Health Equity in the Hemophilia B Community: Perspectives of Patients' Report Findings

Presented by:

THE COALITION FOR HEMOPHILIA B

Rare Rising™

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About Survey Sponsors

The Coalition for Hemophilia B, Inc. is a national nonprofit organization dedicated to improving the quality of life for individuals with hemophilia B and their families. Through education, advocacy, empowerment, and outreach, we strive to ensure that every patient has access to the knowledge, resources, and support they need to navigate their journey with hemophilia B.

For more than 35 years, we have pursued this mission with a family-centered approach, recognizing that hemophilia B affects not only the individual but their entire support system. Our programs bring together individuals from across the United States, fostering lifelong connections, peer support, and advocacy skills that empower patients to take charge of their health and future. To learn more visit www.hemob.org.

RareRising, formerly Upequity, is a registered 501c3 nonprofit that delivers patient-centered, evidence-based research, incubates emerging rare disease entities on their journey and explores novel solutions to positively impact rare disease communities. We engage in work that supports advancing systems and policy changes, eliminating barriers, and producing tangible improvements in people's lives.

Our Principal Investigators are talented researchers from diverse communities with direct experience in rare diseases, health disparity research and direct patient and caregiver research. You can find more information about RareRising at https://www.rarerising.org.

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Biotherapies for Life™

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Executive Summary

Project Overview ••••

The purpose of this project was to conduct a landscape analysis of the barriers or gaps in healthcare access, patient/provider communications, patient advocacy organizational services and support, and patient engagement within the hemophilia B community. The information we collected helped us to better understand and identify recommendations to address the existing access to hemophilia B research and advocacy. This assessment included a survey directed to members of the hemophilia B community and qualitative interviews with several stakeholders including patients and caregivers.

For this report, the results from the survey and key informant interviews have been analyzed to inform best practices, education, and resources within the hemophilia B community and larger rare disease community where applicable.

Our survey was open for data collection from March 15, 2023, to July 15, 2023. It was offered in English and Spanish and was disseminated mainly through social media, and patient organizations. Our initial goal was to obtain a minimum of 100 completed survey responses. We received 610 total survey responses. We also conducted nine focus groups with 37 participants and four individual interviews. One large focus group was conducted in Spanish with 11 participants. Participants received a $50 gift card for their participation. The goal of the individual interviews and focus groups was to provide more qualitative insights into barriers or gaps members in the hemophilia B community face within the following contexts: healthcare access, patient/provider communications, patient advocacy organizational services and support, and patient engagement.

Findings ••••

The study identified several opportunities to enhance the experiences of patients with hemophilia B, particularly by addressing barriers to healthcare access and communication challenges. While the executive summary mainly focuses on these areas for improvement, it is crucial to acknowledge that participants also shared positive aspects of their experiences.

For instance, the strong sense of community among members was evident when participants expressed sentiments like, *"The hemophilia community is like a family... we call each other blood brothers and blood sisters,"* and *"If we're facing any struggles, we can always turn to someone with more experience with hemophilia for support."*

Additionally, the positive impact of community organizations was highlighted in the findings, with over 68 % of patients actively engaging with these organizations to gain valuable information on treatments, medical care, and clinical trials, as well as to connect with fellow community members and explore opportunities to contribute to their community. However, these positive relationships stand in contrast to the challenges many participants identified in key areas.

Our research found that the financial and logistical challenges faced by individuals with hemophilia extend beyond the physical symptoms of the disease. We identified two main types of challenges impacting hemophilia B patients and their caregivers:

- Barriers and gaps in healthcare access, including financial constraints and physical accessibility,
- Challenges in the communication between patients and providers, which can undermine patient trust and ultimately affect health outcomes.

Barriers and Gaps in Healthcare Access:
Financial burdens arise from out-of-pocket costs for care and medications, even with insurance. Additionally, the condition often necessitates frequent medical appointments and potential job disruptions, for patients and caregivers, leading to substantial income loss. Lastly, physical access to care, particularly for those in rural areas or minority communities, can be limited, hindering timely treatment and exacerbating the overall impact of hemophilia on patients' lives. Important highlights included:

- **Costs:** A majority of respondents (54%) reported incurring additional personal costs for care and medicines, beyond their insurance premiums. An estimated 20% stated that their health insurance or drug plan does not cover the full cost of their hemophilia care and medications. Financially, the burden is substantial: 48% of hemophilia patients spend over $5,000 annually on care, and 20% spend over $25,000.
- **Work Impact:** The financial implications of unpaid medical leave are significant for many with hemophilia B. Nearly 30% of respondents and their caregivers frequently need to take unpaid leave for medical reasons, and 36% have had to either quit their jobs or reduce their working hours due to their hemophilia B. The economic impact of this is substantial, with 57% of patients estimating an annual income loss of $5,000 or more, and 21% losing over $25,000. Rural patients face an even greater financial burden, with 27% reporting losses exceeding $25,000 yearly.
- **Physical Access to Care:** Many hemophilia B patients face significant challenges in accessing necessary specialty care. A considerable number need to travel long distances for regular medical care and specialist appointments. While outreach clinics can help mitigate this, 32% of patients report that specialists do not visit their area. Additionally, nearly 1 in 4 respondents (23%) feel they have been denied access to care or specialists due to factors like gender, race, or location, with higher rates among rural patients (45%) and minorities (27%).
- **Emergency Care:** A substantial 47% of respondents reported difficulties in receiving emergency medical care for hemophilia B, and 42% say that transportation to medical appointments has been difficult due to hemophilia B, which can pose a serious challenge in emergency situations. For undiagnosed women, emergency procedures can be even riskier. One respondent related: “So during my emergency C-section, I actually bled out. And instead of them checking me to see if I had hemophilia, they gave me blood transfusions...”

Patient-Provider Communication:
In terms of communication with physicians, the study found substantial challenges related to trust among physicians and patients, particularly in rural areas, among women, and among minority respondents. Research shows that provider-patient trust increases patient health outcomes including decision-making, satisfaction, medication adherence, and shared-decision-making, and that the opposite is true when trust is lacking, and the findings extend to hemophilia patients[1,2].

- **Access to timely care:** Access to timely care is a persistent issue. More than 1 in 3 of hemophilia B patients (37%), struggle to secure immediate appointments, rising to nearly 1 in 2 among minority populations (49%). Furthermore, while 47% of patients found the information received at diagnosis helpful, this figure drops to 31% in rural areas.

  In terms of access to treatment that is timely to the needs of patients, only 2 in 3 female respondents (64%) and 1 in 2 minority respondents (53%) agreed they were receiving timely treatment. The percentage further dropped among rural patients, where 1 in 4 (27%) believed they received timely treatment, highlighting an important unmet need.

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1. Brands, Martijn R et al. “Patients' and health care providers' perspectives on quality of hemophilia care in the Netherlands: a questionnaire and interview study.” Research and practice in thrombosis and haemostasis vol. 7,4 100159. 23 Apr. 2023, doi:10.1016/j.rpth.2023.100159
2. Lerch, S. P., R. Hänggi, Y. Bussmann, et al. "A Model of Contributors to a Trusting Patient-Physician Relationship: A Critical Review Using a Systematic Search Strategy." BMC Primary Care, vol. 25, 2024, p. 194, doi: 10.1186/s12875-024-02435-z.

- **Quality of information:** A similar finding resulted when analyzing how patients rated the quality of information received from providers. About 6 in 10 females (60%) and 1 in 2 minorities (54%) with hemophilia B said they received care from knowledgeable specialists. The number was even lower among rural respondents, where less than 3 in 10 (27%) agreed they received care from knowledgeable specialists.

Selection of Key Recommendations

A critical component of this project was to take what was reported in the survey and in focus groups and identify recommendations for change. A significant number of recommendations were developed that specifically address these barriers to access and communications. Some highlights include:

Barriers or Gaps in Healthcare Access

1. Provide flexible opportunities for healthcare visits such as:
    a. After hours appointments
    b. Telehealth appointments
2. Reduce the travel burden on minority and rural hemophilia B patients and caregivers. Potential examples include:
    a. Engage with community partners or programs to provide transportation services
    b. Increase telehealth opportunities
    c. Create screening tools to verify if a patient needs to schedule an in-person appointment
    d. Provide mobile healthcare services where available
    e. Identify, screen, and evaluate transportation needs

Patient/Provider Communications

1. Create a resource guide in diverse languages that explains the clinical trial process. The guide should include information related to the following:
    a. Potential benefits of participating in a clinical trial
    b. Potential risks related to participating in a clinical trial
    c. Frequently asked questions with answers written in language that community members understand
2. Request that clinical providers provide resources on health information specific to women with hemophilia B. Potential topics include:
    a. A thorough explanation of how hemophilia B affects women
    b. A treatment plan guide based on current standards that provides detailed information on how often women should receive factor or other necessary medical treatment
    c. The testing process for women

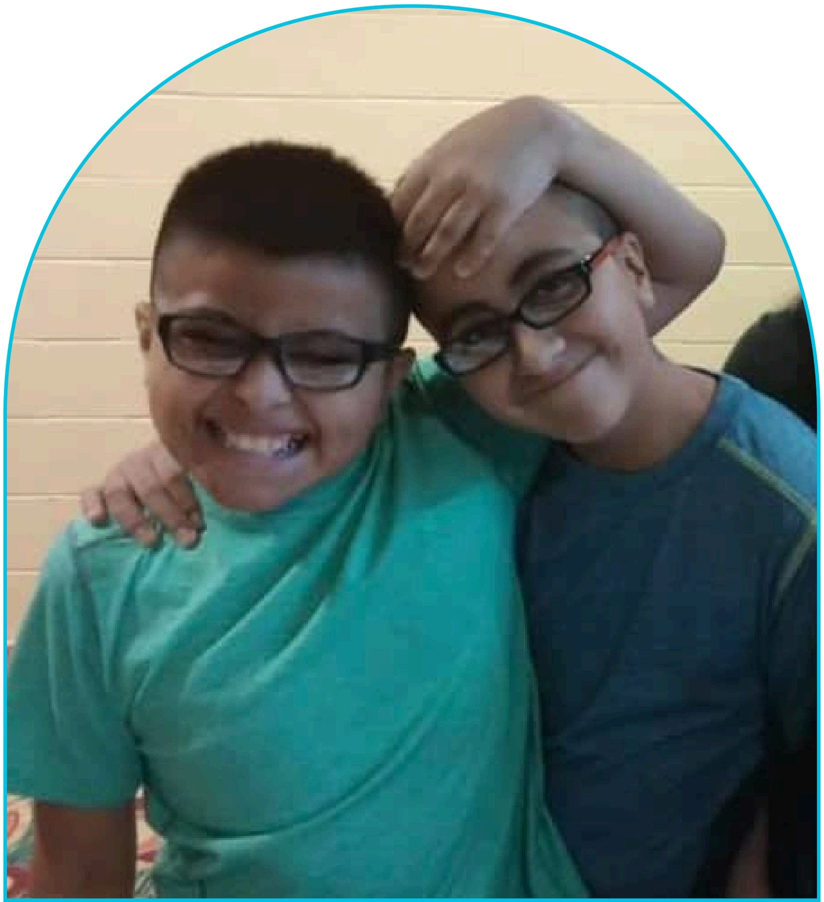
The recommendations leverage Patient Advocacy Organizational Services, Support, and Engagement as important partners to realizing these partnerships. Some highlights include:

Patient Advocacy Organizational Services, Support, and Engagement

1. Offer resources related to the following:
    a. Best practices for navigating insurance companies
    b. Understanding and navigating the various types of pharmacies
    c. Understanding the importance of knowing your family history
2. Create more opportunities to bring awareness about women and bleeding disorders

Conclusion ••••

The detailed findings of this project provide valuable insights into various aspects of healthcare access, patient/provider communications, and patient advocacy organizational services and support within the hemophilia B community. These findings emphasize the importance of addressing financial concerns, improving access to specialists, providing information about clinical trials, and enhancing support services for patients and caregivers. In addition, these findings highlight the need for tailored approaches to address the diverse needs and challenges faced by different demographic groups, including females with hemophilia B, minority groups, and rural patients. By considering these findings and implementing the key recommendations outlined in the report, stakeholders can develop targeted interventions and strategies to improve health equity and enhance the quality of life for individuals with hemophilia B and their families across diverse settings and populations.



Methodology

Introduction

Hemophilia is a bleeding disorder that prevents blood from clotting properly, which can lead to spontaneous bleeding and excessive bleeds after surgery or injury[1,2]. People with hemophilia B have a deficiency in factor IX which results in prolonged bleeding after surgery, or injury and delayed or recurrent bleeding[3,4]. People living with rare chronic genetic diseases such as hemophilia can experience difficulties accessing quality healthcare that meets their specialized needs[1-4]. In addition, specialty care may be very limited based on several factors such as geography, insurance coverage, and socioeconomic status, among others[5]. More importantly, families can experience a host of challenges related to their physical, social, and emotional well-being including financial difficulties[1-5]. Despite these difficulties, the first-hand stories of lived experiences experts (LEEs) and barriers of diverse hemophilia B patients and caregivers are limited[6]. Thus, the purpose of this project was to expand on these experiences by conducting a landscape analysis of the barriers or gaps in healthcare access, patient/provider communications, patient advocacy organizational services and support, and patient engagement within the hemophilia B community. The information we collected helped us to better understand and address the existing access to rare disease research and advocacy. This assessment included a survey (see appendix) directed to members of the hemophilia B community and qualitative interviews with several stakeholders including patients and caregivers with intentional recruitment of voices from people of color, females, and the rural community. For this report, the survey and key informant interview results have been analyzed to inform the development of best practices, education, and resources within the hemophilia B community and larger rare disease community where applicable.

Methods

Survey Development/Administration

We conducted an online survey titled *Health Equity in the Hemophilia B Community: Perspectives of Patients'*. The survey questions, which were mainly close-ended, addressed healthcare access, hemophilia B diagnosis, medications, healthcare provider experiences, insurance coverage, expenses related to hemophilia B, resources, barriers to care, experiences with care, transportation, disparities, and length of care. The survey questions were written in consultation with the Coalition for Hemophilia B and the patient/caregiver advisory council. The advisory council consisted of three individuals identified by the Coalition for Hemophilia B as active community members who are interested in health equity and could provide a diverse firsthand perspective for the project. In addition, the survey was piloted with different stakeholders to ensure the questions were relative, accessible, and comprehensible. The Qualtrics platform was used to create, publish, and distribute the survey. We opened our survey for data collection from March 15, 2023, to July 15, 2023. The survey was offered in English and Spanish and was disseminated mainly through social media, patient organizations, and patient/caregiver referrals. Our initial goal was a minimum of 100 participants completing the survey. We received 610 total survey responses. Participants had the opportunity to participate in a $50 gift card drawing as an incentive for completing the survey. We conducted three total drawings and provided three $50 gift cards in total. We submitted and obtained an Institutional Review Board (IRB) exemption for this project from Advarra IRB.

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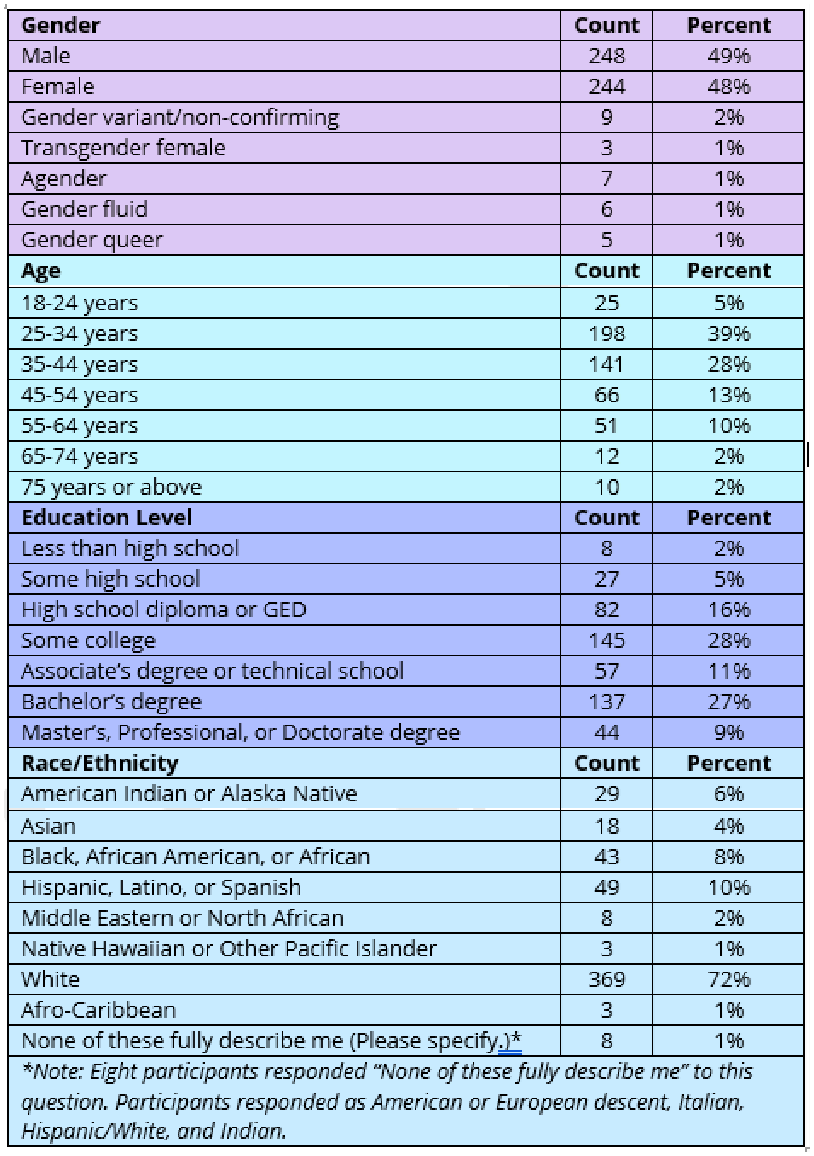
Individual Interviews/Focus Groups

In-depth individual interviews were also conducted with a diverse group of patients and caregivers. We recruited participants by sending a signup link via email to all members of the Coalition for Hemophilia B affiliates asking for volunteers who planned to attend the 2023 Coalition for Hemophilia B Symposium in Orlando, Florida. Forty-four individuals signed up to participate. We followed up with all 44 prospective respondents to confirm participation. We conducted nine focus groups with 37 participants and four individual interviews with four participants. One large focus group was conducted in Spanish. Participants received a $50 gift card for their participation. The goal of the individual interviews and focus groups was to provide more qualitative insights into barriers or gaps in healthcare access, patient/provider communications, patient advocacy organizational services and support, and patient engagement within the hemophilia B community. A guide (see appendix) with semi-structured questions was used during the interview to further understand concerns, if any, among hemophilia B patients and caregivers. Sample questions included: What are some overall barriers or gaps in healthcare access if any? What are some overall barriers to patient/provider communication if any? What are your general thoughts about patient advocacy organizational services and support in the hemophilia B field more broadly? What are your general thoughts about overall strengths and weaknesses with patient engagement in the rare disease community? The guide was written in both English and Spanish to help us reach our Spanish-speaking participants. All focus group and individual interviews were transcribed and recorded if consent was provided. Findings were used to help inform best practices and recommendations included in this final report.

Table 1. Survey Respondent Characteristics



Gender	**Count**	**Percent**
Male	248	49%
Female	244	48%
Gender variant/non-confirming	9	2%
Transgender female	3	1%
Agender	7	1%
Gender fluid	6	1%
Gender queer	5	1%
Age	**Count**	**Percent**
18-24 years	25	5%
25-34 years	198	39%
35-44 years	141	28%
45-54 years	66	13%
55-64 years	51	10%
65-74 years	12	2%
75 years or above	10	2%
Education Level	**Count**	**Percent**
Less than high school	8	2%
Some high school	27	5%
High school diploma or GED	82	16%
Some college	145	28%
Associate's degree or technical school	57	11%
Bachelor's degree	137	27%
Master's, Professional, or Doctorate degree	44	9%
Race/Ethnicity	**Count**	**Percent**
American Indian or Alaska Native	29	6%
Asian	18	4%
Black, African American, or African	43	8%
Hispanic, Latino, or Spanish	49	10%
Middle Eastern or North African	8	2%
Native Hawaiian or Other Pacific Islander	3	1%
White	369	72%
Afro-Caribbean	3	1%
None of these fully describe me (Please specify.)*	8	1%

**Note: Eight participants responded "None of these fully describe me" to this question. Participants responded as American or European descent, Italian, Hispanic/White, and Indian.*

Survey Respondent Overview*

We received 610 individual responses to the survey. The respondents were about equally divided between males (49%) and females (48%). A higher percentage of respondents were 25-34 years old (39%) and indicated their highest level of education as some college (28%). Most respondents were White (72%), followed by Hispanic, Latino, or Spanish (10%).

**In memory of Alfonso*

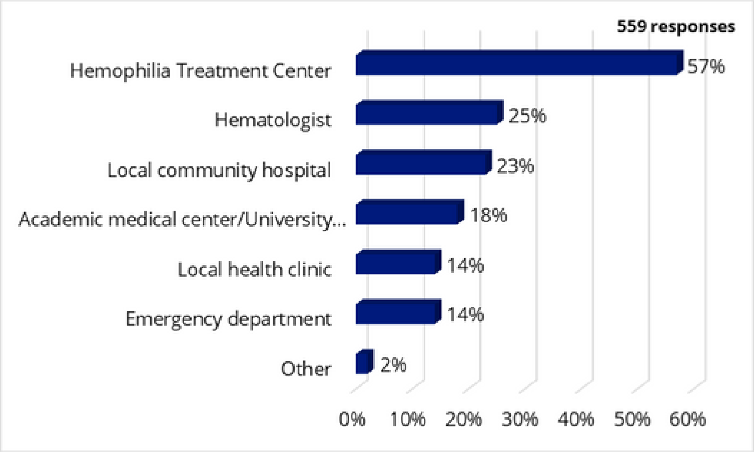
Detailed Findings

Barriers or Gaps in Healthcare Access ••••

Survey respondents were asked about where they receive care for hemophilia B. Over half of respondents indicated they receive care from Hemophilia Treatment Centers (57%) followed by hematologists (25%). Additionally, respondents indicated they usually receive care from other specialty hospitals or healthcare providers such as children's hospitals, and obstetricians.

Figure 1. Care for Hemophilia B

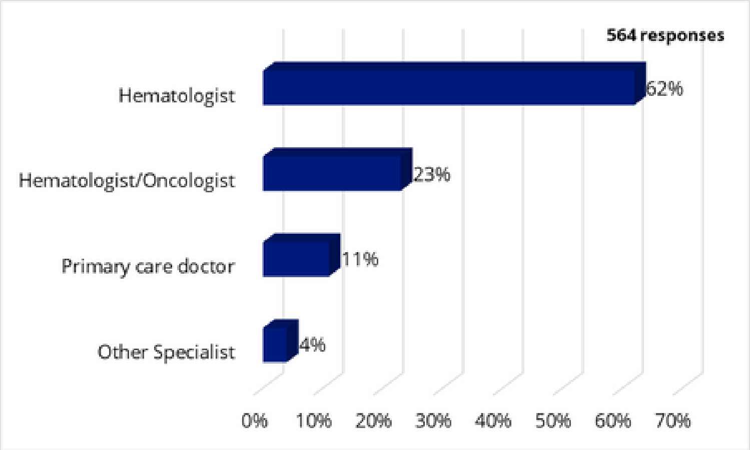
Where do you usually go for care for hemophilia? (Select all that apply)



Most respondents indicated that they received their hemophilia B diagnosis from a hematologist (62%) followed by a hematologist/oncologist (23%), and primary care doctors (11%). Additionally, some respondents indicated "other specialist" (4%) such as pediatricians, dentists, and emergency physicians.

Figure 2. Hemophilia B Diagnosis

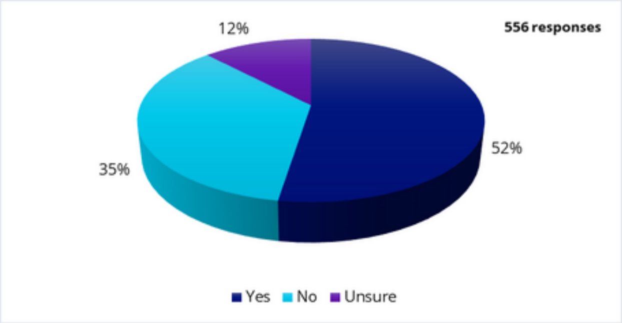
Who diagnosed your hemophilia?



