

WAITING FOR CHRONIC PAIN TREATMENT: IMPACT ON PATIENTS AND
CONSIDERATIONS FOR TERTIARY SERVICES

Anne L. J. Burke

B.A. (Hons.), M. Psych. (Clin.), Dip. Clin. Hyp.

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Declaration

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I acknowledge the support I have received for my research through the provision of an Australian Government Research Training Program Scholarship.

A.L.J. Burke:

Date: 8/11/18

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Abstract

Chronic pain (CP) is a costly, prevalent (20% of adults) and complex condition that often cannot be explained by a single medical diagnosis. Although it has been shown to impact psychological well-being, research examining this relationship has typically adopted a diagnosis-specific lens, rendering it inapplicable to most people with CP. Understanding the psychological impact of CP from a general perspective is therefore important.

The Australian public health system manages CP poorly. Most people cannot access treatment, while those who do face lengthy indefinite waits, the impact of which is unknown. Improving access to CP treatment is a health service imperative, for which resource (re)allocation and service (re)design are important considerations. However, there is no data (national, international) regarding staffing (amounts, types) that are employed within multidisciplinary pain clinics, or consensus about models of care that improve access and patient outcomes. Clarification of the impact of lengthy waitlists and these service-related factors (staffing, care model) is needed.

These issues were explored via four studies. Study 1 meta-analysed data ($N_{\text{studies}}=110$) comparing the psychological functioning of individuals with CP to that of healthy peers. A general, not condition-specific, perspective was used in order to reflect the experience of most people with CP. Results indicated that CP was associated with significant problems across a range of psychological domains; the largest being anxiety, especially pain anxiety/concern, and somatisation.

Study 2 then explored the psychological functioning and health care utilisation of individuals indefinitely waitlisted for a first appointment at a tertiary CP service by prospectively following 339 individuals for three years after referral. Findings highlighted the importance of early intervention (<6 months), especially for women, with deterioration in pain-related interference, distress and pain acceptance evident across longer-term waits; albeit with different sex-patterns.

Next, Study 3 analysed staffing configurations within Australian multidisciplinary CP services. Staffing was explored as an overall total and as a function of the amount of clinical activity

undertaken by the service, thus enabling calculation of individualised resourcing requirements. Results indicated a national consensus in the overall type and amount of staffing employed; the exceptions being psychiatry and occupational therapy. However, clinics that undertook training and research activities appeared to employ comparatively greater medical staff per patient load, while those who did not employed comparatively more allied health.

Finally, Study 4 evaluated whether a group-based pain education session — a resource neutral model designed to expedite treatment access — delivered immediately after referral to a tertiary CP service (pre-clinic) improved outcomes for waitlisted individuals ($N=346$). Despite reasonable acceptance, session attendance was not associated with functional improvements, although referral to (not treatment by) the service was.

Together, these findings suggest that CP profoundly impacts psychological well-being, especially anxiety, and this is exacerbated by lengthy indefinite waits for treatment. Accordingly, treatment should include an anxiety focus and be delivered within six months of referral. However, as staffing resources did not independently determine waitlist length, timely service delivery requires more than extra funds. Pre-clinic education can facilitate this through service factors (e.g., non-engagement), but may not improve patient outcomes.

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List of Publications

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Burke, A.L.J., Mathias, J.L., & Denson, L.A. (2018). Waiting for multidisciplinary chronic pain services: A prospective study over 2.5 years. *Journal of Health Psychology*. DOI:

10.1177/1359105317752828.

Burke, A.L.J., Denson, L.A., Mathias, J.L., & Hogg, M.N. (2015). An analysis of staffing levels and clinical activity in Australian tertiary persistent pain services. *Pain Medicine, 16* (6), 1221-

1237. DOI: 10.1111/pme.12723.

Burke, A.L.J., Denson, L.A., & Mathias, J.L. (2016). Does a brief educational session produce positive change for individuals waiting for tertiary chronic pain services? *Pain Medicine, 17*

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List of Conference Presentations

- Burke, A.L.J. (2013). *Waitlists: What's the Real Impact and Can We Manage Them Differently?*
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- Burke, A.L.J. (2018). *To Waitlist or Not to Waitlist.* Paper presented at the 3rd North American Pain School, Montebello, QC, Canada, June 24th-29th 2018.

Abbreviations

ACT:	Acceptance and Commitment Therapy
AH:	Allied Health
APS:	Australian Pain Society
BDI:	Beck Depression Inventory
BPI:	Brief Pain Inventory
BPI-PI:	Brief Pain Inventory, Pain Interference subscale
BPI-PS:	Brief Pain Inventory, Pain Severity subscale
BSI:	Brief Symptom Inventory
CBT:	Cognitive Behavioural Therapy
CI:	Confidence Interval
CP:	Chronic Pain
CPAQ:	Chronic Pain Acceptance Questionnaire
CR:	Conditioned Response
CS:	Conditioned Stimulus
DASS:	Depression Anxiety and Stress Scale
DNA:	Did Not Attend
EXP:	Experimental
FPQ-III:	Fear of Pain Questionnaire
FTE:	Full-Time Equivalent
GEE:	Generalized Estimating Equation
HADS:	Hospital Anxiety and Depression Scale
HCU:	Health care Utilisation
IASP:	International Association for the Study of Pain
K-10:	Kessler Psychological Distress Scale

MBSR:	Mindfulness-Based Stress Reduction
MDP:	Multidisciplinary Pain
N_{fs} :	Failsafe N statistic
PMGP:	Pain Management Group Programmes
PMU:	Pain Management Unit
PSEQ:	Pain Self-Efficacy Questionnaire
PSQ:	Patient Screening Questionnaire
QOL:	Quality of Life
SCL-90-R:	Revised Symptom Checklist-90
SD:	Standard Deviation
SDRS-5:	Social Desirability Response Set Scale
T:	Time
TAU:	Treatment as Usual
US:	Unconditioned Stimulus
STEPS:	Self-Training Educative Pain Sessions
WHOQOL-BREF:	World Health Organisation Quality of Life, Brief Scale
WIP:	Waiting in Pain

Preface

Context

Chronic pain (CP) is pain that persists beyond the usual period of healing and is typically characterised as occurring on most days for three or more months (Merskey & Bogduk, 1994). It affects one in five people globally and one in three older individuals (>65 years) (Blyth et al., 2001). CP is most prevalent in females (Fillingim, King, Ribeiro-Dasilva, RahimWilliams, & Riley, 2009), indigenous Australians (Vindigni, Griffen, Perkins, Da Costa, & Parkinson, 2004; Vindigni et al., 2005), Culturally and Linguistically Diverse (CALD) populations (Brand et al., 2014), and in socially disadvantaged people (McBeth & Jones, 2007; Portenoy, Ugarte, Fuller, & Haas, 2004). It is associated with a significant societal burden, including an annual economic impact of up to USD \$635 billion (Gaskin & Richard, 2013; Tracey & Bushnelly, 2009; Vos et al., 2012) and a personal impact that spans all facets of life including physical function, mood, interpersonal relationships and social connectedness (Dueñas, Ojeda, Salazar, Mico, & Failde, 2016).

Once considered to be a purely physical phenomenon, it is now understood that CP and pathology are poorly linked (Sharp, 2001). Instead, CP involves a complex interplay between physical, psychological, social and behavioural factors, which combine to determine the way a person experiences pain (Gatchel, 2004). Accordingly, multidisciplinary treatment, which addresses this broad array of factors, is now endorsed as the gold standard for the management of CP conditions (Burke et al., 2016). However, in order to access this treatment, many Australians must endure very long waitlists (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006; Breivik, Eisenberg, & O'Brien, 2013; Hogg, Gibson, Helou, DeGabriele, & Farrell, 2012; Peng et al., 2007). These waits not only delay treatment access for those who are referred, but also actively deter a range of other referrals from being placed because doctors and/or patients choose not endure them (Department for Health and Ageing, 2016). Restricted access to treatment perpetuates the cycle of disability and suffering for many people with CP. Timely access to effective treatment is critical to

help ameliorate the individual and societal impact of CP, but Australian health services are often failing to meet this need.

Problem Statement

It is important to first understand the impact of living with CP, in order to understand the impact that our current approach to service delivery has on those who are seeking treatment. Although there is clear evidence linking psychological factors with the CP experience (e.g., Jensen & Turk, 2014; Morley, Williams, & Eccleston, 2013; Williams, Eccleston, & Morley, 2012), much of the available research has defined its target population not only by the presence or absence of CP, but also by its medical diagnosis; focussing on pain associated with specific conditions such as fibromyalgia (Homann et al., 2012) or arthritis (e.g., Lerman, Smith, & Haythornthwaite, 2017). Although this research provides important insights for particular CP subgroups, many individuals do not fit into discrete diagnostic categories. Instead, the majority of people presenting for care at tertiary CP clinics do not have a clear diagnosis for their pain (Blyth, March, & Cousins, 2003) and/or experience multiple physical comorbidities (e.g., diagnosed with arthritis, chronic fatigue syndrome and chronic low back pain) (Stanos et al., 2016). The extent to which the findings from condition-specific literature can be extrapolated to this large group of people is therefore unclear, leaving clinicians ill-informed about the lived experience of many of their patients and with an inadequate evidence base to inform therapeutic interactions.

Added to this is the fact that poor treatment access has meant that many people with CP experience potentially avoidable consequences because they can't access treatment that could improve their functioning and quality of life. There are no data to demonstrate the impact of lengthy treatment delay on individual outcomes; undermining efforts to advocate for improved treatment access on grounds other than ethical concerns. Accordingly, without additional funding to increase CP services, clinicians and health care providers are faced with the extremely challenging task of redesigning services to maximise effective throughput and minimise wait-times using existing

resources. This requires a clear understanding of the amount of staffing and mix of disciplines that are required to operate a multidisciplinary CP service: data that is also not currently available. Moreover, it requires a change from a model of care that uses waitlists to funnel referrals through a focussed intake process, to one that uses new approaches to deliver earlier intervention and positively assist individuals as soon as possible after they are referred to a multidisciplinary CP service. This data is also lacking, leaving clinical services struggling and patients facing longer than ideal waits.

Aim and Scope of the Research

The aims of this project were therefore two-fold. The first was to investigate the psychological impact of CP and of waiting to access CP treatment. The second was to examine factors related to service design/delivery that are associated with health care access. Although a range of factors impact health care access, this thesis focussed on staff resourcing and a specific model of care. An understanding of staff resourcing was important because staff profiles may contribute to wait-times and thus, may underpin health care access. A pre-clinic education session was chosen as the model of care to examine because it had increasingly been adopted in varying formats in Australian pain clinics, but without adequate evidence to support this type of service reform. In addition, it involved a cost-neutral change to service delivery, which increased the likelihood that it would be used to improve clinical practice, if proven effective. The thesis focussed specifically on pain services that are delivered in tertiary settings because they are the primary providers of multidisciplinary treatment for Australians with CP. Thus, staffing was explored in tertiary public multidisciplinary services and CP was conceptualised from a general, rather than condition-specific, perspective because the majority of individuals who access Australian tertiary pain clinics fall into this category.

Significance of the Research

This project undertook to improve our clinical understanding of the issues relevant to health care delivery for individuals with CP and collect data that could usefully inform practice change to augment treatment access in this sector, recognising clear deficits in the current approaches. In doing so, it provides important data regarding the impact of long and indefinite waitlists on individuals' well-being and health care utilisation (HCU). This is critical information that can inform health care providers and policy makers about the impact of current service delivery practices on patient outcomes. This project also provides much needed data on multidisciplinary staffing profiles for tertiary CP services. The articulation of staffing profiles for tertiary CP services provides essential information to aid service planning and improve treatment access within CP services. Moreover, this project provides key data to augment clinical care, helping clinicians to understand the experiences of those with CP and providing useful information to guide therapeutic intervention and future research. Indeed, the findings from this thesis have already been actively translated to clinical practice; influencing tertiary CP service design and delivery in the state of South Australia. Data from Studies 1, 2 and 4 have informed changes to the model of care and intake processes used by the Pain Management Unit of the Royal Adelaide Hospital, while data from Study 3 enabled the calculation of staffing profiles for predicted levels of clinical activity within new and redesigned multidisciplinary CP services across the state.

Structure of the Thesis

This thesis reports the findings of a research project that involved one meta-analysis and three empirical studies. All four papers have been published in peer-reviewed journals and are presented as separate chapters (Chapters 3-6).

[Chapter 1](#) summarises the current research, theory and practice surrounding CP and its treatment. [Chapter 2](#) provides an Australian context; briefly describing the Australian health care system and discussing the challenges it poses for the effective treatment of CP, before outlining the

main research aims. Next, the four published research articles are presented ([Chapters 3 - 6](#)); each being positioned within the broader research aims by a preamble.

As indicated, the first aim of the project was to understand the psychological impact of living with CP and of waiting for treatment. Although there is a large body of literature exploring aspects of psychological functioning in the presence of CP, it had not previously been synthesised and systematically examined. This was an important first step because it provided a better understanding of the experience of people who are living with CP and therefore a more solid basis from which to contextualise any findings regarding the impact of being indefinitely waitlisted. To this end, Study 1 ([Chapter 3](#)) details a meta-analysis that examined the psychological functioning of individuals living with CP, adopting a general, rather than condition-specific, perspective. Study 2 ([Chapter 4](#)) then builds on these findings by investigating the psychological functioning and HCU of individuals indefinitely waitlisted for a first appointment at a tertiary CP service. This involved prospectively following-up 339 individuals over a three year period after their referral. Due to the longitudinal nature of this study, it was the last of the research papers to be published.

Having investigated the psychological impact of CP and of waiting to access treatment (Aim 1), this thesis sought to investigate two of the service-related factors that are associated with health care access; namely staff resourcing and the model of care that a clinic employs (Aim 2). Specifically, it sought to document staffing in Australian tertiary CP services and to examine whether providing education to individuals at the point of referral to a tertiary service could improve outcomes beyond what was achieved by treatment as usual (waitlisting individuals until a first appointment is available and then providing input). Using data that was collected as part of the Australian Pain Society 'Waiting in Pain' project, Study 3 ([Chapter 5](#)) outlines the multidisciplinary staffing profiles that are used by Australian tertiary CP services. Importantly, these profiles are presented as a function of clinical activity, facilitating the calculation of individualised resourcing requirements needed to meet patient throughput.

Next, Study 4 ([Chapter 6](#)) evaluated whether a group-based pain education session provided at the point of referral to a tertiary pain service (pre-clinic) could improve the outcomes of individuals who were waitlisted for CP treatment. This model of care was chosen because it was 'resource light', which meant that it could be adopted using existing resources and implementation was therefore not dependent upon additional funding/resources. Finally, the discussion ([Chapter 7](#)) draws together the research findings and considers the implications for clinical practice, policy and future research.

[References](#) are located at the end of the thesis in a single list, followed by supplementary materials, which are presented in separate appendices for each paper ([Appendix 1 - 4](#)). Tables and figures are numbered consecutively throughout the manuscript, and inserted at the appropriate place within each chapter.

Chapter 1 : Chronic Pain – An Introduction

1.1 Overview

In any given month, approximately 67% of adults (aged over 15 years) in Australia experience some form of physical pain (Australian Bureau of Statistics, 2012a). Although common, pain may be associated with significant levels of health impairment, disability and psychological distress, especially when chronic. Contemporary conceptualisations have seen a paradigm shift away from viewing chronic, or persistent, pain as a purely biological phenomenon, instead recognising it as a complex interplay between physical, emotional and social variables (IASP: Task Force on Taxonomy, 1994). As will be seen, this has established psychological factors as central in the understanding and treatment of the condition. This chapter begins by defining chronic pain (CP) and reviewing its epidemiology, before discussing how pain models have evolved over time. It then provides a brief historical overview of psychological approaches to CP treatment and how they have been integrated within multidisciplinary models of pain management.

1.2 Definition of Chronic Pain

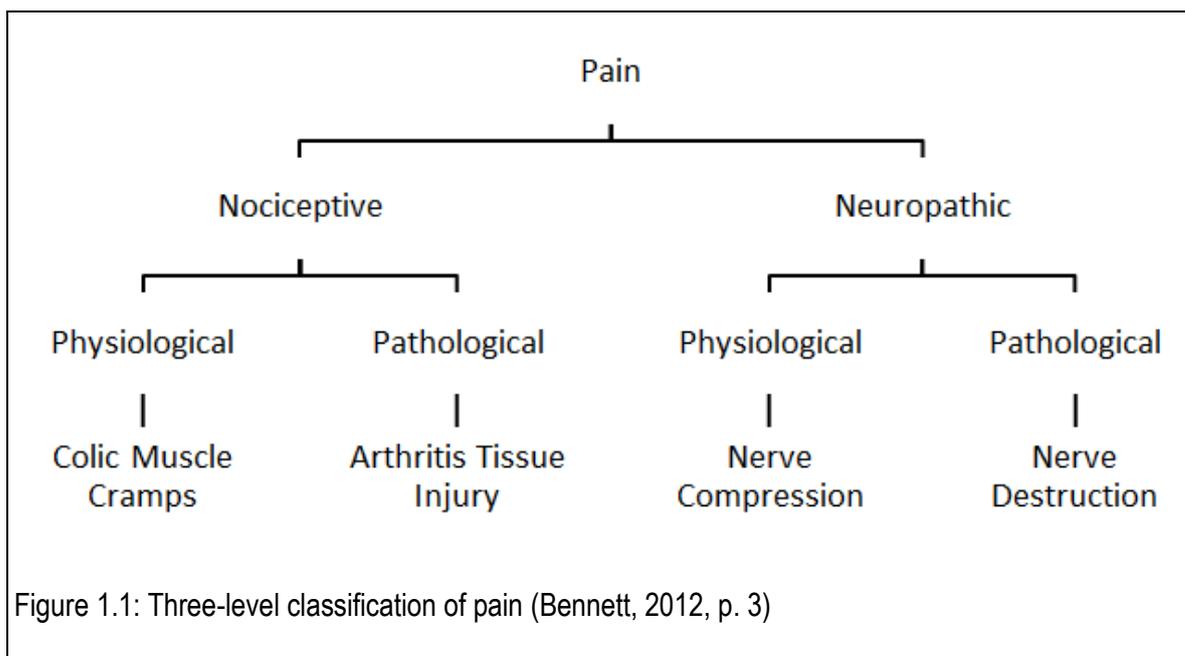
The International Association for the Study of Pain (IASP) defines pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (IASP: Task Force on Taxonomy, 1994, p. 210). In its acute form, pain has an adaptive and evolutionary function: warning a person of imminent danger, preventing or minimising physical harm and supporting recovery (Morrison, Perini, & Dunham, 2013). Acute pain typically has a clearly identified cause (commonly linked with physical injury or disease), promotes behaviour change to support healing, is often well managed with medication, and frequently remits without complication (Macintyre et al., 2010). However, pain that persists beyond the normal period of healing is not adaptive and is considered to be chronic (Bonica, 1953). This move to chronicity can occur as quickly as one month, or over longer periods, such as six or more months.

The commonly accepted definition of chronic, or persistent, pain is pain that occurs on most days in a three (or more) month period (Merskey & Bogduk, 1994). Unlike acute pain, CP can be difficult to localise and is frequently resistant to medical treatments: standard analgesics may offer little or no relief and surgical intervention may even exacerbate symptoms (Jamison, 2011). Although CP may be related to an identifiable disease process, it is often more directly related to increased sensitivity within the nervous system than it is to physical pathology (Phillips & Clauw, 2011), making definitive diagnosis difficult. The shift to chronicity therefore triggers a concurrent shift in treatment focus, away from the *curative* aims of acute pain treatment, towards functional *management* despite persistent pain (Mills, Torrance, & Smith, 2016).

Types of Pain

Medical classification of pain. Broadly speaking, pain can be medically classified at three levels: causal mechanism, type and location (see [Figure 1.1](#)). The first level classifies pain as either nociceptive or neuropathic. *Nociceptive pain* is caused by injury/damage to body tissue, or by physiological changes, such as the development of tumours or cancer cells. It is typically localised to the area of damage/injury (Hudspith, Siddall, & Munglani, 2006), associated with inflammation and frequently described as sharp, aching or throbbing pain (Dworkin, Nagasako, & Galer, 2001). *Neuropathic pain*, on the other hand, is caused by damage to, or functional changes in, the nervous system. Rooted in nerve dysfunction, descriptors such as burning, tingly, numbness or 'pins and needles' are frequently used (Johansen, 2010).

Pain can also be classified by *type*; namely normal (physiological) or abnormal (pathological) processes, and by *location*, involving small body parts (e.g., nerves, tissue, bone) (Bennett, 2012) through to larger regions (e.g., back, pelvis). This simplistic overview facilitates diagnostic pathways, explaining conditions such as diabetic neuropathy and rheumatoid arthritis (Birnbau, Pike, Banerjee, Waldman, & Cifaldi, 2012), and sanctioning labels such as chronic low back pain (Hoy et al., 2014) and pelvic pain (Tripoli et al., 2011).



Medically unexplained pain. Although some pain diagnoses are clear, others are not, partly because the link between pain and pathology is moderate, at best. In fact, pathology is not even a pre-requisite for pain to occur (Sharp, 2001), leaving an estimated 65% of individuals with no clear medical diagnosis for their pain (Blyth, March, & Cousins, 2003). In the absence of an identifiable pathology, individuals may be diagnosed with labels such as ‘undifferentiated CP’, ‘idiopathic pain’ or ‘chronic primary pain’ (Lipowski, 1990; Treede et al., 2015). Although these experiences can be readily explained by our current models of pain (refer [1.6 - The Biopsychosocial Model of Chronic Pain](#)) they are frequently, albeit inaccurately, labelled as *medically unexplained*; a term that often carries significant stigma for the individuals who live with it (Kirmayer, Groleau, Looper, & Dao, 2004).

1.3 Prevalence and Risk Factors

CP affects one in five people globally, with one in ten being newly diagnosed each year (Goldberg & McGee, 2011). This rate increases to one in two (Helme & Gibson, 2001) or three (Blyth, et al., 2001) for older individuals (>65 years). Although less prevalent, young people with CP typically report that pain interferes more with their daily activities than do older people; possibly

because they are involved in more physically demanding roles (e.g., full-time employment, parenting young children).

Clinical data additionally indicate that CP is more commonly experienced by women (20%) than men (17%) (Access Economics, 2007), and that it is associated with greater disability in women (Fillingim, et al., 2009). Women have also demonstrated lower pain thresholds and greater sensitivity to experimentally-induced pain than men (Bartley & Fillingim, 2013; Wiesenfeld-Hallin, 2005). Conversely, men report greater erosion of life satisfaction in the presence of CP and less adaption to pain over time than do women (McNamee & Mendolia, 2014). As with many sex-differences, biological, psychological and social/cultural factors are all likely to contribute to these findings (Pieretti et al., 2016).

The likelihood of experiencing CP also appears to be affected by socioeconomic status, with greater disadvantage associated with an increased prevalence of CP (McBeth & Jones, 2007). This relationship has been demonstrated using multiple indices of socioeconomic status; including income, employment status, level of education and location of residence (Portenoy, et al., 2004). The fact that many of these factors pre-date the onset of CP suggests that they may be social determinants, rather than artefacts of the CP experience. Socioeconomically disadvantaged people are also likely to experience greater pain-related disability and more comorbid chronic health conditions (e.g., diabetes, obesity) than those from more advantaged backgrounds (Everson, Maty, Lynch, & Kaplan, 2002). Lastly, CP has been linked with a number of early life events (e.g., being raised in care, death of a parent, low birth weight) that, although not exclusively a marker of socioeconomic disadvantage, are more common in disadvantaged groups (Macfarlane, 2016). Of note, the relationship between CP and socioeconomic status appears to be moderated by a number of variables, such as psychological well-being, lifestyle factors (e.g., smoking, diet) and working conditions (Bonathan, Hern, & Williams, 2013); many of which, as will be discussed, are amenable to therapeutic intervention.

The Australian Context

Consistent with international data, CP affects one in five Australians each year, or one in three older individuals (>65 years). This is particularly salient given Australia's aging population; with CP rates predicted to increase from around 3.2 million people in 2007, to 5 million in 2025 (Access Economics, 2007). International findings concerning the risk factors for CP have also been replicated in Australia. Specifically, Australian women report higher rates of CP than men (Blyth, et al., 2001) and social disadvantage (e.g. education level, income, employment status) is positively associated with the prevalence of CP in this country (Currow, Agar, Plummer, Blyth, & Abernethy, 2010). Similarly, native Australians (Aboriginal and Torres Straight Islanders) experience disproportionately high rates of CP and particularly low rates of treatment access (Vindigni, et al., 2004; Vindigni, et al., 2005), as do Culturally and Linguistically Diverse (CALD) groups (Brand, et al., 2014).

1.4 The Burden of Chronic Pain

CP is closely associated with many of the primary contributors to the global burden of disease and disability — the largest being low back pain — and frequently results in marked economic and life burden (Hoy, et al., 2014). The economic impact arises from several sources, including: decreased work productivity (Bonathan, et al., 2013), loss of employment, interference with activities of daily living, and increased rates of public health service usage (Blyth, March, Brnabic, & Cousins, 2004), surgery (e.g., estimated average of \$15,000 per lumbar operation) (Gatchel & Okifuji, 2006), absenteeism (Hoffman, Papas, Chatkoff, & Kerns, 2007), disability and medication use (Douglas, Graham, Anderson, & Rogerson, 2004). The annual economic impact of CP has been estimated to be as high as €200 billion in Europe (Tracey & Bushnelly, 2009) and USD\$560-\$635 billion in the United States of America; the latter exceeding America's annual combined costs for cancer, heart disease and diabetes (Gaskin & Richard, 2013). The life impact spans all facets of living from physical function, to mood, interpersonal relationships and social

connectedness (Dueñas, et al., 2016), which are discussed below (see section [1.6 The Biopsychosocial Model of Chronic Pain](#)).

The Australian Context

In Australia, CP is commonly associated with the two greatest contributors to overall disease burden: cancer and musculoskeletal conditions (e.g., arthritis, tendonitis, back pain) (Australian Institute of Health and Welfare, 2014). The annual cost of CP to the Australian economy was estimated to be around AUD\$34.3 billion in 2007, over half of which was borne by those individuals who were living with the condition (Access Economics, 2007). This figure increased to AUD\$55.1 billion in 2012 (Vos, et al., 2012).

1.5 Early Theories of Pain

There have been a range of theories postulated about how our bodies process pain. Originally conceptualised as a purely physical phenomena, theorists have gradually extended their models to account for an increasingly diverse range of stimuli and processing pathways. Specificity Theory and Gate Control Theory have been two of the most influential of the early theories.

Specificity Theory

First proposed by Charles Bell in the mid-1800s (Bell & Shaw, 1868), Specificity Theory postulated that each sensory modality (e.g., touch, pain, temperature) is encoded via its own unique pathway and transmitted to the relevant centre in the brain. CP was therefore defined as a purely physical phenomenon involving nociceptive (i.e., painful) sensory information that was transmitted through the body via an ascending pathway: from peripheral nerves, through the spinal cord and up to the 'pain center' in the brain (see [Figure 1.2](#)) (Moayedi & Davis, 2013). Symptomatic of an underlying physical pathology, the amount/severity of the pain was thought to be indicative of the

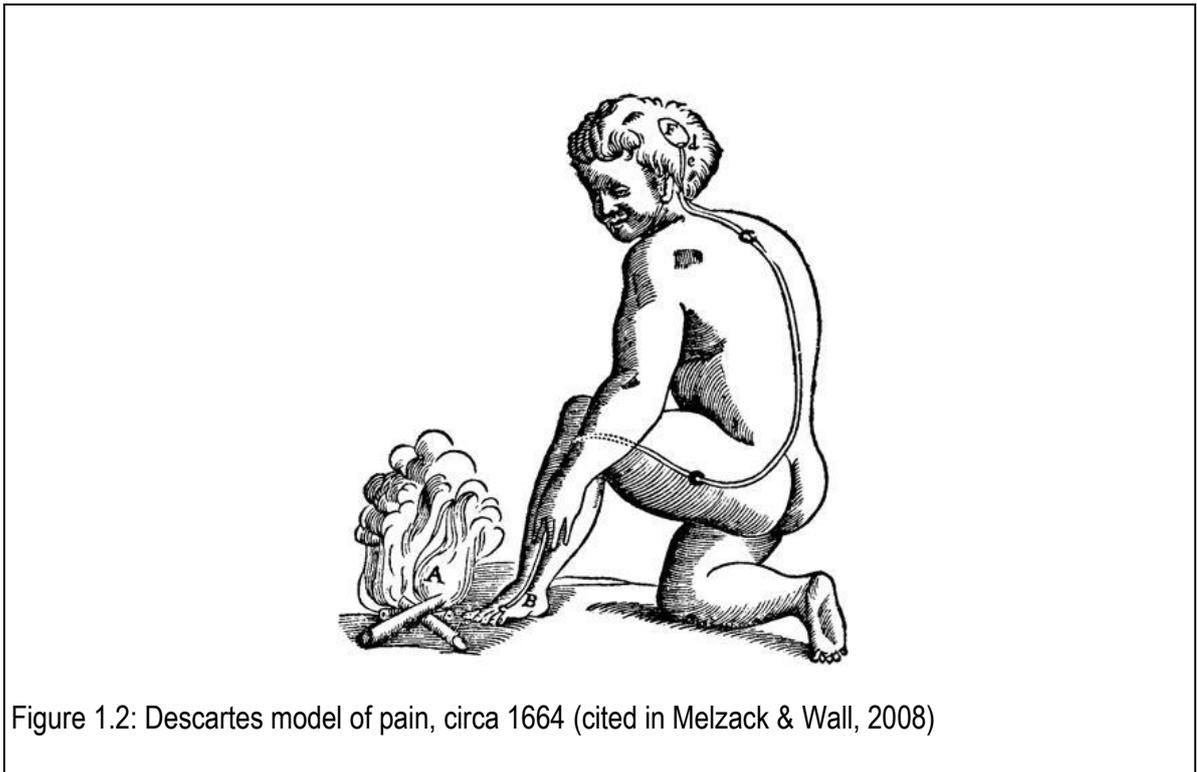


Figure 1.2: Descartes model of pain, circa 1664 (cited in Melzack & Wall, 2008)

degree of change/damage (Gatchel, Peng, Peters, Fuchs, & Turk, 2007). Thus, treatment required localising and changing/removing the underlying physical cause.

Consistent with the principles of Cartesian Dualism (refer Rene Descartes, cited in Melzack & Wall, 2008), pain was attributed to a form of psychological pathology if no physical cause was identified, leading to various diagnoses such as hysteria stemming from disordered menstruation, hypochondria, sympathetic irritability and hallucinations (Hodgkiss, 1991). In short, where pain was experienced in the absence of discernable pathology, the mind was implicated and mental illness was assumed. Although our scientific understanding of pain has evolved, the stigma of mental illness and/or questionable validity remains when pain is experienced in the absence of any clear physical pathology (Kirmayer, et al., 2004). Thus, the implication that it's 'all in your head' poses particular difficulties for a large number of individuals who are labelled as having *medically unexplained* CP (Stone, 2014).

Despite its limitations, Specificity Theory remained the dominant model for many years. However, its inability to account for pain that occurs in the absence of any identified pathology (e.g., phantom limb pain) and pain severity that is discordant with the identified pathology (e.g., psychologically traumatised war veterans), ultimately led to its downfall; being replaced in the popular view by Gate Control Theory (Melzack & Wall, 1965).

Gate Control Theory

Wall and Melzack first published their Gate Control Theory in 1965 and it dramatically changed our understanding of how pain was processed within the body. Gate Control Theory conceptualised pain as something that was *perceived* and, in doing so, made an explicit link between psychological function (perception) and the pain experience. Rather than being a product of nociceptive sensory information that was unidirectionally transmitted via an ascending pathway to the brain, pain was now also thought to be moderated by descending pathways that run from the brain through the spinal cord. In brief, Wall and Melzack (1965) postulated the operation of a neural 'gate' (see [Figure 1.3](#)), situated at the dorsal horn of the spinal cord, through which both small and large nerve fibers passed; transmitting nociceptive and non-nociceptive (non-painful: touch, temperature) sensory information respectively. The gate control system was hypothesized to operate via the substantia gelatinosa (SG), such that activity in the large fibres inhibited nociceptive transmission (closed the gate) and activity in the small fibres excited it (opened the gate). Therefore, Gate Control Theory asserted that the amount of pain experienced by a person was affected not only by the intensity of the nociceptive stimulus (small fibres), but also by the strength of any non-nociceptive information (large fibres) that was simultaneously generated at the pain site. Moreover, this theory asserted that pain was also moderated by psychological processes (thoughts and emotions), which fed back to the gate via the descending pathway, either inhibiting or exciting nociceptive transmissions (Melzack, 1999; Melzack & Wall, 1965).

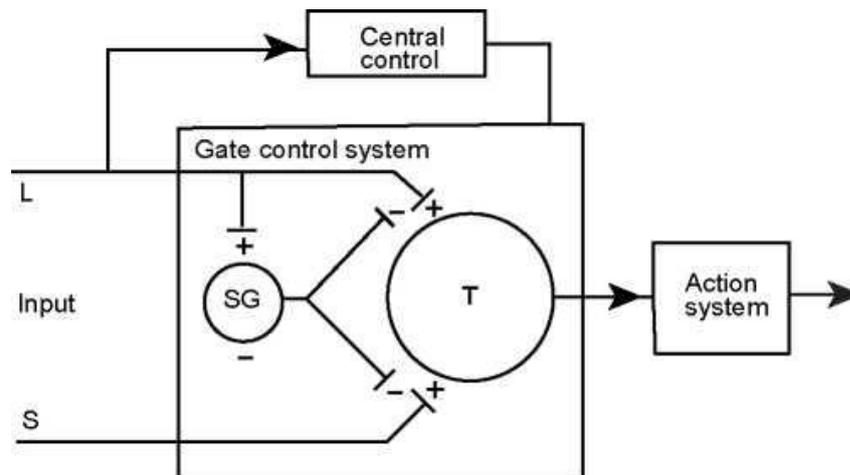


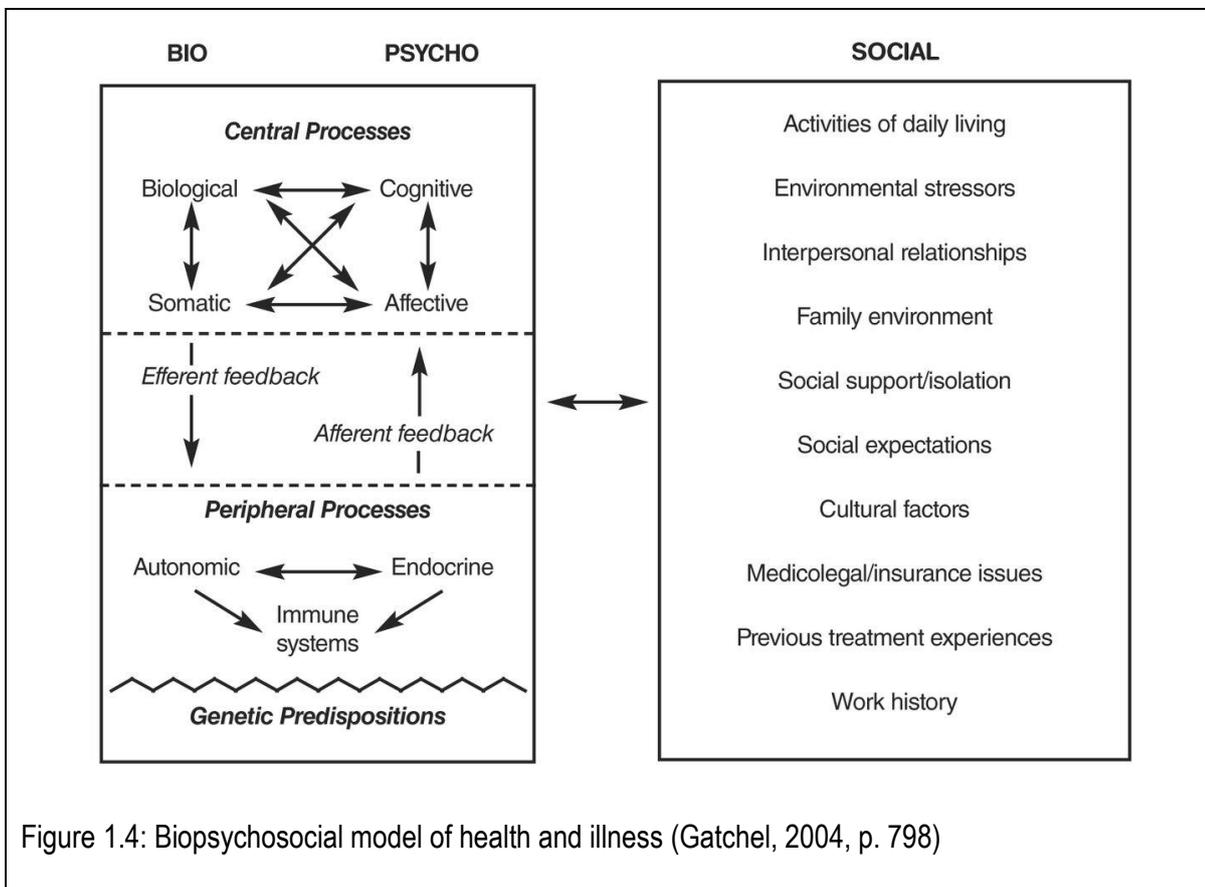
Figure 1.3: Schematic diagram of the gate control theory of pain (Melzack & Wall, 1965, p. 975). Note: L = large nerve fibers; S = small nerve fibres; SG = substantia gelatinosa; T = central transmission cells.

Gate Control Theory, therefore, better accounted for clinical phenomena that were not explained by previous models, including: the phenomenon of referred pain, the nonlinear relationship that may exist between injury and pain, fluctuating pain severity and/or locations, and the fact that pain may persist after an injury has healed (Gatchel, et al., 2007). Whereas Specificity Theory was limited to acute pain, Gate Control Theory was the first model to encompass both acute and chronic pain.

Although several of its components have since been challenged (e.g., postulated distinctions between pre- and post-synaptic function; the role of substantia gelatinosa) (Wall, 1978), Gate Control Theory generated a vast amount of research; arguably more than any previous pain theory. Thus, Wall and Melzack were highly influential in highlighting the complex interplay between physical, cognitive, emotional, behavioural and social influences; factors that form the cornerstones of the currently-used biopsychosocial model of pain (Mendell, 2014).

1.6 The Biopsychosocial Model of Chronic Pain

The more recently adopted biopsychosocial model takes a multifactorial approach to CP, treating it as a combination of both disease and illness; *disease* being the *objective* presence of physical pathology/change and *illness* referring to the *subjective* experience of symptoms and the impact of those symptoms on an individual's life (Gatchel, 2004) (see [Figure 1.4](#)). Illness is thought to be shaped by a range of psychological, social and behavioural factors within both the individual and their surrounding environment (past and present).



Since its inception (for one of the earliest conceptualisations see Loeser, 1982), the biopsychosocial model of pain has been widely adopted and advanced, drawing evidence from a range of areas. This evidence includes studies that have used functional magnetic resonance imaging (fMRI) to demonstrate a link between pain processing and the emotional and cognitive

areas of the brain (e.g., Koyama, McHaffie, Laurienti, & Coghill, 2005). It also includes psychological studies that have demonstrated links between pain, disability and other factors — such as expectations (e.g., Clay et al., 2010), quality of life, emotion (e.g., Keeley et al., 2008) and social relationships (e.g., Dueñas, et al., 2016) — and studies with a physical focus that have demonstrated an interplay between pain, emotion (e.g., fear-avoidance) and functional capacity (e.g., Ledoux, Dubois, & Descarreaux, 2012). This increased understanding of the multifactorial nature of the CP process has highlighted a range of psychological and social factors which influence how pain is *experienced* by an individual. These factors will be discussed below, prior to exploring how they are addressed by psychological approaches to the treatment of CP.

Psychological Factors

Cognition. Beliefs, or cognitions, provide a filter through which individuals interpret information (Turner, Jensen, & Romano, 2000). Individual beliefs about symptoms or circumstances have been highlighted as powerful behavioural drivers (Janz & Becker, 1984). There is now strong support for the role of cognitions in influencing the experience of CP, such that they mediate help-seeking behaviour and treatment engagement, mood, behavioural activation and coping (Turner, et al., 2000). For instance, an internal locus of control (the belief that an individual has the power to exert change) has been associated with an increased use of coping strategies and improved ratings of mood and quality of life, compared to an external locus of control (Crisson & Keefe, 1988; Skevington, 1983). Similarly, individuals who report a greater sense of control over the pain itself have been found to report lower levels of pain-related interference in their daily activities, less psychological distress and an increased use of coping strategies (Jensen, Turner, Romano, & Karoly, 1991). Conversely, repeated unsuccessful attempts to control pain can lead to a generalised sense of helplessness, which is a known risk factor for depression, disability and pain in CP samples (A. Hill, 1993; Keefe, Crisson, Urban, & Williams, 1990). In fact, helplessness has been shown to be a more powerful predictor of pain and disability than fear of pain or passive coping (e.g., avoidance,

withdrawal) (Samwel, Evers, Crul, & Kraaimaat, 2006). Beliefs about the appropriateness and/or utility of certain treatments have also been linked with treatment uptake (Jensen, et al., 1991).

In the CP context, it is important to also consider the beliefs that are held by the self and others regarding the validity of a pain condition that occurs in the absence of any discernible pathology. As noted, pain that could not be explained medically was once deemed to be psychogenic or psychopathological (e.g., “it’s all in your head”) (Hodgkiss, 1991). Although we now know that the relationship between pain and physical pathology is often tenuous, and that pain without pathology is common, this understanding has not yet fully permeated societal views (Stone, 2014). Accordingly, where a diagnosis identifies a physical cause, the condition is often *assumed* (by self and/or others) to have occurred outside of the control of the individual, whereas a diagnosis that implies a psychological basis may suggest the opposite; that it is within the individual’s control. Thus, when symptoms continue despite treatment, a medical diagnosis may offer reassurance, facilitating coping and resilience. Conversely, for those without a definitive diagnosis, treatment failure may promote anxiety and uncertainty, often leaving patients feeling blamed, judged, disbelieved or otherwise disadvantaged in both medical and social circumstances. This can foster a sense of shame and worthlessness, and a strong desire to strive for proof of legitimacy (Kirmayer, et al., 2004; Stone, 2014; Weiner, Perry, & Magnusson, 1988), impacting their experience of pain, the way that symptoms are expressed and their interactions with others (Kirmayer, et al., 2004; Nettleton, 2006).

Affect. Research has consistently demonstrated that psychological problems are common in people with CP (Dersh, Polatin, & Gatchel, 2002). The significant impact of pain on daily life and the often sub-optimal treatment outcomes can leave individuals experiencing a range of negative emotions, including depression (e.g., Bair, Robinson, Katon, & Kroenke, 2003), anxiety (general and health/pain-related) (e.g., McWilliams, Goodwin, & Cox, 2004), worthlessness, hopelessness and

anger (e.g., Fernandez & Turk, 1995). Moreover, it can result in a sense of being judged, blamed and/or overwhelmed (e.g., Stone, 2014).

Emotional distress has been linked with the CP experience in numerous ways; being variously conceptualised as a precipitant, consequence and/or perpetuating factor in the cycle of CP. As noted, affective factors have been shown to moderate pain via descending pathways; either exciting or inhibiting the transmission of nociceptive information (Melzack, 1999; Melzack & Wall, 1965). They have also been shown to impact on pain ratings (e.g., severity, tolerance), individual coping (e.g., activity level, use of coping strategies) and treatment outcomes (e.g., length of hospital stay, complication rates, treatment adherence) (Gatchel, et al., 2007). Thus, emotions influence the experience and interpretation of pain, as well as physiological pain processes.

The distinction between acute and CP is important in this context because it appears likely that the pain-emotion relationship is tied more closely to chronicity than pain onset (Banks & Kerns, 1996; Fishbain, Cutler, Rosomoff, & Rosomoff, 1997). However, the nature of the relationship between CP and emotion has proven to be complex. Psychological distress, for example, has been variously described by researchers as a formal mood disorder (e.g., major depressive disorder), a symptom (e.g., flattened affect), or a general emotional state (e.g., "I'm feeling depressed") (Broome, Saunders, Harrison, & Marwaha, 2015). Different methodologies have also been used to assess these constructs, including self-reports (e.g., psychometric questionnaires, patient reports), clinician assessments (e.g., unstructured or semi-structured clinical interviews) and/or historical information (e.g., case note reviews) (Dersh, et al., 2002). Moreover, the diagnosis of psychological problems is further complicated by the fact that the symptoms of CP and emotional distress often overlap; particularly in the case of depression. In fact, much of the early research into CP and psychological distress employed psychometric measures that focused on somatic content (e.g., BDI: Beck Depression Inventory; BAI: Beck Anxiety Inventory), potentially inflating diagnostic rates.

Similarly, the literature has tended to focus on specific pain *diagnoses*, such as neuropathic pain (Attal, Lanteri-Minet, Laurent, Fermanian, & Bouhassira, 2011) and fibromyalgia (Homann, et al., 2012); or on specific *subgroups*, such as older people (Falsarella et al., 2012) and trauma survivors (Peterlin et al., 2009), limiting its applicability to those who do not have a clear diagnosis or precipitant for their CP. Indeed, one Australian survey found that 65% of people did not have a clear medical diagnosis for their CP and 33% could not identify a clear precipitant (Blyth, March, & Cousins, 2003). CP is also associated with a large number of different medical diagnoses (e.g., whiplash, diabetes, nerve damage) (Breivik, et al., 2006), not all of which have been well-researched, and many people with CP experience a range of medical (e.g., hormonal changes, sleep disorders) and psychological comorbidities (e.g., hopelessness, stress) that are not specific to a particular CP diagnosis or subgroup. As such, it is difficult to compare rates of psychological distress between CP studies. In addition, most studies have been retrospective in nature, making it difficult to determine whether there is a causal relationship between CP and psychological distress.

Social Factors

Although the biopsychosocial model identifies a large number of social variables/factors that have the potential to impact on CP, existing research can be grouped into three main categories: interpersonal relationships, treatment-related factors and work-related factors.

Interpersonal relationships. Just as the beliefs of the individual impact on his/her response to pain, the beliefs of significant others shape how they respond to the person who is experiencing pain, thus influencing the cycle of (dis)ability (e.g., Matos, Bernardes, & Goubert, 2017; Mogil, 2017; Peat, Thomas, Handy, & Croft, 2004). For instance, overly solicitous spousal responses to pain-related behaviours have been associated with increased ratings of pain severity and decreased activity levels (Flor, Kerns, & Turk, 1987). Similarly, it has been suggested that spousal beliefs regarding functional capacity may not only mirror those of injured workers, but sometimes involve greater expectations about permanent disability than those held by the worker

him/herself; thus supporting, and potentially reinforcing, the illness role (McCluskey, Brooks, King, & Burton, 2011). Interpersonal relationships may also be eroded via other aspects of the pain-(dis)ability cycle. Behavioural withdrawal (e.g., missing social events), impaired communication (e.g., as a symptom of a negative mood state) and limited ability to plan (due to the unpredictable nature of pain) are commonly reported by individuals living with CP; while significant others (family, friends) may grapple with other issues, such as changing roles (e.g., spouse vs carer) and the impact of CP on their broader lifestyle (Dueñas, et al., 2016). Together, these factors influence the mood, cognition and behaviour of all parties, thus shaping interpersonal interactions and the way that pain is experienced within that context.

Treatment-related factors. There is considerable evidence regarding the role of iatrogenic (i.e., therapy/clinician/practitioner-induced) factors in CP. Practitioner beliefs about CP and its management influence the treatments they offer to patients and the messages they give to them about (in)appropriate responses to pain (Darlow et al., 2012; Gardner et al., 2017). Similarly, practitioner perceptions regarding the patient him/herself (e.g., motivated vs unmotivated patient) influences therapeutic interactions, with implications for assessment, case conceptualisation and treatment selection (Sharp, 2001).

Where pain exists in the absence of an identified pathology, it may be easier for practitioners to attribute inexplicable symptoms to characteristics of the patient, rather than limitations in medical science, because doing so neutralises the threat to the practitioner's competence and shifts the treatment focus to a different type of health care (i.e., from medical to psychological/psychiatric) (Kirmayer, et al., 2004). As noted, this type of pain is often associated with patient reports of disbelief and disconfirmation from treating practitioners (e.g., Stone, 2014), often leading patients to request additional scans, medical tests or interventions in a strive for legitimacy, and/or to display increasingly demonstrative behaviour during consultations (e.g., defensive, assertive, emotional behaviours). The stigma associated with *medically unexplained* pain has been linked with higher

rates of over-investigation, over-prescribing and greater psychological distress (Kouyanou, Pither, Rabe-Hesketh, & Wessely, 1998). Although intended as a strategy to improve health, this increased engagement with health care and strengthened desire to 'find a diagnosis' ultimately serves to focus a person's attention on the pain, rather than health (or wellness) behaviours, thus reinforcing the sick role (Kouyanou, et al., 1998). Moreover, it can leave practitioners feeling frustrated and/or anxious, perpetuating the cycle of poor communication, disbelief and pain behaviour (Kirmayer, et al., 2004; Stone, 2014).

Work-related factors. There is a wealth of research demonstrating that CP has a marked negative impact on work attendance, efficiency and productivity, and frequently results in early workforce withdrawal/retirement (Dueñas, et al., 2016). Moreover, participation in a workplace insurance/compensation system has been shown to negatively impact on reports of pain severity, mood and pain-related disability (e.g., Blyth, March, Nicholas, & Cousins, 2003; Rainville, Sobel, Hartigan, & Wright, 1997), and has been associated with poorer treatment outcomes (Rohling, Binder, & Langhinrichsen-Rohling, 1995). Although a detailed discussion of workplace injury and return to work is beyond the remit of this thesis, it is important to note that psychosocial factors have been highlighted as important contributors to pain and disability, and, therefore, to successful return to work (Bergbom, Flink, Boersma, & Linton, 2014; J. C. Hill et al., 2011; Nicholas, Linton, Watson, & Main, 2011). An individual's perception about the amount and type of workplace support and/or flexibility that is available to them, as well as the perceptions of their colleagues about their level of (dis)ability, have all been shown to impact workforce participation after pain onset (Brooks, McCluskey, King, & Burton, 2013; Wainwright, Wainwright, Keogh, & Eccleston, 2013).

1.7 Psychological Approaches to the Treatment of Chronic Pain

Although psychological treatments for CP may include a range of therapeutic modalities (e.g., hypnosis, biofeedback), the current discussion focuses on the three types of therapy that have

been most commonly used in this area: behavioural, cognitive and acceptance/mindfulness approaches.

Behavioural Approaches

Similar to the disease-illness distinction within the biopsychosocial model, behaviourists distinguish between nociception and the existence of a pain *problem*. In short, behavioural approaches assert that any *problem* is defined by its outwardly observable signs, such that, although nociception may occur, in the absence of any observable pain behaviour(s), there is no pain *problem* (Fordyce, 1984). Fordyce asserted that pain behaviours are susceptible to the same range of influences as other behaviours (e.g., social context, learning/conditioning, length of exposure to the stimuli); thus recognising the existence of a reciprocal relationship between the behaviours of the person with pain and factors external to the individual, each shaping and influencing the other.

Behavioural approaches are predicated on the principles of operant and classical conditioning. According to the operant model, behaviour that is followed by a reinforcing event (attainment of a positive consequence or avoidance of a negative one) will increase over time, while behaviour that is followed by a negative consequence will not (Lieberman, 1993). Classical conditioning, on the other hand, asserts that individuals learn behavioural responses (conditioned response) by the repeated pairing of a conditioned stimulus with an unconditioned stimulus; such that the conditioned stimulus begins to elicit the conditioned response independent of the unconditioned stimulus (Schneider, Palomba, & Flor, 2004). A behavioural approach to therapy therefore focuses on pain behaviours, rather than the physical condition, with clinicians seeking to identify and extinguish maladaptive contingencies (i.e., those maintaining the pain problem) and replace them with more adaptive behaviours that support wellness (Turk & Flor, 1984).

Behaviour Therapy has been widely used in the treatment of CP and has provided a solid foundation upon which other psychological approaches have been developed. In fact, behaviourists were some of the earliest advocates for physically-focussed treatments, such as relaxation training,

which continue to be used in multidisciplinary settings today (Jensen & Turk, 2014). A thorough critique of Behaviour Therapy is beyond the scope of this thesis, but recent evidence suggests that, although it has contributed to our understanding of CP treatment, it offers limited benefit as a stand-alone therapy, aside from small reductions in catastrophizing immediately after intervention (Day, Thorn, & Burns, 2012; Eccleston, Williams, & Morley, 2009).

Cognitive Approaches

An individual's cognitions, or thoughts, have increasingly been thought to play an important role in many illnesses and there is now strong support for the role of cognitions in influencing the CP experience (e.g., Jensen et al., 2002; Jensen, et al., 1991; Lamé, Peters, Vlaeyen, Kleef, & Patijn, 2005; Vlaeyen & Linton, 2012). Most of this research has adopted models focussing on appraisal, attentional bias and communal coping. The Appraisal Model asserts that an individual evaluates the potential threat of a stressor (primary appraisal) and then applies any relevant beliefs regarding perceived ability to cope (secondary appraisal), thus driving behavioural and cognitive responses (coping) (Severeijns, Vlaeyen, & van den Hout, 2004). The Attention Bias Model, on the other hand, contends that the experience of pain is increased by a heightened focus on pain-related symptoms and experiences (see Dehghani, Sharpe, & Nicholas, 2004; Schoth, Georgallis, & Liossi, 2013). Finally, the Communal Coping Model defines negative cognitive responses (e.g., catastrophizing) as coping strategies that are designed to elicit supportive responses from the surrounding community, which, when successfully applied, ultimately reinforce the pain behaviour and therefore the sick role (Sullivan et al., 2001).

All of these models are accommodated within a cognitive approach to treatment, whereby the therapeutic goal is to help individuals to understand the role of cognitions in the pain-(dis)ability cycle, identify and challenge unhelpful cognitions, and maximise the use of appropriate and helpful self-talk (Ehde & Jensen, 2010). The three cognitions that have been highlighted as particularly important therapeutic targets are catastrophizing, fear-avoidance and self-efficacy.

Catastrophizing. Catastrophizing is an exaggerated or magnified negative response to an aversive stimuli, typically associated with rumination and dire predictions for the future (Sullivan, Bishop, & Pivik, 1995, p. 524). Throughout the literature it has been operationalized in ways that have variously focussed on worry, perceptions of negative expectation, helplessness, hopelessness and coping ability. Catastrophizing has been shown to limit an individual's ability to assimilate competing information, which might discredit their expectations, because anxiety-reduction is typically achieved by avoidance (Van Damme, Crombez, & Eccleston, 2002). As such, it has been strongly linked with greater psychological distress and disability (see Quartana, Campbell, & Edwards, 2009), and reduced quality of life (Lamé, et al., 2005) and attentional capacity (Dick & Rashiq, 2007) in CP groups. Moreover, catastrophizing has been associated with poorer outcomes after some invasive medical treatments (Forsythe, Dunbar, Hennigar, Sullivan, & Gross, 2008; Samwel, Slappendel, Crul, & Voerman, 2000; van Wijk et al., 2008), longer hospital admissions, increased ratings of experimentally-induced pain (Quartana, et al., 2009), and greater medication and health service usage (Keefe, Rumble, Scipio, Giordano, & Perri, 2004).

Fear avoidance. Fear-avoidance is the catastrophic belief that activity will lead to pain and (re)injury and so should be avoided (Vlaeyen & Linton, 2000). As noted, this behavioural avoidance ensures that the opportunity to learn discordant information is also avoided, thereby eliminating the chance to challenge the belief (Van Damme, et al., 2002). Moreover, because fear-avoidance is an anxiety response, avoidance of the activity itself becomes associated with anxiety reduction. Thus, in the absence of competing information, situational avoidance reinforces future avoidance. Fear of pain has been found to be a better predictor of activity avoidance than pain severity or physical pathology, and is a key component of the disability and disuse cycle that is frequently associated with CP (Vlaeyen & Linton, 2012).

Self-efficacy. Pain self-efficacy has been defined as a belief in one's ability to perform a particular activity or to manage a particular situation in the presence of pain (Nicholas, 2007). Based

on the work of Bandura (1977), who argued that change stems from cognitive factors, a person's sense of mastery (self-efficacy) was believed to drive both the initiation of, and persistence with, coping responses. Thus, Bandura proposed that the greater a person's self-efficacy, the more effort they would exert and the longer they would persist in the face of an aversive stimuli. However, where an individual believed that a stimulus was beyond their ability to manage (poor self-efficacy), no effort was expended and the situation was avoided completely. As with other cognitions, Bandura asserted that self-efficacy beliefs were subject to change over time, shaped by experience and learning.

Pain self-efficacy has been linked with higher levels of pain tolerance and engagement in activities, lower levels of psychological distress, and better outcomes after medical and psychological treatments (Keefe, et al., 2004). Moreover, greater self-efficacy (as rated by the patient) has been associated with decreased pain- and avoidance-behaviours (Asgharia & Nicholas, 2001), and lower spousal ratings of disability (Nicholas, Wilson, & Goyen, 1992).

Cognitive behavioural therapy. It is important to include cognitive components in a therapeutic approach for the effective treatment of CP, but they are rarely used in isolation; instead being combined with behavioural approaches under a cognitive behavioural framework. Cognitive Behavioural Therapy (CBT) asserts that "an individuals' pain-related cognitions, beliefs and coping behaviours play key causal roles in determining their adjustment to pain, including psychological distress, pain-related disability and health care utilisation" (Ehde & Jensen, 2010, p. 267). As such, CBT targets cognitions, behaviours and/or social/environmental factors, resulting in varied therapeutic foci and treatment lengths. Despite this inherent variability, all CBT approaches emphasise the individual as an agent of change, promoting the importance of self-management and life-engagement in the presence of pain (Jensen & Turk, 2014).

Some of the techniques that are utilised under the CBT umbrella include relaxation training, cognitive restructuring (replacing unhelpful thoughts with more adaptive alternatives) (Traeger,

2013), behavioural activation (gradual increases in activity, designed to reduce avoidance) (Veale, 2008), activity pacing (activity regulation to facilitate adaptive goal attainment) (Nielson, Jensen, Karsdorp, & Vlaeyen, 2013), goal setting, problem solving and other coping skills training (e.g., distraction, guided imagery, psychoeducation) (Keefe et al., 1990). Although some forms of physical pathology (e.g., disc degeneration) are clearly not amenable to change via these techniques, many other aspects of the pain experience and associated comorbid conditions are (e.g., sleep disturbance, mood disturbance) (e.g., Eccleston, et al., 2009; Morley, Eccleston, & Williams, 1999). Treatment therefore frequently includes a concurrent focus on related issues, such as sleep disturbance, sexual concerns, relationships and communication, diet and nutrition, mood, and lifestyle factors (e.g., substance misuse) (Philips & Rachman, 1996).

CBT is undoubtedly the most widely researched of all psychological treatments for CP (Morley, et al., 2013). It has been shown to improve numerous patient outcomes, such as quality of life, mood, physical function, social engagement, workforce participation, pain-related interference in daily activities, pain severity, and both medication and health care usage (e.g., Castro, Daltro, Kraychete, & Lopes, 2012; Hoffman, et al., 2007; Morley, et al., 1999). However, the significance of these findings have been questioned because early studies, in particular, were plagued with issues relating to poor research designs, study quality and therapist training (e.g., used provisional or trainee psychologists) (Eccleston, et al., 2009; Williams, et al., 2012). Moreover, they tended to recruit highly restricted samples (e.g., very motivated participants who agreed to cease opioid medication and/or live away from their families for 4 weeks excepting weekends) (Peters & Large, 1990; Williams et al., 1993), such that results could not be generalised to wider clinical populations. Recent meta-analyses have also indicated that immediate post-treatment gains frequently decrease over time (Eccleston et al., 2014; Eccleston, et al., 2009; Williams, et al., 2012). Overall, the evidence suggests that CBT is moderately effective (small to medium effect sizes) for the treatment

of CP, with treatment benefits typically diminishing in the longer-term (Ehde, Dillworth, & Turner, 2014).

Acceptance and Mindfulness Approaches

Despite the widespread use and success of CBT in the management of CP, there is evidence to suggest that a specific therapeutic focus on cognitive change may not be necessary to achieve clinical improvement (McCracken & Eccleston, 2003; McCracken & Vowles, 2014; Morley, et al., 1999; Wetherell et al., 2011). In fact, it is now thought that changing the *relationship* that individuals have with their cognitions is more important than changing the *content* of those cognitions. That is, rather than needing to replace unhelpful thoughts with a more adaptive response (as per CBT), it may only be necessary to help individuals disengage from their thoughts so that they are better able to recognise them as thoughts, rather than facts (Segal, Teasdale, & Williams, 2004). This has led to a 'third wave' of psychological therapies (S. C. Hayes, Luoma, Bond, Masuda, & Lillis, 2006): acceptance and mindfulness approaches.

Just as behaviourists define a pain *problem* by the presence (or absence) of pain behaviours, acceptance and mindfulness approaches define it by the strength of an individual's *struggle* with his/her pain: the greater the struggle, the greater the distress (Dahl & Lundgren, 2006). Aversive sensations (physical, emotional, cognitive) are a normal part of the human experience, which can neither be fully controlled nor completely avoided. The more individuals are caught in an unwinnable struggle against these experiences (e.g., pain), the less opportunity they have to engage with meaningful activities; thereby increasing their suffering. Mindfulness and acceptance techniques have been shown to help reduce this struggle and, within the CP context, are most commonly used under the theoretical frameworks of Mindfulness-Based Stress Reduction (MBSR) (see Grossman, Niemann, Schmidt, & Walach, 2004) and Acceptance and Commitment Therapy (ACT) (see Dahl, Wilson, & Nilsson, 2004).

Mindfulness-based stress reduction. Founded on Buddhist teachings, MBSR focuses on improving self-regulation via the daily practice of mindfulness meditation. This form of meditation involves an active and deliberate process by which individuals learn to view their world through a detached lens, noticing aversive stimuli without trying to control them, whilst practicing self-compassion and a non-judgemental approach (Greeson & Eisenlohr-Moul, 2014). MBSR proponents assert that the detached stance of meditation allows individuals to distinguish between the physical sensations of pain and their cognitive and emotional responses to it (e.g., fear, catastrophizing) (Kabat-Zinn, 1982). This altered awareness can diminish the threat response to pain; thereby reducing suffering. Thus, unlike traditional CBT, MBSR focuses on changing an individual's *relationship* to their emotions and cognitions, rather than their content.

Acceptance and commitment therapy. ACT emphasises the use of an 'observer' stance in order to increase psychological flexibility and value-driven behaviour. Similar to MBSR, ACT encourages individuals to focus on noticing aversive experiences as they occur – without judgement or attempts to control – while continuing to behave in ways that are consistent with their values and goals (Kerns, Sellinger, & Goodin, 2011). However, unlike MBSR, ACT does not view active meditation as the primary (or even necessary) vehicle by which this occurs. Instead, the central goals of ACT are to reduce entanglement with cognitions (cognitive defusion) and foster forbearance in aversive situations by minimising avoidance and increasing tolerance for distress. Moreover, it encourages individuals to be more connected with the present moment and actively strive for value-driven goal attainment, despite the presence of pain. ACT aims to foster an individual's ability to be *flexible* in their response to aversive stimuli (psychological flexibility) and increase their *willingness* to experience pain in order to *participate* in valued pursuits (McCracken, Vowles, & Eccleston, 2004).

ACT and MBSR have both been shown to improve mood, sleep, health-related quality of life, life satisfaction, pain, disability, HCU and sick leave (see Dahl, et al., 2004; Greeson & Eisenlohr-Moul, 2014; Rosenzweig et al., 2010; Wicksell, Ahlqvist, Bring, Melin, & Olsson, 2008). However,

the outcomes for mindfulness-based approaches have been found to vary between pain conditions and the extent to which people engage with their treatment (session attendance, completion of homework); with greater engagement leading to larger improvements (Rosenzweig, et al., 2010). Overall, acceptance and mindfulness approaches have been associated with small to medium improvements, which are comparable to those achieved with traditional CBT; with ACT leading to greater improvements than MBSR (McCracken & Vowles, 2014; Veehof, Oskam, Schreurs, & Bohlmeijer, 2011).

1.8 Multidisciplinary Treatment for Chronic Pain

As the clinical understanding of pain has evolved, so too have treatment approaches and these advances have seen dedicated pain clinics become increasingly more common. Early pain clinics adopted a predominantly medical focus, mostly employing anaesthetists due to their experience with the relevant medications and procedures (e.g., nerve blocks). Contemporary services, however, take a more multidisciplinary approach, employing psychiatrists, psychologists, pharmacologists, physiotherapists and nurses who work alongside medical practitioners (Benjamin, 1989; Bonica, 1977). Models of multidisciplinary care are now widely adopted in the pain sector, but they have varying approaches to staffing and treatment across clinics and between countries. In 1990, the International Association for the Study of Pain (IASP) released guidelines regarding the optimal characteristics of pain treatment centres in a bid to address these inconsistencies (IASP: Task Force on Guidelines for Desirable Characteristics for Pain Treatment Facilities, 1990). Specifically, it was recommended that clinics employ at least three different medical or health care specialists of sufficient breadth to adequately cover the biopsychosocial aspects of CP. The centrality of psychosocial factors to the CP experience was strongly endorsed, with the guidelines also stating that, at a minimum, at least one staff member should be either a clinical psychologist or a psychiatrist.

Multidisciplinary clinics are now considered the gold standard for the management of complex CP conditions and are found in many developed countries (Scascighini, Toma, Dober-Spielmann, & Sprott, 2008). In fact, after a detailed review of the high-quality evidence regarding multidisciplinary treatment outcomes, it has been strongly recommended that individuals with intractable CP be referred to a multidisciplinary pain management program that has a solid foundation in psychological therapies (Chou et al., 2009). Such programs have been shown to markedly improve a range of individual (e.g., physical function, mood, quality of life), societal (e.g. work engagement) and health system (e.g., emergency department presentations, hospital admissions, HCU) outcomes (see Gatchel, McGeary, McGeary, & Lippe, 2014). However, despite the aspiration of using specialised pain clinics to facilitate timely access to high-quality care (Bonica, 1977), contemporary pain clinics frequently remain plagued by long waitlists, poor treatment access, inadequate funding and inconsistent models of care (Hogg, et al., 2012); the impact of which forms the focus of this thesis.

1.9 Summary

CP is a common condition that negatively impacts on the functioning and well-being of a large portion of the population (Goldberg & McGee, 2011) and carries a significant burden for the world's economy (Hoy, et al., 2014). More than a purely physical experience, CP is now understood to be a complex combination of physical, psychological, social and behavioural factors (Gatchel, 2004). There is clear evidence that psychological factors play an important role in the CP experience and that psychological interventions aid in the management of this condition (e.g., Jensen & Turk, 2014; Morley, et al., 2013; Williams, et al., 2012). However, much of the research literature is focussed on specific conditions (e.g., low back pain, arthritis), despite the fact that the majority of individuals living with CP either have no clear medical diagnosis for their pain and/or experience multiple comorbidities, thus limiting the generalizability of findings to this large group of

people. Moreover, although multidisciplinary pain clinics are now available in many developed cities, the models of care used by these clinics differ and large numbers of people with CP experience lengthy waits to access treatment (Breivik, et al., 2006; Breivik, et al., 2013; Hogg, et al., 2012; Peng, et al., 2007).

Chapter 2 : Challenges for Policy and Practice – The Australian Context

2.1 Overview

The preceding chapter provided an epidemiological and theoretical overview of CP, discussed our current understanding of the condition, and explored psychological approaches to CP management, which are central to multidisciplinary care. This chapter provides a background to the Australian health care system and discusses how CP is managed within it, before presenting the specific aims of the research that follows.

2.2 Health Care in Australia

Health care in Australia is provided by a combination of private and public services (for an overview see Duckett & Willcox, 2015). Public services are coordinated under the Medicare scheme; a government-run initiative that affords all Australian citizens and permanent residents access to free inpatient admission (hospital stay) and treatment (e.g., generalist and/or specialist treatment, medication, blood tests, imaging) at public hospitals. It also provides for a range of free, or subsidised, outpatient treatments (at public hospitals or medical clinics) with health professionals such as general practitioners, medical specialists, dentists, optometrists and allied health (Australian Bureau of Statistics, 2012b). Medicare is funded through the taxation system, primarily via an income levy that is paid by all wage earners in this country (Biggs, 2016). It is underpinned by the Medical and Pharmaceutical Benefits Schemes which are formal listings of the services/treatments (Medical Benefits Scheme) and prescriptions (Pharmaceutical Benefits Scheme) that are covered by Medicare, along with the scheduled fee that the government has determined is appropriate for each item.

Australians also access health care via private services; most commonly when treatments are not available at public clinics, when individuals want to choose their own health care provider (which is not possible in the public system), or to avoid the often lengthy waits that are frequently

associated with public clinics. However, private treatment can involve additional 'out-of-pocket' expenses because Medicare rebates are lower for services offered in private hospitals (Medicare Benefits Schedule Review Taskforce, 2015) and private fees do not need to be tied to the Medical Benefits Scheme schedule, leaving practitioners free to determine their own rates.

The costs of private health care can be partially offset by purchasing private health insurance, which itself is tiered, depending on what level of out-of-pocket expenses a person is prepared to pay. The Australian Government offers an income-tested tax rebate to partially subsidise the cost of private health insurance premiums for low to middle income earners, in a bid to increase rates of health insurance cover within the community and reduce the drain on public health services (Australian Taxation Office, 2017). Currently, around half of the Australian population is covered by private health insurance: 47% have purchased hospital (inpatient admission) cover and 56% have general outpatient (community-based care) cover (APRA, 2017). However, despite the government rebate, private insurance rates are lowest (33%) in areas of greatest social disadvantage (Australian Bureau of Statistics, 2013). Lower socioeconomic status is also associated with disproportionately higher rates of health care needs (Armstrong, Gillespie, Leeder, Rubin, & Russell, 2007) and lower levels of discretionary income. This, combined with the fact that health insurance premiums and health expenditure in Australia have almost doubled in the past decade (Australian Institute of Health and Welfare, 2014), has meant that private health care is too costly for many and so individuals are increasingly relying on the public system. Accordingly, the remainder of this thesis will focus on treatments that are provided at no cost through the public health care system.

2.3 Primary Health Care and Chronic Pain

It is estimated that more than 25% of a general practitioner's workload in Australia is CP related (Department for Health and Ageing, 2016), with individuals who have CP presenting for care

nearly five times as often as those without (Blyth, et al., 2004). CP is also associated with increased rates of emergency department presentations and hospital admissions in this country; rates that increase exponentially with increased pain-related disability (Access Economics, 2007). This is consistent with international data regarding the primary HCU of individuals with CP (Andersson, Ejlertsson, Leden, & Scherstén, 1999; Hasselstrom, Liu-Palmgren, & Rasjo-Wraak, 2002; Mantyselka et al., 2001). For the majority of Australians, their pain management remains in the primary health care setting, with less than 0.2% accessing tertiary CP services (Semple & Hogg, 2012). Despite this, Australian general practitioners who have a specialist interest in CP remain scarce (Department for Health and Ageing, 2016).

As noted, many public outpatient treatments in Australia are partially, or fully, subsidised by the Medicare scheme. However, despite the demonstrated role of psychological therapies in ameliorating the negative impact of CP and improving the lives of people who are living with it (Eccleston, et al., 2009), publicly-funded community-based psychological services are limited. Under the Medicare 'Chronic Disease Management' scheme (refer Australian Government Department of Health, 2014), individuals with chronic health conditions can access up to a *maximum of five* publicly-funded community-based *allied health sessions* per calendar year, irrespective of the allied health discipline. Although this includes psychology, evidence-based care for CP also recommends treatment from a range of other allied health professionals, such as physiotherapists (Semmons, 2016), occupational therapists (W. Hill, 2016) and dietitians (Brain et al., 2017). Five sessions of allied health treatment per calendar year is, therefore, grossly inadequate to meet the health care needs of people with CP. Moreover, the effectiveness of any intervention that is provided under this funding model may be limited by the fact that many community-based psychologists have inadequate training in the management of CP (Darnall et al., 2016; Fishman et al., 2013). Reliance on the tertiary sector therefore remains high and, as will be shown, numerous publicly-funded CP services struggle to meet demand (Hogg, et al., 2012). Consequently, many

people are never referred for tertiary service care (Department for Health and Ageing, 2016), rendering 80% of Australians with CP unable to access treatments that could improve their functioning and quality of life (Blyth, et al., 2001; National Pain Summit Initiative, 2011).

2.4 Tertiary Health Care and Chronic Pain

Multidisciplinary treatment is a widely endorsed model of care for the management of CP and is the foundation upon which tertiary CP services are designed (Pagé, Ziemianski, & Shir, 2017). Co-ordinated multidisciplinary interventions lead to a range of demonstrable clinical improvements across all three domains of the biopsychosocial model (e.g., Gatchel, et al., 2014; Guzman et al., 2001; Haldorsen et al., 2002; Nicholas, 2008). In Australia, it is estimated that there are approximately 26 public multidisciplinary CP services; with at least one in every state and territory of the nation (Hogg, et al., 2012). Although models of care vary significantly between services (National Pain Summit Initiative, 2011), they can all be classified as Level 1 centres or Level 2 clinics, because they provide interdisciplinary (integrated or co-ordinated multidisciplinary care) patient care, with Level 1 centres additionally participating in research and training activities (IASP, 2009).

With a population of over 24.7 million people (Australian Bureau of Statistics, 2018a), of which over four million are adults living with CP (Access Economics, 2007; Australian Bureau of Statistics, 2017), Australia has approximately one tertiary CP service for every 156,000 people who have the condition. This, combined with poor access to affordable evidence-based care in the community, means that the clinical demand for tertiary CP services is very high and wait-times to access treatment are typically long. Although these lengthy waits are often acknowledged by clinicians, they are grossly underestimated in the literature because the reported median waits often include individuals who have been triaged for rapid access (e.g., cancer and palliative patients). Hence, many published wait-times are in the order of seven to 231 days (Fashler et al., 2016), which

is substantially lower than the two or more years that many Australians with CP experience (Hogg, et al., 2012). The long actual wait-times experienced by many people with CP appear to be universal, with international data suggesting that waits of two years are common (Breivik, et al., 2006; Breivik, et al., 2013) and that this has extended to five years in some regions (Lynch et al., 2007).

2.5 Current Challenges for the Effective Treatment of CP in Australia

Despite the high incidence of CP and the significant burden that it places on individuals, communities and health services, access to appropriate treatment remains out of reach for many Australians. The lengthy waits associated with tertiary CP clinics have direct implications for patient outcomes; with pain duration being negatively associated with return to work rates (Mallen, Peat, Thomas, Dunn, & Croft, 2007) and increased wait-times linked with poorer patient functioning and adjustment (Fogarty & Cronin, 2008). In fact, significant deterioration in health-related quality of life and well-being has been postulated to occur even during the six months between referral and service provision (Lynch, et al., 2007). Although there is an inverse relationship between wait-time and adjustment, there are no data to identify when this deterioration becomes significant or the impact of waiting longer than six months for treatment (Lynch et al., 2008).

In fact, there is a paucity of research specifically targeting the impact of waiting for CP treatment on patient outcomes. Instead, the extant waitlist research is typically focussed on treatment efficacy, rather than waiting, and involves participants who are either waiting for a surgical/invasive procedure or who have been recruited (often via advertisements) from community settings; both of which differ from treatment-seeking individuals who have been waitlisted for public CP services. Moreover, waits for CP services are commonly ill-defined because waitlists are continually adjusted on the basis of updated clinical information and/or incoming triage demands, leaving many people with CP uncertain about when they will be able to access treatment. This uncertainty has been linked with increased psychological distress, impaired concentration and

reduced life-engagement for indefinitely waitlisted individuals (Fogarty & Cronin, 2008); factors which can, in turn, impede effective management of the condition and lead to poorer patient outcomes. Lengthy indefinite waitlists are almost universally condemned (IASP: Task Force on Wait-Times, 2010), but exactly when *long* becomes *too long* is unclear. As such, health care decision-makers are currently unable to determine the true cost of their choices regarding resource allocation or the impact of delayed treatment.

Drivers of Poor Access to Tertiary Chronic Pain Services

The limited access to evidenced-based care that is experienced by many Australians with CP may be tied to a range of factors. From a tertiary service perspective, the three most important drivers of access to treatment are the coding practices, funding models and staffing resources used by Australian public health care providers.

Funding for Australian public health services is allocated via a complex algorithm that includes diagnosis-related groups (see Independent Hospital Pricing Authority, 2017). Diagnosis-related groups are used to code a range of clinical conditions and to collate data about prevalence, length of stay, clinical outcomes, treatment costs etc. Accordingly, they drive the funding allocation and clinical focus of health services. Prior to July 2017, CP was not included in the national list of diagnosis-related groups that was used by major public health agencies (Australian Consortium for Classification Development, 2017). Instead, acute hospital presentations were coded according to the medical condition that was considered to be the primary source of the pain (e.g., cancer, arthritis), thereby overlooking the role of chronicity in the presentation (Commonwealth Department of Health and Aged Care, 1998) and poorly representing CP in Australian health data. In the absence of an established mechanism by which to drive the collection of data to articulate the full extent of the problem, CP has been frequently overlooked in major Australian health care reform agendas.

Funding of evidence-based treatment for CP is similarly problematic under the Medical Benefits Scheme. The Medical Benefits Scheme lists a range of medical procedures for the treatment of CP that the government has chosen to fund/subsidise; from imaging, through to invasive procedures (e.g., insertion of intrathecal pumps or spinal cord stimulators) and surgery (Department of Health, 2018). Although some of these procedures are congruent with current evidence regarding best-practice treatment for the management of CP, many are not. Conversely, the Medical Benefits Scheme does not currently include item numbers for a range of treatment options that are supported by the best-practice literature for CP, including multidisciplinary group programs and allied health interventions. As such, it has been suggested that the current Medical Benefits Scheme schedule inadvertently supports perverse incentives, such as tying individuals to inappropriate, but affordable, procedures and encouraging clinics/practitioners to offer treatments on the basis of remuneration (Medicare Benefits Schedule Review Taskforce, 2015).

