

Executive Summary

1.0 Introduction

NHS Newcastle Gateshead Clinical Commissioning Group (CCG) has been reviewing Accident and Emergency (A&E) services for children. The aim of this review is to ensure that children and young people receive the most appropriate advice and treatment in the right place, at the right time, enabling NHS resources to be used appropriately.

In 2014/15, Involve North East carried out some work on behalf of the CCG which examined the reasons behind parents and guardians presenting at A & E with their children, and specifically those cases that had been identified as clinically inappropriate presentations.

A number of recommendations were made as a result of the work with a particular focus on the cohort of parents with children aged five years and under. One such recommendation was for a symptom checker.

- A local symptom checker be developed with locally specific information about services, including location, opening times and contact details, and when to attend each.
 - The symptom checker should include specific scenarios to help parents make decisions about their child's health and as a starting point should focus on the illnesses, injuries and symptoms highlighted in the report.
 - The information should be easily accessible to ensure parents facing a difficult situation are able to use it and more detailed information is also available.

As a result of this work the CCG, has developed a book which provides expert advice about childhood illnesses for parents of children aged five years and under, around childhood illnesses, what to expect and how to treat it, including when to self-care and when and where to seek appropriate medical help.

The overall aim of this project was to gather parents' views on the draft book before it was committed to print. The views of Health Visitors who come into regular contact with this group were also sought.

The key objectives of the project were to:

- Gauge parents' satisfaction with the appearance of the book
- Gauge parents' understanding of the content book
- Explore parents' beliefs around the usefulness of the book
- Gauge Health Visitor views of the book

The views of 164 parents and guardians were gathered via face-to-face questionnaires and 42 Health Visitors working across Newcastle also gave their views, answering questions 1 to 8 of the questionnaire.

2.0 Findings

The research shows that there is clearly support from parents and guardians and Health Visitors for the development of a book to give advice about childhood illnesses, what to expect and how to treat them.

In terms of the book's title, all Health Visitors and almost two-thirds of parents and guardians liked it, citing its simplicity, memorability and its connection to 'The Red Book' (Personal Child Health Record). However, 33 parents and guardians (20.1%) commented negatively about the title, with 29 stating that it was not clear what the content of the book was and they felt that the title should better reflect its purpose. Four people suggested including a health related picture on the front cover and 10 alternative suggestions for the title were put forward including 'Common Illnesses for 0-5s – What do I do Next?', 'The Baby Illness Guide' and 'Spew and Pool!'

When considering the orange and blue colours schemes proposed, 50.0% of all participants chose the orange colour, 34.5% the blue and the remainder had no preference. Parents and guardians gave reasons for their answers and the main reason both colours were chosen was because they felt that particular colour was easier to read. For one-third of those choosing orange they felt that it fitted well with the title of the book and six people made the point that it was more gender neutral than blue.

In terms of the appearance of the book, all Health Visitors felt it was very good and three-quarters of parents and guardians felt it was good or very good. The latter group particularly liked its size, its brightness, the layout of the pages and the quick references along the top of the pages. The remainder felt it was average or poor and the main issue, also highlighted by Health Visitors, was that the document holds too much information and is "too wordy" and the pages look "busy" and "cluttered".

Suggestions were made by parents and guardians around amendments to the layout including having a standardised layout for the pages so that information is in exactly the same place on the page for each condition, space the text out with sub-headings and not "blobs of colour", change the order of the contents by severity of the condition or a number of people suggested having First Aid first.

A number of parents and guardians queried how accessible the book was and made some suggestions.

- The colour scheme and layout should work for those with visual impairments.
- Ensure it is written in Plain English.
- Have a visual means of communicating the information such as a DVD with a signer.
- Publish the document in other languages.

In terms of the content, one d/Deaf participant queried how they could contact NHS 111 as there is no information on whether this service is accessible to them.

All Health Visitors felt that the content of the book was good or very good and in particular felt that the table on page 37 was useful. The vast majority of parents and

guardians (86.6%) also felt it was good or very good. The remainder felt that it was average or for two people, very poor. Parents and guardians suggested other content to include and in particular a section on:

- Rashes
- Childhood illnesses e.g. chicken pox and slapped cheek
- Skin problems e.g. eczema
- Allergies
- Colic

They also suggested including:

- A quick look-up page of illnesses and which service to go to.
- An explanation of what NHS 111 is for.
- An explanation of the symbols.
- Puzzles so children can be involved when adults read the book.
- A glossary.

A number of amendments to the current text were also suggested and the Health Visitors felt that the language used throughout the book was too clinical.

Almost nine out of ten parents and guardians felt that the book was easy to understand compared to two-thirds of Health Visitors. Three people felt it was difficult or very difficult. Everyone felt that the photographs would be useful to some degree although the Health Visitors suggested more pictures could be used e.g. what to do if someone is choking. The vast majority of participants felt that the role of the symbols were clear; two felt that they were not. Parents and guardians made suggestions about the symbols including being consistent with them, giving them colour and repositioning them on the page.

In terms of the potential effectiveness of the book, the vast majority of parents and guardians (93.3%) stated they would refer to it if they were given one. Eight people said they would not use it and three were unsure. This was because they feared they would lose it, they would prefer to use the internet, they felt that there was too much information or they would prefer to seek reassurance from a health professional.

Having looked at the book, the majority of people said that they would feel confident in dealing with a particular condition although a noticeable minority (13.4%, which equates to 22 people) were unsure. Several of those people gave reasons for this. Three said that they would “still want to speak to someone just to be on the safe side” as they “would want further reassurance”. Another said that they would still use the internet to get additional information. One person said that they would not have confidence because information becomes out-of-date quickly.

