Developing a National Core set of Outcome Measures for Rehabilitation in Rheumatic and Musculoskeletal Diseases

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Who are we?
- Multidisciplinary research group

What do we do?
- Develop and communicate knowledge about rehabilitation in rheumatology
- Promote and strengthen an evidence-based rehabilitation service nationally for people with rheumatic diseases.

Our main target groups
- Health professionals
- Patients
- Politicians and decision makers

www.nkrr.no
www.facebook.com/revmatologiskrehabilitering
A core assignment for the National Advisory Unit is to monitor and communicate quality of rehabilitation for patients with rheumatic diseases.
Patients with rheumatic and musculoskeletal diseases (RMD’s) are in need of rehabilitation throughout periods of their lives.
Evidence is scarce and there is no consensus of what outcome measures to use\textsuperscript{1}

Lack of continuity between specialized care and primary care\textsuperscript{2}

\textsuperscript{1} Kürükdeveci et al J.Rehab.Med. 2011; \textsuperscript{2} Andreassen et al HDIR 2012; \textsuperscript{2} Riksrevisjonen 2012
Aims

• Develop a national core set of outcome measures
  • Both in specialized care and in primary care
  • Both for clinical evaluations and for research
  • Multidisciplinary
  • Feasible and easy to use for patients (max. 20 minutes)

• «A relay baton» in the rehabilitation process, ensuring continuity in transitions between specialized- and primary care.
Two main steps

1. What are the 10 most important aspects to assess in rehabilitation for musculoskeletal diseases?

2. Which instruments are best to measure these 10 aspects?
The Delphi expert group included 46 experts
The process step by step

Selection of aspects of importance

- Fatigue
- Pain
- Mental health
- Quality of life
- Social participation

Brainstorming

3 rounds of Delphi voting rounds

10 ASPECTS OF HEALTH

- Goal attainment
- Motivation
- Coping
- Daily activities (ADL)
- Physical fitness

(random order)
The process - step by step

1. Selection of aspects
   - Brainstorming
   - 3 rounds of Delphi voting rounds
   - 10 ASPECTS OF HEALTH

2. Selection of instruments for pilot test
   - Expert group + + literature search = 172 OM's
   - Inclusion and exclusion acc. to criterias = 22 OM's
   - Work shop Voting = 11 OM's

3. Testing instruments
   - Pilot test (n=387)
   - Analysis of feasibility and responsiveness

4. Selecting instruments for final core set
   - Voting
   - FINAL CORE SET = 9 instruments
Outcome measures in the final core set

- NRS Pain
- NRS Fatigue
- Hopkins Symptom Checklist
- EQ 5D-5L
- Coop Wonca Social Participation
- Patient Specific Functional Scale incl. motivation
- Effective Consumer Scale
- Hannover Functional Scale
- 30 sec sit-to-stand test
To be continued....

- A recommended core set of outcome measures are presented

- The core set is published online at
  [www.nkrr.no/klinisk verktøykasse/faglige anbefalinger](http://www.nkrr.no/klinisk verktøykasse/faglige anbefalinger)

Research article is soon to be submitted.

- The core set is tested in rehabilitation settings for patients with RMD’s but most OM’s are generic so in the future it should also be tested on other diagnostic groups
The Core set in use

The BRIDGE study
Aim 1

• How can we use the core set as a relay baton?
Aim 2

• What happens after rehabilitation in specialised care for patients with RMD’s?
Method

- Multicenter observational study
- 9 rehabilitation centers and hospitals in all regions
- Electronic data collection started Nov 4.
- ~700-1000 patients
- Assessment:
  - admittance
  - discharge
  - 4, 8, and 12 months after rehabilitation
The core set as a relay baton

Mestring

100 tyder på at du i svært stor grad mestrer sykdommen

0 tyder på at du ikke mestrer sykdommen
The core set project thanks

• Exstra-stiftelsen

• Experts included in the Delphi group, and librarian Kari Engen Matre for valuable help in the literature search

• Patients participating in the pilot study
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