

ANNUAL REPORT 2012

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Generation of the Yearly Report

The data extraction for this yearly report and the formatting was done by Dr. Daniel Stekhoven. This document was generated with the open source software Sweave, L^AT_EX and R. Sabine von Känel and Almut Scherer proofread the yearly report.

1 Editorial

1.1 Foreword by the President

2012 was a year of consolidation. The SCQM office, representatives of the sponsors as well as participating researchers accomplished numerous goals of which a few will be mentioned in the following.

A large number of modifications and optimisations of the database were implemented. The main foci of these measures were to facilitate data entry and visit planning, as well as the constant strive for increased data quality.

In the past the SCQM missed-out on patients participating in observational studies performed by industrial entities due to redundancies in the data collection process. To avoid this in the future, industrial partners and SCQM have developed a basis for collaboration. A first observational study including joint data collection is arranged.

The Biobank is enriched with new blood samples at a strong pace. This puts first research studies involving these bio samples within reach. Section 7 of this annual report gives a close review on the expansion of the Biobank.

It is a pleasure to announce that once again several distinguished studies have been published in 2012. Many new scientific projects are ongoing and planned for the coming years. A new feature is the release of slides summarising previous published projects on the online database. The goal is to promote the perception of SCQM as reference platform for research in rheumatology.

The statistical support of research projects by the scientific team of the SCQM office has vastly increased in 2012. This is very pleasant, because such services reduce the reluctance of young researchers to participate. The goal is to further extend this support by offering purposeful and fast statistical products of high quality. An increase in the staffing of the scientific team should be made possible by financial assets acquired by these services. In her review Sabine von Känel gives a more in-depth insight on this matter.

With the enacting of the regulations for research and collaboration in 2011 and follow-up modifications in 2012 the work of the task force "Research and Database" came to a conclusion. These regulations warrant the frictionless research for doctors actively collaborating with the SCQM, while at the same time ensuring the necessary quality standards.

The path of consolidation was further used to intensify the discussion for adding a registry for osteoporosis to the SCQM database. A survey amongst members of the SGR was performed. Contacts with members of the osteoporosis platform, especially its president H. J. Häuselmann, were established. I refer once more to the review of the general manager elaborating with more details on the negotiations which have taken place in 2012.

I sincerely thank all employees of the SCQM office and especially the general manager, Sabine von Känel, for their enormous commitment and excellent work. Also, my gratitude goes to all participating patients and doctors, the sponsors and the researchers for their support which is indispensable for the fruitful advancement of the SCQM foundation.

Adrian Forster
President of the SCQM Board

1.2 Review 2012

Research

The focus of SCQM activities in 2012 was statistical support of research projects. Almut Scherer, who successfully finished her Master of Biostatistics in summer 2012, performed data extractions, data analyses and statistical calculations for numerous projects. Two projects using ultrasound data (SONAR) were also realised, under the lead of Pascal Zufferey. A list of all published and ongoing research projects can be found on page 32.

As of November 2012, data extractions on behalf of the European research project TOCERRA are coordinated at the SCQM office in Zurich. Combined data of the contributing registries is analysed at the SCQM. The project is under the direction of Prof. Cem Gabay and is scheduled for three years. This project has allowed us to generate and finance an additional 60% position for a statistician. This is taking pressure off the staffing bottleneck in the field of statistics at SCQM.

Online Database

Since October 2012, slides with the most important results from research projects involving SCQM data are available from the online database. These slides are made accessible by the principal investigators and can be used for talks/presentations using the appropriate referencing. The online database was further developed to enhance the user friendliness. For example, during data entry coloured input fields show missing information for important questions. Another new useful feature that was implemented in the online Database is the planning of SCQM visits, which allows the patient to enter his/her data before the visit with the rheumatologist. This new feature has two advantages. First, it assures that all relevant SCQM patient data is available to the doctor at the consultation with the patient. Second, the sometimes time-consuming work of the medical practice assistant of asking patients to hand-in their patient questionnaire is rendered unnecessary. This feature is only available for patients who fill-in their questionnaires online. Since more and more elderly people have extensive computer and web knowledge it is to be expected that the number of patients who use online database entry as their method of choice can be further increased.

In 2012, 7.5% of the patient and 81% of the doctor data was entered online.

Biobank

The primary goal of the reporting year was to increase the number of bio sample contributing institutions. 810 patients agreed to store their samples in the Biobank until the end of 2012. Further details can be found in Section 7.

Financing

While cost of operation was covered by sponsors (for a full list of sponsors see page 23), the financing of data extractions, analyses and statistical support for research projects was fully ensured by the research fund, which was established 2011. Each approved research project is entitled to 10 hours of support from one of the scientific employees at SCQM. Additional hours will be charged as described in the regulations for research and cooperation. These

charges flow directly into the research fund. Additionally, the fund was supported by grants and donations by private associations and the Swiss Society of Rheumatology (SGR).

The costs for the Biobank are carried by a private foundation since its initiation and will be covered until 2014. The following year new sources for the financing of the Biobank need to be acquired. Research projects involving bio samples have to be fully financed through external funding. Generally, these projects incorporate large costs for wet lab analyses.

Funding of the pharma industry was substantially decreased by splitting the financing model. This goal was aimed at for some time now. The pharma industry constitutes an important partner of the SCQM Foundation. However, it is important to note that neither the work of the SCQM nor the research projects are influenced in any way by the pharma industry.

Members of the executive and scientific committee work in an honorary capacity. Members of the foundation board may be recompensed if working in a private practice (according to the FMH regulations).

SCQM Office

During the reporting year 11 persons (generating about 480% full-time equivalent(FTE)) were working at the SCQM office:

- 6 employees (monthly wage),
- 3 employees (hourly wage, medical students),
- 1 trainee (Diploma in Office Administration),
- 1 voluntary employee.

Description	FTE
Cohort maintenance: data collection, data extraction, adverse event notices, feedbacks, follow-up visit reminder, etc.	200%
RX scoring (Ratingen Rau)	20%
RX digitalising	15%
Administration, communication	80%
Research project support	80%
Biobank	50%
Advancement of online database	35%

Other Registers

The 2011 started negotiations for establishing an osteoporosis cohort as part of SCQM in joint collaboration with the association Osteoporose Plattform SGR have been intensified. The goal of such a cohort is on one hand the research in the field of secondary osteoporosis and on the other hand the validation of TOPTool. TOPTool was developed by Prof. H.J. Häuselmann (Zurich) and is a web-based tool to calculate the risk of osteoporosis-related fractures in individual patients.

An osteoporosis cohort would substantially improve the already present osteoporosis-relevant data of patients suffering from inflammatory rheumatic diseases in the SCQM register. A collaboration of the two partners closely associated to the Swiss Society of Rheumatology

(SGR) would result in valuable synergies and saving of resources. Negotiations will continue in 2013.

A group of child rheumatologists under the direction of Dr. Michaël Hofer (Lausanne) started a discussion about the establishment of a cohort for juvenile patients suffering from juvenile idiopathic rheumatic diseases. In this context, the disease transition of patients from juvenile to adult will be of great scientific interest. Especially because of these patients only very little longitudinal data is available. Further discussion will show if and in what kind collaborations in this field will be possible.

Vocational Training Event for Medical Practice Assistants

A vocational training event including talks from experts (medical doctors, physical therapists, etc.) about relevant subjects in the field of inflammatory rheumatic diseases was held in Pfaffikon SZ in August 2012. Additionally, the newest features of data entry in the online database were shown in a workshop. Participating practice assistants will be able to support rheumatologist with these tasks. The event was hosted in collaboration with the Swiss League against Rheumatism.

Sabine von Känel
General Manager

2 Contributors to the SCQM Registry

All patients in the SCQM registry are included in one of our three cohorts, that is, axial Spondyloarthritis (axSpA), Psoriatic Arthritis (PsA) or Rheumatoid Arthritis (RA). A written consent is required by all patients prior to study inclusion. The only prerequisite for inclusion is being able to communicate in French, German or Italian. Participating SCQM rheumatologists are based in private practices, regional hospitals and university hospitals.

Table 2 represents all rheumatology offices that have contributed data for at least 10 patients in the year 2012. Table 1 shows the same information for rheumatology clinics in hospitals. A more detailed list of contributing institutions can be found on <http://www.scqm.ch/institutions>.

Patients	Institutions
200+	Universitätsspital Zürich (Zürich), Centre hospitalier universitaire vaudois (Lausanne)
150 - 199	Inselspital Bern (Bern), Kantonsspital St. Gallen (St. Gallen)
100 - 149	Hôpitaux Universitaire de Genève (Genève), Kantonsspital Luzern (Luzern), Kantonsspital Aarau (Aarau), Bethesda-Spital (Basel), Bürgerspital Solothurn (Solothurn)
50 - 99	Kantonsspital Winterthur (Winterthur), Hirslanden Klinik St. Anna (Luzern)
20 - 49	Schulthess Klinik (Zürich), Zuger Kantonsspital (Baar), aarReha Schinznach (Schinznach Bad), Felix Platter Spital (Basel), Hirslanden Klinik Birshof (Münchenstein), RehaClinic Zurzach (Zurzach), Kantonsspital Schaffhausen (Schaffhausen)
10 - 19	Universitätsklinik Balgrist (Zürich), Klinik St. Katharinental (Diessenhofen), Hôpital cantonal Fribourg (Fribourg), Zürcher Höhenklinik (Davos), Reha Rheinfelden (Rheinfelden), Hôpital Fribourgeois (Tafers)

Table 1: Number of patients in hospitals for whom data was contributed in 2012.

