The Cost of Chronic Pain

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Abstract

Background: Chronic pain conditions are amongst the costliest illnesses globally. In the UK, between one-third to one-half of the adult population presents to the National Health Service (NHS) with a chronic pain condition—with back pain alone costing over one-fifth of NHS expenditure. Despite the plethora of research on chronic pain, how the "costs" of chronic pain are defined, and the evidence for, and provision of, effective interventions that mitigate these costs, remains inconsistent. Aims and Methods: This thesis first aimed to examine how the academic literature of the last decade conceptualised the costs of chronic pain though a systematic scoping review (Study 1). Next, this thesis examined the costs of chronic pain on the quality of life factors named by sufferers by conducting binomial logistic regressions on the Health Survey for England, 2017 dataset (Study 2). Finally, this thesis explored the impact of surgery on knee-related quality of life by conducting ANCOVAs on a clinical dataset (Study 3). Results and Conclusions: Findings indicate that academia and patients agree that the subdomains of the construct of quality of life (i.e. mobility, activities of daily living, working capacity, and social and psychological functioning) are the main costs of chronic pain—with patients additionally naming a subdomain of financial security as a cost. Study 2 demonstrated that those with chronic pain are significantly worse off compared to their non-clinical counterparts on each subdomain of quality of life. Finally, Study 3 demonstrated that despite significant improvements in knee-related quality of life post-surgery—these improvements could not be statistically attributed to the surgery itself. Taken together, these studies suggest that chronic pain interventions must holistically address all subdomains of quality of life—as well as financial security—if they are to truly ameliorate the costs of chronic pain on an individual and national level.

Chapter 1 Introduction

Overview

This dissertation is comprised of three studies examining the costs of chronic pain. Study 1 is a systematic scoping review examining the factors the academic literature of the last decade identifies as the "costs" of chronic pain. Study 2 is an exploration of the costs of chronic pain as named by chronic pain sufferers using a national dataset. Finally, Study 3, examines the impact of one type of NHS surgical intervention (i.e. anterior cruciate ligament reconstruction surgery) on the knee-related quality of life of patients using a clinical outcomes dataset. As this study will show, the UK likely substantially underestimates the full financial, social, and psychological costs of chronic pain which in turn leads to an inefficient allocation of resources and suboptimal outcomes for both patients and taxpayers. The aim of this dissertation, through three separate studies, is to address this critical knowledge and evidence gap and help shape national service provision to generate improved outcomes for NHS patients and taxpayers alike. Therefore, this introductory chapter gives a brief background summary of the impacts of chronic pain on quality of life, before examining the topics of chronic pain, quality of life, and a sample of the current treatment approaches for chronic pain.

Background

Chronic pain affects a large proportion of the adult population. A survey of Europe revealed that 22% of respondents had experienced pain within the past month (Langley, 2011). In 2006, Breivik and colleagues reported that 13% of the UK population, or 7.8 million people, suffered from chronic pain (2006). A decade later, these figures had quadrupled—with nearly 28 million individuals, or between one-third and one-half of the entire adult UK population, reporting chronic pain (Fayaz et al., 2016). Rates reported to National Health primary care services (NHS) corroborate this (Phillips, 2006). In 1999, a random survey of GP surgeries found that 50% of respondents reported chronic pain, with 27% experiencing moderately limiting to highly disabling pain (Elliott et al., 1999). Four years later, a follow up study found that the prevalence of chronic pain had increased from 47% to 54%—with 79% of those with chronic pain at baseline still suffering at follow-up (Elliott et al., 2002). In reality, these rates likely underestimate prevalence, as studies have demonstrated that around 27% of sufferers do not seek medical treatment for pain despite reporting daily or constant pain (Woolf & Pfleger, 2003).

Societal Cost of Chronic Pain

Chronic pain is one of the most financially burdensome conditions to society (Gaskin & Richard, 2012; Maniadakis & Gray, 2000; Meerding et al., 1998). Recent estimates suggest that the annual direct costs (e.g. healthcare, medication) and indirect costs (e.g. productivity losses, unpaid care) of chronic pain—may be as high as €12 billion, or 4% of GDP, in some countries (Stubhaug et al., 2024). In fact, the cost of chronic pain to society exceeds those associated with cancer, diabetes, and heart diseases *combined* (Nijs & Lahousse, 2023; Sleed et al., 2005). In the UK, the cost of back pain alone was found to be £12.3 billion pounds annually—or 22% of the national health expenditure and 1.5% of the gross domestic product (Maniadakis & Gray, 2000). The corresponding figure for Germany is more than three times as high, at 48.96 billion EU, which is equivalent to 2.2% of GDP (Wenig et al., 2009). Despite the limitations of cost-of-illness studies and variability in methodology, chronic pain and its sequela are clearly an enormous burden to national budgets.

Chronic pain also imposes a significant burden on healthcare systems, as individuals with chronic pain require healthcare interventions at a markedly higher rate than the general population. For example, a 2024 study examining primary care data from London found that patients with chronic pain had the highest mean annual consultation rate among all long-term conditions, at 15.3 consultations per patient per year—and incurred the highest primary care consultation cost of any long term condition (Shetty et al., 2025). This rate surpassed even common conditions like anxiety and depression, underscoring the enormous demand chronic pain places on primary care resources. However, the pattern of increased healthcare utilization extends beyond primary care.

Chronic pain patients demonstrate higher rates of specialist consultations, A&E visits, and inpatient admissions. Severe chronic pain sufferers have been found to visit healthcare professionals approximately twice as often as the non-clinical population (Collett, 2011). A Norwegian population-based study revealed that the accumulated difference in healthcare costs between individuals with and without chronic pain from 2010 to 2016 was €55,003 per person (Stubhaug et al., 2024). This substantial disparity reflects not only more frequent healthcare encounters, but also the need for more intensive and costly interventions—for example, multidisciplinary specialist care in hospital and community settings, as well as investigations and imaging (Maniadakis & Gray, 2000). Inpatient care represents a significant driver of these elevated costs. Patients with chronic pain and comorbid conditions are more likely to require hospitalization—with severe pain suffers becoming hospitalised three times as often as the general population (Collett, 2011). These admissions are typically longer and more complex, contributing disproportionately to the overall cost. For example, research on osteoarthritis-related chronic pain found that inpatient care was the main reason direct costs were more than double for the chronic pain population than matched controls (Lohan et al., 2023a).

The pharmacological management of chronic pain treatment also contributes significantly to its overall cost burden. The prevalence of polypharmacy (i.e. concurrent use of 10 or more medications) among chronic pain patients is particularly concerning. A 2025 study identified that approximately one in six individuals with chronic pain fell into categories of "often" or "always" experiencing excessive polypharmacy (De Clifford-Faugère et al., 2025). This high use of medications—and particularly opiates—is especially costly. While opioids can be effective for acute pain relief, their long-term use for chronic pain is increasingly refuted due to risks of dependence and tolerance. Patients using opioids for chronic pain require more frequent monitoring, face risks of dependence and addiction, and experience reduced quality of life due to side effects (Zah et al., 2019). Moreover, the health risks associated with polypharmacy are considerable. Multiple medications increase the potential for drug interactions, adverse effects, and medication errors. These risks can raise healthcare utilization and costs, escalating medical needs and expenses.

Personal Costs of Chronic Pain

As well as the societal costs, chronic pain has profound costs to the individual sufferer (Maniadakis & Gray, 2000). Compared to the general population, chronic pain sufferers report significantly poorer QoL (Hadi et al., 2019). In fact, chronic pain sufferers report poorer QoL than those with cancer, neurological disorders, and cardiovascular diseases—with the severity of pain correlating with a reduction in both physical and mental health (Sprangers et al., 2000; Collett, 2011). Indeed, qualitative research shows pain interfering with: physical functioning, professional life, relationships and family life, social life, sleep, and mood (Hadi et al., 2019). The activities of daily living and mobility are also oftentimes severely limited by chronic pain—leading to physical disability, limited autonomy, and the need for care (Bowling, 1996; Phillips, 2006; Rayner et al., 2016; Sprangers et al., 2000).

Difficulties with social functioning and mental health are also typical consequences of chronic pain (Breivik et al., 2006, 2013; Phillips, 2006; Rayner et al., 2016). Pain can limit individuals' ability to participate in social activities, maintain relationships, and engage in community life—oftentimes leading to social isolation, anxiety, and low mood (Bäckryd & Alföldi, 2023). Indeed, common sequela of chronic pain including chronic mental health conditions such as depression, suicidality, social isolation, anxiety, and a profound negative impact chronic pain has on an individual's sense of self and autonomy—with rates of sleep difficulties, anxiety, and depression are approximately twice as high in patients with severe pain when compared to the general population (Breivik et al., 2013; Phillips, 2006; Rayner et al., 2016; Sprangers et al., 2000; Voorhees, 2023; Collett, 2011; Langley, 2011). Those with chronic pain often report feeling like a burden on others around them and a loss of their sense of self and purpose. By stripping sufferers of their ability to engage in activities that were once defining to their sense of self, chronic pain can lead to shame, guilt, self-worth, hopelessness, and helplessness. For example, no longer being able to work and fulfil the role of breadwinner, but instead needing to rely on others, can lead to feelings of worthlessness, shame, and guilt. Chronic pain can also strip sufferers of their sense of their expected future self—throwing long term goals and plans into disarray. Chronic pain can also often impact relationships with sufferer's loved ones—as changes in social roles and limitations to autonomy often develop and disrupt previous relational dynamics (Harris et al., 2003; Kemler & Furnée, 2002; Phillips, 2006; Schwartz et al., 1996).

Clearly, the costs of chronic pain on national economies, healthcare systems, communities, families, and individuals are difficult to overstate. The next section examines how chronic pain is defined and formulates some of the mechanisms by which its costs manifest.

Chronic Pain

Chronic pain is any type of physical pain that persists or recurs daily for more than three months (Treede et al., 2015). Chronic pain is recognised as pain that lasts beyond normal healing time, and therefore no longer serves the function of providing an acute warning to the body of harm. While it is sometimes the result of physical trauma, chronic pain can develop and persist without an obvious organic cause (e.g. medically unexplained symptoms). Pain is traditionally classified by type (e.g., nociceptive, neuropathic, idiopathic, or psychogenic), duration (acute vs. chronic), and severity (mild, moderate, or severe) (Phillips, 2006; McMahon et al., 2013). Chronic pain encompasses a wide array of presentations—including back pain, neck pain, shoulder pain, osteoarthritis, migraine and headache conditions, trigeminal nerve pain, gynaecological conditions (e.g. endometriosis), irritable bowel syndrome, phantom limb pain, rheumatoid arthritis, post-operative pain, fibromyalgia, cancer survivors, and multiple sclerosis (Sleed et al., 2005). However, the diagnostic label of chronic pain has limitations. It can pathologise experiences of pain without adequately capturing the meaning, context, and coping of the sufferer—and may inadvertently promote and reinforce the over-medicalisation of sufferers. Moreover, the three-month threshold for pain becoming classed as chronic versus acute is arbitrary—reflecting medical convention rather than a specific physiological change (Treede et al., 2015).

Chronic pain is a uniquely challenging condition for patients and clinicians. Pain is the body's hard-wired alarm system of harm; as such, humans are inherently avoidant of pain and its causes (Butler & Moseley, 2013). While typically the avoidance of painful stimuli (both internal and external) is a wise approach to mitigating harm and fostering survival, pain which has become chronic is no longer indicative of current harm but instead reflects past physical and emotional trauma. Unfortunately, in the case of chronic pain, the nervous system has become hypersensitised to the experience of pain (both physical and emotional) and continues to use the same alarm signals and avoidance strategies to protect itself long after the initial cause of harm has been resolved (Butler & Moseley, 2013). Given its enduring nature, chronic pain erodes an individual's sense of self and view of others and the world (i.e. internal working models), as well as their ability to engage in values-led activities and relationships. These difficulties can be further reinforced by common comorbidities such as trauma, anxiety, depression (Bäckryd & Alföldi, 2023; Harris et al., 2003; Outcalt et al., 2015; van den Berk-Clark et al., 2017; Voorhees, 2023). Therefore, while chronic pain has historically been treated through analgesic or surgical intervention, researchers and clinicians increasingly seek to holistically address chronic pain in its full biopsychosocial presentation (Burrell & Robinson, 2019; Eccleston, 2011).

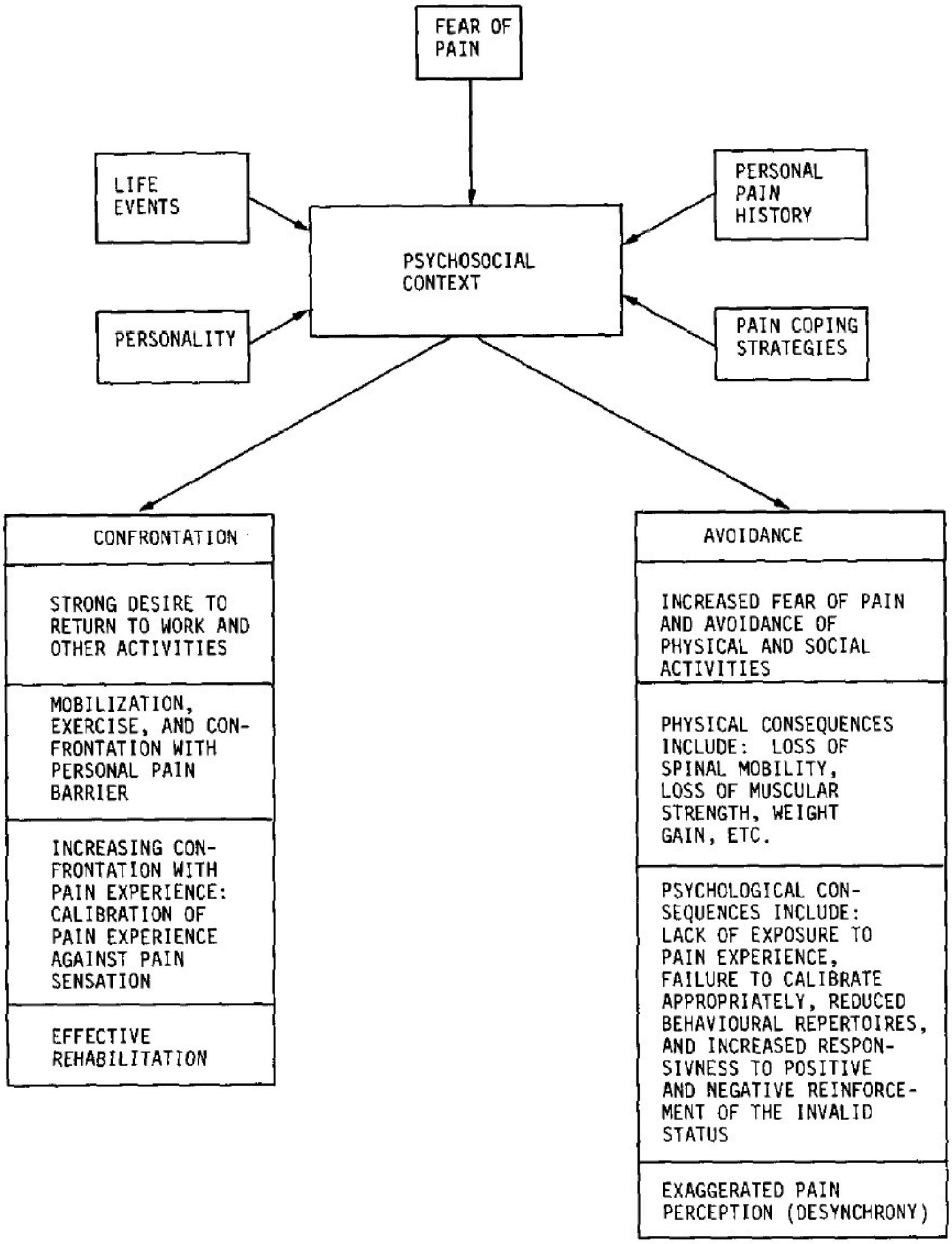
The Psychological Factors Underlying the Development of Chronic Pain

Research has demonstrated that psychological factors are particularly important to the development and treatment of chronic pain as fear of reinjury, coping with pain, pain catastrophising, pain-related fear avoidance can interfere with recovery after an acute injury (Gatchel et al., 2016; Moore et al., 2016; Parr et al., 2012; Zale & Ditre, 2015). In some cases, the experience of pain can lead to "pain catastrophizing" (Quartana et al., 2009). This is a negative cognitive response to pain characterized by worry, rumination, and helplessness in which an individual interprets the experience of pain as a threat. The mindset has three components: rumination (persistent focus on pain), magnification (mental emphasis on pain severity), and helplessness (feeling powerless to control the pain). Increased levels of pain catastrophizing are linked to high pain perception, emotional distress, and poorer treatment outcomes. Pain catastrophising can contribute to the experience of chronic pain by magnifying pain-related fear and avoidance behaviours.

Pain-related fear and avoidance are key constructs to understanding the onset and maintenance of chronic pain. Pain-related fear includes fear of experiencing pain, fear of activities that may cause pain, fear of movement or (re)injury, and pain-related anxiety (Vlaeyen & Linton, 2012). Presented in the seminal paper by Lethem, Slade, and Bentley, the fear-avoidance model was initially proposed to explain the transition from acute pain to chronic pain, then from chronic pain to disability (1983; Figure 1).

Figure 1

The Fear-Avoidance Model of Pain Response (Lethem et al., 1983).



The framework proposes that pain-related fear triggers what would normally be adaptive escape mechanisms have become maladaptive in chronic pain—that is, fear-based avoidant behaviour leads to decreased activity and movement which further disable an individual in the long term. The framework also asserts two extremes along a spectrum of response types to the experience of pain—confrontation and avoidance. Individuals who take the confrontation approach are typically highly motivated to return to work and valued activities, engage in confronting their pain barrier though graded activity, and re-calibrate their expectations of the pain experience as the organic causes resolve. Those taking this approach are also likely to view pain as a temporary issue rather than catastrophic and/or permanent. This approach allows individuals to pace their activity levels—and seek support and communicate when facing barriers. By contrast, the model proposes that those taking avoidant/non-adaptive coping strategies will avoid movement and activity to avoid pain and the related cognitive experiences. This maladaptive coping strategy can have significant long-term consequences for individuals as limiting activity and movement leads to muscular atrophy, isolation, and depression. Limitations in activity also lead to fewer opportunities to recalibrate the reality of pain experienced against expected pain.

Building on this model, researchers began exploring the roles of body hypervigilance, over-estimations of future pain, pain catastrophizing, and motivational barriers in chronic pain (Vlaeyen et al., 2016; Vlaeyen & Linton, 2000). Ultimately pain-related fear and the subsequent experiential (internal and external) avoidance significantly reduce quality of life. Behaviours which were adaptive and protective during the acute phase of recovery can become maladaptive in the long term—leading to physical disability, social isolation, depression, absenteeism, increased healthcare utilisation, and an inability to engage in social and recreational activities (Crombez et al., 2012; Vlaeyen & Linton, 2000). As pain-related avoidance narrows the world of an individual, these consequences perpetuate a negative cycle of progressively increased disability and poorer quality of life (Vlaeyen et al., 2016). The following sections will now examine how quality of life is defined and how chronic pain impacts its underlying domains.

Quality of Life (QoL)

As a biopsychosocial construct, QoL is highly relevant to clinical psychology as it represents a meeting point between internal states and external circumstances. That is, QoL is a multidimensional construct that encompasses both objective life circumstances and subjective experiences of wellbeing (WHO, 1995). Driven by the work of Cambell and his colleagues in the late 1970's, the construct of QoL moved away from simply the satiation of basic needs and "social indicators" such as health, workforce participation, leisure time, relationship status, and healthcare access—towards the inclusion of individual's perceptions, feelings, expectations, and values (Campbell et al., 1976; Maslow, 1943, 1987). While there had previously been no consistent definition of QoL, in 1995, the World Health Organization summarised characteristics of the construct as: 1. subjective (i.e. satisfaction with circumstances rather than objective conditions), 2. multidimensional (i.e. physical, psychological, social, spiritual, level of independence, environment), and 3. inclusive of both positive (e.g. mobility, social functioning) and negative (e.g. negative affect, pain, discomfort, fatigue, energy) dimensions. The WHO also defined QoL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (1995; p 1405). Therefore, drawing on interdisciplinary research, the following section examines six core subdomains of QoL—working capacity, financial resources, psychological state, mobility, social functioning, and the activities of daily living (AoDL)—as well as two factors (BMI and smoking status) that impact QoL—in order to inform the following studies.

Activities of Daily Living (AoDL)

AoDL form the foundation of independent living. AoDL refer to basic self-care tasks such as eating, bathing, dressing, and mobility—as well as the more complex tasks necessary for independent living, such as managing finances, medication management, and transportation

(Lawton & Brody, 1991). Therefore, difficulties in performing AoDL often signal a significant decline in health and QoL. However, difficulties in AoDL are rising; between 2000 and 2019, global disability adjusted life years attributed to limitations of AoDL increased by 12.3% (Steinmetz et al., 2023). These trends appear largely driven by an aging population and rising rates of chronic disease.

Lawton's work on QoL in older adults proposed a multidimensional model in which behavioral competence—or the ability to manage AoDLs—was fundamental to psychological wellbeing and perceived QoL (Lawton, 1991). These ideas have since been expanded upon by research demonstrating that reduced ability to engage in AoDL is associated with lower QoL for conditions such as strokes (Carod-Artal et al., 2000), dementia (Missotten et al., 2008), and chronic pain (Breivik et al., 2006). In chronic illnesses, inability to engage in AoDLs is both a symptom and consequence of disease, making the preservation or restoration of functional ability a key goal of therapeutic interventions. For example, for those with chronic pain, functional limitations frequently reduce social participation, increase psychological distress, and ultimately cause a marked decline in QoL (Hadi et al., 2019). Increasing dependence on caregiver's support with AoDLs imposes changes to family and social dynamics, and potentially harms an individual's sense of self, finances, and mood. By contrast, individuals who feel capable and in control, even if they are aided by assistive devices or support, report higher life satisfaction (Netuveli et al., 2006).

Mobility

Mobility is fundamental to human functioning and independence and has been consistently associated with QoL. Mobility is defined as the ability to move oneself independently within one's environment—including walking, transferring (e.g. from sitting to standing), and navigating spaces (Webber et al., 2010). Mobility is necessary for maintaining autonomy and engaging in social, work, and recreational activities. As such, limitations in mobility often reduce QoL due to increased dependence, reduced social interaction, and a heightened risk of depression and isolation (Hawthorne, 2008; Webber et al., 2010).

A substantial body of research suggests that mobility both determines, and is a proxy of, overall QoL (Groessl et al., 2007; Metz, 2000; Yeom et al., 2008). This is critical within the context of chronic pain, which by its nature, limits mobility. Human beings tend to avoid stimuli which cause pain, which in the context of chronic pain, tends to be movement (Butler & Moseley, 2013). Such limitations to mobility are a predictor of physical disability (Hirvensalo et al., 2000)—and are associated with a higher risk of losing independence, falling, being institutionalised, and dying (Hirvensalo et al., 2000; James et al., 2019; Rubenstein et al., 2001; von Bonsdorff et al., 2006). For example, studies have shown that declines in gait speed are predictive of lower QoL and increased mortality (Studenski et al., 2011). Decreased mobility often triggers a fear of falling, activity restriction, and muscular deconditioning—all of which exacerbate functional declines and further reduce QoL (Cumming et al., 2000). These patterns of decline are particularly visible in populations with musculoskeletal conditions, where impaired mobility is one of the most significant contributors to reduced life satisfaction and increased care needs (Ge et al., 2022; James et al., 2019; von Bülow et al., 2015). However, the relationship between mobility and QoL is not solely physical. Psychologically, the ability to independently and freely move oneself and participate in activities is deeply tied to a person's sense of self, purpose, and self-efficacy (Budd et al., 2022; Lowe et al., 2024; Toledano-González et al., 2019). Limitations on one's ability to move oneself can have significantly negative emotional consequences, evidenced by increased rates of depression and anxiety in populations with reduced mobility (Rantakokko et al., 2013).

Finally, studies also highlight the role of environmental factors in determining how mobility impacts QoL. The availability of public transport, building design, and perceived safety of public spaces can mitigate the effects on QoL that limitations in mobility bring (Clemson et al., 2012). For example, older adults living in walkable neighbourhoods with access to services tend to report better mobility and higher QoL compared to those in less accessible environments(Clarke et al., 2008). Moreover, assistive mobility devices (e.g. wheelchairs or scooters) can improve mobility—although access to such resources is oftentimes dependent on financial resources (Takemasa et al., 2017). Evidence suggests that interventions aimed at retaining or restoring mobility, such as physiotherapy, can measurably improve both physical function and QoL (Clemson et al., 2012; Crocker et al., 2013; Pedersen & Saltin, 2015). However, without adequate infrastructure and assistive devices, limitations on mobility often lead to a decline in activity, increased social isolation, and an eventual decline in mood and cognitive stimulation/capacity. In summary, therefore, the literature consistently highlights that the ability to move independently within one's environment is fundamental to QoL and should be a key focus when considering the QoL of those with chronic pain.

Psychological State

Within the context of QoL, subjective wellbeing (SWB), underlies the WHO's definition of psychological state (Diener, 1984; WHO, 2012). SWB is comprised of three components: positive affect, negative affect, and life satisfaction. Positive affect describes how frequently an individual experiences feelings such as enjoyment, joy, happiness, peace, and contentment, and how hopeful they are about the future (World Health Organization, 2012). Negative affect describes how often an individual describes negative feelings such as sadness, tearfulness, despondency, guilt, anxiety, nervousness, or a lack of pleasure. It also includes consideration of how distressing, how much of an impact these feelings have on daily functioning, and if these include psychological difficulties such as depression and anxiety (World Health Organization, 2012). The following section therefore examines the particular impact of psychological mood disorders such as depression and anxiety on QoL, before examining life satisfaction in a separate section.

Psychological mood disorders such as depression and anxiety can be among the most significant contributors to negative affective states, and therefore, poor QoL. Depression is characterized by persistent feelings of sadness, a loss of interest in activities, fatigue, disruptions to sleep/appetite, and cognitive impairments—all of which negatively impact QoL (Kennedy, 2008). Individuals with depression often reduce their engagement in pleasurable activities, experience difficulties in their social relationships, are less productive at work, and display neglect in their self-care (Egede et al., 2009; Kupferberg & Hasler, 2023; Rost et al., 2014). Anxiety disorders similarly harm QoL as worry and avoidance behaviours limit social engagement and workplace functioning (Barrera & Norton, 2009; Mendlowicz & Stein, 2000). Comorbid depression and anxiety further exacerbates the decline in QoL across all its domains (Freidl et al., 2022; Hohls et al., 2021). For example, sufferers of both conditions are more likely to experience severe physical health problems—which in turn further cause further declines in QoL as such individuals tend to disengagement with treatment (DiMatteo et al., 2000). As such, mood disorders and poor QoL form a vicious cycle—with declines in mood reinforcing declines across all domains of QoL. Moreover, in a recent systematic review, Hohls and colleagues (2021) examined the associations between anxiety, depression, functionality, and QoL (QoL), particularly in populations with chronic conditions, and found that declines in QoL pre-date the onset of these mental health issues. That is, individuals with these disorders experience a marked reduction in QoL prior to the onset of a mood disorder, then further drops in QoL during the disorder episode, and then general improvements in QoL upon remission. However, QoL is lower prior to onset and upon remission for the clinical population when compared to non-clinical populations. These findings suggest that arguments about the directionality or causality between mood disorders and QoL requires further research.

In the context of chronic pain, the co-occurrence of depression and anxiety further complicates QoL outcomes. A recent systematic review explored the associations between anxiety, depression, QoL, and functionality in individuals with chronic conditions (Costa et al., 2025). Their findings involved the data of 2,279 adults and demonstrated that better QoL and higher levels of functionality (i.e. return to work, non-sedentary lifestyle, and no fatigue) are associated with lower levels of anxiety and depression in those with chronic diseases. That is, unsurprisingly, the severity of the chronic condition, loss of functionality, and decline in QoL appear to increase psychological distress. On a whole, the current academic literature demonstrates the consistent relationship between mood disorders and QoL.

Life Satisfaction

A construct closely related to QoL is life satisfaction. Life satisfaction can be defined as the cognitive and emotional evaluation of one's overall QoL (Diener et al., 1985). Life satisfaction describes a person's subjective judgment about how well their life circumstances align with their values, goals, and expectations. Life satisfaction is considered one of the core components of subjective wellbeing—along with positive affect and low negative affect (Diener et al., 1999). However, unlike mood, life satisfaction is considered stable and enduring—although it can change in response to life events/circumstances.

Life satisfaction is impacted by demographic factors (such as age) and life circumstances (such as relationships, work, financial status, and health). In fact, a recent national study conducted by the Office of National Statistics (ONS) indicated that health, marital status, age, and financial circumstances are most strongly associated with positive life satisfaction in the

UK (2019). Age is the demographic characteristics most strongly associated with life satisfaction—following an S-shaped curve over the life course. That is, life satisfaction was found to be high for young adults, dropped to its lowest point at mid-life, rose again near retirement, and then dropped around age 80 (Office for National Statistics, 2019). Individuals who are married or in a civil partnership report higher life satisfaction compared to those with other types of relationship status. Moreover, people who were separated or widowed reported lower life satisfaction compared to singletons. In fact, marital status appears to increasingly matter to life satisfaction—with its influence on life satisfaction becoming more significant when compared to the ONS's national survey conducted 6 years prior (Oguz et al., 2013). This is similar to findings from the longitudinal Harvard Study of Adult Development that demonstrated that marital satisfaction is one of the best predictors of happiness (Waldinger & Schulz, 2010).

Financial and work circumstances also significantly impact life satisfaction. For example, home ownership, the ability to spend on experiences (e.g. hotels, restaurants), and being retired are all associated with greater life satisfaction compared to those renting, spending on essentials, or were unemployed in the 2019 ONS national survey (Office for National Statistics, 2019). This may be because employed individuals overall tend to derive a sense of purpose and social connection through their work, as well as being more financially secure with greater purchasing power. Interestingly however, both household spending and household income were shown to have less of an impact on life satisfaction than any of the aforementioned factors—however, this might be because there were historically low unemployment rates for the 2018 survey.

The most significant and consistent factor shown to affect life satisfaction has been by far health. The aforementioned data from the ONS shows that individuals who report "very good" health are three times more likely to report higher life satisfaction compared to those who class themselves as having “fair” health (2019). Moreover, the odds of reporting high life satisfaction are almost six times lower for those who class themselves as having “very bad” health when compared to individuals reporting “fair” health (2019). This is consistent with national survey data collected six years prior (2011-2012), and suggests health is the biggest contributor to life satisfaction (Oguz et al., 2013)—and is strongly associated with measures of happiness, anxiety, and the perception of one’s life as worthwhile. These findings are highly relevant to understanding the negative impact chronic pain can have on overall life satisfaction. However, the ONS survey findings need to be taken within the context of genetic and personality factors, which have been reported to account for about half of the variation in wellbeing (Diener, 1996). Therefore, most of what influences a person’s wellbeing was potentially not captured within this dataset.

Social Functioning

Research consistently demonstrates that social functioning and connection are cornerstones of QoL (Baumeister & Leary, 1995; Cacioppo & Cacioppo, 2014; Diener & Seligman, 2002; Hawkley & Cacioppo, 2010; Helliwell & Putnam, 2004; Pinquart & Sorensen, 2000). Social functioning, as conceptualised in QoL literature, is understood as ability to engage in fulfilling social relationships and roles, and takes into account the extent to which an individual’s physical or mental health difficulties limit their engagement with family, friends, and their wider social network (Ware & Sherbourne, 1992). Social connection, on the other hand, refers to both the objective (e.g. frequency of contact, number of relationships) and perceived quality (e.g. belongingness, support), presence, and structure of an individual’s social network (Holt-Lunstad et al., 2010; *Social Isolation and Loneliness in Older Adults*, 2020). In fact, Campbell and colleagues seminal work identified social relationships—that is, family relationships and friendships—as the strongest predictors of life satisfaction

(Campbell et al., 1976). Moreover, the longest running longitudinal study on adults, the Harvard Study of Adult Development, has consistently demonstrated that having good quality social connections is the single most important predictor of happiness and health in later life (Waldinger & Schulz, 2010). Further work has indicated that greater diversity in one's social connections (e.g. intimate relationships, family, friendships, community) is also strongly linked to QoL factors and wellbeing (Helliwell & Putnam, 2004).

Unsurprisingly, difficulties in social functioning and limited social connections are consistently associated with negative QoL outcomes. Social isolation (i.e. the lack of contact with other people) and loneliness (i.e. perceived isolation) have serious consequences to health (Holt-Lunstad et al., 2010; *Social Isolation and Loneliness in Older Adults*, 2020). As humans are inherently social animals, one evolutionary model proposes that lonely people see the world as unsafe, and therefore live in a state of hypervigilance (Hawkley & Cacioppo, 2010). A chronic state of loneliness seems to leave the body in a continuous state of stress, with effects ranging from difficulties sleeping, increased risk of cardiovascular disease, delays in wound recovery, and increased mortality rates (Cacioppo & Cacioppo, 2014; Cacioppo & Hawkley, 2003; Hawkley & Cacioppo, 2010; Holt-Lunstad et al., 2010). The impacts on cognitive and mental health are also striking, with loneliness associated with psychosis, personality disorders, suicide, impaired cognitive functioning, decreases in executive control, and cognitive declines over time (Cacioppo et al., 2000; Cacioppo & Hawkley, 2009; DeNiro, 1995; Gow et al., 2007; Hawkley et al., 2009; Institute of Medicine (US) Committee on Pathophysiology and Prevention of Adolescent and Adult Suicide, 2002; Neeleman & Power, 1994; Tilvis et al., 2004; Wilson et al., 2007). Interestingly, hypnotic induction of feelings of loneliness demonstrated that participants reported increased stress, anxiety, anger, fears of negative social judgement, and decreased self-esteem and optimism (Cacioppo et al., 2006). Loneliness has also been shown to predict depression (Cacioppo et al., 2010), and research consistently demonstrates that healthy social connections reduce the incidence of depression (Cruwys et al., 2014; Kawachi & Berkman, 2001; Teo et al., 2013). Overall, these findings suggest that social connection is not just critical to mental health, but also physical health, longevity, and thus overall QoL.

These findings are particularly relevant to populations with life-long illnesses such as chronic pain. For instance, Musich et al. (2019) and Moss et al. (2024) found that in adults with chronic pain or illness, greater social support and engagement were linked to lower pain severity and higher QoL. Similarly, López-García et al. (2005) reported that infrequent contact with friends was associated with QoL declines comparable to those caused by chronic pain. Rhee et al. (2021) highlighted the importance of diverse social networks over perceived support quality, and Lestari et al. (2021) demonstrated that active social participation (e.g., volunteering) significantly improved QoL over time. On a psychosocial level, pain can limit individuals' ability to participate in social activities, maintain relationships, and engage in community life. For example, limitations to mobility can make it difficult to access events or keep social appointments—often stripping sufferers of their previous social roles and causing isolation. These in turn can lead to a perceived lack of support and low mood, which further exacerbate physical symptoms—leading to further declines in QoL (Sleed et al., 2005). Together, these studies affirm that healthy social functioning is a critical determinant of QoL for those with chronic pain.

Working Capacity

Work is a fundamental part of QoL, as it can provide an individual with purpose, meaning, structure, and social connection. In the context of QoL, work is understood to mean any "major activity in which the person is engaged". This might include unpaid or paid work, volunteering, study, or homemaking and childcare (*World Health Organization*, 2012). Working capacity, in this context, will be considered an individual's use of their energy to engage in work (World Health Organization, 2012). One American study found that adults with pain missed between 1-3 more days of work than their counterparts without pain and worked between 300-700 fewer hours per year (Gaskin & Richard, 2012). However, whether work improves or detracts from QoL depends on factors such as autonomy, job quality, and work-life balance (Bhende et al., 2020). Being in employment is consistently linked to greater life satisfaction—as work offers financial security, as well as a sense of purpose and identity (Judge & Watanabe, 1993; Rain et al., 1991). By contrast, unemployment is linked to financial insecurity, social disconnection, and an increased risk of depression/anxiety (Dooley et al., 1996; Paul & Moser, 2009).

Moreover, not all forms of employment are equal. High-stress jobs, with excessive demands and limited autonomy can lead to poor health (Clinchamps et al., 2024; Kivimäki & Kawachi, 2015; Theorell et al., 1990). Karasek and Theorell describe the Job Demand-Control Model (Karasek, 1979; 1990). The model outlines how workplace stress results when employees have high demands but little control, which in turn leads to adverse health outcomes such as increased cardiovascular disease, physical inactivity, and sedentary time (Clinchamps et al., 2024; Kivimäki & Kawachi, 2015; Theorell et al., 1990). By contrast, "active jobs" (i.e. those with high demands and high control) foster growth and learning. Employment that had high demands and low control was found to negatively impact workers' cardiovascular health. The model was later expanded to the Job Demand-Control-Support Model (Johnson & Hall, 1988). This model suggests that workplace social support could mitigate the negative effects of high demand-low control jobs. However, reviews of this model over the last 20 years has found evidence for the addition of support to the original model to be inconsistent and inconclusive, particularly in longitudinal studies (Häusser et al., 2010; Van der Doef & and

Maes, 1999). Regardless, the workplace often serves as a key source of social interaction and can reduce isolation, improving QoL (Holt-Lunstad, 2024). However, the quality of workplace social interactions is important—as toxic cultures of discrimination or bullying damage QoL (Nielsen & and Einarsen, 2012). Overall, these findings suggest that the quality of work may play a significant role in promoting QoL.

The limiting impact of chronic pain on working capacity (often captured through the lens of productivity loss, absenteeism, early retirement, or presenteeism) can be profound. One Norwegian study estimated that 80% of the total costs associated with chronic pain were due to productivity losses (Stubhaug et al., 2024). Based on the World Health Organisation (WHO) estimate of a 22% prevalence of chronic pain, the number of chronic pain days taken per year would be 4,700 million in France, 6,600 million in Germany, 2,400 million in Canada, and 21,500 million in USA (Gureje et al., 1998), while UK estimates have ranged between 23.4 million and 2,150 million pain days taken annually (Sickness Absence in the UK Labour Market - Office for National Statistics, 2023; Phillips, 2009). In the NHS, back pain alone accounts for 40% of sickness days taken (British Pain Society, 2018; Improving Staff Retention, 2022). These figures corroborate peer-reviewed studies across multiple countries that demonstrate that chronic pain is associated with decreases in working capacity (e.g. ability to work fulltime and/or maintain employment) (Gaskin & Richard, 2012; van Leeuwen et al., 2006).

Financial Resources

Related to working capacity is the financial resources available to an individual. Financial resources refers to how well an individual's financial means meet up to their needs and expectations (World Health Organization, 2012). Financial stability is a fundamental determinant of QoL as it influences an individual's sense of security, impacts mental health, and typically determines access to resources. Financial strain and the inability to meet basic needs is highly associated with stress, heightened anxiety, and depression (Richardson et al., 2017). In some cases, this instability creates a vicious cycle, whereby insecurity leads to the symptoms of depression, which in turn impairs earning potential, leading to desperate financial decisions and increased economic strain (Butterworth et al., 2009). Debt further exacerbates the harm on mental health caused by financial instability,with debt being linked to increased suicidal ideation (Turunen & Hiilamo, 2014). By contrast, financial stability enables an individual to access healthcare services, educational opportunities, and leisure and social activities—all of which positively contribute to QoL. For example, individuals with higher socioeconomic status tend to engage in healthy lifestyle behaviours such as regular exercise and balanced diets (Pampel et al., 2010). Financial security also fosters optimism about the future.

The relationship between income and QoL in the UK requires further research (Office for National Statistics, 2023). Findings indicate that income increases happiness and life satisfaction up to a level where basic needs, financial security, and a comfortable standard of living are met (Office for National Statistics, 2019). The ONS 2023 report on QoL emphasizes that, while income is a crucial determinant of wellbeing, its relative importance plateaus once financial stability is reached, with health, relationships, and community engagements then become more significant predictors of overall life satisfaction (Office for National Statistics, 2023). Similarly, it has been argued that beyond this point, factors such as job satisfaction, work-life balance, and social relationships exert a stronger influence on wellbeing than additional financial resources (Lane, 2000). However, economists dispute whether happiness levels off in rich societies. Using multi-country data across income ranges, researchers have found that life satisfaction keeps rising with income without a clear ceiling (Stevenson & Wolfers, 2013). In fact, most studies do not include high net worth individuals and therefore current research likely misrepresents the reality of how significant wealth affects QoL. While the relationship between wealth and QoL may weaken at high incomes, it does not flatline; and even small statistical gains mean the much-claimed happiness plateau in wealthy democracies is not absolute.

These phenomena mean that reductions in working capacity and income caused by chronic pain are both devastating to the financial resources available to an individual and their household and to their mental health. For instance, sufferers of musculoskeletal disorders, such as chronic pain, account for around 20% of benefit recipients in the UK, with sickness absence from incapacity estimated to cost over £100 billion annually (Black, 2008; Phillips, 2009). Chronic pain sufferers also earn less than their peers—with one 2002 Dutch study estimating that mean household incomes were between $2000-4000 less if one adult was affected by chronic pain (Gaskin & Richard, 2012; Kemler & Furnée, 2002). In addition to the impacts on an individuals' income, there are also often costs associated with the informal care provided by loved ones (e.g. loss of earnings), and costs associated with formal social care interventions (e.g. home care, respite care) (Hadi et al., 2019; Kemler & Furnée, 2002). Moreover, out of pocket expenses, such as multiple prescriptions, can be substantial (Kemler & Furnée, 2002). A historical study found that patients using both narcotic and sedative medications spent significantly more on pain medication per month compared to those using no addicting medications or narcotics alone (Turner et al., 1982). While this data is older, it illustrates a pattern that likely persists.

Critiques of QoL as a Construct Applied to Chronic Pain

While the concept of QoL has become a cornerstone of clinical research, its application to chronic pain reveals challenges around validity and interpretability—as well as differences between the construct's theoretical aims and the lived experience of those it has been applied to. First, QoL instruments—whether generic tools like the 36-Item Short Form Survey Instrument (SF-36) (Ware & Sherbourne, 1992) and the EuroQol-5 Dimensions Five-Level Version (EQ-5D-5L) (Rabin & de Charro, 2001), or pain-specific measures such as the Brief Pain Inventory (Cleeland & Ryan, 1994)— rely on cross-sectional measurement time points that fail to capture the continuous, dynamic interplay of coping and “flare ups” (i.e. episodes of increased pain and disability) that characterise living with chronic pain. Moreover, people with chronic pain often recalibrate their expectations and standards of wellbeing in a process known as “response shift” (Rapkin & Schwartz, 2004)—something that cross-sectional QoL measures do not helpfully capture.

The multidimensionality of QoL also presents another issue. As described in the literature review above, discretely dividing out functional domains which, in reality, overlap (e.g. AoDL and mobility, presents an overly reductionistic view of chronic pain. For example, although most QoL scales treat social functioning as discrete domain from psychological functioning, the impact of chronic pain on mood cannot be neatly separated from its influence on social functioning (and vice versa), as the relationship between these factors is dynamic and bidirectional. This and other shortcomings obscure the relationships between these QoL domains, as well as obscure the adaptive coping strategies sufferers may apply. For example, the dynamic relationship between physical pain intensity, the psychological processes of catastrophising and self-efficacy, and the availability of social support are important to coping, but the cross-domain nature of this coping process is not neatly capturable by a standard QoL measure (Giardino et al., 2003; Jensen et al., 2001). Moreover, by privileging such discreate domain scores, QoL measures tend to diminish the value of the interpersonal contexts and meaning-making processes that shape a person’s perception of their QoL and experience of wellbeing.

A third critique of the construct of QoL pertains to the cultural and linguistic biases inherent to standard QoL instruments. Chronic pain is experienced within an individual's sociocultural context—an environment that dictates the norms around what are acceptable forms of help-seeking or expressions of distress (e.g. stoicism, passivity). Yet most validated QoL tools were developed in North American or Western European populations and subsequently translated—rather than culturally co-constructed within mixed ethnic and cultural groups. This Western-centric approach can lead to a misrepresentation of the burden of chronic pain in minority, or non-Western, populations, who may have different emphases on community life or spiritual wellbeing—domains which are rarely assessed by QoL scales.

Finally, the focus of QoL research on symptom reduction (e.g. pain intensity) as a proxy for wellbeing overlooks the deeper processes that individuals with chronic pain oftentimes undergo. For example, individuals with chronic illnesses can undergo post-traumatic growth through meaning-making, adapting life goals, and taking on new social roles (Danhauer et al., 2013; Tedeschi & Calhoun, 2004). However, the domains of QoL (and by extension standardized QoL questionnaires), rarely probe the transformation in values or identity that can accompany long-term illnesses like chronic pain. In neglecting these aspects of suffering and growth, the construct of QoL in chronic pain runs the risk of perpetuating biomedical paradigms that privilege symptom reduction over thriving as indicators of QoL.

Taken together, these critiques could be an argument for further work to reconceptualise QoL in the context of chronic pain—for instance through exploring how to integrate longitudinal, qualitative, and culturally-relevant methodologies which can recognise the complexities of chronic pain and QoL, alongside traditional psychometric scales. Only by addressing these gaps can QoL measures more usefully reflect the complex reality of living with chronic pain.

Current Treatments for Chronic Pain

As demonstrated in the previous sections, the subdomains of QoL are interconnected and chronic pain significantly diminishes every aspect of QoL—often leading to negative feedback cycles where declining QoL affects physical and psychological functioning, work and economic circumstances, and social relationships, which in turn worsen chronic pain perceptions. Likewise, the negative impact of chronic pain therefore extends beyond the individual to affect families, communities, and societies. The following sections will now go on to examine some of the current NHS treatments of chronic pain as a means to examine how services currently attempt to address the costs of chronic pain.

Given its complex impacts, chronic pain rehabilitation requires interdisciplinary biopsychosocial interventions which address the physiological, psychological, and social dimensions of the condition. Best practice interventions should therefore integrate care from general physicians, occupational therapists, specialist anaesthesiologists, nurses, physiotherapists, and clinical psychologists. The use of pharmacological interventions alone for chronic pain is controversial. While antidepressants appear to offer modest efficacy in modulating pain, recent National Institute for Health and Care Excellence (NICE) guidelines strongly discourage the use of opioids, non-steroidal anti-inflammatory drugs (NSAIDs, e.g. Ibuprofen), and paracetamol due to limited long-term benefits and significant risks (NICE, 2021). Meanwhile, physiotherapy for chronic pain oftentimes involves graded exercise programmes that aim to reverse deconditioning and ameliorate pain-related avoidance habits. This can sometimes be complemented by alternative therapies such as acupuncture or massage, however these are typically not remedial.

Non-invasive and non-pharmacological treatments are increasingly considered useful to fostering sustainable positive outcomes for chronic pain patients. This includes evidence-based psychological therapies that target pain fear and avoidance behaviours as well as maladaptive cognitive, emotional, and behavioural responses to pain. Three of the main psychological therapies currently used for chronic pain are: cognitive Cognitive-Behavioural Therapy (CBT), Acceptance and Commitment Therapy (ACT), and Mindfulness-Based Stress Reduction (MBSR). CBT aims to modify catastrophic thoughts using cognitive restructuring and behavioural activation and has been demonstrated to offer approximately 30-50% reduction in pain experiences (Driscoll et al., 2021; Sturgeon, 2014). However, CBT is limited in its efficacy given it privileges a focus on internal experiences over graded exposure to pain avoidance in the service of behavioural change. This contrasts with ACT, which is clinically considered the gold standard treatment type for clinical health conditions such as chronic pain. ACT focuses on increasing psychological flexibility through pain acceptance and committed values-based action. Given its emphasis on behavioural change though graded exposure as well as internal experiences, and its focus on holistic change, ACT is used at both NHS national specialist inpatient centres for chronic pain in the UK (McCracken et al., 2022). ACT has been shown to have efficacy at least as good as CBT, but is more difficult to research and is therefore requires ongoing development of a robust an evidence base (Feliu-Soler et al., 2018). MBSR is based in mindfulness and meditational practices and aims to create distance between the experience of pain and the secondary emotional suffering that occurs in response to it by decoupling the sensation of pain from emotions/thoughts. MBSR interventions indicate around a 20-35% reduction in pain interference in daily life (Driscoll et al., 2021).

The efficacy of ACT versus CBT remains an area of some debate. While meta-analyses show a CBT is slightly superior in short-term pain reduction (d=0.41 vs ACT's d=0.35), ACT demonstrates advantages in long-term chronicity management (Driscoll et al., 2021; Feliu-Soler et al., 2018). That is, research indicates ACT is superior in cost-effectiveness (i.e.. 32% lower healthcare utilization post-treatment), higher adherence (i.e. 18% lower dropout rates versus CBT), and superior long-term gains (i.e. in psychological flexibility and pacing) (Driscoll et al., 2021; Feliu-Soler et al., 2018)—but it is a newer approach and requires ongoing development for its evidence base. Debate over the two approaches centres on the priorities privileged by each model— CBT is primarily symptom-focused, while ACT is function-focused (Hayes, 2004). Specialist treatment increasingly combines the cognitive techniques of CBT with the values-based committed action approach of ACT, potentially mitigating limitations of either approach alone. Whatever approach is applied for patients, current recommendations reflect a paradigm shift toward rehabilitation and functional restoration rather than the elimination of pain (NICE, 2021). Overall, the NICE framework reflects a priority of psychological interventions (ACT/CBT) over biomedical models, an emphasis on supervised exercise programs to restore physical functioning, and cautious use of antidepressants (NICE, 2021). While NICE these guidelines steer practice toward integrated psychological and physical therapies, optimal outcomes continue to require clinician flexibility in matching and tailoring interventions to patients' recovery goals.

Chronic Pain Rehabilitation

Given the biopsychosocial presentation of chronic pain, clinical psychologists are well-equipped to work alongside sufferers (Burrell & Robinson, 2019). A core skill of the profession is formulation, or the summarisation and integration of biopsychosocial causal factors in order to collaboratively form longitudinal hypotheses around presenting difficulties and design a treatment approach (Burrell & Robinson, 2019). In the context of chronic pain, these formulations are best conducted using the lenses of a multidisciplinary team of practitioners—such as physiotherapists, occupational therapists, medical staff (e.g. anaesthesiologists and nurses), and psychologists. Therefore, tertiary-level National Specialist treatment centres in the UK utilise multidisciplinary team formulations which integrate these disciplines to best explain a patient's presentation and devise a treatment plan. The current evidence base supports the use of two theoretical frameworks in the formulation of chronic pain—cognitive behavioural therapy (CBT) and acceptance and commitment therapy (ACT) (NICE, 2021). Therefore, the next sections will now briefly look at how both CBT and ACT are typically used in a clinical setting for chronic pain.

Cognitive Behavioural Therapy Formulation

CBT formulates chronic pain by considering the relationship between thoughts, emotions, behaviours, and body sensations. These automatic responses are considered within the context of experiences, and the beliefs/assumptions these experiences led an individual to form. A formulation and treatment plan are typically constructed based on these experiences and response patterns. It is oftentimes helpful for any clinician engaging in this sense-making process to hold in mind that fear of pain and avoidance is initially a common-sense response to pain and is at its core an adaptive response—not an indication of a mental health difficulty (Bunzli et al., 2016). Interventions based on a cognitive behavioural formulation may therefore include cognitive restructuring (e.g. thought challenging), psychoeducation about the impacts of pain and how it relates to thoughts/emotions/behaviours, relaxation, pacing, behavioural activation, and behavioural experiments. Strategies to interrupt maintenance cycles are then developed to facilitate the development of new ways of thinking and coping. For example, a patient may be experiencing negative cognitions around their loss of role because of chronic pain. These thoughts would likely curb the patient's motivation to engage in enjoyable or meaningful activities, further reinforcing their belief that they are not capable. The lack of meaningful activities might then further damage the client's sense of self-worth, leading to in a vicious cycle that increasingly harms their sense of self. A CBT intervention in this instance could be a combination of behavioural activation and the use of a diary to challenge these thoughts while engaging in pleasurable activities would begin to generate an evidence base for the client to use to disprove their negative beliefs around their capacities and to raise their mood. Particular attention would need to be given to challenge any thoughts that further reinforce the old beliefs around worthlessness. Relaxation techniques might also be taught to help address stress.

Acceptance and Commitment Therapy (ACT) Formulation

ACT is a newer, third wave, therapy developing out of cognitive and behavioural therapies (Hayes, 2004). There are six core factors targeted for intervention within ACT with the aim of developing psychological flexibility. These factors are: acceptance (i.e. allowing thoughts, body sensations, and feelings to come and go without getting hooked into an internal struggle with them—including pain and distress); cognitive defusion (i.e. the ability to observe and label internal experiences and external events from the non-judgemental stance of an observer, rather than being absorbed within them); present moment awareness (i.e. is a state of being actively aware of internal reactions and experiences as they occur); self as context (i.e. an awareness that an individual is more than their experiences or roles within society, but that those events and roles are experienced by a self that has intrinsic value); values (i.e. the domains of life that give an individual meaning and purpose, such as family/community, career, leisure, spirituality, health/wellbeing); and finally, committed action (i.e. values-led behaviours and goals that take an individual towards what they would define as living a meaningful life).

It is important to note that, in contrast to CBT, there is no attempt to restructure thoughts, as in ACT change is sought around how an individual engages with and reacts to their thoughts/emotions/sensations—rather than attempting to control or alter internal experiences.

Instead ACT clinicians support clients in moving away from a curative stance towards their chronic pain (i.e. confronting the difficult reality that their chronic pain is in fact not curable), towards a stance of acceptance that although pain will be present, it need not define them and dominate their lives (Burrell & Robinson, 2019). For example, a client who is struggling with their sense of self following the development of chronic pain may need support in exploring their self as context (rather than self as content) and how to continue moving towards their values domains though committed actions that allow them to mindfully engage in activities that are meaningful to them. The thoughts of self-worth would not be challenged in this case, but instead the client would be encouraged to focus on taking committed actions despite the presence of these negative "passenger" thoughts. The overall goal of the therapy is therefore to allow the patient to flexibly find paths that allow them to continue to live a meaningful life even though pain and distress are present.

An Example of NHS Surgical Intervention

Another example of an intervention commonly used in the NHS to address primarily joint stability, but which may also possibly impact chronic knee pain, is anterior cruciate ligament (ACL) reconstruction surgery. Knee pain is a significant health concern with far-reaching implications for individuals' physical functioning and psychological wellbeing. The causes of knee plan are multifaceted and can be due to a combination of both predisposing and external factors, including osteoarthritis, injuries (e.g. sprains or tears), or tendonitis (Sarmanova et al., 2018). Epidemiological data indicates that between 25-46% of adults suffer from knee pain (Kim et al., 2011; Nguyen et al., 2011), with women reporting higher rates than men (58% and 32%, respectively) (Kim et al., 2011). Concerningly, the prevalence of knee pain is expected to increase to close to one billion by 2050 as the population ages and osteoarthritis (the primary cause of knee pain) becomes more common (Steinmetz et al., 2023). Rising rates of obesity and sedentary lifestyles have also been identified as contributing to this trend (Steinmetz et al., 2023).

