

Norwegian pain registers

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Structured Cooperation between Health Care Systems tackling the societal impact of pain!

2017

# Disclosure Statement of conflict of interest in the context of the subject of this presentation



Within the past 12 months, I or my spouse/partner have had following financial interest/arrangement(s) or affiliation(s)

Support for travel

No

Honoraria for lectures
 No

Honoraria for advisory board activities
 No

Participation in clinical trials
 Novartis and

Grünenthal

Research funding Governmental and non-

commercial bodies

only

Financial shares and options
 No

# My aim is to convince you



The importance of high quality health registers

The importance of support and funding to establish and maintain registers

The need for legislation that secure both patient integrity and the society's access to data and possibilty of data sharing across countries



#### **General registers**

Primary care register

Specialist care
Diagnoses
Treatments

Prescription register

Sick leave/ pension database

Death registry





ORIGINAL ARTICLE

# Socio-economic burden of patients with a diagnosis related to chronic pain – Register data of 840,000 Swedish patients

A. Gustavsson<sup>1</sup>, J. Bjorkman<sup>2</sup>, C. Ljungcrantz<sup>1</sup>, A. Rhodin<sup>2,3</sup>, M. Rivano-Fischer<sup>4</sup>, K.-F. Sjolund<sup>5</sup>, C. Mannheimer<sup>6</sup>



PAIN\* 153 (2012) 2325-2331



www.elsevier.com/locate/pain

Research papers

Pharmaceutical treatment patterns for patients with a diagnosis related to chronic pain initiating a slow-release strong opioid treatment in Sweden

A. Gustavsson <sup>a</sup>, J. Bjorkman <sup>b</sup>, C. Ljungcrantz <sup>a</sup>, A. Rhodin <sup>b,c</sup>, M. Rivano-Fischer <sup>d</sup>, K.-F. Sjolund <sup>e</sup>, C. Mannheimer <sup>f,\*</sup>









Pain Medicine 2013; 14: 1072–1080 Wiley Periodicals, Inc.

# Pharmacological Treatment Patterns in Neuropathic Pain—Lessons from Swedish Administrative Registries

Anders Gustavsson, PhD,\* Johan Bjorkman, MSc,† Christina Ljungcrantz, MSc,\* Annica Rhodin, MD, PhD,† Marcelo Rivano-Fischer, PhD,† Karl-Fredrik Sjolund, MD, PhD,‡ and Clas Mannheimer, MD Prof\*\*



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#### Pain specific register

Population study/register

Longitudinal data

# The Tromsø Pain Study



Christopher Sivert Nielsen<sup>1,2</sup>, Audun Stubhaug<sup>2,3</sup>, Olöf Anna Steingrímsdottír<sup>1</sup>

<sup>1</sup>Norwegian Institute of Public Health, <sup>2</sup>Oslo University Hospital, 

<sup>3</sup>University of Oslo

# **The Tromsø Study Waves**



Wave	Year	Age	N	Response %
Tromsø 1	1974	20-49	6 595	74.4
Tromsø 2	1979-80	20-54	16 621	77.5
Trømsø 3	1986-87	12-67	21 826	75.2
Tromsø 4	1994-95	25-97	27 158	72.3
Tromsø 5	2001-02	30-89	8 130	78.5
Tromsø 6	2007-08	30-87	12 984	65.7
Fit futures 1	2010-11	15-17	1 038	92.7
Fit futures 2	2012-13	17-19	868	77.0
Tromsø 7	2015-16	40-99	21 083	65.0













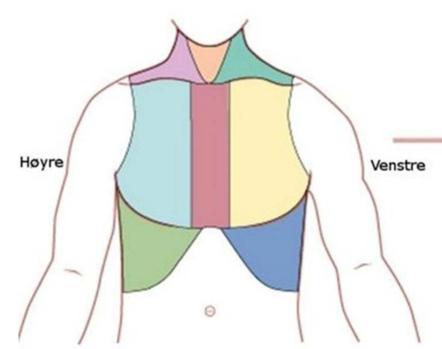




Chronic pain questions
Chronic pain body map (new)
IBS questionnaire (Rome 3)

