The Quality-of-Life-Recorder: A versatile platform for electronic patient questionnaires in research and routine care

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1 Instrument and application example

1.1 About this document

The following text first describes an exemplary application of the Quality-of-Life-Recorder in a project that introduces Quality-of-Life measurement, or Patient Rated Outcomes (PROs), into a setting of routine care:

Rogausch A, Sigle JM, Seibert AJ, Thüring S, Kochen MM, Himmel W
Feasibility and acceptance of electronic quality of life assessment in general practice:
an implementation study.
Health and Quality of Life Outcomes. 7:51 (2009). PMID: 19493355

Afterwards, it presents the concept of the QL-Recorder, its actual implementation in software and documentation, its continuously maintained further development, my support of its application in research and routine patient care, as well as its provision as shareware.

The outlay required to produce a comparable instrument may quite regularly exceed the budget of a single project by several order of magnitude. To document the usability of the instrument beyond an individual research research project, a variety of application examples are listed below.

Development of the QL-Recorder has been driven by the motive of advancing daily patient care as well as health services research at the same time, providing a means to link the two areas more closely together. Electronic patient questionnaires can do this, as they enable you to acquire information from patients' subjective self assessment routinely, and in high technical quality.

Patients' self assessments are nowadays accepted to belong to the foundations of high-class health service provision [Black 2009].

1.2 Application example: Quality-of-Life measurement in family practices

1.2.1 Background

Hardly has health-related Quality-of-Life (HRQoL) ever been measured and observed in family practices (general practices) in a systematic way, although improvements in communication between physicians and patients would be expected from such a practice just as well as broader availability of data on medical problems and outcomes in the patients' view for health services research.

Electronic tools and training might facilitate and thus promote the application of HRQoL questionnaires in routine care. As innovative approaches should be field tested in pilot studies before deployment in larger projects or even general adoption, we studied:

- 1. feasability and acceptance of HRQoL measurement by means of electronic questionnaires on Tablet-PCs in family practices (general practices),
- 2. in how far HRQoL measurement results were felt to be useful for practical patient care, and
- 3. which barriers might possibly hinder the broader adoption of that approach.

1.2.2 Methods

Two questionnaires for patients' self assessment of HRQoL were provided in electronic form: the established and validated instruments SGRQ (St. George's Respiratory Questionnaire, for asthma and COPD) and the EORTC QLQ-C30 (European Organisation for Research and Treatment of Cancer, Quality of Life Questionnaire, Core, 30 Questions, conceived for use by cancer patients, clinical relevance and plausibility for internal medicine and general medicine demonstrated earlier by JS).

The especially patient friendly electronic version of both questionnnaires, to be handled quite alike penciland-paper, deploys the platform AnyQuest for Windows and the conzept of the QL-Recorder (www.qlrecorder.com). Our study used portable Tablet-PCs (FSC ST5010, slate format), which were linked to the existing office IT system via wireless network (WLAN) and a standard interface (GDT/LDT).

The 14 participating German family practices (general practices) had different software for patient administration and different workflows which had to be taken into account. The HRQoL "examination" could be requested from out of the existing patient management software (PMS) in all practices, which would initiate a questionnaire administration session by transmitting the patient ID data from the practice software to the QL-Recorder. The HRQoL measurment results would, depending upon the local environment, either be directly transmitted back into the PMS (into the electronic health record, optinally into the lab results page), and/or printed, and also made provided as PDF-documents. Collected HRQoL data were also stored independently from the PMS on the practice server. Each individual administration of the electronic questionnaire was immediately and automatically scored; and the rendering of results included both numerical data as a graphic representation of the course over time, and simplified cutoff markers for "good" vs. "bad" at 50%. (The software would also support the usage of reference values from a standard population, which could also be chosen to match patient specific criteria, or from the local practice clientele, which could also be computed just in time from simple statistical analysis of available data.)

