SCQM FOUNDATION Swiss Clinical Quality Management in Rheumatic Diseases



ANNUAL REPORT 2010

Contents

1	Edit	orial		3
	1.1	Forewo	ord by the President	3
	1.2	Review	2010	4
		1.2.1	Online database	4
		1.2.2	X-ray database	4
		1.2.3	Biobank project	4
		1.2.4	Communication	5
		1.2.5	Research fund	5
		1.2.6	Financing	5
		1.2.7	Personnel	6
		1.2.8	Data extraction for the yearly report	6
2	Con	tributer	s to the SCQM registry	6
3	Acti	vity Rep	port of the Rheumatoid Arthritis Cohort	6
	3.1	Popula	tion	6
	3.2	Sample		6
	3.3	Variabl	les	7
	3.4	Results	3	8
		3.4.1	Patient characteristics	8
		3.4.2	Variables of Disease Activity	9
		3.4.3	Prescription of Disease Modifying Anti-rheumatic Drugs (DMARDs) . 10	0
		3.4.4	Surgery	2
		3.4.5	Incapability of work and absences at work	3
4	Acti	vity Rep	oort of the Ankylosing Spondylitis Cohort 14	4
	4.1	Backgr	round information \ldots \ldots \ldots \ldots \ldots \ldots 14	4
	4.2	Popula	tion	4
	4.3	Results	$s_{1}, \ldots, \ldots,$	4
		4.3.1	Patient characteristics	4
		4.3.2	Variables of disease activity	
		4.3.3	Prescription of Disease Modifying Anti-rheumatic Drugs (DMARDs) . 14	4
		4.3.4	Surgery	
		4.3.5	Incapability of work and absences at work	5
5	Acti	•	port of the Psoriatic Arthritis Cohort 1	8
	5.1	-	ound information	
	5.2		tion	
	5.3		pllection $\ldots \ldots 13$	
	5.4		$5.\ldots\ldots\ldots\ldots\ldots\ldots\ldots\ldots$	
		5.4.1	Patient characteristics	
		5.4.2	Variables of Disease Activity	
		5.4.3	Prescription of Disease Modifying Anti-rheumatic Drugs (DMARDs) . 19	
		5.4.4	Hospital stay	
		5.4.5	Incapability of work and absences at work	9

6	The	SONAR group	21
	6.1	SONAR rheumatologists	21
	6.2	SONAR visits	21
7	Patr	ons and sponsors	22
	7.1	Patrons	22
	7.2	Funding SCQM Biobank	22
		7.2.1 Funding of running costs	22
		7.2.2 Support development Biobank Online Database	22
	7.3	Donation	23
		7.3.1 Support development RA X-ray Database	23
		7.3.2 Support development patient interface	23
		7.3.3 General	23
8	Ann	ual Acounts	24
	8.1	Auditor's Report	24
	8.2	Balance	25
	8.3	Income Statement	26
	8.4	Annexe	27
9	The	Swiss Clinical Quality Management (SCQM) Foundation in Rheumatic Dis-	
	eases	-	28
	9.1	The SCQM Board	28
	9.2	The Executive Committee	28
	9.3	The Scientific Committees	29
	9.4	The SCQM Office	30
	9.5	The SCQM Organigramm	31
	9.6	List of SCQM Founders	31
10	Rese	earch 2010	32
	10.1	Publications	32
	10.2	Projects in progress	33
11	Ackı	nowledgements	34

1 Editorial

1.1 Foreword by the President

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

For the three longstanding registers in SCQM 2010 has mainly been a year of consolidation. After the introduction of the online version during the previous year, this modality has gained acceptance and is now used by the doctors in the majority of inclusions and patient visits, whereas still a minority of patients are using it today. Further developments in view of easier access and input of data and more succinct feed-back (documentation) for the participants are under way. A major advantage has been achieved in the RA cohort: The patients' X-rays have now all been digitalized and stored at the SCQM office (transfer from University Hospital Zurich) and can be seen on the doctor's screen when a patient's score board is opened. This facilitates the direct comparison of X-rays enormously and gets rid of the never-ending problem of missing X-rays.



The SONAR Group increased both the number of inclusions and visits. Being a small but very dedicated group with a specific agenda, it certainly will deliver useful data for the evaluation of diagnostic ultrasound as a method of imaging in inflammatory rheumatic diseases in clinical practice.

The Biobank Committee has decided on a centralized solution for storing all the biological samples. They will be transported in cold-chain to the Sérothèque Centrale des Hôpitaux Universitaires de Genève, where they will be processed and stored at -80 degrees celcius. The patient information and the rules of procedures have been finalized and submitted to the Ethics Committee of the University of Geneva where it has recently been accepted.

A number of publications in internationally renowned journals and abstracts at the EULAR as well as the ACR Congress have been made and a substantial list of research projects are under way. These efforts are highly welcome and testify of the SCQM database as a valid tool for clinical research. The Board is seeking ways and means to foster research initiatives with SCQM data. It is convinced that the addition of the biobank will increase both the attractiveness and the use of the database data considerably.

All these activities considered we shall never forget that the livelihood of SCQM depends on the engagement of all the participating doctors and patients, of the dedicated team at the SCQM office – above all Mrs. S. von Känel and Dr. A. Scherer – and all the members of the various Committees and the Board of Foundation, where the new members Mr. lic.iur. R. Bräm, PD Dr. D. Kyburz and Prof. Dr. P. Villiger received a warm welcome and have settled in successfully. My sincerest thanks to all of them!

We also gratefully acknowledge the ongoing support of our partners (patrons) from the pharmaceutical industry and our sponsors. A special thank to ARCO Foundation (Mr. M. Kündig) for their most generous and continuing support.

May the SCQM Fondation and all of you have a successful 2011.