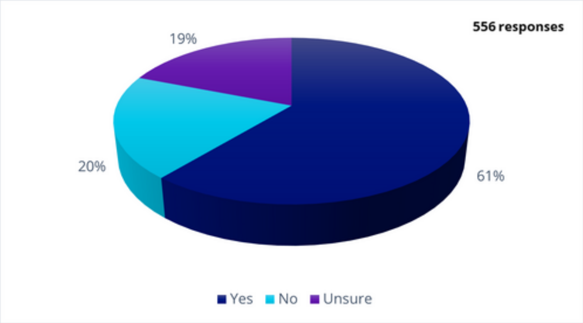
Survey respondents were asked questions about their insurance coverage. A majority of respondents indicated they had to pay additional personal costs for care and medicines in addition to insurance premiums (52%), but a slightly larger percentage indicated that their health insurance covers the cost for care and medicines for hemophilia (61%). Alternatively, 35% of respondents indicated they do not have to pay additional personal costs for care and medicines in addition to insurance premiums and 20% indicated their health insurance does not cover the cost for care and medicines for hemophilia.

Figure 3. Insurance Coverage

a. Do you have to pay additional personal costs for care and medicines for hemophilia in addition to insurance premiums?



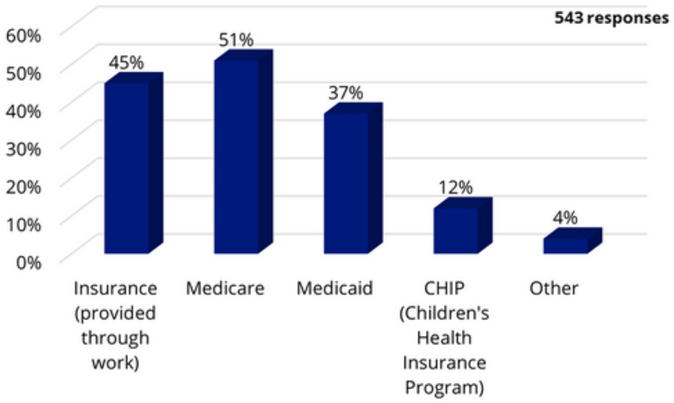
b. My health insurance or drug plan covers the cost for care and medicines for hemophilia.



Survey respondents were asked about their primary health insurance. Half of respondents indicated they currently use Medicare (51%) followed by insurance provided through work, Medicaid, the Children's Health Insurance Program, or other respectively (45%, 37%, 12%, 4%). Respondents who indicated "other" listed Tricare, healthcare marketplace, Genetically Handicapped Persons Program, and health alliance as their primary health insurance.

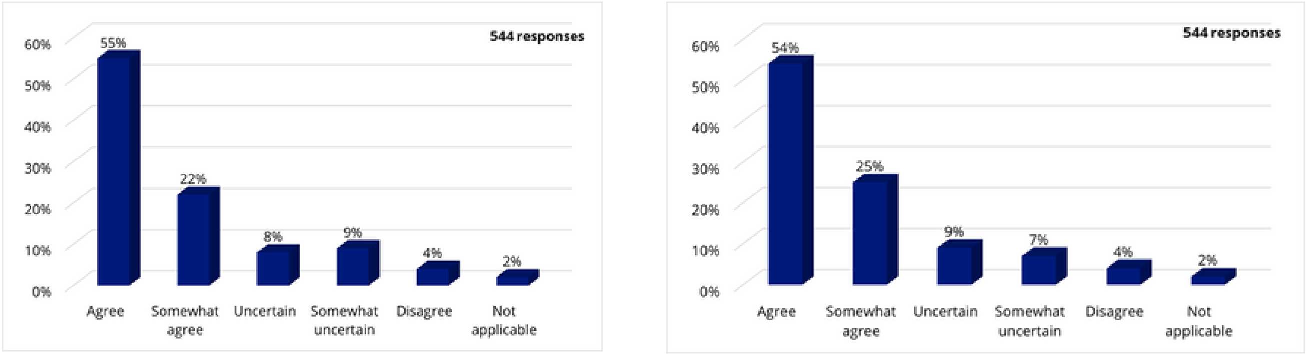
Figure 4. Primary Health Insurance Provider

Please select the primary health insurance you use.



Survey respondents were asked questions about healthcare access, resources, and potential barriers. Respondents most commonly indicated that they agree they are receiving treatment that is timely (55%), they are receiving care and education from specialists and clinics who are knowledgeable (54%), they are able to access the medications they need for hemophilia care (54%), and they currently have access to the information they need to understand and care for hemophilia (51%). A smaller number of respondents indicated they disagree that they often need to take unpaid leave for medical reasons (14%), and they have had to leave a job or reduce work hours because of hemophilia (16%).

Figure 5. Perspectives on Healthcare Access, Resources, and Potential Barriers

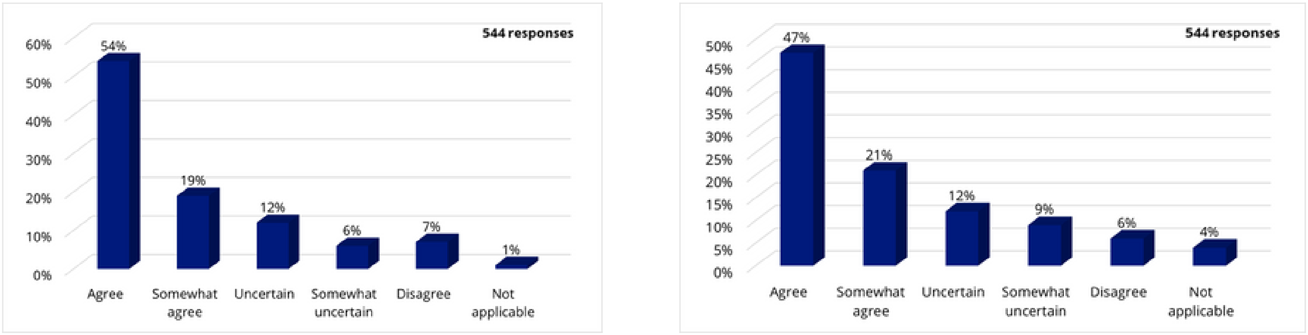


a. I am receiving treatment that is timely to my needs.

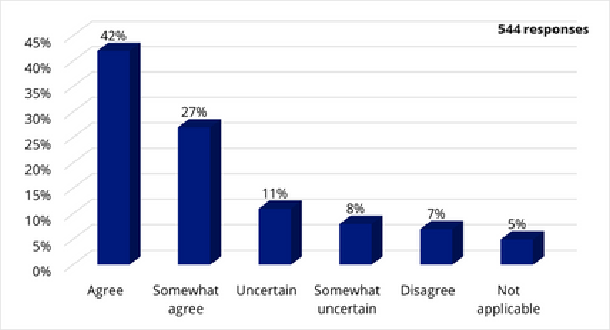
b. I am receiving care and education from specialists and clinics who are knowledgeable about hemophilia

c. I am able to get access to the medications I need for my hemophilia care

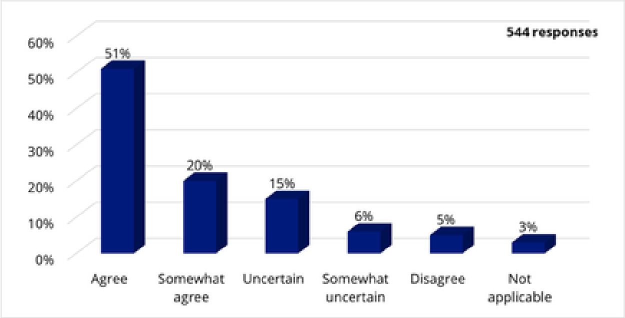
d. The information provided when you were diagnosed was helpful for you and your caregiver/family



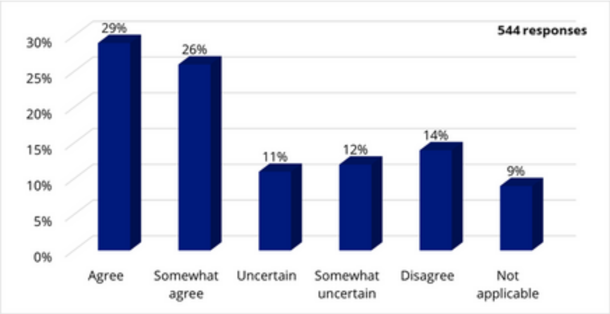
e. The information provided by your healthcare provider when you were diagnosed was clear and understandable



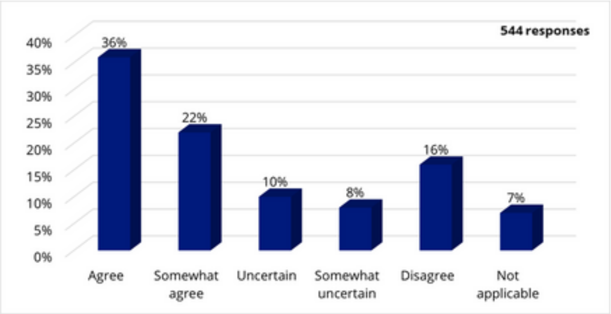
f. You or your caregiver/family currently have access to the information you need to understand and care for hemophilia



g. You or your caregiver/family often need to take unpaid leave for medical reasons



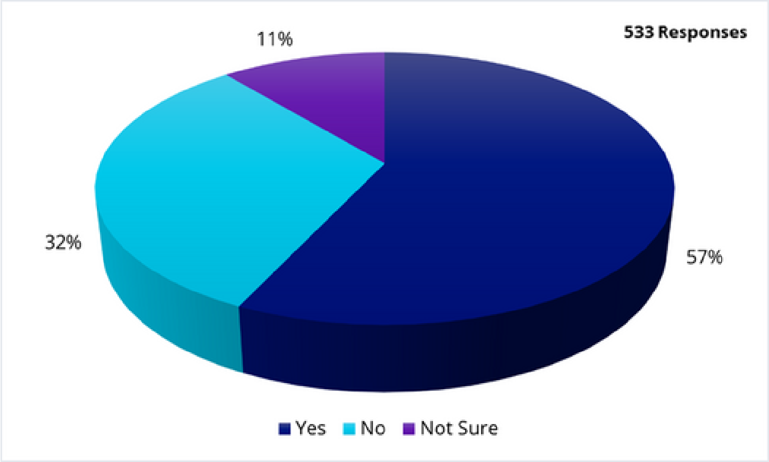
h. You or your caregiver/family have had to leave a job or reduce work hours because of hemophilia.



Survey respondents were asked about whether specialists come to their area to conduct patient outreach clinics to shorten travel time. Most respondents indicated yes (57%), followed by no (32%), and not sure (11%).

Figure 6. Access to Hemophilia Specialists

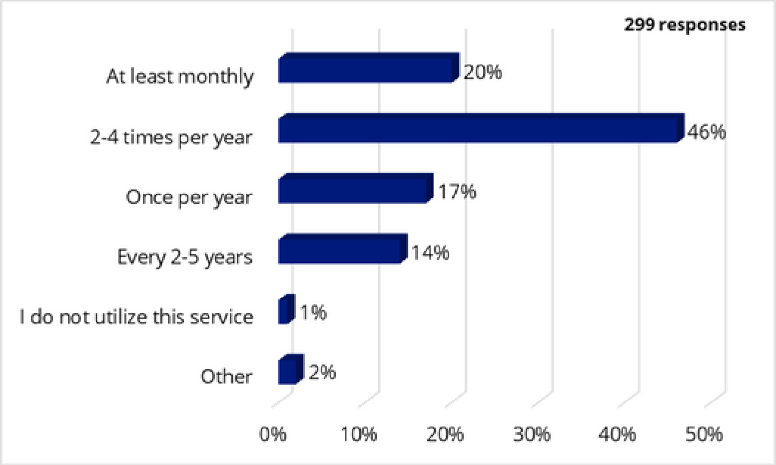
Do specialists for hemophilia ever come to your area to conduct patient outreach clinics to shorten your travel to them?



Survey respondents were asked how often they participate in specialist outreach clinics. The highest percentage of respondents indicated they participate 2-4 times per year (46%) followed by at least monthly (20%), once per year (17%), and every 2-5 years (14%). A small percentage of respondents indicated they did not utilize the service (1%).

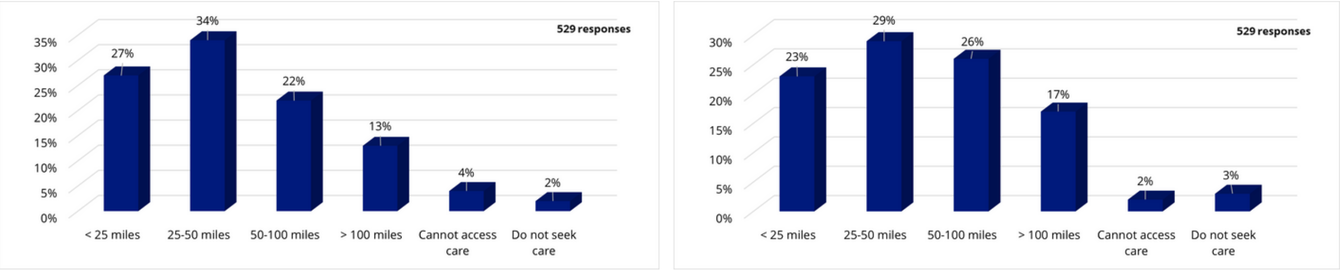
Figure 7. Specialists Service Use

When specialists for hemophilia come to your area to conduct patient outreach clinics to shorten your travel to them, how often do you utilize this service?



Survey respondents were asked questions about how far they travel for care. Roughly a third of respondents indicated they travel 25-50 miles (34%) for regular medical care related to hemophilia followed by less than 25 miles (27%), 50-100 miles (22%), and more than 100 miles (13%). Some respondents indicated they are unable to access care for hemophilia (4%). In addition, when asked how far they needed to travel to see specialists for hemophilia, the largest group of respondents indicated that they travel 25-50 miles (29%) followed by 50-100 miles (26%), less than 25 miles (23%), and more than 100 miles (17%). Some respondents indicated they are unable to access specialist care for hemophilia (3%).

Figure 8. Distance Traveled for Hemophilia Care



a. How far do you need to travel for regular medical care related to hemophilia?

b. How far do you need to travel to see specialists for hemophilia?

Survey respondents were asked if they felt they were ever denied access to hemophilia specialist care due to their gender, race, geographic location, or any other demographic factor. Most respondents indicated they do not feel they were denied access (77%) followed by those who indicated they have (23%). Respondents who indicated they felt they were denied access provided the following explanations, “As a woman it has been very difficult to receive factor when needed. I have recently been given factor by my local primary care physician as my hematologist has been very unhelpful.”, “I’m queer, Black, and a woman. I’m often disregarded or downplayed.”, “Where we live there are no pediatric specialists for hemophilia.”, “I’m always told that women do not have hemophilia.”, “My home address is too far from the hospital.”, and “Ellos asumen que porque eres una mujer no tienes hemofilia aunque los sangrados son excesivos. No quieren hacer pruebas para saber si tenemos hemofilia, aún con segure médico. No puedo pensar qué pasa con tantas mujeres que no tienen un Seguro médico.”

Survey respondents were asked about how they get to their medical appointments. Most respondents indicated they utilize a car (84%) followed by air (8%) and telehealth only (7%). Those who indicated “other” mentioned bicycles, and cabs.

Figure 9. Denied Access to Hemophilia Specialist due to Gender, Race, Geographic Location or Other Factor

Do you feel you are ever denied access to a hemophilia specialist due to your gender, race, geographic location (ex. Rural), or any other demographic factor?

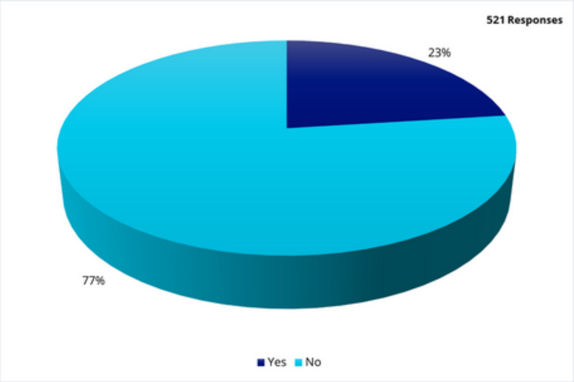
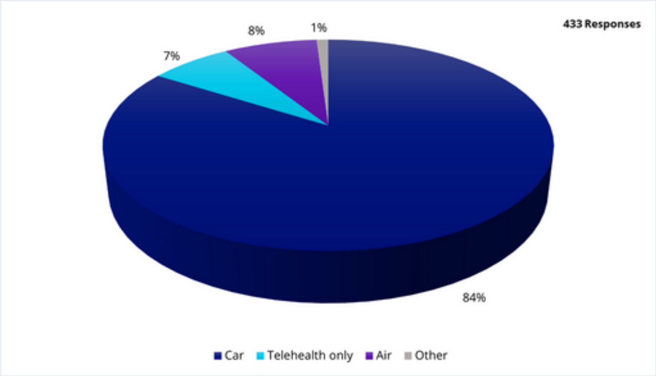


Figure 10. Transportation Type for Hemophilia Medical Appointments

How do you get to your medical appointments? (check all that apply)

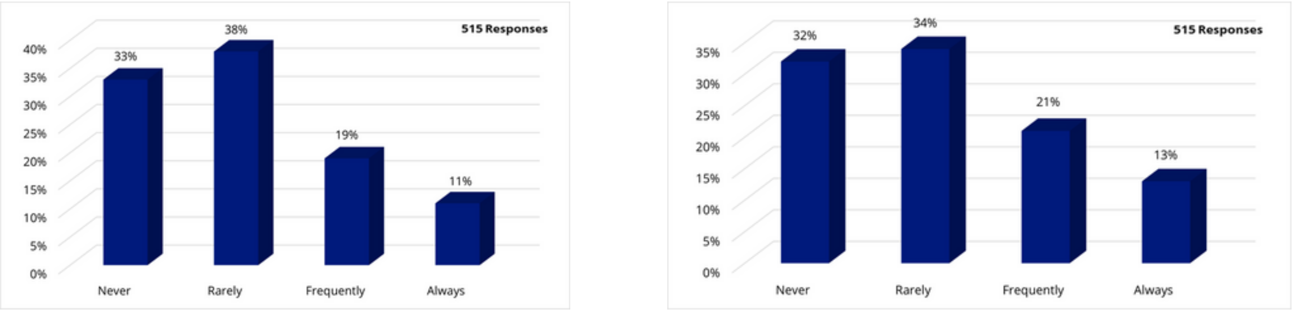


Survey respondents were asked questions about their length of care. Most respondents indicated they rarely need to stay overnight when seeking their regular care for hemophilia (38%). In addition, about a third of respondents indicated they rarely need to stay overnight when seeking specialist care (34%). Alternatively, 19% of respondents indicated they frequently need to stay overnight when seeking regular care and another 21% of respondents indicated they frequently need to stay overnight when seeking their specialist care.

Figure 11. Hemophilia Length of Care

a. Do you typically need to stay overnight when seeking your regular care for hemophilia?

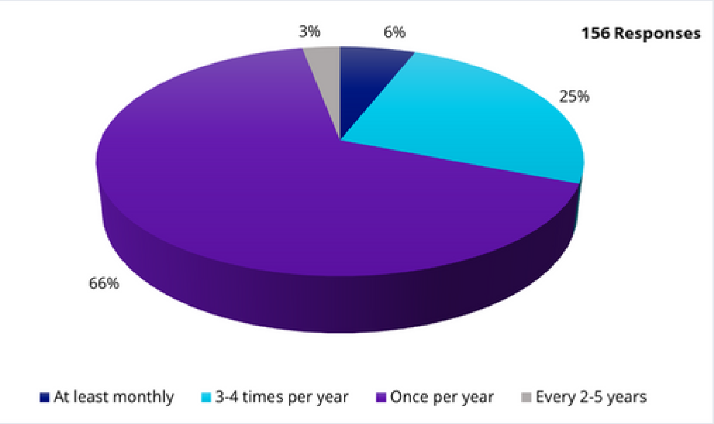
b. Do you typically need to stay overnight when seeking your specialist care for hemophilia?



Survey respondents were asked about how often they receive care. Two-thirds of respondents indicated they received care once per year (66%) followed by 3-4 times/year (25%), at least monthly (6%), and every 2-5 years (3%).

Figure 12. Use of Hemophilia Care

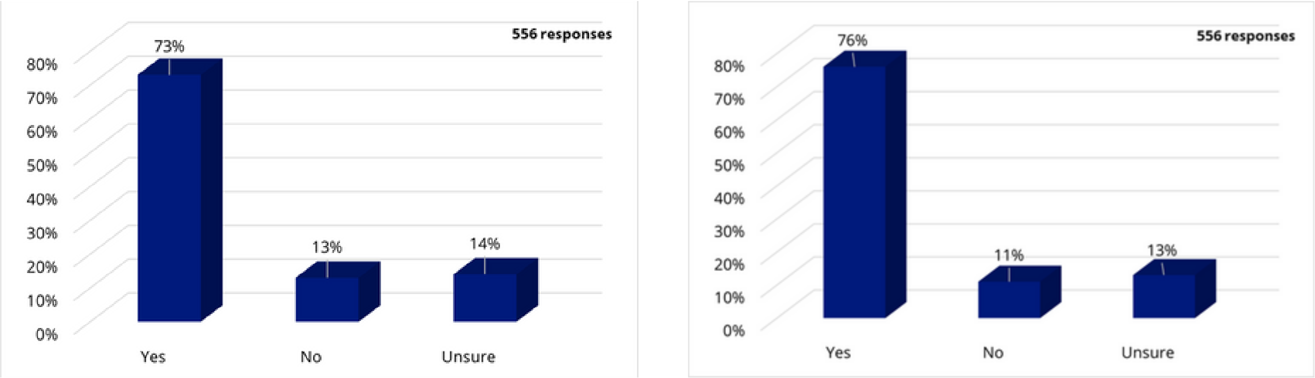
How often do you receive care for your hemophilia?



Patient/Provider Communications ••••

Survey respondents were asked questions about their medications and healthcare provider experience. Respondents predominantly indicated they are aware of medications that are available (73%), the information provided by their health care provider was provided in their preferred language (76%), they were provided information about patient organizations or support groups (56%), they are aware of hemophilia patient organizations that assist patients and families (71%), and they are actively connecting with a patient organization (68%).

Figure 13. Medications and Healthcare Provider Experience

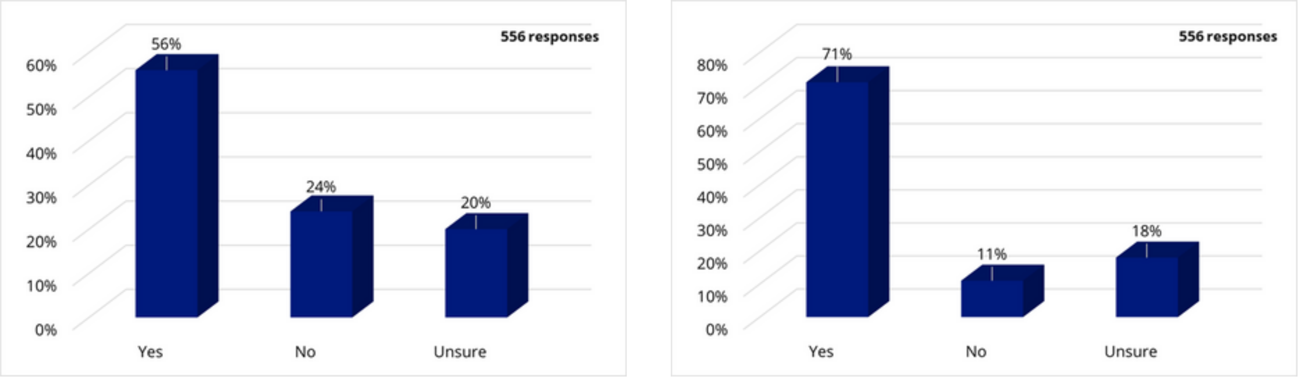


a. I am aware of medications that are available for hemophilia care.

