

ANNUAL REPORT 2011

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Generation of the yearly report

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

Dr. med. Adrian Ciurea, PD Dr. med. Axel Finckh, Prof. Dr Burkhard Möller and Sabine von Känel proofread the yearly report.

1 Editorial

1.1 Foreword by the President

Dr. Hans A. Schwarz, President of the SCQM Foundation

The year 2011 was altogether gratifyingly positive for the SCQM Foundation.

At a meeting in Brunnen on the 6th and 7th of May 2011, the medium-term strategy and the next steps for its implementation were laid down. The objective of establishing SCQM as the recognized platform for research and quality management in rheumatology in Switzerland was welcomed unanimously by all participants. Working groups were formed and target priorities for 2011/12 were set. The four working groups (research and database, policy and communication, financing, other registries) took up their work in the course of the year.



In the biobank, the collection of samples was started after the ethics committee in Geneva had approved the project. Unfortunately, the legal situation regarding the requirement for authorization by the ethics committees in different cantons is still not completely clear.

An increasing number of works are being published in reputable journals with data from the SCQM database. Posters at the EULAR Congress and ACR Conference with SCQM data have already become a tradition. All these scientific activities are to be considered as very positive and are also recognized internationally. The challenge now is to widen the circle of active participants in the scientific work and intensify cooperation.

The efforts to guide further cohorts in the rheumatology field in the context of SCQM continue to prosper. In particular, possibilities have been identified for cooperating with those responsible in the field of osteoporosis. We are in discussion with pediatric rheumatologists concerning their registries and possible interfaces for further documentation in adulthood.

In the year under review, two seats on the Foundation Board as well as the presidency were up for re-election. We are happy to report that Dr R. Klöti from Brugg and Prof. A. So from Lausanne have made themselves available to sit on the Foundation Board and we extend to them a hearty welcome.

Dr. A. Forster from Diessenhofen was elected the new president of the Foundation Board at the end of November 2011 by a clear majority. I heartily congratulate him on being selected and am sure that he will fulfill his office with prudence, energy and diplomacy and guide the SCQM Foundation on the path to success. To this end, I wish Adrian the necessary measure of luck, along with colleagues and co-workers who are as dedicated as those it was my good fortune to have.

The SCQM Foundation would not be conceivable without the untiring and competent efforts of our General Manager Sabine von Känel, Scientific Manager Dr. Almut Scherer, biobank coordinator Dr. Albana Rexhepaj and all the other office staff, or indeed the dedicated members of the Foundation Board and the scientific committees and the representatives of our patrons and the Arco Foundation, who support the enterprise with benevolent interest and often also with active cooperation. I am extremely grateful to them, not just for the past year, but for the whole time in which they have supported, challenged, corrected and encouraged me.

I would also like to thank the many colleagues at doctors' practices and hospitals who take

the trouble to document their patients in the SCQM registries. Without their cooperation SCQM would wither away. Please carry on in the same way and stay loyal to us; all of us at SCQM are very grateful for your support.

I express my cordial thanks to all SCQM participants for their commitment and wish them all the best in their private and professional life and in their activities for SCQM.

For SCQM: Vivat, crescat, floreat!

Dr. Hans A. Schwarz

1.2 Review 2011

Sabine von Känel, General Manager of the SCQM Foundation

At the beginning of May 2011 the SCQM Board and the heads of the Scientific Committees met in Brunnen for a strategy meeting. Also present was a representative from each of our sponsors. Following a detailed analysis of the strengths and weaknesses of SCQM, the strategic goals for the coming years were defined: SCQM is to establish its reputation as the recognized platform for research and quality assurance in rheumatology.

The quality and quantity of data entries from doctors and patients are the fundamental pillars of our cohorts. Interfaces between SCQM software for rheumatology offices and for clinics are high up on the wish lists of many rheumatologists. The large number of different types of software and the very high costs involved mean that, at present, this remains only a remote possibility. Nonetheless, various technical improvements should make the online data entry easier.

The research activity on SCQM data is being stepped up by various means. In the last few years our scientific manager, Dr. Almut Scherer, has built up a strong knowledge of both SCQM data and disease criteria. She is now finishing her Master course in Biostatistics at the University of Zurich, which she has performed alongside her normal work. This course will enable her to provide even better support for researchers in terms of data analysis.



Rheumatologists can now access summary slides of published research projects in the login area of the online database. These slides can be used in individual presentations, provided the source is acknowledged.

Financing its activities poses a huge challenge to the Foundation. Until now, sponsoring agreements have been made every year with pharmaceutical companies that produce biologics. A small proportion of the foundation's costs can be covered by means of donations and services (e.g. data analyses). Specific projects are funded by project sponsors. Like many other NPOs, SCQM is also finding it increasingly difficult to generate sufficient funds for its activities. By appointing a fundraiser, SCQM is seeking to place the process of obtaining financial contributions on a broader basis. The offer of support for the next three years from the Swiss Society of Rheumatology (SGR) is highly welcomed by the SCQM Foundation. With the SCQM Online Database, a suitable tool for tracking patients with inflammatory rheumatic disease is available to all Swiss Rheumatologists. Furthermore the SCQM registries are highly reputable in the international research community, thereby contributing to the international visibility of Swiss rheumatology research.



Figure 1: SCQM information desk at the SGR yearly congress in Bern with Jacqueline Hirt and Almut Scherer.

Both the Swiss Federal Office of Public Health (BAG) and the Swiss Medical Association (FMH), having recognized the enormous value of registries and intend to support them. Indeed, the FMH has set up a working party on medical registries, which will use data from existing cohorts to create a database providing logistical support for any new registries to be set-up. Both the SCQM registry and the AMIS Plus (heart attack) registry are registry models on the national level and will play a key role in this. The BAG also views both registries as models of good practice.

In 2011 the SCQM biobank project was given the go-ahead by the Geneva Ethics Committee. This cleared the way for the launch of the project. Following a trial phase in which the IT logistics, procedures and transport processes were tested, work on collecting the biological samples finally began in the summer of 2011. Our initial objective is to store one blood serum and DNA samples from all patients included in the SCQM. Various studies using biosamples have already been proposed. Carrying these out will require biological material from a huge number of patients. Hence the success of this project will depend directly on the motivation and willingness of rheumatologists to get involved. SCQM provides the equipment for taking the blood samples. It also organizes and finances the regular transport of the samples between doctors' offices/hospitals and the SCQM biobank in an uninterrupted cold chain. Thanks to this biobank the SCQM can continue to improve its already high national and international reputation.

In the year under review SCQM carried out its first continuing education course for Med-

ical Assistants. The events in Bern and Geneva were provided jointly by SCQM, Rheumaliga Schweiz (Swiss League against Rheumatism) and the Schweizerischer Verband Medizinischer Praxis Assistentinnen (Swiss Association of Medical Assistants). The aim was to improve medical assistants' knowledge of the disease patterns of the inflammatory rheumatic diseases (RA, AS, PsA) and their treatment in order to enable the assistants to better support the rheumatologists and patients. The feedback on these events was excellent and the participants themselves have asked that they be continued.