Participating family physicians (general practicioners, GPs) and their staff received a one hour training covering the basic concepts of HRQoL, the study design, and handling of the electronic questionnaire. Handouts for patient education, forms to obtain informed consent, and guides to interpretation of HRQoL results were provided. Afterwards, each practice team could, according to their own judgement, invite patients with chronic disease to complete electronic HRQoL questionnaires during their waiting time. The physician could make use of HRQoL measurement results during the consultation to his discretion.

Patients (who had given additional consent), practice staff and physicians were later given semi-structured telephone interviews regarding their experience and the acceptance of the instrument. The number administrations of the electronic HRQoL questionnaire, HRQoL results, and responses to the telephone interviews were analyzed with quantitative and qualitative methods.

1.2.3 Results

Over the course of 1 year, 523 completed the electronic questionnaires (1–5 times; 664 total assessments). Results showed specific HRQoL impairments, e.g. with respect to fatigue, pain and sleep disturbances. The number of electronic assessments varied substantially between practices. A total of 280 patients, 27 practice assistants and 17 GPs participated in the telephone interviews. Almost all GPs (16/17 = 94%; 95% CI = 73–99%), most practice assistants (19/27 = 70%; 95% CI = 50–86%) and the majority of patients (240/280 = 86%; 95% CI = 82–91%) indicated that they would welcome the use of electronic HRQoL questionnaires in the future. GPs mentioned availability of corresponding local health services (e.g. supportive, physiotherapy) (mean: 9.4 ± 1.0 SD; scale: 1 – 10), sufficient extra time (8.9 ± 1.5) to discuss possibly detected additional requirements of their patients, and easy interpretation of HRQoL results (8.6 ± 1.6) as the most important prerequisites for their use.

Physicians reported that HRQoL assessment facilitated both communication and follow up of patients' conditions. Practice assistants emphasised that routine measurement of HRQoL demonstrated an extra

commitment to patient centred care. Patients viewed it as a tool, which contributed to the physicians' understanding of their individual conditions, problems and personal circumstances.

1.2.4 Conclusion

The pilot study indicates that electronic HRQoL assessment is technically feasible in general practices. It can provide clinically significant information, which can either be used in the consultation for routine care, or for research purposes. While GPs, practice assistants and patients were generally positive about the electronic procedure, several barriers (e.g. practices' lack of time and routine in HRQoL assessment) need to be overcome to enable broader application of electronic questionnaires in every day medical practice.

Technically and with regard to the observed content, the project has successfully been crossing the chasm between university based research and general practice.

Nevertheless, we found substantial variation in the actual usage of HRQoL measurement. The most important barrier hindering routine patient assessments was available time. This raises the question, how a healthcare system can be improved, which on the one hand orders patients to see their physicians quite regularly to obtain follow up subscriptions, and intends to make enormous investments for computer based safety checks against drug interactions - but never sets aside the time for systematic assessment, and sufficient discussion, of patients' subjective state of health, or wellbeing (although just that is exactly what follow up prescriptions and drug interactions should affect).

Another barrier is the question, in how far physicians can interpret HRQoL measurement results, and put them into effect to inform their therapeutic actions. Our project attracted the interest of practices who had been using paper based HRQoL questionnaires already, or who wanted to systematically monitor selected conditions and problems. This illustrates, that physicians can also be motivated to measure HRQoL outside of research projects, and that the needed skills may grow out of routine.

Our project confirms that helpful tools do also work in general practice (family practice). The multidimensionality of clinically relevant HRQoL questionnaires, combined with automatic scoring and generation of course over time plots, enables a synergy between the systematic observation of the patients' opinion (HRQoL, or PROs), more individual care being more easily informed about the each patient's conditions, requirements, and preferences, and a contribution to health services research. Our study might offer motivation and a working set of tools to measure HRQoL more regularly in routine care.