Most people would keep the book with their Personal Child Health Record, with their important documents, in their medicine cabinet or in their changing bag.

Fifty-five people took the opportunity to give any other comments about the draft book. Twenty-four people simply gave their support for the document, 12 people suggested that they would change their behaviour if they had the book, they would

no longer rely on untrusted information from the internet or would be less inclined to use NHS services. A further three people said that the book would give them reassurance.

Five people suggested that the book should be made with a more durable material, two felt that the distribution of the book was key and one suggested having an app with the information or having the information available on the internet.

3.0 Recommendations

It is suggested that NHS Newcastle Gateshead CCG take time to analyse the findings of this research to inform the future development of a book providing advice about childhood illnesses for parents of children aged five years and under. However, from the findings, some recommendations can be made.

3.1 Key recommendation

3.1.1 Development of the book

There is strong support for the book to be developed with 93.3% of people saying they would use it if it was given to them and 86.0% stating that they would feel confident in dealing with a particular condition having read the book.

- It is recommended that the book be developed, taking into consideration the additional recommendations outlined below.

3.2 Other recommendations

When considering the recommendations below it is important to recognise that the majority of people like the current appearance, format and content of the book. However, a minority of people have made suggestions about changes to the book and the majority of these have been included for consideration in advance of a second draft of the document.

3.2.1 Book title

All of the Health Visitors and the majority of parents and guardians (62.2%) rated the book's title very good or good. However, 33 parents and guardians (20.1%) did comment negatively about it with 29 stating that it was not clear what the content of the book was; they felt that the title should better reflect its purpose. Ten people also put forward other suggestions for the book and four people suggested adding some health-related pictures to the front cover.

- It may be worth considering a new name for the book which better reflects its content and take into account the suggestions made by parents and guardians. If this is not deemed necessary consider adding a health-related picture to the front cover of the book or making the NHS logo larger.

3.2.2 Colour scheme

Half of people preferred the orange colour scheme because it was bright and easy to read and fits with the title of the book.

- Although orange is the preferred option, ahead of committing to this colour it is suggested that advice is taken from organisations who work with people with visual impairments to ascertain whether this colour scheme is accessible for them.

3.2.3 Accessibility

In addition to the colour scheme, a number of parents and guardians queried how accessible other aspects of the book were and the Health Visitors were concerned that the language was too clinical.

- Ensure that the layout of the book is accessible for those with visual impairments.
- Ensure the book is written in Plain English.
- Consider developing a visual means of communicating the information such as a DVD with a signer.
- Consider publishing the document in other languages.
- Add an explanation around how to use the NHS 111 and 999 services if you are d/Deaf or Hard of Hearing.
- Consider adding a link to the book on all GP practice websites.

3.2.4 Appearance

Although the majority of people liked the look of the book, one fifth of parents and guardians (34) felt that the book's appearance was average and three thought that it was poor with the main issue being that it held too much information and was too wordy, making the pages cluttered or too busy.

- Consider reducing the amount of information included in each section.
- Consider redesigning the layout of the pages:
 - Have the information in exactly the same place on the page for each condition
 - Space the text out with sub-headings and not "blobs of colour"

Suggestions were also made around the ordering of the book:

- Think about changing the order of the contents by severity of the condition
- Have the First Aid information at the front

3.2.5 Content

Again the vast majority of people including all Health Visitors felt that the book's content was good or very good. However 20 parents and guardians (12.2%) thought it was average and two very poor. They suggested other content to include.

- Consider adding information to the book around other illnesses:
 - Rashes
 - Childhood illnesses – chicken pox, measles, scarlet fever, slapped cheek
 - Skin problems including eczema
 - Allergies

- Colic

People also suggested additional information.

- Consider including:
 - A quick look-up page/glossary of illnesses and which service to go to.
 - An explanation of what NHS 111 is for.
 - An explanation of the symbols.
 - Additional pictures to demonstrate what to do when someone is choking for example.

Suggestions were also made to amend the current text.

- Consider the following:
 - Make the NHS website at the back more obvious.
 - Clarify the 'household cleaning agents' on page 44.
 - Remove the fever graph (also suggested by the Health Visitors).
 - Poisonous substances – include a sentence saying that these things should not be an issue unless the child is choking on it or some other symptoms arise.
 - First aid should be called 'First aid, accidents and injuries'.
 - There should be a separate poo chart for young babies or a sentence describing what their poo will typically look like.
 - Change the 'Hot Children' section to 'Fever and Temperature'.
 - Remove the 'Our Team' section "Not necessary. The public do not care who are in the team or [who] designed the booklet"
- It would be useful to appoint a named person to be responsible for checking the accuracy of information included in the book at planned intervals.

3.2.6 Symbols

Although the vast majority of people felt that the symbols are clear, two asked for further explanation and five made observations about the current symbols.

- Consider the following observations:
 - Position symbols at the bottom of the page – reason then command
 - Give the symbols a colour so they stand out on the page
 - Colour urgent GP appointments red
 - There are two GP symbols and inconsistent use of them
 - Go to A & E symbol is not on the key
 - Call 999 symbol on the key is different in the rest of the book

3.2.7 Distribution

Four people discussed when the book should be distributed to ensure that people actually read it as there was concern that it could get lost. When asked where they would keep the book, 61 people (37.2%) said they would keep it with their Personal Child Health Record. Another person suggested childminders should receive copies that they can keep themselves and distribute.

- Consider handing the book out at the same time as the Personal Child Health Record and asking parents to keep the two documents together.
- Consider distributing the book to registered childminders.