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BLOOD CLOT AND PULMONARY EMBOLISM POLICY REPORT

Submitted by the Agency for Health Care Administration



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INTRODUCTION

Florida Statute section 408.0621 establishes the Blood Clot and Pulmonary Embolism Policy Workgroup (BCPEP or “Workgroup”) for Florida, provides direction to the panel, and requires the submission of an annual and final report to the Governor, the President of the Senate, and the Speaker of the House of Representatives by January 4, 2025. The Agency for Health Care Administration (“Agency”), in conjunction with the State Surgeon General, establishes this Workgroup to promote the development of a risk surveillance system and policy recommendations to improve standards of care, surveillance, detection, treatment, and patient and family education relating to blood clots and pulmonary embolisms. As required, the BCPEP Workgroup Chair and members hereby submit this annual and final report on the Workgroup’s activity, findings, and recommendations.

Emily Adkins Prevention Act: Section 408.0621, Florida Statutes

- (1) The Secretary of Health Care Administration shall establish a blood clot and pulmonary embolism policy workgroup in conjunction with the State Surgeon General.
- (2) The workgroup shall:
 - a. Identify the aggregate number of people who experience blood clots and pulmonary embolisms annually in this state.
 - b. Identify how data is collected regarding blood clots, pulmonary embolisms, and adverse health outcomes associated with these conditions.
 - c. Identify how blood clots and pulmonary embolisms impact the lives of people in this state.
 - d. Identify the standards of care for blood clot surveillance, detection, and treatment.
 - e. Identify emerging treatments, therapies, and research relating to blood clots.
 - f. Develop a risk surveillance system to help health care providers identify patients who may be at a higher risk of forming blood clots and pulmonary embolisms.
 - g. Develop policy recommendations to help improve patient awareness of blood clot risks.
 - h. Develop policy recommendations to help

improve surveillance and detection of patients who may be at a higher risk of forming blood clots in licensed healthcare facilities, including hospitals, nursing homes, assisted living facilities, residential treatment facilities, and ambulatory surgical centers.

- i. Develop policy recommendations relating to guidelines used that affect the standard of care for patients at risk of forming blood clots.
 - j. Develop policy recommendations relating to providing patients and their families with written notice of increased risks of forming blood clots.
- (3)
- a. The workgroup shall be comprised of health care providers, patients who have experienced blood clots, family members of patients who have died from blood clots, advocates, and other interested parties and associations.
 - b. The President of the Senate and the Speaker of the House of Representatives shall each appoint two members to the Workgroup.
 - c. Members of the workgroup shall serve without compensation.
 - d. The State Surgeon General shall appoint the chair of the workgroup.
 - e. The chair is authorized to create subcommittees to help with research, scheduling speakers on important subjects, and drafting a workgroup report and policy recommendations.
 - f. workgroup meetings may be held through teleconference or other electronic means.
- (4)
- a. The Secretary of the Agency for Health Care Administration shall submit a final report detailing his or her findings and recommendations to the Governor, the Senate President, and the House of Representatives Speaker by January 4, 2025.

BACKGROUND

Definition

Deep vein thrombosis (DVT) refers to the development of blood clots in the large veins of the legs or arms. A blood clot is also referred to as a thrombus. Circulation blockage can lead to swelling, redness, tenderness, and pain, often described as cramping or aching.¹⁻²

Often, these thrombi can dislodge and travel to other blood vessels, known as an embolism. Embolisms to the lungs' arteries, termed pulmonary embolism (PE), can impede blood flow and oxygen exchange in the tissue, resulting in symptoms of sudden shortness of breath, chest pain, and palpitations. PE is potentially fatal as it can result in cardiac arrest and sudden death.

Due to the possible evolution of thrombus to embolism, DVT and PE can occur in the same person. Venous thromboembolism (VTE) is a term that collectively refers to the presence of DVT and/or PE in an individual. Approximately two-thirds of patients will have only a DVT, while one-third will have a PE with or without concurrent DVT.³⁻⁴ Specifically, up to 35% of patients diagnosed with DVT will have evidence of PE on imaging tests but no associated symptoms; conversely, 30-70% of patients with symptomatic PE will also have evidence of DVT in the lower extremities.⁵⁻⁷

Diagnosis

A DVT is most often suspected in patients with unilateral swelling, pain, or warmth of an extremity. The diagnostic approach to a DVT is standardized and begins with estimating the pre-test probability of its occurrence. It may incorporate a combination of the initial clinical impression, scoring systems (e.g., Wells score, Modified Wells score), and/or blood tests, including the D-dimer.⁸⁻¹⁰ The D-dimer is a small protein fragment present after the body degrades blood clots; this value is elevated in almost all patients with VTE. The sensitivity of the D-dimer in patients with a DVT is greater than 90% and improves when using age-adjusted cutoffs, especially in elderly patients.¹¹⁻¹² In cases where the suspicion of a DVT remains high, compression ultrasound imaging of the extremities is the imaging method of choice, with a sensitivity and specificity of up to 95%.¹³⁻¹⁴

A PE can manifest in a broad spectrum of features, ranging from no symptoms or mild chest discomfort to severe shortness of breath, shock, cardiac arrest, and sudden death. Although most hemodynamically significant PE arises from DVT in veins of the proximal lower extremities (e.g., popliteal, femoral, iliac), direct objective evidence of a DVT in a patient may not always correlate with PE. Because of the non-specific yet possibly emergent nature of PE and symptom overlap with other critical medical conditions (i.e., myocardial infarction, pericarditis, pneumothorax), the diagnosis involves clinical assessment, scoring systems, laboratory testing, and imaging studies. Although the use of clinical decision-scoring systems or rule-out criteria in addition to a D-dimer test may increase the diagnostic yield of further testing, significant misuse or underutilization of these tools limits their benefit.¹⁵⁻¹⁹

The definitive diagnostic imaging for PE is computed tomography pulmonary angiography (CTPA), which involves timed intravenous contrast administration to enhance the pulmonary arteries and improve detection. CTPA has a specificity and positive predictive value exceeding 90% for diagnosing PE in patients with intermediate to high pre-test probabilities.²⁰⁻²¹ The use of intravenous contrast may be limited in patients with existing renal disease and introduces the risk of an allergic reaction. The potential for these adverse events restricts the universal acquisition of CTPA imaging in all medical situations where a PE may be part of the differential diagnosis and forms the foundation for the continued development of screening tools and clinical decision-making protocols to improve diagnostic strategies. Consequently, there is an inevitable rate of failure in the detection of PE. Approximately 0.3-4% of patients determined to have a low pre-test probability have a PE.²²⁻²⁴ Furthermore, 26-50% of patients with acute PE will experience misdiagnosis or a diagnostic delay of almost seven days.^{25,26} Alternate imaging approaches include ventilation-perfusion scans, but these may be more costly and diagnostically equivalent in high pre-test probability settings as findings are otherwise often indeterminate.

PREVALENCE AND HEALTH IMPACT

Incidence, Prevalence, and Mortality

VTE is a significant and growing public health concern in the United States. The annual incidence of VTE is approximately 1 per 1,000 individuals, resulting in almost 900,000 cases per year.²⁷⁻²⁸ VTE can occur in any situation with an increased tendency for the blood to clot (termed hypercoagulability), slow blood flow, or injury to the walls of the blood vessels. Therefore, major risk factors for VTE include recent hospitalizations or surgery, cancer, immobilization, inflammatory conditions, select medications, nursing home residency, travel, and certain genetic factors. The incidence of VTE increases with age.²⁹ It is also a significant cause of maternal mortality, accounting for up to 10% of maternal deaths in the United States.³⁰ Currently, VTE is the leading cause of preventable hospital death.²⁹ VTE is associated with considerable mortality, with approximately 100,000 deaths per year in the United States, the majority of which are due to sudden death from PE.^{27,29} In-hospital mortality after an acute PE is up to 8%.³¹ The 30-day and 1-year mortality rate after the onset of a VTE is approximately 3% and 20%, respectively.²⁹

Economic Burden

VTE inflicts a significant economic burden on the United States healthcare system due to high treatment costs and long-term complications, including increased re-hospitalization rates and productivity losses. The annual cost of managing newly diagnosed VTE ranges between \$7-10 billion.³² Direct per-patient medical costs can be up to \$15,000 in the first year and rise to a cumulative total of \$23,000 due to various complications. Resource use during hospitalizations for a newly diagnosed VTE can range from \$30,000 to \$37,000.³³ Hospitalizations for recurrent VTE are often more costly than the initial event.³⁴ Long-term complications can include chronic inflammatory damage from DVT in the extremities as well as injury to the lungs after a PE. Medication-related adverse events, including bleeding events from anti-coagulation (commonly known as a “blood thinner”), may also occur. The cost of treating such complications can range from \$1,000-12,000 per event.³²⁻³⁵ Lastly, employees recovering from a VTE

event can suffer from productivity losses of up to approximately \$60,000.³⁶

Challenges and Threats

Despite the overwhelming health and economic burden of VTE, medical care for this condition is limited by suboptimal public awareness, poor and highly variable adherence to guidelines related to the implementation of treatment and prophylaxis (prevention) of VTE, insufficient recognition and management of the potential long-term complications, absence of a robust systemic surveillance system, an absence of dedicated treatment centers or specialized response teams, and inadequate funding towards novel research in the field.

