

2020-11-17

'How to recognize if your child is seriously ill' during COVID-19 lockdown: An evaluation of parents' confidence and health-seeking behaviors

Lim, E

<http://hdl.handle.net/10026.1/16467>

10.3389/fped.2020.580323

Frontiers in Pediatrics

Frontiers Media

All content in PEARL is protected by copyright law. Author manuscripts are made available in accordance with publisher policies. Please cite only the published version using the details provided on the item record or document. In the absence of an open licence (e.g. Creative Commons), permissions for further reuse of content should be sought from the publisher or author.

‘How to recognize if your child is seriously ill’ during COVID-19 lockdown: An evaluation of parents’ confidence and health-seeking behaviors

1 Emma LIM^{1,2}, Ravi D. MISTRY¹, Alexandra BATTERSBY^{1,2}, Kerry DOCKERTY³, Aaron
2 KOSHY⁴, Michelle CHOPRA⁵, Matthew C. CAREY⁶, Jos M. LATOUR^{6,7*}

3

4 **Journal: Frontiers in Pediatric**

5 **Acceptance date: 2 October 2020**

6

7 ¹Great North Children’s Hospital, Newcastle Upon Tyne, United Kingdom.

8 ²Population Health Science Institute, Newcastle University, Newcastle upon Tyne, United Kingdom

9 ³Department of Nursing, Midwifery and Health, Northumbria University, Newcastle, United
10 Kingdom.

11 ⁴Faculty of Medicine and Health, University of Leeds, Leeds, United Kingdom.

12 ⁵Paediatric Anesthesia, University Hospitals Plymouth NHS Trust, United Kingdom.

13 ⁶School of Nursing and Midwifery, Faculty of Health: Medicine, Dentistry and Human Sciences,
14 University of Plymouth, Plymouth, United Kingdom.

15 ⁷Department of Nursing, Hunan Children’s Hospital, Changsha, China.

16 ***Correspondence:**

17 Jos M. LATOUR, University of Plymouth, Plymouth, United Kingdom, jos.latour@plymouth.ac.uk

18 **Keywords:** COVID-19, Parents, Confidence, Anxiety, Health Behavior, Children, Social Isolation,
19 Impact

20 **ABSTRACT**

21 **Background:** Parents' health-seeking behaviors has changed during the COVID-19 pandemic.
22 Providing parents' guidance in decision-making might improve their confidence to seek timely
23 advice when a child becomes ill. The aim of this study was to evaluate the 'How to recognize if your
24 child is seriously ill' leaflet on parents' confidence, health-seeking behaviors, and usefulness during
25 the COVID-19 lockdown.

26 **Method:** A 9-item survey, co-designed with parent advisors, was used measuring confidence and
27 health-seeking behavior. Social media was used for data collection in a 6-week period (April–June
28 2020) during COVID-19 lockdown in the UK. Categorical data were analyzed as frequencies and
29 inductive content analysis was performed with the qualitative data.

30 **Results:** Totally, 171 parents responded. Most parents (n=160, 93.6%) found the leaflet helpful. The
31 leaflet increased the confidence among 116 parents (67.8%) to recognize if their child is ill and 156
32 (91.2%) parents had a better understanding of when and where to seek help. Thirty-three (19.2%)
33 parents used the leaflet while their child was unwell during COVID-19 lockdown and in 14 (42%)
34 cases, the leaflet resulted in changing health-seeking behavior for that episode. Twelve of these
35 parents decided to seek medical consultation when they had not planned to before. Content analysis
36 revealed three categories. 1) Knowledge; parents found the leaflet an objective source to validate
37 their concerns. 2) Usability; parents reported the leaflet was clearly designed. 3) Decision-aid;
38 parents commented the leaflet provided clarification around recognition of serious symptoms and
39 when and where to seek appropriate care.

40 **Conclusions:** Our leaflet provided parents guidance on decision-making and risk-assessment of ill
41 children during COVID-19 lockdown. Parents found it helpful; it increased their confidence and
42 positively changed their health-seeking behaviors. Providing parents with targeted information to
43 recognize serious illness in children at home could potentially foster self-care and safely maintain a
44 reduction of pediatric emergency attendances for self-limiting illnesses.

45 **INTRODUCTION**

46 The COVID-19 pandemic has been marked by the sense of fear and anxiety experienced by both
47 children and families (1, 2). The difference between the COVID-19 pandemic compared to other
48 epidemics is the mandated social isolation and distancing measures. Closure of schools and nurseries
49 has had a huge impact on families with children (3).

50 Pediatric emergency departments have experienced a significant drop in attendances during the first
51 months of lockdown (4). Rates of presentation have fallen by 70% since the start of the pandemic and
52 a report from Italy documented an increase in delayed presentations resulting in avoidable harms and
53 increased pediatric intensive care admissions (5). Parents of unwell children might delay contacting
54 healthcare services fearing nosocomial infection, being isolated from their child or not wanting to
55 burden the hospital during the pandemic. There were concerns from pediatricians that unwell
56 children were more likely to be affected by non-COVID-19 related disease and collateral damage
57 from delayed presentation could be significant. However, a recent study in the UK reported that
58 delayed presentations at emergency departments was rare (4).

59 The COVID-19 pandemic has challenged hospitals in preparing effective response systems (6).
60 Providing and disseminating timely, clear and reliable information for parents has been challenging.
61 The UK National Health Service (NHS) provided guidance for COVID-19 patients in primary care
62 and family doctors services (7). For children, COVID-19 information has been described and
63 explained by Alberca and colleagues (8), and children’s hospitals created webpages to inform
64 children and families (9).

