

# Making pain education better: historical underpinnings & recent innovations – a discussion paper\*.

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## Education as an intervention

Intensive education about ‘how pain works’ is perhaps one of the most significant developments in chronic pain treatment over the last 30 years. What is now being called ‘Pain science education’ (PSE) has evolved from those first trials in ‘intensive neurophysiology education’<sup>1</sup>, the content and delivery of which became widely known as ‘pain neuroscience education’<sup>2</sup> or ‘explaining pain’<sup>3</sup>. Towards the end of the 1990’s, there had emerged a vast disconnect between the scientific understanding of pain (including its protective function, its multifactorial nature, its dynamic nature over time, and the most effective ways of treating it) and the dominant understanding of ‘how pain works’ held by consumers and health professionals alike<sup>4</sup>, an understanding entrenched in an outdated overly simplistic structural pathology model.

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\*PETAL Discussion papers are peer-reviewed by other PETAL members with special attention to being in keeping with the intent of promoting better consumer outcomes and aspiring better learning in pain education. PETAL Discussion papers reflect the views of the author(s) and not necessarily the views of the PETAL Collaboration.

The initial development of intensive education as an intervention was triggered by clear evidence that the biopsychosocial model of pain and the treatments based upon it (primarily at that time cognitive behavioural therapies) made no sense to consumers, nor to most health professionals: if one understands pain to accurately reflect the state of one's tissues, then interventions that do not directly target those tissues, such as active physical and psychological therapies, will of course appear to be nonsense<sup>1,4,5</sup>. There was a risk that, when offered these interventions, consumers would feel that this implied that their pain was in some way not real. Intensive education about 'the neurophysiology of pain' therefore, aimed to give credibility to the best treatments available – active, psychological and self-management skills. It aimed to do this by providing a contemporary understanding of 'how pain works', and by so doing, give power and agency to individuals in making optimal decisions about how to go about mastering the situation in which they find themselves. Or, in more succinct and accessible labels, this new education approach aimed to *enable* and *empower* patients to adopt a biopsychosocial understanding of the problem and thereby pursue a biopsychosocially-based approach to overcoming it. One can readily see the connection between this early mission and the taglines of public-facing pain education initiatives such as Pain Revolution ([www.painrevolution.org](http://www.painrevolution.org)) – 'rethink, re-engage, recover' and Flippin' Pain ([www.flippinpain.co.uk](http://www.flippinpain.co.uk)) – 'engage, educate, empower'.

## **Earliest forms of Pain Education are beneficial**

The earliest randomised controlled trials (RCT) of this new approach to care, when compared to conventional pain education, usual care or waiting list control,<sup>a</sup> demonstrated medium to large effects on pain-related neurophysiology knowledge, and small benefits on movement-evoked pain, pain-related worry, pain-related self-efficacy, pain and disability<sup>4-6</sup>, in individuals with chronic pain. Since those trials, others have been undertaken in various countries, in various settings, and with various diagnostic groups, but the content and format have hardly changed. Over 75 clinical trials of mainly didactic education based almost exclusively on *Explain Pain*<sup>7,8</sup>, and consequent meta-analyses of those trials, have now been conducted. At best, PNE imparts small to medium clinical benefits across a range of chronic pain conditions, in a range of settings and languages<sup>9-15</sup>. Clinical opinion pieces continue to advocate this didactic approach,<sup>16,17,18</sup> presumably because, on average, RCT's tend to show the didactic approach to be mildly helpful. Perhaps, considering the added complexity, resources and time required to enhance that approach, our community has accepted it as 'good enough'. Pain education is, after all, at least as good as anything else going around, at least for chronic back pain - a recent network meta-analysis concluded that, of all the psychological interventions, 'pain education provides the most sustainable improvements',<sup>19</sup> which corroborates years of clinical guidelines that state pain education should be *frontline* care for people with chronic pain. That is, it should be the first thing we do.

