THE VIRGINIA BLEEDING DISORDERS PROGRAM

A PARTNERSHIP WITH VIRGINIA COMMONWEALTH UNIVERSITY

VDH VIRGINIA DEPARTMENT OF HEALTH

VIRGINIA BLEEDING DISORDERS PROGRAM NEEDS ASSESSMENT PROJECT (VBDPAP)

2021

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OVERVIEW

WHAT IS THE VIRGINIA BLEEDING DISORDERS PROGRAM?

The Virginia Bleeding Disorders Program (VBDP) is a program funded by the Virginia Department of Health to provide support for the care and treatment of residents of Virginia with hemophilia and other inherited bleeding disorders.

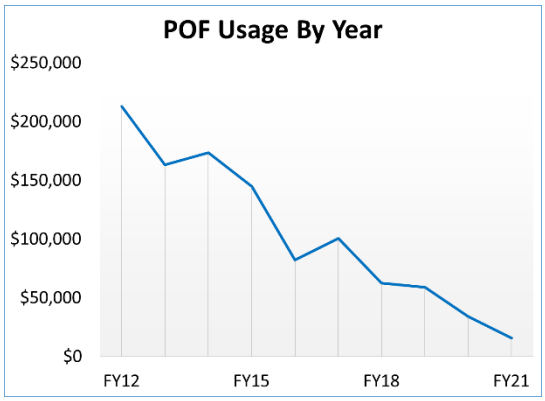
Virginia recognizes that the ongoing medical costs of treating such bleeding disorders often exceed the financial capacity of families, despite insurance coverage. The program supports a system of coordinated, family-oriented, multidisciplinary services for persons of all ages with bleeding disorders.

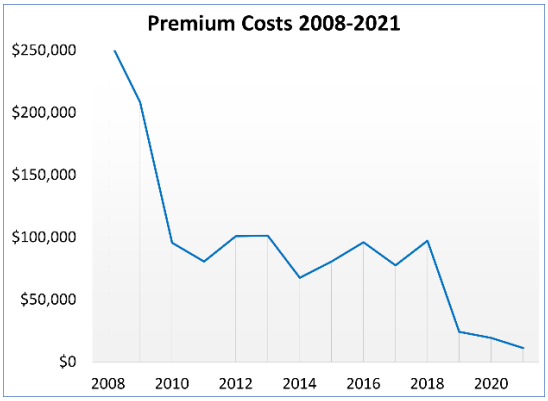
VBDP provides funding for care coordination done by nurses and/or social workers and health insurance consultation at hemophilia treatment centers (HTCs). VBDP also provides limited health insurance premium assistance through PSI, Inc. as well as medication for persons who are uninsured and financially eligible.

WHAT IS THE VBDP NEEDS ASSESSMENT PROJECT?

In the past five years, significant changes in bleeding disorders care and in the health care system have impacted the HTCs funded by VBDP and the community it serves. Among these are changes in the health insurance market (including the implementation of the Affordable Care Act), expansion of Medicaid, expansion of manufacturer compassionate use and copay assistance programs, and changes in hemophilia therapeutics (including longer-acting factor products, new non-factor products and gene therapy). The outcomes of these new therapies have the potential to change the services needed by patients. Furthermore, newer studies have demonstrated that the prevalence of hemophilia is likely higher than what was predicted fifteen years ago. It is likely that the unserved or underserved populations have been underestimated. Historically, the VBDP served primarily patients with hemophilia and severe von Willebrand Disease as their medical costs were assumed to be greater than those with mild bleeding disorders.

In the past five years, VBDP increased funding for care coordination for pediatrics in Northern Virginia and for adult care in the western half of Virginia. Additionally, the numbers of patients served by the program increased from 305 to 414 from FY2012 to FY2021. While funding for care coordination services and the number of patients it serves have increased in the past five years, the need for premium assistance and Pool of Funds have dramatically declined. This has been driven by the aforementioned changes in health care systems. The graphs below delineate these changes.





The purpose of this public health surveillance initiative is to provide descriptive knowledge about the populations of hemophilia in Virginia and to evaluate the extent to which the HTCs in Virginia serve their target population. The information collected through this Needs Assessment Project will assist in program strategic planning, decision making and resource allocation.

The ultimate goal of the VBDP Needs Assessment Project is to meet its codified responsibility to serve residents of Virginia with hemophilia and other inherited bleeding disorders.

WHO PARTICIPATES IN THE VBDP NEEDS ASSESSMENT PROJECT?

- Residents of Virginia with hemophilia and other inherited bleeding disorders who are enrolled in the VBDP
- Patients and Service Providers at Virginia Hemophilia Treatment Centers:
  - Virginia Commonwealth University (VCU)
  - University of Virginia (UVA)
  - Children's Hospital of The King's Daughters (CHKD)
  - Children's National Hospital (CNH)
- Hemophilia Treatment Centers in states adjacent to Virginia
  - Charleston Area Medical Center, Charleston, WVA
  - Georgetown University Hospital, Washington, DC
  - University of North Carolina at Chapel Hill, Chapel Hill, NC
  - West Virginia University Medical Center, Morgantown, WVA
  - Wake Forest University School of Medicine, Wake Forest, NC
- Virginia Department of Health (VDH)
- Virginia Hemophilia Foundation (VHF)
- Hemophilia Association of the Capitol Area (HACA)

VBDP NEEDS ASSESSMENT PROJECT TEAM

RESPONSIBILITIES OF THE NEEDS ASSESSMENT PROJECT TEAM

VBDP Core team at Virginia Commonwealth University

- Provide leadership and in-depth project management
- Prepare preliminary and final reports, including program recommendations
- Present findings to VDH and key stakeholders

Virginia Hemophilia Foundation (VHF) and Hemophilia Association of the Capitol Area (HACA)

- Assist in the survey development to assess the unmet needs of persons and families with bleeding disorders and to assess the influence of changing health care delivery on patients and families.
- Assist in the HTC survey development to assess unmet needs.
- Host focus groups of VHF leadership to identify unmet needs of their constituents and their perceptions of changing health care delivery.
- Increase awareness of this project through VHF educational events, email, and social media.
- Provide a consultant to facilitate stakeholders' groups and assist in qualitative analysis.
- Review results of the surveys and focus groups and provide input.
- Share findings of the VDBP Assessment with constituent group

L. Douglas Wilder School of Government and Public Affairs Survey, Evaluation and Research Lab at Virginia Commonwealth University

- Collaborate with the VBDP project team to review and finalize three survey tools (patient and family; Virginia HTCs and non-Virginia HTCs)
- Create three on-line surveys in RedCap and a public link to each for distribution by the VBDP team.
- Provide VBDP team with a clean data file of all survey results.
- Provide qualitative analysis for the interviews and focus groups conducted by VHF's consultant and prepare report for VBDP.

INDIVIDUAL TEAM MEMBER ROLES

ROLE	NAME
VBDP PROGRAM MANAGER	Janice G. Kuhn
VBDP NEEDS ASSESSMENT PROJECT MANAGER	Erika J. Martin
VBDP NEEDS ASSESSMENT PROJECT COORDINATOR	Lauren Dunn

VHF EXECUTIVE DIRECTOR/ VBDP NEEDS ASSESSMENT PROJECT ADVISOR	Kelly Waters
VHF REPRESENTATIVE	Heather Conner
VHF REPRESENTATIVE	Megan Schowengerdt
HACA REPRESENTATIVE	Brenda Bordelon
CONSULTANT FOR VHF / FOCUS GROUP LEADER	Kelly Macias
VCU SERL/ SURVEY DATA ANALYSIS	Mary Moore
VCU SERL/ SURVEY DATA ANALYSIS	Alexandra Stewart-Jonte

BACKGROUND

INHERITED BLEEDING DISORDERS

Hemophilia A and B are rare inherited X-linked bleeding disorders caused by a deficiency in Factor VIII (FVIII) or Factor IX (FIX), proteins in the blood involved in clotting. The severity of the disease generally correlates with the amount of clotting factor in the blood. Individuals with severe disease have no measurable factor. In severe disease, spontaneous and post-trauma bleeding occurs primarily in joints resulting in painful and debilitating degenerative joint disease. Bleeding into other organs or tissues can be life-threatening. Deficiencies in other clotting factors have also been identified but are even more rare with incidence of less than one in a million.

More commonly, von Willebrand Disease (vWD) is an autosomal inherited bleeding disorder characterized by a qualitative or quantitative defect in von Willebrand factor. Most cases have mild bleeding, primarily mucocutaneous. Inherited platelet disorders have also been characterized with mucosal bleeding and range in presentation from severe to mild, depending upon the type and degree of deficiency.

Treatment for hemophilia and some of the more severe vWD for the past several decades has been intravenous factor replacement. Patients with mild disease may only use factor replacement for acute bleeding episodes, pre-procedures, or surgeries. In severe or moderate disease, prophylactic treatment is the optimal therapy. Personalized therapy using longer-acting factor concentrates may lead to fewer infusions and less risk of bleeding. However, one of the most significant complications of replacement therapy is inhibitor development. This leads to dependence upon bypassing factor agents which are not as effective as standard therapy.

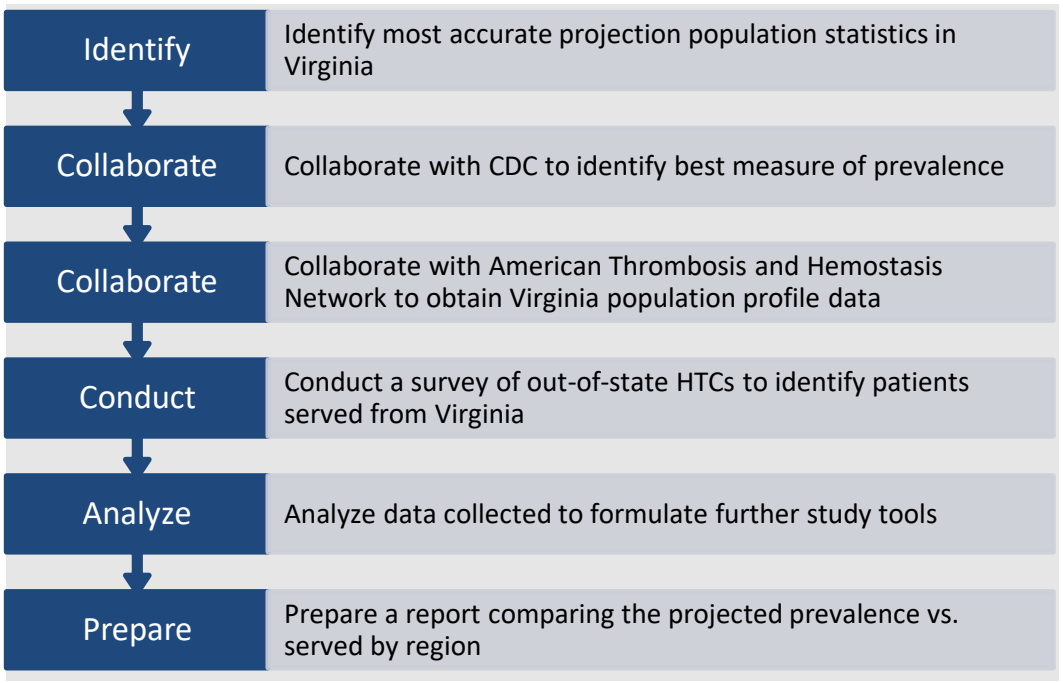
Even with newer, longer acting factor concentrates, repeated, life-long intravenous therapy can be burdensome and costly [1]. For these patients, newer non-factor therapies are becoming available which either substitute for the procoagulant function (Hemlibra®) or target coagulation inhibitors such as the tissue factor pathway inhibitor (Concizumab®). These are medications given subcutaneously, reducing the burden of IV infusions. The former may be given as infrequently as once per month.

The ultimate goal of hemophilia treatment would be a phenotypical cure through gene therapy, meaning that factor levels are nearly normal. Successful gene therapy will need to meet the challenges of long-term safety and effectiveness and the restrictions in candidates for treatment. Additionally, the delivery of gene therapy is complex in terms of institutional requirements and cost.

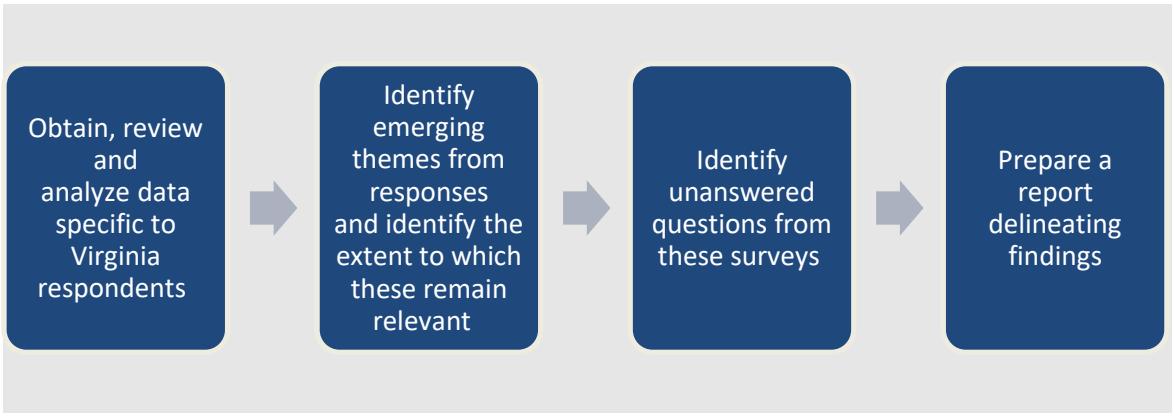
OBJECTIVES- VBDP NEEDS ASSESSMENT PROJECT

The following objectives were developed to provide guidance to conduct a comprehensive assessment of the VBDP in order to evaluate the extent to which the program serves its target population and to evaluate the impact of significant changes in bleeding disorders care and in the funding for health care.

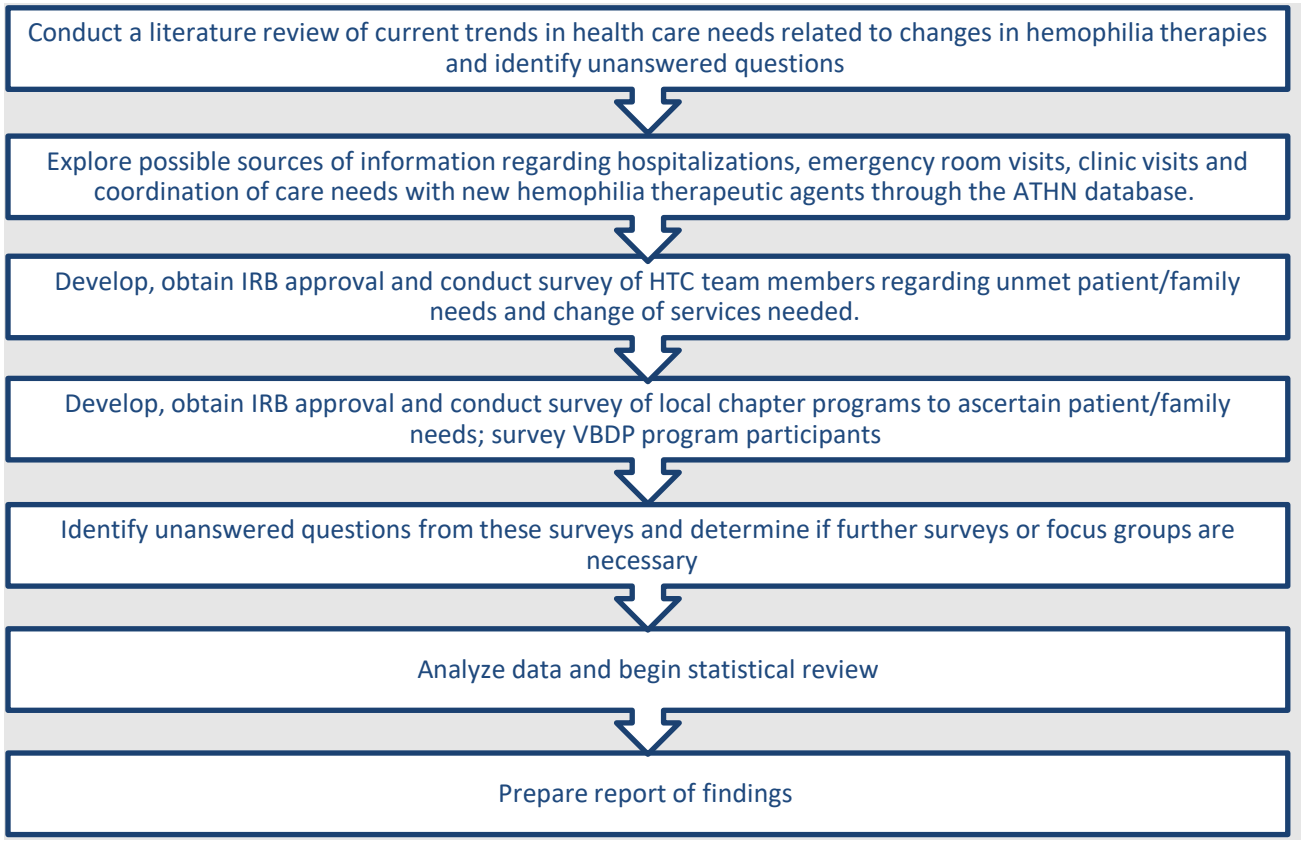
OBJECTIVE 1: TO PROJECT THE PREVALENCE OF HEMOPHILIA IN VIRGINIA BY REGION AND COMPARE TO CURRENT VBDP STATISTICS OF PATIENTS SERVED.



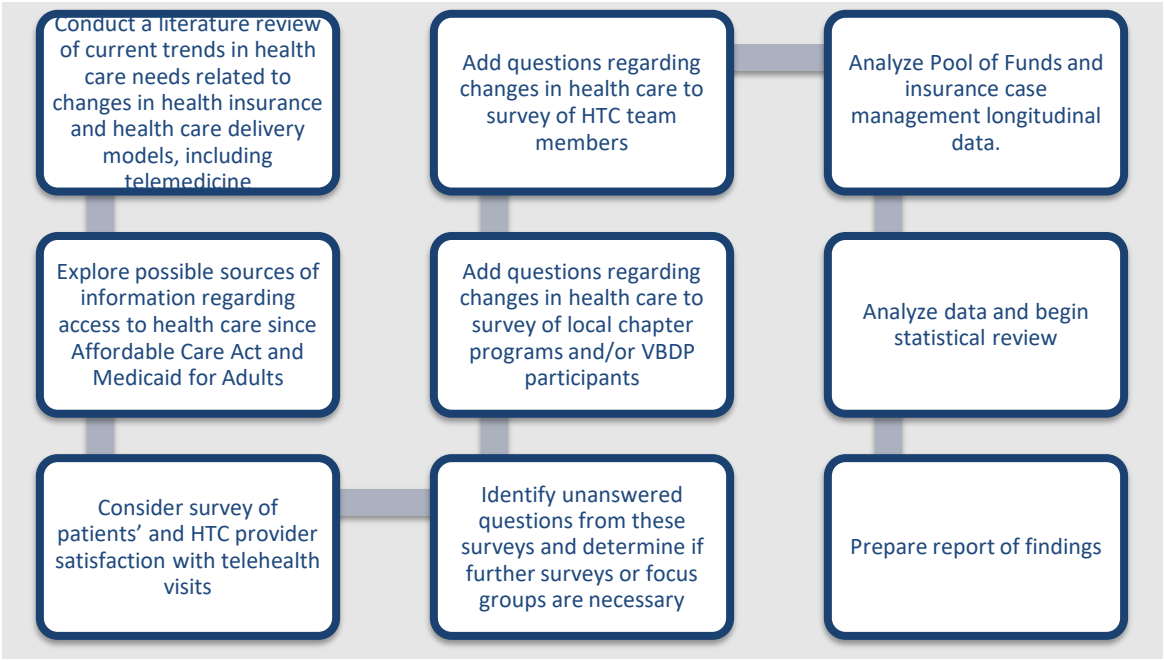
OBJECTIVE 2: TO REVIEW THE NATIONAL HEMOPHILIA PROGRAM COORDINATING CENTER NEEDS ASSESSMENT DATA (2014-2017), HRSA REGIONAL SURVEY (2020), PATIENT SATISFACTION SURVEYS.



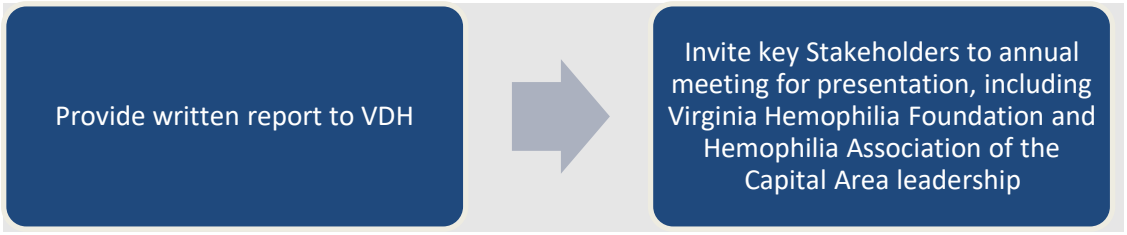
OBJECTIVE 3: TO IDENTIFY THE UNMET PATIENT/FAMILY NEEDS AND CHANGES IN SERVICES NEEDED, CONSIDERING THE CHANGES IN HEMOPHILIA THERAPIES.



OBJECTIVE 4: TO IDENTIFY THE INFLUENCE OF CHANGES IN HEALTH CARE ON CHANGES IN ACCESS TO CARE.



OBJECTIVE 5: TO PRESENT FINDINGS TO VBDP STAKEHOLDERS, LOCAL CHAPTER PROGRAMS AND VDH CENTRAL OFFICE FOR PROGRAM CONSIDERATION.



OBJECTIVE 1: TO PROJECT THE PREVALENCE OF HEMOPHILIA IN VIRGINIA BY REGION AND COMPARE TO CURRENT VBDP STATISTICS OF PATIENTS SERVED

The VBDP Needs Assessment Project aimed to identify all persons with hemophilia who resided in Virginia in 2015 -2019 and to determine the percentage of patients in Virginia cared for at the four hemophilia treatment centers (HTCs) in the state of Virginia.