Patients	Institutions
100+	Praxis Exer / von Mühlenen (Basel), Klinik Impuls (Wetzikon), OsteoRheumaBern (Bern)
80 - 99	Rheumatologie im Silberturm (St. Gallen), Praxis Wicht (Solothurn), Praxis Martin (Liestal), Medizinisches Zentrum Brugg (Brugg)
60 - 79	Praxis Suter (Bern), Praxis Müller-Werth (Sarnen), Praxis Maager (Aarau), IZZ Immunologie-Zentrum Zürich (Zürich), Rheumapraxis Langenthal (Langenthal), Praxis Tauxe (Vevey)
40 - 59	Praxis Chamot (Morges), Praxis Widrig-Bernhardt (St. Gallen), Praxis Badaracco (Lugano), Praxis Elmiger (Bern), Praxis Marbet Grierson (Olten), Praxis Sauvain (Fribourg), Praxis Bosia (Locarno), Praxis Rösler (Bern), Praxis Schneeberger (Martigny), Praxis Carey-Berner (Lausanne), Praxis Masina (Lugano), Praxis Boller (Interlaken)
20 - 39	Praxis Dr. Manuel Klöti (Luzern), Praxis Messikommer (Visp), Praxis Kowalski (Solothurn), Praxis Ziehmann (Zürich), Praxis Gut (Reinach), Praxis Maclachlan / Schwarz (Heiden), Praxis Glenz (Visp), Praxis Kaiser (Thalwil), Praxis Bloesch Anne-Claire (Lausanne), Praxis Gerny (Thun), Praxis A. Wüest (Wädenswil), Praxis Gratzl (Basel), Praxis Schürch (Lausanne), Praxis Meder (Zofingen), Praxis Schwartz (Carouge), Praxis Gäumann (Murten), Praxis Muff (Affoltern a. Albis), Praxis Volken (Sierre), Praxis Frey Dieter (Basel), Praxis Mathieu (Solothurn), Praxis Morell (Schaffhausen), Praxis Schönbächler (Zürich), Praxis Häuselmann (Zürich), Dr Plihal Sumi (Lausanne), Praxis Gerber Markus (Bern), Praxis Picozzi (Einsiedeln), Praxis Neumatt (Aesch)
10 - 19	Praxis Pancaldi (Muralto), Praxis Raccaud (Lausanne), Rheumapraxis Männedorf (Männedorf), Das Rückenzentrum (Thun), Praxis Hasler-Strub (Chur), Praxis Flück (Zürich), Praxis Adank (Biel), Praxis Jaschko (Rümlang), Praxis Pellet (Zürich), Praxis Pfister Julius (Cham), Praxis Medinger Sadowski (Nyon), Praxis Bauer / Pilgrim (Muri), Praxis Christian Brunner (Zürich), Rheumapraxis Spring (Sargans), Rheumapraxis-Schmidt (Bern), Praxis Arnold (Solothurn), Praxis Spiess (Sissach), Praxis M. Walder (Dübendorf), Praxis Bloesch Daniel (Olten), Praxis Turan (Zürich)

Table 2: Number of patients in private practices for whom data was contributed in 2012.

3 Rheumatoid Arthritis Report

3.1 Population

The SCQM registry for rheumatoid arthritis exists since 1995. Overall there are 7424 patients and over 40390 visits in the rheumatoid arthritis cohort (status at end of May 2013). The median number of visits per patient is 4, with a range of up to 64 visits. In 2012, we received one or more visits for 2694 patients.

3.2 X-ray

X-rays (hands and feet ap) from rheumatoid arthritis patients, which are sent to SCQM at inclusion and subsequently at regular intervals get digitalised and stored in the online database. The joints of the feet and hands are evaluated by the Ratingen Rau score. The score can be seen in the online database at the level of the patients scoreboard. The X-rays are accessible and downloadable by the treating rheumatologist at any time from the online database.

3.3 Sample

The results in the following tables and figures are shown for the year 2011 and 2012 and for inclusion or follow-up visits. A follow-up visit could be either a yearly control or an intermediate control. If a patient was recorded with more than one follow-up visit, an average of the available disease activity scores was used.

3.4 Variables

Patient information includes gender, date of birth and date of RA diagnosis. Laboratory tests include rheumatoid factors (RF), erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP). Joint destruction is assessed based on hand and feet X-ray. X-rays are scored in the SCQM office according to the method proposed by Rau et al. (Rau R, Wassenberg S, Herborn G, Stucki G and Gebler A, *A new method of scoring radiographic change in rheumatoid arthritis*, J. Rheumatol. 1998). Clinical assessment includes a 28 swollen and tender joint count, which together with ESR are used to calculate the Disease Activity Score (DAS28). When a rheumatologist has finished entering a new SCQM visit, he is reminded by the online database to check the correctness of the medication data we have for this patient. When the rheumatologist chooses 'side effect' as the reason for discontinuation of a drug, he is asked by the online database to complete an adverse event form. Patient questionnaires include the RA disease activity index (RADAI), the Stanford Health Assessment Questionnaire (HAQ), the SF-36 (SF36 stands for Short-form-36, a generic questionnaire to measure quality of life), the EuroQol and a questionnaire about cardiovascular problems.

3.5 Results

The results of the analysis are shown separately for inclusion and follow-up visits for 2011 and 2012. Patients included in 2011 may also be in the group of the follow-up patients of 2012.

3.5.1 Patient Characteristics

Table 3 shows patient characteristics data. There were 600 patients enrolled in the RA database in 2011. In 2012 we received 489 inclusion questionnaires. 2311 patients had a follow-up visit

	Inclusion 11	Inclusion 12	Follow-up 11	Follow-up 12
Number of patients	600	489	2311	2291
Mean (sd) age [years]	56 (14)	56 (13)	–	–
Female [%]	73	75	–	–
Symptoms–diagnosis [months]	5 (1-12)	6 (2-19)	–	–

Table 3: Patient characteristics of inclusion and follow-up patients in 2011 and 2012. *sd* stands for standard deviation, and *IQR* for inter quartile range of the median time between first symptoms and diagnosis.

in 2011, for 2012, 2291 follow-up visits are in the RA database. About 25% of the patients are male. Newly included patients are on an average 56 years old.

3.5.2 Variables of Disease Activity

The following table presents several variables of disease activity. When more than one questionnaire existed for a patient in the respective period, an average of the visit data was used for the analysis of the follow-up patients. In all tables and figures, the data are shown separately for inclusion and follow-up in 2011 and 2012. For the different scores the mean and the standard deviation are listed. The scores shown are the global health assessment by patient, the RADAI, DAS28 and HAQ (see caption Table 4 for explanation of these acronyms).

	Inclusion 11	Inclusion 12	Follow-up 11	Follow-up 12
Number of patients	600	489	2311	2291
Mean glob. NRS pat.	5.8 (2.3)	5.8 (2.4)	6.2 (2.3)	6.4 (2.3)
mean DAS28(ESR)	3.7 (1.5)	3.6 (1.5)	2.9 (1.2)	2.9 (1.2)
mean DAS28(CRP)	3.5 (1.3)	3.4 (1.3)	2.8 (1)	2.7 (1)
mean RADAI	3.7 (2.1)	3.5 (2)	2.7 (2)	2.6 (2)
mean HAQ	0.8 (0.7)	0.7 (0.6)	0.8 (0.7)	0.7 (0.7)

Table 4: Disease activity at inclusion and at follow-up of patients with the indicated type of visit in 2011 and 2012. Standard deviations are indicated between brackets. Mean glob. NRS pat. is the patients assessment of global health, on a numerical rating scale from 0 to 10 (0 meaning bad health and 10 excellent health). DAS28(ESR) is the Disease activity score, based on tender and swollen joint count and the erythrocyte sedimentation rate (scale 0 – 10, 10 being the maximal disease activity). The RADAI is the Rheumatoid Arthritis Disease Activity Index, which takes patient estimate of disease activity, of joint stiffness and pain in specified joint regions into account (scale 0 – 10, 10 being the highest disease activity). HAQ stands for Health Assessment Questionnaire, which measures physical disability (scale 0 – 3, 3 being the highest level of functional disability).

