

# The BOA -register

Better management of patients with osteoarthritis

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Annual report 2011

[www.boaregistret.se](http://www.boaregistret.se)

The logo features the letters 'BOA' in a large, dark blue, serif font. To the left of the letters is a graphic consisting of three concentric, light blue circular arcs that resemble a stylized 'B' or a ripple effect. The entire logo is set against a light blue gradient background that reflects the text and graphic below it.

*Better management of patients with OsteoArthritis*

This annual report summarizes the results from the Swedish National initiative for Better management of patients with osteoarthritis, BOA, for the year 2011.

A full version in Swedish, and more information about BOA (partly in English) can be found at [www.boaregistret.se](http://www.boaregistret.se)

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## BOA's three branches

BOA stands for Better management of patients with OsteoArthritis. BOA consists of three main branches of activities: 1. Patient education (Supporting self-management of osteoarthritis (OA) programme), 2. Staff training in the implementation and evaluation of Supporting self-management of OA programme to insure equivalency of content and presentation, and 3. The National Quality register, the BOA register. The BOA register is an intervention register for patients with problems from hips and knees.

### Aims and objectives of BOA

BOA's objective is to offer all patients with OA adequate and equivalent information and training according to current treatment guidelines, and that surgery is only to be considered where conservative treatment does not lead to satisfactory results. The aim is to raise the quality of life and activity levels in patients with OA, mainly of the hip and knee, and to reduce health care consumption and sickness absence as a consequence of OA. Patients with OA should be managed in an equivalent manner at their first contact with health care, regardless of location. Previous research has shown that information and individually adjusted training has as beneficial an effect on pain due to OA as medication. In BOA we have utilised this knowledge in an evidence-based programme supporting self-management of OA offered to patients. OA is one of the most common causes of inactivity among older people and many are afraid that activity will damage their joints. Inactivity itself is a large risk factor for poor physical and psychological health and premature mortality (1). Supporting self-management of OA programme aims to raise patient physical activity levels and provide them with knowledge of how they themselves can deal with their illness, avoid ill health and live a good life despite OA. Furthermore, a BOA objective is for physiotherapists to improve their treatment quality by means of systematic evaluation, open comparison and feedback of results.

### Here's how it all began

BOA was initiated in 2008 as a 3-year collaboration with Region Västra Götaland, Region Skåne, Värmland County Council and the County Council of Västerbotten. The background was the high illness absence costs for OA and the knowledge that only a fraction of all patients operated on due to OA have consulted a physiotherapist at some time prior to surgery. This, despite the fact that information, training and weight control constitute the foundation for treatment for OA according to both national and international treatment guidelines. The project was financed by funding from The Swedish Social Insurance Agency and government grants to the regional authorities. BOA was initiated as a pilot project in 2008 in cooperation with 10 units in four regions (Mölnadal, Kungälv, Munkedal, Trollhättan, Vänersborg, Malmö, Trelleborg, Lund, Karlstad, Umeå). Depending on how health care was organised in each region/county both primary care and inpatient units were included in the project. The BOA register became a National Quality register in 2010.

## Patient education – The Supporting self-management of osteoarthritis programme

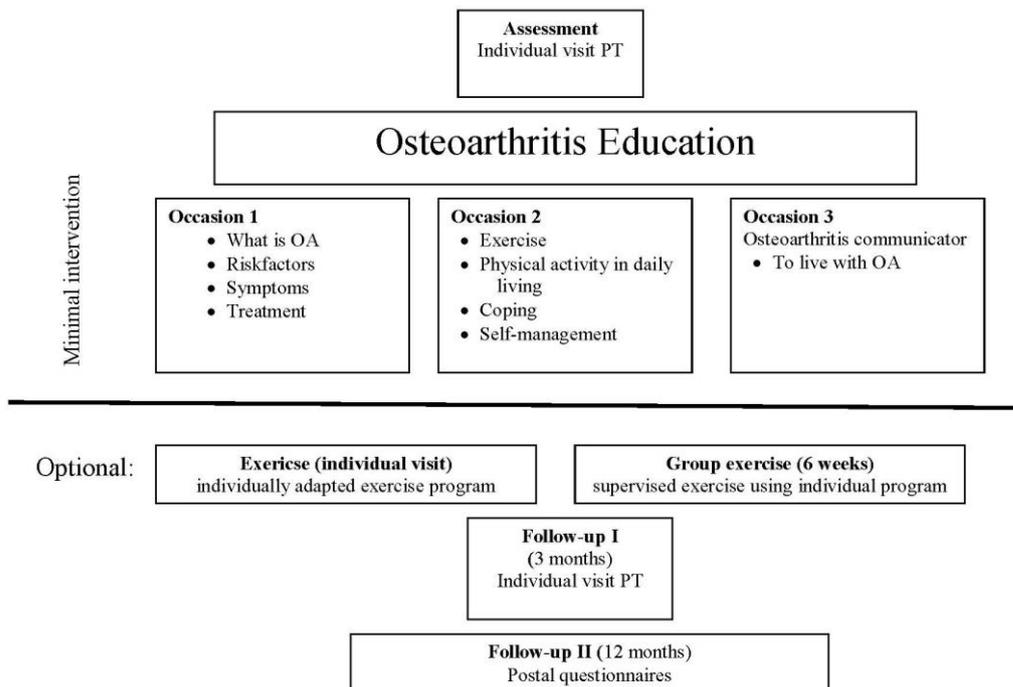
### Target group

Supporting self-management of OA programme turns to patients with hip and knee problems troublesome enough to initiate a health care consultation. X-rays or a previous diagnosis is not a prerequisite. All patients considered gaining benefit from participation in an OA programme meets with a physiotherapist for an individual consultation prior to starting. The patient's medical history and physiotherapist's examination provides the basis for a diagnosis, or can at least exclude other causes of the difficulties. This procedure is in complete accord with The National Board of Health and Welfare's guidelines for musculoskeletal diseases including OA, published in may 2012. According to these guidelines the diagnosis is to be established by means of the medical history, typical symptoms and a clinical examination. X-ray is to be used only in uncertain cases or when a specialist referral is being considered (2). Even if the latter should show that difficulties are not due to OA, treatment as offered in the supporting self-management of OA – information and training – is aimed at disabilities, and where the risks of treatment are negligible. Patients with inflammatory joint disease, other illnesses causing more dominant symptoms (such as malignancy or generalised pain), or a collapsed femoral neck fracture, are primarily in need of another kind of management and are therefore excluded from OA programme and the register. Patients that do not understand Swedish should receive individual treatment, eventually with the help of an interpreter, to insure that they correctly understand the information. They need neither complete the questionnaire registered in the BOA register.

### Information

The osteoarthritis programme arose from current research in the area as well as from patient's thoughts and wishes for treatment of osteoarthritis. The Supporting self-management of OA programme within BOA comprises a "minimal intervention" carried out in a similar way at all units (Figure 1). The contents encompass information of what osteoarthritis is, risk factors, available treatments, and self-care tips. The programme is led by a physiotherapist, and in some areas, an occupational therapist with special training and a thorough knowledge of osteoarthritis. Moreover, the osteoarthritis programme includes a session led by an "expert patient", a patient with osteoarthritis that has completed a special training course to be able to speak of the lived experience of osteoarthritis and of basic treatment. The Swedish Rheumatism Association trains these expert patients or osteoarthritis communicators. The aim of their participation is for participants of an osteoarthritis programme to more easily identify with those providing advice and recommendations, and thus jointly find solutions to those difficulties encountered in everyday physical activities. Where the local rheumatism association has the resources and activities for patients with osteoarthritis, participants of the osteoarthritis programme can deepen their knowledge of osteoarthritis through study circles or lectures through the local association and be offered further training through the auspices of the association. Participation of an osteoarthritis communicator in programmes is cost-free for health care. The osteoarthritis communicator participates on an idealistic basis and the Swedish Rheumatism Association pays for travel expenses.

Better management of patients with OsteoArthritis (BOA)



**Figure 1.** Disposition of the Supporting self-management of OA programme

### Individually customized training

After the theoretical part of the osteoarthritis programme patients are offered an individually tested training program as well as the opportunity to train with this program along with others under the guidance of a physiotherapist. Training is voluntary but the goal is for as many as possible to feel the desire and need to learn more of how to best deal with their illness and the difficulties it entails, through correct training and physical activity in their daily lives. Discussions concerning suitable home exercise and planning for continued physical activity/training after OA programme comprises an important part of the arrangement. Osteoarthritis cannot yet be cured and in order to gain a long lasting effect of training as demanded by the treatment it is also important to plan training far in advance and carry it out continuously. Prolonged illness demands prolonged treatment. Physical activity by prescription can be a suitable tool for health care to stimulate increased activity levels in patients. Long term illness demands long term treatment.

### Educating the profession

Physiotherapists and interested occupational therapists are trained through BOA in order to implement and evaluate OA programme in an equivalent manner. Two-day's education encompasses current evidence with the field and aims to provide in-depth knowledge of OA and its non surgical treatment. Education includes even basic register knowledge, whereby "quality register" is still a relatively new and unknown field within physiotherapy.

## National Quality register

The objective of the OA programme is to influence health-related quality of life, pain, physical activity levels, fear of movement, motivation for surgery, and self-efficacy relating to affecting symptoms. These variables are recorded in the BOA register, along with, among others, patient satisfaction. The physiotherapist implementing OA programme is often also responsible for reporting data to the register. Evaluation takes place prior to OA programme, after three months and after one year. One hundred patients that participated in the one-year follow-up the previous year are chosen at random for yearly follow-ups for the remainder of their lives.

## The current BOA register

Interest for BOA and supporting self-management of osteoarthritis programme is considerable among both patients and care providers. Up until the end of 2011 approximately 1 000 physiotherapists and occupational therapists have been trained according to the BOA-concept. At present 200 units are linked to the register. Data from approximately 10 200 patients have been fed into the register up until May 31, 2012, whereof approximately two thirds so far are followed up after 3 months and a third after 12. All the more units are continuously joining the register. The osteoarthritis programme has become a routine part of health care in many parts of the country and orthopaedic surgeons return referrals for patients that have not met a physiotherapist. The osteoarthritis programme has been assessed at the orthopaedic clinic in Västerbotten, and the long term results are presented in the next chapter "Ongoing studies".

*1. Nuesch E, Dieppe P, Reichenbach S, Williams S, Iff S, and Juni P. All cause and disease specific mortality in patients with knee or hip osteoarthritis: population based cohort study. BMJ. 342: p. d1165.*

*2. Nationella riktlinjer för rörelseorganens sjukdomar 2012. Socialstyrelsen. [www.socialstyrelsen.se](http://www.socialstyrelsen.se)*

# Results 2011

The English version is a summary of the most relevant bits and pieces of the results that might be of international interest. For those with specific interest we refer to the Swedish version where all tables and figures are presented.

This chapter presents the results based on the cumulative data from the first entries of the pilot units from 2008 to December 31, 2011. The "National mean" indicated in this report is used to describe mean values from all registered patients. The "national mean" represents only clinics that have registered at least one patient before the end of 2011, and cannot be considered representing the entire country by more than what is presented in the chapter "Participation and reporting".

The number of individuals in the register are continually updated and validated. Questionnaires can be registered retrospectively, incorrect or missing data corrected and patients can discontinue participation at any time. These factors influence both the number of unit-based individuals as well as all those registered, resulting in yearly variations.

This annual report is based on data from 7607 patients having made at least one visit to a physiotherapist before December 31, 2011. 4418 of these (58%) had registered consultations during 2011. Thirty per cent were assessed by the physiotherapist as having most of their problems with their hips, and 70% their knees. We refer to them in the annual report as patients with osteoarthritis of the hip or knee. Many patients have problems from both hips and knees. In this report we do not distinguish patients with symptoms from several joints from those with single joint problems. One hundred and twenty two patients reported symptoms from a joint other than those reported from the physiotherapist examination and assessment. Seventy-nine patients reported being symptom-free at three months.

## "Case-mix" profile

Patient composition, or case-mix, can vary both geographically and between clinics. This is an important factor to consider when studying results. Variations in age, gender distribution and comorbidity can influence outcomes of one and the same treatment. Osteoarthritis self-management interventions run at hospitals probably have a greater percentage of patients with more advanced osteoarthritis awaiting surgery than self-management interventions in primary care. Hand problems may indicate a more generalised form of osteoarthritis involving several joints. Charnley category C implies that the patient has more problems than osteoarthritis affecting walking ability. Osteoarthritis can have a limited affect on these patients' health-related quality of life due to another illness. Future analyses and annual reports will show the extent of how female gender, age above 65 and osteoarthritis of the hip make up a heavier case mix.