Public awareness of VTE pales in comparison to other primary medical conditions. In one global survey, 44% and 54% of respondents were aware of DVT and PE, respectively, compared to heart attacks, strokes, hypertension, or specific cancers, where awareness rates ranged from 82-90%.³⁷ Despite advances in detection, treatment, and prevention strategies for VTE, its incidence has not significantly decreased in the past several decades, and significant socioeconomic disparities in clinical outcomes persist. Evidence-based guidelines for the prevention and treatment of VTE are not routinely followed by clinical providers, with adherence ranging from 2 to 50% and vary by the specialty of the primary treatment team as well as the gender or age of the patient.³⁸⁻⁴¹ Scoring systems, such as the Caprini score, are underutilized to identify patients at risk for VTE.⁴² Ultimately, up to 40% of cases of VTE may be preventable if guidelines for prophylaxis are followed.⁴¹ Reasons that may limit guideline adherence include lack of familiarity, concerns about bleeding risks, and perceived complexity, especially in special patient populations.

WORKGROUP GOALS

The Workgroup has identified the following points to address in this report:

GOAL 1: Identify the aggregate number of people who experience DVT and PE each year in the State of Florida.

GOAL 2: Identify how patient-specific data for individuals with newly diagnosed VTE and the associated adverse health outcomes is collected and monitored.

GOAL 3: Identify how VTE impacts people's lives in Florida.

GOAL 4: Identify the current standard of care for VTE prophylaxis, treatment, and surveillance.

GOAL 5: Identify emerging therapies and research related to VTE.

GOAL 6: Develop policy recommendations for a monitoring system and database to recognize at-risk individuals and to monitor patients after a diagnosis of VTE.

GOAL 7: Develop policy recommendations for Florida's standard-of-care VTE prevention and treatment strategies.

GOAL 8: Develop policy recommendations to improve public and provider awareness of VTE and its associated risks.

ACTIVITIES AND PROGRESS OF THE WORKGROUP

The Workgroup, consisting of a panel of medical and public health experts and representatives, convened through a series of monthly meetings and interim communications. The Workgroup identified and synthesized relevant data and research from contemporary scientific literature to provide

supporting information and inform the Goals of the Workgroup.

Since the workgroup's chair was appointed in January 2024, the workgroup met eight times to discuss and prepare the report.

BCPEP Timeline



THE WORKGROUP'S RECOMMENDATIONS

Based on the information gathered and synthesized from stakeholder input, public comments, medical experts, and extensive literature review, the Workgroup has developed evidence-based and actionable recommendations to address (1) Prevention, (2) Treatment, (3) Surveillance, and (4) Education.

- 1. IMPLEMENT A STATEWIDE VTE MONITORING SYSTEM:** Develop and deploy a comprehensive monitoring system to collect data on VTE incidents across Florida, utilizing existing healthcare data infrastructure and integrating new data collection methods. **(High Priority Recommendation)**
- 2. STANDARDIZE VTE RISK ASSESSMENT PROTOCOLS:** Mandate using standardized risk assessment tools (e.g., Wells score, Caprini score) in hospitals and healthcare facilities (outpatient and inpatient) to identify patients at higher risk of developing VTE and ensure timely prophylaxis. **(High Priority Recommendation)**
- 3. ENHANCE PUBLIC AWARENESS CAMPAIGNS:** Launch public education initiatives to increase awareness about the risks, symptoms, and prevention of DVT and PE, targeting high-risk populations and healthcare providers. **(High Priority Recommendation)**
- 4. IMPROVE POST-DISCHARGE FOLLOW-UP:** Establish protocols for post-discharge follow-up of VTE patients to monitor for recurrence, manage long-term complications, and ensure adherence to treatment plans. With a specific focus on post-surgical patients, pregnant and post-partum females, and patients considered high risk for developing VTE (cancer patients, ICU patients). This may include establishing quality measures for hospitals to ensure patients receive and take medication appropriately and are monitored for chronic complications. Additionally, all patients discharged from the hospital shall be offered educational and awareness material related to blood clots, even if they have not experienced a blood clot. **(High Priority Recommendation)**
- 5. INCORPORATE SURVEYING FOR VTE PROPHYLAXIS:** Where applicable, establish monitoring for quality improvement into the Agency for Health Care Administration's facility surveying process. This would include adding into the survey process, monitoring to ensure that physicians are properly educating patients on the signs and symptoms of VTE Prophylaxis post discharge.
- 6. IMPROVE DIAGNOSTIC ACCURACY AND TIMELINESS:** Train healthcare providers to recognize symptoms of DVT and PE promptly and ensure access to diagnostic imaging tools for timely and accurate diagnosis. This may include a required continued medical education (CME) course for all healthcare providers.
- 7. EXPAND AWARENESS AND CARE FOR VTE PROPHYLAXIS FOR PREGNANT WOMEN AND POST-PARTUM FEMALES.** Make sure healthcare systems have a system to evaluate VTE risk in pregnant women and post-partum women (up to 12 weeks) who may need prophylactic therapy for VTE. Root cause analysis and reporting on all VTE deaths are required for this population.
- 8. EXPAND ACCESS TO PROPHYLACTIC MEASURES:** Ensure all patients identified as high risk for VTE receive appropriate prophylactic measures, including anticoagulant therapy and mechanical prophylaxis, across all healthcare settings. The state may need to consider implementing a patient assistance program to offset the cost of anticoagulation for patients in the outpatient setting.
- 9. SPECIALIZED VTE TREATMENT CENTERS:** Establish dedicated VTE treatment centers and PE response teams (PERT) or PERT-like teams within hospitals to provide specialized care, ensure adherence to treatment guidelines, and improve patient outcomes. The state should set aside funding for major hospital systems that can serve as tertiary referral centers for VTE management and chronic PE management centers in Florida.
- 10. RECOMMEND STATE SUPPORT AND PROMOTE FLORIDA CENTERS AND HOSPITALS THAT SPECIALIZE IN VTE AND CHRONIC PE CARE.** There is only one Chronic PE surgical center in Florida, and two more are being established.

State-level support of surgical chronic PE centers in Florida can help further develop and build these specialized programs so that patients can access treatment in Florida and do not need to travel out of state for surgery or treatment.

11. PROMOTE RESEARCH AND EMERGING

THERAPIES: Support and fund clinical and translational research into new treatments, therapies, and technologies for VTE prevention and management, including studies on genetic factors and novel anticoagulants.

12. INTEGRATE VTE DATA INTO EXISTING HEALTH

REGISTRIES: Support and expand existing health registries, such as the Florida Stroke Registry and OneFlorida Plus database, to include comprehensive data on VTE incidents, treatments, and outcomes to inform public health strategies better.

13. COLLABORATE WITH NATIONAL VTE

INITIATIVES: Align state policies with national VTE prevention and treatment initiatives, leveraging federal resources and guidelines to enhance the effectiveness of state-level interventions.

14. ENHANCE PROVIDER EDUCATION AND

TRAINING: Develop and implement continuing medical education programs for healthcare providers focused on the latest guidelines for VTE prevention, diagnosis, and treatment.

