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ERN-EuroBloodNet Repository of CPGs/CDSTs

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European Reference Network | Hematological Diseases (ERN EuroBloodNet)

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Disclosure of Conflict of Interest

LUCA MALCOVATI

declares no conflicts of interest

DEFINITIONS

Clinical Practice Guidelines - Clinical practice guidelines (CPGs) are systematically developed statements that include recommendations, intended to optimise patient care, that are informed by a systematic review of evidence and an assessment of the benefit and harms of alternative care options. The level of evidence needs to be stated.

Clinical Consensus Statements - Clinical consensus statements reflect opinions drafted by subject matter experts for which consensus is sought using explicit methodology to identify areas of agreement and disagreement. In contrast to clinical practice guidelines, which are based primarily on high-level evidence, clinical consensus statements are more applicable to situations where evidence is limited or lacking.

Evidence Reports - Evidence reports are systematic reviews that summarise the best available evidence on a topic. Evidence reports are generally used by clinical professional organisations to support the development of clinical practice guidelines or by policy makers to inform their programme planning and research priorities.

Diagnostic, Monitoring and Therapy Pathways - Diagnostic, monitoring and therapy pathways are multidisciplinary management tools which describe the procedure for the care and treatment of a disease, condition or complex procedure. Their aim is to improve the care and management of patients, while enhancing the coordination of healthcare around the patient.

Evidence-based Protocols - Evidence-based protocols are an agreed detailed framework outlining in chronological order the care procedures that will be performed in a designated area of practice. Evidence-based protocols state what should be done, and how it should be done. It is adapted to the health care environment and the available resources.

Do's and Don'ts Factsheets for Diseases - Do's and Don'ts Factsheets are tools that provide advice that needs to be considered when assisting patients with specific rare diseases, conditions or in need of complex procedures. These documents aim to assist patients, caregivers and the medical community in knowing the basic do's and don'ts of common and emergency situations.

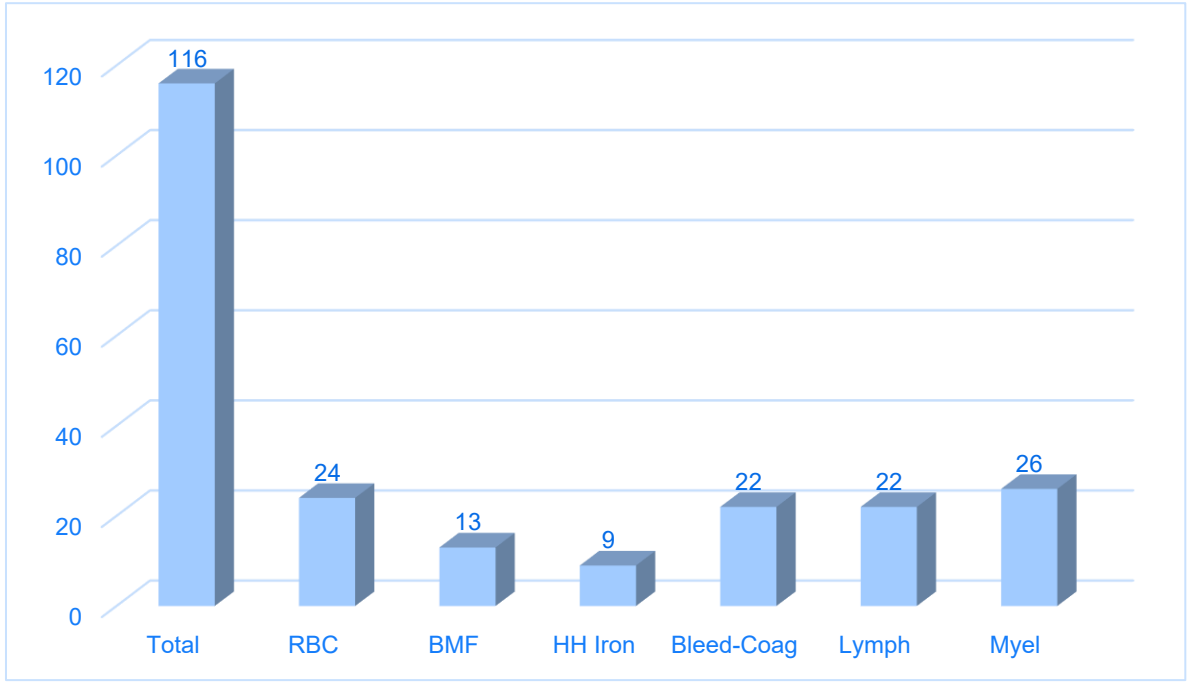
Quality Measures - Quality measures are tools that quantify healthcare processes, outcomes, patient perceptions, and organizational structure and/or systems. These instruments provide clinicians and policy makers with information associated with healthcare performance and the extent to which high quality health care is being provided.