In autumn 2011 the SCQM Board, whose members all work on a voluntary basis, gained two new representatives: Dr Rainer Klöti from Brugg, who has expert knowledge of health policy, will represent rheumatologists working in private offices in the SCQM board. Prof. Alexander So, Head of the rheumatology clinic of the University Hospital of Lausanne, has been elected as the additional representative of French-speaking part of Switzerland.

At the end of the year Dr. Hans Schwarz resigned as the Board's President. Hans Schwarz has proved himself a highly committed leader since being elected President when the Foundation was established in 2004. It is under his aegis that highly motivated young researchers and scientists have added the AS and PsA cohorts to the RA registry. In 2009 data collection via paper questionnaire was abandoned in favor of online data entry. We owe our contracts with authorities and pharmaceutical companies not least to his negotiating skills. After eight years as its President, Hans Schwarz is joining the ranks of the Board's members, where he will continue to enrich the Foundation with his expertise in his new role as 'past-president'.

In November 2011 Dr Adrian Forster from Diessenhofen was elected as the new President of the SCQM Foundation. His term of office began on 1 January 2012.

The work of our highly motivated team at the SCQM office has changed: the staff no longer concentrates solely on recording data as in recent years, but increasingly focusses on the completeness and plausibility of the datasets for specific studies. In general, the activities in terms of communication work and support of our data supplying rheumatologists and their staff has increased. While the tasks have become more varied, the constitution of the team has remained the same for more than two years now.

Sabine von Känel



Figure 2: Excellent team spirit!

2 Contributors to the SCQM registry

All patients in the SCQM registry are included in one of our three cohorts, that is, Ankylosing Spondylitis (AS), 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 1 represents all rheumatology offices that have contributed data for at least 10 patients in the year 2011. Table 2 shows the same information for rheumatology clinics in hospitals. A

more detailed list of contributing institutions can be found on www.scqm.ch/institutions.

144 patients	Praxis Exer & Von Mühlenen (Basel)
81 – 100 patients	Dr. Wicht (Solothurn), Ärztehaus Zetrumspassage (Brugg)
60 – 79 patients	Rheumatologie im Silberturm (St. Gallen), Dr. Martin (Liestal), Clinic Impuls (Wetzikon), Dr. Badaracco (Lugano), Dr. Suter (Bern), Dr. Müller-Werth (Sarnen), Dr. Tauxe (Vevey), IZZ Immunologie-Zentrum Zürich (Zürich),
40 – 59 patients	Dr. Maager (Aarau), Dr. Elmiger (Bern), OsteoRheuma (Bern), Dr. Widrig-Bernhardt (St. Gallen), Dr. Marbet-Grierson (Olten), Dr. Mesikommer (Visp), Dr. Kowalski (Solothurn), Dr. Carey-Berner (Lausanne), Dr. Rösler (Bern)
20 – 39 patients	Dr. Bosia (Locarno), Dr. Sauvain (Fribourg), Dr. Masina (Lugano), Dr. Schneeberger (Martigny), Rheumapraxis Langenthal, Dr. Bloesch (Lausanne), Dr. Chamot (Morges), Dr. Aellen (Nyon), Dr. Schürch (Lausanne), Dr. Volken (Sierre), Dr. Gerny (Thun), Dr. Kaiser (Thalwil), Dr. Morell (Schaffhausen), Dr. Schwartz (Genève), Dr. Gäumann (Murten), Dr. Gratzl (Basel), Dr. Maclachlan (Heiden), Dr. Ziehmann (Zürich), Dr. Muff (Affoltern am Albis), Dr. Gäumann (Bern), Dr. A. Wüest (Wädenswil), Dr. Raccaud (Lausanne), Rheumapraxis Männedorf, Dr. Pancaldi (Muralto), Dr. Boller (Interlaken), Dr. Meder (Zofingen), Dr. Plihal Sumi (Lausanne), Dr. Mathieu (Solothurn)
10 – 19 patients	Dr. Hasler-Strub (Chur), Dr. Bötschi (Romanshorn), Dr. Zufferey (Estavayer-Le-Lac), Dr. Frey (Basel), Dr. Schönbächler (Zürich), Dr. Neumatt (Aesch), Das Rückenzentrum (Thun), Dr. Adank (Biel), Dr. Gerber (Bern), Dr. Reber / Terrier (Baden), Dr. Glenz (Visp), Prof. Dr. Häuselmann (Zürich), Dr. Jaschko (Rümlang), Dr. Pfister (Bülach), Dr. Spring (Sargans), Dr. Eigenmann Meierhofer (Zürich), Dr. Flück (Zürich), Dr. Gut (Reinach), Dr. Pellet (Zürich), Dr. Pfister (Cham), Dr. Sidler (Zug), Dr. Arnold (Solothurn), Dr. Häfelin (Schlieren), Dr. Massmann (Aarau), Dr. Müller (Dietlikon), Dr. Müller (Bern), Dr. Baumgartner (Porrentruy), Dr. Bloesch Daniel (Olten), Dr. Brunner (Zürich), Dr. Harder (Luzern), Dr. Schär (Bern), Dr. Studer (Zürich), Dr. Wüst (Basel), Rheumazentrum Kreuzlingen

Table 1: Number of patients from private practices, for whom data was contributed in 2011.

309 patients	Universitätsspital Zürich
225 patients	Centre hospitalier universitaire vaudois
171 patients	Hôpitaux Universitaire de Genève
120 – 130 patients	Kantonsspital Aarau, Inselspital Bern, Kantonsspital Luzern
100 – 119 patients	Bürgerspital Solothurn, Kantonsspital St. Gallen, Bethesda-Spital (Basel)
50 – 60 patients	Hirslanden Klinik St. Anna (Luzern), Kantonsspital Winterthur, Schulthess Klinik (Zürich), Universitätsklinik Balgrist (Zürich)
20 – 40 patients	Zuger Kantonsspital, Kantonsspital Schaffhausen, Hirslanden Klinik Birshof, aarReha Schinznach, Klinik St. Katharinental (Diessenhofen)
10 – 19 patients	Hôpital cantonal Fribourg, RehaClinic Zurzach, Felix Platter Spital (Basel), Zürcher Höhenklinik,

Table 2: Number of patients from hospitals and university hospitals, for whom data was contributed in 2011.

3 Rheumatoid Arthritis Report

3.1 X-rays

The SCQM RA cohort is characterized among other things by the fact that X-ray images have been collected from patients since the registry came into being. X-rays of hands and feet are collected during the admission checks and subsequently at regular intervals. The x rays are evaluated by SCQM staff by means of rating scores.

In his lecture at the Radiology Workshop at the 2011 SGR Congress Prof. Wassenberg confirmed the good experiences with the score, which is particularly easy to ascertain and includes only the destruction of the bone in hand and toe joints. He pointed out how the score is correlated with disease processes and function restrictions and the linear structure produces no ceiling effect. There was a lively discussion of the feasibility of the score in reference to the subjective estimate of the scorer. The criticisms arising, such as the variability between investigators, were examined this year in the context of the medical master thesis of our X-ray scorer Dominik Loiero. The final version of which is not yet available. In summary it may, however, be said that the rating score is a suitable means of evaluating the radiological process in studies.

