

1 Title Page  
2 This is the article title  
3 “The impact of the Little Orange Book on how parents/carers manage symptoms of illness in children:  
4 A mixed methods study”.  
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19

## 20 **Abstract**

21 Background: Previous literature has highlighted the complexity of supporting an acutely unwell child  
22 and the unnecessary use of services by parents/carers. The Little Orange Book (LOB) was developed  
23 as an information resource for parents/carers of young children to assist in managing symptoms of  
24 childhood illness and to encourage the appropriate use of healthcare services.

25 Objectives: This study aimed to understand parent/carer views and experiences using the Little Orange  
26 Book. Specifically, this study focused on barriers and facilitators to use, the impact on parents'  
27 behaviour and the views on improving the LOB.

28 Methods: An explanatory sequential mixed-methods approach, including qualitative and quantitative  
29 components, was used to collect data regarding parent's experiences using the LOB. Parents and carers  
30 in the North-East of England were invited to participate in an online survey and a subset of these  
31 respondents took part in qualitative interviews. One-hundred-and-twenty-eight parents completed the  
32 online survey and 16 took part in interviews. Qualitative data were analysed using thematic analysis  
33 and quantitative data analysed using descriptive statistical analytical methods.

34 Results: Three themes were identified within the data: *Increasing parental empowerment in managing*  
35 *their child's health, Equality of Access to Health-based Literature* and *Barriers and Facilitators to*  
36 *using the Little Orange Book.*

37 Conclusions: The Little Orange Book was seen as a valuable form of information to support parents  
38 and carers in healthcare decisions. Further development should ensure inclusivity, widen access and  
39 view provision of the information as an opportunity for healthcare professionals to engage with parents.

40 Keywords: Parent/carer, decision making, childhood symptoms, Little Orange Book.

## 41 **Introduction**

42 For parents/carers, making decisions about when and where to access healthcare or health services for  
43 their acutely unwell child is complex [1]. Following interviews with parents of young children [2],  
44 Conlon et al. describe a complex decision-making process in which parents sought care for their  
45 children when a ‘threshold of capacity for self-management’ was exceeded. A recent systematic review  
46 suggested that pre-disposing factors (socioeconomic status, ethnicity and race) may influence parental  
47 decisions on the use of care, which are often based on perceptions of the urgency of the condition [3].  
48 This review highlighted multiple factors featured within parental decision-making, including a need for  
49 reassurance as well as judgments regarding the availability and convenience of services, relationships  
50 with General Practitioners and perceptions of the quality of care in emergency departments.

51 Prompted by dramatic reductions in the use of children’s health services during the Covid-19 pandemic  
52 [4, 5], research has identified several factors feeding into parental decision-making, including making  
53 sense of risk and understanding information about health service availability [6]. While health  
54 information has the potential to cause anxiety [7], some suggest that studies examining health service  
55 use focus too much on help-seeking behaviours rather than the examination of sense-making, which  
56 can create unhelpful, polarised views which classify service use as appropriate or not [8]. Several studies  
57 have concluded that resources to support decision-making or increasing parental knowledge of health  
58 conditions, including self-care, may play an important role in ensuring appropriate healthcare use [1, 9,  
59 10].

60 The Little Orange Book (LOB) [11] is a paediatric health resource developed by the NHS Newcastle  
61 Gateshead Clinical Commissioning Group (NGCCG) in collaboration with healthcare professionals and  
62 parents/carers. The resource aims to support parents/carers with children under 5 years old to manage  
63 common childhood illnesses, emergencies, and critical conditions requiring urgent medical attention.  
64 The paper version of the LOB is freely available from clinical and community settings based in  
65 Newcastle and Gateshead in the Northeast of England and can be downloaded as a digital copy. An  
66 initial evaluation investigated the perceived value of the LOB by parent/carers and healthcare

67 professionals, and the impact of its use on unnecessary use of health services [9]. Parent/carers  
68 completed face-to-face questionnaires or brief feedback cards and healthcare professionals completed  
69 online or paper questionnaires. Participants viewed the layout and content of the LOB positively. The  
70 majority of parents/carers reported referring to the LOB in the event of their child being unwell, noting  
71 an increase in confidence in self-care and appropriate use of health services. Whilst this evaluation was  
72 valuable, there was scope for a further in-depth evaluation focusing on individual parent's experiences  
73 of using the LOB and in particular, barriers and facilitators to use.

