

The BOA-register

Better management of patients with osteoarthritis

Annual report 2013

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Introduction

The BOA-register, “Better Management of patients with Osteoarthritis”, continues to successfully improve the quality of life for an increasing number of patients with osteoarthritis (OA). It is gratifying to note that we in this fourth annual report now have a large enough base in the register to allow us to present all results on a county council level. In fact the number of units is so large that the annual report would be as large as an old fashioned telephone book if we were to print all the tables and figures at a unit level. In consideration to both the environment and the reader we therefore choose to publish all unit tables and figures at www.boaregistret.se only. Despite yearly expansion results seem just as good or better. Patients with OA forms one of the largest diagnosis groups to visit primary care. We see a growing interest from county councils and regions wanting to offer its citizens with OA an evidence-based treatment and, moreover, an opportunity to monitor and improve results with the help of the BOA register.

2013’s annual report includes 295 units and 25 161 patients. When the annual report was compiled (April 2014) the number of units connected to the register was 375.

A supportive osteoarthritis self-management program and the BOA register targets mainly the majority of patients with osteoarthritis never considered for arthroplasty. There has previously been a lack of structured treatment for patients with osteoarthritis in the period before arthroplasty, and variation in care within the country is extensive. The BOA register has captured and shown these variations that now make up the starting point for quality improvement, with the aim of reducing these differences. For the first time we can present results on a regional level in a separate chapter. Consideration should be taken, when making comparisons, to those variations that still exist between regions in the number of patients and size of the population.

BOA converts the scientific evidence for information and training for hip and knee OA to clinical practice in a so-called "supportive osteoarthritis self-management program" lead by a physiotherapist, in many cases in cooperation with an occupational therapist and patient representative. The aim is to provide patients with sufficient knowledge to enable decisions on their health, and support a change in life style to promote better patient-reported health. The BOA-register contains mainly patient-reported outcomes as a basis for quality improvement in healthcare. The physiotherapist reports which treatment the patient previously received as well as adherence to the intervention. Data on a clinical level is presented only for units that have reported a minimum of 10 patients with hip and knee symptoms, respectively. "The country" is represented by means of all patients reporting to the register. All units can retrieve their results online, regardless of the number of patients, and compare it to the country’s mean.

The annual report presents an overview of the register’s contents. Statistics are descriptive and some mean values are presented without statistical dispersion in consideration to the limited material at a clinical level. Results should therefore be considered preliminary and interpreted with caution. All results are paired data, that is, only patients with complete data from initial visit to follow-up are included in the results. Results are presented separately for hip and knee. Breakdown by the most symptomatic joint is based on the physiotherapist's examination. Many patients name symptoms from both the hip and knee.

In order to provide the reader with an overview we have chosen to report patient representation at the clinic, the so-called case-mix, as a value compass. We have also selected a number of outcome variables, indicators, which are presented on a clinical level and compared with the national

average. This is the only result presented on a unit level in the printed version, last in this annual report.

We hope that this fourth annual report will continue to inspire in-depth analyses and the work of improvement within the osteoarthritis field.

A handwritten signature in blue ink on a light green background. The signature is cursive and reads "Carina Thorstensson".

Carina Thorstensson

A handwritten signature in blue ink on a light grey background. The signature is cursive and reads "Leif Dahlberg".

Leif Dahlberg

A handwritten signature in blue ink on a light grey background. The signature is cursive and reads "Göran Garellick".

Göran Garellick

Summary

BOA stands for Better Management of Patients with Osteoarthritis (OA). The BOA register evaluates patient-reported outcomes following a physical therapy intervention – a supportive osteoarthritis self-management program. The self-management program converts the scientific evidence for information and training of the arthritic hip and knee to clinical practice. A supportive osteoarthritis self-management program is lead by a physiotherapist, often in collaboration with an occupational therapist and an osteoarthritis communicator. By means of a supportive osteoarthritis self-management program knowledge gained enables patient decisions regarding personal health, as well as support for life style changes, for the promotion of better health. Osteoarthritis of the hip and knee are among the most common diagnoses in primary care, and the need for early interventions to prevent functional deterioration and worsening of symptoms is considerable. Based on data from four regions/counties comprising 54% of the population over 45 in Sweden, 7% of the population over 45 seek a physician in primary care due to OA of the hip or knee at least once during a five-year period, or 1,5% annually. Seven per cent of the country's population over 45 corresponds to 308 691 persons. That would thus be the entire "osteoarthritis population" in Sweden seeking care at least once during a five-year period. This is without counting all those seeking care with pain from the knees or hips that have not as yet received a diagnosis.

The BOA register has existed as a National Quality Register since December 2010. Both the number of registered patients and affiliated units has in fact doubled each year since its inception. The 2013 annual report encompasses 295 units and 25 161 patients. Since 2012 all municipalities and counties contain units reporting to the register. At the compilation of the annual report (April 2014) 376 units were affiliated with the register.

By referring patients to a supportive osteoarthritis self-management program and recording results in the BOA register the Swedish National Board of Health and Welfare's national guidelines for osteoarthritis have thus been adhered to. This enables the reporting of a measurement of the suggested indicator for proper management of osteoarthritis: that is, the proportion of people with osteoarthritis who received training, supervised practice and advice on weight loss.

The primary aim of BOA is to offer all patients with osteoarthritis adequate information and training according to current treatment guidelines, and that surgery is to be considered only when non-surgical treatment fails to provide satisfactory results. The goal is to increase quality of life and activity levels of patients with osteoarthritis chiefly of the hip and knee, and reduce health care consumption and sick leave as a result of osteoarthritis. Patients with osteoarthritis should be received equally at their first contact with the health care system, regardless of location. Further, BOA aims towards quality improvement within physical therapy by systematic evaluation, open comparison and feedback of results. Each unit reporting data to the register can, at any time, retrieve their results in real time to compare them with the national average.

BOA's goals:

- Improve the EQ5D by 0.10
- Reduce the mean age of the patients in the register (to 58 years)
- Reduce the proportion of those X-rayed (and where X-rays show osteoarthritis findings)
- 150 minutes of weekly activity after one year for 80% of the patients in the register

Goals are set intentionally high but doable in time if each unit strives to improve results. A

prerequisite for the improvement of results is that each unit becomes aware of their current position and considers which factors could possibly improve results. Eight units around the country have been active in this way for six months. All units agreed that this was an edifying endeavour, and many discovered unexpected factors that needed to be dealt with first: if processes and routines for reporting are not functioning it will not be possible to obtain reliable data. By gathering and monitoring results deterioration occurring between three and twelve months can be identified, and measures taken to maintain good results.

User questionnaire results show that many experience frustration over the time expended to enter data, which may lead to registration being prioritized away. Interest to report, and thereby monitor treatment results, also declines when the head of the care unit fails to demand results. Knowledge of the utilization of quality registers in improvement efforts remains low among unit heads within rehabilitation.

Early measures against OA, before symptoms become too difficult, have the greatest potential to prevent disability and poorer health. One hope is for patients to seek a physiotherapist directly for their joint symptoms. There is a small proportion of patients that do so, with a positive trend. We know that many have symptoms for many years before receiving adequate help, even if trends show that we, in 2013, reached patients somewhat earlier in the course of the illness. By increasing knowledge among the general population and care providers that help is available we hope to lower the average age in the register from today's 65 to 58. Our goal, to include patients with problems from the hip and knee before the joint is X-rayed, is in accordance with the Swedish National Board of Health and Welfare's recommendations for clinical diagnostics, as well as a means of reaching patients at an earlier stage in the illness process. No great changes have occurred here, even if we can see slight variations between counties/regions. By means of a supportive osteoarthritis self-management program we wish to reduce the proportion of patients with insufficient physical activity levels. Physical inactivity and fear of joint destruction through training is common among patients with osteoarthritis, which in turn increases the risk for inactivity related diseases. The World Health Organization WHO has suggested that all adults should be physically active, at least at a moderate intensity, for a minimum of 150 minutes weekly. We see that the proportion of patients with insufficient physical activity levels declined from 31% to 22%. The variation of results is large between counties/regions.

We now manage more than 15% of all those over 45 expected to seek care for OA of the knee or hip in a supportive osteoarthritis self-management program. The average calculated from data for the fifteen counties and regions that have entered data shows that 63% of those units running a supportive osteoarthritis self-management program report to the register. This an increase of 7 percentage points since 2012. An average of 79% of the patients having attended a supportive osteoarthritis self-management program during 2013 were registered, which is approximately the same as the previous year, where the figure was estimated at 77%. It is not reasonable to assume that all patients be registered, since a supportive osteoarthritis self-management program also welcomes patients with osteoarthritis of the hands. Many patients with osteoarthritis of the hip and knee also have osteoarthritis of the hands. Patients with osteoarthritis of the hands alone have not as yet been registered. If we assume that BOA had, for the last five years, the current yearly capacity of circa 10 000 patients, we would have reached 50 000 patients, corresponding to 16 % of all those seeking primary care with joint pain, or a diagnosis of osteoarthritis of the hip or knee at least once during the same period. The BOA register has a high response rate. Each question had more than a 97% response rate. During 2013 mailings and reminders were delayed due to lack of resources. Despite late or missing reminders an average of 78% of patients responded to a questionnaire for

the 1-year follow-up in 2013.

For BOA, patient participation, among other things, implies cooperation with the Swedish Rheumatism Association and representatives of those patients comprising a target group for a supportive osteoarthritis self-management program. One of the theory sessions in a supportive osteoarthritis self-management program is led by a patient with experience of living with osteoarthritis and managing problems through life style changes, a so called osteoarthritis communicator. The aim of this cooperation is to provide a good example, and provide participants an opportunity to identify with the osteoarthritis communicator who can tell them that physical activity works. The osteoarthritis communicator is trained by the Swedish Rheumatism Association in the same way that BOA trains all physical and occupational therapists that are to lead a supportive osteoarthritis self-management program. Training aims toward the osteoarthritis communicator to pedagogically speak about and initiate discussions of how an active life style can affect health and joint problems. A physiotherapist with experience of a supportive osteoarthritis self-management program participates in the training of the osteoarthritis communicator, and an osteoarthritis communicator participates in the training of the physical and occupational therapists.

A supportive osteoarthritis self-management program has become routine in health care. In many areas of the country the orthopaedic surgeon returns referrals for patients that have not met a physiotherapist for basic treatment. A supportive osteoarthritis self-management program is included in several guidelines for patients with osteoarthritis of the hip and knee. Some regions have included a supportive osteoarthritis self-management program and the BOA register in their procurement process surrounding care choices. An international interest for the BOA registry's activities has also been noted. Statistics from the website show that 75% of all visitors are from Sweden, while the USA represents 10% of all visitors, Japan 3%, and China, 2%. People from more than 50 countries have visited the BOA-register's website.

BOA has a sister project in Denmark and Norway, and is part of an international network of countries actively working to implement evidence-based guidelines in health care. The findings of this report are presented separately for hips and knees. Patients with complaints from both the hip and knee are classified based on the joint that the physiotherapist assessed as causing the most symptoms. Two-thirds have most of their difficulties from the knees. Circa 70% of patients in the register are women. Gender differences are only presented on a national level in this report. Henceforth, when the number of patients per unit increases, the annual report will present results for men and women separately. We would like to emphasize that the patient base can differ significantly between clinics, whereby we at the BOA registry present data both from orthopaedic clinics and primary care, as well as from the private and public sectors. These aspects must be considered when interpreting results. This annual report should be seen primarily as a description of operations, and as a starting point for future improvement within the field of physical therapy. In regard to quality improvement we would like to encourage all units to actively utilise their results. Thus, possible incorrect data and the validity of the register can be further improved. There are contact persons, also called correspondents, in several counties and regions able to provide support to utilize and further develop local experience and knowledge of osteoarthritis.

The following interesting observations can be highlighted from the results of the BOA-registry's fourth annual report:

- Approximately 15% of the total number of patients over 45 seeking health care yearly for OA are taken care of in a supportive osteoarthritis self-management program and registered in the BOA register.

- Slightly more than two of one hundred patients in a supportive osteoarthritis self-management program come directly without previously having sought health care.
- Patients have had their symptoms on the average nearly six years before coming to a supportive osteoarthritis self-management program. There is great variation between counties and large dispersion among patients.
- More than 80% of the patients underwent radiological examination before coming to a supportive osteoarthritis self-management program, despite the Swedish National Board of Health and Welfare's guidelines stating that x-rays are unnecessary for the diagnosis of osteoarthritis. X-rays probably delay treatment initiation. Variation between counties is considerable.
- The proportion of patients reporting daily or constant pain is reduced after three months for OA of the hip and knee by 24% and 22%, respectively.
 - After one year the proportion with more or less constant pain remains 20% and 27% lower compared to the initial visit for hip and knee respectively.
- Pain intensity is reduced after three months for OA of the hip and knee by 21% and 24%, respectively.
 - After a year there is a sustained improvement of 15% and 20%, respectively.
- After three months the EQ5D increases by an average of 0.07 for OA of the knee and 0.06 for OA of the hip. After one year the mean improvement is 0.05 for OA of the knee and 0.02 for OA of the hip compared to the initial visit. Variation between units is considerable, which provides a good basis for local improvement.
- The proportion of patients with insufficient physical activity to maintain good health is reduced from 31 to 22 percentage following a supportive osteoarthritis self-management program.
- Every fifth patient fears that the joint will be damaged by physical activity before a supportive osteoarthritis self-management program. Following a supportive osteoarthritis self-management program the proportion was reduced to every twentieth patient.
- 93% of the patients were satisfied or very satisfied with a supportive osteoarthritis self-management program after three months. After one year the proportion was 85%.
- 93% of the patients reported, after three months, that they use what they have learned in the program at least every week. After one year the corresponding proportion was 75%.
- Jämtland cares for and registers the highest number of patients in relation to the population of the county, followed by Gotland and Östergötland. Östergötland, Kalmar and Halland have lost a number of registrations compared to last year. In Halland the number of patients registered was reduced by 38%.
- Stockholm, Västra Götaland, Östergötland and Skåne accounted for more than half of the patients registered in 2013.
- One third of the patients beginning a supportive osteoarthritis self-management program were not registered for follow-up visits. This may be partially due to patients being in the midst of an ongoing supportive osteoarthritis self-management

program. The majority are probably due to missing registrations or missed visits. This proportion varies greatly between counties.

- Of the patients reporting having previously consulted a physiotherapist for current symptoms, only 15% of patients with hip osteoarthritis and 23% of patients with knee osteoarthritis were offered adequate basic treatment (information and customized training).
- Only every fifth patient coming to a supportive osteoarthritis self-management program know they have OA or know what OA is. A similarly large proportion were told they have worn out joints, probably increasing the risk for misunderstanding and inactivity.
- Thirteen per cent of those with knee osteoarthritis and 8% of those with hip osteoarthritis report being on sick leave for their symptoms prior to a supportive osteoarthritis self-management program.
- Among patients with OA of the hip 65% were overweight or obese. The corresponding figure for OA of the knee was 80%.
- It is common to have OA in several joints. Only every third patient in a supportive osteoarthritis self-management program has unilateral symptoms. Every third patient with OA of the hip or knee also has symptoms from hand and finger joints.
- Comorbidity is very common for OA. Six of ten with OA of the hip and four of ten with OA of the knee report poor walking ability due to symptoms from both the hip and knee, or of causes other than hip and knee symptoms. A supportive osteoarthritis self-management program has only limited possibilities to affect these other causes.
- Women have more symptoms from the hands in addition to the hip or knee, while a larger proportion of men in the register only have symptoms from one joint. The men in the register thus seem to have less severe joint disease than women.
- In comparison with women twice the proportion of men fear that the joint will be damaged by physical activity.
- Men are more willing to undergo surgery. Every sixth woman and every fourth man have such strong symptoms that they would prefer surgery.
- Men drop out from a supportive osteoarthritis self-management program more often than women, regardless of whether due to surgery or other causes.
- Approximately 75% of the patients in the register report taking joint-related medication.
- 8% report taking herbal medicines. Knowledge of the consumption of herbal medicine can be of importance to the treating physician, whereby some of these can influence the effect of other medication.
- Thirty-four percent of the women and 26% of the men over 75 report taking NSAIDs for their joint symptoms.
- Twenty-five percent of the patients stopped taking joint-related medication after three months. Twenty-eight percent took no joint-related medication at the time of the initial visit but had done so at the three-month follow-up. A reduction in the total proportion of patients taking joint-related medication occurs in some counties, and

an increase in others, following a supportive osteoarthritis self-management program. The increase can partially depend on patients learning to use pain reduction in order to be more active.