The score and X-rays for each patient are shown on the SCQM online database. The X-rays can be consulted online at any time.



Figure 3: F.l.t.r.: Workshop organizer Prof. Dr. Möller, SCQM scientific manager Dr. Scherer and workshop speaker Prof. Dr. Wassenberg.

3.2 Population

The SCQM registry of rheumatoid arthritis exists since 1995. Overall there are 6778 patients and over 36140 visits in the rheumatoid arthritis cohort (status June 11, 2012). The median number of visits per patient is 4, with a range of up to 63 visits. In 2011, we received one or more visits for 2732 patients.

3.3 Sample

The results in the following tables and figures are shown for the year 2010 and 2011 and for inclusion or follow-up visits respectively. 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. The analyses shown in this report were run June 11, 2012.

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, which should not be older

than 6 months compared to the SCQM visit they are sent along with. 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 erythrocyte sedimentation rate (ESR), is 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, and is a generic questionnaire to measure quality of life) and the EuroQol.

3.5 Results

The results of the analysis are shown separately for inclusion and follow-up visits for 2010 and 2011. Patients included in 2010 may also be in the group of the follow-up patients of 2011.

3.5.1 Patient characteristics

	Inclusion 10	Inclusion 11	Follow-up 10	Follow-up 11
Number of patients	560	592	2133	2332
Mean inclusion age (Std.dev., in years)	56 (14)	54 (43)	–	–
% Female	73	73	–	–
IQR time sympt.-diagnosis (months)	5 (1 - 13)	5 (1 - 12)	–	–

Table 3: Patient characteristics of inclusion and follow-up patients in 2010 and 2011. Std.dev. stands for standard deviation, and IQR for inter quartile range of the median.

Table 3 shows patient characteristics data. There were 560 patients enrolled in the RA database in 2010. In 2011 we received 592 inclusion questionnaires. 2133 patients had a follow-up visit in 2010, for 2011, 2332 follow-up visits are in the RA database. Less than a quarter of all patients are male. The 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 2010 and 2011. 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).

As shown in Table 4 and Figure 4, there is a difference between the groups of inclusion patients and follow-up patients. The RADAI and DAS28 scores show a higher disease activity

	Inclusion 10	Inclusion 11	Follow-up 10	Follow-up 11
Number of patients	560	592	2133	2332
Mean glob. NRS pat.	5.6 (2.4)	5.8 (2.3)	6.2 (2.3)	6.2 (2.3)
mean DAS28(ESR)	4 (1.5)	3.6 (1.4)	3 (1.2)	2.9 (1.2)
mean DAS28(CRP)	3.8 (1.4)	3.5 (1.3)	2.9 (1.1)	2.8 (1)
mean RADAI	3.8 (2.2)	3.7 (2)	2.8 (2)	2.7 (2)
mean HAQ	0.9 (0.7)	0.8 (0.7)	0.8 (0.7)	0.8 (0.7)

Table 4: Disease activity at inclusion and at follow-up of patients with the indicated type of visit in 2010 and 2011. 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 Assesment Questionnaire, which measures physical disability (scale 0 – 3, 3 being the highest level of functional disability).

for patients included in 2010 or 2011, 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 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 (Prevo MLL *et al*, Arthritis Rheum 1995). There are four categories: remission ($DAS28 \leq 2.6$), low disease activity ($2.6 < DAS28 \leq 3.2$), moderate disease activity ($3.2 < DAS28 \leq 5.1$) and high disease activity ($DAS28 > 5.1$). The DAS28 score has been widely adopted by researchers in rheumatology both in Europe and world-wide. Figure 5 presents the percentage of the patients for the four categories. About a quarter of patients have a high disease activity at inclusion in 2010 and 2011, 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.

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. Almost 60%

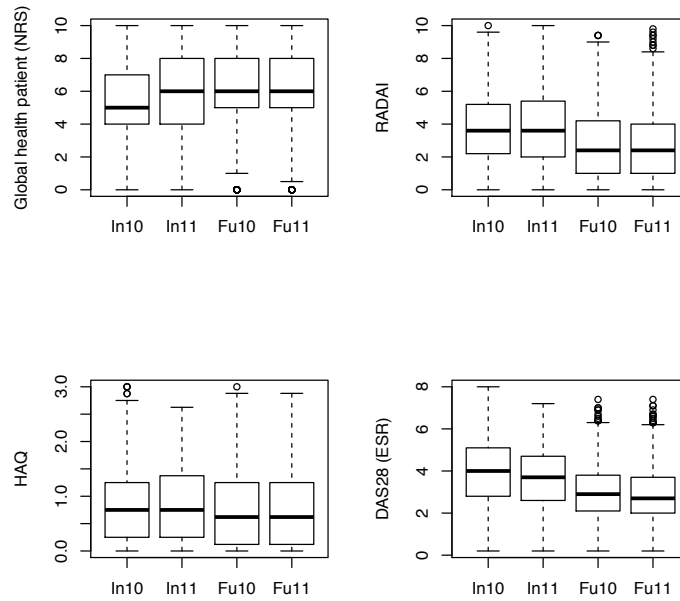


Figure 4: Box plots for the global health estimated by the patient, RADAI, HAQ and DAS28 (ESR). The box plots display median (fat black line in the box) and inter quartile range (range within the box). The data points that lie outside the whiskers are considered outliers. in10 and in11 stands for inclusion visits in 2010 and 2011 respectively and fu10 and fu11 stands for follow-up visit in 2010 and 2011 respectively.

of patients included in 2010 or 2011 were on biologics during at least part of this period (*i.e.* biologic already at inclusion or started briefly after inclusion). In the analyzed group of follow-up patients, about 65% were on a biologic treatment.

3.5.4 Surgery

Both in the inclusion questionnaire as well as in the yearly control questionnaire, the number and type of surgeries are registred. 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 8-9% 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 be performed. The results of these questions are displayed in Table 7.

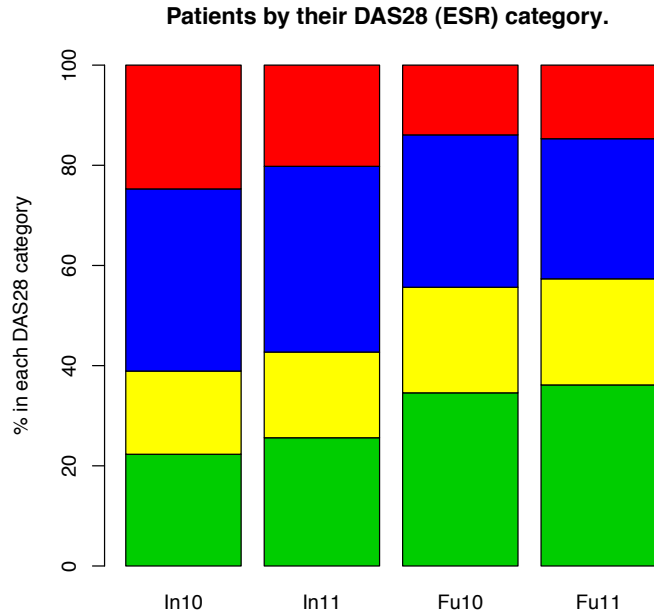


Figure 5: Percentage of patients in each of the DAS28 categories. In green is the percentage of patients in remission, in yellow those with low disease activity, in blue those with moderate disease activity and in red the percentage of patients with high disease activity. In10 and In11 stands for inclusion in 2010 and 2011 respectively, and Fu10 and Fu11 for follow-up visit in 2010 and 2011 respectively.