Without data to demonstrate the extent to which CP underpins HCU and impacts treatment outcomes in this country, CP clinics will continue to struggle to secure sufficient funding to expand their services in line with clinical need. Similarly, health service expenditure for the provision of evidence-based care will remain costly until the funding schedules for treatment services are tied to best practice guidelines. A common approach to managing this tension is to align service provision with available resources; often involving strict clinical prioritization of new referrals. Although fiscally prudent for health service managers in the short-term, this approach is frequently detrimental for patients because it exacerbates waiting periods, further hampering their access to timely treatments.

An alternative approach is to tailor the available resources to clinical need. However, despite considerable evidence to inform multi-disciplinary therapeutic guidelines for CP (e.g., Chan et al., 2011; Eccleston, et al., 2009; Hassett & Williams, 2011; Louw, Diener, Butler, & Puentedura, 2011; Morley, Williams, & Hussain, 2008; Morlion, 2011), there are currently no data regarding the staffing resources that are required to effectively enact these treatments in tertiary clinical settings.

Thus, evidence-based resource design is currently not possible for these multidisciplinary CP services.

Opportunities for Improvement

Government-level improvements. The Australian Government has recognised some of the current challenges to effective health care delivery and commenced efforts to address them. The first of these involved adding CP to the national diagnosis-related groups list, effective July 2017. Public hospital coders are now tasked with ensuring that accurate CP data is collected so that it can be used to inform future health reforms. The second involved assembling a taskforce that has been charged with reviewing all Medical Benefits Scheme item numbers (> 5,700), with the aim of aligning the schedule to best-practice treatment guidelines (refer Department of Health, Australian Government <http://www.health.gov.au/internet/main/publishing.nsf/content/mbsreviewtaskforce>). Although needed, it will take time before the impact of these reforms is felt at a service level. Until then, the onus is on health care providers to do what they can to improve treatment access for individuals living with CP.

Service-level improvements. The often treatment-resistant nature of CP means clinicians may employ a management, rather than curative, approach; similar to the chronic disease models used with conditions like diabetes (Deyo, Mirza, Turner, & Martin, 2009) and heart failure (McAlister, Stewart, Ferrua, & McMurray, 2004). Models of chronic disease management are positioned within a framework of education, active self-management and health coaching from care providers, and emphasise the importance of this activity occurring within the primary health care setting (Dennis et al., 2008; Reynolds et al., 2018). Unfortunately, as noted, primary health care in Australia is not currently well-positioned to deliver this model of care and so individuals with CP are frequently left to languish on tertiary service waitlists, with little assistance available between referral and appointment. However, it has been suggested that tertiary services may be able to ameliorate this

treatment gap by providing some brief intervention to people while they are waiting for their CP clinic appointment (pre-clinic period) (Davies et al., 2011).

One of the first models of pre-clinic education to be piloted in Australia was the Self-Training Educative Pain Sessions (STEPS) model, devised by the Pain Medicine Unit at Fremantle Hospital. Briefly, STEPS is a two day (or six session/eight hour) pre-clinic group program that was designed to educate patients about contemporary understandings of pain processes and promote active self-management. Three-month follow-up data indicated that, although STEPS did not impact patient mood, it did result in significant improvements in a range of other areas for both patients (i.e., improved self-efficacy, reduced disability, impression of change, greater use of strategies) and the service (i.e., reduced wait-times, service costs and need for individual follow-up appointments, and improved attendance rates and patient satisfaction with treatment) (Davies, et al., 2011).

Numerous clinics around Australia have since incorporated pre-clinic education within routine intake processes. Although the formats differ, all are based in the principles of increasing people's understanding about pain processes and fostering active self-management. For instance, Monash Health in Victoria runs the Pain Management Pre-Clinic Education (PACE) programme (refer <http://monashhealth.org/services/services-o-z-monash-health/pain-clinic/>); a two session intervention which takes a total of 5 hours. An even briefer model is run by the Interdisciplinary Persistent Pain Centre in Queensland, where a 90 minute introductory session is offered as the first step in the Treatment Access Pathway (TAP: refer <https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=373328>). However, this initial brief session is designed to be run in conjunction with a subsequent 5 hour group education and assessment session, and consequently, is positioned as an introduction that is augmented by the later session, rather than a stand-alone education session of independent merit. A similar program is run by Hunter Integrated Pain Service in New South Wales (refer <http://www.hnehealth.nsw.gov.au/Pain/Pages/Pain.aspx>), where patients attend a 90-minute

introductory education session, followed by a 5-hour individual or group education and assessment program.

Given the lengthy wait for services that is experienced by many people with CP, the idea of brief intervention at the point of referral is compelling. However, despite considerable debate, optimal program intensity has yet to be determined for either pre-clinic or clinic interventions (British Pain Society, 2013; NSW Agency for Clinical Innovation, 2013). One suggestion is that intensity should be proportional to the degree of disability (physical and psychological) experienced by an individual, with the most disabled requiring the most intensive input. Other research, however, has indicated that even single brief education sessions can have a significant impact on the pain catastrophizing and fear (de Jong et al., 2005), physical performance (Moseley, Nicholas, & Hodges, 2004) and return to work rates (Engers et al., 2008) of individuals living with CP. Although brief education is offered by both the Interdisciplinary Persistent Pain Centre and Hunter Integrated Pain Service, the introductory sessions are positioned as part of a larger intake pathway, rather than as stand-alone sessions. Thus, neither service has examined the specific impact of brief single-session pre-clinic education on patient outcomes (Smith, Jordan, White, Bowman, & Hayes, 2016; Vandermost, 2016). As such, the clinical utility of this model has not been fully evaluated, nor have the service-related impacts of moving resources away from traditional care and, instead, investing them in pre-clinic activities.

2.6 Summary

The preceding two chapters indicate that CP is a common condition that is best conceptualised under a biopsychosocial framework. There is clear evidence linking each part of this model with the experience of CP, but the relationships are complex. For instance, although many aspects of the CP experience are physical in nature, CP frequently occurs in the absence of an identified physical pathology, leaving many individuals with no clear diagnosis for their pain.

Similarly, although emotion has been shown to influence CP, the diagnosis of psychological distress in this patient group is complicated by an overlap between the somatic symptoms of CP and psychological distress. This makes attributing causality for symptoms challenging, impacting clinical definitions of distress and the interpretation of outcomes from diagnostic tools that have a high reliance on somatic items. Moreover, the existing literature that explores the CP-psychological distress relationship has tended to focus on people who have specific pain diagnoses, despite the fact that the majority of individuals do not experience the condition in this way; instead having no clear diagnosis for their pain and/or multiple CP comorbidities (Blyth, March, & Cousins, 2003). Thus, a more global/general understanding of the psychological problems that are associated with CP is required; one that includes the majority of people with CP and better meets the needs of clinicians working with this group.

Although associated with serious economic and life impacts, CP is not well-managed within the Australian health care system. Private health care has become unaffordable for a large portion of the community and publicly-funded community-based services are insufficient to meet the needs of people who are living with CP. Less than 0.2% of Australians with CP are able to access a publicly-funded multidisciplinary service (Semple & Hogg, 2012) and, when they do, many face very long indefinite waits for treatment. Although an inverse relationship between wait-time and adjustment has been suggested, both the time-point at which clinically significant deterioration begins and the impact of waiting longer than six months are unknown (Lynch, et al., 2008). Because waits for public multidisciplinary CP treatment commonly extend well beyond six months, long-term data is needed so that health care decision-makers can determine the true cost of their choices regarding resource allocation and the impact of delayed treatment.

It is imperative that access to evidence-based treatment for CP is improved. While funding reforms have commenced in Australia, the benefits will not translate to clinical practices for some time to come. In the interim, the onus is on health service providers to explore ways that they can

increase treatment access for people with CP. Two possible mechanisms by which to achieve this aim involve resource reallocation and/or service redesign. However, it is not possible to consider reallocating resources within tertiary pain services until it is first understood what resources are currently available (amount and type of staffing). Similarly, although pre-clinic education is now being widely adopted across Australian tertiary pain services, there is no consensus regarding the optimal amount or type of education that should be offered, or indeed the impact of providing this service.

2.7 Aims of the Current Research

Given the large number of people living with CP in this country, most of whom have mixed and/or unclear diagnoses for their pain, and the fact that many of them will experience lengthy waits to access treatment in a public multidisciplinary CP clinic, it is essential that clinicians and health care decision makers improve their understanding of the impact of these wait-times on patient outcomes and actively address ways to improve access to evidence-based care. Thus, the broad aims of this research were: (a) to explore the psychological impact of living with CP and of waiting to access treatment (Studies 1 & 2); and (b) to document the existing staffing resources within Australian tertiary CP services because differences in waiting periods may be linked to differences in staffing (Study 3) and to trial a novel way of deploying existing staff resources in order to facilitate more timely service access and improve patient outcomes (Study 4).

The specific aims of this research were:

Study 1: To systematically document the psychological functioning of people living with CP from a broad, rather than diagnosis-specific, perspective in order to better inform clinical understanding of the majority of people with CP; that is, within the context of comorbidities, symptom variation and/or unclear diagnoses ([Chapter 3](#)). To this end, a meta-analysis was conducted in order to synthesise a large body of research that

has used standardised assessment tools to examine the psychological functioning of adults with CP, relative to their healthy peers. Specifically, this study: (a) compared and contrasted the psychological functioning of individuals with CP to that of healthy controls, and (b) identified those aspects of psychological well-being that were most negatively affected in people with CP.

Study 2: To investigate the impact of a long indefinite wait for treatment on the psychological adjustment and HCU of individuals with CP ([Chapter 4](#)). This involved conducting a longitudinal follow-up of over 330 people who were newly referred to a tertiary pain service. Baselines were established across a range of outcome variables (pain-related interference, pain severity, psychological distress, chronic pain acceptance, quality of life, HCU, medication impact and changes) at the point of referral and individuals were then prospectively followed-up at two months post-referral and then at six-monthly intervals until they received their first appointment. Specifically, this study examined: (a) the impact of being on a long indefinite waitlist on the psychological adjustment and HCU of individuals with CP, (b) the potential mediating role of sex in determining the impact of waiting; and (c) whether there was a critical period following which outcomes noticeably worsened.

Study 3: To describe and systematically examine staffing profiles (amount and disciplines) in Australian tertiary CP services, while taking into account the associated levels of clinical activity, in order to better understand and predict clinical resource needs, thereby providing important benchmark data to inform future service design and delivery ([Chapter 5](#)). Utilising data from the 'Waiting in Pain' survey conducted by the Australian Pain Society, this study compared staffing (medical, nursing, psychiatry, psychology, physiotherapy, occupational therapy, administrative) across tertiary CP services in Australia. The specific aims were to (a) explore state-based staffing ratios

as a function of clinical activity, (b) compare these ratios across all Australian states/territories, and (c) examine the allied health staffing requirements used by clinics to provide a pain management group program.

Study 4: To assess the ability of a brief pre-clinic intervention, delivered at the point of referral, to enhance outcomes for individuals waiting to access a tertiary CP service ([Chapter 6](#)). Using a randomised controlled design, new referrals were allocated to either a 'treatment as usual' (*TAU*: waitlist only) or 'experimental' condition (*EXP*: waitlist PLUS attendance at a three-hour educational session, delivered by a multidisciplinary team of experts). Participants were assessed at intake and followed up at two weeks and six months after attending the session (or equivalent for *TAU* group). The intervention was designed to provide individuals with information and strategies that they could utilise while waiting for their appointment and, as such, was expected to improve psychological well-being and quality of life for those who attended the session, compared with those who did not. A secondary aim was to explore the impact of waiting on these outcomes.

Chapter 3 : Chronic Pain and Psychological Functioning

3.1 Preamble

The previous review highlighted the fact that a very large number of people with CP do not have a clear diagnosis for their pain and/or experience multiple comorbidities (e.g., diagnosed with arthritis, chronic fatigue syndrome and chronic low back pain). Despite this, much of the research examining the impact of CP on psychological functioning has focused on specific conditions/diagnoses (e.g., arthritis, back pain), with the applicability of these findings to the wider CP cohort being unclear. It is therefore important to gain a better understanding of the impact of CP on the psychological functioning of this broader group.

As such, this first study meta-analysed research that had examined the psychological functioning of people living with CP and compared it to that of their healthy peers. Importantly, it took a general, rather than a diagnosis-specific, perspective in order to capture the outcomes of the majority of people with CP who are seen in tertiary pain clinics.

Tables and Figures have been inserted within the text to make it easier for the reader, but supplementary information is presented in [Appendix 1](#) at the end of this thesis. The specific contents of Appendix 1 are as follows:

- Detailed search strategies for each database ([Supplementary Table 3.A](#)),
- Summary demographic information for each of the individual meta-analysed studies ([Supplementary Table 3.B](#)),
- A list of the psychological domains and what studies examined each of these domains (and the specific test/measure that they used) ([Supplementary Tables 3.C - 3.G](#)),
- Cohen's *d* effect sizes for each psychological domain, overall and broken down by specific measure ([Supplementary Figures 3.A - 3.E](#)),

- A numbered reference list of all included studies ([Appendix 1.3](#)) that cross-references to [Supplementary Tables 3.B - 3.G](#) and,
- A copy of the published article, reproduced with permission ([Appendix 1.4](#)).

All of the references cited within this chapter are provided as part of a complete [references](#) list at the end of this thesis.

Study 1

**PSYCHOLOGICAL FUNCTIONING OF PEOPLE LIVING WITH CHRONIC
PAIN: A META-ANALYTIC REVIEW**

This chapter consists of a published paper; however copyright restrictions prevent the reproduction of this paper in its published form. The details of this publication are:

- Burke, A.L.J., Mathias, J.L., & Denson, L.A. (2015). Psychological functioning of people living with chronic pain: A meta-analytic review. *British Journal of Clinical Psychology*, 54, 345–360. DOI: 10.1111/bjc.12078.
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Statement of Authorship

Title of Paper	Psychological functioning of people living with chronic pain: A meta-analytic review
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Principal Author

Name of Principal Author (Candidate)	Anne L. J. Burke
Contribution to the Paper	All authors contributed to study inception. ALJB was solely responsible for search strategy design and execution; data extraction and coding; designing the data analysis and reporting strategy; completing data analysis; and manuscript preparation.
Overall percentage (%)	90%
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.
Signature	Date 16.10.18

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

- i. the candidate's stated contribution to the publication is accurate (as detailed above);
- ii. permission is granted for the candidate to include the publication in the thesis; and
- iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Jane L. Mathias
Contribution to the Paper	All authors contributed to study inception. JLM provided supervisory contributions to all aspects of this research including, but not limited to; discussion of search terms, coding deliberations, data interpretation and manuscript reviews.
Signature	Date 18/10/18
Name of Co-Author	Linley A. Denson
Contribution to the Paper	All authors contributed to study inception. LAD provided supervisory contributions to all aspects of this research including, but not limited to; discussion of search terms, coding deliberations, data interpretation and manuscript reviews.
Signature	Date 31/10/2018

3.2 Abstract

Objectives: Chronic pain (CP; >3 months) is a common condition that is associated with significant psychological problems. Many people with CP do not fit into discrete diagnostic categories, limiting the applicability of research that is specific to a particular pain diagnosis. This meta-analysis synthesised the large extant literature from a general CP, rather than diagnosis-specific, perspective in order to systematically identify and compare the psychological problems most commonly associated with CP.

Methods: Four databases were searched from inception to December 2013 (PsychInfo, Cochrane, Scopus, PubMed) for studies comparing the psychological functioning of adults with CP to healthy controls. Data from 110 studies were meta-analysed and Cohen's *d* effect sizes calculated.

Results: The CP group reported experiencing significant problems in a range of psychological domains (depression, anxiety, somatisation, anger/hostility, self-efficacy, self-esteem and general emotional functioning), with the largest effects observed for pain anxiety/concern and somatisation; followed by anxiety and self-efficacy; then depression, anger/hostility, self-esteem and general emotional functioning.

Conclusions: This study demonstrates, for the first time, that individuals with CP are more likely to experience physically-focussed psychological problems than other psychological problems and that, unlike self-efficacy, fear of pain is intrinsically tied to the CP experience. This challenges the prevailing view that, for individuals with CP, problems with depression are either equal to, or greater than, problems with anxiety; thereby providing important information to guide therapeutic targets.

3.3 Introduction

Approximately 20% of the world's population experiences persistent or chronic pain (CP) (Goldberg & McGee, 2011) - pain that occurs on most days for three or more months (IASP: Task Force on Taxonomy, 1994). With low back pain now the largest contributor to global disability (Hoy, et al., 2014), CP has been shown to negatively impact on many areas of life, including work attendance and productivity (W. F. Stewart et al., 2010), physical function and quality of life (Douglas, et al., 2004), engagement in social or recreational activities (Haythornthwaite & Benrud-Larson, 2000), and medication and health-service usage (Blyth, et al., 2004; Douglas, et al., 2004).

The subjective experience of pain involves a complex interplay between physical, psychological and environmental variables (Flor & Hermann, 2004; Nicholas, 2008). Consequently, many studies have examined the psychological aspects of CP, with research consistently demonstrating that psychological problems are common in people with this condition (Dersh, et al., 2002). Whereas American data indicate that CP is associated with comparable rates of anxiety and depression (Von Korff et al., 2005), Australian data suggest that depression and adjustment disorders are more common (Access Economics, 2007).

Numerous aspects of psychological functioning may impact on, and be affected by, an individual's experience of CP including, but not limited to, mood (e.g., depression, anxiety, stress), feelings of self-mastery (e.g., self-efficacy, self-esteem), attributions about responsibility (e.g., guilt, shame) and grief/loss. Although these have been explored to varying degrees in the CP literature, most research has focussed on depression and anxiety. Similarly, research has tended to focus on specific *diagnoses*, such as neuropathic pain (Attal, et al., 2011) and fibromyalgia (Homann, et al., 2012); or on specific *subgroups*, such as older people (Falsarella, et al., 2012) and trauma survivors (Peterlin, et al., 2009). This focus on specific diagnoses/subgroups is limiting because many people with CP do not have a clear diagnosis or precipitant for their pain. Indeed, one survey found that 65% of people had no clear medical diagnosis for their CP and 33% identified no clear precipitant

(Blyth, March, & Cousins, 2003). Moreover, CP is associated with a large number of different medical diagnoses, not all of which have been well-researched, and many people with CP experience a range of medical and psychological comorbidities that are not specific to a particular CP diagnosis or subgroup.

Thus, while it is undeniably important to understand CP from these specific perspectives, especially where CP is known to be associated with syndrome-specific sequelae (e.g., cancer (Urbaniec, Collins, Denson, & Whitford, 2011), spinal cord injury (North, 1999)), a more global understanding of the psychological problems that are associated with CP is also needed; one that includes the majority of people with CP and better meets the needs of clinicians working with this group. Therefore, this study sought to meta-analyse all quantitative research that used standardised assessment tools to examine the psychological functioning of adults with CP (including specific and non-specific CP diagnoses), relative to their healthy peers. We sought to synthesise this very large literature in order to provide a better clinical understanding of the CP experience and the underlying evidence-base. Self-report measures of emotional functioning were targeted because they are the most frequently used method of assessment in the literature and are also commonly used in clinical practice.

3.4 Materials and Method

Literature Search

Information sources. Four databases (PsychInfo, Scopus, PubMed and The Cochrane Library) were searched for studies that examined the psychological functioning of individuals with CP, published prior to 2014. The searches included singular and plural forms of each term, and regional variations in spelling (e.g., behaviour/behavior) (see Appendix 1 - [Supplementary Table 3.A](#), for search terms). The initial search was very broad in order to ensure that all relevant papers were

identified because CP is an umbrella term that encompasses a variety of labels, is attributed to a range of conditions and has been examined by a number of disciplines.

Eligibility criteria. Studies were only included in the current meta-analysis if they met the following criteria: they recruited a chronic pain sample that (a) was aged ≥ 16 years (commonly-used age for adult pain services) and (b) experienced CP – specifically defined as pain on most days for a period of ≥ 3 months; and the study (c) included a healthy control group that was matched to the CP group; (d) investigated the psychological functioning of both groups utilising standardised self-report assessment tools; (e) was published in English and documented original quantitative research (excludes reviews); (f) was not a case study ($n > 1$); and (g) provided data in a format that permitted the calculation of Cohen's d effect sizes (e.g., mean and SD , t -statistic or exact p -value).

Medical and psychiatric conditions that have syndrome-specific sequelae, and therefore require separate consideration, were excluded because the aim was to examine the general CP experience. Specifically, excluded conditions were: (a) spinal cord injuries; (b) particular medical disorders/conditions (e.g., cancer, cardiac, renal); (c) neurological disorders (e.g., stroke, traumatic brain injury); (d) terminal/palliative conditions; (e) psychiatric conditions (e.g., factitious disorder, psychosis); and (f) personality disorders. Studies examining acute pain onset and/or tolerance were similarly excluded, because the current study was designed to examine people living with CP.

Study appraisal and selection. Critical appraisal and eligibility assessment were performed by the primary author (ALJB). If there was any ambiguity, papers were independently appraised by the full panel of authors and eligibility determined by consensus, following group discussion. If it was not possible to definitively determine eligibility based on the available information, clarification was sought from the corresponding authors. If no response was obtained, that study/variable was excluded from analysis. Where data for the same sample were reported in multiple papers, the paper with the largest sample was included. Matching of the CP and healthy control groups was a key factor in the critical appraisal of studies as it served to minimise extraneous

between-group differences, thereby increasing confidence in the validity of the results. CP and healthy control groups were deemed to be matched if there was either a deliberate attempt to match groups on at least one demographic variable (e.g., age, sex) or post-hoc analyses indicated that groups were demographically comparable. Studies that did not meet either of these criteria for matching were excluded from the meta-analysis. Similarly, all studies were required to use standardised assessment tools to ensure only good quality studies were included. The scope and size of the current study precluded more detailed qualitative evaluation and rating of individual studies. However, both the application of strictly defined eligibility criteria and the weighting of data by the inverse variance (Lipsey & Wilson, 2001), served to minimise the potential impact of poor-quality empirical studies.

Data Extraction and Organisation of Studies

Data relating to: the study (e.g., sample size, country), participants (e.g., age, sex, race), pain (e.g., diagnosis/location, duration) and the measures of psychological functioning (test, scoring method and direction, means and *SDs*, or exact *t*- or *p*-statistics) were extracted from each study via a detailed data extraction form. As different aspects (e.g. cognitive, emotional, somatic) of psychological functioning have been assessed by a large number of alternative measures, the most meaningful way to explore the data was to group measures on the basis of psychological domains (e.g. depression). Different measures varied in their focus, assessing either positive or negative mood-states, consequently scores were re-scaled where necessary (sign inverted but scores unchanged) so that they could be consistently interpreted. For positive domains (self-esteem and self-efficacy), higher scores indicated better outcomes. For all other domains, higher scores indicated greater psychological distress (poorer outcomes). In all cases, positive effects indicated greater levels of the domain in the control group and negative effects indicated greater levels in the CP group. Thus, for depression, a positive effect indicates greater depression in the control group, whereas a negative effect indicates the CP group are more depressed.

Data Analysis

Data were analysed using the 'Comprehensive Meta Analysis' program (Borenstein, Hedges, Higgins, & Rothstein, 2005). Where a study recruited multiple CP and/or control groups and reported data separately, scores were pooled to provide an overall score for each group (CP, controls). If studies provided multiple scores for a single domain (e.g. more than 1 depression score), a mean effect was calculated; thereby ensuring that each study only contributed a single score to the overall mean when the effect sizes from different studies were averaged (Lipsey & Wilson, 2001). Information relating to pain-related litigation and socio-economic status were collected to evaluate whether these variables acted as moderator variables, however, there were insufficient data to analyse these relationships. Similarly, although active treatment-seeking may have reflected an important difference between the CP groups (treatment-seekers may have had more severe conditions and/or comorbidities, and more psychological problems), this could not be examined because it was frequently unclear whether samples recruited from non-treatment settings were receiving care. Thus, any analysis of recruitment source was unlikely to be reliable or informative.

The effect size used in the current analysis was Cohen's d (Cohen, 1988); providing a measure of the standardised difference between the means for the CP and control groups. Effect sizes were interpreted using Cohen's (Cohen, 1988) guidelines, with $d = 0.2$, 0.5 and 0.8 indicating small, medium and large effects, respectively. Consistent with Hopkins and colleagues (Hopkins, Marshall, Batterham, & Hanin, 2009), $d = 2.0$ and 4.0 were labelled very large and extremely large effects.

Heterogeneity analyses, using the I^2 statistic, were performed to assess whether differences in the effect sizes from individual studies reflected chance-based sampling differences (homogeneous effects) or additional sources of variance, possibly reflecting methodological differences between studies (heterogeneous effects). As might be expected, given CP was

examined from a general, rather than diagnosis-specific, perspective, many of the heterogeneity analyses (I^2) were significant ($I^2 > 50$); indicating substantial variability in the findings. Therefore, a more conservative random-effects model was used instead of the traditional fixed-effects model (Higgins, Thompson, Deeks, & Altman, 2003). The latter assumes a 'true' effect that is common across all studies, while a random-effects model assumes that there are differences between studies (e.g., samples and/or diagnoses). In addition, when calculating mean effects, individual effects were weighted by the inverse of their variance in order take into account differences in the precision of the effect size estimates obtained from different studies (Lipsey & Wilson, 2001).

Ninety-five percent confidence intervals (95% CIs) were calculated to test whether the population mean group difference differed significantly from zero; indicated by a CI that does not span 0. Finally, fail-safe N 's (N_{fs}) were calculated to examine the impact of publication bias on the results obtained: N_{fs} indicating the number of unpublished studies with non-significant findings that would be required to render the current results insignificant (Zakzanis, 2001). Calculations were based on the formula outlined by Lipsey and Wilson (2001), using a 0.2 (small effect) (Orwin, 1983). A N_{fs} was considered adequate if it was larger than the number of studies meta-analysed for a given measure.

3.5 Results

After removal of duplicate records, the initial search identified 11,211 records, for which the title and abstracts were assessed against the inclusion criteria by the first author (ALJB). This initial review excluded 10,525 articles because they failed to meet the specified criteria (see [Figure 3.1](#)). Full-text versions of the remaining 686 articles were then sourced and the contents systematically evaluated against the inclusion/exclusion criteria. Following thorough review, 110 papers were retained and their data extracted and meta-analysed.

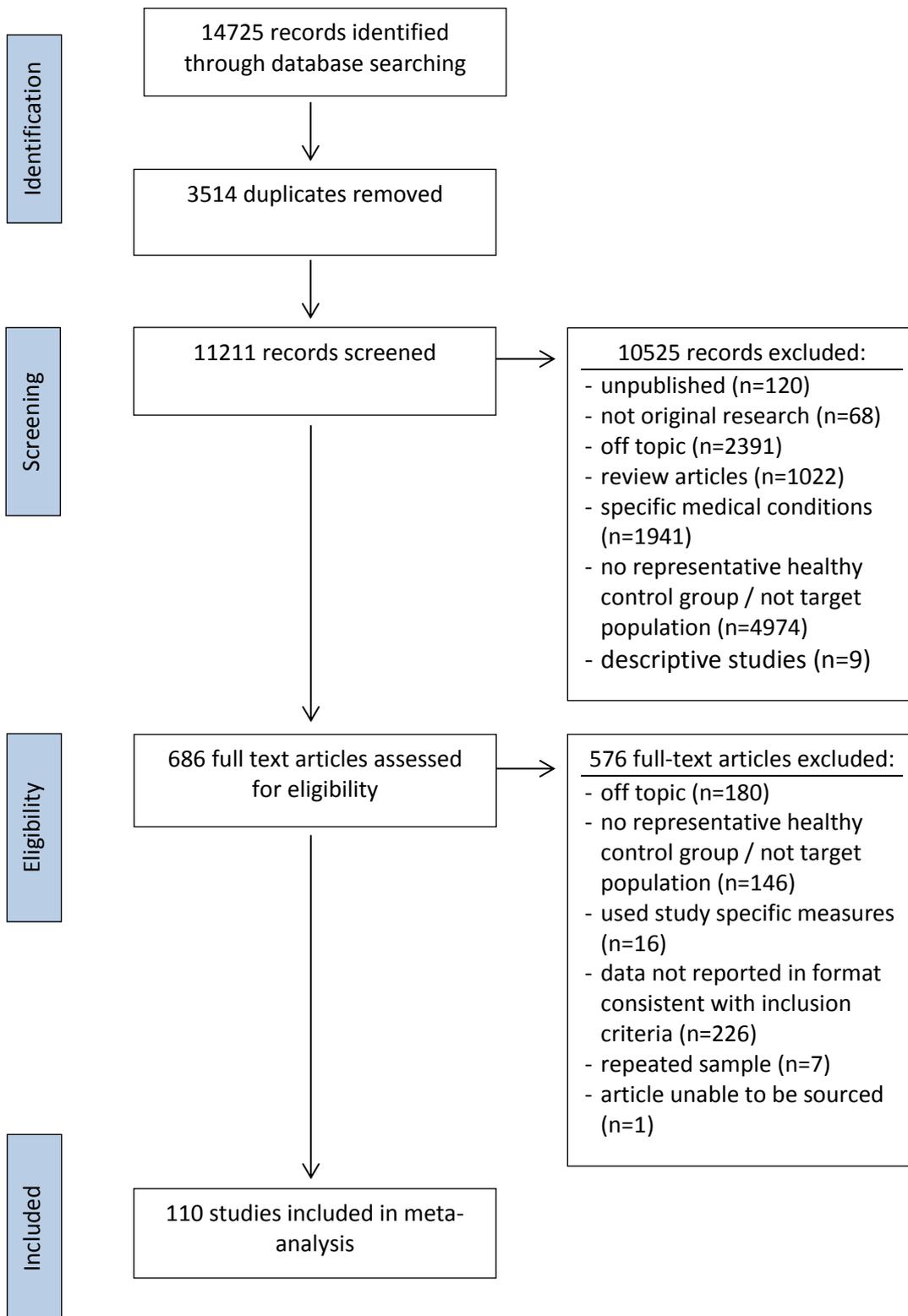


Figure 3.1: PRISMA flow diagram of study selection process

Study Characteristics

All studies were published between 1986 and 2013, with most published in the past 13 years ($n = 86$, 78%). The final sample comprised 67,554 participants (CP + controls), aged 17 to 102 years, most of whom were female ($n = 30,981$, 57%). As seen in [Table 3.1](#), few studies provided information relating to relationship and employment status, education, ethnicity, BMI and, surprisingly, pain duration (see Appendix 1 - [Supplementary Table 3.B](#) for demographic/background details for individual studies). Some studies provided data in a format that did not permit between-study comparisons (e.g., categorical data for age). Where reported, the majority of participants were Caucasian, married/partnered, had some form of employment and had completed secondary schooling. The CP group had experienced pain for one to 15 years ($M = 8.0$ years, $SD = 3.7$). Most studies originated from Europe or America, explored mixed pain conditions, examined deliberately matched samples, and recruited their CP group from treatment settings and controls from the general community (see [Table 3.1](#)).

Psychological Function

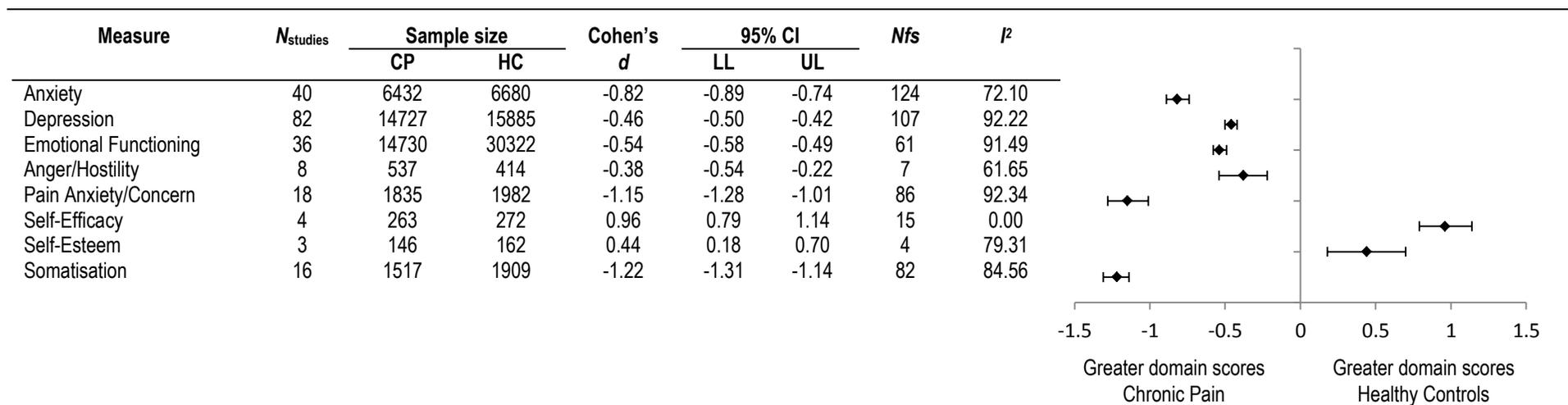
Although there are many forms of psychological functioning that may be relevant to CP, the areas found to be most commonly examined by researchers were depression and anxiety (general and pain-related) and, to a lesser degree, somatisation, anger/hostility, self-efficacy, self-esteem and general emotional functioning (overall mental/emotional health, perceived stress) – thus, subsequent analyses focussed on these areas. The mean effects for each domain are summarised in [Figure 3.2](#). As can be seen, there were moderate to large, significant and robust differences in the psychological functioning of persons with CP, relative to their healthy peers, in all areas. Moreover, the limited overlap in the CIs indicates that there were significant differences in the extent to which many of these domains were affected.

Table 3.1: Summary demographic information for the included samples and studies

	<u>Chronic Pain</u>		<u>Healthy Controls</u>	
	<i>N</i> (%)	<i>N</i> _{studies}	<i>N</i> (%)	<i>N</i> _{studies}
<u>PARTICIPANT INFORMATION</u>				
<i>N</i> _{participants}	25084 (37)	110	42470 (63)	110
Age *	45.6 (11.0)	94	44.4 (11.1)	92
Sex				
Male	6901 (36)	96	16375 (47)	96
Female	12318 (64)		18663 (53)	
Relationship status				
Married/partnered	6514 (63)	28	5809 (62)	28
Not married/partnered	3775 (37)		3587 (38)	
Employment status				
Employed	1372 (64)	14	1845 (71)	14
Not employed	780 (36)		753 (29)	
Years of education *	12.7 (3.3)	14	13.7 (3.4)	14
Ethnicity				
White	7220 (76)	20	6928 (69.7)	20
Not White	2339 (24)		3010 (30.3)	
Body Mass Index (BMI) *	27.0 (1.3)	14	25.6 (1.3)	14
Pain duration (years) *	8.0 (3.7)	37		
<u>STUDY INFORMATION</u>				
Location of origin				
Europe	48 (44)	110		
America	46 (42)			
Australia	9 (8)			
Asia	6 (5)			
Other	1 (1)			
Pain conditions explored				
Mixed	44 (40)	110		
Back	16 (15)			
Fibromyalgia	12 (11)			
Pelvic / abdominal	12 (11)			
Head / neck	8 (7)			
Arthritis	7 (6)			
Facial	7 (6)			
Whiplash	3 (3)			
Neuropathic	1 (1)			
Sample matching				
Matched	75 (68)	110		
Not matched	31 (28)			
Not reported	4 (4)			
Recruitment source				
Treatment seeking	58 (53)	110	3 (3)	110
Community-based	17 (15)		55 (50)	
Primary care	4 (4)		8 (7)	
Mixed	20 (18)		13 (12)	
Students	3 (3)		3 (3)	
Not reported	6 (5)		21 (19)	
Other	2 (2)		7 (6)	

Note: Figures presented are N (%) except where indicated by * to be X (SD).

Figure 3.2: Summary of overall Cohen's d effect sizes for the domains of psychological functioning



Note. CP = chronic pain; HC = healthy control; N_{fs} = Failsafe N's; $I^2 > 50$ indicates significant heterogeneity.

Depression

Depression was the most commonly assessed area of psychological functioning ($N_{\text{studies}} = 82$, see Appendix 1 - [Supplementary Table 3.C](#) and [Supplementary Figure 3.A](#)), with the majority of studies ($n = 77$) using one of 14 measures. Only five studies used multiple measures. The most frequently used measure was the Beck Depression Inventory (BDI; $N_{\text{studies}} = 33$, 40%) (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), followed by the Centre for Epidemiological Studies Depression scale (CES-D) (Radloff, 1977) and the Hospital Anxiety and Depression Scale (HADS-D) (Zigmond & Snaith, 1983). Although the overall mean effect for depression was moderate ($d = -0.46$) (see [Figure 3.2](#)), there was considerable variation between the effects for different measures. However, with the exception of the Kessler Psychological Distress Scale (K-10) (Kessler et al., 2003), which was only used by one study and had an unsatisfactory N_{fs} statistic, all effects were moderate to very large. Moreover, they were significant and negative, indicating consistently higher levels of depression in the CP group.

Anxiety

Anxiety was examined by a total of 40 studies (see Appendix 1 - [Supplementary Table 3.D](#) and [Supplementary Figure 3.B](#)); 36 of which used a single measure of anxiety, while others used two scales. The HADS-A was the most commonly used measure, reported in 12 studies, followed by the State Trait Anxiety Inventory (STAI-S, $N_{\text{studies}} = 8$) (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983). Across all measures, the CP group showed consistently higher levels of anxiety than the controls (negative d), resulting in a large and significant overall mean effect for this construct ($d = -0.82$) (see [Figure 3.2](#)). Significant moderate to very large effects were found for the majority of measures; with the two exceptions having unsatisfactory N_{fs} statistics, raising concerns about the reliability of those findings.

Pain Anxiety/Concern

'Pain anxiety/concern' comprised measures assessing catastrophizing, fear of pain/movement and pain anxiety. In total, 18 studies investigated various aspects using 15 different measures (see Appendix 1 - [Supplementary Table 3.E](#) and [Supplementary Figure 3.C](#)); most commonly the Pain Catastrophising Scale (PCS) (Sullivan, et al., 1995), with total and/or subscale scores being reported by 10 studies (56%). Twelve studies employed a single measure of pain anxiety/concern, while the remainder used two, three or six scales ($N_{\text{studies}} = 3, 2, 1$, respectively). A large overall mean effect ($d = -1.15$) was found for this construct (see [Figure 3.2](#)), with most measures returning large to very large and significant effects. Of note, the only measure to yield a small and non-significant effect for pain anxiety/concern - the Fear of Pain Questionnaire (FPQ-III) (McNeil & Rainwater, 1998) - was only used in a single small-scale study. Moreover, unlike other measures that examine fears relating to the specific CP experience (e.g., *it will make my back pain worse*), the FPQ-III explores fear of pain in relation to a range of activities (e.g., *gulping a hot drink before it has cooled*), none of which are specifically tied to CP.

Somatisation

Somatisation was assessed in 16 studies using eight measures (see Appendix 1 - [Supplementary Table 3.F](#) and [Supplementary Figure 3.D](#)); the most common being the somatisation subscale of the Revised Symptom Checklist-90 (SCL-90-R-S; $N_{\text{studies}} = 6$) (Derogatis, 1994). The overall effect for somatisation was large, negative and significant ($d = -1.2$) (see [Figure 3.2](#)), indicating that the CP group consistently reported higher levels of somatisation than controls. With the exception of the Wahler Physical Symptom Inventory (WPSI) (Wahler, 1968), which had a moderate and significant effect that was susceptible to publication bias, all other measures revealed large and significant effects.

Anger/Hostility

Eight studies explored anger/hostility using four different measures (see Appendix 1 - [Supplementary Table 3.F](#) and [Supplementary Figure Chapter 3.D](#)). Two studies used multiple measures. While the overall effect for this domain was moderate ($d = -0.38$) (see [Figure 3.2](#)), there was marked variability in the range and significance of findings for individual measures. Interestingly, while the largest effect was found using the Brief Symptom Inventory (BSI-H) (Derogatis & Melisaratos, 1983), its longer counterpart (SCL-R-90-H) yielded non-significant results ($p = 0.125$). Non-significant results were also found for the State-Trait Anger Expression Inventory (STAXI-AE) (Spielberger, 1988) ($p = 0.463$). Of note, the findings for these latter two measures were susceptible to publication bias ($N_{fs} < N_{studies}$). Overall, the findings lacked consistency, suggesting that the relationship between anger/hostility and CP is unclear.

Self-Efficacy

Self-efficacy was examined by four studies, with one using multiple measures in order to examine both general and pain-related self-efficacy (see Appendix 1 - [Supplementary Table 3.F](#) and [Supplementary Figure 3.D](#)). Not surprisingly, there was a large and significant difference ($d = 0.96$) between the self-efficacy levels of CP patients and their healthy peers, with the CP group showing substantially less confidence in their ability to bring about change and demonstrate mastery in their lives (see [Figure 3.2](#)). When the specific measures were considered, although not significant, the between-groups difference for pain-related self-efficacy, as measured by the Pain Self-Efficacy Questionnaire (PSEQ) (Nicholas, 2007), was considerably larger ($d = 1.12$) than that found for the more general measures of self-efficacy (General Self-Efficacy Scale; GSES, $d = 0.64$) (Schwarzer & Jerusalem, 1995) or life control (Multidimensional Pain Inventory Life Control subscale; MPI-LC, $d = 0.80$) (Kerns, Turk, & Rudy, 1985). Thus, as might be expected, while the pain group consistently reported lower levels of self-efficacy than did controls, they indicated feeling somewhat better able to

exert control over their life in general, than they did to exert control over the pain itself and their ability to function in its presence.

Self-Esteem

Self-esteem was examined by three studies using one of two measures (see Appendix 1 - [Supplementary Table 3.F](#) and [Supplementary Figure 3.D](#)). Overall, a moderate and significant positive effect ($d = 0.44$) was found (see [Figure 3.2](#)). Although the total sample used to explore this construct was limited (CP: $n = 146$, Controls: $n = 162$) compared to other domains, these results suggest that healthy controls consistently reported having more positive feelings about themselves and their overall self-worth, than did the CP group.

General Emotional Functioning

Finally, general emotional functioning (sometimes conceptualised as distress) - a more global construct - was examined by 36 studies (see Appendix 1 - [Supplementary Table 3.G](#) and [Supplementary Figure 3.E](#)). Most of the 14 measures of this domain were used by between one and four studies, the exception being the Mental Health subscale of the 36 item Short-Form Health Survey (SF-36-MH) (A. L. Stewart, Hays, & Ware, 1988), which was used by over 50% of studies. After inverting the effect sizes for specific scales (SF-12, SF-20, SF-36, Profile of Mood States: POMS (McNair, Lorr, & Droppleman, 1992), World Health Organisation Quality of Life Assessment – Brief: WHOQOL-BREF (Hawthorne, Herrman, & Murphy, 2006)) so that they all measured *impairment* in psychological functioning (rather than positive mood), the weighted overall effect for this domain was moderate and significant ($d = -0.54$), indicating that the CP group consistently reported experiencing greater levels of emotional distress than healthy controls (see [Figure 3.2](#)). The effects for individual measures varied greatly ($d = -0.04$ to $d = -3.85$), with very low N_{fs} statistics indicating that the results for four measures were vulnerable to publication bias.

3.6 Discussion

Life with CP is a complex experience that cannot be adequately understood in purely physical terms or reduced to neat diagnostic groupings. Therefore, it is important that clinicians, planners and policy-makers understand the psychological aspects of the CP experience from a general perspective because comorbidities, symptom variation and/or unclear diagnoses confound interpretations of diagnosis-specific CP research. Consequently, this meta-analysis was designed to synthesise the large CP literature from a broad perspective in order to systematically document the psychological functioning of people living with CP.

Our search of the CP literature revealed a substantial amount of research using diverse constructs and measures to examine a range of different psychological domains; particularly in recent years. Compared with controls, the CP group consistently reported experiencing significant and substantial problems in all aspects of psychological functioning. Not surprisingly, the greatest impact was on those domains that are directly tied to the physical experience of pain; namely pain anxiety/concern and somatisation. One measure of general emotional functioning (BSI) was also particularly compelling because a finding of this magnitude indicates almost no overlap (<3%) between the scores of CP and healthy individuals on this measure (Zakzanis, 2001).

Although somatisation was associated with the largest group difference (effect size), this result is somewhat difficult to interpret because the term is used inconsistently throughout the literature. For instance, in their recent meta-analysis of somatic symptoms, Zijlema and colleagues (2013) interpret somatisation in two quite different ways: the tendency to (a) report/emphasise physical symptoms in the absence of, or to a greater extent than would be expected by the, identified organic pathology; and (b) “experience and communicate somatic distress in response to psychosocial stress” (p 459). Using the first interpretation, it is not surprising that people with CP showed significantly elevated rates of somatisation: CP is not purely a physical experience and commonly lacks clear organic causes. Further, the range of comorbidities often experienced with

CP may impact scores on these scales. However, the second interpretation suggests something different: that individuals living with CP are more likely to experience emotional distress in physical ways, possibly due to a heightened tendency to notice (and respond to) physical sensations, especially ones that are directly related to their pain. The current analysis does not distinguish between these alternative interpretations.

Overall, our findings confirm that CP is associated with a range of impairments in psychological functioning. However, they do not support the assertion that depression is the most commonly experienced problem. Instead, we found that, although individuals with CP were consistently more depressed than their healthy peers, they were comparatively more anxious (see [Figure 3.2](#)) – both in general and in response to pain. Similarly, self-efficacy was also found to be broadly affected across general and pain-related areas. However, of note, the elevated levels of pain anxiety/concern found in the CP group were specifically tied to the CP experience – although the CP group was understandably anxious about exacerbating their condition, they were not more anxious about general pain experiences (e.g., hitting your head).

If an adjustment disorder is defined as a larger-than-expected emotional response (of mixed symptomatology) that impairs a person's ability to cope with a stressful experience or significant life change (World Health Organisation, 1990), it could be argued that many of the domains considered here fall into this broad category. However, it is not possible to comment more definitely here about the frequency of adjustment disorders in CP because researchers have rarely assessed 'adjustment disorders', per se. Rather, our current findings suggest that, of the psychological domains that were assessed, physically-orientated problems (somatisation, pain anxiety/concern) are greater than depression and general impairments in emotional functioning.

It is well documented that the physical symptoms of CP overlap with the symptoms of depression; so much so that an accurate diagnosis of this type of mood disorder can be challenging in a CP setting (Cheatle, 2011; Wong et al., 2011). Indeed, it is possible that this overlap in

symptoms made it difficult for individuals to determine the origin of their symptoms when completing the self-report scales. However, this is unlikely to explain why the CP group were comparatively less depressed than they were anxious, for two reasons. First, the measures do not ask respondents to identify the cause of their symptoms – they merely ask them to indicate whether they experience those symptoms – which should have resulted in higher depression scores (symptoms would be reported, irrespective of cause) and narrowed the difference between depression and anxiety. Second, measures that had fewer somatic items (e.g., HADS, Depression Anxiety and Stress Scale: DASS (Lovibond & Lovibond, 1996)) did not yield noticeably smaller effects than scales with higher somatic content (e.g., BDI). This suggests that, contrary to current clinical thinking, the level of somatic content in the measures did not have a major impact on the results.

With that in mind, there are a number of limitations to this study that warrant consideration. First, research has been inconsistent in its terminology and operationalization of various psychological domains (e.g., somatisation, anger/hostility), making it difficult to interpret some of the current findings and indeed, to select appropriate search terms (e.g. disease versus illness). Second, the study size precluded detailed qualitative evaluation of individual studies to exclude sources of potential bias other than publication bias, sample inconsistency and low quality assessment. Third, because this study focussed on the adult CP population from a general perspective, results may be less applicable to specific groups, especially those with syndrome-specific sequelae. Similarly, this study focussed exclusively on self-report measures. Further research examining specific cohorts (e.g. older people, children, indigenous populations) and other methods of mood assessment (e.g. ICD-10 diagnosis) is now needed. Moreover, we are unable to comment on whether the identified difference predated or resulted from the CP due to the research designs of the original studies. Such information could help improve our understanding of the factors that may pre-dispose and/or protect individuals from transitioning from acute to CP.

In addition, many CP studies that explored treatment outcomes used CP controls, rather than healthy controls, necessitating their exclusion from this meta-analysis. Somewhat surprisingly, an even larger number of studies were excluded because they did not report the basic data required to calculate Cohen's *d* effect sizes. Standards for data reporting have been under increasing scrutiny over recent years, with a strong push for authors to report more detailed data (including effect sizes) when publishing research (American Psychological Association, 2010; Moore et al., 2010). Adoption of these reporting principles in future research would facilitate more comprehensive meta-analyses.

It was intended that this meta-analysis assist in determining the clinical utility of specific measures, but this did not prove to be the case. With the exception of the measures used to assess anger/hostility - where inconsistent findings suggest that the definition and/or measurement of this domain require more careful consideration and examination - the most commonly used measures consistently discriminated between CP and their healthy peers, suggesting that they were suitable for use in clinical contexts.

Finally, there were insufficient data to examine the impact of other variables (e.g., employment, relationship status etc.) on psychological functioning. Again, more detailed reporting would enable an examination of these variables.

Conclusions

In summary, CP is a common condition that is associated with a range of psychological problems. This study revealed that those aspects of psychological functioning that are most closely tied to the physical experience; namely pain anxiety/concern and somatisation, are most affected in people who are living with CP. This challenges previous assertions that depression levels in this population are equal to, or greater than, anxiety levels (Access Economics, 2007; Von Korff, et al., 2005). Not surprisingly, in all areas, the pain-related aspect of the impact was paramount. Although

self-efficacy was globally eroded, pain anxiety/concern remained closely tied to the CP experience and did not extend to more general pain events.

Of note, this study supports the earlier findings of McWilliams and colleagues (2004) who asserted that anxiety in CP populations requires greater attention because anxiety was often more strongly associated with CP than depression in their sample. Interestingly, the relative strength of the depression-CP and anxiety-CP relationships have gone largely unchallenged over the last decade.

Overall, these findings suggest that people with CP are in a debilitating bind. The chronic physical pain that they experience is associated with considerable psychological distress, which is most commonly focussed on physical aspects of the overall experience. Although this physical focus is not surprising in the circumstance, it is likely to heighten their level of attention to, and lower their threshold for, physical symptoms. This may, in turn, further increase the chance that they will notice physical symptoms and interpret them as threatening, thus heightening their distress and discomfort, and perpetuating the cycle. This cycle is discussed in detail in the CP literature, but the present study is the first to quantitatively consolidate the existing research findings and, in doing so, enable a direct statistical comparison between different areas of psychological functioning. Although pain anxiety/concern, somatisation and self-efficacy (particularly pain-related self-efficacy) are common considerations when working with individuals who experience CP, the degree to which they are prioritised in therapy varies greatly. The current meta-analysis suggests that, in order to help individuals break the pain cycle, evidence-based practice in CP should prioritise these aspects of psychological function.

Chapter 4 : The Impact of Waiting to Access Treatment for Chronic Pain

4.1 Preamble

The first study sought to help clinicians better understand the experience of the majority of people with CP who present to tertiary pain clinics for care; namely individuals who have mixed and/or unclear diagnoses for their pain. It did this by systematically examining the literature that explored the psychological functioning of people with CP and contrasted it to that of their healthy peers – an examination that was conducted from a general, rather than diagnosis-specific, perspective. In doing so, it identified the psychological domains that have most commonly been explored in the literature and demonstrated that all were adversely affected in those with CP. Importantly, the study also revealed that it was the anxiety-related domains that were the most profoundly affected; thus challenging the frequent focus on depression in the presence of CP and guiding clinicians to other important treatment foci.

When examining psychological functioning, the meta-analysis was not able to consider the independent contribution of CP versus other variables, such as waiting for treatment, because it was often not clear where in the treatment cycle individuals were placed. Accordingly, this next study was designed to build on these findings by investigating the impact of waiting for treatment on the psychological functioning and HCU of individuals with CP; thus articulating the impact of the long indefinite waits that are experienced by many of the people who are referred for tertiary management. Specifically, it did this by prospectively following individuals who were triaged for a long wait at a public multidisciplinary CP service from the point of referral through to receiving their first appointment. Participant sex was highlighted as a covariate and so this was also considered in analyses.

Importantly, due to the three year nature of this study, data collection was commenced before the results of the meta-analysis were available. The literature review and preparation for Study 3 informed the domains that were assessed, but the findings for specific measures could not

be factored into the design because of the need to get ethical approval and recruitment underway. Accordingly, psychological distress was operationalised in way that fit with the current practices of the clinic and minimised participant burden, but was ultimately less nuanced than the findings of the meta-analysis would go on to suggest.

Of note, the Journal of Health Psychology (where this study was published) requested two specific modifications to the manuscript as a consequence of space constraints: that the flow chart detailing the number of participants at each follow-up be removed and that [Table 4.3](#) be condensed so that only significant results were reported. Thus, the flow chart ([Supplementary Figure 4.A](#)) and complete findings ([Supplementary Table 4.E](#)) were, instead, provided in on-line supplementary materials in order to ensure that the study met the Journal Article Reporting Standards (JARS) of the American Psychological Society (American Psychological Association, 2010). Further, after revising the manuscript in line with the recommendations of reviewers, it then needed to be condensed in order to meet the word limit of the journal; necessitating the removal of some interesting findings regarding changes in self-reported work status from the published article. This information will be explored in the overarching discussion for this thesis ([Chapter 7](#)).

Reviewers for this article also expressed concern about participant attrition across the study. Attrition is an inherent component of all waitlist research, especially for clinically-triaged waitlists. This poses significant problems for research that involves longer-term follow-up because waitlist lengths are non-standard between individuals. Clinical triage determines an individual's initial position on the waitlist, based on information received in the referral, but this is continually updated as it is balanced against other factors, such as competing clinical demand for the service and updated clinical information for the individual. Indeed, this may very well be one of the main reasons for the lack of published data on this topic, with long-term follow-ups potentially having been abandoned or relegated to the file drawer due to uncontrollable variances in factors such as waitlist time and clinical triage. The lack of an evidence-base leaves clinicians poorly supported at a time

when patient numbers are growing and resources are scarce, and the individuals who are experiencing these long and indefinite waits poorly understood because their clinical trajectories are not represented in the extant literature. Information concerning the impact of being waitlisted is therefore needed, in order to inform future practice and policy. Our biostatistician indicated that the analyses were robust through to 2.5 years of waiting/follow-up and, as such, it was agreed that the longer-term (18 months - 2.5 years) data would be maintained within the manuscript, but presented briefly and in a more tentative way than the findings concerning the first 12 months of waiting.

Once again, Tables and Figures have been inserted within the text to facilitate ease of reading, and all supplementary information is presented in [Appendix 2](#):

- The flow chart of participants through each stage of the study, including reasons for loss to follow-up ([Supplementary Figure 4.A](#)),
- The Royal Adelaide Hospital Pain Management Unit's triage codes ([Supplementary Table 4.A](#)),
- Summary data (means, SDs) for age and each of the key outcome variables, broken down by time/follow-up (T2-T7) and participation status (continuing participant, received PMU appointment, opted-out, referral cancelled) ([Supplementary Table 4.B](#)),
- Data (estimated means, standard error) for each of the key outcome variables, broken down by time/follow-up (T1-T7) and participant sex (female, male) ([Supplementary Table 4.C](#)),
- Data (estimates of significant interaction effects) for outcome variables for which there was a significant combined effect of time/follow-up (T1-T7) and participant sex (female, male) ([Supplementary Table 4.D](#)),
- Data (estimates of main effects) regarding the individual impact of time/follow-up (T1-T7) and participant sex (female, male) on outcome variables ([Supplementary Table 4.E](#)), and

- A copy of the published article, reproduced with permission ([Appendix 2.3](#)).

As with the previous chapters, the [references](#) have been included in a complete reference list at the end of this thesis.

Study 2

WAITING FOR MULTIDISCIPLINARY CHRONIC PAIN SERVICES: A PROSPECTIVE STUDY OVER 2.5 YEARS

This chapter consists of a published paper; however copyright restrictions prevent the reproduction of this paper in its published form. The details of this publication are:

- Burke, A.L.J., Mathias, J.L., & Denson, L.A. (2018). Waiting for multidisciplinary chronic pain services: A prospective study over 2.5 years. *Journal of Health Psychology*. DOI: 10.1177/1359105317752828.
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- [Conference presentations](#) are provided in a complete list at the start of this thesis

Statement of Authorship

Title of Paper	Psychological functioning of people living with chronic pain: A meta-analytic review
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Principal Author

Name of Principal Author (Candidate)	Anne L. J. Burke
Contribution to the Paper	All authors contributed to study inception. ALJB was solely responsible for search strategy design and execution; data extraction and coding; designing the data analysis and reporting strategy; completing data analysis; and manuscript preparation.
Overall percentage (%)	90%
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.
Signature	Date 16.10.18

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

- i. the candidate's stated contribution to the publication is accurate (as detailed above);
- ii. permission is granted for the candidate to include the publication in the thesis; and
- iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Jane L. Mathias
Contribution to the Paper	All authors contributed to study inception. JLM provided supervisory contributions to all aspects of this research including, but not limited to; discussion of search terms, coding deliberations, data interpretation and manuscript reviews.
Signature	Date 18/10/18

Name of Co-Author	Linley A. Denson
Contribution to the Paper	All authors contributed to study inception. LAD provided supervisory contributions to all aspects of this research including, but not limited to; discussion of search terms, coding deliberations, data interpretation and manuscript reviews.
Signature	Date 31/10/2018

4.2 Abstract

Despite many patients waiting more than two years for treatment at publicly-funded multidisciplinary chronic pain services, waitlist studies rarely examine beyond six months. We investigated psychological adjustment and health care utilisation of individuals ($N=339$) waiting ≤ 30 months for appointments at an Australian tertiary pain unit. Outcomes were relatively stable during the first six months, but longer-term deteriorations in pain-related interference, distress and pain acceptance were evident; albeit with sex differences. Sexes also differed in uptake of new treatments. Medication use increased over time, but pain severity and medication relief did not. Results suggest early intervention is important, especially for women.

4.3 Introduction

Chronic pain (CP) is associated with a range of physical (Taylor et al., 2016), psychological (Burke, Mathias, & Denson, 2015), social (Dueñas, et al., 2016) and economic consequences, many of which improve with treatment (Gatchel & Okifuji, 2006). Although Australians are eligible for universal health care – including government-subsidized hospitals, diagnostics, specialists and low-cost medications – high demand and limited resources mean that public CP outpatient clinics struggle to provide timely treatment (Fashler, et al., 2016). Up to 80% of Australian adults with CP are denied treatment that could improve their functioning and quality of life (National Pain Summit Initiative, 2011), while others wait over two years for treatment (Hogg, et al., 2012; Peng, et al., 2007); far longer than the eight-week maximum recommended wait (IASP: Task Force on Wait-Times, 2010). In Europe, around 33% fail to receive treatment for their CP; almost 50% report inadequate pain management; and only 2% are managed by specialist services, many with lengthy waits (Breivik, et al., 2013). Although clinicians frequently report long wait-times, published statistics often underestimate the problem because they include rapid access cases (e.g. palliative care), with median waits varying from seven to 231 days (Fashler, et al., 2016); far less than the waits experienced by many patients.

Wait-times, even up to six months, may be associated with poorer health-related quality of life (QOL) and well-being, and increased pain, disability and distress (Fogarty & Cronin, 2008). Accordingly, access to CP treatment is now a key consideration in European health care (Societal Impact of Pain Grünenthal Group, 2017). Although short-term data suggest an inverse relationship between wait-time and adjustment (Fogarty & Cronin, 2008), the point at which clinically-significant deterioration begins, and the impact of longer waits, are unknown (Lynch, et al., 2008). Research specifically examining the impact of waiting for CP treatment on patient outcomes is limited. Instead, research has typically focussed on treatment efficacy and different populations (e.g. surgical waitlists or community samples). It is also unclear whether participants were informed of wait-times when

referred for treatment. Waits for CP services are difficult to predict because waitlists are continually updated, based on clinical information and triage demands: thus, many patients lack definite timelines. This uncertainty has been linked with increased distress, impaired concentration and reduced life-engagement (Fogarty & Cronin, 2008). Lengthy indefinite waitlists are almost universally condemned, but exactly when *long* becomes *too long* is unclear.

Long-term data is needed because waits for public multidisciplinary CP treatment often exceed six months. This project prospectively examined the long-term psychological adjustment and health care utilisation (HCU) of individuals' waitlisted for a public outpatient CP service.

4.4 Materials and Method

Participants

Participants were adults referred to the Pain Management Unit (PMU) of Royal Adelaide Hospital (November 2011-2013), which – as one of two public multidisciplinary CP services in South Australia – assesses, treats and manages adults with CP across a large Australian region. Referrals are triaged and prioritized on the basis of clinical need (see [Supplementary Table 4.A](#)). Individuals triaged for an urgent/semi-urgent (<6 months) appointment (triage codes 1-2) were excluded because we examined the impact of waiting >6 months. Participants needed basic English fluency (determined from referral information) to provide informed consent and complete the questionnaire. All eligible new referrals were invited to participate (see Burke, Denson, & Mathias, 2016 for further details).

Measures

Newly-referred patients routinely complete a screening battery (Patient Screening Questionnaire; PSQ) before being placed on the PMU waitlist; this measure was used to minimise participant-burden. The PSQ collects demographic, health and pain-related information, HCU and

medication use, and includes measures of pain-related interference and pain severity (BPI: Cleeland & Ryan, 1994) and psychological distress (Kessler Distress Scale [K-10]: Kessler, et al., 2003). In addition, the Chronic Pain Acceptance Questionnaire (CPAQ: McCracken, et al., 2004) measured pain willingness (willingness to experience pain in order to perform activities), activity engagement (engagement with meaningful activity) and overall pain acceptance. Lastly, the World Health Organisation QOL-Brief Scale (WHOQOL-BREF: Murphy, Herrman, Hawthorne, Pinzone, & Evert, 2000) assessed QOL using four subscales (physical health, psychological health, social relationships, environment), but the 'overall' and 'health-related' QOL scores were ultimately excluded due to their poor psychometric properties.

Changes in pain-related HCU and medication were also examined in terms of: (1) HCU frequency (mean number of health-related appointments in the previous three months), treatment types (medical, psychological, alternative, physical), and uptake of new treatments since the last survey; and (2) amount of relief that participants reported receiving from their pain medication(s) and changes in medication dose/strength since the previous survey.

Finally, the Social Desirability Response Set Scale (SDRS-5: Hays, Hayashi, & Stewart, 1989) was included to gauge whether participants were responding (intentionally or not) in socially-desirable ways in order to expedite appointment allocation (see Burke, Denson, et al., 2016 for more information).

Procedure

Following triage (T1), all eligible individuals were mailed the PSQ (standard clinic practice) and an invitation to participate (information sheet, consent form, research questionnaires, pre-paid envelope). They were advised that the study would explore the impact of waiting for services on individuals with CP and that their wait-time/treatment would not be affected by their research (non-) participation. Participants were followed-up two months after referral (T2) — coinciding with an optional pre-clinic education session being trialled at the time (see Burke, Denson, et al., 2016) —

and then at six-monthly intervals until their first PMU appointment (T3-T7: six months-2.5 years).

Reminder packs were sent to participants who did not return questionnaires within one month.

Participants were deemed to have opted-out of the study if they did not return two successive mail-outs.

PMU appointments were offered on the basis of chronological referral and clinical need/urgency (assessment with: doctor/doctor & allied health/multidisciplinary panel), but were modified if updated information was received indicating greater urgency. Thus, individuals were not advised of an anticipated wait-time at the point of referral. Study follow-ups ceased when participants received their initial PMU appointment (no longer waitlisted); accounting for some attrition from T1-T7 (see [Supplementary Figure 4.A](#)). Those who declined/withdrew study participation remained on the PMU waitlist and received equivalent waitlist management. Staff who scheduled PMU appointments were blinded to study participation status.

CP and waiting for treatment are both associated with distress (Burke, Mathias, et al., 2015); therefore the mail-out included information about how to access external psychological assistance (services, telephone numbers) while waiting for their PMU appointment. The study was approved by the Research Ethics Committees of Royal Adelaide Hospital (Protocol #111004) and University of Adelaide.

Analyses

Study power was estimated using G*Power and deemed satisfactory (effect size $f = 0.25$, $\alpha_{\text{error probability}} = 0.05$; power = 0.95) (Faul, Erdfelder, Lang, & Buchner, 2007). The potential impact of sex, age, marital status, country of birth, primary pain location and pain duration on outcome was assessed to determine whether they should be entered as covariates into the mixed-model analyses. Backwards elimination indicated that sex was the only variable to contribute to outcomes and thus, was the only covariate.

Next, repeated measures mixed-model analyses examined the impact of Time (T1-T7) on: pain impact (BPI: pain-related interference, pain severity), psychological distress (K-10), pain acceptance (CPAQ), QOL (WHOQOL-BREF), HCU (frequency, type, new treatments) and medication usage (pain relief, change in dose/strength). Significant effects were explored via post-hoc *t*-tests with Sidak corrections. Cohen's *d* was calculated to assess the standardized difference between means across study time-points and interpreted using Cohen's (1988) guidelines (*d* = 0.2, 0.5, 0.8 indicating small, medium, large effects respectively). Finally, ordinal logistic generalized estimating equation (GEE) model analyses examined the impact of Time (T1-T7) on reported uptake of new treatments and changes in medication use (Homish, Edwards, Eiden, & Leonard, 2010).

4.5 Results

Sample Characteristics

In total, 678 referrals were screened for eligibility and 664 invited to participate (see [Supplementary Figure 4.A](#)). Almost half either did not respond (31%, *n* = 209) or opted for a PMU appointment, but declined research participation (17%, *n* = 116). Independent samples *t*-test and χ^2 -square statistics confirmed that there were no significant differences between the age or sex of those who agreed to participate ($M_{\text{age}} = 44.1$, $SD_{\text{age}} = 10.4$; $N_{\text{females}} = 197$, 58%) and those who declined ($M_{\text{age}} = 44.1$, $SD_{\text{age}} = 11.2$; $N_{\text{females}} = 71$, 61%) (age: $t(453) = 0.01$, $p = 0.99$; sex: $\chi^2(1, N = 466) = 0.34$, $p = 0.56$), indicating demographic comparability.

The final sample comprised 339 adults aged 17-83 years; mostly referred by general medical practitioners. Participants were predominantly female, unemployed, un-partnered and Australian-born (see [Table 4.1](#)). Pain was usually long-standing (56% had pain for >5 years), experienced in multiple sites and of unknown aetiology. Consistent with referral to public clinics, most had no private health insurance and were not involved in pain-related litigation; effectively precluding access to private services. Few had previously attended a pain clinic.

Table 4.1: Summary demographic information of the sample

	Females N (%)	Males N (%)	Full Sample N (%)
<u>GENERAL INFORMATION</u>			
<i>N</i> _{participants}	197 (58)	142 (42)	339
<i>Age (Mean, SD)</i>	44.8 (11.0)	43.2 (9.5)	44.1 (10.4)
<i>Relationship status</i>			
Single	77 (39)	70 (49)	147 (43)
Married/de facto	86 (43.5)	43 (30)	129 (38)
Divorced/separated	29 (14.5)	15 (11)	44 (13)
Widowed	1 (0.5)	-	1 (0.5)
Not reported	5 (2.5)	14 (10)	19 (5.5)
<i>Employment status</i>			
Unemployed (due to pain)	62 (31)	62 (43.5)	124 (36.5)
Unemployed (other)	23 (12)	34 (24)	57 (17)
Part-time	25 (13)	8 (5)	33 (10)
Full-time	18 (9)	15 (10)	33 (10)
Home duties	28 (14.5)	4 (3)	32 (9)
Retired	12 (6)	4 (3)	16 (5)
Disability Pension	6 (3)	5 (4)	11 (3)
Student	9 (4.5)	2 (1.5)	11 (3)
Volunteer work	3 (1.5)	1 (1)	4 (1)
Retraining	-	3 (2)	3 (1)
Other	2 (1)	-	2 (0.5)
Casual	1 (0.5)	-	1 (0.5)
Not reported	8 (4)	4 (3)	12 (3.5)
<i>Location of Birth</i>			
Australia	151 (77)	100 (70)	251 (74)
Europe	27 (14)	22 (15)	49 (14)
Asia	9 (5)	8 (6)	17 (5)
Oceania	3 (1)	3 (2)	6 (1.5)
Africa	1 (0.5)	4 (3)	5 (1.5)
South America	1 (0.5)	-	1 (0.5)
North America	-	1 (1)	1 (0.5)
Not reported	5 (2)	4 (3)	9 (3)
<i>Private Health Insurance</i>			
No	142 (72)	113 (80)	255 (75)
Yes	50 (25)	23 (16)	73 (22)
Not reported	5 (3)	6 (4)	11 (3)
<u>PAIN / HEALTH INFORMATION</u>			
<i>Pain in More Than One Site</i>			
Yes	189 (96)	129 (91)	318 (93.5)
No	7 (3.5)	13 (9)	20 (6)
Not reported	1 (0.5)	-	1 (0.5)
<i>Pain Duration</i>			
Greater than 10 years	63 (32)	54 (38)	117 (35)
5 – 10 years	43 (21.5)	30 (21)	73 (21)
3 - 5 years	27 (14)	29 (20)	56 (17)
12mths – 3 years	45 (23)	18 (12.5)	63 (18.5)
6 - 12 months	16 (8)	4 (3)	20 (6)
Less than 6 months	2 (1)	2 (1.5)	4 (1)
Not reported	1 (0.5)	5 (4)	6 (1.5)

Table 4.1 Summary demographic information of the sample cont.

	Females N (%)	Males N (%)	Full Sample N (%)
<u>PAIN / HEALTH INFORMATION cont.</u>			
<i>Primary Pain Site</i>			
Total / Almost total body			
Lower Back / Buttocks	32 (16)	14 (10)	46 (14)
Legs / Feet	69 (35)	65 (45)	134 (40)
Neck / Head / Face / Mouth	25 (13)	14 (10)	39 (12)
Upper Back / Shoulders	17 (8.5)	16 (11)	33 (9.5)
Hip / Abdominal	18 (9)	5 (1)	23 (7)
Arms / Hands	19 (9.5)	9 (7)	28 (7.5)
Anal / Genital / Pelvic / Groin	5 (3)	2 (1.5)	7 (2)
Not reported	4 (2)	6 (4.5)	10 (2.5)
	8 (4)	11 (7)	19 (5.5)
<i>Reason for Pain Onset</i>			
No clear reason			
Illness related	51 (26)	33 (23)	84 (25)
Work / Home accident	45 (22.5)	14 (10)	59 (17.5)
Motor vehicle accident	33 (17)	31 (22)	64 (19)
Post-surgical	17 (9)	18 (12.5)	35 (10)
Other	7 (3.5)	7 (5)	14 (4)
Not reported	38 (19)	35 (24.5)	73 (21.5)
	6 (3)	4 (3)	10 (3)
<i>Seen a Pain Clinic Before</i>			
No			
Yes, multidisciplinary clinic	168 (85)	114 (80)	282 (83)
Pain doctor only	20 (10)	21 (15)	41 (12)
Not reported	4 (2)	3 (2)	7 (2)
	5 (3)	4 (3)	9 (3)
<i>Pain-Related Compensation</i>			
No			
Yes	183 (93)	132 (93)	315 (93)
Not reported	8 (4)	6 (4)	14 (4)
	6 (3)	4 (3)	8 (3)

Participants experienced significant pain-related interference in their ability to perform daily activities and significant psychological distress at intake (T1); with 70% ($n = 238$) reporting 'moderate' or 'severe' (≥ 25) distress (K-10). QOL (WHOQOL-BREF) was also markedly below Australian norms (Murphy, et al., 2000) and there was a high degree of HCU, with an average of 10 health-related appointments/person every three months and many ($n = 120$, 35%) having ≥ 1 weekly appointment(s) (see [Table 4.2](#)).

Throughout the study, 54 people were removed from the waitlist without appointment (34 were self-removed/declined to wait/sought services elsewhere, 17 were cancelled by clinic/duplicate referral/redirection to more appropriate service and 3 of them died). Appointment wait-times varied because referrals were triaged on the basis of clinical information; the mean wait-time was 21 months ($n = 273$; $SD = 10.9$; range = 2-53 months).

Sample Attrition

Sample attrition was of concern (see [Supplementary Figure 4.A](#)), with individuals exiting the study because they either received a PMU appointment (no longer waiting), opted-out (declined to complete further measures while waiting), or cancelled their referral (removed themselves from the waitlist). Regression analyses were conducted to determine whether the four groups (still in/received appointment/opted-out/cancelled appointment) differed in terms of key demographic/outcome variables as a function of overall study participation time. These analyses confirmed that the groups were comparable across age ($R^2 = 0.01$, $F(2, 452) = 1.67$, $p = 0.19$), sex ($R^2 = 0.001$, $F(2, 452) = 2.41$, $p = 0.79$) pain-related interference ($R^2 = 0.01$, $F(2, 446) = 1.92$, $p = 0.15$), pain severity ($R^2 = 0.004$, $F(2, 444) = 0.79$, $p = 0.46$) and psychological distress ($R^2 = 0.01$, $F(2, 443) = 2.31$, $p = 0.10$).

Table 4.2: Estimated means for outcome domains, by Time and Sex (first 12 months of waiting)

Outcome Domain	T1 (intake)			T2 (2 months)			T3 (6 months)			T4 (12 months)			SEX	
	Female	Male	Total	Female	Male	Total	Female	Male	Total	Female	Male	Total	Female	Male
<i>N</i>	197	142	339	117	78	195	84	67	151	54	37	91	197	142
<i>Pain impact (BPI)</i>														
Pain-related interference	7.4 (0.1)	7.4 (0.1)	7.4 (0.1)	7.5 (0.2)	7.1 (0.2)	7.3 (0.1)	7.3 (0.2)	7.2 (0.2)	7.3 (0.2)	7.2 (0.2)	6.5 (0.3)	6.8 (0.2)	7.3 (1.8)	7.2 (1.9)
Pain severity	7.1 (0.1)	6.7 (0.2)	6.9 (0.1)	7.2 (0.2)	6.7 (0.2)	7.0 (0.1)	7.1 (0.2)	6.5 (0.2)	6.8 (0.2)	7.1 (0.3)	6.4 (0.3)	6.7 (0.2)	7.1 (1.9)	6.6 (2.2)
<i>Psychological distress (K-10)</i>	29.9 (0.6)	30.3 (0.7)	30.1 (0.5)	31.0 (0.8)	30.3 (0.9)	30.7 (0.6)	30.2 (0.9)	32.1 (1.0)	31.1 (0.7)	30.4 (1.2)	31.3 (1.4)	30.8 (0.9)	29.7 (9.2)	30.3 (9.1)
<i>Pain acceptance (CPAQ)</i>														
Pain willingness	16.0 (0.6)	13.7 (0.7)	14.9 (0.5)	19.1 (0.7)	17.7 (0.9)	18.4 (0.6)	19.6 (0.9)	16.1 (1.0)	17.9 (0.7)	19.8 (1.0)	16.8 (1.2)	18.3 (0.8)	17.8 (8.1)	15.7 (8.7)
Activity engagement	23.9 (0.9)	22.5 (1.0)	23.2 (0.7)	24.7 (1.0)	24.0 (1.3)	24.3 (0.8)	24.2 (1.2)	23.9 (1.4)	24.1 (0.9)	24.4 (1.4)	21.9 (1.6)	23.1 (1.0)	24.1 (11.8)	23.5 (12.8)
Overall acceptance	39.9 (1.2)	36.3 (1.4)	38.1 (0.9)	44.1 (1.4)	41.8 (1.7)	43.0 (1.1)	43.8 (1.6)	40.2 (1.8)	42.0 (1.2)	44.1 (1.8)	39.0 (2.1)	41.5 (1.4)	41.9 (16.3)	39.3 (17.4)
<i>Quality of life(WHOQOL-BREF)</i>														
Physical health	14.1 (0.3)	14.9 (0.4)	14.5 (0.2)	14.7 (0.4)	15.8 (0.4)	15.2 (0.3)	14.7 (0.4)	15.5 (0.5)	15.1 (0.3)	14.8 (0.5)	15.3 (0.6)	15.1 (0.4)	14.5 (4.0)	15.6 (4.6)
Psychological health	15.7 (0.4)	15.7 (0.4)	15.7 (0.3)	15.8 (0.4)	15.9 (0.5)	15.8 (0.3)	15.7 (0.5)	15.3 (0.5)	15.5 (0.3)	15.2 (0.5)	14.6 (0.6)	14.9 (0.4)	15.7 (5.0)	15.9 (5.2)
Social relationships	8.3 (0.3)	7.4 (0.3)	7.8 (0.2)	7.9 (0.4)	7.3 (0.4)	7.6 (0.3)	9.2 (0.4)	7.2 (0.5)	8.2 (0.3)	7.9 (0.5)	7.2 (0.7)	7.6 (0.4)	8.4 (4.9)	7.4 (2.6)
Environment	23.8 (0.4)	23.0 (0.5)	23.4 (0.3)	24.1 (0.5)	23.0 (0.6)	23.5 (0.4)	23.8 (0.5)	22.8 (0.6)	23.3 (0.4)	24.6 (0.6)	22.8 (0.7)	23.7 (0.5)	24.3 (5.8)	23.0 (5.4)
<i>Health care utilisation</i>														
Frequency	10.6 (0.5)	9.9 (0.6)	10.3 (0.4)	9.4 (0.5)	8.8 (0.6)	9.1 (0.4)	8.6 (0.6)	8.4 (0.7)	8.5 (0.5)	8.9 (0.8)	8.6 (0.9)	8.8 (0.6)	9.4 (6.3)	8.9 (6.4)
Treatment types														
Medical	1.2 (0.1)	1.3 (0.1)	1.2 (0.1)	0.8 (0.1)	0.8 (0.1)	0.8 (0.1)	1.1 (0.1)	1.3 (0.1)	1.2 (0.1)	1.2 (0.1)	1.1 (0.1)	1.1 (0.1)	1.1 (1.4)	1.1 (1.2)
Psychological	1.3 (0.1)	1.1 (0.1)	1.2 (0.1)	0.9 (0.1)	0.8 (0.1)	0.9 (0.1)	1.6 (0.1)	1.3 (0.1)	1.4 (0.1)	1.4 (0.1)	1.2 (0.2)	1.3 (0.1)	1.2 (1.1)	1.1 (1.0)
Alternative	0.4 (0.0)	0.3 (0.1)	0.4 (0.0)	0.3 (0.1)	0.3 (0.1)	0.3 (0.0)	0.5 (0.1)	0.4 (0.1)	0.4 (0.0)	0.5 (0.1)	0.3 (0.1)	0.4 (0.1)	0.4 (0.6)	0.3 (0.6)
Physical	1.3 (0.1)	1.3 (0.1)	1.3 (0.1)	1.1 (0.1)	1.3 (0.1)	1.2 (0.1)	2.3 (0.1)	2.1 (0.1)	2.2 (0.1)	2.3 (0.1)	1.8 (0.2)	2.0 (0.1)	1.5 (1.1)	1.5 (1.2)
N (%) tried new treatment	-	-	-	54 (46)	27 (35)	81 (42)	32 (38)	22 (33)	54 (36)	12 (22)	6 (16)	18 (20)	-	-
Number new tried	-	-	-	2.4 (0.2)	2.7 (0.3)	2.6 (0.2)	2.3 (0.2)	2.8 (0.3)	2.6 (0.2)	1.3 (0.4)	2.0 (0.6)	1.7 (0.4)	2.2 (1.4)	2.7 (1.6)

Note: N = number of participants; BPI = Brief Pain Inventory; K-10 = Kessler Distress Scale; CPAQ = Chronic Pain Acceptance Questionnaire; WHOQOL-BREF = World Health Organisation Quality of Life – Brief Scale. Scores represent estimated mean (standard error) unless indicated otherwise to be N (%).

