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## Using Digital Media to Promote Kidney Disease Education

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### Abstract

Healthcare providers and patients increasingly turn to the Internet—websites as well as social media platforms—for health-related information and support. Informed by research on audience behaviors and preferences related to digital health information, the National Kidney Disease Education Program (NKDEP) developed a comprehensive and user-friendly digital ecosystem featuring content and platforms relevant for each audience. NKDEP's analysis of website metrics and social media conversation mapping related to chronic kidney disease revealed gaps and opportunities, informing the development of a digital strategy to position NKDEP as a trustworthy digital source for evidence-based kidney disease information. NKDEP launched a redesigned website ([www.nkdep.nih.gov](http://www.nkdep.nih.gov)) with enhanced content for multiple audiences as well as a complementary social media presence on Twitter and Facebook, serving to drive traffic to the website as well as actively engage target audiences in conversations about kidney disease. The results included improved website metrics and increasing social media engagement among consumers and healthcare providers. NKDEP will continue to monitor trends, explore new directions, and work to improve communication across digital platforms.

### Keywords

kidney disease; health education; Internet; social media; health care providers

### Introduction

The National Kidney Disease Education Program (NKDEP) was established in 2000 by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). NKDEP works to reduce the morbidity and mortality associated with kidney disease by improving early detection of chronic kidney disease (CKD), facilitating the identification of patients at greatest risk for progression to kidney failure, promoting evidence-based interventions to slow progression of CKD, and supporting the coordination of Federal responses to CKD.

The Chronic Care Model (CCM), an approach which has been shown to improve care and reduce disparities in chronic disease, provides a framework for NKDEP's activities (1, 2). NKDEP strives for the CCM goal of informed and engaged patients and communities,

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prepared and proactive health care providers, and efficient and effective health care systems. Because early identification and management of CKD has been associated with improved outcomes (3, 4, 5, 6), NKDEP encourages primary care providers to take an active role in CKD screening, education, and management prior to referral to a nephrologist. The program also encourages patients to better understand and more actively manage their own CKD and related conditions.

Both providers and patients increasingly turn to the Internet—websites as well as social media platforms—for health-related information and support. NKDEP has made a considerable investment in developing a comprehensive and user-friendly digital ecosystem that contains content relevant to each audience and helps promote the “productive interactions” between patients and providers envisioned by the CCM.

## Digital Health Habits

NKDEP's ongoing investment in digital content and platforms is informed by an understanding of health professional and patient behaviors and preferences related to digital health information. The Internet has become an essential source of health information: 80 percent of Internet users look online for health information and a quarter of Internet users watch health-related videos (7). For those with a chronic condition, almost a quarter of Internet users have gone online to find others with similar health concerns (8). Younger internet users (18-34) are more likely than older users to look online for health information earlier in the patient journey (e.g., for new symptoms, to prepare for a doctor visit) rather than after a diagnosis or medication prescription (9). Many patients make health decisions based on the information they find online: more than 50 percent of patients who use the Internet say they were influenced by online health information and tools when choosing healthcare providers, treatments, and services (9).

Not surprisingly, the number of people using mobile phones for health information is on the rise (9). In 2012, more than 30 percent of all mobile phone owners, including 52 percent of smartphone owners, used their phones to look for health information, almost double the number two years ago (10). African Americans, Latinos, and people ages 18 to 49—as well as people who have experienced a change in their health status, faced a medical crisis, or are caring for a loved one—are more likely to use their phones for this purpose (10).

People are also turning to social networking sites—frequented by 69 percent of online adults, particularly women (11)—for health concerns. Almost a quarter of Internet users have used social networking sites to follow a friend's personal health experience, while 15 percent have obtained health information from them (7).

