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Supplementary Material

Determining the credibility, accuracy and comprehensiveness of websites educating consumers on complex regional pain syndrome accessible in Australia: a systematic review

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Appendix S1. Search Strategies and Instructions

Google search instructions

- Go to home Google site (e.g. Australia www.google.com.au)
- Log off from any Google Accounts
- Clear previous browsing data
    - Options > Advanced settings > Privacy - Clear browsing data > clear Browsing history, Download history, Cookies, Cached images and files from ‘beginning of time’. Alternatively, press Ctrl + Shift + Delete and it can take you straight to this page and you can delete your browsing history.
- Set time range to 'all time'
- Select to delete your browsing history, downloads, cookies and cached images and files
- In Google settings increase search results from 20 - 50 by clicking 'settings' > 'search settings'
- Set Google to search only specific country of interest (Australia) by scrolling to the bottom of the search settings page.
- Copy and paste the first search strategy from table below into Google, to be entered as key search term (e.g. *Complex Regional Pain Syndrome*) + name of country (e.g. *Australia*) + the name of the type of website (e.g. *gov*) = *Complex Regional Pain Syndrome Australia gov*
- Copy and paste the first 50 search results into an empty table
- Clear search history after each search. Delete the same data as you did before (browsing history, cookies, downloads and cached files for 'all time').
- Move onto next search strategy and repeat the above process (e.g. next search strategy for Australia will be *Complex Regional Pain Syndrome Australia org*)

- Ensure to complete all 18 search strategies for Australia. Which will consist of the "Complex Regional Pain Syndrome", "CRPS" and "RSD" key searches.

Complex Regional Pain Syndrome	**CRPS**	**RSD**
Australia (www.google.com.au)		
Government: Complex Regional Pain Syndrome Australia gov **NGOs:** Complex Regional Pain Syndrome Australia org **Consumer organisations:** Complex Regional Pain Syndrome Australia consumer reports **Hospitals:** Complex Regional Pain Syndrome Australia hospital **Universities:** Complex Regional Pain Syndrome Australia university **Professional associations/societies:** Complex Regional Pain Syndrome Australia professional societies	**Government:** CRPS Australia gov **NGOs:** CRPS Australia org **Consumer organisations:** CRPS Australia consumer reports **Hospitals:** CRPS Australia hospital **Universities:** CRPS Australia university **Professional associations/societies:** CRPS Australia professional societies	**Government:** RSD Australia gov **NGOs:** RSD Australia org **Consumer organisations:** RSD Australia consumer reports **Hospitals:** RSD Australia hospital **Universities:** RSD Australia university **Professional associations/societies:** RSD Australia professional societies

Appendix S2. EFIC CRPS Task Force Members Who Contributed and Reviewed to this Study's CRPS Guidelines

Name	Expertise
Frank Birklein	Professor of Neurology, UMC Mainz, Department of Neurology, Germany Doctoral Degree
Florian Brunner	Head of department of Physical Medicine and Rheumatology, Balgrist University Hospital, Switzerland Doctoral Degree
Andreas Goebel	Associated Prof. in Pain Medicine, University of Liverpool, United Kingdom Doctoral Degree
Lorimer Moseley	Director of the Innovation, Implementation & Clinical Translation in Health ('IIMPACT in Health'), the University of South Australia, Australia Lead of the Body in Mind Research Group, the University of South Australia, Australia Qualified Physiotherapist Doctoral Degree
Astrid Terkelson	Associate Professor in research and Neurologist at the Department of Neurology, AARHUS University, Denmark Doctoral degree
Ilona Thomassen	Chairman of the Pain Patients Partnership and CRPS Patient Association Member of the General Board of PAiN Board Member RSDSA (USA CRPS Society) Member CRPS Global (International group of patient organizations and representatives)

