

Development and evaluation of a new website on oral health and Down syndrome

Gemma Rey Otero  | Berta Rivas Mundiña  | Eliane García-Mato |
Iván Varela Aneiros | Lucía Sande López | José Ramón García Iglesias

Medical-Surgical Dentistry Research Group (OMEQUI), Health Research Institute of Santiago de Compostela (IDIS), University of Santiago de Compostela (USC), Santiago de Compostela, Spain

Correspondence

Berta Rivas Mundiña, Department of Surgery and Medical-Surgical Specialties, Faculty of Medicine and Dentistry, University of Santiago de Compostela, c/ Entreríos sn, 15782 Santiago de Compostela, Spain.
Email: berta.rivas@usc.es

Abstract

Aims: The objective of this study was to develop a new website in Spanish on oral health and dental care for use by the relatives/caregivers of individuals with Down syndrome, with the aim of incorporating the strengths and avoids the deficiencies of existing websites.

Methods: A freely accessible website was developed with dental content, whose access criteria included the age of the individual undergoing the consultation and the area of interest (tongue or teeth disease, oral functionality, oral hygiene, and dental visits). The definitive version of the website was analyzed by five external examiners, applying the DISCERN criteria and the Questionnaire to Evaluate Health Web Sites According to European Criteria (QEEC). The website's traffic during the first year of activity was recorded.

Results: The new website is known as “DentiDown”, and its access domain is <https://odontoloxia-accessible.org/dentidown/>. On the home screen, the age group of interest to the user can be accessed. A dropdown menu then opens, listing the various options according to the area of interest. The oral hygiene section provides advice for improving toothbrushing efficacy through demonstration videos. With the DISCERN tool, an overall score of 4.75 ± 0.5 was achieved. With the QEEC, the external examiners' general opinion was highly favorable. The website received the seal of quality from the Accredited Medical Web (AMW). During the first year of activity, a total of 4536 visits from a total of 45 countries were recorded.

Conclusion: A new Spanish website has been developed on oral health for use by the relatives/caregivers of individuals with Down syndrome. The website has been favorably evaluated by external experts and, to date, is the only one with these characteristics with the AMW seal of quality.

KEYWORDS

dentistry, disabilities, down syndrome, internet, website

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1 | INTRODUCTION

The characteristics of Down syndrome (DS) include certain oral manifestations such as a higher rate of plaque and gingivitis than in the general nonsyndromic population,¹ an increased prevalence of periodontal disease,² an increased rate and severity of malocclusions,³ and a high frequency of bruxism.⁴ These dental-skeletal abnormalities participate in the etiology of an orofacial dysfunction, which can affect basic activities such as chewing and swallowing⁵ and negatively affect these patients' oral health-related quality of life.⁶ In short, the oral health condition of individuals with DS should be given special attention.¹

For the past two decades, the Internet has been an unprecedented revolution in the access to medical information,⁷ including oral health-related content.⁸ The Internet is a resource particularly employed by the families of patients with developmental disabilities such as DS.⁹ In 2016, we conducted a pilot study to analyze the quality of the freely accessible webpages available in Spanish with information on DS and dentistry for users who are not healthcare professionals.¹⁰ The search was performed with the Google Spain and Yahoo Spain search engines, combining the terms "Down syndrome" and "dentistry/dentist/dental treatment" (in Spanish). We recently broadened this study to assess the quality of the available online content on dental care for individuals with DS in Spanish and Portuguese.¹¹ To this end, we conducted a simultaneous research study in seven Ibero-American countries (Argentina, Brazil, Chile, Colombia, Spain, Mexico, and Portugal), employing the Google and Bing search engines, inserting combinations of the same keywords as in the pilot study. The conclusion of both studies was that the content available online regarding DS and dentistry was scarce and of highly questionable quality and might therefore provide erroneous information and generate false expectations in these patients' setting.