65 Prior to the COVID-19 pandemic, our team of parents and healthcare professionals developed a
66 parent decision-making and risk assessment leaflet (10) for parents to identify early deterioration of a
67 seriously ill child, including *parental concern* as a trigger to escalate care (11). Due to the decrease in
68 pediatric emergency department (PED) attendances at the early stages of the COVID-19 pandemic,
69 we published our leaflet on the hospital website in February 2020 to support parents in the
70 community. We considered that this intervention would give parents the confidence to access timely
71 healthcare services. To our knowledge, there is limited evidence assessing the impact of advice
72 around healthcare seeking behavior and parental information during the COVID-19 pandemic.

73 The aim of this study was to evaluate the experiences of parents using this decision-making and risk
74 assessment leaflet for a potentially seriously ill child during COVID-19 lockdown. More specifically,
75 we explored the confidence of parents, their health-seeking behaviors, and usefulness of the leaflet.

76 **MATERIALS AND METHODS**

77 An observational service evaluation design was adopted. The ‘Guidelines for Reporting Evaluations
78 based on Observational Methodology’ (GREOM) was used to report this study (12).

79 The Research and Design Service of the Newcastle Upon Tyne Hospitals NHS Foundation Trust
80 approved this study as a service evaluation. The survey was anonymous, and confidentiality of
81 information was assured.

82 **Parent Leaflet**

83 The parent decision-making and risk assessment leaflet ‘How to recognize if your child is seriously
84 ill’ was developed with parents for parents (**Electronic Supplement Material 1**). The content was

85 designed using the NICE ‘Fever in under 5s: assessment and initial management’ (13), pediatric
86 sepsis guidelines, sepsis leaflets for parents (14-16), and studies reporting signs and symptoms of
87 children presenting to pediatric emergency departments (17, 18). Based on the available evidence, the
88 content of the risk assessment symptoms refers to pre-school and primary school children, generally
89 below 12 years of age. Some symptoms have been included when these are specifically related to
90 children below one year or one months of age.

91 The leaflet includes two main sections. The first section explains how to use the leaflet and provides
92 space to write down the details of the child and parental concerns. Additional practical tips and
93 medication use are included. The second section is divided into green, amber, and red with guidance
94 for decision-making of where and how to seek health advice. The risk assessment includes six
95 systems: 1) temperature; 2) breathing; 3) skin, lips and tongue; 4), eating and drinking, 5)
96 toilet/nappies; and 6) activity and body.

97 Ten parents from a local parent support group reviewed the content of the leaflet and compared it
98 with another leaflet (19) published by the Royal College of Paediatrics and Child Health (RCPCH)
99 during the early stages of the COVID-19 pandemic. Overall, there was consensus that our parent
100 decision-making and risk assessment leaflet was preferred as it included parental concern,
101 sufficiently detailed information, and options to write down observations.

102 The distribution of the parent leaflet was implemented without manipulation and could be used in the
103 everyday context during the COVID-19 lockdown. The evaluation was conducted via an online
104 survey with a minimum number of questions designed to be completed in less than five minutes to
105 reduce the burden to respondents during COVID-19 lockdown and was considered a low intensity
106 intervention in the context of the observational methods.

107 **Participants and Recruitment**

108 Participants were parents, carers or guardians of children in the North East of England during the
109 COVID-19 lockdown. The population in the North East of England is around 320,000 and the last
110 census in 2011 documented that 97% of the population described themselves as white British (20).

111 We anticipated a sample size of around 100 parents based on previous work evaluating a parent
112 sepsis leaflet in the South West of England (21). The sample size depended on the voluntary
113 engagement of parents in the community and the promotion of the leaflet. Inclusion criteria were
114 parents, caretakers or guardians with children who downloaded the parent leaflet and the attached
115 invitation with a website-link to complete a short online survey.

116 The method of recruitment was via social media. The leaflet and an invitation to participate was
117 distributed via Twitter, Facebook, and the website of our hospital. Local schools, social services, and
118 COVID-19 support groups informed parents via their chat groups, tweets and messages on Facebook
119 containing a link to the leaflet and online survey.

120 The lockdown in the UK started on 12 March 2020 and was eased on 15 June 2020 allowing the
121 opening of non-essential shops. The recruitment time via social media was six weeks, from 29 April
122 2020 to the first ease of the COVID-19 lockdown on 15 June 2020. We acknowledged that
123 recruitment via social media might include respondents from outside North East of England.
124 Therefore, we included all respondents in the UK but excluded those outside the UK.

125 **Outcomes and Data Collection**

126 The self-administered online survey was designed to address parent's confidence, health-seeking
127 behavior, and general experience of the leaflet. The survey was developed together with our local
128 parent advisory group. Ten parents reviewed the draft of the survey and minor suggestions were
129 provided to improve clarity of the questions and answer option scales. Parents agreed that the final
130 10-item survey was acceptable to complete in the current COVID-19 climate.

131 The final survey included eight closed questions and two optional open-ended questions (**Electronic**
132 **Supplement Material 2**). The first three questions were demographic questions followed by
133 questions measuring health-seeking behavior, experience of the leaflet, and confidence. Two open-
134 ended questions were included to provide parents the option of sharing their experiences and
135 opinions.

136 **Data Analysis**

137 The quantitative analyses were performed using IBM-SPSS version 25.0 (IBM, New York, NY,
138 USA). Categorical data are presented as frequency in percentages. The responses of the two open-
139 ended questions were analyzed by inductive content analysis (22). This included open coding of the
140 narratives and grouping into sub-categories. Abstraction was further enhanced by generating
141 categories described by content-characteristic words.