	Inclusion 10	Inclusion 11	Follow-up 10	Follow-up 11
number of patients	560	592	2133	2332
% patients w. hospital stay	7.3	3.2	4.6	3.2
# patients with OP(s)	107	111	188	203
total # OPs	165	154	193	218
OPs per pat.	0.3	0.3	0.1	0.1

Table 5: Percentage of hospital/rehabilitation clinic stay and number of operations in relation to rheumatoid arthritis reported in inclusion or follow-up visit in 2010 or 2011. In the inclusion, the rheumatologists are asked to list operations since the start of disease, and in yearly control visits only those in the past 12 months. Therefore the number of operations at inclusion and at follow-up are not directly comparable.

	Inclusion 10	Inclusion 11	Follow-up 10	Follow-up 11
Total # of OPs	165	154	193	218
# hand OPs	35	28	51	37
# foot OPs	36	21	40	40
# spine OPs	20	10	18	16
# shoulder OPs	12	13	15	17
# knee OPs	22	28	17	34
# hip OPs	21	32	17	24
# other OPs	19	22	35	50

Table 6: Type of operations reported in 2010 and 2011, of patients who had an inclusion or follow-up visit in 2010 or 2011. In the inclusion, the rheumatologists are asked to list operations since the start of disease, and in yearly control visits only those in the past 12 months. Therefore the number of operations at inclusion and at follow-up are not directly comparable.

	Inclusion 10	Inclusion 11	Follow-up 10	Follow-up 11
number of patients	560	592	2133	2332
% incapable of work	7.5	7.8	6.2	5.9
% absences at work	17.3	16.9	7.5	8.4
% up to 4 weeks	9.3	10.3	4.9	5.4
% more than 4 weeks	6.8	5.9	2.2	2.6

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 Ankylosing Spondylitis Report

4.1 X-rays

Pelvis (ap), lumbar spinal column (ap/lat) and cervical vertebral column (lat) X-rays from AS patients, which are sent to SCQM at inclusion and subsequently at regular intervals, can be viewed in the online database as from the year under review. The sacroileac 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. The evaluation of the existing spinal column images will take place from 2012 in accordance with m-SASSS criteria.

4.2 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, 2285 patients were included in the SCQM AS registry with a total 6948 visits. The median number of visits of all patients in the AS cohort was 2, and the maximum of the number of visits per patient is 16. In 2011 we received one or more visits for 1216 patients.

	Inclusion 10	Inclusion 11	Follow-up 10	Follow-up 11
number of patients	281	366	810	937
mean inclusion age (St.dev., years)	42 (13)	43 (12)	–	–
% Male	57	52	–	–
IQR time sympt.-diagnosis (months)	15 (3 - 80)	25 (6 - 96)	–	–

Table 8: Patient characteristics of inclusion and follow-up patients in 2010 and 2011. St.dev. stands for standard deviation and IQR for inter quartile range of the median.

4.3 Results

4.3.1 Patient characteristics

In 2010, we received 281 inclusions and 810 follow-up visit questionnaires (intermediate control or yearly control) in the database. For 2011, so far 366 inclusion and 937 follow-up questionnaire-sets have flown into the database of ankylosing spondylitis.

More than half of the AS patients in the registry are men (see Table 8) and patients are on average about 43 years old (inclusion 2011). Between diagnosis and entry to the SCQM, a median of 25 months passed in 2011. The range of the time passing between diagnosis and entry into the SCQM is very broad (interquartile range in months 2011 25 (6 - 96)).

4.3.2 Variables of Disease Activity

Figure 6 and Table 9 represent several disease activity and disability variables of the active patients in the AS registry.

	Inclusion 10	Inclusion 11	Follow-up 10	Follow-up 11
number of patients	281	366	810	937
mean glob. NRS pat.	5.5 (2.8)	5.1 (2.7)	3.9 (2.6)	3.8 (2.5)
mean glob. NRS phys.	3.7 (2.3)	3.7 (2.1)	2.1 (1.7)	2.1 (1.7)
mean BASDAI	4.9 (2.3)	4.7 (2.3)	3.7 (2.2)	3.6 (2.3)
mean BASFI	3.4 (2.7)	3.2 (2.6)	2.7 (2.4)	2.6 (2.5)
mean BASMI	2 (2)	1.9 (1.8)	2.2 (2.1)	2.1 (2)

Table 9: Disease activity at inclusion and at follow-up of patients with the indicated type of visit in 2010 and 2011. 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 70% of patients for whom consultations were entered into the SCQM in 2010 and 2011 were on biologics during at least part of this period. This proportion was similar for inclusion and for follow-up patients.

4.3.4 Surgery

In the AS registry, doctors were asked to list operations 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 operations by type.

	Inclusion 10	Inclusion 11	Follow-up 10	Follow-up 11
number of patients	281	366	810	937
% patients w. hospital stay	7.1	6.6	3.5	1.9
# patients with OPs	32	36	22	44
total # OPs	29	41	21	39
OPs per pat.	0.1	0.11	0.03	0.04

Table 10: Hospital or rehabilitation clinic stay in relation to the ankylosing spondylitis arthritis and operations reported in inclusion or follow-up visits in 2010 or 2011. In the inclusion questionnaires of ankylosing spondylitis, the rheumatologists are asked to list hospital stay and operations 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 operations at inclusion and at follow-up are not directly comparable.

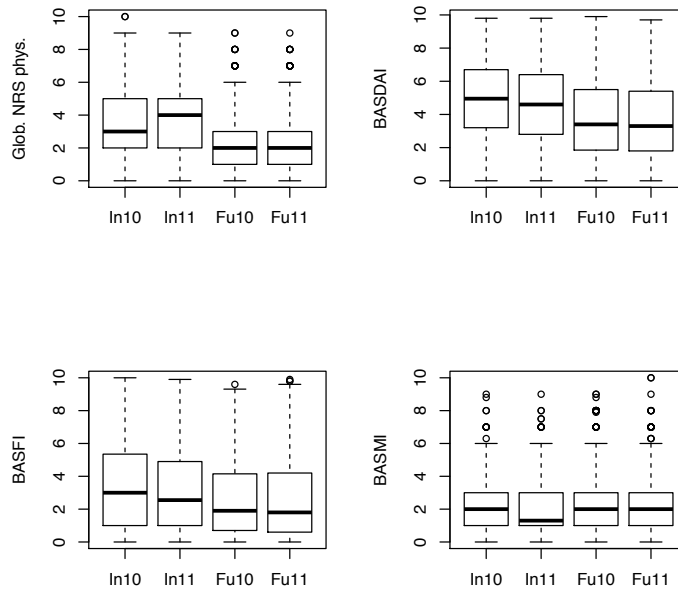


Figure 6: Box plots for the global disease activity estimated by the physician (glob. NRS phys.), BASDAI, BASFI and BASMI. (For a description of these acronyms see table 9). The box plots display median (fat black line in the box) and inter quartile range (range within the box). The data points that lie outside the whiskers are considered outliers. in10 and in11 stands for patients with an inclusion visit in 2010 and 2011 respectively and fu10 and fu11 stands for follow-up visit in 2010 and 2011 respectively.