Patient Information Booklets - Document that provides condition-specific information in lay language, to inform patients on best medical practice in an informative and accessible way. Patient information booklets can be based on a CPG, a CDST or consist of a stand-alone product that provides general information for the patient.

Repository of guidelines and recommendations

Objective: Adoption of International Clinical practice guidelines* classified based on main quality domains

✓ 1st Step: Gathering of international documents from EuroBloodnet members

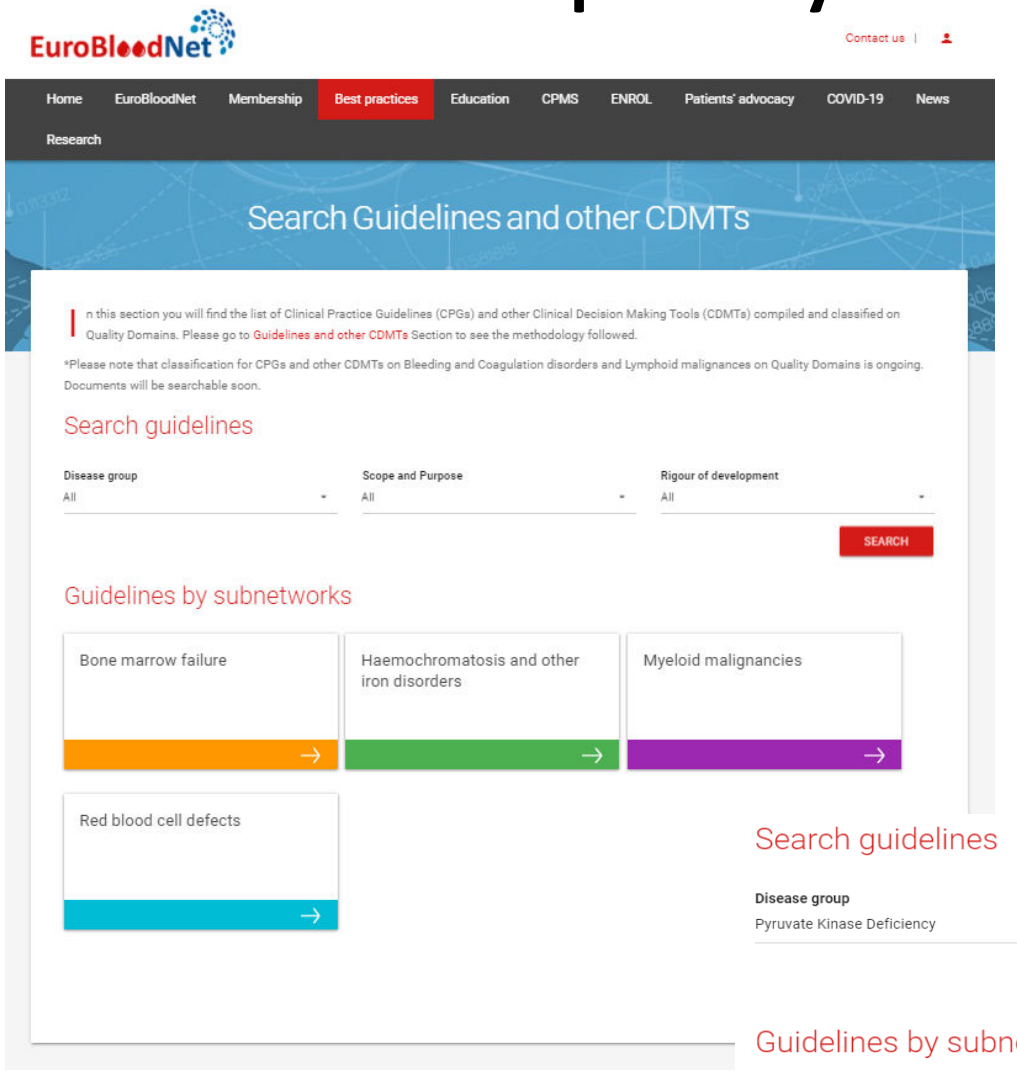


Results: 116 Documents

Bone marrow failures and Hemochromatosis and other rare disorders of iron metabolism subnetworks are found to be the subnetworks with less number of documents