74 This study aimed to explore parent/carers' views and experiences using the LOB. Building on the  
75 previous evaluation, this study utilised a mixed-method approach and explored in-depth the barriers and  
76 facilitators to using the LOB, the perceived impact on parent behaviour when making health-related  
77 decisions for their child, and suggestions for improving the resource. This article outlines the key  
78 findings of a commissioned evaluation of the LOB and will make a new contribution to knowledge of  
79 parental decision-making, distribution of and access to health information, and considerations for future  
80 evaluation methods and research.

81

## 82 **Methods**

### 83 **Design**

84 This study used an explanatory sequential mixed methods design (containing quantitative and  
85 qualitative stages) across two phases [10] underpinned by a pragmatic approach focussed on  
86 understanding the implications for future information provision. Phase one was an online survey aimed  
87 at understanding broad views and impacts of the LOB. These initial findings informed the second phase,  
88 both through allowing purposive sampling based on demographics as well as allowing trends in data to  
89 be explored further through semi-structured interviews with parents/carers in order to gain further  
90 understanding of the views and experiences of using the LOB. While the survey explored the views of  
91 those who had previously received the LOB and those who had not, this paper will focus on

92 parents/carers who received the LOB across both phases, the views of those who did not receive the  
93 LOB are presented elsewhere [12].

## 94 **Ethics**

95 Ethical approval to conduct the evaluation was obtained from Northumbria University Health and Life  
96 Sciences Ethics Committee (reference number: 41385.).

97 The research team provided information about the study to those who had expressed an interest in taking  
98 part and were available to provide further information or answer any questions. Those who participated  
99 in the study provided informed consent virtually (online survey) and written (individual/group  
100 interview). Verbal consent was also obtained at the beginning of each interview. All participants were  
101 provided with a unique identifier for anonymity and no names were included with any data. Regarding  
102 the qualitative components, any possible identifying information (e.g. location or names) were removed  
103 during the transcription process.

104 Survey respondents had the opportunity to be entered into a prize draw to win £25 voucher and  
105 parents/carers who participated in an individual or group interview received a £25 voucher at  
106 completion.

107

## 108 **Participants**

109 A convenience sample of parents/carers from across Newcastle and Gateshead were invited to  
110 participate in both phases of the project. The online survey was publicised via an electronic flier shared  
111 with over 300 health and community services/groups for families and children, 193 nurseries, and via  
112 social media groups, organisational websites, and GP bulletins. A Facebook advertisement was  
113 developed and cross-posted via Instagram and Facebook Messenger. Survey respondents had the  
114 opportunity to 'opt in' to an interview to further explore their views and experiences of using the LOB.

115 The inclusion criteria for the study included being over 18 years old, being a parent/carer or guardian  
116 (including grandparents), live or lived in the North East of England, and the capacity to give informed

117 consent. In total, 128 individuals completed the online survey. Of these 82 had received and used the  
 118 LOB, 24 had received and not used the LOB, and 22 had not received the LOB (see Table 1).

119 **Table 1. Demographics of survey respondents (N=128)**  
 120

Variable	Received and used the Little Orange Book (N=82)	Received and did not use the Little Orange Book (N=24)
<b>Age</b>	25-56 years (mean = 35.85, SD = 5.12)	24-50 years (mean = 36.96, SD = 6.49)
<b>Gender</b>		
Female	95.12%	100%
Male	4.88%	0%
<b>Ethnicity</b>		
White	93.90%	91.67%
Black/African/Caribbean/Black British	3.66%	0%
Asian/Asian British	1.22%	4.17%
Mixed/Multiple Ethnic Groups	1.22%	4.17%
<b>Marital Status</b>		
Married/Civil Partnership	92.68%	91.67%
Single	6.10%	8.33%
Separated	1.22%	0%
<b>Number of Children</b>		
First-time parent	48.7%	41.67%
Two Children	72.50%	69.23%
Three Children	22.50%	23.08%
Four Children	2.50%	7.69%
More than Four Children	2.50%	0%
<b>Employment Status</b>		
Employed full-time	43.90%	54.17%
Employed part-time	36.59%	33.33%
Homemaker/Housewife	10.98%	4.17%
Self-employed	3.66%	0%
Carer	1.22%	4.17%
Unemployed and not currently looking for work	1.22%	0%
Unable to work	1.22%	0%
Prefer not to say	1.22%	0%
Other		4.17%
<b>Version of the LOB</b>		
Paper-based copy	56.10%	70.83%
Online copy	10.98%	10.93%
Both online and paper copies	32.93%	8.33%