Yours sincerely, Hans Schwarz

1.2 **Review 2010**

Sabine von Känel, Executive Secretary of the SCQM Foundation

It is not just the big leaps that move an institution forward – the many small steps also lead to success. Thus, the objective in 2010 was to consolidate what had already been achieved and to tackle many smaller projects and adaptations.

1.2.1 Online database

Improvements were made to the online database throughout the year under review. On the one hand, the research database, to which the data from the online database are mirrored in an anonymized form each day, was replaced with a more stable database, without this being obvious to its users. On the other hand, the speed of the system was vastly improved. Improvements were also made with regard to user-friendliness.

1.2.2 X-ray database

The development of the SCQM's own X-ray database for the X-ray images that had previously been stored in an external database at University Hospital Zurich represented another milestone for the online database. All X-ray images in the online database are one mouse-click away for viewing or downloading.

The Rau score for the images is also displayed. It is planned to integrate the AS cohort's X-ray images into an SCQM X-ray database in 2011. At present, the images are still being stored at University Hospital Balgrist, in an external database system that allows scoring by two readers.

We would like to thank the scientific committee of the AS cohort for scoring (ISG) hundreds of X-ray images free of charge. The scores are essential for the classification of AS patients. We would also like to thank both University Hospital Zürich and University Hospital Balgrist for the X-ray image storage solutions provided to date.

1.2.3 Biobank project

A large project, launched in 2009, was tackled in the year under review: in January 2010, Dr Albana Rexhepaj assumed her role as Study Monitor of the SCQM Biobank. Her first task was to evaluate the infrastructure of the seven key centres (university hospitals and the cantonal hospitals of Aarau and St Gallen) with regard to the processing and storage of biosamples. It quickly became apparent that the conditions in the individual centres deviated strongly from one another. The project leaders therefore decided that it would be beneficial to switch from the decentralised biobank to a centralised solution. Different providers of biobank solutions were subsequently assessed by means of a requirements catalogue and subjected to a selection procedure. In September, the members of the biobank project group decided to award the contract for storing and processing the biosamples to the Serothek Centre of the Department of Genetics and Laboratory Medicine (Head: Prof. Denis Hochstrasser) at Geneva University Hospital.

Patient information, declarations of consent and the rules of the biobank are based on SAMW (Swiss Academy of Medical Sciences) documentation. The company Seantis (on-



line database) was commissioned with developing the IT infrastructure for the logistics of the biobank.

In order to ensure that the samples can also be used in future research projects for which the qualitative requirements are not yet known, the samples have to be generated at the best possible quality. To this end, certain processing and storage requirements must be strictly adhered to.

The collection of the samples will commence in the first few months of 2011, after a test phase in Geneva and Zurich. The biobank is a financially independent project within the SCQM. Thanks to the generous support of the Arco Foundation, as well as grants from both UCB and Pfizer, the financial situation of the project is secure for the first few years.

1.2.4 Communication

Communication is also assuming an increasingly important role for the SCQM. Through regular NEWS publications, rheumatologists are kept up to date with the latest developments in the registry and the functionality of the database. For the presentation of the online data entry in practices and clinics, a member of staff has been available since May 2010 to deal exclusively with this issue.

The SCQM information stand at the SGR congress and at other events allows the SCQM online database to be presented in a clear and uncomplicated way. Patients are kept informed of the activities and research projects of the SCQM registry by means of articles in the journal of the Swiss League Against Rheumatism and those of the patient organizations SVMB (Swiss Bechterew's Disease Association) and SPV (Swiss Society of Polyarthritic Patients).

1.2.5 Research fund

Thanks to a generous donation from the Arco Foundation and UCB, the SCQM has been able to establish a research fund. The money from this fund will be used primarily to support research projects based on SCQM data. All research projects are entitled to ten hours of support from the SCQM scientific manager, on issues such as data analysis or statistics.

1.2.6 Financing

The SCQM's operating costs are covered mainly by contributions from patron companies (see section 7). Identical contracts are negotiated each year with all patron companies, which ensures that our work remains "neutral", i.e. is not dependent on corporate interests.

In September 2010, the company UCB also became a new patron of the SCQM. The cooperation with the patrons is very constructive and is based on mutual respect.

In the year under review, it was possible to support the SCQM's financial basis more broadly, thanks mainly to various donations. For the realization of the patient interface project (realisation 2011), Zürcher Rheumastiftung supported us with a contribution of CHF 10,000. The X-ray database project was supported by the Swiss Society of Rheumatology, to the tune of CHF 10,000. Other contributions were received from the Arco Foundation and from an anonymous donor. Over the past few years, the Swiss association Balgrist has eased our financial burden with interest-free loans. In fact, without such loans, it would not even have been possible to create the online database. In the year under review, the SCQM's financial situation relaxed to such an extent that all debts to third parties could be repaid.

1.2.7 Personnel

At the beginning of the year under review, the SCQM Foundation's employment allocation stood at 360%, around 20% of which relates to the biobank. The SCQM Team is supplemented by medical students who are employed at an hourly wage (around 30%). At the end of April 2010, Ms J. Hirt transferred to the SCQM's team of representatives, where she is responsible for the presentation of online data entry. Since September 2008, Ömer Ünal has been faithfully supporting the SCQM Team with community work.



1.2.8 Data extraction for the yearly report

Data extraction, layout and text were prepared by Almut Scherer, our scientific manager.

2 Contributers 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 2010. 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/arzte/forschung /beitragende-institutionen.

3 Activity Report of the Rheumatoid Arthritis Cohort

3.1 Population

The SCQM registry of rheumatoid arthritis exists since 1995. Overall there are 6323 patients and over 33084 visits in the rheumatoid arthritis cohort (status July 4, 2011). The median number of visits per patient is 4, with a range of up to 62 visits. In 2010, we received one or more visits for 2467 patients.

3.2 Sample

The results in the following tables and figures are shown for the year 2009 and 2010 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 July 4, 2011.

