## Taskforce

### *Strategy and aims*

Vasculearn Network (VLN; formerly North-American Thrombosis Forum), a U.S.-based nonprofit organization, assembled a first-of-its-kind global, multidisciplinary international steering committee of healthcare professionals and trainees, communication experts, mental health experts, and patients who have had VTE (**Figure 1**). The committee was tasked with conceptualizing a healthcare professional-facing tool to convey 1) the essential information for communication at the time of VTE diagnosis and in the weeks and months that follow, and 2) evidence-based best practices for information communication. The target audience for this toolkit is any healthcare professional involved in the care of patients VTE from the time of diagnosis until approximately the completion of the treatment phase.

The steering committee convened through video and in-person conferences between January 2023 and June 2024 and followed a structured process that involved healthcare professionals and patients in all meetings. Consensus was achieved using a multistage modified Delphi technique. The toolkit was developed in phases that included content generation, open review, and iterative refinement based upon feedback. The content generation strategy included three phases: mapping a VTE patient journey, conducting an inventory of information relevant to patients with VTE, and identifying best practices for communication. The International Society on Thrombosis and Haemostasis (ISTH) Scientific and Standardization Committee (SSC) Subcommittee on Predictive and Diagnostic Variables in Thrombotic Disease endorsed this project.

Notably, the toolkit does not include specific answers to patients' questions; for those, we refer to up-to-date scientific resources such as guidelines by the European Society of Cardiology, American Heart association, American Society of Hematology and the American College of Chest Physicians. Rather this study focussed purely on aspects of optimal communication.

## Patient journey mapping

Mapping of the patient care journey (‘patient journey’) is a method to understand opportunities to enhance communication of diagnoses and diseases.[1,2] The structure of the toolkit was based on timepoints, key topics and pivotal moments. The VLN steering committee identified timepoints that are important in the patient journey from the moment of VTE diagnosis until the end of the prescribed treatment phase. Patient experience and clinical care management decisions were included in the timeline to highlight key topics for communication, agnostic to care setting and country. Each key topic was mapped on the timeline and partitioned between diagnostic encounter, therapeutic encounter and follow-up phases of care. Furthermore, care in the context of the encounter type including the inpatient/emergency encounter, outpatient scheduled encounter, and outpatient unscheduled encounter was described. Pivotal moments in the patient journey were identified for both the patient and the healthcare professional. Special attention was paid to aspects of healthcare system navigation. Priorities and aims of communication were included in the pathway, both from the patient and healthcare professional perspective. The identified timepoints were grouped intuitively to inform the framing of best practice communication:

- Immediate term: the immediate term includes the diagnostic encounter, immediate management decisions, and the initial phase of patient orientation to the diagnosis and treatment of VTE. In this term, patients require general information (“what is VTE, why did I get it, and how is it treated?”). The information conversation (initially) often occurs in the emergency department or an acute care setting and involves discharge planning and the first transfer of care. The ‘immediate term’ represents the time from diagnosis to about 1 week.
- Intermediate term: the intermediate term includes the initial response to therapy, resumption of usual family, professional, and social activities, and is localized primarily to the outpatient setting. The intermediate term may also include unscheduled encounters to address early complications (e.g., bleeding), concerns/uncertainties about one’s clinical course, what represents a ‘normal’

trajectory for recovery, and near-term impacts of a VTE diagnosis on daily life and relationships. The intermediate term represents the first 1-2 months of treatment.

- Long term: The long-term period captures concerns surrounding extended phase treatment and response to therapy for VTE including selection of duration of anticoagulant treatment (localized to the scheduled outpatient setting), and identification of any complications or underlying conditions that impact VTE management. Topics often include assessment and diagnosis of any contributing comorbidities (e.g., cancer or inherited or acquired thrombophilia) and assessment for anticipated physical and mental recovery. The long-term phase may include late complications such as recurrent VTE, persistent or discreet bleeding episodes, and post-VTE syndromes such as the emergence of symptoms suggestive of post-thrombotic changes in the limb, chronic thromboembolic disease, and rarely, chronic thromboembolic pulmonary hypertension. Counseling on family planning, discussions regarding future thrombosis risk mitigation, and anticipatory guidance surrounding high-risk situations, as well as instruction relevant to a long-term follow-up plan, is to occur in the long-term phase, defined as 3-6 months post-event and beyond (**Figure 2**).