121  
 122 For phase two, sixteen parents/carers took part in individual and group interviews over Microsoft  
 123 Teams (n=13); face-to-face (n=1), and over the phone (n=2) (see Table 2).

124 **Table 2. Interview participant demographics (N=16)**  
 125

<b>Variable</b>	
<b>Age</b>	25-43 years (mean = 35.19, SD = 4.46)
<b>Use of the Little Orange Book</b>	
Received and used the LOB	87.5%

Received and not used the LOB	6.25%
Had not received the LOB	6.25%
<b>Ethnicity</b>	
White	87.50%
Black/African/Black British	6.25%
Asian/Asian British	6.25%
<b>Marital Status</b>	
Married/Civil Partnership	93.75%
Single	6.25%
<b>Number of Children</b>	
One child	50.00%
Two Children	50.00%
<b>Employment Status</b>	
Employed full-time	50.00%
Employed part-time	37.50%
Homemaker/Housewife	6.25%
Unemployed and not currently looking for work	6.25%
<b>Age of Children*</b>	
Under one years old	43.75%
Between one and two years old	50.00%
Over three years old	56.25%

126

127 This paper presents the views and experiences of the 106 survey recipients and 16 interview participants  
128 who received a version of the LOB.

### 129 **Phase One: Online Survey**

130 The online survey was produced using JISC online surveys and was available for completion between  
131 9<sup>th</sup> April-23<sup>rd</sup> July 2022. The survey was developed specifically for this study and was created in  
132 collaboration with members of the NGCCG.

133 Initial pages of the survey included information about the study and required digital confirmation of  
134 informed consent. The survey included open-text and multiple-choice response options. Survey  
135 respondents were directed to one of three pathways based on their prior receipt and use of the LOB.  
136 Respondents who received and accessed the LOB completed questions about the dissemination of the  
137 resource, previous usage, and possible impact on confidence and decision-making when their child was  
138 unwell. Further questions focused on the design and suggested improvements. For respondents who had  
139 received but not used the LOB, the online survey explored barriers to use, and their use of other sources  
140 of support to assist them in supporting their unwell child. All respondents noted their use of health  
141 services for their child in the previous year, as well as during the Covid-19 pandemic.

142 **Phase Two: Individual and Group Interviews**

143 At the end of the survey, respondents were asked if they would be willing to take part in either an  
144 individual or group interview and, if so, to share their contact details to arrange the interview. Individual  
145 and group interviews were offered to accommodate participant’s personal preferences and to encourage  
146 a representative sample.

147 Those who wanted to participate in interviews were subsequently contacted by a member of the research  
148 team to provide details about this phase of the study, to provide informed consent, and to determine  
149 their preference for an individual or group interview. In total, 16 participants took part in this phase of  
150 the study, 13 through the online survey and 3 through word of mouth. The interviews were conducted  
151 by members of the research team (AJ, LS and MB) and they were audio-recorded. The responses  
152 provided by the interview participants in the Phase One survey were used to personalise the topic guide  
153 to gain a more in-depth understanding of their experiences. For instance, if the participant had indicated  
154 using the LOB for a previous illness, this was directly referenced and asked about in the interview guide.  
155 The topic guide is shown below in table 3:

156 **Table 3. Individual/Group Interview Topic Guide**

157

Question	Prompts
1. Please tell me about your experience of using the Little Orange Book	Digital / online version How helpful did you find it? Can you give any specific examples?
2. How does / has the LOB influence(d) your decision making regarding your child’s symptoms?	How did it impact on your confidence in managing symptoms? How did it influence your use of health care services?
3. Did the LOB play a role in your decision making during the Covid-19 pandemic?	Did your use of the LOB change during the pandemic?
4. What do you think of the design of the LOB?	Can you give some examples of what you like / feel could be improved? Do you have a preference for a particular format (hard copy, digital, mobile app)?
5. Is there anything you would like to add that we haven’t discussed in relation to the LOB?	

