



ANNUAL REPORT 2009

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1 Editorial

1.1 Foreword by the President

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

A very busy time for SCQM it was, indeed, the year 2009. The increasing use of the online version by rheumatologists in practice and in hospitals, the implementation of improvements in the day-to-day applications and the overall very positive response by the users has been both rewarding and challenging for the office staff and the scientific committees of the three cohorts. In larger practices and in hospitals, demonstrations of the online version were given and met with an obvious interest. These demonstrations continue in 2010 on demand and are free of charge.



The SONAR group, *i.e.* rheumatologists with a special interest and training in the use of ultrasound in rheumatology has started a close collaboration with the SCQM. They use the clinical data of their patients as collected in the respective cohorts of SCQM and correlate them with their ultrasonographic findings and other imaging techniques as applicable. The leader of this group, Dr. H.R. Ziswiler, Inselspital Berne, has been given a seat on the Board of the Foundation as an observer, equal to the chairmen of the scientific committees.

At long last a position paper could be developed between the SCQM and santésuisse. santésuisse acknowledges the meaningfulness of a quality management database such as the SCQM and accepts the biologics confirmation as information regarding the high costs, that are often generated in rheumatology offices treating patients with inflammatory rheumatic diseases.

The project of a biobank linked to the SCQM register has gained momentum. Under the lead of Prof. Gabay, all the University Clinics and the Rheumatology Units of Aarau and St. Gallen are involved, and the SCQM is happy to have Dr. Albana Rexhepaj on board as monitor and scientific coordinator for this ambitious project.

After many years of important and very supportive engagement, Mrs. Gisela Dalvit, Prof. Rudolf Kissling and Prof. Paul Hasler retired from the Board of the SCQM Foundation by the end of 2009. My gratitude and sincerest thanks for all their contributions in various forms, their friendship and encouragement join my best wishes for all of them.

Finally, I would also like to extend my thanks to all the members of the SCQM office, Sabine von Känel and Dr. Almut Scherer especially, to the members of the Board and the scientific committees, the representatives of our patrons and sponsors, all of them taking an active interest in our work and last but not least to all the contributors in practices and hospitals who tackle the administrative chores when including their patients in the SCQM register. With the help of all of them we shall continue to improve and enlarge the SCQM for the benefit of all the doctors and their patients involved in the treatment of these severe diseases, for our colleagues engaged in clinical research and finally for Swiss Rheumatology at large.

Yours, Hans Schwarz

1.2 Review 2009

Sabine von Känel, Executive Secretary of the SCQM Foundation

The main focus of our activities in 2009 was on completing the Online Database, which the members of the scientific working groups and the Foundation Board have been involved in preparing since 2008. The content and functionality of the new database were discussed intensively during various meetings with the IT developers and members of the working groups. The task at hand was not about modifying the content of the existing questionnaires. Rather, it was directed at grouping the questions in a more logical way, and to sort them into master data (i.e. data that does not or does hardly change, such as personal data, family history) and visit data (i.e. data that must be nurtured over time, such as medication, disease activity, collected during each doctors' visit). When entering data online, the master data now no longer needs to be filled in for each questionnaire, reducing the time and effort required from the physician and the patient.



While developing the database technology, Seantis – the IT firm commissioned by SCQM – was able to benefit from the expertise of Zitelab, the company responsible for developing the database of the Danish rheumatology registrar.

In January 2009, the final migration of data was performed from the existing database to the Online Database. After an extensive test phase, newly received data was entered directly into the Online Database at the SCQM office. It quickly became apparent that the process for entering data into the Online Database is significantly more efficient than the scanning and checking processes of the “old” database.

At the beginning of the year, various rheumatology clinics, the first being the Inselspital in Berne, as well as a number of rheumatology practitioners, declared themselves ready to test the Online Database as “first users”, and to provide feedback on the system. The majority of this feedback was implemented by Seantis during the development of the database. As a result, we are now able to present an online database that represents high standards in terms of user-friendliness, feedback tools and data protection. We regularly see proof of this both in the responses received during the various online data entry demonstrations performed in clinics and rheumatology practices, and in the rising numbers of users of the Online Database (see Figure 1 below).

We would particularly like to mention the completely revised medication entry screen, which allows data to be entered accurately, and provides physicians with a clear overview of the medication that has been administered. As the new data entry forms allow medication to be recorded more precisely, it becomes more valuable to the scientific community. So-called “data-sharing” also contributes towards achieving a comprehensive level of patient information. It is used when a patient changes physician, or when a patient is being treated by several physicians. The Online Database enables all physicians to view the data of patients being treated by them. This function helps to promote a smooth flow of information, as well as continuity in the treatment of the patient.

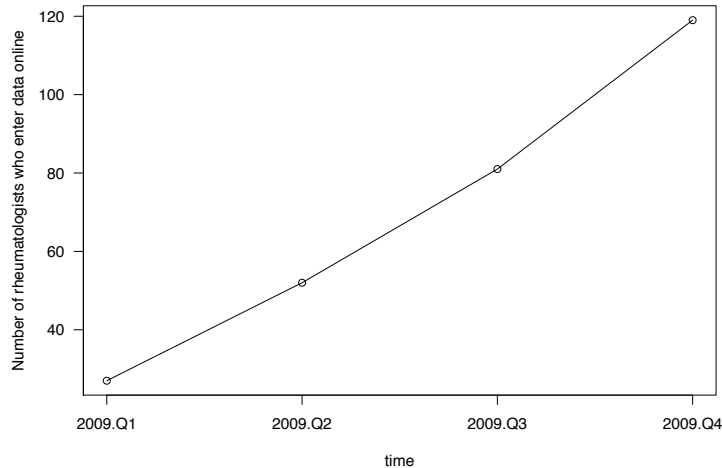


Figure 1: Number of rheumatologists that have used the SCQM Online Database in 2009, displayed for each quarter. Counted are the number of rheumatologists who entered one or more visits in the respective quarter.

1.2.1 Patient interface user poll

Since April 2009, patients have also been able to enter their data electronically in the Online Database. Alongside the physicians, some of the patients have declared themselves ready to test the online data entry process. The patients were thus requested to complete the questionnaires separately online and also in paper form. They were subsequently contacted by telephone, and asked to provide feedback on the user-friendliness of both systems. The results of this feedback are shown in Figure 2.

Most of the patients were recruited by Dr. Pascale Exer and Dr. Ines Von Muehlenen. The data in Figure 2 clearly shows that the people who tested the system were generally content with it. Most patients preferred the online data entry over paper questionnaires. The data of these patients is, however, not representative for all Swiss rheumatology patients. First because of the low number of patients of whom direct feedback was collected, and second because these were patients who were willing to take part in the study, and hence were willing to do online data entry from home in the first place. This means there is a selection bias to computer users.

