



# Epidemiology of chronic pain in the Netherlands

Malgorzata Bala • Trudy Bekkering • Rob Riemsma  
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April 2011

Kleijnen Systematic Reviews Ltd – York – United Kingdom

[www.systematic-reviews.com](http://www.systematic-reviews.com)

Centrum voor pijngeneeskunde van het Erasmus Medisch Centrum – Rotterdam – The Netherlands

[www.erasmusmc.nl/pijn](http://www.erasmusmc.nl/pijn)

Deze uitgave is financieel mogelijk gemaakt door Grünenthal B.V.

De inhoud van het rapport is in volledige onafhankelijkheid tot stand gekomen onder verantwoordelijkheid van de auteurs.



## Table of Contents

Preface.....	5
De epidemiologie van chronische pijn in Nederland.....	7
Executive summary .....	17
Introduction .....	25
Methods .....	27
Results .....	33
Q1. What are the population and demographics?.....	37
Q2. What is the prevalence of chronic pain conditions? .....	41
Q3. What is the incidence of chronic pain conditions? .....	49
Q4. What percentage of chronic pain patients are untreated or inadequately treated .....	57
Q5. How many chronic pain patients present themselves for treatment? .....	65
Q6. How many chronic pain patients get treated, broken down by treatment?.....	75
Q7. What is the compliance of treated chronic pain patients?.....	83
Q8. What is the duration and severity of chronic pain conditions? .....	85
Q9. What are the demographics of chronic pain sufferers? .....	89
Q10. What are the co-morbidities of chronic pain sufferers?.....	95
Q11. How many sufferers have inadequate pain control? .....	101
Q12a. What is the impact of chronic pain on quality of life? .....	105
Q12b. What is the impact of chronic pain on activities of daily living?.....	113
Q12c. What is the impact of chronic pain on depression and other mental illnesses?.....	121
Q12d. What is the impact of chronic pain on isolation and helplessness?.....	129
Q12e. What is the impact of chronic pain on days off work? .....	133
Q12f. What is the impact of chronic pain on incapacity benefits?.....	141
Q13. What are the costs of chronic pain from societal, health care system and patient perspective? .....	147
Q14. What are the issues/determinants of patients' awareness of chronic pain? .....	155
Q15. What are the issues/determinants of health care professionals' awareness of chronic pain?.....	161
Q16. What are the main symptoms and complaints with which patients present themselves to health care professionals? .....	165
Q17. What are the frequencies of drug, non-drug and combined treatments?.....	167
Q18. What are the determinants of treatment choice between drug treatment and non-drug treatment?.....	173
Q19. What are the determinants of treatment choice within drug treatments? .....	177
Q20. What are the determinants of compliance/adherence to drug treatment? .....	179
Q21. What is patients' satisfaction about drug treatments? .....	181
References .....	185
Summary Table .....	189



# Preface

Chronic pain is a burden for society. For the individual patient and his family, it is even worse. In 2001, the European Federation of IASP Chapters (EFIC) launched its declaration on "Chronic Pain as a Major Healthcare Problem, a Disease in its own Right". This declaration stated that "although comprehensive epidemiological data for the European Union are not available, chronic pain is clearly a very widespread condition". Despite this declaration, these epidemiological data on chronic pain are not systematically collected and available, because pain is considered only to be a symptom as part of a specific disease. Chronic pain is not considered as a disease on its own right. Experts all over the world demonstrate that chronic pain has no warning function and that the quality of life of the patient is severely reduced. Finally, chronic pain has major negative impact on national health care budget and expenses. Therefore, making pain more visible should be a major objective.

Epidemiological data are important for decision and policymakers to decide about health care budget and to prioritize on health care issues. However, chronic pain and its impact on society seems to be absent on the agenda of most ministries of Health in Europe and in the Netherlands in particular. Therefore, the present book written by Malgorzata Bala and colleagues is of utmost value and importance to make pain more visible in society. The authors describe the most recent and valuable data on epidemiology of chronic pain in the Netherlands. The following pain syndromes were included in their systematic analysis of the literature: musculo-skeletal pain, neuropathic pain, fibromyalgia, osteoarthritis and rheumatoid arthritis.

For the Netherlands, important questions are answered such as what is the prevalence and the incidence of chronic pain conditions? What percentage of chronic pain patients are untreated or inadequately treated? How many patients present themselves for treatment and what is the compliance of treated chronic pain patients? What is the impact of chronic pain? What is the cost of chronic pain? Detailed information on chronic pain is categorized, selected and presented making this book to a very important resource for health care professionals, policymakers and patient organizations. For the first time, the real impact of chronic pain in the Netherlands can be considered, hopefully paving the way for important decisions and actions to improve the care of pain patients and their quality of life.

Despite specific treatment recommendations on chronic pain, about 18 % of the Dutch general population experience a moderate to severe pain condition and the prevalence of unexplained severe chronic pain in a general practice population is 0.8 %. More than 56 % of patients declare that their chronic pain problem is undertreated. Chronic pain has a high impact on activities of daily living, on depression and mental illnesses, on isolation and helplessness, on days of work and incapacity benefits and on costs in general. Finally, the awareness of patient and health care professionals shows different gaps in the knowledge, training and education on chronic pain.

The presented convincing data calls for the implementation of a coordinated national health program on the prevention, diagnosis and treatment of chronic pain in the Netherlands and in Europe. Health care professionals, patients organizations, scientific organizations, insurance companies and policymakers should cooperate to improve this important goal for the next few years. Consideration of epidemiological data on chronic pain and its impact on society, should lead to a better recognition of the most prevalent disease in society. For years, pain was the forgotten disease. But once you get it, you will never forget this disease!

This book is a beautiful example of making pain visible in society. I recommend you to read it and to use this book as a basis for further discussions on the start of such a national health program.

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# De epidemiologie van chronische pijn in Nederland

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## Inleiding

In 2006 publiceerde Breivik de resultaten van een telefonisch interview in 15 Europese landen en Israël naar de prevalentie, impact op dagelijks leven en behandeling van chronische pijn(1). In dit onderzoek werden 46.394 gescreend met een beperkte vragenlijst. 8815 patiënten voldeden aan de definitie langdurige pijn. Deze definitie was omschreven als pijn  $\geq 6$  maanden waarvan in de laatste maand  $\geq 2$  aanvallen per week en  $\geq 5$  op een 10 punt NRS. Van deze patiënten werd bij 4839 patiënten een diepte interview afgenomen. De vastgestelde prevalentie van chronische pijn in Europa is gemiddeld 19%. De prevalentie varieerde van 12% in Spanje tot 30% in Noorwegen. In Nederland werd een prevalentie vastgesteld van 18% (zie figuur 1).



**Figuur 1.** Breivik et al. 2006. Prevalentie chronische pijn in 15 landen in Europa en Israël



Een belangrijke vraag is hoe het komt dat er deze verschillen zijn? Om deze vraag te beantwoorden is een systematische review uitgevoerd waarin gekeken is naar epidemiologische data uit studies die verricht waren met populaties uit Europa als geheel en separaat uit Denemarken, Frankrijk, Duitsland, Italië, Spanje, Nederland, Zweden en Groot-Brittannië. In totaal zijn 21 onderzoeksvragen geformuleerd. Onderzoeksvragen bij de verschillende populaties betroffen: het verzamelen van informatie over de incidentie en prevalentie van chronische pijn; het verkrijgen van inzicht in behandelingen voor chronische pijn; het verkrijgen van inzicht in de impact van chronische pijn op kwaliteit van leven, algemene dagelijkse levensverrichtingen, verzuimdagen en kosten. Alhier wordt de analyse van studies die zijn verricht in de Nederlandse populatie beschreven.

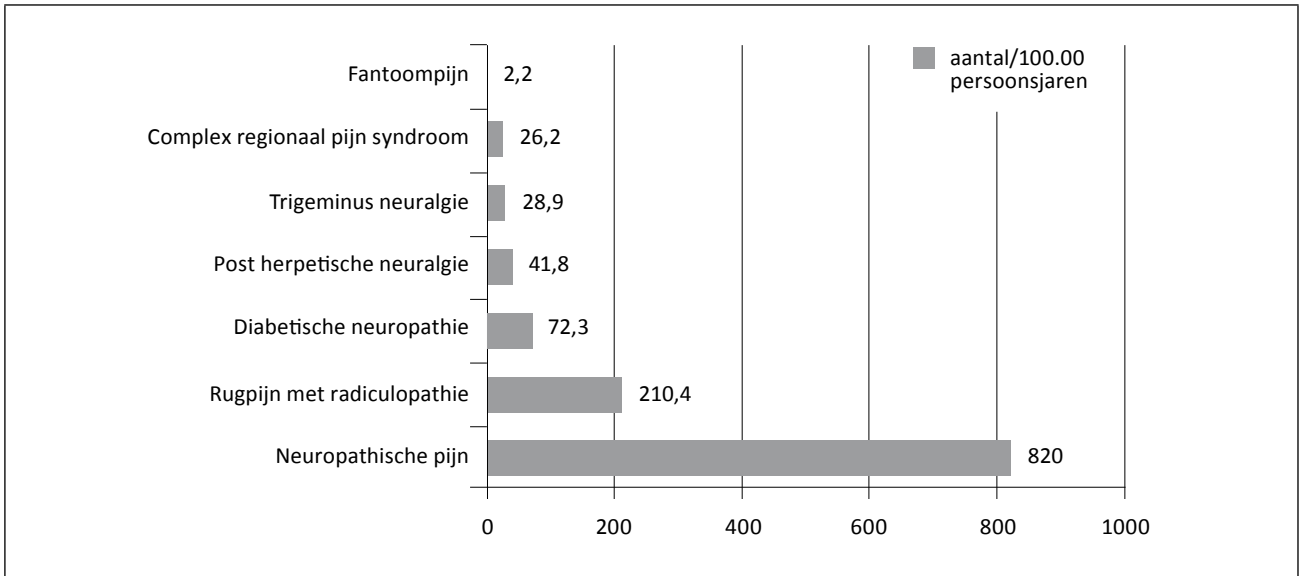
## Methoden

In augustus 2009 is gezocht in MEDLINE, EMBASE, CDSR, CENTRAL, DARE, HTA, en GIN naar relevante artikelen over chronische pijn. Primair zijn titels en abstracts beoordeeld door 2 onderzoekers. Indien er consensus was over bruikbaarheid en indien er onduidelijkheid was werden de volledige artikelen opgevraagd voor nadere beoordeling. Deze werden gesorteerd op de uitgangsvragen en geanalyseerd op kwaliteit. Geïnccludeerd werden primaire studies en systematische reviews vanaf 1995. Chronische pijn werd gedefinieerd als pijn  $\geq 3$  maanden of passend bij een ziekte met een chronisch karakter zoals osteoarthritis, fibromyalgie of reumatoïde arthritis. Geëxcludeerd werden kinderen en adolescenten, hoofdpijn/migraine, Angina Pectoris en pijn bij specifieke ziekten zoals Parkinson en multiple sclerose. Nadere selectie vond plaats op basis van representativiteit, grootte, datum en kwaliteit van de onderzoeken. Data-extractie vond plaats door 1 onderzoeker en werd gecontroleerd door de 2e onderzoeker. De 3-5 meest relevante artikelen per onderzoeksvraag zijn gebruikt voor de analyses.

## Resultaten

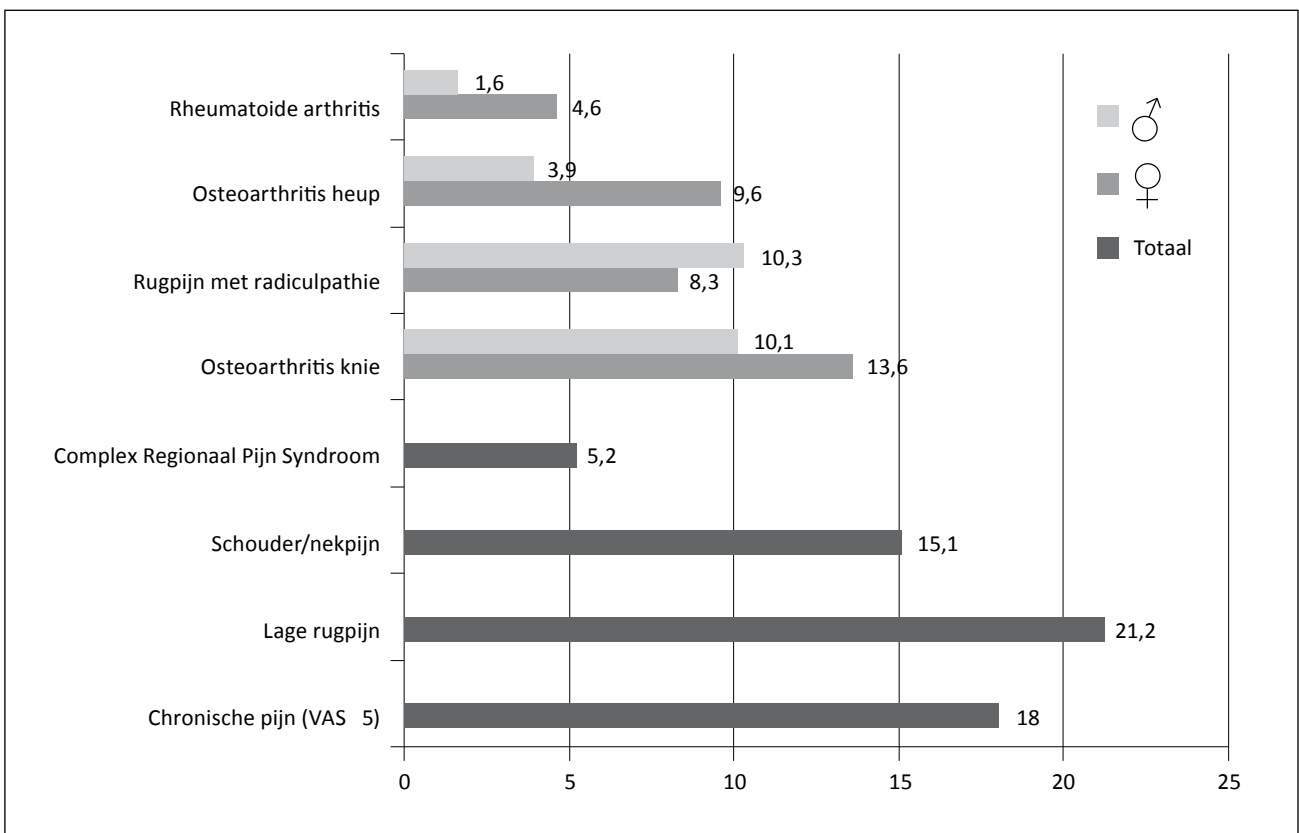
In totaal werden voor heel Europa 16.619 artikelen geïdentificeerd. Na analyse voldeden 119 artikelen die Nederlandse patiënten beschrijven aan de gestelde eisen. Deze werden gebruikt voor de nadere analyse.

De analyses zijn weergegeven in het onderliggende rapport. De eerste uitgangsvraag ging over wat we weten over de incidentie van chronische pijnsyndromen in Nederland. Er zijn eigenlijk slechts 2 onderzoeken die iets zeggen over incidentie. Beide onderzoeken zijn verricht in de IPCI-database, een databank waar huisartsen elektronisch hun patiëntendossiers in bijhouden. Een van de onderzoeken heeft gekeken naar neuropathische pijn en de andere heeft gekeken naar het Complex Regionaal Pijn Syndroom (2,3). Van belangrijke andere pijnsyndromen zoals lage rugpijn, schouder- en nekpijn, arthritis en reumatoïde arthritis hebben we geen cijfers over de incidentie. Rugpijn met radiculopathie komt het vaakst voor, gevolgd door diabetische polyneuropathie en postherpetische neuralgie.



**Figuur 2.** Dieleman et al 2008, de Mos et al 2007 Incidentie specifieke chronische pijnsyndromen in Nederland

De uitgangsvraag naar de prevalentie laat met name data zien voor rugpijn, schouder nekpijn arthritis en rheumatoïde arthritis en in tegenstelling tot de incidentie weten we hier niets over neuropathische pijn. Lage rugpijn, schouder/nek pijn en osteoarthritis van de knie hebben de grootste prevalentie (1, 4, 5) (zie figuur 3). Van patiënten met kanker had 55% pijn en 44% matige of ernstige pijn.



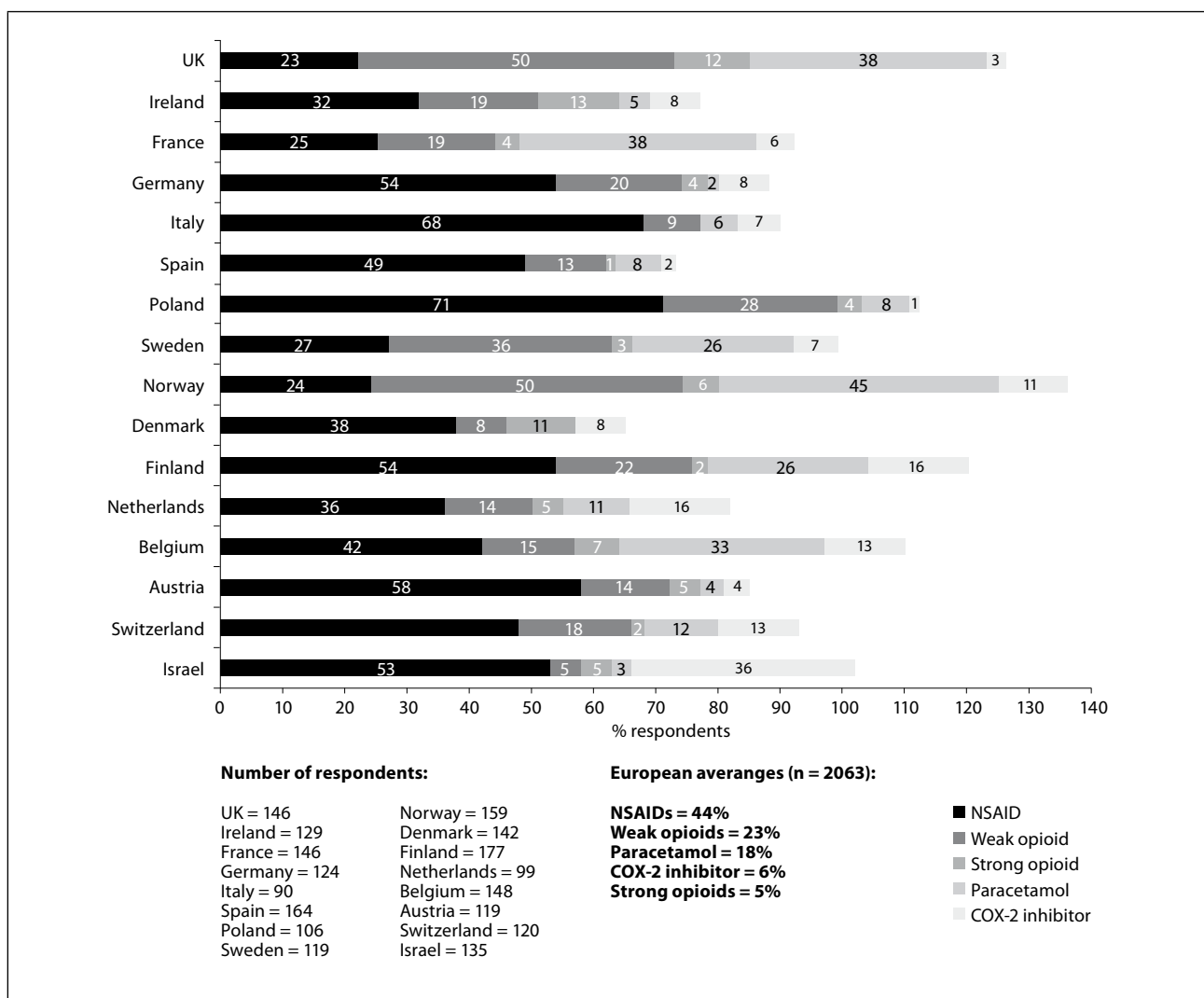
**Figuur 3.** Breivik et al 2006, Kerssens et al 2002, Picavet et al 2003. Prevalentie van chronische pijn in Nederland

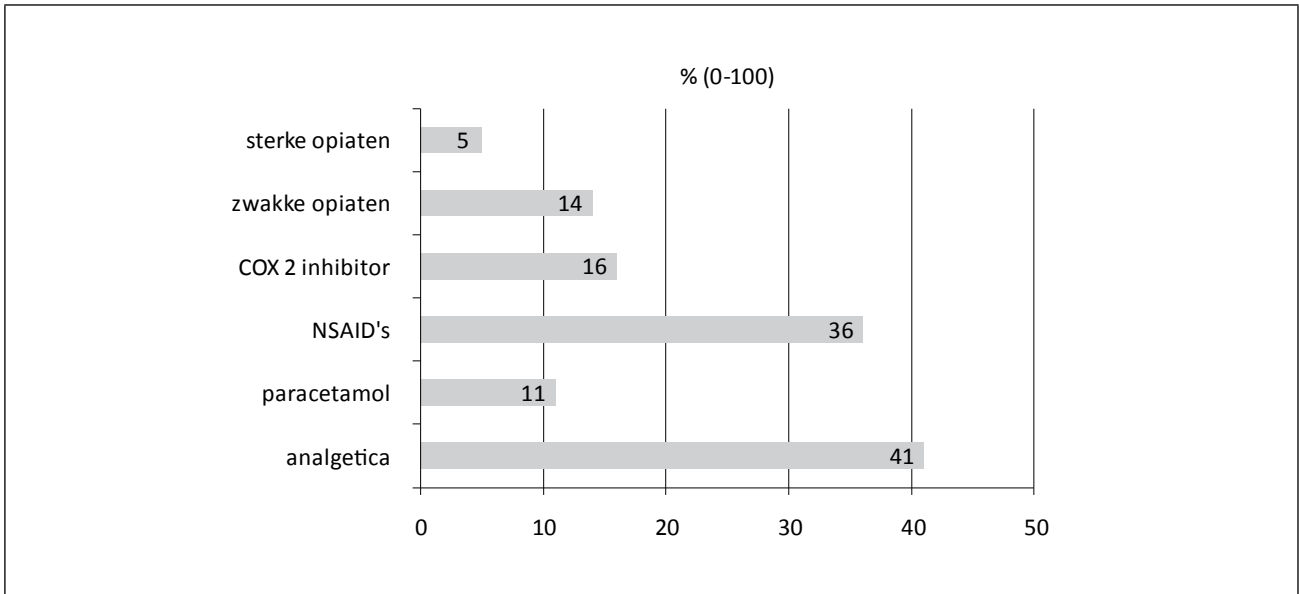
Patiënten met matige tot ernstige chronische pijn algemeen hebben een gemiddelde leeftijd van 51,3 jaar, de man/vrouw verdeling is 40/60 (1). Bij postherpetische neuralgie is de gemiddelde leeftijd 55 jaar en de man/vrouw verdeling 42/58 (6). Bij patiënten met pijn aan de bovenste extremiteit en nek is de gemiddelde leeftijd 65 en de man/vrouw verdeling 71/29 (7).

De gemiddelde duur van chronische pijn in Nederland is 6,5 jaar (1). De gemiddelde pijn bij patiënten met Reumatoïde Arthritis is gemeten op de NHP vragenlijst 13,4 (8). De pijnintensiteit bij chronische RSI is 41,3 mm op een 100 mm VAS schaal (9).

Van alle patiënten met chronische pijn met een VAS van 5 of hoger wordt 57% behandeld (1). Van patiënten met chronische pijn die opgenomen liggen in een verpleeghuis wordt 61% behandeld (10). Respectievelijk 74% en 69% van de patiënten met chronische lage rugpijn en chronische nekpijn wordt behandeld (11,12) en 53% van de patiënten met neuropathische pijn wordt behandeld (2) .

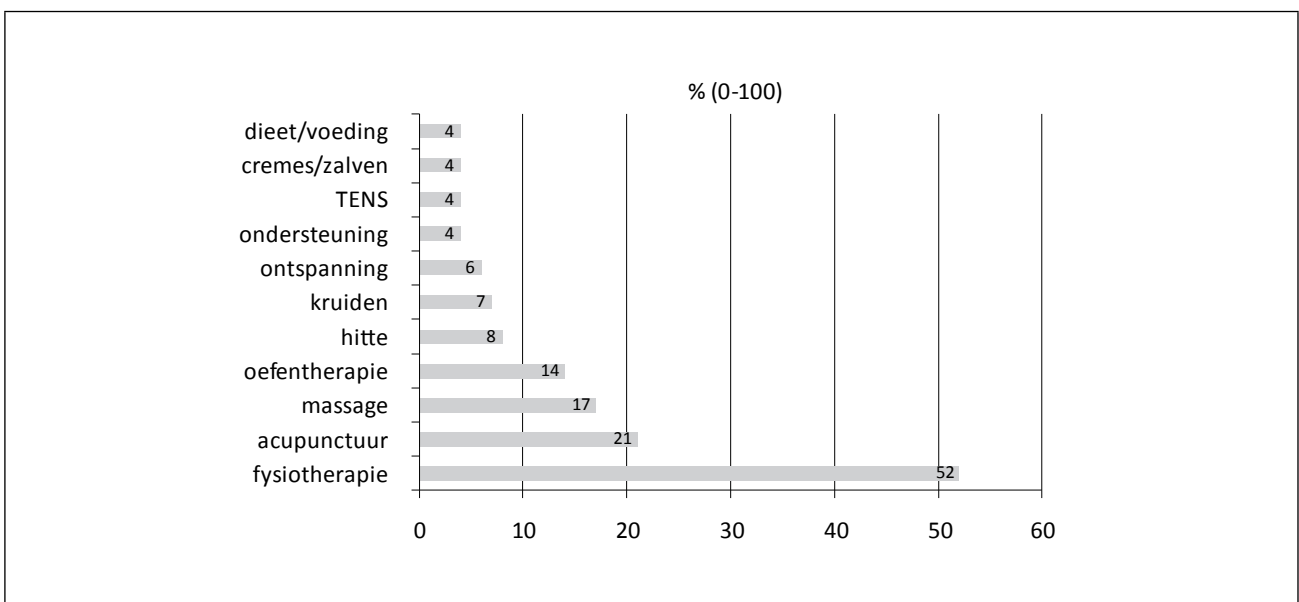
41% van de patiënten met chronische pijn gebruikt een analgeticum. In Nederland zijn de NSAID's het meest populair (1). In de Breivik studie worden grote verschillen gezien in de zin dat in Noord europa opiaten erg populair zijn en in de middellandse zee gebieden nauwelijks voorgeschreven worden. Dit geeft aan dat guidelines nauwelijks gevolgd worden en voorschrift meer afhankelijk lijkt van de lokale folklore en het geloof (zie figuur 4).





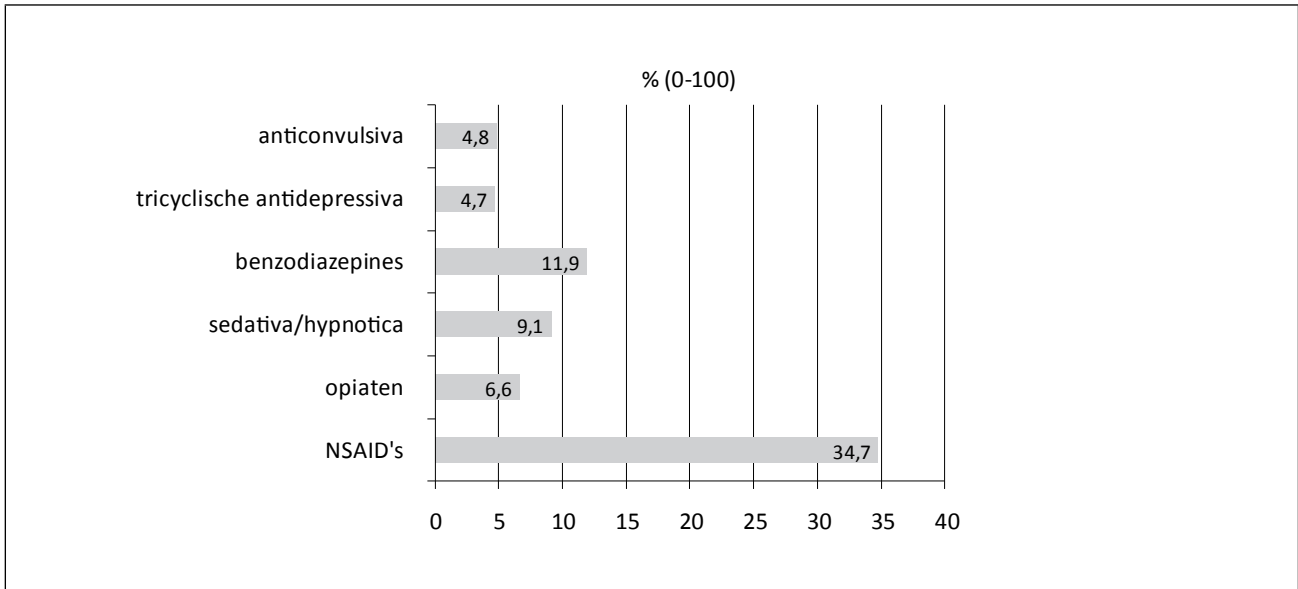
**Figuur 4.** Breivik et al. Percentage patiënten met chronische pijn ( $VAS \geq 5$ ) met een medicamenteuze behandeling in Europa (linksonder) en in Nederland (boven)

Meest populair bij de niet medicamenteuze behandeling zijn fysiotherapie, acupunctuur en massage. Het is opvallend dat cognitieve gedragstherapie nauwelijks of niet wordt toegepast (zie figuur 5).



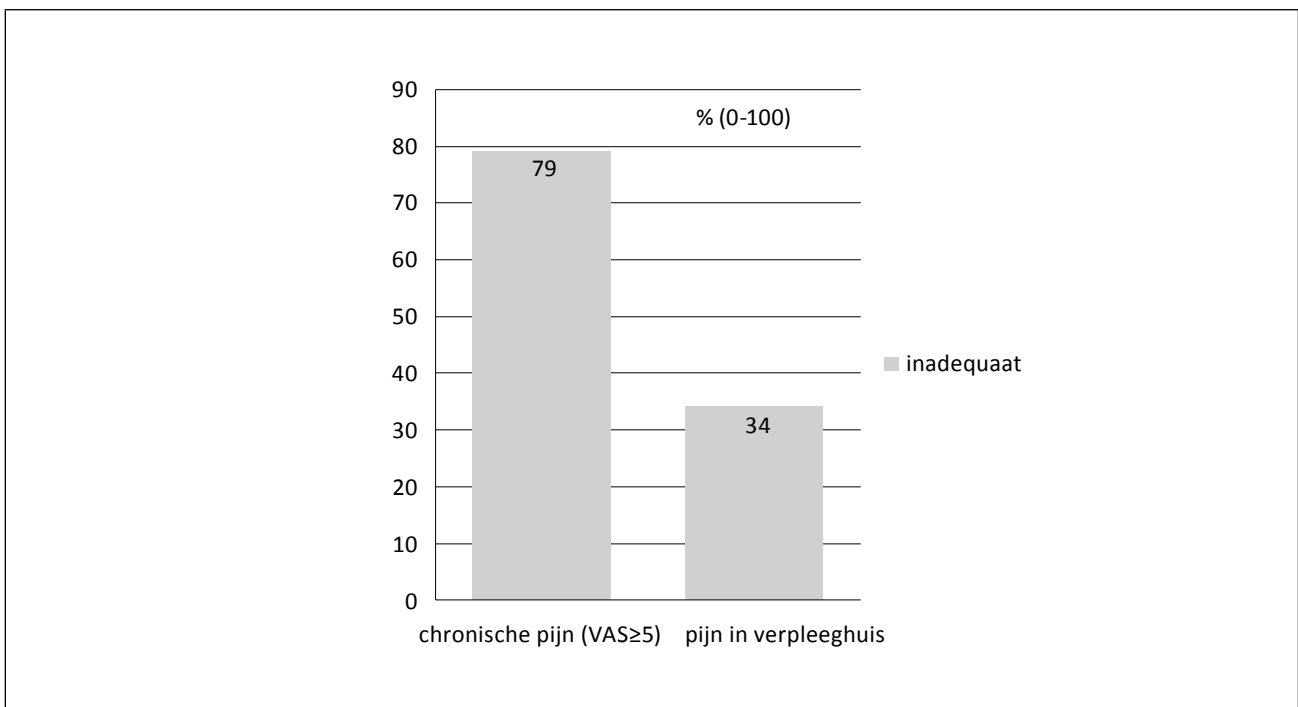
**Figuur 5.** Breivik et al. Percentage patiënten met chronische pijn ( $VAS \geq 5$ ) met een niet medicamenteuze behandeling in Nederland

Onderzoek naar de medicamenteuze behandeling van neuropathische pijn toont als opvallendheid dat het merendeel van de patiënten behandeld wordt met een NSAID, een middel dat niet direct geïndiceerd is bij neuropathische pijn (2) (zie figuur 6).



**Figuur 6.** Dieleman et al. Percentage patiënten met neuropathische pijn met een medicamenteuze behandeling in Nederland

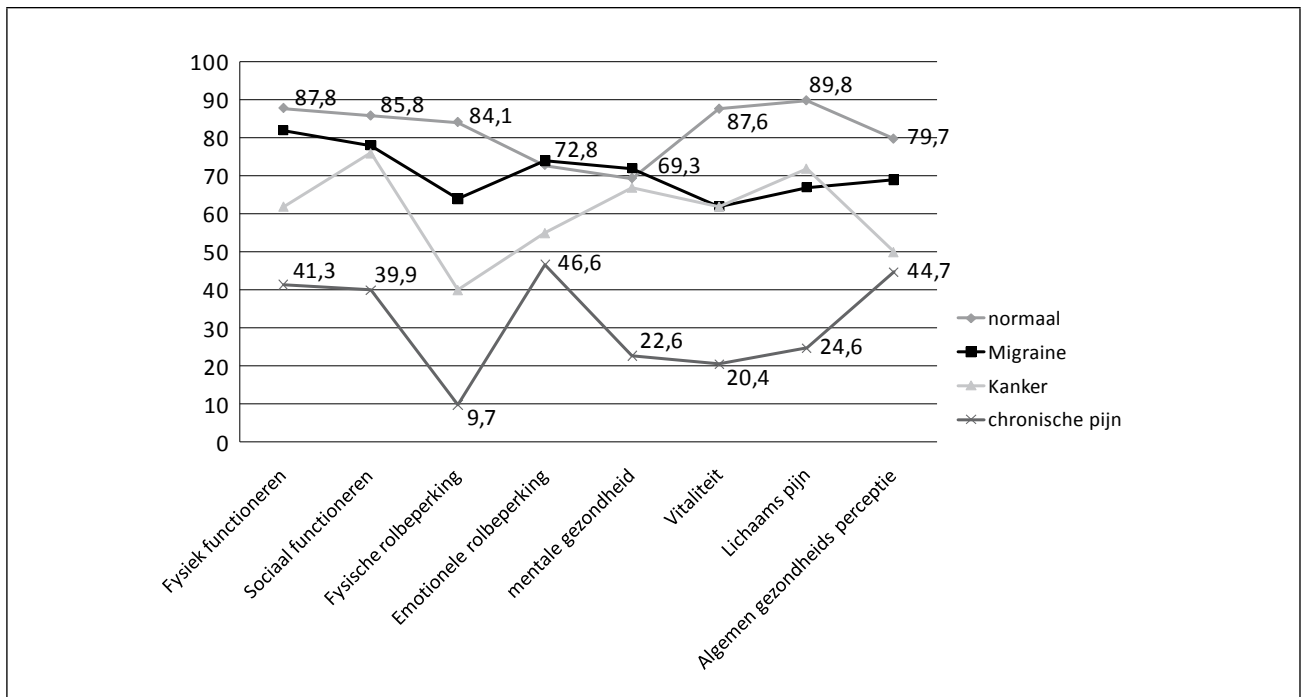
78% van de chronische pijnpatiënten met een VAS groter of gelijk aan 5 ervaart zijn behandeling als inadequaats, 34% van de patiënten in verpleeghuizen ervaart zijn behandeling voor pijn als inadequaats (1,10) (zie figuur 7).



**Figuur 7.** Brevik et al. 2006 en Herk et al 2009. Percentage chronische pijn patiënten die hun behandeling als inadequaats ervaren

In een onderzoek van Lame is gekeken naar de impact van chronische pijn op kwaliteit van leven bij patiënten in een universitair pijnbehandelcentrum. De chronische pijnpatiënt scoort in alle dimensies significant lager

in vergelijking met een normale controle groep. In vergelijking met migraine en kankerpatiënten scoort de chronische pijnpatiënt ook significant lager (13) (zie figuur 8). Bij chronische musculoskeletale klachten scoren patiënten ook lager ten opzichte van de normale controlegroep in een aantal dimensies, hoewel niet zo indrukwekkend als bij de vorige studie. Kwaliteit van leven gemeten bij patiënten met chronische musculoskeletale pijn middels de euroqol toont slechtere scores op alle dimensies(14). In een studie van Alonso uit 2004 wordt de kwaliteit van leven van arthritis patiënten vergeleken met de normale populatie en een aantal andere chronische aandoeningen. De afname van kwaliteit van leven is vergelijkbaar met patiënten met chronisch hartfalen (15).



**Figuur 8.** *Lame et al 2005. Impact op kwaliteit van leven (SF36) bij chronische pijn patiënten in een Nederlands universitair pijnbehandelcentrum*

Uit de studie van Breivik blijkt dat van de patiënten met chronische pijn met een VAS  $\geq 5$  18% niet voor zich zelf kunnen zorgen en 54% niet normaal functioneren (1). Borghouts toont aan dat 38,3% van de patiënten met chronische nekpijn beperkingen ervaart in het dagelijks leven (12). In een studie van Rupp uit 2006 bij patiënten met chronische pijn bij reumatoïde arthritis blijkt dat pijn de belangrijkste predictor is voor beperkingen (16). Bij chronische pijn VAS  $\geq 5$  blijkt in 19% sprake van stemmingsstoornissen (1). In een studie van De Meyttenaere wordt aangetoond dat patiënten met chronische pijn ten opzichte van de normale populatie vaker last hebben van een depressie, gegeneraliseerde angst, agorafobie of paniekstoornis, sociale fobie, posttraumatische stress en alcoholisme en verslaving (17).

In een studie van Borghouts is specifiek gekeken naar het aantal dagen ziekteverlof bij musculoskeletale pijn en nekklachten. In 1 jaar bedroeg het aantal ziekteverlofdagen in Nederland ten gevolge van musculoskeletale pijn meer dan 19 miljoen. Voor nekklachten was dit bijna 1 ½ miljoen (12). Huisstede heeft gekeken naar ziekteverlof bij chronische CANS. Vaak is er sprake van langdurig ziekteverzuim (7). Dit geldt ook voor musculoskeletale aandoeningen, vaak is er sprake van langdurig ziekteverzuim (5).

In 1996 bedroegen de totale kosten van chronische nekklachten in Nederland meer dan 680 miljoen Amerikaanse dollars. Opvallend is dat het overgrote deel (77%) veroorzaakt wordt door indirecte kosten. Het honorarium van medisch specialisten bedroeg slechts 0,2% (12). Boonen heeft gekeken naar de kosten van musculoskeletale aandoeningen. Bij fibromyalgie en chronisch lage rugklachten zit het merendeel in de niet medische kosten. Een aanzienlijk deel van de kosten wordt bepaald door verlies aan productiviteit. Specifiek gekeken naar kosten van verschillende soorten gezondheidszorg bij lage rugklachten blijkt ook het merendeel te zitten in niet medische kosten (18). In een studie van Kemmler is gekeken naar het gemiddeld besteedbaar inkomen voor en na de diagnose Complex regionaal pijn Syndroom. Het besteedbaar inkomen zakt aanzienlijk. Kemmler heeft ook gekeken naar extra kosten door ziekte die niet elders te verhalen zijn. Zeker in relatie tot het gemiddelde netto besteedbaar inkomen zijn dit aanzienlijke bedragen (19).

## Discussie

Er is een hoge incidentie en prevalentie van chronische pijn in Nederland. Niet iedereen wordt behandeld, er is een grote variatie aan behandelingen, relatief veel patiënten ervaren de behandeling als inadequaat. Chronische pijn heeft een forse impact op kwaliteit van leven, ADL, stemming, ziekteverlof en gaat gepaard met aanzienlijke directe en indirecte kosten.

De huidige epidemiologische data tonen echter een aantal beperkingen. Er zijn forse leemtes in data. De kwaliteit van de studies is beperkt: er is beperkte duidelijkheid over representativiteit; het betreft beschrijvende studies zonder aanpassingen voor versturende variabelen of studies van zelfrapportage zonder bevestiging van de diagnose.

Lastig bij epidemiologisch onderzoek naar chronische pijn zijn de verschillen in definitie en classificatie. Een ander lastig aspect is dat onder de term chronische pijn een aantal verschillende aandoeningen vallen. Chronische pijn is niet als aparte ziekte entiteit erkend. Chronische pijn komt niet als zodanig voor in de ICD 10. Hoe moeilijk het is om juiste epidemiologische data te verkrijgen mag blijken uit het onderzoek van de Mos die primair een incidentie toonde van 26, 2 per 100.000 persoonsjaren maar later deze incidentie toch weer bij moest stellen naar een lager getal nadat de patiënten bezocht waren door de onderzoeker zelf (3). Ook het onderzoek van Dieleman vertoont vergelijkbare beperkingen, door Dieleman werd voor trigeminus neuralgie een incidentie vastgesteld van 28,9 per 100.000 persoonsjaren die in het onderzoek van Koopman bijgesteld moest worden naar 12,9 per 100.000 persoonsjaren (2, 20)

In vergelijking met andere chronische aandoeningen komt chronische pijn heel vaak voor. Toch heeft het geen of onvoldoende aandacht van beleidsmakers. Diabetes, chronisch hartfalen, COPD en kanker krijgen veel meer middelen. Door de beleidsmakers wordt een actief beleid gevoerd ten aanzien van preventie en terugdringen van deze aandoeningen. Voor chronische pijn is weinig tot geen aandacht. Chronische pijn wordt niet gezien als een ziekte in zijn eigen recht.

Aanbevelingen zijn dan ook: vergroot awareness, ontwikkel duidelijke definities en een classificatiesysteem, ondersteun research naar epidemiologie en pathofysiologie, verbeter kennis van diagnostiek en interventies, includeer training in chronische pijn in de curricula van alle medische opleidingen en ontwikkel zorgstandaarden voor kwaliteit en uitkomsten.

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# **Executive summary**

Chronic pain is very common but good data are scarce about the prevalence, incidence, diagnosis, severity, treatment, utilization of health care, and the impact of chronic pain on society, health care systems and the patient. Information about the epidemiology of chronic pain can help decision and policy makers decide about health budgets and prioritization, patient segmenting and budget fencing, and therapy budgets, including behavioural therapy and drug budgets. This report aims to provide epidemiological information about chronic pain in the Netherlands using the most representative, recent, comprehensive and valid studies.

Out of 16 619 retrieved titles and abstracts, we selected 155 studies from the Netherlands that were relevant to the project questions. From these, we selected at least three studies per question that provided the most recent, representative and valid data. A summary of the results for each project question follows:

## **Q1. What are the population and demographics of the Netherlands?**

The Dutch population is 16 485 787 029 individuals (per October 2009) with a nearly 1:1 male to female sex ratio. The mean age is 39.9 years. The mean standardized annual income in 2008 was 24 400 Euros; 27 200 Euros for the working population and 21 200 for the non-working population. The employment rate in 2009, was 70.7%, with an unemployment rate of 4.9%.

## **Q2/3. What is the prevalence/incidence of chronic pain conditions in the Netherlands?**

The Dutch population is approximately 16.5 million people in 2009.

The percentage of individuals with chronic pain is 18% (NB this refers to moderate to severe chronic pain).

The prevalence of chronic low back pain 21.2%, of shoulder pain 15.1% and of neck pain 14.3%. No data are available for back pain overall or back pain without radiculopathy.

The prevalence of back pain with radiculopathy can be estimated to be 8.3% for females and 10.3 for males (refers to herniated disc or back).

The prevalence of osteoarthritis of the knee is 13.6 and 10.1 for females and males respectively and the prevalence of osteoarthritis of the hip, these figures are 9.6 and 3.9%. The prevalence of RA is 4.6 and 1.6% for females and males respectively. The prevalence of CRPS is 5.2%

No data were found on the incidence of back pain or arthritis in the Netherlands.

The incidence of neuropathy is 820/100,000 PY. Of all neuropathies, ischias occurs most frequent, with an incidence of 210.4. Incidence of diabetes neuropathy is 72.3, PHN 41.8, trigeminal neuralgia 28.9 and phantom pain 2.2, all per 100,000 PY. The incidence of CRPS is 26.2/100,000PY.

No data were found on prevalence or incidence of post-thoracotomy pain, post-mastectomy pain and CVPS.

## **Q4. What percentage of chronic pain patients from the Netherlands are untreated or inadequately treated**

Four studies reported data regarding Dutch patients untreated for their pain problem. Two were performed in nursing home populations and the definition of untreated was similar – patients who did not receive analgesics. The percentages of such patients varied between 25 and 36%. Two studies were performed in general practice, regarded musculoskeletal pain and reported that 31–36% of patients with neck pain or low back pain visiting their GP received no treatment for their pain.

Three studies reported percentages of inadequately treated patients, which ranged between 34% and 79%. It should be noted that inadequacy of treatment was defined differently in these studies. Smalbrugge et al. 2007 reported on the percentage of patients with inadequate analgesics dosing and van Herk et al 2009 reported inadequate treatment as indicated by Pain Management Index in 34% of nursing home residents, while Breivik et al. 2006 reported inadequate pain relief according to patient assessment.

### **Q5. How many chronic pain patients from the Netherlands present themselves for treatment?**

The five included studies reported data regarding patients having contacts with healthcare due to their pain. The studies reported that around 20% of population had used healthcare services due to low back pain and among patients with low back pain between 30–40% contacted their GP. Among patients with other musculoskeletal pain GP contacts were reported for 40–50% of patients, while for more than 60% of patients with CRPS contacted GP as their first physician. Contacts with other health professionals were also common among patients with pain.

### **Q6. How many chronic pain patients from the Netherlands get treated, broken down by treatment?**

Two studies on treatments for general chronic pain were found. One study, including patients with moderate to severe chronic pain, reported that 14% had seen a pain management specialist and that 33% were prescribed medicines. Furthermore, 52% had tried physiotherapy, 21% acupuncture and 17% massage for their pain. The other study reported on frequency of invasive procedures carried out in Dutch hospitals. 85% of the respondents performed such procedures and performed approximately 63,000 procedures in 1991-1992. Two other studies reported on chronic musculoskeletal pain in general practice. Among patients who visited their GP for low back or neck pain, 36% and 31% did not receive any treatment, respectively. For both indications, medication was most frequently applied treatment (22% of patients with low back pain received medication and 58% of patients with neck pain received paracetamol/aspirin/ NSAIDs). The most frequent used non-drug treatments for low back pain were (bed)rest (6%) and postural advice (6%) and for neck pain heat application (20%) and postural advice (18%).

The last study on neuropathic pain reported only types of medication as treatment. 53% of the patients with neuropathic pain were prescribed medication and 47% were not. NSAIDs were the most commonly used drug; about 35% received this.

### **Q7. What is the compliance of treated chronic pain patients in the Netherlands?**

No studies were located.

## **Q8. What is the duration and severity of chronic pain conditions in the Netherlands?**

Breivik *et al.* (2006) measured the mean duration of general chronic pain for Dutch participants at 6.5 years. Mean pain scores among the 268 Dutch patients with recently diagnosed Rheumatoid arthritis were 13.4 (SD: 2.1); while scores ranged from 8 to 16. Pain intensity as measured on a 100mm VAS scale for patients with chronic RSI was 41.3 (SD: 25.4).

## **Q9. What are the demographics of chronic pain sufferers in the Netherlands?**

The mean age of moderate to severe chronic pain sufferers in the Netherlands was 51.3 years and 60% were female. 47% of all HZ patients were at least 55 years old and 58% were female. 63% of persons with chronic complaints of the upper extremity and neck were female and 29% were 65 years or older.