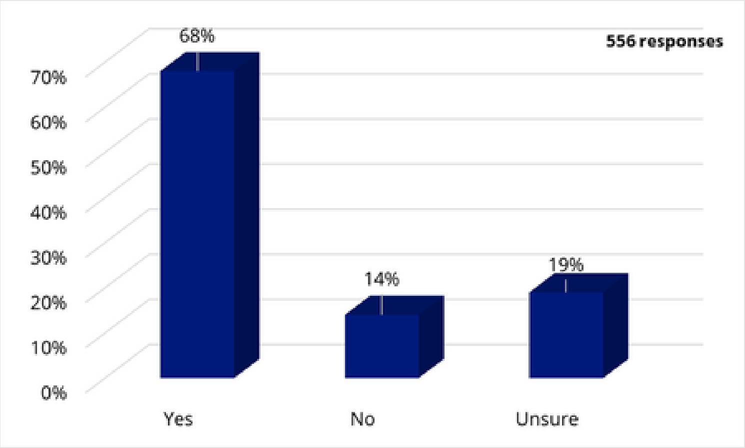
b. The information provided by your healthcare provider was given to you or your caregiver/family in your preferred language.

c. When you were diagnosed, you or your caregiver/family were given information about patient organizations or support groups.

d. Are you or your caregiver/family aware of hemophilia patient organizations that assist patients and families?



e. Are you or your caregiver/family actively connecting with a patient organization?

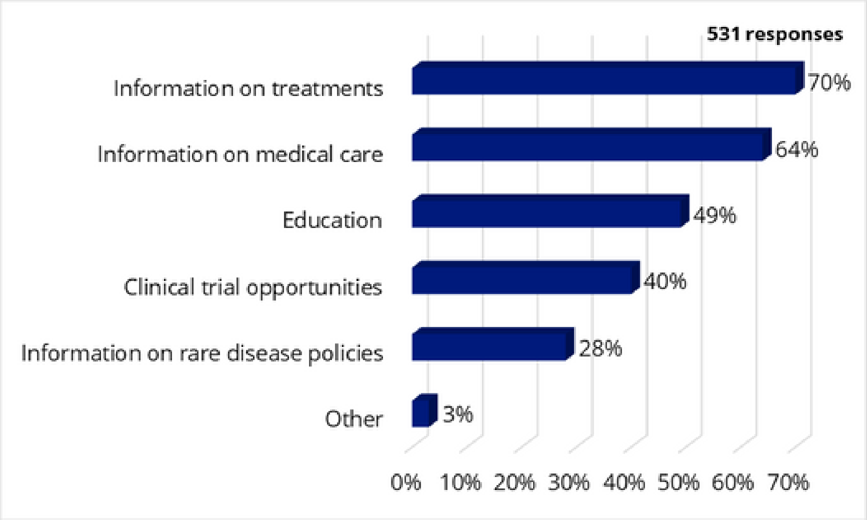


Patient Advocacy Organizational Services, Support, and Engagement

Survey respondents were asked about the benefits received from their hemophilia patient advocacy organization. More than half of respondents indicated they received information on treatments (70%), and they received information on medical care (64%). In addition, respondents indicated receiving educational information (49%), clinical trial opportunities (40%), and information on rare disease policies (28%). Respondents who selected "other" indicated receiving community support, advocacy, love, opportunities to meet others with the same condition, and financial assistance programs.

Figure 14. Hemophilia Patient Advocacy Organization Benefits

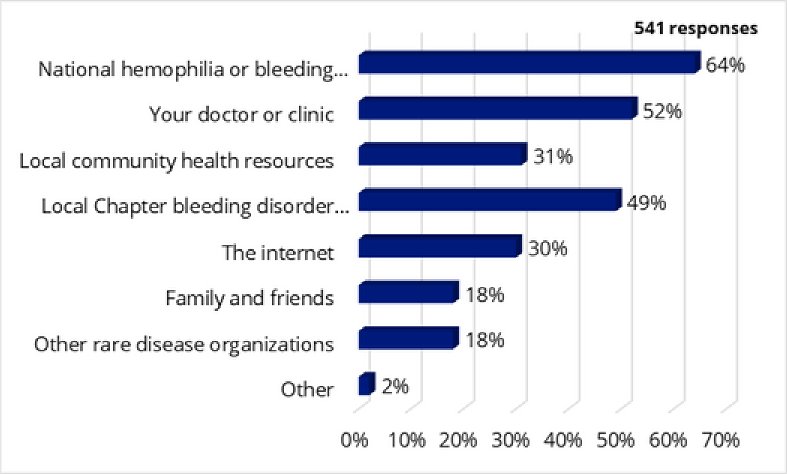
What benefits do you or your caregiver/family receive from your hemophilia patient advocacy organization? (check all that apply)



Survey respondents were asked where they receive information for hemophilia. More than half of respondents indicated they received their information from the national hemophilia or bleeding disorders patient organizations (64%) followed by their doctor or clinic (52%), and local chapter bleeding disorder organizations (49%). Respondents also indicated they receive information from their local community health resources (31%), the internet (30%), family and friends (18%), and other rare disease organizations (18%). Respondents who indicated "other" stated journals, insurance companies, and pharmacists.

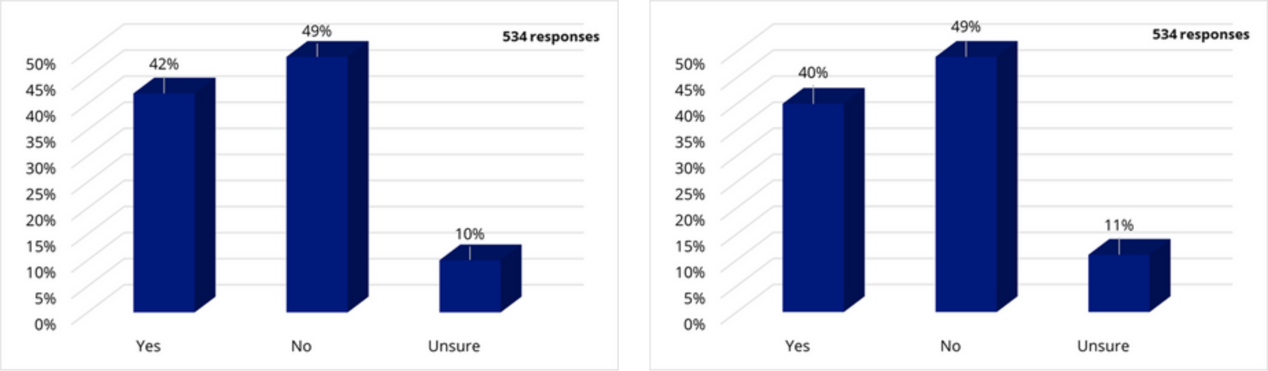
Figure 15. Hemophilia Information Resources

Where do you or your caregiver/family currently receive information for your hemophilia? (check all that apply)



Survey respondents were asked questions about their access to care, experiences with care, and transportation. Respondents typically indicated that they do have access to local doctors for regular care (59%), they do have access to local specialists (58%), they have had difficulties receiving emergency medical care (47%), and that transportation to medical appointments have been physically difficult for them due to hemophilia (42%). Alternatively, respondents indicated that transportation to school hasn't been difficult due to hemophilia (59%), their travel is not out-of-state for their hemophilia care (57%), and that transportation to work has not been difficult for them due to hemophilia (56%).

Figure 16. Hemophilia Access to care, Experiences with Care, and Transportation

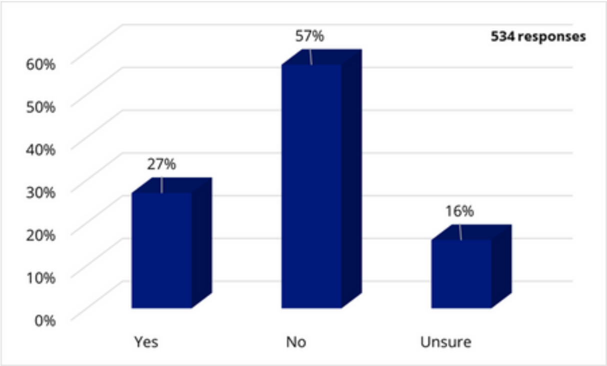


a. Has transportation to medical appointments been physically difficult for you due to hemophilia?

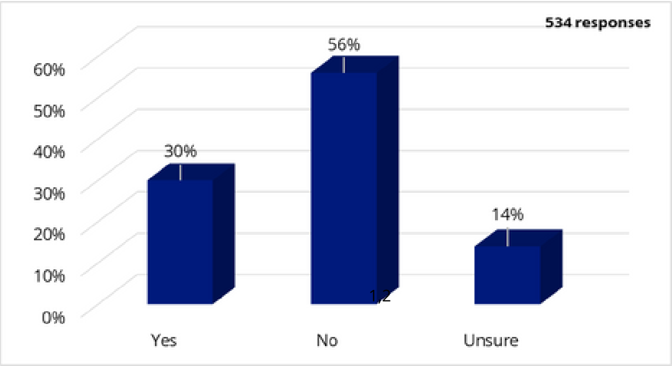
b. Has transportation to medical appointments been financially difficult for you due to hemophilia?

**We defined rural patients as individuals who had to travel further than 50 miles to see a specialists for hemophilia care.*

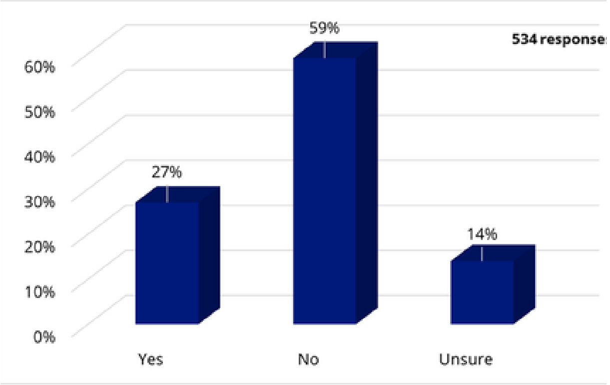
c. Is any of your travel out-of-state for your hemophilia medical care?



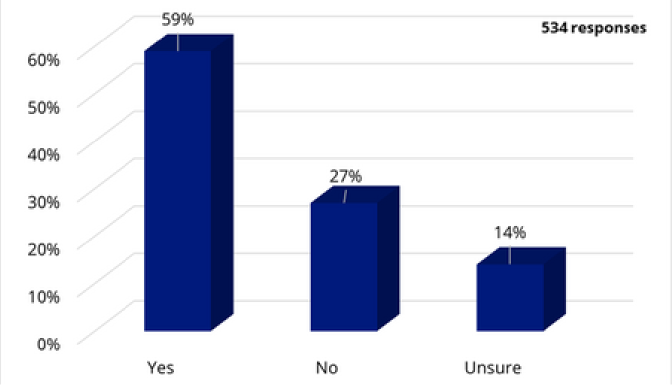
d. Has transportation to work been difficult for you due to hemophilia?



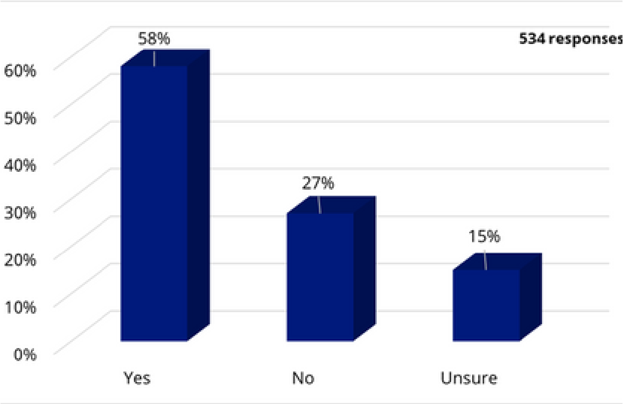
e. Has transportation to school been difficult for you due to hemophilia?



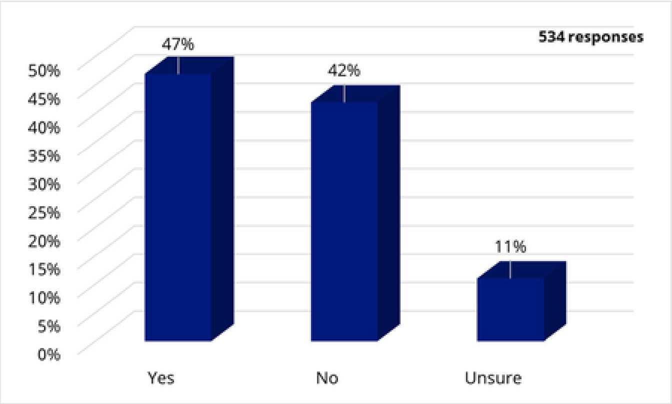
f. Do you have a local doctor nearby (within 50 miles) for your regular hemophilia care?



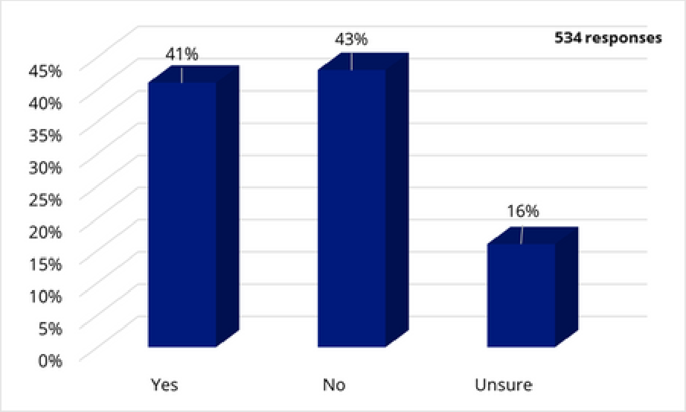
g. Do you have local access to specialists for hemophilia?



h. Have you had difficulties receiving emergency medical care for hemophilia?



i. Have you had difficulties with inpatient care for hemophilia?

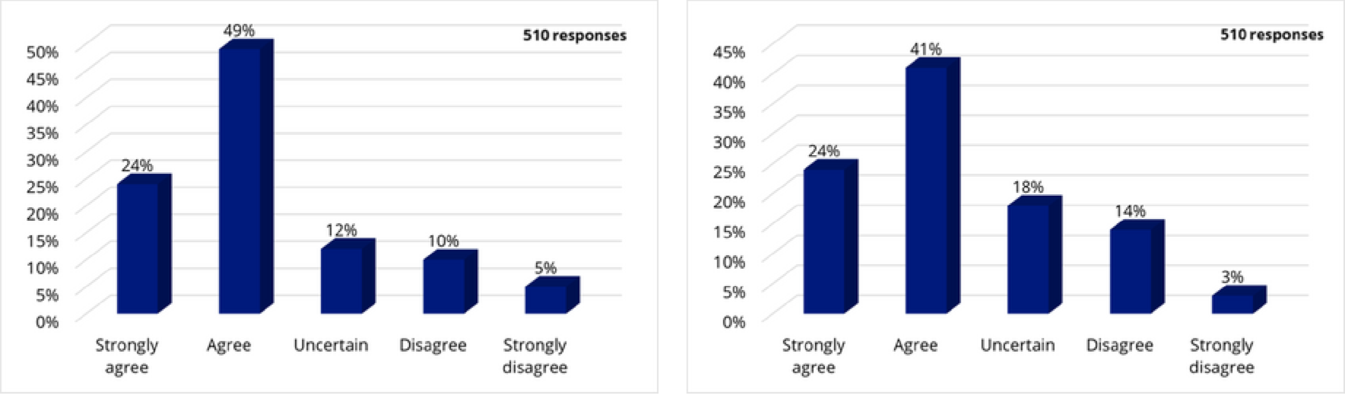


Survey respondents were asked questions about the medical care they receive. A higher percentage of respondents agreed with the following statements: doctors are good about explaining the reason for medical tests (49%), my doctors treat me in a very friendly and courteous manner (46%), and when I go for care they are careful to check everything when treating me (45%). Alternatively, respondents indicated they disagree with the following statements: doctors act too businesslike and impersonal toward me (35%), I have some doubts about the ability of the doctors who treat me (33%), and doctors sometimes ignore what I tell them (30%).

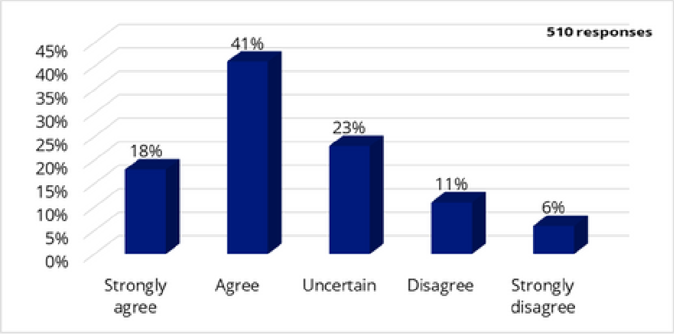
Figure 17. Perceptions on Medical Care

a. Doctors are good about explaining the reason for medical tests.

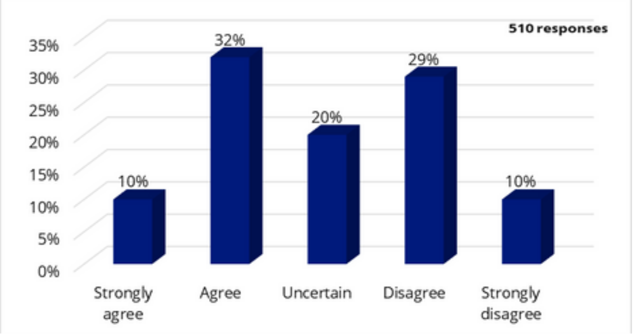
b. I think my doctor's office has everything needed to provide complete medical care.



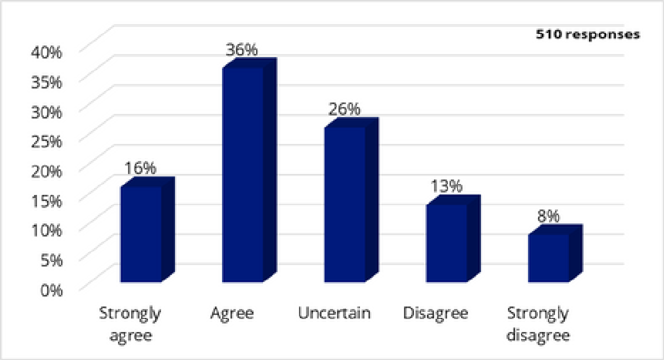
c. The medical care I have been receiving is just about perfect.



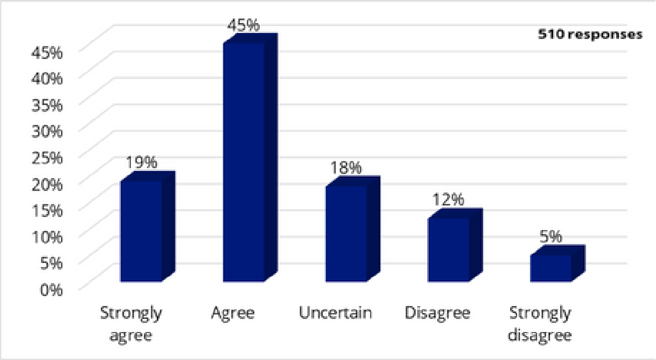
d. Sometimes doctors make me wonder if their diagnosis is correct.



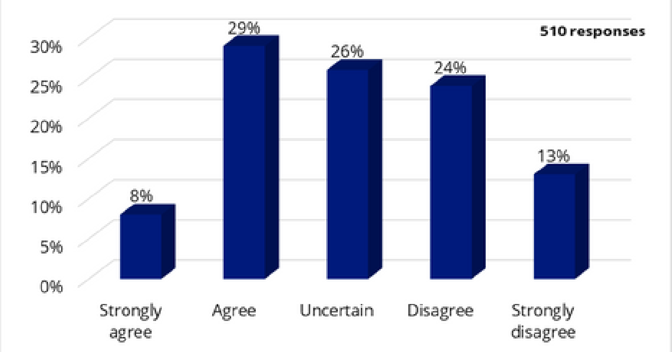
e. I feel confident that I can get the medical care I need without being set back financially



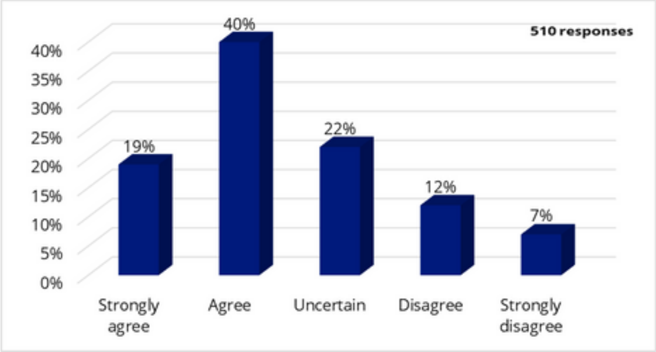
f. When I go for medical care, they are careful to check everything when treating and examining me.



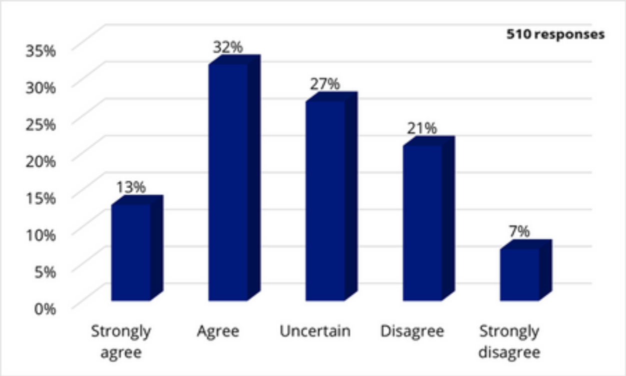
g. I have to pay for more of my medical care than I can afford.



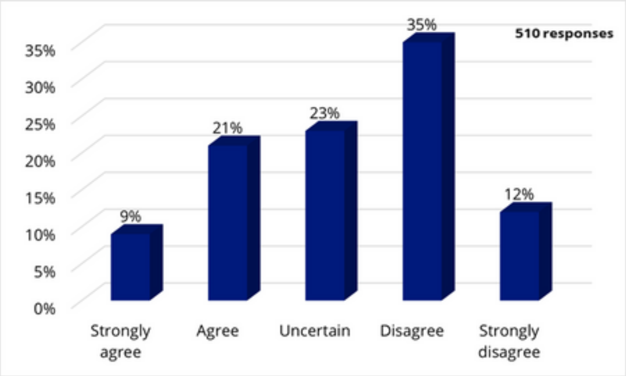
h. I have easy access to medical specialist I need.



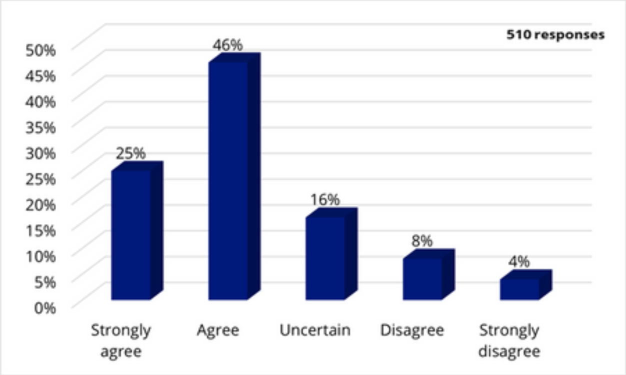
i. Where I get medical care, people have to wait too long for emergency treatment.



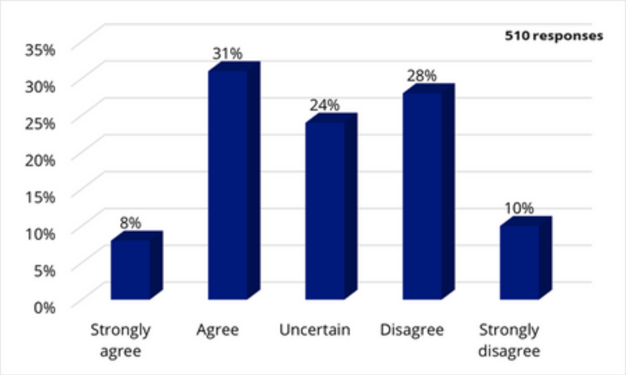
j. Doctors act too businesslike and impersonal toward me.