1.2.2 Rules for research and collaboration

To prepare for the surge in interest in using the SCQM data for studies, some rules were developed in a working group for research and co-operation. These rules clearly regulate the access rights and procedures for requesting data for study projects. At the same time, a page displaying the current study projects was created in the research section of the SCQM website and a “pinboard” was also created, where any studies that have been approved recently by the Foundation Board are displayed for a period of two months. Researchers interested in participating in any of the studies published

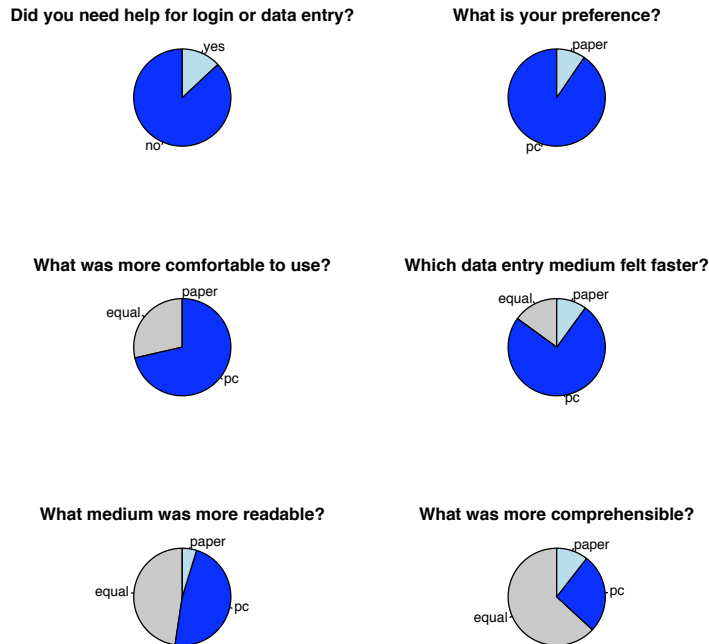


Figure 2: Opinion poll of 20 patients who entered data on paper and online. These patients were called after the data entry and were asked for feedback. For example, they were asked about the ease of use of the online tool and their preference (paper or pc).

on the pinboard can contact A. Scherer, Scientific Manager, SCQM. Rules and regulations and application forms for study projects can be downloaded from the website at any time. In 2009, a great number of projects of studies were submitted and approved by the SCQM Foundation board. All ongoing projects are listed in Section 10.2.

1.2.3 santésuisse

The position paper, which was written in collaboration with santésuisse, specifies that, in the event of a cost audit by santésuisse, private practices may call upon their SCQM biologics confirmation to justify the higher costs. The SCQM confirmation includes all patients receiving biologic therapy who have been included in the SCQM registry by the physician. Patients (only the number of patients, not their names) who underwent biologic therapy during the year in question are shown, providing that an up-to-date entry exists for the patient. For the year 2009, entries between 1st July 2008 and 31st December 2009 are taken into account. With the Online Database, each rheumatologist is able to print this confirmation at the click of a button. The position paper can be downloaded from the SCQM website.

1.2.4 SCQM Team

In the year under review, all members of the SCQM team at our office completed their duties and accomplished their tasks in a highly motivated manner, and approached the new challenges with a flexible outlook. During the first three quarters, the core team was supported by temporary staff when entering data. The large number of paper questionnaires still arriving at the SCQM office could thereby be entered into to the database. Furthermore, the PsA questionnaires that had been collected since 2004 were digitized manually in the Online Database. Towards the end of the year, the amount of incoming paper questionnaires reduced noticeably, and the team manages the data entry without support by temporary staff. The long waiting times to receive feedback reports, which had unfortunately become all too familiar in previous years, can now be considered a thing of the past.

1.2.5 Communication

In May 2009, four introduction courses on online data entry for medical practice assistants and secretaries were held in our office in Altstetten. In November, the SCQM registry was presented in an advanced training course for MPAs on the subject of care for patients with a rheumatoid disease. SCQM had its own stand at various congress and training events for rheumatologists and patient organisations, where it was able to present its online registry to interested parties. Employees of SCQM demonstrated the online data entry process in several hospitals and practices, and advised physicians on how to use the Online Database. SCQM will continue to provide this service in 2010.

Articles regarding the SCQM registry were published in magazines issued by the patient organizations “Swiss Association for Morbus Bechterew” (SVMB) and “Swiss Society of Polyarthritic Patients” (SPV).

In order to push promotion work on the SCQM Online Database, a flyer was produced, describing the benefits of the SCQM registry (see Figure 3). The SCQM database collects patient data for scientific purposes and makes these available to the contributing physicians in form of feed-back. The feed-back provides a compact view of complex information of the last clinical examination of the patient and of the disease evolution (see Figure 4). The SCQM Online Database further provides feed-back on the level of the patient-cohort, supporting the physician in the quality control of his or her patient collective.

With the development of the flyer on the SCQM Online Database, a new image of the SCQM registry was adopted in form of a photo that is displayed on the front of the flyer. This photo suggests how a computer can complement the communication between patient and physician. In our case, this complement is given by the tabular and graphical feed-back, that can form the basis of discussion between rheumatologist and patient. This new image was also implemented on the SCQM webpage www.scqm.ch.

1.2.6 Project Biobank

At the end of 2008, the Swiss National Science Foundation, in its final elimination round, rejected the SCQM’s application for support in establishing an SCQM biobank under the lead of Prof. C.

Qualitätsmanagement leicht gemacht



Figure 3: On the frontpage of the flyer, we point out the core properties of the SCQM registry. These are: 1: Complex information clearly represented, 2: Documentation of the evolution of the patient, 3: Quality control of the patient cohort.

Gabay and in collaboration with the heads of rheumatology at the university hospitals of Basel, Berne, Lausanne and Zurich as well as the rheumatology clinics of Aarau and St. Gallen. In mid-2009, the same group decided to tackle the biobank project without the support of the Swiss National Science Foundation. The project aims to achieve the decentralised storage of serums in the seven hospitals. The information relating to the data is fed into a central database administered by SCQM. Initial preparations for the project were made in the fourth quarter of the year under review. After receiving approval from the relevant ethics committees, it should be possible to begin collecting serums, joint fluid and tissue in the second half of 2010.

The personnel costs of the biobank for SCQM are generously being covered by a private foundation. Sponsors are being sought to cover the infrastructure costs.

Ihr Patient per Mausklick

Die online Datenbank zeigt Ihnen Ihren Patienten in praktischer Übersicht. Das «Scoreboard» (grosse Tabelle) zeigt Ihnen nicht nur den Krankheits- und Therapieverlauf Ihres Patienten, sondern erlaubt Ihnen auch in alten Konsultationen zu blättern.