## **We can, and need to, do much better**

It is one thing to argue that we *should* prioritise pain education, but another thing altogether to actually do it. Indeed, the considerable body of evidence from RCTs does not align with the common experience of pain education reported by HCPs and consumers. Significant

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<sup>a</sup> We contend that one of the first questions one should ask when a treatment effect is observed in an RCT is 'compared to what?'

limitations and barriers to implementation have emerged and, until recently, little has been done to overcome them. Many HCPs report that they have ‘tried the pain talk’ or ‘done explain pain’, but the patient ‘hasn’t bought it’ or ‘that’s not what they want’. Relevant here is a paper published in PAIN a few years ago. It presents data from a clinical audit of patients who had participated in PNE – the didactic information provision model - and then undertaken treatment consisting of ‘the best treatments we have’ – active, psychological and self-management skills training and progressive goal setting<sup>20</sup>. The paper itself was asking whether altered understanding of ‘how pain works’ reduces pain and disability by first reducing catastrophising. However, in our view, the *really interesting bits* were these:

- (i) First, at 12 month follow-up, the vast majority had done either *very* well, or had not changed at all. Those who did really well had demonstrated changes in understanding during the early stages of the intervention – when PNE was the main component of care. Those who didn’t do very well, had not shown the same early changes in understanding. So, when the learning objectives of PNE *were* achieved, patients gained excellent and sometimes transformative pain and disability-related outcomes.
- (ii) The learning objectives of PNE were only achieved in about 50% of patients. This is a clear call to arms – we need to improve our pain education offerings because at the moment we are not doing as well as we might have thought we were, and certainly not as well as we think might be possible. Remember that the health professionals delivering PNE were highly trained and very experienced, some with higher qualifications specific to pain science or management (but, importantly as it turns out, not in pain *education*). We have undertaken qualitative appraisal of patient responses to this didactic form of pain education and revealed very similar themes<sup>21–23</sup>.

## **Patients and health professionals want pain education to improve**

Consumers have clearly identified good pain education as a high care priority<sup>24</sup>, but they seldom receive good education. When we interviewed participants in a recent RCT of a pain education-based complex chronic back pain intervention, their responses told the same story: of all components of the treatment, the educational component was the most difficult; some didn’t expect nor want ‘a pain talk’; some felt invalidated by it; some ‘couldn’t understand what the health professional was going on about’<sup>25</sup>. These discoveries have added compelling arguments for us to turn our attention towards ‘Making Pain Education Better’.

HCPs themselves are also challenged. Some remain resistant to the content<sup>26</sup>; others may feel that a beneficial cognitive intervention undermines their physical rehabilitation skills. In our clinician-researcher networks across countries, HCPs consistently report that they stopped seeing pain education as a mandatory part of pain care ‘because it is too hard and most patients don’t want it’<sup>27,28</sup>.

We have also interviewed a wide range of HCPs, and monitored social media and the peer reviewed literature, for opinion or commentary pieces, to understand more deeply the concerns of HCPs about the expanding role of pain education in pain care – consensus-based clinical guidelines recommend it as frontline care, so why do some HCPs dislike it so much or not integrate it into care? Our impressions are of a diverse range of reasons, at once encouraging and troubling. The vast majority seem to recognise potential power in changing consumer understanding of ‘how pain works’ and that truly transformative outcomes become possible

when understanding of the problem is flipped from one of undetected or uncorrected pathology, to one of a ‘hypersensitive but trainable pain system’<sup>29</sup>. Many HCPs anecdotally describe their own gradual transformation from being threatened by ‘handing over agency and expertise to my patients’, to seeing powerful and enduring benefits of imparting understanding and promoting enablement and empowerment. Many describe their initial concerns about this modern approach not being compatible with their private health care financial model and a very small minority report being dismissed for implementing this modern approach because their employer sees that improved self-mastery and potential recovery means ‘patients need less treatment, which means less business’. However, some HCPs feel that PNE is invalidating, presents content that is not valid, questionable or fallacious, undermines and blames those with ongoing pain despite adopting a biopsychosocial approach, and overly devalues radiological findings and specific but uncommon diagnoses. It is easy to bask in the warmth of the praise of PNE and difficult to bear the chill of its critique. However, by maintaining a sharp focus on prioritising better *consumer* outcomes (rather than better outcomes for the rest of us in ‘the system’), *yet* understanding those who do not endorse a biopsychosocial approach or pain education as a mechanism to facilitate it, and connecting with them on our shared values and intents, it may just be possible to keep driving this field forward.