1.3 The instrument: What is the QL-Recorder and what does it achieve?

1.3.1 Original concept

After Prof. Franz Porzsolt had mentioned the requirement of an electronic patient questionnaire at the Cancer Centre of the University of Ulm, Germany, JS developed the concept of the QL-Recorder in 1993:

An instrument to measure HRQoL, in routine medical service and research settings alike, as easy to use as an audio cassette recorder.

1.3.2 Service provided by the QL-Recorder

The system enables patients to fill in questionnaires directly at the computer. It is conceived in a way that "the computer" goes completely into the background, and neither special explanation nor training is necessary.

The electronic assessment guarantees that collected data are complete, and allows for automatic scoring. This minimizes the effort required for patient assessments. Where patients complete the questionnaire in their waiting time, the perfectly up-to-date, completely scored result of the HRQoL measurement, complete with graphic display and course over time plot, can be used immediately thereafter in the consultation. There are no delays for processing, and no manual work is required.

This makes HRQoL usable in the care for individual patients: To identify current high-priority problems, to define therapeutic goals, and the monitor the course of disease or therapeutic effects in order to verify whether defined goals are being achieved. It also enables providers to install systematic screening measures, and use the results to focus limited ressources onto patients which require them most (e.g. additional psycho-oncological support).

Collected data can also be used for research: Simple analysis tools are already built into the QL-Recorder. Data export to spreadsheets, statistical, and data base software is possible. The former is suitable for quality assurance measures locally performed at the practice level, the later for university based research.

The system has been conceived as a platform that supports various questionnaires (instruments). Patient identification data can contingently be imported from local IT systems, and results automatically transferred back there. Thus, clinical documentation and billing data from *the providers' perspective* can be collected together with outcome data from *the patients' perspective* in the same IT system, from where they may be exported together and analysed via a standard interface.

1.3.3 Original and current QL-Recorder

The original QL-Recorder used a large, printed adoption of the instrument to be administered which was placed onto a digitizing tablet (digitizer). Patients could answer each question simply by ticking an answer located next to it with an electronic pen, or even making a checkmark - very similarly to what they would do with a conventional questionnaire using paper and pencil.

The large format of more than 18" x 12" (more than DIN A3) ensured that even patients with reduced visual capacity could use the system.

In ca. 1996, Pen-Computers (nowadays called: Tablet-PCs) with a clearly readable colour display became available, which integrated the digitizer in the display screen. AnyQuest for Windows was designed with this type of hardware in mind. On such a Pen-Computer or on a system with a more traditional Touch-Screen, it still offered a user interface that resembled paper and pencil very closely. On the other hand, users with a limited budget could deploy the same software on any off-the-shelf PC (and on most retired ones that could be fetched back up from the cellar), as long as their target group of patients was able to handle a mouse.

1.3.4 Applications documenting the significance of the original QL-Recorder

Applications at the Cancer Center and in the Clinic of Internal Medicine of the University of Ulm:

• Initial pilot use took place from 1993 to 1994 in the outpatient clinic for internal medicine with the EORTC QLQ-C30. Feedback from patients was extraordinarily positive:

Patients of to and beyond 90 years of age could handle the system immediately and without any training. Consequently, elderly patients in particular gave positive feedback for our new approach, which meant that we would finally ask them how they felt according to their own opinion, and not merely to the doctor's.¹[P:Sigle 1996]²

 $^{^1\}mathrm{The}$ most important points in the following text appear in italics.

²K: Contribution to scientific meeting with published abstract, F: Publication in scientific journal, P: Doctoral thesis.

