

# The Evolution of Kidney Stone Information Available to Patients: Interest Trends of Social Media and Quality Assessment of Kidney Stone Smartphone Apps

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## Abstract

**Purpose** To identify what information kidney stone patients want and the resources they use to find it, and to evaluate kidney stone-related smartphone apps based on their actionability, understandability, quality, and reliability.

**Methods** Google Trends was used to assess searches related to kidney stones and related smartphone applications (apps) from 2019 to 2021. A questionnaire aimed at ascertaining where patients obtain kidney stone-related information was posted on popular Facebook groups and one Reddit group. Seven popular kidney stone-related apps were evaluated for reliability, quality, actionability, and understandability. Univariate statistical analysis, search volume index, and descriptive statistics were used to assess correlations and impact of variables on outcomes of interest.

**Results** Between 2019 and 2021, the peak search volume index of kidney stones was in the summer and winter. Questionnaire participants obtain most information from their doctor (45%), Reddit and Facebook groups (43%), YouTube (9%), and smartphone apps (4%). 23% reported using a kidney stone app at least once to obtain information. The average smartphone app overall has poor reliability (2.43,  $P < 0.001$ ) and quality (1.96,  $P = 0.039$ ) and poor review of treatment options with side effects (1.36,  $P = 0.689$ ), and does not encourage shared decision-making (2.57,  $P = 0.162$ ). Poor actionability was found in all apps, and good understandability was found in 6 of the 7 apps.

**Conclusion** While physicians are still the most-used resource for patients, patients are increasingly using online platforms and smartphone applications. Urologists should consider engaging kidney stone patients through such platforms to provide reliable educational information.

## Introduction

The prevalence and incidence of kidney stones have increased in the last decade, with about 1 in 10 people affected<sup>[1–3]</sup>. With the continuous evolution of technology and easily obtainable information on the internet, patients have found resources such as YouTube, Facebook groups, Reddit forums, and smartphone apps to answer their questions regarding kidney stones<sup>[4–9]</sup>.

### Key Words

Social media, smartphone app, kidney stones, health literacy, DISCERN, Patient Education Materials and Assessment Tool

### Competing Interests

None declared.

### Article Information

Received on March 22, 2023  
 Accepted on June 10, 2023  
 This article has been peer reviewed.

Soc Int Urol J. 2023;4(5):369–377  
 DOI: 10.48083/IPHG7802

## Abbreviations

PEMAT Patient Education Materials and Assessment Tool  
SVI Search Volume Index

As medical care continues to evolve, online platforms and smartphone apps have provided a way for patients to be more involved in the day-to-day management of their acute and chronic medical conditions[10–12]. The quality and reliability of health care-related smartphone apps are not assessed before publication, and this increases the risk that users will either follow inaccurate information or receive limited information regarding treatment options and side effects[6,7,11,12]. Previous work has mentioned the usefulness of applications (“apps”) in improving the quality of life of patients affected by kidney stones but has also shown that information presented in those apps lacks adherence to guidelines[13]. Other studies have compared apps created to decrease incidence of kidney stones[14]. Our study aims to survey what kidney stone information patients are interested in and where they are obtaining this information, and to assess the top kidney stone-related smartphone apps used.

## Materials and Methods

### Google trends

The preliminary search terms “kidney stones” and “mobile app kidney stones” were used to determine the quantity and frequency of searches both in the United States and worldwide between 2019 and 2021.

### Qualtrics survey

A qualitative survey created on Qualtrics (Seattle, USA) asked patients where they obtain their information on kidney stones, what information they are interested in, and whether they have ever used a kidney stone app. The survey was posted to 2 popular Facebook sites (“Kidney Stones Suck-Support” and “Kidney Stones-Worst Pain Ever”) and 1 Reddit group (“Kidney Stone Support”) that patients with kidney stones frequent.