- Seven percent of the patients in the register have undergone hip or knee arthroplasty within a year.

Our thanks

The BOA register would not have been the same if it had not been for the help of a great many people. Our thanks to those involved at the Registry center Västra Götaland, as well as all those reporting data and using the register in some way to improve the care of patients with osteoarthritis.

Participation and reporting

To determine whether results from the register are representative and generalizable it is important that the register cover the intended population. Data to the register is to be reported thoroughly and accurately. Depending on whether the BOA register is seen as an intervention or a diagnosis register coverage in the register can be described in several ways: 1) by how many entities carrying out a supportive osteoarthritis self-management program also report (coverage) 2) by the proportion of patients attending a supportive osteoarthritis self-management program and are reported (completeness), and 3) how many of those with a diagnosis of hip or knee osteoarthritis are reported. The goal of BOA is for all patients undergoing a supportive osteoarthritis self-management program to be reported. But we also strive to offer all patients with osteoarthritis of the hip and knee a supportive osteoarthritis self-management program as early as possible.

Geographical coverage

Since 2012 all regions had at least one unit reporting to the register. Both the number of patients participating in a supportive osteoarthritis self-management program and the number of units that report to the register have increased markedly every year since its inception in 2008. In 2013 295 units reported to the BOA register. The greatest percentual change in the number of registered patients compared to the previous year can be seen in Västmanland and Örebro, while Östergötland, Kalmar and Halland had a reduction in the number of patients reported. The greatest increase in absolute numbers can be seen in Region Västra Götaland and Stockholm. Several units were affiliated but had not, at the end of 2013, registered any patients. A number of units have stopped reporting to the register. When the annual report was compiled (April 2014), the number of units connected to the register was 375. At the end of 2014 the BOA-register will have trained slightly more than 1 800 physical and occupational therapists in a supportive osteoarthritis self-management program and register skills.

Number of supportive osteoarthritis self-management programs (coverage) and number of patients (completeness) reporting

BOA registers those patients having participated in a supportive osteoarthritis self-management program. Good coverage requires those units running a supportive osteoarthritis self-management program to report *all* patients having participated in the program to the register. However, there is no system for quality control of a supportive osteoarthritis self-management program, and it is difficult to estimate how many are being run without reporting results. A survey was conducted via the correspondents working for BOA on a county council level. Approximately 63% of the units running the program also report to the register. This corresponds to an increase with 7% compared to previous year.

It is also difficult to estimate the proportion of all patients participating in a supportive osteoarthritis self-management program reported (completeness). Physiotherapist (PT) consultations in primary care are not regularly reported to health care databases, and many medical record systems do not have "a supportive osteoarthritis self-management program" as a search term, which makes it difficult to match the number of patients participating. The proportion of registered patients of those participating will never be 100%. Patients with other diseases or diagnoses more symptomatic than osteoarthritis can be assessed as benefiting from a supportive osteoarthritis self-management program, but do not meet the inclusion criteria for registration in BOA. The cause for this is that questions concerning health-related quality of life and pain in the patient questionnaire are probably answered in relation to the influence of other diseases rather than problems related to osteoarthritis.

Patients with only hand osteoarthritis, without symptoms from the hip or knee, are not registered, but may participate in a supportive osteoarthritis self-management program. It is difficult to estimate the proportion of patients that have other symptoms or diseases excluding them from registering. A reasonable estimate can be that an average of 5-10% of participants should not be registered. We have requested correspondents to gather data on the number of patients that have participated in a supportive osteoarthritis self-management program from as many units as possible per county council. We received data from eight county councils. An average based on this data shows that 79% of the patients who had participated in a supportive osteoarthritis self-management program during 2013 had also been registered, which is about the same as during the previous year, where the corresponding number was about 77%.

In order to be able to trust results the register demands high quality data. The response rate of the BOA-register is high. Each question in the patient register has a more than 97% response rate, and a corresponding number for the physiotherapist questions are more than 98%. After one year the questionnaire is sent by mail to the patient followed by a reminder to non-responders. During 2013 the questionnaires and reminders were delayed due to lack of resources. Despite late or lacking reminders an average of 78% of the patients responded in 2013. The corresponding figure during 2012, after one reminder, was 89%.

The project for increased coverage

During 2014 the BOA register was one of 10 registers receiving funding from SALAR (the Swedish Association of Local Authorities and Regions) for efforts to increase the degree of coverage. The project leader is Rita Sjöström, Jämtland, who was previously the project leader for the work of implementing supportive osteoarthritis self-management programs and the BOA register in Jämtland county, Sweden. This work consists initially of auditing and mapping the use of the BOA register, foremost primarily through the county councils/regional correspondents.

The goal is for those running a supportive osteoarthritis self-management program to register, and motivate those reporting to use register data for quality improvement and ensure care.

Number of patients seeking healthcare for osteoarthritis of the knee and hip

The BOA register is not a diagnostic register, but the Swedish National Board of Health and Welfare's treatment guidelines advise that all patients with osteoarthritis of the hip or knee should be offered information and supervised training as a first measure, and that a supportive osteoarthritis self-management program should be accessible to all patients. There is a considerable number of individuals in the population that have lived with their illness for a long time without receiving adequate treatment.

Statistics from health care database in Stockholm show that 131 129 unique individuals with joint pain or a diagnosis of osteoarthritis of the hip or knee visited primary care at least once during a five-year period 2009-2013. This corresponds to joint pain or a diagnosis of osteoarthritis of the hip or knee generated in 15.2 % of the population over 45. The numbers with a diagnosis of OA of the hip and knee were 48 827, or 5.7% of the population. In Region **Västra Götaland** 50 266 individuals, or 7.0% of the population over 45 visited primary care at least once during the same period, with the diagnosis OA of the hip or knee as the primary diagnosis. The corresponding number for joint pain was 118 195 personer, or 16.6% of the population over 45 .

In **Östergötland** 20 611 individuals (10.5% of all over 45) with a diagnosis of hip or knee OA as the primary diagnosis and 43 065 (22% of all over 45) with a diagnosis of joint pain as the primary diagnosis visited primary care at least once during 2009-2013. **Region Skåne's** care database

identifies 46 989 unique individuals seeking primary care with the diagnosis of OA of the hip or knee in 2009-2013, corresponding to 8.4% of the population over 45. The corresponding figure for joint pain was 73 124 individuals, or 13.1% of the population over 45. Statistics from **Kalmar** county show that 18 025 unique individuals consulted primary care (non-private care providers) during the five-year period with the primary diagnosis of joint pain or OA of the hip or knee. Due to replacement of the archive system statistics for the first 18 months are incomplete. However, the number represents 15,2% of the population over 45.

There were 4 301 841 people in Sweden older than 45 by the 31st of December 2013, according to Statistics Sweden. Stockholm, Region Västra Götaland, Östergötland and Region Skåne together stood for 54% of the citizens in this age group. If we assume that the number of individuals with joint pain or a diagnosis of osteoarthritis of the hip or knee seeking primary care are distributed somewhat similarly in the population we can assume that the number of individuals seeking primary care in these four regions (166 693) represent about 54% of the osteoarthritis population in Sweden. Our simple calculations should then estimate the total "osteoarthritis population" seeking primary care in Sweden at least once in a five-year period to be about 308 691, or approximately 7% of the population. This appears reasonable when looking at the statistics from the various regions. If we assume that visits are evenly distributed over time, approximately 61 750, or 1.5% of the population over 45, seek primary care annually due to OA of the hip or knee. It appeared so even in 2011 and 2012 based on estimates made at that time.

According to www.vantetider.se Region Västra Götaland had 93 644 physician consultations in primary care during 2013, while Region Skåne had 59 687. The statistics we have received from the care databases in Västra Götaland and Region Skåne indicate that 22 190 and 16 951 visits, respectively, during 2013 were related to the diagnosis of OA of the hip or knee. This means that 17%, or every sixth visit of all physician consultations in primary care in Region Västra Götaland during 2013 were related to OA of the hip and knee, while the corresponding number in Region Skåne was 28%, or every fourth visit in primary care.

Coverage per county council

- The proportion of the population over 45 consulting for osteoarthritis and reported to BOA

Based on estimates from care databases during 2011, 2012 and 2013 we estimated that 1.5% of the population aged over 45 seek a physician in primary care yearly, with osteoarthritis of the hip or knee as the primary diagnosis. The figure is likely underestimated, whereby joint pain without radiographic changes in many cases is not diagnosed as osteoarthritis, and patients seeking other personnel categories in primary care are not accounted for.

From Statistics Sweden we have obtained population statistics for the age group over 45 by the day of December 31, 2013, according to county councils, and based on this, calculated how many individuals correspond to 1.5% of the population over 45 per county council. This forms the estimated number seeking primary care with OA of the hip or knee as the primary diagnosis. Coverage per county council has, therefore, been calculated by dividing the number reported to the BOA register per county council with the estimated number in each county council seeking primary care yearly. The graph is presented in the Swedish version of the annual report (Figure 2).

The goal is for all who seek primary care with hip and knee osteoarthritis are to be offered a supportive osteoarthritis self-management program if they have not previously done so. BOA included 25 161 patients during the four years of the register's existence (2010-2013), which corresponds to 8.2% of the "OA population" (see previous paragraph). With the present yearly capacity of about 10 000 patients we reached roughly 16% of all those seeking primary care with a

diagnosis of OA of the hip or knee 2013.

Validating data

The results can never be better than the quality of the data collected. The BOA registry strives toward minimizing 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 physiotherapist answers questions concerning previous examinations and treatment, as well as adherence to the intervention. The patient completes a questionnaire at the physiotherapy reception on the first visit and at a follow-up visit after 3 months. Responses are fed into the register by the physiotherapist or in some cases by the administrative personnel. At the one-year follow-up the questionnaire is sent to the patient by mail along with a self-addressed stamped envelope. The physiotherapist answers questions concerning previous examinations and treatment.

Data quality

There are certain limit values for input to the register. The values beyond these limits cannot be entered. In other cases quality controls can be made by means of descriptive reports. A minimal number of responses to questions is presently necessary in order to be able to save the questionnaire, such as the consultation date, or the joint and side which is most symptomatic.

It is possible for each unit to fetch their own reports online in real time. By processing data the possibility for identifying incorrect data increases.

Checks for data quality are now routine procedure for the BOA register twice yearly. Eventual incorrect entries, extreme values or questions without responses are mailed to each respective unit before summer and Christmas breaks when activities at the physical therapy reception are low and time allows checking and correcting the data.

Prior to the production of the 2013 annual report a number of further checks of the input data was carried out in order to confirm data quality. "Impossible" dates (for example a consultation with a date in the future), duplicates and missing values were identified and examined in more detail. Some data could not, for various reasons, be corrected, leaving 3 individuals with extreme or missing data. Forms for 456 individuals from the first visit were lacking, and 55 registrations were duplicates. These were removed from the dataset prior to the compilation of the annual report.

Descriptive data

In this chapter we not only describe patients in the register in regard to a number of factors such as age, BMI, marital status, and proportion of smokers, but also symptom duration, examinations, and treatment prior to a supportive osteoarthritis self-management program.

Number of patients

The number of individuals in the register is being continually updated and validated. Questionnaires can be registered retrospectively, and incorrect or missing data can be corrected or entered at a later date. Patients may discontinue participation at any time. These factors influence the number of unit-based individuals as well as patients registered, and numbers can vary on a yearly basis.

This annual report is based on data from 25161 patients with at least one visit to a physiotherapist before December 31, 2013. 9958 of these (40%) patient consultations were registered in 2013 (Table 4).

Thirty per cent were assessed by the physiotherapist as having most symptoms from hips, and 70% from knees. Division by OA of the hip or knee is based on the physiotherapist's assessment at the first visit, which is, in most cases, in agreement with the patient's experience. A total of 421 patients reported symptoms from a joint other than that reported from the physiotherapist examination and assessment.

After three months 313 patients reported no longer having symptoms. A corresponding number after twelve months was 249. Descriptive data for these individuals showed no greater differences for age, gender or BMI, but they had more often symptoms from only one joint (proportion Charnley A of those symptom-free at three months was 58%, and at twelve months, 55%), most often the knee joint (data not shown). Seventeen patients were symptom-free at both three and twelve months.

Number and proportion followed up after three years

After three months patients having completed a supportive osteoarthritis self-management program are to be offered a physical therapy consultation. This is to take place regardless of whether patients have chosen to participate in training or not. We have, in this annual report, data from 17 371 patients (69%) that completed the three-month follow-up.

Number and proportion followed up at one year

A one-year follow-up was sent to all patients registered for a first visit, still alive and not having dropped out. The follow-up took place approximately twelve to fourteen months after the first visit. A reminder was sent if the reply had not been received within one month. During 2013, 6353 questionnaires were sent for a one-year follow-up. Due to lack of resources reminders were delayed during the year, and when data for the annual report was gathered reminders for the second half of 2013 had not been sent. Despite the lack of reminders 4955 patients responded (78%) to the one-year follow-up in 2013.

Clinical characteristics - Age

The first symptoms of osteoarthritis can often be seen as early as age forty, but it is not unusual for both patient and health care providers to seek other explanations for symptoms than OA. Research have shown that persisting joint pain, where other causes can be excluded, most often is early osteoarthritis. The prevalence of osteoarthritis increases with age because sufferers bear the illness throughout their lives, although symptoms vary over time. The average age of patients at the first visit according to the BOA registry was 65.4 years, ranging from 22 to 97. Age distribution for the

entire register can be seen in Figure 3. Forty percent of the patients are between 65 and 74 years, and 57% of the patients in the register are aged above 65. The mean age for men was 65.7 (SD 9.7) years, and for women 65.3 (SD 9.6)

Symptom duration

A supportive osteoarthritis self-management program should be introduced at an early stage of the illness to minimize unnecessary effects on health-related quality of life and physical functional ability. Symptoms may come and go and do not usually lead to a health care consultation until a number of years have past when symptoms lead to functional problems in daily life. We see, in the BOA register, that those patients coming to a supportive osteoarthritis self-management program have had symptoms on an average of 4 years. The range is extensive with a standard deviation of 5.9 years.

Gender

Studies of osteoarthritis prevalence show slightly more men than women with OA in the under 45 age group. This can depend on the fact that roughly half of all those suffering a meniscus or cruciate ligament injury develops osteoarthritis within 10-15 years. Meniscus injuries in 20-year-olds can thus lead to osteoarthritis at age 35. At more advanced ages, however, osteoarthritis is more common in women. In the BOA register 70% are women. This corresponds well with gender distribution described in other studies.

BMI

Overweight is a known risk factor in the development of osteoarthritis, primarily in knee joints, but also for osteoarthritis of the finger joints. As for correlations between overweight and osteoarthritis of the hip the evidence is not quite clear, even if overweight has a strong correlation with a larger amount of hip problems and risk for 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 WHO, 25 kg/m², with overweight implying a BMI between 25,0 and 30,0; and those with a BMI of 30 or more are classified as obese. BMI is a rough measure, and for people with large muscle mass it may result in misleading values. 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 height and weight should be measured by length gauges and scales. In the BOA register BMI is based mainly on self-reported data, and should therefore be interpreted with some caution.

Patients with osteoarthritis of the hip showed a BMI of 27,0 (SD 4,3) kg/m² compared to 28,5 (SD 4,8) kg/m² for those with osteoarthritis of the knee. Every third patient with osteoarthritis of the hip and every fourth with osteoarthritis of the knee were of normal weight. A third of the patients with osteoarthritis of the knee were obese as compared to a fifth of the patients with osteoarthritis of the hip. Patients reveal their weight only at the program's start. Weight reduction is an integral part of the basic treatment of osteoarthritis. Both weight reduction and increased physical activity involves lifestyle changes for most patients with osteoarthritis. A physiotherapist's expertise lies primarily in the area of physical activity and customized training, which is why a supportive osteoarthritis self-management program focuses primarily on the increase of physical activity levels rather than weight reduction.