## **Q10. What are the co-morbidities of chronic pain sufferers in the Netherlands?**

The three included studies reported comorbidities in several pain conditions. In general pain condition depression was reported in 19% of respondents, in patients with back or neck pain mood disorders were reported by 4.5–9.4% (major depressive disorder was reported by the highest percentage of respondents) of pain sufferers, anxiety disorders by 1.7–7.4% of respondents and alcohol abuse by 1.7%. In patients with musculoskeletal pain coexistence of pain in several locations was reported by 5–7% and more widespread pain including combinations of upper and lower extremities, back or neck and in left and right was reported by 4–6% of respondents.

## **Q11. How many sufferers in the Netherlands have inadequate pain control?**

Breivik *et al.* 2006 reported inadequate pain control from medication according to patients assessment in 79% and inadequate overall pain control in 56%.

## **Q12a. In the Netherlands what is the impact of chronic pain on quality of life?**

The three included studies reported on quality of life in several pain populations. Quality of life scores were low for patients with pain or musculoskeletal diseases. Patients with back pain, other pain and multiple pain locations experienced more functional limitations (physical functioning and role limitations physical) than the other pain groups. In addition, patients with multiple pain localizations scored significantly lower on mental health, vitality and general health.

Patients with osteoarthritis had lower scores on physical summary component than patients not reporting any chronic conditions.

For all musculoskeletal diseases and all quality of life dimensions it was found that having the disease was associated with a worse health related quality of life. The dimensions typically affected by musculoskeletal diseases were physical functioning and pain on the SF36, and the dimensions "mobility" and "pain" on the EQ-5D.

### **Q12b. In the Netherlands what is the impact of chronic pain on activities of daily living?**

The four included studies reported on prevalence of limitation in daily life due to pain or associations between socio-demographic characteristics or disease characteristics and disability in rheumatoid arthritis. In patients with musculoskeletal pain limitation in daily life were reported by 8.5–53% of patients. In patients with rheumatoid arthritis pain was the most important predictor for disability, significant associations were also found for depressive symptoms, radiographic damage and disease activity. Female sex, older age, RF positivity, disease activity and somatic and psychological co-morbidities were found to be risk factors for poor outcome with respect to disability.

### **Q12c. In the Netherlands what is the impact of chronic pain on depression and other mental illnesses?**

The three included studies reported on prevalence of depressive symptoms or associations between disability and health-related quality of life rheumatoid arthritis radiographic joint damage, disease activity, pain, and depressive symptoms. In general pain condition depression was reported in 19% of respondents, in patients with back or neck pain mood disorders were reported by 4.5–9.4% (major depressive disorder was reported by the highest percentage of respondents) of pain sufferers, anxiety disorders by 1.7–7.4% of respondents and alcohol abuse by 1.7%.

### **Q12d. In the Netherlands what is the impact of chronic pain on isolation and helplessness?**

Only two studies were found that reported on isolation or helplessness. One study was on patients with early RA and the other on patients with unexplained chronic pain attending an interdisciplinary treatment centre. Patients with early RA seem to be satisfied with their social support and patients with unexplained pain seem to experience at most moderate helplessness. Resting, however, a passive pain coping strategy seems to be used sometimes to frequent.

For both studies it's unclear whether the populations are representative of the target population. Together with the difficulties interpreting the data, we should conclude that the current data give only a limited view on the impact of chronic pain on isolation and helplessness.

### **Q12e. In the Netherlands what is the impact of chronic pain on days off work?**

The four included studies reported either the number of days off work or the percentage of patients leaving work due to pain for a certain length of time. Mean time lost from work due to general chronic pain in the past

6 months was 6.8 days. One cost-of-illness study reported total number of sick days related to neck disorders as 1 435 044 days. Two studies based on DMC3 data reported the percentages of patients with work leave due to musculoskeletal pain during last year between 4 and 32% depending on the subgroup.

### **Q12f. In the Netherlands what is the impact of chronic pain on incapacity benefits?**

The three included studies reported the proportion of patients receiving disability pension or recognized as being fully or partially disabled for work purposes or incidence of disability claims. In 1996 2.5% of the Netherlands population were receiving disability pension in relation to the neck pain. Over ninety percent of analysed patients with rheumatoid arthritis who had withdrawn from the labour force were officially recognised as being fully or partially disabled for work purposes. The annual incidence rate of low back disability in self-employed medical professionals increased between 1977 and 1989 and the incidence. When incidence of low back disability exceeding one year was compared with general working population the risk for the latter was three times higher.

### **Q13. In the Netherlands, what are the costs of chronic pain from societal, health care system and patient perspective?**

Costs for society due to neck pain in 1996 were estimated to be \$686.2 million. It's not clear what proportion of it refers to chronic neck pain. Cost for three chronic musculoskeletal diseases ranged between 3205 and 8533 euro's per patient per year. Cost for compensation of low back pain disability was 8.0 million in 1989 for a group of self-employed health care professionals. Direct medical costs accounted for 23% for neck pain and between 13 and 32% for the chronic musculoskeletal diseases, depending on the type. For neck pain, paramedical care accounted for the majority of costs (19 of 23%). For the chronic musculoskeletal diseases, large proportions of costs were used for specialist physicians, physiotherapists and prescription drugs. Only one study reported costs for patients; patients with CRPS have a decreased income and the mean out-of-pocket expenses were reported to be \$350 euro per patient per year.

### **Q14. What are the issues/determinants of patients' awareness of chronic pain in the Netherlands?**

Two quantitative studies reported determinants of awareness of chronic pain or disability. Patients who are able to work, who have a better physical role or better physical functioning have less pain. Also, those who experience fewer consequences and symptoms and are less concerned about their illness have less pain. Fear of injury and catastrophizing was associated with more disability.

A qualitative study showed 3 phases in the process of living with chronic pain: first patients aim to be normal, ignoring the pain and with unchanged activities. Then they aim to control and reduce the pain by withdrawing from activities. The pain is in control here. Last, they aim to collaborate with the pain. To do this they have to constantly face dilemmas of prioritizing activities in order to incorporate pain in everyday life.

### **Q15. What are the issues/determinants of health care professionals' awareness of chronic pain in the Netherlands?**

Nursing home staff respondents showed knowledge deficits about several aspects of pain, even though they were satisfied about the way pain was assessed and treated at their wards. Specific knowledge deficits were found regarding pain treatment and medication in elderly nursing home residents. Staff educational level seemed to influence their beliefs and knowledge about pain in elderly nursing home patients.

### **Q16. What are the main symptoms and complaints with which patients present themselves to health care professionals in the Netherlands?**

No studies were located.

### **Q17. What are the frequencies of drug, non-drug and combined treatments in the Netherlands?**

In two out of three studies data for this question referred only to the frequency of drug treatment. The percentage of people that currently were prescribed medicines varied between 33 to 75% in the selected studies. Most of the patients were prescribed NSAIDs. One study reported that specific non-drug treatments had been tried by 21 to 52% of Dutch patients. No data, specifically for the Netherlands, was available on the frequency of overall non-drug or combined drug/nondrug treatments.

### **Q18. What are the determinants of treatment choice between drug treatment and non-drug treatment in the Netherlands?**

Factors influencing choice of treatment for fibromyalgia differ per discipline. The choice is mainly made on the basis of subjective, professional group-bound factors such as EBM, protocols, courses, own experience and experiences of colleagues. For GPs, dynamic patient factors are an important motive in the management of FM.

### **Q19. What are the determinants of treatment choice within drug treatments in the Netherlands?**

No studies were located.

### **Q20. What are the determinants of compliance/adherence to drug treatment in the Netherlands?**

No studies were located.



## Q21. What is patients' satisfaction about drug treatments in the Netherlands?

Only one low quality study, performed in a Dutch nursing home population was found reporting on satisfaction about drug treatment. 60% were satisfied and 21% were not.

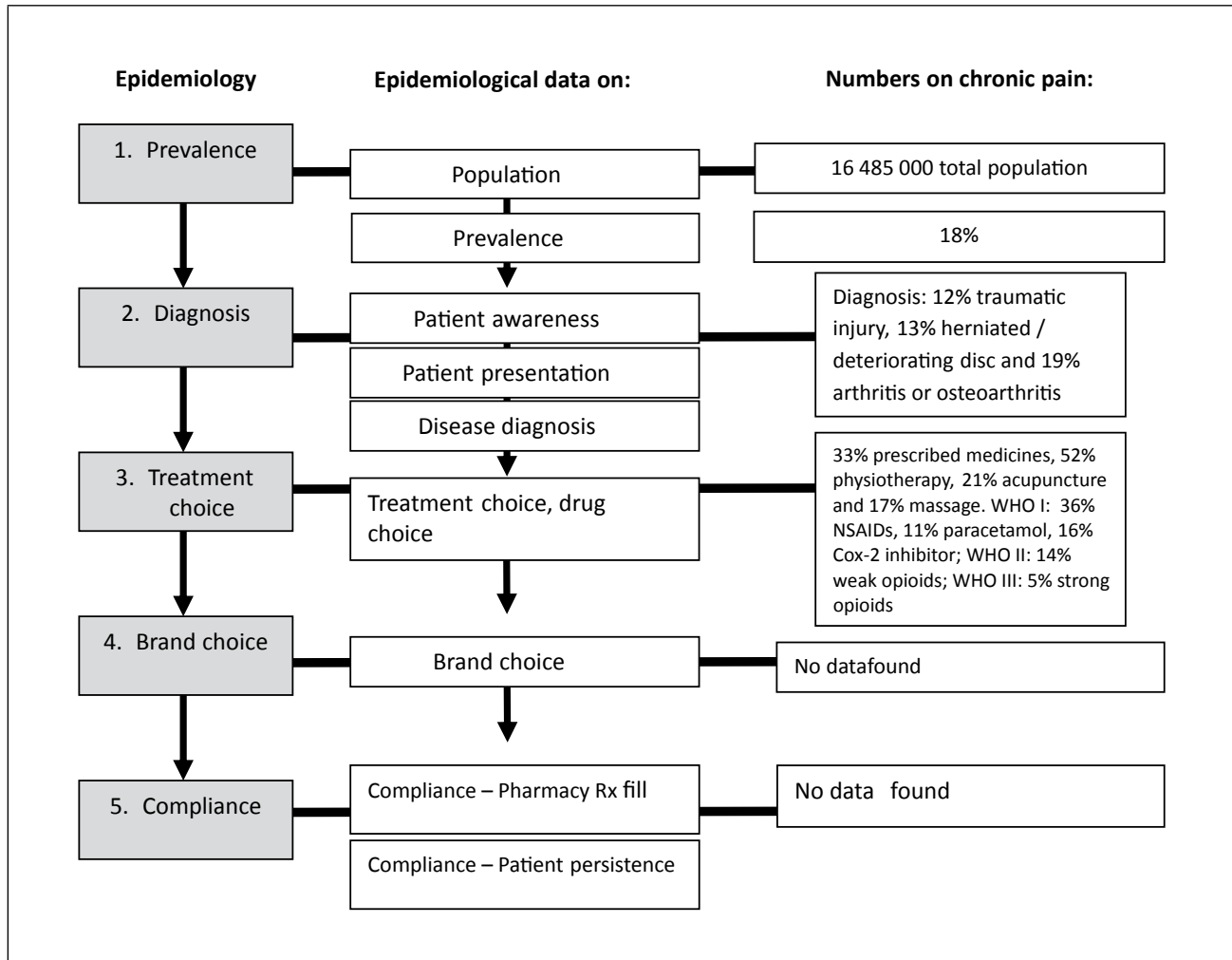


Figure 1. Netherlands epidemiology flow for moderate to severe chronic pain

# Introduction

Estimates of the prevalence of chronic pain vary widely and typically range between 10-30% of the adult population, although studies exist reporting prevalence as low as 2% or as high as 50% [IASP 2003, Breivik 2006]. This wide variation may reflect true differences between populations, but also the use of different definitions of chronic pain in epidemiological studies. Most definitions include continuous or intermittent pain, persisting for more than 3 months. Also, assessment methods vary, mostly involving a survey either by telephone or with data collection in person, using a range of different questionnaires and rating scales.

Typical locations of chronic pain include upper and lower back, head and neck, and joints. Surveys of the location of chronic pain also report sometimes considerable variations. Chronic pain is often reported to be more common among women, in older age groups and in lower income groups.

Severity of chronic pain is another element which is not straightforward to assess, both in terms of definitions of various grades of severity, and in terms of which measurement instruments are used. Compared with chronic pain of mild intensity and minimal disability, individuals with severely disabling chronic pain are more likely to have co-morbid health conditions, poorer self-rated health, problems with mental well-being and social functioning, activities of daily living, work loss, isolation, helplessness, and high health care costs and utilization. Chronic pain is very common but good data about prevalence, incidence, diagnosis, severity, treatment and utilization of health care are scarce. National statistics in Europe do not tend to focus on chronic pain as a discrete entity, but rather see pain as part of other underlying diseases, a symptom. This approach ignores the insight of clinicians specialised in pain treatment that chronic pain is considered a discrete entity in itself, with clear characteristics of symptoms, disability and mental health aspects which are largely independent of the underlying disease or trauma. Many studies of chronic pain prevalence have been based in particular care settings, such as pain clinics, or in particular subgroups with certain underlying diseases.

Information about the epidemiology of chronic pain can be important for decision and policy makers, so that they can decide about health budgets and prioritization, patient segmenting and budget fencing, and therapy budgets, including behavioural therapy and drug budgets. Compared with cardiovascular disease, oncology, diabetes and mental health there often seems to be limited appreciation by decisions makers about the importance of chronic pain, so data about all aspects of the epidemiology of chronic pain from prevalence to cost impacts will be useful for proper information. Chronic pain is an important and frequent medical and public health issue, and there seems to be a need for better understanding of the burden of disease and current treatment practice of chronic pain.

This report aims to provide information about chronic pain in the Netherlands. It is a part of a larger project addressing chronic pain in a range of European countries and Europe as a whole. Our method is a review of the available published and unpublished data, using the principles of systematic reviews in searching and identifying relevant studies, and summarizing their findings. Given the types of questions to be addressed, we aimed to use the most representative, recent, comprehensive and valid studies, rather than summarizing the results of all studies that were found.

# Methods

## **Objective of project**

To undertake a literature review on the most recent epidemiological data on chronic pain.

## **Questions to be addressed**

### ***Epidemiology flow***

1. What are the population and demographics of the Netherlands?
2. What is the prevalence of chronic pain conditions?
3. What is the incidence of chronic pain conditions?
4. What percentage of chronic pain patients are untreated or inadequately treated?
5. How many chronic pain patients present themselves for treatment?
6. How many chronic pain patients get treated broken down by treatment?
7. What is the compliance of treated chronic pain patients?

### ***Questions leading to in depth information to the numbers mentioned in the Epidemiology flow***

8. What is the disease duration of chronic pain conditions?
9. What are the demographics of pain sufferers?
10. What are the co-morbidities of pain sufferers?
11. How many sufferers have inadequate pain control?
12. What is the impact of chronic pain on:
  - a. Quality of life
  - b. Activities of daily living
  - c. Depression and other mental illness
  - d. Isolation, helplessness
  - e. Days off work
  - f. Incapacity benefits
13. What are the costs of chronic pain from a
  - a. Societal perspective?
  - b. Health care system perspective?
  - c. Patient perspective?
14. What are issues/determinants of patients' awareness of chronic pain?
15. What are issues/determinants of health care professionals' awareness of chronic pain?
16. What are the main symptoms and complaints with which patients present themselves to health care professionals?
17. What are the frequencies of drug (per WHO class), non-drug, and combined treatments?
18. What are determinants of treatment choice between drug treatment and non-drug treatment?
19. What are determinants of treatment choice within drug treatments?
20. What are determinants of compliance / adherence to drug treatments?
21. What is patients' satisfaction about drug treatments?

## Inclusion criteria

### *Study characteristics*

Primary studies (epidemiologic, qualitative, cost analyses etc.) or systematic reviews of primary studies published 1995 onwards. Only relevant primary data used in any systematic reviews identified and fulfilling the inclusion criteria were used in the data analysis.

*Exclusions:* non-systematic reviews, studies examining the effectiveness of treatments, comments, letters, editorials; any studies not showing any original data but just expressing opinions.

We expected to use the following types of data: national statistics (question 1), data from national health surveys (questions 2, 3), epidemiological studies (cohort, cross-sectional etc.) (questions 2 to 21), insurance data (data on early retirement, service use, prescriptions etc.) (questions 2, 12, 17), qualitative studies (questions 12, 13, 14, 15, 16, 18, 19, 20, 21), economic analyses (question 13), RCTs (e.g. of specific interventions to increase awareness, adherence with awareness/adherence as main outcome, possibly treatment satisfaction) (questions 14, 15, 20, 21)

### *Patients*

Patients with chronic moderate and/or severe pain from the Netherlands.

*Chronic pain includes:*

- musculo-skeletal pain: back pain / low back pain / shoulder pain / neck pain
- neuropathic pain (e.g. diabetic, post herpetic)
- fibromyalgia
- osteoarthritis
- rheumatoid arthritis

*Exclusions:*

- children and adolescents
- patients with mild pain
- patients with headache / migraine
- patients with angina pectoris
- pain associated with very specific medical conditions, e.g. Parkinson's disease, multiple sclerosis etc.
- studies of non-European participants – unless European data or data for relevant European countries are given separately

## Literature searches

We aimed to identify all relevant studies regardless of publication status (published, unpublished, in press, and in progress), or language.

The search strategies (keywords) were developed specifically for each database (appendix).

*We searched the following databases:*

- MEDLINE (1995 to August 2009)
- EMBASE (1995 to August 2009)
- CDSR (Cochrane Library issue 2 2009)
- CENTRAL (Cochrane Library issue 2 2009)
- DARE (August 2009, CRD website)
- HTA (August 2009, CRD website)
- Guidelines International Network database (August 2009, GIN website)

Furthermore, references in retrieved articles and systematic reviews were checked. Supplementary searches were undertaken as appropriate. Relevant websites were searched for national statistics, insurance data, health surveys and other relevant data. Relevant sites are shown in the appendix. Identified references were downloaded in Reference Manager software for further assessment and handling.

The proposed search strategies (Ovid) are shown in the appendix.

## Methods of study selection, quality assessment and data extraction

This literature review followed the methods and processes recommended in the Centre for Reviews and Dissemination (CRD) "Systematic Reviews: Guidance for undertaking reviews in health care".

### Study selection

Two reviewers independently inspected the title and abstract of each reference identified by the search and determine the potential relevance of each article. For potentially relevant articles, or in cases of disagreement, the full article was obtained, independently inspected, and inclusion criteria will be applied. Any disagreement will be resolved through discussion. Justification for excluding studies from the review (after having retrieved potentially relevant articles) was documented.

Included studies were categorised in order to get a list of relevant studies per question. Where there were more than three studies addressing a single aspect of any question, then for each question the most relevant studies were extracted using the following criteria: size (large preferred), recency (most recent preferred), quality (highest quality preferred), representativeness (populations representative of the general target population preferred). Studies were ranked by these criteria and the three or four highest ranking studies were extracted.

## Assessment of methodological quality

Quality assessment was carried out by one reviewer and checked by a second, using checklists as outlined below. Any disagreements were resolved by consensus. The results of the quality assessment have been used for descriptive purposes to provide an evaluation of the overall quality of the included studies and to provide a transparent method of recommendation for design of any future studies. Based on the findings of the quality assessment, recommendations have been made for the conduct of future studies.

The following quality criteria were used for the assessment of the different study types:  
(criteria to be answered with yes / no / unclear)

### *Observational studies:*

- Adequate description of study design and setting
- Adequate description of eligibility criteria (incl. description of diagnostic criteria for chronic pain condition)
- Study population is representative of target population (sample size, sample selection, demographics)
- Adequate description of outcomes (and how / how often measured), exposures, predictors
- Adequate description of statistical methods (incl. description of potential confounders and effect modifiers and how they were dealt with)
- Adequate description of study participants
- Adequate description of losses to follow-up (for longitudinal studies), loss to follow-up less than 10% at 12 months or less than 25% for longer follow-up
- Results reported as unadjusted and confounder-adjusted including precision

### *RCTs:*

- Adequate method of randomisation
- Adequate allocation concealment
- Adequate blinding (if appropriate)
- Adequate handling of losses to follow-up
- Adequate description of eligibility criteria (incl. description of diagnostic criteria for chronic pain condition), interventions and outcome measurement
- Study population representative of target population (sample size, sample selection, demographics)
- Groups comparable at baseline

### *Qualitative studies:*

- Adequate description / justification of study design and setting
- Adequate description of eligibility criteria (incl. description of diagnostic criteria for chronic pain condition)
- Study population representative of target population (sample size, sample selection, demographics)
- Adequate description of outcomes / questions / procedures
- Adequate description of study participants
- Methods of data summary described and sound (quotes used, data categorisations, theory)



*SRs of observational studies:*

- Adequate description of inclusion criteria (study design, participants, interventions / exposure, outcomes)
- Adequate description of search strategy (sources, keywords, time period, limits)
- Adequate description of study selection
- Adequate description of assessment of confounding
- Adequate description of quality assessment
- Adequate description of data analysis and heterogeneity assessment
- Description of study flow
- Study characteristics of each study included
- Quality of each study included
- Results of each study included and overall

*SRs of RCTs:*

- Adequate description of inclusion criteria (study design, participants, interventions, outcomes)
- Adequate description of search strategy (sources, keywords, time period, limits)
- Adequate description of study selection
- Adequate description of quality assessment of included studies
- Description of trial flow
- Description of data analysis / summary (including heterogeneity)
- Description of study characteristics of the included studies
- Quality of each study included
- Results of each study included and overall

## **Data extraction and presentation**

For each study, data were extracted by one reviewer and checked by a second reviewer. Any disagreements were resolved by consensus.

We employed a narrative method to present the data and for any synthesis. Typically, narrative synthesis involves the use of narrative text and tables to summarise data in order to allow the reader to consider outcomes in the light of differences in study designs and potential sources of bias for each of the studies being reviewed. This involves organising the studies by (as appropriate) intervention, population, or outcomes assessed, summarising the results of the studies, summarising the range and size of the associations these studies report, and describing the most important characteristics and the quality of the included studies.

Study characteristics and quality were presented in tables. Tables of results (including basic demographics of the populations assessed) are presented in tables subdivided by questions.

# Results

## Search, selection and allocation of studies

We retrieved and selected 117 studies from the Netherlands that were relevant to the project questions. Of these, 102 studies were on non-cancer pain and 15 were (also) on cancer pain. The selection process can be viewed in Figure 2. The allocation and number of studies for specific project questions for non-cancer pain can be viewed in Figures 3a-c.

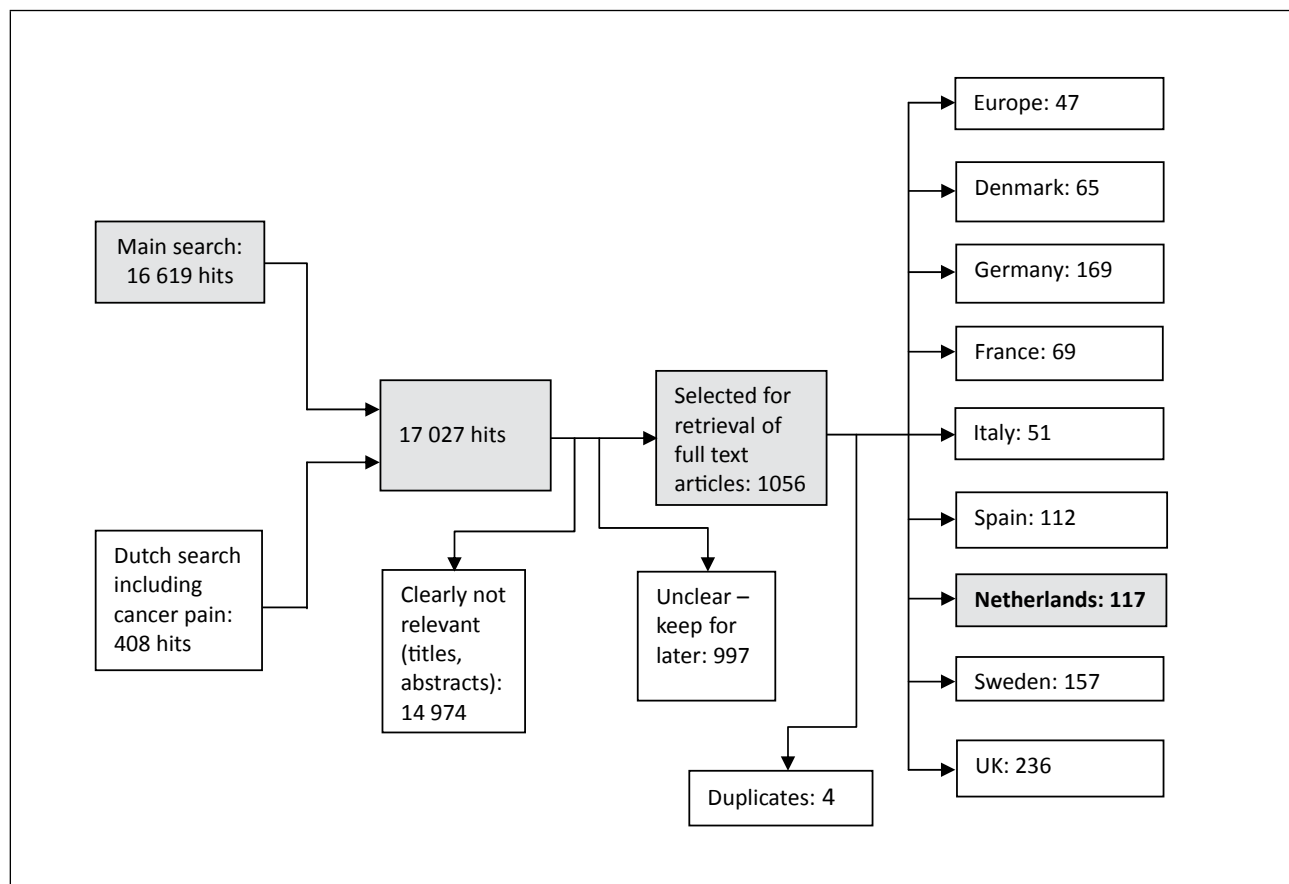
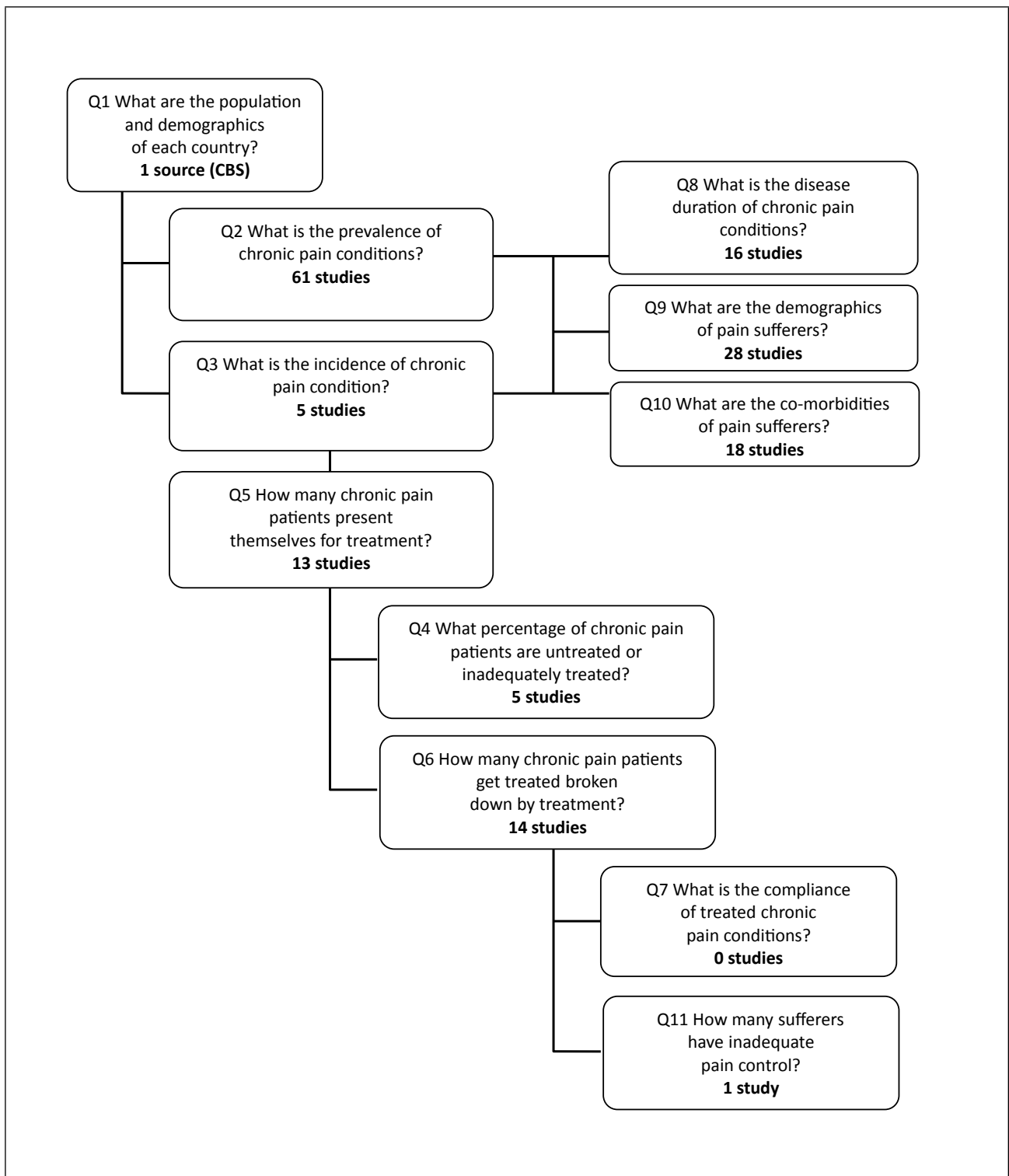
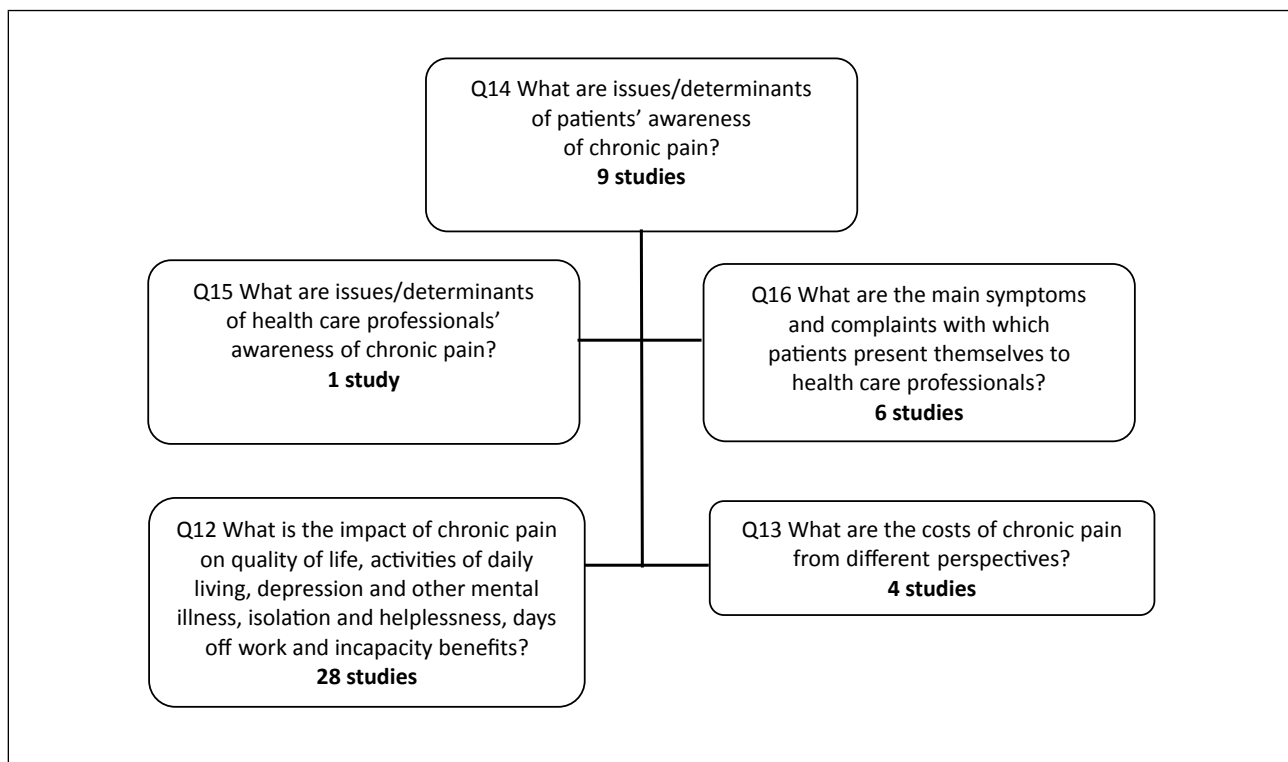
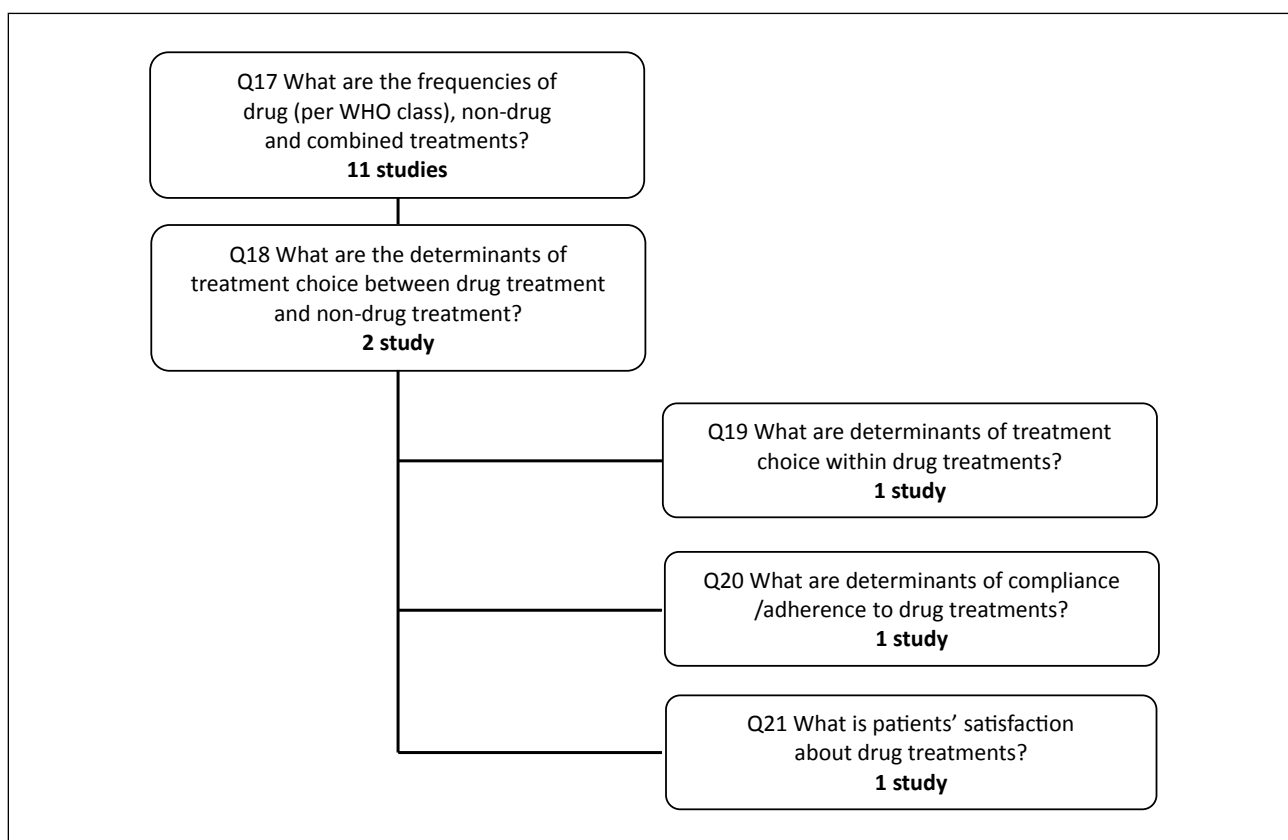


Figure 2. Search and selection of studies

**Figure 3.** Project questions**Figure 3a.** Epidemiology flow for the Netherlands - number of studies located per question



**Figure 3b.** Symptoms, awareness, impact and costs – number of studies located per question



**Figure 3c.** Treatment – number of studies located per question

# **Q1. What are the population and demographics of the Netherlands?**

To answer this question, the online database of the National Office of Statistics [Centraal Bureau voor Statistiek, CBS] was used. Population characteristics and data sources for each category can be viewed in Table 1.

The Dutch population as of October 2009 is 16 485 787 029 individuals with a nearly 1:1 male to female sex ratio. The population by age range is as follows: there are 3.9 million people below 20 years, 4.2 million between 20 and 40 years, 5.8 million between 40 and 65 years, 1.8 million between 65 and 80 and 0.6 million above 80 years. The mean age is 39.9 years.

The mean standardized annual income in 2008 was 24 400 Euros. This includes the gross income from work, income from own company, and incomes through social insurances. It is standardized for differences in size and composition of a household. For the working population the income is 27 200 Euros and for the non-working population 21 200 Euros. The employment rate, percentage of persons who live in the Netherlands with a paid job of at least 12 hours/week in 2009, was 70.7%, with an unemployment rate of 4.9%. Approximately 6.1 million people work as employer in a private company, 903 000 are self-employed and over 656 000 work as civil servant.

Regarding education, 8.4% of adults aged 15 to 65 years in The Netherlands have no qualifications (only elementary school) and 26.4% have completed higher education (high vocational education [in Dutch: Hoger Beroepsonderwijs, HBO] or university).

Ethnicity data was collected for the Netherlands using country of origin in 2009. 80% is native Dutch, 8.5% comes from other European countries, 4.4% comes from Asia, 3.6% from America and 3.3% from Africa. 0.8% originates from Oceania.

The Body Mass Index (BMI) data is based on self-reported height and weight in individuals aged 20 and higher. In 2008, 52% of males and 41% of females were overweight. Of these, 10% of men and 12.2% of women were severely overweight, defined as a BMI above 30kg/m<sup>2</sup>. Forty-two percent of men and 29% of women were moderately overweight, defined as a BMI above 25kg/m<sup>2</sup> and below 30kg/m<sup>2</sup>.

**Table 1.** Population characteristics for the Netherlands

<b>Population Characteristics</b>	<b>Numbers</b>	<b>Per cent</b>	<b>Source of data collection</b>
<b>General Population Data (2009, N and %)</b>			1
Total population	16 485 787	100%	
Females	8 329 391	50.5%	
Males	8 156 396	49.5%	
<b>Population by age range (2009, N and %)</b>			
Below 20 years	3 933 585	23.9%	
20 to 40 years	4 233 861	25.7%	
40-65 years	5 846 526	35.5%	
65-80 years	1 840 607	11.1%	
Above 80 years	631 208	3.8%	
<b>Mean personal annual income in 2008 (Euros)</b>			2
Total population	24 400		
Working population	27 200		
Non-working population	21 200		
<b>Employment in 2009 (N and %)</b>			3, 4
Employment rate	7 753 000	70.7%	
Unemployment rate	379 000	4.9%	
<b>Occupation</b>			5
Employer private company	6 068 000		
Civil servant	656 000		
Director / large shareholder	180 000		
Self-employed	903 000		
Other job	120 000		
Not working	4 442 000		
<b>Education (population between 15-65 years) (N and %)</b>			6
Persons with higher education (at least high vocational education)	2 898 000	26.4%	
Persons with only elementary school	924 000	8.4%	
<b>Country of origin (N and %)</b>			7
Dutch	13 198 081	80.0%	
Africa	543 649	3.3%	
America	598 936	3.6%	
Asia	726 646	4.4%	
Europe (other than Dutch)	1 398 450	8.5%	
Oceania	20 025	0.1%	
<b>Self-reported weight (aged 20+; 2008)</b>			8
BMI >30 (Severely overweight) (% Males)		10.0%	
BMI >30 (Severely overweight) (% Females)		12.2%	
BMI 25-30 (Moderately overweight) (% Males)		42.3%	
BMI 25-30 (Moderately overweight) (% Females)		29.2%	



*Source of data collection*

1.

<http://statline.cbs.nl/StatWeb/publication/?DM=SLNL&PA=37296ned&D1=a&D2=50,I&HDR=G1&STB=T&VW=T>

2.

<http://statline.cbs.nl/StatWeb/publication/?VW=T&DM=SLNL&PA=70957ned&D1=a&D2=0&D3=0&D4=0&D5=0,54-68&D6=I&HD=080523-1734&HDR=G3,G2,G1,G5,T&STB=G4>

3.

<http://statline.cbs.nl/StatWeb/publication/?DM=SLNL&PA=70173NED&D1=0-1,4,6-7,9,13&D2=0&D3=0&D4=I&VW=T>

4.

<http://statline.cbs.nl/StatWeb/publication/?DM=SLNL&PA=70173NED&D1=11,14&D2=0&D3=0&D4=I&HDR=T,G2&STB=G1,G3&VW=T>

5.

<http://statline.cbs.nl/StatWeb/publication/?VW=T&DM=SLNL&PA=70957ned&D1=a&D2=0&D3=0&D4=0&D5=0,54-68&D6=I&HD=080523-1734&HDR=G3,G2,G1,G5,T&STB=G4>

6.

<http://statline.cbs.nl/StatWeb/publication/?DM=SLNL&PA=71822NED&D1=0-1&D2=0&D3=0&D4=0-4&D5=0-1,8-10&D6=0&D7=I&HDR=T,G2,G1,G5,G6&STB=G4,G3&VW=T>

7.

<http://statline.cbs.nl/StatWeb/publication/?DM=SLNL&PA=37325&D1=0&D2=0&D3=0&D4=0&D5=0,2-9,46,95-96,137,152,194,215,232&D6=I&HDR=T,G2,G3,G5&STB=G1,G4&VW=T>

8.

<http://statline.cbs.nl/StatWeb/publication/?DM=SLNL&PA=03799&D1=242,254,267-270&D2=0-2,4-7&D3=0&D4=I&HDR=G2,T&STB=G1,G3&VW=T>

**Q2. What is the prevalence of chronic pain conditions in the Netherlands?**

From 61 studies, we selected the three studies that were most relevant to this question (Breivik et al. 2006, Kerssens et al. 2002 and the DCM<sub>3</sub> study, for which we extracted two papers (Picavet and Schouten 2003 Pain / Picavet and Hazes 2003 Ann Rheum Dis).

Breivik et al. (2006) performed a large telephone survey to explore the prevalence, impact on daily life and treatment of chronic pain in Israel and 15 European countries, among which the Netherlands were included. Persons received an initial screening questionnaire comprising twelve questions and those who suffered from long-lasting pain were subsequently interviewed in-depth using a second structured questionnaire. From the Netherlands, 300 persons suffering chronic pain were interviewed. Kerssens et al. (2002) performed a cross-sectional study using data from a registration network to estimate the prevalence of unexplained severe chronic pain in general practice and to report medical as well as psychological descriptions of patients suffering from this condition.

The Dutch Musculoskeletal Complaints and Consequences Cohort (DCM<sub>3</sub>) study is a population-based cohort study on musculoskeletal pain in the Netherlands, performed in 1998 (Picavet and Schouten 2003, Picavet and Hazes 2003). Respondents who reported musculoskeletal pain were asked to answer questions on pain characteristics and consequences, for each pain location. This study included 3664 persons (response or 46.9%), of which 74.5% reported any musculoskeletal pain during the past 12 months. See Table 2 for study characteristics.

**Table 2.** Characteristics of the studies selected for question 2

Study details	Population	Outcomes and analysis
<p><b>Breivik et al. 2006</b></p> <p><b>Study design</b> Cross-sectional study</p> <p><b>Study method</b> Telephone survey in two parts. First, persons were screened for chronic pain. Those who qualified were interviewed in-depth</p>	<p><b>Type of chronic pain</b> Long-lasting pain: chronic pain for at least 6 months, and pain in last month, and pain at least 2 times/week, and rating pain intensity at least 5 on 10-point NRS</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> 3197 respondents, among which 300 persons with long-lasting pain Of the pain-sufferers, 60% were female with a mean age of 51.3 years (Refusal rates to telephone survey – 51%, screening refusal rate – 4%)</p> <p><b>Patient selection</b> Subjects with long-lasting pain (see definition above). Mean duration of pain at time of in-depth interview – 6.5 yrs</p>	<p><b>Outcomes measured</b> Duration, location, intensity of pain. Tolerance, time course of pain, impact pain on activities daily life, employment status, emotional status. Visits to doctors, visits to pain management specialist, treatment (medication and non-medication), effectiveness of treatment, satisfaction with doctors, respondents’ attitudes and beliefs about pain and pain treatment, respondents’ perception of the attitude of others to their pain</p> <p><b>Pain severity</b> 18% reported severe pain</p> <p><b>Analyses</b> Descriptive analysis only. No subgroups were reported (for the Netherlands)</p>

Study details	Population	Outcomes and analysis
<p><b>Kerssens et al. 2002</b></p> <p><b>Study design</b> Cross-sectional study</p> <p><b>Study method</b> Data were collected from the Dutch Sentinel Practice Network. GPs included patients based on the study's inclusion criteria and researchers searched the database using relevant codes from classifications regarding pain syndromes or pain medication</p>	<p><b>Type of chronic pain</b> Unexplained severe chronic pain</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> N= 586 Age between 18 and 75 71% female</p> <p><b>Patient selection</b> Between 18 and 75 years of age; pain which had lasted at least 6 months; pain is the most prominent aspect in the clinical presentation; pain is serious enough to justify clinical attention; pain has led to obvious discomfort and disability in daily life for at least 1 month</p>	<p><b>Outcomes measured</b> MPI (Multidimensional Pain Inventory) including scales for: Pain Severity; Interference; Life Control; Affective Distress; Support; Punishing Response; Solicitous Response; Distracting Response; Household Chores; Outdoor work; Social Activities; General Activities</p> <p><b>Pain severity</b> Mean (SD) on scale 0-6 current pain: 3.7 (1.7) average in last week: 4.1 (1.5)</p> <p><b>Analyses</b> Descriptive statistics, association between variables using nonparametric correlation coefficient for interval variables and Chi-square for nominal variables</p>
<p><b>DMC<sub>3</sub> study (Picavet &amp; Schouten 2003, Picavet &amp; Hazes 2003)</b></p> <p><b>Study design</b> Cross-sectional study, cohort study</p> <p><b>Study method</b> Mailed questionnaire with general and health questions. Screening question for each anatomical area: Did you have had pain in 'anatomical area' during the past 12 months? Screen positives were asked to answer questions on pain characteristics and its consequences for each area</p>	<p><b>Type of chronic pain</b> Self-report musculoskeletal pain (screening question: Did you have had pain in 'anatomical area' during the past 12 months?)</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> N= (respondents) 3664 Gender 50.9% females, 49.1% men Age: 47% 25-44 yrs, 34.6% 45-64 yrs, 18.4% 65+ yrs (NB weighted to present a distribution of sex, age, marital status and region of living equal to that of the Netherlands in 1998)</p> <p><b>Patient selection</b> Dutch inhabitants of 25 years and older, who completed the questionnaire</p>	<p><b>Outcomes measured</b> period prevalence, point prevalence, prevalence of chronic pain, course of pain, consequences of pain (utilization of health care, sick leave and limitation in daily life)</p> <p><b>Pain severity</b> roughly 15% reported severe pain and 70% mild pain</p> <p><b>Analyses</b> descriptive, frequencies, multivariate logistic regression</p>

## Q2. Study quality

The quality of Breivik et al. (2006) was rated as moderate. The methods were clearly stated in this study, with clear eligibility criteria and an adequate description of study participants. However, it was not clear if the population participating in the study was representative of target population. Outcomes and their measurement were adequately described; but there was no description of statistical methods used and results were not reported as unadjusted and confounder-adjusted including precision.