Knee pain has a multidimensional impact on QoL. In relations to physical abilities, knee pain sufferers report significantly worse physical functioning on measures such as the Western Ontario and McMaster Universities Osteoarthritis (WOMAC) Index and Short Form 12 (SF-12) (Bellamy et al., 1988; Ware et al., 1996). The limitations that knee pain places on mobility can lead to deconditioning and weight gain. Knee pain also dramatically impacts sufferers socially and psychologically (Chaidou et al., 2022). Froe example, the decreased mobility caused by chronic knee pain can lead to social isolation, a decrease in participation in valued activities such as leisure, work, and the activities of daily living, and depression (Chaidou et al., 2022). As such, the wide-reaching impacts of knee pain showcase the need for a holistic, biopsychosocial, and interdisciplinary approach to understanding and rehabilitating those suffering from knee pain.

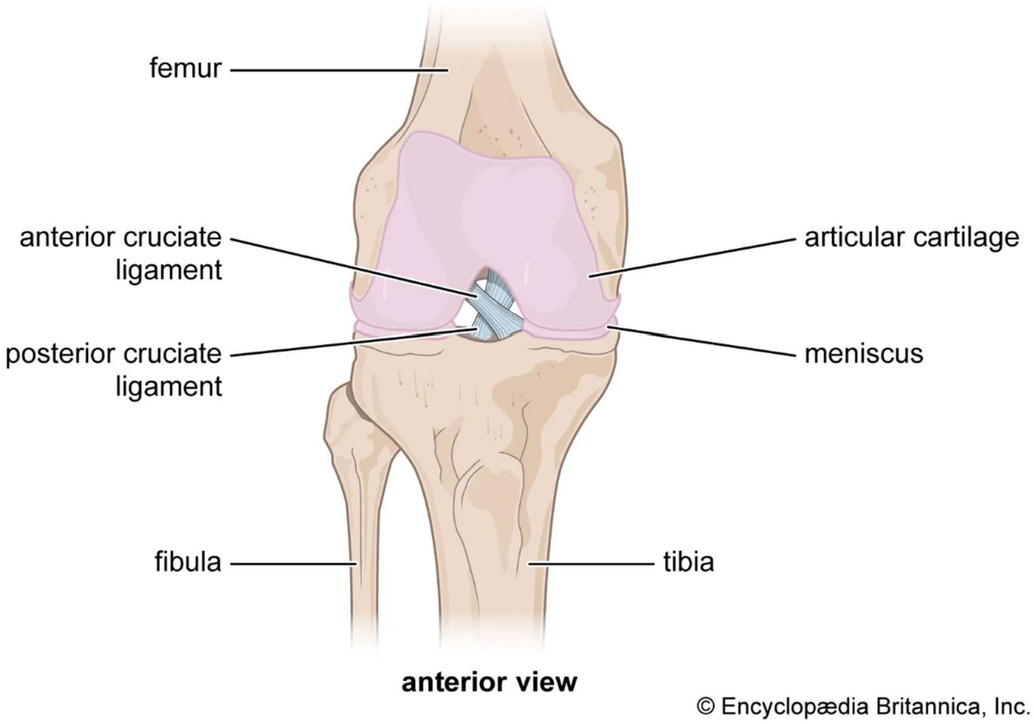
Anterior Cruciate Ligament (ACL) Reconstructive Surgery.

The ACL is a ligament in the knee that gives stability during movement (Figure 2). ACL reconstruction surgery repairs the ACL after it has been torn (Abram et al., 2019). ACL reconstruction surgery is a common procedure. For example, in the United States, annual ACL reconstruction rates are around one hundred thousand procedures per year. However, the evidence indicates a gender discrepancy in reconstruction rates, with women being up to eight times more likely to require surgery in adolescence as compared to men (Csintalan et al., 2008). Moreover, there are two peaks over the life course of injury, ages 14-17 (due to muscular and hormonal factors) and 45-49 (linked to workplace injuries) (Csintalan et al., 2008). The ACL is typically torn during highly demanding activity involving the knee (e.g. pivots, sudden stops, or jumping). Studies indicate that 65% of tears occur during pivoting activities, with football and basketball accounting for 40% of injuries (Csintalan et al., 2008).

While not everyone requires surgery, the procedure is particularly indicated for those who wish to return to intense physical activity levels for employment or leisure purposes.

Figure 2

Anterior anatomical view of the knee, including anterior cruciate ligament (Copyright Encyclopaedia Brittanica)

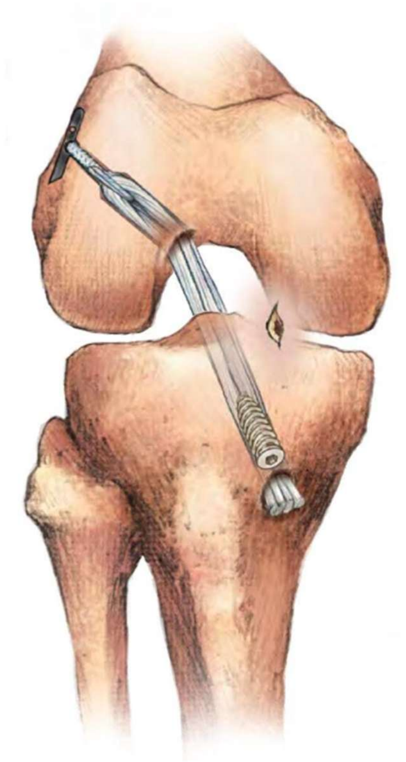


ACL reconstruction surgery can be conducted as a less invasive, key-hole surgery—i.e. through small incisions and using a camera to guide the surgeon (Di Paolo et al., 2021; Sonnery-Cottet et al., 2017). The aim of surgery is to replace the damaged ligament with a graft from the patient's own body (e.g. a hamstring tendon), or from a donor, in order to stabilise the knee—but the procedure does not necessarily reduce pain—meaning patients may in fact be left with chronic pain or may have an improvement in knee pain (Abram et al., 2019). The surgeon prepares the knee for the graft by removing the damaged ACL. Next, holes are drilled into the thigh and shin bones and the graft is threaded through these holes and secured (Figure 3). Overtime, the body develops new tissue around the graft, strengthening the knee. Post-operatively, patients are encouraged to begin movement early on to avoid stiffness, beginning with physiotherapy to regain strength, stability, and flexibility in the knee (Shelbourne & Nitz, 1990). Jumping and running are not recommended until the knee is fully healed. The overall success of ACL reconstruction surgery depends on many factors, including pre-operative physical strength, engagement in appropriately paced and consistent rehabilitation, other injuries sustained during the incident, and psychological readiness/motivation (Abram et al., 2019).

Numerous studies have examined whether ACL reconstruction surgery leads to significant improvements in QoL—oftentimes using validated measures such as the Knee injury and Osteoarthritis Outcome Score (KOOS) QoL subscale. Large cohort studies have consistently reported significant post-operative gains in KOOS QoL subscales. For example, a study analysing data from over 45,000 patients who underwent ACL reconstruction between 2005 and 2019 found statistically and clinically meaningful improvements across all KOOS subscales from pre-operative assessments to 1- and 2-year follow-ups, with the greatest gains noted in the QoL and sport/recreation subscales (Winkler et al., 2023). Another study followed patients for up to 10 years post-ACL reconstruction and found sustained improvements in QoL (Magnussen et al., 2015). Similar results were found at 2 years, 6 years, and 10 years post-operatively in KOOS scores, suggesting that the benefits of surgery extend into the long term for many patients (MOON Knee Group et al., 2018). Research focusing on older patients (>50 years) also demonstrated that this demographic can achieve substantial QoL improvements after ACL reconstruction, countering earlier assumptions that age may be a limiting factor. In this population, functional knee scores, psychological well-being, and KOOS QoL scores all improved post-operatively (Çokyaşar et al., 2023).

Figure 3

Image of the post-operatively reconstructed ACL ligament (Ozer, 2025)



Factors Impacting ACL Reconstruction Surgical Outcomes and Quality of Life. A complex combination of physical, demographic, surgical, and psychological factors appear to have a significant influence on whether ACL surgery translates into QoL gains. The most consistent predictors of little gain in QoL include: higher baseline KOOS scores (as these reduce the available margin for improvement), comorbid injuries that complicate recovery (e.g. cartilage or meniscal damage), revision surgery, and demographic factors (Filbay et al., 2014; Kaarre et al., 2023; Koca et al., 2023). Pre-operative physical characteristics such as quadricep strength, limitations on range of motion in the knee (i.e. flexion), and high levels of pain negatively impact recovery (Valk et al., 2013). Patients undergoing simultaneous repair of the meniscus or cartilage will often report lower scores on self-reported measures of function (e.g. Knee Injury and Osteoarthritis Outcome Scale) (MARS Group et al., 2017). Moreover, patients who struggle with adherence to rehabilitation protocols may have poorer QoL post-operatively (Mihelic et al., 2011).

While there is significant evidence demonstrating that many patients report meaningful improvements in QoL after ACL reconstruction, a significant minority do not. A systematic review assessing long-term outcomes (≥5 years) after ACL reconstruction concluded that while many patients report subjective improvement, knee-related QoL scores often remain below population norms of those without any knee injuries—with contributors to poor outcomes included osteoarthritis, meniscal injuries, and repeat surgical interventions (Filbay et al., 2014). Moreover, a major registry-based study involving over 16,000 patients found that approximately 44% did not achieve the minimal important change on the KOOS Sport/Recreation and QoL subscales one year after ACL reconstruction (Kaarre et al., 2023). Key predictors of poor outcomes in this study included being female or younger, the presence of cartilage damage, and higher baseline KOOS scores. Finally, a matched-pair analysis comparing primary ACL reconstruction patients to those undergoing a revision surgery found the latter group had significantly worse long-term outcomes—that is, at a 5-year minimum follow-up, patients in the revision group reported reduced satisfaction, lower KOOS QoL scores, and poorer functional outcomes, despite engaging in similar activity levels (Koca et al., 2023). In summary, ACL reconstruction is associated with substantial QoL improvements in a majority of patients, but outcomes are not universal. The KOOS QoL subscale has proven particularly sensitive in capturing these differences however.

Evidence for the role of gender on QoL outcomes is more complex and remains the subject of some debate. Although males are more likely to require ACL reconstruction, studies indicate that females are more at risk of ACL injury comparted to males due to anatomical differences in the quadricep/tibial angle and increased laxity (Devana et al., 2022). While some studies have reported no significant differences in ACL reconstruction outcomes between males and females (Salmon et al., 2006), others have indicated that males have improved outcomes (Senorski et al., 2019) and females experience greater rates of failure (MARS Group et al., 2017). Interestingly, five years post-operatively, females appear to be less likely to return to pre-injury activity levels (Bruder et al., 2023; Tan et al., 2016), which may be why females report lower ratings on the sports and recreation domains on self-reported measures, even where there are no significant differences in their symptoms, pain, AoDL, and QoL (Swirtun & Renström, 2008). However, on balance, gender appears to inconsistently impact the QoL outcomes of patients after ACL reconstruction (Ferrari et al., 2001; MOON Knee Group et al., 2018). Surgical factors and comorbidities are also important to determining ACL reconstruction success and post-operative QoL (Barenius et al., 2010).

Regardless of gender, two key health behaviour factors are particularly highlighted in the literature and in clinical practice as potentially playing a role in post-operative outcomes and QoL—smoking status and body mass index. Tobacco smoking, defined as the inhalation of smoke from burning tobacco products such as cigarettes, cigars, or pipes, remains one of the leading preventable causes of death worldwide. While the physiological consequences of smoking have been extensively documented, ranging from cardiovascular diseases and respiratory disorders to cancer—the impact of smoking on an individual's QoL is often overlooked (Doll et al., 2004). Smoking is associated with significantly lower QoL scores, with smokers consistently reporting poorer physical functioning, increased pain, lower energy levels, and greater limitations in performing daily activities when compared to non-smokers (Coste et al., 2014; Rezaei et al., 2017; Strandberg et al., 2008; Vogl et al., 2012). However, beyond the physical health consequences, smoking also adversely affects the psychological and social dimensions of QoL. For example, studies have identified a strong correlation between smoking and increased rates of depression, anxiety, and perceived stress—suggesting a bidirectional relationship in which tobacco use both contributes to, and is maintained by, poor mental health (Mykletun et al., 2008). Furthermore, smoking-related stigma, social isolation, and the economic burden (i.e. through the cost of tobacco products), further diminish overall QoL (Crittendon et al., 2024).

The negative impact of smoking on healing after surgery has been extensively documented. For example, a systematic review concluded that smoking impairs healing by reducing adaptive inflammatory responses, reducing collagen synthesis/deposition, and reducing oxygenation and metabolic recovery processes (Sørensen, 2012). For ACL surgery specifically, research also indicates that smoking status is a key determinant in post- ACL reconstruction QoL outcomes. A 2006 study indicated that pain intensity, pain frequency, and joint instability/laxity were worse post-operatively for smokers (Karim et al., 2006). A 2016 systematic review of the literature corroborated these findings, highlighting that studies consistently found that smokers reported significantly poorer scores on outcome measures, were at higher risk of complications post-surgery (i.e. developing infections), and had increased joint instability (Guskiewicz et al., 1995; Keizer & Otten, 2019; Novikov et al., 2016). Moreover, smokers were less likely to return to their pre-injury levels of activity (Karim et al., 2006). More positivity, research also suggest that smoking cessation can rapidly restore tissue oxygenation and increase healthy inflammatory responses within a month—suggesting that smoking cessation counselling should be a part of pre-operative discussions with patients (Sørensen, 2012).

Body Mass Index (BMI) has also been shown to typically play an important role in QoL. BMI is a widely used measure that assesses an individual's body weight relative to their height; providing a non-invasive measurement tool for categorizing individuals into underweight, normal weight, overweight, or obese weights (WHO, 2000). While a measure of BMI does not allow for the differentiation between body fat and lean mass, it remains a practical indicator of health outcomes (Bhurosy & Jeewon, 2013). Numerous studies have shown that individuals classified as overweight or obese according to BMI consistently report lower scores of QoL, particularly in physical functioning and general health (Jia & Lubetkin, 2005; Kolotkin et al., 2001). Higher BMIs are also linked to increased rates of depression, reduced self-esteem, and social stigmatization (Atlantis & Baker, 2008). An analysis of a global health dataset of over ten thousand participants indicated that underweight (BMI < 18.5) and morbidly obese (BMI ≥ 40) individuals report significantly lower QoL scores when compared to normal-weight peers (Kolotkin et al., 2012). The relationship between BMI and QoL is further complicated by the presence of comorbid conditions. Obesity is a major risk factor for numerous chronic illnesses, including type 2 diabetes, cardiovascular disease, and osteoarthritis, all of which also lower QoL (Finkelstein et al., 2003). The compounding effect of these conditions may explain why there appears to be a dose-dependent relationship between QoL and BMI; i.e. individuals in higher obesity categories report increasingly poorer QoL (Han et al., 2011). Gender also has an effect—with women demonstrating steeper QoL reductions per BMI unit increase compared to men, potentially reflecting sociocultural pressures on women's body image (Zhang et al., 2019). Importantly, even small reductions in BMI have been associated with meaningful improvements in QoL. Evidence from intervention studies indicates that weight loss is frequently accompanied by enhancements in physical mobility, pain reduction, and improved mood and social engagement (Dixon et al., 2008). This suggests that BMI can be a modifiable factor through which QoL may be enhanced.

Considering the effect of BMI on QoL within the context of surgery, a study of approximately 30,000 patients undergoing orthopaedic surgery of the knee or hip found that patients with higher BMIs were at greater risk of post-operative complications (e.g. infections and in-hospital medical events), were less likely to be discharged home and had longer hospital stays, lost more blood during surgery, and had higher rates of readmission than those with normal BMIs (Abdulla et al., 2020). In the context of ACL reconstruction, a large, multi-site study demonstrated that higher BMI was also associated with poorer self-reported outcome measures two years post-surgery (MARS Group et al., 2017). This may be because increased weight places greater strain on the reconstructed ligament, potentially compromising long-term stability and limiting activity. Moreover, higher BMI's may in some cases limit engagement in post-surgical rehabilitation, further contributing to worse long-term QoL outcomes.

Research has also demonstrated that psychological factors are particularly important to QoL after surgery as challenges such as fear of reinjury, coping with pain, pain catastrophising, kinesiophobia (i.e. fear of movement), and pain-related fear avoidance can interfere with rehabilitation and instead facilitate the development of chronic pain (Tavares et al., 2022). In addition, many patients fear reinjury, which increases hesitation towards participating in the activities of daily living or sport, even after full physical recovery from the initial injury. As previously described, patients who are hypervigilant to the experience of pain often have slower recoveries as they avoid the necessary movement and rehabilitation that facilitates healing. Moreover, research also shows that pain catastrophizing predicts prolonged disability post-reconstruction—again operating through the mechanism of avoidance. Patients also often find that motivation can be challenging, as the long and slow process of rehabilitation can be disheartening. Social and rehabilitation support is therefore particularly important during the recovery process to avoid the development of such psychological barriers. By contrast, preoperative psychological readiness and the absence of kinesiophobia have also been shown to drive positive QoL outcomes. Patients displaying higher levels of psychological readiness and lower levels of kinesiophobia before surgery are more likely to report improved QoL postoperatively (Tavares et al., 2022). Taken together, the evidence highlights that QoL after ACL reconstructive surgery is multifaceted and influenced by a combination of demographic, psychological, and physical factors—underscoring the importance of addressing modifiable risk factors pre- and post-operatively—and the need for a holistic clinical approach to optimize post-operative QoL outcomes for patients.

Rationale, Objectives, and Research Questions

As demonstrated by this literature review, chronic pain is a major global health concern with substantial personal, social, and economic consequences. Indeed, the UK economy and NHS expenditure is significantly negatively impacted by chronic pain—and will increasingly be so—as the population ages, life expectancies rise, and healthcare sector inflation increases (OECD, 2019; WHO, 2023). While it is widely acknowledged that chronic pain imposes a significant burden on individuals and health systems, what constitutes the 'costs' of chronic pain remains insufficiently defined and inadequately problematized by the literature. Definitions are frequently inconsistent or implicit, with little reflection on how the underlying epistemological assumptions shape what is made visible or invisible by current models. As a result, the field currently lacks a coherent framework for understanding the multi-dimensional nature of the costs of chronic pain.

Economic considerations guiding policy and healthcare spending predominantly frame the burden of chronic pain in terms of direct healthcare expenditures and indirect costs, such as productivity losses (Dueñas et al., 2016; Phillips, 2009), making no mention of what patients themselves consider as costs. This limited focus risks reinforcing a narrow biomedical and economic outlook that overlooks the broader psychological and social costs of living with chronic pain. For example, the emotional distress of feeling like a burden, the stigma surrounding an ailment that is primarily invisible, and the social isolation caused by the episodic nature of the condition, often remain invisible to large-scale socioeconomic costing exercises, despite their profound implications on wellbeing and QoL (De Ruddere & Craig, 2016; Karos et al., 2020).

Such narrow metrics can also perpetuate marginalisation—privileging those aligned with current policies and utilitarian resource allocation rather than reaching populations underserved by healthcare systems (Buchman et al., 2017; Eccleston et al., 2020). This raises important ethical concerns: that is, what and whose costs are being measured, by whom, and for what purpose—concerns particularly highlighted by the highly inconsistent provision of chronic pain services across geographical regions in the UK and availability of only two NHS national specialist treatment centres in the whole of England. To begin to make a coherent case for further funding and expanded public services, commissioners and policy makers need a consistent conceptualisation of the costs of chronic pain, an understanding of the impact of the condition from the perspective of sufferers, and clear evidence of how to ameliorate the full national, psychological, social, and financial impacts of the condition.

Therefore, the following three studies forming this dissertation will aim to address these gaps in the field by generating a coherent conceptualisation of what is understood to be the cost of chronic pain in the academic literature, before examining the QoL impacts of the costs as named by patients themselves. Finally, this thesis will examine the efficacy of one type of current NHS intervention to begin to interrogate if what the NHS is currently providing is sufficient to improve patients' QoL.

Aims and Objective

The overarching objective of this study is to critically examine how the costs of chronic pain are conceptualised and operate in the lives of sufferers, with a view to informing future research and NHS service commissioning and intervention delivery.

The specific study objectives include:

a. *Study 1: A Systematic Scoping Review of How the Cost of Chronic Pain is Conceptualised*

To interrogate how the academic literature of the last decade conceptualises the costs of chronic pain though a systematic scoping review.

b. *Study 2: An Analysis of the Costs of Chronic Pain on Quality of Life as Identified by Patients*

To examine the impact of chronic pain on the QoL factors named by patients themselves in a secondary quantitative analysis of a nationwide dataset (Health Survey for England, 2017).

c. *Study 3: Treating Chronic Pain—An Example of the Effects of an NHS Surgical Intervention for Knee Pain on Quality of Life.*

To explore the QoL outcomes of one type of NHS intervention (i.e. ACL reconstructive surgery), by conducting a secondary qualitative analysis of one service's clinical outcomes dataset.

Research Questions

As such, the research questions for these three studies are as follows:

Study 1:

1. How does the academic literature of the last 10 years characterise and operationalise the concept of the 'cost' of chronic pain in adult populations?
2. Are there differences in the way 'cost' is characterised—for example, by geographical areas, by adults versus older adult populations, or across time?

Study 2: What are the costs of chronic pain on the domains that people with chronic pain name as the most important costs?

Study 3: When controlling for the effects of smoking status and BMI, do patient's scores of knee-related QoL improve six months after surgery? One year after surgery? Two years after surgery?

Chapter 2: A Scoping Review of the Costs of Chronic Pain in Adults

Introduction

As described in the previous chapter, research consistently demonstrates that chronic pain conditions and their common sequelae (i.e. depression and anxiety) comprise the costliest conditions globally (Global Burden of Disease Study 2013 Collaborators, 2015; James et al., 2018). A collection of socioeconomic and psychosocial sequelae is typically cited as the 'costs' of chronic pain (e.g. loss of work, prescription charges, hours of care received, low mood)—however, there is significant heterogeneity in both the constructs measured and the variables used to operationalise these constructs. Moreover, despite the significant body of research into chronic pain, how the cost of chronic pain in adults is understood by the research community remains inconsistent. A preliminary search for other systematic and scoping reviews in relevant databases (e.g. JBI Evidence Synthesis, Cochrane Database of Systematic Review, PubMed, and Epistemonikos) resulted in no other reviews being found on this topic. In fact, the only similar scoping review focused strictly on studies utilising a cost-of-illness methodology for back pain (Zemedikun et al., 2021). Therefore, there remains a clear lack of consensus around how the cost of chronic pain is conceptualised and operationalised.

As such, the following chapter describes a systematic scoping review conducted to interrogate what is meant by the 'cost' of chronic pain in the current academic literature—prior to delving into further quantitative study of the topic in subsequent chapters. A scoping review is an evidence summarization process that aims to clarify concepts or definitions in a particular field by systematically mapping the literature (Aromataris et al., 2024; Tricco et al., 2018). In contrast to a systematic review, scoping reviews do not aim to synthesise evidence, generate new narratives, or result in practice changes—but instead to provide a systematically-created, descriptive map of the current literature (Aromataris et al., 2024).

Therefore, a scoping review is the best suited methodological approach to meeting this chapter's aim to broadly characterise what is currently meant by the 'cost' of chronic pain as a foundation for further research.

Review Questions

This scoping review asks the following research questions:

1. How does the academic literature of the last 10 years characterise and operationalise the concept of the 'cost' of chronic pain in adult populations?
2. Are there differences in the way 'cost' is characterised—for example, by geographical areas, by adults versus older adult populations, or across time?

Methodology

This systematic scoping review was conducted in accordance to the Joanna Briggs Institute and Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) best practice guidelines (Aromataris et al., 2024; Tricco et al., 2018).

Inclusion and Exclusion Criteria

English-language articles published in academic journals from the last ten years which discussed any form of 'cost' to adult, chronic pain populations were included. Sources solely published in academic journals were included as the aim of this scoping review was to elucidate how the academic and associated clinical community conceptualises 'cost' in the context of chronic pain research. Therefore, studies which examined children or acute pain—as well as unpublished, non-academic journal sources, or non-English sources, were excluded. No studies were excluded based on the type of methodological design or geography—therefore, international and both quantitative and qualitative studies were evaluated for inclusion based on the above criteria. Finally, letters to the editor and opinion papers published in academic journals were included in order to capture any current debate on the subject.

Search Strategy

Six academic databases (Scopus, APA PsychINFO, APA PsychArticles, Business Source Ultimate, IDEAS, and MEDLINE Ultimate) were searched for English-language studies published between 2014 and 2024, using a consistent set of key terms. A subject matter librarian was consulted on the search terms and strategy to ensure the robustness of the search strategy. Where available, the database search limiters applied allowed for the automatic exclusion of non-English publications, articles older than 10 years, or articles that addressed groups other than adults. Any minor variations in key terms was based on database interface—however search terms and strategy remained consistent across databases. The exact terms used per database are outlined in Appendix A. References of all studies included in the full-text screening phase of the review were also screened for inclusion.

Study Selection and Screening Process

Once screened for inclusion by title and abstract, articles were uploaded into Zotero reference management software and duplicates removed in preparation for full-text screening. Sources included at this stage were retrieved in full text format and their citation details imported into Zotero. The full text of these selected citations was then examined against the inclusion criteria. Sources were categorised as included for data extraction or excluded using Zotero's organisational facilities. Reasons for exclusion of articles at the level of full text were recorded for each excluded source as a note attached to the reference (Appendix B). Exclusion reasons included: no extractable data (i.e. data reported was not relevant to the research questions, a non-chronic pain sample, methodological commentary only, interventional trials, prevalence or predisposing factors only studies); inclusion of participants less than 18 years old in the sample; and a lack of availability of full-text article.

Any articles included for data extraction after full-text screening then had their references screened for additional sources. The relevant articles from citation screenings were also added into the Zotero reference manager folder, duplicates removed, and included in the full-text screening phase. Appendix C contains a screen capture of the Zotero folder used to organise articles included for full text screening, while Appendix D shows all articles included at full text screening. The results of the search and the study inclusion process is presented in a PRISMA flow diagram (Figure 4) and reported in full below.

Data Extraction and Analysis

In accordance to JBI and PRISMA best practice guidelines, this scoping review followed a deductive approach—that is, a template data extraction table (Appendix E) was created prior to data collection (Aromataris et al., 2024). The extracted data included specific details about the studies (e.g. geographical location, methodology, analyses) and the populations examined (e.g. age group, type of pain, sample size)—as well as details of key cost constructs/variables used per study.

Following a pilot test of the data extraction sheet on two included sources in Microsoft Excel by the researcher, adjustments were made to additionally capture the categories of costs to independence and costs to recreation/leisure. Once all included resources had been identified, the researcher began a process of iterative immersion in the sources and extraction of the data. Immersion in the data indicated this deductive approach was appropriate, as the data extracted using the standardised extraction template appropriately addressed the research questions at hand (Aromataris et al., 2024). Data was extracted into the final version of the standardised data extraction table from each included source (Appendix E).

Once the extracted data had been cleaned and checked for relevance to the research question by the reviewer, the process of analysis began. The decision was made to conduct descriptive and frequency analyses as these methods best addressed the review's aim of mapping how the cost of adult chronic pain is characterised in the current academic literature.

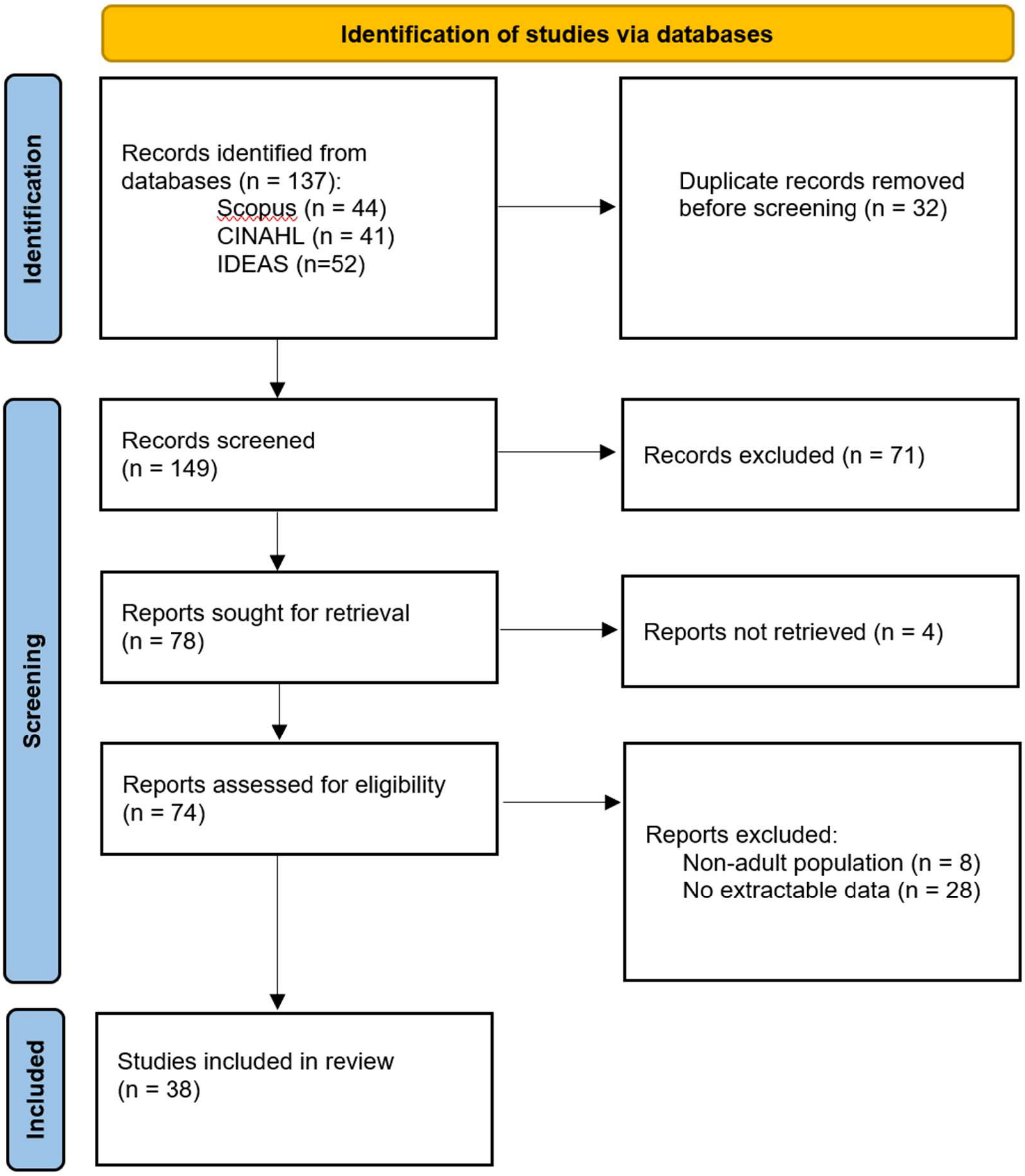
Descriptive and analytic frequency counts were conducted within Microsoft Excel and by hand-written tallies (Appendices E and G). Therefore, the frequency counts are presented below as a means of generating an overview of what is meant by the 'cost' of chronic pain across various fields of study and geographical regions—as well as by chronic pain condition.

Results

The search resulted in a total of articles from 137 from databases and 44 articles from references. From these 181 articles, a total of 32 duplicates were removed—resulting in 147 articles for title and abstract screening. Seventy-one of these articles were removed by title and abstract screening—while 78 were retained for full text screening. Of the 78 articles full-text screened, 40 articles were further excluded based on the aforementioned exclusion criteria—while the remaining 38 articles were included in these analyses. A detailed table including a summary of the main characteristics of the included studies is included in Appendix F.

Figure 4

PRISMA diagram for the scoping review process (adapted from the PRISMA statement by Moher and colleagues (2009)).



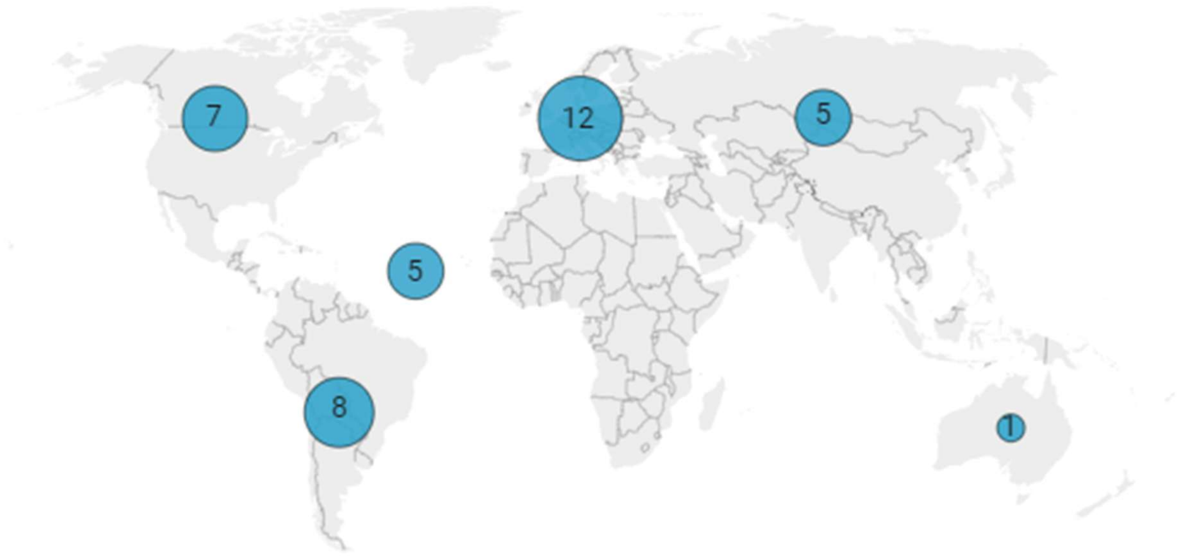
Descriptive Data

The 38 articles included 8 studies from the South America (22%)(Carregaro et al., 2020; Espinoza et al., 2022; Ferretti et al., 2018; Lemos et al., 2019; Mastela et al., 2023; Morete et al., 2018; Paz et al., 2021; Vargas et al., 2018), 7 from North America (18%) (Bazargan et al., 2021; De La Rosa et al., 2024; Domenichiello & Ramsden, 2019; Rasu et al., 2014; D. M. Smith, 2015; Spears et al., 2020; Yang & Grol-Prokopczyk, 2021), 5 from Asia (13%) (Bai & Cheng, 2022; Chen et al., 2022; Inoue et al., 2015; Mohamed Zaki & Hairi, 2014; Xue et al., 2021), 12 from Europe (32%) (Achterberg, 2019; Azevedo et al., 2016; Bernfort et al., 2015; Glette et al., 2021; Hadi et al., 2019; Larsson et al., 2016; Lazkani et al., 2015; Lohan et al., 2023; Mayer et al., 2019; Muñoz Cortés et al., 2022; Nielsen et al., 2021; Wojcieszek et al., 2022), and one from Australia (3%) (Hopkins et al., 2022)(Figure 5). Five studies covered two or more geographical regions or were global (13%) (Chang et al., 2022; Global Burden of Disease Study 2013 Collaborators, 2015; James et al., 2018; Macchia, 2023; Stagg et al., 2024).

Countries represented included: Korea (n=1)(Chang et al., 2022), China (n=2) (Bai & Cheng, 2022; Xue et al., 2021), Denmark (n=1) (Nielsen et al., 2021), Brazil (n=6) (Carregaro et al., 2020; Ferretti et al., 2018; Lemos et al., 2019; Mastela et al., 2023; Morete et al., 2018; Paz et al., 2021), the United States (n=8) (Bazargan et al., 2021; Chang et al., 2022; De La Rosa et al., 2024; Domenichiello & Ramsden, 2019; Rasu et al., 2014; Smith, 2015; Spears et al., 2020; Yang & Grol-Prokopczyk, 2021), Malaysia (n=1) (Mohamed Zaki & Hairi, 2014), Spain (n=1) (Muñoz Cortés et al., 2022), Japan (n=1)(Inoue et al., 2015), Chile (n=2) (Espinoza et al., 2022; Vargas et al., 2018), the United Kingdom (n=2) (Hadi et al., 2019; Lohan et al., 2023), Australia (n=1) (Hopkins et al., 2022), France (n=1) (Lazkani et al., 2015), the Netherlands (n=1) (Achterberg, 2019), Sweden (n=2) (Bernfort et al., 2015; Larsson et al., 2016), Tiawan (n=1) (Chen et al., 2022), Portugal (n=1) (Azevedo et al., 2016), Poland (n=1) (Wojcieszek et al., 2022), Austria (n=1) (Mayer et al., 2019), and Norway (n=1) (Glette et al., 2021).

Figure 5

Geographical Spread of Studies



NB. Multiregional studies represented by central Atlantic Ocean sphere. NB. Circle placed in the Atlantic Ocean represents the 5 studies which covered two or more geographical regions or were global.

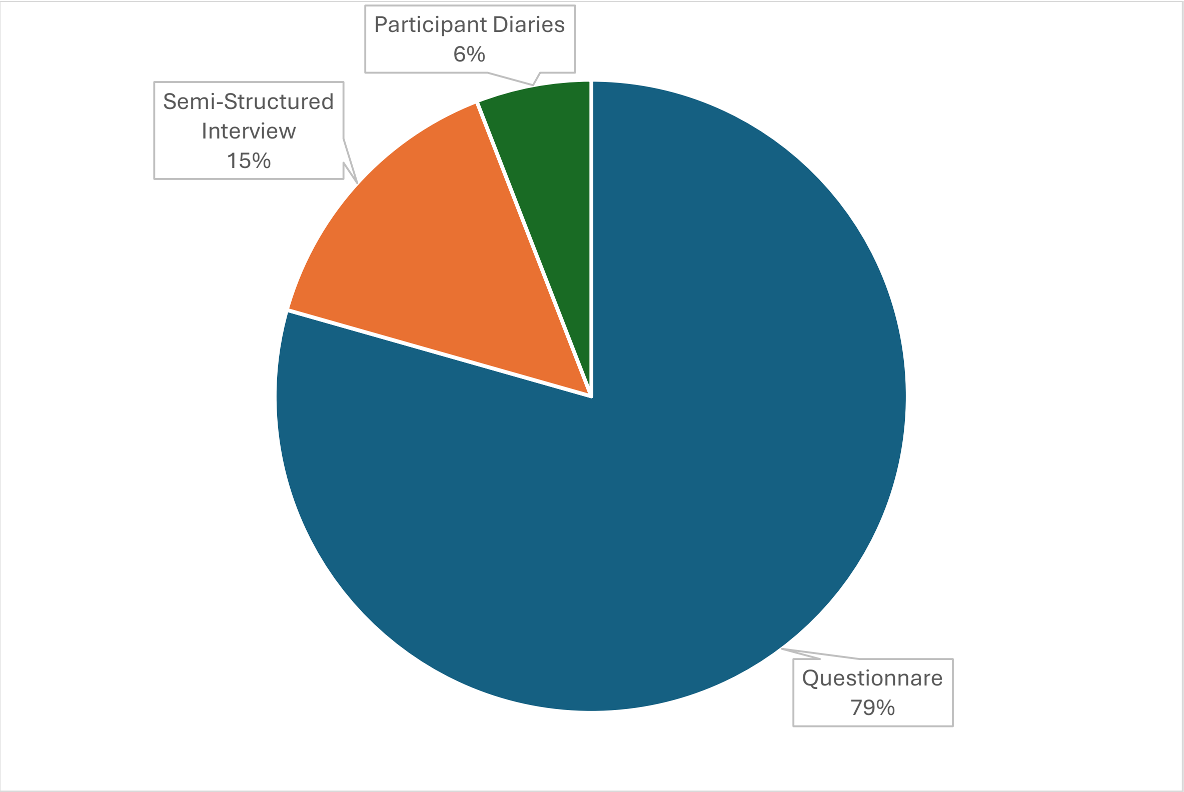
Most studies included participants with a mix of more than two chronic pain conditions (n=30, 79%) (Achterberg, 2019; Azevedo et al., 2016; Bai & Cheng, 2022; Bazargan et al., 2021; Bernfort et al., 2015; Chang et al., 2022; De La Rosa et al., 2024; Domenichiello & Ramsden, 2019; Espinoza et al., 2022; Ferretti et al., 2018; Glette et al., 2021; Hadi et al., 2019; Hopkins et al., 2022; Inoue et al., 2015; James et al., 2018; Larsson et al., 2016; Lazkani et al., 2015; Lemos et al., 2019; Macchia, 2023; Mastela et al., 2023; Mayer et al., 2019; Mohamed Zaki & Hairi, 2014; Morete et al., 2018; Nielsen et al., 2021; Paz et al., 2021; Rasu et al., 2014; Smith, 2015; Stagg et al., 2024; Vargas et al., 2018; Yang & Grol-Prokopczyk, 2021). However, a few studies focused on specific pain conditions—for example, three studies examined the costs of lower back pain (8%)(Global Burden of Disease Study 2013 Collaborators, 2015; S. L. James et al., 2018; Spears et al., 2020), three examined osteoarthritis (8%) (Lohan et al., 2023; Wojcieszek et al., 2022; Xue et al., 2021), one examined rheumatoid arthritis (3%) (Chen et al., 2022), and one examined osteogenesis (3%) (Muñoz Cortés et al., 2022).

Most articles examined adult samples (n= 21; 55%) (Azevedo et al., 2016; Carregaro et al., 2020; Chen et al., 2022; De La Rosa et al., 2024; Espinoza et al., 2022; Glette et al., 2021; Global Burden of Disease Study 2013 Collaborators, 2015; Hadi et al., 2019; Hopkins et al., 2022; Inoue et al., 2015; James et al., 2018; Lohan et al., 2023; Macchia, 2023; Mayer et al., 2019; Muñoz Cortés et al., 2022; Nielsen et al., 2021; Rasu et al., 2014; Spears et al., 2020; Stagg et al., 2024; Vargas et al., 2018; Xue et al., 2021); while 17 studies focused exclusively on samples of older adults (45%) (Achterberg, 2019; Bai & Cheng, 2022; Bazargan et al., 2021; Bernfort et al., 2015; Chang et al., 2022; Domenichiello & Ramsden, 2019; Ferretti et al., 2018; Larsson et al., 2016; Lazkani et al., 2015; Lemos et al., 2019; Mastela et al., 2023; Mohamed Zaki & Hairi, 2014; Morete et al., 2018; Paz et al., 2021; Smith, 2015; Wojcieszek et al., 2022; Yang & Grol-Prokopczyk, 2021). Of the experimental articles included, study sample sizes ranges between 20 and 55,945. However, six of the secondary analysis survey studies, of national or global data, did not list their sample sizes (46%) (Achterberg, 2019; Carregaro et al., 2020; Domenichiello & Ramsden, 2019; Espinoza et al., 2022; Global Burden of Disease Study 2013 Collaborators, 2015; James et al., 2018; Macchia, 2023; Rasu et al., 2014; Stagg et al., 2024; Vargas et al., 2018).

Studies' data collection methods were dominated by the use of surveys—with 27 studies using questionnaire data (79%) (Azevedo et al., 2016; Bai & Cheng, 2022; Bazargan et al., 2021; Bernfort et al., 2015; Chang et al., 2022; De La Rosa et al., 2024; Espinoza et al., 2022; Ferretti et al., 2018; Glette et al., 2021; Global Burden of Disease Study 2013 Collaborators, 2015; Inoue et al., 2015; S. L. James et al., 2018; Larsson et al., 2016; Mastela et al., 2023; Mohamed Zaki & Hairi, 2014; Morete et al., 2018; Muñoz Cortés et al., 2022; Nielsen et al., 2021; Paz et al., 2021; Rasu et al., 2014; Wojcieszek et al., 2022; Xue et al., 2021; Yang & Grol-Prokopczyk, 2021), five using semi-structure interviewing (15%) (Chen et al., 2022; Hadi et al., 2019; Hopkins et al., 2022; Lemos et al., 2019; Stagg et al., 2024), and two using participant diaries (6%) (Mayer et al., 2019; D. M. Smith, 2015) (Figure 6). Sixteen of the studies analysed secondary data (42%) (Azevedo et al., 2016; Carregaro et al., 2020; Chang et al., 2022; De La Rosa et al., 2024; Espinoza et al., 2022; Global Burden of Disease Study 2013 Collaborators, 2015; Hadi et al., 2019; S. L. James et al., 2018; Larsson et al., 2016; Lazkani et al., 2015; Mohamed Zaki & Hairi, 2014; Rasu et al., 2014; Spears et al., 2020; Stagg et al., 2024; Vargas et al., 2018; Yang & Grol-Prokopczyk, 2021)—with the majority of these studies using national survey data (n=11, 29%). Nine studies utilised publicly available health register data (24%) (Azevedo et al., 2016; Carregaro et al., 2020; De La Rosa et al., 2024; Espinoza et al., 2022; Global Burden of Disease Study 2013 Collaborators, 2015; Hadi et al., 2019; James et al., 2018; Larsson et al., 2016; Lazkani et al., 2015; Lohan et al., 2023b; Mayer et al., 2019; Rasu et al., 2014; Spears et al., 2020; Vargas et al., 2018), while only one study utilised private insurance data (3%)(Spears et al., 2020).

Figure 6

Data Collection Methods of Studies



Most studies utilised a quantitative approach to their analyses (n= 28; 74%) (Azevedo et al., 2016; Bai & Cheng, 2022; Bazargan et al., 2021; Bernfort et al., 2015; Carregaro et al., 2020; Chang et al., 2022; De La Rosa et al., 2024; Espinoza et al., 2022; Ferretti et al., 2018; Glette et al., 2021; Global Burden of Disease Study 2013 Collaborators, 2015; Inoue et al., 2015; S. L. James et al., 2018; Larsson et al., 2016; Lazkani et al., 2015; Lohan et al., 2023b; Mastela et al., 2023; Mayer et al., 2019; Mohamed Zaki & Hairi, 2014; Morete et al., 2018; Muñoz Cortés et al., 2022; Nielsen et al., 2021; Paz et al., 2021; Rasu et al., 2014; Spears et al., 2020; Vargas et al., 2018; Wojcieszek et al., 2022; Xue et al., 2021; Yang & Grol-Prokopczyk, 2021). Only a handful of studies conducted qualitative analyses (n= 3, 8%) (Chen et al., 2022; Hopkins et al., 2022; D. M. Smith, 2015) or utilised mixed methodologies (n= 3, 8%)(Hadi et al., 2019; Lemos et al., 2019; Stagg et al., 2024)—while two sources were reviews (5%)(Domenichiello & Ramsden, 2019; Stagg et al., 2024), and two were commentaries (5%)(Achterberg, 2019; Macchia, 2023). Of the quantitative analysis methods described, the vast majority of studies cited the use of a type of regression analysis (n= 24;

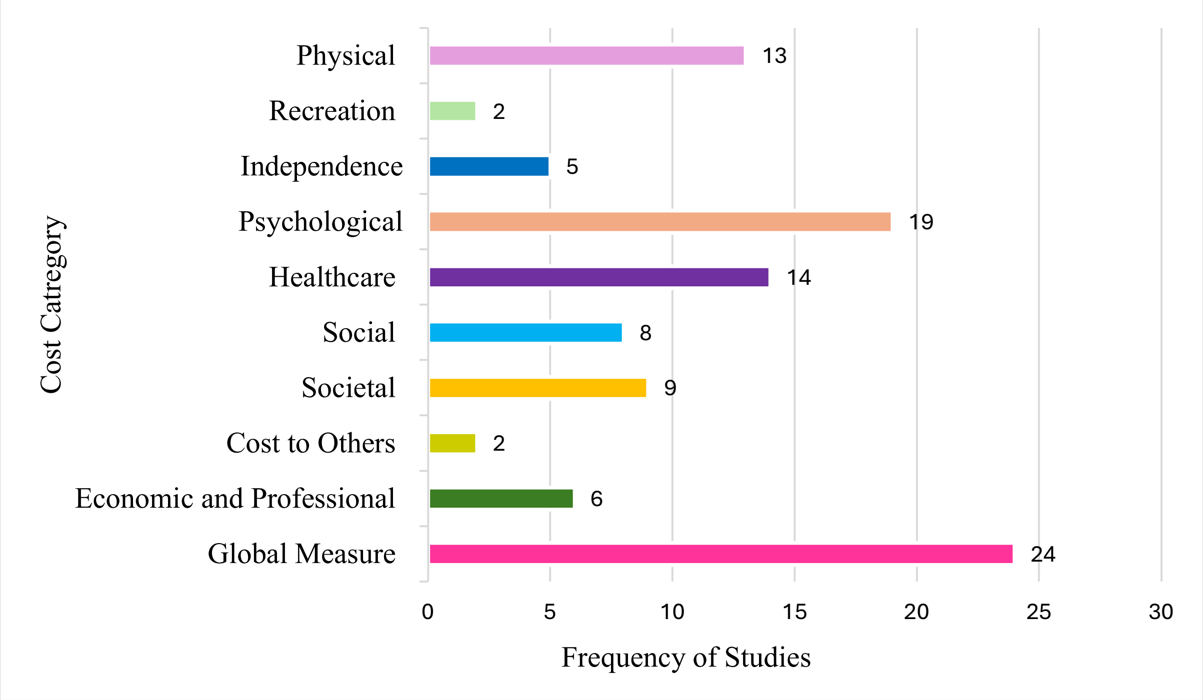
63%); while two used ROC analyses (5%)(Lazkani et al., 2015; Mastela et al., 2023), two used frequency counts (5%)(Rasu et al., 2014; Spears et al., 2020), two used chi-squared tests (5%)(De La Rosa et al., 2024; Wojcieszek et al., 2022). Finally, of the qualitative methodologies described, two used thematic analysis (5%)(Hadi et al., 2019; Hopkins et al., 2022), one used content analysis (3%)(Chen et al., 2022), one used the day reconstruction diary method (3%)(D. M. Smith, 2015), and one used qualitisation (3%)(Stagg et al., 2024).

Constructs and Variables Used to Capture Cost

There was high heterogeneity in how cost was conceptualised, measured, and analysed within studies. However, the constructs and variables used to capture the cost of chronic pain broadly fell into the following categories: Global Measure of Cost (DALY,QALY), economic and professional costs to the individual (e.g. redundancy, loss of pension), cost to others (e.g. informal care), Societal Cost (e.g. productivity loss, gross domestic product, cost to public healthcare systems), Social Cost (e.g. isolation), Healthcare Cost (e.g. prescriptions, healthcare appointments), Psychological Cost (e.g. low mood, anxiety), Costs to Independence (e.g. limited ability to engage in household tasks), Recreation and Leisure Costs, and Physical Costs (e.g. inactivity) (Figure 7). The variables captured within these categories will be described in detail below.

Figure 7

Frequencies of Cost Categories Identified within Studies



Global Measure of Cost

Twenty-four of the thirty-eight included studies identified a form of global cost to those suffering chronic pain (63%)—making it the most frequently used conceptualisation of the cost of chronic pain across studies. Within this category, QoL was the most frequently used construct—with eighteen studies naming it (47%). Three studies indicated an increase in the years lived with disability (8%). One study identified a decline in self-rated health status (3%)—while another listed a loss in health status utilities as a cost (3%).

Economic and Professional Costs to Individual

Six studies indicated costs to the individual economically and professionally (16%). The negative costs of chronic pain on career and individual financial status was highlighted in economic, as well as psychosocial, constructs. For example, studies noted costs such as: early retirement (n=3, 8%), loss of pension (n=1, 3%), job loss (n=4, 11%), income loss (n=2, 5%), financial stress (n=2, 5%), and decreased educational attainment (n=1, 3%). Increased instability at work were also noted as costs (i.e. increased adjustments to work (n=1, 3%) and increased changes in work role (n=2, 5%)). However, studies also noted chronic pain cost by increasing work-related stress (n=2, 5%)—as well as negatively impacting work relationships (n=1, 3%), belief in future ability to work (n=1, 3%), identity as a worker (n=1, 3%), and work self-efficacy (n=1, 3%).

Cost to Others

Two of the thirty-eight studies identified costs to others in the form of unpaid, informal care by relatives for chronic pain sufferers (5%).

Societal Costs

Nine studies identified costs on a societal level due to chronic pain (24%). Most of these studies generally noted productivity loss (n=7, 18%) as the key cost of chronic pain to society. However, several studies specifically named aspects within the construct of productivity as costs—including increased absenteeism (n=7, 18%), reduced working hours (n=3, 8%), presenteeism (n=1, 3%) or productivity losses due to medical appointments/hospitalisation. On a national level, a handful of studies conceptualised the cost of chronic pain as the percentage of national GDP lost due to chronic pain (n=2, 5%), an increased cost to public healthcare systems (n=1, 3%), or the annual cost of chronic pain to the country (n=1, 3%). One study also named the cost of special public housing due to chronic pain (n=1, 3%).

Social Costs

Eight studies highlighted social costs due to chronic pain (21%). In social contexts, the broad costs of chronic pain identified included: social isolation (n=4, 11%) and a decreased satisfaction with social participation (n=1, 3%).

However, studies specifically noted that chronic pain impacted friendships and family relationships (i.e. a decline in number of friends (n=1, 3%), negative impact on family/relationships (n=2, 5%), difficulties parenting (n=1, 3%)); as well as negatively impacted intimate relationships (i.e. inability to fulfil partners expectations (n=1, 3%) and loss of intimacy (n=1, 3%)).

Healthcare Costs

Fourteen (37%) of the included studies identified healthcare costs due to chronic pain—which depending on regional healthcare structures—accounted for both individual and national cost burden. Eleven studies calculated the cost of chronic pain as the total cost of healthcare use (29%). Increased medical appointments and treatments were named as costs in most of these studies—two studies named more frequent inpatient treatments/rehabilitation (5%), seven studies named higher rates and longer durations of hospitalisations (18%), eight studies named more frequent general practitioner visits (21%), seven studies named a higher frequency of outpatient medical appointments (e.g. nurses, pain specialists) (18%), and four studies named increased A&E attendance (11%). Studies also named a range of specialist allied health treatments such as: physiotherapy (n=4, 11%), chiropractic therapy (n=1, 3%), massage therapy (n=1, 3%), pedicure care (n=1, 3%), acupuncture (n=1, 3%), biofeedback(n=1, 3%), occupational therapy (n=1, 3%), psychological therapy (n=2, 5%) , home help services (n=3, 8%), or non-pharmacological treatments (n=2, 5%). Increased use and cost of medications was named as a cost in 14 studies (37%)—specifically prescription medication use/cost (n=9, 24%), increased use of pain medications (n=2, 5%), polypharmacy (n=2, 5%), and non-prescription medication use (n=1, 3%). Moreover, interventional approaches such as medical imaging/testing (n=2, 5%), radiofrequency abulation (n=1, 3%), and injections (e.g. steroid, botox) (n=3, 8%) were named six times (16%). Finally, one study highlighted a decreased satisfaction with medical care (n=1, 3%); while another named difficulty in accessing healthcare (n=1, 3%), as costs of chronic pain.

