Supplementary Online Content

Leake, HB, Moseley, GL, Stanton, TR, O'Hagan, E, Heathcote, LC. What do patients value learning about pain? A mixed-methods survey on the relevance of target concepts after pain science education

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Supplementary 6 (S6). Distribution of ratings of perceived importance of pain education concepts, from people with persistent who had have improved following a pain science-based intervention and self-report that they last saw the treating clinician <u>about 18 months ago</u> (n=35).

Supplementary 7 (S7). Distribution of ratings of perceived importance of pain education concepts, from people with persistent pain who had improved following a pain science-based intervention and self-report that they last saw the treating clinician <u>about 2 years ago</u> (n=15).

Supplementary 8 (S8). Distribution of ratings of perceived importance of pain education concepts, from people with persistent pain who had improved following a pain science-based intervention and self-report that they last saw the treating clinician <u>more than 2 years ago</u> (n=8).

This supplementary material has been provided to give readers additional information about the work.

Supplementary 1 (S1). Template for Intervention Description and Replication (TIDieR) for the pain science education intervention.

Item	Intervention group
1. Brief name: *'Provide the name or a phrase that describes the intervention.'*	Pain science education
2. Why: *'Describe any rationale, theory, or goal of the elements essential to the intervention'*	Treatment sessions are based on contemporary educational theories. The rational behind the intervention is clearly and comprehensively described elsewhere and covered in detail in Moseley & Butler [5]. The goal of pain science education is to identify conceptual models that are inaccurate and likely to be barriers to recovery, to assist the patient in learning accurate concepts that are likely to facilitate participation in best practice care – active, psychological and self-management strategies – and to promote recovery. There is a large literature on concepts that fit this description and they too have been described in detail elsewhere [5]. The practical goal is to develop and implement a tailored study program that forms the basis of, and integrates with, active, psychological and self-management skills training to promote patient-defined recovery.
3. What (Materials): *'Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g. online appendix, URL)'*	The following educational materials were used during interventions: the books Explain Pain [1], Painful Yarns [3], and The Explain Pain Handbook: Protectometer [4]; the website and accompanying video and information Tame the Beast [7], bespoke drawings.
4. What (Procedures): *'Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities.'*	The tailored nature of the intervention means that detailed description of all interventions is not feasible, however core components are described elsewhere [2; 6]. Pain education formed an initial and foundational component of intervention for all participants, but it is accurate to also say that this was part of usual care for the treating clinician. The term 'pain *science* education' is included to position the content, delivery methods and learning objectives as being based on the wide body of literature on 'explaining pain' (aka pain neuroscience education), thus it differs from other types of pain *management* education that focus on 'how to' pain coping skills, surgical matters, use of medications, 'back school' type programs. The

	intervention was 'education focussed' which denotes that all interventions were grounded in and centred around enabling and empowering patients to employ contemporary pain rehabilitation strategies, broadly involving active and psychological strategies aimed at increasing functional and physical engagement, and self-management skills. All procedures generally met criteria for educational techniques, motivational interviewing, vicarious and experiential learning, graded physical and functional exposure, pacing, relaxation, imagery and functional progression.
5. Who provided: *'For each category of intervention provider (e.g. psychologist, nursing assistant), describe their expertise, background and any specific training given.'*	The treating clinician (GLM) is a clinical physiotherapist with 28 years clinical experience. A wide range of other clinicians were also involved in working with participants towards their goals and no attempt was made to guide or monitor these interventions. However, all participating clinicians received basic training in contemporary pain science and care from the primary clinician.
6. How: *'Describe the modes of delivery (e.g. face-to-face or by some other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group.'*	Treatments were delivered either face-to-face or via telephone or video conferencing (i.e., telehealth).
7. Where: *'Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.'*	Face-to-face sessions were conducted in a consulting room, a café or a park, in Adelaide, South Australia. Telehealth consultations were conducted with the therapist in a consulting room and the patient at their home or a local clinical facility.
8. When and how much: *'Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose.'*	Treatment with the primary clinician (GLM) (i.e. the initial education and study program) involved between 1 to 6 face-to-face sessions and between 2 to 8 telephone or video calls. This variability reflects the heterogeneity in the clinical cohort.
9. Tailoring: *'If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when, and how'*	All interventions were tailored to the patient with respect to: the specific learning objectives identified by the clinician; the nature of physical and functional exposure/upgrading' the other clinicians involved in care. Tailoring of interventions was necessary as the cohort was heterogenous with respect to diagnosis, duration of