142 **RESULTS**

143 During the six-week data collection, 171 parents responded to the online survey. Of the 170
144 respondents who completed the postcode question, 148 (86.5%) were living in the North East of
145 England and 22 (13.5%) were living in the rest of the UK. Half of the parents (n=87; 50.9%) reported
146 having two children in their household followed by 46 (26.9%) parents having one child (**Table 1**).
147 Most of the parents (n=159, 93%) were white British reflecting the population ethnicity in the North
148 East of England (**Table 1**).

149 In terms of health-seeking behaviors and first point of contact when their child is unwell, 87 (50.9%)
150 of the parents reported that they usually visit and seek advice from their family doctor. A further 59
151 (34.5%) parents reported that they first would call NHS 111, a free non-emergency medical helpline.
152 Only 14 (8.2%) parents reported that they would visit the emergency department (**Table 2**).

153 Overall, most parents perceived the leaflet as being helpful (93.6%). Of these, 89 (52%) parents
154 found the leaflet very helpful and 71 (41.5%) as somewhat helpful. The leaflet increased the
155 confidence of parents (n=116, 67.8%) in recognizing if their child is seriously ill (**Table 2**).
156 Furthermore, 156 (91.2%) parents reported that they had a better understanding of when and where to
157 seek help. There were 33 (19.3%) parents who used the leaflet while their child was unwell and in 14
158 (42%) cases the leaflet resulted in changing health-seeking behavior for that episode. Of these, 12
159 parents chose to take their child to seek medical attention where they hadn't planned to before and 12
160 of these 14 parents reported an increased in confidence in recognizing if their child was unwell. In
161 the group of parents where their health-seeking behavior was not changed (n=19) only 10 parents
162 reported an increased in confidence.

163 Content analysis of the free text responses revealed three categories: Knowledge, Usability and
164 Decision-aid (**Table 3**). The category Knowledge included three sub-categories where parents
165 commented on the leaflet as being an objective source to validate their concerns. Parents wrote that
166 the leaflet was an *essential resource* while staying at home. The leaflet was valued by parents
167 because of the *age-specificity* of some of its information. This helped parents in their *medical*

168 *assessment* when their child was becoming sick. The category Usability included the sub-categories
 169 *linguistic clarity* and *visual clarity* where parents reported that the leaflet was clearly designed
 170 including the traffic light color coding system on when and how to seek medical attention. The
 171 category Decision-aid had two sub-categories. The sub-category *response calibration* was related to
 172 the systematic breakdown of symptoms that provided clarification about what to observe, when to
 173 make the decision to seek further advice and who to contact. Some parents reported that the leaflet
 174 gave them more *confidence* in their decision-making.

175 The same categories were used in analyzing the free-text responses related to suggestions for
 176 improvements (**Table 4**). In the Knowledge category, the *risk guidance* was deemed to be unclear by
 177 some parents and they cautioned over the ambiguity of symptoms to seek help in the amber category
 178 of the leaflet. The category Usability included comments on the *linguistic* and *visual clarity*. Two
 179 parents commented that the leaflet could be written in easier language as the leaflet could be
 180 challenging for parents with low literacy skills. Another parent suggested using bullet points rather
 181 than tick boxes before every symptom. In the Decision-aid category, parents suggested that the leaflet
 182 could increase *confidence* by emphasizing parental concern (or gut instinct) more prominently. Three
 183 parents highlighted that the leaflet does not cover specific emergencies such as anaphylaxis, diabetic
 184 ketoacidosis and febrile convulsions or meningitis.

185 **DISCUSSION**

186 This project aimed to explore the experiences of parents using an information leaflet to help them
 187 recognize serious illness in their children and respond appropriately during the COVID-19 lockdown.
 188 The leaflet provided parents with detailed information to support decision-making and seek timely
 189 medical advice. Our leaflet was co-produced with local parents via an iterative process. Information
 190 material that is co-produced and evaluated by target stakeholders has been shown to be more
 191 effective in improving knowledge and health-seeking behaviors (23).

192 Parents of unwell children are in a position of vulnerability and are aware of being perceived as
 193 worriers by healthcare professionals and their friends/family (24, 25). Parents fear hospital
 194 attendance with its perceived risks while social distancing has removed normal access to formal and
 195 informal social support structures. Febrile illnesses increases parental anxiety (26), especially when
 196 other symptoms are already present (25). This was clearly heightened during the COVID-19
 197 pandemic (27), especially with fever being a central tenet of the case definition. Parents desire a clear
 198 source of information that they can independently access to empower themselves, validate their
 199 concerns and reassure them that they have taken the appropriate course of action when caring for
 200 their febrile child (25). Our leaflet provided this through detailed and comprehensive information.

201 Baseline knowledge is vital and gaps in parents' knowledge have been identified; most parents
 202 cannot identify the temperature at which a child is said to be febrile (25). This has resonance with our
 203 findings as many respondents commented positively on our inclusion of age-specific temperature
 204 thresholds. Supplying information on management is crucial to guide appropriate and timely use of
 205 healthcare services for parents and avoid unnecessary consultations (28). Importantly, comprehensive
 206 multi-topic information on febrile illness is more effective at reducing parental anxiety and increasing
 207 confidence than single differentials of fevers (26). This is because children often present with a
 208 constellation of symptoms alongside a fever.

209 Most parents in our study would see their GP first. This health-seeking behavior is well established
 210 with parents in high-income countries (25). Often parents consult printed or electronic reference

211 material before deciding what course of action to take (26). There is limited evidence on parents'
212 health-seeking behavior during COVID-19. The NHS has noted a one-third drop in emergency
213 department attendances (29) and GP appointments (30) coupled with a 50-times rise in online triage
214 information being accessed (31) during the current outbreak. This indicates many more people are
215 seeking authoritative reference material prior to attending and suggests there is an opportunity to
216 influence primary care and PED attendance.