The quality of Kerssens et al. (2002) was rated moderate. The study design, outcomes and statistical methods were adequately described and the sample was representative of the target population of general practice. However, the eligibility criteria were unclear because of lacking diagnostic criteria, the description of study participants was poor and included only age and gender and the results were presented without measures of precision.

Picavet (2003 Pain) is a high quality study and Picavet (2003 Ann Rheum Dis) a moderate quality study. The methods were clearly stated in both papers with clear eligibility criteria and a clear description of study participants. However, it was not clear if the population participating in the study was representative of target population. Outcomes and their measurement and statistical methods were adequately described and results were clearly reported as unadjusted and confounder-adjusted including precision. In the follow-up study (Picavet 2003 Ann Rheum Dis) the loss to follow-up was 15% at 6 months. Therefore this paper was rated moderate quality while the other paper (Picavet 2003 Pain) was rated high quality.

## Q2. Results

### General chronic pain

*Breivik et al. 2006*

The prevalence of moderate to severe chronic pain in Netherlands was 18% among 3197 adults (>18 years) responding to a computer-aided telephone screening interview. Chronic pain was defined as pain lasting more than 6 months, having pain during the last month, several times during the last week, and last experienced pain having an intensity 5 or more on a Numeric Rating Scale: 1 (no pain) to 10 (worst pain imaginable). The most common causes for chronic pain were: arthritis/osteoarthritis (19%), herniated/deteriorated discs (13%) and traumatic injury (12%).

*Kerssens et al. 2002*

The overall prevalence of unexplained severe chronic pain was 7.91 per 1000 enlisted patients in general practice. It was highest in the subgroup of patients aged 50 to 54 (see table 3). The prevalence of unexplained severe chronic pain was low in patients below 34 years.

**Table 3.** Age specific prevalence estimates of unexplained severe chronic pain in general practice. Estimates are based on 344 patients

Age	Estimate per 1000 patients
18-24 yrs	1.87
25-29 yrs	1.59
30-34 yrs	3.52
35-39 yrs	8.98
40-44 yrs	10.71
45-49 yrs	10.35
50-54 yrs	16.95
55-59 yrs	13.50
60-64 yrs	10.33
65-69 yrs	8.82
70-75 yrs	11.26
Total	7.91

### Chronic musculoskeletal pain

DMC<sub>3</sub> study (Picavet and Schouten 2003 Pain / Picavet and Hazes 2003 Ann Rheum Dis).

Almost three-quarter (74.5%) of the Dutch population aged 25 years and over reported any musculoskeletal pain during the past 12 months (Picavet 2003 Pain). 44.4% reported musculoskeletal pain lasting longer than 3 months. This pain was most frequently located in the lower back (prevalence 21.2%) and in the shoulders (15.1%) and neck (14.3%). More detailed locations are reported in Table 4 below. The prevalence of chronic widespread pain in upper and lower extremities, in back or neck and in left and right side of the body is 5.2%.

**Table 4.** Prevalence (% and 95% confidence limits) of chronic musculoskeletal pain by anatomical area and site (Picavet 2003 Pain)

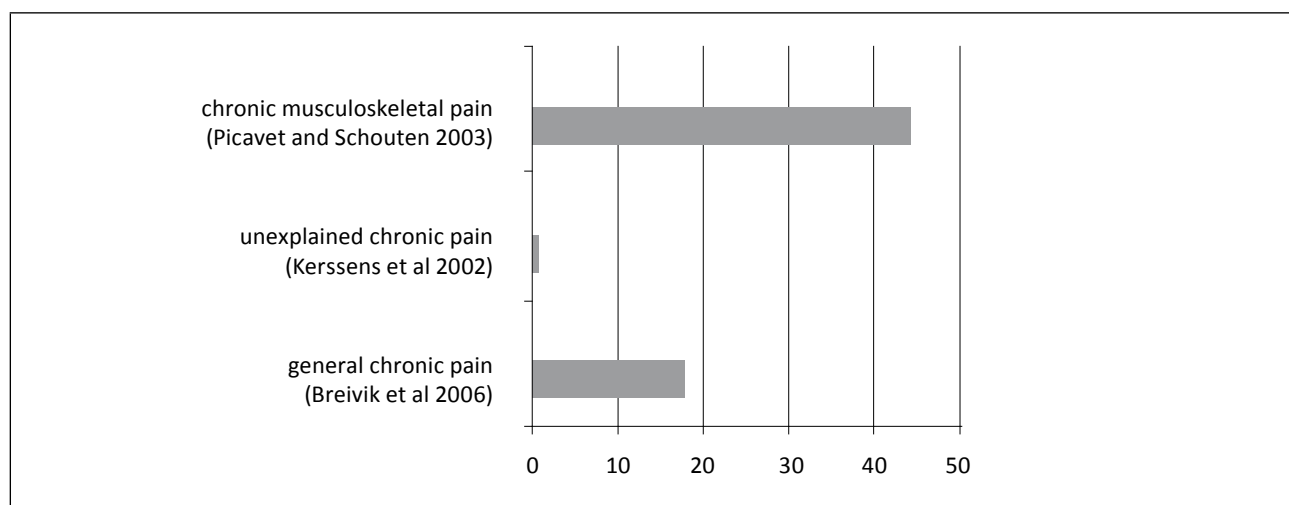
Pain location	Prevalence of chronic pain
Neck	14.3 (±1.1)
Shoulders	15.1 (±1.2)
Higher back	6.2 (±0.8)
Elbow	5.3 (±0.7)
Wrist/hand	9.3 (±0.9)
Lower back	21.2 (±1.3)
Hip	7.4 (±0.8)
Knee	11.7 (±1.0)
Ankle	3.5 (±0.6)
Foot	5.0 (±0.7)
No pain	55.6 (±1.6)
One site	21.6 (±1.3)
2-3 sites	15.6 (±1.2)
4 or more	7.2 (±0.8)
Upper and lower extremities and back or neck, left and right	5.3 (±0.7)
Upper and lower extremities and back, left and right	3.8 (±0.7)
Upper and lower extremities and back or neck	5.8 (±0.8)
Upper and lower extremities and back	4.2 (±0.6)

Another paper based on the same cohort (Picavet 2003 Ann Rheum Dis) presented the prevalence of self-reported chronic musculoskeletal diseases, separately for females and for males. The most prevalent disease was tendinitis or capsulitis (17.2 and 15.4% for females and males, respectively). Other diseases with a prevalence of at least 10% were: herniated disc or back in females, and epicondylitis and osteoarthritis of the knee in both males and females. The percentage of patients that still reported these diseases after 6 months varied between 42.5 and 77.1%. Table 5 presents the figures per disease.

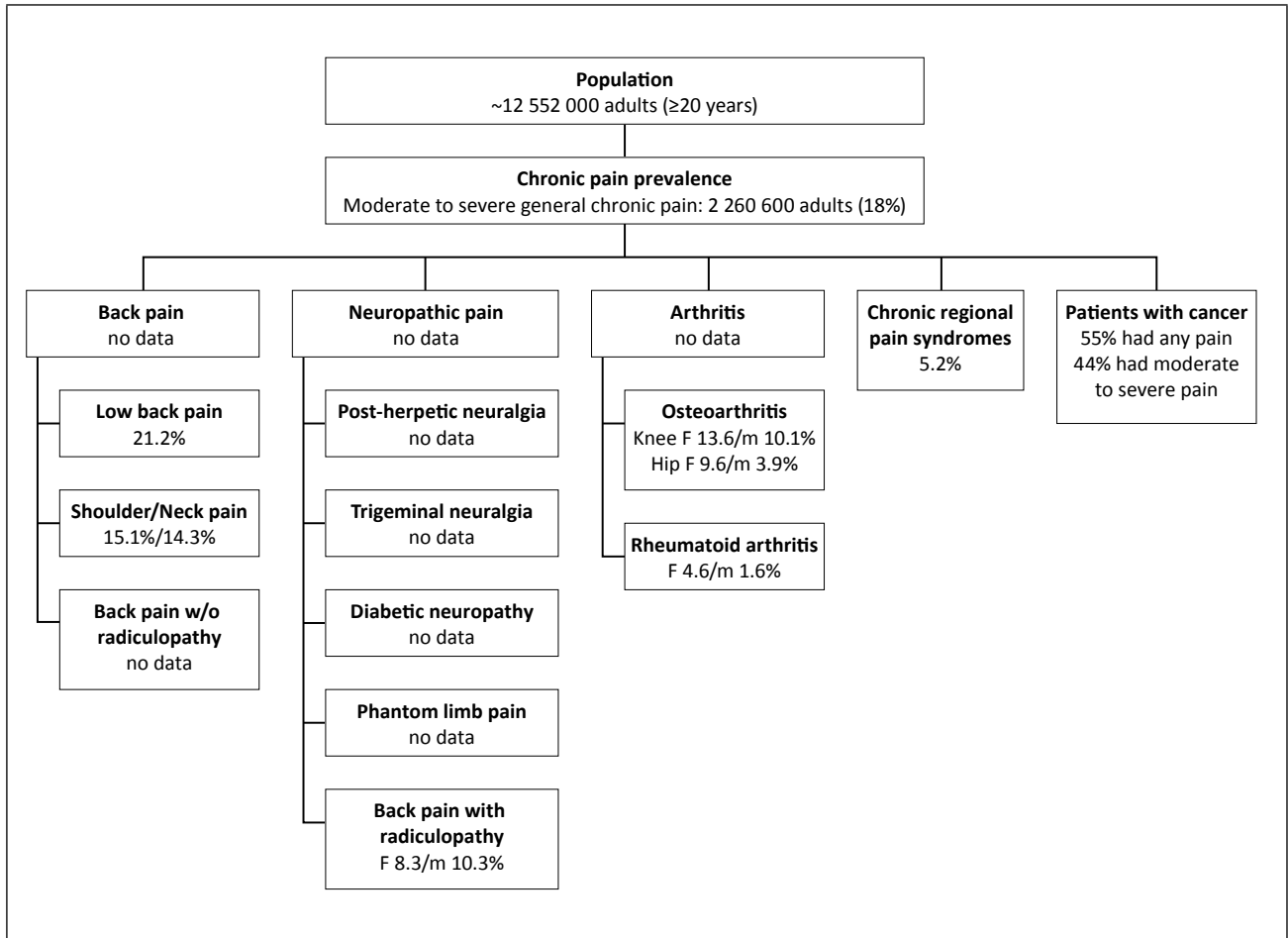
**Table 5.** Prevalence of self-reported musculoskeletal diseases (%) and percentage of patients still reporting these diseases after 6 months (Picavet 2003 Ann Rheum Dis)

Disease	Prevalence (95%CI) in women	Prevalence (95%CI) in men	Patients still reporting the disease after 6 months (%)
Herniated disc of back	8.3 (±1.2)	10.3 (±1.5)	73.0
Gout	2.3 (±0.7)	3.7 (±0.9)	64.0
RSI	2.0 (±0.6)	1.9 (±0.7)	42.5
Epicondylitis	11.6 (±1.4)	10.4 (±1.5)	66.0
Osteoarthritis of knee	13.6 (±1.5)	10.1 (±1.5)	77.1
Osteoarthritis of hip	9.6 (±1.3)	3.9 (±0.9)	67.5
Osteoporosis	9.9 (±1.3)	1.9 (±0.7)	64.6
Whiplash	2.6 (±0.7)	1.6 (±0.6)	70.9
Rheumatoid arthritis	4.6 (±0.9)	1.6 (±0.6)	56.7
Other chronic arthritis	4.4 (±0.9)	2.2 (±0.7)	47.4
Fibromyalgia	2.1 (±0.6)	0.2 (±0.2)	67.7
Tendinitis or capsulitis	17.2 (±1.7)	15.4 (±1.8)	60.4
Other*	22.3 (±1.8)	20.1 (±2.0)	
Combinations reported by >3% of the population			Total population
epicondylitis and tendinitis or capsulitis			4.2%
osteoarthritis of knee and hip			5.3%
osteoarthritis of knee with osteoporosis			3.6%
osteoarthritis of knee with tendinitis or capsulitis			3.6%
osteoarthritis of hip with osteoporosis			3.0%

\* Most of these were (pain) complaints listed later in the questionnaire or fractures/accidents. Other mentioned diseases were osteoarthritis (19 times), sciatica (14), scoliosis (13), pelvis instability (8), herniated disc in the neck (8), ankylosing spondylitis (6), stroke (5), bursitis (5), Scheuermann’s disease (4), spondylitis, and some neurological diseases like chronic polyneuropathy (3), myasthenia gravis (2), and Ménière’s disease (2). Once only were mentioned, for instance, polymyalgia rheumatica, Dupuytren’s disease, hammer toe, psoriatic arthritis, Tietze’s syndrome, and Paget’s disease.



**Figure 4.** Summary of prevalence (in percentages) of different types of chronic pain in the Netherlands



**Figure 5.** Taxonomy of prevalence chronic pain conditions in the Netherlands

## Q2. Summary

The prevalence of chronic musculoskeletal pain is 44.4% in the Netherlands. Frequently, low back pain, shoulder pain and neck pain are locations for such pain. Common underlying causes are tendinitis or capsulitis, epicondylitis and osteoarthritis of the knee for females and males and herniated disc or back in females.

The prevalence of general chronic pain in the Netherlands is 18% and the prevalence of unexplained severe chronic pain in a general practice population 0.8.





**Q3. What is the incidence of chronic pain conditions in the Netherlands?**

We selected four studies that were relevant to this question (De Mos et al 2007, Dieleman et al 2008, Opstelten et al 2005 and Steenstra et al 2006).

De Mos et al (2007) aimed to estimate the incidence of complex regional pain syndrome (CRPS) in the general population during 1996–2005. For this purpose, a retrospective cohort study was conducted using the Integrated Primary Care Information (IPCI) database, a general practice research database with records from 600,000 patients. Potential CRPS cases were identified by a sensitive search algorithm including synonyms and abbreviations for CRPS. Subsequently, cases were validated by electronic record review, supplemented with original specialist letters and information from an enquiry of general practitioners.

Dieleman et al. (2008) used the same general practice research IPCI database containing longitudinal patient data to retrieve data retrospectively, and aimed to estimate the incidence and assessed treatment approaches of neuropathic pain conditions in the general population between 1996 and 2003. Case definition relied on GP and specialists symptoms and diagnosis recorded in the medical record with the GP.

Opstelten et al (2005) aimed to determine the incidence of Herpes Zoster (HZ) and Post-herpetic Neuralgia (PHN) in a primary care population and to identify risk factors for the occurrence of PHN. This study used data from the database of the “Huisartsen Netwerk Utrecht” a different general practice research database comprising 22 general practices and representing 49,000 people, from 1994 to 1999. Cases were identified by searching the database using an ICPC code and free text and medical records were reviewed for confirmation.

Steenstra et al (2006) performed a retrospective descriptive study at population level to compare the incidence of occupational disability as a result of back and neck pain in 1980–1985 to 1999–2000 and to explain the findings. Occupational disability can be claimed after 52 weeks of sick leave. Statistics from the National Institute of Social Insurance in the Netherlands are used to calculate age and gender specific incidence rates for back pain diagnoses based on the ICD-classification. See Table 6 for study characteristics.

**Table 6.** Characteristics of the studies selected for question 3

Study details	Population	Outcomes and analysis
<p><b>Dieleman et al. 2008</b></p> <p><b>Study design</b> Retrospective cohort study</p> <p><b>Study method</b> A search conducted in the IPCI database - a longitudinal general practice research database</p>	<p><b>Type of chronic pain</b> Neuropathic pain</p> <p><b>Confirmation of diagnosis</b> Case definition relied on GP and specialists symptoms and diagnosis recorded in the medical record with the GP. GP diagnoses were accepted if they recurred in the patient record and if typical neuropathic pain symptoms were present</p> <p><b>Sample size and demographics</b> 362,693 persons (1,116,215 person years) Age and gender distribution similar to Dutch population 9810 incident cases</p> <p><b>Patient selection</b> Potential cases were identified in the database between 1996 and 2003 through an inclusive search on free text and ICPC code. Then the medical records were reviewed by medically trained persons</p>	<p><b>Outcomes measured</b> incidence rates of 13 subtypes of neuropathic pains, prescribed treatments</p> <p><b>Pain severity</b> Not reported</p> <p><b>Analyses</b> Age and gender specific incidence rates of different types of neuropathic pain, Cox-regression analysis for the relative risk and 95% confidence interval of neuropathic pain for women versus men</p>
<p><b>De Mos et al. 2007</b></p> <p><b>Study design</b> Retrospective cohort study</p> <p><b>Study method</b> A search conducted in the IPCI database - a longitudinal general practice research database</p>	<p><b>Type of chronic pain</b> Complex regional pain syndrome</p> <p><b>Confirmation of diagnosis</b> 3 sets of criteria: IASP, Bruehl and Veldman</p> <p><b>Sample size and demographics</b> The database contains records of &gt;600,000 patients from more than 150 GPs. This population is representative of the Dutch population regarding age and sex Source population: 217,653 people from 52 practices</p> <p><b>Patient selection</b> Potential cases between 1996 and 2005 were identified by a sensitive search and subsequently validated by means of electronic record review, specialists' letters and information from an enquiry of GPs</p>	<p><b>Outcomes measured</b> Incidence rate, standardized morbidity ratios</p> <p><b>Pain severity</b> Not reported</p> <p><b>Analyses</b> Descriptive statistics, (Chi-square test, univariate logistic regression, Student's t-test), K-statistics for interrater agreement for diagnostic criteria</p>

Study details	Population	Outcomes and analysis
<p><b>Opstelten et al 2005</b></p> <p><b>Study design</b> Cross-sectional / survey (Retrospective data collection)</p> <p><b>Study method</b> A search conducted in the Huisartsen Netwerk Utrecht" database, a general practice research database over a 5-year period</p>	<p><b>Type of chronic pain</b> Herpes zoster (HZ) and post herpetic neuralgia (PHN). PHN was defined as any pain that persisted at least 1 month after HZ diagnosis</p> <p><b>Confirmation of diagnosis</b> GP diagnosis (ICPC code 32 S70 (HZ) or GP confirmation of HZ)</p> <p><b>Sample size and demographics</b> N=837 58% female</p> <p><b>Patient selection</b> All HZ patients diagnosed between 1 August 1994 and 31 July 1999 were identified by searching the database for ICPC code 32 S70 (HZ) and for free text ('zoster'). Medical records were reviewed for confirmation</p>	<p><b>Outcomes measured</b> Incidence of HZ (in different age groups), risk of PHN 1 and 3 months after HZ diagnosis, potential risk indicators for PHN</p> <p><b>Pain severity</b> Severity not reported. Persistent pain 3 months after HZ diagnosis was reported in the medical records of 2.6% (95% CI: 1.7, 4.0) of the HZ patients</p> <p><b>Analyses</b> Univariate and multivariate logistic regression models, Spearman's correlation coefficient</p>
<p><b>Steenstra et al. 2006</b></p> <p><b>Study design</b> Cross-sectional/ survey (Retrospective data collection)</p> <p><b>Study method</b> Descriptive study using statistics from the National Institute of Social Insurance between 1980-1985 and 1999-2000</p>	<p><b>Type of chronic pain</b> Persons who claimed occupational disability due to back disorders. Persons can claim this after 52 weeks of sick-leave</p> <p><b>Confirmation of diagnosis</b> A benefit is granted after a disability evaluation, which includes a health examination by an insurance physician</p> <p><b>Sample size and demographics</b> In 1999-2000, the number of insured persons was 6,710,551 57% males</p> <p><b>Patient selection</b> Diagnoses were coded using ICD-10</p>	<p><b>Outcomes measured</b> incidence of occupational disability as a result of back disorders</p> <p><b>Pain severity</b> Not reported</p> <p><b>Analyses</b> incidence rates per 1000 person years, incidence rate ratios, percentages in-/decrease</p>

### Q3. Study quality

The study of Dieleman et al. (2008) was rated moderate quality. The study reported on a representative sample and study design, eligibility criteria, outcomes and statistical methods were adequately described. However, the study population and loss to follow-up were not reported adequately.

The study of De Mos et al (2007) was rated moderate quality. The study reported on a representative sample and study design, eligibility criteria, study population and outcomes were adequately described. However, the description of statistical methods was inadequate as no information was given about potential confounders and it was not clear whether results were reported as adjusted or unadjusted.

The study of Opstelten et al (2002) was rated as moderate quality. It was unclear whether the study sample was representative of the target sample and the description of participants was inadequate. However, study design, eligibility criteria, statistical methods and outcomes were adequately described. Also results were clearly reported as adjusted or unadjusted with precision.

The study of Steenstra et al (2006) was rated moderate. The study design, outcome and statistical methods were adequately described and the study used a representative population. However, the eligibility criteria and study participants were inadequately described and results were presented without precision.

### Q3. Results

#### *Neuropathic pain*

##### *Dieleman et al. 2008*

The total amount of follow-up time for the 362,693 eligible patients was 1,116,215 years (on average three years per person). A total of 9810 first-time diagnoses of various types of neuropathic pain in 9311 persons were identified during the study period. The overall incidence rate of neuropathic pain was 8.2 per 1000 person years (95%CI 8.0 to 8.4). Mononeuropathy and carpal tunnel syndrome were the most common types of neuropathic pain with the incidence rates of 4.3 and 2.3 per 1000 person years, respectively.

The incidence rate of neuropathic pain gradually decreased over calendar time from 9.8 per 1000 person years (95%CI 9.1 to 10.6) in 1996 to 7.5 per 1000 person years (95%CI 7.1 to 8.0) in 2002 and was consistently higher in women. A peak incidence was observed between the ages 50 and 90 with a maximum of 18.1 per 1000 person years between age 70 and 79. Men and women had a similar age dependent incidence rate.

Women were, however, significantly more often affected than men with 10.1 female cases per 1000 person years (95%CI 9.9 to 10.4) versus 6.2 male cases per 1000 person years (95%CI 6.0 to 6.4).

**Table 7.** Incidence rates of various types of neuropathic pain between 1996 and 2004

Type of neuropathic pain	Incidence rate per 100,000 PY	95% confidence interval
Mononeuropathy (excluding ischias)	209.8	199.7 to 216.6
Ischias	210.4	202.1 to 219.1
Carpal tunnel syndrome	233.1	222.0 to 239.8
Diabetic peripheral neuropathy	72.3	67.3 to 77.2
Post-herpetic neuropathy	41.8	38.1 to 45.7
Trigeminal neuralgia	28.9	25.8 to 32.1
Cervical radiculopathy	16.6	14.3 to 19.1
Phantom limb syndrome	2.2	1.5 to 3.3
Total* number of first-time diagnoses	878.9	861.6 to 896.4

\* Not all types reported in the paper have been extracted here, so numbers may not add up to total

**Complex Regional Pain Syndrome (CRPS)***De Mos et al. 2007*

In the final population of 217,653 persons registered with at least 1 year of valid history at one of the 52 active practices in the IPCI database, 238 incident cases of CRPS could be identified and validated. The incidence rate of CRPS in the Netherlands was 26.2 per 100,000 person years (95%CI 23.0 to 29.7).

Gender-specific incidence rates based on the reconfirmed diagnoses for females and males were 40.4 (95% CI 34.8 to 46.8) and 11.9 (95% CI 9.0 to 15.4) per 100,000 person years, respectively. The incidence of CRPS was more than threefold higher in females than in males (RR 3.4, 95% CI 2.9 to 3.9). The incidence rate of CRPS did not change significantly over time between 1996 and 2005 (results not reported). The incidence varied profoundly with age, the highest incident rate was observed in the group 61 to 70 years (see table 8 below).

**Table 8.** Age-specific incidence rates (per 100,000 PY) of complex regional pain syndrome

Age group	Males IR per 100,000 PY	Females IR per 100,000 PY	Total IR per 100,000 PY
<10	2.0	2.0	2.0
10-19	1.8	14.9	8.2
20-29	6.2	28.0	16.8
30-39	9.0	27.7	18.1
40-49	15.5	27.2	21.4
50-59	24.4	72.1	47.9
60-69	31.4	121.3	77.2
70-79	12.2	58.1	38.4
>80	0.0	47.5	31.9
Total	11.9 (9.0 to 15.4)	40.4 (34.8 to 46.8)	26.2 (23.0 to 29.7)

**Herpes zoster and postherpetic neuralgia***Opstelten et al. 2002*

Over the five-year period, a total of 837 patients have been diagnosed with herpes zoster. The calculated incidence of HZ was 3.4/1000 patients/year (95%CI 2.9 to 3.9). Persistent pain 3 months after HZ diagnosis was reported in the medical records of 2.6% (95%CI 1.7 to 4.0). Both incidence and risk of PHN increased with age (see table 9 below).

**Table 9.** Incidence of herpes zoster and risk of postherpetic neuralgia after diagnosis of herpes zoster in different age groups

Age group (n persons)	Incidence per 1000 PY (95%CI)	Risk of PHN after 3 months
<45yrs (n=30605)	2.1 (1.9 to 2.2)	0.3% (0.01 to 1.7)
45-54 years (n=6987)	3.6 (3.2 to 4.1)	0.8% (0.02 to 4.3)
55-64 years (n=4782)	5.8 (5.2 to 6.5)	2.9% (0.8 to 7.2)
65-74 years (n=3700)	6.5 (5.8 to 7.4)	3.3% (0.9 to 8.3)
>74 years (n=2925)	9.1 (8.1 to 10.2)	9.0% (4.8 to 15.2)
Total	3.4 (2.9 to 3.9)	2.6% (1.7 to 4.0)

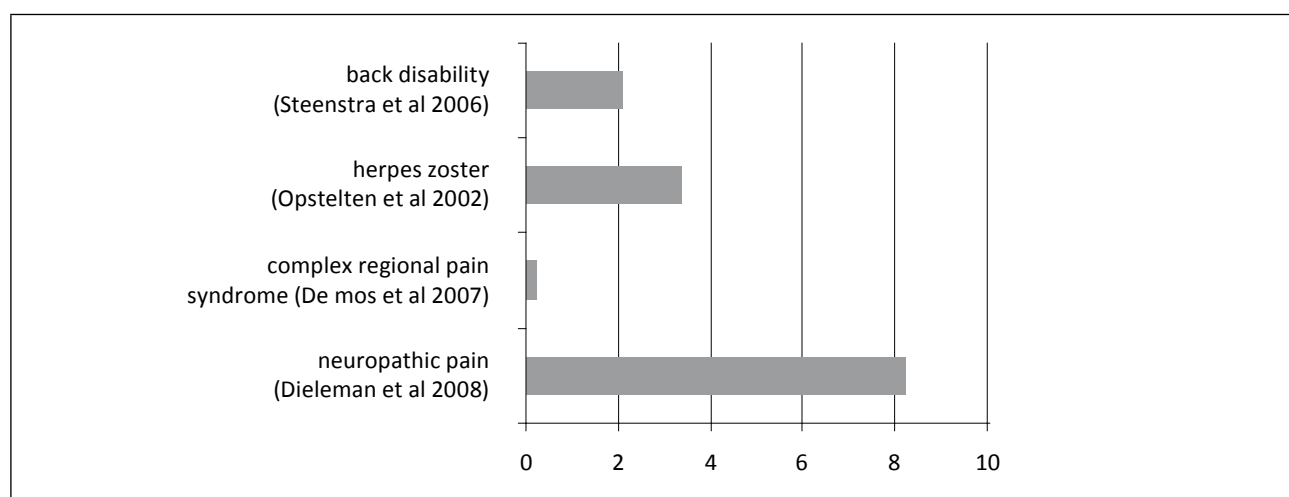
### Back disorders

Steenstra et al. 2006

In 1999-2000, incidence of occupational disability as a result of all back disorders was 2.02 per 1000 workers per year for men. Among these, the incidence of non-specific back pain (dorsalgia) was 0.54 and 0.06 for non-specific neck pain (cervicalgia). The total incidence for women was 2.14 per 1000 workers per year. The incidence of non-specific back pain was 0.76 and non-specific neck pain 0.10 for women.

**Table 10.** Total incidence per 1000 person years of occupational disability as a result of back disorders (deforming dorsopathies, spondylopathies or other dorsopathies) over 1999-2000 per age group

Age group	Men	Women
<25 yrs	0.21	0.52
25-34 yrs	1.15	1.71
35-44 yrs	2.30	2.32
45-54 yrs	3.10	3.66
>55 yrs	4.57	4.81
Total	2.02	2.14



**Figure 6.** Summary of incidence rates (per 1000 person years) for several indications

### Q3. Summary

Four studies were selected that reported on different types of chronic pain.

The overall incidence rate of neuropathic pain was 8.2 per 1000 person years (95%CI 8.0 to 8.4). Women have a consistently higher incident rate than men and mononeuropathy and carpal tunnel syndrome were the most common types of neuropathic pain.



### Q3 - Epidemiology of chronic pain in the Netherlands

The overall incidence rate of Complex Regional Pain Syndrome was 26.2 per 100,000 person years (95%CI 23.0 to 29.7). The incidence of CRPS was more than threefold higher in females than in males (RR 3.4, 95% CI 2.9 to 3.9). The incidence varied profoundly with age, the highest incident rate was observed in the group 61 to 70 years .

The incidence rate of Herpes Zoster (HZ) was 3.4/1000 patients/year (95%CI 2.9 to 3.9). Persistent pain 3 months after HZ diagnosis was reported in the medical records of 2.6% (95%CI 1.7 to 4.0). Both incidence of HZ and risk of persistent pain after diagnosis increased with age.

The incidence of occupational disability as a result of back disorders was 2.02 and 2.14 per 1000 workers per year for men and women, respectively.

**Q4. What percentage of chronic pain patients from the Netherlands are untreated or inadequately treated**

#### Q4 - Epidemiology of chronic pain in the Netherlands

We located five studies that were relevant to this question (Borghouts et al. 1999, Breivik et al. 2006, Smalbrugge et al. 2007 and Van Herk et al. 2009, van Tulder et al. 1998).

Borghouts et al (1999) performed a retrospective study with the aim to describe the management in patients with chronic neck pain in general practice. Results on 517 patients were collected using questionnaire completed by PGs and patients.

Breivik et al. (2006) performed a large telephone survey to explore the prevalence, impact on daily life and treatment of chronic pain in 15 European countries and Israel, among which the Netherlands. Persons received an initial screening questionnaire and those who suffered from long-lasting pain were subsequently interviewed in-depth using a second structured questionnaire. From the Netherlands, 300 persons suffering chronic pain were interviewed.

Smalbrugge et al. 2007 used data from 350 participants of Amsterdam Groningen Elderly Depression (AGED) cohort study performed in 14 Dutch nursing homes to determine prevalence, course, correlates, recognition and treatment of pain among Dutch nursing home-patients and to make a comparison with international data.

Van Herk et al. (2009) performed a cross-sectional multicenter study of 233 residents of Dutch nursing homes. The study aimed to assess the prevalence and intensity of pain in older adults living in Dutch nursing homes and assess the characteristics of pain and the analgesics prescribed as well as impact of pain on daily functioning.

Van Tulder et al. (1998) described the course of chronic low back pain and the performed diagnostic and therapeutic procedures for 524 patients with chronic low back pain in general practice. GPs and patients were asked to complete questionnaire at baseline and at 4, 8 and 12 months follow-up.

**Table 11.** Characteristics of the studies selected for question 4

Study details	Population	Outcomes and analysis
<p><b>Borghouts et al. 1999</b> (Scand J Prim Health Care)</p> <p><b>Study design</b> Descriptive retrospective study</p> <p><b>Study method</b> GPs provided information on procedures provided and patients completed a self-administered questionnaire covering a 12-month period</p>	<p><b>Type of chronic pain</b> Chronic neck pain</p> <p><b>Confirmation of diagnosis</b> Patients with ICPC code L01 or L83 were included; medical records of patients were checked by the GPs on inclusion and exclusion criteria</p> <p><b>Sample size and demographics</b> 517 eligible, 487 assessed (253 responders – data from GPs and patients, 234 non-responders – data from GPs) Responders: median age 51 (IQR 41-60), 60% females Non-responders: median age 55 (IQR 44-62), 56% females</p> <p><b>Patient selection</b> patients with neck pain (ICPC code L01 or L83), registered with GPs participating in the Registration Network of Family Practices of the Maastricht University, aged between 18 and 70 years, symptoms present for at least 6 months before baseline</p>	<p><b>Outcomes measured</b> GP questionnaire: diagnosis, frequency of GPs visits, diagnostic modalities, therapeutic interventions and referrals to medical specialists or paramedical therapists The patients' questionnaire: patient characteristics, pain intensity, sickness related to work and visits to medical specialists and paramedical therapists, onset and frequency of pain episodes during the previous 12 months, severity of current pain</p> <p><b>Pain severity</b> mean severity for responders 4.9 (SD 2.4)</p> <p><b>Analyses</b> Descriptive statistics, Mann-Whitney tests for differences between responders and non-responders, t-tests for differences in mean age and chi-square test to compare sex in the two groups</p>
<p><b>Breivik et al. 2006</b></p> <p><b>Study design</b> Cross-sectional study</p> <p><b>Study method</b> Telephone survey in two parts. First, persons were screened for chronic pain. Those who qualified were interviewed in-depth</p>	<p><b>Type of chronic pain</b> Long-lasting pain: chronic pain for at least 6 months, and pain in last month, and pain at least 2 times/week, and rating pain intensity at least 5 on 10-point NRS</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> Total sample: 4839; Netherlands: 300 persons with long-lasting pain Demographics for all countries together: 52% female mean age 50 years. For the Netherlands: female 60%, mean age 51.3 years</p> <p><b>Patient selection</b> Subjects with long-lasting pain (see definition above)</p>	<p><b>Outcomes measured</b> Duration, location, intensity of pain. Tolerance, time course of pain, impact pain on activities daily life, employment status, emotional status Visits to doctors, visits to pain management specialist, treatment (medication and non-medication), effectiveness of treatment, satisfaction with doctors, respondents' attitudes and beliefs about pain and pain treatment, respondents' perception of the attitude of others to their pain</p> <p><b>Pain severity</b> 18% reported severe pain</p> <p><b>Analyses</b> Descriptive analysis only. No subgroups were reported (for the Netherlands)</p>

Study details	Population	Outcomes and analysis
<p><b>Smalbrugge et al.</b></p> <p><b>Study design</b> Longitudinal-cohort study</p> <p><b>Study method</b> data collected in the Amsterdam Groningen Elderly Depression (AGED) study; twice face to face interview; pain measured with pain-subscale Nottingham Health Profile; recognition of pain and treatment – chart review</p>	<p><b>Type of chronic pain</b> Self-reported pain</p> <p><b>Confirmation of diagnosis</b> Self-reported pain according to the pain subscale of the Dutch version of the Nottingham Health Profile (8 items with a yes-no format and a score ranging from 0 to 8 (0 = no pain symptoms))</p> <p><b>Sample size and demographics</b> n = 350 at baseline 229 at follow up mean age 79.3; SD 8.3; range:55–99, female 68.9%</p> <p><b>Patient selection</b> subjects in 14 nursing homes aged 55 years and over, speakers of Dutch and able to communicate sufficiently, without serious hearing problems or severe cognitive impairment (Mini-Mental State Examination <math>\geq</math> 15) Excluded: patients with at baseline an expected stay of less than 6 months</p>	<p><b>Outcomes measured</b> Prevalence of pain, course of pain; Recognition and treatment of pain (nursing home physician and chart review); Cognitive functioning (MMSE); Depressive symptoms (Geriatric Depression Scale); Anxiety (Schedules for Clinical Assessment in Neuropsychiatry); Sleep (SCAN); Presence of physical illness (questionnaire of 13 somatic diseases) Functional limitations (Groningen Activity Restriction Scale)</p> <p><b>Pain severity</b> At baseline 27.5% (n = 94) serious pain symptoms (“unbearable pain” or “constant pain”) and 40.5% (n = 138) mild pain symptoms (reported positive on other items but had no “unbearable pain” and no “constant pain”) At follow up 58.6% “unbearable pain” and 66.0% “constant pain” still present at 6 months</p> <p><b>Analyses</b> descriptive, chi square, crude odds ratios (OR) and corresponding 95% confidence intervals (CI), multiple logistic regression to calculate adjusted odds ratios</p>
<p><b>Van Herk et al. 2009</b></p> <p><b>Study design</b> cross-sectional / survey</p> <p><b>Study method</b> A standardized pain questionnaire was used based on the McGill Pain Questionnaire to measure aspects on pain. The use of analgesics was extracted from medical charts</p>	<p><b>Type of chronic pain</b> Self-reported pain in previous week. For 72% the pain was chronic (at least 3 months)</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> 233 residents completed questionnaires Median age 79 years (IQR 73-84) 70% were female</p> <p><b>Patient selection</b> residents without cognitive impairment</p>	<p><b>Outcomes measured</b> Characteristics of pain, pain treatment, pain management index (how well is pain managed), impact pain on sleep and ADL, satisfaction pain treatment</p> <p><b>Pain severity</b> Median pain intensity was 5 (IQR 2-7), 88 reported moderate or severe pain (<math>\geq</math> 4 on NRS)</p> <p><b>Analyses</b> Nonparametric data are given as median and interquartile range (IQR). Differences in demographics between the nursing homes are analyzed by chi-squared tests and Kruskal-Wallis tests. The multiple linear regression method was used to indentify interferences with sleep and ADL, with pain intensity for the previous week as dependent variable</p>

Study details	Population	Outcomes and analysis
<p><b>Van Tulder et al. 1998</b></p> <p><b>Study design</b> longitudinal / cohort study</p> <p><b>Study method</b> GPs provided information on diagnosis and treatments. Patients completed questionnaires at baseline and during follow-up</p>	<p><b>Type of chronic pain</b> Chronic low back pain</p> <p><b>Confirmation of diagnosis</b> Patients with ICPC code L03 or L86 were included; researchers checked patient questionnaire if patients met inclusion criteria with respect to the duration of the back pain</p> <p><b>Sample size and demographics</b> 524 patients (368 participants - data from GPs and patients, 156 non-participants -data from GPs) Mean age of participants: 41.1 years (SD 10), 51% men</p> <p><b>Patient selection</b> GPs selected prevalent cases from computer files: included were patients with low back pain with or without radiating symptoms, aged between 20-60 years, had had current symptoms for at least 3 months</p>	<p><b>Outcomes measured</b> frequency of diagnostic modalities, therapeutic interventions and referrals to paramedical therapists and medical specialists, patient characteristics, average pain intensity (10-p ordinal scale), global measurement of improvement, number of episodes of low back pain, absenteeism from work, functional status (Roland Disability Questionnaire), general health perception (Nottingham Health Profile), visits to paramedical and complementary therapists and medical specialists</p> <p><b>Pain severity</b> mean (SD) 10-p scale at baseline 5.6 (2.9) median (IQR) NHP pain subscale at baseline 40.5 (10.5-69.8)</p> <p><b>Analyses</b> Descriptive statistics, differences between groups using Mann-Whitney tests or t-tests</p>

## Q4. Study quality

Borghouts et al (1999 Scand J Prim Health Care) was rated moderate. Although the study design was clear, the dates of recruitment were lacking. Furthermore, it was unclear whether the sample was representative – the paper stated that the patient population in the network reflect the Dutch general population but it was not clear on which variables that is. Lastly, it was not clear whether the results were adjusted or unadjusted for confounders.

The quality of the Breivik et al. study was rated as moderate; in this study it was not clear that the population was representative and the statistical methods were not clearly described.

The Smalbrugge et al. 2007 study quality was rated as moderate mainly because it was unclear if the sample was representative of all nursing home residents and loss to follow up was over 30% at 6 months.

The Van Herk et al. study was rated low mainly because it was not clear that the sample was representative of all nursing home residents, the eligibility criteria were not clearly described and nor were the statistical methods and it was unclear if the results were reported as unadjusted and confounder-adjusted including precision.

The quality of Van Tulder et al (1998) was rated moderate. The study included a sample of patients that was representative for the Dutch general population, but the time period of recruitment was not stated. Eligibility criteria, outcomes, included population and method of analysis were clearly described. It was unclear whether the results were adjusted or unadjusted for confounders.

## Q4. Results

### ***Percentage of patients untreated***

#### ***General pain***

*Breivik et al. 2006*

One third of the chronic pain patients in Europe (31%) were not treated for their pain. These figures were not presented separate for the Netherlands.

*Smalbrugge et al. 2007*

Of 197 patients who reported pain symptoms at baseline 36% did not receive any prescription for analgesics (Fig.1). Of these, forty-seven (38.8%) had mild pain symptoms and 23 (30.3%) had serious pain symptoms.

*Van Herk et al. 2006*

Of 153 residents of nursing homes who reported that they had experienced pain in the previous week, 38 (24.8) were not prescribed analgesics (Fig.1). Of the 88 residents with an NRS 4 for present pain, and the 41 residents with intolerable pain at present, 19 (22%) and 12 (29%), respectively, did not receive any pain medication.

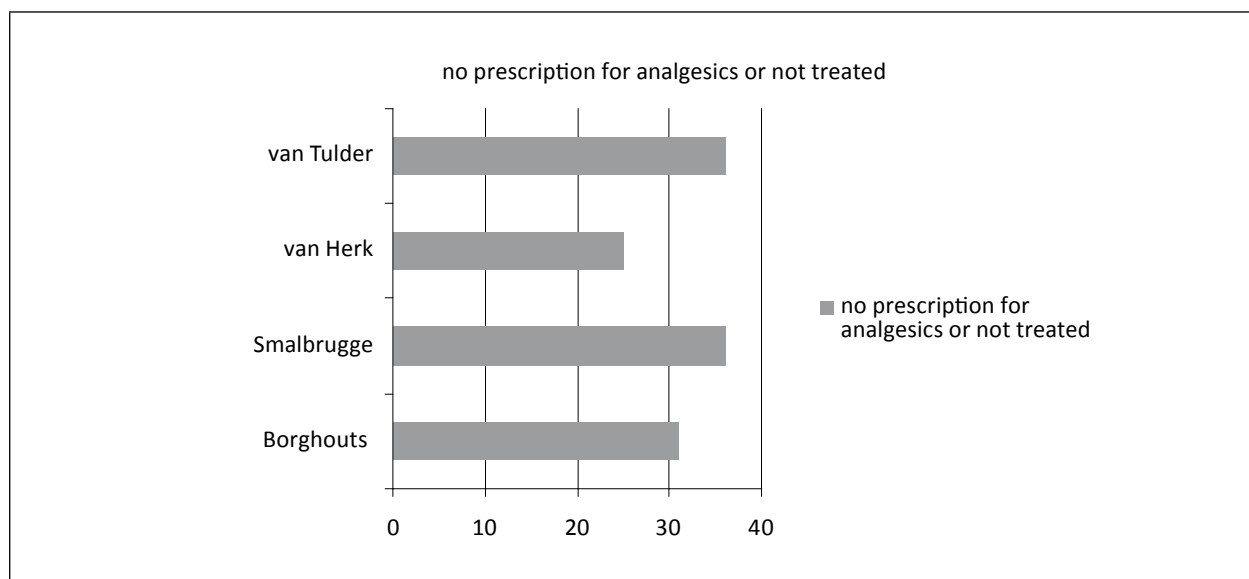
#### ***Chronic musculoskeletal pain***

*Borghouts et al. 1998 (Scand J Prim Health Care)*

This study assessed the treatment of 487 patients with chronic neck pain in general practice. In total population 67% of patients had no therapy. Forty four percent of included patients visited the GP for neck pain in the previous year, of them 31% did not receive treatment (Fig.1).

*Van Tulder et al. 1998*

This study assessed treatments of 524 patients with chronic low back pain in general practice, 72.8% (95% CI 68.8–76.8) of them received no treatment. Forty two percent of total population visited their GP during 12 months follow up because of their low back pain and 36% of them received no treatment (Figure 7).



**Figure 7.** Percentage of patients with pain who did not receive prescription for analgesics or did not receive treatment from their GP

### Percentage of patients inadequately treated

*Brevik et al. 2006*

Out of 119 respondents 79% reported inadequate pain control from medication (affirmative answer to the question: "Are there ever times when your pain medicines are not adequate to control your pain?") while a European average was 64%. Out of 274 respondents 56% reported inadequate pain control (affirmative answer to the question: "Would you say your pain is being adequately controlled?") while a European average was 40%.

*Smalbrugge et al. 2007*

Inadequacy of pain treatment was reported in terms of prescribed daily dose/defined daily dose ratio (PDD/DDD-ratio) which is used as an indication of the adequacy of dosing. According to the authors' definition the ratio below 2/3 is indicative of underdosing. For opioids, 69.2% of the patients had a PDD/DDD-ratio lower than 2/3. For paracetamol a PDD/DDD-ratio was lower than 2/3 in 30.8% of the patients.

*Van Herk et al. 2006*

Thirty-four percent of 159 residents were treated inadequately as reflected by the Pain Management Index (PMI), which reflects how well pain is managed with pharmacologic interventions by comparing the analgesic prescribed with the level of pain intensity.

## Q4. Summary

Four studies reported data regarding Dutch patients untreated for their pain problem. Two were performed in nursing home populations and the definition of untreated was similar – patients who did not receive analgesics. The percentages of such patients varied between 25 and 36%. Two studies were performed in general practice,



regarded musculoskeletal pain and reported that 31–36% of patients with neck pain or low back pain visiting their GP received no treatment for their pain.

Three studies reported percentages of inadequately treated patients, which ranged between 34% and 79%. It should be noted that inadequacy of treatment was defined differently in these studies. Smalbrugge et al. 2007 reported on the percentage of patients with inadequate analgesics dosing and van Herk et al 2009 reported inadequate treatment as indicated by Pain Management Index in 34% of nursing home residents, while Breivik et al. 2006 reported inadequate pain relief according to patient assessment.

**Q5. How many chronic pain patients from the Netherlands present themselves for treatment?**

We found 13 relevant studies and selected five studies for this question (de Mos et al. 2009, Huisstede et al. 2008, Picavet et al. 1999, Picavet and Schouten 2003, Picavet et al. 2008).

De Mos et al. 2009 aimed to describe treatment (pharmacological and other) and referral patterns in a population-based selection of 102 CPRS patients during a study period (1996–2005) before issuing of the Dutch evidence-based treatment guidelines (2006).

Huisstede et al. 2008, Picavet and Schouten 2003 and Picavet et al. 2008 were based on DMC3 population survey data based on 3664 respondents. Huisstede et al. 2008 aimed to study the prevalence of upper extremity disorders (UEDs) and neck as a total and complaints of the arm, neck and/or shoulder (CANS) not caused by acute trauma or any systemic disease as defined in the CANS model in the open population and to assess socio-demographic and health characteristics of chronic symptoms. The aim of Picavet and Schouten 2003 study was to present estimates on the prevalence of musculoskeletal pain of five different anatomical areas and ten anatomical sites, and their consequences and risk groups in the general Dutch population. Picavet et al. 2008 described the utilization of health care services among persons with low back pain on the basis of DMC3 survey and registration data from DNSGP-2 study based on 293,636 respondents.

Picavet et al. 1999 aimed to study the burden of illness of low back problems and prevalence and consequences in the working and the non-working population on the basis of cross-sectional MORGEN study.