## Changes over time

The changes after 3 and 12 months for a number of patient-reported variables are presented below. All results represent matched data. This implies that only individuals having undergone a one-year follow-up before December 31, 2011 *and* with data from all three follow-ups are presented. Results are shown separately for patients with most symptoms from the hip or knee, respectively.

## EQ5D

The EQ5D is a measure of health-related quality of life. The patient answers five questions concerning mobility, hygiene, usual activity, pain, and anxiety/depression. There are three alternative responses to each question (no problems, moderate problems, severe problems), and, based on the responses, an index can be calculated ranging from 0 to 1, where 0 is equivalent to "death" and 1 to "optimal health". The EQ5D-index can assume values below zero, implying that health status is considered worse than death. The EQ5D has been used in a large number of studies of different illnesses and diagnoses and can even be used for health economic calculations. The goal of BOA is to reach patients before their health-related quality of life has been too greatly affected, and by means of the supported osteoarthritis self-management intervention achieve a change in the EQ5D of 0.10. Currently we show an increase of 0.07 after three months. After one year the change is 0.04 compared with EQ5D prior to self-management intervention.

## Pain VAS

The Visual Analogue Scale (VAS) is an instrument for estimating pain from 0 (no pain) to 100 (worst imaginable pain). The reliability of the VAS has been discussed in scientific studies. Pain is a subjective experience, and since pain is experienced in so many different ways it is difficult to compare VAS between individuals. The VAS should be used only to measure changes in pain over time. One of the great advantages of the VAS is its simplicity for use in the clinic. For a change to be clinically meaningful it should be at least 10.

## Self-efficacy for affecting pain and other symptoms

The Supported osteoarthritis self-management intervention aims, among other things, to increase physical activity levels for patients with osteoarthritis of the hip and knee. This entails a change in life style for many participants. Life style changes are difficult and demanding. A possibly decisive factor for the success of the change is self-efficacy. Low self-efficacy concerning symptoms, i.e. a lack of belief that symptoms can be affected by changes in life-style, will probably negatively affect motivation to life-style changes. Studies have shown that high self-efficacy concerning symptoms can be of great value in the initiation and successful implementation of life style changes such as becoming physically active. The Arthritis Self-Efficacy Scale (ASES) is used by BOA for measuring changes in self-efficacy for affecting pain and other symptoms. The ASES starts from 10 (low self-efficacy) to 100 (high self-efficacy) and a clinically meaningful change should be greater than 10.

**Table 1.** Changes over time in patient-reported variables

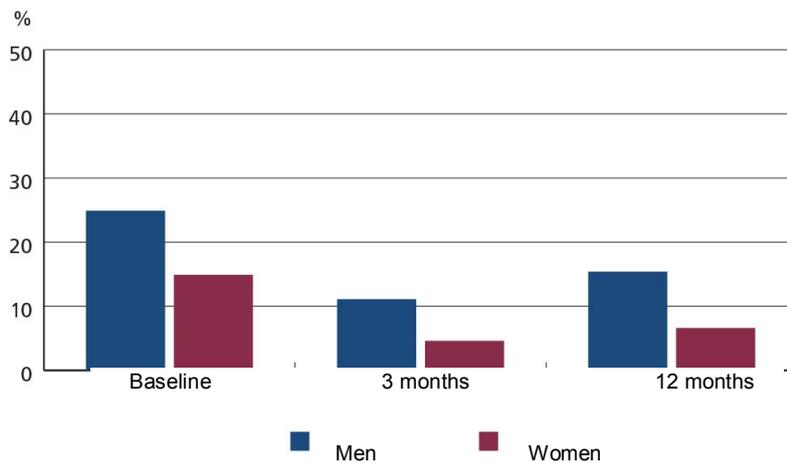
	Hip				Knee			
	Number	Baseline	3 months	12 months	Number	Baseline	3 months	12 months
EQ5D	507	0.62	0.69	0.66	1267	0.64	0.72	0.69
VAS pain	510	49	40	42	1278	48	38	39
ASES symptom	501	67	70	64	1228	67	72	66
ASES pain	499	60	64	57	1225	62	68	61

## Fear of joint damage

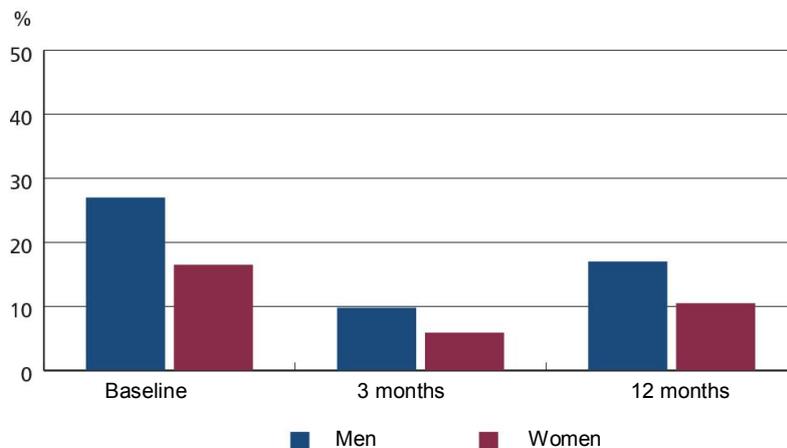
It is a common misunderstanding among patients that joints "wear out" and that continued use or activity will cause further damage. This type of misunderstanding can be an obstacle to physical activity, and information from the supported osteoarthritis self-management

intervention aims toward changes of understanding. The figures below, 1a and 1b, shows the proportion of patients fearing joint damage due to physical activity or training prior to self-management intervention (baseline), and at three and twelve months for the entire register (cumulative number). The results for men and women and for the hip and knee are presented separately.

**Figure 1a. Hip.** The proportion of patients fearing joint damage due to physical activity.



**Figure 1b. Knee.** The proportion of patients fearing joint damage due to physical activity.

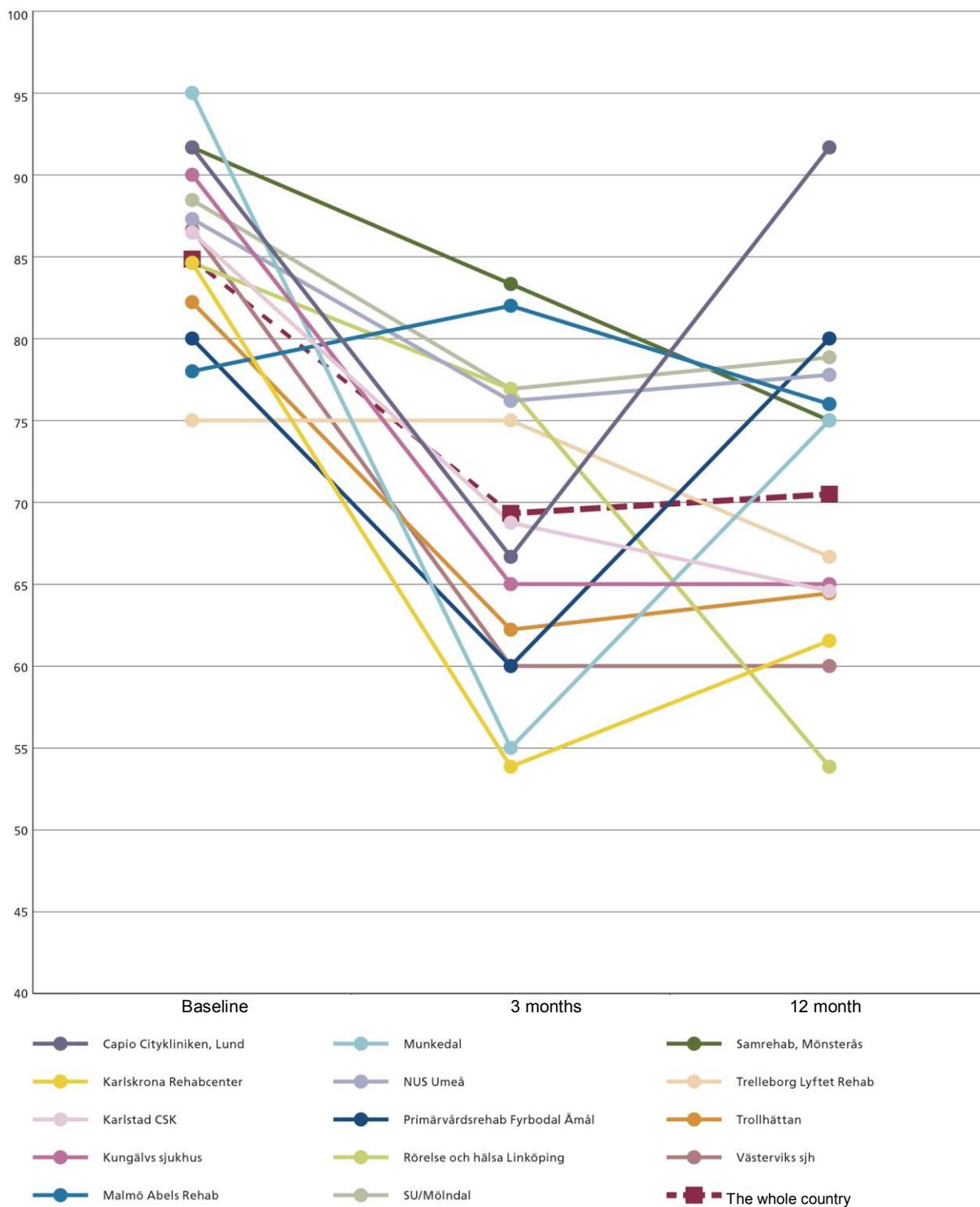


### Proportion with daily pain

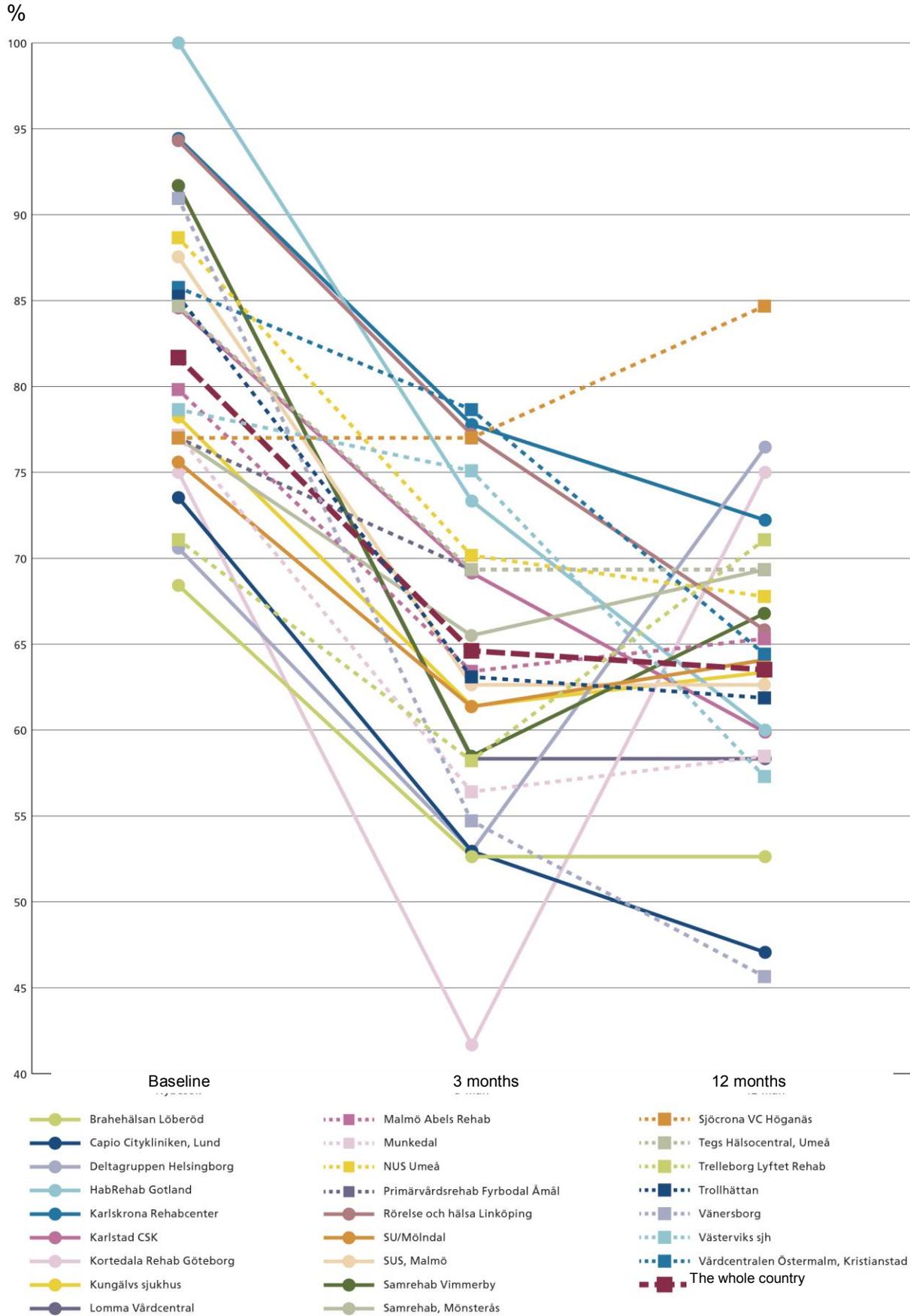
Osteoarthritic pain frequently relapses. Periods of more intense pain are followed by periods of less or no pain. These periods can vary in duration from one or a few days up to several months or years, and are difficult to predict. The figures below, 2a and 2b, show the proportion of patients at the first consultation (baseline), at three and twelve months indicating daily or constant pain from the hip or knee, respectively. Each line represents a clinic. Only clinics with at least 10 patients having completed the one-year follow-up prior to December 31, 2011 and retaining data from all three occasions are presented in the figure.

