ERN | EuroBloodNet

13th June 2025 - EHA Congress

Designing Patient-Centered Care: Patient Journeys from Educational Programs & Patient Versions of Guidelines. Pilot of von Willebrand Disease and Burkitt Lymphoma

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European Reference Network
Hematological Diseases (ERN EuroBloodNet)

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Disclosure of Conflict of Interest

The author declares no conflict of interest.

Patient Journeys

- A visual or narrative tool that maps the typical steps a patient takes through a disease: from first symptoms to diagnosis, treatment, daily management, and long-term care
- Includes clinical, emotional, and social experiences
- Developed with patients, caregivers, and clinicians, highlighting needs, barriers, and goals

Patient Versions of Guidelines

- A simplified, accessible version of evidence-based clinical guidelines
- Written for patients, not for doctors
- Explains e.g.: What care to expect, which options exist,
- Always aligned with official recommendations
- Ideally, it should be developed with patients, but this is not yet standard practice. Within the ERN, however, it has been developed in collaboration with patients.

Patient Journeys

- Lived experience-based
- Maps the real-life pathways
- Focus on needs and burdens in care
- Created with patients

Patient Versions of Guidelines

- Evidence-based recommendations
- Explains the ideals standard of care
- Focus on standard of care & rights
- Written for patients

Why they are useful tools?

1. Empower patients to better understand their condition
2. Support shared decision-making
3. Identify gaps in care and highlight unmet needs
4. Promote patient-centered healthcare and policy change

Patient Journeys from Educational Programs

Pilot of von Willebrand Disease

European
von Willebrand Disease
Community

EHC
european haemophilia consortium
Advocating for people with haemophilia and congenital bleeding disorders

Steering Committee:

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European
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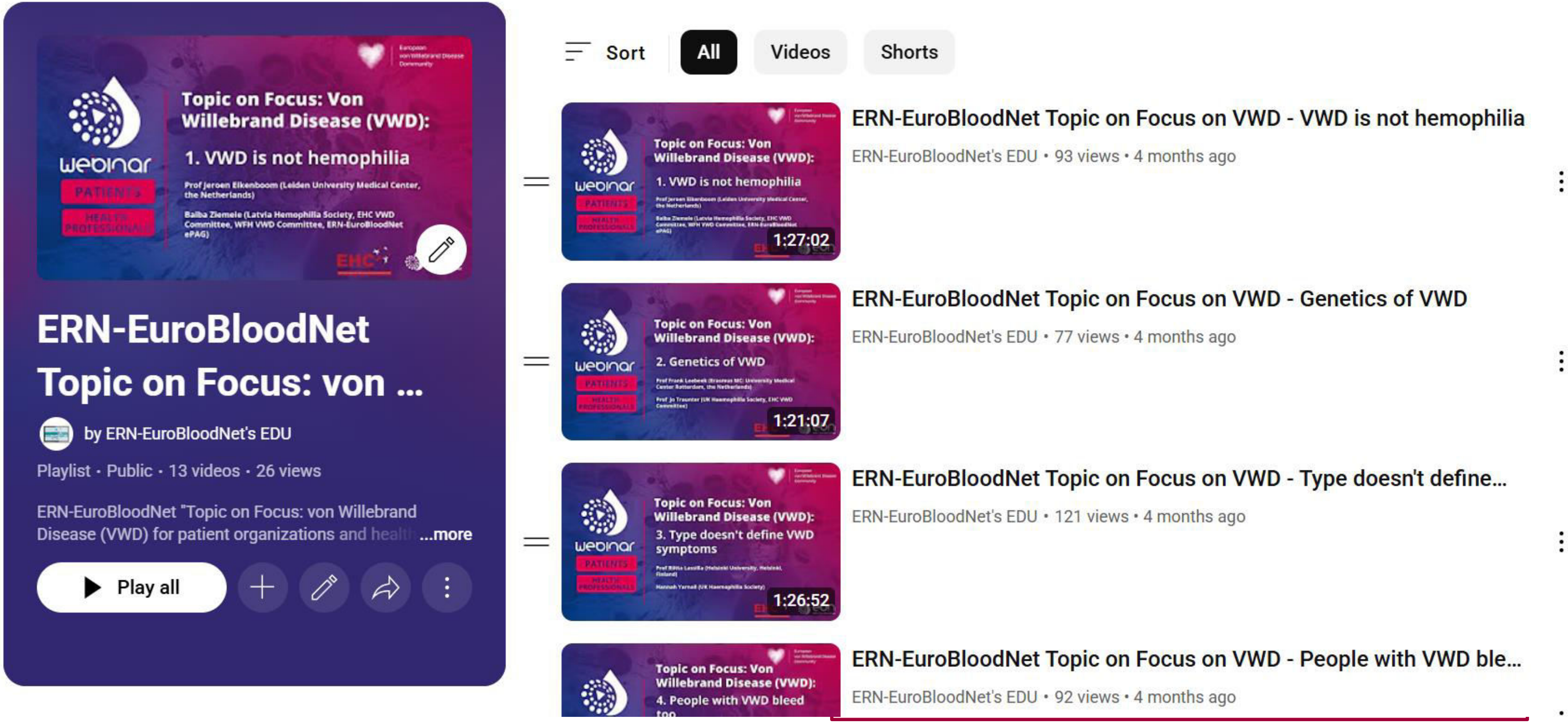
Preparation: A Patient Journey Built *from* and *as* an Educational Program