METHODS: In July 2020, the VBDP Core team at VCU requested the assistance of American Thrombosis & Hemostasis Network (ATHN) to obtain VA population profile data from the CDC (Centers for Disease Control) Public Health Surveillance Project for Bleeding Disorders (Community Counts) for years 2015 to 2019. Population profile (PP) data was obtained for all VA residents with hemophilia (FVIII and FIX deficiency) who received care throughout the US HTC Network (USHTCN). Data included HTC number, year of visit, year of birth, gender, race, ethnicity, residence 3-digit zip code, and hemophilia type and severity. HTC PP data for all males with hemophilia residing in VA who received care in a federally supported US HTC was used to determine the number of VA male residents with hemophilia that access care at a federally funded HTC outside of the state and to compare those numbers with those who access care at VA HTCs. Additionally, Bridged-Race postcensal estimates of the VA resident population developed for the National Center for Health Statistics by the U.S. Census Bureau was obtained from the Division of Population Health Data of the VA Department of Health [2]. Hemophilia prevalence rate was estimated by dividing the number of unduplicated 2015-2019 Population Profile cases residing in Virginia by the estimated Virginia male population in 2015-2019 (n= 4,163,842) and multiplied by 100,000 to express the estimate as the number of cases per 100,000 males. The VA male population estimates for years 2015 to 2019 were used to project the prevalence of hemophilia in VA by region and age. The prevalence data was used to evaluate the extent to which the VBDP serves its target population.

VIRGINIA PREVALENCE RATE ESTIMATION: The estimated prevalence rate of hemophilia in VA based on the number of males with hemophilia who resided in VA and received care at a network HTC (n=478) during the same 5-year study period is **11.5 cases per 100,000** males ("crude estimate") which slightly increased to **12 per 100,000** males after adjustment for the differences in the age distributions of the US and hemophilia population. Age-adjusted rates were calculated using Age-adjusted Weights for U.S. 2000 Standard Population [3]. The estimated prevalence of FVIII deficiency was 8.9 cases per 100K males and for FIX deficiency was 2.6 cases per 100K males. The age-adjusted regional prevalence in VA ranged from 4.4 per 100K in Southwest VA to 17.7 per 100K in Hampton Roads. The hemophilia prevalence rate for whites and blacks was 7.7 and 2.9 cases per 100K, respectively and for Hispanics of either race was 1.3 cases per 100K.

RESULTS: There were 478 unduplicated 2015-2019 HTC PP cases for males with hemophilia who reside in Virginia. Of those cases, 369 (77%) had factor VIII and 109 (23%) had factor IX deficiency. Among those with known severity levels (n=477), 262 (55%) were severe, 93 (19%) were moderate, and 122 (26%) were mild. Among non-Hispanic blacks, 67% of the hemophilia cases were severe, 17% were moderate and 16% were mild, whereas among non-Hispanic whites, 51% of the hemophilia cases were severe, 19% were moderate and 30% were mild. Among Hispanics, 52% of the hemophilia cases were severe, 24% were moderate and 24% were mild. Slightly more than half of the population profile cases were adults (52%). The mean age ($\pm$SD) was 26 ($\pm$19) years, and the median age was 21 years. The overall study population was younger than the Virginia male population (median 37 years). Compared with the race distribution for

males in VA, blacks were over-represented (25% vs 20%), while whites (68% vs 72%) and Asians (5% vs 7%) were under-represented. Ethnicity proportions among the cases for males with hemophilia were the same as the general male population in VA. More than half reside in Hampton Roads (30%) and Northern Virginia (27%). Only 4% of the cases did not have insurance and all of them received care at a VA HTC. Overall, 423 (88%) of the cases who reside in Virginia visited one of the four HTCs funded by VBDP. There were 55 (12%) cases seen outside of state and the majority of those were seen at Georgetown University Hospital HTC (9%).

DISCUSSION: The estimated hemophilia prevalence of 12 cases per 100K in this study is consistent with the most recent analysis conducted by CDC and the U.S. HTC network using data collected during 2012–2018 on all male patients who visited federally supported U.S. HTCs. Investigators reported an age-adjusted prevalence 15.7 per 100K US males and a range of 11.7 - 14.4 per 100K males for the state of VA [4]. The upper estimate matches our 20% adjustment for the assumed proportion of patients not seen at HTCs, as suggested in previous prevalence studies [4,5,6]. Based on the current data, we estimate that there are between 500 and 600 males with hemophilia living in the state of Virginia today and $\geq$80% receive care at a network HTC. Approximately 70-80% of the VA male hemophilia population receives care from the VBDP. Levels of hemophilia severity differed between non-Hispanics whites, non-Hispanic-blacks, and the Hispanic population of patients with hemophilia and it is suggestive that there is a percentage of minorities in VA that are underdiagnosed or underserved. When comparing prevalence rate of hemophilia in VA based on the number of males with hemophilia who resided in VA and received care at a network HTC with the number of cases receiving care from the VBDP, we identified differences between the estimated prevalence rate and the actual number of individuals served in the Northern VA, Roanoke, and Southwest VA. This data suggests that the population in these regions may be encountering some barriers to care and therefore seek care outside of the VBDP and some even outside of the U.S. HTC network.

This prevalence study has limitations. The prevalence rate was based solely on 2015-2019 population profile cases for males with hemophilia who reside in Virginia and are seen at a federally funded HTC. The study did not include data for patients seen outside of the HTC network, which could result in an underestimation of overall occurrence of hemophilia in VA.

CONCLUSION: Not all males with hemophilia in VA receive care at a federally funded HTC. A percentage of males with hemophilia in VA receive care at an out-of-state HTC. Regional differences in the distribution of the hemophilia population in VA may require further examination of differences in access to hemophilia care.

See Appendix B for detailed data and figures.

OBJECTIVE 2: TO REVIEW THE NATIONAL HEMOPHILIA PROGRAM COORDINATING CENTER NEEDS ASSESSMENT DATA (2014-2017), HRSA REGIONAL SURVEY (2020), PATIENT SATISFACTION SURVEYS

PATIENT SATISFACTION IN HEALTH CARE IS A KEY QUALITY METRIC, ASSOCIATED WITH ADHERENCE AND BETTER OUTCOMES.

The U.S. Hemophilia Treatment Network, supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS), has conducted three National Patient Satisfaction Surveys (PSS) of HTC patient care since 2014 and a National HTC Needs Assessment in 2020.

FIRST NATIONAL PSS SURVEY

The first PSS National Survey of U.S. HTCs was conducted in 2014. The response rate included 5006 individuals who obtained care from 133 HTCs nationally [7]. Respondents indicated satisfaction with HTC care “always” or “usually” (A/U) ranging from 94 to-98%. There were no differences noted based on patient gender, age, race, ethnicity, language, diagnosis, severity, region, or frequency of HTC contact. A/U patient satisfaction with the HTC hematologist, nurse, social worker, or physical therapist ranged from 95 to 97% and A/U satisfaction with the five HTC care processes was 95%. A/U satisfaction with adolescent transition services ranged from 88 to 92% among 12–17-year-olds. Insurance (26.4%) and language (21.2%) were rated as “always” or “usually” a barrier in getting needed HTC services.

SECOND NATIONAL PSS SURVEY

The second PSS National Survey of U.S. HTCs was conducted in 2018, nearly 4800 HTC patients or caregivers answered the survey [8]. The 2018 survey included two additional questions: satisfaction with the HTC 340B factor/pharmacy program, and whether hemophilia patients had an active inhibitor. Overall HTC care satisfaction of respondents reported being “always” or “usually” (A/U) satisfied was 96%. Reported A/U satisfaction with the HTC hematologist, nurse or nurse practitioner, social worker, or physical therapist was 85%. A/U satisfaction with HTC services and HTCs provision of care ranged from 93 to 98% and 92% with adolescent transition services. Insurance (13%) and language (8%) were rated as “always” or “usually” a barrier in getting needed HTC services, a decrease from the previous PSS results.

THIRD NATIONAL PSS SURVEY

A third PSS National Survey of U.S. HTCs was conducted in 2021. The survey yielded 5,308 respondents, representing 92% of U.S. HTCs. Preliminary results show continued satisfaction with 97% of respondents "always or usually satisfied" with HTC care. The 2021 survey included questions about telehealth for the first time. Ninety-six percent of respondents who had participated in at least one telehealth visit responded being "usually or always" satisfied with HTC care. Data from the most recent survey is currently being analyzed and will be compared to the previous two surveys to discover trends and areas that HTCs may need support.

HTC NEEDS ASSESSMENT

The HTC Needs Assessment was a national survey conducted via Survey Monkey. Part I was conducted in early fall 2020 (101 unique respondents of 140 HTCs) and part II in early winter 2021 (90 unique respondents) [9].

Mid-Atlantic Region 3 response rates for Part I included 15 of 16 HTCs and Part II 10 of 16 HTCs. The responses were primarily from the Primary Contact at each HTC (11/15 for Part I, the remaining were Medical Director and 1 other and Part II 9/10 were the Primary Contacts, and 1 Medical Director).

The top priorities for Mid-Atlantic Region 3 HTCs included: Support for comprehensive care (80%), Improving access to care (80%), Minimizing ED (Emergency Dept) visits (53%) Managing Hemlibra® (53%), Decreasing loss to follow up (53%) and improving access to care for females (53%).

Further assessment of provider perceived patient access to care barriers included: distance to HTC (22%), transportation (20%), and no insurance/underinsured (22%)

The data reported in this publication was collected on behalf of the U.S. Hemophilia Treatment Center Network and supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of the Hemophilia Treatment Centers (SPRANS) grant.

OBJECTIVES 3 & 4: IDENTIFY THE UNMET PATIENT/FAMILY NEEDS AND CHANGES IN SERVICES NEEDED, CONSIDERING THE CHANGES IN HEMOPHILIA THERAPIES & IDENTIFY THE INFLUENCE OF CHANGES IN HEALTH CARE ON CHANGES IN ACCESS TO CARE.

LITERATURE REVIEW OF UNMET PATIENT/FAMILY NEEDS BY POPULATION

PATIENTS WITH MILD TO MODERATE HEMOPHILIA

The needs of patients with mild to moderate hemophilia, including women are underrepresented in published needs assessments, quality of life measures and studies of outcomes, disease burden or the financial impact of their disease. In a roundtable discussion of a multidisciplinary panel of experts, caregivers and members of advocacy groups [10] the unmet needs identified were: a) knowledge of hemophilia throughout the lifespan; b) consistent interaction with the HTC and hemophilia community; c) the need for guidelines related to mild disease and the unique needs of women; d) assistance with the impact of episodic care on school and work; e) assistance with the negative impact on relationships; and f) help with the impact of their disease on activities. Moreover, in a retrospective chart review of three HTCs from 2012-2018 [11] noted the unique burdens on women and girls with hemophilia not only related to reproductive health and the need for screening, diagnosis and treatment guidelines and awareness by both patients and providers. Computer modeling using medical insurance claims data in 2020 [12] support the unmet needs of patients with mild inherited bleeding disorders such as von Willebrand Disease (VWD). Their analysis suggests there may be a considerable number of patients with symptomatic, undiagnosed VWD or other mucocutaneous bleeding among the US commercially insured population.

FEMALES WITH INHERITED BLEEDING DISORDERS

As noted above, females with inherited bleeding disorders, including hemophilia, are often underrepresented in published studies. According to most estimates, for each male with hemophilia, there are approximately 2.7 to 5 potential female carriers, 1.5 actual somatic carrier and 0.3 to 1 carrier with FVIII or FIX < 0.4 IU/mL [13]. In addition to females with hemophilia due to their carrier status, women, and girls with VWD and rare factor deficiencies are disproportionately affected not only due to monthly menstrual cycle bleeding, but also pregnancy and obstetrical events. Advances in clinical care and research of patients with inherited bleeding disorders have focused primarily on male patients with hemophilia [14].

PATIENTS MAKING CHOICES ABOUT NEWER FACTOR CONCENTRATES, HEMLIBRA®, GENE THERAPY

To study the unmet needs of patients with hemophilia, expert meeting and focus groups focus groups of adult hemophilia patients and parents of hemophiliac children were held as well as a survey was mailed to patients in Germany, Austria, and Switzerland [15]. The representative survey demonstrated how people with hemophilia (PWH) and their parents want to be informed about new products, which information they prefer and from whom they wish to receive this information. Effective communication between patients and the HTCs and patient organizations and the role of shared decision-making was underscored. Similarly, interviews of 30 US patients periodically after switching to Hemlibra® were conducted. 50% noted that they would have preferred additional information about the medication, management, and side effects before switching products although continued treatment after the interviews [16]. Others have underscored this need for shared decision-making (SDM) in the light of multiple effective therapies in hemophilia [17]. It has been proposed that this SDM model be incorporated into comprehensive care to optimize patient outcomes as defined by the patient and to track outcomes of importance. Moreover, health care providers (HCP) and patients/families should consider the patient's developmental stage, health literacy and cultural background, preferences and goals, and barriers to implementation. Patients also receive education on treatment options outside scheduled visits considering risks and benefits, availability, and cost.

PATIENTS LIVING IN RURAL AREAS

A survey of Canadian HCPs regarding perceptions of inequities in care for patients with inherited bleeding disorders [18] indicated that patients in rural areas experienced significant lack of access to care. An analysis of a survey of 327 participants (50% adult, 64% severe hemophilia) in six states in the US [19] concluded that most patients denied barriers to HTC utilization; however, of the 14% who identified barriers the most frequently reported barriers were "distance to the clinic" for children (44%). Moreover, a cost analysis of Canadian families with children who have hemophilia [20] found that they bear costs for their care despite universal, comprehensive health care coverage. These costs (direct and indirect) are mainly associated with the travel distance to the clinic and represent a significant burden to those families who live the furthest from the clinic. Their results demonstrate that the total cost to attend the HTC increased by $2.16 per kilometer from the HTC. Their results underscore the need for strategies to improve access to a specialized pediatric multidisciplinary bleeding disorders team.

PATIENTS WITH HEALTH INSURANCE BARRIERS

In 2020, a review of 16 large health insurance plans in the US [21] found wide variations in how plans covered Hemophilia A treatments. Plans added conditions on coverage beyond the Federal Drug

Administration's labeling roughly half of the time, generally related to frequency of bleeding. Variable coverage affects access to treatment and may have implications on disease management.

PATIENTS TRANSITIONING TO ADULTHOOD

Primary prophylaxis represents the best available care for young adults with severe hemophilia, but clinical outcomes and quality of life remain impaired compared with the general population [22]. Primary prophylaxis is associated with the levels of anxiety and depression that are similar to those reported by people using on-demand treatment. Pain is common and is accompanied by presenteeism at a level comparable to that reported in people with osteoarthritis, an older population with more joint disease. In roundtable discussions of patients, caregivers and providers identified among young adults with hemophilia [23], issues related to transition were identified. These include psychosocial issues related to maturity, personal responsibility, and increased independence, as well as concerns regarding when and with whom to share information about one's hemophilia, limited awareness of educational and financial resources, and a low perceived value of regular hematology care. The initiatives proposed herein highlight important opportunities for health care professionals at pediatric and adult hemophilia treatment centers, as well as national organizations, community groups, and career counselors, to address key unmet needs of this patient population.

RACIAL AND ETHNIC MINORITIES

Among adolescent and young adults with moderate to severe hemophilia, non-whites were more than five times more likely to report high levels of chronic pain, which predicted worse overall physical quality of life, bodily pain, physical and social functioning, and greater role limitations due to physical health [24]. This was not related to adherence with recommended treatment. Moreover, the prevalence of high-titer inhibitors in the Hispanic participants was 24.5% compared to 16.4% for White non-Hispanic patients in an analysis of the Universal Data Collection database by Carpenter et al. A better understanding may lead to tailored treatment programs, or other therapies, to decrease or prevent inhibitor development for the leading complication of hemophilia care [25].

SURVEYS AND FOCUS GROUPS OF HTC MEMBERS AND HTC PATIENTS AND FAMILIES

The goal of the surveys and focus groups as part of the VBDP Needs Assessment Project was to assess the influence changing health care delivery services on patient and families, including but not limited to new treatment modalities, telehealth, outreach to unserved or underserved populations and funding constraints.

DESIGN AND DEVELOPMENT PLAN FOR SURVEYS AND FOCUS GROUPS

VBDP's core team at VCU contracted with VHF to assist in the assessment of the program because VHF has access to patients and families affected by bleeding disorders throughout the Commonwealth and has a strong collaborative relationship with HACA. VHF and HACA provided guidance in the development of surveys that would be sent to persons and families with bleeding disorders and HTC surveys that would be sent to all Virginia HTCs and Non-Virginia HTCs in neighboring states. VHF and HACA also assisted with increasing awareness of this project through email and social media and hosting focus groups to identify unmet needs of their constituents and their perceptions of changing health care delivery. VBDP's core

team contracted with VCU's Survey and Evaluation Research Laboratory (SERL) for survey consultation and creation and to observe focus groups and provide data analysis. SERL assisted VBDP core team with formulation of survey and focus group questions, creation of online surveys in REDCap (Research Electronic Data Capture) and with gathering and analyzing data.

This project received a determination of "non-research" status by VCU Institutional Review Board (IRB), therefore, it is not subject to the regulations and no IRB review or approval was required.

VIRGINIA AND NON-VIRGINIA HEMOPHILIA TREATMENT CENTER SURVEY

METHODS: On May 17, 2021, the VBDP Core team at VCU distributed an invitation with a public link to the REDCap survey to 21 providers at the 4 VA HTCs (VCU, CNH/PSV, CHKD, UVA) and to 18 providers in 5 non-VA HTCs in adjacent states (DC, WV, NC). The main goal of the VA-HTC survey was to identify unmet patient/family needs and change of services needed to better serve Virginia residents receiving care at VA-HTCs. The main goal of the non-VA HTC survey was to understand the needs of Virginia residents that seek their bleeding disorders care at HTCs outside of Virginia. Quantitative data was obtained through closed-ended questions using dichotomous and multiple-choice type of questions (Likert-scale, rating scale, rank order, and checklists) and qualitative data to capture providers' opinions and comments was obtained through open-ended questions. Surveys were closed to participants on June 30, 2021. Upon completion, SERL provided a clean and documented datafile for the survey.

SAMPLE AND RESPONSE RATE:

VA HTC SURVEY Sixteen providers from VA HTCs responded to the survey (76% response rate). Three physicians (19%), 7 nurses or nurse practitioners (44%), 5 social workers (31%) and 1 administrator (6%) participated. The majority of the VA HTC respondents only treat pediatric patients (69%). Only two centers in VA treat adult patients and survey respondents indicated that they treat only adult (6%) or adult and pediatric patients (25%). To protect the confidentiality of respondents, the survey did not include questions that would identify their HTC; therefore, data is not available on the response rate per HTC; however, the high response rate for the VA HTC survey indicates that all four centers are represented in the survey data.

- More than 50% of VA HTCs offer physicians/nurse practitioners, social workers, and mental health services via telehealth. Challenges encountered during telehealth visits include inability to do a complete examination (69%), lack of lab coordination (69%), lack of internet connection (50%), increased barriers for ESL patients (44%) and lack of smart phones (38%).
- Delay in diagnosis from symptom onset in groups with inherited bleeding disorders is frequently seen in hemophilia carriers, patients with milder symptoms and undocumented immigrants. Survey respondents see inequities among groups with limited English proficiency (37%), undocumented immigrants (36%), and low socioeconomic status (27%).
- The top 3 insurance barriers experienced by participants are high copays (45%), lengthy prior authorization process (32%) and HTC not in network (23%).
- Seventy three percent of survey respondents feel that distance to treatment is a barrier to nearly half of their patients, and 56% provide a satellite clinic primarily because of the distance their patients must travel. Satellite clinics are staffed by physicians, nurses, social workers, and physical therapists.
- Most respondents (88%) feel that additional outreach for ongoing routine follow-up, more contact with patients and fewer in-person visits are needed for patients that have switched from taking factor replacement therapy to Hemlibra® therapy.

- Respondents feel that, in addition to the current services that VBDP funds, it should fund support for outreach to underserved (60%), assistance with satellite clinics (53%) and statewide awareness and public education of bleeding disorders (47%).

NON-VA HTC SURVEY Six providers from non-VA HTCs responded to the survey that was sent to 5 centers in neighboring states (Georgetown, Charleston Medical Center, West Virginia Medical Center, Wake Forest, and UNC). These HTCs were chosen because they are located in states geographically adjacent to Virginia and had been identified by the CDC Public Health Surveillance Project for Bleeding Disorders (Community Counts) Population Profile. The Non-VA HTC survey response rate was 33%. Data is not available regarding the response rate per non-VA HTC.

- All non-VA HTC survey respondents indicated that they serve patients who reside in VA and 50% indicated that their center accepts VA Medicaid plans.
- The main reasons that patients are served outside of VA are distance or geographic barrier (83%) and patient/family preference of providers (67%).

HTC SURVEY- MAIN THEMES:

VA HTC SURVEY

1. **Certain groups are underserved:**
   - Inequities are reported in non-English speaking patients, patients with immigration status issues, and patients with low socioeconomic status.
   - Women, patients with mild bleeding symptoms, and patients with immigration status issues experience a delay in diagnosis.
2. **Insurance:** High copays, burdensome prior authorization requirements, and insurance plans that do not have HTCs in their network of providers are the most significant insurance barriers
3. **Distance to Care:** The distance from the patient's home to the HTC is a barrier to treatment.
4. **Changing Treatment and Patient Needs**: Most providers state that Factor VIII Deficient patients on Hemlibra® have less need for in person visits but more need for outreach and contact than patients not on Hemlibra®.
5. **Unmet Needs:** Mental health, pain management and substance abuse disorder services are unmet needs.

NON-VA HTC SURVEY

- **Reason that patients are served outside of VA:** Distance or geographical barriers to HTC is the primary reason; however, provider preference is also important.

While these themes emerged most strongly, Appendix C includes detailed survey results and figures.

VBDP PATIENTS/FAMILY SURVEY

METHODS: On May 17, 2021, patient/family survey invitations were sent out by email or direct mail to 392 households to reach 414 patients served by any of the four HTCs in VA. Survey invitations sent by e-mail included a public link to the REDCap Patient/Family Survey. Surveys sent by direct mail included a web address to the REDCap survey in a cover letter for those who preferred to respond electronically. Surveys were available in English and in Spanish. The main goals of the survey were to identify unmet patient/family needs, barriers to healthcare among patients and implications of changes in treatment of bleeding disorders. Each HTC patient per household was invited to complete the survey, since the needs and issues depend on the patient's age and severity of their condition. The survey was divided into two sections. Questions in the first section pertained to the entire household and questions in the second section referred to each individual patient. The survey included an option to add additional patients and answer the same questions for each individual patient in the household. To protect the confidentiality of respondents, surveys were not connected to home or email addresses and data was completely de-identified. Quantitative data was obtained through closed-ended questions using dichotomous and multiple-choice type of questions (Likert-scale, rating scale, rank order, and checklists) and qualitative data to capture responders' opinions and comments was obtained through open-ended questions. Open-ended questions were targeted at specific patient age groups. Surveys were closed to participants on June 30, 2021. Upon completion, SERL provided a clean and documented datafile for the survey.

