

ARTIGO ORIGINAL

Development and validation of a website on biological neonatal screening

Desenvolvimento e validação de um website sobre triagem neonatal biológica

Desarrollo y validación de un sitio web sobre tamizaje biológico neonatal

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Abstract

Objective: Describe the development and validation of a website on biological neonatal screening. **Method:** Descriptive study of technological production on development and validation of a website on biological neonatal screening developed from the ADDIE model, aimed at nursing professionals who work in Primary Health Care, pregnant women and family members of newborns. In the first three phases, the content based on scientific information was built and organized. In the last two steps of the method, content was evaluated by judges. **Results:** Elaborated website "Teste do Pezinho Gotas de Amor" in theyear 2022. Nurses and pregnant women evaluated the product through questions about content and design. The evaluation had agreement index 1 for all questions. **Conclusion:** The website has the potential to collaborate with the continued education of nursing on theheel prick test, as well as health education for pregnant women and their families, in an easily accessible digital médium, contributing to the access of information about the subject.

Descriptors: Neonatal Screening; Nursing; Pregnant Women.

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Resumo

Objetivo: Descrever o processo de desenvolvimento e validação de um *website* sobre triagem neonatal biológica. **Método:** Trata-se de um estudo descritivo, de produção tecnológica, com desenvolvimento e validação de um *website* sobre triagem neonatal biológica a partir do modelo ADDIE, destinado aos profissionais de enfermagem que atuam na Atenção Primária à Saúde, gestantes e familiares de recém-nascidos. **Resultados:** Descreve-se as etapas de elaboração do *website* “Teste do Pezinho Gotas de Amor”, ocorrida no ano de 2022. Para a avaliação, o corpo de juízes foi composto por enfermeiros e gestantes, os quais avaliaram o produto através de questões sobre conteúdo e design. Na avaliação obteve-se índice de concordância 1 para todas as questões. **Conclusão:** O *website* tem potencial de colaborar com a educação continuada da enfermagem, bem como educação em saúde para gestantes e familiares, em um meio digital de fácil acesso, contribuindo para acesso de informação sobre o tema.

Descritores: Triagem neonatal; Enfermagem; Gestantes.

Resumen

Objetivo: Describir el proceso de desarrollo y validación de una página web sobre tamizaje biológico neonatal. **Método:** Se trata de un estudio descriptivo de producción tecnológica, con el desarrollo y validación de un sitio web sobre tamizaje biológico neonatal basado en el modelo ADDIE, dirigido a profesionales de enfermería que trabajan en Atención Primaria de Salud, mujeres embarazadas y familias de recién nacidos. **Resultados:** Se describen las etapas de desarrollo del sitio web “Gotas de Amor”, que tuvo lugar en 2022. Para la evaluación, el jurado estuvo formado por enfermeras y embarazadas, que valoraron el producto mediante preguntas sobre contenido y diseño. La evaluación obtuvo un índice de acuerdo de 1 en todas las preguntas. **Conclusión:** El sitio web tiene potencial para colaborar con la formación continuada de enfermería, así como con la educación sanitaria de las gestantes y sus familias, en un medio digital de fácil acceso, contribuyendo al acceso a la información sobre el tema.

Descriptores: Tamizaje Neonatal; Enfermería; Embarazadas.

INTRODUCTION

The National Neonatal Screening Program (PNTN), established through Ministerial Decree GM/MS No. 822/2001, mandates neonatal screening actions for all live births and is considered a program of great national importance as it encompasses the fundamental principles and guidelines of the Unified Health System (SUS). The PNTN includes biological neonatal screening and clinical screenings, which are Ocular Neonatal Screening (eye test), Auditory Neonatal Screening (hearing test),

Congenital Heart Disease Screening (heart test), and evaluation of the lingual frenulum (tongue test), the latter added in 2014 through Law 13002, completing the clinical screenings. All the program's objectives require responsibility from the three levels of government—federal, state, and municipal—and foresee shared actions in both Primary Care and Medium and High Complexity care.^{1,2}

In addition to clinical screenings, the PNTN (National Neonatal Screening Program) mandates biological neonatal



screening (NBS), popularly known as the heel prick test. NBS is capable of diagnosing diseases caused by inborn errors of metabolism early and during the asymptomatic phase. To avoid serious and irreversible consequences, these diseases need to be diagnosed in the first weeks of the baby's life; if not identified, they can often lead to the newborn's death.¹