217 Several limitations need to be addressed. We used an online web-based survey and recruitment via
218 social media both of which could have resulted in selection bias. Parents who have limited access to
219 social media platforms, the internet, computers or smartphones may not have had the opportunity to
220 be included or been able to access the leaflet. This may be a particular issue in socially deprived areas
221 or in middle- and low-income countries without ready internet access. Newcastle-upon-Tyne has
222 large socially deprived areas and we worked together with local charities such as the Newcastle West
223 End Schools Trust and Newcastle local authority and agencies affiliated with the West Partnership
224 who kindly supported the project in printing and distributing the parent leaflet to ensure wide access.
225 We also received support from community groups, schools and health visitors who were willing to
226 advertise the parent leaflet on their websites. We also acknowledge the limitation of the short survey.
227 The survey was designed to generate a general understanding of the parents' experiences, confidence
228 and health-seeking behaviors and was intentionally kept short to reduce the burden of parents to
229 complete the survey. Validated instruments exist, such as the 34-item Family Empowerment Scale
230 (32) and the 15-item Karitane Parenting Confidence Scale (33), but are significantly longer to
231 administer.

232 In conclusion, the majority of parents found our parent information leaflet on decision-making and
233 risk-assessment in ill children, helpful and improved their confidence. The leaflet may have changed
234 health-seeking behavior during the COVID-19 social isolation period and contributed to parents'
235 better understanding of when and where to seek medical attention if their child becomes unwell.

236 The silver lining to the COVID-19 pandemic has been the reduction in PED attendances. Providing
237 parents with targeted information when a child becomes seriously ill at home could potentially foster
238 self-care and safely maintain this reduction of PED attendances for self-limiting illnesses. Our study
239 shows parents welcome this information and are actively seeking trusted sources of healthcare
240 information and acting on them. The onus is on healthcare practitioners and institutions to understand
241 this need and deliver quality healthcare support and education widely. Now we need further research
242 to understand the effectiveness of our parent information leaflet during the 'new normal' including
243 children's (long-term) health outcomes, particularly focusing on the most disadvantaged sectors and
244 their access to health information.

245

246 REFERENCES

- 247 1. Fegert JM, Vitiello B, Plener PL, Clemens V. Challenges and burden of the Coronavirus 2019
248 (COVID-19) pandemic for child and adolescent mental health: a narrative review to highlight clinical
249 and research needs in the acute phase and the long return to normality. *Child Adolesc Psychiatry*
250 *Ment Health.* (2020) 14:20. <https://doi.org/10.1186/s13034-020-00329-3>
- 251 2. Rajkumar RP. COVID-19 and mental health: A review of the existing literature. *Asian J*
252 *Psychiatr.* (2020) 52:102066. <https://doi.org/10.1016/j.ajp.2020.102066>

- 253 3. Viner RM, Russell SJ, Croker H, Packer J, Ward J, Stansfield C, et al. School closure and
 254 management practices during coronavirus outbreaks including COVID-19: a rapid systematic review.
 255 *Lancet Child Adolesc Health.* (2020) 4:397-404. [https://doi.org/10.1016/S2352-4642\(20\)30095-X](https://doi.org/10.1016/S2352-4642(20)30095-X)
- 256 4. Roland D, Harwood R, Bishop N, Hargreaves D, Patel S, Sinha I. Children's emergency
 257 presentations during the COVID-19 pandemic. *Lancet Child Adolesc Health.* (2020) online ahead of
 258 print June 26, 2020. [https://doi.org/10.1016/S2352-4642\(20\)30206-6](https://doi.org/10.1016/S2352-4642(20)30206-6)
- 259 5. Lazzerini M, Barbi E, Apicella A, Marchetti F, Cardinale F, Trobia G. Delayed access or
 260 provision of care in Italy resulting from fear of COVID-19. *Lancet Child Adolesc Health.* (2020)
 261 4:e10. [https://doi.org/10.1016/S2352-4642\(20\)30108-5](https://doi.org/10.1016/S2352-4642(20)30108-5)
- 262 6. Zhang Y, Sun Z, Latour JM, Hu B, Qian J. Hospital response to the COVID-19 outbreak: The
 263 experience in Shanghai, China. *J Adv Nurs.* (2020) 76:1483-5. <https://doi.org/10.1111/jan.14364>
- 264 7. Razai MS, Doerholt K, Ladhani S, Oakeshott P. Coronavirus disease 2019 (covid-19): a guide
 265 for UK GPs. *BMJ.* (2020) 368:m800. <https://doi.org/10.1136/bmj.m800>
- 266 8. Alberca G, Fernandes, I., Sato, M., Alberca, R. What Is COVID-19? *Frontiers Young Minds.*
 267 (2020) 8:74. doi: 10.3389/frym.2020.00074
- 268 9. Hospital GOS. Coronavirus (COVID-19) – information for children, young people and
 269 families [https://www.gosh.nhs.uk/news/coronavirus-covid-19-information-children-young-people-](https://www.gosh.nhs.uk/news/coronavirus-covid-19-information-children-young-people-and-families)
 270 [and-families](https://www.gosh.nhs.uk/news/coronavirus-covid-19-information-children-young-people-and-families) (2020) [accessed 5 July 2020]
- 271 10. Hospital TGNCs. How to recognise if your child is seriously ill. [http://www.newcastle-](http://www.newcastle-hospitals.org.uk/assets/media/How_to_recognise_if_your_child_is_seriously_ill.pdf)
 272 [hospitals.org.uk/assets/media/How to recognise if your child is seriously ill.pdf](http://www.newcastle-hospitals.org.uk/assets/media/How_to_recognise_if_your_child_is_seriously_ill.pdf) (2020)
 273 [accessed 5 July 2020]
- 274 11. Harley A, Latour JM, Schlapbach LJ. The Role of Parental Concerns in the Recognition of
 275 Sepsis in Children: A Literature Review. *Front Pediatr.* (2019) 7:161.
 276 <https://doi.org/10.3389/fped.2019.00161>
- 277 12. Portell M, Anguera MT, Chacón-Moscoso S, Sanduvete-Chaves S. Guidelines for reporting
 278 evaluations based on observational methodology. *Psicothema.* (2015) 27:283-9. doi:
 279 10.7334/psicothema2014.276
- 280 13. National Institute of Health and Care Excellence. Fever in under 5s: assessment and initial
 281 management NICE guideline [NG143] <https://www.nice.org.uk/guidance/ng143> (2019) [accessed 5
 282 July 2020]
- 283 14. Latour J, Bracefield S, Sadler P, O'Connor A, Endacott R. Assessment of Early Sepsis in
 284 Children by Parents and General Practitioners: an Evaluation. *Eur J Pediatr.* (2016) 175;1558-9.
- 285 15. Tavaré A, O'Flynn N. Recognition, diagnosis, and early management of sepsis: NICE
 286 guideline. *Br J Gen Pract.* (2017) 67:185-6. <https://bjgp.org/content/67/657/185>
- 287 16. Weiss SL, Peters MJ, Alhazzani W, Agus MSD, Flori HR, Inwald DP, et al. Surviving Sepsis
 288 Campaign International Guidelines for the Management of Septic Shock and Sepsis-Associated
 289 Organ Dysfunction in Children. *Pediatr Crit Care Med.* (2020) 21:e52-e106. doi:
 290 10.1097/PCC.0000000000002198
- 291 17. Elshout G, van Ierland Y, Bohnen AM, de Wilde M, Oostenbrink R, Moll HA, et al. Alarm
 292 signs and antibiotic prescription in febrile children in primary care: an observational cohort study. *Br*
 293 *J Gen Pract.* (2013) 63:e437-44. <https://bjgp.org/content/63/612/e437>