158



159 The topic guide was used to focus the interviews and ensure all participants were asked the same  
160 questions to reduce interviewer bias. The aim of the interviews was to obtain a more detailed insight  
161 into the views and experiences of parents/carers regarding the role of the LOB in guiding decisions  
162 about managing childhood symptoms as well as to understand their views about the design of the  
163 resource.

164

## 165 **Data Analysis**

166 Descriptive statistics were calculated from the responses from the phase one online survey and are  
167 presented alongside the qualitative analysis. Open-response questions from the survey and the phase  
168 two qualitative interviews were analysed using deductive thematic analysis [13]. This involved member  
169 of the research team independently reading and re-reading the qualitative data in order to generate initial  
170 codes which were combined into broader themes. At this point, the research team met to collectively  
171 review the initial codes and themes before refining them further and agreeing on the final themes  
172 presented in the results section.

## 173 **Results**

174 Three themes were generated from the individual interviews and the online survey open-question  
175 responses and are outlined below.

### 176 **Increasing parental empowerment in managing their child's health**

177 This theme describes the impact of the LOB in terms of parent's empowerment in managing symptoms  
178 of childhood illness. In doing so, this provides examples of when the LOB was used, the impact on  
179 parent's confidence and the use of health services.

180 76.42% of survey respondents who used the LOB stated that this guided healthcare decisions when their  
181 child was unwell. To many parents/carers, the LOB was seen as a first step in identifying possible

182 illnesses and what actions could be taken to support their child. In this sense, it was seen as valuable,  
183 quick, always available, and prevented unnecessary use of services:

184 *“... they’re a bit off, and I’m a bit worried about them, but I don’t want to just*  
185 *start panicking or ringing 111 or whatever. And that’s usually when we go to the*  
186 *orange book... it provides me with what to do next... It’s quicker than ringing up*  
187 *111. It’s quicker than ringing up your GP. I think it’s just, like, almost like a little,*  
188 *like, flow or how-to guide of what to do next.” (P006, Interview Participant)*

189 First-time parents appeared to value having the LOB as a health resource, particularly those without  
190 access to support networks or concerns surrounding receiving outdated advice. Nearly half (41.78%) of  
191 survey participants who had used the LOB were first-time parents.

192 *“...I thought was brilliant idea and especially as a first-time mom...I don't have*  
193 *my parents, so I can't ask them about things. I can ask my grandma, but obviously*  
194 *she's older... it's more of like old fashioned values and it might not be up to date*  
195 *with what's recommended to do now... even just to learn about them without*  
196 *scaring yourself” (P015, Interview Participant)*

197 For parents with multiple children, the LOB could be seen as less useful due to their experience and  
198 knowledge already developed with their older children, however this was unclear in both the survey  
199 and the interviews. One exception to this could be parents who had children with a large age gap.

200 *“It doesn’t contain anything of use to me, I got it when I had my third child.”*  
201 *(P005, Survey Respondent)*

202 Most (85.37%) survey respondents who had used the LOB reported increased confidence in supporting  
203 their child who was experiencing symptoms of illness. Similarly, 89.03% of survey respondents  
204 reported that the LOB had facilitated identifying the most appropriate service to assist their child. This  
205 was further reflected in the qualitative analysis, with some parents reporting using the LOB guided their

206 use of health care services, facilitated in judging the severity of symptoms, and in some cases, directed  
207 them to the appropriate administration of medication.

208 *“When my little girl had chicken pox, I felt really worried, the book put my mind*  
209 *at rest, and I got help from the pharmacy. I bought calamine lotion, I might have*  
210 *given Ibuprofen, but the book advised paracetamol, I shared this advice with*  
211 *friends as it’s not something I knew about.” (P027, Survey Respondent)*

212 Some parents described using the information within the LOB to guide decisions surrounding schools  
213 and nursery settings. However, some parents reported the advice may not align with the procedures at  
214 nurseries.