Accordingly, we proposed conducting a brief survey (data not published) to determine the format in which the potential users (typically the guardians of individuals with DS) prefer receiving this type of information. The screening was conducted among the attendees of the XVIII National Meeting of Families of Individuals with Down syndrome (*XVIII Encuentro Nacional de Familias de Personas con Síndrome de Down*), which took place in December 2018 in Santiago de Compostela (Spain). Of the 90 individuals who answered the survey, approximately 33% had sought information online on oral health and dental problems in DS, 62.7% of whom stated that it was easy to find the information. The same proportion had also found the information useful for making decisions. Most of the

respondents (63.3%) suggested that they would prefer this type of information be made available on a website.

We therefore proposed this study, whose aim was to develop a new website in Spanish on oral health and dental care for use by relatives/caregivers of individuals with Down syndrome, which incorporates the strengths and avoids the deficiencies of already existing websites.

2 | METHODOLOGY

2.1 | Preparation of the new website

Taking into account the preferences expressed in the survey conducted on the families of individuals with DS, we developed a freely accessible website with dental content for individuals with DS, whose access criteria included the age of the individual undergoing the consultation and the area of interest (medical conditions of the tongue or teeth, oral functionality, oral hygiene and dental visits).

The aim was to create a specific and easily accessible and navigable website that had a visually attractive interface, with useful and verified content, specifically preventing the information from inducing errors or generating false expectations in these patients' setting, as has occurred with most previously available webpages with these characteristics.¹⁰

After completing the first version of the website, access was provided confidentially to 30 potential users (guardians of individuals with DS) who voluntarily answered a survey on accessibility and satisfaction provided online through the Google platform. The survey consisted of the following questions: What is the website user's age? To what age group does the individual belong for whom you are seeking information? Were you able to access website easily? Was the organization of the information in the website appropriate and was the website easy to search? What was the level of difficulty of the language and expressions used in the website? Did you find what you were looking for? If you did not find what you were looking for, what type of information you were searching for? The survey results were used as a feedback mechanism to develop the definitive version of the website.

2.2 | Evaluation of the new website

The definitive version of the website was analyzed by 5 external examiners, all of them dentists with 15–30 years of professional experience in managing patients with DS. These examiners applied the criteria of the DISCERN tool¹² and the Questionnaire to Evaluate Health Web Sites According to European Criteria (QEEC).¹³ We also

attempted to obtain certification of the trust seals Health on the Net (HONcode)¹⁴ and Accredited Medical Web (AMW).¹⁵

2.3 | Registration of activity in the new website

To perform a quantitative analysis of the use of the new website over one year since its commissioning, we assessed the access using the Google Analytics and Google statistics tools, employing the following variables: frequency of webpage visits, user sex, user age, language in which the user's browser is configured (Spanish–Spain, Spanish–Mexico, Spanish–Chile, etc.) and the country from which the site was accessed.

3 | RESULTS

The new website was called “DentiDown”, and its access domain is <https://odontologia-accessible.org/dentidown/>. The home page (Figure 1) that welcomes users included an interactive tree through which (by clicking on the age range of interest to the user) users can access information of a specific dental nature for a specific age range. The established age ranges were 0–5 years, 6–13 years, 14–18 years, adults and older adults. The lower part of the webpage shows the affiliations of those responsible for developing the website and provides a number of links to more information.

When accessing a specific age group, the website opens a dropdown menu that includes the following options on the area of interest: tongue, teeth, mouth (functions), oral hygiene and dental visit.

To facilitate the search for information, the same areas of interest are repeated for all age ranges. By clicking on each of them, a series of questions are shown, which are adapted to each age range and reflect the most common questions that can arise with regard to individuals with DS of a certain age. These questions are detailed in Tables 1 and 2.

The section on oral hygiene (Figure 2) lists several recommendations for helping improve the efficacy of routine toothbrushing adapted to the characteristics of each age range, providing demonstration videos for this purpose. For older adults, systemic factors that can affect the oral cavity are also referenced. Lastly, various conditions for which a dentist visit is recommended are listed.