Primary Health Care (PHC) is responsible for collecting the newborn screening test (NBT), as the ideal collection period is preferably from the 3rd to the 5th day of the newborn's life. PHC is responsible for collecting and sending the sample according to the guidelines of the National Newborn Screening Program (PNTN). Therefore, maternal and child health care actions in PHC are important in preventing morbidity and mortality, since infant mortality is an important public health indicator, as it deals with premature and, in most cases, preventable deaths. Furthermore, the presence of congenital anomalies is strongly associated with infant mortality, which reinforces the importance of early detection of malformations through newborn monitoring, ensuring specialized care, as well as providing quality of life and reducing deaths from this cause.^{1,3}

In 2021, Law 14154 was published with the aim of improving the National Newborn Screening Program (PNTN). This

legislation expanded the number of diseases that can be screened for by the newborn screening test; initially, it was possible to diagnose six diseases: Phenylketonuria, Congenital Hypothyroidism, Sickle Cell Disease, Cystic Fibrosis, Congenital Adrenal Hyperplasia, and Biotinidase Deficiency. After 2021, many states have been expanding the number of diseases screened for in the newborn screening test. Furthermore, the Law stipulated that healthcare professionals must inform pregnant women, during prenatal and postpartum care, about the importance of the newborn screening test and any differences between the disease coverage offered by the SUS (Brazilian Public Health System) and the private sector.^{1,4}

Given this, it is evident how important it is for nursing professionals to be prepared to guide pregnant women and their families, since misinformation can compromise the satisfactory collection of the test, interfering with early diagnosis and consequently delaying the start of treatment. It is necessary to improve the knowledge of primary health care professionals, as well as pregnant women and their families, about a test that can change the course of a disease through timely treatment. In this sense, using technological resources in health education practices is an important strategy, given that



society is increasingly seeking information through digital resources. Furthermore, educational practices bring improvements to the health team and the user, and access must be of high quality, understandable, and tangible to the public to enhance the expansion of care.⁵⁻⁷

Therefore, this study aimed to describe the development and validation process of a website on biological neonatal screening, which can be used as a strategy to assist in the continuing education of health professionals and health education of users. At the end of the study, this technological product will promote access to quality information based on scientific evidence and facilitate the continuing education of primary health care nursing professionals, assisting in the knowledge of pregnant women and their families about biological neonatal screening. Furthermore, the tool may contribute to achieving the targets for collecting samples from live newborns satisfactorily and within the established timeframe.

METHOD

This is a descriptive, technological production study involving the development and validation of a website about biological neonatal screening. The website is a product of the Professional Master's Program in Nursing at a university

in the south of the country and was built for nursing professionals working in Primary Health Care, pregnant women, and their families.

For the website development, the chosen method was the ADDIE model – Analyze, Design, Develop, Implement, and Evaluate – combined with product promotion. This method incorporates theories inherited from Institutional Design, where its main characteristic is systematization; that is, each stage depends on the data from the previous stage and, in case of failures, allows for corrective actions, improving the process. Therefore, the model comprised five phases, namely:

1. Analysis: identifying needs, objectives, and characteristics;
2. Design: what knowledge should the user acquire through the product and what tools will be used;
3. Development: refers to the development of the product and the identification of the need for feedback in the previous process;
4. Implementation: deploy the product;
5. Evaluation: identify the level of satisfaction of the evaluators, identify necessary corrective measures.⁸⁻¹⁰

It is noteworthy that, in this work, the Implementation and Evaluation stages correspond to the website validation process and were developed as a single



stage. Dissemination involved making the website available online for access to its content by healthcare professionals, pregnant women, and their families.

The creation and structuring tool used was Google Sites, a tool for creating web pages offered by Google. It is a free resource where the website is linked to the author's email account and can be edited whenever necessary. The images are from a free license available on a graphic design platform.

The website validation was performed by 12 judges, six nurses (inclusion criteria: currently working in prenatal and postpartum care at a health unit or managing primary health care, with one year or more of experience) and six pregnant women (inclusion criteria: pregnant women in their second or third trimester of pregnancy, aged 18 or older).

The evaluation period took place from April 25, 2022 to May 30, 2022. Recruitment was conducted via an invitation on the author's and the University's Postgraduate Program's social media (Facebook and Instagram). The link to participate remained available until at least five participants were obtained from each group, and participation was closed when each group of judges had six participants.