## **Health workforce capacity and the expertise gap**

HCPs with advanced qualifications or skills in treating people with chronic pain do exist, but there are not many of them relative to vast numbers of people living with chronic pain and these HCPs still report that pain education is a very difficult skill to master, despite their training. The overwhelming majority of highly trained HCPs seem to recognise the massive need for better pain education and care but, on the potential solution to this problem, they are divided. Many see the only solution is to massively increase the number of highly skilled pain-specialising HCPs, the availability of pain specialist services and intensive multidisciplinary pain management programs.

Our discussions with such experts reveal two important foundations to their position: First, they are passionate advocates for people challenged by chronic pain. We must remember that chronic pain remains stigmatised<sup>30</sup>, is poorly understood, and many with chronic pain have felt blamed or invalidated by HCPs they have encountered. It is appropriate within this context to advocate for better treatment for this group. Second, some report that providing ‘generalist’ HCPs with the resources to better treat chronic pain patients undermines their own significant investment in becoming an expert. And yet, they do not dispute that many with higher level training in pain management *still* find pain education very difficult and that better resources, to add credibility to the message, and to guide both patient and practitioner through learning experiences and activities that actually change understanding, would be invaluable. It seems reasonable to worry that a less qualified HCP will not successfully deliver education that they, a highly qualified HCP, finds difficult to do. To summarise, this group of expert HCPs seems to identify that resourcing generalist HCPs to be better pain educators, presents a significant risk to both patient and expert.

These matters present a pragmatic challenge: should we invest in the long-term process of upskilling thousands of HCPs with extensive pain management training and make specialist pain services widely available and easily accessible? Or should we invest in bringing standardised, high-quality pain education into primary care and occupational rehabilitation settings in a way that does not depend on extensive HCP training? Perhaps we should do both. The former will probably improve outcomes: multidisciplinary specialist pain services tend to

offer better outcomes for people highly challenged by chronic pain, at least when compared to usual care. The latter will probably improve outcomes too: providing primary care and occupational rehabilitation HCPs with the skills and resources to impart deep learning about 'how pain works' should result in better patient/worker outcomes. In fact, even light-touch pain education, spread widely in primary care, can be helpful – one programme had immediate impact, equating to over 25,000 patient-months of opioid use being avoided in the 22 month follow-up period.<sup>31</sup> The most parsimonious conclusion is probably that while some patients need specialist pain services, many don't, especially if, and it is a big if, we can scaffold non-specialist HCPs with the tools to deliver effective pain education.

Napkin maths points to the importance of focussing on better pain education that is *not* dependent on specialist pain HCPs. For example, In the UK approximately 28million (~44%) people live with chronic pain of whom about 7.6million (~12%) have moderate to severely disabling chronic pain<sup>32</sup>. It is estimated that in the UK there is 0.8 medical pain consultants per 100,000 population<sup>33</sup>. Similar ratios exist in Australia, for medical or allied health professionals (there are 77 Pain Revolution 'Local Pain Educators' and fewer specialist pain physiotherapists, but over 2.5m Australians with high impact chronic pain). Arguably, focusing on upskilling specialists with such ratio's will have limited impact and will not be feasible in the foreseeable future. Moreover, according to the current crop of pain specialist HCPs, they would still require tools and resources to improve their education outcomes beyond about 50% success rates.

Perhaps the only positive of the sheer volume of patients in need is that it should ease those concerns held by some specialist pain HCPs, that providing non-specialist HCPs with tools and guides to deliver effective pain education presents a risk to the role of pain experts. Specialist pain HCPs will still have more patients than they can serve; waiting lists will remain long; consumers will continue to 'wait in pain'.