Table 4.2: Estimated means for outcome domains, by Time and Sex (first 12 months of waiting) cont.

Outcome Domain	T1 (intake)			T2 (2 months)			T3 (6 months)			T4 (12 months)			SEX	
	Female	Male	Total	Female	Male	Total	Female	Male	Total	Female	Male	Total	Female	Male
<i>Medication usage</i>														
% relief received	41.9 (1.8)	39.0 (2.1)	40.4 (1.4)	42.2 (2.2)	39.4 (2.6)	40.8 (1.7)	43.6 (2.3)	39.8 (2.7)	41.7 (1.8)	42.5 (2.9)	35.4 (3.6)	39.0 (2.3)	42.2 (23.5)	38.3 (24.3)
Change since last (N, %)														
Taking stronger / more	-	-	-	49 (42)	21 (27)	70 (36)	34 (40)	21 (31)	55 (36)	27 (50)	14 (38)	41 (45)	-	-
Nil, taking same	-	-	-	45 (38)	43 (55)	88 (45)	37 (44)	30 (45)	67 (44)	22 (41)	13 (35)	35 (39)	-	-
Taking weaker / less	-	-	-	16 (14)	9 (12)	25 (13)	6 (7)	8 (12)	14 (9)	3 (5)	7 (19)	10 (11)	-	-
Ceased all medication	-	-	-	2 (2)	4 (5)	6 (3)	4 (5)	3 (4)	7 (5)	1 (2)	1 (3)	2 (2)	-	-
Not reported	-	-	-	5 (4)	1 (1)	6 (3)	3 (4)	5 (8)	8 (6)	1 (2)	2 (5)	3 (3)	-	-

Note: N = number of participants; BPI = Brief Pain Inventory; K-10 = Kessler Distress Scale; CPAQ = Chronic Pain Acceptance Questionnaire; WHOQOL-BREF = World Health Organisation Quality of Life – Brief Scale. Scores represent estimated mean (standard error) unless indicated otherwise to be N (%).

Next, we compared the key outcomes at each follow-up (T2-T6) of groups defined by their participation status at the following time-point (T3-T7), to determine whether those who continued in the study differed from those who did not (received appointment/opted-out/cancelled appointment). All group differences were non-significant at each time-point, with one exception: individuals who received a PMU appointment at T3 reported more psychological distress at T2 ($M = 33.7$, $SD = 8.3$) than those who opted-out of the study ($M = 25.4$, $SD = 7.6$) at T3 ($F(3,191) = 30.94$, $p = 0.028$) (see [Supplementary Table 4.B](#)). This aligns with PMU triage practices (those reporting greater psychological distress received earlier appointments). Overall, these analyses suggest that those who continued were comparable to those who opted-out.

Finally, levels of socially-desirable responding were compared at each follow-up to evaluate any variance in response validity. The tendency toward socially-desirable responding did not differ over time or between sexes (Time: $F(6, 540) = 1.36$, $p = 0.230$; Sex: $F(1, 675) = 0.103$, $p = 0.310$), nor was there an interaction effect (Time x Sex: $F(6, 540) = 0.61$, $p = 0.720$). Scores fell well below normative standards across all time-points (see [Supplementary Table 4.B](#)), suggesting that participants were not consciously or unconsciously distorting their responses.

Although the preceding analyses indicated that continuing participants were not a biased sample, ongoing attrition (due to participants receiving PMU appointments or opting-out of the study) meant that the T5-T7 samples were small; reducing statistical power and certainty in the conclusions drawn from these data. Hence, the data for the first 12 months (T1-T4), when the samples were large, were examined first. In the absence of research examining very long waits, we also examined T1-T7 in order to determine whether there were any noteworthy preliminary findings. Given the reduced statistical power of these T1-T7 analyses, there is a risk that some changes/findings may go undetected; consequently they provide a conservative estimate of the impact of long wait-times.

Pain Impact (BPI)

First year (T1-T4). Pain-related interference changed significantly over the first year of waiting (Time: $F(3, 135) = 3.70, p = 0.013$), with post-hoc analyses indicating that participants reported steadily decreasing amounts of pain-related interference, such that T4 scores were significantly less than at intake (T1) ($M_{\text{difference}} = 0.55, p = 0.008, d = 0.18$). Sex differences were not evident ($F(1, 252) = 2.61, p = 0.108$). Pain severity did not change over Time ($F(3, 134) = 0.70, p = 0.554$), but there was a small sex difference ($F(1, 249) = 5.40, p = 0.021$); with females reporting more severe pain (see [Tables 4.2](#) and [4.3](#)). No interaction effects were found ($F(3, 135) = 2.33, p = 0.077$; and $F(3, 134) = 0.24, p = 0.871$, respectively).

Longer-term trends (T1-T7). Although males reported decreasing pain-related interference in the longer-term, females experienced relatively stable levels until T6, followed by a significant increase, with a marked sex difference at T7 (interaction: $F(6, 24) = 10.98, p < 0.001$). Notably, the T3-T6 findings equated to medium to large and significant effects, with the three-point difference in BPI scores at T7 being clinically meaningful (see [Supplementary Tables 4.C](#) and [4.D](#)). The sex differences in pain severity were maintained in the longer-term ($F(1, 141) = 4.77, p = 0.031$), but time-related changes also became apparent ($F(6, 30) = 3.20, p = 0.015$): pain severity was higher at T7 than all other times, except T2. The T5 and T6 findings equated to medium and large effects, respectively (see [Supplementary Tables 4.C](#) and [4.E](#)).

Psychological Distress (K-10)

First year (T1-T4). Psychological distress did not differ across Time ($F(3, 137) = 1.18, p = 0.319$) or Sex ($F(1, 264) = 0.43, p = 0.514$), nor was the interaction significant ($F(3, 137) = 1.75, p = 0.159$).

Table 4.3: Estimates of significant main effects (Time and Sex) on outcome domains

Outcome Domain	Time vs. T4	TIME				SEX			
		Estimate	95% CI		d	Estimate	95% CI		d
			LL	UL			LL	UL	
<i>Pain impact (BPI)</i> Pain severity	1	0.03	-0.46	0.51	-	-0.68 *	-1.48	0.11	0.10
	2	0.15	-0.31	0.61	-				
	3	0.02	-0.48	0.52	-				
<i>Pain acceptance (CPAQ)</i> Pain willingness	1	-3.79 ***	-5.75	-1.84	0.22	-2.89	-5.90	0.12	-
	2	-0.69	-2.60	1.21	-				
	3	-0.26	-2.16	1.64	-				
Overall pain acceptance	1	-4.03 *	-7.54	-0.53	0.13	-5.00	-10.49	0.48	-
	2	0.28	-2.99	3.52	-				
	3	-0.05	-2.96	2.85	-				
<i>Quality of life (WHOQOL-BREF)</i> Social relationships	1	0.37	-0.24	0.97	-	-1.02 *	-2.01	-0.03	0.11
	2	0.12	-0.47	0.72	-				
	3	1.27	-0.29	2.84	-				
<i>Health care utilisation</i> Frequency	1	1.66 *	0.05	3.27	0.11	-0.22	-2.61	2.17	-
	2	0.48	-1.07	2.02	-				
	3	-0.43	-1.79	0.93	-				
Treatment types Medical	1	0.01	-0.24	0.26	-	0.06	-0.36	-0.36	0.48
	2	-0.39 *	-0.71	-0.08	0.18				
	3	-0.03	-0.28	0.22	-				

Note: BPI=Brief Pain Inventory; CPAQ=Chronic Pain Acceptance Questionnaire; WHOQOL-BREF=World Health Organisation Quality of Life – Brief Scale. Scores represent M (SD) unless indicated otherwise to be N (%).

*** = p<0.001; ** p<0.01; * p<0.05

Table 4.3: Estimates of significant main effects (Time and Sex) on outcome domains cont.

Outcome Domain	Time vs. T4	TIME				SEX			
		Estimate	95% CI		d	Estimate	95% CI		d
			LL	UL			LL	UL	
<i>Health care utilization cont.</i>									
<i>Treatment types cont.</i>									
Psychological	1	-0.18	-0.47	0.11	-	-0.26	-0.71	0.19	-
	2	-0.54 **	-0.84	-0.24	0.26				
	3	0.17	-0.12	0.46	-				
Alternative	1	-0.09	-0.23	0.06	-	-0.17	-0.40	0.06	-
	2	-0.16 *	-0.31	-0.01	0.15				
	3	0.02	-0.12	0.17	-				
Physical	1	-0.95 ***	-1.26	-0.63	0.33	-0.49	-1.01	0.04	-
	2	-1.19 ***	-1.53	-0.85	0.38				
	3	-0.02	-0.36	0.33					
Number of new treatments	1	-	-	-	-	0.75	-0.08	1.58	-
	2	1.23 ***	0.60	1.86	0.44				
	3	1.02 **	0.37	1.67	0.35				

Note: BPI=Brief Pain Inventory; CPAQ=Chronic Pain Acceptance Questionnaire; WHOQOL-BREF=World Health Organisation Quality of Life – Brief Scale. Scores represent M (SD) unless indicated otherwise to be N (%).

*** = p<0.001; ** p<0.01; * p<0.05

Longer-term trends (T1-T7). Despite comparable early levels of distress (T1-T2), females reported less distress than males in the medium-term (T3-T4) and more distress in the longer-term (T5-T7) (interaction: $F(6, 34) = 41.27, p < 0.001$) (see [Supplementary Tables 4.C](#) and [4.D](#)). Those differences were greatest at T4 and T6 (large effects). Interestingly, these findings largely reflected fluctuating levels of distress in males: females reported a steady increase in distress over time – most noticeably from T4 on – while males reported oscillating levels; peaking at T6 and markedly reducing by T7. Notably, at T7, the distress reported by males ($M = 18.8, SD = 7.7$) was lower than intake; the only time when scores were within the healthy range (“likely to be well”).

Pain Acceptance (CPAQ)

First year (T1-T4). Pain willingness was impacted by both Time ($F(3, 136) = 16.46, p < 0.001$) and Sex ($F(1, 243) = 7.87, p = 0.005$), with post-hoc analyses indicating that the levels of pain willingness at T2-T4 were all significantly greater than at intake (T1) (T2: $M_{\text{difference}} = 3.53, p < 0.0001, d = 0.36$; T3: $M_{\text{difference}} = 2.96, p < 0.001, d = 0.24$; T4: $M_{\text{difference}} = 3.50, p < 0.001, d = 0.26$) and, overall, women reported more willingness than men ($M_{\text{difference}} = 32.52, p = 0.005, d = 0.16$) (see [Tables 4.2](#) and [4.3](#)). Activity engagement, however, did not differ across either domain (Time: $F(3, 137) = 1.29, p = 0.281$; Sex: $F(1, 272) = 0.66, p = 0.417$). Finally, although overall pain acceptance was unaffected by Sex ($F(1, 273) = 3.88, p = 0.050$), it was impacted by Time ($F(3, 131) = 10.10, p < 0.001$); with acceptance increasing significantly at T2 and T3, compared to intake (T1) (T2: $M_{\text{difference}} = 4.90, p < 0.001, d = 0.30$; T3: $M_{\text{difference}} = 3.94, p = 0.001, d = 0.21$), before decreasing, albeit not significantly, by T4 (12 months) (see [Tables 4.2](#) and [4.3](#)). There were no significant Time x Sex interactions for pain acceptance (pain willingness: $F(3, 136) = 0.62, p = 0.604$; activity engagement: $F(3, 137) = 0.33, p = 0.806$; overall pain acceptance: $F(3, 131) = 0.39, p = 0.760$).

Longer-term trends (T1-T7). Over time, pain willingness increased for women until T6, after which it returned to T1 levels. Men reported a different pattern, showing greater variability over time, but improving at T7 compared to intake (T1) (interaction: $F(6, 29) = 9.54, p < 0.001$) (see

[Supplementary Tables 4.C](#) and [4.D](#)). T6 was particularly notable because it equated to a medium effect. Although activity engagement was stable during the first year (T4), a significant Time x Sex interaction effect was evident at T7 ($F(6, 33) = 40.21, p < 0.001$): whereas females reported reasonably stable activity levels up to T4, followed by a gradual reduction, males reported oscillating levels (lowest at T4 and highest at T6). These sex differences represented small to medium effects (see [Supplementary Tables 4.C](#) and [4.D](#)). The findings for overall pain acceptance confirmed those in the first year, with acceptance continuing to increase over time (Time: $F(6, 27) = 5.11, p = 0.001$).

Quality of Life (WHOQOL-BREF)

First year (T1-T4). Physical health changed over Time ($F(3, 139) = 3.09, p = 0.029$), with post-hoc analyses indicating that the physical aspects of QOL increased significantly at T2 compared to T1 ($M_{\text{difference}} = 0.73, p = 0.019, d = 0.17$), but was then stable. Social relationships showed a small sex difference ($F(1, 252) = 9.58, p = 0.002$), with females reporting higher social QOL (see [Tables 4.2](#) and [4.3](#)). All other domains were unaffected by Time (psychological health: $F(3, 133) = 1.52, p = 0.213$; social relationships: $F(3, 157) = 1.33, p = 0.268$; environment: $F(3, 134) = 0.34, p = 0.794$), Sex (physical health: $F(1, 266) = 2.84, p = 0.093$; psychological health: $F(1, 303) = 0.11, p = 0.737$; environment: $F(1, 288) = 3.87, p = 0.050$), or an interaction between the two (physical health: $F(3, 139) = 0.23, p = 0.877$; psychological health: $F(3, 133) = 0.29, p = 0.834$; social relationships: $F(3, 157) = 0.38, p = 0.767$; environment: $F(3, 134) = 0.44, p = 0.727$).

Longer-term trends (T1-T7). Although physical health changed over Time ($F(6, 532) = 2.25, p = 0.038$), model estimates and post-hoc analyses were non-significant; suggesting that any changes were minimal (see [Supplementary Tables 4.C](#) and [4.E](#)). Although there was a small main effect of Sex for social relationships at T4, this was not significant by T7 ($F(1, 686) = 3.27, p = 0.071$). In contrast, despite scores being comparable throughout the first year, women reported significantly higher environmental aspects of QOL than males in the longer-term ($F(1, 614) = 3.90, p = 0.049$) (see [Supplementary Tables 4.C](#) and [4.E](#)).

Health Care Utilisation (HCU)

First year (T1-T4). Frequency of HCU changed significantly during the first year (Time: $F(3, 137) = 5.42, p = 0.001$), with post-hoc analyses indicating that participants attended fewer health care appointments at T2 and T3 than they did at T1 (T2: $M_{\text{difference}} = 1.17, p = 0.010, d = 0.18$; T3: $M_{\text{difference}} = 1.81, p = 0.003, d = 0.20$) (see [Tables 4.2](#) and [4.3](#)). There were no Sex ($F(1, 241) = 0.37, p = 0.546$) or interaction ($F(3, 137) = 0.12, p = 0.948$) effects.

For treatment type, there was a significant Time x Sex interaction in the use of physical treatments in the first 12 months ($F(3, 131) = 2.85, p = 0.040$): although both reported comparable use at T1, females decreased their use at T2, but increased at T3-T4. Males were stable across T1-T2, then increased their use at T3-T4; resulting in a marked Sex difference in the use of physical treatments at T2 (Estimate = 0.69, $p = 0.014, d = 0.19$). No interaction effects were found for any other treatment type (medical: $F(3, 136) = 0.06, p = 0.983$; psychological: $F(3, 131) = 1.00, p = 0.396$; alternative: $F(3, 134) = 0.57, p = 0.633$) and there were no main effects for Sex (medical: $F(1, 251) = 0.46, p = 0.496$; psychological: $F(1, 218) = 3.04, p = 0.083$; alternative: $F(1, 263) = 3.26, p = 0.072$). With the exception of alternative treatments, all were impacted by Time (medical: $F(3, 136) = 8.86, p < 0.001$; psychological: $F(3, 131) = 17.00, p < 0.001$; alternative: $F(3, 134) = 2.25, p = 0.086$) (see [Tables 4.2](#) and [4.3](#)). Specifically, fewer medical treatments were used at T2 than at T4, with post hoc analyses indicating that T2 levels were lower than all other time-points (T1: $M_{\text{difference}} = 0.42, p < 0.001, d = 0.28$; T3: $M_{\text{difference}} = 0.40, p = 0.001, d = 0.28$; T4: $M_{\text{difference}} = 0.40, p = 0.011, d = 0.23$). Similarly, psychological treatments were used least at T2 (T1: $M_{\text{difference}} = 0.30, p < 0.001, d = 0.30$; T3: $M_{\text{difference}} = 0.56, p < 0.001, d = 0.49$; T4: $M_{\text{difference}} = 0.43, p = 0.003, d = 0.28$) and most at T3 ($M_{\text{difference}} = 0.25, p = 0.014, d = 0.17$), suggesting a spike in uptake while waiting. Overall it appears that the use of treatments decreased immediately following referral, but increased over time while waiting for an appointment; in several instances equating to meaningful changes (medium effects).

GEE modelling of the number of new treatments tried during the first 12 months indicated that it was related to Time ($\chi^2(2, N = 221) = 12.82, p = 0.002$), with individuals being more than twice as likely to try a new treatment at T2 (OR = 2.85; 95% CI = 1.61, 5.05; $p < 0.001$) and T3 (OR = 2.20; 95% CI = 1.24, 3.91; $p = 0.007$), than at T4. The Sex ($\chi^2(1, N = 221) = 2.30, p = 0.129$) and Time x Sex interaction ($\chi^2(2, N = 221) = 0.54, p = 0.764$) effects were both non-significant. For those who tried new treatment(s), mixed-model analyses revealed that the number varied over time ($F(2, 43) = 8.30, p = 0.001$), such that individuals tried more new treatments at T2 and T3, than at T4 (medium and small-to-medium effects) (see [Tables 4.2](#) and [4.3](#)). There were also significant sex differences ($F(1, 56) = 6.17, p = 0.016$); males tried more new treatments than females ($M_{\text{difference}} = 0.56, p = 0.016, d = 0.28$). The interaction effect was not significant ($F(2, 43) = 0.47, p = 0.629$).

Longer-term trends (T1-T7). As per the first year, HCU frequency continued to decrease over Time ($F(6, 10) = 17.62, p < 0.001$), with fewer health-related appointments attended at T5 and T6, than T7. T6 was particularly notable (large effect), with four fewer appointments every three months than at T7 (see [Supplementary Tables 4.C](#) and [4.E](#)). For treatment type, there was again a significant Time x Sex interaction for *physical* treatments ($F(6, 560) = 2.47, p = 0.023$), but model estimates and post-hoc analyses indicated that any longer-term differences were small ($p < 0.05$). However, significantly fewer physical treatments were used at both T1 and T2, than at T7 (Time: $F(6, 560) = 2.47, p = 0.023$). Whereas use of *alternative* treatments was reasonably stable during the first year (T1-T4), it was less so in the longer-term (Time: $F(6, 539) = 3.06, p = 0.006$): post-hoc analyses indicated that after a small non-significant reduction at T2, the use of alternative treatments increased significantly by T6 (compared to T2) ($M_{\text{difference}} = 0.31, p = 0.035, d = 0.23$). The findings for *medical* treatments were consistent with T1-T4, with use being lowest immediately following referral (T2) than at all other times (T1: $M_{\text{difference}} = 0.45, p < 0.001, d = 0.27$; T3: $M_{\text{difference}} = 0.42, p = 0.001, d = 0.30$; T5: $M_{\text{difference}} = 0.066, p = 0.001, d = 0.29$; T6: $M_{\text{difference}} = 0.82, p = 0.002, d = 0.29$)

(Time: $F(6, 549) = 7.35, p < 0.001$). Thus, treatment use decreased immediately following referral, but frequently increased with continued waiting.

With respect to new treatments, the data indicate new treatment uptake continued to change over Time ($\chi^2(5, N = 221) = 25.27, p < 0.001$), with the interaction between Time and Sex also significant ($\chi^2(1, N = 221) = 4.17, p = 0.041$): over the longer-term, males were 38% less likely to try new treatment(s) (OR = 0.62; 95% CI = 0.40, 0.98; $p = 0.041$). For those who tried new treatment(s), the T1-T4 sex difference in the number of treatments was lost by T7 ($F(1, 76) = 2.81, p = 0.098$). Although the effect of Time was significant ($F(5, 116) = 2.63, p = 0.027$), the differences were small (model estimates and post-hoc analyses both non-significant).

Medication Usage

First year (T1-T4). Time ($F(3, 137) = 0.47, p = 0.705$) and Sex ($F(1, 228) = 2.92, p = 0.089$) did not impact on the amount of medication-related relief and there was no significant interaction ($F(3, 137) = 0.24, p = 0.867$). Changes in dose/strength, were unaffected by Time ($\chi^2(2, N = 188) = 1.89, p = 0.390$) but GEE analysis revealed a significant Sex difference ($\chi^2(1, N = 188) = 5.15, p = 0.023$), such that females were almost twice as likely to report an increase in their medication dose/strength (OR = 1.93; 95% CI = 0.84, 4.46; $p = 0.12$). Indeed, 36%-45% of the sample reported taking more/stronger medication than they had previously at each time-point (see [Table 4.2](#)). There was no Time x Sex interaction ($\chi^2(2, N = 188) = 0.38, p = 0.829$).

Longer-term trends (T1-T7). The results concerning medication use were supported in the longer-term (see [Supplementary Tables 4.C](#) and [4.E](#)), with females being more likely to report an increase in the dose/strength of their medication throughout the study.

4.6 Discussion

We examined the psychological adjustment and HCU of adults while waiting for up to 2.5 years for a first appointment at an Australian multidisciplinary CP service. Waits were non-standard because referrals were triaged, based on clinical need. Thus, participants exited the study (received an appointment) at different times which, when combined with those who opted-out or whose referral was cancelled, meant that there were fewer people in the longer-term follow-ups (T5-T7) than the first year (T1-T4). Although participants who completed the study were comparable to those who did not, smaller samples impact statistical power. Although tentative, our longer-term findings (T1-T7) are the only published data exploring the long waits experienced by many people with CP. Sample attrition is an inherent difficulty in longitudinal studies of clinically-triaged waitlists, possibly explaining the dearth of research examining long waits.

The impact of waiting on psychological adjustment and HCU was mixed. Some domains showed deterioration: more commonly for women than men and usually after one or more years ($\geq T4$). Although the one-year data indicated decreasing pain interference and stable psychological distress, there may be longer-term sex differences. Whereas males reported that pain interfered less in their daily activities after six months (T3) (improvement), females were stable for the first two-years, followed by a large increase (T7) (decline). Similarly, women reported increasing distress over time (rapidly escalating at one-year post-referral; T4), but men fluctuated with no clear pattern, ending (T7) with below-intake (T1) levels. Similarly, pain acceptance was stable (activity engagement) or improved (pain willingness, overall pain acceptance) in the first year, but women deteriorated after 18 months (T5, activity engagement) and 2.5 years (T7, pain willingness), while men oscillated before improving. Although tentative, these longer-term findings highlight the changing impact of waiting for treatment over prolonged periods.

The types of HCU sought also changed following referral to the PMU; overall HCU decreased immediately following referral (T2, T3), followed by significant increases in the use of

psychological therapies at six months (T3), alternative therapies at two-years (T6) and physical therapies at 2.5 years (T7). This contrasted with a reduction in overall HCU frequency during the same period (18-24 months), suggesting that health care became more focussed. However, it is unclear whether this decrease occurred because participants did not attend appointments — due to better self-management or reduced hope about benefits — or whether appointments decreased for other reasons (e.g. awaiting PMU appointment). Although the underlying cause(s) are unclear, these changes have implications for health planning.

Perhaps surprisingly, some domains appeared largely unaffected by the long indefinite wait. Despite females reporting more severe pain (consistent with research by Bartley & Fillingim, 2013), pain severity was relatively stable for everyone in the first year, with longer-term findings suggesting this continued before spiking at 2.5 years (T7). This is consistent with the reports of stable medication-related pain relief. Nevertheless, over a third of the sample, and twice as many women, reported an increase in the dose/strength of their medication at each survey. This accords with recent research suggesting that women frequently obtain equal or greater access to pharmacotherapy than men, including polypharmacy, which may defy best-practice guidelines (Oliva et al., 2015). Unfortunately, sex differences in medication use at baseline could not be examined because this information was not collected. Males may have entered the waitlist on more optimal doses, whereas females may have started at suboptimal doses, thus requiring increased pain relief. Indeed, the relatively stable ratings of pain severity and medication relief may have been achieved because medication dose/strength increased. Prescribing may also have been influenced by other factors (e.g., greater longer-term distress/pain-related interference in females), although dosage changes did not correlate with ratings of pain severity or relief, implying that medication increased without benefit.

QOL was similarly unchanged over time. Males generally reported less satisfaction with their social relationships (first year) and environmental supports/opportunities (longer-term) than

females. Although consistent with literature asserting that males experience significantly greater erosion of QOL when in pain (McNamee & Mendolia, 2014), other aspects of QOL were not similarly impaired. However, given baseline QOL was well-below Australian norms, further deterioration may have been unlikely.

In terms of intervention, no critical time or endpoint was highlighted by the data. However, pain acceptance — an important precursor for change — peaked between two and six months post-referral, suggesting that therapeutic change may be optimized if interventions are delivered during that period. Moreover, although the overall stability in numerous domains in the six months (T3) after referral (T1) challenges reports of participant deterioration during that period (Lynch, et al., 2008), our preliminary findings suggest that longer waits (>12 months) were associated with increasing distress and decreasing function, especially in women; supporting the view that earlier intervention is important.

In combination, the findings appear conclusive for women, but clear guidelines for men could not be established because their coping was more variable. Although men reported comparatively greater psychological distress than women in the medium-term, the reverse occurred in the longer-term. Moreover, although new treatment uptake was greater for females, women also reported patterns of stable or declining adjustment, suggesting limited benefit. Together, these findings suggest that despite being more variable, men tended to fare comparatively better than women during long and indefinite waits, implying a possible trend towards improved coping with, if not adaptation to, pain.

Study Limitations

First, almost half of those who were invited declined participation. Despite being demographically comparable (age, sex) to the study sample, they may have differed in other important ways. For example, non-participation may have reflected greater psychological distress or, conversely, participation may have been motivated by the desire for assistance, with more

distressed people enrolling. Nevertheless, the final sample resembled others recruited from public multidisciplinary CP services, across multiple dimensions (e.g. demographics, pain duration, distress, pain-related interference, pain severity) (e.g., Smith, et al., 2016) and was therefore likely to be broadly representative. Second, only self-report data were collected; with obvious implications for response validity in the current context. The question exploring HCU treatment types asked about *treatments tried (ever)*, rather than *treatments currently using*. Scores on this variable should not decrease, but did, possibly influenced by pain-levels at the time of responding, resulting in impaired recall. However, estimates of pain severity were either stable (females) or decreased (males) from intake to two years, suggesting this is unlikely. Similarly, participants' responses did not appear to have been influenced by social desirability. It is therefore likely that, in general, responses were reliable (within limitations of self-report) and that some responses to the 'treatment types' question reflected current, not historical, use. Third, although prospective and repeated assessments were completed, there was no comparison group (randomised access to treatment is ethically unacceptable) making it difficult to dismantle any confounding influences of initial triage and other factors (e.g. hospital admissions, advocacy) on the timing of the PMU appointments. Fourth, sample attrition from T1-T7 reduced the power of our analyses, possibly underestimating the extent of the impact of waiting. Finally, as noted elsewhere (Burke, Denson, et al., 2016), the follow-up assessments may have had some intrinsic benefit (e.g., participants feeling attended to), potentially ameliorating some impact of waiting to access treatment, particularly indefinite waiting. Similarly, providing participants with information about other sources of psychological assistance (duty-of-care/ethical requirement), may have also had benefits. Qualitative research exploring patient perceptions of waiting would be a useful future addition.

Overall, this study suggests that an indefinite wait of 12 months-2.5 years to access multidisciplinary CP treatment may be associated with deterioration across important functions (pain-related interference, psychological distress, pain willingness, activity engagement). Females

typically reported the greatest levels of impairment, whereas males fluctuated, often improving by the end of the waiting period. There were also meaningful changes in a range of variables (e.g., medication usage, treatment uptake) that require further exploration. Importantly, our data suggest that, for women at least, intervening within six months of referral to a CP service may help optimise outcomes; a recommendation that needs evaluation.

Chapter 5 : Staffing in Australian Tertiary Chronic Pain Clinics

5.1 Preamble

Having established the psychological impact of living with CP and of lengthy indefinite waits for treatment, this project then addressed its secondary aim, which was to explore service-related factors that may impact access to CP treatment. The first target for this examination was staff resources in Australian tertiary CP services.

Although there are evidence-based guidelines for the treatment of CP, there does not appear to be any research establishing the amount and mix of staff resources that are necessary to effectively enact evidence-based care in this clinical population. This creates problems when (re)designing health care services because it is unclear whether long wait-times primarily reflect insufficient resourcing *or* an inefficient use of the available resources. Therefore, this third paper surveyed and critically examined multidisciplinary staffing profiles in tertiary CP centres across Australia. Importantly, staffing was considered in terms of specific disciplines (medical, psychiatry, nursing, physiotherapy, clinical psychology, occupational therapy, administrative) and numbers, and as a function of clinical activity (staff per patient), thus facilitating the calculation of individualised clinical profiles.

The published article for this chapter ([Appendix 3.2](#)) referred to persistent rather than chronic pain because that was the preferred term of the fourth author (MNH). It has been changed to CP in the body of the chapter so that consistent terminology is used throughout this larger thesis document.

Tables and Figures are inserted within the text and online supplementary information is presented in [Appendix 3](#):

- Survey questions ([Appendix 3.1](#)), and
- A copy of the published article (reproduced with permission) ([Appendix 3.2](#)).

All [references](#) have been included in a complete reference list at the end of this thesis.

Study 3

AN ANALYSIS OF MULTIDISCIPLINARY STAFFING LEVELS AND CLINICAL ACTIVITY IN AUSTRALIAN TERTIARY PERSISTENT PAIN SERVICES

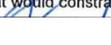
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Principal Author

Name of Principal Author (Candidate)	Anne L. J. Burke		
Contribution to the Paper	ALJB and MNH were responsible for study inception. ALJB was solely responsible for study design, data coding, statistical analysis and manuscript preparation.		
Overall percentage (%)	85%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	16.10.18

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

- the candidate's stated contribution to the publication is accurate (as detailed above);
- permission is granted for the candidate to include the publication in the thesis; and
- the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Linley A. Denson		
Contribution to the Paper	LAD consulted across all aspects of this research and manuscript preparation, providing expert supervisory input.		
Signature		Date	31/10/2018

Name of Co-Author	Jane L. Mathias		
Contribution to the Paper	JLM consulted across all aspects of this research and manuscript preparation, providing expert supervisory input.		
Signature		Date	18/10/18

Name of Co-Author	Malcolm N. Hogg		
Contribution to the Paper	ALJB and MNH were responsible for study inception. MNH was responsible for data collection (conducting study interviews) and provided expert knowledge, particularly in relation to data interpretation and manuscript reviews.		
Signature		Date	2/10/18

5.2 Abstract

Objective: To document staffing (medical, nursing, allied health (AH), administrative) in Australian multidisciplinary chronic pain services and relate them to clinical activity levels.

Methods: Of the 68 adult outpatient chronic pain services approached (Dec 2008 – Jan 2010), 45 agreed to participate, received over 100 referrals/year, and met the contemporaneous IASP criteria for Level 1 or 2 multidisciplinary services. Structured interviews with Clinical Directors collected quantitative data regarding staff resources (disciplines, amount), services provided, funding models and activity levels.

Results: Compared to Level 2 clinics, Level 1 centres reported higher annual demand (referrals), clinical activity (patient numbers), and absolute numbers of medical, nursing and administrative staff, but comparable numbers of AH staff. When staffing was assessed against activity levels, medical and nursing resources were consistent across services, but Level 1 clinics had relatively fewer AH and administrative staff. Metropolitan and rural services reported comparable activity levels and discipline-specific staff ratios (except occupational therapy). The mean annual AH staffing for pain management group programs was 0.03 full-time equivalent (FTE) staff per patient.

Conclusions: Reasonable consistency was demonstrated in the range and mix of most disciplines employed, suggesting they represented workable clinical structures. The greater number of medical and nursing staff within Level 1 clinics may indicate a lower multidisciplinary focus, but this needs further exploration. As the first multidisciplinary staffing data for chronic pain clinics, this provides critical information for designing and implementing clinical services. Mapping against clinical outcomes to demonstrate the impact of staffing patterns on safe and efficacious treatment delivery is required.

5.3 Introduction

Chronic Pain (CP) costs Australia \$AUD34.3 billion annually (Access Economics, 2007). With a point-prevalence of approximately 20% (Blyth, et al., 2001), around 3.2 million Australians were living with this condition in 2007. Population aging estimates suggests this figure will reach 5.0 million by 2050 (National Pain Summit Initiative, 2011). Despite the high incidence of CP and its associated disease-burden, timely access to appropriate treatment is out of reach for many Australians. Indeed, approximately 80% of people fail to receive an intervention that could improve their functioning and quality of life (National Pain Summit Initiative, 2011), while those who do receive treatment endure wait-times of six-18 months or longer (Hogg, et al., 2012), during which time their health and well-being often deteriorate (Lynch, et al., 2008).

Although the day-to-day care of people with CP occurs in primary care settings, a significant proportion of patient consultation and advice regarding complex case management is provided by tertiary pain units. As outlined by the International Association for the Study of Pain (IASP) (IASP, 2009), these units are multidisciplinary in nature, offering an integrated range of services spanning assessment and treatment of physical and mental health, pharmacotherapy, medical procedures (e.g., nerve blocks), physical therapies, psychosocial interventions (e.g., cognitive behavioural therapy, acceptance and commitment therapy), group programs and education. Many of these clinical teams are also heavily involved in training and research activities – developing the evidence-base and workforce of the future. Recommendations are available regarding the disciplines that should be represented in these clinics and the types of services that should be provided (Gatchel & Okifuji, 2006; National Pain Summit Initiative, 2011), but in the absence of a clear formulae for clinic structure, the exact types and amounts of services offered may vary greatly.

As outlined by Health Workforce Australia (HWA), significant innovations are needed in both health care delivery and training, for the Australian health care system to be sustainable (Health Workforce Australia, 2012). In the midst of major health care reforms (Council of Australian

Governments, 2011), the health system is under increasing pressure to enhance patient outcomes by facilitating timely access to services. The current wait-times associated with accessing tertiary pain services demonstrate that the present model of care is inappropriate to address clinical need and/or that units are inadequately staffed.

From a model of care perspective, considerable evidence is available to inform multidisciplinary therapeutic guidelines for CP (Chan, et al., 2011; Eccleston, et al., 2009; Hassett & Williams, 2011; Louw, et al., 2011; Morley, et al., 2008; Morlion, 2011) and Australian pain clinicians are actively moving beyond established methods of service delivery to trial novel initiatives, such as pre-clinic education sessions (Davies, et al., 2011), on-line treatments (Dear et al., 2013) and enhanced links with primary care (C. Hayes & Hodson, 2011). There has also been a strong national endeavour across CP services to actively monitor patient outcomes, in order to ensure that the treatments provided actually result in improved function and quality of life for patients (refer NSW Department of Health). Despite these initiatives, however, there are currently no empirical data regarding the staffing resources that are required to effectively assess and treat CP in tertiary clinical settings, or the impact of different staffing levels and patterns on patient outcomes.

Careful resource allocation is crucial to patient care. For inpatients, at least, the impact of nursing and medical staffing levels on service delivery is well-documented. Suboptimal staffing is associated with problems in assessment and treatment delivery, longer admissions, and higher complication rates and medical costs (Cho, Ketefian, Barkauskas, & Smith, 2003; Holmes, Handrinos, Theologus, & Salzberg, 2011). While tertiary pain services employ doctors and nurses, they also employ significant numbers of allied health (AH) professionals; most commonly psychologists, physiotherapists and occupational therapists (National Pain Summit Initiative, 2011). The impact of AH staffing is less well understood, due to factors such as inadequate systems for capturing workforce information (Harris, Gavel, & Conn, 2002); smaller and more fragmented professional structures for AH (Campbell, Smedts, Lowe, Keane, & Smith, 2010); less directly

established relationships between specific AH interventions and clinical outcomes; and unclear service tracking due to variable funding models, not all of which are attributable to specific disciplines (National Health Workforce Planning and Research Collaboration, 2010; Schoo, Boyce, Ridoutt, & Santos, 2008). Because this gap in the data involves a significant proportion of the multidisciplinary pain management workforce, it creates problems for evidence-based health care design in tertiary CP services.

The 'Standards for Adult Inpatient Medical Rehabilitation Services' produced by the Australian Faculty of Rehabilitation Medicine (AFRM) (Australasian Faculty of Rehabilitation Medicine, 2005) currently provide the most comprehensive guidelines for multidisciplinary staffing. Detailing numerous aspects of service delivery, including staffing, equipment requirements and treatment guidelines, this document has identified and quantified many of the major service needs for medical rehabilitation providers. These Standards can, and do, inform tertiary outpatient CP services, but they do not specify optimal or minimum staffing establishments for such pain clinics, or provide an evidence-base for resource allocation. In order to make informed choices about service design and delivery, service directors first need to understand the current staffing configurations of multidisciplinary pain clinics, after which they can evaluate these models in terms of patient outcomes and thereby work to maximise service efficiencies — a major consideration for sustainable health care. The first stage of this process was undertaken by the 'Waiting in Pain' (WIP) project of the Australian Pain Society (a chapter of IASP). Primary outcome data from the WIP project has been reported previously; detailing clinic structure, funding models and activity, as well as wait-times to access services (Hogg, et al., 2012). This paper extends the findings of the WIP project by offering the first detailed analysis of the staffing associated with Australian tertiary outpatient services for adults with CP, thereby providing valuable information that can inform service design and delivery.

5.4 Method

Sample and Data Collection

As stated above, the study data were collected as part of the WIP project of the Australian Pain Society (APS), which explored the provision of outpatient CP services in Australia (Hogg, et al., 2012). After an exhaustive search — spanning a pre-existing APS facility directory, internet searches and consultation with local experts — 68 adult CP services were identified and contacted, 57 (84%) of which agreed and were eligible to participate in the WIP study (three did not respond; six declined; two were excluded due to low referrals: <100 per/year) (see Hogg, et al. (2012) for a more detailed account of the recruitment method). Because the focus of the current analysis was on the structure and function of multidisciplinary clinics, we excluded an additional nine clinics that operated under a limited pain clinic model (not offering multi- or inter-disciplinary care) and three with a single-discipline model, resulting in a final sample of 45 publicly and/or privately funded multidisciplinary pain clinics.

Outcome Measures

CP Service Directors (medical, nursing, AH) completed structured interviews (see [Appendix 3.1](#)), either face-to-face or by telephone, between December 2008 and January 2010. Interviews were conducted by M.N.H and/or a research officer. Where necessary, responses were later clarified by telephone/email.

Participants were provided in advance with the interview questions, which covered: the various disciplines that they employed (medical, nursing, psychiatry, psychology, physiotherapy, occupational therapy, administrative); staffing levels (i.e. full-time equivalent (FTE) staffing — total number of hours worked by paid staff (part-time, full-time and casual/sessional employees) divided by the number of hours worked by a full-time staff member); types of outpatient service provided; funding models; annual referral numbers; and patient activity levels. The provision of Pain

Management Group Programmes (PMGP) was specifically explored because this was deemed to be a key indicator of services that offered co-ordinated interdisciplinary care, compared with those who facilitated multidisciplinary input in a non-integrated fashion (e.g., referred to independent allied health services as required). In addition, qualitative information was sought regarding the evolution of services, barriers to optimal care and service development plans, however, data was reported in insufficient levels to permit meaningful analysis of this information. The data sources used by respondents were also documented, with most basing their estimates on electronic systems or paper-based records (see [Table 5.1](#)). Although somewhat less reliable than the more objective data sources, informed estimates were deemed acceptable as the research method (i.e., providing respondents with the structured interview questions in advance) facilitated the collection of relevant data/information prior to the interview, thereby maximising data accuracy. Full-time equivalent (FTE) figures for psychiatry were recorded separately to general medical FTE because psychiatry was not consistently provided by all services and, where available, represented a secondary consultancy role that was distinct from the initial medical assessment.

Using the IASP classification system for multidisciplinary pain treatment services available at the time of data collection (IASP, 2009), each clinic was coded as Level 1 (i.e., multidisciplinary pain [MDP] management centre offering coordinated interdisciplinary patient care, research and training) or Level 2 (MDP management clinic operating as for Level 1, but without regular research and teaching activities).

Data Analysis

Quantitative data were analysed using IBM SPSS Statistics 20 (SPSS Inc, 2011). Descriptive statistics explored clinic characteristics, funding models, service locations and data sources. Homogeneity of variance was checked using Levene's test for equality of variance. Analysis of variance and *t*-tests were used to explore differences in staffing numbers across clinic and discipline type, clinical activity, location of service delivery (rural vs. metro, Australian states),

Table 5.1: Source of data and general service information

	<i>n</i>	%
<i>Source of data</i>		
Electronic system	20	44.4
Clinic lists	18	40.0
Informed estimates	7	15.6
<i>Service location</i>		
Rural	8	17.8
Metropolitan	37	82.2
<i>FTE employed</i>		
Rural *	4.9	3.3
Metropolitan *	8.0	4.6
Total *	7.4	4.5
<i>Funding Source</i>		
Public (>90%)	25	55.6
Private (>90%)	11	24.4
Mixed	9	20
<i>Links with acute pain service (APS)</i>		
No connection	19	42.2
Independent but connected to APS	21	46.7
Located within APS	5	11.1

Note. FTE = full time equivalent; APS = acute pain service. Data reported is *n* (%) except where marked with an *, indicating data is *M* (*SD*).

and PMGP factors (e.g., programme intensity, location). Cohen's *d* measured the magnitude of the effects ($d = .3, .5, .8$ equate to small, medium, large effects, respectively (Cohen, 1988)). Confidence intervals (CI) were also calculated for *d* to examine the significance of the observed effects: CIs that span zero are not statistically significant.

Ethics Approval

The study was approved by the Human Research Ethics Committee of Royal Melbourne Hospital (HREC 2008.119).

5.5 Results

Most of the 45 services included in this study were based in capital cities, connected to an acute pain service and partly, or mostly, publicly-funded (see [Table 5.1](#)). Clinic sizes ranged from 0.9 FTE (Victoria, rural) to 20.9 FTE (Queensland, metropolitan).

Clinic Type

Using IASP criteria (IASP, 2009), 26 services were classified as Level 1 and 19 as Level 2. Mean FTEs by discipline and clinic type are summarised in [Table 5.2](#). Overall, Level 1 centres employed significantly more staff than did Level 2 clinics ($t(43) = 2.91, p = 0.006, d = 0.09$): specifically, more medical ($t(39.0) = 6.70, p < 0.001, d = 1.8$), psychiatry ($t(30.74) = 3.38, p = 0.002, d = 1.1$), nursing ($t(37) = 2.61, p = 0.013, d = 0.9$), and administrative ($t(38) = 2.29, p = 0.028, d = 0.7$) staff. However, the service types were comparable regarding the number of AH staff they employed.

Clinic Activity

Consistent with the finding that Level 1 centres employed more staff in all disciplines, except AH, they reported receiving significantly more referrals ($t(43) = 3.37, p = 0.002, d = 1.1$) and seeing more new patients ($t(43) = 3.09, p = 0.004, d = 0.09$) each year than Level 2 clinics. Nationally, Level 1 centres saw around 65% (range: 43% SA to 90% ACT) of their annual new referrals, whereas Level 2 clinics saw approximately 73% (range: 52% QLD to 100% SA). Despite there being no differences in overall AH staffing between Level 1 and 2 clinics, there were significant differences between Australian states in the employment of occupational therapists within both Level 1 and 2 services (Level 1: $F(5, 11) = 3.23, p = 0.049$; Level 2: $F(6, 9) = 6.75, p = 0.006$), and in the employment of psychiatrists in Level 1 services ($F(6, 15) = 5.98, p = 0.002$) (see [Table 5.2](#)).

Table 5.2: Staff numbers: mean FTE (standard deviation) by discipline and clinic type

	TOTAL FTE	Medical	Psychiatry	Nursing	Physiotherapy	Psychology	Occupational Therapy	Administrative	Annual # New Referrals	Annual # New Patients Seen
<i>National TOTAL</i>	7.4 (4.5) N=45	2.1 (1.5) N=45	0.2 (0.2) N=33	1.5 (1.3) N=39	1.1 (0.9) N=41	1.0 (0.7) N=41	0.5 (0.5) N=33	1.7 (1.3) N=40	766 (575) N=45	514 (363) N=45
LEVEL 1 MDP CENTRE										
<i>Total</i>	9.0 (4.6) ** N=26	3.0 (1.3) *** N=26	0.3 (0.2) ** N=22	1.9 (1.2) * N=24	1.1 (0.7) N=23	1.1 (0.7) N=23	0.5 (0.6) N=17	2.1 (1.3) * N=22	988 (494) ** N=26	645 (239) ** N=26
NSW	7.3 (4.7) N=11	2.5 (1.1) N=11	0.3 (0.2) N=9	2.0 (1.4) N=9	0.8 (0.9) N=10	0.8 (0.8) N=10	0.3 (0.3) N=5	1.7 (1.3) N=9	796 (326) N=11	598 (276) N=11
VIC	8.9 (2.4) N=5	3.6 (1.0) N=5	0.1 (0.1) N=5	1.3 (0.7) N=5	1.3 (0.4) N=4	1.5 (0.6) N=4	0.6 (0.7) N=4	1.6 (0.6) N=4	745 (274) N=5	545 (126) N=5
QLD	13.2 (10.9) N=2	3.8 (2.5) N=2	0.8 N=1	2.8 (1.8) N=2	2.0 N=1	2.1 N=1	2.0 N=1	3.3 (1.8) N=2	1766 (826) N=2	766 (119) N=2
WA	10.8 (5.1) N=3	3.2 (1.8) N=3	0.1 (0.1) N=2	1.8 (1.7) N=3	1.4 (0.6) N=3	1.0 (0.6) N=3	0.5 (0.3) N=3	2.8 (1.4) N=3	1000 (200) N=3	700 (173) N=3
SA	12.8 (1.8) N=2	4.1 (1.6) N=2	0.4 (0.2) N=2	2.8 (0.3) N=2	1.0 (0.4) N=2	2.0 (0.0) N=2	-	2.5 (0.7) N=2	1850 (212) N=2	800 (283) N=2
Tas	8.0 N=1	2.7 N=1	0.7 N=1	2.0 N=1	1.3 N=1	1.3 N=1	-	-	1500 N=1	900 N=1
ACT	7.9 (0.9) N=2	1.6 (0.6) N=2	-	1.8 (1.7) N=2	0.8 (0.4) N=2	1.0 (0.0) N=2	0.3 (0.4) N=2	2.5 (2.1) N=2	739 (370) N=2	664 (476) N=2
NT	-	-	-	-	-	-	-	-	-	-
LEVEL 2 MDP CLINIC										
<i>Total</i>	5.3 (3.6) N=19	1.0 (0.7) N=19	0.1 (0.1) N=11	0.9 (1.1) N=15	1.1 (1.1) N=18	0.8 (0.6) N=18	0.5 (0.5) N=16	1.2 (1.2) N=18	461 (549) N=19	335 (430) N=19
NSW	5.4 (2.2) N=4	1.1 (0.5) N=4	0.2 (0.3) N=2	1.5 (1.3) N=3	0.7 (0.3) N=4	1.0 (0.1) N=4	0.1 (0.1) N=2	1.4 (1.1) N=4	288 (85) N=4	231 (121) N=4
VIC	4.3 (4.5) N=7	1.0 (0.8) N=7	-	0.1 (0.1) N=4	1.4 (1.8) N=6	0.7 (0.7) N=6	0.4 (0.3) N=6	1.4 (1.9) N=6	741 (846) N=7	509 (671) N=7

Note. FTE = full time equivalent; MDP = multidisciplinary pain; SA = South Australia; VIC = Victoria; Tas = Tasmania; NSW = New South Wales; ACT = Australian Capital Territory; QLD = Queensland; NT = Northern Territory; WA = Western Australia; Effect Size=Cohen's *d*. SD and confidence intervals are shown in parentheses for means and effect sizes (Cohen's *d*) respectively. *** = $p < 0.001$; ** $p < 0.01$; * $p < 0.05$

Table 5.2: Staff numbers: mean FTE (standard deviation) by discipline and clinic type cont.

	TOTAL FTE	Medical	Psychiatry	Nursing	Physiotherapy	Psychology	Occupational Therapy	Administrative	Annual # New Referrals	Annual # New Patients Seen
LEVEL 2 MDP CLINIC cont.										
QLD	5.5 (3.7) N=4	0.6 (0.5) N=4	-	0.9 (1.3) N=4	1.0 (0.5) N=4	0.5 (0.4) N=4	0.6 (0.3) N=4	1.0 (0.8) N=4	260 (161) N=4	135 (33) N=4
WA	11.0 N=1	1.0 N=1	-	1.0 N=1	2.0 N=1	2.5 N=1	2.0 N=1	2.0 N=1	500 N=1	500 N=1
SA	2.8 N=1	0.6 N=1	0.1 N=1	1.0 N=1	0.1 N=1	0.2 N=1	-	0.8 N=1	568 N=1	568 N=1
Tas	-	-	-	-	-	-	-	-	-	-
ACT	7.8 N=1	1.3 N=1	0.0 N=1	3.0 N=1	1.0 N=1	1.0 N=1	0.5 N=1	1.0 N=1	100 N=1	100 N=1
NT	4.8 N=1	1.3 N=1	-	-	1.0 N=1	1.0 N=1	1.0 N=1	0.5 N=1	221 N=1	171 N=1
<i>Effect size</i>	0.9 (0.3, 1.5)	1.8 (1.1, 2.5)	1.1 (0.4, 1.9)	0.9 (0.2, 1.5)	0.0 (-0.6, 0.6)	0.5 (-0.2, 1.1)	0.0 (-0.7, 0.7)	0.7 (0.1, 1.4)	1.1 (0.6, 1.5)	0.9 (0.3, 1.6)

Note. FTE = full time equivalent; MDP = multidisciplinary pain; SA = South Australia; VIC = Victoria; Tas = Tasmania; NSW = New South Wales; ACT = Australian Capital Territory; QLD = Queensland; NT = Northern Territory; WA = Western Australia; Effect Size=Cohen's *d*. SD and confidence intervals are shown in parentheses for means and effect sizes (Cohen's *d*) respectively.

*** = $p < 0.001$; ** $p < 0.01$; * $p < 0.05$

An examination of staff resources is more meaningful when evaluated against clinical activity. Detailed information regarding the range of specific clinical activities was not collected, but [Table 5.3](#) displays the national mean average staffing levels (FTE) for each discipline/procedure type, per hundred new patients. Despite lower referral and activity rates, Level 2 clinics had significantly more administrative and AH (all types) staff resources per patient than Level 1. The fact that Level 1 and 2 clinics employed comparable numbers of medical and nursing staff (when assessed against their activity levels) suggests that they were providing similar amounts of medical care. Level 1 and 2 clinics also provided similar rates of medical procedures, both minor (e.g., epidural steroids and nerve blocks) ($t(42) = 0.36, p = 0.719, d = 0.29$) and major (e.g., spinal cord stimulation and intrathecal pumps) ($t(41) = 0.94, p = 0.352, d = 0.11$). Of note, medical procedure rates were calculated on the basis of number of 'new patients' seen and therefore do not reflect overall caseload (new + existing patients) rates. Irrespective, while there was no significant difference between the clinic types overall, the range within both clinic categories indicates significant variability across individual clinics in their use of these types of medical procedures (see [Table 5.3](#)).

Location of Service

Sixty-two percent ($n = 23$) of the metropolitan based services were classified as Level 1 centres ($n = 23$), compared with 38% ($n = 3$) of rural services. Overall, as summarised in [Table 5.4](#), metropolitan and rural based services reported employing comparable numbers of staff across most disciplines ($t(43) = 1.79, p = 0.081, d = 0.7$); the exception being doctors, who were employed in greater numbers in metropolitan based services ($t(43) = 2.34, p = 0.024, d = 0.9$). Metropolitan and rural services also reported receiving comparable numbers of new referrals ($t(43) = 1.71, p = 0.095, d = 0.7$) and seeing similar numbers of new patients ($t(43) = 1.31, p = 0.197, d = 0.5$) each year. When staffing was considered as a function of clinical activity (number of new patients seen each year), the results indicated that, with the exception of occupational therapists — who were employed

Table 5.3: National average staffing levels (FTE) and provision of interventional procedures per 100 new patients seen

	National Total			Level 1 MDP centre			Level 2 MDP clinic			Effect Size
	<i>M (SD)</i>	Range	<i>n</i>	<i>M (SD)</i>	Range	<i>n</i>	<i>M (SD)</i>	Range	<i>n</i>	
/100 new pts	5.1 (3.6)	0.9-20.0	45	6.5 (2.4) **	3.0-11.0	26	3.4 (4.3)	0.9-20.0	19	0.9 (0.3, 0.1)
<i>Total service FTE</i>	1.9 (1.5)	0.2-7.8	45	1.4 (0.6)	0.3-3.1	26	2.6 (2.1) *	0.2-7.8	19	-0.8 (-1.5, -0.2)
Medical	0.5 (0.3)	0.1-1.3	45	0.5 (0.2)	0.1-0.9	26	0.4 (0.3)	0.1-1.3	19	0.4 (-0.2, 1.0)
Psychiatry	0.0 (0.1)	0.0-0.2	33	0.0 (0.0)	0.0-0.1	22	0.0 (0.1)	0.0-0.2	11	0.0 (-0.8, 0.8)
Nursing	0.4 (0.6)	0.0-3.0	39	0.3 (0.2)	0.0-0.9	24	0.6 (0.9)	0.0-3.0	15	-0.5 (-1.2, 0.1)
<i>Total Allied Health FTE</i>	0.7 (0.6)	0.0-2.5	45	0.4 (0.3)	0.0-0.9	26	1.1 (0.7) ***	0.0-2.5	19	0.6 (0.0, 1.2)
Physiotherapy	0.3 (0.3)	0.0-1.0	41	0.2 (0.1)	0.0-0.4	23	0.5 (0.3) ***	0.0-1.0	18	-1.4 (-2.1, -0.7)
Clinical Psychology	0.3 (0.2)	0.0-1.0	41	0.2 (0.1)	0.0-0.5	23	0.4 (0.3) ***	0.0-1.0	18	-0.9 (-1.6, -0.3)
Occupational Therapy	0.2 (0.2)	0.0-0.8	33	0.1 (0.1)	0.0-0.3	17	0.3 (0.2) **	0.0-0.8	16	-1.3 (-2.0, -0.5)
Administrative	0.4 (0.3)	0.0-1.3	40	0.3 (0.1)	0.1-0.7	22	0.5 (0.4) *	0.0-1.3	18	-0.7 (-1.4, -0.1)
<i>Procedures</i>										
Minor	62.4 (75.4)	0.0-400.0	44	66.0 (60.1)	5.7-283.3	25	57.6 (93.4)	0.0-400.0	19	0.1 (-0.5, 0.7)
Major	1.9 (3.7)	0.0-22.0	43	2.4 (4.5)	0.0-22.0	25	1.3 (2.2)	0.0-6.7	18	0.3 (-0.3, 0.9)

Note. FTE = full time equivalent; /100 new pts = mean number per 100 new patients seen each year; MDP = multidisciplinary pain; minor procedures = procedures such as epidural steroids or nerve blocks; major procedures = procedures such as intrathecal pumps or spinal cord stimulation; effect Size=Cohen's *d*. *SD* and confidence intervals are shown in parentheses for means and effect sizes (Cohen's *d*) respectively.

*** = $p < 0.001$; ** $p < 0.01$; * $p < 0.05$

Table 5.4: Staff numbers: Mean FTE (standard deviation) by discipline and per 100 new patients seen for metropolitan and rural based services

	Metro		Rural		Effect Size	Metro /100 new pts			Rural /100 new pts			Effect Size
	M (SD)	N	M (SD)	N		M (SD)	Range	N	M (SD)	Range	N	
<i>TOTAL FTE</i>	8.0 (4.6)	37	4.9 (3.3)	8	0.7 (-0.1, 1.5)	1.9 (1.4)	0.2-7.8	37	2.2 (2.1)	0.3-6.3	8	-0.2 (-0.9, 0.6)
Medical	2.3 (1.5) *	37	1.1 (0.8)	8	0.9 (0.1, 1.6)	0.5 (0.3)	0.1-1.3	37	0.4 (0.3)	0.2-1.1	8	0.3 (-0.4, 1.1)
Psychiatry	0.2 (0.2)	29	0.1 (0.1)	4	0.5 (-0.5, 1.6)	0.04 (0.05)	0.0-0.2	29	0.01 (0.01)	0.0-0.03	4	0.6 (-0.4, 1.7)
Nursing	1.6 (1.3)	33	1.2 (1.0)	6	0.3 (-0.6, 1.2)	0.4 (0.6)	0.0-3.0	33	0.6 (0.8)	0.0-2.2	6	-0.3 (-1.2, 0.6)
Physiotherapy	1.1 (1.0)	34	0.9 (0.4)	7	0.2 (-0.6, 1.0)	0.3 (0.3)	0.0-1.0	34	0.5 (0.3)	0.2-0.8	7	-0.7 (-1.5, 0.2)
Clinical Psychology	1.1 (0.7)	34	0.6 (0.4)	7	0.8 (-0.1, 1.6)	0.3 (0.2)	0.0-1.0	34	0.4 (0.3)	0.0-0.8	7	-0.5 (-1.3, 0.4)
Occupational Therapy	0.5 (0.6)	29	0.6 (0.3)	4	-0.2 (-1.2, 0.9)	0.1 (0.2) **	0.0-0.6	29	0.4 (0.3)	0.2-0.8	4	-1.4 (-2.5, -0.3)
Administration	1.8 (1.3)	33	1.4 (1.3)	7	0.3 (-0.5, 1.1)	0.4 (0.3)	0.3-1.3	33	0.5 (0.4)	0.1-1.0	7	-0.3 (-1.1, 0.5)
<i>Annual # new referrals</i>	832 (602)	37	458 (286)	8	0.7 (-0.1, 1.4)							
<i>Annual # new patients seen</i>	547 (366)	37	362 (329)	8	0.5 (-0.3, 1.3)							
<i>/100 new patients</i>	5.5 (3.7)	37	3.6 (3.29)	8								

Note. FTE = full time equivalent; Metro = metropolitan; /100 new pts = mean number per 100 new patients seen each year. Effect Size=Cohen's *d*. SD and confidence intervals are shown in parentheses for means and effect sizes (Cohen's *d*) respectively.

** p<0.01; * p<0.05

in greater proportions by rural than metropolitan services ($t(31) = -3.28, p = 0.003, d = -1.4$) — metropolitan and rural clinics employed comparable amounts of staff across the disciplines for the numbers of patients that were seen.

Pain Management Group Programmes

Pain Management Group Programmes (PMGPs) are a common model of care in tertiary pain units and were offered by most clinics (Level 1: $n = 24, 92\%$; Level 2: $n = 15, 79\%$). PMGPs are primarily staffed by AH - most often psychologists and physiotherapists. Medical and/or nursing team members commonly provide input to PMGP sessions but unfortunately these data were not captured in the WIP survey, precluding an analysis of this aspect of staffing.

Similar numbers of new patients were seen each year by clinics who offered a PMGP and those who did not ($t(43) = -0.48, p = 0.631, d = 0.21$). Of these new patients, a greater percentage participated in a group programme in Level 2 clinics ($M = 40.4\%, SD = 55.7$), than in Level 1 ($M = 11.1\%, SD = 6.5$) ($t(37) = -2.57, p = 0.014, d = 0.81$). For AH, there was no significant difference in overall FTE between services with a PMGP ($M = 2.3, SD = 1.6$) and those without ($M = 1.7, SD = 2.8$) ($t(43) = -0.82, p = 0.416, d = 0.34$).

For clinics that provided specific PMGP data, there was marked variation in the duration (total therapy hours) of group programmes ($M = 68.6$ hours, $SD = 30.1$, range: 5-120, $n = 39$) and the associated AH FTE ($M = 1.60, SD = 1.3$, range: 0.3-4.0 FTE, $n = 24$). However, because PMGP duration did not differ significantly across service models ($t(37) = 0.48, p = 0.633, d = 0.16$) or location ($F(7, 31) = 0.69, p = 0.683$), these categories (clinic level, metropolitan vs rural) were collapsed for the remaining analyses. PMGP staffing and activity data are presented in [Table 5.5](#).

Given the variability in duration, frequency of contact and therapy hours, PMGPs were categorised based on their intensity (defined as total number of therapy hours for each patient) into: low: <30 hours ($n = 2, 5.13\%$); medium: 30-50 hours ($n = 11, 28.2\%$); moderate: 51-90 hours ($n = 13, 33.3\%$); and high: >90 hours ($n = 13, 33.3\%$). An examination of AH staffing patterns revealed

Table 5.5: Group programme activity levels and allied health FTE

	AH FTE			Hours / PMGP			Patients Seen			AH FTE / PMGP Patient		
	M (SD)	Range	n	M (SD)	Range	n	M (SD)	Range	n	M (SD)	Range	n
<i>National Total</i>	1.6 (1.3)	0.3-4.0	24	68.6 (30.1)	5-120	39	72.4 (60.7)	1-300	39	0.03 (0.02)	0.01-0.07	24
NSW	1.2 (1.3)	0.3-3.8	9	67.4 (33.5)	5-105	14	55.4 (42.7)	1-150	14	0.02 (0.02)	0.01-0.05	9
VIC	1.6 (1.3)	0.4-3.6	7	80.4 (32.7)	32-120	9	87.4 (72.4)	26-250	9	0.02 (0.01)	0.01-0.03	7
QLD	3.4 (-)	-	1	62.8 (26.6)	39-100	5	126.0 (106.7)	40-300	5	0.03 (-)	-	1
WA	4. (-)	-	1	82.5 (20.6)	60-100	4	62.5 (5.0)	60-70	4	0.07 (-)	-	1
SA	1.7 (1.8)	0.4-3.0	2	62.5 (46.)	30-95	2	78.0 (31.1)	56-100	2	0.02 (0.02)	0.01-0.03	2
Tas	-	-	-	40.0 (-)	-	1	50.0 (-)	-	1	-	-	-
ACT	1.5 (0.8)	1.0-2.4	3	49.7 (14.6)	36-65	3	55.0 (30.4)	35-90	3	0.04 (0.03)	0.01-0.07	3
NT	0.4 (-)	-	1	48.0 (-)	-	1	12.0 (-)	-	1	0.03 (-)	-	1
<i>Program Intensity</i>												
(a) <30 hrs	0.3 (-)	-	1	12.5 (10.6)	5-20	2	10.5 (13.4)	1-20	2	0.02 (-)	-	1
(b) 30-50 hrs	0.8 (0.3)	0.4-1.2	6	39.6 (6.9)	30-50	11	70.4 (78.3)	12-300	11	0.02 (0.00)	0.01-0.03	6
(c) 51-90 hrs	1.1 (1.2)	0.3-3.4	7	63.6 (10.5)	51-80	11	56.8 (40.4)	12-140	11	0.03 (0.02)	0.01-0.07	7
(d) >90 hrs	2.5 (1.2) *	0.8-4.0	10	101.0 (8.9)	90-120	15	93.7 (56.6)	35-250	15	0.03 (0.02)	0.01-0.07	10
<i>Level 1 MDP Centre</i>												
Total	1.8 (1.3)	0.3-3.8	14	70.4 (33.2)	5-120	24	69.1 (41.5)	1-150	24	0.03 (0.02)	0.01-0.07	14
NSW	1.5 (1.5)	0.3-1.8	6	62.4 (36.0)	5-105	11	59.4 (46.4)	1-150	11	0.02 (0.02)	0.01-0.05	6

Note. AH FTE = allied health full-time equivalent; hours / PMGP = total treatment hours per Pain Management Group Program; patients seen = total number of new patients seen per annum; FTE/PMGP patient = mean average FTE per Pain Management Group Program patient.

* p<0.05

Table 5.5: Group programme activity levels and allied health FTE cont.

	<u>AH FTE</u>			<u>Hours / PMGP</u>			<u>Patients Seen</u>			<u>AH FTE / PMGP Patient</u>		
	<i>M (SD)</i>	<i>Range</i>	<i>n</i>	<i>M (SD)</i>	<i>Range</i>	<i>n</i>	<i>M (SD)</i>	<i>Range</i>	<i>n</i>	<i>M (SD)</i>	<i>Range</i>	<i>n</i>
<i>Level 1 MDP Centre cont</i>												
VIC	2.2 (1.3)	1.0-3.6	3	110.3 (11.8)	96-120	4	86.3 (50.2)	35-150	4	0.03 (0.00)	0.02-0.03	3
QLD	3.4 (-)	-	1	55 (-)	-	1	140 (-)	-	1	0.02 (-)	-	1
WA	-	-	-	76.7 (20.8)	60-100	3	63.3 (5.8)	60-70	3	-	-	-
SA	1.7 (1.8)	0.4-2.2	2	62.5 (46.0)	30-95	2	78.0 (31.1)	56-100	2	0.02 (0.02)	0.01-0.03	2
Tas	-	-	-	40.0 (-)	-	1	50.0 (-)	-	1	-	-	-
ACT	1.8 (0.8)	1.2-2.4	2	56.5 (12.0)	48-65	2	62.5 (38.9)	35-90	2	0.04 (0.04)	0.01-0.07	2
<i>Level 2 MDP Clinic</i>												
Total	1.3 (1.2)	0.4-4.0	10	65.6 (25.1)	32-100	15	77.7 (84.4)	12-300	15	0.03 (0.02)	0.01-0.07	10
NSW	0.8 (0.2)	0.6-1.0	3	86.0 (12.5)	72-96	3	40.7 (25.3)	12-60	3	0.03 (0.02)	0.02-0.05	3
VIC	1.2 (1.2)	0.4-3.0	4	56.6 (21.0)	32-90	5	88.4 (92.6)	26-250	5	0.02 (0.00)	0.01-0.02	4
QLD	-	-	-	64.8 (30.3)	39-100	4	122.5 (122.8)	40-300	4	-	-	-
WA	4.0 (-)	-	1	100 (-)	-	1	60 (-)	-	1	0.07 (-)	-	1
ACT	1.0 (-)	-	1	36.0 (-)	-	1	40 (-)	-	1	0.03 (-)	-	1
NT	0.4 (-)	-	1	48.0 (-)	-	1	12 (-)	-	1	0.03 (-)	-	1

Note. AH FTE = allied health full-time equivalent; hours / PMGP = total treatment hours per Pain Management Group Program; patients seen = total number of new patients seen per annum; FTE/PMGP patient = mean average FTE per Pain Management Group Program patient.

* p<0.05

significant differences ($F(3, 23) = 4.33, p = 0.017$). Specifically, medium and moderate intensity PMGPs had significantly fewer AH staff dedicated to their groups than did the most intensive model ($t(14) = -3.26, p = 0.006, d = -1.34; t(15) = -2.27, p = 0.039, d = -0.89$, respectively). When programme intensity was mapped against clinical activity, results indicated that groups saw a similar number of patients each year irrespective of the format of the programme ($F(3, 35) = 1.63, p = 0.20$). As noted above, it is important to evaluate the adequacy of staffing by additionally examining the clinical activity to which those resources are allocated. An examination of PMGP staffing as a function of the number of patients treated annually indicated no significant difference between the models ($F(3, 20) = 0.64, p = 0.596$), suggesting that, regardless of programme intensity, the staff-to-patient ratio was consistent; with 0.03FTE of AH staff required per patient treated.

5.6 Discussion

The 'Waiting in Pain' (WIP) project of the Australian Pain Society previously reported poor access to multidisciplinary care for Australians living with CP; and longer wait-times for publicly-funded services than within the private sector (Hogg, et al., 2012). This project sought to describe and systematically examine staffing in Australian tertiary CP services in terms of the associated clinical activity levels, in order to better understand and predict clinical resource needs and inform future developments in this sector of Australian health care.

In summary, across Australia, Level 1 centres consistently employ more medical, nursing and administrative staff, and annually receive more new referrals and see more new patients than their Level 2 counterparts. Despite this higher clinical activity, the amount of AH staffing is comparable: thus patients at Level 2 clinics are likely to have greater access to AH resources, both individually and group-based, than patients seen at Level 1 centres. This is consistent with the finding that a greater percentage of patients in Level 2 clinics completed a PMGP than in Level 1 centres. Moreover, because offering a PMGP was not associated with higher AH staffing, it is likely

that in clinics without a PMGP, AH provide other services, probably individual assessment and treatment sessions. The same is true for administrative staffing: as a function of clinical activity levels, resources in Level 1 centres are stretched significantly further than they are in Level 2 clinics. It is acknowledged, however, that although larger clinics have comparatively fewer staff than their smaller counterparts, this may partly reflect increased efficiencies due to larger size (i.e. economies of scale). Thus, adequate or necessary staffing may not always be directly proportional to clinical activity or patient numbers. It is not possible to draw firmer conclusions here because some other variables relevant to issues of workload and throughput — such as staff expertise and/or length of relevant experience, staff stress, retention rates, incident reports and efficiency modelling — were beyond the scope of the WIP data set.

Our findings suggest that the additional clinical activity in Level 1 centres is largely undertaken by medical and/or nursing staff. This may imply that Level 1 centres deliver a more medical, rather than multidisciplinary, approach to CP: a suggestion that is consistent with the finding of increased patient participation in PMGP's in Level 2, compared with Level 1, clinics. However, the major distinction between IASP Level 1 and 2 classifications is the provision of teaching and training — part of which includes medical training via junior medical staff rotations and, more specifically, the Faculty of Pain Medicine (FPM) fellowship program (1-2 years). Typically, trainees undertaking this fellowship are paid employees of the unit and provide clinical services to patients; as such, they are included in recorded staff establishments. Therefore, although a component of the medical FTE found in Level 1 centres may reflect their additional teaching/training/trainee roles, the higher levels of patient activity and nursing FTE in Level 1 clinics suggest that these trainees' duties were largely clinical in nature and, therefore, could still be considered to reflect a medical focus. Of note, potentially similar AH training activities were not captured in this study because, unlike their medical counterparts, AH trainees are unpaid and consequently not recorded within staffing establishments. Moreover, as specific information regarding the clinical activities of AH outside of PMGP's was not

captured, it is not possible to accurately assess the amount of multidisciplinary activity provided across services. Until detailed information about the full range of clinical, training and research activities are systematically collected for all disciplines, the suggestion that Level 1 centres have a more medical focus remains to be confirmed. However, despite the availability of a large amount of information to inform models of care for CP, the variability in PMGP intensity levels and rates of patient participation, as well as in the use of medical procedures (both minor and major) suggests that there is not yet agreement regarding an optimal care configuration for multidisciplinary pain services.

With the exception of medical staff, metropolitan and rural based services were reasonably comparable in terms of the staffing models (disciplines and amounts) that they employed, the level of clinical demand they experienced and the number of new patients they saw each year. It is interesting to note that the higher numbers of medical FTE in metropolitan services did not translate to increased clinical activity (number of new patients seen). One possible explanation for this might be that rural clinics see a different case-mix of patients; with metropolitan clinics receiving more complex referrals, possibly from other city-based medical specialists. Such cases may require longer and/or more frequent consultations, effectively reducing the number of appointment times available for new patients. Alternatively, it is possible that rural services are better connected with their primary care colleagues and thus more able to support and co-ordinate care that is provided primarily in the community. Clinical activity was operationalised here as the number of new patients seen per annum: thereby capturing patient intake data but not data regarding patients that were then seen in an ongoing or recurrent way (i.e. return appointments rather than new appointments). Indeed, differences in case-mix and availability of/links with community services (both impacting on need for ongoing management by a pain service) may contribute to the differences in national median wait-times for CP services reported previously (Level 1: 150 days, Level 2: 90 days) (Hogg, et al., 2012). As such, more detailed examination of case-mix and service information is needed to

better understand this finding and indeed, to fully understand the rates of medical intervention reported.

Overall, the reasonable consistency demonstrated in the range and mix of disciplines employed by CP services across Australia (apart from the variation in occupational therapy staffing) suggests that current clinic configurations represent workable clinical structures. Accordingly, our study provides some empirical support for use of these configurations as initial guidelines when designing CP clinics. An important limitation, however, is that we are not able to comment on service quality or patient outcomes. Thus, we cannot say whether these employment and activity levels necessarily translate to effective or efficient services. Indeed, it is clear from long waiting lists and annual unmet clinical needs (Hogg, et al., 2012) that current arrangements are inadequate.

Another limitation of this study is that it did not fully explore or document the complete range of treatments and/or activities provided by clinics, hampering our ability to fully appreciate nuances of staff utilisation. As stated above, this is particularly relevant for AH whose activity outside of PMGPs was not explored at all. It remains unclear whether lower levels of AH staffing equate to a less multidisciplinary focus or whether, in fact, AH were engaged in other multidisciplinary activities. Similarly, the survey failed to capture the contributions of doctors and nurses to PMGPs, leaving this aspect of staffing unexamined. Although considerable efforts were made to maximise the accuracy of the data, it did not all come from electronic systems. Finally, almost 20% of the clinics approached declined to participate. Thus, the degree to which our results can be generalised to those clinics, or indeed to international equivalents, is not clear.

This report represents one step toward maximising treatment efficiencies and outcomes in the area of CP: documenting the first Australian data on multidisciplinary staff resources ([Table 5.2](#)), the discipline-specific staff cost per/100 patients of providing this service in ISAP defined Level 1 and 2 clinics ([Table 5.3](#)); and the AH cost of PMGPs ([Table 5.5](#)). Future research needs to explore: the relationship between staffing levels and patient outcomes, medical/nursing input to PMGPs, and the

clinical activity of AH staff outside PMGPs. This would help to clarify whether Level 1 centres use resources more effectively or whether Level 2 clinics, in fact, have more available resources and are more truly multidisciplinary in nature. Further, the contribution of occupational therapy to CP services needs to be clarified to address the variable involvement of this discipline across current service models. It is only by systematically gathering this information that we will be able to provide a detailed understanding of the impact of staffing resources and patterns on treatment outcomes for people with CP.

Chapter 6 : Does Pre-Clinic Intervention Help Reduce the Negative Impact of Waiting to Access Treatment for Chronic Pain?

6.1 Preamble

Multidisciplinary care is considered best-practice for CP treatment, but many services struggle to cope with the growing demand, resulting in lengthy waits for patients. Thus far, this thesis has demonstrated that these waiting periods have a significant negative impact on waitlisted individuals; more so for women than men and from 12 months on (Study 2, [Chapter 4](#)). An intervention delivered within the first six months following referral therefore appears to be important, but there is no information regarding the best way to achieve this within the existing funding and staffing constraints. The relative consistency that was observed in the range and mix of disciplines employed by CP services across Australia suggests that clinics have developed workable staffing structures (Study 3, [Chapter 5](#)). Consequently, earlier interventions are likely to require increased staffing levels, rather than a change in mix of disciplines that are employed.

In the absence of any increased funding to better resource these services, clinicians have recently focussed on devising novel approaches to service delivery — including the provision of a brief intervention during the pre-clinic (waitlist) period. However, the best model of care for this type of intervention has yet to be determined; with the programs that are being utilised across clinics differing in both their intensity and frequency. Brief single interventions are particularly attractive because they are more readily supported using existing resources than are more intensive models that require more clinical input; a critical consideration in the context of constrained funding for health services.

This fourth study therefore sought to examine whether a single brief pre-clinic education session improved the well-being and QOL of individuals entering the waitlist for a tertiary CP service. Of note, this paper was published before Study 2 and so additionally includes an exploration of the

impact of the first six months of waiting to access CP treatment; data that was expanded upon in the 2.5 year longitudinal study.

Tables and Figures have been inserted within the text to make it easier to read and a copy of the published article (reproduced with permission) is presented as supplementary information in [Appendix 4](#). As per previous chapters, all references have been compiled into a complete [references](#) list which is presented at the end of this thesis.

Study 4

DOES A BRIEF EDUCATIONAL SESSION PRODUCE POSITIVE CHANGE FOR INDIVIDUALS WAITING FOR TERTIARY CHRONIC PAIN SERVICES?