To evaluate the questions, the CI

(concordance index) was calculated, and a question was considered adequate when the CI reached at least 0.8 points. The evaluation instrument included questions related to content, presentation, reliability of information, and clarity. A Likert-type measurement scale was used to measure each question. The interval on the scale for each question was considered to be from four to one. Finally, an open-ended question was included for opinions and suggestions regarding the website.¹¹

The result for each item of the assessment instrument was presented in absolute frequency, and the CI calculation was performed using the formula $CI = NC / (NC + ND)$, where NC represents the level of agreement (totally or partially) and ND disagreement (totally or partially).^{12,13} The research was approved by the Ethics and Research Committee under opinion number 52746921.3.00005345. The research participants signed the Informed Consent Form (ICF), which clarified the risks of research in a virtual environment, according to CONEP Circular Letter 2021.¹⁴

RESULTS

Website development and validation

Figure 1 details the ADDIE steps used to build the website.





Figure 1 - ADDIE steps used to build the website.

In the analysis phase, it was initially determined that the target audience for the developed product would be nursing staff working in primary health care (PHC), as they are the professionals involved in the test collection process. Furthermore, it is emphasized that PHC is the preferred point of entry for neonatal biological screening (NBS), and instructions for test collection should begin during the pregnancy-puerperium cycle so that collection occurs in the first days of the baby's life. However, despite the importance of the test for the child's health, misinformation among

parents, family members, and healthcare professionals compromises the effectiveness of neonatal biological screening.¹⁵⁻¹⁷ For this reason, in addition to healthcare professionals, the website also targeted pregnant women and their families to provide an easily accessible means of information for this group.

In the design phase, the logo was created using a free graphic design platform, used to create visual content. Figure 2 shows the logo developed for the website.



Figure 2 – Website logo.

In the development phase, the product was built and organized according to the learning objects (videos, images) identified as necessary to convey the

information, and were inserted into the website on six pages. Figure 3 schematically presents the pages that make up the website.