**Figure 2a. Hip.** The proportion of patients with daily pain.

%



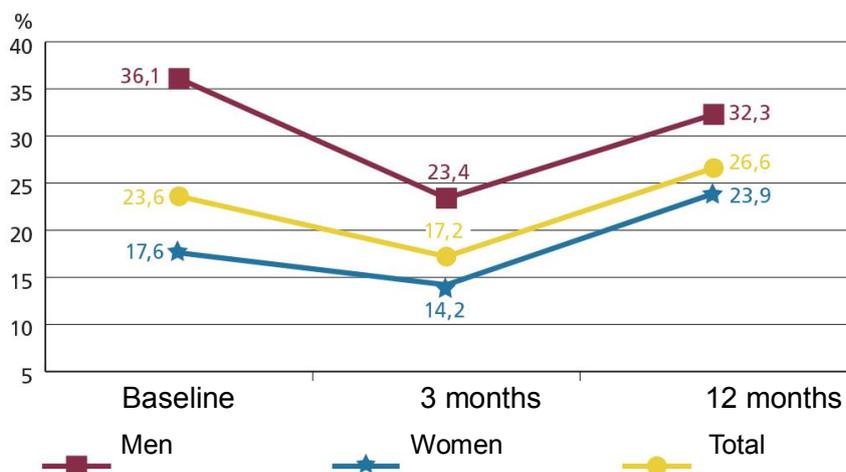
**Figure 2b. Knee.** The proportion of patients with daily pain.



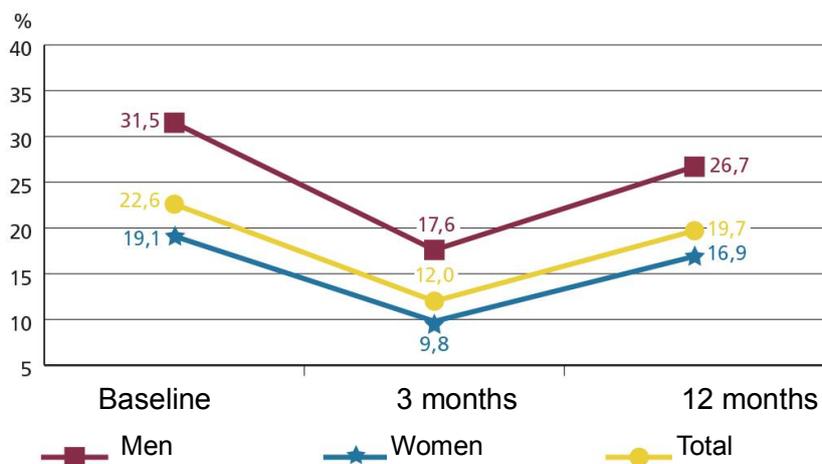
## Desire for surgery

Many patients erroneously believe that surgery is the only treatment for osteoarthritis, and that osteoarthritic hips and knees must be replaced sooner or later. They then desire surgery as soon as possible to gain as much benefit as possible from their new joint. This attitude can convey false expectations, and the figure below shows the proportion of patients desiring surgery before (baseline) the supported osteoarthritis self-management intervention and after three and twelve months for the hip and knee, respectively. The figures 3a and 3b represent the entire register (cumulative data), and is presented according to gender.

**Figure 3a. Hip.** The proportion of patients who desire surgery.



**Figure 3b. Knee.** The proportion of patients who desire surgery.



## Opinions of the supported osteoarthritis self-management intervention

After three months 91% of the patients stated that the supported osteoarthritis self-management intervention was good or very good; 5% thought it neither good nor bad, and 0.7% (34 patients) stated they thought the intervention was bad or very bad. Three per cent could not decide or did not respond. For descriptive characteristics for those that felt that the intervention was bad compared to the others we refer to the previous annual report ([www.boaregistret.se](http://www.boaregistret.se)).

## Knowledge use from the supported osteoarthritis self-management intervention

One way of measuring the utility of the supported osteoarthritis self-management intervention is to ask patients how often they use the knowledge gained from the intervention in daily life. After three months 62% stated using knowledge daily or several times daily, and 91% said they used what they had learned at least weekly. Seven per cent couldn't decide or hadn't responded. One per cent said they never used what they had learned in the osteoarthritis intervention. After one year 71% said they still used what they had learned at least weekly and 35% used the knowledge from the intervention daily.

## Number of patients and clinical characteristics

### Age

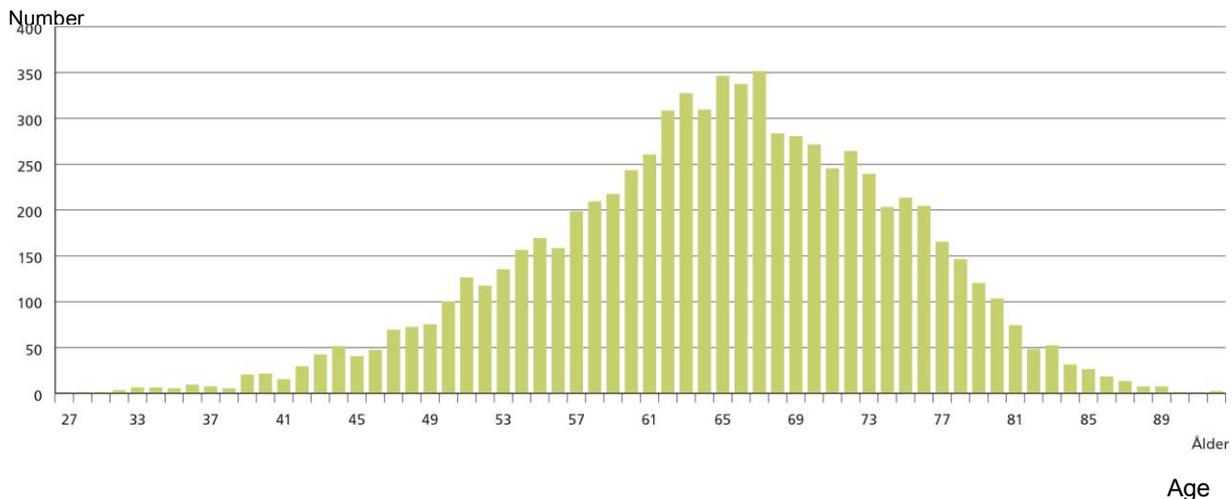
Osteoarthritis occurs even in younger patients albeit less frequently. The first symptoms of osteoarthritis can often be seen as early as at forty years of age. But it is not unusual for both patient and health care providers to seek other explanations for symptoms than osteoarthritis. Research has shown that constant joint pain without other explanations is, in most cases, the first sign of osteoarthritis. Symptoms may come and go and do not often lead to medical consultations before a number of years when problems lead to functional difficulties in daily life. Since osteoarthritis is incurable the prevalence constantly increases with age. The mean age for patients at the first visit to the BOA-register was 64.7 years. The age distribution for the entire register can be seen in Figure 4. The mean age for men was 64.7 (SD 9.9) years and 64.7 (SD 9.6) for women.

### Gender

Studies of osteoarthritis prevalence in the population show somewhat more men than women with osteoarthritis in the under 45-age group. This can depend on the fact that roughly half of all those suffering meniscus or cruciate ligament injury develop osteoarthritis within 10-15 years. Injuries in 20-year-olds can thus lead to osteoarthritis in 35-year-olds. Joint injuries are common in contact sports such as football and handball, sports with greater male participation than female. At more advanced ages it is, however, more common with osteoarthritis in

women. In the BOA-register 71% were women. In the previous annual report we noted a difference in the proportion of men and women concerning a number of variables, and are presented again according to gender in this annual report. A more nuanced analysis of gender differences should be studied in future more specific research projects in the register.

**Figure 4.** The age distribution for the BOA-register



## BMI

Overweight is a known risk factor in the development of osteoarthritis, primarily in knee joints, but also for osteoarthritis of the finger joints. Concerning correlations between overweight and osteoarthritis of the hip the evidence is not quite clear, even if overweight has shown a strong correlation with hip problems and risk for hip replacement surgery. The body mass index (BMI) is often used for classification of body weight in relation to body mass. BMI is calculated by dividing body weight expressed in kg with height squared, expressed in meters. The limit for normal weight is, according to World Health Organisation,  $25 \text{ kg/m}^2$ , overweight implies a BMI between 25.0 and 29.99, and people with a BMI of 30 or more are classified as obese. BMI is a rough measure and very muscular people can show misleading results.

In the BOA-register we study mean values for groups of individuals. In this way single values become less important. In order to gain reliable values length gauges and scales should measure height and weight. In the BOA-register BMI is based mostly on the patient's self-reported data, and should therefore be interpreted with some caution.

Patients with hip osteoarthritis had a BMI of  $27.0 \text{ (SD } 4.5) \text{ kg/m}^2$  compared with  $28.7 \text{ (SD } 8.2) \text{ kg/m}^2$  for knee osteoarthritis. The proportion of overweight was equally great for hip and knee osteoarthritis. Every third patient with hip osteoarthritis was of normal weight and every fourth with knee osteoarthritis. A third of the patients with knee osteoarthritis were obese compared to a fifth of the patients with hip problems.

## Problems from hand and finger joints

Osteoarthritis of the hand is very common. After 65 years of age it is more common to have

osteoarthritis in some finger joint than not to have it at all. Many patients with osteoarthritis of the hip and knee also have symptoms from their hands, which influences their daily activities. There is not nearly the amount of research for the treatment of hand osteoarthritis as for hip, and above all, osteoarthritis of the knee. On the other hand there is nothing indicating that information and adjusted physical activity as presented in the osteoarthritis self-management intervention would be injurious to people with osteoarthritis of the hand. Hip and knee osteoarthritis in combination with osteoarthritis of the hand can be an indication of more a generalised condition, affecting more of the body's joints (three or four joint systems). In the BOA-register we see that despite only registering patients with hip or knee symptoms, four of ten patients also report symptoms from their hand or finger joints.

Table 2 shows that the BOA-register does not generally show any gender differences for age or BMI. However, women to a greater extent have problems from their hips and hands while men are more afflicted by knee problems. A greater proportion of the women have problems from one knee/hip (Charnley A) whereby men often have bilateral symptoms.

**Table 2.** Age, BMI, proportion of patients with most symptoms from hip, hand, and unilateral symptoms for both men and women.