Psychological Costs

Nineteen studies identified psychological costs due to chronic pain—making it the second most frequently cited cost category (50%). The mental health costs identified by studies varied greatly. While a few studies kept their measure of psychological cost generalised (e.g. emotional cost (n=1, 3%), poor mental health (n=2, 5%), increased psychological distress (n=1, 3%)—most studies identified a specific aspect of psychological state which was thought to most embody the cost of chronic pain. For example, studies specifically identified time spent suffering (n=1, 3%), decreased resilience (n=1, 3%), increased anger/frustration (n=1, 3%), and perceived burdensomeness (n=1, 3%). However, the most common psychological cost noted by studies was depression/low mood (n=13, 34%); followed by some form of anxiety (n=9, 24%)—including generalised anxiety (n=5, 13%), worry (n=1, 3%), kinesiophobia (n=1, 3%), social anxiety (n= 1, 3%), or self-consciousness (n=1, 3%). Studies also highlighted behavioural changes resulting from these psychological costs such as: social avoidance (n=1, 3%), increased rates of substance misuse (n=1, 3%), increased suicidality (n=1, 3%), decreased adherence with medication regimen (n=1, 3%), and increased helplessness/passivity (n=1, 3%). Finally, studies also indicated several psychological costs suffered to life satisfaction (n=2, 5%) and sense of self—for example, decreased overall self-efficacy (n=1, 3%), and the perceived inability to fulfil others' expectations (n=1, 3%).

Costs to Independence

Five studies highlighted specific costs to the independence of chronic pain sufferers (13%). This cost category was captured by studies in the form of decreased autonomy (n=2, 5%), inability to engage in daily tasks (n=4, 11%), and decline in hygiene/selfcare (n=2, 5%).

Recreation Costs

Two studies noted cost to recreation in their evaluation of the impact of chronic pain (5%). The most frequently cited cost to recreation was reduced engagement in lifestyle or leisure activities (n=3, 8%). One study also cited a reduction in free time as a cost of chronic pain (3%).

Physical Costs

Thirteen of the studies included highlighted physical costs associated with chronic pain (34%). Studies listed a range of physical costs associated with chronic pain. The most frequent cost was a decline in physical activity and functioning (n=8, 21%)—followed by increased sleep disorders (n=5, 13%). Two studies each identified a higher BMI/obesity (5%), sensory decline (5%), and fatigue (5%) as costs. Increased incidence of diabetes (3%), stiffness (3%), frailty (3%), accelerated cognitive decline (3%), falls (3%), premature death (3%), hypertension (3%), psoriatic arthritis (3%), and asthma (3%) were all named in one study each as costs of chronic pain. A decline in walking (3%) and ability to engage in sports (3%) were also named as costs in one study each.

Costs Categories Identified by Region, Age Group, and Year

By geographical region, there were noticeable differences in what cost categories were identified as consequences of chronic pain (Table 1). For example, while there were roughly comparable rates in the measurement of healthcare costs in North America and Europe (North America 57% versus Europe 42%)—North American studies did not at all identify societal, recreation, independence, or informal care (i.e. cost to others) costs, while European studies did. By contrast to North America, South American studies more frequently identified societal and independence costs (25% and 25%). In Asian and global studies, the most frequently used cost category was a global measure—with 80% and 60% of studies utilising them. Asian studies most frequently identified physical costs (60%), while the sole Australian study focused exclusively on healthcare costs.

Table 1

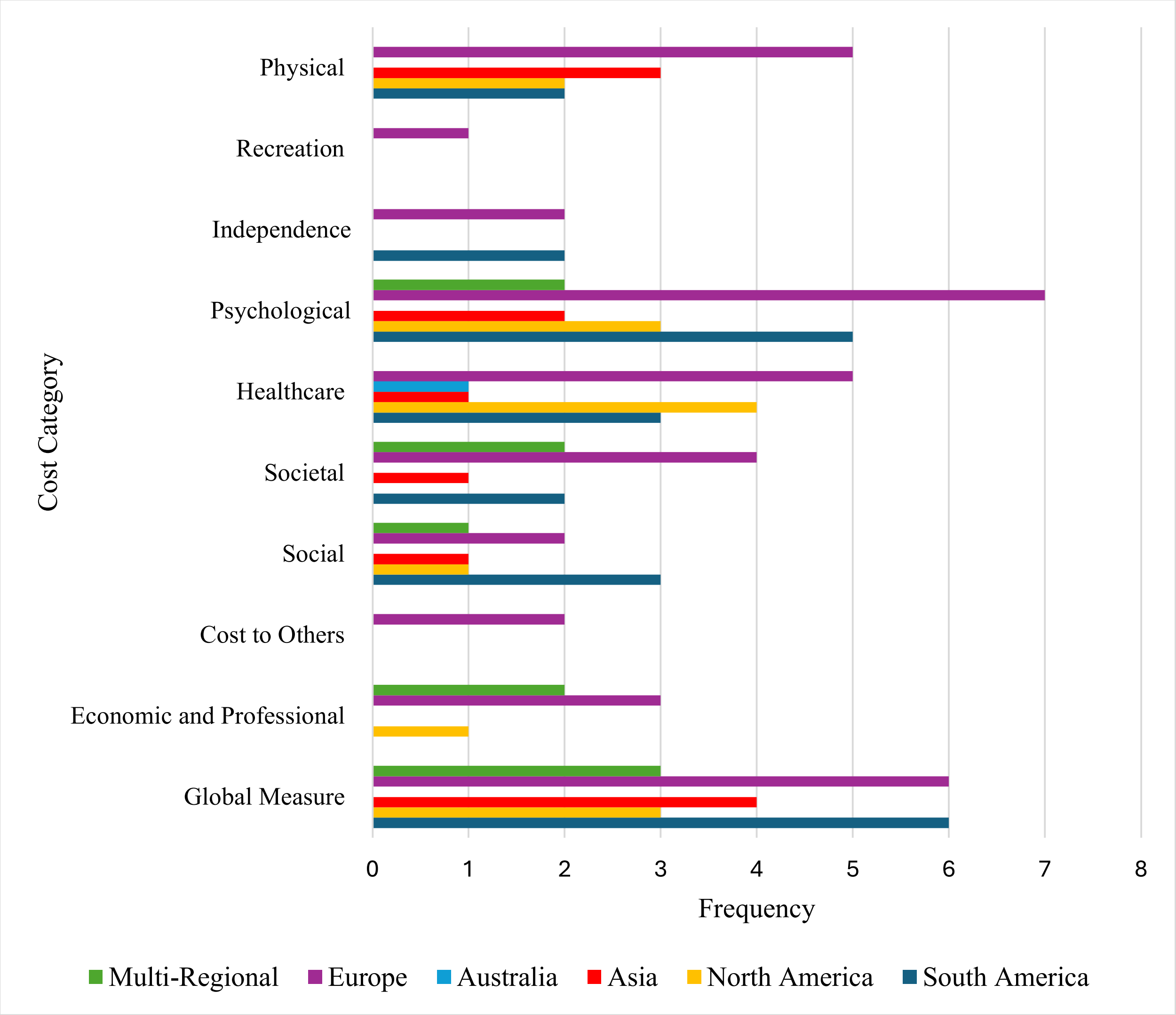
Frequencies and Percentages of Cost Categories Used within Geographical Regions

		Region					
		South America	North America	Asia	Australia	Europe	Multi-Regional
Total Frequency of Category Use (Percentage of Use of Category within Geographical Region)	Global Measure	6 (75)	3 (43)	4 (80)	0 (0)	6 (50)	3 (60)
	Economic/ Professional	0 (0)	1 (14)	0 (0)	0 (0)	3 (25)	2 (40)
	Cost to Others	0 (0)	0 (0)	0 (0)	0 (0)	2 (17)	0 (0)
	Social	3 (38)	1 (14)	1 (20)	0 (0)	2 (17)	1 (20)
	Societal	2 (25)	0 (0)	1 (20)	0 (0)	4 (33)	2 (40)
	Healthcare	3 (38)	4 (57)	1 (20)	1 (100)	5 (42)	0 (0)
	Psychological	5 (63)	3 (43)	2 (40)	0 (0)	7 (58)	2 (40)
	Independence	2 (25)	0 (0)	0 (0)	0 (0)	2 (17)	0 (0)
	Recreation	0 (0)	0 (0)	0 (0)	0 (0)	1 (8)	0 (0)
	Physical	2 (25)	2 (29)	3 (60)	0 (0)	5 (42)	0 (0)
	Total Studies Per Region (Percentage of Total Studies)	8 (21)	7(18)	5(13)	1(3)	12(32)	5(13)

Across regions, the global QoL and psychological costs of pain were the categories most consistently highlighted. Encouragingly, psychological costs were identified in approximately half the studies across all regions—with a range between 40-63% of studies. South American and European studies particularly tended to highlight the psychological costs of chronic pain—(63% and 58% respectively) (Figure 8).

Figure 8

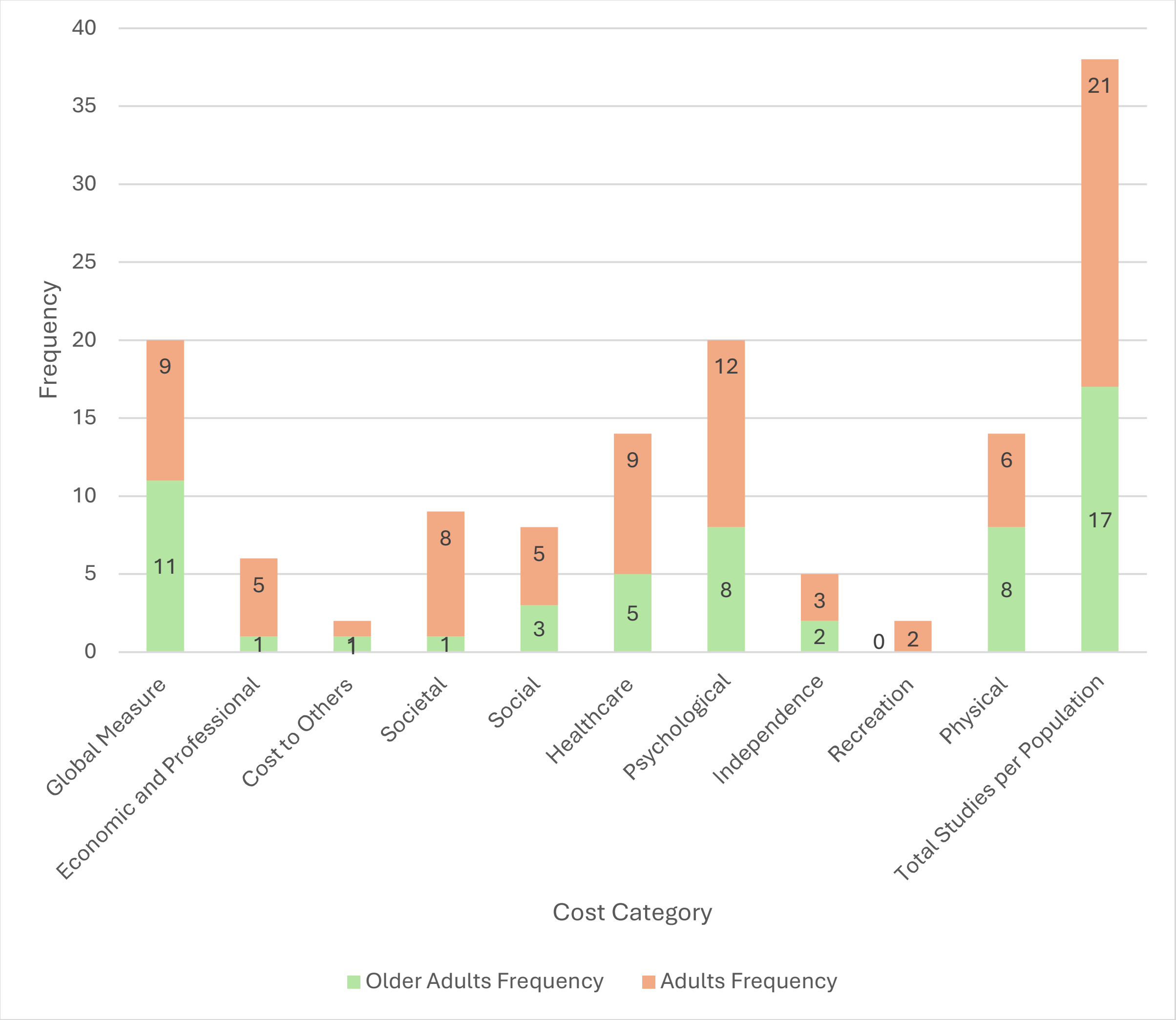
Geographical Spread of the Use of Cost Categories



Studies examining older adults tended to focus on global QoL (65%), psychological (47%), and physical (47%) costs—while adult studies focused on global QoL (43%), healthcare (43%), and psychological costs (57%) (Figure 9). Unsurprisingly, adult studies focused on societal costs (e.g. productivity losses) much more frequently than in older adult studies (38% versus 6%). The economic and professional costs to the individual and costs to recreation were also much more highlighted in adult versus older adult studies— 24% vs 6% and 10% vs 0% respectively. The cost to physical abilities was the only category significantly more represented in older adult studies that adult—47% versus 29%, respectively. Interestingly, costs to others (i.e. informal care), social, and independence costs were highlighted roughly equally across the two populations (6% / 18%/ 12% OA versus 5% / 24%/ 14% adults, respectively)—despite the increased need for care in older populations and older adult isolation rates, and typical loss of independence experienced in later life.

Figure 9

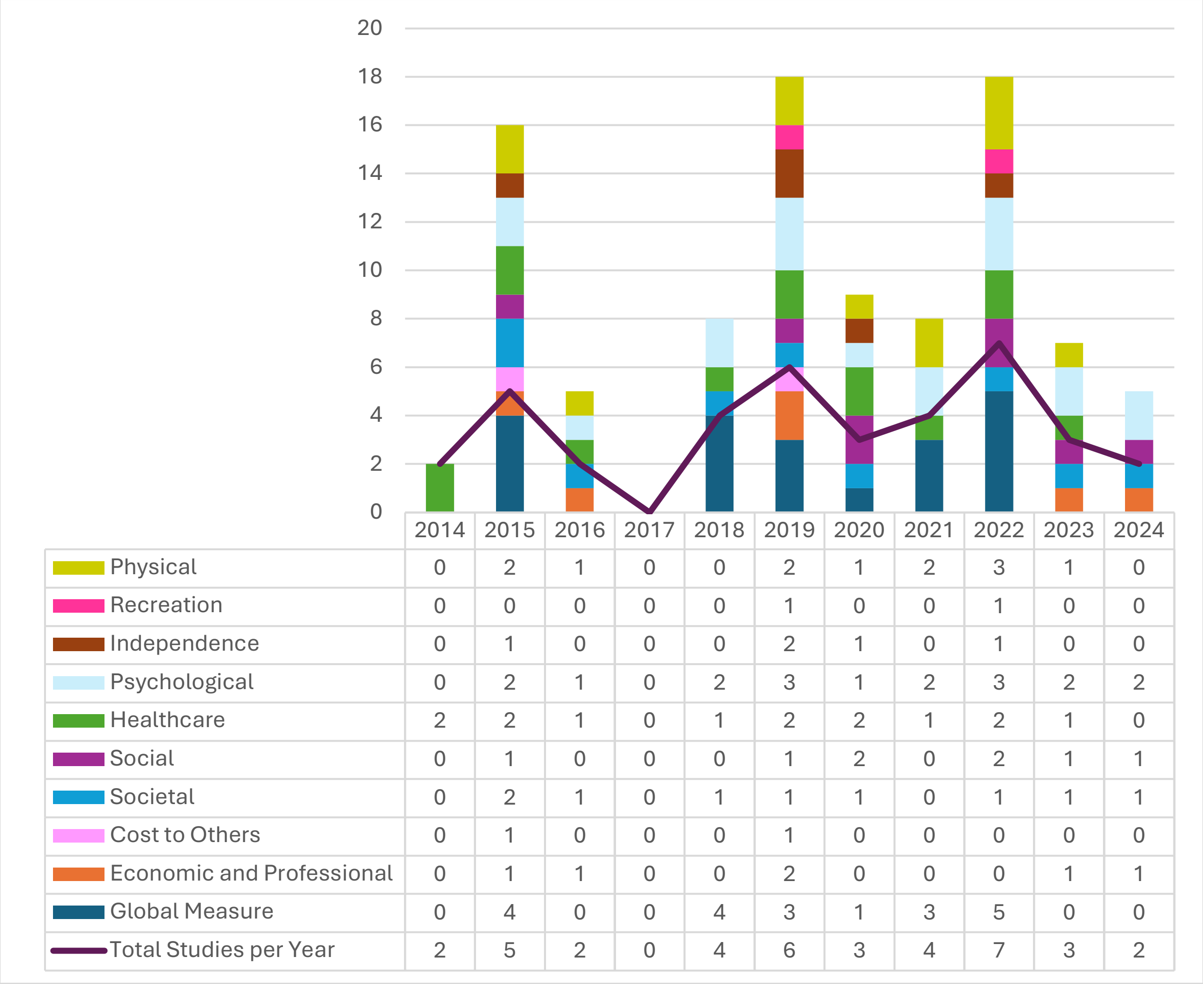
Cost Categorisation in Older Adult versus Adult Studies



Finally, while there was a spike of studies published in 2015 (n=5), there are relatively few studies published between 2014-2017 (Figure 10). In fact, there were no studies published in 2017. The largest burst of studies published on the topic was between 2018-2022. However, overall, there appears to be little change in the categories used to understand the cost of chronic pain in the last decade.

Figure 10

Cost Categories Used by Year and Total Studies per Year



	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024
Physical	0	2	1	0	0	2	1	2	3	1	0
Recreation	0	0	0	0	0	1	0	0	1	0	0
Independence	0	1	0	0	0	2	1	0	1	0	0
Psychological	0	2	1	0	2	3	1	2	3	2	2
Healthcare	2	2	1	0	1	2	2	1	2	1	0
Social	0	1	0	0	0	1	2	0	2	1	1
Societal	0	2	1	0	1	1	1	0	1	1	1
Cost to Others	0	1	0	0	0	1	0	0	0	0	0
Economic and Professional	0	1	1	0	0	2	0	0	0	1	1
Global Measure	0	4	0	0	4	3	1	3	5	0	0
Total Studies per Year	2	5	2	0	4	6	3	4	7	3	2

Measures and Variables Used to Capture Cost

There was significant heterogeneity in the measures used by studies to capture the cost of chronic pain. In fact, a total of 36 measurement methods were used across the included 38 studies (Figure 11). Studies most often assessed a cost variable using an un-named prompt from a national survey (n=55). This method was closely followed by using mathematical modelling of publicly available data to generate a cost variable (n=53). Following these, the most used measurement method was an interview prompt (n=30) or a measure designed by research team (n=26). Twenty-one of the thirty-six measurement methods were only used in one study—further highlighting the enormous heterogeneity of measurement methods.

Moreover, despite most studies reporting some measure of QoL (n=24, 63%)—just under half appear to have operationalised this construct using an unnamed survey prompt or mathematical modelling of public data. That is, validated measures of QoL were only reported to have been used 15 out of the 24 times QoL was reported in studies (i.e. 63%)—with five studies using the EQ5D/3D (21%), five studies using SF-12 (21%), two using the EQ5D-VAS (8%), and three using the SF-36 (13%).

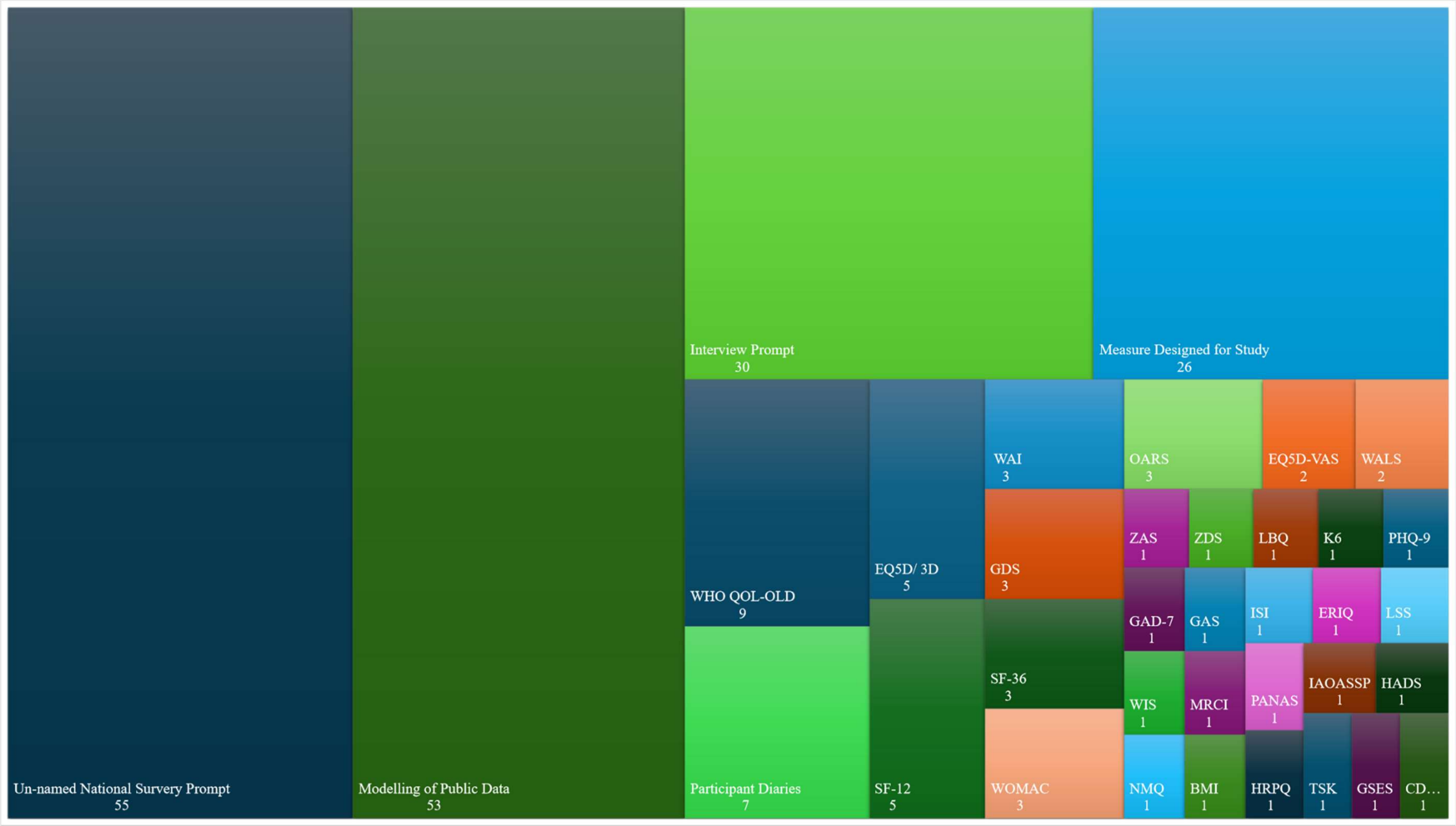


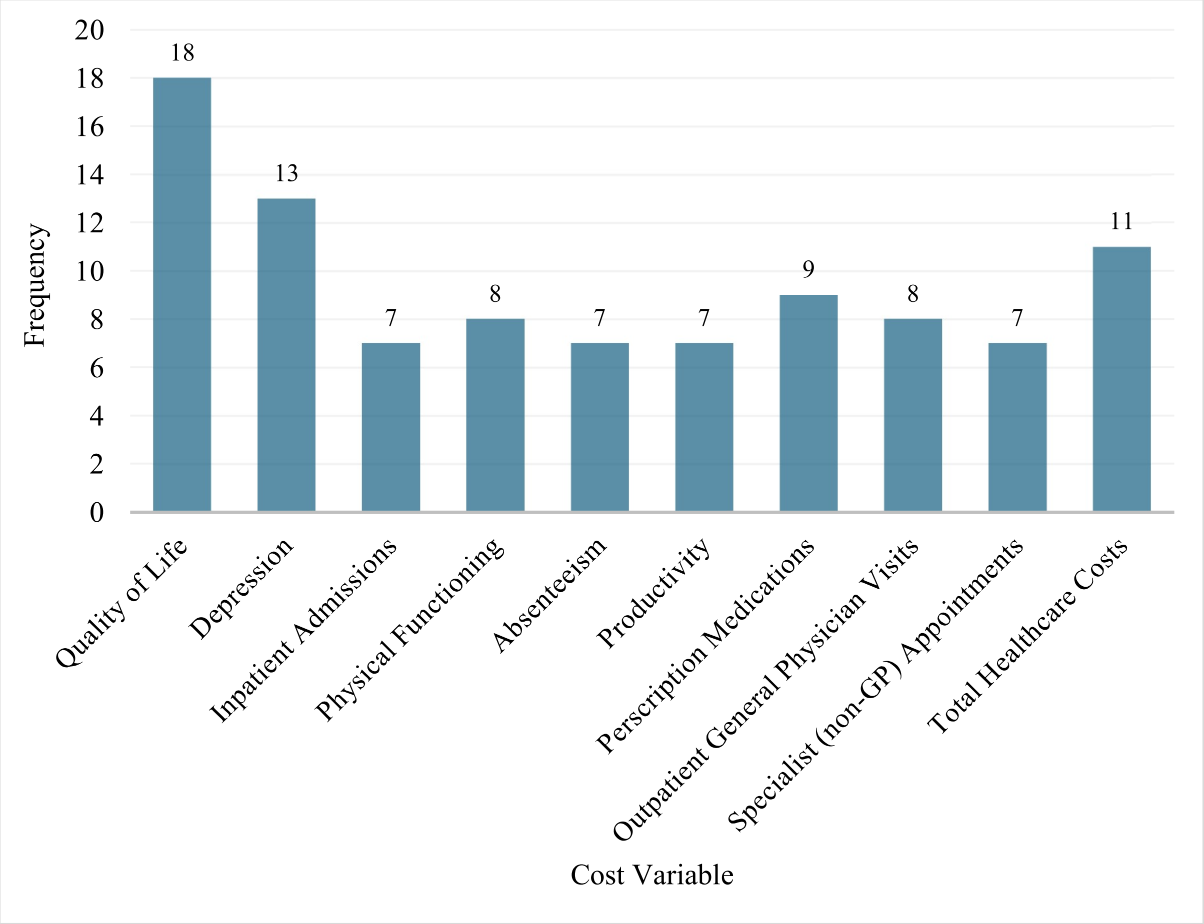
Figure 11

Studies by methodological type. Abbreviations: EQ-5D-5L / EQ-5D-3L; EQ-5D Visual Analogue Scale (EQ5D-VAS); 12-Item Short Form Health Survey (SF-12); Zung Self-Rated Anxiety Scale (ZAS); Zung Self-Rated Depression Scale (ZDS); Leave Behind Questionnaire (LBQ); Kessler 6-Item Psychological Distress Scale (K6); Patient Health Questionnaire (PHQ-9); Generalised Anxiety Disorder Assessment (GAD-7); Work Ability Index (WAI); Work Ability Limitation Scale (WALS); Work Instability Scale (WIS); Nordic Musculoskeletal Questionnaire (NMQ); Effort Reward Imbalance Questionnaire (ERIQ); Interview Prompt; World Health Organization Quality of Life Questionnaire-Older Adults Module (WHO QOL-OLD); Geriatric Depression Scale (GDS); 36-Item Short Form Health Survey questionnaire (SF-36); Grimsby's Activity Scale (GAS); Medication Regimen Complexity Index (MRCI); Body Mass Index (BMI); Insomnia Severity Index (ISI); Western Ontario & McMaster Osteoarthritis Index Scale (WOMAC); Life Satisfaction Scale (LSS); Positive Affect/Negative Affect Schedule (PANAS); Instrumental Activities of Daily Living Scale (OARS); Health Related Productivity Questionnaire (HRPQ); Instrument to Acces Older Adult Satisfaction with Social Participation

Overall, there was vast herterogeniety in the variables used to operationalise the cost of chronic pain. A total of one hundred unique varaiables used to measure cost were identified within the included studies. Of these, 56 (56%) variables were only used by one study. Of the remaining forty-four variables, only ten were used seven or more times (i.e. in greater than 18% of studies) (Figure 12). In fact, only three variables were used in 25% or more of studies—QoL (n=18, 47%), depression (n= 13, 34%), and total healthcare costs (n=11, 29%). The remaining thirty-four variables were used in less than 10% of studies.

Figure 12

Top Ten Most Frequent Variables Used to Operationalise the Cost of Chronic Pain.



Discussion

This review examined 38 studies with the aim of interrogating what is meant by the 'cost' of chronic pain in the current academic literature. This scoping review effectively informed the research questions of how the academic literature of the last decade characterised and operationalised the 'cost' of chronic pain in adult populations—and if there were any differences in how cost was understood across time, geography, or adult age groups. As demonstrated by the results, while there is some consistency in the broad, overarching categories used to conceptualise the cost of chronic pain in the academic literature (e.g. QoL), there remains little consensus in how cost is specifically defined or operationalised.

Summary of Cost Conceptualisation and Measurement

Overall, the cost identified by the most studies was a global measure reflecting overall QoL (n=24, 63%). This was followed by the psychological costs (n=19, 50%) and healthcare costs (n=14, 37%) of chronic pain. Interestingly, physical (n=13, 34%), societal (n= 9, 24%), social (n= 8, 21%), economic/ professional (n= 6, 16%), and independence (n=5, 13%) costs were less frequently highlighted by the literature. The least captured costs were those of informal care (n= 2, 5%) and recreation/leisure (n=2, 5%).

Interestingly, for a physical health condition such as chronic pain, studies cited psychological costs more frequently than physical costs. Futhermore, the single most-cited mental health cost was depression. Indeed, global public health studies over the last three decades demonstrate that depression (along with the chronic pain conditions lower back pain and headache) are three of the top four causes of years lived with disability (YLDs) globally—making them some of the costliest conditions globally (Global Burden of Disease Study 2013 Collaborators, 2015; James et al., 2018). The lack of change in these trends is concerning as this represents a significant proportion of global YLDs that have been shown to decrease productivity and increase suicidality—but are amenable to low-cost interventions (James et al., 2018). However, despite the persistent emphasis on the psychological impacts of chronic pain demonstrated by this review, psychological services for chronic pain remain underfunded and sparse—particularly in comparison to physical services. Within this context, the findings of this review highlight the importance of addressing the psychological costs of chronic pain through further investment in the psychological therapies for those suffering from chronic pain.

This review also highlighted some interesting trends in the literature that should be further explored in future research. The majority of studies that referred to productivity loss (i.e. job loss, absenteeism, presenteeism) classed it as a societal cost. However, a notable divergence was observed in North American studies, which predominantly classified productivity losses as individual costs. This discrepancy in conceptualization appears to be predicated on cultural rather than empirical factors, and implies how the costs are being measured differs by culture—adding an additional layer of comlpexity to conducting global comparisons. Also, the observed similarity in costs related to independence, socialization, and informal care between adult and older adult chronic pain sufferers suggests that perhaps the onset of chronic pain in middle adulthood precipitates losses in independence and socialization analogous to those typically associated with older adulthood.

Finally, the enormous heterogeneity of measures—as well as the prevasive use of unvalidated measures and mathematical modelling to capture the costs-- raises significant concerns about the ability to replicate individual study findings. This is particularly illustrated in the case of QoL—where despite being reported in the majority of studies—only 63% of the studies reported using validated measures. The results of this review echo the only other comparable scoping review examining the costs of back pain (Zemedikun et al., 2021). Zemedikun and colleagues conclude that the inconsistency identified in the use of standardised measures, and the use of estimates on national and global levels, raised concerns around the differences in data available and the conclusions that can be drawn (2021). Recommendations for future research would include cost analyses which use validated, reliable measures to elicit cost data—as well as the exact reporting of prompts used.

Differences in Conceptualisation of Cost Across Time, Adult Age Group, and Geographical Region

Despite the heterogeneity in cost categorisation and measurement between studies, there was relative consistency in the over-arching cost categories used by the academic literature over the last decade. The number of studies published peaked in 2022. We may initially attribute this uptick in attention to chronic pain as a consequence of the Covid-19 global pandemic and its consequences—however, the upward trend of studies began in 2018, a year before the pandemic began. Instead, this trend might be helpful to contextualise within the entry of the Baby Boomer generation into their mid-seventies. Currently, the Baby Boomer generation is the largest population cohort. Their collective entry into older adulthood may in fact be the impetus for the increased interest in chronic pain as global healthcare systems begin to face the impact of an aging global population.

The lack of focus on the costs to older adult recreation and economic status is concerning—and may be an oversight by researchers and public policy makers that leaves older adults in a difficult financial position—as well as without the means to engage in recreational activities which may lift mood and help ameliorate depression. The cost to older adult financial security and leisure are important areas of future research—particularly within the context of a rapidly aging population.

Finally, European studies measured the societal costs much more frequently than North American studies—which may be attributed to cultural differences in what is prioritised as a cost. European studies also appeared to have the broadest definitions of cost. That is, in contrast to all other regions, European studies alone encompassed the full spectrum of cost domains. However, this may be because the European region contributed the most studies to this review. Moreover, it is important to note that the sample size within regions is relatively small, and therefore, limits generalisation of these trends. Further research is necessary to unpick the cultural patterns that may be impacting how the cost of chronic pain is conceptualised and measured across regions.

Limitations and Further Research Recommendations

One key limitation which may have influenced results was the use of summary measures by the majority of studies. Within these summary measures of cost, categories of cost such as independence, physical, psychological, and social, are all considered. This implies that the tallies of this review—and therefore the tolls they represent—are a significant underestimation. However, without access to studies' raw data, it is impossible to unpick which subdomains within these global measures were most frequently identified as costs by these studies. Combined with the heterogeneity of global measures used, a fine-grain comparison on this level was beyond the scope of this review. Moreover, the sample sizes excluded a fine-grained analysis of population by region, or studies by year/region/population. For instance, a line of inquiry into any differences in how pain is costed in older adults cross-culturally or if global aging trends generated the impetus for the uptick in additional research would have be useful to examine further.

Only English publications were accessible to this researcher given the time/financial constraints of the doctoral context. This review also did not utilise grey literature, policy documents, or social media testimonials given its aim to explore the current academic literature on the topic—however, these perspectives may have added another useful lens to this subject. An exploration of these bodies of materials may be useful to consider in future research. Finally, this review did not utilise multiple reviewers for the piloting or review process. While best practice would have been multiple extractors who then worked together to reach consensus of the extracted data, this was beyond the resources available to the doctoral candidate conducting the review.

The costs to educational attainment and mortality should be further examined. There is a likely underrepresentation of the costs of chronic pain to educational attainment in this review due to the exclusion of adolescent and young adult cohorts, who are typically most susceptible to this impact. This is a limitiation that should be addressed in future reseach examining the costs of pain across the full lifespan. Finally, premature mortality is a cost of chronic pain that is oftentimes missed in the literature because pain does not directly cause death. However, chronic pain is linked to opiode overdose, suicidality, and decreased physical activity—all of which are mechanisms through which it elevates mortality rates. Therefore, future research should examine how these hidden costs may be operating.

Conclusion

This scoping review has begun to illuminate the complex nature of how the cost of chronic pain is conceptualized and operationalized in recent academic literature. The findings demonstrate that overall QoL is the key cost highlighted by academia, followed by psychological costs such as depression. However, the review also exposes considerable heterogeneity in measurement approaches which poses a challenge for comparative analysis.

The observed differences in cost conceptualization across geographical regions, particularly between European and North American studies, highlight the influence of cultural factors on how chronic pain's impact is understood and measured. Furthermore, the increasing trend in published studies, potentially linked to the aging global population, suggests a growing recognition of chronic pain as a significant public health concern.

Moving forward, there is a clear need for standardized, validated measures in cost analysis, as well as more comprehensive investigations into the economic and psychosocial impacts of chronic pain on older adults. Future research should also aim to address the limitations identified in this review, including the underrepresentation of certain cost domains and inconsistencies in measures. Ultimately, this review underscores the necessity for a more methodologically standardized approach to understanding and addressing the costs of chronic pain in both research and policy contexts. The following chapters will further delve into the quantitative study of the costs of chronic pain informed by these results, specifically examining the most cited cost of chronic pain—overall quality of life.

Chapter 3: Methodology of Studies 2 and 3

Overview

Previous chapters introduced the constructs of chronic pain, QoL, and ACL reconstructive surgery, outlined the research aims for the current three studies, and highlighted that the cost of chronic pain (as understood in the recent academic literature) is QoL through a systematic scoping review (Study 1). The following chapter will outline the methodologies of Study 2, a secondary quantitative study exploring the costs of untreated chronic pain in adults participating in Health Survey England, 2017; and Study 3, a secondary quantitative examination of the effects of ACL reconstruction surgery on the QoL of the patients of an NHS Orthopaedics Service. The philosophical positioning, research designs, and methods, and rationale for these decisions, for both Studies 2 and 3 will be examined in detail. This will include a discussion of samples, measures, ethics, and data management. Finally, a discussion of the analytic methods chosen for this study will be outlined.

Research Paradigm: Ontology, Epistemology, and Methodology

The epistemological paradigm ascribed to by researchers influences how they conceptualise both reality and knowledge, and their methodological decisions (Field, 2013; Pallant, 2020). Positivism, social constructionism, and critical realism are three of the most influential paradigms, each presenting ontological and epistemological assumptions that shape methodological choices. This section explores these three paradigms, highlighting their differences, strengths and weaknesses; before finally examining why critical realism offers the most balanced approach for the subsequent two studies.

Ontology refers to the nature of reality, specifically whether it exists independently as an external reality or is socially constructed. Ontological stances range along a spectrum from realism, which proposes an objective, external reality independent of human interpretation, to relativism, which argues that reality is not an independent external entity but is instead socially constructed through human interactions, language, and sociocultural contexts (Coolican, 2017; Crotty, 1998). Epistemology refers to the nature and scope of knowledge; that is, what knowledge is and how it is obtained (Pallant, 2020). These ontological and epistemological positions inform researchers' choices of methodology and methods, which refer to the systematic processes used to generate knowledge (Coolican, 2017).

Positivism

Positivism is founded on realist ontology, which asserts that an objective external world exists independent of subjective interpretation (Coolican, 2017; Popper, 1959). Positivism also argues that the mechanisms underlying this external reality can be understood through empirical observation and systematic measurement (Coolican, 2017; Field, 2013). Epistemologically, positivism proposes that knowledge can be discovered through hypothesis testing—and asserts that researchers can maintain objectivity (by minimising bias and subjectivity) in the pursuit of universal knowledge (Coolican, 2017; Pallant, 2020). Methodologically, this school of thought prioritises quantitative techniques such as experiments and surveys, and its methods emphasise replicability, reliability, and generalisability. The aim of positivist research is oftentimes to establish causal relationships between variables (Creswell & Creswell, 2023). For example, a large-scale HSE survey used to measure aspects of QoL would align with positivism because it generates quantitative data for statistical analysis.

Despite its strength in generating generalisable experimental results, positivism can be criticised on several fronts. Its approach can be called reductionist, as it neglects the subjectivity and richness of the human experience in order to simplify complex social experiences in order to focus on quantitatively measurable variables (Denzin (ed) & Lincoln, 2005). Moreover, its assumption of the researcher's objectivity is flawed, as all researchers are human beings who are influenced by theoretical orientation, sociocultural context, and individual biases (Denzin & Lincoln, 2005). Finally, positivism does not account for power dynamics and the role of meaning in human behaviour (Christensen, 2024).

Social Constructionism

Social constructionism is grounded in a relativist ontology and, contrary to positivism, challenges the notion of objective reality. Instead, social constructionism proposes that meaning is co-created within contemporary sociocultural contexts (Denzin (ed) & Lincoln, 2005). Epistemologically, it asserts that knowledge is influenced by power relations and meaning making, and is not discovered but instead constructed through interaction, language, and interpretative inter- and intra-personal processes (Denzin (ed) & Lincoln, 2005). Therefore, knowledge is subjective, not a universal truth, from a social constructionism perspective (Denzin (ed) & Lincoln, 2005). Unlike positivist approaches that seek breadth and generalisability, social constructionist research aso focuses on depth and richness of data—and it therefore favours qualitative research methods which allow for an in-depth exploration of meaning and subjective experiences (e.g. ethnography, narrative analysis, and discourse analysis).

That said, despite its strength in providing insights into the role of language, culture, and meaning making in human experiences, critics argue that social constructionism may risk undermining shared truths and objective knowledge (Hammersley, 1992). While generalisability is not a goal of social constructionist research, the mostly limited sample sizes employed in social constructionist research can make it difficult to use to formulate policy recommendations to benefit those it is attempting to give voice to. This same emphasis on subjective interpretation makes social constructionist research vulnerable to criticisms of methodological rigor and replicability, leading to difficulties in convincing large organisations or governmental policymakers to utilise results in large-scale decision making and change processes (Seale, 1999).

Critical Realism

Critical realism offers a third, alternative, paradigm that integrates elements of both positivism and social constructionism (Danermark et al., 2019). Ontologically, critical realism proposes a graded structure of reality which consists of three layers—the empirical (i.e. experiences and perceptions), the actual (i.e. events that occur even if unobserved), and the real (i.e. structures and mechanisms that cause events). Unlike positivism, critical realism acknowledges that not all aspects of reality are directly observable. However, it also stands in contrast to social constructionism as it asserts that an objective reality exists and can be recognised through its observable effects (Danermark et al., 2019; Pilgrim, 2014). Epistemologically, critical realism suggests that while reality exists independently, our knowledge of this reality is mediated through social, historical, and cognitive processes—and is, therefore, fallible. Critical realism applies retroductive (i.e. abductive) reasoning to uncover the causal mechanisms is seeks to elucidate. Abductive reasoning involves working backward from observed data to construct a tentative hypothesis that may explain underlying mechanisms within a given context (Danermark et al., 2019). Therefore, this approach involves deriving hypotheses based on empirical observations and then engaging in hypothesis testing—while still engaging in critical reflection and acknowledging the limitations of knowledge (Giese & Schnapp, 2021). Methodologically, critical realism allows for the application of both quantitative and qualitative methods in testing hypotheses (Danermark et al., 2019).

Despite its strength in seeking to apply a balanced approach to the creation of knowledge and understanding of reality, critical realism has been criticised for its complex theoretical foundations. This is because its three-layered ontology does not easily lend itself to direct application in empirical research (Maxwell, 2012). Additionally, while critical realism attempts to integrate quantitative and qualitative methods, it does not always provide clear methodological guidelines for achieving this in practice (Maxwell, 2012). Finally, critical realism has been criticised as pushing the limits of what research is capable of because it simultaneously attempts to produce universal knowledge while also acknowledging the social construction of the world (Runhardt, 2023).

Epistemological Foundations of the Present Studies

The study of chronic pain requires an approach that acknowledges both measurable indicators and subjective experiences. Positivism, with its emphasis on quantifiable data, provides useful tools for measuring QoL through standardised metrics such as income levels, medical/ disease indices, and employment status. However, a purely positivist approach risks overlooking the subjective and socially constructed aspects of the holistic costs of chronic pain, such as the values and perspectives underlying a measure of QoL. It also excludes a discussion of researcher reflexivity and the impact the researcher's decision-making and stance had on the study. Conversely, social constructionism offers rich insights into how individuals and communities construct notions of wellbeing. However, it may lack the empirical rigor needed to establish generalisable findings that translate into evidence which can influence and drive the commissioning of NHS services and allocation of resources.

By contrast, critical realism offers a balanced approach appropriate to this study. That is, critical realism acknowledges that certain aspects of chronic pain costs can be quantified through objective measures (e.g. income), while also accepting that these do not fully capture the broader social, cultural, and systemic dimensions of the cost of chronic pain. Critical realism therefore allows for the full examination of factors that are both socially constructed (e.g. QoL) and those that are directly observable (e.g. medical history, income), while still also permitting hypothesis testing based on clinically observable patterns. Additionally, critical realism allows for the acknowledgement that although the following quantitative analysis provides empirical observations, these findings rely on fallible self-report measures, that are typically culturally and demographically specific (e.g. EQ5D, KOOS). Moreover, while this study utilises a quantitative methodology with hypothesis testing, the critical realist lens allows it to acknowledge that its findings reflect current trends in QoL and chronic pain research, as well as contemporary data collection practices, which in turn, influence analysis and interpretation. Therefore, by applying a critical realist approach, this study attempts to define the reality of what constitutes the "costs" of chronic pain, while also recognising its own limitations of researcher biases. Given this balance, critical realism was particularly valuable to this study in its broader aim to inform policy and NHS service development, as it generated evidence-based insights while also accounting for social complexities.

Design

Conceptual Design: The Costs of Chronic Pain as Named by Those with Chronic Pain

While the scoping review of Study 1 highlighted that academia understands overall QoL as the cost of chronic pain, this conceptualisation is lacking because patients themselves have not been consulted in its creation. However, Bowling (1996), addressed this gap by asking a sample of 2,031 patients what the costs of chronic pain were to them—generating a list of most frequently cited factors (listed here in order of importance to patients): mobility, social functioning (and recreational activities), working capacity, activities of daily living, depression/anxiety, and financial insecurity. Fortunately, this indicates there is largely agreement between the costs as named by patients and the subdomains researchers use to operationalise QoL (i.e. mobility, usual activities (including work and social capacities), self-care, psychological state, and pain/discomfort)—with the additional cost subdomain of financial security included by patients. Therefore, combining the QoL cost highlighted in

Study 1, Bowling provides a patient-led framework which will guide the examination of costs that will be conducted in Study 2 (1996).

Methodological Design

Primary research is research which collects data firsthand, while secondary data is that is conducted using materials which have previously been collected. Secondary data analysis, which is defined as the analysis of data originally collected for another purpose, presents a useful approach for researchers seeking efficient and cost-effective methodologies (A. K. Smith et al., 2011). Secondary data analysis avoids some of the logistical hurdles associated with primary data collection– such as obtaining NHS ethical approval or the need for research funding in order to collect large, representative samples for quantitative research. Given the scale of samples and standardisation of measures offered by many secondary datasets (e.g. national survey samples), this type of research design can still provide robust results for comparative analyses.

However, secondary data analysis is not without limitations. Researchers using secondary data may not have access to the contextual factors that influenced the data collection processes (Pallant, 2020). Moreover, researchers have no control over the questions or measures used to address constructs of interest and may therefore find the data is limited in its utility to answer certain questions. Intimate knowledge of the dataset, how it was collected, coded, and organised is therefore critical in avoiding inadvertent confounding in secondary research. Also, a significant investment of time is required to familiarise oneself with and clean the data into a useable form for each study. Despite these constraints, secondary data analysis offers a cost-effective means of building on primary study objectives through the re-examination of unutilised or underutilised data, as well as the opportunity to leverage existing data to contribute to the rapid advancement of knowledge in a field.

Data Collection

Study 2: Health Survey for England 2017

The Health Survey for England (HSE) is an annual, nationally representative cross-sectional survey established in 1991 to monitor health trends among the general population in England (University College London, HSE, 2017.) The HSE aims to provide annual data on the nation's health, estimate the prevalence of specific health conditions and associated risk factors, examine health differences between population subgroups, and monitor progress towards health targets. HSE's standardised protocols ensure data consistency and quality--making it a valuable for analysing public health patterns over time in England. This sample was used to address the research question for Study 2 as it was a large, nationally representative sample where the costs of chronic pain could be interrogated.

The HSE included adults aged 16 and over, and children aged 0 to 15, living in private households in England. As well as demographic information, the HSE captures healthcare usage, lifestyle factors (e.g. diet, weight, smoking, alcohol use), general health, and long-standing illness. Specialist modules are included annually, with the 2017 survey including the additional topics of adult chronic pain and social care provision, as well as updates on the general health and long-standing illness sections. These updates and inclusions of chronic pain data made HSE 2017 the most appropriate dataset for examining this study's research questions via a large, robust, nationally representative sample.

The HSE employs clustered, stratified, multistage random sampling. The survey methodology involved a three-prong approach: self-completed questionnaires, a face-to-face interview, and a nurse's visit. Informed consent was gained from all participants over 16 years of age through a mix of verbal and written consent (Appendix H. Participant Information Sheet). Verbal consent was not recorded, but used for taking part in the survey, answering individual questions, completing the self-reported questionnaires, and for measurements some of the physiological measures. All measures used by this study fell under the verbal consent procedures of the original research team. Participants were interviewed by nurse practitioners at home. The 2017 sample comprised 9,612 addresses selected randomly from 534 postcode sectors. In total, 7,997 adults and 1,985 children were interviewed, with 5,196 adults and 1,195 children participating in the subsequent nurse visit. During nurse visits, consent was obtained to measure height and weight– as well as to sample blood and saliva. Adults and children aged 13-15 were interviewed directly, while parents answered for younger children on most topics. Demographic data was collected as part of the HSE data collection process. Data was collected using a standardised prompt booklets and recorded in standardised record-keeping forms. A sample of the interview prompts, including the questions asked to assess chronic pain and its impacts and demographic characteristics, as well as a sample of the booklet of self-reported measures (e.g. EQ-5D-5L), are included in Appendices I and J. Full documentation on the survey is available from the NHS Digital website (Health Survey for England 2017 [NS] - NHS England Digital). As such, a strength of this dataset is its size and representativeness of the English population; as well as the robustness of the data collection procedures. Despite changes since 2017, such as demographic changes and the impacts of the Covid-19 pandemic, the data remains relevant to examine.

The annual, fully anonymised HSE dataset is made available via the UK Data Service– a national data repository offering access to a range of datasets. Ethical approval was sought and granted by the UK Data Service for use in this study, and the HSE 2017 was accessed from the UK Data Service in May 2024. Use of the Special Licence dataset HSE 2017 dataset was considered but was found to be unnecessary to addressing the research questions. The HSE 2017 database was stored on the secure university servers, using Box and IBM

SPSS version 29 software, for the duration of this research, and will be deleted upon the completion of this degree (i.e. before January 2026).

Study 3: NHS Orthopaedics Service ACL Database

Study three utilised a database of NHS patients from an NHS Orthopaedic Service in the north of England specialised in knee surgery. This dataset was selected primarily because it examined the QoL outcomes of patients receiving a common musculoskeletal NHS treatment in England—making this third study a useful examination of the impact of an NHS intervention on the key cost identified by the previous two studies (i.e. QoL). This dataset was also selected because it had QoL outcomes data collected at several timepoints—allowing this study to examine changes in QoL at baseline (pre-intervention), 6 months post-operatively, one year post-operatively, and two years post-operatively. Moreover, this dataset is an NHS clinical outcomes dataset of a physical intervention that pain patients have also sometimes experienced, i.e. a surgery. Participants who underwent a specific type of knee surgery, ACL reconstruction, were used as the sample for this study because it is an evidence-based, and routine, treatment for patients on the NHS—granting the opportunity to examine the impact of a standard NHS intervention on the QoL of patients. While ACL patients do not typically have major pain issues, they were a relevant population to examine as, similarly to chronic pain patients, a musculoskeletal issue impacts their physical capacities and often has a knock-on effect their QoL. Finally, the dataset was readily available for secondary analysis—allowing for an examination of an NHS musculoskeletal intervention on patient QoL outcomes in England that fit within the scope of this doctoral thesis.

Patients undergoing ACL reconstruction surgery within this clinic for the first time were selected as the sample population from this dataset. Patients were recruited upon their admission to this orthopaedic service—and opted into the research as part of their routine treatment within the clinic. Data on the patient’s age, gender, BMI, smoking status, work status, weeks off work, as well as KOOS and EQ5D scores were collected at baseline. KOOS and EQ5D data was collected at 6 months, 12 months, and 2 years post-operatively. All data was collected by the specialised NHS clinical team in the context of clinical interviews prior to ACL reconstruction surgery. At pre-operative appointments, clinical staff used standardised questionnaire guides and prompts to assess demographic data (e.g. age, smoking status, BMI, sex, ethnicity), as well as questionnaires on pain and QoL (Appendices K and L. Patient Information Sheets and Pre/Post-Operative Patient Reported Outcomes forms). Patient information sheets outlined the optional nature of participation in data collection and requested patients opt in by completing and returning the provided questionnaire packs (e.g. KOOS, EQ5D3L) to the clinical team. Patients were followed up for their QoL outcomes at their follow up appointments within the clinic at six months post-surgery, and then at later timepoints, by post. A highly experienced data manager anonymised and collated data into a service-wide, secure database before conducting further cleaning and monitoring. For purposes of this study, the team were contacted by the supervising clinician of this research study—who was a known previous collaborator. The potential research questions were formulated under the guidance of the clinical team, and their input was used to drive the design of this study to ensure that the outcomes would be informative to their service and clinical practice. The team’s consent to use this data for this research was therefore granted, and fully anonymised data was provided directly to the researchers of this study in February 2025 by the research manager of the service. The database was securely stored on university servers using Box and Microsoft Excess software. This anonymous data was kept securely stored for the duration of this degree and will be deleted upon completion (before March 2026).

Ethics

Use of the HSE 2017 dataset was sought via institutional access through the University of Essex. The HSE survey has been commissioned by NHS Digital and conducted by the Joint Health Surveys Unit of NatCen Social Research and UCL's Department of Epidemiology and Public Health for over 30 years, with no obvious conflict of interest indicated by the publishers or data repository (UK Data Service). As a secondary data study, the ethical considerations made in the original HSE 2017 data collection process will sufficiently cover this study.

All data was fully anonymised by the UK Data Service before it was made accessible to researchers. Therefore, there was no risk to the confidentiality of the participants by using this dataset for this study. Appendix M demonstrates the electronic End User License Agreement signed to gain access to the HSE 2017 dataset via the UK Data Service Repository website. The full details of the terms of this agreement can be found at: https://ukdataservice.ac.uk/app/uploads/cd137-enduserlicence.pdf. Once granted access, the anonymised data was accessed on a personal laptop that remained in secure storage at all times outside of use, as per ethical approval guidance. However, further ethical considerations will be further reflected upon within a later discussion of researcher reflexivity as this effected the interpretation, write up, and dissemination of results of this study.

For Study 3, the decision not to seek additional formal ethical approval was justified on the basis that the project involved secondary analysis of fully anonymised routine clinical data provided by an NHS orthopaedic unit (the data owner). However, the data owners provided the text provided to all participants—which had been approved by their NHS Trust's information governance team (Appendix P). Because all identifiers had been irreversibly removed by the data owners prior to transfer, the dataset could not be linked back to individual patients, thereby meeting established criteria for non-identifiable information under UK GDPR and NHS Health Research Authority (HRA) guidance. The HRA states that research using non-identifiable information that has previously been collected during routine care does not require NHS Research Ethics Committee review, provided no additional data are gathered and no identifiable information is accessed (HRA, 2022). Consistent with these principles and with common academic practice for secondary analyses of anonymised datasets (e.g.,(Hoonaard & Hamilton, 2016)), the study posed no identifiable risk to participants and therefore did not require further ethical review processes.

