

### CPG Evaluation Form: Pre implementation

Please answer the questions below to help us evaluate the usefulness and effectiveness of our guidelines, as well as learn more about those using the information contained in the publication.

Section A: General Information						
How did you hear about this guideline? Please tick all that apply and provide details where applicable	<ul> <li>Journal searches (e.g. PubMed)</li> <li>Event (e.g. DEBRA conference, EB study day)</li> <li>Recommendation (e.g. family member, clinician)</li> <li>DEBRA communication (e.g. newsletter, website, social media)</li> <li>Other (please specify)</li> </ul>					
Why have you chosen to review this guideline?						
<b>City and country:</b> Residence						
DEBRA group affiliation: If applicable						
Which of the following best describes you? Please tick all that apply	Group A Professionals Clinician Allied health professional Professional carer	Group B Non-professionals Person living with EB *Caregiver (family member) Caregiver (friend) Friend	Group C Other Other (please provide details)			
	Please continue with Section B	Please continue with Section C	Please continue with Section B or C (as appropriate)			

Section B: Professionals						
Your institute: Name and address (including country)						
Tell us about the type of EB services you offer:	🗆 Hospital	Community	□ Home service	□ Other (please specify)		
Please tick all that apply and provide details						

<sup>\*</sup> For the purposes of this document, a caregiver indicates a non-professional. If you are a carer in a professional capacity, please tick the 'Professional carer' option in Group A.



Please tell us who works with EB patients at your institute: Please tick all that apply and circle the number of relevant people	<ul> <li>Dietician, n</li> <li>Dentist</li> <li>Physiothero</li> <li>Podiatrist</li> <li>Occupatio</li> </ul>	gist cialist) st, psychotherapist nutritionist apist nal therapist, hanc cer/social support		1 1 1 1 1 1 1 1 1 1	2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2	3 3 3 3 3 3 3 3 3 3 3 3 3 3	4+ 4+ 4+ 4+ 4+ 4+ 4+ 4+ 4+ 4+ 4+
Please give a summary of the EB service(s) your institute provides: 300 words maximum; please attach and use additional pages, if needed							
Target groups: Please tick all that apply and provide approximate numbers, where applicable	Living with EB Newborn o Children (0 Children (8 Teenagers Young adu Adults (25+ Other (pleo	-7) -12) (12-18) Its (18-25) )	EBS	JEB	DDEB	RDEB	KS
Before reading the guideline, what information do you/your team already know about this clinical issue?	Knowledge a 1 None	bout this clinical is: <b>2</b>	sue: 3	4	* <b>Y</b>	5 Expe	ert <b>No</b>
Please circle the number you feel best reflects your experience and/or tick the most appropriate box, where applicable	Do you have an EB specialist working with you? *If yes, do they have expertise in the guideline topic? * If yes, Please provide details:						



	How confident are you/your team in providing care for EB patients relating to this issue?				
	1	2	3	4	5
	Not at all confident				Extremely confident
	How often do you/your team manage this clinical issue?				
	1	2	3	4	5
	Less than yearly	Yearly	Monthly	Weekly	Daily
Describe how you think this guideline will benefit your service users:					
Including patients, clients, families, etc.					

Section C: Non-professionals								
Which type of EB do you (your family member/friend) have?			DDEB end) have not o	□ RDEB fficially been d	□ KS iagnosed			
Before reading the guideline, what information do you	How confider	How confident are you to get appropriate care in this clinical area?						
already know about this clinical issue?	Not at all confident				Extremely confident			
Please circle the number you feel best reflects your experience and/or tick the most appropriate box, where applicable	<ul> <li>No one is a</li> <li>I only have</li> <li>I have a percent communication</li> <li>I only have</li> </ul>	vailable to h written infor erson I can re ation a local, ger association has experier has EB exper quire care	mation about the each by phone, e neral doctor gives me suppo	e clinical area email, or other				



How often do	you (your fan	nily member/frie	end) experience	e this problem?
1	2	3	4	5
Less than yearly	Yearly	Monthly	Weekly	Daily
How do you (y	our family me	ember/friend) n	ormally manag	e this problem?

DEBRA International (DI) would like to further contact respondents to this guideline survey a year later for post evaluation measurement. The purpose of this additional survey is to evaluate the use of the guideline after its principles have been applied in practice.

#### **Declaration**

I understand that the information I provide will be used for data collection and guideline evaluation purposes only.

I understand that all data collected through these surveys will be anonymised and will not become identifiable in the evaluation process.

I understand that if DI would like to contact me in the future, they will only be able to do so for the purposes of being asked to complete the post evaluation survey, unless consent has otherwise been obtained for additional purposes.

I understand I am under no obligation to complete the post evaluation survey once I receive it, and that I am able to change or withdraw my consent at any time by notifying DI (office@debrainternational.org). I understand if consent is withdrawn, DI will destroy all identifiable records (i.e. contact details provided with the pre or post evaluation surveys).

I understand I have the right to ask to see any information and records held about me by DI.

I give my consent for DI to contact me after one year with a post evaluation guideline survey.

For more details on how DI uses your information, please visit <u>www.debra-international.org</u>.

Contact Details					
Full name					
Signature		Date			
Email					