

**EVALUATING THE
LITTLE
ORANGE
BOOK.**

THE RESEARCH TEAM

This evaluation has been conducted by a team of academics and researchers from across the Northeast who are members of FUSE.

FUSE is the Centre for Translational Research in Public Health and operates across the five universities in the northeast: Durham, Newcastle, Northumbria, Sunderland and Teesside.



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CONTENTS

THE RESEARCH TEAM	2
ACKNOWLEDGEMENTS	3
LIST OF TABLES	6
LIST OF FIGURES	7
EXECUTIVE SUMMARY	8
INTRODUCTION	10
COVID-19 and health service use The Little Orange Book	
AIMS	13
Objectives	

METHODS	14
Design Phase One: Online survey and feedback cards Recruitment The online survey Feedback cards Who took part? Phase Two: Individual and group interviews Who took part?	
DATA ANALYSIS	27
FINDINGS	27
DISTRIBUTION OF THE LITTLE ORANGE BOOK	28
Where did parent/carers receive The Little Orange Book? Recommending The Little Orange Book to other parents/carers Explanation when receiving The Little Orange Book Understanding more about parents/carers who had not received The Little Orange Book Summary Recommendations	

HOW PARENTS/CARERS ARE USING THE LITTLE ORANGE BOOK	33
Making decisions about child/rens' health The use of healthcare services The experiences of parents/carers who did not receive The Little Orange Book Making decisions about attending education settings The experience of first-time parents Summary Recommendations	
THE DESIGN AND FORMAT OF THE LITTLE ORANGE BOOK	44
The credibility of The Little Orange Book Visual content and layout of The Little Orange Book Written content Opinions about the format of The Little Orange Book Summary Recommendations	
CASE STUDIES	53
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DISCUSSION	57
Dissemination practices Role in parental decision-making Other points of consideration	
STRENGTHS AND LIMITATIONS	61
RECOMMENDATIONS	62
Recommendations for practice Recommendations for enhancing the format and content of the LOB Recommendations for future evaluations of the LOB Recommendations for enhancing the distribution and awareness of the LOB	
CONCLUSION	64
REFERENCES	65

LIST OF TABLES

How survey respondents found out about the online survey	17
Demographics of the survey respondents	20
Demographics of the interview participants	23

LIST OF FIGURES

Evaluation study design	14
Study recruitment poster	16
Survey pathway	17
Brief feedback cards	18
Survey respondents	19
Location where the LOB was first received	28
Best way to reach those that had not received the LOB	31
Avenue of receiving health information by those who have not received the LOB	39

EXECUTIVE SUMMARY

The Little Orange Book (LOB) was developed by the Newcastle Gateshead Clinical Commissioning Group (NGCCG) in 2016. It is a guide to help parents and carers of children aged five and under, living in Gateshead and Newcastle upon Tyne (Newcastle), to manage common childhood illnesses, as well as more serious conditions.

Since then, the LOB has been distributed to a range of clinical and community settings, including health visitors, General Practitioners (GPs), Accident and Emergency (A&E) departments, and maternity services. A version of the LOB is also available online.

The LOB contains information to increase knowledge and self-management of childhood illnesses to inform decision-making about seeking advice and accessing health services appropriately. A key aim is to reduce the number of clinically inappropriate GP and A&E referrals and attendances. Based on a review of use of A&E services by NGCCG between 2014 and 2015, a symptom checker for parent/carers was recommended to guide these decisions.

This evaluation study was carried out independently and the aims build on the previous evaluation. The evaluation aims to understand parent/carer views of the LOB since its introduction and explores how this is used and impacts on behaviour or confidence to manage symptoms of childhood illness. An additional aim was exploring the changes in accessing health services for child/ren in the context of the COVID-19 pandemic.

The study followed a mixed method design including two phases. Phase One was an online survey completed by 128 respondents who were split into three groups:

- Parents/carers who received/accessed and used the LOB (82 respondents)
- Parents/carers who received/accessed and did not use the LOB (24 respondents)
- Parents/carers who did not receive/access the LOB (22 respondents)

In Phase One, five brief feedback cards were also included in analysis. Phase Two involved individual/group interviews with 16 parent/carers who lived in the Northeast of England, 14 had received/accessed and used the LOB, one had received/accessed but not used the LOB and one had not received/accessed the LOB.

The findings from both phases of the evaluation were integrated and presented in a chronological journey featuring three stages; how the LOB is distributed, how it is used, and parent/carer views about the content and format.

Key Findings

Findings highlighted key issues relating to the dissemination of the LOB. The majority of LOBs were distributed via community health appointments, particularly through midwives, GPs or health visitors. However, parent/carers described variations with the distribution and availability of the LOB, with some not being offered it. Despite this, there were instances of the LOB being shared outside the Newcastle and Gateshead area due to recommendations from parents/carers. Whilst some of those who had received a version of the LOB described having a useful explanation when this was first provided, others reported receiving no information about how to use the LOB. One potential population where the LOB may have a significant impact were first-time parent/carers. Those who have multiple children stated they were less likely to use this resource due to less anxiety about managing symptoms of childhood illness.

A large percentage of those who received/accessed the LOB indicated that it increased their confidence in caring for their unwell child/ren. Parent/carers reported the LOB helped them to identify potential causes of symptoms and provided suggestions for management through monitoring, self-care and/or seeking advice from healthcare services. However, this was not context dependent, and its value is in complementing parental experience, intuition, and judgement.

Over half of parent/carers reported that the information in the book made them more likely to access non-emergency services and less likely to access emergency services when their child/ren showed signs of childhood illnesses and complaints.

Most participants viewed the LOB as trustworthy and reliable due to the association with the NHS, however some questioned whether this was solely provided to prevent healthcare use. There were some concerns about ensuring that the content of the LOB is kept up to date due to risks associated with circulation of outdated information.

Overall, the design and format of the LOB was viewed positively. Of note were the traffic light system, which was used to understand the severity of symptoms/complaints, and images, which conveyed information in an accessible way and provided reassurance. However, the visual content could be more inclusive relating to different ethnicities, particularly relating to identifying different rashes. The use of visual 'tabs' to separate conditions was welcomed and could be further developed by use of physical "tabs" as an index divider to aid navigation through the LOB. There was variation regarding preference for a digital or hardcopy format. Whilst there are some key advantages with digital resources, it was important to ensure that these would not act as a replacement for hard copies.

There was difficulty recruiting to both phases. Of note, there was a limited response rate to the brief feedback cards with organisations not receiving these or unable to promote research studies. Alternative approaches to recruitment through social media and direct contact with parent/children groups had greater impact. The wider impact of staff shortages and need for restoration of availability and opportunities to engage with services such as midwifery and health visiting, could explain some of the recruitment difficulties.

INTRODUCTION

Despite a large proportion of childhood illness being managed at home (Bruijnzeels et al, 1998), parent/carers report finding it difficult to make appropriate decisions regarding when to seek health care (Ehrich, 2003; Houston & Pickering, 2000).

Discussions about why people use services often feed into a wider, sometimes moral, narrative around healthcare use in which behaviour is deemed 'appropriate' or 'inappropriate' (Pope et al, 2019; Ehrich, 2003), though given the complexities described in the literature, this view may be oversimplistic.

Previous work has focused on paediatric attendance in primary care; suggesting that consultations use considerable resource, and may result in unnecessary treatment (Schneider et al, 2019). However, unscheduled care is much more often the focus of research; perhaps motivated by data which suggests that children under five years old are more than twice as likely to access unscheduled care than the general population (O'Cathain et al, 2007).

In the general population, a high proportion of presentations (up to 40%) to emergency departments are for non-urgent conditions (Carret et al, 2009). While it is vital to ensure that children receive appropriate care, there is a need to understand demand from a service planning perspective. A 2013 study, based in an Emergency Department, suggested that parent/carers struggle to accurately assess the seriousness of child/rens' health conditions and often over-estimate the severity; concluding that earlier educational intervention may have reduced unnecessary attendance (Kubicek et al, 2012). Conlon (2021) reported that parent/carers of child/ren under-12 described a complex decision-making process regarding seeking healthcare. These parent/carers attended unscheduled care when their 'threshold' to self-manage their child's health condition at home was exceeded; this was affected by factors such as parents' experience, need for reassurance and desire to avert risk. Participants in this study also discussed appropriateness of use of health services and the need for support and knowledge in relation to making healthcare decisions.

A recent systematic review, which examined factors influencing unscheduled paediatric healthcare use, highlighted a number of 'pre-disposing factors' to accessing services unnecessarily, which included ethnicity, race, and socioeconomic status. The latter encompassed education, income and deprivation levels (Nicholson et al, 2020). This review also described a large number of factors influencing both decisions to attend and the choice of location of unscheduled healthcare. These included the need for reassurance, availability and satisfaction with primary care services, convenience and perceived quality of emergency departments, as well as judgements of the severity of the child's health problem. Taken as a whole, this body of literature suggests that decisions to use children's health services are influenced by a multitude of pre-existing attributes and factors influencing decision-making.

COVID-19 and health service use

The COVID-19 pandemic has dramatically changed the use of health services. In the first United Kingdom (UK) national lockdown in March 2020, there was an immediate and dramatic fall in paediatric emergency department attendance (Shanmugavadivel et al, 2021). This was accompanied by concern expressed by the Royal College of Paediatrics & Child Health (2020) over the risk of serious consequences of delayed healthcare. A survey of 4,075 UK paediatricians suggested that in the most serious cases, delay in presentation may have led to deaths (Lynn et al, 2021).

Little research has examined reasons for these changing patterns of attendance. One study suggested that contributing factors included the impact of public health measures on reducing the incidence of conditions, such as injuries and viral conditions, as well as a reduction in GP referrals (McDonnel et al, 2020). Authors also concluded that reductions in attendances for complex long-term conditions may indicate avoidance by parent/carers.

An Italian study suggested that fear of COVID-19 resulted in delays in access and provision of care (Lazzerini et al, 2020). A Canadian publication suggested that logistical factors may have contributed to this phenomenon such as

child care difficulties, closure of primary care services and changes to hospital visitation policies (Chanchlani et al, 2020). Our own qualitative work during the first UK Lockdown (currently undergoing peer-review), described some parents' uncertainty of how healthcare seeking fitted with government 'Stay Home' advice. While more research is necessary to understand the short and long term impact on the use of children's health services, current literature suggests that COVID-19 added additional factors such as service availability, perceptions of risk and understanding of public health messaging to an already complex decision-making process.



THE LITTLE ORANGE BOOK

In 2016, The Little Orange Book (LOB) was developed by the Newcastle Gateshead Clinical Commissioning Group (NGCCG), as a guide to help parents and carers of children aged five and under living in Gateshead and Newcastle upon Tyne (Newcastle) to manage common childhood illnesses, as well as more serious conditions such as meningitis and sepsis.

Since then, it has been distributed by a range of clinical and community settings across Newcastle and Gateshead, including health visitors, General Practitioners (GPs), practice nurses, Accident and Emergency departments (A&E), maternity services and primary care settings.

The LOB contains information to increase knowledge, and self-management of childhood illnesses and informs decision-making about when to seek advice and access health services appropriately. A key aim of the LOB was to reduce the number of clinically inappropriate GP and A&E referrals and attendance. This was based on a review of use of A&E services by the NGCCG between 2014 and 2015, which recommended the creation of a symptom checker to guide parent/carer decisions.

An evaluation conducted by INVOLVE North East (2018) included health professionals across different services as well as parents in Newcastle and Gateshead. The evaluation showed that professionals and parents were highly supportive of the LOB and key findings demonstrated it was helpful in increasing understanding of common childhood illnesses, as well as informing decisions about when self-care is appropriate and when to seek further advice from health professionals and services such as A&E.

This evaluation recommended that an app was introduced to support the paper-based and online pdf version, that the content was updated, that different language versions were developed and also that the LOB needed to be distributed more widely across the region. It was also recommended that further evaluations were undertaken once use of the LOB was more established within the Newcastle and Gateshead areas.



AIMS

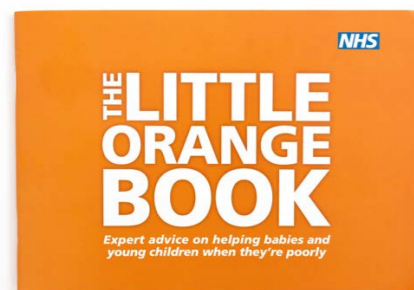
The aim of this evaluation is to understand parent/carer views of the LOB since its introduction, building on the information and recommendations within the previous evaluation.

OBJECTIVES

1. To identify a sample of parent/carers from each geographic area (Gateshead and Newcastle) who have received the LOB,
2. To identify if, and how parent/carers use the book, what they liked about it, barriers to use and if/how it could be improved,
3. To explore any perceived impacts of the book, for example behaviour change of parents, increased confidence to manage health conditions and use of health services,
4. To consider 2) and 3) in the context of the COVID-19 pandemic any changes to how health services are accessed,
5. To identify suggestions for further development of the book,
6. To make recommendations for future research.



METHODS

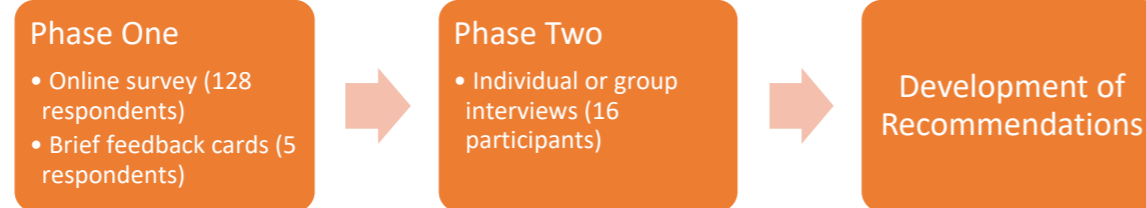


DESIGN

The evaluation study adopted a mixed-methods exploratory sequential design (Creswell & Creswell, 2018) to explore experiences of using the LOB, the perceived impact of this, and views of the design and layout of the LOB (see Figure 1).