**Table 12.** Characteristics of the studies selected for question 5

Study details	Population	Outcomes and analysis
<p><b>de Mos et al. 2009</b></p> <p><b>Study design</b> Retrospective observational</p> <p><b>Study method</b> patient identified from The Integrated Primary Care Information Project (IPCI) database; GP confirmation of diagnosis; patients questionnaire, interview and a physical examination (diagnostic verification); referrals also from IPCI database and specialist letters, prescriptions from IPCI and pharmacy dispensing data</p>	<p><b>Type of chronic pain</b> Complex regional pain syndrome (CRPS)</p> <p><b>Confirmation of diagnosis</b> diagnostic criteria for CRPS as established by International Association for the Study of Pain (IASP)</p> <p><b>Sample size and demographics</b> N = 102 Mean age 51 years (range 12–86) Female 79%</p> <p><b>Patient selection</b> Patients selected from an electronic general practice (GP) database (Integrated Primary Care Information Project) incident during study period with at least 1 year of valid history within the IPCI database (1996–2005) still active in the IPCI database in 2006 and able to provide additional information, who participated in diagnosis verification (International Association for the Study of Pain criteria) and assessment of referrals and treatment</p>	<p><b>Outcomes measured</b> referrals, treatment for CRP</p> <p><b>Pain severity</b> NR</p> <p><b>Analyses</b> descriptive, frequencies, Kaplan-Meier survival analysis for time to treatment (from the index date)</p>

Study details	Population	Outcomes and analysis
<p><b>Huisstede et al. 2008</b></p> <p><b>Study design</b> Cross-sectional/ survey</p> <p><b>Study method</b> DMC3 study - national health survey of musculoskeletal conditions; postal questionnaire – with general questions and health questions. After screening question for each of 5 anatomical areas Additional questions regarding pain in this area and its consequences; general health was measured using the Short Form(SF)-36</p>	<p><b>Type of chronic pain</b> Upper extremity disorders (UED) and neck pain; complaints of the arm, neck and/or shoulder (CANS; excluding UED caused by an acute trauma or a systemic disease)</p> <p><b>Confirmation of diagnosis</b> NR; only screening question: "did you have pain in 'anatomic area' during the past 12 months?"</p> <p><b>Sample size and demographics</b> 3664 respondents 25–44 years 47.0%, 45–64 years 34.6%, 65+ years 18.4% Female 50.9%</p> <p>chronic UED 996 chronic UED due to systemic disease or acute trauma 299 chronic CANS 697</p> <p><b>Patient selection</b> DMC3 - Dutch population aged 25 years and above; this study - persons with musculoskeletal upper extremity and neck disorders in 4 anatomic sites: neck, shoulder, elbow, and wrist/hand</p>	<p><b>Outcomes measured</b> 12-month prevalence, point prevalence, and prevalence of chronic pain (pain at baseline and lasting more than 3 months in the last 12 months) course of pain, consequences of pain (contact with general practitioner, medical specialist or physiotherapist, work leave, limitations in daily life), general health</p> <p><b>Pain severity</b> self-reported - severe or mild chronic total UED Continuous severe pain 5.4% Recurrent severe pain 12.7% Chronic CANS Continuous severe pain 3.9% Recurrent severe pain 12.8%</p> <p><b>Analyses</b> Descriptive analysis only</p>
<p><b>Picavet and Schouten 2003</b></p> <p><b>Study design</b> Cross-sectional study</p> <p><b>Study method</b> DMC3 study - national health survey of musculoskeletal conditions; postal questionnaire – with general questions and health questions. After screening question for each of 5 anatomical areas Additional questions regarding pain in this area and its consequences; socio-demographic characteristics</p>	<p><b>Type of chronic pain</b> Neck, shoulder, higher back 44.5% Elbow, wrist/hand 23.2% Lower back 43.9% Hip, knee 28% Ankle, foot 14.9%</p> <p><b>Confirmation of diagnosis</b> NR; only screening question: "did you have pain in 'anatomic area' during the past 12 months?"</p> <p><b>Sample size and demographics</b> Total sample: 3664 respondents weighted to present a distribution of sex, age, marital status and region of living equal to that of the Netherlands in 1998: Sex men 49.1% women 50.9% Age group 25-44 47.0% 45-64 34.6% 65+ 18.4%</p> <p><b>Patient selection</b> Dutch inhabitants of 25 years and older</p>	<p><b>Outcomes measured</b> Musculoskeletal pain period prevalence, point prevalence, prevalence of chronic pain, course of pain, consequences of pain (contact with general practitioner, medical specialist or physiotherapist, use of medicines, work leave, limitations in daily life, and work disability)</p> <p><b>Pain severity</b> self-reported - severe or mild roughly 15% severe pain</p> <p>Neck, shoulder or higher back Continuous severe pain 3.1% recurrent severe pain 8.3% Elbow or wrist/hand Continuous severe pain 4.0% recurrent severe pain 11.0% Lower back Continuous severe pain 3.5% recurrent severe pain 15.4% Hip or knee Continuous severe pain 5.2% recurrent severe pain 10.1% Ankle or foot Continuous severe pain 6.1% recurrent severe pain 12.4%</p> <p><b>Analyses</b> descriptive, frequencies, multivariate logistic regression</p>

Study details	Population	Outcomes and analysis
<p><b>Picavet et al. 2008</b></p> <p><b>Study design</b> Cross-sectional survey and registration of general practice data</p> <p><b>Study method</b> contact with health services: DMC3-cross-sectional study - postal survey; Registration data –the second Dutch National Survey of General Practice (DNSGP-2) carried out in 104 general practices with 195 participating GPs</p>	<p><b>Type of chronic pain</b> Low back pain</p> <p><b>Confirmation of diagnosis</b> DMC3 – self reported chronic low back pain (lasting longer than 3 months) Register - Low back pain was defined using ICPC-codes L02, L03, and L86 that stand for back symptoms or complaints, and low back pain with and without radiation</p> <p><b>Sample size and demographics</b> Total sample: 3664 in DMC3 and 293,636 in register Mean age and percentage of male/female NR</p> <p><b>Patient selection</b> Dutch population of 25 years and older</p>	<p><b>Outcomes measured</b> Utilization of health services due to low back pain - contact with GP, contact with medical specialist, contact with physiotherapist</p> <p><b>Pain severity</b> NR</p> <p><b>Analyses</b> Descriptive</p>
<p><b>Picavet et al. 1999</b></p> <p><b>Study design</b> Cross-sectional study</p> <p><b>Study method</b> data from the MORGEN-study - questionnaires and for those who screened positive supplementary questionnaire and a medical examination at the regional Public Health Service (PHS) in each town</p>	<p><b>Type of chronic pain</b> Low back pain</p> <p><b>Confirmation of diagnosis</b> Screening question illustrated by a drawing of a complete human figure indicating the area between L1 and the gluteal folds (painted black) as the area of interest</p> <p><b>Sample size and demographics</b> Total sample: n = 13927 (weighted for the age and sex distribution of the Dutch population aged 20 ± 59 y in 1994) working population n = 8482 male 60% 20–29 yrs 27.6% 30–39 yrs 32% 40–49 yrs 27.1% 50–59 yrs 13.3% non working population n = 5340 male 34.4% 20–29 yrs 27.6% 30–39 yrs 21.4% 40–49 yrs 23.6% 50–59 yrs 27.3%</p> <p><b>Patient selection</b> men and women aged 20 - 59 y who were living in three towns located in different regions in the Netherlands</p>	<p><b>Outcomes measured</b> The 12 month period prevalence of low back problems, chronic low back problems (longer than three months); low back problems with radiation to the leg(s); low back pain consequences - activity limitation, use of health services, work disabled, work change or adaptation</p> <p><b>Pain severity</b> NR</p> <p><b>Analyses</b> descriptive, logistic regression analysis</p>

## Q5. Study quality

The quality of the de Mos et al. 2009 study and Huisstede et al. 200 study was rated as moderate, as it in both studies was unclear that the population was representative and the statistical methods were not clearly described and the results were not reported as unadjusted and confounder-adjusted including precision. In de Mos et al. 2009 study it was unclear that the population was representative  
In the Huisstede et al. 2008 study there was no adequate description of the eligibility criteria,

Picavet et al. 1999 study and the Picavet and Schouten 2003 quality were rated as high quality. In both studies one item was missing – they did not provide adequate description of eligibility criteria.

The quality of the Picavet et al. 2008 study was rated as low, mainly because there was no adequate description of the eligibility criteria, it was unclear that the population was representative, there was no adequate description of study participants and the results were not reported as unadjusted and confounder-adjusted including precision.

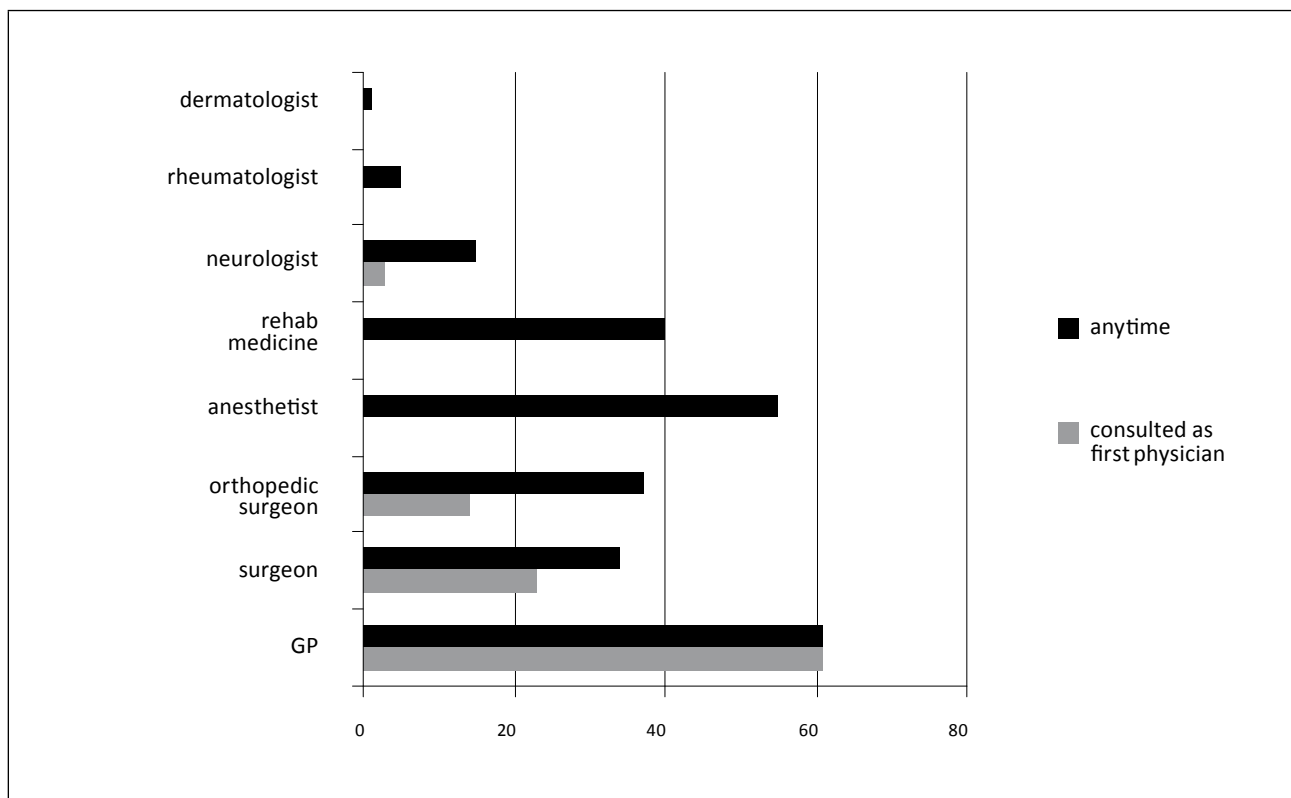
## Q5. Results

### ***Complex regional pain syndrome***

#### *De Mos et al. 2009*

Most CRPS patients visited the GP as the first physician, before consulting a medical specialist. In 63% of these cases, the GP already suspected or made the CRPS diagnosis. Patients with CRPS following a soft tissue injury presented at the GP first instead of a medical specialist (75% vs. 25%), while patients with CRPS after surgery usually first presented at the medical specialist (17% vs. 83%). Cases precipitated by a fracture presented themselves at GP and specialist equally often (46% vs. 55%). GP and other physicians consulted as first – (figure 8).

Over 80% of the patients visited a medical specialist at some point during their disease course. On average, a patient consulted 2.4 different specialties of physicians. The anesthetist was the most commonly involved medical specialist, while rehabilitation medicine was the second most consulted specialty. Medical specialists referred to an anesthetist or to rehabilitation medicine in more than half of the cases, while GPs referred more to (orthopedic) surgeons. The most common referral pattern was from GP to (orthopedic) surgeon to anesthetist or to rehabilitation medicine. In most cases (>80%), the CRPS diagnosis had been made before consultation of the anesthetist or rehabilitation medicine specialist.

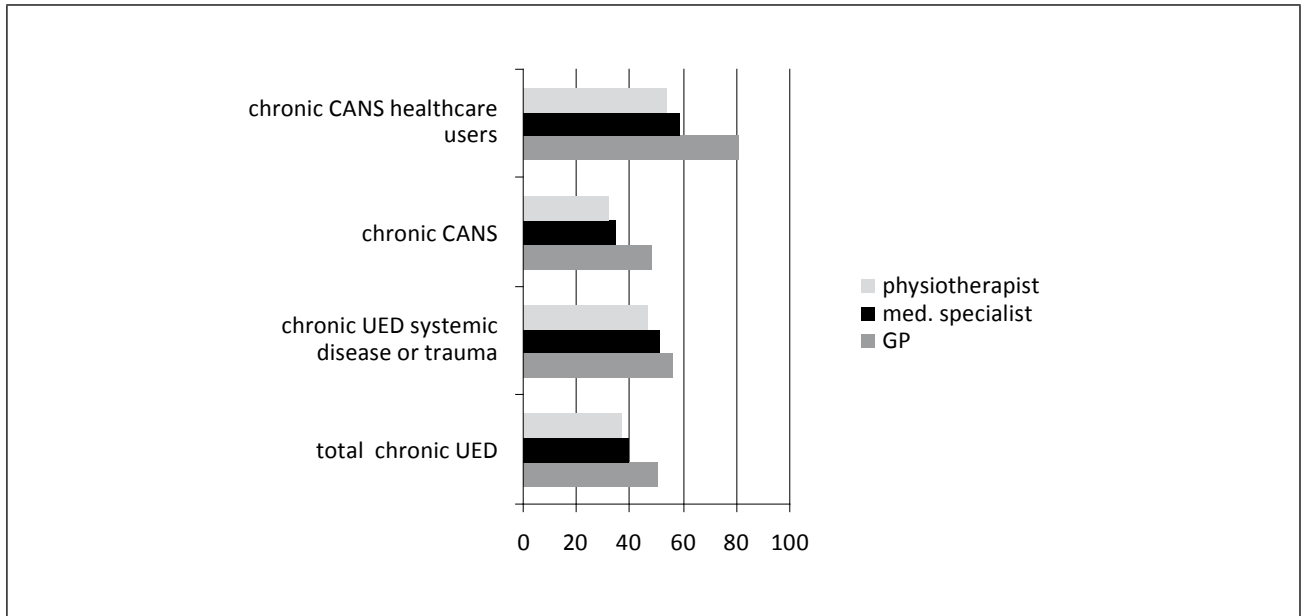


**Figure 8.** Percentage of patients visiting specific health professional as first physician and anytime during disease course

**Musculoskeletal pain**

Huisstede et al. 2008

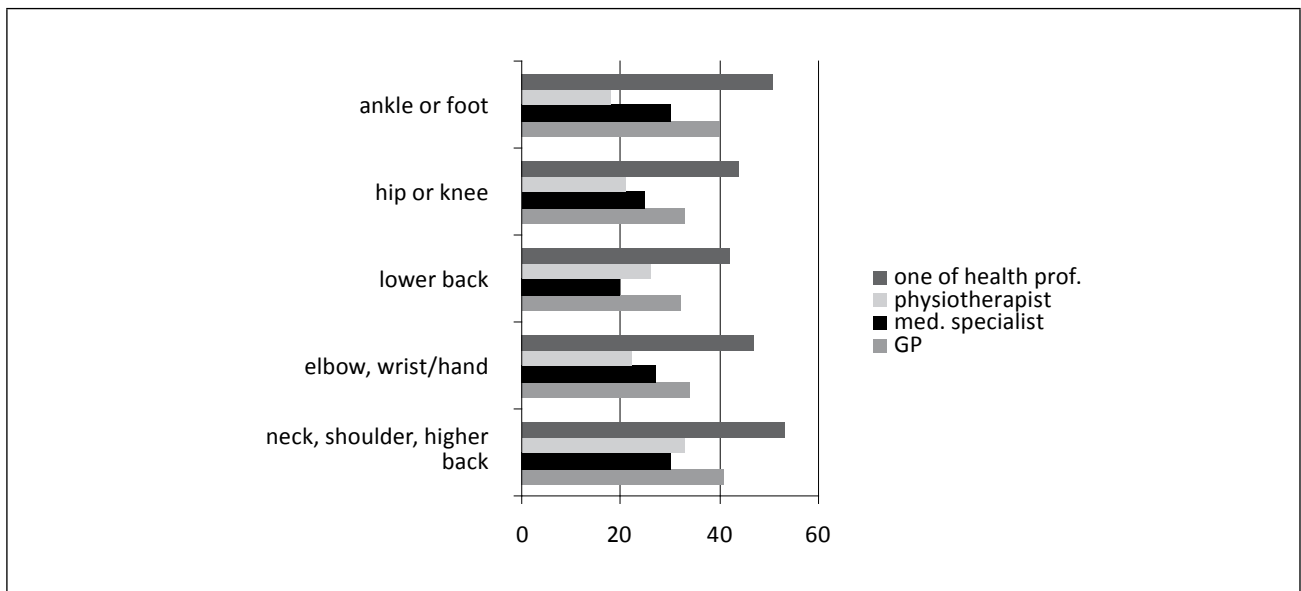
Half of the patients with chronic UED reported contact with the GP, 40% reported contact with medical specialist and over one third reported contact with physiotherapist in the last 12 months due to their symptoms. In the subgroups of patients with chronic UED due to acute trauma or systemic disease and chronic CANS similar percentages reported contact with the GP in the last 12 months, while more patients from the first subgroup reported contact with medical specialist and physiotherapist in the last 12 months. Among patients with chronic CANS 58% reported the contact with healthcare professional in the last 12 months – in most patients it was the GP, in more than half – medical specialist and physiotherapist (Figure 9).



**Figure 9.** Percentage of patients visiting specific health professional in different subgroups of symptoms, DMC3 study (UED – upper extremity disorders and neck pain, CANS – complaints of the arm, neck and/or shoulder)

Picavet and Schouten 2003

Almost half of those reporting musculoskeletal pain in any of the 5 examined locations reported contact with any health professional because of their specific musculoskeletal pain during the last year (Fig. 3). Roughly between 30 and 40% reported contact with the GP, between 20 and 30% contact with a medical specialist and between 20 and 30% a contact with the physiotherapist (Figure 10).



**Figure 10.** Percentage of patients with musculoskeletal pain visiting specific health professional by anatomical area of pain, DMC3 study



**Low back pain**

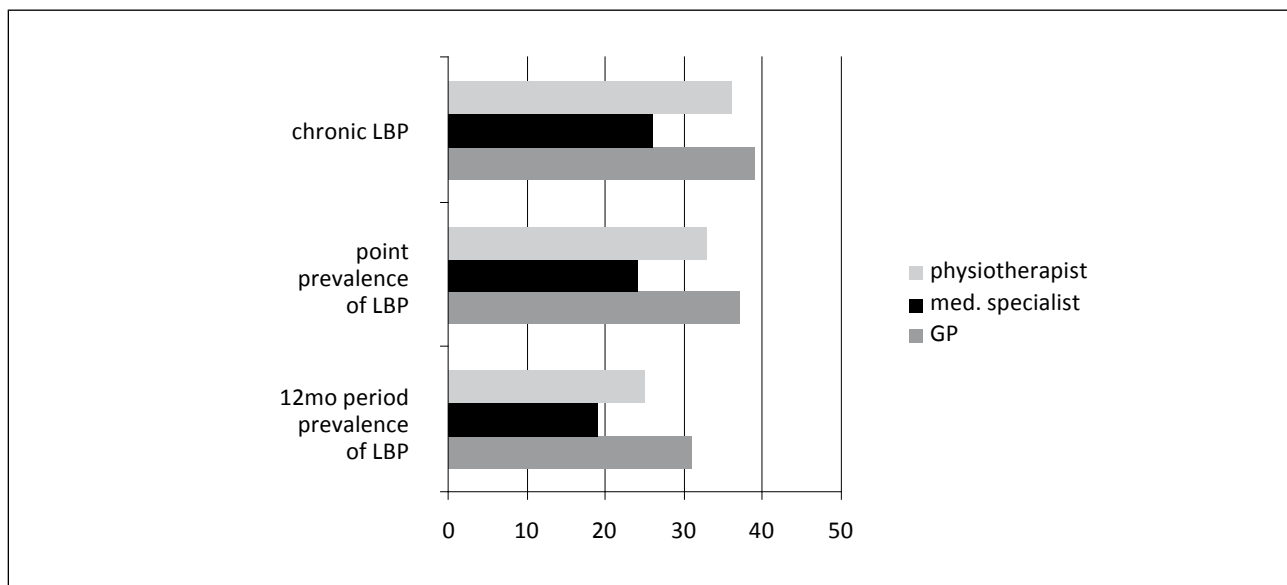
*Picavet et al. 2008*

In DMC3 survey 13% of respondents reported contact with GP due to low back pain.

People reporting low back pain 12 month period prevalence had higher healthcare contact frequencies than those without low back pain. This was true for contact with GP (82.2% vs. 72.8%), contact with medical specialist (37.3% vs. 33.7%), and contact with physiotherapist (33.2% vs. 16.5%). The most frequently mentioned medical specialists were the neurologist and occupational physician.

For people reporting point prevalence or chronic low back pain the frequencies were slightly higher – for GP contact 85.1% and 84.9%, for medical specialist 41.8% and 43.0%, for physiotherapist 40.2% and 41.8% respectively.

Frequencies of contacts with healthcare services due to low back pain in people with 12 month low back pain period prevalence are presented in Figure 4. Contacts due to low back pain represented 37% of total contacts with GPs, 51% of total contacts with medical specialists and 76% of total contacts with physiotherapist. This figures were slightly higher among people reporting point prevalence or chronic low back pain – 44% of total and 46% of total for GP, for medical specialist 58% of total and 61% of total for medical specialist, 82% of total and 87% of total for physiotherapist.



**Figure 11.** Percentage of patients with low back pain visiting specific health professional due to low back pain (LBP –low back pain), DMC3 study

In registration data 8.9% of population had contact with GP due to low back pain, on average 8.2 contacts in 1 year, 1.6 contacts due to low back pain (20% of total contacts). Among the patients with low back pain, 28.5% were referred to medical specialist care of which 20% were due to low back pain (mainly neurology and orthopedics). Referral to physiotherapists or paramedical services was found by 25.9% of those with low back pain, and the majority was due to low back pain (83.8%).

For both sources of data, the health services utilization was higher among women than among men, especially among the higher age groups.

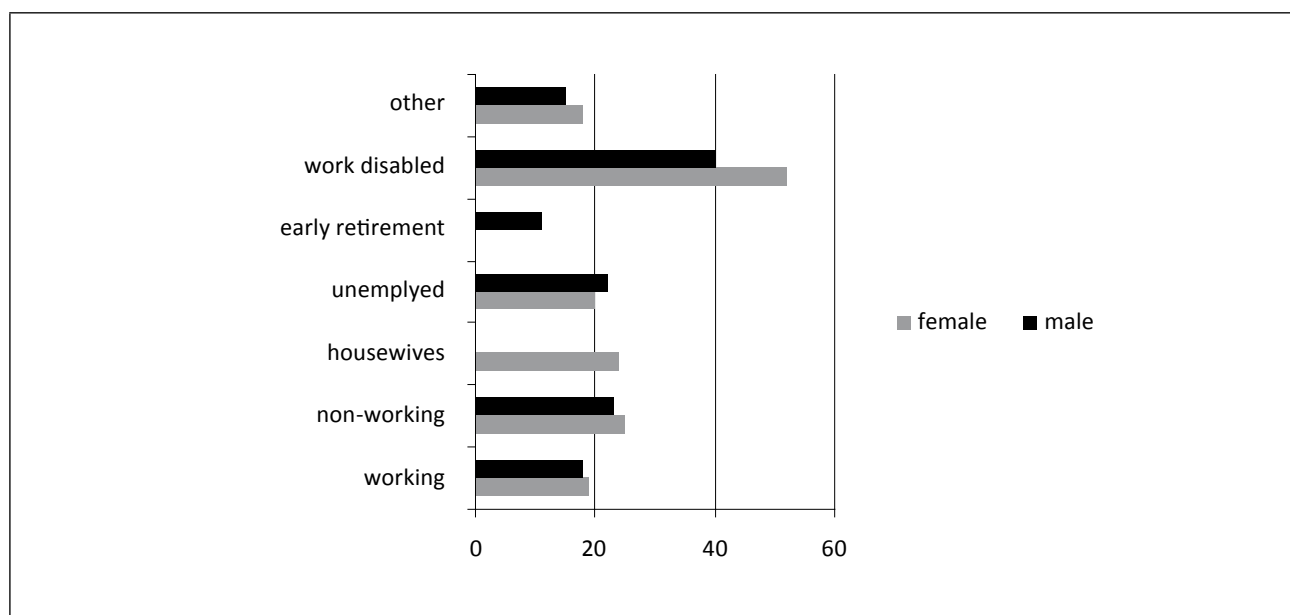
Health service utilization was higher among those with a low educational level compared with high educational level, especially for GP-contacts due to low back pain. These differences were more pronounced for the survey data (low: 17.1% vs. high: 8.7%) than for the registration data (low: 11.3% vs. high: 7.1%). The registration data show higher referral figures for those with a higher educational level: referral to physiotherapists due to low back pain is 18.7% for the lower educated and 24.2% for the higher educated.

*Picavet et al. 1999*

(values weighted for the age and sex distribution of the Dutch population aged 20 - 59 y in 1994)

The use of healthcare services due to low back pain was reported by less than 20% of male working population and more than 20% of male non-working population (unemployed, on early retirement, work disabled and other; Figure 12).

The use of healthcare services was reported by about 20% of female working population and one quarter of female non-working population (housewives, unemployed, work disabled, other ; Fig. 5).



**Figure 12.** Percentage of respondents reporting the use of healthcare services due to low back pain in working and non-working (total and subgroups) population, MORGEN study

### Q5. Summary

The five included studies reported data regarding patients having contacts with healthcare due to their pain. The studies reported that around 20% of population had used healthcare services due to low back pain and among patients with low back pain between 30–40% contacted their GP. Among patients with other musculoskeletal pain GP contacts were reported for 40–50% of patients, while for more than 60% of patients with CRPS contacted GP as their first physician. Contacts with other health professionals were also common among patients with pain.



**Q6. How many chronic pain patients from the Netherlands get treated, broken down by treatment?**

Of 14 relevant studies, we selected five studies for this question; two were on chronic non-cancer pain (Breivik et al. 2006, Vandasselaar 2002), two were on chronic musculoskeletal pain (Van Tulder 1998, Borghouts 1999 Scand J Prim Health Care) and the remaining was on neuropathic pain (Dieleman et al. 2008).

Breivik et al. (2006) performed a large telephone survey to explore the prevalence, impact on daily life and treatment of chronic pain in Israel and 15 European countries, among which the Netherlands. Persons received an initial screening questionnaire and those who suffered from long-lasting moderate to severe pain were subsequently interviewed in-depth using a second structured questionnaire. From the Netherlands, 300 persons suffering chronic pain were interviewed.

Van Dasselaar (2002) describes the results of a national enquiry to assess the number of invasive pain control procedures carried out in Dutch hospitals for chronic cancer and chronic non-cancer pain. In this report only results for non-cancer pain will be described. The response rate was 98%. In this study no patient data were collected.

Van Tulder et al. (1998) described the course of chronic low back pain and the performed diagnostic and therapeutic procedures for 524 patients with chronic low back pain in general practice. GPs and patients were asked to complete questionnaire at baseline and at 4, 8 and 12 months follow-up.

Borghouts et al (1999) performed a retrospective study with the aim to describe the management in patients with chronic neck pain in general practice. Results on 517 patients were collected using questionnaire completed by GPs and patients.

Dieleman et al. (2008) performed a population based cohort study to estimate the incidence and assessed treatment approaches of neuropathic pain conditions in the general population. The study population included persons registered for at least one year in the Integrated Primary Care Information (IPCI) database between 1996 and 2003. See Table 13 for characteristics of selected studies.

**Table 13.** Characteristics of the studies selected for question 6

Study details	Population	Outcomes and analysis
<p><b>Breivik et al. 2006</b></p> <p><b>Study design</b> Cross-sectional study</p> <p><b>Study method</b> Telephone survey in two parts. First, persons were screened for chronic pain. Those who qualified were interviewed in-depth</p>	<p><b>Type of chronic pain</b> Long-lasting pain: chronic pain for at least 6 months, and pain in last month, and pain at least 2 times/week, and rating pain intensity at least 5 on 10-point NRS</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> Total sample: 4839; Netherlands: 300 persons with long-lasting pain Demographics for all countries together: 52% female mean age 50 years. For the Netherlands: female 60%, mean age 51.3 years</p> <p><b>Patient selection</b> Subjects with long-lasting pain (see definition above)</p>	<p><b>Outcomes measured</b> Duration, location, intensity of pain. Tolerance, time course of pain, impact pain on activities daily life, employment status, emotional status Visits to doctors, visits to pain management specialist, treatment (medication and non-medication), effectiveness of treatment, satisfaction with doctors, respondents' attitudes and beliefs about pain and pain treatment, respondents' perception of the attitude of others to their pain</p> <p><b>Pain severity</b> 18% reported severe pain</p> <p><b>Analyses</b> Descriptive analysis only. No subgroups were reported (for the Netherlands)</p>
<p><b>Van Dasselaaar 2002</b></p> <p><b>Study design</b> Retrospective study</p> <p><b>Study method</b> Hospitals completed questionnaires about procedure</p>	<p><b>Type of chronic pain</b> Chronic non-cancer pain</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> All hospitals were invited, response rate was 98%</p> <p><b>Patient selection</b> Invasive pain procedures for non-cancer chronic pain performed in hospitals during 1990-1991</p>	<p><b>Outcomes measured</b> The organisation of pain departments, availability of personnel, material and space facilities, the use of treatment protocols, type and number of cancer and non-cancer pain control procedures done</p> <p><b>Pain severity</b> Not reported</p> <p><b>Analyses</b> Descriptive analysis</p>
<p><b>Van Tulder et al. 1998</b></p> <p><b>Study design</b> longitudinal / cohort study</p> <p><b>Study method</b> GPs provided information on diagnosis and treatments. Patients completed questionnaires at baseline and during follow-up</p>	<p><b>Type of chronic pain</b> Chronic low back pain</p> <p><b>Confirmation of diagnosis</b> Patients with ICPC code L03 or L86 were included; researchers checked patient questionnaire if patients met inclusion criteria with respect to the duration of the back pain.</p> <p><b>Sample size and demographics</b> 524 patients (368 participants - data from GPs and patients, 156 non-participants -data from GPs) Mean age of participants: 41.1 years (SD 10), 51% men</p> <p><b>Patient selection</b> GPs selected prevalent cases from computer files: included were patients with low back pain with or without radiating symptoms, aged between 20-60 years, had had current symptoms for at least 3 months</p>	<p><b>Outcomes measured</b> frequency of diagnostic modalities, therapeutic interventions and referrals to paramedical therapists and medical specialists, patient characteristics, average pain intensity (10-p ordinal scale), global measurement of improvement, number of episodes of low back pain, absenteeism from work, functional status (Roland Disability Questionnaire), general health perception (Nottingham Health Profile), visits to paramedical and complementary therapists and medical specialists</p> <p><b>Pain severity</b> mean (SD) 10-p scale at baseline 5.6 (2.9) median (IQR) NHP pain subscale at baseline 40.5 (10.5-69.8)</p> <p><b>Analyses</b> Descriptive statistics, differences between groups using Mann-Whitney tests or t-tests</p>

Study details	Population	Outcomes and analysis
<p><b>Borghouts et al. 1999</b> (Scand J Prim Health Care)</p> <p><b>Study design</b> Descriptive retrospective study</p> <p><b>Study method</b> GPs provided information on procedures provided and patients completed a self-administered questionnaire covering a 12-month period</p>	<p><b>Type of chronic pain</b> Chronic neck pain</p> <p><b>Confirmation of diagnosis</b> Patients with ICPC code L01 or L83 were included; medical records of patients were checked by the GPs on inclusion and exclusion criteria</p> <p><b>Sample size and demographics</b> 517 eligible, GPs completed data on 487 (253 responders – data from GPs and patients, 234 non-responders – data from GPs) Responders: median age 51 (IQR 41-60), 60% females Non-responders: median age 55 (IQR 44-62), 56% females</p> <p><b>Patient selection</b> patients with neck pain (ICPC code L01 or L83), registered with GPs participating in the Registration Network of Family Practices of the Maastricht University, aged between 18 and 70 years, symptoms present for at least 6 months before baseline</p>	<p><b>Outcomes measured</b> GP questionnaire: diagnosis, frequency of GPs visits, diagnostic modalities, therapeutic interventions and referrals to medical specialists or paramedical therapists The patients' questionnaire: patient characteristics, pain intensity, sickness related to work and visits to medical specialists and paramedical therapists, onset and frequency of pain episodes during the previous 12 months, severity of current pain</p> <p><b>Pain severity</b> mean severity for responders 4.9 (SD 2.4)</p> <p><b>Analyses</b> Descriptive statistics, Mann-Whitney tests for differences between responders and non-responders, t-tests for differences in mean age and chi-square test to compare sex in the two groups</p>
<p><b>Dieleman et al. 2008</b></p> <p><b>Study design</b> longitudinal / cohort study</p> <p><b>Study method</b> Study conducted in the IPCI database - a longitudinal general practice research database containing data of more than 500,000 patients records</p>	<p><b>Type of chronic pain</b> Neuropathic pain</p> <p><b>Confirmation of diagnosis</b> Case definition relied on GP and specialists symptoms and diagnosis recorded in the medical record with the GP. GP diagnoses were accepted if they recurred in the patient record and if typical neuropathic pain symptoms were present.</p> <p><b>Sample size and demographics</b> 362,693 persons (1,116,215 person years) Age and gender distribution similar to Dutch population</p> <p><b>Patient selection</b> All individuals from the IPCI database with at least one year of follow-up</p>	<p><b>Outcomes measured</b> incidence rates of 13 subtypes of neuropathic pains, prescribed treatments</p> <p><b>Pain severity</b> Not reported</p> <p><b>Analyses</b> Age and gender specific incidence rates of different types of neuropathic pain, Cox-regression analysis for the relative risk and 95% confidence interval of neuropathic pain for women versus men</p>

## Q6. Study quality

The quality of the study of Breivik et al. (2006) was rated as moderate. The description of study design, eligibility criteria, outcome and study participants was adequate. However, it was not clear whether the population was representative and the statistical methods were not clearly described.

The quality of the study of Van Dasselaaar (2002) was rated low because the eligibility criteria and the outcomes were not clearly described. Furthermore, a description of statistical methods and study participants was lacking. Also it was not clear whether the results were adjusted or unadjusted.

The quality of Van Tulder et al (1998) was rated moderate. The study included a sample of patients that was representative for the Dutch general population, but the time period of recruitment was not stated. Eligibility criteria, outcomes, included population and method of analysis were clearly described. It was unclear whether the results were adjusted or unadjusted for confounders.

Borghouts et al (1999 Scand J Prim Health Care) was rated moderate. Although the study design was clear, the dates of recruitment were lacking. Furthermore, it was unclear whether the sample was representative – the paper stated that the patient population in the network reflect the Dutch general population but it was not clear on which variables that is. Lastly, it was not clear whether the results were adjusted or unadjusted for confounders.

The study of Dieleman et al. (2008) was also rated moderate quality. The study reported on a representative sample and study design, eligibility criteria, outcomes and statistical methods were adequately described. However, the study population and loss to follow-up were not reported adequately.

## Q6. Results

### ***General chronic pain***

#### *Breivik et al. 2006*

300 Dutch patients with chronic moderate to severe pain were interviewed. Of these, 14% had ever seen a pain management specialist and 33% were currently prescribed medicines (36% NSAIDs, 16% a COX-2 inhibitor, 14% weak opioids, 11% paracetamol and 5% strong opioids). For non-drug treatments: 52% had tried physiotherapy, 21% had tried acupuncture and 17% had tried massage for their pain.

#### *Van Dasselaaar 2002*

Eighty-five per cent of the responding hospitals performed invasive procedures on patients with chronic non-cancer pain. In a 1-year period, approximately 63,000 invasive procedures have been done. Of these, about 16,000 trigger point injections and test procedures were carried out. Table 14 specifies the numbers for other procedures.



**Table 14.** Number of invasive procedure for chronic non-malignant pain in Dutch hospitals in 1990-1991

Type of treatment	Number of procedures
Percutaneous facet denervation:	
Cervical region	4150
Thoracic region	1645
Lumbosacral region	6142
Rhizotomy dorsal ganglion:	
Cervical region	2915
Thoracic region	955
Lumbosacral region	2535
Spinal injection:	
Cervical region	4016
Thoracic region	4458
Lumbosacral region	14834
Highly specialized techniques:	
Injection Gasser's ganglion	833
Temperature controlled radiofrequency lesion of:	
Gasserian ganglion	901
Stellate ganglion	1327
Sphenopalatine ganglion	700
Total	45411

### **Chronic musculoskeletal pain**

*Van Tulder et al. 1998*

This study assessed treatments of 524 patients with chronic low back pain in general practice. 72.8% received no treatment. Forty two percent of total population visited their GP during 12 months follow up because of their low back pain and of these, 36% received no treatment. In the total population medication was the most frequent reported therapeutic modality (21.6%), and NSAIDs were used most often. With regard to non-drug treatments, postural advice was given to 6.1% of the patients and (bed)rest was advised to 5.7%. Table X below present results in more detail.

*Borghouts et al. 1998 (Scand J Prim Health Care)*

This study assessed the treatment of 487 patients with chronic neck pain in general practice. 44% visited the GP for neck pain in the previous year. Of the patients who visited their GP, 31% did not receive treatment. Medication, specifically paracetamol / aspirin / NSAIDs, was the most frequent applied treatment; 58% of the patients who visited their GP received this. With regard to non-drug treatment, the application of heat was used in 20% of patients and postural advice in 18%. Other treatments were used less frequent. See table 15 below for details.

**Table 15.** Therapeutic modalities of chronic low back or neck pain in general practice during 12 months

Treatment	Chronic low back pain (n=524)		Chronic neck pain			
	%*	95% confidence interval	Patients with GP consultation (n=212)		Total population (n=487)	
			n	%*	n	%*
No therapy	72.8	68.8 to 76.8	65	31	310	67
Medication	21.6	17.9 to 25.3	-	-	-	-
Paracetamol/aspirin	3.9	2.3 to 6.2	-	-	-	-
NSAID	16.3	12.8 to 19.8	-	-	-	-
Paracetamol/aspirin/NSAID	-	-	120	58	120	26
Benzodiazepine	3.3	1.8 to 5.5	23	10	23	5
Antidepressants	-	-	7	3	7	2
Other medication	0.7	0.1 to 2.0	16	8	16	3
Heat application	4.0	2.4 to 6.2	39	20	39	8
(Bed)rest	5.7	3.8 to 8.2	22	11	22	5
Injection	0.4	0.05 to 1.5	-	-	-	-
Postural advice	6.1	4.1 to 8.7	35	18	35	8
Work advice	1.3	0.5 to 2.7	-	-	-	-
Collar	-	-	7	3	7	2
Other treatment	3.0	1.6 to 4.9	6	3	6	1

\* Percentage of patients who were treated at least once with a specific therapeutic modality during the 12-months prospective follow-up. Several modalities could be applied to 1 participant so these percentages cannot be added up to form a total score

### Neuropathic pain

*Dieleman et al. 2008*

This study reported only types of medication as treatment. It's not clear whether other treatments were not given to this population or whether these were not assessed.

53% of the patients with neuropathic pain were prescribed medication and 47% were not. NSAIDs were the most commonly used drug (34.7%) followed by benzodiazepines (11.9%), sedative/hypnotics (9.1%) and opioids (6.6%). Anticonvulsants and tricyclic antidepressants were used by 4.8% and 4.7% of patients, respectively.

## Q6. Summary

Two studies on treatments for general chronic pain were found. One study, including patients with moderate to severe chronic pain, reported that 14% had seen a pain management specialist and that 33% were prescribed medicines. Furthermore, 52% had tried physiotherapy, 21% acupuncture and 17% massage for their pain.

The other study reported on frequency of invasive procedures carried out in Dutch hospitals. 85% of the respondents performed such procedures and performed approximately 63,000 procedures in 1991-1992.

Two other studies reported on chronic musculoskeletal pain in general practice. Among patients who visited their GP for low back or neck pain, 36% and 31% did not receive any treatment, respectively. For both indications, medication was most frequently applied treatment (22% of patients with low back pain received medication and 58% of patients with neck pain received paracetamol/aspirin/ NSAIDs). The most frequent used non-drug treatments for low back pain were (bed)rest (6%) and postural advice (6%) and for neck pain heat application (20%) and postural advice (18%).

The last study on neuropathic pain reported only types of medication as treatment. 53% of the patients with neuropathic pain were prescribed medication and 47% were not. NSAIDs were the most commonly used drug; about 35% received this.

**Q7. What is the compliance of treated chronic pain patients in the Netherlands?**

## **Q7** - Epidemiology of chronic pain in the Netherlands

No studies were found reporting on compliance of treated chronic pain patients in the Netherlands.

**Q8. What is the duration and severity of chronic pain conditions in the Netherlands?**

We located 16 studies relevant to this question and selected three for this project (Table 16).

One was rated as high quality and two were rated medium quality. Breivik et al. (2006) performed a large telephone survey to explore the prevalence, impact on daily life and treatment of chronic pain in 15 European countries and Israel, among which the Netherlands. Persons received an initial screening questionnaire and those who suffered from long-lasting pain were subsequently interviewed in-depth using a second structured questionnaire. From the Netherlands, 300 persons suffering chronic pain were interviewed.

Sluiter *et al.* (2008) was a medium quality postal questionnaire sent to all members of the national chronic repetitive strain injury (RSI) patient association (n=1121). The aim was to study differences between working and sick-listed RSI patients in the Netherlands with respect to indices of quality of life and illness perception. Quality of life and cognitive illness perception were assessed, as well as demographic, complaint-related and work activities characteristics.

Suurmeijer *et al.* (2001) was a high quality longitudinal cohort study that followed 573 patients with recently diagnosed Rheumatoid arthritis (RA), including 268 from the Netherlands, 216 from Norway, and 89 from France to examine the quality of life (QoL) profiles and to relate these to disease and impairment variables.

**Table 16.** Characteristics of studies relevant to Question 8: pain duration and severity

Study details	Population	Outcomes and analysis
<p><b>Breivik et al. 2006</b></p> <p><b>Study design</b> Cross-sectional study</p> <p><b>Study method</b> Telephone survey in two parts. First, persons were screened for chronic pain. Those who qualified were interviewed in-depth</p>	<p><b>Type of chronic pain</b> Long-lasting pain: chronic pain for at least 6 months, and pain in last month, and pain at least 2 times/week, and rating pain intensity at least 5 on 10-point NRS</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> Total sample: 4839; Netherlands: 300 persons with long-lasting pain Demographics for all countries together: 52% female mean age 50 years For the Netherlands: female 60%, mean age 51.3 years</p> <p><b>Patient selection</b> Subjects with long-lasting pain (see definition above)</p>	<p><b>Outcomes measured</b> Duration, location, intensity of pain. Tolerance, time course of pain, impact pain on activities daily life, employment status, emotional status Visits to doctors, visits to pain management specialist, treatment (medication and non-medication), effectiveness of treatment, satisfaction with doctors, respondents' attitudes and beliefs about pain and pain treatment, respondents' perception of the attitude of others to their pain</p> <p><b>Pain severity</b> 18% reported severe pain</p> <p><b>Analyses</b> Descriptive analysis only. No subgroups were reported (for the Netherlands)</p>

Study details	Population	Outcomes and analysis
<p><b>Sluiter et al. 2008</b></p> <p><b>Study design</b> Cross-sectional postal survey</p> <p><b>Study method</b> Postal questionnaire was sent to all members of the national RSI patient association</p>	<p><b>Type of chronic pain</b> Chronic repetitive strain injury (RSI) patients.</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> n=1121 assessable returned questionnaires; Working group (n=745); sick-listed group (n=376) Mean age: 40.8 (SD 8.7); Women: 67%; High education: 67%</p> <p><b>Patient selection</b> Members of the national RSI patient association in march 2005.</p>	<p><b>Outcomes measured</b> Quality of life and cognitive illness perception. Pain scale of SF-36; pain intensity using VAS (0-100)</p> <p><b>Analyses</b> Multivariate ANOVA controlling for age, gender, and education level or nonparametric tests (Mann-Whitney) were performed to test differences between the two groups of RSI patients</p>
<p><b>Suurmeijer et al. 2001</b></p> <p><b>Study design</b> Longitudinal study</p> <p><b>Study method</b> Part of the European Research on Incapacitating Disease and Social Support data. A series of clinical and psychosocial data collected on 4 (the Netherlands, France) and 3 (Norway) occasions, with 1-year intervals separating the waves of data collection</p>	<p><b>Type of chronic pain</b> Patients with recently diagnosed Rheumatoid arthritis (RA)</p> <p><b>Confirmation of diagnosis</b> RA according to the 1987 American College of Rheumatology (formerly the American Rheumatism Association) criteria</p> <p><b>Sample size and demographics</b> 573 patients (268 from the Netherlands, 216 from Norway, and 89 from France) n=268; Mean age (SD): 54.4 (11.8); Women: 64% Mean disease duration since RA diagnosis, months: 21.9 (SD: 13.9)</p> <p><b>Patient selection</b> Residence in the sampling areas, age between 20 and 70 years, diagnosis of RA and a disease duration of 4 years or less</p>	<p><b>Outcomes measured</b> Disease: ESR; Impairment: Ritchie Articular Index; fatigue and pain (NHP); Disability: GARS and HAQ; Handicap: Leisure and ILRA Rosenberg Self-Esteem scale and psychological distress (GHQ28); Satisfaction (SSQS)</p> <p><b>Analyses</b> Descriptive data (mean, SD) for pain</p>

## Q8. Study quality

The quality of Breivik et al. (2006) was rated as moderate. The methods were clearly stated in this study, with clear eligibility criteria and an adequate description of study participants. However, it was not clear if the population participating in the study was representative of target population. Outcomes and their measurement were adequately described; but there was no description of statistical methods used and results were not reported as unadjusted and confounder-adjusted including precision.

Sluiter et al. was also rated moderate quality. The authors did not describe the eligibility criteria adequately, results were not sufficiently reported and the representativeness of the study population was unclear. The study by Suurmeijer et al. was rated as high quality. It was not clear that the population was representative, but all other quality items were fulfilled.



## Q8. Results

### ***Pain severity***

*Suurmeijer et al. 2001*

Mean pain scores among the 268 Dutch patients with recently diagnosed Rheumatoid arthritis were 13.4 (SD: 2.1), while scores ranged from 8 to 16. Forty-three percent of Dutch RA patients had low pain scores ( $\leq 13$ )

*Sluiter et al. 2008*

Pain intensity as measured on a 100mm VAS scale was 41.3 (SD: 25.4) for the total group of 1121 chronic repetitive strain injury (RSI) patients. The working group (N=745) scored 36.2 (SD: 24.7), while the sick-listed group (N=376) scored 51.6 (SD: 23.9).

### ***Pain Duration***

*Breivik et al. 2006*

From the Netherlands, 300 participants with moderate to severe chronic pain were included. Both screening questionnaire and in-depth interview contained questions about pain duration. The results for participating countries were presented on graphs and included means without standard deviations. The mean duration of chronic pain for Dutch participants was 6.5 years.

*Suurmeijer et al. 2001*

Pain duration was not reported, but duration of disease was reported. Mean disease duration since RA diagnosis in months was 21.9 (SD: 13.9) for the Dutch RA patients. However, disease duration of 4 years or less was one of the inclusion criteria.

## Q8. Summary

### ***Pain severity and duration***

*General chronic pain:*

Breivik *et al.* (2006) measured the mean duration of general chronic pain for Dutch participants at 6.5 years. Breivik *et al.* (2006) was rated medium quality and, as the authors compared their sample favourably to the general population of the Netherlands, we considered their results to be representative.

*Patients with recently diagnosed Rheumatoid Arthritis (RA)*

Mean pain scores among the 268 Dutch patients with recently diagnosed Rheumatoid arthritis were 13.4 (SD: 2.1); while scores ranged from 8 to 16.

*Patients with chronic repetitive strain injury (RSI)*

Pain intensity as measured on a 100mm VAS scale was 41.3 (SD: 25.4).

