study characteristics, contextual information, and all  
8  
9 208 CADs' verbatim quotations on 10 articles; this resulted in the final dataset shown in box 2, which  
10  
11  
12 209 GD then used to extract data on the remaining articles.

13  
14  
15 **Box 2 Data extracted**

16  
17 Study characteristics:

- 18 - First author
- 19 - Year published
- 20 - Country of origin
- 21 - No. CAD participants
- 22 - Age range of CAD participants
- 23 - Male to female (or non-binary) ratio
- 24 - Other participants (e.g., parents)
- 25 - Methods
- 26 - Methodology (or analytical approach)

27  
28  
29 Contextual information:

- 30 - Study focus (the experience being explored)
- 31 - Health setting
- 32 - Health condition
- 33 - Length of healthcare encounter being explored

34  
35  
36 CADs' quotations:

- 37 - All first-person direct quotations, where CADs are talking about HCPs
- 38 - Age and gender referenced to each quotation

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40 210 When key information was missing or unclear, we sought clarification from primary authors. All  
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42 211 authors independently reviewed the extracted information for its fitness to address the aims  
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44 212 and purpose of the study, subsequently conferring to optimise the validity of the dataset.

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47 213 **Step 5: Collating, summarising, and reporting the results**

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50 214 We first analysed the basic characteristics of included studies. We then identified themes in the  
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52 215 verbatim quotations following Braun and Clarke's method of thematic analysis as defined by  
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54 216 their checklist (included in online supplementary file 3).[49,50] GD immersed herself in the data,  
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56 217 reviewing all quotations on Microsoft Excel, using NVivo 12 qualitative analysis software to  
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58 218 support generation of codes and construction of themes.[51] Other team members supported

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5 219 her interpretation, by reviewing quotations first individually, and then collectively. We  
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7 220 systematically interrogated the data for themes that had meaning in relation to the research  
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9 221 question, revising candidate themes periodically (with the aid of a visual thematic map) to  
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11 222 ensure these were coherent, distinctive, complementary, and relevant. The ensuing thematic  
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13 223 structure had central concepts, which we used to organise subordinate themes and their  
14  
15 224 associated codes. Throughout this process, we constantly compared our evolving interpretation  
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17 225 against the original data, including a final 'quality control' check of the synthesis against all  
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19 226 quotations.[49,50]  
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23 227 In keeping with our interpretive stance, we used our different subject positions as  
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25 228 paediatricians, a family doctor, and an adult internist to interpret CADs' words reflexively and  
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27 229 arrive at 'beyond-surface insights', so that the themes were amenable to an additional stage of  
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29 230 phenomenological synthesis.[34,50] As we did this, the gamut of emotional content in CADs'  
30  
31 231 words became an increasingly compelling influence on our interpretation. CADs' emotional  
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33 232 expressions tended to have quite distinct 'valence' (defined as the attractiveness [positive  
34  
35 233 valence] or averseness [negative valence] of the emotions described) which linked in recurring  
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37 234 ways to HCPs' reported behaviours.[52,53] So, for example, a HCP who related well to a child  
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39 235 might engender trust, while an HCP who related poorly might engender mistrust.  
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44 236 Whilst crude dichotomies between positive/negative emotions and behaviours do not reflect  
45  
46 237 the subtlety of interpretive research, links between these contrasting behaviours were so clearly  
47  
48 238 present that they offered a parsimonious way of presenting our results. The Results section uses  
49  
50 239 the terms 'favourable' and 'unfavourable' to specify what are, in reality, nuanced polarities. To  
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52 240 epitomize these important themes in ways that could encourage HCPs to emulate favourable  
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54 241 behaviours, we present predominantly favourable behaviours, but provide negative counter-  
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56 242 examples to emphasize the breadth of CADs' experiences. As in previous research,[54] we used  
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58 243 CADs' own words, as far as possible, to construct a narrative of findings that was as true as  
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5 244 possible to the phenomena experienced and narrated by children. We use the wording 'HCPs did  
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7 245 X' as a shorthand for the more correct wording, 'CADs experienced HCPs as doing X'.  
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#### 10 246 **Step 6: Stakeholder consultations**

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12 247 As recommended by Levac et al.,[36] GD, AT, and RC (with research ethics and governance  
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14 248 approvals) recruited CADs aged 8-16 from inpatient wards in the Royal Belfast Hospital for Sick  
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16 249 Children (RBHSC) to two focus groups whose aim was to consolidate and elaborate on findings.  
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18 250 Participants and parents chose whether parents should attend. We presented candidate themes  
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20 251 along with exemplar quotations and facilitated discussions, asking participants to comment on  
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22 252 provisional findings and provide suggestions for practice. We audio-recorded sessions and  
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24 253 transcribed recordings verbatim. We reviewed transcripts alongside the provisional findings to  
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26 254 authenticate, build upon, and summarise a final narrative of results. Participants' identities are  
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28 255 pseudonymised in the results section.  
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#### 33 256 **Patient and public involvement**

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36 257 The essence of this research was to involve children, albeit as expressed verbatim by other  
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38 258 researchers. The stakeholder consultation further fulfilled the patient and public involvement  
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40 259 component of the research by ensuring findings disseminated were intelligible and relevant.  
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## 44 260 **RESULTS**

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46 261 We identified 1,359 articles, excluding 1,015 by screening and 245 by reviewing full texts, and  
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48 262 categorised reasons for exclusion on a PRISMA flow diagram (shown in figure 1).  
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### 51 263 **Overview of included studies**

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54 264 Table 3 presents an overview of included studies (n=99), published between 1992 and 2018. In  
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56 265 total, 4,448 CADs, aged 11 months to 18 years, participated. Most studies included 8 to 50  
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58 266 participants (n=73), aged 7 or older (n=70), and used interviews only (n=64). Studies commonly  
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5 267 included CADs with chronic and potentially debilitating or life-threatening conditions (such as  
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7 268 asthma and cancers), explored long-term experiences (over months to years), and focused on  
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9 269 hospital care. Further descriptive findings and figures are presented in online supplementary file  
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For peer review only

Table 3 Study characteristics

Study details		CAD participants			Design		Contextual information				Data
First author, year	Country	n	Age (yrs)	M:F	Methods	Methodology/analytical approach	Study focus (experience of)	Health setting	Health condition	Length of encounter	Quotes (n)
Aalsma <i>et al.</i> , 2014[55]	US	19	11-17	12:7	INT	Qualitative	CAMHS	Non-specific	Mental health illness	Long-term	5
Alex MR, 1992[56]	Canada	24	7-11	13:11	INT, Q	Content analysis	Pain	Hospital	Surgical (post-op)	Short-term	4
Anderson <i>et al.</i> , 2017[57]	England	6	15-18	3:3	INT	Interpretative phenomenological analysis	Lung transplantation	Hospital	Post-lung transplantation	Long-term	6
Ångström-Brännström <i>et al.</i> , 2008[58]	Sweden	7	4-10	3:4	INT (PT)	Thematic analysis	Being comforted	Hospital	Chronic	Short-term	6
Ångström-Brännström <i>et al.</i> , 2014[59]	Sweden	9	3-9	5:4	INT	Content analysis	Comfort during cancer treatment	Hospital	Cancer	Long-term	3
Beresford <i>et al.</i> , 2003[60]	England	63	11-16	27:36	INT, FG (PT)	Framework method	Communicating	Hospital	Chronic	Long-term	14
Boyd <i>et al.</i> , 1998[61]	Canada	6	10-13	2:4	INT (PT), WT	Grounded theory	Hospital and coping strategies	Hospital	Surgical (chronic)	Long-term	3
Brown <i>et al.</i> , 2014[62]	US	19	11-17	12:7	INT	Grounded theory	Therapeutic alliances	Hospital	Mental health illness	~	16
Carney <i>et al.</i> , 2003[63]	Scotland	213	4-17	115:98	INT, FTQ	Thematic analysis	Healthcare	Hospital	Non-specific	Non-specific	9
Cheng <i>et al.</i> , 2003[64]	Taiwan	90	5-14	45:45	INT	Content analysis	Pain	Hospital	Non-specific	Non-specific	1
Cheng <i>et al.</i> , 2016[65]	Taiwan	11	12-18	7:4	INT	Content analysis	Cancer recovery	Hospital	Cancer	Long-term	1
Christofides <i>et al.</i> , 2016[66]	Canada	19	8-18	7:12	INT	Thematic analysis	Research participation	Hospital	Cystic fibrosis	Long-term	3
Clift <i>et al.</i> , 2007[67]	Wales	6	11-15	3:3	INT	Qualitative	Emergency admission	Hospital	Non-specific	Short-term	7
Colver <i>et al.</i> , 2018[68]	England	374	14-18	219:155	INT, Q, OBS	Constant comparison	Transition	Hospital	Medical	Long-term	2
Corsano <i>et al.</i> , 2015[69]	Italy	27	6-15	12:15	INT	Qualitative	Emotional events	Hospital	Cancer/ blood disorders	Long-term	4
Coyne <i>et al.</i> , 2006[70]	Ireland	55	7-18	30:25	INT, FG	Constant comparison analysis	Participating/ decision-making	Hospital	Non-specific	Non-specific	52
Coyne, 2006a[71]	Ireland	11	7-14	~	INT	Grounded theory	Hospitalisation	Hospital	Non-specific	~	1
Coyne, 2006b[72]	Ireland	11	9-14	~	INT (PT), FTQ, OBS	Grounded theory	Participating	Hospital	Non-specific	~	4
Coyne <i>et al.</i> , 2007[73]	Ireland	17	7-16	~	INT	Qualitative	Hospitalisation	Hospital	Non-specific	Non-specific	8