### Kidney stone-related smartphone app selection

A cross-sectional, qualitative study on 7 kidney stone smartphone apps supported on iOS, Android, or both was conducted. The apps were chosen on the basis of the information app developers provided on their total number of downloads and daily number of users. Selection criteria for apps included greater than 1000 total downloads across both iOS and Android platforms, as well as containing information related to kidney stones.

### DISCERN

The DISCERN tool was used to evaluate the quality and reliability of information on 7 kidney stone smartphone

apps compared with established urological kidney stone management guidelines and recommendations[15,16]. The tool consists of 16 questions to assess the reliability and quality of information on treatment options in a publication[17]. Apps were evaluated by 3 of the authors.

### The Patient Education Materials Assessment Tool (PEMAT)

The PEMAT tool, a 26-question assessment, was used to assess the understandability and actionability of information provided in the 7 kidney stone smartphone apps based on urological kidney stone management guidelines and recommendations[15,16–18]. A score of 70% among the individual apps was used as a cutoff to differentiate poor versus good understandability and actionability. This threshold was chosen on the basis of previously published work, and apps were evaluated by the same 3 authors[19,20].

### Statistical analysis

All statistical analyses were performed using Microsoft Excel Version 16.43 with data analysis ToolPak. Univariate statistical analysis was performed to assess smartphone apps according to the following parameters: reliability, quality, encouragement of shared decision-making with doctors, understandability, and actionability. An alpha level of 0.05 determined statistical significance in all instances. SVI and descriptive statistics were used for categorical variables.