215 *“I suspect different nurseries will have different policies... I think I remember*  
216 *thinking that what was considered green, amber and red wasn’t necessarily what*  
217 *our nursery was... Because, for some of them you can say can you be off nursery*  
218 *or not... Yes/No. And I think our nursery... I felt like was taking more of a*  
219 *blanket kind of... You can come in if you’ve got a cold, but that was kind of about*  
220 *it.” (P011, Interview Participant)*

221 Other participants described negative experiences or views which could impede usage and reduce their  
222 perception of the LOB.

223 *“I felt that is strongly discouraged seeking NHS assistance and that alone caused*  
224 *concern. I’ll make that judgement myself as a parent. ... I felt it discouraged*  
225 *accessing services at all” (P032, Survey Participant)*

226 *“My child burnt themselves and as per the little orange book, I asked my local*  
227 *pharmacist for advice. Their reaction appeared to be of surprise and why was I*  
228 *asking them. I felt that it was pointless and made me less confident in the advice*  
229 *provided in the book” (P026, Survey Respondent)*

230 Whilst the content of the LOB was seen as valuable, some participants argued the importance of also  
231 using parental instincts regarding their child’s health.

232 *“I wouldn’t say, if something in the book said, ‘you don’t need to seek medical*  
233 *advice’ but something in me was telling me I needed to, I still would.” (P014,*  
234 *Interview Participant)*

### 235 **Equality of Access to Health-based Literature**

236 The Equality of Access to Health-based Literature explores the dissemination and visibility of the LOB  
237 and the value of explanations when receiving this resource. The accessibility of health literature is  
238 directly associated with awareness of the resource including how the information is disseminated. As  
239 can be seen from Table 3, most survey respondents received the LOB at a health appointment in the  
240 community.

241 **Table 3. Reports of where survey respondents received the LOB (n=106)**

<b>Health appointment in the community (e.g. GP surgery, midwife or health visitor)</b>	64.15%
<b>Educational setting (e.g. school, nursery or childcare setting)</b>	8.49%
<b>Health appointment in secondary care (e.g. Outpatients or Accident and Emergency)</b>	7.55%
<b>Family member or friend</b>	7.55%
<b>Accessed online</b>	4.72%
<b>Community centre</b>	1.89%
<b>Can’t remember</b>	3.77%
<b>Other</b>	1.89%

242 Some participants felt that the LOB was not easily accessible, lacked visibility, or its importance was  
243 not made clear to them on receipt.

244 *“More focus on it with [health visitor]. I didn’t realise I had it for ages. It wasn’t*  
245 *explained to me at all. I found it with some handouts.” (P096, Survey Respondent)*

246 Conversely, one participant reported that the LOB was highly visible which could indicate variation  
247 between locations.

248 *“... I’d said, oh, I felt like I’d been offered this book quite a few times – I don’t*  
249 *know how you missed it” (P004, Interview Participant)*

250 Although an online version of the LOB is available, several participants were unaware of its online  
251 availability. Some described how this knowledge would have impacted their use of the LOB and how  
252 they would value the resource.

253 *“I would have downloaded it to my phone and just used it all the time... I think it’s*  
254 *good to have the... The paper version of it, but I probably would have used the*  
255 *digital one... it’s just one less thing to have to remember to pack, because you’ve*  
256 *always got on you... But now I know that this exists, I’ll probably get my Mum to*  
257 *put it on her phone as well” (P009, Interview Participant)*

258 Some participants provided suggestions to increase the awareness and accessibility of the LOB which  
259 included providing the resource with pre-existing resources, such as “The Little Red Book” (personal  
260 child health record). Providing the LOB antenatally was seen as beneficial by some participants to allow  
261 familiarisation with the resource in advance of their child’s birth.

262 *“Making aware of it to the mum before the baby was born, no time to consult it*  
263 *during the first month” (P101, Survey Respondent).*

264 Nearly half (47.56%) of survey respondents reported that they did not receive an explanation of the  
265 resource when it was provided to them. Crucially, interview participants highlighted that they would  
266 benefit from an explanation of the resource by health and social care staff upon receipt to support  
267 awareness and understanding.