- 294 18. van Ierland Y, Elshout G, Moll HA, Nijman RG, Vergouwe Y, van der Lei J, et al. Use of
 295 alarm features in referral of febrile children to the emergency department: an observational study. *Br*
 296 *J Gen Pract.* (2014) 64:e1-9. <https://bjgp.org/content/64/618/e1>
- 297 19. Royal College of Paediatrics and Child Health. Advice for parents during coronavirus.
 298 [https://www.rcpch.ac.uk/sites/default/files/2020-](https://www.rcpch.ac.uk/sites/default/files/2020-04/covid19_advice_for_parents_when_child_unwell_or_injured_poster.pdf)
 299 [04/covid19 advice for parents when child unwell or injured poster.pdf](https://www.rcpch.ac.uk/sites/default/files/2020-04/covid19_advice_for_parents_when_child_unwell_or_injured_poster.pdf) (2020) [accessed 5 July
 300 2020]
- 301 20. Jamieson M, Northumberland County Council. Ethnicity and Religion in Northumberland:
 302 Northumberland Knowledge Research Report.
 303 [https://www.northumberland.gov.uk/NorthumberlandCountyCouncil/media/Northumberland-](https://www.northumberland.gov.uk/NorthumberlandCountyCouncil/media/Northumberland-Knowledge/NK%20people/Demographics/Ethnicity-and-Religion-March-2013.pdf)
 304 [Knowledge/NK%20people/Demographics/Ethnicity-and-Religion-March-2013.pdf](https://www.northumberland.gov.uk/NorthumberlandCountyCouncil/media/Northumberland-Knowledge/NK%20people/Demographics/Ethnicity-and-Religion-March-2013.pdf) (2013) [accessed
 305 5 July 2020]
- 306 21. Latour J, Bracefield S, Sadler P, Endacott R, O'Connor A. Early Sepsis in Children
 307 Assessment by Parents: an Evaluation.
 308 [https://pearl.plymouth.ac.uk/bitstream/handle/10026.1/15571/EarlySepsisChildrenAssessmentParents](https://pearl.plymouth.ac.uk/bitstream/handle/10026.1/15571/EarlySepsisChildrenAssessmentParentsEvaluation_ESCAPE-Report_20160216.pdf?sequence=1&isAllowed=y)
 309 [Evaluation_ESCAPE-Report_20160216.pdf?sequence=1&isAllowed=y](https://pearl.plymouth.ac.uk/bitstream/handle/10026.1/15571/EarlySepsisChildrenAssessmentParentsEvaluation_ESCAPE-Report_20160216.pdf?sequence=1&isAllowed=y) (2016) [accessed 5 July
 310 2020]
- 311 22. Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs.* (2008) 62:107-15.
 312 <https://doi.org/10.1111/j.1365-2648.2007.04569.x>
- 313 23. van de Maat JS, van Klink D, den Hartogh-Griffioen A, Schmidt-Cnossen E, Rippen H, Hoek
 314 A, et al. Development and evaluation of a hospital discharge information package to empower
 315 parents in caring for a child with a fever. *BMJ Open.* (2018) 8:e021697.
 316 <http://dx.doi.org/10.1136/bmjopen-2018-021697>
- 317 24. De S, Tong A, Isaacs D, Craig JC. Parental perspectives on evaluation and management of
 318 fever in young infants: an interview study. *Arch Dis Child.* (2014) 99:717-23. doi:
 319 10.1136/archdischild-2013-305736
- 320 25. Thompson AP, Nesari M, Hartling L, Scott SD. Parents' experiences and information needs
 321 related to childhood fever: A systematic review. *Patient Educ Couns.* (2020) 103:750-63.
 322 <https://doi.org/10.1016/j.pec.2019.10.004>
- 323 26. Neill S, Roland D, Jones CH, Thompson M, Lakhanpaul M. Information resources to aid
 324 parental decision-making on when to seek medical care for their acutely sick child: a narrative
 325 systematic review. *BMJ Open.* (2015) 5:e008280. doi:10.1136/bmjopen-2015-008280
- 326 27. Ebrahim AH, Saif ZQ, Buheji M, AlBasri N, Al-Husaini FA, Jahrami H. COVID-19
 327 information-seeking behavior and anxiety symptoms among parents. *OSP J Health Care Med.* (2020)
 328 1:1-9.
- 329 28. de Bont EG, Loonen N, Hendrix DA, Lepot JM, Dinant GJ, Cals JW. Childhood fever: a
 330 qualitative study on parents' expectations and experiences during general practice out-of-hours care
 331 consultations. *BMC Fam Pract.* (2015) 16:131. <https://doi.org/10.1186/s12875-015-0348-0>
- 332 29. NHS England. A&E Attendances and Emergency Admissions.
 333 <https://www.england.nhs.uk/statistics/statistical-work-areas/ae-waiting-times-and-activity/> (2020)
 334 [accessed 5 July 2020]