## Information inventory

The steering committee first listed all timepoints, topics, and pivotal moments identified through the systematic review of the literature, as well as questions that patients with VTE and their caregivers reported as commonly encountered informed by their own experience. The group further searched the National Blood Clot Alliance, World Thrombosis Day, and Thrombosis Canada websites for existing teaching materials, and interrogated the VLN ‘patient content needs’ list that is a repository for all questions brought forth by patients during VLN support group meetings.

All frequently asked questions and information items identified through the search were listed in an Excel spreadsheet and grouped based on the time periods identified in the patient journey. The list was then curated by the working group, duplicates were removed, similar topics were merged, and topics found to be out of scope were removed. As the project progressed, a second version of the document linked frequently asked questions (‘Patient perspective’) with corresponding information items (‘Healthcare professional perspective’), and further classified items based on timepoints in the patient journey, clinical setting (e.g., acute care, scheduled outpatient visit, etc.), primary categories (e.g., diagnosis, treatment, women’s health, etc.) and secondary categories (e.g., anticoagulant education, side effects, lifestyle implications as subcategories in the primary ‘Treatment’ category). Timepoints from the acute care visit to the end of the treatment phase informed the ranking of items included in the patient journey. Each timepoint entry was mapped onto the patient journey timeline. The final list of communication content deemed as a ‘must-have’ was included in the finalized patient journey. After validation by the steering committee, the list was used by the technical team to develop the toolkit.

## Best communication practices

We conducted a comprehensive literature review in PubMed, CINHAL, Web of Science, and the Cochrane Library using predefined search terms that informed the content for a scoping review.[3] We considered eligible studies that focused on communication for acute encounters in VTE and cardiovascular disease. The aim of the scoping review was to identify existing tools, guidance, or best practices to inform optimal communication with patients. Evidence from the review was disseminated among the panelists and supplemented with personal experiences reported by the patients and healthcare professionals on the steering committee, and from other resources, i.e., health communication guidelines and dedicated resources such as vital talk and the Serious Illness Conversation Guide as recommended by our communication expert (LvV).

The main themes identified by literature search and group discussion were core tenets of appropriate health communication, health literacy, and inequity, the provision of information to manage anxiety and psychosocial stress, and evidence-based communication practices in the acute event (including a discharge conversation), and in the long-term elective care setting.[3] We did not find any prospective studies assessing the impact of certain communication strategies in patients with VTE, which underscored the relevance of this project. The best practices relevant to these five themes are summarized in **Table 1**, subdivided over the three timepoints, and integrated in the final toolkit.

Key aspects to good communication are language concordance, understanding the need for information, appropriate dosing of information, ensuring that essential information has been received being mindful of and bridging inequity, the careful management of patient expectations, and empowering patients to take responsibility for their health. For example, asking a patient about their understanding of the condition at the outset of the clinical encounter can help develop trust and level-set healthcare professional-patient communication such that topics and issues of key relevance to the patient are identified and addressed early in the patient’s journey. In stressful situations information recall is significantly impaired and iterative assessment of patient comprehension and the partitioning of information over time is advised.[4] Low health literacy is common and is estimated to be present in

48% of all people in the European Union.[5] By speaking in simple lay language and using techniques such as those shown in table 1, literacy levels can be better accommodated and patient retention and comprehension of information can be improved.