124 patients	Praxis Exer & Von Mühlenen (Basel)						
.	× /						
81 – 100 patients	Dr. Wicht (Solothurn), Klinic Impuls (Wetzikon)						
60 – 79 patients	Ärztehaus Zetrumspassage (Brugg), Rheumatologie im Silberturm (St.						
	Gallen), Dr. Suter (Bern), Dr. Martin (Liestal)						
40 – 59 patients	Dr. Badaracco (Lugano), Dr. Zufferey (Estavayer-Le-Lac), Dr.						
	Tauxe (Vevey), Dr. Müller-Werth (Sarnen), Dr. Lehman (Bern), Dr.						
	Marbet-Grierson (Olten), Dr. Maager (Aarau), Dr. Chamot (Morges),						
	Dr. Kowalski (Solothurn), Dr. Massikommer (Visp), Dr. Gäu-						
	mann (Murten), Dr. A. Wüest (Wädenswil), Rheumapraxis Männedorf						
	(Männedorf), Dr. Volken (Sierre), Dr. Plihal Sumi (Lausanne), Dr.						
	Ziehmann (Zürich), Dr. Schürch (Lausanne), Dr. Mathieu (Solothurn),						
	Dr. Muff (Affoltern am Albis)						
20 – 39 patients	Dr. Sauvain (Fribourg), Dr. Aellen (Nyon), Dr Carey-Berner (Lau-						
L.	sanne), Dr. Rösler (Bern), Dr. Widrig-Bernhardt (St. Gallen), Dr.						
	Schwartz (Genève), Dr. Masina (Lugano), Dr. Bosia (Locarno), Dr.						
	Raccaud (Lausanne), IZZ Immunologie-Zentrum Zürich (Zürich), Dr. Pancaldi (Muralto), Dr. Elmiger (Bern), Dr. Schneeberger (Martigny),						
	Pancaldi (Muralto), Dr. Elmiger (Bern), Dr. Schneeberger (Martigny), Dr. Gratzl (Basel), Dr. Maclachlan (Heiden), Dr. Gerny (Thun), Dr.						
	Kaiser (Thalwil), Dr. Morell (Schaffhausen),						
10 – 19 patients	Dr. Bloesch (Lausanne), Dr. Schönbächler (Zürich), Dr. Bourqui						
	(Bulle), Dr. Frey (Basel), Dr. Gerber (Bern), Dr. Pfister (Cham),						
	Dr. Sidler (Zug), Rheumapraxis Langenthal (Langenthal), Dr. Pfis-						
	ter (Bülach), Dr. Meder (Zofingen), Dr. Boller (Interlaken), Dr.						
	Eigenmann Meierhofer (Zürich), Dr. Moser (Liestal), Dr. Häfelin						
	(Schlieren), Dr. Bötschi (Romanshorn), Das Rückenzentrum (Thun),						
	Dr. Putzi (Regensdorf), Dr. Seglias (Burgdorf), Dr. Harder (Luzern),						
	Dr. Leuba Manueddu (Neuchâtel), Dr. Senn (Zürich), Dr. Tinner (We- infelden), Dr. Cut (Beinech), Dr. Flück (Zürich), Dr. Baber (Ter						
	infelden), Dr. Gut (Reinach), Dr. Flück (Zürich), Dr. Reber / Ter-						
	rier (Baden), Dr. Adank (Biel), Rheumazentrum Kreuzlingen (Kreuz-						
	lingen), Dr. Glenz (Visp), Dr. Hasler-Strub (Chur), Zentrum Gerber						
	Häuselmann Kremer (Zürich), Dr. Jaschko (Rümlang), Dr. Spring (Sar-						
	gans), Dr. Bloesch Daniel (Olten), Dr. Merlin (Baden)						

Table 1: Number of patients from private practices, for whom data was contributed in 2010.

3.3 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 calculated the

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

Table 2: Number of patients from hospitals and university hospitals, for whom data was contributed in 2010.

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.

3.4 Results

The results of the analysis are shown separately for inclusion and follow-up visits for 2009 and 2010. Patients included in 2009 may also be in the group of the follow-up patients of 2010.

3.4.1 Patient characteristics

	Inclusion 09	Inclusion 10	Follow-up 09	Follow-up 10
Number of patients	516	547	2113	2111
Mean inclusion age (Std.dev., in years)	55 (14)	56 (14)	_	_
% Female	76	73	-	-
IQR time symptdiagnosis (months)	5 (0 - 14)	5 (1 - 13)	_	_

Table 3: Patient characteristics of inclusion and follow-up patients in 2009 and 2010. Std.dev. stands for standard deviation, and IQR for inter quartile range of the median.

Table 3 shows patient characteristics data. There were 516 patients enrolled in the RA database in 2009. In 2010 we received 547 inclusion questionnaires. 2113 patients had a follow-up visit in 2009, for 2010, 2111 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.

3.4.2 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 2009 and 2010. For the different scores the mean and the standard deviation are listed. The scores shown are the global health assessment by patient, the RADAI, DAS28 and HAQ (see caption Table 4 for explanation of these acronyms).

	Inclusion 09	Inclusion 10	Follow-up 09	Follow-up 10
Number of patients	516	547	2113	2111
Mean glob. NRS pat.	5.5 (2.3)	5.6 (2.4)	6.1 (2.3)	6.2 (2.3)
mean DAS28(ESR)	4.1 (1.4)	4 (1.5)	3.1 (1.2)	3 (1.2)
mean RADAI	4.1 (2.1)	3.8 (2.1)	2.8 (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 2009 and 2010. Standard deviations are indicated between brackets. Mean glob. NRS pat. is the patients assessment of global health, on a numerical rating scale from 0 to 10 (0 meaning bad health and 10 excellent health). DAS28(ESR) is the Disease activity score, based on tender and swollen joint count and the erythrocyte sedimentation rate (scale 0 - 10, 10 being the maximal disease activity). The RADAI is the Rheumatoid Arthritis Disease Activity Index, which takes patient estimate of disease activity, of joint stiffness and pain in specified joint regions into account (scale 0 - 10, 10 being the highest disease activity). HAQ stands for Health Assessment Questionnaire, which measures physical disability (scale 0 - 3, 3 being the highest level of functional disability).