SAMPLE AND RESPONSE RATE: The patient and family survey yielded 78 respondents (20% response rate). Forty-four adult patients (56%) and 34 parents, caregivers, or legal guardians (44%) responded to the survey. The majority of the adult patients were between ages 37 to 64, while the majority of children were between ages 6 and 15 years old (Table 1). All four HTCs were represented in the survey data: VCU (57%), CNH/PSV (15%), CHKD (13%), UVA (15%). All 6 health regions in VA were represented: Central (41%), Hampton Roads (29%), Northern (17%), Blue Ridge (8%), Roanoke (4%), and Southwest (1%). Demographic data of survey respondents is shown in Table 1 and data is compared to data from patients who currently receive care through the VBDP.

- Nearly all respondents (95%) receive care within two hours from their home and transportation to clinic is not a problem for most (94%).
- All respondents indicated they have health insurance; most have insurance access through an employer (59%) and have not experienced insurance problems within the past year (66%). For those who have experienced insurance problems, the top three problems within the past year have been with authorization for medications or services, copays, and insurance networks. Nearly half (47%) use copay assistance programs for bleeding disorder medications (mostly copay cards from drug makers).
- Most respondents (75%) are interested in telehealth visits, 60% have participated in a telehealth visit, and 99% have internet access at home and have a cell phone or computer that they can use for telehealth visits.
- All respondents reported being moderately to very satisfied with their HTC's care coordination, and 99% can reach their HTC when they need to coordinate care. Of the 22% of patients who had surgery in the past year, 82% said that the HTC helped coordinate this care. Forty-three percent of patients or caregivers of patients under 21 years, who responded that their HTC helps with school/daycare issues, would like more help in coordinating school and daycare issues, including emergency and health plans as well as special education plans and post high school planning.

- Over a third of patients changed their primary medication in the past three years, with the most significant medication change related to starting Hemlibra®. Of those changing to Hemlibra®, 91% still prefer the same visit frequency.
- In terms of providers at HTC visits, over 75% report receiving physician, nursing, social work, and physical therapy services. Of those who wanted additional services at the comprehensive visit, nutrition was the most requested service.

TABLE 1. Demographic Data for patient/family survey respondents vs. VBDP participants

	Survey Respondents N= 78		VBDP Participants N=414	
Age Categories (years)	**n**	**%**	**n**	**%**
0 to 5	6	8	62	15
6 to 15	19	25	125	30
16 to 20	8	10	63	15
21 to 25	1	1	32	8
26 to 36	6	8	51	12
37 to 64	19	25	65	16
> 64	11	14	16	4
Missing	7	9	0	0
Gender Identity	**n**	**%**	**n**	**%**
Male	66	85	374	90
Female	11	14	40	10
No answer	1	1		
Race	**n**	**%**	**n**	**%**
White	58	74	266	64
Black or African American	6	8	106	25
Asian	6	8	29	7
Multiracial/ multicultural	7	9	11	3
No answer	1	1	2	1
Ethnicity	**n**	**%**	**n**	**%**
Not-Hispanic or Latino	72	92	374	90
Hispanic or Latino	5	7	38	9
No answer	1	1	2	1
Bleeding Disorder Type	**n**	**%**	**n**	**%**
FVIII Deficiency	52	67	273	66
FIX Deficiency	12	15	71	17
VWD	9	12	54	13
Other Factor Deficiency	5	6	16	4
Bleeding Disorder Severity	**n**	**%**	**n**	**%**
Severe	41	53	226	55
Moderate	8	10	39	9
Mild	13	17	69	17
Other, Unidentified, Unknown	16	20	78	19
Clinic	**n**	**%**	**n**	**%**
VCU	44	57	194	47
UVA	11	15	87	21
CNH/PSV	11	15	74	18
CHKD	10	13	59	14
Geographic Region	**n**	**%**	**n**	**%**
Central	32	41	119	29
Northern	13	17	95	23

Roanoke	3	4	29	7
Southwest	1	1	7	2
Hampton Roads	22	29	104	25
Blue Ridge	6	8	60	14

Limitations of Survey:

As noted from Table 1 above, the survey respondents were largely representative of the VBDP participants in terms of diagnosis, severity of disease, gender identity and ethnicity. Black or African Americans are underrepresented in the survey. Older patients and those from the Central Virginia region are over-represented.

MAIN THEMES:

1. **Overall Satisfaction:** Patients are satisfied with their HTC care.
2. **Insurance:** All survey respondents had insurance and the majority do not report insurance barriers, but authorizations for medications or services are the largest insurance difficulty.
3. **Distance to Care:** Distance was not identified as a barrier, but transportation is a barrier for some patients. Patients are interested in telehealth options and the majority have cell phone/internet access.
4. **Changing Treatment and Patient Needs**: Patients on Hemlibra® report less interaction with HTC but want same appointment frequency
5. **Unmet Needs:** There is interest in more nutrition services and mental health services.

While these themes emerged most strongly, Appendix D includes detailed survey results and figures.

Focus Groups

METHODS: VBDP's core team contracted with VCU's SERL to observe focus groups and conduct a qualitative analysis of the groups. Four focus group meetings were held via zoom between April 12 and June 28, 2021. Three out of the four focus groups were conducted with 13 key chapter stakeholders and one with 7 members of the chapter team. The SERL team observed and took notes of these focus groups off camera. Three out of the four focus groups asked questions to key chapter stakeholders, which included patients and/or family members that have volunteered with the chapter, and one focus group asked questions to members of the chapter team, which included VHF and HACA staff as well as constituents. After the focus group meetings concluded, the SERL team performed a qualitative analysis using a systematic approach that highlighted emergent themes within each question asked.

MAIN THEMES:

1. T**he proximity of a patient to a treatment center impacts access to care.** In all four focus groups, the hard to reach or underserved regions mentioned Southwest Virginia and rural areas in Virginia. Areas that do not have access to a treatment center were cited as hard to reach, while areas close to a treatment center receive enough support. Attendees gave insight into how support can be spread to these areas. These insights included continuing to use and develop the technology that

was required by the recent COVID 19 pandemic to increase the connection between urban and rural areas. They also suggested providing mobile centers that visit these localities to provide care periodically and recruiting volunteers in areas without a treatment center.

2. R**acial minority patients and non-English speaking patients are underserved**. Focus group attendees listed People of Color and non-English speaking community specifically as being underserved. The language barrier was cited, as well as cultural differences in certain minority communities that discourage patients from asking for help because of the stigma that is often associated with having an illness. Reaching these populations through generational mentorships was mentioned as an avenue for outreach. While some participants indicated that they could not be certain that these communities were underserved (lack of data), the groups consistently mentioned that they believed that they were based on participation at events that they had attended.
3. W**omen are being misdiagnosed, undiagnosed or not taken seriously by health professionals**. Focus group participants mentioned how women, including patients that are older than 50 and those that are carriers are a consistently underserved population about their bleeding disorder care. It was consistently mentioned that and finding the right physician when transitioning from pediatric to adult care is difficult for them as well. Finding care when transitioning away from pediatric care was mentioned in other contexts as well. While the recent opening of the UVA adult treatment center seemed to alleviate some of this difficulty, it was still mentioned as an issue by many participants.
4. **Education and awareness** were also identified as a need for this community. Education of medical students and other health practitioners on bleeding disorders in general was believed necessary, as well as better education on how to diagnose and determine the best treatment needs. Focus group participants indicated that education needs to begin with the pediatrician and then carry on to other specialties to provide comprehensive care for bleeding disorder patients. It was felt strongly that this increase in education around bleeding disorders needs to be integrated into medical school curricula as well. A need for more general awareness around insurance was also a key topic. Participants mentioned how important insurance is to an individual with a bleeding disorder and how there are so many challenges surrounding insurance and high costs for treatment that the public often does not know about. The costs associated with having a bleeding disorder need to be examined so that support and advocacy can be strengthened.

FURTHER ANALYSIS OF DISTANCE PATIENTS TRAVEL TO HTC

Rationale: Distance to HTC was a recurrent concern in the provider surveys and focus groups results. However, distance to care was not identified as a barrier in the patient/family survey. To further understand the barrier of distance to care, an analysis from the VBDP database was conducted.

METHODS: In October of 2021, the current registry of 432 patients on the VBDP were evaluated to ascertain distance from home to HTC. The distance from patient zip code to their HTC zip code was ascertained.

RESULTS: 284 (66%) of the patients on the VBDP reside greater than 50 miles from their HTC. Patients who receive care at UVA live furthest from their HTC, and the majority (68%) live greater than 50 miles away.

Forty-two percent of those patients live in Southwest VA and Roanoke regions. Seventy-five (58%) of adult patients that receive care at VCU live greater than 50 miles from the clinic. Of those patients, 51% live in the Hampton Roads region and 49% travel from Southwest and Roanoke area. (See Table 2 below).

Table 2. Analysis of distance to Hemophilia Treatment Center (HTC)

HTC	n	Average miles (min, max)	% Traveling > 50 miles
UVA Peds	60	89 (8, 227)	77% (62% from Roanoke and Southwest regions)
UVA Adult	34	72 (1,275)	53% (44% from Roanoke and Southwest regions)
VCU Peds	60	36 (4,188)	37% (Primarily within their region)
VCU Adult	131	59 (1,224)	58%; (51% from Hampton Roads region)
CNH	76	20 (1, 95)	8% (All within their region)
CHKD	71	28 (3,110)	13% (Primarily within their region)

DISCUSSION: Although the respondents to the patient and family survey did not identify distance to HTC as a barrier, MANY patients travel considerable distances to seek care at an HTC. This disparity may be related to the geographic location of the respondents, meaning that those who responded lived closer to an HTC or it may be the perception of the respondents. That is, patients who lived a distance from the HTC may not view this as a barrier to care.

DISCUSSION OF VBDPAP THEMES

DOES VBDP SERVE ITS TARGET POPULATION?

Over eighty percent of the projected males with hemophilia in Virginia receive care at an HTC and most participate in the VBDP. Differences in the estimated prevalence and actual numbers served by the program were noted in the Northern Virginia, Roanoke, and Southwest Virginia areas. This suggests that some Virginia residents with hemophilia in these areas may be encountering some barriers to care or are seeking care outside the national HTC network. Of the Virginia residents with hemophilia seen out-of-state, the majority are seen at Georgetown University Hospital.

Several limitations are noteworthy in this analysis. The study did not include data for patients seen outside of the HTC network which could result in an underestimation of overall occurrence of hemophilia in VA. Moreover, the only inherited bleeding disorder studied by this analysis was hemophilia in males. Therefore, females with hemophilia and all genders with other inherited bleeding disorders are not represented. These groups are less well studied, and prevalence rates vary widely among existing reports.

ARE PATIENTS/FAMILIES SATISFIED WITH CARE THEY ARE RECEIVING THROUGH HTC?

Patient satisfaction in health care is associated with adherence and better outcomes. To measure satisfaction, three National Patient Satisfactions Surveys have been conducted from 2014-2021. In each of these surveys, in patient overall satisfaction with HTCs' services, greater than 93% stated that they were always or usually satisfied with care. All patients and families surveyed in this project were moderately to very satisfied with HTC care coordination.

WHAT UNMET NEEDS OF PATIENTS AND FAMILIES ARE IDENTIFIED?

Results from the three surveys and a current literature review have identified several unmet needs of patients and families.

1. Distance to care or travel to HTC was seen as a barrier to care. This is most notable for patients at the UVA pediatric and adult HTCs and for the VCU adult HTC. Areas of the state in which patients travel the greatest distance to an HTC are Southwest Virginia and Roanoke as well as Hampton Roads (for adult care). Patients in rural areas in general have been identified as an underserved group and further assessment is needed to delineate the barriers. Non-Virginia HTC providers rate distance to care as the primary reason Virginia residents seek HTC care outside of the Commonwealth.
2. While most patients on the VBDP have access to health insurance, HTC providers, patients and key stakeholders identified insurance as a barrier to care. Providers and patients noted that copays especially for clinic visits and labs, lengthy prior authorization process, and insurance network access to HTC were the most significant problems. Almost half of the patients surveyed use manufacturer copay programs. Focus groups also noted that lack of awareness and education about insurance was a barrier.
3. Both the HTC and patient surveys identified mental health services as an unmet need. The top five priority services for HTC providers also included substance abuse and pain management services as well as genetics counseling and dental care. Of patients reporting an interest in additional services,

nutritional service is the most requested. Patients/families of children under age 21 expressed an interest in more help with coordinating school and daycare issues.

WHAT GROUPS ARE UNDERSERVED OR UNSERVED BY THE VBDP?

Results from the HTC provider survey and focus groups support current literature that cite the following groups* in the inherited bleeding disorder community as being underserved. Providers added that these groups experience delays to diagnosis.

1. Patients with limited English proficiency
2. Patients with immigration status concerns
3. Patients with low socioeconomic status
4. Females, especially those with heavy menses as the presenting symptom
5. Patients with mild bleeding symptoms
6. Racial minorities. These groups are not specifically identified by the HTC survey but are noted in focus groups and literature review. The review of the VBDP patients in comparison to projected prevalence of patients with hemophilia notes a disparity in minority groups. Moreover, the VBDP patient survey notes that racial minorities were underrepresented in the survey.

**These groups are not discrete groups, and they are not presented in order of significance.*

WHAT SERVICES, IF ANY, ARE NEEDED TO MEET THE CHANGES IN HEALTH CARE DELIVERY SYSTEMS AND BLEEDING DISORDER TREATMENT?

The advent of new long-acting factor concentrates, non-factor therapeutics and gene therapy is significantly changing bleeding disorder treatment. In the VBDP patient/family survey, 38% of the respondents had changed their treatment in the past three years. The majority of those who changed treatment transitioned to Hemlibra®. Patients surveyed who are taking Hemlibra® report less interaction with HTC but want the same appointment frequency with their HTC. Most HTC provider respondents (88%) feel that additional outreach for ongoing routine follow-up,

more contact with patients and fewer in-person visits are needed for patients that have switched from taking factor replacement therapy to Hemlibra®. The response rate to survey questions about gene therapy is too low to provide meaningful information.

Almost 75% of the VBDP program respondents were very or somewhat interested in telehealth visits. However, HTC providers identify challenges in these visits. At least half report an inability to do a complete exam, a lack of lab coordination and lack of internet connection. Increased barriers were noted in communicating with patients whose primary language is not English.

SHOULD VBDP CONTINUE THE SAME SERVICES? ARE OTHER SERVICES NEEDED?

All the HTC respondents suggest that nursing or social work care coordination services continue to be supported by VBDP. Over 85% also suggest continuing assistance with bleeding disorders medication, health insurance consultation and premium assistance. These respondents identified support for outreach to underserved, assistance with satellite clinics and statewide awareness and public education about bleeding disorders as priorities for other services that VBDP should fund in the future. Over half of the

respondents already provide some satellite clinics. The focus groups, moreover, underscore the need for education and awareness, but targeted medical providers for education and insurance as priority for awareness.

RECOMMENDATIONS (WITH LEAD)

EXPAND ACCESS TO VBDP FOR PATIENTS WITH INHERITED BLEEDING DISORDERS OTHER THAN FACTOR DEFICIENCIES

Issue: HTCs are serving Virginia residents with inherited bleeding disorders other than factor deficiencies, but these patients have not been targeted for enrollment into VBDP. These include patients with mild disease and women with bleeding disorders that were identified in the VBDPAP surveys and focus groups.

Strategies:

1. Reconsider enrollment process for VBDP. (Central Office, Program)
    a. Consider an "all-in" approach to enrollment, by eliminating the VBDP application for care coordination services and replace with an ATHN report completed quarterly by the HTCs
        i. De-identified data may not need patient or family consent
        ii. Eliminates barriers to enrollment created with application completion
        iii. Better captures care coordination services being provided by RN/SW through VBDP support
    b. Consider contract with ATHN to develop form. (Central Office, Program)
    c. Explore Pennsylvania Hemophilia Program as example, considering data use concerns. (Central Office, Program)
    d. Continue to use applications as needed for POF and premium assistance
    e. Consider data not captured without applications and identify need or utilization of this data (Central Office, Program)
2. Analyze HTC Hemophilia and Thrombosis Data Set reports from Virginia HTCs to identify which groups may still be underserved. (Program)
3. Explore public health strategies with chapter support to increase awareness for women, mild disease patients and undocumented individuals. (Central Office, Program, HTCs, chapters)

SUPPORT STRATEGIES TO REDUCE DISTANCE AS A BARRIER TO CARE

Issue: Distance to care and transportation were identified by providers as barriers to accessing HTC care

Strategies:

1. Identify HTC needs to support increasing telehealth and satellite clinic options. Consider the unique challenges of telehealth visits for patients whose primary language is not English and consider best practices in telehealth. (Central Office, Program and HTCs)
2. Explore and disseminate existing transportation support resources (Program, HTCs, chapters)
3. Explore contracting with Georgetown HTC to serve significant adult population not receiving VBDP services in Northern Virginia. (Central Office, Program, CNH HTC)

REDUCE INSURANCE BARRIERS

Issue: The use of premium assistance and pool of funds for hemophilia medications have decreased in the past several years. Providers and patients have noted that copays for clinic visits and/or labs as well as cumbersome prior authorization processes and restrictions on network access are current barriers to care.

Strategies:

1. Consider reducing or eliminating pool of funds and insurance premium assistance and redirecting funds. (Central Office, Program)
2. Identity and disseminate best practices for insurance prior authorizations to reduce HTC and patient burden. (Program, HTCs)
3. Consider further analysis of copays' needs (since technical error in surveys limited interpretation of answers to this question). Specifically, explore Medicare copay issues. (Program, HTCs, Chapter)
4. Consider further analysis of health care access for undocumented individuals. (Program, HTCs, Chapter)

PROVIDE SUPPORT TO PATIENTS DURING DRAMATIC CHANGES IN BLEEDING DISORDERS TREATMENT

Issues: The increased use of non-factor therapeutic treatments has changed the needs of some patients with hemophilia. Providers have noted the need for more outreach and patients are interested in alternatives to in person visits. The impact of gene therapy was not able to be delineated in this project.

Strategies:

1. Support outreach efforts for continuity of care. (Program, HTCs)
2. Consider alternatives to in person visits. (Program, HTCs)
3. Consider further evaluation of the impact of gene therapy in the future. (Program)

INCREASE ACCESS TO SERVICES FOR MENTAL HEALTH, SUBSTANCE ABUSE, PAIN MANAGEMENT, GENETICS COUNSELING, NUTRITION SERVICES, DENTAL CARE.

ASSIST PARENTS OF YOUNG CHILDREN IN COORDINATING DAYCARE AND SCHOOL ISSUES.

Issue: Access to mental health services was identified as a primary unmet need.

Strategies:

1. Identify and disseminate information about existing mental health resources. Consider community-based resources and telehealth alternatives. (Program, HTCs, Chapters)
2. Continue to fund care coordination services through HTCs to help patients and families identify and access resources.
3. Encourage and support expanding genetics and nutrition services at HTC (Central office, Program, HTCs)
4. Analyze further the daycare and school coordination issues for families. Specifically survey educational consultants to understand if COVID affected these needs. (Program, HTCs)
5. Analyze further the dental care needs of patients, specifically considering lack of awareness of Medicaid funding for dental care. (Program, HTCs)
6. Alter transition calls for HTC pediatric referring centers to complete semi-annual call with HTC adult providers, considering specifically school-related issues during transition. (HTCs)

APPENDIX A: References

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Appendix B: Prevalence Rate Study

Virginia Bleeding Disorders Program Assessment 2020
(5-Year study- 2015-2019)

The VBDP Needs Assessment Project aimed to identify all persons with hemophilia who resided in Virginia in 2015 -2019 and to determine the percentage of patients in Virginia cared for at the four hemophilia treatment centers (HTCs) in the state of Virginia.

	VBDP n=423		**PP n=478**	
DIAGNOSIS	**n**	**%**	**n**	**%**
FVIII	329	78	369	77
FIX	94	22	109	23
SEVERITY	**n**	**%**	**n**	**%**
FVIII-severe	204	62	227	62
FVIII- moderate	54	16	60	16
FVIII-mild	71	22	82	22
FIX-severe	30	32	35	32
FIX- moderate	28	30	33	30
FIX-mild	35	37	40	37
FIX-unknown	1	1	1	1
AGE (yrs.)	**n**	**%**	**n**	**%**
0-5	56	13	57	12
6-10	57	13	59	12
11-15	53	13	53	11
16-20	59	14	59	12
21-25	58	14	59	12
26-36	57	13	76	16
37 & over	81	19	115	24
RACE	**n**	**%**	**n**	**%**
White	272	64.3	319	66.7
Black	120	28.4	121	25.3
Asian	18	4.3	22	4.6
More than 1 race	10	2.4	11	2.3
Other	3	0.6	5	1.0
ETHNICITY	**n**	**%**	**n**	**%**
Not Hispanic or Latino	348	90	432	90
Hispanic or Latino	39	10	46	10
REGION	**n**	**%**	**n**	**%**
Blue Ridge	41	10	44	9
Hampton Roads	142	34	142	30
Central VA	116	27	117	24
Southwest VA	6	1	8	2
Roanoke	33	8	39	8

Northern VA	85	20	128	27
INSURANCE	**n**	**%**	**n**	**%**
Insured	372	96.1	419	96.3
Not Insured	14	3.6	15	3.4
Unknown	1	0.3	1	0.2

VBDP HTCs	**n**	**%**
HTC137- VCUHS	213	44.6
HTC131- CNMC	82	17.2
HTC135- UVA	66	13.8
HTC138- CHKD	62	13.0
Total	**423**	**88**
OUT OF STATE HTCs	**n**	**%**
HTC132- Georgetown	**43**	**9**
Other HTCs (*Mt. Sinai, NY, Beth Israel, NJ, WVMC, WV, CMC, WV, Wake Forest, NC, Chapel Hill, NC, Univ. of South FL, Fort Worth CHC, TX, North TX CHC, TX, St Luke's, ID)*	12	3
Total	**55**	**12**

Distribution of hemophilia by race/ethnicity and hemophilia severity (PP Data)

	Severe		Moderate		Mild		
Race/Ethnicity	**n**	**%**	**n**	**%**	**n**	**%**	**Total**
Non-Hispanic white	140	51	50	18	87	31	277
Non-Hispanic black	80	67	20	17	19	16	119
Hispanic	24	52	11	24	11	24	46
All other races	40	42	12	29	12	29	41
Unknown	1	1	0	0	0	0	1

Virginia Prevalence Rate estimation: Prevalence rate was estimated for the state of Virginia by dividing the number of unduplicated 2015-2019 Population Profile visits for persons with Factor VIII or Factor IX deficiency who reside in Virginia (n=478) by the estimated Virginia male population in 2015-2019 (n= 4,163,842) and multiplied by 100,000 to express the estimate as the number of cases per 100,000 males.