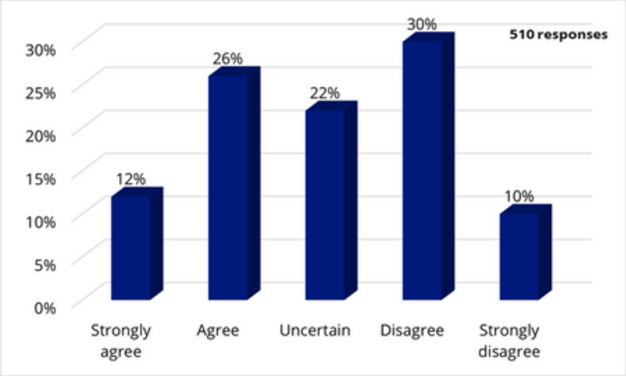
k. My doctor treats me in a very friendly and courteous manner.



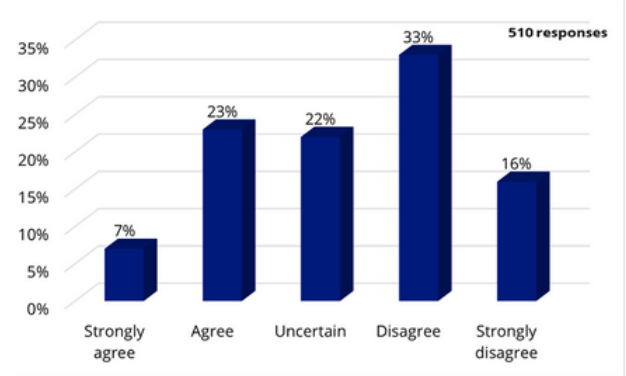
l. Those who provide my medical care sometimes hurry too much when they treat me.



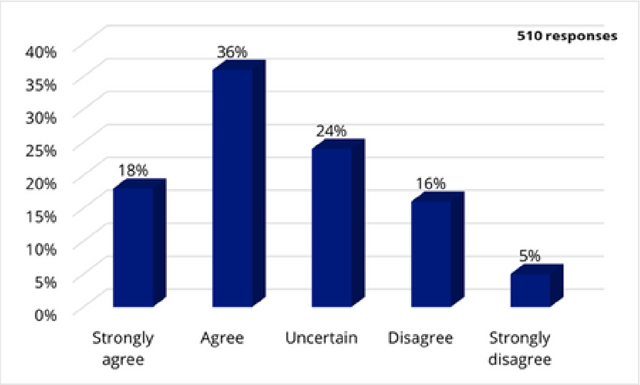
m. Doctors sometimes ignore what I tell them.



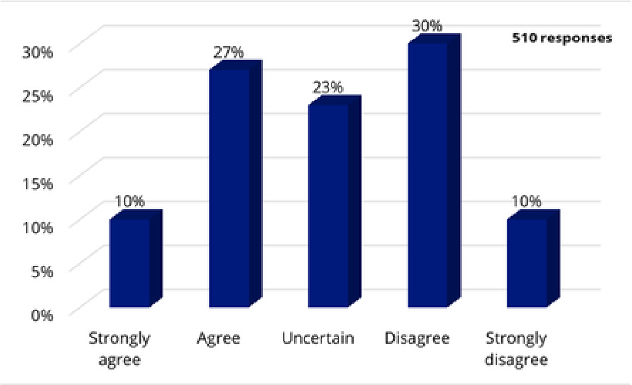
n. I have some doubts about the ability of the doctors who treat me.



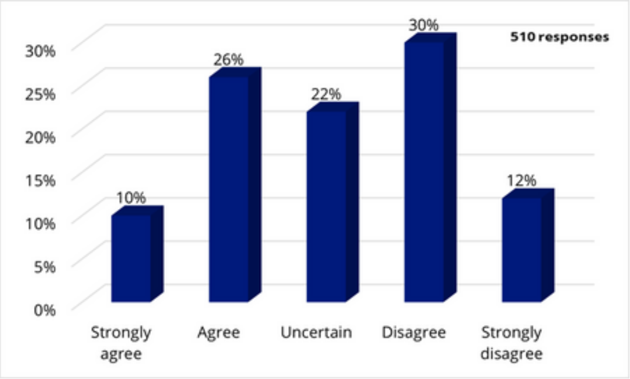
o. Doctors usually spend plenty of time with me.



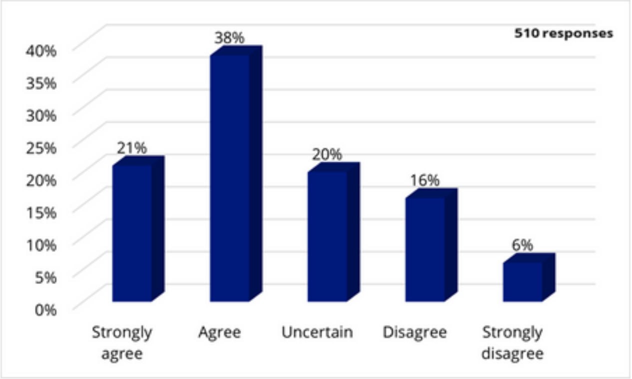
p. I find it hard to get an appointment for medical care right away.



q. I am dissatisfied with some things about the medical care I receive.



r. I am able to get medical care whenever I need it.

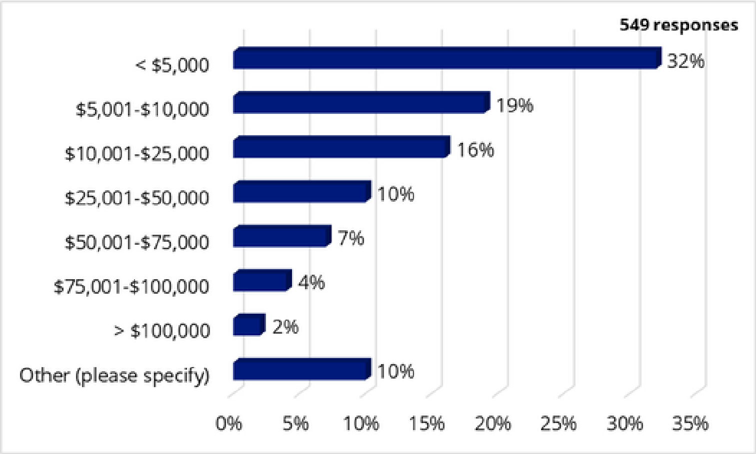


General Information ••••

Survey respondents were asked how much their family spends on hemophilia B care and medicine. The highest percentage of respondents indicated they spend less than $5,000/year (32%) followed by $5,001-$10,000/year, $10,001-$25,000/year, $25,001-$50,000/year, $50,001-$75,000/year, $75,001-$100,000/year, and more than $100,000 respectively (19%, 16%, 10%, 7%, 4%, 2%).

Figure 18. Yearly Expenses for Hemophilia B Care and Medicine

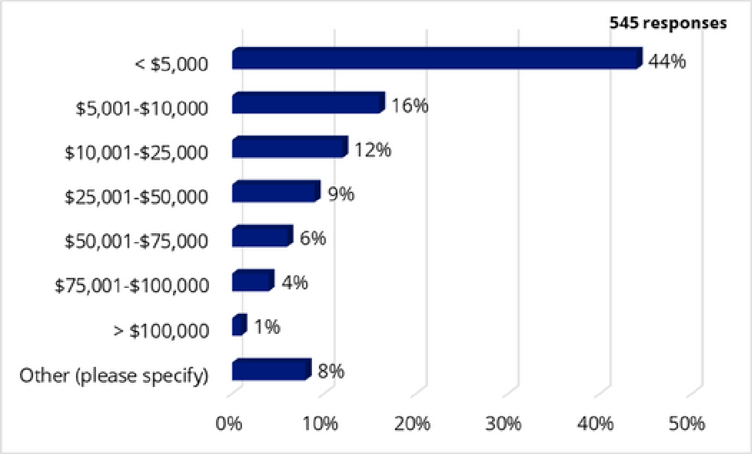
What does your family spend each year for care and medicine for hemophilia? (please do not include the cost of your monthly insurance premiums)



Survey respondents were asked how much they spend each year to travel for hemophilia B care. The highest percentage of respondents indicated they spend less than $5,000/year (44%) followed by $5,001-$10,000/year, $10,001-$25,000/year, $25,001-$50,000/year, $50,001-$75,000/year, $75,001-$100,000/year, and more than $100,000 respectively (16%, 12%, 9%, 6%, 4%, 1%).

Figure 19. Yearly Expenses for Hemophilia B Care and Medicine

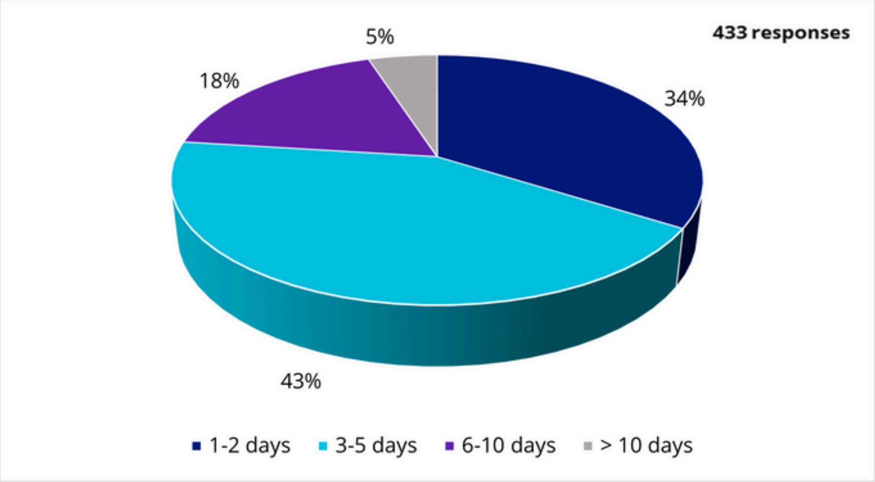
What does your family spend each year for travel for hemophilia care?



Survey respondents were asked about needing days off work or school for health reasons due to hemophilia. Respondents most indicated they take off 3-5 days/month (43%) followed by 1-2 days/month, 6-10 days/month, and >10 days/month respectively (34%, 18%, 5%).

Figure 20. Work/School Related Absences for Hemophilia B Care

How often, if at all, do you or your caregiver/family need days off work or school for health reasons due to hemophilia? (per month on average)



Survey respondents were asked to estimate the amount of wages lost due to needing days off for health reasons related to hemophilia. The highest percentage of respondents indicated an estimate of less than $5,000/year (28%) followed by $5,001-$10,000/year, $10,001-$25,000/year, $25,001-$50,000/year, $50,001-$75,000/year, $75,001-$100,000/year, and more than $100,000 respectively (21%, 15%, 10%, 6%, 4%, 1%).

Figure 21. Lost Wages for Health Reasons due to Hemophilia B

What would you estimate the amount of wages lost to needing days off work for health reasons due to hemophilia?

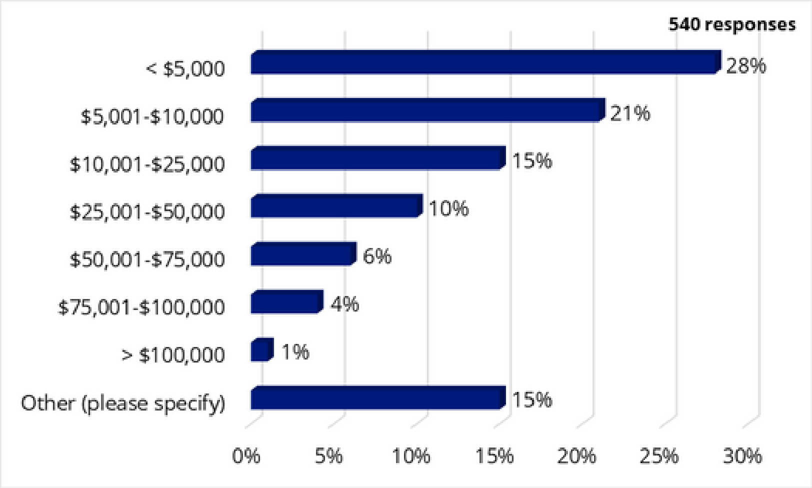
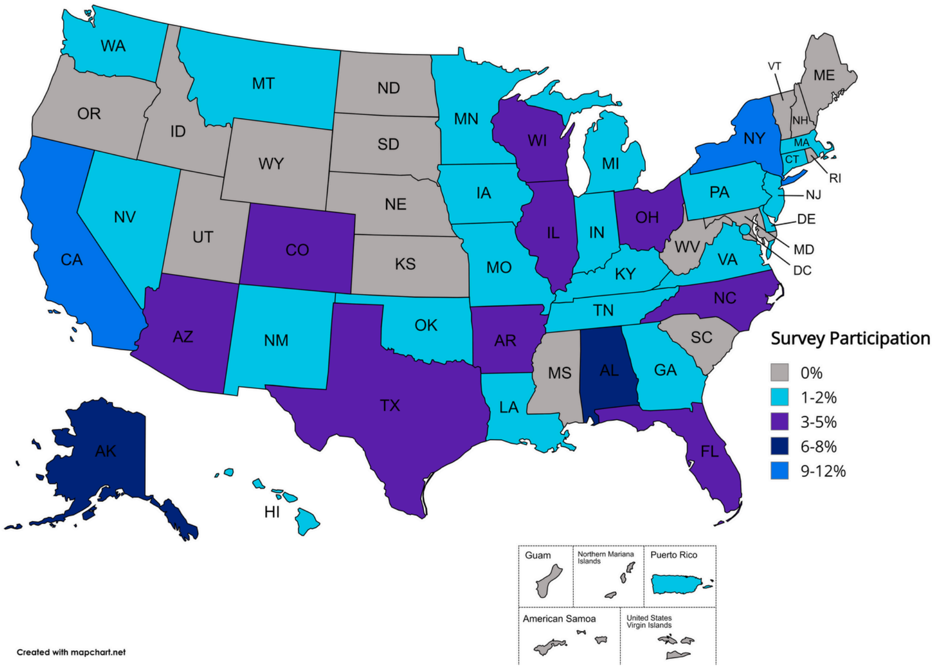


Figure 21. Respondent Geographic Location

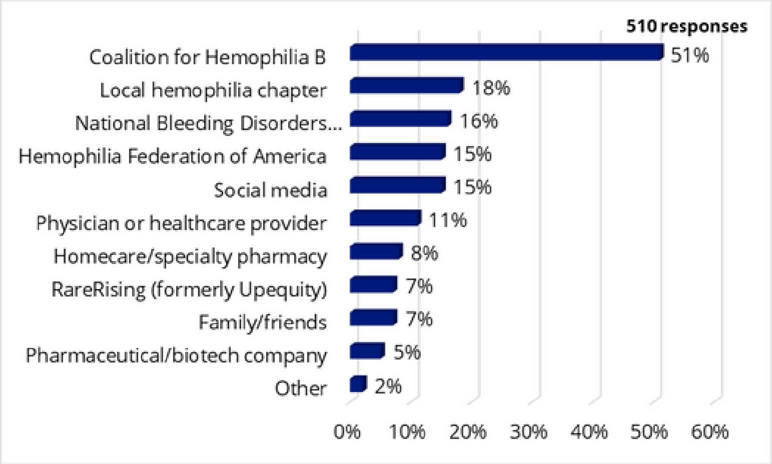
What state do you currently live in?

Survey respondents were asked about where they currently live. We received representation from the majority of states with the exception of the following Idaho, Kansas, Maine, Maryland, Mississippi, Nebraska, New Hampshire, North Dakota, Oregon, Rhode Island, South Carolina, South Dakota, Utah, Vermont, West Virginia, Wyoming, U.S. Virgin Islands, American Samoa, Northern Mariana Islands, and Guam. The states with the highest percentage of respondents were Alabama (12%) and California (12%), followed by Alaska (8%) and New York (8%), Colorado (4%), Illinois (4%), and Texas (4%).



Survey respondents were asked about where they found out about the survey. About half of respondents indicated they became aware of the survey from the Coalition for Hemophilia B (51%) followed by their local hemophilia chapter (18%). Additionally, respondents indicated they found out about the survey from the National Hemophilia Foundation (16%), Hemophilia Federation of America (15%), their physician or health care provider (11%), and RareRising (7%). Note: Coalition for Hemophilia B conducted an exhaustive (email, print mail, social media) outreach as well as a direct outreach through family, pharmaceutical manufacturer, homecare, and beyond to encourage participation in the survey.

Figure 22. Survey Awareness
How did you find out about this survey? (select all that apply)



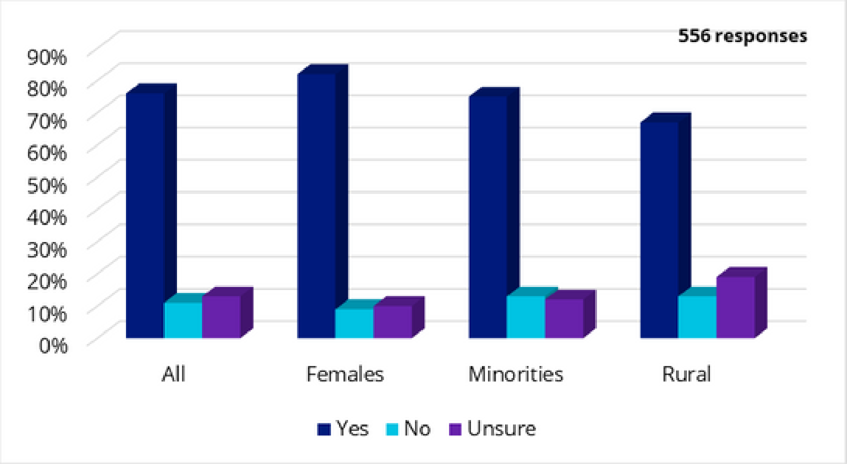
Detailed Findings by Group

Barriers or Gaps in Healthcare Access ••••

Survey respondents were asked if their healthcare provider provided information in their preferred language. We segmented this question into responses based on the following categories: all respondents, females with hemophilia B, minority groups, and rural patients. Most females with hemophilia B (82%) indicated they received information in their preferred language compared to minority groups (75%), and rural patients (67%). A higher percentage of the minority group (13%), and rural patient respondents (13%) indicated they did not receive information in their preferred language from their healthcare provider compared to females with hemophilia B (9%).

Figure 24: Care Related Information

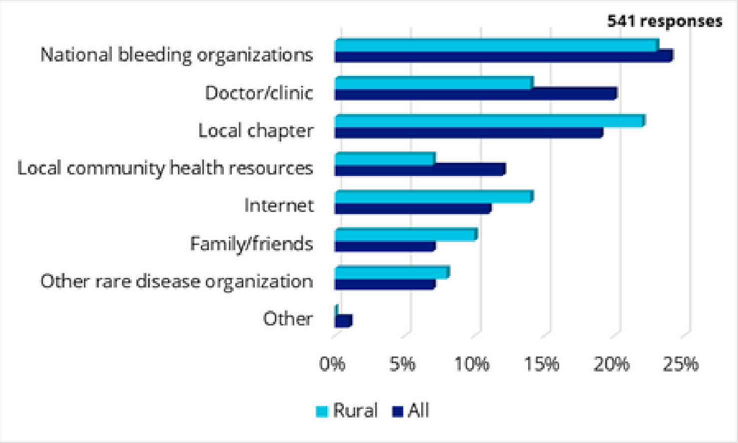
The information provided by your healthcare provider was given to you or your caregiver/family in your preferred language.



Survey respondents were asked where they received information about hemophilia B. We segmented this question into responses based on the following categories: all respondents, females with hemophilia B, minority groups, and rural patients. There were very small differences among females with hemophilia B and minority groups. However, among rural participants, there was a higher percentage of respondents who indicated they received their information from local community health resources (14%) and local doctors or clinics (7%) compared to most respondents.

Figure 25: Health Literacy

Where do you or your caregiver/family currently receive information for your hemophilia? (check all that apply)



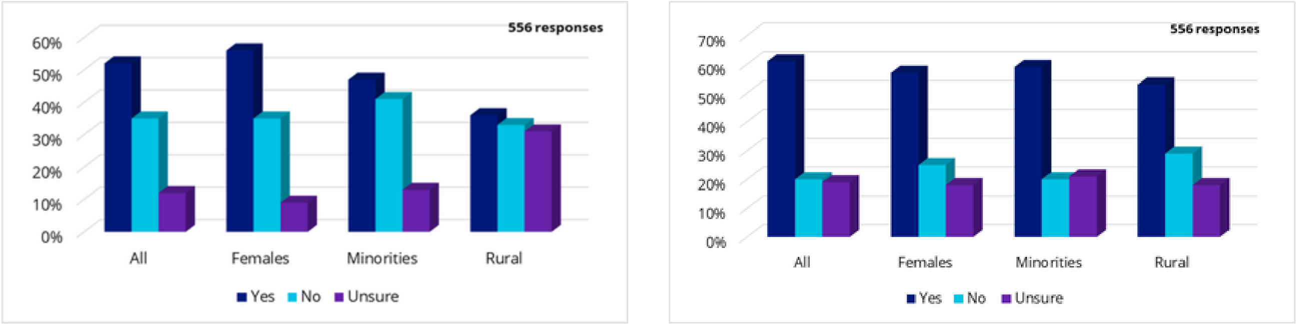
**We defined females with hemophilia as individuals who identify as female and as a person with hemophilia B. This was determined by responses to survey question #25 and #28.*

**We defined minority groups as individuals who identified as any category other than "White" by responses to survey question #29.*

**We defined rural patients as individuals who had to travel further than 50 miles to see a specialists for hemophilia care. This was determined by responses to survey question #16.*

Survey respondents were asked if they had to pay additional costs for their care. In addition, they were asked if their health insurance covers their costs for care and medicine. We segmented this question into responses based on the following categories: all respondents, females with Hemophilia B, minority groups, and rural patients. More females with hemophilia B (56%) indicated they had to pay additional costs for care compared to minority (47%) and rural respondents (36%). More minority respondents (59%) indicated their health insurance covers their costs for care and medicine followed by females with hemophilia B (57%) and rural respondents (53%).

Figure 26: Insurance Coverage Information



a. Do you have to pay additional personal costs for care and medicines for hemophilia in addition to insurance premiums?

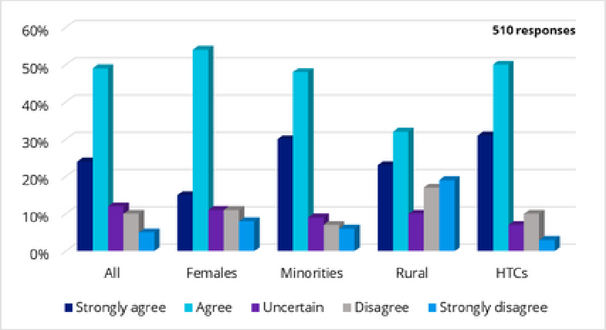
b. My health insurance or drug plan covers the cost for care and medicines for hemophilia.

Survey respondents were asked how they feel about the medical care they receive. We segmented this question into responses based on the following categories: all respondents, females with hemophilia B, minority groups, and rural patients. We also segmented this question into responses based on where respondents indicated they were receiving care: local health clinic, local community hospital, emergency department, academic medical center, other specialty hospital, hemophilia treatment center, and hematologist. A higher percentage of minority (30%) respondents indicated they strongly agreed that doctors are good about explaining the reason for medical tests compared to females with hemophilia B (15%) and rural (23%) respondents. A higher percentage of rural (22%) respondents indicated they strongly disagreed that the medical care they are receiving is just about perfect compared to females with hemophilia B (10%) and minority (8%) respondents. In addition, a higher percentage of minority (27%) respondents indicated they strongly agree that doctors usually spend plenty of time with me compared to females with hemophilia B (8%) and rural (13%) respondents.