15. ADDRESS HEALTH GAPS IN VTE OUTCOMES:

Identify and address socioeconomic and underserved populations in VTE incidence and outcomes through targeted interventions to ensure access to care.

These recommendations aim to create a robust framework for preventing, treating, and monitoring VTE in the State of Florida. By doing so, they aim to ultimately reduce the incidence and improve outcomes for those affected by blood clots.

GOAL 1: Identify the aggregate number of people who experience DVT and PE each year in the State of Florida.

As of April 2024, the population of the State of Florida was projected to be 22.9 million individuals and growing. Based on the published population-level data and reported annual incidence of VTE of approximately 1 to 2 per 1,000 individuals, an estimated 22,900-45,800 people in Florida are afflicted by VTE annually. Health indicator data for the State of Florida is currently provided by the Florida Community Health Assessment and Resource Tool Set, powered by Florida's Bureaus of Community Health Assessment and Vital Statistics. In 2022, the age-adjusted incidence of blood clot-related emergency department visits was 80.5 per 100,000 (21,340 individuals), hospitalizations were 86.3 per 100,000 (25,583 individuals), and deaths were 2.8 per 100,000 (846 individuals). More specifically, in 2022, the age-adjusted incidence of pulmonary embolism-related emergency department visits was 11.8 per 100,000 (3,118 individuals), hospitalizations were 46.4 per 100,000 (13,926 individuals), and deaths were 1.7 per 100,000 (531 individuals). In all cases, the age-adjusted incidence has gradually increased since 2005. The available data also demonstrates significant variability in the incidence of VTE depending on the county within the State of Florida from which the data is sampled.

Emergency Department Visit Counts and Age-Adjusted Rates per 100,000 People in the State of Florida		
All Blood Clots		
Year	Count	Age-Adjusted Rate
2018	17,374	71.5
2019	19,140	76.9
2020	17,202	67.9
2021	20,251	78.3
2022	21,340	80.5
Pulmonary Embolism Only		
Year	Count	Age-Adjusted Rate
2018	1,646	6.8
2019	2,246	9.1
2020	2,339	9.3
2021	2,995	11.7
2022	3,118	11.8

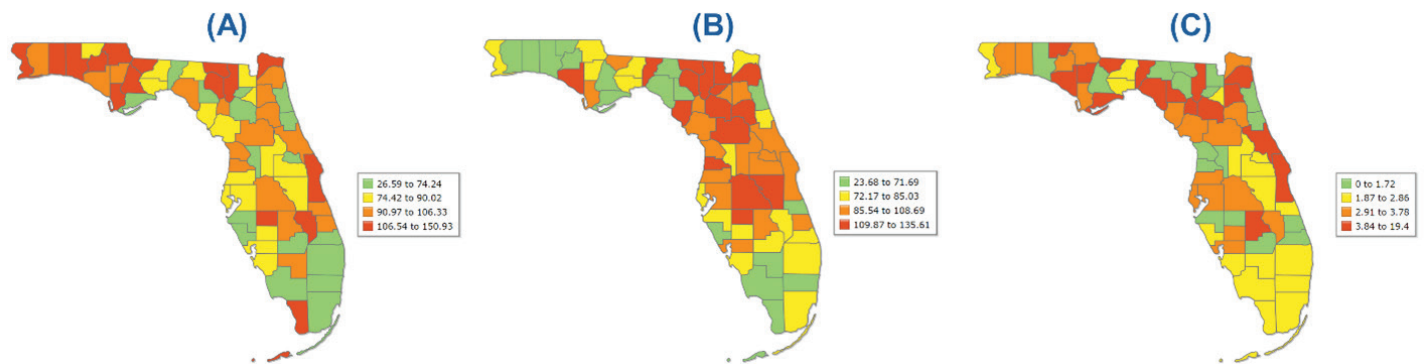
Data Source: Agency for Health Care Administration

Hospitalization Counts and Age-Adjusted Rates per 100,000 People in the State of Florida		
All Blood Clots		
Year	Count	Age-Adjusted Rate
2018	25,327	94.5
2019	25,203	91.3
2020	23,538	83.1
2021	25,192	86.8
2022	25,583	86.3
Pulmonary Embolism Only		
Year	Count	Age-Adjusted Rate
2018	12,651	47.0
2019	12,733	45.9
2020	12,496	43.5
2021	13,852	47.4
2022	13,926	46.4

Data Source: Agency for Health Care Administration

Death Counts and Age-Adjusted Rates per 100,000 People in the State of Florida		
All Blood Clots		
Year	Count	Age-Adjusted Rate
2018	769	2.7
2019	774	2.7
2020	852	3.0
2021	893	3.0
2022	846	2.8
Pulmonary Embolism Only		
Year	Count	Age-Adjusted Rate
2018	474	1.7
2019	514	1.8
2020	543	1.8
2021	577	1.9
2022	531	1.7

Data Source: Agency for Health Care Administration



Age-adjusted Emergency Department Visits (A), Hospitalizations (B), and Deaths (C) from Blood Clots, Rate Per 100,000 People in the Counties of the State of Florida (2022).

Data Source: Agency for Health Care Administration

However, most of the sources for this data are secondary (data collection is not conducted, contracted, funded by, or overseen by the Florida Department of Health) and may vary by indication. Additionally, the information is sourced from data from which the health indicator was the primary diagnosis. This is noteworthy as studies have demonstrated that the accuracy of primary diagnosis charting in medical encounters within the United States ranges from 55-80%, with marked variability depending on the clinical setting and methods used for data collection and analysis.⁴³⁻⁴⁵ Without a standardized and established systematic surveillance system, obtaining sufficiently accurate data regarding the prevalence and incidence of VTE events in the State of Florida is impossible. This workgroup's strongest recommendation is to fund state-level surveillance and monitoring of VTE to obtain accurate data on annual incidence and prevalence over time.

GOAL 2: *Identify how patient-specific data for individuals with newly diagnosed VTE and the associated adverse health outcomes can be collected and monitored.*

The growing awareness of VTE as a crucial public health concern has been emphasized by the convention of the American Public Health Association and the Centers for Disease Control and Prevention in 2003, the Surgeon General's Workshop on DVT in 2006, and the National Workshop between the American Society of Hematology and the Centers for Disease Control and Prevention in 2010.⁴⁶⁻⁴⁸ These proceedings summarily delivered a call to action, highlighting the lack of public awareness of VTE, failure in appropriate screening, risk stratification and prevention of VTE, a need for collaboration between government and medical professional societies, and the potential benefit of a systematic surveillance system for VTE. Although a systematic surveillance system for VTE has yet to be implemented, such a provision could provide more accurate data on the disease burden of this underdiagnosed medical disorder, especially in special populations (e.g., racial and ethnic minority individuals, elderly patients, individuals with disabilities, individuals living in long-term care facilities or nursing residences). Moreover, risk factors for onset, clinician adherence to standardized guidelines for prevention and treatment, and long-term complications for VTE may be clarified to guide effective health practices and inform public policies.

Based on the initial Framework for Program Evaluation in Public Health, the Centers for Disease Control and Prevention prepared Updated Guidelines for Evaluating Public Health Surveillance Systems in 2001.⁴⁹ These guidelines describe methods for establishing and evaluating surveillance systems to ensure that public health problems are effectively and efficiently monitored. Briefly, the specific health-related event should be sufficiently examined to describe the purpose, operation, and objectives of the surveillance system, detail the necessary resources to employ the system, identify partners to facilitate its functions (i.e., data collection, maintenance, analysis), and routinely assess data quality and performance.