268 *“I didn’t know that we’d received it... I was sorting out some paperwork in the*  
269 *bookcase and the pocket that the health visitor had given us – I’d looked through*  
270 *some of it, but not all of it – she didn’t really say what was in there. And I found it*

271 *in there and realised what it was and how important it was... It was just 'Here's a*  
272 *pocket full of some information, if you need it. Have a look through and you can*  
273 *get in touch with us if you've got any questions.' But if I'd known what the content*  
274 *of it was and how important it was, I wouldn't have just...* (P009, Interview  
275 *Participant)*

276 However, those who had been provided with an explanation found it beneficial.

277 *"My regular health visitor... She provided it along with a few, like, other things...*  
278 *and she talked me through it... You know, it's quite clear... This is you can manage*  
279 *at home. This is you might want to consult someone. And this is an emergency, you*  
280 *know. As well as the helpful tips it gives as well, from time to time...* (P002,  
281 *Interview Participant)*

282 Furthermore, 45% of respondents who had not received the LOB felt distribution via health  
283 professionals (such as midwives, general practitioners, and health visitors) would be preferable. This  
284 can also provide the ability to be reviewed during key points of contact.

285 *"It's provided to the parents without much explanation because they're not gonna*  
286 *take them when they've got a newborn, and they're gonna think that actually, that*  
287 *doesn't affect my child. But then to review the information of the Little Orange*  
288 *Book at the development checks, so such as some people have them at like 3*  
289 *months, six months or a year."* (P015, Interview Participant)

290

## 291 **Barriers and Facilitators to using the Little Orange Book**

292 The final theme identifies the value of peer-to-peer dissemination, credibility and trustworthiness, and  
293 the clear format of information provided. Key barriers included a lack of diversity and the perception  
294 that the sole purpose of the LOB was to prevent access to health services. Recommendation of the book  
295 from peers was both a facilitator to use and dissemination. The majority of survey respondents (92.68%)

296 who had received and used the LOB reported that they would recommend it to others. Several  
297 participants described sharing the LOB with family members caring for their child or with friends. As  
298 a result of peer-to-peer dissemination, the resource was accessed and used more widely beyond the  
299 geographically intended audience.

300 *“I have downloaded the digital format and passed it on to numerous friends who*  
301 *have newborns. It’s very reassuring to have this to hand rather than having to rely*  
302 *on internet search which always seemed to provide a worst-case scenario and*  
303 *panic” (P014, Survey Participant)*

304 In contrast, only 58.33% of the 24 survey respondents who had received but not used the resource would  
305 recommend it to others.

306 Of the 106 survey respondents who received and accessed the LOB, 76.42% used it when their child/ren  
307 were unwell. The affiliation of the resource with the NHS was viewed positively and felt *“more reliable*  
308 *than searching online for answers”* (P053, Survey Respondent). However, some participants queried  
309 whether the content was maintained to ensure it was current and remained accurate while some were  
310 unaware of multiple and/or newer versions of the resource.

311 *“Because it is... You know, medically, it’s come from the NHS... It’s come from a*  
312 *reliable source. And that’s the information that you would get, probably, first if*  
313 *you rang 111. So, yeah... I’ve got masses of confidence in the orange book.”*  
314 *(P001, Interview Participant)*

315 Conversely, despite acknowledging the value of the LOB, one participant queried whether the “tone”  
316 of the resource was intended to act as a deterrent from access to emergency services.

317 *“...I felt like the whole concept of the book was potentially to stop people going to*  
318 *A&E. And I kind of found it useful, otherwise... Because that’s the kind of tone of*  
319 *the NHS, kind of, PR and stuff at the minute. The don’t go to A&E with this. And*  
320 *don’t visit your GP with that. And they’re kind of pushing further on to*

321 *pharmacists. I thought that was probably the essence of the book in the first*  
322 *place.” (P004, Interview participant)*

323 Several features of the LOB design supported the use of the resource. 87% of participants reported that  
324 they were guided by the traffic light system to guide decision-making, including for acute symptom  
325 management in the presence of long-term conditions. 92.69% of survey respondents who had used the  
326 LOB reported the design to be useful including having tabs to differentiate the sections, although some  
327 participants suggested progression of the design to include physical tabs to support content navigation.

