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Clinical Research

Assessment of the Information Sources and Interest in Research Collaboration Among Individuals with Vascular Ehlers-Danlos Syndrome

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Background: Patient-centered research requires active engagement of patients. The vascular Ehlers-Danlos Syndrome (vEDS) research collaborative was established to ascertain patient-centered vEDS research priorities and to engage affected individuals as research partners. Evaluation of access to information and interest in research among individuals with vEDS was the first step undertaken as part of this work.

Methods: A 28-question survey was created to evaluate 4 domains of interest: diagnostic and clinical care history, vEDS experience, information resources, and willingness to collaborate with researchers. The survey was created in REDCap™ and disseminated between January and April 2018 via the vEDS social media pages, blogs, and advocacy Web sites. Results were collated and described. A single open-ended question yielded additional narrative data, which were analyzed qualitatively.

Results: Of the 300 responses, 228 (76%) were completed on behalf of oneself. The vEDS diagnosis was confirmed by genetic testing for 85% of respondents. When asked "Did a physician explain vEDS to you and how to manage it?" 25% answered *no*. Most had a primary care provider (65%), cardiologist (56%), and vascular surgeon (52%). Only 32% had a local vascular surgeon. The most commonly reported frustration was *no cure/treatment available* and the *emergency rooms do not know what VEDS is* (64.5% and 61.8%, respectively). The Internet was the most useful information source (62.3%) followed by a geneticist (18.4%). Most

Presented at the Pacific Northwest Vascular Society Annual Meeting, Seattle, WA, on October 11, 2018 and in part at the fifth GenTAC Thoracic Aortic Disease Summit, Portland, OR, on October 7, 2018.

Funding: Research was funded through a Patient-Centered Outcomes Research Institute (PCORI) Award (7718436).

Disclosures: None to report.

Conflicts of interest: None to report.

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Ann Vasc Surg 2019; ■: 1–9
https://doi.org/10.1016/j.avsg.2019.06.010

Manuscript received: March 25, 2019; manuscript accepted: June 8, 2019; published online: ■ ■ ■

(87.7%) are willing to share their medical records for research studies (87.7%) and wished to be contacted about future studies (83.8%); however, only 65.4% would be willing to upload medical records via a secure confidential Web application. The most common reason for interest in research partnership was to advance research for a treatment/cure (83.8%) and helping others learn from their experiences (82.9%). The qualitative analysis provided additional insights into the patient experience living with vEDS.

Conclusions: Among individuals with vEDS, there is substantial frustration with the lack of treatment, lack of knowledge among health care providers, and a high degree of interest in research involvement. The survey highlights an opportunity to discuss the optimal modality for research participation and methodologies for building trust in the research teams. The methodology lessons learned can also be applied to other rare vascular diseases.

INTRODUCTION

Patient engagement is an integral aspect of patient-centered outcomes research. The definition of patient engagement by the Agency for Healthcare Research and Quality is ''the involvement in their own care by individuals and others they designate to engage on their behalf, with the goal that they make competent, well-informed decisions about their health and health care and take action to support those decisions.''[1] The study of rare genetically triggered vascular disease is challenging because of the small numbers and limited natural history data.[2,3] Vascular Ehlers-Danlos Syndrome (vEDS) is a rare syndrome with an estimated frequency of 1:50,000 and is associated with arterial fragility and high risk of mortality.[4–9]

We established a vEDS collaborative in 2018 with the vision of supporting the vEDS community in driving a patient-centered scientific research to improve the management of vEDS and increase the quality of life for all those impacted by the disease.[10] Our goal is to create and sustain a diverse and collaborative network of stakeholders, individuals, and organizations to understand patient needs and determine the research methods best suited to study the adverse health implications associated with vEDS. To this end, our strategy has been to (1) build the infrastructure necessary for researchers to create and sustain partnerships with patients and other stakeholders that will inform their research work; (2) to connect stakeholders with the resources and education necessary to empower them in maintaining equitable and meaningful patient-researcher partnerships; and (3) to create cooperation opportunities between patient groups to empower advocacy organizations and advance research efforts. In our first stage of engagement, we sought to assess the information resources available to individuals affected with vEDS, vEDS diagnostic history, experience living with vEDS, and willingness to collaborate with researchers.