Healthcare providers, including physicians, physician assistants (PAs), nurse practitioners, and nurses, are utilizing digital tools and resources professionally. Providers report spending 10-20 hours a week online for professional purposes (12). Physicians in the United States are using mobile digital devices—85 percent own a smartphone and 62 percent own a tablet—and more than half of those who own mobile devices report using them at point of care with patients (12). A third of physicians surveyed reported changing a patient's treatment as a result of an Internet search (13), and more than two-thirds report using online videos to keep up with clinical information (12).

Physicians in the United States—particularly those under age 35—also use online networks and social media with patients and other physicians (13, 14). Physicians are engaging in social networking sites both personally and professionally: a 2011 survey found that almost 90 percent use social media for personal purposes and more than 65 percent use it for professional purposes (14).

Compared to physicians, PAs and nurses spend slightly more time online for professional purposes and use smartphones substantially more often during patient consultations (15). Nurses and PAs report using digital support materials and tools for patient education (15). More than 68 percent of nurses use Facebook, while about 11 percent use Twitter (16).

Health educators have begun to offer providers and patients a wide range of online resources, including videos, interactive tools, and social media communities that complement standard websites. Moreover, these resources are being used across the six elements of the CCM—community, the health system, self-management support, delivery system design, decision support, and clinical information systems—to foster prepared practice teams and informed, activated patients as well as support systematic changes. For example, consumers are finding self-management support from mobile phone applications that track their diet or medications. Providers are increasingly using tablets during the patient encounter (12), streamlining the clinical information system and receiving decision support.

To build on the knowledge available from published sources, NKDEP conducted its own research to explore existing digital resources and identify opportunities for growth. We analyzed existing NKDEP web content in light of the anticipated needs and goals of key audiences to determine gaps and establish priorities for website redesign. We also analyzed web metrics to identify which web content was the most popular, and which appeared the most challenging to locate, to inform our redesign.

In addition, we conducted conversation mapping research to examine the breadth and depth of discussions on English- and Spanish-language social media sites and identify those communities and conversations most relevant to CKD and NKDEP's objectives. This included using Radian6 (now Salesforce Marketing Cloud) to search a variety of social media sites and platforms (e.g., blogs, social networks, forums, and review sites) to identify health professional and patient/public discussions about chronic kidney disease or NKDEP, and then analyzing these conversations to identify the most active sites, most influential participants, and most popular topics.

This research revealed that health professionals, as well as patients and the public, are actively discussing kidney disease via social media channels. Most health professional activity takes place on Twitter, where a variety of health professionals post links to breaking news, research, events, CKD-related advice, and research findings and articles. Through blogs or other online content, providers also provide additional facts and commentary on scientific studies to help patients understand their implications.

Our research found that when providers discuss CKD in social media, they typically discuss new studies related to treatment or the importance of prevention, often in tandem with other diseases that can be prevented by leading a healthy lifestyle. The tone of health professional posts is authoritative and educational; providers do not appear to be using social media to ask for advice on diagnoses or providing CKD education to patients.

Our social media research also showed that patients, caregivers, and the public actively use social media channels, particularly Facebook, to demonstrate their knowledge about kidney disease and share stories about themselves and their loved ones. Additionally, we found that myths about CKD may be amplified by social media.

## Developing the NKDEP Digital Ecosystem

Based on our research findings, NKDEP sought to position itself as a trustworthy digital source for evidence-based kidney disease information that would be useful for both

providers and patients, helping people connect with each other and find information to share with others. We created both static and interactive tools for professionals, such as expanded web content, dialogue-modeling videos, and a lesson builder for patient educators. We also created user-friendly content for patients, focusing on plain language principles, incorporating video, and promoting content sharing via social media.

Our digital engagement objectives were to build awareness and engagement online among key target audiences, strengthen NKDEP's reach and impact using social media platforms, and complement other outreach efforts. We also sought to build NKDEP awareness and reputation by initiating and joining relevant conversations on blogs, Twitter, and Facebook. Our process included clearly defining our goals for each audience and designing a targeted, purposeful digital strategy to meet those goals. Our corresponding strategies included actively participating in relevant discussions online; forging a clear identity and demonstrating NKDEP's perspective, personality, and other attributes important for successful online engagement; and maintaining a steady stream of online activity to generate ongoing awareness of, and participation with, the program.