328 *“...the colours are really helpful and that kind of traffic light... system is really*  
329 *helpful. It’s consistent throughout and it helps with that kind of accessibility that I*  
330 *mentioned and that you know, I guess even if the text is a challenge to you, you*  
331 *can see by the colour system like how alarming something is or is not, which is*  
332 *really positive” (P016, Interview Participant)*

333 Furthermore, 82.93% of respondents felt guided by the imagery within the book, finding the visual  
334 content beneficial for symptom identification and management, which was reinforced by qualitative  
335 responses and interviews. However, 47.56% would have preferred additional photographic content,  
336 which some participants acknowledged was available on the NHS website.

337 Several participants raised concerns about a lack of inclusivity and diversity of representation within  
338 the images, which could influence recommendations of the resource. A key example was the meningitis  
339 rash looking visually different on different skin tones and as a result, could be “*life-threatening*” (P132,  
340 Survey respondent).

341 *“The pictures are alright... but I think they should use babies of different races in*  
342 *here. Have a picture of an Asian child, a French.... if you can include fair and*  
343 *brown kids with rashes, to indicate also how does it look like... Instead of fair skin*  
344 *and then the redness of it...” (P008, Interview Participant)*

345 Of the survey respondents who had received and used the LOB, 92.60% felt that the information was  
346 easy to understand. Participants reported that the information was “*simply written*” (P006 Survey



347 respondent), not too “*medically complex*” (P036, Survey Respondent) and “*concise and relevant*”  
348 (P007, Interview Participant). Conversely, some participants critiqued the amount of information  
349 provided but some appreciated the delicate balance with providing detailed information and the size  
350 and usability of the resource.

351 *“...I wouldn’t like to see the book being too bulky, if I’m honest, because it is a*  
352 *quick reference guide. And I think that’s what it should be used for. But I do think*  
353 *there could be a little bit more context to it.” (P003, Interview Participant)*

354 Participants had varied preferences regarding whether the book should be available as a hard copy,  
355 digital version (online) or as a digital application (app). For some participants, a mobile app would be  
356 more accessible and useful however others valued a paper-based resource.

357 *“There’s something about having a hard copy in your hand there, particularly if*  
358 *you’ve got a little one there you know, and you’re dealing with a screaming child*  
359 *and you’re kind of stressed... (P010, Interview Participant)*

360 Additional comments related to the design, format and content included that the resource should  
361 signpost to other resources, such as mental health support services and paediatric first-aid training.

362

## 363 **Discussion and Recommendations for Practice**

364 The findings of this study support assertions that parents have a range of information needs with  
365 regarding their child’s health and healthcare. Parents described a sense-making process in which  
366 feelings of stress and anxiety were present but highlighted the potential of health information to reassure  
367 and signpost to available services. In doing so, the LOB was seen as valuable in supporting parental  
368 and carer decision-making about managing common childhood symptoms of illness. Many participants  
369 reported the LOB had increased their knowledge of common complaints but also helped them to decide  
370 whether there was a need to contact healthcare services; previous research has suggested that these are  
371 two key factors in increasing the appropriate utilisation of health services [1,7,8]. This aligns with the

372 purpose of the LOB which was intended to help parents and carers use services appropriately. The LOB  
373 was found to particularly benefit new parents and those with an age gap between their children;  
374 expectant and new parents have been identified as having specific educational needs which include a  
375 need to understand 'what is normal' and reduce levels of anxiety [13]. Here, this suggests there is a real  
376 need for information and support during these key stages.