## **New wave pain education programs – learning from education research**

Putting learning and education science research findings at the heart of pain education has led to transformative changes in practice in the last five or so years. These changes have been integrated into government funded clinical trials that are still underway; new strategies and resources are becoming available in HCP resources<sup>34</sup>. These changes have also led to the international Pain Education Team Aspiring Learning (PETAL) Collaboration ([www.petalcollaboration.org](http://www.petalcollaboration.org)) and are already being taught in UniSA's Professional Certificate in Pain Science and Education, a core component of Pain Revolution's Local Pain Educator (LPE) training program. Such is the vast difference between PNE and the contemporary approach, the PETAL Collaboration has renamed the contemporary approach 'Pain Science Education', in order to allow easy differentiation between the two.

'New wave' pain education programs take a constructivist approach and include active learning tasks and a range of conceptual change strategies that have been shown in over 300 meta-analyses, involving several million participants<sup>35</sup> to improve learning – the evidence is vast and compelling. The potential of applying this approach to pain education is substantial, and the logic is simple: if the didactic 'old school' pain education is beneficial, which over 75 clinical trials suggest it is, then new wave pain education is likely to be more beneficial, and more effective pain education will deliver better pain outcomes.

Notwithstanding the developments already integrated, a current focus of research and clinical innovation in pain education is to develop capacity building programs (eg Pain Revolution's LPE and Local Pain Collective programs), clinical tools and guides that will make it easier for non-specialist HCPs to foster in their clients deep learning about 'how pain works'. That HCPs are crying out for clinical tools to improve their practice has caught the eye of researchers, providers and investors alike.

One clinical tool that has gained substantial investment and is pushing outcomes forward is that of virtual reality (VR), delivering embodied, active learning experiences under the supervision of non-specialist (or specialist) primary care HCPs or occupational rehabilitation providers. VR is not new to the chronic pain space,<sup>36</sup> but utilising its unique capacity to provide learning experiences, and designing these experiences around key learning objectives identified by recovered consumers to be the most important for their recovery,<sup>37,38</sup> is a potential game changer. Author GLM has been advising one digital health company – Reality Health<sup>A</sup> – on their product, and is cautiously optimistic that delivering pain education utilising the clinical tool they have developed and clear simple HCP/rehabilitation provider and patient guides, will indeed be that game changer, particularly as access to VR technology and off-the-shelf hardware becomes more widespread. Here is the reasoning, based on the account presented above, behind GLM accepting Reality Health's invitation to be Chief Scientific Advisor during the 3-year development process:

1. Robust evidence shows that learning 'how pain works' can drastically improve pain-related outcomes.
2. In a range of other fields, embodied learning experiences delivered through VR, with guided exercises and educator guides, increase the proportion of learners who achieve learning objectives, and the depth to which they learn them.
3. There is no reason these tried and true principles should not apply to learning about pain.
4. Increasing the proportion of patients who achieve learning objectives identified by recovered consumers to be important, and the extent to which they learn them, should offer significant improvements in individual and population-level pain outcomes.
5. Developing a VR-enhanced education programme focussing on learning objectives that have emerged from extensive consumer research, should provide better outcomes, more easily and be deliverable within mainstream primary care and occupational rehabilitation settings.

## **A VR-enhanced education-only occupational rehab programme benchmarked against specialist pain services**

The first real world data are in and the cautious optimism seems at this stage well founded, although rigorous clinical trials are still in their early stages. Australian Occupational Rehabilitation provider IPAR<sup>b</sup> has devised a VR-enhanced pain education program, that is delivered by rehabilitation providers as part of a return to work plan for people off work due to

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<sup>b</sup> A reminder here that IPAR has provided a research grant to GLM to evaluate safety and acceptability of the Reality Health VR modules in Veterans, and has sponsored the 2023 Pain Revolution Rural Outreach Tour (GLM is unpaid CEO of the non-profit Pain Revolution).

chronic pain<sup>c</sup>. The program, called *Rethinking Recovery* has now graduated over 50 patients and IPAR has generously shared their outcome data, analysed by Dr Dianne Sheppard from Monash University.