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

Figure 1: Evaluation study design



Phase One: Online survey and feedback cards

The online survey and brief feedback cards explored experiences of using the LOB and views of the design/layout. Parent/carers who were located in Newcastle and Gateshead were invited to complete the online survey and/or brief feedback card via a range of different recruitment methods outlined below.

Parent/carers who had not received/accessed the LOB were also invited to complete the online survey to explore their views about the usefulness of this resource, and to establish methods to identify gaps in dissemination.

Recruitment



Three posters (see Figure 2) and 10 brief feedback cards were posted to 197 sites across Newcastle and Gateshead. Organisations were asked to return the feedback cards via an included self-addressed envelope.

The sites were as follows:

- 72 GP surgeries/Health centres/Walk-in centres
- 100 Chemists/Pharmacies
- 16 Children Services (e.g. Children Centres, 0-19 services)
- Five hospital services



Posters

Two posters were posted to 117 organisations across Newcastle and Gateshead:

- 65 Dentists
- 52 Opticians



NCGC Website

Information about the evaluation study and the survey link was advertised on the NGCCG website.



GP Bulletin Boards

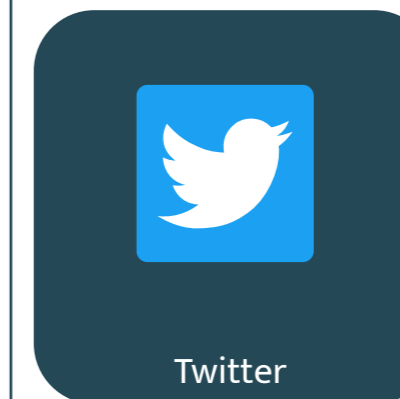
A brief description of the evaluation study was shared to GP online bulletin boards across Newcastle and Gateshead at regular intervals between April-July 2022. These sites were asked to share with patients and advertise in waiting rooms.



Electronic Flier

Members of the research team contacted 193 organisations asking them to share information about the evaluation study with their child/parent groups:

- 85 Nurseries in Newcastle and Gateshead
- 18 Children Services (e.g. Children Centres)
- 90 Children/Parent Groups



Twitter

An electronic flier was regularly shared by NGCCG's Twitter account and by the research team. 11 organisations were tagged and asked to reshare.



Emails to Newcastle and Northumbria University Staff and Students

Information about the study and an electronic flier was disseminated across health-based departments in Newcastle and Northumbria University.



Three parent/children groups were visited by members of the research team who spoke to attendees about the study and handed out fliers.

Face to Face Recruitment



Facebook

An electronic flier was regularly shared on the NGCCG's Facebook page. The research team also contacted 35 Facebook pages/groups:

28 children/parent groups or networks
Seven local miscellaneous groups

A Facebook business page was created to raise awareness of the evaluation and to enable a wider reach of parent/carers in the Newcastle and Gateshead area. No individuals were directly invited by the research team to like and interact with the page.

An advertisement for the evaluation study was developed through Facebook which enabled cross-posting to Instagram and Facebook Messenger. Advertisements consisted of one sponsored post (paid via additional external funding) in addition to several unpaid posts. Posts including a range of images from the LOB, information about the evaluation and the survey link. The Facebook advertisement reached 6166 individuals, there were 84 engagements and 80 clicks to the survey.



Figure 2: Study recruitment poster

EVALUATING THE LITTLE ORANGE BOOK



Would you like to complete a short survey about the Little Orange Book? Have Your Say!
To participate, scan the QR code or visit:

<https://northumbria.onlinesurveys.ac.uk/lob-evaluation>

You do not need to have used the Little Orange Book to participate in this survey.
If you would like this information provided in another language or format, please contact Dr Lynette Shotton by email at: lynette.shotton@northumbria.ac.uk



Table 1: How survey respondents found out about the online survey.

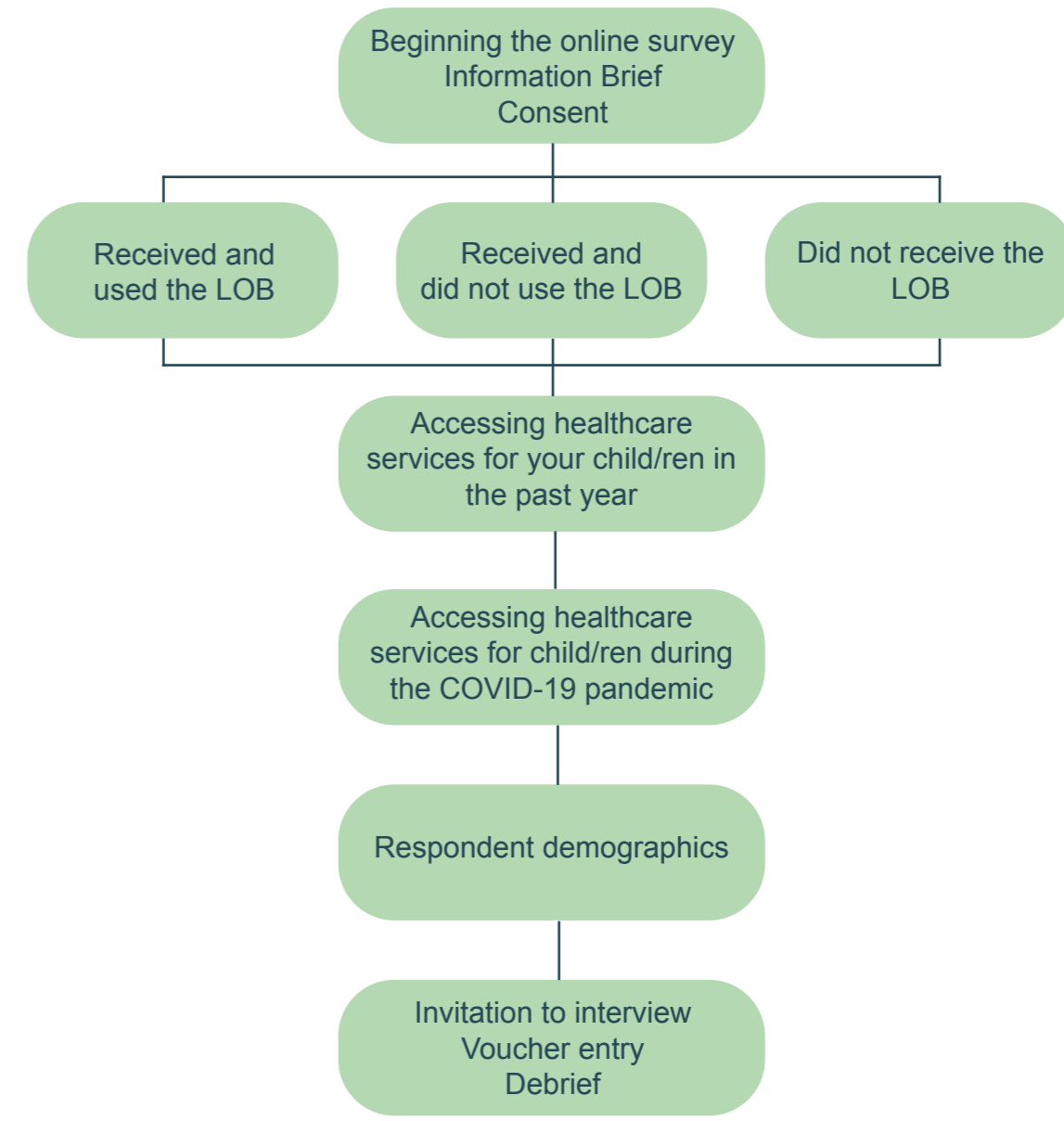
Social media	(42.19%)
Nursery/childcare provider	(14.06%)
Word of mouth	(11.72%)
Employment	(7.81%)
School	(7.03%)
Children/Parent group or Children Centre	(4.69%)
University	(3.91%)
GP surgery	(3.13%)
Prefer not to say	(2.34%)
Other*	(1.56%)
Hospital	(0.78%)
Pharmacy	(0.78%)

* Other = Email and Haref Bulletin Newsletter

The Online Survey

The online survey was available on JISC Online Surveys between 9th April-23rd July 2022. Respondents were provided with study information and the option to provide informed consent before being able to commence with the survey. After giving informed consent, respondents were allocated to specific pathways depending on their response to key questions; (1) whether they had received or accessed a version of the LOB and, if selecting receipt, (2) if they had used their copy/version when their child/ren was unwell (see Figure 3).

Figure 3: Survey pathway



Those who received and used the LOB answered questions about the following:

- a) Receiving the LOB
- b) Previous use of the LOB
- c) Impact of the LOB on:
 - o Parent/carer confidence in managing child/ren's symptoms of illness
 - o Use of health services by their child in the previous year, during the COVID-19 pandemic and during nation-wide lockdowns.
 - o Making decisions when their child/ren were unwell
- d) Views of the design/layout of the LOB
- e) Suggestions of how to improve the LOB

Those who stated that they had received and not used the LOB, were asked to explain why this was not used, whether anything could encourage use, and where they accessed health advice when their child was unwell.

Survey respondents who had not received the LOB, were shown images of the resource and asked the following:

- Perceived value of the LOB as a resource when their child/ren were unwell
- Examples when the LOB would have been useful
- Explanations why this wouldn't be used (if applicable)
- Information that should be included within the LOB
- How to present the information
- Best way to disseminate the LOB

All survey respondents were asked about their use of healthcare services for their child within the past year and during the COVID-19 and nationwide lockdowns. All survey respondents were invited to state whether they were interested in participating in a group or individual interview to further elaborate on their views and experiences, before being given the opportunity to be entered into a prize draw to win a £25 voucher.

Feedback cards

Ten brief feedback cards were sent to organisations to gain a brief snapshot of views about the LOB (see Figure 4). The feedback cards provided brief information about the study and also included a link and a QR code to the online survey.

The cards contained the following questions:

- 1) How have you used the LOB?
- 2) How did it help you?
- 3) How can we improve it?
- 4) Postcode

Figure 4: Brief feedback cards



Who Took Part?

Survey respondents were located in the Northeast of England, with the majority based in Newcastle and Gateshead.

A total of 132 individuals accessed the online survey. Of these 132 individuals, four were excluded due to one being a tester response to ensure the survey was active, two declined to participate, and one did not meet eligibility for inclusion.

This resulted in **128 respondents** included in analysis which were split into three groups:

- 1) Survey respondents who received/accessed and used the LOB (**82 respondents**)
- 2) Survey respondents who received/accessed but did not use the LOB (**24 respondents**)
- 3) Survey respondents who did not receive or access the LOB (**22 respondents**)

The demographics of all survey respondents are provided in Table 2.

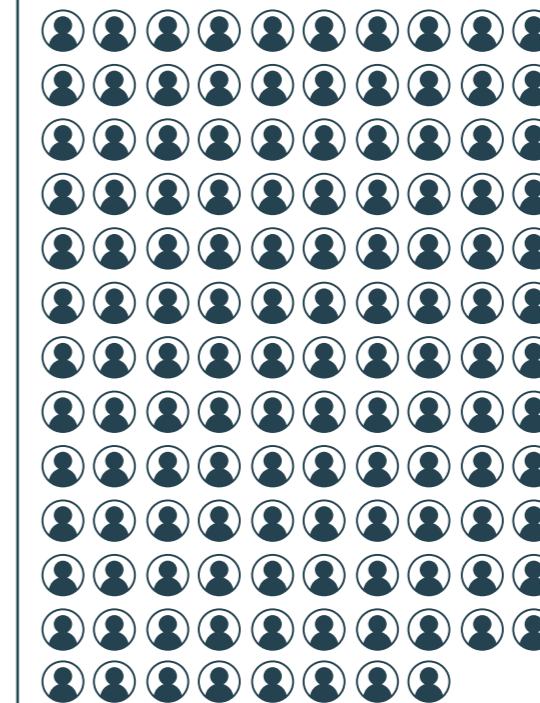
Of those who received and used the LOB:

- **46.34%** lived in **Newcastle**
- **35.37%** lived in **Gateshead**
- **18.30%** lived in **other locations**

82.81% of survey respondents had received a hard copy or accessed an online version of the LOB. Of these participants:

- **25.47%** received/accessed the LOB between 2016-2017
- **36.79%** received/accessed the LOB between 2018-2020
- **30.19%** received/accessed the LOB between 2021-2022
- **7.55%** were unable to remember when they first received/accessed the LOB

Figure 5: Survey respondents



128 TOTAL SURVEY RESPONDENTS



24 SURVEY RESPONDENTS RECEIVED/ACCESSED BUT DID NOT USE THE LOB



82 SURVEY RESPONDENTS RECEIVED/ACCESSED AND USED THE LOB



22 SURVEY RESPONDENTS DID NOT RECEIVE THE LOB

Five feedback cards were returned and included in analysis. These cards represent the views of five parent/carers based in Newcastle across two postcodes.

Table 2: Demographics of the survey respondents (N = 128)

The demographics of the 128 survey respondents are presented in the table below. 'N' represents the total number of survey respondents and 'n' represents the number of survey respondents in each category.