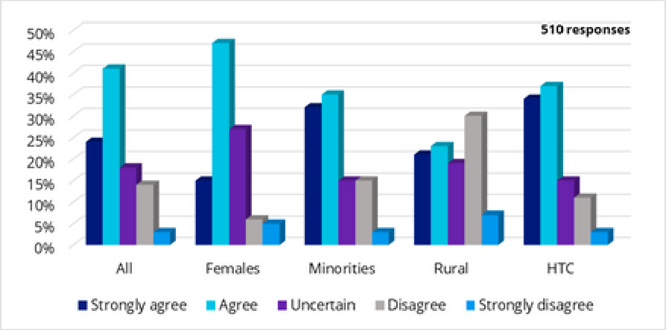
A higher percentage of respondents receiving care at a hemophilia treatment center (34%) strongly agreed their doctor's office has everything needed to provide complete medical care compared to those receiving care at a local health clinic (6%) or a local community hospital (13%). A higher percentage of respondents receiving care at the emergency room (21%) strongly disagreed that the medical care they received is just about perfect compared to those receiving care at a specialty hospital (5%) or a hematologist (5%). In addition, no respondents receiving care at the emergency department (0%) strongly agreed they have access to medical specialists they need compared to those receiving care at a specialty hospital (19%), a hematologist (19%), or a hemophilia treatment center (30%).

Figure 27: Care Related Information

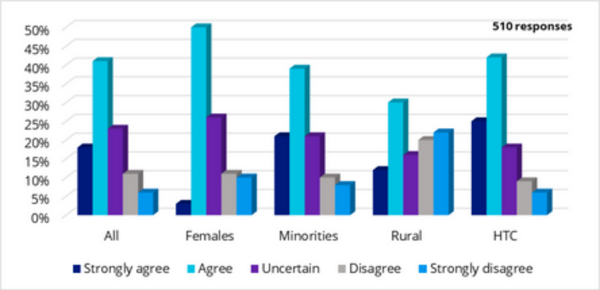
a. Doctors are good about explaining the reasons for medical tests.



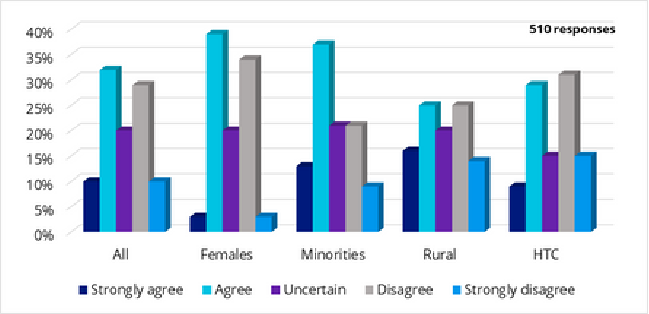
b. I think my doctor's office has everything needed to provide complete medical care.



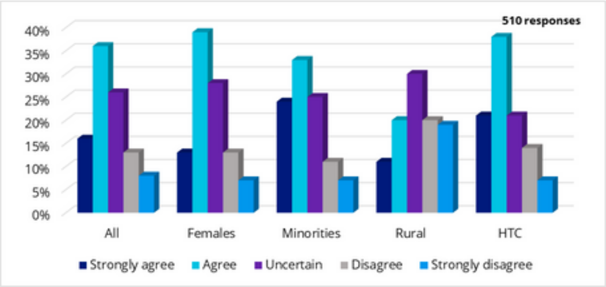
c. The medical care I have been receiving is just about perfect.



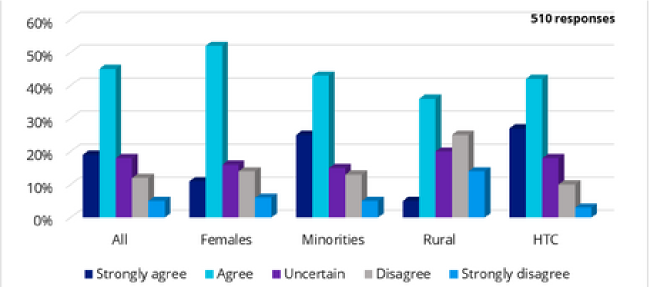
d. Sometimes doctors make me wonder if their diagnosis is correct.

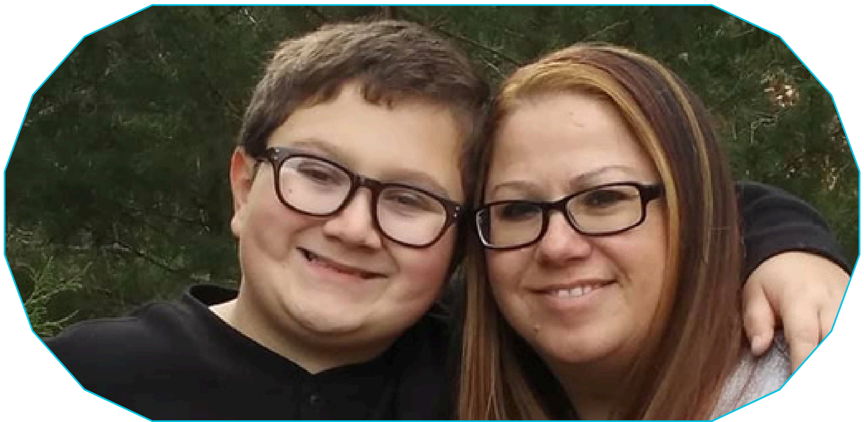


e. I feel confident that I can get the medical care I need without being set back financially.

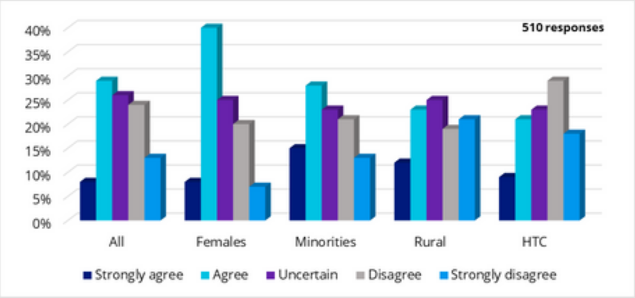


f. When I go for medical care, they are careful to check everything when treating and examining me.

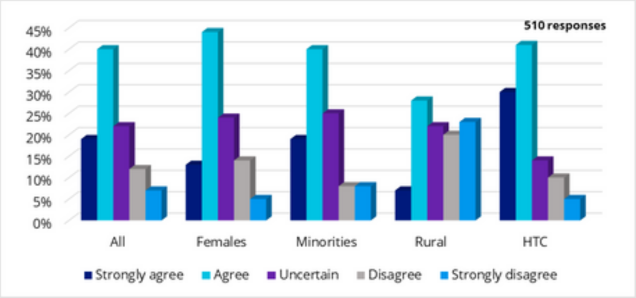




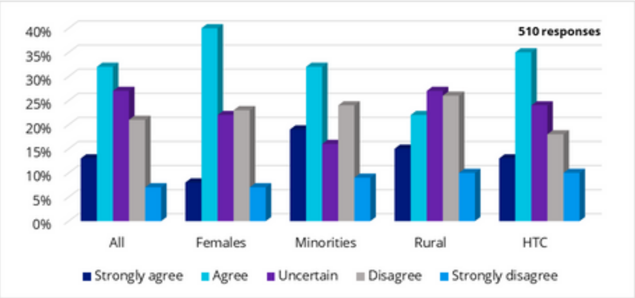
g. I have to pay for more of my medical care than I can afford.



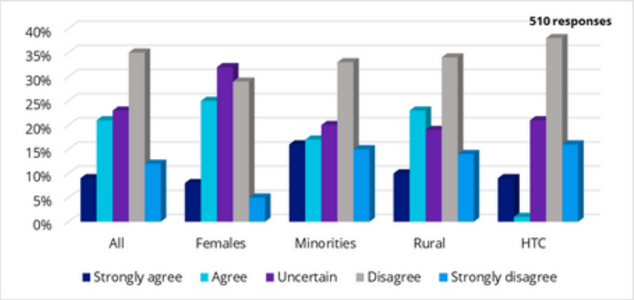
h. I have easy access to medical specialists I need.



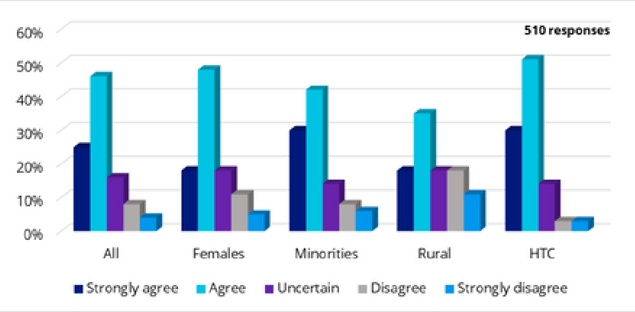
i. Where I get medical care, people have to wait too long for emergency treatment.



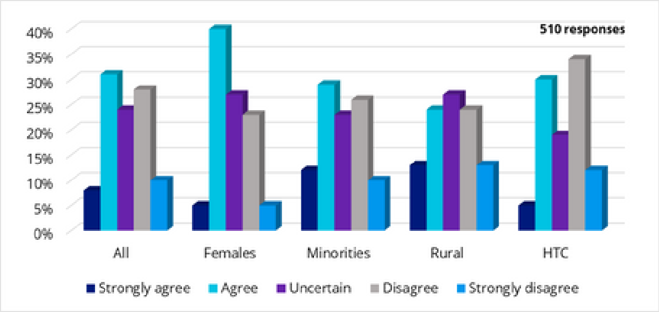
j. Doctors act too businesslike and impersonal toward me.



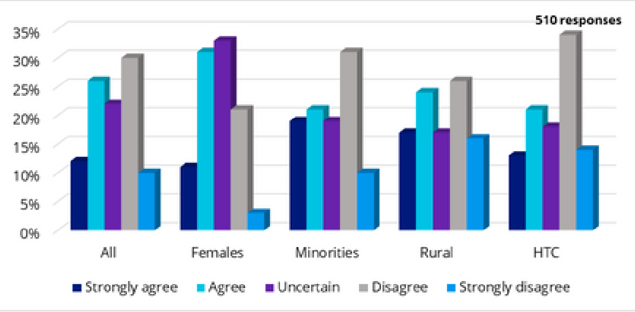
k. My doctor treats me in a very friendly and courteous manner.



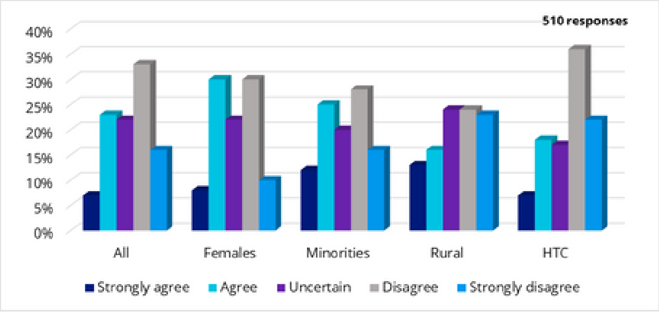
l. Those who provide my medical care sometimes hurry too much when they treat me.



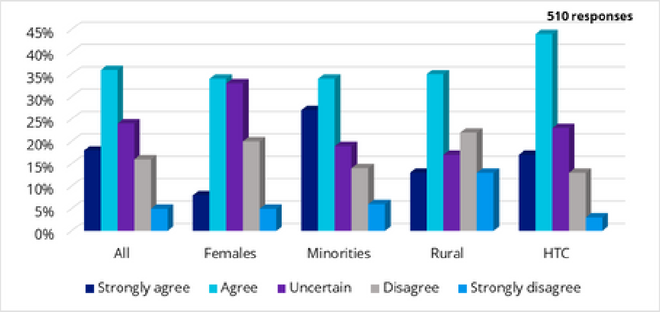
m. Doctors sometimes ignore what I tell them.



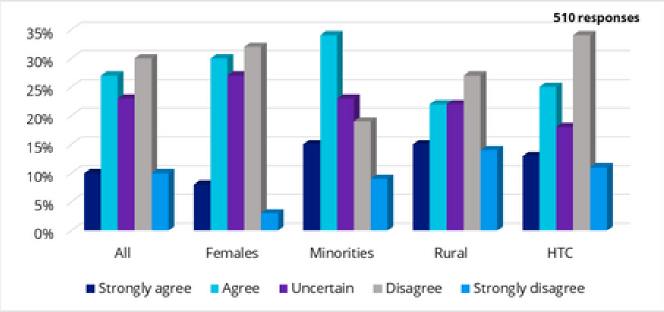
n. I have some doubts about the ability of the doctors who treat me.



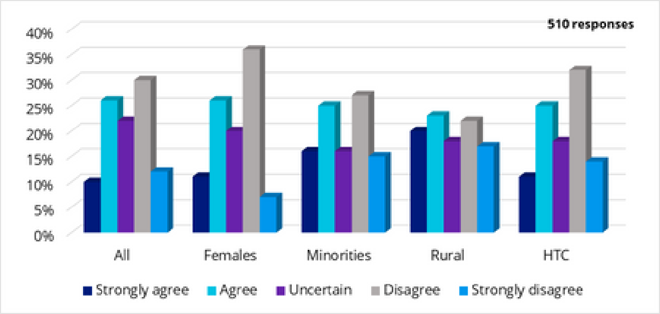
o. Doctors usually spend plenty of time with me.



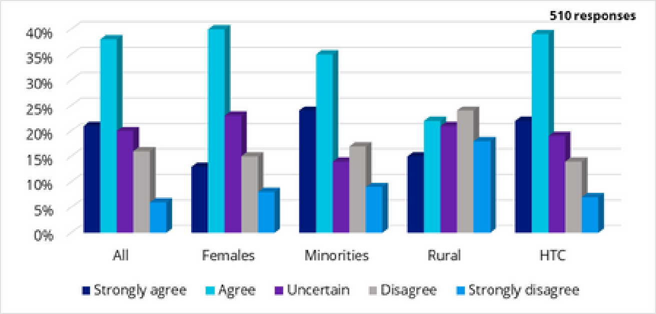
p. I find it hard to get an appointment for medical care right away.



q. I am dissatisfied with some things about the medical care I receive.



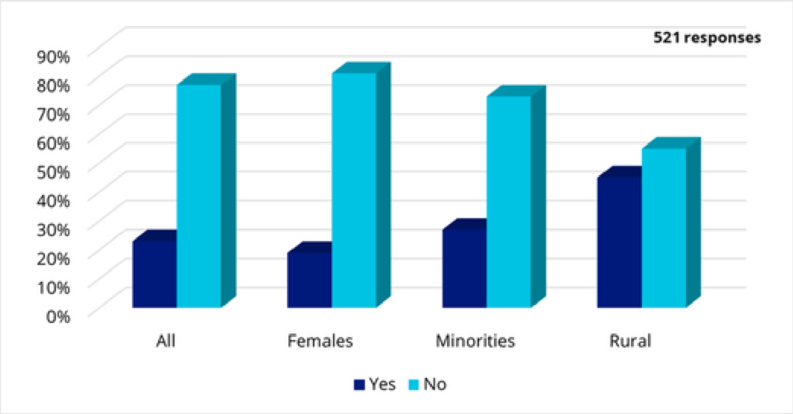
r. I am able to get medical care whenever I need it.



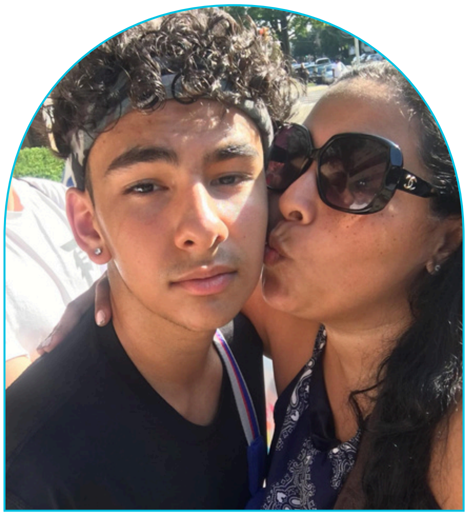
Survey respondents were asked if they ever felt they were denied access to a hemophilia specialist due to gender, race, geographic location, or any demographic factor. Almost half of the rural respondents (45%) indicated they felt they were denied access followed by minority (27%) and females with hemophilia B respondents (19%).

Figure 28: Care Related Information

Do you feel you are ever denied access to a hemophilia specialist due to your gender, race, geographical location (ex. Rural) or any other demographic factor?



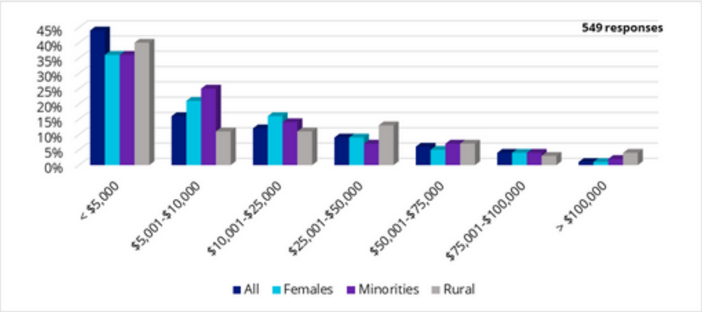
Remote rural patients may only be able to realistically access one location for care. Patients living less remote may have multiple options. They may be able to switch care providers.



Survey respondents were asked how much their family spends each year for travel for hemophilia care. We segmented this question into responses based on the following categories: all respondents, females with hemophilia B, minority groups, and rural patients. Over a third of female respondents with hemophilia B (36%) and minority respondents (36%) indicated they spend less than $5,000 on travel. Rural respondents (40%) indicated they spend the least on hemophilia B travel compared to females and minority respondents with hemophilia B.

Figure 29: Burdens

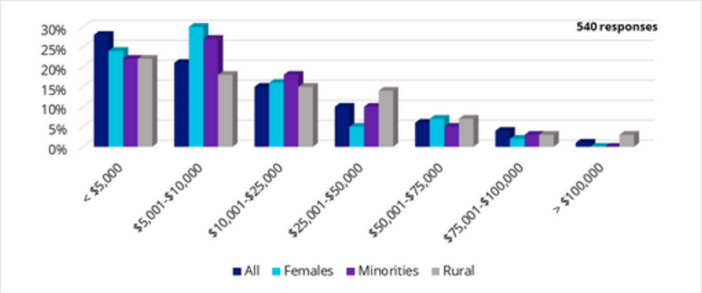
What does your family spend each year for travel for hemophilia?



Survey respondents were asked for estimates for wages lost to needing days off work for health reasons due to hemophilia. We segmented this question into responses based on the following categories: all respondents, females with hemophilia B, minority groups, and rural patients. Females with hemophilia B (30%) and minority respondents (27%) indicated similar responses losing between $5,000-$10,000. Fewer rural respondents (18%) indicated losing $5,000-$10,000 compared to females with hemophilia B and minority respondents. In addition, fewer females with hemophilia B (5%) reported losing $25,000-$50,000 compared to minority (10%) and rural (14%) respondents. Rural respondents (3%) were the only participants to indicate spending more than $100,000.

Figure 30: Burdens

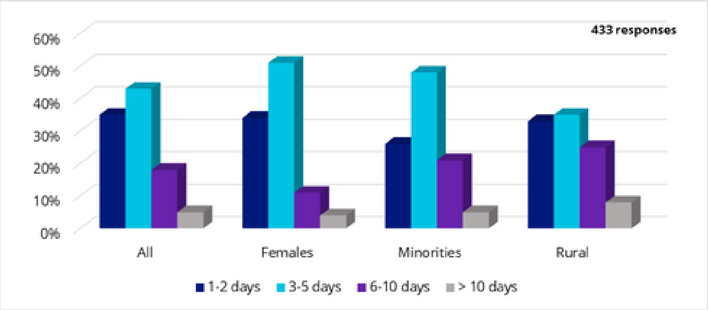
What would you estimate the amount of wages lost to needing days off work for health reasons due to hemophilia?



Survey respondents were asked how often their caregiver/family need days off work or school for health reasons due to hemophilia. We segmented this question into responses based on the following categories: all respondents, females with hemophilia B, minority groups, and rural patients. More females with hemophilia B reported needing 1-2 days/month and 3-5 days per month (34% and 51% respectively) compared to minority and rural respondents. More minority (21%) and rural (25%) respondents indicated needing 6-10 days/month. More rural respondents (8%) indicated needing >10 days per month.

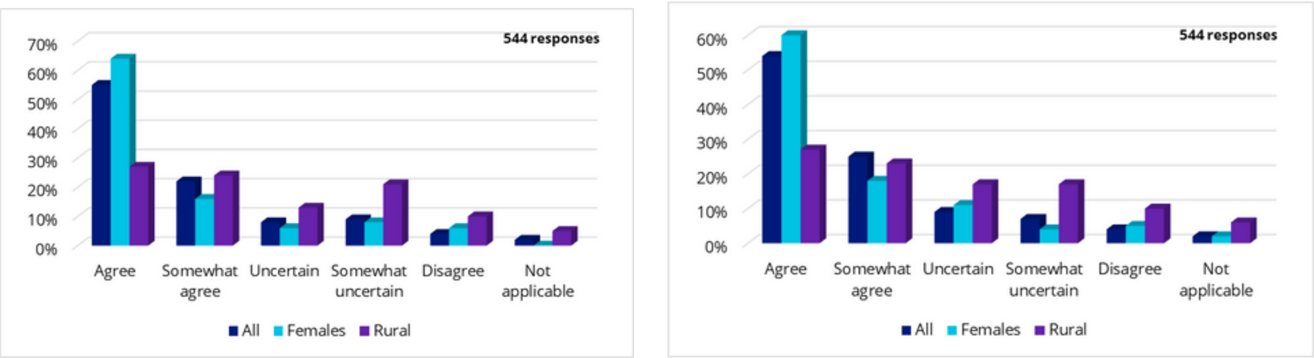
Figure 31: Burdens

How often, if at all, do you or your caregiver/family need days off work or school for health reasons due to hemophilia? (per month on average)



Survey respondents were asked how they felt about healthcare access, resources, and potential barriers. We segmented this question into responses based on the following categories: all respondents, females with hemophilia B, minority groups, and rural patients. More than half of females with hemophilia B (64%) and minority (53%) agreed they were receiving treatment that is timely to their needs. Only 27% of rural respondents indicated they agreed they were receiving treatment that is timely to their needs. In addition, 27% of rural respondents indicated they agreed they were receiving care and education from specialists and clinics who are knowledgeable about hemophilia B compared to females with hemophilia B (60%) and minority (54%) respondents. Compared to females with hemophilia B (7%) and minority (11%) respondents, rural (20%) respondents indicated they somewhat disagreed the information provided when diagnosed was helpful.

Figure 32: Healthcare access, resources, and potential barriers

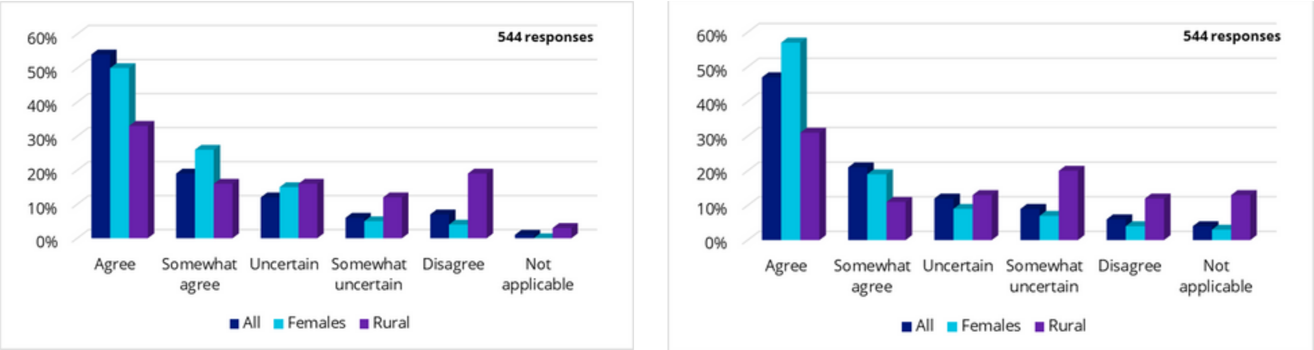


a. I am receiving treatment that is timely to my needs.