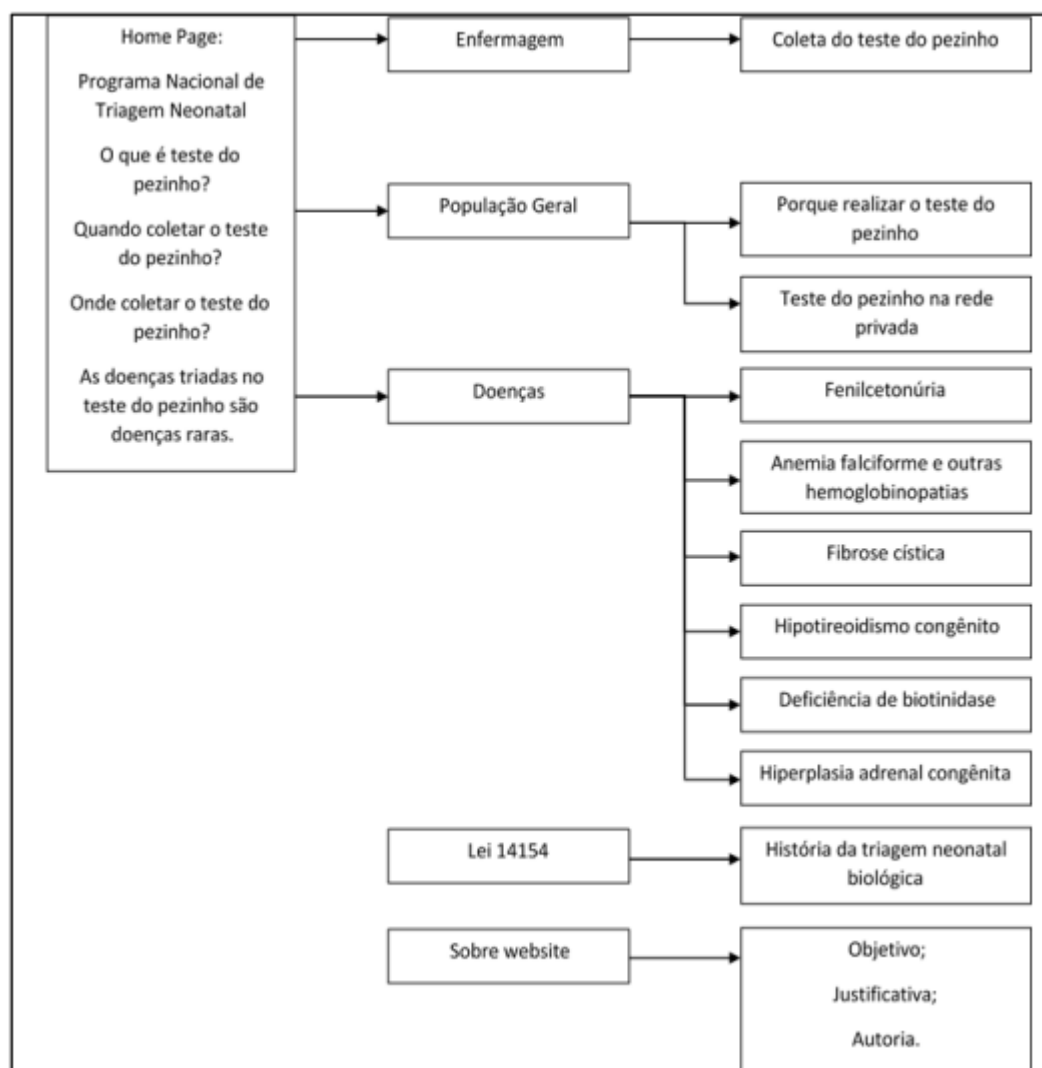


Figure 3 - Schematic representation of the pages that make up the website.

The layouts used were those pre-established in Google Sites. In addition, the image carousel feature was chosen, where information was presented as a sequence of images, making the text more pleasant to read. The same graphic design platform used to create the logo was employed to construct the images and text used in the image carousel. Regarding the informational videos, a video from the Ministry of Health and a video created by the author explaining the National Newborn

Screening Program (PNTN) were used. The newborn screening test collection procedure was addressed using a "step-by-step" approach, distributing the information in stages to ensure safety throughout the process.

After construction and adjustments to the website pages, it was made available on the web through the following address: sites.google.com/view/testedopezinhogotasdeamor. The website's homepage can be seen in Figure 4.

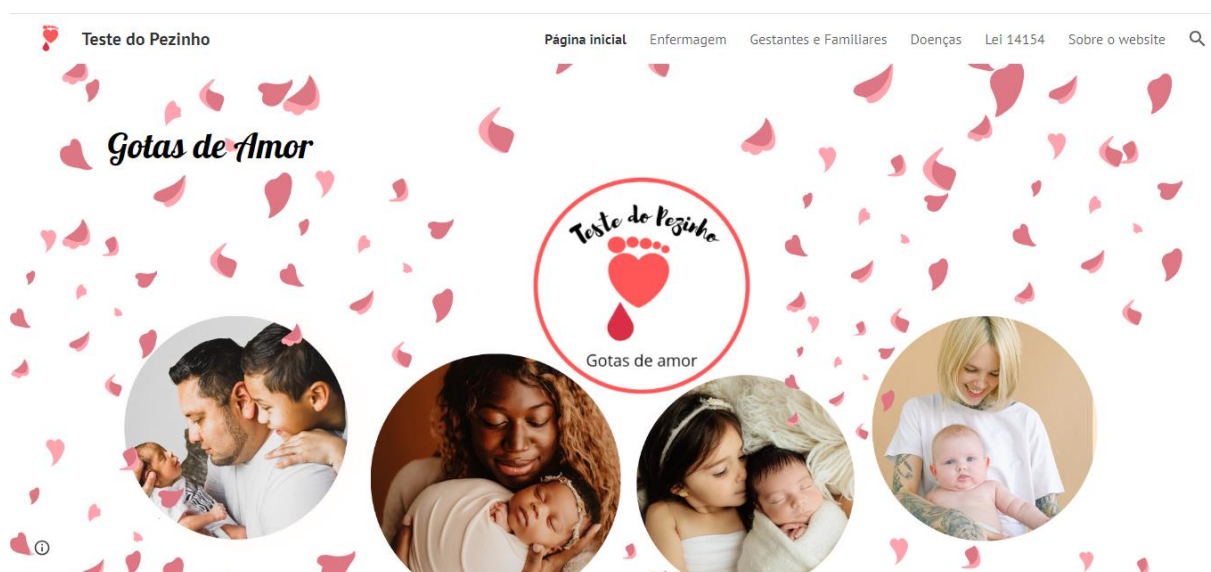


Figure 4 -Website homepage.

Sequentially, implementation and evaluation correspond to the last two stages of the method. These involve evaluating the website and were conducted by two groups of judges comprised of the target audience for whom the product was designed: nurses and pregnant women. Judges were recruited through an invitation via the author's social media (Facebook and Instagram) and the Postgraduate Nursing Program at the author's affiliated university. The link to participate remained available until at least five participants were obtained from each group, and was closed when each group of judges had six participants, totaling 12 members.