MATERIALS AND METHODS

A 28-question anonymous survey was created in REDCap™ to evaluate 4 domains of interest: diagnostic and clinical care history, vEDS experience, information resources, and interest in research and willingness to collaborate with researchers. The survey also provided one open-ended question at the end asking if there was/were any personal experience(s) the participant would be willing to share that had not already been asked. The study was reviewed by the University of Washington Human Subjects Division and deemed exempt (#00003861) because of the minimal risk and nonidentifiable nature of the study. Consent by the participant is given by reply to the survey.

Announcement of the vEDS Collaborative survey was disseminated between January and April 2018 via vEDS public and private social media pages:

- Facebook: vascular Ehlers-Danlos secret group (363 members), The Ehlers-Danlos Society (https://www.facebook.com/pg/ehlers.danlos/posts/ (80,573 followers)
- Twitter (https://twitter.com/vEDSCollabo)
- Reddit (https://www.reddit.com/comments/7vny42)
- YouTube (https://youtu.be/QRVFVJGZQgQ)

Examples of the announcements on social media are included in the Appendix. Additional announcements were made on the advocacy Web sites created and maintained by members of the vEDS Collaborative: fighteds.org, Annabelle's Challenge, Ryan's Challenge, EDS Today, and the Ehlers-Danlos Society. Individuals with vEDS 18 years and older as well as family members were invited to participate. Family members were also invited to participate.

Survey data were analyzed using Microsoft Excel 2013 (Microsoft, Redmond, WA) and SPSS 19.0 for Windows (SPSS Inc, Chicago, IL). Categorical data

were presented as numbers and percentages. Narrative responses to the single open-ended question were analyzed using conventional qualitative content analysis.[11]

RESULTS

A total of 300 responses were submitted to the survey. The survey was completed on behalf of oneself by 228 (76%) respondents and on the behalf of someone else by 57 (19%) respondents. An additional 15 (5%) survey respondents did not answer this question.

The survey was fully completed by 285 individuals, with 100 (35%) providing narrative feedback to the open-ended question. The location of the response was noted in 280 cases. Most of the responses were from the United States ($n = 182$; 65%) followed by the United Kingdom ($n = 43$; 15.4%) and Canada ($n = 18$; 6.4%). Figure 1 demonstrates a map of the United States and the world by frequency of response from each state and country, respectively.

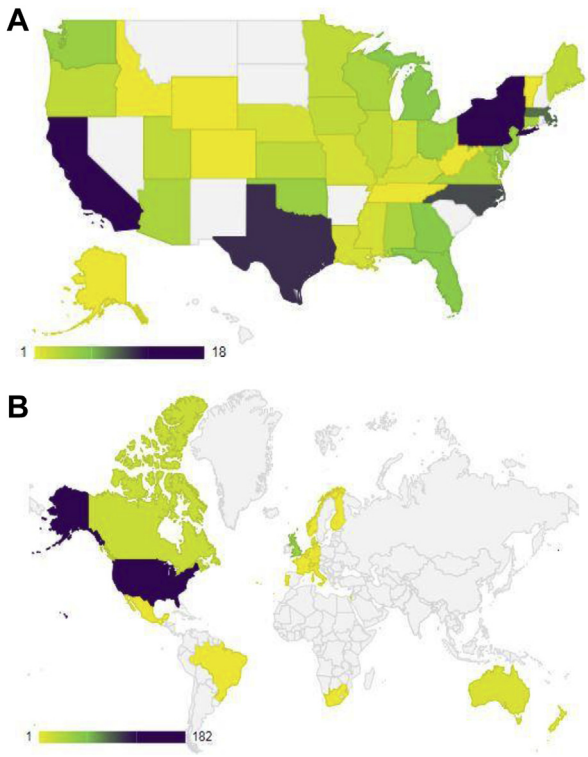

Fig. 1. A map of the **(A)** United States and **(B)** world showing the frequency of responses to the vascular Ehlers-Danlos Research Collaborative Survey by state and country, respectively.