As shown in Table 4 and Figure 1, there is a difference between the groups of inclusion patients and follow-up patients. The RADAI and DAS28 scores show a higher disease activity for patients included in 2011 or 2012, as compared to patients that had a follow-up visit in these years. Note that this is a cross-sectional comparison, *i.e.*, we do not evaluate the change in disease activity in patients between inclusion and follow-up. The same trend can be seen for the other relevant scores like the RADAI and DAS28. However, functional disability as

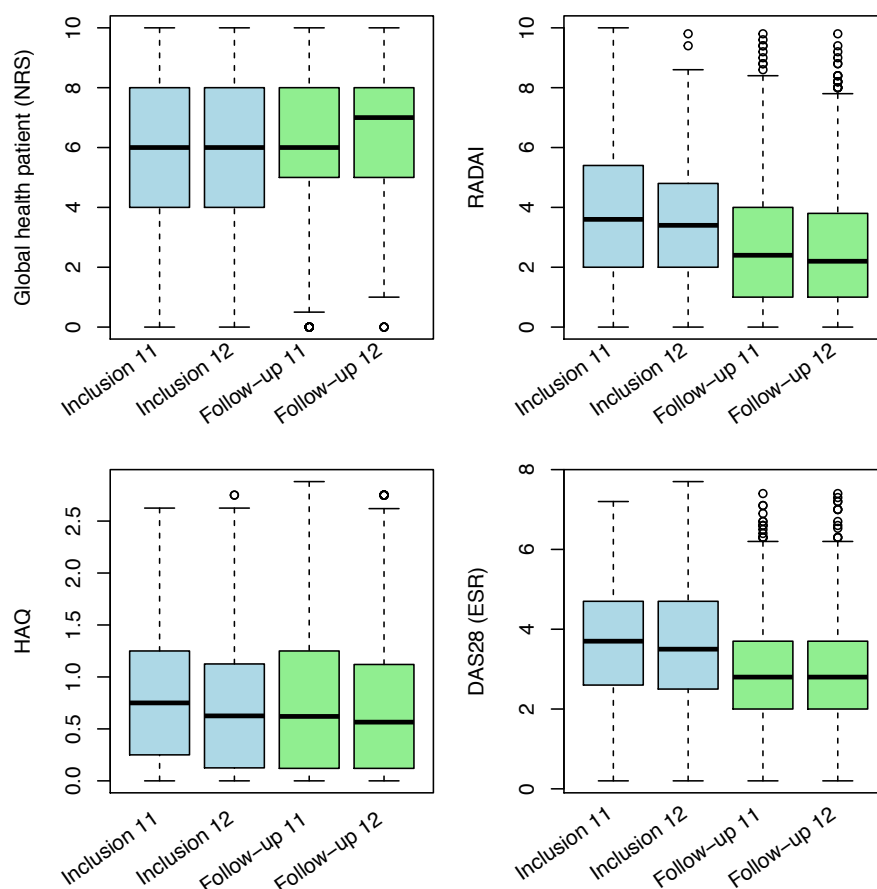


Figure 1: Box plots for the global health estimated by the patient, RADAI, HAQ and DAS28 (ESR). The box plots display median (fat black line in the box) and inter quartile range (range within the box). The data points that lie outside the whiskers are considered outliers.

measured by the mean HAQ score (Health Assessment Questionnaire) shows less variation, which is expected since this outcome measure is less sensitive to change. The DAS28 is a composite measure of the underlying inflammatory disease activity. The DAS28 can be classified into disease activity categories, such as high, moderate or low disease activity. This interpretation is based on a classification system suggested by experienced rheumatologists (Van Gestel AM *et al*, Arthritis Rheum. 1998) and has been shown to have predictive validity on development of joint destruction (Prevoo MLL *et al*, Arthritis Rheum 1995). There are four categories: remission ($\text{DAS28} \leq 2.6$), low disease activity ($2.6 < \text{DAS28} \leq 3.2$), moderate disease activity ($3.2 < \text{DAS28} \leq 5.1$) and high disease activity ($\text{DAS28} > 5.1$). The DAS28 score has been widely adopted by researchers in rheumatology both in Europe and world-wide. Figure 2 presents the percentage of the patients for the four categories. About a quarter of patients have a high disease activity at inclusion in 2011 and 2012, whereas only about 10% respectively 15% of the follow-up patients belong to this category. Over a third of the follow-up patients, however, are in remission. This trend to lower disease activity at follow-up is probably related to the initiation of adequate anti-rheumatic therapy after inclusion into the registry.

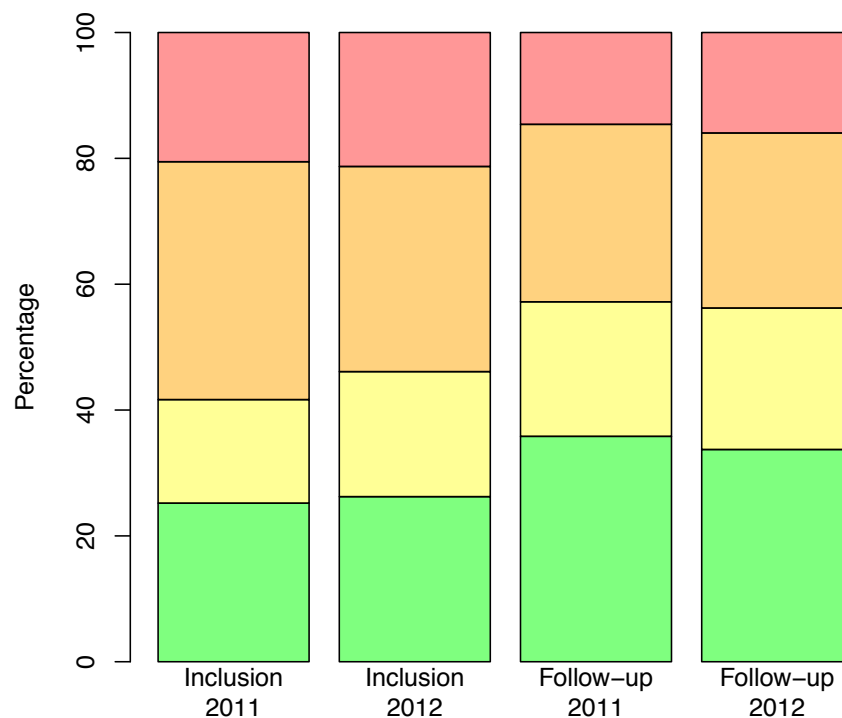


Figure 2: Percentage of patients in each of the DAS28 (ESR) categories. In green is the percentage of patients in remission, in yellow, orange and red the patients with low, moderate and high disease activity, respectively.

3.5.3 Prescription of Disease Modifying Anti-rheumatic Drugs (DMARDs)

Disease Modifying Anti-rheumatic Drugs (DMARDs) are an important element in the treatment of rheumatoid arthritis. The most prescribed DMARD in active SCQM patients remains Methotrexate, followed by Leflunomide, Hydroxychloroquin and Sulfasalazine.

3.5.4 Surgery

Both in the inclusion questionnaire as well as in the yearly control questionnaire, the number and type of surgeries are registered. In the inclusion questionnaire, all surgeries prior to inclusion are recorded, whereas in the yearly control questionnaire only new surgeries are captured. Therefore, the inclusion and follow-up data can not be compared directly. As shown in Table 5, for about 20% of the patients, a surgery was reported to have occurred before inclusion. At follow-up visits, an operation was reported for about 9% of the patients.

The type of surgeries, and how often they were reported, is listed in Table 6. Surgeries at hands, feet and knees were most common, followed by hip and shoulder surgeries.

3.5.5 Incapability of Work and Absences at Work

In the yearly questionnaire, patients are asked whether or not they were unable to work or if they had had absences at work during the last 12 months. No external validation of these self-reported data has so far been performed. The results of these questions are displayed in Table 7.

	Inclusion 11	Inclusion 12	Follow-up 11	Follow-up 12
Number of patients	600	489	2311	2291
Hospital stay [%]	4.5	4.9	3.7	3.8
Patients with surgery	113	106	213	202
Surgeries total	158	147	229	220
Surgeries per patient	0.26	0.3	0.1	0.1

Table 5: Percentage of hospital/rehabilitation clinic stay and number of surgeries in relation to rheumatoid arthritis reported in inclusion or follow-up visit in 2011 or 2012. In the inclusion, the rheumatologists are asked to list surgeries since the start of disease, and in yearly control visits only those in the past 12 months. Therefore the number of surgeries at inclusion and at follow-up are not directly comparable.

	Inclusion 11	Inclusion 12	Follow-up 11	Follow-up 12
Total	158	147	229	220
Hand	29	30	38	38
Foot	23	26	41	46
Spine	11	9	16	17
Shoulder	14	12	18	13
Knee	28	26	35	34
Hip	33	18	28	22
Other	20	26	53	50

Table 6: Type of surgeries reported in 2011 and 2012, of patients who had an inclusion or follow-up visit in 2011 or 2012. In the inclusion, the rheumatologists are asked to list surgeries since the start of disease, and in yearly control visits only those in the past 12 months. Therefore the number of surgeries at inclusion and at follow-up are not directly comparable.