	<b>Men (n=2202)</b>	<b>Women (n=5405)</b>
<b>Age, mean (SD)</b>	64.7 (9.9)	64.7 (9.6)
<b>BMI, mean (SD)</b>	28.2 (4.5)	28.2 (7.1)
<b>Proportion hip, %</b>	9.37	21.07
<b>Proportion hand, %</b>	7.25	34.88
<b>Proportion Charnley A, %</b>	10.99	22.58

## Marital status and sick leave

People with difficulties reading and understanding Swedish can find it difficult to complete the questionnaires, which are not yet available in other languages. Language difficulties are not a barrier for getting information in the supported osteoarthritis self-management intervention, but teaching is then preferably on an individual basis. Patients registered in the BOA register should have a good understanding of the Swedish language.

Osteoarthritis afflicts a large portion of the working population. Half of those in the BOA-register are under 65 years of age. Medical leave, sickness compensation, and production loss make up large proportions of societal costs as a consequence of osteoarthritis. Patients with osteoarthritis of the knee are more often on medical leave than the general population (1). It is unclear if this is due to osteoarthritis, or as a consequence of comorbidity. Sick leave alone with no other intervention has no or only a limited effect on OA of the hip or knee. People with osteoarthritis that have physically heavy work should probably consider the possibilities of other activities. Work can in many cases be seen as an activity that can contribute to reducing difficulties as a consequence of osteoarthritis, just as with physical activity. One of the objectives of BOA is that knowledge and individually adjusted training will reduce medical leave as a result of osteoarthritis of the hip and knee.

Presented below are the self-reported marital statuses and medical leave divided according to hips and knees as well as for men and women that underwent a three-month follow-up during

2011 (Table 3a and 3b).

**Table 3a. Hip.** Characteristics for patients who have been to individual physiotherapist visit at 3 months, 2011.

	First individual visit	Marital status				Swedish birth		Swedish citizen		Sick leave		Sick leave >3 months	
		Cohabiting		Living alone		N	%	N	%	N	%	N	%
		Number	N	%	N								
<b>Man</b>	188	159	85	28	15	179	95	184	98	19	10	8	4
<b>Woman</b>	484	327	68	157	32	448	93	473	98	43	9	16	3
<b>Total</b>	672	486	72	185	28	627	93	657	98	62	9	24	4

**Table 3b. Knee.** Characteristics for patients who have been to individual physiotherapist visit at 3 months, 2011.

	First individual visit	Marital status				Swedish birth		Swedish citizen		Sick leave		Sick leave >3 months	
		Cohabiting		Living alone		N	%	N	%	N	%	N	%
		Number	N	%	N								
<b>Man</b>	502	415	83	85	17	465	93	494	98	60	12	21	4
<b>Woman</b>	1318	937	71	379	29	1208	92	1297	98	191	14	70	5
<b>Total</b>	1820	1352	74	464	26	1673	92	1791	98	251	14	91	5

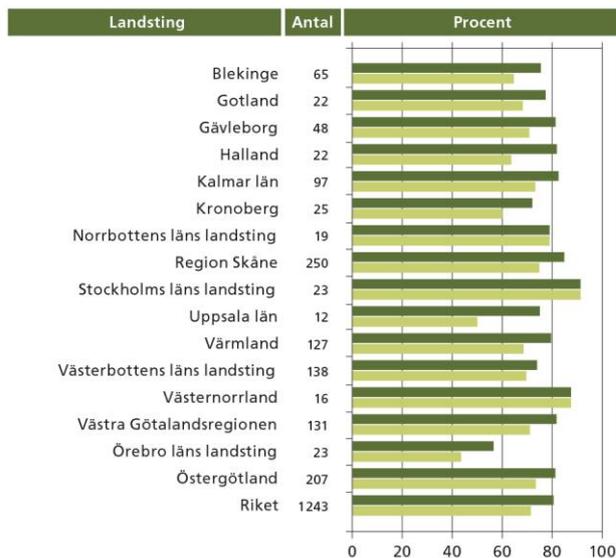
## Proportion radiographic osteoarthritis

For many years the diagnosis of osteoarthritis has been based on radiographic changes, with or without symptoms. The diagnosis is often a prerequisite for treatment initiation. The procedures surrounding osteoarthritis diagnostics has led many people with symptoms but no radiological changes to receiving no form of treatment. The Swedish Board of Health and Welfare has established in its new guidelines that osteoarthritis is to be diagnosed with the aid of the medical history and clinical examination, and that radiological examination should be used only in unclear cases, or if a specialist referral is under consideration. In BOA the diagnosis is based on the medical history and examination, and by excluding other possible causes of hip and knee problems. X-ray is not necessary.

We strive to reach patients with problems from the hip and knee as early as possible in the course of the disease to reach the best effect through life style changes and increased activity levels. The figures below (Figure 5a and 5b) show the proportions of patients in the register having been x-rayed and those with radiological findings, respectively. The trend in comparison to previous years is that fewer patients were x-rayed in 2011, but more than four of five were x-rayed upon entrance to the osteoarthritis self-management intervention with three of four showing radiological findings typical for osteoarthritis. The variations between counties are relatively large, indicating different routines in the management of patients with osteoarthritis in Sweden.

**Figure 5a. Hip.** The proportions of patients in the register having been x-rayed and those with radiological findings, respectively.

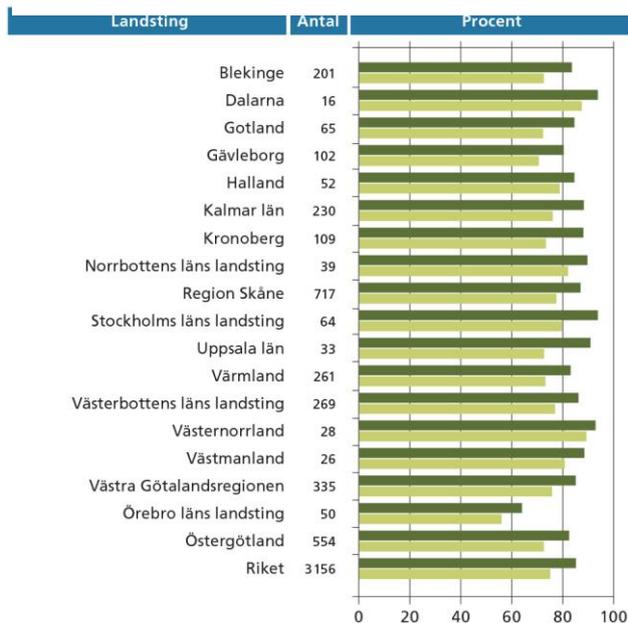
2011



■ Proportion x-rayed      ■ Proportion radiographic osteoarthritis

**Figure 5b. Knee.** The proportions of patients in the register having been x-rayed and those with radiological findings, respectively.

2011



## Charnley categories

Osteoarthritis can appear in one or several joints at the same time. Comorbidity is also very common in osteoarthritis. It is impossible to say what is the cause and effect, but inactivity-related illnesses such as diabetes, high blood pressure and cardiovascular disease are highly prevalent in patients with osteoarthritis. A more recent study has also shown that osteoarthritis implies an increased risk for early mortality, probably connected with the presence of just these inactivity-related illnesses (2).

The Charnley category is a simple way of measuring comorbidity. The Charnley category is basically calculated by means of two questions: "Have you problems from the other hip/knee?" "Have you for some other reason difficulties walking?" Charnley category A stands for unilateral problems, category B for bilateral, and category C for any other illnesses affecting walking ability. This is, of course, a rough measurement of comorbidity whereby there can be several diagnoses or problems that don't affect walking ability. However, one can say that category C patients assess themselves as less mobile than the other two. In the BOA-register 36% of the patients with OA of the hip and 34% of the knee that were included in 2011 were classified as Charnley C.

## Previous treatment

Health care providers have informed many osteoarthritis patients that nothing can be done. Patients have consequently received no treatment whatsoever other than possibly pain relief using medication. Many have tried different medicines with varying results and only a minority have been referred to a physiotherapist or other adequate non-surgical or non-pharmacological treatment. A contributing factor for this erroneous point of view among both patients and health care personnel is most likely the myths about osteoarthritis that live on, such as "natural aging" and "wear and tear". The latest decades' research now enables us to know better. There is much to be done mostly by patients themselves, with the help and support of correct advice and guidance.

## Previous treatments at the physiotherapist

Patients in the BOA-register reply to questions from the physiotherapist concerning earlier treatments. Patients can apply for the supported osteoarthritis self-management intervention directly and have thus not necessarily been in contact with health care prior to the intervention. About half the patients indicated having met a physiotherapist for their hip or knee problems before the self-management intervention. This does not, however, always imply that patients have received adequate basic treatment. According to both national and international guidelines all patients with osteoarthritis of the hip and knee should be offered information, individually adjusted training and advice on weight reduction when needed. This also comprises the evidence forming the Swedish Board of Health and Welfare's guidelines. About 50% of the patients in the BOA-register had met a physiotherapist prior to the supported osteoarthritis self-management intervention, but only 12% of the patients with hip osteoarthritis and 22% of the patients with knee osteoarthritis were offered adequate basic treatment.

## Pharmaceuticals

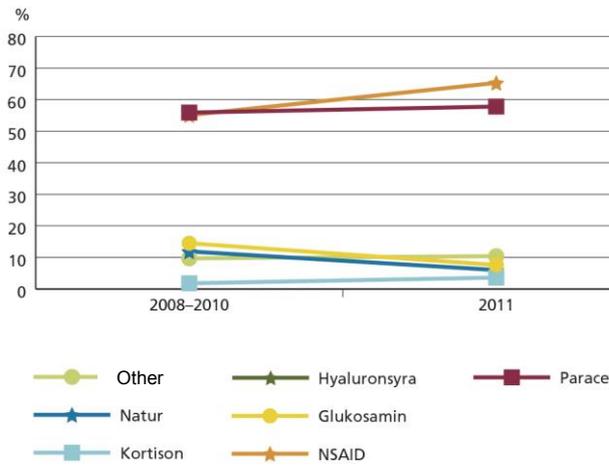
Pain reducing medication is recommended as a complementary treatment when information and physical activity are insufficient. Pharmaceuticals that stop the most intense pain can be

needed in order to remain active, and should only be used as an exception and for short periods as the only treatment. Paracetamol is recommended as the drug of choice. If insufficient, or when there are contraindications for paracetamol, non-steroid anti-inflammatory drugs (NSAID) are recommended. Glucosamine is mentioned on the “not-recommended” list in the Swedish Board of Health and Welfare’s guidelines since there are no high quality or impartial studies that have been able to show adequate effect. The same goes for hyaluronic acid. Cortisone injections can have a good but short lasting effect. A number of natural medicines claim in ads to have a good effect but there is currently only very limited evidence for these results.

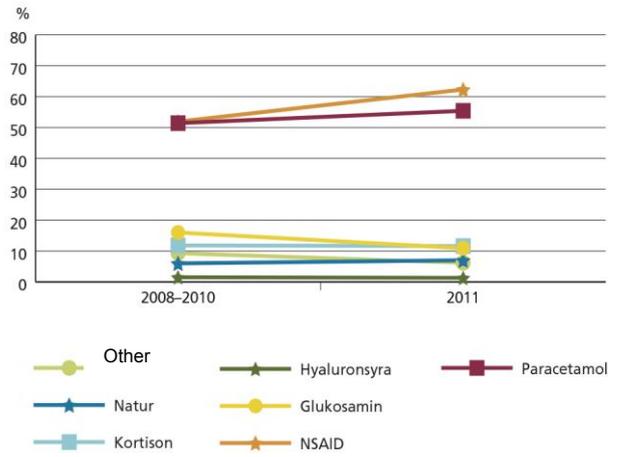
Patients themselves state in the BOA register which medications they take for their hip and knee problems. Three fourths of the patients stated in 2011 that they took some joint-related medication. Paracetamol and NSAID preparations were used regularly. The use of NSAID preparations for men has increased since last year, while women have increased their use of paracetamol. The proportion of patients that reported taking glucosamine has decreased since the previous annual report (figure 6a-7b). Cortisone injections are the most common in the knee joint since injection in the hip joint requires fluoroscopy of the joint to ensure accuracy. One of ten patients use herbal medicines. This can be valuable information since some preparations can have a negative influence on the effect of other medications. “Other” means for example Tramadol and Lederspan.

Each patient can take more than one preparation. Distribution of medication indicates the total amount of medications taken by the patients in the register. It says nothing of how many preparations are taken by each individual.