### Website Redesign

In 2012, NKDEP launched a redesigned website ([www.nkdep.nih.gov](http://www.nkdep.nih.gov)) with enhanced, easy-to-understand content for multiple audiences, including: people at risk for and diagnosed with kidney disease, all the members of patients' health care teams, the broader clinical and public health community, Federal agencies that work on kidney disease and related issues, and others interested in learning more about kidney disease.

NKDEP significantly expanded its online offering for health care professionals, a priority audience. The focus was on primary care providers and patient educators, including doctors, nurse practitioners, physician assistants, diabetes educators, dietitians, social workers, nurses, and pharmacists. The website's new *Identify and Manage Patients* section distills evidence-based information for primary care professionals to assist with patient management—from initial CKD diagnosis to preparation for renal replacement therapy (RRT). After a review of existing online content about CKD, NKDEP identified a need for simple, basic content that could demystify CKD for providers in primary care settings. We also identified which of the existing site content was most popular, along with common search terms related to CKD, to ensure users would find the content they were already using as well as other needed content that had not previously been available on the site.

NKDEP created a detailed outline of content that was reviewed by a cross-section of providers on the NKDEP Coordinating Panel—including physicians, nephrologists, diabetes educators, and dietitians—to ensure it was comprehensive and organized logically. The content also was reviewed for accuracy by the American Society of Nephrology CKD Advisory Group. Final review of content and language was conducted by NKDEP subject matter experts.

A key feature of the professional content on the new website is the online *Kidney Disease Education Lesson Builder*, which helps users create and deliver educational sessions to help patients manage their CKD and prepare for RRT. We sought to make the Lesson Builder modular, adaptable, comprehensive, and measurable. The content is presented as an integrated suite of materials, with both learner and educator versions. The tool is divided into six lesson plans, each of which includes learning objectives, sample session starters, recommended session content, patient education materials that can be printed and ordered, clinical information for educators, sample outcome assessment questions, and visual teaching aids that can be used during the sessions. The lesson plan content meets the needs of qualified providers seeking to deliver the Kidney Disease Education Services benefit, as

defined by the Centers for Medicare & Medicaid Services. A sample pack of the patient education materials recommended for all six lesson plans can be ordered in NKDEP's online resource center.

Content for consumers also was refreshed and expanded. The *Learn about Kidney Disease* section offers basic information about kidney disease and its risk factors, questions for people at risk to ask their health care team, and an explanation of the tests needed for those at risk. The *Living with Kidney Disease* section contains diet and lifestyle changes for people with CKD, resources to help people with CKD work with their health care team, and information on kidney failure treatment. The *Get Involved* section encourages consumers and professionals to become kidney health champions by sharing NKDEP educational information with their families, faith communities, and health and professional organizations.

The research on Spanish-language websites revealed a significant gap in kidney disease information for Spanish speakers. To meet this need, we adapted the consumer-oriented content of the English site to the United States Hispanic population. The section was developed by Spanish speakers and contains culturally adapted content, images, and design. Recognizing that mobile device usage is high among this audience, we created a mobile-optimized version of this section.

Reflecting the importance of health-related video content for both providers and consumers, the redesigned site integrates and highlights NKDEP-developed multimedia. For providers, the site offers a library of short skills-building videos (in English and Spanish) that model provider-patient interactions around common CKD questions. These videos are also placed throughout the consumer sections of the site as an alternate format for key information. For health champions, a feature video—using real footage of NKDEP materials being used at community events—demonstrates the value of discussing kidney disease at family reunions and in faith-based settings. The site also promotes videos with personal stories from consumers about using NKDEP materials. Social media is incorporated on the site through live Facebook and Twitter feeds on appropriate pages as well as opportunities to share content throughout the site.