	condition, comorbidities and severity, and highly variable in how quickly the learning objectives were achieved.
10. Modifications: *'If the intervention was modified during the course of the study, describe the changes (what, why, when, and how).'*	No modifications to the treatment are reported as the intervention varied between participants (i.e. there was no set intervention).
11. How well (Planned): *'If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them.'*	Assessment of intervention adherence or fidelity was not planned. This was not a clinical effectiveness study.
12. How well (Actual): *'If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.'*	Intervention adherence or fidelity was not assessed.

Supplementary 2 (S2). List of questions included in survey
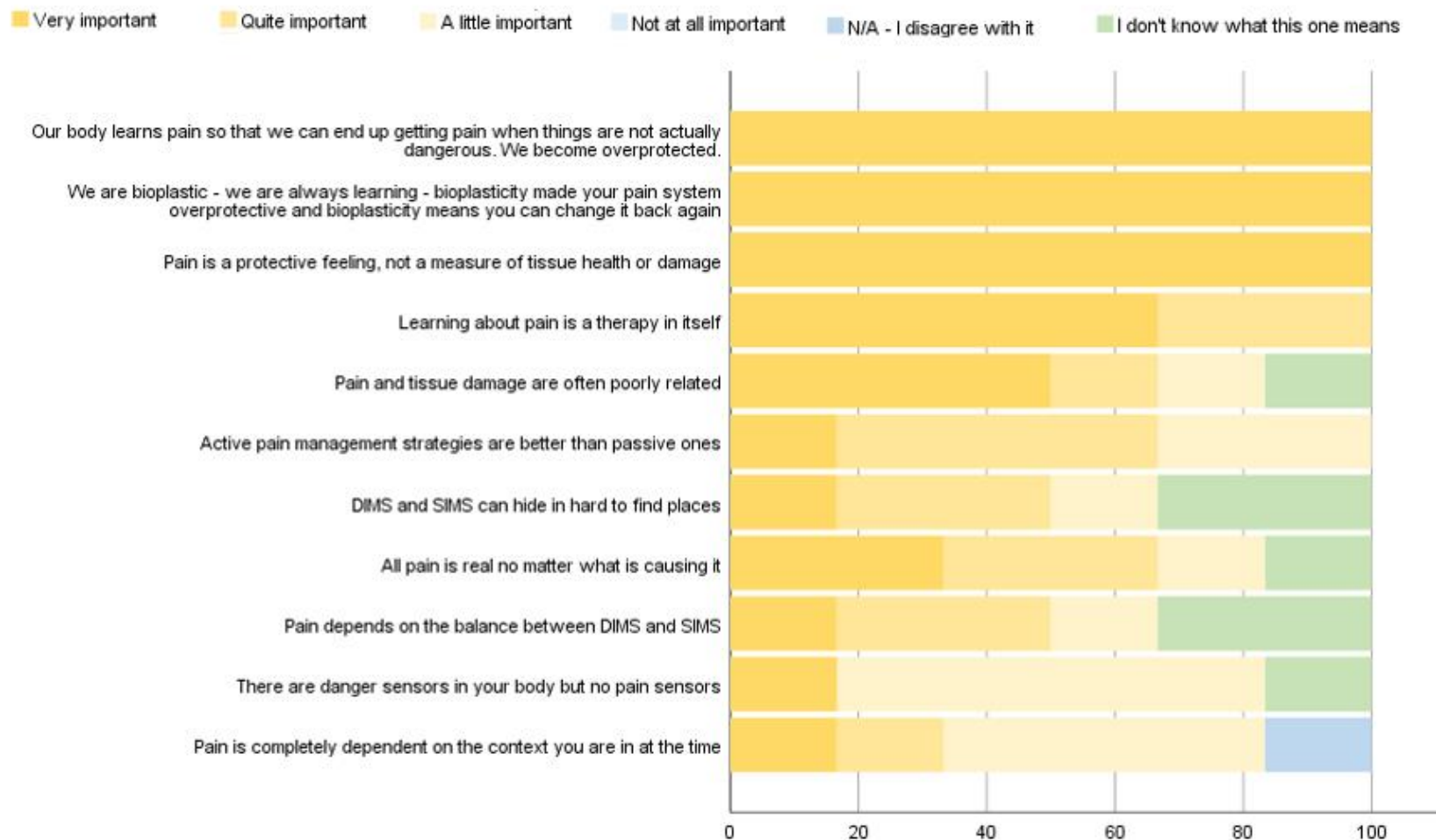
1. **How old are you?** (multiple choice: 'Under 18', '18-24', '25-34', '35-44', '45-54', '55-64', '65+')
2. **What is your gender?** (multiple choice: 'Male', 'Female', 'Rather not say')
3. **What is the highest level of school that you have completed?** (multiple choice: 'Primary school', 'Some high school', 'High school diploma', 'Some university (but no degree)', 'Bachelor's degree', 'Post-graduate degree', 'A trade'.)
4. **When you first saw [clinicians name], how long had you had your pain condition?** (multiple choice: '< 6 months', '6 - 12 months', '1 - 2 years', '3 - 5 years', '5 - 10 years', '> 10 years'.
5. **When you first saw [clinician's name], which of the following best matched your problem?** (multiple choice: 'Back pain', 'Back and leg pain', 'Back pain and widespread pain', 'Widespread pain', 'CRPS', 'Neck pain', 'Leg or foot pain', 'Arm or hand pain', 'Neck and arm pain', 'Other (please specify)'
6. **How long ago did you first see [clinicians name]?** (multiple choice: 'about 6 months ago', 'about a year ago', 'about 18 months ago', 'about 2 years ago', 'more than 2 years ago'