This chapter consists of a published paper; however copyright restrictions prevent the reproduction of this paper in its published form. The details of this publication are:

- Burke, A.L.J., Denson, L.A., & Mathias, J.L. (2016). Does a brief educational session produce positive change for individuals waiting for tertiary chronic pain services? *Pain Medicine*, 17 (12), 2203–2217. DOI: 10.1093/pm/pnw125.
- Journal 5-Year Impact Factor = 3.05
- [Conference presentations](#) are provided in a complete list at the start of this thesis

Statement of Authorship

Title of Paper	Does a brief educational session produce positive change for individuals waiting for tertiary chronic pain services?
Publication Status	<input checked="" type="checkbox"/> Published <input type="checkbox"/> Accepted for Publication <input type="checkbox"/> Submitted for Publication <input type="checkbox"/> Unpublished and Unsubmitted work written in manuscript style
Publication Details	Burke, A.L.J., Denson, L.A., & Mathias, J.L. (2016). Does a brief educational session produce positive change for individuals waiting for tertiary chronic pain services? <i>Pain Medicine</i> , 17 (12), 2203–2217. DOI: 10.1093/pm/pnw125.

Principal Author

Name of Principal Author (Candidate)	Anne L. J. Burke				
Contribution to the Paper	All authors contributed to study inception. ALJB was solely responsible for study design, participant recruitment, data collection, statistical analysis, data interpretation and manuscript preparation.				
Overall percentage (%)	90%				
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.				
Signature	<table border="1" style="width: 100%;"> <tr> <td style="width: 80%;"></td> <td style="width: 20%;">Date</td> </tr> <tr> <td></td> <td>16.10.18</td> </tr> </table>		Date		16.10.18
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Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

- i. the candidate's stated contribution to the publication is accurate (as detailed above);
- ii. permission is granted for the candidate to include the publication in the thesis; and
- iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Linley A. Denson				
Contribution to the Paper	LAD consulted across all aspects of this research and manuscript preparation, providing expert supervisory input.				
Signature	<table border="1" style="width: 100%;"> <tr> <td style="width: 80%;"></td> <td style="width: 20%;">Date</td> </tr> <tr> <td></td> <td>31/10/2018</td> </tr> </table>		Date		31/10/2018
	Date				
	31/10/2018				

Name of Co-Author	Jane L. Mathias				
Contribution to the Paper	JLM consulted across all aspects of this research and manuscript preparation, providing expert supervisory input.				
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6.2 Abstract

Objectives: To examine (1) whether a single brief pre-clinic educational session improved the well-being and quality of life of individuals entering the waitlist for a tertiary chronic pain (CP) service, and (2) the impact of waiting for services on these outcomes.

Methods: Participants were 346 adults, with basic English skills and non-urgent triage codes, who were recruited on referral to a tertiary Australian metropolitan CP unit. Participants were randomised across two conditions: 'treatment as usual' (normal waitlist) and 'experimental' (normal waitlist plus a three-hour CP educational session). The educational session encouraged self-management and life engagement despite pain. Multiple outcomes (pain acceptance, pain-related interference, psychological distress, health care utilisation [frequency, types], quality of life, health knowledge/beliefs), as well as pain severity and symptom exaggeration, were assessed at intake and again at two weeks and six months post-educational session (or equivalent for the waitlist group).

Results: Satisfaction with the educational session was moderate-to-high, but attendance was not associated with improved outcomes. At two weeks, all study participants reported significant improvements in pain acceptance (willingness, overall acceptance), health care utilisation (frequency) and quality of life (physical); which were maintained/enhanced at six months. Use of psychological and physical therapies increased significantly by six months. There was no functional deterioration while waitlisted.

Conclusions: Attending a brief pre-clinic education session did not improve function. There was no deterioration in waitlisted participants who agreed to be involved in research and who completed study measures at two and six months, but referral was associated with short-term functional improvements. This is the first study to link positive change with referral to, rather than treatment by, a tertiary CP service.

6.3 Introduction

Chronic pain (CP) is a major contributor to the global burden of disease; with one in ten people being newly diagnosed each year (IASP & EFIC). Not surprisingly, CP has been linked with significant impairment across a range of psychological domains, including anxiety, depression and quality of life (QOL) (Burke, Mathias, et al., 2015). It is also associated with physical and occupational restrictions (Douglas, et al., 2004; W. F. Stewart, et al., 2010), withdrawal from valued life activities (Haythornthwaite & Benrud-Larson, 2000), and increased health care utilization (HCU) (Blyth, et al., 2004). Despite its high prevalence and associated costs, CP is often poorly represented in the diagnostic data collected by health agencies (Commonwealth Department of Health and Aged Care, 1998; Tian, Zlateva, & Anderson, 2013), resulting in limited public funding for CP services.

Research supports multidisciplinary care as best practice for CP (Hassett & Williams, 2011), leading to improved physical and psychological adjustment for patients (National Pain Summit Initiative, 2011). Typically, this involves contributions from medical, nursing, psychological, physiotherapy and psychiatric professionals (Burke, Denson, Mathias, & Hogg, 2015). However, many multidisciplinary CP services struggle to meet increasing demand, resulting in significant wait-times for assessment and treatment (Hogg, et al., 2012; Peng, et al., 2007), during which patients' health and well-being may deteriorate (Lynch, et al., 2008). Accordingly, CP clinicians are developing alternative ways to address clinical needs, including brief interventions in the pre-clinic (waitlist) period. One exemplar is the Self-Training Educative Pain Sessions (STEPS) model (Davies, et al., 2011), which involves a two-day (or six-session) pre-clinic group program that educates patients about pain processes and promotes active self-management. Three-month follow-up data indicated that, although STEPS did not impact on anxiety or depression, the two-day program afforded numerous other benefits to patients (i.e., improved self-efficacy, reduced disability, impression of change, greater strategy use) and service delivery (i.e., reduced wait-time, costs and

need for individual follow-up appointments, greater attendance rates and patient satisfaction with treatment). Moreover, the incorporation of STEPS into the clinic's core intake process resulted in a significant reduction in demand for individual clinic appointments, with just over half of all patients opting not to pursue additional input beyond the STEPS program (Davies, et al., 2011).

Given the lengthy wait for services experienced by many, the idea of a brief session at referral is compelling. Despite considerable debate in the CP literature, optimal group program intensity has yet to be determined for either clinic or pre-clinic interventions (British Pain Society, 2013; NSW Agency for Clinical Innovation, 2013). It has however, been suggested that intensity should be directly proportional to the degree of disability (physical and psychological) experienced by individuals, with the most disabled persons requiring the most intensive programs (NSW Agency for Clinical Innovation, 2013). In addition, other research has supported the potential impact of single brief educational sessions on the pain catastrophizing and fear (de Jong, et al., 2005), physical performance (Moseley, et al., 2004), and return to work rates of individuals living with CP (Engers, et al., 2008).

The current project therefore sought to evaluate whether a single brief multidisciplinary CP educational session of three hours duration — adopting a low-intensity model, conducive to implementation using existing clinical resources — could yield positive benefits, both in the short- (two weeks) and intermediate-term (six months), for individuals waiting to access a tertiary CP service. A secondary aim was to document any changes in participants' well-being during the first six months on a waitlist for CP services in order to explore the independent effects of waiting for treatment.

6.4 Method

Participants

Participants were adults who were newly referred to the Pain Management Unit (PMU) of the Royal Adelaide Hospital between November 2011 and November 2013. The PMU is a 'Multidisciplinary Pain Centre' (IASP, 2009) situated in the largest accredited teaching hospital in the state of South Australia. It provides a range of coordinated multidisciplinary services to adults living with CP. Referrals are actively triaged, based on a range of clinical factors, and wait-times are typically long; often exceeding two years. Individuals referred for cancer/palliative care, early intervention (e.g. for Complex Regional Pain Syndrome) or intervention within six months were excluded from this study because initial appointments were likely to occur before completion of the proposed educational session and/or follow-up time-points (two weeks, six months). Individuals referred prior to November 2011 were excluded because all recruitment occurred at the time of referral. Finally, basic English fluency and literacy skills were required in order to complete the study components (session presentation, handouts, outcome measures). All eligible patients (screened on the basis of referral information and PMU triage processes) newly referred to the PMU during the recruitment period were approached to participate in the study.

Study Design

A randomised research design was employed, whereby a random number allocation list was produced using an online generator (<http://graphpad.com/quickcalcs/randomize1.cfm>) to guide the allocation of potential study participants (ordered on the basis of sequential referral date) to one of two conditions — standard waitlist management ('treatment as usual': *TAU*) or standard waitlist management plus educational session ('experimental': *EXP*). Once randomised, individuals were sent the associated paperwork (standard PMU questionnaires plus study information for the *TAU* or *EXP* conditions, respectively) inviting them to participate in the study. Participants were told that the

research was designed to investigate the impact of waiting for services on individuals living with CP and to determine whether changes to waitlist management could improve outcomes. An 'opt-out' model was utilised for the educational session in order to maximize attendance (Treweek et al., 2010), thus each *EXP* group participant was notified of the date and time of the session to which they had been allocated and advised that they were welcome to reschedule to another session if desired. Allocation was initially randomised equally (1:1) between the *EXP* and *TAU* groups. However, unequal randomisation (2 *EXP* : 1 *TAU*) was subsequently adopted to more evenly balance group numbers and maximize statistical power for the between-groups analyses (Dumville, Hahn, Miles, & Torgerson, 2006) because lower uptake and greater drop-out rates were observed in the *EXP* condition.

Intervention

Each educational session was facilitated by a multidisciplinary panel of PMU staff — a pain consultant physician, psychologist and physiotherapist — all with significant experience in CP. The length of the session (three hours) was based on the recommendations of a meta-analytic review (Engers, et al., 2008), which suggested that a minimum of 2.5 - three hours duration was required for an educational session to be beneficial. Session content was standardized via a PowerPoint presentation to ensure consistency across presentations and included information about: CP processes, the clinical unit and what to expect from treatment, the role of psychological factors in pain and ways to manage pain (e.g., relaxation, mindfulness, challenging thinking etc.), goal setting, sleep hygiene, distraction/attention focus, self-care, exercise, activity pacing and medication. Consistent with the literature on the self-management of CP, the session was designed to encourage participants to critically review their approach to pain management by (1) providing basic education about pain processes, including neurobiological conceptualisations (Moseley, et al., 2004); (2) exploring the limitations of medications in CP management; and (3) exploring ways of enhancing QOL, despite experiencing ongoing pain (Davies, et al., 2011; National Pain Summit Initiative, 2011).

In doing so, we communicated that the role of the pain management team was to support effective CP management, rather than to provide better analgesia or a cure for CP. Thus, the central goal of the session was to inform and encourage a psychological shift from the often fruitless quest for pain cessation or control, to a stance of acceptance and life engagement in the face of pain. Printed handouts were produced to support and supplement the session information (distributed at the commencement of each session), because group outcomes are thought to be enhanced by the provision of written literature (Bennett, Bagnall, & Closs, 2009).

Measures

Consistent with contemporaneous clinic practice, at the point of referral, individuals were required to complete and return an intake screening measure prior to being placed on the clinic booking queue. This measure — the Patient Screening Questionnaire (PSQ) — was based on a triage questionnaire sourced from Hunter Integrated Pain Service (New South Wales Department of Health). The PSQ explores information related to pain (onset, duration, pattern, site(s), compensation status), HCU (frequency, treatment types) and demographic information (sex, age, marital and work status). The PSQ also includes validated measures of pain severity (four items of the Brief Pain Inventory: BPI-PS (Cleeland & Ryan, 1994)), pain-related interference (seven items of the Brief Pain Inventory: BPI-PI (Cleeland & Ryan, 1994)) and psychological distress (Kessler Distress Scale: K-10 (Kessler, et al., 2003)); all of which were used in the current study to minimize respondent burden (see [Table 6.1](#) for details of the study measures).

A range of other outcome measures were additionally utilised in order to more fully explore the multifaceted experience of living with CP: measures of pain acceptance (Chronic Pain Acceptance Questionnaire: CPAQ (McCracken, et al., 2004)), QOL (World Health Organisation QOL-Brief Scale: WHOQOL-BREF (Murphy, et al., 2000)), pain-related health knowledge and beliefs, and symptom exaggeration (see [Table 6.1](#)). Pain acceptance was assessed because of its

Table 6.1: Overview of measures used in the study

Domain Assessed	Measure	Number of Items	Time Period assessed	Possible Score Range	Reference
<i>Pain acceptance</i>	CPAQ	20			(McCracken, et al., 2004)
Pain willingness		9	“as it applies to you”	0-54	
Activity engagement		11	“as it applies to you”	0-66	
Overall acceptance		20	“as it applies to you”	0-120	
<i>Pain-related interference</i>	BPI-PI	7	previous 24 hours	0-10	(Cleeland & Ryan, 1994)
<i>Psychological distress</i>	K-10	10	previous 4 weeks	10-50	(Kessler, et al., 2003)
<i>Health care utilisation (HCU)</i>	PSQ	18			
Frequency		5	previous 3 months	0-40	
Treatment types		13	-	0-13	
<i>Quality of life (QOL)</i>	AWHOQOL-BREF	26			(Murphy, et al., 2000)
Physical health		7	previous 4 weeks	7-35	
Psychological health		6	previous 4 weeks	6-30	
Social relationships		3	previous 4 weeks	3-15	
Environment		8	previous 4 weeks	8-40	
Overall		1	previous 4 weeks	1-5	
Overall Health		1	previous 4 weeks	1-5	
<i>Health knowledge/beliefs (HKB)</i>	Study specific	5	-	5-25	
<i>Pain Severity</i>	BPI-PS	4			(Cleeland & Ryan, 1994)
Worst pain		1	previous 24 hours	0-10	
Least pain		1	previous 24 hours	0-10	
Average pain		1	on average	0-10	
Current pain		1	right now	0-10	
<i>Symptom exaggeration</i>	SDRS-5	5	-	0-5	

Note: BPI-PI = Brief Pain Inventory, Pain Interference subscale; K-10 = Kessler Distress Scale; PSQ = Patient Screening Questionnaire; CPAQ = Chronic Pain Acceptance Questionnaire; AWHOQOL-BREF = Australian World Health Organisation Quality of Life Brief Scale; BPI-PS = Brief Pain Inventory, Pain Severity subscale; SDRS-5 = Social Desirability Response Set Scale.

influence on psychological distress, engagement with physical activity and QOL (Mason, Mathias, & Skevington, 2008). The QOL measure was chosen because it explores QOL more broadly than many other measures and was therefore more inclusive of the range of ways that CP may impact on this domain. The study-specific health knowledge/beliefs measure was devised to explore participants' understanding of CP and its management, and, specifically, awareness of concepts presented within the educational session (*EXP* group). Although not an outcome measure, pain severity ('current' pain) was included because it was an important consideration when assessing the impact of waiting to access a CP service. This was particularly salient because it had the potential to influence responses on other questionnaires; with higher pain at the time of responding possibly being associated with greater reported distress and impaired recall. However, it is important to note that pain reduction was not a core goal of the educational session; consequently we did not expect ratings of pain severity to be influenced by session attendance. Likewise, symptom exaggeration was included because we recognized that a desire to expedite appointment allocation may potentially influence responses; either deliberately or unintentionally. Accordingly, a measure of symptom exaggeration (Social Desirability Response Set Scale: SDRS-5) (Hays, et al., 1989) was included at the end of the health knowledge/beliefs measure, following two study-specific linking items (i.e. "my pain impacts on the way that I respond to others" and "I find that I am more understanding of the difficulties of others") devised specifically to prevent the symptom exaggeration items from appearing discordant with preceding questions.

Finally, a study-specific measure was developed to assess participant satisfaction with the pre-clinic educational session. Attendees were asked to rate five items on a five-point scale, ranging from '1' (not at all) to '5' (completely). Specifically, they rated: satisfaction with the overall presentation, usefulness of the presentation and printed materials, whether the individual's thinking had changed as a result of attending the session and, if it had, the degree of perceived usefulness of that change. Participants were also asked whether they would have liked more information about

anything in particular and, if so, what. Space was then offered for participants to provide unstructured feedback.

Procedure

Following referral and initial medical triage, potential participants were randomised and sent the intake screening measure (PSQ), as well as the appropriate study information sheet (*EXP* or *TAU*), consent form and intake research questionnaire pack. The study documents outlined the aims of the project and invited research participation, while emphasizing that individuals were free to decline or discontinue participation at any time without affecting wait-times or later treatment. Following questionnaire completion and study consent, participants in the *TAU* group were placed on a booking queue, pending notification of an available appointment (standard PMU practice at that time). *EXP* participants were placed on the same booking queue and details of their educational sessions (date, time, location, description) were provided in their information sheets.

Because the initial questionnaire pack was sent out with the PSQ (Time 1: T1), a condensed version was generated for follow-up to avoid unnecessary duplication (e.g., birthplace). *EXP* participants were followed-up at two weeks (Time 2: T2) and six months (Time 3: T3) after their pre-clinic session. Feedback on the session was sought from attendees at T2. The *TAU* group was sent the same questionnaires (excluding the session feedback form) at equivalent times. By T3, 7% of participants ($n = 24$) had attended, or been offered, an initial clinic appointment. Individuals who did not return a pack within one month were sent a reminder pack, with a note encouraging them to return the completed measures. Reply paid self-addressed envelopes accompanied all packs.

Although it was not anticipated that completion of the study measures would cause undue discomfort, it is well documented that CP is frequently associated with significant levels of psychological distress (Burke, Mathias, et al., 2015). Hence, each mail-out included information outlining options for gaining assistance with distress, whether resulting from participation in this

project or other causes. Finally, as a means of thanking participants for their involvement, every mail-out included a thank-you note encouraging them to “relax and enjoy a cuppa”. Taped to each note was an individually sealed tea bag.

The study was approved by the Research Ethics Committee of Royal Adelaide Hospital (Protocol #111004). Participant randomisation, mail-outs, questionnaire scoring and data entry were all completed by the ALJB. Moreover, ALJB attended the start of each session to introduce the presenters to the attendees, explain the research aims and answer any research-related questions. The researcher then handed the session over to the clinical team and left the room.

Statistical Analyses

Independent samples *t*-tests and chi-square statistics were calculated to assess differences between those *EXP* participants who ‘failed to attend’ the pre-clinic educational session (without notice) and those who ‘declined to attend’ (contacted the unit in advance to advise of non-attendance). These analyses indicated that there was no significant difference between the two groups on any of the demographic/background variables (age: $t(152) = -0.34, p = 0.73$; sex: $\chi^2(1, N=154) = 0.04, p = 0.84$; relationship status: $\chi^2(3, N=148) = 2.22, p = 0.53$; employment: $\chi^2(11, N=149) = 15.93, p = 0.14$; born in Australia: $\chi^2(1, N=150) = 0.04, p = 0.83$; non-Australian location of birth: $\chi^2(3, N=35) = 2.51, p = 0.47$; previous contact with pain clinic: $\chi^2(2, N=151) = 1.27, p = 0.53$; private health insurance: $\chi^2(1, N=148) = 0.12, p = 0.73$; pain duration: $\chi^2(5, N=150) = 4.69, p = 0.46$; compensation: $\chi^2(1, N=149) = 1.27, p = 0.26$; pain in more than 1 site: $\chi^2(1, N=154) = 2.19, p = 0.14$; primary pain site: $\chi^2(11, N=144) = 10.61, p = 0.48$; reason for pain onset: $\chi^2(7, N=148) = 2.80, p = 0.90$). Thus, they were combined to form a third group - ‘did not attend’ (*DNA*) - for all subsequent analyses.

Power calculations conducted via G*Power (Faul, et al., 2007) indicated that the study was adequately powered (effect size $f = 0.25$, $\alpha_{\text{error probability}} = 0.05$; power = 0.95). As recommended by

Armijo-Olivo and colleagues (2009), data was analyzed using an 'as treated' rather than 'intention to treat' protocol because the large number of participants in the DNA group did not receive any treatment at all. One-way analyses of variance were used to check for differences between the groups on the independent variables at T1 in order to ensure that they were comparable at intake. Repeated measures mixed-model analyses then explored the impact of Time (T1, T2, T3) and Group (*EXP*, *DNA*, *TAU*) on the dependent variables (outcome measures: pain acceptance, pain-related interference, psychological distress, HCU, QOL, health knowledge/beliefs) (Armijo-Olivo, et al., 2009). Where main effects were found, post-hoc analyses using *t*-tests with Bonferroni corrections explored the differences. In accordance with current recommendations regarding calculation of effect size for this type of analysis, *d* was calculated to provide a measure of the standardized difference between the means for the three groups (Dunlap, Cortina, Vaslow, & Burke, 1996; Feingold, 2013) and was interpreted using Cohen's (Cohen, 1988) guidelines: with $d = 0.2$, 0.5 and 0.8 indicating small, medium and large effects, respectively.

6.5 Results

Participant Characteristics at Intake

As [Figure 6.1](#) depicts, 712 people were invited to participate in the research. Six declined referral to the PMU, one could not be contacted, four had consulted another clinic and three did not meet the English language requirements. Of the remaining 698 individuals, 33% ($n = 232$) did not respond and 17% ($n = 120$) only returned the PSQ, thereby securing their position on the clinic booking queue, but declining to participate in the study. This resulted in a final research sample of 346 people, ranging in age from 22 to 83 years, the majority of whom were female, not partnered, unemployed as a result of their pain and Australian-born (see [Table 6.2](#)). An independent samples *t*-test and chi-square statistic indicated that there was no significant difference in age or sex mix between those individuals who agreed to participate in the study and those who declined to do so

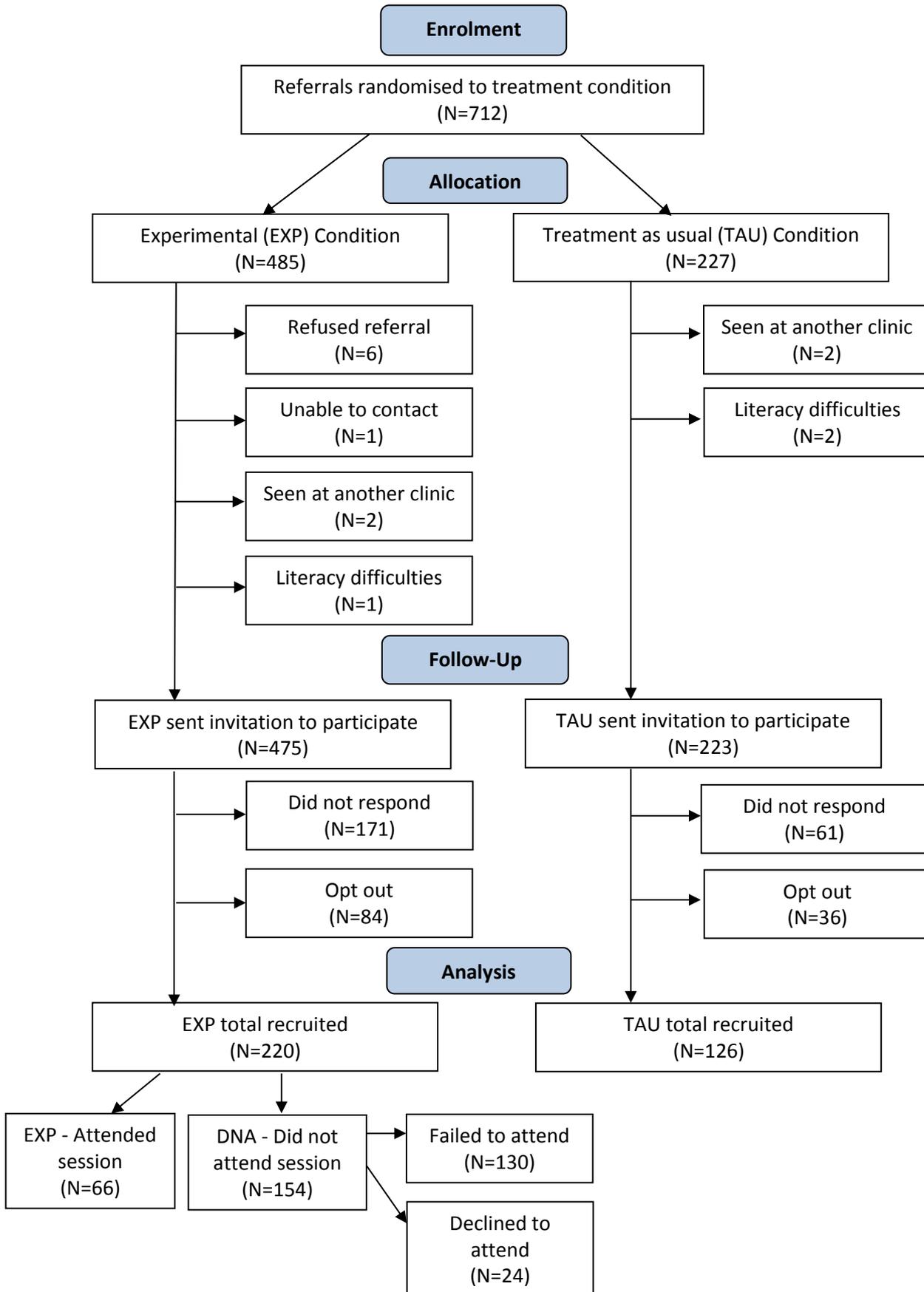


Figure 6.1: Flow of participants through the study

Table 6.2: Summary demographic information of the sample

	EXP	DNA	TAU	Full Sample
	<i>N (%)</i>	<i>N (%)</i>	<i>N (%)</i>	<i>N (%)</i>
GENERAL INFORMATION				
<i>N</i> _{participants}	66 (19)	154 (45)	126 (36)	346
Age (Mean, SD)	46.2 (9.9)	45.0 (10.2)	41.8 (10.3)	44.1 (10.3)
Sex				
Female	44 (67)	87 (56)	67 (53)	198 (57)
Male	22 (33)	67 (44)	59 (47)	148 (43)
Relationship status				
Single	20 (30)	67 (43)	63 (50)	150 (43)
Married/de facto	29 (44)	60 (39)	42 (33)	131 (38)
Divorced/separated	14 (21)	20 (13)	12 (10)	46 (13)
Widowed	-	1 (1)	-	1 (0.5)
Not reported	3 (5)	6 (4)	9 (7)	18 (5.5)
Employment status				
Unemployed (due to pain)	27 (41)	60 (39)	41 (33)	128 (37)
Unemployed (other reasons)	10 (15)	19 (12)	29 (23)	58 (17)
Part-time	5 (7.5)	14 (9)	14 (11)	33 (9.5)
Full-time	5 (7.5)	15 (10)	12 (10)	32 (9)
Home duties	11 (17)	13 (8.5)	8 (6)	32 (9)
Retired	3 (4.5)	11 (7)	2 (2)	16 (5)
Disability Support Pension	2 (3)	4 (2.5)	7 (5)	13 (4)
Student	2 (3)	4 (2.5)	5 (4)	11 (3)
Volunteer work	-	3 (2)	1 (1)	4 (1)
Retraining	-	3 (2)	1 (1)	4 (1)
Other	-	2 (1.5)	-	2 (0.5)
Casual	-	1 (1)	-	1 (0.5)
Not reported	1 (1.5)	5 (3)	6 (4)	12 (3.5)
Location of Birth				
Australia	48 (73)	115 (75)	95 (75)	258 (72)
Europe	9 (14)	26 (17)	15 (12)	50 (14)
Asia	5 (8)	3 (2)	9 (7)	17 (5)
Oceania	-	4 (2.5)	1 (1)	5 (2)
Africa	1 (1)	2 (1)	2 (2)	5 (2)
South America	1 (1)	-	-	1 (1)
North America	-	-	1 (1)	1 (1)
Not reported	2 (3)	4 (2.5)	3 (2)	9 (3)
PAIN / HEALTH INFORMATION				
Pain in More Than One Site				
Yes	63 (95.5)	143 (93)	118 (94)	324 (93.5)
No	3 (4.5)	11 (7)	7 (5)	21 (6)
Not reported	-	-	1 (1)	1 (0.5)
Pain Duration				
Greater than 10 years	24 (36)	60 (39)	37 (29)	121 (35)
5 – 10 years	10 (15)	34 (22)	30 (24)	74 (21)
12mths – 3 years	11 (17)	28 (18)	24 (19.5)	63 (18)
3 - 5 years	16 (24)	18 (12)	24 (19.5)	58 (17)
6 - 12 months	5 (8)	9 (5.5)	6 (4)	20 (6)

Note: EXP = Experimental Group (attend pre-clinic educational session); DNA = Did Not Attend Group (did not attend pre-clinic session); TAU = Treatment As Usual Group (waitlist).

Table 6.2: Summary demographic information of the sample cont.

	EXP	DNA	TAU	Full Sample
	<i>N (%)</i>	<i>N (%)</i>	<i>N (%)</i>	<i>N (%)</i>
<u>PAIN / HEALTH INFORMATION cont.</u>				
<i>Pain Duration cont.</i>				
Less than 6 months	-	1 (1)	3 (2)	4 (1)
Not reported	-	4 (2.5)	2 (2)	6 (2)
<i>Primary Pain Site</i>				
Lower Back / Buttocks	21 (32)	67 (44)	49 (39)	137 (39.5)
Total / Almost total body	11 (17)	16 (10)	19 (15)	46 (13)
Legs / Feet	8 (12)	15 (9.5)	16 (13)	39 (11)
Neck	3 (4.5)	11 (7)	5 (4)	19 (5.5)
Head / Face / Mouth	3 (4.5)	8 (5)	5 (4)	16 (5)
Upper Back	5 (7.5)	7 (4.5)	3 (2)	15 (4.5)
Hip	3 (4.5)	6 (4)	4 (3)	13 (4)
Abdominal	2 (3)	7 (4.5)	4 (3)	13 (4)
Shoulders	2 (3)	2 (1.5)	5 (4)	9 (3)
Arms / Hands	2 (3)	2 (1.5)	3 (2)	7 (2)
Anal / Genital	-	-	4 (3)	4 (1)
Groin	1 (1.5)	2 (1.5)	1 (1)	4 (1)
Pelvic	1 (1.5)	1 (1)	-	2 (0.5)
Chest	-	-	2 (2)	2 (0.5)
Not reported	4 (6)	10 (6)	6 (5)	20 (5.5)
<i>Reason for Pain Onset</i>				
No clear reason	16 (24)	36 (23)	33 (26.5)	85 (24)
Other	15 (23)	33 (21)	26 (21)	74 (21)
Other illness related	12 (18)	23 (15)	23 (18)	58 (17)
Work accident	8 (12)	29 (19)	18 (14)	55 (16)
Motor vehicle accident	7 (11)	16 (10)	15 (12)	38 (11)
Post-surgical	4 (6)	6 (4)	4 (3)	14 (4)
Home accident	3 (4.5)	4 (3)	4 (3)	11 (3)
Cancer	-	1 (1)	-	1 (1)
Not reported	1 (1.5)	6 (4)	3 (2.5)	10 (3)
<i>Seen a Pain Clinic Before</i>				
No	54 (82)	124 (80)	107 (85)	285 (82)
Yes, multidisciplinary clinic	10 (15)	23 (15)	11 (9)	44 (13)
Pain doctor (single discipline only)	1 (1.5)	4 (3)	3 (2)	8 (2)
Not reported	1 (1.5)	3 (2)	5 (4)	9 (3)
<i>Pain-Related Compensation</i>				
No	64 (97)	142 (92)	114 (91)	320 (92)
Yes	1 (1.5)	7 (5)	8 (6)	16 (5)
Not reported	1 (1.5)	5 (3)	4 (3)	10 (3)
<i>Private Health Insurance</i>				
No	47 (71)	117 (76)	98 (78)	262 (76)
Yes	19 (29)	31 (20)	23 (18)	73 (21)
Not reported	-	6 (4)	5 (4)	11 (3)

Note: EXP = Experimental Group (attend pre-clinic educational session); DNA = Did Not Attend Group (did not attend pre-clinic session); TAU = Treatment As Usual Group (waitlist).

(i.e. 'opt out' group: $M_{age} = 44.3$, $SD_{age} = 11.6$, range = 17-79 years; $N_{females} = 73$, 61%) (age: $t(464) = 0.21$, $p = 0.84$; sex: $\chi^2(3, N=466) = 3.78$, $p = 0.29$).

Most participants indicated that they experienced pain in more than one site and just over half of the sample ($n = 195$, 56%) said that their pain had persisted for five or more years, often in the absence of a clear cause. Consistent with referral to a public health service with lengthy wait-times, most participants had not previously consulted a multidisciplinary pain service, were not involved in pain-related litigation and did not have private health insurance (see [Table 6.2](#)). As can be seen in [Table 6.3](#), scores on the Pain Interference subscale of the Brief Pain Inventory (BPI-PI) (Cleeland & Ryan, 1994) at T1 indicated that participants experienced a high level of pain-related interference in their ability to undertake daily activities. Psychological distress was also prevalent at T1, with the majority of respondents ($N = 245$, 71%) reporting symptoms in the "moderate" or "severe" range (≥ 25) of the Kessler Distress Scale (K-10) (Kessler, et al., 2003). These phenomena were also reflected in the measure of HCU, with participants reporting an average of 10 health-related appointments every three months ($M = 10.4$, $SD = 6.5$) and weekly appointments being reported by a third of participants ($N = 127$, 37%). As might be expected, scores on the Australian World Health Organisation QOL Brief Scale (AWHOQOL-BREF) (Murphy, et al., 2000) indicated marked impairment across all QOL domains for the present sample when compared with Australian normative data (Murphy, et al., 2000). Finally, scores for 'current pain' on the Pain Severity subscale of the BPI (BPI-PS) revealed that the sample as a whole reported experiencing a significant amount of physical pain at T1.

As indicated, one-way analyses of variance were performed to check whether the three Groups (*EXP*, *DNA*, *TAU*) were comparable prior to the intervention. These analyses showed that there were no significant differences between the Groups at T1 on any of the measures, indicating that they were comparable prior to the study intervention in terms of: pain acceptance (CPAQ – pain willingness: $F(2,322) = 0.46$, $p = 0.63$; activity engagement: $F(2,322) = 0.71$, $p = 0.49$; total

Table 6.3: Mean (SD) scores on the outcome measures, by assessment times and group

	Full Sample at Intake (T1)	T1			T2			T3		
		EXP	DNA	TAU	EXP	DNA	TAU	EXP	DNA	TAU
<i>CPAQ</i>										
Pain Willingness	15.0 (8.0)	15.2 (8.0)	15.3 (8.1)	14.4 (8.0)	19.6 (7.9)	19.0 (7.6)	17.5 (8.3)	19.2 (6.7)	18.3 (8.1)	17.1 (11.1)
Activity Engagement	23.2 (11.9)	23.5 (12.9)	23.9 (11.9)	22.2 (11.3)	25.0 (12.8)	24.9 (12.4)	23.7 (11.6)	24.7 (13.1)	23.7 (12.3)	25.9 (14.5)
Overall Pain Acceptance	38.2 (16.6)	38.7 (17.6)	39.3 (16.7)	36.6 (16.0)	44.6 (15.7)	44.0 (16.7)	41.2 (16.3)	43.8 (16.4)	42.0 (15.6)	43.0 (20.3)
<i>BPI-PI</i>										
	7.4 (1.7)	7.3 (1.5)	7.3 (1.7)	7.5 (1.6)	7.2 (1.7)	7.2 (1.8)	7.6 (2.1)	6.9 (1.8)	7.2 (1.8)	7.2 (2.5)
<i>K-10</i>										
	30.0 (8.7)	30.0 (9.2)	29.8 (8.6)	30.3 (8.6)	31.3 (8.4)	29.5 (8.8)	31.9 (9.7)	28.5 (8.0)	31.1 (9.0)	30.0 (11.0)
<i>HCU</i>										
Frequency	10.4 (6.5)	11.2 (6.5)	10.1 (6.7)	10.5 (6.2)	10.8 (6.3)	8.6 (6.3)	8.9 (6.0)	8.2 (4.9)	8.7 (7.6)	7.8 (5.8)
<i>Treatment Types</i>										
Medical	1.2 (1.3)	1.6 (1.3)	1.2 (1.1)	1.1 (1.4)	0.4 (0.5)	0.4 (0.7)	0.5 (0.8)	1.2 (1.0)	1.3 (1.1)	1.0 (1.0)
Psychological	1.2 (1.3)	1.4 (1.8)	1.2 (1.4)	1.2 (0.9)	0.5 (0.6)	0.8 (0.7)	0.7 (0.7)	1.5 (1.0)	1.4 (1.2)	1.3 (1.0)
Alternative	0.4 (0.6)	0.4 (0.5)	0.4 (0.6)	0.3 (0.6)	0.2 (0.6)	0.2 (0.4)	0.2 (0.4)	0.6 (0.7)	0.4 (0.5)	0.4 (0.6)
Physical	1.4 (1.0)	1.5 (0.9)	1.3 (1.0)	1.3 (1.0)	1.0 (1.0)	1.2 (0.9)	1.0 (0.8)	2.2 (1.0)	2.1 (1.4)	2.3 (1.2)
New (total)	-	-	-	-	2.4 (1.3)	2.6 (1.5)	2.5 (1.6)	2.5 (1.5)	2.6 (1.5)	2.5 (1.7)
<i>AWHOQOL-BREF</i>										
Physical Health	14.4 (4.0)	14.5 (4.1)	14.4 (3.8)	14.3 (4.1)	15.2 (4.8)	15.5 (4.3)	14.8 (4.5)	15.4 (3.5)	15.4 (4.2)	15.8 (5.5)
Psychological Health	15.7 (4.8)	15.9 (4.9)	15.8 (4.7)	15.4 (5.0)	15.3 (4.9)	16.1 (4.8)	15.6 (5.8)	15.4 (4.6)	15.3 (4.8)	16.6 (6.0)
Social Relationships	7.9 (3.0)	7.9 (3.0)	7.9 (3.0)	7.8 (2.9)	7.6 (2.9)	7.7 (2.7)	7.7 (2.6)	7.3 (2.6)	9.2 (10.3)	8.0 (2.8)
Environment	23.4 (5.6)	23.8 (5.6)	23.8 (5.6)	22.8 (5.2)	23.7 (5.9)	24.7 (5.8)	22.7 (5.7)	24.4 (5.4)	23.9 (5.6)	23.9 (5.4)
Overall QOL	2.4 (0.9)	2.4 (0.9)	2.4 (0.9)	2.4 (0.9)	2.4 (1.0)	2.6 (0.9)	2.4 (1.0)	2.5 (0.9)	2.3 (0.9)	2.6 (1.1)
Overall Health	1.9 (0.9)	1.8 (0.8)	1.9 (0.9)	1.9 (0.9)	1.9 (1.0)	1.9 (0.9)	1.8 (0.8)	1.9 (0.8)	2.0 (1.4)	1.9 (1.0)
<i>HKB</i>										
	14.4 (2.8)	14.1 (2.9)	14.6 (2.7)	14.5 (3.0)	14.9 (3.0)	15.0 (2.7)	14.3 (2.8)	14.4 (2.2)	14.9 (2.4)	14.5 (2.7)
<i>BPI-PS</i>										
	6.9 (1.9)	7.1 (1.8)	6.8 (2.0)	7.0 (1.8)	6.7 (2.3)	7.0 (1.8)	6.8 (2.6)	7.3 (1.8)	6.5 (2.3)	6.7 (2.7)
<i>SDRS-5</i>										
	1.8 (1.5)	1.8 (1.5)	1.9 (1.5)	1.8 (1.4)	2.1 (1.7)	1.7 (1.5)	1.8 (1.5)	2.1 (1.6)	1.8 (1.5)	1.7 (1.4)

Note: T1 = Time 1 (intake); T2 = Time 2 (2-week post-session follow-up); T3 = Time 3 (6-month follow-up); EXP = Experimental Group (attended pre-clinic session); DNA = Did Not Attend Group (did not attend pre-clinic session); TAU = Treatment As Usual Group (waitlist); CPAQ = Chronic Pain Acceptance Questionnaire; BPI-PI = Brief Pain Inventory, Pain Interference subscale; K-10 = Kessler Distress Scale; HCU = Health care utilisation; AWHOQOL-BREF = Australian World Health Organisation Quality of Life Brief Scale; HKB = Health Knowledge/Beliefs; BPI-PS = Brief Pain Inventory, Pain Severity subscale – current pain; SDRS-5 = Social Desirability Response Set Scale.

acceptance: $F(2,322) = 0.89, p = 0.41$), pain-related interference (BPI-PI: $F(2,344) = 0.62, p = 0.54$), psychological distress (K-10: $F(2,340) = 0.10, p = 0.90$), HCU ($F(2,337) = 0.67, p = 0.51$), treatments tried (medical: $F(2,336) = 2.51, p = 0.08$, psychological: $F(2,336) = 0.68, p = 0.51$, alternative: $F(2,336) = 1.67, p = 0.19$, physical: $F(2,336) = 0.76, p = 0.47$), quality of life (AWHOQOL-BREF - physical health: $F(2,329) = 0.05, p = 0.95$, psychological health: $F(2,329) = 0.31, p = 0.74$, social relationships: $F(2,329) = 0.02, p = 0.98$, environment: $F(2,329) = 0.96, p = 0.38$, overall QOL: $F(2,331) = 0.07, p = 0.93$, overall health: $F(2,331) = 0.87, p = 0.42$), health knowledge/beliefs (HKB: $F(2,329) = 0.59, p = 0.55$); current pain severity (BPI-PS: $F(2,341) = 0.53, p = 0.59$); and symptom exaggeration (SDRS-5: $F(2,328) = 0.03, p = 0.97$).

Pre-Clinic Session: Participant Evaluation

Of the 66 people who attended an educational session, 39 (59%) returned a partially- or fully-completed evaluation form, providing feedback about the session and indicating their satisfaction with the content and style of presentation. Overall, the feedback indicated a reasonable level of acceptance, with most participants ($n = 30, 77%$) reporting that they were at least 'moderately' satisfied with the session and many being 'mostly' ($n = 13, 33%$) or 'completely' ($n = 10, 26%$) satisfied. Similarly, the majority of participants reported having found the information presented in the session to be at least 'moderately' useful ($n = 27, 69%$), with many rating it as 'mostly' ($n = 13, 33%$) or 'completely' ($n = 10, 26%$) useful. There was however, a mixed response to the printed materials, with comparable numbers of participants describing them as either 'not at all/a little' helpful ($n = 17, 44%$) or 'mostly'/ 'completely' helpful ($n = 15, 38%$). Despite these generally positive responses, most respondents stated at T2 that the session had influenced their thinking about the pain 'moderately' or less ($n = 35, 90%$), with many saying 'not at all' ($n = 15, 38%$). Thus, although respondents reported being satisfied with session content and delivery, and asserted that the information had been helpful, they did not believe that it had influenced the way that they interpreted or responded to their pain.

Next, mixed-model analyses of variance were performed to examine the impact of Group (*EXP, DNA, TAU*) and Time (T1, T2, T3) on outcome measures. There were no significant Group by Time interactions; consequently interaction effects are not discussed below. Similarly, results were not impacted by age, sex, pain severity, primary pain location or pain duration, thus covariate analyses are also not discussed.

Pain Acceptance (CPAQ)

Results indicated that Group did not impact significantly any of the areas of pain acceptance (pain willingness: $F(2, 270) = 1.19, p = 0.31$; activity engagement: $F(2, 303) = 0.28, p = 0.75$; overall pain acceptance: $F(2, 302) = 0.73, p = 0.48$), indicating that attendance at the educational session did not influence these measures. The level of activity engagement was similarly unaffected by Time ($F(2, 167) = 1.83, p = 0.16$). However, there was a main effect for Time across two aspects of pain acceptance: pain willingness ($F(2, 181) = 26.05, p < 0.001, d = 0.44$) and overall pain acceptance ($F(2, 169) = 16.31, p < 0.001, d = 0.30$). Post-hoc analyses indicated that, for the sample as a whole, pain willingness and overall pain acceptance increased over time, with participants reporting improved levels at T2 and T3, compared to T1 (see [Table 6.4](#)). The fact that the changes in pain willingness were associated with a medium effect, suggests that this particular finding reflects clinically meaningful change.

Pain-Related Interference (BPI-PI)

Consistent with the findings for activity engagement, the level of pain-related interference in daily activities did not differ significantly between Groups ($F(2, 227) = 0.64, p = 0.53$) or across Time ($F(2, 180) = 1.01, p = 0.37$) (see [Table 6.4](#)).

Table 6.4: Mean (SD) scores on the outcome measures for the full sample at each time-point, and for each group overall (across times)

	<u>Time of Assessment</u>			<u>Group</u>		
	T1	T2	T3	EXP	DNA	TAU
<i>CPAQ</i>						
Pain Willingness	15.0 (8.0)	18.5 (7.9) ^{a***}	18.1 (8.9) ^{a***}	17.5 (7.9)	17.0 (8.1)	15.9 (8.9)
Activity Engagement	23.2 (11.9)	24.4 (12.1)	24.7 (13.2)	24.2 (12.8)	24.1 (12.1)	23.4 (12.1)
Overall Pain Acceptance	38.2 (16.6)	43.0 (16.3) ^{a***}	42.7 (17.4) ^{a***}	41.7 (16.9)	41.2 (16.5)	39.9 (17.2)
<i>BPI-PI</i>	7.4 (1.7)	7.3 (1.9)	7.1 (2.0)	7.2 (1.6)	7.3 (1.8)	7.5 (1.9)
<i>K-10</i>	30.0 (8.7)	30.8 (9.1)	30.2 (9.5)	30.0 (8.7)	30.0 (8.7)	30.7 (9.4)
<i>HCU</i>						
Frequency	10.4 (6.5)	9.1 (6.2) ^{a*}	8.3 (6.5) ^{a***}	10.4 (6.2)	9.4 (6.8)	9.5 (6.1)
Treatment Types						
Medical	1.2 (1.3)	0.5 (0.7) ^{a***}	1.2 (1.1) ^{b***}	1.3 (1.2)	1.1 (1.1)	1.0 (1.3)
Psychological	1.2 (1.3)	0.7(0.7) ^{a***}	1.4 (1.1) ^{b***}	1.3 (1.5)	1.2 (1.3)	1.1 (0.9)
Alternative	0.4 (0.6)	0.2 (0.4) ^{a*}	0.4 (0.6) ^{b***}	0.4 (0.6)	0.4 (0.6)	0.3 (0.6)
Physical	1.3 (1.0)	1.1 (0.9) ^{a*}	2.2 (1.2) ^{a,b***}	1.4 (1.0)	1.5 (1.2)	1.5 (1.1)
New (Total)	-	2.5 (1.5)	2.5 (1.5)	8.5 (6.8)	8.1 (6.6)	8.0 (6.4)
<i>AWHOQOL-BREF</i>						
Physical Health	14.4 (4.0)	15.2 (4.5) ^{a*}	15.5 (4.5) ^{a**}	14.9 (4.2)	14.9 (4.1)	14.8 (4.5)
Psychological Health	15.7 (4.8)	15.8 (5.2)	15.8 (5.2)	15.6 (4.8)	15.8 (4.7)	15.7 (5.5)
Social Relationships	7.9 (3.0)	7.7 (2.7)	8.4 (7.2)	7.7 (2.9)	8.2 (5.5)	7.8 (2.8)
Environment	23.4 (5.6)	23.7 (5.8)	24.0 (5.5)	23.9 (5.6)	24.0 (5.7)	23.0 (5.5)
Overall QOL	2.4 (0.9)	2.5 (1.0)	2.4 (1.0)	2.4 (0.9)	2.4 (0.9)	2.4 (1.0)
<i>HKB</i>	14.4 (2.8)	14.7 (2.8)	14.6 (2.5)	14.4 (2.8)	14.7 (2.6)	14.4 (2.9)
<i>BPI-PS</i>	6.9 (1.9)	6.9 (2.2)	6.8 (2.3)	7.1 (1.9)	6.8 (2.0)	6.9 (2.1)
<i>SDRS-5</i>	1.8 (1.5)	1.8 (1.5)	1.8 (1.4)	1.9 (1.6)	1.8 (1.5)	1.8 (1.4)

Note: T1 = Time 1 (intake); T2 = Time 2 (2-week post-session follow-up); T3 = Time 3 (6-month follow-up); EXP = Experimental Group (attended pre-clinic session); DNA = Did Not Attend Group (did not attend pre-clinic session); TAU = Treatment As Usual Group (waitlist); CPAQ = Chronic Pain Acceptance Questionnaire; BPI-PI = Brief Pain Inventory, Pain Interference subscale; K-10 = Kessler Distress Scale; HCU = Health care utilisation; AWHOQOL-BREF = Australian World Health Organisation Quality of Life Brief Scale; HKB = Health Knowledge/ Beliefs; BPI-PS = Brief Pain Inventory, Pain Severity subscale – current pain; SDRS-5 = Social Desirability Response Set Scale.

*** = $p < 0.001$; ** $p < 0.01$; * $p < 0.05$

^a = significant difference compared to T1; ^b = significant difference compared to T2

Psychological Distress (K-10)

Psychological distress was also not significantly impacted by Group ($F(2, 313) = 0.29, p = 0.75$) or Time ($F(2, 180) = 1.24, p = 0.29$), indicating that distress was not altered by session attendance or time spent waiting to access CP treatment (see [Table 6.4](#)).

Health Care Utilisation (HCU)

Frequency. The results concerning frequency of HCU showed that the Groups did not differ significantly on this measure ($F(2, 298) = 0.66, p = 0.52$), meaning that session attendance did not impact frequency of health care access. There was, however, a small main effect for Time ($F(2, 180) = 8.26, p < 0.001, d = 0.16$), with participants reporting lower levels of HCU at T2 and T3, compared with intake (see [Table 6.4](#)). Thus, participants attended significantly fewer health-related appointments after having been referred to the pain service than they did prior to referral. Of note, although not statistically significant, the rates of HCU for the EXP and TAU groups continued to decrease further between T2 and T3, whereas HCU rates for the DNA group did not (see [Table 6.3](#)).

Treatment types. The types of treatments that participants reported having tried did not vary significantly between the Groups: medical ($F(2, 248) = 0.55, p = 0.58$); psychological ($F(2, 219) = 0.38, p = 0.68$); alternative ($F(2, 218) = 0.96, p = 0.39$); physical ($F(2, 215) = 0.40, p = 0.67$). However, all aspects of this domain did change significantly across Time: medical ($F(2, 204) = 29.64, p < 0.001, d = 0.63$); psychological ($F(2, 127) = 33.78, p < 0.001, d = 0.46$); alternative ($F(2, 164) = 7.32, p = 0.001, d = 0.27$); physical ($F(2, 165) = 58.41, p < 0.001, d = 0.31$). Specifically, post-hoc analyses indicated that participants reported having tried markedly fewer treatments at T2 than they did at either T1 or T3 (see [Table 6.4](#)). Moreover, although the levels of use reported for medical and alternative treatments were reasonably stable between T1 and T3, the reported levels for psychological and physical treatments were higher at T3 than at T1, indicating an increased uptake of these types of treatment six months after being referred to the PMU. The small to

medium-large effect sizes associated with the use of treatments over time suggest that the majority of these changes represent clinically observable differences — especially with respect to medical and psychological treatments. In terms of new treatments tried/retried, there was no significant difference between the groups at either T2 or T3 ($F(2, 80) = 0.14, p = 0.87$; and $F(2, 53) = 0.04, p = 0.96$ respectively) (see [Table 6.3](#)).

Quality of Life (AWHOQOL-BREF)

QOL was assessed in terms of multiple domains, none of which differed significantly between Groups: physical ($F(2, 301) = 0.22, p = 0.81$); psychological ($F(2, 323) = 0.02, p = 0.98$); social ($F(2, 221) = 0.61, p = 0.54$); environmental ($F(2, 307) = 1.12, p = 0.33$); overall QOL ($F(2, 293) = 0.20, p = 0.82$). Similarly, most aspects of QOL assessed did not vary over Time: psychological ($F(2, 173) = 0.37, p = 0.69$); social ($F(2, 177) = 0.92, p = 0.40$); environmental QOL ($F(2, 173) = 0.10, p = 0.90$); overall QOL ($F(2, 177) = 1.15, p = 0.32$). The exception to this was physical QOL, for which there a small positive main effect ($F(2, 176) = 4.45, p = 0.013, d = 0.17$); with post-hoc analysis indicating significant improvements at T2 and T3, compared with T1 (see [Table 6.4](#)).

Health Knowledge/Beliefs (HKB)

Consistent with other findings, results for health knowledge/beliefs were non-significant for Group ($F(2, 274) = 1.14, p = 0.32$) and Time ($F(2, 193) = 0.99, p = 0.37$), indicating that neither attendance at the educational session nor time spent waiting to access CP treatment impacted significantly on the level of pain-related knowledge reported by participants (see [Table 6.4](#)).

Pain Severity (BPI-PS)

Consistent with the previous domains, ratings of 'current' pain severity did not differ significantly across Group ($F(2, 249) = 0.36, p = 0.70$) or Time ($F(2, 135) = 0.11, p = 0.90$),

suggesting that the study results were not unduly influenced by pain fluctuations at the time of responding (see [Table 6.4](#)).

Symptom Exaggeration (SDRS-5)

With respect to symptom exaggeration, the between-groups comparison was non-significant ($F(2, 291) = 0.32, p = 0.73$) as was the comparison across Time ($F(2, 174) = 0.08, p = 0.93$) (see [Table 6.4](#)). Notably, the level of bias in responding was below the normative median for the measure on all three occasions. As such, responses were unlikely to have been excessively influenced by a desire to respond in socially desirable ways and were therefore deemed to provide reasonably accurate representations (within the limitations of self-report measurements).

6.6 Discussion

Chronic pain (CP) is a common condition, which negatively impacts on a range of important life domains. Many CP services struggle to meet patient demands, frequently resulting in long wait-times. The need to improve access to appropriate treatments for individuals living with CP has led clinicians to explore therapeutic opportunities in the pre-clinic (waitlist) period. Given the accumulating evidence for pre-clinic and brief interventions, this study explored whether therapeutic benefits could be achieved from a single brief intervention — a three-hour pre-clinic educational session — for patients newly referred to the waitlist of a tertiary CP service. More specifically, we examined whether this single educational session had an impact on pain acceptance (CPAQ), pain-related interference in daily activities (BPI-PI), psychological distress (K-10), HCU (frequency, type), quality of life (AWHOQOL-BREF) and health knowledge/beliefs. We also explored the impact of waiting six months for CP treatment.

In terms of the pre-clinic education session, the results indicated that this was a negative trial: although participants reported reasonable satisfaction with the session itself, there was no significant benefit associated with session attendance in any of the areas we assessed. On

reflection, this is probably not surprising given that, despite its longer duration and significant positive impacts, the STEPS program was also unable to reduce psychological distress (anxiety, depression, mental health composite scores) (Davies, et al., 2011).

In addition, we experienced a large self-selected exclusion rate, with 33% of referrals declining to engage with the PMU at all and 17% opting to engage with the unit but not participate in the research. Little is known about how these individuals compare, demographically or psychologically, with the included sample. Moreover, 70% of the respondents who were offered a pre-clinic session did not attend (*DNA* group). Again, little is known about their reasons for non-attendance. It is possible that individuals 'voted with their feet', deliberately choosing not to engage with an intervention that they did not perceive to be valuable. Equally plausible is that invitees felt unable to attend due to factors such as pain/disability, emotional difficulties, life demands, physical access issues etc. In hindsight, follow-up telephone calls may have proven informative.

Many public CP services struggle with high rates of non-response and non-attendance. Inclusion of a pre-clinic educational session (such as that trialed here) as a mandatory portion of the intake process is becoming increasingly common. Based on data regarding pre-clinic session uptake rates, completion rates and reported demand for individual follow-up after pre-clinic session completion (Davies, et al., 2011), it is easy to see how service efficiencies (i.e. decreased wait-time/occasions of service/clinic costs) could accumulate by adopting this model. If, however, the primary driver in service delivery is therapeutic outcomes — rather than economic gains — then more detailed consideration of a range of patient factors is required in order to better understand these findings. For instance, it is interesting to note that those individuals who chose not to engage early with the service — the *DNA* group who were offered, but did not attend, an educational session — were the only ones to report increased psychological distress and decreased engagement in valued activities six months after being referred to the PMU (T3), despite initial improvements post-referral (T2) (see [Table 6.3](#)). Moreover, they were the only group whose level of HCU remained

stable during this period (T2 - T3) — the other two groups attended pain-related health care appointments less frequently following referral to the tertiary service. Although these differences did not reach significance, this same trend was not observed in the other two groups. This suggests that there may be individual patient variables associated with low treatment engagement that may perpetuate unhelpful pain cycles, thereby increasing distress, fostering help-seeking behaviors including attendance at health care appointments (possibly as a mechanism via which to gain reassurance) and entrenching patterns of avoidance and withdrawal. However, as the groups were comparable on all of the areas assessed at the time of referral, we are unable to determine whether the *DNA* group's lack of engagement with treatment at the tertiary service was due to premorbid/individual factors or other processes. Moreover, it is not possible to say whether session effects may have been different if a motivational approach to the follow-up of non-attenders had been employed – an activity that was not possible given existing staffing resources. As outlined by Williams and colleagues (Williams, et al., 2012), matching patients to treatments, based on diagnostic groupings (i.e. unresolved CP), rather than individual factors, can lead to poor treatment alliances, resulting in reduced treatment adherence post-intervention. This erodes potential outcomes that might be achieved by selecting more effectively aligned patient groups. Therefore, more information is needed about who might benefit from a brief pre-clinic education session and who might not; the latter needing alternative management.

With respect to the impact of waiting six months for CP services, the numerous main effects found for Time across the sample as whole suggest that, where change occurred, this change was positive. Shortly after referral (T2), study participants reported a significant decrease in the frequency of health care use (all types) and significantly improved pain acceptance (pain willingness and overall pain acceptance) and QOL (physical); all of which were maintained, or improved, at six-month follow-up (T3). Further, there was a change in the types of health care sought by participants over time, with significant increases in the use of psychological and physical therapies at six months

(T3) compared with intake (T1). These findings are important for two reasons. The overall stability demonstrated in numerous areas from referral (T1) to the six month follow-up (T3) challenges previous reports that waiting up to six months is associated with declines in patient functioning (Lynch, et al., 2008) — at least for individuals who voluntarily participate in research involving intermittent follow-up surveys. Second, and perhaps more importantly, this is the first time that functional benefits have been linked with referral to — rather than treatment by — a tertiary CP service; suggesting that there may be something about *being referred to*, and *intermittently followed-up by*, a tertiary pain clinic that may be beneficial to patients, thereby highlighting what may be an important time-point for intervention.

With new referrals reporting an average of 10 pain-related health care appointments every three months, and 37% reporting weekly appointments, it is evident that CP is one of the most expensive health conditions of developed countries around the world (Gaskin & Richard, 2013; National Pain Summit Initiative, 2011). It is therefore interesting that, following referral to a tertiary CP service, many individuals changed the way that they approached, or engaged with, their health care. Specifically, many individuals reported attending progressively fewer health care appointments following referral to a tertiary pain service than they did before. For the sample as a whole, this decrease in health care appointments occurred despite an increase in the use of psychological and physical CP treatments. Following referral to a tertiary CP service, it is possible that health care became more targeted than it had been before, specifically focusing on physical or psychological strategies. That is, referral may have marked a shift in the way that patients (and perhaps their health care providers) viewed their condition: defining the problem as a CP issue, rather than another acute condition (i.e. an unresolved medical/surgical issue) and deciding that it should now be treated by a tertiary CP service instead of other active treatments. This shift may represent the creation of essentially a new diagnosis for the patient — potentially carrying renewed hope for effective treatments by the specialist service and also changing, or reducing, engagement with other

clinicians. Alternatively it is possible that referral was triggered by a period of acute distress and, accordingly, participants experienced a natural subsidence of symptoms following referral as the acute distress resolved. In the absence of a non-referred control group to explore this in more detail, it is not possible to draw definite conclusions.

The current study is not without limitations; most notably the reliance on self-report measures which, despite assurances to the contrary, may have been perceived by participants as potentially influencing their wait-time. In particular, it must be acknowledged that T2 was associated with a significant reduction across all domains in the number of treatments individuals reported having tried. This question explored the *number of treatments that had been tried (ever)*, not treatments that were *currently being used*; consequently domain scores should not have decreased. Hence, the findings for this variable should be viewed with caution. It is possible that individuals misunderstood the question — reporting strategies/treatments that they were currently using, rather than a tally of all treatments that they had ever tried. Alternatively, reports may have been affected by unreliable memory. It is also possible that, at T2, individuals felt somewhat more compelled to respond in socially desirable ways, as they became aware that wait-times could be lengthy. Although we concluded that the study data had not been unduly influenced by symptom exaggeration (because scores were below the normative median at all three time-points), the potential for biased responding was greater at T2 than at either of the other assessment points. Intermittent follow-up may also have resulted in participants feeling supported, or attended to, by the tertiary service — thereby mediating the level of distress/deterioration experienced. Similarly, cognitive shifts may have resulted from repeated administration of survey items — particularly the CPAQ, completion of which may encourage patients to rethink their approach to life engagement despite ongoing pain — rather than other factors. Moreover, randomisation, data collection and analyses were conducted by the primary author and therefore were not blinded. Finally, our data were all derived from newly-referred patients who volunteered for the study and completed

intermittent follow-up questionnaires. We are unable to comment on wait-times of more than six months duration, or on the experiences of those newly-referred individuals who either did not return the PSQ (thereby failing to engage at all with the PMU service) or who returned the PSQ and entered the clinic booking queue, but declined to participate in this research.

Future researchers could usefully expand on this study in numerous ways. Exploration of a range of pre-clinic intervention lengths (e.g., three hours, half day, full day) would greatly assist in identifying optimal program intensity. Seeking feedback from, and providing motivational interventions to, individuals who were invited to, but did not attend, sessions may also be productive. Qualitative exploration of patient and general practitioner conceptualisations of pain pre- and post-referral to a tertiary CP service may better inform our understanding about referral decisions and how they influence engagement with health care. Comparison of individuals referred to a tertiary CP service with non-referred individuals would also better inform our understanding of the impact of the referral process on individuals living with CP. Low treatment engagement is costly for both patients and agencies. Therefore a more detailed consideration of individuals who fail (or decline) to engage with CP treatment may help clarify whether poor engagement with clinical services is better predicted by pre-disposing/individual factors, or aspects of the referral process itself: information that may meaningfully assist clinics to engage with these patients. Similarly, more detailed monitoring of patient progress while waiting for services — including comparison with a non-referred group — would assist in clarifying the existence and scope of any critical intervention period, thereby facilitating more targeted service delivery. Such research would be aided by a randomised controlled trial comparing the impact of early clinical intervention (rather than an educational session) with standard appointment scheduling.

Overall, we were unable to demonstrate any significant improvements for newly-referred people on a waitlist as a result of a brief single pre-clinic educational session. Future research could usefully conduct further examination of referral and pre-clinic experiences, individual engagement

factors and options to inform matching of interventions with participants. Interestingly, unlike previous research (Lynch, et al., 2008), in waitlisted participants who agreed to be involved in research and who completed study measures at two and six months follow-up, a wait of six months to access an appointment at a tertiary CP service was *not* associated with significant deterioration in patient well-being. Instead, referral was associated with short-term functional improvements — in the first one to two months after referral to the tertiary pain service, participants reported improvements in a range of areas, including pain acceptance (willingness and overall acceptance), frequency of health care appointments and QOL (physical). This is the first time that functional benefits have been linked with referral to, rather than treatment by, a tertiary pain service; highlighting what may be an important time-point for targeted interventions.

Chapter 7 : Discussion

Chronic pain (CP) is a prevalent and costly condition, for which most Australians cannot access multidisciplinary care without first enduring a very long wait. What happens to people during this period is not well understood, nor is the solution for this clinical challenge clear. This thesis was motivated by a clinician's desire to examine the impact that current approaches to service delivery were having on the people who were referred for treatment, and to assess some of the available options that may facilitate more timely access to evidence-based care; the ultimate goal being to improve the quality of life of people living with CP.

The broad aims of this project were; (a) to investigate the psychological impact of CP and of waiting to access CP treatment, and (b) to examine two factors that are related to service design/delivery which impact on health care access, namely staff resourcing and a specific model of care (pre-clinic education). This involved conducting a meta-analysis, a large-scale randomised controlled trial with prospective longitudinal follow-up, and a survey of Australian CP clinics. The focus throughout was on public tertiary services because this is where the majority of Australians with CP access multidisciplinary care for their condition. This final chapter summarises the findings from each study, then explores the implications that they pose for CP-related practice, policy and research, before discussing the main limitations of the overall research project.

7.1 Summary of the Findings

Study 1: Meta-Analysis Examining Psychological Functioning

Study 1 ([Chapter 3](#)) synthesised a large literature exploring the relationship between CP and psychological distress, deliberately taking a broad perspective in order to account for the complexity of the CP experience. Data from 110 studies were meta-analysed and those aspects of psychological functioning that had been most commonly explored in people with CP were identified. Specifically, these were depression, anxiety, pain anxiety/concern, somatisation, anger/hostility, self-

efficacy, self-esteem and general emotional functioning — all of which were found to be significantly impaired in people with CP. However, contrary to previous assertions that depression is the leading psychological issue in this population (Access Economics, 2007; Von Korff, et al., 2005), this meta-analysis indicated that the more physically-focussed aspects were, in fact, the most profoundly affected; namely, pain anxiety/concern and somatisation. This suggests that the psychological distress associated with CP may lead to a heightened focus on, and therefore lower threshold for, physical symptoms; increasing the chance that physical symptoms are noticed and interpreted as threatening, thus heightening distress and discomfort, and perpetuating the cycle. This cycle of pain, distress and disability is discussed in detail in the CP literature (e.g., Vlaeyen & Linton, 2000; Vlaeyen & Linton, 2012) and the current data suggest that, in order to break it, therapeutic intervention should prioritise these physically-focussed aspects of psychological function.

A core challenge for this meta-analysis proved to be the inconsistent ways in which the psychological domains were conceptualised and assessed in the literature; with the same domains often being assessed using a variety of different measures, each documenting slightly different aspects. For example, the pain anxiety/concern domain was examined using 15 different measures, most of which explicitly focussed on pain that was directly related to the CP experience (e.g., *it will make my back pain worse*), some that focussed on health but not specifically CP (e.g., *I am sometimes afraid that I have a serious illness*), and one that focussed on general painful experiences that were not at all related to CP (e.g., *gulping a hot drink before it has cooled*). Although the measures varied, most discriminated between CP and healthy controls. The one exception to this was anger/hostility, where the different measures yielded inconsistent findings, suggesting that the definition and/or measurement of this construct requires careful consideration in any future research that assesses this domain. Similarly, the term somatisation was used inconsistently; being conceptualised as physical symptoms which exceeded the level that would be predicted by pathology, or as emotional distress that is experienced in physical ways. The first explanation is

unsurprising given the poor relationship between CP and physical pathology (Sharp, 2001), but the second suggests that individuals with CP are more likely to experience emotional distress in physical ways, possibly due to an increased vigilance towards physical, especially CP-related, sensations. This project could not distinguish between these two competing conceptualisations and so further examination is required because they have different implications for research and clinical practice. Balanced against this, the use of different measures to explore the same domain also highlighted some interesting findings. Specifically, fear of pain was found to be greater for CP-related scenarios than it was for general pain scenarios, suggesting that this fear is explicitly tied to the CP experience and that there is a level of discrimination within pain-related fear that had not previously been highlighted.

Study 2: Waiting for Chronic Pain Treatment

Study 2 ([Chapter 4](#)) built on these findings by investigating how the psychological functioning of individuals with CP was impacted by lengthy indefinite waits for treatment. The previous meta-analysis was not able to examine this issue because it was often unclear in the literature where individuals were in their treatment cycle. Study 2 also examined the impact of waiting for treatment on the health care utilisation of individuals referred for management at a tertiary CP service and the role of sex in moderating these outcomes; the latter having been highlighted as an important variable in exploratory data analyses. Accordingly, this study followed 339 participants for 2.5 years after they entered an indefinite, clinically-triaged waitlist for treatment at a tertiary CP service ($M_{\text{wait-time}} = 21$ months). Individuals were assessed at the point of intake (T1), at two months after referral (T2) and then at six-monthly intervals (T3-T7) until they received their first appointment with the pain service.

Sample attrition over the course of the follow-up period was of concern, with people exiting the study for several reasons: they received their first appointment with the clinic (no longer waiting), they opted-out of the study (declined to complete further measures while waiting for an appointment)

or they cancelled their referral (removed themselves from the waitlist). Thus, the data were examined to ensure that the final included sample was representative of the larger pool of referred individuals. These checks indicated that the people who completed the study were comparable to those who did not (did not respond, opted-out, withdrew from study) in terms of age and sex at the point of intake (T1). Moreover, when study participation status (still in study, received appointment, opted-out, cancelled appointment) was considered, the groups were shown to be comparable across a number of key domains, including age, sex, pain-related interference in the performance of daily activities, pain severity and psychological distress. That said, sample sizes were smaller for the longer-term follow-up time-points than they were for the first 12 months of waiting, consequently those findings were interpreted more cautiously. Importantly, unlike previous research that has typically used surgical waitlists or community samples, this study recruited individuals from a waitlist at a CP service. It also undertook a much longer follow-up than is generally seen in CP studies of this type, therefore providing critical and directly relevant, albeit tentative, information which can guide service planning and health-related policy.

At the point of referral (T1), participants reported significant pain-related interference in their ability to perform daily activities, high levels of psychological distress, frequent health-related appointments and pronounced dissatisfaction with their quality of life (QOL). This did not change markedly over the first 12 months of waiting, with pain severity, psychological distress and engagement in meaningful activities all remaining stable throughout the first year. Where change occurred during this time period, it was typically positive; with pain-related interference, pain acceptance (overall and pain willingness), physical aspects of QOL and frequency of health care use all improving. This relative stability continued in the longer-term for some domains. For example, pain severity remained stable for the first two years (T1-T6); although females reported more severe pain, overall, than males. The amount of relief that participants reported receiving from their medication also remained stable throughout (T1-T7), despite the fact that 36-45% of the sample

reported an increase in the dose/strength of their medication each time that they were surveyed. Again, this was more common amongst females than males. QOL was similarly unchanged across the period of waiting (T1-T7), with participants consistently reporting marked impairment at each time-point, although males reported less overall satisfaction with their social relationships (first year) and environmental supports/opportunities (longer-term) than females.

Other domains were significantly impacted by the lengthy treatment waits, albeit differently for each sex. Pain-related interference steadily declined for males over time, but females remained stable for the first two years before experiencing a sharp increase (T7). Females also reported increasing levels of psychological distress, especially from 12 months of waiting (T4) onwards, but males fluctuated before ending with less distress (T7) than they reported when they were first referred (T1). Similar patterns were seen for pain acceptance, where females deteriorated over time (T5: activity engagement, T7: pain willingness), but males oscillated before improving. There were also changes in the types of health care sought, with an overall decrease in the use of health services immediately following referral (T2, T3), followed by significant increases in the use of psychological (T3), alternative (T6) and physical therapies (T7). The frequency of pain-related health care appointments, on the other hand, decreased. In short, although this study did not identify a critical time-point for intervention, longer waits (>12 months) were associated with increasing distress and decreasing function, especially in females.

Last, a finding that was not reported in the published article, but was of considerable interest, was a shift in self-reported work status that occurred in the early period following referral to the tertiary service. Specifically, there was a seven-fold increase in the number of people who reported receiving a government disability pension during the first few months of being waitlisted for treatment. Although this may have represented a significant increase in the uptake of government-supported pensions, most people reported that this was not a change in status; meaning that nearly half (41%) of those who were receiving the disability pension at T2 answered differently on the intake

questionnaire. Given that levels of social-desirability in responding did not exceed normative standards or change significantly over time, it appears unlikely that this was a deliberate shift in self-representation. Thus, it may reflect a change in the way that individual's perceived their potential for future workforce participation. As indicated, this information was removed from the final manuscript at the direction of the publishing journal because of word count limits.

Study 3: Staff Resourcing

Having addressed the first aim, this research sought to examine the second aim — to explore two important service-related factors (staffing, model of care) that are associated with health care access. Accordingly, Study 3 ([Chapter 5](#)) explored the staff resources (amount, type) that were employed in Australian tertiary CP services ($N = 45$), in case staffing was tied to waitlist length. Importantly, staffing was considered in terms of both the absolute numbers of staff that were employed by a clinic and as a function of the number of new patients that were seen by those clinics each year. Clinics were classified using the IASP criteria (IASP, 2009) for Levels 1 and 2 multidisciplinary pain (MDP) services; with both providing interdisciplinary care, but Level 1 additionally undertaking research and teaching activities.

The staffing profiles were consistent for most disciplines; the exceptions being occupational therapy (Level 1 and 2 services) and psychiatry (Level 1), which were employed in varying numbers by these services, suggesting that their role in tertiary CP services needs to be elucidated. When compared to Level 2 clinics, Level 1 centres received more new referrals, saw more new patients, and employed more medical, nursing and administrative staff, but comparable numbers of allied health staff. Service location (rural vs. metropolitan) did not impact on clinical demand (number of new referrals) or activity (number of new patients seen), but medical staff were employed in greater absolute numbers in metropolitan-based services and patients had comparatively greater access to occupational therapy in rural clinics.

Pain Management Group Programmes (PMGPs) were offered by most services but in very different formats, with the frequency and duration of programmes varying considerably (range: 5-120 hours). Although PMGPs are largely run by allied health staff, the services that offered group programmes didn't employ more allied health staff than those that did not. Overall, the most intensive programs (>90 hours) employed more allied health staff than did those using less intensive models (51-90 hours, 30-50 hours), but they also saw more patients each year. Consequently, a consistent amount of allied health staff were employed to deliver a PMGP, irrespective of the intensity/format of the programme: 0.03FTE of allied health staff for each patient who participated in a group.

These results provide much needed data that can be used to inform workforce planning for tertiary CP services. However, although waitlist lengths and wait-times were not examined in this study, this information had been examined and reported elsewhere (Hogg, et al., 2012). When this was considered along with the current findings, it was clear that staffing was consistent across clinics that had different waitlist lengths. In combination, the findings from this and the Hogg et al. (2012) study therefore suggest that improving access to tertiary CP treatment will require more than just additional staff resources. It may require a change to the way that services are provided within clinics.

Study 4: Pre-Clinic Education

Accordingly, Study 4 ([Chapter 6](#)) explored whether changing the way that referrals were managed by a tertiary CP service improved the psychological adjustment of individuals who were waitlisted for treatment. This involved conducting a large-scale randomised controlled trial in order to examine whether attending a three-hour educational session, shortly after referral and prior to being seen at a tertiary pain clinic, promoted better outcomes for individuals than treatment as usual (waitlisted without intervention). This study was embedded within the larger longitudinal follow-up

that was reported in Study 2 ([Chapter 4](#)), consequently participants were assessed when they were first waitlisted (T1), two months after they had attended the pre-clinic session (T2) and six months later (T3). Individuals were sent an appointment for the educational session once they returned the clinic's intake measure (PSQ: Patient Screening Questionnaire) and provided they additionally consented to participate in the study. These appointments were rescheduled if people requested a change in date however, this altered the follow-up interval for those individuals because the T2 assessment was tied to attendance at the educational session.

Overall, individuals reported being reasonably satisfied with the content and delivery of the educational session, but attendance was not associated with significant change in any of the domains that were assessed; namely, people's pain acceptance (pain willingness, activity engagement, overall pain acceptance), pain impact (pain-related interference, pain severity), psychological distress, health care use (frequency, treatment type), QOL, and understanding of CP and its management (health knowledge/beliefs). Accordingly, both models of care — waitlisted without intervention and pre-clinic education then waitlisted — proved to be comparable in terms of patient outcomes. Notably however, participation in the pre-clinic education session was low for multiple reasons including the fact that 33% of all referrals to the pain clinic declined to engage with the service at all and another 17% declined to participate in the study. In addition, 70% of those who were offered a pre-clinic session failed to attend. This lack of engagement with clinical services that are provided on an optional basis has implications for treatment access; with lower engagement resulting in fewer people needing appointments, thus expediting the allocation of appointments to those who are waitlisted.

This study also examined the impact of the first six months of waiting for treatment and found that individuals did not deteriorate in a number of important psychological domains during this time. Instead, the QOL (physical) of participants improved and individuals reported being more willing to experience pain in order to do things that they valued (pain willingness, overall pain

acceptance). Their health care usage also changed, with the frequency of appointments and uptake of new treatments decreasing after being referred to the tertiary service (T2). Although their uptake of psychological and physical treatments had increased again by six months (T3), the overall frequency of appointments did not.

The impact of this early period of waiting for treatment appeared to be moderated by how effectively, or otherwise, an individual engaged with the tertiary service. Specifically, those people who were offered but did not attend an educational session (the *DNA* group) were the only ones who reported a worsening of psychological distress and decreased engagement in valued activities six months after being waitlisted, despite initially improving shortly after referral (T2). Moreover, they were the only people whose level of health care use remained stable during this period (T2 - T3); while others (*EXP* and *TAU* groups) attended appointments less frequently. As with Study 2, those who did and did not attend the educational session were comparable in terms of the domains that were assessed prior to the study (pain acceptance, pain impact, psychological distress, health care use, QOL, and understanding of CP and its management), but it is possible that other variables moderated the extent to which people engaged with the clinical service.

Together, these findings suggest that referral to a tertiary CP service was associated with improvements across a range of domains for individuals with CP, highlighting what may be an important time-point for intervention. This finding contrasts with that of an earlier systematic review, which found that waiting up to six months for treatment at a CP service was associated with worsening health-related quality of life and depression (Lynch, et al., 2008). Although that review was focussed on individuals seeking care at a CP service, it was not clear within the study whether individuals were on a definite or indefinite waitlist list, and analyses were hampered by the variable use of measures to assess certain domains and differing CP populations across studies (e.g., fibromyalgia, chronic low back pain, tension headache, CP). Thus, it may not fully reflect the impact

of the long and indefinite waitlists that are experienced by many of the people who are referred to tertiary CP services in Australia, and elsewhere.

7.2 Clinical Implications and Directions for Future Research

Psychological Functioning

The psychological well-being of individuals living with CP was examined via a meta-analysis ([Chapter 3](#)) and a large-scale clinical study with longitudinal follow-up ([Chapters 4](#) and [6](#)). The findings from these studies indicated that psychological functioning was consistently impaired in the presence of CP. Although depression has been most commonly linked with CP in the literature (Access Economics, 2007; Von Korff, et al., 2005), the current research suggests that individuals with CP were comparatively more anxious than they were depressed. This is not the first time that anxiety has been highlighted as a primary consideration in this cohort (McWilliams, et al., 2004) and the findings are consistent with models that describe the perception of threat as a key factor in determining how individuals interpret and respond to pain sensations (Eccleston, 2012). However, despite this, the relative emphasis on depression in people with CP has largely gone unchallenged (e.g., Woo, 2010). The current findings suggest that this should be revisited. Although depression and anxiety are frequently comorbid in people with CP, research designed to specifically compare and contrast the experiences of anxiety and depression in CP samples is needed in order to elucidate their relative contribution to the CP-disability cycle and thus better inform treatment.