Study details		CAD participants			Design		Contextual information				Data
First author, year	Country	n	Age (yrs)	M:F	Methods	Methodology/analytical approach	Study focus (experience of)	Health setting	Health condition	Length of encounter	Quotes (n)
Coyne <i>et al.</i> , 2011[74]	Ireland	55	7-18	31:24	INT, FG	Qualitative	Communicating/ decision-making	Hospital	Non-specific	Non-specific	20
Coyne <i>et al.</i> , 2012[75]	Ireland	38	7-18	~	INT (PT)	Content analysis	Hospital and HCPs	Hospital	~	~	24
Coyne <i>et al.</i> , 2014[76]	Ireland	20	7-16	11:9	INT (PT)	Constant comparison analysis	Participating/ decision-making	Hospital	Cancer	Long-term	2
Coyne <i>et al.</i> , 2015[77]	Ireland	15	12-18	6:9	INT, FG	Thematic analysis	CAMHS	Non-specific	Mental health illness	Long-term	6
Coyne <i>et al.</i> , 2016[78]	Ireland	20	7-16	11:9	INT	Grounded theory	Communicating	Hospital	Cancer	Long-term	6
Curtis <i>et al.</i> , 2017[79]	England	17	5-16	~	INT (PT), OBS	Ethnographic	Single/ shared rooms	Hospital	~	~	3
Das <i>et al.</i> , 2017[80]	India	14	8-15	~	FG	Qualitative	Living with HIV	Non-specific	HIV	Long-term	1
Day <i>et al.</i> , 2006[81]	England	11	9-14	5:6	FG	Thematic Analysis	CAMHS	Non-specific	Mental health illness	Long-term	13
Dell'Api <i>et al.</i> , 2007[82]	Canada	5	10-17	2:3	INT	Qualitative	Interacting with HCPs	Hospital	Non-specific	Long-term	19
Dixon-Woods <i>et al.</i> , 2002[83]	England	20	8-16	9:11	INT	Constant comparison analysis	Asthma services	Community	Asthma	Long-term	12
Edgecombe <i>et al.</i> , 2010[84]	England	22	11-18	16:6	INT	Thematic analysis	Asthma services	Hospital	Asthma	Long-term	5
Ekra <i>et al.</i> , 2012[85]	Norway	9	7-12	5:4	INT, OBS (PT)	Hermeneutic phenomenology	Hospitalisation	Hospital	TIDM	Long-term	2
Engvall <i>et al.</i> , 2016[86]	Sweden	13	5-15	6:7	INT (PT)	Content Analysis	Radiotherapy	Hospital	Cancer	Long-term	2
Forsner <i>et al.</i> , 2005[87]	Sweden	7	7-10	4:3	INT	Thematic analysis	Illness	Hospital	~	Short-term	4
Forsner <i>et al.</i> , 2009[88]	Sweden	9	7-11	2:7	INT, OBS	Hermeneutic phenomenology	Fear	Hospital	Non-specific	Short-term	4
Garth <i>et al.</i> , 2009[89]	Australia	10	8-12	3:7	INT	Grounded theory	Participating	Non-specific	Cerebral palsy	Long-term	3
Gill <i>et al.</i> , 2016[90]	England	12	14-17	2:10	INT	Thematic analysis	CAMHS inpatient ward	Non-specific	Mental health illness	Long-term	2
Griffiths <i>et al.</i> , 2011[91]	Australia	9	8-16	~	INT	Interpretative phenomenological analysis	Living with cancer	Non-specific	Cancer	Long-term	3
Haase <i>et al.</i> , 1994[92]	US	7	5-18	3:4	INT (PT)	Colaizzi's method of phenomenological analysis	Completing cancer treatment	Non-specific	Cancer	Long-term	6
Hall <i>et al.</i> , 2013[93]	England	17	8-17	~	INT	Thematic analysis	Life with repaired cleft lip/ palate	Non-specific	Cleft lip/ palate	Long-term	1



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Study details		CAD participants			Design		Contextual information				Data
First author, year	Country	n	Age (yrs)	M:F	Methods	Methodology/analytical approach	Study focus (experience of)	Health setting	Health condition	Length of encounter	Quotes (n)
Han <i>et al.</i> , 2011[94]	China	29	7-14	16:13	INT	Content analysis	Cancer	Hospital	Cancer	Long-term	2
Hanson <i>et al.</i> , 2017[95]	US	30	4-14	16:14	INT	Narrative analysis	Pain	Hospital	Fractured arm	Short-term	5
Harper <i>et al.</i> , 2014[96]	England	10	16-18	3:7	INT	Interpretative phenomenological analysis	CAMHS	Non-specific	Mental health illness	Long-term	8
Hart <i>et al.</i> , 2018[97]	England	14	14-16	~	INT	Thematic analysis	CAMHS	Non-specific	Mental health illness	Long-term	2
Hawthorne <i>et al.</i> , 2011[98]	England	21	7-16	12:9	FG	Thematic analysis	Diabetes services	Hospital	T1DM	Long-term	8
Hinton <i>et al.</i> , 2015[99]	England	21	8-17	6:15	INT (PT)	Constant comparison analysis	A multiple sclerosis diagnosis	Non-specific	Multiple sclerosis	Long-term	3
Hodgins <i>et al.</i> , 1997[100]	Canada	85	5-13	38:41	INT, Q	Mixed-method	Venepuncture	Hospital	Non-specific	Short-term	3
Hutton, 2005[101]	Australia	7	13-18	3:4	INT (PT)	Qualitative	Adolescent wards	Hospital	Cystic fibrosis/asthma	Long-term	3
Jachyra <i>et al.</i> , 2018a[102]†	Canada	8	11-17	4:4	INT	Interpretative phenomenological analysis	Talking about weight	Non-specific	ASD	Long-term	6
Jachyra <i>et al.</i> , 2018b[103]†	Canada	8	11-17	4:4	INT	Interpretative phenomenological analysis	Talking about weight	Non-specific	ASD	Long-term	4
Jensen <i>et al.</i> , 2012[104]	Denmark	8	8-10	5:3	INT (PT)	Thematic analysis	Acute hospitalisation	Hospital	Medical	Short-term	6
Jongudomkarn <i>et al.</i> , 2006[105]	Thailand	49	4-18	31:18	INT, FG, OBS, PT	Content analysis	Pain	Non-specific	Non-specific	Long-term	1
Kluthe <i>et al.</i> , 2018[106]	Canada	18	6-17	11:7	INT	Content analysis	IBD diagnosis	Hospital	IBD	Long-term	1
Koller <i>et al.</i> , 2010[107]	Canada	21	5-18	12:9	INT (PT)	Grounded theory	Hospitalisation during SARS	Hospital	Non-specific	Long-term	2
Koller, 2017[108]	Canada	26	5-18	11:15	INT (PT)	Thematic analysis	Medical education/participating	Hospital	Chronic	Long-term	10
Kortesluoma <i>et al.</i> , 2006[109]†	Finland	44	4-11	~	INT	Content analysis	Pain	Hospital	Non-specific	Non-specific	1
Kortesluoma <i>et al.</i> , 2008[110]†	Finland	44	4-11	27:17	INT	Content analysis	Pain	Hospital	Non-specific	Non-specific	7
Lewis <i>et al.</i> , 2007[111]	Australia	9	8-16	5:4	INT	Cognitive mapping	Receiving care	Hospital	~	~	5
Livesley <i>et al.</i> , 2013[16]	England	15	5-15	3:2	INT (PT), OBS	Critical ethnography, constant comparison analysis	Hospitalisation	Hospital	Surgical	Long-term	4
Lowes <i>et al.</i> , 2015[23]	Wales	518	7-15	~	FTQ	Qualitative descriptive analysis	Life with T1DM and services	Hospital	T1DM	Long-term	8

Study details		CAD participants			Design		Contextual information				Data
First author, year	Country	n	Age (yrs)	M:F	Methods	Methodology/analytical approach	Study focus (experience of)	Health setting	Health condition	Length of encounter	Quotes (n)
Macartney <i>et al.</i> , 2014[112]	Canada	12	9-18	6:6	INT	Content analysis	Life after a brain tumour	Non-specific	Brain tumour	Long-term	1
Manookian <i>et al.</i> , 2014[113]	Iran	6	6-17	3:3	INT	Interpretative phenomenological analysis	Stem cell transplantation	Hospital	Cancer & blood disorders	Long-term	4
Marcinowicz <i>et al.</i> , 2016[114]	Poland	22	10-16	8:14	INT	Content analysis	Nurse relationships and wards	Hospital	~	~	7
Marshman <i>et al.</i> , 2010[115]	England	10	12-14	5:5	INT, Q	Framework analysis	Malocclusion treatment	Non-specific	Malocclusion	Long-term	1
McNelis <i>et al.</i> , 2007[116]	India	11	7-15	6:5	FG	Thematic analysis	Living with epilepsy	Non-specific	Epilepsy	Long-term	2
McPherson <i>et al.</i> , 2017[117]	Canada	17	6-18	8:9	INT	Phenomenology, thematic analysis	Talking about weight	Hospital	Spina Bifida	Long-term	3
McPherson <i>et al.</i> , 2018[118]	Canada	18	10-17	9:9	INT, FG	Thematic analysis	Talking about weight	Hospital	Non-specific	Long-term	3
Moules, 2009[119]	England	138	9-14	82:56	INT (PT)	Framework analysis	Hospital care	Hospital	~	~	3
Nguyen <i>et al.</i> , 2010[120]	Sweden	40	7-12	~	INT, Q, vital signs	Content analysis	Music therapy for lumbar puncture	Hospital	Cancer	Short-term	1
Nilsson <i>et al.</i> , 2011[121]	Sweden	39	5-10	32:7	INT	Content analysis	Pain	Hospital	Skin trauma	Short-term	4
Noreña Peña <i>et al.</i> , 2011[122]†	Spain	30	8-14	13:17	INT, OBS	Critical incident technique	Communicating with nurses	Hospital	Surgical	~	24
Noreña Peña <i>et al.</i> , 2014[123]†	Spain	30	8-14	13:17	INT, OBS	Critical incident technique	Communicating with nurses	Hospital	Surgical	~	22
Olausson <i>et al.</i> , 2006[124]	Sweden	18	4-18	8:10	INT	Hermeneutic phenomenology	Life after transplantation	Non-specific	Post- transplant	Long-term	6
Pelander <i>et al.</i> , 2004[125]	Finland	40	4-11	28:12	INT	Content analysis	Nursing care	Hospital	Chronic (T1DM & other)	Long-term	3
Pelander <i>et al.</i> , 2010[126]	Finland	388	7-11	198:188 *	FTQ	Content analysis	Hospitalisation	Hospital	Non-specific	Non-specific	2
Pölkki <i>et al.</i> , 1999[127]	Finland	20	7-11	~	INT, WT	Content analysis	Pain	Hospital	Non-specific	~	1
Pope <i>et al.</i> , 2018[128]	Australia	15	4-8	11:4	INT (PT)	Thematic analysis	Pain and nurses' roles	Hospital	Trauma	Short-term	1
Randall, 2012[129]	England	21	0.9-17	8:12 *	INT, FG (PT), PTD	Colaizzi's method of phenomenological analysis	Community children's nursing	Community	Non-specific	Long-term	4
Rankin <i>et al.</i> , 2018[130]	Scotland	24	9-12	13:11	INT (PT)	Thematic analysis	Managing T1DM	Non-specific	T1DM	Long-term	1
Roper <i>et al.</i> , 2018[27]	England	16	7-15	9:7	INT	Qualitative	Research participation/ consent	Hospital	Asthma or anaphylaxis	Short-term	7