7. **Have you had any other medical or health intervention for your pain problem since then? If so, tick all that apply.** (multiple choice: 'Psychological therapy', 'Surgery', 'Pain management programme at a hospital', 'Online pain coaching', 'Physiotherapy', 'None', 'Other (please specify)'
8. **How are things now compared to when you first saw [clinicians name]?** (multiple choice: 'Completely better – I have recovered', 'Much better', 'Better', 'About the same', 'Worse', 'Much worse'.
9. **Why do you think you have improved?** (free format response (FFR))
10. **There are a few strategies below. Not all of them will necessarily apply to you. Please rate how important you think they are.** (Likert scale: 'not at all important'; 'a little important'; 'quite important'; 'very important'; 'N/A'
    - Understanding the biological processes that cause pain and how the body learns pain and becomes overprotective.
    - Identifying your own DIMS and SIMS
    - Retraining your overprotective pain system
    - Retraining your deconditioned body
    - Learning skills to help you cope with pain and better manage life with pain
    - Seeing a psychologist for skills specific to anxiety, depression or PTSD
11. **Now rate the same strategies in terms of how difficult they are to do.** (Likert scale: 'Easy', 'a little difficult', 'quite difficult', 'very difficult', 'N/A'.
    - Understanding the biological processes that cause pain and how the body learns pain and becomes overprotective.
    - Identifying your own DIMS and SIMS
    - Retraining your overprotective pain system
    - Retraining your deconditioned body
    - Learning skills to help you cope with pain and better manage life with pain
    - Seeing a psychologist for skills specific to anxiety, depression or PTSD
12. **Pain researchers talk about 'important pain concepts'. These are concepts or ideas that we think are important for people in pain to understand. If you had to state the most important pain concept for you, what would it be?** (FFR)