With collaboration between healthcare providers, community and government representatives, and other professional organizations, having a systematic surveillance system for the State of Florida that operationally defines, monitors, and assesses VTE is feasible. One of the most important challenges in system implementation is identifying databases and

resources to facilitate effective disease surveillance. Proceedings from the conventions and workshops on VTE discussed the feasibility of extending existing national registries to incorporate VTE surveillance operations. Databases included the Paul Coverdell National Acute Stroke Registry, the Pregnancy Risk Assessment Monitoring System, and the Thrombosis and Hemostasis Centers Research and Prevention. The National Workshop between the American Society of Hematology and the Centers for Disease Control and Prevention highlighted key limitations of these resource infrastructures, including survivorship bias of the data, significant variability and reliability of diagnostic methods, and inaccuracy in primary diagnosis charting. Multicenter registries dedicated to the observation, monitoring, and data collection and analysis of VTE are lacking. The National Pulmonary Embolism Response Team (PERT) Consortium is a data registry of over 5,000 patients collected from over 30 hospitals and a quality assessment and improvement tool for hospitalizations and longitudinal follow-up.⁵⁰⁻⁵¹ It must be noted that this initiative focuses exclusively on benchmarks in the diagnosis, treatment, and outcomes of PE. While the PERT Consortium may offer a more compatible registry for a VTE surveillance system, all multicenter or national databases and registries are currently limited by a lack of robust correspondence with emergency department encounters and outpatient data. The latter is particularly noteworthy as VTE events are increasingly being diagnosed and managed on an outpatient basis.⁵²

In general, national databases may face challenges in the heterogeneity of data collected (e.g., diverse demographics, varying public health priorities), broad and inefficient resource utilization or allocation, and administrative obstacles regarding healthcare systems, data sharing agreements, and privacy regulations. Therefore, state-level registries utilized in conjunction may most effectively facilitate a VTE surveillance system. For example, the Florida Stroke Registry, maintained by the University of Miami, systematically stores health information and performance metrics from 180 Florida stroke centers and hospitals to improve evidence-based practices. The existing network allows for the examination of incidence, prevalence, and risk factors for stroke and has emphasized a data-driven examination of health disparities in stroke care. The

Florida Stroke Registry collects acute data from the American Heart Association's Get With the Guidelines Stroke database. Recently, the program has made strides in linking metrics from the Florida Department of Health's Florida Emergency Medical Service Tracking and Reporting System and the Agency for Healthcare Administration's inpatient, ambulatory, and emergency department data to associate all phases of care (i.e., pre-hospital emergency medical services, in-hospital care, long-term follow-up) to improve the available statewide outcome data substantially. Additionally, the Florida Stroke Registry Regional Dashboard, a quality improvement tool initiated in 2016 by stakeholders from Broward and Palm Beach County, has allowed select regional centers to evaluate and compare primary performance measures. Therefore, the existing resource infrastructure within the Florida Stroke Registry could reliably support the surveillance of VTE, especially for key health data (i.e., prevalence, incidence, risk factors) and outcome measures (i.e., prophylaxis rate, recurrence, and long-term complications).

Due to differences in presentation, detection, and treatment, the Florida Stroke Registry, as described, may fail to capture certain instances of VTE that are diagnosed in the outpatient setting, which develop following an acute hospitalization or that result in sudden death. Identification of VTE as a contributing factor or cause of death is particularly challenging given declining autopsy rates in the country, even though such procedures may unveil VTE in those with low initial clinical suspicion.⁵³⁻⁵⁴ Using a statewide electronic system to search through medical reports for radiographic identification of a DVT or PE via ultrasound or computed tomography chest imaging, respectively, can identify more patients for longitudinal evaluation. This may potentially be conducted via the OneFlorida Plus database. Maintained by the University of Florida, this healthcare data repository provides access to patient-level electronic health record data from healthcare systems across the State of Florida and across Florida and from select Georgia and Alabama cities.

GOAL 3: *Identify how VTE impacts people's lives in the State of Florida.*

VTE events can significantly impact patients' social, psychological, and economic lives. After experiencing a VTE, approximately 50% of patients experience depression, 40% report anxiety, and up to 70% endorse intrusive symptoms of flashbacks, nightmares, and hypervigilance consistent with post-traumatic stress disorder.⁵⁵⁻⁶² These disorders are often persistent, with a long-term psychosocioeconomic influence on the quality of life through social isolation and fear of recurrence, as well as disrupted income via loss of employment and decrease in productivity. Concerns about the future health consequences of VTE can lead to fatigue and health anxiety. The anxiety associated with recurrence in survivors of VTE can manifest in more frequent visits to the emergency department for an evaluation, resulting in considerable exposure to ionizing radiation and increased healthcare costs without a new diagnosis.³² Long-term medical complications of VTE may produce symptoms that also negatively affect quality of life, social relationships, and productivity. For example, one long-term manifestation of DVT is post-thrombotic syndrome, characterized by chronic pain, itching, swelling, discoloration, or ulceration of the affected area because of persistent inflammation and venous valve damage.^{63,64} The associated symptoms and economic burden can substantially limit people's participation in society and compromise the quality of life. Language barriers are particularly important in the State of Florida and can further compound these challenges, making it difficult for individuals to express their health concerns and symptoms, understand care instructions, and receive appropriate treatment. This societal barrier and others can result in healthcare consumers delaying or avoiding medical care, leading to poorer health outcomes and higher emergency department visits for otherwise treatable medical conditions.⁶⁵⁻⁶⁶

VTE also significantly impacts the loved ones and family members of affected patients.^{61-62,67-68} Initial diagnosis and treatment, especially in emergent cases, can cause significant psychological distress. Low awareness and misunderstanding about the causes and genetic risks associated with VTE can generate collective anxiety and concern among family members. VTE-related complications requiring ongoing medical care and costs related to healthcare services, as well as loss of employment, may lead to significant social, emotional, lifestyle,

and economic changes that affect family members. Due to the scarcity of targeted psychological counseling, educational programs, or other resources, the well-being of loved ones and family members may be negatively impacted long after the inciting VTE event.

GOAL 4: *Identify the current standards of care for VTE prophylaxis, treatment, and surveillance.*

Although evidence-based guidelines for the prevention and treatment of VTE are readily available, including the American Society of Hematology 2020 Guidelines and the American College of Chest Physicians 2021 Guidelines, the significant variability in adherence to and utilization of these standard-of-care practices undermines effective management of VTE.⁶⁹⁻⁷⁰ The cornerstone of therapy for VTE is anticoagulation, commonly referred to as “blood thinners”, which prevent clot growth as the body’s natural systems gradually dissolve it. There is substantial literature regarding risk stratification of patients with VTE, choice of anticoagulant selection, suitability for procedural interventions, and other preventative and management practices. This report aims to briefly review VTE-related recommendations and focus on shortcomings, challenges, and areas for improvement in VTE’s risk assessment, prevention, treatment, and surveillance.

Risk-assessment and Prophylaxis

VTE prophylaxis refers to the use of therapy to prevent or reduce the risk of VTE. Medical treatment in the form of anticoagulants, at a dose lower than that used in individuals with confirmed VTE, is most often used for VTE prophylaxis. In some instances, such as patients with a high risk for bleeding, mechanical devices such as intermittent pneumatic compression are used, an inflatable sleeve worn over the extremities to promote blood circulation. In patients with a confirmed DVT who cannot be treated with anticoagulation, another preventative intervention is the use of an implantable filter to reduce the risk of subsequent PE. This filter is placed in the vena cava, a large vein that returns blood to the heart and lungs and acts to catch blood clots that may embolize from the DVT. Evidence-based guidelines for primary and secondary VTE prophylaxis exist.⁷¹⁻⁷⁵ However, proper utilization of VTE prophylaxis remains suboptimal as up to 50% of high-risk individuals may fail to receive the recommended preventative therapies.^{38-41,76-78} This includes inappropriate early discontinuation or substandard therapy selection. Appropriately and consistently applying evidence-based VTE prophylactic measures is necessary, as emphasized in the Surgeon General’s Workshop on DVT in 2006.⁴⁷

The single most significant risk factor for developing VTE is hospitalization for an acute medical illness or surgery.⁷⁹ Prophylaxis can significantly reduce the incidence of VTE in hospitalized patients.^{77,80} Therefore, the 2010 Safe Practices for Better Healthcare by the National Quality Form endorses thorough evaluations of each hospitalized patient for the risk of developing VTE and the implementation of evidence-based prophylaxis.⁸¹ Patients hospitalized for an acute medical condition should be assessed for their risk of VTE; however, no prediction score is validated in this setting, the use of risk calculators such as the Padua Prediction Score, IMPROVE risk score, or the GENEVA risk score may augment the assessment.⁸²⁻⁸⁴ Patients with a moderate or high risk of VTE should definitively be treated with pharmacologic prophylaxis unless contraindicated.