Response on Behalf of Self

The survey was completed on behalf of one's self by 228 individuals. When asked about access to the Internet, 97.8% reported having access to Internet at home and 93.9% had a smartphone. The social media platform used for any purpose was predominantly Facebook (94.3%; $n = 215$). The most common platform to receive this survey was via Facebook (56.9% of the 239 responses to this question), whereas only 10.9% heard about the survey via their friends and family members.

Diagnostic and clinical care history. Most ($n = 193$; 84.6%) had a diagnosis of vEDS confirmed by molecular testing (e.g., blood, saliva, and/or skin biopsy), and most ($n = 159$; 82.4%) knew the specific genetic mutation. When asked, ''Did a physician explain vEDS to you and how to manage it?'' nearly one-third (30.3%; $n = 69$) answered *no*. Table I summarizes the data of the diagnosis of vEDS and the most useful sources of information about vEDS. Figure 2 details the type of health care providers seen, the type of providers available locally, and the type of providers who coordinate their care. A primary care provider (PCP) coordinated the care for more than a third of the individuals (36.8%) although most had a PCP at the local level (74.6%). In 20% of the cases, no one coordinates the care for the patient. Vascular surgeons were the primary specialists involved in the care of the patients in 46.1%, but only 29.4% had a vascular surgeon available to them locally. The median annual vEDS-related physician visits was 4 (interquartile range, 2−10) annual visits.

Experience with vEDS. When asked about the frustrating aspects of the vEDS diagnosis, *no cure or treatment available* was the most frequent response (64.5%) followed by the *emergency rooms do not know what vEDS is* (61.8%). Figure 3 details the responses to the questions regarding the most frustrating aspects of vEDS diagnosis.

Information resources. Most reported that the Internet provided the most useful information about vEDS (62.3%; $n = 142$) followed by information obtained from a geneticist ($n = 42$; 18.4%). Information pertaining to vEDS was most commonly found using an Internet search engine ($n = 99$; 43.4%). When asked, ''What sites did you find the best information?'' multiple sites were noted (Fig. 4). What was notable is that most of the sites listed as providing the best information (67%) were patient advocacy and patient support groups. Facebook was the most commonly used social medial platform (89.3%) for vEDS-related activities.

Interest in research and willingness to collaborate with researchers. The most common reason cited for being interested in partnering with vEDS

Table I. How the diagnosis of vEDS was made and the most useful sources of information used by individuals with responding to the vEDS Research Collaborative Survey

N (%)	Filled out the survey on behalf of self ($n = 228$)	Filled out the survey on behalf of others ($n = 57$)
Who made your vEDS diagnosis?		
Geneticist	157 (68.9)	34 (59.6)
Vascular surgeon	14 (6.1)	5 (8.8)
Cardiologist	10 (4.4)	5 (8.8)
Rheumatologist	9 (3.9)	0
General surgeon	5 (2.2)	2 (3.5)
Self-diagnosed	5 (2.2)	0
PCP	3 (1.3)	2 (3.5)
Other/unknown	25 (10.9)	8 (14)
How long have you known about your diagnosis?		
<1 year	35 (15.4)	12 (21.1)
1–5 years	89 (39)	22 (38.6)
6–10 years	46 (20.2)	8 (14)
>10 years	56 (24.6)	14 (24.6)
No response	2 (0.9)	1 (1.8)
Where did you find information about vEDS that was the most useful for you?		
Internet	142 (62.3)	30 (52.6)
Geneticist	42 (18.4)	12 (21.1)
Cardiologist	13 (5.7)	6 (10.5)
PCP	9 (3.9)	0
Vascular surgeon	8 (3.5)	3 (5.3)
General surgeon	1 (0.4)	1 (1.8)
other physician	9 (3.9)	2 (3.5)
No answer	4 (1.8)	3 (5.3)
How did you find your information?		
I used a search engine (Google, Bing, etc.)	99 (43.4)	15 (26.3)
Another person with vEDS gave me a place to go	13 (5.7)	8 (14)
My physician gave me a place to look it up	10 (4.4)	1 (1.8)
Findzebra.com	1 (0.4)	0
Other	18 (7.9)	6 (10.3)
No answer	87 (38.4)	27 (47.4)