# **Q9. What are the demographics of chronic pain sufferers in the Netherlands?**

We located 28 studies that were relevant to this question and selected three for this project (Table 17).

The first was a medium quality study (Breivik *et al.* 2006) using a large telephone survey to explore the prevalence, impact on daily life and treatment of chronic pain in 15 European countries and Israel, among which the Netherlands. Persons received an initial screening questionnaire and those who suffered from long-lasting pain were subsequently interviewed in-depth using a second structured questionnaire. From the Netherlands, 300 persons suffering chronic pain were interviewed.

The second study (Huisstede *et al.* 2008) was a moderate quality study based on DMC3 population survey data including 3664 respondents. Huisstede *et al.* 2008 aimed to study the prevalence of upper extremity disorders (UEDs) and neck as a total and complaints of the arm, neck and/or shoulder (CANS) not caused by acute trauma or any systemic disease as defined in the CANS model in the open population and to assess socio-demographic and health characteristics of chronic symptoms.

The third study (Opstelten *et al.* 2005) was a moderate quality study aimed to determine the incidence of Herpes Zoster (HZ) and Postherpetic Neuralgia (PHN) in a primary care population and to identify risk factors for the occurrence of PHN. This study used data from the database of the “Huisartsen Netwerk Utrecht” a general practice research database, from 1994 to 1999. Cases were identified by searching the database using an ICPC code and free text and medical records were reviewed for confirmation.

**Table 17.** Characteristics of the studies relevant to Question 9

Study details	Population	Outcomes and analysis
<p><b>Breivik et al. 2006</b></p> <p><b>Study design</b> Cross-sectional study</p> <p><b>Study method</b> Telephone survey in two parts. First, persons were screened for chronic pain. Those who qualified were interviewed in-depth</p>	<p><b>Type of chronic pain</b> Long-lasting pain: chronic pain for at least 6 months, and pain in last month, and pain at least 2 times/week, and rating pain intensity at least 5 on 10-point NRS</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> Total sample: 4839; Netherlands: 300 persons with long-lasting pain Demographics for all countries together: 52% female mean age 50 years For the Netherlands: female 60%, mean age 51.3 years</p> <p><b>Patient selection</b> Subjects with long-lasting pain (see definition above)</p>	<p><b>Outcomes measured</b> Duration, location, intensity of pain Tolerance, time course of pain, impact pain on activities daily life, employment status, emotional status Visits to doctors, visits to pain management specialist, treatment (medication and non-medication), effectiveness of treatment, satisfaction with doctors, respondents’ attitudes and beliefs about pain and pain treatment, respondents’ perception of the attitude of others to their pain</p> <p><b>Pain severity</b> 18% reported severe pain</p> <p><b>Analyses</b> Descriptive analysis only. No subgroups were reported (for the Netherlands)</p>

Study details	Population	Outcomes and analysis
<p><b>Huisstede et al. 2008</b></p> <p><b>Study design</b> Cross-sectional/ survey</p> <p><b>Study method</b> DMC3 study - national health survey of musculoskeletal conditions; postal questionnaire – with general questions and health questions. After screening question for each of 5 anatomical areas Additional questions regarding pain in this area and its consequences; general health was measured using the Short Form(SF)-36</p>	<p><b>Type of chronic pain</b> Upper extremity disorders (UED) and neck pain; complaints of the arm, neck and/or shoulder (CANS; excluding UED caused by an acute trauma or a systemic disease)</p> <p><b>Confirmation of diagnosis</b> NR; only screening question: "did you have pain in 'anatomic area' during the past 12 months?"</p> <p><b>Sample size and demographics</b> 3664 respondents 25–44 years 47.0%, 45–64 years 34.6%, 65+ years 18.4% Female 50.9%</p> <p>chronic UED 996 chronic UED due to systemic disease or acute trauma 299 chronic CANS 697</p> <p><b>Patient selection</b> DMC3 - Dutch population aged 25 years and above; this study - persons with musculoskeletal upper extremity and neck disorders in 4 anatomic sites: neck, shoulder, elbow, and wrist/hand</p>	<p><b>Outcomes measured</b> 12-month prevalence, point prevalence, and prevalence of chronic pain (pain at baseline and lasting more than 3 months in the last 12 months) course of pain, consequences of pain (contact with general practitioner, medical specialist or physiotherapist, work leave, limitations in daily life), general health</p> <p><b>Pain severity</b> self-reported - severe or mild chronic total UED Continuous severe pain 5.4% Recurrent severe pain 12.7% Chronic CANS Continuous severe pain 3.9% Recurrent severe pain 12.8%</p> <p><b>Analyses</b> Descriptive analysis only</p>
<p><b>Opstelten et al 2005</b></p> <p><b>Study design</b> Cross-sectional / survey</p> <p><b>Study method</b> A search conducted in the Huisartsen Netwerk Utrecht" database, a general practice research database over a 5-year period</p>	<p><b>Type of chronic pain</b> Herpes zoster (HZ) and post herpetic neuralgia (PHN). PHN was defined as any pain that persisted at least 1 month after HZ diagnosis</p> <p><b>Confirmation of diagnosis</b> GP diagnosis (ICPC code 32 S70 (HZ) or GP confirmation of HZ)</p> <p><b>Sample size and demographics</b> N=837 58% female</p> <p><b>Patient selection</b> All HZ patients diagnosed between 1 August 1994 and 31 July 1999 were identified by searching the database for ICPC code 32 S70 (HZ) and for free text ('zoster'). Medical records were reviewed for confirmation</p>	<p><b>Outcomes measured</b> Incidence of HZ (in different age groups); Risk of PHN 1 and 3 months after HZ diagnosis</p> <p><b>Pain severity</b> Severity not reported. Persistent pain 3 months after HZ diagnosis was reported in the medical records of 2.6% (95% CI: 1.7, 4.0) of the HZ patients</p> <p><b>Analyses</b> Multivariate logistic regression model</p>

## Q9. Study quality

### ***Breivik et al. 2006***

The quality of Breivik *et al.* (2006) was rated as moderate. The methods were clearly stated in this study, with clear eligibility criteria and an adequate description of study participants. However, it was not clear if the population participating in the study was representative of target population. Outcomes and their measurement were adequately described; but there was no description of statistical methods used and results were not reported as unadjusted and confounder-adjusted including precision.

### *Huisstede et al. 2008*

The quality of the Huisstede *et al.* 2008 study was rated as moderate, as it was unclear that the population was representative of the target sample, the statistical methods were not clearly described and the results were not reported as unadjusted and confounder-adjusted including precision. There was no adequate description of the eligibility criteria.

### *Opstelten et al. 2002*

This study was rated as moderate quality. It was unclear whether the study sample was representative of the target sample and the description of participants was inadequate. However, study design, eligibility criteria, statistical methods and outcomes were adequately described. Also results were clearly reported as adjusted or unadjusted with precision.

## Q9. Results

### ***Moderate to severe general chronic pain***

#### *Breivik et al. 2006*

Of the 300 chronic pain participants interviewed, 82% reported moderate pain and 18% reported severe pain. The mean age of chronic pain sufferers in the Netherlands was 51.3 years and 60% were female.

### ***Herpes zoster (HZ) and post herpetic neuralgia (PHN)***

#### *Opstelten et al. 2002*

A total of 47% of all HZ patients were at least 55 years old and 58% were female. Age was found to be an independent risk indicator for the occurrence of PHN (adjusted OR for 55-74 years: 4.2 (95% CI: 1.8, 9.7); adjusted OR for >75 years: 10.7 (95% CI: 4.6, 25.1)).

### ***Chronic musculoskeletal pain***

#### *Huisstede et al. 2008*

Nine hundred and ninety-six (996) persons With Chronic Complaints of the Upper Extremity and Neck (UEDs) were included in the study. Sixty-three percent (63%) of these were female and 29% were 65 years or older.

## Q9. Summary

### **General Chronic Pain**

Breivik *et al.* (2006) reported the mean age of moderate to severe chronic pain sufferers in the Netherlands was 51.3 years and 60% were female.

### **Herpes zoster (HZ) and post herpetic neuralgia (PHN)**

Opstelten *et al.* (2002) found that 47% of all HZ patients were at least 55 years old and 58% were female.

### **Chronic musculoskeletal pain**

Huisstede *et al.* (2008) found that 63% of persons with UEDs were female and 29% were 65 years or older.

We considered all three studies (Breivik *et al.* 2006, Opstelten *et al.* 2002, Huisstede *et al.* 2008) to be of moderate quality and judge the Breivik *et al.* results to be representative of the target population (moderate to severe chronic pain sufferers in the Netherlands). In the study by Opstelten *et al.* it was unclear whether the study sample was representative of the target sample.



**Q10. What are the co-morbidities of chronic pain sufferers in the Netherlands?**



We located 18 relevant studies and selected three for this question (Breivik et al. 2006, Demyttenaere et al. 2007 and Picavet and Schouten 2003).

Breivik et al. (2006) performed a large telephone survey to explore the prevalence, impact on daily life and treatment of chronic pain in 15 European countries and Israel, among which the Netherlands. Persons received an initial screening questionnaire and those who suffered from long-lasting pain were subsequently interviewed in-depth using a second structured questionnaire. From the Netherlands, 300 persons suffering chronic pain were interviewed.

Demyttenaere et al. 2007 aimed to estimate the prevalence of 12-month chronic back or neck pain in the general population of 85 088 participants in 17 countries in Europe, the Americas, the Middle East, Africa, Asia, and the South Pacific and to estimate the occurrence of specific 12-month mood, anxiety disorders, and alcohol abuse/dependence among persons with chronic back or neck pain as well as to investigate which mental disorders were most strongly associated with chronic back or neck pain and to assess the consistency of the associations between chronic back or neck pain and mental disorders.

Picavet and Schouten 2003 was based on DMC<sub>3</sub> population survey data with 3664 respondents. It aimed to present estimates on the prevalence of musculoskeletal pain of five different anatomical areas and ten anatomical sites, and their consequences and risk groups in the general Dutch population.

**Table 18.** Characteristics of the study selected for question 10

Study details	Population	Outcomes and analysis
<p><b>Breivik et al. 2006</b></p> <p><b>Study design</b> Cross-sectional study</p> <p><b>Study method</b> Telephone survey in two parts. First, persons were screened for chronic pain. Those who qualified were interviewed in-depth</p>	<p><b>Type of chronic pain</b> Long-lasting pain: chronic pain for at least 6 months, and pain in last month, and pain at least 2 times/week, and rating pain intensity at least 5 on 10-point NRS</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p>Sample size and demographics Total sample: 4839; Netherlands: 300 persons with long-lasting pain Demographics for all countries together: 52% female mean age 50 years. For the Netherlands: female 60%, mean age 51.3 years</p> <p><b>Patient selection</b> Subjects with long-lasting pain (see definition above)</p>	<p><b>Outcomes measured</b> Duration, location, intensity of pain Tolerance, time course of pain, impact pain on activities daily life, employment status, emotional status Visits to doctors, visits to pain management specialist, treatment (medication and non-medication), effectiveness of treatment, satisfaction with doctors, respondents' attitudes and beliefs about pain and pain treatment, respondents' perception of the attitude of others to their pain</p> <p><b>Pain severity</b> 18% reported severe pain</p> <p><b>Analyses</b> Descriptive analysis only. No subgroups were reported (for the Netherlands)</p>

Study details	Population	Outcomes and analysis
<p><b>Demyttenaere et al. 2007</b></p> <p><b>Study design</b> Population surveys of community-dwelling adults in 17 countries in Europe, the Americas, the Middle East, Africa, Asia, and the South Pacific (N = 85,088).</p> <p><b>Study method</b> Face-to-face survey with questions about chronic conditions adapted from the US Health Interview Survey (National Center for Health Statistics, 1994)</p>	<p><b>Type of chronic pain</b> Back or neck pain</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> Netherlands sample n=1094 Mean age 45.0 Female 50.9%</p> <p><b>Selection</b> All respondents who met criteria for any mental disorder and a probability sample of other respondents were administered part-2 (assessment of chronic physical conditions)</p>	<p><b>Outcomes measured</b> The 12-month prevalence of either back or neck pain The prevalence of mental disorders among people with chronic back/neck pain</p> <p><b>Analyses</b> Odds ratios (OR) for the association of each mental disorder with the pain condition were estimated for each survey. Adjusted ORs were estimated to assess the association of any mood disorder, any anxiety, and any alcohol abuse/dependence with back or neck pain</p> <p><b>Pain severity</b> Not reported</p>
<p><b>Picavet and Schouten 2003</b></p> <p><b>Study design</b> Cross-sectional study</p> <p><b>Study method</b> DMC3 study - national health survey of musculoskeletal conditions; postal questionnaire – with general questions and health questions. After screening question for each of 5 anatomical areas Additional questions regarding pain in this area and its consequences; socio-demographic characteristics</p>	<p><b>Type of chronic pain</b> Neck, shoulder, higher back 44.5% Elbow, wrist/hand 23.2% Lower back 43.9% Hip, knee 28% Ankle, foot 14.9%</p> <p><b>Confirmation of diagnosis</b> NR; only screening question: "did you have pain in 'anatomic area' during the past 12 months?"</p> <p><b>Sample size and demographics</b> Total sample: 3664 respondents weighted to present a distribution of sex, age, marital status and region of living equal to that of the Netherlands in 1998: Sex men 49.1% women 50.9% Age group 25-44 47.0% 45-64 34.6% 65+ 18.4%</p> <p><b>Patient selection</b> Dutch inhabitants of 25 years and older</p>	<p><b>Outcomes measured</b> Musculoskeletal pain period prevalence, point prevalence, prevalence of chronic pain, course of pain, consequences of pain (contact with general practitioner, medical specialist or physiotherapist, use of medicines, work leave, limitations in daily life, and work disability)</p> <p><b>Pain severity</b> self-reported - severe or mild roughly 15% severe pain</p> <p>Neck, shoulder or higher back Continuous severe pain 3.1% recurrent severe pain 8.3% Elbow or wrist/hand Continuous severe pain 4.0% recurrent severe pain 11.0% Lower back Continuous severe pain 3.5% recurrent severe pain 15.4% Hip or knee Continuous severe pain 5.2% recurrent severe pain 10.1% Ankle or foot Continuous severe pain 6.1% recurrent severe pain 12.4%</p> <p><b>Analyses</b> descriptive, frequencies, multivariate logistic regression</p>

## Q10. Study quality

The quality of the Breivik et al. 2006 study and Demyttenaere et al. 2007 study was rated as moderate; In both studies it was unclear that the population was representative, in the Breivik study the statistical methods were not clearly described, in Demyttenaere study the eligibility criteria were not clearly described.

Picavet and Schouten 2003 study was rated as high quality; only one item was missing – the authors did not provide adequate description of eligibility criteria.

## Q10. Results

### ***Comorbidities in general pain conditions***

#### *Breivik et al. 2006*

Among 251 of Dutch respondents 12% reported traumatic injury, 13% herniated/deteriorating disc and 19% arthritis or osteoarthritis as causes of their pain. These were also the most commonly reported causes for the whole Europe.

Among 294 of Dutch respondents 19% reported being diagnosed with depression by a medical doctor as a results of their pain, while the European average was 21%.

### ***Comorbidities in musculoskeletal pain – several pain locations***

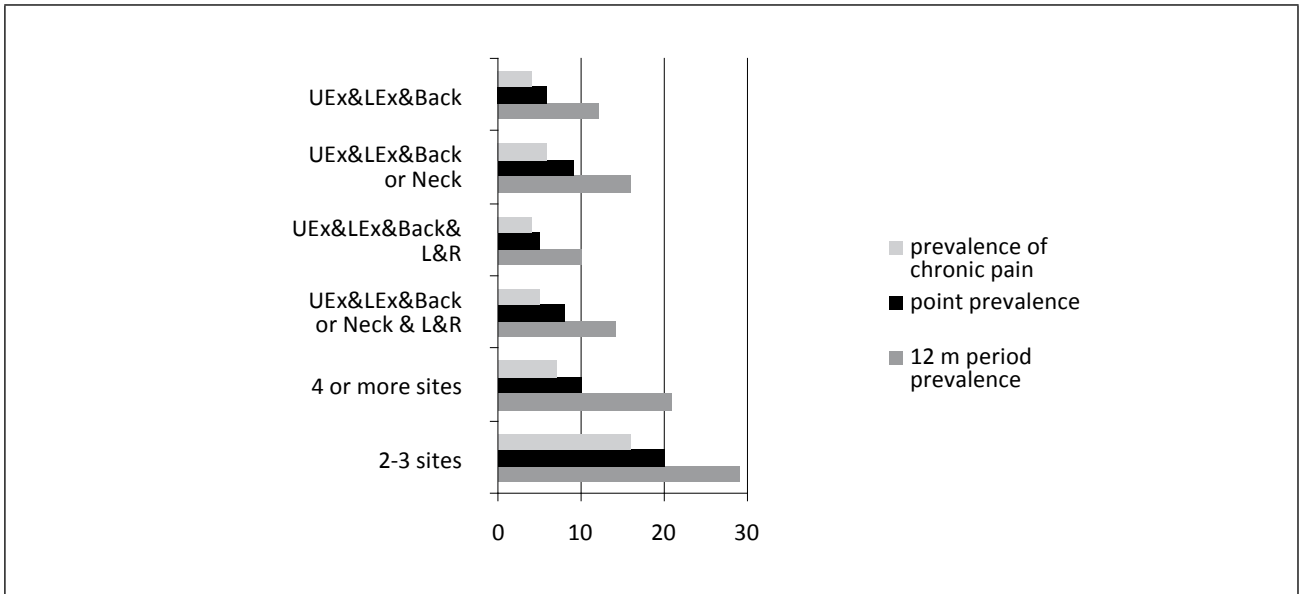
#### *Picavet and Schouten 2003*

The authors described coexistence of pain in several locations among 3664 respondents. 12 month period prevalence of musculoskeletal pain in 2–3 sites was about 30%, while in 4 or more sites about 20%. The 12 month period prevalence of musculoskeletal pain in combinations of upper and lower extremities, back or neck and in left and right was over 10% (Figure 13).

Point prevalence of musculoskeletal pain in 2–3 sites was about 20%, while in 4 or more sites – about 10%.

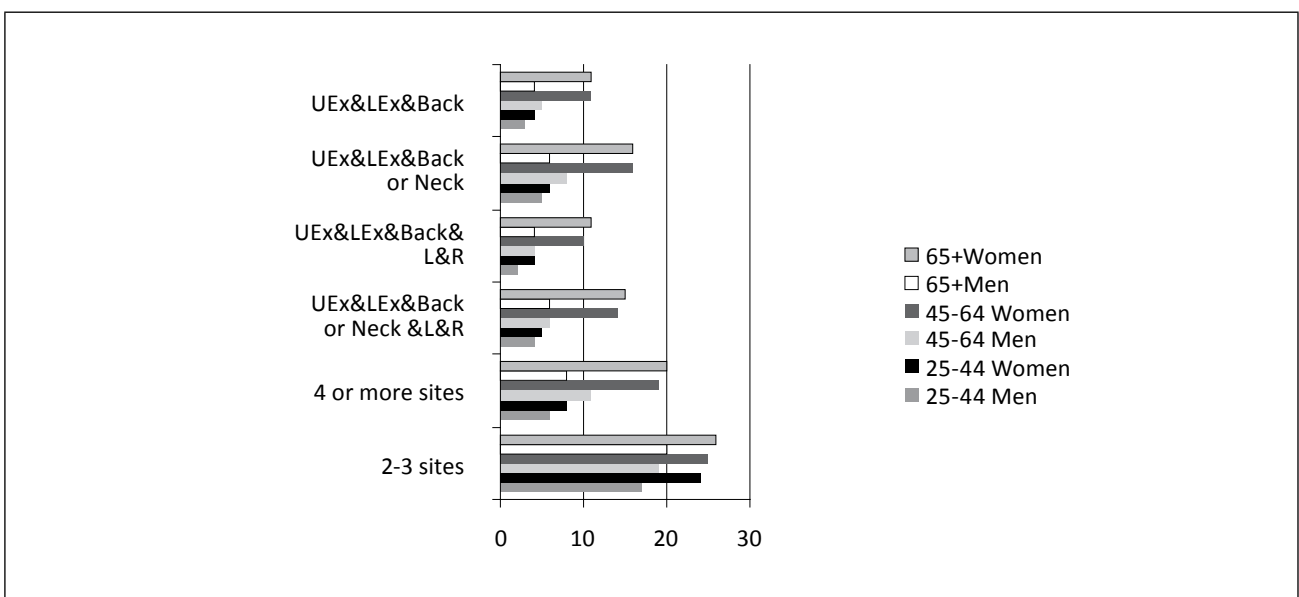
The point prevalence of musculoskeletal pain in combinations of upper and lower extremities, back or neck and in left and right was 5–9% (Figure 13)

Prevalence of chronic musculoskeletal pain in 2–3 sites was about 5%, while in 4 or more sites – about 7%. The prevalence of chronic musculoskeletal pain in combinations of upper and lower extremities, back or neck and in left and right 4–6% (Figure 13).



**Figure 13.** Prevalence of musculoskeletal pain (12 month period prevalence, point prevalence, prevalence of chronic pain) in 2 or more sites and combinations of locations (UEx – upper extremity, LEx – lower extremity, L – left, R – right)

When prevalence of current musculoskeletal pain (point prevalence) was analysed in age groups (25–44, 45–64 and 65+) the lowest values for 2–3 sites, 4 or more sites and combinations (upper extremities, neck, back, left, right) for men and for women were noted in the youngest age group (Figure 14). The prevalence increased with age in women, while in men the values were higher for the age group 45–64 and then for men they decreased for the oldest age group in most of the cases. For 2–3 sites, 4 or more sites and combinations (upper extremities, neck, back, left, right) the prevalence was higher for women than for men (Figure 14).



**Figure 14.** Prevalence of current musculoskeletal pain in 2 or more sites and combinations of locations by gender and age group (UEx – upper extremity, LEx – lower extremity, L – left, R – right)

**Co-morbid mental health conditions in patients with back/neck pain**

*Demyttenaere et al. 2007*

Prevalence of mood disorders among persons with versus without back/neck pain:

Major depressive episode: 4.4% no back or neck pain; 9.4% back or neck pain; OR 2.3 (1.5, 3.6)

Dysthymia: 1.2% no back or neck pain; 4.5% back or neck pain; OR 4.2 (1.8, 9.7)

Prevalence (%) of anxiety disorders among persons with versus without back/neck pain:

Generalized anxiety disorder: 0.8% no back or neck pain; 2.1% back or neck pain; OR 2.8 (1.0, 7.7)

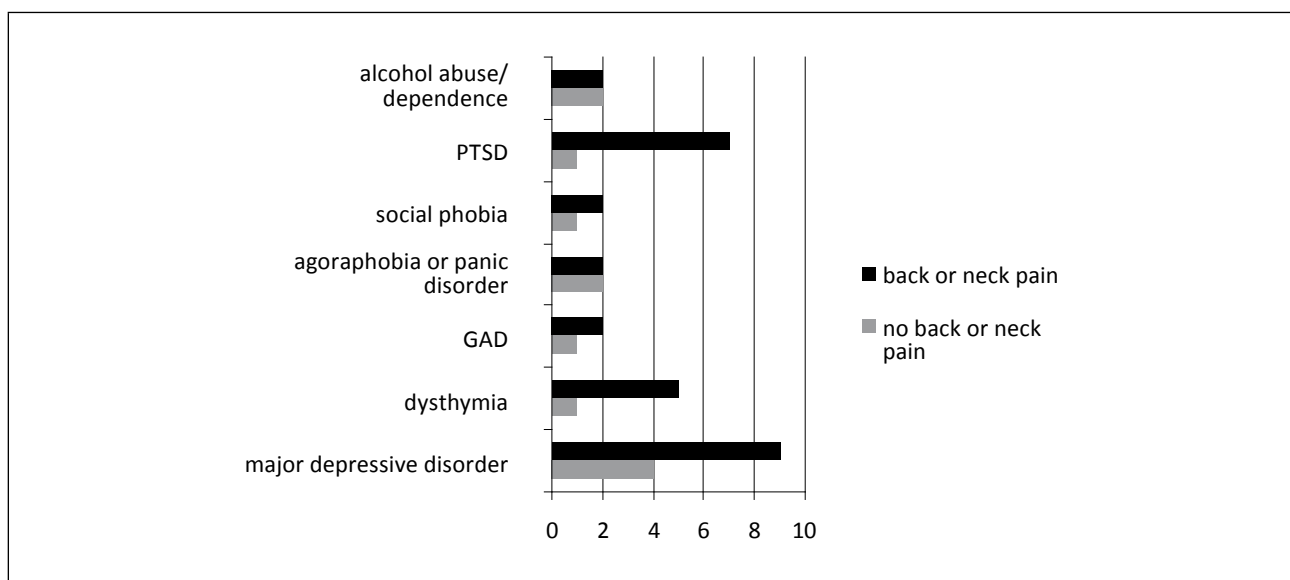
Agoraphobia or Panic disorder: 1.7% no back or neck pain; 1.7% back or neck pain; OR 1.0 (0.4, 2.6)

Social Phobia: 1.0% no back or neck pain; 2.4% back or neck pain; OR 2.5 (0.8, 7.7)

Posttraumatic stress disorder: 1.4% no back or neck pain; 7.4% back or neck pain; OR 4.4 (1.5, 13.3)

Prevalence (%) of alcohol abuse/dependence disorders among persons with versus without back/neck pain:

1.7% no back or neck pain; 1.7% back or neck pain; OR 1.3 (0.5, 3.2)



**Figure 15.** Percentage of patients with back or neck pain with co-morbid mental conditions

**Q10. Summary**

The three included studies reported comorbidities in several pain conditions. In general pain condition depression was reported in 19% of respondents, in patients with back or neck pain mood disorders were reported by 4.5–9.4% (major depressive disorder was reported by the highest percentage of respondents) of pain sufferers, anxiety disorders by 1.7–7.4% of respondents and alcohol abuse by 1.7%. In patients with musculoskeletal pain coexistence of pain in several locations was reported by 5–7% and more widespread pain including combinations of upper and lower extremities, back or neck and in left and right was reported by 4–6% of respondents.

**Q11. How many sufferers in the Netherlands have inadequate pain control?**

We located one study that was relevant to this question (Breivik et al. 2006).

Breivik et al. (2006) performed a large telephone survey to explore the prevalence, impact on daily life and treatment of chronic pain in 15 European countries and Israel, among which the Netherlands. Persons received an initial screening questionnaire and those who suffered from long-lasting pain were subsequently interviewed in-depth using a second structured questionnaire. From the Netherlands, 300 persons suffering chronic pain were interviewed.

**Table 19.** Characteristics of the study selected for question 11

Study details	Population	Outcomes and analysis
<p><b>Breivik et al. 2006</b></p> <p><b>Study design</b> Cross-sectional study</p> <p><b>Study method</b> Telephone survey in two parts. First, persons were screened for chronic pain. Those who qualified were interviewed in-depth</p>	<p><b>Type of chronic pain</b> Long-lasting pain: chronic pain for at least 6 months, and pain in last month, and pain at least 2 times/week, and rating pain intensity at least 5 on 10-point NRS</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> Total sample: 4839; Netherlands: 300 persons with long-lasting pain Demographics for all countries together: 52% female mean age 50 years. For the Netherlands: female 60%, mean age 51.3 years</p> <p><b>Patient selection</b> Subjects with long-lasting pain (see definition above)</p>	<p><b>Outcomes measured</b> Duration, location, intensity of pain Tolerance, time course of pain, impact pain on activities daily life, employment status, emotional status Visits to doctors, visits to pain management specialist, treatment (medication and non-medication), effectiveness of treatment, satisfaction with doctors, respondents' attitudes and beliefs about pain and pain treatment, respondents' perception of the attitude of others to their pain</p> <p><b>Pain severity</b> 18% reported severe pain</p> <p><b>Analyses</b> Descriptive analysis only. No subgroups were reported (for the Netherlands)</p>

## Q11. Study quality

The quality of the Breivik et al. study was rated as moderate; in this study it was not clear that the population was representative and the statistical methods were not clearly described.

## Q11. Results

The authors reported that out of 119 respondents 79% reported inadequate pain control from medication (affirmative answer to the question: "Are there ever times when your pain medicines are not adequate to control your pain?") while a European average was 64%. Out of 274 respondents 56% reported inadequate overall pain control (affirmative answer to the question: "Would you say your pain is being adequately controlled?") while a European average was 40%.

## **Q11. Summary**

Breivik et al. 2006 reported inadequate pain control from medication according to patients assessment in 79% and inadequate overall pain control in 56%.





**Q12a. In the Netherlands what is the impact of chronic pain on quality of life?**

We located three studies that were relevant to this question (Alonso et al. 2004, Lame et al. 2005 and Picavet and Hoeymans 2004).

Alonso et al. 2004 aimed to assess the impact of common chronic conditions on HRQL among the general populations of eight countries: Denmark, France, Germany, Italy, Japan, the Netherlands, Norway and the United States.

Lame et al. 2005 aimed to investigate pain cognitions and quality of life of chronic pain patients referred to a multi-disciplinary university pain management clinic and to search for predictors of quality of life.

Picavet and Hoeymans 2004 was based on DMC<sub>3</sub> population survey data with 3664 respondents. It aimed to examine the health related quality of life of persons with one or more self reported musculoskeletal diseases, as measured by the short form 36 item health status survey (SF-36) and the Euroqol questionnaire (EQ-5D).

**Table 20.** Characteristics of the study selected for question 12a

Study details	Population	Outcomes and analysis
<p><b>Alonso et al. 2004</b></p> <p>Study Design Cross-sectional survey</p> <p>Study Method Cross-sectional mail and interview surveys</p>	<p>Type of chronic pain Arthritis (defined as "arthritis or a type of rheumatic disease")</p> <p>Confirmation of diagnosis Self-reported</p> <p>Sample Size and Demographics Total: 24936 Netherlands N = 4059 Mean age = 43.4 (SD 17.9) 46.1% males</p> <p>Patient selection General population normative data. The International Quality of Life Assessment (IQOLA) project protocol established that the sample should represent the age and gender characteristics of the population and should be representative of the various regions in a country. For the Netherlands: representative of the general Amsterdam population (using age, gender, marital status and residential district)</p>	<p>Outcomes measured Prevalence of chronic conditions Health-related quality of life (HRQL) measures (SF-36 Health Survey)</p> <p>Pain Severity Not reported</p> <p>Analyses Adjusted, multivariate linear regression analysis</p>

Study details	Population	Outcomes and analysis
<p><b>Lame et al. 2005</b></p> <p><b>Study design</b> Cross-sectional/ survey</p> <p><b>Study method</b> Patients completed a set of mailed questionnaires</p>	<p><b>Type of chronic pain</b> Neck pain and/or brachialgia (23.3%); back pain and/or sciatica (27.9%); other pain, such as CRPS I en II, neuropathic pain syndrome, trigeminus neuralgia, fibromyalgia and RA (15.7%); multiple pain localisations (30.1%)</p> <p><b>Confirmation of diagnosis</b> NR</p> <p><b>Sample size and demographics</b> N=1208 mean 49.9 years SD 14.7 female 62%</p> <p><b>Patient selection</b> a population of the outpatient's clinic for Pain and Pain management of the University Hospital Maastricht. Each new non-malignant pain patient between February 2000 and March 2002 was mailed the questionnaire which had to be completed before first appointment with the physician</p>	<p><b>Outcomes measured</b> demographic information, pain cause, localisation and duration Qol (Rand-36*), pain coping and cognition list (PCCL), pain catastrophising scale (PCS) and the McGill pain questionnaire (MPQ). * is same as SF-36</p> <p><b>Pain severity</b> NR</p> <p><b>Analyses</b> Student's t test, Levene's test for equality of variance, ANOVA, hierarchical stepwise regression analyses</p>
<p><b>Picavet and Hoeymans 2004</b></p> <p><b>Study design</b> Cross-sectional/ survey</p> <p><b>Study method</b> DMC3 study - national health survey of musculoskeletal conditions; postal</p>	<p><b>Type of chronic pain</b> Musculoskeletal pain: herniated disc (spine), gout, RSI, epicondylitis, OA knee, OA hip, osteoporosis, whiplash, RA, other chronic arthritis, fibromyalgia, tendinitis and capsulitis</p> <p><b>Confirmation of diagnosis</b> Self-reported</p> <p><b>Sample size and demographics</b> Total 3664 respondents</p> <p><b>Patient selection</b> DMC3 – a random sample of Dutch inhabitants aged 25 years and above, who completed the questionnaires</p>	<p><b>Outcomes measured</b> Quality of life (SF 36, EQ5D)</p> <p><b>Pain severity</b> NR</p> <p><b>Analyses</b> Descriptive analysis weighted for age, sex, region, and marital status of the Netherlands' population in 1998</p>

## Q12a. Study quality

The study of Alonso et al 2004 was rated as moderate quality. The study population was representative of the target population and study outcomes, statistical methods were adequately described. Also, it was clear whether results were presented with or without adjustment and precision was given. However there was no description of the eligibility criteria of participants and the relevant dates for recruitment and data collection were not reported.

Lame et al. 2005 study was rated as low quality. The study design, outcomes and the study participants were adequately described, but there was no adequate description of eligibility criteria, it was unclear that the

population was representative, the statistical methods were not clearly described and it was unclear if the results were not reported as unadjusted or confounder-adjusted.

The quality of the study of Picavet and Hoeymans 2004 was rated as moderate. The study population was representative of the target population and study design, outcomes, statistical methods were adequately described. Also, it was clear whether results were presented with or without adjustment and precision was given. However, there was no adequate description of the eligibility criteria and study participants.

## Q12a. Results

### *Several pain populations*

*Lame et al. 2005*

The included pain population reported low quality of life on each domain. Differences between the pain groups were found on all domains with the exception of role limitations emotional. Patients with back pain, other pain and multiple pain locations experienced more functional limitations (physical functioning and role limitations physical) than the other pain groups. In addition, patients with multiple pain localizations scored significantly lower on mental health, vitality and general health. Patients with other pain showed significantly lower scores on bodily pain than the other pain groups. Gender differences were found for physical functioning, role limitations physical, vitality, bodily pain and general health, whereby women reported lower scores than men (Table 2 1).

When the values of quality of life were compared with other chronic pain populations in the Netherlands and a healthy reference population the chronic pain patient from the multi-disciplinary university pain clinic scored significant lower on all domains than each of the other groups.

**Table 21.** Quality of life mean scores for total pain population, according to age and in pain groups

	<b>Dimensions of Rand-36 questionnaire, mean (SD)</b>							
	<b>PF</b>	<b>SF</b>	<b>RF</b>	<b>RE</b>	<b>MH</b>	<b>VT</b>	<b>BP</b>	<b>GH</b>
Total	41.3 (26.3)	39.9 (27.0)	9.7 (24.3)	46.6 (46.1)	56.7 (22.6)	39.8 (20.4)	24.6 (17.9)	44.7 (21.4)
Men	44.0 (26.2)*	41.4 (27.0)	12.3 (26.7)*	47.2 (45.6)	57.7 (21.8)	42.5 (20.4)*	27.0 (18.4)*	46.4 (21.0)*
Women	39.6 (26.2)	39.0 (27.0)	8.2 (22.5)	46.3 (46.5)	56.1 (23.0)	38.1 (20.2)	23.1 (17.3)	43.6 (21.7)
Neck pain (1)	55.1 (23.1)#2,4	43.7 (27.7)#4	9.9 (25.0)	47.0 (46.4)	57.7 (22.9)	43.5 (21.1)#4	24.9 (18.3)#3	48.8 (20.8)#4
Back pain (2)	31.0 (21.1)#1,3	38.3 (27.2)	8.6 (22.5)#3	47.8 (45.9)	60.1 (22.2)#4	41.4 (19.2)#4	22.7 (17.3)#3	47.3 (21.7)#4
Other pain (3)	49.8 (31.0)#2,4	43.7 (26.8)	16.7 (31.3)#2,4	49.4 (47.0)	57.6 (21.4)	40.6 (21.2)	30.2 (19.5)#1,2,4	46.8 (21.9)#4
Multiple pain localisations (incl. headache) (4)	34.0 (23.0)#1,3	36.4 (25.8)#1	7.4 (20.8)#3	42.5 (45.5)	52.4 (23.0)#2	35.2 (19.8)#1,2	23.2 (16.5)#3	37.4 (19.7) #1,2,3

\*Significant difference between men and women; # Significant difference ( $p < 0.05$ ) with pain group corresponding to the numbers in superscript; PF, physical functioning; SF, social functioning; RP, role limitation physical; RE, role limitation emotional; MH, mental health; VT, vitality; BP, bodily pain; GH, general health

## **Musculoskeletal pain**

### **Arthritis**

*Alonso et al. 2004*

Participants who reported that they had arthritis scored 4.1 points lower on the Physical Summary Component of the SF-36 than respondents who did not report any chronic conditions, who scored a mean score of 53.4. Participants with arthritis also scored 1.0 points higher than those without chronic conditions on the Mental Summary Component for the SF-36, who had a mean score of 55.2.

### **Musculoskeletal diseases**

*Picavet and Hoeymans 2004*

For all musculoskeletal diseases and all quality of life dimensions it was found that having the disease was associated with a worse health related quality of life (Table 22). Subjects with any of the 12 musculoskeletal diseases had significantly lower scores on all SF-36 dimensions than those without musculoskeletal disease, especially for physical functioning (SF-36 score 75.2 (SE 0.5) vs 87.8 (SE0.5)), role limitations from physical problems (67.1 (SE 0.9) vs 85.8 (SE 0.8)), and bodily pain (68.5 (SE 0.6) vs 84.1 (SE0.5)). Those reporting a musculoskeletal disease also reported more health problems on the EQ-5D dimensions than those without a musculoskeletal disease, for example, for mobility (29.9% vs 10.5%), pain/discomfort (62.5% v 31.2%), and usual activities (34.5% v 12.4%).

With an increasing number of musculoskeletal conditions the health related quality of life deteriorated. In general, the health related quality of life scores for subjects with coexistent musculoskeletal disorders were worse than those with only one specific disease.

The dimensions typically affected by musculoskeletal diseases were physical functioning and pain on the SF36, and the dimensions "mobility" and "pain" on the EQ-5D. The diseases with the worst health related quality of life for those dimensions were: osteoarthritis of the knee or hip, rheumatoid arthritis, other types of chronic arthritis, osteoporosis, and fibromyalgia. The diseases with the least severe scores on these dimensions were epicondylitis, whiplash injury, repetitive strain injury, and tendinitis and capsulitis.

For the health related quality of life dimensions involving mental health problems, most musculoskeletal diseases did not score lower than the general population. These dimensions included vitality, role limitation due to emotional problems, and mental health on the SF36, and the dimension anxiety/depression on the EQ-5D. Two exceptions were fibromyalgia (for all these dimensions) and rheumatoid arthritis (only a low score on vitality) (see Table 22 on next page).

## **Q12a. Summary**

The three included studies reported on quality of life in several pain populations. Quality of life scores were low for patients with pain or musculoskeletal diseases. Patients with back pain, other pain and multiple pain locations experienced more functional limitations (physical functioning and role limitations physical) than the other pain groups. In addition, patients with multiple pain localizations scored significantly lower on mental health, vitality and general health.

Patients with arthritis had lower scores on physical summary component than patients not reporting any chronic conditions.

For all musculoskeletal diseases and all quality of life dimensions it was found that having the disease was associated with a worse health related quality of life. The dimensions typically affected by musculoskeletal diseases were physical functioning and pain on the SF36, and the dimensions "mobility" and "pain" on the EQ-5D.

**Table 22.** Percentage of respondents reporting any problem on EQ5D dimension and mean score of SF-36 questionnaire in patients with musculoskeletal diseases

	N	Any problem (moderate and severe) on EQ-5D dimension, % (SE)					Dimensions of SF-36 questionnaire, mean (SE)							
		M	SC	UA	P/D	A/D	PF	RP	BP	GH	VT	SF	RE	MH
Herniated disc (spine)	368	29.9 (1.9)	8.1 (1.1)	36.6 (2.2)	65.3 (2.7)	27.7 (2.1)	73.2 (1.1)	65.8 (2.0)	67.3 (1.3)	62.9 (1.1)	61.4 (1.1)	77.7 (1.2)	82.6 (1.7)	73.2 (0.9)
Gout	138	31.9 (3.5)	3.6 (1.9)	32.8 (4.0)	59.2 (4.7)	22.8 (3.8)	75.6 (2.0)	68.1 (3.6)	70.2 (2.2)	64.7 (1.9)	60.8 (1.9)	79.1 (2.2)	78.7 (3.0)	73.2 (1.7)
RSI	63	27.7 (4.3)	7.4 (2.3)	44.4 (4.9)	78.7 (5.8)	23.3 (4.7)	73.5 (2.5)	65.1 (4.4)	64.5 (2.7)	64.9 (2.3)	60.2 (2.4)	79.2 (2.7)	82.7 (3.7)	72.8 (2.0)
Epicondylitis	418	21.5 (1.8)	3.7 (1.0)	32.0 (2.1)	54.0 (2.5)	21.3 (2.0)	80.5 (1.1)	68.1 (1.9)	71.0 (1.2)	67.8 (1.0)	63.1 (1.0)	82.4 (1.1)	82.8 (1.6)	75.1 (0.9)
Osteoarthritis of knee	547	44.1 (1.7)	10.0 (1.0)	40.9 (2.0)	71.1 (2.4)	28.3 (1.9)	67.6 (1.0)	61.0 (1.9)	62.7 (1.1)	60.1 (1.0)	58.8 (1.0)	75.7 (1.1)	80.4 (1.6)	72.0 (0.9)
Osteoarthritis of hip	354	56.3 (2.3)	14.8 (1.3)	51.9 (2.7)	76.6 (3.2)	26.8 (2.6)	62.4 (1.4)	52.8 (2.5)	59.1 (1.5)	60.0 (1.3)	56.8 (1.3)	73.2 (1.5)	80.5 (2.1)	73.5 (1.2)
Osteoporosis	280	41.3 (2.5)	16.1 (1.4)	49.3 (2.9)	72.3 (3.4)	30.3 (2.7)	64.3 (1.4)	55.9 (2.6)	60.9 (1.6)	58.6 (1.3)	56.7 (1.4)	69.8 (1.6)	77.2 (2.2)	68.9 (1.2)
Whiplash	79	20.1 (4.1)	6.1 (2.2)	41.0 (4.6)	71.3 (5.5)	24.2 (4.4)	72.3 (2.3)	57.6 (4.2)	62.7 (2.6)	63.0 (2.2)	58.3 (2.3)	77.3 (2.5)	78.0 (3.5)	72.3 (1.9)
Rheumatoid arthritis	156	52.1 (3.3)	15.6 (1.9)	54.3 (3.8)	80.6 (4.6)	28.5 (3.7)	62.3 (2.0)	49.0 (3.5)	58.0 (2.2)	52.1 (1.8)	52.2 (1.9)	70.3 (2.1)	72.3 (3.0)	69.2 (1.6)
Other chronic arthritis	155	42.5 (3.3)	16.3 (1.8)	49.8 (3.8)	78.1 (4.4)	33.1 (3.6)	65.0 (1.9)	54.7 (3.4)	57.3 (2.1)	53.3 (1.8)	54.5 (1.8)	69.9 (2.0)	74.1 (2.8)	70.7 (1.6)
Fibromyalgia	43	66.7 (5.5)	12.3 (3.0)	73.8 (6.3)	93.1 (7.6)	4.17 (6.1)	55.0 (3.2)	41.4 (5.8)	48.2 (3.6)	50.1 (3.0)	39.9 (3.1)	60.3 (3.4)	81.5 (4.8)	64.1 (2.6)
Tendinitis and capsulitis	587	29.5 (1.5)	6.6 (0.8)	37.7 (1.7)	65.1 (2.0)	22.7 (1.6)	75.3 (0.8)	62.9 (1.5)	66.2 (0.9)	63.1 (0.8)	60.5 (0.8)	79.4 (0.9)	83.4 (1.3)	73.8 (0.7)
One MSD	957	22.7 (1.1)	4.5 (0.6)	26.3 (1.3)	53.3 (1.5)	20.4 (1.3)	80.0 (0.6)	74.3 (1.2)	73.8 (0.7)	67.7 (0.6)	64.6 (0.6)	83.2 (0.7)	86.7 (1.0)	76.0 (0.6)
Two MSD	478	33.1 (1.7)	6.5 (1.0)	39.8 (1.9)	71.1 (2.3)	23.6 (1.9)	72.7 (1.0)	63.0 (1.8)	65.5 (1.0)	64.0 (0.9)	60.2 (1.0)	79.6 (1.1)	84.0 (1.5)	73.8 (0.8)
Three MSD	193	49.0 (2.8)	12.3 (1.6)	52.2 (3.2)	82.2 (3.8)	30.3 (3.2)	63.4 (1.6)	53.2 (3.0)	57.0 (1.8)	55.8 (1.6)	56.0 (1.6)	69.1 (1.8)	76.0 (2.6)	69.9 (1.4)
Four or more MSD	148	57.2 (3.2)	19.7 (1.9)	66.7 (3.7)	85.8 (4.4)	39.1 (3.7)	56.2 (1.8)	34.9 (3.3)	47.1 (2.0)	50.2 (1.8)	47.8 (1.8)	63.9 (2.1)	66.0 (2.9)	65.8 (1.6)
Any MSD	1776	29.9 (0.9)	6.6 (0.5)	34.5 (1.0)	62.5 (1.2)	23.3 (1.0)	75.2 (0.5)	67.1 (0.9)	68.5 (0.6)	64.6 (0.5)	61.6 (0.5)	79.8 (0.6)	83.7 (0.8)	74.3 (0.4)
No MSD	1888	10.5 (0.8)	2.3 (0.4)	12.4 (0.9)	31.2 (1.1)	14.8 (0.9)	87.8 (0.5)	85.8 (0.8)	84.1 (0.5)	72.8 (0.4)	69.3 (0.5)	87.6 (0.5)	89.8 (0.8)	79.7 (0.4)

M, mobility; SC, self care; UA, usual activities; P/D, pain/discomfort; A/D, anxiety/depression; PF, physical functioning; RP, role function physical aspect; BP, bodily pain; GH, general; health; VT, vitality; SF, social functioning; RE, role function emotional aspect; MH, mental health; MSD, musculoskeletal disease, RSI, repetitive strain injury





**Q12b. In the Netherlands what is the impact of chronic pain on activities of daily living?**

We located four studies that were relevant to this question (Huisstede et al. 2008, Picavet and Schouten 2003, Rupp et al. 2006 ScanJRheumatol, Rupp et al. 2006 J Rheumatol).

Huisstede et al. 2008 and Picavet and Schouten 2003 were based on DMC<sub>3</sub> population survey data with 3664 respondents. Huisstede et al. 2008 aimed to study the prevalence of upper extremity disorders(UEDs) and neck as a total and complaints of the arm, neck and/or shoulder (CANS) not caused by acute trauma or any systemic disease as defined in the CANS model in the open population and to assess sociodemographic and health characteristics of chronic symptoms. The aim of Picavet and Schouten 2003 study was to present estimates on the prevalence of musculoskeletal pain of five different anatomical areas and ten anatomical sites, and their consequences and risk groups in the general Dutch population.

Rupp et al. 2006 ScanJRheumatol and Rupp et al. 2006 J Rheumatol were based on a longitudinal study in patients with rheumatoid arthritis (RA). Rupp et al. 2006 ScanJRheumatol aimed to study the associations between disability and health-related quality of life, and radiographic joint damage, disease activity, pain, and depressive symptoms among 307 patients with RA while Rupp et al. 2006 J Rheumatol aimed to assess the predictive value of selected socio-demographic characteristics, RA-specific clinical factors, and comorbidity with respect to patient-reported health outcomes, i.e., pain, disability, and health-related quality of life, among 882 patients with RA.