In individuals hospitalized for surgery, fatal PE is the leading preventable cause of death postoperatively. Synthesis of the collective literature from 1975 to 2005 thoroughly illustrates that pharmacologic prophylaxis prevents almost all fatal cases of VTE in post-surgical patients.⁸⁵⁻⁸⁸ The Caprini Risk Score is a widely used risk assessment model that evaluates the risk of VTE in surgical patients by incorporating multiple weighted variables to generate a cumulative score, stratifying patients into discrete risk categories.⁸⁹⁻⁹⁰ This score increases in a non-linear fashion, reflecting the rising incidence of VTE in high-risk groups. Scores of > 8 in surgical patients have been associated with a 1-5% incidence of fatal PE if anticoagulant prophylaxis is not used. A Modified Caprini Risk Assessment Model, adapted by the American College of Chest Physicians, has been validated in VTE risk assessment for patients undergoing general and abdominal-pelvic surgeries to guide prophylaxis initiation and has also been correlated to major trauma, neurosurgery, thoracic, and cardiac surgeries.^{71,73,74} Patients undergoing major orthopedic surgery are at a high risk of symptomatic VTE; medical prophylaxis is almost always employed and may be extended up to 35 days following the surgery, depending on the procedure.⁷⁵

Almost 400 published peer-reviewed articles have represented more than 5 million patients in studies using and validating the Caprini Risk Score as a comprehensive, evidence-based algorithm to guide

Are You at Risk for DVT?

Complete this risk assessment tool to find out.

Name _____ Male Female Today's Date _____

Only your doctor can determine if you are at risk for Deep Vein Thrombosis (DVT), a blood clot that forms in one of the deep veins of your legs. A review of your personal history and current health may determine if you are at risk for developing this condition. Take a moment to complete this form for yourself (or complete it for a loved one). Then be sure to talk with your doctor about your risk for DVT and what you can do to help protect against it. Your doctor may want to keep a copy in your file for future reference.

DIRECTIONS:
 1. Check all statements that apply to you.
 2. Enter the number of points for each of your checked statements in the space at right.
 3. Add up all points to reach your total DVT Risk Score. Then, share your completed form with your doctor.

Add 1 point for each of the following statements that apply now or within the past month:

- Age 41–60 years _____
 - Minor surgery (less than 45 minutes) performed or planned _____
 - Major surgery (more than 45 minutes) performed within the last month _____
 - Visible varicose veins _____
 - A history of Inflammatory Bowel Disease (IBD) (for example, Crohn's disease or ulcerative colitis) _____
 - Swollen legs (current) _____
 - Overweight or obese (Body Mass Index above 25) _____
 - Heart attack _____
 - Congestive heart failure _____
 - Serious infection (for example, pneumonia) _____
 - Lung disease (for example, emphysema or COPD) _____
 - On bed rest or restricted mobility (leg brace) _____
 - Other risk factors (1 point each)*** _____
- ***Additional risk factors not tested in the validation studies but shown in the literature to be associated with VTE include BMI above 40, smoking, diabetes requiring insulin, chemotherapy, blood transfusions, and length of surgery over 2 hours.

For women only: Add 1 point for each of the following statements that apply:

- Current use of birth control or Hormone Replacement Therapy (HRT) _____
- Pregnant or had a baby within the last month _____
- History of unexplained stillborn infant, recurrent spontaneous abortion (more than 3), premature birth with toxemia or growth restricted infant. _____

Add 2 points for each of the following statements that apply:

- Age 61–74 years _____
- Current or past malignancies (excluding skin cancer, but not melanoma) _____
- Planned major surgery lasting longer than 45 minutes (including laparoscopic and arthroscopic) _____
- Plaster cast that has kept you from moving your leg within the last month _____
- Tube in blood vessel in neck or chest that delivers blood or medicine directly to heart within the last month (also called central venous access, PICC line, or port) _____
- Confined to a bed for 72 hours or more _____

Add 3 points for each of the following statements that apply:

- Age 75 or over _____
- History of blood clots, either Deep Vein Thrombosis (DVT) or Pulmonary Embolism (PE) _____
- Family history of blood clots (thrombosis) _____
- Personal or family history of positive blood test indicating an increased risk of blood clotting _____

Add 5 points for each of the following statements that apply now or within the past month:

- Elective hip or knee joint replacement surgery _____
- Broken hip, pelvis or leg _____
- Serious trauma (for example, a fall, multiple broken bones or car accident) _____
- Spinal cord injury resulting in paralysis _____
- Experienced a stroke _____

 Add up all your points to get your total DVT Risk Score

- What does your DVT Risk Score mean?**
- Risk scores may indicate your odds of developing a DVT during major surgery or while being hospitalized for a serious illness.
 - Studies have shown if you have 0-2 risk factors, your DVT risk is small. This risk increases with the presence of more risk factors.
 - Airplane passengers who fly more than five hours may also be at risk for DVT.
 - Please share this information with your doctor who can determine your DVT risk by evaluating all of these factors.

Adapted with permission. Our thanks to ISMS member, J. A. Caprini, MD associated with NorthShore University HealthSystem October 2024

prophylaxis and prevent fatal VTE. Cases in which the model has generated inaccurate risk assessment have often involved suboptimal appraisal of the risk factors, such as failing to investigate the patient's family history of VTE fully. In 2014, Boston University introduced a mandatory prophylaxis pathway in surgical patients based on the Caprini Risk Score.⁹¹ Physicians were allowed to opt out by providing a valid medical reason. The duration of prophylaxis depended on the individual's overall risk score. 89% of moderate-risk and 77% of high-risk patients initially adhered to the corresponding recommended prophylaxis regimen. The incidence of post-surgical VTE decreased to one-half of a percent following the implementation of this program, which has persisted to the present time. These findings, in addition to results of similar programs published in the interim, demonstrate that consistent and mandatory implementation of an evidence-based prophylaxis pathway can effectively reduce the risk of post-surgical VTE.

Evidence-based guidelines for VTE prophylaxis also exist for special populations, such as patients with cancer.⁹²⁻⁹⁷ Hospitalized cancer patients are at high risk for VTE, but the rate of appropriate utilization is substandard.⁹⁵⁻⁹⁷ The incidence of VTE is also higher in residents of nursing homes or long-term care facilities, with a 2-30-fold increased risk when compared to the general population.⁹⁸⁻¹⁰⁰ Although guidelines from the American Society of Hematology recommend against routine VTE prophylaxis in chronically immobilized outpatient residents of nursing homes, the elevated risk of VTE should be considered during their evaluation.

Treatment

The treatment of VTE depends on the patient's hemodynamic stability and overall risk assessment. Anticoagulation is the foundation of therapy, initiated to stabilize and prevent the growth of the identified clot. Based on the circumstances and underlying risk factors associated with the individual's VTE, the duration of anticoagulation ranges from 3 months to indefinite treatment. The choice of agent is conditional on patient-specific factors, including tolerability, cost, and compatibility with other medications.

The diagnostic evaluation of suspected cases of DVT and PE may be inappropriate in approximately 30%

and 40% of patients, respectively, leading to under-treatment and long-term consequences.^{101,102} Risk factors for inappropriate management include an age of greater than 75 years old, active anticoagulant use, and concomitant chronic conditions (e.g., heart failure, lung disease). A lack of adherence to established pre-test probability scoring and diagnostic guidelines is also associated with substandard evaluations. Inappropriate management, namely the lack of initiation of anticoagulation, can significantly increase the risk of subsequent VTE occurrence.