- 335 30. NHS Digital. Appointments in General Practice - March 2020. [https://digital.nhs.uk/data-](https://digital.nhs.uk/data-and-information/publications/statistical/appointments-in-general-practice/march-2020)
336 [and-information/publications/statistical/appointments-in-general-practice/march-2020](https://digital.nhs.uk/data-and-information/publications/statistical/appointments-in-general-practice/march-2020) (2020)
337 [accessed 5 July 2020]
- 338 31. NHS Digital. Coronavirus (COVID-19) increase in use of NHS Digital tech.
339 <https://digital.nhs.uk/coronavirus/nhs-digital-tech-analytics#nhs-111-online> (2020) [accessed 5 July
340 2020]
- 341 32. Koren PE, DeChillo N, Friesen BL. Measuring Empowerment in Families Whose Children
342 Have Emotional Disabilities: A Brief Questionnaire. *Rehab Psychol.* (1992) 37:305-21.
- 343 33. Crncec R, Barnett B, Matthey S. Review of scales of parenting confidence. *J Nurs Meas.*
344 (2010) 18:210-40. doi: 10.1891/1061-3749.18.3.210

345 **Conflict of Interest**

346 The authors declare that the research was conducted in the absence of any commercial or financial
347 relationships that could be construed as a potential conflict of interest.

348 **Author Contributions**

349 EL, AB, KD, and JML developed the intervention. EL, AB, KD, AK, MCh, MCh and JML initiated
350 the evaluation and contributed to the design of the study. EL, AB, KD, RM contributed to the data
351 collection. EL, RM, MCh, JML contributed to the data analysis and interpretation. EL and JML
352 drafted the first manuscript. All authors contributed to manuscript revisions and approved the final
353 version of the manuscript. All authors agree to be accountable for the content of the work.

354 **Funding**

355 No funding.

356 **Acknowledgments**

357 The authors like to thank all parents who have been involved in the development of the leaflet. We
358 like to thank Joanne Mulholland and Annemarie Troy-Smith for their support and valuable advice on
359 the leaflet. We thank all parents for completing the survey during the COVID-19 lockdown; your
360 advice has been invaluable.

361 **Data Availability Statement**

362 The dataset is available from the corresponding authors upon request.

363 **Table 1.** Characteristics of participants (n=171)

Parents	n (%)
Number of children in household	
1	46 (26.9)
2	87 (50.9)
3	33 (19.3)
4	5 (2.9)
Ethnicity	
White British	159 (93.0)
White other	4 (2.3)
White and Asian	2 (1.2)
White and Black African	2 (1.2)
White Irish	1 (0.6)
Indian	1 (0.6)
Black or Black British	1 (0.6)
Other Mixed	1 (0.6)
Region in UK	
North East of England	148 (86.5)
Rest of UK	22 (13.5)

364

365 **Table 2.** Experiences of parent information leaflet (n=171)

Parents	n (%)
What would you normally do if you were worried about your ill child?	
A&E	14 (8.2)
NHS 111	59 (34.5)
Home	2 (1.2)
GP	87 (50.9)
Walk-in center	9 (5.2)
How helpful did you find this leaflet?	
Very helpful / somewhat helpful	160 (93.6)
Neutral	10 (5.8)
Not helpful at all / a little unhelpful	1 (0.6)
After reading this leaflet, how do you feel about recognizing if your child is seriously ill?	
More confident	116 (67.8)
The same	55 (32.2)
Less confident	0
After reading this leaflet, do you have a better understanding of when and where to seek the right healthcare for your ill child?	
No better	15 (8.8)
A bit better	90 (52.6)
A lot better	66 (38.6)
If you are using this because your child is unwell: was this decision different to what you thought before?	
Yes, seek medical attention	12 (7.0)
Yes, didn't seek medical attention	2 (1.2)
The same	19 (11.1)
Not applicable	138 (80.7)