	Inclusion 11	Inclusion 12	Follow-up 11	Follow-up 12
Number of patients	600	489	2311	2291
Incapable of work [%]	7.8	7.4	6.1	6.1
Absent at work [%]	17	22.1	8.7	7.7
Up to 4 weeks [%]	10.2	12.5	5.6	4.6
More than 4 weeks [%]	6.2	7.6	2.7	2.8

Table 7: Percentage of patients current incapability of work due to the rheumatic disease and absences of work in the last 12 months due to the rheumatic disease. For the absence at work we further display whether this was short or longer absence at work. All displayed percentages are relative to the total number of patients for whom we had a visit in the indicated period. The sum of the percentages of absences less than 4 weeks and more than 4 weeks is below the total percentage of patients with absences at work, because for some of these patients, this information was not reported.

4 Axial Spondyloarthritis Report

4.1 Population

All patients with axial spondyloarthritis, independent of age, disease duration, severity and type of medication, can participate in this prospective, observational cohort study. All Swiss rheumatologists are encouraged to contribute. At the time of analysis of this report, 2710 patients were included in the SCQM axSpA registry with a total 8890 visits. The median number of visits of all patients in the axSpA cohort was 3, and the maximum of the number of visits per patient is 22. In 2012 we received one or more visits for 1285 patients (status at end of May 2013).

	Inclusion 11	Inclusion 12	Follow-up 11	Follow-up 12
Number of patients	366	316	949	1018
Mean (sd) age [years]	43 (12)	43 (12)	–	–
Male [%]	52	48	–	–
IQR symp.–diag. [months]	26.5 (6-103.25)	18.5 (4-64)	–	–

Table 8: Patient characteristics of inclusion and follow-up patients in 2011 and 2012. *sd* stands for standard deviation and *IQR* for inter quartile range of the median time between first symptoms and diagnosis..

4.2 X-rays

Pelvis (ap), lumbar spinal column (ap/lat) and cervical vertebral column (lat) X-rays from axial spondyloarthritis (axSpA) patients, which are sent to SCQM at inclusion and subsequently at regular intervals. The sacroiliac joints are evaluated by the modified New York score by the members of the scientific committee. The score can be seen in the online database at the level of the patient's scoreboard.

4.3 Results

4.3.1 Patient Characteristics

In 2011, we received 366 inclusions and 949 follow-up visit questionnaires (intermediate control or yearly control) in the database. For 2012 316 inclusion and 1018 follow-up questionnaire-sets were entered into the database of axSpA.

About half of the axSpA patients in the registry are men (see Table 8) and patients are on average about 43 years old (inclusion 2012). Between diagnosis and entry to the SCQM, a median of 18.5 months passed in 2012. The range of the time passing between diagnosis and entry into the SCQM has compared to 2011 improved (interquartile range in months 2012 18.5 (4-64)).

4.3.2 Variables of Disease Activity

Figure 3 and Table 9 represent several disease activity and disability variables of the active patients in the axSpA registry.

	Inclusion 11	Inclusion 12	Follow-up 11	Follow-up 12
Number of patients	366	316	949	1018
Mean global NRS pat.	5.1 (2.7)	5.4 (2.7)	3.8 (2.5)	3.8 (2.6)
Mean global NRS phys.	3.7 (2.1)	3.7 (2.2)	2.1 (1.7)	1.9 (1.7)
Mean BASDAI	4.7 (2.3)	4.8 (2.3)	3.6 (2.3)	3.6 (2.3)
Mean BASFI	3.2 (2.6)	3.3 (2.6)	2.6 (2.5)	2.5 (2.4)
Mean BASMI	2 (1.9)	1.7 (1.6)	2.1 (2)	2.1 (2)

Table 9: Disease activity at inclusion and at follow-up of patients with the indicated type of visit in 2011 and 2012. Standard deviation is indicated between brackets. Glob. NRS pat. and glob. NRS phys. stand for the global estimate of disease activity on a numerical rating scale by the patient and the physician respectively. BASDAI stands for Bath Ankylosing Spondylitis Disease Activity Index, BASFI for the Bath Ankylosing Spondylitis Functionality Index and BASMI for the Bath Ankylosing Spondylitis Metrology Index. All of these indexes are on a scale from 0 – 10, 0 being no disease activity and 10 maximal disease activity.

4.3.3 Prescription of Biologics

Approximately 80% of axSpA patients who attended at least one visit in 2012 were on biologics during at least part of this period.

4.3.4 Surgery

In the axSpA registry, doctors were asked to list surgeries related to the disease since the start of disease (at inclusion visit) or in the last 12 months (at yearly control visit). Table 10 lists the number of patients that had a surgery and the total number of surgeries. Table 11 lists the number of surgeries by type.

	Inclusion 11	Inclusion 12	Follow-up 11	Follow-up 12
Number of patients	366	316	949	1018
Hospital stay [%]	6.8	7	1.9	2.9
Patient with surgery	38	31	44	53
Surgeries total	43	27	39	44
Surgeries per patient	0.12	0.09	0.04	0.04

Table 10: Hospital or rehabilitation clinic stay in relation to the ankylosing spondylitis arthritis and surgeries reported in inclusion or follow-up visits in 2011 or 2012. In the inclusion questionnaires of ankylosing spondylitis, the rheumatologists are asked to list hospital stay and surgeries since the start of disease, whereas in yearly control visits only over the past 12 months. Therefore the number of patients with a hospital stay and the number of surgeries at inclusion and at follow-up are not directly comparable.

4.3.5 Incapability of Work and Absences at Work

In the yearly questionnaire, patients are asked whether or not they were unable to work or if they had had absences at work during the last 12 months. No external validation of these

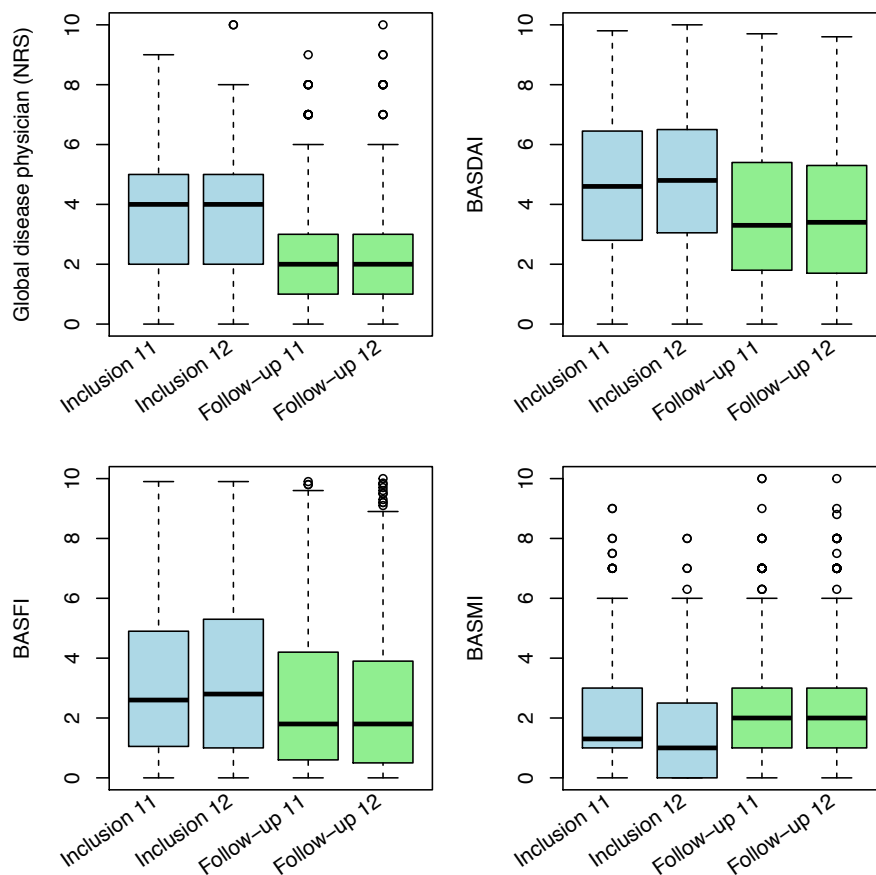


Figure 3: Box plots for the global disease activity estimated by the physician (glob. NRS phys.), BASDAI, BASFI and BASMI. (For a description of these acronyms see table 9). The box plots display median (fat black line in the box) and inter quartile range (range within the box). The data points that lie outside the whiskers are considered outliers.

self-reported data has so far be performed. The results of these questions are displayed in Table 12.

	Inclusion 11	Inclusion 12	Follow-up 11	Follow-up 12
Total	43	27	39	44
Spine straightening	3	2	1	1
Other spine	8	3	6	5
Shoulder	4	4	4	6
Knee	4	1	3	4
Hip	2	5	5	5
Other	22	12	20	23

Table 11: Type of surgeries reported in inclusion or follow-up visits in 2011 or 2012. In the inclusion questionnaires of ankylosing spondylitis, the rheumatologists are asked to list hospital stay and surgeries since the start of disease, whereas in yearly control visits only over the past 12 months. Therefore the number of patients with a hospital stay and the number of surgeries at inclusion and at follow-up are not directly comparable.

