



ERN Guidelines project: Clinical Practice Guidelines/Clinical Decision Support Tools Needs survey

Fields marked with * are mandatory.

Contact information

Please, answer the following questions about the needs for Clinical Decision Support Tools in your Network.

*** Name of ERN:**

- | | |
|---|--|
| <input type="radio"/> ERN BOND | <input type="radio"/> ERN EURO-NMD |
| <input type="radio"/> ERN CRANIO | <input type="radio"/> ERN EYE |
| <input type="radio"/> Endo-ERN | <input type="radio"/> ERN GENTURIS |
| <input type="radio"/> ERN EpiCARE | <input type="radio"/> ERN GUARD-HEART |
| <input type="radio"/> ERKNet | <input type="radio"/> ERN ITHACA |
| <input type="radio"/> ERN-RND | <input type="radio"/> MetabERN |
| <input type="radio"/> ERNICA | <input type="radio"/> ERN PaedCan |
| <input type="radio"/> ERN LUNG | <input type="radio"/> ERN RARE-LIVER |
| <input type="radio"/> ERN Skin | <input type="radio"/> ERN ReCONNET |
| <input type="radio"/> ERN EURACAN | <input type="radio"/> ERN RITA |
| <input checked="" type="radio"/> ERN EuroBloodNet | <input type="radio"/> ERN TRANSPLANT-CHILD |
| <input type="radio"/> ERN eUROGEN | <input type="radio"/> VASCERN |

*** Name** of respondent (first, last):

María del Mar Mañú Pereira

*** Email address** of respondent:

mar.manu@vhir.org

Diseases/conditions that need to be analyzed:

* **How many diseases/conditions** within the scope of your Network **do you think that require CPGs /CDSTs most urgently** according to clinical need and scientific uncertainty? (in the following pages we will ask you some questions about each one)

- 1 6
 2 7
 3 8
 4 9
 5 10

Although we are aware that there must be more than 10 diseases/conditions within your ERN that need some type of CPG/CDST, we request up to a maximum of 10 because the ERN Guidelines project includes the development of a maximum of 2 CPGs/CDSTs and the appraisal/adaptation of a maximum of 5 CPGs /CDSTs for each ERN, therefore, in no case is it expected to be able to provide CPGs/CDSTs to more than 10 diseases/conditions per ERN.

Information on the **first disease/condition** candidate for CPG/CDST.

* **Name** of the disease/condition:

Systematic mastocytosis

* Targeted patient **population**:

indolent mastocytosis, smoldering mastocytosis, aggressive mastocytosis, mastocytosis with an associated hematologic neoplasm, mast cell leukemia

* What particular **aspects of the disease/condition** are of interest to be addressed by your ERN? (select all that apply):

- Epidemiology
 Prevention
 Diagnosis
 Prognosis
 Treatment
 Patient, disease or condition management
 Other

* Depending on the identified need of each ERN and according to the available scientific evidence, it is possible to develop different types of clinical decision support tools. Please, [click here](#) for definitions and information on the different types of ERN clinical decision support tools. Please, **choose the type of clinical decision support tool that best meets the expectations of the network for the proposed disease/condition** (select all that apply):

- Clinical Practice Guideline
 Clinical Consensus Statement
 Evidence Report
 Diagnostic-Monitoring-Therapeutic Pathway

- Evidence-based Protocol
- Do's and Don'ts Factsheets
- Quality Measure
- Patient Information Booklet

If there is already a high-quality tool that meets the identified needs, instead of developing a new tool, the existing one could be adapted. If there are any previous CPGs/CDSTs suitable to cover the need identified, please specify as much as possible (title, author, year, website link if available):

None

Information on the **second disease/condition** candidate for CPG/CDST.

* **Name** of the disease/condition:

Chronic neutropenia

* Targeted patient **population**:

patients aged 0- to adult age with chronic neutropenia including genetically determined, autoimmune, secondary to immune-dysregulation, Idiopathic forms typical of the adult/elderly patients

* What particular **aspects of the disease/condition** are of interest to be addressed by your ERN? (select all that apply):

- Epidemiology
- Prevention
- Diagnosis
- Prognosis
- Treatment
- Patient, disease or condition management
- Other

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None

Information on the **third disease/condition** candidate for CPG/CDST.