In the interim, these findings suggest that anxiety is an important therapeutic consideration for clinicians who are working with this cohort. Despite a well-established link between anxiety and CP (e.g., Keefe, et al., 2004; Vlaeyen & Linton, 2000), current treatments vary in the extent to which they effectively address anxiety. For instance, graded in vivo exposure and acceptance and commitment therapy have been shown to reduce fear-avoidance more effectively in people with CP than mixed cognitive behavioural approaches and graded activity (Bailey, Carleton, Vlaeyen, &

Asmundson, 2009). Moreover, the choice of therapeutic intervention and subsequent outcomes are heavily influenced by clinician training and expertise (Stein & Lambert, 1995) but, despite its prevalence, CP is often not well-covered in post-graduate training programs (Darnall, et al., 2016; Fishman, et al., 2013), leaving many clinicians poorly-equipped to work effectively in this area. This research confirms that anxiety, particularly anxiety about CP-related scenarios, is an important component of the overall experience of CP and suggests that clinicians who are working with this patient group should ensure they are well versed in how to effectively treat this aspect of the CP-disability cycle.

This research also highlights the need for clinicians to be mindful of the different ways that psychological functioning can be impacted by CP. For example, the understanding that anxiety is explicitly tied to the CP experience in this patient cohort may lead clinicians to direct the focus of behavioural interventions and cognitive work towards specific aspects of CP-related experiences/activities. Similarly, clinicians should be encouraged to actively explore differences between chronic and general pain scenarios to assist them identify strengths and strategies that may facilitate improved coping in the presence of CP.

Defining and Measuring Aspects of Psychological Function

As stated, the meta-analysis ([Chapter 3](#)) highlighted considerable variation in the ways that psychological functioning was defined and assessed in the literature. Indeed, psychological distress was assessed in the current research (clinical study and longitudinal follow-up; [Chapters 4](#) and [6](#)) using a general measure of distress (K10), whereas the findings of the meta-analysis would recommend a more detailed examination. However, it was not possible for the design of the clinical study to be fully informed by the findings of the meta-analysis because of the longitudinal nature and timing requirements of the project. Nevertheless, these inconsistencies pose a number of challenges for clinicians and researchers when the same terms are used to refer to different things

within the literature. For instance, it is difficult to select appropriate search terms when conducting systematic reviews and meta-analyses, or to compare findings from different studies when domains are inconsistently operationalised.

Notwithstanding these caveats, most outcomes were not unduly impacted by the variability in measures that were used to assess different constructs; with most yielding similar results and consistently discriminating between individuals with CP and healthy controls. Moreover, within a domain, the findings from measures that had a small amount of somatic content did not differ significantly from those that had much more somatic content. This was unexpected because persons with CP are likely to endorse more physical symptoms on scales that have a high somatic content. This is particularly true for depression, where the overlap of symptoms between CP and depression is high (Wong, et al., 2011) and could therefore be expected to lead to larger differences between the groups. However, in this research, the measures equally discriminated between people with CP and those without, regardless of the extent to which they contained somatic content.

Although this appears true for the between-group comparisons that researchers explore, clinicians use measures on an individual basis to inform assessments of outcomes that have been achieved by therapeutic intervention. That is, not only do they want to know *if* an individual is psychologically impaired, compared to a healthy population, they also want to know *how* impaired that person is, so that they can examine changes in the level of impairment before and after an intervention. An assessment of therapeutic change relies on the availability of relevant normative data, but this is often not available for CP samples, particularly for measures that have a greater somatic focus. If clinicians choose to use these measures for individual assessment purposes, they must source published normative information that is appropriate for use with CP populations (e.g., Lopez, Pierce, Gardner, & Hanson, 2013; Nicholas, Asghari, & Blyth, 2008) or employ statistical methods, such as *minimal clinically important difference*, which determine the amount of change required in order to indicate that a person has benefitted from the intervention (Crosby, Kolotkinc, &

Williams, 2003; Frahm Olsen et al., 2018). Thus, clinicians may choose measures on a different basis than researchers do.

Consequences of Waiting for Chronic Pain Treatment

Despite previous reports to the contrary (Fogarty & Cronin, 2008; Lynch, et al., 2008), the current data indicate that indefinite waits of six months or less for treatment at a tertiary CP service did not lead to deterioration. After that time, if deterioration occurred, it was typically more pronounced in females than males. In fact, although males frequently fluctuated in their responses on individual measures, they oftentimes experienced some improvement by the end of the waiting period; possibly indicating improved coping with, if not adaptation to, pain.

When considering these findings, it is important to note that the research process of intermittent follow-up may itself have had some intrinsic benefit for people, with the additional attention potentially ameliorating the impact of waiting to access treatment. Similarly, as part of the research process, there was an ethical obligation to provide individuals with information about options for obtaining psychological assistance during the waitlist period and this may have also had benefits. Thus, qualitative research exploring patient perceptions of waiting appears indicated.

Nevertheless, the early follow-up data suggest that the very process of being referred to a tertiary pain clinic may prompt a shift in the way that individuals and/or their general practitioners view, or respond to, pain; indicating this may be a critical aspect of the waiting period that requires further examination. For example, the decreased frequency of health care appointments that occurred following referral to the tertiary service, despite targeted increases in the use of specific treatment types (psychological, alternative, physical) indicates that health care became more focussed. The reasons for this shift are not clear, but it was suggested that there may have been a change in how the individual and/or their treating practitioner(s) conceptualised the pain; re-defining it as a chronic, rather than acute, condition which needed to be treated by a tertiary CP service. Accordingly, individuals and/or their practitioner(s) may have chosen not to access/recommend other

active treatments pending review at the tertiary clinic. Alternatively, it is possible that individuals may have improved their self-management practices following referral to the tertiary service, or experienced some natural subsidence of their symptoms and/or distress following a period of acute exacerbation.

The findings regarding self-reported work status were also thought to reflect a shift in the way that individuals with CP conceptualised their future opportunities. Specifically, the 'unemployed due to pain' that was reported at referral (T1) may have implied *hope* for the future (e.g. "I can return to work if I can change/stop the pain"); whereas 'disability pension' that was reported at follow-up (T2) may have implied *hopelessness* (e.g. "I can't work again"). If it is true that identified work status reflects perceptions of hope/hopelessness for the future, then for those participants who were receiving disability pensions at intake, but initially identified themselves as unemployed, referral may originally have been associated with *hope*, which then shifted towards *hopelessness* following treatment delay. Further exploration of individual factors, including hope and optimism across the referral and waitlist phases, therefore appears warranted.

Finally, there were also improvements across a range of functional measures (pain-related interference, pain acceptance, QOL) in the short-term follow-up period, many of which were not maintained in the longer-term. Further exploration of factors that can impact the way an individual copes with, and responds to, CP during the referral and waitlist period is needed. A comparison of referred and non-referred individuals would also be useful to explore whether these changes are specifically related to the experience of being referred and waitlisted, or whether they are temporal changes that occur independent of this process.

In terms of health care delivery, the frequency with which participants in the clinical studies ([Chapters 4](#) and [6](#)) were attending health-related appointments at the point of referral to the tertiary service is compelling; averaging 10 appointments every three months, with 37% of the sample attending at least weekly appointments. This attests to the substantial economic impact of CP

(Access Economics, 2007) and highlights the amount of time that individuals spend seeking assistance for their condition. However, the marked increase in the reported dose/strength of medication that occurred at each follow-up was of particular concern. Again, this was far more likely to be reported by females than males. The specific cause of this increase was not examined, but the fact that medication dose/strength did not align with reports of pain severity or medication-related pain relief, suggests that these increases were potentially ineffective. Given the recent rise in deaths that have been attributed to prescription medication, particularly opioids (Australian Bureau of Statistics, 2018b; Rudd, Aleshire, Zibbell, & Gladden, 2016), this finding is very concerning and requires urgent review.

Considerations for Improving Treatment Access at Tertiary Chronic Pain Services

Staffing and intake models of tertiary pain clinics. As noted, treatment access is impacted by a range of factors including the numbers and disciplines of staffing that are employed by services, and the intake processes that clinics use to manage new referrals. These factors were explored via a survey of Australian tertiary CP clinics ([Chapters 5](#)) and a large randomised controlled trial ([Chapter 6](#)). The survey demonstrated that there was reasonable consistency in the pattern of staffing (discipline, amount) that was employed by Australian tertiary clinics (except occupational therapy and psychiatry), suggesting that services have identified effective workforce structures. Importantly, these data were presented in a way that enables the calculation of staffing profiles (amounts and types), based on known/predicted amounts of clinical activity, and thus, can be used to inform workforce planning and development.

This is a first step toward informed service planning, but more information is needed. The lengthy waitlists that exist across Australia (Hogg, et al., 2012) indicate that the existing arrangements are inadequate to meet the full level of clinical demand that tertiary CP services experience. Although workforce models have been established, this research suggests that

improved access to evidence-based care will require more than simply additional staff resources. Moreover, it highlights the current disparity in models of care that are offered by tertiary CP services, with rates and formats of PMGPs, access to allied health staffing and focus on medical interventions all varying across clinics. The extent to which these factors underpin differences in waitlist lengths for individual services needs further examination.

One model of care that purportedly facilitates treatment access and improves patient outcomes involves educating newly referred individuals about how the body processes pain and methods for improving self-management during the period between being referred for specialist treatment and receiving their first appointment (Davies, et al., 2011). The current research demonstrated that providing education to individuals before they were placed onto a waitlist could impact treatment access, although not necessarily in the way it was intended. Many public CP services struggle with high rates of non-response and non-attendance, and so it was not surprising that around one third of new referrals in the clinical study declined to engage with the unit. Indeed, this is part of the reason why many Australian clinics have now adopted pre-clinic education as a mandatory part of the intake process. Had attendance at the educational session been a pre-requisite for being waitlisted for a first appointment in this trial and had attendance levels been the same, wait-times at the Pain Management Unit would have significantly decreased; these non-attendance rates would have resulted in only 44% of new referrals being waitlisted for an appointment, rather than 66%. Other pilot projects have reported similarly low rates of engagement and completion for pre-clinic education, as well as decreased future engagement with the tertiary service after having attended this type of intervention (e.g., Davies, et al., 2011). Hence, it is easy to see how service efficiencies, such as decreased wait-time, occasions of service and clinic costs, could rapidly accumulate using this pre-clinic education model.

However, from a clinical perspective, this trial proved ineffective; with pre-clinic education neither helping nor harming participants. Two factors may have singularly or jointly contributed to

the low participation rate that was found for this model of care: individuals and/or their treating practitioner(s) may not have perceived the intervention to be valuable, or invitees may have experienced difficulties that precluded their attendance at the scheduled session (e.g., pain/disability, emotional difficulties, life demands, physical access issues). In hindsight, it would have been beneficial to explore this directly and/or employ some motivational techniques that would enhance engagement. However, although not effective in this study, other studies have demonstrated therapeutic benefit from educational sessions (e.g., de Jong, et al., 2005; Engers, et al., 2008; Moseley, et al., 2004; Sawhney, Watt-Watson, & McGillion, 2017) and so further examination of this model is warranted (e.g., Darnall et al., 2018). Future researchers could usefully explore options for improving participation in, and engagement with, this type of intervention in order to improve treatment outcomes and identify the optimal intensity for pre-clinic intervention. It would also be useful to explore the positioning of any pre-clinic intervention within subsequent waitlist management, in case the experience of being indefinitely waitlisted immediately following the session undermined the potential impact of the intervention. It may be that the effectiveness of the pre-clinic intervention would be enhanced if patients were subsequently treated within a defined time period (e.g. six months).

In short, improving access to evidence-based care will require consideration of a range of service-related aspects including: the amount and type of staffing that is employed, the intake practices that are used (e.g., pre-clinic education + waitlist vs. waitlist only), the types and amounts of treatments that are provided (e.g., group vs. individual sessions, primarily medical intervention vs. primarily allied health intervention vs. interdisciplinary intervention), the case-mix/complexity of referrals, and links with community-based services; all of which require further exploration. Researchers should also examine the amount and type of staffing that clinics employ alongside measures of patient outcomes (e.g., level of physical activity, workforce participation, psychological functioning, health care usage) and service factors (e.g., waitlist length, number of new patients

seen, average number sessions per patient treated) in order to determine the staffing profiles that optimise clinical performance. From a broader systems perspective, consumers, clinicians, health care decision makers and other key stakeholders all need to be educated (Hogans, Watt-Watson, Wilkinson, Carr, & Gordon, 2018) about the detrimental impact of lengthy indefinite waits for CP treatment, and the importance of clinically-focussed research to clarify the factors that impede timely care delivery and facilitate the development of treatments/strategies to improve outcomes for patients.

Treatment engagement. This research highlights the importance of better understanding the reasons behind poor engagement with tertiary CP services and treatment models. The low participation rate that was associated with our clinical studies ([Chapters 4](#) and [6](#)) indicates that a more detailed exploration of the factors that underlie poor/non-engagement is warranted. This may help clarify whether it is better predicted by pre-disposing or individual factors, or aspects of the referral process itself; information which may assist clinics to engage more effectively with these people. The current research also suggests that treatment engagement may be associated with adjustment during the waitlist period, with the group of non-engagers reporting more distress, lower pain acceptance and higher rates of health care usage ([Chapter 4](#)) than other individuals during this time. Once again, this highlights a need for a more detailed exploration of the individual factors that underlie participation in treatment. This information may usefully inform the patient-treatment matching process, such that clinicians could more effectively identify who might benefit from a particular type of intervention (e.g., brief pre-clinic educational session) and who might not; the latter group potentially needing an alternative method of engagement and treatment.

Acceptable waiting periods. The current data suggest that, at least for females, waiting periods of longer than six months lead to deterioration in a range of areas, with individuals reporting that they experienced more difficulty performing routine daily activities because of their pain, more distress, greater reliance on health care services, increasing prescription of medication

(doses/strength) and a decreased willingness to experience pain in order to undertake valued activities (pain acceptance). As such, developing national standards which cap waiting periods for CP services at six months appears important. By providing treatment within this time-frame, it may be possible to optimise outcomes for individuals with CP, especially females, and avoid the deterioration that occurs with longer waits. This now needs to be directly evaluated.

It is also possible that providing treatment even earlier, within two to six months of referral, may further optimise outcomes for people with CP because a range of functional improvements were seen during this time period. It may be that individuals are better positioned to make changes if intervention is provided during this period of relative improvement, thus increasing therapeutic engagement and efficacy. Again, the impact of different wait-times should be directly tested; ideally via a randomised controlled trial comparing and contrasting the impact of providing intervention within two months of referral to a tertiary CP service versus within six months. Doing so would determine if shorter wait-times are indicated and provide important data to inform future guidelines.

7.3 Translation of the Research

This research has had immediate translational effects — directly influencing health care reform in the state of South Australia, where the research was undertaken. Although not intended to improve patient outcomes, the Pain Management Unit now uses a pre-clinic education session as part of its standard intake process for all non-urgent (i.e., not cancer/palliative) referrals (refer <https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/health+services/outpatient+services/outpatient+clinics/central+adelaide+lnh+specialist+and+outpatient+clinics/pain+management+unit+outpatient+services+at+central+adelaide>). This change was implemented for several reasons. First, staff received feedback from consumers and their care providers about some of the benefits that people had experienced after attending the pre-clinic session, when individuals attended their initial appointment in the Pain Management Unit. Second, clinicians also noted

improvements in individual presentations between attendance at the pre-clinic session and the first appointment in the clinic. These included changed attitudes towards medical management for CP and increased openness to self-management as a treatment methodology. Third, the unit believed that it was important to increase motivation for active self-management amongst people who were referred for treatment, even during the waitlist period; a group-based pre-clinic session was a resource-efficient way to do this. Fourth, educating patients about what they could (and could not) expect from the clinical service and about strategies that they could use to improve their management of their pain resulted in fewer people being placed on the clinic's waitlist, because some individuals decided that they did not need/want an appointment. The pre-clinic session has since undergone several revisions to refine the content and delivery style, and continues to be evaluated by the Pain Management Unit.

Perhaps the largest translational impact to date has been achieved by exploring the staffing resources that are employed in Australian tertiary CP services ([Chapter 5](#)). It is important to improve access to evidence-based care for people living with CP in the state of South Australia, because they experience the longest waits in the country to access tertiary CP services (Hogg, et al., 2012). Poor treatment access was one of the driving factors that underpinned the current research and it was partially addressed in 2016 as part of a broader reform of the public health system that the South Australian Government called 'Transforming Health' (Department for Health and Ageing, 2016; Government of South Australia, 2017). The reform strategy for CP involved a multimillion dollar investment over a three-year period (Goodes, 2018), but there was no data to guide the development of staffing profiles for the newly developed and/or expanded services. As such, FTE modeling from Study 3 ([Chapter 5](#)) and historical referral data from the Pain Management Unit — the largest CP service in the state — were used to develop the staffing profiles that provided the basis for the service reform. These figures were then adjusted by the implementation committee on the basis of activity and funding levels that were agreed with Department of Health.

7.4 Limitations of the Research Project

The limitations of the individual studies have been discussed in the relevant chapters ([Chapters 3, - 6](#)). The following discussion focusses on the broader limitations of this research project.

Psychological functioning was examined in the clinical studies ([Chapters 4 and 6](#)) using a single general measure of distress (K10). This measure was chosen because it formed part of the intake screening questionnaire (PSQ) that all new referrals to the Pain Management Unit were required to complete; thus minimising participant burden. In hindsight, given the findings of the meta-analysis ([Chapter 3](#)), it would have been useful to examine more specific aspects of psychological functioning including depression, anxiety and pain-related anxiety. Doing so would have provided further clarification about the relationship between CP and psychological functioning, including the clinical foci that were suggested by the meta-analysis of the existing literature. However, as indicated, the longitudinal design of the clinical studies meant that data collection commenced before the results of the meta-analysis were available and so it was not possible for the clinical study design to be fully informed by those findings. Moreover, participant burden was a primary consideration when selecting questionnaires and it is likely that completion rates would have been further eroded if participants were asked to complete additional measures.

Research that is undertaken in clinical settings faces unique challenges and this is particularly relevant for research in pre-clinical settings. First, data for both clinical studies ([Chapters 4 and 6](#)) were collected simultaneously, which meant that the pre-clinic education study ([Chapter 6](#)) was effectively prioritised and so timelines were adjusted on the basis of participation in that project. In particular, the first follow-up (T2) was specifically timed to occur shortly after attendance at the educational session; which, when rescheduled, affected the timing of the next follow-up. This resulted in some individuals being waitlisted longer than was reflected because the time period between T1 and T2 was effectively increased when the appointment was rescheduled. Similarly, the

speed with which individuals returned their intake measures varied greatly but, consistent with local clinical practices at the time, waitlist length was timed from when the person responded. In hindsight, coding for this information may have proven informative in order to examine whether delayed responding was associated with participation in treatment and/or clinical outcomes. It was also not possible to identify or eliminate the potential influence of other study design factors in mediating outcomes over time; such as intermittent follow-up, the provision of information about how to access psychological supports, or repeated-measures assessment.

Next, this research was reliant on self-report measures because individuals were followed-up by mail *before* being assessed in person by the Pain Management Unit, which meant that more objective assessments of mood and level of function were not available. Where possible, checks were undertaken to assess the validity of these quantitative responses (social desirability, pain severity at the time of responding) and they indicated that, within the bounds of self-report, participant responses appeared to be reliable. In hindsight, including an additional qualitative component, exploring individual perceptions about waiting for treatment, may have provided further information to guide the development of wait-time standards.

A large number of people chose not to participate in this research and/or the specific model of care (pre-clinic education) that was being piloted ([Chapters 4](#) and [6](#)). Although checks indicated that the final sample was representative of the larger group of referred individuals, it was not possible to compare or contrast the experiences of these various groups in additional ways (e.g., duration or location of pain, relationship status, reason for pain onset, history of treatments tried) and so it remains possible that they differed in other important aspects. Clinically triaged waitlists are, by definition, non-standard, which means that sample attrition is an inherent difficulty in a longitudinal study, complicating statistical analyses. Given the frequency with which lengthy treatment waits are experienced by people with CP, and the dearth of publications examining these waiting periods, the

current longer-term findings represent an important, albeit tentative, addition to the existing knowledge base.

Finally, data for the staffing paper ([Chapter 5](#)) was collected by the Australian Pain Society as part of the 'Waiting in Pain' project and so it was not possible to have any input into the questions that were included or their phrasing. This resulted in omissions in important areas such as service quality (e.g. patient outcomes) and efficiencies (e.g., new:return appointment ratios), the full suite of treatments provided by a clinic outside of PMGPs and medical interventions, and the number of unpaid trainee positions. This latter point (unpaid trainee positions) is particularly relevant for provisional psychologist positions because they were not represented in the staffing profiles; whereas provisional psychologist positions are unpaid roles in Australia, medical trainees who are participating in the Faculty of Pain Medicine fellowship program (the primary medical training program used in Australian CP services) are paid and thus, were included.

7.5 Conclusion

This research addresses an important, but largely neglected, area of clinical practice: the long and indefinite waits that people with CP face in order to access evidence-based care, and the psychological impact of both CP and waiting for treatment. The current data suggests that treatment should be delivered within six months of referral to a tertiary CP service, and have a clear and deliberate focus on physically-focussed emotional difficulties (somatisation) and anxiety, particularly pain-related anxiety. It is possible that earlier intervention (e.g. within two to six months of referral) may further improve outcomes, but this needs to be evaluated. National and international standards, which include these maximum wait-times, are needed in order to help people avoid the deterioration that is associated with longer-term waits for treatment.

Clinical services must now determine how to most effectively expedite treatment access. The current data provide staffing profiles that can usefully guide service development, but they also

indicate that improved access to treatment requires more than just additional funding for increased staff. This research demonstrated that changing the model of care for service intake can facilitate treatment access by reducing the number of people who are placed on a waitlist. In this instance, the provision of a pre-clinic educational session prior to being placed on an indefinite waitlist did not improve individual outcomes. However, the fact that many individuals did not take up this opportunity meant that using it as a mandatory part of the intake process would significantly reduce the number of people who became waitlisted at a clinic, thus greatly reducing clinical wait-times and improving treatment access. Although effective from a service efficiency perspective, this does not promote the individual improvement that clinical health services are ethically required and tailored to deliver. As such, further research is now needed to identify the staffing profiles and models of care that *both* optimise clinical performance and expedite care delivery.

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Appendix 1: Supplementary Information for Chapter 3

Appendix 1.1 Supplementary Tables for Chapter 3

Supplementary Table 3.A: Search strategies used by search engine

Search Engine	Search Strategy
PubMed / Cochrane	<p>(((((((((((((psychological stress[tiab] OR psychological stresses[tiab] OR psychological stressor[tiab] OR psychological stressors[tiab]) OR (life stress[tiab] OR life stresses[tiab] OR life stressfulness[tiab] OR life stressing[tiab] OR life stressor[tiab] OR life stressors[tiab])) OR Mental suffering[tiab] OR Emotional stress[tiab] OR suffering[tiab] OR ("depressive disorder"[MeSH Terms] OR "depression"[MeSH Terms])) OR "depressive disorder"[MeSH Terms] OR (adjustment disorder[tiab] OR adjustment disordered[tiab] OR adjustment disorders[tiab])) OR "anxiety"[MeSH Terms] OR "anxiety disorders"[MeSH Terms] OR (physical activities[tiab] OR physical activity[tiab] OR physical activity/behavior[tiab] OR physical activity/education[tiab] OR physical activity/energy[tiab] OR physical activity/exercise[tiab] OR physical activity/fitness[tiab] OR physical activity/inactivity[tiab] OR physical activity/increased[tiab] OR physical activity/participation[tiab] OR physical activity/reduction[tiab] OR physical activity/rehabilitation[tiab] OR physical activity/week[tiab])) OR (motor activities[tiab] OR motor activity[tiab] OR motor activity/energy[tiab] OR motor activity/performance[tiab])) OR Physical function[tiab] OR health care utilisation[tiab] OR "quality of life"[MeSH Terms] OR "activities of daily living"[MeSH Terms] OR (leisure activities[tiab] OR leisure activity[tiab])) AND (pain[tw] AND (chronic disease[mh] OR chronic*[tiab]))</p> <p>Limits: Humans, English, All Adult: 16+ years</p>
PsychInfo	<p>((DE "Depression (Emotion)" OR TI "Depression (Emotion)" OR AB "Depression (Emotion)") OR (DE "Emotional States" OR TI "Emotional States" OR AB "Emotional States") OR (DE "Anger" OR TI "Anger" OR AB "Anger") OR (DE "Anxiety" OR TI "Anxiety" OR AB "Anxiety") OR (DE "Distress" OR TI "Distress" OR AB "Distress") OR (DE "Emotional Trauma" OR TI "Emotional Trauma" OR AB "Emotional Trauma") OR (DE "Fear" OR TI "Fear" OR AB "Fear") OR (DE "Frustration" OR TI "Frustration" OR AB "Frustration") OR (DE "Grief" OR TI "Grief" OR AB "Grief") OR (DE "Guilt" OR TI "Guilt" OR AB "Guilt") OR (DE "Helplessness" OR TI "Helplessness" OR AB "Helplessness") OR (DE "Hopelessness" OR TI "Hopelessness" OR AB "Hopelessness") OR (DE "Shame" OR TI "Shame" OR AB "Shame") OR (DE "Suffering" OR TI "Suffering" OR AB "Suffering") OR (DE "Psychological Stress" OR TI "Psychological Stress" OR AB "Psychological Stress") OR (DE "Stress" OR TI "Stress" OR AB "Stress") OR (DE "Major Depression" OR TI "Major Depression" OR AB "Major Depression") OR (DE "Adjustment Disorders" OR TI "Adjustment Disorders" OR AB "Adjustment Disorders") OR (DE "Anxiety" OR TI "Anxiety" OR AB "Anxiety") OR (DE "Anxiety Disorders" OR TI "Anxiety Disorders" OR AB "Anxiety Disorders") OR (DE "Acute Stress Disorder" OR TI "Acute Stress Disorder" OR AB "Acute Stress Disorder") OR (DE "Posttraumatic Stress Disorder" OR TI "Posttraumatic Stress Disorder" OR AB "Posttraumatic Stress Disorder") OR (DE "Physical Activity" OR TI "Physical Activity" OR AB "Physical Activity") OR (DE "Active Living" OR TI "Active Living" OR AB "Active Living") OR (DE "Activity Level" OR TI "Activity Level" OR AB "Activity Level") OR (DE "Health Behavior" OR TI "Health Behavior" OR AB "Health Behavior") OR (DE "Health Behaviour" OR TI "Health Behaviour" OR AB "Health Behaviour") OR (DE "Physical Fitness" OR TI "Physical Fitness" OR AB "Physical Fitness") OR (DE "Health Care Utilization" OR TI "Health Care Utilization" OR AB "Health Care Utilization") OR (DE "Health Care Costs" OR TI "Health Care Costs" OR AB "Health Care Costs") OR (DE "Quality of Life" OR TI "Quality of Life" OR AB "Quality of Life") OR (DE "Activities of Daily Living" OR TI "Pain" OR AB "Chronic Pain" OR DE "Chronic Pain") OR (TI "Pain" OR AB "Pain" "Activities of Daily Living" OR AB "Activities of Daily Living")) AND ((TI "Chronic OR DE "Pain") OR (TI "Back pain" OR AB "Back pain" OR DE "Back pain") OR (TI "Headache" OR AB "Headache" OR DE</p>

Supplementary Table 3.A: Search strategies used by search engine cont.

Search Engine	Search Strategy
Scopus	<p>"Headache") OR (TI "Myofascial pain" OR AB "Myofascial pain" OR DE "Myofascial pain") OR (TI "Neuralgia" OR AB "Neuralgia" OR DE "Neuralgia") OR (TI "Neuropathic pain" OR AB "Neuropathic pain" OR DE "Neuropathic pain") OR (TI "Somatoform pain disorder" OR AB "Somatoform pain disorder" OR DE "Somatoform pain disorder") OR (TI "Fibromyalgia" OR AB "Fibromyalgia" OR DE "Fibromyalgia") OR (TI "Arthritis" OR AB "Arthritis" OR DE "Arthritis"))</p> <p>(TITLE-ABS-KEY-AUTH("chronic" AND "pain")) AND ((("psychological stress" OR "psychological stresses" OR "psychological stressor" OR "psychological stressors") OR ("life stress" OR "life stresses" OR "life stressfulness" OR "life stressing" OR "life stressor" OR "life stressors") OR ("mental suffering") OR ("emotional stress") OR "suffering" OR ("depressive disorder" OR "depression") OR ("adjustment disorder" OR "adjustment disordered" OR "adjustment disorders") OR ("anxiety" OR "anxiety disorders") OR ("physical activities" OR "physical activity" OR "physical activity/behaviour" OR "physical activity/education" OR "physical activity/energy" OR "physical activity/exercise" OR "physical activity/fitness" OR "physical activity/inactivity" OR "physical activity/increased" OR "physical activity/participation" OR "physical activity/reduction" OR "physical activity/rehabilitation" OR "physical activity/week") OR ("motor activities" OR "motor activity" OR "motor activity/energy" OR "motor activity/performance") OR "physical function" OR "health care utilisation" OR "quality of life" OR "activities of daily living" OR ("leisure activities" OR "leisure activity")) AND (LIMIT-TO(EXACTKEYWORD, "Human") OR LIMIT-TO(EXACTKEYWORD, "Adult")) AND (LIMIT-TO(LANGUAGE, "English")) AND (LIMIT-TO(SRCTYPE, "j")) AND (LIMIT-TO(EXACTKEYWORD, "Human") OR LIMIT-TO(EXACTKEYWORD, "Adult")) AND (LIMIT-TO(LANGUAGE, "English")) AND (LIMIT-TO(SRCTYPE, "j"))</p>

Supplementary Table 3.B: Demographic information retrieved from studies

Study	Year	Country of Origin	N		Age		Males		Education (years)		Caucasian		Employed		Married / Partnered		Pain Type	Recruitment Source		Matched
			CP	HC	CP	HC	CP	HC	CP	HC	CP	HC	CP	HC	CP	HC		CP	HC	
1	2002	America	95	95	44.2 (1.4)	44.2 (1.4)	14	14	15.1 (3.8)	15.0 (3.8)	-	-	47	76	57	66	mixed	community	community	yes
2	2007	Europe	105	79	37.8 (12.0)	36.0 (10.6)	25	17	-	-	105	79	-	-	-	-	head / neck FM	treatment seeking	-	yes
3	2009	Europe	100	100	50.5 (9.6)	50.3 (11.4)	7	7	-	-	-	-	-	-	63	64	FM	community	community	yes
4	2000	America	30	2474	49.5 (14.2)	43.6 (17.4)	16	1055	-	-	-	-	-	-	-	-	back	treatment seeking	community	no
5	2012	America	23	29	25.6 (1.6)	25.4 (1.4)	0	0	-	-	20	28	-	-	-	-	pelvic / abdo mixed	mixed	-	yes
6	1997	America	19	22	36.4 (9.7)	36.4 (9.8)	12	13	-	-	-	-	-	-	-	-	mixed	treatment seeking	other	yes
7	2005	America	36	29	38. (10.9)	39.7 (10.5)	14	11	-	-	-	-	-	-	-	-	mixed	treatment seeking	other	yes
8	1991	America	97	49	46.7 (-)	45.5 (-)	97	49	13.1 (8.2)	14.7 (10.2)	78	41	-	-	-	-	back	treatment seeking	community	yes
9	2011	Europe	1593	1237	-	-	-	-	-	-	-	-	-	-	-	-	mixed	community	community	no
10	2012	Europe	30	15	48.5 (10.2)	45.1 (9.1)	0	0	-	-	-	-	-	-	-	-	back	mixed	community	yes
11	2011	Asia	666	362	46.2 (12.7)	32.4 (8.1)	127	195	-	-	-	-	-	-	546	252	mixed	treatment seeking	community	no
12	1996	America	42	26	41.0 (11.0)	38.0 (15.0)	42	26	14.0 (4.0)	15.0 (3.0)	43	29	40	25	34	15	pelvic / abdo mixed	mixed	mixed	yes
13	2008	America	3135	3494	-	-	993	1514	-	-	2564	2725	-	-	1956	2393	mixed	community	community	no
14	2008	America	3391	2298	-	-	1258	1122	-	-	2547	1630	-	-	1948	1287	mixed	community	community	no
15	1992	America	467	1097	20.1 (4.8)	19.7 (3.3)	-	-	-	-	-	-	-	-	-	-	mixed	students	students	no
16	2005	Europe	45	45	47.2 (10.2)	45.7 (8.1)	21	21	-	-	-	-	-	-	-	-	back	treatment seeking	community	yes
17	2008	America	85	117	22.3 (6.7)	20.5 (5.7)	14	47	-	-	62	38	-	-	-	-	head / neck mixed	students	students	no
18	2006	America	31	20	46.2 (10.5)	43.4 (11.0)	18	9	-	-	-	-	-	-	-	-	mixed	mixed	mixed	yes

Note: abdo = abdominal; FM = Fibromyalgia; neuro = neuropathic; WAD = whiplash associated disorder. Study number relates to numbered reference list presented at the end of this appendix.

Supplementary Table 3.B: Demographic information retrieved from studies cont.

Study	Year	Country of Origin	N		Age		Males		Education (years)		Caucasian		Employed		Married / Partnered		Pain Type	Recruitment Source		Matched
			CP	HC	CP	HC	CP	HC	CP	HC	CP	HC	CP	HC	CP	HC		CP	HC	
19	2001	America	310	73	40.6	43.2	192	41	-	-	-	-	-	-	-	-	back	mixed	-	no
20	1990	America	20	20	40.3 (10.5)	45.4 (14.2)	11	9	13.3 (2.0)	14.3 (2.2)	-	-	-	-	-	-	back	treatment seeking	community	yes
21	2010	America	687	1239	-	-	587	1137	-	-	100	102	-	-	290	471	mixed	other	other	no
22	2009	Europe	25	23	41.7 (5.4)	42.8 (10.8)	0	0	-	-	-	-	-	-	-	-	FM	treatment seeking	-	yes
23	1990	America	11	10	68.5 (6.6)	74.5 (8.3)	6	4	11.6 (3.8)	13.1 (4.2)	-	-	-	-	-	-	mixed	treatment seeking	community	yes
24	2007	Europe	207	105	47.1 (15.3)	45.8 (17.1)	115	60	-	-	-	-	-	-	-	-	mixed	treatment seeking	community	yes
25	2005	America	55	55	32.3 (12.5)	32.6 (12.7)	2	2	14.7 (2.4)	15.0 (2.1)	-	-	-	-	-	-	facial	treatment seeking	mixed	yes
26	2008	America	30	30	49.6 (12.5)	46.6 (10.0)	-	-	14.2 (2.5)	15.2 (4.3)	-	-	-	-	-	-	FM	mixed	mixed	yes
27	1998	America	7	7	36.2 (5.4)	34.0 (3.8)	0	0	14.0 (4.5)	15.3 (3.2)	6	6	-	-	7	7	mixed	community	community	yes
28	2009	America	19	21	51.7 (12.2)	50.3 (12.7)	8	10	14.0 (2.7)	15.1 (2.5)	11	14	-	-	-	-	arthritis	treatment seeking	-	yes
29	1999	Europe	26	14	28.3 (7.0)	30.1 (2.8)	0	0	-	-	-	-	-	-	-	-	pelvic / abdo	treatment seeking	treatment seeking	yes
30	1995	Europe	256	64	45.4 (7.4)	45.4 (7.4)	107	31	-	-	-	-	-	-	-	-	mixed	treatment seeking	other	yes
31	2005	Australia	39	35	37.4 (5.3)	38.3 (5.5)	0	0	4.6 (1.9)	4.6 (1.9)	-	-	16	21	27	19	mixed	mixed	mixed	yes
32	1998	Asia	144	31	40.8 (11.8)	44.9 (14.0)	-	-	-	-	-	-	-	-	-	-	mixed	treatment seeking	community	yes
33	2009	Europe	97	97	44.6 (8.6)	41.0 (10.1)	14	24	-	-	-	-	66	74	76	74	mixed	treatment seeking	-	no
34	1990	America	163	50	42.7 (-)	42.7 (-)	-	-	-	-	-	-	-	-	-	-	mixed	mixed	mixed	yes
35	2013	America	177	193	59.2 (6.0)	56.7 (5.9)	54	77	-	-	-	-	-	-	92	86	arthritis	mixed	community	yes
36	2006	Australia	248	356	-	-	0	0	-	-	253	307	-	-	-	-	pelvic / abdo	community	community	no
37	2010	America	108	125	20.6 (1.6)	-	21	42	-	-	-	-	-	-	-	-	mixed	students	students	yes
38	2008	Europe	27	27	52.0 (6.9)	48.5 (9.0)	10	10	-	-	-	-	-	-	-	-	mixed	treatment seeking	community	yes

Note: abdo = abdominal; FM = Fibromyalgia; neuro = neuropathic; WAD = whiplash associated disorder. Study number relates to numbered reference list presented at the end of this appendix.

Supplementary Table 3.B: Demographic information retrieved from studies cont.

Study	Year	Country of Origin	N		Age		Males		Education (years)		Caucasian		Employed		Married / Partnered		Pain Type	Recruitment Source		Matched
			CP	HC	CP	HC	CP	HC	CP	HC	CP	HC	CP	HC	CP	HC		CP	HC	
39	2002	Europe	89	89	49.6 (16.9)	43.3 (12.5)	9	11	-	-	-	-	-	-	-	-	head / neck	community	community	yes
40	2011	Australia	45	38	51.3 (11.3)	45.4 (12.8)	11	9	-	-	-	-	-	-	-	-	facial	treatment seeking	mixed	yes
41	2012	America	20	20	41.8 (6.1)	29.8 (6.5)	0	0	-	-	-	-	-	-	-	-	FM	treatment seeking	community	yes
42	1998	Europe	320	4929	67.3 (7.4)	69.7 (8.1)	80	2231	-	-	-	-	-	-	-	-	head / neck	primary care	primary care	no
43	2010	America	70	76	59.4 (7.5)	68.0 (8.7)	5	25	-	-	60	67	25	16	-	-	FM	mixed	mixed	no
44	2004	Europe	50	35	43.4 (8.4)	41.8 (10.7)	24	16	-	-	-	-	-	-	-	-	mixed	-	-	no
45	1996	America	62	55	39.6 (11.1)	40.1 (11.2)	-	-	-	-	-	-	-	-	-	-	mixed	community	community	yes
46	2006	Europe	19	25	34.1 (9.3)	30.6 (7.3)	0	0	-	-	-	-	-	-	-	-	pelvic / abdo	treatment seeking	primary care	yes
47	2004	America	37	30	44.9 (8.0)	44.1 (7.7)	0	0	-	-	-	-	-	-	32	28	FM	treatment seeking	community	yes
48	2004	America	33	37	45.4 (8.3)	44.6 (7.7)	0	0	-	-	-	-	-	-	-	-	FM	treatment seeking	community	yes
49	2012	America	29	32	69.0 (7.0)	67.3 (5.1)	15	20	-	-	-	-	-	-	-	-	back	community	community	yes
50	2007	Europe	46	35	56.0 (-)	59.0 (-)	7	11	-	-	-	-	-	-	-	-	facial	treatment seeking	primary care	yes
51	1999	Europe	21	21	66.0 (7.6)	65.0 (9.1)	1	1	-	-	-	-	-	-	-	-	facial	treatment seeking	primary care	yes
52	1986	Europe	30	30	31.8 (9.7)	31.7 (7.9)	0	0	-	-	-	-	-	-	22	21	pelvic / abdo	treatment seeking	-	yes
53	2001	America	21	10	-	-	20	4	-	-	-	-	-	-	-	-	back	treatment seeking	-	yes
54	2002	America	57	74	43.9 (14.6)	42.1 (12.0)	0	0	-	-	54	61	-	-	-	-	pelvic / abdo	mixed	mixed	yes
55	2000	Australia	38	28	-	-	-	-	-	-	-	-	-	-	-	-	head / neck	community	community	yes
56	1995	Europe	75	25	45.7 (9.7)	45.6 (9.1)	27	8	-	-	-	-	-	-	-	-	mixed	mixed	community	yes
57	2011	Europe	113	56	40.5 (11.5)	38.1 (11.0)	43	29	-	-	-	-	-	-	95	36	mixed	treatment seeking	community	no
58	1994	Other	15	15	-	-	0	0	-	-	-	-	-	-	-	-	back	-	-	yes

Note: abdo = abdominal; FM = Fibromyalgia; neuro = neuropathic; WAD = whiplash associated disorder. Study number relates to numbered reference list presented at the end of this appendix.

Supplementary Table 3.B: Demographic information retrieved from studies cont.

Study	Year	Country of Origin	N		Age		Males		Education (years)		Caucasian		Employed		Married / Partnered		Pain Type	Recruitment Source		Matched
			CP	HC	CP	HC	CP	HC	CP	HC	CP	HC	CP	HC	CP	HC		CP	HC	
59	2011	Asia	1770	9737	-	-	699	4443	-	-	-	-	-	-	-	-	mixed	community	community	yes
60	2012	Europe	34	32	51.5 (20.4)	55.4 (22.0)	7	12	-	-	-	-	-	-	-	-	mixed	mixed	-	yes
61	2004	America	40	40	49.4 (6.0)	49.5 (7.7)	0	0	-	-	-	-	-	-	-	-	FM	treatment seeking	-	yes
62	2009	Europe	250	60	45.4 (12.2)	44.0 (11.3)	0	0	-	-	-	-	-	-	231	56	mixed	treatment seeking	-	yes
63	2011	America	78	124	36.4 (4.5)	33.4 (4.6)	0	0	-	-	56	78	-	-	78	124	arthritis	other	other	no
64	2007	Europe	987	1517	55.0 (16.7)	50.0 (17.4)	399	674	-	-	900	1372	516	974	-	-	mixed	primary care	primary care	no
65	1996	Europe	69	36	39.1 (13.3)	-	12	0	-	-	-	-	-	-	-	-	head / neck back	primary care	other	yes
66	2008	Europe	32	19	43.1 (10.2)	41.6 (11.1)	11	6	-	-	-	-	-	-	-	-	head / neck back	treatment seeking	community	yes
67	2005	America	43	28	49.7 (11.7)	46.8 (9.5)	4	2	-	-	-	-	-	-	-	-	FM	treatment seeking	community	yes
68	1998	Europe	20	20	-	-	8	8	-	-	-	-	-	-	-	-	mixed	treatment seeking	-	yes
69	1995	Europe	38	19	49.0 (12.2)	48.5 (9.9)	14	7	-	-	-	-	-	-	-	-	arthritis	treatment seeking	community	yes
70	2011	Europe	428	776	50.3 (10.7)	44.9 (15.7)	182	322	-	-	-	-	-	-	-	-	mixed	community	community	no
71	2009	America	587	513	43.4 (13.0)	45.8 (13.3)	243	271	-	-	-	-	542	477	435	388	head / neck neuro	community	community	no
72	2011	America	14	9	67.6 (11.2)	59.0 (4.1)	4	3	-	-	-	-	-	-	-	-	head / neck neuro	treatment seeking	-	no
73	2006	Europe	161	70	51.9 (15.9)	41.7 (18.3)	61	32	-	-	-	-	-	-	-	-	mixed	treatment seeking	community	no
74	2005	Europe	49	44	51.1 (9.8)	45.6 (13.0)	23	18	-	-	-	-	-	-	-	-	mixed	treatment seeking	community	no
75	2007	America	162	158	73.6 (5.2)	73.5 (4.8)	83	94	-	-	141	142	-	-	99	100	back	mixed	mixed	yes
76	2012	Europe	88	42	45.1 (13.6)	48.1 (14.5)	27	18	-	-	-	-	-	-	-	-	mixed	mixed	primary care	yes
77	2009	Europe	779	1579	56.8 (12.6)	55.2 (19.2)	336	786	-	-	-	-	-	-	-	-	arthritis	treatment seeking	community	no
78	2005	Europe	264	112	65.5 (-)	64.8 (9.5)	102	43	-	-	-	-	-	-	-	-	arthritis	-	-	yes

Note: abdo = abdominal; FM = Fibromyalgia; neuro = neuropathic; WAD = whiplash associated disorder. Study number relates to numbered reference list presented at the end of this appendix.

Supplementary Table 3.B: Demographic information retrieved from studies cont.

Study	Year	Country of Origin	N		Age		Males		Education (years)		Caucasian		Employed		Married / Partnered		Pain type	Recruitment Source		Matched
			CP	HC	CP	HC	CP	HC	CP	HC	CP	HC	CP	HC	CP	HC		CP	HC	
79	2007	Australia	51	46	33.3 (13.7)	36.8 (13.1)	0	0	-	-	-	-	-	-	-	-	pelvic / abdo	mixed	community	yes
80	2002	Europe	40	40	37.1 (11.9)	36.3 (11.6)	8	9	-	-	-	-	15	17	31	29	mixed	treatment seeking	-	yes
81	2004	Europe	70	42	60.7 (21.2)	38.8 (10.4)	0	0	-	-	-	-	-	-	61	37	mixed	mixed	community	-
82	2005	Australia	49	20	37.7 (10.4)	31.3 (10.0)	16	8	-	-	-	-	-	-	-	-	mixed	mixed	community	-
83	2012	Europe	36	36	27.4 (6.8)	24.3 (5.8)	8	4	-	-	-	-	-	-	26	21	facial	treatment seeking	mixed	yes
84	2004	America	59	59	28.0 (6.9)	26.6 (6.2)	0	0	-	-	-	-	-	-	-	-	facial	mixed	community	yes
85	2011	Asia	15	15	41.0 (-)	41.0 (-)	-	-	-	-	-	-	-	-	-	-	back	treatment seeking	-	yes
86	2010	Europe	18	30	40.0 (-)	40.0 (-)	0	0	-	-	-	-	-	-	-	-	head / neck	treatment seeking	community	-
87	2008	America	33	44	48.0 (6.8)	48.0 (6.8)	0	0	-	-	-	-	-	-	-	-	FM	treatment seeking	community	yes
88	2007	America	38	37	48.9 (9.6)	45.0 (8.3)	38	37	13.7 (2.8)	13.8 (2.3)	-	-	27	34	33	27	pelvic / abdo	treatment seeking	community	no
89	1990	Australia	40	20	36.8 (11.5)	37.5 (9.5)	0	0	-	-	-	-	-	-	-	-	mixed	treatment seeking	community	yes
90	2003	Europe	45	21	48.8 (-)	45.9 (12.7)	-	-	14.4 (2.4)	15.3 (2.7)	-	-	-	-	-	-	mixed	treatment seeking	community	yes
91	2011	Australia	278	1314	59.8 (10.9)	59.8 (10.9)	278	1314	-	-	-	-	-	-	-	-	FM	community	community	no
92	2007	Europe	40	20	46.0 (10.6)	42.1 (14.0)	14	6	-	-	28	15	18	34	16	7	back	treatment seeking	community	yes
93	2005	Australia	398	491	46.1 (14.4)	42.3 (17.7)	179	219	-	-	-	-	-	-	-	-	mixed	treatment seeking	community	no
94	2010	Europe	154	58	38.3 (10.3)	39.2 (10.0)	0	0	-	-	-	-	-	-	-	-	pelvic / abdo	treatment seeking	community	yes
95	2007	Europe	101	47	-	-	-	-	-	-	-	-	-	-	-	-	facial	-	-	yes
96	2009	Europe	1396	1520	-	-	-	-	-	-	-	-	-	-	-	-	mixed	primary care	primary care	-
97	2011	America	84	50	-	-	0	0	-	-	-	-	-	-	-	-	pelvic / abdo	treatment seeking	primary care	yes

Note: abdo = abdominal; FM = Fibromyalgia; neuro = neuropathic; WAD = whiplash associated disorder. Study number relates to numbered reference list presented at the end of this appendix.

Supplementary Table 3.B: Demographic information retrieved from studies cont.

Study	Year	Country of Origin	N		Age		Males		Education (years)		Caucasian		Employed		Married / Partnered		Pain type	Recruitment Source		Matched
			CP	HC	CP	HC	CP	HC	CP	HC	CP	HC	CP	HC	CP	HC		CP	HC	
98	2011	Asia	126	72	41.3 (8.5)	37.0 (10.4)	0	0	5.9 (3.1)	7.9 (4.4)	-	-	-	-	109	56	mixed	treatment seeking	community	no
99	2009	Europe	14	25	51.1 (11.1)	51.7 (7.2)	0	0	-	-	-	-	-	-	-	-	mixed	treatment seeking	-	yes
100	2007	Europe	40	40	47.0 (11.0)	47.0 (11.2)	14	14	-	-	-	-	19	23	-	-	WAD	community	other	yes
101	2003	America	24	33	42.0 (7.2)	41.0 (7.6)	10	11	15.0 (3.7)	18.0 (2.7)	24	33	22	33	16	22	back	treatment seeking	community	yes
102	1992	America	22	21	27.6 (7.7)	31.2 (7.8)	0	0	-	-	-	-	-	-	17	9	pelvic / abdo	treatment seeking	treatment seeking	yes
103	2012	Europe	28	29	40.1 (7.1)	35.4 (10.6)	0	0	-	-	-	-	13	23	-	-	WAD	treatment seeking	community	no
104	2008	Europe	25	15	53.0 (-)	45.0 (-)	4	1	-	-	-	-	6	18	18	14	WAD	community	mixed	no
105	1994	America	106	46	-	-	0	0	-	-	-	-	-	-	-	-	mixed	treatment seeking	treatment seeking	no
106	2011	Europe	15	15	50.4 (4.6)	49.0 (6.7)	-	-	-	-	-	-	-	-	-	-	FM	-	-	yes
107	1993	America	77	40	-	-	-	-	-	-	-	-	-	-	-	-	back	treatment seeking	community	yes
108	2006	America	163	160	73.6 (5.2)	73.5 (4.9)	80	94	-	-	141	142	-	-	99	100	back	mixed	mixed	yes
109	2005	Europe	39	36	53.1 (-)	52.0 (-)	10	7	-	-	-	-	-	-	-	-	arthritis	treatment seeking	community	yes
110	2011	Asia	1731	3270	-	-	-	-	-	-	-	-	-	-	-	-	mixed	-	community	no

Note: abdo = abdominal; FM = Fibromyalgia; neuro = neuropathic; WAD = whiplash associated disorder. Study number relates to numbered reference list presented at the end of this appendix.

Supplementary Table 3.C: Studies included in the analyses for depression, by measure

Measure	N_{studies}	Study
BDI	33	2, 6, 7, 8, 15, 17, 20, 22, 23, 24, 27, 28, 40, 41, 43, 44, 46, 47, 49, 53, 58, 66, 67, 69, 80, 81, 89, 90, 91, 99, 101, 106, 107
BDI-SF	1	48
BSI-D	3	12, 31, 98
CES-D	13	5, 10, 35, 37, 45, 55, 63, 71, 72, 75, 83, 88, 100
DASS-D	1	93
GDS	3	33, 60, 108
HADS-D	13	9, 11, 26, 56, 57, 68, 70, 76, 86, 92, 94, 103, 110
HRSD	3	8, 23, 107
K-10	1	13
MHI-D	1	87
PHQ	1	21
POMS-D	1	85
SCL-90-R-D	7	3, 25, 50, 51, 66, 84, 105
ZSRDS	5	19, 29, 30, 34, 52

Note. BDI = Beck Depression Inventory; BDI-SF = Beck Depression Inventory Short-Form; BSI-D = Brief Symptom Inventory, Depression subscale; CES-D = Center for Epidemiologic Studies Depression Scale; DASS-D = Depression, Anxiety, Stress Scale, Depression subscale; GDS = Geriatric Depression Scale; HADS-D = Hospital Anxiety and Depression Scale, Depression subscale; HRSD = Hamilton Rating Scale for Depression; K-10 = Kessler Psychological Distress Scale; MHI = Mental Health Inventory, Depression subscale; PHQ = Patient Health Questionnaire; POMS-D = Profile of Mood States Depression subscale; SCL-90-R-D = Symptom Checklist-90-Revised, Depression subscale; ZSRDS = Zung Self-Rating Depression Scale. Study number relates to numbered reference list presented at the end of this appendix.

Supplementary Table 3.D: Studies included in the analyses for anxiety, by measure

Measure	N_{studies}	Study
ASI	5	6, 7, 18, 86, 103
BAI	5	22, 45, 46, 80, 81
BSI-A	3	12, 31, 98
DASS-A	1	93
GAD-7	1	83
HADS-A	12	9, 11, 26, 56, 57, 68, 76, 86, 92, 94, 103, 110
MHI-A	1	87
MHQ	1	52
MMPI-A	1	32
POMS-TA	1	85
SCL-90-R-A	4	3, 25, 66, 105
STAI-S	8	6, 7, 10, 24, 27, 40, 61, 89
STAI-SF	1	82

Note. ASI = Acute Stress Inventory; BAI = Beck Anxiety Inventory; BSI-A = Brief Symptom Inventory, Anxiety subscale; DASS-A = Depression, Anxiety, Stress Scale, Anxiety subscale; GAD-7 = Generalised Anxiety Disorder Assessment; HADS-A = Hospital Anxiety and Depression Scale, Anxiety subscale; MHI-A = Mental Health Inventory, Anxiety subscale; MHQ = Middlesex Hospital Questionnaire; MMPI-A = Minnesota Multiphasic Personality Inventory, Anxiety subscale; POMS-TA = Profile of Mood States, Tension/Anxiety subscale; SCL-90-R-A = Symptom Checklist-90-Revised, Anxiety subscale; STAI-S = State-Trait Anxiety Inventory, State Anxiety subscale; STAI-SF = State-Trait Anxiety Inventory Short-Form. Study number relates to numbered reference list presented at the end of this appendix.

Supplementary Table 3.E: Studies included in the analyses for pain anxiety/concern, by measure

Measure	N_{studies}	Study
BORG-FH	1	66
BORG-FI	1	66
CIPS	1	92
CSQ-C	3	17, 55, 56
FABQ	3	33, 66, 103
FPQ-III	1	18
IAS-FIP	1	18
MSPQ	1	19
PASS	3	7, 18, 103
PCS	7	21, 40, 49, 60, 86, 100, 103
PCS-H	1	103
PCS-M	1	103
PCS-R	1	103
SHAI	2	73, 92
TSK	3	49, 74, 100

Note. BORG-FH = Fear of Harm Back Scale; BORG-FI = BORG, Fear of Injury/Re-injury subscale; CIPS = Catastrophising in Pain Scale; CSQ-C = Coping Strategies Questionnaire, Catastrophising subscale; FABQ = Fear Avoidance Beliefs Questionnaire; FPQ-III = Fear of Pain Questionnaire; IAS-FIP = Illness Attitudes Scale, Fear of Illness and Pain subscale; MSPQ = Modified Somatic Perception Questionnaire; PASS = Pain Anxiety Sensitivity Index; PCS = Pain Catastrophising Scale, Total score; PCS-H = Pain Catastrophising Scale, Helplessness subscale; PCS-M = Pain Catastrophising Scale, Magnification subscale; PCS-R = Pain Catastrophising Scale, Rumination subscale; SHAI = Short Health Anxiety Inventory; TSK = Tampa Scale of Kinesophobia. Study number relates to numbered reference list presented at the end of this appendix.

Supplementary Table 3.F: Studies included in the analyses for somatisation, anger/hostility, self-efficacy and self-esteem, by measure

Measure	N_{studies}	Study
<i>Somatisation</i>		
BAS	1	102
BSI-S	3	12, 31, 98
MHQ-S	1	52
PHQ	1	21
SCL-90-R-S	6	3, 25, 33, 50, 66, 84
SOMS	2	29, 99
SOMS-7	1	83
WPSI	1	105
<i>Anger/Hostility</i>		
BSI-H	3	12, 31, 98
SCL-90-R-H	3	3, 25, 66
STAXI-AE	2	2, 55
STAXI-S	2	2, 55
<i>Self-Efficacy</i>		
GSES	2	86, 103
MPI-LC	1	25
PSEQ	2	75, 103
<i>Self-Esteem</i>		
RSS	2	23, 38
SSES	1	37

Note. GSES = General Self Efficacy Scale; MPI-LC = Multidimensional Pain Inventory, Life Control subscale; PSEQ = Pain Self-Efficacy Questionnaire; RSS = Rosenberg Self-Esteem Scale; SSES = State Self-Esteem Scale; BSI-H = Brief Symptom Inventory, Hostility subscale; SCL-90-R-H = Symptom Checklist-90-Revised, Hostility subscale; STAXI-AE = State-Trait Anger Expression Inventory, Expressed Anger subscale; STAXI-S = State-Trait Anger Expression Inventory, State Anger subscale; STAXI-T = State-Trait Anger Expression Inventory, Trait Anger subscale; BAS = Barsky Amplification Scale; BSI-S = Brief Symptom Inventory, Somatisation subscale; MHQ-S = Middlesex Hospital Questionnaire, Somatisation subscale; PHQ = Patient Health Questionnaire; SCL-90-R-S = Symptom Checklist-90-Revised, Somatisation subscale; SOMS = Screening for Somatoform Symptoms; SOMS-7 = Screening for Somatoform Symptoms (7 item short-form); WPSI = Wahler Physical Symptom Inventory. Study number relates to numbered reference list presented at the end of this appendix.

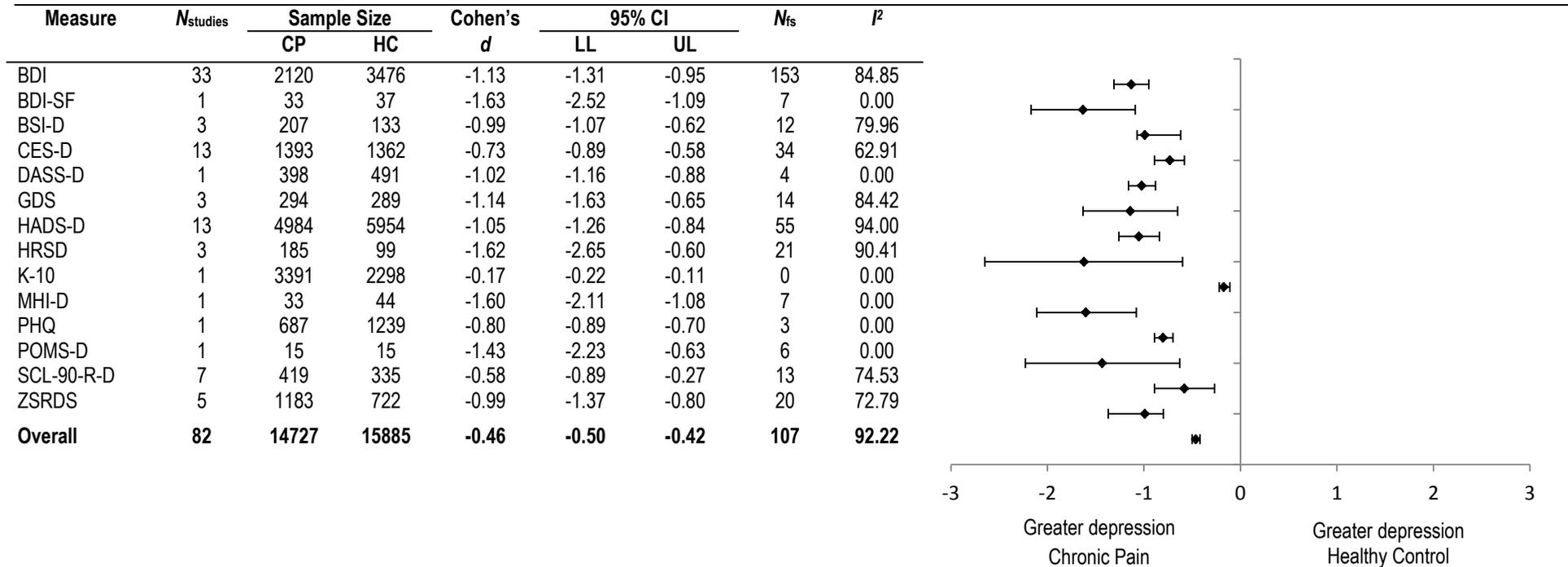
Supplementary Table 3.G: Studies included in the analyses for general emotional functioning, by measure

Measure	N_{studies}	Study
BSI-GS	3	12, 67, 98
DASS-S	1	93
Duke-AD	1	62
GHQ	3	1, 64, 102
HSCL-25	1	16
MPI-AD	2	25, 54
NHP-ER	1	65
POMS	1	48
PSS	3	35, 37, 41
SCL-90-R	1	48
SF-12-MH	4	9, 14, 70, 110
SF-20-MH	1	42
SF-36-MH	18	1, 4, 28, 36, 39, 40, 50, 54, 59, 61, 78, 77, 79, 95, 96, 102, 104, 109
WHOQOL-BREF-P	1	97

Note. BSI-GS = Brief Symptom Inventory, Global Symptom Index; DASS-S = Depression, Anxiety and Stress Scale, Stress subscale; Duke-AD = Duke Anxiety Depression Scale; GHQ = General Health Questionnaire; HSCL-25 = Hopkins Symptom Checklist; MPI-AD = Multidimensional Pain Inventory, Affective Distress subscale; NHP-ER = Nottingham Health Profile, Emotional Reaction subscale; POMS = Profile of Mood States; PSS = Perceived Stress Scale; SCL-90-R = Symptom Checklist-90-Revised; SF-12-MH = The Short Form (12) Health Survey, Mental Health subscale; SF-20-MH = The Short Form (20) Health Survey, Mental Health subscale; SF-36-MH = The Short Form (36) Health Survey, Mental Health subscale; WHOQOL-BREF = World Health Organisation Quality of Life Scale – Brief, Psychological subscale. Study number relates to numbered reference list presented at the end of this appendix.

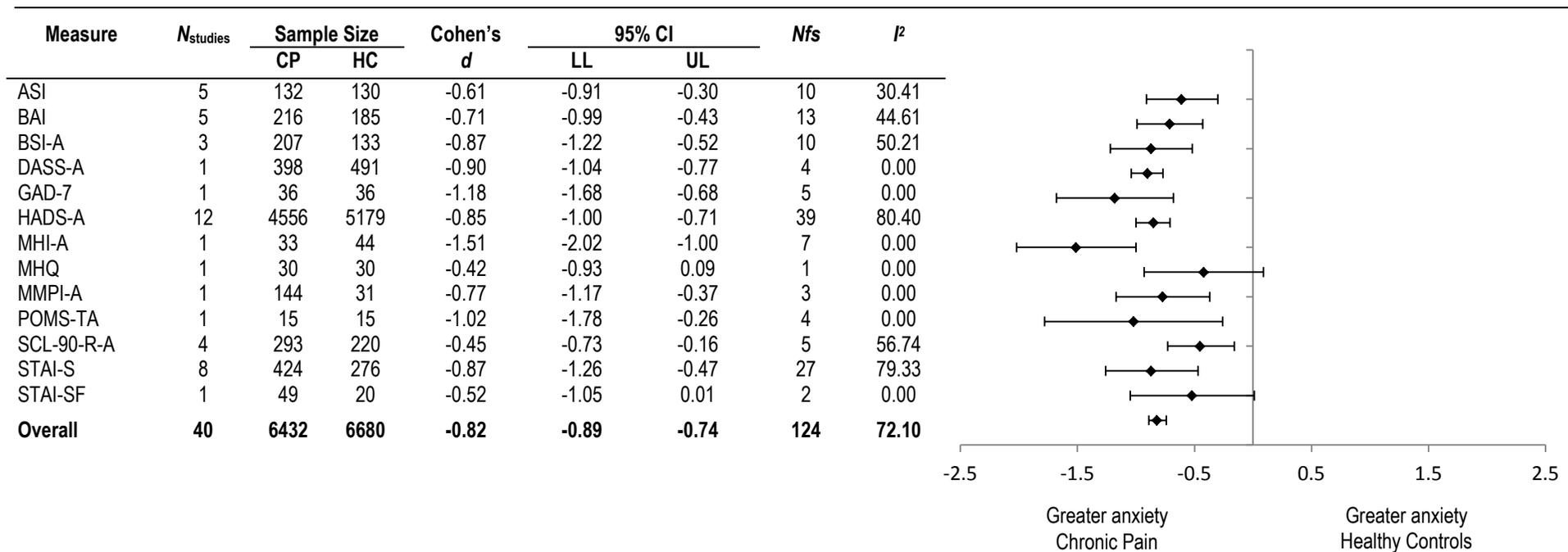
Appendix 1.2 Supplementary Figures for Chapter 3

Supplementary Figure 3.A: Cohen's *d* effect sizes for depression; overall and by measure



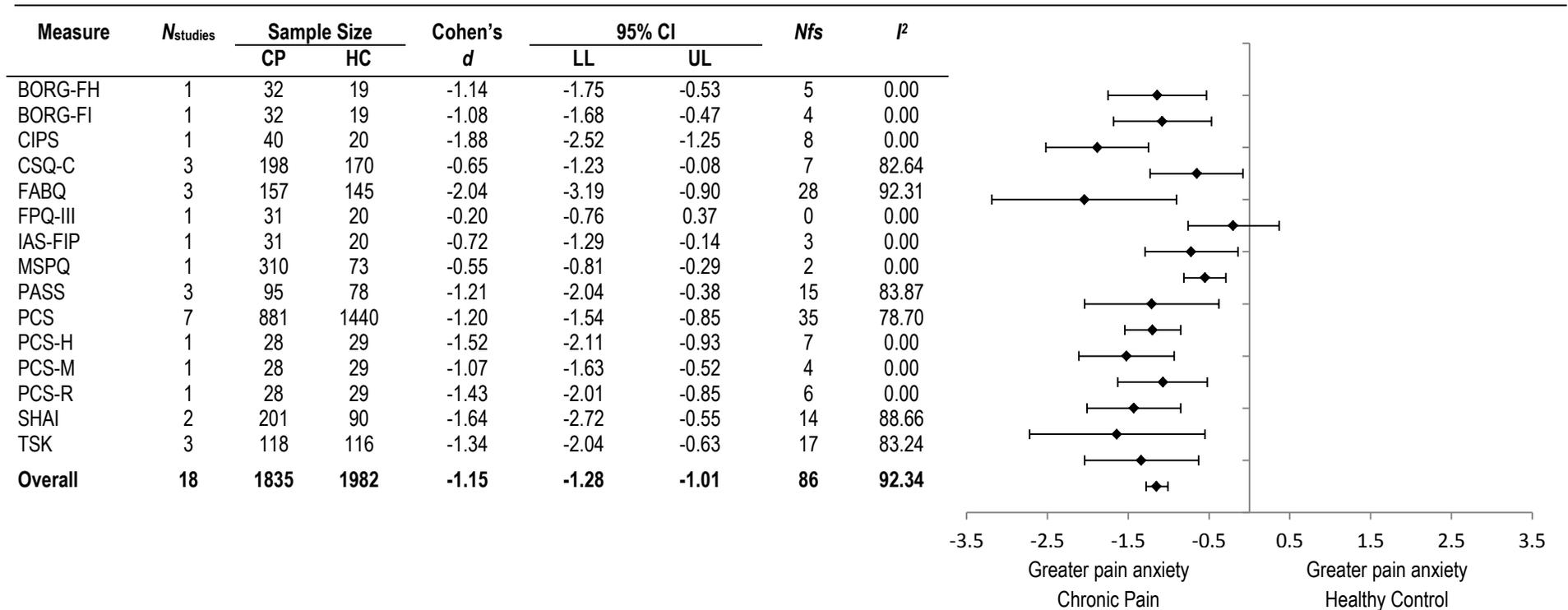
Note. CP = chronic pain; HC = healthy control; *N*_{fs} = Failsafe *N*'s; *I*² > 50 indicates significant heterogeneity; BDI = Beck Depression Inventory; BDI-SF = Beck Depression Inventory Short-Form; BSI-D = Brief Symptom Inventory, Depression subscale; CES-D = Center for Epidemiologic Studies Depression Scale; DASS-D = Depression, Anxiety, Stress Scale, Depression subscale; GDS = Geriatric Depression Scale; HADS-D = Hospital Anxiety and Depression Scale, Depression subscale; HRSD = Hamilton Rating Scale for Depression; K-10 = Kessler Psychological Distress Scale; MHI = Mental Health Inventory, Depression subscale; PHQ = Patient Health Questionnaire; POMS-D = Profile of Mood States Depression subscale; SCL-90-R-D = Symptom Checklist-90-Revised, Depression subscale; ZSRDS = Zung Self-Rating Depression Scale.

Supplementary Figure 3.B: Cohen's d effect sizes for anxiety; overall and by measure



Note. CP = Chronic Pain; HC = Health Control; N_{fs} = Failsafe N's; $I^2 > 50$ indicates significant heterogeneity ; ASI = Acute Stress Inventory; BAI = Beck Anxiety Inventory; BSI-A = Brief Symptom Inventory, Anxiety subscale; DASS-A = Depression, Anxiety, Stress Scale, Anxiety subscale; GAD-7 = Generalised Anxiety Disorder Assessment; HADS-A = Hospital Anxiety and Depression Scale, Anxiety subscale; MHI-A = Mental Health Inventory, Anxiety subscale; MHQ = Middlesex Hospital Questionnaire; MMPI-A = Minnesota Multiphasic Personality Inventory, Anxiety subscale; POMS-TA = Profile of Mood States, Tension/Anxiety subscale; SCL-90-R-A = Symptom Checklist-90-Revised, Anxiety subscale; STAI-S = State-Trait Anxiety Inventory, State Anxiety subscale; STAI-SF = State-Trait Anxiety Inventory Short-Form.

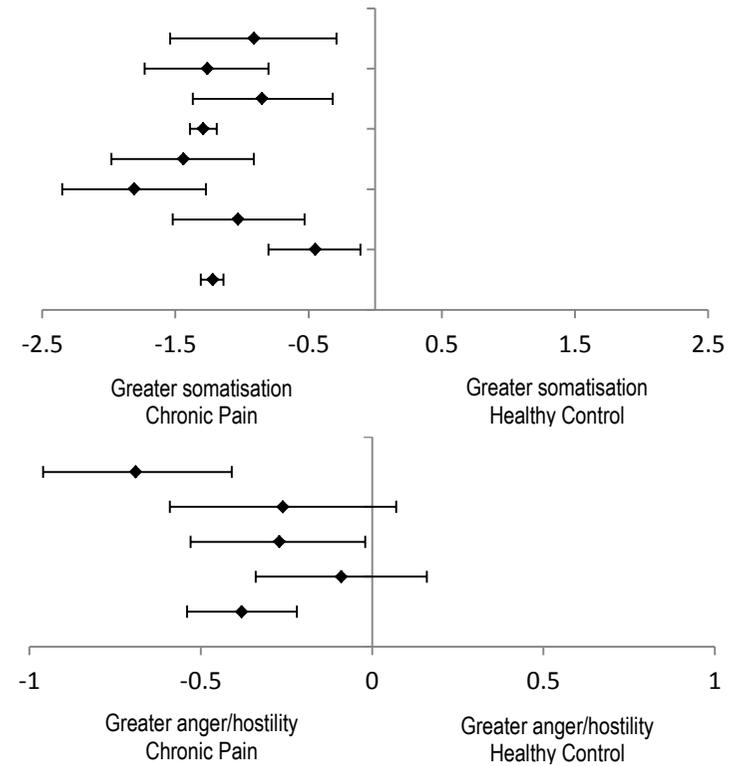
Supplementary Figure 3.C: Cohen's d effect sizes for pain anxiety/concern; overall and by measure



Note. CP = chronic pain; HC = healthy control; N_{fs} = Failsafe N's; I² > 50 indicates significant heterogeneity; BORG-FH = Fear of Harm Back Scale; BORG-FI = BORG, Fear of Injury/Re-injury subscale; CIPS = Catastrophising in Pain Scale; CSQ-C = Coping Strategies Questionnaire, Catastrophising subscale; FABQ = Fear Avoidance Beliefs Questionnaire; FPQ-III = Fear of Pain Questionnaire; IAS-FIP = Illness Attitudes Scale, Fear of Illness and Pain subscale; MSPQ = Modified Somatic Perception Questionnaire; PASS = Pain Anxiety Sensitivity Index; PCS = Pain Catastrophising Scale, Total score; PCS-H = Pain Catastrophising Scale, Helplessness subscale; PCS-M = Pain Catastrophising Scale, Magnification subscale; PCS-R = Pain Catastrophising Scale, Rumination subscale; PHODA = Photographs of Activities of Daily Living Scale; SHAI = Short Health Anxiety Inventory; TSK = Tampa Scale of Kinesophobia.

Supplementary Figure 3.D: Cohen's d effect sizes for somatisation, anger/hostility, self-efficacy and self-esteem; overall and by measure

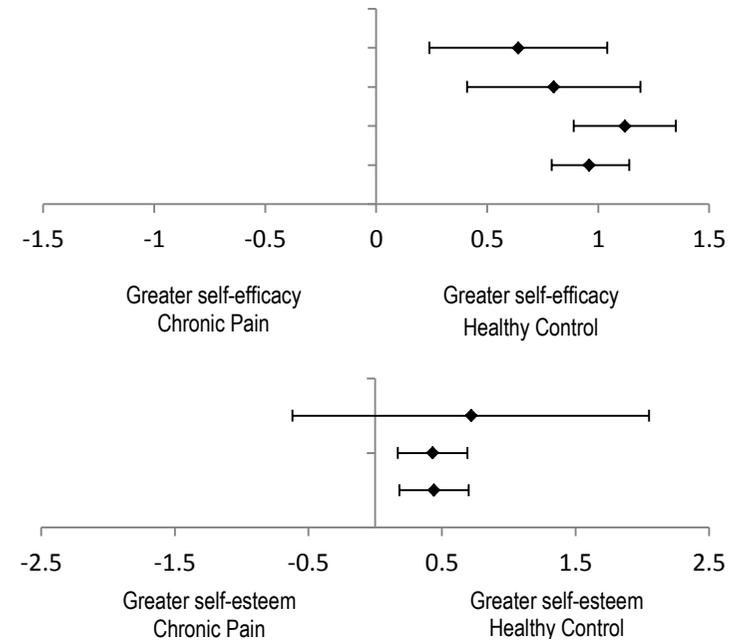
Measure	N _{studies}	Sample Size		Cohen's d	95% CI		N _{fs}	I ²
		CP	HC		LL	UL		
<i>Somatisation</i>								
BAS	1	22	21	-0.91	-1.54	-0.29	4	0.00
BSI-S	3	207	133	-1.26	-1.73	-0.80	16	69.18
MHQ-S	1	30	30	-0.85	-1.37	-0.32	3	0.00
PHQ	1	687	1239	-1.29	-1.39	-1.19	5	0.00
SCL-90-R-S	6	389	365	-1.44	-1.98	-0.91	37	90.12
SOMS	2	40	39	-1.81	-2.35	-1.27	16	0.00
SOMS-7	1	36	36	-1.03	-1.52	-0.53	4	0.00
WPSI	1	106	46	-0.45	-0.80	-0.11	1	0.00
Overall	16	1517	1909	-1.22	-1.31	-1.14	82	84.56
<i>Anger/Hostility</i>								
BSI-H	3	207	133	-0.69	-0.96	-0.41	7	24.24
SCL-90-R-H	3	187	174	-0.26	-0.59	0.07	1	53.25
STAXI-AE	2	143	107	-0.27	-0.53	-0.02	1	0.00
STAXI-S	2	143	107	-0.09	-0.34	0.16	1	0.00
Overall	8	537	414	-0.38	-0.54	-0.22	7	61.65



Note. CP = chronic pain; HC = healthy control; N_{fs} = Failsafe N's; I² > 50 indicates significant heterogeneity; GSES = General Self Efficacy Scale; MPI-LC = Multidimensional Pain Inventory, Life Control subscale; PSEQ = Pain Self-Efficacy Questionnaire; RSS = Rosenberg Self-Esteem Scale; SSES = State Self-Esteem Scale; BSI-H = Brief Symptom Inventory, Hostility subscale; SCL-90-R-H = Symptom Checklist-90-Revised, Hostility subscale; STAXI-AE = State-Trait Anger Expression Inventory, Expressed Anger subscale; STAXI-S = State-Trait Anger Expression Inventory, State Anger subscale; BAS = Barsky Amplification Scale; BSI-S = Brief Symptom Inventory, Somatisation subscale; MHQ-S = Middlesex Hospital Questionnaire, Somatisation subscale; PHQ = Patient Health Questionnaire; SCL-90-R-S = Symptom Checklist-90-Revised, Somatisation subscale; SOMS = Screening for Somatoform Symptoms; SOMS-7 = Screening for Somatoform Symptoms (7 item short-form); WPSI = Wahler Physical Symptom Inventory

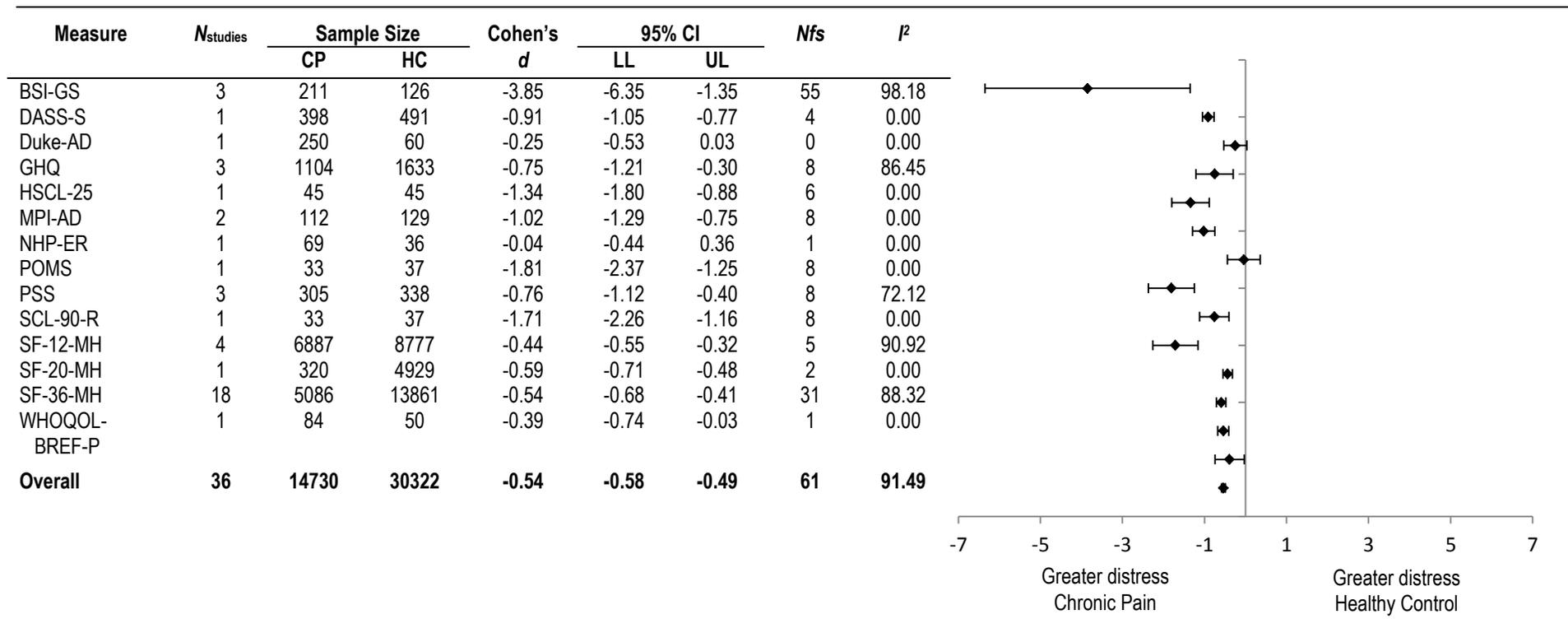
Supplementary Figure 3.D: Cohen's d effect sizes for somatisation, anger/hostility, self-efficacy and self-esteem; overall and by measure cont.

