Stories from the guideline development panels

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Content

- Priorities (2016-2017)
- The DEBRA International CPG standard
- The Journey of CPGs
- International access to published CPGs
- The Future

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

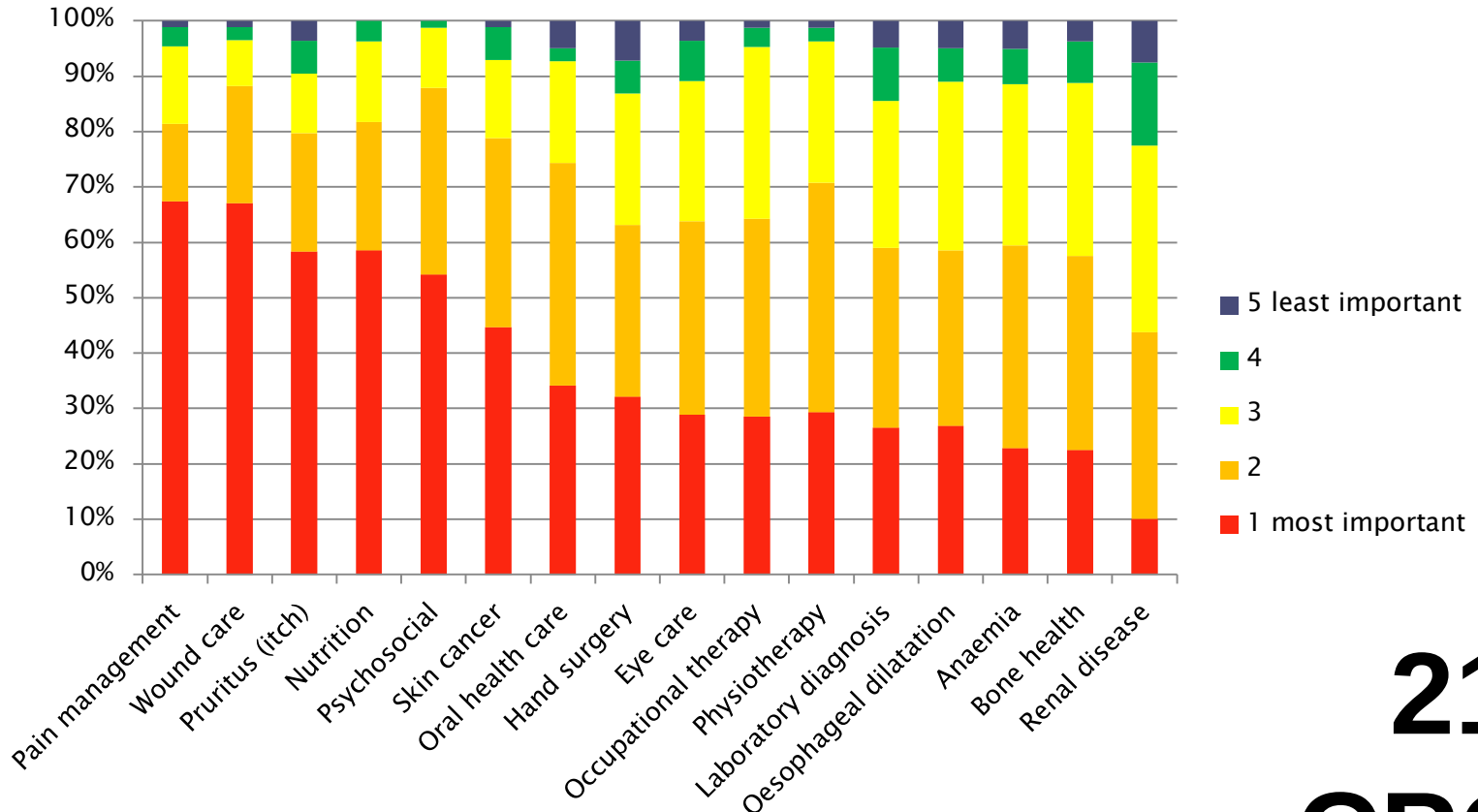
Clinical practice guidelines (CPGs)

- **DEBRA International** is undertaking a long-term initiative to develop CPGs for EB, in order to **improve the clinical care of people with EB.**

- It is **unusual** for the development of CPGs to be **led by a patient organisation** but, in the case of a rare disease such as EB, it is unlikely that guidelines would be developed **without the drive of patients.**

- **Despite being well-placed to lead** such an initiative, there have been some major **challenges for DEBRA to address** in order to ensure its future success.

Priorities of the EB community for CPGs (n=87/90)