Screenshot Medication

Medikation

Laufende Medikation

Medikament	Start	Dosisanpassung	Dosierung (mg)	Dosierungsterrnal	
Abacavir (Dorvick)	01.12.19		750,0	Alle 4 Wochen	Dosisanpassung Stop
Mefenoxale	15.11.14	10.01.07	10,0	Pro Woche	Dosisanpassung Stop
		10.01.07	10,0	Pro Woche	[Ändern] [Löschen]
		22.01.05	15,0	Pro Woche	[Ändern] [Löschen]
	15.11.14		20,0	Pro Woche	[Ändern]

Beendete Medikation

Medikament	Start	Dosisanpassung	Dosierung (mg)	Dosierungsterrnal	Stop	Abbruchgrund
Agalmatol (Diamid)	31.03.03		20,0	Pro Woche	12.11.09	erniedrigte Wirksamkeit

Screenshot Patient

Detail Screenshot Patient

Screenshot Eingabe Gelenkuntersuchung

Wenn Sie z.B. auf die Anzahl druckdolente Gelenke in der Tabelle klicken, gelangen Sie zur Eingabemaske, wo die Lokalisation der betroffenen Gelenke dargestellt ist.

Figure 4: One of the pages of the flyer gives an overview of some of the functionalities of the SCQM Online Database on the level of the individual patient. It demonstrates the density of information and also the ease with which the data this information is based on can be created and accessed. It further points out where rheumatologists can find printable feed-back on the disease evolution and on the last visit of the patient.

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 hospitals that have at least 10 patients in the SCQM registry. Table 2 shows the same information for rheumatology practices that have explicitly allowed us to publish their contribution in this annual report, by responding to our survey at the end of summer 2009.

10 – 19 patients	Hirslanden Klinik Birshof, Hôpital cantonal Fribourg, RehaClinic Zurzach, Thurgauer Klinik, Zürcher Höhenklinik (Davos)
20 – 39 patients	aarReha Schinznach, Felix Platter Spital (Basel), Hirslanden Klinik St. Anna (Luzern), Kantonsspital Schaffhausen, Kantonsspital St. Gallen, Stadtspital Triemli (Zürich), Zuger Kantonsspital
40 – 59 patients	Bethesda-Spital, Centre Hospitalier Universitaire Vaudois, Schulthess Klinik (Zürich)
60 – 79 patients	Bürgerspital Solothurn, Kantonsspital Winterthur
80 – 99 patients	Kantonsspital Aarau
100 – 119 patients	Universitätsklinik Balgrist (Zürich), Hôpitaux Universitaire de Genève, Kantonsspital Luzern
120 – 139 patients	Inselspital Bern
380 patients	Universitätsspital Zürich

Table 1: Number of patients from hospitals and university hospitals, for whom data was contributed in 2009.

10 – 19 patients	Dr. Bloesch Anne-Claire (Lausanne), Dr. Christen (Lugano), Dr. Gerny (Thun), Dr. Schlör-Dörr (Reinach), Dr. Schönbächler (Zürich), Dr. Tinner (Weinfelden), Dr. Wüest (Basel), Dr. Sauvain (Fribourg), Dr. Schwartz (Genève)
20 – 39 patients	Dr. Carey-Berner (Lausanne), Dr. Chamot (Morges), Dr. Elmiger (Bern), Dr. Gratzl (Basel), Dr. Kowalski (Solothurn), Dr. Maager (Aarau), Dr. Marbet-Grierson (Olten)
40 – 59 patients	Dr. Müller-Werth (Sarnen), Dr. Tauxe (Vevey)
60 – 79 patients	Praxis im Silberturm (St. Gallen)
80 – 99 patients	Dr. Wicht (Solothurn)
100 – 199 patients	Praxis Caravatti, Widmer & Wyrsh (Wetzikon), Praxis Exer & Von Mühlönen (Basel)

Table 2: Number of patients from private practices, for whom data was contributed in 2009.

3 Activity Report of the Rheumatoid Arthritis Cohort

3.1 Population

The SCQM registry of rheumatoid arthritis exists since 1995. All patients in Switzerland with rheumatoid arthritis, 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. Overall there are over 5700 patients and over 34000 visits in the rheumatoid arthritis cohort (status Mid May 2010). The median number of visits per patient is 3, up to 63 visits. 2490 patients had had at least one SCQM visit with a rheumatologist in the year 2009. The distribution of the so called “active” patients is seen in Table 1, showing the actual assignment of the patients to clinics or practices.

3.2 Sample

The results in the following tables and figures are shown for the year 2008 and 2009 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 End of May 2010.

3.3 Data collection

A clinical examination and laboratory blood tests are included during initial, intermediate control and annual control visits. Patients are asked to complete their patient questionnaires either on paper or online. The paper forms are sent to the SCQM office, where they are entered into the Online Database by our office staff. In the Online Database, feedback on the evolution of the disease activity scores and the medication of the patient, as well as a text report of the last visit can be downloaded by the rheumatologists.

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 2008 and 2009. Patients included in 2008 may also be in the group of the follow-up patients 2009.

3.5.1 Patient characteristics

	Inclusion 08	Inclusion 09	Follow-up 08	Follow-up 09
Number of patients	406	491	2042	2058
Mean age (Std.dev., in years)	54 (14)	54 (15)	58 (13)	58 (13)
% Female	74	77	79	77
IQR time sympt.-diagnosis (months)	3 (0 - 12)	5 (0 - 13)	–	–

Table 3: Patient characteristics of inclusion and follow-up patients in 2008 and 2009. Std.dev. stands for standard deviation, and IQR for inter quartile range of the median.

Table 3 shows patient characteristics data. As mentioned above, the so called “active” patients of the years 2008 and 2009 were analyzed. There were 406 patients enrolled in the RA database in 2008. For 2009 we received 491 inclusion questionnaires. 2042 patients had a follow-up visit in 2008, for the year 2009, 2058 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 54 years old, and the mean age of the follow-up patients is 58 years.

3.5.2 Variables of Disease Activity

The following table presents several variables of disease activity. Since, for some patients, more than one questionnaire is entered into the SCQM per year, 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 2008 and 2009. 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 5, 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 2008 or 2009, 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

	Inclusion 08	Inclusion 09	Follow-up 08	Follow-up 09
Number of patients	406	491	2042	2058
Mean glob. NRS pat.	5.1 (2.5)	5.5 (2.3)	6.1 (2.4)	6.1 (2.3)
mean DAS28(ESR)	4.3 (1.4)	4 (1.4)	3.1 (1.3)	3.1 (1.2)
mean RADAI	4.1 (2.2)	4.1 (2.1)	2.7 (2)	2.8 (2)
mean HAQ	0.9 (0.7)	0.9 (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 2008 and 2009. 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).

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 6 presents the percentage of the patients for the four categories. About a quarter of patients have a high disease activity at inclusion in 2008 and 2009, whereas only about 10% 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. More than half of patients who had a follow up visit in 2009 were under biologics treatment (Abatacept, Adalimumab, Etanercept, Infliximab, Rituximab, Tocilizumab).