2015 Estimated male population in VA = 4,124,765 (APPS.vdh.virginia.gov)
2016 Estimated male population in VA = 4,136,814 (APPS.vdh.virginia.gov)
2017 Estimated male population in VA = 4,166,727 (APPS.vdh.virginia.gov)
2018 Estimated male population in VA = 4,190,648 (APPS.vdh.virginia.gov)
2019 Estimated male population in VA = 4,200,257 (APPS.vdh.virginia.gov)
AVERAGE ESTIMATED MALE POPULATION IN VA= 4,163,842

Estimated Prevalence Rate= 11.5* cases per 100,000 males (8.9 FVIII def + 2.6 FIX def)
*This prevalence rate is based only on Factor VIII or Factor IX deficient patients who reside in Virginia who received care at a network HTC during the period 2015-2019.

The estimated prevalence of HA & HB over the 5-year study period **is 11.5 cases per 100,000** males ("crude estimate") which slightly increased to 12 per 100,000 males after adjustment for the differences in the age

distributions of the US and hemophilia population. Age-adjusted rates were calculated using Age-adjusted Weights for U.S. 2000 Standard Population

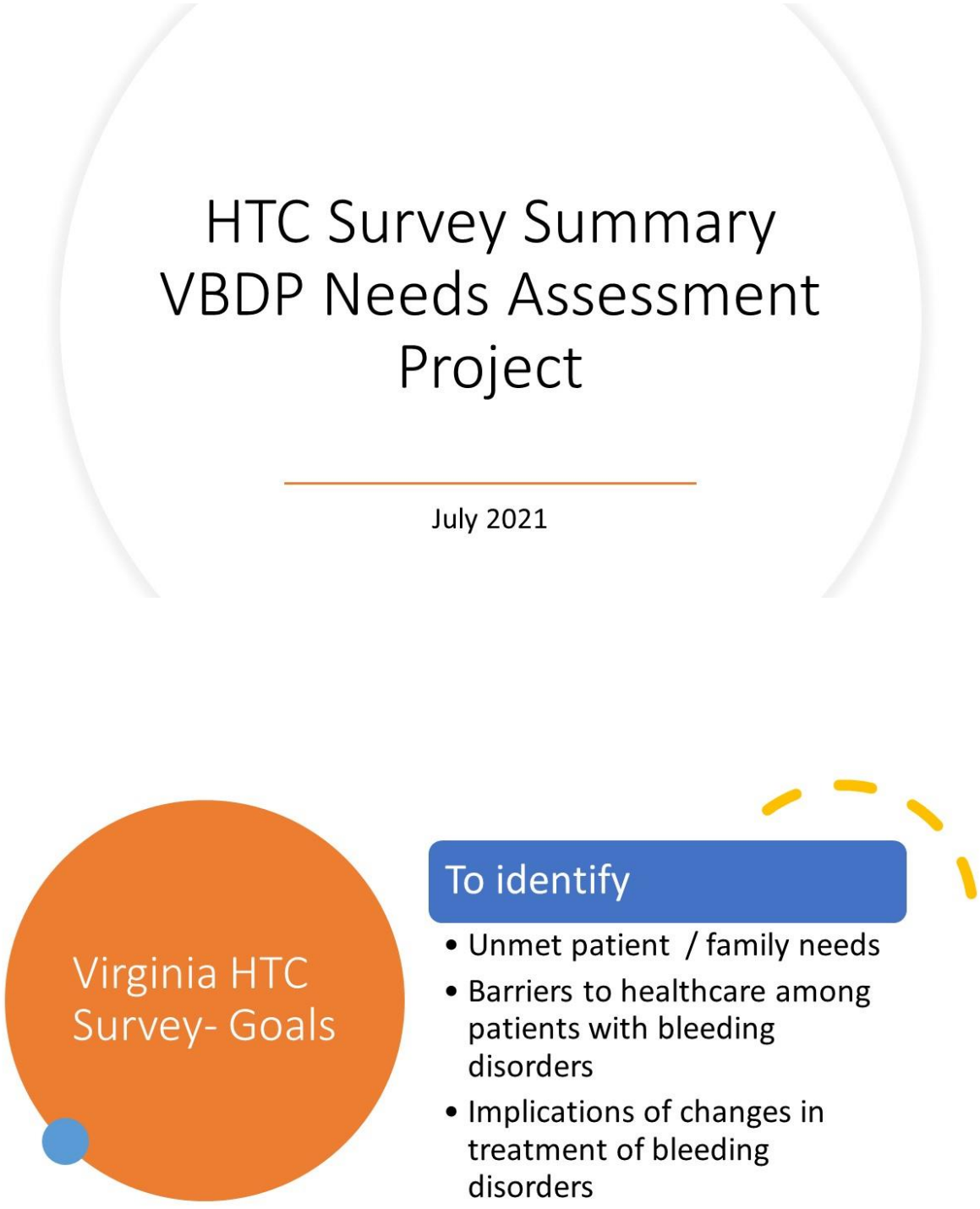
Age Group	PP-Hemophilia cases in VA (a)	VA Male Population (millions) (b)	Rate per 100,000 (c=(a / b) x 100,000)	*Weight (d)	Weighted Rate (cxd)
0-4	42	261417	16.1	0.069	1.11
5-14	118	531262	22.2	0.146	3.23
15-24	117	578298	20.2	0.139	2.81
25-34	76	599846	12.7	0.136	1.72
35-44	41	545307	7.5	0.163	1.22
45-54	27	559458	4.8	0.135	0.65
55-64	27	525131	5.1	0.087	0.45
65-74	20	352034	5.7	0.066	0.38
75-84	8	159741	5.0	0.045	0.22
85+	2	51348	3.9	0.016	0.06
TOTAL	**478**	**4163842**	11.5	**1.0000**	**12**

Regional Prevalence Rate estimation: Prevalence rate was estimated by dividing the number of unduplicated 2015-2019 Population Profile visits for persons with Factor VIII or Factor IX deficiency who reside in each region of Virginia by the estimated Virginia male population in 2015-2019 in the same region and multiplied by 100,000 to express the estimate as the number of cases per 100,000 males.

Region	Hemophilia cases in VA PP(a)	VA Male Population (millions) (b)	Rate per 100,000 (c=(a / b) x 100,000)	*5%
NOVA	128	1277814	10.0	**10.5**
BLUE RIDGE	44	410608	10.7	**11.3**
CENTRAL	117	965011	12.1	**12.7**
HAMPTON	142	843286	16.8	**17.7**
ROANOKE	39	476214	8.2	**8.6**
SW	8	190909	4.2	**4.4**
TOTAL PP	**478**	**4163842.2**	**11.5**	**12**

Region	Hemophilia cases in VBDP (a)	VA Male Population (millions) (b)	Rate per 100,000 (c=(a / b) x 100,000)	*11%	*15%
NOVA	85	1277814	6.7	**7.5**	**7.9**
BLUE RIDGE	41	410608	10.0	**11.3**	**11.8**
CENTRAL	116	965011	12.0	**13.6**	**14.2**
HAMPTON	142	843286	16.8	**19.0**	**19.9**
ROANOKE	33	476214	6.9	**7.8**	**8.2**
SW	6	190909	3.1	**3.6**	**3.7**
TOTAL VBDP	**423**	**4163842.2**	**10.2**	**11.5**	**12.0**

Appendix C: HTC Survey Summary



Virginia HTC Survey- Focus Areas

01

Comparison of current provider services and referral network to anticipated needs

02

Impact of insurance, distance to care and socio-cultural barriers

03

Change in patient and HTC needs with new therapies

Virginia HTC Survey

Survey sent to 4 centers in VA

- Virginia Commonwealth University (VCU)
- University of Virginia (UVA)
- Children's National Hospital and Pediatric Specialists of Virginia (CNH/PSV)
- Children's Hospital of the King's Daughters (CHKD)

16 survey responses received

Virginia HTC Survey

Clinic roles of survey respondents:

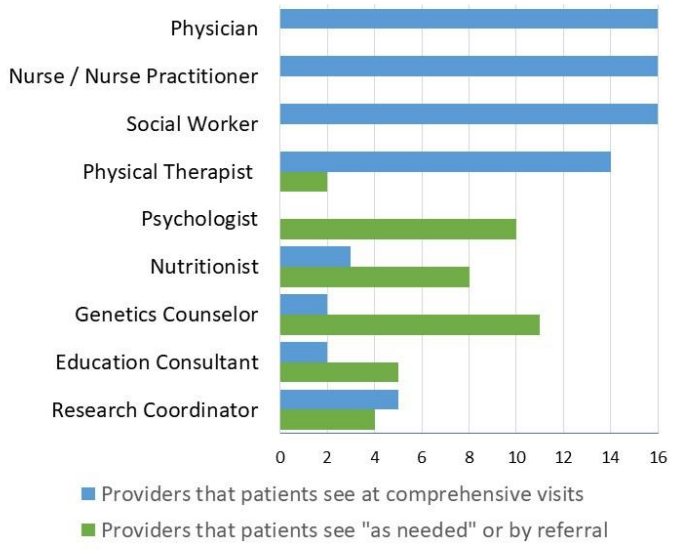
- Physician (19%)
- Nurse/ Nurse Practitioner (44%)
- Social Worker (31%)
- Administrator (6%)

Patients that survey respondents treat:

- Peds (69%)
- Adults (6%)
- Peds & Adults (25%)

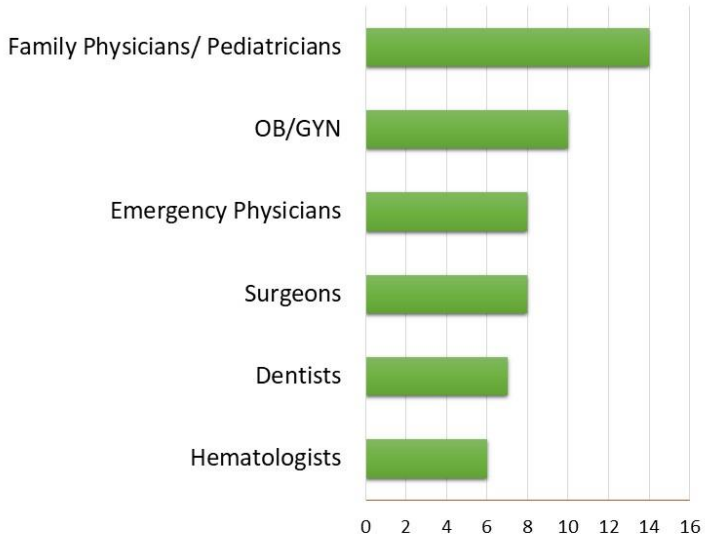
Virginia HTC Survey

Providers seen at HTCs



Virginia HTC Survey

Providers from which HTCs typically receive referrals



Virginia HTC Survey

Reasons why patients are referred to an HTC:

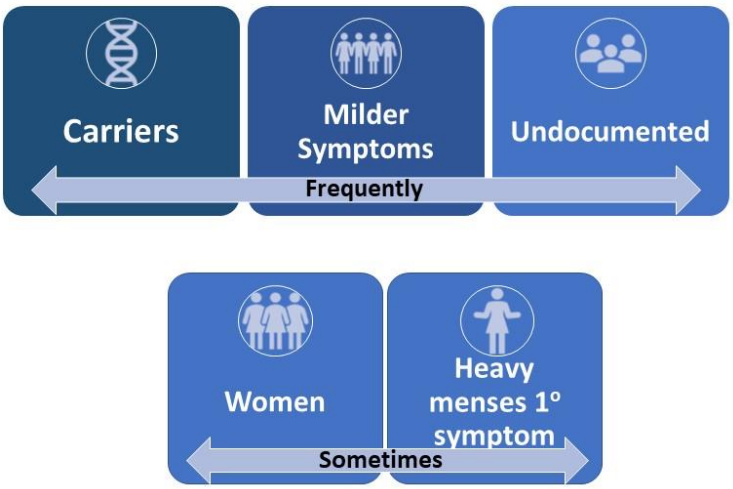
Most common: Symptoms of excessive bleeding

Second most common: Family history

Virginia HTC Survey

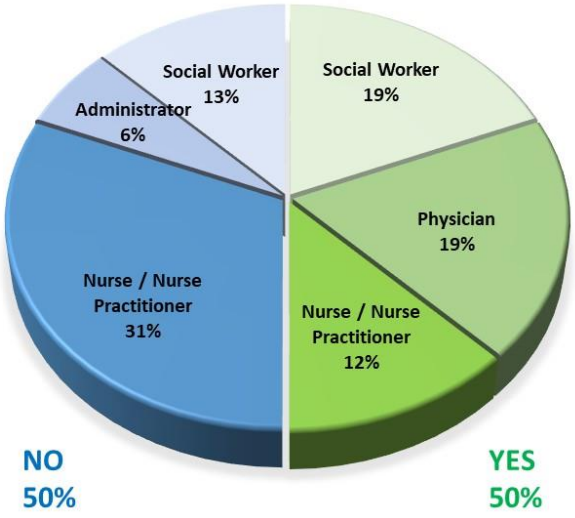
Delay in diagnosis from symptom onset to referral in certain patient groups

Patients that are/have…



Virginia HTC Survey

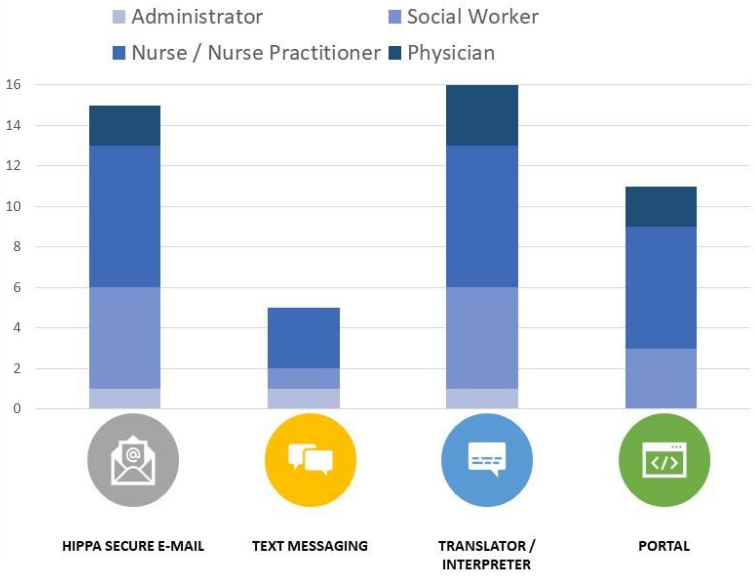
Enough providers and clinic time to see patients?



Virginia HTC Survey

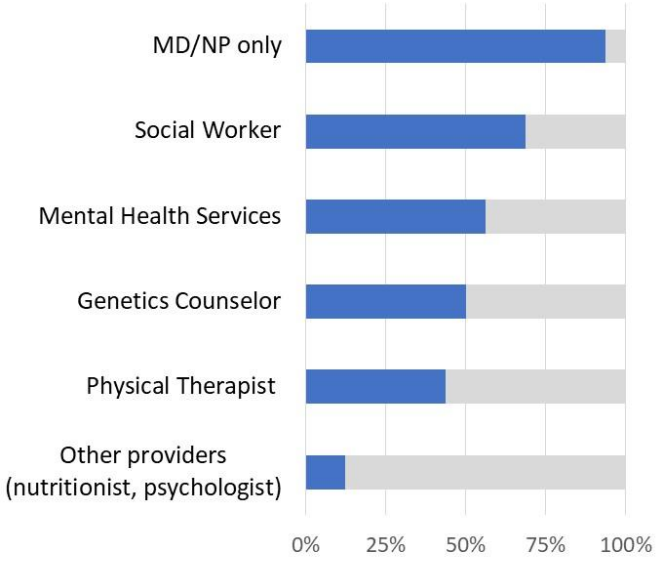
Ways providers communicate with patients*

*(IN ADDITION TO MAIL AND PHONE CALLS)



Virginia HTC Survey

Telehealth options offered by HTCs



Virginia HTC Survey

Challenges encountered with telehealth visits

INABILITY TO DO A COMPLETE EXAMINATION
69%

LACK OF LAB COORDINATION
69%

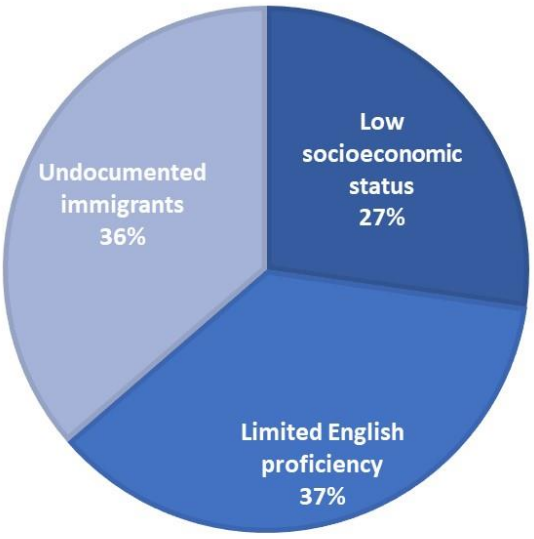
LACK OF INTERNET CONNECTION
50%

INCREASED BARRIERS FOR ESL PATIENTS
44%

LACK OF SMART PHONE
38%

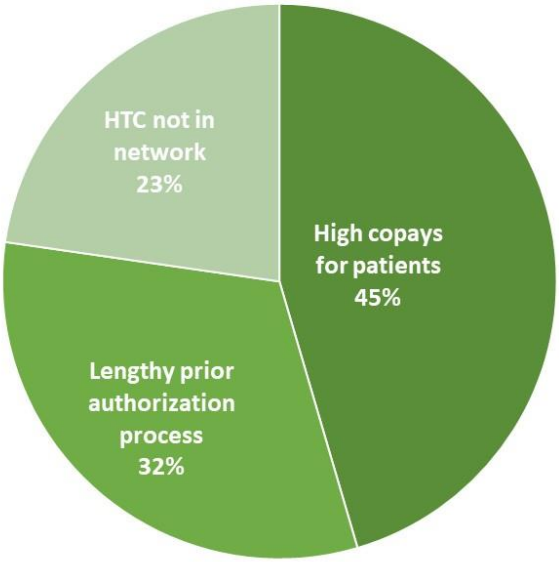
Virginia HTC Survey

Inequities seen among certain groups of patients with bleeding disorders



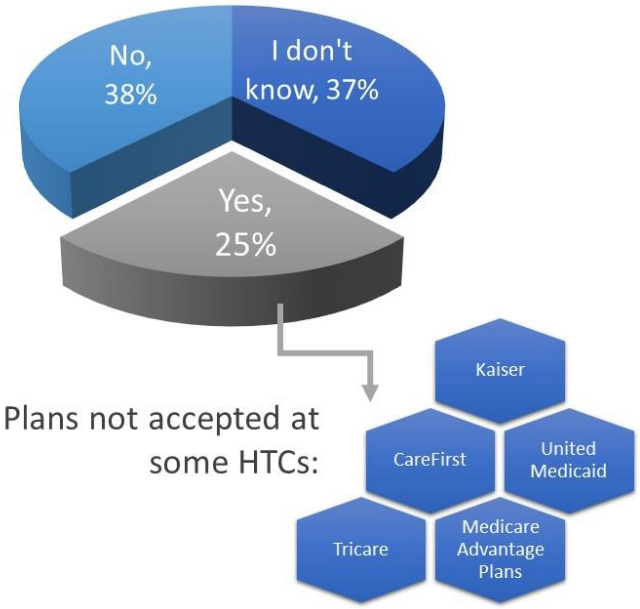
Virginia HTC Survey

Top 3 insurance barriers experienced by respondents



Virginia HTC Survey

Are there plans not accepted at HTCs?

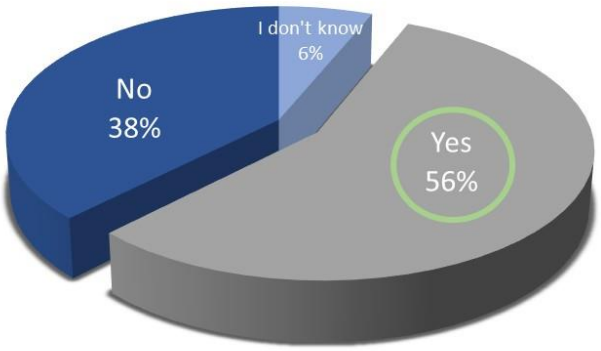


Virginia HTC Survey

73% of survey respondents feel that distance to treatment is a barrier to 25-50% of their patients

Virginia HTC Survey

Do you provide a satellite clinic?



89% Are providing a satellite clinic because of the distance their patients travel

Virginia HTC Survey

How is satellite clinic staffed?

All satellite clinics

PHYSICIAN

NURSE

SOCIAL WORKER

PHYSICAL THERAPIST

Some satellite clinics

PHYSICIAN ASSISTANT OR NURSE PRACTITIONER

RESEARCH COORDINATOR

Virginia HTC Survey

Have the needs of FVIII Deficient patients changed with Hemlibra?