13. **Here is a list of what researchers have come up with for 'Important pain concepts'. Don't go and change your last answer because we wanted to know YOURS before you saw ours! Please rate how important these ones seem to you.** (Likert scale: 'Not at all important', 'a little important', 'quite important', 'very important', 'I don't know what this one means', 'N/A – I disagree with it'

    - There are danger sensors in your body but no pain sensors
    - Pain and tissue damage are often poorly related
    - Learning about pain is a therapy in itself
    - We are bioplastic - we are always learning - bioplasticity made your pain system overprotective and bioplasticity means you can change it back again
    - Active pain management strategies are better than passive ones
    - Our body learns pain so that we can end up getting pain when things are not actually dangerous. We become overprotected.
    - Pain is completely dependent on the context you are in at the time
    - DIMS and SIMS can hide in hard to find places
    - Pain is a protective feeling, not a measure of tissue health or damage
    - Pain depends on the balance between DIMS and SIMS
    - All pain is real no matter what is causing it.

14. **If we decide to collate everyone's responses and write a journal article about it, we will need to get ethics approval. It will help us if you tell us now whether you would be happy for your responses to be included in that paper. You cannot be identified in any way. We can't get your responses to you, nor notify you of the article happening, if it does, because we don't know who has responded to this survey and who hasn't. All that said, it is completely fine to say no to this question: Are you happy for us to include your responses in a journal article in the event we choose to write one?** (binary choice: 'yes', 'no'.)

15. **Thanks so much for taking the time to fill this out - it will be very helpful for us. I have one final question - the approach [clinician's name] takes to persistent pain is based on giving people an in depth understanding of pain, how it works and what can contribute to it, then encouraging them to take a 'biopsychosocial approach' to recovery. How likely would you be to recommend this approach to someone else?** (multiple choice: 'Very Likely', 'Likely', 'Neither Likely or Unlikely', 'Unlikely', 'Very Unlikely'