366 A&E=Emergency department; GP=General Practitioner (family doctor).

367

368 **Table 3.** Parent’s experiences of leaflet

Categories	Sub-categories	Narratives
Knowledge	Essential resource	This sort of thing should be given to new parents on discharge from NICU or postnatal wards too I feel especially at the moment. (R65) Concise and something that can stay in inside of cupboard where medicines are kept. (R132)
	Age-specificity	I liked that there was more specific advice for newborns and under ones as often information is not at all age specific. (R43) The exact temperatures for various ages are useful. (R13)
		My child is under 1 and I now feel I like more of the signs to look out for in his age group (R74)
	Medical assessment	It makes it simpler to assess symptoms as serious or less serious. It brings lots of information into one place that is easy to use. (R72) It has lots of signs to look out for which some parents might not know what to look out for. (R2) It helps focus your mind on the signs that potentially are the more serious ones to look for and separate those out clearly to help you make more of an informed decision about what person/service you should contact or what care might be suitable. (R65)
Usability	Linguistic clarity	I found the leaflet very informative and well structured. I like how it has clear points [...] and think it is really easy to follow. (R66) Very informative leaflet with clear information (R165)
	Visual clarity	The traffic light system is excellent and simple to understand (R65) good to have a checklist to refer to especially when worried about your child (R135)
Decision-aid	Response calibration	It helped clarify the difference between seeking the GP’s advice and going to hospital (R80) It’s good to see it broken down in terms of symptoms and response need (R119)
	Confidence	There were times when my children were younger when in hindsight I should have taken them in to hospital. It was have bolstered my confidence that I wasn’t “making a fuss” if I’d read this. (R119) Much more information than you can usually get from leaflets. It would make me more confident and less likely to start googling which usually makes things even more confusing! (R43)

369
370

371 **Table 4.** Suggestions provided by parents

Categories	Sub-categories	Narratives
Knowledge	Risk Guidance	The only question i have is in the Amber bit. Child not quite right, this would fit for both children every time they are ill but they don't always need healthcare. (R139)
		I was only a little confused by amber - if they show just 1 of these symptoms is it amber or is it several. the red seemed clearer in that all those symptoms would alarm me and it's reassuring that I'm right to be alarmed and just get hold of emergency services. (R172)
		High risk factors are obvious and clear. The Amber ones could be taken out of context. What if baby just has one of those listed, is that enough to be worried? Some of those symptoms could relate to something else and not a cause a great deal of concern (R112)
Usability	Linguistic clarity	Some of the language could be simpler. Especially in last page management of fever. Do not give child shower or cold cloths as will spike temperature. Do not lower temperature too quickly. The language on alternating paracetamol and ibuprofen could be clearer too. (R128) Although I can understand it there is a lot of writing which pay but [may put] some people off from looking at it. Especially those with limited English or poor literacy skills (R26)
	Visual clarity	The squares in the red and amber make it a tick list - like you are counting symptoms- that's not message is it? It's if your child has any of these symptoms. It should be bullet points. (R47)
Decision-aid	Confidence	The 'less interested' statement Is really vague it would be better to have something about parents instinct that something wrong. (R102)
	Disease-specific advice	Information about febrile seizures would be useful to include. Like what to do if they have a seizure. (R128)

372

373

Supplementary Material 1

374

375

376 **‘How to recognize if your child is seriously ill’ during COVID-19 lockdown: A service evaluation of parents’ self-confidence and**
377 **health-seeking behaviors**

378

379 Emma LIM, Alexandra BATTERSBY, Kerry DOCKERTY, Ravi MISTRY, Aaron KOSHY, Michelle CHOPRA, Matthew CAREY,
380 Jos M. LATOUR

381

382

383 **Supplementary File 1: The parent decision-making and risk assessment leaflet ‘How to recognize if your child is seriously ill’**

384

385



The Newcastle upon Tyne Hospitals
NHS Foundation Trust

Practical Things You Can Do to Help Your Child

- Check your child during the night to see if they are getting better.
- If you are concerned that your child is not improving or has new symptoms (such as a new rash) follow the advice on the front of this leaflet.
- If your child is hot to touch, take their temperature with a thermometer.
- Children with fever should not be under, or over, dressed. If your child is hot to touch remove a layer of their clothing.
- Tepid sponging is no longer recommended for the treatment of fever.
- Offer your child regular drinks (where a baby is breastfed, the most appropriate fluid is breast milk).
- If your child is due to have immunisations please consult your GP, Practice Nurse or Health Visitor for advice — there may be no need to delay their appointment.
- If you need to keep your child away from nursery or school while they are unwell and have a fever please notify the nursery or school. Your Health Visitor, Community Nurse or GP will be able to advise you if you are unsure.
- Keep a diary of symptoms.

Using Medication to Help

- If your child is distressed or very unwell you may use Paracetamol or Ibuprofen to help them feel more comfortable - however it is not always necessary.
- Don't routinely give both Paracetamol and Ibuprofen at the same time — use one, and if your child has not improved 1-2 hours later you may want to try giving the other medication.
- Please read the instructions on the medication bottle first for dose and frequency. Be aware of the maximum dose which can be given over a 24 hour period.
- You could ask your local community pharmacist for more advice about medication.
- Never give Aspirin to a child.

NHS 111

To contact the NHS 111 service simply dial '111' (free from mobiles and landlines).

If you need language support or translation please inform the member of staff you speak to.



Information for parents and guardians

How to recognise if your child is seriously ill



How to Use This Leaflet

Most children with a fever get better quickly and without problems, but a very small number of children may develop a serious infection with sepsis (a bloodstream infection) that requires urgent treatment in hospital.

The information inside this leaflet is designed to help you monitor your child's condition if they have a raised temperature, so you can know when to ask for help and can describe the symptoms. You need to regularly check your child for changing or worsening symptoms, and follow the advice given to you by health professionals. Please bring this leaflet with you if you re-attend or use another health service.

If you are given this leaflet by a health professional they should fill in the below section with specific advice for you.

Child's Name: Child's Age:

Parent/Carer Name:

Clinician's Name: Date/Time:

Parental concerns:

.....