YES (88%)

Top 3 ways needs have changed

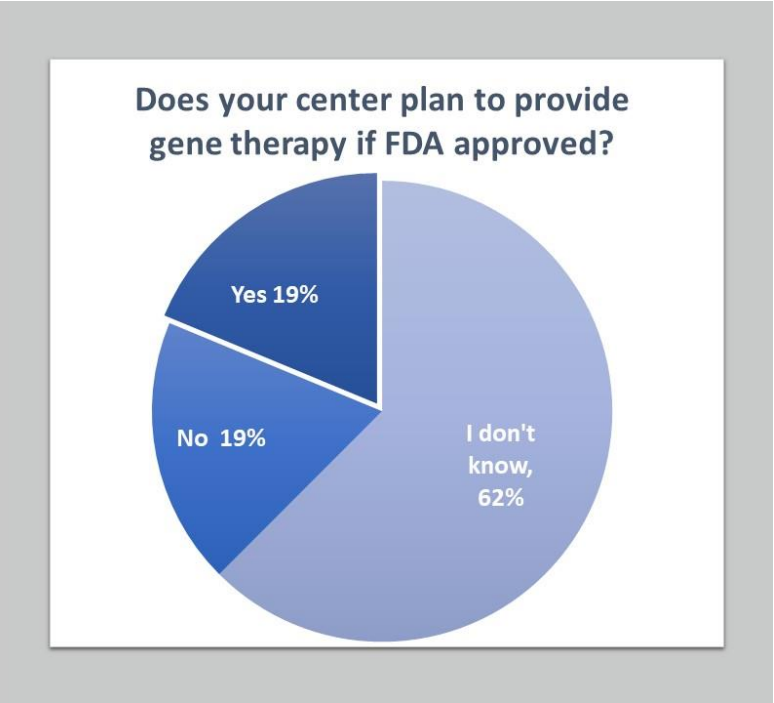
Additional outreach for ongoing routine follow-up	More contact with patients is needed	Fewer in-person visits are needed

Virginia HTC Survey

Gene Therapy

Services needed to provide therapy

- ✓ Time for increased visits
- ✓ Pharmacy services (including management of biological agent)
- ✓ Infusion services
- ✓ Local labs and home care services
- ✓ Health insurance prior authorization and follow-up

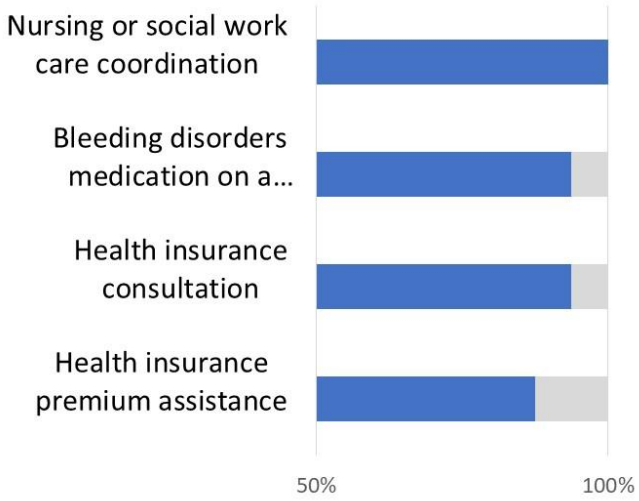


Virginia HTC Survey

Patient / Family Needs

Top 5 needs HTCs are not able to fully address

- Mental health services
- Addiction services
- Pain management services
- Genetics counseling
- Dental care



Virginia HTC Survey

Services VBDP should continue to fund

Virginia HTC Survey

Top 3 other services that VBDP should fund in the future

SUPPORT FOR OUTREACH TO UNDERSERVED (60%)

ASSISTANCE WITH SATELLITE CLINICS (53%)

STATEWIDE AWARENESS AND PUBLIC EDUCATION OF BLEEDING DISORDERS (47%)

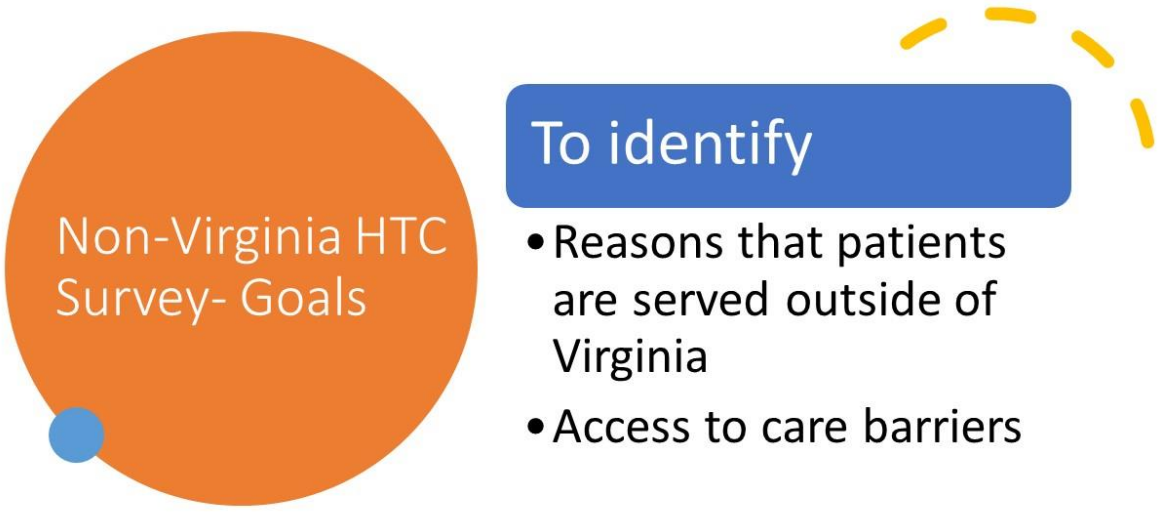
Virginia HTC Survey

Other thoughts/comments from survey respondents

- The support from VBDP is critical for the outreach from our HTC into VA
- Patients with the most significant insurance barrier are those who have Medicare but no supplemental policy to help with copays.
- Aging patient population has increased the need for care coordination and teaching/education of family members and other providers.
- Increasing satellite clinics would reduce the travel barrier and may be appealing to milder patients who do not see the need to travel long distances for care.
- Local hematologists, even those with expertise in coagulation, do not have resources needed to manage patients except in acute circumstances to stabilize before transfer.
- Need additional physicians for adult patients to reach more patients efficiently

Non-Virginia HTC Survey Summary
VBDP Needs Assessment Project

July 2021



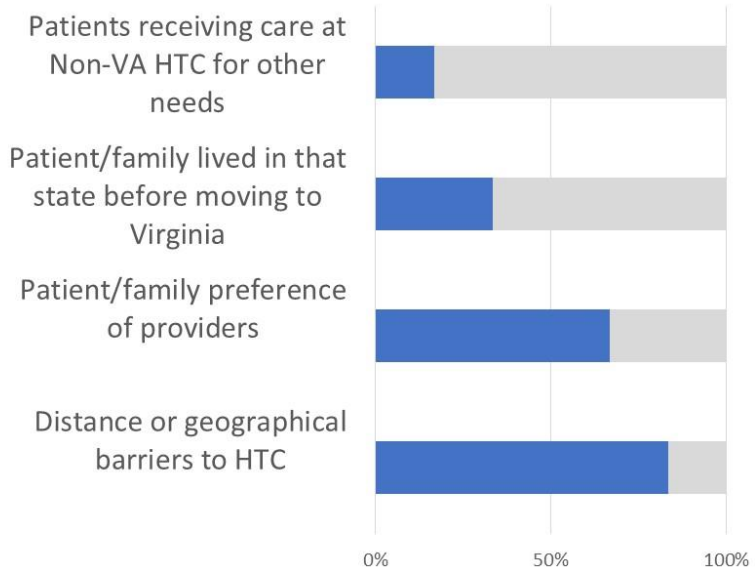
Non- Virginia HTC Survey

Survey sent to 15 nurses, doctors and social workers at 5 centers outside of VA

- Georgetown (DC)
- Charleston Medical Ctr (West Virginia)
- WVU Medical Ctr (West Virginia)
- Wake Forest (North Carolina)
- University of North Carolina Chapel Hill (North Carolina)

33% survey response rate

Focus of survey questions: barriers to accessing care

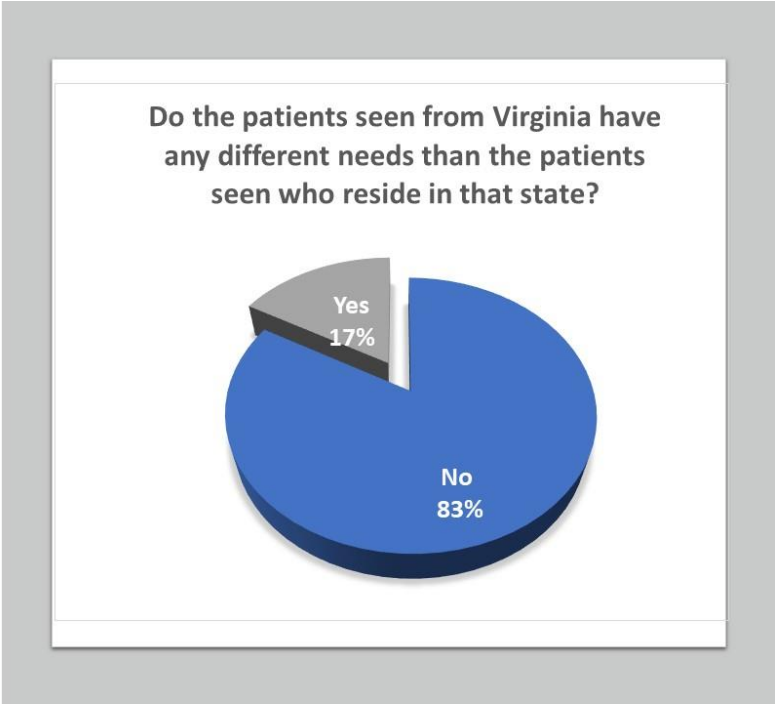


Non- Virginia HTC Survey

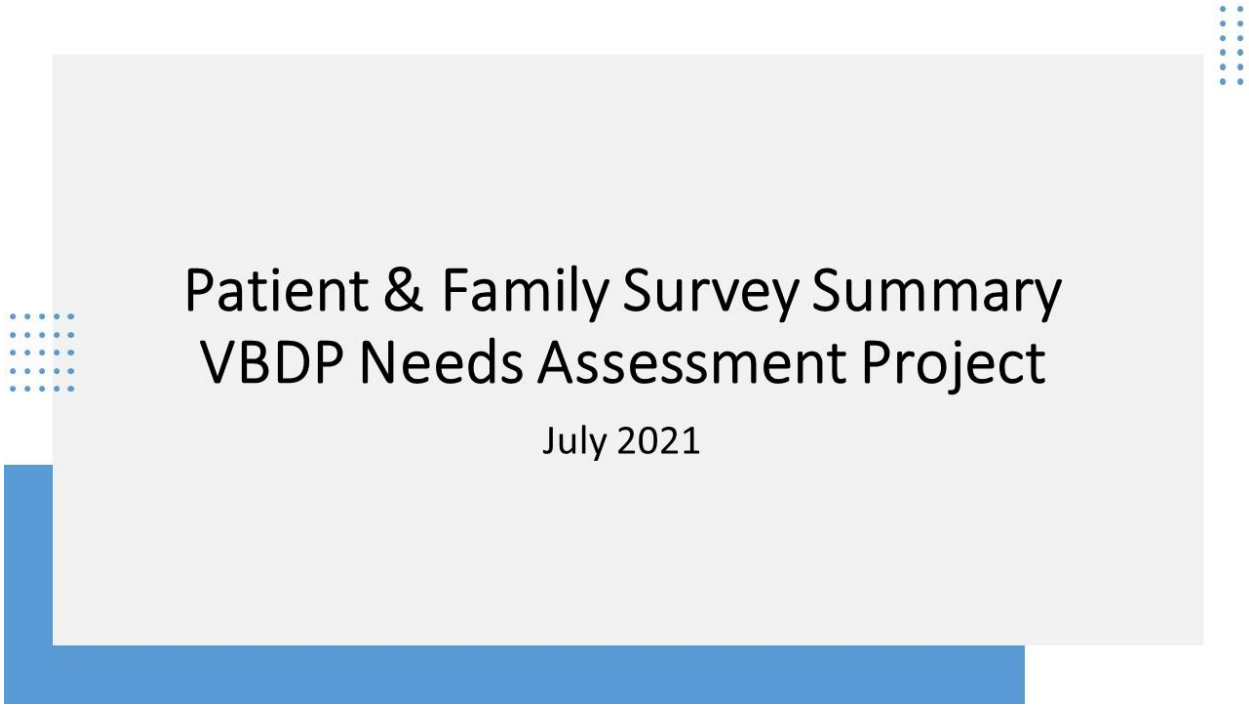
Reasons that patients are served outside of Virginia

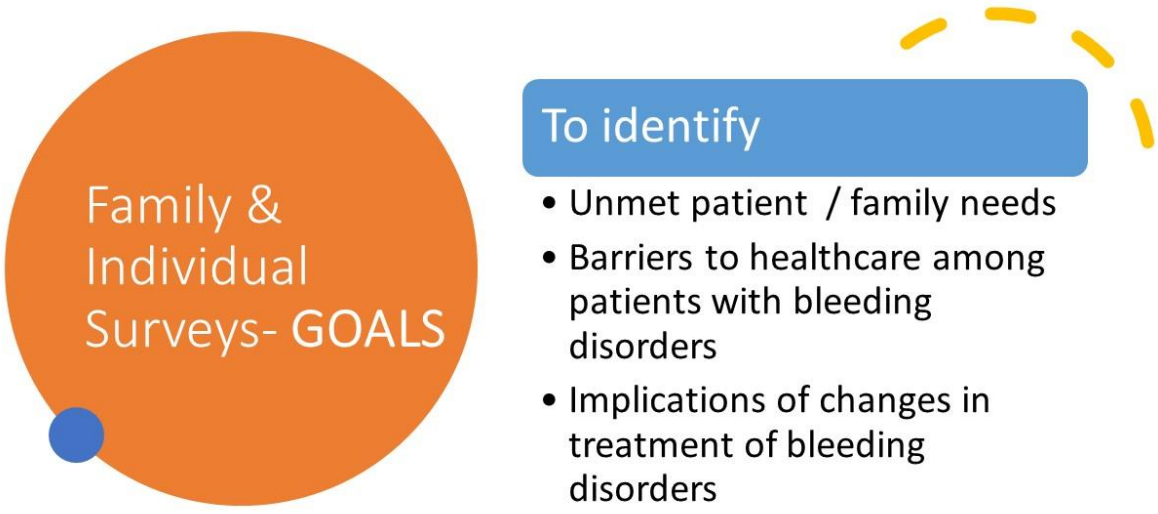
Non-Virginia HTC Survey

Survey respondents felt that more resources in SWVA could change the need for patients to seek care outside of the state



Appendix D: VBDP Patient/Family Survey Summary



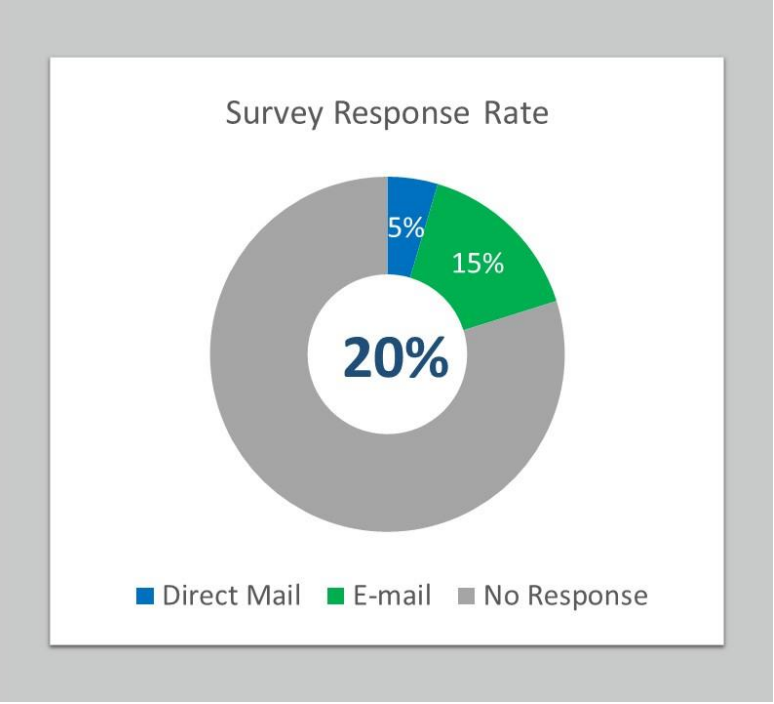


Family & Individual Surveys- Focus Areas

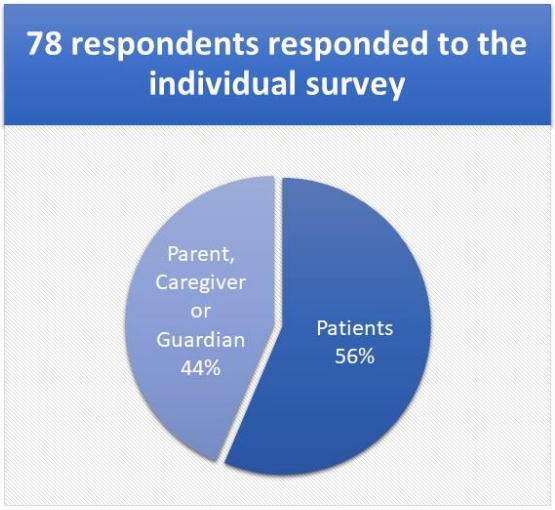
1. Comparison of current provider services and referral network to anticipated needs
2. Impact of insurance, distance to care and socio-cultural barriers
3. Change in patient and HTC needs with new therapies

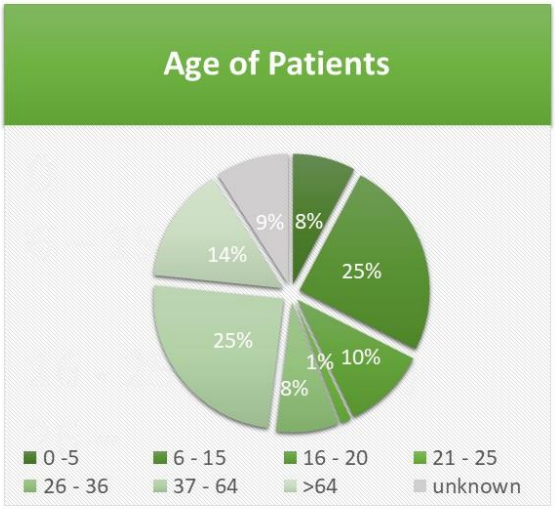
Family & Individual Surveys

Survey sent to 392 households to reach 414 patients served by any of the four HTCs in VA



Individual Survey

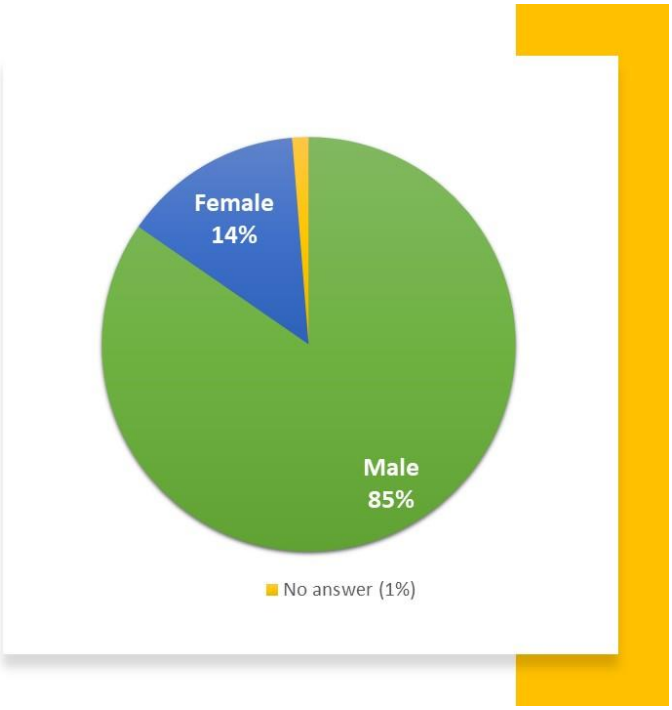




Individual Survey

Demographics:

- Patients' Gender Identity

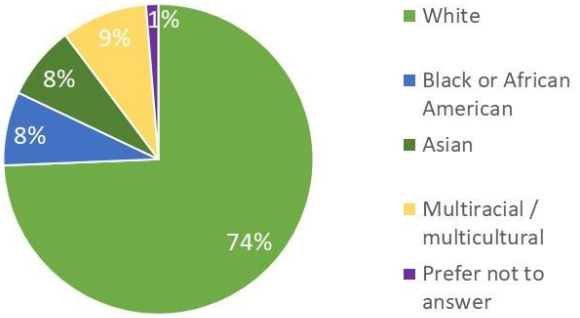


Individual Survey

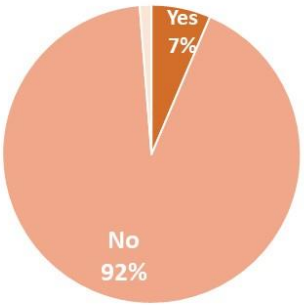
Demographics:

- Patient's Race & Ethnicity

Race



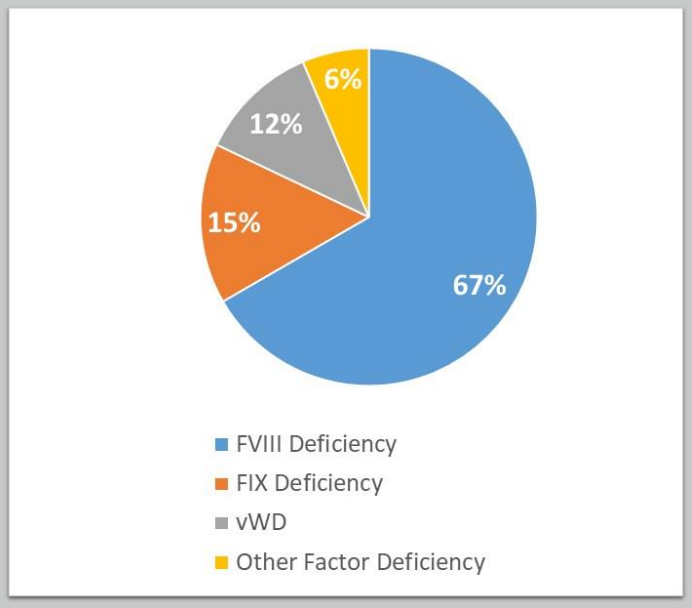
Hispanic, Latino or Spanish origin



Individual Survey

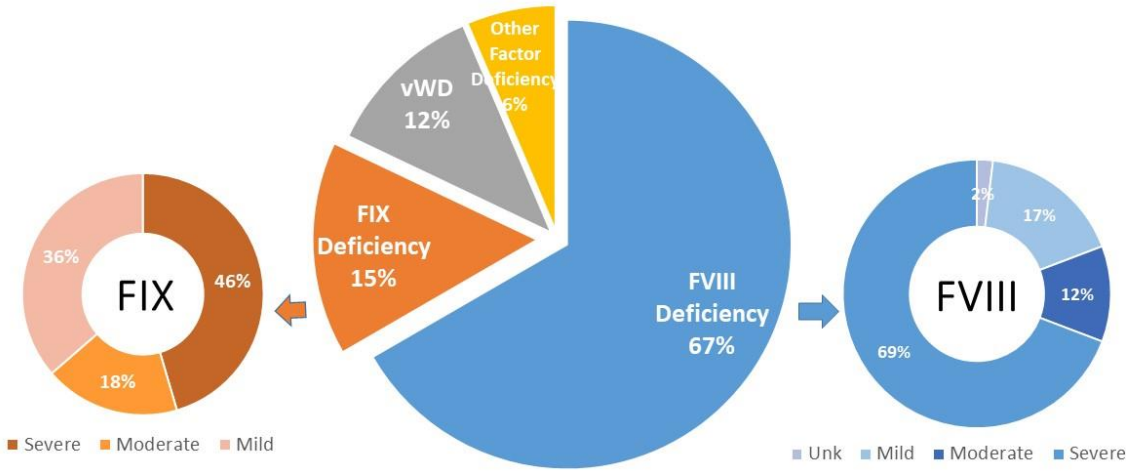
Demographics:

- Patients' Diagnosis



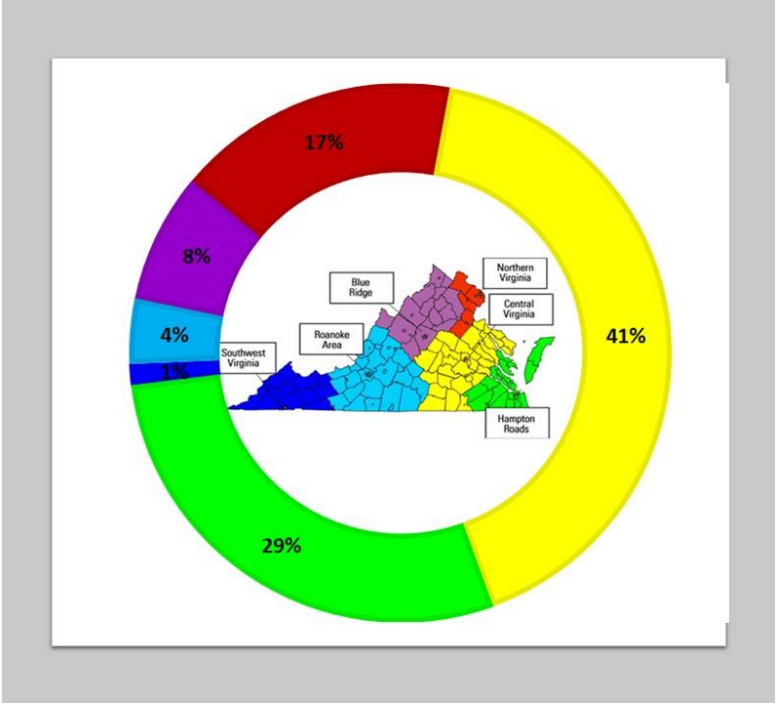
Individual Survey

Factor Deficiency Severity



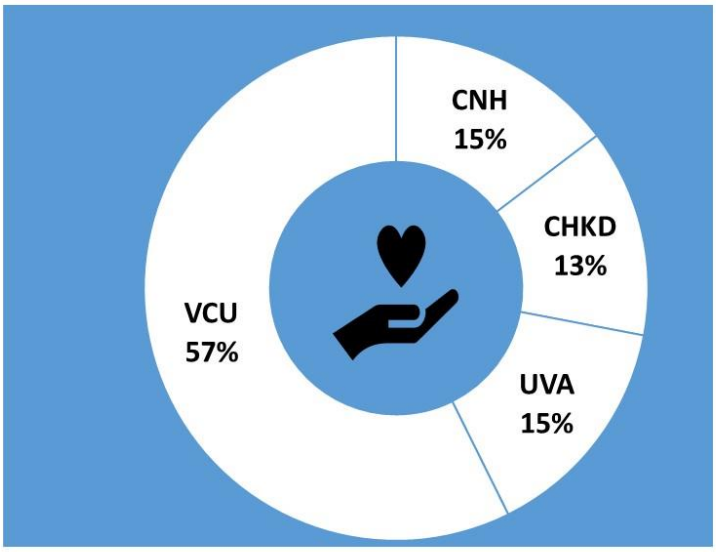
Individual Survey

Virginia regions where survey respondents reside



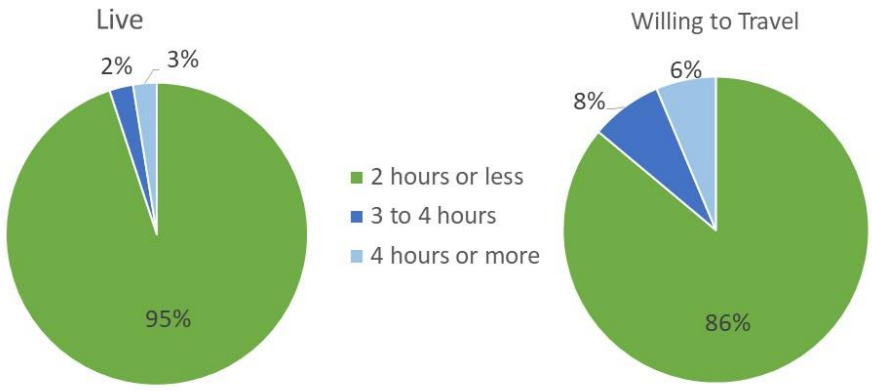
Individual Survey

HTC which provides patient care of survey respondents



Family Survey

Distance families/individuals live from their HTC and distance they are willing to travel to HTC care



Family Survey

All survey respondents indicated that they could get care at the HTC closest to their home

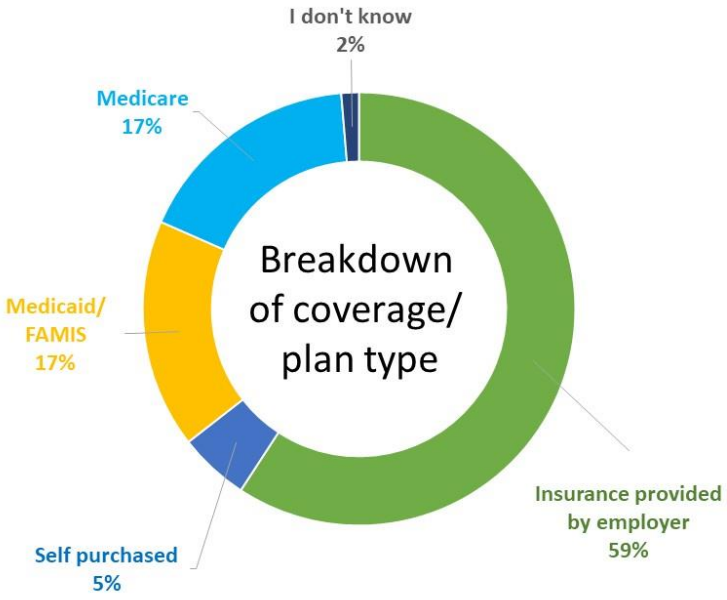
Transportation to clinic is a problem for 6% of survey respondents.

Those respondents indicated that the following would be of help:

- ✓ More options for telehealth visits (60%)
- ✓ Gas cards (20%)

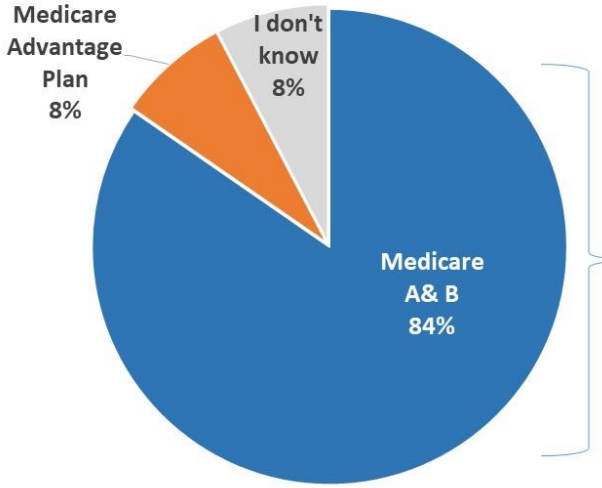
Family Survey

All survey respondents indicated they have health insurance

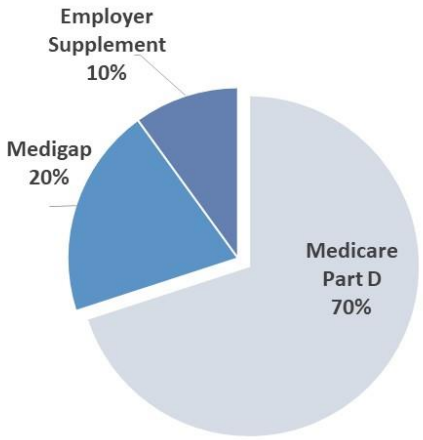


Family Survey

Medicare Coverage Type



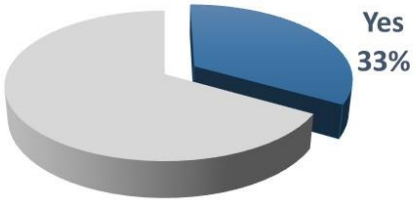
Medicare A & B Supplements



Family Survey

Insurance problems in the past year

Insurance problems in the past year?



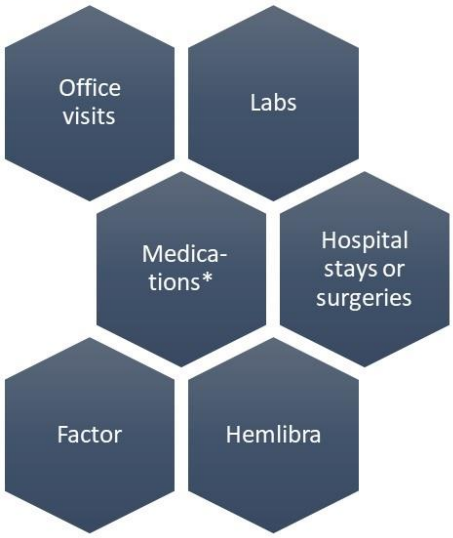
Top 3 insurance problems

Difficulties or problems with:

- Authorization for medications or services (n=17)
- Copays (n=9)
- Insurance networks (n=8)

Family Survey

Some survey respondents have experienced problems with copays for



*other medications, not related to hemophilia

Family Survey

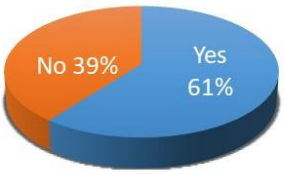
96% of survey respondents don't get help paying for their monthly insurance premium

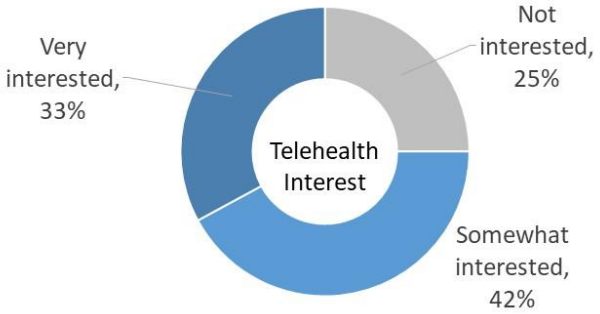
For those who get help, help comes from:

- ✓ PSI
- ✓ Another charity group

Family Survey

Have participated in a telehealth visit

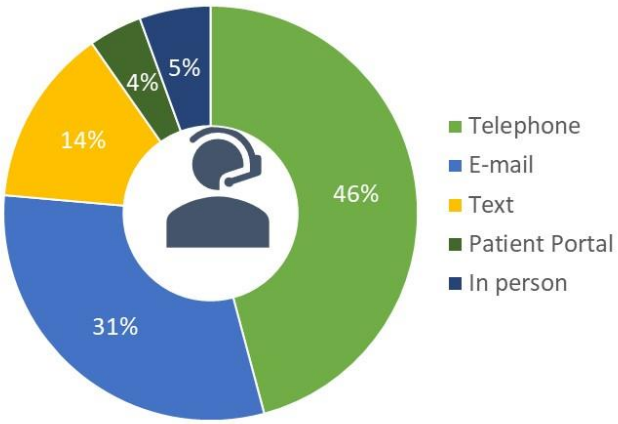




Family Survey

99% of survey respondents have internet access at home and have a cell phone or computer that they can use for telehealth visits

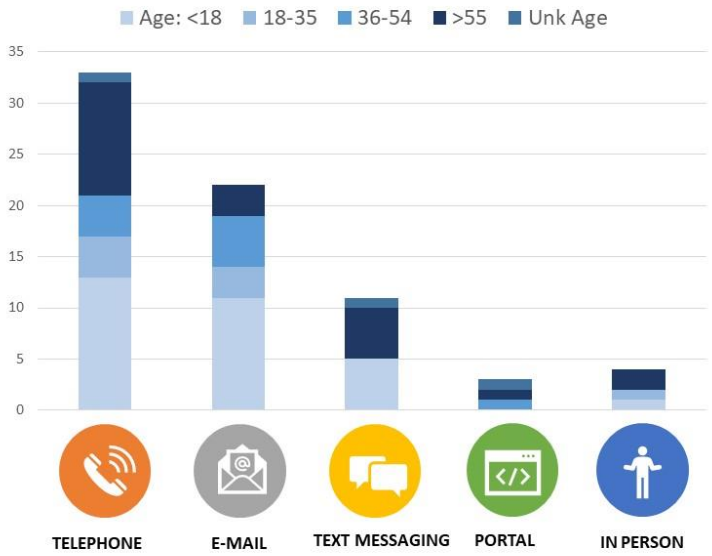
Preferred method of communication with HTC for non-urgent issues



Family Survey

Preferred method of communication with HTC for non-urgent issues-

by patient age

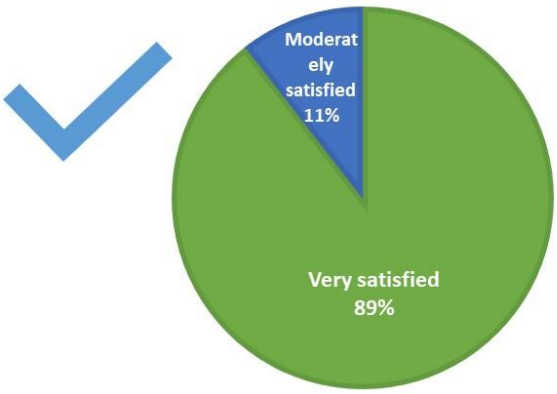


Family Survey

Survey respondents can reach the HTC when they need to coordinate patient care

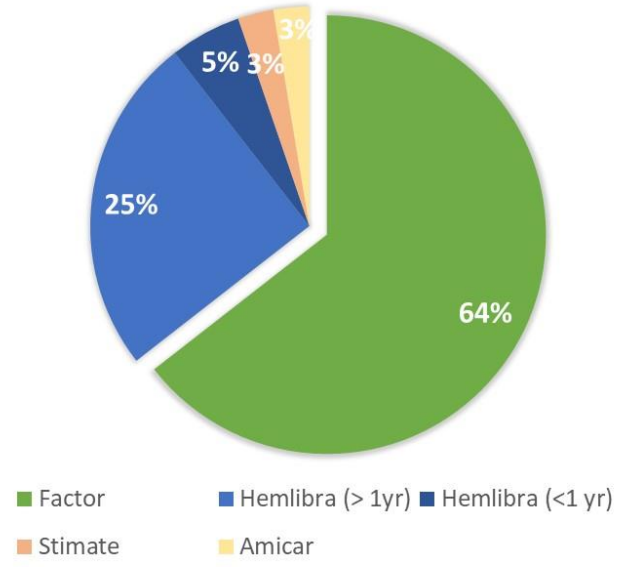
Family Survey

100% of survey respondents are satisfied with their care coordination



Individual Survey

Main medication taken to treat the bleeding disorder



Individual Survey

38% of patients have changed their treatment in the past 3 years

53% of those patients said that their needs for services from HTC have changed

77% of those patients have changed the treatment to Hemlibra

Individual Survey

Need for services from HTC due to change in treatment for bleeding disorder

Individual Survey

Patients on Hemlibra

44% of patients contact HTC less since starting on Hemlibra

91% would like to have the same appointment frequency at their HTC after changing to Hemlibra

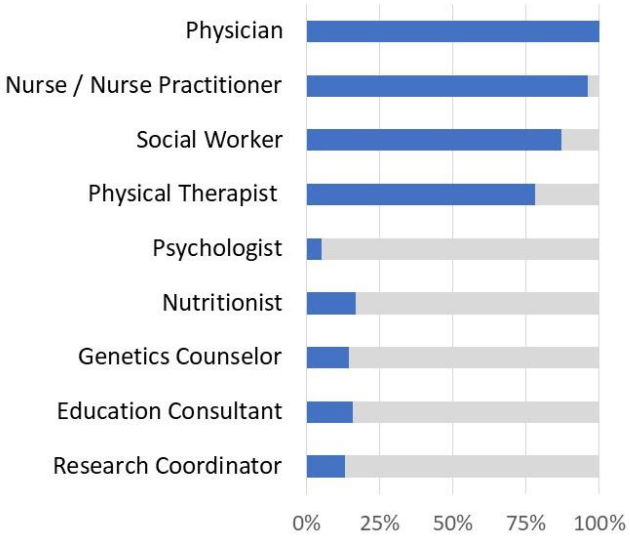
Individual Survey

SURGERIES - 22% OF PATIENTS HAD SURGERIES IN THE PAST YEAR

PATIENT'S HTC HELPED COORDINATE THE SURGICAL PLAN 82% OF THE TIMES

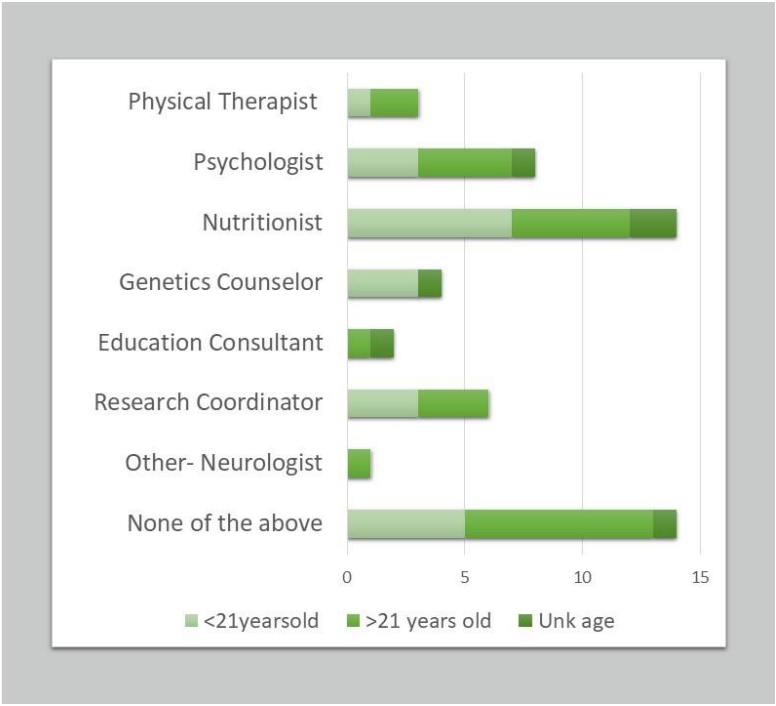
Individual Survey

Providers that patients see at comprehensive visits



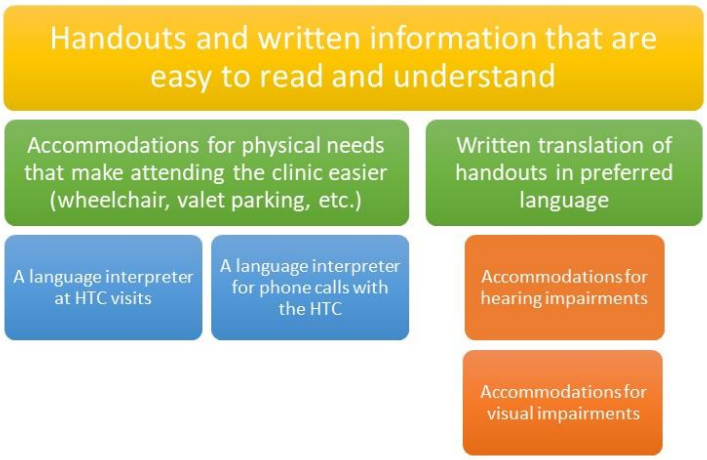
Individual Survey

Providers that patients do not currently see, but would like to have available at HTC



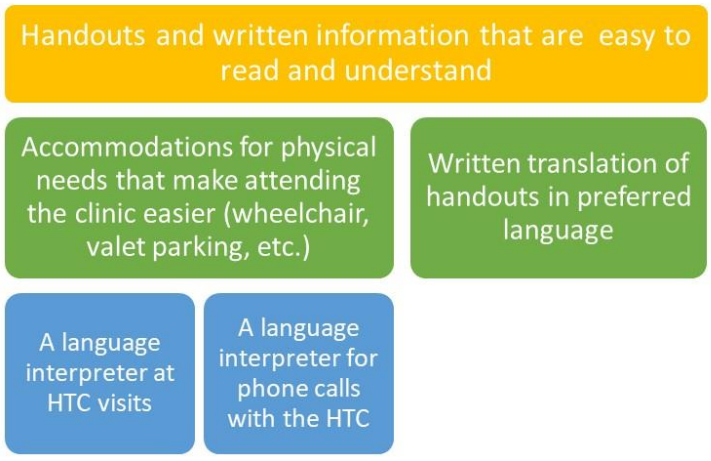
Individual Survey

Services that respondents' HTCs currently provide:



Individual Survey

Services that respondents need from their HTC:



Individual Survey

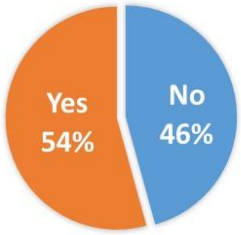
For patients ages 12 to 21

Topics respondents would like more information about for preparing for adult care

Individual Survey

For patients under age 21

Does your HTC help you with school / daycare issues?



School or daycare issues survey respondents would like more help with

Emergency plans

Medical plan

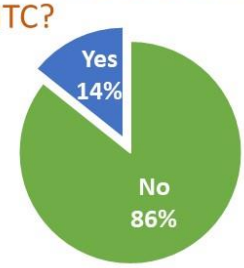
IEP/504 plan development

Post high school/ college planning

Individual Survey

For patients 55 and older

Are there any areas you would like more assistance with from your HTC?