16. **Anything else you want us to know? Don't feel obliged at all, but if you would like to say anything else, here is your chance.** (FFR)
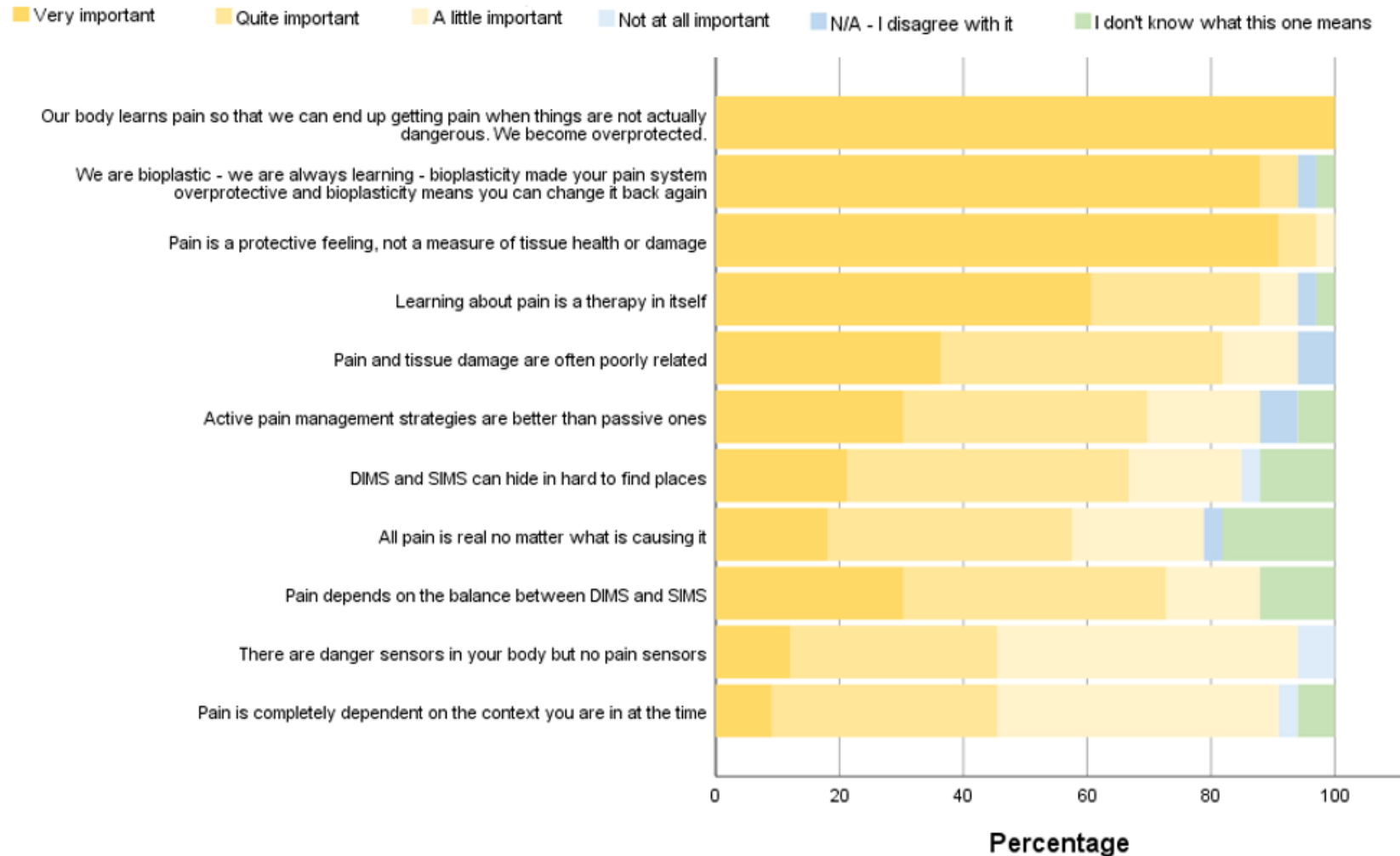
Supplementary 3 (S3). Example of thematic analysis coding procedure.