Measure	N _{studies}	Sample Size		Cohen's d	95% CI		Nfs	I ²
		CP	HC		LL	UL		
<i>Self-Efficacy</i>								
GSES	2	46	59	0.64	0.24	1.04	4	0.00
MPI-LC	1	55	55	0.80	0.41	1.19	3	0.00
PSEQ	2	190	187	1.12	0.89	1.35	9	5.18
Overall	4	263	272	0.96	0.79	1.14	15	0.00
<i>Self-Esteem</i>								
RSS	2	38	37	0.72	-0.62	2.05	5	84.83
SSES	1	108	125	0.43	0.17	0.69	1	0.00
Overall	3	146	162	0.44	0.18	0.70	4	79.31



Note. CP = chronic pain; HC = healthy control; Nfs = Failsafe N's; I² > 50 indicates significant heterogeneity; GSES = General Self Efficacy Scale; MPI-LC = Multidimensional Pain Inventory, Life Control subscale; PSEQ = Pain Self-Efficacy Questionnaire; RSS = Rosenberg Self-Esteem Scale; SSES = State Self-Esteem Scale; BSI-H = Brief Symptom Inventory, Hostility subscale; SCL-90-R-H = Symptom Checklist-90-Revised, Hostility subscale; STAXI-AE = State-Trait Anger Expression Inventory, Expressed Anger subscale; STAXI-S = State-Trait Anger Expression Inventory, State Anger subscale; BAS = Barsky Amplification Scale; BSI-S = Brief Symptom Inventory, Somatisation subscale; MHQ-S = Middlesex Hospital Questionnaire, Somatisation subscale; PHQ = Patient Health Questionnaire; SCL-90-R-S = Symptom Checklist-90-Revised, Somatisation subscale; SOMS = Screening for Somatoform Symptoms; SOMS-7 = Screening for Somatoform Symptoms (7 item short-form); WPSI = Wahler Physical Symptom Inventory

Supplementary Figure 3.E: Cohen's d effect sizes for general emotional functioning; overall and by measure



Note. CP = chronic pain; HC = healthy control; N_{fs} = Failsafe N's; *I*² > 50 indicates significant heterogeneity; BSI-GS = Brief Symptom Inventory, Global Symptom Index; DASS-S = Depression, Anxiety and Stress Scale, Stress subscale; Duke-AD = Duke Anxiety Depression Scale; GHQ = General Health Questionnaire; HSCL-25 = Hopkins Symptom Checklist; MPI-AD = Multidimensional Pain Inventory, Affective Distress subscale; NHP-ER = Nottingham Health Profile, Emotional Reaction subscale; POMS = Profile of Mood States; PSS = Perceived Stress Scale; SCL-90-R = Symptom Checklist-90-Revised; SF-12-MH = The Short Form (12) Health Survey, Mental Health subscale; SF-20-MH = The Short Form (20) Health Survey, Mental Health subscale; SF-36-MH = The Short Form (36) Health Survey, Mental Health subscale; WHOQOL-BREF-P = World Health Organisation Quality of Life Scale – Brief, Psychological subscale.

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Appendix 1.4 Published article for Chapter 3

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Psychological functioning of people living with chronic pain: A meta-analytic review

Anne L. J. Burke^{1,2*}, Jane L. Mathias² and Linley A. Denson²

¹Royal Adelaide Hospital, Australia

²School of Psychology, The University of Adelaide, Australia

Objectives. Chronic pain (CP; >3 months) is a common condition that is associated with significant psychological problems. Many people with CP do not fit into discrete diagnostic categories, limiting the applicability of research that is specific to a particular pain diagnosis. This meta-analysis synthesized the large extant literature from a general CP, rather than diagnosis-specific, perspective to systematically identify and compare the psychological problems most commonly associated with CP.

Methods. Four databases were searched from inception to December 2013 (PsychINFO, The Cochrane Library, Scopus, and PubMed) for studies comparing the psychological functioning of adults with CP to healthy controls. Data from 110 studies were meta-analysed and Cohen's *d* effect sizes calculated.

Results. The CP group reported experiencing significant problems in a range of psychological domains (depression, anxiety, somatization, anger/hostility, self-efficacy, self-esteem and general emotional functioning), with the largest effects observed for pain anxiety/concern and somatization; followed by anxiety and self-efficacy; and then depression, anger/hostility, self-esteem and general emotional functioning.

Conclusions. This study demonstrates, for the first time, that individuals with CP are more likely to experience physically focussed psychological problems than other psychological problems and that, unlike self-efficacy, fear of pain is intrinsically tied to the CP experience. This challenges the prevailing view that, for individuals with CP, problems with depression are either equal to, or greater than, problems with anxiety, thereby providing important information to guide therapeutic targets.

Practitioner points

Positive clinical implications

- This is the first time that the CP literature has been synthesized from a general perspective to examine psychological functioning in the presence of CP and provide practical recommendations for assessment and therapy.
- Individuals with CP were most likely to experience psychological problems in physically focussed areas – namely pain anxiety/concern and somatization.
- Although fear of pain was intrinsically tied to the CP experience, self-efficacy was not.
- CP was more strongly associated with anxiety than with depression.

*Correspondence should be addressed to Anne L. J. Burke, Psychology Department, Royal Adelaide Hospital, Level 5, Allied Health Building, North Terrace, Adelaide, SA 5000, Australia (email: anne.burke@health.sa.gov.au).

Limitations

- The study focuses on the general CP literature, adults and research-utilizing self-report measures.
- Meta-analyses are limited by the empirical literature on which they are based.

Approximately 20% of the world's population experiences persistent or chronic pain (CP; Goldberg & McGee, 2011) – Pain that occurs on most days for 3 or more months (IASP, 1994). With low back pain now the largest contributor to global disability (Hoy *et al.*, 2014), CP has been shown to negatively impact on many areas of life, including work attendance and productivity (Stewart *et al.*, 2010), physical function and quality of life (Douglas, Graham, Anderson, & Rogerson, 2004), engagement in social or recreational activities (Haythornthwaite & Benrud-Larson, 2000), and medication and health service usage (Blyth, March, Brnabic, & Cousins, 2004; Douglas *et al.*, 2004).

The subjective experience of pain involves a complex interplay between physical, psychological, and environmental variables (Flor & Hermann, 2004; Nicholas, 2008). Consequently, many studies have examined the psychological aspects of CP, with research consistently demonstrating that psychological problems are common in people with this condition (Dersh, Polatin, & Gatchel, 2002). Although American data indicate that CP is associated with comparable rates of anxiety and depression (Von Korff *et al.*, 2005), Australian data suggest that depression and adjustment disorders are more common (Access Economics, 2007).

Numerous aspects of psychological functioning may impact on, and be affected by, an individual's experience of CP including, but not limited to, mood (e.g., depression, anxiety, stress), feelings of self-mastery (e.g., self-efficacy, self-esteem), attributions about responsibility (e.g., guilt, shame), and grief/loss. Although these have been explored to varying degrees in the CP literature, most research has focussed on depression and anxiety. Similarly, research has tended to focus on specific *diagnoses*, such as neuropathic pain (Attal, Lanteri-Minet, Laurent, Fermanian, & Bouhassira, 2011) and fibromyalgia (Homann *et al.*, 2012), or on specific *subgroups*, such as older people (Falsarella *et al.*, 2012) and trauma survivors (Peterlin *et al.*, 2009). This focus on specific diagnoses/subgroups is limiting because many people with CP do not have a clear diagnosis or precipitant for their pain. Indeed, one survey found that 65% of people had no clear medical diagnosis for their CP and 33% identified no clear precipitant (Blyth, March, & Cousins, 2003). Moreover, CP is associated with a large number of different medical diagnoses, not all of which have been well-researched, and many people with CP experience a range of medical and psychological comorbidities that are not specific to a particular CP diagnosis or subgroup.

Thus, while it is undeniably important to understand CP from these specific perspectives, especially where CP is known to be associated with syndrome-specific sequelae (e.g., cancer: Urbaniec, Collins, Denson, & Whitford, 2011; and spinal cord injury: North, 1999), a more global understanding of the psychological problems that are associated with CP is also needed, one that includes the majority of people with CP and better meets the needs of clinicians working with this group. Therefore, this study sought to meta-analyse all quantitative research that used standardized assessment tools to examine the psychological functioning of adults with CP (including specific and non-specific CP diagnoses), relative to their healthy peers. We sought to synthesize this very large literature in order to provide a better clinical understanding of the CP experience and the underlying evidence base. Self-report measures of emotional functioning were targeted because they are the most frequently

used method of assessment in the literature and are also commonly used in clinical practice.

Method

Literature search

Information sources

Four databases (PsychInfo, Scopus, PubMed, and The Cochrane Library) were searched for studies that examined the psychological functioning of individuals with CP, published prior to 2014. The searches included singular and plural forms of each term and regional variations in spelling (e.g., behaviour/behavior; see Supporting information, Table S1a, for search terms). The initial search was very broad to ensure that all relevant papers were identified because CP is an umbrella term that encompasses a variety of labels, is attributed to a range of conditions and has been examined by a number of disciplines.

Eligibility criteria

Studies were only included in the current meta-analysis if they met the following criteria: they recruited a CP sample that (1) was aged ≥ 16 years (commonly used age for adult pain services) and (2) experienced CP – specifically defined as pain on most days for a period of ≥ 3 months; and the study (3) included a healthy control group that was matched to the CP group, (4) investigated the psychological functioning of both groups utilizing standardized self-report assessment tools, (5) was published in English and documented original quantitative research (excludes reviews), (6) was not a case study ($n > 1$), and (7) provided data in a format that permitted the calculation of Cohen's d effect sizes (e.g., mean and SD , t -statistic, or exact p -value).

Medical and psychiatric conditions that have syndrome-specific sequelae, and therefore require separate consideration, were excluded because the aim was to examine the general CP experience. Specifically, excluded conditions were as follows: (1) spinal cord injuries, (2) particular medical disorders/conditions (e.g., cancer, cardiac, renal), (3) neurological disorders (e.g., stroke, traumatic brain injury), (4) terminal/palliative conditions, (5) psychiatric conditions (e.g., factitious disorder, psychosis), and (6) personality disorders. Studies examining acute pain onset and/or tolerance were similarly excluded, because the current study was designed to examine people living with CP.

Study appraisal and selection

Critical appraisal and eligibility assessment were performed by the primary author (ALJB). If there was any ambiguity, papers were independently appraised by the full panel of authors and eligibility determined by consensus, following group discussion. If it was not possible to definitively determine eligibility based on the available information, clarification was sought from the corresponding authors. If no response was obtained, that study/variable was excluded from analysis. Where data for the same sample were reported in multiple papers, the paper with the largest sample was included. Matching of the CP and healthy control groups was a key factor in the critical appraisal of studies as it served to minimize extraneous between-group differences, thereby increasing confidence in the validity of the results. CP and healthy control

groups were deemed to be matched if there was either a deliberate attempt to match groups on at least one demographic variable (e.g., age, gender) or post-hoc analyses indicated that groups were demographically comparable. Studies that did not meet either of these criteria for matching were excluded from the meta-analysis. Similarly, all studies were required to use standardized assessment tools to ensure only good-quality studies were included. The scope and size of the current study precluded more detailed qualitative evaluation and rating of individual studies. However, both the application of strictly defined eligibility criteria and the weighting of data by the inverse variance (Lipsey & Wilson, 2001) served to minimize the potential impact of poor-quality empirical studies.

Data extraction and organization of studies

Data relating to the study (e.g., sample size, country), participants (e.g., age, gender, race), pain (e.g., diagnosis/location, duration), and the measures of psychological functioning (test, scoring method and direction, means and *SDs*, or exact *t*- or *p*-statistics) were extracted from each study via a detailed data extraction form. As different aspects (e.g., cognitive, emotional, somatic) of psychological functioning have been assessed by a large number of alternative measures, the most meaningful way to explore the data was to group measures on the basis of psychological domains (e.g., depression). Different measures varied in their focus, assessing either positive or negative mood states; consequently, scores were rescaled where necessary (sign inverted but scores unchanged) so that they could be consistently interpreted. For positive domains (self-esteem and self-efficacy), higher scores indicated better outcomes. For all other domains, higher scores indicated greater psychological distress (poorer outcomes). In all cases, positive effects indicated greater levels of the domain in the control group and negative effects indicated greater levels in the CP group. Thus, for depression, a positive effect indicates greater depression in the control group, whereas a negative effect indicates the CP group is more depressed.

Data analysis

Data were analysed using the 'Comprehensive Meta Analysis' programme (Borenstein, Hedges, Higgins, & Rothstein, 2005). Where a study recruited multiple CP and/or control groups and reported data separately, scores were pooled to provide an overall score for each group (CP, controls). If studies provided multiple scores for a single domain (e.g., more than 1 depression score), a mean effect was calculated, thereby ensuring that each study only contributed a single score to the overall mean when the effect sizes from different studies were averaged (Lipsey & Wilson, 2001). Information relating to pain-related litigation and socio-economic status was collected to evaluate whether these variables acted as moderator variables; however, there were insufficient data to analyse these relationships. Similarly, although active treatment seeking may have reflected an important difference between the CP groups (treatment seekers may have had more severe conditions and/or comorbidities, and more psychological problems), this could not be examined because it was frequently unclear whether samples recruited from non-treatment settings were receiving care. Thus, any analysis of recruitment source was unlikely to be reliable or informative.

The effect size used in the current analysis was Cohen's *d* (Cohen, 1988); providing a measure of the standardized difference between the means for the CP and control groups.

Effect sizes were interpreted using Cohen's (Cohen, 1988) guidelines, with $d = 0.2$, 0.5 and 0.8 indicating small, medium, and large effects, respectively. Consistent with Hopkins and colleagues (Hopkins, Marshall, Batterham, & Hanin, 2009), $d = 2.0$ and 4.0 were labelled very large and extremely large effects.

Heterogeneity analyses, using the I^2 statistic, were performed to assess whether differences in the effect sizes from individual studies reflected chance-based sampling differences (homogeneous effects) or additional sources of variance, possibly reflecting methodological differences between studies (heterogeneous effects). As might be expected, given CP was examined from a general, rather than diagnosis-specific, perspective, many of the heterogeneity analyses (I^2) were significant ($I^2 > 50$), indicating substantial variability in the findings. Therefore, a more conservative random-effects model was used instead of the traditional fixed-effects model (Higgins, Thompson, Deeks, & Altman, 2003). The latter assumes a 'true' effect that is common across all studies, while a random-effects model assumes that there are differences between studies (e.g., samples and/or diagnoses). In addition, when calculating mean effects, individual effects were weighted by the inverse of their variance in order to take into account differences in the precision of the effect size estimates obtained from different studies (Lipsey & Wilson, 2001).

Ninety-five per cent confidence intervals (95% CIs) were calculated to test whether the population mean group difference differed significantly from zero, indicated by a CI that does not span 0. Finally, fail-safe N 's (N_{fs}) were calculated to examine the impact of publication bias on the results obtained: N_{fs} indicating the number of unpublished studies with non-significant findings that would be required to render the current results insignificant (Zakzannis, 2001). Calculations were based on the formula outlined by Lipsey and Wilson (2001), using a 0.2 (small effect; Orwin, 1983). A N_{fs} statistic was considered adequate if it was larger than the number of studies meta-analysed for a given measure.

Results

After removal of duplicate records, the initial search identified 11,211 records, for which the title and abstracts were assessed against the inclusion criteria by the first author (ALJB). This initial review excluded 10,525 articles because they failed to meet the specified criteria (see Figure 1). Full-text versions of the remaining 686 articles were then sourced and the contents systematically evaluated against the inclusion/exclusion criteria. Following thorough review, 110 papers were retained and their data extracted and meta-analysed.

Study characteristics

All studies were published between 1986 and 2013, with most published in the past 13 years ($n = 86$, 78%). The final sample comprised 67,554 participants (CP + controls), aged 17–102 years, most of whom were women ($n = 30,981$, 57%). As seen in Table 1, few studies provided information relating to relationship and employment status, education, ethnicity, BMI and surprisingly, pain duration (see Table S1b, for demographic/background details for individual studies). Some studies provided data in a format that did not permit between-study comparisons (e.g., categorical data for age). Where reported, the majority of participants were Caucasian, married/partnered, had some form of employment and had completed secondary schooling. The CP group had experienced pain for one to 15 years ($M = 8.0$ years, $SD = 3.7$). Most studies originated

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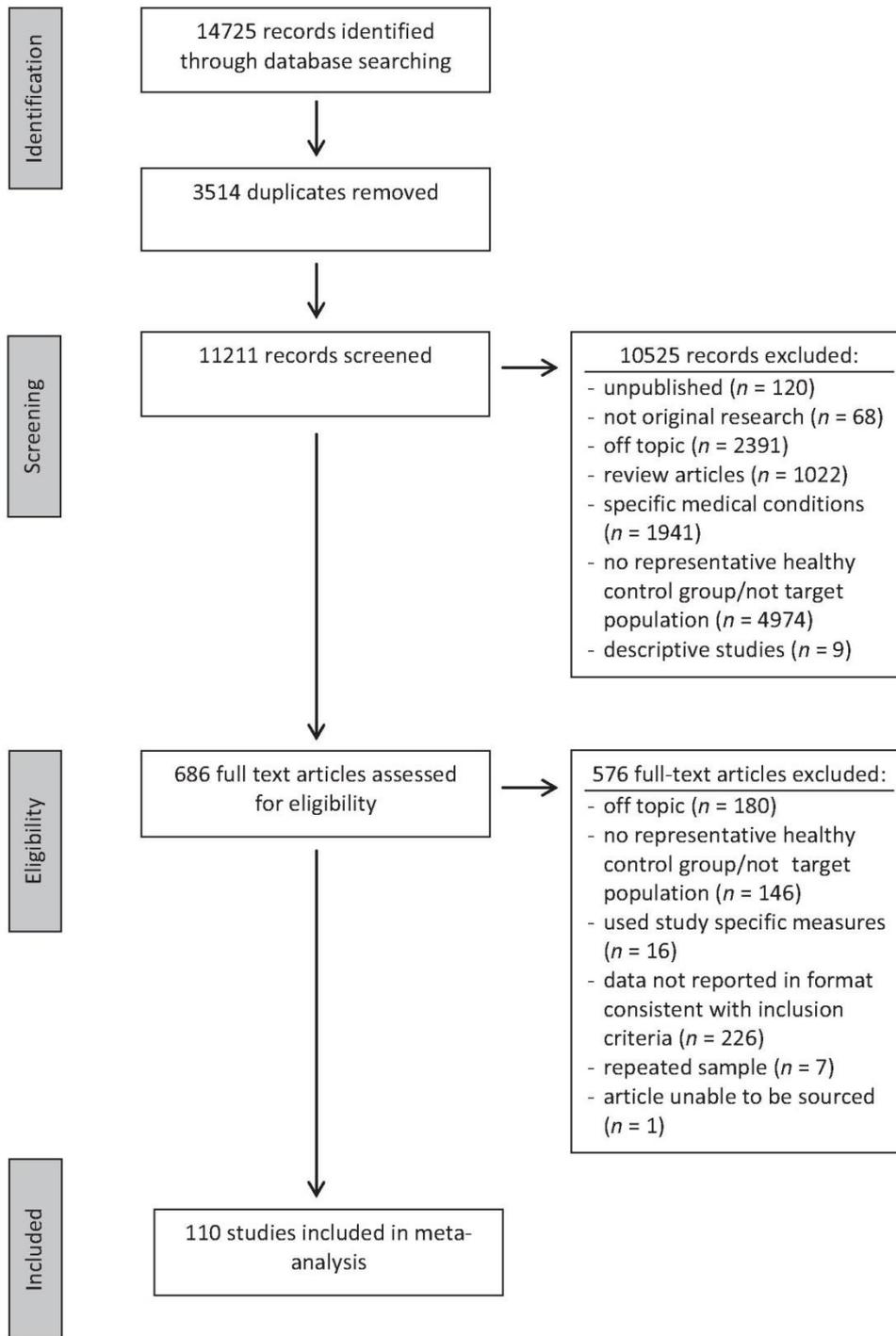


Figure 1. PRISMA flow diagram of study selection process.

Table 1. Summary demographic information for the included samples and studies

	Chronic pain		Healthy controls	
	<i>N</i> (%)	<i>N</i> _{studies}	<i>N</i> (%)	<i>N</i> _{studies}
Participant information				
<i>N</i> _{participants}	25,084 (37)	110	42,470 (63)	110
Age *	45.6 (11.0)	94	44.4 (11.1)	92
Gender				
Male	6,901 (36)	96	16,375 (47)	96
Female	12,318 (64)		18,663 (53)	
Relationship status				
Married/partnered	6,514 (63)	28	5,809 (62)	28
Not married/partnered	3,775 (37)		3,587 (38)	
Employment status				
Employed	1,372 (64)	14	1,845 (71)	14
Not employed	780 (36)		753 (29)	
Years of education*	12.7 (3.3)	14	13.7 (3.4)	14
Ethnicity				
White	7,220 (76)	20	6,928 (69.7)	20
Not White	2,339 (24)		3,010 (30.3)	
Body Mass Index (BMI)*	27.0 (1.3)	14	25.6 (1.3)	14
Pain duration (years)*	8.0 (3.7)	37		
Study Information				
Location of origin				
Europe	48 (44)	110		
America	46 (42)			
Australia	9 (8)			
Asia	6 (5)			
Other	1 (1)			
Pain conditions explored				
Mixed	44 (40)	110		
Back	16 (15)			
Fibromyalgia	12 (11)			
Pelvic/abdominal	12 (11)			
Head/neck	8 (7)			
Arthritis	7 (6)			
Facial	7 (6)			
Whiplash	3 (3)			
Neuropathic	1 (1)			
Sample matching by study design				
Deliberately matched	75 (68)	110		
Not deliberately matched	31 (28)			
Not reported	4 (4)			
Recruitment source				
Treatment seeking	58 (53)	110	3 (3)	110
Community based	17 (15)		55 (50)	
Primary care	4 (4)		8 (7)	
Mixed	20 (18)		13 (12)	
Students	3 (3)		3 (3)	
Not reported	6 (5)		21 (19)	
Other	2 (2)		7 (6)	

Note. Figures presented are *N* (%) except where indicated by * to be *X* (*SD*).

from Europe or America, explored mixed pain conditions, examined deliberately matched samples and recruited their CP group from treatment settings and controls from the general community (see Table 1).

Psychological function

Although there are many forms of psychological functioning that may be relevant to CP, the areas found to be most commonly examined by researchers were depression and anxiety (general and pain-related) and, to a lesser degree, somatization, anger/hostility, self-efficacy, self-esteem and general emotional functioning (overall mental/emotional health and perceived stress) – thus, subsequent analyses focussed on these areas. The mean effects for each domain are summarized in Figure 2. As can be seen, there were moderate to large, significant and robust differences in the psychological functioning of persons with CP, relative to their healthy peers, in all areas. Moreover, the limited overlap in the CIs indicates that there were significant differences in the extent to which many of these domains were affected.

Depression

Depression was the most commonly assessed area of psychological functioning ($N_{\text{studies}} = 82$, see Table S1c and Figure S1a), with the majority of studies ($n = 77$) using one of 14 measures. Only five studies used multiple measures. The most frequently used measure was the Beck Depression Inventory (BDI; $N_{\text{studies}} = 33$, 40%) (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), followed by the Centre for Epidemiological Studies Depression scale (CES-D; Radloff, 1977), and the Hospital Anxiety and Depression Scale (HADS-D; Zigmond & Snaith, 1983). Although the overall mean effect for depression was moderate ($d = -0.46$; see Figure 2), there was considerable variation between the effects for different measures. However, with the exception of the Kessler Psychological Distress Scale (K-10; Kessler *et al.*, 2003), which was only used by one study and had an unsatisfactory N_{fs} statistic, all effects were moderate to very large. Moreover, they were significant and negative, indicating consistently higher levels of depression in the CP group.

Anxiety

Anxiety was examined by a total of 40 studies (see Table S1d and Figure S1b): 36 of which used a single measure of anxiety, while others used two scales. The HADS-A was the most

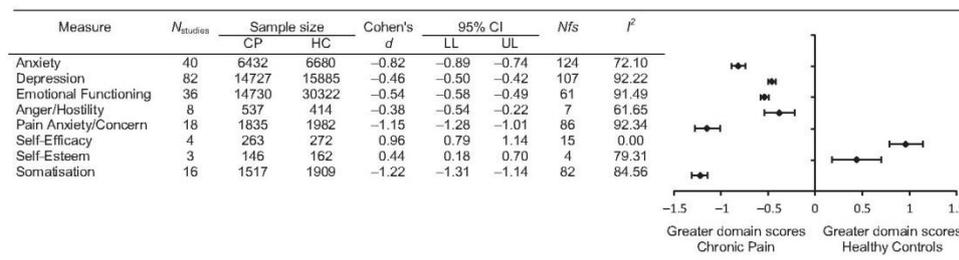


Figure 2. Summary of overall Cohen's d effect sizes for the domains of psychological functioning. *Note.* CP, chronic pain; HC, healthy control; N_{fs} , fail-safe N 's; $I^2 > 50$ indicates significant heterogeneity.

commonly used measure, reported in 12 studies, followed by the State-Trait Anxiety Inventory (STAI-S, $N_{\text{studies}} = 8$; Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983). Across all measures, the CP group showed consistently higher levels of anxiety than the controls (negative d), resulting in a large and significant overall mean effect for this construct ($d = -0.82$; see Figure 2). Significant moderate to very large effects were found for the majority of measures, with the two exceptions having unsatisfactory N_{fs} statistics, raising concerns about the reliability of those findings.

Pain anxiety/concern

'Pain anxiety/concern' comprised measures assessing catastrophizing, fear of pain/movement and pain anxiety. In total, 18 studies investigated various aspects using 15 different measures (see Table S1e and Figure S1c); most commonly the Pain Catastrophising Scale (PCS; Sullivan, Bishop, & Pivik, 1995), with total and/or subscale scores being reported by 10 studies (56%). Twelve studies employed a single measure of pain anxiety/concern, while the remainder used two, three, or six scales ($N_{\text{studies}} = 3, 2, 1$, respectively). A large overall mean effect ($d = -1.15$) was found for this construct (see Figure 2), with most measures returning large to very large and significant effects. Of note, the only measure to yield a small and non-significant effect for pain anxiety/concern – the Fear of Pain Questionnaire (FPQ-III; McNeil & Rainwater, 1998) – was only used in a single small-scale study. Moreover, unlike other measures that examine fears relating to the specific CP experience (e.g., *it will make my back pain worse*), the FPQ-III explores fear of pain in relation to a range of activities (e.g., *gulping a hot drink before it has cooled*), none of which are specifically tied to CP.

Somatization

Somatization was assessed in 16 studies using eight measures (see Table S1f and Figure S1d), the most common being the somatization subscale of the Revised Symptom Checklist-90 (SCL-90-R-S; $N_{\text{studies}} = 6$; Derogatis, 1994). The overall effect for somatization was large, negative and significant ($d = -1.2$; see Figure 2), indicating that the CP group consistently reported higher levels of somatization than controls. With the exception of the Wahler Physical Symptom Inventory (WPSI; Wahler, 1968), which had a moderate and significant effect that was susceptible to publication bias, all other measures revealed large and significant effects.

Anger/Hostility

Eight studies explored anger/hostility using four different measures (see Table S1f and Figure S1d). Two studies used multiple measures. While the overall effect for this domain was moderate ($d = -0.38$; see Figure 2), there was marked variability in the range and significance of findings for individual measures. Interestingly, while the largest effect was found using the Brief Symptom Inventory (BSI-H; Derogatis & Melisaratos, 1983), its longer counterpart (SCL-R-90-H) yielded non-significant results ($p = .125$). Non-significant results were also found for the State-Trait Anger Expression Inventory (STAXI-AE; Spielberger, 1988; $p = .463$). Of note, the findings for these latter two measures were susceptible to publication bias ($N_{\text{fs}} < N_{\text{studies}}$). Overall, the findings lacked consistency, suggesting that the relationship between anger/hostility and CP is unclear.

Self-efficacy

Self-efficacy was examined by four studies, with one using multiple measures to examine both general and pain-related self-efficacy (see Table S1f and Figure S1d). Not surprisingly, there was a large and significant difference ($d = 0.96$) between the self-efficacy levels of CP patients and their healthy peers, with the CP group showing substantially less confidence in their ability to bring about change and demonstrate mastery in their lives (see Figure 2). When the specific measures were considered, although not significant, the between-group difference for pain-related self-efficacy, as measured by the Pain Self-Efficacy Questionnaire (PSEQ; Nicholas, 2007), was considerably larger ($d = 1.12$) than that found for the more general measures of self-efficacy (General Self-Efficacy Scale; GSES, $d = 0.64$; Schwarzer & Jerusalem, 1995) or life control (Multidimensional Pain Inventory Life Control subscale; MPI-LC, $d = 0.80$; Kerns, Turk, & Rudy, 1985). Thus, as might be expected, while the pain group consistently reported lower levels of self-efficacy than did controls, they indicated feeling somewhat better able to exert control over their life in general, than they did to exert control over the pain itself and their ability to function in its presence.

Self-esteem

Self-esteem was examined by three studies using one of two measures (see Table S1f and Figure S1d). Overall, a moderate and significant positive effect ($d = 0.44$) was found (see Figure 2). Although the total sample used to explore this construct was limited (CP: $n = 146$, controls: $n = 162$) compared to other domains, these results suggest that healthy controls consistently reported having more positive feelings about themselves and their overall self-worth, than did the CP group.

General emotional functioning

Finally, general emotional functioning (sometimes conceptualized as distress) – a more global construct – was examined by 36 studies (see Table S1g and Figure S1e). Most of the 14 measures of this domain were used by between one and four studies, the exception being the Mental Health subscale of the 36-item Short-Form Health Survey (SF-36-MH; Stewart, Hays, & Ware, 1988), which was used by over 50% of studies. After inverting the effect sizes for specific scales (SF-12, SF-20, SF-36, Profile of Mood States: POMS – McNair, Lorr, & Droppleman, 1992; World Health Organisation Quality of Life Assessment – Brief: WHOQOL-BREF – Hawthorne, Herrman, & Murphy, 2006) so that they all measured *impairment* in psychological functioning (rather than positive mood), the weighted overall effect for this domain was moderate and significant ($d = -0.54$), indicating that the CP group consistently reported experiencing greater levels of emotional distress than healthy controls (Figure 2). The effects for individual measures varied greatly ($d = -0.04$ to $d = -3.85$), with very low N_{fs} statistics indicating that the results for four measures were vulnerable to publication bias.

Discussion

Life with CP is a complex experience that cannot be adequately understood in purely physical terms or reduced to neat diagnostic groupings. Therefore, it is important that

clinicians, planners and policy-makers understand the psychological aspects of the CP experience from a general perspective because comorbidities, symptom variation, and/or unclear diagnoses confound interpretations of diagnosis-specific CP research. Consequently, this meta-analysis was designed to synthesize the large CP literature from a broad perspective in order to systematically document the psychological functioning of people living with CP.

Our search of the CP literature revealed a substantial amount of research using diverse constructs and measures to examine a range of different psychological domains, particularly in recent years. Compared with controls, the CP group consistently reported experiencing significant and substantial problems in all aspects of psychological functioning. Not surprisingly, the greatest impact was on those domains that are directly tied to the physical experience of pain, namely pain anxiety/concern and somatization. One measure of general emotional functioning (BSI) was also particularly compelling because a finding of this magnitude indicates almost no overlap (<3%) between the scores of CP and healthy individuals on this measure (Zakzanis, 2001).

Although somatization was associated with the largest group difference (effect size), this result is somewhat difficult to interpret because the term is used inconsistently throughout the literature. For instance, in their recent meta-analysis of somatic symptoms, Zijlema *et al.* (2013) interpret somatization in two quite different ways: the tendency to (1) report/emphasize physical symptoms in the absence of, or to a greater extent than would be expected by the, identified organic pathology; and (2) 'experience and communicate somatic distress in response to psychosocial stress' (p. 459). Using the first interpretation, it is not surprising that people with CP showed significantly elevated rates of somatization: CP is not purely a physical experience and commonly lacks clear organic causes. Further, the range of comorbidities often experienced with CP may impact scores on these scales. However, the second interpretation suggests something different: that individuals living with CP are more likely to experience emotional distress in physical ways, possibly due to a heightened tendency to notice (and respond to) physical sensations, especially ones that are directly related to their pain. The current analysis does not distinguish between these alternative interpretations.

Overall, our findings confirm that CP is associated with a range of impairments in psychological functioning. However, they do not support the assertion that depression is the most commonly experienced problem. Instead, we found that, although individuals with CP were consistently more depressed than their healthy peers, they were comparatively more anxious (see Figure 2) – both in general and in response to pain. Similarly, self-efficacy was also found to be broadly affected across general and pain-related areas. However, of note, the elevated levels of pain anxiety/concern found in the CP group were specifically tied to the CP experience – Although the CP group was understandably anxious about exacerbating their condition, they were not more anxious about general pain experiences (e.g., hitting your head).

If an adjustment disorder is defined as a larger-than-expected emotional response (of mixed symptomatology) that impairs a person's ability to cope with a stressful experience or significant life change (World Health Organisation, 1990), it could be argued that many of the domains considered here fall into this broad category. However, it is not possible to comment more definitely here about the frequency of adjustment disorders in CP because researchers have rarely assessed 'adjustment disorders', per se. Rather, our current findings suggest that, of the psychological domains that were assessed, physically orientated problems (somatization and pain

anxiety/concern) are greater than depression and general impairments in emotional functioning.

It is well documented that the physical symptoms of CP overlap with the symptoms of depression, so much so that an accurate diagnosis of this type of mood disorder can be challenging in a CP setting (Cheatle, 2011; Wong *et al.*, 2011). Indeed, it is possible that this overlap in symptoms made it difficult for individuals to determine the origin of their symptoms when completing the self-report scales. However, this is unlikely to explain why the CP group was comparatively less depressed than they were anxious, for two reasons. First, the measures do not ask respondents to identify the cause of their symptoms – they merely ask them to indicate whether they experience those symptoms – which should have resulted in higher depression scores (symptoms would be reported, irrespective of cause) and narrowed the difference between depression and anxiety. Second, measures that had fewer somatic items (e.g., HADS, Depression Anxiety and Stress Scale [DASS]; Lovibond & Lovibond, 1996) did not yield noticeably smaller effects than scales with higher somatic content (e.g., BDI). This suggests that, contrary to current clinical thinking, the level of somatic content in the measures did not have a major impact on the results.

With that in mind, there are a number of limitations to this study that warrant consideration. First, research has been inconsistent in its terminology and operationalization of various psychological domains (e.g., somatization, anger/hostility), making it difficult to interpret some of the current findings and, indeed, to select appropriate search terms (e.g., disease versus illness). Second, the study size precluded detailed qualitative evaluation of individual studies to exclude sources of potential bias other than publication bias, sample inconsistency and low-quality assessment. Third, because this study focussed on the adult CP population from a general perspective, results may be less applicable to specific groups, especially those with syndrome-specific sequelae. Similarly, this study focussed exclusively on self-report measures. Further research examining specific cohorts (e.g., older people, children, indigenous populations) and other methods of mood assessment (e.g., ICD-10 diagnosis) is now needed. Moreover, we are unable to comment on whether the identified difference predated or resulted from the CP due to the research designs of the original studies. Such information could help improve our understanding of the factors that may pre-dispose and/or protect individuals from transitioning from acute to CP.

In addition, many CP studies that explored treatment outcomes used CP controls, rather than healthy controls, necessitating their exclusion from this meta-analysis. Somewhat surprisingly, an even larger number of studies were excluded because they did not report the basic data required to calculate Cohen's *d* effect sizes. Standards for data reporting have been under increasing scrutiny over recent years, with a strong push for authors to report more detailed data (including effect sizes) when publishing research (American Psychological Association, 2010; Moore *et al.*, 2010). Adoption of these reporting principles in future research would facilitate more comprehensive meta-analyses.

It was intended that this meta-analysis assist in determining the clinical utility of specific measures, but this did not prove to be the case. With the exception of the measures used to assess anger/hostility – where inconsistent findings suggest that the definition and/or measurement of this domain require more careful consideration and examination – the most commonly used measures consistently discriminated between CP and their healthy peers, suggesting that they were suitable for use in clinical contexts.

Finally, there were insufficient data to examine the impact of other variables (e.g., employment, relationship status, etc.) on psychological functioning. Again, more detailed reporting would enable an examination of these variables.

Conclusions

In summary, CP is a common condition that is associated with a range of psychological problems. This study revealed that those aspects of psychological functioning that are most closely tied to the physical experience, namely pain anxiety/concern and somatization, are most affected in people who are living with CP. This challenges previous assertions that depression levels in this population are equal to, or greater than, anxiety levels (Access Economics, 2007; Von Korff *et al.*, 2005). Not surprisingly, in all areas, the pain-related aspect of the impact was paramount. Although self-efficacy was globally eroded, pain anxiety/concern remained closely tied to the CP experience and did not extend to more general pain events.

Of note, this study supports the earlier findings of McWilliams, Goodwin and Cox (2004) who asserted that anxiety in CP populations requires greater attention because anxiety was often more strongly associated with CP than depression in their sample. Interestingly, the relative strengths of the depression–CP and anxiety–CP relationships have gone largely unchallenged over the last decade.

Overall, these findings suggest that people with CP are in a debilitating bind. The chronic physical pain that they experience is associated with considerable psychological distress, which is most commonly focussed on physical aspects of the overall experience. Although this physical focus is not surprising in the circumstance, it is likely to heighten their level of attention to, and lower their threshold for, physical symptoms. This may, in turn, further increase the chance that they will notice physical symptoms and interpret them as threatening, thus heightening their distress and discomfort, and perpetuating the cycle. This cycle is discussed in detail in the CP literature, but the present study is the first to quantitatively consolidate the existing research findings and, in doing so, enable a direct statistical comparison between different areas of psychological functioning. Although pain anxiety/concern, somatization and self-efficacy (particularly pain-related self-efficacy) are common considerations when working with individuals who experience CP, the degree to which they are prioritized in therapy varies greatly. The current meta-analysis suggests that, to help individuals break the pain cycle, evidence-based practice in CP should prioritize these aspects of psychological function.

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Conflict of interest declaration

There are no relationships that may lead to conflict of interest. However, while not representing a conflict of interest, the primary author wishes to disclose the following commercial engagements. The primary author has received honoraria for GP/nursing education sessions and steering committee participation from Mundipharma and Pfizer/

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Supporting Information

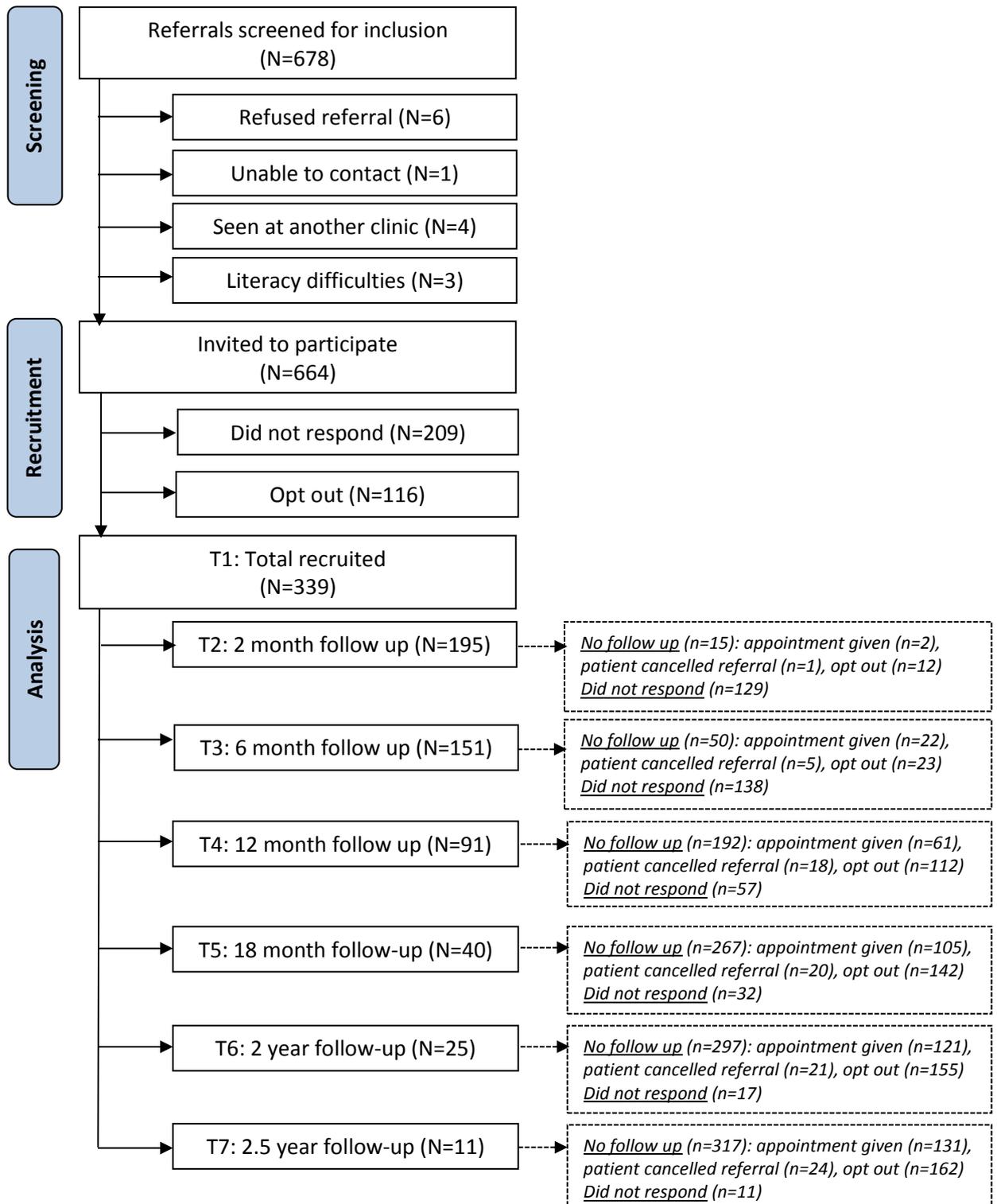
The following supporting information may be found in the online edition of the article:

Figure S1. Cohen's *d* effect sizes for (a) depression; overall and by measure, (b) anxiety; overall and by measure, (c) pain anxiety/concern; overall and by measure, (d) somatisation, anger/hostility, self-efficacy and self-esteem; overall and by measure, (e) general emotional functioning; overall and by measure.

Table S1. (a) Search strategies used by search engine; (b) Demographic information retrieved from studies; (c) Studies included in the analyses for depression, by measure; (d) Studies included in the analyses for anxiety, by measure; (e) Studies included in the analyses for pain anxiety/concern, by measure; (f) Studies included in the analyses for somatisation, anger/hostility, self-efficacy and self-esteem, by measure; and (g) Studies included in the analyses for general emotional functioning, by measure.

Appendix 2: Supplementary Information for Chapter 4

Appendix 2.1 Supplementary Figure for Chapter 4



Supplementary Figure 4.A: Flow of participants through the study

Appendix 2.2 Supplementary Tables for Chapter 4

Supplementary Table 4.A: PMU triage codes

Triage Category	Description
Code 1	Cancer/palliative pain: for early intervention
Code 2	Early intervention likely to improve patient outcomes (i.e. Complex Regional Pain Syndrome)
Code 3	Elderly and/or young and/or neuropathic pain (i.e. post-surgical pain)
Code 4A	Mini multidisciplinary panel assessment required (medical, psychology)
Code 4B	Full multidisciplinary panel assessment required (medical, nursing, physiotherapy, psychology, psychiatry)
Code 5	Opiate issues require specific attention

Supplementary Table 4.B: Mean (standard deviation) of age and key outcome variables, by time-point and study participation status

Time-point	Domain	Participation Status				Total
		Still in Study	Received Appointment	Opt Out	Cancelled Referral	
T2 (2 months)	Age	47.8 (10.2)	43.6 (11.4)	44.4 (10.9)	43.0 (6.3)	43.9 (10.4)
	Pain-related interference (BPI)	7.4 (1.6)	7.2 (2.2)	7.5 (1.7)	8.0 (1.6)	7.4 (1.7)
	Pain severity (BPI)	6.9 (1.9)	7.2 (1.9)	6.8 (2.2)	7.8 (1.8)	6.9 (2.0)
	Psychological distress (K-10)	30.1 (8.8)	31.0 (8.6)	30.3 (19.2)	29.0 (4.8)	30.2 (12.7)
	Socially-desirable responding (SDRS-5)	1.8 (1.5)	2.3 (1.6)	2.0 (1.7)	1.6 (1.7)	1.8 (1.5)
T3 (6 months)	Age	44.4 (10.1)	14.8 (11.7)	44.1 (10.4)	45.6 (9.4)	43.9 (10.4)
	Pain-related interference (BPI)	7.3 (1.9)	7.5 (2.0)	7.3 (1.7)	6.6 (2.2)	7.3 (1.9)
	Pain severity (BPI)	6.9 (2.1)	7.3 (2.2)	6.0 (2.8)	5.5 (2.4)	6.9 (2.2)
	Psychological distress (K-10)	30.3 (9.2)	33.7 (8.3)	25.4 (7.6) *	30.4 (10.0)	30.8 (9.1)
	Socially-desirable responding (SDRS-5)	1.9 (1.5)	1.8 (1.5)	1.8 (1.4)	1.5 (1.7)	1.8 (1.5)
T4 (1 year)	Age	46.2 (9.3)	42.2 (11.3)	43.8 (10.4)	46.2 (9.3)	43.9 (10.4)
	Pain-related interference (BPI)	6.8 (2.2)	7.4 (2.0)	7.1 (1.1)	7.1 (1.4)	7.1 (2.0)
	Pain severity (BPI)	6.5 (2.5)	6.9 (2.2)	7.3 (2.1)	6.6 (1.8)	6.8 (2.3)
	Psychological distress (K-10)	28.2 (9.6)	32.1 (9.4)	29.2 (6.3)	33.6 (10.3)	30.2 (9.5)
	Socially-desirable responding (SDRS-5)	1.9 (1.5)	1.8 (1.3)	2.0 (1.6)	1.4 (1.1)	1.8 (1.4)
T5 (1.5 years)	Age	46.8 (8.6)	42.2 (11.3)	43.8 (10.4)	46.2 (9.3)	43.9 (10.4)
	Pain-related interference (BPI)	6.8 (2.3)	6.7 (1.8)	6.7 (1.4)	7.7 (-)	6.7 (2.0)
	Pain severity (BPI)	6.7 (2.3)	6.9 (2.1)	6.5 (1.7)	8.0 (-)	6.8 (2.2)
	Psychological distress (K-10)	28.5 (11.1)	28.7 (10.1)	28.6 (8.2)	40.0 (-)	28.7 (10.4)
	Socially-desirable responding (SDRS-5)	1.5 (1.5)	1.7 (1.6)	1.5 (1.7)	2.0 (-)	1.6 (1.5)
T6 (2 years)	Age	48.4 (7.9)	42.56 (11.1)	43.9 (10.3)	45.7 (9.4)	43.9 (10.5)
	Pain-related interference (BPI)	7.0 (1.7)	6.9 (1.9)	-	-	6.9 (1.8)
	Pain severity (BPI)	7.0 (2.4)	7.6 (1.4)	-	-	7.2 (2.1)
	Psychological distress (K-10)	26.7 (9.3)	28.4 (9.1)	-	-	27.3 (9.1)
	Socially-desirable responding (SDRS-5)	2.0 (1.5)	2.45 (1.5)	-	-	2.2 (1.5)
T7 (2.5 years)	Age	47.7 (9.9)	43.1 (11.0)	44.0 (10.3)	46.2 (9.0)	43.9 (10.5)
	Pain-related interference (BPI)	6.9 (2.4)	6.2 (2.2)	9.7 (-)	6.8 (2.8)	6.9 (2.4)
	Pain severity (BPI)	6.4 (2.6)	7.5 (1.3)	7.0 (-)	5.5 (0.7)	6.6 (2.1)
	Psychological distress (K-10)	29.3 (10.8)	28.2 (10.1)	45 (-)	32.7 (4.5)	30.2 (10.1)
	Socially-desirable responding (SDRS-5)	1.7 (1.9)	2.0 (1.5)	1.0 (-)	0.3 (0.6)	1.6 (1.7)

Note: BPI = Brief Pain Inventory; K-10 = Kessler Distress Scale; SDRS-5 = Social Desirability Response Set Scale.

* p<0.05

Supplementary Table 4.C: Estimated means for outcome domains, by Time and Sex

Outcome Domain	T1 (intake)			T2 (2 months)			T3 (6 months)			T4 (12 months)		
	Female	Male	Total	Female	Male	Total	Female	Male	Total	Female	Male	Total
<i>N</i>	197	142	339	117	78	195	84	67	151	54	37	91
<i>Pain impact (BPI)</i>												
Pain-related interference	7.4 (0.1)	7.4 (0.1)	7.4 (0.1)	7.5 (0.2)	7.1 (0.2)	7.3 (0.1)	7.3 (0.2)	7.2 (0.2)	7.3 (0.2)	7.2 (0.2)	6.5 (0.3)	6.8 (0.2)
Pain severity	7.1 (0.1)	6.7 (0.2)	6.9 (0.1)	7.2 (0.2)	6.7 (0.2)	7.0 (0.1)	7.1 (0.2)	6.5 (0.2)	6.8 (0.2)	7.1 (0.3)	6.4 (0.3)	6.7 (0.2)
<i>Psychological distress (K-10)</i>	29.9 (0.6)	30.3 (0.7)	30.1 (0.5)	31.0 (0.8)	30.3 (0.9)	30.7 (0.6)	30.2 (0.9)	32.1 (1.0)	31.1 (0.7)	30.4 (1.2)	31.3 (1.4)	30.8 (0.9)
<i>Pain acceptance (CPAQ)</i>												
Pain willingness	16.0 (0.6)	13.7 (0.7)	14.9 (0.5)	19.1 (0.7)	17.7 (0.9)	18.4 (0.6)	19.6 (0.9)	16.1 (1.0)	17.9 (0.7)	19.8 (1.0)	16.8 (1.2)	18.3 (0.8)
Activity engagement	23.9 (0.9)	22.5 (1.0)	23.2 (0.7)	24.7 (1.0)	24.0 (1.3)	24.3 (0.8)	24.2 (1.2)	23.9 (1.4)	24.1 (0.9)	24.4 (1.4)	21.9 (1.6)	23.1 (1.0)
Overall acceptance	39.9 (1.2)	36.3 (1.4)	38.1 (0.9)	44.1 (1.4)	41.8 (1.7)	43.0 (1.1)	43.8 (1.6)	40.2 (1.8)	42.0 (1.2)	44.1 (1.8)	39.0 (2.1)	41.5 (1.4)
<i>Quality of life(WHOQOL-BREF)</i>												
Physical health	14.1 (0.3)	14.9 (0.4)	14.5 (0.2)	14.7 (0.4)	15.8 (0.4)	15.2 (0.3)	14.7 (0.4)	15.5 (0.5)	15.1 (0.3)	14.8 (0.5)	15.3 (0.6)	15.1 (0.4)
Psychological health	15.7 (0.4)	15.7 (0.4)	15.7 (0.3)	15.8 (0.4)	15.9 (0.5)	15.8 (0.3)	15.7 (0.5)	15.3 (0.5)	15.5 (0.3)	15.2 (0.5)	14.6 (0.6)	14.9 (0.4)
Social relationships	8.3 (0.3)	7.4 (0.3)	7.8 (0.2)	7.9 (0.4)	7.3 (0.4)	7.6 (0.3)	9.2 (0.4)	7.2 (0.5)	8.2 (0.3)	7.9 (0.5)	7.2 (0.7)	7.6 (0.4)
Environment	23.8 (0.4)	23.0 (0.5)	23.4 (0.3)	24.1 (0.5)	23.0 (0.6)	23.5 (0.4)	23.8 (0.5)	22.8 (0.6)	23.3 (0.4)	24.6 (0.6)	22.8 (0.7)	23.7 (0.5)
<i>Health care utilisation</i>												
Frequency	10.6 (0.5)	9.9 (0.6)	10.3 (0.4)	9.4 (0.5)	8.8 (0.6)	9.1 (0.4)	8.6 (0.6)	8.4 (0.7)	8.5 (0.5)	8.9 (0.8)	8.6 (0.9)	8.8 (0.6)
Treatment types												
Medical	1.2 (0.1)	1.3 (0.1)	1.2 (0.1)	0.8 (0.1)	0.8 (0.1)	0.8 (0.1)	1.1 (0.1)	1.3 (0.1)	1.2 (0.1)	1.2 (0.1)	1.1 (0.1)	1.1 (0.1)
Psychological	1.3 (0.1)	1.1 (0.1)	1.2 (0.1)	0.9 (0.1)	0.8 (0.1)	0.9 (0.1)	1.6 (0.1)	1.3 (0.1)	1.4 (0.1)	1.4 (0.1)	1.2 (0.2)	1.3 (0.1)
Alternative	0.4 (0.0)	0.3 (0.1)	0.4 (0.0)	0.3 (0.1)	0.3 (0.1)	0.3 (0.0)	0.5 (0.1)	0.4 (0.1)	0.4 (0.0)	0.5 (0.1)	0.3 (0.1)	0.4 (0.1)
Physical	1.3 (0.1)	1.3 (0.1)	1.3 (0.1)	1.1 (0.1)	1.3 (0.1)	1.2 (0.1)	2.3 (0.1)	2.1 (0.1)	2.2 (0.1)	2.3 (0.1)	1.8 (0.2)	2.0 (0.1)
N (%) tried new treatment	-	-	-	54 (46)	27 (35)	81 (42)	32 (38)	22 (33)	54 (36)	12 (22)	6 (16)	18 (20)
Number new tried	-	-	-	2.4 (0.2)	2.7 (0.3)	2.6 (0.2)	2.3 (0.2)	2.8 (0.3)	2.6 (0.2)	1.3 (0.4)	2.0 (0.6)	1.7 (0.4)
<i>Medication usage</i>												
% relief received	41.9 (1.8)	39.0 (2.1)	40.4 (1.4)	42.2 (2.2)	39.4 (2.6)	40.8 (1.7)	43.6 (2.3)	39.8 (2.7)	41.7 (1.8)	42.5 (2.9)	35.4 (3.6)	39.0 (2.3)
Change since last (N, %)												
Taking stronger / more	-	-	-	49 (42)	21 (27)	70 (36)	34 (40)	21 (31)	55 (36)	27 (50)	14 (38)	41 (45)
Nil, taking same	-	-	-	45 (38)	43 (55)	88 (45)	37 (44)	30 (45)	67 (44)	22 (41)	13 (35)	35 (39)
Taking weaker / less	-	-	-	16 (14)	9 (12)	25 (13)	6 (7)	8 (12)	14 (9)	3 (5)	7 (19)	10 (11)
Ceased all medication	-	-	-	2 (2)	4 (5)	6 (3)	4 (5)	3 (4)	7 (5)	1 (2)	1 (3)	2 (2)
Not reported	-	-	-	5 (4)	1 (1)	6 (3)	3 (4)	5 (8)	8 (6)	1 (2)	2 (5)	3 (3)
<i>Symptom exaggeration (SDRS-5)</i>	1.9 (0.1)	1.7 (0.1)	1.8 (0.1)	1.9 (0.1)	1.7 (0.2)	1.8 (0.1)	1.8 (0.1)	1.8 (0.2)	1.8 (0.1)	1.6 (0.2)	1.5 (0.2)	1.5 (0.1)

Note: N = number of participants; BPI = Brief Pain Inventory; K-10 = Kessler Distress Scale; CPAQ = Chronic Pain Acceptance Questionnaire; WHOQOL-BREF = World Health Organisation Quality of Life – Brief Scale; SDRS-5 = Social Desirability Response Set Scale. Scores represent estimated mean (standard error) unless indicated otherwise to be N (%).

Supplementary Table 4.C: Estimated means for outcome domains, by Time and Sex cont.

Outcome Domain	T5 (1.5 years)			T6 (2 years)			T7 (2.5 years)			SEX	
	Female	Male	Total	Female	Male	Total	Female	Male	Total	Female	Male
<i>N</i>	25	15	40	17	8	25	6	5	11	197	142
<i>Pain impact (BPI)</i>											
Pain-related interference	7.3 (0.3)	6.4 (0.4)	6.9 (0.2)	7.3 (0.4)	6.3 (0.6)	6.8 (0.4)	8.3 (0.4)	5.2 (1.9)	6.8 (0.3)	7.5 (0.2)	6.6 (0.2)
Pain severity	7.0 (0.3)	6.5 (0.4)	6.7 (0.2)	7.0 (0.3)	6.5 (0.4)	6.7 (0.2)	7.7 (0.3)	6.6 (0.3)	7.1 (0.2)	7.2 (0.2)	6.6 (0.2)
<i>Psychological distress (K-10)</i>	32.0 (1.2)	29.9 (1.6)	30.9 (1.0)	34.3 (1.6)	34.7 (2.1)	34.5 (1.3)	39.8 (1.8)	21.7 (2.1)	30.7 (1.4)	32.5 (0.7)	30.0 (0.8)
<i>Pain acceptance(CPAQ)</i>											
Pain willingness	19.4 (1.5)	19.2 (1.9)	19.3 (1.2)	21.1 (1.7)	16.7 (2.3)	18.9 (1.4)	16.1 (1.3)	18.1 (1.5)	17.1 (1.0)	18.7 (0.7)	16.9 (0.9)
Activity engagement	23.2 (1.6)	24.8 (2.0)	24.0 (1.3)	20.9 (2.1)	30.4 (2.8)	25.7 (1.70)	17.0 (2.8)	25.7 (3.5)	21.4 (2.2)	22.6 (1.1)	24.8 (1.3)
Overall pain acceptance	42.5 (2.4)	43.4 (3.0)	42.9 (1.9)	42.6 (2.9)	43.2 (4.0)	42.9 (2.5)	38.3 (3.6)	42.3 (4.1)	40.3 (2.7)	42.2 (1.4)	40.9 (1.8)
<i>Quality of life (WHOQOL-BREF)</i>											
Physical health	15.1 (0.6)	15.2 (0.8)	15.1 (0.5)	14.0 (0.7)	16.2 (1.1)	15.1 (0.6)	15.4 (1.2)	17.7 (1.3)	16.6 (0.6)	14.7 (0.4)	15.8 (0.4)
Psychological health	15.0 (0.7)	15.0 (0.9)	15.0 (0.6)	14.2 (0.8)	15.6 (1.1)	14.9 (0.7)	14.9 (1.2)	15.1 (1.3)	15.0 (0.9)	15.2 (0.4)	15.3 (0.5)
Social relationships	7.8 (0.7)	6.4 (1.0)	7.1 (0.6)	7.3 (0.9)	6.5 (1.3)	6.9 (0.8)	7.9 (1.5)	7.5 (1.6)	7.7 (1.1)	8.0 (0.3)	7.1 (0.4)
Environment	23.3 (0.8)	22.2 (1.0)	22.7 (0.6)	23.7 (0.9)	22.4 (1.3)	23.1 (0.8)	25.3 (1.4)	22.2 (1.6)	23.7 (1.1)	24.1 (0.5)	22.6 (0.6)
<i>Health care utilisation</i>											
Frequency	7.7 (0.9)	7.8 (1.1)	7.7 (0.7)	6.3 (0.8)	5.0 (1.0)	5.6 (0.6)	11.1 (1.1)	7.9 (1.3)	9.5 (0.9)	8.9 (0.5)	8.1 (0.6)
<i>Treatment types</i>											
Medical	1.3 (0.2)	1.5 (0.3)	1.4 (0.2)	1.3 (0.2)	1.9 (0.3)	1.6 (0.2)	1.5 (0.4)	1.6 (0.4)	1.5 (0.3)	1.2 (0.1)	1.4 (0.1)
Psychological	1.3 (0.2)	1.3 (0.2)	1.3 (0.1)	1.2 (0.2)	1.4 (0.3)	1.3 (0.2)	1.2 (0.3)	0.9 (0.4)	1.0 (0.2)	1.3 (0.1)	1.1 (0.1)
Alternative	0.6 (0.1)	0.5 (0.1)	0.6 (0.1)	0.6 (0.1)	0.6 (0.2)	0.6 (0.1)	0.4 (0.2)	0.3 (0.2)	0.3 (0.1)	0.5 (0.1)	0.4 (0.1)
Physical	2.4 (0.2)	1.7 (0.2)	2.1 (0.1)	2.3 (0.2)	2.3 (0.3)	2.3 (0.2)	2.3 (0.4)	1.9 (0.4)	2.1 (0.3)	2.0 (0.1)	1.8 (0.1)
<i>N (%) tried new</i>	5 (20)	1 (7)	6 (15)	5 (29)	1 (13)	6 (24)	2 (33)	1 (20)	3 (27)	-	-
Number new tried	1.0 (1.0)	1.0 (1.4)	1.0 (0.9)	1.8 (0.7)	-	1.8 (0.7)	1.0 (1.0)	1.0 (1.4)	1.0 (0.9)	1.6 (0.3)	1.9 (0.4)
<i>Medication</i>											
% relief received	47.0 (3.3)	35.6 (4.3)	41.3 (2.7)	34.3 (4.7)	35.8 (6.4)	35.0(4.0)	25.0 (3.7)	9.7 (4.5)	17.3 (2.9)	41.9 (1.8)	37.5 (2.3)
<i>Change since last (N, %)</i>											
Taking stronger / more	14 (56)	3 (20)	17 (43)	9 (53)	1 (12)	10 (40)	3 (50)	2 (40)	5 (46)	-	-
Nil, taking same	9 (36)	7 (47)	16 (40)	5 (29)	5 (63)	10 (40)	2 (33)	1 (20)	3 (27)	-	-
Taking weaker / less	-	3 (20)	3 (7)	2 (12)	2 (25)	4 (16)	1 (17)	1 (20)	2 (18)	-	-
Ceased all medication	-	-	-	1 (6)	-	1 (4)	-	-	-	-	-
Not reported	2 (8)	2 (13)	4 (10)	-	-	-	-	1 (20)	1 (9)	-	-
<i>Symptom exaggeration (SDRS-5)</i>	2.0 (0.2)	1.7 (0.3)	1.9 (0.2)	1.5 (0.3)	2.0 (0.5)	1.7 (0.3)	1.2 (0.3)	1.9 (0.3)	1.5 (0.2)	1.5 (0.2)	1.5 (0.2)

Note: N = number of participants; BPI = Brief Pain Inventory; K-10 = Kessler Distress Scale; CPAQ = Chronic Pain Acceptance Questionnaire; WHOQOL-BREF = World Health Organisation Quality of Life – Brief Scale; SDRS-5 = Social Desirability Response Set Scale. Scores represent estimated mean (standard error) unless indicated otherwise to be N (%).

Supplementary Table 4.D: Estimates of significant interaction effects (Time x Sex) on outcome domains

Outcome Domain	Time	Estimate	95% CI		d	Graphical Representation of Significant Interactions
			LL	UL		
<i>Pain impact (BPI)</i> Pain-related interference	1	3.01 ***	1.96	4.06	0.33	
	2	2.62 ***	1.55	3.69	0.37	
	3	3.09 ***	2.14	4.03	0.57	
	4	2.34 ***	1.30	3.38	0.50	
	5	2.25 **	1.00	3.50	0.63	
	6	2.10 **	0.76	3.44	0.67	
<i>Psychological distress (K-10)</i>	1	18.57 ***	12.99	24.14	0.36	
	2	17.45 ***	11.93	22.96	0.45	
	3	20.06 ***	12.96	27.16	0.46	
	4	19.06 ***	13.33	24.80	0.71	
	5	16.03 ***	8.40	23.65	0.68	
	6	18.47 ***	11.10	25.84	1.00	
<i>Pain acceptance (CPAQ)</i> Pain willingness	1	-4.34 *	-8.26	-0.43	0.12	
	2	-3.50	-7.98	0.98	-	
	3	-5.52 ***	-8.28	-2.77	0.32	
	4	-5.05 *	-9.05	-1.05	0.27	
	5	-2.30	-8.22	3.63	-	
	6	-6.34 *	-11.68	-1.01	0.49	
Activity engagement	1	-10.02 *	-19.18	-0.85	0.13	
	2	-9.43 *	-18.77	-0.09	0.15	
	3	-9.00 *	-17.91	-0.09	0.17	
	4	-11.16 *	-20.78	-1.54	0.25	
	5	-7.15 *	-13.74	-0.56	0.37	
	6	0.79	-8.39	9.96	-	

Note: BPI = Brief Pain Inventory; K-10 = Kessler Distress Scale; CPAQ = Chronic Pain Acceptance Questionnaire; WHOQOL-BREF = World Health Organisation Quality of Life – Brief Scale; SDRS-5 = Social Desirability Response Set Scale.

*** = $p < 0.001$; ** $p < 0.01$; * $p < 0.05$

Supplementary Table 4.E: Estimates of main effects (Time and Sex) on outcome domains

Outcome Domain	Time vs. T7	TIME				SEX				
		Estimate	95% CI		<i>d</i>	Estimate	95% CI		<i>d</i>	
			LL	UL			LL	UL		
<i>Pain impact (BPI)</i>										
Pain-related interference	1	-0.90 *	-1.59	-0.22	0.15	-3.10 ***	-4.17	-2.03	0.33	
	2	-0.82 *	-1.50	-0.13	0.18					
	3	-1.09 **	-1.70	-0.47	0.31					
	4	-1.12 **	-1.79	-0.45	0.38					
	5	-1.05 *	-1.84	-0.26	0.49					
	6	-1.09 *	-1.90	-0.29	0.58					
Pain severity	1	-0.57 *	-1.12	-0.02	0.11	-1.03 *	-1.88	-0.18	0.13	
	2	-0.45	-0.95	0.05	-					
	3	-0.57 *	-1.07	-0.07	0.19					
	4	-0.59 *	-1.16	-0.02	0.22					
	5	-0.69 **	-1.19	-0.19	0.45					
	6	-0.66 ***	-0.98	-0.34	0.87					
<i>Psychological distress (K-10)</i>	1	-9.91 ***	-13.54	-6.28	0.30	-18.13 *	-23.60	-12.67	0.36	
	2	-8.76 ***	-12.36	-5.15	0.35					
	3	-9.61 ***	-14.27	-4.95	0.33					
	4	-9.41 ***	-13.13	-5.69	0.54					
	5	-7.81 **	-12.65	-2.97	0.52					
	6	-5.44 *	-10.13	-0.76	0.47					
<i>Pain acceptance (CPAQ)</i>										
	Pain willingness	1	-0.28	-2.58	2.52	-	2.04	-2.03	6.10	-
		2	3.08 *	0.19	5.96	0.15				
		3	3.54 ***	1.77	5.30	0.36				
		4	3.70 **	1.06	6.35	0.30				
		5	3.38	-0.35	7.11	-				
6		4.99 **	1.73	8.25	0.63					
Activity engagement	1	6.83 *	1.18	12.48	0.14	8.70	-0.65	18.06	-	
	2	7.69 *	1.93	13.46	0.20					
	3	7.19 *	1.69	12.68	0.22					

Note: N=number of participants; BPI=Brief Pain Inventory; K-10=Kessler Distress Scale; CPAQ=Chronic Pain Acceptance Questionnaire; WHOQOL-BREF=World Health Organisation Quality of Life – Brief Scale; SDRS-5=Social Desirability Response Set Scale. Scores represent M (SD) unless indicated otherwise to be N (%).

*** = p<0.001; ** p<0.01; * p<0.05

Supplementary Table 4.E: Estimates of main effects (Time and Sex) on outcome domains cont.

Outcome Domain	Time vs. T7	TIME				SEX			
		Estimate	95% CI		d	Estimate	95% CI		d
			LL	UL			LL	UL	
Activity engagement cont.	4	7.35 *	1.37	13.34	0.27				
	5	6.23 **	2.22	10.23	0.52				
	6	3.90	-1.66	9.47	-				
Overall pain acceptance	1	1.59	-6.20	9.37	-	3.96	-7.87	15.80	-
	2	5.83	-2.20	13.85	-				
	3	5.53	-2.18	13.23	-				
	4	5.77	-2.05	13.58	-				
	5	4.19	-3.84	12.23	-				
	6	4.29	-3.73	12.30	-				
Quality of life (WHOQOL-BREF) Physical health	1	-1.35	-3.65	0.95	-	2.25	-1.21	5.71	-
	2	-0.75	-3.07	1.56	-				
	3	-0.74	-3.06	1.59	-				
	4	-0.59	-2.94	1.76	-				
	5	-0.38	-2.83	2.06	-				
	6	-1.41	-3.94	1.11	-				
Psychological health	1	0.72	-1.61	3.04	-	0.14	-3.40	3.68	-
	2	0.82	-1.51	3.16	-				
	3	0.74	-1.61	3.08	-				
	4	0.28	-2.09	2.65	-				
	5	0.02	-2.44	2.49	-				
	6	-0.76	-3.31	1.78	-				
Social relationships	1	0.44	-2.52	3.41	-	-0.41	-4.77	3.96	-
	2	0.08	-2.91	3.07	-				
	3	1.33	-1.67	4.34	-				
	4	0.07	-2.98	3.12	-				
	5	-0.05	-3.23	3.14	-				
	6	-0.62	-3.92	2.68	-				

Note: N=number of participants; BPI=Brief Pain Inventory; K-10=Kessler Distress Scale; CPAQ=Chronic Pain Acceptance Questionnaire; WHOQOL-BREF=World Health Organisation Quality of Life – Brief Scale; SDRS-5=Social Desirability Response Set Scale. Scores represent M (SD) unless indicated otherwise to be N (%).

*** = p<0.001; ** p<0.01; * p<0.05

Supplementary Table 4.E: Estimates of main effects (Time and Sex) on outcome domains cont.

Outcome Domain	Time vs. T7	Estimate	TIME		d	Estimate	SEX		d
			95% CI				95% CI		
			LL	UL			LL	UL	
Environment	1	-1.43	-4.18	1.33	-	-3.06 *	-7.24	1.12	0.14
	2	-1.20	-3.96	1.57	-				
	3	-1.44	-4.22	1.34	-				
	4	-0.71	-3.52	2.10	-				
	5	-1.98	-4.90	0.94	-				
	6	-1.54	-4.56	1.47	-				
<i>Health care utilisation</i> Frequency	1	-0.44	-3.08	2.20	-	-3.17	-7.43	1.09	-
	2	-1.66	-4.69	1.38	-				
	3	-2.46	-5.05	0.12	-				
	4	-2.11	-4.53	0.32	-				
	5	-3.37 *	-6.22	-0.52	0.47				
	6	-4.80 ***	-6.95	-2.66	1.04				
Treatment types Medical	1	-0.27	-1.01	0.48	-	0.10	-1.00	1.21	-
	2	-0.70	-1.44	0.05	-				
	3	-0.32	-1.07	0.43	-				
	4	-0.29	-1.05	0.47	-				
	5	-0.11	-0.91	0.68	-				
	6	-0.16	-0.98	0.66	-				
Psychological	1	0.09	-0.55	0.73	-	0.30	-1.25	0.65	-
	2	-0.28	-0.92	0.36	-				
	3	0.44	-0.20	1.08	-				
	4	0.25	-0.40	0.89	-				
	5	0.09	-0.58	0.77	-				
	6	0.03	-0.66	0.72	-				
Alternative	1	0.01	-0.34	0.37	-	-0.14	-0.67	0.39	-
	2	-0.06	-0.41	0.30	-				
	3	0.13	-0.23	0.48	-				

Note: N=number of participants; BPI=Brief Pain Inventory; K-10=Kessler Distress Scale; CPAQ=Chronic Pain Acceptance Questionnaire; WHOQOL-BREF=World Health Organisation Quality of Life – Brief Scale; SDRS-5=Social Desirability Response Set Scale. Scores represent M (SD) unless indicated otherwise to be N (%).

*** = p<0.001; ** p<0.01; * p<0.05

Supplementary Table 4.E: Estimates of main effects (Time and Sex) on outcome domains cont.

Outcome Domain	Time vs. T7	TIME				SEX			
		Estimate	95% CI		d	Estimate	95% CI		d
			LL	UL			LL	UL	
Alternative cont.	4	0.10	-0.26	0.46	-				
	5	0.20	-0.18	0.58	-				
	6	0.23	-0.15	0.62	-				
Physical	1	-0.99 **	-1.67	-0.30	0.15	-0.48	-1.50	0.54	-
	2	-1.24 ***	-1.93	-0.55	0.19				
	3	-0.06	-0.76	0.63	-				
	4	-0.05	-0.75	0.65	-				
	5	0.07	-0.66	0.80	-				
	6	0.01	-0.74	0.77	-				
Number new treatments	1	-	-	-	-	0.07	-3.41	3.54	-
	2	1.51	-0.54	3.56	-				
	3	1.33	-0.74	3.36	-				
	4	0.39	-1.78	2.56	-				
	5	0.00	-2.83	2.84	-				
	6	0.83	-1.73	3.38	-				
<i>Medication usage</i> % relief from medication	1	17.27	0.24	34.30	-	-1.42	-26.86	24.01	-
	2	17.22	0.13	34.32	-				
	3	18.68	1.48	35.88	-				
	4	17.29	-0.01	34.59	-				
	5	21.11	3.25	38.97	-				
	6	9.72	-8.75	28.20	-				
<i>Symptom exaggeration</i> (SDRS-5)	1	-0.17	-1.05	0.71	-	-0.75	-2.06	0.56	-
	2	-0.14	-1.03	0.74	-				
	3	-0.32	-1.21	0.57	-				
	4	-0.53	-1.42	0.37	-				
	5	-0.02	-0.95	0.91	-				
	6	-0.43	-1.40	0.53	-				

Note: N=number of participants; BPI=Brief Pain Inventory; K-10=Kessler Distress Scale; CPAQ=Chronic Pain Acceptance Questionnaire; WHOQOL-BREF=World Health Organisation Quality of Life – Brief Scale; SDRS-5=Social Desirability Response Set Scale. Scores represent M (SD) unless indicated otherwise to be N (%).

*** = p<0.001; ** p<0.01; * p<0.05

Appendix 2.3 Published article for Chapter 4



Article

Waiting for multidisciplinary chronic pain services: A prospective study over 2.5 years

Anne LJ Burke^{1,2} , Jane L Mathias²
and Linley A Denson²

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Abstract

Despite many patients waiting more than 2 years for treatment at publicly funded multidisciplinary chronic pain services, waitlist studies rarely examine beyond 6 months. We investigated psychological adjustment and health-care utilisation of individuals ($N=339$) waiting ≤ 30 months for appointments at an Australian tertiary pain unit. Outcomes were relatively stable during the first 6 months, but long-term deteriorations in pain-related interference, distress and pain acceptance were evident, albeit with sex differences. Sexes also differed in uptake of new treatments. Medication use increased over time, but pain severity and medication relief did not. Results suggest that early intervention is important, especially for women.

Keywords

chronic pain, health-care utilisation, psychological adjustment, waiting, waitlist

Introduction

Chronic pain (CP) is associated with a range of physical (Taylor et al., 2016), psychological (Burke et al., 2015), social (Dueñas et al., 2016) and economic consequences, many of which improve with treatment (Gatchel and Okifuji, 2006). Although Australians are eligible for universal health care – including government-subsidized hospitals, diagnostics, specialists and low-cost medications – high demand and limited resources mean that public CP outpatient clinics struggle to provide timely treatment (Fashler et al., 2016). Up to 80 per cent of Australian adults with CP are denied treatment that could improve their functioning and quality of life (QOL; National Pain Summit Initiative, 2011), while others wait over 2 years for treatment (Hogg et al., 2012); far longer than the 8-week maximum recommended wait (International Association for the Study of Pain (IASP), 2010).

In Europe, around 33 per cent fail to receive treatment for their CP, almost 50 per cent report inadequate pain management and only 2 per cent are managed by specialist services, many with lengthy waits (Breivik et al., 2013). Although clinicians frequently report long wait-times, published statistics often underestimate the problem because they include rapid access cases (e.g. palliative care), with median waits varying from 7 to 231 days, far less than the waits experienced by many patients.

