



Co-designing a website with and for youth, so they can better manage their health

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ABSTRACT

Objective: To co-design a website aimed to empower youth to ask questions to encourage productive, meaningful conversations with their health care providers.

Methods: The research team recruited adolescent stakeholders (ages 11–17) through flyers distributed at local Young Men's Christian Association (YMCA) locations, clinics, and school nurses. Eleven adolescents who had at least one chronic medical condition were selected as members of the two youth advisory boards. Youth participated in five co-design meetings to give input on website content and refinement over a two-and-a-half-year period. The youth reviewed the website in various stages of development.

Results: Youth wanted a website with simple, straightforward language that would be understood by someone between the ages of 11–17 years with a reputable URL. The website content includes ADHD, asthma, vaping/smoking, diabetes, seizures, anxiety, panic disorder, depression, addiction, stimulants, bullying, eating disorders, and sexually transmitted infections. Youth wanted general background content, helpful resources, question prompt lists, and videos encouraging youth involvement in care.

Conclusions: A credible co-designed website with information on different health topics that contains question prompt lists and videos for utilization during health care visits has the potential to increase adolescent involvement in their care.

Innovation: This website is an innovative intervention aimed at informing and encouraging youth to be more actively involved in their care across a range of healthcare conditions.

1. Introduction

Approximately 25% of children living in the United States have been diagnosed with a chronic condition that requires frequent visits with health care providers [1]. It has been estimated that adolescents only participate about 10% of the time in their visits, yet taking an active role in your own health is thought to improve health outcomes and decrease health care utilization [2,3]. There are currently many barriers to care that prevent youth from being active participants during medical visits [4]. Adolescents report that the three main barriers to self-management are intimidation, uncertainty of what questions to ask, and parental oversight in managing their health [4,5]. Research shows that when given the proper tools, youth are more likely to participate in their care [4].

Simple, scalable interventions, such as pre-visit videos and prompt lists, which are easy to implement and disseminate, could help youth

engage more during pediatric primary care visits. In our prior work, we found that a youth asthma video and question prompt list intervention significantly increased youth question-asking and provider education about asthma [5,6]. We also found that youth who received the intervention and asked their providers questions were significantly more likely to have improved quality-of-life and asthma control at 12 months [7].

Therefore, we wanted to create a comprehensive website to house question prompt lists and videos on various youth health topics that they can use as a resource to empower them to be more involved in their care. In our prior work, we found that the majority of adolescents with chronic conditions believed a website for adolescents with chronic conditions could be very useful; the youth wanted basic medical condition and treatment information and prompt lists that adolescents could use during visits with health care providers [6].

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Adolescents use technology often; estimates are that 95% of adolescents have access to a smart phone with 45% reporting they are on their smart phone “almost constantly” [3]. Therefore, when designing a website for adolescents, it is imperative to cater to the tendency to be on their phones. Several studies have shown positive correlations between improved health outcomes and technology usage, specifically phone applications [2,3]. When researchers were designing a website on transitions of care for adolescents in Ireland, 56% of adolescents said they would want to receive information via mobile phone application and 31% stated a website [8].

By utilizing website-based platforms, adolescents have direct access to information that encourages them to become engaged in their health care from an early age [8]. Adolescents regularly search for health information online, but there is currently no web platform based in the United States that contains materials that adolescents can use to actively partner with health care providers [8]. This research aims to address this gap by developing a website for adolescents to encourage them to take charge of their own health.

2. Methods

2.1. Creation of advisory boards

This study was approved by the Institutional Review Board at the University of North Carolina (UNC). Youth stakeholders were recruited through flyers distributed at local Young Men's Christian Association (YMCA) locations (these are community recreation centers that serve all genders and ages), clinics, and school nurses. Interested youth emailed the project manager if they wanted to participate. Participants were eligible if they were between the ages of 11 and 17 years with at least one self-reported chronic medical condition and spoke English. Two youth advisory boards were created—one in Western North Carolina and one in Central North Carolina. This allowed the research team to have access to youth from diverse backgrounds. Table 1 presents the demographics of the

youth advisory board members. The youth advisory boards consisted of eleven adolescent stakeholders, seven from Western North Carolina and four from Central North Carolina. All eleven stakeholders self-reported at least one chronic medical condition with 45% of participants reporting ADHD (Table 1). All adolescents were in middle or high school at the time of the original advisory board meetings. This methodology stems from a similar study conducted in Ireland where youth advisory boards helped design a website centered around transitions of care [9].