Measures

Study 2: EuroQol-5 Dimensions Five-Level Version (EQ-5D-5L)(EuroQol Group, 1990)

The EQ-5D-5L is one of the most widely used measures to evaluate overall health globally. It is a self-reported measure which describes QoL along five dimensions: mobility, self-care, usual activities, pain and discomfort, and anxiety and depression. Responders complete a five-level scale per dimension as well as a visual analogue scale to evaluate overall health. The resulting description of a person's state of health can be converted into an overall number using country-specific value sets. Alternatively, scores from the 5-point descriptive section of the measure can be reported as a 5-digit number (i.e. profile). Both forms of resulting scores can be used to inform clinical and economic healthcare decision making. The test-retest reliability (ICC= 0.70 – 0.90), internal consistency (α =0.65 – 0.75), and construct validity (r = 0.60 – 0.80) are within good to strong ranges.

Study 3: Knee injury and Osteoarthritis Outcome Score (KOOS)(Roos et al., 1998)

The KOOS is a 42-item self-reported questionnaire developed as an extension of the Western Ontario and McMaster Universities Arthritis Index (WOMAC) (Bellamy et al., 1988; Roos et al., 1998). The KOOS is validated for use in active, younger patients with osteoarthritis or knee injury and is best administered for populations with high physical activity demand levels and when assessing long term outcomes (Nilsdotter et al., 2009). The KOOS covers five domains: activities of daily living function, pain, sports and recreation function, disease specific symptoms, and knee-related QoL and is advantageous to assessing long term outcomes. However, for the purposes of this study, solely the QoL subscale was used. The KOOS-QOL subscale is composed of our questions addressing knee-related difficulties, knee awareness, lack of knee confidence, and knee-related lifestyle modification. The KOOS was found to be reliable (mean 67%, range 54-84%) with good internal consistency (QoL subscale Cronbach's alpha 0.71) and test-retest reliability (QoL subscale interclass correlation coefficient 0.83).

Analytic Methods

Study 2: Binomial Logistic Regression

Binomial Logistic Regression (BLR) is a statistical method which explores the relationship between a dichotomous, categorical dependent variable (i.e. a variable with two possible outcomes such as yes/no) and two or more independent categorical variables (Pallant, 2020, Ch 14). This method models the probability of the dependent event occurring, and is therefore useful in psychological research aiming to determine the presence or absence of a specific outcome (e.g. having mobility problems or not having mobility problems). This is in contrast to linear regression, which instead predicts a continuous outcome such a psychometric scale score (Field, 2013).

The interpretation of BLR includes examining output such as the: Wald statistics to assess the significance of each predictor, Omnibus Test of Model Coefficients, which assesses overall model's fit by looking at significance (i.e. p values less than 0.05), and odds ratios (Exp(B)) to interpret effect sizes. Odds ratios greater than one suggest an increased likelihood of an outcome occurring with an increase in the predictor; while values less than one suggest a decreased likelihood of an outcome happening with an increase in the predictor (Pallant, 2020). There is some debate around the usefulness of also examining pseudo R statistics (i.e. Hosmer-Lemeshow test or Nagelkerke R-squared) (Tabachnick & Fidell, 2019). Finally, several assumptions must be met to use BLR. While normality is not assumed, checks of sample size, outliers, multicollinearity (i.e. no correlations greater than 0.7 between independent variables), and the independence of observations are necessary to avoid undermining the validity of results (Pallant, 2020).

BLR has several strengths that make it practical for psychological research. First, its ability to analyse categorical, dichotomous variables makes it particularly useful for common research questions in psychology; for example, examining treatment adherence in the absence or presence of a condition. It can also evaluate difference types of independent variables in the model, including demographic characteristics or psychological traits. Moreover, as it does not require data to be normally distributed it is particularly useful to real-world clinical data which is oftentimes not normal (Field, 2018). Finally, the interpretation of odds ratios offers a simple way of evaluating and communicating how much an independent variable increases or decreases the chance of an outcome.

However, there are also some limitations to using BLR. Reliability of the method can be affected by small sample sizes or too many variables (Tabachnick & Fidell, 2019). Moreover, the relationship between independent and dependent variables must be correctly specified at the coding stage, otherwise interpretations can be misleading (Pallant, 2020). Finally, BLR assumes that each observation is independent, meaning it does not work well with repeated measures data or non-distinct groups.

Study 3: Analysis of Covariance

Analysis of Covariance (ANCOVA) is a statistical technique that combines features of both ANOVA (Analysis of Variance) and regression. It is used to compare the means of a dependent variable across (two or more) groups, while statistically controlling for the effects of one or more continuous covariates (i.e. potentially confounding variables that might affect outcomes) (Tabachnick & Fidell, 2013). In psychological research, ANCOVA is commonly used to evaluate treatment effects while adjusting for potentially confounding baseline covariates such as demographic characteristics or variations in pre-treatment symptomology (Field, 2013). ANCOVA effectively levels the playing field by statistically controlling for those initial differences (Tabachnick and Fidell, 2019). Therefore, by controlling for variance associated with the covariates, ANCOVA increases statistical power (i.e. makes it easier to detect differences between groups) and controls for confounding variables that could obscure the effect of the independent variable (Tabachnick & Fidell, 2013). This facilitates the accuracy of both randomised control trials and observational studies by controlling for potentially confounding variables that might mask the effect of treatment interventions.

ANCOVA operates under several key assumptions: 1. linearity, or that relationship between the dependent variable and the covariates must be linear within each level of the independent variable; 2. homogeneity of the regression slopes across treatment groups (i.e. the relationship, or slope, between the covariate and the dependent variables must be the same across all independent groups); 3. the independence of the covariates and treatment effect, that is, the data must meet the assumption that there is no influence of treatment on covariate measurements; 4. normality of residuals, or that the errors of the dependent variable should be normally distributed within each group; 5. homoscedasticity, or the variance of the dependent variable should be roughly equal across all levels of the independent variable (assessed by Levene’s Test); 6. reliable measurement of the covariate; and finally, 7. each participant's data must be independent (Field, 2013). Violations of any of these assumptions can lead to biased results or misinterpretation. However, if these assumptions hold, ANCOVA provides “adjusted means” for each outcome group—showing what the group averages would look like if all participants started at the same covariate value (Field, 2013).

One strength of ANCOVA is its ability to control for pre-existing differences among groups in observational designs where random assignment to outcome groups is not feasible (Tabachnick & Fidell, 2019). However, a key limitation is the reliance on, and number of, assumptions necessary to be met before it is possible to apply this method. For example, should the homogeneity of regression slopes be violated, or measurement error occur in the covariates, the ANCOVA will likely lead to inaccurate conclusions (Tabachnick & Fidell, 2019). Moreover, ANCOVAs performance degrades significantly if there are confounders not accounted for within the analysis. Therefore, while ANCOVA is a powerful tool, it requires careful attention to the selected covariates and underlying assumptions before it can be successfully applied.

ANCOVA was chosen as the analytic method as it would allow for comparison of change between pre- and post- operative time points while allowing to control for potentially confounding factors (i.e. covariates). The clinical observations of the surgical team indicated that it would be important to consider BMI, gender, and smoking status on surgical outcomes. Literature searches corroborated the clinical intuition of the impact of BMI and smoking status on ACL reconstruction surgery, so these were added to the model as covariates (Abdulla et al., 2020; Karim et al., 2006; MARS Group et al., 2017; Novikov et al., 2016; Sørensen, 2012). However, a literature search indicated that there was no consistent evidence for the effect of gender on KOOS QoL scores specifically after ACL surgery, so this covariate was dropped from the analysis (Salmon et al., 2006).

Variable Selection and Data Management

Study 2 data was managed using IBM SPSS version 29; while study 3 utilised Microsoft Excel. Data was prepared for regression analyses though recoding and management of missing variables. An overview of the variables used in the analyses and their preparation is presented in the following section.

Study 2

Based on the literature review, six independent variables were also selected: chronic pain, age, ethnicity, marital status, education, and gender. Age and gender were particularly indicated as potential confounds within the literature examining the costs as chronic pain sufferers named them and were therefore included in the models to avoid misrepresentation (Bowling 1996). Given the number of variables being tested, all variables were recoded into binomial categorical variables to facilitate interpretation. Therefore each variable included two levels indicating the presence or absence of the factor of interest, and a third level to capture missing/not applicable values. Missing values were coded as system missing within SPSS, and each variable was checked for sufficient sample size within each category. For example, the presence of chronic pain indicated was indicated by the variable (*More3m*), which reflected the prompt "Have you had this pain or discomfort for more than three months?". The variable was recoded to "yes chronic pain" = 1, "no chronic pain" = 0, unknown = 4). The dependent variables were similarly recoded. For example, mobility was recoded from eight categories (-9 = refused, -8 = don't know, -1 = not applicable, 1= no problems walking about, 2 = slight problems walking about, 3 = moderate problems walking about, 4 = severe problems walking about, 5= unable to walk about) into three categories (1 = yes, problems with mobility, 2= no problems with mobility, 4= missing or not applicable). Derived variables, or variables created out of other collected variables, were used in the case of financial resources, martial status, age, ethnicity, working capacity, and highest educational level**.** From within the HSE 2017 dataset, six dependent variables were selected to best capture the constructs identified by chronic pain population as most important to their QoL (Bowling, 1996). This included variables to measure working capacity (variable *HRPactiv2*), mobility, the activities of daily life, life satisfaction, psychological state, and financial resources. Three domains from the EQ-5D-5L were used as dependent variables: Anxiety/Depression (variable *Anxiet17*), Usual Activities (variable *UsualA17*), and Mobility (variable *Mobil17*).

For purposes of this study, financial resources was captured using a derived variable of income (variable *HHInc2*). The Household Finances Survey from the ONS indicates that the median household disposable net income in the UK is £34,400 (£45,000 gross income) in 2023 (GOV.UK, n.d.; Office for National Statistics, 2024). A 2024 UK charity report on the Minimum Income Standard (MIS) reinforces this, showing that a single individual in the UK requires an annual income of £28,000 to achieve a socially acceptable standard of living, while a couple with two children needs £69,400 per year (mean £48,700) (Davis, A et al., 2024). Moreover, an American study from 2010 suggests that wellbeing gains from income level-off beyond approximately £75,000 per year (or approximately £48,500 based on contemporary exchange rates) (Kahneman & Deaton, 2010). In order to reach a consensus among these three findings, the mean was calculated to reach a figure of £47,400. These findings collectively suggest that for the pragmatic purposes of this study, an income of around £47,000 (gross) could be set as a threshold above which an acceptable QoL standard could be achieved in the UK when the data set was collected in 2017.

Finally, as it was not possible to capture the impact of chronic pain on social and leisure activities in this dataset, the variable of life satisfaction (variable *SCSatis*) was added into the analysis to attempt to capture some elements of these costs of chronic pain. The variable was recoded from ordinal into categorical using the SPSS transform function, and divided into two categories for purposes of analysis. As the mean of the population was 7.69, scores at or above the mean of seven were taken to indicate good levels of life satisfaction, while scores below seven were taken to indicate poor levels of life satisfaction.

Study 3

From a service-wide clinical database, patients who underwent ACL reconstruction surgery were collated into the database used for Study 3. The KOOS knee-related QoL score was used as the outcome measure to evaluate QoL at four time points: pre-surgery, 6 months post-surgery, 12 months post-surgery, and two years post-surgery. While QoL data for the EQ5D3L was available, it was inconsistent across time points, and therefore, the more consistent dataset available for KOOS QoL subscores were used. Cases with missing values at the pre-operative time point were removed from the analysis, leaving 212 patient cases available for analyses.

The clinical team hypothesised that smoking status, BMI, and gender would have confounding effects on surgical outcomes. As the literature corroborated the hypotheses for BMI and smoking status, this study entered smoking status and BMI as covariates in the model; while the KOOS QoL subscore at baseline was treated as the independent variable. However, the literature did not corroborate that gender was a significant predictor of KOOS QoL score in particular, so this was not entered into the analysis (MOON Knee Group et al., 2018). The dependent variables were KOOS QoL subscores at six months, twelve months, and two years post-operatively. Patients who were having revision surgery were not included in the analysis as the literature indicated that these patients tended to have more complex clinical pathologies which would potentially confound results.

Chapter 4 Results

The previous chapter detailed the methodologies and methods used to examine the research questions of Studies 2 and 3. As described, Study 2 examined the question of what the cost, as named by sufferers, of chronic pain is, using the HSE 2017 dataset and binomial logistic regressions; while Study 3 asked if NHS ACL reconstruction patients reported improved QoL at three time points post-surgery, using ANCOVA to control for the effect of smoking status and BMI. The following chapter will now go on to describe the results of Studies 2 and 3.

Study 2

Frequency Statistics

Frequencies were run to check the spread of categorical variables (i.e. gender, age, psychological state, work, income, AoDL, mobility, chronic pain, marital status, ethnicity, and highest level of education) and the ordinal variable (i.e. life satisfaction) (Table 2). The total sample included 9,982 individuals—comprised of 4507 males (45.2%) and 5475 females (54.8%). The age distribution was relatively even across adult age bands—with the sample stratified as follows: 977 individuals between 18-29 years (9.8%), 2,580 individuals between 30-49 years (25.9%), 2667 individuals between 50-69 years (26.8%), 1544 individuals between 70-89 years (15.5%), and 72 individuals over 90 years (0.7%). Ethnicity data indicated that 8,532 participants (85.5%) identified as White, followed by 790 (7.9%) Asian, 318 (3.2%) Black, 221 (2.2%) of mixed or multiple ethnic backgrounds, and 78 (0.8%) identifying with another ethnic group. Missing or unclear responses were minimal (n = 43, 0.4%). Marital status data showed that 4,277 participants (42.8%) were married or in a civil partnership, 1,479 (14.8%) were single, and 959 (9.6%) were cohabiting. Separated, divorced, and widowed individuals accounted for 157 (1.6%), 554 (5.5%), and 571 (5.7%) of the sample, respectively. Missing data totalled 1,985 cases (19.9%). Education data was varied, with 2,259 respondents (22.6%) holding a degree-level qualification or higher, 4,016

(40.2%) having below-degree-level qualifications, and 1,685 (16.9%) reporting no formal qualifications. A further 2,022 cases (20.3%) were recorded as not applicable. Finally, chronic pain was reported by 2,988 individuals (29.9%). Only 439 respondents (4.4%) explicitly reported not experiencing chronic pain. The remaining 6,555 cases (65.7%) were marked as not applicable, possibly due to age-based filtering or survey design.

In relation to working capacity and financial security, the largest group of the sample, 6,428 individuals (64.4%), reported being in paid employment or self-employed. 2,341 (23.5%) reported being retired. Other work categories included looking after the home or family (n = 544, 5.4%) and permanent inability to work due to long-term sickness or disability (n = 286, 2.9%). The smallest valid category was “Waiting to take up paid work” (n = 26, 0.3%). There were 5 missing cases (0.1%). Financial security (i.e. household income) data were highly skewed, with 8,807 cases (88.2%) marked as not applicable. Among the valid responses, the most common income band was "up to £10,400," reported by 92 individuals (0.9%). The smallest valid category was "£31,200 less than £33,800" (n = 15, 0.2%). A total of 284 respondents (2.8%) selected “don’t know,” and 139 (1.4%) refused to answer.

With regards to daily functioning, 5,652 participants (56.6%) reported no problems performing usual activities, while 830 (8.3%) reported slight problems, and 459 (4.6%) reported moderate problems. Severe problems were reported by 244 individuals (2.4%), and 75 (0.8%) stated they were unable to do their usual activities. There were 62 missing responses (0.6%). The largest category was "No problems doing usual activities" (n = 5,652, 56.6%), and the smallest was "Unable to do usual activities" (n = 75, 0.8%). Similarly, 5,530 individuals (55.4%) reported no problems with mobility, while 827 (8.3%) and 480 (4.8%) reported slight and moderate mobility issues, respectively. Severe mobility limitations and inability to walk were reported by 365 (3.7%) and 49 (0.5%) individuals, respectively. There were 71 missing or unclear responses (0.7%). The largest category was "No problems walking about" (n = 5,530, 55.4%), and the smallest was "Unable to walk about" (n = 49, 0.5%).

Life satisfaction was assessed using an ordinal scale ranging from 0 (not at all satisfied) to 10 (completely satisfied). Life satisfaction ratings were generally positive—the median life satisfaction score was 8 (n = 1,930, 19.3%), followed by 9 (n = 1,541, 15.4%) and 7 (n = 1,101, 11.0%). A total of 950 respondents (9.5%) rated their satisfaction below 7 (i.e., scores 0–6), while 4,733 (47.4%) rated their satisfaction above 7 (i.e., scores 8–10). Missing or inapplicable responses accounted for 2,728 cases (27.3%). Finally, in terms of psychological status, 5,055 participants (50.6%) reported not being anxious or depressed, while 1,343 (13.5%) reported slight anxiety or depression, and 610 (6.1%) reported moderate levels. Severe and extreme levels of anxiety/depression were reported by 182 (1.8%) and 69 (0.7%) individuals, respectively. Missing or inapplicable responses comprised 2,723 cases (27.3%).

Table 2

Frequencies and Percentages for Demographic and Quality of Life Variables

Variable	Category	Frequency (n)	Percentage (%)
Demographics			
Age	18–29	977	9.8%
	30–49	2,580	25.9%
	50–69	2,667	26.7%
	70–89	1,444	14.5%
	90+	72	0.7%
	Missing/Not applicable	1,985	19.9%
Sex	Male	4,507	45.2%
	Female	5,475	54.8%
Marital Status	Single	1,479	14.8%

Variable	Category	Frequency (n)	Percentage (%)
	Married/Civil partnership	4,277	42.8%
	Separated	157	1.6%
	Divorced	554	5.5%
	Widowed	571	5.7%
	Cohabiting	959	9.6%
	Missing/Not applicable	1,985	19.9%
Ethnicity	White	8,532	85.5%
	Asian	790	7.9%
	Black	318	3.2%
	Mixed/Other	299	3.0%
	Missing/Refused/Don't know	43	0.4%
Education	Degree or higher	2,259	22.6%
	Below degree	4,016	40.2%
	No qualification	1,685	16.9%
	Missing/Not applicable	2,022	20.3%
Chronic Pain	Yes	2,988	29.9%
	No	439	4.4%
	Missing/Not applicable	6,555	65.7%
Quality of Life			
Psychological State	Not anxious or depressed	5,055	50.6%
	Slightly anxious or depressed	1,343	13.5%
	Moderately anxious or depressed	610	6.1%
	Severely anxious or depressed	182	1.8%
	Extremely anxious or depressed	69	0.7%
	Missing/Refused/Don't know/Not applicable	2,723	27.3%
Working Capacity	Employed/self-employed	6,428	64.4%
	Retired	2,341	23.5%
	Looking after home/family	544	5.4%
	Permanently unable to work	286	2.9%
	Other	383	3.8%
	Missing/Don't know	5	0.1%
Financial Security (Household Income)	Up to £10,400	92	0.9%
	Other specified bands	572	5.9%
	Don't know	284	2.8%
	Refused	139	1.4%
	Missing/Not applicable	8,807	88.2%
Mobility	No problems walking	5,530	55.4%
	Slight problems	827	8.3%

Variable	**Category**	**Frequency (n)**	**Percentage (%)**
	Moderate problems	480	4.8%
	Severe problems	365	3.7%
	Unable to walk	49	0.5%
	Missing/Refused/Don't know/Not applicable	2,731	27.3%
Activities of Daily Living	No problems	5,652	56.6%
	Slight problems	830	8.3%
	Moderate problems	459	4.6%
	Severe problems	244	2.4%
	Unable to perform activities	75	0.8%
	Missing/Refused/Don't know/Not applicable	2,722	27.3%
Life Satisfaction	Score 0–6 (below 7)	950	9.5%
	Score = 7	1,101	11.0%
	Score 8–10 (above 7)	4,733	47.4%
	Missing/Not applicable	2,728	27.3%

Binomial Logistic Regressions

Assumptions Testing (i.e. Multicollinearity, Outliers, Sample Size) and Analysis

All conditions were checked to have been met for binomial regression. Initial descriptive statistics were run to evaluate the number of cases per variable level that was sufficient for analysis. Data was checked for influential cases (e.g. outliers) using Cook’s distance—ensuring no values equal to or above one (indicating an influential case) were found. Finally, the absence of multicollinearity was evaluated using correlation matrix. No values above 0.7 were found amongst variables—barring the dependent variables activities of daily living and mobility. However, this was deemed appropriate to proceed with given patients with chronic pain named these as separate constructs that impacted their QoL (Bowling, 1996). Binomial logistic regressions were then conducted to examine the association between chronic pain on the odds that a respondent would report difficulties along the subdomains of QoL identified by those suffering with chronic pain (i.e. mobility, activities of daily living, financial resources, and psychological state), as well as life satisfaction. the null hypothesis (H_0) was that the presence of chronic pain was not associated with the likelihood of reporting poorer outcomes along these QoL dimensions. The model contained six independent variables (chronic pain, age, ethnicity, marital status, education, gender). Results for each subdomain of QoL are detailed below.

Results by QoL Domain

Mobility

Mobility was significantly associated with chronic pain. The full model containing all predictors was statistically significant, $X^2(6, N=7090) = 1876.04, p<0.00$), indicating that the model was able to distinguish between those who had chronic pain and those who did not. The model correctly classified 79.80% of cases. Roughly 35% of the variance in mobility was accounted for by the independent variables of the model (Nagelkerke $R^2 = 0.348$; Hosmer and Lemeshow $\chi^2 = 14.870, p < .062$). No statistically significant relationship was indicated with sex or ethnicity. As demonstrated in Table 3, only four of the independent variables made a unique statistically significant contribution to the model (age, marital status, chronic pain, highest level of education). Those experiencing chronic pain were more likely to exhibit mobility difficulties than those without chronic pain ($B = 2.254$, $SE = 0.069$, $p<0.00$). That is, the strongest predictor of difficulties with mobility was the presence of chronic pain, recording an odds ratio of 9.52. This indicates that those with chronic pain were almost ten times more likely to report difficulties with mobility as compared to those who did not have chronic pain (Exp(B)= 9.52, 95% CI [8.32,10.89]), controlling for all other factors in the model.

Table 3

Binomial Logistic Regression Predicting Mobility Outcomes

Predictor	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for Exp(B) Lower	Upper
Age	-1.03	0.07	225.84	1	0.00	0.36	0.31	0.41
Marital Status	-0.48	0.07	48.96	1	0.00	0.62	0.55	0.71
Chronic Pain	2.25	0.07	1077.61	1	0.00	9.52	8.32	10.89
Ethnicity	0.00	0.11	0.00	1	0.98	1.00	0.81	1.24
Highest Educational Level	0.52	0.08	41.61	1	0.00	1.68	1.43	1.96
Sex	0.05	0.07	0.50	1	0.48	1.05	0.92	1.19

Note. Logistic regression coefficients (B), standard errors (S.E.), Wald statistics, degrees of freedom (df), significance levels (Sig.), odds ratios [Exp(B)], and 95% confidence intervals (CI) for Exp(B) are reported for each predictor.

Activities of Daily Living (AoDL)

The ability to engage in AoDL was significantly associated with the presence of chronic pain. That is, the full model containing all predictors was statistically significant, $X^2(1, N=7099) =1623.84, p<0.00)$, indicating that the model was able to distinguish between those who had chronic pain and those who did not. The model correctly classified 79.3% of cases, with roughly 31% of the variance in activities of daily living accounted for by the model (Nagelkerke R^2 of 0.31; Hosmer and Lemeshow $\chi^2 = 24.12, p < .002$). As demonstrated in Table 4, only three of the independent variables made a unique statistically significant contribution to the model (age, marital status, and educational level). Those experiencing chronic pain are more likely to exhibit limitations to their AoDL compared to those without chronic pain ($B= 2.22, SE= 0.07, p<0.00$). That is, the strongest predictor of difficulties with AoDL was the presence of chronic pain, recording an odds ratio of 9.23. This indicates that those with chronic pain were nine times more likely to have limitations to their AoDL than those who did not have chronic pain (Exp(B)= 9.23, 95% CI [8.06,10.58]), controlling for all other factors in the model. No statistically significant relationship was indicated with sex or ethnicity.

Table 4

Binomial Logistic Regression Predicting AoDL Outcomes

							95% C.I. for Exp(B)	
Predictor	B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
Age	-0.66	0.07	91.12	1	0.00	0.52	0.45	0.59
Marital Status	-0.45	0.07	44.86	1	0.00	0.64	0.56	0.73
Chronic Pain	2.22	0.07	1020.70	1	0.00	9.23	8.06	10.58
Ethnicity	0.13	0.11	1.28	1	0.26	1.14	0.91	1.41
Highest Educational Level	0.48	0.08	35.56	1	0.00	1.61	1.38	1.89
Sex	-0.06	0.07	0.84	1	0.36	0.94	0.83	1.07

Note. Logistic regression coefficients (B), standard errors (S.E.), Wald statistics, degrees of freedom (df), significance levels (Sig.), odds ratios [Exp(B)], and 95% confidence intervals (CI) for Exp(B) are reported for each predictor.

Financial Resources

Income was significantly associated with chronic pain. The full model containing all predictors was statistically significant, $X^2(6, N= 651) = 77.25, p<0.00$), indicating that the model was able to distinguish between those who had chronic pain and those who did not. The model correctly classified 64.8% of cases, with roughly 15% of the variance in income accounted for by the model (Nagelkerke $R^2 = 0.15$; Hosmer and Lemeshow $\chi^2 = 6.37$, p= 0.50). As demonstrated in Table 5, only three of the independent variables made a unique statistically significant contribution to the model (chronic pain, marital status, and highest level of education). There was no statistically significant relationship with age, sex, or ethnicity. The strongest predictor of living in a household with an income below £46,800/year was the presence of chronic pain, recording an odds ratio of 2.06. This indicates that those with chronic pain were twice as likely to report a lower household income as compared to those who did not have chronic pain (Exp(B)=2.06, 95% CI [1.43, 2.95]), controlling for all other factors in the model.

Table 5

Binomial Logistic Regression Predicting Financial Resources

							95% C.I. for Exp(B)	
Predictor	B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
Age	-0.39	0.31	1.59	1	0.21	.67	0.37	1.24
Marital Status	-1.24	0.18	49.85	1	0.00	.29	0.21	0.41
Chronic Pain	0.72	0.19	15.22	1	0.00	2.06	1.43	2.95
Ethnicity	0.12	0.26	0.21	1	0.65	1.13	0.67	1.89
Highest Educational Level	0.60	0.20	8.87	1	0.00	1.83	1.23	2.72
Sex	-0.21	0.17	1.51	1	0.22	0.81	0.58	1.13

Note. Logistic regression coefficients (B), standard errors (S.E.), Wald statistics, degrees of freedom (df), significance levels (Sig.), odds ratios [Exp(B)], and 95% confidence intervals (CI) for Exp(B) are reported for each predictor.

Working Capacity

Working status was significantly associated with chronic pain. The full model containing all predictors was statistically significant, $X^2(6, N=7750) = 3628.50, p<0.00$), indicating that the model was able to distinguish between those who had chronic pain and those who did not. The model correctly classified 81.90% of cases. Roughly 51% of the variance in working status was accounted for by the independent variables of the model (Nagelkerke $R^2 = 0.51$; Hosmer and Lemeshow $\chi^2 = 28.67$, $p < 0.00$). As demonstrated in Table 6, all independent variables, barring gender, made a unique statistically significant contribution to the model (age, ethnicity, marital status, chronic pain, highest level of education). Those experiencing chronic pain were more likely to not be in paid work than those without chronic pain (B = 0.57, SE = 0.06, $p<0.00$); with chronic pain sufferers nearly twice as likely to not be in paid employment than those who did not have chronic pain, controlling for all other factors in the model (Exp(B)= 1.76, 95% CI [1.56, 1.99]). However, the strongest predictor of not being in paid work was highest level of education, recording an odds ratio of 2.01. This indicates that those educated at or above degree level were twice as likely to be in paid employment when compared to those educated below degree level (Exp(B)= 2.01, 95% CI [1.75, 2.32]), even if they suffered from chronic pain.

Table 6

Binomial Logistic Regression Predicting Working Capacity

							95% C.I. for Exp(B)	
Predictor	B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
Sex	-0.04	0.06	0.32	1	0.57	0.97	0.86	1.09
Highest Educational Level	0.70	0.07	95.07	1	0.00	2.01	1.75	2.317
Ethnicity	-0.22	0.09	5.52	1	0.02	0.80	0.67	0.97
Marital Status	-0.86	0.06	178.54	1	0.00	0.43	0.38	0.48
Chronic Pain	0.57	0.06	81.32	1	0.00	1.76	1.56	1.99
Age	-3.37	0.08	1850.99	1	0.00	0.04	0.03	0.04

Note. Logistic regression coefficients (B), standard errors (S.E.), Wald statistics, degrees of freedom (df), significance levels (Sig.), odds ratios [Exp(B)], and 95% confidence intervals (CI) for Exp(B) are reported for each predictor.

Psychological State

Depression and/or anxiety symptoms were also significantly associated with chronic pain. The full model containing all predictors was statistically significant, $X^2(6, N=7090) = 507.36$, $p<0.00$), indicating that the model was able to distinguish between those who had chronic pain and those who did not. The model correctly classified 71% of cases. Roughly 10% of the variance in mobility was accounted for by the independent variables of the model (Nagelkerke $R^2 = 0.098$; Hosmer and Lemeshow $\chi^2 = 17.05$, $p < .03$). As demonstrated in Table 7, all of the independent variables made a unique statistically significant contribution to the model (age, gender, ethnicity, marital status, chronic pain, highest level of education). Those experiencing chronic pain were more likely to exhibit depression and/or anxiety symptoms than those without chronic pain ($B = 0.93$, $SE = 0.06$, $p<0.00$). In fact, the strongest predictor of negative psychological state was the presence of chronic pain, recording an odds ratio of 2.54. This indicates that those with chronic pain were two and a half times more likely to report negative psychological states as compared to those who did not have chronic pain (Exp(B)=2.54, 95% CI [2.28, 2.283]), controlling for all other factors in the model.

Table 7

Binomial Logistic Regression Predicting Psychological State

							95% C.I. for EXP(B)	
Predictor	B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
Sex	-0.30	0.06	29.99	1	0.00	0.74	0.67	0.82

Highest Educational Level	0.13	0.06	4.65	1	0.03	1.14	1.01	1.30
Ethnicity	0.27	0.09	9.15	1	0.00	1.31	1.10	1.56
Marital Status	-0.63	0.06	126.84	1	0.00	0.53	0.48	0.60
Chronic Pain	0.93	0.06	285.63	1	0.00	2.54	2.28	2.83
Age	0.46	0.06	52.99	1	0.00	1.58	1.40	1.80

Note. Logistic regression coefficients (B), standard errors (S.E.), Wald statistics, degrees of freedom (df), significance levels (Sig.), odds ratios [Exp(B)], and 95% confidence intervals (CI) for Exp(B) are reported for each predictor.

Life Satisfaction

Finally, life satisfaction was significantly associated with chronic pain. The full model containing all predictors was statistically significant, $X^2(6, N=7093) = 665.60, p<0.00$), indicating that the model was able to distinguish between those who had chronic pain and those who did not. The model correctly classified 80.6% of cases. Roughly 14.2% of the variance in mobility was accounted for by the independent variables of the model (Nagelkerke $R^2 = 0.142$; Hosmer and Lemeshow $\chi^2 = 6.64$, $p < 0.58$). No statistically significant relationship was indicated with sex. As demonstrated in Table 8, five of the independent variables made a unique statistically significant contribution to the model (age, marital status, chronic pain, ethnicity, highest level of education). Those experiencing chronic pain were more likely to exhibit lower than average life satisfaction than those without chronic pain (B = 1.18, SE = 0.07, $p<0.00$). In fact, the strongest predictor of lower than average life satisfaction was the presence of chronic pain, recording an odds ratio of 3.26. This indicates that those with chronic pain were three times more likely to report lower than average life satisfaction as compared to those who did not have chronic pain (Exp(B)= 3.26, 95% CI [2.87,3.70]), controlling for all other factors in the model.

Table 8

Binomial Logistic Regression Predicting Life Satisfaction

							95% C.I. for EXP(B)	
Predictor	B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
Age	0.32	0.07	19.21	1	0.00	1.37	1.19	1.58
Marital Status	-0.98	0.06	234.01	1	0.00	0.38	0.33	0.43
Chronic Pain	1.18	0.07	334.65	1	0.00	3.26	2.87	3.70
Ethnicity	-0.23	0.10	5.57	1	0.02	0.79	0.65	0.96
Highest Educational Level	0.46	0.08	35.77	1	0.00	1.58	1.36	1.84
Sex	-0.03	0.06	0.29	1	0.59	0.97	0.85	1.10

Note. Logistic regression coefficients (B), standard errors (S.E.), Wald statistics, degrees of freedom (df), significance levels (Sig.), odds ratios [Exp(B)], and 95% confidence intervals (CI) for Exp(B) are reported for each predictor.

Therefore, all regressions demonstrated a statistically significant negative relationship between the presence of chronic pain and every measure of QoL named by chronic pain sufferers– as well as on life satisfaction.

Study 3: ANCOVAs

Descriptive Statistics

Descriptive statistics were run for continuous variables (i.e. preoperative QoL scores; post-operative QoL scores at 6 months, 12 months, 2 years; age; and BMI) (Table 9). The mean age of the sample was 29.9 years (range= 16 - 64, standard deviation (SD)= 10.17). The mean BMI was 26.17 (SD= 4.89), with a range of 14.10 to 43.60. The mean score of pre-operative QoL scores was 33.05 (n= 205; SD= 21.08; range= 0 - 100), while the six-month post-operative QoL scores average was 54.00 (n= 149; SD= 21.07; range= 0 -100). One year post-operative scores average was 60.82 (n= 118; SD= 24.97; range= 6 - 100); two year post-operative scores average was 64.34 (n= 76; SD= 25.22; range= 0 - 100). Frequencies were also run to check the descriptive statistics of categorical variables (i.e. smoking status and sex) (Figures 13 and 14). The total sample included 212 patients—comprised of 152 males (71.7%) and 59 females (27.8%). The sample contained 153 non-smokers (85.5%), 6 former smokers (3.4%), and 20 smokers (11.2%). Demographic analyses therefore revealed that this sample was predominately young males, who were non-smokers. This is in line with expectations as an ACL reconstruction surgery is most often required due to an acute, athletic injury rather than normal wear and tear of joints.

Table 9

Demographic Characteristics of Sample

	Sample Size (n)	Minimum	Maximum	Mean	Standard Deviation
Age	211	16	64	29.91	10.17
Body Mass Index	141	14.10	43.60	26.17	4.89
Pre-Operative Knee-Related QoL	205	0	100	33.05	21.08
6-month Post-Operative Knee-Related QoL	149	0	100	54.00	21.07
12-month Post-Operative Knee-related QoL	118	6	100	60.82	24.97
2 years Post-Operative Knee-Related QoL	76	0	100	64.34	25.22

Figure 13

Smoking Status of Sample

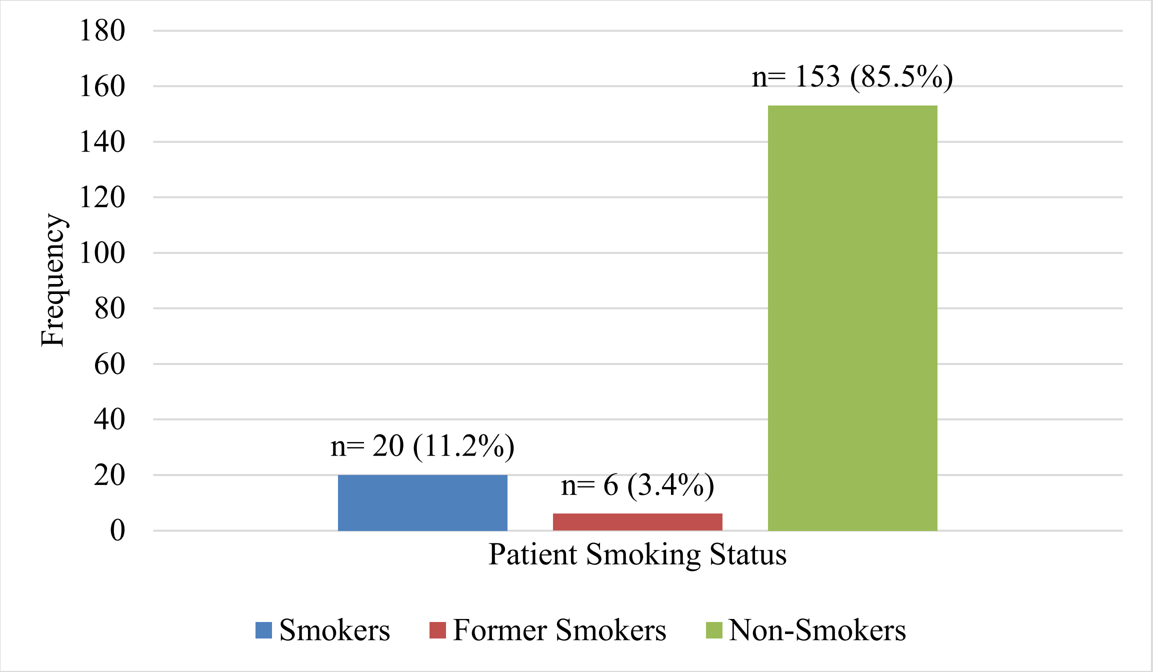
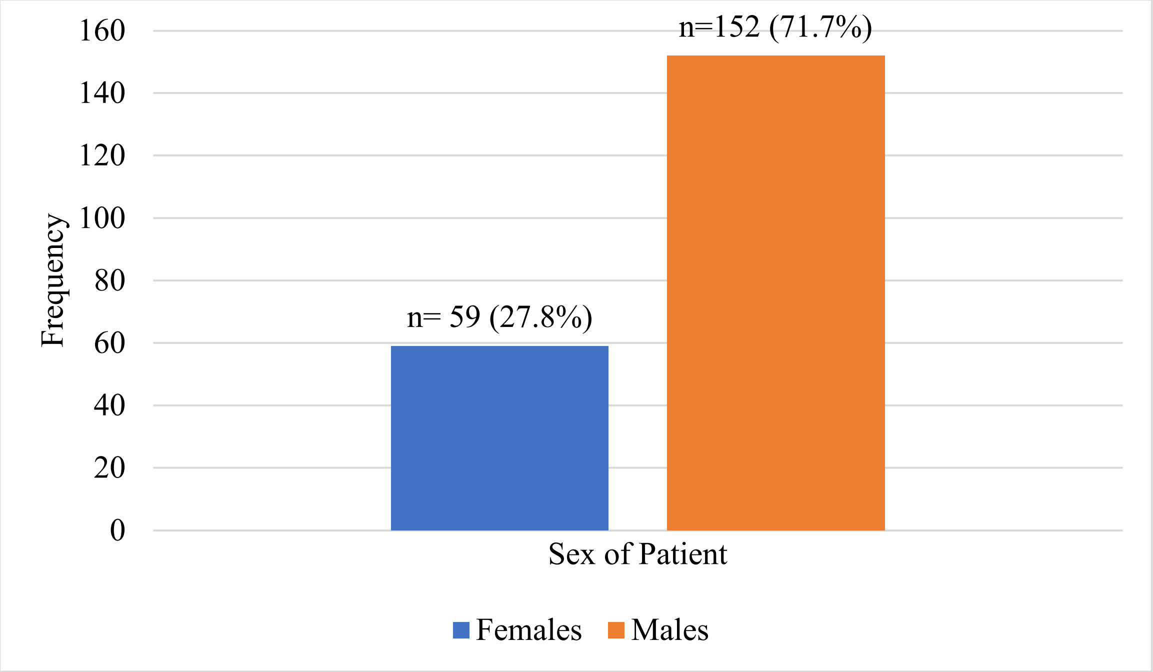


Figure 14

Sex within the Sample



Data and Test Assumptions Checks

Before testing the specific ANCOVA assumptions, the general assumptions for a regression analysis were checked. That is, the assumptions of the level of measurement (i.e. continuous dependent variable), random sampling, independence of observations (i.e. no between-subject interactions), and normality were found to have not been not violated (Pallant, 2020). An inspection of histograms was conducted to examine for outliers and normality—skewness (i.e. symmetry of the distribution) and kurtosis (i.e. peakedness of the distribution) indicated relative normality of distributions. The 5% trimmed mean (i.e. mean without top and bottom 5% of scores) was also checked against means to ensure outliers did not have a strong effect on means.

Next, additional assumptions were checked prior to the running of the ANCOVA. First, as the covariates (smoking status and BMI were measured prior to surgery, the data met the assumption that there was no influence of treatment on covariate measurements. Second, the reliability of covariates was ensured as covariates were reliably measured by the surgical clinical team; that is, BMI was measured using appropriate height and weight measurement techniques, and smoking status was noted in clinical interview. Third, strong correlations were checked for among the covariates using correlational matrix to avoid potentially confounding relationships. As per interpretive norms, no strong correlations (i.e. r = 0.80 or above) was found between smoking status and BMI (r= 0.59), and therefore, the analysis was safe to proceed with (Pallant, 2020). Fourth, testing for sphericity (i.e. Mauchly's Test) was not necessary as only two time points were being evaluated by each ANCOVA. Fifth, the potential for curvilinear relationships between dependent variable and covariates was checked for by examining fit lines for scatterplots (of continuous covariate), and no curvilinear relationships were identified. Finally, the assumption of the homogeneity of regression slopes and homogeneity of variance (i.e. Levene's Test) were not necessary to examine as there was only one intervention type being evaluated (no comparison of treatment groups). The homogeneity of regression slopes assumption would have examined if the relationship between the dependent variable and covariates was similar across all treatment groups by examining the slopes of regression lines (Pallant, 2020).

ANCOVA Results

As previously described, ANCOVA was chosen as the analytic method as such a model would allow for comparison of change between time points while allowing to control for potentially confounding factors (i.e. covariates). The covariates chosen to be controlled for—smoking status (categorical) and BMI (continuous)—were based on factors the literature indicated were significant to post-operative outcomes—as well as the clinical observations of the surgical team (He et al., 2022; Kerkhoffs et al., 2012; Oberbek & Synder, 2015). Gender was not entered into the model as there was no consistent evidence for post-operative differences in KOOS QoL sub-scores based on gender (Ferrari et al., 2001; MOON Knee Group et al., 2018; Perez et al., 2020). Therefore, the pre-operative knee-related QoL KOOS score (continuous) was used as the independent variable. Finally, the dependent variable was considered the postoperative KOOS knee-related QoL score at 6 months, one year, and 2 years post-procedure (continuous), respectively. However, two caveats necessitated the use of separate ANCOVA regressions for each time point. First, the QoL scores six months post-surgery were strongly correlated with post-operative QoL scores at two years (r=0.70, p<0.00)—and the QoL post-operative scores at one year were strongly correlated with QoL post-operative scores at two years (r=0.79, p<0.00). Second, because the original sample size of n= 212 was reduced to a sample of n=24 by a lack of KOOS QoL data consistently across all four time points, the sample size was too small to run a single repeated measures ANCOVA.

Postoperative QoL Outcomes: Six Months

An ANCOVA was conducted to examine knee-related QoL changes after ACL reconstruction surgery after six months, while controlling for BMI and smoking status. The within-subjects item was surgery with two measurement points: pre-surgery and six months post-surgery. The independent variable was the pre-operative KOOS knee-related QoL subscale score, and the dependent variable consisted of knee-related QoL scores on the KOOS administered 6 months after surgery. Data was available for n= 95 patients who completed KOOS QoL scores before surgery and six months post-surgery. The mean pre-operative KOOS QoL score was 34.27 (SD = 20.87); while the mean 6-month post-operative KOOS QoL score was 53.92 (SD = 19.32). Checks of preliminary test assumptions for ANCOVA were satisfactory. After adjusting for covariates of BMI and smoking status, regression results indicated there was no significant difference between knee-related QoL scores before surgery and six months after surgery (F(1,92) = 2.23, p = 0.14, partial eta squared (partial η^2) = 0.02). By contrast, pairwise comparisons indicated a statistically significant mean difference between pre- and six-month postoperative knee-related QoL scores (mean difference= 19.65, $p < 0.001$). Moreover, neither smoking status nor BMI had a significant interaction with post-operative scores (F (1, 92) = 0.14, p = 0.71, partial η^2 = 0.002) and (F (1, 92) = 0.39, p = 0.54, η^2 = 0.004), respectively. Overall, the lack of statistically significant regression findings indicated that the statistically significant improvements in knee-related QoL from pre-surgery to 6 months post-surgery could not be attributed to the surgery by this model.

Postoperative QoL Outcomes: One Year

A second ANCOVA was conducted to examine knee-related QoL changes after ACL reconstruction after twelve months, while controlling for BMI and smoking status. Again, the within-subjects item was surgery with two measurement points: pre-surgery and twelve months post-surgery. The independent variable was the pre-operative KOOS QoL subscale score, and the dependent variable consisted of QoL scores on the KOOS administered twelve months after surgery. Data was available for n= 74 patients who completed KOOS QoL scores before surgery and 12 months post-surgery. The mean pre-operative KOOS QoL score was 34.44 (SD = 21.06); while the mean 12-month post-operative KOOS QoL score was 66.39 (SD = 21.35). Checks of the preliminary assumptions for ANCOVA were again satisfactory. After adjusting for covariates of BMI and smoking status, regression results indicated there was no significant difference between knee-related QoL scores before surgery and 12 months after surgery F(1,71) = 1.15, p = 0.29, partial η^2 = 0.02. Pairwise comparisons again indicated a statistically significant mean difference between pre- and 12-month postoperative knee-related QoL (mean difference=31.96, $p < 0.01$). Neither smoking status or BMI had a significant interaction with post-operative scores, (F(1,71) = 0.92, p = 0.34, partial η^2 = 0.01) and (F(1,71) = 0.05, p = 0.83, partial η^2 = 0.001), respectively. Overall, the lack of statistically significant regression findings indicated that the observed improvement in knee-related QoL scores from pre- to one year post-surgery could not be attributed to ACL surgery.

Postoperative QoL Outcomes: Two Years

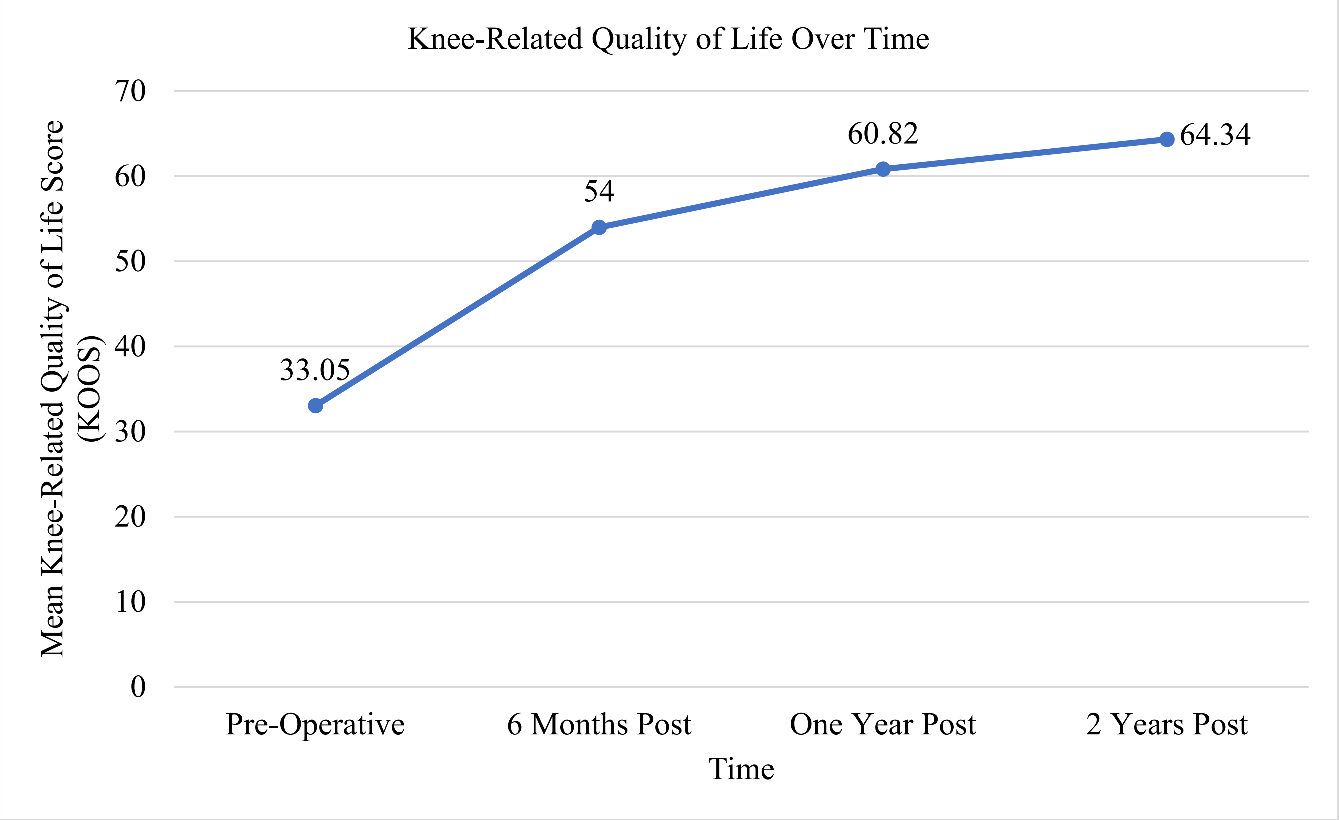
A final ANCOVA was conducted to examine knee-related QoL changes after ACL reconstruction after 2 years, while controlling for BMI and smoking status. The within-subjects item was again surgery with two measurement points: pre-surgery and two years post-surgery. The independent variable was the pre-operative KOOS QoL subscale score, and the dependent variable consisted of QoL scores on the KOOS administered 2 years after surgery. Checks of preliminary assumptions were satisfactory. However, data was only available for n= 44 patients who completed KOOS QoL scores at both pre-surgery and two years post-surgery. Typically, a sample size of thirty is considered as a minimum threshold for statistical testing—meaning the relatively small sample size of this 2-year post-operative analysis will have limited its ability to capture statistically significant change. The mean pre-operative KOOS QoL score was 31.30 (SD = 20.77); while the mean 2-year post-operative KOOS QoL score was 65.17 (SD = 25.86). After adjusting for covariates of BMI and smoking status, regression results indicated there was no significant difference between knee-related QoL scores before surgery and 2 years after surgery ($F(1, 41) = 0.22$, $p = 0.64$, partial $\eta^2 = 0.005$). However, pairwise comparisons again indicated a statistically significant mean difference between pre- and 2-year postoperative knee-related QoL scores (mean difference= 33.88, $p < .001$). BMI did not have a significant interaction with post-operative scores in the context of surgery ($F(1, 41) = 2.76$, $p = 0.10$, partial $\eta^2 = 0.06$)—however smoking status had a significant interaction with knee-related QoL scores two years after surgery ($F(1, 41) = 14.80$, $p < .001$, Partial $\eta^2 = 0.27$). Overall, the lack of statistically significant regression findings indicated that the statistically significant improvements in knee-related QoL from pre to 2 years post-surgery could not be attributed to surgery by this model.

Trends Across Time Points

Overall, there was a steady trend of improvement in knee-related QoL scores overtime (Figure 15). The mean score of knee-related QoL before surgery was 33.05, six-months post-operatively was 54.00, one-year post-operatively was 60.82, and two years post-surgery was 64.34. However, as the regressions above demonstrate, these changes in knee-related QoL cannot be attributed to surgery by this model. Nonetheless, knee-related QoL scores show a sharp improvement from pre-op to 6 months, followed by a plateau at 12 months—supporting the idea that most gains occur within the first 6 months post-surgery. Finally, non-smokers were likely to have better knee-related QoL by 2 years post-surgery.

Figure 15

Knee-Related QoL scores Over Time (Pre-surgery to 2 years Post-surgery)



Post Hoc Statistical Power Testing

As the sample size for this study was predetermined ($n = 212$), a post-hoc statistical power evaluation was used (rather than a sample size calculation) to determine the extent to which this sample would allow for a reliable estimation of the change in KOOS QoL scores following ACL reconstruction. Post-hoc analyses were carried out to estimate the smallest effect sizes the study was able to detect with 80% power, given the number of participants remaining at each post-surgical timepoint. The ANCOVA results were: 6-month $F(1,92)=2.23$, $p=0.14$, partial $\eta^2=0.02$ (observed power=0.32); 12-month $F(1,71)=1.15$, $p=0.29$, partial $\eta^2=0.02$ (observed power=0.19); and 24-month $F(1,41)=0.22$, $p=0.64$, partial $\eta^2=0.01$ (observed power=0.08). These small effect sizes combined with the low observed power, indicates that these analyses had limited ability to detect subtle changes over time using these sample sizes. That is, the amount of improvement observed from pre- to post-surgery was statistically very small, and the number of participants remaining at post-surgical timepoints was also quite limited. This combination means the analyses did not have enough statistical strength to reliably identify small improvements—even if they were present. Therefore, if the true changes were modest rather than large, the study would struggle to detect them—meaning that the non-significant results do not necessarily imply that no improvement occurred.

The sensitivity analysis showed that in order to achieve 80% power, the study would have needed effects of roughly $f=0.29$ ($\eta^2\approx0.08$) at 6 months, $f=0.33$ ($\eta^2\approx0.10$) at 12 months, and $f=0.43$ ($\eta^2\approx0.16$) at 24 months. This means that the sample sizes available at the 12- and 2-year timepoints were only large enough to reliably detect moderate to large changes in KOOS QoL. Smaller, but still clinically meaningful, improvements would likely go undetected by these analyses simply because the sample had become too small to provide adequate statistical power.

In summary, the non-significant findings at later follow-ups should be interpreted cautiously, as they do not necessarily indicate no improvement. Rather, the study was not sufficiently powered to detect small changes after post-surgical attrition (Cohen, 1988).

Chapter 5 Discussion

The following chapter will discuss the findings of Studies 2 and 3 within the context of the current literature and findings of the systematic scoping review of Study 1. Limitations and reflections on the study will be explored. Finally, practical applications, dissemination plans, and areas for future research will be discussed.

Study 2

As Study 1 indicated there was agreement between the academic literature and chronic pain sufferers that the cost of chronic pain is QoL, Study 2 aimed to examine these key identified subdomains of QoL in a large, nationally representative sample. Overall, findings were in line with the literature— confirming that chronic pain sufferers are significantly more likely to report impairments in mobility and AoDL, higher rates of anxiety and/or depression, lower household incomes, decreased working capacity, and lower life satisfaction.

The ability to move independently and confidently through one's environment is fundamental to maintaining autonomy, social participation, and psychological wellbeing—and therefore, is the foundation of QoL. This study's findings confirmed that chronic pain sufferers are dramatically more likely to report impairments in mobility and the AoDL. This is consistent with previous research highlighting the limits chronic pain places on independence and autonomy through its impact on physical functioning (Breivik et al., 2006, 2013; Ge et al., 2022; Hadi et al., 2019; Hirvensalo et al., 2000; R. J. E. James et al., 2019; Sprangers et al., 2000; von Bülow et al., 2015; Webber et al., 2010). These findings emphasise the importance of physiotherapeutic and functional/occupational interventions as key components of care for populations with chronic pain.