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

	Inclusion 10	Inclusion 11	Follow-up 10	Follow-up 11
Total # of OPs	29	41	21	39
# SS OPs	1	3	2	1
# other Spine OPs	2	7	2	6
# shoulder OPs	5	4	3	4
# knee OPs	2	4	1	3
# hip OPs	4	2	6	5
# other OPs	15	21	7	20

Table 11: Type of operations reported in inclusion or follow-up visits in 2010 or 2011. In the inclusion questionnaires of ankylosing spondylitis, the rheumatologists are asked to list hospital stay and operations 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 operations at inclusion and at follow-up are not directly comparable. SS OP is spine straightening operation.

	Inclusion 10	Inclusion 11	Follow-up 10	Follow-up 11
number of patients	281	366	810	937
% incapable of work	14.2	7.9	7.7	5.7
% absences at work	32.4	26.5	17.2	17.1
% up to 4 weeks	18.5	18	12.8	12.1
% more than 4 weeks	13.2	7.9	3.3	4.2

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 April 2011), there were over 1074 patients in the registry of psoriatic arthritis with a total of 3382 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 2011, we received one or more visits for 609 patients.

5.3 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 socioeconomic issues of the disease. Important aspects like involvement of the skin and osteoporosis are also considered. Unlike the other two registries radiographic information is not yet collected.

5.4 Results

5.4.1 Patient characteristics

	Inclusion 10	Inclusion 11	Follow-up 10	Follow-up 11
number of patients	153	167	401	483
mean inclusion age (Std.dev., years)	51 (12)	50 (13)	–	–
% Male	44	57	–	–
IQR time sympt.-diagnosis (months)	18.5 (4 - 62)	33 (8 - 89)	–	–

Table 13: Patient characteristics of inclusion and follow-up patients in 2010 and 2011. Std.dev. stands for standard deviation and IQR for inter quartile range of the median.

In 2010, we received 153 inclusions and 401 follow-up visit questionnaires (intermediate control or yearly control) in the database. In 2011 167 inclusion and 483 follow-up questionnaire-sets have flown into the database of psoriatic arthritis.

	Inclusion 10	Inclusion 11	Follow-up 10	Follow-up 11
number of patients	153	167	401	483
mean glob. NRS pat.	4.2 (2.9)	4 (2.8)	3.6 (2.8)	3.3 (2.5)
mean glob. NRS phys.	3.6 (2.3)	3.1 (2.2)	2.1 (2)	1.9 (1.7)
Mean swollen 68	4.2 (5.7)	3.5 (5.3)	1.8 (3.5)	1.4 (2.7)
Mean tender 68	7.4 (9.3)	7.7 (9.9)	4.2 (7.8)	3.2 (5.7)
mean Skin phys	1.8 (1.5)	1.9 (1.7)	1.4 (1.4)	1.3 (1.3)
mean Skin pat.	2 (1.7)	2.1 (1.7)	1.7 (1.4)	1.7 (1.4)
mean NRS Pain pat.	4 (2.8)	4.2 (2.8)	3.6 (2.8)	3.5 (2.7)

Table 14: Disease activity at inclusion and at follow-up of patients with the indicated type of visit in 2010 and 2011. Standard deviation is given between 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).

5.4.2 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.

5.4.3 Prescription of Biologics

About 55 and 60% of patients included in 2010 or 2011 were on biologics during at least part of this period respectively (*i.e.* biologic already at inclusion or started briefly after inclusion). In the analyzed group of follow-up patients, about 70% were on a biologic treatment.

5.4.4 Hospital stay

	Inclusion 10	Inclusion 11	Follow-up 10	Follow-up 11
number of patients	153	167	401	483
% patients w. hospital stay	4.6	3.6	4.7	2.5

Table 15: Hospital or rehabilitation clinic stay in relation to the psoriatic arthritis in inclusion or follow-up visits in 2010 or 2011.

5.4.5 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 10	Inclusion 11	Follow-up 10	Follow-up 11
number of patients	153	167	401	483
% incapable of work	5.2	6.6	5.7	6.2
% absences at work	14.4	16.2	12.2	10.1
% up to 4 weeks	9.2	12	9.7	6.6
% more than 4 weeks	4.6	4.2	2.2	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).

6.2 SONAR visits

Overall there are 472 RA patients with 638 visits at the end of 2011. The median number of visits per RA patient is 1, with a range of up to 6 visits. In 2011, we received one or more visits for 344 RA patients.

Table 18 shows the number of SONAR visits in 2010 and 2011, irrespective of the diagnose of the patient.

	Total trained	active 2010	active 2011
University hospital	68	16	15
Other hospital	52	10	8
Rheumatology Office	67	14	8

Table 17: Number of rheumatologists trained for SONAR and number of rheumatologists that have entered SONAR visit(s) in 2010 or 2011.

	In 2010	In 2011	Fu 2010	Fu 2011
Number of SONAR visits	89	181	106	212
Number of patients with SONAR visits	71	162	97	186
On biologic during SONAR visit	23	102	59	138
Biologic started after SONAR visit	7	12	4	16

Table 18: The number of SONAR visits, the number of patients with SONAR visits and the number of patients that was either under biologic at the time of sonography, or that initiated a biologic treatment within 14 days of the sonographic examination. “In” stands for inclusion and “Fu” for follow-up visit.

7 Biobank

The central Biobank of the SCQM is located in the Serothek Center of Geneva University Hospital, in the Department of Genetic Medicine and Laboratory (Head: Prof. Denis Hochstrasser). Dr. Albana Rexhepaj is the SCQM staff member responsible for the smooth running of the SCQM Biobank.

Prof. Dr. Cem Gabay, Head of Rheumatology Department (Geneva University Hospital) is the lead of the SCQM Biobank. Its Scientific Advisory Board is made up of the rheumatology department heads of the five university and of several cantonal hospitals in Switzerland (see section 11.3).

7.1 Objectives and research

The primary objective of the SCQM Biobank is to collect one sample of serum and DNA from each patient included in the SCQM registry. In the context of research projects, further samples may become necessary, for example at specific time points in the course of the disease and its treatment. Prior to collection of biosamples, an informed consent must be signed by the patient.