As shown in Table 4 and Figure 1, there is a difference between the groups of inclusion patients and follow-up patients. The RADAI and DAS28 scores show a higher disease activity for patients included in 2009 or 2010, 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 (Prevoo 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 2 presents the percentage of the patients for the four categories. About a quarter of patients have a high disease activity at inclusion in 2009 and 2010, whereas only about 10% respectively 15% of

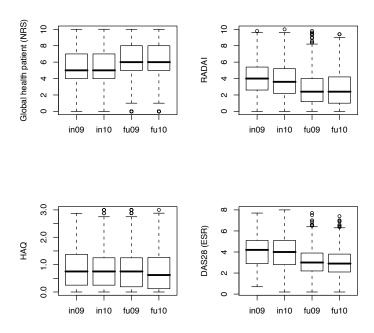
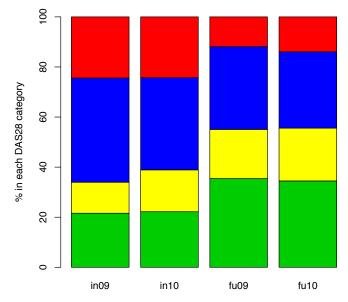


Figure 1: Box plots for the global health estimated by the patient, RADAI, HAQ and DAS28 (ESR). The box plots display median (fat black line in the box) and inter quartile range (range within the box). The data points that lie outside the whiskers are considered outliers. in09 and in10 stands for inclusion visits in 2009 and 2010 respectively and fu09 and fu10 stands for follow-up visit in 2009 and 2010 respectively.

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.

3.4.3 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. About 50 to 60% of patients included in 2009 or 2010 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, more than 70% were on a biologic treatment.



Patients by their DAS28 (ESR) category.

Figure 2: 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. in09 and in10 stands for inclusion in 2009 and 2010 respectively, and fu09 and fu10 for follow-up visit in 2009 and 2010 respectively.

3.4.4 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 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.

	Inclusion 09	Inclusion 10	Follow-up 09	Follow-up 10
number of patients	516	547	2113	2111
% patients w. hospital stay	3.9	6.9	4	4
# patients with OP(s)	99	106	188	186
total # OPs	153	163	210	191
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 2009 or 2010. 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 09	Inclusion 10	Follow-up 09	Follow-up 10
Total # of OPs	153	163	210	191
# hand OPs	37	34	46	50
# foot OPs	34	36	51	40
# spine OPs	13	20	12	17
# shoulder OPs	11	11	13	15
# knee OPs	24	22	34	16
# hip OPs	21	21	29	17
# other OPs	13	16	23	35

Table 6: Type of operations reported in 2009 and 2010, of patients who had an inclusion or follow-up visit in 2009 or 2010. 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. Amongst the patients with inclusion in 2010, follow up in 2009 and follow up in 2010, there were 3, 2 and 1 with a spine straightening operation respectively. Since this is a very unusual operation for RA patients, this operation is not listed in the table.

3.4.5 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 10 months. No external validation of these selfreported data has so far be performed. The results of these questions are displayed in Table 7.

	Inclusion 09	Inclusion 10	Follow-up 09	Follow-up 10
number of patients	516	547	2113	2111
% incapable of work	9.9	7.5	7.3	6.3
% absences at work	16.3	17.6	9.2	7.4
% up to 4 weeks	8.7	9.3	5.7	4.9
% more than 4 weeks	6.4	6.9	2.8	2.2

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 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 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, 1977 patients were included in the SCQM AS registry with a total 5666 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 15. In 2010 we received one or more visits for 1020 patients.

	Inclusion 09	Inclusion 10	Follow-up 09	Follow-up 10
number of patients	304	271	771	797
mean inclusion age (St.dev., years)	42 (13)	41 (13)	-	-
% Male	57	58	-	-
IQR time symptdiagnosis (months)	15 (3 - 84)	15 (3 - 81)	_	_

Table 8: Patient characteristics of inclusion and follow-up patients in 2009 and 2010. St.dev. stands for standard deviation and IQR for inter quartile range of the median.

4.3 Results

4.3.1 Patient characteristics

In 2009, we received 304 inclusions and 771 follow-up visit questionnaires (intermediate control or yearly control) in the database. For 2010, so far 271 inclusion and 797 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 41 years old (inclusion 2010). Between diagnosis and entry to the SCQM, a median of 15 months passed in 2010. The range of the time passing between diagnosis and entry into the SCQM is very broad (interquartile range in months 2010 15 (3 - 81)).

4.3.2 Variables of disease activity

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

4.3.3 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

	Inclusion 09	Inclusion 10	Follow-up 09	Follow-up 10
number of patients	304	271	771	797
mean glob. NRS pat.	5.6 (2.6)	5.5 (2.9)	3.8 (2.6)	3.9 (2.6)
mean glob. NRS phys.	3.8 (2.1)	3.7 (2.3)	2.1 (1.8)	2(1.8)
mean BASDAI	5 (2.1)	4.9 (2.3)	3.6 (2.3)	3.7 (2.2)
mean BASFI	3.6 (2.7)	3.4 (2.7)	2.7 (2.5)	2.7 (2.4)
mean BASMI	2(2)	2(2)	2.1 (2.1)	2.2 (2.1)

Table 9: Disease activity at inclusion and at follow-up of patients with the indicated type of visit in 2009 and 2010. 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 Metrology Index. All of these indexes are on a scale from 0 - 10, 0 being no disease activity and 10 maximal disease activity.