* **Name** of the disease/condition:

Primary central nervous lymphoma (PCNSL)

* Targeted patient **population**:

adults

* What particular **aspects of the disease/condition** are of interest to be addressed by your ERN? (select all that apply):

- Epidemiology
- Prevention
- Diagnosis
- Prognosis
- Treatment
- Patient, disease or condition management
- Other

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Adapting existing ESMO guidelines would be a good starting point - <https://www.sciencedirect.com/science/article/pii/S0923753419316400?via%3Dihub>

Information on the **fourth disease/condition** candidate for CPG/CDST.

* **Name** of the disease/condition:

Burkitt lymphoma (BL)

* Targeted patient **population**:

adults

* What particular **aspects of the disease/condition** are of interest to be addressed by your ERN? (select all that apply):

- Epidemiology
- Prevention
- Diagnosis
- Prognosis
- Treatment
- Patient, disease or condition management
- Other

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None

Information on the **fifth disease/condition** candidate for CPG/CD.

* **Name** of the disease/condition:

Blastic plasmacytoid dendritic cell neoplasm (BPDCN)

* Targeted patient **population**:

BPDCN at any disease stage

* What particular **aspects of the disease/condition** are of interest to be addressed by your ERN? (select all that apply):

- Epidemiology
- Prevention
- Diagnosis
- Prognosis
- Treatment
- Patient, disease or condition management
- Other

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None

Information on the **sixth disease/condition** candidate for CPG/CDST.

* **Name** of the disease/condition:

Large granular lymphocytes leukemia

* Targeted patient **population**:

any patient with Large granular lymphocytes leukemia

* What particular **aspects of the disease/condition** are of interest to be addressed by your ERN? (select all that apply):

- Epidemiology
- Prevention
- Diagnosis
- Prognosis
- Treatment
- Patient, disease or condition management
- Other

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None

Information on the **seventh disease/condition** candidate for CPG/CDST.

* **Name** of the disease/condition:

Long term complications including liver Disease & Osteoporosis in Haemoglobinopathies

* Targeted patient **population**:

adults with SCD or Thalassemia with long-term complications

*

What particular **aspects of the disease/condition** are of interest to be addressed by your ERN? (select all that apply):

- Epidemiology
- Prevention
- Diagnosis
- Prognosis
- Treatment
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None

Information on the **eighth disease/condition** candidate for CPG/CDST.

* **Name** of the disease/condition:

Hemochromatosis

* Targeted patient **population**:

adults

* What particular **aspects of the disease/condition** are of interest to be addressed by your ERN? (select all that apply):

- Epidemiology
- Prevention
- Diagnosis

- Prognosis
- Treatment
- Patient, disease or condition management
- Other

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It will be soon submitted for publication a position paper by the International Bioiron Society (involving all experts in the field) with an update of the Hemochromatosis nomenclature

Information on the **ninth disease/condition** candidate for CPG/CDST.

* **Name** of the disease/condition:

Congenital dyserythropoietic anaemias (CDAs)

* Targeted patient **population**:

Adult and paediatric patients

* What particular **aspects of the disease/condition** are of interest to be addressed by your ERN? (select all that apply):

- Epidemiology
- Prevention
- Diagnosis
- Prognosis
- Treatment
- Patient, disease or condition management
- Other

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- Quality Measure
- Patient Information Booklet

If there is already a high-quality tool that meets the identified needs, instead of developing a new tool, the existing one could be adapted. If there are any previous CPGs/CDSTs suitable to cover the need identified, please specify as much as possible (title, author, year, website link if available):

None

Information on the **tenth disease/condition** candidate for CPG/CDST.

* **Name** of the disease/condition:

Functional platelet disorders

* Targeted patient **population**:

Adult and paediatric patients

* What particular **aspects of the disease/condition** are of interest to be addressed by your ERN? (select all that apply):

- Epidemiology
- Prevention
- Diagnosis
- Prognosis
- Treatment
- Patient, disease or condition management
- Other

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- Evidence-based Protocol
- Do's and Don'ts Factsheets
- Quality Measure
- Patient Information Booklet

If there is already a high-quality tool that meets the identified needs, instead of developing a new tool, the existing one could be adapted. If there are any previous CPGs/CDSTs suitable to cover the need identified, please specify as much as possible (title, author, year, website link if available):

None

Comments:

We welcome any additional information about the selected diseases/conditions and/or required CPGs /CDSTs:

The order do not reflect any prioritization criteria but thematic areas

* **Would you like to participate in a virtual interview** and talk further about your ERN CPGs/CDSTs needs (duration: 20-30 min)?

Yes No

If so, a person from the ERN Guidelines Team will contact you through the email you have already provided us within the next months. Thank you!

The survey has been finished.
Thank you very much for your cooperation.

Contact

[Contact Form](#)