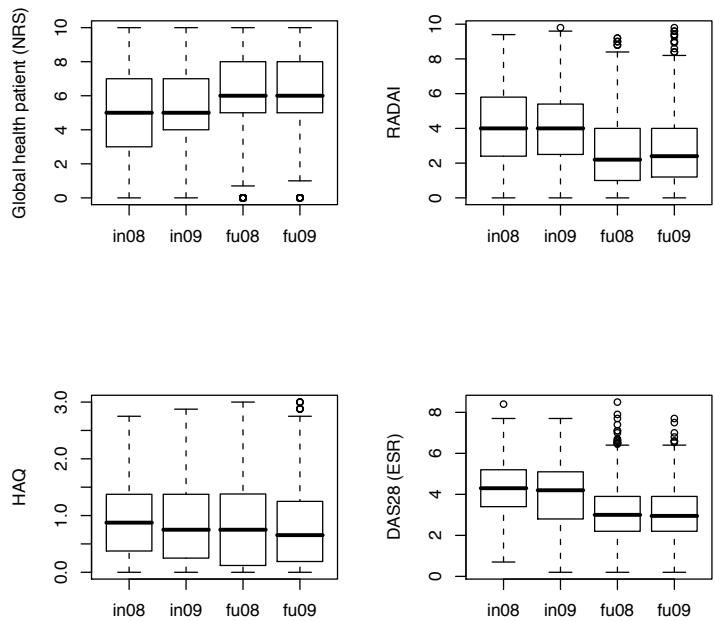


Figure 5: Box plots for the global health estimated by the patient, RADAI, HAQ and DAS28 (ESR). The box plots display median (fat black line in the box) and inter quartile range (range within the box). The data points that lie outside the whiskers are considered outliers. in08 and in09 stands for inclusion visits in 2008 and 2009 respectively and fu08 and fu09 stands for follow-up visit in 2008 and 2009 respectively.

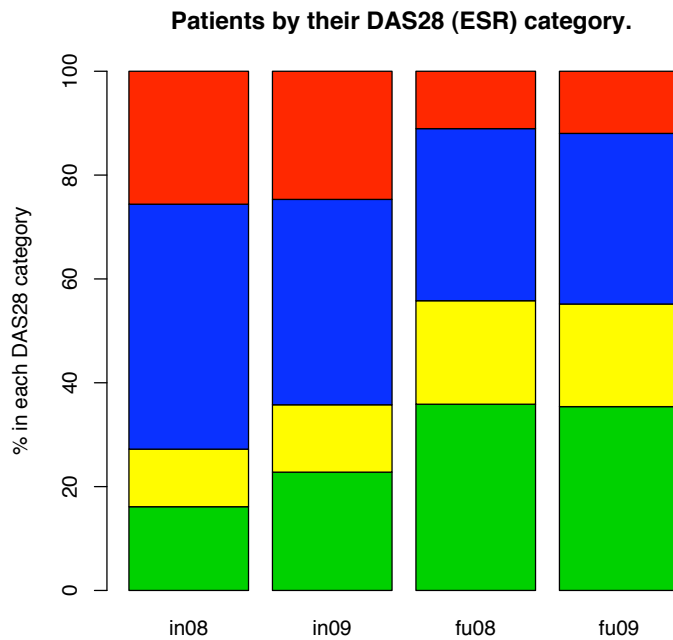


Figure 6: Percentage of patients in each of the DAS28 categories. In green is the percentage of patients in remission, in yellow those with low disease activity, in blue those with moderate disease activity and in red the percentage of patients with high disease activity. in08 and in09 stands for inclusion in 2008 and 2009 respectively, and fu08 and fu09 for follow-up visit in 2008 and 2009 respectively.

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 9-11% 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. For one patient with an inclusion visit in 2008, and for two patients with follow-up visit in 2009, a spine-straightening operation was reported. Since this is an atypical operation for patients with rheumatoid arthritis, it is not listed separately. This is the reason why, in Table 6, the sum of the number of operations by type and the sum listed in the first line of the table do not add up in these two cases.

	Inclusion 08	Inclusion 09	Follow-up 08	Follow-up 09
number of patients	406	491	2042	2058
patients w. hospital stay	6.2	3.1	5.4	3.4
# patients with OP(s)	85	90	230	183
total # OPs	120	141	277	203
OPs per pat.	0.3	0.3	0.1	0.1

Table 5: Number of hospital/rehabilitation clinic stay and operations in relation to rheumatoid arthritis reported in inclusion or follow-up visit in 2008 or 2009. 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.

3.5.5 Unemployment due to rheumatoid arthritis

In the questionnaires for rheumatoid arthritis that were introduced in 2008, the patients are asked whether they had to reduce or quit their job due to their rheumatic disease and if yes, since when. In 2008 we still received a lot of old questionnaires, in which this question was not posed. Therefore, the numbers reported for 2008 and 2009 in Table 7 are not comparable. The data displayed are patient reported only.

	Inclusion 08	Inclusion 09	Follow-up 08	Follow-up 09
Total # of OPs	120	141	277	203
# hand OPs	31	36	65	44
# foot OPs	28	29	80	50
# spine OPs	11	12	20	11
# shoulder OPs	10	10	19	12
# knee OPs	18	23	51	32
# hip OPs	21	18	41	29
# other OPs	0	13	1	23

Table 6: Type of operations reported in 2008 and 2009, of patients who had an inclusion or follow-up visit in 2008 or 2009. 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 08	Inclusion 09	Follow-up 08	Follow-up 09
number of patients	406	491	2042	2058
% patients reduced job	(11.3)	12.8	(12.7)	15.6
median duration reduction (years)	1.5	2	7	8
% patients quit job	(10.6)	10.2	(13.2)	15.5
median duration (years)	2	4	7	7

Table 7: Percentage of patients who reduced or quit their job due to their rheumatic disease and median duration of reduction or interruption of work. The values for 2008 are indicated between brackets because only part of the questionnaires for 2008 were of the new type, that contained the questions on reduction or quitting of the job due to the rheumatic disease.

4 Activity Report of the Ankylosing Spondylitis Cohort

4.1 Background information

The SCQM registry on ankylosing spondylitis exists since 2004.

4.2 Population

All patients with axial spondylarthritides (ankylosing spondylitis, early disease forms), 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 mid May 2010, there were over 1600 patients in the registry of ankylosing spondylitis with a total of over 4300 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 13. In 2009 we received one or more visits for over 1000 patients.

4.3 Data collection

As for RA, there are inclusion, yearly control and intermediate control questionnaires. If relevant changes of disease activity or therapy occur, a questionnaire for an intermediate control should be filled in. All questionnaires are available in German and in French. Beside the use of internationally validated instruments, data on laboratory tests and four standardised radiographs every two years are collected. Patients are classified according to the modified New York criteria (mNY; clinical criterium and assessment of pelvis radiograph by two experts is consensus). Assessment of the clinical ASAS classification criteria for axial spondyloarthritis 2009 can be performed in patients not fulfilling the mNY criteria. For the analyses presented below, all patients in the AS cohort were analyzed. This is a very heterogeneous group of patients, containing all patients in the cohort for whom we received data in 2009.