Appendix S3. Critical Appraisal Recommendations

TASK FORCE GENERAL GUIDELINES **General Website Appraisal**	
Diagnosis	Specifies that the "Budapest" diagnostic criteria for CRPS must be used in diagnosing the condition
	States that the diagnosis of CRPS does not require diagnostic tests, except to exclude other diagnoses – mainly through the use of magnetic resonance imaging (MRI) and nerve conduction measurements
Referral and management	States that the management of mild (mild pain and mild disability) CRPS may not require a multi-professional team
	States that those diagnosed with CRPS must be appropriately assessed; establishing any triggers, pain intensity, quality of life, sleep and mood. Whilst also the interference of their pain on their participation levels and activities of daily living.
	States that referrals to specialised care* must be initiated for patients who do not have clearly reducing pain and improving function within 2 months of commencing treatment for their CRPS despite good patient engagement in rehabilitation *Specialised care can be defined as specialised pain management facilities/services that offer therapeutic management of chronic pain conditions, including CRPS, by registered professionals with specialisation in the field**

	States that referrals to specialised care must be initiated for patients with complications such as CRPS spread, fixed dystonia, myoclonus, skin ulcerations or infections or malignant oedema in the affected limb, and those with extreme psychological distress.
	States that the therapeutic management of CRPS must include a multidisciplinary approach, incorporating psychologically informed rehabilitative pain management programmes (PMP).
	If spinal cord stimulation is recommended, evidence base and context must be included
Prevention	States that there is currently insufficient evidence to suggest strategies that effectively prevent CRPS
Pain management	States that CRPS patients should talk to their medical team regarding drugs and medications
	States that patients must have access to pharmacological treatment
	States that all patients with CRPS must receive a pain treatment plan consistent with their geographically relevant guidelines.
	States that patients must receive a tailored rehabilitation plan
	States that CRPS patients must receive stopping rules and a medication reduction plan once receiving any drugs/medications (to reduce unwarranted side effects)
	States that CRPS assessments must be repeated as appropriate, because both the natural development of the disease and therefore the treatment may change over time

Physical and vocational rehab.	States that a CRPS patient's limb function, overall function and activity participation, (including in the home and at work or school), must be assessed early and repeatedly as appropriate
	States that patients with CRPS must have access to rehabilitation treatment, delivered by physiotherapists and/or occupational therapists, as early as possible in their treatment pathway.
Identifying and treating distress	States that all CRPS patients must be screened for distress including depression, anxiety, post-traumatic stress, pain-related fear and avoidance. This must be repeated where appropriate.
	States that where required, patients must have access to evidence-based psychological treatment.
Treatment	States that Surgery may be indicated for type 2 CRPS when there is an identifiable remediable nerve lesion (eg certain cases of neuropathic pain due to either nerve compression by scar tissue, neuroma formation or perioperative nerve injury, such as through a needle stitch) but not before **1 year** after the active process has resolved.
	States that the natural recovery from CRPS is frequent within 18–24 months after CRPS onset and can occur even in very longstanding cases.
	States that amputation is not justified within 24 months after CRPS onset, excepting extreme cases of intractable infection of the affected limb that cannot be controlled with antibiotics.
Long term care	States that there are currently no mandatory long-term care standards, due to insufficient support

Drug and medications that **ARE ENDORSED**	Drug and medications that **ARE NOT ENDORSED**
Codeine,	Cannabis sativa extract
Dihydrocodeine,	Lamotrigine
Tramadol, only if acute rescue therapy is needed	Oxcarbazepine
Non-steroidal anti-inflammatory drugs (NSAIDs)	Venlafaxine
Paracetamol, as appropriate.	Topical Capsaicin cream/patches
Nortriptyline (Tricyclic antidepressant),	Levetiracetam
Imipramine (Tricyclic antidepressant),	Topiramate
Amitriptyline, (Tricyclic antidepressant),	Sodium valproate
Duloxetine,	Lacosamide
Gabapentin (anticonvulsant)	Morphine
Pregabalin (anticonvulsant)	Tramadol (this is referring to long-term use)
Intrathecal baclofen treatment (BUT only in specialised centres)	Intravenous regional sympathetic blocks (IVRSB) with guanethidine should not be used routinely
	Low-dose immunoglobulin treatment
	Treatment with lenalidomide
	Regional botulinum toxin
	Ziconotide
	Ketamine – anaesthetic, high-dose treatment (‘ketamine coma’)
	Ketamine – oral
	Memantine

	Oral phenoxybenzamine
	Analgesic cream
	Ketamine infusion combined with nerve block
	Brachial plexus analgesia

