

Psychosocial Guidelines: Appendix 3

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

Section B: Professionals	
Your institute: <i>Name and address (including country)</i>	
Tell us about the type of EB services you offer: <i>Please tick all that apply and provide details</i>	<input type="checkbox"/> Hospital <input type="checkbox"/> Community <input type="checkbox"/> Home service <input type="checkbox"/> Other (please specify)

* 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.

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<p>Please tell us who works with EB patients at your institute:</p> <p><i>Please tick all that apply and circle the number of relevant people</i></p>	<table border="0"> <tr> <td><input type="checkbox"/> Consultant</td> <td>1</td> <td>2</td> <td>3</td> <td>4+</td> </tr> <tr> <td><input type="checkbox"/> Dermatologist</td> <td>1</td> <td>2</td> <td>3</td> <td>4+</td> </tr> <tr> <td><input type="checkbox"/> Surgeon</td> <td>1</td> <td>2</td> <td>3</td> <td>4+</td> </tr> <tr> <td><input type="checkbox"/> Nurse (specialist)</td> <td>1</td> <td>2</td> <td>3</td> <td>4+</td> </tr> <tr> <td><input type="checkbox"/> Psychologist, psychotherapist</td> <td>1</td> <td>2</td> <td>3</td> <td>4+</td> </tr> <tr> <td><input type="checkbox"/> Dietician, nutritionist</td> <td>1</td> <td>2</td> <td>3</td> <td>4+</td> </tr> <tr> <td><input type="checkbox"/> Dentist</td> <td>1</td> <td>2</td> <td>3</td> <td>4+</td> </tr> <tr> <td><input type="checkbox"/> Physiotherapist</td> <td>1</td> <td>2</td> <td>3</td> <td>4+</td> </tr> <tr> <td><input type="checkbox"/> Podiatrist</td> <td>1</td> <td>2</td> <td>3</td> <td>4+</td> </tr> <tr> <td><input type="checkbox"/> Occupational therapist, hand therapist</td> <td>1</td> <td>2</td> <td>3</td> <td>4+</td> </tr> <tr> <td><input type="checkbox"/> Social worker/social support</td> <td>1</td> <td>2</td> <td>3</td> <td>4+</td> </tr> <tr> <td><input type="checkbox"/> Other (please specify)</td> <td>1</td> <td>2</td> <td>3</td> <td>4+</td> </tr> </table>	<input type="checkbox"/> Consultant	1	2	3	4+	<input type="checkbox"/> Dermatologist	1	2	3	4+	<input type="checkbox"/> Surgeon	1	2	3	4+	<input type="checkbox"/> Nurse (specialist)	1	2	3	4+	<input type="checkbox"/> Psychologist, psychotherapist	1	2	3	4+	<input type="checkbox"/> Dietician, nutritionist	1	2	3	4+	<input type="checkbox"/> Dentist	1	2	3	4+	<input type="checkbox"/> Physiotherapist	1	2	3	4+	<input type="checkbox"/> Podiatrist	1	2	3	4+	<input type="checkbox"/> Occupational therapist, hand therapist	1	2	3	4+	<input type="checkbox"/> Social worker/social support	1	2	3	4+	<input type="checkbox"/> Other (please specify)	1	2	3	4+
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<p>Please give a summary of the EB service(s) your institute provides:</p> <p><i>300 words maximum; please attach and use additional pages, if needed</i></p>																																																													
<p>Target groups:</p> <p><i>Please tick all that apply and provide approximate numbers, where applicable</i></p>	<table border="0"> <thead> <tr> <th>Living with EB (years of age)</th> <th>EBS</th> <th>JEB</th> <th>DDEB</th> <th>RDEB</th> <th>KS</th> </tr> </thead> <tbody> <tr> <td><input type="checkbox"/> Newborn and neonatal</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td><input type="checkbox"/> Children (0-7)</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td><input type="checkbox"/> Children (8-12)</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td><input type="checkbox"/> Teenagers (12-18)</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td><input type="checkbox"/> Young adults (18-25)</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td><input type="checkbox"/> Adults (25+)</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td><input type="checkbox"/> Other (please specify)</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </tbody> </table>	Living with EB (years of age)	EBS	JEB	DDEB	RDEB	KS	<input type="checkbox"/> Newborn and neonatal						<input type="checkbox"/> Children (0-7)						<input type="checkbox"/> Children (8-12)						<input type="checkbox"/> Teenagers (12-18)						<input type="checkbox"/> Young adults (18-25)						<input type="checkbox"/> Adults (25+)						<input type="checkbox"/> Other (please specify)																	
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<p>Before reading the guideline, what information do you/your team already know about this clinical issue?</p> <p><i>Please circle the number you feel best reflects your experience and/or tick the most appropriate box, where applicable</i></p>	<p>Knowledge about this clinical issue:</p> <table border="0"> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> <td></td> <td></td> </tr> <tr> <td style="text-align: center;">None</td> <td></td> <td></td> <td></td> <td style="text-align: center;">Expert</td> <td></td> <td></td> </tr> <tr> <td></td> <td></td> <td></td> <td></td> <td></td> <td style="text-align: center;">*Yes</td> <td style="text-align: center;">No</td> </tr> <tr> <td></td> <td></td> <td></td> <td></td> <td></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td></td> <td></td> <td></td> <td></td> <td></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td></td> <td></td> <td></td> <td></td> <td></td> <td colspan="2">* If yes, Please provide details:</td> </tr> </table>	1	2	3	4	5			None				Expert								*Yes	No						<input type="checkbox"/>	<input type="checkbox"/>						<input type="checkbox"/>	<input type="checkbox"/>						* If yes, Please provide details:																			
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	<p>How often do you (your family member/friend) experience this problem?</p> <table style="width: 100%; text-align: center;"> <tr> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> </tr> <tr> <td>Less than yearly</td> <td>Yearly</td> <td>Monthly</td> <td>Weekly</td> <td>Daily</td> </tr> </table> <p>How do you (your family member/friend) normally manage this problem?</p>	1	2	3	4	5	Less than yearly	Yearly	Monthly	Weekly	Daily
1	2	3	4	5							
Less than yearly	Yearly	Monthly	Weekly	Daily							

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@debra-international.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 www.debra-international.org.

Contact Details			
Full name			
Signature		Date	
Email			