Study details		CAD participants			Design		Contextual information				Data
First author, year	Country	n	Age (yrs)	M:F	Methods	Methodology/analytical approach	Study focus (experience of)	Health setting	Health condition	Length of encounter	Quotes (n)
Ruhe <i>et al.</i> , 2016[131]	Switzerland	17	9-17	11:6	INT	Thematic analysis	Participating	Hospital	Cancer	Long-term	1
Ryals, 2011[132]	US	8	13-17	6:2	INT	Phenomenology	Therapeutic relationships	Non-specific	Mental health illness	Long-term	59
Saarikoski <i>et al.</i> , 2018[133]	Finland	19	6-12	7:12	FG	Content analysis	Therapeutic intervention	Community (school)	Enuresis	Long-term	1
Salmela <i>et al.</i> , 2010[134]	Finland	90	4-6	~	INT	Colaizzi's method of phenomenological analysis	Hospital related fears	Hospital	~	~	4
Schalkers <i>et al.</i> , 2014[135]	The Netherlands	63	6-18	31:32	INT (PT), WT	Action research	Hospital care	Hospital	Non-specific	~	8
Schmidt <i>et al.</i> , 2007[136]	US	65	5-18	34:31	INT, FTQ	Thematic analysis	Nurses in hospital	Hospital	Non-specific	Non-specific	45
Spalding <i>et al.</i> , 2016[137]	England	7	8-14	2:5	WS (PT)	Action research, thematic analysis	Good doctors	Hospice	Palliative	Long-term	3
Stevens <i>et al.</i> , 2006[138]	Canada	14	7-16	9:5	INT	Content analysis	Home chemotherapy	Community (home)	Cancer	Long-term	1
Taylor <i>et al.</i> , 2010[139]	England	14	12-18	~	INT	Framework analysis	Life after transplantation	Non-specific	Liver transplant	Long-term	6
Vejzovic <i>et al.</i> , 2014[140]	Sweden	17	10-17	5:12	INT	Content analysis	Preparing for colonoscopy	Hospital	Suspected IBD	Short-term	4
Vindrola-Padros, 2012[141]	Argentina	10	8-16	5:5	INT (PT)	Narrative analysis	Living with cancer	Non-specific	Cancer	Long-term	4
Wangmo <i>et al.</i> , 2016[142]	Switzerland	17	9-17	11:6	INT	Qualitative	Cancer services and treatment	Hospital	Cancer	Long-term	5
Watson <i>et al.</i> , 2009[143]	US	9	14-18	7:1:1#	INT	Grounded theory	Assessing CAMHS & mental illness	Non-specific	Mental health illness	Long-term	1
Wen <i>et al.</i> , 2013[144]§	Singapore	203	4-18	~	INT, OBS	Thematic analysis	Pain	Non-specific	Surgical (post-op)	Non-specific	15
Wise, 2002[145]	US	9	7-15	~	INT (PT)	Hermeneutic phenomenology	Transplantation	Non-specific	Liver transplant	Long-term	7
Wong <i>et al.</i> , 2012[146]	China	79	10-13	54:25	FG	Qualitative	Weight-loss program	Community (school)	Obesity	Long-term	1
Woodgate, 2008[147]	Canada	13	9-17	7:6	INT	Constant comparison analysis	Cancer symptoms	Non-specific	Cancer	Long-term	1
Wray <i>et al.</i> , 2018[148]	England	543	8-16	~	INT, FG, Q	Framework Analysis	Healthcare	Hospital	~	~	5
Xie <i>et al.</i> , 2016[149]	China	21	7-12	12:9	INT	Content Analysis	Lumbar puncture	Hospital	ALL	Short-term	15
Young <i>et al.</i> , 2003[150]	England	13	8-17	8:5	INT	Constant comparison analysis	Communicating	Hospital	Cancer	Long-term	7

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Note:

Non-specific, not focusing on a certain type or area; ALL, acute lymphoblastic leukaemia; ASD, autism spectrum disorder; CAMHS, child and adolescent mental health service; HIV, human immunodeficiency virus; IDB, inflammatory bowel disease; SARS, severe acute respiratory syndrome; T1DM, type 1 diabetes mellitus. FG, focus groups; FTQ, free-text questionnaires; INT, interviews; OBS, observations; PT, participatory techniques employed; PTD, photo talk diaries; Q, quantitative questionnaires; WS, workshops; WT, writings; ~, unable to ascertain; \*, numerical inconsistency detected in source article; †, same study with different quotations presented; §, qualitative systematic review; #, non-binary gender.

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5 **278 Children's and adolescents' experiences**  
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7  
8 279 Six-hundred and sixty-nine quotations referred to CADs' experiences of HCPs, most of whom

9  
10 280 were doctors or nurses. CADs also spoke about their experiences with counsellors,

11  
12 281 psychologists, social workers, and dentists. CADs' ages (available for 397 quotations), ranged

13  
14 282 from 5-18 years (average 13); male and female participants were equally represented (see

15  
16 283 supplementary file 5). All quotations extracted are available at doi:10.5061/dryad.z08kprrc2;

17  
18 284 quotations presented below are cited in online supplementary file 6.

19  
20 285 CADs' favourable experiences were of HCPs forming trusting relationships and involving them in

21  
22 286 healthcare discussions and decisions and their unfavourable experiences were generally towards

23  
24 287 the opposite pole.

25  
26 288 Forming trusting relationships

27  
28 289 *Their nature*

29  
30 290 Being in a trusting relationship was feeling a 'bond', having an 'emotional attachment', or having

31  
32 291 a 'best friend'. CADs and HCPs knew each other, could 'relate to' each other, and really

33  
34 292 understood each other. There was openness, transparency, and there was trust. CADs trusted in

35  
36 293 HCPs to provide 'good care', knowing they would do everything necessary, and do it right.

37  
38 294 *Their origins*

39  
40 295 At first, HCPs were 'strangers'; CADs did not know the HCPs, who they were, and how they were.

41  
42 296 HCPs, likewise, did not know CADs, their histories, or their personalities. Repeated contact and

43  
44 297 dialogue built and reinforced relationships: 'As time passed, [...] we created that bond.'

45  
46 298 HCPs engendered trusting relationships by demonstrating positive attributes, including being

47  
48 299 able to empathise. CADs trusted in HCPs who were 'very smart', 'experienced', '[knew] what to

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5 300 do', '[took] care', and did 'everything the best they [could]'. They trusted HCPs who were  
6  
7 301 'truthful', '100% with you', and 'just [told] you straight up.' Such HCPs did 'not tell children any  
8  
9 302 lies'; 'nothing [was] hidden'. CADs built trusting relationships with HCPs who were 'really nice',  
10  
11 303 'nurturing, caring, and helpful people who [were] there for you', and had a 'good sense of  
12  
13  
14 304 [humour]'.

15  
16  
17 305 HCPs related to CADs by understanding them: 'she knew what I was talking about, she knew  
18  
19 306 what I was feeling, she knew how I was feeling.' HCPs 'took time to get to know' CADs and had  
20  
21 307 'real conversations, not just [HCP]-patient discussions', in which they shared experiences and  
22  
23 308 got to know each other personally. CADs could better relate to HCPs who were 'down to earth'  
24  
25 309 and had 'a lot in common'.

### 26 27 28 29 310 *Their effects*

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31  
32 311 Trust was vital: 'you gotta have trust.' Trusting relationships improved CADs' healthcare  
33  
34 312 experiences by promoting positive emotions. CADs felt 'satisfied' and 'happy'. They enjoyed  
35  
36 313 their time with HCPs and had 'good memories'. CADs were more able to 'open up' or 'tell  
37  
38 314 anything' to HCPs whom they trusted. Trusting relationships gave CADs hope that HCPs could  
39  
40 315 'cure [the] illness' or help lessen the pain. CADs who trusted HCPs submitted themselves more  
41  
42 316 willingly to recommended treatments: 'whatever happens I let them [HCPs] do what they have  
43  
44 317 to do to help me get better.' And they consciously chose to remain with or seek out HCPs they  
45  
46 318 trusted. CADs admired trustworthy HCPs: 'individually [they're] all heroes.' And they aspired to  
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48 319 be like them: 'Because you can save people [...] I'm going to be a children's doctor.'

### 49 50 51 52 53 320 Being involved in healthcare discussions and decisions

### 54 55 56 321 *The nature of involvement*

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5 322 CADs who were fully involved in healthcare discussions felt they knew everything; 'everything  
6  
7 323 [was] always clear' to them. They had a seat at the table to discuss issues that affected them and  
8  
9 324 felt acknowledged as key stakeholders. CADs worked 'together' with HCPs and parents; they felt  
10  
11  
12 325 as though they were respected, taken 'seriously', and treated 'as an equal'.  
13  
14

15 326 *Its origins*

16  
17 327 HCPs involved CADs by including them in conversations, sharing information, providing  
18  
19 328 opportunities to ask questions, taking time to answer, and listening to their wider needs and  
20  
21 329 preferences. HCPs who promoted involvement used simple words, communicated in a timely  
22  
23 330 way, gave accurate information at the right pace, and explained things so that CADs understood.  
24  
25 331 These HCPs brought CADs 'into all the conversations' by talking to CADs 'as much as they [talked  
26  
27 332 to the] parents'. Parents facilitated CADs' involvement in the presence of HCPs or afterwards by  
28  
29 333 '[breaking] the words down in an easier explanation'. HCPs promoted participation by 'listening'  
30  
31 334 to and respecting CADs' requests: 'I tell them I don't want this and they ... understand'. For more  
32  
33 335 complex decisions, CADs took a joint approach: 'me because I know my own body, my parents  
34  
35 336 because they know what's best for me [...] and the paediatrician because they are qualified.'  
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41 337 *Its effects*