researchers was *I want to advance research for treatment and a cure* (83.8%) followed by *sharing my experience will help physicians, researchers, and other patients* (82.9%). When asked to rank the most important goal of vEDS research, 41.6% noted that *discovering effective treatments* was the most important goal for vEDS research. When asked if they were willing to share their medical records for future vEDS research studies, 87.7% replied in the affirmative. Most wished to be contacted for participating in future research studies ($n = 191$; 83.8%); however, only 65.4% would be willing to upload medical records via a secure confidential Web application as detailed in Table II.

Response on Behalf of Others

A total of 57 respondents filled the survey on behalf of others in the family including multiple family members. Specifically, they filled out the survey on behalf of a spouse in 11 (19.3%) cases, a child in 34 (59.6%) cases, and other family members in the remaining cases. The specific responses with regard to how the diagnosis of vEDS was made, the most useful sources of information, are summarized in Table I, whereas responses about interest in research and willingness to collaborate with researchers are summarized in Table II.

Response to the Open-Ended Question regarding Personal Experiences Individuals Wished to Share

The most common short answer to this question was yes, *too many* experiences to fit in the provided space and yes, but the emotion surrounding the experience(s) was *too raw* to be able to share. The personal narratives that were shared centered less on vEDS as a disease and more on what it is like to *live with* vEDS. Collectively, the narratives united into one

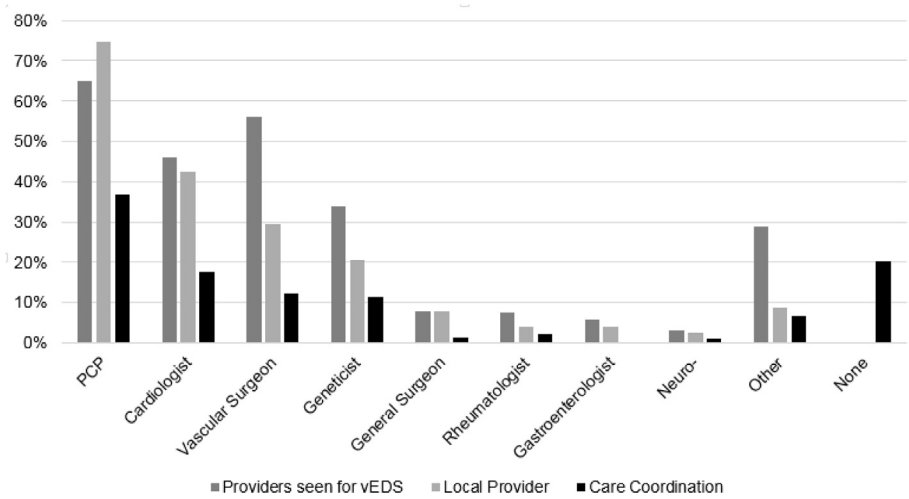

Fig. 2. The type of health care providers seen by individuals with vascular Ehlers-Danlos syndrome, the providers available locally to them, and the providers who coordinate their care. Neuro, neurologist or neurointerventionalist.