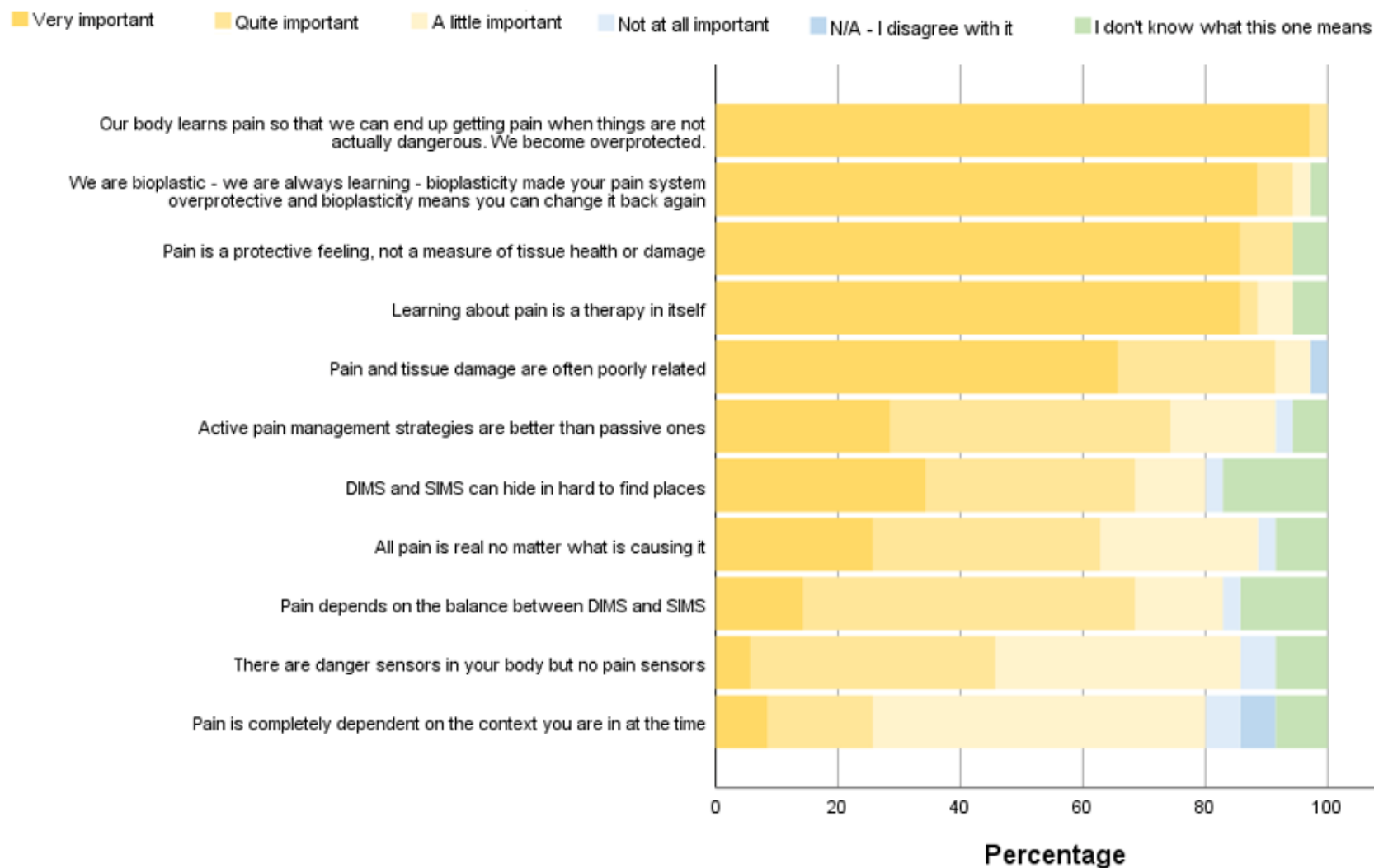| Data	Codes	Candidate theme	Theme
"Chronic pain is overprotective and you are actually safe, not in danger." (P33, neck pain)†	Pain as over reactive I can be sore but safe Pain may not indicate real danger	I can retrain my pain system	I can retrain my overprotective pain system
"The idea of training my pain back to normal makes a lot of sense and I think learning how to do that has led to my improvement so far." (P16, neck/arm pain)*	You can retrain an overprotective pain system It is okay to move despite pain	Pain protects, but can become overprotective	
"That we learn pain and that we can unlearn pain. This was the most important thing for me. I even got this put in a frame on my kitchen wall and reminded me and [partner] about it every day." (P40, back/leg pain)†	Pain adapts (pain as changeable) Hope that pain will change You can unlearn pain		