2.2. Procedure

A total of five advisory board meetings were completed between November 2019 and February 2022. Two were in-person and three were conducted via Zoom due to the COVID-19 pandemic and in compliance with local social distancing requirements. Youth were compensated either \$50 cash for in-person attendance or \$50 in an Amazon gift card for virtual attendance. For the two in-person youth advisory board sessions, discussions were audio-recorded and transcribed verbatim with identifiers removed. For the virtual youth advisory board sessions, moderators took written notes only. The youth advisory board sessions were moderated by investigators. Youth advisory board findings were used to create and modify the website content.

Table 2 contains the topics covered at each advisory board meeting. The first advisory board session focused on seven different areas of website content and design: text, colors, format, videos, question prompt list, and other. Youth stakeholders were first asked a series of questions regarding their online usage including how frequently they watch videos, what types of web-based platforms they frequented, and how they utilized the internet to search for specific health information. Next, they were asked about their opinions on designing a new website. These areas included discussions around text type, website color, website format, usage of videos, question prompt lists, topics, and general thoughts on websites. Originally, the website was supposed to focus on two chronic conditions, asthma and ADHD. Therefore, we showed youth our asthma videos and question prompt lists and asked whether they should be included on the website. At the time, the ADHD materials were not developed.

Based on the input from the youth, a mock draft of the website was created for their review at the next advisory board meeting. The first website draft consisted of a prototype, static layout and asthma content. During this meeting, youth were asked to react to the website's name, design, and content. Also, we asked for their thoughts on how they liked the layout compared to the adolescent-focused transitions of care website from Ireland (www.SteppingUp.ie) [9]. Discussion about website design was focused on the use of headers, drop-down bars, specific coloring, and formatting of text. The website content only included asthma, but youth were asked to discuss the inclusion or exclusion of videos, pictures, prompt lists, and information on asthma triggers.

The third advisory board session focused on a second draft of the website, with an updated website name. The website address of www.iuveo.org was selected with the tagline of “Information for the evolving teenager”. The address name was derived from a combination of the Latin word for juvenile (*iuvenalis*), using IUUV and VEO is an anagram on *evo* (evolution). The second website version was functional with a carousel-based photo navigation system to accommodate a scalable number of topics. It included a preview of other medical conditions, topic images for youth to react to, and thoughts on ways to access the website. Youth were asked to react to the ADHD and asthma content since these topics were the original focus of the research team when creating the website. For this session and sessions moving forward, the youth were asked for feedback on the website and the information and topics they wanted included.

The expansion of website topics was discussed in-depth during this session. It stemmed directly from the previous youth advisory board session, as co-designers were insistent that other topics impacting adolescents should be included. These topics were conditions such as anxiety, addiction, panic disorder, and depression. These medical conditions had no content at the time. Our team also asked how adolescents accessed the website,

Table 1
Youth advisory board demographics.

	Total
Number of Adolescents	11
Gender	
Male	36.36% (n = 4)
Female	63.63% (n = 7)
Hispanic or Latino	9.09% (n = 1)
Race	
Black or African American	18.18% (n = 2)
White	81.81% (n = 9)
Age	
11–14 years	18.18% (n = 2)
15–17 years	81.81% (n = 9)
Medical Condition	
ADHD	45.45% (n = 5)
Asthma	36.36% (n = 4)
ADD	9.09% (n = 1)
Arthritis	0% (n = 0)
Anxiety	9.09% (n = 1)
Depression	9.09% (n = 1)
Sickle Cell Trait	9.09% (n = 1)

Table 2
Youth website design suggestions.