Areas which respondents would like more assistance:

UNDERSTANDING MEDICARE

COORDINATING WITH SPECIALISTS

QUESTIONS ABOUT LONG TERM CARE

Appendix E: Surveys

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Page 1

HTC Members Survey

Please complete the survey below.

Thank you!

The Virginia Bleeding Disorders Program (VBDP) provides support for the care and treatment of persons with hemophilia and other inherited bleeding disorders. It provides funding for care coordination done by nurses and/or social workers and health insurance consultation at hemophilia treatment centers. VBDP also provides limited health insurance premium assistance through PSI, Inc. as well as medication for persons who are uninsured and financially eligible.

In the past few years, significant changes have taken place to help persons obtain health insurance. Also, new treatments have dramatically changed hemophilia care. Because of your involvement with either the Virginia Hemophilia Foundation (VHF) or the Hemophilia Association of the Capitol Area (HACA), we are asking for your input as we evaluate how these changes should influence the VBDP.

Do you agree to participate in this survey?
- ○ I agree to take part in this survey
- ○ I do not agree to take part in this survey

Thank you for agreeing to take this survey. Please click "Next Page" to begin.

1. Which of the following is your role in clinic?
- ○ Physician
- ○ Physician Assistant
- ○ Nurse
- ○ Nurse Practitioner
- ○ Social Worker
- ○ Other

Please specify: _____

2. What types of patients do you treat?
- ○ Peds only
- ○ Adults only
- ○ Peds and Adults

3. Which providers do patients routinely see at comprehensive visits? (check all that apply)
- ☐ Physician
- ☐ Nurse
- ☐ Social Worker
- ☐ Physical Therapist
- ☐ Psychologist
- ☐ Nutritionist
- ☐ Genetics Counselor
- ☐ Education Consultant
- ☐ Research Coordinator
- ☐ Other

Please specify: _____

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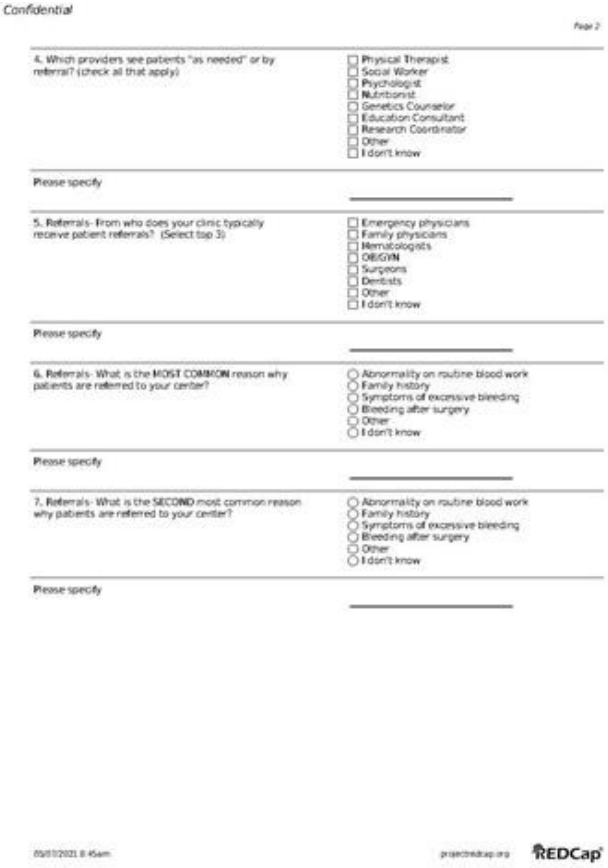

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Page 2

4. Which providers see patients "as needed" or by referral? (check all that apply)
- ☐ Physical Therapist
- ☐ Social Worker
- ☐ Psychologist
- ☐ Nutritionist
- ☐ Genetics Counselor
- ☐ Education Consultant
- ☐ Research Coordinator
- ☐ Other
- ☐ I don't know

Please specify: _____

5. Referrals- From who does your clinic typically receive patient referrals? (Select top 3)
- ☐ Emergency physicians
- ☐ Family physicians
- ☐ Hematologists
- ☐ OB/GYN
- ☐ Surgeons
- ☐ Dentists
- ☐ Other
- ☐ I don't know

Please specify: _____

6. Referrals- What is the MOST COMMON reason why patients are referred to your center?
- ○ Abnormality on routine blood work
- ○ Family history
- ○ Symptoms of excessive bleeding
- ○ Bleeding after surgery
- ○ Other
- ○ I don't know

Please specify: _____

7. Referrals- What is the SECOND most common reason why patients are referred to your center?
- ○ Abnormality on routine blood work
- ○ Family history
- ○ Symptoms of excessive bleeding
- ○ Bleeding after surgery
- ○ Other
- ○ I don't know

Please specify: _____

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8. Referrals- How often do you see a delay in diagnosis from symptom onset for the following groups with inherited bleeding disorders?

	Always	Most of the time	Sometimes	Not very often	Never	I don't know
Men	○	○	○	○	○	○
Women	○	○	○	○	○	○
Patients from lower socioeconomic status	○	○	○	○	○	○
Undocumented patients	○	○	○	○	○	○
Patients for whom English is not their first language	○	○	○	○	○	○
Patients with milder symptoms	○	○	○	○	○	○
Carriers	○	○	○	○	○	○
Females with heavy menses as primary symptom	○	○	○	○	○	○
Patients living in rural VA	○	○	○	○	○	○
Other	○	○	○	○	○	○

If you saw any delay in diagnosis from symptom onset with inherited bleeding disorders for the "Other" category, please specify.: _____

9. Do you have enough providers and clinic time to see patients?
- ○ Yes
- ○ No
- ○ I don't know

10. Communication- In what ways are you able to communicate with your patients? (check all that apply)
- ☐ Portal like
- ☐ Translation/ Interpreter Services
- ☐ Text messaging
- ☐ HIPAA secure E-mail
- ☐ I don't know

11. Telehealth Visits- What options for telehealth visits do you provide? (check all that apply)
- ☐ Genetics counseling
- ☐ Physical therapy
- ☐ Mental health services
- ☐ Social worker
- ☐ MD/NP only
- ☐ Other provider
- ☐ I don't know

Please specify: _____

12. Telehealth Visits- What challenges have you encountered with telehealth visits? (check all that apply)
- ☐ Lack of internet connection
- ☐ Lack of smart phone
- ☐ Inability to do a complete examination
- ☐ Lack of lab coordination
- ☐ Increased barriers for ESL patients
- ☐ I don't know

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Please consider characteristics such as race, ethnicity, gender, immigration status, type of bleeding disorder, and socioeconomic level. Are there groups where you see inequity to treatment around bleeding disorders? You may list up to three.: _____

14. What insurance barriers do you experience? (check all that apply)
- ☐ HTC not in network
- ☐ Lengthy prior authorization process
- ☐ High copays for patients
- ☐ Other
- ☐ I don't know

Please specify: _____

15. Are there insurance plans that are not accepted at your HTC?
- ○ Yes
- ○ No
- ○ I don't know

List any that you know aren't accepted: _____

Where do you refer patients if so?: _____

16. Distance- What proportion of your patients experience travel distance as a barrier to treatment?
- ○ None
- ○ 25%
- ○ Half
- ○ 75%
- ○ All
- ○ I don't know

17. Satellite Clinics- Do you provide a satellite clinic?
- ○ Yes
- ○ No
- ○ I don't know

Do you feel a satellite clinic would be of benefit to your patients?
- ○ Yes
- ○ No

What would you need in order to provide a Satellite Clinic? (check all that apply)
- ☐ Space
- ☐ Travel reimbursement
- ☐ Laboratory space
- ☐ Phlebotomy services
- ☐ Other

Please specify: _____

Are you providing a Satellite Clinic because of the distance some of your patients have to travel?
- ○ Yes
- ○ No

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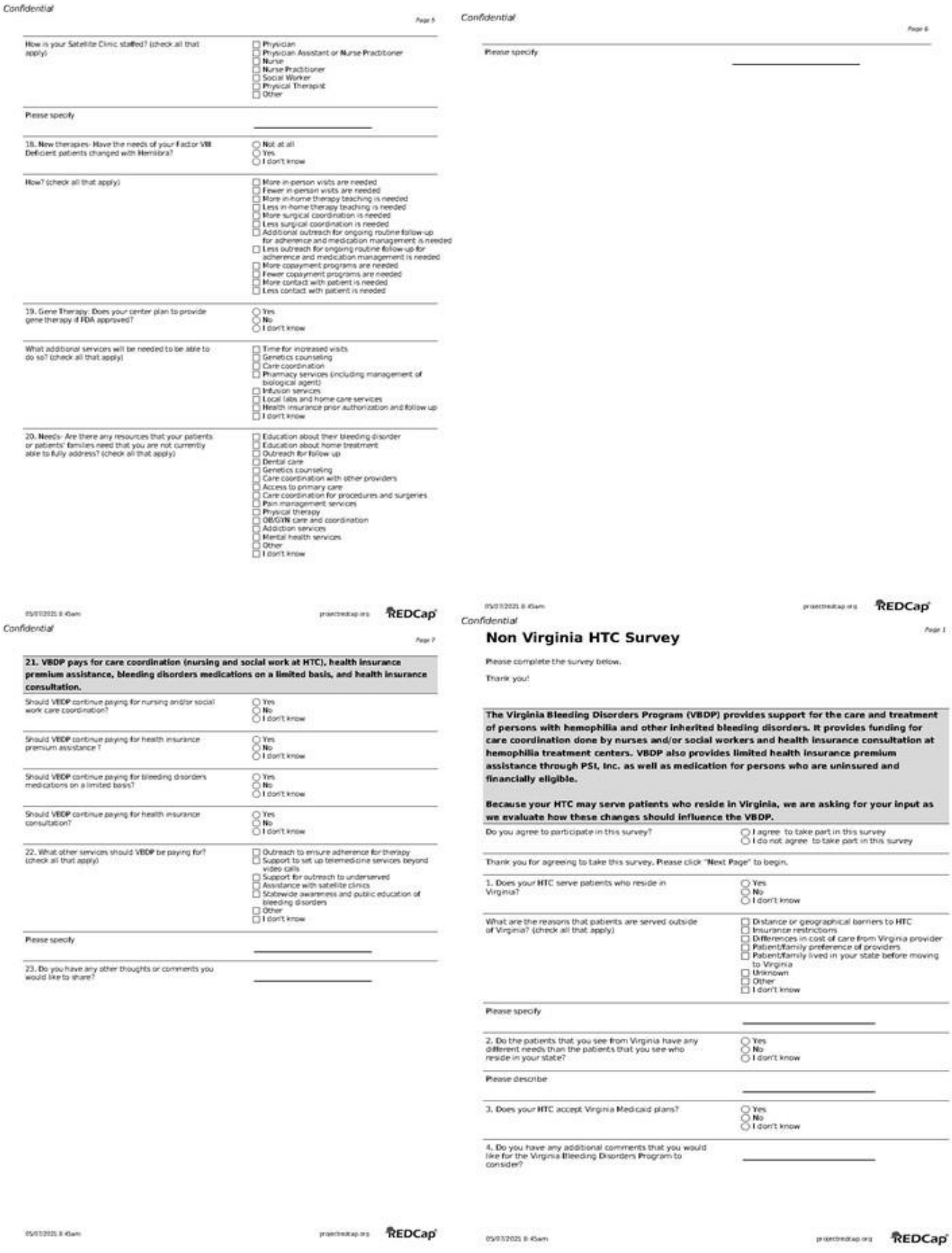

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How is your Satellite Clinic staffed? (check all that apply)
- ☐ Physician
- ☐ Physician Assistant or Nurse Practitioner
- ☐ Nurse
- ☐ Nurse Practitioner
- ☐ Social Worker
- ☐ Physical Therapist
- ☐ Other

Please specify: _____

18. New therapies- Have the needs of your Factor VIII Deficient patients changed with Hemlibra?
- ○ Not at all
- ○ Yes
- ○ I don't know

How? (check all that apply)
- ☐ More in-person visits are needed
- ☐ Fewer in-person visits are needed
- ☐ More in-home therapy teaching is needed
- ☐ Less in-home therapy teaching is needed
- ☐ More surgical coordination is needed
- ☐ Less surgical coordination is needed
- ☐ Additional outreach for ongoing routine follow-up for adherence and medication management is needed
- ☐ Less outreach for ongoing routine follow-up for adherence and medication management is needed
- ☐ More copayment programs are needed
- ☐ Fewer copayment programs are needed
- ☐ More contact with patient is needed
- ☐ Less contact with patient is needed

19. Gene Therapy: Does your center plan to provide gene therapy if FDA approved?
- ○ Yes
- ○ No
- ○ I don't know

What additional services will be needed to be able to do so? (check all that apply)
- ☐ Time for increased visits
- ☐ Genetics counseling
- ☐ Care coordination
- ☐ Pharmacy services (including management of biological agent)
- ☐ Infusion services
- ☐ Local labs and home care services
- ☐ Health insurance prior authorization and follow up
- ☐ I don't know

20. Needs- Are there any resources that your patients or patients' families need that you are not currently able to fully address? (check all that apply)
- ☐ Education about their bleeding disorder
- ☐ Education about home treatment
- ☐ Outreach for follow up
- ☐ Dental care
- ☐ Genetics counseling
- ☐ Care coordination with other providers
- ☐ Access to primary care
- ☐ Care coordination for procedures and surgeries
- ☐ Pain management services
- ☐ Physical therapy
- ☐ OB/GYN care and coordination
- ☐ Addiction services
- ☐ Mental health services
- ☐ Other
- ☐ I don't know

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Please specify: _____

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21. VBDP pays for care coordination (nursing and social work at HTC), health insurance premium assistance, bleeding disorders medications on a limited basis, and health insurance consultation.

Should VBDP continue paying for nursing and/or social work care coordination?
- ○ Yes
- ○ No
- ○ I don't know

Should VBDP continue paying for health insurance premium assistance?
- ○ Yes
- ○ No
- ○ I don't know

Should VBDP continue paying for bleeding disorders medications on a limited basis?
- ○ Yes
- ○ No
- ○ I don't know

Should VBDP continue paying for health insurance consultation?
- ○ Yes
- ○ No
- ○ I don't know

22. What other services should VBDP be paying for? (check all that apply)
- ☐ Outreach to ensure adherence for therapy
- ☐ Support to set up telemedicine services beyond video calls
- ☐ Support for outreach to underserved
- ☐ Assistance with satellite clinics
- ☐ Statewide awareness and public education of bleeding disorders
- ☐ Other
- ☐ I don't know

Please specify: _____

23. Do you have any other thoughts or comments you would like to share? _____

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Page 1

Non Virginia HTC Survey

Please complete the survey below.

Thank you!

The Virginia Bleeding Disorders Program (VBDP) provides support for the care and treatment of persons with hemophilia and other inherited bleeding disorders. It provides funding for care coordination done by nurses and/or social workers and health insurance consultation at hemophilia treatment centers. VBDP also provides limited health insurance premium assistance through PSI, Inc. as well as medication for persons who are uninsured and financially eligible.

Because your HTC may serve patients who reside in Virginia, we are asking for your input as we evaluate how these changes should influence the VBDP.

Do you agree to participate in this survey?
- ○ I agree to take part in this survey
- ○ I do not agree to take part in this survey

Thank you for agreeing to take this survey. Please click "Next Page" to begin.

1. Does your HTC serve patients who reside in Virginia?
- ○ Yes
- ○ No
- ○ I don't know

What are the reasons that patients are served outside of Virginia? (check all that apply)
- ☐ Distance or geographical barriers to HTC
- ☐ Insurance restrictions
- ☐ Differences in cost of care from Virginia provider
- ☐ Patient/family preference of providers
- ☐ Patient/family lived in your state before moving to Virginia
- ☐ Unknown
- ☐ Other
- ☐ I don't know

Please specify: _____

2. Do the patients that you see from Virginia have any different needs than the patients that you see who reside in your state?
- ○ Yes
- ○ No
- ○ I don't know

Please describe: _____

3. Does your HTC accept Virginia Medicaid plans?
- ○ Yes
- ○ No
- ○ I don't know

4. Do you have any additional comments that you would like for the Virginia Bleeding Disorders Program to consider? _____

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Page 1

Hemophilia Treatment Center (HTC) Patient's Needs Survey

Please complete the survey below. Thank you!

In this survey, "you" always refers to the patient. If you are a parent or legal guardian, please remember that "you" refers to the child patient.

We invite each HTC patient per household to complete the survey, since the needs and issues depend on the patient's age and severity of their condition.

The first set of questions in the survey pertain to your entire household. The next set of questions will refer to each individual patient and you will have the opportunity to add additional patients in your household.

SECTION I - Please respond thinking about your entire household if there is more than one HTC Patient

Geography/ Transportation

How far do you live from your HTC?
- ○ less than 1 hour
- ○ 1-2 hours
- ○ 3-4 hours
- ○ greater than 4 hours

How far are you willing to travel to HTC care?
- ○ less than 1 hour
- ○ 1-2 hours
- ○ 3-4 hours
- ○ greater than 4 hours

Is there any HTC close to your home where you cannot get care?
- ○ No
- ○ Yes- What are the barriers? (check all that apply)
  - ☐ Insurance not in network
  - ☐ Does not have financial assistance program to help with costs
  - ☐ Does not see patients without insurance
  - ☐ Does not provide HTC services I need
  - ☐ Patient/family preference of providers
  - ☐ Other (Please specify other barriers):_____

Is transportation to clinic a problem?
- ○ No
- ○ Yes- What would help? (check all that apply)
  - ☐ gas cards
  - ☐ more options for telehealth visits
  - ☐ satellite clinic located closer to where I live
  - ☐ fewer appointments
  - ☐ different appointment times: afternoon, evening, more days of the week
  - ☐ Other (Please specify what would help):_____

Insurance

Do you have health insurance?
- ○ No
- ○ Yes- What kind of PRIMARY health insurance do you have:
  - ☐ Insurance through my job (or parent/ spouse job)
  - ☐ Insurance I buy on my own
  - ☐ Medicaid/ FAMIS
  - ☐ Tricare
  - ☐ I don't know what kind of insurance I have
  - ☐ Medicare- *What kind of Medicare coverage do you have?* **(check all that apply)**
    - ○ Medicare A
    - ○ Medicare B
    - ○ Insurance supplement through my job/ former job
    - ○ I am not sure what kind of Medicare plan I have
    - ○ Medicare D
    - ○ Medicare Advantage plan
    - ○ Medigap supplement plan

In the last year, have you missed a dose or treatment due to insurance problems?
- ○ No
- ○ Yes

Confidential

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What insurance problems have you experienced in the last year? **(check all that apply)**
- ○ none
- ○ access to health insurance
- ○ problems with cost for Stimate
- ○ problems with cost for Amicar
- ○ problems with **copays**
- ○ problems with paying for home nursing
- ○ difficulty with insurance networks
- ○ difficulty with authorization for medications or services
- ○ difficulty obtaining supplies
- ○ problems affording monthly insurance premium

→ *For which of the following have you had problems with copays?* **(check all that apply)**
- ○ for labs
- ○ for hospital stays or surgeries
- ○ for Hemlibra
- ○ for supplies
- ○ for office visits
- ○ for factor
- ○ for other medications (not hemophilia related)

Do you use copay assistance programs for bleeding disorder medications?
- ○ No
- ○ Yes- Which ones? **(check all that apply)**
  - ☐ copay card from drug maker
  - ☐ copay assistance from charitable foundation
  - ☐ help from family members
  - ☐ occasional emergency assistance through local chapter or other hemophilia organization for medication costs
  - ☐ I get copay help but I am not sure from which program
  - ☐ Other- *(Please specify other copay assistance program):*_____

Do you get help paying for your monthly insurance premium?
- ○ No
- ○ Yes- How do you get help? (check all that apply)
  - ☐ PAN Foundation Premium Assistance program
  - ☐ The Alliance Fund premium assistance program
  - ☐ Help from family, friends, or others
  - ☐ Help from another charity group
  - ☐ I am not sure which group helps pay for my insurance premiums
  - ☐ PSI Premium Assistance Program → *Were you referred by the VBDP?* ○ Yes ○ No ○ *I don't know*

Telehealth

Have you participated in a telehealth visit?
- ○ Yes
- ○ No

How interested are you in telehealth visits?
- ○ Very Interested
- ○ Somewhat Interested
- ○ Not Interested

Do you have internet access in your home?
- ○ Yes
- ○ No

Do you have a cell phone or computer you can use for telehealth visits?
- ○ Yes
- ○ No

Communication

What is your preferred method of communication with your HTC for NON URGENT issues?
- ○ Telephone
- ○ Email
- ○ Text
- ○ Patient Portal in electronic medical record
- ○ In person

Confidential

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Are you (the patient or patient's parent/guardian) able to reach the HTC when you need help coordinating patient care (for example managing a bleed, learning home treatment, coordinating with other health care providers or managing surgeries)?
- ○ Never
- ○ Sometimes
- ○ Often
- ○ Always

How satisfied are you (the patient or patient's parent/guardian) with the coordination of your care?
- ○ Very Satisfied
- ○ Moderately Satisfied
- ○ Slightly Satisfied
- ○ Not Satisfied

SECTION II - Patient's Survey - Individual

These set of questions will refer to each individual patient and you will have the opportunity to add additional patients in your household.
In this survey, "you" always refers to the patient. If you are a parent or legal guardian, please remember that "you" refers to the child patient.