Symptoms 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. In a supportive osteoarthritis self-management program patients with osteoarthritis only of the hand are welcome, but these are not registered at present. A development project is underway to enable registration of these patients and report results back to clinic in the future. Patients with hand symptoms in addition to hip and knee symptoms are registered. Osteoarthritis of the hip and knee in combination with osteoarthritis of the finger joint can be an indication of more generalised osteoarthritis, affecting three or more of the body's joints systems. In the BOA register we see that every third patient (29% of those with osteoarthritis of the hip, 32% of those with osteoarthritis of the knee) report also having symptoms from their hand and finger joints.

Among patients with knee osteoarthritis compared to hip osteoarthritis; BMI is somewhat higher (28.5 kg/m² versus 27.0 kg/m²); the proportion of women somewhat greater (70.6% compared to 68.8%); and it is a bit more usual having hand symptoms (32.2% compared to 29.1%). Mean age is 0.7 years lower in the group with knee osteoarthritis (65.2 versus 65.9).

Proportion of smokers

Smoking entails many known risk factors, and quitting is demanded before surgery can be performed, since smoking leads to poorer healing. Questions concerning smoking are also included in the Swedish National Board of Health and Welfare's disease prevention measures. Since September 2012 the BOA register also includes questions concerning smoking. The connection between osteoarthritis and smoking is not entirely clear, and results are contradictory. There are studies that show that smoking can have a protective effect [1, 2]. A recently published extensive epidemiological study from China showed that smoking reduces the risk for knee arthroplasty, adjusted for BMI, physical activity level, premature death, and other known risk factors [3]. In the study the authors assert that quitting smoking is not discussed as a prerequisite for surgery in China, which could otherwise be considered a plausible explanation. The mechanism behind smoking's protective factor is unknown. Gathering information on smoking habits in the BOA register provides us with the possibility of studying the effects of smoking on other factors of osteoarthritis such as experienced pain, health-related quality of life, and results of a supportive osteoarthritis self-management program.

Marital status and sick leave

Language difficulties are no obstacle for receiving information in a supportive osteoarthritis self-management program, but the program is perhaps better performed individually. People with difficulties reading and understanding Swedish may have difficulties completing the questionnaire, which has not yet been translated into other languages. A prerequisite for being registered in a supportive osteoarthritis self-management program in the BOA register is for the patient to have a good comprehension of the Swedish language, resulting in a small proportion of foreign born patients.

Osteoarthritis afflicts a large portion of the working population. Half of those in the BOA-register are under the age of 65. Sick leave, sickness compensation, and loss of productivity make up large proportions of societal costs as a consequence of osteoarthritis. Around 13% of those with osteoarthritis of the knee are on sick leave and 8% of those with osteoarthritis of the hip. Sick leave alone without other measures has no or little effect on osteoarthritis of the hip and knee. One of the objectives of BOA is to reduce the proportion of patients on sick leave due to osteoarthritis of the hip and knee. People with osteoarthritis that have physically heavy work should probably consider the possibilities of other activities. Prolonged sitting also affects the development of osteoarthritis negatively. A job with varied tasks or opportunities for movement and motion can often help reduce symptoms caused by osteoarthritis, just as much as physical training. Work also contributes to

focusing on factors outside the body, which can help distract from the pain. By merging the BOA-register with registers from the National Social Insurance Office we may identify the impact of the supported osteoarthritis self-management program on sick leave in future.

Charnley index

Osteoarthritis can affect all joints with hyaline cartilage and appear in one joint only or in several joints at the same time. It is also common for people with OA to have one or more other illnesses. Osteoarthritis can in many cases be considered a lifestyle disease influenced negatively by inactivity and overweight. Osteoarthritis is also a common cause of inactivity, particularly among the elderly. Inactivity also increases the risk for other illnesses such as diabetes, high blood pressure, and coronary heart diseases, all of which are common in patients with osteoarthritis. Charnley index is a simple way of measuring comorbidity. The Charnley index is basically calculated by means of two questions: "Do you have problems from the other hip/knee?" and "Do you have difficulties walking for some other reason?" 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 do not affect walking ability. However, one can say that category C patients assess themselves as less mobile than category A and B. A third of the patients in the BOA-register have symptoms from only one joint (35,1% of those with osteoarthritis of the hip, 37,7% of those with osteoarthritis of the knee), while 58% of those with osteoarthritis of the hip and 43% of those with osteoarthritis of the knee state other reasons for walking difficulties than osteoarthritis in the joint in question. A supportive osteoarthritis self-management program probably has the best effect on those in Charnley category A.

Proportion with radiographically verified osteoarthritis prior to the supportive osteoarthritis self-management program

The Swedish Board of Health and Welfare has established in guidelines (2012) 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. 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. 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 for participation in a supportive osteoarthritis self-management program. 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. During 2013 approximately 80% of all patients had radiographically verified osteoarthritis before they came to the supported osteoarthritis self-management program. The variations between county councils are relatively large, which indicates differing routines in the management of patients with OA in Sweden.

Patient explanations

Patients sometimes are told that osteoarthritis is a result of "wear and tear" of the joints. This choice of words is unfortunate since they lead thoughts to worn out joints, not to be used, and fear of harm from further activity. In actuality, research shows that the quality of osteoarthritic cartilage is improved by dynamic loading such as in walking, bicycling and training. The risk for OA and poor health is greater among those inactive rather than those that are active. It is important that the sufferer is also aware of the implications of osteoarthritis and, most importantly, that patients

themselves can do much to influence symptoms and function. The results of a survey by BOA in the fall of 2012 showed that 6 of 10 adults over the age of 40 could not tell what osteoarthritis was.

In the BOA records, we see that one-fifth of the patients were told that they had worn out joints before they got to a supportive osteoarthritis self-management program. Many have been told that they have osteoarthritis, but do not know what osteoarthritis means or what to do about it. From 2012 a new response option was introduced to the BOA form: "The patient have not sought medical care for current joint problems before". In time it is hoped that a large proportion of patients will go directly to a physiotherapist and a supportive osteoarthritis self-management program without prior medical consultation.

Previous physical therapy

Patients can apply for a supportive osteoarthritis self-management program directly without necessarily having been in contact with health care prior to a supportive osteoarthritis self-management program. This is relatively new to patients, and 1.5-2% of the patients in the BOA register that have come directly to a supportive osteoarthritis self-management program. Patients in the BOA-register reply to questions from the physiotherapist concerning earlier treatments. About 50% of the patients in the BOA-register had met a physiotherapist prior to the supportive osteoarthritis self-management program. This does not, however, always imply that patients have received adequate basic treatment. Only about 15% of the patients with osteoarthritis of the hip and 23% of the patients with osteoarthritis of the knee were offered adequate basic treatment. According to both national and international guidelines all patients with osteoarthritis of the hip or knee are to be offered information, individually adapted training and advice on weight loss when needed. This is also the evidence that forms the basis for the National Board of Health and Welfare's Guidelines.

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 the only treatment as an exception and for short periods. Paracetamol is recommended as the drug of choice. If insufficient, or when there are contraindications for paracetamol, non-steroid anti-inflammatory pain reducing medication (NSAID) is recommended. Glucosamin is mentioned on the "not-recommended" list in the The Swedish Board of Health and Welfare's guidelines since there are no high quality or impartial studies to show adequate effect. The same is true for hyaluronic acid. Cortisone injections can have a good but short lasting effect. A number of herbal remedies and alternative treatments claim in ads to have a good effect but there is currently very limited evidence for these results.

Patients themselves state in the BOA-register which medications they take for their hip and knee problems. Seventy-five percent of the patients stated in 2013 that they took some joint-related medication. Paracetamol and NSAID preparations were used regularly and were used by about half the patients. The proportion of patients reporting use of glucosamine is roughly 6%, which is comparable to last year. Eight percent state using some herbal preparations. This can be valuable information since some preparations can have a negative influence on the effect of other medication. Paracetamol, NSAID, glucosamine and herbal remedies can be purchased by patients themselves. Joint injections are administered by doctors. Cortisone injections are most common in the knee joint since injection in the hip joint requires fluoroscopy to ensure injection accuracy.

Every tenth patient with osteoarthritis of the knee received a cortisone injection in the joint during 2013. Use of cortisone injections varies between county councils. Hyaluronic acid is sparingly used, in line with National Board of Health and Welfares recommendations. Each patient can take more than one preparation. Distribution of medication indicates the distribution of the total amount of medication taken by the patients in the register and says nothing of how many preparations are taken by each individual.

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 most symptomatic joint, and for the opposite side. For osteoarthritis of the knee 19% state having been operated on the symptomatic joint and 13% on the contralateral side. The proportion operated on the most symptomatic or contralateral hip are less than 10%.

Patients dropping out of a supportive osteoarthritis self-management program

Patients getting a hip or knee implant prior to completing the one-year follow-up are marked as drop-outs in the BOA register. The number of drop-outs due to receiving a knee or hip implant is 1780 patients (7%). Of these 66% were women, 51% had hip **osteoarthritis** and 30% had, moreover, hand/finger symptoms. In the rest of the register 29% had hip **osteoarthritis**. Even patients dropping out for other reasons are to be reported to the register. A total of 2884 patients (11%) had not completed the supportive osteoarthritis self-management program for some reason at one year follow-up; 64% women, 29% had hip osteoarthritis, and 31% had hand/finger symptoms.

1. Felson, D.T., et al., *Risk factors for incident radiographic knee osteoarthritis in the elderly: the Framingham Study*. Arthritis Rheum, 1997. **40**(4): p. 728-33.
2. Jarvholm, B., et al., *Age, bodyweight, smoking habits and the risk of severe osteoarthritis in the hip and knee in men*. Eur J Epidemiol, 2005. **20**(6): p. 537-42.
3. Leung, Y.Y., et al., *Cigarette smoking and risk of total knee replacement for severe osteoarthritis among Chinese in Singapore - the Singapore Chinese health study*. Osteoarthritis Cartilage, 2014.

Areas for improvement, target goals and quality indicators

Based on the goals of BOA and a supportive osteoarthritis self-management program, as well as the Swedish National Board of Health and Welfare's guidelines for osteoarthritis and disease preventive methods, BOA's steering group has developed target levels for the register both as a the whole and for each unit. These target levels can assist users of the register in identifying possible areas for improvement in order to achieve established goals.

Target levels

- Improve the EQ5D by 0.10
- Reduce the mean age of the register (to 58 years)
- Reduce the proportion of those X-rayed (and where X-rays show osteoarthritis findings)
- The proportion of those insufficiently active (accumulating less than 150 minutes of physical activity per week) should be less than 20% after one year

Motivation for selected levels

The EQ5D is an index for the measurement of health-related quality of life. It is calculated by five questions, resulting in an index from zero to one, where *zero* corresponds to a health-related quality of life equal to death and *one* to full health. A change in patient-reported outcome of 10%, or in this case 0.10, is generally considered a clinically meaningful change. Total hip replacement (THR) increases the EQ5D by 0.36 according to the Hip Arthroplasty Register's annual report. THR is thus a successful but major procedure for the patient. Patients about to undergo THR have a mean EQ5D of 0.34. Patients coming to a supportive osteoarthritis self-management program have a mean EQ5D of 0.64 for osteoarthritis of the hip and 0.66 for osteoarthritis of the knee. This implies that we reach patients at an earlier stage of the illness process, before their health-related quality of life deteriorates to levels prior to THR, but that the potential for improvement is also narrower. A change must, of course, also be related to the cost of the intervention. A costly measure could well be justified if patients feel better in the long run, while a less costly measure may still be cost effective while providing less change. An improvement in the EQ5D of 0.10 after one year is a relatively lofty goal, but probably not impossible if each unit strives to improve performance.

Early interventions for osteoarthritis, before symptoms become too severe, have the greatest potential to prevent disability and impaired health. We know that many have symptoms for years before seeking medical care. By increasing awareness of available help we hope to lower the average age for patients in the register from 65 to 58 years.

The mean age has been relatively stable at approximately 65 years over the past four years.

Improvement work initiated by a number of units to gradually reach younger patients as well as patients at an earlier stage of the illness is presented in Chapter *Improvements in BOA*.

According to the Swedish National Board of Health and Welfare's guidelines for osteoarthritis the diagnosis should be made clinically, by means of the medical history and typical clinical findings. X-rays should be used only in cases of uncertainty, or when considering a referral to an orthopedic specialist. This can significantly reduce the time between the first symptom and a diagnosis compared to making a diagnosis based on X-rays. It can take 10-15 years from first symptoms until osteoarthritic changes become visible on X-rays. During this time, many patients are referred to several different health care providers without having received a clear explanation, and many are worried about the cause of their symptoms. The proportion of those X-rayed when entering a supportive osteoarthritis self-management program is still high, but has been somewhat lowered compared to the previous year. For patients with OA of the hip the proportion of those X-rayed

2013 was 79.3%, compared with 80.2% for 2012. The corresponding figure for OA of the knee was 83.0% compared to 84.3% for the previous year. Patients probably had symptoms for many years upon entering a supportive osteoarthritis self-management program. Our goal to include patients with disorders from the hip and knee before the joint is x-rayed is part of the efforts to monitor the Swedish National Board of Health and Welfare's recommendation for clinical diagnostics, as well as a way of reaching patients at an earlier stage of the disease process.

One way is to spread the knowledge of being able to consult a physiotherapist and enter the program directly without having to first consult a physician. 1.9% of patients with OA of the hip and 1.5% of those with OA of the knee in the register enter a supportive osteoarthritis self-management program directly.

If patients had had their symptoms for, at the most, two years before entering a supportive osteoarthritis self-management program the mean age in the register would be 61 instead of the present 65.

A goal of a supportive osteoarthritis self-management program is a higher physical activity level. Physical inactivity and an unrealistic fear of joint destruction through activity is common among patients with osteoarthritis, which in turn increases the risk for inactivity-related diseases. The World Health Organization (WHO) has suggested that all adults should be physically active, at least at a moderate intensity, for a minimum of 150 minutes weekly. Since 1 September, 2012 the BOA register has included these questions in a patient questionnaire, and in this report the results for change between the initial visit and the three-month follow-up are presented. The registry's goal is for the proportion of those insufficiently active to be less than 20% after one year. (Since the question was introduced in September 2012 the number we could follow up after one year remains relatively small, thus the results for one-year follow-up are presented in the next report). The proportion of insufficiently physically active at the first visit is 31.5% of those with OA of the hip, and 31.1% of those with OA of the knee. After three months the proportion of insufficiently active sank to 22.0 and 22.6%, respectively. The goal for each unit is to lower the number of these by 10 percentage points between the initial visit and the one-year follow-up. One can read about measures taken at a number of units to stimulate activity levels among participants in a supportive osteoarthritis self-management program in the chapter *Improvements in BOA*.

Quality indicators

An indicator is, simply stated, a measure reflecting quality within an area, which also can indicate a trend over time. An indicator should reflect scientific plausibility, be relevant and, moreover, interpretable and measurable. Data forming the basis for indicators should be available for continual registration in the information system, such as computerized medical records, registers and other sources of data. Indicators possible to measure and interpret but where information systems require development or synchronization are known as development indicators.

The goal is for indicators to be used to:

- enable monitoring of health care's process development, results and costs over time – locally, regionally, and nationally
- initiate improvement of health care's quality on a local, regional, and national level
- increase accessibility to information (open comparisons) concerning health care's processes, results and costs for the various parties involved

National guidelines for musculoskeletal diseases

The Swedish National Board of Health and Welfare's national guidelines, published in May 2012, contains recommendations for diagnosis, treatment and rehabilitation of musculoskeletal diseases

for an evidence-based, fair and equitable health care throughout the country. In summary, the guidelines recommend that health care providers diagnose with the help of the medical history and clinical findings such as pain, stiffness after activity and reduced function; that radiological examination is used only where there is uncertainty regarding symptom causes; and that arthroscopic surgery with joint debridement and meniscus resection for OA of the knee is not performed. The treatment of OA of the hip or knee according to guidelines is scheduled, supervised and long term training, which has been shown as effective as analgesics.