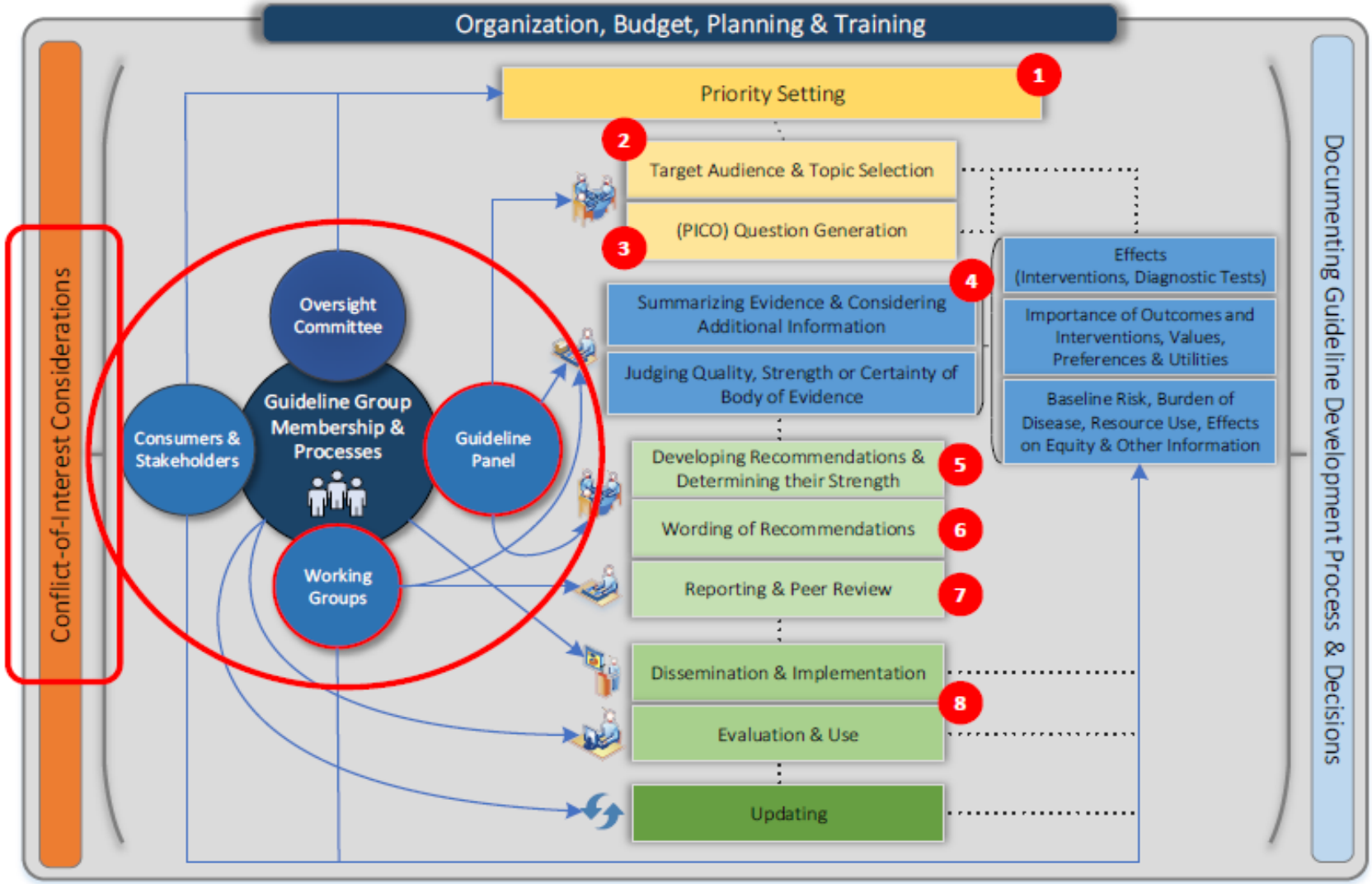


21 CPGs

Recommendations

- **Maximising the value of the network**
- Many of whom have committed to work 1 or more CPGs
- **128 volunteers** have been working on the **9 CPGs** this year representing almost **all continents** (Europe, North and South America, Asia and Australia),
- **22** (17%) of these are **people living with EB** from **7 countries** around the world, are acting as **full panel members.**

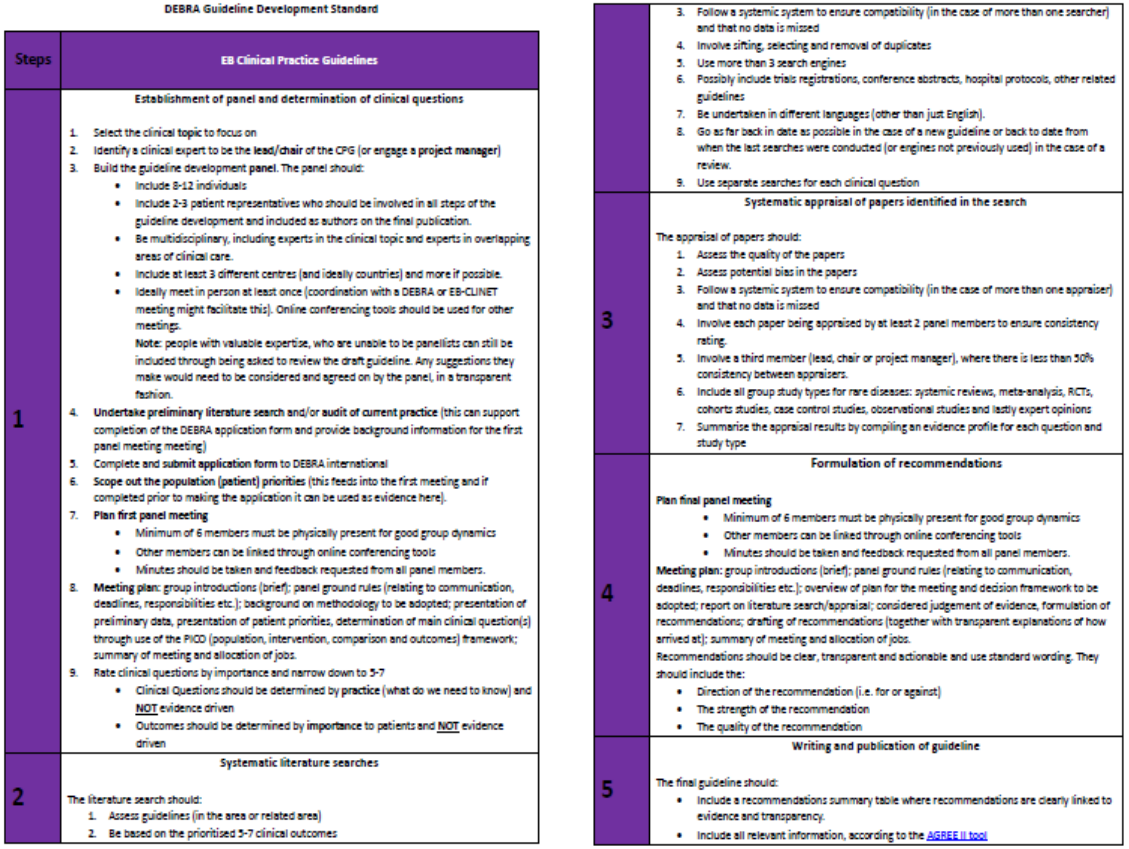
250



Schünemann et al. Guidelines 2.0: systematic development of a comprehensive checklist for a successful guideline enterprise. CMAJ. 2014 Feb 18;186(3):E123-42.
http://cebgrade.mcmaster.ca/guidecheck.html

Other Recommendations

- A DEBRA Guideline Development **Standard**
- **Translation** of guidelines
- **Communicating updates** (website/social media channels)