The accessibility and satisfaction survey conducted on the potential users of the website (guardians of individuals with DS) ($n = 30$) was preferentially answered, in decreasing order, by individuals 31–45 years of age (33%),

46–60 years of age (29%), >60 years of age (19%), 19–30 years of age (14%) and <18 years of age (5%), of whom 51% were female and 49% were male. Forty-eight percent of the individuals for whom the information was sought were adults, followed by children aged 6–13 years (19%), adolescents aged 14–18 years (14%), older adults (14%) and, lastly, children 0–5 years of age (5%). Forty-eight percent of the respondents thought that access was very easy, 47% considered it easy and 5% considered it satisfactory (none considered it difficult or very difficult). The manner in which the information was organized within the website was considered appropriate and the search was considered very easy by 62% of the respondents, easy by 33% and satisfactory by 5% (none considered it difficult or very difficult). The language and expressions used in the website were considered very easy to understand by 67% of the respondents, easy by 24% and satisfactory by 9% (none considered it difficult or very difficult). Ninety-one percent of the respondents stated that they had found all the information they had sought, while 9% had only partially found the information.

The following respondent demands led to changes in the definitive version of the website: (1) Include information regarding the repercussion of the most prevalent systemic comorbidities in DS on these patients' oral cavity and their management in the dental setting; (2) Supplement the information on oral hygiene techniques for individuals with DS with a limited degree of cooperation.

3.1 | Evaluation of the new website

The analysis of the website conducted by the external examiners using the DISCERN tool achieved an overall score of 4.75 ± 0.5 . The question with the lowest score referred to whether the sources of information were clearly specified, obtaining a score of 4 ± 0.82 . The rest of the questions received a score ranging from 4.5 to 5.

In terms of the evaluation conducted with the QEEC, the external examiners' general opinion was highly favorable (Criterion 18). In terms of the new website's shortcomings, however, all agreed that the website did not clearly describe the procedure for updating information (Criterion 9) and that there was a lack of accessibility for individuals with disabilities and learning difficulties (Criterion 17). The examiners also indicated a lack of specification of the sources of funding for the website's development and maintenance (Criterion 5) and a lack of clarity in the declaration of the procedure used for selecting links (Criterion 13).

We attempt to obtain certification of the Health on the Net (HONcode) trust seal, but the link has not been

