




Patient version of SIGN guideline on eating disorders
 Consultation report on: Eating disorders booklet

Invited Reviewers

						Response Percent	Response Total
1	I have lived experience of an eating disorder					23.08%	3
2	I am a carer of someone who has experience of eating disorder					15.38%	2
3	I am a health and social care professional (please give details in comments box below)					23.08%	3
4	I am a member of the public with an interest in this topic					7.69%	1
5	I am a representative from an organisation (in the comments box below, please give details of the nature and purpose of your organisation, for example, voluntary organisation, providing support to people)					15.38%	2
6	Other (please give details):					23.08%	3
Statistics						answered	13
	Minimum	1	Mean	3.43	Std. Deviation	1.84	
	Maximum	6	Variance	3.39	Std. Error	0.49	skipped
Other (please give details): (3)							
1	22/11/2021 17:56 PM ID: 179584799	I am a parent of two daughters who have both been diagnosed with anorexia nervosa. One is recovered.					
2	04/12/2021 12:55 PM ID: 180383552	Patient representative on SIGN Council					
3	09/12/2021 17:06 PM ID: 180788447	Public partner with HIS					







In addition to survey respondents, two parents met with Karen Graham to provide feedback on the booklet.

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1. Please tell us what you think about the way the booklet is written? Do you think the tone and language is appropriate?																																																						
Comments received					Group Response					Editorial response																																												
					<table border="1"> <thead> <tr> <th colspan="5"></th> <th>Response Percent</th> <th>Response Total</th> </tr> </thead> <tbody> <tr> <td>1</td> <td>Yes</td> <td colspan="3"></td> <td>100.00%</td> <td>11</td> </tr> <tr> <td>2</td> <td>No</td> <td colspan="3"></td> <td>0.00%</td> <td>0</td> </tr> <tr> <td colspan="2">Statistics</td> <td>Minimum</td> <td>1</td> <td>Mean</td> <td>1</td> <td>Std. Deviation</td> <td>0</td> <td>Satisfaction Rate</td> <td>0</td> <td>answered</td> <td>11</td> </tr> <tr> <td colspan="2"></td> <td>Maximum</td> <td>1</td> <td>Variance</td> <td>0</td> <td>Std. Error</td> <td>0</td> <td colspan="2"></td> <td>skipped</td> <td>2</td> </tr> </tbody> </table>										Response Percent	Response Total	1	Yes				100.00%	11	2	No				0.00%	0	Statistics		Minimum	1	Mean	1	Std. Deviation	0	Satisfaction Rate	0	answered	11			Maximum	1	Variance	0	Std. Error	0			skipped	2
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It could be accompanied by an animation, easy read and BSL versions (British Sign Language)					√ We are developing animated videos for young people and an easy read document. We usually translated into other languages and BSL if we receive a request. This is to ensure there is a need for this before producing these formats.					√ Agree with changes																																												
Sensitively written while being upfront.					√																																																	
Very good					√																																																	
Suitable and written in a friendly manner and doesn't dictate to people. Easy to understand					√																																																	
I feel it would be easy for a young person or adult to					√																																																	