DEBRA Guideline Development Standard

Steps	EB Clinical Practice Guidelines
1	**Establishment of panel and determination of clinical questions** 1. Select the clinical topic to focus on 2. Identify a clinical expert to be the **lead/chair** of the CPG (or engage a **project manager**) 3. Build the guideline development **panel**. The panel should: • Include 8-12 individuals • Include 2-3 patient representatives who should be involved in all steps of the guideline development and included as authors on the final publication. • Be multidisciplinary, including experts in the clinical topic and experts in overlapping areas of clinical care. • Include at least 3 different centres (and ideally countries) and more if possible. • Ideally meet in person at least once (coordination with a DEBRA or EB-CLINET meeting might facilitate this). Online conferencing tools should be used for other meetings. Note: people with valuable expertise, who are unable to be panellists can still be included through being asked to review the draft guideline. Any suggestions they make would need to be considered and agreed on by the panel, in a transparent fashion. 4. **Undertake preliminary literature search** and/or **audit of current practice** (this can support completion of the DEBRA application form and provide background information for the first panel meeting meeting) 5. Complete and **submit application form** to DEBRA international 6. **Scope out the population (patient) priorities** (this feeds into the first meeting and if completed prior to making the application it can be used as evidence here). 7. **Plan first panel meeting** • Minimum of 6 members must be physically present for good group dynamics • Other members can be linked through online conferencing tools • Minutes should be taken and feedback requested from all panel members. 8. **Meeting plan:** group introductions (brief); panel ground rules (relating to communication, deadlines, responsibilities etc.); background on methodology to be adopted; presentation of preliminary data, presentation of patient priorities, determination of main clinical question(s) through use of the PICO (population, intervention, comparison and outcomes) framework; summary of meeting and allocation of jobs. 9. Rate clinical questions by importance and narrow down to 5-7 • Clinical Questions should be determined by **practice** (what do we need to know) and **NOT** evidence driven • Outcomes should be determined by **importance** to patients and **NOT** evidence driven
2	**Systematic literature searches** The literature search should: 1. Assess guidelines (in the area or related area) 2. Be based on the prioritised 5-7 clinical outcomes 3. Follow a systemic system to ensure compatibility (in the case of more than one searcher) and that no data is missed 4. Involve sifting, selecting and removal of duplicates 5. Use more than 3 search engines 6. Possibly include trials registrations, conference abstracts, hospital protocols, other related guidelines 7. Be undertaken in different languages (other than just English). 8. Go as far back in date as possible in the case of a new guideline or back to date from when the last searches were conducted (or engines not previously used) in the case of a review. 9. Use separate searches for each clinical question
3	**Systematic appraisal of papers identified in the search** The appraisal of papers should: 1. Assess the quality of the papers 2. Assess potential bias in the papers 3. Follow a systemic system to ensure compatibility (in the case of more than one appraiser) and that no data is missed 4. Involve each paper being appraised by at least 2 panel members to ensure consistency rating. 5. Involve a third member (lead, chair or project manager), where there is less than 50% consistency between appraisers. 6. Include all group study types for rare diseases: systemic reviews, meta-analysis, RCTs, cohorts studies, case control studies, observational studies and lastly expert opinions 7. Summarise the appraisal results by compiling an evidence profile for each question and study type
4	**Formulation of recommendations** **Plan final panel meeting** • Minimum of 6 members must be physically present for good group dynamics • Other members can be linked through online conferencing tools • Minutes should be taken and feedback requested from all panel members. **Meeting plan:** group introductions (brief); panel ground rules (relating to communication, deadlines, responsibilities etc.); overview of plan for the meeting and decision framework to be adopted; report on literature search/appraisal; considered judgement of evidence, formulation of recommendations; drafting of recommendations (together with transparent explanations of how arrived at); summary of meeting and allocation of jobs. Recommendations should be clear, transparent and actionable and use standard wording. They should include the: • Direction of the recommendation (i.e. for or against) • The strength of the recommendation • The quality of the recommendation
5	**Writing and publication of guideline** The final guideline should: • Include a recommendations summary table where recommendations are clearly linked to evidence and transparency. • Include all relevant information, according to the AGREE II tool

Step 1

Establishment of panel and determination of clinical questions

- **The Topic**
- **Application form**
- The Panel
- The clinical question(s)
- The PICO (population, intervention, comparison and outcomes)

New topics

- Podiatry
- **Women health and child birth**
- Sexuality
- Anaesthetics and clinical procedure
- Gastrostomy

EB Anaemia CPG application 2017

- http://www.debra-international.org/cpgs/for-eb-professionals/we-need-you.html

Step 1

Panel

- 8-12 panel members
- 2-3 people living with EB as full panel members and included as authors
- Multidisciplinary
- At least 3 different centres (and ideally countries) and more if possible.

EB Laboratory diagnosis CPG International panel

EB Psychosocial CPG panel members

STEP 1

EB Physiotherapy CPG panel meeting planing, agenda and time zones

EB physiotherapy clinical practice guideline development

List for EB-CLINET 1st panel meeting Monday 25th September 2017

	Name (role)	Country	Specialty
1	Amy Weissman (Lead)	USA	Physiotherapy
2	Jennifer Chan (co lead)	USA	OT
3	Michelle Wood	UK	Physiotherapy (P)
4	Beata Faitli	UK	Parent of child with EB
5	Rebecca Bodan	USA	Parent of child with EB
6	Phuong Khuu	USA	Dermatologists
7	Kristy Steinau	USA	Physiotherapy
8	Kaye Sjoholm	USA	Physiotherapy
9	Marita Black	USA	Physiotherapy
10	Kaycie Artus	USA	Physiotherapy
11	Julio Salas	Mexico	Dermatologists
12	Lisa Lazzarotto	Canada	OT
13	Jamil Lati	Canada	Physiotherapy

PT CPG EB Panel 9.25.17 Agenda
EB CLINET - Salzburg

Agenda Item	Key Content/Discussion	Expected Action/Outcomes
Introductions	• In-Person: Amy, Jennifer, Kristy, Michelle, Julio, Becky, Chantal, and Michelle • Conferencing-in: Marita, Kaye, Kaycie, Phuong, Lisa, Beata, and Jamil	
Basics of a Clinical Practice Guideline	• CPG Basics and development timeline. • SIGN used as an example	• Review and discuss Debra CPG Guidelines • SIGN and GRADE PDFs are available for review on Basecamp
Scoping survey Results	• Share updated results	•
Identifying Physiotherapy/PT Clinical questions, PICOs and outcomes	• Collaborate to develop our clinical question(s) and PICOS. • Identify outcomes	•
Identifying Key Terms for Literature Search	• Highlight our Key Terms • Utilize medical librarian and university if you have access	•
Identify Panel Member Roles	• All can assist with literature search • Critical Appraisers • Reviewers	•
Use of Master Database Spreadsheet	• Introduce spreadsheet to begin to ID appropriate articles to appraise	•
Our next steps…		•

World Time Zone to coordinate as many panel members to be involved as possible…

Salzburg Time	London (GMT) – 1 hour	New York/Toronto (EST) – 6 hours	Denver, Colorado (MST) – 8 hours	Arizona/California (PST) – 9 hours
Amy, Jennifer, Michelle, Julio (AM), Kristy, Becky (AM), Chantal	Beata	Marita, Lisa, Jamil	Kaycie	Kaye, Phuong
0900	0800	0300	0100	0000
1000	0900	0400	0200	0100
1100	1000	0500	0300	0200
1200	1100	0600	0400	0300
1300	1200	0700	0500	0400
1400	1300	0800	0600	0500
1500	1400	0900	0700	0600
1600	1500	1000	0800	0700

Step 1

Framing clinical questions according to PICO

Population: Who

Intervention: What to do

Comparison: Compared to what

Outcomes: Why and when

EB Occupational therapy (OT) CPG panel PICOs work

Patient/Problem	Intervention	Comparison	Outcome
EB Patients	Interdigitally wrap hands or use orthoses / Splints	Pt's that don't wrap or use orthoses	less incidence of hand surgery or
EB Patients	interdigitally wrap hands or use orthoses	Pt's that don't wrap or use orthoses	increased hand function longer (Independence levels – writing, etc)
EB Patients	OT Consultation	No OT consultation	Independence in ADLs
EB Patients	OT	No OT	Number of outside activities
EB Patients	Task-Specific Training and Adaptations/Modifications-		Independence Levels in ADLs and Self-care (at age

