



Case study:

Guidelines for EB (epidermolysis bullosa)

Dr Avril Kennan
Eurordis Membership Meeting, 2014

Talk overview

A little about EB



The need to develop clinical practice guidelines for EB



How we initiated the project



Challenges experienced



Efforts to improve the project



Some general thoughts on clinical practice guidelines in RD

EB (epidermolysis bullosa)



Clinical care for EB



Our aim is to have a guideline that supports decision making, in each of the major aspects of care. They should be:

- The only such guideline
- Developed to the highest standards possible
- Available to all

Why develop guidelines for EB?

A complex condition to treat

Being rare adds to this challenge

Limited guidance for clinicians

Varied clinical practice



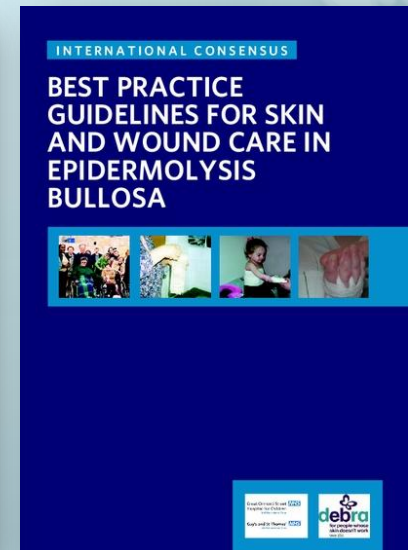
Who else would do it?

Early experiences in the project



Dr Francis Palisson

Approached leaders in the EB medical field and encouraged them to develop guidelines.



Challenges in the development of EB guidelines

Variation in adoption of a methodology

Very demanding for clinical leads

Duplication of effort

Lack of an evidence base

The need to be international



UNORTHODOX METHODS OF WOUND CARE IN EB

While those with EB seen at centres in the UK are fortunate to have access to a great selection of dressings, others in less developed countries or where finances are limited must seek alternative methods of wound care.

Table 17 shows a few examples we have learned from resourceful families and healthcare professionals.

Strengthening the project

Refining the processes and providing more support

This is how life feels to people with EB.



Developing a guideline for EB

What is the DEBRA International clinical practice guideline? DEBRA International embarked on a project in 2009 to improve patients, by creating a series of clinical practice guidelines (CPG) one guideline for each of the major clinical areas involved in the condition but each of the guidelines should be developed to the high standards required for the use of an appropriate methodology, complete trial process and the involvement of a panel of experts and patient representatives. For an overview of the project's purpose, see [Clinical Practice Guidelines \(CPG\) for EB](#).

Hand Surgery in EB	high priority
Oesophageal Dilatation in EB	high priority
Eye Care in EB	high priority
Diagnosis of EB	high priority
Anaemia in EB	priority
Occupational Therapy in EB	priority
Renal Disease in EB	priority
Social and psychological care	under consideration
Physiotherapy in EB	under consideration

DEBRA International / Registered Charity No. 219152763488

debra
International

DEBRA International
Clinical practice guideline submission form

✓ Please read all sections of the [Developing a guideline for EB](#) page on the DEBRA International website, before completing this document.

(A) GENERAL INFORMATION

APPLICANT

Title	Surname	First names

INSTITUTION

Department	Post held by Applicant
Full official postal address of Applicant	Telephone number

(B) PROPOSED GUIDELINE TOPIC

PROPOSED TOPIC

PROPOSED DURATION

PROPOSED START DATE

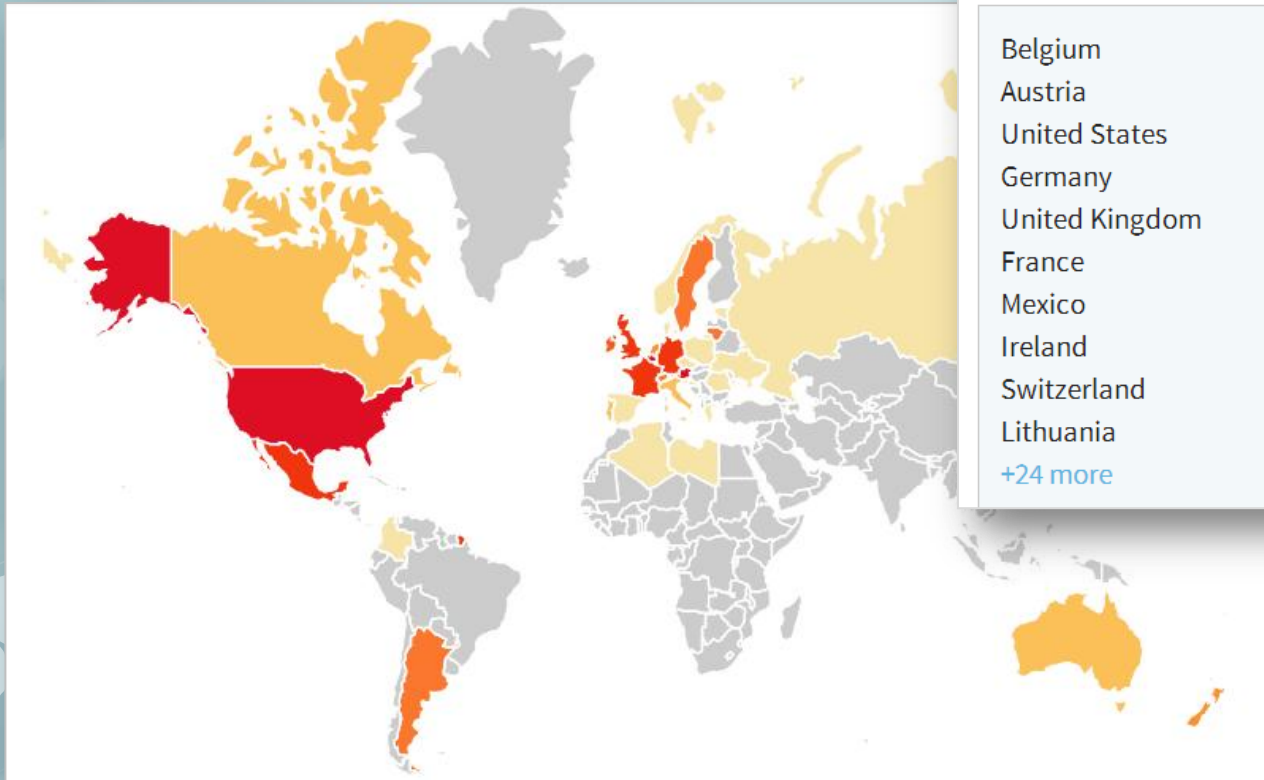
DD / MM / YYYY

Guidance notes

Prioritising topics

Application form

Putting out a call



Top Countries (clicks / % of total)

Belgium	9	9%
Austria	8	8%
United States	8	8%
Germany	7	7%
United Kingdom	7	7%
France	7	7%
Mexico	6	6%
Ireland	5	5%
Switzerland	4	4%
Lithuania	4	4%
+24 more		

Challenges that have arisen

Do interested groups really understand what is involved?

How to we persuade people to be guideline leaders?

How do we manage expectations around DEBRA's involvement?

What to do if more than one person wants to lead?



What do we still need to work on?



Providing guidance on methodology

Formalising patient involvement



Considering issues around implementation

Ensuring they are accessible for all



Ensuring they influence future research



Are CPGs in RD possible and meaningful?

Force
consensus

Encourage
patient
input

Point to
gaps in the
research

Provide
something
to build on

Principled but pragmatic

Thank you!



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