The clinical and biobank data is made available to any researcher after submission of a research proposal and application and the successful review of this by the scientific advisory board of the Biobank and the board of the Foundation.

7.2 Collection and transport

The SCQM provides the material required for taking blood and transporting the samples free of charge. Samples should be collected in context of a regular blood examination, so as not to burden the patient unnecessarily. When collecting serum, the blood must be centrifuged on location. The blood collection date has to be entered in the patients record in the online database to allow organization of the transport of the samples to the central Biobank in Geneva. The serum and DNA samples must be stored at -20 degrees Celcius until they are collected by the transport courier. The courier ensures a cool-chain transport of the samples to the central Biobank in Geneva (using a cool-box and dry ice). The samples are picked up every two weeks. SCQM will inform the practices or clinics of the collection time/date in advance.



In the central Biobank, the samples are checked upon arrival and are subsequently processed for storage according to defined processes and stored at -80 degrees Celcius.

7.3 Ethics Committee Approval

The SCQM Biobank has received the Ethic Committee Approval in the cantons Geneva, Zürich, Waadt, Aargau, Solothurn, and St. Gallen.

7.4 Samples collected

The biosample collection has started at the Geneva University Hospital. At the end of 2011, 144 biosample were collected.

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.



9 Sponsoring

The SCQM receives annual contributions of biologics producing pharmaceutical companies. These contributions are not tied to restrictions in terms of research and/or publications.



Bristol-Myers Squibb



10 Annual Accounts

10.1 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, 2011.

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 be 'A. Thut', written over a horizontal line.

Andreas Thut
licensed expert auditor
auditor in charge

A handwritten signature in black ink, appearing to be 'T. Koller', written over a horizontal line.

Tanja Koller
licensed auditor

Brugg, February 28, 2012

– Financial statements 2011 (balance sheet, income statement and notes)

10.2 Balance

Company Balance Sheet as per	12/31/11 CHF	12/31/10 CHF
ASSETS		
Cash and bank	606,112.40	428,874.53
Debtors	21,396.25	6,687.50
Prepayments and accrued income	8,147.00	5,540.60
CURRENT ASSETS	635,655.65	441,102.63
IT equipment (Hard- and Software)	2,000.00	3,992.71
Onlinedatabase	0.00	48,792.30
Tangible fixed assets	2,000.00	52,785.01
FIXED ASSETS	2,000.00	52,785.01
ASSETS	637,655.65	493,887.64
LIABILITIES		
Accrued liabilities	23,616.44	6,192.06
Accruals and deferred income	82,800.00	32,735.50
LIABILITIES	106,416.44	38,927.56
Project Biobank	124,794.91	137,809.16
Research fund	94,362.05	20,777.35
PROJECTS / FUNDS	219,156.96	158,586.51
Dedication assets	80,000.00	80,000.00
Retained profit last year	216,373.57	163,250.41
Profit current year	15,708.68	53,123.16
Retained profit 31.12.	232,082.25	216,373.57
FOUNDATION ASSETS	312,082.25	296,373.57
LIABILITIES	637,655.65	493,887.64

Seite 1

10.3 Income Statement

Company Income Statement	2,011.00 CHF	2,010.00 CHF
Income from sponsoring	602,432.77	540,008.91
Income from accessorial services	0.00	4,950.00
Databasesharing	8,900.00	12,750.00
Advanced training	7,100.00	0.00
Donations	0.00	72,500.00
Financial yield	1,664.75	1,540.00
Other incomes	1,072.96	600.00
Income foundation	621,170.48	632,348.91
Salaries and related costs	(345,826.08)	(368,930.04)
Rent expenses	(29,099.12)	(29,644.46)
Servicing, repairs, replacement	(225.19)	(100.00)
Insurance of property	(960.20)	(960.20)
Expenses for information technology	(8,089.61)	(37,634.94)
Expenses for information technology onlinedatabase	(102,872.27)	(31,919.98)
Administrative expenses	(53,395.41)	(34,816.03)
Communication	(13,803.33)	(10,113.63)
Financial expenses	(389.10)	(442.90)
Other expenses	(16.48)	(3,495.42)
Depreciation	(50,785.01)	(61,168.15)
Expenses foundation	(605,461.80)	(579,225.75)
PROFIT (+) / LOSS (-) FOUNDATION STATEMENT	15,708.68	53,123.16
Fonds für Onlinedatenbank		
Contributions	157,407.41	60,000.00
Donations	0.00	170,000.00
Expenses	(170,421.66)	(95,100.04)
Profit- (+) / loss (-)	(13,014.25)	134,899.96
Research fund		
Contributions	10,000.00	30,000.00
Donations	42,500.00	0.00
Income from accessorial services	26,259.70	0.00
Expenses	(5,175.00)	(9,222.65)
Profit- (+) / loss (-)	73,584.70	20,777.35
Creation (-) / liquidation (+) projects und funds	(60,570.45)	(155,677.31)
RESULT PROJECTS UND FUNDS	0.00	0.00
NET PROFIT	15,708.68	53,123.16

Seite 1

10.4 Annexe

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 aims to establish and operate 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 SCQM Foundation decided – in collaboration with the heads of the rheumatology clinics at the university hospitals of Basel, Bern, Geneva, Lausanne and Zurich, as well as the rheumatology clinics at the cantonal hospitals of Aarau and St Gallen – to establish a centralised biobank for all patients who are included in the SCQM register. This 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, so that 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.

11 Board and Committees

11.1 The SCQM Board

The members of the SCQM Board (status 31.12.2011):

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

11.2 The Executive Committee

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

- Dr. Hans A. Schwarz (President), Emeritus Head of Rheumatology Dep., Bethesda hospital, Basel
- lic. iur. René Bräm, Managing director of the Swiss Association Morbus Bechterew
- Dr. Adrian Forster, Head of Rehabilitation Dep., Clinic St. Katharinental, Diessenhofen
- 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

11.3 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 Zürich
- 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

11.4 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 Zürich
- Dr. Ines von Mühlennen, Specialist Rheumatology FMH, Basel
- Prof. Dr. Ulrich Walker, Felixplatter hospital, Basel

AS 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 Zürich
- Dr. Bettina Weiss, Rheumatology Clinic, Universitätsklinik 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, Universitätsklinik Balgrist, Zürich
- Prof. Dr. Nikhil Yawalkar, Dematology Clinic, University Hospital (Insel), Bern

SONAR Committee

- Dr. Hansruedi Ziswiler (Chairman), Dep. of Rheumatology and Clinical Immunology / Allergology, University Hospital (Insel), Bern
- 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 Zürich
- Dr. Stefan Mariacher, RehaClinic Baden, Baden
- Prof. Dr. Burkhard Möller (Chairman), 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 Zürich
- Dr. Pascal Zufferey, Rheumatology Clinic, University hospital Lausanne (CHUV), Lausanne