¹Royal Adelaide Hospital, Australia

²The University of Adelaide, Australia

Corresponding author:

Anne LJ Burke, Psychology Department, Royal Adelaide Hospital, Port Road, Adelaide, SA 5000, Australia.
Email: a.burke@health.sa.gov.au

Wait-times, even up to 6 months, may be associated with poorer health-related QOL and well-being and increased pain, disability and distress (Fogarty and Cronin, 2008). Accordingly, access to CP treatment is now a key consideration in European health care (Societal Impact of Pain Grünenthal Group, 2017). Although short-term data suggest an inverse relationship between wait-time and adjustment (Fogarty and Cronin, 2008), the point at which clinically significant deterioration begins and the impact of longer waits are unknown (Lynch et al., 2008). Research specifically examining the impact of waiting for CP treatment on patient outcomes is limited. Instead, research has typically focussed on treatment efficacy and different populations (e.g. surgical waitlists or community samples). It is also unclear whether participants were informed of wait-times when referred for treatment. Waits for CP services are difficult to predict because waitlists are continually updated based on clinical information and triage demands; thus, many patients lack definite timelines. This uncertainty has been linked with increased distress, impaired concentration and reduced life-engagement (Fogarty and Cronin, 2008). Lengthy indefinite waitlists are almost universally condemned, but exactly when *long* becomes *too long* is unclear.

Long-term data are needed because waits for public multidisciplinary CP treatment often exceeds 6 months. This project prospectively examined the long-term psychological adjustment and health-care utilisation (HCU) of individuals waitlisted for a public outpatient CP service.

Materials and method

Participants

Participants were adults referred to the Pain Management Unit (PMU) of Royal Adelaide Hospital (November 2011–2013), which – as one of two public multidisciplinary CP services in South Australia – assesses, treats and manages adults with CP across a large Australian region. Referrals are triaged and prioritised based on clinical need (see Supplementary

Table A). Individuals triaged for an urgent/semi-urgent (<6 months) appointment (triage codes 1 and 2) were excluded because we examined the impact of waiting >6 months. Participants needed basic English fluency (determined from referral information) to provide informed consent and complete the questionnaire. All eligible new referrals were invited to participate (see Burke et al. (2016) for further details).

Measures

Newly referred patients routinely complete a screening battery (Patient Screening Questionnaire (PSQ)) before being placed on the PMU waitlist; this measure was used to minimise participant burden. The PSQ collects demographic, health and pain-related information, HCU and medication use, and includes measures of pain-related interference and pain severity (Brief Pain Inventory (BPI), Cleeland and Ryan, 1994) and psychological distress (Kessler Distress Scale (K-10), Kessler et al., 2003). In addition, the Chronic Pain Acceptance Questionnaire (CPAQ; McCracken et al., 2004) measured pain willingness (willingness to experience pain in order to perform activities), activity engagement (engagement with meaningful activity) and overall pain acceptance. Finally, the World Health Organization QOL-Brief Scale (WHOQOL-BREF; Murphy et al., 2000) assessed QOL using four subscales (physical health, psychological health, social relationships and environment), but the ‘overall’ and ‘health-related’ QOL scores were ultimately excluded due to their poor psychometric properties.

Changes in pain-related HCU and medication were also examined in terms of (1) HCU frequency (mean number of health-related appointments in the previous 3 months), treatment types (medical, psychological, alternative and physical) and uptake of new treatments since the last survey and (2) amount of relief that participants reported receiving from their pain medication(s) and changes in medication dose/strength since the previous survey.

Finally, the Social Desirability Response Set Scale (SDRS-5; Hays et al., 1989) was included

to gauge whether participants were responding (intentionally or not) in socially desirable ways in order to expedite appointment allocation (see Burke et al., 2016 for more information).

Procedure

Following triage (T1), all eligible individuals were mailed the PSQ (standard clinic practise) and an invitation to participate (information sheet, consent form, research questionnaires and pre-paid envelope). They were advised that the study would explore the impact of waiting for services on individuals with CP and that their wait-time/treatment would not be affected by their research (non-) participation. Participants were followed up 2 months after referral (T2) – coinciding with an optional pre-clinic education session being trialled at the time (see Burke et al., 2016) – and then at 6-month intervals until their first PMU appointment (T3–T7: 6 months–2.5 years). Reminder packs were sent to participants who did not return questionnaires within 1 month. Participants were deemed to have opted out of the study if they did not return two successive mail-outs.

PMU appointments were offered on the basis of chronological referral and clinical need/urgency (assessment with doctor/doctor and allied health/multidisciplinary panel) but were modified if updated information was received indicating greater urgency. Thus, individuals were not advised of an anticipated wait-time at the point of referral. Study follow-ups ceased when participants received their initial PMU appointment (no longer waitlisted), accounting for some attrition from T1 to T7 (see Supplementary Figure A). Those who declined/withdrew study participation remained on the PMU waitlist and received equivalent waitlist management. Staff members who scheduled PMU appointments were blinded to study participation status.

CP and waiting for treatment are both associated with distress (Burke et al., 2015); therefore, the mail-out included information about how to access external psychological assistance (services and telephone numbers) while waiting

for their PMU appointment. The study was approved by the Research Ethics Committees of Royal Adelaide Hospital (Protocol #111004) and University of Adelaide.

Analyses

Study power was estimated using G*Power and deemed satisfactory (effect size $f=0.25$, $\alpha_{\text{error probability}}=0.05$, power=0.95; Faul et al., 2007). The potential impact of sex, age, marital status, country of birth, primary pain location and pain duration on outcome was assessed to determine whether they should be entered as covariates into the mixed-model analyses. Backwards elimination indicated that sex was the only variable to contribute to outcomes and thus, was the only covariate.

Next, repeated measures mixed-model analyses examined the impact of time (T1–T7) on pain impact (BPI: pain-related interference and pain severity), psychological distress (K-10), pain acceptance (CPAQ), QOL (WHOQOL-BREF), HCU (frequency, type and new treatments) and medication usage (pain relief and change in dose/strength). Significant effects were explored via post hoc *t*-tests with Sidak corrections. Cohen's *d* was calculated to assess the standardised difference between means across study time-points and interpreted using Cohen's (1988) guidelines ($d=0.2$, 0.5 and 0.8, indicating small, medium and large effects, respectively). Finally, ordinal logistic generalised estimating equation (GEE) model analyses examined the impact of time (T1–T7) on reported uptake of new treatments and changes in medication use (Homish et al., 2010).

Results

Sample characteristics

In total, 678 referrals were screened for eligibility and 664 were invited to participate (see Supplementary Figure A). Almost half did not respond (31%, $n=209$) or declined research participation (17%, $n=116$). Independent samples *t*-test and χ^2 statistics confirmed that there were

no significant differences between the age or sex of those who agreed to participate ($M_{\text{age}}=44.1$, $SD_{\text{age}}=10.4$; $N_{\text{females}}=197$ (58%)) and those who declined ($M_{\text{age}}=44.1$, $SD_{\text{age}}=11.2$; $N_{\text{females}}=71$ (61%); age: $t(453)=0.01$, $p=0.99$; sex: $\chi^2(1, N=466)=0.34$, $p=0.56$), indicating demographic comparability.

The final sample comprised 339 adults aged 17–83 years, mostly referred by general medical practitioners. Participants were predominantly female, unemployed, un-partnered and Australian-born (see Table 1). Pain was usually long-standing (56% had pain for >5 years), experienced in multiple sites and of unknown aetiology. Consistent with referral to public clinics, most had no private health insurance and were not involved in pain-related litigation, effectively precluding access to private services. Few had previously attended a pain clinic.

Participants experienced significant pain-related interference in their ability to perform daily activities and significant psychological distress at intake (T1), with 70 per cent ($n=238$) reporting 'moderate' or 'severe' (≥ 25) distress (K-10). QOL (WHOQOL-BREF) was also markedly below Australian norms (Murphy et al., 2000) and there was a high degree of HCU, with an average of 10 health-related appointments/person every 3 months and many ($n=120$, 35%) having ≥ 1 weekly appointment(s) (see Table 2).

Throughout the study, 54 people were removed from the waitlist without appointment (34 were self-removed/declined to wait/sought services elsewhere, 17 were cancelled by clinic/duplicate referral/redirection to more appropriate service and 3 of them died). Appointment wait-times varied because referrals were triaged on the basis of clinical information; the mean wait-time was 21 months ($n=273$, standard deviation (SD)=10.9, range=2–53 months).

Sample attrition

Sample attrition was of concern (see Supplementary Figure A), with individuals exiting the study because they either received a PMU appointment (no longer waiting), opted

out (declined to complete further measures while waiting) or cancelled their referral (removed themselves from the waitlist). Regression analyses were conducted to determine whether the four groups (still in/received appointment/opted-out/cancelled appointment) differed in terms of key demographic/outcome variables as a function of overall study participation time. These analyses confirmed that the groups were comparable across age ($R^2=0.01$, $F(2, 452)=1.67$, $p=0.19$), sex ($R^2=0.001$, $F(2, 452)=2.41$, $p=0.79$), pain-related interference ($R^2=0.01$, $F(2, 446)=1.92$, $p=0.15$), pain severity ($R^2=0.004$, $F(2, 444)=0.79$, $p=0.46$) and psychological distress ($R^2=0.01$, $F(2, 443)=2.31$, $p=0.10$).

Next, we compared the key outcomes at each follow-up (T2–T6) of groups defined by their participation status at the following time point (T3–T7) to determine whether those who continued in the study differed from those who did not (received appointment/opted-out/cancelled appointment). All group differences were non-significant at each time point with one exception: individuals who received a PMU appointment at T3 reported more psychological distress at T2 ($M=33.7$, $SD=8.3$) than those who opted out of the study ($M=25.4$, $SD=7.6$) at T3 ($F(3, 191)=30.94$, $p=0.028$; see Supplementary Table B). This aligns with PMU triage practices (those reporting greater psychological distress received earlier appointments). Overall, these analyses suggest that those who continued were comparable to those who opted out.

Finally, levels of socially desirable responding were compared at each follow-up to evaluate any variance in response validity. The tendency towards socially desirable responding did not differ over time or between sexes (time: $F(6, 540)=1.36$, $p=0.230$; sex: $F(1, 675)=0.103$, $p=0.310$), nor was there an interaction effect (time \times sex: $F(6, 540)=0.61$, $p=0.720$). Scores fell well below normative standards across all time points (see Supplementary Table B), suggesting that participants were not consciously or unconsciously distorting their responses.

Table 1. Summary demographic information of the sample.

General information	Females N (%)	Males N (%)	Full sample N (%)	Pain/health information	Females N (%)	Males N (%)	Full sample N (%)
No. of participants	197 (58)	142 (42)	339	Pain in more than one site	189 (96)	129 (91)	318 (93.5)
Age (years; mean, SD)	44.8 (11.0)	43.2 (9.5)	44.1 (10.4)	Yes	7 (3.5)	13 (9)	20 (6)
Relationship status				No	1 (0.5)	–	1 (0.5)
Single	77 (39)	70 (49)	147 (43)	Not reported			
Married/de facto	86 (43.5)	43 (30)	129 (38)	Pain duration			
Divorced/separated	29 (14.5)	15 (11)	44 (13)	Greater than 10 years	63 (32)	54 (38)	117 (35)
Widowed	1 (0.5)	–	1 (0.5)	5–10 years	43 (21.5)	30 (21)	73 (21)
Not reported	5 (2.5)	14 (10)	19 (5.5)	3–5 years	27 (14)	29 (20)	56 (17)
Employment status				12 months–3 years	45 (23)	18 (12.5)	63 (18.5)
Unemployed (due to pain)	62 (31)	62 (43.5)	124 (36.5)	6–12 months	16 (8)	4 (3)	20 (6)
Unemployed (other)	23 (12)	34 (24)	57 (17)	Less than 6 months	2 (1)	2 (1.5)	4 (1)
Part-time	25 (13)	8 (5)	33 (10)	Not reported	1 (0.5)	5 (4)	6 (1.5)
Full-time	18 (9)	15 (10)	33 (10)	Primary pain site			
Home duties	28 (14.5)	4 (3)	32 (9)	Total/almost total body	32 (16)	14 (10)	46 (14)
Retired	12 (6)	4 (3)	16 (5)	Lower back/buttocks	69 (35)	65 (45)	134 (40)
Disability pension	6 (3)	5 (4)	11 (3)	Legs/feet	25 (13)	14 (10)	39 (12)
Student	9 (4.5)	2 (1.5)	11 (3)	Neck/head/face/mouth	17 (8.5)	16 (11)	33 (9.5)
Volunteer work	3 (1.5)	1 (1)	4 (1)	Upper back/shoulders	18 (9)	5 (1)	23 (7)
Retraining	–	3 (2)	3 (1)	Hip/abdominal	19 (9.5)	9 (7)	28 (7.5)
Other	2 (1)	–	2 (0.5)	Arms/hands	5 (3)	2 (1.5)	7 (2)

(Continued)

Table 1. (Continued)

General information	Females N (%)	Males N (%)	Full sample N (%)	Pain/health information	Females N (%)	Males N (%)	Full sample N (%)
Casual	1 (0.5)	–	1 (0.5)	Anal/genital/pelvic/groin	4 (2)	6 (4.5)	10 (2.5)
Not reported	8 (4)	4 (3)	12 (3.5)	Not reported	8 (4)	11 (7)	19 (5.5)
Location of birth				Reason for pain onset			
Australia	151 (77)	100 (70)	251 (74)	No clear reason	51 (26)	33 (23)	84 (25)
Europe	27 (14)	22 (15)	49 (14)	Illness related	45 (22.5)	14 (10)	59 (17.5)
Asia	9 (5)	8 (6)	17 (5)	Work/home accident	33 (17)	31 (22)	64 (19)
Oceania	3 (1)	3 (2)	6 (1.5)	Motor vehicle accident	17 (9)	18 (12.5)	35 (10)
Africa	1 (0.5)	4 (3)	5 (1.5)	Post-surgical	7 (3.5)	7 (5)	14 (4)
South America	1 (0.5)	–	1 (0.5)	Other	38 (19)	35 (24.5)	73 (21.5)
North America	–	1 (1)	1 (0.5)	Not reported	6 (3)	4 (3)	10 (3)
Not reported	5 (2)	4 (3)	9 (3)	Seen a pain clinic before			
Private health insurance				No	168 (85)	114 (80)	282 (83)
No	142 (72)	113 (80)	255 (75)	Yes, multidisciplinary clinic	20 (10)	21 (15)	41 (12)
Yes	50 (25)	23 (16)	73 (22)	Pain doctor only	4 (2)	3 (2)	7 (2)
Not reported	5 (3)	6 (4)	11 (3)	Not reported	5 (3)	4 (3)	9 (3)
				Pain-related compensation			
				No	183 (93)	132 (93)	315 (93)
				Yes	8 (4)	6 (4)	14 (4)
				Not reported	6 (3)	4 (3)	8 (3)

SD: standard deviation.

Table 2. Estimated means for outcome domains, by time and sex (first 12 months of waiting).

Outcome domain	T1 (intake)			T2 (2 months)			T3 (6 months)			T4 (1 year)				
	N	Female	Male	Total	Female	Male	Total	Female	Male	Total	Female	Male	Total	
		Female	Male		Female	Male		Female	Male		Female	Male		
N	197	142	339	117	78	195	84	67	151	54	37	91	197	142
Pain impact (BPI)														
Pain-related interference	7.4 (0.1)	7.4 (0.1)	7.4 (0.1)	7.5 (0.2)	7.1 (0.2)	7.3 (0.1)	7.3 (0.1)	7.3 (0.2)	7.2 (0.2)	7.3 (0.2)	7.2 (0.2)	6.5 (0.3)	6.8 (0.2)	7.2 (1.9)
Pain severity	7.1 (0.1)	6.7 (0.2)	6.9 (0.1)	7.2 (0.2)	6.7 (0.2)	7.0 (0.1)	7.1 (0.2)	6.5 (0.2)	6.8 (0.2)	6.8 (0.2)	7.1 (0.3)	6.4 (0.3)	6.7 (0.2)	7.1 (1.9)
Psychological distress (K-10)	29.9 (0.6)	30.3 (0.7)	30.1 (0.5)	31.0 (0.8)	30.3 (0.9)	30.7 (0.6)	30.2 (0.9)	32.1 (1.0)	31.1 (0.7)	31.1 (0.7)	30.4 (1.2)	31.3 (1.4)	30.8 (0.9)	29.7 (9.2)
Pain acceptance (CPAQ)														
Pain willingness	16.0 (0.6)	13.7 (0.7)	14.9 (0.5)	19.1 (0.7)	17.7 (0.9)	18.4 (0.6)	19.6 (0.9)	16.1 (1.0)	17.9 (0.7)	17.9 (0.7)	19.8 (1.0)	16.8 (1.2)	18.3 (0.8)	17.8 (8.1)
Activity engagement	23.9 (0.9)	22.5 (1.0)	23.2 (0.7)	24.7 (1.0)	24.0 (1.3)	24.3 (0.8)	24.2 (1.2)	23.9 (1.4)	24.1 (0.9)	24.4 (1.4)	21.9 (1.6)	23.1 (1.0)	24.1 (11.8)	23.5 (12.8)
Overall acceptance	39.9 (1.2)	36.3 (1.4)	38.1 (0.9)	44.1 (1.4)	41.8 (1.7)	43.0 (1.1)	43.8 (1.6)	40.2 (1.8)	42.0 (1.2)	44.1 (1.8)	39.0 (2.1)	41.5 (1.4)	41.9 (16.3)	39.3 (17.4)
Quality of life (WHOQOL-BREF)														
Physical health	14.1 (0.3)	14.9 (0.4)	14.5 (0.2)	14.7 (0.4)	15.8 (0.4)	15.2 (0.3)	14.7 (0.4)	15.5 (0.5)	15.1 (0.3)	15.1 (0.3)	14.8 (0.5)	15.3 (0.6)	15.1 (0.4)	14.5 (4.0)
Psychological health	15.7 (0.4)	15.7 (0.4)	15.7 (0.3)	15.8 (0.4)	15.9 (0.5)	15.8 (0.3)	15.7 (0.5)	15.3 (0.5)	15.5 (0.3)	15.2 (0.5)	14.6 (0.6)	14.9 (0.4)	15.7 (5.0)	15.9 (5.2)
Social relationships	8.3 (0.3)	7.4 (0.3)	7.8 (0.2)	7.9 (0.4)	7.3 (0.4)	7.6 (0.3)	9.2 (0.4)	7.2 (0.5)	8.2 (0.3)	7.9 (0.5)	7.2 (0.7)	7.6 (0.4)	8.4 (4.9)	7.4 (2.6)
Environment	23.8 (0.4)	23.0 (0.5)	23.4 (0.3)	24.1 (0.5)	23.0 (0.6)	23.5 (0.4)	23.8 (0.5)	22.8 (0.6)	23.3 (0.4)	24.6 (0.6)	22.8 (0.7)	23.7 (0.5)	24.3 (5.8)	23.0 (5.4)
Health-care utilisation														
Frequency	10.6 (0.5)	9.9 (0.6)	10.3 (0.4)	9.4 (0.5)	8.8 (0.6)	9.1 (0.4)	8.6 (0.6)	8.4 (0.7)	8.5 (0.5)	8.9 (0.8)	8.6 (0.8)	8.6 (0.9)	8.8 (0.6)	8.9 (6.4)
Treatment types														
Medical	1.2 (0.1)	1.3 (0.1)	1.2 (0.1)	0.8 (0.1)	0.8 (0.1)	0.8 (0.1)	1.1 (0.1)	1.3 (0.1)	1.2 (0.1)	1.2 (0.1)	1.2 (0.1)	1.1 (0.1)	1.1 (0.1)	1.1 (1.2)
Psychological	1.3 (0.1)	1.1 (0.1)	1.2 (0.1)	0.9 (0.1)	0.8 (0.1)	0.9 (0.1)	1.6 (0.1)	1.3 (0.1)	1.4 (0.1)	1.4 (0.1)	1.4 (0.1)	1.2 (0.2)	1.3 (0.1)	1.2 (1.1)
Alternative	0.4 (0.0)	0.3 (0.1)	0.4 (0.0)	0.3 (0.1)	0.3 (0.1)	0.3 (0.0)	0.5 (0.1)	0.4 (0.1)	0.4 (0.0)	0.5 (0.1)	0.3 (0.1)	0.4 (0.1)	0.4 (0.6)	0.3 (0.6)
Physical	1.3 (0.1)	1.3 (0.1)	1.3 (0.1)	1.1 (0.1)	1.3 (0.1)	1.2 (0.1)	2.3 (0.1)	2.1 (0.1)	2.2 (0.1)	2.2 (0.1)	2.3 (0.1)	1.8 (0.2)	2.0 (0.1)	1.5 (1.2)
Tried new treatment (N (%))	-	-	-	54 (46)	27 (35)	81 (42)	32 (38)	22 (33)	54 (36)	54 (36)	12 (22)	6 (16)	18 (20)	-
Number new tried	-	-	-	2.4 (0.2)	2.7 (0.3)	2.6 (0.2)	2.3 (0.2)	2.8 (0.3)	2.6 (0.2)	2.6 (0.2)	1.3 (0.4)	2.0 (0.6)	1.7 (0.4)	2.2 (1.4)
Medication usage														
Per cent relief received	41.9 (1.8)	39.0 (2.1)	40.4 (1.4)	42.2 (2.2)	39.4 (2.6)	40.8 (1.7)	43.6 (2.3)	39.8 (2.7)	41.7 (1.8)	42.5 (2.9)	35.4 (3.6)	39.0 (2.3)	42.2 (23.5)	38.3 (24.3)
Change since last (N, %)														
Taking stronger/more	-	-	-	49 (42)	21 (27)	70 (36)	34 (40)	21 (31)	55 (36)	55 (36)	27 (50)	14 (38)	41 (45)	-
Nil, taking same	-	-	-	45 (38)	43 (55)	88 (45)	37 (44)	30 (45)	67 (44)	67 (44)	22 (41)	13 (35)	35 (39)	-
Taking weaker/less	-	-	-	16 (14)	9 (12)	25 (13)	6 (7)	8 (12)	14 (9)	14 (9)	3 (5)	7 (19)	10 (11)	-
Ceased all medication	-	-	-	2 (2)	4 (5)	6 (3)	4 (5)	3 (4)	7 (5)	7 (5)	1 (2)	1 (3)	2 (2)	-
Not reported	-	-	-	5 (4)	1 (1)	6 (3)	3 (4)	5 (8)	8 (6)	8 (6)	1 (2)	2 (5)	3 (3)	-

N: number of participants; BPI: Brief Pain Inventory; K-10: Kessler Distress Scale; CPAQ: Chronic Pain Acceptance Questionnaire; WHOQOL-BREF: World Health Organization Quality of Life-Brief Scale. Scores represent estimated mean (standard error) unless indicated otherwise to be N (%).

Although the preceding analyses indicated that continuing participants were not a biased sample, ongoing attrition (due to participants receiving PMU appointments or opting-out of the study) meant that the T5–T7 samples were small, reducing statistical power and certainty in the conclusion drawn from these data. Hence, the data for the first 12 months (T1–T4), when the samples were large, were examined first. In the absence of research examining very long waits, we also examined T1–T7 in order to determine whether there were any noteworthy preliminary findings. Given the reduced statistical power of these T1–T7 analyses, there is a risk that some changes/findings may go undetected; consequently, they provide a conservative estimate of the impact of long wait-times.

Pain impact (BPI)

First year (T1–T4). Pain-related interference changed significantly over the first year of waiting (time: $F(3, 135)=3.70, p=0.013$), with post hoc analyses indicating that participants reported steadily decreasing amounts of pain-related interference, such that T4 scores were significantly less than those at intake (T1; $M_{\text{difference}}=0.55, p=0.008, d=0.18$). Sex differences were not evident ($F(1, 252)=2.61, p=0.108$). Pain severity did not change over time ($F(3, 134)=0.70, p=0.554$), but there was a small sex difference ($F(1, 249)=5.40, p=0.021$), with females reporting more severe pain (see Tables 2 and 3). No interaction effects were found ($F(3, 135)=2.33, p=0.077$ and $F(3, 134)=0.24, p=0.871$, respectively).

Long-term trends (T1–T7). Although males reported decreasing pain-related interference in the long term, females experienced relatively stable levels until T6, followed by a significant increase, with a marked sex difference at T7 (interaction: $F(6, 24)=10.98, p<0.001$). Notably, the T3–T6 findings equated to medium-to-large and significant effects, with the three-point difference in BPI scores at T7 being clinically meaningful (see Supplementary Tables C and D). The sex differences in pain severity were

maintained in the long term ($F(1, 141)=4.77, p=0.031$), but time-related changes also became apparent ($F(6, 30)=3.20, p=0.015$); pain severity was higher at T7 than all other times, except T2. The T5 and T6 findings equated to medium and large effects, respectively (see Supplementary Tables C and E).

Psychological distress (K-10)

First year (T1–T4). Psychological distress did not differ across time ($F(3, 137)=1.18, p=0.319$) or sex ($F(1, 264)=0.43, p=0.514$), nor was the interaction significant ($F(3, 137)=1.75, p=0.159$).

Long-term trends (T1–T7). Despite comparable early levels of distress (T1–T2), females reported less distress than males in the medium term (T3–T4) and more distress in the long term (T5–T7; interaction: $F(6, 34)=41.27, p<0.001$; see Supplementary Tables C and D). Those differences were highest at T4 and T6 (large effects). Interestingly, these findings largely reflected fluctuating levels of distress in males; females reported a steady increase in distress over time – most noticeably from T4 on – while males reported oscillating levels; peaking at T6 and markedly reducing by T7. Notably, at T7, the distress reported by males ($M=18.8, SD=7.7$) was lower than intake, the only time when scores were within the healthy range ('likely to be well').

Pain acceptance (CPAQ)

First year (T1–T4). Pain willingness was impacted by both time ($F(3, 136)=16.46, p<0.001$) and sex ($F(1, 243)=7.87, p=0.005$), with post hoc analyses indicating that the levels of pain willingness at T2–T4 were all significantly greater than those at intake (T1; T2: $M_{\text{difference}}=3.53, p<0.0001, d=0.36$; T3: $M_{\text{difference}}=2.96, p<0.001, d=0.24$; T4: $M_{\text{difference}}=3.50, p<0.001, d=0.26$), and overall, women reported more willingness than men ($M_{\text{difference}}=32.52, p=0.005, d=0.16$; see Tables 2 and 3). Activity engagement, however, did not differ across either domain (time: $F(3, 137)=1.29,$

Table 3. Estimates of significant main effects (time and sex) on outcome domains.

Outcome domain	Time vs T4	Time			Sex				
		Estimate	95% CI		<i>d</i>	Estimate	95% CI		<i>d</i>
			Lower	Upper			Lower	Upper	
Pain impact (BPI)									
Pain severity	1	0.03	-0.46	0.51	-	-0.68*	-1.48	0.11	0.10
	2	0.15	-0.31	0.61	-				
	3	0.02	-0.48	0.52	-				
Pain acceptance (CPAQ)									
Pain willingness	1	-3.79***	-5.75	-1.84	0.22	-2.89	-5.90	0.12	-
	2	-0.69	-2.60	1.21	-				
	3	-0.26	-2.16	1.64	-				
Overall pain acceptance	1	-4.03*	-7.54	-0.53	0.13	-5.00	-10.49	0.48	-
	2	0.28	-2.99	3.52	-				
	3	-0.05	-2.96	2.85	-				
Quality of life (WHOQOL-BREF)									
Social relationships	1	0.37	-0.24	0.97	-	-1.02*	-2.01	-0.03	0.11
	2	0.12	-0.47	0.72	-				
	3	1.27	-0.29	2.84	-				
Health-care utilisation									
Frequency	1	1.66*	0.05	3.27	0.11	-0.22	-2.61	2.17	-
	2	0.48	-1.07	2.02	-				
	3	-0.43	-1.79	0.93	-				
Treatment types									
Medical	1	0.01	-0.24	0.26	-	0.06	-0.36	0.48	-
	2	-0.39*	-0.71	-0.08	0.18				
	3	-0.03	-0.28	0.22	-				
Psychological	1	-0.18	-0.47	0.11	-	-0.26	-0.71	0.19	-
	2	-0.54***	-0.84	-0.24	0.26				
	3	0.17	-0.12	0.46	-				
Alternative	1	-0.09	-0.23	0.06	-	-0.17	-0.40	0.06	-
	2	-0.16*	-0.31	-0.01	0.15				
	3	0.02	-0.12	0.17	-				
Physical	1	-0.95***	-1.26	-0.63	0.33	-0.49	-1.01	0.04	-
	2	-1.19***	-1.53	-0.85	0.38				
	3	-0.02	-0.36	0.33	-				
Number of new treatments	1	-	-	-	-	0.75	-0.08	1.58	-
	2	1.23***	0.60	1.86	0.44				
	3	1.02**	0.37	1.67	0.35				

BPI: Brief Pain Inventory; CPAQ: Chronic Pain Acceptance Questionnaire; WHOQOL-BREF: World Health Organization Quality of Life-Brief Scale; CI: confidence interval.

Scores represent *M* (SD) unless indicated otherwise to be *N* (%).

****p* < 0.001, ***p* < 0.01, **p* < 0.05.

p = 0.281; sex: $F(1, 272) = 0.66, p = 0.417$). Finally, although overall pain acceptance was unaffected by sex ($F(1, 273) = 3.88, p = 0.050$), it was impacted

by time ($F(3, 131) = 10.10, p < 0.001$), with acceptance increasing significantly at T2 and T3, compared to intake (T1; T2: $M_{\text{difference}} = 4.90, p < 0.001$,

$d=0.30$; T3: $M_{\text{difference}}=3.94$, $p=0.001$, $d=0.21$), before decreasing, albeit not significantly, by T4 (12 months; see Tables 2 and 3). There were no significant time \times sex interactions for pain acceptance (pain willingness: $F(3, 136)=0.62$, $p=0.604$; activity engagement: $F(3, 137)=0.33$, $p=0.806$; overall pain acceptance: $F(3, 131)=0.39$, $p=0.760$).

Long-term trends (T1–T7). Over time, *pain willingness* increased for women until T6, after which it returned to T1 levels. Men reported a different pattern, showing greater variability over time, but improving at T7 compared to intake (T1; interaction: $F(6, 29)=9.54$, $p<0.001$; see Supplementary Tables C and D). T6 was particularly notable because it equated to a medium effect. Although *activity engagement* was stable during the first year (T4), a significant time \times sex interaction effect was evident at T7 ($F(6, 33)=40.21$, $p<0.001$), whereas females reported reasonably stable activity levels up to T4, followed by a gradual reduction, males reported oscillating levels (lowest at T4 and highest at T6). These sex differences represented small to medium effects (see Supplementary Tables C and D). The findings for *overall pain acceptance* confirmed those in the first year, with acceptance continuing to increase over time (time: $F(6, 27)=5.11$, $p=0.001$).

QOL (WHOQOL-BREF)

First year (T1–T4). *Physical health* changed over time ($F(3, 139)=3.09$, $p=0.029$), with post hoc analyses indicating that the physical aspects of QOL increased significantly at T2 compared to T1 ($M_{\text{difference}}=0.73$, $p=0.019$, $d=0.17$) but was then stable. *Social relationships* showed a small sex difference ($F(1, 252)=9.58$, $p=0.002$), with females reporting higher social QOL (see Tables 2 and 3). All other domains were unaffected by time (psychological health: $F(3, 133)=1.52$, $p=0.213$; social relationships: $F(3, 157)=1.33$, $p=0.268$; environment: $F(3, 134)=0.34$, $p=0.794$), sex (physical health: $F(1, 266)=2.84$, $p=0.093$; psychological

health: $F(1, 303)=0.11$, $p=0.737$; environment: $F(1, 288)=3.87$, $p=0.050$) or an interaction between the two (physical health: $F(3, 139)=0.23$, $p=0.877$; psychological health: $F(3, 133)=0.29$, $p=0.834$; social relationships: $F(3, 157)=0.38$, $p=0.767$; environment: $F(3, 134)=0.44$, $p=0.727$).

Long-term trends (T1–T7). Although *physical health* changed over time ($F(6, 532)=2.25$, $p=0.038$), model estimates and post hoc analyses were non-significant, suggesting that any changes were minimal (see Supplementary Tables C and E). Although there was a small main effect of sex for *social relationships* at T4, this was not significant by T7 ($F(1, 686)=3.27$, $p=0.071$). In contrast, despite scores being comparable throughout the first year, women reported significantly higher *environmental* aspects of QOL than males in the long term ($F(1, 614)=3.90$, $p=0.049$; see Supplementary Tables C and E).

HCU

First year (T1–T4). *Frequency* of HCU changed significantly during the first year (time: $F(3, 137)=5.42$, $p=0.001$), with post hoc analyses indicating that participants attended fewer health-care appointments at T2 and T3 than they did at T1 (T2: $M_{\text{difference}}=1.17$, $p=0.010$, $d=0.18$; T3: $M_{\text{difference}}=1.81$, $p=0.003$, $d=0.20$; see Tables 2 and 3). There were no sex ($F(1, 241)=0.37$, $p=0.546$) or interaction ($F(3, 137)=0.12$, $p=0.948$) effects.

For *treatment type*, there was a significant time \times sex interaction for the use of physical treatments in the first 12 months ($F(3, 131)=2.85$, $p=0.040$); although both reported comparable use at T1, females decreased their use at T2, but increased at T3–T4. Males were stable across T1–T2 and then increased their use at T3–T4, resulting in a marked sex difference in the use of physical treatments at T2 (estimate=0.69, $p=0.014$; $d=0.19$). No interaction effects were found for any other treatment type (medical: $F(3, 136)=0.06$, $p=0.983$; psychological: $F(3, 131)=1.00$, $p=0.396$;

alternative: $F(3, 134)=0.57, p=0.633$), and there were no main effects for sex (medical: $F(1, 251)=0.46, p=0.496$; psychological: $F(1, 218)=3.04, p=0.083$; alternative: $F(1, 263)=3.26, p=0.072$). With the exception of alternative treatments, all were impacted by time (medical: $F(3, 136)=8.86, p<0.001$; psychological: $F(3, 131)=17.00, p<0.001$; alternative: $F(3, 134)=2.25, p=0.086$; see Tables 2 and 3). Specifically, fewer medical treatments were used at T2 than at T4 (see Tables 2 and 3), with post hoc analyses indicating that T2 levels were lower than all other time points (T1: $M_{\text{difference}}=0.42, p<0.001; d=0.28$; T3: $M_{\text{difference}}=0.40, p=0.001; d=0.28$; T4: $M_{\text{difference}}=0.40, p=0.011; d=0.23$). Similarly, psychological treatments were used least at T2 (T1: $M_{\text{difference}}=0.30, p<0.001; d=0.30$; T3: $M_{\text{difference}}=0.56, p<0.001; d=0.49$; T4: $M_{\text{difference}}=0.43, p=0.003; d=0.28$) and most at T3 ($M_{\text{difference}}=0.25, p=0.014; d=0.17$), suggesting a spike in uptake while waiting. Overall, it appears that the use of treatments decreased immediately following referral but increased over time while waiting for an appointment, in several instances equating to meaningful changes (medium effects).

GEE modelling of the number of *new treatments* tried during the first 12 months indicated that it was related to time ($\chi^2(2, N=221)=12.82, p=0.002$), with individuals being more than twice as likely to try a new treatment at T2 (odds ratio (OR)=2.85; 95% confidence interval (CI)=1.61, 5.05; $p<0.001$) and T3 (OR=2.20; 95% CI=1.24, 3.91; $p=0.007$) than at T4. The sex ($\chi^2(1, N=221)=2.30, p=0.129$) and time \times sex interaction ($\chi^2(2, N=221)=0.54, p=0.764$) effects were both non-significant. For those who tried new treatment(s), mixed-model analyses revealed that the number varied over time ($F(2, 43)=8.30, p=0.001$) such that individuals tried more new treatments at T2 and T3 than at T4 (medium and small-to-medium effects; see Tables 2 and 3). There were also significant sex differences ($F(1, 56)=6.17, p=0.016$); males tried more new treatments than females ($M_{\text{difference}}=0.56, p=0.016; d=0.28$). The

interaction effect was not significant ($F(2, 43)=0.47, p=0.629$).

Long-term trends (T1–T7). As per the first year, *HCU frequency* continued to decrease over time ($F(6, 10)=17.62, p<0.001$), with fewer health-related appointments attended at T5 and T6 than at T7. T6 was particularly notable (large effect), with four fewer appointments every 3 months than at T7 (see Supplementary Tables C and E). For *treatment type*, there was again a significant time \times sex interaction for *physical* treatments ($F(6, 560)=2.47, p=0.023$), but model estimates and post hoc analyses indicated that any long-term differences were small ($p<0.05$). However, significantly fewer physical treatments were used at both T1 and T2, than at T7 (time: $F(6, 560)=2.47, p=0.023$). Whereas use of *alternative* treatments was reasonably stable during the first year (T1–T4), it was less so in the long term (time: $F(6, 539)=3.06, p=0.006$); post hoc analyses indicated that after a small non-significant reduction at T2, the use of alternative treatments increased significantly by T6 (compared to T2; $M_{\text{difference}}=0.31, p=0.035, d=0.23$). The findings for *medical* treatments were consistent with T1–T4, with use being lowest immediately following referral (T2) than at all other times (T1: $M_{\text{difference}}=0.45, p<0.001, d=0.27$; T3: $M_{\text{difference}}=0.42, p=0.001, d=0.30$; T5: $M_{\text{difference}}=0.66, p=0.001, d=0.29$; T6: $M_{\text{difference}}=0.82, p=0.002, d=0.29$; time: $F(6, 549)=7.35, p<0.001$). Thus, treatment use decreased immediately following referral, but frequently increased with continued waiting.

With respect to *new treatments*, the data indicate that new treatment uptake continued to change over time ($\chi^2(5, N=221)=25.27, p<0.001$), with the interaction between time and sex also significant ($\chi^2(1, N=221)=4.17, p=0.041$); over the long term, males were 38 per cent less likely to try new treatment(s) (OR=0.62; 95% CI=0.40, 0.98; $p=0.041$). For those who tried new treatment(s), the T1–T4 sex difference in the number of treatments was lost by T7 ($F(1, 76)=2.81, p=0.098$). Although the effect of time was significant ($F(5, 116)=2.63, p=0.027$), the differences were

small (model estimates and post hoc analyses were both non-significant).

Medication usage

First year (T1–T4). Time ($F(3, 137)=0.47$, $p=0.705$) and sex ($F(1, 228)=2.92$, $p=0.089$) did not impact on the amount of medication-related *relief* and there was no significant interaction ($F(3, 137)=0.24$, $p=0.867$). Changes in *dose/strength* were unaffected by time ($\chi^2(2, N=188)=1.89$, $p=0.390$), but GEE analysis revealed a significant sex difference ($\chi^2(1, N=188)=5.15$, $p=0.023$) such that females were almost twice as likely to report an increase in their medication dose/strength (OR=1.93; 95% CI=0.84, 4.46). Indeed, 36–45 per cent of the sample reported taking more/stronger medication than they had previously at each time point (see Table 2). There was no time \times sex interaction ($\chi^2(2, N=188)=0.38$, $p=0.829$).

Long-term trends (T1–T7). The results concerning medication use were supported in the long term (see Supplementary Tables C and E), with females being more likely to report an increase in the dose/strength of their medication throughout the study.

Discussion

We examined the psychological adjustment and HCU of adults while waiting for up to 2.5 years for a first appointment at an Australian multi-disciplinary CP service. Waits were non-standard because referrals were triaged, based on clinical need. Thus, participants exited the study (received an appointment) at different times which, when combined with those who opted out or whose referral was cancelled, meant that there were fewer people in the long-term follow-ups (T5–T7) than the first year (T1–T4). Although participants who completed the study were comparable to those who did not, smaller samples impact statistical power. Although tentative, our long-term findings (T1–T7) are the only published data exploring the long waits experienced by many people

with CP. Sample attrition is an inherent difficulty in longitudinal studies of clinically triaged waitlists, possibly explaining the dearth of research examining long waits.

The impact of waiting on psychological adjustment and HCU was mixed. Some domains showed deterioration, more commonly for women than men and usually after one or more years ($\geq T4$). Although the 1-year data indicated decreasing *pain interference* and stable *psychological distress*, there may be long-term sex differences. Whereas males reported that pain interfered less in their daily activities after 6 months (T3; improvement), females were stable for the first 2 years, followed by a large increase (T7; decline). Similarly, women reported increasing distress over time (rapidly escalating at 1 year post referral; T4), but men fluctuated with no clear pattern, ending (T7) with below-intake (T1) levels. Similarly, *pain acceptance* was stable (activity engagement) or improved (pain willingness, overall pain acceptance) in the first year, but women deteriorated after 18 months (T5, activity engagement) and 2.5 years (T7, pain willingness), while men oscillated before improving. Although tentative, these long-term findings highlight the changing impact of waiting for treatment over prolonged periods.

The *types of HCU* sought also changed following referral to the PMU; overall HCU decreased immediately following referral (T2, T3), followed by significant increases in the use of psychological therapies at 6 months (T3), alternative therapies at 2 years (T6) and physical therapies at 2.5 years (T7). This contrasted with a reduction in overall *HCU frequency* during the same period (18–24 months), suggesting that health care became more focussed. However, it is unclear whether this decrease occurred because participants did not attend appointments – due to better self-management or reduced hope about benefits – or whether appointments decreased for other reasons (e.g. awaiting PMU appointment). Although the underlying cause(s) are unclear, these changes have implications for health planning.

Perhaps surprisingly, some domains appeared largely unaffected by the long indefinite wait. Despite females reporting more severe pain (consistent with research by Bartley and Fillingim, 2013), pain severity was relatively stable for everyone in the first year, with long-term findings suggesting this continued before spiking at 2.5 years (T7). This is consistent with the reports of stable medication-related pain relief. Nevertheless, over a third of the sample, and twice as many women, reported an increase in the dose/strength of their medication at each survey. This accords with recent research suggesting that women frequently obtain equal or greater access to pharmacotherapy than men, including polypharmacy, which may defy best-practice guidelines (Oliva et al., 2015). Unfortunately, sex differences in medication use at baseline could not be examined because this information was not collected. Males may have entered the waitlist on more optimal doses, whereas females may have started at suboptimal doses, thus requiring increased pain relief. Indeed, the relatively stable ratings of pain severity and medication relief may have been achieved because medication dose/strength increased. Prescribing may also have been influenced by other factors (e.g. greater long-term distress/pain-related interference in females), although dosage changes did not correlate with ratings of pain severity or relief, implying that medication increased without benefit.

QOL was similarly unchanged over time. Males generally reported less satisfaction with their social relationships (first year) and environmental supports/opportunities (long term) than females. Although consistent with literature asserting that males experience significantly greater erosion of QOL when in pain (McNamee and Mendolia, 2014), other aspects of QOL were not similarly impaired. However, given baseline QOL was well below Australian norms, further deterioration may have been unlikely.

In terms of intervention, no critical time or endpoint was highlighted by the data. However, pain acceptance – an important precursor for

change – peaked between 2 and 6 months post referral, suggesting that therapeutic change may be optimised if interventions are delivered during that period. Moreover, although the overall stability in numerous domains in the 6 months (T3) after referral (T1) challenges reports of participant deterioration during that period (Lynch et al., 2008), our preliminary findings suggest that longer waits (>12 months) were associated with increasing distress and decreasing function, especially in women, supporting the view that earlier intervention is important.

In combination, the findings appear conclusive for women, but clear guidelines for men could not be established because their coping was more variable. Although men reported comparatively greater psychological distress than women in the medium term, the reverse occurred in the long term. Moreover, although new treatment uptake was greater for females, women also reported patterns of stable or declining adjustment, suggesting limited benefit. Together, these findings suggest that despite being more variable, men tended to fare comparatively better than women during long and indefinite waits, implying a possible trend towards improved coping with, if not adaptation to, pain.

Study limitations

First, almost half of those who were invited declined participation. Despite being demographically comparable (age and sex) to the study sample, they may have differed in other important ways. For example, non-participation may have reflected greater psychological distress or, conversely, participation may have been motivated by the desire for assistance, with more distressed people enrolling. Nevertheless, the final sample resembled others recruited from public multidisciplinary CP services, across multiple dimensions (e.g. demographics, pain duration, distress, pain-related interference, pain severity; Smith et al., 2016) and was therefore likely to be broadly representative. Second, only self-report data were

collected, with obvious implications for response validity in the current context. The question exploring HCU treatment types asked about *treatments tried (ever)*, rather than *treatments currently using*. Scores on this variable should not decrease, but did, possibly influenced by pain levels at the time of responding, resulting in impaired recall. However, estimates of pain severity were either stable (females) or decreased (males) from intake to 2 years, suggesting this is unlikely. Similarly, participants' responses did not appear to have been influenced by social desirability. It is therefore likely that, in general, responses were reliable (within limitations of self-report) and that some responses to the 'treatment types' question reflected current, not historical, use. Third, although prospective and repeated assessments were completed, there was no comparison group (randomised access to treatment is ethically unacceptable) making it difficult to dismantle any confounding influences of initial triage and other factors (e.g. hospital admissions and advocacy) on the timing of the PMU appointments. Fourth, sample attrition from T1 to T7 reduced the power of our analyses, possibly underestimating the extent of the impact of waiting. Finally, as noted elsewhere (Burke et al., 2016), the follow-up assessments may have had some intrinsic benefit (e.g. participants feeling attended to), potentially ameliorating some impact of waiting to access treatment, particularly indefinite waiting. Similarly, providing participants with information about other sources of psychological assistance (duty-of-care/ethical requirement) may have also had benefits. Qualitative research exploring patient perceptions of waiting would be a useful future addition.

Overall, this study suggests that an indefinite wait of 12 months to 2.5 years to access multi-disciplinary CP treatment may be associated with deterioration across important functions (pain-related interference, psychological distress, pain willingness and activity engagement). Females typically reported the greatest levels of impairment, whereas males fluctuated, often improving by the end of the waiting period.

There were also meaningful changes in a range of variables (e.g. medication usage and treatment uptake) that require further exploration. Importantly, our data suggest that, for women at least, intervening within 6 months of referral to a CP service may help optimise outcomes, a recommendation that needs evaluation.

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Supplementary Material

Supplementary material is available for this article online.

ORCID iD

AnneLJBurke  <https://orcid.org/0000-0002-0109-2950>

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Appendix 3: Supplementary Information for Chapter 5

Appendix 3.1 WIP Interview Questions

Australian Pain Society

Secretariat: c/o DC conferences

PO Box 637 North Sydney, NSW 2069



RMH-Pain Management Services

Clinics: Rehabilitation, Interventional, Aged Care,
Neurosurgical

Cognitive-Behavior-Activity-Therapy Programmes

Clinical Education and Research

Waiting in Pain: a systematic survey of persistent and chronic pain management services in Australia

Site:

Location:

Date of interview:

Data sources/quality:

Do you consent to contact details being collated by APS: Yes/ No

SECTION A: clarification of previous responses from medical director of service

What is the name of your service?

separate name for PMP?

What is the structure of your service?

relevant history, development,

is it associated with an acute pain service,

predominant disciplines,

qa/outcome processes,

pre-assessment questionnaires.

Staffing levels? FTE fractions of each

medical: specialities,
 faculty fellows/trainees,
 allied health,
 nursing,
 pharmacy, admin

CORE Q 1: MDP Centre (multi/inter discipl, meetings, research, teaching)
 MDP Clinic (no research, teaching)
 Pain clinic (no multi/inter discipl)
 Modality orientated clinic (?single pract/modality)

Funding model for your service? Public (state) Private Other (describe)
 relevant %, use of state grants/hospital funding, medicare clinics

CORE Q2: > 90% public
 Commonwealth
 State
 >90% private
 % Mix

Numbers of new referrals per annum?

focus on outpatient,
 chronic referrals;
 number self-referred from acute service

CORE Q3: referrals pa
 new pts seen pa

Sources of referrals (%)? GP Specialists Hospital
 Predominant speciality?

Any explanation of referral base?

Do you define a catchment area?

Description of clinical case mix?

Eg back, neck, headache, opioid issues

Current numbers of clients on waiting list and average time for initial assessment?

how are they managed?;

any contact with referral source or patient eg telephone?

Do you have a process for more urgent referrals, and if so, approx waiting time?

which patients are considered for early assessment?

Do you reject referrals? If so, how many pa?

why: regional catchment area, pathology, drug issues?

where sent?

Additional waiting time for allied health assessments and/or therapy?

if its at initial assessment,

how are they chosen for multidisciplinary review?

process for allied health review?

% total referrals proceeding to AH review

CORE Q4: current wait time for new persistent pain medical assessment in days

What does your service provide? PLUS approximate numbers pa?

Interventional procedures: eg's

Minor: epidural steroids, nerve blocks, RFA

Major: spinal cord stimulation, intrathecal pumps

Other: epiduroscopy, vertebroplasty, IDET

Individual Allied Health therapy:

total referrals?

single vs multiple therapists?

Group Pain Management Programs: eg's

referred for consideration vs total accepted?

% of total clinic referrals?

Inpatient care

how? why?

describe process and therapy provided eg with block for CRPS, rehab for country pts?

Other services: eg specialty clinics

specifically: palliative care/cancer pain; aged pain; headaches; fibromyalgia

how are they triaged, managed?

What external services do you utilise?; relevant numbers pa, linked to your service?

Palliative care

Liaison psychiatry?

Drug and Alcohol?

Complimentary therapy: acupuncture, other?

CORE Q5: number of funded Faculty of Pain Medicine training positions

CORE Q6: current number of research projects clinical (involve pt care)
non-clinical (scientific, QA projects)

Any comments:

development plans; current threats?

CORE Q7: barriers to the pain service development/maintenance/growth (major/mild/minor/none)

- funding
 - referrals
 - lack of trained staff
 - local political support
 - other
-

SECTION B: an investigation of Allied Health based Pain Management Programs

Name of PMP's

development history

range of programs: aged, disease, culture specific

Staffing structure/levels

range, FTE's, etc

Philosophies

modelling

CORE Q8: do you offer a group PMP?

Assessment processes:

referral processes

inclusion/exclusion criteria

Screening questionnaires used

general

disability

psychological

Clinical assessments

objective measures

CORE Q9: outcome measures used (list)

Team meeting(s)

medical supervision

frequency, structure

Program structure:

timetable, number of participants, duration

individual therapy?

motivational interviewing?

physiology education?

exercise group?

hydrotherapy?

family/spouse therapy?

specific skills/specialist therapy?

follow-up/revision program?

CORE Q10: hours of therapy involved in your group PMP

Thoughtput:

numbers assessed pa

numbers accepted pa

numbers completed pa

do you provide long term followup/booster sessions?

Any comments?

published outcomes?

costs/funding?

changes planned?

Appendix 3.2 Published article for Chapter 5



Pain Medicine 2015; 16: 1221–1237
Wiley Periodicals, Inc.

REHABILITATION SECTION

Original Research Article

An Analysis of Multidisciplinary Staffing Levels and Clinical Activity in Australian Tertiary Persistent Pain Services

Anne L. J. Burke, M.Psych,^{*,†,‡}
Linley A. Denson, Ph.D,[†] Jane L. Mathias, Ph.D,[†]
and Malcolm N. Hogg, MBBS^{‡,§}

^{*}Royal Adelaide Hospital, Psychology Department and Pain Management Unit, South Australia;

[†]University of Adelaide, Faculty of Health Sciences, School of Psychology, South Australia; [‡]The Australian Pain Society, New South Wales; [§]The Royal Melbourne Hospital, Department of Anaesthesia and Pain Management, Victoria

Reprint requests to: A. Burke, Pain Management Unit, Level 6 Emergency Block, Royal Adelaide Hospital, North Terrace Adelaide SA 5000, Australia. Tel: +61 8 8222-5403; Fax: +61 8 8222-5904; E-mail: anne.burke@health.sa.gov.au.

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Australia and Medtronic Australasia. The "Waiting in Pain" project, which forms the basis of this analysis, is a systematic investigation of persistent pain services in Australia and was partially funded via a grant from the Australian Pain Society.

Abstract

Objective. To document staffing (medical, nursing, allied health [AH], administrative) in Australian multidisciplinary persistent pain services and relate them to clinical activity levels.

Methods. Of the 68 adult outpatient persistent pain services approached (Dec'08–Jan'10), 45 agreed to participate, received over 100 referrals/year, and met the contemporaneous International Association for the Study of Pain criteria for Level 1 or 2 multidisciplinary services. Structured interviews with Clinical Directors collected quantitative data regarding staff resources (disciplines, amount), services provided, funding models, and activity levels.

Results. Compared with Level 2 clinics, Level 1 centers reported higher annual demand (referrals), clinical activity (patient numbers) and absolute numbers of medical, nursing and administrative staff, but comparable numbers of AH staff. When staffing was assessed against activity levels, medical and nursing resources were consistent across services, but Level 1 clinics had relatively fewer AH and administrative staff. Metropolitan and rural services reported comparable activity levels and discipline-specific staff ratios (except occupational therapy). The mean annual AH staffing for pain management group programs was 0.03 full-time equivalent staff per patient.

Conclusions. Reasonable consistency was demonstrated in the range and mix of most disciplines

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employed, suggesting they represented workable clinical structures. The greater number of medical and nursing staff within Level 1 clinics may indicate a lower multidisciplinary focus, but this needs further exploration. As the first multidisciplinary staffing data for persistent pain clinics, this provides critical information for designing and implementing clinical services. Mapping against clinical outcomes to demonstrate the impact of staffing patterns on safe and efficacious treatment delivery is required.

Key Words. Chronic Pain; Allied Health; Industry; Standards of Care; Persistent Pain; Pain Management; Staff Resources

Introduction

Chronic Pain (CP) costs Australia \$AUD34.3 billion annually [1]. With a point-prevalence of approximately 20% [2], around 3.2 million Australians were living with this condition in 2007. Population aging estimates suggests this figure will reach 5.0 million by 2050 [3]. Despite the high incidence of CP and its associated disease-burden, timely access to appropriate treatment is out of reach for many Australians. Indeed, approximately 80% of people fail to receive an intervention that could improve their functioning and quality of life [3], while those who do receive treatment endure wait-times of 6–18 months or longer [4], during which time their health and well-being often deteriorate [5].

Although the day-to-day care of people with CP occurs in primary care settings, a significant proportion of patient consultation and advice regarding complex case management is provided by tertiary pain units. As outlined by the International Association for the Study of Pain (IASP) [6], these units are multidisciplinary in nature, offering an integrated range of services spanning assessment and treatment of physical and mental health, pharmacotherapy, medical procedures (e.g., nerve blocks), physical therapies, psychosocial interventions (e.g., cognitive behavioral therapy, acceptance, and commitment therapy), group programs and education. Many of these clinical teams are also heavily involved in training and research activities—developing the evidence-base and workforce of the future. Recommendations are available regarding the disciplines that should be represented in these clinics and the types of services that should be provided [3,7], but in the absence of a clear formulae for clinic structure, the exact types and amounts of services offered may vary greatly.

As outlined by Health Workforce Australia, significant innovations are needed in both health care delivery and training, for the Australian health care system to be sustainable [8]. In the midst of major health care reforms [9], the health system is under increasing pressure to enhance patient outcomes by facilitating timely access

to services. The current wait times associated with accessing tertiary pain services demonstrate that the present model of care is inappropriate to address clinical need and/or that units are inadequately staffed.

From a model of care perspective, considerable evidence is available to inform multidisciplinary therapeutic guidelines for CP [10–15] and Australian pain clinicians are actively moving beyond established methods of service delivery to trial novel initiatives, such as preclinic education sessions [16], on-line treatments [17] and enhanced links with primary care [18]. There has also been a strong national endeavor across persistent pain services to actively monitor patient outcomes, to ensure that the treatments provided actually result in improved function and quality of life for patients (refer NSW Department of Health). Despite these initiatives, however, there are currently no empirical data regarding the staffing resources that are required to effectively assess and treat CP in tertiary clinical settings, or the impact of different staffing levels, and patterns on patient outcomes.

Careful resource allocation is crucial to patient care. For inpatients, at least, the impact of nursing and medical staffing levels on service delivery is well-documented. Suboptimal staffing is associated with problems in assessment and treatment delivery, longer admissions, and higher complication rates and medical costs [19,20]. While tertiary pain services employ doctors and nurses, they also employ significant numbers of allied health (AH) professionals; most commonly psychologists, physiotherapists, and occupational therapists [3]. The impact of AH staffing is less well understood, due to factors such as inadequate systems for capturing workforce information [21]; smaller and more fragmented professional structures for AH [22]; less directly established relationships between specific AH interventions and clinical outcomes; and unclear service tracking due to variable funding models, not all of which are attributable to specific disciplines [23,24]. Because this gap in the data involves a significant proportion of the multidisciplinary pain management workforce, it creates problems for evidence-based health-care design in tertiary persistent pain services.

The “Standards for Adult Inpatient Medical Rehabilitation Services” produced by the Australian Faculty of Rehabilitation Medicine [25] currently provide the most comprehensive guidelines for multidisciplinary staffing. Detailing numerous aspects of service delivery, including staffing, equipment requirements, and treatment guidelines, this document has identified and quantified many of the major service needs for medical rehabilitation providers. These Standards can, and do, inform tertiary outpatient persistent pain services, but they do not specify optimal or minimum staffing establishments for such pain clinics, or provide an evidence-base for resource allocation. To make informed choices about service design and delivery, service directors first need to understand the current staffing configurations of multidisciplinary pain

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clinics, after which they can evaluate these models in terms of patient outcomes and thereby work to maximize service efficiencies—a major consideration for sustainable health care. The first stage of this process was undertaken by the “Waiting in Pain” (WIP) project of the Australian Pain Society (APS; a chapter of IASP). Primary outcome data from the WIP project has been reported previously; detailing clinic structure, funding models, and activity, as well as wait times to access services [4]. This article extends the findings of the WIP project by offering the first detailed analysis of the staffing associated with Australian tertiary outpatient services for adults with persistent pain, thereby providing valuable information that can inform service design and delivery.

Method

Sample and Data Collection

As stated above, the study data were collected as part of the WIP project of the APS, which explored the provision of outpatient persistent pain services in Australia [4]. After an exhaustive search—spanning a pre-existing APS facility directory, internet searches, and consultation with local experts—68 adult persistent pain services were identified and contacted, 57 (84%) of which agreed and were eligible to participate in the WIP study (three did not respond; six declined; two were excluded due to low referrals: <100 per/year) (see [4] for a more detailed account of the recruitment method). Because the focus of the current analysis was on the structure and function of multidisciplinary clinics, we excluded an additional nine clinics that operated under a limited pain clinic model (not offering multidisciplinary or interdisciplinary care) and three with a single-discipline model, resulting in a final sample of 45 publicly and/or privately funded multidisciplinary pain clinics.

Outcome Measures

GP Service Directors (medical, nursing, AH) completed structured interviews (see Appendix 1), either face-to-face or by telephone, between December 2008 and January 2010. Interviews were conducted by M.N.H. and/or a research officer. Where necessary, responses were later clarified by telephone/email.

Participants were provided in advance with the interview questions, which covered: the various disciplines that they employed (medical, nursing, psychiatry, psychology, physiotherapy, occupational therapy, administrative); staffing levels (i.e., full-time equivalent [FTE] staffing—total number of hours worked by paid staff (part-time, full-time and casual/sessional employees) divided by the number of hours worked by a full-time staff member); types of outpatient service provided; funding models; annual referral numbers; and patient activity levels. The provision of Pain Management Group Programmes (PMGPs) was specifically explored because this was deemed to be a key indicator of serv-

Table 1 Source of data and general service information

	<i>n</i>	%
Source of Data		
Electronic system	20	44.4
Clinic lists	18	40.0
Informed estimates	7	15.6
Service Location		
Rural	8	17.8
Metropolitan	37	82.2
FTE employed		
Rural*	4.9	3.3
Metropolitan*	8.0	4.6
Total*	7.4	4.5
Funding Source		
Public (>90%)	25	55.6
Private (>90%)	11	24.4
Mixed	9	20
Links with Acute Pain (AP)		
No connection	19	42.2
Independent but connected to AP	21	46.7
Located within AP service	5	11.1

FTE = full time equivalent; AP = acute pain. Data reported is *n* (%) except where marked with an *, indicating data is *M* (SD).

ices that offered co-ordinated interdisciplinary care, compared with those who facilitated multidisciplinary input in a nonintegrated fashion (e.g., referred to independent AH services as required). In addition, qualitative information was sought regarding the evolution of services, barriers to optimal care and service development plans, however, data was reported in insufficient levels to permit meaningful analysis of this information. The data sources used by respondents were also documented, with most basing their estimates on electronic systems or paper-based records (see Table 1). Although somewhat less reliable than the more objective data sources, informed estimates were deemed acceptable as the research method (i.e., providing respondents with the structured interview questions in advance) facilitated the collection of relevant data/information prior to the interview, thereby maximizing data accuracy. FTE figures for psychiatry were recorded separately to general medical FTE because psychiatry was not consistently provided by all services and, where available, represented a secondary consultancy role that was distinct from the initial medical assessment.

Using the IASP classification system for multidisciplinary pain treatment services available at the time of data collection [6], each clinic was coded as Level 1 (i.e., multidisciplinary pain [MDP] management center offering coordinated interdisciplinary patient care, research and training) or Level 2 (MDP management clinic operating as for Level 1, but without regular research and teaching activities).

Burke et al.**Data Analysis**

Quantitative data were analysed using IBM SPSS Statistics 20 [26]. Descriptive statistics explored clinic characteristics, funding models, service locations, and data sources. Homogeneity of variance was checked using Levene's test for equality of variance. Analysis of variance and *t*-tests were used to explore differences in staffing numbers across clinic and discipline type, clinical activity, location of service delivery (rural vs metro, Australian states), and PMGP factors (e.g., programme intensity, location). Cohen's *d* measured the magnitude of the effects (*d* = 0.3, 0.5, 0.8 equate to small, medium, large effects, respectively, [27]). Confidence intervals were also calculated for *d* to examine the significance of the observed effects: CIs that span zero are not statistically significant.

Ethics Approval

The study was approved by the Human Research Ethics Committee of Royal Melbourne Hospital (HREC 2008.119).

Results

Most of the 45 services included in this study were based in capital cities, connected to an acute pain service and partly, or mostly, publicly funded (see Table 1). Clinic sizes ranged from 0.9 FTE (Victoria, rural) to 20.9 FTE (Queensland, metropolitan).

Clinic Type

Using IASP criteria [6], 26 services were classified as Level 1 and 19 as Level 2. Mean FTEs by discipline and clinic type are summarized in Table 2. Overall, Level 1 centers employed significantly more staff than did Level 2 clinics ($t(43) = 2.91, P = 0.006, d = 0.09$): specifically, more medical ($t(39.0) = 6.70, P < 0.001, d = 1.8$), psychiatry ($t(30.74) = 3.38, P = 0.002, d = 1.1$), nursing ($t(37) = 2.61, P = 0.013, d = 0.9$), and administrative ($t(38) = 2.29, P = 0.028, d = 0.7$) staff. However, the service types were comparable regarding the number of AH staff they employed.

Clinic Activity

Consistent with the finding that Level 1 centers employed more staff in all disciplines, except AH, they reported receiving significantly more referrals ($t(43) = 3.37, P = 0.002, d = 1.1$) and seeing more new patients ($t(43) = 3.09, P = 0.004, d = 0.09$) each year than Level 2 clinics (see Table 2). Nationally, Level 1 centers saw around 65% (range: 43% SA to 90% ACT) of their annual new referrals, whereas Level 2 clinics saw approximately 73% (range: 52% QLD to 100% SA). Despite there being no differences in overall AH staffing between Level 1 and 2 clinics, there were significant differences between Australian states in the employment of occupational therapists within both Level 1 and 2

services (Level 1: $F(5,11) = 3.23, P = 0.049$; Level 2: $F(6,9) = 6.75, P = 0.006$), and in the employment of psychiatrists in Level 1 services ($F(6,15) = 5.98, P = 0.002$) (see Table 2).

An examination of staff resources is more meaningful when evaluated against clinical activity. Detailed information regarding the range of specific clinical activities was not collected, but Table 3 displays the national mean average staffing levels (FTE) for each discipline/procedure type, per 100 new patients. Despite lower referral and activity rates, Level 2 clinics had significantly more administrative and AH (all types) staff resources per patient than Level 1. The fact that Level 1 and 2 clinics employed comparable numbers of medical and nursing staff (when assessed against their activity levels) suggests that they were providing similar amounts of medical care. Level 1 and 2 clinics also provided similar rates of medical procedures, both minor (e.g., epidural steroids and nerve blocks) ($t(42) = 0.36, P = 0.719, d = 0.29$) and major (e.g., spinal cord stimulation and intrathecal pumps) ($t(41) = 0.94, P = 0.352, d = 0.11$). Of note, medical procedure rates were calculated on the basis of number of "new patients" seen and, therefore, do not reflect overall caseload (new + existing patients) rates. Irrespective, while there was no significant difference between the clinic types overall, the range within both clinic categories indicates significant variability across individual clinics in their use of these types of medical procedures (see Table 3).

Location of Service

Sixty-two percent ($n = 23$) of the metropolitan-based services were classified as Level 1 centers ($n = 23$), compared with 38% ($n = 3$) of rural services. Overall, as summarized in Table 4, metropolitan and rural-based services reported employing comparable numbers of staff across most disciplines ($t(43) = 1.79, P = 0.081, d = 0.7$); the exception being doctors, who were employed in greater numbers in metropolitan-based services ($t(43) = 2.34, P = 0.024, d = 0.9$). Metropolitan and rural services also reported receiving comparable numbers of new referrals ($t(43) = 1.71, P = 0.095, d = 0.7$) and seeing similar numbers of new patients ($t(43) = 1.31, P = 0.197, d = 0.5$) each year. When staffing was considered as a function of clinical activity (number of new patients seen each year), the results indicated that, with the exception of occupational therapists—who were employed in greater proportions by rural than metropolitan services ($t(31) = -3.28, P = 0.003, d = -1.4$)—metropolitan and rural clinics employed comparable amounts of staff across the disciplines for the numbers of patients that were seen.

Pain Management Group Programmes

PMGPs are a common model of care in tertiary pain units and were offered by most clinics (Level 1: $n = 24, 92%$; Level 2: $n = 15, 79%$). PMGPs are primarily staffed by AH—most often psychologists and

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Table 2 Staff numbers: mean FTE (standard deviation) by discipline and clinic type

	TOTAL FTE	Medical	Psychiatry	Nursing	Physiotherapy	Clinical psychology	Occupational therapy	Administrative	Annual # new referrals	Annual # new patients seen
National TOTAL	7.4 (4.5) N = 45	2.1 (1.5) N = 45	0.2 (0.2) N = 33	1.5 (1.3) N = 39	1.1 (0.9) N = 41	1.0 (0.7) N = 41	0.5 (0.5) N = 33	1.7 (1.3) N = 40	766 (575) N = 45	514 (363) N = 45
Level 1 MDP Centre Total	9.0 (4.6) [†] N = 26	3.0 (1.3) [*] N = 26	0.3 (0.2) [†] N = 22	1.9 (1.2) [‡] N = 24	1.1 (0.7) N = 23	1.1 (0.7) N = 23	0.5 (0.6) N = 17	2.1 (1.3) [‡] N = 22	988 (494) [†] N = 26	645 (239) [†] N = 26
NSW	7.3 (4.7) N = 11	2.5 (1.1) N = 11	0.3 (0.2) N = 9	2.0 (1.4) N = 9	0.8 (0.9) N = 10	0.8 (0.8) N = 10	0.3 (0.3) N = 5	1.7 (1.3) N = 9	796 (326) N = 11	598 (276) N = 11
VIC	8.9 (2.4) N = 5	3.6 (1.0) N = 5	0.1 (0.1) N = 5	1.3 (0.7) N = 5	1.3 (0.4) N = 4	1.5 (0.6) N = 4	0.6 (0.7) N = 4	1.6 (0.6) N = 4	745 (274) N = 5	545 (126) N = 5
QLD	13.2 (10.9) N = 2	3.8 (2.5) N = 2	0.8 N = 1	2.8 (1.8) N = 2	2.0 N = 1	2.1 N = 1	2.0 N = 1	3.3 (1.8) N = 2	1766 (826) N = 2	766 (119) N = 2
WA	10.8 (5.1) N = 3	3.2 (1.8) N = 3	0.1 (0.1) N = 2	1.8 (1.7) N = 3	1.4 (0.6) N = 3	1.0 (0.6) N = 3	0.5 (0.3) N = 3	2.8 (1.4) N = 3	1000 (200) N = 3	700 (173) N = 3
SA	12.8 (1.8) N = 2	4.1 (1.6) N = 2	0.4 (0.2) N = 2	2.8 (0.3) N = 2	1.0 (0.4) N = 2	2.0 (0.0) N = 2	—	2.5 (0.7) N = 2	1850 (212) N = 2	800 (283) N = 2
Tas	8.0 N = 1	2.7 N = 1	0.7 N = 1	2.0 N = 1	1.3 N = 1	1.3 N = 1	—	—	1500 N = 1	900 N = 1
ACT	7.9 (0.9) N = 2	1.6 (0.6) N = 2	—	1.8 (1.7) N = 2	0.8 (0.4) N = 2	1.0 (0.0) N = 2	0.3 (0.4) N = 2	2.5 (2.1) N = 2	739 (370) N = 2	664 (476) N = 2
NT	—	—	—	—	—	—	—	—	—	—
Level 2 MDP Clinic	5.3 (3.6) N = 19	1.0 (0.7) N = 19	0.1 (0.1) N = 11	0.9 (1.1) N = 15	1.1 (1.1) N = 18	0.8 (0.6) N = 18	0.5 (0.5) N = 16	1.2 (1.2) N = 18	461 (549) N = 19	335 (430) N = 19
NSW	5.4 (2.2) N = 4	1.1 (0.5) N = 4	0.2 (0.3) N = 2	1.5 (1.3) N = 3	0.7 (0.3) N = 4	1.0 (0.1) N = 4	0.1 (0.1) N = 2	1.4 (1.1) N = 4	288 (85) N = 4	231 (121) N = 4
VIC	4.3 (4.5) N = 7	1.0 (0.8) N = 7	—	0.1 (0.1) N = 4	1.4 (1.8) N = 6	0.7 (0.7) N = 6	0.4 (0.3) N = 6	1.4 (1.9) N = 6	741 (846) N = 7	509 (671) N = 7

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Table 2 Continued

	TOTAL FTE	Medical	Psychiatry	Nursing	Physiotherapy	Clinical psychology	Occupational therapy	Administrative	Annual # new referrals	Annual # new patients seen
QLD	5.5 (3.7) N = 4	0.6 (0.5) N = 4	—	0.9 (1.3) N = 4	1.0 (0.5) N = 4	0.5 (0.4) N = 4	0.6 (0.3) N = 4	1.0 (0.8) N = 4	260 (161) N = 4	135 (33) N = 4
WA	11.0 N = 1	1.0 N = 1	—	1.0 N = 1	2.0 N = 1	2.5 N = 1	2.0 N = 1	2.0 N = 1	500 N = 1	500 N = 1
SA	2.8 N = 1	0.6 N = 1	0.1 N = 1	1.0 N = 1	0.1 N = 1	0.2 N = 1	—	0.8 N = 1	568 N = 1	568 N = 1
Tas	—	—	—	—	—	—	—	—	—	—
ACT	7.8 N = 1	1.3 N = 1	0.0 N = 1	3.0 N = 1	1.0 N = 1	1.0 N = 1	0.5 N = 1	1.0 N = 1	100 N = 1	100 N = 1
NT	4.8 N = 1	1.3 N = 1	—	—	1.0 N = 1	1.0 N = 1	1.0 N = 1	0.5 N = 1	221 N = 1	171 N = 1
Effect size	0.9 (0.3, 1.5)	1.8 (1.1 2.5)	1.1 (0.4, 1.9)	0.9 (0.2, 1.5)	0.0 (-0.6, 0.6)	0.5 (-0.2, 1.1)	0.0 (-0.7, 0.7)	0.7 (0.1, 1.4)	1.1 (0.6, 1.5)	0.9 (0.3, 1.6)

FTE = full time equivalent; MDP = multidisciplinary pain; SA = South Australia; VIC = Victoria; Tas = Tasmania; NSW = New South Wales; ACT = Australian Capital Territory; QLD = Queensland; NT = Northern Territory; WA = Western Australia; Effect Size = Cohen's *d*. SD and confidence intervals are shown in parentheses for means and effect sizes (Cohen's *d*), respectively.

* *P* < 0.001.

† *P* < 0.01.

‡ *P* < 0.05.

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Table 3 National average staffing levels (FTE) and provision of interventional procedures per 100 new patients seen

	National Total			Level 1 MDP centre			Level 2 MDP clinic			Effect size
	M (SD)	Range	n	M (SD)	Range	n	M (SD)	Range	n	
/100 new pts	5.1 (3.6)	0.9–20.0	45	6.5 (2.4) [†]	3.0–11.0	26	3.4 (4.3)	0.9–20.0	19	0.9 (0.3, 0.1)
Total service FTE	1.9 (1.5)	0.2–7.8	45	1.4 (0.6)	0.3–3.1	26	2.6 (2.1) [†]	0.2–7.8	19	-0.8 (-1.5, -0.2)
Medical	0.5 (0.3)	0.1–1.3	45	0.5 (0.2)	0.1–0.9	26	0.4 (0.3)	0.1–1.3	19	0.4 (-0.2, 1.0)
Psychiatry	0.0 (0.1)	0.0–0.2	33	0.0 (0.0)	0.0–0.1	22	0.0 (0.1)	0.0–0.2	11	0.0 (-0.8, 0.8)
Nursing	0.4 (0.6)	0.0–3.0	39	0.3 (0.2)	0.0–0.9	24	0.6 (0.9)	0.0–3.0	15	-0.5 (-1.2, 0.1)
Total Allied Health FTE	0.7 (0.6)	0.0–2.5	45	0.4 (0.3)	0.0–0.9	26	1.1 (0.7) [*]	0.0–2.5	19	0.6 (0.0, 1.2)
Physiotherapy	0.3 (0.3)	0.0–1.0	41	0.2 (0.1)	0.0–0.4	23	0.5 (0.3) [*]	0.0–1.0	18	-1.4 (-2.1, -0.7)
Clinical Psychology	0.3 (0.2)	0.0–1.0	41	0.2 (0.1)	0.0–0.5	23	0.4 (0.3) [*]	0.0–1.0	18	-0.9 (-1.6, -0.3)
Occupational Therapy	0.2 (0.2)	0.0–0.8	33	0.1 (0.1)	0.0–0.3	17	0.3 (0.2) [†]	0.0–0.8	16	-1.3 (-2.0, -0.5)
Administrative	0.4 (0.3)	0.0–1.3	40	0.3 (0.1)	0.1–0.7	22	0.5 (0.4) [†]	0.0–1.3	18	-0.7 (-1.4, -0.1)
Minor Procedures	62.4 (75.4)	0.0–400.0	44	66.0 (60.1)	5.7–283.3	25	57.6 (93.4)	0.0–400.0	19	0.1 (-0.5, 0.7)
Major Procedures	1.9 (3.7)	0.0–22.0	43	2.4 (4.5)	0.0–22.0	25	1.3 (2.2)	0.0–6.7	18	0.3 (-0.3, 0.9)

FTE = full time equivalent; /100 new pts = mean number per 100 new patients seen each year; MDP = multidisciplinary pain; minor procedures = procedures such as epidural steroids or nerve blocks; major procedures = procedures such as intrathecal pumps or spinal cord stimulation; Effect Size = Cohen's *d*. SD and confidence intervals are shown in parentheses for means and effect sizes (Cohen's *d*), respectively.

* *P* < 0.001.

[†] *P* < 0.01.

[‡] *P* < 0.05.

Table 4 Staff numbers: mean FTE (standard deviation) by discipline and per 100 new patients seen for metropolitan and rural-based services

	Metro		Rural		Metro /100 new pts			Rural /100 new pts			Effect size
	M (SD)	N	M (SD)	N	M (SD)	Range	N	M (SD)	Range	N	
TOTAL FTE	8.0 (4.6)	37	4.9 (3.3)	8	1.9 (1.4)	0.2-7.8	37	2.2 (2.1)	0.3-6.3	8	-0.2 (-0.9, 0.6)
Medical	2.3 (1.5) [†]	37	1.1 (0.8)	8	0.5 (0.3)	0.1-1.3	37	0.4 (0.3)	0.2-1.1	8	0.3 (-0.4, 1.1)
Psychiatry	0.2 (0.2)	29	0.1 (0.1)	4	0.04 (0.05)	0.0-0.2	29	0.01 (0.01)	0.0-0.03	4	0.6 (-0.4, 1.7)
Nursing	1.6 (1.3)	33	1.2 (1.0)	6	0.4 (0.6)	0.0-3.0	33	0.6 (0.8)	0.0-2.2	6	-0.3 (-1.2, 0.6)
Physiotherapy	1.1 (1.0)	34	0.9 (0.4)	7	0.3 (0.3)	0.0-1.0	34	0.5 (0.3)	0.2-0.8	7	-0.7 (-1.5, 0.2)
Clinical Psychology	1.1 (0.7)	34	0.6 (0.4)	7	0.3 (0.2)	0.0-1.0	34	0.4 (0.3)	0.0-0.8	7	-0.5 (-1.3, 0.4)
Occupational Therapy	0.5 (0.6)	29	0.6 (0.3)	4	0.1 (0.2)*	0.0-0.6	29	0.4 (0.3)	0.2-0.8	4	-1.4 (-2.5, -0.3)
Administration	1.8 (1.3)	33	1.4 (1.3)	7	0.4 (0.3)	0.3-1.3	33	0.5 (0.4)	0.1-1.0	7	-0.3 (-1.1, 0.5)
Annual # new referrals	832 (602)	37	458 (286)	8							
Annual # new patients seen	547 (366)	37	362 (329)	8							
/100 new patients	5.5 (3.7)	37	3.6 (3.29)	8							

FTE = full time equivalent; Metro = metropolitan; /100 new pts = mean number per 100 new patients seen each year. Effect Size = Cohen's *d*. SD and confidence intervals are shown in parentheses for means and effect sizes (Cohen's *d*), respectively.

* *P* < 0.01.

† *P* < 0.05.

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physiotherapists. Medical and/or nursing team members commonly provide input to PMGP sessions but unfortunately these data were not captured in the WIP survey, precluding an analysis of this aspect of staffing.