In certain high-risk or select groups of patients with VTE, alternative therapy or interventions may be indicated. In patients with a DVT, a large clot burden that obstructs blood flow and threatens the viability of the limb warrants more emergent intervention than therapeutic anticoagulation. In these cases, a thrombolytic medication may be administered, accelerating blood clot breakdown. Rather than administering the therapy intravenously (i.e., systemically), delivery through a catheter, known as catheter-directed thrombolysis, directly to the site of the DVT is performed.⁶⁹⁻⁷⁰ There are certain risk factors that absolutely prohibit the use of thrombolytic therapy due to the high risk of bleeding and other adverse events, including significant active bleeding, a history of intracranial hemorrhage, known cerebral vascular lesions or neoplasms, or an ischemic stroke within the past three months. In patients with an unacceptably high risk of bleeding or who fail to appropriately respond to thrombolytic therapy, mechanical extraction of the clot (i.e., thrombectomy) via a catheter or open surgery may be pursued. In the absence of these complicating factors, the addition of thrombolysis or thrombectomy to standard therapeutic anticoagulation for the management of DVT has not routinely demonstrated benefit.

Due to PE's emergent nature, this medical entity's management is more nuanced. Therapeutic anticoagulation is the treatment of choice for newly diagnosed PE who are hemodynamically stable following initial resuscitative measures. Current recommendations advocate for administering systemic thrombolysis over catheter-directed thrombolysis in patients who remain hemodynamically unstable.^{69,70,103} The evidence for the efficacy of systemic thrombolysis in high-

risk, unstable patients with PE is more robust when compared to the paucity of data available for management with catheter-directed thrombolysis. Moreover, systemic administration is more readily available when compared to the time and resources involved in preparing a catheter-directed approach. The management of patients with a high-risk PE who have an unacceptably high bleeding risk or fail to respond to systemic thrombolysis is not clearly defined, often varying based on the available resources and expertise of the institution. Mechanical extraction of the clot (i.e., embolectomy) via a catheter or open surgery and catheter-directed thrombolysis may be pursued. Current challenges and areas of interest in the thrombolytic treatment of PE include identifying candidates for whom therapy is appropriate, determining the suitability of thrombolysis for not only high-risk patients but also intermediate-high-risk patients who may not necessarily be acutely hemodynamically unstable, exploring low-dose regimens to mitigate bleeding risks, and developing alternative treatment strategies for patients who fail to respond to thrombolysis.¹⁰⁴⁻¹⁰⁶

Long-term Monitoring

Long-term monitoring and surveillance of patients with VTE is necessary to guide the duration of anticoagulation therapy, prevent the recurrence of VTE, and manage complications. There is a substantial risk of recurrence of VTE in the first year following diagnosis, which remains elevated up to 10 years following the initial event.¹⁰⁷ This is associated with up to a 4-fold increased long-term mortality rate.¹⁰⁸ Long-term complications include bleeding following the initiation of anticoagulation therapy as well as disorders related to the site of the blood clot. Chronic venous insufficiency is a condition of decreased blood return and consequent increased blood pressure in the venous system of the lower extremities. Stagnant blood can stimulate chronic, local inflammation that leads to swelling, skin discoloration, varicose veins, and, more rarely, venous stasis ulcers. Chronic venous insufficiency may occur in almost one-third of patients within 5-10 years following an acute DVT event; the management of severe manifestations of chronic venous insufficiency, such as venous stasis ulcers, can impart an annual cost of over \$5,000 per person.¹⁰⁹⁻¹¹² Signs and symptoms of chronic

venous insufficiency can progress in severity due to persistent venous obstruction and valvular damage, leading to post-thrombotic syndrome. Up to half of patients with a DVT may experience post-thrombotic syndrome. In the United States, healthcare services associated with treating post-thrombotic syndrome add an estimated annual direct cost of at least \$200 million with an average discounted per-patient lifetime cost of \$3069.¹¹³⁻¹¹⁵ Furthermore, at least 2 million workdays are lost annually due to prohibitive symptoms.¹¹⁶ Lastly, up to 4% of patients with a PE within the prior two years may develop chronic pulmonary thromboembolic pulmonary hypertension (CTEPH), a rare and possibly fatal syndrome in which elevated pressure in the blood vessels of the lungs produces progressive shortness of breath.^{63,64,117} Societal costs in patients with CTEPH may be up to 8 times higher than in the general population, primarily driven by productivity loss as well as the burden of surgical procedures and life-long anticoagulation.¹¹⁸

The rate of accurate diagnosis and treatment of post-thrombotic syndrome is not known due to limited evidence in the literature. Although there is no standardized management strategy, the use of lower extremity compression instruments (e.g., graduated compression stockings, Velcro compression wraps, intermittent pneumatic compression devices), as well as exercise and lifestyle modifications (e.g., daily pool immersion), may mitigate overall disease burden, highlighting the need for appropriate long-term and routine outpatient evaluations.¹¹⁹ CTEPH is a chronic disease in which blood clots in the vessels of the lungs cause increased resistance to flow and elevated pressure, resulting in progressive shortness of breath and other disabling symptoms. Five-year survival rates can vary from approximately 70-96% depending on whether the patient receives medical and/or surgical intervention.¹²⁰⁻¹²² Evidence suggests that the median delay in diagnosis of CTEPH may be up to 21 months following symptom onset.¹²³ Given the severity of CTEPH as well as the potential benefit of prompt recognition and therapy, numerous associations advocate for dedicated surveillance and monitoring in patients with a newly diagnosed PE. In cases of high-risk features or persistent symptoms, it is recommended that patients receive repeat imaging and testing approximately

three months after diagnosis to investigate the possibility of CTEPH.¹²⁴⁻¹²⁶ This may be best suited for Pulmonary Hypertension Care Centers with extensive experience in diagnosing and managing this disorder. There are multiple CTEPH referral centers in Florida, but only one offers surgical intervention (pulmonary thromboendarterectomy surgery) for patients, with two others currently being developed. This surgery is considered a first-line intervention for many patients. Many patients are referred out of state for surgical intervention. The support of these surgical centers can help address a growing unmet need in Florida and expand the availability of this treatment to many patients.

Overall, there is notable variability and overall low rates of follow-up for VTE, which may be attributed to poor patient education emphasizing the medical seriousness of the diagnosis and its complications, a lack of communication between inpatient and outpatient healthcare networks, financial constraints, and improper systematic interventions to ensure the establishment of follow-up appointments. Rates of nonadherence or early discontinuation of the prescribed anticoagulation regimen for VTE can be as high as 50%, depending on the studied population.¹²⁷⁻¹²⁹ Failure rates in long-term monitoring and follow-up in patients with a newly diagnosed VTE emphasize the need for a systematic monitoring system to identify at-risk individuals, support benchmarks in care, and ensure routine outpatient follow-up to encourage physician-patient interactions, continuing education, adherence to therapy, and early recognition of complications.

GOAL 5: *Identify emerging therapies and research related to VTE.*

Considering current limitations and challenges in managing VTE, promising emerging therapies address diagnosis, clinical management, medical treatment, and interventional alternatives. Advancements in imaging techniques and the discovery of new biomarkers, such as soluble P-selectin, to augment the VTE diagnostic platform are underway.¹³⁰ Artificial intelligence has also been proposed to aid radiologists in rapidly interpreting and detecting PE in medical images.¹³¹

Due to the complexity of the management of PE, especially emergent cases, the first PERT was established in 2012 by a multi-disciplinary team of providers at Massachusetts General Hospital. The overall goal of this initiative was to develop a coordinated and comprehensive team of multiple specialists to deliver rapid and individualized clinical management recommendations for patients with PE. Since its inception, more than 100 healthcare institutions worldwide have adopted the PERT model.^{50,132-134} The system-wide implementation of a multidisciplinary team mobilized for new diagnoses of PE has facilitated improvements in risk stratification, decision-making, utilization of advanced therapies, and clinical outcomes such as reduced length of hospitalization.¹³⁵⁻¹³⁶ These models have also incorporated streamlined post-hospitalization monitoring and follow-up to enhance recognition of complications and ensure adherence to anticoagulation therapy. The National PERT Consortium has also co-sponsored prospective trials of advanced interventional therapies for PE. The 2019 European Society of Cardiology guidelines for the diagnosis and management of acute PE delivered a class IIa level C recommendation for the utility of the PERT model.¹³⁷

During the process of clot formation, there are specific proteins called coagulation factors as well as related substances that interact in a sequential pathway. Modern medical treatment for VTE has involved anticoagulation therapy that selectively inhibits key coagulation factors, namely Factor X, within this cascade to slow clotting within the individual. Although the rate of minor bleeding events associated with the use of modern anticoagulation for the treatment of VTE is not well described, clinically significant major bleeding events occur at a rate of 6.62 per 100 treatment years.¹³⁸ Although data is limited, one study found

that 27% of providers opted for a reduced duration of anticoagulation treatment for VTE due to concerns about bleeding risks.¹³⁹ Emerging anticoagulant strategies to address these concerns include novel therapies that selectively target Factors XI and XII of the clotting pathway; early studies investigating the potential targeting of these factors as opposed to Factor X have demonstrated similar prophylactic and treatment efficacy with significantly reduced bleeding events.¹⁴⁰⁻¹⁴² Medical therapies focusing on the body's innate capacity to dissolve clots are also being researched.¹⁴³ Thrombin-activatable fibrinolysis inhibitor is a protein with a function that ultimately slows clot breakdown; inhibitors of this protein are currently being investigated to facilitate clot dissolution in the acute phase of VTE. These agents may also have a role in mitigating the onset of CTEPH. Finally, inhibitors of inflammatory cells and mediators within the vessel wall are being studied to reduce the risk of post-thrombotic syndrome.