11.5 The SCQM Office

- Sabine von Känel, General Manager
- Dr. Almut Scherer, Scientific Manager
- Dr. Albana Rexhepaj, monitor SCQM Biobank
- Jacqueline Hirt, free-lance Online Database representative
- Heinz Wyrsh, responsible for RA
- Susanne Frieser, assistant for administration and responsible for PsA
- Dominik Loiero, RA X-rays scoring
- Daniele Gianoli, X-ray digitization
- Guillaume Wuilleret, responsible for AS
- Ömer Ünal, voluntary work

11.6 The SCQM Organigramm

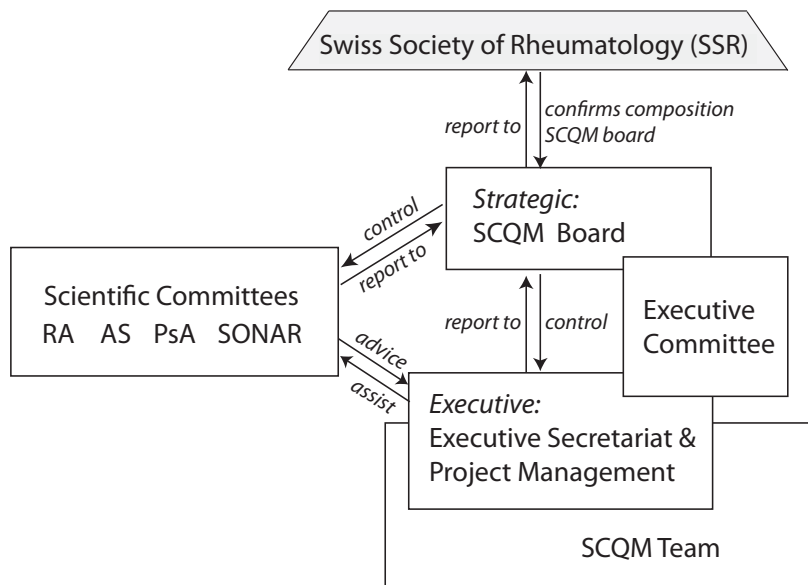


Figure 7: Organigramm of the SCQM.

11.7 List of SCQM Founders

- aarReha, Schinznach Bad
- Abteilung für Rheumatologie und Rehabilitation, Kantonsspital St. Gallen
- Abteilung für Rheumatologie/Rehabilitation, Kantonsspital Schaffhausen
- Hôpitaux Universitaires de Genève, Div. de Rhumatologie, Genève
- Hôpital cantonal de Fribourg, Service de Rhumatologie, Fribourg
- Klinik Adelheid AG, Unterägeri
- Klinik für Rheumatologie und Klinische Immunologie/Allergologie, Inselspital Bern
- Klinik für Rheumatologie und Rehabilitation des Bewegungsapparates, Klinik Valens
- Klinik für Rheumatologie und Rehabilitation, Bethesda Spital, Basel
- Klinik für Rheumatologie und Rehabilitation, Stadtspital Triemli, Zürich
- Klinik Schloss Mammern AG
- Rehabilitationszentrum Leukerbad AG
- Rehabilitationszentrum Bürgerspital Solothurn
- RehaClinic Zurzach

- Reha Rheinfelden
- Rheumaklinik Kantonsspital Luzern
- Rheumaklinik Kantonsspital Winterthur
- Rheumaklinik und Institut für Physikalische Medizin und Rehabilitation, Kantonsspital Aarau
- Rheumaklinik und Institut für Physikalische Medizin, Universitätsspital Zürich
- Rheumatologische Universitätsklinik, Felix Platter-Spital, Basel
- Service de Rhumatologie, Médecine Physique et Réadaptation, Centre Hospitalier Universitaire Vaudois, Lausanne
- Klinik St. Katharimental, Diessenhofen
- Universitätsklinik Balgrist, Abteilung für Rheumatologie, Zürich
- Rheumaliga Schweiz, RLS
- Schweizerische Gesellschaft für Rheumatologie, SGR

12 Research 2011

12.1 Publications

- *Differential drug retention between anti-TNF agents and alternative biological agents after inadequate response to an anti-TNF agent in rheumatoid arthritis patients*, Martin Du Pan S, Scherer A, Gabay C, Finckh A, Ann Rheum Dis. *in press*.
- *Evolution of Radiographic Joint Damage in Rituximab Versus TNF Antagonists in Rheumatoid Arthritis Patients with Inadequate Response to TNF antagonists*, Finckh A, Möller B, Dudler J, Walker U.A., Kyburz D, and Gabay C, on the behalf of the physicians of the Swiss Clinical Quality Management for Rheumatoid Arthritis. Ann Rheum Dis. *in press*.
- *Pain is the most important predictor of psychosocial health in patients with Rheumatoid Arthritis*. Courvoisier D & Finckh A et al. Arthritis Care Res. 2011 Oct 3.
- *Highest clinical effectiveness of rituximab in autoantibody-positive patients with rheumatoid arthritis and in those for whom no more than one previous TNF antagonist has failed: pooled data from 10 European registries*. Chatzidionysiou K & Gabay C et al. Ann Rheum Dis. 2011 Sep;70(9):1575-80. Epub 2011 May 12.
- *Effectiveness of disease-modifying antirheumatic drug co-therapy with methotrexate and leflunomide in rituximab-treated rheumatoid arthritis patients: results of a 1-year follow-up study from the CERERRA collaboration*. Chatzidionysiou K & Gabay C et al. Ann Rheum Dis. 2011 Oct 4. [Epub ahead of print]

- *The long-term impact of early treatment of rheumatoid arthritis on radiographic progression: a population-based cohort study.* Kyburz D, Gabay C, Michel BA, Finckh A; for the physicians of the SCQM-RA, Rheumatology (Oxford) 2011 Jan 21. [Epub ahead of print].

12.2 Abstracts presented at conferences

12.2.1 ACR congress, Chicago

- *Subclinical Peripheral Synovitis Detected by ultrasound In Patients with Axial Spondyloarthritis.* Pascal Zufferey, Cecile Mouly Jr, Hans Rudolf Ziswiler and Jean Dudler. Poster presentation, Arthritis & Rheum, 2011, Vol 63 (10 Suppl), Nr. 499
- *Rheumatologist's Expert Opinion Is An Important Determinant of Tumor Necrosis Factor Blocking Agent Prescription in Axial Spondyloarthritis: Results From the Swiss Clinical Quality Management Axial Spondyloarthritis Cohort.* Almut Scherer, Ulrich Weber, Pascale Exer, Jürg Bernhard, Jean Dudler, Giorgio Tamborrini, Bettina Weiss, Rüdiger Mueller, Beat A. Michel, Rudolf O. Kissling and Adrian Ciurea on behalf of the SCQM Rheumatologists. Poster presentation, Arthritis & Rheum, 2011, Vol 63 (10 Suppl), Nr. 527
- *The Effect of DMARD Co-Therapy on Anti-TNF Drug Retention in 1630 Spondyloarthritis Patients.* Michael J. Nissen, Adrian Ciurea, Burkhard Moller, Jürg Bernhard, Rüdiger Mueller, Bettina Weiss, Giorgio Tamborrini, Almut Scherer, Cem Gabay and Axel Finckh. Oral presentation, Arthritis & Rheum, 2011, Vol 63 (10 Suppl), Nr. 2637
- *Anemia Is An Independent Indicator of Disease Progression In Rheumatoid Arthritis,* Möller B, Wisler D, Scherer A, Villiger PM, Finckh A, on behalf of the SCQM-RA. Poster presentation, Arthritis & Rheum, 2011, Vol 63 (10 Suppl), Nr. 2114.