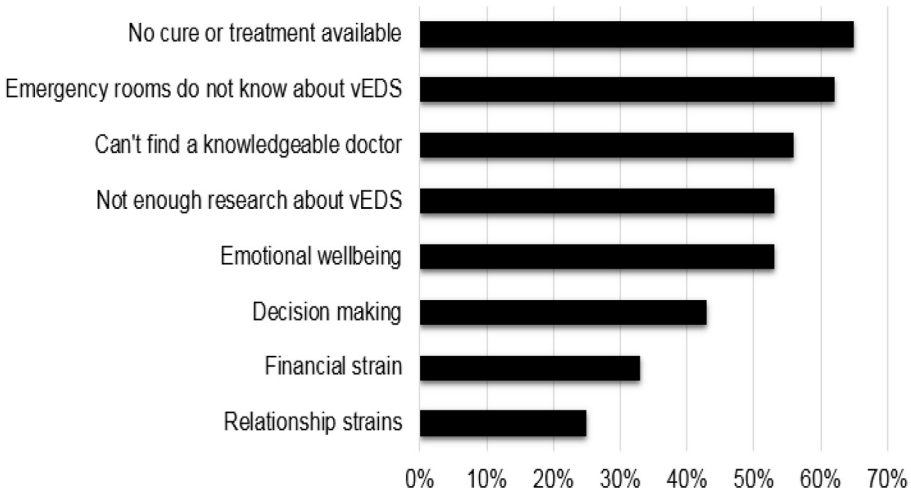

Fig. 3. The most frustrating aspects of the vascular Ehlers-Danlos syndrome diagnosis.

voice simply asking to be listened to, believed, and helped. As one individual shared, ''There needs to be 'something in the middle' of *no help* and *hospice* ….'' The overarching theme from the narratives was *Living with vEDS* and the 3 subthemes were *I'm weary*, *I'm afraid*, and *I need your compassion/help* (Table III).

Although the open-ended question was about experiences that had *not* already been asked about, many participants opted to share common vEDS events (e.g., aneurysms). They also shared their continued struggles/challenges/frustration with their health care and providers, all of which resulted in too many visits. In addition, they shared experiences with delays in diagnosis needed care and preventable harm. Three areas were continually highlighted:

- No central contact/too few specialists/access to the care I need is limited.
- Too many medical doctors/PCPs do not know about/are not educated about/do not understand what vEDS is, how to diagnose it, and/or how to help individuals who have it.
- Too many emergency department providers have no understanding of vEDS and/or no access to someone who does. This was seen as particularly significant because patients felt the emergency department is where they needed to be seen when life-threatening events occurred.

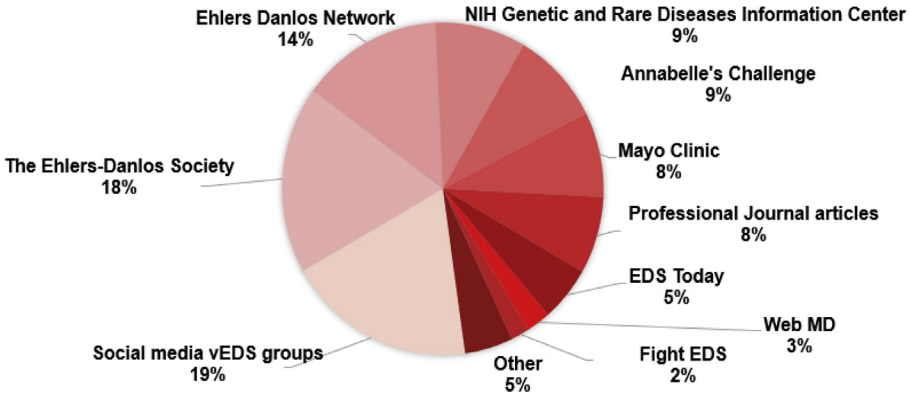

Fig. 4. Online sites used by individuals with the vascular Ehlers-Danlos syndrome noted in response to the question ''What sites did you find the best information?''