	Received and used the LOB (n=82)	Received but did not use the LOB (n=24)	Did not receive the LOB (n=22)
AGE	25-56 years (mean = 35.85, SD = 5.12)	24-50 years (mean = 36.96, SD = 6.49)	28-69 years (mean = 41.00, SD = 10.05)
GENDER			
Female	95.12%	100.00%	86.36%
Male	4.88%	0.00%	13.64%
ETHNICITY			
White	93.90%	91.67%	86.36%
Black/African/Black British	3.66%	0.00%	0.00%
Asian/Asian British	1.22%	4.17%	13.64%
Mixed/Multiple ethnic groups	1.22%	4.17%	0.00%
MARITAL STATUS			
Married/Civil partnership	92.68%	91.67%	90.91%
Single	6.10%	8.33%	0.00%
Separated/divorced	1.22%	0.00%	9.09%
FIRST-TIME PARENT			
Yes	48.78%	41.67%	36.36%
No	51.22%	58.33%	63.64%
NUMBER OF CHILDREN			
Two children	72.50%	69.23%	76.92%
Three children	22.50%	23.08%	15.38%
Four children	2.50%	7.69%	7.69%
More than four children	2.50%	0.00%	0.00%

	Received and used the LOB (n=82)	Received but did not use the LOB (n=24)	Did not receive the LOB (n=22)
LIVING ARRANGEMENTS OF CHILDREN			
Live with respondent full-time	97.56%	95.83%	86.36%
Live with respondent part-time	2.44%	0.00%	0.00%
Other	0.00%	4.17%	4.55%
Prefer not to say	0.00%	0.00%	9.09%
EMPLOYMENT STATUS			
Employed full-time	43.90%	54.17%	50.00%
Employed part-time	36.59%	33.33%	36.36%
Homemaker	10.98%	4.17%	0.00%
Self-employed	3.66%	0.00%	0.00%
Carer	1.22%	4.17%	0.00%
Unemployed and not currently looking for work	1.22%	0.00%	0.00%
Unable to work	1.22%	0.00%	0.00%
Prefer not to say	1.22%	0.00%	0.00%
Retired	0.00%	0.00%	9.09%
Student	0.00%	0.00%	4.55%
Other	0.00%	4.17%	0.00%
EDUCATION LEVEL			
Level 2 (e.g. GCSE, NVQ)	4.88%	0.00%	4.55%
Level 3 (e.g. A level)	10.98%	12.50%	22.73%
Level 4/5 (e.g. Undergraduate diploma)	15.85%	4.17%	4.55%
Level 6 (e.g. Bachelor's degree)	23.17%	41.67%	27.27%
Level 7 (e.g. Master's degree)	32.93%	25.00%	4.55%
Doctorate	9.76%	16.67%	27.27%
Other	2.44%	0.00%	4.55%
Prefer not to say	0.00%	0.00%	4.55%
FORMAT OF LOB RECEIVED			
Paper-based copy	56.10%	70.83%	Not applicable
Online Version	10.98%	20.83%	
Both	32.93%	8.33%	

Phase Two: Individual and group interviews

The second phase of the evaluation study comprised of 16 audio-recorded individual/group interviews with parents/carers from the Northeast of England, particularly from Newcastle and Gateshead. Interview participants were recruited from the online survey (n=13) or via word of mouth (n=3). The interviews lasted between 34-58 minutes and were audio recorded and transcribed verbatim.

Interviews served to further expand on the points raised within Phase One and questions were adapted from participant's answers from the survey where possible. As with Phase One, individuals who had received/accessed but not used the LOB, and those who had not received/accessed the LOB were invited to share their views.

The interview topic guide included questions focusing on:

- Demographic information
- Experiences of using the LOB
- Views on the LOB design
- Impact of the COVID-19 pandemic on accessing services for children
- Challenges faced when making decisions about child/ren's health

Who took part?

Sixteen parent/carers took part in interviews. The interviews were conducted using Microsoft Teams (n=13), face-to-face (n=1) and via telephone (n=2). Interview participants were located in Newcastle (n=9), Gateshead (n=6) and North Tyneside (n=1). All participants were female and had child/ren who lived with them full-time. 14 participants had received and used the LOB, one had received but not used the LOB, and one had not received a copy of the LOB. An overview of participant demographics is presented in Table 3.



Table 3: Demographics of the interview participants (N = 16)

	Interview Participants (N=16)
AGE	25-43 years (mean = 35.19, SD = 4.46)
GENDER	
Female	100.00%
Male	0.00%
ETHNICITY	
White	87.50%
Black/African/Black British	6.25%
Asian/Asian British	6.25%
Mixed/Multiple ethnic groups	0.00%
MARITAL STATUS	
Married/Civil partnership	93.75%
Single	6.25%
Separated/divorced	0.00%
NUMBER OF CHILDREN	
One child	50.00%
Two children	50.00%

	Interview participants (N=16)
LIVING ARRANGEMENTS OF CHILDREN	
Live with respondent full-time	100.00%
Live with respondent part-time	0.00%
Other	0.00%
Prefer not to say	0.00%
EMPLOYMENT STATUS	
Employed full-time	50.00%
Employed part-time	37.50%
Homemaker/housewife	6.25%
Self-employed	0.00%
Carer	0.00%
Unemployed and not currently looking for work	6.25%
Unable to work	0.00%
Prefer not to say	0.00%
Retired	0.00%
Student	0.00%
Other	0.00%
AGE OF CHILDREN (includes multiple responses)	
Under one years old	43.75%
Between one and two years old	50.00%
Over three years old	56.25%

Interview Participants

This section further describes the 16 parents/carers that participated in individual/group interviews. The names provided are not the real names of the participants (pseudonyms) to protect their identity.



Participant 1:
PENELOPE

Penelope is a 35-year-old woman living in Gateshead in the Northeast of England. She is the mother of two children who are 19 months old and five months old. The children live with her. Penelope is employed full-time and is in a relationship (married/civil partnership or cohabiting). Penelope is of a white ethnic origin. She received and used a hard copy of the LOB.



Participant 2:
SKYE

Skye is a 34-year-old woman who lives in Gateshead in the Northeast of England. She is a mother to one child who lives with her full-time. Her child is five months old. Skye is in a relationship (married/civil partnership or cohabiting) and is employed full-time. She is of a white ethnic origin. Skye accessed and used both the online version and hard copy of the LOB.



Participant 3:
BELLA

Bella is a mother to two children who are five years old and 16 months old. The children live with her full-time. Bella is 38 years old, lives in Newcastle Upon Tyne (Northeast of England) and is in a relationship (married/civil partnership or cohabiting). Bella is of a white ethnic origin and is employed on a part-time basis. She received and used a hard copy of the LOB.



Participant 4:
FRANCINE

Francine is 36 years old, and she is the mother to one child who is seven months old who lives with her full-time. She is in a relationship (married/civil partnership or cohabiting) and lives in Gateshead (Northeast of England). Francine is employed full time and is of a white ethnic origin. She accessed and used both the online version and a hard copy of the LOB.



Participant 5:
JANE

Jane is a 42-year-old woman who lives in Gateshead in the Northeast of England. Jane is not in a relationship (single) and is employed full-time. She is a mother of one child who is nine weeks old and lives with her full-time. Jane is of a white ethnic origin. She received and used a hard copy of the LOB.



Participant 6:
JESSICA

Jessica is a 36-year-old woman who lives in Newcastle Upon Tyne in the Northeast of England. She is a mother to two children who live with her full-time. Her children are four years old and two years old. Jessica is in a relationship (married/civil partnership or cohabiting) and is employed full-time. She is of a white ethnic origin. She received and used a hard copy of the LOB.



Participant 7:
WILMA

Wilma is a mother to two children who are five years old and two years old. The children live with her full-time. Wilma is 37 years old, lives in Newcastle Upon Tyne (Northeast of England) and is in a relationship (married/civil partnership or cohabiting). Wilma is of a White ethnic origin and is employed on a part-time basis. She accessed and used both the online version and a hard copy of the LOB.



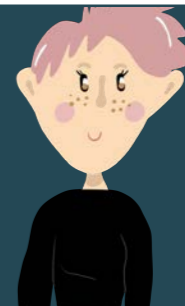
Participant 8:
ANGELICA

Angelica is 34 years old and is in a relationship (married/civil partnership or cohabiting). She lives in Newcastle Upon Tyne in the Northeast of England. Her two children aged 10 years and 17 months old, live with her full-time. Angelica is of a black ethnic origin. She is unemployed and is not currently looking for work. Angelica received and used a hard copy of the LOB.



Participant 9:
DAISY

Daisy is a 43-year-old woman who lives in Newcastle Upon Tyne in the Northeast of England. Daisy is in a relationship (married/civil partnership or cohabiting) and is employed on a full-time basis. She is a mother to one child, who lives with her full-time and is three years old. She is of a white ethnic origin and used a hard copy of the LOB.



Participant 10:
REBECCA

Rebecca is 34 years old and lives in Newcastle upon Tyne in the Northeast of England. She is the mother of a 3-year-old child who lives with her full-time. She is in a relationship (married/civil partnership or cohabiting) and currently works part-time. Rebecca is female and of white ethnic origin. She has received and used a hard copy of the LOB when her child was unwell.



Participant 11:
PATTI

Patti is a 35-year-old mother, to one child who is two years old and lives with her on a full-time basis in Newcastle Upon Tyne (Northeast of England). Patti is employed full-time, is of a white ethnic origin, and is in a relationship (married/civil partnership or cohabiting). She received and used a hard copy of the LOB.



Participant 14:
NORRIE

Norrie is a 35-year-old female of white ethnic origin who is currently living in Gateshead. She is in a relationship (married/civil partnership or cohabiting) and is in part-time employment. Norrie has two children, aged five and one, who live with her full-time. She has received a hard copy of the LOB and used this when her children were unwell.



Participant 12:
LOLA

Lola is a 27-year-old woman who lives in Gateshead in the Northeast of England. She is a mother to one child who is five months old who lives with her full-time. Lola is in a relationship (married/civil partnership or cohabiting), is of a white ethnic origin and is employed on a full-time basis. She received a hard copy of the LOB but has not used it.



Participant 15:
TRACEY

Tracey is a 25-year-old mother, of white ethnic origin, to three children (one biological child and two step-children) who live with her full time. Tracey is a homemaker (housewife) and is in a relationship (married/civil partnership or cohabiting). Despite living in North Tyneside in the Northeast of England, Tracey has accessed an online version of the LOB after finding out about this on social media.



Participant 13:
HELGA

Helga is a 37-year-old woman who is a mother to two children (aged 3 years and 7 months) who live with her full-time. She is in a relationship (married/civil partnership or cohabiting). Helga lives in Newcastle Upon Tyne (in the Northeast of England). She is employed on a part-time basis and is of an Asian ethnic origin. Helga did not receive a copy of the LOB and was not aware of this until she saw information about the study.



Participant 16:
MONA

Mona is a 35-year-old, white female. She lives in Newcastle Upon Tyne with her two adopted children, aged two and four years old. She is in a relationship (married/civil partnership or cohabiting) and is currently working part-time. She has received a hard copy of the LOB and has used this when her children were unwell.

DATA ANALYSIS

The descriptive statistics from the self-report survey were analysed using Microsoft Excel. Open-response questions from the survey and data from qualitative interviews were analysed using a pragmatic approach informed by thematic analysis (Braun and Clarke, 2006).

Thematic analysis consists of six steps:

1. Becoming familiar with the data
2. Creating initial codes
3. Developing initial themes from the codes
4. Reviewing the themes
5. Defining and explaining the themes
6. Producing the final report

The themes generated were mapped against the research questions and presented as categories within the chronological journey of receiving and using the LOB. Both the descriptive statistics and open-response questions were integrated with the individual/group interview data.

We described three interviews, representing a spectrum of experiences, in detail in the form of case studies.

FINDINGS

The themes generated from the survey and interview data are integrated and presented as a chronological journey, beginning with how the LOB is distributed, how it is used and views of parent/carers about the content and format. These findings formed the basis for recommendations which focus on building on the strengths of the LOB, as well as increasing awareness and distribution. Interview participants are referred to by pseudonyms and survey respondents have been given unique identifiers, for example P104.

Distribution of the Little Orange Book

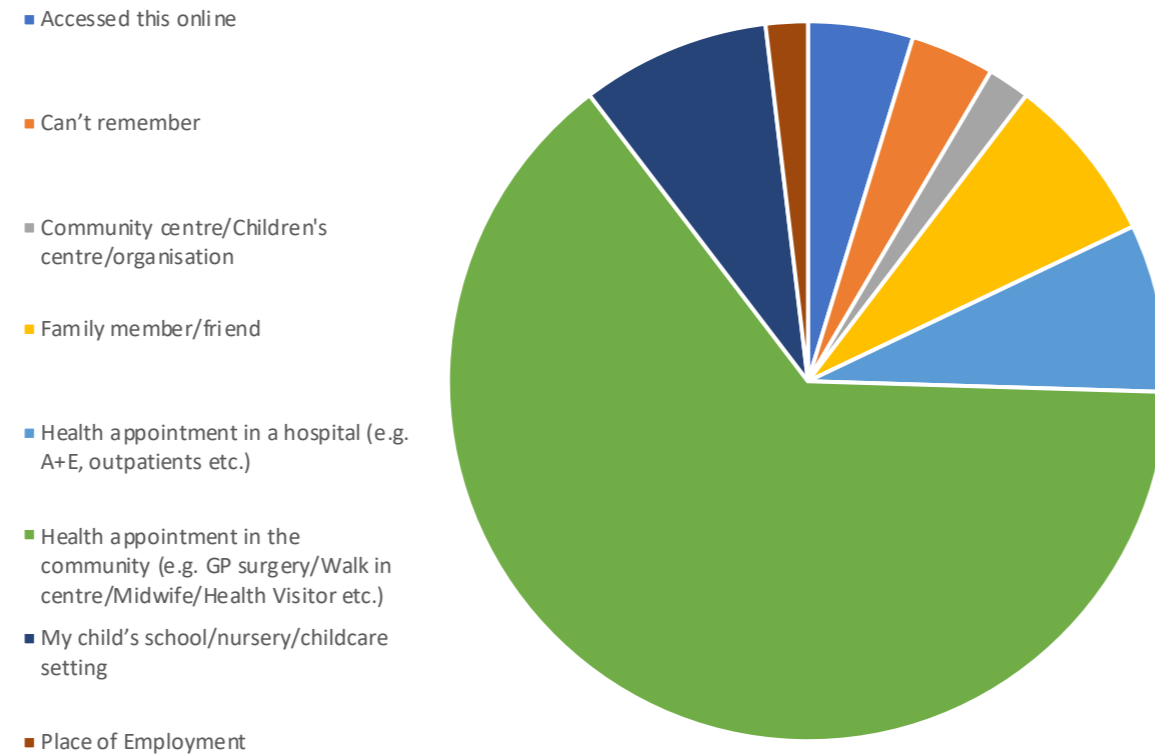
This section explores the distribution of the LOB, focusing on who received this and how. The views of parent/carers who had not received the LOB are also explored to identify any potential gaps in dissemination and ensure wider access.