Supplementary 4 (S4). Distribution of ratings of perceived importance of pain education concepts, from people with persistent pain who had improved following a pain science-based intervention and self-report that they last saw the treating clinician <u>about 6 months ago</u> (n=6).
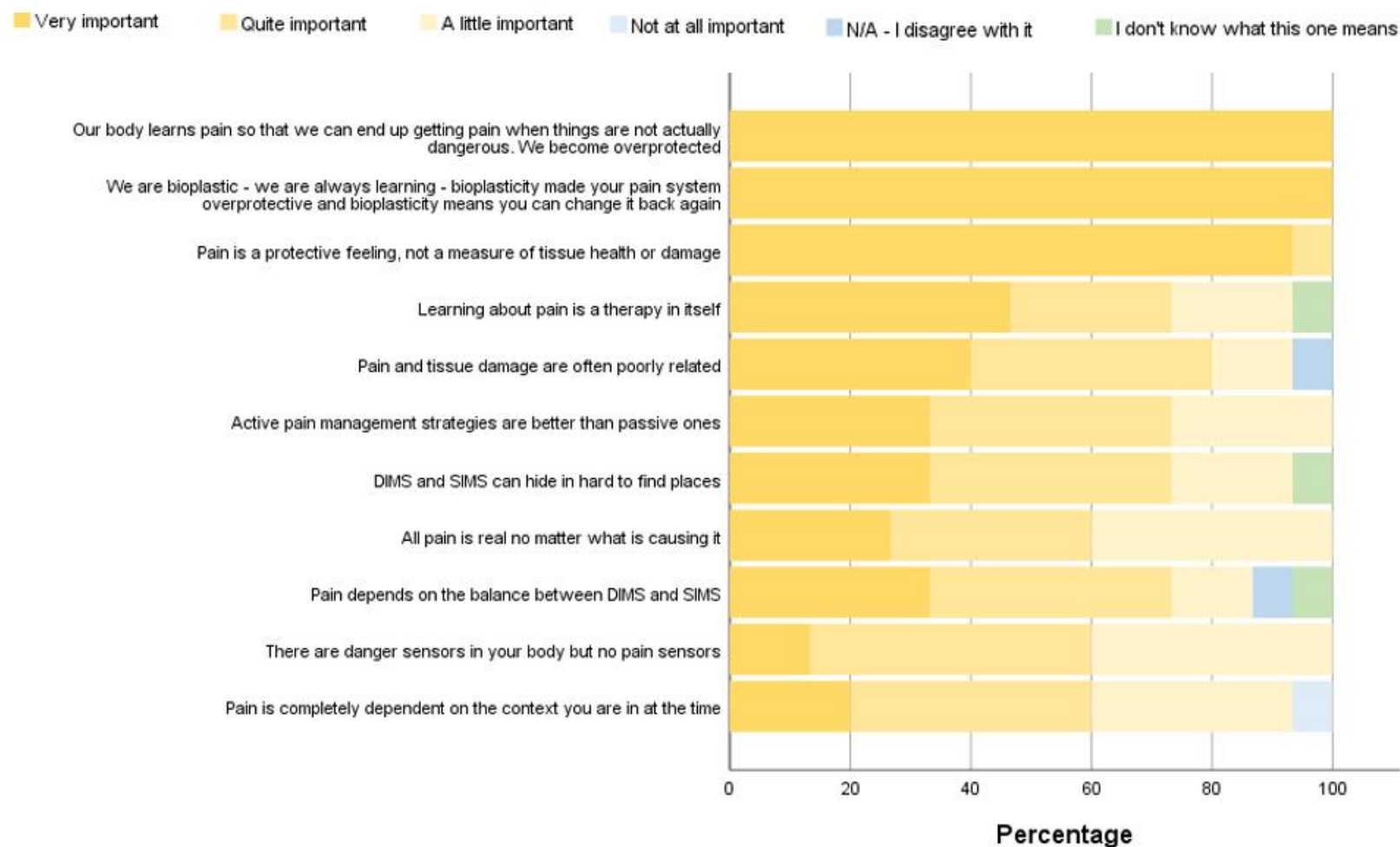
Supplementary 5 (S5). Distribution of ratings of perceived importance of pain education concepts, from people with persistent pain who had improved following a pain science-based intervention and self-report that they last saw the treating clinician <u>about one year ago</u> (n=33).
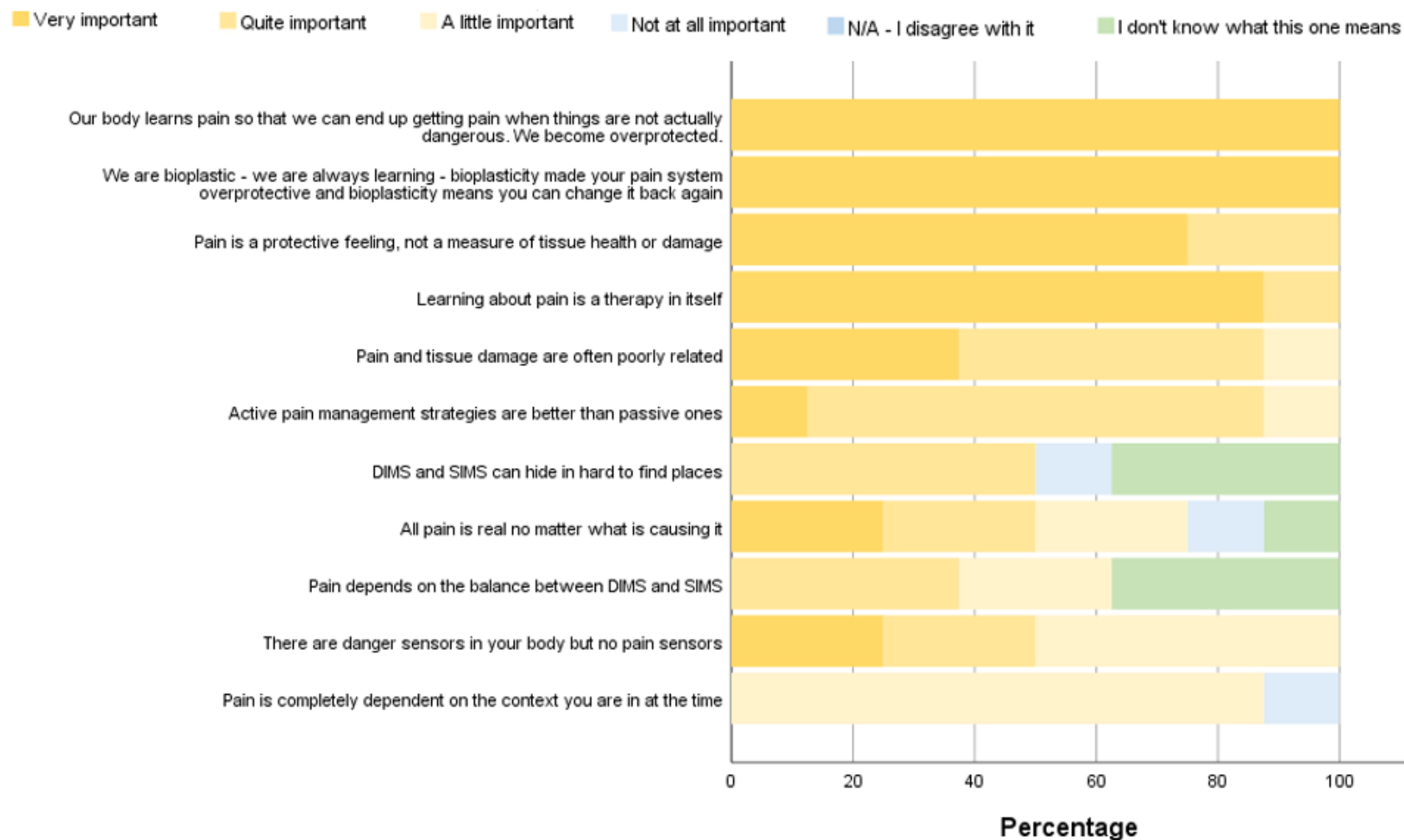
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References

[1] Butler DS, *et al.* Explain Pain. Adelaide: NOI Publications, 2013.

[2] Moseley GL. (2004) European Journal of Pain 8(1):39-45.

[3] Moseley GL. Painful Yarns: Metaphors and stories to help understand the biology of pain. Canberra: Dancing Giraffe Press, 2008.

[4] Moseley GL, *et al.* The Explain Pain Handbook: Protectometer. Adelaide: noigroup, 2015.

[5] Moseley GL, *et al.* Explain Pain Supercharged. Adelaide: Noigroup Publications, 2017.

[6] Moseley GL, *et al.* (2004) Clinical Journal of Pain 20:324-330.

[7] Tame the Beast. Tame the Beast - It's Time to Rethink Persistent Pain, 2017.