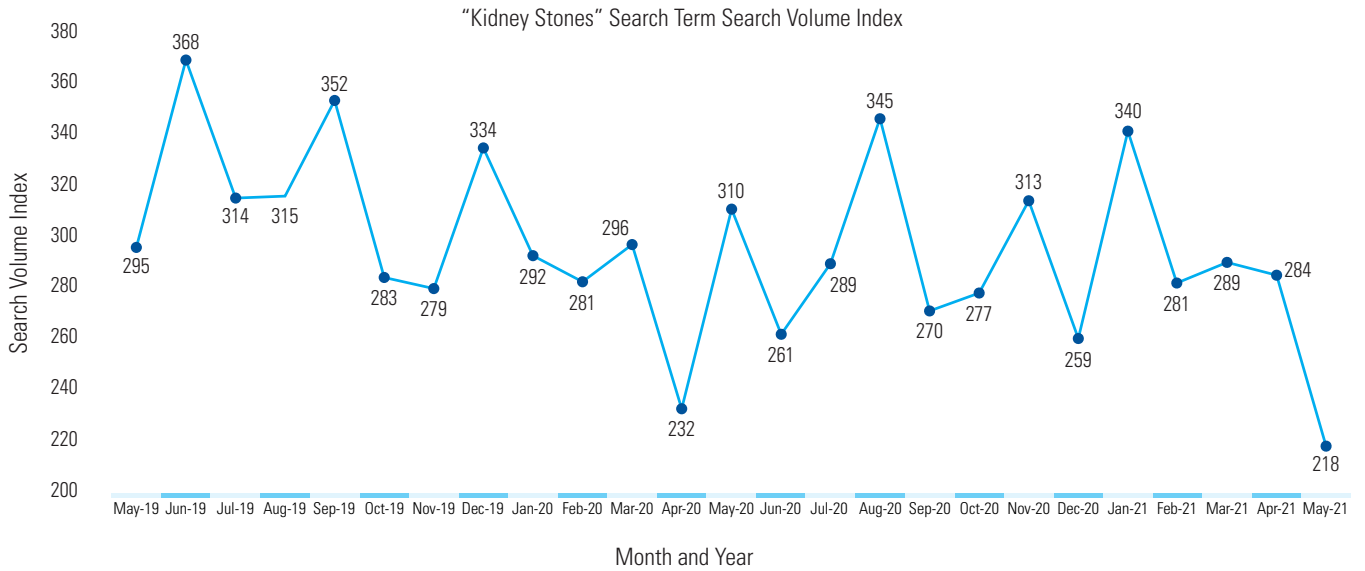
## Results

Per Google Trends, in 2019–2021 the peak Search Volume Index (SVI) of > 320 for kidney stones was in the summer months (June 2019, September 2019, and August 2020) and winter months (December 2019 and January 2021) (Figure 1). States with the top kidney stone searches were in the Southeast (Kentucky, Tennessee, Mississippi, Alabama, West Virginia, North and South Carolina), Midwest (Indiana), Southwest (Oklahoma), and West (Utah). Google Trends also demonstrated increasing interest in kidney stone-related smartphone apps with a 60% and 80% increase in the US and the world, respectively (Figure 2).

From the questionnaire posted to the Facebook and Reddit support groups, 92% of participants (n = 141) revealed that they have had kidney stones, with 50% having had 4 or more stones. According to the demographic information supplied by questionnaire responders, most were female (63.6%), with the majority between 20 and 35 years old (37%), followed by participants 51 to 64 years old (30.4%), and 36 to 50 years old (28%). The majority of the survey participants obtained information from their doctor’s office (45%), followed by websites like WebMD, Reddit, Pubmed, Mayo Clinic, and University of Chicago (43%), YouTube (9%), and smartphone apps (4%).