Successful communication includes acknowledgement of inequity and distrust in healthcare. Awareness of inequity should be raised when verbal and nonverbal signals of mistrust are observed. Further best practice includes offering the patient to partner in the way they want, inviting them to bring important people from their community to the encounter, and assess for prior healthcare exposure to discrimination. Both anxiety and psychological stress are reported among VTE survivors, but empathetic encounters, awareness of former experiences, and acknowledgement of harm from poor prior care experiences can help mitigate psychological distress.[6]

Communication with patients in the acute care setting is particularly challenging -yet necessary- in an unfamiliar, often hectic environment. Empathy and empathetic gestures can greatly enhance the effectiveness of communication and include sitting with the patient, demonstrating interest in them as an individual (rather than just 'a person with a clot'), and responding directly and clearly to any emotional concerns. Patient anxiety surrounding a new VTE diagnosis can be alleviated by assuring the patient that it is not expected that they will be able to recall all aspects of the initial encounter, that they will have additional questions after they leave the acute care setting, and that follow-up with their primary provider is an essential component in their overall care. Empathy, in conjunction with prioritizing information, may help enhance communication and comprehension, reduce information overload, and establish the trust necessary for patients to transition successfully into intermediate and long-term care.

Communication during planned intermediate and long-term follow-up provides the opportunity for patients to engage advocates, such as a significant other or friend, in their care. Advising the patient to prepare in advance of the visit by documenting a list of key questions will also advance patient agency and empowerment. Transfer of care (e.g., from secondary to primary care) represents a high-risk timepoint; by offering communication consistency, this tool supports continuity of patient care when moving between providers.

Steering committee discussion and objective considerations around the quality of identified best practices led to a consensus list of final recommendations incorporated in the toolkit.

### Toolkit online development

An online toolkit accessible by computer, tablet, or mobile phone that would serve as a resource for healthcare professionals and patients and inform optimization of the patient journey upon diagnosis of acute VTE was constructed. A commercial design team (TodayTomorrow) was selected and contracted by VLN to build the web-based interface. The challenge for the design team was to transform a data-rich Excel sheet into an accessible and engaging resource.

The team first strategized with the panelists to define the key information to include in the toolkit and chose 'time' as the core navigation variable. Using the timeline as a cornerstone, visitors can delve into topics relevant to the diagnosis or treatment of VTE by either scrolling or filtering based on their interests. To emphasize the contrast between the patient and healthcare professional perspectives, the design team created a tab to toggle between these perspectives. Users can explore the connections between different issues and gain insight into patient concerns. The design aesthetics distinguish between foreground and background elements to create an intuitively navigable interface.

To allow for input from content experts outside of the taskforce, an open review period was held and conducted in English. The project team invited attendees of the 2024 ISTH Congress to act as reviewers. Each reviewer received a link to the draft tool and a short survey comprising 3 questions to be answered using a 5-point Likert scale (1=disagree, 5 strongly agree). Twenty reviewers submitted a review report: 70% reported that they agreed or strongly agreed with the following statements: ‘The toolkit design is intuitive and easy to navigate’, ‘the toolkit content is clear’ and ‘the toolkit is useful for teaching healthcare professionals how to communicate with patients.’ Moreover, detailed feedback was provided about the reviewers’ experience using this toolkit, and several suggestions for making the toolkit more user-friendly were received. Reviewers tested the tool on both desktop/laptop computers and mobile devices. The toolkit was refined and improved based on feedback from our reviewers. The ISTH Standardization Subcommittee on Predictive and Diagnostic Variables also reviewed and provided feedback on toolkit content and presentation.

### Participation and role of patient partners

Patients and content expert contributors were integral to all stages and aspects of this work that ensured iterative, collaborative creation of the toolkit. Patient representatives were equal partners along with healthcare professionals to inform care delivery, analysis, and decision-making. Meeting content was overtly presented in lay terms to ensure patient comprehension and deliberate pauses in discussion were implemented to solicit patient opinions. Patients' contributions were three-fold. First, patient lived experiences provided insight regarding healthcare professional-patient interactions at the time of diagnosis and treatment of VTE. By sharing their stories and perspectives, patients provided a nuanced insight into the communication gaps and barriers. Second, patient input assured alignment of necessary clinical information (e.g., how blood thinners work), with the lived experience and wider information of day-to-day concerns (such as 'Can I go to the dentist?'). Third, patient presence was an omnipresent reminder of the personal impact of effective—or ineffective—communication on well-being and treatment adherence.