** Clinical practice guidelines, recommendations and expert opinion*

Repository of CPGs/CDSTs

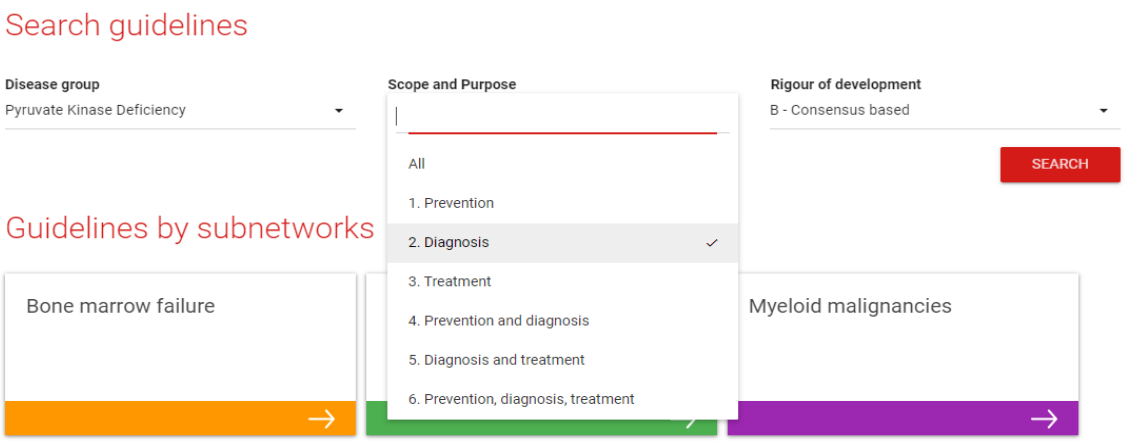


- ✓ 1st Step: Gathering of international documents from EuroBloodnet members
  - ➢ 116 documents

- ✓ 2nd Step: Classification of documents on main quality domains
  - ➢ Domain 1: Scope and purpose: Prevention, Diagnosis, Treatment
  - ➢ Domain 2: Patients' involvement
  - ➢ Domain 3: Rigour of development:

A: evidence and consensus-based guidelines / recommendations
B: consensus-based guidelines / recommendations
C: expert opinion

http://www.eurobloodnet.com/best-practices/guidelines-repository/



Needs and challenges

Repository of CPG and CDST

Expansion & Update

1) Revision of information from members in Evaluation and Monitoring
2) Classification in Quality Domains

Reliability of repository

Monitoring of implementation

Monitoring of implementation of CPGs/CDSTs

Disease	Sickle Cell Disease	HFE-hemochromatosis	Anemia due to genetic disorders of iron metabolism and heme disorders	Myelodysplastic syndromes
Clinical outcome indicators	1. Newborn screening	1. Screening of first degree relatives of patients	1. Diagnosis within 6 months after presentation	1. Cytogenetic analysis
	2. Vaccination (meningococcus, streptococcus pneumoniae, capsulated cocci)	2. HFE-gene testing when both TSAT and ferritin are increased	2. Screening of family members	2. Erythropoiesis stimulating agents for lower risk MDS
	3. Antibiotic prophilaxis until 5 ye at least	3. Phlebotomise (bi) weekly when ferritin are increased to target ferritin between 50 and 100 ug/l, thereafter iron parameters patients should be monitored and re-accumulation should be prevented	3. Timely start of treatment	3. Lenalidomide for lower risk MDS with del 5q
	4. Transcranial Doppler starting at 2 ye	4. Patients with suspected overlaod should undergo TSAT and ferritin testing, and only HFE testing when TSAT is increased		4. Azacitidine for high risk MDS
	5. Availability of Hydroxyurea treatment	5. Before phlebotomy patients should be screened for end organ damage (liver, heart, endocrine organs, joints)		5. Allogeneic stem cell transplantation for high risk MDS
				6. Mutation analysis by next generation sequencing
				7. Access to clinical trials