- At the meeting of the German Cancer Society ("Deutscher Krebskongress") in 1994, the HRQoL of 120 participants of a satellite symposion was measured with the QLQ-C30 using paper forms, to be able to assess the large number of participants in parallel, but these forms where afterwards scored via the digitizing tablet and the QL-Recorder software. The statistical analysis could be presented at the end of the same session the only irregular finding in our colleagues was significantly elevated Fatigue.
- As early as 1994, routine HRQoL measurement was offered to all outpatients of the University Clinic for Internal Medicine by means of 5 QL-Recorders set up in a Local Area Network (LAN). Within 4 weeks, more than 1.100 questionnaire administrations were performed. Results were immediately printed out and added to the patient records. Results from the original validation of the QLQ-C30 could be replicated. Moreover, clinical plausibility and relevance of this questionnaire for patients of various specialties were be demonstrated. At least 96% of all eligible patienten were invited to participate, and also took part in the study. The age distribution resembled the one of the German population. A final poll among staff members found no additional workload.

This demonstrated that a routine patient assessment using the QL-Recorder is both feasible and well accepted, as long as it is implemented in a suitable organisational way. [K:Sigle 1995, F:Sigle 1996, P:Sigle 1996]³

• Several colleagues also performed projects that used the QL-Recorder as part of their doctoral thesis, both in the inpatient setting and on the admission ward. [P:Gebhard 1997, P:Schimitzek 1999, P: Holch 2000].

Changes after the retirement of the head physician of the Clinic for Internal Medicine, however, effectively terminated the use of the QL-Recorder at the place of its development.

Nevertheless, use of the system continued at other places for years:

• In a specialized clinic for pulmonology, where HRQoL was routinely assessed with the EORTC QLQ-C30 and afterwards automatically imported into an electronic tumor documentation system (T-REG, Rosenbeck).

This system made combined use of both HRQoL data and other parameters from tumor documentation for clinical applications (reports and reminders to colleagues, progress monitoring for individual patients) as well as for scientific analysis. [K:von Bültzingslöwen 1999]

- In the practice for oncology Dr. Rethfeld, Düsseldorf: here, routine measurement of HRQoL with the EORTC QLQ-C30 in all patients was one precondition for the coverage of certain treatment costs by public health insurance as part of a specially negotiated pilot project (Modellprojekt).
- In multiple clinics that focused on complementary medicine in order to document HRQoL with the EORTC QLQ-C30 in all oncology patientes. The resulting data pool could be used e.g. to perform an analysis "on demand", which illustrated the correlation between HRQoL at admittance and survival time for patients with pancreatic cancer.

Thus, the QL-Recorder made possible a study to analyze the prognostic value of HRQoL in an freely selectable patient population from routinely collected data. [P:Höhmann 2000, F:Höhmann 2003]

³K: Contribution to scientific meeting with published abstract, F: Publication in scientific journal, P: Doctoral thesis.

1.3.5 Applications documenting the significance of the advanced QL-Recorder

Altogether, there are about 70 registered national and international users. In 1999, at least 20.000 patient assessments had already been carried out on QL-Recorders.

Each of the following examples either documents that the system can perform in one certain field, or illustrates an application that contributed to multiple publications:

- Doctoral theses deploying the QL-Recorders are given in the list of literature references.
- Oncology outpatient clinic of Prof. Alan Coates, Dubbo, Australia: Measurement of HRQoL with an electronic version of the EORTC QLQ-C30 based upon AnyQuest vor Windows in routine care among 11 patients. Data export, transmission via Internet, statistical analysis by JS in Germany, publikation of a report on the experience and a graph with HRQoL results in the WWW (08.01.1997)⁴.
- Kantonsspital Chur, Switzerland: MLHFQ Minnesota Living With Heart Failure Questionnaire in participants of an RCT with Cardiomyopathy (1999-2000).
- Glaxo-Wellcome, Global Health Outcomes: Electronic patient questionnaires as added value service for a drug, plus transformation of diagnostic criteria into questions which are comprehensible for and can be directly answered by patients: Electronic version of the IBSQOL and the ROME-II criteria in 19 languages (1999 and 2000).
- Family practice (general practice) of Dr. W. Streibl, Knittlingen: Use of the QL-Recorder by JS as assistant physician in a rural general practicec. First bi-directional integration into the existing practice management system via the GDT/LDT interface. QLQ-C30, HADS, ca. 200 quesitonnaire administrations during 1 year (2000-2001).
- Schmerztagesklinik (pain clinic) of the Department of Anaesthesia of the Klinikum Rosenheim: Routine monitoring of HRQoL in participants of pain (treatment/coping) courses with the SF-36 (initial) and the QLQ-C30 (2004-2006).
- Geriatric Center Wienerwald GZW, Vienna, Austria: Proxy rating of HRQoL of old-old patients with dementia by physicians and nurses in a study to validate the specific HRQoL-questionnaire "Vienna List": More than 700 assessments with the Vienna-List, Barthel-Index, Spitzer-Index, BADEM Brief Assessment for Dementia and Depression, BCRS Brief Cognitive Rating Scale, GDS Global Deterioration Scale. [F:Kojer 2004]
- Clinic for Psychiatry and Psychotherapy for Children and Adolescents at the University of Ulm, u.a.:
 - LQ-KID: Development and application of a computer based approach to assess the HRQoL of chronically ill children and adolescents [F:Goldbeck 2003], [F:Goldbeck 2005]
 - Cooperation project with multiple centers of the CVJM: BADO, CBCL, YABCL, YSR u.a.: [Lutz 2005], [Keller 2006] (requested literature has been supplied, to be added)
- University Clinic Graz for Gynecology and Obstetrics, Austria:
 - Study on incontinentia: Patient assessments with electronic adoptions of the KHQ King's Health Questionnaire and SF-36 on the QL-Recorder: [F:Bjelic-Radisic 2006]

 $^{^{4}}See:$ www.ql-recorder.com/intro/whatdone.htm (bottom of the page)

- Quality of Life and psychosocial burden in pregnancy: EPDS Edinburgh Postnatal Depression Scale (and other instruments) [F:Mautner 2009, P:Mautner 2008] New Investigator Award the International Society for Quality of Life Research 2008, for the Poster: "Pregnancy and Birth - The impact of medical and psychosocial factors on quality of life and wellbeing".
- Western General Hospital, Edinburgh, UK, with funding by the ICRF: 5 QL-Recordes used for routine assessment of outpatients with using (among others) subscales for Pain, Fatigue and Global QoL of the QLQ-C30, as well as the HADS and PHQ-9 questionnaires. Originally designed to screen all patients and focus limited ressources onto selected patients, ca. 3.000 assessments. [F:Walker 2008; F:Storey 2007; F:Strong 2007]
- Universität Zhejiang, Institute of Social Medicine and Family Medicine: Cross validation of a Chinese translation of the eSF-36 on the QL-Recorder versus a paper version [P:Chen 2005, F:Chen 2007, K:Chen 2007]
- Ludwig-Maximilians-Universität LMU and Technische Universität München TUM, with funding by the Deutsche Krebshilfe e.V.: Comparison of the electronic eSIRO with a paper version of the SIRO Stress Index RadioOnkology at the clinics for radiation therapy of both universities. The elektronische Fassung was better accepted by staff and patients, costs less time to use, and is (therefore, even when the investment costs for 4 Tablet-PCs are included) more cost efficient. Production of a CD-ROM with self installing software for free distribution of the eSIRO to radiation clinics e.g. for screening for high levels of psychosocial burden, in order to focus or ensure psychooncologic support to these patients. [K:Herschbach 2006]
- Institut for Therapieforschung IFT Gesundheitsförderung, Munich: Collection of sociodemographic data and assessment with the FLZ-M as part of psychotherapeutic care. Individual results and course over time for the FLZ-M are produced in graphical form together with mit generic, and patient specific reference areas selected according to age and sex. (since 2009, Berg).
- University Clinic Göttingen:
 - Department of Pharmacology: Patient questionnaires in a clinical study on effects of opiates (2001-2002, Vormfelde SV et al., literature requested)
 - Department of Family Medicine / General Practice: Patient satisfaction with care in the University Clinic vs. in the Hospital Neu-Mariahilf: a project of students of the course "Quality-of-Life and patient satisfaction with care" by WH and JS (2005)
 - Department of Family Medicine / General Practice: Use in 14 family practices (general practices), with interfacing to the existing practice management system. More than 600 assessments with the SGRQ and QLQ-C30. [F:Rogausch 2009, K:Rogausch 2006] Poster prize (2. rank) of the 40. Kongress the Deutschen Gesellschaft for Allgemein- and Familienmedizin (DEGAM) (2006) for the poster: "Electronic assessment of Quality-of-Life in the family practice (general practice) setting: first results".
- Specialists who have inquired for similar installations of the system and have been using them as a consequence of the project of the Uni Göttingen:
 - Dr. Tummes, Oncologist, Aachen (Selected items from the EORTC QLQ-C30 and its modules, which correspond to manageable problems)
 - Dr. Hein, Pulmonologist, Hamburg (Epworth-Skala)