	Inclusion 11	Inclusion 12	Follow-up 11	Follow-up 12
Number of patients	366	316	949	1018
Incapable of work [%]	7.9	7.9	5.9	8.5
Absent at work [%]	26.8	33.9	16.9	16.3
Up to 4 weeks [%]	18.3	24.1	11.9	11.8
More than 4 weeks [%]	7.9	9.2	4.1	3.6

Table 12: Percentage of patients current incapability of work due to the rheumatic disease and absences of work in the last 12 months due to the rheumatic disease. For the absence at work we further display whether this was short or longer absence at work. All displayed percentages are relative to the total number of patients for whom we had a visit in the indicated period. The sum of the percentages of absences less than 4 weeks and more than 4 weeks is below the total percentage of patients with absences at work, because for some of these patients, this information was not reported.

5 Psoriatic Arthritis Report

5.1 Background Information

The registry on psoriatic arthritis (PsA) exists since 2004.

5.2 Population

All patients in Switzerland with PsA, independent of age, disease duration, severity and type of therapy can participate. It is not only a biologics registry, but a prospective observational cohort study. All Swiss rheumatologists are encouraged to contribute. At the time of analysis of this report (end of May 2013), there were over 1287 patients in the registry of psoriatic arthritis with a total of 4360 visits. The median number of visits of all patients in the PsA cohort was 3, and the maximum of the number of visits per patient is 21. In 2012, we received one or more visits for 669 patients.

5.3 X-ray

X-rays (hands and feet ap, Pelvis ap, lumbar spinal column ap/lat and cervical vertebral column lat) from psoriatic arthritis patients, which are sent to SCQM at inclusion and subsequently at regular intervals get digitalised and stored in the online database. The X-rays are accessible and downloadable at any time from the online database. These X-rays will not be scored at the moment. They may be evaluated in a study in the future.

5.4 Data Collection

The questionnaires consist of an inclusion and a yearly control set. If relevant changes of disease activity or therapy occur, a questionnaire for an intermediate control should be filled in. In the Online Database, all questionnaires are available in German, French and Italian. The aims of the registry are the collection of data on disease activity and functional parameters, the effectiveness of different therapies and socio-economic issues of the disease. Important aspects like involvement of the skin and osteoporosis are also considered. The X-ray collection for PsA patients starts in 2013.

5.5 Results

5.5.1 Patient Characteristics

	Inclusion 11	Inclusion 12	Follow-up 11	Follow-up 12
Number of patients	170	176	470	518
Mean (sd) age [years]	50 (13)	51 (13)	–	–
Male [%]	56	50	–	–
IQR symp.–diag. [months]	32 (8-92)	39 (12-89)	–	–

Table 13: Patient characteristics of inclusion and follow-up patients in 2011 and 2012. *sd* stands for standard deviation and IQR for inter quartile range of the median time between first symptoms and diagnosis.

In 2012, we received 170 inclusions and 470 follow-up visit questionnaires (intermediate control or yearly control) in the database. In 2011 176 inclusion and 518 follow-up questionnaire-sets have flown into the database of psoriatic arthritis.

	Inclusion 11	Inclusion 12	Follow-up 11	Follow-up 12
Number of patients	170	176	470	518
Mean global NRS pat.	3.9 (2.8)	4.9 (2.7)	3.3 (2.6)	3.1 (2.5)
Mean global NRS phys.	3.2 (2.2)	3.5 (2.2)	1.9 (1.7)	1.7 (1.6)
Mean swollen 68	3.6 (5.3)	3.9 (5.5)	1.4 (2.7)	1.4 (2.8)
Mean tender 68	7.7 (9.7)	7.2 (11)	3.2 (5.7)	3.2 (6.4)
Mean skin phys.	2 (1.7)	1.8 (1.6)	1.4 (1.3)	1.3 (1.3)
Mean skin pat.	2 (1.7)	2.1 (1.7)	1.7 (1.4)	1.6 (1.4)
Mean NRS pain pat.	4.2 (2.8)	5.1 (2.8)	3.5 (2.7)	3.2 (2.6)

Table 14: Disease activity at inclusion and at follow-up of patients with the indicated type of visit in 2011 and 2012. Standard deviation is given in brackets. NRS stands for Numerical Rating Scale. Glob. NRS pat. and glob. NRS phys. stand for the global estimate of disease activity by the patient and the physician respectively. Skin phys. and Skin pat. stand for the skin infestation, which is described on a scale of 0 (None) to 6 (Very strong).

5.5.2 Variables of Disease Activity

Table 14 displays relevant disease activity measures of patients with psoriatic arthritis. As shown in table 14, there is a difference between the groups of inclusion patients and follow-up patients. In this cross-sectional representation, the global estimate of disease activity by the physician and patient (glob. NRS pat. and glob. NRS phys. respectively) tends to be higher for patients that are included in the SCQM than for those that are in follow-up visits. The same trend can be seen for the other relevant scores like the patient pain and skin problems. The number of swollen and tender joints of patients in follow-up visits is only half of that of patients with an inclusion visit.

5.5.3 Prescription of Biologics

About 84% of the patients who had at least one visit in 2012 were on a biologic for at least a part of the reporting period.

5.5.4 Hospital Stay

	Inclusion 11	Inclusion 12	Follow-up 11	Follow-up 12
Number of patients	170	176	470	518
Hospital stay [%]	4.1	3.4	2.6	3.3

Table 15: Hospital or rehabilitation clinic stay in relation to the psoriatic arthritis in inclusion or follow-up visits in 2011 or 2012.

5.5.5 Incapability of Work and Absences at Work

In the yearly questionnaire, patients are asked whether or not they were unable to work or if they had had absences at work during the last 12 months. No external validation of these self-reported data has so far been performed. The results of these questions are displayed in Table 16.

	Inclusion 11	Inclusion 12	Follow-up 11	Follow-up 12
Number of patients	170	176	470	518
Incapable of work [%]	6.5	10.2	7	4.8
Absent at work [%]	15.9	23.9	10.6	11.8
Up to 4 weeks [%]	11.8	17	6.8	8.7
More than 4 weeks [%]	4.1	6.2	3.4	3.1

Table 16: Percentage of patients current incapability of work due to the rheumatic disease and absences of work in the last 12 months due to the rheumatic disease. For the absence at work we further display whether this was short or longer absence at work. All displayed percentages are relative to the total number of patients for whom we had a visit in the indicated period. The sum of the percentages of absences less than 4 weeks and more than 4 weeks is below the total percentage of patients with absences at work, because for some of these patients, this information was not reported.

6 The SONAR Group

Since 2009 ultrasound data are available in the SCQM database. Physicians who have completed the educational program on sonography for arthritis and rheumatism are given access in the Online Database to fields for entering ultrasound examination data. The scores of the ultrasound examinations are visible to all physicians involved in the treatment of a patient, which ensures a smooth flow of information.

6.1 SONAR Rheumatologists

Roughly equal numbers of rheumatologists from university hospitals, other hospitals and rheumatology practices have taken part in the SONAR training. So far, the rheumatologists from university hospitals have been more active in entering SONAR visits than other rheumatologists (see Table 17).

	Total trained	Active 2011	Active 2012
University hospital	108	20	32
Other hospital	61	8	10
Rheumatology Office	73	8	9

Table 17: Number of rheumatologists trained for SONAR and number of rheumatologists that have entered SONAR visit(s) in 2011 or 2012.

6.2 SONAR Visits

Since the start of the SONAR data collection 473 RA patients with 639 visits were recorded up to the end of 2012. The median number of visits per RA patient is 1, with a range of up to 6 visits.

Table 18 shows the number of SONAR visits in 2011 and 2012, irrespective of the diagnose of the patient.

	Inclusion 11	Inclusion 12	Follow-up 11	Follow-up 12
Number of SONAR visits	180	125	217	348
Patients with SONAR visits	162	112	190	316
Patient on biologic	105	63	142	256
Biologic started after	13	11	17	13

Table 18: *The number of SONAR visits, the number of patients with SONAR visits and the number of patients which were either under biologic at the time of sonography, or initiated a biologic treatment within 14 days of the sonographic examination.*

7 Biobank

The SCQM Biobank is located in the Serothek Centre of Geneva University Hospital, Département de Médecine génétique et de Laboratoire (Head: Prof. Denis Hochstrasser). Its primary objective is to collect a sample of serum and DNA from all patients who are included in the SCQM registry and those who are still to be added to it. There are no exclusion criteria for the patients donating their bio samples to the Biobank: All patients in Switzerland, independent of age, disease duration, severity and type of therapy can participate as long as they have provided their written consent to bio materials being collected.