42  
43 338 CADs viewed involvement as 'most important, as in the end it is about [them]'. CADs enjoyed  
44  
45 339 being involved; it was 'brilliant', and they looked forward to their next visit. CADs were more  
46  
47 340 satisfied with healthcare; they found it 'interesting and informational'. Getting to 'learn  
48  
49 341 something new' made them feel 'comfortable and confident'. CADs could 'make better  
50  
51 342 decisions' because they were 'fully informed'. This promoted self-advocacy and self-efficacy:  
52  
53 343 'I'm asking the doctor more questions myself than having my Dad do it.'  
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58 344 Not forming trusting relationships or being involved  
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5 345 CADs described unfavourable experiences, which broadly *mirrored* favourable ones. For  
6  
7 346 instance, trust was undermined by HCPs getting things wrong, being 'nasty', and not '[seeming]  
8  
9 347 that concerned'. HCPs being unfamiliar to CADs because they were 'too busy' or because HCPs  
10  
11 348 or CADs moved to other services prevented trusting relationships forming. HCPs excluded CADs  
12  
13 349 by using 'big words', speaking too fast, or telling them nothing, so that CADs could not  
14  
15 350 understand. HCPs neglecting to ask CADs or asking in a tokenistic way prevented them 'having a  
16  
17 351 say': 'they [HCPs] might ask me "is that ok" [...] in such a way that I kind of feel like I don't have  
18  
19 352 any other option but [to] agree with them'. HCPs and parents side-lined CADs by talking behind  
20  
21 353 the curtains so CADs could not hear or sticking them 'in the middle' of a conversation where  
22  
23 354 they could not interrupt. Some parents told CADs to keep quiet or dominated conversations:  
24  
25 355 'you try to say something but then your parents just say shhhhh! [...] They come out and say, [...]  
26  
27 356 did you understand that, you say no, they say, you should have asked them, and then you say,  
28  
29 357 oh you didn't let me, they say rubbish!'  
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35 358 Not trusting people or understanding what was happening made CADs fearful. HCPs who made  
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37 359 CADs feel 'rejected' and objectified, 'like a piece of machinery', enraged them. CADs found it  
38  
39 360 'hard to talk', disengaged in conversations, and left the talking to their parents. Not trusting in  
40  
41 361 HCPs or being uninvolved meant some CADs hated hospital or clinic, they objected to attending,  
42  
43 362 and sought information or guidance from other sources.  
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### 363 Stakeholder consultations

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49 364 Two CAD inpatients participated in each of two focus groups (3 females and 1 male, aged 11-15  
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51 365 years) lasting 67 and 93 minutes respectively. Their medical conditions included type 1 diabetes,  
52  
53 366 coeliac disease, spina bifida, and spinal/brain surgery. No parents attended. Three authors (GD,  
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55 367 AT, & RC) attended both consultations and a hospital play specialist attended the first  
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57 368 consultation. Participants identified with the provisional findings and elaborated on them (table  
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369 4). All wanted some degree of involvement in their own care though the amount of information  
370 and level of participation they wanted depended on their age, what was being discussed, and  
371 individual preferences. Box 3 offers take-home messages for HCPs.

For peer review only

372 **Table 4 Stakeholder findings: Focus group participants' experiences mapped to overarching themes**

Overarching themes	Forming trusting relationships	Being involved in healthcare discussions and decisions
Favourable experiences	<p>Rachel, a young girl with diabetes, described having a very good relationship with the diabetic team and ward staff: <i>'Hm, it's just the nurses really like nice. Like, the first night I was staying over they were staying it's a sleepover and stuff.'</i> (Rachel, FG1, line 746 &amp; 747) She acknowledged how continuity of care helped her become more familiar with the staff: <i>'they're always in the clinic when I am there.'</i> (Rachel, FG1, line 678) She commented on how the diabetic team got to know her, by chatting casually and taking an interest in her wider life: <i>'they like asked me what school I'm going to this year' and about 'my baby sister and stuff.'</i> (Rachel, FG1, line 815-819)</p> <p>Participants experienced some HCPs as being easier to talk to than others. Rachel felt that she could talk to the diabetic team: <i>'[...] I can talk to them more 'cos you know them.'</i> (Rachel, FG1, line 621) From the perspective of Laura, a young girl with a recent diagnosis of diabetes, a caring nature was an important factor: <i>'[HCPs who] make you feel as if they care [were easier to talk to].'</i> (Laura, FG2, line 432)</p>	<p>Laura was well informed by her hospital consultant, who had seen her when she was first diagnosed with diabetes: <i>'My consultant like came the day before [...] and he explained the whole thing in detail.'</i> (Laura, FG2, line) Laura's experience of being well informed resembled Rachel's: <i>'The doctor like normally tells me everything that I need to know anyway and they put it in like ways that I like, know.'</i> (Rachel, FG1, line 657 &amp; 658)</p> <p>Sarah, an adolescent with spina bifida and scoliosis, felt she had some control over her treatment: <i>'Uhm, I might have to get the surgery on my back, because I've got scoliosis, em, so if it gets like really, it's not too bad but if it gets worse I have to have surgery so I feel as if I have like a choice because I don't have to have it, and I don't want it. [...] I don't want to have it.'</i> (Sarah, FG2, line 743-748)</p> <p>Although all participants wanted to be informed, the oldest participant, Darren, a young boy with spina bifida and epilepsy, preferred his parents to ask and answer questions, and doctors to make decisions on his behalf:  <i>'GD: Do you ever have any questions [Darren]?'  Darren: Ah...don't think so.  AT: Are you happy for your parents to ask the questions?  Darren: Yeah.  AT: And you just listen?  Darren: Yeah [smiling and laughing].'</i> (Verbatim excerpt, FG1, line 555-560)</p>
Unfavourable experiences	<p>Sarah found it difficult to trust HCPs who were uncaring: <i>'Well yesterday I had to get a line [cannula] in and there was four different doctors that tried [...] and I thought like the doctors didn't really care, they were just gonna get it in, they didn't really care what I was thinking. [...] Well I know they needed to do it. But they didn't care, [...] they didn't care if they hurt me.'</i> (Sarah, FG2, line 438-441 &amp; 512)</p>	<p>During her cannulation experience, Sarah felt angry because HCPs failed to grant her wishes: <i>'I always tell them to put it, try my feet first because I don't have any feeling in my feet [...] I told the doctor not to put it in there and they still did it. [...] I was really cross after it because I thought all that pain.'</i> (Sarah, FG2, line 460-465)</p> <p>Sarah spoke about feeling excluded when a doctor spoke discretely to her mother: <i>'No but it does happen to people like they feel they're left out. [...] Today, [...] a doctor was explaining something to me and he was just about to leave and when he was just about to leave he said to my mum, "If you want to ask a question I can come back" so I kind of thought is he doing that because he doesn't want me to hear my mother asking the question.'</i> (Sarah, FG2, line 612 &amp; 619-622)</p>

373 Note: Rachel, Laura, Sarah, and Darren are pseudonyms (participants aged 11-15 years)

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5 **375 Box 3 Take-home messages for HCPs**  
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8 Focus group participants provided take-home messages about how HCPs, could deliver high-  
9 quality child-centred care:

- 10 1. *'Explain.'* (Laura, FG2, line 409) *'Explain it in a child friendly way.'* (Sarah, FG2, line  
11 411) *'Because if the child is really young it has to be explained in a different way. At  
12 an age you're able to understand [or HCPs will] scare them.'* (Sarah, FG2, line 658-  
13 663)  
14  
15 2. *'They should explain what they are going to do before they do it, and like [...] always  
16 say who they are and what they're gonna do [...] [and at] what time [...], and  
17 explain what was gonna happen and why [...].'* (Rachel, FG1, line 498-510)  
18  
19 3. *'I think just tell everyone together. [...] Because like telling your mum and dad first  
20 you'll see the expression on their face and then you're already gonna know.'* (Laura,  
21 FG2, line 651-654)  
22  
23 4. *'Always like ask [children] do you have any questions [...] ask [to check  
24 understanding].'* (Sarah, FG2, line 388 & 416-417)  
25  
26 5. *'Whenever [children] come in, try and treat them like nicer, em.'* (Darren, FG1, line  
27 992) *'Like treat them the same as everybody else so they all feel the same.'* (Rachel,  
28 FG1, line 993)

29 Note: Rachel, Laura, Sarah, and Darren are pseudonyms (participants aged 11-15 years)  
30

31 **377 DISCUSSION**

32  
33 378 CADs' experiences were influenced by HCPs forming relationships and involving them:

34  
35 379 engendering trust and involving CADs satisfied them, made them happier when undergoing  
36  
37 380 procedures and treatments, and better able to confide. HCPs did this by being personable, wise,  
38  
39 381 and sincere, relating at a personal level, bringing CADs into conversations and decisions, and  
40  
41 382 speaking in child-friendly ways. Conversely, not relating to or involving CADs, communicating  
42  
43 383 ineffectively by using inappropriately technical language or positioning CADs as 'piggy-in-the-  
44  
45 384 middle' between HCPs and parents resulted in CADs being fearful, angry, resistant, and  
46  
47 385 disengaged.

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50  
51 386 These findings add to earlier studies, which identified intimate relationships,[78,111,151]  
52  
53 387 trust,[78] and involvement,[48,152] as important ingredients of caring well for CADs. They  
54  
55 388 corroborate a recent systematic review of decision-making experiences, which found that HCPs  
56  
57 389 (and parents) made adolescents feel fearful, anxious, and depersonalised when they withheld  
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5 390 information or denied involvement.[152] Parents had a significant influence on HCPs'  
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7 391 experiences in our study too, by facilitating or impeding communication. Overcoming parental  
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9 392 primacy, over-involvement, over-protectiveness,[48,78,152] and wishes to withhold information  
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11  
12 393 remains a substantial challenge for HCPs.[78]  
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### 15 394 **Strengths and limitations**

16  
17 395 Our synthesis advances understanding of CADs' experiences of HCPs because of its  
18  
19 396 comprehensiveness, analysis of interrelationships between the nature, origins, and effects of  
20  
21 397 trust and involvement, and its advocacy for CADs' autonomy. It provides a blueprint for CCC,  
22  
23 398 which has, until now, largely depended on theory and expert consensus rather than empirical  
24  
25 399 evidence.[8] Our findings endorse the concept and importance of CCC, whilst showing how  
26  
27 400 much work is needed to put this principle into practice. Our review was innovative in the way it  
28  
29 401 used phenomenology, a theory that is highly relevant to the topic, to inform a rigorous  
30  
31 402 interpretive synthesis. This allows us to go beyond cataloguing publications and draw empirically  
32  
33 403 supported conclusions about how HCPs could care more effectively for CADs. This, we suggest, is  
34  
35 404 a significant contribution to the scholarship of evidence synthesis.  
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41 405 As with most qualitative syntheses, we present a broad overview, whose findings are potentially  
42  
43 406 transferable across a range of clinical contexts. We took an iterative approach to article  
44  
45 407 selection and ensured adequate time for rigorous interpretive analysis; while some evidence  
46  
47 408 may have been published since we searched the databases, this is an inherent limitation in  
48  
49 409 research that goes to such lengths to analyse a huge evidence-base and synthesise information.  
50  
51 410 We doubt that this materially affects our conclusions since the nature of human relationships  
52  
53 411 are unlikely to change in 12 months. Consulting with stakeholders, whilst obviously desirable, is  
54  
55 412 often omitted from scoping reviews.[153] Our consultation sample was admittedly small and  
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5 413 relatively homogenous, but participants spoke informatively about their experiences, which  
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7 414 helped consolidate and authenticate the findings.  
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10 415 Our conclusions are susceptible to both publication and interpretation bias because more  
11  
12 416 emotive material tends to attract greater attention. This limitation is partially offset by our  
13  
14 417 rigorous adherence to methodological standards. Another limitation, imposed by the non-  
15  
16 418 specific nature of studies and inexplicit reporting of metadata by primary authors, is that we  
17  
18 419 could not analyse how different types of HCP, or participants' ages or illnesses, affected CADs'  
19  
20 420 experiences. Restricting the scope to English language publications excluded non-English  
21  
22 421 speaking children from distinct cultural groups. This is an important topic for future study.  
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#### 26 422 **Implications for policy, research, and practice**