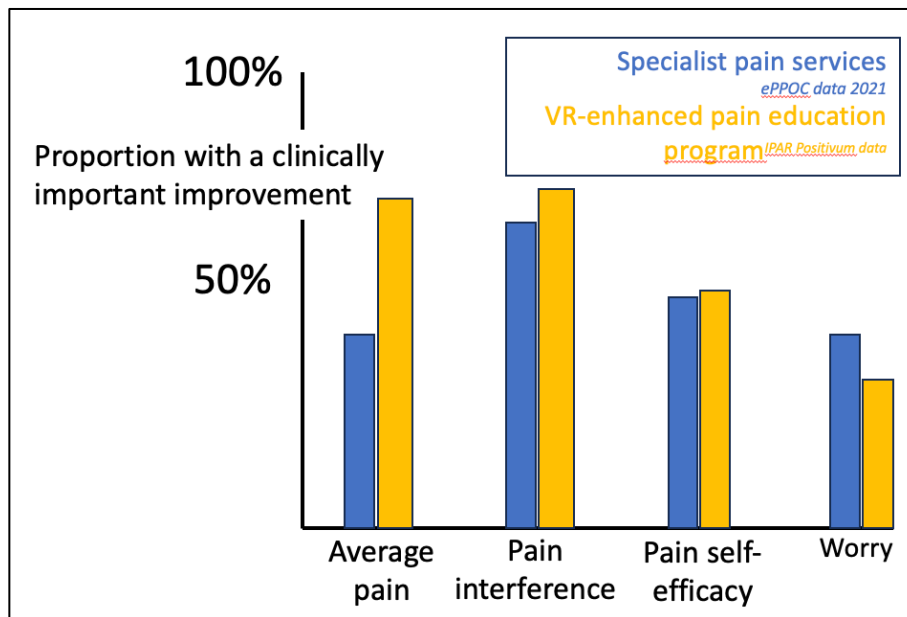
The *Rethinking Recovery* response to intervention, and proportion of participants gaining ‘good’ vs ‘bad’ outcomes, can be benchmarked against the ePPOC outcomes for Specialist Pain Services in Australia, available through the ePPOC Annual Reports<sup>39</sup> and presented in the literature.<sup>40</sup> However, there are very important baseline considerations of which we need to remain cognisant during such benchmarking:

1. The *Rethinking Recovery* programme is a VR-enhanced education intervention. It does not include CBT, group sessions, or physical or functional upgrading components; it does not involve deprescribing or medication review; it is delivered by a rehabilitation worker (at this stage also an allied health professional) who has participated in an in-house training programme provided by Pain Revolution, consisting of several online seminars and Q and A sessions. IPAR advises that a majority of the providers involved had also completed a NOIgroup weekend course on pain science and education, but none of them are titled or specialist HCPs. *Rethinking Recovery* is not a pain management programme and does not aim to be one. The focus is on attaining specific learning objectives through both immersive embodied experiences and active learning strategies. Those learning objectives were identified by recovered consumers to be most helpful for their own recovery. By attaining learning objectives, *Rethinking Recovery* aims to impart improvements in the key mediators of functional and work related outcomes: pain-related self-efficacy, pain severity and pain interference.
2. To benchmark response to *Rethinking Recovery* against specialist pain services via ePPOC data needs to consider who the patients are. On available baseline metrics such as pain-related self-efficacy, duration since onset, pain severity, interference and mood, the cohorts are similar. Importantly however, data on other common determinants of health outcomes – socioeconomic, educational attainment, minority group membership, social living situation for example<sup>41</sup> – are not available. These social determinants of health are likely to be more important in a cohort who attend a public specialist pain service than they are in the *Rethinking Recovery* cohort. A greater proportion of the *Rethinking Recovery* cohort was not working at baseline and all were compensable through workers’ compensation, income protection or motor vehicle accident schemes. The proportion of patients for whom outcome data are available was 96% for *Rethinking Recovery* and 24% for the ePPOC cohort. This suggests that the ePPOC data are likely to over-estimate outcomes because those who don’t respond are more likely to disengage from data collection. ePPOC data involve thousands of patients; these *Rethinking Recovery* data involve 53 participants – we can have more confidence that the ePPOC data are not going to change as more patients enrol than we can have in the *Rethinking Recovery* data.