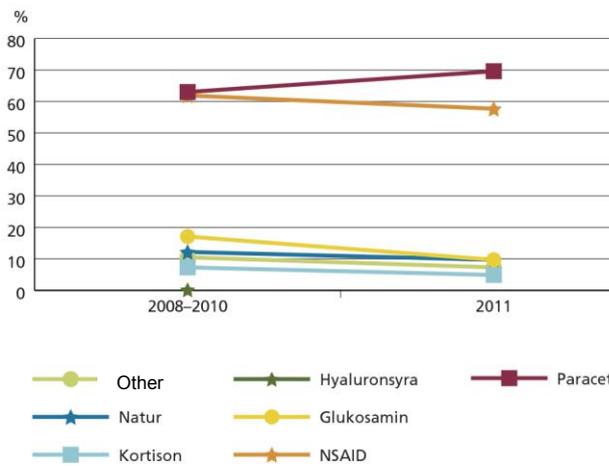
**Figure 6a. Hip.** Proportion of men who used joint-related medication.



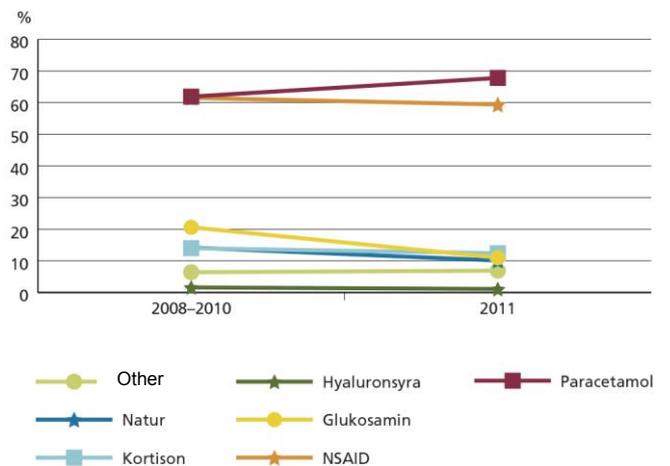
**Figure 7a. Knee.** Proportion of men who used joint-related medication.



**Figure 6b. Hip.** Proportion of women who used joint-related medication.



**Figure 7b. Knee.** Proportion of women who used joint-related medication.



## Previous surgery

In the BOA-register the physiotherapist asks the patient about previous joint-related surgery (not muscle or other soft tissue surgery) for the symptomatic as well as for the contralateral side. For knee osteoarthritis approximately every fifth patient has been operated on for the most symptomatic joint and every tenth on the opposite side. Many arthroscopies are performed on doubtful grounds and unnecessarily according to open comparisons between counties in 2009, and The Swedish Board of Health and Welfare advice against arthroscopic surgery for osteoarthritis in the national guidelines for musculoskeletal diseases/osteoarthritis. The trend is for a somewhat lesser proportion reporting that they were operated on with joint-related surgery for their knees during 2011. The proportion operated on for hip problems is less than 10%.

A third (31%) of all men in the BOA-register have reported undergoing joint surgery of the most problematic knee as opposed to 17% of the women.

## How osteoarthritis has been described to patients

Previous descriptions of osteoarthritis as "wear and tear" are ill advised since patients think of worn out joints not to be used due to fear of wearing them out through further activity. Lately research show that inactivity is a greater risk factor for osteoarthritis and poor health in connection with osteoarthritis, and that cartilage need dynamic loading such as in walking, cycling, and aerobic exercises. It is important for the patient to know what osteoarthritis is and that there is much one can do oneself to influence symptoms and function.

In the BOA-register we see that about a fifth of the patients were informed that they had worn out joints prior to the osteoarthritis intervention. Many were informed that they suffered from osteoarthritis, but did not know what this was or what to do about it. Seen from a county perspective and over time we see a tendency to a reduction of the term "wear and tear". A fifth of the patients had gained no information about their joint problems whatsoever. This can also depend on them not having been in contact with health care prior to the supported osteoarthritis self-management intervention.

## Dropouts/operated

A total of 433 patients (5.7%) had been operated before the 12-month follow-up. Operation implies total joint replacement of the hip or knee. Six hundred and fifty-four patients (8.6%) dropped out from the supported osteoarthritis self-management intervention before the 12-month follow-up for reasons other than surgery.

## Practice

All clinics delivering the supported osteoarthritis self-management programme and reporting to the BOA-register full-fill the minimal intervention in BOA. Where training is offered it should be set up according to the principles used in BOA. However, there are other possibilities for each clinic to adjust content and extent to local resources. How the osteoarthritis intervention is run at each clinic is what we call practice. Variations in practice for the different clinics can affect results. It is therefore a factor to be considered, along with for example case-mix, when interpreting the results of the intervention.

Training of muscle function is not based on a specific number of exercises, sets or repetitions,

but on neuromuscular control and movement quality. Pain during training is no obstacle but should not exceed the limit for what is considered acceptable to the patient. An eventual increase of pain after training should also be gone within 24 hours, otherwise duration and/or intensity should be adjusted. Interviews with patients have shown that feedback is experienced as a particularly important aspect of training. The physiotherapist is present and available for continuous feedback of movement quality and execution, choice of exercise and dosage on each training occasion. Home exercises and continued activity after the supported osteoarthritis self-management intervention's completion is planned, parallel to the supervised training, to stimulate continuity and a health-inducing activity level over time.

Not all clinics have access to training equipment and thus cannot offer training. Others have chosen to focus on information alone and can then have a greater flow of patients. Not all clinics have established cooperation with a local patient organisation and can thus have difficulties offering the services of an osteoarthritis communicator. Some clinics work with other professionals such as occupational therapists or dieticians within the sphere of the supported osteoarthritis self-management intervention. Other factors that may vary between clinics are patient flow, number of involved lecturers, length and number of sessions per programme.

1. Hubertsson, et al, Risk of sick leave and disability pension in working-age women and men with knee osteoarthritis , *Ann Rheum Dis*, in press
2. Nuesch, E., et al., *All cause and disease specific mortality in patients with knee or hip osteoarthritis: population based cohort study*. *BMJ*, 2011. 342: p. d1165.

## Participation and reporting

To determine whether results from the register are representative and generalizable it is important that the register covers the intended population. Coverage for the BOA-register can be described as the number of participants in the OA programme reported to the register or how many of all those diagnosed with hip and knee OA are registered, depending on whether the BOA register is considered an intervention or diagnosis register. The goal is for all patients undergoing OA programme to be registered, and that all patients with hip and knee OA shall be offered Supporting self-management of OA programme as early as possible.

### Geographic coverage

The number of OA programmes having reported patients to the BOA register has increased from 39 in 2010 to 80 in 2011. More units are linked, but, had not as of the beginning of 2011, registered patients (Table 13 "Units not having registered"). Even the number of county councils/regions with OA programmes reporting to the register have increased from 11 to 18, out of a total of 21. During 2012 all county councils/regions consisted of at least one unit reporting to the register.

At the end of 2012 the BOA register will have trained approximately 1 200 physiotherapists and occupational therapists in the supported OA programme and register skills. At the time of compiling the annual report (June 2012) there were 200 units connected to the register .

The BOA register is chiefly an intervention register. Adequate coverage implies that all active OA programmes report to the register. There is, however, no systematic means for checking the number of OA programmes, and it is difficult to estimate how many are active but not reporting. In Skåne physiotherapists Malin Jönsson-Lundgren and Therese Jönsson along with administrator Pernilla Lindström mapped the number and location of units operating OA programmes and reporting to the BOA register. In March 2012 there were 26 units in Skåne reporting to the BOA register.

### Prevalence of Osteoarthritis (OA) in the population

It is difficult to estimate the prevalence of OA. Approximately 15% of the population under 60 are estimated having knee problems such as those associated with OA, and that the majority develop radiographic changes in time. OA of the hip joint is not as common, while hand and finger joint OA, or OA of the spinal joints is much more common. About 40% of the population are over 55 and more than half of those over 70 are estimated to have OA in some joint. The diagnosis is made in several ways, depending on symptoms, radiological findings or both. Radiological classification varies as well, such as limit value selection or OA criteria. Symptoms arise often long before it is possible to radiologically verify the diagnosis. We know, moreover, that only a minority of all those with an OA diagnosis seek health care and consultations in primary health care are not routinely reported. According to the National Board of Health and Welfare's national guidelines for OA the diagnosis should be made with the aid of the medical history, usual symptoms and typical clinical findings. Radiological examination should be used only when considering a specialist referral.

Many have inaccurately received the information that OA is a matter of aging, worn out joints, with nothing to be done but undergo surgery when symptoms becomes too troublesome. However, we know that it is but a minority of those with OA that become candidates for implant surgery. Based on studies we can assume that about 10–15% of all those with the diagnosis of OA ever develop difficulties requiring surgery. According to the

Swedish hip arthroplasty register and the knee arthroplasty register, approximately 30 000 implant operations are performed on the hip and knee yearly in Sweden. The Swedish National Board of Health suggests that an indicator of good care should be that as many patients as possible with a joint implant due to OA shall have completed self-management of OA programme prior to surgery. The yearly base for OA programmes is thus at least 30 000 patients. Self-management of OA programmes should be introduced as soon as symptoms appear. During 2011 circa 4 400 patients that attended OA programmes were registered, which corresponds to circa 15% of all those operated on in one year.

## Number of patients seeking healthcare for knee and hip OA

Due to the lack of reliable data for the number of individuals with hip and knee OA (Diagnosis code M16 and M17) within primary care on a national level, we have chosen to ask a selection of county councils/regions to present data for a number of patients with the diagnosis codes M16 and M17 from regional health care databases. Some OA patients seek care several times per year, while others do so sporadically or not at all. In order to collect as many individuals with hip and knee OA as possible we have requested data on the number of unique individuals that have at some time sought primary care during a five-year period (2007–2011).

Statistics from health care databases in Stockholm show that 43 897 unique individuals with OA of the hip or knee as primary diagnosis generating at least one visit to primary care during the period 2007–2011. This corresponds to 5.3% of the population over 45. In Dalarna 12 516 persons, or 9.1% of the 45-year-old population, visited primary care with the diagnosis hip and knee OA during the period of 2007–2011. The number of persons seeking primary care in Dalarna due to hip and knee OA have principally doubled during the period, from 2 799 to 5 326. In Östergötland 21 235 individuals consulted open care some time during 2007–2011 with the diagnosis hip and knee OA as either primary or secondary diagnosis. This corresponds to 11.1% of the population over 45 years of age.

In Region Västra Götaland 22 284 individuals made 61 825 visits to primary care during 2007–2011 with hip OA as the primary diagnosis. The corresponding number for OA of the knee was 38 958 individuals and 117 567 visits. 61 242 individuals made 179 392 visits during a five year period. This corresponds to 8.8% of the population over 45.

The 31<sup>st</sup> of December 2011, 4 203 439 people in Sweden were older than 45, according to Statistics Sweden. Stockholm, Dalarna, Östergötland and Västra Götaland together comprised 44% of the population in this age group. If we assume that the number of individuals with OA of the hip and knee are distributed somewhat similarly to the population we can also assume that the combined number of individuals in these four county councils/regions (138 890) represent circa 45% of the OA population of Sweden. Our simple estimates would then approximate the total "OA- population" seeking primary care in Sweden at least once during a five year period to roughly 308 600 persons, or about 7% of the population. This appears reasonable when considering the statistics from the different county councils/regions.

The BOA-register as yet encompasses only four year's of operations, where the first two years consisted of pilot operations. During these four years activities have been gradually built up, and the capacity to manage patients has increased. Thus far, 7 607 patients have completed the

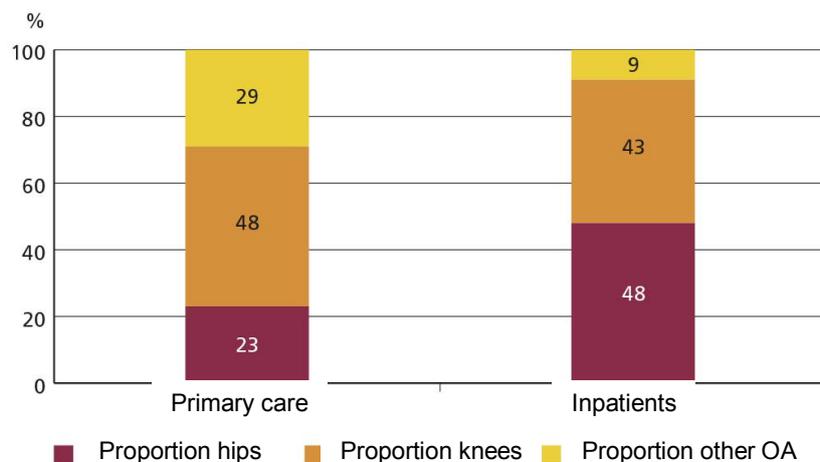
supporting self-management of OA programme, corresponding to 2.5% of the “OA population”. If we instead assume that we, in five years, had had the current yearly capacity of 2011 of about 4 400 patients, we would have reached 22 000 patients in five years, or 7% of all those seeking primary care with the diagnosis of OA of the hip or knee.