- Dres. Boencke & Braun, Psychiatry and Psychotherapy, Göttingen (Patient satisfaction with care to support local QM)
- During the last months, three more clinical projects have begun in several specialties covering the local hospital as well as the highly specialized university department. Contact to these users can be established upon request.

1.3.6 Particular features of the QL-Recorder with AnyQuest for Windows

AnyQuest for Windows still follows the concept of the QL-Recorder which means that it can be used as easily as possible.

It provides a platform for electronic quesitonnaires with broad usability. Depending upon the patients in the target group, you may use either a common PC with a mouse (even a previously retired, simple machine may suffice), or a PC with a touch-screen, or a Tablet-PC (Pen-Computer) to be operated with the finger or a stylus can be used. One system can be prepared to offer multiple configurations with different questionnaires. If required, the system can be configured so that a questionnaire administration session can start automatically after power on without any other manual intervention. Secured configurations are possible and described in the available documentation.

The software was designed specifically to administer electronic questionnaires to patients; thus the contained answer fields or linear analog scales etc. are more easy to use, than e.g. the usual standard elements ("GUI widgets") found in WWW forms or other programs.

A running questionnaire administration session can be interrupted at any time and resumed later. Immediately after a patient has completed a questionnaire (or multiple questionnaires), the results are computed according to the scoring rules of the instrument(s). External computation programs and data sources can be integrated if required. Missing answers cannot occur from unintentionally overlooked questions; and when a patient indicates that she cannot or does not want to answer a question, then some additional explanation can be asked for.

The software can produce printouts (or e.g. PDF documents) with given answers, computed results from a single questionnaire administration, or plotting the course over a patient's results over time from multiple assessments. Static or dynamically computed reference values from reference populations or from locally collected data can be included in the printouts. These may even be automatically adopted to match e.g. sex and age of the patient.

Basic statistical functionality allows you to select results, group them, and compute descriptive statistics on the press of a button. Box plots and a plot showing the distribution of results of patient populations over time and the available range can also be generated very easily.

This meets the requirements of users who want to produce simple analyses, but do not have any statistics software available or be unfamiliar with its use.

Questionnaire definition files can include formulas which control the selection of modules, the sequence of questions, dynamically generated changes of questionnaires, and the computation of results. Specific requirements, e.g. like the rule from the EORTC QLQ-C30 scoring manual that a result shall be computed only where 50% or more of the answers belonging to that dimension are available, are supported by the implemented computation functionality. It is possible to call external programs and exchange data with these, to import external patient id data, or to automatically pass on collected data to other systems via text files and/or standard interfaces (e.g. GDT/LDT). The transmission proper can use data storage media or networks. Barcode readers, card readers and other devices, or programs to automatically generate cryptographic signatures on or encrypt collected data can also be linked in a simple way.