Indicators in national guidelines for musculoskeletal diseases

Those indicators presented to evaluate and monitor the implementation of guidelines for musculoskeletal diseases are partially general, that is, valid for all diseases encompassed by the guidelines, and partially specific for OA. The general indicators are development indicators. A development indicator lacks national data sources, but can still be followed up on a local or regional level. All general indicators can be described for OA by means of the BOA register, even if the number of patients in some county councils are still relatively low:

Development indicator 1:1: Measurement of height and weight

Development indicator 1:2: Insufficient physical activity

Development indicator 1:3: Overall health-related quality of life (EQ5D)

The BOA registry participates in a project initiated by The Swedish Board of Health and Welfare to evaluate the general and specific indicators for OA. This work is to be completed during May/June 2014. The evaluation takes place partially through links with other national registries to secure data. The OA-specific indicators are:

Indicator 2.1: Arthroscopic surgery for osteoarthritis of the knee: Number of arthroscopies with principal diagnosis knee osteoarthritis per 100 000.

Indicator 2.2: Proportion of persons with OA \geq 75 prescribed NSAID treatment.

There is, moreover, a suggested guideline-specific development indicator for OA:

Development indicator 2:3: The proportion of persons with OA of the hip and knee that have received instruction, supervised training and advice on weight loss. This indicator is calculated as the proportion of persons with OA of the hip and knee that have received instruction, supervised training and advice on weight loss, for example in a supportive osteoarthritis self-management program, divided by the number of persons with OA at the unit. Publication of the Swedish Board of Health and Welfare's work evaluating adherence will further illuminate these indicators. Within the BOA register we can currently present somewhat modified presentations of indicators 2.2 and 2.3.

Proportion of persons with OA \geq 75 years of age subjected to NSAID treatment

NSAIDs should be used with caution in the elderly due to the risk for side effects. One quality indicator according to the Swedish Board of Health and Welfare's open comparisons of health care quality and effectiveness are the proportion of persons with OA \geq 75 that have been prescribed NSAID treatment. The Swedish Board of Health and Welfare writes in its indicator report for quality medication for the elderly: *"Cox-inhibitor (NSAID) (M01A excl. M01AX05): Used occasionally by the elderly for pain relief where the medication has no clear-cut advantages over paracetamol (for example, OA). Treatment of elderly people with these medications implies an increased risk for ulcers and bleeding in the alimentary canal, edema, and cardiac and renal impairment. Aside from the risk of cox inhibitors exacerbating heart failure, they can, through interaction, lower the effect of both diuretics (loop diuretics and, to some extent, thiazides) and ACE inhibitors. Furthermore, recent studies suggest that at least some COX inhibitors (even the non-selective) can increase the risk of coronary infarction and stroke. Note that certain cox inhibitors*

are available over-the-counter and can therefore be obtained without a prescription, and, consequently, without the knowledge of the treating physician.”

Since NSAIDs can be bought at a newsstand or grocery it is difficult to monitor their use with the aid of the drug register that only includes prescription drugs. It is not certain that patients remember to relate their use of NSAIDs to the physician, and studies have shown that health providers seldom ask patients which medications they are taking. There are no secure sources from which to gather information thus making indicators difficult to interpret. It is, thus, also difficult to indicate a suitable level for an indicator. The Swedish Board of Health and Welfare vaguely states that “the proportion should be lower than among people under 75”. The BOA register consists of self-reported data. The proportion over 75 using NSAIDs is greater among women compared to men with the exception of the first years in the register. The reason for this difference is unknown. Of those women over 75 coming to a consultation prior to entering a supportive osteoarthritis self-management program a third report using NSAIDs, while the corresponding figure for men is roughly a fourth. In the age group below 75 half the women and 40% of the men report using NSAIDs for their joint symptoms.

Proportion of persons with OA treated in a supportive osteoarthritis self-management program

The BOA registry registers patients with OA of the hip and knee that have received patient education, supervised training and advice on weight loss in a supportive osteoarthritis self-training program. The focus is on education, information and supervised training. Visits to primary care are not routinely reported in any national register. Data for consultations with caregivers other than physicians are also lacking. This hinders the calculation of indicator 2.3 whereby it is difficult to safely say how many patients with OA visit the units on a national or county council basis. In the chapter on Participation and Reporting, we have estimated the proportion of the population over 45 expected to seek primary care due to OA of the hip or knee, based on data from a number of health care databases. These calculations show, for the third year in a row, that approximately 1.5% of the population over 45 seek primary care with a diagnosis of OA of the hip or knee. Based on population statistics from Statistics Sweden for the different county councils/regions we can calculate the proportion of those that sought primary care during 2013. This becomes the denominator in our calculation. The BOA register shows how many individuals that have completed a supportive osteoarthritis self-training program and were registered, which forms the predicate in the equation. Figure 2 (page 15 in the Swedish PDF-version of the annual report) shows the proportion of persons with OA of the hip or knee treated with a supportive osteoarthritis self-training program (and reported in the BOA register) of the estimated number of persons seeking primary care due to OA of the hip or knee.

The proportion completing a supportive osteoarthritis self-training program

Registering a patient in the BOA register does not necessarily imply that the patient has received high quality care. Adequate treatment demands two entries in the BOA register, the initial visit and the three-month follow-up. Patients not completing a supportive osteoarthritis self-management program for any reason are to be reported to the register in a separate patient profile. A large number of patients leaving the program should initiate an inquiry into possible causes. Registration of only the initial visit can be due either to a missed follow-up or a missed registration. The proportion of patients completing a supportive osteoarthritis self-management program (three-month follow-up) thus provides an indication of the quality and effectiveness of the supportive osteoarthritis self-management program and the reporting of the individual unit in the county council/region. As seen in figure 14 (number and proportion at three months per county council) there is considerable variation between county councils/regions.

Results 2013

This chapter presents the results based on cumulative data from the first entries of the pilot units from 2008 to December 31, 2013. The “country as a whole” indicated in this report describes mean values from all registered patients. This represents only clinics that have registered at least one patient before the end of 2013, and cannot be considered representative of the entire country any more than that presented in the chapter on “Participation and reporting”.

For figures and tables illustrating the results, please see the Swedish version on www.boaregistret.se

Results in the printed version of this annual report are reported mainly on a county council level. All results on a unit level are presented at the BOA register’s website (www.boaregistret.se). When interpreting the data it should be taken into consideration that some county councils still have a relatively small number of patients reported. Changes after 3 and 12 months are reported for a number of patient-reported variables. Distribution measurements are not reported and results should be interpreted with caution whereby the number of patients in some cases are still relatively low. As for interpretation of clinically based results the case-mix should be considered as well as for how a supportive osteoarthritis self-management programme is run at the unit (praxis). All results are paired data. This implies that only individuals that have completed a supportive osteoarthritis self-management programme before the 31st of December 2013 and retaining data from all follow-ups are presented. Results are presented separately for patients with greatest severity of symptoms from the hip and knee, respectively.

Case-mix and results after three months for a number of selected indicators are presented last in the Swedish report.

EQ5D

The EQ5D measures health-related quality of life. The patient answers five questions on mobility, hygiene, activity, pain and anxiety/depression. There are three choices for each question (no symptoms, moderate symptoms, extreme symptoms) and based on the responses an index can be calculated ranging from 0 to 1, where 0 equals "death" and 1 equals "full health". The EQ5D index can assume values less than zero, which means that they rate their health as worse than death. The EQ5D has been used in numerous studies of various diseases and diagnoses, and can also be used for health economic calculations. Our goal in BOA is to reach patients before their health-related quality of life has been affected excessively, and that through a supportive osteoarthritis self-management programme make a difference in the EQ5D of 0.1 after one year. At present, we can show a mean change in the EQ5D after three months of 0.06 for osteoarthritis of both the hip and knee. After one year, the change is on average 0.02 for osteoarthritis of the hip, and 0.05 for osteoarthritis of the knee, compared with prior to the supportive osteoarthritis self-management programme. The major challenge is to improve or maintain a change over time.

County council/units with less than 50 complete registrations (3 and 12 months) on the EQ5D for hip and knee, respectively, are presented separately, but contribute to the national value.

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 clinical use. For a change to be

clinically meaningful it should be at least 10. A decrease of VAS over time means improvement. The results at the clinical level are sorted by one-year results.

Self-efficacy concerning pain and other symptoms

A supportive osteoarthritis self-management programme 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 intervention is self-efficacy. Low self-efficacy concerning symptoms 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 how changes in self-efficacy affects pain and other symptoms. The ASES starts from 10 (low self-efficacy) to 100 (high self-efficacy) and a meaningful change should be greater than 10. Only units with at least 20 completed registrations are presented.

Fear of joint damage through physical activity

It is a common misunderstanding among patients that joints “wear out” and that continued use or activity will cause further damage. Many also believe that pain or other symptoms means that one should avoid activity that triggers symptoms. This type of misunderstanding can be an obstacle to physical activity, and information from the osteoarthritis school aims toward attitude changes. Such a misunderstanding can be an obstacle to physical activity and activities of daily living. The information provided in a supportive osteoarthritis self-management programme aims inter alia at changing perception among patients (see Chapter on Patient Participation).

Insufficient physical activity

Measuring physical activity is difficult. There are no validated and reliable questionnaires for patients with osteoarthritis. We have, until the 31st of August 2012, used three questions from the Public Health Institute’s studies in BOA. When The Swedish National Board of Health and Welfare published new guidelines for disease prevention methods in 2011, there were questions about tobacco use, alcohol consumption, physical activity and diet. We decided to replace questions from the Public Health Institute with the The Swedish National Board of Health and Welfare’s two proposed questions about physical activity. The new questions were introduced on September 1, 2012. Results in this annual report are based solely on the Swedish National Board of Health and Welfare’s questions.

One of the goals of a supportive osteoarthritis self-management programme is to motivate patients to regular physical activity on a level sufficient for maintaining good health. The World Health Organization recommends that all adults should accumulate at least 150 minutes of activity per week, regardless of age and disease. Activity Minutes are a combination of the number of minutes of physical activity (at least 10 minutes at a time) and number of minutes of exercise of at least moderate intensity. Physical activity is defined as all forms of bodily movement that increases the pulse. Training is physical activity aimed toward a specific goal, such as the improvement of joint mobility, strength or stamina. Training should be carried out with a minimum of moderate intensity, in other words, to become slightly out of breath or sweaty. When summarizing activity minutes each minute of training is valued at two activity minutes, twice as much as one minute of physical activity (Activity minutes = minutes physically active + 2x (minutes training)).

BOA’s goal is that 80% of the patients shall achieve 150 activity minutes/week after one year. This can also be expressed by the proportion of those insufficiently active should be less than 20%. The

goal for each unit is to reduce the proportion insufficiently physically active by 10 percentage points after one year. Since the questions were introduced first in September 2012 there is still only a small proportion of patients that have been able to be followed up at one year. Results of the one-year follow-up are therefore to be presented in the next annual report.

Proportion with daily pain

Osteoarthritic pain frequently relapses. Periods of more intense pain are followed by periods of lesser or no pain. These periods may vary in duration from a few days up to several months or years and are difficult to predict. In the entire register 84% of patients with osteoarthritis of the hip indicate daily pain at the first visit. The proportion sinks to 65% after three months and remains at 17% under the initial values after one year, at 67%. Corresponding figures for OA of the knee are 82% at the first visit, 62% after three months and 60% after one year: A reduction of over 20%.

Use of joint-related medication

Medication should be seen either as a complementary treatment for osteoarthritis, when information and adapted physical activity does not result in adequate results, or to enable physical activity and exercise. Medication should only be taken for limited periods and only as an exception as the sole treatment due to the risk for side effects. Customized training can have the same effect on pain as medication, but without the negative side effects. One way of measuring the effect of a supportive osteoarthritis self-management programme is to study the change in patient-reported use of joint-related medication. It is, however, not as simple as measuring the proportion of those saying they have ceased with medication. Many OA patients are afraid of side effects and, therefore, do not take medication even when in pain. This can have a negative effect on health, wellbeing, and activity levels. A better alternative can be to learn when and how to use analgesics in order to live a more active and richer life.

In the BOA register we do not ask how often or how much medication is used. Neither do we ask whether medication is prescribed or over-the-counter. These are factors that need to be analysed in greater detail, along with which medications are stopped or started, to draw conclusions on what are considered as good results. A greater proportion stopping than starting medication could be considered as progress.

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. The proportion seeking a surgical solution is higher among men than women.

Gender perspective

Women have more symptoms from the hands in addition to the hip or knee, while a greater proportion of men in the register are of Charnely category A, which entails symptoms from only one joint. The men in the register thus appear to have milder joint disease than the women.

Data on marital status and sick leave for men and women having completed a supportive osteoarthritis self-management programme, that is having completed the three-month follow-up, showed no major gender differences other than that the women lived alone to a greater extent. Men are more afraid of injuring their joints through physical activity, and more men want to undergo surgery. When it comes to the proportion of men and women that take NSAIDs, the trend is declining for both men and women with knee and hip OA, and even more so for women with OA of

the knee while the proportion appears relatively stable for women with OA of the hip. For both hip and knee OA the proportion of men over 75 taking NSAIDs was greatest 2008-2010, but, since 2011 for knee OA and 2012 for hip OA, the proportion of women is greater. What this entails and how these factors influence the results of a supportive osteoarthritis self-management programme can we, at present, only speculate upon. A research project in the planning phase aims to illuminate possible gender differences for certain variables after a supportive osteoarthritis self-management programme. Further research is needed in order to completely illuminate and understand symptom differences, treatment and results for men and women with OA.

What do patients think of a supportive osteoarthritis self-management programme?

- **Percentage considering a supportive osteoarthritis self-management programme as good or very good**

After three months 93% of patients reported that they thought that a supportive osteoarthritis self-management programme was good or very good. The corresponding figure after one year was 85%.

In connection with the one-year follow-up the registry sometimes receives letters from participants:

"If someone reads this:

A fantastic programme!

I recommend it to friends in all parts of the country!"

"I am so grateful that I had the opportunity to participate in a supportive osteoarthritis self-management programme. I would have had my knee operated on if I hadn't participated in a supportive osteoarthritis self-management programme.

I didn't want surgery."

"...the best about a supportive osteoarthritis self-management programme was that I gained insight into the importance of training, walks, etc., and that it's not dangerous if it hurts afterwards, so long as the pain lasts only a few hours"

Percentage daily using the knowledge from a supportive osteoarthritis self-management programme

One way to measure the benefit of a supportive osteoarthritis self-management programmes is to ask patients how often they use what they have learned in the supportive osteoarthritis self-management programmes in their everyday lives. After three months 62% indicate using what they have learned in a supportive osteoarthritis self-management programme once or several times a day, and 93% say they use what they have learned at least once weekly. After one year 75% stated that they still use what they learned at least weekly. Thirty-eight per cent use the knowledge gained in a supportive osteoarthritis self-management programme daily.

Despite the fact that the number of units running a supportive osteoarthritis self-management programme has avalanched during the four years of the register it appears that the level of quality has been maintained if we evaluate how often patients report using what they have learned. If we compare the size of the proportion reporting using what they have learned at least weekly at the three-month follow-ups over time, it has been relatively unchanged, somewhat over 90% since the start.

Participation in a supportive osteoarthritis self-management programme

The minimal intervention in a supportive osteoarthritis self-management programme (see Figure 1) consists of information on osteoarthritis and available treatments. The information is provided by physiotherapists, and in some cases, occupational therapists, who have gone through a two-day course in osteoarthritis and a supportive osteoarthritis self-management programme. Information about lifestyle changes such as weight loss or exercise may seem insurmountable and difficult to absorb for those with joint pain and difficulty moving without pain. The same message from someone one can identify with and in a similar situation, can be experienced as easier to receive. In a supportive osteoarthritis self-management programme we work with osteoarthritis communicators, i.e. patients with osteoarthritis who have tried to follow recommendations and have experienced the difference a change in lifestyle and activity level can bring. Osteoarthritis communicators are trained by the Swedish Rheumatism Association to share, in an educational way, their experiences of non-surgical treatment and how to live a good life in spite of osteoarthritis.