Topics Asked About	Suggestions	Website Changes
<p>Session One</p> <p>Preferred website text, colors, formatting, additional topics, and inclusion of question prompt lists and videos</p>	<ul style="list-style-type: none"> • No small text, bulleted lists • Light colors-yellow, blues, navy blue, white • Pictures, charts, big headings • Electronic prompt list would be very helpful 	<ul style="list-style-type: none"> • First basic draft of website shell was designed • Asthma videos and question prompt list were added • Add prompt list PDF download
<p>Session Two</p> <p>Feedback on website title and first website draft</p>	<ul style="list-style-type: none"> • Shorter, more concise title • Vocabulary was too high level • Videos and animated content preferred to block--text 	<ul style="list-style-type: none"> • Website renamed and branded as “Iuveo” • More topics were added beyond asthma and ADHD
<p>Session Three</p> <p>Feedback on second website draft and accessibility</p>	<ul style="list-style-type: none"> • Some graphics used had negative connotations • Separation between blocks of texts • Navigating between topics was difficult (drop--down) • Website was accessible via phone and computer, or tablet 	<ul style="list-style-type: none"> • Topic header's graphic was changed • Color separation between content areas to visually break up text • Carousel-based photo navigation bar to move from topic to topic • Two questions were put at the top of each section for consistency and to draw users into topic
<p>Session Four</p> <p>Feedback on third website draft</p>	<ul style="list-style-type: none"> • Topics should include information on self and helping a friend • Topics should contain the same general information between sections • Utilizing both visual and written mediums for different learners 	<ul style="list-style-type: none"> • Questions placed in first person and third person point of view at the beginning of each topic • Consistency in section headers (symptoms, seeking help, treatment etc.) • Key points were included as text with video to summarize • Wording changes and some content added
<p>Session Five</p> <p>Feedback on fourth website draft</p>	<ul style="list-style-type: none"> • Hyperlink to bottom of page for “Need Help Now?” to make more accessible • Consistency for amount of information for treatment options and “Need Help Now?” • Video animation and content well received • Prompt lists had good questions and progression 	<ul style="list-style-type: none"> • Added medical and psychosocial content to treatment section • Jump links added to topic of each page to “Need Help Now?” • Wording changes and some content added

including questions about usage of a computer or smart phone, and whether any obstacles were encountered from a technology standpoint.

After the third meeting, the research team met regularly over several months to create and review draft content and question prompt lists for the additional topics that were added to the site. The team made sure that content was at a sixth grade reading level or below. The team had funding to create ADHD videos and received funding to add a stimulant misuse section and a “stimulants and addiction” video. The youth helped co-design all these videos in separate meetings.

The fourth advisory board session included a new draft of the website content. The youth were asked about wording for the half of the website content focusing on the following topics: asthma, ADHD, vaping/smoking, diabetes, anxiety, seizures, and sexually transmitted infections (STIs). A research associate wrote the content areas based on input from the youth advisory board and was subsequently verified by team members. The final advisory board session focused on youth reactions to the additional website topics: panic disorder, depression, addiction, bullying, eating disorders, and stimulant misuse.

3. Results

In the first meeting that focused on website usage and design, youth stakeholders indicated that text should involve large fonts that are easily discernable. The youth also felt websites that consisted of drop-down menus or content that was in bulleted form was easier to follow. The advisory board preferred websites that utilized yellow and blue colors. Other feedback included the integration of pictures and videos to better share the content for visual learners. For feedback regarding the inclusion of question prompt lists, stakeholders thought they would be useful. They wanted the ability to download PDFs of the prompt list so they could mark it up and add their own questions, if needed, to take to the doctor's office. The last area discussed was increasing the trustworthiness of the

website, among the target audience. Stakeholders believed the website should include the URL ending in .org or .edu as a way to increase credibility. They did not want any personal data collection or ID based login.

In the second advisory board session, the youth stated they did not like the first website static mockup with a drop-down navigation system. The youth were asked to react to the title “Advocating for what you want with your doctor, and other health tips”. They did not like this title. They stated language should be straightforward and simple when talking to adolescents. They preferred use of the word teenager over teen and adolescent. They wanted additional topics beyond asthma and ADHD, and vocabulary that a general teenager would understand rather than traditional medical terms. Youth also suggested adding sections about reaching out to discuss your health beyond doctors, including teachers, family members and friends. They also recommended adding helpful resources that pertained to each medical condition. Finally, regarding website expansion, the youth suggested including topics like mental health, vaping, and addiction.

During the third session, the youth felt the website had significantly improved. Table 2 contains their feedback. They thought the website was very straightforward and easy to navigate with the carousel-based photo navigation system at the top. The youth's major changes for content format styling included using less text or headers to separate the blocks of text. They also felt that stating directly who this website was created by and that it had input from two youth advisory boards would increase credibility. The advisory boards liked the website name (www.iuveo.org) better than previous titles. The youth accessed the website through both computers, androids, and iPhones, but not tablets and reported no problems accessing the website.

