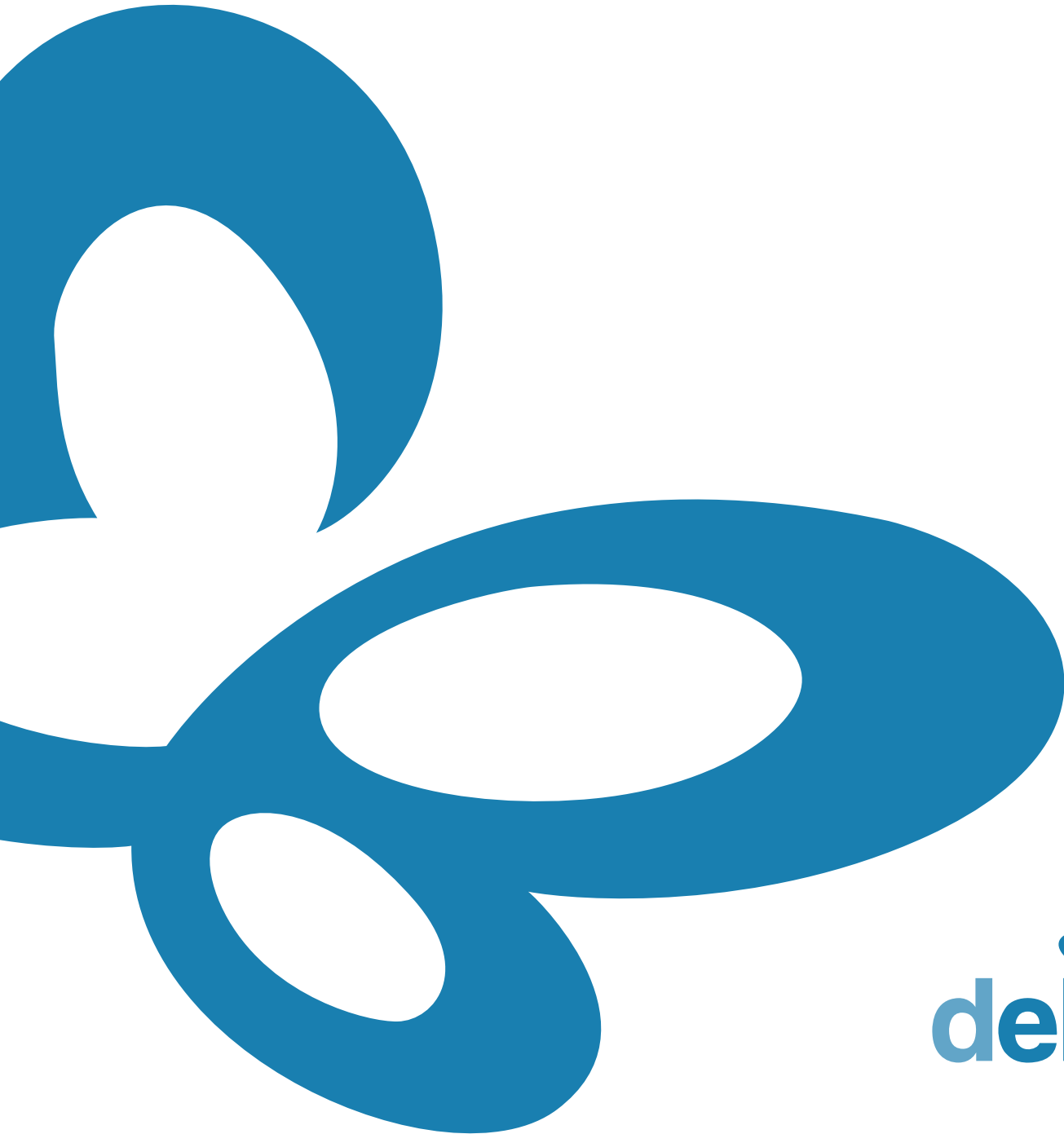


FACT SHEET

EB CLINICAL

PRACTICE GUIDELINES



EB Clinical Practice Guidelines

What are they and why are they important?

CPGS OVERVIEW

Clinical practice guidelines (CPGs) are a set of recommendations for clinical care, based on evidence gained from medical science and, where no formal evidence exists, expert opinion.

The CPGs help patients understand available treatment options – medicinal, surgical, etc. – and empower patients to have informed consent to work in partnership with their clinicians in developing their own clinical plan. For healthcare professionals, the CPGs are useful in recommending treatment for specific conditions based on generally recognised standard parameters, as well as help review treatment benefits and possible harms with their patient.

Where patient numbers are considered small, such as the case for rare diseases (e.g. Epidermolysis Bullosa – EB), CPGs are vital in providing internationally consistent standards of care. The CPGs also highlight situations where there is a lack of evidence, which identifies gaps in knowledge of the condition and could shape future research.



DEBRA'S INVOLVEMENT

DEBRA International (DI) is one of the few patient organisations in the world leading the development of CPGs.

DI aims to produce guidelines for all the major clinical areas involved in the care of people with EB. These guidelines will help improve the clinical and social care of EB patients across the globe. Until there is a cure, there is probably no greater way to positively impact the lives of people with EB.

Other EB CPGs are available; however, the majority of current and future work to be produced is coordinated and collaborated internationally to reduce costs and duplication. Additionally, the CPGs produced with DEBRA involved, on average, have been more highly rated than others.

CPG TOPICS COVERED

Because the EB CPGs are patient driven, the topics are chosen based on priorities set by the EB Community. The international EB Community was surveyed and more than 20 topics were chosen/requested. A total of 7 topics are prioritised and around 10 are active at any given time.

The priorities might be reset based on groundbreaking research, technological advances, or concerns over safety.

CURRENT SELECTED GUIDELINE TOPICS:

- Oral Health
- Nutrition: Constipation
- Laboratory Diagnosis
- Pregnancy, Childbirth, and Aftercare
- Wound Care
- Occupational Therapy
- Physiotherapy
- Sexuality
- Cancer Management
- Psychosocial
- Hand Surgery and Rehabilitation Therapy
- Pain Management
- Podiatry
- Anaemia

FUTURE SELECTED GUIDELINE TOPICS:

- Renal Disease
- Anaesthetics and clinical procedure
- Bone Health
- Oesophageal dilatation and Reflux
- Gastrostomy
- Eye Care

STAGES OF CPG DEVELOPMENT

Broadly, guidelines are developed by assembling an international multidisciplinary panel of relevant clinical experts and patients. This panel then:

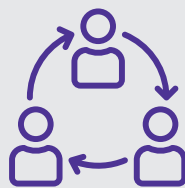


KEY FACTS:



260+ VOLUNTEERS

from the EB
Community



6-12 MEMBERS

on each
CPG panel



20+ COUNTRIES

involved in
CPG development



€37,400

average cost
per guideline*



3+ COUNTRIES

involved with
each guideline



18-24 MONTHS

to complete
a single guideline

*Cost includes: training, publishing, meetings, writing and coordinating, a patient version, admin and other support.

BENEFITS FOR THE EB COMMUNITY

Volunteers on the CPG panels range from those living with EB to those with clinical and scientific backgrounds. Taking part in this process facilitates international networking and collaboration:

-  Sharing knowledge and increasing understanding of a variety of subject areas
-  Learning from the experiences of others
-  Enhancing CVs
-  Becoming an avenue to publish further research
-  Sharing workloads and responsibilities
-  Providing a tangible output for EB sufferers

To learn more about the EB Clinical Practice Guidelines, please visit:

 <http://www.debra-international.org/clinical-guidelines.html>

Get involved with DEBRA International

www.debra-international.org

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