Collected data can be exported for external analysis (e.g. using SAS, SPSS, Excel etc.) either after interactive selection or globally. To prepare data collected with AnyQuest for a meta-analysis, it is sufficient to put all result files from all participating users into a single directory. Afterwards, AnyQuest can automatically generate a data export table, which contains the content from all result files, sorted by questionnaire and category, which can directly be processed e.g. by the statistics packages named above. Skripts to transfer collected data into SQL data bases are also available.

An editor enables users to generate their own electronic questionnaires, or to adopt paper questionnaires to the system by themselves. The time required to do for a HRQoL typical patient questionnaire, may usually be between minutes and a few hours - and the resulting electronic questionnaire will function including data collection, result computation, single- and course-over-time-printout, built in statistics, data export - and have a large pool of already available electronic questionnaires with compatible handling and data storage.

This approach produces more in less time, than any dedicated programming project for any single new questionnaire could do. Existing questionnaire definition files, as well as a collection of prototype question layouts can be recycled during the adoption of new questionnaires.

A fast input mode supports the scoring of paper questionnaires for cross validation studies or data collection in completely different scenarios.

AnyQuest for Windows is significantly smaller than a WWW browser. "Security leaks" are much less probable. The software runs on all versions of MS Windows, from version 3.1 up to Vista 32 Bit, and additionally under WINE for Linux and in Emulators. The program runs on older PCs as well as on modern, PC-compatible Tablet-PCs, Pen-Computers, Mobile Clinical Assistants, and Netbooks with or without a Digitizer/Touch-Screen. It may be used on completely isolated computers, or in local or wide area network systems. The level of integration into existing IT environments can be tailored exactly to meet requirements. This allows for very low-cost projects as well as for very innovative ones.

A working reference solution, AnyQuest Server, demonstrates a data base and WWW based backend to support multicentric studies with on-line monitoring and analysis. An editor enables users to generate their own electronic questionnaires, or to adopt paper questionnaires to the system by themselves. The time required to do for a HRQoL typical patient questionnaire, may usually be between minutes and a few hours - and the resulting electronic questionnaire will function including data collection, result computation, single- and course-over-time-printout, built in statistics, data export - and have a large pool of already available electronic questionnaires with compatible handling and data storage.

Moreover, there is a Java-Application providing a feasibility study for a player for available questionnaire definition files which can be used via WWW-Browsers, or deployed on mobile phones and similar devices.

1.3.7 Scale of the product and the underlying development

Software, documentation and other products in the periphery of the QL-Recorder were created over 16 years. The functionality was conceived according to the author's vision, and consistently enhanced to meet actual requirements of application projects. For quality assurance, older versions were archived and changes completely documented. All development work was provided by the author himself.

The current version 3.37 of the core program has more than 70.000 lines of code. The source of the context sensitive on-line help system has more than 7.500 lines (or paragraphs). Costs for a single line of code are usually estimated at 10 USD for simple tasks, up to 1.000 USD for mission critical projects (medicine, space flight). Even the most conservative estimate for the core program alone would position the generation of a tool of similar complexity from scratch quite out of reach for most projects.

Some 100 questionnaire definition files with adoptions of a variety of instruments in various languages are currently available.

The QL-Recorder has been used to perform several 10.000 questionnaire administrations already; and studies comparing it with paper questionnaires with regard to reliability and costs are available.

Earnings from application projects would not have been sufficient to fund the costs of a similar project on a commercial basis, or in a scientific institution under their usual conditions.

1.3.8 Availability and aims

The software of the current QL-Recorder, prepared configurations with selected questionnaire definition files, publications, documentation materials - including comprehensive, illustrated manuals - and videos are available on www.ql-recorder.com. The Software is provided as Shareware; the license agreement explicitly states that users can ultimately determine the registration fee themselves, according to the budget they have available.

Usage free of charge is explicitly offered for students and other users who do not have any budget.

The aim of promoting routine measurement of HRQoL in everyday patient care, by providing and supporting a suitable tool, is also clearly named.

1.3.9 Conclusion: Significance of the QL-Recorder

Both, the features of the QL-Recorder, and the available evidence for its usability, would be hard to create again for any new development. The underlying investment in working time exceeds the total budget of usual projects by far.