In the fourth meeting, youth provided wording and other suggested changes on the following topics: asthma, ADHD, vaping/smoking, diabetes, anxiety, seizures, and STIs. Overall the youth liked the website. Major changes included switching the point of view for questions at the top of each section so that one related to the reader and one related to the friend

of a reader, adding key points below videos to summarize, and maintaining consistency in content between sections. Other suggestions included focusing more content on the science behind the disease state and increasing ease of access to reduce clicks.

The final advisory board session focused again on youth's reactions to the panic disorder, depression, addiction, bullying, eating disorder, and stimulant misuse sections (Table 1). Consistency between sections was once again reiterated with the desire for all topics to have a similar number of resources available. To increase quick access to content lower on the webpage, the advisory board also wanted jump links at the top of the page. Fig. 1 contains an image of the website's landing page that resulted from youth input from all five meetings. The youth were very positive about the website.

4. Discussion and conclusion

4.1. Discussion

Throughout the five youth advisory board sessions, the youth had a clear vision of website preferences. The focus on using simple language that is easily understood by any youth between the ages of 11 and 17, shaped the website in a unique way that differs from current websites available to the public that tend to be at high literacy levels. Also, the youth were very thoughtful in ensuring the information was portrayed in a variety of ways including a mixture of short videos, text, and graphics to appeal to different users.

The website originally was going to focus solely on asthma and ADHD. However, based on youth feedback, nine additional topics were added (diabetes, seizures, anxiety, panic disorder, depression, stimulants, bullying, eating disorders, and STIs). In addition to chronic medical condition topics, youth also wanted sections of the website to focus on vaping and addiction. As additional content was requested, the youth also requested broadening the points of view available on the website, to include both readers but also how to assist friends of readers. To make the website more trustworthy, the suggestion of using a URL with .org was adopted.

Each advisory board consisted of English-speaking adolescents from North Carolina, which limited insight and preferences from youth who speak a different language. Another limitation is the team only received

funding to create quality videos on asthma, ADHD, and stimulant misuse and addiction. Throughout the co-design process, the importance of using videos to reinforce content messages was re-iterated. As work with the youth advisory board continues, the study team is seeking funding to further develop videos for the website, expand topics as they arise, and develop a social media strategy for dissemination.

4.2. Innovation

This work is innovative in several ways. First, we used novel methods to design our website, which are new to the United States. Our team co-designed this website with youth, for youth, to specifically focus on empowering youth to be more involved in their medical visits and health care. For example, by engaging in an iterative co-design approach, youth partners had the opportunity to react to early drafts and make suggestions for refinement. As a result, while the original intention of the website was to focus on chronic medical conditions, youth partners broadened the scope of the website to incorporate bullying and many mental health and substance use topics. Additionally, youth partners made suggestions to lower stigma and broaden appeal by having the website focus on information-seeking for themselves or to help their friends. Consequently, each section's heading has a question targeted to the teen themselves and one focused on a friend of the teen (e.g., have you thought about vaping?, do you know someone who vapes often?). Another innovation of the website is that it contains materials to improve teen confidence or self-efficacy in asking questions. First, the website contains one-page question prompt lists that youth can use with their providers or other trusted adults focused on each website topic. The teens can print the question prompt lists and check which questions they want to ask. Second, the website has videos which attempt to model behavior for youth through scenarios that use either teen actors or animation. This novel feature helps teens see how health and other topics can be brought up with providers or trusted adults. Another novel feature of this website is that it gives youth the ability to learn more about sensitive topics in private (e.g. vaping, STIs). It also is written at a sixth grade reading level to accommodate teens of different literacy backgrounds. Most health websites in the United States are at too high of a reading level and they are not co-designed with youth. The website can be disseminated widely through medical clinics, schools,