	Inclusion 08	Inclusion 09	Follow-up 08	Follow-up 09
number of patients	277	290	610	757
mean age (St.dev., years)	42 (12)	42 (13)	43 (12)	44 (12)
% Male	63	57	65	65
IQR time sympt.-diagnosis (months)	13 (3 - 96)	14 (3 - 79)	–	–

Table 8: Patient characteristics of inclusion and follow-up patients in 2008 and 2009. St.dev. stands for standard deviation and IQR for inter quartile range of the median.

4.4 Results

4.4.1 Patient characteristics

In 2008, we received 277 inclusions and 610 follow-up visit questionnaires (intermediate control or yearly control) in the database. For 2009, so far 290 inclusion and 757 follow-up questionnaire-sets have flown into the database of ankylosing spondylitis.

About two thirds of the AS patients in the registry are men (see Table 8) and patients are on average about 42 and 44 years old (inclusion and follow-up patients for 2009 respectively). Between diagnosis and entry to the SCQM, a median of 13 and 14 months passed in 2008 and 2009 respectively. The range of the time passing between diagnosis and entry into the SCQM is very broad (interquartile range in months 2009 14 (3 - 79)).

4.4.2 Variables of disease activity

Figure 7 and Table 9 represent several disease activity and disability variables of the active patients in the AS registry.

	Inclusion 08	Inclusion 09	Follow-up 08	Follow-up 09
number of patients	277	290	610	757
mean glob. NRS pat.	5.6 (2.8)	5.6 (2.6)	3.7 (2.6)	3.8 (2.6)
mean glob. NRS phys.	3.9 (2.1)	3.8 (2.2)	2.2 (1.8)	2.1 (1.8)
mean BASDAI	5 (2.3)	5 (2.1)	3.6 (2.2)	3.6 (2.3)
mean BASFI	3.6 (2.6)	3.6 (2.6)	2.6 (2.4)	2.7 (2.5)
mean BASMI	2.4 (2)	2.1 (2)	2.3 (2.1)	2.1 (2.1)

Table 9: Disease activity at inclusion and at follow-up of patients with the indicated type of visit in 2008 and 2009. 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.

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

TNF-inhibitors are efficacious in the symptomatic treatment of AS (Zochling J et al.. ASAS/-EULAR recommendations for the management of ankylosing spondylitis Ann Rheum Dis 2006; 65(4): Epub 2005 Aug. 26.). The evidence for a reduction of structural progression by treatment with TNF-inhibitors, is, however, limited (Baraliakos X et al.. Radiographic progression in patients with ankylosing spondylitis after 4 yrs of treatment with the anti-TNF-alpha antibody infliximab. Rheumatology 2008; 46(9): 1450 – 1553.).

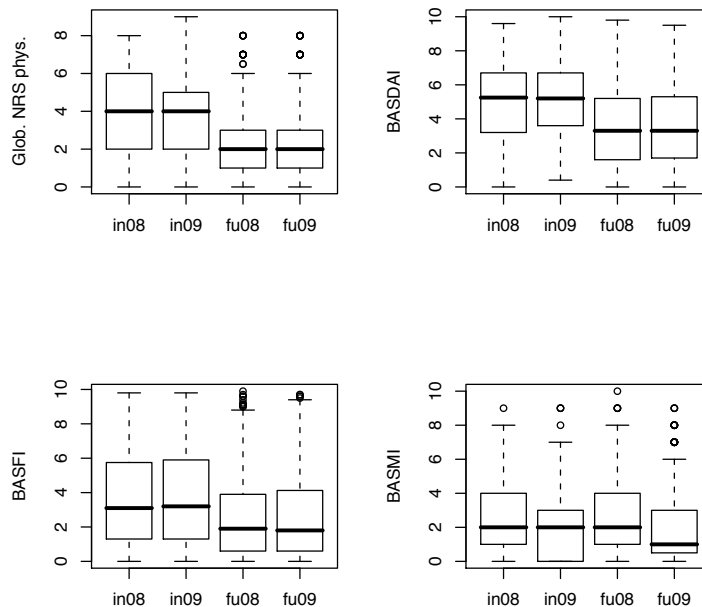


Figure 7: Box plots for the global disease activity estimated by the physician (glob. NRS phys.), BASDAI, BASFI and BASMI. (For a description of these acronyms see table 9). The box plots display median (fat black line in the box) and inter quartile range (range within the box). The data points that lie outside the whiskers are considered outliers. in08 and in09 stands for patients with an inclusion visit in 2008 and 2009 respectively and fu08 and fu09 stands for follow-up visit in 2008 and 2009 respectively.

In the SCQM AS registry, 54% of the 757 patients, for whom a questionnaire was available in 2009, were on anti-TNF treatment at this most recent visit. Of these, 125 were treated with infliximab, 141 with etanercept and 143 with adalimumab.

4.4.4 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 an surgery and the total number of surgeries. Table 11 lists the number of operations by type.

4.4.5 Unemployment due to ankylosing spondylitis

Patients are asked whether, and if so, since what year, they have had to reduce or quit their job due to their rheumatic disease. The data displayed are patient reported only.

	Inclusion 08	Inclusion 09	Follow-up 08	Follow-up 09
number of patients	277	290	610	757
% patients w. hospital stay	14.8	8.6	5.2	4.8
# patients with OPs	40	33	21	25
total # OPs	47	36	21	25
OPs per pat.	0.2	0.1	0	0

Table 10: Hospital or rehabilitation clinic stay in relation to the ankylosing spondylitis arthritis and operations reported in inclusion or follow-up visits in 2008 or 2009. 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.

	Inclusion 08	Inclusion 09	Follow-up 08	Follow-up 09
Total # of OPs	47	36	21	25
# SS OPs	4	3	1	0
# other Spine OPs	0	1	0	2
# shoulder OPs	5	8	0	4
# knee OPs	3	2	2	3
# hip OPs	7	3	6	6
# other OPs	28	19	12	10

Table 11: Type of operations reported in inclusion or follow-up visits in 2008 or 2009. 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 08	Inclusion 09	Follow-up 08	Follow-up 09
number of patients	277	290	610	757
% patients reduced job	11.9	13.4	13.77	13.3
median duration reduction (years)	5	5	5	7
% patients quit job	16.6	5.5	8.9	11.1
median duration (years)	4	4	5.5	5

Table 12: Percentage of patients who reduced or quit their job due to their rheumatic disease, and median duration of reduction or interruption of work.

5 Activity Report of the Psoriatic Arthritis Cohort

5.1 Background information

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

With the help of additional personnel, the PsA questionnaires collected since 2004 could be entered into the newly created PsA database within six months. As a result, this data is now also available for research purposes. Since the second half of the year under review, it has been possible to send the rheumatologists feedback from PsA entries.

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 mid May 2010, there were over 740 patients in the registry of psoriatic arthritis with a total of more than 2000 visits. The median number of visits of all patients in the PsA cohort was 2, and the maximum of the number of visits per patient is 18. In 2009, we received one or more visits for over 500 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. All questionnaires are available in German and in French. The aims of the register 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. Unlike the other two registries radiographic information is not yet collected.