## References

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## Tables and figures

**Table 1**: schematic overview of best communication practices across the three main time points of the patient journey, as included in the toolkit.

| Main themes identified | Best practices | Immediate period | Intermediate period | Long-term period |
|---|---|---|---|---|
| Basics of appropriate healthcare communication | • Ensure language concordance, use interpreter if necessary. Use simple lay language, explain jargon.<br>• Provide information in a format that doesn't rely on audio recall only such as visuals or written & recorded information (if legally permitted and custom), to increase patient empowerment, ensuring acceptable readability scores of written information.<br>• Identify ways to 'chunk' the information, grouping it in ways which reduce the number of specific details an individual has to recall.[7]<br>• Make sure to assess the information need: start with establishing existing knowledge *(”What do you know about a blood clot?”)*, which helps developing trust, establishing the level of communication, identifying main knowledge gaps and understanding the individual's desire to obtain information to satisfy their conscious or unconscious need.<br>• Use a teach back tool to assure that the essential information has been received well. Make this does not give the impression of an interrogation but use wording such as “*Can you please tell me in your own words what I just told you? This will ensure that* | √ | √ | √ |

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| | *I provided you all the right information*”. With the latter sentence, you divert from subjecting the patient to a ‘test’ | | | |
| Dealing with health literacy | Use the teach-back approach and simple lay language. Understand that people in distress all have some form of health literacy | √ | √ | √ |
| Addressing and providing information to manage anxiety and psychosocial stress | ● Make sure to manage expectations: 1) inform patients of the next opportunities to talk to healthcare professionals about their VTE, and who they can turn to in case of (new) alarm symptoms, 2) make sure they understand the natural course of their symptoms (including what symptoms are normal and what needs (urgent) checking, 3) explain that there are multiple disciplines involved in the care of VTE, so they may get different information because of different perspectives/experience, 4) normalise psychological distress, but do not overstress this, for instance along this line: *”It’s perfectly normal to feel worried about this, but if you’re not that’s fine too. If you are worried, then here’s some things you can do.”.*<br>● Avoid remarks which bluntly/casually indicate severity or dissonantly suggest the patient is lucky such as “you dodged a bullet”. Do focus on helping the patient understand *their* condition which will help them identify themselves amidst the potentially overwhelming amount of information online/VTE information, and address and discuss common misconceptions such as the difference between PE and stroke.<br>● Show empathy, appropriate guidance can be found at:<br>✓ NURSE statement: https://www.vitaltalk.org/guides/responding-to-emotion-respecting/ | √ | √ | √ |

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|---|---|---|---|---|
| | ✓ GUIDE tool: https://www.vitaltalk.org/guides/serious-news/<br>✓ Serious Illness Conversation Guide: https://www.ariadnelabs.org/resources/downloads/serious-illness-conversation-guide/<br>✓ E.M.P.A.T.H.Y. tool [8]<br>✓ Empathy Circle [9]<br>● Be mindful of and bridge inequity, appropriate guidance can be found at https://www.vitaltalk.org/guides/bridging-inequity/ | | | |
| Communication in the acute event including discharge conversation | ● Sit down when you speak to the patient, even during busy shifts, and treat the patient as if they matter by showing interest in the person surrounding the clot.<br>● Weight of the info cannot be provided at the emergency room, basics are 1) diagnosis, 2) treatment, 3) selfcare and 4) what's to come including a moment that patients will receive more information and which alarm symptoms they need to be mindful of. By starting with '*it is absolutely essential that you know this*', the importance of listening carefully is highlighted. More detailed and tailored information should be provided as the patient journey progresses and ideally by the same healthcare professional for consistency; some form of overview of what was discussed/said is needed when different healthcare professionals communicate with the patient over time. | √ | | |