The evidenced poorer physical functioning for those with chronic pain is known to be closely related to psychological wellbeing and life satisfaction. While the relationships between QoL subdomains was not statistically examined within this study, results nonetheless show that chronic pain sufferers were significantly more likely to report moderate to extreme levels of anxiety or depression and lower life satisfaction than their counterparts. These findings corroborate the wealth of literature linking chronic pain to psychological difficulties and declines in life satisfaction (Breivik et al., 2013; Budd et al., 2022; Collett, 2011; Costa et al., 2025; Hadi et al., 2019; Office for National Statistics, 2019). When people can freely move and do as they wish, they tend to have a stronger sense of self and their roles, find meaning and purpose in their lives, and have greater self-efficacy. By contrast, these losses in autonomy can strip an individual of these aspects of the self and meaning (Budd et al., 2022; Lowe et al., 2024; Toledano-González et al., 2019). Therefore, these results emphasise the need to support chronic pain sufferer's physical functioning, autonomy, and psychological wellbeing (e.g. through interdisciplinary rehabilitation, assistive technology, and inclusive design) in order to bolster their QoL.

Findings around working capacity were also in line with the literature, in that those with chronic pain were much more likely to not be in paid employment when compared to those without pain (Gaskin & Richard, 2012; van Leeuwen et al., 2006). However, interestingly, the best predictor of employment status, despite the presence of pain, was educational level.

This is consistent with previous research demonstrating that those educated to degree level or higher were much more likely to be able to remain in paid employment when compared to those educated below degree level—despite the presence of chronic pain (de Rijk et al., 2009; Gerdtham & Johannesson, 2003; Michaud et al., 2006; Slebus et al., 2007). Therefore, higher educational attainment appears to be a protective factor despite chronic pain. The protective effect of educational attainment might be for a few reasons—first, this may suggest that those with higher educational degrees were less likely to be in manual labour, pointing to the impact of job type on the ability to work despite chronic pain (Michaud et al., 2006). Next, those with greater levels of education are oftentimes afforded, and able to advocate for, more flexibility in their working environment and pattern (e.g. remote or part-time work). This flexibility would make work accessible to those with higher educational degrees despite their chronic pain condition (Andersson et al., 2013; de Rijk et al., 2009). Understood within the Job Demand-Control model (Karasek, 1979), where flexibility and autonomy in work roles is linked to better QoL, it is reasonable to hypothesise that those with chronic pain in such flexible working environments would have improved QoL both because of this flexibility and because they have been able to remain in work.

Although paid employment served as a proxy for working capacity in this study, one caveat is that the questions about work included in this dataset did not capture how individuals felt about their work/colleagues, if their work was flexible, or the quality of their working environment—meaning this study could not examine the subjective experience of work required to truly capture if participant's work was conducive to QoL. Without this examination it is impossible to gauge if specific work contexts would improve QoL for chronic pain sufferers. For example, it may be that people with chronic pain remain in work that negatively impacts their overall QoL (e.g. poor salary), because their options for finding employers that will meet adaptive needs is limited. Overall, however, these findings support previous research showing that chronic pain reduces productivity and labour force participation—while adding the nuance that factors such as educational access and flexible working need to be examined for their potentially positive effects on the QoL of chronic pain sufferers—as well as on productivity on a national scale.

In regards to earning capacity, findings around financial security were also in line with the literature—that is, those with chronic pain have less household income than those without (Gaskin & Richard, 2012; Kemler & Furnée, 2002). However, despite the plethora of research on chronic pain, it is striking how little research examines the cost of chronic pain on household income. Indeed, despite the scale of this dataset, income data was missing in 88% of cases. These lacks may reflect British cultural taboos which designate discussions of income and money as 'vulgar' (Fox, 2014; Trachtman, 1999; YouGov, 2025). Such norms would not only influence participants willingness to share this information, but also the unwillingness of healthcare professionals to inquire about this information (Moscrop et al., 2019; Moscrop & MacPherson, 2014). Healthcare staff often cite privacy concerns for their patients' data as the rationale for their reticence (Moscrop et al., 2019)—however, this study's findings highlight that broader shifts need to be made to address the underlying reasons that collection of income data is avoided by researchers (Moscrop & MacPherson, 2014). At present, the systematic underreporting of UK household income and its impacts on QoL and health (of both economically disadvantaged and privileged socioeconomic groups) is suggestive of broader structural inequalities resistant to change (American Academy of Nursing, 2015; Moscrop & MacPherson, 2014).

Study 3

Study 3 employed ANCOVA to evaluate the impact of ACL reconstruction surgery on knee-related QoL, controlling for BMI and smoking status. While knee-related QoL scores increased at 6 months, 1 year, and 2 years post-surgery, the changes could not be attributed to surgery by this analyses.

At 6 months post-surgery, knee-related QoL significantly improved ($p < .001$, mean difference = 19.65), although the main effect of surgery on knee-related QoL did not reach statistical significance in this model ($p = .139$). That is, a while there was a statistically significant increase in QoL from pre to six month post-operative time points (pairwise comparison), the regression analysis testing for the effect of surgery while the effects of smoking and BMI were controlled for did not demonstrate a statistically significant result. Moreover, the interactions between surgery and smoking status, and surgery and BMI were also not significant. This indicates that neither smoking status nor BMI significantly influenced the knee-related QoL changes from pre- to 6 months post-surgery.

The ANCOVA of one-year post-surgery knee-related QoL scores compared to pre-operative scores once again demonstrated that QoL significantly improved post-surgery—as seen in pairwise comparisons—but could not attribute this improvement to surgery. However, the pairwise comparisons once more demonstrated a significant mean difference of -31.96 ($p < .001$), meaning post-surgery QoL is significantly higher than pre-surgery QoL—but this change in QoL cannot be attributed to surgery in this sample.

Finally, results of the two-year post-operative ANOCOVA indicated an increase in knee-related QoL from pre-surgery to 2 years post-surgery—however, the sample size (n=44) at this time point makes the following findings tentative. Regression results testing the effect of surgery on knee-related QoL suggest that there is no significant change in QoL from pre-surgery to 2 years post-surgery when controlling for smoking status and BMI.

However, these results should be interpreted with caution as the sample sizes available post-surgical timepoints were not large enough to reliably detect smaller, but potentially clinically significant changes in the KOOS QoL scores. Therefore, the non-significant findings should be interpreted cautiously, as the sample sizes limited the ability of this study to rule out QoL improvements. Instead results indicate that larger samples are required to reliably detect QoL changes after surgery.

The Effect of Health Behaviours: Smoking Status and BMI

BMI did not influence the knee-related QoL changes after ACL repair surgery in these regression models. By contrast, by 2 years post-surgery, smoking status has a large influence on the effect of surgery on QoL improvement (Partial $\eta^2 = 0.27$). That is, QoL improvement two years post-surgery differs depending on smoking status.

Summary of Study 3

Overall, the analysis of knee-related QoL from pre- to post-operative time points showed significant increases in QoL scores. Nevertheless, the improvement of knee-related QoL could not be statistically attributed to surgery by the present models. These findings contrasted with general expectation in the literature that by improving joint stability, surgery would also improve knee-related QoL (Pedersen & Saltin, 2015). Regardless, there is evidence that surgery does not always result in improved QoL. For example, a study of 16,000 patients found that just less than half of patients (44%) did not report significant improvements in QoL post-ACL reconstruction (Kaarre et al., 2023). A systematic review also found that patients with chronic sciatica managed non-surgically had significantly greater improvements in QoL scores than those who underwent surgery (Filbay et al., 2014). Similarly, Kirkley and colleagues demonstrated that for knee osteoarthritis, arthroscopic surgery did not improve QoL scores beyond those achieved with interdisciplinary therapy (2008). Taken together, these findings and the literature appear to indicate that other moderating and confounding factors may be affecting knee-related QoL after surgery. Until these factors can be elucidated through future research, the risks and costs of surgery need to be weighed up against the possible gains on a case-by-case basis—and multidisciplinary treatments need to be considered as an alternative route to improving the QoL of patients.

One hypothesis for these null findings is that important confounding factors were not accounted for within these models—significantly limiting the ANCOVAs. Literature findings suggest that the presence of osteoarthritis, meniscal injuries, engagement in postoperative rehabilitation, or a lack of social support may be key factors in QoL post-operatively—all factors that could not be captured within this dataset (Filbay et al., 2014; Kaarre et al., 2023). There also may have been a sub-groups within this sample which confounded results. For example, patients who did not experience pain, but only sought surgery for increased joint stability; or patients who experienced a variety of chronic pain conditions that further lowered their knee-related QoL. There may have also been patients within this sample who managed their knee injuries well enough to not have a dramatic impact to their QoL despite the injury (e.g. using a brace, physiotherapy, or by altering their activities in such a way that allowed them to continue with values-led activities). These patients would not have reported low knee-related QoL before surgery or a dramatic improvement in QoL after surgery. Given this sample was a relatively young, active population, it is possible that they had high enough pre-morbid QoL scores that meaningful change due to surgery would have been difficult to detect. However, it is also of note that knee-related QoL might not have been a fine enough measure of change if these scenarios were at play within the data—meaning a change in knee-related QoL might not be the best indicator of meaningful change for this particular injury and population. Instead, a simple questionnaire asking how life has changed pre-injury to post-injury and pre-injury to post-surgery might have more effectively captured meaningful change for this population. Unfortunately, the data limited the ability to explore these potentially confounding scenarios within the sample. Future research would need to address if there are such variations/trends within the sample to adequately address these potential confounds.

The lack of statistically significant regression findings could also be due to several other factors. First, although it was the best measure available within this sample, there are several issues around the KOOS use to capture post-ACL surgery QoL. First, the KOOS QoL subscale is only made up of 4 questions that focus exclusively on knee-related QoL—limiting its ability to capture the multiple domains beyond knee-related physical health that QoL is comprised of. Systematic review results suggest that studies using KOOS-QoL scores (versus other measures of QoL) report lower QoL than population norms—although this assertion was based on only two studies included within the review (Filbay et al., 2014). Moreover, this same review demonstrated that ACL outcome studies that use the SF-36 (a more general measure of QoL) report similar or higher QoL scores than populations norms. This and other research suggests that QoL scores differ based on what QoL scale is used (Kvist & Pettersson, 2024). Taken together, this evidence may suggest that positive QoL results post-ACL surgery might be over-reported in the literature, depending on what measure of QoL has been used. Next, while a large change in knee-related QoL was seen from pre-operative to the 6 month time point, it may be that patients were still recovering functionality, but are not fully recovered, and therefore still rate their QoL with an optimistic lens of further gains in QoL. However, one to two years post-surgery, self-reported judgements of QoL in this active population may have been influenced by patient frustration with a lack of ability to return to pre-injury levels of activity. It may also be that although the effects of surgery may have passed by one to two years, new life events that impact QoL may have in fact occurred.

Interestingly, correlations between post-operative QoL scores at 6 months were shown to be highly correlated to QoL scores at two years—and post-operative QoL scores at one year were shown to be highly correlated to QoL two years post-surgery. Therefore QoL scores at 6 months could have been used as a proxy of QoL at 2 years post-surgery. That is, it seems that if a patient reports poor QoL at 6 months post-surgery, it is most likely they will report poor QoL at two years post-surgery as well—meaning there are likely factors beyond joint-stability getting in the way of improved knee-related QoL.

The relatively small sample sizes under-powered the analyses and impacted their ability to statistically detect significant change—despite potentially meaningful clinical change having occurred. Another approach would be to examine these findings using the minimal clinically important difference (MCID)—rather than statistical significance. The MCID is defined as the minimum threshold of improvement that patients perceive as significant (Guyatt et al., 1987). The MCID is used instead of statistical significance in evaluations of clinical interventions because it indicates whether the change in outcome score reflects a meaningful change to patients—rather than is a change that is unlikely to be due to chance. This is important because p values are sample size dependent—meaning large sample sizes can detect statistically significant changes that are clinically meaningless to patients. Moreover, clinical samples are often too small to achieve statistical significance—even if interventions generate clinically meaningful changes for patients.

The literature specifically evaluating ACL reconstruction outcomes using MCID remains limited—however, there is some indication that somewhere between a 10-point to 25.9-point change on the KOOS QoL subscale score indicates a MCID threshold for patients (Beletsky et al., 2021; Culvenor et al., 2020). For example, using a prospective cohort design, Beletsky and colleagues identified that a change in average score of 25.9 points (MCID) on the KOOS QoL subscale represented the threshold at which meaningful improvement was indicated by patients (2021). By contrast, using data from over 3,000 patients in the Swedish Knee Ligament Registry, Culvenor and colleagues demonstrated that one year post-ACL reconstruction, a 10-point improvement in the KOOS total score (which includes the QoL subscale), was associated with an additional 0.21 quality-adjusted life years (QALYs) accrued over the subsequent four years (2020)[1]. Taken together, these finding suggest that although larger improvements in knee-related QoL are necessary to be perceived as meaningful by patients, even smaller improvements have measurable implications on a large scale if economic measures of health are applied.

In the case of the present findings, if the more stringent MCID threshold of a 25.9 point improvement is applied to the post-ACL reconstruction KOOS QoL subscores, results indicate that by twelve months a clinically important change threshold had been met in knee-related QoL for patients when compared to pre-surgery (MCID mean difference= 31.96). There was also a clinically significant improvement in knee-related QoL for patients by two years as compared to pre-surgery (MICD mean difference= 33.88). Interestingly, despite a statistically significant correlation between post-operative QoL scores at 6 months and two years, MCID was not achieved six months post-operatively by this standard (change of only 19.65 points).

The caveat remains that while surgery may be contributing to the improvements in knee-related QoL (by improving joint stability), the present ANCOVA analyses does not indicate that these MCID thresholds have been met due to the surgery. Regardless, these findings underscore the growing recognition that meaningful improvements in QoL do not only depend on surgical interventions, but are more likely to be meaningfully impacted by holistic

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[1] QALYs is measure used in economic evaluations to indicate how many additional years of life lived in perfect health are likely to be added to an individual’s life based on an intervention.

rehabilitation approaches that address the broader biopsychosocial and economic factors that make up QoL.

Finally, findings around health behaviours were mixed in relation to the literature. BMI was not negatively associated with knee-related QoL as expected—but contrasted with the literature suggesting that higher BMI predicts poorer recovery, and therefore, reduced QoL (Takemasa et al., 2017). However, this may have been because the sample was predominantly young men with roughly average BMIs—who sustained an injury typically through intense athletic activity. It may have been there was little scope to explore a range of BMIs within this relatively small sample—and that a young, male, athletic sample should not be compared to research on QoL after surgery conducted on the average adult population. Moreover, smoking status did not impact 6 month and one-year outcomes, but at the two-year mark, smokers were shown to report poorer knee-related QoL when contrasted to non-smokers. While the literature indicates that smoking would be expected to negatively impact recovery from surgery at every timepoint, it may be these effects were not large enough to impact the knee-related QoL of this relatively young, athletic sample—or that the effect of smoking on knee-related QoL took time to manifest. It may also be that a differentiation should be made between cigarette smokers and those who vape—as the type of smoking behaviour may have had a further confounding effect. Regardless, the literature on the impacts of smoking typically indicate that smoking causes harm over the long term—which is in line with the findings of this study and the wider literature (Zah et al., 2019; Gaskin & Richard, 2012; Nijs & Lahousse, 2023).

Psychological and Emotional Burdens of Chronic Pain

Chronic pain has profound psychological and emotional costs for sufferers, fundamentally shaping their lives. Patients' accounts highlight the damage chronic pain does to emotional wellbeing, identity, and daily functioning (Driscoll et al., 2021; Hadi et al., 2019). These burdens span across QoL domains—eroding social relationships, impeding work and social roles, and undermining financial stability (Driscoll et al., 2021). Many individuals describe feelings of frustration, helplessness, and isolation as they struggle with pain that healthcare systems typically fail to adequately address (Driscoll et al., 2021). Chronic pain is also frequently accompanied by mental health problems, including depression and anxiety, which further exacerbate suffering and disability (Driscoll et al., 2021). The International Association for the Study of Pain defines pain as an "unpleasant sensory and emotional experience," underscoring that psychological processes are inseparable from the experience of pain (2011). Thus, beyond physical symptoms, chronic pain's toll includes psychological burdens that can undermine individuals' sense of self and meaning in life (Driscoll et al., 2021). These insights have prompted a shift away from reductionist biomedical understandings of pain toward more nuanced psychosocial perspectives (Sunde et al., 2024).

Psychological Theory and Clinical Models Applied to Chronic Pain: CBT, ACT, Pain Catastrophizing, and Biopsychosocial Models

Several psychological theories offer a conceptual grounding for understanding how cognitive, emotional, and social processes interact with the physical experience of chronic pain. The biopsychosocial model provides an overarching framework, proposing that biological mechanisms, psychological processes, and sociocultural factors all shape pain and disability (Engel, 1977). Building on this foundation, cognitive theories have been particularly influential. The fear-avoidance model proposes that negative interpretations of pain (e.g., interpreting pain as dangerous) generates pain-related fear, which in turn leads to avoidance of activity, physical deconditioning, and worsening pain (Vlaeyen & Linton, 2012). A central mechanism within this cycle is pain catastrophising—a cognitive pattern characterised by magnification of pain signals, rumination, and feelings of helplessness (Turner et al., 2002). Catastrophising reliably predicts short-term increases in pain and long-term disability trajectories, and can amplify pain through attentional and emotional pathways (Turner et al., 2002). Together, the biopsychosocial model and these cognitive-behavioural theories highlight why chronic pain so deeply affects emotional functioning and quality of life, and why psychological treatments that address thought/emotion/behaviour patterns are central to effective pain management.

Psychological Interventions and Integrated Pain Management

A wide range of psychological interventions have demonstrated efficacy in mitigating the impacts of chronic pain. CBT is one common approach, targeting catastrophic thinking, fear-driven avoidance, and maladaptive behavioural patterns, to improve functioning (Sunde et al., 2024). Evidence from interdisciplinary CBT-based pain management programmes indicates small-to-medium improvements in pain and physical functioning and large improvements in psychological well-being (Smith & Doe, 2016). In contrast to CBT, ACT focuses less on symptom reduction/cognitive restructuring, and more on developing psychological flexibility—helping patients to accept the difficult internal experiences associated with pain, while pursuing valued activities despite its presence (McCracken & Vowles, 2014). ACT has a strong evidence base, with meta-analyses showing reductions in distress and disability across multiple chronic pain conditions (Feliu-Soler et al., 2018; Veehof et al., 2016). Both CBT and ACT are endorsed by the National Institute for Health and Care Excellence as first-line psychological therapies for chronic primary pain (NICE, 2021). These interventions achieve their greatest impact when delivered within interdisciplinary rehabilitation models, such as those implemented at the Bath Centre for Pain Services and INPUT. These national specialist rehabilitation programmes integrate physiotherapy, occupational therapy, medical review, and group psychological therapy (ACT-based), aiming to rebuild functioning across physical, emotional, and social domains. Interdisciplinary rehabilitation programmes consistently demonstrate substantial functional and psychological improvement in chronic pain populations-- supporting the conclusion that chronic pain must be addressed through holistic, biopsychosocial interventions (Smith & Doe, 2016).

Limitations

This dissertation had several methodological and conceptual limitations. The most prominent of these relates to the use of secondary data. While this enabled access to large-scale and routine clinical outcomes datasets, it simultaneously limited research questions and analyses to the available variables. For example, one variable critical to understanding QoL in chronic pain populations—social support—was not possible to include in Study 2. The HSE 2017 variable "SocialP," which assessed pain-related interference with social and leisure activities, was only administered to participants with chronic pain. Consequently, it was not possible to compare this social functioning between chronic pain and non-pain groups, despite its significant impact on QoL. Moreover, it is important to note that ACL reconstruction surgery is primarily used to improve joint stability rather than chronic pain. It was not possible to ascertain from the dataset which patients has developed chronic pain within this sample, so it may have been that chronic pain was not a primary complaint within this sample. Moreover, additional information which may have been useful about Study 3's sample population was also not available—for example, information on other knee injuries and their potential impact on recovery (e.g. collateral ligament injury, meniscal injury, chondral injury). Regardless, the study gives us an indication of the relationship of one type of surgical interventions to QoL outcomes—and highlights the need for further research exploring interventions that specifically target chronic pain.

Further design and data constraints shaped the interpretation of results. For example, Study 2 employed a cross-sectional design as the HSE dataset only administered the chronic pain impact questionnaires in a single year (2017). Consequently, individual trajectories in these variables could not be examined, and the chronic pain sample could not be compared to the non-clinical sample longitudinally. More broadly, cross-sectional data does not allow for inferences about the temporal order of changes, change processes over time (e.g. the effects of aging), or causation to be made. Study 3, although longitudinal in nature, was underpowered because of its small sample size, further constraining the ability to detect subtle within-person effects. Together, these factors limited the models' capacity to describe the complex nature of QoL outcomes in these populations over time.

Attrition further exacerbated these issues in Study 3, as sample data at each follow-up point was diminished—successively weakening the ANCOVAs ability to detect significant change. Notably, Study 2 included substantial missing data for the variable of household income. This may reflect cultural taboos as participants from lower socioeconomic backgrounds may be less inclined to disclose financial information due to stigma. As a result, the dataset may underrepresent those experiencing the most acute financial hardship—as well as mask the impact of higher incomes on QoL. Finally, although the EQ5D and EQ5D-VAS overall QoL scores would have been preferable to the KOOS knee-specific measure of QoL in Study 3 (as they are broader measures of QoL), these were ultimately excluded due to insufficient follow-up data ($n < 30$).

Beyond missing values, the nature of the available data also posed challenges. For example, household-level income was used as a proxy for individual financial stability, but this may obscure important confounds. For example, income alone may not reflect financial insecurity, as factors such as debt, obligations, or behavioural factors (e.g. gambling) are not accounted for. The real-world applicability of dated fixed income thresholds as an indicator of QoL is also highly limited (e.g. Kahneman & Deaton's $75,000 benchmark)—as these thresholds were calculated without including the high-earners, do not reflect net salaries and geographical disparities in costs of living, and are significantly out-dated. Additionally, the use of a single-item prompt to capture psychological state by HSE dataset in Study 2 (instead assessing both anxiety/depression in one prompt), meant the data lacked the granularity required to differentiate between affective states and severity levels, thereby limiting the ability to draw any condition-specific conclusions.

Finally, this research relied predominantly on objective indicators—such as income, employment, and mobility—to operationalise QoL. While these indicators offer practical value for policy and service planning, they do not capture the subjective dimensions of wellbeing. The inclusion of a global self-rated life satisfaction measure was intended to address this gap; however, the richness of subjective experience, including personal values, expectations, and emotional states, remained unexplored. As Campbell and colleagues (1976) noted, full understanding QoL requires direct engagement with how individuals feel about the conditions of their lives—requiring a mixed methods approach to have been taken.

Practice Implications

The findings of this project underscore the need to intervene across QoL domains to effectively manage the costs of chronic pain. After overall QoL, mental health (i.e. depression) was the second most cited cost of chronic pain. Therefore, there is a key role for clinical psychology in advocating and designing interdisciplinary rehabilitation services that address not only physical rehabilitation but also the psychological—as well as the economic and social—costs of chronic pain. For instance, this study highlighted how educational attainment significantly alter the capacity of an individual with chronic pain to remain in work—and the dearth of research examining the impact of income on QoL. Although these factors both require further research, the availability of flexible working options for those with greater levels of education is one likely explanation that would be relatively simple to implement—particularly since the Covid-19 pandemic. Given the sheer scale of productivity losses due to chronic pain, advocating for relatively simple employment policy changes that allow patients flexible working could mitigate the millions of pounds of losses linked to chronic pain—improving QoL for patients while also increasing economic output on a national and global level.

The lack of significant findings in Study 3 QoL further reinforces the need for NHS interventions to focus on more than just surgical approaches to manage chronic pain. Study 2 findings on the multidimensional QoL costs of chronic pain emphasises the importance of interdisciplinary interventions for chronic pain. Taken together, results indicate that good practice should involve interdisciplinary interventions including: physiotherapy, occupational therapy, career/financial counselling, health behaviour interventions (e.g. smoking cessation), and psychology. Findings therefore lend support to the national specialist model of chronic pain rehabilitation which utilises interdisciplinary, Acceptance and Commitment Therapy groups to support chronic pain sufferers across full spectrum of QoL costs. Finally, the correlation between six month and two-year postoperative knee-related QoL scores in Study 3 suggests that perhaps early post-surgical assessments could be used to identify patients at risk for persistently poor QoL— and potentially offering insight into a critical intervention window.

Conclusions

Overall, these three studies have resulted in an understanding of the cost of chronic pain as a cost across all domains of QoL. The scoping review demonstrated agreement between the factors that academia and patients stated were the costs of chronic pain—highlighting that the cost of chronic pain spans across all traditional subdomains of QoL with the addition of financial security. While the costs of chronic pain to healthcare systems and national economies have been extensively studied, the QoL cost of income to those with chronic pain remains unexamined. Moreover, the importance of educational attainment on the working status of those with chronic pain also highlights the systemic changes that likely will be required to ensure the costs of chronic pain are ameliorated at the individual and national level.

Study 3 revealed the limited power of surgical intervention alone in improving QoL outcomes. These findings suggest that interventions must address broader biopsychosocial and economic determinants to achieve meaningful QoL change for chronic pain patients. Together, the three studies comprising this thesis highlight the inadequacy of narrowly defined clinical or economic metrics in capturing the costs of chronic pain. Despite current trend of UK healthcare commissioning to focus on medical interventions or pharmacology, the true cost of chronic pain—quality of life—cannot be addressed using a traditional medical, i.e. curative, approach. Instead, findings suggest that interventions must reflect the multimodality of QoL through interdisciplinary, holistic rehabilitation approaches.

Future Research Directions

The limitations identified in this dissertation particularly highlight several specific areas that warrant further investigation. For example, the heterogeneity in QoL measurement found in Study 1 highlights the need for future research in standardising QoL instruments to enable valid cross-study interpretation. Income, educational attainment, and social functioning and their relationship to QoL in chronic pain need to be further explored. Despite participants naming financial security as a cost, this remains excluded from most research on chronic pain. Future research should move beyond using national income averages and instead assess net income in relation to local cost-of-living indices, as national figures obscure substantial geographic disparities and net values. Moreover, given the limitations of using household income, future studies should examine both individual-level and household income levels—as well as consider spending patterns which have been found to have a stronger association with life satisfaction (Office for National Statistics, 2019). The relationship between chronic pain and employment also requires further exploration—particularly regarding the role of educational attainment on the ability to remain in work despite pain and the factors underlying this. Future research should include children and young people in any evaluation of the costs of chronic pain as educational attainment is likely to have been affected for those who developed chronic pain during childhood—and which is in turn being reflected in lifelong working capacity. Future research should also incorporate both objective indicators (e.g. number and types of social relationships) and subjective evaluations (e.g. perceived social support and connectedness) of social functioning and its impact on QoL in chronic pain. Moreover, future studies must address the issue of high rates of missing data in key variables such as income. Establishing robust data collection protocols and transparent handling of missing cases will enhance the validity and generalisability of future findings. Future research should also prioritise longitudinal, mixed-methods studies that integrate subjective and objective data to offer a richer understanding of how QoL is impacted over time in individuals with chronic pain. Combining patient-reported outcomes with socioeconomic indicators and qualitative data can better capture the multidimensional nature of the cost of chronic pain.

Study 3 highlighted complexities in post-operative QoL outcomes that also warrant further exploration. First, samples sizes of future studies needs to be large enough to adequately power the findings. Next, the role of gender needs to be explored for its impact on surgical outcomes—despite the lack of evidence base at present. Future research on ACL reconstruction should explore alternative covariates that are more closely aligned with the determinants of QoL in chronic pain populations (e.g. physical rehabilitation, psychosocial support, employment and financial support). Moreover, future studies should explore health behaviours—such as smoking and engagement in physiotherapy—as potentially moderating variables in QoL trajectories. The use of broader QoL instruments, such as the EQ5D, may offer more robust assessments of QoL than condition-specific tools like the KOOS, and follow-up assessments at alternative time points (e.g., 9, 11, or 13 months) may be better suited to capture post-recovery QoL and unpick the potentially confounding influence of other life events. Future research should also employ ANCOVA or similar methods to control for baseline QoL scores, which can be highly correlated with post-operative outcomes.

Finally, future research should evaluate different interdisciplinary rehabilitation interventions that combine medical and physical interventions with psychological, financial, occupational, and social components—such as pain management programmes. Curiously, the current evidence base for interdisciplinary pain management programmes remains mixed—despite these programmes holistically targeting patient's QoL across subdomains—and despite patient's consistent qualitative feedback that such programmes are life-changing. The widening gap between the practice-based evidence observed by chronic pain clinicians and the evidence base reported for these programmes warrants significant in-depth research before they are eliminated from NHS services.

Dissemination Plans

Dissemination thus far has included conference and feedback presentations—including presentations of findings at the School of Health and Social Care conferences at the

University of Essex and a presentation at the European School of Pain at the University of Sienna in June 2025(Appendix N). Results were also presented to the clinical team providing the data for Study 3 in July 2025 (Appendix O). The clinical team indicted that null results were not unexpected as ACL surgery typically only improves joint stability. The clinical team also shared that QoL management of ACL deficient knees was sometimes conducted through non-surgical interventions; and that there remains a substantial dearth of NHS post-operative care (e.g. physiotherapy)—further leading to future research directions. The clinical team has requested a slide deck for their use and has suggested the researcher presents results at the ESSKA conference next year. The findings of this project will hopefully also be prepared as up to three manuscripts for publication in relevant peer-reviewed journals, such as *BMJ Open*, *Knee Surgery, Sports Traumatology,* Arthroscopy *(KSSTA),* or *PAIN.*

Reflexivity and Reflective Account

Despite my use of quantitative methodologies, this project remained rooted in a critical realist stance—requiring me to reflect on myself and my position throughout the research process. My professional background in clinical psychology and direct experience working with patients suffering from chronic pain influenced the selection of my research questions and interpretation of results. It would have been impossible to assert that I held a detached, unbiased stance towards my research or the topic. My interest in chronic pain as a clinician, researcher, and human being, stems from my own lived experience—and the years I have spent working alongside hundreds of sufferers through intense interdisciplinary rehabilitation. Finding ways to improve the QoL for those living with chronic pain will likely be my life's work—so I cannot be counted as an objective, unaffected observer by any stretch of the imagination. My own lenses shaped the research questions and methodologies I applied—and shapes how I will use this knowledge in my future clinical and professional practice.

My interest in conducting this project was to identify the costs commissioners need to be aware of in order to accurately fund services that improve the QoL of those with this condition. I chose quantitative methodologies in large part because I wanted to learn methods, generate results, and use language that the Integrated Care Boards would value. I titled my thesis the "cost" of chronic pain in order to begin to challenge the narrative around what is considered worth investing in by the ICBs—and to begin to evidence that the poor QoL of those suffering with chronic pain is a "cost" too high to ignore in service contracting conversations. I hope through this research I have demonstrated that there is more to the cost of a chronic pain than can be captured by healthcare utilisation values.

As is bound to happen over the course of doctoral research, this dissertation involved falling down several rabbit holes and multiple iterations of the analyses. I had a brief foray into structural equation modelling and R, considered the use of an additional special license access dataset from the UK Data Service, and even ran non-parametric testing on another research question around the impact of different interventions using the HSE 2017 dataset. Unfortunately, none of these were particularly fruitful paths, and were therefore abandoned. The running of the HSE 2017 data using chi-squared tests was a particularly painful lesson at the time. I had hoped to examine if there was a difference in the QoL outcomes of patients who had attended a pain management programme (PMP), a cognitive behavioural group, or a support group. As a keen advocate of interdisciplinary PMPs, it was the question I was most excited about answering. After all results had been interpreted and written up, I realised the independence of the outcome variables could not be established. Essentially, the means by which the data had been coded meant there was potential overlap in the intervention groups, and therefore, the groups may not be independent. Those who had attended a pain management group could have also attended a CBT group, and a support group as well (i.e. Prompt: Have you attended a pain management group? Anything else, e.g. a CBT group?

Anything else, i.e. a psychoeducation group?). The data was coded in such a way that there was no way to isolate if a person had had one, or all three, of the interventions—and there was potentially an additive effect between treatments which would have confounded the results. The mistake brought home the importance of checking all statistical assumptions before attempting to run any analysis—particularly when using secondary data. It also cemented the understanding that routine clinical data must be collected and coded in a way that allows for the independent evaluation of its efficacy if it is to be used to evidence treatment impact.

I began this doctoral journey having forgotten the basics of statistical testing and SPSS. Over the course of the last two years, the steadfast teaching and guidance of my supervisors has meant I have been able to successfully apply methodologies I initially found very intimidating to my research questions—and even generate useful findings. I therefore have my supervisors to thank for not only helping to shape this project, but also imbuing in me the confidence to approach research and statistics again. Being their supervisee meant I learned what a lasting, positive impact a mentor can have, and what it looks like to be a good guide to the next generations of scientist-practitioners. Moreover, these painful cul-de-sacs of work have amounted to learning how to manage large datasets, choose and apply statistical techniques appropriate to my research questions, and interpret the results of routine outcome data—all learning that I will take forward into my next roles.

The next steps of my journey will include working as a clinical psychologist in an interdisciplinary chronic pain team—delivering pain management programmes and designing and maintaining the service's routine clinical outcomes data systems. Learning how to bring research funding into these clinical settings to allow for ongoing dissemination and research will be the next challenges (e.g. exploring NIHR funding applications). Which forms of interdisciplinary interventions best support the overall QoL of those with chronic pain remains an outstanding question from this work that I wish to address urgently. I therefore hope this work will serve a as platform for my ongoing research.

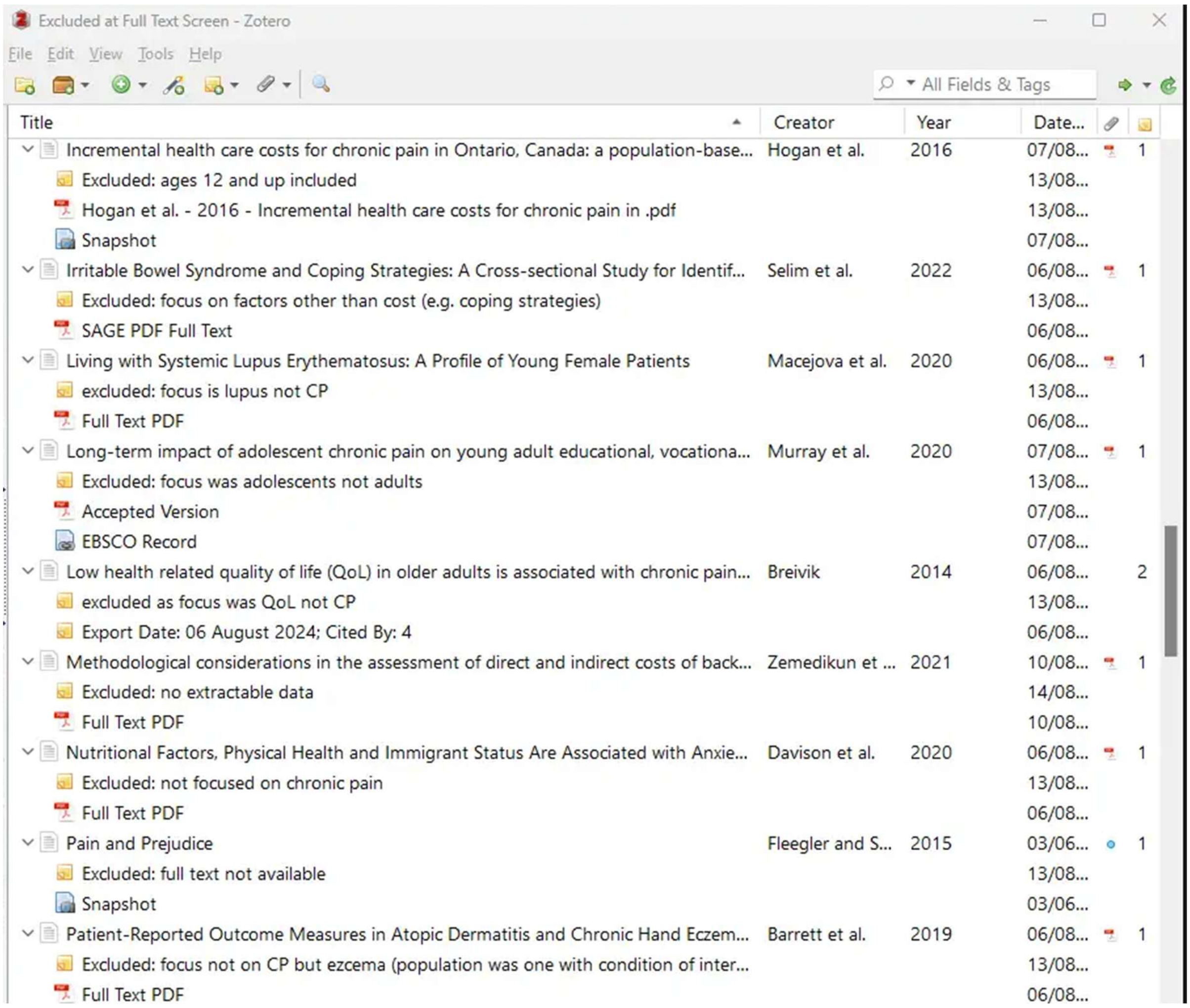
Appendices

Appendix A. Study 1 Scoping Review Search Strategy

Database	Exact Search Terms	Limiters Applied	Results Returned
Scopus	TI costs OR cost OR expense OR price OR "disability adjusted life year" OR "quality of life" OR burden OR impact OR toll OR expenditure OR fee OR fees OR utilisation OR utilization OR charge OR outlay OR payment AND “chronic pain” or “long term pain” AND adults or adult or elderly or senior or “middle age” or older	Document type limited to: Article, Review, Letter, Note, Editorial Keywords limited to: Chronic Pain Excluded: Adolescent, Child Source type: journal English Language 2014-present	44
CINAHL Ultimate (searches within APA PsychINFO, APA PsychArticles, Business Source Ultimate, and MEDLINE Ultimate)	TI (costs or cost or expense or price or "quality of life" or burden or impact or “disability adjusted life year” or toll or expenditure or fee or fees or utilisation or utilization or charge or charges or outlay or payment or payments)	Publication Date: 20140101-20241231; Peer Reviewed; English Language; Age Related: All Adult: 19+ years; Language: English; Publication Year: 2014-2024; Publication Status: Fully Published; Exclude Book Reviews; Exclude Non-Article Content; Age Groups: Young Adulthood (18-29	41

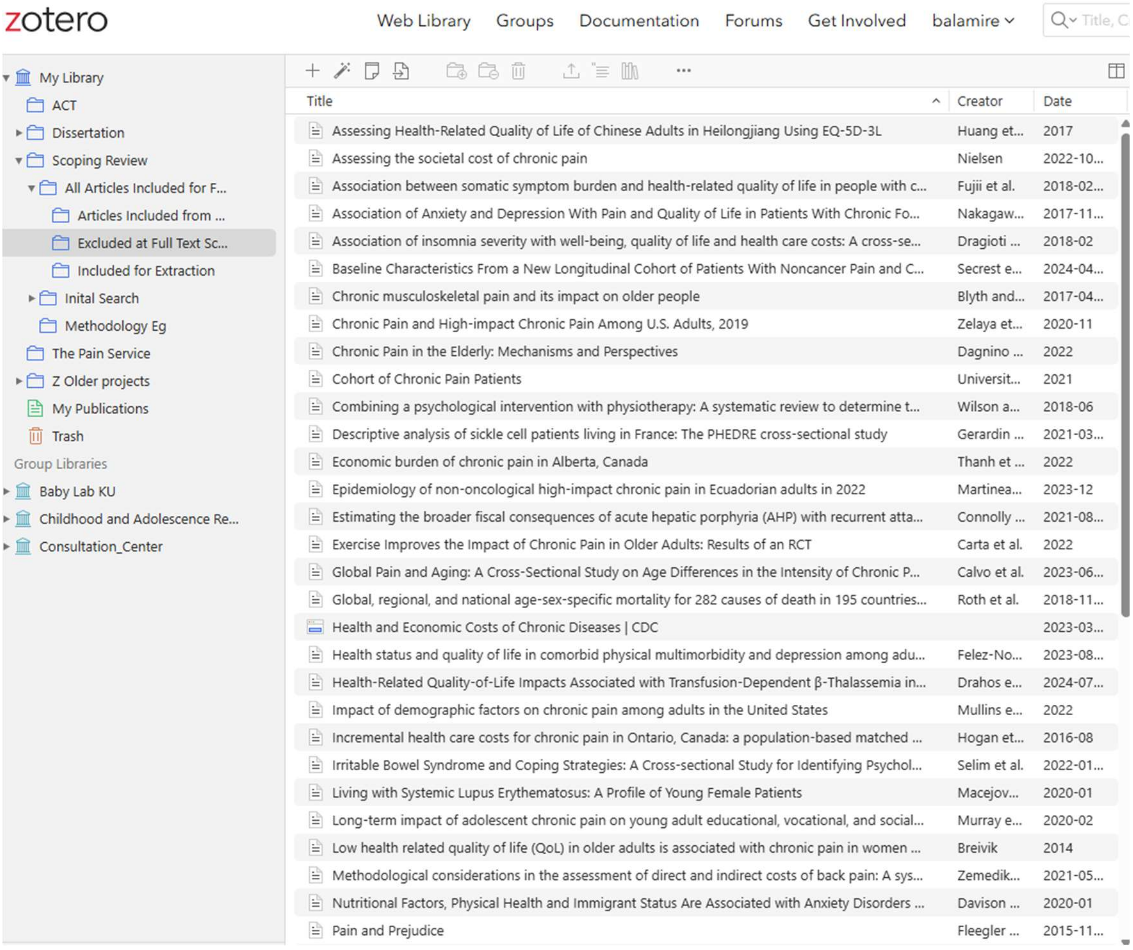
	AND ("chronic pain" or "long term pain") AND (adults or adult or elderly or senior or "middle age" or older)	yrs), Thirties (30-39 yrs), Middle Age (40-64 yrs), Aged (65 yrs & older), Very Old (85 yrs & older); Population Group: Human; Publication Year: 2014-2024; Publication Status: fully published; Publication Type: Peer Reviewed Journal; English language; Language: English; Age Groups: Adulthood (18 yrs & older), Young Adulthood (18-29 yrs), Thirties (30-39 yrs), Middle Age (40-64 yrs), Aged (65 yrs & older), Very Old (85 yrs & older); Population Group: Human; Exclude Dissertations; Publication Type: Academic Journal; Document Type: Article, Editorial, Letter; Language: English; English Language; Language: English; Publication Type: Academic Journal; Age Groups: All Adult Expanders - Apply equivalent subjects Search modes - Proximity	
IDEAS (searches within RePec Econ Database)	cost | quality of life + chronic pain + adult	Year of Publication 2014-2024	52

Appendix B. Scoping Review Sources Excluded Following Full-Text Review

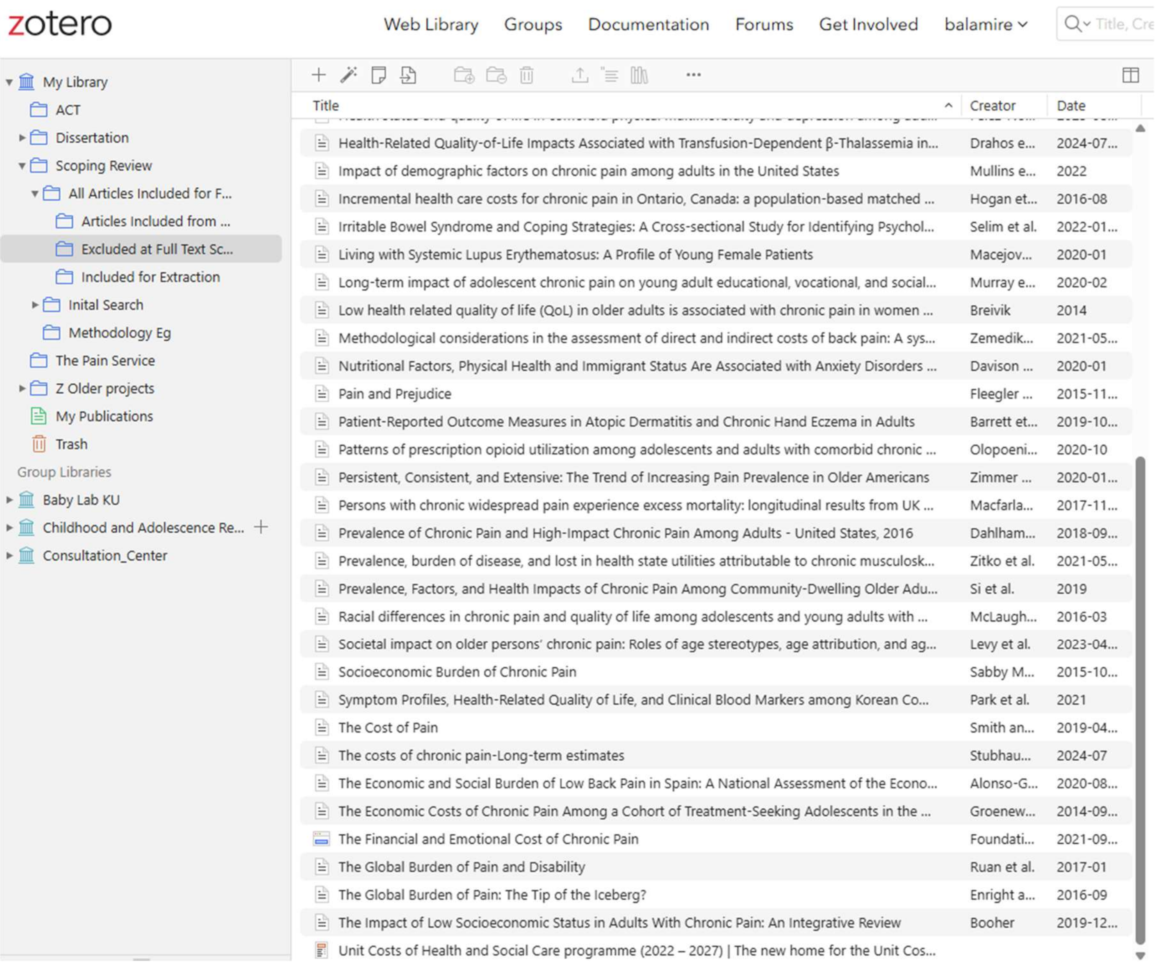


Title	Creator	Year	Date...		
Incremental health care costs for chronic pain in Ontario, Canada: a population-base...	Hogan et al.	2016	07/08...		1
Excluded: ages 12 and up included			13/08...		
Hogan et al. - 2016 - Incremental health care costs for chronic pain in .pdf			13/08...		
Snapshot			07/08...		
Irritable Bowel Syndrome and Coping Strategies: A Cross-sectional Study for Identif...	Selim et al.	2022	06/08...		1
Excluded: focus on factors other than cost (e.g. coping strategies)			13/08...		
SAGE PDF Full Text			06/08...		
Living with Systemic Lupus Erythematosus: A Profile of Young Female Patients	Macejova et al.	2020	06/08...		1
excluded: focus is lupus not CP			13/08...		
Full Text PDF			06/08...		
Long-term impact of adolescent chronic pain on young adult educational, vocationa...	Murray et al.	2020	07/08...		1
Excluded: focus was adolescents not adults			13/08...		
Accepted Version			07/08...		
EBSCO Record			07/08...		
Low health related quality of life (QoL) in older adults is associated with chronic pain...	Breivik	2014	06/08...		2
excluded as focus was QoL not CP			13/08...		
Export Date: 06 August 2024; Cited By: 4			06/08...		
Methodological considerations in the assessment of direct and indirect costs of back...	Zemedikun et ...	2021	10/08...		1
Excluded: no extractable data			14/08...		
Full Text PDF			10/08...		
Nutritional Factors, Physical Health and Immigrant Status Are Associated with Anxie...	Davison et al.	2020	06/08...		1
Excluded: not focused on chronic pain			13/08...		
Full Text PDF			06/08...		
Pain and Prejudice	Fleegler and S...	2015	03/06...		1
Excluded: full text not available			13/08...		
Snapshot			03/06...		
Patient-Reported Outcome Measures in Atopic Dermatitis and Chronic Hand Eczem...	Barrett et al.	2019	06/08...		1
Excluded: focus not on CP but ezcema (population was one with condition of inter...			13/08...		
Full Text PDF			06/08...		

NB. Exclusion reasons were noted for each article in an attached note in Zotero.

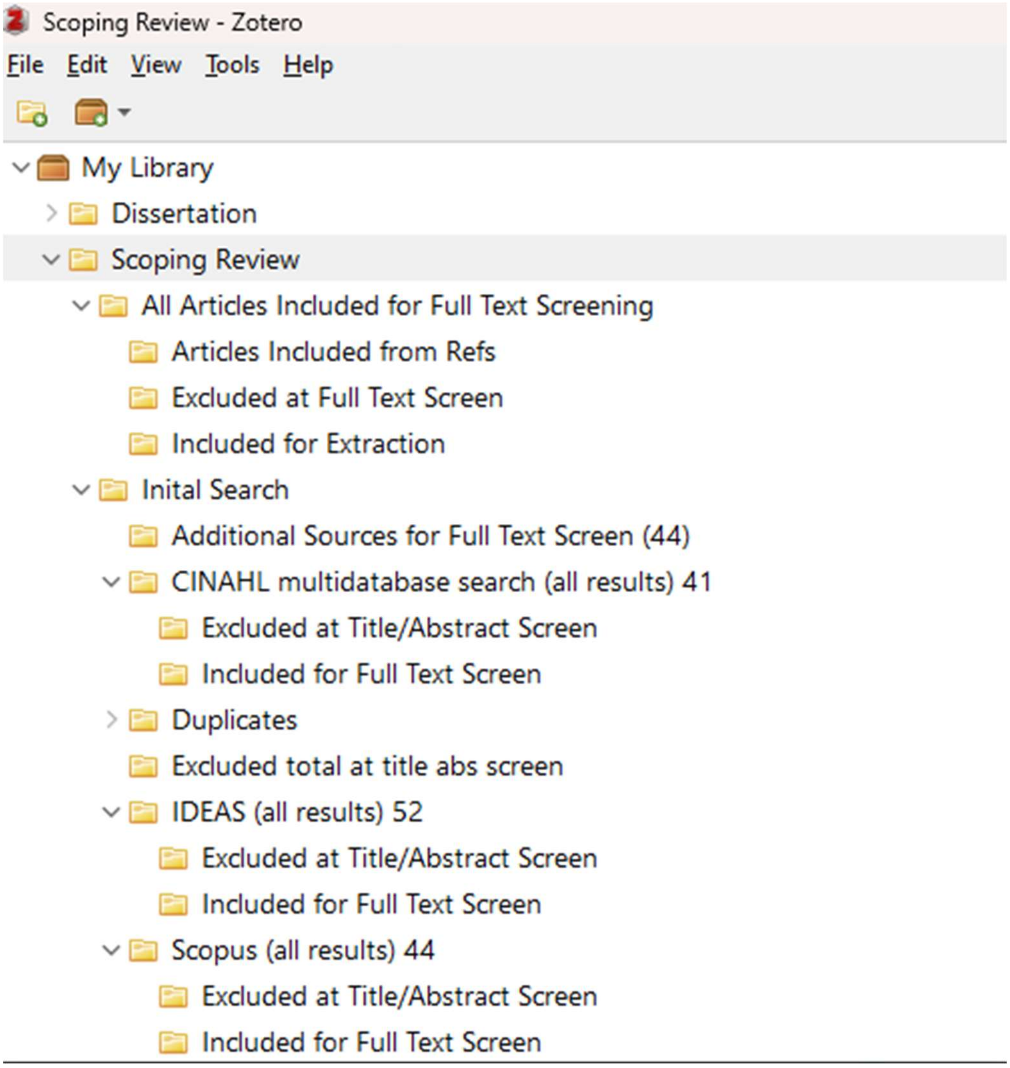


Title	Creator	Date
Assessing Health-Related Quality of Life of Chinese Adults in Heilongjiang Using EQ-5D-3L	Huang et...	2017
Assessing the societal cost of chronic pain	Nielsen	2022-10...
Association between somatic symptom burden and health-related quality of life in people with c...	Fujii et al.	2018-02...
Association of Anxiety and Depression With Pain and Quality of Life in Patients With Chronic Fo...	Nakagaw...	2017-11...
Association of insomnia severity with well-being, quality of life and health care costs: A cross-se...	Dragioti ...	2018-02
Baseline Characteristics From a New Longitudinal Cohort of Patients With Noncancer Pain and C...	Secrest e...	2024-04...
Chronic musculoskeletal pain and its impact on older people	Blyth and...	2017-04...
Chronic Pain and High-impact Chronic Pain Among U.S. Adults, 2019	Zelaya et...	2020-11
Chronic Pain in the Elderly: Mechanisms and Perspectives	Dagnino ...	2022
Cohort of Chronic Pain Patients	Universit...	2021
Combining a psychological intervention with physiotherapy: A systematic review to determine t...	Wilson a...	2018-06
Descriptive analysis of sickle cell patients living in France: The PHEDRE cross-sectional study	Gerardin ...	2021-03...
Economic burden of chronic pain in Alberta, Canada	Thanh et ...	2022
Epidemiology of non-oncological high-impact chronic pain in Ecuadorian adults in 2022	Martinea...	2023-12
Estimating the broader fiscal consequences of acute hepatic porphyria (AHP) with recurrent atta...	Connolly ...	2021-08...
Exercise Improves the Impact of Chronic Pain in Older Adults: Results of an RCT	Carta et al.	2022
Global Pain and Aging: A Cross-Sectional Study on Age Differences in the Intensity of Chronic P...	Calvo et al.	2023-06...
Global, regional, and national age-sex-specific mortality for 282 causes of death in 195 countries...	Roth et al.	2018-11...
Health and Economic Costs of Chronic Diseases | CDC		2023-03...
Health status and quality of life in comorbid physical multimorbidity and depression among adu...	Felez-No...	2023-08...
Health-Related Quality-of-Life Impacts Associated with Transfusion-Dependent β-Thalassemia in...	Drahos e...	2024-07...
Impact of demographic factors on chronic pain among adults in the United States	Mullins e...	2022
Incremental health care costs for chronic pain in Ontario, Canada: a population-based matched ...	Hogan et...	2016-08
Irritable Bowel Syndrome and Coping Strategies: A Cross-sectional Study for Identifying Psychol...	Selim et al.	2022-01...
Living with Systemic Lupus Erythematosus: A Profile of Young Female Patients	Macejov...	2020-01
Long-term impact of adolescent chronic pain on young adult educational, vocational, and social...	Murray e...	2020-02
Low health related quality of life (QoL) in older adults is associated with chronic pain in women ...	Breivik	2014
Methodological considerations in the assessment of direct and indirect costs of back pain: A sys...	Zemedik...	2021-05...
Nutritional Factors, Physical Health and Immigrant Status Are Associated with Anxiety Disorders ...	Davison ...	2020-01
Pain and Prejudice	Fleegler ...	2015-11...