At the end of 2012, the Biobank of the SCQM had registered 810 biokits. A total of 40 institutions, three university hospitals, three regional hospitals, and 34 private practices have contributed to this collection. 37% of all bio samples have been collected in the French-speaking area, with 84% of them being a contribution of the two university hospitals located in Geneva and Lausanne. In contrast, in the German-speaking area the contribution of private practices as compared to that of hospitals (university and regional) has been 50%.

The following table shows how the bio samples are distributed through the different cohorts and according to gender.

	RA	PsA	axSpA	undifferentiated
Number of biokits	476 (59%)	102 (13%)	202 (25%)	30 (4%)
Female patients	355 (75%)	40 (39%)	88 (44%)	23 (77%)
Male patients	121 (25%)	62 (61%)	114 (56%)	7 (23%)

7.1 Adjustment of Sample Procession and Transportation

SCQM provides all materials required for taking blood and for the transportation of the bio samples. The biological specimens, blood for DNA and serum, are stored locally (initially at -20°C) before they are sent to the central Biobank, where they will be further processed,

aliquoted and stored at -80°C . After experiencing that many private practices can only freeze the samples at a minimum of -18°C , we adjusted our protocol to include also these practices in the Biobank. The second adjustment of our procedures concerns the frequency of sample transportation to the Serothek in Geneva. The samples are collected from the practices or hospitals and transported to the Serothek by a courier in a cool box with dry ice. Initially, the samples were picked up every second week. As the number of institutions contributing to the Biobank steadily increased during 2012, transport costs increased as well. To keep these costs reasonable we changed the transport procedure by picking up the bio samples every four weeks.

7.2 Research with Bio Samples

The clinical data and the Biobank data are available according to the regulations for research and collaboration. Project applications must be submitted to the SCQM office. Applications will be assessed by the Scientific Advisory Board and approved by the Foundation Board of SCQM. During 2012 there has been one official request for bio samples from Prof. Dr. Burkhard Möller, Inselspital Bern. The bio samples will be used to study the prevalence of iron deficiency in RA - a cross sectional study. The request was approved at the end of 2012.

8 Donations

The Arco Foundation supports the running costs of the SCQM Biobank with yearly contributions. Additionally, the Arco Foundation has generously provided a further donation to the SCQM Research fund. The Swiss Society of Rheumatology (SGR) has decided to support the SCQM financially for three years (2012-2014).



9 Main Sponsors

The SCQM receives annual contributions of biologics producing pharmaceutical companies. These contributions cover the costs of operation. Because of the new financing model they do not cover the costs for work related to data extraction and analysis. Contributions are not tied to restrictions in terms of research and/or publications.



10 Sponsors



11 Grants

Some research projects that were initiated in 2012 have received financial contributions by:

- the Swiss Bechterew Foundation
- abbvie
- Pfizer

These contributions are not tied to restrictions in terms of research and/or publications.

12 Annual Accounts

12.1 Auditor's Report

Treuhand
Wirtschaftsprüfung
Gemeindeberatung
Unternehmensberatung
Steuer- und Rechtsberatung
Informatik – Gesamtlösungen



**Report of the statutory auditors
on the limited statutory examination**
to the member of the foundation board of
SCQM Foundation Swiss Clinical Quality
Management in Rheumatic Diseases
8048 Zürich

As statutory auditors, we have examined the financial statements (balance sheet, income statement and notes) of SCQM Foundation Swiss Clinical Quality Management in Rheumatic Diseases for the year ended December 31, 2012.

These financial statements are the responsibility of the member of foundation board. Our responsibility is to perform a limited statutory examination on these financial statements. We confirm that we meet the licensing and independence requirements as stipulated by Swiss law.

We conducted our examination in accordance with the Swiss Standard on the Limited Statutory Examination. This standard requires that we plan and perform a limited statutory examination to identify material misstatements in the financial statements. A limited statutory examination consists primarily of inquiries of company personnel and analytical procedures as well as detailed tests of company documents as considered necessary in the circumstances. However, the testing of operational processes and the internal control system, as well as inquiries and further testing procedures to detect fraud or other legal violations, are not within the scope of this examination.

Based on our limited statutory examination, nothing has come to our attention that causes us to believe that the financial statements do not comply with Swiss law, the articles of incorporation and the rules and regulations of the foundation.

OBT AG

A handwritten signature in black ink, appearing to read 'A. Thut'.

Andreas Thut
licensed expert auditor
auditor in charge

A handwritten signature in black ink, appearing to read 'T. Koller'.

Tanja Koller
licensed auditor

Brugg, April 11, 2013

12.2 Balance

Company Balance Sheet as per	31.12.2012 CHF	31.12.2011 CHF
ASSETS		
Cash and bank	702'610.76	606'112.40
Debtors	427.65	21'396.25
Prepayments and accrued income	44'149.20	8'147.00
CURRENT ASSETS	747'187.61	635'655.65
IT equipment (Hard- and Software)	1.00	2'000.00
Tangible fixed assets	1.00	2'000.00
FIXED ASSETS	1.00	2'000.00
ASSETS	747'188.61	637'655.65
LIABILITIES		
Accrued liabilities	6'073.26	23'616.44
Accruals and deferred income	96'912.50	82'800.00
LIABILITIES	102'985.76	106'416.44
Project Biobank	158'862.86	124'794.91
Research fund	179'361.19	94'362.05
PROJECTS / FUNDS	338'224.05	219'156.96
Dedication assets	80'000.00	80'000.00
Retained profit last year	232'082.25	216'373.57
Profit (+) / loss (-) current year	-6'103.45	15'708.68
Retained profit 31.12.	225'978.80	232'082.25
FOUNDATION ASSETS	305'978.80	312'082.25
LIABILITIES	747'188.61	637'655.65

12.3 Income Statement

Company Income Statement	2012 CHF	2011 CHF
Income from sponsoring	502'500.00	602'432.77
Database sharing	8'900.00	8'900.00
Advanced training	2'920.00	7'100.00
Sponsoring	3'000.00	0.00
Financial yield	1'367.95	1'664.75
Other incomes	12'592.59	1'072.96
Income project Tocera	11'040.60	0.00
Income foundation	542'321.14	621'170.48
Salaries and related costs	-386'240.77	-345'826.08
Rent expenses	-31'908.73	-29'099.12
Servicing, repairs, replacement	-2'915.95	-225.19
Insurance of property	-960.20	-960.20
Expenses for information technology	-12'819.16	-8'089.61
Expenses for information technology online database	-54'565.75	-102'872.27
Administrative expenses	-31'682.38	-53'395.41
Communication	-13'039.99	-13'803.33
Financial expenses	-240.20	-389.10
Other expenses	-354.64	-16.48
Depreciation	-1'999.00	-50'785.01
Expenses project Tocera	-11'190.60	0.00
Expenses project Osteoporose	-507.22	0.00
Expenses foundation	-548'424.59	-605'461.80
PROFIT (+) / LOSS (-) FOUNDATION STATEMENT	-6'103.45	15'708.68
Biobank project		
Contributions	170'000.00	157'407.41
Expenses	-135'932.05	-170'421.66
Profit (+) / loss (-)	34'067.95	-13'014.25
Research fund		
Contributions	44'800.00	10'000.00
Donations	72'500.00	42'500.00
Income from accessorial services	37'886.49	26'259.70
Expenses	-70'187.35	-5'175.00
Profit (+) / loss (-)	84'999.14	73'584.70
Creation (-) / liquidation (+) projects und funds	-119'067.09	-60'570.45
RESULT PROJECTS UND FUNDS	0.00	0.00
NET PROFIT (+) / LOSS (-)	-6'103.45	15'708.68

12.4 Annexe

Notes to Financial Statements	2012 CHF	2011 CHF
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Formation and purpose of the foundation

The SCQM Foundation (Swiss Clinical Quality Management in Rheumatic Diseases), based in Zurich, was established by notarial deed on 1 October 2003 and entered in the commercial register on 12 February 2004.

The foundation operates an independent rheumatology research platform that does not represent any local, regional or personal interests. It follows neither profit-making nor self-help motives. In particular, the foundation's purpose is to continuously improve the quality of treatment for rheumatoid arthritis, ankylosing spondylitis and psoriatic arthritis by means of a feedback-based measurement system.

Fire insurance values of the fixed assets

Plant, equipment and IT	130'000.00	130'000.00
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Biobank project

The clinical, socio-economic and radiological data of the SCQM Foundation are completed by biosamples since 2011. The biosamples are stored in a central biobank. They are available for scientific study projects (rules for research and collaboration). The biobank is financed independently of the SCQM Foundation's operating costs.

Research fund

On 27 October 2010, the Foundation Board decided to use the research contributions from companies and donors to establish a research fund. With these funds only scientific work such as data analysis, statistics etc. should be financed. The contributions cannot be used for operating costs.

Details relating to the performance of a risk assessment

The Foundation Board has performed sufficient periodic risk assessments and introduced all subsequent measures necessary to ensure that the risk of a seriously incorrect statement in the accounts is minimal.