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29 423 Our findings add impetus to the movement to design, deliver, and further characterise child-  
30  
31 424 centred healthcare,[154] which has important implications for HCPs, educators, researchers, and  
32  
33 425 policymakers. Our empirical augmentation of this conceptual model supports these initiatives.  
34  
35 426 To achieve the vision of CCC, there is a need for communication strategies, training,  
36  
37 427 assessments, and feedback (from CADs, specifically) at both the undergraduate and  
38  
39 428 postgraduate levels of health professions education. Further research will be needed to address  
40  
41 429 the long-term sustainability and effectiveness of CCC. Evidence on how healthcare policy,  
42  
43 430 practice, and legislation can influence child-centred approaches is also long overdue. Further  
44  
45 431 research could also examine how age, illness, gender, and the cultures of different professions  
46  
47 432 influence the drive for CCC. Further implications for practice include the need for HCPs to  
48  
49 433 examine how professional boundaries between themselves and CADs are characterized, and  
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51 434 consider how best to respect CADs' preferences when it goes against 'best practice'.  
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#### 56 435 **ABBREVIATIONS**

1  
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5 436 CADs- Children and adolescents  
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8 437 CCC- Child-centred care  
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10  
11 438 CINAHL- Cumulative Index to Nursing and Allied Health Literature  
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14 439 FCC- Family-centred care  
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17 440 HCPs- Healthcare professionals  
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20 441 PCC- Patient-centred care  
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23 442 RBHSC- Royal Belfast Hospital for Sick Children  
24

25  
26 443 **DECLARATIONS**  
27

28 444 **Ethics approval and consent to participate**  
29

30  
31 445 Ethical approval for focus groups was obtained from the Office for Research Ethics Committees  
32

33 446 Northern Ireland (reference: 19/NI/0070), while research governance was obtained from the  
34

35  
36 447 Belfast Health and Social Care Trust, Northern Ireland. Queen's University Belfast (QUB)  
37

38 448 sponsored the study in accordance with the UK Policy Framework for Health and Social Care.  
39  
40

41 449 **Consent for publication**  
42

43  
44 450 Consent for publication was gained.  
45  
46

47 451 **Availability of data and materials**  
48

49 452 All data are available in this article, or supplementary materials and open access repositories.  
50  
51

52 453 **Supplementary materials**  
53

54  
55 454 The content has been supplied by the authors.  
56  
57

58 455 **Competing interests**  
59  
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1  
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7

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16  
17

18 461 **Authors' contributions**  
19

20  
21 462 GD conceived the review, sought approvals, secured funding, led the execution, and led the  
22  
23 463 write-up. GD, AT & RC completed the focus groups. MK, RC, AT & TD assisted with data  
24  
25 464 selection, analyses, and manuscript revision. All authors read and approved the final manuscript.  
26  
27

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36  
37  
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2  
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4  
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7

8 478 **Data availability**  
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11 479 Extra data can be accessed via the Dryad data repository at <http://datadryad.org/> with the doi:  
12  
13 480 10.5061/dryad.t76hdr817  
14  
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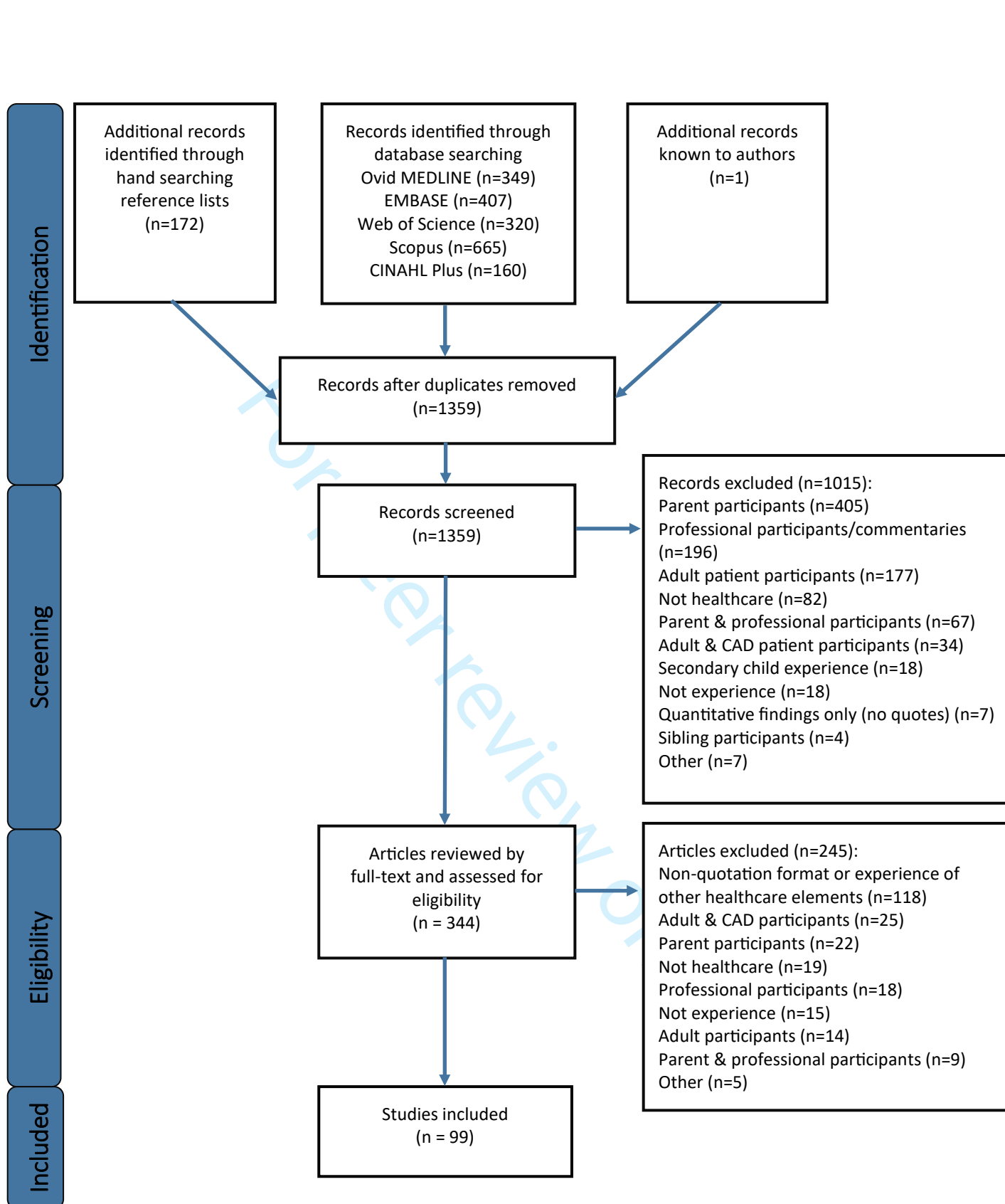
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10 876 **FIGURE CAPTIONS**  
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- 13 877 Figure 1 PRISMA flow diagram  
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Note 'Other' (n=12) reasons for excluding records/articles included: participants' ages unclear (n=4); no full-text available or unobtainable in English (n=7); same study as included article (n=1).

### PRISMA-ScR Checklist

This supplementary information includes the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist (1).

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE # (untracked version)
<b>TITLE</b>			
Title	1	Identify the report as a scoping review.	p.1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	p.3-4, background not required in abstract as per journal guidance
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	p.6-8
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	p.8 & 9
<b>METHODS</b>			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	p.9 and reference list. Not registered.
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	p.9-12 (Table 2)
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	p. 9 & 10 (Table 1)
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	p. 9 & 10, Supp file 2
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	p. 10 & 11
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	p. 13 (box 2)
Data items	11	List and define all variables for which data were	p. 13

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE # (untracked version)
		sought and any assumptions and simplifications made.	
Critical appraisal of individual sources of evidence <sup>§</sup>	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Critical appraisal not done. Rationale on p.11
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	p. 13-15
<b>RESULTS</b>			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	p. 15 (Figure 1)
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	p. 15 (Table 2)
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	p. 15 (Table 2) & Dryad data
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	p. 15, 16, 23-26, & supp file 4.
<b>DISCUSSION</b>			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	p. 29-30
Limitations	20	Discuss the limitations of the scoping review process.	P. 30-31
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	p. 31
<b>FUNDING</b>			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	p. 32

JB1 = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

\* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable

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3 to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used  
4 in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).  
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7 REFERENCE:

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9 1. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for scoping reviews (PRISMA-  
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MEDLINE search	
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2.	Hospitals/
3.	Community Mental Health Services/ or Mental Health Services/ or Community Health Services/ or Community Health Nursing/
4.	School Health Services/
5.	1 or 2 or 3 or 4
6.	Stress, Psychological/
7.	Emotions/
8.	emotion*.mp.
9.	experienc*.mp.
10.	6 or 7 or 8 or 9
11.	5 and 10
12.	limit 11 to "all child (0 to 18 years)"
13.	((child* or infant* or adolescen* or teen?age* or boy* or girl* or toddler*) adj5 (view* or opinion* or feeling* or emotion* or experience* or perception* or first?hand* or their* or say?in or decision* or choice* or choos* or autonomon* or interview* or art or "art* therap*")).mp.
14.	12 and 13
15.	Qualitative Research/
16.	14 and 15

key: mp, multi-purpose search; adj5, search within adjacent 5 words.

## Braun &amp; Clarke 15-point Thematic Analysis Checklist

Process	No.	Criteria	Response
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'	Both focus group transcripts transcribed to an appropriate level of detail and checked against tapes.
Coding	2	Each data item has been given equal attention in the coding process	We reviewed all quotations to generate coding.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive	Themes, and the findings described herein, were developed from a complete coding process of the entire dataset. The coding process was thorough, inclusive and comprehensive, as all quotations were used to generate codes, and develop themes. Each theme was developed based on numerous codes gathered across a range of articles and participants quotations.
	4	All relevant extracts for all each theme have been collated	Yes.
	5	Themes have been checked against each other and back to the original data set	Yes.
	6	Themes are internally coherent, consistent, and distinctive	Yes.
Analysis	7	Data have been analysed- interpreted, made sense of- rather than just paraphrased or described	Yes, evident from the results.
	8	Analysis and data match each other- the extracts illustrate the analytic claims	The analysis and findings from it closely match the data set.
	9	Analysis tells a convincing and well-organised story about the data and topic	Yes.
	10	A good balance between analytical narrative and illustrative extracts is provided	Yes. Illustrative extracts have been used within the results section.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly	Yes.
Written report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated	Yes, stated in the methods section.
	13	There is good fit between what you claim you do, and what you show you have done- i.e. described method and reported analysis are consistent	Yes.