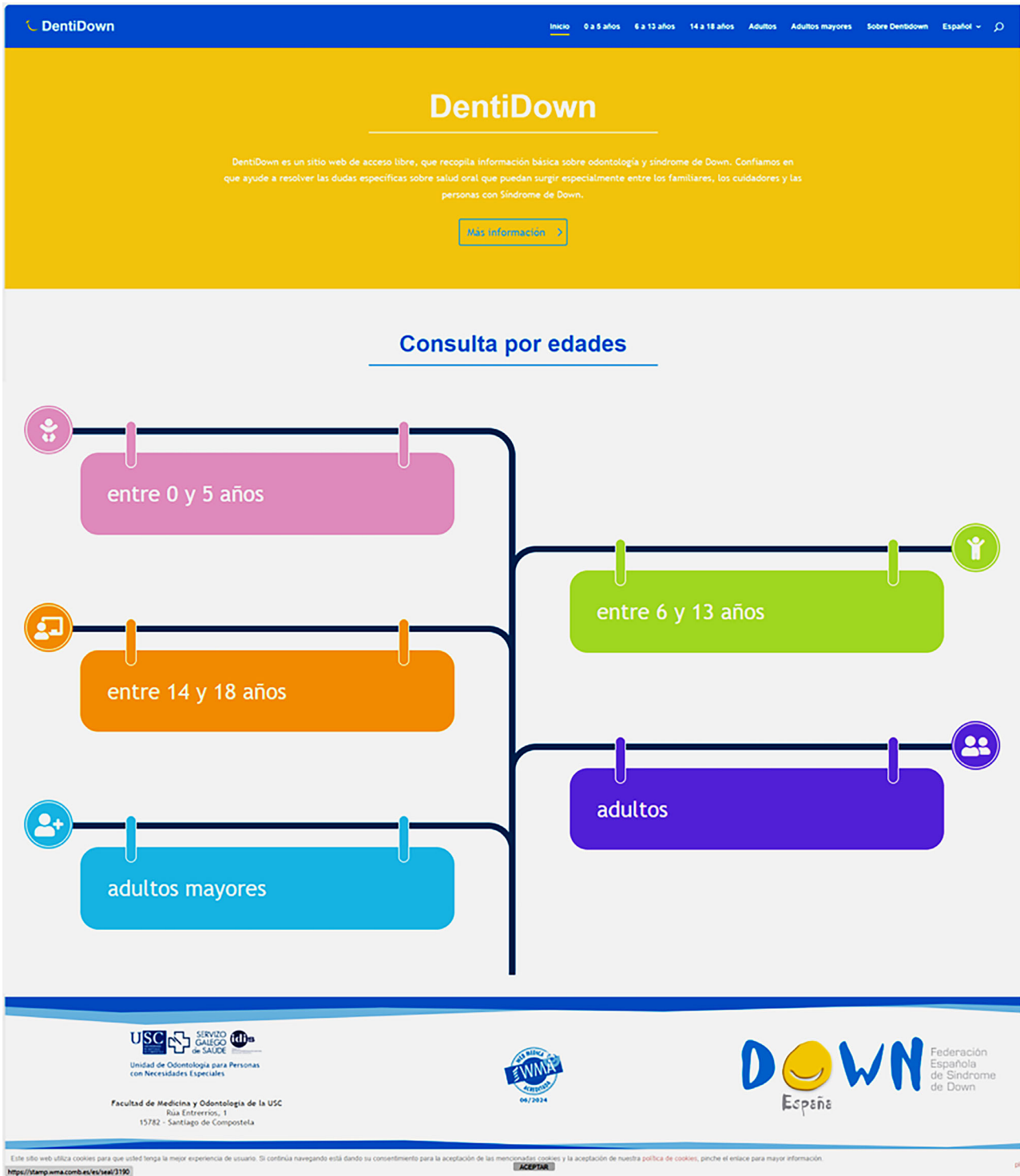


FIGURE 1 Home screen of “DentiDown” website.

functional since 2022. We requested the Accredited Medical Web (AMW) seal, which after requesting small changes (such as providing a contact email address to which comments and suggestions can be sent) ultimately accredited the new website.

3.2 | Registration of activity in the new website

During the first year of activity, a total of 4536 visits were recorded, which were conducted by 2122 users, 191 (9%)

TABLE 1 Issues regarding the tongue, teeth and mouth of children and adolescents.

Age, years	Area of interest	Issues
0–5	Tongue	<ul style="list-style-type: none"> • The tongue is almost always outside the mouth
	Teeth	<ul style="list-style-type: none"> • When should “milk” (temporary) teeth erupt? • How can we relieve the discomfort caused by the eruption of milk teeth? • How do we know if a tooth is missing? • Why are milk teeth important? • How can we tell if they have cavities? • Why do they grind their teeth?
	Mouth (functionality)	<ul style="list-style-type: none"> • Their pronunciation is poor • They have difficulties breastfeeding • They cannot chew properly • They cannot retain saliva in the mouth, resulting in drooling • Difficulties when breathing
6–13	Tongue	<ul style="list-style-type: none"> • The tongue is almost always outside the mouth • The tongue has marks on the sides • The tongue has cracks
	Teeth	<ul style="list-style-type: none"> • How we know if they have all their teeth? • Are their wisdom teeth going to erupt? • The shape of their teeth is peculiar • Their teeth enamel is different • The teeth are twisted or in unusual positions • How can we tell if they have cavities? • Their gums bleed • Why do they grind their teeth?
	Mouth (functionality)	<ul style="list-style-type: none"> • Their lips are frequently cracked • They cannot chew properly • They cannot retain saliva in the mouth, resulting in drooling • Their pronunciation is poor • Difficulties when breathing
14–18	Tongue	<ul style="list-style-type: none"> • The tongue is almost always outside the mouth • The tongue has marks on the sides • The tongue has cracks
	Teeth	<ul style="list-style-type: none"> • How we know if they have all their teeth? • Are their wisdom teeth going to erupt? • The shape of their teeth is peculiar • Their teeth enamel is different • The teeth are twisted or in unusual positions • How can we tell if they have cavities? • Their gums bleed • Why do they grind their teeth?
	Mouth (functionality)	<ul style="list-style-type: none"> • Their lips are frequently cracked • They cannot chew properly • They cannot retain saliva in the mouth, resulting in drooling • Their pronunciation is poor • Difficulties when breathing