Methods

Outcomes

Should be

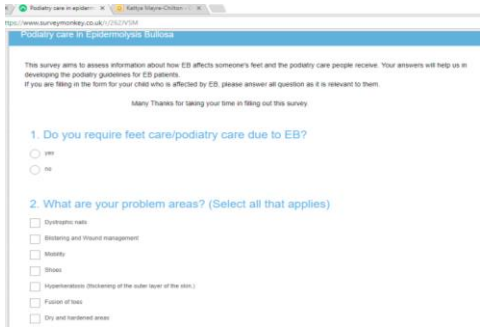
importance driven

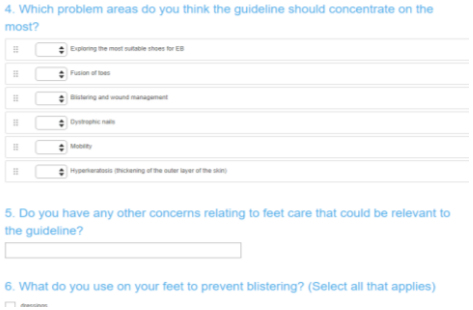
NOT

evidence driven

5-7 outcomes per clinical questions are prioritised

EB Podiatry CPG panel member living with EB lead survey





EB Hand Surgery and Rehabilitation Therapy CPG stall at AGM

EB Laboratory diagnosis CPG scoping example

Scoping people /families with EB

CHILE Person answering the questionnaire:	DS, Mother of a 8 years old patient with RDEB gen sev	NK 35 years old Daughter, patient and mother of a 4 years old patient with DDEB	NC, 34 years old RDEB gen intermediate patient, father of 2 healthy children
Age at diagnosis	5	5	5
Skin biopsy	4	5	5
Turn around of the diagnostics	5	3	5
Method which is used	2	5	3
Prenatal diagnosis	5	3	4
Counselling	5	5	5
Other, please include:	It would be good to have a book to guide patient treatment depending on the lab result. Maybe this book could be deliver together with the lab result.	When suspecting an inherited EB type, include other family members to the Lab diagnosis obtain fast and reliable data	-

EB Psychosocial CPG focus-group

Step 2

- Systematic literature searches

EB Psychosocial CPG panel steps

	P	Q	R	S	T	U
1	Intervention	AND	therap* (as in therapy, therapies etc.)	AND/ Or?	Intervention	process to support
2	Psychological		Cognitive behavioural therapy		Social support	Community social support
3	Psychologist	AND	Coping with skills training	AND/ Or?	social workers	Social care
4	Psychotherapist	AND	Adjustment techniques	AND/ Or?	Community support	Family support
5	psycho*	AND	Life coaching	AND/ Or?		Developmental Transition Support e.g., Neo-natal and post-natal support
6	counselling	AND	Relationship building	AND/ Or?		Developmental Transition Support e.g., transition to school
7	counsellor	AND	Education e.g. in screening	AND/ Or?		Developmental Transition Support e.g., transition to adolescence
8		AND	Training e.g. in screening	AND/ Or?		Developmental Transition Support e.g., transition to adulthood
9		AND	Education e.g. in psychosocial interventions	AND/ Or?		Developmental Transition Support e.g., transition to parenthood
10		AND	Training e.g. in psychosocial interventions	AND/ Or?		Developmental Transition Support e.g., transition to university
11		AND	Parenting Interventions	AND/ Or?		Developmental Transition Support e.g., transition to work
12		AND	Coping and social skills training	AND/ Or?		End of life

	A	B	C	D	E	F	G	H	I	J	K	L	M	N
1			Search engines to cover in March 2017											
2		Search engines	Medline (PubMed MeSH)	Embase Emtree	PsychInfo	CINHAL	Scopus	Dialnet	Google academic	British Nursing Index	HMIC (Health management Information consortium)	AMED (Allied & complementary medicine)	Health business elite	The main search engine for NICE
3	1	Kate Martin		☑			☑			☑	☑	☑	☑	☑
4	2	Estrella Guerrero S						☑☑	☑☑					
5	3	Nora Garcia G						☑☑	☑☑					
6	4	Petra de Graaf M			☑☑					?	?	?	?	?
7	5	Kattya Mayre-Chilton	☑				☑			?	?	?	?	?
8	6	Rebecca Bodan				☑								
9	7	Bronagh Kennedy				☑								
10	8	Fiona Browne	☑☑											
11	9	Kristina Soon		☑			☑			☑	☑	☑	☑	☑
12														
13		Searches in language terms	English	☑	Spanish	☑	Dutch	☑	French	☑	Norwegian	☑	Croatian	☑
14														

Outcome vot ...

