

# Assessment of Newborn Screening Parent Education Materials

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The authors have indicated they have no financial relationships relevant to this article to disclose.

## ABSTRACT

**OBJECTIVE.** The purpose of this study was to measure the readability and user-friendliness (clarity, complexity, organization, appearance, and cultural appropriateness of materials) of parent education brochures on newborn screening.

**METHODS.** We studied English-language versions of the brochures that state newborn screening programs prepare and distribute. We obtained brochures from 48 states and Puerto Rico. We evaluated each brochure for readability with the Flesch reading ease formula. User-friendliness of the brochures was assessed with an instrument we created that contained 22 specific criteria grouped into 5 categories, ie, layout, illustrations, message, manageable information, and cultural appropriateness.

**RESULTS.** Most current newborn screening brochures should be revised to make them more readable and user-friendly for parents. Ninety-two percent of brochures were written at a reading level that is higher than the average reading level of US adults (eighth-grade level). In most brochures, the essential information for parents was buried. Although all brochures were brief and focused on the newborn screening tests being performed, 81% needed improvement in getting to the point quickly and making it easy for parents to identify what they needed to know or to do. None of the brochures scored high in all 22 criteria on the user-friendliness checklist.

**CONCLUSIONS.** Parent education materials about newborn screening should be revised to be easier to read and more user-friendly, by lowering the reading difficulty to eighth-grade level and focusing on issues such as layout, illustrations, message, information, and cultural appropriateness. It is important that state newborn screening programs and organizations work with parents to develop and to evaluate materials to ensure that they are user-friendly.

[www.pediatrics.org/cgi/doi/10.1542/peds.2005-2633L](http://www.pediatrics.org/cgi/doi/10.1542/peds.2005-2633L)

doi:10.1542/peds.2005-2633L

### Key Words

newborn screening, readability, suitability, user-friendliness

### Abbreviation

FRE—Flesch reading ease

Accepted for publication Dec 27, 2005

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275); published in the public domain by the American Academy of Pediatrics

**T**HE NEED FOR written patient education materials that can be understood easily by the public is a recognized priority at the national level.<sup>1-3</sup> A recent report by the Institute of Medicine indicated that 90 million US adults have trouble reading, understanding, and acting on most health information.<sup>1</sup> The Institute of Medicine report and numerous other studies found that a great deal of written patient information is unnecessarily complex and is written at a difficulty level that is higher than the average eighth-grade-level reading skill of US adults.<sup>1-8</sup>

Experts in patient education and health communication recommend that patient brochures be written with a reading difficulty below the eighth-grade level and that attention be paid to the user-friendliness (clarity, complexity, organization, appearance, and cultural appropriateness) of such materials.<sup>2,4-10</sup> Evidence suggests that almost all patients, not only those with limited literacy skills, prefer easy-to-read materials over more-complex or more-comprehensive materials.<sup>2,8,11</sup> Furthermore, a recent, evidence-based report from the Agency of Healthcare Research and Quality indicated that user-friendly, plain-language, written materials can increase patients' knowledge.<sup>9</sup>

The Newborn Screening Task Force of the American Academy of Pediatrics stated that education of parents is an important component of programs that screen newborns for genetic and inherited disorders<sup>12,13</sup> and written brochures represent the most common method of providing that education.<sup>13</sup> Despite the recommendation of the task force that "... evaluation of parent education materials should be ongoing,"<sup>12</sup> a review of the literature revealed no evaluation of the reading level or user-friendliness of newborn screening parent education brochures.

The purpose of this study was to measure the readability and user-friendliness of these brochures. We studied currently available, English-language, parent education brochures about newborn screening that are used across the United States.

## METHODS

### Study Design

We studied the English-language versions of the parent education brochures about newborn screening that state health departments prepare and distribute. We limited our study to the brochures used to provide information about the initial screening; we did not evaluate brochures that discussed follow-up testing of infants whose initial test results were abnormal.

The National Newborn Screening and Genetics Resource Center collected and provided these parent education brochures for us in 2003. We obtained brochures from 48 states and Puerto Rico. The Rhode Island Health Department did not have a parent education brochure

about initial newborn screening, and the Wyoming Health Department did not provide one.

### Evaluation Process

We evaluated each brochure for readability with the Flesch reading ease (FRE) formula. We assessed user-friendliness with scoring criteria that are described below.

### Readability (FRE Formula)

The FRE formula is one of the most widely used measures to determine readability of text.<sup>14</sup> The formula is  $206.835 - (1.015 \times ASL) - (84.6 \times ASW)$ , where ASL is the average sentence length (the number of words divided by the number of sentences) and ASW is the average number of syllables per word (the number of syllables divided by the number of words).