Where did parent/carers receive the Little Orange

An overview of where participants first received the LOB is provided in Figure 6. The majority of participants received a paper-copy of the LOB from community health services, such as midwives and health visitors.

Participants suggested that the LOB could be combined with other healthcare resources or provided prior to birth of their child/ren as part of a “maternity pack” (P104, Survey Respondent, North Tyneside). Respondents felt that awareness of the book could be increased and that health visitors could play a key role in this:

Figure 6: Location where the LOB was first received (N = 106)*



* Some participants received the book from more than one location

“I wonder if, maybe going forward, it gets given out with the little Red Book in a printed version or whatever”
(Patti, Interview Participant, Newcastle)



Regarding other healthcare settings, several participants described receiving the LOB by chance, claiming that this was not highly visible in health and community settings:

“More focus on it with [health visitor]. I didn't realise I had it for ages. It wasn't explained to me at all. I found it with some handouts.”

(P096, Survey Respondent, Newcastle)

“It could be combined with the red book. So all information is in one place.”

(P007, Survey Respondent, Gateshead)

“I don't see the Orange Book around I think it was just very opportunist that my GP had them... I don't see them often... we've got like the leisure centres connected to our - like another primary care centre and stuff. In our area - I never see them.”

(Rebecca, Interview Participant, Newcastle)



“I go to a baby group, and there was [sic] people who weren't aware of it. So, I had said to, kind of, maybe pick one up. And it is handy to, kind of, carry around and... And I'd said, oh, I felt like I'd been offered this book quite a few times - I don't know how you've missed it”
(Francine, Interview Participant, Gateshead)

“Making aware [sic] of it to the mum before the baby was born, no time to consult it during the first month”

(P101, Survey Respondent, Newcastle)

However one participant disagreed:



Recommending The Little Orange Book to other Parents/Carers

Of the 82 survey respondents who had received and had used the LOB, **92.68%** reported that they would recommend the LOB to other parents/carers of young children:

"Very helpful and have sent it on to numerous friends with new-borns... I have downloaded the digital format and passed it on to numerous friends who have new-born's."

(P014, Survey Respondent, Gateshead)

"I love it and give it to every friend who has a new baby - posting it to those elsewhere! It's simple and helpful"

(P078, Survey Respondent, Newcastle)

"I think I gave it to my mam at one point. My mam was looking after her for a while, and I thought it would be nice to put in her nappy bag to kind of say if you panic about anything there's a little book in there."

(Francine, Interview Participant, Gateshead)

Although the LOB is currently a local resource, there were instances of it being shared outside the Newcastle and Gateshead areas. Some participants suggested that national availability would ensure wider benefits from the information contained:

"Oh, well, they'll need to get it out across the country, then."

(Skye, Interview Participant, Gateshead)

"...some friends that ... come from another county originally. So I've sent it to... to Lincolnshire, which is where I'm from to my friends there."

(Mona, Interview Participant, Newcastle)

The 24 survey respondents who had received but had not used the LOB were less likely to recommend it to others (**58.33%** reported recommending to others).

Reasons included preferences for a digital format or accessing information online which will be covered in more detail later in this section.

Explanation when receiving The Little Orange Book

47.56% of survey respondents stated that they had not received an explanation from their healthcare professional when receiving the LOB. This was reflected in the interview data:

"Like I say, was just within the [hospital pack]. So... It was literally handed to me and, kind of, that was it. Obviously when I did go through the pack, I did find it useful. But there was no explanation... Or subsequent explanation - other than being given the pack."

(Penelope, Interview Participant, Gateshead)

Where explanations had been given, participants found this helpful:

"But, yes, my regular health visitor... she gave me, and she talked me through it. And going, you know, how it basically works... This is you can manage at home. This is you might want to consult someone. And this is an emergency, you know. As well as the helpful tips it gives as well, from time to time."

(Skye, Interview Participant, Gateshead)

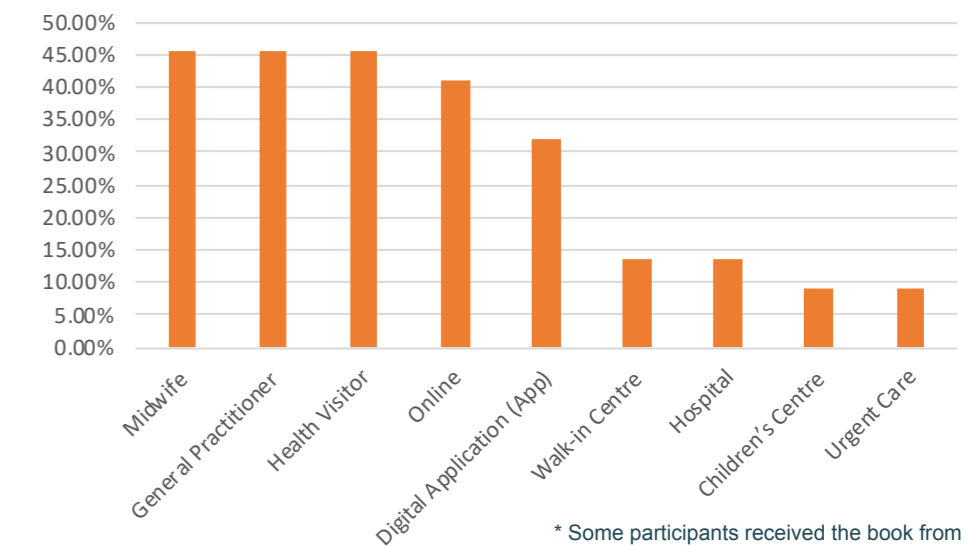
"It's provided to the parents without much explanation because they're not gonna take them when they've got a newborn, and they're gonna think that actually, that doesn't affect my child. But then to review the information of the Little Orange Book at the development checks, so such as some people have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

(Tracey, Interview Participant, North Tyneside)

Understanding more about parents/carers who had not received The Little Orange Book

Of the total survey respondents, **17.19%** had not received a hard copy or accessed an online version of the LOB, suggesting a gap in dissemination. As can be seen from Figure 7, **45.00%** of survey respondents who had not received the LOB reported that the best way to reach them would be through community health services, such as midwife, GP and health visitors, or in a digital format.

Figure 7: Best way to reach those who had not received The Little Orange Book (N=22)*



* Some participants received the book from more than one location

Summary

The findings show that the majority of those who received the LOB did so from community health appointments (such as health visitors or midwife appointments), consistent with the findings from the previous evaluation (INVOLVE North East, 2018). However, whilst this previous evaluation recommended that the LOB should continue to be distributed across Newcastle and Gateshead via a range of different services (such as hospitals and libraries), this evaluation suggests that distribution via these platforms is limited. Additionally, participants reported sharing the LOB with other parents/carers outside of the Newcastle and Gateshead area which suggests there may be a potential value and opportunity for distribution beyond these regions.

A high percentage of survey respondents did not receive an explanation about the LOB when receiving it, but felt this would have been useful. This further highlights the need for a strategic approach to dissemination and reinforcing the resource at different points of contact with health professionals.

The information obtained from those who had not received/accessed the LOB highlights the variation in access and distributing practices across the Newcastle and Gateshead regions. Despite this, there was still a preference to receive this via community health settings, such as health visitors, GPs or midwives. This could indicate a need to encourage promotion by these key health care professionals across the Newcastle and Gateshead regions as well as encouraging wider awareness across healthcare networks, such as pharmacies.

RECOMMENDATIONS

- To review and develop a strategic approach to disseminating and raising awareness of the purpose of the LOB across Newcastle and Gateshead. Emphasis should be placed on initial dissemination and explanation by community health services, such as health visitors and midwives, with the role of wider and continuing healthcare services to support awareness raising and embed use generally at points of contact with parent/carers.



How parents/ carers are using The Little Orange Book

This section considers how the LOB was used in the context of self-care and decision-making regarding use of healthcare services, as well as the impact of COVID-19 on these processes. Discussion about the role of confidence in making decisions and the credibility of information is also presented.

Making decisions about child/ren's health

Of those who received and used the LOB, **76.42%** used it to make healthcare decisions for symptoms of illness in their child/ren. The survey respondents and feedback cards were positive about the content included within the LOB:

"Invaluable resource to often sleep deprived hormonal parents"

(P023, Survey Respondent, Sunderland)

"Gave me advice, helped me stay calm"

(Feedback Card 1, Newcastle)

Of the 82 survey respondents who had used the LOB, **85.37%** reported that it increased confidence in caring for their child/ren when unwell. There was a consensus that the LOB supported parents making decisions about their child/ren's health, such as managing symptoms of childhood illness and providing reassurance. In some instances, this was an initial point of reference when their child was unwell:

"I will check the orange book first to see if I can get a course of action before anything else."

(P084, Survey Respondent, Newcastle)

"Review content in book first before taking action."

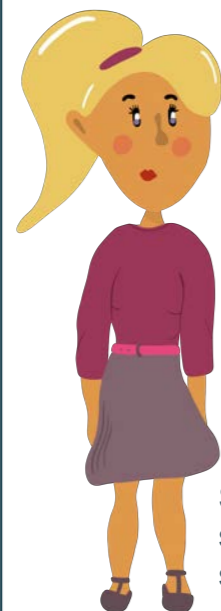
(P037, Survey Respondent, Gateshead)

“... First port of call ...”

This was reflected by interview participants who referred to the LOB as their “first port of call” (Daisy, Interview Participant, Newcastle) in managing symptoms of childhood illness. Participants valued understanding more about health complaints, knowing when to seek advice, and information about how long symptoms may last:

“You don’t know what’s normal and what’s not normal. So, I think it’s helpful just to have those little... Little, like, bits and tips that are just, sort of, giving you an idea of what you... What you should be looking out for, and what you shouldn’t. And what’s not normal. I think that helps you make your decision as well. And it’s kind of reassurance, even though it’s sort of from afar on a... On a page. But I think just knowing that, okay, this is normal - that’s okay. It’s okay for them to be poorly. Because they can’t be healthy all the time. I think that’s helpful.”

(Jessica, Interview Participant, Newcastle)



“We love it. So, when I say we, I’m talking about me and my husband. And we know where it is and it’s the go-to. You know, so if the boys are poorly, it’s “Go and get the Little Orange Book, check this out...”

(Wilma, Interview Participant, Newcastle)

Survey respondents reported using the LOB to identify potential causes of symptoms of illness and suggestions for management through monitoring, self-care and/or seeking advice from healthcare services:

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

(P027, Survey Respondent, Gateshead)

“The book contains information on the most common illnesses I have encountered in my children from birth. The colour coded system has helped me hugely in understand the seriousness of my children’s symptoms and how best to monitor and treat them without needing to get this advice from a healthcare professional. I trust the information in the book.”

(P080, Survey Respondent, Newcastle)

“But you’ve got that middle ground of, oh, they’re a bit off, and I’m a bit worried about them, but I don’t want to just start panicking or ringing 111 or whatever. And that’s usually when we go to the orange book - so, I guess that’s what it is for me. Is that it provides me with what to do next, when you’re in that... Like, I’m not quite sure where to go phase. And it’s quick. It’s quicker than ringing up 111. It’s quicker than ringing up your GP. I think it’s just, like, almost like a little, like, flow or how-to guide of what to do next. And sometimes that’s all you need to, like, yeah, clarify your thoughts and know what to do next.”

(Jessica, Interview Participant, Newcastle)



These examples referred to this “middle ground” where parents/carers found it difficult to make a decision. While information provided in the LOB was helpful, parents/carers also described basing decisions on prior knowledge and experience or parental instinct:

“I wouldn’t want them to rely solely on the book and follow instincts if a child is unwell too”

(P055, Survey Respondent, Gateshead)

“I used my own knowledge to decide who to contact because I am a medical professional ... useful for parents with no medical knowledge, particularly anxious parents”

(P046, Survey Respondent, location not provided)

“I wouldn’t say, if something in the book said ‘you don’t need to seek medical advice’ but something in me was telling me I needed to, I still would.”

(Norrie, Interview Participant, Newcastle)



The above quotes suggest that the LOB can be used to complement pre-existing health knowledge and parental instinct. However, to some participants, the value placed on parental instinct was a barrier to using the LOB. The LOB is not context dependent; whilst the advice can help guide parent/carers, this was used in conjunction with, rather than in place of, parental judgement:

“It really depends, doesn’t it? So, it said if your child has ingested water-based glue, it doesn’t matter. But I thought it does – it depends how much and... Do you know what I mean? But it’s a little bit flippant in that section, which I thought was potentially dangerous.”