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 2009; 46(9): 1450 - 1553.).

About 50 to 60% of patients included in 2009 or 2010 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, more than 80% were on a biologic treatment.

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

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 10 months. No external validation of these selfreported data has so far be performed. The results of these questions are displayed in Table 12.

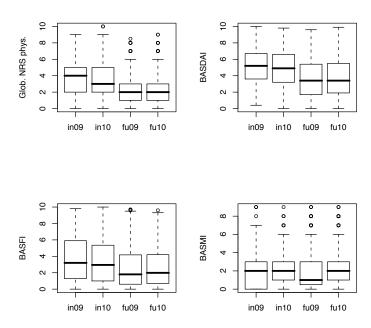


Figure 3: Box plots for the global disease activity estimated by the physician (glob. NRS phys.), BASDAI, BASFI and BASMI. (For a description of these acronyms see table 9). The box plots display median (fat black line in the box) and inter quartile range (range within the box). The data points that lie outside the whiskers are considered outliers. in09 and in10 stands for patients with an inclusion visit in 2009 and 2010 respectively and fu09 and fu10 stands for follow-up visit in 2009 and 2010 respectively.

	Inclusion 09	Inclusion 10	Follow-up 09	Follow-up 10
number of patients	304	271	771	797
% patients w. hospital stay	8.2	7.4	4.8	3.5
# patients with OPs	33	32	25	22
total # OPs	35	29	25	21
OPs per pat.	0.12	0.11	0.03	0.03

Table 10: Hospital or rehabilitation clinic stay in relation to the ankylosing spondylitis arthritis and operations reported in inclusion or follow-up visits in 2009 or 2010. 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 09	Inclusion 10	Follow-up 09	Follow-up 10
Total # of OPs	35	29	25	21
# SS OPs	3	1	0	2
# other Spine OPs	1	2	2	2
# shoulder OPs	8	5	4	3
# knee OPs	2	2	3	1
# hip OPs	3	4	6	6
# other OPs	18	15	10	7

Table 11: Type of operations reported in inclusion or follow-up visits in 2009 or 2010. 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 09	Inclusion 10	Follow-up 09	Follow-up 10
number of patients	304	271	771	797
% incapable of work	8.6	14	4.3	7.7
% absences at work	38.5	32.5	19.5	17.2
% up to 4 weeks	21.4	18.5	13.9	12.9
% more than 4 weeks	15.1	13.3	5.1	3.3

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 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 mid 2009, 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 the time of analysis of this report (End of May 2011), there were over 917 patients in the registry of psoriatic arthritis with a total of 2700 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 20. In 2010, we received one or more visits for 503 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, French and Italian. The aims of the register 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 09	Inclusion 10	Follow-up 09	Follow-up 10
number of patients	163	148	348	391
mean inclusion age (Std.dev., years)	47 (12)	52 (12)	-	-
% Male	52	45	-	-
IQR time symptdiagnosis (months)	27 (7 - 87)	18 (4 - 62)	_	_

Table 13: Patient characteristics of inclusion and follow-up patients in 2009 and 2010. Std.dev. stands for standard deviation and IQR for inter quartile range of the median.

In 2009, we received 163 inclusions and 348 follow-up visit questionnaires (intermediate control or yearly control) in the database. In 2010, so far 148 inclusion and 391 follow-up

	Inclusion 09	Inclusion 10	Follow-up 09	Follow-up 10
number of patients	163	148	348	391
mean glob. NRS pat.	4.8 (3)	4.3 (2.9)	3.1 (2.7)	3.6 (2.7)
mean glob. NRS phys.	4 (2.4)	3.6 (2.3)	2.1 (2)	2.1 (2)
Mean swollen 68	4.5 (5.3)	4.1 (5.7)	1.9 (3.7)	1.8 (3.4)
Mean tender 68	8.3 (11)	7.4 (9.3)	5.2 (9.4)	4.2 (7.8)
mean Skin phys	2.1 (1.6)	1.8 (1.5)	1.4 (1.4)	1.4 (1.4)
mean Skin pat.	2.3 (1.7)	2(1.7)	1.6 (1.4)	1.7 (1.4)
mean NRS Pain pat.	4.7 (2.8)	4.1 (2.8)	3.4 (2.8)	3.6 (2.8)

questionnaire-sets have flown into the database of psoriatic arthritis.

Table 14: Disease activity at inclusion and at follow-up of patients with the indicated type of visit in 2009 and 2010. 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 Disease Modifying Anti-rheumatic Drugs (DMARDs)

About 40 to 50% of patients included in 2009 or 2010 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, more than 80 to 90% were on a biologic treatment.

5.4.4 Hospital stay

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 10 months. No external validation of these selfreported data has so far be performed. The results of these questions are displayed in Table 16.

	Inclusion 09	Inclusion 10	Follow-up 09	Follow-up 10
number of patients	163	148	348	391
% patients w. hospital stay	7.4	4.1	5.2	4.9

Table 15: Hospital or rehabilitation clinic stay in relation to the psoriatic arthritis in inclusion or follow-up visits in 2009 or 2010.

	Inclusion 09	Inclusion 10	Follow-up 09	Follow-up 10
number of patients	163	148	348	391
% incapable of work	12.3	4.7	6.9	5.9
% absences at work	20.9	13.5	10.9	12
% up to 4 weeks	11.7	8.8	7.5	9.7
% more than 4 weeks	4.3	4.1	1.1	2

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

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 trained	active 2009	active 2010
University hospital	64	16	12
Other hospital	46	10	2
Rheumatology Office	62	13	4

Table 17: Number of rheumatologists trained for SONAR and number of rheumatologists that have entered SONAR visit(s) in 2009 or 2010.