The output of the FRE formula is a number ranging from 0 (very difficult to read) to 100 (easy to read). Table 1 displays FRE scores and grade-equivalent reading levels to which the scores correspond. FRE scores of 65 to  $\geq 70$  are considered the cutoff values for plain language suitable for text in a patient education brochure.<sup>15</sup>

### User-Friendliness

User-friendliness of written health education materials refers to the organization and complexity of the content, the appearance of the format, and the overall tone and cultural appropriateness. Several manuals or checklists are available to help guide the development of user-friendly materials,<sup>2,4,5,15</sup> but none was designed specifically for research purposes. We used these checklists and manuals to create a research instrument to score user-friendliness.

The instrument we created contains 22 specific criteria grouped into 5 categories, as shown in Table 2. The 5 categories are layout, illustrations, message, manageable information, and cultural appropriateness.

Layout refers to aspects of the appearance of a brochure that might influence reading ease. Important aspects of layout that make reading easier include appropriate font (12 point or larger, with minimal use of italics and bold text), use of ample white space and short paragraphs, and inclusion of bullets and boxes to help break up the text.

**TABLE 1** FRE Scores and Corresponding Grade Levels

FRE Score	Approximate Grade Level
100-91	5th
90-81	6th
80-71	7th
70-61	8th-9th
60-51	10th-12th
50-31	College
30-0	Graduate school

**TABLE 2** User-Friendliness of Newborn Screening Parent Brochures

Specific Characteristics	Proportion of Work Needed to Make More User-Friendly, %		
	Little	Some	Much
Layout makes it easier to read			
Font is $\geq 12$ points	51	41	8
Avoids all-capital letters, italics, and specialty fonts	41	45	14
Ample white space	4	55	41
Short paragraphs (<4–5 lines)	0	49	51
Information well organized visually (eg, bullets and boxes)	8	59	33
Illustrations			
Used and serve purpose	18	67	15
Clear and realistic	63	31	6
Easy to understand	38	54	8
Clear message			
Cover, title, and headings support message	16	73	11
Headings are short and explanatory	65	25	10
Gets to point quickly	19	67	14
Action messages (what to do) are presented first	4	69	27
Message is likely clear	17	65	18
Manageable information			
Sentences are short	8	88	4
Words are familiar or defined	2	82	16
Personalizes some information	45	53	2
Requires little math skill	59	31	10
Focuses on need to know	14	73	13
Cultural appropriateness			
Well targeted to audience	11	73	16
Friendly, reassuring tone	41	57	2
Familiar pictures, words, and situations	4	82	14
Avoids stereotypes	88	12	0

Illustrations should reflect realism and understandability and should reinforce or explain the meaning of the text. They should not serve only a decorative purpose.

Clarity of the brochure's message is one of the most important criteria. Scoring items for message included a clear title and headings, concise content with action messages (what to do) presented first, and a clear overall message of what the reader is being asked to do.

Manageable information refers to whether the content of the brochure is presented in a way that will be manageable by average readers. Specifically, we scored whether information is presented with short sentences and familiar words, whether information is presented in a way that personalizes it for the reader, and whether information is limited to what parents need to know, rather than what is nice to know.

Cultural appropriateness is the degree to which the materials are targeted to the audience; in the case of newborn screening, the audience is parents and families of newborn infants. It also includes the extent to which the brochure presents information in a personal reassuring tone.

Three reviewers used the aforementioned criteria, which are listed in Table 2, to evaluate the brochures for user-friendliness. Specifically, they reviewed each of the brochures and noted how much effort (little or no effort, some effort, or much effort) would be needed to bring the brochure to an acceptable level of user-friendliness for each of the 22 items on the 49 brochures. For 95% of these items, all 3 reviewers assigned the same scores. In the 5% of cases for which reviewers assigned different scores, differences were discussed until a majority consensus was reached.

## RESULTS

### Readability

The mean FRE score of the written newborn screening materials was 53.26 (SD: 3.61), which corresponds to a 10th- to 12th-grade reading level (Fig 1). More than one fourth (27%) of the brochures had FRE scores of <50, which indicates reading difficulty at or above the college level. Only 8% had FRE scores of >70 (ie, reading difficulty below the eighth-grade level), which, as mentioned earlier, is the recommended reading level for patient education materials.