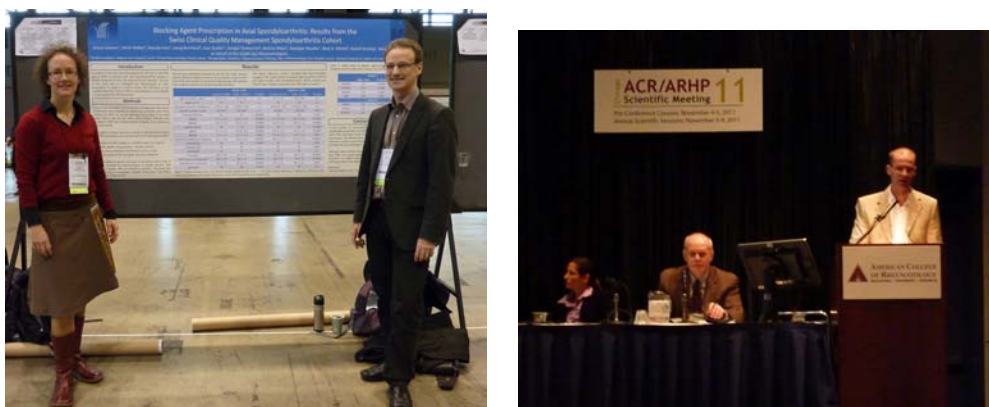


Figure 8: At the ACR 2011 in Chicago, the first research results based on SCQM Spondyloarthritis patients were presented. Left: Poster presentation by Dr. Adrian Ciurea and Dr. Almut Scherer. Right: Oral presentation by Dr. Michael Nissen.

12.2.2 Congrès Français de Rhumatologie, Paris

- *Evolution de degré d'activité de la maladie à l'introduction et après 1 an de traitement biologique chez les patients souffrant de polyarthrite rhumatoïde en Suisse.* P. Zufferey et al. (O.96).

12.2.3 SGR yearly congress, Bern

- *Axial Spondyloarthritis, Data from the SCQM-SpA cohort,* Oral presentation Dr. Adrian Ciurea.
- *After failure of an anti-TNF it is unknown whether another anti-TNF or a new biological should be administered in second or third intention,* Dr. Sophie Martin Du Pan et al, Poster presentation.

12.2.4 EULAR congress, London

- *Comparison of drug retention between new biological agents and classic anti-TNF agents in TNF inadequate response rheumatoid arthritis patients,* S. Martin Du Pan et al., Poster presentation, SAT0298.
- *Characteristics of the Swiss patients with RA at the introduction of biologics based on the SCQM registry in comparison with other selected registries,* P. Zufferey et al, AB0691.

12.3 Projects in progress

- *Evaluating the cross-cultural comparability of the Rheumatoid Arthritis Disease Activity Index (RADAI) scores across countries using three differential item functioning methods,* study lead Mart de Laar and Jaap Fransen (University Twente).
- *Do structural differences between anti-TNF agents result in dissimilar rates of secondary loss of effectiveness and related drug adjustments?,* study lead: Dr. Sophie Martin Du Pan and PD Dr. Axel Finckh (University Hospital Geneva (HUG)).
- *Rituximab-mediated B-Lymphocyte depletion and RA flares,* study lead: PD Dr. Axel Finckh (HUG).
- *Ultrasound Findings according to the SONAR score in Patients in Remission according to new 2011 ACR-EULAR remission,* study lead: Dr. Pascal Zufferey (University Hospital Lausanne (CHUV)).
- *Smoking as a possible environmental link between HLA-B27 and spondyloarthritis,* study lead: Dr. Adrian Ciurea (University Hospital Zurich (USZ)).
- *Response to TNF inhibition in early versus late axial spondyloarthritis ,* study lead: Dr. Adrian Ciurea (USZ).
- *Inter- und Intrauntersucherreliabilität des Ratingen Score in der SCQM Datenbank.* Master thesis Dominik Loiero. Study lead Prof. Dr. Diego Kyburz.

- *Predictors for duration of remission after discontinuation of biologics therapy*, study lead Prof. Dr. Diego Kyburz (USZ).
- *Characteristics of Swiss RA patients at initiation of biologic agents in comparison with selected European and US registries*, study lead Pascal Zufferey (Centre Hospitalier Universitaire Lausanne (CHUV)).
- *Joint involvement in psoriatic arthritis: Application of the CASPAR classification criteria for PsA and changes in joint involvement over time*, study lead Prof. Dr. Burkhard Möller (Insel Hospital Berne (Insel)).
- *Impact of conventional DMARD co-therapy on the effectiveness of TNF-inhibitors in Ankylosing Spondylitis*, study lead Dr. Michael Nissen (HUG).
- *Determinants of TNFa inhibitor prescription in the practice-based Swiss prospective observational cohort of axial SpA patients SCQM AS*, study lead Dr. Ulrich Weber (University Clinic Balgrist (Balgrist)).
- *Efficiency, comparison of drug retention rates and role of treatment switch between TNF-inhibitors in the SCQM AS cohort*, study lead Dr. Adrian Ciurea (USZ).
- *Determinants of radiographic progression over 4 years in the SCQM AS cohort*, study coordinator, study lead Dr. Adrian Ciurea (USZ).
- *Renal safety of conventional nonsteroidal antirheumatic drugs and Coxibs in the long term treatment: A prospective cohort analysis*, study lead Prof. Dr. Burkhard Möller (Insel).
- *Anaemia in a large patient cohort with rheumatoid arthritis*, study lead Prof. Dr. Burkhard Möller.
- *Sibling Study: RA screening in family members*, study lead PD Dr. med. Axel Finckh.
- *Frequency, determinants and outcome of radiographically defined hip involvement in the practice-based Swiss prospective observational cohort of axial SpA patients SCQM AS*, study lead Dr. Pascale Exer (private practice in Basel) and Dr. Ulrich Weber, (Balgrist).
- *Determinants of Fatigue and response to treatment in the practice-based Swiss prospective observational cohort of axial SpA patients SCQM AS*, study coordinators Dr. Pascale Exer (private practice in Basel) and Dr. Ulrich Weber (Balgrist).
- *Frequency and determinants of osteoporosis in the practice-based Swiss prospective observational cohort of axial SpA patients SCQM AS*, study coordinators Dr. Jürg Bernhard (Bürgerspital Solothurn) and Dr. Ulrich Weber (Balgrist).
- *Characteristics of the early disease stage in the practice-based Swiss prospective observational cohort of axial SpA patients SCQM AS*, study coordinators Dr. Jürg Bernhard (Bürgerspital Solothurn) and Dr. Ulrich Weber (Balgrist).