## Care needs

The need for supported self-management of OA programmes varies from county council to county council due to a varying population base. Based on estimates of how large a proportion of the population over 45 years with OA and the number of units per county council connected to the BOA register, “patient pressure” per unit can then be calculated (Table 4 “Coverage”). It is difficult to estimate how many of all those that seek primary care with the diagnosis OA of the hip and knee require self-management of OA programme, but the need is considerably larger than the current capacity, indicated by the table “coverage”. The need for early management and non-surgical treatment has also been pointed out in an article recently published in the Lancet, where it was confirmed that the number of knee replacements are increasing yearly in several countries, and are being performed on younger and younger individuals. With an aging and more overweight population the demand for implant surgery will increase all the more (1). Implant surgery is in most cases an excellent treatment, but recent studies have shown that many patients operated with hip and knee implants still have pain following surgery. A new review article showed that between 7% and 23% felt they still had significant pain after hip replacement surgery and between 10% and 34% following knee replacement surgery (2). The authors convey a great need for information, whereby many have unrealistic expectations and/or are operated for doubtful indications. There is also a need to identify factors influencing outcomes. This is one of BOA’ objectives, and in the future linkage the BOA register with the hip and knee register can contribute to increased knowledge of when treatments succeed and for whom.

Proportionately more patients with hip OA are implant operated. The numbers from Stockholm County show that the greatest proportion of OA inpatients have OA of the hip, while patients with OA of the knee and other joints make up the majority within primary care. OA of the knee makes up 48% of all OA-related visits to primary care in Stockholm county, while OA of the hip comprises 23%. Within inpatient care, on the other hand, OA of the knee corresponds to 43% of all OA-related visits, while hips represent 48% (Figure 8).

**Figure 8.** Proportion of patients with OA diagnosis in primary and secondary care in Stockholm County

**Figur 27.** Fördelning av artrosdiagnoser i öppen respektive slutenvård i Stockholms län.**Table 4. Coverage**

County councils	Number of inhabitant >45 years	Assumed number of patients seeking primary care with OA in hip and knee (7%)	Number of units per county council	Assumed number of persons with OA per unit
Västerbotten	116 379	8 147	13	626
Blekinge	73 933	5 175	6	862
Gävleborg	136 512	9 556	9	1 061
Kalmar	117 099	8 197	7	1 170
Norrbottn	123 153	8 621	7	1 231
Värmland	134 492	9 414	7	1 344
Halland	139 389	9 757	7	1 393
Skåne	544 835	38 138	25	1 525
Gotland	28 951	2 027	1	2 026
Västra Götaland	695 826	48 708	17	2 865
Kronoberg	84 487	5 914	2	2 957
Uppsala	141 778	9 924	3	3 308
Östergötland	192 153	13 451	4	3 362
Västernorrland	119 508	8 366	2	4 182
Västmanland	118 844	8 319	1	8 319
Örebro	128 825	9 018	1	9 017
Dalarna	137 415	9 619	1	9 619
Stockholm	826 471	57 853	4	14 463

The table show number of connected units to BOA register per county councils at the end of 2011 (note that not all units had reported patients to the register). Number of inhabitants 45 years old and older the 31<sup>st</sup> of December 2011 according to Statistics Sweden. Number of patients seeking healthcare for OA is based on statistics from health care databases in Stockholm, Dalarna, Östergötland and Västra Götaland, which show that 7% of the population seeks primary care due to OA of the hip or knee. Number of patients per BOA unit is estimated by dividing number of care-seeking patient with number of units.



## Validating data

The risk for incorrect data entries increases due to the several stages involved in data collection. The BOA register strives toward minimising the sources of error and has created routines for providing users the opportunity to check and correct their data. Thanks to the fact that participating units themselves use the data fed into the register the probability of eventual incorrect entries being revealed, corrected and thereby improved also increases as does the quality of the register's data.

The majority of the data in the BOA register is based on patient-reported outcomes. The PT answers questions concerning previous examinations and treatment, as well as adherence to the intervention. So-called "objective" measurements have long been based on measurements taken and interpreted by health care personnel. There are several studies showing that "objective data" is not always in agreement with the patient's opinion. Providing the patient with a possibility to mark on a scale or enter a check in a questionnaire can consequently be considered more "objective" if concerning the patient's feelings.

The patient completes a questionnaire at the PT reception on the first visit and on a follow-up visit after 3 months. Responses are fed into the register by the PT, or in some cases by the administrative personnel. We hope that within the foreseeable future we will be able to retain patient reported data in the register in a legally correct manner without intermediaries by having the patient respond directly on a touch screen. Touch screens also increase the likelihood of all being answered, since a response is required in order to move on to the following question in the questionnaire.

### Response rates and "missing values"

The BOA register currently enjoys a high response rate for all questions. The question with the highest proportion of missing values, having been left unanswered by 2.8% of the first consultation patients, is the question "Have you been on sick leave during the last year due to your hip/knee problems?". There can be several reasons for this, but the most probable is that patients are unsure as to whether sick leave was related to their joint problems or to something else. For PTs the question of which joint-related medication the patient takes is the one most frequently left unanswered (2.8%). A probable reason for this can be that the PT lacks access to patient medical records and are unsure of which medication patients are taking. At the three-month follow-up 98% of the patients answered all questions in the patient questionnaire. For the PT the question of medication remains the greatest source of missing values, even if only 3.9% of the cases are missing.

At the one-year follow-up the questionnaire is sent to the patient. Of the 1 518 one-year follow-ups sent during 2011, 89.7% were returned first after a reminder. 95% of these were answered. The question most often left unanswered at the one-year follow-up was "Do you have problems with your other hip/knee"?

### Data quality

There are certain limit values for input to the register. The values beyond these regions cannot be entered. In other cases quality controls can be made by means of descriptive reports. It is currently possible for each unit to fetch their own reports online in real time. By processing data the possibility for identifying incorrect data increases.

Prior to the production of the 2011 annual report a number of controls of entered data were carried out to confirm data quality. "Impossible" dates (such as consultations in the 1900s), extreme values (for example height under one meter) and missing values were identified and examined in more detail, whereupon those units that had registered the incorrect data were contacted and given the possibility of correcting their data. Some of the data, for some reason, could not be corrected, that is, 195 individuals with extreme or missing dates, and 9 that lacked information for the most troublesome joint. These were removed from the data set before consolidating the annual report.

Control of the data quality will be routinely carried out twice yearly from 2012. Eventual incorrect entries are mailed to respective units before summer and Christmas holidays, when activities at the physiotherapy reception is usually slower and time available to check and correct and data.

## BOA and improvement efforts

The BOA register is the first National Quality register fully based on a physiotherapeutic intervention. Physiotherapists (PTs) report to the register. It is also largely the PT's area of operations that can be quality improved through feedback from the results of the efforts of clinical improvement.

### Education in register and improvement skills

Effectiveness is not only a catchword within healthcare. It is important to put time and resources into effective measures, that is, methods capable of producing as desired and optimal effects as possible in relation to conveyed costs. Simply expressed, a costly and resource-intensive treatment should provide better results than a cheaper one to motivate the use of greater resources. The result, on the other hand, must not necessarily be immediately noticeable, but may have to be evaluated during an extended period of time, for example by means of gradually reduced care needs or illness absence.

Within health care in general and perhaps physiotherapy in particular focus has often been on production; "points and money". The results of the PT's contribution have not been systematically evaluated on a group level. Which is why PTs have had no strong means (numbers) of argumentation for the retention of their services in times of resource cutbacks.

Swedish healthcare should treat all equally and build on science and proven experience. Many current physiotherapy treatments are not scientifically documented. This does not imply that they have no effect, but only that they have not been systematically evaluated. Physiotherapy is strongly based on proven experience, leading to national variations.

As for OA of the hip and knee, there is considerable evidence for the effects of information/knowledge and adjusted physical activity (as presented in OA programmes). It is relatively inexpensive with little risk for side effects and can thus be recommended despite modest results on a group level. The effect can vary for individuals, and it is not presently possible to predict who will gain the most benefit of OA programme or who will need to complement it in the form of analgesics, technical aids or surgery.

BOA trains PTs and occupational therapists (OTs) to present and evaluate OA programme in a

uniform manner. Whereby all units within the BOA register have a common denominator, so-called minimal intervention, we have the possibility to systematically gather patient reported outcomes and study the total results. This provides the unique possibility to evaluate our activities and show treatment results directly from daily clinical activities. We also have the possibility, by means of the large number of patients, to study subgroups of patients in order to identify those gaining the greatest benefit of the treatment. This knowledge can, via the quality register, be returned to health care to further effectiveness, so that the right treatment is given to the right patient.

The use of National Quality registers in clinical practice is new to PTs. There is a need for increased knowledge of the potential of quality registers in health care and improvement skills, both on an undergraduate level and for clinically active physiotherapists. For a register to benefit patients at an individual clinic, time is required for PTs to report to the register, study results, and reflect on possible areas of improvement. BOA has now provided us with the possibility of spreading practical improvement skills. We arrange one-day courses both on a commission and in-house basis to increase the number of units reporting to the BOA register, and to increase the use of internal results within an organisation. The units' use of internal results eases the uncovering of eventual entry errors thereby improving the quality of the data.

## Regional network

Due to the work of adjusting structure and organisation to the rapidly growing number of units in the register, regional networks and contacts become all the more significant. There are possibilities within these networks to discuss both pressing questions from the users, as well as provide support and exchange experiences of OA programme and the register.

### Network Skåne

During the fall of 2011 Malin Jönsson-Lundgren and Therese Jönsson along with administrator Pernilla Lindström mailed to PTs and OTs that had taken the course in the supported OA programme to determine the number of OA programmes not reporting results to the BOA-register in Skåne and neighbouring counties. There was contact data in the register for a total of 130 persons at 70 units. In many cases data was out of date and responses were retained from only 18 units. The BOA-register showed that there were 26 units in the region linked to BOA in March 2012. OA programmes reporting to the register are still sparse in the Southeastern parts of Skåne. It is, however, unclear whether there are OA programmes not reporting to the register.

The first network meeting was held in Skåne in March 2012. Invited also were therapists responsible for OA programmes, but who had not yet begun reporting to the BOA register. The invitation was sent to a total of 68 units based on a compilation from last autumn's survey. Eighteen units (11 that report to the BOA register and 7 not yet connected) participated in the network meeting. The meeting was primarily a discussion of the work with OA programmes and further development of our network. Most were underway with reporting and thought it functioned well. The greatest "obstacle" according to participants was finding the time to follow up the quality of their data. Those that had not as yet begun reporting were unsure of the needed time.

It was decided at the meeting that Malin along with Pernilla would begin supporting each unit by reviewing the data and providing feedback. All participants gave their mandate to have

their data reviewed. It was also decided to arrange a new network meeting in the fall of 2012 but to extend it to a half or full day, which would allow time for a guest speaker. There was also a request to arrange a register skills day in Skåne in the fall. It was a popular meeting that would hopefully lead to increased cooperation and an exchange of knowledge.

## Network Värmland

There has been a network of slightly more than 40 physiotherapists in Värmland since 2008 working with OA programmes and pre- and postoperative physiotherapy for implant surgery patients. Physiotherapists within the network are active within both the private and public sectors. There are usually about 15 people at these meetings that meet a few half days each term, maintain contact through the mail by means of a mailing list and website:

[www.liv.se/artrosskolor](http://www.liv.se/artrosskolor). The network has collaborated on care programs and routines, which have been published at: [www.liv.se/vardprogram](http://www.liv.se/vardprogram).

The contents of a simple, new information flyer was discussed at the March 2012 information meeting for physiotherapists in Arvika. Discussions took place concerning the postoperative routines that were written, the work of recruiting expert patients to the OA programmes throughout the county, the National Board of Health and Welfare's new preliminary guidelines for OA and the scientific articles forming the basis for training recommendations. Maria Klässbo convened the meetings, booked rooms, ordered refreshments, and wrote notices. The task of taking notes was passed around to the participants.