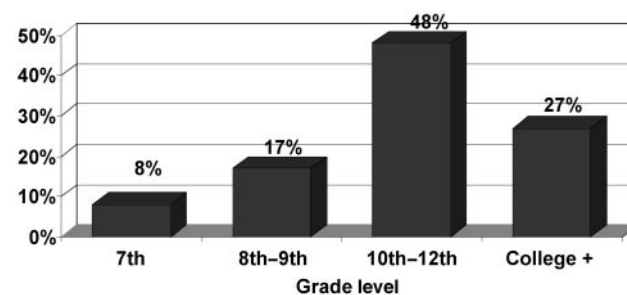
Readability often varied substantially within materials. The highest reading levels were found in text with lengthy sentences and multisyllabic words, particularly when medical terms and jargon were used in explanations of the diseases. The following is an example of text from a brochure written at the college reading level.

Galactosemia is an elevation of blood galactose levels. This occurs when the body cannot metabolize the sugar, galactose, which is the breakdown product of lactose metabolism. Galactosemia has an incidence of ~1:40 000 to 60 000 births. Any of 3 enzymes may be absent in the metabolism because of a genetic defect. When galactosemia is not detected and treated early, liver damage, cataracts, retinal hemorrhage, mental retardation, and even death can result.

### User-Friendliness

#### Layout

Most brochures (51%) used an appropriate font (12 point or larger, with minimal use of bold or italics).



**FIGURE 1** Reading difficulty (grade-equivalent reading level) of newborn screening brochures. Each histogram bar indicates the percentage of brochures written at the indicated reading difficulty level.

Fourteen percent, however, needed much improvement in the amount of white space used, 51% needed much improvement in shortening paragraphs, and 33% needed much improvement in breaking up the text by using bullets and boxes.

### *Illustrations*

A sizable number of brochures (82%) needed some or much improvement in how they used illustrations and in the purpose of the illustrations. Thirty-four percent of the brochures had images of toddlers, which weakened the message that screening is for newborns. Sixty-two percent also needed at least some work with respect to illustrations that were not easy to understand (eg, a few brochures used an image of a stork, which may be outdated and not well understood by the current generation of new parents). Watermarks, which were used frequently as background illustrations, made text difficult to read.

### *Message*

Although all brochures were brief and focused on the newborn screening tests being performed, only 19% got to the point quickly or made it easy for parents to pick out what they needed to know or do. Ninety-six percent of the brochures needed at least some improvement in presenting action messages (what to do), because the action message was often hidden in the text. The following is an example of text in which the action message is lost.

If your infant is tested before he or she is 24 hours old, the test needs to be repeated within 7 days. Most of the time these disorders show up in the blood within the first 24 hours of life and treatment can be started early. The purpose of the repeat test is to detect a disorder if it does not show up in the blood until after the first 24 hours. Ask your doctor to repeat the Newborn Screening Test on your infant if the first test is done before 24 hours of age.

Only a few brochure covers (16%) needed a great deal of work, but most (84%) needed at least some work. The covers that were most user-friendly contained illustrations and titles that stated the purpose of the brochure clearly (eg, *Newborn Screening: Tests That Can Help Protect Your New Infant's Health*). Some titles were vague (eg, *First Thing's First*), however, and others would have little meaning to individuals who had no training in medicine or public health (eg, *Newborn Screening Program*).

Headings that helped make the message clearer and easier to follow were short and explanatory or used question-and-answer formats (eg, Why must my infant be screened? How will I get the results?), rather than single words or abstract phrases that might not be understood by the general public (eg, galactosemia or newborn screening). Most brochures used headings to break

up text and to let parents know what would be discussed next, but 84% needed at least some improvement in this area.

### *Manageable Information*

Most newborn screening brochures contained a large amount of information that was probably unfamiliar to most new mothers. Most brochures (86%) needed some or much work in focusing on what parents need to know, rather than what is nice to know.

In particular, most brochures provided a great deal of information that focused on bureaucratic or scientific terminology (eg, "State law [State Statutes Chapter 253.13] requires that all infants have newborn screening before they leave the hospital after birth"). This obscured the need-to-know messages such as what newborn screening is, why it is done, and what parents need to do if retesting is necessary.

The following example is from a brochure with a friendly tone and conversational language.

- Most infants are just fine when they are born.
- We test all infants because a few infants look healthy but have a rare health problem.
- If we find problems early, we can help prevent serious problems like mental retardation or death.

### *Cultural Sensitivity*

As a whole, the brochures were culturally sensitive and avoided stereotypes. No brochure had illustrations or examples that were offensive, but not every brochure contained photographs of infants that reflected the target audience.

## **DISCUSSION**

The newborn screening parent education materials we examined included some user-friendly elements. However, 92% of the brochures were written at a reading level that exceeds the average reading level of US adults. Furthermore, no brochure scored high for all 22 criteria on the user-friendliness checklist. Most current newborn screening brochures could be revised to make them more readable and more user-friendly for parents.