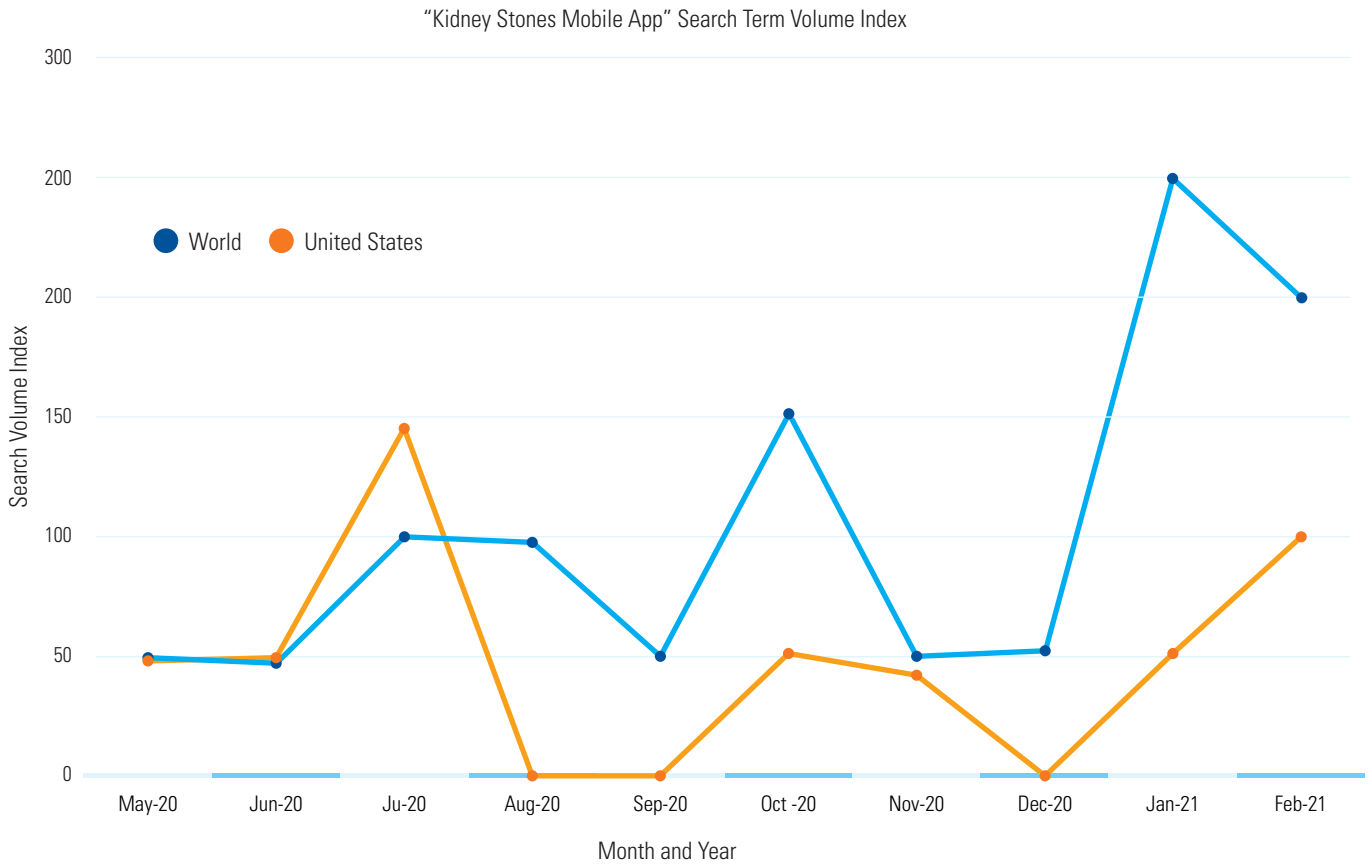
**FIGURE 1.**

Google Trends Search Volume Index score for the 'kidney stones' search term from May 2019 to May 2021



**FIGURE 2.**

Google Trends Search Volume Index score for the 'kidney stones mobile app' search term in the US and worldwide from May 2020 to February 2021



Although Google Trends shows increased interest in kidney stone-related apps, only 23% of questionnaire participants answered that they have ever searched for information on them. Of those who had, the majority used an app for obtaining information on diet and water intake (42.8%), while others used it for information on kidney stone procedures (25.6%), medicine related to kidney stone pain (23.9%), and other information including when to go to the emergency department, homeopathic solutions, causes of stones, and pain post-kidney stone procedure (7.7%). Of those who noted using kidney stone apps, 54.1% reported using them daily, while others had reported using them weekly (32.4%), monthly (5.4%), and once (8.1%).

Seven kidney stone smartphone apps were included for evaluation based on their total number of downloads (**Table 1**). Six of the 7 kidney stone apps selected were created by non-medical professionals (*My Healthy Kidney*, *Renal Diet Advisor*, *Kidney Stones [Oxalate]*, *Reduce Stones*, *OxiPur-Gout*, and *Kidney Stone*). Only the app, *Stone MD: Kidney Stones* was created by a medical professional. *Oxalate Food Counts (Kidney Stones)* had the greatest total number of downloads (352 298) and number of daily users (2537). *Stone MD: Kidney Stones* had the second greatest total number of downloads on both Android and iOS (8560 and 7400, respectively); however, less than 2% of its users use it daily (**Table 1**). Despite its being the only kidney stone smartphone app created by medical professionals, users did not prefer it over the other apps.

When the 7 smartphone apps were evaluated with the DISCERN tool (**Figure 3**), the average score was categorized as moderately relevant with clear aims, but poor reliability (1.63), poor quality (1.54), poor shared decision-making (2.54), and poor overall rating (1.96). Reviewers using the DISCERN tool agreed the quality and reliability were poor amongst apps (2.43,  $P < 0.001$  and 1.96,  $P = 0.039$ , respectively). Reviewers agreed that the average quality of treatment options amongst the 7 apps was poor (1.58,  $P = 0.491$ ). Reviewers felt that the information provided in the apps regarding treatment options, possible side effects, and overall information was poor, and the publication reliability was moderate (3.21,  $P = 0.007$ ). The actionability of all 7 apps was also poor. However, all but one smartphone app (*Kidney Stones [Oxalate]*) had good understandability (**Figure 4**). *Stone MD: Kidney Stones*, unlike the other 6 smartphone apps, had no commercial bias and limited misinformation on actionability, understandability, and quality of treatment options discussed in its app.