Table II. Interest in research among individuals with vEDS and willingness to collaborate with researchers

N (%)	Filled out the survey on behalf of self ($n = 228$)	Filled out the survey on behalf of others ($n = 57$)
I am interested in partnering with vEDS researchers because		
Sharing my experience will help physicians, researchers, and other patients	189 (82.9)	35 (61.4)
As a patient, I have experience that physicians and researchers may not understand	155 (68)	21 (36.8)
I want to advance research for treatment and a cure	191 (83.8)	46 (80.7)
Other	17 (7.5)	5 (8.8)
If there was a secure confidential application hosted to enable patients to upload medical records for research purposes, would you be willing to use it?		
Yes	149 (65.4)	28 (49.1)
Unsure	69 (30.3)	26 (45.6)
No	5 (2.2)	2 (3.5)
No reply	5 (2.2)	1 (1.8)
In your opinion, what is the most important goal of vEDS research?		
Discovering effective treatments	95 (41.6)	29 (50.9)
Educating care providers	69 (30.3)	8 (14)
Identifying the best ways for me to manage my disease	49 (21.5)	17 (29.8)
Knowing how often I need screening	2 (0.9)	0
Other	11 (4.8)	2 (3.5)
No reply	2 (0.9)	1 (1.8)

DISCUSSION

We sought to assess the existing networks and infrastructures that could be used in building patient-researcher partnerships in vEDS research. We evaluated 4 domains of interest: diagnostic and clinical care history, vEDS experience, information resources, and willingness to collaborate with researchers. This work is part of the larger goal of creating a community of vEDS stakeholders with a commitment to developing patient-centered research proposals. The results of which can be translated to clinically meaningful care guidelines that can be rapidly disseminated among patients and care providers. Our work highlighted the substantial frustration with the lack of treatment for vEDS, lack of disease-specific knowledge by health care providers, variation in care experiences, and a high degree of interest in research involvement to resolve these concerns.

Several thought-provoking themes regarding quality of care emerged. Nearly one-third reported never having a physician explain the condition or medical management. Furthermore, the information provided by patient advocacy groups

Table III. The three major subthemes in response to the open-ended question regarding personal experiences among individuals affected by vEDS

I'm afraid	Just waiting for the next life-threatening thing to happen
	I know I am in danger of dying (you live your whole life just waiting)
	We all have close calls
	I have lost my entire family to this disease
	I am the last one left
	I should be dead, but I am still here
	This disease runs deep in my family
I need your compassion/help	I often feel lonely/isolated/depressed
	Need to be taken seriously/believed (I was once told I was faking/lying about my condition)
	Often ignored/disregarded/not heard (My doctors do not know how to help me, so they do not do anything)
	No resources for living your best life with vEDS
	Resources for children, siblings, parents are nonexistent
	Need an overview of the whole experience
	I am dying to live
I'm weary	I am struggling/trying to balance my personal safety and privacy at work
	I live with pain (never stops)
	Joint pain, dislocation, temporomandibular joint
	Leg cramps/spasms/ruptured muscles
	Back pain, spinal issues
	Sick everyday
	I look bad/I have thin skin/tears easily/bruise easily
	I have extreme fatigue/unable to do basic daily things
	I have digestive issue
	• Malabsorption/need iron/B12 infusions
	• Diverticulosis/-itis
	• Mitochondrial comorbidities

on the Internet was noted as the most useful information regarding vEDS, even more than the information obtained from physicians involved in the care. In addition, one in 5 respondents noted that they do not have a physician coordinate their care. This suggests that individuals with a diagnosis of vEDS are often left to learn about the disease on their own, in addition to creating and/or managing their own care teams. As a result, much of the information received by patients is from community resources and patient advocacy groups, rather than the medical establishment. These responses highlight discrepancies in care and information available for the community. This may be based on the lack of data available to physicians and health care providers to support medical management and care for this patient population. Indeed a great deal of frustration was due to lack of knowledge by health care providers. This identified an opportunity to translate the results of the survey to joint efforts to improve care in individuals with vEDS. These include the work toward establishing a toll-free number where physicians can discuss vEDS-related cases with global experts and the creation of an education curriculum for health care providers. One avenue we are pursuing is the creation of Vascular EDS ECHO via Project ECHO® (https://www.ehlers-danlos.com/echo/) hosted by the Ehlers-Danlos Society. In addition, we plan on further exploring health-related quality of life concerns among individuals with vEDS and their family members.