(Francine, Interview Participant, Newcastle)

There were other barriers to use or continued use:


“I forgot about it- we moved house and it got put in a box. Would love to have a digital copy or an app so I don’t risk losing it”

(P090, Survey Respondent, Unknown)



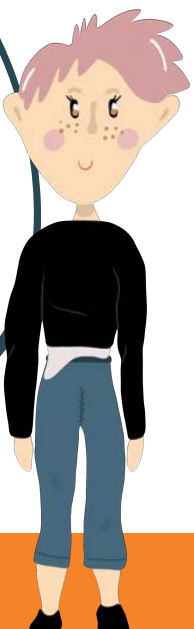
The use of healthcare services

Not only was the LOB seen to increase confidence in managing symptoms of childhood illness by parent/carers, but there were reports of it influencing how they accessed healthcare services. For example, of those who had received and used the LOB, **57.31%** reported that the information in the book made them more likely to access non-emergency services and **58.53%** were less likely to access emergency services. Survey respondents and interview participants described checking the LOB before accessing health care services as well as seeking reassurance about the need to seek further advice:



"It reassured us that we didn't need to take any other precautions, such as taking her to A&E or making an appointment with the GP, when she was so poorly and didn't really need to go... So we could just focus on kind of looking after her."


(Daisy, Interview Participant, Newcastle)



"...it would kind of really reassure you is to kind of longevity of some of the illnesses -that was particularly helpful. So I kind of 'cause we get a lot of conflicting advice from family members, for example -Saying Oh no, that cough needs to be checked out, but actually it would say that quite often the cough can last for like couple of weeks and so getting information like that was helpful for me"

(Rebecca, Interview Participant, Newcastle)

Whilst this aligns with the aim of the LOB to support parent/carers to manage symptoms of childhood illness more confidently and access services when needed, Tracey made the following comment:




"Yes, it was an idea to go straight to the [LOB]... rather than asking family members or going on that NHS website or even sometimes I, I got deterred from texting the health visitor on something that I thought wasn't very important for her. So, to be honest, I don't want the health visitor to think that I'm just seeking advice over every sniffle and cough... The fear of judgment of it allays the fear of just being labelled as the panic, the panicky mum, or an overprotective mum. Without a doubt that that anxiety stops a lot."

(Tracey, Interview Participant, North Tyneside)

Whilst allaying concerns can be seen as a positive feature of the LOB, the above quote highlights additional concerns, such as fear of being labelled, which could influence access to key healthcare services. Again, as outlined previously, an introductory explanation of the LOB and returning to this at follow-up health contacts would be of value in addressing these perceptions.

89.03% of survey respondents who had received and used the LOB, reported it had helped them to identify the most appropriate service. Additionally, **58.54%** of these survey respondents stated that the LOB increased their confidence in requesting same-day GP appointments. The LOB was described as supporting parental decision-making and providing reassurance and increased confidence in relation to accessing healthcare services appropriately:



"It's made me make the right decision and not access services that I don't need"

(P036, Survey Respondent, Gateshead)

"I have been able to look up whether the illness they almost certainly have is something that does/doesn't require a visit to the doctor"

(P088, Survey Respondents, Newcastle)

Participants felt that they were "less likely to seek advice for simple ailments" following use of the LOB (P050, Survey Respondent, Gateshead). It was described as providing the "information needed" (P007, Survey Respondent, Gateshead) meaning that participants no longer felt they needed to contact a healthcare professional:

"So it's give us the confidence and the knowledge of when I can request information from pharmacist rather than automatically to GP."

(Tracey, Interview Participant, North Tyneside)

"It has signposted me to the right service. I feel more confident when to access pharmacy, GP, 111, or home care. Whereas before I panicked and went straight to urgent care."

(P021, Survey Respondent, Consett)

One participant described a disparity between the LOB and healthcare services:

"My child burnt themselves and as per the little orange book, I asked my local pharmacist for advice. Their reaction appeared to be of surprise and why was I asking them. I felt that it was pointless and made me less confident in the advice provided in the book"

(P026, Survey Respondent, Gateshead)

This perhaps suggests that work with key services to raise awareness of guidance in the LOB would be valuable.

The COVID-19 pandemic introduced additional factors to consider within parental decision making, however the LOB was still described as useful as the need to use services appropriately was perceived as increasingly important in order to avoid overburdening services:

"It's such a useful family reference guide and during the pandemic even though my child is over 5 it was so helpful in deciding what action to take"

(P026, Survey Respondent, Gateshead)

"Because I had this resource, it meant I had something... You know, it made me kind of feel that before I start trying to use services that are already struggling because of COVID and COVID-related stuff, having something to, kind of, go and direct me, and go... Make me decide whether or not I actually needed to go that far and start contacting services..."

(Skye, Interview Participant, Gateshead)



"And I used the orange book before that, but I think particularly during COVID and it was like -it was it was good because it was much more difficult and more stressful trying to access healthcare."

(Rebecca, Interview Participant, Newcastle)

For some of the participants, the effect of COVID-19 was subtle but emphasised the need to use services appropriately, particularly if first-time parents to a newborn:

"I mean, the clinics – we can't just walk in – like you have to have an appointment and then the appointments are like three weeks down the line, sort of thing, if not like a month. So little things like that"

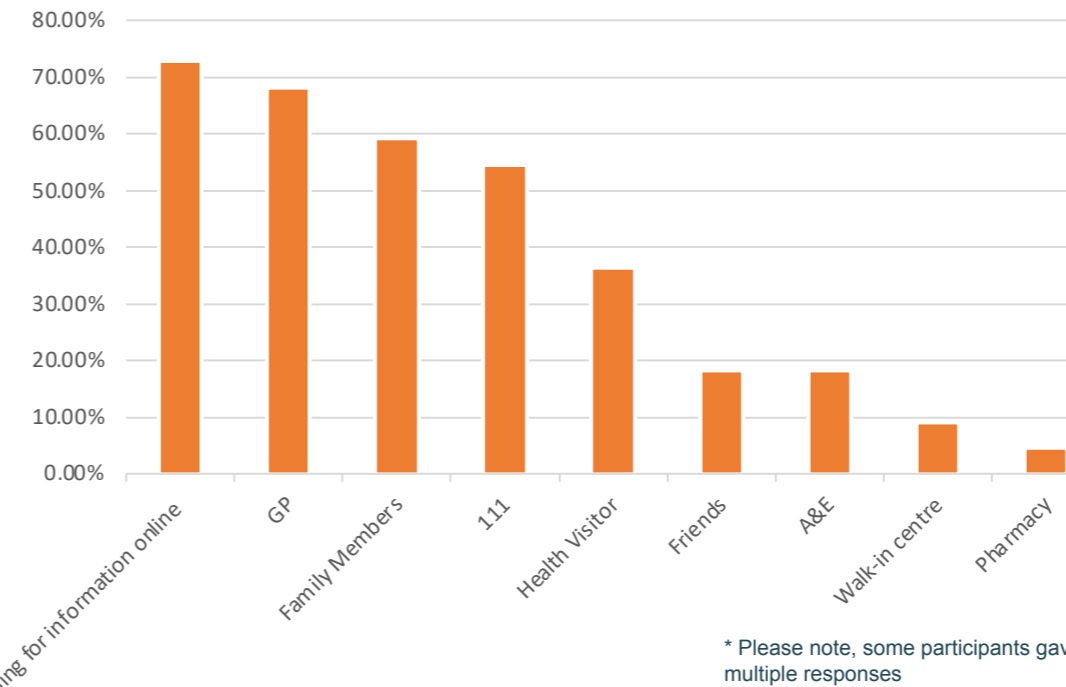
(Lola, Interview Participant, Gateshead)



The experiences of parents/carers who did not receive The Little Orange Book

An overview of how the survey respondents who had not received the LOB, accessed information about their child/ren's health is presented in Figure 8.

Figure 8: Avenue of receiving health information by those who have not received the LOB (N = 75)*



Of the 22 survey respondents who had not received the LOB, **86.36%** felt they could have used this to make decisions caring for their child/ren during illness. Indeed, **54.55%** of the 22 participants who did not receive the LOB reported that they accessed health care services for their child/children during the COVID-19 pandemic and nationwide lockdowns. It is possible that these parent/carers may also have benefitted from accessing the LOB during this time.

These respondents describe instances where the LOB would have been valuable:

"When my child first showed signs of chickenpox but it was unclear to us whether it was definitely the virus."

(P075, Survey Respondent, location not provided)

"Basic steps to take but most importantly what signs are that something is more serious"

(P095, Survey Respondent, location not provided)

"I was not given a little orange book when I had my children but on the preview page it would have been helpful to have more info on conjunctivitis as my daughter had as a newborn and I wasn't sure what to do"

(P092, Survey Respondent, location not provided)

Making decisions about Attending education settings

75.61% of Survey Respondents stated that the LOB helped them decide whether their child/ren should attend educational settings (such as nurseries and schools):

"It is an excellent tool for understanding common child health issues and helps put parents at ease about caring for their child and accessing the right service. Also perfect for knowing if they can attend nursery/ school..."

(P021, Survey Respondent, Consett)

"Referred to book to check if child could go to nursery with conjunctivitis"

(P022, Survey Respondent, Gateshead)

"You know, because she had chickenpox. Like, it was quite useful to know, you know, how long they should stay off school for and stuff like... That information is in there. Yeah, and I guess just about... Like, I do like the first aid section of it"

(Penelope, Interview Participant, Gateshead)

"But pre-COVID and now that things are getting a bit more back to normal, it was really helpful, in terms of should they be off or not."

(Wilma, Interview Participant, Newcastle)

However, some of the participants felt there was a mismatch between the advice given in the LOB and their nursery policy:

"I suspect different nurseries will have different policies... I can't remember what it was, but I think I remember thinking that what was considered green, amber and red wasn't necessarily what our nursery was... Because, for some of them you can say can you be off nursery or not... Yes/No. And I think our nursery... I felt like was taking more of a blanket kind of... You can come in if you've got a cold, but that was kind of about it... And anything else, you needed to have a PCR test for everything else. And I thought, well, if this book is telling you no, they can go to nursery, but the nursery [says no]"

(Patti, Interview Participant, Newcastle)

Whilst the LOB has a clear value in helping parents and carers make decisions about sending their children to nursery/educational settings, as with health networks, there is a need to work with key education providers to ensure that policies and advice in the LOB align.

The experience of first-time parents

48.78% of survey respondents who had used the LOB were first-time parents. Of these only 11 respondents had a new-born child and 56% of these reported that the LOB influenced how they would usually access healthcare services. It was clear that there were some specific benefits for first-time parents, particularly those without family support:

"To help them make informed decisions, especially for first time parents who don't want to feel silly by contacting a GP, etc"

(P067, Survey Respondent, Unknown)

"As a first-time parent, it eases my anxiety in knowing how and when to access appropriate medical care for my child."

(P006, Survey Respondent, Gateshead)

"I thought was brilliant idea and especially as a first time mom... I don't have my parents, so I can't ask them about things. I can ask my grandma, but obviously she's older, so it's more of like old fashioned values and it might not be up to date with what's recommended to do now so I thought it was a brilliant idea – even just to learn about them without scaring yourself"

(Tracey, Interview Participant, North Shields)

"It's got its own place. So, I know where it is. My husband knows where it is. We both know where... So, we can all... If we do just have a concern or we just want to know something... You know, as first-time parents, you know, everything is scary. You know. So, being able to go, oh, actually, no... No, she's fine. She's fine."

(Skye, Interview Participant, Gateshead)

"Yes - lots of lessons learnt from child one that can be used with child 2. Inexperience with child one made healthcare decisions much harder."

(P074, Survey Respondent, Newcastle)

It was unclear how useful the LOB was to parents/carers of multiple children. Participants who reported having more than one child were less anxious about their child/ren's health, less likely to access healthcare services, and were more confident making healthcare decisions:

“Has made me less worried and anxious and not feel like I need medical assistance unless emergency”

(P003, Survey Respondent, Gateshead)

“Yes. I’m less anxious certainly about many minor viral illnesses than I was when I had my first children, but sometimes maybe more anxious. For example my eldest son had a febrile seizure as a baby and I find myself much more concerned about fevers than I used to be this time around.”

(P016, Survey Respondent, Gateshead)

Those with multiple children described how a growing amount of experience dealing with symptoms of childhood illness, made finding new information in the LOB less likely:

“It doesn’t contain anything of use to me, I got it when I had my third child.”

(P005, Survey Respondent, Unknown)

Despite this, survey respondents who reported a large age gap between children valued the resource for providing up-to-date information:

“I have a nine year old and 19 month old. I feel that social media awareness of illnesses have probably unintentionally kept me up to date. I always think it’s good to go on instinct but myself and husband are reluctant to use already pressured NHS services so we’ll do check online and the book for certainty prior to accessing services - unless an emergency”

(P020, Survey Respondent, Newcastle)

Summary

Findings suggest that the LOB plays an important role in parental decision-making regarding the use of health care services and sending children to educational settings.

A strength of this evaluation is that the views of parent/carers who had not received the LOB were included. These participants reported feeling that the LOB would have been helpful in supporting previous healthcare decisions they had made about their child/ren. This further supports the need for wide and inclusive distribution.

Parents described the LOB as helpful in improving confidence in deciding whether to monitor symptoms of illness and when to access further advice and support. In particular, a group who described this lack of confidence in assessing risk and making decisions were new parents. This group reported the LOB to be a valuable source of information, highlighting the importance of ensuring distribution amongst new parents.

It is important to determine how different groups benefit from the LOB to help inform a targeted approach to dissemination, as well as understanding the level of engagement and explanation needed from healthcare professionals, such as health visitors. With a more focused approach which encompasses specific groups of healthcare professionals, such as health visitors and midwives, to disseminate the LOB, there would need to be a streamlined approach to continued training/updating of key professionals.

RECOMMENDATIONS

- Alongside previous recommendations to expand the reach of the LOB, to develop a more focused approach to distribution to ensure that all new parents have access.
- To ensure that parents/carers understand the LOB is to support their existing knowledge and parental judgement and instincts.
- To provide and/or raise awareness of the LOB as part of universal and targeted provision.
- To ensure that all key services (health and education), who are the point of contact for parent/carers regarding their child/ren's health, are aware of, regularly updated and encouraged to signpost the LOB.