5.4 Results

5.4.1 Patient characteristics

	Inclusion 08	Inclusion 09	Follow-up 08	Follow-up 09
number of patients	142	151	281	334
mean age (Std.dev., years)	48 (13)	47 (12)	50 (11)	50 (11)
% Male	47	50	55	53
IQR time sympt.-diagnosis (months)	31.5 (6 - 97)	27 (6 - 86)	–	–

Table 13: Patient characteristics of inclusion and follow-up patients in 2008 and 2009. Std.dev. stands for standard deviation and IQR for inter quartile range of the median.

In 2008, we received 142 inclusions and 281 follow-up visit questionnaires (intermediate control or yearly control) in the database. In 2009, so far 151 inclusion and 334 follow-up questionnaire-sets have flown into the database of psoriatic arthritis.

	Inclusion 08	Inclusion 09	Follow-up 08	Follow-up 09
number of patients	142	151	281	334
mean glob. NRS pat.	5 (3.2)	4.8 (3)	3 (2.5)	3.2 (2.7)
mean glob. NRS phys.	4.2 (2.5)	4 (2.4)	1.7 (1.8)	2 (2)
Mean swollen 68	4.7 (6.4)	4.6 (5.4)	1.8 (4)	1.8 (3.7)
Mean tender 68	7.8 (9.7)	8.4 (11.2)	3.7 (6.3)	5.2 (9.5)
mean Skin phys	2.2 (1.7)	2.1 (1.6)	1.2 (1.3)	1.4 (1.4)
mean Skin pat.	2.2 (1.7)	2.3 (1.7)	1.6 (1.5)	1.6 (1.4)
mean NRS Pain pat.	4.9 (3)	4.6 (2.8)	3.2 (2.7)	3.4 (2.8)

Table 14: Disease activity at inclusion and at follow-up of patients with the indicated type of visit in 2008 and 2009. 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).

	Inclusion 08	Inclusion 09	Follow-up 08	Follow-up 09
number of patients	142	151	281	334
% patients w. hospital stay	4.2	7.3	2.8	5.1

Table 15: Hospital or rehabilitation clinic stay in relation to the psoriatic arthritis in inclusion or follow-up visits in 2008 or 2009.

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 Unemployment due to psoriatic arthritis

Patients are asked whether, and if so, since what year, they have had to reduce or quit their job due to their rheumatic disease. The data displayed are patient reported only.

	Inclusion 08	Inclusion 09	Follow-up 08	Follow-up 09
number of patients	142	151	281	334
% patients reduced job	11.3	11.9	16.4	15
median duration reduction (years)	2.5	6	6	7
% patients quit job	7.7	7.9	16	9.9
median duration (years)	3	2.5	4	5

Table 16: Percentage of patients who reduced or quit their job due to their rheumatic disease and median duration of reduction or interruption of work.

6 The SONAR group

In the latter half of 2009 a decision was reached with the Sonar Group (a group of rheumatologists that enhances sonographic expertise within the field of rheumatology) to extend the SCQM database to incorporate ultrasound entries. 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 rheumatologists trained	Number rheumatologists active in 2009
University hospital	57	11
Other hospital	26	1
Rheumatology Office	47	4

Table 17: Number of rheumatologists trained for SONAR and number of rheumatologists that have entered SONAR visit(s) in 2009.

6.2 SONAR visits

	Inclusion 2009	Follow-up 2009
Number of SONAR visits	22	17
Number of patients with SONAR visits	22	17
On biologic during SONAR visit	9	8
Biologic started after SONAR visit	1	1

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.

Table 18 displays the number of SONAR visits that have been entered in 2009 for patients that had an inclusion or follow-up visit in 2009. In 2009, there was no patient with more than one SONAR visit, therefore the numbers in line 1 and 2 of Table 18 are equal. About half of the

patients were under biologic treatment during the sonography and two patients initiated biologic treatment within 2 weeks of the sonographic examination.

7 Patrons and sponsors

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

7.1 Patrons



7.2 Sponsor development Online Database



7.3 Interest free loan for development Online Database



7.4 Sponsor Project SCQM Biobank



7.5 Donation



8 Annual Accounts

8.1 Auditor's Report

Treuhand
Wirtschaftsprüfung
Gemeindeberatung
Unternehmensberatung
Steuer- und Rechtsberatung
Informatik – Gesamtlösungen



**Bericht der Revisionsstelle
zur Eingeschränkten Revision**
an den Stiftungsrat der
SCQM Foundation Swiss Clinical Quality
Management in Rheumatic Diseases
8048 Zürich

Als Revisionsstelle haben wir die Jahresrechnung (Bilanz, Betriebsrechnung und Anhang) der SCQM Foundation Swiss Clinical Quality Management in Rheumatic Diseases für das am 31. Dezember 2009 abgeschlossene Geschäftsjahr geprüft. Die Eingeschränkte Revision der Vorjahresangaben ist von einer anderen Revisionsstelle vorgenommen worden.

Für die Jahresrechnung ist der Stiftungsrat verantwortlich, während unsere Aufgabe darin besteht, diese zu prüfen. Wir bestätigen, dass wir die gesetzlichen Anforderungen hinsichtlich Zulassung und Unabhängigkeit erfüllen.

Unsere Revision erfolgte nach dem Schweizer Standard zur Eingeschränkten Revision. Danach ist diese Revision so zu planen und durchzuführen, dass wesentliche Fehlaussagen in der Jahresrechnung erkannt werden. Eine Eingeschränkte Revision umfasst hauptsächlich Befragungen und analytische Prüfungshandlungen sowie den Umständen angemessene Detailprüfungen der beim geprüften Unternehmen vorhandenen Unterlagen. Dagegen sind Prüfungen der betrieblichen Abläufe und des internen Kontrollsystems sowie Befragungen und weitere Prüfungshandlungen zur Aufdeckung deliktischer Handlungen oder anderer Gesetzesverstösse nicht Bestandteil dieser Revision.

Bei unserer Revision sind wir nicht auf Sachverhalte gestossen, aus denen wir schliessen müssten, dass die Jahresrechnung nicht Gesetz, Stiftungsurkunde und Reglement entspricht.

OBT AG

A handwritten signature in black ink, appearing to be 'A. Thut', written over a horizontal line.

Andreas Thut
zugelassener Revisionsexperte

A handwritten signature in black ink, appearing to be 'J. Häusermann', written over a horizontal line.