	14	The language and concepts used in the report are consistent with the epistemological position of the analysis	Yes.
	15	The researcher is positioned as <i>active</i> in the research process; themes do not just 'emerge'	Yes.

## REFERENCE:

1. Braun V, Clarke V. Successful qualitative research: a practical guide for beginners. London: SAGE Publications Ltd; 2013.

### **Additional Scoping Review Results: Basic numerical analysis and figures**

This supplementary information includes additional findings and graphical illustrations from basic numerical analysis.

#### *Trend in study publications over time*

On average, four studies were published each year and the rate of publication rose progressively, increasing to 11 per year in 2018 (as shown in Figure 1).

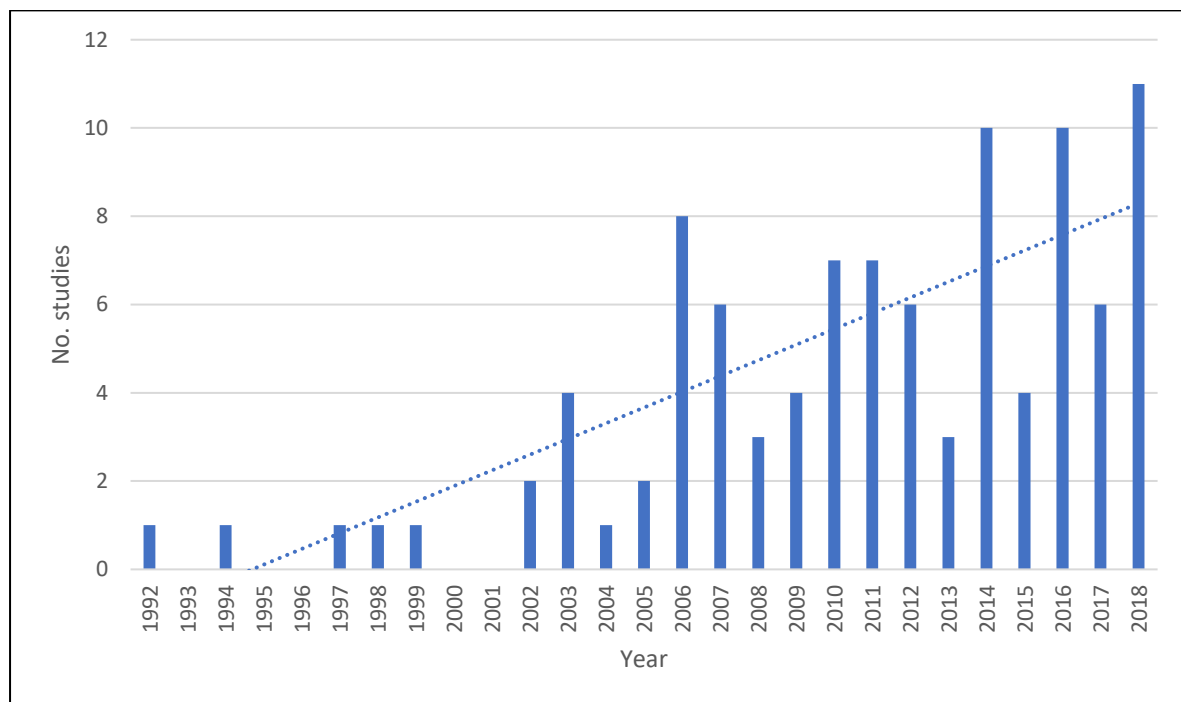


Figure 1 Years of publications

#### *Countries of origin*

Figure 2 illustrates the geographical distribution of included studies on the world map and figure 3 lists countries of origin (n=21) including the number of studies pertaining to each country. Eighty-eight studies originated in western or more developed countries of which the UK (n=26), Canada (n=15), Ireland (n=9), Sweden (n=9), and the United States (n=9) were most common.

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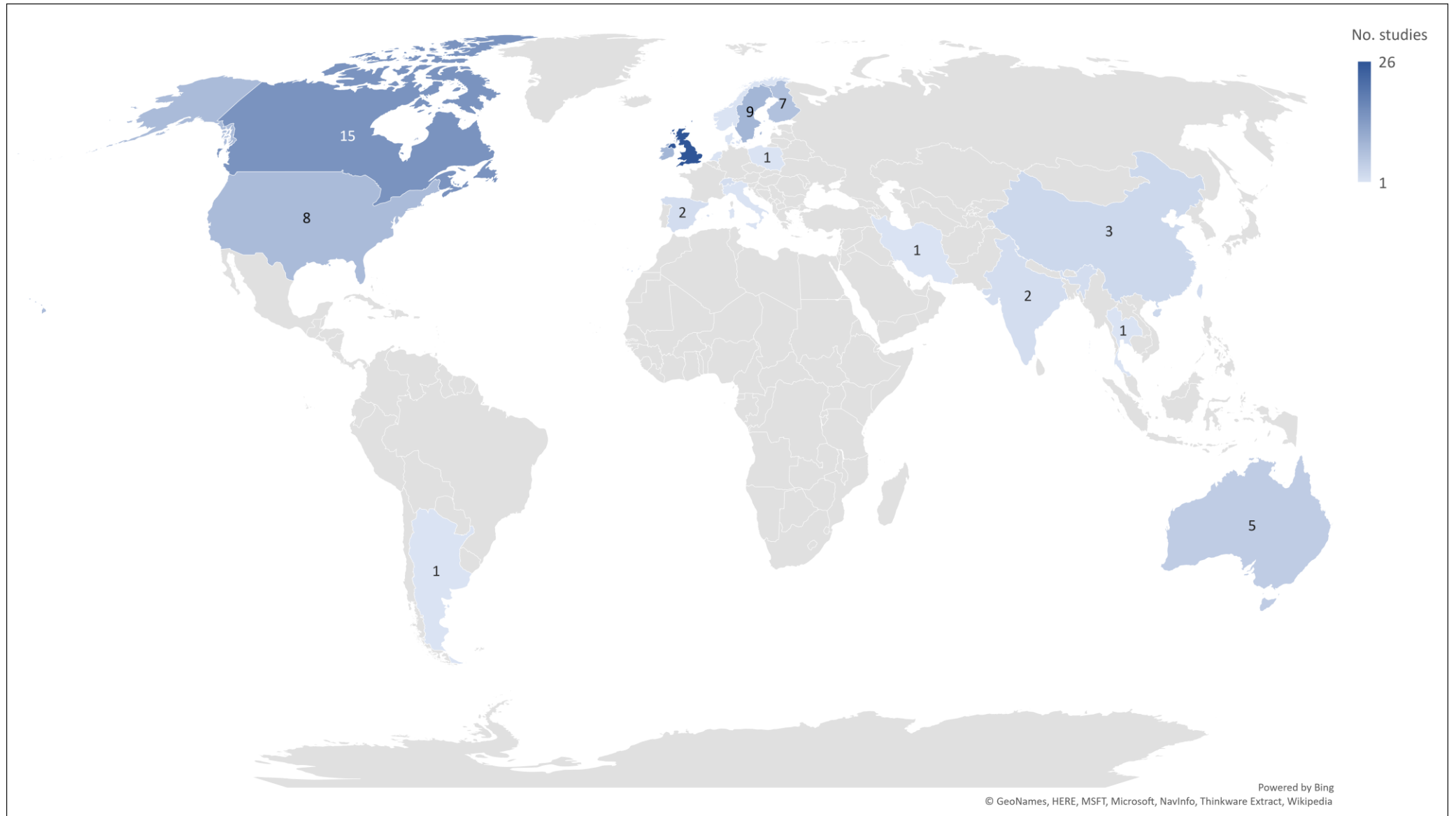