Database

EB Psychosocial CPG panel work

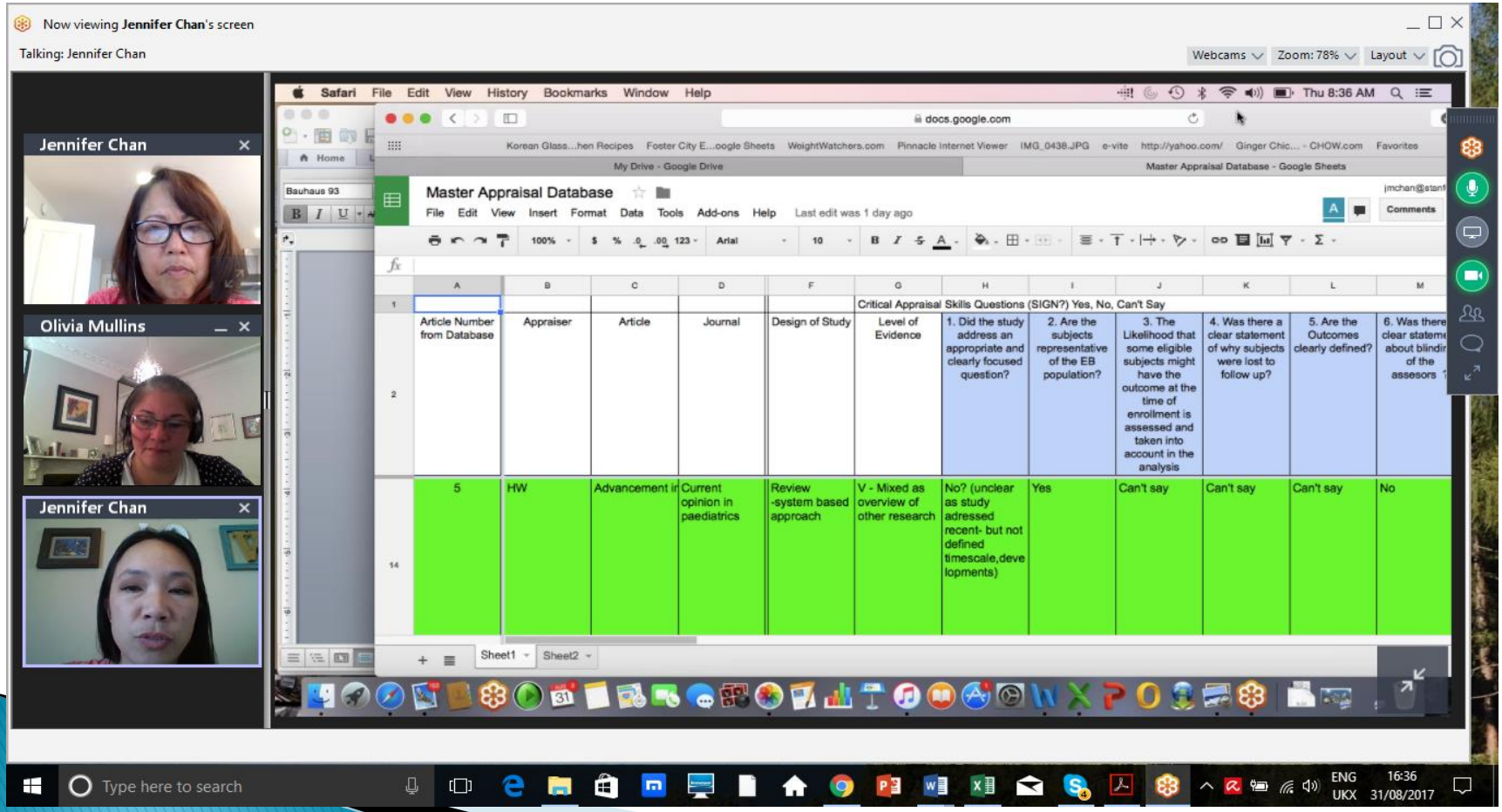
Numbre	embers/Srch engine	Title of Article	AUTHORS	Journal	Year	Volume	Pages	Type eg full paper, abstract, TRUST guidance	Abstract	Language	dublicate
1	BK	CINAHL	Epidermolisis bullosa en un paciente neonatal: caso clinico	Abad Molto, P, Ribera S, Miriam P.T et al.	Enfermeria Clinica	2015	25(3)	143-145	Journal article	abstract not available - needs sourcing	Spanish	
2	FB	Pubmed/M	Molecular epidemiology of hereditary epidermolysis bullosa in a Middle Eastern	Abu Sa'd J, Indelman M, Pfendner E, Falik-Zaccai TC, Mizrachi-Koren M, Shalev S, Ben Amitai D, Raas-Rothshild A, Adir-Shani A, Borochowitz ZU, Gershoni-Baruch R, Khayat M, Landau D, Richard G, Bergman R, Uitto J, Kanaan M, Sprecher E.	J Invest Dermatol	2006	126(4):777-81.	777-81	Journal article	Epidermolysis bullosa (EB) encompasses a large group of inherited blistering skin disorders caused by mutations in at least 10 genes. Numerous studies, mainly performed in European and US families with EB, have revealed a number of characteristic epidemiological and genetic features, which form the basis for current diagnostic and counseling strategies. However, little is currently known about the molecular epidemiology of EB in Middle East populations. In the present study, we assessed 55 EB families for pathogenic sequence alterations in the 10 genes known to be associated with EB. Our results show unique EB subtype distribution and patterns of inheritance in our cohort. We also failed to detect recurrent mutations frequently encountered in Europe and the US, and did not consistently observe genotype-phenotype correlations formerly established in Western populations. Thus, the molecular epidemiology of EB in the Middle East is significantly different from that previously delineated in Europe and the US. Our data raise the possibility that similar differences may also be found in other genetically heterogeneous groups of disorders, and indicate the need for population-specific diagnostic and management approaches.	ENGLISH	
3	BK	CINAHL	The psychosocial impact of chronic wounds on patients with severe epidermolysis bullosa	Adni T, Martin K, Mudge.	Journal of wound c	2012	21(11)	528-563	Journal article-re	OBJECTIVE:To explore the lived experience of individuals with chronic wounds associated with dystrophic and junctional epidermolysis bullosa (EB),to improve understanding and, therefore, enhance the care provided to this group of patients by acquiring in depth data on the psychosocial issues that affect them. METHOD: A phenomenological study using interpretive phenomenological analysis was employed. A purposive sampling method was used with six individuals replying to postal invitation to participate. RESULTS: Following one-to-one interviews, six superordinate themes were identified. These were: coping, pain, perceptions, emotional impact, social impact and support network, each with subordinate themes. All of the superordinate themes have been identified by previous research into chronic wounds, burns and disfiguring conditions; however, new subordinate themes arose. CONCLUSION: This study highlighted the need for individuals with EB to have a	English	13

Search strategy | Database of articles | Appraisal table | List of ref order | Search engine alocation | Outcome vote %

267 duplicate articles were removed leaving 280 articles to filter before gray literature is added, 150 articles were selected for filtering for appraisal

Step 3 Systematic appraisal of papers identified in the search

EB Occupational therapy (OT) CPG appraisal work



EB Psychosocial CPG guide and appraisal excel table

	Question	Decision guideline
Overview	1. Does the title reflect the content?	Do you think the title describes the article?
	2. Are the authors contact details and institute reported?	Does the paper tell you where the authors are working or which institute they are representing and how you can contact minimum one of them? Normally in the front page of the paper.
	3. Does the abstract summarize the key components?	Can all the important components (context, subjects, methodology, results, conclusions, ...) of the study be found briefly in the abstract?
	4. Is the rationale for undertaking the research clearly outlined?	Do they explain well why this study was necessary and which contribution there is to the scientific field?
	5. Has there been a comprehensive literature review and a clearly outline process?	Did they report about the review process and their used methodology (= YES) or is there just an introduction based on literature (= NO).
	6. Is the aim of the research clearly stated?	Do they have a statement what the research aim was and was this clear to you?
	7. Has it been approved by an ethical board?	Do they mention any approval of an ethic board or do they report ethical consideration concerning the study?
	Sampling bias	Please, try to evaluate if the selection process of the study sample identify - -
Is this a quantitative research?		
Quantitative research	8. Does this study have a control group?	Do they to anotl
	9. Is the study design clearly identified, and is the rationale for choice of design evident?	Does th was cho questio
	10. Is there an experimental hypothesis	