of whom accessed the website on more than one occasion. The sex could be determined in only 40.1% of the users, with 66.8% male and 33.2% female. The predominant age ranges of the individuals who visited the website were 25–34 years (34.8%) and 35–44 years (33.0%); the lowest number of users were those older than 65 years (5.9%).

The information that raised the most interest in decreasing order was that regarding the following age ranges: 0–5 years (951 visits), 6–13 years (570 visits), adult (469 visits), 14–18 years (196 visits) and older adults (156 visits).

With regard to the language configured in the users' browsers, the most common was “Spanish-Spain” with a total of 1042 users (49.1%), followed by “Spanish-Mexico”

TABLE 2 Issues regarding the tongue, teeth and mouth of adults and older adults.

Age, years	Area of interest	Issues
Adults	Tongue	<ul style="list-style-type: none"> • The tongue is almost always outside the mouth • The tongue has marks on the sides • The tongue has cracks
	Teeth	<ul style="list-style-type: none"> • The shape of their teeth is peculiar • Their teeth enamel is different • How can we tell if they have cavities? • Their gums bleed and their teeth shift • Why do they grind their teeth? • How can lost teeth be replaced?
	Mouth (functionality)	<ul style="list-style-type: none"> • Their lips are frequently cracked • They cannot chew properly • They cannot retain saliva in the mouth, resulting in drooling • Difficulties when breathing
Older adults	Tongue	<ul style="list-style-type: none"> • The tongue is almost always outside the mouth • The tongue has marks on the sides • The tongue has cracks
	Teeth	<ul style="list-style-type: none"> • The shape of their teeth is peculiar • Their teeth enamel is different • How can we tell if they have cavities? • Their gums bleed and their teeth shift • Why do they grind their teeth? • How can lost teeth be replaced?
	Mouth (functionality)	<ul style="list-style-type: none"> • Their lips are frequently cracked • They cannot chew properly • They cannot retain saliva in the mouth, resulting in drooling • Difficulties when breathing

with 394 users (18.5%) and “Spanish-United States” with 166 users (7.8%).

The website was accessed from a total of 45 countries, highlighting due to its special prevalence in terms of users Spain ($n = 1091$), Mexico ($n = 193$) and the United States ($n = 152$); in terms of the number of sessions, there was Spain ($n = 2400$), Argentina ($n = 419$) and Mexico ($n = 371$).

4 | DISCUSSION

It has been suggested that DS represents a good model for translating the recommendations published in health apps for mobile devices, helping to improve the degree of compliance.¹⁶ There is already prior experience with interventions based on webpages and mediated by the parents of children with DS that have indicated that this is a viable and effective tool.¹⁷ This study presents a new freely accessible website with information on oral health for individuals with DS, which has been developed in an attempt to avoid the disadvantages of currently available websites.^{10,11} The website was designed considering the criteria for dental issues of interest (anatomy, function, oral hygiene and professional advice) and age.

As has already been indicated, certain dental-skeletal and functional abnormalities are especially prevalent and severe in individuals with DS.^{1–4,6} However, oral health has traditionally not been included in the national health evaluation guidelines for individuals with DS.¹⁸ Recently, the American Academy of Pediatrics, when referring to children with DS, suggested only that parents should be reassured, telling them that the patterns of delayed and irregular tooth eruption are common and that hypodontia is also more common than in nonsyndromic children.¹⁹ In other countries such as Sweden, however, the national medical guidelines for children with DS make explicit recommendations on oral health from very young ages.²⁰ In recent decades, there has been a significant increase in the life expectancy of individuals with DS, which entails substantial changes in their medical and societal needs,²¹ although the dental treatment needs of adults with intellectual and developmental disability (including DS) are considerable.²² In general, oral problems are not included among the concerns raised by older adults with mild to moderate intellectual disability in the health setting.²³