1. The educational program was designed following the structure of a patient journey, all critical health stages for vWD

2. Each webinar tackled a specific stage, identified through collaborative work with: Patient support groups (to reflect lived experiences and needs) Expert health professionals (to align with clinical pathways and guidelines)

→ Outcome

The program naturally evolved into a structured patient journey,
with learning objectives and take-home messages mirroring real-life care phases



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by ERN-EuroBloodNet's EDU

Playlist • Public • 13 videos • 26 views

ERN-EuroBloodNet "Topic on Focus: von Willebrand Disease (VWD) for patient organizations and healt ...more

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Phases 1 & 2: Mapping and Structure

1. Extract "take-home messages" from each webinar
2. Generate and cluster key concepts by disease stage: *Awareness, Diagnosis, Psychosocial Adaptation, Daily Management, Female Life Stages, Emergency, Ageing*
3. Tag each concept by:Type (clinical, psychosocial, etc.), *Target population, Stakeholders involved*
4. Steering Commitee validated the journey via Delphi
5. Final format (video, flyer, interactive map…)

Key aspect:

- ✓ Validation of clusters/tags by session speakers (experts via ERN + patients via EHC)
- ✓ Literature review planned for benchmarking with other chronic diseases
- ✓ ERNs expert centers and National Patients Organisations focusing on vWD will be added in the journey

Patient Versions of Guidelines.

Pilot of Burkitt Lymphoma

LYMPHOMA
COALITION

Steering Committee:

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LYMPHOMA COALITION

PVGs: Challenges and Recommendations:

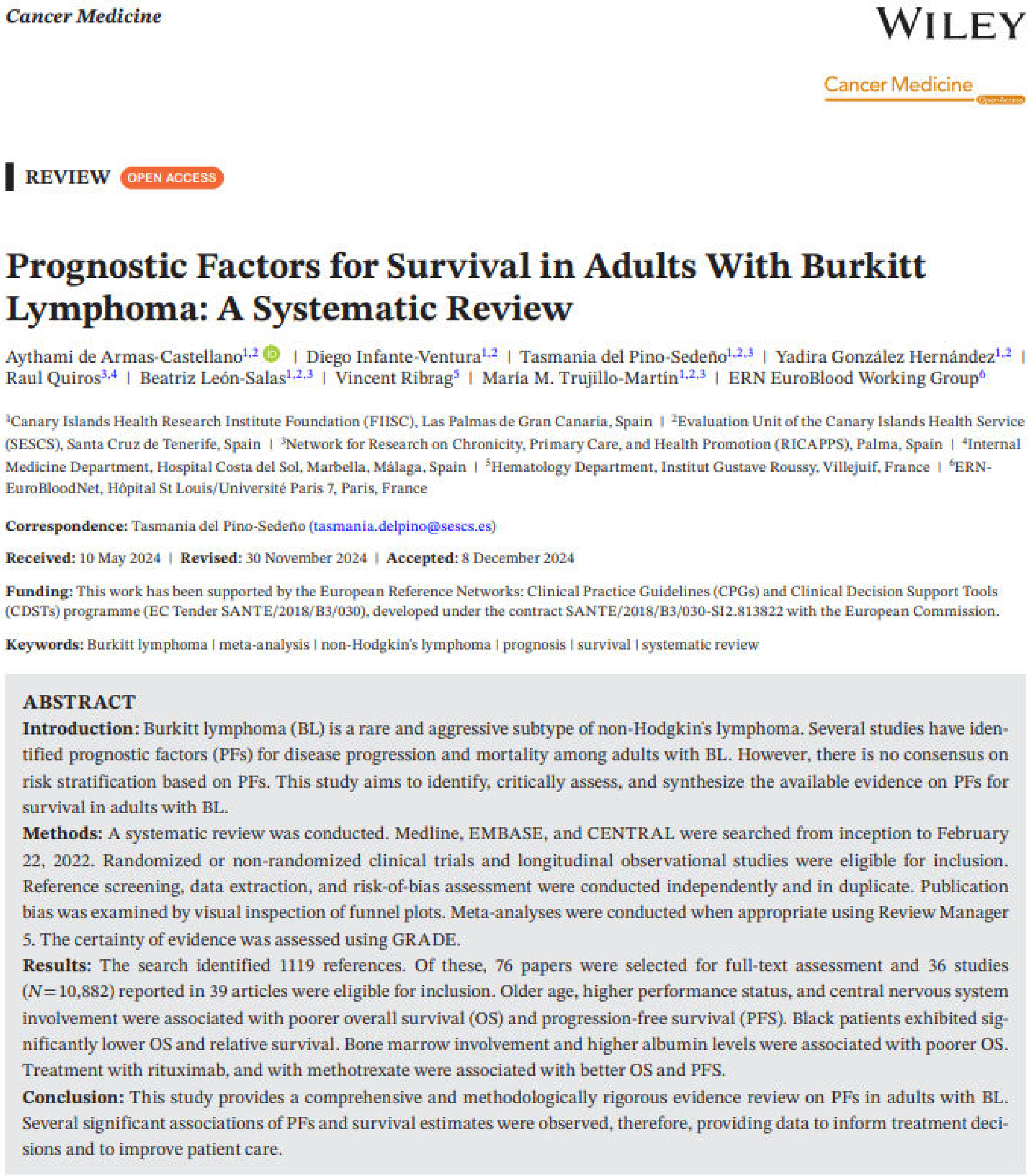
Barriers

- Limited resources (time & funding)
- Lack of standardized methodologies
- Access to a clear, high-quality clinical guideline to base the PVG
- Difficulties in reaching consensus among stakeholders.

Developped & Endorsed by the ERN-EuroBloodNet

Easy accessibility and right to develop PVGs

In collaboration with ePAGs



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Prognostic Factors for Survival in Adults With Burkitt Lymphoma: A Systematic Review

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Keywords: Burkitt lymphoma | meta-analysis | non-Hodgkin's lymphoma | prognosis | survival | systematic review

ABSTRACT

Introduction: Burkitt lymphoma (BL) is a rare and aggressive subtype of non-Hodgkin's lymphoma. Several studies have identified prognostic factors (PFs) for disease progression and mortality among adults with BL. However, there is no consensus on risk stratification based on PFs. This study aims to identify, critically assess, and synthesize the available evidence on PFs for survival in adults with BL.

Methods: A systematic review was conducted. Medline, EMBASE, and CENTRAL were searched from inception to February 22, 2022. Randomized or non-randomized clinical trials and longitudinal observational studies were eligible for inclusion. Reference screening, data extraction, and risk-of-bias assessment were conducted independently and in duplicate. Publication bias was examined by visual inspection of funnel plots. Meta-analyses were conducted when appropriate using Review Manager 5. The certainty of evidence was assessed using GRADE.

Results: The search identified 1119 references. Of these, 76 papers were selected for full-text assessment and 36 studies ($N = 10,882$) reported in 39 articles were eligible for inclusion. Older age, higher performance status, and central nervous system involvement were associated with poorer overall survival (OS) and progression-free survival (PFS). Black patients exhibited significantly lower OS and relative survival. Bone marrow involvement and higher albumin levels were associated with poorer OS. Treatment with rituximab, and with methotrexate were associated with better OS and PFS.

Conclusion: This study provides a comprehensive and methodologically rigorous evidence review on PFs in adults with BL. Several significant associations of PFs and survival estimates were observed, therefore, providing data to inform treatment decisions and to improve patient care.

Collaborative Planning & Patient-Centered Drafting

1. Steering Commitee: From guideline authors identify 4 health professionals, Patient advocates
2. Lived Experience Council: Identify patients with Burkitt Lymphoma Ensuring EU geographical representation

Define the Framework

- Clarify target audience and guideline sections to adapt
- Assign roles, responsibilities, and set review methods

Begin Co-Creation Process

- Identify key patient-relevant recommendations
- Simplify complex content; use plain language
- Consider FAQ/narrative style, short paragraphs, bullets
- Conduct feedback sessions with patient advocates

Validation, Accessibility & Sustainable Impact

Validate the Draft

- Clinical accuracy check
- Readability & relevance reviewed by patient advocates
- Optional: testing with external patient group

Ensure Accessibility

- Visual aids, icons, accessible fonts
- Screen reader compatibility, translations
- Decide the format & translate the document in different languages

Dissemination Strategy

- Share via websites, clinics, social media, patient orgs
- Include a link to the full clinical guideline
- For booster CBH: Include a list of expert centers in Europe via ERN, and a list of Patients organisations in Europe via Lymphoma Coalition

THANK YOU!

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