Title	Creator	Date
Health-Related Quality-of-Life Impacts Associated with Transfusion-Dependent β-Thalassemia in...	Drahos e...	2024-07...
Impact of demographic factors on chronic pain among adults in the United States	Mullins e...	2022
Incremental health care costs for chronic pain in Ontario, Canada: a population-based matched ...	Hogan et...	2016-08
Irritable Bowel Syndrome and Coping Strategies: A Cross-sectional Study for Identifying Psychol...	Selim et al.	2022-01...
Living with Systemic Lupus Erythematosus: A Profile of Young Female Patients	Macejov...	2020-01
Long-term impact of adolescent chronic pain on young adult educational, vocational, and social...	Murray e...	2020-02
Low health related quality of life (QoL) in older adults is associated with chronic pain in women ...	Breivik	2014
Methodological considerations in the assessment of direct and indirect costs of back pain: A sys...	Zemedik...	2021-05...
Nutritional Factors, Physical Health and Immigrant Status Are Associated with Anxiety Disorders ...	Davison ...	2020-01
Pain and Prejudice	Fleegler ...	2015-11...
Patient-Reported Outcome Measures in Atopic Dermatitis and Chronic Hand Eczema in Adults	Barrett et...	2019-10...
Patterns of prescription opioid utilization among adolescents and adults with comorbid chronic ...	Olopoeni...	2020-10
Persistent, Consistent, and Extensive: The Trend of Increasing Pain Prevalence in Older Americans	Zimmer ...	2020-01...
Persons with chronic widespread pain experience excess mortality: longitudinal results from UK ...	Macfarla...	2017-11...
Prevalence of Chronic Pain and High-Impact Chronic Pain Among Adults - United States, 2016	Dahlham...	2018-09...
Prevalence, burden of disease, and lost in health state utilities attributable to chronic musculosk...	Zitko et al.	2021-05...
Prevalence, Factors, and Health Impacts of Chronic Pain Among Community-Dwelling Older Adu...	Si et al.	2019
Racial differences in chronic pain and quality of life among adolescents and young adults with ...	McLaugh...	2016-03
Societal impact on older persons' chronic pain: Roles of age stereotypes, age attribution, and ag...	Levy et al.	2023-04...
Socioeconomic Burden of Chronic Pain	Sabby M...	2015-10...
Symptom Profiles, Health-Related Quality of Life, and Clinical Blood Markers among Korean Co...	Park et al.	2021
The Cost of Pain	Smith an...	2019-04...
The costs of chronic pain-Long-term estimates	Stubhau...	2024-07
The Economic and Social Burden of Low Back Pain in Spain: A National Assessment of the Econo...	Alonso-G...	2020-08...
The Economic Costs of Chronic Pain Among a Cohort of Treatment-Seeking Adolescents in the ...	Groenew...	2014-09...
The Financial and Emotional Cost of Chronic Pain	Foundati...	2021-09...
The Global Burden of Pain and Disability	Ruan et al.	2017-01
The Global Burden of Pain: The Tip of the Iceberg?	Enright a...	2016-09
The Impact of Low Socioeconomic Status in Adults With Chronic Pain: An Integrative Review	Booher	2019-12...
Unit Costs of Health and Social Care programme (2022 – 2027) | The new home for the Unit Cos...		

Appendix C. Zotero Organisational System Used for Scoping Review



- My Library
  - Dissertation
  - Scoping Review
    - All Articles Included for Full Text Screening
      - Articles Included from Refs
      - Excluded at Full Text Screen
      - Included for Extraction
    - Inital Search
      - Additional Sources for Full Text Screen (44)
      - CINAHL multidatabase search (all results) 41
        - Excluded at Title/Abstract Screen
        - Included for Full Text Screen
      - Duplicates
      - Excluded total at title abs screen
      - IDEAS (all results) 52
        - Excluded at Title/Abstract Screen
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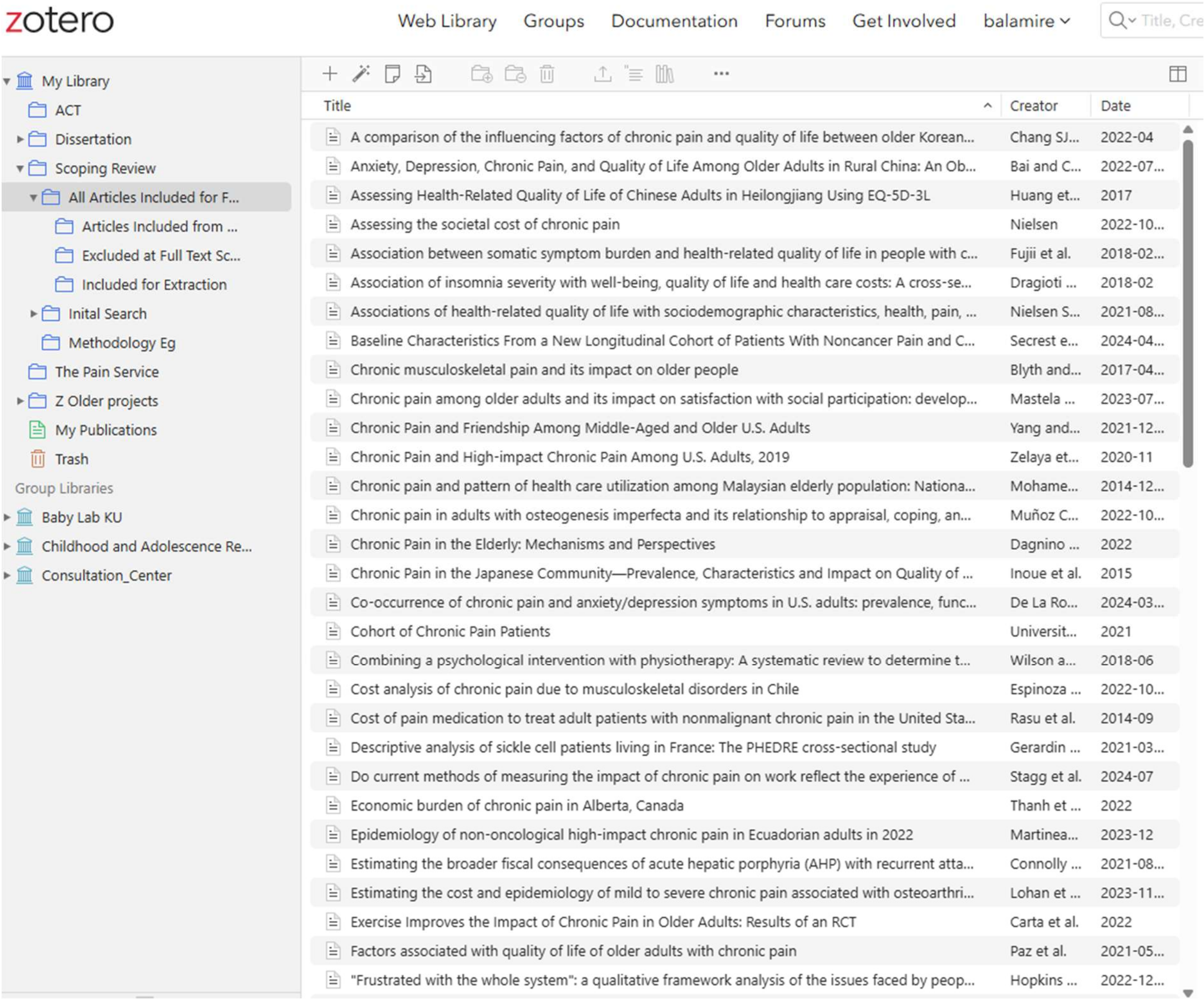
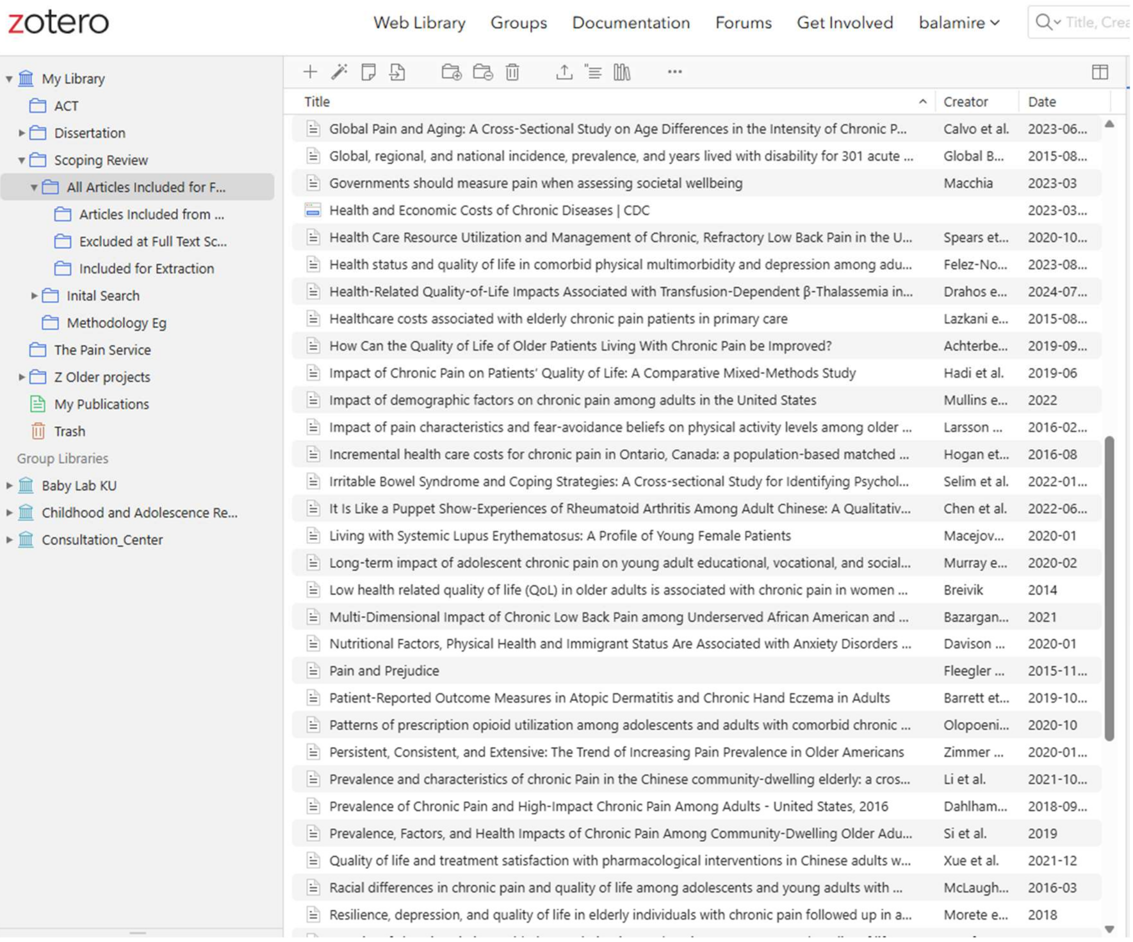
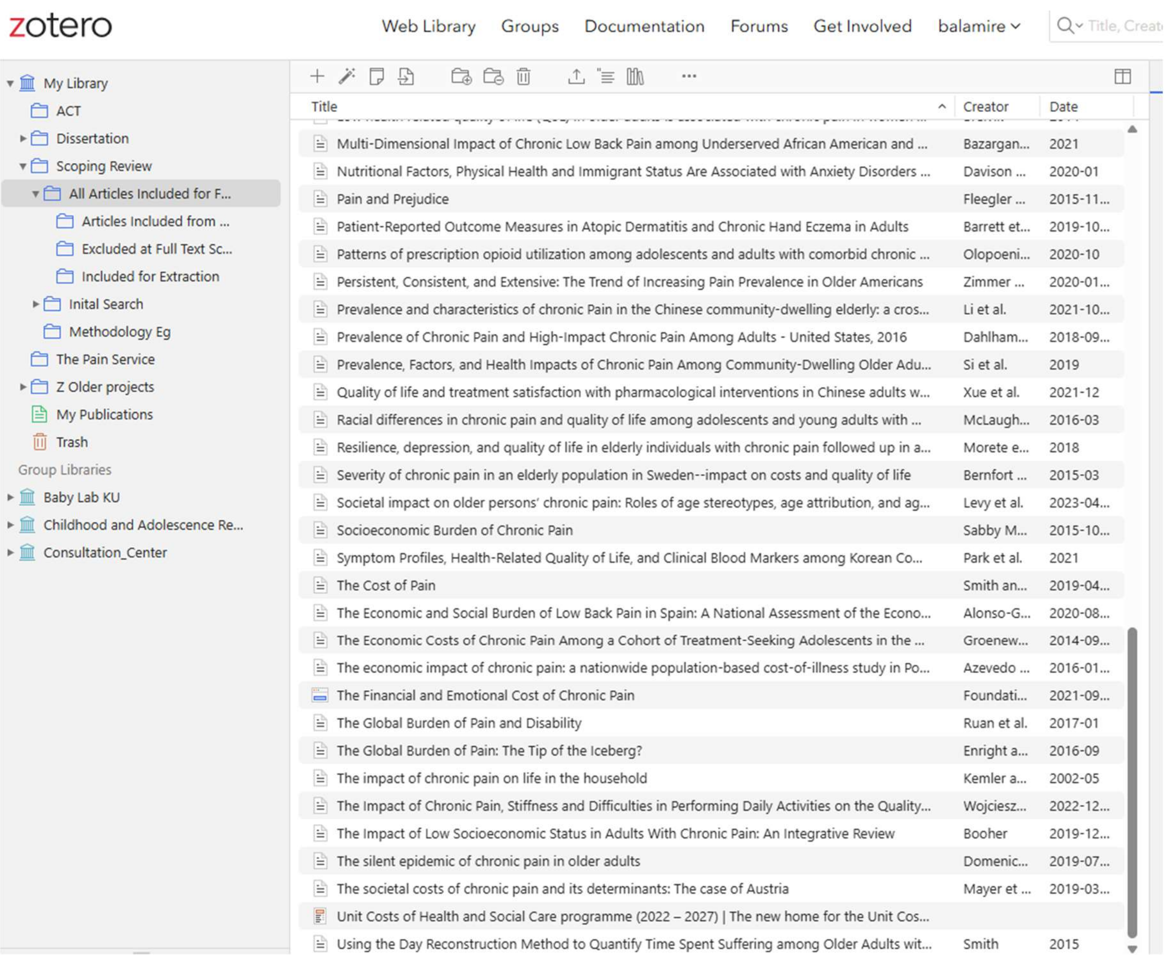
Appendix D. Articles Included at Full Text Screening



Title	Creator	Date
A comparison of the influencing factors of chronic pain and quality of life between older Korean...	Chang SJ...	2022-04
Anxiety, Depression, Chronic Pain, and Quality of Life Among Older Adults in Rural China: An Ob...	Bai and C...	2022-07...
Assessing Health-Related Quality of Life of Chinese Adults in Heilongjiang Using EQ-5D-3L	Huang et...	2017
Assessing the societal cost of chronic pain	Nielsen	2022-10...
Association between somatic symptom burden and health-related quality of life in people with c...	Fujii et al.	2018-02...
Association of insomnia severity with well-being, quality of life and health care costs: A cross-se...	Dragioti ...	2018-02
Associations of health-related quality of life with sociodemographic characteristics, health, pain, ...	Nielsen S...	2021-08...
Baseline Characteristics From a New Longitudinal Cohort of Patients With Noncancer Pain and C...	Secrest e...	2024-04...
Chronic musculoskeletal pain and its impact on older people	Blyth and...	2017-04...
Chronic pain among older adults and its impact on satisfaction with social participation: develop...	Mastela ...	2023-07...
Chronic Pain and Friendship Among Middle-Aged and Older U.S. Adults	Yang and...	2021-12...
Chronic Pain and High-impact Chronic Pain Among U.S. Adults, 2019	Zelaya et...	2020-11
Chronic pain and pattern of health care utilization among Malaysian elderly population: Nationa...	Mohame...	2014-12...
Chronic pain in adults with osteogenesis imperfecta and its relationship to appraisal, coping, an...	Muñoz C...	2022-10...
Chronic Pain in the Elderly: Mechanisms and Perspectives	Dagnino ...	2022
Chronic Pain in the Japanese Community—Prevalence, Characteristics and Impact on Quality of ...	Inoue et al.	2015
Co-occurrence of chronic pain and anxiety/depression symptoms in U.S. adults: prevalence, func...	De La Ro...	2024-03...
Cohort of Chronic Pain Patients	Universit...	2021
Combining a psychological intervention with physiotherapy: A systematic review to determine t...	Wilson a...	2018-06
Cost analysis of chronic pain due to musculoskeletal disorders in Chile	Espinoza ...	2022-10...
Cost of pain medication to treat adult patients with nonmalignant chronic pain in the United Sta...	Rasu et al.	2014-09
Descriptive analysis of sickle cell patients living in France: The PHEDRE cross-sectional study	Gerardin ...	2021-03...
Do current methods of measuring the impact of chronic pain on work reflect the experience of ...	Stagg et al.	2024-07
Economic burden of chronic pain in Alberta, Canada	Thanh et ...	2022
Epidemiology of non-oncological high-impact chronic pain in Ecuadorian adults in 2022	Martinea...	2023-12
Estimating the broader fiscal consequences of acute hepatic porphyria (AHP) with recurrent atta...	Connolly ...	2021-08...
Estimating the cost and epidemiology of mild to severe chronic pain associated with osteoarthri...	Lohan et ...	2023-11...
Exercise Improves the Impact of Chronic Pain in Older Adults: Results of an RCT	Carta et al.	2022
Factors associated with quality of life of older adults with chronic pain	Paz et al.	2021-05...
"Frustrated with the whole system": a qualitative framework analysis of the issues faced by peop...	Hopkins ...	2022-12...



Title	Creator	Date
Global Pain and Aging: A Cross-Sectional Study on Age Differences in the Intensity of Chronic P...	Calvo et al.	2023-06...
Global, regional, and national incidence, prevalence, and years lived with disability for 301 acute ...	Global B...	2015-08...
Governments should measure pain when assessing societal wellbeing	Macchia	2023-03
Health and Economic Costs of Chronic Diseases | CDC		2023-03...
Health Care Resource Utilization and Management of Chronic, Refractory Low Back Pain in the U...	Spears et...	2020-10...
Health status and quality of life in comorbid physical multimorbidity and depression among adu...	Felez-No...	2023-08...
Health-Related Quality-of-Life Impacts Associated with Transfusion-Dependent β-Thalassemia in...	Drahos e...	2024-07...
Healthcare costs associated with elderly chronic pain patients in primary care	Lazkani e...	2015-08...
How Can the Quality of Life of Older Patients Living With Chronic Pain be Improved?	Achterbe...	2019-09...
Impact of Chronic Pain on Patients' Quality of Life: A Comparative Mixed-Methods Study	Hadi et al.	2019-06
Impact of demographic factors on chronic pain among adults in the United States	Mullins e...	2022
Impact of pain characteristics and fear-avoidance beliefs on physical activity levels among older ...	Larsson ...	2016-02...
Incremental health care costs for chronic pain in Ontario, Canada: a population-based matched ...	Hogan et...	2016-08
Irritable Bowel Syndrome and Coping Strategies: A Cross-sectional Study for Identifying Psychol...	Selim et al.	2022-01...
It Is Like a Puppet Show-Experiences of Rheumatoid Arthritis Among Adult Chinese: A Qualitativ...	Chen et al.	2022-06...
Living with Systemic Lupus Erythematosus: A Profile of Young Female Patients	Macejov...	2020-01
Long-term impact of adolescent chronic pain on young adult educational, vocational, and social...	Murray e...	2020-02
Low health related quality of life (QoL) in older adults is associated with chronic pain in women ...	Breivik	2014
Multi-Dimensional Impact of Chronic Low Back Pain among Underserved African American and ...	Bazargan...	2021
Nutritional Factors, Physical Health and Immigrant Status Are Associated with Anxiety Disorders ...	Davison ...	2020-01
Pain and Prejudice	Fleegler ...	2015-11...
Patient-Reported Outcome Measures in Atopic Dermatitis and Chronic Hand Eczema in Adults	Barrett et...	2019-10...
Patterns of prescription opioid utilization among adolescents and adults with comorbid chronic ...	Olopoeni...	2020-10
Persistent, Consistent, and Extensive: The Trend of Increasing Pain Prevalence in Older Americans	Zimmer ...	2020-01...
Prevalence and characteristics of chronic Pain in the Chinese community-dwelling elderly: a cros...	Li et al.	2021-10...
Prevalence of Chronic Pain and High-Impact Chronic Pain Among Adults - United States, 2016	Dahlham...	2018-09...
Prevalence, Factors, and Health Impacts of Chronic Pain Among Community-Dwelling Older Adu...	Si et al.	2019
Quality of life and treatment satisfaction with pharmacological interventions in Chinese adults w...	Xue et al.	2021-12
Racial differences in chronic pain and quality of life among adolescents and young adults with ...	McLaugh...	2016-03
Resilience, depression, and quality of life in elderly individuals with chronic pain followed up in a...	Morete e...	2018



Title	Creator	Date
Multi-Dimensional Impact of Chronic Low Back Pain among Underserved African American and ...	Bazargan...	2021
Nutritional Factors, Physical Health and Immigrant Status Are Associated with Anxiety Disorders ...	Davison ...	2020-01
Pain and Prejudice	Fleegler ...	2015-11...
Patient-Reported Outcome Measures in Atopic Dermatitis and Chronic Hand Eczema in Adults	Barrett et...	2019-10...
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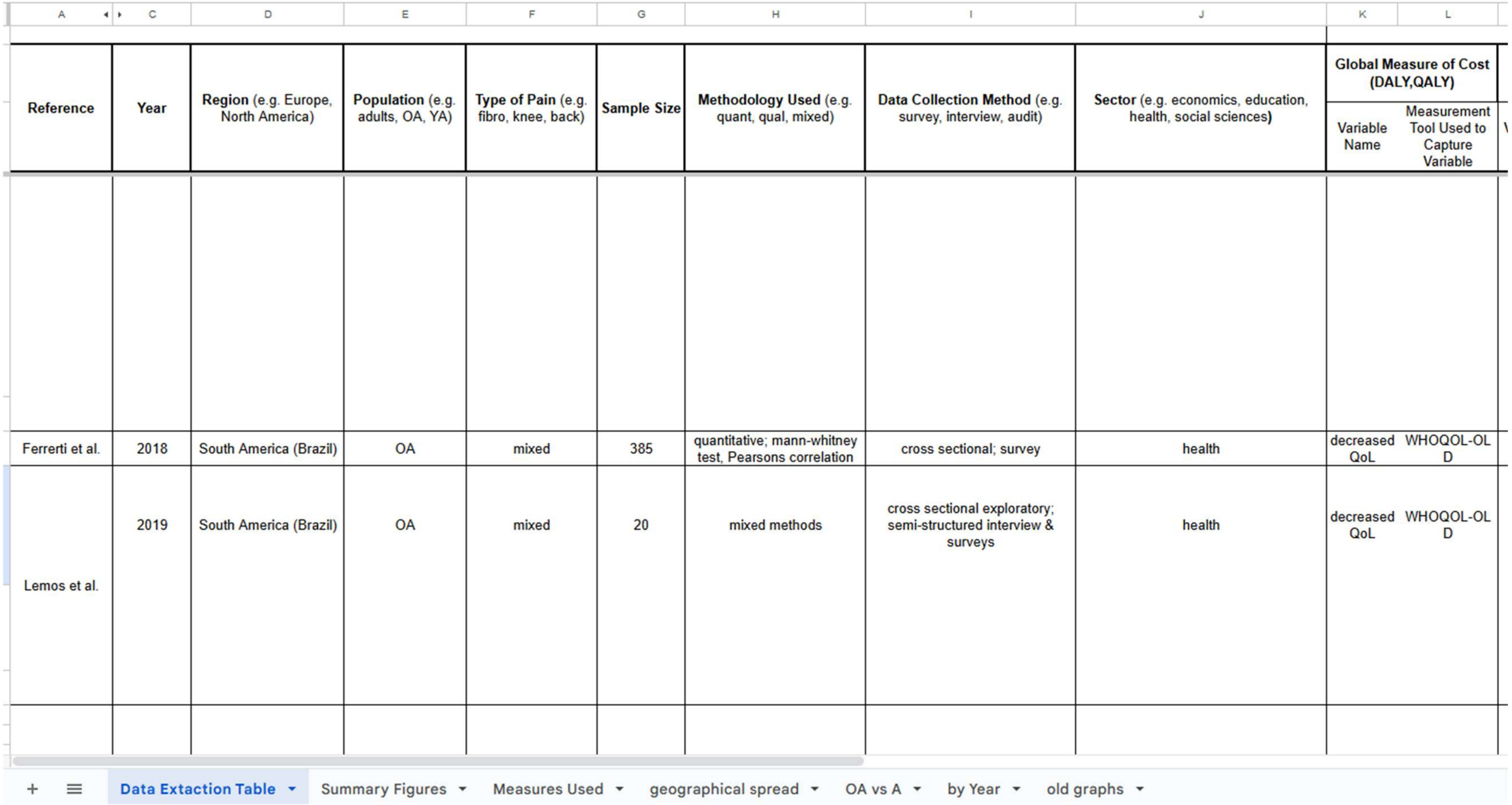
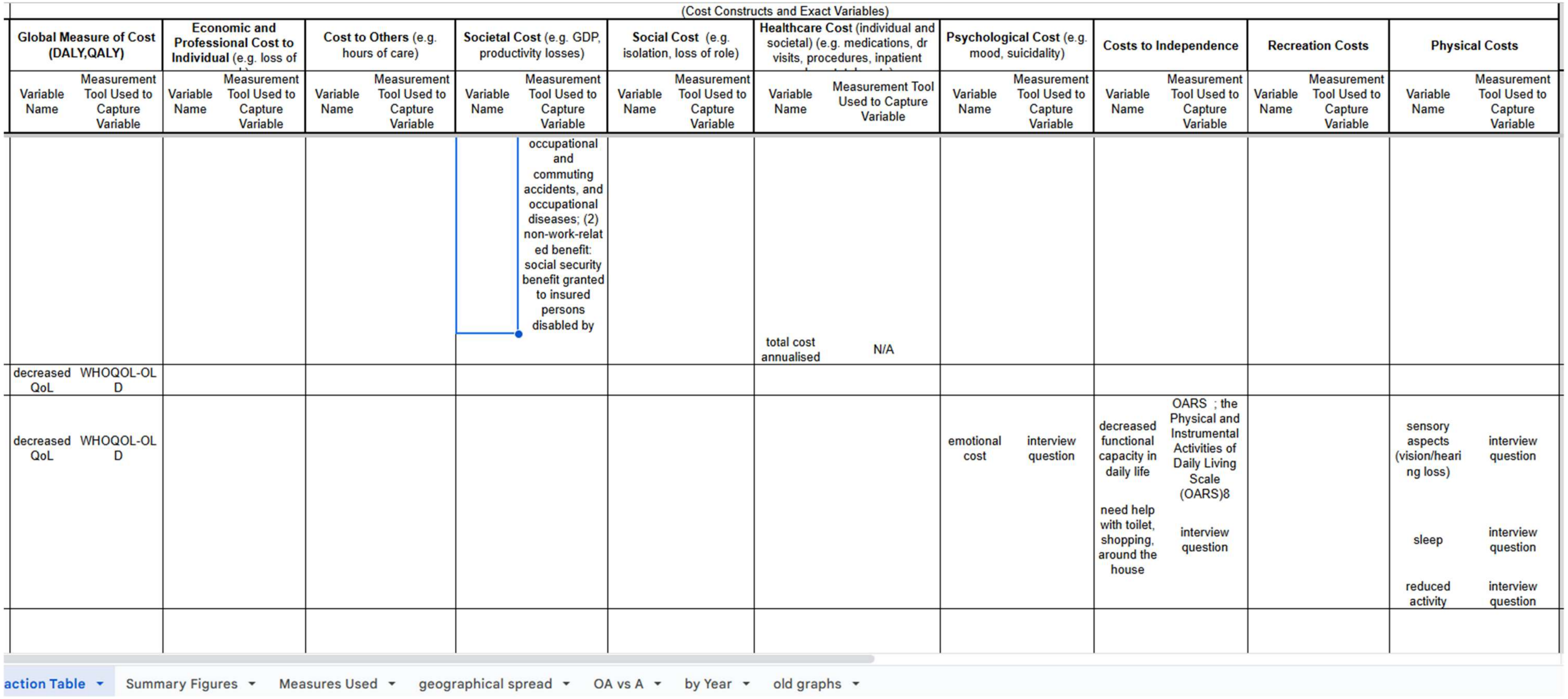
Racial differences in chronic pain and quality of life among adolescents and young adults with ...	McLaugh...	2016-03
Resilience, depression, and quality of life in elderly individuals with chronic pain followed up in a...	Morete e...	2018
Severity of chronic pain in an elderly population in Sweden--impact on costs and quality of life	Bernfort ...	2015-03
Societal impact on older persons' chronic pain: Roles of age stereotypes, age attribution, and ag...	Levy et al.	2023-04...
Socioeconomic Burden of Chronic Pain	Sabby M...	2015-10...
Symptom Profiles, Health-Related Quality of Life, and Clinical Blood Markers among Korean Co...	Park et al.	2021
The Cost of Pain	Smith an...	2019-04...
The Economic and Social Burden of Low Back Pain in Spain: A National Assessment of the Econo...	Alonso-G...	2020-08...
The Economic Costs of Chronic Pain Among a Cohort of Treatment-Seeking Adolescents in the ...	Groenew...	2014-09...
The economic impact of chronic pain: a nationwide population-based cost-of-illness study in Po...	Azevedo ...	2016-01...
The Financial and Emotional Cost of Chronic Pain	Foundati...	2021-09...
The Global Burden of Pain and Disability	Ruan et al.	2017-01
The Global Burden of Pain: The Tip of the Iceberg?	Enright a...	2016-09
The impact of chronic pain on life in the household	Kemler a...	2002-05
The Impact of Chronic Pain, Stiffness and Difficulties in Performing Daily Activities on the Quality...	Wojciesz...	2022-12...
The Impact of Low Socioeconomic Status in Adults With Chronic Pain: An Integrative Review	Booher	2019-12...
The silent epidemic of chronic pain in older adults	Domenic...	2019-07...
The societal costs of chronic pain and its determinants: The case of Austria	Mayer et ...	2019-03...
Unit Costs of Health and Social Care programme (2022 – 2027) | The new home for the Unit Cos...		
Using the Day Reconstruction Method to Quantify Time Spent Suffering among Older Adults wit...	Smith	2015

Appendix E. Template Data Extraction Table



Reference	Year	Region (e.g. Europe, North America)	Population (e.g. adults, OA, YA)	Type of Pain (e.g. fibro, knee, back)	Sample Size	Methodology Used (e.g. quant, qual, mixed)	Data Collection Method (e.g. survey, interview, audit)	Sector (e.g. economics, education, health, social sciences)	Global Measure of Cost (DALY,QALY)	
									Variable Name	Measurement Tool Used to Capture Variable
Ferrerti et al.	2018	South America (Brazil)	OA	mixed	385	quantitative; mann-whitney test, Pearsons correlation	cross sectional; survey	health	decreased QoL	WHOQOL-OLD
Lemos et al.	2019	South America (Brazil)	OA	mixed	20	mixed methods	cross sectional exploratory; semi-structured interview & surveys	health	decreased QoL	WHOQOL-OLD



(Cost Constructs and Exact Variables)

Global Measure of Cost (DALY,QALY)		Economic and Professional Cost to Individual (e.g. loss of		Cost to Others (e.g. hours of care)		Societal Cost (e.g. GDP, productivity losses)		Social Cost (e.g. isolation, loss of role)		Healthcare Cost (individual and societal) (e.g. medications, dr visits, procedures, inpatient		Psychological Cost (e.g. mood, suicidality)		Costs to Independence		Recreation Costs		Physical Costs	
Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable
							occupational and commuting accidents, and occupational diseases; (2) non-work-related benefit: social security benefit granted to insured persons disabled by			total cost annualised	N/A								
decreased QoL	WHOQOL-OLD																		
decreased QoL	WHOQOL-OLD											emotional cost	interview question	decreased functional capacity in daily life need help with toilet, shopping, around the house	OARS ; the Physical and Instrumental Activities of Daily Living Scale (OARS)8 interview question			sensory aspects (vision/hearing loss) sleep reduced activity	interview question interview question interview question

Appendix F. Scoping Review: Summary of Included Studies Characteristics

Reference	Year	Region (e.g. Europe, North America)	Population (e.g. adults, OA, YA)	Type of Pain (e.g. fibro, knee, back)	Sample Size	Methodology Used (e.g. quant, qual, mixed)	Data Collection Method (e.g. survey, interview, audit)	Sector (e.g. economics, education, health, social sciences)	(Cost Constructs and Exact Variables)																	
									Global Measure of Cost (DALY,QALY)		Economic and Professional Cost to Individual (e.g. loss of work)		Cost to Others (e.g. hours of care)		Societal Cost (e.g. GDP, productivity losses)		Social Cost (e.g. isolation, loss of role)		Healthcare Cost (individual and societal) (e.g. medications, dr visits, procedures, inpatient days, total costs)		Psychological Cost (e.g. mood, suicidality)		Costs to Independence		Recreation Costs		Physical Costs	
									Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable
Chang SJ et al.	2022	North America (USA); Asia (Korea)	OA	mixed	270	Quantitative ; Structural Equation Modelling	secondary data; questionnaire	Health	decreased quality of Life	EQ5D; EQ VAS																		
Bai & Cheng	2022	Asia (China)	OA	mixed	244	Quantitative; stepwise multiple linear regressions	multisite, cross-sectional; questionnare	Health	Decreased quality of Life	SF-12											increased anxiety incsreased depression	Zung Self-Rating Anxiety Scale (SAS), 1971 Zung Self-Rating Depression Scale (SDS), 1965						
Nielsen et al	2021	Europe (Denmark)	adults	mixed	144	Quantitative; multiple linear regressions	cross-sectional ; questionnaire	Health	Decreased quality of Life	EQ5d 5L; EQ VAS																	greater sleep disturbance	Danish Health Authority's National Health Survey 2015 categorical scale
Mastela et al.	2023	South America (Brazil)	OA	mixed	102	Quantitative; instrament validation ROC	survey	Health									decreased satisfaction with social participation	Instrament to assess older adults satisfaction with their social participation (IAPSI)										
Yang & Grol-Pokopczyk	2020	North America (USA)	OA	mixed	4598	Quantitative; OLS regressions	secondary data; questionnaire	health									decreased number of friends (greater in men than women)--understood as a threat to social self	Leave Behind Questionnaires: "Do you have any friends?"; respondents who answered affirmatively were asked, "How many of your friends would you say you have a close relationship with?" ; "On average, how often do you meet up with any of your friends?"; the affective domain of friendship was assessed using the										
Mohamed Zaki & Hairi	2014	Asia (Malaysia)	OA	mixed	4954	Quantitative; Zero Inflated Poisson (ZIP) regression	secondary data; questionnaire	health											increased frequency of hospitalisation	. Hospitalization was measured by asking, "In the last twelve months, have you ever been admitted to hospital?". The respondent who reported any hospitalization within that period were also asked about frequency of hospital admission, place of hospitalization and type of care received during hospitalization. Responses to place of hospitalization were divided into public, private or a combination for the purpose of analysis. Responses to type of care received were divided into in-patient nursing care, in-patient rehabilitative care and in-patient long term care.								
Munoz Cortes et al.	2022	Europe (Spain)	Adults	osteogenesis	418	Quantitative ; Pearson Correlation Analysis	questionnaire	health	decreased quality of life	SF-12							social life family	VAS questionnaire designed by research team VAS questionnaire designed by research team					hygiene household chores autonomy	VAS questionnaire designed by research team VAS questionnaire designed by research team VAS questionnaire designed by research team	Leisure Free time	VAS questionnaire designed by research team VAS questionnaire designed by research team	sport physical activity	VAS questionnaire designed by research team VAS questionnaire designed by research team

									(Cost Constructs and Exact Variables)																			
Reference	**Year**	**Region** (e.g. Europe, North America)	**Population** (e.g. adults, OA, YA)	**Type of Pain** (e.g. fibro, knee, back)	**Sample Size**	**Methodology Used** (e.g. quant, qual, mixed)	**Data Collection Method** (e.g. survey, interview, audit)	**Sector** (e.g. economics, education, health, social sciences)	**Global Measure of Cost (DALY,QALY)**		**Economic and Professional Cost to Individual** (e.g. loss of work)		**Cost to Others** (e.g. hours of care)		**Societal Cost** (e.g. GDP, productivity losses)		**Social Cost** (e.g. isolation, loss of role)		**Healthcare Cost** (individual and societal) (e.g. medications, dr visits, procedures, inpatient days, total costs)		**Psychological Cost** (e.g. mood, suicidality)		**Costs to Independence**		**Recreation Costs**		**Physical Costs**	
									Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable
Inoue et al	2015	Asia (Japan)	Adults	mixed	2701	quantitative; logistic regression	cross-sectional ; questionnaire	health	decreased quality of life	EQ5D					increased absence from work	self report question created by research team-- amount of tiem taken off due to pain in last year					increased psychological distress	Kessler 6-item psychological distress scale (K6)						
De La Rosa et al.	2024	North America (USA)	adults	mixed	31997	quantitative; adjusted Rao-Scott Chi Squared Test	National Health Interview Survey 2019; self report questionnaire	health													increased prevalence of clinically sig	PHQ-9						
																					increased prevalence of clinically sig anxiety	GAD-7						
Espinoza et al	2022	South America (Chile)	adults	mixed (highest costs come from 1. lower back pain and 2. fibromyalgia)	N/A	quantitative (decision model exercise, Markov Model; Bayesian 10,000 Montecarlo simulation)	National Health Survey 2016-17 ; VAS (Pain)	health	QALY	Loss in health status utilities (LHSU) --> converted into QALYs by multiplying by one year; LHSU was estimated through the modeling exercise. The reported disutility for the disability related to the pain of each of the five MSKD considered was					Productivity Cost	private and public insurance databases-- no variables named ; human capital approach			theraputic management of CP	no variable measures named ; Finally, to characterize second-order uncertainty for costs related to pain management, depression, and anxiety, we adopted aBayesian approach using classical techniques of probabilistic sensitivity analysis suggested for economic evaluations. We ran a10,000 Montecarlo simulation based on which we estimated 95% credibility intervals. Because of the estimates for sick leave and productivity losses we obtained directly from the data, we provide 95%	increased depression	no variable measures named ; Depression/anxiety prevalence was estimated using the depression/anxiety caused bya chronic pain-attributable fraction (dPAF)						
																			theraputic management of anxiety	no variable measures named ; Finally, to characterize second-order uncertainty for costs related to pain management, depression, and anxiety, we adopted a Bayesian approach using classical techniques of probabilistic sensitivity analysis suggested for economic evaluations. We ran a10,000 Montecarlo simulation based on which we estimated 95% credibility intervals. Because of the estimates for sick leave and productivity losses we obtained directly from the data, we provide 95% confidence intervals. The list	increased anxiety	no variable measures named ; Depression/anxiety prevalence was estimated using the depression/anxiety caused bya chronic pain-attributable fraction (dPAF)						
															Increased sick days	private and public insurance databases-- no variables named			theraputic management of depression	no variable measures named ; Finally, to characterize second-order uncertainty for costs related to pain management, depression, and anxiety, we adopted aBayesian approach using classical techniques of probabilistic sensitivity analysis suggested for economic evaluations. We ran a10,000 Montecarlo simulation based on which we								

									(Cost Constructs and Exact Variables)																			
Reference	Year	Region (e.g. Europe, North America)	Population (e.g. adults, OA, YA)	Type of Pain (e.g. fibro, knee, back)	Sample Size	Methodology Used (e.g. quant, qual, mixed)	Data Collection Method (e.g. survey, interview, audit)	Sector (e.g. economics, education, health, social sciences)	Global Measure of Cost (DALY,QALY)		Economic and Professional Cost to Individual (e.g. loss of work)		Cost to Others (e.g. hours of care)		Societal Cost (e.g. GDP, productivity losses)		Social Cost (e.g. isolation, loss of role)		Healthcare Cost (individual and societal) (e.g. medications, dr visits, procedures, inpatient days, total costs)		Psychological Cost (e.g. mood, suicidality)		Costs to Independence		Recreation Costs		Physical Costs	
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																			Total health costs per condition	calculated by modelling and publically available data-- no exact variables named.								
																			medication costs	no variable measures named								
Rasu et al.	2014	North America (USA)	adults	mixed	N/A	quantitative ; frequency calculations	cross sectional; National Ambulatory Medical Care Survey (NAMCS) 2000-2007.	health											outpatient doctor visits	frequency from survey records								
																			perscription costs	frequency of perscription and typical doses noted from survey records: "Expenditure for a specific pain medication was calculated by multiplying the volume of medications prescribed between 2000 and 2007 (referred to as "frequency" by NAMCS) with average price for 30-day supply at the maximum daily dose (calculated from Red Book) of the specific pain medication."								
	2024	Worldwide : Europe (n 31), North America (n 20), Australasia (n 4), the Middle East (n 1), multiple areas (n 3), and South America (n 1)	Adults	mixed	N/A	Mixed methods review; qualitisation	secondary qualitative data	health			loss of pension	qualitative interview			productivity	WAI, WALS, and Work Instability Scale (WIS)	work relationships	Six items from the Demand Control Support Questionnaire assessing workplace support from supervisors and colleagues (support from supervisors or employer; support from colleagues) (Rashid, 2018) [61] Items included items about getting on with colleagues and supervisors,			work related stress	Six items from the Effort-Reward Imbalance Questionnaire (negative psychosocial work impacts (e.g. work-related stress, job strain) (Dawson, 2011) [18] Items about different aspects of being fixated on work and work problems, even when not at work. [Strongly disagree/disagr						
											job adjustments	Nordic Musculoskeletal Questionnaire: Have you ever had to change jobs or duties (even temporarily) because of the trouble? No/Yes			absenteeism	Single item assessing sick leave; Work Ability Index (WAI)					work self-efficacy	Single item assessing work self-efficacy (self efficacy)-- How strong is your belief that you will cope with functioning in the ordinary work force? [0-10 scale; higher scores indicating higher self-efficacy].						

Reference	Year	Region (e.g. Europe, North America)	Population (e.g. adults, OA, YA)	Type of Pain (e.g. fibro, knee, back)	Sample Size	Methodology Used (e.g. quant, qual, mixed)	Data Collection Method (e.g. survey, interview, audit)	Sector (e.g. economics, education, health, social sciences)	(Cost Constructs and Exact Variables)																			
									Global Measure of Cost (DALY,QALY)		Economic and Professional Cost to Individual (e.g. loss of work)		Cost to Others (e.g. hours of care)		Societal Cost (e.g. GDP, productivity losses)		Social Cost (e.g. isolation, loss of role)		Healthcare Cost (individual and societal) (e.g. medications, dr visits, procedures, inpatient days, total costs)		Psychological Cost (e.g. mood, suicidality)		Costs to Independence		Recreation Costs		Physical Costs	
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Stagg et al.											change of job job loss	Items include questions on: 1) occasional loss of work hours or work interruptions, 2) change in the type or nature of work, or 3) permanent changes of work hours or job Participants asked to choose one of the following options when asked about the consequences of pain on their job: Job loss (fired/voluntary termination), change in job/professional responsibilities (e.g. time reduction, task changing), change of job or switching profession, early retirement, long term sick leave (≥ 3 months)			reduced working hours at-work productivity	Single item from the Health Related Productivity Questionnaire. Participants asked to indicate which work impacts they had experienced due to illnesses (pain)/ treatments: forced to work part-time when they wanted to Work Ability Limitations Scale (WALS)					beliefs about future work ability negative impact on worker identity	One item from the WAI assessing future work ability expectations (de Vries, 2013) [20] Item estimating belief of ability to do current job with present state of health in two years' time [Unlikely – Not qualitative interview						
Lohan et al.	2023	Europe (UK)	adults	osteoarthritis	23016	Quantitative; univariable Poisson regression models, ANOVA	Clinical Practice Research Datalink Gold (primary care linked to) Hospital Episode Statistics (HES) ; retrospective, longitudinal, observational cohort study	health											perscriptions GP outpatient ED medication duration or total direct	unnamed variable from national survey unnamed variable from unnamed variable from unnamed variable from unnamed variable from unnamed variable from unnamed variable from	depression anxiety	unnamed variable from national survey unnamed					hypertention psoriatic asthma diabetes higher BMI	unnamed variable from national survey unnamed unnamed unnamed unnamed
Paz et al.	2020	South America (Brazil)	OA	mixed	239	Quantitative ; multiple linear regressions	cross-sectional ; questionnaire	health	QAYL	World Health Organization Quality of Life-Old (WHOQOL-OLD)							social participation declines intimacy	WHO QOL-OLD WHO QOL-			depression	WHO QOL-OLD	autonomy losses	WHO QOL-OLD			sensory ability losses	WHO QOL-OLD
Hopkins et al.	2022	Australia	adults	mixed	26	Qualitative ; thematic analysis	semi-structured interviews	health											difficulties accessing healthcare services	interview questions								
Global Burden of Disease Study 2013 Collaborators	2015	global	adults	lower back pain	N/A	quantitative; Bayesian meta-regression method (DisMod-MR)	survey	public health	Increased Years lived with Disability (YLD)	N/A																		
James et al.	2018	global	adults	lower back pain & headache disorders	N/A	quantitative; Bayesian meta-regression method (DisMod-MR)	survey	public health	Increased Years lived with Disability (YLD)	N/A																		
Macchia	2023	global	adults	mixed	N/A	comment	N/A	public health			job loss early financial loss of educatio	N/A N/A N/A N/A N/A			cost to absenteeis cost to	N/A N/A N/A					higher rates increased decreased work- poor social	N/A N/A N/A N/A N/A N/A						

									(Cost Constructs and Exact Variables)																			
Reference	**Year**	**Region** (e.g. Europe, North America)	**Population** (e.g. adults, OA, YA)	**Type of Pain** (e.g. fibro, knee, back)	**Sample Size**	**Methodology Used** (e.g. quant, qual, mixed)	**Data Collection Method** (e.g. survey, interview, audit)	**Sector** (e.g. economics, education, health, social sciences)	**Global Measure of Cost (DALY,QALY)**		**Economic and Professional Cost to Individual** (e.g. loss of work)		**Cost to Others** (e.g. hours of care)		**Societal Cost** (e.g. GDP, productivity losses)		**Social Cost** (e.g. isolation, loss of role)		**Healthcare Cost** (individual and societal) (e.g. medications, dr visits, procedures, inpatient days, total costs)		**Psychological Cost** (e.g. mood, suicidality)		**Costs to Independence**		**Recreation Costs**		**Physical Costs**	
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Spears et al.	2020	North America (USA)	adults	low back pain	55945	quantitative; frequencies	secondary data; IBM MarketScan Research databases from 2009 to 2016	health											utlization of pain medications physiotherap chiropractor steriod trigger point botulinum psychologica massage occupational radiofrequen acupuncture biofeedback total health ER visits inpatient outpatient	filled valid perscriptions # of services per patients and # of services per patients and # of services per patients and # of services per patients and # of services per patients and # of services per patients and # of services per patients and # of services per patients and # of services per patients and # of services per patients and # of services per patients and calced from database # of services per patients and # of services per patients and # of services per patients and								
Lazkani et al.	2015	Europe (France)	OA	mixed	1379	quantitative; multiple logistic regression model, ROC curve	secondary data; S.AGE Cohort (primary GP data)	health									relationships	0-4 point scale completed by GP	prescriptions hospitalisati nurse visits physiotheray pedicure medical medical total costs of home	The cost of each medication was based on the selling price provided from the national cost was obtained by GP recorded data ; A home GP recorded data GP recorded data GP recorded data GP recorded data Costs were calculated for GP recorded data	depression	Geriatic Depression Scale	daily activities	Instramental Activities of Daily Living			walking sleep physical	0-4 point scale completed by GP 0-4 point scale Activities of
Achterberg	2019	Europe (Netherlands)	OA	mixed	N/A	comment	N/A	N/A	QOL	N/A											depression	N/A						
Hadi et al.	2019	Europe (UK)	Adults	mixed	79 + 19	Mixed methods: thematic analysis & one sample Z test	semi structured interviews & secondary data (Third Oxford and Lifestyles Survey and Welsh Health Survey)	health	QOL	Short Form-36 Health Survey (Version 2)SF-36	loss of work change drop of financial	interview prompt interview prompt interview prompt interview prompt					difficulties parenting social social inability to percieved	interview prompt interview interview interview interview			depression anger/	Hospital Anxiety and Depression Scale interview	inability to perform daily tasks	interview prompt			sleep deprivation physical fatigue self-care	interview prompt interview prompt interview prompt interview prompt
Larsson et al.	2016	Europe (Sweden)	OA	mixed	1141	quantitative; logistic regression	survey; Swedish National Register of Inhabitants	health	self-rated overall health	SF-12											kinesiophobia (exvcessive self efficacy	Tampa Scale of Kinesiophobia General Self-					level of physical activity	Grimby's Activity Scale
Chen et al.	2022	Asia (Tiawan)	Adults	rheumatoid arthritis	30	qualitative; content analysis	interviews ; convenience sampling	health									limited/de	interview			worry helplessnes self	interview interview interview					limited	interview
Bazargan et al.	2021	Northern America (USA)	OA	mixed	905	quantitative; multivariate generalised linear models (GLM) with Poisson	convenience and snowball sampling ; survey	health	Health related QoL self rated health status	 Self-rated Health Status (SRH): Participants reported SRH using a single question: "In general, would you say your									physician visits ER admissions Hospital Admissions number of perscriptions used lower satisfaction with medical care medication complexity	ED Utilization, Office-Based Provider Visits, and Hospital Admissions: Participants were ED Utilization, Office-Based Provider Visits, and Hospital Admissions: Participants were asked how many times they had utilized ED, stayed overnight at hospital as a patient, and visited a provider at their office in the last 12 months. ED Utilization, Office-Based Provider Visits, and Hospital Admissions: Participants were asked how many times they had utilized ED, stayed overnight at hospital as a patient, and visited a provider at their office in the last 12 months. interview prompt Accessibility of medical care: This variable was measured using five items: (1) In the last 12 months, have you needed to see a doctor but could not see one? (2) Overall, how difficult is it for you to get medication regimen complexity index (MRCI)	lower adherence with decreased mental health quality of life depressive symtoms	N/A SF-12 (mental health subscale) Short Geriatric Depression Scale (GDS)					decreased physical health increased number of falls sleep disorder obesity	SF-12 (physical health subscale) single item asking participants to report a single fall or multiple falls in the year before the interview (yes = 0; no = 1) Insomnia Severity Index (ISI) BMI
Xue et al.	2021	Asia (China)	Adults	osteoarthritis of the knee	601	quantitative ; linear regression model	multicenter observational, cross-sectional; survey	health	HRQoL	EQ5D-5L																		
	2018	South America (Brazil)	OA	mixed	108	quantitative ; nonparametric Mann-Whitney	cross-sectional ; survey	health	Quality of life	Quality of life was assessed											lower resilience	Connor-Davidson						

									(Cost Constructs and Exact Variables)																			
Reference	**Year**	**Region** (e.g. Europe, North America)	**Population** (e.g. adults, OA, YA)	**Type of Pain** (e.g. fibro, knee, back)	**Sample Size**	**Methodology Used** (e.g. quant, qual, mixed)	**Data Collection Method** (e.g. survey, interview, audit)	**Sector** (e.g. economics, education, health, social sciences)	**Global Measure of Cost (DALY,QALY)**		**Economic and Professional Cost to Individual** (e.g. loss of work)		**Cost to Others** (e.g. hours of care)		**Societal Cost** (e.g. GDP, productivity losses)		**Social Cost** (e.g. isolation, loss of role)		**Healthcare Cost** (individual and societal) (e.g. medications, dr visits, procedures, inpatient days, total costs)		**Psychological Cost** (e.g. mood, suicidality)		**Costs to Independence**		**Recreation Costs**		**Physical Costs**	
									Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable
Morete et al.																					increased frequency	The Geriatric Depression						
Bernfort et al.	2015	Europe (Sweden)	OA	mixed	6611	Quantitative ; analysis of variance	cross sectional survey ; national databases	health	QoL	EQ5D 5L			care from relatives	survey completed by relatives and database on wage losses: second questionnaire was mailed to the relatives who they identified as their main caregivers. This second questionnaire asked these relatives about what kind of support they provided and how many hours they spent caring for their elderly relative. This support included domestic chores,	special housing	costs incurred by the municipalities was retrieved from a register provided by the municipality. In addition, the register contains the number of days in special housing. Total costs can be calculated by the use of the standard cost per day.			total healthcare cost	total average annual cost to society in terms of health care, drugs, municipal services, and informal care								
																			hospitalisation days	retrieved from the Health Care Register in Östergötland (HCR Ö)								
																			inpatient treatments	retrieved from the Health Care Register in Östergötland (HCR Ö)								
																			outpatient Dr visits	retrieved from the Health Care Register in Östergötland (HCR Ö)								
																			perscription costs	National Board of Health and Welfare (Socialstyrelsen) maintains a register on drug prescription. The register contains information on prescribed medications that have been retrieved by patients.								
																			home help services	costs incurred by the municipalities was retrieved from a register provided by the Linköping municipality. consumption of the different home help services with hours and prices attached to								
Azevdeo et al	2016	Europe (Portugal)	adults	mixed	562	Quantitative; cost of illness analysis (mixed Poisson-gamma models; human capital method)	questionnaires; secondary analysis of cross-sectional national survey	health			early retirement	N/A			work absenteeism	Based on the human capital method, indirect costs associated to productivity losses due to work absenteeism, early			pain medications	Direct healthcare costs were calculated for each patient by adding the costs of pain medicines, non-pharmacologic pain treatment modalities, medical consultations in primary care and hospital settings, consultations with other healthcare								
											job loss	N/A							non-pharmacological treatment modalities	additional structured questionnaire assessing in more detail healthcare resource use and issues regarding indirect costs of CP [27].								
																			medical consultations (family physician, private, hospital, pain clinic)	additional structured questionnaire assessing in more detail healthcare resource use and issues regarding indirect costs of CP [27].								
																			medical tests	additional structured questionnaire assessing in more detail healthcare resource use and issues regarding indirect costs of CP								
																			total indirect/ direct costs annualised	calc'd from databases								

(Cost Constructs and Exact Variables)