Headaches Muscular Skeletal Pain

Chandlers fatigue scale Bergen Insomnia scale HSCL, HADS

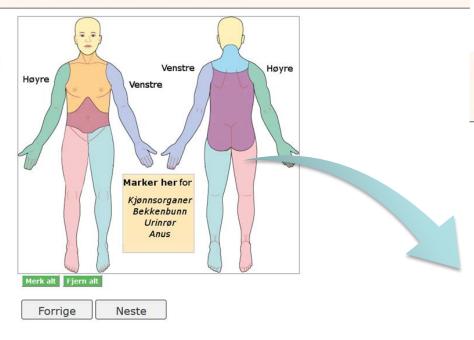


### **Hierarchical Digital Body Map**

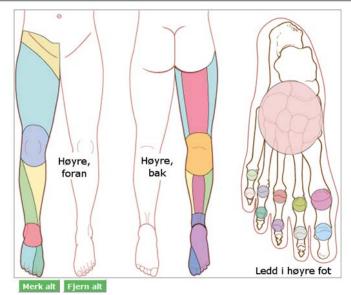


Klikk på alle områder hvor du har hatt smerte i løpet av *de siste 4 ukene*. Har du *ikke* hatt smerte de siste 4 ukene, går du videre til neste side.

Hvis du bare har hatt smerter i en del av et område skal du likevel markere hele området. Etterpå vil du få opp **detaljbilder** fra dine smerteområder, hvor du skal markere mer presist hvor smertene ligger. Du skal angi hvor du har hatt smerte, **ikke** hvor du tror årsaken til smerten ligger. Du kan fjerne merking ved å klikke en gang til på området.



Klikk på alle områder hvor du har hatt smerte i løpet av *de siste 4 ukene*. Hvis du bare har hatt smerter i en del av et område skal du likevel markere hele området. Du skal angi hvor du har hatt smerte, *ikke* hvor du tror årsaken til smerten ligger. Du kan fjerne merking ved å klikke en gang til på området.



Forrige Neste

# Tromsø 7 Experimental pain protocol N = 20 000 General population







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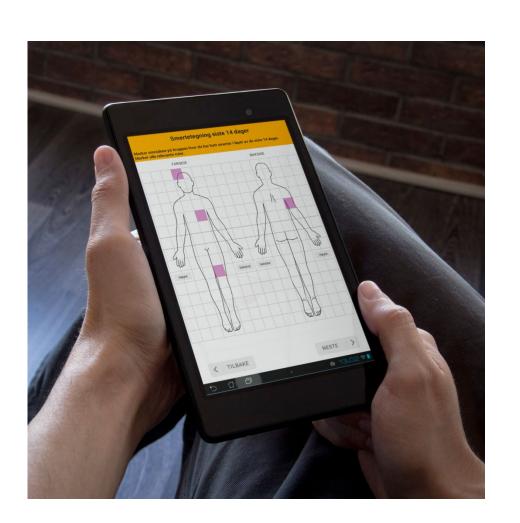
Longitudinal data

MDP clinic register

Follow up

# Pasients answer web-based questionnaires at clinic and at home before/during treatment + long-term follow-up





Demography Pain history QOL Anxiety/depression/fatigue

Pain catastrophizing, injustice experience.
Sleep
Coping

Expediations

++

Results are available for the clinician

Diagnoses (ICD10/11)
Treatments

Follow up after 6, 12, 36 months

## Patients admitted to MDP, Oslo



Mean age 50 y

Duration pain condition: 8,3 y

Employed or student: 36.4 %

Application for disability pension: 31 %

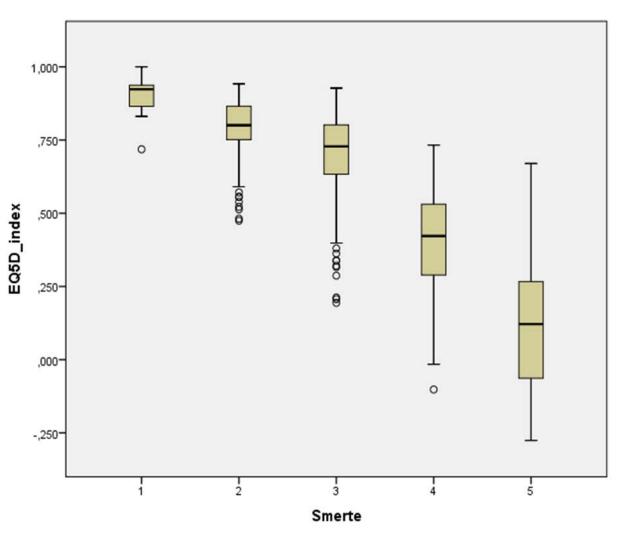
Litigation: 14.6

High scores for catastrophizing, injustice experience, fatigue and insomnia

Low scores for QOL



## EQ-5D-5L and pain- Oslo university hospital



1: Neither pain nor discomfort

5: Severe pain or discomfort



# What's next step?



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Linking Individual data

Sosial security number

**QALY** 

Costeffectiveness

Patient trajectories

Population study/register

Longitudinal data

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