**Table 23.** Characteristics of the study selected for question 12b

Study details	Population	Outcomes and analysis
<p><b>Huisstede et al. 2008</b></p> <p><b>Study design</b> Cross-sectional/ survey</p> <p><b>Study method</b> DMC3 study - national health survey of musculoskeletal conditions; postal questionnaire – with general questions and health questions. After screening question for each of 5 anatomical areas Additional questions regarding pain in this area and its consequences; general health was measured using the Short Form(SF)-36</p>	<p><b>Type of chronic pain</b> Upper extremity disorders (UED) and neck pain; complaints of the arm, neck and/or shoulder (CANS; excluding UED caused by an acute trauma or a systemic disease)</p> <p><b>Confirmation of diagnosis</b> NR; only screening question: “did you have pain in ‘anatomic area’ during the past 12 months?”</p> <p><b>Sample size and demographics</b> 3664 respondents 25–44 years 47.0%, 45–64 years 34.6%, 65+ years 18.4% Female 50.9%</p> <p>chronic UED 996 chronic UED due to systemic disease or acute trauma 299 chronic CANS 697</p> <p><b>Patient selection</b> DMC3 - Dutch population aged 25 years and above; this study - persons with musculoskeletal upper extremity and neck disorders in 4 anatomic sites: neck, shoulder, elbow, and wrist/hand</p>	<p><b>Outcomes measured</b> 12-month prevalence, point prevalence, and prevalence of chronic pain (pain at baseline and lasting more than 3months in the last 12 months) course of pain, consequences of pain (contact with general practitioner, medical specialist or physiotherapist, work leave, limitations in daily life), general health</p> <p><b>Pain severity</b> self-reported - severe or mild chronic total UED Continuous severe pain 5.4% Recurrent severe pain 12.7% Chronic CANS Continuous severe pain 3.9% Recurrent severe pain 12.8%</p> <p><b>Analyses</b> Descriptive analysis only</p>

Study details	Population	Outcomes and analysis
<p><b>Picavet and Schouten 2003</b></p> <p><b>Study design</b> Cross-sectional study</p> <p><b>Study method</b> DMC3 study - national health survey of musculoskeletal conditions; postal questionnaire – with general questions and health questions. After screening question for each of 5 anatomical areas Additional questions regarding pain in this area and its consequences; socio-demographic characteristics</p>	<p><b>Type of chronic pain</b> Neck, shoulder, higher back 44.5% Elbow, wrist/hand 23.2% Lower back 43.9% Hip, knee 28% Ankle, foot 14.9%</p> <p><b>Confirmation of diagnosis</b> NR; only screening question: "did you have pain in 'anatomic area' during the past 12 months?"</p> <p><b>Sample size and demographics</b> Total sample: 3664 respondents weighted to present a distribution of sex, age, marital status and region of living equal to that of the Netherlands in 1998: Sex men 49.1% women 50.9% Age group 25-44 47.0% 45-64 34.6% 65+ 18.4%</p> <p><b>Patient selection</b> Dutch inhabitants of 25 years and older</p>	<p><b>Outcomes measured</b> Musculoskeletal pain period prevalence, point prevalence, prevalence of chronic pain, course of pain, consequences of pain (contact with general practitioner, medical specialist or physiotherapist, use of medicines, work leave, limitations in daily life, and work disability)</p> <p><b>Pain severity</b> self-reported - severe or mild roughly 15% severe pain</p> <p>Neck, shoulder or higher back Continuous severe pain 3.1% recurrent severe pain 8.3% Elbow or wrist/hand Continuous severe pain 4.0% recurrent severe pain 11.0% Lower back Continuous severe pain 3.5% recurrent severe pain 15.4% Hip or knee Continuous severe pain 5.2% recurrent severe pain 10.1% Ankle or foot Continuous severe pain 6.1% recurrent severe pain 12.4%</p> <p><b>Analyses</b> descriptive, frequencies, multivariate logistic regression</p>
<p><b>Rupp et al. 2006 ScanJRheumatol</b></p> <p><b>Study design</b> longitudinal / cohort study</p> <p><b>Study method</b> a self-administered postal questionnaire and a short clinical assessment (Disease Activity Score DAS28), the erythrocyte sedimentation rate (ESR), radiographic progression, RA related pain, depressive symptoms, disability, comorbidity, HRQoL; Information on disease duration abstracted from the patients' files</p>	<p><b>Type of chronic pain</b> Rheumatoid arthritis</p> <p><b>Confirmation of diagnosis</b> RA according to the 1987 revised American College of Rheumatology (ACR) criteria</p> <p><b>Sample size and demographics</b> Baseline n = 330, follow up: n = 307 Mean age 58.1 yrs [SD13.4]; Median age 59.6 yrs [IQR 49.1; 68.9] Female 71%</p> <p><b>Patient selection</b> patients registered at an outpatient centre for rheumatology and rehabilitation in Amsterdam or at one of its affiliated outpatient clinics, randomly selected based on disease duration. Inclusion criteria: RA according to the 1987 revised American College of Rheumatology (ACR) criteria, age &gt;16 years, sufficient command of the Dutch language and valid radiographs and 28-joint-count available for baseline and follow up</p>	<p><b>Outcomes measured</b> RA related pain on VAS, depressive symptoms (a Dutch version of the Centre for Epidemiological Study–Depression Scale (CES-D)), disease impact - disability (the validated Dutch questionnaire capacities of daily life (VDF)), comorbidity, HRQoL (a validated Dutch version of the RAND-36), radiographic damage (modified Sharp/ van der Heijde method), disease activity (DAS 28)</p> <p><b>Pain severity</b> VAS 0–100 mm Pain (VAS; 0–100) baseline mean 36.8 [SD 26.1], median 32.0 [IQR15.0; 56.0] follow up mean 34.5 [SDS 26.4], median 28.5 [IQR 11.0; 56.0]</p> <p><b>Analyses</b> Multivariate linear regression analyses (cross-sectional approach and longitudinal approach)</p>

Study details	Population	Outcomes and analysis
<p><b>Rupp et al. 2006 JRheumatol</b></p> <p><b>Study design</b> longitudinal / cohort study</p> <p><b>Study method</b> a self-administered postal questionnaire and twice a short clinical assessment (Disease Activity Score DAS28) and the erythrocyte sedimentation rate (ESR); RA related pain, somatic and psychological comorbidity (depressive symptoms), disability, HRQoL; Information on disease duration and RF positivity abstracted from the patients' files</p>	<p><b>Type of chronic pain</b> Rheumatoid arthritis</p> <p><b>Confirmation of diagnosis</b> RA according to the 1987 revised American College of Rheumatology (ACR) criteria</p> <p><b>Sample size and demographics</b> Baseline n = 882, follow up: n = 529 Mean age 59.8 (SD 14.8) Female 71.9%</p> <p><b>Patient selection</b> patients registered at an outpatient centre for rheumatology and rehabilitation in Amsterdam or at one of its affiliated outpatient clinics, randomly selected based on disease duration. Inclusion criteria: RA according to the 1987 revised American College of Rheumatology (ACR) criteria, age &gt;16 years, sufficient command of the Dutch language to complete the questionnaire</p>	<p><b>Outcomes measured</b> RA related pain on VAS, disability (the validated Dutch questionnaire capacities of daily life (VDF)), somatic comorbidity (a self-report list, adapted from the Health Interview Survey of Statistics Netherlands), HRQoL (a validated Dutch version of the RAND-36), disease activity (DAS 28), psychological comorbidity (depressive symptoms (a Dutch version of the Centre for Epidemiological Study–Depression Scale (CES-D))</p> <p><b>Pain severity</b> VAS 0–100 mm mean 40.6 (SD 28.1)</p> <p><b>Analyses</b> mixed-effect modeling procedure ProcMixed of SAS using random intercept linear regression models; univariate analyses (Student t tests and chi-square tests), multivariate logistic regression analyses; odds ratios (OR) of the logistic regression model, with 95% confidence intervals (95% CI). OR were adjusted for all other variables in the model</p>

## Q12b. Study quality

The quality of Huisstede et al. 2008 study was rated as moderate, it was unclear that the population was representative and the statistical methods were not clearly described and the results were not reported as unadjusted and confounder-adjusted including precision and there was no adequate description of the eligibility criteria.

Picavet and Schouten 2003 study was rated as high quality; only one item was missing – the authors did not provide adequate description of eligibility criteria.

The quality of Rupp et al. 2006 ScanJRheumatol study was rated as moderate. it was unclear that the population was representative and the statistical methods were not clearly described.

Rupp et al. 2006 JRheumatol study quality was rated as moderate. Loss to follow up was more than 25% for 5 years of follow up and as compared with those who did not respond the participants had higher HRQoL values, less disability,, they were younger and had overall a more favorable socioeconomic status, but they did not differ with respect to gender.

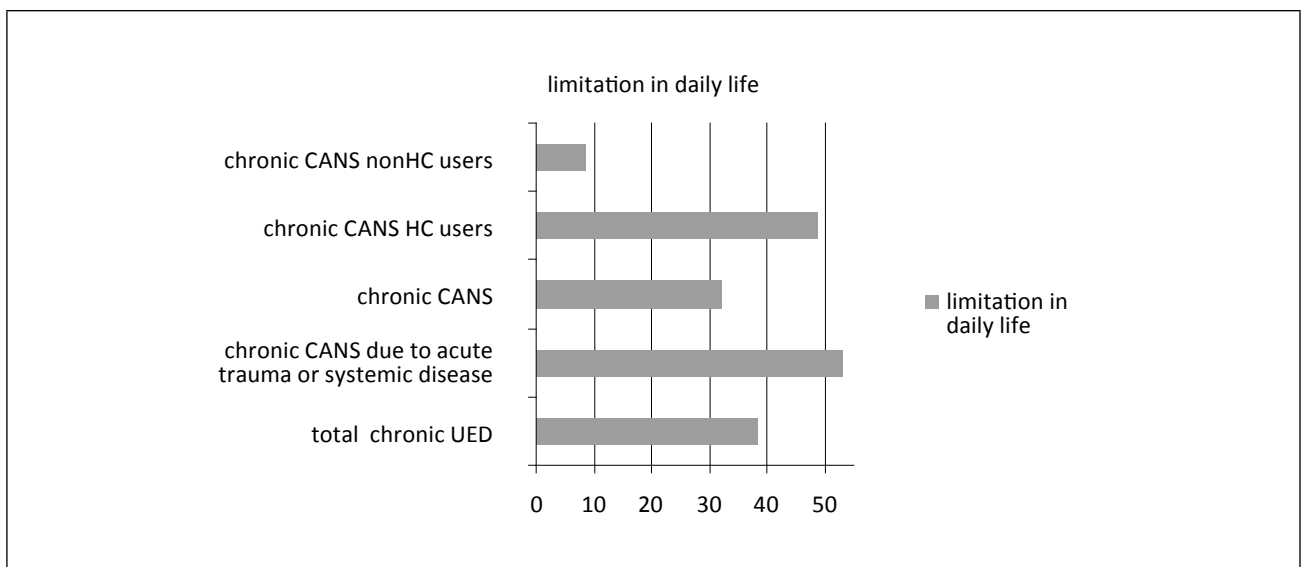
## Q12b. Results

### *Musculoskeletal pain*

*Huisstede et al. 2008*

Among people with chronic upper extremity and neck complaints (UED) 38.3% reported limitation in daily life due to their pain complaints in the last year. In the subgroup of people with chronic upper extremity and neck complaints due to systemic disease or acute trauma more than half (52.9%) reported limitation in daily life due to their complaints in the last year.

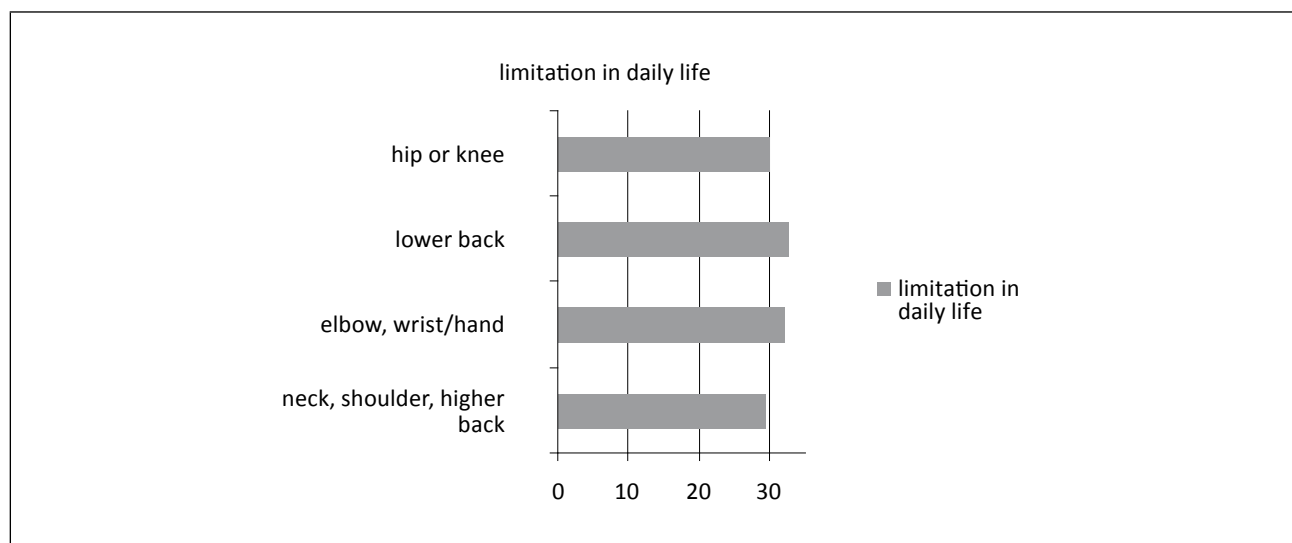
Among people with complaints of the arm, neck and/or shoulder (CANS) not caused by acute trauma or any systemic disease about one third (32.1%) reported limitation in daily life due to their complaints in the last year. In the subgroup of patients with CANS who were using healthcare the percentage was 48.9 and in those not using healthcare it was 8.5. The figure below presents percentage with limitation in daily life to patients in complaints in the subgroups and according to its length.



**Figure 16.** Limitation in daily life in the last year due to their complaints among participants with upper extremity and neck complaints and subgroups (CANS – complaints of the arm, neck and/or shoulder not caused by acute trauma or any systemic disease, HC – healthcare, UED – chronic upper extremity and neck complaints)

*Picavet and Schouten 2003*

Roughly 30% reported limitation in daily life in the last year due to their musculoskeletal pain. Figure presents the results according to different locations.



**Figure 17.** Limitation in daily life in the last year among participants with musculoskeletal pain complaints by location

### Rheumatoid arthritis

Rupp et al. 2006 *ScanJRheumatol*

Disability was measured with the validated Dutch questionnaire capacities of daily life (VDF) which consists of 20 items measuring the degree of difficulty a patient has in performing activities of daily living (ADL) in eight areas (dressing and grooming, arising, eating, walking, hygiene, gripping, reaching, and other activities). Scores 0–3, with higher scores indicating more disability.

Mean values at baseline were 0.46 (SD 0.48) and at follow up 0.56 (SD 0.56) and median values were at baseline 0.3 (IQR 0.05, 0.7) and at follow up 0.4 (IQR 0.1, 0.9).

In cross-sectional approach pain was the most important predictor for disability (regression coefficient B 0.007 [95% CI 0.005; 0.009]; standardized  $\beta = 0.359$ ;  $p < 0.001$ ). For depressive symptoms (regression coefficient B 0.013 [95% CI 0.008; 0.019];  $p < 0.001$ ) and radiographic damage (regression coefficient B 0.002 [95% CI 0.001; 0.003];  $p < 0.001$ ) and disease activity (regression coefficient B 0.081 [95% CI 0.046; 0.116];  $p < 0.001$ ) statistically significant associations were found. Depressive symptoms were slightly more important than radiographic damage (standardized  $\beta$  0.232 vs 0.216) and disease activity showed a stronger association than radiographic damage with disability (standardized  $\beta$  0.236 vs 0.216). Age, gender, disease duration, comorbidity, were not significantly related to disability.

In longitudinal approach change in pain was the most important predictor for changes in disability (regression coefficient B  $-0.005$  [95% CI  $-0.006$ ;  $-0.003$ ]; standardized  $\beta = -0.330$ ;  $p < 0.001$ ). Progression in radiographic joint damage (regression coefficient B  $-0.003$  [95% CI  $-0.005$ ;  $-0.000$ ];  $p < 0.05$ ) and change in disease activity (regression coefficient B  $-0.060$  [95% CI  $-0.093$ ;  $-0.026$ ];  $p < 0.001$ ) were also significantly associated with change in disability. Change in disease activity had a stronger association than radiographic progression with

changes in disability (standardized  $\beta$   $-0.195$  vs  $-0.135$ ). Age, gender, disease duration, comorbidity and change in depressive symptoms were not statistically significantly associated with change in disability.

*Rupp et al. 2006 JRheumatol*

Disability was measured with the validated Dutch questionnaire capacities of daily life (VDF) which consists of 20 items measuring the degree of difficulty a patient has in performing activities of daily living (ADL) in eight areas (dressing and grooming, arising, eating, walking, hygiene, gripping, reaching, and other activities). Scores 0–3, with higher scores indicating more disability.

Mean values at baseline were 0.66 (SD 0.62).

The authors divided patients into showing much poorer health outcomes (10% poorest) and much better outcomes (10% best). With respect to disability “poorest outcomes patients” were, in comparison to “best outcomes patients,” more often women (85.2% vs 56.8%), they were older (67.7 years vs 61.6 years), had low SES (47.1% vs 21.%), had paid work less often (1.2% vs 23.9%), and were more often divorced or widowed (40.7% vs 15.9%). Further, they were positive for RF (73.9% vs 58.6%), had a higher disease activity assessment (4.6 vs 2.9), they reported more somatic (1.9 vs 0.8) and psychological comorbidity (20.6 vs 7.7).

Risk factors for poor outcome with respect to disability were : female sex (OR 2.2 [95% CI 1.1–4.5];  $p < 0.05$ ) and older age (OR 1.3 [95% CI 1.1–1.6];  $p < 0.05$ ), RF positivity (OR 2.0 [95% CI 1.1–3.5];  $p < 0.05$ ) and disease activity (OR 1.7 [95% CI 1.3–2.3];  $p < 0.001$ ) as well as somatic (OR 1.2 [95% CI 1.0–1.5];  $p < 0.05$ ) and psychological comorbidity (OR 1.1 [95% CI 1.1–1.1];  $p < 0.001$ ).

Disease activity (OR 0.7 [95% CI 0.6–0.8];  $p < 0.01$ ) and psychological comorbidity (OR 0.9 [95% CI 0.9–1.0];  $p < 0.001$ ) hampered good outcomes with respect to disability.

## Q12b. Summary

The four included studies reported on prevalence of limitation in daily life due to pain or associations between socio-demographic characteristics or disease characteristics and disability in rheumatoid arthritis. In patients with musculoskeletal pain limitation in daily life were reported by 8.5–53% of patients. In patients with rheumatoid arthritis pain was the most important predictor for disability, significant associations were also found for depressive symptoms, radiographic damage and disease activity. Female sex, older age, RF positivity, disease activity and somatic and psychological co-morbidities were found to be risk factors for poor outcome with respect to disability.





**Q12c. In the Netherlands what is the impact of chronic pain on depression and other mental illnesses?**

We located four studies that were relevant to this question (Breivik et al. 2006, Demyttenaere et al. 2007 and Rupp et al. 2006 *ScanJRheumatol*, Rupp et al. 2006 *J Rheumatol*).

Breivik et al. (2006) performed a large telephone survey to explore the prevalence, impact on daily life and treatment of chronic pain in 15 European countries and Israel, among which the Netherlands. Persons received an initial screening questionnaire and those who suffered from long-lasting pain were subsequently interviewed in-depth using a second structured questionnaire. From the Netherlands, 300 persons suffering chronic pain were interviewed.

Demyttenaere et al. 2007 aimed to estimate the prevalence of 12-month chronic back or neck pain in the general population of 85 088 participants in 17 countries in Europe, the Americas, the Middle East, Africa, Asia, and the South Pacific and to estimate the occurrence of specific 12-month mood, anxiety disorders, and alcohol abuse/dependence among persons with chronic back or neck pain as well as to investigate which mental disorders were most strongly associated with chronic back or neck pain and to assess the consistency of the associations between chronic back or neck pain and mental disorders.

Rupp et al. 2006 *ScanJRheumatol* and Rupp et al. 2006 *J Rheumatol* are based on a longitudinal study in patients with rheumatoid arthritis (RA). Rupp et al. 2006 *ScanJRheumatol* aimed to study the associations between disability and health-related quality of life, and radiographic joint damage, disease activity, pain, and depressive symptoms among 307 patients with RA while Rupp et al. 2006 *J Rheumatol* aimed to assess the predictive value of selected socio-demographic characteristics, RA-specific clinical factors, and comorbidity with respect to patient-reported health outcomes, i.e., pain, disability, and health-related quality of life, among 882 patients with RA.

**Table 24.** Characteristics of the study selected for question 12c

Study details	Population	Outcomes and analysis
<p><b>Breivik et al. 2006</b></p> <p><b>Study design</b> Cross-sectional study</p> <p><b>Study method</b> Telephone survey in two parts. First, persons were screened for chronic pain. Those who qualified were interviewed in-depth</p>	<p><b>Type of chronic pain</b> Long-lasting pain: chronic pain for at least 6 months, and pain in last month, and pain at least 2 times/week, and rating pain intensity at least 5 on 10-point NRS</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> Total sample: 4839; Netherlands: 300 persons with long-lasting pain Demographics for all countries together: 52% female mean age 50 years For the Netherlands: female 60%, mean age 51.3 years</p> <p><b>Patient selection</b> Subjects with long-lasting pain (see definition above).</p>	<p><b>Outcomes measured</b> Duration, location, intensity of pain Tolerance, time course of pain, impact pain on activities daily life, employment status, emotional status Visits to doctors, visits to pain management specialist, treatment (medication and non-medication), effectiveness of treatment, satisfaction with doctors, respondents' attitudes and beliefs about pain and pain treatment, respondents' perception of the attitude of others to their pain</p> <p><b>Pain severity</b> 18% reported severe pain</p> <p><b>Analyses</b> Descriptive analysis only. No subgroups were reported (for the Netherlands)</p>
<p><b>Demyttenaere et al. 2007</b></p> <p><b>Study design</b> Population surveys of community-dwelling adults in 17 countries in Europe, the Americas, the Middle East, Africa, Asia, and the South Pacific (N = 85,088)</p> <p><b>Study method</b> Face-to-face survey with questions about chronic conditions adapted from the US Health Interview Survey (National Center for Health Statistics, 1994)</p>	<p><b>Type of chronic pain</b> Back or neck pain</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> Netherlands sample n=1094 Mean age 45.0 Female 50.9%</p> <p><b>Selection</b> All respondents who met criteria for any mental disorder and a probability sample of other respondents were administered part-2 (assessment of chronic physical conditions)</p>	<p><b>Outcomes measured</b> The 12-month prevalence of either back or neck pain The prevalence of mental disorders among people with chronic back/neck pain</p> <p><b>Analyses</b> Odds ratios (OR) for the association of each mental disorder with the pain condition were estimated for each survey. Adjusted ORs were estimated to assess the association of any mood disorder, any anxiety, and any alcohol abuse/dependence with back or neck pain</p> <p><b>Pain severity</b> Not reported</p>

Study details	Population	Outcomes and analysis
<p><b>Rupp et al. 2006</b> <b>ScanJRheumatol</b></p> <p><b>Study design</b> longitudinal / cohort study</p> <p><b>Study method</b> a self-administered postal questionnaire and a short clinical assessment (Disease Activity Score DAS28), the erythrocyte sedimentation rate (ESR), radiographic progression, RA related pain, depressive symptoms, disability, comorbidity, HRQoL; Information on disease duration abstracted from the patients' files</p>	<p><b>Type of chronic pain</b> Rheumatoid arthritis</p> <p><b>Confirmation of diagnosis</b> RA according to the 1987 revised American College of Rheumatology (ACR) criteria</p> <p><b>Sample size and demographics</b> Baseline n = 330, follow up: n = 307 Mean age 58.1 yrs [SD13.4]; Median age 59.6 yrs [IQR 49.1; 68.9] Female 71%</p> <p><b>Patient selection</b> patients registered at an outpatient centre for rheumatology and rehabilitation in Amsterdam or at one of its affiliated outpatient clinics, randomly selected based on disease duration. Inclusion criteria: RA according to the 1987 revised American College of Rheumatology (ACR) criteria, age &gt;16 years, sufficient command of the Dutch language and valid radiographs and 28-joint-count available for baseline and follow up</p>	<p><b>Outcomes measured</b> RA related pain on VAS, depressive symptoms (a Dutch version of the Centre for Epidemiological Study–Depression Scale (CES-D)), disease impact - disability (the validated Dutch questionnaire capacities of daily life (VDF)), comorbidity, HRQoL (a validated Dutch version of the RAND-36), radiographic damage (modified Sharp/ van der Heijde method), disease activity (DAS 28)</p> <p><b>Pain severity</b> VAS 0–100 mm Pain (VAS; 0–100) baseline mean 36.8 [SD 26.1], median 32.0 [IQR15.0; 56.0] follow up mean 34.5 [SDS 26.4], median 28.5 [IQR 11.0; 56.0]</p> <p><b>Analyses</b> Multivariate linear regression analyses (cross-sectional approach and longitudinal approach)</p>
<p><b>Rupp et al. 2006</b> <b>JRheumatol</b></p> <p><b>Study design</b> longitudinal / cohort study</p> <p><b>Study method</b> a self-administered postal questionnaire and twice a short clinical assessment (Disease Activity Score DAS28) and the erythrocyte sedimentation rate (ESR); RA related pain, somatic and psychological comorbidity (depressive symptoms), disability, HRQoL; Information on disease duration and RF positivity abstracted from the patients' files</p>	<p><b>Type of chronic pain</b> Rheumatoid arthritis</p> <p><b>Confirmation of diagnosis</b> RA according to the 1987 revised American College of Rheumatology (ACR) criteria</p> <p><b>Sample size and demographics</b> Baseline n = 882, follow up: n = 529 Mean age 59.8 (SD 14.8) Female 71.9%</p> <p><b>Patient selection</b> patients registered at an outpatient centre for rheumatology and rehabilitation in Amsterdam or at one of its affiliated outpatient clinics, randomly selected based on disease duration. Inclusion criteria: RA according to the 1987 revised American College of Rheumatology (ACR) criteria, age &gt;16 years, sufficient command of the Dutch language to complete the questionnaire</p>	<p><b>Outcomes measured</b> RA related pain on VAS, disability (the validated Dutch questionnaire capacities of daily life (VDF)), somatic comorbidity (a self-report list, adapted from the Health Interview Survey of Statistics Netherlands), HRQoL (a validated Dutch version of the RAND-36), disease activity (DAS 28), psychological comorbidity (depressive symptoms (a Dutch version of the Centre for Epidemiological Study–Depression Scale (CES-D)))</p> <p><b>Pain severity</b> VAS 0–100 mm mean 40.6 (SD 28.1)</p> <p><b>Analyses</b> mixed-effect modeling procedure ProcMixed of SAS using random intercept linear regression models; univariate analyses (Student t tests and chi-square tests), multivariate logistic regression analyses; odds ratios (OR) of the logistic regression model, with 95% confidence intervals (95% CI). OR were adjusted for all other variables in the model</p>

## Q12c. Study quality

The quality of the Breivik et al. 2006 study, Demyttenaere et al. 2007 study and Rupp et al. 2006 ScanJRheumatol study was rated as moderate. In all studies it was unclear that the population was representative, in the Breivik and Rupp study the statistical methods were not clearly described, in Demyttenaere study the eligibility criteria were not clearly described.

Rupp et al. 2006 JRheumatol study quality was rated as moderate. Loss to follow up was more than 25% for 5 years of follow up and as compared with those who did not respond the participants had higher HRQoL values, less disability, they were younger and had overall a more favorable socioeconomic status, but they did not differ with respect to gender.

## Q12c. Results

### **General chronic pain**

#### *Breivik et al. 2006*

Among 294 of Dutch respondents 19% reported being diagnosed with depression by a medical doctor as a results of their pain, while the European average was 21%.

### **Back/neck pain**

#### *Demyttenaere et al. 2007*

Prevalence of mood disorders among persons with versus without back/neck pain:

Major depressive episode: 4.4% no back or neck pain; 9.4% back or neck pain; OR 2.3 (1.5, 3.6)

Dysthymia: 1.2% no back or neck pain; 4.5% back or neck pain; OR 4.2 (1.8, 9.7).

Prevalence (%) of anxiety disorders among persons with versus without back/neck pain:

Generalized anxiety disorder: 0.8% no back or neck pain; 2.1% back or neck pain; OR 2.8 (1.0, 7.7)

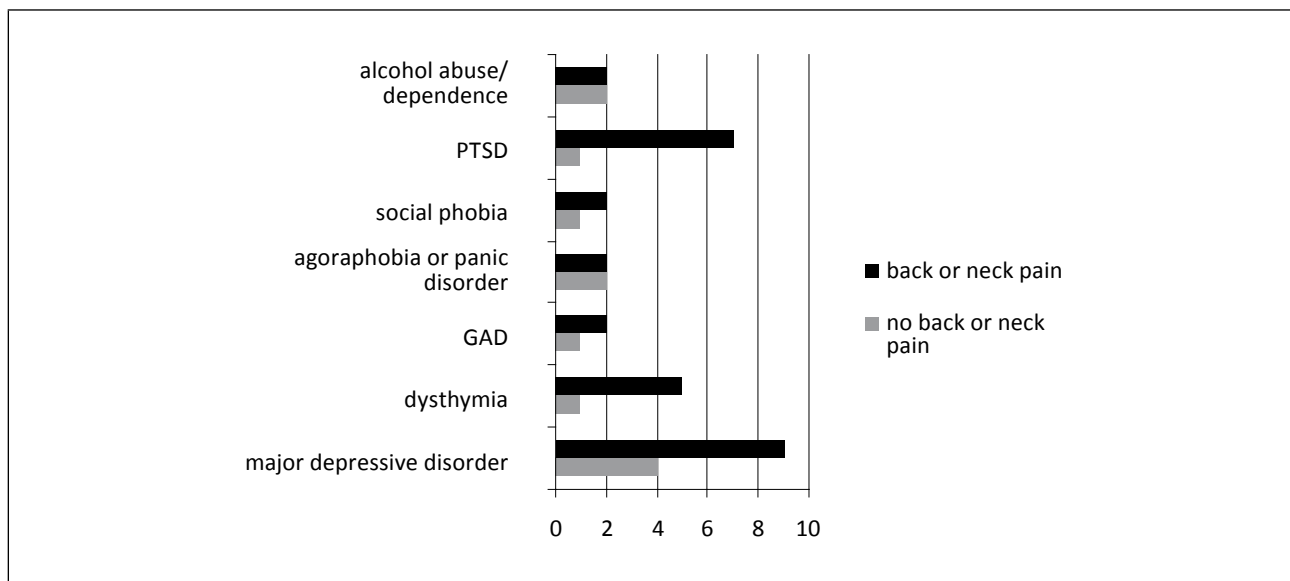
Agoraphobia or Panic disorder: 1.7% no back or neck pain; 1.7% back or neck pain; OR 1.0 (0.4, 2.6)

Social Phobia: 1.0% no back or neck pain; 2.4% back or neck pain; OR 2.5 (0.8, 7.7)

Posttraumatic stress disorder: 1.4% no back or neck pain; 7.4% back or neck pain; OR 4.4 (1.5, 13.3).

Prevalence (%) of alcohol abuse/dependence disorders among persons with versus without back/neck pain:

1.7% no back or neck pain; 1.7% back or neck pain; OR 1.3 (0.5, 3.2).



**Figure 18.** Prevalence of mental illnesses in patients with back or neck pain (GAD – generalised anxiety disorder, PTSD – posttraumatic stress disorder)

**Rheumatoid arthritis**

Rupp et al. 2006 ScanJRheumatol

Depressive symptoms were assessed by Centre for Epidemiological Study-Depression Scale (CES-D; Scores 0 to 60, with higher scores indicating more depressive symptomatology). Mean values at baseline were 10.3 (SD 8.2) and at follow up 10.5 (SD 7.9) and median values were at baseline 9.0 (IQR 4, 14) and at follow up 10.0 (IQR 4, 14.4).

Mental component of quality of life was assessed with the use of mental component summary (MCS) scale from RAND-36 (Higher scores indicate better health status). Mean values at baseline were 50.9 (SD 10.6) and at follow up 50.0 (SD 10.1). Median values were at baseline 54.2 (IQR 44.8, 58.6) and at follow up 53.0 (IQR 43.2, 57.7).

In cross sectional approach depressive symptoms appeared to be the most important predictor for mental health (MCS) (regression coefficient B -0.895 [ 95% CI -1.006; -0.784]; p<0.001). Depressive symptoms were also significantly related to disability (regression coefficient B 0.013 [95% CI 0.008; 0.019]; p<0.001) and slightly more important than radiographic damage. Depressive symptoms were not significantly related to physical component summary scale of RAND-36. A statistically significant association between radiographic damage and MCS was found (regression coefficient B 0.034 [95% CI 0.015; 0.053]; p<0.001). Age, gender, disease duration, comorbidity, disease activity and pain were not significantly related to MCS.

In longitudinal approach change in depressive symptoms was the most important predictor for change in mental health (MCS) (regression coefficient B -0.781 [95% CI -0.964; -0.599]; p<0.001), but was not statistically significantly associated with change in disability and physical component summary scale of

RAND-36. Age, gender, disease duration, comorbidity, disease activity, pain and progression in radiographic joint damage were not significantly associated with change in MCS.

*Rupp et al. 2006 JRheumatol*

Psychological comorbidity (depressive symptoms) was assessed by Centre for Epidemiological Study-Depression Scale (CES-D; Scores 0 to 60, with higher scores indicating more depressive symptomatology). Mean values at baseline were 12.3 (SD 9.2). Mental component of quality of life was assessed with the use of mental component summary (MCS) scale from RAND-36 (Higher scores indicate better health status). Mean values at baseline were 49.2 (SD 11.4).

The authors divided patients into showing much poorer health outcomes (10% poorest) and much better outcomes (10% best). "Poorest outcomes patients" reported more psychological comorbidity than "best outcomes patients" (19–27 vs 4–8; all  $p < 0.001$ ). With respect to MCS "poorest outcomes patients, in comparison to "best outcomes patients" had low SES (31% vs 20.5%), less often had paid work (5.7% vs 21.6%), more often were divorced or widowed (32.2% vs 15.9%), reported more somatic (1. vs 0.9) and psychological comorbidity (27.4 vs 4.4).

Disease activity seemed to decrease the risk of poor mental health as measured by MCS (OR 0.6 [95% CI 0.4–0.8];  $p < 0.001$ ). Psychological comorbidity consistently increased the risk for poor outcomes with respect to pain (OR 1.1 [95% CI 1.1–1.1];  $p < 0.001$ ), disability (OR 1.1 [95% CI 1.1–1.1];  $p < 0.001$ ), physical component summary scale (OR 1.1 [95% CI 1.0–1.1];  $p < 0.001$ ) and MCS (OR 1.3 [95% CI 1.2–1.4];  $p < 0.001$ ).

Medium SES hampered good mental health as measured by MCS (OR 0.5 [95% CI 0.2–0.9];  $p < 0.05$ ). Somatic appeared to be associated with good outcome of MCS (OR 1.3 [95% CI 1.0–1.7];  $p < 0.05$ ). Psychological comorbidity hampered good outcomes with respect to pain (OR 0.9 [95% CI 0.8–0.9];  $p < 0.001$ ), disability (OR 0.9 [95% CI 0.9–1.0];  $p < 0.001$ ), PCS (OR 0.9 [95% CI 0.8–0.9];  $p < 0.001$ ), and MCS (OR 0.7 [95% CI 0.7–0.9];  $p < 0.001$ ).

## Q12c. Summary

The three included studies reported on prevalence of depressive symptoms or associations between disability and health-related quality of life rheumatoid arthritis radiographic joint damage, disease activity, pain, and depressive symptoms. In general pain condition depression was reported in 19% of respondents, in patients with back or neck pain mood disorders were reported by 4.5–9.4% (major depressive disorder was reported by the highest percentage of respondents) of pain sufferers, anxiety disorders by 1.7–7.4% of respondents and alcohol abuse by 1.7%. In patients with rheumatoid arthritis depressive symptoms appeared to be the most important predictor for mental health and were significantly related to disability. Psychological comorbidity (depressive symptoms) was also a risk factor for poor outcomes and to hamper good outcomes with respect to all health outcomes (pain, disability, physical component summary scale and mental component summary scale).





**Q12d. In the Netherlands what is the impact of chronic pain on isolation and helplessness?**

We found two studies that were relevant to this question: EURIDISS (Suurmeijer et al 2001, Strating 2006) on social support and Samwel et al (2006) on helplessness.

European Research on Incapacitating Disease and Social Support (EURIDISS) is a multicenter, multidisciplinary longitudinal European study set up to explore the relationships between “disease variables,” “social support,” and a number of quality of life (QoL) measures among patients with early rheumatoid arthritis (RA). Suurmeijer et al (2001) examined the QoL profiles of these patients and related these to disease and impairment variables as indicated, respectively, by erythrocyte sedimentation rate (ESR) and by tender joint count (Ritchie Articular Index), fatigue, and pain. Strating et al (2006) examined the strength and stability of the relationships between disease-related factors (joint tenderness, pain, and functional disability), social support, and distress over time.

Samwel et al. (2006) performed a cross-section study to examine the relative contribution of helplessness, fear of pain, and passive pain-coping to pain level, disability, and depression in chronic pain patients attending an interdisciplinary pain center.

**Table 25.** Characteristics of the studies selected for question 12d

Study details	Population	Outcomes and analysis
<p><b>EURIDISS</b></p> <p><b>Study design</b> longitudinal / cohort study</p> <p><b>Study method</b> The present study uses part of the EURIDISS data of 573 patients with recently diagnosed RA (268 from the Netherlands, 216 from Norway, and 89 from France). A series of clinical and psychosocial data were collected on 4 (the Netherlands, France) and 3 (Norway) occasions, with 1-year intervals separating the waves of data collection</p>	<p><b>Type of chronic pain</b> Rheumatoid arthritis pain</p> <p><b>Confirmation of diagnosis</b> RA according to the 1987 American College of Rheumatology (formerly the American Rheumatism Association) criteria</p> <p><b>Sample size and demographics</b> Sample from the Netherlands N=268, 64% female Mean age 54.4 years (SD 11.8)</p> <p><b>Patient selection</b> Inclusion criteria are residence in the sampling areas, age between 20 and 70 years, diagnosis of RA according to the 1987 American College of Rheumatology criteria, and disease duration of 4 years or less</p>	<p><b>Outcomes measured</b> Disease: Erythrocyte sedimentation rate (ESR). Impairment: Ritchie Articular Index (RAI); Subscales “fatigue” and “pain” of the Nottingham Health Profile (NHP) Disability: Groningen Activity Restriction Scale (GARS); Health Assessment Questionnaire (HAQ). Handicap: Leisure; Independent Living With RA (ILRA) The “mental domain” of QoL: Rosenberg Self-Esteem scale (RSE) and the 28-item version of the General Health Questionnaire (GHQ28) measuring psychological distress Satisfaction: Social Support Questionnaire: Satisfaction With Supportive Transactions (SSQS)</p> <p><b>Pain severity</b> Sample from the Netherlands Mean 13.4 (SD: 2.1); 43% had low pain scores (<math>\leq 13.00</math>)</p> <p><b>Analyses</b> Descriptive data (mean, SD) for pain</p>

Study details	Population	Outcomes and analysis
<p><b>Samwel et al. 2006</b></p> <p><b>Study design</b> Cross-sectional / survey</p> <p><b>Study method</b> Patients completed questionnaires and diary for 7 days</p>	<p><b>Type of chronic pain</b> Unexplained chronic pain for which no biomedical cause could be identified</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> N=169, 63.9% females mean age 47.1 years (SD 13.9)</p> <p><b>Patient selection</b> Recruited from patients accepted for interdisciplinary pain treatment between November 1999 and January 2001: patients had to be at least 18 years with their pain problem present for more than 3 months</p>	<p><b>Outcomes measured</b> pain intensity (10 cm VAS), disability (Pain Disability Index), Depression (depression scale of Symptom Checklist-90), fear of pain (Tampa scale of Kinesophobia), Passive Pain coping (Pain Coping Inventory), helplessness (Helplessness scale of the Illness Cognition Questionnaire)</p> <p><b>Pain severity</b> mean (SD): 54.3 (19.9)</p> <p><b>Analyses</b> Pearson correlation coefficients, regression analyses with pain level, disability, and depression as dependent variables</p>

## Q12d. Study quality

The study of Suurmeijer was rated as a high-quality study. Study design, eligibility criteria, outcomes, statistical methods and study participants were adequately reported. Loss to follow-up was just 8% over 4 years and results were clearly reported as adjusted or unadjusted with precision. However, it was unclear whether the population was representative of the target population.

The study of Samwel et al. (2006) was rated moderate quality. Eligibility criteria were unclear and it was unclear whether the study sample was representative of the target sample. Also the outcomes were poorly reported as the ranges per scale and the direction were not clear. However, study design and statistical methods were adequately described. Also results were clearly reported as adjusted or unadjusted with precision.

## 12d. Results

### Isolation

#### EURIDISS

No results on isolation were found but EURIDISS reported data on satisfaction of patients with RA on social support using the satisfaction with supportive transactions questionnaire (a scale from 23 to 69), consisting of the subscale ESS (emotional support satisfaction, from 11 to 33) and the subscale SCS (Social companionship satisfaction, from 5-15). Higher score indicate more satisfaction.

Overall SSQS (Social support questionnaire for satisfaction with supportive transactions) is 64.9 (SD 4.6), for ESS (emotional support satisfaction) 31.1 (SD 2.7) and for SCS (Social companionship satisfaction) 13.8 (1.5) (Suurmeijer et al 2001). No differences were found during the follow-up period of 4 years for ESS and SCS (Strating et al. 2006). (see Table 26 below).

**Table 26.** Mean and SD for SSDQ, ESS and SCS during follow-up

	Mean over all years	T1	T2	T3	T4	T5
SSDQ* (23-69)	64.9 (4.6)	-	-	-	-	-
ESS* (11-33)	31.1 (2.7)	30.6 (3.6)	30.9 (3.3)	31.1 (3.1)	31.2 (3.4)	28.0 (3.1)
SCS* (5-15)	13.8 (1.5)	13.6 (1.9)	13.8 (1.9)	13.8 (1.6)	13.7 (2.0)	13.7 (1.9)

\* higher score indicates better functioning.

ESS: emotional support satisfaction; SCS: social companionship satisfaction

### Helplessness

Samwel et al (2006)

Helplessness was measured using the Helplessness scale of the Illness Cognition Questionnaire, with a range from 6 to 24 and a higher score representing more helplessness. Passive coping was measured using the Pain Coping Inventory. The PCI is rated on a 4-point Likert scale (1=rarely or never to 4, very frequent).

The mean (SD) score for helplessness the total group was 14.6 (4.7). The means for passive coping were as follows: Worrying: 2.0 (0.5); Retreating: 1.5 (0.5), Resting: 2.5 (0.6). There were no significant differences between pain subgroups (see table 27)

**Table 27.** Mean (SD) of helplessness and passive coping for the total sample and subgroups based on location of pain

	Total sample (n=169)	Back pain (n=48)	Leg pain (n=41)	Neck/ Shoulder pain (n=26)	Other pain location (n=36)	More than 1 pain location (n=18)
Helplessness	14.6 (4.7)	15.6 (4.2)	14.1 (4.0)	16.2 (5.1)	14.5 (3.7)	16.3 (3.7)
Passive coping						
Worrying	2.0 (0.5)	2.2 (0.5)	2.0 (0.5)	2.2 (0.5)	2.2 (0.5)	2.1 (0.5)
Retreating	1.5 (0.5)	1.5 (0.4)	1.5 (0.5)	1.8 (0.5)	1.6 (0.5)	1.5 (0.4)
Resting	2.5 (0.6)	2.6 (0.6)	2.5 (0.8)	2.7 (0.6)	2.6 (0.7)	2.6 (0.6)

### Q12d. Summary

Only two studies were found that reported on isolation or helplessness. One study was on patients with early RA and the other on patients with unexplained chronic pain attending an interdisciplinary treatment centre. Patients with early RA seem to be satisfied with their social support and patients with unexplained pain seem to experience at most moderate helplessness. Resting, however, a passive pain coping strategy seems to be used sometimes to frequent. For both studies it's unclear whether the populations are representative of the target population. Together with the difficulties interpreting the data, we should conclude that the current data gives only a limited view on the impact of chronic pain on isolation and helplessness.

**Q12e. In the Netherlands what is the impact of chronic pain on days off work?**

We located four studies that were relevant to this question (Borghouts et al. 1999, Breivik et al. 2006, Huisstede et al. 2008 and Picavet and Schouten 2003).

Borghouts et al (1999) investigated the costs of neck pain in the Netherlands in 1996 to assess the financial burden to society. The study was based on prevalence data and data sources included national registries, reports of research institutes and health care authorities.

Breivik et al. (2006) performed a large telephone survey to explore the prevalence, impact on daily life and treatment of chronic pain in 15 European countries and Israel, among which the Netherlands. Persons received an initial screening questionnaire and those who suffered from long-lasting pain were subsequently interviewed in-depth using a second structured questionnaire. From the Netherlands, 300 persons suffering chronic pain were interviewed.

Huisstede et al. 2008 and Picavet and Schouten 2003 were based on DMC3 population survey data with 3664 respondents. Huisstede et al. 2008 aimed to study the prevalence of upper extremity disorders(UEDs) and neck as a total and complaints of the arm, neck and/or shoulder (CANS) not caused by acute trauma or any systemic disease as defined in the CANS model in the open population and to assess socio-demographic and health characteristics of chronic symptoms. The aim of Picavet and Schouten 2003 study was to present estimates on the prevalence of musculoskeletal pain of five different anatomical areas and ten anatomical sites, and their consequences and risk groups in the general Dutch population.