To ensure that busy providers can quickly find what they need, we applied best practices in website design to make the most important and popular data easily accessible via a minimal number of clicks. We aimed to strike a balance between offering the most popular content from the existing site and promoting important content/tools that had been underutilized. The main goal of the website was to ensure that visitors—patients, healthcare professionals, partners, and other internal and external stakeholders—would more easily find the information they were looking for as well as discover other relevant information.

Best practices informed the information architecture and user interface development. Content was structured by users' purpose and context (e.g., living with kidney disease, managing patients) rather than by their identity (e.g., patients, providers) to help users quickly determine what they will find in each section of the site. Because the website hosts a wealth of information, the site inevitably got “deep,” with multiple levels of nested pages. To elevate this nested content, we developed a rollover “mega menu” that displays up to two levels of navigation, providing an overview of the content within each section and a way for visitors to click directly into a nested page. We also created shortcuts on the mega menus to the most popular content, links on every page that promote content across the site, and a central *Resource Center* to host all NKDEP-produced resources and tools. Interface design was an important factor: in order to accommodate so much content on a page, we kept the branding minimal and used white space, large headings, and titles to allow easy scanning of

content. In addition, through every stage of the site's development, accessibility was a top consideration, and we ensured compliance with Section 508 of The Rehabilitation Act (17).

We conducted several rounds of usability testing on the site's architecture, navigation, and user interface with health professionals, consumers (including Spanish speakers), and organizational partners. Feedback across audiences was positive, with important areas of improvement noted in each round.

## Social Media

Based on the research findings, NKDEP launched a social media presence to complement its digital resources, serving to drive traffic to the website as well as actively engage target audiences in direct, two-way conversations about kidney disease. To ensure we could spark and join conversations across multiple target audiences, NKDEP established itself with a distinct identity on the social media channels that were most appropriate for each audience: Twitter for health professionals and Facebook for consumers.

NKDEP's Twitter handle, managed by the NKDEP director (Andrew Narva), positions NKDEP as a trusted, authoritative source for CKD-related news and information for health professionals. In particular, it aims to generate conversation among primary care providers about identifying and treating patients at high risk for CKD; facilitate CKD care by primary care professionals by covering topics such as risk factors, treatment/management best practices, patient education, and relevant NIH research; and promote events in which NKDEP and Dr. Narva are participants or are relevant to NKDEP's goals. Using an individual nephrologist (Dr. Narva) as the NKDEP "voice" on Twitter was selected as the best way to engage providers looking for expert advice and opinions about CKD. The handle (@NarvaNKDEP) links Dr. Narva to his role as NKDEP director—combining both personality and authority, which provides him with greater flexibility while conveying a sense of approachable expertise to his Twitter followers.

NKDEP also offers a *Make the Kidney Connection* Facebook page for people affected by kidney disease and community health champions. The page aims to engage Facebook users who are advocates for kidney disease in their networks and communities as well as people who have kidney disease or are at risk. It also serves as a way to connect with audiences at highest risk for kidney failure, particularly African Americans and Hispanics, who are heavy users of social networking sites (11) and who view government use of social media as helpful and informative (18). With increasing numbers of members and interaction among members, this Facebook page facilitates meaningful conversation and information exchange, and provides a forum for sharing stories about kidney health (e.g., adopting healthy behaviors, experiences with providers). It also regularly directs members to content on the NKDEP site and related NIH program sites. For the Twitter and Facebook accounts, NKDEP created and adheres to commenting guidelines that specify online monitoring and response protocols. NKDEP also has a YouTube channel, which shares testimonials from consumers and professionals about using the materials as well as the short web videos about common CKD questions described above.