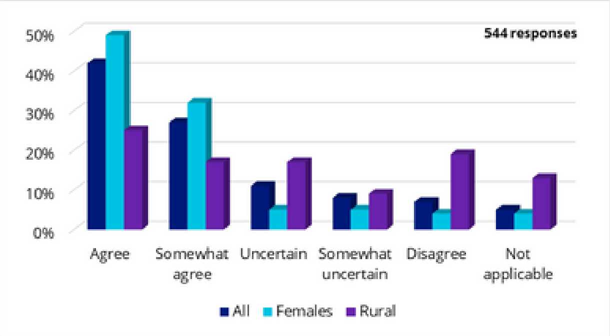
b. I am receiving care and education from specialists and clinics who are knowledgeable about hemophilia.

c. I am able to get access to the medications I need.

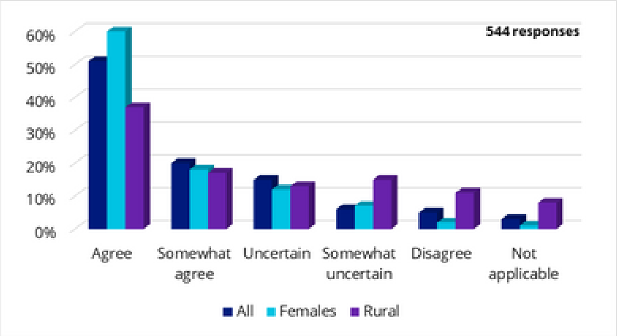
d. The information provided when you were diagnosed was helpful.



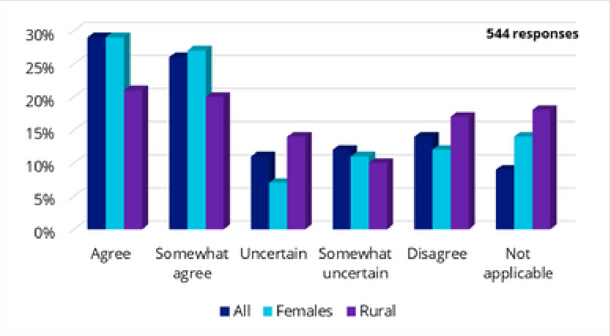
e. The information provided by your healthcare provider when you were diagnosed was clear and understandable to you and your caregiver/family.



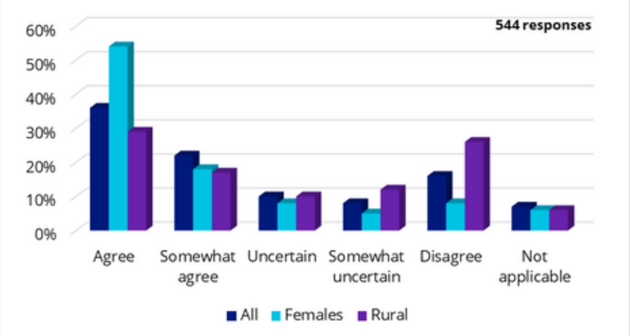
f. You or your caregiver/family currently have access to the information you need to understand and care for hemophilia.



g. You or your caregiver/family often need to take unpaid leave for medical reasons.



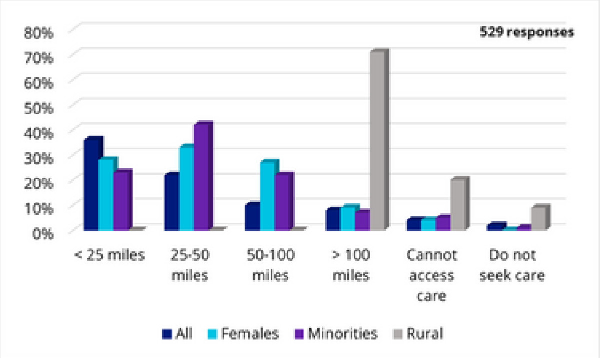
h. You or your caregiver/family have had to leave a job or reduce work hours because of hemophilia.



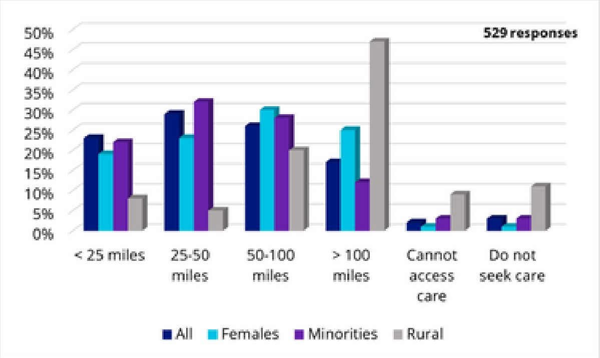
Survey respondents were asked how far they have to travel for care. We segmented this question into responses based on the following categories: all respondents, females with hemophilia B, minority groups, and rural patients. The majority of rural (71%) respondents indicated the need to drive between 50-100 miles for regular care compared to females with hemophilia B (27%) and minority (22%) respondents. A higher percentage of rural (20%) respondents also indicated they needed to drive more than 100 miles to access regular care compared to females with hemophilia B (9%) and minority (7%) respondents. In addition, almost half of rural (47%) respondents indicated the need to drive more than 100 miles for specialist care compared to females with hemophilia B (25%) and minority respondents (12%).

Figure 33: Travel

a. How far do you need to travel for regular medical care related to hemophilia?



b. How far do you need to travel to see specialists for hemophilia?



Individual/Focus Group Interview Findings

We conducted nine focus group interviews with 37 participants and four individual interviews with four participants, all of which elicited insights into barriers or gaps in healthcare access, patient/provider communications, patient advocacy organizational services and support, and patient engagement within the hemophilia B community. Participants received a $50 gift card for their participation. See Table 2 for more specific information on focus groups and individual participants.

Table 2: Individual Interview/Focus Group Overview

a. Focus Group Categories and Participants

Males with hemophilia B (age 31 or older) 3 participants	Males with hemophilia B (age 31 or older) 2 participants	Female caregivers (age 31 and older) 4 participants
Male caregivers (age 18 and older) 2 participants	Female caregivers (age 31 and older) 5 participants	Females with hemophilia B (age 18 and older) 5 participants
Young adults with hemophilia B (age 18-30) 2 participants	Females with hemophilia B and caregivers 3 participants	Spanish-speaking all participants 11 participants

b. Individual Interview Categories

Female with hemophilia B & caregiver (age 31 and older) 1 participant	Female caregivers (age 31 and older) 1 participant	Females with hemophilia B (age 18 and older) 1 participant
Male with hemophilia B (age 31 and older) 2 participants		

Hemophilia Treatment Center Experiences

Many focus group/individual interview participants expressed their gratitude for the hemophilia treatment centers (HTCs). They described how being a part of the HTC has changed their care and overall experience. For example, one participant stated,

> “We are very grateful or thankful to have an amazing team at our hemophilia treatment center. I know I've heard other people say like, oh, my gosh, our HTC is horrible. I couldn't even imagine where I would be at if I didn't have the team that we have ..., and, you know, just everybody at our ...HTC. Because they are amazing.”

Another participant stated,

> “....our hemophilia treatment center is phenomenal. It [is phenomenal]. Yeah. So between [the social worker that they have there are, you know, ... nurse, a doctor. They are amazing]. When I was talking with them, they were like, Okay, we're going to do this, this, this and this. And we need you to do this, this and this.”

Although many participants expressed great experiences with their HTC, some identified barriers related to access to resources with limited social workers, and case managers. For example,

> “[En nuestro] HTC tenemos una hematóloga excelente, una hematóloga que nos da herramientas a nosotros como padres para poder llegar a las asociaciones y a los lugares correctos. Tenemos nuestra enfermera, pero no tenemos el trabajador social, no tenemos el manejador de casos ni los recursos adicionales.”
>
> ["In our HTC], we have an excellent hematologist, a hematologist who provides us as parents with tools to reach the right associations and places. We have our nurse, but we don't have a social worker, we don't have the case manager, or the additional resources.”

Other participants discussed the numerous benefits of receiving care at a HTC; however, they also expressed how some HTCs could become intrusive even feeling they wanted to treat their lives rather than just serve as the healthcare facility. For example,

> “And also dealing with a lot of the HTCs...They have, not all of them, but a good share of them have ‘God Complex’ and they get so entwined in your life. It's like not only do they want to treat your hemophilia, they want to treat your life period. Basically, it's like, oh, you can't do this, or I need a drug. Oh, no, no, you can't get that we're not we won't provide it.”

One participant shared her personal experience of identifying as a female with hemophilia B and the lack of care she received from her hematologist. She stated,

> “And then I still have like, I have a hematologist who basically says, like, when I had my son, I was supposed to go see him. And he just called me and he's like, I don't really think you need to be seen. And then never saw me. And then I'm supposed to get factor for my wisdom teeth. And the oral surgeon will not do it unless I have factor. And the hematologist won't give me factor. I've had my wisdom teeth for five years.”

Provider Communication ••••

Many participants discussed the benefits and strengths of communicating with their providers. Some expressed satisfaction with how their providers answers their questions even to the point of feeling like family. They enjoyed having these personal connections with their providers given that oftentimes they had to seek care frequently. For example,

> “[The HTC] gave [the clinical trial as] one of our options. So, when we got his diagnosis at our first appointment with [our] HTC, they gave us four different medications to choose from. And one of those four was the study. And I really, I asked a bunch of questions.... Like, like, what are your concerns about it, you know, and they said, we really, honestly don't have any concerns about this drug... And so that's what we ended up going with, but we had questions about the other drugs that they gave, you know, options that they gave us and they were able to answer those just as well as they did with everything else. And so, again, like we are so fortunate to have our team at the HTC and have them be so knowledgeable and so caring.”

Other participants discussed wanting to change their medications for various reasons and receiving pushback from their providers. They felt that oftentimes their providers tell them what medications they should take without considering their specific needs or asks. For instance,

> “Ahorita ya estoy batallando, es que no quieren aceptar a veces los nuevos medicamentos. A mi. Que uno va y les diga, “O, mira, yo quiero probar este.” No, ellos quieren que tu uses el que ellos te dan. Es más, ni si quiera te preguntan. Te dicen, “Vas A usar ahora esto.” Y por ejemplo. Como yo, que ya tengo muchos años con información y esto, como por ejemplo ahora, yo siento que el mío no le está sirviendo al que lo cambiaron, tiene unos meses y ha tenido muchos sangrados, y usted está usando dos factores al mismo tiempo. . . .Y yo le dije ¿Por qué me van a dar dos si no se supone que le quitaron el port para que le probara un medicamento que ustedes le dieron? Y por que cuando tiene sangrados tiene que usar el que ya usaba por muchísimos años? Ahorita el esta usando dos... No quieren aceptar lo que uno les lleva aunque uno les explique, mire, me explicaron esto y esto hay nuevas opciones. Para. Ellos, ellos están bien y uno está bien.”
>
> [“Right now, I'm struggling because sometimes they don't want to accept new medications. Like in my case. You go and tell them, “Oh, look, I want to try this.” No. They want you to use what they give you. Moreover, they don't even ask you. They tell you, “You're going to use this now.” And for example, like me, who has a lot of years of experience and knowledge, like now, I feel that mine isn't working for him since they changed it; he’s had many bleeds, and you're using two factors at the same time. . . . And I said, “And why are you giving him two if didn’t you remove the port so he could try a medication that you were giving him? And why, when he has bleeds, do I have to use the one I've been using for many years?' Right now, he's using two... They don't want to accept what one brings them even if one explains to them, look, they explained this to me and there are new options. For them, they're fine, and everything is fine.”]

Other participants felt the communication from their providers wasn’t clear enough in terms of long-term medication side-effects. Oftentimes, they felt they were given information that did not provide a full scope of what the future entails in terms of their long-term healthcare goals. For example,

> “You know, I feel like with any drug that you are on for a continuous basis, I feel like your body may get used to it. You know, so my body is accustomed to this one drug? Is it still gonna have the same effects? Or will it change? You know, I'm saying that's, that's my question. You know, is this still gonna be helpful for me 10 years later? Or do I need to switch this up? And like, I don't know how this medication works, you know? So I [feel like when I asked those kind of questions, I don't really get a real response]. Is it still working? Okay, cool. Yeah. So no long term thought. Yeah, and that's my question.”

Some participants expressed initial satisfaction with their healthcare providers only to have their healthcare team change due to various reasons. Once their team changed, they expressed reduced communication with their provider which has resulted in a completely different experience. They mentioned,

> “Yo con mi anterior que estaba era perfecto. Ellos me decían todas las opciones que tenía desde psicólogo, el terapista, la trabajadora social, el doctor. Tenía todo un equipo completo que me ayudaba. Cuando me cambié de HPC a otro, la doctora me dijo Este factor es el que va a usar. No me dijo “Quiere usar este?” Me dijo “Este es el que va a usar.” Le dije “No, ese no va a usar. Va a usar este porque este es el que yo quiero, porque es de larga duración.” Entonces me dice Pero es que este es mejor, le dije. “Lo siento, pero no.” A raíz de eso, yo voy y me ve lo básico. Lo básico no me lleva con los demás especialistas, ya no. Entonces, también muchas veces esa es una barrera que hay.”
>
> [”With my previous [provider], everything was perfect. They told me all the options I had, from psychologists and therapists to social workers and doctors. I had a complete team that supported me. When I switched to another healthcare provider, the doctor told me, 'This is the factor you’re going to use.' She didn't say, 'Would you like to use this?' She said, 'This is what you’re going to use.' I told her, 'No, I’m not going to use that. I’m going to use this one because it’s the one that I want because it's long-lasting.' She said, 'But this one is better,' and I said, 'I'm sorry, but no.' As a result, I only get the basics now. The basics. They don't connect me with the other specialists anymore. So, many times, that's also a barrier.”]

Female Experiences with Hemophilia B ••••

Many females expressed very unique experiences to finding out they had hemophilia. Many of these experiences were life threatening and changed how they felt about accessing care in the future. For example,

> “So during my emergency C section, I actually bled out. And instead of them checking me to see if I had hemophilia, they gave me blood transfusions... So three months later, I had to take my fitness test. I'm out there doing push-ups and sit ups and running, doing a two mile run and doing this exercise. My incision actually burst - it was oozing... So years past ... My doctor saw cysts on my ovaries and he wanted to remove them. So of course, he asked for my family history. I told him hemophilia runs in my family. He was like, well, I'm not touching you until you get tested for hemophilia. And I was like, well, they said, I couldn't have hemophilia]. So I went to a hematologist and sure enough, I tested and my levels came back at like 12% factor nine deficiency. So needless to say, that was kind of like a gut punch. Because for years I've known something was wrong with me. I would just bruise easily. I bleed like crazy doing my menstrual. But that was my norm. So I didn't even know that wasn't normal.”

Another participant stated,

> “I got my tubes tied and my whole stomach blew up. I barely made it out our car. And my shirt got warm. And I looked down and saw a blood clot this big come out of my stomach. So I ran back, waddled back in there, like something's wrong. The next few days, my whole stomach was bruised from getting my tubes tied. And I kept calling and saying the wounds not closing and there’s a huge blood clot in there. Something's wrong. They keep telling me to just put pressure on it. So, I finally went in to see my normal doctor, two weeks post-surgery and I still had a gaping hole in my stomach and they handled it. That's why I'm terrified of surgeries. I hear so many like horror stories about healing from surgery that I won't have anything else done.”

Other participants expressed a lack of resources available for women who have hemophilia. Although they were happy to receive a diagnosis, they felt it didn’t really change their overall access to care. Many physicians were not equipped with the appropriate knowledge to provide them with a care plan. For example,

> “The issue that I had with my providers, is once I found out that I do, in fact have hemophilia, there were no resources for me. You know, saying like, Okay, you got hemophilia. Okay, cool. But I've been living my life, all this time, not knowing. So why does there have to be a difference in how I care for myself? You know what I'm saying, and that part wasn't presented to me. I still don't feel like they view me the same as my son. And that's not okay. It's like why don't I have a real treatment plan? And why is it that I have to present questions to you in order to make something happen. So should I be getting a weekly factor? I don't know. You know, I don't know, because nobody's actually done any kind of real test on me.”

Some women expressed satisfaction with their care. They felt their providers were knowledgeable and provided them with the care they needed. For instance,

> “I will say as far as the treatment is concerned, once I found out they were more than willing to accommodate me. I don't have a problem getting factor when I need it. The biggest issue that I have is questions on medication. Like, I've been on his medication for an extended period of time. Is my body going to get used to it? Should I switch? And when I have those kinds of conversations, I don't feel like they want to listen as much, you know. But what's hurtful for me is all the other stories that I hear from women who have bleeding disorders, who can't get the medication, can't get the treatment, who struggle getting the diagnosis.”

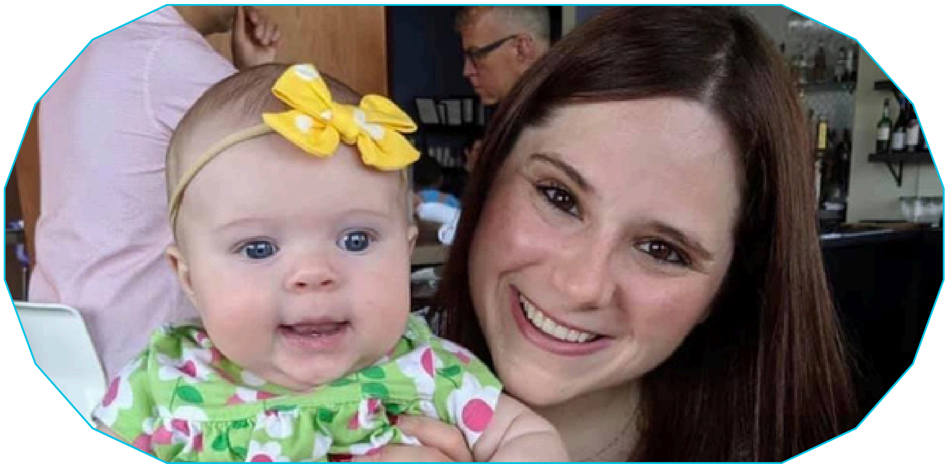
Many women discussed the lack of knowledge and acceptance with women being diagnosed with hemophilia. They mentioned how this lack of acceptance can present issues within their own families. For example,

> “I mean, one of the nurses has been doing this for like 40, almost 50 years. She was welcoming to the idea that women have issues, okay. So she advocated for me to get a hysterectomy. And I've got prophylaxis care for joint damage. So that's been really helpful. And to the opposite point of that, like I have family, my brother is a hemophiliac. And the way that he was raised in it, he is very bitter about me being diagnosed. So as a female in this particular area, like even being here, it's really hard for me to accept and talk about like, I'm a hemophiliac, and yeah, my percentages are 47%. I'm a bleeder. Like, I know this because my knees get huge and my arthritis is so bad that I'm going to need a knee replacement. I've almost died having surgeries before and, like, you know, you lose the ability to have kids and that's like all of that stuff is a lot, but it's hard to, to discuss it with other people and like, take ownership of, I'm diagnosed with this and it's okay.”

Insurance Company Barriers and Supports ••••

Some participants described how difficult it can be to have a drug approved. They felt the insurance was more worried about looking out for their bottom line at the expense of potential serious side effects for their child. For instance,

> “Well, they submitted [the claim] to insurance and insurance denied it. And so, I called them. And they're like, it isn't covered on your plan. But we'll let you take out another drug. And I was like, No, we're not switching like what are you talking about? This is my doc, my son's doctor is, prescribing this life saving medication. And you're telling me you're not going to cover it, but you'll cover something else. Like I get it. It's like Coke and Pepsi. But switching has so many other like, just scary side effects and, you know, things that can happen, like to switch for no reason, just because the insurance doesn't want to pay for it like no. So it was about three and a half months of appeals letters. Why can't insurance just see the person side of things? Why is it so difficult? Like, the insurance companies, they just look at that, you know, that bottom number and they see like, oh, gosh, that's gonna cost us a lot of money. Yeah, but this one won't. Let's just have them switch, you know, but in the meantime, like, my kids are thinking, you know, they're gonna die, or their brother's gonna die. And it's terrifying.”



Many participants expressed the difficulty of trying to navigate insurance companies even for those who have a medical background. They emphasized how overwhelming it could be for others with limited healthcare knowledge. For example,

> Una de las barreras que a mí se me dio el año pasado fue aseguranza médico. Tenemos que aprender a navegar cómo navegar lo que es el mundo médico en referencias, cuáles son tus derechos, aprobaciones, denials, que apelen y todo eso tenemos que aprender porque son barreras muy grandes. . . . Trabajo yo en un centro médico, entonces más o menos sabía que eso se tenía que hacer, pero luego me pongo a pensar y la gente que no tiene conocimiento cómo navegar lo que es el centro de lo que es medicina, doctores, aseguranza, autorizaciones, me siento mal porque digo, si yo la estoy batallando bien mucho y de repente te intimidan porque estás hablando con una persona que es profesional, que es especialista y tú le dices lo opuesto, pues te intimidas, pero son unas de las barreras bien grandes.
>
> [“One of the barriers I faced last year was medical insurance. We have to learn how to navigate the medical world in terms of references, knowing our rights, dealing with approvals and denials, appealing decisions, and all that we have to learn because these are very significant barriers. . . . I work in a medical center, so I kind of knew that these things needed to be done, but then I think about people who don't have knowledge about navigating the medical system, doctors, insurance, authorizations, and I feel bad because I think, if I struggle so much with it and suddenly you get intimidated because you're talking to a professional person, who is a specialist, and you contradict them, well, you get intimidated, but these are some of the big barriers.”]

One participant mentioned how they persevered through having an insurance appeal overturned for their child. They expressed the importance of having a support system to assist through a process that can be very difficult for families. For example,

> “People at the insurance were like, well, you know, if you and your husband get a divorce, and you go on government insurance, all of this would be provided it wouldn't be a problem. Thanks. Thanks for the advice. You know what I mean? Like, are you kidding me? Yeah. One lady was like, Are you sure that your son really has hemophilia A, and that he needs this medication? And I was like, No, you know what he doesn't. I said he has hemophilia B. Like, I just need to talk to the same person. Yeah, you know what I mean? Like, I'm done talking to like, 12 different people, every time I call. And, you know, like, I'm not redoing this. And I think like the persistence, the help of the team that you know, that we have or that I was able to reach out to and have access to that that's how we were finally able to get it you know, the appeal overturned and get it approved, but it's only approved for a year.”

A few participants discussed great experiences with their insurance providers; however, they emphasized how important it was to know how to navigate your insurance company. For example,

> “We have a certain type of insurance, which can be a nightmare, unless you know how to navigate it. But we have not paid one dime for anything, not his factor or not anything. So it's a blessing it is, you know, socialized healthcare, if you know how to navigate it really well. So that's something that's been really great, because I know a lot of people have to pay really big cost for things. But we've been very lucky with that.”

Some participants discussed how different the world is now in terms of access to care and good health insurance. They expressed how even if you have access to insurance, it doesn’t mean that it is the best for your condition. For instance,

> “When I first started off in the professional realm of hemophilia. I was working for a chapter and our model was okay, we taught in our meetings that the kids need to go to school, get good grades, get a good job, get great health insurance, and they will be taken care of for the rest of their life if they can do that. And that's not really true anymore. Because the great job doesn't guarantee great insurance. And you know, insurance doesn't always equal great. And even if it's great for your coworker who has diabetes, it doesn't mean your bleeding sores are going to be included in that and it's going to work for you. There's always going to be a battle, it's, it's not cut and dry anymore.”

Hemophilia Organizations and Resources

Participants expressed their satisfaction with the level of resources they have access to, especially from the Coalition for Hemophilia B. They mentioned how coalition leaders played important roles in solving hemophilia issues that affected their family.

> “So, I called the coalition. And I was, (filler), of course, in tears. She's like, oh, my gosh, okay, we got this, we're going to do this, we're going to do this, then I called our local chapter, and they were helping. They linked us to one lady at our chapter, she deals with insurance, they said she can help navigate you through insurance. And then, (filler), just like the people who I've met throughout the community, I called other moms, Hey, did you ever have this problem with your insurance? What did you do? How did you do this? (filler), knowing the people who I knew, (filler), thank God that I finally reached out to the community, because I don't think I would have known what to do at that point. (filler), and lucky for me, everybody who I thought of they were like, we will help you. Yeah, we can do this. (filler) I couldn't even imagine where we would be without them.”