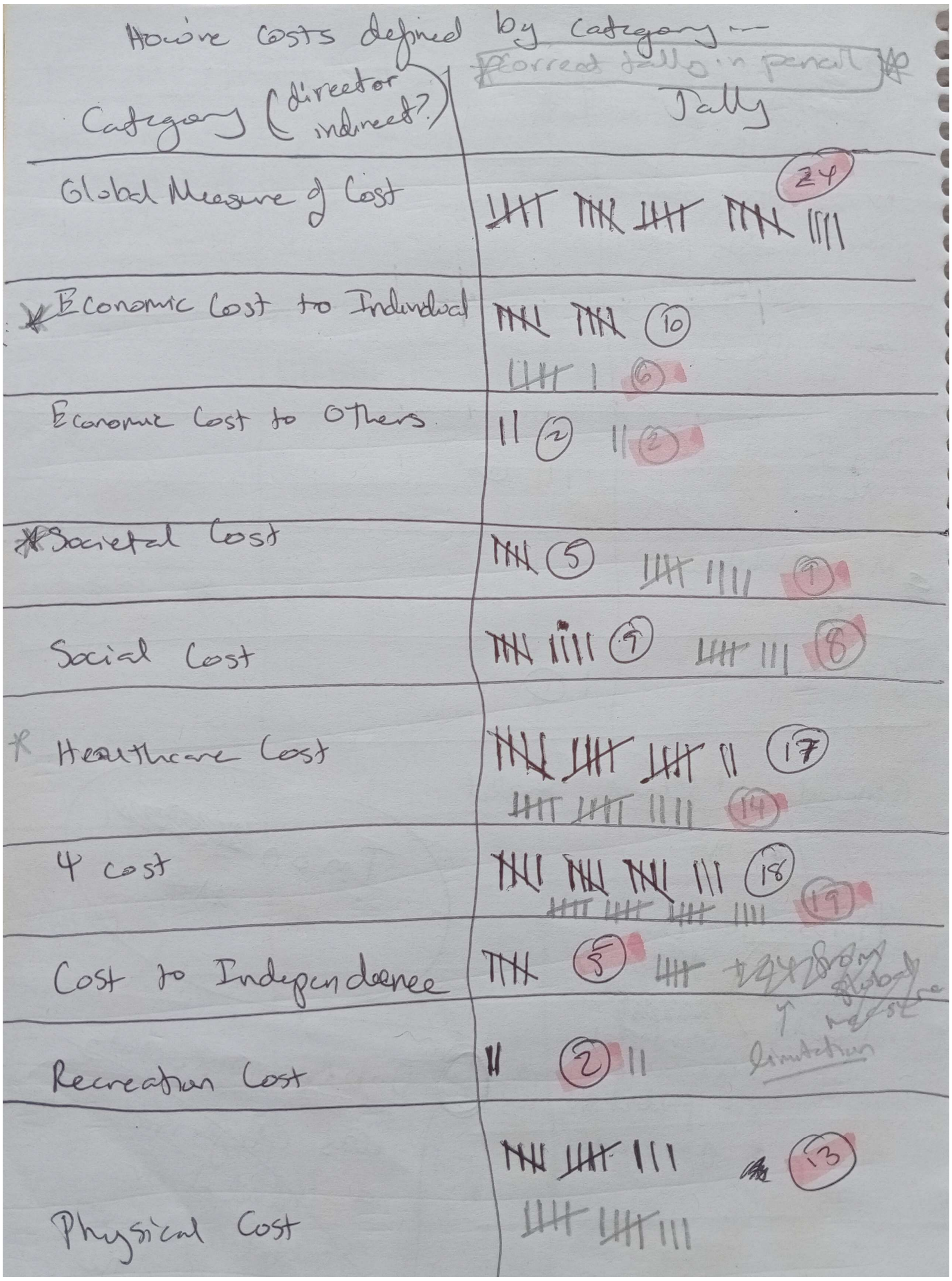
Reference	Year	Region (e.g. Europe, North America)	Population (e.g. adults, OA, YA)	Type of Pain (e.g. fibro, knee, back)	Sample Size	Methodology Used (e.g. quant, qual, mixed)	Data Collection Method (e.g. survey, interview, audit)	Sector (e.g. economics, education, health, social sciences)	Global Measure of Cost (DALY,QALY)		Economic and Professional Cost to Individual (e.g. loss of work)		Cost to Others (e.g. hours of care)		Societal Cost (e.g. GDP, productivity losses)		Social Cost (e.g. isolation, loss of role)		Healthcare Cost (individual and societal) (e.g. medications, dr visits, procedures, inpatient days, total costs)		Psychological Cost (e.g. mood, suicidality)		Costs to Independence		Recreation Costs		Physical Costs	
									Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable
Wojcieszek et al.	2022	Europe (Poland)	OA	Knee Osteoarthritis	300	quantitative; chi squared, spearman correlation,	questionnaires; cross sectional	health	QoL	World Health Organization Quality of																	stiffness level of loss of	Western Ontario and McMaster Osteoarthritis Western Ontario Western Ontario
Domenichiello & Ramsden	2019	North America (USA)	OA	mixed	N/A	review	N/A	health											polypharmacy	N/A							premature death frailty accelerated	N/A N/A N/A
Mayer et al.	2019	Europe (Austria)	adults	mixed	54	quantitative; cost of illness (bottom up approach); multivariate ordinary least square regression framework,	cost diary; public national databases	health			over the counter medications perscription copay fees private therapists other expenses	participant diary record participant diary record participant diary record participant diary record	informal care household help	Informal caregiving was valued at the level of minimum wage [38] cost diaries	presenteeism (working but performance being impacted by health) Lost productivity due to early retirement / disability pension or part-time work Lost productivity due to physician consultations Lost productivity due to sick leave Lost productivity due to rehabilitation stays Lost productivity due to inpatient hospitalization	measured based on a VAS 0 not capable of working to 100 best working capability Productivity loss was valued based on the average gross income in Austria using the human capital approach as recommended Productivity loss was valued based on the average gross income in Austria using the human capital approach as Productivity loss was valued based on the average gross income in Austria using the human Productivity loss was valued based on the average gross income in Austria using the human capital approach as recommended Productivity loss was valued based on the average gross income in Austria using			perscription medication radiological proceedures GP specialist apt hospital outpatient dept physiotherapy inpatient inpatient	public databases Unit costs were retrieved from anumber of sources (Table 1) based on the DHE Unit Cost Online Database for Austria [34, 35]. Direct medical services (excluding out-of-pocket expenses) were valued from the perspective of the public payer (for details, see S1 Text) Unit costs were retrieved from anumber of sources (Table 1) based on the DHE Unit Cost Online Database for Austria [34, 35]. Direct medical services (excluding out-of-pocket expenses) were valued from the perspective of the public payer (for Unit costs were retrieved from anumber of sources (Table 1) based on the DHE Unit Cost Online Database for Austria [34, 35]. Direct medical services (excluding out-of-pocket expenses) were Unit costs were retrieved from anumber of sources (Table 1) based on the DHE Unit Cost Online Database for Austria [34, 35]. Direct medical services (excluding out-of-pocket expenses) were valued from the perspective of the public payer (for details, see S1 Text). Unit costs were retrieved from anumber of sources (Table 1) based on the DHE Unit Cost Online Database for Austria [34, 35]. Direct medical services (excluding out-of- Unit costs were retrieved from Unit costs were retrieved from					reduced lifestyle activities	cost diaries		
	2015	North America (USA)	OA	mixed	122	qualitative; day reconstruction method (DRM)	structured diary	health	QoL	An overall QOL question asked participants to choose a number between 0 and 100 that best represents their current QOL (0 _ the worst imaginable	lower income	interview question									time spent suffering Lower life satisfaction	DRM diary Overall life satisfaction was measured with the Satisfaction with Life Scale (Diener et al., 1985).					fatigue	interview question

									(Cost Constructs and Exact Variables)																			
Reference	**Year**	**Region** (e.g. Europe, North America)	**Population** (e.g. adults, OA, YA)	**Type of Pain** (e.g. fibro, knee, back)	**Sample Size**	**Methodology Used** (e.g. quant, qual, mixed)	**Data Collection Method** (e.g. survey, interview, audit)	**Sector** (e.g. economics, education, health, social sciences)	**Global Measure of Cost (DALY,QALY)**		**Economic and Professional Cost to Individual** (e.g. loss of work)		**Cost to Others** (e.g. hours of care)		**Societal Cost** (e.g. GDP, productivity losses)		**Social Cost** (e.g. isolation, loss of role)		**Healthcare Cost** (individual and societal) (e.g. medications, dr visits, procedures, inpatient days, total costs)		**Psychological Cost** (e.g. mood, suicidality)		**Costs to Independence**		**Recreation Costs**		**Physical Costs**	
									Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable
Smith																					depression	positive and negative affect over the previous four days was measured using the positive affect/negative affect schedule (Watson et al., 1988). This instrument includes a list of 20 different feelings and emotions. Survey respondents are asked to						
Vargas et al.	2018	South America (Chile)	adults	mixed (however most costly was LBP & OA of the knee)	N/A	quantitative ; Markov cohort model	publically available data, National Health survey,	health	YDL	Years lived with disability correspond to the equivalent number of years spent with maximum disability (equivalent to death). This metric requires incidence data, disease duration in years, and a disability weight (from GDB study), which reflects the severity of the disease where 0 represents perfect health and 1 represents disability equivalent to					productivity losses	productivity losses were measured as monetary costs following the human capital approach. This method is based on the fact that the association between productive time and health9 is the average market wage. The 2014 to 2015 private sector medical leave database was examined to estimate the total number of medical leaves according to the International Classification of			dr viits	Ministry of health cost study database, international and local clinic guidelines, & expert estimates.	depression	For depression, it was possible to calculate the PAF, which corresponds to the proportion of cases of a disease that can be avoided in a given population if a given risk factor was not present.39 Data from the 2010 NHS were used to estimate this parameter for all diseases except MFS. For the latter, a literature review was conducted to obtain the						
															% of national GDP lost due to CP				physiotherapy	Ministry of health cost study database, international and local clinic guidelines, & expert estimates.	anxiety	A literature review was also conducted to estimate the proportion of patients in the whole population						
															annual cost of CP to the country				medications	To put a monetary value to each health resource, "the published public payer (FONASA) annual tariff 10 and the 2011 Health Resources Cost Study" requested by FONASA 6 were used. "pharmaceuticals not included in any of these data sources, the average price was requested to the institution responsible for the purchasing of national health supplies" ([Vargas et al., p. 5]								
Glette et al.	2021	Europe (Norway)	adults	mixed	4764	quantitative ; linear mixed models	HUNT study (longitudinal population ased study) ; survey	health													depression	MHI-5 (from the SF-36 Health Survey)						
	2020	South America (Brazil)	adults	LBP	N/A	cost of illness (top down approach / societal perspective) ; regression ;	secondary data; National databases 2012-2016	health							total cost as a % of GDP loss	N/A			imaging	To estimate the expenses of healthcare utilization associated with LBP, we								

(Cost Constructs and Exact Variables)

Reference	Year	Region (e.g. Europe, North America)	Population (e.g. adults, OA, YA)	Type of Pain (e.g. fibro, knee, back)	Sample Size	Methodology Used (e.g. quant, qual, mixed)	Data Collection Method (e.g. survey, interview, audit)	Sector (e.g. economics, education, health, social sciences)	Global Measure of Cost (DALY,QALY)		Economic and Professional Cost to Individual (e.g. loss of work)		Cost to Others (e.g. hours of care)		Societal Cost (e.g. GDP, productivity losses)		Social Cost (e.g. isolation, loss of role)		Healthcare Cost (individual and societal) (e.g. medications, dr visits, procedures, inpatient days, total costs)		Psychological Cost (e.g. mood, suicidality)		Costs to Independence		Recreation Costs		Physical Costs	
									Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable	Variable Name	Measurement Tool Used to Capture Variable
Carregaro et al.															days absent from work	to estimate productivity losses, data from the Ministry of Social Insurance (INSS) was used, and included information regarding the duration of the work absence due to disabilities and associated			outpatient costs	Outpatient care expenses included ambulatory services/procedures, such as medical and allied healthcare consultations, examinations, diagnostic imaging, clinical and surgical procedures, physiotherapy procedures, and other procedures.								
															productivity loss	to estimate productivity losses, data from the Ministry of Social Insurance (INSS) was used, and included information regarding the duration of the work absence due to disabilities and associated			inpatient costs	inpatient care, the following cost items were obtained: hospital services (i.e., daily rate; room fees; food; personal hygiene; bed support; hospital supplies; allied healthcare professional services; medications and diagnostic and therapeutic auxiliary services); professional services (health professionals); intensive care unit (ICU) expenses (including the use of all equipment for intensive care, technical teams, and 24-hour patient monitoring); companion daily								
																			total cost annualised	N/A								
Ferrerti et al.	2018	South America (Brazil)	OA	mixed	385	quantitative; mann-whitney test, Pearsons correlation	cross sectional; survey	health	decreased QoL	WHOQOL-OLD																		
Lemos et al.	2019	South America (Brazil)	OA	mixed	20	mixed methods	cross sectional exploratory; semi-structured interview & surveys	health	decreased QoL	WHOQOL-OLD											emotional cost	interview question	decreased functional capacity in	"OARS", the Physical and Instrumental			sensory aspects (vision/hearin	interview question
																							need help with toilet, shopping, around the house	interview question			sleep	interview question
																											reduced activity	interview question

Appendix G. Scoping Review Hand Coded Data Tally Table Sample

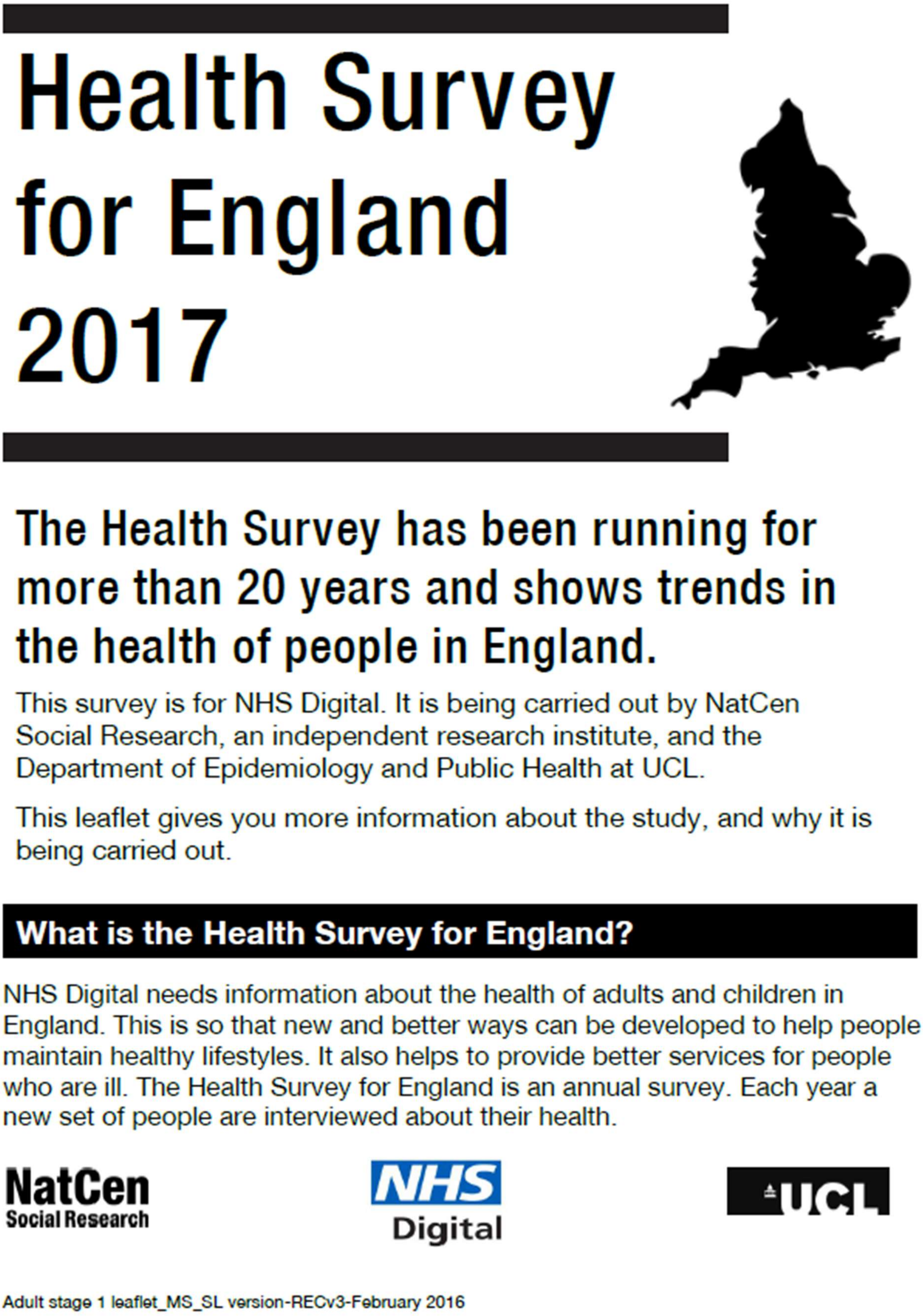


How're costs defined by category —

Corrected tally in pencil

Category (direct or indirect?)	Tally
Global Measure of Cost	𝍸 𝍸 𝍸 𝍸 |||| ㉔
*Economic Cost to Individual	𝍸 𝍸 ⑩ 𝍸 | ⑥
Economic Cost to Others	|| ② || ②
*Societal Cost	𝍸 ⑤ 𝍸 |||| ⑨
Social Cost	𝍸 |||| ⑨ 𝍸 ||| ⑧
* Healthcare Cost	𝍸 𝍸 𝍸 || ⑰ 𝍸 𝍸 |||| ⑭
4 cost	𝍸 𝍸 𝍸 ||| ⑱ 𝍸 𝍸 𝍸 |||| ⑲
Cost to Independence	𝍸 ⑤ 𝍸 ~~[illegible]~~ from global measure ↑ limitation
Recreation Cost	|| ② ||
Physical Cost	𝍸 𝍸 ||| ⑬ 𝍸 𝍸 |||

Appendix H: Study 2 Adult Participant Information Sheet



Health Survey for England 2017

The Health Survey has been running for more than 20 years and shows trends in the health of people in England.

This survey is for NHS Digital. It is being carried out by NatCen Social Research, an independent research institute, and the Department of Epidemiology and Public Health at UCL.

This leaflet gives you more information about the study, and why it is being carried out.

What is the Health Survey for England?

NHS Digital needs information about the health of adults and children in England. This is so that new and better ways can be developed to help people maintain healthy lifestyles. It also helps to provide better services for people who are ill. The Health Survey for England is an annual survey. Each year a new set of people are interviewed about their health.

NatCen Social Research

NHS Digital

UCL

Adult stage 1 leaflet_MS_SL version-RECv3-February 2016

What does the survey cover?

The Health Survey for England has questions about your general health. It also asks about factors that can affect your health, including things such as smoking and drinking.

If you agree, the survey also collects some physical measurements such as height, weight, and waist and hip measurements. We will give you more information about this later on. You can agree to take part in some sections of the survey and not others.

We also ask about some personal details such as age, sex and employment. This is to help interpret the health information you give us.

Why have you come to my household?

A visit to every household in England would take too long and cost too much money. Instead we select a random sample of addresses, and ask the people at each of these addresses to take part.

Do I have to take part?

Taking part is **voluntary**. In all our surveys we rely on voluntary co-operation. The success of the survey depends on the goodwill of those asked to take part. The more people who do take part, the more useful the results will be. You are free to withdraw from the survey at any time. However, we will not be able to remove individual information after the survey results have been published.

How long will the survey take?

This varies from person to person and depends on how many people live in your household. The interviewer will discuss this with you and will arrange a time to visit that suits you.

What happens after the interview?

If you agree, the interviewer will arrange for a qualified nurse to visit at a time that is convenient for you. This is so that some measurements can be taken.

The nurse will measure blood pressure (for those aged 5+), waist and hip measurement (for those aged 11+). For everyone aged 4 and over the nurse will ask for consent to collect a sample of saliva (spit). For adults (aged 16+) the nurse will also ask for consent to collect a blood sample.

The nurse will have to ask you for written permission before he/she can take a sample of saliva or blood. You are of course free to choose not to give a sample, even if you are willing to help the nurse with everything else.

The analysis of all the measurements and samples will tell us a lot about the health of the population. During the visit, the nurse will be able to explain the importance of these measurements and answer any questions you may have.

Do I get anything from the survey?

Yes. We can give you a record of your measurements and blood sample results. If you agree, we will also send your blood pressure and blood sample results to your GP. She/He will be able to interpret them for you and give you advice if necessary. Your GP may also want to include the results in any future report about you.

Other benefits from the survey will be indirect and will come from any improvements in health and in health services which result from the survey.

Is the survey confidential?

Yes. We take great care to protect the confidentiality of the information people give us. We take careful steps to ensure that the information is secure at all times. The survey is anonymous - results will not be presented in a form which reveals your identity. This will only be known to certain members of the NatCen and UCL research team. The information collected is used for research and statistical purposes only. It is dealt with according to the 1998 Data Protection Act.

We would only have to tell someone else what you say if, during the interview, you tell us about possible harm to yourself or others. If you agree, your name, address and date of birth, but no other information, will be passed to the NHS Central Register. This would help if we wanted to follow up your health status in the future.

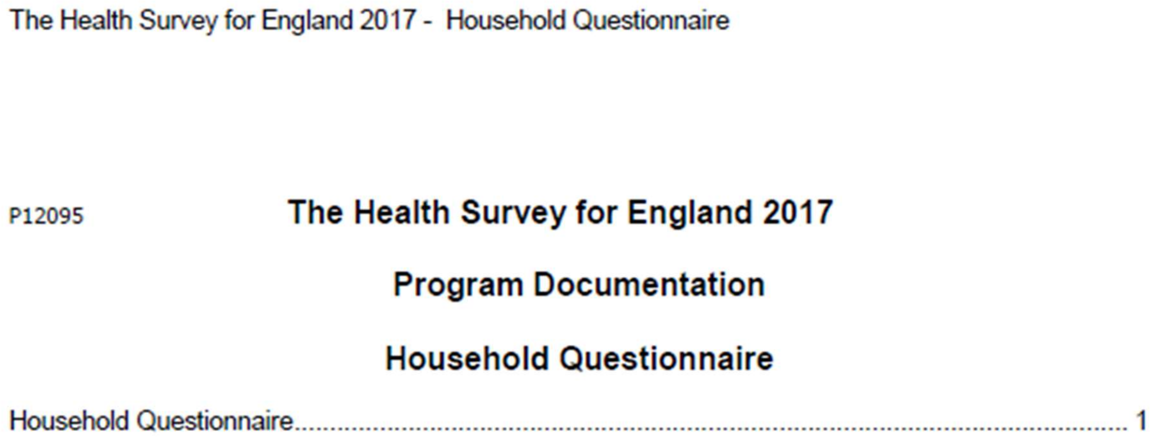
How will the data be used?

The answers you give are put together with the answers collected from thousands of other people across England and the survey findings are published in a report. The data we collect as part of the survey is also useful to lots of other people. We will make a copy of the anonymous dataset available in the UK Data Archive for people to use for research, teaching or personal educational development. This won't include any information that could be used to identify you. You can find out more about the UK Data Archive at https://www.ukdataservice.ac.uk/about-us. Researchers can also apply to request more detailed data. The HSCIC and NatCen will carefully review all requests to make sure we protect your privacy. We would never give anyone personal details like your name or address and data would only be used for research and statistical purposes.

Will I be able to see the survey results?

Yes. Each year a report is published about Health Survey results. You can find the reports on the Health and Social Care Information Centre's website: http://content.digital.nhs.uk/healthsurveyengland

Appendix I: Study 2 Sample of Health Survey for England 2017 Nurse Interview Prompts



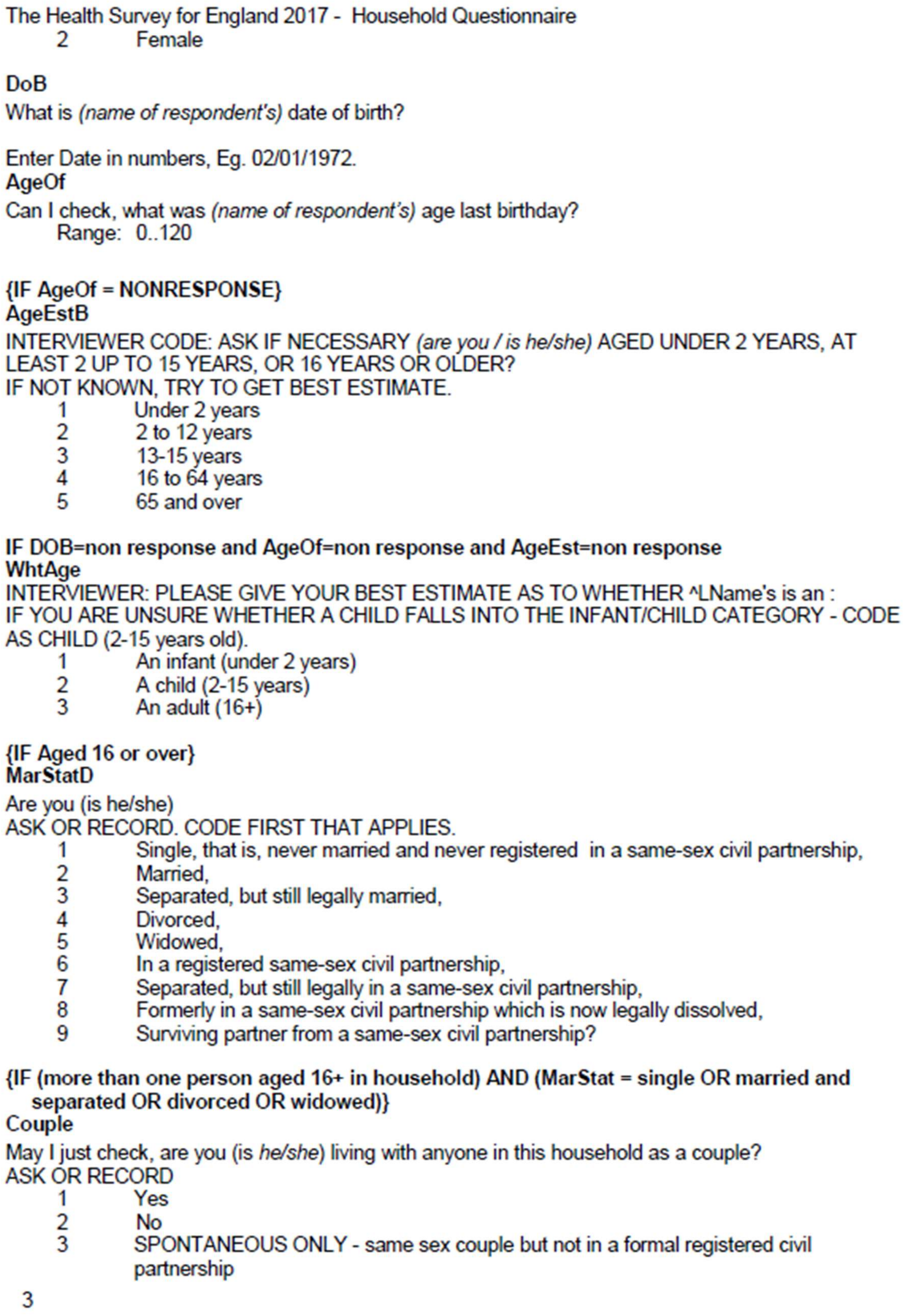
The Health Survey for England 2017 - Household Questionnaire

P12095

The Health Survey for England 2017

Program Documentation

Household Questionnaire



2 Female

DoB

What is *(name of respondent's)* date of birth?

Enter Date in numbers, Eg. 02/01/1972.

AgeOf

Can I check, what was *(name of respondent's)* age last birthday?

Range: 0..120

{IF AgeOf = NONRESPONSE}

AgeEstB

INTERVIEWER CODE: ASK IF NECESSARY *(are you / is he/she)* AGED UNDER 2 YEARS, AT LEAST 2 UP TO 15 YEARS, OR 16 YEARS OR OLDER?

IF NOT KNOWN, TRY TO GET BEST ESTIMATE.

1 Under 2 years
2 2 to 12 years
3 13-15 years
4 16 to 64 years
5 65 and over

IF DOB=non response and AgeOf=non response and AgeEst=non response

WhtAge

INTERVIEWER: PLEASE GIVE YOUR BEST ESTIMATE AS TO WHETHER ^LName's is an :

IF YOU ARE UNSURE WHETHER A CHILD FALLS INTO THE INFANT/CHILD CATEGORY - CODE AS CHILD (2-15 years old).

1 An infant (under 2 years)
2 A child (2-15 years)
3 An adult (16+)

{IF Aged 16 or over}

MarStatD

Are you (is he/she)

ASK OR RECORD. CODE FIRST THAT APPLIES.

1 Single, that is, never married and never registered in a same-sex civil partnership,
2 Married,
3 Separated, but still legally married,
4 Divorced,
5 Widowed,
6 In a registered same-sex civil partnership,
7 Separated, but still legally in a same-sex civil partnership,
8 Formerly in a same-sex civil partnership which is now legally dissolved,
9 Surviving partner from a same-sex civil partnership?

{IF (more than one person aged 16+ in household) AND (MarStat = single OR married and separated OR divorced OR widowed)}

Couple

May I just check, are you (is *he/she*) living with anyone in this household as a couple?

ASK OR RECORD

1 Yes
2 No
3 SPONTANEOUS ONLY - same sex couple but not in a formal registered civil partnership

Chronic Pain

ASK ALL AGE 16+

INTERVIEWER: Now follows some questions about pain.
AnyPain
Are you **currently** troubled by **pain or discomfort**, either all the time or on and off?

1	Yes
2	No

IF 'No' END

{IF 'Yes' AT AnyPain}
More3m
Have you had this **pain or discomfort** for more than 3 months?

1	Yes
2	No

IF 'No' END

{IF'Yes'AT More3m}
SitePain
Where is this pain or discomfort?
CODE ALL THAT APPLY
PROBE: Where else?

1	Back pain
2	Neck or shoulder pain
3	Headache, facial or dental pain
4	Stomach ache or abdominal pain
5	Pain in your arms, hands, hips, legs or feet
6	Chest pain
7	Other pain

[Info screen] The next questions ask you to rate the intensity of your pain on a scale from 0 to 10, where 0 represents no pain and 10 represents pain as bad as it could be.

PainNow
How would you rate your pain **right now**? Please include the effects of any medication taken
REPEAT IF NECESSARY: On a scale from 0 to 10 where 0 is no pain and 10 is pain as bad as it could be
0….10

WorstP
In the last three months, how would you rate your **worst** pain? Please include the effects of any medication taken
REPEAT IF NECESSARY: On a scale from 0 to 10 where 0 is no pain and 10 is pain as bad as it could be
0….10

UsualP
And in the last three months, **on average**, how would you rate your pain? That is, your usual pain at times you were in pain. Please include the effects of any medication taken
REPEAT IF NECESSARY: On a scale from 0 to 10 where 0 is no pain and 10 is pain as bad as it could be
0….10

SHOW CARD C1
ImpactP
In the last 3 months, how many days did your pain keep you from doing your usual activities like work, school or housework?

0	None
1	1 day
2	2 days
3	3-4 days
4	5-6 days
5	7-10 days
6	11-14 days
7	15-24 days
8	25-30 days
9	31-60 days
10	61-75 days
11	76-90 days

DailyP
In the past three months how much has the pain interfered with your **daily activities**? Tell me on a scale of 0-10, where 0 is “no interference” and 10 is "unable to carry on any activities"

0….10

SocialP
In the last three months, how much has this pain changed your ability to take part in **recreational, social and family activities**? Tell me on a scale of 0-10, where 0 is “no change” and 10 is "extreme change"

0….10

WorkP
In the last three months, how much has this pain changed your **ability to work**, including housework?
REPEAT IF NECESSARY: Use the same scale, where 0 is "no change" and 10 is "extreme change"

0…..10

ENDIF

SeenP
SHOW CARD C2
Have you seen any of the professionals or advisors on this card about support or help to manage your pain?
CODE ALL THAT APPLY
PROBE: Which others

1 Your GP
2 Nurse at your GP practice
3 Specialist pain services such as a doctor, nurse or physiotherapist at a hospital or clinic
4 Clinical psychologist
5 Osteopath or chiropractor
6 Acupuncturist
7 Pharmacist
8 Other – please specify)
9 None of these

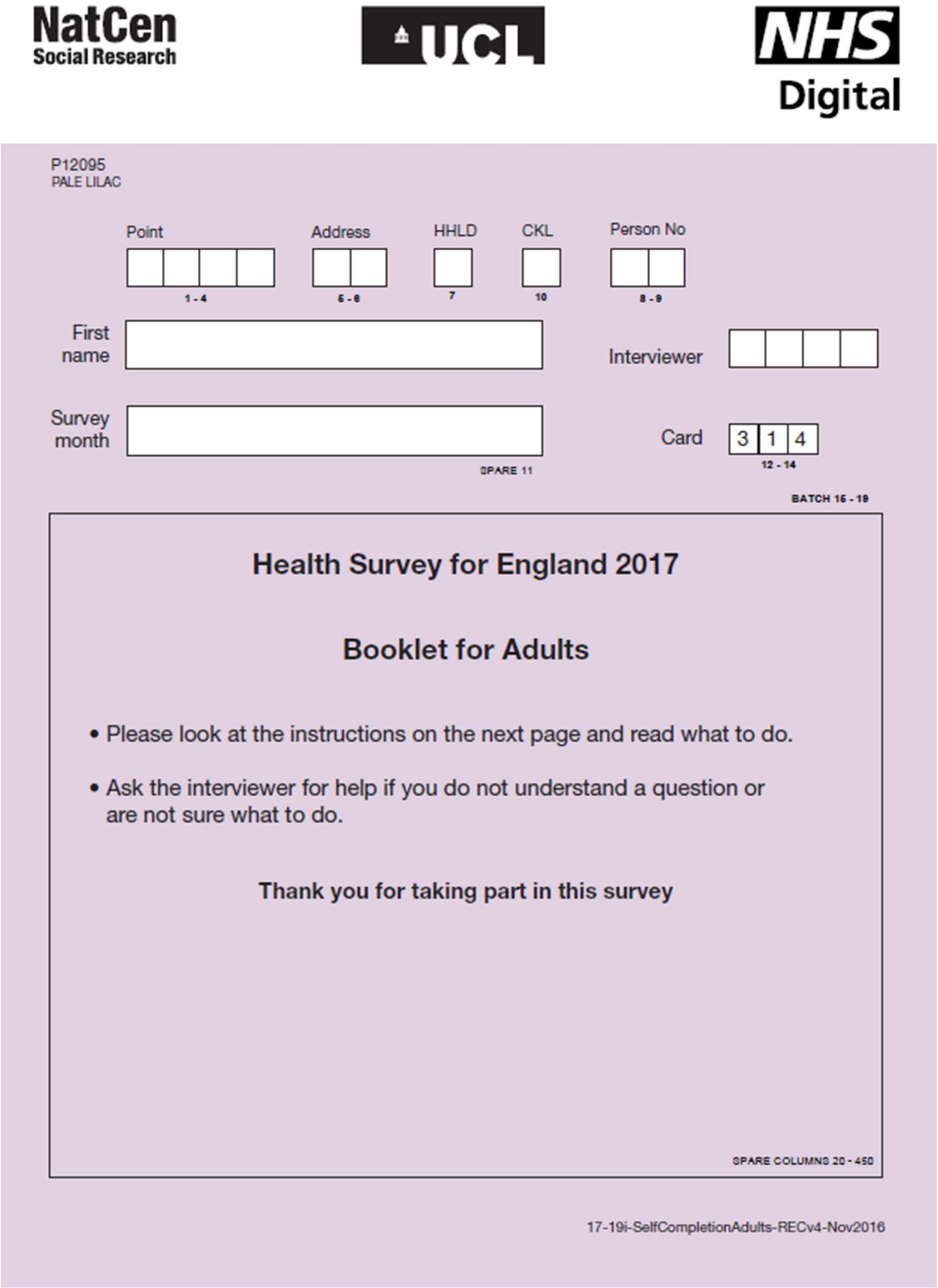
IF SeenP=Other, ASK
SeenPX
Please describe who
Open response

SHOWCARD C3
SupGrp
This card shows some things that people may be involved with to help manage their pain. Have you attended any of these for your pain? PROBE: Which others?
CODE ALL THAT APPLY

1 Patient support group
2 Pain management programme
3 Psychological programme such as Cognitive Behavioural Therapy
4 None of these

ENDIF

Appendix J: Health Survey for England 2017 Questionnaire Booklet for Adults



NatCen Social Research

UCL

NHS Digital

P12095
PALE LILAC

Point ☐☐☐☐ 1 - 4
Address ☐☐ 5 - 6
HHLD ☐ 7
CKL ☐ 10
Person No ☐☐ 8 - 9

First name ☐

Interviewer ☐☐☐☐

Survey month ☐
SPARE 11

Card 3 1 4
12 - 14

BATCH 15 - 19

Health Survey for England 2017

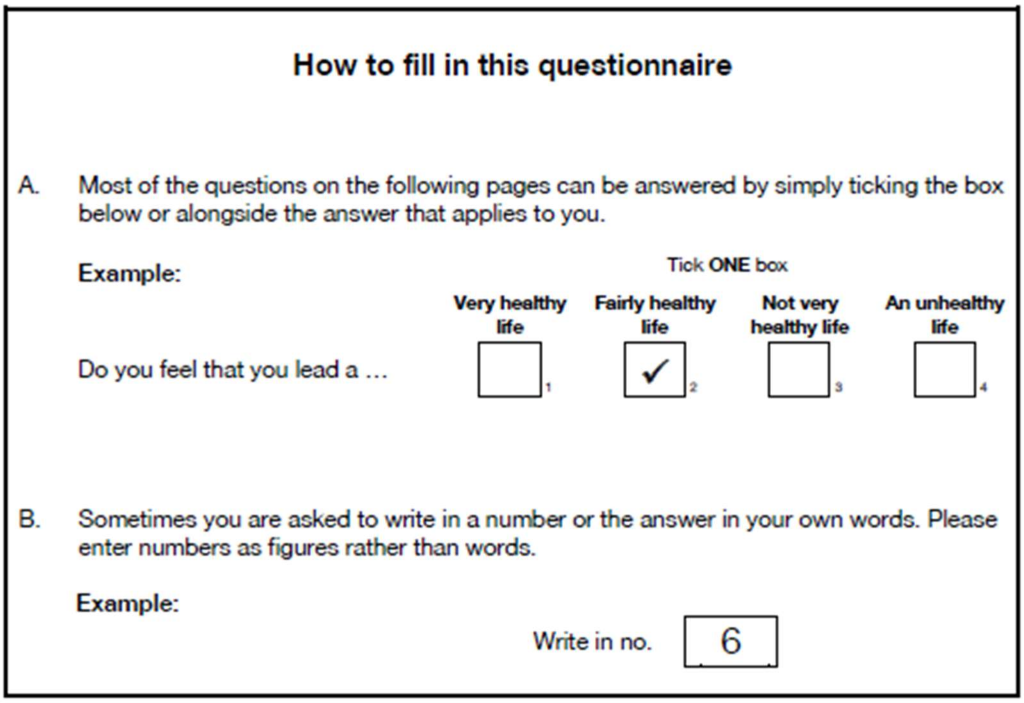
Booklet for Adults

- Please look at the instructions on the next page and read what to do.
- Ask the interviewer for help if you do not understand a question or are not sure what to do.

Thank you for taking part in this survey

SPARE COLUMNS 20 - 450

17-19i-SelfCompletionAdults-RECv4-Nov2016



How to fill in this questionnaire

A. Most of the questions on the following pages can be answered by simply ticking the box below or alongside the answer that applies to you.

Example:

Tick **ONE** box

	Very healthy life	**Fairly healthy life**	**Not very healthy life**	**An unhealthy life**
Do you feel that you lead a …	☐ 1	☑ 2	☐ 3	☐ 4

B. Sometimes you are asked to write in a number or the answer in your own words. Please enter numbers as figures rather than words.

Example:

Write in no. 6

General health today

Now we would like to know how your health is **today.**

Please answer **ALL** the questions. Under each heading, please tick the ONE box that best describes your health **TODAY.**

Q69 **Mobility**

Tick ONE box

I have no problems in walking about ☐1 451

I have slight problems in walking about ☐2

I have moderate problems in walking about ☐3

I have severe problems in walking about ☐4

I am unable to walk about ☐5

Q70 **Self-Care**

Tick ONE box

I have no problems washing or dressing myself ☐1 452

I have slight problems washing or dressing myself ☐2

I have moderate problems washing or dressing myself ☐3

I have severe problems washing or dressing myself ☐4

I am unable to wash or dress myself ☐5

Q71 **Usual activities** *(e.g. work, study, housework, family or leisure activities)*

Tick ONE box

I have no problems doing my usual activities ☐1 453

I have slight problems doing my usual activities ☐2

I have moderate problems doing my usual activities ☐3

I have severe problems doing my usual activities ☐4

I am unable to do my usual activities ☐5

Q72 **Pain/Discomfort**

Tick ONE box

I have no pain or discomfort ☐ 1
I have slight pain or discomfort ☐ 2 454
I have moderate pain or discomfort ☐ 3
I have severe pain or discomfort ☐ 4
I have extreme pain or discomfort ☐ 5

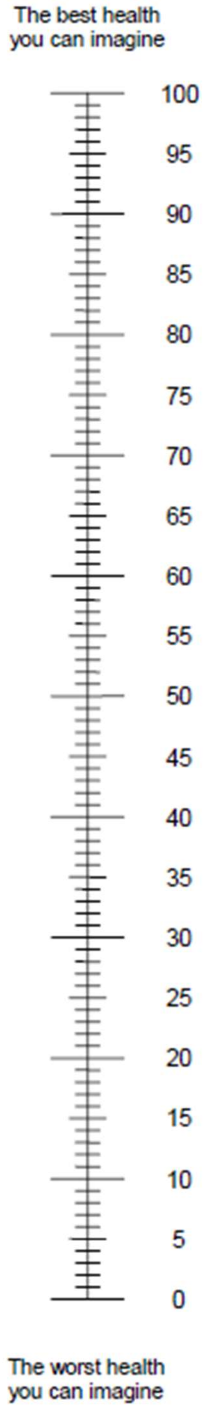
Q73 **Anxiety/Depression**

Tick ONE box

I am not anxious or depressed ☐ 1
I am slightly anxious or depressed ☐ 2 455
I am moderately anxious or depressed ☐ 3
I am severely anxious or depressed ☐ 4
I am extremely anxious or depressed ☐ 5

Q74

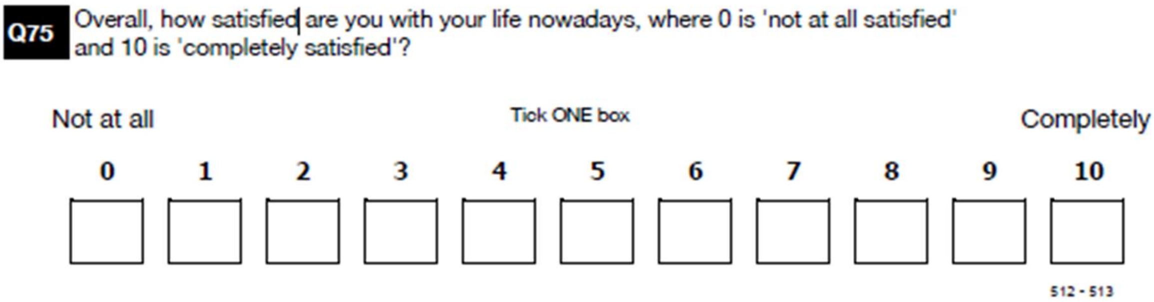
- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the <u>best</u> health you can imagine.
  0 means the <u>worst</u> health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.



YOUR HEALTH TODAY = ☐

456 - 458

SPARE COLUMNS 459 - 511



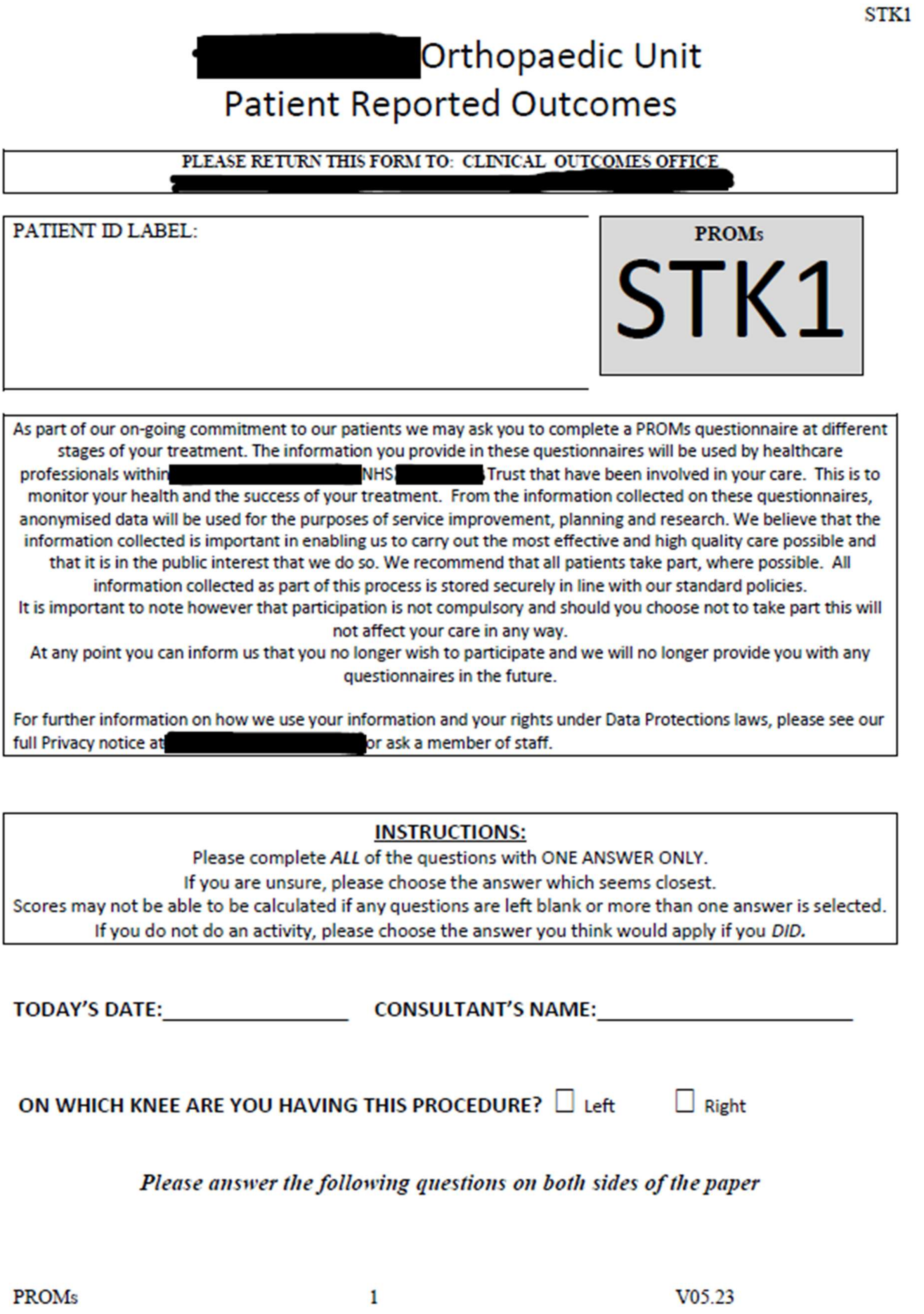
Q75 Overall, how satisfied are you with your life nowadays, where 0 is 'not at all satisfied' and 10 is 'completely satisfied'?

Not at all Tick ONE box Completely

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

512 - 513

Appendix K. Study 3 Pre-Operative Patient Questionnaire Packs and Information Sheet



STK1

[redacted] Orthopaedic Unit
Patient Reported Outcomes

PLEASE RETURN THIS FORM TO: CLINICAL OUTCOMES OFFICE
[redacted]

PATIENT ID LABEL:

PROMs
STK1

As part of our on-going commitment to our patients we may ask you to complete a PROMs questionnaire at different stages of your treatment. The information you provide in these questionnaires will be used by healthcare professionals within [redacted] NHS [redacted] Trust that have been involved in your care. This is to monitor your health and the success of your treatment. From the information collected on these questionnaires, anonymised data will be used for the purposes of service improvement, planning and research. We believe that the information collected is important in enabling us to carry out the most effective and high quality care possible and that it is in the public interest that we do so. We recommend that all patients take part, where possible. All information collected as part of this process is stored securely in line with our standard policies.
It is important to note however that participation is not compulsory and should you choose not to take part this will not affect your care in any way.
At any point you can inform us that you no longer wish to participate and we will no longer provide you with any questionnaires in the future.

For further information on how we use your information and your rights under Data Protections laws, please see our full Privacy notice at [redacted] or ask a member of staff.

INSTRUCTIONS:

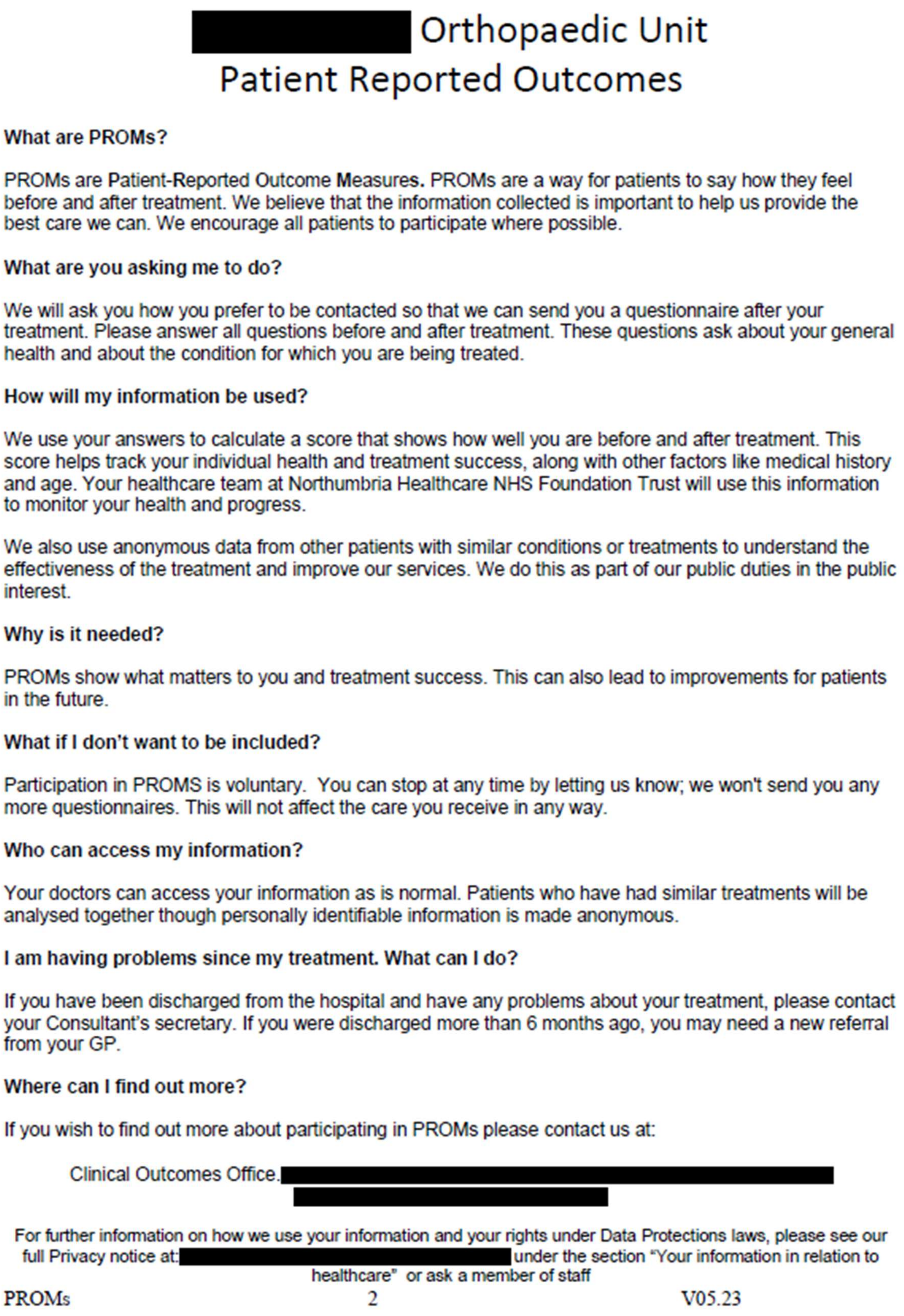
Please complete *ALL* of the questions with ONE ANSWER ONLY.
If you are unsure, please choose the answer which seems closest.
Scores may not be able to be calculated if any questions are left blank or more than one answer is selected.
If you do not do an activity, please choose the answer you think would apply if you *DID.*

TODAY'S DATE:________________ **CONSULTANT'S NAME:**______________________

ON WHICH KNEE ARE YOU HAVING THIS PROCEDURE? ☐ Left ☐ Right

Please answer the following questions on both sides of the paper

PROMs 1 V05.23



[redacted] Orthopaedic Unit
Patient Reported Outcomes

What are PROMs?

PROMs are Patient-Reported Outcome **M**easures**.** PROMs are a way for patients to say how they feel before and after treatment. We believe that the information collected is important to help us provide the best care we can. We encourage all patients to participate where possible.

What are you asking me to do?

We will ask you how you prefer to be contacted so that we can send you a questionnaire after your treatment. Please answer all questions before and after treatment. These questions ask about your general health and about the condition for which you are being treated.

How will my information be used?

We use your answers to calculate a score that shows how well you are before and after treatment. This score helps track your individual health and treatment success, along with other factors like medical history and age. Your healthcare team at Northumbria Healthcare NHS Foundation Trust will use this information to monitor your health and progress.

We also use anonymous data from other patients with similar conditions or treatments to understand the effectiveness of the treatment and improve our services. We do this as part of our public duties in the public interest.

Why is it needed?

PROMs show what matters to you and treatment success. This can also lead to improvements for patients in the future.

What if I don't want to be included?

Participation in PROMS is voluntary. You can stop at any time by letting us know; we won't send you any more questionnaires. This will not affect the care you receive in any way.

Who can access my information?

Your doctors can access your information as is normal. Patients who have had similar treatments will be analysed together though personally identifiable information is made anonymous.

I am having problems since my treatment. What can I do?

If you have been discharged from the hospital and have any problems about your treatment, please contact your Consultant's secretary. If you were discharged more than 6 months ago, you may need a new referral from your GP.

Where can I find out more?

If you wish to find out more about participating in PROMs please contact us at:

Clinical Outcomes Office.[redacted]

For further information on how we use your information and your rights under Data Protections laws, please see our full Privacy notice at:[redacted] under the section "Your information in relation to healthcare" or ask a member of staff

PROMs 2 V05.23

[redacted] Orthopaedic Unit
Patient Reported Outcomes

Patient Information Questionnaire

We now have a system which allows you to complete future PROMs questionnaires online if preferred. These are sent at approximately 6-months and 1-year after your surgery.

If you would like us to send you a link to complete your answers online please give us your details below. You may select more than one if wanted. If you choose neither, we will post a paper form to your home as normal.

E-mail link to online questionnaire ☐ **SMS** link to online questionnaire ☐

E-mail address (CAPITAL LETTERS for clarity) ______________________________

Mobile phone number ____

Q1. Do you smoke?

☐ Never smoked ☐ Current smoker ☐ Ex-smoker

Q2. Do you vape or use an E-Cigarette (include all types of tobacco) ?