## Discussion

Google Trends showed peak SVI for kidney stones during the summer months, which correlates with the

lack of fluid intake, heat, and humidity. The increased SVI for kidney stones during the winter of 2020 and 2021 could also potentially be related to the COVID-19 pandemic. Fewer people were visiting their doctor and instead relied on websites and online platforms to receive medical information[21,22]. Potentially, the combination of a more sedentary lifestyle for many during the pandemic and lack of ability to see their doctor during this period led to increased online searching during the winter months. Ongoing evaluation of this behavior will shed light on whether this trend continues as we emerge from the pandemic.

Per Google Trends, a high SVI for kidney stones outside of the traditional southeastern kidney stone belt was observed. Some have suggested that with global warming comes possible northward movement of what was once the southeastern US kidney stone belt[23]. This could possibly explain the Google Trend peak SVIs seen in Kentucky, West Virginia, and Indiana. According to a climate model of intermediate severity warming, an increasing proportion of the US population is living in high-risk zones for kidney stones[23]. As temperatures rise in certain regions of the country, there will likely be a direct relationship with kidney stone incidence. These temperature rises may not be related to what is traditionally known as the summer months. Per model predictions, there will be a climate related increase of 1.6 to 2.2 million lifetime cases of kidney stones by 2050, with an increased concentration of kidney stone incidence in the region from Kansas to Kentucky[23]. This correlates with Google Trends peak SVI in states like Kentucky, Oklahoma, Utah, and Indiana, with data from between 2005 and 2015, demonstrating a rise from 0.6% to 0.9%[24].

The advance of technology has made it easier for patients to access information on the internet and other devices, some of which may not be medically sound. Survey participants still considered their doctor their number one resource; however, patients are beginning to gravitate towards other easily accessible but not necessarily reliable resources such as YouTube, Facebook groups, Reddit, and smartphone apps. Interest in smartphone apps that include/provide kidney stone information has increased in recent years. This increase may be related to the COVID-19 pandemic during which patients did not have easy access to urologists. However, it is unclear if smartphone app use will remain popular among this subdivision of patients.

Of the 7 kidney stone-related smartphone apps evaluated, *Oxalate Food Counts (Kidney Stones)* is the most popular based on its total number of downloads and daily users. This is likely to be because this app targets a wider audience than just kidney stone formers. Its audience includes patients with medical conditions such

**TABLE 1**

Apps and number of downloads and users

Smartphone app name	App (platform)				Summary of app purpose	Rating by users
	iOS		Android			
	Total number of downloads	Number of daily users	Total number of downloads	Number of daily users		
Kidney Stones (Oxalate)	750	188	250	63	Provides information on how to prevent recurrent calcium oxalate kidney stones with personalized food suggestions.	1/5 by 3 people
Reduce Stones	–	–	1150	79	Provides advice about various stone prevention methods including diet control and waterlog reminders.	5/5 by 13 people
OxiPur-Gout and Kidney Stone	30000	Unknown	–	–	Provides information on stone formation and low purine and oxalate food using Wikipedia as a reference.	4.5/5 by 157 people
My Healthy Kidney	1681	31	–	–	Uses algorithms created by renal specialists for renal diet planning.	4.3/5 by 71 people
Renal Diet Advisor	–	–	6420	1428	Provides information on steps to monitor electrolyte and fluid intake.	3.9/5 by 26 people
Stone MD: Kidney Stones	7400	50–100	8560	50–100	Calculates individual risk of kidney stone recurrence, suggests personalized diets, encourages adequate water balance, and sends reminders for stent removal.	3.9/5 by 21 people
Oxalate Food Counts (Kidney Stones)	–	–	352 298	2537	Provides low calcium oxalate diet suggestions.	4.8/5 by 112 people

as hyperoxaluria, irritable bowel disease, and fibromyalgia who are trying to reduce their oxalate intake. In contrast, other apps specifically target app users who have kidney stones and kidney-related diseases. According to the DISCERN and PEMAT tools, *Oxalate Food Counts (Kidney Stones)* was easier to understand than *My Healthy Kidney* and *Kidney Stones (Oxalate)* but not as easy to understand as the other 4 apps. Its actionability was average.