.....

Specific Safety Netting Advice from Clinician:

.....

.....

.....



GREEN (Low Risk: Self Care Advice)

If none of the above factors are present, use the advice on the next page to provide the care your child needs at home. It's sometimes hard to be sure about particular signs and symptoms. If you feel that your child may be seriously ill, or if something that concerns you is not on these lists, contact your GP or 111 for advice.

AMBER (Medium Risk: Ask for Advice)

Many (but not all) children with these symptoms are seriously unwell and need to be assessed by a health professional promptly. If your child has any of the AMBER symptoms below contact your GP, NHS 111 or walk-in centre promptly.

Temperature

- Raised temperature (more than 37.5°C) for 5 days or more
- Shivering or shaking

Breathing

- Nostrils flaring (change size with each breath)
- Breathing faster than normal
- Breathing that's unusually noisy or sounds 'crackly'
- Cough that sounds like a seal barking

Skin, Lips & Tongue

- Unusually pale skin
- Dry mouth, lips and/or tongue
- Rash that fades when pressed firmly (use a clear glass)

Eating & Drinking

- Baby under 1 year who is not feeding (or taking less than half their usual amount of milk)
- Feeding or eating much less than normal
- Has vomited (been sick) more than twice in the last 24 hours
- Under 1 year old with vomiting and /or diarrhoea

Toilet/Nappies

- Under 1 year old with more than 5 watery poos (diarrhoea) in the last 24 hours
- Only one wee or wet nappy in eight hours

Activity & Body

- Less interested than usual in playing or "not quite right"
- Difficult to wake up or unusually sleepy
- Swelling of a limb or joint
- Not using/putting weight on an arm, leg, hand or foot

AMBER
Contact GP
Practice, Walk-in
Centre or call
'111'

RED (High Risk: Take Action)

Many (but not all) children with these features are seriously unwell. If your child has any of the RED symptoms below they need to be assessed straight away in an Emergency Department (A&E). Dial '999' for an ambulance if necessary.

Temperature

- Temperature over 38°C in babies under 3 months
- Temperature over 39°C in babies aged 3 to 6 months
- Any high temperature in a child who cannot be encouraged to show interest in anything
- Low temperature (below 36°C, check 3 times in a 10 minute period)

Breathing

- Finding it much harder to breathe than normal – looks like they are working hard
- Making 'grunting' noises with every breath (in newborns this may sound like a lamb bleating)
- Very fast breathing (more than 1 breath each second in babies under 1 year)
- Can't say more than a few words at once (for older children who normally talk)
- Breathing that obviously 'pauses'

Skin, Lips & Tongue

- Skin is blue, mottled (purplish, red) or very pale
- Lips or tongue are bluish
- Eyes look 'sunken'
- Hands and feet are unusually cold to touch
- Rash that does not fade when pressed firmly (use a clear glass)

Eating & Drinking

- Baby under 1 month old with no interest in feeding
- Not drinking for more than 8 hours (when awake)
- Extremely thirsty or unable to keep fluids down
- Persistently vomiting for more than 24 hours
- Bloody, black or brown vomit/sick

Toilet/Nappies

- Not had a wee or wet nappy for 12 hours

Activity & Body

- Soft spot on a baby's head is bulging
- Child is floppy
- Not responding to family or carers, or very irritable
- Weak, 'high pitched' or continuous crying in a younger child
- Hard to wake up, won't stay awake or doesn't seem to recognise you
- Stiff neck, especially when trying to look up and down
- Older children who are confused
- The child has a seizure (a fit)

RED
If you think your child
needs an ambulance or
urgently needs to be seen,
take child to the
Emergency Department
(A&E). Dial '999'
if necessary

Supplementary Material 2; Online Survey

389

390

391

'How to recognize if your child is seriously ill' during COVID-19 lockdown: A service evaluation of parents' self-confidence and health-seeking behaviors

392

393

Emma LIM, Ravi D. MISTRY, Alexandra BATTERSBY, Kerry DOCKERTY, Aaron KOSHY, Michelle CHOPRA, Matthew CAREY, Jos M. LATOUR

Question	Answer option
How many children do you have?	Number
What ethnic group would you put yourself in?	White British; White Irish; Other White; White and Black Caribbean; White and Black African; White and Asian; Other mixed Group; Asian or Asian British; Indian; Pakistani; Bangladeshi; Other Asian Ethnic Group; Black or Black British; Caribbean; African; Other Black Ethnic Group; Chinese, Rather not say; Other
What is the first part of your postcode? For example, NE15 or NE3 (as appropriate)	Open space
What would you normally do if you were worried about your ill child?	<input type="radio"/> Go to A&E <input type="radio"/> Phone 111 <input type="radio"/> Stay at home <input type="radio"/> Go to the GP <input type="radio"/> Go to the walk-in centre
How helpful did you find this leaflet?	1. Not helpful at all 2. Somewhat helpful 3. Neutral 4. A little unhelpful 5. Very helpful
Optional: Please tell us more	Free text
After reading this leaflet, how do you feel about recognising if your child is seriously ill?	<input type="radio"/> Less confident <input type="radio"/> The same <input type="radio"/> More confident
Optional: Please tell us more	Free text
After reading this leaflet, do you have a better understanding of when and where to seek the right healthcare for your ill child?	<input type="radio"/> No better <input type="radio"/> A bit better <input type="radio"/> A lot better
If you are using this because your child is unwell: was this decision different to what you thought before?	<input type="radio"/> Yes, I didn't seek medical attention and I would have stayed at home <input type="radio"/> Yes, I went to seek medical attention and would have stayed at home <input type="radio"/> No, it was the same <input type="radio"/> Not applicable

394