The National Board of Health and Welfare recommends, in the national guidelines for musculoskeletal disorders, that patients with hip and osteoarthritis of the knee should be offered supervised exercise for an extended time (2). Those who accept to participate in a supportive osteoarthritis self-management programmes are offered, in most cases, an individually adapted and tested training programme, and the opportunity to practice this programme under the guidance and supervision of a physiotherapist for six weeks or more. Group training is carried out along with others with osteoarthritis. The patient can choose which elements in a supportive osteoarthritis self-management programmes that he/she wishes to participate in. If the patient actively chooses to keep their exercise programme and participate in group training, he/she has also gone from being a passive recipient to being an active and motivated participant.

There are large variations between the units in terms of participation. There may be several explanations. Neither the causes nor consequences of these differences can be seen directly in the results, but are subject to local analyses.

Two-year follow-up

Each year, the two-year follow-up is sent to 100 randomly selected patients among those that responded to the one-year follow-up the previous year. They are then monitored annually for as long as they live. The number of patients with a two-year follow-up accumulates each year. For the 205 patients completing a two-year follow-up 2013 the EQ5D was 0.67 and pain VAS 40. Sixty-eight percent of the patients indicate using the knowledge gained in a supportive osteoarthritis self-management programme at least every week.

Praxis

Aside from case-mix one can assume that routines and resources at each unit for a supportive osteoarthritis self-management programme can influence results. How a supportive osteoarthritis self-management programme is run at each clinic is what we call praxis.

BOAs policy is that all those running a supportive osteoarthritis self-management programme are to have been trained in managing a supportive osteoarthritis self-management programme, and the registrant should have completed training in register skills at least equivalent to those offered by BOA. The main goal is knowing the patient's best interests. This requires evaluation and analysis. Each unit offering structured information corresponding to a supportive osteoarthritis self-management programme to patients and evaluating and registering their results in the BOA-register fulfil what we call minimal intervention. Advice about exercise and activity can be organized in a way that best suits the unit. Training is implemented in a way that each department considers

appropriate, provided that the structure is similar for all patients involved in a supportive osteoarthritis self-management programme at the unit. The structure is reported to the register once yearly, or when a change occurs, through the praxis document on the website. Training is optional. The patient's choice of exercise (supervised or home training) is registered.

Not all clinics have access to training equipment and thus cannot always 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 osteoarthritis 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 osteoarthritis programme. Examples of other factors that can vary between clinics are patient flow, number of involved lecturers, length and number of sessions per programme.

"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.

The case-mix profile consists of six variables:

- **Percentage with most symptoms from the hip.** It appears as if a supportive osteoarthritis self-management programme has slightly less effect on osteoarthritis of the hip.
- **Proportion with hand problems.** Symptoms from the hands may indicate a more generalized form of osteoarthritis affecting multiple joints.
- **Proportion of Charnley category C.** Charnley C means that the patient has problems other than osteoarthritis affecting walking ability, or has symptoms from both the hip and knee. For these patients, a supportive osteoarthritis self-management programme has a limited effect on health-related quality of life and physical activity, as there is another illness present.
- **Percentage age 65 or older.** We do not yet know whether a supportive osteoarthritis self-management programme has the best effect on younger or older patients. The hypothesis is that intervention early in the course of the disease has the greatest potential for improvement.
- **Percentage on the waiting list for surgery.** Patients with more severe osteoarthritis awaiting surgery have worse outcomes. The very fact that you are waiting for surgery can also affect expectations.
- **Proportion of women.** For many medical conditions, women have a worse prognosis. It is unclear whether female gender means a better or worse starting point for a supportive osteoarthritis self-management programme. Further analyses will show which gender constitutes the most difficult case mix.

The left hand column of the graphs on page 98 ff in the Swedish version shows graphically how subject demographics (case-mix) are throughout the country (yellow) and at the different units (blue). A large blue area corresponds to a "difficult" case-mix and a small area means in this case "best" conditions for successful results. The limit value is set to the respective variables' largest and smallest value, respectively ± 1 standard deviation (SD). Case-mix is presented for those patients

comprising a basis for the value compass. When interpreting the clinic's value compass and results the case mix must be considered.

The value compass contains the following variables:

- EQ5D gains after 3 months
- Change in pain after three months. A value in the periphery means a reduction in pain.
- Change in fear of movement after three months. A value in the periphery represents a greater proportion of reduced fear of movement.
- Application of knowledge represents the proportion stating use of what they have learned in a supportive osteoarthritis self-management programme every week, every day or several times a day. Satisfaction with a supportive osteoarthritis self-management programme corresponds to the proportion of those who felt that a supportive osteoarthritis self-management programme was good or very good.

For details of the values for each variable, see Table 21

Improvements in BOA

It is with satisfaction that we can confirm that more and more physiotherapists reporting to the BOA register are discovering the clinical benefits of a quality register. By means of the BOA register one can not only monitor the effects of a physical therapy intervention or a supportive osteoarthritis self-management programme but also learn more of resource utilization and the quality of care. The results from BOA can be used to improve the entire continuum of care for patients with osteoarthritis of the hip and knee.

Target levels as incentives and guides

The BOA registry has chosen target levels useful for measuring impact on outcomes and processes: Improvement of the EQ5D-score by 0.1 after 12 months; 80% of patients to reach 150 minutes of moderate physical activity after 12 months; mean age at first visit to be lowered to 58 years; and the proportion of those X-rayed before a supportive osteoarthritis self-management programme reduced. These target levels are relatively high and "resistant" to change, which is to say it may take time until change and improvement are affected so that target levels are reached. By measuring unit results in relation to target levels and formulating advantageous changes for approaching targets, each unit can evaluate the impact of its improvement efforts in real-time in the report module of the quality register's website. BOA's report functions enable defining specific time intervals for desired results, thereby allowing result comparisons before and after specific changes. It is essential to evaluate whether a change actually leads to improvement. Solely focusing on results can, however, be misleading. Time and resources are to be used for effective measures, that is, measures that lead to the best possible results in relation to costs. In other words, an expensive or more resource-demanding treatment should lead to better results than a less costly one to motivate the utilisation of greater resources.

Results, on the other hand, need not be immediately noticeable, but may require an extended period of evaluation, with a greater number of outcome variables such as reduced care needs and/or sick leave. There is also the question of relevant measurement and evaluation. The main concern is true clinical significance and not the process per se. A new concept for measuring quality with the help of the BOA register is to measure the proportion of patients that complete a supportive osteoarthritis self-management programme including the three-month follow-up.

Using register data beneficial to both the patients and the organization

The use of a national quality register is relatively new to physical therapists. There is a need for in-depth knowledge concerning the potential of quality registers within health care and improvement efforts, both at the undergraduate level and for clinically active physical therapists. Prerequisites for a register's benefit to patients of an individual clinic are; 1) adequate time for data registration and 2), adequate time to extract and study data to consider possible areas for improvement. Another factor strongly contributing to the application of data is whether results are requested by the head of the clinic. Discussing results at workplace meetings is also an invigorating means of using data to streamline procedures and minimize time wasters. BOA provides us with possibilities to spread practical knowledge for improvement. We organize one-day courses both as commissioned and in-house to increase the number of units reporting to the BOA register, and to increase knowledge of how to collect and use results. When the units use their results eventual input errors are more easily revealed thus improving the quality of the data.

Eight care units participated in BOA quality improvement project

In the autumn of 2013 an improvement project in the BOA register was initiated, with support from

the Registry Centre of Västra Götaland through means provided by the Swedish Association of Local Authorities and Regions (SALAR). The aim of the project was for participating units to gain knowledge of operational improvement work, and apply it to work in progress.

An invitation to the project was sent to all units using the BOA register, eight of which decided to participate: HabRehab Gotland, Sälen-Lima, Matfors HC, Abels rehab Malmö, Närhälsan Rehabmottagning Trollhättan, Kortedala Rehabcenter, Rehab väst LIM and Rörelse o hälsa Linköping.

A prerequisite for participation was approval by the unit manager and he/she allotting time for improvement work. Thus, a number of units initially expressed interest but later withdrew since they could not meet these basic requirements. At an introductory instructional seminar in October 2013 the units learned more of the work of improvement and how it could be used practically. Diverse tools for identifying problems and areas of improvement, for example, structured brainstorming and flow charts, were presented and tested in practical workshops. The units themselves identified areas for improvement based on BOA's target levels. The project period was short because a presentation was to take place within six months. The units were therefore requested to identify reasonable goals and a suitable work timetable. A project manager for each unit ensured work progress, but it was strongly emphasized that the entire team involved in a local supportive osteoarthritis self-management programme was to cooperate in the work effort.

After six months a final seminar was held (April 2014). The units were then gathered once more for participants to relate their experiences of the project. All agreed that the project was very useful and confirmed that, despite the short time allotted, ambitious and goal-oriented efforts were carried out at the units with the help of the new methods, which greatly accelerated the processes of quality improvement.

These positive experiences inspired us at the registry to continue working toward improvement projects and knowledge within BOA, and we will announce new possibilities for participation in similar projects.

Examples of lowering the mean age in the register

It was realized at the **Närhälsan Rehab unit, Trollhättan (Närhälsan Rehabmottagning Trollhättan, Sweden)** that the effects of the efforts were not measurable for the short project period, but instead set a short term goal of spreading information concerning a supportive osteoarthritis self-management programme among care providers, emphasizing the importance of early care. After having identified the problem area it was agreed to focus on information to care personnel at open care units, orthopedic clinics, rehabilitation centers and patients. Another area of focus was to analyze accessibility to a supportive osteoarthritis self-management programme for working patients. Efforts resulted in an informative, succinct, and professionally illustrated brochure about a supportive osteoarthritis self-management programme for the general public; a poster with concise information for a supportive osteoarthritis self-management programme placed at the rehab center, open care units and orthopedic clinics, and written information to care personnel indicating what was of importance when referring patients to a supportive

As a curiosity, it was mentioned that a woman wanted to give away a supportive osteoarthritis self-management program as a Christmas gift to her husband, which has to be considered a solid endorsement of the unit's osteoarthritis school activities.

osteoarthritis self-management programme. The unit has, moreover, informed of a supportive osteoarthritis self-management programme at local open care units, booked information meetings at the orthopedic clinic, and, informed colleagues at the work place on the work of improvement with the help of the BOA register. The effects of these efforts on the mean age in a supportive osteoarthritis self-management programme will be evaluated continually along with the spread of information.

In **Sälen-Lima** it was decided to tackle the problem of a high mean age in a supportive osteoarthritis self-management programme by means of personnel education about OA, and among other things, to discuss routines and how information for a supportive osteoarthritis self-management programme is presented to patients. It was realised that these areas could be particularly decisive in shortening the patient's path through the care process, which is a prerequisite for providing the proper care in an earlier phase of the disease. Sälen-Lima is a small primary health care centre with about four supportive osteoarthritis self-management programmes yearly. The supportive osteoarthritis self-management programme is an important part of their activities. This small unit has good possibilities for exploiting short paths of communication, and the improvement project has increased awareness of a supportive osteoarthritis self-management programme among the unit's personnel, increasing the possibility to reach patients earlier on. Here too the aim is to bring forth written information to the general public. Spreading information of the existence of a supportive osteoarthritis self-management programme, and what it is, enables patients to directly apply for participation in a self-management programme. As a curiosity, a woman mentioned wanting to give away a supportive osteoarthritis self-management programme as a Christmas present to her husband, which has to be considered a solid endorsement of the unit's supportive osteoarthritis self-management programme.

Gotland, too, sought to lower the mean age in supportive osteoarthritis self-management programmes and they chose to inform other care units that could identify and refer patients to a supportive osteoarthritis self-management programme. Gotland had previously worked toward maintaining a higher activity level after one year for patients having participated in a supportive osteoarthritis self-management programme (see below).

Examples of how to increase the proportion of physically active one year following a supportive osteoarthritis self-management programme

It was previously observed on the island of **Gotland** that the proportion of individuals who were sufficiently physically active at one year follow-up after a supportive osteoarthritis self-management programme was lower compared to three month follow-up, and much thought was given on how to work toward maintaining physical activity levels between three months and one year. A while ago physical activity on prescription (FaR) was introduced after completion of the supportive osteoarthritis self-management programme. With the aid of the registry one can see the effects, and that the proportion of participants achieving 150 minutes of at least moderate physical activity after one year was over 80%. It was decided that continuing efforts would include further structuring of the successful work with FaR by introducing telephone follow-ups at 3, 6 and 9 months. It was also decided to discuss operations and coordinate efforts so that all worked in a similar manner. Furthermore, cooperation with lifestyle clinics was introduced.

Kortedala also chose to work towards an increase of the proportion of those sufficiently physically active following a supportive osteoarthritis self-management programme through more frequent follow-ups. Moreover, the goal was to increase the number of registered patients in the BOA register, since this was low during the previous year. A low number of patients creates difficulties in

interpreting results from the registry. Participant physical activity levels were followed up and combined with questions from the register about how often they engaged in physical activity and training, both during the supportive osteoarthritis self-management programme and 6 months later, to capture possible activity lulls. Where a decrease in physical activity level was discovered an individual consultation was booked to discuss and increase motivation for physical activity. This led to a measurable change in the proportion of patients reaching the 150 activity minutes/week after three months, a sub goal in this time limited project. The continuing work consists of evaluating the effects after one year, and to study the effects on other variables such as health-related quality of life and pain. It was considered that the extra effort needed for follow-ups and motivational interviews was small in relation to the effects. The continuing work will also strive toward identifying the necessary frequency of follow-ups needed to maintain the effect on levels of physical activity, and to identify those who lose motivation.

In **Rehab Väst LIM** the physical activity minutes were on the agenda for desired improvement. The short follow-up period created difficulties in monitoring the effect of some measures, and it was decided, moreover, to consider patient satisfaction with the present version of the supportive osteoarthritis self-management programme . A questionnaire was provided to the participants in the supportive osteoarthritis self-management programme and a checklist was made up so that all physical therapists working with the supportive osteoarthritis self-management programme would work in a similar manner. In order to aid participants in getting over obstacles to physical activity a card presenting “good advice” was written. Efforts to evaluate the effects of a more structured method and further focus on physical activity will continue.

At **Rörelse och Hälsa in Linköping** the goal was to improve levels of physical activity among patients, however, when studying the figures, the importance of ensuring that data was actually entered in the register became apparent. A large number of missing entries at three months made it difficult to measure and interpret changes over time. It was consequently necessary to retreat and survey routines for gathering and registering data. A step in the process was setting further goals, namely that 95% of all patients completing a supportive osteoarthritis self-management programme should complete the questionnaire; and 95% of the completed questionnaires should be registered by the physical therapist. It was decided to follow the manuals in the register and extract monthly statistics to monitor registration, and thus enable evaluation of the results of physical activity levels.

Abel's Rehab in Malmö experienced how a relatively large proportion of patients desisted from guided training. This resulted in making training ”compulsory” rather than voluntary. Consequently, more patients participated in guided training. However, a tendency was seen for more and more participants requesting to continue after the completed training period, and that independence was consequently reduced. During the seminar discussions and reviews of the different units’ efforts it became evident that a ”compulsory” training session could have a negative effect on both patient motivation to train and to continued adherence to training. Thus, participants in Malmö will be followed up to determine how this change in patient recommendations influences levels of physical activity, and how patients use what they learned in a supportive osteoarthritis self-management programme after one year. In order to know if changes really lead to improvement they must be continually evaluated and measured in different ways.

The work in **Matfors** was chiefly aimed towards increasing awareness of a supportive osteoarthritis self-management programme, and to bring in more units to the register, so that a greater number of patients could be included. This work was not measurable within the framework of an improvement project, but in-job training and education have been planned, and in the future we will be able to

check whether the number of units and patients from Västernorrland will increase.