These apps were evaluated using urological guidelines, and the majority of the apps were found to be lacking in clarity, sources of additional support and information, and honesty about possible risks with treatments discussed and how these treatments can affect overall quality of life. The majority also did not encourage patients to follow-up with their doctors. Compared with the other 6 apps, *Stone MD: Kidney Stones* (the only app created by medical professionals and with a conscious effort to follow urological guidelines), had the best actionability and the second-best understandability after *Reduce Stones*. Although it was not the most popular kidney stone app, *Stone MD: Kidney Stones* could potentially

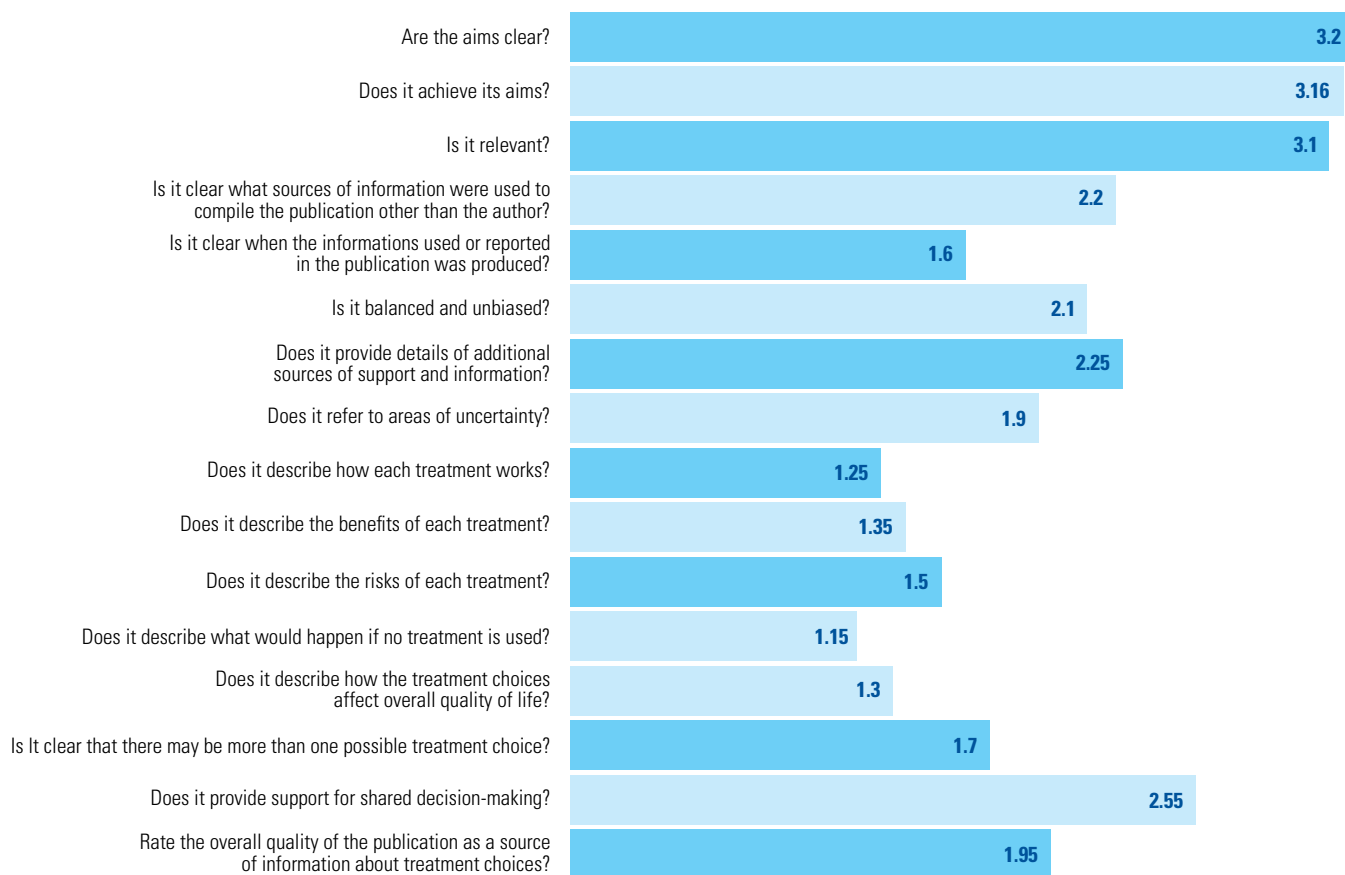
improve patient compliance and lower the risk of stone formation, in users[25]. Overall, these kidney stone apps have the potential to be a platform delivering accurate and high-quality information to patients while enhancing patient understandability and encouraging shared decision-making with their physicians. Self-management programs for patients, such as smartphone apps, have been associated with improved health outcomes[12–14]. At a low cost, the apps are easily accessible and can further optimize patient-centered care[10,11]. Urologists may consider working with smartphone app developers to create kidney stone apps that follow urological guidelines, are of high quality, and are easily understandable.