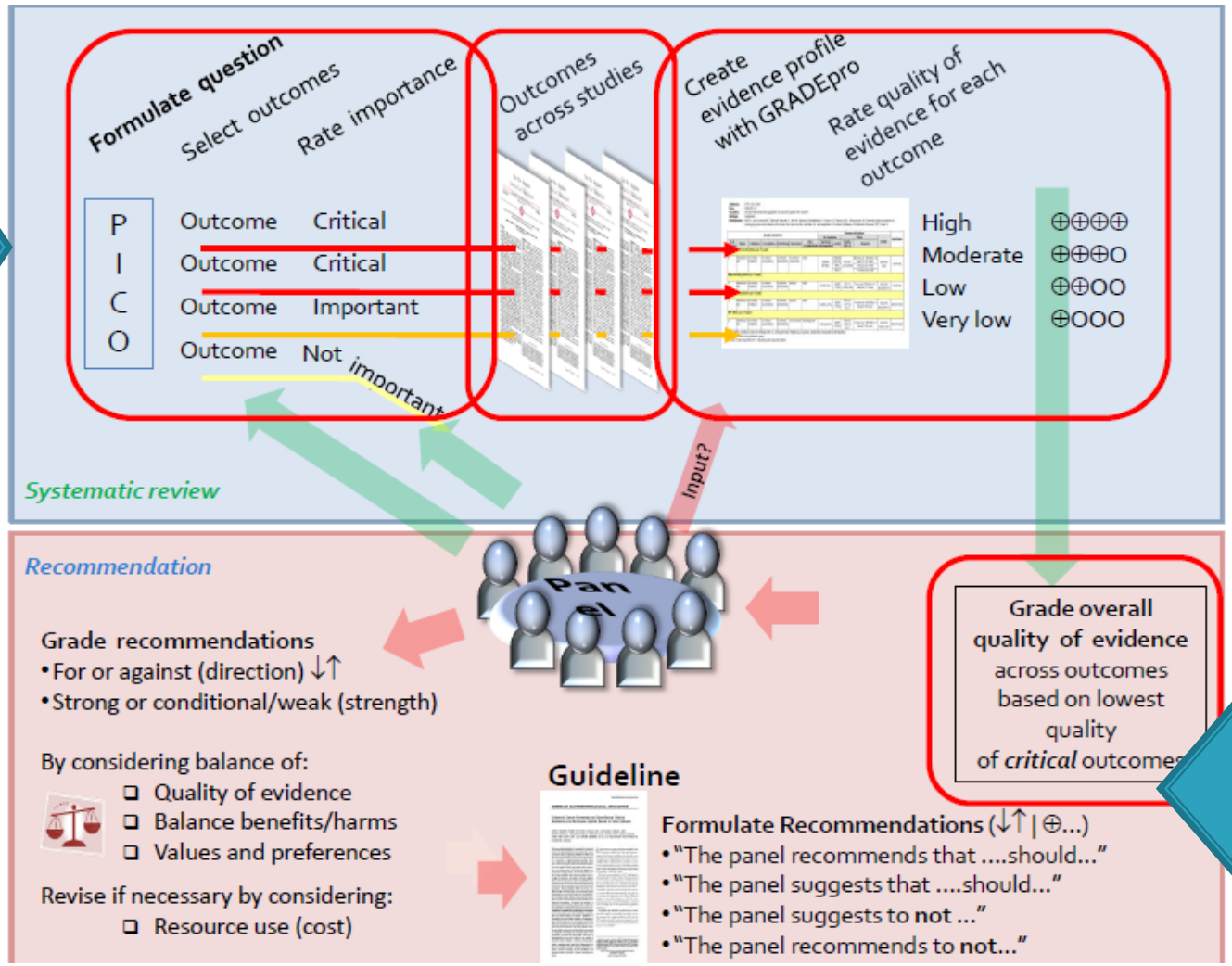
				PART ONE: ELIGIBIL				PART TWO: QUALITY ASSESSMENT				
			Articles					Overview				
		Initials of who search		Parti	Outco	Design	If you have answered NO to any of these questions please STOP HERE.					
Number from database table	Appraiser initials		where they in full PDF	Do the partici pants in the study have EB, a fam	Is the outcom e(s) one or some of the follow n:	Is the methdology one of the following: Quantitative, Qualitative, Systemic reviews, Me	If you have answered YES for all questions, please proceed to Part Two.	1. Does the title reflect the content?	2. Are the authors contact details and institute reported?	3. Does the abstract summarise the key components?	4. Is the rationale for undertaking the research clearly outlined?	5. Has there been a comprehensive literatur review with a clearly outlined process?
33	SG	KMC	abstract	Yes	No	No	STOP					
33	EGS			Yes	No	No	STOP					
36	FB	KMC	Abstract	YES	YES	YES	STOP					
	BK			YES	YES	YES	STOP					
37	FP	BK	Journal article-									
37	EGS/KMC			YES	YES	YES	PROCEED	YES	YES	YES	YES	YES
39	PdeG	KMC	Full paper	YES	YES	YES	PROCEED	YES	YES	YES	YES	NO
	SG			Yes	Yes	Yes	PROCEED	YES	Yes	Yes	Yes	No
40	AD	KMC	STOP			NO	STOP					
	KS		unable to access			NO	STOP					
47	GS	KM	Research	YES	YES	YES	PROCEED	YES	YES	NO	NO	NO
	KS											
48	AD	BK	STOP	YES	YES	NO	STOP					
48	EGS			YES	YES	NO	STOP					
52	KS	FB	No abstract									

Step 3 Outcome summary tables

EB Psychosocial CPG Outcome summary table draft

	Study ID	Sample populations: What type of EB	Number of subjects with EB (N=)	Study Design/ Method	Quality Framework	What are the results of the study?	Quality rating with SIGN	Average rating for family outcome	initials	Risk of Bias	Risk of bias %
1	10	ALL	204	Quantitative	92%	Future public policy decisions and interventions for EB or other rare diseases, at a national and EU level, should aim to take patient level cost disparities and HRQOL effects into account.	2++		KMC	2	50%
9	132	ALL	21	Quantitative	86%	Parents of children with EB suffer from a great burden of coping with the disease. Need for support is increased. Unpredictability of EB is the most difficult	2+		SG	2	50%
7	111	RDEB: recessive dystrophic epidermolysis bullosa	13/16	Qualitative	85%	This qualitative research examines the impact of a gastrostomic tube on EB patients. Generally they suggest a better and open communicatio about the decision process. More specific they give a lot informations about aspects healthcare providers should keep in mind.	2+		SG	1	25%
2	215	EBS; JEB; DDEB; RDEB; KS	12/185	Quantitative	81%	EB has a severe impact on QoL and impairs the health status in the majority of patients. On average female patients have a worse QoL. The main determinants of the carers' burden are the severity and extent of the disease, and the poor QoL of the patient. Children suffer more than adults. Psychological support and close monitoring with QoL measurements may help patients with EB and their carers.	2-(+)		KMC(EGG)	2	50%

Physio, HS&RT, Diagnosis, Anaemia



OT, Psychosocial Podiatry,

Step 4 & 8
Summary of recommendations

EB Skin and Wound care CPG review published 2017

Key recommendations

Key recommendations are based on the results of the literature review and the experience of the guideline development group. The recommendations in this table are not arranged according to importance but rather in the order they occur in the main body of the document.