377 Some participants reported trusting the LOB due to this being an NHS resource. However, there was  
378 also a need to enhance the resource, particularly in relation to improving inclusivity but also  
379 consistency. There were examples where other services, such as pharmacies and nurseries, had different  
380 practices from those outlined in the LOB. This is a key challenge for both healthcare professionals and  
381 the recipients of advice and is known to be increasingly important as the sources of information about  
382 health increase [14]. Whilst it is difficult to understand the full impact of receiving conflicting  
383 information, it is known that this can lead to confusion as well as criticism and mistrust of services [14]  
384 and highlights the need for joined-up policy and information practices. The consequences may be linked  
385 to levels of health literacy and empowerment and so may affect some service users more than others.  
386 What must be noted is that the sample included in this evaluation may not be reflective of the wider  
387 population as 80% of participants were in employment and 65.86% were educated to degree level or  
388 above. This could suggest a link between educational attainment and increased likelihood of using the  
389 LOB, as well as levels of confidence and ability to use a range of sources of information to make  
390 appropriate decisions. Wider literature notes the well-established link between education and health and  
391 the widening health gap between those who are less educated than their peers [15]. Although  
392 educational attainment does not necessarily mean in-depth knowledge of child health, it does increase  
393 the ability to access, understand and use healthcare information [16]. Therefore, it is important that  
394 work is done to ensure that all families have access to relevant information to care for their children.  
395 This should incorporate a range of different approaches including resources such as the LOB and  
396 materials in both hard copy and digital formats, which was noted as beneficial in this evaluation, as well  
397 as the support of key services.

398 Consideration should be given to how resources such as the LOB are distributed but also how parents  
399 are guided in their use. This evaluation suggested that universal services, such as midwives and health  
400 visitors, are well placed to distribute hard copies of the LOB and raise awareness of digital access, and  
401 that these interactions may be valuable opportunities for healthcare professionals to signpost parents.  
402 This connects well with their role in supporting children and families. Indeed, in recent years there has  
403 been renewed political emphasis on the importance of supporting parents/carers during the first 1001  
404 days of life and governmental ambitions to provide joined-up support, as well as information for  
405 families when needed [17]. It must be noted that these ambitions are set against a backdrop of challenges  
406 for the health and social care sector in relation to long-term funding and staff shortages. Of particular  
407 note is the impact on key services, such as health visiting, which are tasked with delivering this agenda  
408 in the presence of immense challenges for parents and families, including the cost-of-living crisis,  
409 increased numbers of parents living with mental health problems and increased prevalence of domestic  
410 abuse and adversity, all posing real risks to the health and wellbeing of babies and young children [18].  
411 Alongside this, there has been increasing recognition that there are insufficient health visitors to meet  
412 the needs of families with a loss of almost 40% of the health visiting workforce since 2015 [18]. This  
413 is perhaps where resources such as the LOB play an important role. Indeed, this evaluation found that  
414 during the pandemic, the LOB was valuable in the context of limited access to services and the message  
415 to stay home, however some parents felt strongly that the LOB was a mechanism to deter the use of  
416 services. This underlines the need for the LOB to be explained and used to compliment, rather than  
417 replace other forms of support.

418 A key strength of this evaluation is that the overwhelming support for the LOB as an intervention was  
419 consistent with findings of a previous evaluation, which included professionals and service users [9].  
420 This suggests that there is a real need for educational and decision-making resources, although as  
421 mentioned previously this is perhaps reflective of the high levels of educational attainment in the  
422 sample. The mixed methods approach allowed us to capture the views of 128 participants and to ask in-  
423 depth questions about the use of the LOB. Whilst the respondents were overwhelmingly mothers, the  
424 sample did include some fathers, foster carers, adoptive parents and parents of minority ethnic origin.

425 A larger sample still might increase diversity and provide more insight into how the LOB could be  
426 developed and meet the needs of more parents/carers.

427 Resources such as the LOB can provide important information to support parents and carers in decision-  
428 making. However, this evaluation shows that careful thought should be given to how they are  
429 developed, delivered and integrated with other local services to have wider benefit to all parents and  
430 carers. This includes reviewing how inclusive the content is but also conducting evaluations such as  
431 this to determine who is using the resource and how, and identifying groups who may not be accessing  
432 appropriate information resources but have support needs with regards to making decisions about  
433 children's healthcare. The overwhelming support for the LOB suggests that it needs to be more widely  
434 embedded across Newcastle and Gateshead but equally that the resource is likely to be of benefit to  
435 parents and carers beyond these locations.

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505 [young-children-are-missing-out-on-the-governments-promise-of-the-best-start-in-life/](https://ihv.org.uk/news-and-views/news/health-visitor-survey-finds-that-more-babies-and-young-children-are-missing-out-on-the-governments-promise-of-the-best-start-in-life/)  
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507

## 508 **Supporting Information**

509 Ethics Approval

510 Survey

511 Data Availability Statement

512 Financial Disclosure Statement

513