ERN-EuroBloodNet CPGs/CDSTs

Production/Endorsement of new CPGs/CDSTs :

- Evidence-based
- Consensus-based
- Expert opinion

DG SANTE support action to ERNs:

1. Assist ERNs and their healthcare providers in the process of development, appraisal and implementation of CPGs and CDSTs
2. Improve the capacity of the ERNs in their tasks to produce and adhere to high quality CP and CDSTs

EHA Memorandum of Understanding:

1. Bring together task forces on best practices from both bodies to create synergies

Elaboration CPGs

Systematic search for evidence	•Systematic searches of important bibliographic databases using sensitive key words
Determining the CPG scope	•A framework that describes the epidemiology of the disease or condition and the aspects of care and the settings is covered by the guideline
Preparing the work plan	•Specifying the guideline development project plan including timelines and project costs<
Forming the guideline development group (GDG)	•Describing the composition and runnig of GDG •Managing the conflict of interest
Developing the clinical questions	•Developing clinical question according to an objective approach, e.g. PICO framework
Selecting relevant evidence	•Inclusion and exclusion criteria for selecting the evidence
Appraising identified research evidence	•Appraising identified evidences using objective instruments (for example AMSTAR 2 for systematic reviews)
Evidence synthesis and analysis	•Describing synthesis approaches of primary studies, including meta-analysis etc. •Appraising and summarizing the quality of evidence.
Creating recommendations	•Interpreting the evidence to make recommendations and the wording and format of recommendations •Grading the strength of recommendations
Final stakeholder consultation	•Final consultation with stakeholders before publishing the guideline
Publishing	•Describing different publication formats (full guideline, quick reference guides, information for patient)
Guideline implementation strategies	•Describing how the recommendations can be put into Practice
Updating recommendations	•Describes the process, timeline, frequency and criteria for updating recommendations

Elaboration Clinical Consensus Statements

Consensus coordination team	• Constitution of the team that will lead and oversee the development of the consensus process.
Recruitment of participants	• Composition of the consensus panel (participants).
Clinical consensus method	• Selection of the method the method that will be used to reach consensus
Development of the questions	• Development of the questions that will be used to foster the initial discussions and develop the next ones.
Edition of the consensus	• Edition of the document that describes the consensus process and its results, including the clinical consensus statements.

4.1.1 | *Delphi*

Delphi is an iterative technique based on successive rounds of questionnaires that aims at reducing the range of responses and help the group to arrive at something closer to expert consensus[12].

Delphi is more appropriate when the number of experts is high and/ or it is difficult to meet face-to-face for logistical or economic reasons, e.g. when the consensus panel (participants) are geographically dispersed[13].

4.1.2 | *Nominal Group Technique (NGT)*

The nominal group technique (NGT) is a structured interaction based on silently and individually generated ideas that are discussed and ranked in a group session where all the consensus panel (participants) voice their opinions.

4.1.3 | *Consensus Development Conference (CDC)*

CDC is a semi-public process where consensus panel (participants) receive information from experts and interest groups and reach consensus after several rounds of discussion.

The CDC are frequently used to agreeing about on the safety, efficacy and/or appropriateness of using various medical procedures, drugs, and devices[18] that raise public interest. It is an appropriate method when the subject in question is of social relevance and/ or carries some controversy that transcends the professional field.

ERN-EuroBloodNet New CPGs/CDSTs produced by the ERN

Diagnosis and treatment of Burkitt lymphoma in adults: clinical practice guidelines from ERN-EuroBloodNet
Vincent Ribrag (*Gustave Roussy, Paris)*

ERN-EuroBloodNet Recommendations on Sickle Cell Disease
Béatrice Gulbis (*H.U.B. Hôpital Erasme – ULB, Brussels)*

EHA/ERN-EuroBloodNet Recommendations on Rare Hemolytic Anaemia
Richard van Wijk (*University Medical Center Utrecht)*

Clinical practice guidelines on Vexas Syndrome endorsed by ERN-Eurobloodnet
Pierre Fenaux *(AP-HP – Hôpital Saint Louis)*

Designing Patient-Centered Care: Patient Journeys from Educational Programs and Patient Versions of Guidelines. Pilot of von Willebrand Disease and Burkitt Lymphoma
Mariangela Pellegrini (*AP-HP – Hôpital Saint Louis)*

THANK YOU!

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