6.2 SONAR visits

	In 2009	In 2010	Fu 2009	Fu 2010
Number of SONAR visits	23	80	21	105
Number of patients with SONAR visits	22	64	21	96
On biologic during SONAR visit	9	20	10	57
Biologic started after SONAR visit	1	7	1	3

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 Patrons and sponsors

7.1 Patrons

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









tions.

- 7.2 Funding SCQM Biobank
- 7.2.1 Funding of running costs



7.2.2 Support development Biobank Online Database







7.3 Donation

7.3.1 Support development RA X-ray Database



7.3.2 Support development patient interface

The Zürcher Rheuma Stiftung made a significant financial contribution to the development of the patient data entry interface.

7.3.3 General



8 Annual Acounts

8.1 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, 2010.

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

Andreas Thut licensed expert auditor auditor in charge

Brugg, April 7, 2011

T. Kolles

Tanja Koller licensed auditor

Financial statements 2010 (balance sheet, income statement and notes)



Mitglied der TREUHAND BKAMMER OBT AG, Paradiesstrasse 15, 5201 Brugg / Switzerland Phone +41 56 462 56 66, Fax +41 56 462 56 81, www.obt.ch

8.2 Balance

SCQM Foundation Swiss Clinical Quality Management in Rheumatic Diseases, 8048 Zürich

Company Balance Sheet as per	12/31/10 CHF	12/31/09 CHF
	CHF	UNF
ASSETS		
Cash and bank	428,874.53	379,586.02
Debtors	6,687.50	7,087.20
Prepayments and accrued income	5,540.60	0.00
CURRENT ASSETS	441,102.63	386,673.22
IT equipment (Hard- and Software)	3,992.71	10,381.00
Onlinedatabase	48,792.30	97,584.60
Tangible fixed assets	52,785.01	107,965.60
FIXED ASSETS	52,785.01	107,965.60
ASSETS	493,887.64	494,638.82
LIABILITIES		
Accrued liabilities	6,192.06	68,479.21
Accruals and deferred income	32,735.50	0.00
Long term loan Klinik Balgrist	0.00	180,000.00
LIABILITIES	38,927.56	248,479.21
Project Biobank	137,809.16	2,909.20
Research fund	20,777.35	0.00
PROJECTS / FUNDS	158,586.51	2,909.20
FROJECTS / FUNDS	156,560.51	2,909.20
Dedication assets	80,000.00	80,000.00
Retained profit last year	163,250.41	128,772.75
Profit current year	53,123.16	34,477.66
Retained profit 31.12.	216,373.57	163,250.41
FOUNDATION ASSETS	296,373.57	243,250.41
	200,010.01	270,200.41
LIABILITIES	493,887.64	494,638.82
	100,001104	101,000.02

Seite 1

8.3 Income Statement

SCQM Foundation Swiss Clinical Quality Management in Rheumatic Diseases, 8048 Zürich