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	understand. Not too much information on each page either.																																				
	Tone and language suitable for this booklet.	√																																			
	Very comprehensive booklet with intense, medical language used at times which always was explained in layman's terms. I found page 16 a lot to take in but realise the necessity. Perhaps the phrase "therapy is modular and time limited" could be clearer.	√ Minor changes to definitions to make easier to read	√ Agree with changes																																		
	I like the layout. Easy to follow and clear content	√																																			
2. Please tell us what you think of the content. Does the content help patients and the public understand what the latest research and good practice supports around assessment, diagnosis, management and self-care?																																					
	Comments received	Group Response	Editorial response																																		
<table border="1"> <tr> <td>1</td> <td>Yes</td> <td></td> <td>90.91%</td> <td>10</td> </tr> <tr> <td>2</td> <td>No</td> <td></td> <td>9.09%</td> <td>1</td> </tr> <tr> <td colspan="2">Statistics</td> <td>Minimum</td> <td>1</td> <td>Mean</td> <td>1.09</td> <td>Std. Deviation</td> <td>0.29</td> <td>Satisfaction Rate</td> <td>9.09</td> <td>answered</td> <td>11</td> </tr> <tr> <td colspan="2"></td> <td>Maximum</td> <td>2</td> <td>Variance</td> <td>0.08</td> <td>Std. Error</td> <td>0.09</td> <td></td> <td></td> <td>skipped</td> <td>2</td> </tr> </table>				1	Yes		90.91%	10	2	No		9.09%	1	Statistics		Minimum	1	Mean	1.09	Std. Deviation	0.29	Satisfaction Rate	9.09	answered	11			Maximum	2	Variance	0.08	Std. Error	0.09			skipped	2
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	You mention 'safe exercise' in recovery. For some people, particularly people with anorexia nervosa, there may be no such thing as safe exercise. Movement compulsions need to be completely overcome before full recovery can happen. So	√ Group feel it is important to include this information from the guideline. Exercise will be done in collaboration with a treatment.	√																																		

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	<p>to encourage someone to participate in 'safe' exercise could prolong their recovery. It would be better not to mention exercise at all.</p> <p>RED-S is just a socially acceptable name for anorexia nervosa. It's fascinating that athletes can have some physically induced condition but for someone who's not an athlete they need to talk about the problems in their relationships and the 'underlying psychological causes' of their condition. Why is this treated differently? Can we please treat people with anorexia in the same way. They have also developed disordered eating because of an energy deficit just like someone who happens to be an athlete (or has perhaps turned to athletics because they developed an ED).</p> <p>SSCM. 'involves talking to a therapist who will help you to understand what's causing your eating disorder'. As we've established with RED-S, there is no underlying cause, just a lack of nutrition/energy deficit. Trying to find an underlying psychological call wastes time and will keep someone stuck in their disorder.</p>	<p>This paragraph has been removed as this is not a diagnostic criteria.</p> <p>Amended</p>	
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	Yes, it is useful to get current, recognised and good quality information.	√	
	It's really good you are producing a booklet for people affected by eating disorder. There is a lot of information available but I think having something from an organisation that looks at the latest evidence is useful. Credibility is important. How will you make sure people can access this? Are there dissemination plans? I would say you would need to make the effort to make people aware of this. You can see there has been so much work put into this, it would be a shame to not have it used.	√ Health boards and third sector organisations will be advised when this is available. We will promote this on social media platforms. Beat and other organisations have agreed to promote this on their websites/newsletters.	√
	<p>It says on the front cover that its for adults etc but as it includes recommendations for children with an eating disorder (which I presume is aimed at adult carers) maybe you should explain in the section 'Who is this booklet for' why it should not be given to children.</p> <p>The explanations of therapies are varied in their complexity. For example 'Schema therapy is an integrative model with a strong relational emphasis designed to address deeper core belief structures, coping mechanisms and relational patterns.' is too jargonistic, as is 'specialist integrative therapy' etc.</p> <p>The following section 'Severe and enduring eating disorders The course of an eating disorder is individual and there is huge variation in length of illness and time to treat. Some people may not respond to a course of an evidence-based treatment, however, recoveries are also reported after more than twenty years.'</p>	<p>√ Changed to 'a booklet for people living with eating disorders as this will also be relevant to adolescents. Sentences added to include adolescents.</p> <p>Simplified</p> <p>Amended for clarification</p>	<p>√ Agree with changes</p>