Further initiatives for improvement

Osteoarthritis management in Kalmar County

BOA:s supportive osteoarthritis self-management programme has been run in the county of Kalmar since 2009 when this form of education was introduced to the county. All of the county's district rehab units are able to offer patients with osteoarthritis participation in a supportive osteoarthritis self-management programme. However, statistics from BOA show that compliance to the concept could be improved and thereby patient management can be optimized.

In the project running from April 2014 until 30 March 2015, the work is aimed toward improving OA management in the county, through early care and proper measures for this patient category. This is in line with the Swedish National Board of Health and Welfare's national guidelines from 2012. The aim is to strive for equivalent management throughout the county with regard to local conditions.

The focus of the project will be on information to co-workers at the rehab centers, open care units and orthopedic clinics, and written information to care personnel indicating what is of importance when referring patients to a supportive osteoarthritis self-management programme through personal visits to the respective unit. During the year training efforts will be carried out by training more coworkers in teaching patients in BOA:s supportive osteoarthritis self-management programme. An inspirational lecture has been planned to stimulate and encourage relevant personnel and strive toward adherence to BOA. Occupational therapists in the project will form a common routine for, in a structured manner, the enablement of documentation of the proportion of patients with symptoms only from hand or finger osteoarthritis. The project's aim is also to develop increased patient participation by means of a mutual exchange of knowledge between local patient organizations. The goals of the project are to increase the proportion of participants registered with BOA, lower the mean age through early care, reduce the proportion of participants of working age that have been X-rayed prior to a supportive osteoarthritis self-management programme, and to reduce the number on sick leave at the 3-month follow-up.

By Helen Lilja and Malin Hallin, Licensed physical therapists, Kalmar County.

Jämtland's county council received the year's BOA-award 2012 – what happened next?

The award aided in raising the bar higher to achieve our goals. Therefore, during the spring, collaboration with Anna Swansson-Danielsson, informant at the county's Public Health Centre, was begun. The aim was to spread knowledge of BOA to both the general public and personnel within Jämtland county (JLL). This was to realise the goal of patients coming in time to BOA's supportive osteoarthritis self-management programme to impede the disease and gain a less painful life. Another goal was to increase patient quality of life and a better and faster rehabilitation following an eventual operation.

Besides all the completed supportive osteoarthritis self-management programmes according to the BOA-concept and registrations in the BOA register the following activities/measures have been completed:

- Continued coordinator for BOA in the county, 20%
- Locally adjusted information at www.1177.se
- Meetings with the county's physical therapists to discuss continued efforts with BOA

Cooperation with the Public Health Centre resulted in:

- Communication plan
- Press release
- Posters set up at health centers and hospital
- Production of information to patients
- Slideshow of BOA that physical therapists can show and inform about at workplace meetings
- Information on Jämtland County's website
- Information about BOA at the Public Health Center's newsletter to Jämtland's collaborators
- Reports on Jämtlands radio, P4
- 31/1-14 Rita Sjöström and Ulla Schill were invited to Jämtland County's inspiration day with the theme "How does working with disease preventive methods pay off". The headline at our presentation was "A supportive osteoarthritis self-management programme, Structured treatment and successful implementation".

In Jämtland County 21 health centres have reported osteoarthritis patients to the BOA register during 2013. During the same period 669 patients participated in a supportive osteoarthritis self-management programme and registered in the BOA register compared with 424 patients in 2012. We can see a continued reduction in the number of patients waiting for knee and hip arthroplasty. The number undergoing surgery in 2013 is comparable with the number in 2012. The orthopaedic ward at Östersund hospital has, since 2008, worked with the concept of "accelerated rehabilitation" in connection with knee and hip arthroplasty. Many measures have been taken to better prepare patients as well as shorten care time. A supportive osteoarthritis self-management programme has contributed to a better flow in the continuum of care and even better prepared patients, which is now reflected in even shorter treatment time for this patient category.

Year	2010	2013
Hip arthroplasty	4.9 care days	3.6 care days
Knee arthroplasty	5.5 care days	4.6 care days

Among other things, thanks to the reduced treatment time, the production of knee and hip arthroplasties could be increased from 360 in 2010 to 472 in 2013. This has strongly contributed to enabling residents of Jämtland and Härjedalen to be operated at their local hospitals.

Another important signal we have received is that the need for carrying out knee arthroscopies is felt to be less thanks to physical therapist efforts in the work with supportive osteoarthritis self-management programmes.

Östersund 140401, by Rita Sjöström, BOA's physical therapist manager and Ulla Schill, managing director of orthopaedics

Patient participation

The form and content of the supportive osteoarthritis self-management program has been partially influenced by patient understanding of osteoarthritis and its treatments. The BOA register includes patient participation in the intervention, in training of health care professionals as well as in the BOA steering committee. Cooperation between health care professionals and the patient organisation (The Swedish Rheumatism Association) also takes place in the education of patients with osteoarthritis to become specially trained ‘osteoarthritis communicators’.

Osteoarthritis is classified as a rheumatic disease and the interests of osteoarthritis patients in Sweden are seen to by means of a strong patient organisation, the Swedish Rheumatism Association. The Swedish Rheumatism Association’s mission is mainly to spread knowledge to and via members, organisations and districts. Supportive osteoarthritis self-management programs in primary care are held in cooperation with the Swedish Rheumatism Association, which is an example of this distribution of knowledge. The Rheumatism Association’s specially trained osteoarthritis communicators cooperate with physiotherapists and occupational therapists in delivery of the program to patients. The osteoarthritis communicator participates actively in one session by leading an interactive discussion about how to live a good life with osteoarthritis and the perceived benefits of an active lifestyle. He or she is also encouraging participants in the program to share tips on how to best manage daily living, despite symptoms. The osteoarthritis communicator shall quite simply be a role model and an example of how to move on, and facilitate an interactive talk among participants in the program. By involving a patient (osteoarthritis communicator) experienced in living with osteoarthritis a new approach to the message that it is not dangerous to move when it hurts can be introduced, including information that training is an effective treatment. The osteoarthritis communicator can make the difference between hope and hopelessness, or between will and the lack of it among the participants in the program.

An aim of cooperation is also, through the good example of osteoarthritis communicators, to increase compliance to exercise over time among participants of a supportive osteoarthritis self-management program, by empowering participants, increasing inner motivation to change, and increasing responsibility for self-care. Another aim is, by means of the Swedish Rheumatism Association, to offer those participants unfamiliar or uncomfortable with a gym and unable or unwilling to train at home, a possibility of continuity of training within the activities arranged by the local associations, after the completion of the self-management program. This cooperation serves benefit to all those involved.

The Swedish Rheumatism Association’s cooperation with BOA provides unique patient participation on several levels: on a national level in BOA’s steering committee and (representing both the Swedish Rheumatism Association and the patient perspective) in the research group, on a county level where BOA’s contact persons cooperate with the Rheumatism Association’s district manager for local patient education, and on a local level where the local physiotherapist is in contact with the osteoarthritis communicator of the Swedish Rheumatism Association, who in turn cooperates with a supportive osteoarthritis self-management program. Patient participation is also seen in the training of physiotherapists /occupational therapists, and BOA participates in the Swedish Rheumatism Association’s training of osteoarthritis patient informants. The importance of cooperation with osteoarthritis communicators to increase internal motivation among participants in the supported osteoarthritis self-management program is stressed during the education of clinicians, along with practical information on how to proceed to make it happen.

With an increasing number of clinics holding supportive osteoarthritis self-management programs comes an increasing demand for osteoarthritis communicators. In 2013, 50 new communicators were trained by the Rheumatism association throughout the country, and there are currently roughly 150 active communicators. There are trained communicators that offer to participate in the programs in all the Swedish Rheumatism Associations 24 districts. Approximately 1330 programs were held in 2013 in cooperation with patient associations and primary care.

Osteoarthritis communicator activities within the Swedish Rheumatism Association are organized so that the Association's central office is responsible for educating the osteoarthritis communicators, and each Association district has a manager for communicator activities, and the local associations are responsible for recruiting new informants if needed.

"Only someone who has needed help can truly help others."

In Väckarklockor [Alarm Clocks], by Gunilla Brattberg.

Research projects in BOA

Swedish National Quality Registers form an extensive source of data for research and for the development of new knowledge. The BOA register provides data of interest to all professionals, for both hypothesis-generation and clinical description of the care of patients with osteoarthritis. Using data from the register is also a means of quality control. There is no shortage of ideas, and in the coming years we can look forward to new knowledge from a growing number of research projects within the BOA register.

The research advisory board

In order to promote the use of register data for research a research group was established in 2013. The group consists of osteoarthritis researchers from various professions, as well as a research partner from the Swedish Rheumatism Association. The group evaluates project ideas presented to the register from researchers around the country and can aid in the interpretation and analysis of data, initiate projects, grant applications, and participate as co-authors and advisors. The group consists of:

- Carina Thorstensson, Assistant Professor, RPT, University of Gothenburg
- Göran Garellick, Professor of Orthopedics, University of Gothenburg
- Katarina Johansson, Research partner, Swedish Rheumatism Association
- Kjell Nilsson, Professor of Orthopedics, Umeå University
- Leif Dahlberg, Professor of Orthopedics, Lund University
- Maria Klässbo, PhD, RPT, Värmland County
- Martin Englund, Assistant Professor of Epidemiology, Lund University
- Nabi Pirouzi, Fil Dr, Statistician Register Centre Västra Götaland
- Per Kristiansson, Assistant Professor, General Practice, Uppsala University
- Stefan Lohmander, Professor of Orthopedics, Lund University

Research Database

We have, in 2014 at www.boaregistret.se, launched a database for research projects in connection with the BOA register. Documents and templates for researchers available for downloading are presented here, along with the current status of those projects carried out with the aid of register data, along with popular scientific summaries for patients and the general public. We also hope to receive sound ideas for possible future research projects by way of this website.

Doctoral projects

The effect of a supportive osteoarthritis self-management program on physical activity levels as measured by an accelerometer in patients with osteoarthritis of the knee and hip, respectively, Therese Jönsson, RPT.

The aim is to study whether a supportive osteoarthritis self-management program can influence physical activity levels in patients with osteoarthritis of the knee and hip, and which factors are decisive to change.

Masters projects

- Development of a treatment process for patients with osteoarthritis of the knee; a cost-effectiveness study.
Chan-Mei Ho, RPT.

The aim of the project is to see if a physiotherapist as a first measure for patients with osteoarthritis of the knee can increase the cost effectiveness of the care process.

- Self-efficacy and a supportive osteoarthritis self-management program - changes over time and the association of physical activity and pain.
Åsa Degerstedt, RPT.
The aim is to study whether baseline self-efficacy influences the results of a supportive osteoarthritis self-management program.
- Which factors influence a patient's choice of not training after a supportive osteoarthritis self-management program?
Anna-Marika Eggertsson, RPT.
The aim is to see if there is a difference between groups that choose not to physically train and those that choose to train after completing theoretical training according to the BOA concept. The study is based on data from the BOA register.
- Does comorbidity effect the results after a supportive osteoarthritis self-management program
Anna Ernstgård RPT
The aim is to study how comorbidity measured by the Charnley index (causes other than hip and knee symptoms affecting walking ability) influence changes in physical activity levels after a supportive osteoarthritis self-management program.
- Self-estimated pain and health-related quality of life of participants of a supportive osteoarthritis self-management program with and without osteoarthritis of the hand. A quantitative study based on data from the BOA register.
Lice-Lotte Johansson, OTR/L
The study's aim is to see if there is a difference in results for patients with osteoarthritis of the hip, knee and hand/finger joints compared with those who only have symptoms from the lower extremities.
- Changes in fear of movement after a supportive osteoarthritis self-management program.
Malin Jönsson-Lundgren, RPT
The aim is to study whether a supportive osteoarthritis self-management program can affect fear of movement in patients with osteoarthritis, and which variables influence fear of movement.
- Differences between men and women in results of a supportive osteoarthritis self-management program with regard to the EQ5D and physical activity.
Karin Åkesson, RPT
The aim is to highlight possible differences between men and women after a supportive osteoarthritis self-management program, with particular regard to health-related quality of life and physical activity levels.
- A study of the thoughts, difficulties and uncertainties in patients responding to an Arthritis Self-Efficacy Scale-Swe -A think aloud study based on 12 in-depth interviews.
Sofie Bergman, RPT
The aim is to find out how patients comprehend and respond to questions about self-efficacy

included in a patient questionnaire in BOA.

- The effect of a supportive osteoarthritis self-management program and training on pain, symptoms, ADL, sport/leisure time activities and illness-related quality of life in people with osteoarthritis of the hip and knee.

Mia Johansson, RPT

The aim is to evaluate the effect of a supportive osteoarthritis self-management program on self-estimated pain and function for patients on a waiting list to an orthopaedic surgeon and having completed a supportive osteoarthritis self-management program while waiting.

Currently at BOA

A steady stream of activities, great and small, comprise a challenge to those of us working with the administration of the BOA register. Efforts toward improvements in data registration, increase in patient participation, and the use of register data are part of the tasks we, more or less, continually work with and consider. Below are some of the other activities taking place in and about the register.

The BOA award 2013

The BOA register's annual award is presented to an individual, care unit or county/region that has made a meritorious contribution or effort worthy of the attention of the Better Management of Patients with Osteoarthritis. For 2013, the Health Care Department of Region Västra Götaland received the award with the following motivation:

"The Health Care Department of Region Västra Götaland constitutes an example by suggesting that a supportive osteoarthritis self-management program and reporting to the BOA register should be included in the regional Requirements and Quality Handbook. The suggestion displays foresight by showing understanding of the importance of structured physiotherapeutic/occupational therapeutic care by systematic evaluation of patients with osteoarthritis."

Since the award was received an agreement for care was reached for rehabilitation services in Region Västra Götaland. The agreement included a supportive osteoarthritis self-management program and BOA registration.

BOA received "Dagens Medicin" (Today's Medicine) honorary mention

BOA was nominated for "Guldskalpellén" 2014. This is a prize awarded annually by the health care political paper "Dagen's Medicin" to the health care innovator of the year. A nomination is noteworthy and an acknowledgement of the organization. The competition is rough and a record number of entries, 57, were nominated for the prize in 2014. BOA did not win, but received one of two honorary mentions. Congratulations to us all! The award ceremony took place in connection with a theme day about Elderly Life in Movement held in Stockholm in September.

Internationalization

It is gratifying to see that the BOA concept is now spreading outside of Sweden's borders. The BOA register has a sister operation in Denmark, known as GLA:D, Godt liv med artrose i Danmark (good life with osteoarthritis in Denmark www.glaidd.dk) Ewa Roos is register director and GLA:D published its first annual report in 2013. Funding was provided for initiating an osteoarthritis register in Norway equivalent to BOA. Mayarna Risberg and Inger Holm are register initiators.

A decisive factor for effective cooperation between countries is the use of common variables when reporting. It was decided in Denmark to basically use the same approach and variables as BOA. Norway, too, is considering a similar approach to allow multicenter studies.

International discussions have been initiated with Canada, Australia, USA and England, where similar initiatives are under way to optimize care of patients with osteoarthritis. The goal is to spread the message throughout the world and gradually harmonize variables to increase knowledge of variations and areas for improvement.

BOA hand and BOA shoulder

Patients with OA mainly of the hip, knee and hand come to a supportive osteoarthritis self-management program. At present we monitor those with OA of the hip or knee and hand in the register, but we have not as yet registered the results for those with only OA of the hand. BOA has, for some time, strived to include even those patients in the register, where they are already being taken care of in a similar manner. The work has been more or less on a voluntary basis. The next phase is to identify the variables to be included in BOA hand, and perform a trial test of data entries at a number of clinics.

Interest has been shown, from the shoulder and elbow register, to start a non-surgical intervention and registration similar to that for patients with hip and knee symptoms. BOA looks kindly on this development, but has decided that both for the hand and shoulder, the energy and efforts should to be delegated to others than those currently involved in BOA hip and knee.

User Survey to the BOA register's users

All National Quality registers are urged to evaluate user viewpoints of the register's usefulness. This is possible by means of a service provided by Alstra AB. During the spring of 2014 the BOA register sent out a web-based questionnaire with the aid of this service to all of its users.