Therapeutic approaches that **ARE ENDORSED**	Therapeutic approaches that **ARE NOT ENDORSED**
Patient education and support	Anaesthetic blockade with specific agents
General exercises and strengthening	Dry needling
Mirror visual feedback	Hyperbaric oxygen therapy
Transcutaneous electrical nerve stimulation (TENS)	Local anaesthetic infusion with physiotherapy
Pacing, prioritising and planning activities	Nerve decompression
Relaxation techniques	Plasma exchange
Hydrotherapy	Combined spinal cord stimulation and intrathecal therapy
Oedema control strategies	Electroconvulsive therapy (ECT)
Self-administered tactile and thermal desensitisation with the aim of normalising touch perception	Lycra pressure garments (eg ‘second skin’ devices)
Functional activities	Motor cortex stimulation
Facilitating self-management of condition	Neurofeedback
Gait re-education	Peripheral nerve stimulation
Postural control	Surgical sympathectomy
Goal setting	
Coping skills	

Sleep hygiene	
Vocational support	
SHORT TERM Splinting	
Graded motor imagery	
Strategies to correct body perception disturbance, involving looking, touching and thinking about the affected body part	
Functional movement techniques to improve motor control and awareness of affected limb position	
Conflict allodynia re-education to reduce fear of physical contact with others in community settings	
Mental visualisation to normalise altered size and form perception of affected body part	
Principles of stress loading	
Management of CRPS-related dystonia	

Appendix S4. Recommendation codes with examples

Code	Description	Example	Accuracy category
Appropriate Endorsement (AE)	A suggestion given by a website that appropriately promotes a strategy that was 'endorsed' in any of the included General, Medicine/Supplement, or Therapeutic Recommendations.	Appropriately endorsing the importance of patient education and support in managing CRPS, which is found in the 'Endorsed' section of the Therapeutic Recommendations.	Clear accurate recommendations
Appropriate Dismissal (AD)	A suggestion given by a website that appropriately dismisses a strategy that was 'not endorsed' in any of the included General, Medicine/Supplement, or Therapeutic Recommendations.	Appropriately dismissing the use of dry needling as a therapeutic strategy in managing CRPS, which is found in the 'Not Endorsed' section of the Therapeutic Recommendations.	Clear accurate recommendations
Dismissed (DIS)	A suggestion given by a website that dismisses a strategy that was not mentioned in any of the included General, Medicine/Supplement, or Therapeutic Recommendations.	Dismissing the use of social work to help manage CRPS, which is not included in any of the Recommendations.	Clear accurate recommendations
Inappropriate Endorsement (IE)	A suggestion given by a website that inappropriately promotes a strategy that was 'not endorsed' by the recommendations.	Inappropriately endorsing the use of Morphine in managing CRPS, which is found in the 'Not Endorsed' section of the Medicine/Supplement Recommendations.	Clear inaccurate recommendations

Inappropriate Dismissal (ID)	A suggestion given by a website that inappropriately dismisses a strategy that was 'endorsed' in any of the strategies in any of the included General, Medicine/Supplement, or Therapeutic Recommendations.	Inappropriately dismissing the use of relaxation techniques as a therapeutic strategy in managing CRPS, which is found in the 'Endorsed' section of the Therapeutic Recommendations.	Clear inaccurate recommendations
Appropriate Recommendation Inappropriate Endorsement (AR+IE)	A suggestion given by a website that promotes any of the strategies mentioned in any of the included General, Medicine/Supplement, or Therapeutic Recommendations, but is inappropriately communicated or does not meet all criteria for meeting that specific recommendation.	Spinal stimulation is endorsed by the guidelines but only if additional evidence and context is given. If spinal cord stimulation is suggested but no additional information is provided the recommendation is coded as inappropriately communicated, or not meeting all criteria for that recommendation.	Clear inaccurate recommendations
Endorsed (EN)	A suggestion given by a website that promotes a strategy that was not mentioned in any of the included General, Medicine/Supplement, or Therapeutic Recommendations.	Endorsing the use of Vitamin C supplements to manage CRPS, which is not included in any of the recommendations.	Clear inaccurate recommendations
Unclear (UNC)	A suggestion given by a website that is not clearly targeted to CRPS or when a suggestion was vague or generic in the description.	A directive to "consider long term care" or pain relieving drugs without further information.	Unclear recommendations