Innovative interventional alternatives, including catheter-directed thrombolysis and mechanical thrombectomy, are also being studied to manage acute VTE.¹⁴⁴⁻¹⁴⁵ These investigations have emphasized the utility of such procedures to reduce the clot burden in high-risk patients with PE and decrease the incidence of post-thrombotic syndrome. The PERT Consortium has also co-sponsored the APEX-AV, HI-PEITHO, and STORM-PE clinical trials. These studies aim to investigate the utility of investigational interventional devices for treating VTE, including patients with intermediate-risk features.

GOAL 6: *Develop policy recommendations for a monitoring system and database to recognize at-risk individuals and to monitor patients after a diagnosis of VTE.*

With any public health policy recommendation, essential features include (1) active stakeholder and community engagement, (2) identification of legal frameworks to support the policy, (3) utilization of evidence-based decision-making, (4) allocation of appropriate resources and infrastructure, (5) development of methods for monitoring, evaluation, and quality assurance, (6) commitment to sustainability, and (7) provision of educational and advocacy services. Proceedings from the convention of the American Public Health Association and the Centers for Disease Control and Prevention in 2003, the Surgeon General's Workshop on DVT in 2006, and the National Workshop between the American Society of Hematology and the Centers for Disease Control and Prevention in 2010 previously endorsed recommendations to improve diagnosis, prevention, treatment, long-term monitoring, education, and advocacy for VTE.⁴⁶⁻⁴⁸ These proposals can be extended to guide policies and strategies for implementing a state-wide surveillance system for VTE.

With increased stakeholder support, funding, and resource investment, the infrastructures inherent to two Florida databases, the Florida Stroke Registry and OneFlorida Plus, can be extended and translated to monitoring VTE healthcare data in the State of Florida. The development of various specialized VTE programs can generate additional avenues of management that may be directly integrated into the long-term monitoring and evaluation of patients. For example, funding of PERT centers across the State of Florida can support dedicated multidisciplinary teams that not only rapidly identify and treat hospitalized patients with VTE but also assure outpatient follow-up with Pulmonary Hypertension Centers, hematology clinics, and other specialty services to manage medical therapy and long-term complications. Participants of this network can actively contribute to and maintain the data registry as well as satisfy healthcare benchmarks.

The State of Florida has the highest proportion of older adults (65 years or older) in the United States, with an increasing demand for and engagement with nursing homes and assisted living facilities.¹⁴⁶⁻¹⁴⁷ The aging population within the State of Florida and the age-associated elevated risk of VTE emphasize critical features that must

be addressed while implementing a surveillance system. Health indicators and outcome data from individuals at long-term care facilities should be included in the design of such a surveillance system and any future research conducted within this field. Several examples of infrastructures, registries, and networks have monitored data and information from long-term care facilities to improve healthcare outcomes. One study in the United Kingdom utilized the Cumulative Sum technique to develop the Continuous Monitoring of Emergency Admissions method.¹⁴⁸ This procedure was used to detect unusually high rates of hospital admissions for individuals within care homes and trigger an alert to investigate healthcare quality and other benchmarks. In 2022, the National Institute on Aging funded the Long-Term Care Data Cooperative to integrate the electronic health records from major specialty vendors with Medicare claims to support a longitudinal registry and encourage research in residents' healthcare outcomes.¹⁴⁹ Lastly, in 2023, a national automated surveillance system was developed in Norway to identify SARS-CoV-2 outbreaks within long-term care facilities in near real-time.¹⁵⁰ The results and success of these initiatives may inform the development of the VTE monitoring system and integration of healthcare data from long-term care facilities.

The successful implementation and maintenance of a monitoring system for VTE will provide state-wide information on (1) the true incidence and prevalence of VTE, (2) the geographic distribution and demographic breakdown of VTE, including age, sex, and ethnicity, (3) the rate of appropriate utilization of evidence-based preventative and treatment measures, and (4) the effectiveness of systematic long-term outpatient follow-up and monitoring. This data will also aid in identifying healthcare disparities among racial and ethnic minority individuals as well as allow for dedicated evaluation of high-risk groups (e.g., elderly patients, patients in long-term care facilities, pregnant patients, patients with cancer, and patients undergoing surgery). The longitudinal execution of this program will also help assess changes in these features and the achievement of healthcare benchmarks and identify areas of need for future research.

GOAL 7: *Develop policy recommendations for standard-of-care VTE prevention and treatment strategies in the State of Florida.*

While there may be subtle specialty-specific nuances to preventing and managing VTE, several contemporary guidelines provide unified standard-of-care recommendations.^{69-75,92-95} Promoting enhanced, appropriate utilization of these evidence-based practices is essential to improving clinical outcomes in this population. Passive guideline dissemination is insufficient to boost adherence rates. Active strategies include computer-based alerts and decision tools, continuing education on prophylaxis and treatment (e.g., grand rounds, electronic courses), and audit and feedback. Additionally, a team of dedicated healthcare personnel (e.g., physicians, pharmacists, nurses) may be established to review admitted patients to identify high-risk patients who are not currently on appropriate prophylaxis. A multifaceted approach

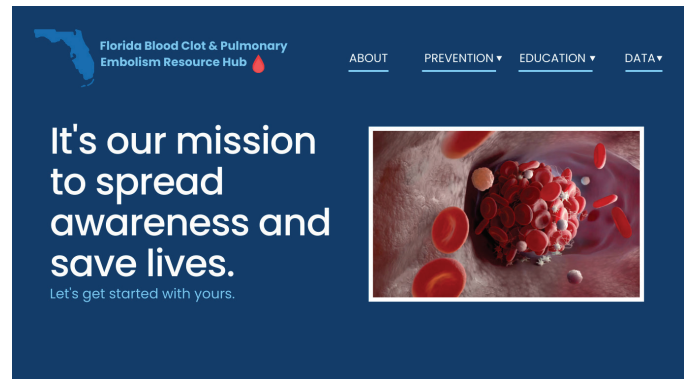
implementing multiple active interventions can significantly increase the proportion of patients receiving VTE prophylaxis.¹⁵¹⁻¹⁵⁶ Regarding the diagnosis and treatment of acute VTE in hospitalized patients, the support of PERT centers can facilitate timely and appropriate clinical management, including the use of advanced interventions. The combination of proactive computer-based decision tools, PERTs, and a dedicated surveillance system can also ensure proper outpatient follow-up, monitoring, and achievement of standard-of-care benchmarks. Importantly, evaluation for appropriate physician documentation of assessment of VTE risk is an essential measure as the rate of adequate prophylactic prescription. These programs should be actively monitored for quality assurance and development to promote the continuous improvement of prophylaxis and treatment of VTE.