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<sup>c</sup> Delivery of the *Rethinking Recovery* programme within an occupational rehabilitation setting has raised the important question ‘Is an education programme delivered, so far, by HCPs, really rehabilitation or should it be considered a ‘treatment’? Arguments for the latter include: that it is delivered by HCPs (counter arguments include - much occupational rehabilitation is delivered by HCPs and if the provider believes HCPs will gain better outcomes then surely they are entitled to use them); it provides education and most clinical care involves education (a counter argument is that most occupational rehabilitation centres on advice and education). For these reasons, we conclude *Rethinking Recovery*, delivered within the context it is, is appropriately classified as rehabilitation.

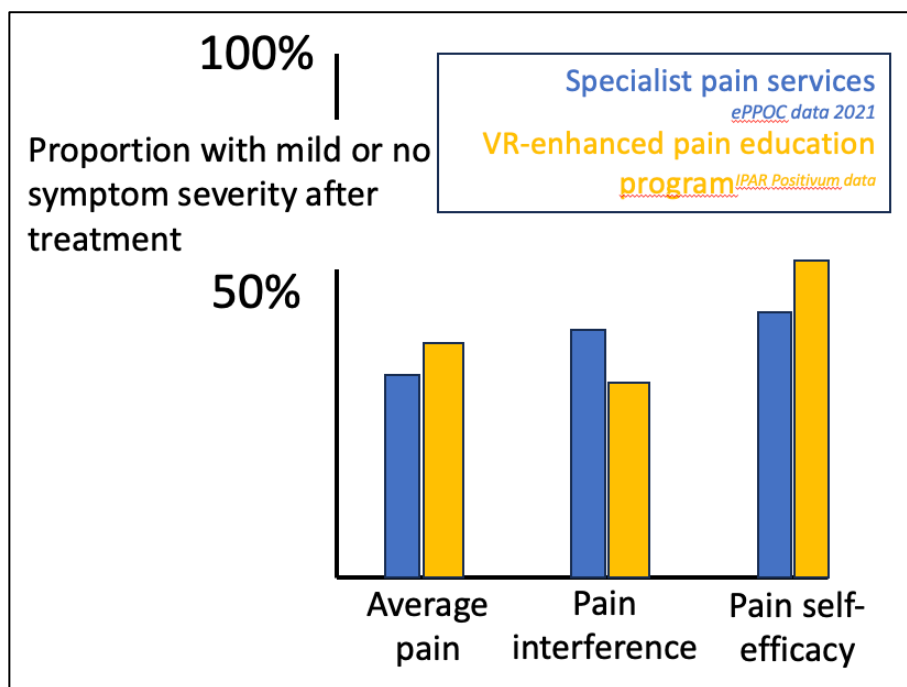
3. The *Rethinking Recovery* programme involves 10 hours intervention and the median number of hours of intervention for the ePPOC data was 26.



**Figure 1. Response to intervention**

Percentage of patients demonstrating a clinically significant improvement according to ePPOC guidelines<sup>39</sup>, from Specialist Pain Services<sup>39</sup> (blue columns) and the VR-enhanced pain education programme (yellow columns).

Brief visual inspection of these data strongly suggest that the *response* to a pain education programme (Fig. 1), consisting of VR-based embodied learning experiences and an HCP guide to promote active and deep learning, and the *outcomes* of that programme (Fig. 2), are not inferior to the *response to* and *outcomes of* specialist pain services. It is critical to not over-interpret these data however, remember that the ePPOC cohort may well represent a group of people who face more significant barriers to recovery than the *Rethinking Recovery* cohort. Also, these are real world data, not clinical trial data, so we cannot compare them as we would in a clinical trial. Real world data are very valid but generalisation, and interpretation of *why* outcomes occur, is not recommended.



**Figure 2. Outcomes of care**

Percentage of patients demonstrating a 'good' response according to Tardif et al<sup>40</sup>, from Specialist Pain Services<sup>40</sup> (blue columns) and the VR-enhanced pain education programme (yellow columns).