It has been suggested that caregivers of individuals with DS should receive professional instruction on toothbrushing techniques adapted to different age ranges, given that in many cases they must actively help these patients in

Consejos de higiene oral

- Aún tratándose de una persona adulta, no hay que descuidarse a la hora de realizar la higiene oral
- Se debe establecer un orden de cepillado para no olvidarse de ninguna zona
- Se pueden utilizar un cepillo eléctrico o uno manual, ya que ambos son eficaces si se aplican de manera correcta
- La duración tiene que ser de 2 a 3 minutos
- El cepillado debe realizarse 3 veces al día y el de la noche es el más importante
- Si utiliza prótesis dentales de quitar y poner, debe cepillarlas después de cada comida con un cepillo específico para prótesis o un cepillo de uñas y jabón neutro
- Si utiliza prótesis dentales fijas debe limpiar minuciosamente por debajo de la prótesis con cepillos interproximales, hilo dental o irrigadores de agua



FIGURE 2 Oral hygiene advice and illustrative video for older adults with Down syndrome.

performing routine oral hygiene procedures.²¹ Significant differences have been detected among children and adults in the frequency and duration of toothbrushing and in the preference for the type of toothbrush.²¹ The need for applying assisted toothbrushing techniques varies. According to a recently conducted survey in Sweden, more than 72% of parents of children and adolescents with DS help them clean their teeth daily.²⁴ A number of authors have indicated that this frequency is approximately 36% in children older than 10 years,²⁵ while other authors argue for maintaining the monitoring in children aged 12–16 years²⁶ and even in one of every three adults.²¹

The website also provides information on suspicious lesions and situations that justify asking for help from a dental practitioner. In Europe, check-ups and prophylactic sessions are the most common reasons why patients with DS visit the dentist, both children and adults.^{24,21} In some

non-European countries, however, the main reason for the visit is pain or the need for restorative treatment.²⁷ In countries such as Sweden, the recommended age for starting periodic dental visits for children with DS is 1 year at most, according to the national medical guidelines,²⁰ while in the United Kingdom, for example, a considerable percentage of adults with DS do not have access to regular medical check-ups, despite the high frequency of common medical complications.²⁸

When evaluating the new website, the external examiners gave it a DISCERN score much higher than those achieved by currently available websites in Spanish on this subject,¹¹ and the lowest assessed question was the one referring to the sources of information. With the QEEC tool, the examiners also obtained a highly favorable assessment, although a number of shortcomings related to the updating of information, funding sources and link

selection remained. For the first time, a Spanish website of these characteristics achieved an AMW accreditation seal. The website is directed towards relatives/caregivers of individuals with DS and not directly to the interested party, which could represent its main limitation, especially if we consider that individuals with intellectual disability typically are highly conscious of the stigmatization of their social setting regarding access and use of the Internet, in issues linked to competence, media literacy, cognitive skills and decision making.²⁹ Based on the neurological characteristics of individuals with DS (e.g., auditory deficiencies, motor limitations and intellectual disability), specific guidelines have been proposed for developing webpages directed at this group, focused on promoting their accessibility and management,³⁰ but their implementation is complex and represents a challenge for the future development of a version adapted for the Internet.

In conclusion, this study developed a new Spanish website on oral health for use by the relatives/caregivers of individuals with DS, whose opinion has been taken into consideration during the development process. The website has been favorably evaluated by external experts and, to date, is the only one with these characteristics with the AMW seal of quality. The future tasks include promoting the international dissemination of the website and designing an adapted version directed towards individuals with DS as potential direct users.

CONFLICT OF INTEREST STATEMENT

The authors declare that they have no conflicts of interest regarding the research, authorship or publication of this study.

ORCID

Gemma Rey Otero  <https://orcid.org/0009-0006-7457-0497>

Berta Rivas Mundiña  <https://orcid.org/0000-0003-4976-395X>

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