I am a: **(select one - parent should complete form if the patient is under 18 years old)**
- ○ Patient
- ○ Patient's Parent, Caregiver, or Guardian

Patient's Age: (enter number of years in box, zero for infants less than 1 year old) ☐

Patient's Diagnosis:
- ○ FVIII deficiency
- ○ FIX deficiency
- ○ vWD
- ○ Other: (Please specify):_____

Severity of deficiency:
- ○ Mild
- ○ Moderate
- ○ Severe
- ○ I don't know

What is the patient's race? (Check all that apply)
- ☐ White
- ☐ Black or African American
- ☐ Asian
- ☐ Native American or Alaskan Native Native
- ☐ Hawaiian/ Pacific Islander
- ☐ Multiracial/ multicultural
- ☐ Prefer not to answer

Is the patient Hispanic, Latino or Spanish origin?
- ○ Yes
- ○ No
- ○ Prefer not to answer

To which gender identity does the patient identify most?
- ○ Female
- ○ Male
- ○ Transgender Female
- ○ Transgender Male
- ○ Gender Variant/ Non-Conforming
- ○ Not listed
- ○ Prefer not to answer

Confidential

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In what region of Virginia does the patient live (based on the map)?
- ○ Central Virginia
- ○ Northern Virginia
- ○ Blue Ridge
- ○ Hampton Roads
- ○ Roanoke Area
- ○ Southwest Virginia

What is the patient's preferred language?
- ○ English
- ○ Spanish
- ○ Other (specify):

Which HTC provides the patient's care?
- ○ Virginia Commonwealth University (VCU)
- ○ University of Virginia (UVA)
- ○ Children's Hospital of The King's Daughters (CHKD)
- ○ Children's National Hospital (CNH)

Medical Questions

What is the MAIN medicine that you (the patient) take to treat the bleeding disorder?
- ○ Factor
- ○ Stimate
- ○ Amicar
- ○ Hemlibra- *How long have you (the patient) been using Hemlibra?*
  - ☐ 6 months or less
  - ☐ greater than 6 months but less than 1 yeargreater than 1 year

If you take Hemlibra- Do you contact your HTC more or less since starting Hemlibra?
- ○ More
- ○ Less
- ○ Same

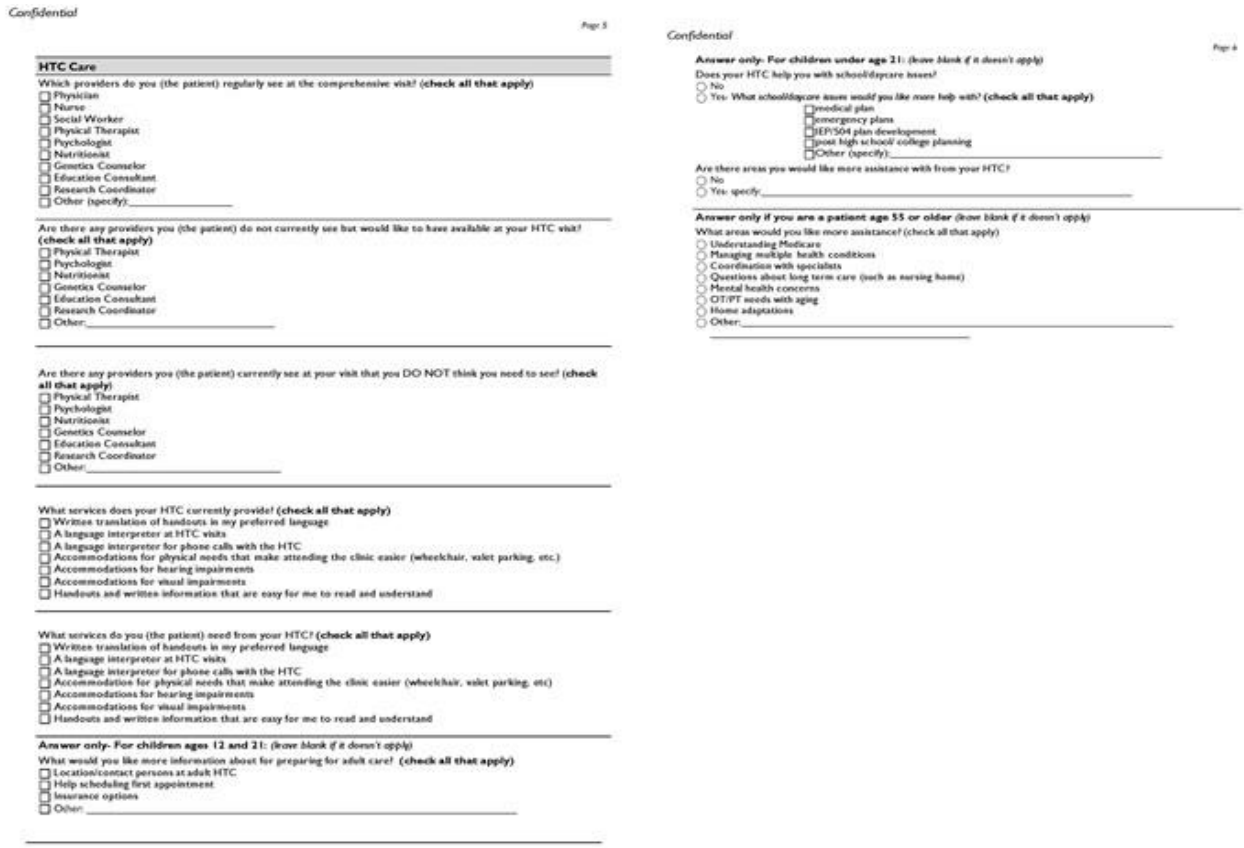
If you take Hemlibra- How often would you like to have appointments at your HTC after changing to Hemlibra?
- ○ More
- ○ Less
- ○ Same

Have you (the patient) changed your treatment for prevention or treatment of bleeds in the past 3 years?
- ○ No
- ○ Yes

How have the services you (the patient) need from your HTC changed because of this change in treatment?
- ○ Increased
- ○ Decreased
- ○ Not changed
- ○ Different services needed

Have you (the patient) had any surgeries or procedures in the past year?
- ○ No
- ○ Yes

Did the HTC help coordinate the surgical plan?
- ○ Yes
- ○ No
- ○ I don't know



Confidential

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HTC Care

Which providers do you (the patient) regularly see at the comprehensive visit? **(check all that apply)**

- ☐ Physician
- ☐ Nurse
- ☐ Social Worker
- ☐ Physical Therapist
- ☐ Psychologist
- ☐ Nutritionist
- ☐ Genetics Counselor
- ☐ Education Consultant
- ☐ Research Coordinator
- ☐ Other (specify):_____

Are there any providers you (the patient) do not currently see but would like to have available at your HTC visit? **(check all that apply)**

- ☐ Physical Therapist
- ☐ Psychologist
- ☐ Nutritionist
- ☐ Genetics Counselor
- ☐ Education Consultant
- ☐ Research Coordinator
- ☐ Other:_____

Are there any providers you (the patient) currently see at your visit that you DO NOT think you need to see? **(check all that apply)**

- ☐ Physical Therapist
- ☐ Psychologist
- ☐ Nutritionist
- ☐ Genetics Counselor
- ☐ Education Consultant
- ☐ Research Coordinator
- ☐ Other:_____

What services does your HTC currently provide? **(check all that apply)**

- ☐ Written translation of handouts in my preferred language
- ☐ A language interpreter at HTC visits
- ☐ A language interpreter for phone calls with the HTC
- ☐ Accommodations for physical needs that make attending the clinic easier (wheelchair, valet parking, etc.)
- ☐ Accommodations for hearing impairments
- ☐ Accommodations for visual impairments
- ☐ Handouts and written information that are easy for me to read and understand

What services do you (the patient) need from your HTC? **(check all that apply)**

- ☐ Written translation of handouts in my preferred language
- ☐ A language interpreter at HTC visits
- ☐ A language interpreter for phone calls with the HTC
- ☐ Accommodation for physical needs that make attending the clinic easier (wheelchair, valet parking, etc)
- ☐ Accommodations for hearing impairments
- ☐ Accommodations for visual impairments
- ☐ Handouts and written information that are easy for me to read and understand

Answer only- For children ages 12 and 21: *(leave blank if it doesn't apply)*

What would you like more information about for preparing for adult care? **(check all that apply)**

- ☐ Location/contact persons at adult HTC
- ☐ Help scheduling first appointment
- ☐ Insurance options
- ☐ Other: _____

Confidential

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Answer only- For children under age 21: *(leave blank if it doesn't apply)*

Does your HTC help you with school/daycare issues?

- ○ No
- ○ Yes- What school/daycare issues *would you like more help with?* **(check all that apply)**
  - ☐ medical plan
  - ☐ emergency plans
  - ☐ IEP/504 plan development
  - ☐ post high school/ college planning
  - ☐ Other (specify):_____

Are there areas you would like more assistance with from your HTC?

- ○ No
- ○ Yes: specify:_____

Answer only if you are a patient age 55 or older *(leave blank if it doesn't apply)*

What areas would you like more assistance? (check all that apply)

- ○ Understanding Medicare
- ○ Managing multiple health conditions
- ○ Coordination with specialists
- ○ Questions about long term care (such as nursing home)
- ○ Mental health concerns
- ○ OT/PT needs with aging
- ○ Home adaptations
- ○ Other:_____

Confidential

Encuesta para pacientes de los Centros para el Tratamiento de la Hemofilia (CTH) del Virginia Bleeding Disorders Program

Por favor complete la siguiente encuesta. ¡Gracias!

En esta encuesta, "usted" siempre se refiere al paciente. Si es padre o tutor legal, recuerde que "usted" se refiere al *niño paciente.*

Invitamos a cada paciente de CTH por hogar a completar la encuesta, ya que las necesidades y los problemas dependen de la edad del paciente y la gravedad de su condición

El primer grupo de preguntas de la encuesta corresponde a todo su hogar. El siguiente grupo de preguntas se referirá a cada paciente individual y tendrá la oportunidad de agregar pacientes adicionales en su hogar.

SECCIÓN I - Responda pensando en todo su hogar si hay más de un paciente del CTH

Geografía / transporte

¿A qué distancia vive de su CTH?
- ○ menos de 1 hora
- ○ 1-2 horas
- ○ 3-4 horas
- ○ más de 4 horas

¿Qué tan lejos está dispuesto a viajar para atención en un CTH?
- ○ menos de 1 hora
- ○ 1-2 horas
- ○ 3-4 horas
- ○ más de 4 horas

¿Hay algún CTH cerca de su casa donde no pueda recibir atención?
- ○ No
- ○ Sí- ¿Cuáles son las barreras? **(marque todo lo que corresponda)**
  - ☐ Seguro que no está en la red
  - ☐ No tiene un programa de asistencia financiera para ayudar con los costos.
  - ☐ No atiende a pacientes sin seguro.
  - ☐ No proporciona los servicios de CTH que necesito
  - ☐ Preferencia de los proveedores del paciente / familia
  - ☐ Otro (*indique las barreras*):_____

¿Es un problema el transporte a la clínica?
- ○ No
- ○ Sí- ¿Qué ayudaría? **(marque todo lo que corresponda)**
  - ☐ tarjetas para gasolina
  - ☐ Más opciones para visitas de Telesalud
  - ☐ Clínica similar ubicada más cerca de donde vivo
  - ☐ Menos citas
  - ☐ Diferentes horarios de citas: tarde, noche, más días de la semana
  - ☐ Otro (*indique lo que ayudaría*):_____

Seguro

¿Tiene seguro médico?
- ○ No
- ○ Sí- ¿Qué tipo de seguro médico PRIMARIO tiene?
  - ☐ Seguro a través de mi trabajo (o trabajo de padre / cónyuge)
  - ☐ Seguro que compro por mi cuenta
  - ☐ Medicaid/ FAMIS
  - ☐ Tricare
  - ☐ No sé qué tipo de seguro tengo
  - ☐ Medicare- *¿Qué tipo de cobertura de Medicare tiene?* **(marque todo lo que corresponda)**
    - ○ Medicare A
    - ○ Medicare B
    - ○ No estoy seguro de qué tipo de plan de Medicare tengo
    - ○ Medicare D
    - ○ Plan Medicare Advantage
    - ○ Plan de suplemento de Medigap
    - ○ Suplemento de seguro a través de mi trabajo actual/anterior

En el último año, ¿ha omitido una dosis o un tratamiento debido a problemas con el seguro?
- ○ No
- ○ Sí

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¿Qué problemas con el seguro ha tenido durante el último año? **(marque todo lo que corresponda)**
- ○ ninguno
- ○ acceso a un seguro médico
- ○ problemas con el costo de Stimate
- ○ problemas con el costo de Amicar
- ○ problemas con los **copagos**
- ○ problemas para pagar la enfermería a domicilio
- ○ dificultad con las redes de seguros
- ○ dificultad con la autorización de medicamentos o servicios
- ○ dificultad para obtener suministros/materiales
- ○ problemas para pagar la prima mensual del seguro

→ *¿Para cuál de los siguientes ha tenido problemas con los copagos? (marque todo lo que corresponda)*
- ○ para pruebas de laboratorio
- ○ para hospitalizaciones o cirugías
- ○ para Hemlibra
- ○ para suministros/materiales
- ○ para visitas al consultorio
- ○ para factor
- ○ para otros medicamentos (no relacionados con la hemofilia)

¿Utiliza programas de asistencia para copagos de medicamentos para trastornos hemorrágicos?
- ○ No
- ○ Sí- ¿Cuáles? **(marque todo lo que corresponda)**
  - ☐ Tarjeta de copago del fabricante de medicamentos
  - ☐ Asistencia para copagos de una fundación benéfica
  - ☐ Ayuda de miembros de la familia
  - ☐ Asistencia de emergencia ocasional para los costos de los medicamentos a través del capítulo local u otra organización de hemofilia
  - ☐ Recibo ayuda con el copago, pero no estoy seguro a través de cuál programa
  - ☐ Otro (*por favor indique cuál*):_____

¿Recibe ayuda para pagar la prima mensual de su seguro?
- ○ No
- ○ Sí- ¿Cómo consigue ayuda? **(marque todo lo que corresponda)**
  - ☐ Programa de Asistencia Premium de la Fundación PAN
  - ☐ El programa de asistencia para las primas de Alliance Fund
  - ☐ Ayuda de familiares, amigos u otras personas
  - ☐ Ayuda de otro grupo benéfico
  - ☐ No estoy seguro cuál grupo me ayuda a pagar las primas de mi seguro.
  - ☐ Programa de asistencia para primas de PSI → *¿Fue referido por el VBDP?* ○ Sí ○ No ○ No lo sé

Telesalud

¿Ha participado en una visita de Telesalud?
- ○ Sí
- ○ No

¿Qué tan interesado está en las visitas de Telesalud?
- ○ Muy interesado
- ○ Algo interesado
- ○ No interesado

¿Tiene acceso a Internet en su casa?
- ○ Sí
- ○ No

¿Tiene un teléfono celular o una computadora que pueda usar para visitas de Telesalud?
- ○ Sí
- ○ No

Comunicación

¿Cuál es su método preferido de comunicación con su CTH para problemas NO URGENTES?
- ○ Teléfono
- ○ Correo electrónico (e-mail)
- ○ Texto
- ○ Portal para pacientes en el récord médico electrónico
- ○ En persona

Confidential 3

¿Puede usted (el paciente o el padre / tutor del paciente) comunicarse con el CTH cuando necesita ayuda para coordinar la atención del paciente (*por ejemplo, controlar una hemorragia, aprender el tratamiento en el hogar, coordinar con otros proveedores de atención médica o manejar cirugías*)?
- ○ Nunca
- ○ Algunas veces
- ○ Frecuentemente
- ○ Siempre

¿Qué tan satisfecho está (el paciente) con la coordinación de su atención?
- ○ Muy Satisfecho
- ○ Moderadamente satisfecho
- ○ Un poco satisfecho
- ○ No satisfecho

SECCIÓN II - Encuesta al paciente

Esta sección se refiere a cada paciente individual y tendrá la oportunidad de agregar pacientes adicionales en su hogar.
En esta encuesta, "usted" siempre se refiere al paciente. Si es padre o tutor legal, recuerde que "usted" se refiere al niño paciente.

Soy: (escoja una respuesta - **uno de los padres debe completar el formulario si el paciente es menor de 18 años**)
- ○ Paciente
- ○ El padre, cuidador del paciente, o tutor legal

Edad del paciente: (escriba el número de años en la casilla, escriba cero para niños menores de un año) ☐

Diagnóstico del paciente:
- ○ Deficiencia de Factor 8
- ○ Deficiencia de Factor 9
- ○ Enfermedad de Von Willebrand
- ○ Otro trastorno de la coagulación (indique el trastorno:_____

Severidad de deficiencia :
- ○ Leve
- ○ Moderada
- ○ Severa
- ○ No sé la severidad

Raza del paciente **(marque todo lo que corresponda)**
- ☐ Blanco
- ☐ Negro o afroamericano
- ☐ Asiático
- ☐ Indígena norteamericano o de Alaska
- ☐ Hawaiano o isleño del Pacífico
- ☐ Multiracial/ multicultural
- ☐ Prefiero no responder

¿Es el paciente hispano, latino o de la Península Ibérica?
- ○ Sí
- ○ No
- ○ Prefiero no responder

¿Con cuál identidad de género se identifica el paciente?
- ○ Mujer
- ○ Hombre
- ○ Mujer transgénero
- ○ Hombre transgénero
- ○ No binario/ tercer género
- ○ No listado
- ○ Prefiero no responder

Confidential 4

¿En cuál región of Virginia vive (de acuerdo al mapa)?
- ○ Central Virginia
- ○ Northern Virginia
- ○ Blue Ridge
- ○ Hampton Roads
- ○ Roanoke Area
- ○ Southwest Virginia

¿Cuál es el idioma de preferencia del paciente?:
- ○ Inglés
- ○ Español
- ○ Otro idioma (*indique cuál*):_____

¿Cuál Centro para el Tratamiento de la Hemofilia (CTH) provee el cuido del paciente?
- ○ Virginia Commonwealth University (VCU)
- ○ University of Virginia (UVA)
- ○ Children's Hospital of The King's Daughters (CHKD)
- ○ Children's National Hospital (CNH)

Preguntas Medicas:

¿Cuál es el medicamento PRINCIPAL que toma el paciente para tratar su trastorno hemorrágico?
- ○ Factor
- ○ Stimate
- ○ Amicar
- ○ Hemlibra- *¿Cuánto tiempo ha estado usando Hemlibra?*
  - ○ 6 meses o menos
  - ○ más de 6 meses, pero menos de 1 año
  - ○ más de 1 año

Si usa Hemlibra- ¿Se pone en contacto con su CTH más o menos desde que inició Hemlibra?
- ○ Más
- ○ Menos
- ○ Igual

Si usa Hemlibra- ¿Con qué frecuencia le gustaría tener citas en su CTH después de cambiarse a Hemlibra?
- ○ Más
- ○ Menos
- ○ Igual

¿Ha cambiado usted (el paciente) su tratamiento para la prevención o el tratamiento de hemorragias en los últimos 3 años?
- ○ No
- ○ Sí

¿Cómo han cambiado los servicios que usted (el paciente) necesita de su CTH debido a este cambio de tratamiento?
- ○ Aumentado
- ○ Disminuido
- ○ Sin cambio
- ○ Necesidad de diferentes servicios

¿Ha tenido cirugías o procedimientos en el último año?
- ○ No
- ○ Sí

¿El CTH ayudó a coordinar su plan de cirugía?
- ○ Sí
- ○ No
- ○ No lo sé

Cuido del CTH:

¿Cuáles proveedores ve regularmente en su visita integral en el CTH? **(marque todo lo que corresponda)**
- ☐ Doctor
- ☐ Enfermero
- ☐ Trabajador social
- ☐ Terapeuta físico
- ☐ Psicólogo
- ☐ Nutricionista
- ☐ Consejero genético
- ☐ Consultor educativo
- ☐ Coordinador de investigación
- ☐ Otro (indique cuál):_____

¿Hay algún proveedor que no ve actualmente pero que le gustaría tener disponible en su visita al CTH? **(marque todo lo que corresponda)**
- ☐ Terapeuta físico
- ☐ Psicólogo
- ☐ Nutricionista
- ☐ Consejero genético
- ☐ Consultor educativo
- ☐ Coordinador de investigación
- ☐ Otro (indique cuál):_____

¿Hay algún proveedor que ve actualmente en su visita que NO cree que necesite? **(marque todo lo que corresponda)**
- ☐ Terapeuta físico
- ☐ Psicólogo
- ☐ Nutricionista
- ☐ Consejero genético
- ☐ Consultor educativo
- ☐ Coordinador de investigación
- ☐ Otro (indique cuál):_____

¿Qué servicios ofrece su CTH actualmente? **(marque todo lo que corresponda)**
- ☐ Traducción escrita de folletos en mi idioma preferido
- ☐ Un intérprete de idiomas en las visitas al CTH
- ☐ Un intérprete de idiomas para llamadas telefónicas con el CTH
- ☐ Adaptaciones para necesidades físicas que faciliten la asistencia a la clínica (silla de ruedas, estacionamiento con servicio de valet., etc.)
- ☐ Adaptaciones para discapacidades auditivas
- ☐ Adaptaciones para discapacidades visuales
- ☐ Folletos e información escrita que sean fáciles de leer y comprender.

¿Qué servicios necesita de su CTH? **(marque todo lo que corresponda)**
- ☐ Traducción escrita de folletos en mi idioma preferido
- ☐ Un intérprete de idiomas en las visitas al CTH
- ☐ Un intérprete de idiomas para llamadas telefónicas con el CTH
- ☐ Adaptaciones para necesidades físicas que faciliten la asistencia a la clínica (silla de ruedas, estacionamiento con servicio de valet., etc.)
- ☐ Adaptaciones para discapacidades auditivas
- ☐ Adaptaciones para discapacidades visuales
- ☐ Folletos e información escrita que sean fáciles de leer y comprender.

Pregunta solo para pacientes entre edades 12 and 21 años: *(déjelo en blanco si no se aplica)*
¿Sobre qué le gustaría obtener más información para prepararse para el cuidado como adulto? **(marque todo lo que corresponda)**
- ☐ Contactos en el CTH para adultos
- ☐ Ayuda para programar la primera cita
- ☐ Opciones de seguro
- ☐ Otro: _____

Pregunta solo para pacientes menores de 21 años: *(déjelo en blanco si no se aplica)*
¿Su CTH le ayuda con asuntos de la escuela / guardería?
- ○ No
- ○ Sí- *¿Con cuáles asuntos de la escuela / guardería le gustaría recibir más ayuda?* **(marque todo lo que corresponda)**
  - ☐ Plan médico
  - ☐ Planes de emergencia
  - ☐ Desarrollo del plan IEP / 504
  - ☐ Planificación posterior a la escuela secundaria / universidad
  - ☐ Otro (indique cuál):_____

¿Hay áreas en las que le gustaría recibir más ayuda de su CTH?
- ○ No
- ○ Sí- (indique cuál):_____

Pregunta solo para pacientes de 55 o más *(déjelo en blanco si no se aplica)*
¿En qué áreas le gustaría recibir más ayuda? **(marque todo lo que corresponda)**
- ○ Entender Medicare
- ○ Manejo de múltiples condiciones de salud
- ○ Coordinación con especialistas
- ○ Preguntas sobre la atención a largo plazo (como hogares de ancianos)
- ○ Asuntos de salud mental
- ○ Necesidades de Terapia Ocupacional / Terapia Física con la edad
- ○ Adaptaciones para el hogar
- ○ Otro:_____