We found that generally, consumers of health-related information predominately desire to know about diet, remedies, general kidney stone information, and pain management. Kidney stone apps are a single example of how smartphone apps and social media play an ever-increasing role in patient-centered health care[12]. However, as we have demonstrated, there is little oversight of the quality and reliability of information on these smartphone apps, and our evaluation suggests they have



**FIGURE 3.**

The mean DISCERN score results evaluating the 7 kidney stone apps



little concern about commercial bias or misinformation. Uncensored health information distributed online and through smartphone apps may be contributing to patients' specific interest in kidney stone dietary and fad trends[26]. Without being consciously aware of it, patients may find their online interactions influencing their health-related decisions[26]. For instance, diet-related companies may become appealing to patients if they sponsor kidney stone apps or pay for advertisements on them[26–28]. Additionally, app users may be frequenting some of these apps because of positive reviews from trusted contacts, but misinformation can easily spread through word of mouth, specifically from trusted sources.

Furthermore, unless patients have good communication with their urologists, they may be less likely to adhere to a treatment plan and more likely to seek information from other sources[29]. Urologists may be able to further engage their patients and continually work towards a more transparent relationship, in which patients are more likely to discuss their kidney stone questions and patient health outcomes are better[30]. Kidney stone smartphone apps can enhance patient-centered care if they are unbiased and follow urological guidelines.