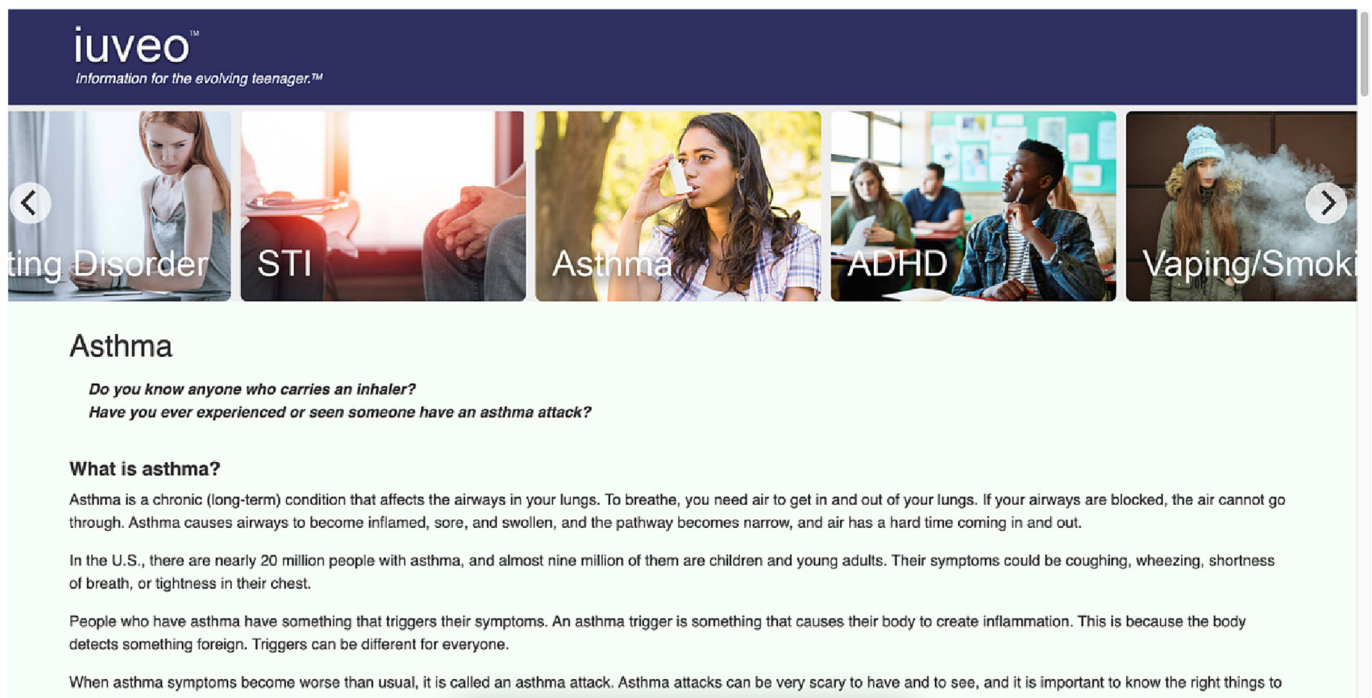


Fig. 1. Current website design.

YMCAs, and Boys and Girls clubs. The website gives youth tools that they can use to ask questions of their health care providers and trusted adults.

In summary, this work is novel because it generated a website product shaped by youth partners in real time to be appealing to them. During the ever evolving technological and social media landscape, consultation with adolescents in real time allowed for greater exploration and creation of video and image content. In this regard, youth are far more technologically savvy and encouraged breaking away from traditional health education material. General information became more dynamic and streamlined in nature, to facilitate interactions with adolescents who respond better to 'bite sized' clear information. This streamlining also allowed us to expand the number of health topics presented. In summary, it is the novel nature of content creation for this website that not only lends itself to increased credibility, but applicability to youth across the United States.

4.3. Conclusion

Our team co-designed a website with youth which resulted in the creation of a unique product: <http://iuveo.org/>. The youth advisory boards viewed the end product as something that youth could use when looking for information for themselves or their friends.

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CRediT authorship contribution statement

Megan Wright: Writing – original draft, Conceptualization, Formal analysis. **Kathleen C Thomas:** Conceptualization, Formal analysis, Writing – review & editing. **Delesha Carpenter:** Conceptualization, Formal analysis, Writing – review & editing. **Charles Lee:** Software, Conceptualization, Formal analysis, Writing – review & editing. **Imelda Coyne:** Methodology, Conceptualization, Formal analysis, Writing – review & editing. **Nacire Garcia:** Conceptualization, Formal analysis, Project administration, Writing – review & editing. **Abena Adjei:** Conceptualization, Formal

analysis, Writing – review & editing. **Betsy Sleath:** Conceptualization, Formal analysis, Validation, Funding acquisition, Writing – original draft, Supervision.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Betsy Sleath reports financial support was provided by The Duke Endowment.

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