13 Board and Committees

13.1 The SCQM Board

The members of the SCQM Board (status 31.present.2012):

- Dr. Adrian Forster (President), Head of Rehabilitation Dep., Clinic St. Katharinental, Diessenhofen
- lic. iur. René Bräm, Managing director of the Swiss Association Morbus Bechterew
- Prof. Dr. Cem Gabay (Vice-President), Head of Rheumatology Dep., University hospital Geneva
- Dr. Rainer Klöti, Specialist Rheumatology FMH, Brugg
- Prof. Dr. Diego Kyburz, Leading physician Rheumatology clinic, University hospital Zurich
- Dr. Marie-Josèphe Sauvain, Specialist Rheumatology FMH, Fribourg and University Hospital (Inselspital) Bern
- Dr. Hans A. Schwarz, Emeritus Head of Rheumatology Dep., Bethesda hospital, Basel
- Prof. Dr. Alexander So, Head of Rheumatology Clinic, University hospital Lausanne (CHUV), Lausanne
- Prof. Dr. Peter Villiger, Director Dep. of Rheumatology and Clinical Immunology / Allergology, University Hospital (Insel) Bern

13.2 The Executive Committee

The task of the executive committee is to prepare decisions for the Board members.

- Dr. Adrian Forster, Head of Rehabilitation Dep., Clinic St. Katharinental, Diessenhofen
- lic. iur. René Bräm, Managing director of the Swiss Association Morbus Bechterew
- Prof. Dr. Diego Kyburz, Leading physician Rheumatology clinic, University hospital Zurich
- Dr. Hans A. Schwarz (President), Emeritus Head of Rheumatology Dep., Bethesda hospital, Basel
- Prof. Dr. Peter Villiger, Director Department of Rheumatology and Clinical Immunology / Allergology, University Hospital (Inselspital) Bern
- Sabine von Känel, General Manager
- Dr. Almut Scherer, Scientific Manager

13.3 The SCQM Biobank

- Prof. Dr. Cem Gabay (Chairman), Head of Rheumatology Dep., University hospital Geneva
- Prof. Dr. Paul Hasler, Head of Rheumatology Dep., Cantonal Hospital Aarau
- Prof. Dr. Johannes von Kempis, Head of Rheumatology Dep., Cantonal Hospital St. Gallen
- Prof. Dr. Beat Michel, Head of Rheumatology clinic, University Hospital Zurich
- Prof. Dr. Alexander So, Head of Rheumatology Dep., University Hospital Lausanne
- Prof. Dr. Alan Tyndal, Head of Rheumatology Dep., Felix Platter Spital, Basel
- Prof. Dr. Peter Villiger, Director Dep. of Rheumatology and Clinical Immunology / Allergology, University Hospital (Insel) Bern

13.4 The Scientific Committees

The committees mainly deal with the scientific aspects of the registry, their members are experts in the field of the respective registry. At least one member of the commission is a private practitioner in order to bring in the relevant inputs of a private practice. The chairman of each committee is listed first and other members alphabetically.

RA Committee

- PD Dr. Axel Finckh (Chairman), Rheumatology Clinic, University Hospital Geneva
- PD Dr. Jean Dudler, Rheumatology Clinic, Cantonal Hospital Fribourg
- Prof. Dr. Diego Kyburz, Rheumatology Clinic, University Hospital Zurich
- Dr. Ines von Mühlennen, Specialist Rheumatology FMH, Basel
- Prof. Dr. Ulrich Walker, Felix-Platter Hospital, Basel

axSpA Committee

- Dr. Adrian Ciurea (Chairman), Rheumatology Clinic, University Hospital Zürich
- Dr. Jürg Bernhard, Bürgerspital Solothurn
- Dr. Pascale Exer, Specialist Rheumatology FMH, Basel
- Dr. Rüdiger Müller, Rheumatology Clinic, Cantonal Hospital St. Gallen
- Dr. Michael Nissen, Rheumatology Clinic, University Hospital Geneva
- Dr. Giorgio Tamborini, Rheumatology clinic, University Hospital Zurich
- Dr. Martin Toniolo, Rheumatology Clinic, University Hospital Zurich
- Dr. Bettina Weiss, Rheumatology Clinic, University Clinic Balgrist, Zürich

PsA Committee

- Prof. Dr. Burkhard Möller (Chairman), Dep. of Rheumatology and Clinical Immunology / Allergology, University Hospital (Insel), Bern
- PD Dr. Jean Dudler, Rheumatology Clinic, Cantonal Hospital Fribourg
- Dr. Bettina Weiss, Rheumatology Clinic, University Clinic Balgrist, Zürich
- Prof. Dr. Nikhil Yawalkar, Dermatology Clinic, University Hospital (Insel), Bern

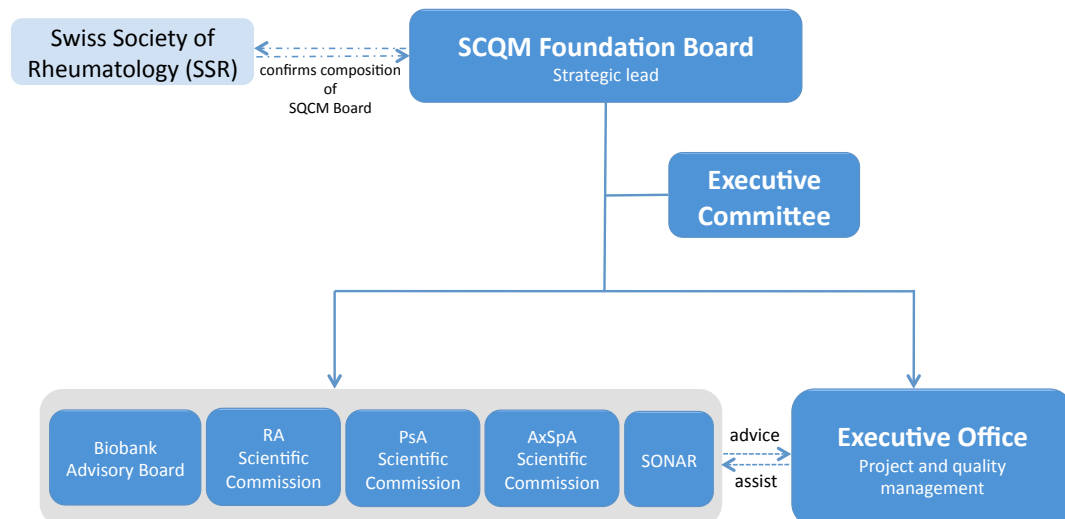
SONAR Committee

- Dr. Pascal Zufferey (Deputy of SONAR group), Rheumatology Clinic, University hospital Lausanne (CHUV), Lausanne
- Dr. Laure Brulhart, Rheumatology Clinic, University Hospital Geneva
- Prof. Dr. Thomas Gerber, Center for Rheumatology and Bone Diseases, Zürich
- Dr. Andreas Krebs, Rheumatology Clinic, University Hospital Zurich
- Dr. Stefan Mariacher, RehaClinic Baden, Baden
- Prof. Dr. Burkhard Möller, Dep. of Rheumatology and Clinical Immunology / Allergology, University Hospital (Insel), Bern
- Dr. Andrea Stärkle Bär, Rheumatology Clinic, University hospital Zürich
- Dr. Giorgio Tamborini, Rheumatology Clinic, University Hospital Zurich
- Dr. Hansruedi Ziswiler, Dep. of Rheumatology and Clinical Immunology / Allergology, University Hospital (Insel), Bern

13.5 The SCQM Office

- Sabine von Känel, General Manager
- Dr. Almut Scherer, Scientific Manager
- Dr. Albana Rexhepaj, Monitor SCQM Biobank
- Jacqueline Hirt, Monitor Online Database, Data Entry Coach
- Heinz Wyrsh, responsible for RA and PsA
- Susanne Frieser, Assistant for Administration and responsible for PsA (until Oct. 2012)
- Myriam Riek, Scientific Assistant TOCERRA project (starting Nov. 2012)
- Dominik Loiero, RA X-rays scoring
- Daniele Gianoli, X-ray digitisation
- Guillaume Wuilleret, responsible for axSpA
- Ömer Ünal, voluntary employee

13.6 The SCQM Organigram



14 Research 2012

14.1 Publications

- *Disease Activity in Rheumatoid Arthritis Patients at Initiation of Biologic Agents and 1 Year of Treatment: Results from the Swiss SCQM registry.* Pascal Zufferey et al., Joint Bone Spine, July 2012.
- *Evolution of Radiographic Joint Damage in Rituximab-Treated versus TNF-Treated Rheumatoid Arthritis Cases with Inadequate Response to TNF Antagonists.* Axel Finckh et al., Ann Rheum Dis, March 2012.
- *Pain as an Important Predictor of Psychosocial Health in Patients with Rheumatoid Arthritis.* Delphine S Courvoisier et al., Arthritis care & research, Feb. 2012; 64(2):190-6.
- *Differential drug retention between anti-TNF agents and alternative biological agents after inadequate response to an anti-TNF agent in rheumatoid arthritis patients.* Sophie Martin Du Pan et al., Ann Rheum Dis, Jan. 2012.