**Table 28.** Characteristics of the study selected for question 12e

Study details	Population	Outcomes and analysis
<p><b>Borghouts et al. 1999</b></p> <p><b>Study design</b> Cost-of-illness study</p> <p><b>Study method</b> Study is based on prevalent cases of neck pain. Direct medical costs and indirect costs were estimated using national registries, reports of research institutes and health care authorities</p>	<p><b>Type of chronic pain</b> Neck pain</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> Not reported</p> <p><b>Patient selection</b> All prevalent cases in 1996 were included</p>	<p><b>Outcomes measured</b> direct medical costs (hospital care, medical procedures, medical specialists fees, ambulatory hospital care, general practice care and paramedical care), indirect costs (absenteeism, disability)</p> <p><b>Pain severity</b> Not reported</p> <p><b>Analyses</b> Human capital Method; Friction Cost Method</p>

Study details	Population	Outcomes and analysis
<p><b>Breivik et al. 2006</b></p> <p><b>Study design</b> Cross-sectional study</p> <p><b>Study method</b> Telephone survey in two parts. First, persons were screened for chronic pain. Those who qualified were interviewed in-depth</p>	<p><b>Type of chronic pain</b> Long-lasting pain: chronic pain for at least 6 months, and pain in last month, and pain at least 2 times/week, and rating pain intensity at least 5 on 10-point NRS</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> Total sample: 4839; Netherlands: 300 persons with long-lasting pain Demographics for all countries together: 52% female mean age 50 years For the Netherlands: female 60%, mean age 51.3 years</p> <p><b>Patient selection</b> Subjects with long-lasting pain (see definition above)</p>	<p><b>Outcomes measured</b> Duration, location, intensity of pain. Tolerance, time course of pain, impact pain on activities daily life, employment status, emotional status Visits to doctors, visits to pain management specialist, treatment (medication and non-medication), effectiveness of treatment, satisfaction with doctors, respondents' attitudes and beliefs about pain and pain treatment, respondents' perception of the attitude of others to their pain</p> <p><b>Pain severity</b> 18% reported severe pain</p> <p><b>Analyses</b> Descriptive analysis only. No subgroups were reported (for the Netherlands)</p>
<p><b>Huisstede et al. 2008</b></p> <p><b>Study design</b> Cross-sectional/ survey</p> <p><b>Study method</b> DMC3 study - national health survey of musculoskeletal conditions; postal questionnaire – with general questions and health questions. After screening question for each of 5 anatomical areas Additional questions regarding pain in this area and its consequences; general health was measured using the Short Form(SF)-36</p>	<p><b>Type of chronic pain</b> Upper extremity disorders (UED) and neck pain; complaints of the arm, neck and/or shoulder (CANS; excluding UED caused by an acute trauma or a systemic disease)</p> <p><b>Confirmation of diagnosis</b> NR; only screening question: "did you have pain in 'anatomic area' during the past 12 months?"</p> <p><b>Sample size and demographics</b> 3664 respondents 25–44 years 47.0%, 45–64 years 34.6%, 65+ years 18.4% Female 50.9%</p> <p>chronic UED 996 chronic UED due to systemic disease or acute trauma 299 chronic CANS 697</p> <p><b>Patient selection</b> DMC3 - Dutch population aged 25 years and above; this study - persons with musculoskeletal upper extremity and neck disorders in 4 anatomic sites: neck, shoulder, elbow, and wrist/hand</p>	<p><b>Outcomes measured</b> 12-month prevalence, point prevalence, and prevalence of chronic pain (pain at baseline and lasting more than 3months in the last 12 months) course of pain, consequences of pain (contact with general practitioner, medical specialist or physiotherapist, work leave, limitations in daily life), general health</p> <p><b>Pain severity</b> self-reported - severe or mild chronic total UED Continuous severe pain 5.4% Recurrent severe pain 12.7% Chronic CANS Continuous severe pain 3.9% Recurrent severe pain 12.8%</p> <p><b>Analyses</b> Descriptive analysis only.</p>



Study details	Population	Outcomes and analysis
<p><b>Picavet and Schouten 2003</b></p> <p><b>Study design</b> Cross-sectional study</p> <p><b>Study method</b> DMC3 study - national health survey of musculoskeletal conditions; postal questionnaire – with general questions and health questions. After screening question for each of 5 anatomical areas Additional questions regarding pain in this area and its consequences; socio-demographic characteristics</p>	<p><b>Type of chronic pain</b> Neck, shoulder, higher back 44.5% Elbow, wrist/hand 23.2% Lower back 43.9% Hip, knee 28% Ankle, foot 14.9%</p> <p><b>Confirmation of diagnosis</b> NR; only screening question: “did you have pain in ‘anatomic area’ during the past 12 months?”</p> <p><b>Sample size and demographics</b> Total sample: 3664 respondents weighted to present a distribution of sex, age, marital status and region of living equal to that of the Netherlands in 1998: Sex men 49.1% women 50.9% Age group 25-44 47.0% 45-64 34.6% 65+ 18.4%</p> <p><b>Patient selection</b> Dutch inhabitants of 25 years and older</p>	<p><b>Outcomes measured</b> Musculoskeletal pain period prevalence, point prevalence, prevalence of chronic pain, course of pain, consequences of pain (contact with general practitioner, medical specialist or physiotherapist, use of medicines, work leave, limitations in daily life, and work disability)</p> <p><b>Pain severity</b> self-reported - severe or mild roughly 15% severe pain</p> <p>Neck, shoulder or higher back Continuous severe pain 3.1% recurrent severe pain 8.3% Elbow or wrist/hand Continuous severe pain 4.0% recurrent severe pain 11.0% Lower back Continuous severe pain 3.5% recurrent severe pain 15.4% Hip or knee Continuous severe pain 5.2% recurrent severe pain 10.1% Ankle or foot Continuous severe pain 6.1% recurrent severe pain 12.4%</p> <p><b>Analyses</b> descriptive, frequencies, multivariate logistic regression</p>

## Q12e. Study quality

Borghouts et al (1999) was rated as a study of moderate quality. The study was representative for the target population. However the eligibility criteria were not clearly described and the sample includes a proportion of non-chronic neck pain. Furthermore a description of the included population was lacking and it was unclear if the results were presented as adjusted or unadjusted.

The quality of the Breivik et al. 2006 study was rated as moderate; it was unclear that the population was representative, and the statistical methods were not clearly described.

The quality of Huisstede et al. 2008 study was rated as moderate, it was unclear that the population was representative and the statistical methods were not clearly described and the results were not reported as unadjusted and confounder-adjusted including precision and there was no adequate description of the eligibility criteria.

Picavet and Schouten 2003 study was rated as high quality; only one item was missing – the authors did not provide adequate description of eligibility criteria.

## Q12e. Results

### ***General chronic pain***

*Brevik et al. 2006*

Among the whole European group of respondents who were working mean time lost from work due to pain in the past 6 months was 7.8 days. Fifty-five percent had lost no days at all, 11% had lost one to three days, 12% had lost four to nine days, 9% had lost 10 to 15 days, and 13% had lost at least 16 days.

Among 86 of Dutch respondents mean time lost from work (full or part time) due to pain in the past 6 months was 6.8 days.

### ***Musculoskeletal pain***

*Borghouts et al. 1999*

The authors calculated the total number of sick days due to musculoskeletal diseases and neck disorders in 1996. They reported two methods of the calculations.

Using human capital method the number of sick days regarding diseases of musculoskeletal system was 19 367 744 and the number of sick days related to neck disorders was 1 435 044.

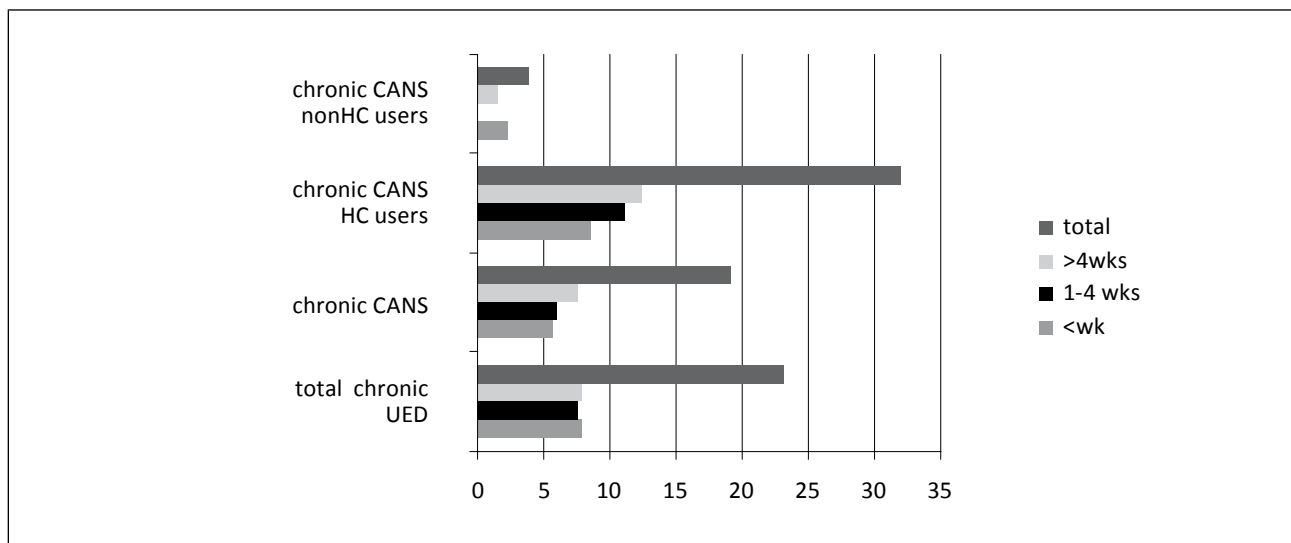
Using friction cost method the number of sick days regarding neck pain for less than 90 days was estimated to be 487 915 days. The total number of patients who had sick leave for neck pain for more than 90 days was estimated to be 4935. The number of sick days for patients with sick leave for more than 90 days regarding their neck was estimated to be 444 150.

*Huisstede et al. 2008*

The authors reported the percentage of patients who left work due to their complaints in the last year among patients with paid work and age 25–64 years.

For patients who had paid work the majority did not report work leave because of their pain complaint.

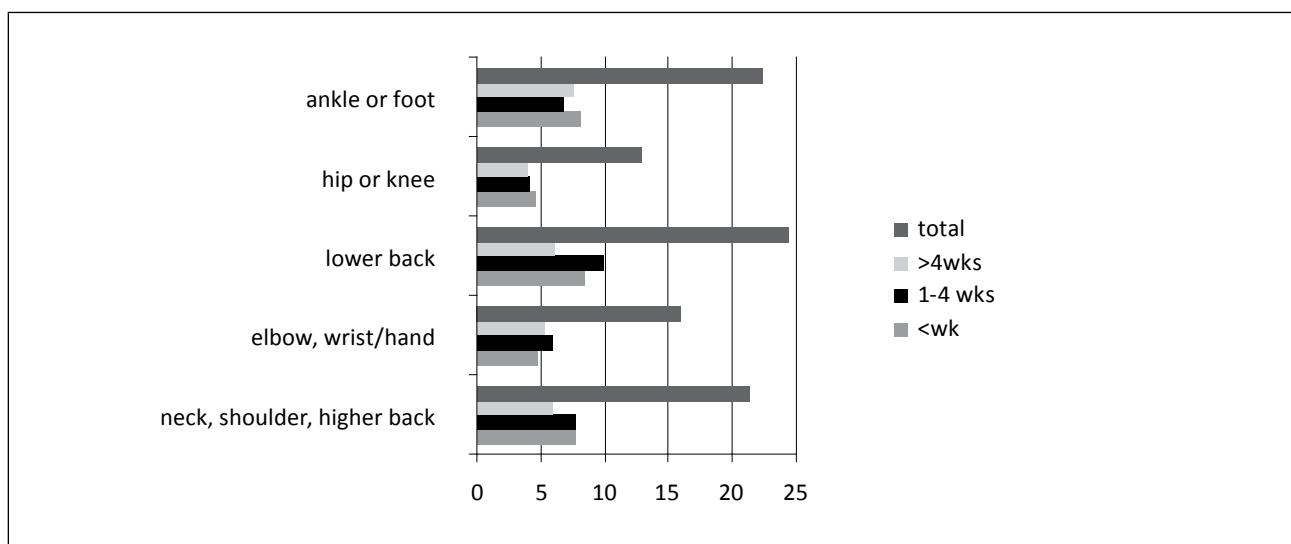
Among people with chronic upper extremity and neck complaints (UED) 23% left their work in the last year. Among people with complaints of the arm, neck and/or shoulder (CANS) not caused by acute trauma or any systemic disease about 19% left their work due to their complaints in the last year. In the subgroup of patients with CANS who were using healthcare the percentage was 32 and in those not using healthcare it was 3.9. The figure below presents work leave due to patients in complaints in the subgroups and according to its length.



**Figure 19.** Work leave in the last year among participants with upper extremity and neck complaints and subgroups by its length (CANS – complaints of the arm, neck and/or shoulder not caused by acute trauma or any systemic disease, HC – healthcare, UED – chronic upper extremity and neck complaints)

Picavet and Schouten 2003

For patients who had paid work the majority did not report work leave because of their pain complaint. The highest percentage with work leave during the last year was found for low back pain: almost a quarter (24.4%) of those with low back pain reported sick leave in the past year. For pain of ankle or foot (22.4%) and neck, shoulder or higher back (21%) work leave was also relatively common but for pain of elbow or wrist/hand (16%) and pain of hip or knee (13%) sick leave was less frequent. The figure below presents work leave due to patients in complaints in the subgroups and according to its length.



**Figure 20.** Work leave in the last year among participants with musculoskeletal pain complaints by location and work leave length

**Q12e. Summary**

The four included studies reported either the number of days off work or the percentage of patients leaving work due to pain for a certain length of time. Mean time lost from work due to general chronic pain in the past 6 months was 6.8 days. One cost-of-illness study reported total number of sick days related to neck disorders as 1 435 044 days. Two studies based on DMC3 data reported the percentages of patients with work leave due to musculoskeletal pain during last year between 4 and 32% depending on the subgroup.



**Q12f. In the Netherlands what is the impact of chronic pain on incapacity benefits?**

We located three studies that were relevant to this question (Borghouts et al. 1999, Chorus et al. 2001, van Doorn et al. 1995).

Borghouts et al (1999) investigated the costs of neck pain in the Netherlands in 1996 to assess the financial burden to society. The study was based on prevalence data and data sources included national registries, reports of research institutes and health care authorities.

Chorus et al. 2001 study aimed to assess separate and combined effects of work factors and behavioural coping in relation to withdrawal from the labour force among 720 patients with rheumatoid arthritis (RA).

Van Doorn (1995) investigated low back disability among self-employed dentists, veterinarians, physicians and physical therapists in the Netherlands from 1977 to 1989. For this purpose a retrospective study was performed based on data from a private non-profit mutual insurance company.

**Table 29.** Characteristics of the study selected for question 12f

Study details	Population	Outcomes and analysis
<p><b>Borghouts et al. 1999</b></p> <p><b>Study design</b> Cost-of-illness study</p> <p><b>Study method</b> Study is based on prevalent cases of neck pain. Direct medical costs and indirect costs were estimated using national registries, reports of research institutes and health care authorities</p>	<p><b>Type of chronic pain</b> Neck pain</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> Not reported</p> <p><b>Patient selection</b> All prevalent cases in 1996 were included</p>	<p><b>Outcomes measured</b> direct medical costs (hospital care, medical procedures, medical specialists fees, ambulatory hospital care, general practice care and paramedical care), indirect costs (absenteeism, disability)</p> <p><b>Pain severity</b> Not reported</p> <p><b>Analyses</b> Human capital Method; Friction Cost Method</p>

Study details	Population	Outcomes and analysis
<p><b>Chorus et al. 2001</b></p> <p><b>Study design</b> cross-sectional / survey</p> <p><b>Study method</b> a self-administered questionnaire containing several standardised instruments. Data on socio-demographic factors, disease characteristics, functional abilities, health related quality of life, present and past working conditions, and coping with the disease</p>	<p><b>Type of chronic pain</b> RA</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> Total n = 720 withdrawn from the labour force after diagnosis n=343 age at the time of study 20–29 1.8% 30–39 10.2% 40–49 27.5% 50–59 60.2% male 29.9% in paid employment at time of study n=377 age at the time of the study 20–29 6.2% 30–39 14.9% 40–49 42.7% 50–59 36.2% male 43.9%</p> <p><b>Patient selection</b> Eligible patients identified from the national Standardised Diagnosis Register of Rheumatic Diseases (SDR); a random sample of patients with RA aged 16–59 years was selected from a geographically representative sample of 35 rheumatologists in 17 practices in the Netherlands. Patients contacted by mail by their own rheumatologist. For the present analysis only those patients with paid employment at the time of diagnosis or at any time after being diagnosed with RA were included</p>	<p><b>Outcomes measured</b> Socio-demographic characteristics, disease activity (RADAI), functional abilities in daily life (HAQ), work factors (a Dutch generic structured instrument, the Vocational Handicap Questionnaire (VHQ)), behavioural coping styles (validated Coping with Rheumatic Stressors (CORS))</p> <p><b>Pain severity</b> Not reported</p> <p><b>Analyses</b> chi square, t tests; unconditional logistic regression analysis, logistic regression analysis, multivariate regression analysis</p>
<p><b>Van Doorn, 1995</b></p> <p><b>Study design</b> Retrospective cohort study</p> <p><b>Study method</b> Data came from private non-profit mutual insurance company insuring self-employed dentists, veterinarians, physicians and physical therapists</p>	<p><b>Type of chronic pain</b> Low back pain</p> <p><b>Confirmation of diagnosis</b> By medical advisor of insurance company</p> <p><b>Sample size and demographics</b> 1,119 claims filled by 39 persons; 38% referred to absence of &gt; 3 months</p> <p><b>Patient selection</b> All claims for low back pain disability between 1977-1989</p>	<p><b>Outcomes measured</b> Total costs for compensation of disability, starting age, claims per months, chronic LBP disability, incidence rate, duration, long-term LBP disability, recurrence</p> <p><b>Pain severity</b> Not reported</p> <p><b>Analyses</b> Descriptive analyses; Chi square, Wilcoxon Rank Sum Test, BMDP' stepwise logistic regression, Kaplan-Meier method, Mantel-Cox test, multivariate analysis – Cox regression model</p>



## Q12f. Study quality

Borghouts et al (1999) was rated as a study of moderate quality. The study was representative for the target population. However the eligibility criteria were not clearly described and the sample includes a proportion of non-chronic neck pain. Furthermore a description of the included population was lacking and it was unclear if the results were presented as adjusted or unadjusted.

Chorus et al. 2001 study was rated as moderate quality. There was no adequate description of study design and setting and no adequate description of eligibility criteria. It was also unclear if the study was representative for target population.

Van Doorn (1995) also has been rated low as the eligibility criteria, the representativeness of the population and the statistical methods and the way the results have been reported were not clear. Also, the study participants have not been well described.

## Q12f. Results

### ***Musculoskeletal pain***

#### *Borghouts et al. 1999*

The proportion of patients receiving a disability pension in relation to the neck pain (based on ICD-codes) in the Netherlands in 1996 appeared to be 2.5%.

#### *Van Doorn et al. 1995*

Low back disability claims from self-employed medical professionals were analysed. Between 1977 to 1989 the number of low back disability claims increased every year. The average number of recurrences per person (claiming low back disability more than once) was 0.55 (0–13).

The starting age of the first claim was higher for specific causes of low back pain when compared with nonspecific causes. There was seasonal variation in the number of disability claims – in December there were more claims than expected. Fifty nine percent of all claims were due to nonspecific low back pain and 34% due to specific low back pain, for 7.1% no classification could be made. Chronic low back disability developed in 23% of all claims, in 12% of the claims for nonspecific low back pain and in 45% of the claims for specific low back pain.

Claims of six months duration or more accounted for 19% of nonspecific low back pain from subjects treated conservatively, 40% of the claims from subject who had surgery and 1.4% from subjects for whom no treatment was reported.

Claims of six months duration or more accounted for 46% of specific low pain from subjects treated conservatively, 49% from subject who had surgery and 8.6% from subjects for whom no treatment was reported.

For 261 claims made by 247 persons the disability was chronic. Some of the chronically disabled were permanently disabled and they will receive the compensation until the insurance policy expires. The median duration until expiration of insurance policy was 10 (1.5–36) years. The permanently chronically disabled group contained more claimants who were >50% disabled ( $p < 0.001$ ), in the age group over 54 years ( $p < 0.001$ ).

The annual incidence rate of low back disability increased from 3.5 per 1000 persons at risk in 1977 to 7.4 in 1989 (adjusted for profession, age and deferred period). When analysed by professional subgroups, physical therapist and veterinarians compared to dentists had significantly greater risk of claiming low back disability (RR 2.67 [95% CI 2.23–3.19] and 2.04 [95% CI 1.72–2.43]), while physicians had no significantly different risk (RR 0.7 [95% CI 0.72–1.06]).

Age groups over 35 years had significantly greater risk than the age group under 35 years (RR 2.15 [95% CI 1.2–2.52] for 35–44 years, RR 2.22 [95% CI 1.81–2.71] for 45–54 years and RR 2.26 [95% CI 1.8–2.4] for 55–65 years).

The risk of chronic low back disability for physical therapists and veterinarians compared to dentists was significantly higher (RR 3.17 [95% CI 2.22–4.55] and RR 3.23 [95% CI 2.31–4.5]) and for physicians it was lower (RR 0.4 [95% CI 0.25–0.66]). The risk also increased with age, when compared to those under 35 years (RR 3.34 [95% CI 2.28–4.9] for 35–44 years, RR 4.83 [95% CI 3.06–7.63] for 45–55 years and RR 11.24 [95% CI 7.14–17.7] for 55–65 years).

Incidence of low back disability exceeding one year adjusted for differences in distribution according to age and gender was 0.85 per 1000 person-years among self-employed medical professionals versus 2.56 per 1000 person-years among general working population. The general working population had three times greater risk of claiming low back disability lasting longer than one year than self-employed medical professionals (RR 2.99 [95% CI 2.35–3.82]).

The median duration of all the claims was 51 days [95% CI 41–58]. The chance of returning to work decreased with increasing duration. Among first claimants the chance to return to work within 2 years after the start of the disability decreased from 89% at the start to 71 percent after 90 days and 50% after 10 days. After 1 year the chance of returning to work within 2 years after the start of disability was 22%.

## Rheumatoid arthritis

*Chorus et al. 2001*

Most of the patients (94.4%) who had withdrawn from the labour force were officially recognised as being fully ( $\geq 80\%$  disabled; 68.9% of patients) or partially disabled ( $< 80\%$  disabled; 25.5% of patients) for work purposes since they received a government work disability pension. Partial work disability was recognized in 14.4% of the patients who still had paid employment (significant difference when compared with those withdrawn).

## **Q12f. Summary**

The three included studies reported the proportion of patients receiving disability pension or recognized as being fully or partially disabled for work purposes or incidence of disability claims. In 1996 2.5% of the Netherlands population on disability pension were receiving disability pension in relation to the neck pain. Over ninety percent of analysed patients with rheumatoid arthritis who had withdrawn from the labour force were officially recognised as being fully or partially disabled for work purposes. The annual incidence rate of low back disability in self-employed medical professionals increased between 1977 and 1989 and the incidence. When incidence of low back disability exceeding one year was compared with general working population the risk for the latter was three times higher.

**Q13. In the Netherlands, what are the costs of chronic pain from societal, health care system and patient perspective?**

Four studies reported data on cost of chronic pain in the Netherlands (Borghouts et al. 1999, Boonen et al 2005; Kemler and Furnée, 2002; Van Doorn, 1995). Of these, three reported on costs for society (Borghouts, Boonen and Van Doorn), two on costs for the health care system (Borghouts and Boonen) and one on costs for the patient (Kemler and Furnée, 2002).

Borghouts et al (1999) investigated the costs of neck pain in the Netherlands in 1996 to assess the financial burden to society. The study was based on prevalence data and data sources included national registries, reports of research institutes and health care authorities.

Boonen et al (2005) compared the cost-of-illness of three musculoskeletal conditions. Patients with fibromyalgia (FM), chronic low back pain (CLBP), and ankylosing spondylitis (AS) who were referred to a specialist and participated in three randomised trials completed a cost diary for the duration of the study, comprising direct medical and non-medical resource utilisation and inability to perform paid and unpaid work. The RCTs were performed during 1993-1995 for FM and CLBP and in 1999 for AS.

Kemler and Furnée (2002) studied what happens in a family when one member suffers from chronic pain. They assessed the effect on employment status, time allocation, additional domestic help and out-of-the-pocket expenses of Dutch patients with complex regional pain syndrome (CRPS) and their spouses.

Van Doorn (1995) investigated low back disability among self-employed dentists, veterinarians, physicians and physical therapists in the Netherlands from 1977 to 1989. For this purpose a retrospective study was performed based on data from a private non-profit mutual insurance company. See Table 30 for study characteristics.

**Table 30.** Characteristics of the studies selected for question 13

Study details	Population	Outcomes and analysis	Cost data
<p><b>Borghouts et al. 1999</b></p> <p><b>Study design</b> Cost-of-illness study</p> <p><b>Study method</b> Study is based on prevalent cases of neck pain. Direct medical costs and indirect costs were estimated using national registries, reports of research institutes and health care authorities</p>	<p><b>Type of chronic pain</b> Neck pain</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> Not reported</p> <p><b>Patient selection</b> All prevalent cases in 1996 were included</p>	<p><b>Outcomes measured</b> direct medical costs (hospital care, medical procedures, medical specialists fees, ambulatory hospital care, general practice care and paramedical care), indirect costs (absenteeism, disability)</p> <p><b>Pain severity</b> Not reported</p> <p><b>Analyses</b> Human capital Method; Friction Cost Method</p>	<p><b>Cost for society:</b> Total cost (direct and indirect) Total indirect costs (absenteeism and disability)</p> <p><b>Costs for health care:</b> Total direct medical costs (costs for hospital care, medical procedures, medical specialists fee, ambulatory hospital care, general practice, and paramedical care)</p>

Study details	Population	Outcomes and analysis	Cost data
<p><b>Boonen et al. 2005</b></p> <p><b>Study design</b> Cost-of-illness study</p> <p><b>Study method</b> Patients who participated in three randomised trials completed a cost diary for the duration of the study</p>	<p><b>Type of chronic pain</b> Fibromyalgia (FM), chronic low back pain (CLBP), and ankylosing spondylitis (AS)</p> <p><b>Confirmation of diagnosis</b> FM: College of Rheumatology (ACR) classification criteria for fibromyalgia, CLBP: low back pain for more than six months without evidence of a specific spinal disease AS: modified New York criteria</p> <p><b>Sample size and demographics</b> FM: n=69, mean age 44.9 (SD 9.4) 13% males CLBP: n=110, mean age 40.9 (SD 8.7) 40% males AS: n=111, mean age 47.8 (SD 10.1), 71% males</p> <p><b>Patient selection</b> Patients participated in 3 RCTs; patients with FM or CLBB were referred by physicians and patients with AS were recruited through the patient association</p>	<p><b>Outcomes measured</b> Direct medical costs, direct non-medical costs, productivity loss costs</p> <p><b>Pain severity</b> Not reported</p> <p><b>Analyses</b> Friction Costs Method for productivity loss, univariate analysis for differences in costs, multivariate regression analyses</p>	<p><b>Cost for society:</b> Total cost (direct and productivity loss costs)</p> <p><b>Costs for health care:</b> Total direct medical costs (costs general practitioner, specialist physician, physiotherapist, complementary medicine, psychotherapist, hospital admissions, prescription drugs, OTC drugs)</p>
<p><b>Kemler and Furnée, 2002</b></p> <p><b>Study design</b> Cross sectional/survey</p> <p><b>Study method</b> Patient completed a 7-day diary</p>	<p><b>Type of chronic pain</b> Chronic refractory complex regional pain syndrome (CRPS)</p> <p><b>Confirmation of diagnosis</b> Diagnostic criteria of the International Association for the Study of Pain (IASP)</p> <p><b>Sample size and demographics</b> N=50 Mean age (SD)=39 (11) years 30% males, 70% females</p> <p><b>Patient selection</b> Consecutively sampled</p>	<p><b>Outcomes measured</b> Employment status, household income, time allocation, domestic help and out-of-pocket expenses</p> <p><b>Pain severity</b> All had a mean pain intensity of at least 5 (on a 10-p VAS)</p> <p><b>Analyses</b> Fisher's exact tests: to compare proportions of employment status, independent samples t-test: to compare time allocation results and out-of-pocket expenses. Bonferroni correction was used to account for multiple significance testing</p>	<p><b>Costs for patient:</b> Out-of-pocket expenses, household income before and after diagnosis</p>

Study details	Population	Outcomes and analysis	Cost data
<p><b>Van Doorn, 1995</b></p> <p><b>Study design</b> Retrospective cohort study</p> <p><b>Study method</b> Data came from private non-profit mutual insurance company insuring self-employed dentists, veterinarians, physicians and physical therapists</p>	<p><b>Type of chronic pain</b> Low back pain</p> <p><b>Confirmation of diagnosis</b> By medical advisor of insurance company</p> <p><b>Sample size and demographics</b> 1,119 claims filled by 839 persons; 38% referred to absence of &gt; 3 months</p> <p><b>Patient selection</b> All claims for low back pain disability between 1977-1989</p>	<p><b>Outcomes measured</b> Total costs for compensation of disability</p> <p><b>Pain severity</b> Not reported</p> <p><b>Analyses</b> Descriptive analyses; Chi square, Wilcoxon Rank Sum Test, BMDP' stepwise logistic regression, Kaplan-Meier method, Mantel-Cox test, multivariate analysis – Cox regression model</p>	<p><b>Costs for society</b> Total costs for compensation of disability</p>

### Q13. Study quality

Borghouts et al (1999) was rated as a study of moderate quality. The study was representative for the target population. However the eligibility criteria were not clearly described and the sample includes a proportion of non-chronic neck pain. Furthermore a description of the included population was lacking and it was unclear if the results were presented as adjusted or unadjusted.

Boonen et al (2005) was also rated as moderate quality study. This study was based on data of RCTs. In addition, there is a difference between the number of patients randomized and the number of patients included in the analysis, as only the patients who completed cost diaries during the study were included in this cost-of-illness study and it's unclear whether the population is representative of the overall population. And except for paid work and work disability it is unclear if the results presented were unadjusted or adjusted for confounders.

Kemler and Furnée (2002) has been rated low because it was not clear when the study took place (unclear design) and it's unclear whether the population is representative. Also the statistical methods are poorly described and for the reported results it's unclear whether or not these have been adjusted.

Van Doorn (1995) also has been rated low as the eligibility criteria, the representativeness of the population and the statistical methods and the way the results have been reported were not clear. Also, the study participants have not been well described.

### Q13. Results

In this section all relevant results will be described per study. The summary combines results of papers and presents results for a. Society, b. Health care and c. Patient.

## Results per study

### Borghouts et al (1999)

The total costs for neck pain in 1996 were estimated at \$686.2 million. Of this, 23% was related to direct medical costs and 77% to indirect medical costs (see table 31). Total costs for indirect non-medical costs depend on the method of calculation used (table 32).

**Table 31.** Annual costs of neck pain in The Netherlands in 1996 (Borghouts et al. 1999)

Component	Costs (in US \$)	% of total costs
Hospital care	17 336 397	3
Medical procedures	2 170 648	0.3
Medical specialists fee	1 586 790	0.2
Ambulatory hospital care	726 259	0.1
General practice	4 360 448	0.6
Paramedical care	133 443 333	19
Total direct medical costs	159 623 875	23
Absenteeism	185 422 035	27
Disability	341 108 500	50
Total indirect non-medical costs	526 530 535	77
Total	686 154 410	100

**Table 32.** Indirect non-medical costs of neck pain in 1996 (in US \$): HCM vs FCM

Method	Absenteeism (US \$)	Disability	Total costs
Human Capital Method	185 422 035	341 108 500	526 530 535
Friction Cost method	96 345 695	-	96 345 695

### Boonen et al. 2005

Below, costs for three types of musculoskeletal disorders are presented: fibromyalgia, chronic low back pain and ankylosing spondylitis. Total annual costs per patient for fibromyalgia are 7814, for chronic low back pain 8533 and for ankylosing spondylitis 3205 euro's. Direct medical costs accounted for are 32% for AS, 17% for FM and 13% for CLBP. Tables 33 and 34 specify annual costs for different health care resources and sources of non-medical costs directly related to the disease.

**Table 33a.** Annual direct, indirect and total costs per patient for fibromyalgia

Costs	Mean (E/pt/year)	Median (E/pt/year)	%
Direct medical costs	1311	673	17%
Direct non-medical costs	3930	2362	50%
Total direct costs	5241	3166	67%
Productivity (friction) costs	2573	0	33%
Total costs	7814	5145	100%



**Table 33b.** Annual direct, indirect and total costs per patient for chronic low back pain

Costs	Mean (E/pt/year)	Median (E/pt/year)	%
Direct medical costs	1104	594	13%
Direct non-medical costs	4491	2502	53%
Total direct costs	5594	3770	66%
Productivity (friction) costs	2939	0	34%
Total costs	8533	5068	100%

**Table 33c.** Annual direct, indirect and total costs per patient for ankylosing spondylitis

Costs	Mean (E/pt/year)	Median (E/pt/year)	%
Direct medical costs	1043	691	32%
Direct non-medical costs	1330	1330	41%
Total direct costs	2373	2373	74%
Productivity (friction) costs	834	0	26%
Total costs	3205	1793	100%

**Table 34a.** Annual costs for different health care resources for patients with fibromyalgia

Costs	Mean (E/pt)	Median (E/pt)	%
General practitioner	81	35	1.5%
Specialist physician	296	155	5.6%
Physiotherapist	297	0	5.7%
Complementary medicine	180	0	3.4%
Psychotherapist	-		
Hospital admissions	226	0	4.3%
Prescription drugs	183	87	3.5%
Non-prescription drugs	50	133	0.9%
Direct medical costs	1311	673	25%
Unpaid household help	829	93	15.8%
Paid household help	1505	0	28.7%
Paid and unpaid help	2334	964	44.5%
Inactivity	1454	336	27.7%
Aids/appliances/adaptations	142	0	2.7%
Direct non-medical costs	3930	2362	75%
Total direct costs	5241	3166	100%

**Table 34b.** Annual costs for different health care resources for patients with chronic low back pain

Costs	Mean (E/pt)	Median (E/pt)	%
General practitioner	85	53	1.5%
Specialist physician	243	78	4.3%
Physiotherapist	185	0	3.3%
Complementary medicine	97	0	1.7%
Psychotherapist	124	0	2.2%
Hospital admissions	167	0	3.0%
Prescription drugs	186	41	3.3%
Non-prescription drugs	24	0	0.4%
Direct medical costs	1104	594	20%
Unpaid household help	782.5	0	14.0%
Paid household help	1410	0	25.2%
Paid and unpaid help	2193	840	39.2%
Inactivity	1925	0	34.4%
Aids/appliances/adaptations	372	0	6.6%
Direct non-medical costs	4491	2502	80%
Total direct costs	5594	3770	100%

**Table 34c.** Annual costs for different health care resources for patients with ankylosing spondylitis

Costs	Mean (E/pt)	Median (E/pt)	%
General practitioner	37	23	1.5%
Specialist physician	215	202	9.1%
Physiotherapist	449	226	18.9%
Complementary medicine	41	0	1.7%
Psychotherapist	-		
Hospital admissions	48	0	2.0%
Prescription drugs	249	148	10.5%
Non-prescription drugs	4	0	0.2%
Direct medical costs	1043	691	44%
Unpaid household help	261	0	11%
Paid household help	454	0	19.1%
Paid and unpaid help	715	0	30%
Inactivity	584	0	24.6%
Aids/appliances/adaptations	31	0	1.3%
Direct non-medical costs	1330	0	56%
Total direct costs	2373	1305	100%

*Van Doorn, 1995*

Total costs for compensation of low back pain disability among self-employed dentists, veterinarians, physicians and physical therapists was 7.5 million NLG in 1987 and 8.0 million in 1989. Over the period 1977-1989, 1,119 claims were made for low back pain disability by 839 claimants. 23% of the claims accounted for 90% of the compensation paid and for 89% of disability days.

*Kemler and Furnée (2002)*

CRPS had a negative effect on income of patients or their families. For single people, the mean net yearly income decreased from \$8,500 to \$5,500. For male patients, the mean net family income decreased from \$26,000 to \$22,000 and for females. For female patients, the mean net family income decreased from \$24,500 to \$22,500 per year.

Mean out-of-pocket expenses related to CRPS were \$ 1,350 per patient per year. This amount was 1,600 for families with a male patient and 1250 for families with a female patient (difference was not significant).

### **Q13. Summary**

Costs for society due to neck pain in 1996 were estimated to be \$686.2 million. It's not clear what proportion of it refers to chronic neck pain. Cost for three chronic musculoskeletal diseases ranged between 3205 and 8533 euro's per patient per year. Cost for compensation of low back pain disability was 8.0 million in 1989 for a group of self-employed health care professionals.

Direct medical costs accounted for 23% for neck pain and between 13 and 32% for the chronic musculoskeletal diseases, depending on the type. For neck pain, paramedical care accounted for the majority of costs (19 of 23%). For the chronic musculoskeletal diseases, large proportions of costs were used for specialist physicians, physiotherapists and prescription drugs.

Only one study reported costs for patients; patients with CRPS have a decreased income and the mean out-of-pocket expenses were reported to be \$1350 euro per patient per year.

**Q14. What are the issues/determinants of patients' awareness of chronic pain in the Netherlands?**

#### Q14 - Epidemiology of chronic pain in the Netherlands

Only three studies reported results that were relevant to this question (Sluiter and Frings-Dresen, 2008, Verbunt et al, 2003, Satink et al, 2004).

Sluiter and Frings-Dresen (2008) studied differences between working and sick-listed patients with chronic repetitive strain injury (RSI) with respect to quality of life and illness perception. For this purpose, they performed a cross-sectional study, sending a questionnaire to all 3250 members of the national RSI patient association.

Verbunt et al (2003) performed a survey in patients with non-specific chronic low back pain, referred to a rehabilitation center for a pain program. The authors tested the assumption that fear of injury leads to disability and physical deconditioning in these patients and evaluated the relation between disability and physical deconditioning.

Satink et al (2004) performed a qualitative study and examined the influence of chronic low back pain on the motives for activities in the patients' daily lives (occupational performance). They assessed what activities patients carried out, what motives they had for those activities and how pain affected that. See Table 35 for study characteristics.

**Table 35** Characteristics of the studies selected for question 14

Study details	Population	Outcomes and analysis
<p><b>Sluiter and Frings-Dresen, 2008</b></p> <p><b>Study design</b> Cross-sectional study</p> <p><b>Study method</b> A postal questionnaire was sent to all members of the national RSI patient association</p>	<p><b>Type of chronic pain</b> Repetitive Strain Injury (RSI)</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> 3250 were invited, the response was 36% Mean age 40.8 (SD 8.7) years 67% female 67% had high education</p> <p><b>Patient selection</b> Self-selection (those who returned the questionnaire)</p>	<p><b>Outcomes measured</b> Pain (VAS 0-100); Quality of life using 7 subscales of SF-36 (physical role functioning, emotional role functioning, social functioning, pain, mental health, vitality, and physical functioning VAS to rate present general quality of life with respect to health and quality of life with respect to health before the RSI complaints started (higher score is better quality of life) Brief illness perception questionnaire (IPQ-B) for cognitive illness perception. Demographic, complaint-related and work activities characteristics</p> <p><b>Pain severity</b> Mean (SD) VAS 0-100- higher score more pain): 41.3 (25.4) Mean (SD) SF-36 subscale 0-100 - higher score less pain): 54.7 (21.6)</p> <p><b>Analyses</b> Descriptive analysis (means and SDs); multivariate analysis or nonparametric tests (Mann-Whitney) were performed to test differences between working and sick-listed patients</p>
<p><b>Verbunt et al, 2003</b></p> <p><b>Study design</b> Cross-sectional study</p> <p><b>Study method</b> Patients completed questionnaires</p>	<p><b>Type of chronic pain</b> Non-specific low back pain for at least 3 months</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> N=37; 11 women, 26 men Mean age 45.2 (SD 7.8) years 70% has paid job</p> <p><b>Patient selection</b> Patients with non-specific low back pain, aged between 18 and 65 years, referred to rehabilitation center</p>	<p><b>Outcomes measured</b> Perceived disability (Roland Disability Questionnaire), fear of movement (Tampa Scale for kinesiophobia), depression (Beck Depression Inventory), catastrophizing (Pain catastrophizing Scale), physical factors (physical activities, aerobic fitness, body composition)</p> <p><b>Pain severity</b> Not reported</p> <p><b>Analyses</b> Descriptive analyses, Student t-test and Mann-Whitney tests to compare two groups, Spearman rank correlation for bivariate correlations, multiple regression analysis</p>

Study details	Population	Outcomes and analysis
<p><b>Satink et al 2004</b></p> <p><b>Study design</b> Qualitative study</p> <p><b>Study method</b> 7 clients were interviewed</p>	<p><b>Type of chronic pain</b> Low back pain for more than 3 years</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> N=7; 4 women, 3 men Age range 42-70</p> <p><b>Patient selection</b> Purposive sampling via rehabilitation center that provides pain programs. Patients with a current paid job or with acute depression were excluded</p>	<p><b>Outcomes measured</b> Daily occupations, motives for performing these, impact of pain on these motives</p> <p><b>Pain severity</b> Not reported</p> <p><b>Analyses</b> Qualitative analysis (Constant comparative method)</p>

## Q14. Study quality

The quality of the study of Sluiter and Frings-Dresen (2008) was rated as moderate. The description of eligibility criteria was inadequate; this study included members of the RSI patient association but did not confirm the diagnosis. Furthermore, it was unclear whether the population was representative: the response was 36% and the recruitment method is likely to have resulted in a selective sample of patients. Furthermore, it was unclear whether reported results were adjusted or unadjusted.

The study quality of Verbunt et al (2003) was also rated as moderate because of unclear eligibility criteria of the study sample. Also, it was not clear whether the study sample was representative of the target population.

The quality of the Satink (2004) study was rated low. Because of the small sample size, this study is unlikely to be representative. Furthermore the date of study (design) and the eligibility criteria were unclear. Also outcomes and method of data summary were unclear.

## Q14. Results

### RSI

#### *Sluiter and Frings-Dresen 2008*

Mean pain intensity (VAS) was 41.3 (SD 25.4) for the whole population; patients who were working reported less pain than those who were sick-listed (36.2 vs. 51.6,  $p < 0.001$ ). For the variables physical functioning and illness perception at least moderate correlations (coefficient  $> 0.40$ ) were found with pain intensity. The associations were as follows: patients that were able to work, those with a better physical role or a better physical functioning had less pain (correlations -0.48, -0.45 and -0.52, respectively). And, patients who experienced fewer consequences, those who experienced fewer symptoms and those who were less concerned about their illness had less pain (correlations 0.51, 0.64, 0.46, respectively). No p-values were reported for these associations.

**Low back pain***Verbunt et al. 2003*

The mean score of perceived disability (RDQ) was 11.4 (SD 5.4). Women felt more disabled than men (14.9 vs 9.9,  $p < 0.05$ ). Both fear of injury and catastrophizing correlated with disability (correlation coefficients 0.44,  $p < 0.01$ ) and 0.45,  $p < 0.05$ , respectively). A multiple linear regression analyses to explain disability included gender, fear of injury and catastrophizing with an adjusted  $R^2$  of 28%.

*Satink 2004*

This qualitative study identified three phases in the process of living with chronic low back pain. In the first phase, patients had the wish to be normal and wanted to meet social and personal expectations. Participants fought against the pain to be active and did not want to accept the existence of pain or the experienced limitations, which led to ignoring the pain. However, patients experienced that they could not ignore the pain and that the pain had overpowered them.

In the second phase, the pain took control and the patients withdrew from social participation. Patients seemed to believe or hope that withdrawal from occupations would lead to control and thus a reduction of pain. However, the withdrawal caused negative emotions, and a kind of new pain ('emotional pain'). Patients started to realize the impact of the pain and the consequences of withdrawal from occupations on their life. This led to a wish to prioritize and participate in occupations that patients really wanted to do.

In the third phase, patients became more conscious of the dynamics and dilemma's between self, the pain, and the environment. Patients experienced that acceptance of and listening to the pain as a part of themselves led to better control of the pain. Patients had become aware that they could choose between occupations and social interactions 'with or without pain' sometimes they would choose to do nothing and decrease the pain and at other moments they chose engaging activities or social participation even when they knew that it would cause more pain.

**Q14. Summary**

Two quantitative studies reported determinants of awareness of chronic pain or disability. Patients who are able to work, who have a better physical role or better physical functioning have less pain. Also, those who experience fewer consequences and symptoms and are less concerned about their illness have less pain. Fear of injury and catastrophizing was associated with more disability.

A qualitative study showed 3 phases in the process of living with chronic pain: first patients aim to be normal, ignoring the pain and with unchanged activities. Then they aim to control and reduce the pain by withdrawing from activities. The pain is in control here. Last, they aim to collaborate with the pain. To do this they have to constantly face dilemmas of prioritizing activities in order to incorporate pain in everyday life.





**Q15. What are the issues/determinants of health care professionals' awareness of chronic pain in the Netherlands?**

## Q15 - Epidemiology of chronic pain in the Netherlands

We located one study that was relevant to this question (Zwakhalen et al. 2007). It used a cross-sectional survey design to develop a psychometrically sound questionnaire and to gather information about knowledge and beliefs of nursing staff regarding various aspects of pain in elderly patients with dementia. It also aimed to compare the results with respect to beliefs about pain between several categories of nurses (based on educational level and work experience). The results were based on the answer to a 17-item questionnaire. The items of the questionnaire were divided into four components: 1) contrasting aspects of pain in elderly with aspects of pain in younger people, 2) pain assessment and treatment in their workplace, 3) medication aspects, and 4) beliefs regarding pain and pain treatment in the elderly.

**Table 36.** Characteristics of the study selected for question 15

Study details	Population	Outcomes and analysis
<p><b>Zwakhalen et al. 2007</b></p> <p><b>Study design</b> Cross-sectional study</p> <p><b>Study method</b> a questionnaire – demographic information and statements about pain to measure knowledge and attitudes about pain (five-point Likert scale from 1= completely disagree, 5= completely agree)</p>	<p><b>Type of chronic pain</b> Pain in elderly with dementia</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> 168 nurses: 123 nursing home staff, 25 PhD students in nursing science, 20 registered nurses in training to become pain nurse specialists staff mean age 36.7 years SD 10.5, female 88.6% PhD mean age 38.6 years SD 9.5, female 84% trainee mean age 36.2 years SD 8, female 60%</p> <p><b>Participant selection</b> All nursing staff from the psychogeriatric wards of the two nursing homes in the Netherlands, and two additional groups : a convenience sample of 25 PhD students in nursing science and a group of 20 registered nurses in training to become pain nurse specialists</p>	<p><b>Outcomes measured</b> Knowledge and beliefs about pain in elderly nursing home residents with dementia</p> <p><b>Pain severity</b> Not reported</p> <p><b>Analyses</b> Descriptive, a principal components analysis (PCA), internal consistency analyses, nonparametric Mann-Whitney U tests</p>

## Q15. Study quality

The quality of Zwakhalen et al. 2007 study was rated as low mainly because there was no adequate description of study design and settings and no description of eligibility criteria, it was unclear if the study sample was representative for the target population, there was an inadequate description of statistical methods and it was unclear if the results reported were unadjusted or confounder-adjusted.

## Q15. Results

The authors found that many nursing home staff showed knowledge gaps or negative beliefs about pain in elderly people with dementia, which could contribute to inadequate assessment and treatment. They also demonstrated that educational level is an important factor.

***The results of nursing home staff were as follows:***

- 1) Most respondents reported that elderly patients do not experience less pain than younger people and that they do not experience pain less intensely than younger patients and disagreed with the statement that assessing pain in dementia patients was a matter of guessing.
- 2) A large majority of nursing home staff were convinced that pain was being correctly assessed (83%) and treated (83%) at their ward, and that there was a great deal of attention paid to pain in dementia patients (80%).
- 3) The question of whether pain medication should be administered when necessary, rather than according to a fixed schedule generated all possible answers (no unanimity).
- 4) No unanimity was noted for questions "pain is a part of the aging process", "older people are more likely to be affected by pain than younger people" and "pain medication, if administered in large quantities, easily leads to addiction among the elderly".  
Only 28% of the nursing home staff were aware of the fact that older people are affected more often by pain than younger people (ie, that incidence rates of chronic pain are known to be higher for the elderly than for younger people).

***Results compared between groups of nurses:***

1. Nursing home staff vs trainee pain nurse specialists  
Significant differences were observed. The trainee pain nurse specialists had more realistic beliefs and knowledge about pain in dementia patient group. Significant differences between the groups were most often related to issues of pain medication. All trainee pain nurse specialists disagreed with the statement "Pain medication should only be administered to patients suffering from severe pain".  
While none of the trainee pain nurse specialists agreed that it is better to administer pain medication only 'when necessary', rather than according to a fixed schedule, a large number of nursing home nurses agreed with this statement, not recognizing the value of fixed regular analgesia.  
Findings also indicated that the nursing home staff respondents were more anxious about the risk of addiction than the trainee pain nurse specialists.
2. Nursing home staff and PhD students  
Significant differences were also observed, mostly relating to the same issues as in the comparison above. Nursing home staff respondents had higher scores on all items belonging to the second component, referring to pain management at the ward.
3. Nursing home staff groups according to their experience  
No significant differences in responses were found between nursing home staff who had less than five years vs five or more years.

## **Q15. Summary**

Nursing home staff respondents showed knowledge deficits about several aspects of pain, even though they were satisfied about the way pain was assessed and treated at their wards. Specific knowledge deficits were found regarding pain treatment and medication in elderly nursing home residents. Staff educational level seemed to influence their beliefs and knowledge about pain in elderly nursing home patients.

**Q16. What are the main symptoms and complaints with which patients present themselves to health care professionals in the Netherlands?**

**Q16** - Epidemiology of chronic pain in the Netherlands

No studies were found reporting on symptoms and complaints with which patients present themselves to health care professionals in the Netherlands.