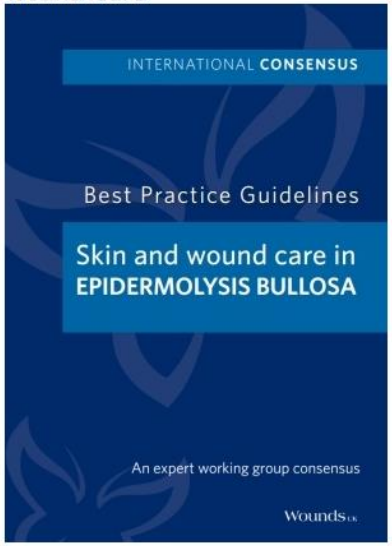
Box 1

Key recommendations	Strength of recommendation	Level of evidence	Key references
EB is a lifelong disorder that requires specialist intervention and consideration to minimise complications and improve quality of life. Ideally, management should take place in a specialised centre by a multi-disciplinary team	D	4	Badger, O'Haver et al, 2013; Denyer 2009; Pope, Lara-Corrales et al, 2012; Pillay 2008, El, Zambruno et al, 2014
In severe EB the individual's ability to heal can be compromised by malnutrition, anaemia, pruritus and pain, and should be treated appropriately	D	4	Badger, O'Haver et al, 2013; El, Zambruno et al, 2014; Lara-Corrales, Arbuckle et al, 2010; Mellerio 2010; Pope, Lara-Corrales et al, 2012; Schober-Flores 2003; Pope, Lara-Corrales et al, 2013
Careful skin and wound assessment should be undertaken regularly. Management must be tailored to both the type of EB and wound characteristics	D	4	Badger, O'Haver et al, 2013; Denyer 2009; Denyer 2010; Elluru, Contreras et al, 2013; Pope, Lara-Corrales et al, 2012; Pope, Lara-Corrales et al, 2013; Schober-Flores 2003; Sibbald, Zuker et al, 2005; El, Zambruno et al, 2014
Atraumatic dressings should be used to prevent further blistering, skin and wound bed damage	D	4	Abercrombie, Mather et al, 2008; Badger, O'Haver et al, 2013; Denyer 2009; Denyer 2000; Denyer 2010; El, Zambruno et al, 2014; Kirkorian, Weitz et al, 2014; Lara-Corrales, Arbuckle et al, 2010; Mellerio, Weiner et al, 2007; Pillay 2008; Pope, Lara-Corrales et al, 2012; Elluru, Contreras et al, 2013; Gonzalez 2013
People with EB and their carers are experts in the management of their condition and their involvement is paramount	D	4	Badger, O'Haver et al, 2013; Pope, Lara-Corrales et al, 2012; van, Lettinga et al, 2008
The choice of wound management strategies should balance efficacy, patient choice and	D	3,4	Kirkorian, Weitz et al, 2014; Sibbald, Zuker et al, 2005; Stevens 2014

Step 5 & 6 Published guidelines

Oral Healthcare

Wound Care



Cancer Management

Pain Management

Promote research by identifying gaps

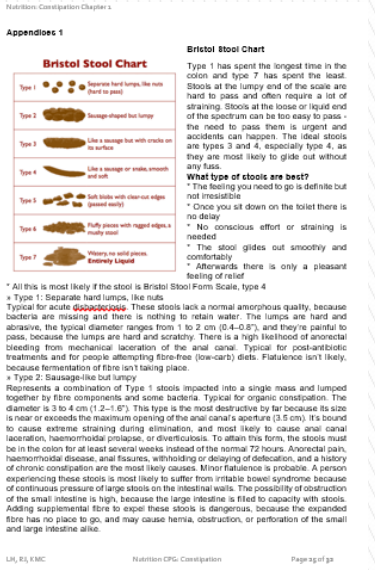
http://www.debra-international.org/clinical-guidelines/complete-eb-guidelines.html

Step 7
Dissemination & implementation

- Conference and meeting presentations
- Published Open access
- DEBRA International website
  - http://www.debra-international.org/clinical-guidelines/complete-eb-guidelines.html
- EB-CLINET website
  - http://www.eb-clinet.org/guidelines-cpgs/complete-eb-guidelines.html

- Implementations tools in the Appendix

EB Nutrition: constipation CPG draft



Appendices 1

Bristol Stool Chart

Bristol Stool Chart

Type 1 has spent the longest time in the colon and type 7 has spent the least. Stools at the lumpy end of the scale are hard to pass and often require a lot of straining. Stools at the loose or liquid end of the spectrum can be too easy to pass - the need to pass them is urgent and accidents can happen. The ideal stools are types 3 and 4, especially type 4, as they are most likely to glide out without any fuss.

What type of stools are best?

* The feeling you need to go is definite but not irresistible
* Once you sit down on the toilet there is no delay
* No conscious effort or straining is needed
* The stool glides out smoothly and comfortably
* Afterwards there is only a pleasant feeling of relief

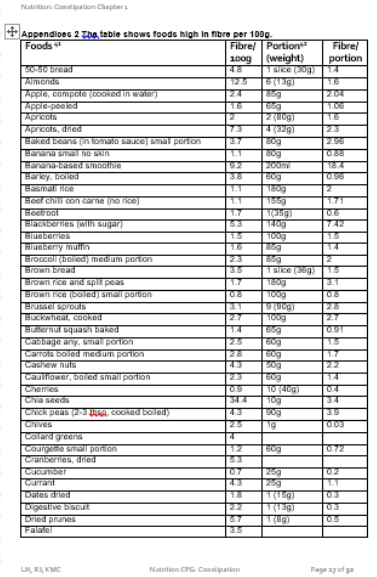
* All this is most likely if the stool is Bristol Stool Form Scale, type 4

x Type 1: Separate hard lumps, like nuts

Typical for acute dysbacteriosis. These stools lack a normal amorphous quality, because bacteria are missing and there is nothing to retain water. The lumps are hard and abrasive, the typical diameter ranges from 1 to 2 cm (0.4–0.8"), and they're painful to pass, because the lumps are hard and scratchy. There is a high likelihood of anorectal bleeding from mechanical laceration of the anal canal. Typical for post-antibiotic treatments and for people attempting fibre-free (low-carb) diets. Flatulence isn't likely, because fermentation of fibre isn't taking place.