14.2 Abstracts Presented at Conferences

14.2.1 ACR/ARHP Annual Meeting Washington

- *SCQM Foundation, Exhibit to Promote Awareness of Clinical Trials, Registries, Repositories and Cohorts Related to Rheumatology and Rheumatic Diseases.* Adrian Forster and Albana Rexhepaj, Zurich. Poster presentation.
- *Anemia May Provide Clinically Relevant Information Beyond Conventional Disease Activity Assessment to Predict Radiographic Damage Progression in Rheumatoid Arthri-*

tis. (Session: Rheumatoid Arthritis - Clinical Aspects I: Risk Factors and Prediction of Rheumatoid Arthritis. Burkhard Möller, Bern. Oral presentation.

- *Is Late Onset Rheumatoid Arthritis (LORA) Really a Distinct Entity of RA? Results From the Swiss Observational Cohort (Session: Rheumatoid Arthritis - Clinical Aspects I: Risk Factors and Prediction of Rheumatoid Arthritis), Rüdiger Müller, St. Gallen. Oral presentation.*
- *Early RA Patients Fulfilling the New 2010 ACR/EULAR Criteria, Display Better Clinical Responses to DMARD Therapy but Have Higher Radiographic Damage Progression Than Patients with Early RA Not Fulfilling the 2010 ACR/EULAR Criteria (Session: Rheumatoid Arthritis - Clinical Aspects III: Infections/Risk Factors for Incident Rheumatoid Arthritis /Metrology/Classification/Biomarkers/ Predictors of Rheumatoid Arthritis Activity & Severity). Rüdiger Müller, St. Gallen. Poster presentation.*
- *The Caspar Classification Criteria and Response to TNF Blockade in Rheumatologists Practice: A Large Observational Cohort Study (Session: Spondylarthropathies and Psoriatic Arthritis: Clinical Aspects and Treatment). Burkhard Möller, Bern. Poster presentation.*
- *Sensitivity to Change of the Ultrasound synovitis SONAR Score in RA Patients: Results of the Scqm Cohort (Session: Imaging of Rheumatic Diseases: Ultrasound, Nuclear Medicine and Fluorescence Imaging). Pascal Zufferey, Lausanne. Poster presentation.*

14.2.2 Bechterew Symposium Zurich

- *Made in Switzerland, Results of SCQM Follow-up Examinations. Adrian Ciurea, Zurich. Oral presentation.*
- *Results of the Studies Based on the Swiss Cohorts Data. Adrian Ciurea, Zurich. Oral presentation.*
- *SCQM - Axial SpA - The Database. Almut Scherer, Zurich. Oral presentation.*
- *Smoking and Spondyloarthritis. Rüdiger Müller, St. Gallen. Oral presentation*

14.2.3 Congress Geneva

- *Rheumatoid Arthritis – What Can be Learnt From the SCQM? Axel Finckh, Geneva. Oral presentation.*
- *Smoking is Associated With a Less Favourable Course of Disease Activity in Spondyloarthritis Patients with Elevated Acute Phase Reactants. Adrian Ciurea et al., Zurich. Oral presentation.*
- *Sensitivity to Change of the Ultrasound Synovitis SONAR Score in RA Patients. Preliminary Results of the SCQM Cohort. Pascal Zufferey et al., Lausanne. Poster exhibitions (P5).*

14.2.4 EULAR Congress, Berlin

- *Persistence of Ultrasound Synovitis in the Patients Fulfilling the DAS and/or the New ACR /EULAR RA Remission Definitions: Results of the Sonar Score Applied to the Patients of the SCQM Cohort (RA remission: prediction and imaging, Scientific Session).* Pascal Zufferey et al., Lausanne. Oral presentation.
- *Tobacco Smoking is Associated with Increased Disease Activity in HLA-B27 Positive Axial Spondyloarthritis Patients, but Does not per se Alter the Course of Disease Activity (Abstract Session: Spondyloarthritis - translational science).* Adrian Ciurea et al., Zurich. Oral Presentation

14.2.5 Master Theses

- *Intra- and Interrater-Reliability of the Ratingen Score in the SCQM Database.* Dominik Loiero, Zurich, 2012.
- *Treatment Response to Tumor Necrosis Factor-alpha Inhibiting Substances in Axial Spondyloarthritis Patients: Adjustment for Baseline Differences in the Analysis of Longitudinal Observational Data.* Almut Scherer, SCQM Foundation Zurich, Master thesis in Statistics, August 2012.

14.3 Projects in Progress

14.3.1 Rheumatoid Arthritis

- *The Prevalence of Iron Deficiency in RA - a Cross Sectional Study.* Burkhard Möller, Bern.
- *Joint Damage Progression in Rheumatoid Arthritis Clinical Remission State.* Elena Ciubotariu, Geneva. Manuscript submitted to Journal of Rheumatology.
- *Characterization and Effectiveness Analysis of Biological Agents Used in Monotherapy in Rheumatoid Arthritis.* Cem Gabay, Geneva. Abstract at EULAR 2013.
- *Anaemia in a Large Patient Cohort With Rheumatoid Arthritis.* Burkhard Möller, Bern, Axel Finckh, Geneva et al. Submission in ARD.
- *Major Cardiovascular Events and their Clinical and Biological Predictive Markers in Rheumatoid Arthritis, Ankylosing Spondylitis, and Psoriatic Arthritis: A Swiss Cohort Study.* Paola Chevallier, Geneva. This study received the Abbott Price 2011.
- *Predictors for Duration of Remission After Discontinuation of Biologics Therapy.* Diego Kyburz, Zurich.
- *Rituximab-Mediated B-Lymphocyte Depletion and RA Flares.* Axel Finckh, Geneva.
- *Are Structural Differences Between anti-TNF Agents Associated With Dissimilar Rates of Secondary Loss of Effectiveness and Drug Adjustments?* Sophie Martin Du Pan, Geneva. Abstract accepted at EULAR 2013 & Manuscript in progress.
- *Comparison of Causes of Drug Discontinuation Between anti-TNF Agents and 'non-anti-TNF Biologic Agents' in Anti-TNF Inadequate Responder Rheumatoid Arthritis Patients.*

Sophie Martin Du Pan, Geneva. Abstract accepted at EULAR 2013 & Manuscript in progress.

- *The Impact of Statins on Structural Bone Damage in Rheumatoid Arthritis.* Axel Finckh, Geneva.
- *Pan-European Database Analysis of Abatacept Effectiveness Data.* Axel Finckh Geneva.
- *The Evolving Clinical Picture of Early Rheumatoid Arthritis Depending on the 2010 ACR/EULAR Classification Criteria: Results from the SCQM RA.* Rüdiger Müller, St.Gallen.
- *Renal Safety of Conventional Nonsteroidal Antirheumatic Drugs and Coxibs in the Long Term Treatment: A prospective Cohort Analysis.* Axel Finckh, Burkhard Möller et al.: Oral presentation EULAR 2011, manuscript in preparation.
- *Ultrasound Findings According to the SONAR Score in Patients in Remission According to new 2012 ACR-EULAR Remission.* Pascal Zufferey, Lausanne.
- *Characteristics of Swiss RA Patient at Initiation of Biologic Agents in Comparison With Selected European and US Registries.* Pascal Zufferey, Lausanne.
- *Sibling study: RA Screening in Family Members.* Axel Finckh, Geneva.

14.3.2 Axial Spondyloarthritis

- *Response to TNF Inhibition in Early Versus Late Axial Spondyloarthritis.* Adrian Ciurea, Zurich.
- *Smoking as a Possible Environmental Link between HLA-B27 and Spondyloarthritis.* Adrian Ciurea, Zurich.
- *Impact of Conventional DMARD Co-Therapy on the Effectiveness of TNF-Inhibitors in Ankylosing Spondyloarthritis.* Michel Nissen, Geneva.
- *Efficiency, Comparison of Drug Retention Rates and Role of Treatment Switch between TNF-Inhibitors in the SCQM axSpA Cohort.* Adrian Ciurea, Zurich.
- *Determinants of Radiographic Progression over 4 Years in the SCQM axSpA Cohort.* Adrian Ciurea, Zurich.

14.3.3 Psoriatic Arthritis

- *Joint Involvement in Psoriatic Arthritis: Application of the CASPAR Classification Criteria for PsA and changes in joint involvement over time.* Burkhard Möller, Bern.

14.4 International Collaboration

- *CERRERA: Longitudinal data on the use of Rituximab for the treatment of Rheumatoid Arthritis.* (Swiss representative: Cem Gabay, Geneva. So far three peer-reviewed publications.
- *TOCERRA : effectiveness and safety of Tocilizumab in a large cohort of patients followed longitudinally in several European registries.* study lead Cem Gabay.

