

Optimizing Primary Care FOR Patients with Rare Diseases

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How Do Primary Care Clinicians Get Information on Rare Diseases?

New Survey Reveals Surprising Sources of Information for Patient Management

In January, Rare Opportunities in Primary Care* conducted a survey of 672 clinicians who provide primary care for patients with rare diseases.¹ The purpose of this survey was to better characterize the educational and resource needs of these clinicians.

The results revealed that 75% of these clinicians want to learn more about identifying rare diseases in the primary care, urgent care, and emergency care settings. Additionally, 63% want to know more about utilizing appropriate tools and resources to manage primary care in their patients with rare diseases, and almost half want to learn where to look for resources, how to find support, and how to develop successful referral networks.¹

Respondents also cited several other educational needs related to rare diseases, including emerging research advancements; incidence and prevalence; managing autoimmune conditions; long-term care considerations; insurance/medication coverage; economic burden; patient/caregiver and family support; nutrition; geriatric care; and end-of-life support.¹

*The research presented in this paper was conducted under the organization's former name, the Association for Comprehensive Care in Rare Diseases (ACCORD). The survey conducted was distributed with the help of Frontline Medical Communications.

The following health care professionals participated in a December 2015 call to discuss the results of Rare Opportunities in Primary Care's August 2015 survey on the topic of unmet needs in patients with rare diseases. The content of this white paper reflects the results of a second survey that was developed in follow-up to that discussion.

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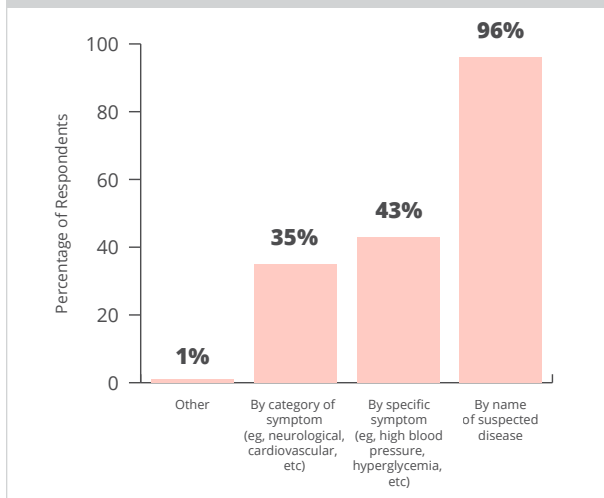
Google Cited as a Leading Source for Information on Rare Diseases

The survey asked clinicians to describe the resources they use to find information that can help them manage primary care issues for their patients with rare diseases. The methods cited were similar to those for finding information relevant to their overall practice.¹ However, the availability of information related to management of primary care for patients with rare diseases is much more limited.²

The overwhelming majority of respondents reported using Google for information, although Medscape and PubMed were selected frequently as well. Additionally, although it was not a listed option, many respondents entered UpToDate® as a frequently used online tool.¹

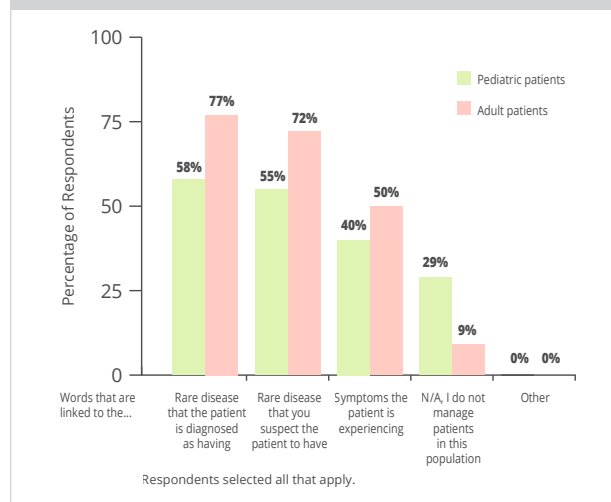
Survey respondents were asked to provide specific examples of how they utilize Internet search engines and online tools to find information related to diagnosis of a rare disease. Nearly all respondents indicated that they search by the specific disease name when using a search engine/online tool (Figure 1).¹ This can create obvious challenges when the diagnosis has not yet been made, or when the name of the disease is unknown. How does a clinician research a condition that has not yet been identified?

Figure 1. Internet Search Methods Used by Respondents (n = 448)¹



Once a patient has been diagnosed with a rare disease, the Internet remains the primary source of information for clinicians. When managing primary care for both pediatric and adult patient populations, respondents typically use search terms linked to the rare disease in question (Figure 2).¹

Figure 2. Internet Search Terms Used by Respondents (n = 448)¹



Ninety percent of survey respondents said that the information they find on the Internet impacts their management approach for primary care-related issues in patients with rare diseases.¹ This indicates that medical information positioned on the Internet—which is not always vetted—may be molding national discourse on primary care management for patients with rare diseases. Given that vetting information on the Internet has its own challenges, it is clear that authoritative information and resources are needed in this area.