The questionnaire includes 14 questions. Of 705 available mail addresses to users of the BOA register 58 resulted in automatic replies saying that the addresses had no recipients, or that the server blocked the mail. Of 647 possible responses we got back 238 completed questionnaires, resulting in a response frequency of 37%. Of these users 68% reported having read the annual report. Half, 50%, reported having used register data for improvement work during the last year, 40% had used data in their clinical work, and 13% for research. Six of those 238 responding were department heads.

One of the overall goals of National Quality Registers is for 80% of department heads to use data from quality registers in their work before the close of 2016. This is probably a significant factor for stimulating the use of register data in clinical and improvement work. The BOA register's user questionnaire reveals that managers seldom ask for results. Only 18% state that managers have asked for results from the register. Six of ten users state never having personally extracted data from the register, and every other user feels great benefit from the register for follow-up and improvement of operations. Among those that haven't extracted data from the register are many new users that have not yet gotten seriously started with reporting. Otherwise, lack of demand, inexperience, lack of time, and lack of knowledge of how to use data, or that users feel no benefit to their work as a reason for not using data from the register.

Other viewpoints seen in the survey are that registration is considered time consuming, and that it is not granted priority by department heads and managers. Help is desired by users to spread information of the register's usefulness to department heads, along with greater knowledge of how to use data. Direct input, via webbased questionnaires, is another request. There is also a desire for more charts and diagrams available in real time from the register making it possible to follow results over time, and compare results with other units or national averages. There is also a need for following patients individually in output data reports.

National board of health and welfare

The BOA register has difficulties validating data using the Swedish Patient Register (PAR), where all visits to inpatient care are registered, as many hospital based registers are doing, since visits to a physiotherapist in primary care are not regularly reported. We have therefore contacted the Registry

service at The Swedish National Board of Health and Welfare for possible help in interlinking with the aim of illuminating the following questions:

- 1. Can participation in a supportive osteoarthritis self-management program reduce the number of adverse events after total hip replacement?**
We know that the total of adverse events are roughly 5% in the Swedish Arthroplasty Register (SHPR), which is actually very low. Several are related to symptoms from comorbidity, which a supportive osteoarthritis self-management program should be able to influence.
- 2. Can participation in a supportive osteoarthritis self-management program influence health care consumption?**
By interlinking with PAR we would like to know if people with the diagnoses M16 and M17 that have at some time been registered with the BOA register use less primary care and inpatient care, respectively, after completing a supportive osteoarthritis self-management compared with people with the same diagnosis not found registered with BOA.
- 3. Can participation in a supportive osteoarthritis self-management program influence prescribing of medication?**
By interlinking BOA, the Swedish Pharmaceutical Register and PAR, we wish to compare prescribing of glucosamine, hyaluronic acid, multiple cortisone injections and NSAIDs for the diagnoses M16 and M17 that are registered or not registered, respectively, with BOA.
- 4. Can participation in a supportive osteoarthritis self-management program reduce the need for X-ray / MRI / arthroscopy?**
By interlinking BOA and PAR and comparing care measure codes for plain x-ray hip / knee, knee arthroscopy and magnetic resonance imaging (MRI) of the hip and knee for diagnoses M16 and M17, we aim to study whether there are differences in the measures for those within and without BOA.

Interlinking is relatively easily performed. The difficulty is obtaining comparable groups and interpreting results. The analyses are under way and the results cannot thus be presented in this annual report. If we find a feasible way to manage data, the first step will be to report this type of result longitudinally.

Discussion

Tendencies for change in routines of care and patients

Small changes may be due solely to chance, making it difficult to draw any major conclusions until developments can be observed over several years. We would, however, like to point out several tendencies worthy of attention. The proportion of patients believing they have worn out joints has decreased from 20 to 18%. Somewhat fewer patients have been X-rayed before coming to a supportive osteoarthritis self-management program, a reduction from 80% to 79% for osteoarthritis of the hip and 84% to 83% for osteoarthritis of the knee. The number of patients in the register seeking a physiotherapist and a supportive osteoarthritis self-management program directly has nearly quadrupled, even if the proportion is still scarcely 2%. We now manage over 15% of all adults over 45 years of age expected to seek care due to osteoarthritis of the hip or knee. This is an increase from 7% in 2011, and from 12% in 2012. Patients have had symptoms long before coming to a supportive osteoarthritis self-management program, but the trend is positive. We reach patients with osteoarthritis of the hip somewhat earlier in the course of the illness, while they estimate their health-related quality of life to 0.66 according to the EQ5D (0.65 for 2012).

We would have liked to have seen a tendency toward reaching a greater proportion of those of working age, but this was not the case. Even the mean age in the register was relatively unaltered over time. The proportion of people on sick leave at new visits has increased by one per cent since 2012.

The use of register data

One of the overall goals of the National Quality Registries is for 80% of health care managers to use data from quality registers in their work before the end of 2016. Management's involvement at different levels and requesting results is probably an important prerequisite for the utilisation of register data and improvement efforts. It became apparent, from the BOA register's user survey, that management seldom requested results, and that registration was seen as time-consuming, which led to lower priority. Of those responding only 18% stated that management had asked for results from the register. The benefits of quality registers are still relatively unknown in rehabilitation, especially for their internal benefits. It is a relatively common misunderstanding that data is entered just so that "the Register" can use it for research. Much of today's health care focuses on production and budgeting. Costs (time) must pay off directly in order to motivate investment. Operational development efforts and quality improvement saves, in successful cases, considerable time and resources, while providing better results for patients. However, this can seldom be seen short term, but requires continual monitoring of results and trends. Often, an evaluation with variables other than those found in the register is needed, such as the number of visits per individual, to enable seeing where the greatest gains can be made. Health care consumption, sick leave, comorbidity and care time in connection with hospital stays are factors we can study in the future through cross linking with the national patient register (including all inpatient care visits and diagnoses on individual level) and the register from the Swedish National Board of Health and Welfare comprising sociodemographic variables. The Swedish National Board of Health and Welfare's guidelines clearly state that the introduction of "regularly supervised training for an extended time" will probably demand increased resources. By presenting the current situation and variations between counties and regions we hope to stimulate and motivate them to provide increased resources.

The user survey was sent to users with log in to the register when contact information for unit heads was lacking. Six of those 238 responding were unit heads. The response rate was low at 37%. It is

likely that users interested in the register were more likely to respond, which could have led to an overestimation of results, since these check their data more often than others. Six of ten had personally extracted data, and 50% felt they benefited from the register. There were also some first time users among responders. These had not as yet seriously begun to register and, consequently, had not yet begun to retrieve any data.

We must continue spreading knowledge of how quality registers can be used by physiotherapists clinically. By further developing output reports, by setting good examples, and offering support and tools for quality improvement we hope to further inspire more units to use their results for an even better management of patients with osteoarthritis.

Patients have symptoms for (too) many years prior to a supportive self-management program

Patients in the BOA register have had symptoms for an average of four years before coming to a supportive osteoarthritis self-management program. The figure is based on self-reported data. Symptoms from osteoarthritis often come gradually making it difficult for patients to recall how and when they began. Our figures show that 50% of the patients had symptoms between 0 and 10 years, implying that half had symptoms for over ten years. Even if we assume a large margin of error these figures indicate that patients seek and receive treatment late in the course of the disease. If we had reached patients presently found in the register within two years of the onset of symptoms the mean age would have been 61 instead of the current 65. We believe that a supportive osteoarthritis self-management program makes the greatest difference early on in the course of the illness due to gaining the knowledge that it is not dangerous to be active, and to optimally manage symptoms. A supportive osteoarthritis self-management program is not directed mainly to those patients that are candidates for arthroplasty but to the 80% that will *not* need surgery. Through a supportive self-management program these patients can be offered an effective and evidence-based treatment alternative. There are indications that a supportive self-management program can also influence the results of arthroplasty. The likelihood of patient satisfaction after surgery increases if the patient is well informed with adequate expectations. During 2013 roughly 10 000 patients were registered in the BOA register, which corresponds to about a third of the number of those receiving arthroplasty of the hip or knee in Sweden in one year. When the number of patients in both BOA and The Swedish Hip Arthroplasty Register (SHPR) become slightly larger we have the possibility to study how a supportive self-management program influences, for example, length of stay and adverse events in connection with arthroplasty by interlinking individuals found in several registers, after ethical approval, using the personal identification number. At the end of 2013 a total of 1780 patients (7%) received a hip or knee replacement before the one-year follow-up.

There are several reasons why patients come to a supportive osteoarthritis self-management program first after many years of symptoms. On the one hand there may be a cumulative number of patients with symptoms but have not previously had treatment options before the start of a supportive self-management program. On the other hand patients can be bounced around in health care before coming to the right place. There are still few patients in Sweden who know they can seek a physiotherapist directly with symptoms from joints and muscles. The physiotherapist makes a diagnosis and refers patients further to specialist care or a doctor in unclear cases. In the BOA register we see that as yet only two hundred patients sought a physiotherapist directly for symptoms. Using, for example, the webbased care guide, 1177.se, to advertise access to a supportive self-management program makes it easier for patients to find the program. More information about when to consult a physiotherapist is needed. Many patients still think there is nothing to be done, or that early symptoms indicate a meniscal injury requiring surgery. Our goal is

to reduce the mean age to 58. This does *not* mean that patients developing symptoms at an older age or seeking late in the course of the disease are not welcome to a supportive osteoarthritis self-management program, but that we strive to reach a larger proportion of those of working age. Currently, four of ten patients in the register are under 65. Data from SHPR shows a mean age for primary hip replacement in Sweden 2012 is 67.1 for men and 69.7 for women. The knee arthroplasty register presents the mean age for knee replacement at slightly under 69. In BOA the mean age for men is 65.7, and for women 65.3. By working toward lowering the mean age we can reach patients with information at an earlier stage of the disease.

A persistent problem is that treatment has seldom been initiated before osteoarthritis signs are visible radiologically. This can take many years from the first symptoms, since osteoarthritis develops slowly. Correlation between radiological findings and symptoms are weak, and the findings of X-rays do not influence the treatment of osteoarthritis, especially during early courses of the illness.

According to the Swedish National Board of Health and Welfare's national guidelines for osteoarthritis the diagnosis is established with the help of the medical history, common symptoms and typical clinical signs. X-rays should be used only in unclear cases where a specialist referral is under consideration. In the BOA register we see that a clear majority, about 80%, of the patients were already X-rayed before coming to a supportive self-management osteoarthritis program. By presenting, in future annual reports, how the proportion of those X-rayed changes over time the BOA register can show how compliance to the Swedish National Board of Health and Welfare's guidelines appears in different counties. A supportive osteoarthritis self-management program is to be prescribed when symptoms from the hip or knee joint are of such intensity that the patient seeks health care, regardless of radiological findings.

By lowering the mean age and reaching patients with knowledge of osteoarthritis and self-care earlier on in the course of the illness, we have better possibilities of halting the worsening of health-related quality of life, otherwise seen as a consequence of osteoarthritis. Compared with 2012 we can see a slight change in the input values for the EQ5D for people with osteoarthritis of the hip, which possibly indicates that we are on the right path. The mean value of the EQ5D prior to a supportive osteoarthritis self-management program 2012 was 0.64, compared to 0.66 for 2013. After three months the value for osteoarthritis of the hip was 0.71, which is the same as in 2012. This implies that we reach patients earlier, but, on the other hand, with slightly lesser gains compared with previous years. Room for improvement is less. According to a public health questionnaire from Stockholm in 1998 the EQ5D index was approximately 0.80 for persons between 60 and 80 [4].

Insufficient physical activity

Pain is a major concern of osteoarthritis. More than eight of ten patients have daily pain when starting a supportive osteoarthritis self-management program. The proportion decreases by about twenty percentage points after a supportive osteoarthritis self-management program and remains so after one year. Reducing pain can be a decisive step in getting started with physical activity, something that not only can relieve the symptoms of osteoarthritis but is also of crucial importance. Sitting still is the "new smoking"; the health risks are many, and many are aware of the risks, but continue despite this with an unhealthy habit. We see that the proportion of patients with insufficient physical activity is reduced after a supportive osteoarthritis self-management program, from 31 to 22 percent. Several counties have a proportion of inactive patients of less than 20% after three months, which is the target level after one year. These are promising results. Each unit can monitor

results after one year, and in future annual reports we have the possibility of following events one year after a supportive osteoarthritis self-management program. Great variations exist between units and counties, but the essential factor is status after a year. Success in maintaining a higher level of activity among patients can entail large gains in public health and, consequently, reduced costs to society. In time, we will also be able to monitor the level of activity among the one hundred patients per year followed annually over time.

Differences between men and women

A factor of possible significance for the level of physical activity is the fear that physical activity can further injure the joint. This fear can be the result of a previous lack or misleading information of what osteoarthritis is and how it is best treated. Approximately every fifth patient (18%) has learned that they have worn out joints, something that can lead to concern for greater wear and tear through physical activity. This is a slight reduction compared to the previous year where it was 20%. Fear of damaging the joint through activity can be seen in twice the proportion of men compared with women. At the initial visit 22% of the men stated fear of damaging the joint, while the corresponding proportion among women was 13%. Future research will hopefully explain the basis for this difference. These differences remain after three months and one year, even if both men and women experience a reduced fear of movement after a supportive self-management program. The proportion is halved after one year.

Other noteworthy gender differences in the register are that women have hand symptoms in addition to the hip or knee more often than men, while a greater proportion of men in the register are of Charnley category A, which means symptoms from one joint only. The men in the register thus appear to have a milder form of joint disease than the women. A supportive osteoarthritis self-management program probably has the best effect on those of Charnley category A. Patients with other conditions that can affect walking ability, such as coronary heart disease, chronic obstructive pulmonary disease and neurological diseases, are classified as Charnley C. The intervention presented in a supportive osteoarthritis self-management program is chiefly aimed toward joint symptoms. Of those individuals stating no symptoms after completion of the supportive osteoarthritis self-management program a majority were classified as Charnley A. By interlinking, in the future, with the Swedish Patient Register (PAR) we can highlight the proportion of patients in the BOA register with other illnesses, and which illnesses are most common, as well as the short and long term effect on results, concerning both patient-reported outcome and health care consumption. Men desire surgery more often than women, and the proportion of men that undergo surgery or leave a supportive osteoarthritis self-management program for other reasons is greater than for women in the register. Consumption of NSAIDs is greater among women than men in the BOA register. The cause is not known. NSAIDs should not be prescribed to people over 75 due to the risk for side effects. Of those women over 75 years of age coming to the first visit prior to the supportive osteoarthritis self-management program one-third report using NSAIDs, while the corresponding proportion for men is one-fourth. In the age group under 75 half the women and 40% of the men report using NSAIDs for their joint symptoms.

It is for future studies to show how the extent of these differences are related to psychological and social factors, or whether there are actual differences in how osteoarthritis is expressed purely physiologically in men and women.

Differences between hip and knee osteoarthritis

Overweight and obesity are more pronounced among patients with osteoarthritis of the knee than with osteoarthritis of the hip (BMI 28.5 kg/m² compared with 27.0 kg/m²). The proportion of women among those with osteoarthritis of the hip is somewhat higher than among those with

osteoarthritis of the knee (70.6% versus 68.8%), and it is somewhat more common with a combination of hand symptoms and osteoarthritis of the hip than hand symptoms and osteoarthritis of the knee (32.2% versus 29.1%). These differences are in accordance with epidemiological studies.