Regarding the profile of the nursing judges, it was identified that all work in the state of Rio Grande do Sul, only one did not

have a specialization in public health, 33% had worked in primary health care for less than 5 years, and 50% had been practicing for more than 10 years. As for the profile of the pregnant women who evaluated the website, it was identified that all live in Rio Grande do Sul, with 50% residing in the metropolitan region. Furthermore, 66% were in their first pregnancy, and the majority had completed higher education. Additionally, the age of the pregnant women ranged from 25 to 37 years, with an average age of 33.8 years.

After evaluation and analysis, a confidence interval of 1 was obtained for all questions. It is noteworthy that, in addition to the evaluation, the judges could make suggestions to improve the website, which were fully addressed. In the evaluation of

the website content by nurses, only three evaluators assigned the concept "partially agree" to three items of the evaluation. Regarding the suggestions to improve the website, evaluator A suggested...*wide dissemination*; evaluator B suggested *that the content could be part of an application* and evaluator C suggested *that the videos were not linked to YouTube, because some public services have blocked YouTube content*. The other reviewers only praised the product.

In the pregnant women's evaluation of the content, only two judges rated two evaluated items as "partially disagree." Regarding the suggestion for improving the website, only judge A suggested...*To further discuss the topic of newborn screening tests in the private healthcare system*. The other reviewers stated that the website was complete and that the product was very good. After the evaluation and analysis, all the adjustments suggested by the experts were made, except for the development of an app, a suggestion left for future study.

Website promotion

The product was publicized through various media outlets, initially among the researcher's fellow nurses and nursing technicians, as well as on her social media. Additionally, the website was featured on the website and social media stories of the Coren (Regional Nursing Council) of Rio

Grande do Sul during the first week of August 2022. Furthermore, the Postgraduate Nursing Program at the university to which the research is linked also promoted the product on its social media, significantly contributing to its reaching the largest possible audience.

DISCUSSION

With the development of the proposed website, it is expected that it will be a means of providing quality information, enabling access through various digital devices. To this end, the content was built based on recommendations from the Ministry of Health, the 2016 Technical Manual for Biological Neonatal Screening, as well as an integrative literature review of the last five years carried out by the author^{1,18}, in addition to other relevant scientific publications on the subject.

It is important to highlight that nursing plays a significant role in the National Neonatal Screening Program (PNTN), and should be familiar with all information regarding biological neonatal screening in order to inform mothers about the test and perform sample collection appropriately. Furthermore, in most cases, the superficial knowledge of postpartum women on the subject, along with weaknesses in guidance and procedures,



indicate the need to invest in professional training.^{16,18}

Therefore, considering this audience as essential in the collection of the newborn screening test, and for whom the website was intended, the perspective of nurses and pregnant women was significant in evaluating the product in terms of the clarity of information and the relevance of the content provided, being well-rated as having valid and reliable information.

Due to the popularity of the internet, social networks are the main platforms in terms of user numbers, and the use of this resource allows the dissemination of information to a larger number of people, who can access the product in various locations.¹⁹ Nevertheless, health education motivates individuals to change their attitudes, leading to disease prevention and behavioral change. In this context, the use of digital media is also a well-accepted strategy for disseminating content, due to its large population reach, reducing the distance between the population and health professionals, and providing reliable information.²⁰

Therefore, combining health education with digital resources is a successful partnership, as it allows information to be delivered quickly and accessed anywhere. This result confirms the purpose of creating the website "Teste do

Pezinho Gotas de Amor" (Newborn Screening Drops of Love).

CONCLUSION

The construction of a website about TNB aims to address the need for investment in education on the subject. Therefore, it is expected that the website will contribute to the continuing education of nurses in primary health care, as well as serve as a tool to clarify doubts about the collection procedure, its relevance to families' lives, and clarify questions about the legislation on the subject, reducing collection errors due to lack of information. Furthermore, it is envisioned that the website will indirectly contribute to increasing the coverage of the test within the recommended period.

For pregnant women and their families, this website is expected to be a source of quality information to answer questions regarding the newborn screening test and its importance. In addition, it is intended that, through the promotion of this product, TNB (Newborn Screening Test) will become better known, encouraging the dissemination of the test and, consequently, expanding its coverage.

It is noteworthy that the creation of the website was made possible through the use of digital media, enabling the selection of judges, the carrying out of the evaluation,



and subsequent dissemination. The website “Teste do Pezinho Gotas de Amor” (Newborn Screening Drops of Love) can be accessed through various digital devices and provides clear and objective information, contributing to the promotion of health in newborn screening.

Finally, it is worth highlighting that nursing plays a relevant role in TNB, being

responsible not only for collecting the sample, but also for disseminating information, providing guidance, and encouraging the examination. Therefore, the development of tools such as the website described in this study illustrates its significant role in helping to achieve this goal.

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