

## Summary of the handbooks

Please find below a summary of the set of methodological handbooks and tools for the prioritisation, appraisal, adaptation, development and implementation of CPGs and CDSTs for rare diseases developed for ERNs and based on relevant existing methodologies applicable to rare diseases, as well as general methodological approaches with broad international consensus.

### **Handbook #1: Prioritisation of Rare Diseases that Require CPGs or CDSTs**

This handbook includes a detailed explanation of the prioritisation criteria and process, including the use of the prioritisation tool.

### **Handbook #2: Appraisal of Existing CPGs and CDSTs for Rare Diseases**

This handbook includes a pragmatic process for evaluating the methodological quality of CPGs, CDSTs and informative documents for rare diseases, including the use of CPG and CDST appraisal tools.

### **Handbook #3: Adaptation and Adoption of CPGs and CDSTs**

This handbook describes the elements that should be addressed in order to decide on whether a CPG or a CDST for rare diseases can be adopted or adapted and indicates the actions that must be followed to adopt and adapt a CPG and a CDST for rare diseases.

### **Handbooks #4 - 11: Handbooks for the Development of CPGs and CDSTs for Rare Diseases**

These handbooks explain the steps for developing CPGs or CDSTs for rare diseases, including the definition of their scope and purpose, the formulation of clinical questions and the search, selection, appraisal and synthesis of scientific evidence, among other aspects. There is a development handbook for CPGs and each CDSTs covered in this toolkit.

- ✓ **Handbook #4:** Methodology for the Development of CPGs for Rare Diseases.
- ✓ **Handbook #5:** Methodology for the Development of Clinical Consensus Statements for Rare Diseases.
- ✓ **Handbook #6:** Methodology for the Development of Evidence Reports for Rare Diseases.
- ✓ **Handbook #7:** Methodology for the Development of Diagnostic, Monitoring and Therapeutic Pathways for Rare Diseases.
- ✓ **Handbook #8:** Methodology for the Development of Evidence-based Protocols for Rare Diseases.
- ✓ **Handbook #9:** Methodology for the Development of Do's and Don't's

Factsheets for Diseases for Rare Diseases.

- ✓ **Handbook #10:** Methodology for the Development of Quality Measures for Rare Diseases.
- ✓ **Handbook #11:** Methodology for the Development of Patient Information Booklets for Rare Diseases.

### **Handbook #12: Implementation and Evaluation of the Uptake of CPGs and CDSTs for Rare Diseases**

This handbook provides the steps necessary to implement CPGs or CDSTs for rare diseases, including the selection of the specific CPG or CDST to be implemented, implementation planning, context analysis, design of the interventions and methods to carry out the evaluation of the implementation and uptake of the CPG or CDST, development of the implementation roadmap and design of the continuous improvement mechanism.