The key ‘take-home’ here is that a purely educational intervention – in this case the IPAR *Rethinking Recovery* occupational rehabilitation VR-enhanced pain education programme – seems to offer important clinical benefits at a fraction of the cost of specialist pain services and with a much shorter delay between referral and episode of care. One might suggest that such new wave pain education should at least be seen as an important step in the pathway of returning people with disabling chronic pain to work. It remains to be seen as to whether the *Rethinking Recovery* programme would enhance the outcomes of subsequent specialist pain services that also include group and individualised psychological therapies and physical upgrading, or whether baseline data will allow prediction of who will and won’t respond to *Rethinking Recovery*, with the latter perhaps being fast-tracked to specialist pain services. Similarly, following the *Rethinking Recovery* education programme with an activity-based physiotherapy or exercise training, with functional or work-related goal-targeted intervention, would be expected to improve these outcomes substantially, but, again, that remains to be seen. Finally, following this cohort for a year will allow statements about sustainability of clinical gains.

## Recommendations for now

Things are moving very quickly in this field, but if we are serious about driving research discoveries to better lives right now, then the available data ‘out there’ point to several actions that we can implement immediately.

1. It is imperative that HCPs do not let unfounded anxiety around ‘losing our referral base’ or ‘undermining our advanced training’ provide ANOTHER barrier to the 2.5million Australians and 7.6million Brits with high impact chronic pain gaining access to high quality pain care<sup>d</sup>. Programs such as IPARs *Rethinking Recovery* take a compelling body of evidence and build a new wave pain education intervention which, no doubt, will be reviewed, refined, and updated, as data come in. Specialist pain HCPs may need to be reassured that demand for better pain care exponentially exceeds supply of specialist pain services and that providing effective pain education more quickly has long-term social, personal and economic benefits. There is, arguably, a moral imperative to develop and implement tools that will improve pain education outcomes, especially in light of its ubiquitous place at the top of clinical guidelines-based ‘must do’ lists. The sheer scope of the problem is such that there is no genuine threat to specialist pain HCPs of us pursuing better outcomes in primary and occupational rehabilitation settings. It seems likely that the most impacted 10% or so - those with very complex, very high impact pain conditions - will need specialist pain services. However, all the evidence suggests that the other 90%, with high impact chronic pain, will greatly benefit if they can access an informed health provider who can deliver effective pain education, earlier in their clinical journey.
2. Public-facing initiatives such as Pain Revolution and Flippin’ Pain aim to ‘shift the entire bell curve’ of pain and disability outcomes by delivering ‘whole of community education’ about ‘how pain works’ and ‘how it is best prevented and treated’, and upskilling HCPs in how to bring their colleagues and communities along with them.

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<sup>d</sup> We can confidently apply similar per capita numbers to other Western democracies. This discussion paper is biased towards Australia and Britain because that is the context in which the authors are most involved.

Immediate options to reduce the personal, social and economic burden of chronic pain include: scaling up these programs; working with primary and local health networks to build HCP capacity; delivering effective public messaging campaigns that impart understanding not just around *what* are the most effective ways to prevent and treat chronic pain, but *why* they are the most effective; co-designing viable service delivery models that consider local context. All available metrics suggest that if this multiple component strategy, focussed on understanding, enablement and empowerment, shifted just 1 in 20 of those whose life is compromised by chronic pain, it would return on the investment many times over.

3. Primary care and occupational rehabilitation settings provide a golden opportunity to deliver high quality, credible, consumer-informed pain education, using strategies and frameworks that have been irrefutably proven in educational settings. HCPs report needing such clinical tools and guides to deliver better pain education. Innovations such as VR-based embodied learning programs may be a game changer. Early examples of VR-enhanced new wave education such as that being implemented in IPAR's *Rethinking Recovery* give good reason to be optimistic: pain severity, interference and pain-related self-efficacy outcomes – the most important mediators of wellbeing improvements - seem comparable to that being achieved by specialist pain services (remember the important caveats here though!), at a fraction of the time and economic investment in both HCP training and care delivery. This does not negate the need for specialist pain HCPs but it seems very likely to shift recovery trajectories for a large proportion of people challenged by chronic pain.

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