Similar numbers of new patients were seen each year by clinics who offered a PMGP and those who did not ($t(43) = -0.48, P = 0.631, d = 0.21$). Of these new patients, a greater percentage participated in a group programme in Level 2 clinics ($M = 40.4\%, SD = 55.7$), than in Level 1 ($M = 11.1\%, SD = 6.5$) ($t(37) = -2.57, P = 0.014, d = 0.81$). For AH, there was no significant difference in overall FTE between services with a PMGP ($M = 2.3, SD = 1.6$) and those without ($M = 1.7, SD = 2.8$) ($t(43) = -0.82, P = 0.416, d = 0.34$).

For clinics that provided specific PMGP data, there was marked variation in the duration (total therapy hours) of group programmes ($M = 68.6$ hours, $SD = 30.1$, range: 5–120, $n = 39$) and the associated AH FTE ($M = 1.60, SD = 1.3$, range: 0.3–4.0FTE, $n = 24$). However, because PMGP duration did not differ significantly across service models ($t(37) = 0.48, P = 0.633, d = 0.16$) or location ($F(7,31) = 0.69, P = 0.683$), these categories (clinic level, metropolitan vs rural) were collapsed for the remaining analyses. PMGP staffing and activity data are presented in Table 5.

Given the variability in duration, frequency of contact and therapy hours, PMGPs were categorized based on their intensity (defined as total number of therapy hours for each patient) into: low: <30 hours ($n = 2, 5.13\%$); medium: 30–50 hours ($n = 11, 28.2\%$); moderate: 51–90 hours ($n = 13, 33.3\%$); and high: >90 hours ($n = 13, 33.3\%$). An examination of AH staffing patterns revealed significant differences ($F(3,23) = 4.33, P = 0.017$). Specifically, medium and moderate intensity PMGPs had significantly fewer AH staff dedicated to their groups than did the most intensive model ($t(14) = -3.26, P = 0.006, d = -1.34$; $t(15) = -2.27, P = 0.039, d = -0.89$, respectively). When programme intensity was mapped against clinical activity, results indicated that groups saw a similar number of patients each year irrespective of the format of the programme ($F(3,35) = 1.63, P = 0.20$). As noted above, it is important to evaluate the adequacy of staffing by additionally examining the clinical activity to which those resources are allocated. An examination of PMGP staffing as a function of the number of patients treated annually indicated no significant difference between the models ($F(3,20) = 0.64, P = 0.596$), suggesting that, regardless of programme intensity, the staff-to-patient ratio was consistent; with 0.03FTE of AH staff required per patient treated.

Discussion

The WIP project of the APS previously reported poor access to multidisciplinary care for Australians living with CP; and longer wait times for publicly funded services than within the private sector [4]. This project sought to

describe and systematically examine staffing in Australian tertiary persistent pain services in terms of the associated clinical activity levels, to better understand and predict clinical resource needs and inform future developments in this sector of Australian health care.

In summary, across Australia, Level 1 centers consistently employ more medical, nursing and administrative staff, and annually receive more new referrals and see more new patients than their Level 2 counterparts. Despite this higher clinical activity, the amount of AH staffing is comparable: thus, patients at Level 2 clinics are likely to have greater access to AH resources, both individually and group-based, than patients seen at Level 1 centers. This is consistent with the finding that a greater percentage of patients in Level 2 clinics completed a PMGP than in Level 1 centers. Moreover, because offering a PMGP was not associated with higher AH staffing, it is likely that in clinics without a PMGP, AH provide other services, probably individual assessment and treatment sessions. The same is true for administrative staffing: as a function of clinical activity levels, resources in Level 1 centers are stretched significantly further than they are in Level 2 clinics. It is acknowledged, however, that although larger clinics have comparatively fewer staff than their smaller counterparts, this may partly reflect increased efficiencies due to larger size (i.e., economies of scale). Thus, adequate or necessary staffing may not always be directly proportional to clinical activity or patient numbers. It is not possible to draw firmer conclusions here because some other variables relevant to issues of workload and throughput—such as staff expertise and/or length of relevant experience, staff stress, retention rates, incident reports, and efficiency modeling—were beyond the scope of the WIP dataset.

Our findings suggest that the additional clinical activity in Level 1 centers is largely undertaken by medical and/or nursing staff. This may imply that Level 1 centers deliver a more medical, rather than multidisciplinary, approach to persistent pain: a suggestion that is consistent with the finding of increased patient participation in PMGP's in Level 2, compared with Level 1, clinics. However, the major distinction between IASP Level 1 and 2 classifications is the provision of teaching and training—part of which includes medical training via junior medical staff rotations and, more specifically, the Faculty of Pain Medicine fellowship program (1–2 years). Typically, trainees undertaking this fellowship are paid employees of the unit and provide clinical services to patients; as such, they are included in recorded staff establishments. Therefore, although a component of the medical FTE found in Level 1 centers may reflect their additional teaching/training/trainee roles, the higher levels of patient activity and nursing FTE in Level 1 clinics suggest that these trainees' duties were largely clinical in nature and, therefore, could still be considered to reflect a medical focus. Of note, potentially similar AH training activities were not captured in this study because, unlike their medical counterparts, AH trainees

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Table 5 Group programme activity levels and Allied Health FTE

	AH FTE		Hours / PMGMP		Patients seen		AH FTE / PMGMP patient	
	M (SD)	Range	M (SD)	Range	M (SD)	Range	M (SD)	Range
National Total	1.6 (1.3)	0.3-4.0	68.6 (30.1)	5-120	72.4 (60.7)	1-300	0.03 (0.02)	0.01-0.07
NSW	1.2 (1.3)	0.3-3.8	67.4 (33.5)	5-105	55.4 (42.7)	1-150	0.02 (0.02)	0.01-0.05
VIC	1.6 (1.3)	0.4-3.6	80.4 (32.7)	32-120	87.4 (72.4)	26-250	0.02 (0.01)	0.01-0.03
QLD	3.4 (-)	-	62.8 (26.6)	39-100	126.0 (106.7)	40-300	0.03 (-)	-
WA	4. (-)	-	82.5 (20.6)	60-100	62.5 (5.0)	60-70	0.07 (-)	-
SA	1.7 (1.8)	0.4-3.0	62.5 (46.)	30-95	78.0 (31.1)	56-100	0.02 (0.02)	0.01-0.03
Tas	-	-	40.0 (-)	-	50.0 (-)	-	-	-
ACT	1.5 (0.8)	1.0-2.4	49.7 (14.6)	36-65	55.0 (30.4)	35-90	0.04 (0.03)	0.01-0.07
NT	0.4 (-)	-	48.0 (-)	-	12.0 (-)	-	0.03 (-)	-
Program Intensity								
(a) <30 hrs	0.3 (-)	-	12.5 (10.6)	5-20	10.5 (13.4)	1-20	0.02 (-)	-
(b) 30-50 hrs	0.8 (0.3)	0.4-1.2	39.6 (6.9)	30-50	70.4 (78.3)	12-300	0.02 (0.00)	0.01-0.03
(c) 51-90 hrs	1.1 (1.2)	0.3-3.4	63.6 (10.5)	51-80	56.8 (40.4)	12-140	0.03 (0.02)	0.01-0.07
(d) >90 hrs	2.5 (1.2)*	0.8-4.0	101.0 (8.9)	90-120	93.7 (56.6)	35-250	0.03 (0.02)	0.01-0.07
Level 1 MDP Centre								
Total	1.8 (1.3)	0.3-3.8	70.4 (33.2)	5-120	69.1 (41.5)	1-150	0.03 (0.02)	0.01-0.07
NSW	1.5 (1.5)	0.3-1.8	62.4 (36.0)	5-105	59.4 (46.4)	1-150	0.02 (0.02)	0.01-0.05
VIC	2.2 (1.3)	1.0-3.6	110.3 (11.8)	96-120	86.3 (50.2)	35-150	0.03 (0.00)	0.02-0.03
QLD	3.4 (-)	-	55 (-)	-	140 (-)	-	0.02 (-)	-
WA	-	-	76.7 (20.8)	60-100	63.3 (5.8)	60-70	-	-
SA	1.7 (1.8)	0.4-2.2	62.5 (46.0)	30-95	78.0 (31.1)	56-100	0.02 (0.02)	0.01-0.03
Tas	-	-	40.0 (-)	-	50.0 (-)	-	-	-
ACT	1.8 (0.8)	1.2-2.4	56.5 (12.0)	48-65	62.5 (38.9)	35-90	0.04 (0.04)	0.01-0.07
Level 2 MDP Clinic								
Total	1.3 (1.2)	0.4-4.0	65.6 (25.1)	32-100	77.7 (84.4)	12-300	0.03 (0.02)	0.01-0.07
NSW	0.8 (0.2)	0.6-1.0	86.0 (12.5)	72-96	40.7 (25.3)	12-60	0.03 (0.02)	0.02-0.05
VIC	1.2 (1.2)	0.4-3.0	56.6 (21.0)	32-90	88.4 (92.6)	26-250	0.02 (0.00)	0.01-0.02
QLD	-	-	64.8 (30.3)	39-100	122.5 (122.8)	40-300	-	-
WA	4.0 (-)	-	100 (-)	-	60 (-)	-	0.07 (-)	-
ACT	1.0 (-)	-	36.0 (-)	-	40 (-)	-	0.03 (-)	-
NT	0.4 (-)	-	48.0 (-)	-	12 (-)	-	0.03 (-)	-

AH FTE = allied health full-time equivalent; hours / PMGMP = total treatment hours per Pain Management Group Program; patients seen = total number of new patients seen per annum; FTE/PMGMP patient = mean average FTE per Pain Management Group Program patient.
* P < 0.05.

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are unpaid and consequently not recorded within staffing establishments. Moreover, as specific information regarding the clinical activities of AH outside of PMGP's was not captured, it is not possible to accurately assess the amount of multidisciplinary activity provided across services. Until detailed information about the full range of clinical, training, and research activities are systematically collected for all disciplines, the suggestion that Level 1 centers have a more medical focus remains to be confirmed. However, despite the availability of a large amount of information to inform models of care for persistent pain, the variability in PMGP intensity levels, and rates of patient participation, as well as in the use of medical procedures (both minor and major) suggests that there is not yet agreement regarding an optimal care configuration for multidisciplinary pain services.

With the exception of medical staff, metropolitan and rural-based services were reasonably comparable in terms of the staffing models (disciplines and amounts) that they employed, the level of clinical demand they experienced and the number of new patients they saw each year. It is interesting to note that the higher numbers of medical FTE in metropolitan services did not translate to increased clinical activity (number of new patients seen). One possible explanation for this might be that rural clinics see a different case-mix of patients; with metropolitan clinics receiving more complex referrals, possibly from other city-based medical specialists. Such cases may require longer and/or more frequent consultations, effectively reducing the number of appointment times available for new patients. Alternatively, it is possible that rural services are better connected with their primary care colleagues and thus more able to support and coordinate care that is provided primarily in the community. Clinical activity was operationalized here as the number of new patients seen per annum: thereby capturing patient intake data but not data regarding patients that were then seen in an ongoing or recurrent way (i.e., return appointments rather than new appointments). Indeed, differences in case-mix and availability of links with community services (both impacting on need for ongoing management by a pain service) may contribute to the differences in national median wait times for persistent pain services reported previously (Level 1: 150 days, Level 2: 90 days) [4]. As such, more detailed examination of case-mix and service information is needed to better understand this finding and indeed, to fully understand the rates of medical intervention reported.

Overall, the reasonable consistency demonstrated in the range and mix of disciplines employed by persistent pain services across Australia (apart from the variation in occupational therapy staffing) suggests that current clinic configurations represent workable clinical structures. Accordingly, our study provides some empirical support for use of these configurations as initial guidelines when designing persistent pain clinics. An important limitation, however, is that we are not able to comment on service quality or patient outcomes. Thus, we cannot say whether these employment and activity levels necessarily

translate to effective or efficient services. Indeed, it is clear from long waiting lists and annual unmet clinical needs [4] that current arrangements are inadequate.

Another limitation of this study is that it did not fully explore or document the complete range of treatments and/or activities provided by clinics, hampering our ability to fully appreciate nuances of staff utilization. As stated above, this is particularly relevant for AH whose activity outside of PMGPs was not explored at all. It remains unclear whether lower levels of AH staffing equate to a less multidisciplinary focus or whether, in fact, AH were engaged in other multidisciplinary activities. Similarly, the survey failed to capture the contributions of doctors and nurses to PMGPs, leaving this aspect of staffing unexamined. Although considerable efforts were made to maximize the accuracy of the data, it did not all come from electronic systems. Finally, almost 20% of the clinics approached declined to participate. Thus, the degree to which our results can be generalized to those clinics, or indeed to international equivalents, is not clear.

This report represents one step toward maximizing treatment efficiencies and outcomes in the area of persistent pain: documenting the first Australian data on multidisciplinary staff resources (Table 2), the discipline-specific staff cost per/100 patients of providing this service in ISAP defined Level 1 and 2 clinics (Table 3); and the AH cost of PMGPs (Table 4). Future research needs to explore: the relationship between staffing levels and patient outcomes, medical/nursing input to PMGPs, and the clinical activity of AH staff outside PMGPs. This would help to clarify whether Level 1 centers use resources more effectively or whether Level 2 clinics, in fact, have more available resources and are more truly multidisciplinary in nature. Further, the contribution of occupational therapy to persistent pain services needs to be clarified to address the variable involvement of this discipline across current service models. It is only by systematically gathering this information that we will be able to provide a detailed understanding of the impact of staffing resources and patterns on treatment outcomes for people with persistent pain.

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APPENDIX :

Australian Pain Society
Secretariat: c/o DC conferences
PO Box 637 North Sydney, NSW 2069

Ph: 02 9954 4400
Fax: 02 9954 0666
Email: aps@dconferences.com.au



RMH-Pain Management Services
Clinics: Rehabilitation, Interventional, Aged Care, Neurosurgical
Cognitive-Behavior-Activity-Therapy Programmes
Clinical Education and Research

RMH-Pain Management Services office
Ph: 8387 2254
Fax: 8387 2149

Waiting in Pain: a systematic survey of persistent and chronic pain management services in Australia

Chief Investigator: Dr Malcolm Hogg, Royal Melbourne Hospital; Victorian councillor, APS

Site:
Location:
Date of interview:
Data sources/quality:
Do you consent to contact details being collated by APS: Yes/ No

SECTION A: clarification of previous responses from medical director of service

What is the name of your service?
separate name for PMP?

What is the structure of your service?

relevant history, development,
is it associated with an acute pain service,
predominant disciplines,
qa/outcome processes,
pre-assessment questionnaires.

Staffing levels? FTE fractions of each

medical: specialities,
faculty fellows/trainees,
allied health,
nursing,
pharmacy, admin

CORE Q 1: MDP Centre (multi/inter discipl, meetings, research, teaching)
MDP Clinic (no research, teaching)
Pain clinic (no multi/inter discipl)
Modality orientated clinic (?single pract/modality)

Funding model for your service? Public (state) Private Other (describe)
relevant %, use of state grants/hospital funding, medicare clinics

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CORE Q2: > 90% public
Commonwealth
State
>90% private
% Mix

Numbers of new referrals per annum?
focus on outpatient,
chronic referrals;
number self-referred from acute service

CORE Q3: referrals pa
new pts seen pa

Sources of referrals (%)?	GP	Specialists	Hospital
Predominant speciality?			
Any explanation of referral base?			
Do you define a catchment area?			

Description of clinical case mix?
Eg back, neck, headache, opioid issues

Current numbers of clients on waiting list and average time for initial assessment?
how are they managed?; any contact with referral source or patient eg telephone?

Do you have a process for more urgent referrals, and if so, approx waiting time?
which patients are considered for early assessment?

Do you reject referrals? If so, how many pa?
why: regional catchment area, pathology, drug issues?; where sent?

Additional waiting time for allied health assessments and/or therapy?
if its at initial assessment,
how are they chosen for multidisciplinary review?
process for allied health review?
% total referrals proceeding to AH review

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CORE Q4: current wait time for new persistent pain medical assessment in days

What does your service provide? and approximate numbers pa

Interventional procedures: eg's

Minor: epidural steroids, nerve blocks, RFA

Major: spinal cord stimulation, intrathecal pumps

Other: epiduroscopy, vertebroplasty, IDET

Individual Allied Health therapy:

total referrals? single vs multiple therapists?

Group Pain Management Programs: eg's

referred for consideration vs total accepted? % of total clinic referrals?

Inpatient care

how? why?

describe process and therapy provided eg with block for CRPS, rehab for country pts?

Other services: eg specialty clinics

specifically: palliative care/cancer pain; aged pain; headaches; fibromyalgia

how are they triaged, managed?

What external services do you utilise?; relevant numbers pa, linked to your service?

Palliative care

Liaison psychiatry?

Drug and Alcohol?

Complimentary therapy: acupuncture, other?

CORE Q5: number of funded Faculty of Pain Medicine training positions

CORE Q6: current number of research projects

clinical (involve pt care)

non-clinical (scientific, QA projects)

Any comments:

development plans; current threats?

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- CORE Q7:** barriers to the pain service development/maintenance/growth (major/mild/minor/none)
- funding
 - referrals
 - lack of trained staff
 - local political support
 - other
-
-

SECTION B: an investigation of Allied Health based Pain Management Programs

Name of PMP's
development history
range of programs: aged, disease, culture specific

Staffing structure/levels
range, FTE's, etc

Philosophies
modelling

CORE Q8: do you offer a group PMP?

Assessment processes:
referral processes
inclusion/exclusion criteria

Screening questionnaires used
general
disability
psychological

Clinical assessments
objective measures

CORE Q9: outcome measures used (list)

Team meeting(s)
medical supervision
frequency, structure

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Program structure:

timetable, number of participants, duration

individual therapy?

motivational interviewing?

physiology education?

exercise group?

hydrotherapy?

family/spouse therapy?

specific skills/specialist therapy?

follow-up/revision program?

CORE Q10: hours of therapy involved in your group PMP

Throughput:

numbers assessed pa

numbers accepted pa

numbers completed pa

do you provide long term followup/booster sessions?

Any comments?

published outcomes?

costs/funding?

changes planned?

Appendix 4.1 Published article for Chapter 6

Pain Medicine 2016; 17: 2203–2217
doi: 10.1093/pm/pnw125

OXFORD

EDUCATION & TRAINING SECTION

Original Research Article

Does a Brief Educational Session Produce Positive Change for Individuals Waiting for Tertiary Chronic Pain Services?

Anne L. J. Burke, MPsych,^{*,†} Linley A. Denson, PhD,[†] and Jane L. Mathias, PhD[†]

^{*}Pain Management Unit, Royal Adelaide Hospital, South Australia; [†]School of Psychology, Faculty of Health Sciences, University of Adelaide, South Australia, Australia

Correspondence to: A. Burke, Pain Management Unit, Level 6 Emergency Block, Royal Adelaide Hospital, North Terrace, Adelaide, SA 5000, Australia. Tel: +61 8 8222-5403; Fax: +61 8 8222-5904; E-mail: a.burke@sa.gov.au.

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Abstract

Objectives. To examine: 1) whether a single brief pre-clinic educational session improved the well-being and quality of life of individuals entering the

wait-list for a tertiary chronic pain (CP) service; and 2) the impact of waiting for services on these outcomes.

Methods. Participants were 346 adults, with basic English skills and non-urgent triage codes, who were recruited on referral to a tertiary Australian metropolitan CP unit. Participants were randomized across two conditions: “treatment as usual” (normal wait-list) and “experimental” (normal wait-list plus a 3-hour CP educational session). The educational session encouraged self-management and life engagement despite pain. Multiple outcomes (pain acceptance, pain-related interference, psychological distress, health care utilization [frequency, types], quality of life, health knowledge/beliefs), as well as pain severity and symptom exaggeration, were assessed at intake and again at 2 weeks and 6 months post-educational session (or equivalent for the wait-list group).

Results. Satisfaction with the educational session was moderate-to-high, but attendance was not associated with improved outcomes. At 2 weeks, all study participants reported significant improvements in pain acceptance (willingness, overall acceptance), health care utilization (frequency) and quality of life (physical), which were maintained/enhanced at 6 months. Use of psychological and physical therapies increased significantly by 6 months. There was no functional deterioration while wait-listed.

Conclusions. Attending a brief pre-clinic education session did not improve function. There was no deterioration in wait-listed participants who agreed to be involved in research and who completed study measures at 2 and 6 months, but referral was associated with short-term functional improvements. This is the first study to link positive change with referral to, rather than treatment by, a tertiary CP service.

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Key Words. Chronic Pain; Pre-Clinic Education; Waiting-List; Pain Acceptance

Introduction

Chronic pain (CP) is a major contributor to the global burden of disease, with one in ten people being newly diagnosed each year [1]. Not surprisingly, CP has been linked with significant impairment across a range of psychological domains, including anxiety, depression and quality of life (QOL) [2]. It is also associated with physical and occupational restrictions [3,4], withdrawal from valued life activities [5], and increased health care utilization [6]. Despite its high prevalence and associated costs, CP is often poorly represented in the diagnostic data collected by health agencies [7,8], resulting in limited public funding for CP services.

Research supports multidisciplinary care as best practice for CP [9], leading to improved physical and psychological adjustment for patients [10]. Typically, this involves contributions from medical, nursing, psychological, physiotherapy and psychiatric professionals [11]. However, many multidisciplinary CP services struggle to meet increasing demand, resulting in significant wait times for assessment and treatment [12,13], during which patients' health and wellbeing may deteriorate [14]. Accordingly, CP clinicians are developing alternative ways to address clinical needs, including brief interventions in the pre-clinic (wait-list) period. One exemplar is the Self-Training Educative Pain Sessions (STEPS) model [15], which involves a 2-day (or six-session) pre-clinic group program that educates patients about pain processes and promotes active self-management. Three-month follow-up data indicated that, although STEPS did not impact on anxiety or depression, the 2-day program afforded numerous other benefits to patients (i.e., improved self-efficacy, reduced disability, impression of change, greater strategy use) and service delivery (i.e., reduced wait-time, costs and need for individual follow-up appointments, greater attendance rates and patient satisfaction with treatment). Moreover, the incorporation of STEPS into the clinic's core intake process resulted in a significant reduction in demand for individual clinic appointments, with just over half of all patients opting not to pursue additional input beyond the STEPS program [15].

Given the lengthy wait for services experienced by many, the idea of a brief session at referral is compelling. Despite considerable debate in the CP literature, optimal group program intensity has yet to be determined for either clinic or pre-clinic interventions [16,17]. It has, however, been suggested that intensity should be directly proportional to the degree of disability (physical and psychological) experienced by individuals, with the most disabled persons requiring the most intensive programs [17]. In addition, other research has supported the potential impact of single brief educational sessions on the pain catastrophizing and fear [18],

physical performance [19], and return to work rates of individuals living with CP [20].

The current project therefore sought to evaluate whether a single brief multidisciplinary CP educational session of 3 hours duration—adopting a low-intensity model, conducive to implementation using existing clinical resources—could yield positive benefits, both in the short- (2 weeks) and intermediate-term (6 months), for individuals waiting to access a tertiary CP service. A secondary aim was to document any changes in participants' wellbeing during the first 6 months on a wait-list for CP services in order to explore the independent effects of waiting for treatment.

Method

Participants

Participants were adults who were newly referred to the Pain Management Unit (PMU) of the Royal Adelaide Hospital between November 2011 and November 2013. The PMU is a "Multidisciplinary Pain Centre" [21] situated in the largest accredited teaching hospital in South Australia. It provides a range of coordinated multidisciplinary services to adults living with CP. Referrals are actively triaged, based on a range of clinical factors, and wait times are typically long; often exceeding 2 years. Individuals referred for cancer/palliative care, early intervention (e.g., for Complex Regional Pain Syndrome) or intervention within 6 months were excluded from this study because initial appointments were likely to occur before completion of the proposed educational session and/or follow-up time-points (2 weeks, 6 months). Individuals referred prior to November 2011 were excluded because all recruitment occurred at the time of referral. Finally, basic English fluency and literacy skills were required in order to complete the study components (session presentation, handouts, outcome measures). All eligible patients (screened on the basis of referral information and PMU triage processes) newly referred to the PMU during the recruitment period were approached to participate in the study.

Study Design

A randomized research design was employed, whereby a random number allocation list was produced using an online generator (<http://graphpad.com/quickcalcs/randomize1.cfm>) to guide the allocation of potential study participants (ordered on the basis of sequential referral date) to one of two conditions: standard wait-list management—treatment as usual (*TAU*); or standard wait-list management plus educational session—experimental (*EXP*). Once randomized, individuals were sent the associated paperwork (standard PMU questionnaires plus study information for the *TAU* or *EXP* conditions, respectively) inviting them to participate in the study. Participants were told that the research was designed to investigate the impact of waiting for services on individuals living with CP and to determine whether

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changes to wait-list management could improve outcomes. An “opt-out” model was utilized for the educational session in order to maximize attendance [22], thus each *EXP* group participant was notified of the date and time of the session to which they had been allocated and advised that they were welcome to re-schedule to another session if desired. Allocation was initially randomized equally (1:1) between the *EXP* and *TAU* groups. However, unequal randomization (2 *EXP*: 1 *TAU*) was subsequently adopted to more evenly balance group numbers and maximize statistical power for the between-groups analyses [23] because lower uptake and greater drop-out rates were observed in the *EXP* condition.

Intervention

Each educational session was facilitated by a multidisciplinary panel of PMU staff—a pain consultant physician, psychologist and physiotherapist—all with significant experience in CP. The length of the session (3 hours) was based on the recommendations of a meta-analytic review [20], which suggested that a minimum of 2.5–3 hours duration was required for an educational session to be beneficial. Session content was standardized via a PowerPoint presentation to ensure consistency across presentations and included information about: CP processes, the clinical unit and what to expect from treatment, the role of psychological factors in pain and ways to manage pain (e.g., relaxation, mindfulness, challenging thinking, etc.), goal setting, sleep hygiene, distraction/attention focus, self-care, exercise, activity pacing and medication. Consistent with the literature on the self-management of CP, the session was designed to encourage participants to critically review their approach to pain management by [1] providing basic education about pain processes, including neurobiological conceptualizations [19]; [2] exploring the limitations of medications in CP management; and [3] exploring ways of enhancing QOL, despite experiencing ongoing pain [10,15]. In doing so, we communicated that the role of the pain management team was to support effective CP management, rather than to provide better analgesia or a cure for CP. Thus, the central goal of the session was to inform and encourage a psychological shift from the often fruitless quest for pain cessation or control, to a stance of acceptance and life engagement in the face of pain. Printed handouts were produced to support and supplement the session information (distributed at the commencement of each session), because group outcomes are thought to be enhanced by the provision of written literature [24].

Measures

Consistent with contemporaneous clinic practice, at the point of referral, individuals were required to complete and return an intake screening measure prior to being placed on the clinic booking queue. This measure—the Patient Screening Questionnaire (PSQ)—was based on a triage questionnaire sourced from Hunter Integrated

Pain Service (New South Wales Department of Health). The PSQ explores information related to pain (onset, duration, pattern, site(s), compensation status), health care utilization (frequency, treatment types) and demographic information (gender, age, marital and work status). The PSQ also includes validated measures of pain severity (four items of the Brief Pain Inventory: BPI-PS [25]), pain-related interference (seven items of the Brief Pain Inventory: BPI-PI [25]) and psychological distress (Kessler Distress Scale: K10 [26]); all of which were used in the current study to minimize respondent burden (see Table 1 for details of the study measures).

A range of other outcome measures were additionally utilized in order to more fully explore the multifaceted experience of living with CP: measures of pain acceptance (Chronic Pain Acceptance Questionnaire: CPAQ [27]), QOL (World Health Organisation QOL-Brief Scale: WHOQOL-BREF [28]), pain-related health knowledge and beliefs, and symptom exaggeration (see Table 1). Pain acceptance was assessed because of its influence on psychological distress, engagement with physical activity and QOL [29]. The QOL measure was chosen because it explores QOL more broadly than many other measures and was therefore more inclusive of the range of ways that CP may impact on this domain. The study-specific health knowledge/beliefs measure was devised to explore participants’ understanding of CP and its management, and, specifically, awareness of concepts presented within the educational session (*EXP* group). Although not an outcome measure, pain severity (“current” pain) was included because it was an important consideration when assessing the impact of waiting to access a CP service. This was particularly salient because it had the potential to influence responses on other questionnaires; with higher pain at the time of responding possibly being associated with greater reported distress and impaired recall. However, it is important to note that pain reduction was not a core goal of the educational session; consequently we did not expect ratings of pain severity to be influenced by session attendance. Likewise, symptom exaggeration was included because we recognized that a desire to expedite appointment allocation may potentially influence responses; either deliberately or unintentionally. Accordingly, a measure of symptom exaggeration (Social Desirability Response Set Scale: SDRS-5) [30] was included at the end of the health knowledge/beliefs measure, following two study-specific linking items (i.e., “my pain impacts on the way that I respond to others” and “I find that I am more understanding of the difficulties of others”) devised specifically to prevent the symptom exaggeration items from appearing discordant with preceding questions.

Finally, a study-specific measure was developed to assess participant satisfaction with the pre-clinic educational session. Attendees were asked to rate five items on a five-point scale, ranging from “1” (not at all) to “5” (completely). Specifically, they rated: satisfaction with the overall presentation, usefulness of the presentation

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Table 1 Overview of measures used in the study

Domain assessed	Measure	Number of items	Time period assessed	Possible score range	Reference
Pain acceptance	CPAQ	20			(27)
Pain willingness		9	“as it applies to you”	0–54	
Activity engagement		11	“as it applies to you”	0–66	
Overall acceptance		20	“as it applies to you”	0–120	
Pain-related interference	BPI-PI	7	previous 24 hours	0–10	(25)
Psychological distress	K-10	10	previous 4 weeks	10–50	(26)
Health care utilization (HCU)	PSQ	18			
Frequency		5	previous 3 months	0–40	
Treatment types		13	–	0–13	
Quality of life (QOL)	AWHOQOL-BREF	26			(28)
Physical health		7	previous 4 weeks	7–35	
Psychological health		6	previous 4 weeks	6–30	
Social relationships		3	previous 4 weeks	3–15	
Environment		8	previous 4 weeks	8–40	
Overall		1	previous 4 weeks	1–5	
Overall Health		1	previous 4 weeks	1–5	
Health knowledge/beliefs (HKB)	Study specific	5	–	5–25	
Pain severity	BPI-PS	4			(25)
Worst pain		1	previous 24 hours	0–10	
Least pain		1	previous 24 hours	0–10	
Average pain		1	on average	0–10	
Current pain		1	right now	0–10	
Symptom exaggeration	SDRS-5	5	–	0–5	

BPI-PI = Brief Pain Inventory, Pain Interference Subscale; K-10 = Kessler Distress Scale; PSQ = Patient Screening Questionnaire; CPAQ = Chronic Pain Acceptance Questionnaire; AWHOQOL-BREF = Australian World Health Organisation Quality of Life Brief Scale; BPI-PS = Brief Pain Inventory, Pain Severity Subscale; SDRS-5 = Social Desirability Response Set Scale.

and printed materials, whether the individual's thinking had changed as a result of attending the session and, if it had, the degree of perceived usefulness of that change. Participants were also asked whether they would have liked more information about anything in particular and, if so, what. Space was then offered for participants to provide unstructured feedback.

Procedure

Following referral and initial medical triage, potential participants were randomized and sent the intake screening measure (PSQ), as well as the appropriate study information sheet (*EXP* or *TAU*), consent form and intake research questionnaire pack. The study documents outlined the aims of the project and invited research participation, while emphasizing that individuals were free to decline or discontinue participation at any time without affecting wait-times or later treatment. Following questionnaire completion and study consent, participants in the *TAU* group were placed on a booking queue, pending notification of an available appointment (standard PMU practice at that time). *EXP* participants were placed on the same booking queue and details of

their educational sessions (date, time, location, description) were provided in their information sheets.

Because the initial questionnaire pack was sent out with the PSQ (Time 1: T1), a condensed version was generated for follow-up to avoid unnecessary duplication (e.g., birthplace). *EXP* participants were followed-up at 2 weeks (Time 2: T2) and 6 months (Time 3: T3) after their pre-clinic session. Feedback on the session was sought from attendees at T2. The *TAU* group was sent the same questionnaires (excluding the session feedback form) at equivalent times. By T3, 7% of participants (N=24) had attended, or been offered, an initial clinic appointment. Individuals who did not return a pack within one month were sent a reminder pack, with a note encouraging them to return the completed measures. Reply paid self-addressed envelopes accompanied all packs.

Although it was not anticipated that completion of the study measures would cause undue discomfort, it is well documented that CP is frequently associated with significant levels of psychological distress [2]. Hence, each mail-out included information outlining options for gaining assistance with distress, whether resulting from

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participation in this project or other causes. Finally, as a means of thanking participants for their involvement, every mail-out included a thank-you note encouraging them to “relax and enjoy a cuppa.” Taped to each note was an individually sealed tea bag.

The study was approved by the Research Ethics Committee of Royal Adelaide Hospital (Protocol #111004). Participant randomization, mail-outs, questionnaire scoring and data entry were all completed by ALJB. Moreover, ALJB attended the start of each session to introduce the presenters to the attendees, explain the research aims and answer any research-related questions. The researcher then handed the session over to the clinical team and left the room.

Statistical Analyses

Independent samples *t*-tests and chi-square statistics were calculated to assess differences between those *EXP* participants who “failed to attend” the pre-clinic educational session (without notice) and those who “declined to attend” (contacted the unit in advance to advise of non-attendance). These analyses indicated that there was no significant difference between the two groups on any of the demographic/background variables: age: $t(152) = -0.34, P = 0.73$; gender: $\chi^2(1, N = 154) = 0.04, P = 0.84$; relationship status: $\chi^2(3, N = 148) = 2.22, P = 0.53$; employment: $\chi^2(11, N = 149) = 15.93, P = 0.14$; born in Australia: $\chi^2(1, N = 150) = 0.04, P = 0.83$; non-Australian location of birth: $\chi^2(3, N = 35) = 2.51, P = 0.47$; previous contact with pain clinic: $\chi^2(2, N = 151) = 1.27, P = 0.53$; private health insurance: $\chi^2(1, N = 148) = 0.12, P = 0.73$; pain duration: $\chi^2(5, N = 150) = 4.69, P = 0.46$; compensation: $\chi^2(1, N = 149) = 1.27, P = 0.26$; pain in more than one site: $\chi^2(1, N = 154) = 2.19, P = 0.14$; primary pain site: $\chi^2(11, N = 144) = 10.61, P = 0.48$; reason for pain onset: $\chi^2(7, N = 148) = 2.80, P = 0.90$. Thus, they were combined to form a third group—“did not attend” (DNA)—for all subsequent analyses.

Power calculations conducted via G*Power [31] indicated that the study was adequately powered (effect size $f = 0.25$, $\alpha_{\text{error probability}} = 0.05$; power = 0.95). As recommended by Armijo-Olivo and colleagues [32], data was analyzed using an “as treated” rather than “intention to treat” protocol because the large number of participants in the DNA group did not receive any treatment at all. One-way analyses of variance were used to check for differences between the groups on the independent variables at T1 in order to ensure that they were comparable at intake. Repeated measures mixed-model analyses then explored the impact of Time (T1, T2, T3) and Group (*EXP*, *DNA*, *TAU*) on the dependent variables (outcome measures: pain acceptance, pain-related interference, psychological distress, health care utilization, QOL, health knowledge/beliefs) [32]. Where main effects were found, post-hoc analyses using *t*-tests with Bonferroni corrections explored the differences. In accordance with current

recommendations regarding calculation of effect size for this type of analysis, *d* was calculated to provide a measure of the standardized difference between the means for the three groups [33,34] and was interpreted using Cohen’s [35] guidelines: with $d = 0.2, 0.5$ and 0.8 indicating small, medium and large effects, respectively.

Results

Participant Characteristics at Intake

As Figure 1 depicts, 712 people were invited to participate in the research. Six declined referral to the PMU, one could not be contacted, four had consulted another clinic and three did not meet the English language requirements. Of the remaining 698 individuals, 33% ($N = 232$) did not respond and 17% ($N = 120$) only returned the PSQ, thereby securing their position on the clinic booking queue, but declining to participate in the study. This resulted in a final research sample of 346 people, ranging in age from 22 to 83 years, the majority of whom were female, not partnered, unemployed as a result of their pain and Australian-born (see Table 2). An independent samples *t*-test and chi-square statistic indicated that there was no significant difference in age or gender mix between those individuals who agreed to participate in the study and those who declined to do so (i.e., “opt out” group: $M_{\text{age}} = 44.3, SD_{\text{age}} = 11.6$, range = 17–79 years; $N_{\text{females}} = 73, 61\%$); age: $t(464) = 0.21, P = 0.84$; gender: $\chi^2(3, N = 466) = 3.78, P = 0.29$.

Most participants indicated that they experienced pain in more than one site and just over half of the sample ($N = 195, 56\%$) said that their pain had persisted for 5 or more years, often in the absence of a clear cause. Consistent with referral to a public health service with lengthy wait-times, most participants had not previously consulted a multidisciplinary pain service, were not involved in pain-related litigation and did not have private health insurance (see Table 2). As can be seen in Table 3, scores on the Pain Interference subscale of the Brief Pain Inventory (BPI-PI) [25] at T1 indicated that participants experienced a high level of pain-related interference in their ability to undertake daily activities. Psychological distress was also prevalent at T1, with the majority of respondents ($N = 245, 71\%$) reporting symptoms in the “moderate” or “severe” range (≥ 25) of the Kessler distress scale (K-10) [26]. These phenomena were also reflected in the measure of health care utilization (HCU), with participants reporting an average of 10 health-related appointments every 3 months ($M = 10.4, SD = 6.5$) and weekly appointments being reported by a third of participants ($N = 127, 37\%$). As might be expected, scores on the Australian World Health Organisation QOL brief scale (AWHOQOL-BREF) [28] indicated marked impairment across all QOL domains for the present sample when compared with Australian normative data [28]. Finally, scores for “current pain” on the pain severity subscale of the BPI (BPI-PS) revealed

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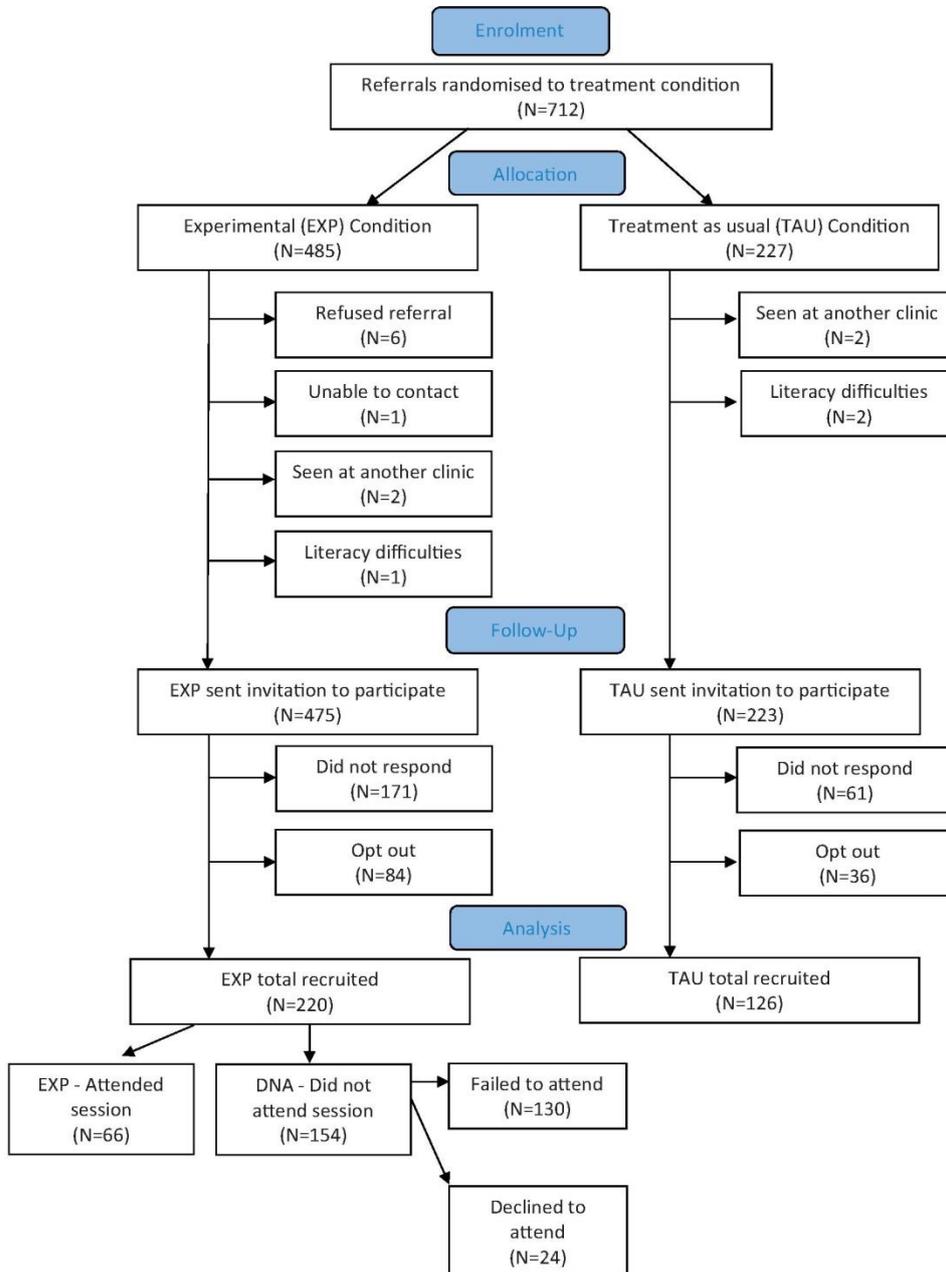


Figure 1 Flow of participants through the study.

that the sample as a whole reported experiencing a significant amount of physical pain at T1.

As indicated, one-way analyses of variance were performed to check whether the three Groups (EXP, DNA,

TAU) were comparable prior to the intervention. These analyses showed that there were no significant differences between the Groups at T1 on any of the measures, indicating that they were comparable prior to the study intervention in terms of: pain acceptance

Outcomes of Brief Pre-Clinic Education**Table 2** Summary demographic information of the sample

	EXP N (%)	DNA N (%)	TAU N (%)	Full sample N (%)
General information				
Participants	66 (19)	154 (45)	126 (36)	346
Age (mean, SD)	46.2 (9.9)	45.0 (10.2)	41.8 (10.3)	44.1 (10.3)
Gender				
Female	44 (67)	87 (56)	67 (53)	198 (57)
Male	22 (33)	67 (44)	59 (47)	148 (43)
Relationship status				
Single	20 (30)	67 (43)	63 (50)	150 (43)
Married/de facto	29 (44)	60 (39)	42 (33)	131 (38)
Divorced/separated	14 (21)	20 (13)	12 (10)	46 (13)
Widowed	–	1 (1)	–	1 (0.5)
Not reported	3 (5)	6 (4)	9 (7)	18 (5.5)
Employment status				
Unemployed (due to pain)	27 (41)	60 (39)	41 (33)	128 (37)
Unemployed (other reasons)	10 (15)	19 (12)	29 (23)	58 (17)
Part-time	5 (7.5)	14 (9)	14 (11)	33 (9.5)
Full-time	5 (7.5)	15 (10)	12 (10)	32 (9)
Home duties	11 (17)	13 (8.5)	8 (6)	32 (9)
Retired	3 (4.5)	11 (7)	2 (2)	16 (5)
Disability support pension	2 (3)	4 (2.5)	7 (5)	13 (4)
Student	2 (3)	4 (2.5)	5 (4)	11 (3)
Volunteer work	–	3 (2)	1 (1)	4 (1)
Retraining	–	3 (2)	1 (1)	4 (1)
Other	–	2 (1.5)	–	2 (0.5)
Casual	–	1 (1)	–	1 (0.5)
Not reported	1 (1.5)	5 (3)	6 (4)	12 (3.5)
Location of birth				
Australia	48 (73)	115 (75)	95 (75)	258 (72)
Europe	9 (14)	26 (17)	15 (12)	50 (14)
Asia	5 (8)	3 (2)	9 (7)	17 (5)
Oceania	–	4 (2.5)	1 (1)	5 (2)
Africa	1 (1)	2 (1)	2 (2)	5 (2)
South America	1 (1)	–	–	1 (1)
North America	–	–	1 (1)	1 (1)
Not reported	2 (3)	4 (2.5)	3 (2)	9 (3)
Pain/health information				
Pain in more than one site				
Yes	63 (95.5)	143 (93)	118 (94)	324 (93.5)
No	3 (4.5)	11 (7)	7 (5)	21 (6)
Not reported	–	–	1 (1)	1 (0.5)
Pain duration				
More than 10 years	24 (36)	60 (39)	37 (29)	121 (35)
5–10 years	10 (15)	34 (22)	30 (24)	74 (21)
12 months–3 years	11 (17)	28 (18)	24 (19.5)	63 (18)
3–5 years	16 (24)	18 (12)	24 (19.5)	58 (17)
6–12 months	5 (8)	9 (5.5)	6 (4)	20 (6)
Less than 6 months	–	1 (1)	3 (2)	4 (1)
Not reported	–	4 (2.5)	2 (2)	6 (2)
Primary pain site				
Lower back/buttocks	21 (32)	67 (44)	49 (39)	137 (39.5)
Total/almost total body	11 (17)	16 (10)	19 (15)	46 (13)
Legs/feet	8 (12)	15 (9.5)	16 (13)	39 (11)

(continued)

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Table 2 Continued

	EXP N (%)	DNA N (%)	TAU N (%)	Full sample N (%)
Neck	3 (4.5)	11 (7)	5 (4)	19 (5.5)
Head/face/mouth	3 (4.5)	8 (5)	5 (4)	16 (5)
Upper back	5 (7.5)	7 (4.5)	3 (2)	15 (4.5)
Hip	3 (4.5)	6 (4)	4 (3)	13 (4)
Abdominal	2 (3)	7 (4.5)	4 (3)	13 (4)
Shoulders	2 (3)	2 (1.5)	5 (4)	9 (3)
Arms/hands	2 (3)	2 (1.5)	3 (2)	7 (2)
Anal/genital	–	–	4 (3)	4 (1)
Groin	1 (1.5)	2 (1.5)	1 (1)	4 (1)
Pelvic	1 (1.5)	1 (1)	–	2 (0.5)
Chest	–	–	2 (2)	2 (0.5)
Not reported	4 (6)	10 (6)	6 (5)	20 (5.5)
Reason for pain onset				
No clear reason	16 (24)	36 (23)	33 (26.5)	85 (24)
Other	15 (23)	33 (21)	26 (21)	74 (21)
Other illness related	12 (18)	23 (15)	23 (18)	58 (17)
Work accident	8 (12)	29 (19)	18 (14)	55 (16)
Motor vehicle accident	7 (11)	16 (10)	15 (12)	38 (11)
Post-surgical	4 (6)	6 (4)	4 (3)	14 (4)
Home accident	3 (4.5)	4 (3)	4 (3)	11 (3)
Cancer	–	1 (1)	–	1 (1)
Not reported	1 (1.5)	6 (4)	3 (2.5)	10 (3)
Seen a pain clinic before				
No	54 (82)	124 (80)	107 (85)	285 (82)
Yes, multidisciplinary clinic	10 (15)	23 (15)	11 (9)	44 (13)
Pain doctor (single discipline only)	1 (1.5)	4 (3)	3 (2)	8 (2)
Not reported	1 (1.5)	3 (2)	5 (4)	9 (3)
Pain-related compensation				
No	64 (97)	142 (92)	114 (91)	320 (92)
Yes	1 (1.5)	7 (5)	8 (6)	16 (5)
Not reported	1 (1.5)	5 (3)	4 (3)	10 (3)
Private health insurance				
No	47 (71)	117 (76)	98 (78)	262 (76)
Yes	19 (29)	31 (20)	23 (18)	73 (21)
Not reported	–	6 (4)	5 (4)	11 (3)

EXP = experimental group (attend pre-clinic educational session); DNA = did not attend group (did not attend pre-clinic session); TAU = treatment as usual group (wait-list).

(CPAQ–pain willingness: $F[2, 322]=0.46, P=0.63$; activity engagement: $F[2, 322]=0.71, P=0.49$; total acceptance: $F[2, 322]=0.89, P=0.41$); pain-related interference (BPI-PI: $F[2, 344]=0.62, P=0.54$); psychological distress (K-10: $F[2,340]=0.10, P=0.90$); health care utilization (HCU: $F[2, 337]=0.67, P=0.51$); treatments tried (medical: $F[2, 336]=2.51, P=0.08$); psychological: $F[2, 336]=0.68, P=0.51$; alternative: $F[2, 336]=1.67, P=0.19$; physical: $F[2, 336]=0.76, P=0.47$); quality of life (AWHOQOL-BREF—physical health: $F[2, 329]=0.05, P=0.95$; psychological health: $F[2, 329]=0.31, P=0.74$; social relationships: $F[2, 329]=0.02, P=0.98$; environment: $F[2, 329]=0.96, P=0.38$; overall QOL: $F[2, 331]=0.07, P=0.93$; overall

health: $F[2,331]=0.87, P=0.42$); health knowledge/beliefs (HKB: $F[2, 329]=0.59, P=0.55$); current pain severity (BPI-PS: $F[2, 341]=0.53, P=0.59$); and symptom exaggeration (SDRS-5: $F[2, 328]=0.03, P=0.97$).

Pre-Clinic Session: Participant Evaluation

Of the 66 people who attended an educational session, 39 (59%) returned a partially- or fully-completed evaluation form, providing feedback about the session and indicating their satisfaction with the content and style of presentation. Overall, the feedback indicated a reasonable level of acceptance, with most participants ($N=30, 77%$) reporting that they were at least “moderately”

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Table 3 Mean (SD) scores on the outcome measures, by assessment times and group

	T1				T2				T3				
	Full sample at intake (T1)		DNA	TAU	EXP	DNA	TAU	EXP	DNA	TAU	EXP	DNA	TAU
<i>CPAQ</i>													
Pain willingness	15.0 (8.0)	15.2 (8.0)	15.3 (8.1)	14.4 (8.0)	19.6 (7.9)	19.0 (7.6)	17.5 (8.3)	19.2 (6.7)	18.3 (8.1)	17.1 (11.1)	18.3 (8.1)	17.1 (11.1)	17.1 (11.1)
Activity engagement	23.2 (11.9)	23.5 (12.9)	23.9 (11.9)	22.2 (11.3)	25.0 (12.8)	24.9 (12.8)	23.7 (11.6)	24.7 (13.1)	23.7 (12.3)	25.9 (14.5)	23.7 (12.3)	25.9 (14.5)	25.9 (14.5)
Overall pain acceptance	38.2 (16.6)	38.7 (17.6)	39.3 (16.7)	36.6 (16.0)	44.6 (15.7)	44.0 (16.7)	41.2 (16.3)	43.8 (16.4)	42.0 (15.6)	43.0 (20.3)	42.0 (15.6)	43.0 (20.3)	43.0 (20.3)
<i>BPI-PI</i>	7.4 (1.7)	7.3 (1.5)	7.3 (1.7)	7.5 (1.6)	7.2 (1.7)	7.2 (1.8)	7.6 (2.1)	6.9 (1.8)	7.2 (1.8)	7.2 (2.5)	7.2 (1.8)	7.2 (2.5)	7.2 (2.5)
<i>K-10+</i>	30.0 (8.7)	30.0 (9.2)	29.8 (8.6)	30.3 (8.6)	31.3 (8.4)	29.5 (8.8)	31.9 (9.7)	28.5 (8.0)	31.1 (9.0)	30.0 (11.0)	31.1 (9.0)	30.0 (11.0)	30.0 (11.0)
<i>HCU—frequency</i>	10.4 (6.5)	11.2 (6.5)	10.1 (6.7)	10.5 (6.2)	10.8 (6.3)	8.6 (6.3)	8.9 (6.0)	8.2 (4.9)	8.7 (7.6)	7.8 (5.8)	8.7 (7.6)	7.8 (5.8)	7.8 (5.8)
<i>HCU—treatment types</i>													
Medical	1.2 (1.3)	1.6 (1.3)	1.2 (1.1)	1.1 (1.4)	0.4 (0.5)	0.4 (0.7)	0.5 (0.8)	1.2 (1.0)	1.3 (1.1)	1.0 (1.0)	1.3 (1.1)	1.0 (1.0)	1.0 (1.0)
Psychological	1.2 (1.3)	1.4 (1.8)	1.2 (1.4)	1.2 (0.9)	0.5 (0.6)	0.8 (0.7)	0.7 (0.7)	1.5 (1.0)	1.4 (1.2)	1.3 (1.0)	1.4 (1.2)	1.3 (1.0)	1.3 (1.0)
Alternative	0.4 (0.6)	0.4 (0.5)	0.4 (0.6)	0.3 (0.6)	0.2 (0.6)	0.2 (0.4)	0.2 (0.4)	0.6 (0.7)	0.4 (0.5)	0.4 (0.6)	0.4 (0.5)	0.4 (0.6)	0.4 (0.6)
Physical	1.4 (1.0)	1.5 (0.9)	1.3 (1.0)	1.3 (1.0)	1.0 (1.0)	1.2 (0.9)	1.0 (0.8)	2.2 (1.0)	2.1 (1.4)	2.3 (1.2)	2.1 (1.4)	2.3 (1.2)	2.3 (1.2)
New (total)	—	—	—	—	2.4 (1.3)	2.6 (1.5)	2.5 (1.6)	2.5 (1.5)	2.6 (1.5)	2.5 (1.7)	2.6 (1.5)	2.5 (1.7)	2.5 (1.7)
<i>AWHOQOL-BREF</i>													
Physical health	14.4 (4.0)	14.5 (4.1)	14.4 (3.8)	14.3 (4.1)	15.2 (4.8)	15.5 (4.3)	14.8 (4.5)	15.4 (3.5)	15.4 (4.2)	15.8 (5.5)	15.4 (4.2)	15.8 (5.5)	15.8 (5.5)
Psychological health	15.7 (4.8)	15.9 (4.9)	15.8 (4.7)	15.4 (5.0)	15.3 (4.9)	16.1 (4.8)	15.6 (5.8)	15.4 (4.6)	15.3 (4.8)	16.6 (6.0)	15.3 (4.8)	16.6 (6.0)	16.6 (6.0)
Social relationships	7.9 (3.0)	7.9 (3.0)	7.9 (3.0)	7.8 (2.9)	7.6 (2.9)	7.7 (2.7)	7.7 (2.6)	7.3 (2.6)	9.2 (10.3)	8.0 (2.8)	9.2 (10.3)	8.0 (2.8)	8.0 (2.8)
Environment	23.4 (5.6)	23.8 (5.6)	23.8 (5.6)	22.8 (5.2)	23.7 (5.9)	24.7 (5.8)	22.7 (5.7)	24.4 (5.4)	23.9 (5.6)	23.9 (5.4)	23.9 (5.6)	23.9 (5.4)	23.9 (5.4)
Overall QOL	2.4 (0.9)	2.4 (0.9)	2.4 (0.9)	2.4 (0.9)	2.4 (1.0)	2.6 (0.9)	2.4 (1.0)	2.5 (0.9)	2.3 (0.9)	2.6 (1.1)	2.3 (0.9)	2.6 (1.1)	2.6 (1.1)
Overall health	1.9 (0.9)	1.8 (0.8)	1.9 (0.9)	1.9 (0.9)	1.9 (1.0)	1.9 (0.9)	1.8 (0.8)	1.9 (0.8)	2.0 (1.4)	1.9 (1.0)	2.0 (1.4)	1.9 (1.0)	1.9 (1.0)
<i>HKB</i>	14.4 (2.8)	14.1 (2.9)	14.6 (2.7)	14.5 (3.0)	14.9 (3.0)	15.0 (2.7)	14.3 (2.8)	14.4 (2.2)	14.9 (2.4)	14.5 (2.7)	14.9 (2.4)	14.5 (2.7)	14.5 (2.7)
<i>BPI-PS</i>	6.9 (1.9)	7.1 (1.8)	6.8 (2.0)	7.0 (1.8)	6.7 (2.3)	7.0 (1.8)	6.8 (2.6)	7.3 (1.8)	6.5 (2.3)	6.7 (2.7)	7.3 (1.8)	6.5 (2.3)	6.7 (2.7)
<i>SDRS-5</i>	1.8 (1.5)	1.8 (1.5)	1.9 (1.5)	1.8 (1.4)	2.1 (1.7)	1.7 (1.5)	1.8 (1.5)	2.1 (1.6)	1.8 (1.5)	1.7 (1.4)	1.8 (1.5)	1.7 (1.4)	1.7 (1.4)

Note: T1 = time 1 (intake); T2 = time 2 (2-week post-session follow-up); T3 = time 3 (6-month follow-up); EXP = experimental group (attended pre-clinic session); DNA = did not attend group (did not attend pre-clinic session); TAU = treatment as usual group (wait-list); CPAQ = Chronic Pain Acceptance Questionnaire; BPI-PI = Brief Pain Inventory; Pain Interference subscale; K-10 = Kessler Distress Scale; HCU = health care utilization; AWHOQOL-BREF = Australian World Health Organisation Quality of Life Brief Scale; HKB = health knowledge/beliefs; BPI-PS = Brief Pain Inventory, Pain Severity subscale — current pain; SDRS-5 = Social Desirability Response Set Scale.

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satisfied with the session and many being “mostly” (N=13, 33%) or “completely” (N=10, 26%) satisfied. Similarly, the majority of participants reported having found the information presented in the session to be at least “moderately” useful (N=27, 69%), with many rating it as “mostly” (N=13, 33%) or “completely” (N=10, 26%) useful. There was however, a mixed response to the printed materials, with comparable numbers of participants describing them as either “not at all/a little” helpful (N=17, 44%) or “mostly/completely” helpful (N=15, 38%). Despite these generally positive responses, most respondents stated at T2 that the session had influenced their thinking about the pain “moderately” or less (N=35, 90%), with many saying “not at all” (N=15, 38%). Thus, although respondents reported being satisfied with session content and delivery, and asserted that the information had been helpful, they did not believe that it had influenced the way that they interpreted or responded to their pain.

Next, mixed-model analyses of variance were performed to examine the impact of Group (*EXP*, *DNA*, *TAU*) and Time (T1, T2, T3) on outcome measures. There were no significant Group by Time interactions; consequently interaction effects are not discussed below. Similarly, results were not impacted by age, gender, pain severity, primary pain location or pain duration, thus covariate analyses are also not discussed.

Pain Acceptance (CPAQ)

Results indicated that Group did not impact significantly any of the areas of pain acceptance (pain willingness: $F [2, 270]=1.19, P=0.31$; activity engagement: $F [2, 303]=0.28, P=0.75$; overall pain acceptance: $F [2, 302]=0.73, P=0.48$), indicating that attendance at the educational session did not influence these measures. The level of activity engagement was similarly unaffected by Time ($F [2, 167]=1.83, P=0.16$). However, there was a main effect for Time across two aspects of pain acceptance: pain willingness ($F [2, 181]=26.05, P<0.001, d=0.44$) and overall pain acceptance ($F [2, 169]=16.31, P<0.001, d=0.30$). Post-hoc analyses indicated that, for the sample as a whole, pain willingness and overall pain acceptance increased over time, with participants reporting improved levels at T2 and T3, compared to T1 (Table 4). The fact that the changes in pain willingness were associated with a medium effect, suggests that this particular finding reflects clinically meaningful change.

Pain-Related Interference (BPI-PI)

Consistent with the findings for activity engagement, the level of pain-related interference in daily activities did not differ significantly between Groups ($F [2, 227]=0.64, P=0.53$) or across Time ($F [2, 180]=1.01, P=0.37$) (Table 4).

Psychological Distress (K10)

Psychological distress was also not significantly impacted by Group ($F [2, 313]=0.29, P=0.75$) or Time ($F [2, 180]=1.24, P=0.29$), indicating that distress was not altered by session attendance or time spent waiting to access CP treatment (Table 4).

Health-Care Utilization (HCU)

Frequency. The results concerning frequency of health care utilization showed that the Groups did not differ significantly on this measure ($F [2, 298]=0.66, P=0.52$), meaning that session attendance did not impact frequency of health care access. There was, however, a small main effect for Time ($F [2, 180]=8.26, P<0.001, d=0.16$), with participants reporting lower levels of HCU at T2 and T3, compared with intake (Table 4). Thus, participants attended significantly fewer health-related appointments after having been referred to the pain service than they did prior to referral. Of note, although not statistically significant, the rates of HCU for the *EXP* and *TAU* groups continued to decrease further between T2 and T3, whereas HCU rates for the *DNA* group did not (Table 3).

Treatment types. The types of treatments that participants reported having tried did not vary significantly between the Groups: medical ($F [2, 248]=0.55, P=0.58$); psychological ($F [2, 219]=0.38, P=0.68$); alternative ($F [2, 218]=0.96, P=0.39$); physical ($F [2, 215]=0.40, P=0.67$). However, all aspects of this domain did change significantly across Time: medical ($F [2, 204]=29.64, P<0.001, d=0.63$); psychological ($F [2, 127]=33.78, P<0.001, d=0.46$); alternative ($F [2, 164]=7.32, P=0.001, d=0.27$); physical ($F [2, 165]=58.41, P<0.001, d=0.31$). Specifically, post-hoc analyses indicated that participants reported having tried markedly fewer treatments at T2 than they did at either T1 or T3 (Table 4). Moreover, although the levels of use reported for medical and alternative treatments were reasonably stable between T1 and T3, the reported levels for psychological and physical treatments were higher at T3 than at T1, indicating an increased uptake of these types of treatment 6 months after being referred to the PMU. The small to medium-large effect sizes associated with the use of treatments over time suggest that the majority of these changes represent clinically observable differences—especially with respect to medical and psychological treatments. In terms of new treatments tried/retried, there was no significant difference between the groups at either T2 or T3 ($F [2, 80]=0.14, P=0.87$; and $F [2, 53]=0.04, P=0.96$ respectively) (Table 3).

Quality of Life (AWHOQOL-BREF)

QOL was assessed in terms of multiple domains, none of which differed significantly between Groups: physical ($F [2, 301]=0.22, P=0.81$); psychological ($F [2, 323]=0.02, P=0.98$); social ($F [2, 221]=0.61,$

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Table 4 Mean (SD) scores on the outcome measures for the full sample at each time point, and for each group overall (across times)

	Time of assessment			Group		
	T1	T2	T3	EXP	DNA	TAU
<i>CPAQ</i>						
Pain willingness	15.0 (8.0)	18.5 (7.9)* [†]	18.1 (8.9)* [†]	17.5 (7.9)	17.0 (8.1)	15.9 (8.9)
Activity engagement	23.2 (11.9)	24.4 (12.1)	24.7 (13.2)	24.2 (12.8)	24.1 (12.1)	23.4 (12.1)
Overall pain acceptance	38.2 (16.6)	43.0 (16.3)* [†]	42.7 (17.4)* [†]	41.7 (16.9)	41.2 (16.5)	39.9 (17.2)
<i>BPI-PI</i>	7.4 (1.7)	7.3 (1.9)	7.1 (2.0)	7.2 (1.6)	7.3 (1.8)	7.5 (1.9)
<i>K-10+</i>	30.0 (8.7)	30.8 (9.1)	30.2 (9.5)	30.0 (8.7)	30.0 (8.7)	30.7 (9.4)
<i>HCU—frequency</i>	10.4 (6.5)	9.1 (6.2)** [†]	8.3 (6.5)* [†]	10.4 (6.2)	9.4 (6.8)	9.5 (6.1)
<i>HCU—treatment types</i>						
Medical	1.2 (1.3)	0.5 (0.7)* [†]	1.2 (1.1)* [‡]	1.3 (1.2)	1.1 (1.1)	1.0 (1.3)
Psychological	1.2 (1.3)	0.7(0.7)* [†]	1.4 (1.1)* [‡]	1.3 (1.5)	1.2 (1.3)	1.1 (0.9)
Alternative	0.4 (0.6)	0.2 (0.4)** [†]	0.4 (0.6)* [‡]	0.4 (0.6)	0.4 (0.6)	0.3 (0.6)
Physical	1.3 (1.0)	1.1 (0.9)** [†]	2.2 (1.2)* ^{†‡}	1.4 (1.0)	1.5 (1.2)	1.5 (1.1)
New (total)	—	2.5 (1.5)	2.5 (1.5)	8.5 (6.8)	8.1 (6.6)	8.0 (6.4)
<i>AWHOQOL-BREF</i>						
Physical health	14.4 (4.0)	15.2 (4.5)** [†]	15.5 (4.5)***	14.9 (4.2)	14.9 (4.1)	14.8 (4.5)
Psychological health	15.7 (4.8)	15.8 (5.2)	15.8 (5.2)	15.6 (4.8)	15.8 (4.7)	15.7 (5.5)
Social relationships	7.9 (3.0)	7.7 (2.7)	8.4 (7.2)	7.7 (2.9)	8.2 (5.5)	7.8 (2.8)
Environment	23.4 (5.6)	23.7 (5.8)	24.0 (5.5)	23.9 (5.6)	24.0 (5.7)	23.0 (5.5)
Overall QOL	2.4 (0.9)	2.5 (1.0)	2.4 (1.0)	2.4 (0.9)	2.4 (0.9)	2.4 (1.0)
<i>HKB</i>	14.4 (2.8)	14.7 (2.8)	14.6 (2.5)	14.4 (2.8)	14.7 (2.6)	14.4 (2.9)
<i>BPI-PS</i>	6.9 (1.9)	6.9 (2.2)	6.8 (2.3)	7.1 (1.9)	6.8 (2.0)	6.9 (2.1)
<i>SDRS-5</i>	1.8 (1.5)	1.8 (1.5)	1.8 (1.4)	1.9 (1.6)	1.8 (1.5)	1.8 (1.4)

T1 = time 1 (intake); T2 = time 2 (2-week post-session follow-up); T3 = time 3 (6-month follow-up); EXP = experimental group (attended pre-clinic session); DNA = did not attend group (did not attend pre-clinic session); TAU = treatment as usual group (wait-list); CPAQ = Chronic Pain Acceptance Questionnaire; BPI-PI = Brief Pain Inventory, Pain Interference Subscale; K-10 = Kessler Distress Scale; HCU = health care utilization; AWHOQOL-BREF = Australian World Health Organisation Quality of Life Brief Scale; HKB = health knowledge/beliefs; BPI-PS = Brief Pain Inventory, Pain Severity Subscale – current pain; SDRS-5 = Social Desirability Response Set Scale.

* $P < 0.001$; ** $P < 0.05$; *** $P < 0.01$.

[†]significant difference compared to T1.

[‡]significant difference compared to T2.

$P = 0.54$); environmental ($F [2, 307] = 1.12, P = 0.33$); overall QOL ($F [2, 293] = 0.20, P = 0.82$). Similarly, most aspects of QOL assessed did not vary over Time: psychological ($F [2, 173] = 0.37, P = 0.69$); social ($F [2, 177] = 0.92, P = 0.40$); environmental QOL ($F [2, 173] = 0.10, P = 0.90$); overall QOL ($F [2, 177] = 1.15, P = 0.32$). The exception to this was physical QOL, for which there a small positive main effect ($F [2, 176] = 4.45, P = 0.013, d = 0.17$); with post-hoc analysis indicating significant improvements at T2 and T3, compared with T1 (Table 4).

Health Knowledge/Beliefs (HKB)

Consistent with other findings, results for health knowledge/beliefs were non-significant for Group ($F [2, 274] = 1.14, P = 0.32$) and Time ($F [2, 193] = 0.99, P = 0.37$), indicating that neither attendance at the educational session nor time spent waiting to access CP

treatment impacted significantly on the level of pain-related knowledge reported by participants (Table 4).

Pain Severity (BPI-PS)

Consistent with the previous domains, ratings of “current” pain severity did not differ significantly across Group ($F [2, 249] = 0.36, P = 0.70$) or Time ($F [2, 135] = 0.11, P = 0.90$), suggesting that the study results were not unduly influenced by pain fluctuations at the time of responding (Table 4).

Symptom Exaggeration (SDRS-5)

With respect to symptom exaggeration, the between-groups comparison was non-significant ($F [2, 291] = 0.32, P = 0.73$), as was the comparison across Time ($F [2, 174] = 0.08, P = 0.93$) (Table 4). Notably, the level of bias in responding was below the normative

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median for the measure on all three occasions. As such, responses were unlikely to have been excessively influenced by a desire to respond in socially desirable ways and were therefore deemed to provide reasonably accurate representations (within the limitations of self-report measurements).

Discussion

Chronic pain (CP) is a common condition, which negatively impacts on a range of important life domains. Many CP services struggle to meet patient demands, frequently resulting in long wait-times. The need to improve access to appropriate treatments for individuals living with CP has led clinicians to explore therapeutic opportunities in the pre-clinic (wait-list) period. Given the accumulating evidence for pre-clinic and brief interventions, this study explored whether therapeutic benefits could be achieved from a single brief intervention—a 3-hour pre-clinic educational session—for patients newly referred to the wait-list of a tertiary CP service. More specifically, we examined whether this single educational session had an impact on pain acceptance (CPAQ), pain-related interference in daily activities (BPI-Pi), psychological distress (K10), health care utilization (frequency, type), quality of life (AWHOQOL-BREF) and health knowledge/beliefs. We also explored the impact of waiting 6 months for CP treatment.

In terms of the pre-clinic education session, the results indicated that this was a negative trial: although participants reported reasonable satisfaction with the session itself, there was no significant benefit associated with session attendance in any of the areas we assessed. On reflection, this is probably not surprising given that, despite its longer duration and significant positive impacts, the STEPS program was also unable to reduce psychological distress (anxiety, depression, mental health composite scores) [15].

In addition, we experienced a large self-selected exclusion rate, with 33% of referrals declining to engage with the PMU at all and 17% opting to engage with the unit but not participate in the research. Little is known about how these individuals compare, demographically or psychologically, with the included sample. Moreover, 70% of the respondents who were offered a pre-clinic session did not attend (*DNA* group). Again, little is known about their reasons for non-attendance. It is possible that individuals “voted with their feet,” deliberately choosing not to engage with an intervention that they did not perceive to be valuable. Equally plausible is that invitees felt unable to attend due to factors such as pain/disability, emotional difficulties, life demands, physical access issues, etc. In hindsight, follow-up telephone calls may have proven informative.

Many public CP services struggle with high rates of non-response and non-attendance. Inclusion of a pre-clinic educational session (such as that trialed here) as a mandatory portion of the intake process is becoming

increasingly common. Based on data regarding pre-clinic session uptake rates, completion rates and reported demand for individual follow-up after pre-clinic session completion [15], it is easy to see how service efficiencies (i.e., decreased wait-time/occasions of service/clinic costs) could accumulate by adopting this model. If, however, the primary driver in service delivery is therapeutic outcomes—rather than economic gains—then more detailed consideration of a range of patient factors is required in order to better understand these findings. For instance, it is interesting to note that those individuals who chose not to engage early with the service—the *DNA* group who were offered, but did not attend, an educational session—were the only ones to report increased psychological distress and decreased engagement in valued activities 6 months after being referred to the PMU (T3), despite initial improvements post-referral (T2) (Table 3). Moreover, they were the only group whose level of health care utilization remained stable during this period (T2–T3)—the other two groups attended pain-related health care appointments less frequently following referral to the tertiary service. Although these differences did not reach significance, this same trend was not observed in the other two groups. This suggests that there may be individual patient variables associated with low treatment engagement that may perpetuate unhelpful pain cycles, thereby increasing distress, fostering help-seeking behaviors, including attendance at health care appointments (possibly as a mechanism via which to gain reassurance), and entrenching patterns of avoidance and withdrawal. However, as the groups were comparable on all of the areas assessed at the time of referral, we were unable to determine whether the *DNA* group’s lack of engagement with treatment at the tertiary service was due to premorbid/individual factors or other processes. Moreover, it is not possible to say whether session effects may have been different if a motivational approach to the follow-up of non-attenders had been employed—an activity that was not possible given existing staff resources. As outlined by Williams and colleagues [36], matching patients to treatments, based on diagnostic groupings (i.e., unresolved CP) rather than individual factors, can lead to poor treatment alliances, resulting in reduced treatment adherence post-intervention. This erodes potential outcomes that might be achieved by selecting more effectively aligned patient groups. Therefore, more information is needed about who might benefit from a brief pre-clinic education session and who might not; the latter group needing alternative management.

With respect to the impact of waiting 6 months for CP services, the numerous main effects found for Time across the sample as whole suggest that, where change occurred, this change was positive. Shortly after referral (T2), study participants reported a significant decrease in the frequency of health care use (all types) and significantly improved pain acceptance (pain willingness and overall pain acceptance) and QOL (physical); all of which were maintained, or improved, at 6-month

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follow-up (T3). Further, there was a change in the types of health care sought by participants over time, with significant increases in the use of psychological and physical therapies at 6 months (T3) compared with intake (T1). These findings are important for two reasons. The overall stability demonstrated in numerous areas from referral (T1) to the 6-month follow-up (T3) challenges previous reports that waiting up to 6 months is associated with declines in patient functioning [14]—at least for individuals who voluntarily participate in research involving intermittent follow-up surveys. Second, and perhaps more importantly, this is the first time that functional benefits have been linked with referral to—rather than treatment by—a tertiary CP service; suggesting that there may be something about *being referred* to, and *intermittently followed-up* by, a tertiary pain clinic that is beneficial to patients, thereby highlighting what may be an important time-point for intervention.

With new referrals reporting an average of 10 pain-related health care appointments every 3 months, and 37% reporting weekly appointments, it is evident that CP is one of the most expensive health conditions of developed countries around the world [10,37]. It is therefore interesting that, following referral to a tertiary CP service, many individuals changed the way that they approached, or engaged with, their health care. Specifically, many individuals reported attending progressively fewer health care appointments following referral to a tertiary pain service than they did before. For the sample as a whole, this decrease in health care appointments occurred despite an increase in the use of psychological and physical CP treatments. Following referral to a tertiary CP service, it is possible that health care became more targeted than it had been before, specifically focusing on physical or psychological strategies. That is, referral may have marked a shift in the way that patients (and perhaps their health care providers) viewed their condition: defining the problem as a CP issue, rather than another acute condition (i.e., an unresolved medical/surgical issue) and deciding that it should now be treated by a tertiary CP service instead of other active treatments. This shift may represent the creation of essentially a new diagnosis for the patient—potentially carrying renewed hope for effective treatments by the specialist service and also changing, or reducing, engagement with other clinicians. Alternatively, it is possible that referral was triggered by a period of acute distress and, accordingly, participants experienced a natural subsidence of symptoms following referral as the acute distress resolved. In the absence of a non-referred control group to explore this in more detail, it is not possible to draw definite conclusions.

The current study is not without limitations; most notably the reliance on self-report measures which, despite assurances to the contrary, may have been perceived by participants as potentially influencing their wait-time. In particular, it must be acknowledged that T2 was associated with a significant reduction across all

domains in the number of treatments individuals reported having tried. This question explored the *number of treatments that had been tried* (ever), not treatments that were *currently being used*; consequently domain scores should not have decreased. Hence, the findings for this variable should be viewed with caution. It is possible that individuals misunderstood the question – reporting strategies/treatments that they were currently using, rather than a tally of all treatments that they had ever tried. Alternatively, reports may have been affected by unreliable memory. It is also possible that, at T2, individuals felt somewhat more compelled to respond in socially desirable ways, as they became aware that wait-times could be lengthy. Although we concluded that the study data had not been unduly influenced by symptom exaggeration (because scores were below the normative median at all three time points), the potential for biased responding was greater at T2 than at either of the other assessment points. Intermittent follow-up may also have resulted in participants feeling supported, or attended to, by the tertiary service—thereby mediating the level of distress/deterioration experienced. Similarly, cognitive shifts may have resulted from repeated administration of survey items—particularly the CPAQ, completion of which may encourage patients to rethink their approach to life engagement despite ongoing pain—rather than other factors. Moreover, randomization, data collection and analyses were conducted by the primary author and therefore were not blinded. Finally, our data were all derived from newly referred patients who volunteered for the study and completed intermittent follow-up questionnaires. We are unable to comment on wait-times of more than 6 months duration, or on the experiences of those newly referred individuals who either did not return the PSQ (thereby failing to engage at all with the PMU service) or who returned the PSQ and entered the clinic booking queue, but declined to participate in this research.

Future researchers could usefully expand on this study in numerous ways. Exploration of a range of pre-clinic intervention lengths (e.g., 3 hours, half day, full day) would greatly assist in identifying optimal program intensity. Seeking feedback from, and providing motivational interventions to, individuals who were invited to, but did not attend, sessions may also be productive. Qualitative exploration of patient and general practitioner conceptualizations of pain pre- and post-referral to a tertiary CP service may better inform our understanding about referral decisions and how they influence engagement with health care. Comparison of individuals referred to a tertiary CP service with non-referred individuals would also better inform our understanding of the impact of the referral process on individuals living with CP. Low treatment engagement is costly for both patients and agencies. Therefore a more detailed consideration of individuals who fail (or decline) to engage with CP treatment may help clarify whether poor engagement with clinical services is better predicted by pre-disposing/individual factors, or aspects of the referral process itself: information that may meaningfully assist clinics to

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engage with these patients. Similarly, more detailed monitoring of patient progress while waiting for services—including comparison with a non-referred group—would assist in clarifying the existence and scope of any critical intervention period, thereby facilitating more targeted service delivery. Such research would be aided by a randomized controlled trial comparing the impact of early clinical intervention (rather than an educational session) with standard appointment scheduling.

Overall, we were unable to demonstrate any significant improvements for newly referred people on a wait-list as a result of a brief single pre-clinic educational session. Future research could usefully conduct further examination of referral and pre-clinic experiences, individual engagement factors and options to inform matching of interventions with participants. Interestingly, unlike previous research [14], in waitlisted participants who agreed to be involved in research and who completed study measures at 2 and 6 months follow-up, a wait of 6 months to access an appointment at a tertiary CP service was *not* associated with significant deterioration in patient wellbeing. Instead, referral was associated with short-term functional improvements—in the first 1 to 2 months after referral to the tertiary pain service, participants reported improvements in a range of areas including pain acceptance (willingness and overall acceptance), frequency of health care appointments and QOL (physical). This is the first time that functional benefits have linked with referral to, rather than treatment by, a tertiary pain service; highlighting what may be an important time-point for targeted interventions.

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