## Occupational therapists in BOA

Throughout the country teams of PTs and occupational therapists cooperate in Supporting self-management of OA. By utilising knowledge and neuromuscular function both in training situations and activities of daily living beneficial loading and movement patterns gain an even greater importance. The occupational therapist (OT) thus has a significant role in the OA programme for hips and knees. A significant proportion of patients with OA have symptoms from their hand and finger joints. Of those registered in BOA for OA of the hip and knee we see that somewhat less than four of ten also report hand symptoms. Many patients have only OA of the hands.

Available research concerning first and foremost basic treatment of OA has focused chiefly on OA of the knee. OA of the hip has been sparsely researched and only a small proportion of all OA research deals with OA of the hand. There is, however, good reason to believe that patients with OA of the hands benefit from information on what OA is and how one can manage everyday life. They are therefore welcome to the Supporting self-management of OA, but we have not as yet registered patients with OA solely of the hands. Since the fall of 2011 a group of OTs have been working with the task of finding methods of evaluation suitable for use in the BOA register for assessing the effect of self-management of OA programme and adjusted training for OA of the hands. Even the design of a hand training program and the contents of osteoarthritis programme are being discussed from the perspective of hand osteoarthritis. The goal is to create a "hand-module" for BOA and for occupational therapists to report to the register as well.

## BOA in Denmark

The Supporting self-management of OA has crossed the border to Denmark. A Danish colleague, Sören Thorgaard Skou, participated in teaching at the OA programme and has since then translated the concept to Danish. Pilot activities for the OA programme have been tested

at the orthopaedic surgical research unit at Århus hospital in Danmark as a preventive means of keeping people over 55 at work. Results were very satisfactory so that there are now plans to spread the concept throughout Denmark. The OA hip programme of the Värmland County model has also been translated to Danish and evaluated in studies by Erik Poulsen (1). In Denmark BOA is called GLAD instead – Godt Liv med Artrose in Denmark or A good life with OsteoArthritis. In Denmark a national steering group has been appointed, and training for Danish physiotherapists is being planned with Swedish cooperation.

1. Poulsen E, et al. Non-surgical treatment of hip osteoarthritis. Hip school, with or without the addition of manual therapy, in comparison to a minimal control intervention: protocol for a three-armed randomized clinical trial. BMC Musculoskeletal Dis 2011;12:88

# The Swedish National Board of Health and Welfare's guidelines and BOA

The Swedish National Board of Health and Welfare's national guidelines for musculoskeletal diseases, including OA, was published in May 2012. They are meant to contribute to just and equal health care throughout the country.

## New guidelines for musculoskeletal diseases /OA

The Swedish National Board of Health and Welfare's national guidelines are to provide support in choosing priorities and provide guidance for choosing treatments and methods health care and social welfare organizations should place their resources. The guidelines contain recommendations for the diagnostics, treatment, and rehabilitation of musculoskeletal disorders. They shed light on areas where the need for guidance is great due to a lack of consensus, controversial issues or a need for quality development. The objective is to aid health care in the effective use of its resources, distribute them equally based on need, governed by systematic and open priorities. The aim is also to enable quality care for patients. The recommendations provide guidance for decisions on a group level. They also indirectly provide guidance and support for decisions affecting individuals, although there can, of course, be situations that motivate health care personnel to depart from the recommendations. The Swedish National Board of Health and Welfare's recommendations are a result of a collective assessment of:

- The seriousness of the condition
- The utility of the intervention for the condition (effect)
- The evidence for the effect (the strength of the scientific evidence)
- The cost effectiveness of the intervention (compared to other interventions or no intervention whatsoever)

## Guidelines for OA

The guidelines recommend that health care should diagnose with the aid of an overall assessment of the medical history, three common symptoms and three typical clinical findings. Usual symptoms for OA are pain, stiffness following inactivity and reduced function. Examples of typical findings of a knee examination are crepitations (a crackling sound that can be heard in a joint with OA), reduced range of motion and swelling. A hip examination can reveal clinical findings such as limited flexion and internal rotation as well as pain in internal rotation. Radiological examination is used when despite an adequate history, examination and assessment of clinical findings there is uncertainty as to the cause of the symptoms, or when a specialist referral is under consideration. Arthroscopy and MRI should not be used for diagnostic purposes.

Periodic, supervised, long term training is recommended for OA of the hip or knee. The Swedish National Board of Health and Welfare recommends that health care not treat OA of the hip or knee with glucosamine or hyaluronan. These substances have no effect on pain or

joint function. Furthermore, the Swedish National Board of Health and Welfare holds the view that health care should *not* perform arthroscopic surgery in the form of joint debridement with meniscal resection for OA of the knee joint. Arthroscopy has no better effect on pain and function than training and analgesics in the treatment of OA. (1).

### Indicators of good care

Further, the Swedish National Board of Health and Welfare suggests that an indicator of good care of OA should be the proportion of persons that have been educated, received supervised training and advice concerning weight reduction, that is to say the treatment offered in OA programmes. The Swedish National Board of Health and Welfare has described this indicator as a development indicator and writes: "There is currently a lack of data sources to development indicators for the continual follow-up, on a national level. However, there may be other conditions on a regional and local level, and certain development indicators can be currently followed within the frame of some quality registers. In order to provide for a continual follow-up of development indicators it is of the utmost importance to have a targeted focus on the development of a modern system for quality follow-up, where data can be systematically entered into the system of medical records. Data should then be automatically accessible to diverse follow-up systems. Data necessary for tracking indicators should also be placed in existing or future quality registers." (1)

### Economic consequences

The guidelines state further that "The Swedish National Board of Health and Welfare estimates that recommendations for physical training for OA will lead to some degree of increased costs to health care, even if the measures are relatively inexpensive. The recommendations will probably imply that more patients will be offered physical training than at the present, demanding resources in the form of physiotherapeutic competence. Cost increases will most likely vary between regions." (1)

On the other hand the Swedish National Board of Health and Welfare implies that millions can be saved yearly by not treating with glucosamine or hyaluronan, or the use of arthroscopic surgery. Compliance to the guidelines for OA can result in an overall yearly saving of between 20 and 25 million SEK.

### BOA and the guidelines

Care of patients with osteoarthritis according to the BOA concept follows the Swedish National Board of Health and Welfare's guidelines. Patients under care within BOA need no X-ray confirmed diagnosis but are to be assessed according to symptoms, clinical findings and medical history. OA programme offers education, individually adjusted training and advice on weight reduction. A home exercise program and other alternatives to maintain continuity for long term training are also introduced during OA programme. The significance of being continually physically active is emphasised throughout patient education. Through reports to the BOA register the proportion of patients offered education, supervised training and advice on weight reduction can be measured, thus providing the clinic a measurement of the indicator for good care in OA.

1. Nationella riktlinjer för rörelseorganens sjukdomar 2012. Socialstyrelsen.  
[www.socialstyrelsen.se](http://www.socialstyrelsen.se)



## Discussion

### Osteoarthritis is a public health problem

Our estimates show that about 7% of the population over 45 with a diagnosis of OA of the hip or knee as primary diagnosis seek primary care. This is probably an underestimate of both the incidence of OA and the proportion of persons seeking care due to problems related to OA. Studies from Region Skåne show that only 10% of all those over 18 and 27% of those over 65 with a diagnosis of OA in some extremity joint consult a physician (1). Moreover many have problems for years before the diagnosis is established.

### Supporting self-management of OA follows the Swedish National Board of Health and Welfare's national guidelines for OA

The Swedish National Board of Health and Welfare's guidelines for OA published in May 2012 state that the OA diagnosis should be made by means of the medical history and clinical examination, and that patients with OA of the hip and knee should be offered regular supervised and continual training. Radiological examinations should only be used in uncertain cases or where a specialist consultation is being considered. An indicator for good care for OA is the proportion of patients with OA that have been educated and received supervised training and advice on weight reduction. Clinics that offer patients with clinically verified OA of the hip and knee OA programme and report to the BOA register thus follow the national guidelines.

It is satisfying to note that there is a tendency toward change in the choice of words concerning OA. It remains that about 20 % of patients have been given the explanation that they have worn out joints, but the percentage has decreased by a few per cent compared to figures in the previous annual report. Describing OA as wear and tear is misleading causing many patients to believe that they wear out their joints even more if they train or load their joints. In direct contrast, cartilage needs dynamic loading, and adjusted training is the best treatment for OA. OA should be described as a disease that can affect the complete joint and is called osteoarthritis. Patients should also know that the joint can recover, that the prognosis is good in most cases and that there is much they can do themselves to feel well despite having OA.

### Effect of supporting self-management of OA programme

The OA programme reduces pain and improves quality of life for patients with OA of the hip and knee. The effects are somewhat similar for the hip and knee, but patients with hip problems are slightly worse off stating more problems at the primary consultation. The proportion reporting daily or constant pain is lowered by about 15% after three months and remains so at one year. Pain intensity is estimated on a visual analogue scale (VAS) from 0 (no pain) to 100 (worst imaginable pain). A change of 10 is considered, in most cases, clinically significant. An average group level reduction of VAS pain by 9 after three months and 7 after one year can be observed in the BOA register for patients with OA of the hip.

Patients with knee OA report an average reduction of 10 after 3 months and 9 after one year. Feedback from results and quality improvement at the individual clinics provide strong possibilities for further improvement of the total result. A reduction of pain could mean patients needing less care, analgesics, and sick leave, which could lead to significant health economic effects. These results say nothing of individual variations of the results. In order to further study which patients gain the greatest advantage of OA programme and possible health economic effects further studies and linkage with, for example, health care databases, The National Pharmaceutical Register and the Swedish Social Insurance Agency are necessary.

Interestingly, there is an increase in self-efficacy directly after self-management of OA programme which, however, completely disappears after one year, leaving patients with a worse status than at the primary consultation. A possible explanation could be that the patients had difficulties maintaining their activity levels and coping strategies on their own. The three months of advice and support provided by OA programme can be, for some, too short for a lasting change in life style.

The evaluation instrument ASES-S used for measuring self-efficacy has been tested for patients with either arthrosis or arthritis. However, the instrument has its weakness and many patients experience difficulties in estimating their ability by means of the questions in the ASES. The visible changes can thus partially depend on the evaluation instrument's construction. Eventual factors influencing both self-efficacy and other outcome measures should be analysed in detail in separate studies.

## Comorbidity

It is difficult to achieve a clinically significant and lasting change on a group level. Many patients have other illnesses and conditions influencing their pain, function and health related quality of life. Comorbidity is very common in OA, particularly for those over 65. Roughly a third of patients in the BOA register are classified as Charnley category C, that is to say lowered walking ability for reasons other than osteoarthritis of the hip and knee. Health related quality of life can thus be influenced by these other causes and illnesses as well. Supporting self-management of OA may have a positive effect on hip and knee problems, but cannot be assumed to influence other conditions to the same degree. However, the recommendation to be physically active is an essential part of the treatment of practically all medical conditions and is included as a part of all of the Swedish National Board of Health and Welfare's guidelines.

## Physical activity

Osteoarthritis is one of the most common causes of inactivity among the elderly and the fear that activity will damage the joints most likely contributes to this inactivity. We see, in the BOA register, that four of ten, practically every other patient, fears that the joint will be injured by physical activity when they come to self-management of OA programme. Men are more concerned than women that the joint will be damaged. Results show that only every fifth person with OA of the knee and every sixth with OA of the hip are physically active on a level sufficient to prevent poor health, and that this level is more or less constant over time. An interesting Swedish study shows that physical activity/inactivity is not the same as physical condition (cardiovascular fitness) (2). Inactivity and physical condition each influence the risk for cardiovascular related disease. This implies that intensive training three days weekly is not sufficient for avoiding poor health if one sits still the remainder of the time, and vice versa, that a life with many short sequences of activity can have positive effects even if aerobic

capacity is not that good. To avoid sitting still thus appears to be at least as important as training to increase aerobic capacity. This is interesting, since it is easier for someone who has not been active to introduce short sequences of activity in their daily lives, and find the motivation to stand up now and again, compared to initiating longer and more intensive training sessions. Increased physical activity levels are reported by practically every other patient at three months. Patients with OA of the knee have, to a slightly greater extent, increased their activity level. Since the question is posed with regard to change the last three months (and not since the start of self-management of OA programme) we cannot draw any definite conclusions from the question at the one-year follow-up, and cannot therefore say whether those positive results remain over time. Neither do we take consideration to previous activity levels. A patient that is already active at a sufficiently high level to maintain good health may not increase his/her activity level and therefore won't contribute to the reported statistics.