Income from sponsoring Income from accessorial services Databasesharing Donations Financial yield Other incomes Income foundation Salaries and related costs Rent expenses Servicing, repairs, replacement Insurance of property Expenses for information technology Expenses for information technology Expenses for information technology Expenses for information technology onlinedate Administrative expenses Communication Financial expenses Other expenses Depreciation Expenses foundation PROFIT (+) / LOSS (-) FOUNDATION STATEM	CHF 540,008.91 4,950.00 12,750.00 72,500.00 1,540.00 600.00 632,348.91 (368,930.04)	CHF 554,646.85 7,100.00 45,000.00 980.30 0.90 607,728.05
Income from accessorial services Databasesharing Donations Financial yield Other incomes Income foundation Salaries and related costs Rent expenses Servicing, repairs, replacement Insurance of property Expenses for information technology Expenses for information technology onlinedate Administrative expenses Communication Financial expenses Other expenses Depreciation Expenses foundation PROFIT (+) / LOSS (-) FOUNDATION STATEM Project Biobank	4,950.00 12,750.00 72,500.00 1,540.00 600.00 632,348.91	7,100.00 0.00 45,000.00 980.30 0.90
Databasesharing Donations Financial yield Other incomes Income foundation Salaries and related costs Rent expenses Servicing, repairs, replacement Insurance of property Expenses for information technology Expenses for information technology onlinedate Administrative expenses Communication Financial expenses Other expenses Depreciation Expenses foundation PROFIT (+) / LOSS (-) FOUNDATION STATEM Project Biobank	12,750.00 72,500.00 1,540.00 600.00 632,348.91	0.00 45,000.00 980.30 0.90
Donations Financial yield Other incomes Income foundation Salaries and related costs Rent expenses Servicing, repairs, replacement Insurance of property Expenses for information technology Expenses for information technology onlinedate Administrative expenses Communication Financial expenses Other expenses Depreciation Expenses foundation PROFIT (+) / LOSS (-) FOUNDATION STATEM Project Biobank	72,500.00 1,540.00 600.00 632,348.91	45,000.00 980.30 0.90
Financial yield Other incomes Income foundation Salaries and related costs Rent expenses Servicing, repairs, replacement Insurance of property Expenses for information technology Expenses for information technology onlinedata Administrative expenses Communication Financial expenses Other expenses Depreciation Expenses foundation PROFIT (+) / LOSS (-) FOUNDATION STATEM Project Biobank	1,540.00 600.00 632,348.91	980.30 0.90
Other incomes Income foundation Salaries and related costs Rent expenses Servicing, repairs, replacement Insurance of property Expenses for information technology Expenses for information technology onlinedate Administrative expenses Communication Financial expenses Other expenses Depreciation Expenses foundation PROFIT (+) / LOSS (-) FOUNDATION STATEM Project Biobank	600.00 632,348.91	0.90
Income foundation Salaries and related costs Rent expenses Servicing, repairs, replacement Insurance of property Expenses for information technology Expenses for information technology onlinedata Administrative expenses Communication Financial expenses Other expenses Other expenses Depreciation Expenses foundation PROFIT (+) / LOSS (-) FOUNDATION STATEM Project Biobank	632,348.91	
Salaries and related costs Rent expenses Servicing, repairs, replacement Insurance of property Expenses for information technology Expenses for information technology onlinedata Administrative expenses Communication Financial expenses Other expenses Depreciation Expenses foundation PROFIT (+) / LOSS (-) FOUNDATION STATEM Project Biobank	, , , , , , , , , , , , , , , , , , ,	607,728.05
Rent expenses Servicing, repairs, replacement Insurance of property Expenses for information technology Expenses for information technology onlinedata Administrative expenses Communication Financial expenses Other expenses Depreciation Expenses foundation PROFIT (+) / LOSS (-) FOUNDATION STATEM Project Biobank	<mark>(368,930.04)</mark>	
Servicing, repairs, replacement Insurance of property Expenses for information technology Expenses for information technology onlinedate Administrative expenses Communication Financial expenses Other expenses Depreciation Expenses foundation PROFIT (+) / LOSS (-) FOUNDATION STATEM Project Biobank		(390,155.65)
Insurance of property Expenses for information technology Expenses for information technology onlinedate Administrative expenses Communication Financial expenses Other expenses Depreciation Expenses foundation PROFIT (+) / LOSS (-) FOUNDATION STATEM Project Biobank	(29,644.46)	(36,739.13)
Expenses for information technology Expenses for information technology onlinedate Administrative expenses Communication Financial expenses Other expenses Depreciation Expenses foundation PROFIT (+) / LOSS (-) FOUNDATION STATEM Project Biobank	(100.00)	0.00
Expenses for information technology onlinedate Administrative expenses Communication Financial expenses Other expenses Depreciation Expenses foundation PROFIT (+) / LOSS (-) FOUNDATION STATEM Project Biobank	(960.20)	(733.80)
Administrative expenses Communication Financial expenses Other expenses Depreciation Expenses foundation PROFIT (+) / LOSS (-) FOUNDATION STATEM	(37,634.94)	(9,304.47)
Communication Financial expenses Other expenses Depreciation Expenses foundation PROFIT (+) / LOSS (-) FOUNDATION STATEM Project Biobank	(31,919.98)	1,661.22
Financial expenses Other expenses Depreciation Expenses foundation PROFIT (+) / LOSS (-) FOUNDATION STATEM Project Biobank	(34,816.03)	(51,959.33)
Other expenses Depreciation Expenses foundation PROFIT (+) / LOSS (-) FOUNDATION STATEM Project Biobank	(10,113.63)	(16,517.05)
Depreciation Expenses foundation PROFIT (+) / LOSS (-) FOUNDATION STATEM Project Biobank	(442.90)	(473.55)
Expenses foundation PROFIT (+) / LOSS (-) FOUNDATION STATEM Project Biobank	(3,495.42)	(9,776.33)
PROFIT (+) / LOSS (-) FOUNDATION STATEM	(61,168.15)	(59,252.30)
Project Biobank	(579,225.75)	(573,250.39)
-	53,123.16	34,477.66
-		
	60,000,00	20,000,00
Contributions	60,000.00	20,000.00
Donations	170,000.00	0.00
Expenses	(95,100.04)	(17,090.80)
Profit- (+) / loss (-)	134,899.96	2,909.20
Research fund Contributions	30,000.00	0.00
Expenses		0.00
Profit- (+) / loss (-)	(9,222.65) 20,777.35	0.00 0.00
Project Onlinedatabase		
Expenses	0.00	(50,607.05)
Profit- (+) / loss (-)	0.00	(50,607.05)
Creation (-) / liquidation (+) projects und fun	(155,677.31)	47,697.85
RESULT PROJECTS UND FUNDS	0.00	0.00
NET PROFIT	53,123.16	34,477.66

Seite 1

8.4 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

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.

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

9.1 The SCQM Board

The members of the SCQM Board:

- 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., Thurgauer Clinic St. Katharinental, Diessenhofen
- PD 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. Peter Villiger, Director Department of Rheumatology and Clinical Immunology / Allergology, University Hospital (Inselspital) Bern

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., Bethesda hospital, Basel
- lic. iur. René Bräm, Managing director of the Swiss Association Morbus Bechterew
- Dr. Adrian Forster, Head of Rehabilitation Dep., Thurgauer Clinic St. Katharinental, Diessenhofen
- Prof. Dr. Peter Villiger, Director Department of Rheumatology and Clinical Immunology / Allergology, University Hospital (Inselspital) Bern
- Sabine von Känel, Executive Secretary
- Dr. Almut Scherer, Scientific Manager

9.3 The Scientific Committees

The committees 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. 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
- PD Dr. Diego Kyburz, Rheumatology clinic, University hospital Zürich
- Dr. Ines von Mühlenen, medical specialist 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, medical specialist FMH, Basel
- Dr. Rüdiger Müller, Cantonal hospital St. Gallen
- Dr. Giorgio Tamborini, Rheumatology clinic, University hospital Zürich
- Dr. Bettina Weiss, Universitätsklinik Balgrist, Zürich

PsA Committee

- Prof. Dr. Burkhard Möller (Chairman), University hospital (Inselspital), Bern
- PD Dr. Jean Dudler, Rheumatology clinic, Cantonal hospital Fribourg
- Dr. Bettina Weiss, Universitätsklinik Balgrist, Zürich
- Prof. Dr. Nikhil Yawalkar (Dermatologist), Inselspital, Bern

SONAR Committee

- Dr. Hansruedi Ziswiler (Chairman), University hospital (Inselspital), Bern
- Dr. Laure Brulhart, Rheumatology Clinic, University hospital Geneva
- Dr. Thomas Gerber, Center for rheumatology and bone diseases, Zürich
- Dr. Andreas Krebs, Rheumatology clinic, University hospital Zürich



Figure 4: The SCQM Team. Left photo: From left to right: Jacqueline Hirt, Susanne Frieser, Heinz Wyrsch, Albana Rexhepay, Sabine Von Kaenel, Almut Scherer. Right photo: Dominik Loiero and Guillaume Wuilleret.