GOAL 8: *Develop policy recommendations for improving public and provider awareness of VTE and the associated risks.*

Public awareness of VTE in 2015 was significantly low when compared to other medical conditions, with approximately half of respondents indicating an understanding of DVT and PE.³⁷ Contemporary evidence indicates that awareness has not significantly changed.¹⁵⁷ A minority of respondents can adequately detail the symptoms of VTE or that it is preventable, and approximately one-third can identify risk factors, such as hospitalization, surgery, pregnancy, cancer, or old age. The American Heart Association and the American Society of Clinical Oncology emphasize the importance of improving public education as informed patients are more likely to report symptoms early to facilitate diagnosis, understand the severity of the disease process, and adhere to prescribed prophylactic or treatment measures.^{92,93,158} It has been recommended that awareness of VTE be integrated into hospital benchmarks and pay-for-performance programs.

While public awareness of VTE is low, patients and families affected by VTE indicate a strong interest in educational initiatives.¹⁵⁹ In a global survey of patients with cancer, 78.8% highlighted VTE awareness as highly relevant, with almost 50% expressing concern over the quality of communication regarding its associated symptoms, risk factors, and ability to cause harm.¹⁶⁰ Increasing awareness of VTE can be done through comprehensive educational programs.¹⁶¹ This includes public health campaigns through various forms of media (e.g., centralized website, television and internet advertisements, social media engagement, physical flyers) and community outreach programs. In honor of journalist David Bloom, who died of a PE from a DVT, the month of March was designated DVT awareness month in 2015; the significance of this memory should continue to be emphasized as part of public awareness initiatives. The National Blood Clot Alliance is a voluntary health organization that has led the public health campaign with the Stop The Clot initiative, providing many patient resources on VTE.

High-risk individuals should be identified and given access to these programs and risk assessment tools. For example, individuals undergoing surgery should be provided with their Caprini Risk Score, and recently hospitalized patients should be provided



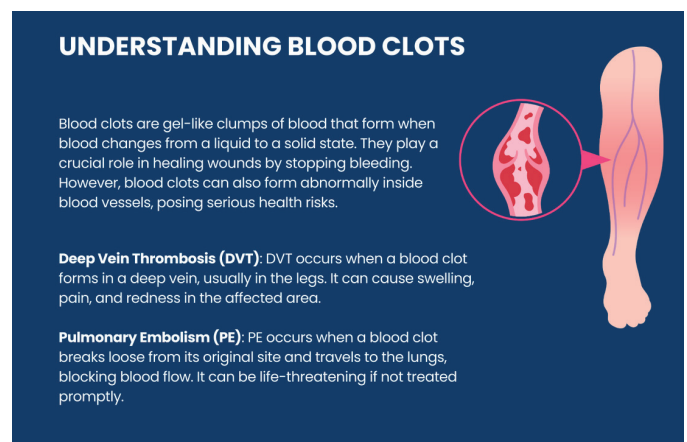
The screenshot shows the top navigation bar of the Florida Blood Clot & Pulmonary Embolism Resource Hub website. The navigation menu includes 'ABOUT', 'PREVENTION', 'EDUCATION', and 'DATA'. The main content area features a dark blue background with the text: 'It's our mission to spread awareness and save lives. Let's get started with yours.' To the right of the text is a circular image showing a microscopic view of a blood vessel with a red blood cell and a white blood cell.



The screenshot shows the 'KNOW YOUR RISK' section of the website. The text reads: 'On average, one American dies of a blood clot every 6 minutes. Blood clots can impact anyone regardless of age, gender, ethnicity, or race. There are many risk factors, including:'. A list of risk factors is provided: Cancer, Hospitalization and surgery, Pregnancy, Being overweight, Smoking, Trauma, and Immobility or sitting for long periods. To the right is a blue button labeled 'TAKE YOUR RISK ASSESSMENT' with a sub-button that says 'Click to know your risk assessment'.



The screenshot shows the 'ABOUT US' section of the website. The text reads: 'This website serves as a centralized resource hub for blood clot and pulmonary embolism patients, their loved ones, and health care providers. Use this website to access trusted information on prevention, treatment, and management strategies.' Below this is a paragraph about Deep vein thrombosis (DVT) and its prevalence. At the bottom, it states 'This website was created to help Floridians:' followed by a list of goals: 'Understand blood clots and their treatment options.' and 'Access reliable resources for prevention and management.'




The screenshot shows the 'UNDERSTANDING BLOOD CLOTS' section of the website. The text explains that blood clots are gel-like clumps of blood that form when blood changes from a liquid to a solid state. It also notes that blood clots can form abnormally inside blood vessels, posing serious health risks. To the right is an illustration of a human leg with a red circle highlighting a blood vessel. Below the text are two definitions: 'Deep Vein Thrombosis (DVT): DVT occurs when a blood clot forms in a deep vein, usually in the legs. It can cause swelling, pain, and redness in the affected area.' and 'Pulmonary Embolism (PE): PE occurs when a blood clot breaks loose from its original site and travels to the lungs, blocking blood flow. It can be life-threatening if not treated promptly.'

with written notice of their increased risk of blood clot formation. Healthcare professional training in the form of continuing education on VTE prophylaxis management guidelines and optimal communication practices can improve the quality of disseminated information. Education should focus on the critical symptoms of VTE and the urgency of prompt healthcare evaluation, as well as the associated risk factors and preventability of the disorder.





In individuals with a new diagnosis of VTE, an integrated, patient-centered, and multidisciplinary approach can ensure they have accurate, actionable knowledge needed to manage their disease successfully and its treatment and reduce the risk of long-term complications and adverse outcomes.¹⁶²⁻¹⁶³ Effective patient education and discharge planning from the hospital are two crucial pillars in the transition of care that allow patients and their caregivers to assume responsibility for their health safely and meaningfully. This effort should be a continual process, occurring at multiple stages during the patient’s hospitalization and continuing in the outpatient setting. A standardized and comprehensive VTE education program in the healthcare system will identify potential barriers (e.g., health literacy, language skills, social support system) and detail the individual diagnosis and treatment plan (e.g., mechanism of therapy, dosing schedules, medication interactions, potential side effects) using validated, patient-centric communication techniques that avoid medical jargon and emphasize the importance of long-term follow-up. Ultimately, an effective patient education strategy following a diagnosis of VTE will result in improved overall health outcomes, enhanced patient satisfaction, reduced psychological distress, and decreased healthcare costs.

PREVENTION

Preventing blood clots and pulmonary embolism is crucial for maintaining optimal health and well-being. Take proactive steps to reduce your risk.



PREVENTING BLOOD CLOTS

-  Tell your doctor if you have any risk factors for blood clots.
-  Know your risks and recognize signs and symptoms.
-  Before any surgery, talk with your doctor about blood clots.
-  See your doctor as soon as you can if you do have any symptoms.

WHEN TO SEE A HEALTHCARE PROVIDER

The immediate effects of a blood clot are nonspecific and can occur due to several different medical reasons.

You should get immediate medical attention if you develop any symptoms that could be associated with a blood clot.



These include:

- Swelling of your arm or leg
- Shortness of breath
- Chest pain
- Vision changes, trouble speaking, or weakness or sensory changes on one side of the face or body
- Severe abdominal pain

You will likely need diagnostic tests to determine the underlying cause of your symptoms. Sometimes the timing may provide clues that a blood clot caused the symptoms, but that’s not always the case.

DATA AND STATISTICS

Up to 900,000 people in the United States are affected by venous thromboembolism (VTE, a blood clot), each year

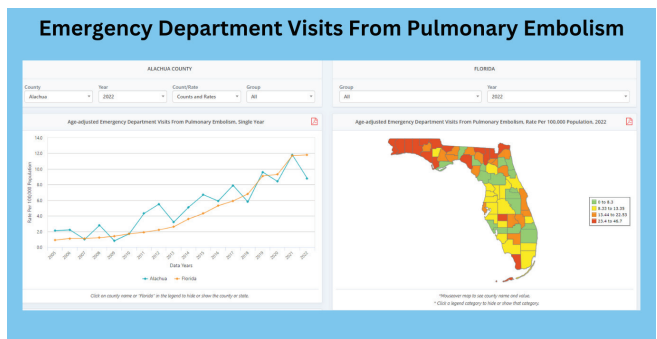
– More Stats

People are at particularly high risk for VTE during or just after a hospitalization (with or without surgery), during cancer treatment, and during or just after pregnancy

– Learn More

An estimated 60,000-100,000 Americans die of VTE each year and many others have long-term complications from a VTE

– Listen to podcast



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