**Q17. What are the frequencies of drug, non-drug and combined treatments in the Netherlands?**



Of 11 relevant studies, we selected three studies that were most informative to this question (Breivik et al. 2006, Van Herk et al. 2009 and Dieleman et al. 2008).

Breivik et al. (2006) performed a large telephone survey to explore the prevalence, impact on daily life and treatment of chronic pain in 15 European countries and Israel, among which the Netherlands. Persons received an initial screening questionnaire and those who suffered from long-lasting pain were subsequently interviewed in-depth using a second structured questionnaire. From the Netherlands, 300 persons suffering chronic pain were interviewed.

Van Herk et al. (2009) performed a cross-sectional multicenter study of 233 residents of Dutch nursing homes. The study aimed to assess the prevalence and intensity of pain in older adults living in Dutch nursing homes and assess the characteristics of pain and the analgesics prescribed as well as impact of pain on daily functioning.

Dieleman et al. (2008) performed a population based cohort study to estimate the incidence and assessed treatment approaches of neuropathic pain conditions in the general population. The study population included persons registered for at least one year in the Integrated Primary Care Information (IPCI) database between 1996 and 2003. See Table 37 for study characteristics.

**Table 37.** Characteristics of the studies selected for question 17

Study details	Population	Outcomes and analysis
<p><b>Breivik et al. 2006</b></p> <p><b>Study design</b> Cross-sectional study</p> <p><b>Study method</b> Telephone survey in two parts. First, persons were screened for chronic pain. Those who qualified were interviewed in-depth</p>	<p><b>Type of chronic pain</b> Long-lasting pain: chronic pain for at least 6 months, and pain in last month, and pain at least 2 times/week, and rating pain intensity at least 5 on 10-point NRS</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> Total sample: 4839; Netherlands: 300 persons with long-lasting pain Demographics for all countries together: 52% female mean age 50 years For the Netherlands: female 60%, mean age 51.3 years</p> <p><b>Patient selection</b> Subjects with long-lasting pain (see definition above)</p>	<p><b>Outcomes measured</b> Duration, location, intensity of pain Tolerance, time course of pain, impact pain on activities daily life, employment status, emotional status Visits to doctors, visits to pain management specialist, treatment (medication and non-medication), effectiveness of treatment, satisfaction with doctors, respondents' attitudes and beliefs about pain and pain treatment, respondents' perception of the attitude of others to their pain</p> <p><b>Pain severity</b> 18% reported severe pain</p> <p><b>Analyses</b> Descriptive analysis only. No subgroups were reported (for the Netherlands)</p>

Study details	Population	Outcomes and analysis
<p><b>Van Herk et al. 2009</b></p> <p><b>Study design</b> cross-sectional / survey</p> <p><b>Study method</b> A standardized pain questionnaire was used based on the McGill Pain Questionnaire to measure aspects on pain. The use of analgesics was extracted from medical charts</p>	<p><b>Type of chronic pain</b> Self-reported pain in previous week. For 72% the pain was chronic (at least 3 months)</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> 233 residents completed questionnaires Median age 79 years (IQR 73-84) 70% were female</p> <p><b>Patient selection</b> residents without cognitive impairment</p>	<p><b>Outcomes measured</b> Characteristics of pain, pain treatment, pain management index (how well is pain managed), impact pain on sleep and ADL, satisfaction pain treatment</p> <p><b>Pain severity</b> Median pain intensity was 5 (IQR 2-7), 88 reported moderate or severe pain (<math>\geq 4</math> on NRS)</p> <p><b>Analyses</b> Nonparametric data are given as median and interquartile range (IQR). Differences in demographics between the nursing homes are analysed by chi-squared tests and Kruskal-Wallis tests. The multiple linear regression method was used to identify interferences with sleep and ADL, with pain intensity for the previous week as dependent variable</p>
<p><b>Dieleman et al. 2008</b></p> <p><b>Study design</b> longitudinal / cohort study</p> <p><b>Study method</b> Study conducted in the IPCI database - a longitudinal general practice research database containing data of more than 500,000 patients records</p>	<p><b>Type of chronic pain</b> Neuropathic pain</p> <p><b>Confirmation of diagnosis</b> Case definition relied on GP and specialists symptoms and diagnosis recorded in the medical record with the GP. GP diagnoses were accepted if they recurred in the patient record and if typical neuropathic pain symptoms were present</p> <p><b>Sample size and demographics</b> 362,693 persons (1,116,215 person years) Age and gender distribution similar to Dutch population</p> <p><b>Patient selection</b> All individuals from the IPCI database with at least one year of follow-up</p>	<p><b>Outcomes measured</b> incidence rates of 13 subtypes of neuropathic pains, prescribed treatments</p> <p><b>Pain severity</b> Not reported</p> <p><b>Analyses</b> Age and gender specific incidence rates of different types of neuropathic pain, Cox-regression analysis for the relative risk and 95% confidence interval of neuropathic pain for women versus men</p>

## Q17. Study quality

The quality of the studies of Breivik et al. and Dieleman et al. were both rated as moderate; in the Breivik study it was not clear that the population was representative and the statistical methods were not clearly described. Dieleman et al. did not describe the study population adequately and loss to follow-up was not reported adequately.

The Van Herk et al. study was rated low mainly because it was not clear that the sample was representative of all nursing home residents, the eligibility criteria were not clearly described and nor were the statistical methods.

## Q17. Results

### **General chronic pain**

*Breivik et al. 2006*

300 Dutch patients with chronic pain were interviewed. Of these, 33% (n=99) were currently prescribed medicines: 36% were using NSAIDs, 14% weak opioids, 5% strong opioids, 11% paracetamol and 16% a COX-2 inhibitor. Of non-drug treatments it was reported that 21% of Dutch patients had tried acupuncture, 52% had tried physical therapy and 17% had tried massage.

One third of the chronic pain patients in Europe (31%) were not treated for their pain. 69% had used non-drug treatments. Most respondents (53%) had not taken any non-prescription oral pain medicines in the last six months and 36% had taken one or two. 79% had ever taken prescription medicine. Most respondents (52%) were currently taking prescription pain medicine, 26% stopped taking prescription medicine. These figures were not presented separate for the Netherlands.

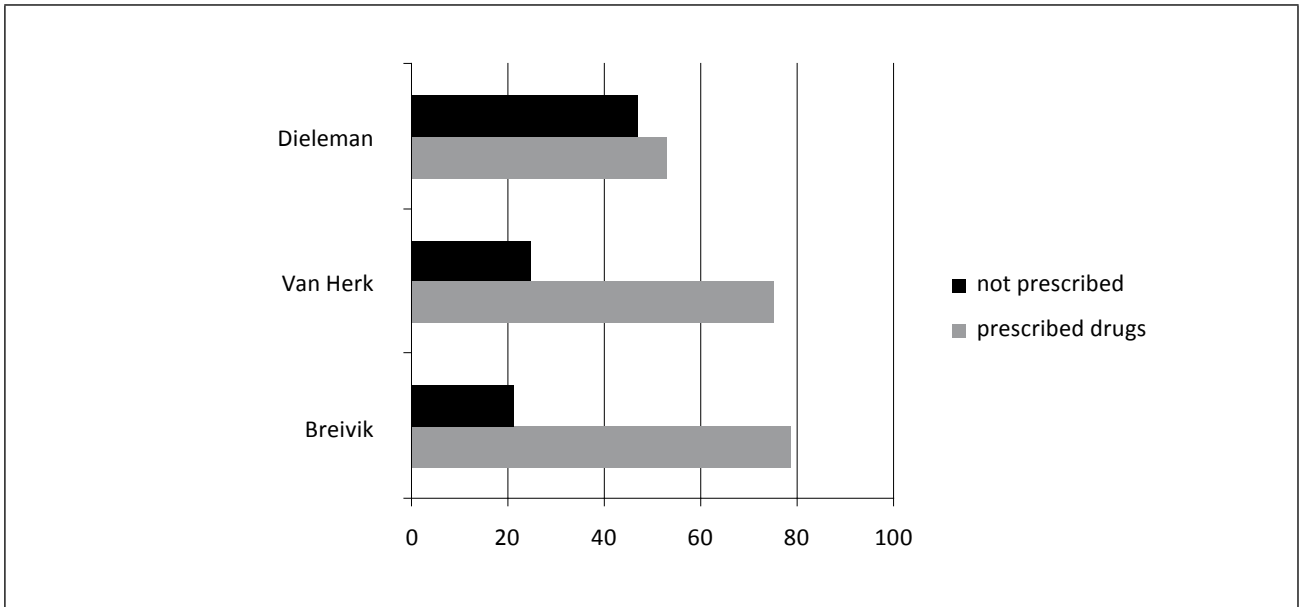
*Van Herk et al. 2006*

153 residents of nursing homes reported that they had experienced pain in the previous week. Of these, 38 (24.8) were not prescribed analgesics, 65 (42.5%) were prescribed non-opioids, 13 (8.5%) weak opioids, 16 (10.5%) strong opioids. The majority of the residents in pain (61%) received analgesics on a routine basis, and 38 (25%) did not receive analgesics at all. Of the 88 residents with an NRS 4 for present pain, and the 41 residents with intolerable pain at present, 19 (22%) and 12 (29%), respectively, did not receive any pain medication.

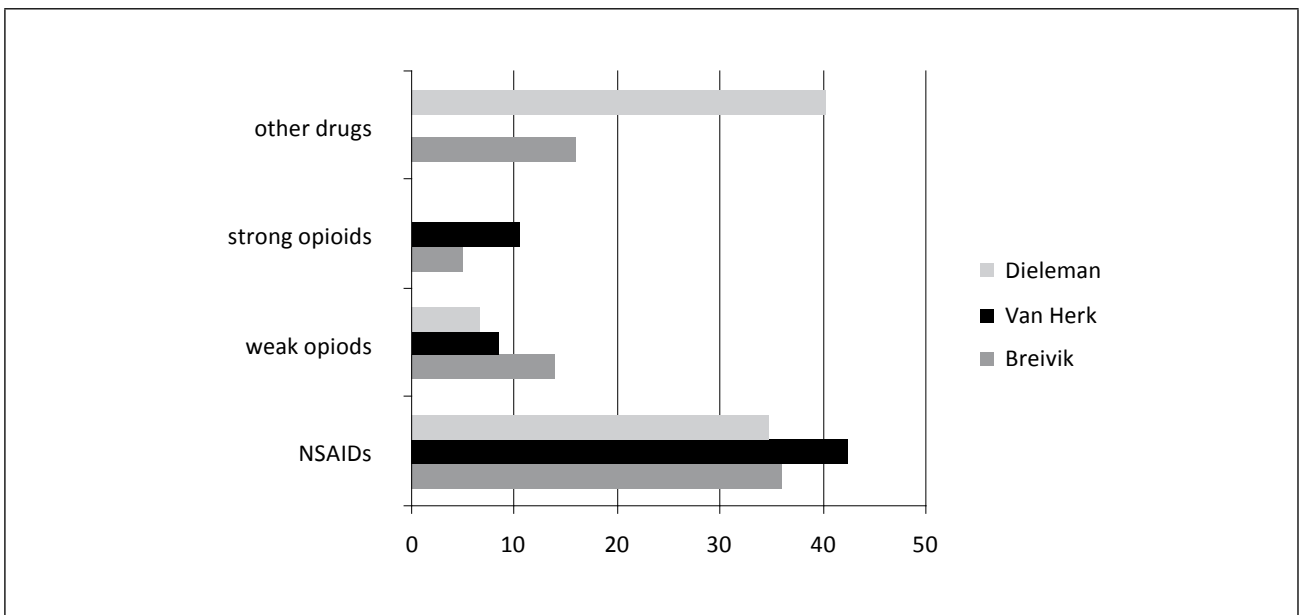
### **Neuropathic pain**

*Dieleman et al. 2008*

53% of the patients with neuropathic pain were prescribed medication and 47% were not treated. NSAIDs were the most commonly used drug (34.7%) followed by benzodiazepines (11.9%), sedative/hypnotics (9.1%) and opioids (6.6%). Anticonvulsants and tricyclic antidepressants were used by 4.8% and 4.7% of cases respectively.



**Figure 21.** Percentage of patients with and without prescribed drugs for chronic pain (NB Breivik 2006 refers to 'patients ever taking prescription drugs')



**Figure 22.** Percentage of patients that were prescribed NSAIDs, weak opioids, strong opioids or other drugs for their pain. (NB Dieleman et al. do not differentiate between weak and strong opioids and the NSAIDs category also includes aspirin)

## **Q17. Summary**

In two out of three studies data for this question referred only to the frequency of drug treatment. The percentage of people that currently were prescribed medicines varied between 33 to 75% in the selected studies. Most of the patients were prescribed NSAIDs.

One study reported that specific non-drug treatments had been tried by 21 to 52% of Dutch patients. No data, specifically for the Netherlands, was available on the frequency of overall non-drug or combined drug/nondrug treatments.

**Q18. What are the determinants of treatment choice between drug treatment and non-drug treatment in the Netherlands?**

We located one study that was relevant to this question (Kroese et al. 2008).

Kroese et al. 2008 aimed to gather information from five types of professionals (GPs, rheumatologists, physical therapists, psychologists, rehabilitation specialists) on their usual management methods for fibromyalgia in order to assess whether treatment regimens have changed in the Netherlands during a period of 6 years and to gain insight into the therapeutic motives of the professionals.

**Table 38.** Characteristics of the studies selected for question 18

Study details	Population	Outcomes and analysis
<p><b>Kroese et al. 2008</b></p> <p><b>Study design</b> cross-sectional / survey</p> <p><b>Study method</b> self administered questionnaire sent to general practitioners, rheumatologists, rehabilitation specialists, physical therapists and psychologists</p>	<p><b>Type of chronic pain</b> Fibromyalgia</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> 1998: 320 respondents (out of 715): 59 GPs, 63 rheumatologists, 71 physical therapist, 41 psychologists, 86 rehabilitation specialists 2005: 303 respondents (out of 750): 52 GPs, 89 rheumatologists, 54 physical therapist, 39 psychologists, 69 rehabilitation specialists Age and gender not reported</p> <p><b>Patient selection</b> The samples of 150 practitioners selected from the Dutch Medical Directory or from their respective professional associations. For the disciplines in which less than 150 practitioners were working, all professionals were included</p>	<p><b>Outcomes measured</b> Management of fibromyalgia - common methods of treatment Referrals to other specialists 2005 questionnaire – factors that influence the choice of a treatment for fibromyalgia by practitioners</p> <p><b>Pain severity</b> Not reported</p> <p><b>Analyses</b> descriptive, the non-parametric Kruskal–Wallis test</p>

### Q18. Study quality

The quality of the study of Kroese et al. 2008 was rated as low mainly because the description of eligibility criteria was unclear, it was unclear if the study sample was representative for the target population, there was no description of statistical methods and study participants and the results were not reported as unadjusted and confounder-adjusted including precision.

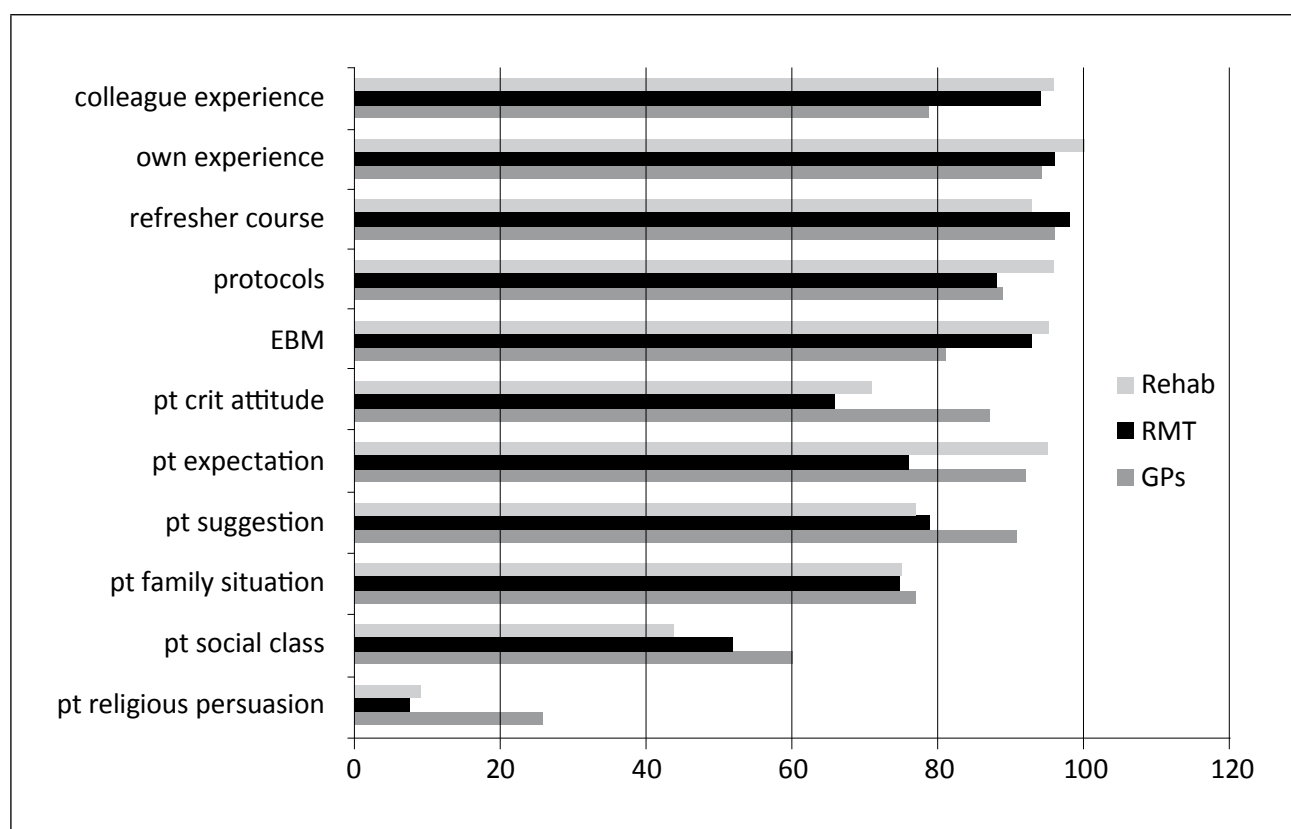
## Q18. Results

### Fibromyalgia

Kroese et al. 2008

This study reported determinants of treatment choice in general rather than determinants of choice between drug and non-drug treatment.

Figure 23 presents factors that influence the choice of treatment for fibromyalgia by practitioners. From this figure, it can be seen that the practitioners' treatment choices for fibromyalgia are led more by the 'professional group' (ie EBM, protocols, courses, own experience and experiences of colleagues) than by the 'patient/consumer' (ie all patient factors). Concerning the professional group, it is notable that subjective factors, for instance own experiences, seem to be more important for rheumatologists and rehabilitation specialists than for GPs. The GP is mostly guided by objective factors, such as publications and research results, but not to the same extent as the other two medical disciplines. Regarding the patient/consumer as influencing factor, dynamic aspects, for instance, the expectations of the patient, are much more important than static characteristics, such as the social class of the patient. Especially for GPs, dynamic factors are very important motives for their treatment choices.



**Figure 23.** Percentage of professionals reporting factors influencing their fibromyalgia treatment choice (GP = general practitioner, RMT = rheumatologists, Rehab = rehabilitation specialists; pt = patient)



## **Q18. Summary**

Factors influencing choice of treatment for fibromyalgia differ per discipline. The choice is mainly made on the basis of subjective, professional group-bound factors such as EBM, protocols, courses, own experience and experiences of colleagues. For GPs, dynamic patient factors are an important motive in the management of FM.

**Q19. What are the determinants of treatment choice within drug treatments in the Netherlands?**

**Q19** - Epidemiology of chronic pain in the Netherlands

No studies were found reporting on the determinants of treatment choice within drug treatments in the Netherlands.

**Q20. What are the determinants of compliance/adherence to drug treatment in the Netherlands?**

**Q20** - Epidemiology of chronic pain in the Netherlands

No studies were found reporting on the determinants of compliance/adherence to drug treatment in the Netherlands.

**Q21. What is patients' satisfaction about drug treatments in the Netherlands?**

We found only one study that was relevant to this question (Van Herk et al. 2009).

Van Herk et al. (2009) performed a cross-sectional multi-centre study of 233 residents of Dutch nursing homes. The study aimed to assess the prevalence and intensity of pain in older adults living in Dutch nursing homes and assess the characteristics of pain and the analgesics prescribed.

See Table 39 for study characteristics.

**Table 39.** Characteristics of the only study found for question 21

Study details	Population	Outcomes and analysis
<p><b>Van Herk et al. 2009</b></p> <p><b>Study design</b> cross-sectional / survey</p> <p><b>Study method</b> A standardized pain questionnaire was used based on the McGill Pain Questionnaire to measure aspects on pain. The use of analgesics was extracted from medical charts</p>	<p><b>Type of chronic pain</b> Self-reported pain in previous week. For 72% the pain was chronic (at least 3 months)</p> <p><b>Confirmation of diagnosis</b> Not reported</p> <p><b>Sample size and demographics</b> 233 residents completed questionnaires Median age 79 years (IQR 73-84) 70% were female</p> <p><b>Patient selection</b> residents without cognitive impairment</p>	<p><b>Outcomes measured</b> Characteristics of pain, pain treatment, pain management index (how well is pain managed), impact pain on sleep and ADL, satisfaction pain treatment</p> <p><b>Pain severity</b> Median pain intensity was 5 (IQR 2-7), 88 reported moderate or severe pain (&gt;= 4 on NRS)</p> <p><b>Analyses</b> Nonparametric data are given as median and interquartile range (IQR). Differences in demographics between the nursing homes are analyzed by chi-squared tests and Kruskal-Wallis tests. The multiple linear regression method was used to identify interferences with sleep and ADL, with pain intensity for the previous week as dependent variable</p>

## Q21. Study quality

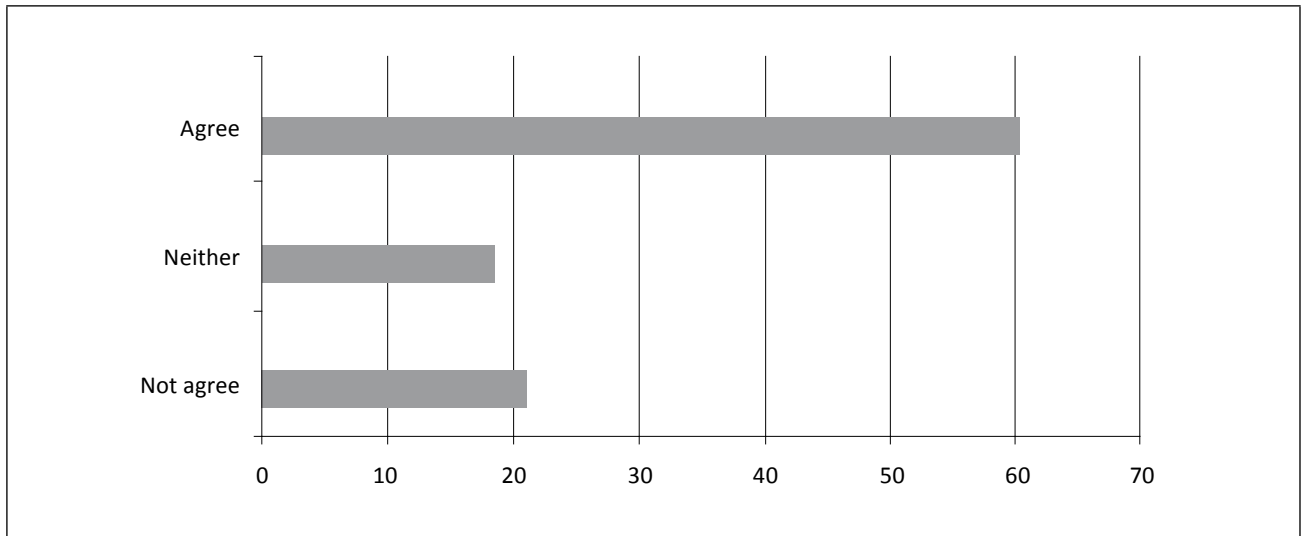
The Van Herk et al. study was rated low mainly because it was not clear that the sample was representative of all nursing home residents, the eligibility criteria were not clearly described and nor were the statistical methods and it was unclear if the presented results were unadjusted or adjusted for confounders.

## Q21. Results

### General chronic pain

Van Herk et al. 2006

146 residents of nursing homes reported that they had experienced pain in the previous week and answered the questions on pain treatment. Of these, 88 (60.3%) agreed with the statement 'I am satisfied about the pain treatment', 31 (21.2%) did not agree and 27 (18.5) did neither.



**Figure 24.** Opinion of patients on the statement 'I am satisfied about the pain treatment'

## Q21. Summary

Only one low quality study, performed in a Dutch nursing home population was found reporting on satisfaction about drug treatment. 60% were satisfied and 21% were not.





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# Summary Table

Table 40. Summary of study quality, results and concluding statements for project questions 2 through 21

Question	Number of studies and quality (low, med, high)	Results		Conclusion
		Chronic pain	Moderate or severe chronic pain	
2 prevalence of chronic pain	61 studies relevant  <b>Three studies selected</b> Breivik 2006-med Kerssens 2002-med DCM3 study (Picavet 2003 Pain - high / Picavet 2003 Ann Rheum Dis - med)	<b>Chronic musculoskeletal pain &gt; 3 months:</b> 44.4% (Picavet 2003 Pain) <b>Chronic diseases (self-reported) with &gt;10% prevalence (males vs females)</b> Tendinitis / capsulitis 15.4 vs 17.2% Herniated disc or back: 10.3 vs 8.3% Epicondylitis: 10.4 vs 11.6% Osteoarthritis of knee: 10.1 vs 13.6% (Picavet 2003 Ann Rheum Dis)	<b>Moderate to severe pain &gt; 6 months</b> 18% of Dutch population suffered from moderate to severe chronic pain in 2003 (Breivik 2006)  <b>Unexplained severe chronic pain in general practice:</b> 7.91 per 1000 enlisted patients in general practice (Kerssens 2002)	The DCM3 study and Kerssens used a representative population The DCM3 study is rated high quality and Breivik and Kerssens medium
3 incidence of chronic pain	Five studies relevant  <b>Four studies selected</b> De Mos 2007-med Dieleman 2008-med Opstelten 2005-med Steenstra 2006-med	<b>The overall incidence rates</b> - neuropathic pain 8.2/1000 PY (95%CI 8.0 to 8.4) (Dieleman 2008) - Complex Regional Pain Syndrome 26.2/100,000 PY (95%CI 23.0 to 29.7) (De Mos 2007) - Herpes zoster (HZ) 3.4/1000 PY (95%CI 2.9 to 3.9) (Opstelten 2005) - Persistent pain 3 months after HZ diagnosis reported in medical records of 2.6% (95%CI 1.7 to 4.0) - incidence of occupational disability as a result of back disorders: 2.02 and 2.14 per 1000 workers per year for men and women, resp. (Steenstra 2006)		De Mos 2007, Dieleman 2008 and Steenstra 2006 used a representative population All studies were rated medium quality
4 % untreated	<b>Five studies located</b>  Borghouts 1999-med Breivik et al. 2006-med Smalbrugge 2007-med Van Herk 2009-low Van Tulder 1998-med	<b>Percentage untreated:</b> - between 25 and 36% (patients in nursing homes who do not receive medication) (Van Herk 2009, Smalbrugge 2007) - between 31 and 36% (patients with neck or low back pain who visit their GP)(Borghouts 1999; Van Tulder 1998) <b>Percentages inadequately treated:</b> - up to 69% of nursing home residents (patients with inadequate analgesics dosing) (Smalbrugge 2007) - 34% of nursing home residents (inadequate treatment as indicated by Pain Management Index) (Van Herk 2009)	<b>Percentages inadequately treated:</b> - 79% of general chronic pain population inadequate pain control from medication (affirmative answer to the question: "Are there ever times when your pain medicines are not adequate to control your pain?") - 56% of general chronic pain population inadequate pain control (affirmative answer to the question: "Would you say your pain is being adequately controlled?") (Breivik 2006)	Van Tulder 1998 was the only study that included a representative population Four studies were rated medium quality and Van Herk 2009 was rated low quality

Question	Number of studies and quality (low, med, high)	Results		Conclusion
		Chronic pain	Moderate or severe chronic pain	
<p><b>5</b> % who present for pain treatment</p>	<p><b>Thirteen studies located</b></p> <p><b>Five studies selected</b> De Mos 2009-med Huisstede 2008-med Picavet 1999-high Picavet and Schouten 2003-high Picavet 2008-low</p>	<p><b>Complex regional pain syndrome</b></p> <ul style="list-style-type: none"> <li>- 61% CRPS patients visited the GP as the first physician; &gt;80% of the patients visited a medical specialist at any time (on average 2.4 different specialties) anesthetist was the most commonly consulted (55%) (deMos 2009)</li> </ul> <p><b>Musculoskeletal pain</b></p> <ul style="list-style-type: none"> <li>- 50% of the patients with chronic upper extremity disorders and neck pain (UED) reported contact with the GP, 40% – contact with medical specialist and 37% –contact with physiotherapist in the last 12 months due to their symptoms (Huisstede 2008)</li> <li>- around 50% of patients with musculoskeletal pain in any of the 5 examined locations (neck, shoulder, higher back; elbow, wrist/hand; lower back; hip, knee; ankle, foot) reported contact with any health professional because of their specific musculoskeletal pain during the last year; 30–40% – GP, 20–30% – medical specialist and 20–30% – physiotherapist (Picavet and Schouten 2003)</li> <li>- 9–13% of population had contact with GP due to low back pain during last year; 39% people with chronic low back pain reported GP contact, 26% – medical specialist and 36% – physiotherapist (Picavet 2008)</li> <li>- 19% of working and 24% of non-working men and women reported use of healthcare services due to low back pain (Picavet 1999)</li> </ul>		<p>Picavet 1999 and Picavet and Schouten 2003 used a representative population These studies were also rated high-quality. De Mos 2009 and Huisstede were rated medium and Picavet 2000 low quality</p>
<p><b>6</b> % who get treated, broken down by treatment</p>	<p>Fourteen studies relevant</p> <p><b>Five studies selected:</b> Breivik 2006-med Van Dasselaar 2002-low Van Tulder 1998-med Borghouts 1999 -med Dieleman 2008-med</p>	<p><b>Chronic non-cancer pain:</b></p> <ul style="list-style-type: none"> <li>- In 1991/1992 approx. 63,000 invasive procedures were performed in Dutch hospitals (Van Dasselaar 2002)</li> </ul> <p><b>Chronic musculoskeletal pain in general practice (patients who visited GP) :</b></p> <ul style="list-style-type: none"> <li>- 36 and 31% no treatment for low back or neck pain, respectively</li> <li>- medication most frequently applied treatment (22% of patients with low back pain received medication and 58% of patients with neck pain received paracetamol/aspirin/ NSAIDs).</li> <li>- The most frequent used non-drug treatments for low back pain were (bed)rest (6%) and postural advice (6%) and for neck pain heat application (20%) and postural advice (18%). (Van Tulder 1998/Borghouts 1999)</li> </ul> <p><b>Neuropathic pain</b></p> <ul style="list-style-type: none"> <li>- 53% were prescribed medication (Dieleman 2008)</li> </ul>	<p><b>General chronic pain:</b></p> <ul style="list-style-type: none"> <li>- 14% saw pain specialist</li> <li>- 33% prescribed medicines</li> <li>- 52% tried physiotherapy</li> <li>- 21% tried acupuncture</li> <li>- 17% tried massage (Breivik 2006)</li> </ul>	<p>Only the studies of Van Tulder 1998 and Dieleman 2008 used representative populations Four studies were rated medium quality and Van Dasselaar 2002 was rated low quality</p>



Summary Table - Epidemiology of chronic pain in the Netherlands

Question	Number of studies and quality (low, med, high)	Results		Conclusion
		Chronic pain	Moderate or severe chronic pain	
<b>7</b> % who comply with their treatment	No studies were found			
<b>8</b> disease duration of chronic pain conditions	16 studies relevant  <b>Three studies selected:</b> Breivik 2006-med Sluiter 2008-med Suurmeijer 2001-high	<b>Severity</b> <b>Rheumatoid Arthritis (RA):</b> Mean pain (range 8-16): 13.4 (SD: 2.1) (Suurmeijer 2001) <b>Chronic repetitive strain injury (RSI):</b> Mean pain (100 p VAS): 41.3 (SD: 25.4) (Sluiter 2008)	<b>Duration</b> <b>General chronic pain:</b> Mean of 6.5 years (Breivik 2006)	None of the studies clearly used a representative population Suurmeijer 2001 was rated high-quality and Breivik 2006 and Sluiter 2001 medium quality
<b>9</b> demographics of chronic pain sufferers	28 studies relevant  <b>Three studies selected:</b> Breivik 2006-med Huisstede 2008-med Opstelten 2002-mod	<b>Herpes zoster (HZ) and post herpetic neuralgia (PHN)</b> - 47% of all HZ patients ≥ 55 years - 58% females (Opstelten 2002) <b>Chronic musculoskeletal pain (upper extremity and neck pain):</b> - 63% females - 29% ≥65 years (Huisstede 2008)	<b>General chronic pain:</b> - mean age 51.3 years - 60% females (Breivik 2006)	None of the studies clearly used a representative sample All studies were rated medium quality
<b>10</b> co-morbidities of chronic pain sufferers	18 studies relevant  <b>Three studies selected:</b> Breivik 2006-med Demyttenaere 2007-med Picavet 2003-high	<b>Musculoskeletal pain</b> - 30% coexistence of pain in several locations (Picavet 2003) <b>Chronic back/neck pain:</b> - 9.4% major depressive episode - 4.5% dysthymia - 2.1% generalized anxiety disorder - 1.7% agoraphobia / panic disorder - 2.4% social phobia - 7.4% posttraumatic stress disorder - 1.7% alcohol abuse/dependence disorders (Demyttenaere 2007)	<b>General chronic pain:</b> - 19% depression (Breivik 2006)	Picavet 2003 was rated as high quality study that used a representative population The other two studies were unclear about representativeness of the population and were rated medium quality
<b>11</b> % with inadequate pain control	<b>One study found:</b> Breivik 2006-med		<b>General chronic pain:</b> - 79% inadequate pain control from medication - 56% inadequate overall pain control (Breivik 2006)	It was unclear whether the population of Breivik was representative, the study was rated medium quality

Question	Number of studies and quality (low, med, high)	Results		Conclusion
		Chronic pain	Moderate or severe chronic pain	
<p><b>12a</b> impact QoL</p>	<p><b>Three studies selected:</b> Alonso 2004-med Lame 2005-low Picavet 2004-med</p>	<p><b>Several pain populations</b></p> <ul style="list-style-type: none"> <li>- low QoL on each domain in patients with pain; patients with back pain, other pain and multiple pain locations experienced more functional limitations (physical functioning and role limitations physical) than the other pain groups; patients with multiple pain localizations scored lower on mental health, vitality and general health. Patients with other pain had lower scores on bodily pain than the other pain groups; women had lower scores than men (Lame 2005)</li> </ul> <p><b>Musculoskeletal pain</b></p> <ul style="list-style-type: none"> <li>- participants with arthritis scored 4.1 points lower on the Physical Summary Component of the SF-36 than respondents who did not report any chronic conditions (a mean score of 53.4); participants with arthritis also scored 1.0 points higher than those without chronic conditions on the Mental Summary Component for the SF-36 (a mean score of 55.2) (Alonso 2004)</li> <li>- subjects with any of the 12 musculoskeletal diseases (MSD) had lower scores on all SF-36 dimensions than those without MSD, especially for physical functioning (75.2 (SE 0.5) vs 87.8 (SE0.5)), role limitations from physical problems (67.1 (SE 0.9) vs 85.8 (SE 0.8)), and bodily pain (68.5 (SE 0.6) vs 84.1 (SE0.5)); Those with MSD had more health problems on the EQ-5D dimensions than those without MSD (mobility (29.9% vs 10.5%), pain/discomfort (62.5% v 31.2%), and usual activities (34.5% v 12.4%)); with an increasing number of MSD the health related quality of life deteriorated (Picavet 2004)</li> </ul>		<p>The populations of Alonso 2004 and Picavet 2004 were representative, and these studies were rated medium quality Lame 2005 was rated low quality</p>

Summary Table - Epidemiology of chronic pain in the Netherlands

Question	Number of studies and quality (low, med, high)	Results		Conclusion
		Chronic pain	Moderate or severe chronic pain	
<p><b>12b</b> impact ADL</p>	<p><b>Four studies selected:</b> Huisstede 2008-med Picavet and Schouten 2003-high Rupp 2006 ScanJRheumatol-med Rupp 2006 J Rheumatol-med</p>	<p><b>Musculoskeletal pain</b></p> <ul style="list-style-type: none"> <li>- 38.3% of people with UED reported limitation in daily life due to their pain complaints in the last year (Huisstede 2008)</li> <li>- roughly 30% reported limitation in daily life in the last year due to their musculoskeletal pain (neck, shoulder or higher back, elbow or wrist/hand, lower back, hip or knee) (Picavet and Schouten 2003)</li> </ul> <p><b>Rheumatoid arthritis</b></p> <ul style="list-style-type: none"> <li>- disability in VDF (higher scores – more disability) mean values at baseline 0.46 (SD 0.48) and at follow up 0.56 (SD 0.56); pain was the most important predictor for disability, significant associations were also found for depressive symptoms, radiographic damage and disease activity (Rupp 2006 ScanJRheumatol)</li> <li>- disability in VDF mean values at baseline were 0.66 (SD 0.62); female sex, older age, RF positivity, disease activity and somatic and psychological comorbidities were found to be risk factors for poor outcome with respect to disability (Rupp 2006 JRheumatol)</li> </ul>		<p>Only the population of the high-quality study Picavet 2003 was rated representative Other studies were rated medium quality</p>
<p><b>12c</b> impact depression</p>	<p><b>Four studies selected:</b> Breivik 2006-med Demyttenaere 2007-med Rupp 2006 ScanJRheumatol-med Rupp 2006 J Rheumatol-med</p>	<p><b>Back/neck pain</b></p> <ul style="list-style-type: none"> <li>- prevalence of: major depressive episode 9.4%, dysthymia 4.5%; generalized anxiety disorder 2.1%; agoraphobia or panic disorder 1.7%; social phobia 2.4%; posttraumatic stress disorder 7.4%; alcohol abuse/ dependence disorders 1.7%</li> </ul> <p><b>Rheumatoid arthritis</b></p> <ul style="list-style-type: none"> <li>- depressive symptoms mean values at baseline 10.3 (SD 8.2) and at follow up 10.5 (SD 7.9) in CES-D (Scores 0 to 60, with higher scores – more symptoms); MCS of RAND-36 (Higher scores indicate better health status) mean values at baseline 50.9 (SD 10.6) and at follow up 50.0 (SD 10.1); depressive symptoms the most important predictor for mental health and were significantly related to disability (Rupp 2006 ScanJRheumatol)</li> <li>- depressive symptoms in CES-D mean values at baseline 12.3 (SD 9.2); MCS of RAND-36 mean values at baseline were 49.2 (SD 11.4); depressive symptoms were a risk factor for poor outcomes and hampered good outcomes with respect to pain, disability, Qol (Rupp 2006 JRheumatol)</li> </ul>		<p>In none of the studies a representative population was used All studies were rated medium quality</p>

Question	Number of studies and quality (low, med, high)	Results		Conclusion
		Chronic pain	Moderate or severe chronic pain	
<b>12d</b> impact isolation	<b>Two studies found:</b> EURIDISS 2001-high; Strating 2006) Samwel 2006-med	<b>Rheumatoid arthritis:</b> - Overall SSQS (Social support questionnaire for satisfaction with supportive transactions: range 23-69, higher is better) mean 64.9 (SD 4.6) - ESS (emotional support satisfaction, range 11-33) mean 31.1 (SD 2.7) - SCS (Social companionship satisfaction, range 5-15) mean 13.8 (1.5) (Suurmeijer et al 2001)	<b>Unexplained chronic pain</b> - mean (SD) for helplessness (range 6-24, higher is worse) 14.6 (4.7) (Samwel 2006)	For both studies it was unclear whether the population was representative Suurmeijer 2001 was a high-quality study and Samwel 2006 medium-quality
<b>12e</b> impact days off work	<b>Four studies selected:</b> Borghouts 1999-med Breivik 2006-med Huisstede 2008-med Picavet and Schouten 2003-high	<b>Musculoskeletal pain</b> - 1 435 044 sick days related to neck disorders and 19 367 744 sick days regarding diseases of musculoskeletal system in 1996 in the Netherlands (human capital method); 487 915 sick days because of neck pain when leave for <90 days and 444 150 sick days due to neck pain when leave for >90 days (friction cost method) (Borghouts 1999) - 23% of patients with UED and paid work and age 25–64 years had work absence in the last year (Huisstede 2008) - 24% of people with low back pain reported sick leave in the past year; 22% of people with pain of ankle or foot, 21% of people with neck, shoulder or higher back pain 16% with pain of elbow or wrist/hand and 13% with pain of hip or knee (Picavet and Schouten 2003)	<b>General chronic pain</b> - mean time lost from work (full or part time) due to pain in the past 6 months was 6.8 days (Breivik 2006)	Picavet 2003 and Borghouts 1999 used a representative population Quality of Picavet 2003 was rated high and the other three studies medium
<b>12f</b> impact incapacity benefits	<b>Three studies found:</b> Borghouts 1999-med Chorus 2001-med van Doorn 1995-low	<b>Musculoskeletal pain</b> - 2.5% of patients receiving a disability pension received it in relation to the neck pain (based on ICD-codes) in the Netherlands in 1996 (Borghouts 1999) - the annual incidence rate of low back disability increased from 3.5 per 1000 persons at risk in 1977 to 7.4 in 1989; incidence of low back disability >1year was 0.85 per 1000 person-years among self-employed medical professionals vs 2.56 per 1000 person-years among general working population (RR 2.99 [95% CI 2.35–3.82]) (Van Doorn 1995) <b>Rheumatoid arthritis</b> - 94% of patients withdrawn from the labour force officially recognised as being fully (≈80% disabled; 69% of patients) or partially disabled (<80% disabled; 25% of patients) for work purposes; partial work disability recognized in 14% of the patients in paid employment (Chorus 2001)		Only Borghouts 1999 used a representative population Study quality of Borghouts 1999 and Chorus 2001 were rated medium and Van Doorn low

Summary Table - Epidemiology of chronic pain in the Netherlands

Question	Number of studies and quality (low, med, high)	Results		Conclusion
		Chronic pain	Moderate or severe chronic pain	
<p><b>13</b> economic costs</p>	<p><b>Four studies found:</b> Borghouts 1999-med Boonen 2005-med Kemler and Furnée 2002-low Van Doorn 1995-low</p>	<p><b>Costs for society</b> - neck pain in 1996 \$686.2 million (Borghouts 1999) - three chronic musculoskeletal diseases: between 3205 and 8533 E/pt/year (Boonen 2005) - compensation of low back pain disability in 1989: 8.0 million (self-employed health care professionals)(Van Doorn 1995) <b>Direct medical costs</b> - neck pain 23%: paramedical care accounted for the majority of costs (19 of 23%) (Borghouts 1999) - chronic musculoskeletal diseases between 13 and 32%: large proportions of costs were used for specialist physicians, physiotherapists and prescription drugs (Boonen 2005) <b>Cost for patients:</b> - patients with CRPS have a decreased income - mean out-of-pocket expenses \$1350 euro per patient per year (Kemler 2002)</p>		<p>Only Borghouts 1999 used a representative population Study quality of Borghouts 1999 and Boonen 2005 was rated medium and of Kemler 2002 and Van Doorn low</p>
<p><b>14</b> determinants of patient awareness of chronic pain</p>	<p><b>Three studies found:</b> Sluiter 2008-med Verbunt 2003-med Satink 2004-low</p>	<p><b>Determinants awareness RSI chronic pain:</b> - Patients who are able to work, who have a better physical role or better physical functioning have less pain - Patients who experience fewer consequences and symptoms and are less concerned about their illness have less pain (Sluiter 2008) <b>Determinants awareness of LBP disability</b> - Fear of injury and catastrophizing was associated with more disability (Verbunt 2003) <b>Three phases in the process of living with chronic pain:</b> - 1. pts aim to be normal, ignoring the pain and with unchanged activities - 2. pts aim to control and reduce the pain by withdrawing from activities. The pain is in control here - 3. pts aim to collaborate with the pain. To do this they have to constantly face dilemmas of prioritizing activities in order to incorporate pain in everyday life (Satink 2004)</p>		<p>None of the studies used a representative sample Sluiter 2008 and Verbunt 2003 were rated medium-quality and Satink 2004 low quality</p>

Question	Number of studies and quality (low, med, high)	Results		Conclusion
		Chronic pain	Moderate or severe chronic pain	
<b>15</b> determinants of health care professional awareness of chronic pain	<b>One study found:</b> Zwakhalen 2007-low	<b>Pain in elderly with dementia:</b> Nursing home staff respondents showed knowledge deficits about several aspects of pain, even though they were satisfied about the way pain was assessed and treated at their wards. Specific knowledge deficits were found regarding pain treatment and medication in elderly nursing home residents. Staff educational level seemed to influence their beliefs and knowledge about pain in elderly nursing home patients (Zwakhalen 2007)		It was unclear whether the sample of Zwakhalen 2007 was representative and the quality was rated low
<b>16</b> main presenting symptoms and complaints	No studies were found			
<b>17</b> frequency of drug, non-drug and combined treatments	11 studies were found  <b>Three were selected:</b> Breivik 2006-med Van Herk 2009-low Dieleman 2008-med	<b>Pain in nursing homes residents</b> 75.2% were prescribed analgesics: - 42.5% non-opioids - 8.5% weak opioids - 10.5% strong opioids (Van Herk 2009) <b>Neuropathic pain</b> 53% prescribed medication - 34.7% NSAIDs - 11.9% benzodiazepines - 9.1% sedative/hypnotics - 6.6% opioids - 4.8% anticonvulsants - 4.7% tricyclic antidepressants (Dieleman 2008)	<b>General chronic pain</b> 33% (n=99) were prescribed medicines: - 36% NSAIDs - 14% weak opioids - 5% strong opioids - 11% paracetamol - 16% a COX-2 inhibitor Non-drug treatments - 21% tried acupuncture - 52% tried physical therapy - 17% tried massage. (Breivik et al. 2006) <b>At least moderate pain in nursing home residents (n=88)</b> - 22% not prescribed medication <b>Intolerable pain in nursing home residents (n=41)</b> - 29% not prescribed medication (Van Herk 2009)	None of the studies clearly used a representative sample Breivik 2006 and Dieleman 2008 were rated medium quality and Van Herk low-quality

Summary Table - Epidemiology of chronic pain in the Netherlands

Question	Number of studies and quality (low, med, high)	Results		Conclusion
		Chronic pain	Moderate or severe chronic pain	
<p><b>18</b> determinants of treatment choice between drug and non-drug treatments NL</p>	<p><b>One studies found:</b> Kroese 2008-low</p>	<p><b>Fibromyalgia:</b> Factors influencing choice of treatment for fibromyalgia differ per discipline. The choice is mainly made on the basis of subjective, professional group-bound factors such as EBM, protocols, courses, own experience and experiences of colleagues. For GPs, dynamic patient factors are an important motive in the management of FM</p>		<p>It was unclear whether the sample of Kroese 2008 was representative, the quality was rated low</p>
<p><b>19</b> determinants of treatment choice within drug treatments NL</p>	<p>No studies were found</p>			
<p><b>20</b> determinants of compliance to drug treatment</p>	<p>No studies were found</p>			
<p><b>21</b> patient satisfaction with drug treatment</p>	<p><b>One study found:</b> Van Herk 2009-low</p>	<p><b>Pain in nursing home residents (n=146):</b> Statement "I am satisfied about the pain treatment": - 60.3% agreed - 21.2% did not agree - 18.5% did neither (Van Herk 2009)</p>		<p>It was unclear whether the sample of Van Herk 2009 was representative, the quality was rated low</p>







Dit boek is tot stand gekomen door een samenwerkingsverband tussen Kleijnen Systematic Reviews Ltd. en het centrum voor pijngeneeskunde van het Erasmus Medisch Centrum.