Patient/Caregiver Resources Described as Lacking

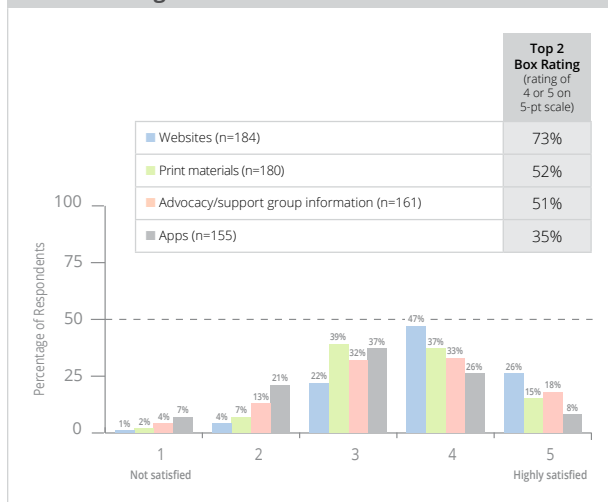
More than half of the survey respondents indicated that their practices lack patient/caregiver resources for primary care-related issues involving rare diseases. Of the 41% of survey respondents whose practices do offer these types of resources, the majority indicated that websites and print materials are the most common formats for patient/caregiver resources.¹

Clinician respondents are not completely satisfied with the quality of the patient/caregiver resources available to them (Figure 3).¹ This level of satisfaction represents an unmet need for effective resources.

Clinicians Are Eager for Enhanced Professional Communication

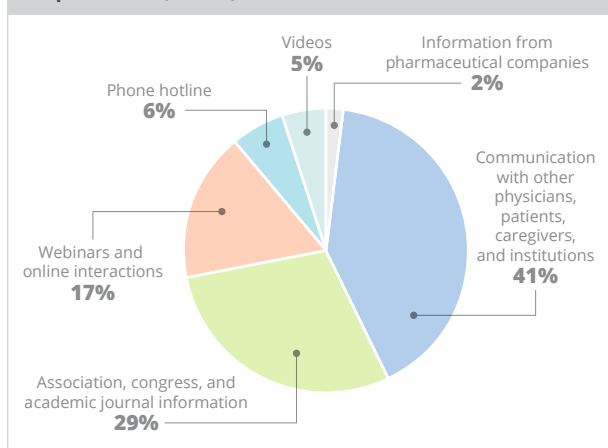
Survey respondents are seeking opportunities to communicate about the management of primary care-related issues in patients with rare diseases. With limited resources available, more than 40%

Figure 3. Respondent Satisfaction with Available Patient/Caregiver Resources¹



of respondents would like to improve the lines of communication between other clinicians, patients, caregivers, and institutions (Figure 4).¹

Figure 4. Additional Resources Considered Valuable by Respondents (n = 85)¹



Other ideas included making association, congress, and academic journal information available to patients/caregivers, access to webinars and other online tools, phone hotlines and video series dedicated to providing care information for specific rare diseases, and informational resources from pharmaceutical companies that develop drugs to treat rare diseases.¹

These Gaps and More to Be Addressed Through Web-Based CME Initiative

Rare Opportunities in Primary Care hopes to provide access to quality medical education and to fill unmet needs within the primary care and rare disease space through its Web-based CME initiative, *Optimizing Primary Care for Patients with Rare Diseases*. The first program of its kind, this CME initiative will help clinicians:

- Identify clinical clues that expedite diagnosis of rare diseases in different clinical settings
- Describe the role of genetic testing in diagnosing patients with suspected rare diseases
- Develop successful referral networks
- Optimize care for pediatric patients
- Utilize tools and resources to manage the whole patient
- Locate resources for clinical practice

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This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint providership of the University of Cincinnati and Health and Wellness Education Partners (HWeP).

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Background

People with rare diseases have common medical needs. In the United States alone, rare diseases cumulatively affect the lives of 30 million people,³ and each of these 30 million people seek routine care from a primary care clinician. Characterizing the primary care clinicians who manage patients with rare diseases may shed light on the educational needs of this group. Rare Opportunities in Primary Care aims to better understand who these clinicians are and what information they need to help them care for their patients with rare diseases.

An initial August 2015 survey of 536 clinicians provided insight into the educational gaps associated with managing primary care issues for patients with rare diseases.⁴ This survey was telling, revealing that clinicians lack confidence when it comes to identifying and diagnosing patients with rare diseases and providing primary care for these patients. Further, the large majority of clinicians noted that their practices lack standard protocols for providing primary care of patients with rare diseases.

Extensive research has been conducted regarding how clinicians search for information related to their practice. For example, a 2012 study by Manhattan Research and Google surveyed 506 clinicians in the US,⁵ finding that clinicians of all ages utilize digital resources to locate information to guide clinical decisions. In fact, clinicians spend twice as much time utilizing digital resources as they do print resources.³

Although a world of knowledge exists on how clinicians use Internet resources to find information on primary care issues, there are virtually no data on how clinicians search for information related to primary care issues in patients with rare diseases. The January 2016 survey reported here was conducted in part to address this knowledge gap.¹

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