- Dr. Stefan Mariacher, aarReha Schinznach
- Prof. Dr. Burkhard Möller, University hospital (Inselspital), Bern
- Dr. Andrea Stärkle Bär, Rheumatology clinic, University hospital Zürich
- Dr. Giorgio Tamborini, Rheumatology clinic, University hospital Zürich
- Dr. Pascal Zufferey, University hospital Lausanne

9.4 The SCQM Office

- Sabine von Känel, executive secretary
- Dr. Almut Scherer, scientific manager
- Dr. Albana Rexhepaj, monitor SCQM Biobank
- Heinz Wyrsch, responsible for RA
- Susanne Frieser, assistant for administration and responsible for PsA
- Dominik Loiero, RA X-rays scoring and digitizing of X-rays
- Guillaume Wuilleret, responsible for AS
- Jacqueline Hirt, free-lance SCQM Online Database representative
- Ömer Ünal, voluntary work

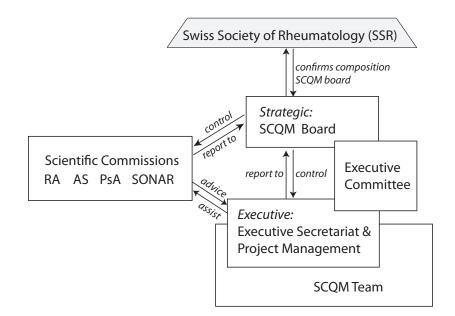


Figure 5: Organigramm of the SCQM.

9.5 The SCQM Organigramm

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, Kantonssspital Aarau
- Rheumaklinik und Institut für Physikalische Medizin, Universitätsspital Zürich
- Rheumatologische Universitätsklinik, Felix Platter-Spital, Basel
- Service de Rhumatologie, Médicine 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 2010

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 2010.

- Finckh A, Scherer A, Lubbeke A, Schwarz H, and Gabay C, "The impact of body weight on the progression of radiographic joint damage in Rheumatoid Arthritis patients". Oral presentation at the 2010 ACR/ARHP Annual Scientific Meeting, Atlanta, November 7-12, 2010.
- Curtis JR, Jain A, Askling J, Bridges SL Jr, Carmona L, Dixon W, Finckh A, Hyrich K, Greenberg JD, Kremer J, Listing J, Michaud K, Mikuls T, Shadick N, Solomon DH, Weinblatt ME, Wolfe F, Zink A., "A comparison of patient characteristics and outcomes in selected European and U.S. rheumatoid arthritis registries". Semin Arthritis Rheum. 2010 Aug;40(1):2-14.e1.
- Walker UA, Courvoisier DS, Dudler J, Aeberli D, von Kempis J, Scherer A, Finckh A, "Do new biologics meet the unmet medical need in rheumatoid arthritis? Safety and efficacy of abatacept following B-cell depletion". Rheumatology 2010 Aug 17; Epub ahead of print.
- B. Möller, D. Wisler, S. Adler, A. Scherer, P.M. Villiger, A. Finckh; physicians of SCQM, "Renal safety of nonsteroidal antirheumatic drugs (NSAIDS) is better than their image.
 ". Oral presentation at the 2010 EULAR Annual Scientific Meeting, Rome, June 16-19, 2010

- Finckh A, Dudler J, Wermelinger F, Ciurea A, Kyburz D, Gabay C, Bas S; physicians of SCQM, "Influence of anti-infliximab antibodies and residual infliximab concentrations on the occurrence of acquired drug resistance to infliximab in rheumatoid arthritis patients.". Joint Bone Spine. 2010 Jul;77(4):313-8. Epub 2010 May 14.
- Finckh A, Ciurea A, Brulhart L, Möller B, Walker UA, Courvoisier D, Kyburz D, Dudler J, Gabay C, "Which subgroup of rheumatoid arthritis patients benefits from switching to rituximab versus alternative anti-TNF agents after previous failure to anti-TNF agent?". Ann Rheum Dis. 2010 Feb; 68(2): 387-93. Epub 2009 May 4.
- Nissen MJ, Gabay C, Scherer A, Finckh A, on behalf of the physicians of the SCQM-RA. "The effect of alcohol on radiographic progression in rheumatoid arthritis", Arthritis Rheum. 2010 Mar 8. [Epub ahead of print].

10.2 Projects in progress

- Inter- und Intrauntersucherreliabilität des Ratingen Score in der SCQM Datenbank. Master thesis Dominik Loiero. Study lead PD Dr. Diego Kyburz.
- Predictors for duration of remission after discontinuation of biologics therapy. Study lead PD Dr. Diego Kyburz.
- Characteristics of Swiss RA patients at initiation of biologic agents in comparison with selected European and US registries. Study lead Dr. Pascal Zufferey (Centre Hospitalier Universitaire Lausanne (CHUV)).
- Long-term safety and tolerance of new biologic agents in 'real-world' rheumatoid arthritis patients. A population based cohort study. Study lead Dr. Sophie Martin Du Pan (University Hospital Geneva (HUG)).
- Joint involvement in psoriatic arthritis: Application of the CASPAR classification criteria for PsA and changes in joint involvement over time. Study lead Dr. Burkhard Möller (Insel Hospital Berne).
- Cost-effectiveness of Tocilizumab in Switzerland: A Microsimulation Approach. Study lead Dr. Simon Wieser (Winterthur Institute Health Economics).
- 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 TNFinhibitors 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, Jerôme 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, Jerôme 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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