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|---|---|---|---|---|
| Communication in the long-term elective care setting | ● Involve primary caretakers/significant others/first-line relatives by either inviting them to be present during the visit to the clinic, or by instructing the patient to sit with family members in advance of the visit to list everything that needs to be asked; this will also empower patients by legitimating priming all these questions.<br>● Make sure to assess the information need and repeat information where relevant.<br>● Make sure patients understand why there is a follow-up meeting (”*there may be further testing and treatment decisions may be taken*”) rather than leaving patients uninformed so they may worry that they need to dee the physician because something is wrong.<br>● When discussing potential complications or discussing the need for specific therapeutic interventions in the future, start with *“What to do if…. (you get pregnant, get surgery and so on)*”, thus empowering patients to take their responsibility, rather than to explain what the therapeutic consequence would be (“in case of future surgery, prolonged thromboprophylaxis is recommended”).<br>● Make sure the patients understands who his/hers case manager is, i.e. who will keep overview over their situation and is their primary contact, supporting nonabandonment. | | √ | √ |

**Figure 1:** Composition of the international, multidisciplinary steering committee

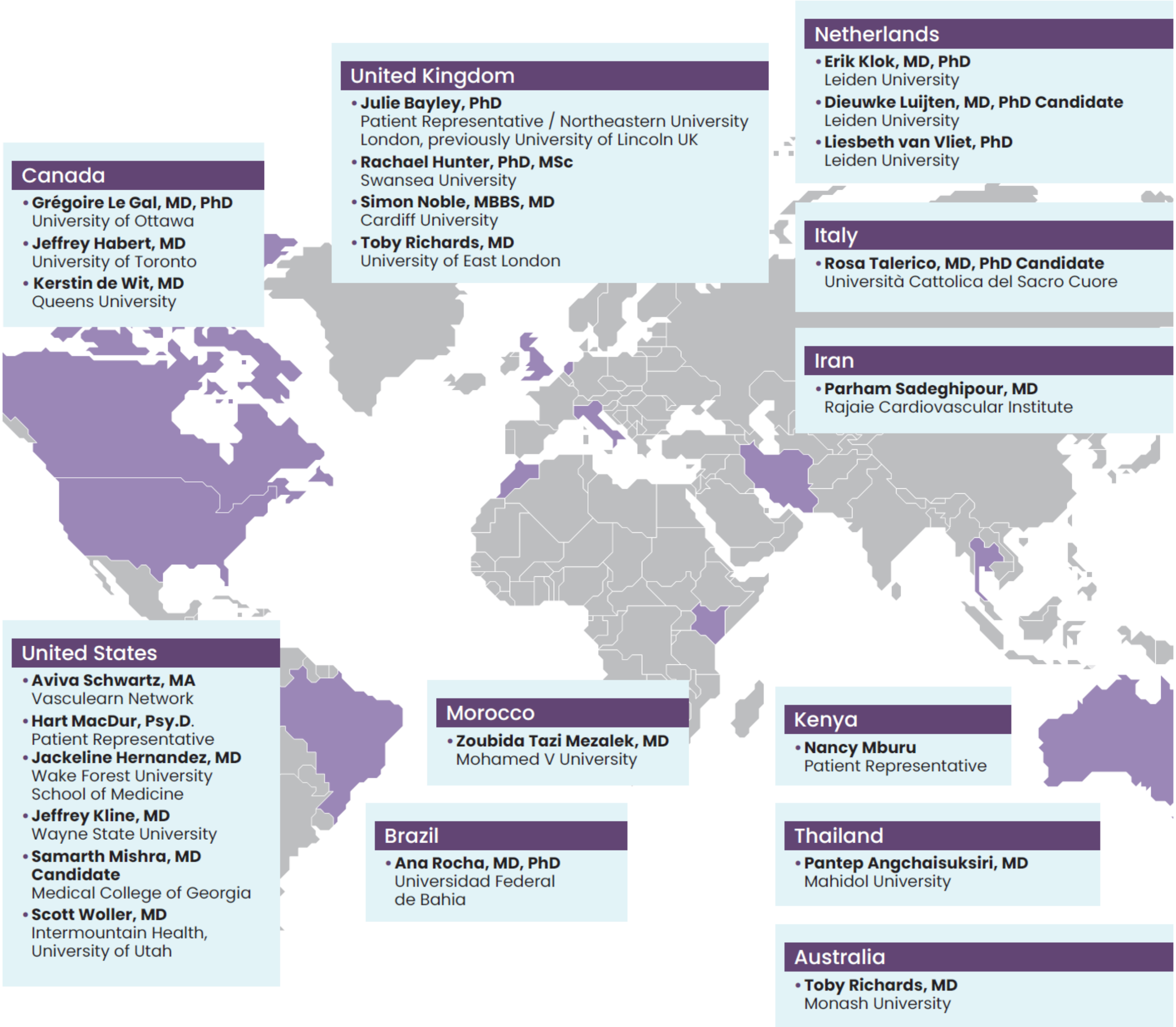

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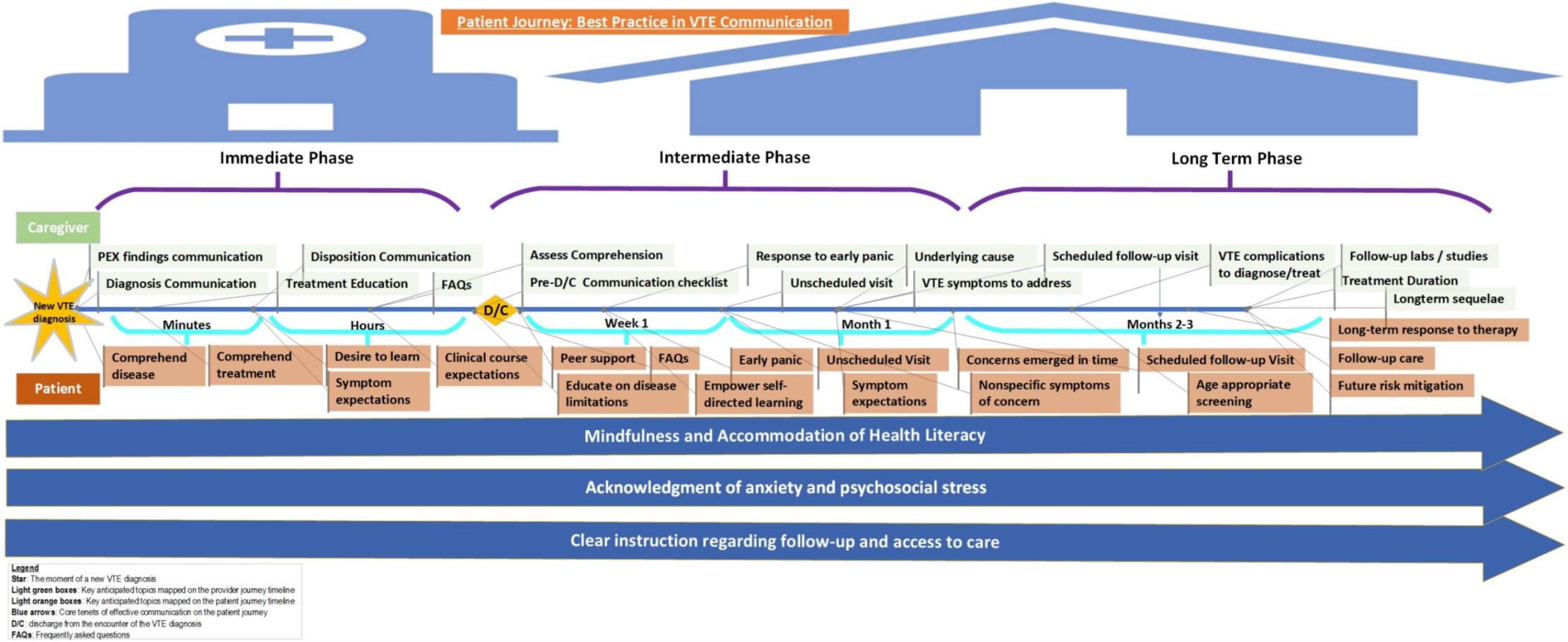
**Figure 2**: The VTE patient journey



**Legend**
**Star**: The moment of a new VTE diagnosis
**Light green boxes**: Key anticipated topics mapped on the provider journey timeline
**Light orange boxes**: Key anticipated topics mapped on the patient journey timeline
**Blue arrows**: Core tenets of effective communication on the patient journey
**D/C**: discharge from the encounter of the VTE diagnosis
**FAQs**: Frequently asked questions