Figure 2 Map of geographical distribution of studies

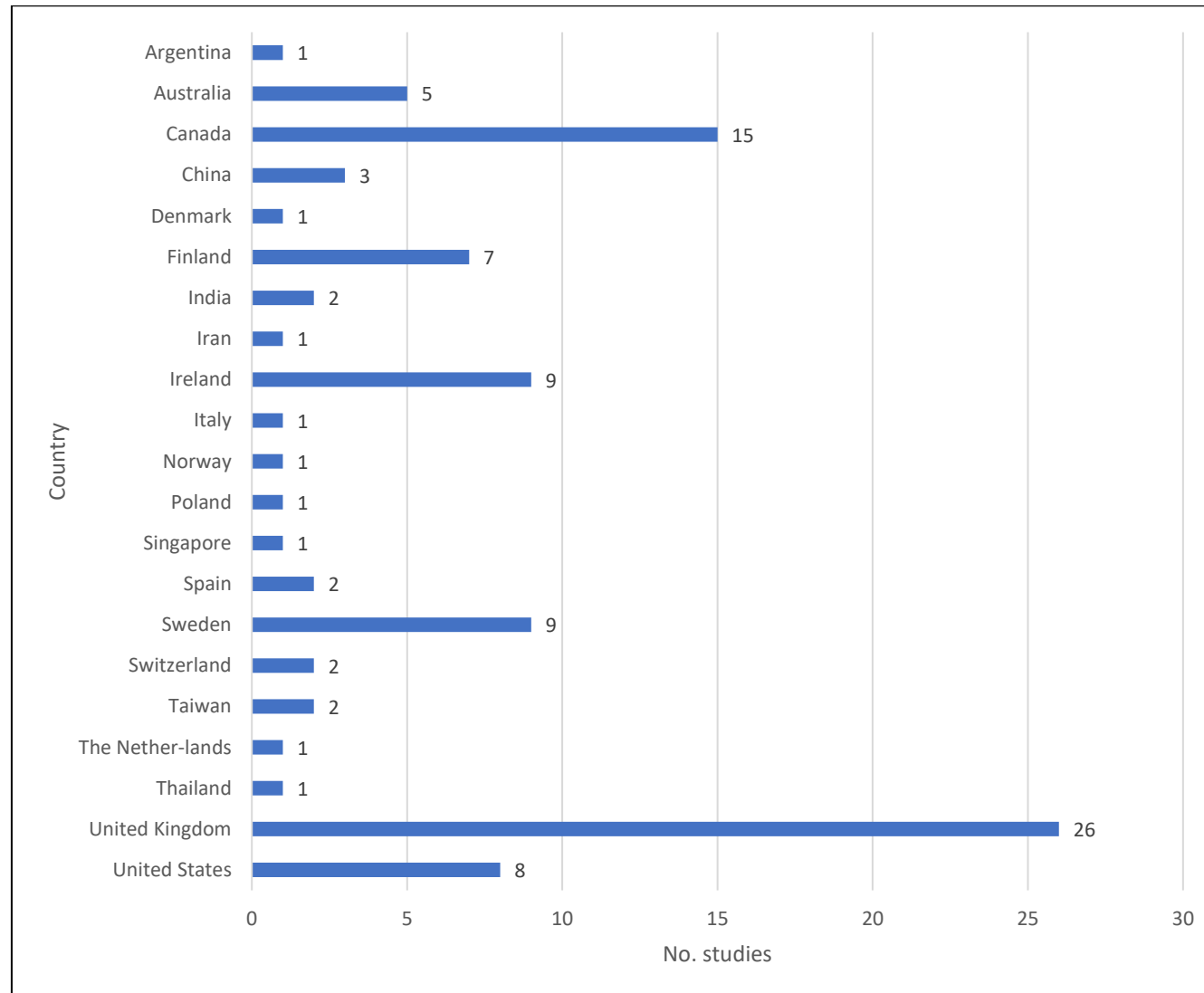


Figure 3 Number of studies per country

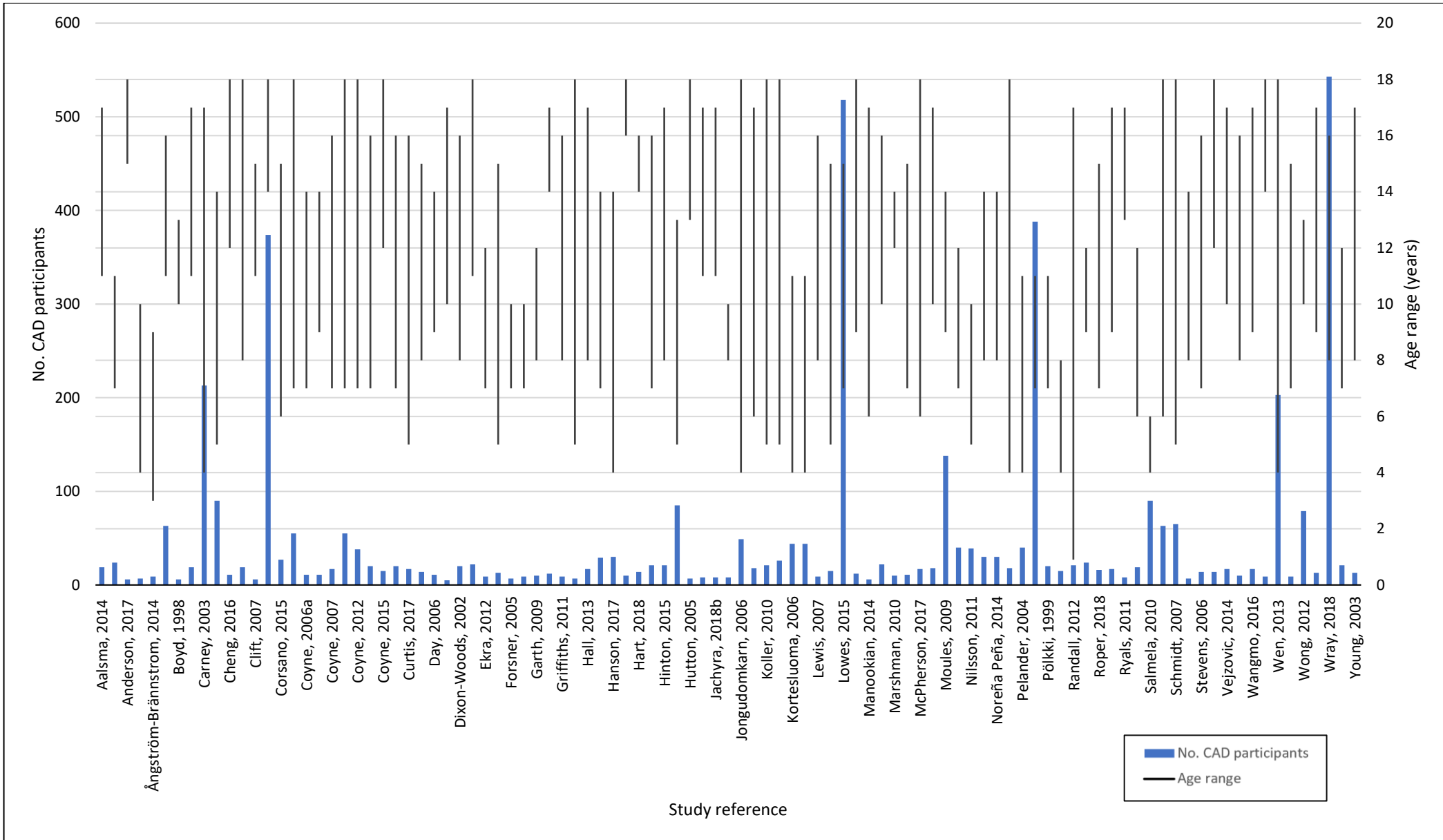


Figure 4 Number of CAD participants per study and age ranges

### *CAD participants*

The number of CAD participants per study and age ranges are illustrated in figure 4. Age ranges varied, however, most studies recruited CAD participants aged 6-17 years. Studies tended to recruit between 8 to 50 participants; seven studies recruited over 100.

### *Additional participants*

Most studies recruited CADs only (n=72). Some studies recruited other participants (n=27); who were parents, HCPs, and teachers (figure 5).

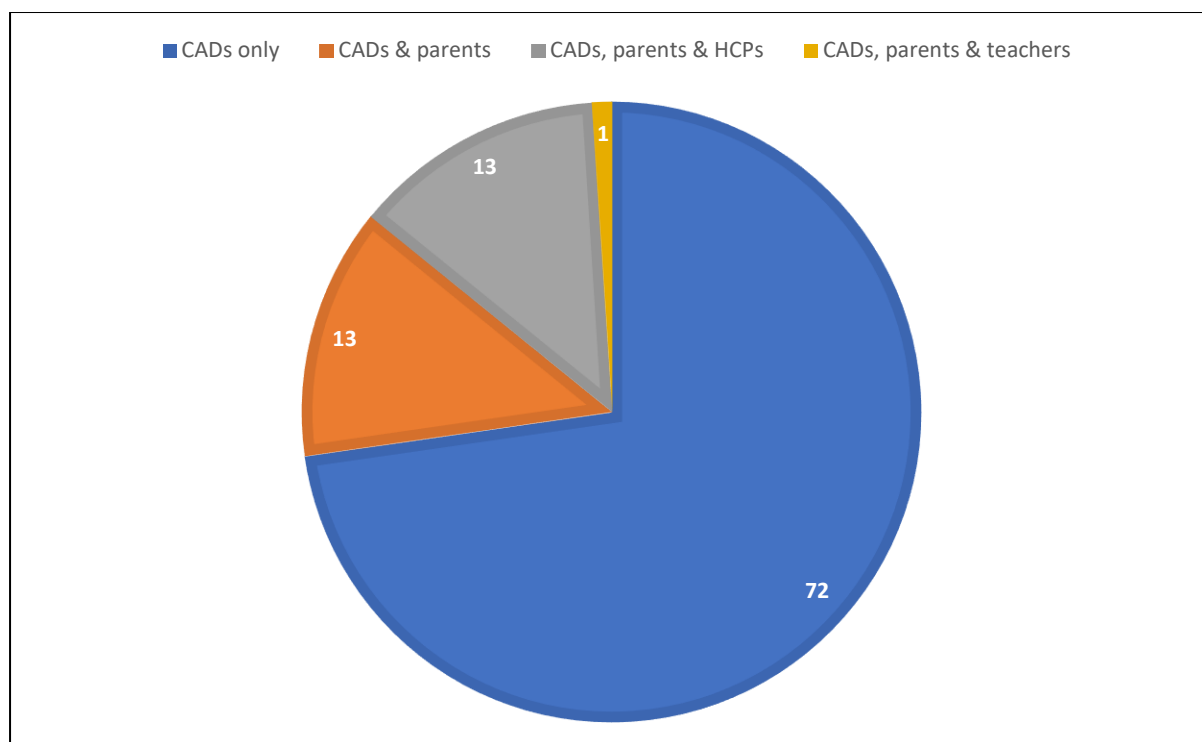


Figure 5 Study participants

### *Study methods*

Most studies used a single method; interviews were most prevalent, followed by focus groups, free-text questionnaires, and workshops (figure 6). Twenty-nine studies used 2 or 3 methods; commonly, interviews combined with observation or focus groups (figure 7).