### **Reading Difficulty**

Our findings support those of other studies that demonstrated a mismatch between the reading skills of parents and the reading skills needed to comprehend commonly used parent education materials.<sup>6-8</sup> Readability formulas, such as the FRE formula or the Flesch-Kincaid Grade Level calculation contained in commercial word-processing programs, can be used to estimate the reading level required to read and to understand materials.

It is important to keep in mind, however, that reading difficulty formulas are imprecise measures of readability

and must be used with caution, for 2 reasons. First, it cannot be assumed that patients can read and understand text at a level that corresponds to their education levels.<sup>5-7</sup> Adults' comprehension levels are often 2 grades below their reading levels and 2 to 5 grades below their education levels.<sup>6,7</sup> Second, although these formulas can be used to measure reading difficulty of blocks of text, they do not consider other factors that contribute to reading ease, such as the 22 criteria we included in our checklist.

### Layout

Of the items on our checklist, some are particularly important. Layout, for example, is critical. If the brochure is not visually appealing and well formatted for reading ease, then parents may not read the brochure regardless of the quality of the content.

### Illustrations

Similarly, illustrations are important because they contribute to visual appeal and can help convey or reinforce messages. Most experts suggest that the illustrations for patient education brochures should be considered during the initial stages of brochure design, rather than being selected as an afterthought.

### Message

We found that most brochures would benefit from having clearer titles on the cover. Within the brochures, essential information was often buried among details and scientific words. Brochures could be improved if the most important messages were given first, if illustrations were used to emphasize important points, and if it were easy for parents to pick out what they needed to know and to do.

### Manageable Information

It is important to provide parents with information about newborn screening because research indicates that parents and their families are generally unfamiliar with these screening tests.<sup>16</sup> To make the information manageable, however, it is important not to overload parents with details. The focus needs to be on what parents need to know, rather than on what is nice to know. Indeed, parents in focus groups reported that they were not interested in many details about diseases in newborn screening programs.<sup>16</sup> However, our study revealed that most brochures provide a large amount of information, which often focuses on the legal reasons for testing or scientific descriptions of the diseases. Most brochures could be improved if the overall number of messages were limited to what was most relevant to parents at the time of screening.

### Cultural Appropriateness

For newborn screening materials, and indeed for any patient education materials, it is important that the content be culturally sensitive and that parents perceive the information to be personally relevant and acceptable to their age, culture, and experience. Although the brochures we evaluated were respectful and avoided stereotypes and some used a friendly conversational tone and personal pronouns (eg, "important to you," "your infant"), most brochures could be improved if more attention were paid to targeting new parents, by using words, pictures, and covers that would be understandable and culturally appealing to them (eg, pictures representing their race and/or ethnicity).

### Limitations

Our study evaluated parent education materials from nearly every state in the United States, but a few limitations of our methods should be noted. First, only English-language brochures were evaluated in this study. Second, although the FRE formula is a widely used and well-accepted method for assessing the reading difficulty of text, the score provides only an estimate of reading difficulty, based on the lengths of words, sentences, and paragraphs. The score is somewhat imprecise, estimating the difficulty of text within  $\pm 1.5$  grade levels.

Third, the scoring of our user-friendly checklist was subjective, in that we did not have well-defined criteria to determine what constituted the need for little to none, some, or much effort to revise the brochures. However, the inter-rater reliability (95% concordance among 3 different raters) suggests that differences among the 3 scoring categories were clear and unambiguous.

Fourth, we made assumptions about the readability of the parent education brochures on the basis of national data regarding the literacy skills of US adults. Although such assumptions are probably reasonable, it should be noted that we did not assess specifically the reading skills of parents receiving the education brochures.

### CONCLUSIONS

On the basis of the results of our study, parent education materials regarding newborn screening should be revised so that most US adults can understand them. This would require changing the reading difficulty level from the current average 10th- to 12th-grade level to an eighth-grade level or lower. These educational materials also could be revised to make them more user-friendly, with a focus on issues such as layout, illustrations, message, information, and cultural appropriateness. In addition, a critical aspect of developing truly parent-centered materials is parent involvement; intended readers can best determine what key messages are needed, as well as the optimal way to convey them. It is important that state newborn screening programs and organiza-

tions work with parents to develop and to evaluate materials, to ensure that the materials are user-friendly.

## ACKNOWLEDGMENTS

This project was funded by the Health Resources and Services Administration, through contract 258-03-0004 and a Health Resources and Services Administration subcontract with the University of California, Los Angeles (contract 240-01-0033).

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DOI: 10.1542/peds.2005-2633L

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