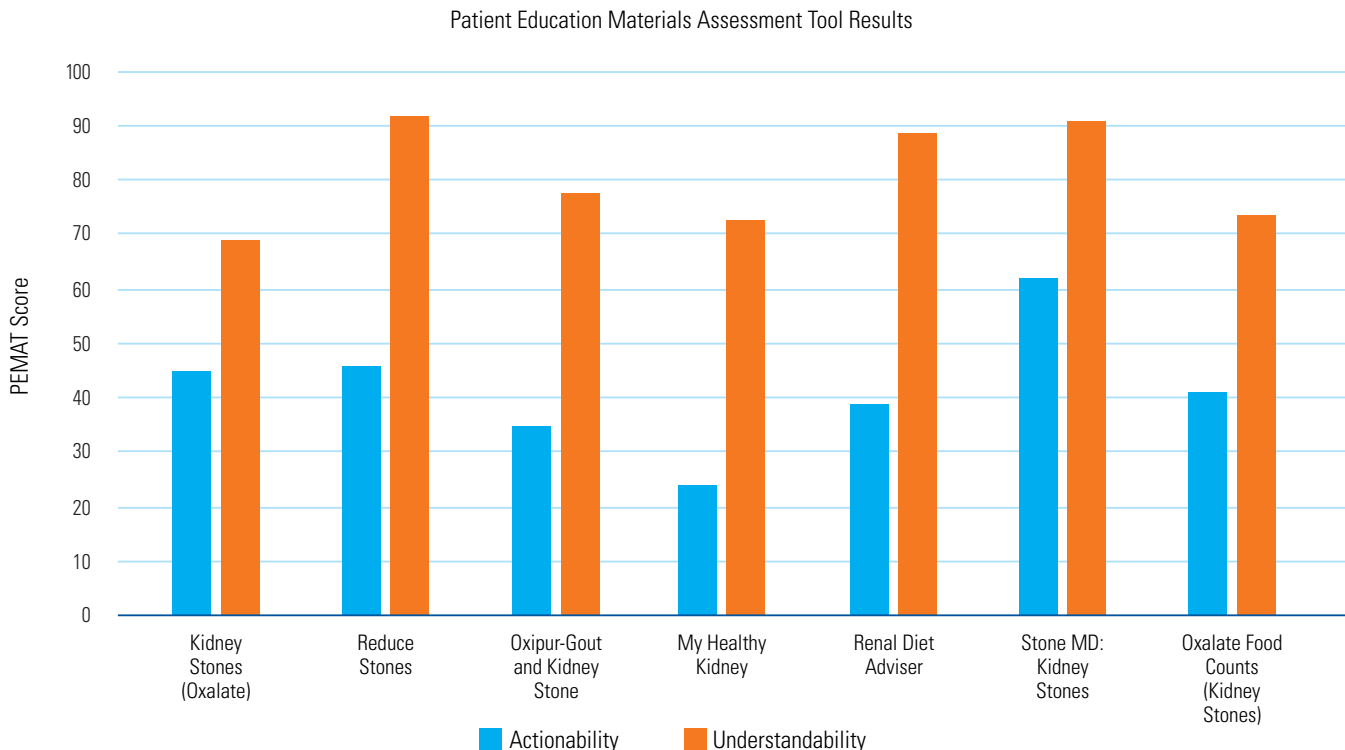
The findings of this study should be considered with a notable limitation. Most of the data obtained is from kidney stone patients who engage on social media like Facebook and Reddit and other platforms like smartphone apps. As those in older age groups are less likely to use these platforms, the data may not reflect their activities.

Misinformation may become more widespread and easily obtained than scientifically rooted professional advice. If urologists and the medical community do not engage patients on these social media and app platforms, there will be more opportunity for spread of misinformation, especially among the Generation Y and Z groups. Given the trend of increasing online activity, it will progressively become more important for urologists to engage with patients on these platforms in coming years. Without accurate information to combat misinformation, the consequences for patient care are worrisome.

## Conclusion

Patients are making increasing efforts to be more involved in their medical care. Though their doctor is still their number one source of information, patients are

**FIGURE 4.**  
PEMAT score actionability and understandability of kidney stone apps



using social media and other platforms like smartphone apps more often. However, many of these sources contain misinformation. Kidney stone patients would benefit if their urologists directed them to high-quality information based on guidelines published by urologic societies. Urologists may also consider engaging users on such platforms and involving a multi-disciplinary approach to distribute accurate information to their patients.

### Acknowledgements

**Funding:** No funds, grants, or other support was received.

**Compliance with Ethical Standards:** This study did not require informed consent.

Google Trends has publicly accessible data and does not involve human subjects. The Qualtrics survey was

conducted on a voluntary basis without compensation by members of social media groups who have a history of kidney stones. Google Trends and the Qualtrics survey fulfill criteria for exemption by the Institutional Review Board (IRB) of the University of California, Los Angeles.

**Authors' Contributions:** K Kunitsky: data collection, management, and analysis, manuscript writing/editing. RA Takele: Protocol/project development, data collection and management, data analysis, manuscript writing/editing. P Diaz: Protocol/project development, data collection. J Lim: data collection, manuscript editing. PM Patel: Protocol/project development, manuscript editing. KB Scotland: Protocol/project development, manuscript editing.

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