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	<p>is unclear in meaning. Is it that they may respond to a treatment even if they have had the disorder untreated for more than 20 years. Or may the treatment start working even if it has been given for over 20 years. I assume the former but the wording is ambiguous and could be depressing.</p> <p>Gives a good overview of what therapies are available.</p>	<p>√</p>	
	<p>Content is helpful.</p> <p>Offers helpful information for people to understand the problem and how people can get help. It gives good information about how parents/carers can support people. Information about the importance of getting help early is spot on. It's so important to highlight this. <i>Personal information was shared which will not be included in the consultation report as the purpose of the consultation exercise was to gather feedback on the booklet itself rather than experiences.</i></p> <p>Amount of information is sufficient and people can ask CAMHS for more information relevant for them. I would use this when asking about treatments for my daughter.</p> <p>Section on recovery is really positive.</p> <p>Useful that treatments are explained as much of the time these are mentioned with no explanation.</p> <p>Useful to acknowledge that ED affects the whole family and that parents/carers need support. <i>Personal experience shared that will not be included in the consultation report as not the purpose of the consultation.</i></p> <p>Useful to have the information about moving between services. Might be helpful to have a quote here since there is</p>	<p>√</p> <p>√</p> <p>√</p> <p>√</p> <p>√</p> <p>√</p> <p>√</p>	

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	space.		
	<p>I wonder if some stats would be useful?</p> <p>I also note there is no information on autism spectrum disorder and eating disorders. I see many children and young people with these comorbid conditions.</p>	<p>√ Added in Beat's estimate for UK rate.</p> <p>There was no robust evidence to make recommendations about managing eating disorders in people who have autism.</p>	<p>√ Agree with changes</p>
	<p>It is so important for parents to have this type of information. Too often parents are forgotten about and turn to the internet for information. <i>Story shared with KG</i>. Some of the definitions are quite complex though. Perhaps these could be improved? It's very clear in the booklet that it's based on the evidence which is really helpful.</p>	<p>√ Some definitions condensed slightly for readability</p>	<p>√ Agree with changes</p>
	<p>Very comprehensive information with good practice/research highlighted throughout. Particularly liked pages 28-29 with all</p>	<p>√</p>	

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	the support organisations and helplines available.		
	<p>Yes I think so. Gives enough information for people to look in to more detail or discuss with clinicians.</p> <p>On Page 27, I think the E in ECHO now stands for Experienced rather than Expert.</p> <p>On Page 28, we now have a dedicated Beat Scotland helpline number 0808 801 0432 and email scotlandhelp@beateatingdisorders.org.uk in addition to the main UK details provided</p>	<p>√</p> <p>Changed.</p> <p>Beat dedicated line info added</p>	
<p>3. Please share any ideas about the use of graphics for inclusion in our booklet.</p> <ul style="list-style-type: none"> • What type of image for the front cover would be meaningful? • Are there sections of the booklet that could be enhanced by graphics? 			
	Comments received	Group Response	Editorial response
	No stereotypes : scales, measuring tapes, white girls clutching their stomachs or heads, apples, empty plates	√	
	<p>See above: some sort of focus group with lived experience involvement would be recommended.</p> <p>To make it accessible pictures, graphics/animation or drawings can be added. It would be good to distribute in accessible formats, not just booklet but animation, easy read, social media clips, BSL film clips with voice, subtitles and audio description.</p>	<p>√</p> <p>See above re videos for young people</p>	√
	<p>It's a difficult one. People don't want images of food or scales! Perhaps just a few icons to brighten it up.</p> <p>Physical activity - perhaps icon for this?</p> <p>Family based therapy - family icon</p> <p>You could show image of ECG?</p>	<p>√</p> <p>Thank you for your suggestions</p>	

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	The whole book needs jazzing up.	√ Agree. We were unsure what type of images to use which is why we asked this question, to make sure images are meaningful.	√ Agree with changes
	Avoid negative and stereotypical images Use icons The style of SIGN's other information for the public is helpful Any white space could be filled with a graphic	√	
	Something nondescript.	√	
	Not sure. Icons that wouldn't be upsetting. Would be good to add images to each section to make it attractive.	√	
	Sometimes graphics help break up pages when there's a lot of information and make it less intense to read	√	
	Perhaps but I think it looks good as it is.	√	