Jules Häusermann
zugelassener Revisor
Leitender Revisor

Brugg, 23. März 2010

– Jahresrechnung 2009 (Bilanz, Betriebsrechnung und Anhang)

8.2 Balance

Bilanz per 31. Dezember 2009	Berichtsjahr CHF	Vorjahr CHF
A K T I V E N		
Flüssige Mittel	379'586.02	407'916.54
Forderungen aus Lieferungen und Leistungen gegenüber Dritten	1'102.90	48'420.00
Andere kurzfristige Forderungen	5'984.30	13'874.65
UMLAUFVERMÖGEN	386'673.22	470'211.19
EDV (Hard- und Software)	10'381.00	20'841.00
Onlinedatenbank	97'584.60	78'576.90
Sachanlagen	107'965.60	99'417.90
ANLAGEVERMÖGEN	107'965.60	99'417.90
A K T I V E N	494'638.82	569'629.09

Bilanz per 31. Dezember 2009	Berichtsjahr CHF	Vorjahr CHF
PASSIVEN		
Verbindlichkeiten aus Lieferungen und Leistungen gegenüber Dritten	31'419.85	26'705.93
Andere kurzfristige Verbindlichkeiten	37'059.36	53'543.36
Darlehensschulden	180'000.00	230'000.00
Fonds für Onlinedatenbank	0.00	50'607.05
Fonds für Biobank	2'909.20	0.00
Fonds	2'909.20	50'607.05
FREMDKAPITAL	251'388.41	360'856.34
Widmungskapital	80'000.00	80'000.00
Vortrag vom Vorjahr	128'772.75	58'636.52
Jahreserfolg	34'477.66	70'136.23
Bilanzgewinn 31.12.	163'250.41	128'772.75
STIFTUNGSKAPITAL	243'250.41	208'772.75
PASSIVEN	494'638.82	569'629.09

8.3 Income Statement

Betriebsrechnung 2009	Berichtsjahr CHF	Vorjahr CHF
Ertrag aus Sponsoring	554'646.85	540'000.00
Ertrag aus zusätzlichen Dienstleistungen	7'100.00	0.00
Spenden	65'000.00	186'000.00
Übriger Ertrag	0.90	1'500.00
Ertrag	626'747.75	727'500.00
Personalaufwand	-390'155.65	-383'909.53
Raumaufwand	-36'739.13	-49'863.25
Aufwand Biobank	-17'090.80	0.00
Sachversicherungen	-733.80	-76.50
Informatikaufwand	-9'304.47	-28'260.02
Informatikaufwand Onlinedatenbank	-48'945.83	-20'816.05
Verwaltungsaufwand	-51'959.33	-60'651.95
Kommunikation	-16'517.05	-10'803.52
Übriger Aufwand	-9'776.33	-4'365.40
Abschreibungen	-59'252.30	-48'429.85
Aufwand	-640'474.69	-607'176.07
Erfolg vor Zinsen	-13'726.94	120'323.93
Finanzertrag	980.30	1'130.05
Finanzaufwand	-473.55	-710.70
Erfolg vor Fondsveränderung	-13'220.19	120'743.28
Auflösung Fonds	67'697.85	99'392.95
Zuweisung Fonds	-20'000.00	-150'000.00
JAHRESERFOLG	34'477.66	70'136.23

8.4 Annexe

Anhang der Jahresrechnung 2009	Berichtsjahr CHF	Vorjahr CHF
Brandversicherungswerte der Sachanlagen Mobilien, Einrichtungen und EDV	130'000.00	230'000.00
Verbindlichkeiten gegenüber Vorsorgeeinrichtungen	103.15	0.00

Angaben über die Durchführung einer Risikobeurteilung

Der Stiftungsrat hat periodisch ausreichende Risikobeurteilungen vorgenommen und allfällige sich daraus ergebende Massnahmen eingeleitet, um zu gewährleisten, dass das Risiko einer wesentlichen Falschaussage in der Rechnungslegung als klein einzustufen ist.

9 The Swiss Clinical Quality Management (SCQM) Foundation in Rheumatic Diseases

9.1 The SCQM Board

The members of the SCQM Board are (as of December 2009):

- Dr. Hans A. Schwarz (President), Emeritus Head of Rheumatology Dep. Bethesdaspital, Basel
- Prof. Dr. Cem Gabay (Vice-President), Hôpitaux Universitaires de Genève
- Ms Gisela Dalvit, Emeritus Head of the Swiss League against Rheumatism
- Dr. Adrian Forster, Thurgauer Klinik St. Katharinental, Diessenhofen
- Prof. Dr. Paul Hasler, Kantonsspital Aarau, Aarau
- Prof. Dr. Rudolph Kissling, Universitätsklinik Balgrist, Zürich
- Dr. Marie-Josèphe Sauvain, medical specialist FMH, Fribourg
- Markus Bärtschi, Roche (Schweiz) AG, patrons representative

9.2 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. Bethesdaspital, Basel
- Ms Gisela Dalvit, Emeritus Head of the Swiss League against Rheumatism
- Dr. Adrian Forster, Thurgauer Klinik St. Katharinental, Diessenhofen
- Prof. Dr. Rudolph Kissling, Universitätsklinik Balgrist, Zürich
- Sabine von Känel, Executive Secretary
- Dr. Almut Scherer, Scientific Manager

9.3 The Scientific Committees

The commissions mainly deal with the scientific aspects of the register, their members are experts in the field of the respective register. At least one member of the commission is a private practitioner in order to bring in the relevant inputs of a private practice.

RA Commission

- Dr. Axel Finckh (Chairman), Hôpitaux Universitaires de Genève
- Dr. Ines von Mühlennen, medical specialist FMH, Basel
- Dr. Jean Dudler, Centre Hospitalier Universitaire Vaudois, Lausanne
- PD Dr. Diego Kyburz, Universitätsspital Zürich
- Prof. Dr. Ulrich Walker, Felixplatter hospital, Basel

AS Commission

- Dr. Ulrich Weber (Chairman), Universitätsklinik Balgrist, Zürich
- Dr. Pascale Exer, medical specialist FMH, Basel
- Dr. Jürg Bernhard, Bürgerspital Solothurn
- Dr. Adrian Ciurea, Universitätsspital Zürich
- Dr. Giorgio Tamborini, Universitätsspital Zürich

PsA Commission

- PD Dr. Burkhard Möller (Chairman), Inselspital, Bern
- Dr. Jean Dudler, Centre Hospitalier Universitaire Vaudois, Lausanne
- Dr. Bettina Weiss, Universitätsklinik Balgrist, Zürich
- Prof. Dr. Nikhil Yawalkar (Dermatologist), Inselspital, Bern

SONAR Commission

- Dr. Hansruedi Ziswiler (Chairman), Inselspital, Bern
- Dr. Thomas Gerber, Zentrum für Rheuma- und Knochenerkrankungen, Zürich
- PD Dr. Burkhard Möller, Inselspital, Bern

- Dr. Laure Brulhart, Hôpitaux Universitaires de Genève
- Dr. Andreas Krebs, Universitätsspital Zürich
- Dr. Andrea Stärkle Bär, Universitätsspital Zürich
- Dr. Stefan Mariacher, aarReha Schinznach
- Dr. Giorgio Tamborini, Universitätsspital Zürich
- Dr. Pascal Zufferey, Centre Hospitalier Universitaire Vaudois, Lausanne