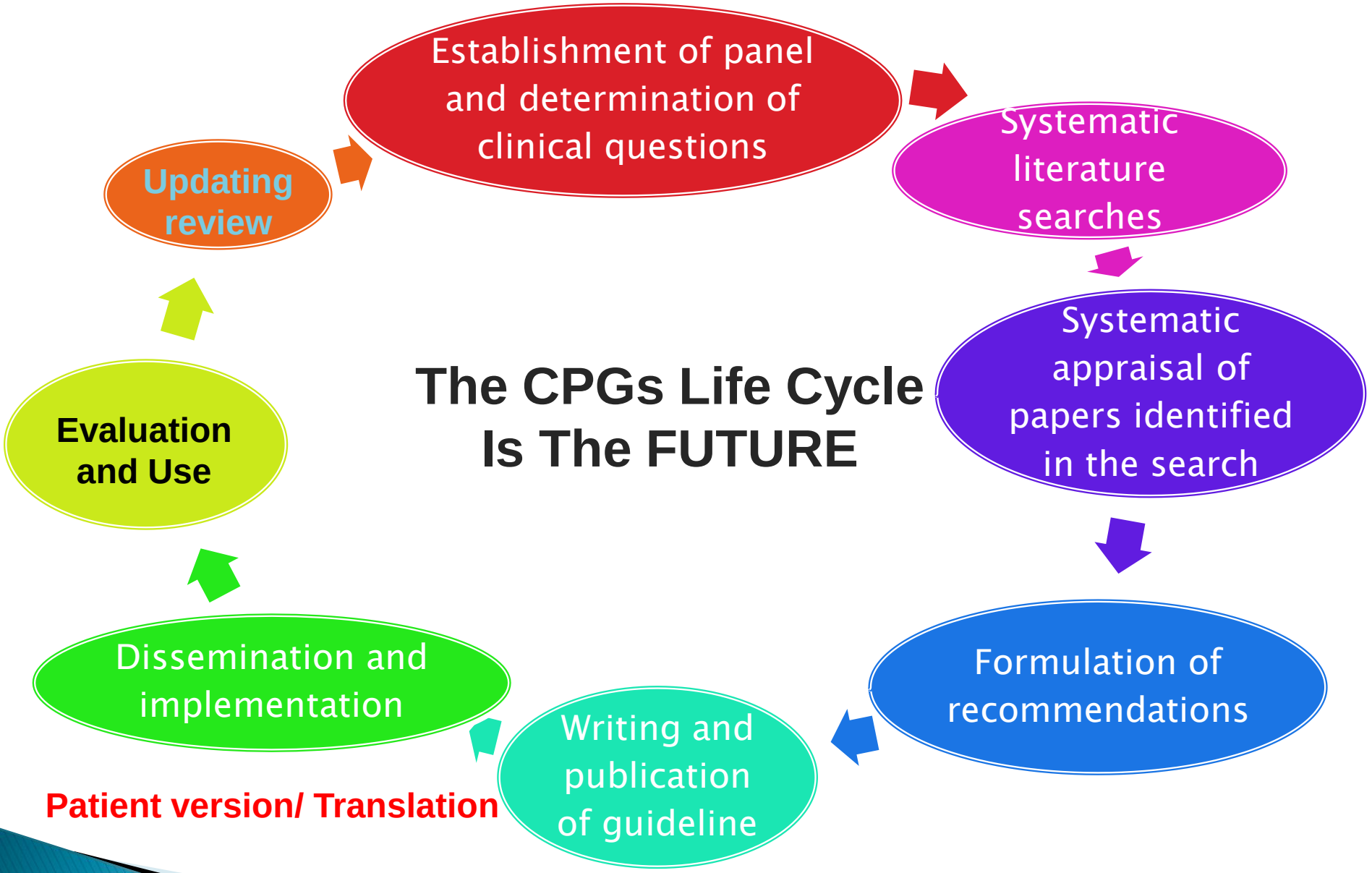
x Type 2: Sausage-like but lumpy

Represents a combination of Type 1 stools impacted into a single mass and lumped together by fibre components and some bacteria. Typical for organic constipation. The diameter is 3 to 4 cm (1.2–1.6"). This type is the most destructive by far because its size is near or exceeds the maximum opening of the anal canal's aperture (3.5 cm). It's bound to cause extreme straining during elimination, and most likely to cause anal canal laceration, haemorrhoidal prolapse, or diverticulosis. To attain this form, the stools must be in the colon for at least several weeks instead of the normal 72 hours. Anorectal pain, haemorrhoidal disease, anal fissures, withholding or delaying of defecation, and a history of chronic constipation are the most likely causes. Minor flatulence is probable. A person experiencing these stools is most likely to suffer from irritable bowel syndrome because of continuous pressure of large stools on the intestinal walls. The possibility of obstruction of the small intestine is high, because the large intestine is filled to capacity with stools. Adding supplemental fibre to expel these stools is dangerous, because the expanded fibre has no place to go, and may cause hernia, obstruction, or perforation of the small and large intestine alike.



Appendices 2 The table shows foods high in fibre per 100g.

Foods [53]	Fibre/ 100g	Portion[23] (weight)	Fibre/ portion
50-50 bread	4.8	1 slice (30g)	1.4
Almonds	12.5	6 (13g)	1.6
Apple, compote (cooked in water)	2.4	85g	2.04
Apple-peeled	1.6	65g	1.06
Apricots	2	2 (80g)	1.6
Apricots, dried	7.3	4 (32g)	2.3
Baked beans (in tomato sauce) small portion	3.7	80g	2.96
Banana small no skin	1.1	80g	0.88
Banana-based smoothie	9.2	200ml	18.4
Barley, boiled	3.8	60g	0.98
Basmati rice	1.1	180g	2
Beef chilli con carne (no rice)	1.1	155g	1.71
Beetroot	1.7	1(35g)	0.6
Blackberries (with sugar)	5.3	140g	7.42
Blueberries	1.5	100g	1.5
Blueberry muffin	1.6	85g	1.4
Broccoli (boiled) medium portion	2.3	85g	2
Brown bread	3.5	1 slice (36g)	1.5
Brown rice and split peas	1.7	180g	3.1
Brown rice (boiled) small portion	0.8	100g	0.8
Brussel sprouts	3.1	9 (90g)	2.8
Buckwheat, cooked	2.7	100g	2.7
Butternut squash baked	1.4	65g	0.91
Cabbage any, small portion	2.5	60g	1.5
Carrots boiled medium portion	2.8	60g	1.7
Cashew nuts	4.3	50g	2.2
Cauliflower, boiled small portion	2.3	60g	1.4
Cherries	0.9	10 (40g)	0.4
Chia seeds	34.4	10g	3.4
Chick peas (2-3 tbsp, cooked boiled)	4.3	90g	3.9
Chives	2.5	1g	0.03
Collard greens	4		
Courgette small portion	1.2	60g	0.72
Cranberries, dried	5.3		
Cucumber	0.7	25g	0.2
Currant	4.3	25g	1.1
Dates dried	1.8	1 (15g)	0.3
Digestive biscuit	2.2	1 (13g)	0.3
Dried prunes	5.7	1 (8g)	0.5
Falafel	3.5		


Establishment of panel and determination of clinical questions
Systematic literature searches
Systematic appraisal of papers identified in the search
Formulation of recommendations
Writing and publication of guideline
Dissemination and implementation
Evaluation and Use
Updating review
The CPGs Life Cycle Is The FUTURE
Patient version/ Translation

Panel meetings at EB-CLINET 2017

EB Hand Surgery & Rehabilitation Therapy CPG

EB Occupational therapy (OT) CPG

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Thank you

- **Have you had experience of these?**
- **Do you what to join these panels?**
- **Please email me (Kattya) to link you**

1. Women health & child birth
2. Dental health
3. Sexuality
4. Anaesthetics & clinical procedure
5. Gastrostomy
6. Bone health
7. Eye care
8. Renal

http://www.debra-international.org/clinical-guidelines/complete-eb-guidelines.html