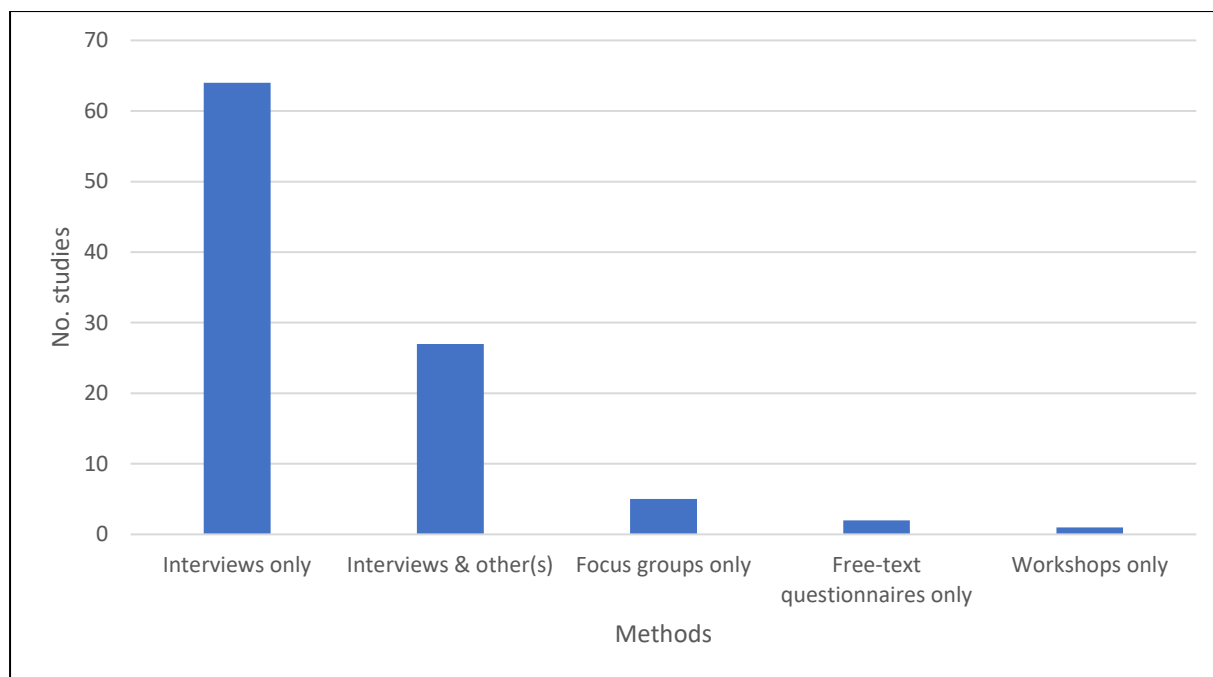


Figure 6 Methods classification

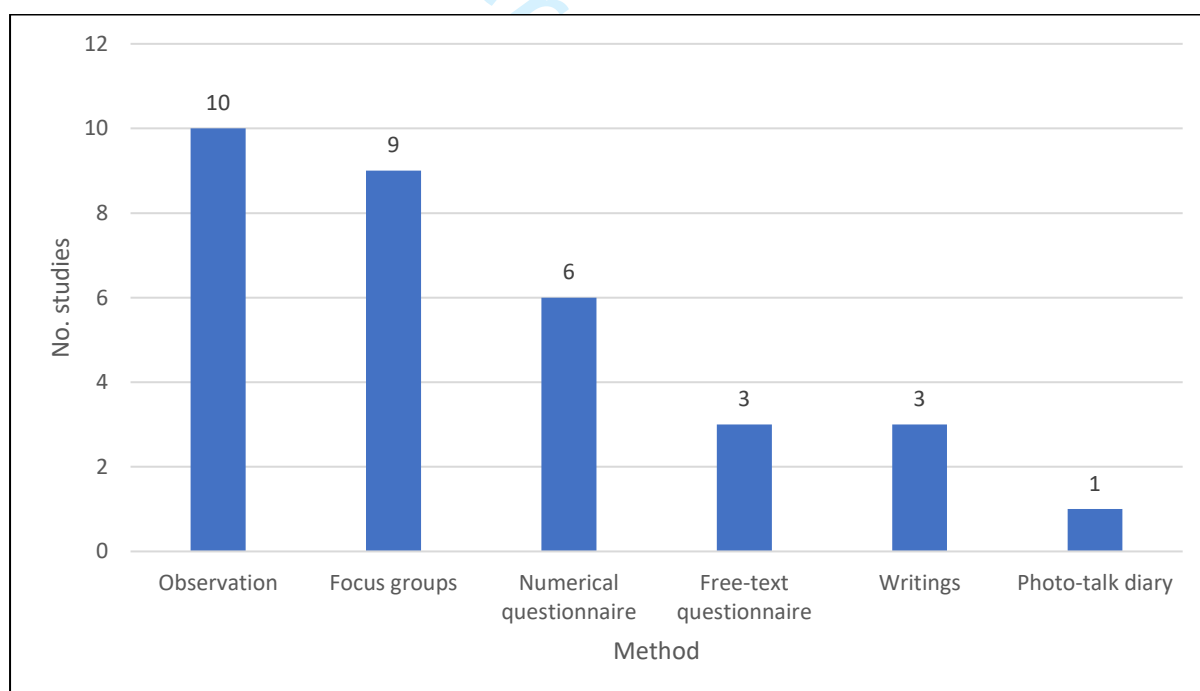


Figure 7 Methods conducted with interviews

### CADs' ages and genders from extracted quotes

Figure 1 illustrates the age distribution of quotations extracted. CADs aged 11-14 were more commonly quoted, while those aged 5-8 years were quoted less. Many quotations referenced CADs' ages (n=379, 56.7%) and genders (n=390, 58.3%); of which 52% were female.

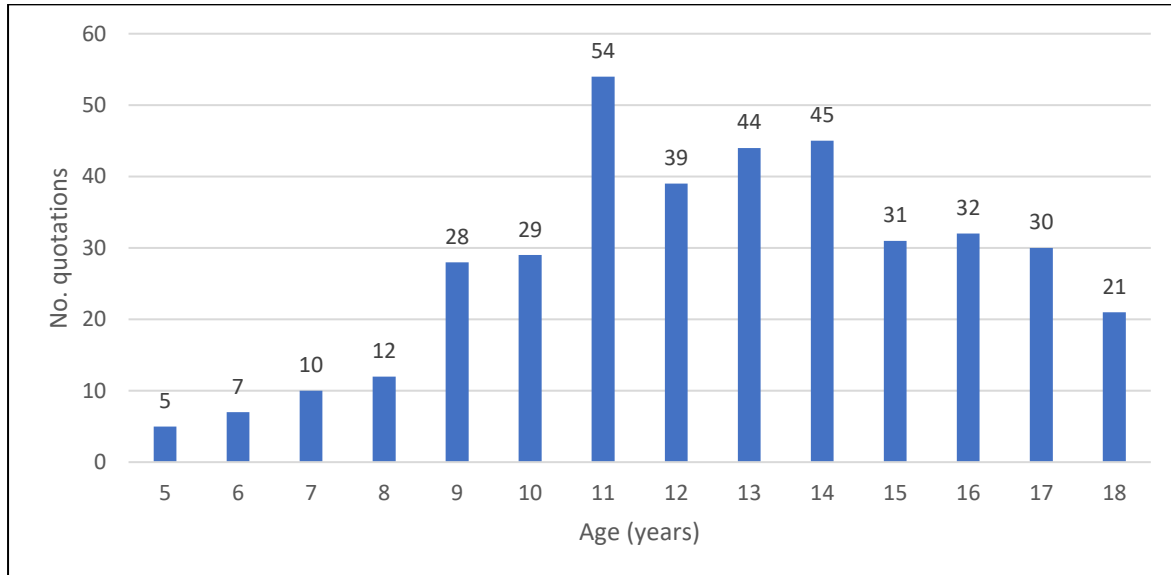


Figure 1 CAD participant ages, from extracted quotes



Quotations presented in results section

The full quotations extracted from articles are accessible using the Dryad unique identifier

<https://doi.org/10.5061/dryad.z08kprrc2>

Quote no.	Quote as written in results section	Quote reference (first author, year, quote no.)
1	'bond'	Ryals, 2011(49)
2	'emotional attachment'	Brown et al., 2014(04)
3	'best friend'	Ryals, 2011(33)
4	'relate to'	Ryals, 2011(32)
5	'good care'	Ångström-Brännström et al., 2008(05)
6	'strangers'	Coyne et al., 2015(02)
7	'As time passed, [...] we created that bond.'	Ryals, 2011(29)
8	'very smart'	Coyne et al., 2014(02)
9	'experienced'	Hodgins et al., 1997(02)
10	'[knew] what to do'	Day et al., 2006(04)
11	'[took] care'	Noreña Peña, 2011(21)
12	'everything the best they [could]'	Boyd, 1998(03)
13	'truthful'	Brown et al., 2014(15)
14	100% with you'	Brown et al., 2014(15)
15	'just [told] you straight up.'	Brown et al., 2014(15)
16	'not tell children any lies'	Koller et al., 2010(02)
17	'nothing [was] hidden'	Coyne et al., 2016(01)
18	'really nice'	Clift et al., 2007(06)
19	'nurturing, caring and helpful people who [were] there for you'	Schmidt et al., 2007(01)
20	'good sense of [humour]'	Schmidt et al., 2007(15)
21	'she knew what I was talking about, she knew what I was feeling, she knew how I was feeling.'	Ryals, 2011(20)
22	'took time to get to know'	Brown et al., 2014(06)
23	'real conversations, not just [HCP]-patient discussions'	Schmidt et al., 2007(31)
24	'down to earth'	Ryals, 2011(45)
25	'a lot in common'	Ryals, 2011(22)
26	'you gotta have trust.'	Ryals, 2011(42)
27	'satisfied'	Wangmo et al. 2016(05)
28	'happy'	Corsano et al. 2015(04)
29	'good memories'	Manookian et al, 2014(03)
30	'open up'	Ryals, 2011(42)
31	'tell anything'	Beresford et al, 2003(06)
32	'cure [the] illness'	Han et al, 2011(01)
33	'whatever happens I let them [HCPs] do what they have to do to help me get better.'	Boyd & Hunsberger, 1998(01)
34	'individually [they're] all heroes.'	Anderson et al., 2017(04)
35	'Because you can save people [...] I'm going to be a children's doctor.'	Olausson et al., 2006(01)
36	'everything [was] always clear'	Schalkers et al., 2014(04)
37	'together'	Dell'Api et al., 2007(07)
38	'seriously'	Clift et al., 2007(05)
39	'as an equal'	Clift et al., 2007(05)

40	'into all the conversations'	Coyne et al., 2011(15)
41	'as much as they [talked to the] parents'	Edgecombe et al., 2010(03)
42	'[breaking] the words down in an easier explanation'	Coyne et al., 2006(13)
43	'listening'	Coyne et al., 2006(03)
44	'I tell them I don't want this and they ... understand'	Coyne et al., 2006(03)
45	'me because I know my own body, my parents because they know what's best for me [...] and the paediatrician because they are qualified.'	Garth et al., 2009(02)
46	'most important, as in the end it is about [them]'	Schalkers et al., 2014(04)
47	'brilliant'	Moules, 2009(01)
48	'interesting and informational'	Lowes et al., 2015(02)
49	'learn something new'	Lowes et al., 2015(03)
50	'comfortable and confident'	Lowes et al., 2015(02)
51	'make better decisions'	Coyne & Kirwan, 2012(23)
52	'fully informed'	Coyne & Kirwan, 2012(23)
53	'I'm asking the doctor more questions myself than having my Dad do it.'	Coyne et al., 2006(15)
54	'nasty'	McPherson et al., 2018(03)
55	'[seeming] that concerned'	Coyne, 2006b(02)
56	'too busy'	Coyne et al., 2006(28)
57	'big words'	Coyne et al., 2006(16)
58	'they [HCPs] might ask me "is that ok" and they ask me in such a way that I kind of feel like I don't have any other option but [to] agree with them'	Coyne et al., 2015(01)
59	'behind the curtains'	Coyne et al., 2011(20)
60	'in the middle'	Coyne et al., 2006(18)
61	'you try to say something but then your parents just say shhhh! [...] They come out and say, [...] did you understand that, you say no, they say, you should have asked them, and then you say, oh you didn't let me, they say rubbish!'	Hawthorne et al., 2011(04)
62	'rejected'	Coyne et al., 2006(17)
63	'like a piece of machinery'	Coyne, 2006b(04)
64	'hard to talk'	Anderson et al., 2017(01)