Research and collaboration

- Dr. Hans A. Schwarz, Emeritus Head of Rheumatology Dep. Bethesdaspital, Basel
- Prof. Dr. Cem Gabay, Hôpitaux Universitaires de Genève
- Dr. Axel Finckh, Hôpitaux Universitaires de Genève
- PD Dr. Burkhard Möller, Inselspital, Bern
- Sabine von Känel, Executive Secretary
- Dr. Almut Scherer, Scientific Manager
- Dr. Sigrid Aigner, Bristol-Myers Squibb

9.4 The SCQM Office

- Sabine von Känel, executive Secretary
- Almut Scherer, scientific manager
- Susanne Frieser, assistant for Administration and PsA
- Jacqueline Hirt, assistant for AS
- Heinz Wyrsh, assistant for RA
- Helene Uhlmann, assistant digitizing AS X-rays
- Mirta Viviani, assistant RA X-rays scoring (until 08.2009)
- Cathrin Fässler, assistant digitizing RA X-rays (until 06.2009)
- Dominik Loiero, assistant RA X-rays scoring and digitizing (from 08.2009)
- Sandra Acklin and Thomas Hunziker, temporary assistants responsible for data entry
- Ünal Ömer, voluntary work

9.5 The SCQM Organigramm

The Organigramm of the SCQM Foundation is displayed graphically in Figure 8. The SCQM office team reports to the Board of the Foundation. Operative issues are discussed first within the Executive Board, which consists of representatives of the Board of the Foundation and of the scientific and general manager of the SCQM office. Important points are presented to the Board of the Foundation at the board meetings. The SCQM office team is in regular contact with the members of the Scientific Commissions.

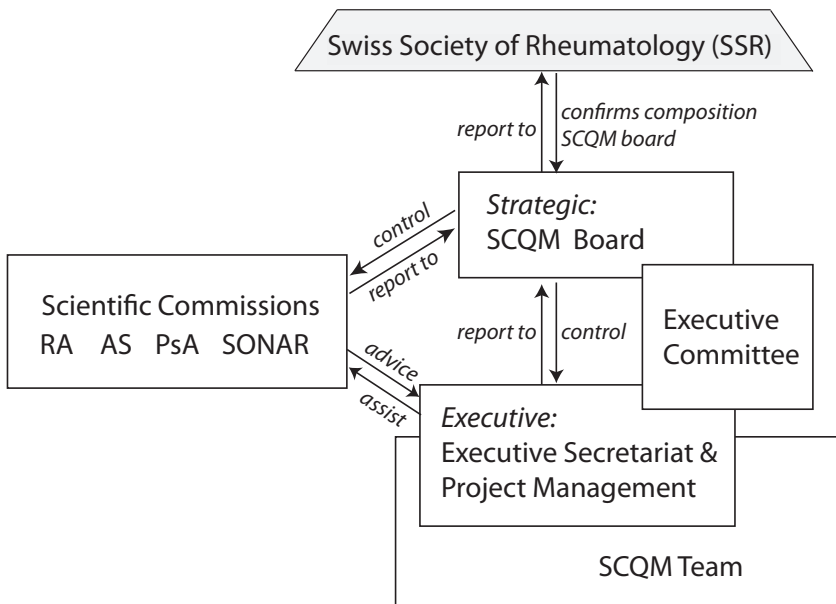


Figure 8: Organigramm of the SCQM.

9.6 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
- Thurgauer Klinik St. Katharinental, Diessenhofen
- Universitätsklinik Balgrist, Abteilung für Rheumatologie, Zürich
- Rheumaliga Schweiz, RLS
- Schweizerische Gesellschaft für Rheumatologie, SGR

10 Research 2009

10.1 Publications

The following manuscripts on SCQM data were finalized, submitted and accepted by the most highly rated journals in the field of rheumatology in 2009.

- Finckh A, Scherer A, George Reed PhD, Jeffrey Greenberg MD, MPH, Lubbeke A, Schwarz H, Gabay C, Joel Kremer, MD. Obesity and RA Disease Severity: A Comparison Between European and American RA Patients. Poster presentation at the 2009 ACR/ARHP Annual Scientific Meeting, to be held in Philadelphia, PA, October 16-21, 2009.

- Pan SM, Dehler S, Ciurea A, Ziswiler HR, Gabay C, Finckh A, on behalf of the Swiss Clinical Quality Management Physicians. Comparison of drug retention rates and causes of drug discontinuation between anti-tumor necrosis factor agents in rheumatoid arthritis. *Arthritis and Rheumatism*, 2009 May 15;61(5):560 – 8.
- Finckh A, Dehler S, Gabay C, on behalf of the Swiss Clinical Quality Management Physicians. The effectiveness of leflunomide as a co-therapy of tumour necrosis factor inhibitors in rheumatoid arthritis: a population-based study. *Annals of the Rheumatic Diseases*, 2009 Jan;68(1):33 – 9

10.2 Projects in progress

- Abatacept after Rituximab in RA patients, study lead Prof. Dr. Ulrich Walker (Universitätsspital Basel).
- Determinants of TNFa inhibitor prescription in the practice-based Swiss prospective observational cohort of axial SpA patients SCQM AS, study coordinator Dr. Ulrich Weber (Universitätsklinik Balgrist).
- Efficiency, comparison of drug retention rates and role of treatment switch between TNF-inhibitors in the SCQM AS cohort, study coordinator Dr. Adrian Ciurea (Universitätsspital Zürich).
- Determinants of radiographic progression over 4 years in the SCQM AS cohort, study coordinator Dr. Adian Ciurea (Universitätsspital Zürich).
- Renal safety of conventional nonsteroidal antirheumatic drugs and Coxibs in the long term treatment: A prospective cohort analysis, Axel Finckh, Burkhard Möller et al.
- Anaemia in a large patient cohort with rheumatoid arthritis, Burkhard Möller, Axel Finckh et al.
- Enbrel CARE market research, evaluation of data by Dr. med. Axel Finckh.
- Cross-validation of parameters estimation in longitudinal SEM, Jérôme Glauser, Delphine Courvoisier, Axel Finckh et al.
- Evolution of general health assessment as measured by SF-36 in patients suffering from Rheumatoid Arthritis using Structural Equation Modeling, Jérôme Glauser, Delphine Courvoisier, Axel Finckh et al.
- Sibling Study: RA screening in family members, Dr. med. Axel Finckh et al.
- Frühinfekte nach orthopädischen Eingriffen bei Patienten mit entzündlich-rheumatischen Erkrankungen, Dr. med. Inès Kramers-de Quervain et al.

- CERRERA: Suivi des données longitudinales concernant l'utilisation du rituximab dans le traitement de la polyarthrite rhumatoïde. Swiss representative: Prof. Cem Gabay.
- Frequency, determinants and outcome of radiographically defined hip involvement 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, (Universitätsklinik 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 (Universitätsklinik 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 (Universitätsklinik 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 (Universitätsklinik Balgrist).
- Impact of conventional DMARD co-therapy on the effectiveness of TNF-inhibitors in Ankylosing Spondylitis. Study lead Dr. Michael Nissen (Hôpital Universitaire Genève).

11 Acknowledgements

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