The design and format of The Little Orange Book

This section will focus on the content and format of the LOB, including perceived credibility and key features such as the traffic light system, pictures and the format.

The credibility of The Little Orange Book

Of the 106 Survey Respondents who received/accessed the LOB, **76.42%** reported using it when their child/ren were unwell. It was clear from the qualitative data that the LOB was seen as a trustworthy and reliable resource to access advice and information. This view was largely due to the LOB's association with the NHS:

"Because it is... You know, medically, it's come from the NHS... It's come from a reliable source. And that's the information that you would get, probably, first if you rang 111. So, yeah... I've got masses of confidence in the orange book."

(Penelope, Interview Participant, Gateshead)



"Feels more reliable than searching online for answers"

(P053, Survey Respondent, Unknown)

However, despite noting the value of the LOB for informing parents and providing reassurance, one interview participant felt that the resource was designed to dissuade general access to emergency services:

"...it does, kind of, deter me from seeking other advice, because I can just look something quite simple up in the book, and that's the end of it. I feel better and I can, kind of, leave it at that... I felt the whole tone was a little bit of a kind of... Deterrent from [accessing services]. Kind of, just phone 111 if you're worried. It does kind of... If you want urgent help, phone 111. Which I thought was odd, because why aren't we phoning 999?"

(Francine, Interview Participant, Gateshead)



There was a debate about how to ensure the LOB was kept up to date in order to continue providing current and reliable health information. Some interview participants were unaware of new versions of the LOB:

"I've just noticed this newer version actually has, like, off nursery or school - and it's got a yes and a no circle. I'm downloading this newer version..."

(Jessica, Interview Participant, Newcastle)



Visual content and layout of The Little Orange Book

The traffic light system is a key feature of the LOB which aims to help parent/carers understand the severity of symptoms of childhood illness and, in turn, make decisions about how these are managed. Many interview participants viewed the traffic light system as simple, clear, quick and easy to use, helping prioritise and allay concerns about childhood illnesses.

87.00% of survey respondents who had received and used the LOB reported that the traffic light system helped guide them. This was reinforced during interviews:

"I've definitely used it for, like, fever. Like, you know, if they've got a temperature - working out at what point is it that I could be calling 111 or whatever. I find, like, the traffic light system quite good."

(Penelope, Interview Participant, Gateshead)

"...the colours are really helpful and that kind of traffic light... system is really helpful. It's consistent throughout and it helps with that kind of accessibility that I mentioned and that you know, I guess even if the text is a challenge to you, you can see by the colour system like how alarming something is or is not, which is really positive"

(Mona, Interview Participant, Newcastle)

Whilst some of the participants used it for general childhood illnesses, such as raised temperature, others felt it had value in managing their child's symptoms in the presence of a long-term condition:

"And with my second we already do a traffic light system for his heart as he's got three heart conditions and I find it a lot [less] stressful having something to follow so we aren't always in the hospital for non important stuff."

(P102, Survey Respondent, Chester-le-street)

82.93% of the parents/carers who had received and used the LOB felt that pictures and visual images were helpful in managing symptoms of childhood illness. Images guided participants to identify symptoms and supported them in determining the correct course of action:

"... I like that there's pictures of the various rashes or, you know, ailments that they're describing, because that's sort of what you're looking for as a parent"

(Wilma, Interview Participant, Newcastle)

"it's give us that confidence not only to recognise ailments, but to know how to deal with stuff. And to have it that I know it's there and that can refer back at any time. I don't have to remember all of the information about chicken pox or remember all of the information."

(Tracey, Interview Participant, North Tyneside)

"...And it's got like the thermometer in the baby's armpit - just even that, which I think is quite useful just to - a quick "Oh, right - if I don't want to read the whole thing, this is where you've got to put it, this is what you've got to do" or read the instructions that come with the thermometer. You can just look at the picture and to "Oh, right. Okay. That's how I do it." And it just makes it a bit quicker overall."

(Lola, Interview Participant, Gateshead)

Whilst **47.56%** stated that they would like more pictures included, **37.80%** were indifferent and **13.42%** felt more images were unnecessary:

"And there are some pictures of different examples of rashes, there's hardly any pictures compared to the ones on the website"

(Bella, Interview Participant, Newcastle)

Some participants felt the visual content could be more inclusive:

"Wouldn't recommend for dark skinned babies. Can be life threatening for e.g. meningitis is not red spots on a dark skinned baby"

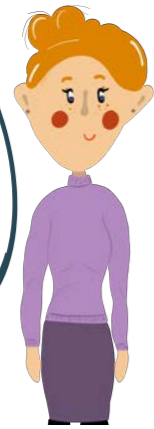
(P132, Survey Respondent, Newcastle)

"The pictures are alright. But I feel that maybe they should... I don't know if it's a factor, but I think they should use babies of different races in here. Have a picture of an Asian child, a French... I don't know... Different...[....] So... Maybe, back to what I was saying, if you can include fair and brown kids with rashes, to indicate also how does it look like... Instead of fair skin and then the redness of it, maybe. That's my thought"

(Angelica, Interview Participant, Newcastle)

"I suppose one thing, just to be... I know this is an overall problem - all of the babies are white in here"

(Jane, Interview Participant, Newcastle)



92.69% of survey respondents who had received and used the LOB reported the layout of the LOB as "good" and "useful". Interview participants valued the separation of conditions and use of 'tabs'. Some suggested that these 'tabs' could be further developed as a physical index divider to aid navigation:

"So, when it's got the tab and it tells you what you can do for that condition at home and it's bullet-pointed, which I think is really good [...] I think it's got quite good pictures in it, especially for the rashes and stuff like that. I think..."

(Daisy, Interview Participant, Newcastle)



"I think it would be kind of useful if it had sort of like little tabs almost down the side, so you could very quickly just flick to what you needed to, rather than potentially going past it and then having to go back through, which is why we tend to sort of go to like a Google search kind of thing, because then the answer's going to be right there hopefully. Where you can quite easily like miss a page – pages might get stuck together – things like that."

(Lola, Interview Participant, Newcastle)



Written content

92.60% of survey respondents who had received and used the LOB reported that the information provided was easy to understand. Feedback suggested that the information was relevant, accessible, clear and concise:

"It's a clearly laid out information source. Gives simply written information with appropriate illustration and highlights what to look out for."

(P006, Survey Respondent, Gateshead)

"Useful at a glance information that isn't too medically complex but enough to understand the severity of an illness"

(P036, Survey Respondent, Gateshead)

"It was a quick reference guide with succinct information. Better than using internet"

(P041, Survey Respondent, Gateshead)

"The book contains information on the most common illnesses I have encountered in my children from birth"

(P080, Survey Respondent, Newcastle)

Whilst the content of the LOB was generally well received, there were mixed opinions about whether the depth of information was satisfactory. Some participants describing this content as "quite vague" (P125, Survey Respondent, Newcastle), however this could be influenced by the context of the situation and grounded in participant's prior experiences:

"You know, there's that sort of contents page, so you can quickly see where you want to be, you know, in terms of flipping to what it is that you need. It doesn't feel like there's too much information in there. So, it's usually all quite concise and relevant... You know, it's very sort of, you know, handily sized and easily thumbed through at the minute. And because it's that size, it fits in a cabinet. You know, like it's not a big A4 thing, so I think it's probably good as it is, you know"

(Wilma, Interview Participant, Newcastle)



"It's just little tidbits of each thing. So... If you were really... Like, if it's kind of... If you feel like it's really urgent, or if you want, kind of... More of an understanding of something, and more of a talk through on something – it's kind of a quick paragraph on each thing, really. And it doesn't kind of say what to do next"

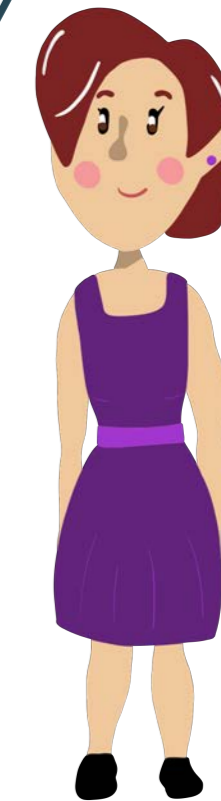
(Francine, Interview Participant, Gateshead)



Parents did recognise that adding more information and detail would detract from the intention of the LOB as a quick reference guide:

"I wouldn't like to see the book being too bulky, if I'm honest, because it is a quick reference guide. And I think that's what it should be used for. But I do think there could be a little bit more context to it."

(Bella, Interview Participant, Newcastle)



Opinions about the format of The Little Orange Book

Despite an online version of the LOB being available, three interview participants, Penelope (Gateshead), Bella (Newcastle) and Rebecca (Newcastle), were not aware of this prior to participating in this evaluation.

There was variation amongst the participants regarding the most useful format for the LOB, some valued a hardcopy:

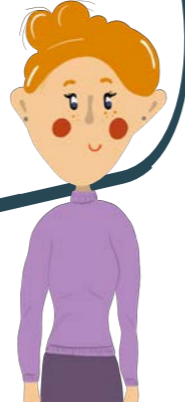
“There’s something about having a hard copy in your hand there, particularly if you’ve got a little one there you know, and you’re dealing with a screaming child and you’re kind of stressed and. You, you, don’t maybe feel like -I don’t know, there’s just. There’ll be something probably to do with - how your brain functions looking at something electronically scrolling through it, but actually having something in your hand and looking at it”.

(Rebecca, Interview Participant, Newcastle)



“You know, I don’t want an online PDF, for example, I mean, I know it is available online, but if it was online, I just wouldn’t have look[ed] at it”.

(Jane, Interview Participant, Newcastle)



Some others expressed a clear preference for a digital version of the LOB, such as a mobile phone app:

“Remembering to use it as it’s not an app on my phone like other resources... A good resource but not as accessible as an app. Have to save link and can’t find where this is saved.”

(P057, Survey Respondent, location not provided)

“I like having it in hand. That probably costs them more to produce, but it is nice to just be able to grab. And it would seem like it would be more logical just to have it online and scroll through, but there’s something about an old-fashioned book that I like to be able to pick up. And, like I said, you can put it in the changing bag or... Whoever is looking after her knows that that’s in there. Just to think, oh, was that okay and...? I quite like having it to shove somewhere and... In the, kind of, first aid kit, kind of thing”.

(Francine, Interview Participant, Gateshead)



“I am unlikely to use a paper copy. An app would be useful for a digital copy”

(P085, Survey Respondent, location not provided)

One participant who had used the hard copy of the LOB suggested that different formats of this information may alter the way in which they used it, giving the example that a mobile app would mean that other people involved in a child’s care could have access to the information:

“If it’s through an app, it’s more accessible for someone and then as well, both parents could have the app on the phone... and even grandparents could have the app on the phone if grandparents were looking after little ones who become unwell.”

(Norrie, Interview Participant, Gateshead)



What was clear from parents was that current advice was essential and even for those who had a preference for a paper copy of the LOB, they acknowledged that this may lead to problems and the potential for out-of-date information to be in circulation:

“You know, but there is that risk. I’m all about version control, but there is, yeah, that risk there that you could have a very outdated one”.

(Jessica, Interview Participant, Newcastle)



Summary

In summary, parents/carers viewed the content of the LOB positively. There was a general consensus that the traffic light system should continue, and that this provides a valuable way for parents to assess symptoms of childhood illness and make decisions about monitoring and seeking further advice/intervention. Similarly, pictures and visual content were praised, however participants stated that these should be more inclusive of all members of the community, particularly those of minority ethnic origin.

There are conflicting views about the format of the LOB. Given that literature suggests the internet serves as a frequent source of information, but also that health information seeking represents a dynamic, developing process (Ramsey et al., 2017), it would seem sensible to provide the LOB in a range of formats to maximise the usefulness of the information. What is clear that there needs to be consideration of ensuring the content remains up-to-date. This is, perhaps, less of an issue with a digital version, but future editions should clearly identify the version, date of publication and disclaimer that the content was correct at the time of publication.

RECOMMENDATIONS

- To continue to include visual content, in particular the traffic light system and images.
- To improve the diversity/inclusivity of images, particularly in photographs used to show complaints (such as rashes), to better include individuals of minority ethnic origin.
- Decisions about adding more detail/depth to the hardcopy LOB should be treated with caution. One solution would be add further detail to a digital resource, which the hardcopy could signpost parents/carers to, if they require more information.
- Future versions of the LOB would benefit from a clearly identified version number, date of publication and a disclaimer that the content was correct at the time of publication



CASE STUDIES

Three case studies are presented below to provide an in-depth understanding of the experiences using, or the value of receiving, the LOB.

Case Study 1: Skye

Skye is a 34-year-old female, who lives in Gateshead, and is currently on maternity leave. She and her husband have recently become parents after having their first child Susie, who is now five months old. When Susie has been unwell, Skye has used the NHS 111 service and contacted her General Practitioner. Skye was aware of the LOB and has used both the paper and online versions of the book. Her health visitor provided her with a copy of the LOB in 2021-2022. She accessed the online version of the LOB via an app that lists children's health services, although she acknowledged it can take time to access and would benefit from being a separate digital app. She felt that the online version was more accessible when traveling but prefers the booklet when at home. Skye has learning difficulties (dyslexia) and uses a lot of online apps and resources to support this but finds being able to handle a physical book easier for her.

“... Not turning a mountain into a molehill...”

The book, which she keeps on her daughter's changing table, provides reassurance when she is concerned about her daughter's health and can “nip a concern in the bud before it becomes a full-blown panic”. Reducing her feelings of panic means she does not access NHS 111 or 999 emergency services unnecessarily. Experiencing a pregnancy during COVID-19, at a time when face-to-face consultations were reduced, meant that Skye felt she had a resource to access without contacting over-stretched services.