A larger proportion of the patients during 2011 compared with the previous year describe having increased their physical activity levels in three months. The proportion stating they train at least once a week increase after OA programme and the results remain over time. Two thirds of the patients report that they train to such an extent that they get out of breath and sweat at least once weekly after OA programme. An increased activity level has significantly positive effects on health and can lead to reduced needs for health care, and consequently large gains to both individuals and health care. During 2012 we adjusted the questions on physical activity in the BOA register somewhat so that they now completely agree with the Swedish National Board of Health and Welfare's formulations in the national guidelines for disease preventive methods 2011. We also put forth a question on tobacco, taken from the same guidelines.

## The proportion seeking surgery

Many patients incorrectly believe that surgery is the only treatment for OA and that arthritic hip and knee joints must be replaced by new joints sooner or later. They then want surgery as soon as possible to get the most out of their new joint. This attitude can create false expectations of surgical results. A joint implant can have limitations compared to a natural joint, and function in an implanted joint can never be the same as in a healthy joint. A review article published in the spring of 2012 showed a trend that those operated both in Sweden and other European countries are all the more younger (1). Younger individuals often have higher demands on activity and live a more active life. The risk that the implant won't live up to patient expectations or will wear out mechanically due to excessive activity increases. Replacing an implant is a much larger intervention than initial hip replacement. Measures to postpone an eventual operation can thus reduce the risk for reoperation. The proportion of patients desiring surgery is reduced after self-management of OA programme. The greatest change is seen in patients with OA of the knee, where the proportion after one year is still less than before OA programme. As for hips an increase of the proportion desiring surgery between three months and one year can be seen. A study from the orthopaedic clinic in Umeå shows a slight increase of the proportion operated between three months and one year, but that the proportion satisfied after OA programme thereafter is relatively constant. This study also showed that patients under 60 have the greatest benefit of self-management of OA programme, but those older have a greater need for surgery. In the BOA register we have not studied how age affects outcome. However, it is noteworthy that men desire surgery to a considerably greater extent than women in all three situations.

## Treatment compliance

Supporting self-management of OA is based foremost on information and education aimed to provide patients with OA knowledge of the nature of OA and what they themselves can do to reduce their difficulties. Knowledge of the effects of training/inactivity, how to train and tips of what can be done to increase activity levels make up the central part of the programme. The significance of reducing overweight is also discussed and illuminated, but to a lesser extent and only theoretically. To increase activity levels and lose weight implies a life style change for most patients with OA. To change habits demands motivation and determination. To change two things in life at the same time is extremely demanding. We therefore, in BOA, choose to focus on one life style change – activity increase. There are several studies showing that, from a health viewpoint, it is better to be well trained and overweight than untrained and thin. The practical section of the education is based on individually adjusted physical activity and is selectable for patients. Eighty-five per cent of patient choose an individually adjusted training program and 65% participate in supervised training. Those that do not make an active choice to train can either be currently involved in well-functioning training, or for different reasons are not motivated or lack the possibility to participate. In the north, or in the islands, geographical factors make patients choose to train on their own. Difficulties getting away from work at the times offered for supervised training can also cause training to take place largely at home or at the gym. It may also depend on some clinics not offering supervised training. Units with a very high percentage of patients participating in supervised training may have well motivated patients, but it can also be an effect of training being obligatory, ordered by the physiotherapist. Many patients do what the PT says, but are not always internally motivated to permanent activity increase. Whether freedom of choice or point in time for the introduction of training influences compliance and motivation to training over time is an interesting question for coming analyses of the results.

## OA diagnostics

It has long been common practice to diagnose based on the simultaneous occurrence of radiological changes and symptoms. It can take many years from the first symptoms until OA changes are radiologically detectable, and agreement between symptoms and radiological changes is weak. This leads, in many cases to unnecessary examinations, uncertainty for both health care and patient, and patients being sent home with no further treatment. The new guidelines from the Swedish National Board of Health and Welfare state, however, that the diagnosis can be made without radiological examination in most cases, which provides the opportunity for an earlier diagnosis and intervention. A large proportion coming to self-management of OA programme have been previously X-rayed and about just as many show radiological changes. This can be a sign that patients do not seek or are referred to treatment relatively late in the illness process. The average number of patients in the register partially indicates the same thing. Our goal is to reach patients early in the disease process, when knowledge and life style changes can be expected to have the greatest effect on both symptoms, health-related quality of life and activity levels. The greatest proportion of patients are X-rayed in Stockholm county (over 90%), while less than half the patients in Örebro have undergone radiological examination before attending OA programme. This should be taken into consideration when interpreting results.

Open comparisons claim that a large proportion of knee arthroscopy in those over 40 are performed on doubtful indications. This has been taken up in the media during the last year and has gained recognition in the Swedish National Health and Welfare national guidelines.

We see in the BOA register that the proportion of joint-related operations before self-management of OA programme has been slightly reduced compared to the previous annual report (20% for 2011 compared with 22% for 2008–2010). The proportion of men that undergo operations is nearly twice as large as the proportion of women.

## Gender differences

Gender differences are not presented in a separate chapter in this annual report. The proportions of women in the BOA register are 70% with OA of the hip and 72% with OA of the knee. This is in good agreement with gender distribution in a number of epidemiological studies. A comparison of characteristics for men and women at the primary consultation prior to OA programme shows no differences in age or BMI. Women have more problems from their hands and finger joints (49% compared with 25% for men). The men are more often classified as Charnley category A, that is problems only from one hip or knee. This could imply that the women are “sicker” as a result of their OA than men. Despite this we can observe in the register that men leave OA programme more frequently, undergo surgery more often, consume more NSAIDs, and are more afraid that the joint will be injured by physical activity. A deeper analysis of the register’s results for gender differences in both experience of the illness and treatment is an interesting and important structure for future research projects.

## Development of the BOA register

Activities within the BOA register are steadily increasing. We have noted that 58% of the approximately 7 600 registered patients were reported first in 2011. This was somewhat surprising, since the first annual report encompassed three years of operations (2008–2010). The 2011 annual report is based on data from 80 units in 18 of 21 county councils. When compiling the annual report (June 2012) 200 units were noted from all the county councils. This is satisfying, but it also creates heavy demands on the organisation, routines and structure. Routines for validation and control of limit values have been worked out contributing to continually better data quality. We see that there are more units connected, but not all have as yet reported to the register. This could depend on the units’ need for support in commencing work with the register. The creation of a regional network can increase possibilities for this type of support, as well as discussions concerning the register and its results. Units failing to report to the register may also depend on the significant amount of energy and resources placed on the units’ continuous reorganizations and choice of care processes; or that units focus on production rather than on evaluation and results. The work of improvement and quality registers is a relatively new phenomenon within physiotherapy/rehabilitation. Treatment assessment, in the event that assessment occurs at all, is often entered as a notation in the medical records. These notes are not usually suitable for compilation or presentation at a group level. A national quality register enables systematic evaluation of physiotherapeutic intervention for clinics on both the own department, regional, and national level. It is first after assessing physiotherapy activities that it can be decided whether resources are being correctly used. Units are encouraged to set aside time to study internal results and use them for local and eventual regional development.

## The Register’s coverage

It is difficult to measure coverage for a physiotherapeutic intervention in primary care, whereby these visits are not (yet) routinely entered in the patient register. Our approach is to gather data from a number of counties for the number of visits to primary care of patients diagnosed with OA of the hip or knee (M16/M17) as primary diagnosis resulted in data from

four counties corresponding to 44% of the Swedish population. Variations between these counties when seeking care are relatively large. Stockholm, where the proportion of visits to primary care was slightly over 5%, has the countries lowest average age and a high proportion of private care providers not found in the counties treatment databases. It is also difficult to estimate how large a share of all patients at the self-management of OA programme that have been reported to the register, when we are without knowledge of where OA programmes are being held.

1. A Turkiewicz, IF Petersson, M Englund. Consultation prevalence of osteoarthritis in upper and lower limbs in southern Sweden. Abstract OARSI 2011
2. Ekblom-Bak, E., et al., Independent associations of physical activity and cardiovascular fitness with cardiovascular risk in adults. *Eur J Cardiovasc Prev Rehabil*, 2009. 17(2): p. 175-80
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## On going studies

In the previous annual report we mentioned the good results from the supporting self-management of OA programme at the department of orthopaedics at Umeå University Hospital. Introducing patients on the waiting list for eventual implant surgery due to OA of the hip or knee to OA programme reduced the need for consulting orthopaedic specialists. This indicates that self-management of OA programme has the potential to postpone the need for surgery. The question is whether the results last over time. This has been evaluated in a follow-up of patients 1–3.5 years after completing OA programme.

### Supporting self-management of OA programme at the orthopaedic department of Norrland University Hospital (NUS) in Umeå, Sweden

OA programme according to the BOA concept was started in the fall 2008 semester in Västerbotten County Council (VCC) at the orthopaedic department of Norrland University Hospital (NUH). The self-management of OA programme was operated by 2 physiotherapists on a full time basis until April 2011 for a total of 44 groups. The OA programme was closed as a result of a county council decision to transfer the running of the OA programme to primary care within VCC up until the spring term of 2011.

Before the start of a supporting self-management of OA programme in Umeå it was relatively unusual for patients in primary care with an OA diagnosis of the hip or knee to receive systematic physiotherapy treatment, and those that received physiotherapy, usually only received some training advice. At the start of the OA programme it was decided that patients referred to the orthopaedic clinic NUH with the diagnosis/inquiry of OA of the hip or knee and residing within the Umeå health care district would be randomly offered self-management of OA programme while awaiting a physician consultation. It was made clear to the participating patients that after completing OA programme they had the right to consult a physician according to the referral if they so wished. However, if they felt the result of OA programme was successful the physician consultation was cancelled and the OA programme's physiotherapist wrote a referral reply. All participating patients were also guaranteed a physician consultation at the orthopaedic clinic within one year after OA programme's completion if the initially good results should worsen.

At the end of the OA programme in the spring of 2011 a total of 270 patients had been offered and begun OA programme. Approximately 10 patients chose to discontinue OA programme. The reasons could have been lack of time, poor motivation, dissatisfaction with the results, or problems with the journeys to and from the OA programme. Of the initially participating patients 65% had OA of the knee and 35% of the hip. Women comprised 60% and the proportion of patients over 60 years of age was 66%. These patients' fates have been followed up in April-May 2012, which implies that the shortest follow-up is one year and the longest 3.5 years. (An additional 115 patients referred from the orthopaedic clinic's physicians took part in the OA programme after a visit to the orthopaedic clinic's physician. Their results are not included in this presentation).

### Results

Of the total number of patients (270) 26% have been operated or are on the waiting list for

surgery at this time. The majority of these (22%) were operated within one year after OA programme. At the completion of the OA programme a bit more than 61% were satisfied with the results. Within the first year the number of satisfied patients was somewhat reduced but stabilised thereafter so that 48% were still satisfied at the 1-3.5 years follow-up. The frequency of surgery and proportion of patients "satisfied" with OA programme hardly differs between the sexes. On the other hand one can note that relatively more patients with OA of the knee gained benefit of the OA programme along with patients under 60.

### Discussion/Conclusion

Slightly more than 61% of the patients, referred from primary care to the orthopaedic clinic of Norrland University Hospital with the diagnosis of OA of the hip or knee, had improved so much after completing OA programme that they immediately decided they did not need to consult an orthopaedic surgeon to discuss surgery. During the year following OA programme some of the patients worsened so that after one year barely 49% of patients were still satisfied. The majority of patients that did not improve by OA programme were operated within one year. Interestingly, the results after one year appeared to stabilise during the following years so that 48% were satisfied at the end of the follow-up period. Supporting self-management of OA programme appears to get better results for knee than for hip OA, and similarly it appeared that younger patients responded better than those over 60. Results clearly show that many patients in primary care with OA of the hip and knee can be adequately treated so that referral to surgery can be postponed. Clinical guidelines for the treatment of OA in primary care were introduced at the end of 2011 based on these good results. These include the demand for completing supporting self-management of OA programme before referral to an orthopaedic surgeon.