The register's results also indicate that symptoms from the hip joint are more difficult to relieve with a supportive self-management program than symptoms from the knee. Patients with osteoarthritis of the hip have greater difficulties walking due to causes other than symptoms from the joint in question than patients with osteoarthritis of the knee, indicating that comorbidity is more common for osteoarthritis of the hip. Of those individuals symptom-free after a supportive osteoarthritis self-management program a larger proportion have symptoms from the knee joint at the initial visit compared with other patients in the register. Patients with osteoarthritis of the hip report a somewhat milder effect on health-related quality of life after a supportive self-management program, and also seek surgery to a greater extent than patients with osteoarthritis of the knee. This is despite the fact that the proportion reporting daily pain has declined on the whole by 17 percentage points for osteoarthritis of the hip, and that pain intensity has declined from VAS 48 at the initial visit to VAS 38 after three months, and VAS 41 after one year. This change in pain is not without significance even if somewhat lower than for osteoarthritis of the knee. Factors other than experienced pain can be decisive in the experience of symptoms and results after a supportive self-management program. Register results indicate some uncertainty among physiotherapists concerning how to treat symptomatic osteoarthritis of the hip. Of all those having visited a physiotherapist for hip symptoms prior to a supportive osteoarthritis self-management program only 15% had received adequate treatment. The corresponding figure is 23% for patients with osteoarthritis of the knee.

Growth of the register

When the numbers of units and patients rapidly increase it is essential to monitor the quality of both the intervention and the register. A supportive self-management program should provide patients with sound and useful tools to manage their daily lives. The proportion of patients stating use of what they have learned in a supportive osteoarthritis self-management program after three months has been above 90% yearly, despite an increase in both the number of units and patients. After one year the corresponding figure is about 75%.

Of the 205 patients completing the two-year follow-up in 2013, 68% report still using the knowledge gained in a supportive osteoarthritis self-management program at least every week.

As a supportive osteoarthritis self-management program spreads throughout health care the need for providing it in other languages increases. A supportive osteoarthritis self-management program can be presented on an individual basis or with an interpreter in case of language difficulties. The questionnaire is not yet in languages other than Swedish, limiting the number of foreign born patients in the register. There are plans to translate both the questionnaire and the supportive self-management program to other languages.

Coverage

The proportion of those treated in a supportive self-management program (and registered in the BOA register) of all those over 45 expected to seek a primary care physician due to osteoarthritis of the hip or knee has increased yearly, which is good news. Jämtland still stands out as the county most successful in relation to the county's population as a whole. Gotland rose to second place easing out Östergötland to third best place in this year's table. Halland has lost a number of registrations and, thus, its position on the list compared with last year. We see a decrease in the

number of registrations by 38% (from 173 to 108). The reason is unclear, but the change has been observed by the contact person in Halland, who is planning activities to improve coverage in the county.

This estimate is based on data from a number of county councils, which has been approximated to cover the entire country. The statistics from the health care databases included data from the four largest counties in regard to population. It is of course possible that there are variations between counties related to size. Every year we send requests to several smaller counties as well, but it has been more difficult to gain responses from these or compare their data. There are people under 45 in the register, which can be seen as a source of error in this estimate. The proportion under 45 is, however, only about 2%, and an eventual error in relation to how many over 45 are managed in a supportive self-management program can be assumed to be equally distributed throughout the counties.

Patients not completing a supportive osteoarthritis self-management program are registered in a separate patient profile. 18% of the patients cease participation before the one-year follow-up; 7% due to arthroplasty and 11% for other causes. For a complete treatment two registrations in the BOA register are needed, the first visit and the three-month follow-up. Follow-up is essential for both the patient and the monitoring of a supportive osteoarthritis self-management program. A large proportion of the patients are registered only for an initial visit. The proportion completing a supportive osteoarthritis self-management program and registered at the three-month follow-up is a modest 69%. There are large variations between counties in the proportion of those completing the program, from 48% (Gävleborg) to 92% (Gotland). Patients with only an initial visit registered indicate a missed follow-up or registration. The proportion of patients completing a supportive osteoarthritis self-management program (three-month follow-up) provides an indication of both the quality and effectiveness of a supportive self-management program, and of the degree of registration at the individual unit or county/region. Now, when a supportive self-management program and registration in the BOA register are part of the agreements between care units and county councils, and included in the requirements and quality manuals of more and more counties, it is important to reflect on how we can use the register to evaluate quality rather than productivity. A large proportion of patients completing a supportive osteoarthritis self-management program can become a measure of good health care quality.

There are a large number of units connected to the register without having registered patients. Some of them are new units and have not yet had time to report, but a relatively large number have been connected for many years. We also see a number of units that have previously reported but later ceased reporting. In some cases we know that there have been organisational changes, such as a move from an orthopaedic clinic to primary care. In other cases reorganisation can lead to closing down or starting new units. In some other instances we have no known causes. They will be contacted to find out the causes and possible solutions.

Upcoming changes and updates

All updates to the questionnaires and variables require discussions at several levels. Everyone from system developers and information technicians to statisticians and users must be informed of how and when a transition from one group of questions to another is to occur. It is essential to carefully consider beforehand what the consequences of such changes are in order to be able to compare results over time.

Many users point out that questions of self-efficacy are experienced by many patients as difficult.

Doubt concerning how to interpret questions and response alternatives can influence responses in a way that is difficult to control. The results show no great changes in the ASES after three months, and a worsening compared with the initial visit after one year. By studying subgroups of patients in ongoing research studies we can learn more about how ASES is influenced and influences different factors. Should it become evident that ASES makes no contribution, those eleven questions will be removed from the questionnaire. On the other hand, if ASES is shown to be important to certain patients we will rework the questions (using item response analyses). A preliminary analysis has shown that six questions and five response alternatives would probably provide practically as much information as the current eleven questions with ten response alternatives.

The EQ5D is now developed to contain five response alternatives. This scale has been shown more sensitive to changes. The EQ5D is now also available with a Swedish tariff, or set of values [5]. We still use, as most other registers and researchers, the English set of values, which has been used for decades. The EQ5D "is owned" by the Euro-QoL-group, that monitors usage. Provided that we, even in the future, are permitted to use the EQ5D in quality registers, we have plans to convert BOA's EQ5D values according to the Swedish value set before the next annual report.

References

1. Felson, D.T., et al., *Risk factors for incident radiographic knee osteoarthritis in the elderly: the Framingham Study*. Arthritis Rheum, 1997. **40**(4): p. 728-33.
2. Jarvholm, B., et al., *Age, bodyweight, smoking habits and the risk of severe osteoarthritis in the hip and knee in men*. Eur J Epidemiol, 2005. **20**(6): p. 537-42.
3. Leung, Y.Y., et al., *Cigarette smoking and risk of total knee replacement for severe osteoarthritis among Chinese in Singapore - the Singapore Chinese health study*. Osteoarthritis Cartilage, 2014.
4. Burström K. *Hälsorelaterad livskvalitet mätt with EQ5D – en beskrivning av instrumentet samt resultat from en befolkningsundersökning i Stockholm län*. Samhällsmedicin, Stockholms läns landsting. Katarina Tryck AB 2002.
5. Burstrom, K., et al., *Swedish experience-based value sets for EQ-5D health states*. Qual Life Res, 2014. **23**(2): p. 431-42.

BOA's three branches

BOA stands for Better management of patients with Osteoarthritis (OA). BOA consists of three main branches of activities: patient education (a supportive osteoarthritis self-management programme), staff training in the implementation and evaluation of a supportive osteoarthritis self-management programme to insure equivalency of content and presentation, and the National Quality register, the BOA register. The BOA register is an intervention register for patients with symptoms from the hips and knees, and evaluates the results of a physiotherapy intervention - the supportive osteoarthritis self-management programme.

Aims and objectives of BOA

BOA's objectives are to offer all patients with OA adequate and equivalent information and training according to current treatment guidelines, and to consider surgery only 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 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 for patients with OA has as beneficial an effect on pain as medication. In BOA we have utilised this knowledge in an evidence-based supportive osteoarthritis self-management programme offered to patients. OA is one of the most common causes of inactivity among the elderly, and many fear that activity will damage their joints. Inactivity itself is a large risk factor for poor physical and psychological health and premature mortality (1). An evidence-based supportive osteoarthritis self-management programme aims to raise physical activity levels and provide knowledge of how patients 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 treatment quality by means of systematic evaluation, open comparison and feedback of results.

1. Patient education - An evidence-based supportive osteoarthritis self-management programme

Target group

The evidence-based supportive osteoarthritis self-management programme targets patients with hip and knee symptoms troublesome enough to initiate a health care consultation. X-rays or a previous diagnosis is not a prerequisite. All patients considered able to gain benefit from participation in a supportive osteoarthritis self-management programme meet with a physiotherapist for an individual consultation prior to starting the programme. The patient's medical history and physiotherapist's examination provides the basis for a diagnosis, or can at least exclude other causes of symptoms. 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 symptoms are not due to OA, treatment as offered in the supportive osteoarthritis self-management programme – information and training – is aimed at disabilities, and 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 more in need of another kind of management, and are therefore excluded from the supportive osteoarthritis self-management 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

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

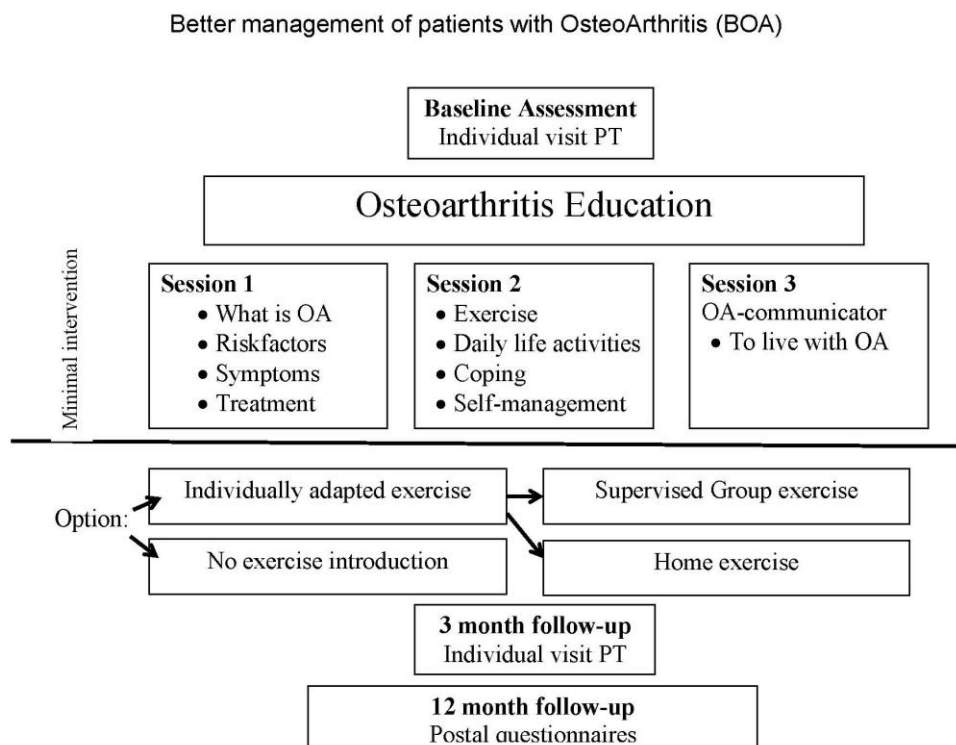


Figure 1. Plan for a supportive osteoarthritis self-management programme.

Individually customized training

Following the theoretical part of the supportive osteoarthritis self-management programme patients are offered an individually tested training program and an opportunity to train with others under the guidance of a physiotherapist. Training can include sessions to improve fitness, strength and function. Training of muscle function is not based on an exact number of specific exercises, sets or repetitions, but on neuromuscular control and movement quality. Pain during training is not an obstacle, but should not exceed the limit for what is experienced by the patient as acceptable. An eventual increase of pain after training should disappear within 24 hours. Otherwise, the length and/or intensity should be adjusted. Patient interviews have shown that feedback is experienced as an especially important aspect of training. The physiotherapist is present and accessible for continual feedback on both the quality and execution of the exercise as well as the choice and dosage at each training session.

Training is voluntary but the programme aims for as many as possible to feel the desire and need to learn more of how to best deal with their illness and the accompanying difficulties, through correct training and daily physical activity. Follow-up of all patients occurs three months after the first visit, or at the programme's conclusion. Discussions concerning suitable home exercise and planning for continued physical activity/training after a supportive osteoarthritis self-management programme is an important part of the intervention and should be introduced early, taking place along with supervised training. Training can effectively reduce symptoms of OA but the effect is only temporary. A lasting effect of training of treatment demands planning and continuous training. Prescribed physical activity can be a suitable tool for health care to stimulate increased activity levels of patients. Long lasting illness demands long lasting treatment.

2. Training of professionals

Physical therapists and interested occupational therapists are trained through BOA to enable carrying out and evaluating a supportive osteoarthritis self-management programme in an equivalent manner. A two-day training programme includes current evidence in the field and strives to provide deeper knowledge of OA and its non-surgical treatment. The training also includes basic knowledge of registers, since quality registers within physiotherapy are still relatively new and unfamiliar.

3. The National Quality Register

A supportive osteoarthritis self-management programme aims at influencing health-related quality of life, pain, physical activity levels, kinesiophobia, motivation to surgery, and self-efficacy for influencing symptoms. These variables are registered in the BOA register, along with, among other items, patient satisfaction. The physiotherapist leading a supportive osteoarthritis self-management programme usually also reports to the register. Evaluation takes place prior to a supportive osteoarthritis self-management programme, after three months (at the end of a supportive osteoarthritis self-management programme) and after one year. One hundred patients that responded to the one-year follow-up the previous year are chosen at random each coming year for a yearly follow-up for as long as they live.

Facts about BOA

BOA was initiated in 2008 as a 3-year collaboration between the Regions of Västra Götaland and Skåne, and Värmland's and Västerbotten's county councils, financed by The Swedish Social Insurance Agency and government financing to the regions. The BOA registry was introduced as a National Quality Registry in 2010.

Organisation

The BOA register is commissioned and supported by the Swedish Association of Local Authorities and Regions, the Swedish Association of Physiotherapists, the Swedish Association of Occupational Therapists, and the Swedish Orthopaedic Association. The register is financed mainly by grants from the steering committee for National Quality Registers and Region Västra Götaland. The BOA register is linked to the Register Centre Västra Götaland.

Steering Committee

Beryl Svanberg replaced Ingrid Cederlund in 2014 as patient representative in the steering committee. Malin Jönsson-Lundgren left the steering committee. Per Kristiansson, Associate Professor of General Practice, Uppsala University joined in 2014.

Register director

Carina Thorstensson, Chairman, Associate Professor, RPT, Register center Region Västra Götaland, Göteborg

Leif Dahlberg, Professor, head of the Department of Orthopaedics, Inst. Of Clinical Sciences, Lund Clinical Sciences, Lund University, Skåne University Hospital, Lund, Sweden

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Ingrid Stenhagen Coordinator, Register centrum Region Västra Götaland, Göteborg

Contact persons

The goal is at least one so-called contact person, or correspondent, for each region/county council for the BOA register. This contact person is to work on a regional level to improve completeness, fulfill the registry's target levels and identify areas for improvement. More specifically, this implies for example:

- Making an inventory of the number of clinics providing supportive osteoarthritis self-management programs and, if necessary, initiate the start-up of a supportive osteoarthritis self-management program at clinics.
- Ensuring that those clinics who run a supportive osteoarthritis self-management program undergo training in a supportive osteoarthritis self-management program.
- Ensuring that all supportive osteoarthritis self-management programs in the region report to the BOA register.
 - Listing obstacles for registration
 - Offering support
 - Initiating training in register skills
- Creating a network for those clinics running a supportive osteoarthritis self-management program.
- Stimulating the use of internal results for operative development and quality improvement, for example by comparing and discussing results between clinics at network meetings.
- Following up and discussing data quality on a clinic level.
- Being a spokesperson
 - Providing information between registry management and users, and to policy makers, administrators and health care providers in the region.
- Stimulating marketing of BOA to care units
 - Encouraging care units to inform physicians and district nurses about the supportive osteoarthritis self-management program to meet the goal of reaching patients as early as possible in the course of the disease.

To facilitate support and discussion of results and data quality, the contact person should be delegated assignments from the primary care administration. These assignments entitle access to data from the different units with a common administration (county council/region). An authorized representative for the administration signs the contract. A template for such contract can be obtained from the registry. Private care providers may delegate this authorisation to the contact person for the county council/region. (For care providers in the private sector the contract is valid for only one care provider per contract).