Many participants discussed how the hemophilia community is like their family that continues to grow. They felt the community was so important in terms of being able to relate to each other and the importance of not feeling alone. For example,

> “The hemophilia community (filler), it's like a family in a way. Because, I mean, there's a reason why we call each other like blood brothers and everything and blood sisters, you feel me? (filler), if we’re like undergoing like any struggle, like by ourselves, you know, we can always like, look towards, (filler), someone with more experience with hemophilia, to kind of like vouch for us for like, the situations that we're going through, (filler), when we feel, you know, alone, but in reality, we're not necessarily alone it’s just that we're not looking in the right directions, or like the spots, (filler), I feel like that's like my experience with the community.”

Others expressed how the community has been there for them in so many ways such as assisting with limited resources of factor and also professionally. For instance,

> “I had a bad bleed. And it was my last dose. And I didn't have any more factor for that week. And so they helped me out with factor. This is why I say I love this family too, because you know, it's your people, but it also gives you the opportunity to share your story in a more productive way. Because I have gotten so many opportunities, participating in councils, being part of committees, speaking. So, I'm a patient advocate.”

Many women participants talked about how important it was to have access to hemophilia meetings and resources. They discussed how they've learned so much from the community especially information related to women with hemophilia. For example,

> "So maybe in 2019, I did a women's retreat. For women with hemophilia, it's like, wasn't more like about your kids, it was more like you're a carrier. You could have hemophilia. And it was talking about those kinds of things. And that was incredible. I met some incredible people there. And then last year, I got to go with the coalition to Arizona for another women's retreat, which was incredible. And that's kind of what made me be like, okay, we can do symposium, because I still am, like, nervous about not knowing enough, or, you know, what, if somebody asked me a question, and I don't know, or what if I don't understand this and, and at first, it was so terrifying. And now it's like, these women, you know, they're not here to be like, Oh, that girl doesn't know what she's talking about. They're like, hey, you need to know this a little bit better. Let me help you figure it out. And they're like, they're so welcoming. Like, every time you leave an event with the coalition, I was telling my mom like you're gonna leave and your heart is going to be so full. The more that we are learning we're like, this is normal, and like you just leave feeling so fulfilled and just so ready to like, take on the world, you know?"

Hemophilia B History ••••

There were many participants who expressed how important it was to keep the history of hemophilia alive. Hemophilia has such an important history that is filled with some negative incidents, but they also emphasized how important it was to not dwell on the past. One participant mentioned,

> "(filler), this community as far as advocacy, (filler), we went through it. Seeing our friends and family members die. (filler), it really brought the community together. And that's when the anger was evident, (filler) there was anger at that time. Now, it's changed. You want people to remember, you know, the past, but you don't want to dwell on the past, but (filler), people and the younger ones need to understand that stuff did happen, (filler)."

Other participants expressed the history of having access to bad blood and how it affected the hemophilia community. They stated,

> "In the early 70s, that's when the concentrate that we take now came out. But that concentrate was made from whole blood. Where they were getting that blood, a lot of times was very sketchy such as prisons. They weren't testing it. They knew it was bad. It was pharmaceutical greed. It was they knew and they lied to us. Some people knew and they said, don't worry, you know, go ahead and continue to use the product and stuff. A lot of people took them for their word, and you were infected at that time."

Another participant expressed the frustration with being experiments and the anger during that time in hemophilia history. He stated,

> "We were the, as one of our friends describes, we were the canaries in the coal mine. (filler) why is this community dying? (filler) it was tough when it really hit in the early 80s, because it was described as a gay disease, (filler), because the homosexual community was dying and then there's this subset of these bleeders dying as well. And so getting separated was tough because when it first hit, it was like, (filler), it's just this group of people dying and we don't really care. But finally, we were able to get enough voices you know that it was out there, but that's (filler) where the anger came from. They knew about it. They lied to us. Just for the greed. Factor has been very expensive, forever. And they were making a lot of money off of it. So it was a dark, dark time."

More participants emphasized the importance of having mentors as a young individual with hemophilia and how important it is to share the history with the newer generation of individuals with hemophilia, so they can continue to fight for legislative rights. For instance,

> "I'm lucky I had some really great mentors throughout my life. When I turned 18, I met some awesome men, may they all rest in peace, and the few that are still alive, like me, they keep the fight going. But they put the fight in me that I could expect more. And unfortunately, not everybody has that exposure. And I think that's where on the chapter level when the organization nonprofit level, where we have to show our younger community members, you know, you know, 40, 30, 20s, that, you know, you have to stay vigilant, because everything disappears, you know, it can all be taken away. You know, we didn't get, you know, clean medication, the moment we found out, it was dirty, it was tainted, right. You know, 10,000 people had to get, you know, infected and then we had to spread it amongst our own community first before anything really happened. So they need to know."

Language Barriers ••••

Many participants discussed the importance of hosting events in Spanish and how important it was in bringing the community together. They expressed how helpful it is to have information in Spanish for the Spanish-speaking community. For example,

> <<Yo lo que iba a comentar es lo primero es buscar todas las asociaciones que tenemos cerca de nosotros. Ellas generalmente tienen diversos eventos de todo tipo. Obviamente, lo importante es saber que nuestra asociación ofrece eventos en español, que eso es lo más importante, porque si no, acabamos en la misma historia. Pero hay muchas asociaciones que realmente ya están dando mucha información en español. Eso es lo importante, o sea, para conocer otras familias, para escuchar cómo se están manejando y hay diferentes sesiones que se ofrecen, por ejemplo, de todo tipo, ¿no? Este psicológico o cómo manejarse en pareja. Simplemente también los niños es importante que participen en esos eventos. Al principio, igual mi hijo decía <¿por qué a mí?> Y yo pensaba que yo era la única que estaba así como soy la única que está en esto. Pero cuando te acercas a las asociaciones, te das cuenta de que hay otras familias que están pasando por lo mismo.>>
>
> ["What I was going to say is that the first thing to do is to look for all the associations we have near us. They generally have a variety of events of all kinds. Obviously, the important thing is to make sure our association offers events in Spanish, which is the most important thing, because otherwise, we end up in the same situation. But there are many associations that are already providing a lot of information in Spanish. That is what's important, I mean, to meet other families, to hear how they are managing, and there are different sessions offered, for example, of all kinds, right? Psychological sessions or how to manage as a couple. It's also important for the children to participate in those events. At first, my son would say, 'Why me?' And I thought I was the only one going through this, like I'm the only one dealing with this. But when you get closer to the associations, you realize there are other families going through the same thing."]

Other participants emphasized the importance of advocacy within the Spanish-speaking hemophilia B population. They mentioned how important it was to make this community known by making their voices heard throughout the community in order to have their needs met. For instance,

> <<Tenemos que hacer presencia, porque muchas veces lo que pasa es que ellos dicen <No hay nadie, nadie habla español, en esta comunidad nadie habla español,> porque a veces lo que pasa es que no participamos, porque no entendemos. Entonces, para ellos no existimos, porque como no hay nadie que hable español, como si no existiéramos. Entonces, lo que tenemos que hacer es, como esta vez, ¿cuántos sabemos? No hay ninguna sesión en español, pero tenemos que hacer presencia y pedirla.>>
>
> [“We have to be present, because many times what happens is that they say, ‘There’s no one, no one speaks Spanish in this community, no one speaks Spanish,’ because sometimes what happens is that we don’t participate, because we don’t understand. So, to them, we don’t exist, because since there’s no one who speaks Spanish, it’s as if we didn’t exist. So, what we have to do is, like this time, how many of us are there? There’s no session in Spanish, but we have to be present and ask for it.”]

Another participant stated,

> <<Yo creo que las cosas de abogacía, como bien ella dice, se están trabajando. Van como que a paso un poco lento, se están trabajando, pero una de las cosas que tenemos que abogar claramente es lo que están diciendo, que no importa en qué estado estemos, en qué territorio estemos, debemos abogar, porque esta información en español quizás una de las cosas que podemos solicitar de primera instancia, que sea más rápido que los programas que aunque estén en inglés hay un traductor. Porque podemos empezar por ahí, eso es mucho más rápido que quizás tener la información impresa en español, pero tenemos que abogar por eso, decir presente, yo en mi caso, admiro mucho a esa familia porque sin tiener mucho conocimiento en inglés y vinieron a un programa totalmente en inglés y eso es abogacía, eso es lo que ellos están haciendo es abogacía. Así que, para mí, yo creo que podemos empezar por ahí, solicitar eso a esta comunidad que es muy bonita, que es la coalición y decirles <mire, somos una comunidad latina que de hecho este año lo estuve el año pasado, este año he visto más latinos que el año pasado, que el año pasado.> Y para mí es una necesidad y entiendo que a cierto punto debe ser obligatorio, porque los latinos somos muchos en Estados Unidos.>>
>
> ["I believe that the matters of advocacy, as she rightly says, are being worked on. They are progressing somewhat slowly, but they are being worked on. However, one of the things we clearly need to advocate for is what they are saying, that it doesn't matter what state we are in, what territory we are in, we must advocate for this information in Spanish. Perhaps one of the first things we can request is that it happens more quickly, that even if the programs are in English, there is a translator. Because we can start there; that is much faster than perhaps having the information printed in Spanish. But we need to advocate for this, to make our presence known. In my case, I greatly admire that family because without a lot of familiarity with English, they attended a program entirely in English, and that is advocacy. What they are doing is advocacy. So, for me, I think we can start there, requesting this from this very nice community, which is the Coalition, and telling them, 'Look, we are a Latino community that, in fact, this year I was here last year, and this year I have seen more Latinos than last year.' And for me, it is a necessity, and I understand that at some point, it should be mandatory, because there are many of us Latinos in the United States."]

Future Recommendations

Based on the results from our surveys, focus groups, and individual interviews, we recommend the following:

Barriers or Gaps in Healthcare Access

1. Provide flexible opportunities for healthcare visits such as:
    a. After hours appointments
    b. Create a long-term policy for covering ongoing telehealth appointments post COVID
    c. Engage NBDF's Medical and Science Advisory Council's (MASAC) or Hemophilia Alliance to develop recommendations or guidance for extending hours, telehealth, outreach models, etc.

2. Reduce the travel burden on minority and rural hemophilia B patients and caregivers. Potential examples include:
    a. Engage with community partners or programs to provide transportation services
    b. Increase telehealth opportunities
    c. Engage with local health centers to reach rural families
    d. Increase the number of traveling hemophilia treatment center clinics held in rural communities
    e. Combine with other rare disease medical specialties to conduct traveling outreach clinics
    f. Create screening tools to verify if a patient needs to schedule an in-person appointment
    g. Provide mobile healthcare services where needed
    h. Identify, screen, and evaluate transportation needs and lobby for coverage of car services
    i. Develop new or extend funding for existing travel assistance programs
    j. Increase funding for rural outreach to bring clinical care rural

3. Engage with healthcare providers on issues related to hemophilia B by enacting the following:
    a. Provide educational curriculum and resources for emergency department physicians, nurses, other relevant healthcare providers, and staff on engaging with hemophilia B patients and caregivers within the emergency room
    b. Survey medical professionals who serve as physicians and nurses to ascertain their knowledge of hemophilia B; the study can also be expanded to include current medical school students, instructors, and program directors to learn more about what medical schools teach (and do not teach) about hemophilia B patients

4. Create a protocol for ER physicians, nurses, other relevant healthcare providers, and staff to engage with hemophilia B patients and caregivers during ER visits. Potential topics include:
    a. Improve distribution of National Bleeding Disorders Foundation's (NBDF) Medical and Science Advisory Council's (MASAC) existing but not well-publicized Guidelines for Emergency Department Management of Individuals with Hemophilia and Other Bleeding Disorders and other guidelines as important educational tools for health providers Create a long-term policy for covering ongoing telehealth appointments post COVID
    b. Instructions for accessing ports
    c. Protocol for caregiver to infuse patients
    d. Tailored admissions process

5. Provide educational resources for healthcare providers, and medical students related to the following:
    a. Utilizing already developed algorithms and/or creating treatment plans for women with hemophilia B based on current standards
    b. Create different access options for care (telehealth, outreach to rural locations, extend hours of operation, etc.)
    c. Improve general educational content on hemophilia B
        i. Lobby the American Medical Association (AMA), medical schools and teaching hospitals to improve their education and training of hemophilia generally
    d. Increase / improve diagnosing a woman with hemophilia B
        i. Lobby legislators to increase funding for research, care and treatment for hemophilia B
        ii. Create recommendations that can be used to lobby for clear insurance coverage for females with hemophilia B
        iii. Challenge medical schools and teaching hospitals to improve their curriculum for the diagnosis, care and treatment of females with hemophilia B

Patient/Provider Communications ••••

1. Create a resource guide that explains the clinical trial process. The guide should include information related to the following:
    a. Potential benefits of participating in a clinical trial
    b. Potential risks related to participating in a clinical trial
    c. Frequently asked questions with answers written in language that community members understand
    d. General materials written in language that community members understand
2. Request that providers provide resources on health information specific to women with hemophilia B. Potential topics include:
    a. A thorough explanation of how hemophilia B affects women (in languages they understand)
    b. A treatment plan guide based on current standards that provides detailed information on how often women should receive factor or other necessary medical treatment
    c. The testing process for women - and improve the number of women who can be tested.
    d. Regular protocol for testing girls with a family history (early in life, not waiting until menstruation years).
3. Request that providers create or provide mental health resources for patients
4. Request that providers create or provide health information for patients relevant to best healthcare practices for the life of one’s disease
5. Create a resource guide for providers that addresses patient/provider communication etiquette and the importance of listening to patients
6. Request that providers create a resource guide that allows patients to understand all treatment options relevant to them including options outside of the HTC
7. Accountability for clinical care providers to be accountable for seeing all patients (mild- severe).

Patient Advocacy Organizational Services, Support, and Engagement ••••

1. Offer resources related to the following: (English and Spanish)
   a. Best practices for navigating insurance companies (e.g., switching insurance providers, transitioning from a clinical trial that covered the cost of medicine to paying your own medicine, understanding which plans cover specific medicines, and the appeals process)
   b. Understanding the various types of pharmacies
   c. Understanding the importance of knowing your family history
   d. Extended family education (culturally focused, participation of all caregivers)

2. Create more opportunities to bring awareness about women and bleeding disorders (i.e. meetings, retreats)

3. Create an awareness campaign tailored for multiple audiences on women and bleeding disorders addressing how to talk to providers, how providers can engage with women, getting tested, receiving a diagnosis, and receiving a treatment plan. (English and Spanish)
   a. Pick a hemophilia B "day" or females with hemophilia "day" to recognize (during Bleeding Disorders Month) for social outreach. (federal and/or state-based)
   b. Establish state-based proclamation days for women with hemophilia B
   c. Recognize hemophilia B minority communities during Minority Health Month

4. Create an opportunity for women to identify their specific needs so resources can be developed appropriately
   a. Create a women's advocacy day on Capitol Hill. (Women in hemophilia, bleeding disorders or even rare diseases generally)
   b. Lobby for coverage of diagnosis, care and treatment for women
   c. Host a legislative women's caucus meeting to educate Congress about females with hemophilia
   d. Champion national Healthy People 2040 goals that improve the lives of females with hemophilia

5. Create a mental health toolkit including the following information:
   a. Effective ways to cope with a hemophilia B diagnosis
   b. Marriage resources
   c. Single parent resources
   d. Resources specific to caregivers (parents and extended caregivers in household)
   e. Resources related to finding balance, and life outside of a bleeding disorder

6. Create a hemophilia toolkit that includes helpful resources that patients and caregivers can provide as a resource to their health care provider (i.e. binder with relevant studies, patient health information) in English / Spanish

7. Create a tailored advocacy program to train individuals at each stage of their life (advocates by age group – young adults, adults, older adults)

8. Identify additional opportunities for the hemophilia B individuals after they age out of camp into adulthood

9. Create a mentorship program where individuals can serve in mentee/mentor roles as a resource throughout their lifetime. These mentorship programs can focus on:
    a. Advocacy
    b. Understanding the history of hemophilia B
    c. Women with bleeding disorders
    d. Advocacy includes recruiting across all age groups
    e. Individuals with a new hemophilia B diagnosis
    f. Caregivers
    g. Individuals with hemophilia B who have no family history of hemophilia B

10. Improve transition for child services to adult services
    a. Create a toolkit that prepares families to transition
    b. Increase covered and transition time for transition age of 18 to 26 years for pediatrics at HTCs

11. Create a "Hemophilia B 101" toolkit for school systems/students so they can understand what hemophilia B is and proper ways to communicate with families

12. Create a resource specific to hemophilia B individuals who may not have a family history (spontaneous mutation) explaining how spontaneous mutations happen, and mental health topics addressing guilt (English/Spanish)

13. Engage the patient community on understanding insurance and how to effectively choose a provider that is specific to one's needs

14. Create continuous communication after large meetings that include potential solutions for topics discussed

15. Create active learning courses for individuals to learn about each of the hemophilia stakeholders. Courses can be specific to the following and their role in the larger hemophilia B ecosystem:
    a. Social workers
    b. Doctors
    c. Nurses
    d. Health Insurance companies and policies
    e. Hemophilia B chapters
    f. Hemophilia B national organizations
    g. Industry providers engaged with patients and caregivers
    h. School/teachers, babysitters/care providers

16. Provide more opportunities to engage with rural, female, and minority patients and caregivers on topics related to financial resources to access healthcare
    a. Improve advocacy education in these communities
    b. Increase advocacy engagement in these communities

17. Create financial programs specific to the unique needs of rural, female, and minority patients and caregivers
    a. Advocate for increased funding for programs
        i. Includes Title 5 grants, transportation programs
        ii. Build stronger state partnerships with nonprofits supporting these communities
    b. Analyze and evaluate existing programs, looking for improvement opportunities
18. Explore opportunities to create meaningful programs at the local level for females with hemophilia B
19. To offset travel burden for patients and caregivers, create more virtual engagement opportunities
    a. Improve telehealth access

Sharing Research Results ••••

The Coalition for Hemophilia B and RareRising will continue to identify and share relevant results and takeaways from this research at various hemophilia and bleeding disorders events and on numerous digital, print, and social media platforms. The recommendations to expand thought community and stakeholder input. This report is not exhaustive, additional research is encouraged in order to further define and take action to improve equity in hemophilia B in the US.

Appendix

Survey Questions ••••

Q1. All questions in this survey are generally termed using "you" or "your" but should be understood to be referring to the person with hemophilia. / Todas las preguntas de esta encuesta generalmente se denominan "usted" o "su", pero debe entenderse que se refieren a la persona con hemofilia.

Where do you usually go for care for hemophilia (Select all that apply.)? / ¿Dónde suele acudir para recibir atención para la hemofilia (seleccione todas las que correspondan)?

- Local Health Clinic / Clínica de salud local
- Local community hospital / Hospital comunitario local
- Emergency department / Departamento de emergencia
- Academic medical center/ University hospital /Centro médico académico/hospital universitario
- Hemophilia Treatment Center /Centro de Tratamiento de Hemofilia
- Hematologist / Hematólogo
- Other specialty hospital (Children, Women's Oncology, etc.) / Hospital de otras especialidades (Infantil, Mujer, Oncología, etc.)
- Other (Please specify) / Otro (Por favor especifique.)

Q2. Who diagnosed your hemophilia? / ¿Quién diagnosticó su hemofilia?
-Primary care doctor / Médico de atención primaria
-Hematologist / Hematólogo
-Hematologist/Oncologist / Hematólogo/Oncólogo
-Other Specialist (Please specify) / Otro especialista (especifique)

Q3. These next questions are about medications and your healthcare provider experience. Please reach each one carefully. / Las siguientes preguntas son sobre medicamentos y la experiencia con su proveedor de atención médica. Por favor, lea cada uno detenidamente.				
Do you have to pay additional personal costs for care and medicines for hemophilia in addition to insurance premiums? / ¿Tiene usted que pagar costos personales adicionales por atención y medicamentos para la hemofilia además de las primas del seguro?	Yes / Sí	No / No	Unsure / No lo sé	Not applicable / No aplicable
I am aware of medications that are available for hemophilia care. / Conozco los medicamentos disponibles para el cuidado de la hemofilia.	Yes / Sí	No / No	Unsure / No lo sé	Not applicable / No aplicable
My health insurance or drug plan covers the cost for care and medicines for hemophilia. / Mi seguro médico o plan de medicamentos cubre el costo de la atención y los medicamentos para la hemofilia.	Yes / Sí	No / No	Unsure / No lo sé	Not applicable / No aplicable
The information provided by your healthcare provider was given to you or your caregiver/family in your preferred language? / Su proveedor de atención médica le proporcionó información en su idioma preferido, ya sea a usted o a su cuidador/familia.	Yes / Sí	No / No	Unsure / No lo sé	Not applicable / No aplicable

Q3. Continued / Continuación				
When you were diagnosed, you or your caregiver/family were given information about patient organizations or support groups for hemophilia. / Cuando le diagnosticaron, usted o su cuidador/familia recibieron información sobre organizaciones de pacientes o grupos de apoyo para la hemofilia.	Yes / Sí	No / No	Unsure / No lo sé	Not applicable / No aplicable
Are you or your caregiver/family aware of hemophilia patient organizations that assist patients and families? / ¿Usted o su cuidador/familia conocen las organizaciones de pacientes con hemofilia que ayudan a los pacientes y sus familias?	Yes / Sí	No / No	Unsure / No lo sé	Not applicable / No aplicable
Are you or your caregiver/family actively connecting with a patient organization? / ¿Usted o su cuidador/familia se conectan activamente con una organización de pacientes?	Yes / Sí	No / No	Unsure / No lo sé	Not applicable / No aplicable

Q4. These next questions are about your insurance coverage. Please read each one carefully. / Estas siguientes preguntas son sobre su cobertura de seguro. Por favor lea cada una cuidadosamente.				
Do you have to pay additional personal costs for care and medicines for hemophilia in addition to insurance premiums? /¿Tiene que pagar costos personales adicionales por atención y medicamentos para la hemofilia además de las primas del seguro?	Yes / Sí	No / No	Unsure / No lo sé	Not applicable / No aplicable
My health insurance or drug plan covers the cost for care and medicines for hemophilia. / Mi seguro médico o plan de medicamentos cubre el costo de la atención y los medicamentos para la hemofilia.	Yes / Sí	No / No	Unsure / No lo sé	Not applicable / No aplicable

Q5. Please select the primary health insurance you use (Check all that apply.): / Seleccione el seguro de salud primario que usa (marque todo lo que corresponda.):
-Insurance (provided through work) / Seguro (proporcionado a través del trabajo)
-Medicare / Medicare
-Medicaid / Medicaid
-CHIP (Children's Health Insurance Program) / CHIP (Programa de Seguro Médico para Niños)
-Other government programs (please specify - VA, TriCare, etc.) / Otros programas gubernamentales (especifique: VA, TriCare, etc.)
-Other (Please specify.) / Otro (por favor especifique.)
-No insurance / Sin seguro

Q6. What does your family spend each year for care and medicine for hemophilia (Please do not include the cost of your monthly insurance premiums.)? / ¿Cuánto gasta su familia cada año en atención y medicamentos para la hemofilia (no incluya el costo de las primas mensuales de su seguro)?