The role of vascular surgeons in caring for individuals with vEDS merits discussion. Almost two-thirds of the affected individuals have been evaluated by a vascular surgeon; however, only half of those had access to a vascular surgeon available to them locally. This is likely a reflection of where these patients live. In general, individuals with vEDS are referred to tertiary care centers[2] for where they are likely to see a vascular surgeon knowledgeable with the disease process. However, it is important that individuals with vEDS also establish care with a local vascular surgeon in the event of an emergency when transfer may not be feasible.[2]

From a research perspective, most respondents believe that research is highly relevant and are highly motivated in participating in future vEDS

research. The study was designed initially for the population in the United States; however, the global reach with more than a third of the respondents based outside the United States highlights the presence of a population of patients who are interested in research and highly motivated to participate. In terms of operationalizing sharing medical data for research purposes, only 65% noted that they are comfortable with uploading personal health information to an online application. This creates an opportunity to discuss the optimal modality for individuals with vEDS to participate in research as well as methodologies for building trust in research teams. Most of the contemporary health care data can be extrapolated from the use of patient portals, also called personal health records (PHRs). Since 2006, the use of PHR has shown an increase in use, primarily driven by the Centers for Medicare & Medicaid Services and Medicaid Electronic Health Record (EHR) incentive program meaningful use criteria.[12] The idea is to allow each individual to keep his or her health care information in one location, thus increasing personal participation in health care and enhancing health literacy.[13] Patients' interest and ability to use patient portals has been shown to be strongly influenced by personal factors, such as age, ethnicity, education level, health literacy, health status, and role as a caregiver.[14] That said, the US health care system uses multiple PHR platforms, and there is no direct communication between the different platforms even among hospitals using the same EHR platforms. To address this need, commercial patient-facing platforms are being developed to allow the patients to input their health care information and upload their records to keep them in one location. These commercial platforms not only allow sharing PHR with physicians but also create new opportunities for patients to participate in research by granting permission for the information to be transferred for research purposes and to answer survey questions.

The survey results have the potential limitation of generalizability. The survey respondents had access to this survey via the Internet and learned about the survey via online announcement. This group may not be representative of individuals with barriers to electronic tools utilization. These barriers include computer literacy, access to the Internet, and social media utilization. In addition, the survey was only offered in English, thus quite possibly did not capture the population of individuals for whom English is not a native language. A second limitation is related to the deidentified nature of the questionnaire, and as such the verification of the presence of a genetically confirmed vEDS versus a clinical diagnosis only was not ascertained; neither were demographics, comorbid conditions, and health care experiences evaluated.

Despite the limitations, the lessons learned from this survey and the work related to establishing the vEDS research collaborative are tailored toward empowering individuals with vEDS as stakeholders in patient-centered vEDS research. We plan to continue this work and report in the near future on the results of the research prioritization initiative meeting, which took place in July 2018. The vEDS research collaborative work is ongoing with plan to expand the network of stakeholders on a global level and include vascular surgeons and basic science researchers interested in vEDS. The survey reported here is an essential starting point to understand patient needs and determine the research methods best suited to study the adverse health implications associated with vEDS.

CONCLUSIONS

In this early assessment work by the vEDS collaborative, we demonstrated that there is substantial frustration with the lack of treatment for vEDS and lack of knowledge by health care providers, variation in care experiences, and a high degree of interest in research involvement to resolve these concerns. The survey highlights an opportunity to discuss the optimal modality for individuals with vEDS to participate in research as well as methodologies for building trust in research teams. The results of this survey will be translated toward establishing a toll-free number where physicians can discuss vEDS-related cases with global experts and the creation of an education curriculum for health care providers. The methodology lessons learned are not only relevant to vEDS but also can be applied to other rare vascular diseases such as genetically triggered aortopathies and arteriopathies.

The authors thank everyone who responded to the survey for their time, willingness to share, and insights. Without their contributions, this work could not have been possible.

SUPPLEMENTARY DATA

Supplementary data related to this article can be found at https://doi.org/10.1016/j.avsg.2019.06.010.

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