“... I think, really strengthens my confidence to be a parent.”

Having a dedicated location for the book enables both Skye and her husband to access it quickly. Skye does not have any family who live locally who are able to support her decision-making. The LOB has provided support to her to know whether she needs to access services urgently and when and how she can manage Susie's health at home.

“Just a little anti-worry guide”

The LOB stopped Skye from calling others for advice or searching online which she felt often made her panic. She felt the book took her first-time parent worries away. Skye believes that the LOB should be distributed more widely to others, particularly first-time parents. She felt the LOB empowered her to advocate for Susie by providing her with knowledge of common health conditions.

Skye reports that due to having dyslexia, visual images and the traffic light system in the LOB supported her to access information. Additionally, because the LOB uses blue text, she found it easier to read, with clear headlines and information separated into boxes.

“From a dyslexic point of view ... it's actually easy to read.”

Skye feels that she may have benefitted from receiving the book prior to birth, for example during antenatal classes. She felt that the book may benefit from having the title changed due to potential confusion with the red book.



Case Study 2: Angelica

“... Grandma’s old tales ...”

Angelica is a 34-year-old, Black-African, female. Angelica has two children; Vicky who is 10 years old and Jake who is 17 months old. In the past year, Angelica has used several forms of healthcare services when her children have been unwell. These services included NHS 111, the local walk-in centre, consulting her GP and emergency services at the hospital.

Angelica was informed about the LOB by her midwife and was provided with a version of the book via email. She received a paper copy of the LOB in 2021-2022 when she attended a vaccination clinic with her youngest child. She did not keep the email due to online storage space and felt that accessing the book online was more difficult than a paper version.

“but then again, coming from my ethnic background, we have a lot of superstition and all sorts of home remedies ...”

Before moving to the UK, Angelica was used to using the “superstitious remedies” provided by her mother and was frequently supported by her mother when managing her eldest child’s illnesses. Angelica found that the LOB conflicted with the advice that her mother provided. Angelica chose to follow the advice provided in the LOB reporting that she prefers to “stick to science”.

“... and then she’s like, no, we are Africans and white people do not know how to heal children”

Angelica noticed differences in healthcare provision between the UK and Africa, reporting that antibiotics would be more frequently given in Africa for “flu”.

“I couldn’t understand, how does the body heal itself”

She also noted differences with circumcision practices, which the NHS does not provide, unless for a medical reason. She has had thoughts of recommending the book to a friend who has immigrated from another country but feels that they may doubt the advice it provides. Angelica queried whether it was possible for the LOB to be translated into other languages such as Urdu to support accessibility. Angelica acknowledged that the illustrations within the LOB were ethnically diverse. However, she felt that inclusion of photographs of rashes and skin conditions on children of different ethnicities would be beneficial, particularly as those conditions can be hard to diagnose on different skin tones.

“And then she (doctor) made a joke of, like ... I’m so sorry, but doctors – white doctors are not good at diagnosing eczema on skins of brown kids.”



Angelica’s youngest child was born during the COVID-19 pandemic. She was unclear about healthcare changes due to it being her first experience of birth in the UK but felt that it did not change how she accessed services. However, after her son experienced a hospital admission due to COVID-19, Angelica felt that information specific to the virus should be added to the book. She used the LOB during the pandemic because it was readily accessible to her.

Angelica felt that the LOB could include links to signpost parents to mental health support should they need it. Angelica previously benefitted from attending a children’s first aid course and felt that other parents would benefit from a link to training options. Angelica gained confidence after reading the LOB. She felt that the LOB both saved her time and reduced unnecessary visits to healthcare providers. She felt that the traffic light system supported her decision-making. It also provided immediate support when waiting to speak to professionals. It has reduced her feelings of panic when her children are unwell or following an accident.

Case Study 3: Helga

Helga is a 37-year-old Asian-Chinese woman who lives in Newcastle-Upon-Tyne. Helga has two children aged three years old and seven months old. Helga did not receive a copy of the LOB. She is employed on a part-time basis. Other than postnatal care and routine childhood appointments (vaccination), Helga has not needed to access healthcare services in the past year, as her children have not been unwell.

Helga reports that she is relaxed about healthcare based upon her previous experiences. This was demonstrated in her reluctance to access healthcare services for eczema due to not considering it to be an “illness”. Prior to taking part in this evaluation, Helga was not aware of the LOB. She has received a collection of leaflets and the red book when her children were born.

To manage concerns with her children’s health, Helga typically consults the NHS website.

“Because I normally have had to always check NHS website and go...?”

At first glance, Helga felt that the LOB contained a lot of text, however that personally suited her method of accessing information.

“It’s quite wordy”

Helga commented that the volume of pictures felt “overloaded” but also recognised the benefit of viewing images to understand the severity of a condition.

“I always find it quite reassuring when you look up NHS, the picture they give you are usually much worse than what your child’s got.”

Helga felt that a health and illness resource for young children should typically include whether remedies are available over the counter to support home-management of common childhood illnesses, for example, chicken pox.

She felt she would prefer to use a physical copy of the LOB rather than to access an online resource and indicated that she would travel with a physical copy of the book.

“In an emergency that’s even better, because one thing I don’t want is having to use my phone while my hands are full.”

Helga describes that she and her husband have different approaches to the management of their children’s health, partly due to her own family members having professional medical experience. A trusted resource such as the NHS can evidence and support decision-making between parents and grandparents, who may have a different approach. Helga referred to the book as an “authority” and that it would be “reassuring”, particularly at a time when children are “unwell and you’re already kind of firefighting” as a couple.

“But if you have something physical you can go ... here’s the book... it’s not ... I’m not making this up...”

When considering the decision-making processes of the couple, Helga feels that the physical nature of a book would support shared decision-making rather than independent internet searching. She also felt the book could be shared with her children.

“... I don’t really want to try any old ... you know, old wives’ tales and mysteries ...”

Helga trusts the NHS and information provided, based upon previous positive experiences with her children. She reports that she does not consult non-NHS websites and resources such as “mum’s websites”, because she feels listening to the advice of health professionals has been sufficient. She felt access to a copy of the LOB would reduce the need for healthcare appointments.

Helga believes that her approach to illness has changed between her first and second-born children. She is now less reluctant to administer medication such as Calpol. She felt that the only thing that would prevent her from using the LOB was if it contained inaccurate information or was “too biased” with “an agenda”.

“only if it turned out to be wrong ...”

Helga felt that the LOB design was dated but also noted that it served its purpose. She also suggested that it would be improved by allowing space for notetaking. She felt that merging the LOB with the red book may be beneficial.

“for you to develop a record of things... you know, like a disease bingo...”



DISCUSSION

Dissemination practices

Our evaluation showed that there was variation in approaches to distribution across Newcastle and Gateshead. This led to some parent/carers either not receiving the LOB or having awareness of it and others being offered the resource multiple times. This variation reflects concerns about postcode lotteries or unequal access to health. These concerns have been well documented and continue to feature highly in government policies where the need to level up and reduce health disparities are key priorities (Department for Health and Social Care, 2021).

These findings suggest that the approach to disseminating the LOB is reviewed and that a streamlined approach is introduced using a small number of key services, such as midwives and health visitors, to disseminate the LOB. This approach could be further supported by wider strategies to raise awareness of the LOB in addition to the availability of copies that could be provided opportunistically to individuals who are not aware of the LOB or do not access these services.

Opportunistic distribution may be beneficial by services including community organisations, pharmacies, GP surgeries and acute health services such as A&E.

Using universal services, such as midwifery or health visiting services, as the main approach to dissemination of resources for parents/carers with pre-school children (Public Health England, 2021) would help address the varied access noted in this evaluation, as well as allow for first-time parents to be prioritised. Whilst it is accepted that both professions are experiencing significant challenges, particularly in relation to staff shortages (Royal College of Midwives, 2022; Institute for Health Visiting, 2022) this approach would not require new ways of working and could easily be incorporated within current approaches to service delivery.

Alongside a strategic approach to dissemination, thought should be given to how the LOB is provided/promoted. Our evaluation showed variation in relation to whether an explanation about the role of the LOB was given and that parents /carers would welcome this, as well as the value of reminding parents/carers about it at ongoing universal, targeted, specialist and opportunistic contacts. Again, this would not require significant changes to practice, and this could be incorporated within these existing contacts.



Role in parental decision-making

Participants who received the LOB viewed it as extremely important in assisting decision-making when children were unwell. Those who had not received the LOB recounted occasions where they believed the LOB would have supported their decision-making processes about their child/ren's health. While it is not possible to draw conclusions on whether or not this resulted in more 'appropriate' use of services, it is valuable to understand that this source of information was used in the decision making and a previous study suggested that parents with access to resources containing information about symptoms and home care may be more likely to access care unnecessarily (Schneider et al, 2019). It is perhaps important to note that 'less' use of healthcare services does not necessarily equate to more appropriate healthcare and metrics such as 'inappropriate Emergency Department attendance' may overlook the need to ensure that children access emergency services when they need to.

While the LOB was seen as giving valuable guidance, there were some concerns from parents/carers about the role of parental judgement within decision making. However there were counter examples of where parents and carers described listening to their instinct when it came to making healthcare decisions.

Conlon (2021) described a process in which parents decide to use care once they exceeded a 'threshold' over which they were not confident to manage their child's condition at home. Relating this to data from this evaluation, parents described a group of health concerns which were neither a condition which could clearly be managed at home, or a condition requiring urgent care. It was within these 'middle ground' conditions where the LOB may have been particularly useful. Furthermore parents described the LOB giving them information and tools to help manage their child/ren's condition at home which could be interpreted as helping to raise this threshold. The idea of increasing parent/carer confidence and ability to recognise and treat non-serious health conditions at home while being able to identify serious concerns is in keeping with the original aims of the LOB. This supports further emphasis on the need to view the book as a resource to be used in conjunction with personal judgement and instinct.

While participants emphasised the role of the LOB within decision making, this is clearly a complex process incorporating the parent/carer's level of confidence and parental intuition. This further emphasises the potential benefit for providing the LOB as part of a process of engagement. Elsewhere in the NHS, the emphasis to 'Making Every Contact Count' has seen health professionals incorporating lifestyle questions into routine appointments; while the focus of the LOB is outside this remit, viewing it as a tool to promote conversations with healthcare professionals may both increase the visibility and utility of the resource; as well as through existing distribution channels such as health visitors and midwives, routine and emergency healthcare settings, such as GP emergency departments, out-of-hours services and walk-in centres may offer opportunity for conversation.

In addition to decisions about healthcare settings, the LOB provided information to help parent/carers to make judgements about whether or not to send their children to educational settings. This is an important intersection between healthcare and education settings and previous research has highlighted a complex decision-making which takes into account the nature of child/ren's illness but also the policy of the school/nurse and personal circumstance (Carroll et al, 2016). Several parent/carers highlighted that the information in the LOB was inconsistent with policies of their particular school or nursery. This highlights the need for awareness of the book among education providers and the value of joined-up practice.

COVID-19 appeared to introduce further complexity with regard to availability of services. While parent/carers did not explicitly describe avoiding treatment for health concerns, they did describe COVID-19 being a consideration in relation to the availability of services and whether they should be accessing services overstretched by a public health emergency. In light of serious concerns and reports from health professionals (Lynn et al, 2021) and suggestion that fear may prevent attendance (Lazzerini et al, 2020), it is important that parents understand if, and how, public health emergencies such as COVID-19 affect how they should use services. While it is not possible to predict the nature of future public health emergencies, this study flags the need to consider how best to inform parents about how they should use health services for their child/ren in these scenarios.

Content and format

Parent/carers valued the inclusion of visual content, in particular the traffic light system which provided a straightforward point of reference about the severity of symptoms of childhood illness and therefore aided parent/carer decision-making. Of note, was the image which facilitated identifying different rashes, however limitations were raised regarding inclusivity and more pictures of individuals from minority ethnic backgrounds were requested. A previous systematic review identified ethnicity as a 'pre-disposed' factor influencing unscheduled paediatric healthcare use (Nicholson et al., 2020). It is possible that inclusion of inclusive images could impact access to services as well as uptake of the LOB. Future versions of the LOB should aim to be more inclusive and representative by offering an expanded catalogue of example images.

Participants reported that the content included in the LOB was useful and appropriate, describing instances where this increased confidence, provided reassurance, and aided decision making. It was clear that perceptions of the information were influenced by the parent/carer's prior experience and based on their child/ren's health history.

Survey respondents encompassed a range of parents who had received the LOB over a six-year period (from 2016-present day). Whilst this is representative of a wider group of parents/carers, given the changing nature of health advice, it is clear that some of these parents/carers have a copy that contains out-of-date information and advice. The concern of ensuring that advice was kept up-to-date was expressed by both survey respondents (Phase One) and interview participants (Phase Two). It is important that the LOB incorporates some form of version control, such as a version number or date of publication, as well as an acknowledgement that the information contained in each edition may be subject of change in later copies.

Whilst it was clear that a hardcopy of the LOB was valuable to some of the participants, parent/carers acknowledged the value of a digital version. Key advantages included transportability and the ability to share with others more easily and efficiently. Recently, the Department of Health & Social Care (2022) outlined the future plan for the continuation of incorporating digitalisation in health and social care. In this plan, there is a focus on promoting independence in managing health by increasing the performance of pre-existing digital resources, such as the NHS website or App.

There will continue to be a transition towards more digital-based care in order to encourage service users' independence in managing their, or their child/ren's, health. However, whilst the advantages of digital resources are clear, it is important to ensure that these should not act as a replacement for hardcopies. Doing so, would reduce uptake and restrict access to populations who are digitally excluded. In 2020, The Office for National Statistics reported that internet access is increasing and currently 96% of UK households have access, however it is clear that the remaining 4% could be disadvantaged in terms of health resource access. There has been four key reasons for digital exclusion identified, those who see no benefit to digital access, those who report not having access to the right support to get online, viewing technology as too complex, and financial reasons (French, Quinn and Yates, 2019).