☐ Never ☐ Current vaper/e-cig user ☐ Former vaper/e-cig user

Q3. Please tell us your height and weight:

What is your height? You can use imperial (ft. & in.) or metric (cm).

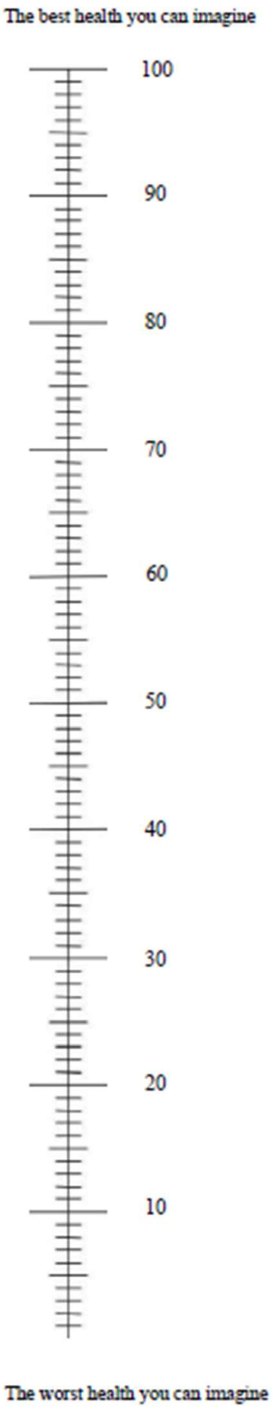
Height __________ Feet and inches ☐ Centimetres ☐

What is your weight? You can use imperial (st. & lbs.) or metric (kg).

Weight __________ Stones and pounds ☐ Kilogrammes ☐

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the <u>best</u> health you can imagine. 0 means the <u>worst</u> health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY
- Now, please write the number you marked on the scale in the box below

YOUR HEALTH TODAY = ☐



[redacted] Knee Unit
Patient Reported Outcomes

This section asks about you and your health in general.

Under each heading, please tick the ONE box that best describes your health TODAY

Mobility

☐ I have no problems in walking about
☐ I have some problems in walking about
☐ I am confined to bed

Self- care (i.e. washing and dressing)

☐ I have no problems with self-care
☐ I have some problems self-care
☐ I am unable to wash or dress myself

Usual activities (i.e. work, study, housework, family or leisure activities)

☐ I have no problems with performing my usual activities
☐ I have some problems with performing my usual activities
☐ I am unable to perform my usual activities

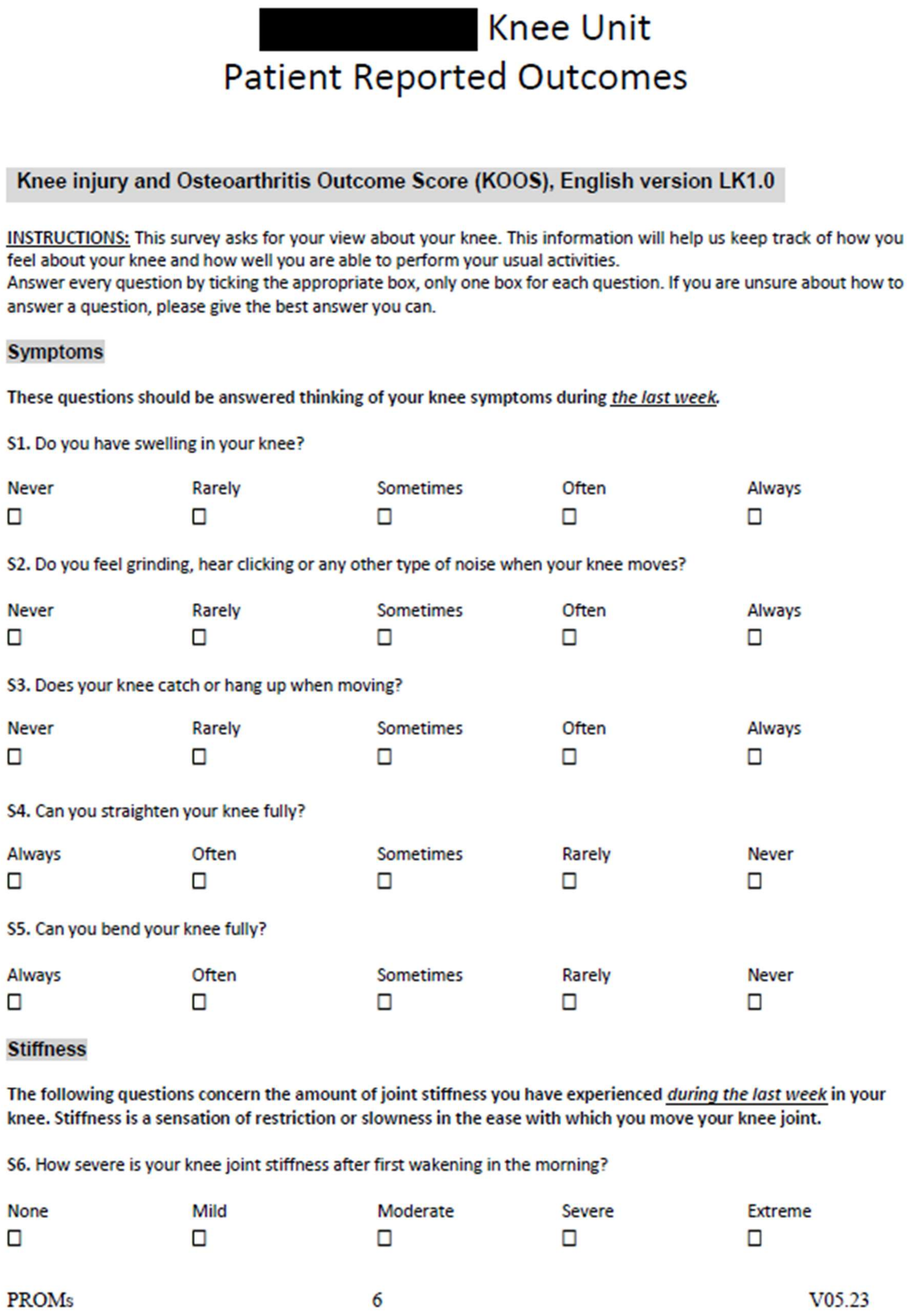
Pain/Discomfort

☐ I have no pain or discomfort
☐ I have moderate pain or discomfort
☐ I have extreme pain or discomfort

Anxiety/Depression

☐ I am not anxious or depressed
☐ I am moderately anxious or depressed
☐ I am extremely anxious or depressed

OFFICE USE ONLY **EQ-5D 3L Index (TTO) score:**



[redacted] Knee Unit
Patient Reported Outcomes

Knee injury and Osteoarthritis Outcome Score (KOOS), English version LK1.0

INSTRUCTIONS: This survey asks for your view about your knee. This information will help us keep track of how you feel about your knee and how well you are able to perform your usual activities.
Answer every question by ticking the appropriate box, only one box for each question. If you are unsure about how to answer a question, please give the best answer you can.

Symptoms

These questions should be answered thinking of your knee symptoms during *the last week*.

S1. Do you have swelling in your knee?

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐

S2. Do you feel grinding, hear clicking or any other type of noise when your knee moves?

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐

S3. Does your knee catch or hang up when moving?

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐

S4. Can you straighten your knee fully?

Always	Often	Sometimes	Rarely	Never
☐	☐	☐	☐	☐

S5. Can you bend your knee fully?

Always	Often	Sometimes	Rarely	Never
☐	☐	☐	☐	☐

Stiffness

The following questions concern the amount of joint stiffness you have experienced *during the last week* in your knee. Stiffness is a sensation of restriction or slowness in the ease with which you move your knee joint.

S6. How severe is your knee joint stiffness after first wakening in the morning?

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

[redacted] Knee Unit
Patient Reported Outcomes

S7. How severe is your knee stiffness after sitting, lying or resting ***later in the day***?

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

Pain

P1. How often do you experience knee pain?

Never	Monthly	Weekly	Daily	Always
☐	☐	☐	☐	☐

What amount of knee pain have you experienced *the last week* during the following activities?

P2. Twisting/pivoting on your knee

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

P3. Straightening knee fully

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

P4. Bending knee fully

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

P5. Walking on flat surface

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

P6. Going up or down stairs

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

P7. At night while in bed

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

[redacted] Knee Unit
Patient Reported Outcomes

P8. Sitting or lying

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

P9. Standing upright

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

Function, daily living

The following questions concern your physical function. By this we mean your ability to move around and to look after yourself. For each of the following activities please indicate the degree of difficulty you have experienced *<u>in the last week</u>* due to your knee.

A1. Descending stairs

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A2. Ascending stairs

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

For each of the following activities please indicate the degree of difficulty you have experienced in *<u>the last week</u>* due to your knee.

A3. Rising from sitting

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A4. Standing

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A5. Bending to floor/pick up an object

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A6. Walking on flat surface

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

[redacted] Knee Unit
Patient Reported Outcomes

A7. Getting in/out of car

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A8. Going shopping

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A9. Putting on socks/stockings

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A10. Rising from bed

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A11. Taking off socks/stockings

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A12. Lying in bed (turning over, maintaining knee position)

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A13. Getting in/out of bath

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A14. Sitting

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A15. Getting on/off toilet

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

[redacted] Knee Unit
Patient Reported Outcomes

For each of the following activities please indicate the degree of difficulty you have experienced in *the last week* due to your knee.

A16. Heavy domestic duties (moving heavy boxes, scrubbing floors, etc)

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A17. Light domestic duties (cooking, dusting, etc)

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

Function, sports and recreational activities

The following questions concern your physical function when being active on a higher level. The questions should be answered thinking of what degree of difficulty you have experienced *during the last week* due to your knee.

SP1. Squatting

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

SP2. Running

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

SP3. Jumping

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

SP4. Twisting/pivoting on your injured knee

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

SP5. Kneeling

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

[redacted] Knee Unit
Patient Reported Outcomes

Quality of Life

Q1. How often are you aware of your knee problem?

Never	Monthly	Weekly	Daily	Constantly
☐	☐	☐	☐	☐

Q2. Have you modified your life style to avoid potentially damaging activities to your knee?

Not at all	Mildly	Moderately	Severely	Totally
☐	☐	☐	☐	☐

Q3. How much are you troubled with lack of confidence in your knee?

Not at all	Mildly	Moderately	Severely	Extremely
☐	☐	☐	☐	☐

Q4. In general, how much difficulty do you have with your knee?

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

OFFICE USE ONLY KOOS SCORING					
SYMPT	PAIN	ADL	S&R	QOL	TOTAL

Thank you very much for completing this survey.

Please take a moment to check you have answered all questions on both sides of the paper.

THE REMAINING QUESTIONS ARE FOR COMPLETION BY YOUR SURGEON

[redacted] Knee Unit
Patient Reported Outcomes

SURGICAL DETAILS CONT FROM BACK PAGE…

PROCEDURE DETAILS:

PARTIAL MENISCECTOMY **Medial** ☐ **Lateral** ☐

Meniscal Status at end of Procedure

Normal Medial Meniscus ☐ 2/3 remaining ☐ 1/3 remaining ☐ <10% remaining ☐

Normal Lateral Meniscus ☐ 2/3 remaining ☐ 1/3 remaining ☐ <10% remaining ☐

MENISCAL REPAIR **Medial** ☐ **Lateral** ☐

Root ☐ Anterior third ☐ Middle third ☐ Posterior third ☐

Outside-in ☐ Inside-out ☐ All inside ☐

Device: Fastfix ☐ Ultrafix ☐ Air (Stryker) ☐ Sharpshooter ☐

CHONDROPLASTY

Patella ☐ Medial femoral condyle ☐ Lateral femoral condyle ☐

MICROFRACTURE

Patella ☐ Medial femoral condyle ☐ Lateral femoral condyle ☐

MOSAICPLASTY ☐

Patella ☐ Medial femoral condyle ☐ Lateral femoral condyle ☐

PLICA EXCISION ☐ **LATERAL RELEASE PATELLA** ☐

REMOVAL LOOSE BODIES ☐ **SHAVING OF FAT PAD** ☐

ANY OTHER PROCEDURAL DETAILS NOT LISTED :

____

____

____

____

____

[redacted] Knee Unit
Patient Reported Outcomes

SURGEON TO COMPLETE THIS SECTION

DATE OF SURGERY: ___/___/____ **HOSPITAL:** ____________________

OPERATING SURGEON: ______________ **ASSISTANT GRADE:** ________________

LATERALITY: Left ☐ Right ☐

PURPOSE OF ARTHROSCOPY: **DIAGNOSTIC** ☐ **THERAPEUTIC** ☐ **PLANNING** ☐

PLAIN X-RAY PERFORMED:	**YES** ☐	**NO** ☐
DEGENERATIVE ARTHRITIS (on FILM):	YES ☐	NO ☐
PRE-OPERATIVE MRI PERFORMED:	**YES** ☐	**NO** ☐
DEGENERATIVE ARTHRITIS (on MRI):	YES ☐	NO ☐
MENISCAL TEAR (on MRI):	YES ☐	NO ☐

ACL INTEGRITY: **INTACT** ☐ **PARTIAL TEAR** ☐ **COMPLETE TEAR** ☐ **PREVIOUS ACL SURGERY** ☐

ARTICULAR CARTILAGE:

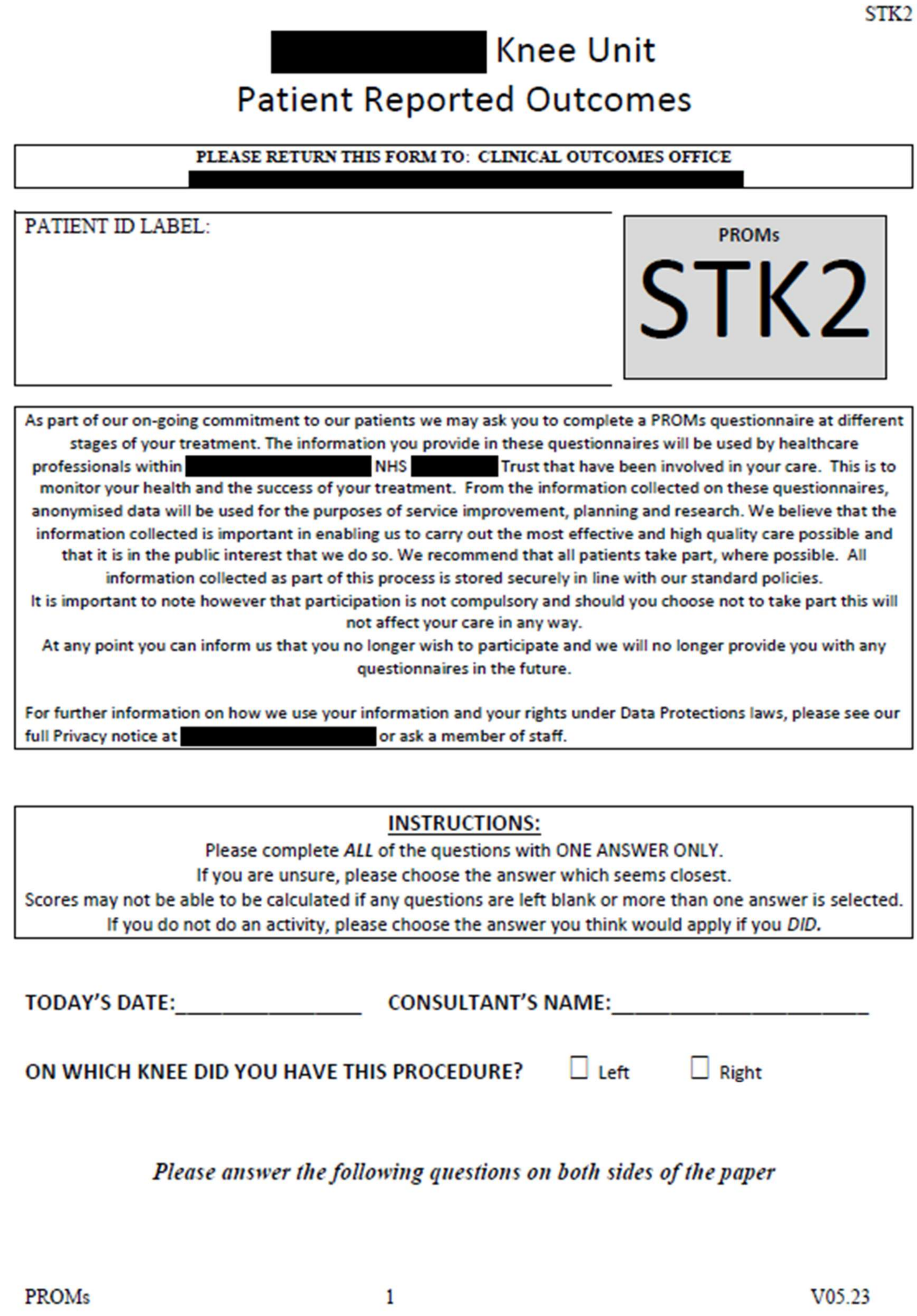
If damage identified please complete the table below with marks in the appropriate box for each location.

Area of damage	Normal	Partial thickness	Full thickness (Grade 4) - FOCAL	Full thickness (Grade 4) - DIFFUSE
Patella				
Trochlea				
Medial femoral condyle				
Medial tibial plateau				
Lateral femoral condyle				
Lateral tibial plateau				

Osteochondral Lesion ☐

Location: ____(free text)

Appendix L: Study 3 Post-Operative Patient Questionnaire Packs



STK2

[redacted] Knee Unit
Patient Reported Outcomes

PLEASE RETURN THIS FORM TO: CLINICAL OUTCOMES OFFICE
[redacted]

PATIENT ID LABEL:

PROMs
STK2

As part of our on-going commitment to our patients we may ask you to complete a PROMs questionnaire at different stages of your treatment. The information you provide in these questionnaires will be used by healthcare professionals within [redacted] NHS [redacted] Trust that have been involved in your care. This is to monitor your health and the success of your treatment. From the information collected on these questionnaires, anonymised data will be used for the purposes of service improvement, planning and research. We believe that the information collected is important in enabling us to carry out the most effective and high quality care possible and that it is in the public interest that we do so. We recommend that all patients take part, where possible. All information collected as part of this process is stored securely in line with our standard policies.
It is important to note however that participation is not compulsory and should you choose not to take part this will not affect your care in any way.
At any point you can inform us that you no longer wish to participate and we will no longer provide you with any questionnaires in the future.

For further information on how we use your information and your rights under Data Protections laws, please see our full Privacy notice at [redacted] or ask a member of staff.

INSTRUCTIONS:

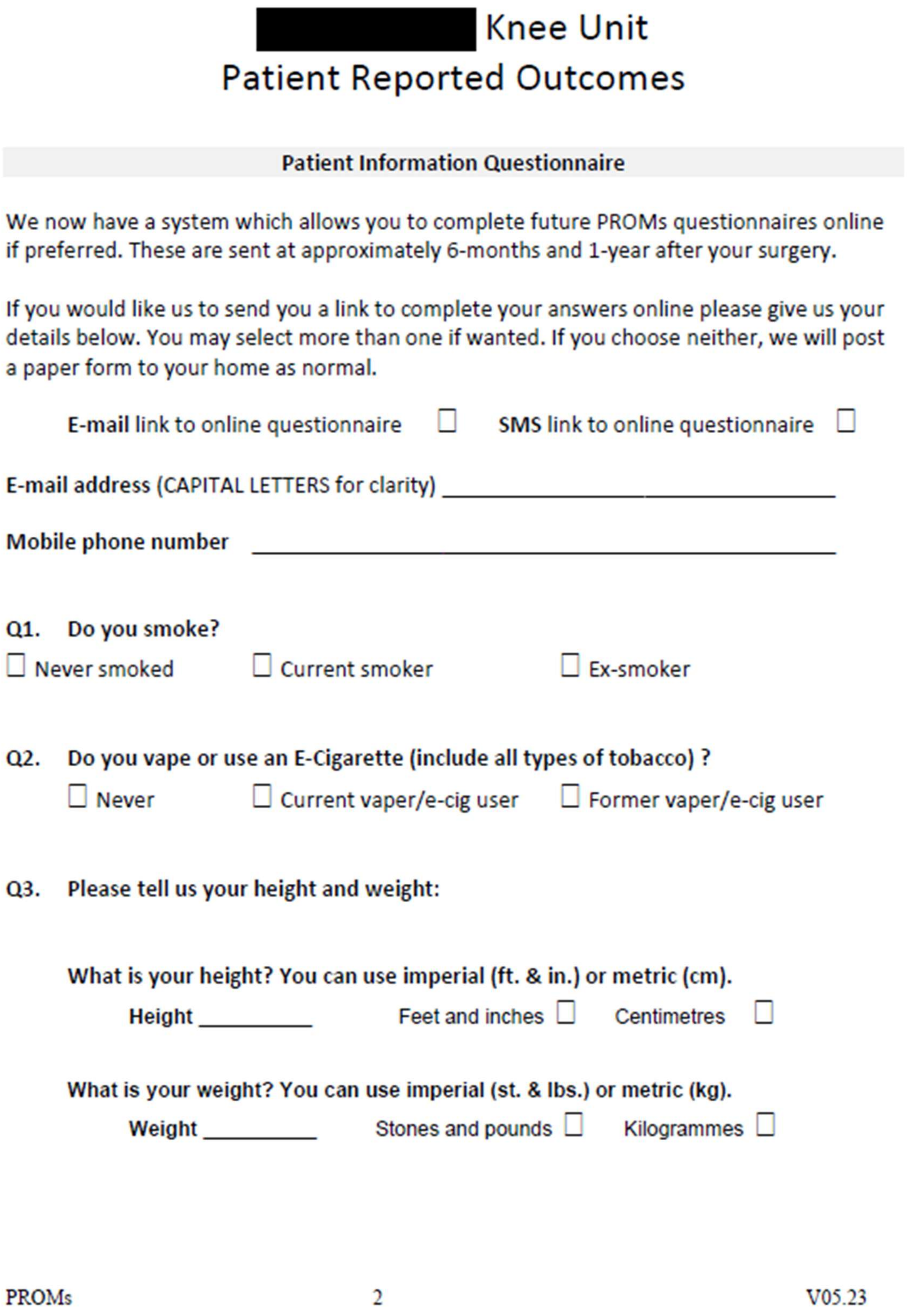
Please complete *ALL* of the questions with ONE ANSWER ONLY.
If you are unsure, please choose the answer which seems closest.
Scores may not be able to be calculated if any questions are left blank or more than one answer is selected.
If you do not do an activity, please choose the answer you think would apply if you *DID.*

TODAY'S DATE:_______________ **CONSULTANT'S NAME:**_____________________

ON WHICH KNEE DID YOU HAVE THIS PROCEDURE? ☐ Left ☐ Right

Please answer the following questions on both sides of the paper

PROMs 1 V05.23



[redacted] Knee Unit
Patient Reported Outcomes

Patient Information Questionnaire

We now have a system which allows you to complete future PROMs questionnaires online if preferred. These are sent at approximately 6-months and 1-year after your surgery.

If you would like us to send you a link to complete your answers online please give us your details below. You may select more than one if wanted. If you choose neither, we will post a paper form to your home as normal.

E-mail link to online questionnaire ☐ **SMS** link to online questionnaire ☐

E-mail address (CAPITAL LETTERS for clarity) ______________________________

Mobile phone number ______________________________

Q1. Do you smoke?

☐ Never smoked ☐ Current smoker ☐ Ex-smoker

Q2. Do you vape or use an E-Cigarette (include all types of tobacco) ?

☐ Never ☐ Current vaper/e-cig user ☐ Former vaper/e-cig user

Q3. Please tell us your height and weight:

What is your height? You can use imperial (ft. & in.) or metric (cm).

Height __________ Feet and inches ☐ Centimetres ☐

What is your weight? You can use imperial (st. & lbs.) or metric (kg).

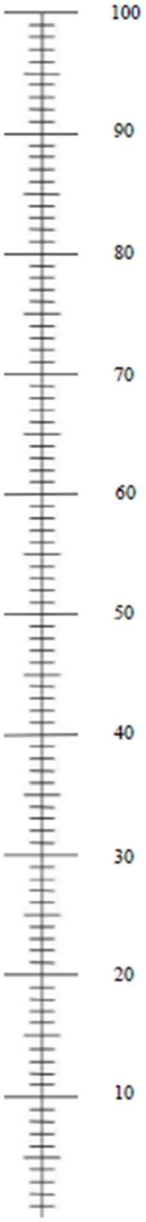
Weight __________ Stones and pounds ☐ Kilogrammes ☐

PROMs 2 V05.23

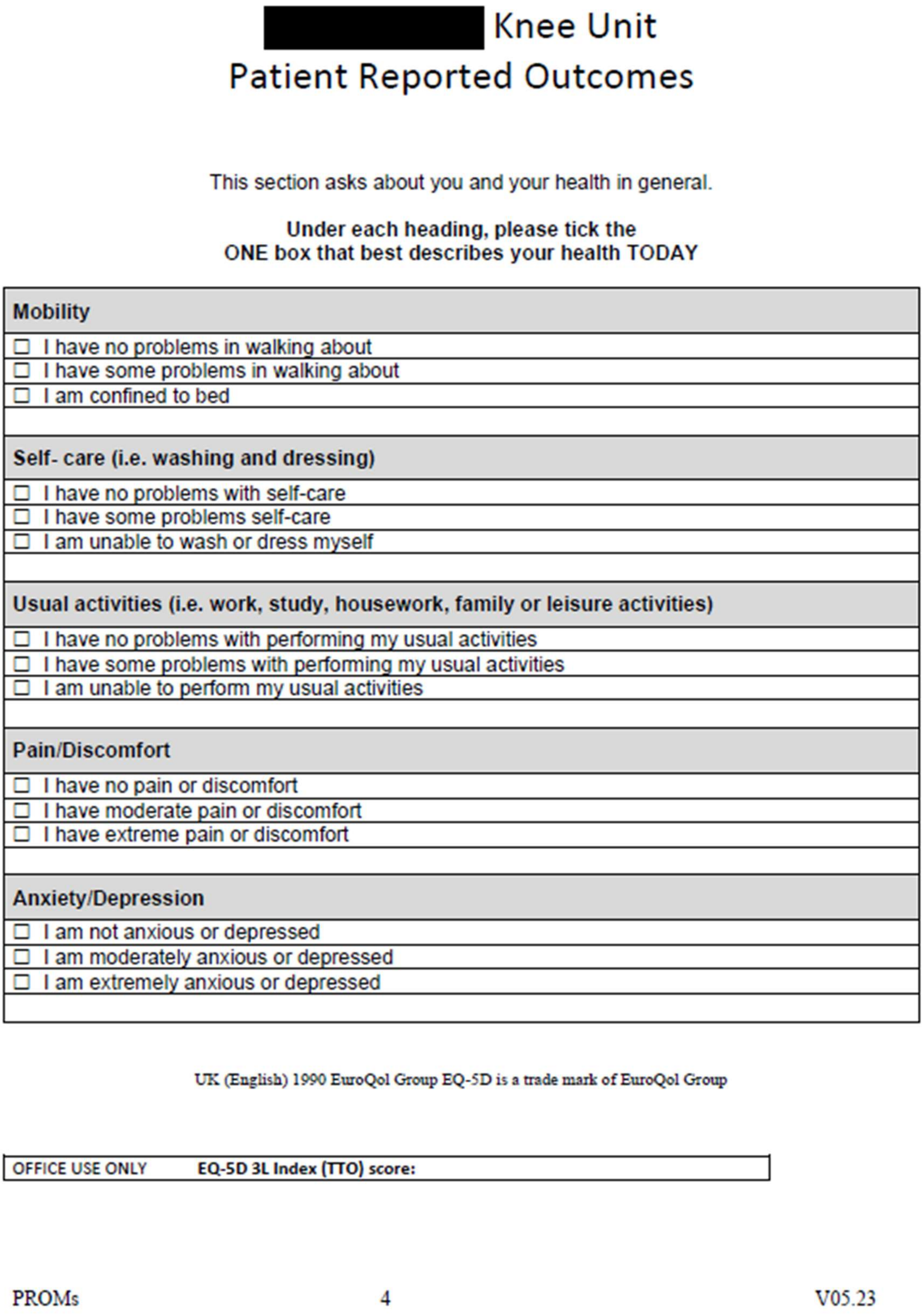
- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the <u>best</u> health you can imagine. 0 means the <u>worst</u> health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY
- Now, please write the number you marked on the scale in the box below

YOUR HEALTH TODAY = ☐

The best health you can imagine



The worst health you can imagine



[redacted] Knee Unit
Patient Reported Outcomes

This section asks about you and your health in general.

Under each heading, please tick the
ONE box that best describes your health TODAY

Mobility

☐ I have no problems in walking about
☐ I have some problems in walking about
☐ I am confined to bed

Self- care (i.e. washing and dressing)

☐ I have no problems with self-care
☐ I have some problems self-care
☐ I am unable to wash or dress myself

Usual activities (i.e. work, study, housework, family or leisure activities)

☐ I have no problems with performing my usual activities
☐ I have some problems with performing my usual activities
☐ I am unable to perform my usual activities

Pain/Discomfort

☐ I have no pain or discomfort
☐ I have moderate pain or discomfort
☐ I have extreme pain or discomfort

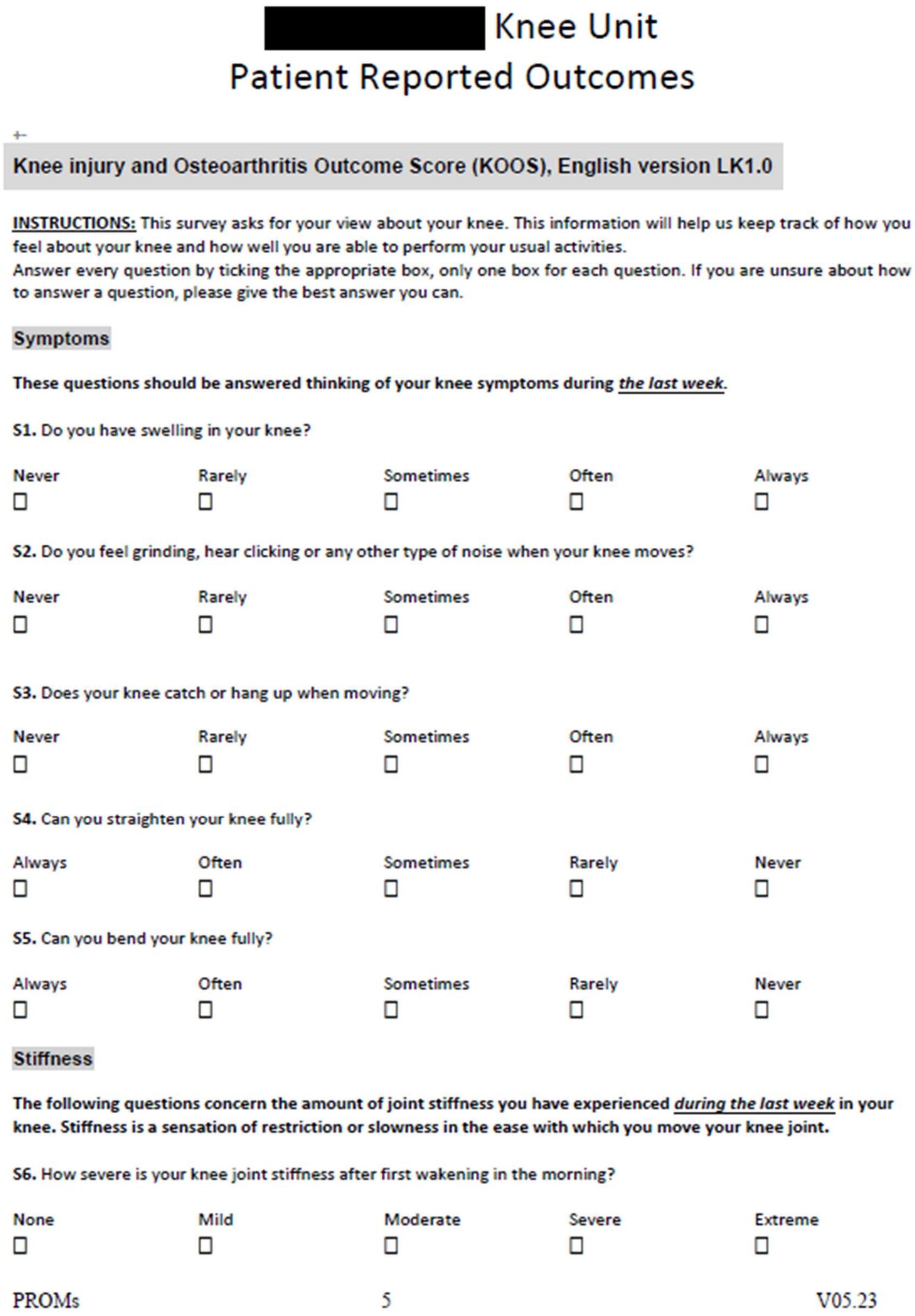
Anxiety/Depression

☐ I am not anxious or depressed
☐ I am moderately anxious or depressed
☐ I am extremely anxious or depressed

UK (English) 1990 EuroQol Group EQ-5D is a trade mark of EuroQol Group

OFFICE USE ONLY	**EQ-5D 3L Index (TTO) score:**

PROMs 4 V05.23



[redacted] Knee Unit
Patient Reported Outcomes

Knee injury and Osteoarthritis Outcome Score (KOOS), English version LK1.0

INSTRUCTIONS: This survey asks for your view about your knee. This information will help us keep track of how you feel about your knee and how well you are able to perform your usual activities.
Answer every question by ticking the appropriate box, only one box for each question. If you are unsure about how to answer a question, please give the best answer you can.

Symptoms

These questions should be answered thinking of your knee symptoms during *the last week*.

S1. Do you have swelling in your knee?

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐

S2. Do you feel grinding, hear clicking or any other type of noise when your knee moves?

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐

S3. Does your knee catch or hang up when moving?

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐

S4. Can you straighten your knee fully?

Always	Often	Sometimes	Rarely	Never
☐	☐	☐	☐	☐

S5. Can you bend your knee fully?

Always	Often	Sometimes	Rarely	Never
☐	☐	☐	☐	☐

Stiffness

The following questions concern the amount of joint stiffness you have experienced *during the last week* in your knee. Stiffness is a sensation of restriction or slowness in the ease with which you move your knee joint.

S6. How severe is your knee joint stiffness after first wakening in the morning?

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

[redacted] Knee Unit
Patient Reported Outcomes

S7. How severe is your knee stiffness after sitting, lying or resting ***later in the day***?

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

Pain

P1. How often do you experience knee pain?

Never	Monthly	Weekly	Daily	Always
☐	☐	☐	☐	☐

What amount of knee pain have you experienced *the last week* during the following activities?

P2. Twisting/pivoting on your knee

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

P3. Straightening knee fully

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

P4. Bending knee fully

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

P5. Walking on flat surface

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

P6. Going up or down stairs

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

P7. At night while in bed

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

P8. Sitting or lying

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

[redacted] Knee Unit
Patient Reported Outcomes

P9. Standing upright

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

Function, daily living

The following questions concern your physical function. By this we mean your ability to move around and to look after yourself. For each of the following activities please indicate the degree of difficulty you have experienced *in the last week* due to your knee.

A1. Descending stairs

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A2. Ascending stairs

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

For each of the following activities please indicate the degree of difficulty you have experienced in *the last week* due to your knee.

A3. Rising from sitting

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A4. Standing

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A5. Bending to floor/pick up an object

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A6. Walking on flat surface

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A7. Getting in/out of car

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

[redacted] Knee Unit
Patient Reported Outcomes

A8. Going shopping

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A9. Putting on socks/stockings

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A10. Rising from bed

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A11. Taking off socks/stockings

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A12. Lying in bed (turning over, maintaining knee position)

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A13. Getting in/out of bath

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A14. Sitting

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

A15. Getting on/off toilet

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

For each of the following activities please indicate the degree of difficulty you have experienced in *__the last week__* due to your knee.

A16. Heavy domestic duties (moving heavy boxes, scrubbing floors, etc)

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

[redacted] Knee Unit
Patient Reported Outcomes

A17. Light domestic duties (cooking, dusting, etc)

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

Function, sports and recreational activities

The following questions concern your physical function when being active on a higher level. The questions should be answered thinking of what degree of difficulty you have experienced *__during the last week__* due to your knee.

SP1. Squatting

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

SP2. Running

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

SP3. Jumping

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

SP4. Twisting/pivoting on your injured knee

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

SP5. Kneeling

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

Quality of Life

Q1. How often are you aware of your knee problem?

Never	Monthly	Weekly	Daily	Constantly
☐	☐	☐	☐	☐

Q2. Have you modified your life style to avoid potentially damaging activities to your knee?

Not at all	Mildly	Moderately	Severely	Totally
☐	☐	☐	☐	☐

[redacted] Knee Unit
Patient Reported Outcomes

Q3. How much are you troubled with lack of confidence in your knee?

Not at all	Mildly	Moderately	Severely	Extremely
☐	☐	☐	☐	☐

Q4. In general, how much difficulty do you have with your knee?

None	Mild	Moderate	Severe	Extreme
☐	☐	☐	☐	☐

OFFICE USE ONLY KOOS SCORING					
SYMPT	PAIN	ADL	S&R	QOL	TOTAL

Final part: Post operative Questionnaire

Q1a. Have you returned to work after your surgery?

- ☐ **I am not working – I did not work prior to surgery for other reasons**
- ☐ **I am not working - I did not work prior to surgery because of the problem for which I had surgery**
- ☐ **I am planning to return to work once I feel able or once my consultant allows me**
- ☐ **I have returned to work**
- ☐ **I am retired**

Q1b. For how many weeks were you off work because of the problem for which you had surgery (leave blank if not applicable)? ____________ Weeks

[redacted] Knee Unit
Patient Reported Outcomes

Q2. How satisfied are you with the outcome of this operation?

☐ Very satisfied ☺☺ ☐ Quite satisfied ☺ ☐ Neither satisfied nor dissatisfied 😐 ☐ Quite dissatisfied ☹ ☐ Very dissatisfied ☹☹

Q3. How likely are you to recommend the <u>hospital</u> to friends/family if they required similar care/treatment?

☐ **Extremely likely** ☐ **Likely** ☐ **Neither likely nor unlikely** ☐ **Unlikely** ☐ **Don't know**

Q4. How likely are you to recommend the <u>consultant</u> to friends/family if they required similar care/treatment?

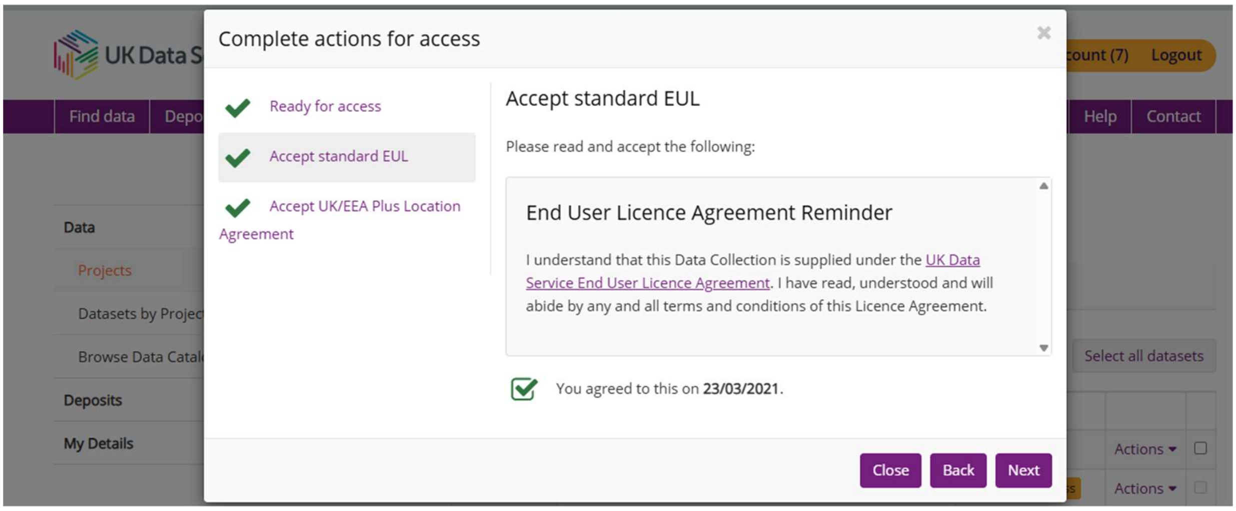
☐ **Extremely likely** ☐ **Likely** ☐ **Neither likely nor unlikely** ☐ **Unlikely** ☐ **Don't know**

Any additional comments or feedback?

General comments will be collated and passed on to your consultant and/or team as appropriate.

If you have any specific concerns or questions, please contact your consultant's secretary for clinical advice or follow up.

Appendix M. Access to the HSE 2017 dataset via the UK Data Service Repository website.



Complete actions for access

✓ Ready for access

✓ Accept standard EUL

✓ Accept UK/EEA Plus Location Agreement

Accept standard EUL

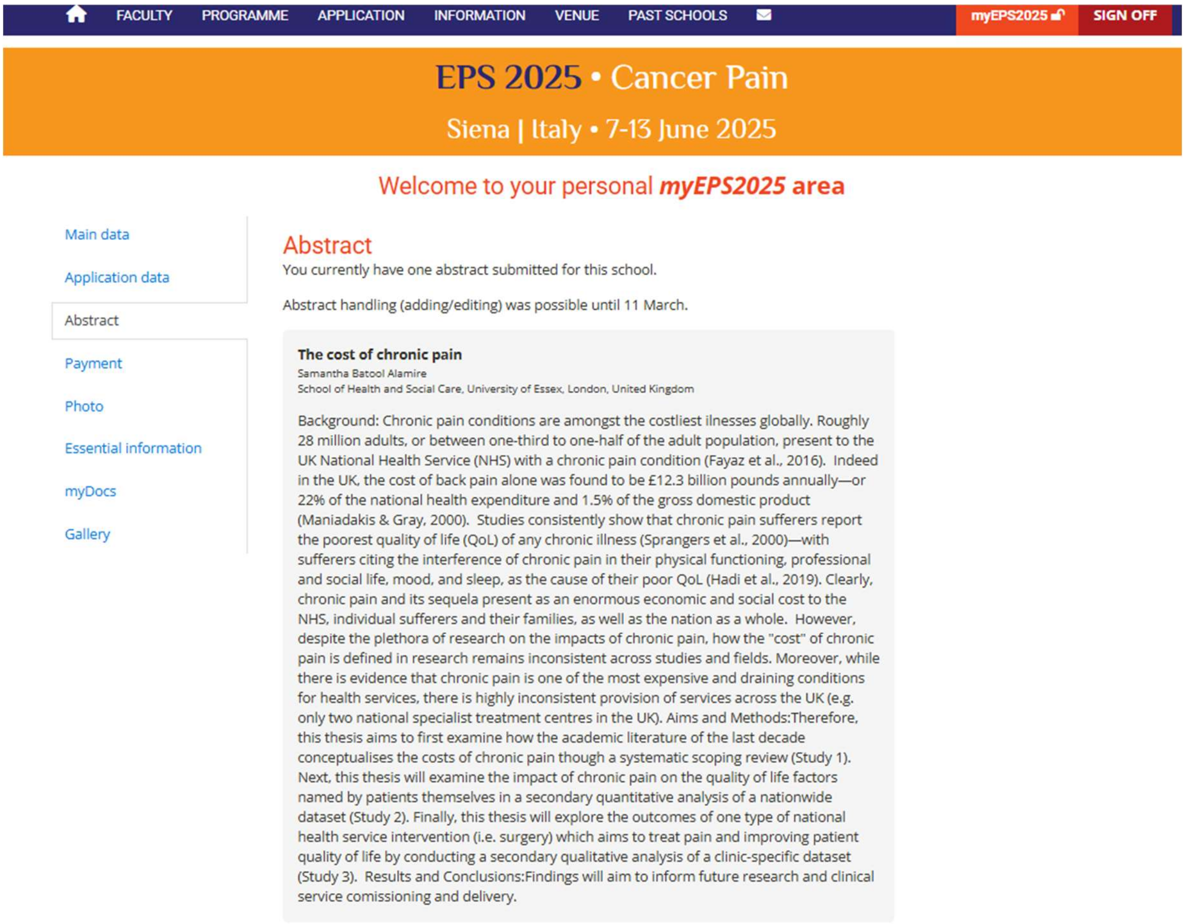
Please read and accept the following:

End User Licence Agreement Reminder

I understand that this Data Collection is supplied under the UK Data Service End User Licence Agreement. I have read, understood and will abide by any and all terms and conditions of this Licence Agreement.

☑ You agreed to this on **23/03/2021**.

Appendix N. Abstract Submitted to European School of Pain, University of Sienna, June 2025.



EPS 2025 • Cancer Pain

Siena | Italy • 7-13 June 2025

Welcome to your personal ***myEPS2025* area**

Abstract

You currently have one abstract submitted for this school.

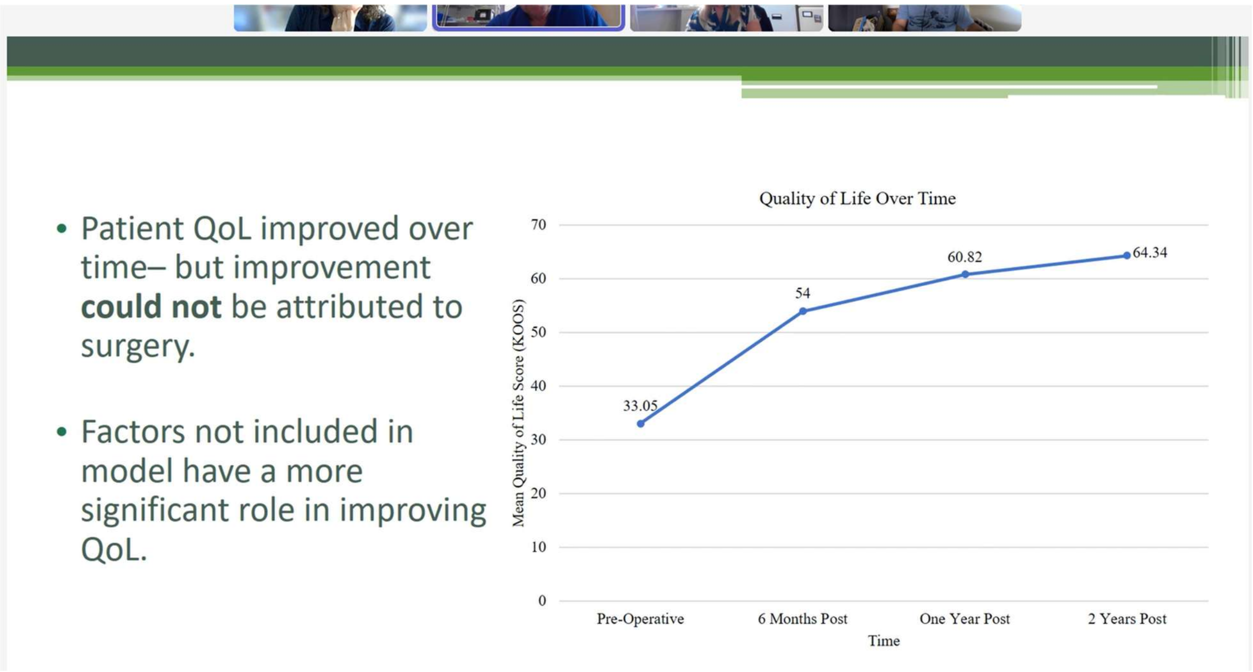
Abstract handling (adding/editing) was possible until 11 March.

The cost of chronic pain

Samantha Batool Alamire
School of Health and Social Care, University of Essex, London, United Kingdom

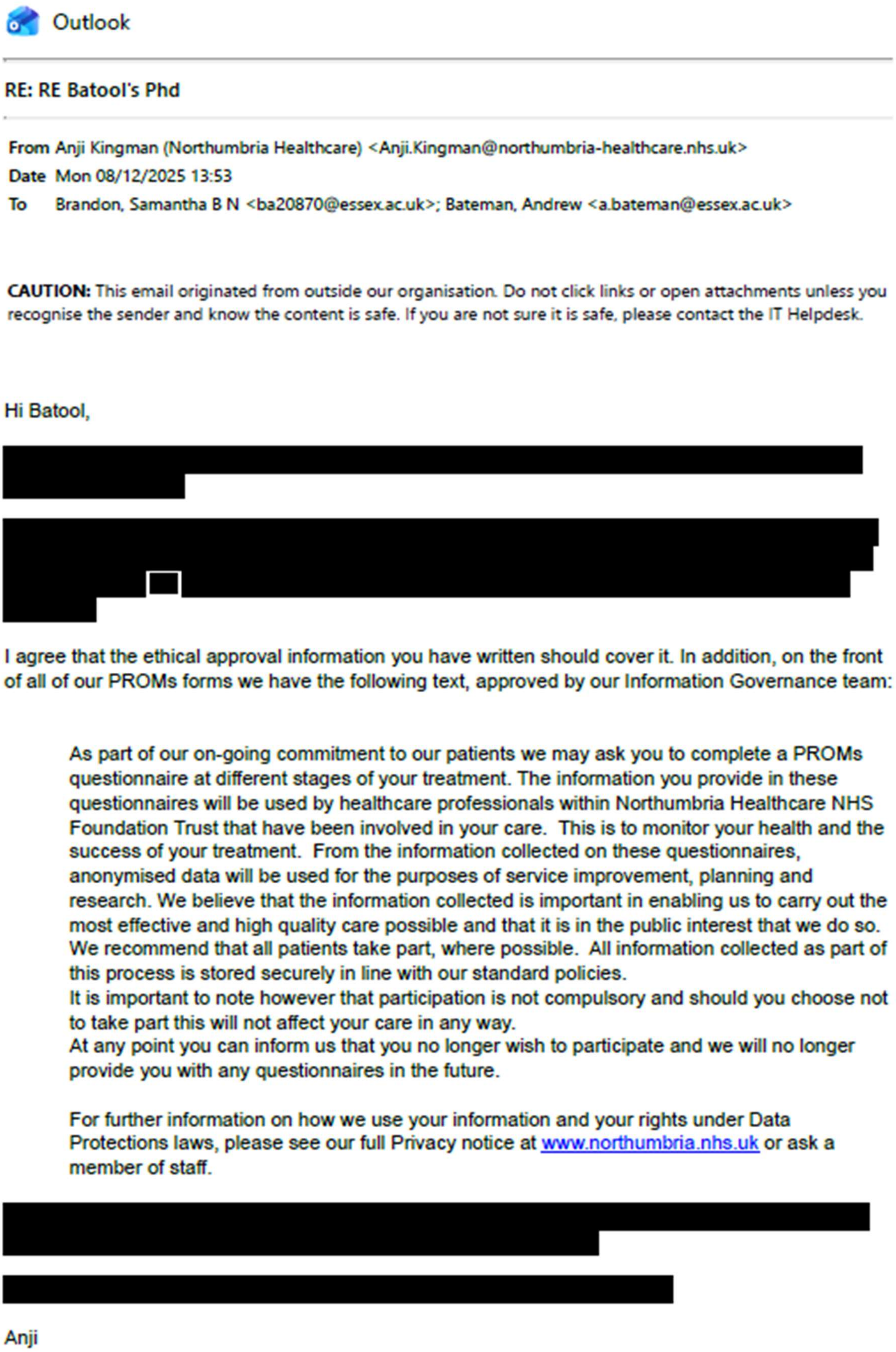
Background: Chronic pain conditions are amongst the costliest ilnesses globally. Roughly 28 million adults, or between one-third to one-half of the adult population, present to the UK National Health Service (NHS) with a chronic pain condition (Fayaz et al., 2016). Indeed in the UK, the cost of back pain alone was found to be £12.3 billion pounds annually—or 22% of the national health expenditure and 1.5% of the gross domestic product (Maniadakis & Gray, 2000). Studies consistently show that chronic pain sufferers report the poorest quality of life (QoL) of any chronic illness (Sprangers et al., 2000)—with sufferers citing the interference of chronic pain in their physical functioning, professional and social life, mood, and sleep, as the cause of their poor QoL (Hadi et al., 2019). Clearly, chronic pain and its sequela present as an enormous economic and social cost to the NHS, individual sufferers and their families, as well as the nation as a whole. However, despite the plethora of research on the impacts of chronic pain, how the "cost" of chronic pain is defined in research remains inconsistent across studies and fields. Moreover, while there is evidence that chronic pain is one of the most expensive and draining conditions for health services, there is highly inconsistent provision of services across the UK (e.g. only two national specialist treatment centres in the UK). Aims and Methods:Therefore, this thesis aims to first examine how the academic literature of the last decade conceptualises the costs of chronic pain though a systematic scoping review (Study 1). Next, this thesis will examine the impact of chronic pain on the quality of life factors named by patients themselves in a secondary quantitative analysis of a nationwide dataset (Study 2). Finally, this thesis will explore the outcomes of one type of national health service intervention (i.e. surgery) which aims to treat pain and improving patient quality of life by conducting a secondary qualitative analysis of a clinic-specific dataset (Study 3). Results and Conclusions:Findings will aim to inform future research and clinical service comissioning and delivery.

Appendix O. Anonymised Screenshot of Results Meeting with Study 3 Team



- Patient QoL improved over time– but improvement **could not** be attributed to surgery.
- Factors not included in model have a more significant role in improving QoL.

Appendix P. NHS Information Governance Approved Text for Participants (Study 3)



RE: RE Batool's Phd

From Anji Kingman (Northumbria Healthcare) <Anji.Kingman@northumbria-healthcare.nhs.uk>
Date Mon 08/12/2025 13:53
To Brandon, Samantha B N <ba20870@essex.ac.uk>; Bateman, Andrew <a.bateman@essex.ac.uk>

CAUTION: This email originated from outside our organisation. Do not click links or open attachments unless you recognise the sender and know the content is safe. If you are not sure it is safe, please contact the IT Helpdesk.

Hi Batool,

[redacted]

[redacted]

I agree that the ethical approval information you have written should cover it. In addition, on the front of all of our PROMs forms we have the following text, approved by our Information Governance team:

> As part of our on-going commitment to our patients we may ask you to complete a PROMs questionnaire at different stages of your treatment. The information you provide in these questionnaires will be used by healthcare professionals within Northumbria Healthcare NHS Foundation Trust that have been involved in your care. This is to monitor your health and the success of your treatment. From the information collected on these questionnaires, anonymised data will be used for the purposes of service improvement, planning and research. We believe that the information collected is important in enabling us to carry out the most effective and high quality care possible and that it is in the public interest that we do so. We recommend that all patients take part, where possible. All information collected as part of this process is stored securely in line with our standard policies.
> It is important to note however that participation is not compulsory and should you choose not to take part this will not affect your care in any way.
> At any point you can inform us that you no longer wish to participate and we will no longer provide you with any questionnaires in the future.
>
> For further information on how we use your information and your rights under Data Protections laws, please see our full Privacy notice at www.northumbria.nhs.uk or ask a member of staff.

[redacted]

[redacted]

Anji

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