-Less than $5,000/year / Menos de $5,000/año
-$5,001 - $10,000 per year / $5,001 - $10,000 por año
-$10,001 - $25,000 per year / $10,001 - $25,000 por año
-$25,001 - $50,000 per year / $25,001 - $50,000 por año
-$50,001 - $75,000 per year / $50,001 - $75,000 por año
-$75,001 - $100,000 per year / $75,001 - $100,000 por año
-More than $100,000 per year / Más que $100,000 por año
-Not sure / No estoy seguro
-Other (Please specify.) / Otro (por favor especifique.)
-Prefer not to answer / Prefiero no contestar

Q7. What does your family spend each year for travel for hemophilia care? / ¿Cuánto gasta su familia cada año en viajes para el cuidado de la hemofilia?
-Less than $5,000/year / Menos de $5,000/año
-$5,001 - $10,000 per year / $5,001 - $10,000 por año
-$10,001 - $25,000 per year / $10,001 - $25,000 por año
-$25,001 - $50,000 per year / $25,001 - $50,000 por año
-$50,001 - $75,000 per year / $50,001 - $75,000 por año
-$75,001 - $100,000 per year / $75,001 - $100,000 por año
-More than $100,000 per year / Más que $100,000 por año
-Not sure / No estoy seguro
-Other (Please specify.) / Otro (por favor especifique.)
-Prefer not to answer / Prefiero no contestar

Q8. These next questions are about how you feel about healthcare access, resources, and potential barriers. Please read each one carefully, keeping in mind the medical care you are receiving now. (If you have not received care recently, think about what you would expect if you needed care today.) How strongly do you AGREE or DISAGREE with each of the following statements? / Las siguientes preguntas son sobre cómo se siente con respecto al acceso a la atención médica, los recursos y las posibles barreras. Lea cada una con atención, teniendo en cuenta la atención médica que está recibiendo ahora. (Si no ha recibido atención recientemente, piense en lo que esperaría si necesitara atención hoy). ¿En qué medida está de ACUERDO o EN DESACUERDO con cada una de las siguientes afirmaciones?

I am receiving treatment that is timely to my needs? / ¿Estoy recibiendo un tratamiento oportuno a mis necesidades?	Agree / De acuerdo	Somewhat Agree / Parcialmente de acuerdo	Uncertain / Incierto	Somewhat Disagree / Algo en desacuerdo	Disagree / Desacuerdo	Not Applicable / No aplica
I am receiving care and education from specialists and clinics who are knowledgeable about hemophilia. / Recibo atención y educación de especialistas y clínicas que tienen conocimientos sobre la hemofilia.	Agree / De acuerdo	Somewhat Agree / Parcialmente de acuerdo	Uncertain / Incierto	Somewhat Disagree / Algo en desacuerdo	Disagree / Desacuerdo	Not Applicable / No aplica
I am able to get access to the medications I need for my hemophilia care. / Puedo tener acceso a los medicamentos que necesito para el cuidado de mi hemofilia.	Agree / De acuerdo	Somewhat Agree / Parcialmente de acuerdo	Uncertain / Incierto	Somewhat Disagree / Algo en desacuerdo	Disagree / Desacuerdo	Not Applicable / No aplica

Q8. Continued / Continuación

The information provided when you were diagnosed was helpful to you and your caregiver/family. / La información proporcionada cuando le diagnosticaron fue útil para usted y su cuidador/familia.	Agree / De acuerdo	Somewhat Agree / Parcialmente de acuerdo	Uncertain / Incierto	Somewhat Disagree / Algo en desacuerdo	Disagree / En desacuerdo	Not Applicable / No aplicable
The information provided by your healthcare provider when you were diagnosed was clear and understandable to you and your caregiver/family. / La información proporcionada por su proveedor de atención médica cuando recibió el diagnóstico fue clara y comprensible para usted y su cuidador/familia.	Agree / De acuerdo	Somewhat Agree / Parcialmente de acuerdo	Uncertain / Incierto	Somewhat Disagree / Algo en desacuerdo	Disagree / En desacuerdo	Not Applicable / No aplicable
You or your caregiver/family currently have access to the information you need to understand and care for hemophilia. / ¿Usted o su cuidador/familia a menudo necesitan tomar una licencia sin sueldo por razones médicas?	Agree / De acuerdo	Somewhat Agree / Parcialmente de acuerdo	Uncertain / Incierto	Somewhat Disagree / Algo en desacuerdo	Disagree / En desacuerdo	Not Applicable / No aplicable
You or your caregiver/family often need to take unpaid leave for medical reasons? / Usted o su cuidador/familia actualmente tienen acceso a la información que necesitan para comprender y cuidar la hemofilia.	Agree / De acuerdo	Somewhat Agree / Parcialmente de acuerdo	Uncertain / Incierto	Somewhat Disagree / Algo en desacuerdo	Disagree / En desacuerdo	Not Applicable / No aplicable
You or your caregiver/family have had to leave a job or reduce work hours because of hemophilia. / Usted o su cuidador/familia han tenido que dejar un trabajo o reducir las horas de trabajo debido a la hemofilia.	Agree / De acuerdo	Somewhat Agree / Parcialmente de acuerdo	Uncertain / Incierto	Somewhat Disagree / Algo en desacuerdo	Disagree / En desacuerdo	Not Applicable / No aplicable

Q9. How often, if at all, do you or your caregiver/family need days off work or school for health reasons due to hemophilia (per month, on average)? / ¿Con qué frecuencia, si alguna, usted o su cuidador/familia necesitan días libres en el trabajo o la escuela por motivos de salud debido a la hemofilia (al mes, en promedio)?
-1-2 days per month / 1-2 días por mes
-3-5 days per month / 3-5 días por mes
-6-10 days per month / 6-10 días por mes
->10 days per month / >10 días por mes
-Not applicable / No aplicable

Q10. What would you estimate the amount of wages lost to needing days off work for health reasons due to hemophilia? / ¿Cuál estimaría usted la cantidad de salarios perdidos por necesitar días libres de trabajo por razones de salud debido a la hemofilia?
-Less than $5,000/year / Menos de $5,000/año
-$5,001 - $10,000 per year / $5,001 - $10,000 por año
-$10,001 - $25,000 per year / $10,001 - $25,000 por año
-$25,001 - $50,000 per year / $25,001 - $50,000 por año
-$50,001 - $75,000 per year / $50,001 - $75,000 por año
-$75,001 - $100,000 per year / $75,001 - $100,000 por año
-More than $100,000 per year / Más que $100,000 por año
-Not sure / No estoy seguro
-Other (Please specify.) / Otro (por favor especifique.)
-Prefer not to answer / Prefiero no contestar

Q11. What benefit do you or your caregiver/family receive from your hemophilia patient advocacy organization? (Check all that apply.): / ¿Qué beneficio recibe usted o su cuidador/familia de su organización de defensa de pacientes con hemofilia (marque todas las que correspondan)?:
-Education / Educación
-Information on medical care / Información sobre atención médica
-Information on treatments / Información sobre tratamientos
-Clinical trial opportunities / Oportunidades de ensayos clínicos
-Information on rare disease policies / Información sobre pólizas de enfermedades raras
-Other (Please specify.) / Otra (por favor especifique.)
-Not applicable / No aplicable

Q12. Where do you or your caregiver/family currently receive information for your hemophilia (Check all that apply.)? / ¿Dónde recibe usted o su cuidador/familia actualmente información sobre su hemofilia (marque todo lo que corresponda)?
- Your doctor or clinic / La clínica de su doctor
- Local community health resources / Recursos de salud de la comunidad local
- National hemophilia or bleeding disorders patient organizations / Organizaciones nacionales de pacientes con hemofilia o trastornos hemorrágicos
- Local Chapter bleeding disorder organizations / Su organización o capítulo local de trastornos de sangrado
- Other rare disease organizations / Otras organizaciones de enfermedades raras
- The Internet / Internet
- Family and friends / Familia y amigos
- Other (Please specify.) / Otra (por favor especifique.)

Q13. These next questions are about transportation, access to care, and your experiences with care. Please read each one carefully. / Las siguientes preguntas son sobre la transportación, el acceso a la atención y sus experiencias con la atención. Por favor, lea cada uno detenidamente.				
Has transportation to medical appointments been physically difficult for you due to hemophilia? / ¿El transporte a las citas médicas ha sido físicamente difícil para usted debido a la hemofilia?	Yes / Sí	No / No	Unsure / No lo sé	Not applicable / No aplicable
Has transportation to medical appointments been financially difficult for you due to hemophilia? / ¿Ha sido difícil para usted la transportación al trabajo debido a la hemofilia?	Yes / Sí	No / No	Unsure / No lo sé	Not applicable / No aplicable
Is any of your travel out-of-state for your hemophilia medical care? / ¿Alguno de sus viajes es fuera del estado para su atención médica de hemofilia?	Yes / Sí	No / No	Unsure / No lo sé	Not applicable / No aplicable
Has transportation to work been difficult for you due to hemophilia? / ¿El transporte a las citas médicas ha sido económicamente difícil para usted debido a la hemofilia?	Yes / Sí	No / No	Unsure / No lo sé	Not applicable / No aplicable

Q13. Continued / Continuación				
Has transportation to school been difficult for you due to hemophilia? / ¿Ha sido difícil para usted la transportación a la escuela debido a la hemofilia?	Yes / Sí	No / No	Unsure / No lo sé	Not applicable / No aplicable
Do you have a local doctor nearby (within 50 miles) for your regular hemophilia care? / ¿Tiene un médico local cerca (dentro de un radio de 50 millas) para su atención regular de la hemofilia?	Yes / Sí	No / No	Unsure / No lo sé	Not applicable / No aplicable
Do you have local access to specialists for hemophilia? / ¿Tiene acceso local a especialistas en hemofilia?	Yes / Sí	No / No	Unsure / No lo sé	Not applicable / No aplicable
Have you had difficulties receiving emergency medical care (emergency department care or ambulance/paramedic services) for hemophilia? / ¿Ha tenido dificultades para recibir atención médica de emergencia (atención en el departamento de emergencias o servicios de ambulancia/paramédicos) para la hemofilia?	Yes / Sí	No / No	Unsure / No lo sé	Not applicable / No aplicable
Have you had difficulties with inpatient care for hemophilia? / ¿Ha tenido dificultades con la atención hospitalaria por hemofilia?	Yes / Sí	No / No	Unsure / No lo sé	Not applicable / No aplicable

Q14. Do specialists for hemophilia ever come to your area to conduct patient outreach clinics to shorten your travel to them? / ¿Vienen a su área, alguna vez, especialistas en hemofilia para llevar a cabo clínicas de extensión para pacientes a fin de acortar su viaje hasta ellos?
-Yes / Sí
-No / No
-Not sure / No estoy seguro

Q15. When specialists for hemophilia come to your area to conduct patient outreach clinics to shorten your travel to them, how often do you utilize this service? / Cuando los especialistas en hemofilia vienen a su área para llevar a cabo clínicas de extensión para pacientes a fin de acortar su viaje hasta ellos, ¿con qué frecuencia utiliza este servicio?
-At least monthly / Al menos mensualmente
-3-4 times per year / 3-4 vez al año
-Once per year / 1 vez al año
-Every 2-5 years / Cada 2-5 al año
-Other (Please specify.) / Otro (Por favor, especifique).
-I do not utilize this service. / No utilizo este servicio.

Q16. These next questions are about how far you have to travel for care. Please read each one carefully. / Las siguientes preguntas se refieren a la distancia que usted tiene que viajar para recibir atención. Por favor, lea cada uno detenidamente.						
I am receiving treatment that is timely to my needs? / ¿Estoy recibiendo un tratamiento oportuno a mis necesidades?	Less than 25 miles / Menos de 25 millas	25 – 50 miles / 25 – 50 millas	50 – 100 miles / 50 – 100 millas	More than 100 miles / Más de 100 millas	I am unable to access care for hemophilia / No puedo acceder a la atención para la hemofilia.	I do not seek care for hemophilia / No busco atención para la hemofilia.

Q16. Continued / Continuación						
How far do you need to travel to see specialists for hemophilia? / ¿Qué tan lejos debe viajar para ver a especialistas en hemofilia?	Less than 25 miles / Menos de 25 millas	25 – 50 miles / 25 – 50 millas	50 – 100 miles / 50 – 100 millas	More than 100 miles / Más de 100 millas	I am unable to access care for hemophilia / No puedo acceder a la atención para la hemofilia.	I do not seek care for hemophilia / No busco atención para la hemofilia.

Q17. Do you feel you are ever denied access to a hemophilia specialist due to your gender, race, geographic location (ex. rural), or any other demographic factor? If so, please explain why. / ¿Cree que alguna vez se le ha negado el acceso a un especialista en hemofilia debido a su género, raza, ubicación geográfica (p. ej., rural) o cualquier otro factor demográfico? Si es así, explique por qué
-Yes, please explain. / Sí, por favor explique
-No / No

Q18. How do you get to your medical appointments (Check all that apply.)? / ¿Cómo llega a sus citas médicas (marque todo lo que corresponda)?
-Car / Automóvil
-Train, bus, or other public transportation / Tren, autobús, u otro transporte público
-Air / Aire
-Telehealth only / Solo telesalud
-Other / Otro

Q19. These next questions are about your length of care. Please read each one carefully. / Las siguientes preguntas son sobre la duración de su atención. Por favor, lea cada una detenidamente.					
Do you typically need to stay overnight when seeking your regular care for hemophilia? / ¿Por lo general, necesita pasar la noche cuando busca su atención regular para la hemofilia?	Never / Nunca	Rarely / Casi nunca	Frequently / Frecuentemente	Always / Siempre	Not applicable / No aplicable
Do you typically need to stay overnight when seeking your specialist care for hemophilia? / ¿Por lo general, necesita pasar la noche cuando busca atención especializada para la hemofilia?	Never / Nunca	Rarely / Casi nunca	Frequently / Frecuentemente	Always / Siempre	Not applicable / No aplicable

Q20. These next questions are about how often you receive care. Please read each one carefully. / Las siguientes preguntas son sobre la frecuencia con la que recibe atención. Por favor, lea cada uno detenidamente.					
How often per year do you see a specialist for hemophilia medical care? / ¿Cuántas veces al año usted ve a un especialista para la atención médica de la hemofilia?	At least monthly / Por lo menos mensualmente	3-4 times per year / 3-4 veces al año	Once per year / Una vez al año	Every 2-5 years / Cada 2-5 años	Not applicable / No aplicable
How often per year do you see a general medical care professional for hemophilia medical care? / ¿Cuántas veces al año usted ve a un profesional de atención médica general para el cuidado de la hemofilia?	At least monthly / Por lo menos mensualmente	3-4 times per year / 3-4 veces al año	Once per year / Una vez al año	Every 2-5 years / Cada 2-5 años	Not applicable / No aplicable

Q21. These next questions are about how you feel about the medical care you receive. Please read each one carefully, keeping in mind the medical care you are receiving now. (If you have not received care recently, think about what you would expect if you needed care today.) How strongly do you AGREE or DISAGREE with each of the following statements? / Las siguientes preguntas son sobre cómo se siente con respecto a la atención médica que recibe. Lea cada una con atención, teniendo en cuenta la atención médica que está recibiendo ahora. (Si no ha recibido atención recientemente, piense en lo que esperaría si necesitara atención hoy). ¿En qué medida está de ACUERDO o EN DESACUERDO con cada una de las siguientes afirmaciones?						
Doctors are good about explaining the reason for medical tests. / Los médicos son buenos para explicar el motivo de las pruebas médicas.	Strongly Agree / Totalmente de acuerdo	Agree / De acuerdo	Uncertain / No lo sé	Disagree / En Desacuerdo	Strongly Disagree / Totalmente en desacuerdo	Not applicable / No aplicable
I think my doctor's office has everything needed to provide complete medical care. / Creo que el consultorio de mi médico tiene todo lo necesario para brindar una atención médica completa.	Strongly Agree / Totalmente de acuerdo	Agree / De acuerdo	Uncertain / No lo sé	Disagree / En Desacuerdo	Strongly Disagree / Totalmente en desacuerdo	Not applicable / No aplicable
The medical care I have been receiving is just about perfect. / La atención médica que he estado recibiendo es casi perfecta.	Strongly Agree / Totalmente de acuerdo	Agree / De acuerdo	Uncertain / No lo sé	Disagree / En Desacuerdo	Strongly Disagree / Totalmente en desacuerdo	Not applicable / No aplicable
Sometimes doctors make me wonder if their diagnosis is correct. / A veces los médicos hacen que yo dude si su diagnóstico es correcto.	Strongly Agree / Totalmente de acuerdo	Agree / De acuerdo	Uncertain / No lo sé	Disagree / En Desacuerdo	Strongly Disagree / Totalmente en desacuerdo	Not applicable / No aplicable
I feel confident that I can get the medical care I need without being set back financially. / Confío en que puedo obtener la atención médica que necesito sin que esto me afecte financieramente.	Strongly Agree / Totalmente de acuerdo	Agree / De acuerdo	Uncertain / No lo sé	Disagree / En Desacuerdo	Strongly Disagree / Totalmente en desacuerdo	Not applicable / No aplicable
When I go for medical care, they are careful to check everything when treating and examining me. / Cuando recibo atención médica, se aseguran de revisar todo cuidadosamente durante mi tratamiento y examen.	Strongly Agree / Totalmente de acuerdo	Agree / De acuerdo	Uncertain / No lo sé	Disagree / En Desacuerdo	Strongly Disagree / Totalmente en desacuerdo	Not applicable / No aplicable
I have to pay for more of my medical care than I can afford. / Me veo obligado a pagar más de lo que puedo por los servicios médicos que recibo	Strongly Agree / Totalmente de acuerdo	Agree / De acuerdo	Uncertain / No lo sé	Disagree / En Desacuerdo	Strongly Disagree / Totalmente en desacuerdo	Not applicable / No aplicable

Q21. Continued / Continuación

I have easy access to medical specialists I need. / Tengo fácil acceso a los médicos especialistas que necesito.	Strongly Agree / Totalmente de acuerdo	Agree / De acuerdo	Uncertain / No lo sé	Disagree / En Desacuerdo	Strongly Disagree / Totalmente en desacuerdo	Not applicable / No aplicable
Where I get medical care, people have to wait too long for emergency treatment. / Donde recibo atención médica, la gente tiene que esperar demasiado para recibir tratamiento de emergencia.	Strongly Agree / Totalmente de acuerdo	Agree / De acuerdo	Uncertain / No lo sé	Disagree / En Desacuerdo	Strongly Disagree / Totalmente en desacuerdo	Not applicable / No aplicable
Doctors act too businesslike and impersonal toward me. / Los médicos actúan demasiado serios e impersonales conmigo.	Strongly Agree / Totalmente de acuerdo	Agree / De acuerdo	Uncertain / No lo sé	Disagree / En Desacuerdo	Strongly Disagree / Totalmente en desacuerdo	Not applicable / No aplicable
My doctors treat me in a very friendly and courteous manner. / Mis médicos me tratan de manera muy amable y cortés.	Strongly Agree / Totalmente de acuerdo	Agree / De acuerdo	Uncertain / No lo sé	Disagree / En Desacuerdo	Strongly Disagree / Totalmente en desacuerdo	Not applicable / No aplicable
Those who provide my medical care sometimes hurry too much when they treat me. / Quienes me brindan atención médica a veces se apresuran demasiado cuando me atienden.	Strongly Agree / Totalmente de acuerdo	Agree / De acuerdo	Uncertain / No lo sé	Disagree / En Desacuerdo	Strongly Disagree / Totalmente en desacuerdo	Not applicable / No aplicable
Doctors sometimes ignore what I tell them. / A veces los médicos ignoran lo que les digo.	Strongly Agree / Totalmente de acuerdo	Agree / De acuerdo	Uncertain / No lo sé	Disagree / En Desacuerdo	Strongly Disagree / Totalmente en desacuerdo	Not applicable / No aplicable
I have some doubts about the ability of the doctors who treat me. /Tengo algunas dudas sobre la capacidad de los médicos que me atienden.	Strongly Agree / Totalmente de acuerdo	Agree / De acuerdo	Uncertain / No lo sé	Disagree / En Desacuerdo	Strongly Disagree / Totalmente en desacuerdo	Not applicable / No aplicable
Doctors usually spend plenty of time with me. / Los médicos suelen pasar mucho tiempo conmigo.	Strongly Agree / Totalmente de acuerdo	Agree / De acuerdo	Uncertain / No lo sé	Disagree / En Desacuerdo	Strongly Disagree / Totalmente en desacuerdo	Not applicable / No aplicable

Q21. Continued / Continuación						
I find it hard to get an appointment for medical care right away. / Me resulta difícil obtener una cita para recibir atención médica de inmediato.	Strongly Agree / Totalmente de acuerdo	Agree / De acuerdo	Uncertain / No lo sé	Disagree / En Desacuerdo	Strongly Disagree / Totalmente en desacuerdo	Not applicable / No aplicable
I am dissatisfied with some things about the medical care I receive. / No estoy satisfecho con algunos aspectos sobre la atención médica que recibo.	Strongly Agree / Totalmente de acuerdo	Agree / De acuerdo	Uncertain / No lo sé	Disagree / En Desacuerdo	Strongly Disagree / Totalmente en desacuerdo	Not applicable / No aplicable
I am able to get medical care whenever I need it. / Puedo obtener atención médica cuando la necesito.	Strongly Agree / Totalmente de acuerdo	Agree / De acuerdo	Uncertain / No lo sé	Disagree / En Desacuerdo	Strongly Disagree / Totalmente en desacuerdo	Not applicable / No aplicable

Q22. The following questions are about your demographics. Which of the following categories describe you (Select all that apply.)? / Las siguientes preguntas son sobre su información demográfica. ¿Cuál de las siguientes categorías lo describe? (Seleccione todas las que apliquen.)?
-Person with Hemophilia B / Persona con Hemofilia B
-Caregiver of Adult with Hemophilia B / Cuidador de adulto con Hemofilia B
-Caregiver of Child (under 18) / Cuidador del niño (menor de 18 años)
-Other (Please specify.) / Otra (por favor especifique.)

Q23. Which category below includes your age? / ¿Qué categoría a continuación incluye su edad?
-18-24 years / 18-24 años
-25-34 years / 25-34 años
-35-44 years / 35-44 años
-45-54 years / 45-54 años
-55-64 years / 55-64 años
-65-74 years / 65-74 años
-75 years or above / 75 años o más
-Prefer not to answer / Prefiero no contestar

Q24. What state do you currently live in? / ¿En qué estado vive actualmente?

Q25. How do you describe your gender identity (Select all that apply.)? / ¿Cómo describe su identidad de género (seleccione todas las opciones que correspondan)?
-Male / Masculino
-Female / Femenino
-Gender variant/Non-conforming / Variante de género/No conforme
-Agender / Agénero
-Gender fluid / Fluido de género
-Gender queer / Género queer
-Transgender Female / Mujer transgénero
-Transgender Male / Hombre transgénero
-Not listed (Please specify) / No listado (Por favor especifique)
-Prefer not to answer / Prefiero no contestar

Q26. Which of the following categories describe you (Select all that apply.)? / ¿Cuál de las siguientes categorías lo describe (selecciona todas las opciones que correspondan)?
-American Indian or Alaska Native / Indio americano o nativo de Alaska
-Asian / Asiático
-Black, African American, or African / Negro, afroamericano o africano
-Hispanic, Latino, or Spanish / Hispano, latino o español
-Middle Easter of North African / Oriente Medio del Norte de África
-Native Hawaiian of Other Pacific Islander / Nativo de Hawái U Otras islas del Pacífico
-White / Blanco
-Afro-Caribbean / Afrocaribeño
-None of these fully describe me (Please specify.) / Ninguno de estos me describe completamente (especifique)
-Prefer not to answer / Prefiero no contestar

Q27. What is the highest degree or level of school you have completed? / ¿Cuál es el grado o nivel escolar más alto que ha completado?
-Less than high school / Menos de la escuela secundaria
-Some high school / Algo de secundaria
-High school diploma or GED / Diploma de escuela secundaria o GED
-Some college / Algo de universidad
-Associate's degree or technical school / Título de grado asociado o escuela técnica
-Bachelor's degree / Bachillerato o Licenciatura
-Master's, Professional or Doctorate degree / Maestría, Profesional o Doctorado
-Prefer not to answer / Prefiero o contestar

Q28. How did you find out about this survey? (Select all that apply.) / ¿Cómo se enteró de esta encuesta? (Seleccione todas las opciones que correspondan.)
-Coalition for Hemophilia B / Coalición por la Hemofilia B
-Local hemophilia Chapter / Capítulo de hemofilia local
-National Hemophilia Foundation / Fundación Nacional de Hemofilia
-Hemophilia Federation of America / Federación Americana de Hemofilia
-RareRising / RareRising
-Homecare / Specialty Pharmacy / Atención domiciliaria / Farmacia especializada
-Pharmaceutical / Biotech company / Empresa farmacéutica/biotecnológica
-Physician or health care provider / Médico o proveedor de atención médica
-Social media / Redes sociales
-Family/friends / Familia/amigos
-Other (Please specify) / Otro (Por favor especifique)
-Prefer not to answer / Prefiero no contestar