Other points of consideration

One point of consideration is the difficulty recruiting an adequate sample size for the online survey and brief feedback cards (Phase One). Initially, information about the survey and feedback cards were disseminated across GP surgeries and key locations, across Newcastle and Gateshead, who were identified by the NGCCG as having received and distributed copies of the LOB. It became apparent that this was not an effective recruitment or cost-effective strategy due to limited survey responses and only 5 returned brief feedback cards. Investigations revealed that the posters/feedback cards had not been received or these organisations would not, or in some cases lacked the capacity, to advertise for research studies. Alternative recruitment methods, such as Facebook advertisements or contacting parent/children groups, were shown to be more effective and resulted in 126 survey respondents. However, this did not meet the initial recruitment target. Future research could further explore recruitment options following the COVID-19 pandemic to ensure the most effective approach to reaching eligible participants.

As noted previously in this section, the COVID-19 pandemic produced significant pressures on health services, the legacy of which, continues and is reflected in recent concerns about workforce pressures. Midwifery and health visiting shortages are of key concern in relation to the LOB. Additionally, the need to restore services and uptake of these within local populations is needed (The Kings Fund, 2022) and participants in this evaluation referred to reluctance to add to the burden on services alongside remote consultations and reduced contacts with health care providers. This may help explain some of the challenges we have faced in recruiting parent/carers to this evaluation.

Strengths and Limitations

A key strength is that this evaluation has built on prior work by incorporating the views of parent/carers who have not received a version of the LOB. In doing so, this offers a unique viewpoint into reaching a demographic who have been missed, raising awareness of the LOB, whilst also exploring the value of introducing such a health resource to this population. However, it was difficult to identify the ages of the children of these parent/carers who responded to the survey and, whilst some of this group were eligible and should have received the LOB, it is possible that some of this sample had older children. Despite this, these parent/carers could still offer a unique and valuable insight based on their prior experiences.

As previously outlined, this evaluation used a range of different recruitment methods for the Phase One online survey which reflected ongoing attempts to increase response rates. In total, 128 parents/carers completed the online survey and the numbers within each group (received and used the LOB, received and did not use the LOB, and did not receive the LOB) varied.

Similarly, only 16 parent/carers participated in Phase Two with the majority of these based in Newcastle. It is possible that recruiting a larger sample could further incorporate the views and experiences of parent/carers from both Newcastle and Gateshead, and strengthen findings.

Whilst the majority of survey respondents and participants were white females caring for their own birth children, both Phase One and Two incorporated the views of other demographics, such as males, individuals of minority groups, and parents/carers of fostered or adopted children. The ability to recruit a more diverse sample, perhaps with a focus on male parent/carers and those from more varied ethnic backgrounds, would provide a more representative view of the facilitators and barriers to using the LOB, experiences of use, and views of format and design.

Finally, this evaluation focused on the views of the LOB as a concept as opposed to focusing on specific versions. This does mean that it was not possible to determine the impact of changes between versions. For instance, the inclusion of more images and advice regarding COVID-19, which features in the more recent versions. However, in doing so, this evaluation included a range of views from parent/carers at different points of the parenting journey whilst also highlighting the importance of version control and ensuring that information is up-to-date.

RECOMMENDATIONS

Recommendations for practice

The following recommendations for practice are provided:

- 1) To review and develop a strategic approach to disseminating and raising awareness of the purpose of the LOB across Newcastle and Gateshead (and across the North East and North Cumbria). Emphasis should be placed on initial dissemination and explanation by community health services. Priority should be given to first-time parent/carers and those with a large gap between children.
- 2) When disseminating the LOB, professionals should ensure that parent/carers understand the LOB is to support their existing knowledge and parental judgement and instincts.
- 3) To provide and/or raise awareness of the LOB as part of universal and targeted provision (such as health visitors and midwives).
- 4) To ensure that all key services (health and education), who are the point of contact for parent/carers regarding their child/ren's health, are aware of, regularly updated on and are encouraged to signpost the LOB.
- 5) To continue to include visual content, in particular the traffic light system and images.
- 6) To improve the diversity/inclusivity of images, particularly in photographs used to show complaints (such as rashes), to better include individuals of minority ethnic origin.
- 7) Decisions about adding more detail/depth to the hardcopy LOB should be treated with caution. One solution would be add further detail to a digital resource, which the hardcopy could signpost parent/carers to, if they require more information.
- 8) Future versions of the LOB would benefit from a clearly identified version number, date of publication and a disclaimer that the content was correct at the time of publication

Recommendations for enhancing the content and format of the LOB

- Include a clear version number, date of publication and disclaimer that content of the LOB is correct at the time of publication.

- Photographs should continue to be included. The inclusivity of these could be improved to show how complaints such as rashes can be identified in individuals of minority ethnic origin.
- Consider adding more depth to the LOB with caution. We propose clear signposting to further detail in an additional digital version or resource.

- The traffic light system should continue.

Recommendations for future evaluations of the LOB

Future evaluation of the hard-copy and digital version of the LOB are needed to understand ongoing impact and contribution to knowledge of and management of childhood symptoms. Emphasis should be on understanding the impact on:

- The mail-shots (postal method) had limited impact on recruitment and should be reviewed in future evaluations as it is unclear whether parent/carers were given access to the recruitment materials.
- The use of brief feedback cards or the method of distribution of the feedback cards may require review in future evaluations as only a minimal number were returned.

- Further evaluations would benefit from a longer (minimum 12-month) evaluation period.
- Recruitment methods in future evaluations should be reviewed and should consider specific groups of individuals such as fathers, grandparents and those of different ages and backgrounds.
- Future evaluation is needed to understand the role of key stakeholders and professional groups in developing, disseminating and embedding the LOB in practice.

- Social media and digital approaches could be prioritised for recruitment.
- While complex, it would be valuable to understand the impact of the LOB in terms of whether its use ultimately affects health service utilisation by parents and children.

Recommendations for enhancing the distribution and awareness of the LOB

- 1) Develop a strategic and streamlined approach to dissemination. We propose this is via midwifery and health visiting services, with other services supporting this and having access to a smaller back up supply of LOBs.
- 2) Ensure first-time parents are prioritised to receive copies of the LOB.
- 3) Ensure an explanation of the role of the LOB is given and we propose this is at the point it is distributed via midwifery and health visiting services, as well as being mentioned in on-going contacts with parents/carers.
- 4) Ensure key stakeholders are updated about content and changes to content of the LOB.
- 5) Raise awareness of the value of the LOB beyond Newcastle and Gateshead and develop a strategy for wider roll out of the LOB.

CONCLUSION

In conclusion, this evaluation has added to previous evaluation work and presents a contemporary overview showing how the LOB is distributed and used within Newcastle and Gateshead. The evaluation has added new insight by including data from a sample of parents/carers who have not accessed the LOB, which helps understand how best to reach them. The evaluation recommends continuation of the LOB and that more comprehensive distribution and the potential to embed the LOB is needed both across Newcastle and Gateshead, but also the potential for wider roll out to benefit parent/carers beyond these two areas.



REFERENCES

- Braun, V. and Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), pp.77-101.
- Bruijnzeels, M.A., Foets, M., Van der Wouden, J.C., Van den Heuvel, W.J. and Prins, A.D., 1998. Everyday symptoms in childhood: occurrence and general practitioner consultation rates. *British Journal of General Practice*, 48(426), pp.880-884.
- Carret, M.L.V., Fassa, A.C.G. and Domingues, M.R., 2009. Inappropriate use of emergency services: a systematic review of prevalence and associated factors. *Cadernos de saude publica*, 25, pp.7-28.
- Chanchlani, N., Buchanan, F. and Gill, P.J., 2020. Addressing the indirect effects of COVID-19 on the health of children and young people. *Cmaj*, 192(32), pp.E921-E927.
- Conlon, C., Nicholson, E., De Brún, A., McDonnell, T. and McAuliffe, E., 2021. Stuff you think you can handle as a parent and stuff you can't. Understanding parental health seeking behaviour when accessing unscheduled care: A qualitative study. *Health Expectations*, 24(5), pp.1649-1659.
- Creswell, J. W., and Creswell, J. D., 2018. *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. 5th edn, SAGE, Los Angeles.
- Department for Health and Social Care (2021) About us. London: DHSC
- Department of Health & Social Care (2022). A plan for digital health and social care. London: DHSC
- Ehrich, K., 2003. Reconceptualizing 'inappropriateness': researching multiple moral positions in demand for primary healthcare. *Health*, 7(1), pp.109-126.
- Fran E. Carroll, Leila Rooshenas, Amanda Owen-Smith, Hareth Al-Janabi, Sandra Hollinghurst, Alastair D. Hay, Factors influencing parents' decision-making when sending children with respiratory tract infections to nursery, *Journal of Public Health*, Volume 38, Issue 2, June 2016, Pages 281–288,
- French, T., Quinn, L., and Yates, S. (2019). *Digital Motivation: Exploring the reasons people are offline*. The Good Things Foundation.
- Houston, A.M. and Pickering, A.J., 2000. 'Do I don't I call the doctor': a qualitative study of parental perceptions of calling the GP out of hours. *Health Expectations*, 3(4), pp.234-242.
- Involve North East (2018). The Little Orange Book six month review: The views of health care professionals and parents/carers. UK
- Institute for Health Visiting (2022) Health visitor workforce numbers in England reach an all-time low. Available at: <https://ihv.org.uk/news-and-views/news/health-visitor-workforce-numbers-in-england-reach-an-all-time-low/> (accessed 1.9.22)

Kubicek K, Liu D, Beaudin C, Supan J, Weiss G, Lu Y, Kipke MD. A profile of nonurgent emergency department use in an urban pediatric hospital. *Pediatr Emerg Care*. 2012 Oct;28(10):977-84. doi: 10.1097/PEC.0b013e31826c9aab. PMID: 23023463; PMCID: PMC3464348.

Lazzerini M, Barbi E, Apicella A, Marchetti F, Cardinale F, Trobia G. Delayed access or provision of care in Italy resulting from fear of COVID-19. *Lancet Child Adolesc Health*. 2020 May;4(5):e10-e11. doi: 10.1016/S2352-4642(20)30108-5. Epub 2020 Apr 9. PMID: 32278365; PMCID: PMC7146704.

Lynn, R.M., Avis, J.L., Lenton, S., Amin-Chowdhury, Z. and Ladhani, S.N., 2021. Delayed access to care and late presentations in children during the COVID-19 pandemic: a snapshot survey of 4075 paediatricians in the UK and Ireland. *Archives of disease in childhood*, 106(2), pp.e8-e8.

McConkey, R. and Wyatt, S., 2020. Exploring the fall in A&E visits during the pandemic. UK: The Health Foundation URL: <https://www.health.org.uk/news-and-comment/charts-and-infographics/exploring-the-fall-in-ae-visits-during-the-pandemic> [accessed 2021-06-29].

McDonnell, T., Nicholson, E., Conlon, C., Barrett, M., Cummins, F., Hensey, C. and McAuliffe, E., 2020. Assessing the impact of COVID-19 public health stages on paediatric emergency attendance. *International journal of environmental research and public health*, 17(18), p.6719.

Nicholson, E., McDonnell, T., De Brún, A., Barrett, M., Bury, G., Collins, C., Hensey, C. and McAuliffe, E., 2020. Factors that influence family and parental preferences and decision-making for unscheduled paediatric healthcare—systematic review. *BMC health services research*, 20(1), pp.1-23.

O’Cathain A, Knowles E, Munro J, Nicholl J. Exploring the effect of changes to service provision on the use of unscheduled care in England: population surveys. *BMC Health Serv Res*. 2007;7(1):61.

Office for National Statistics (2020). Internet access – households and individuals, Great Britain: 2020. UK.

Pope, C., McKenna, G., Turnbull, J., Prichard, J. and Rogers, A., 2019. Navigating and making sense of urgent and emergency care processes and provision. *Health Expectations*, 22(3), pp.435-443.

Public Health England (2021) Health visiting and school nursing service delivery model. Available at: <https://www.gov.uk/government/publications/commissioning-of-public-health-services-for-children/health-visiting-and-school-nursing-service-delivery-model> (accessed 1.9.22)

Ramsey, I., Corsini, N., Peters, M.D. and Eckert, M., 2017. A rapid review of consumer health information needs and preferences. *Patient education and counseling*, 100(9), pp.1634-1642.

Royal College of Midwives (2022) Position statement. Safe midwife staffing. Available from: <https://www.rcm.org.uk/media/5537/rcm-position-statement-safe-midwife-staffing.pdf>

Schneider, A., Cabral, C., Herd, N., Hay, A., Kesten, J.M., Anderson, E., Lane, I., Beck, C. and Michie, S., 2019. Reducing primary care attendance intentions for pediatric respiratory tract infections. *The Annals of Family Medicine*, 17(3), pp.239-249.

Shanmugavadivel, D., Liu, J.F., Gilhooley, C., Elsaadany, L. and Wood, D., 2021. Changing patterns of emergency paediatric presentations during the first wave of COVID-19: learning for the second wave from a UK tertiary emergency department. *BMJ paediatrics open*, 5(1).

The Royal College of Paediatrics and Child Health. COVID-19 - statement on delayed presentations 2020 Available from: <https://www.rcpch.ac.uk/news-events/news/covid-19-statement-delayed-presentations>.

Watt, T., Firth, Z., Fisher, R., Thorlby, R. and Kelly, E., 2020. Use of primary care during the COVID-19 pandemic. Patient-level data analysis of the impact of COVID-19 on primary care activity in England.