## Results

In 2012, the NKDEP web site received more than 1.4 million visits. For the first six months after the launch of the redesigned site, website metrics improved markedly: average monthly visitors increased by 34 percent, average visit duration increased by 8 percent, and the exit rate from the homepage (which is inversely related to engagement with the site) decreased from 75 percent to 30 percent. The site received high satisfaction scores—achieving 88



percent overall—on the ForeSee survey, a customer satisfaction survey administered on the NIDDK websites.

As indicated by the content being accessed on the site, health professionals are a key user audience. GFR (glomerular filtration rate) calculators continue to be a popular resource, receiving more than 65,000 visits a quarter. A large portion of the site's visitors come from bookmarks (likely for the calculator) or typing in the URL directly, showing that professionals are aware of the NKDEP site and the resources it offers. Resources for dietitians are among the most downloaded. The provider modeling web videos have received a steady increase in traffic; since being posted to YouTube in 2011, the videos have received nearly 125,000 views.

As part of promotion for the redesigned site, 20 organizational partners shared information with their members, including more than 35 mentions in social media channels, which led to 5,000 hits to the website. The success of these promotions reflects the relevance of the expanded content to health professional audiences; for example, the American Association of Nurse Practitioners (AANP) provided a link to a particular resource in its e-newsletter, leading the resource to become a top entry page for the site and the AANP to be a top referring site.

In addition, the Spanish-language site garnered media coverage in top-tier Spanish-language outlets, including CNN and Univision, resulting in more than 35 million impressions and increased traffic to and engagement with the site. The media's interest in the Spanish-language content may result from the lack of patient-friendly resources about kidney disease for this audience.

For NKDEP's social media channels, we achieved more than 3,500 “likes” on the *Make the Kidney Connection* Facebook page and 375 followers of the Twitter handle. On average, this participation results in more than 35,000 impressions per month (10,000 unique impressions) of NKDEP content across Facebook and Twitter, with more than 600 people sharing or discussing NKDEP-created content across Facebook and Twitter every month. In 2012, Facebook became one of the top 15 referrers to the NKDEP website, reflecting success in driving traffic from the *Make the Kidney Connection* page and promotion by partners.

## Discussion

Educating patients and providing resources to providers about disease diagnosis, management, and treatment are important charges for Federal health education programs. These efforts are especially critical for CKD—where self-management behaviors and decisions about when to initiate treatment and/or prepare for RRT can have a significant impact on outcomes (3, 4, 5, 6). While there continues to be a need for many traditional communication channels, the future of much of this education is clearly in the digital space. Both providers and consumers have come to expect digital resources that are customizable, interactive, and optimized for delivery across a variety of mobile platforms.

Developing a successful digital strategy requires thoughtful, current research that yields insights about audience needs as well as the best content and platforms to meet those needs. It is also crucial to know and apply best practices in digital and social media communication, and to stay current with trends and new technologies (e.g., health applications, gaming) that encourage and support extended, deeper engagement with target audiences.

Another key consideration is the evaluation of digital efforts against measurable goals and objectives. Ongoing evaluation has never been more possible or immediate than it is with real-time web analytics tools. NKDEP regularly gathers web data on the content being accessed as well as social media metrics on participation and engagement. In the future, we hope to measure our impact by examining the relationship between digital efforts and behavior change.

NKDEP has spent years developing a digital ecosystem that we believe meets the needs of providers and patients and helps fulfill the CCM vision of “more productive interactions” between the two. We continue to explore new directions and work to improve how we communicate with the clinical community and patients across all of our digital platforms. We welcome feedback, and are open to collaborating on partnerships to expand our resources and extend our reach to continue to meet the needs of the kidney community.

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### Clinical Summary

- NKDEP developed a strategic digital ecosystem to meet the health information needs of patients and healthcare providers related to kidney disease, aiming to enable productive interactions that can improve care.
- NKDEP's digital strategy was grounded in research and insights about the target audiences' online behaviors and preferences.
- NKDEP selected targeted social media platforms to complement its website presence and further engage both healthcare providers and consumers.