The QL-Recorder makes the measurement of HRQoL with electronic questionnaires practical with little effort, it is available for users without a budget, can be handled by patients without any training, and therefore provides new perspectives for individual patient care and research.

2 Literature reference

2.1 Publications from projects using the QL-Recorder

2.1.1 Selected spectrum of topics

The following publications deal directly with the measurement of health related Quality-of-Life, with health services research in general practice (family practice), with the relationship between research and practical patient care, computer based data collection, or the QL-Recorder. Additional literature as available on www.jsigle.com/cv and www.ql-recorder.com/document

2.1.2 Personal publications in scientific journals

- Rogausch A, Sigle JM, Seibert AJ, Thüring S, Kochen MM, Himmel W
 Feasibility and acceptance of electronic quality of life assessment in general practice: an implementation study.
 Health and Quality of Life Outcomes. 7:51 (2009). PMID: 19493355
- Chen TH, Li L, Sigle JM, Du YP, Wang HM, Lei J Crossover randomized trial of the electronic version of the Chinese SF-36. J Zhejiang Univ Sci B 8:604-8 (2007). PMID: 17657865
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 Elektronische Erfassung von medizinischen Daten in deutschen Hausarztpraxen:
 Ein Telefon-Survey.
 Z Ärztl Fortbild Qualitätssich. 99(9):573-80 (2005). PMID: 16398199
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- Himmel W, Kühne I, Chenot JF, Scheer N, Primas I, Sigle J Blockpraktikum Allgemeinmedizin: Evaluation des studentischen Unterrichts in Allgemeinpraxen. Gesundheitswesen; 66(7):457-61 (2004); PMID: 15314738
- 6. Porzsolt F, Kojer M, Schmidl M, Greimel ER, Sigle J, Richter J, Eisemann M
 A new instrument to describe indicators of well-being in old-old patients with severe dementia-the Vienna List.
 Health Qual Life Outcomes, 2:10 (2004); PMID: 14975057
- 7. Wetzel D, Scheidt-Nave C, Rogausch A, Heidenreich R, Sigle J, Himmel W, Scheer N, Niebling W, Böckmann H, Kochen MM, Hummers-Pradier E
 Medizinische Versorgung in the Praxis (MedViP) eine Modellstudie zur Verbesserung the hausärztlichen Versorgungsforschung in Deutschland.
 Z Allgemeinmed, 79: 394-398 (2003)

- Höhmann D, Hager ED, Sigle J Prognostische Signifikanz von EORTC QLQ-C30 Daten for Patienten mit Pankreaskarzinom. DZO (Z Onkol) 35: 59-69 (2003)
- Porzsolt F, Wölpl CP, Sigle JM, Rist CE
 Lebensqualität unter moderner Pharmakotherapie.
 Excerpta Oncologica Ciba, 4: 75-87 (1996)
- 10. Sigle JM, Porzsolt F

Practical aspects of quality-of-life measurement: design and feasibility study of the quality-of-life recorder and the standardized measurement of quality of life in an outpatient clinic.

Cancer Treatment Reviews 22 (supplement A): 75-89 (1996); PMID: 8625353

2.1.3 Personal book contributions

1. Sigle J

Electronically Supported Outcome Measurement. In: Beuth J (Ed.): Complementary Oncology (englischsprachige Ausgabe). Hippokrates Verlag/Thieme Verlagsgruppe. 80-90 (2005)

- Kuhnhardt H, Dannert E, Porzsolt F, Sigle J Medizinisches Qualitätsmanagement. In: Lehman T (Ed.): Handbuch the medizinischen Informatik. Carl Hanser Verlag, 2. Edition, 773-814, ISBN 3-446-22701-6 (2005)
- Porzsolt F, Kojer M, Schmidl M, Greimel E, Sigle J, Richter J, Eisemann M Fremdbewertung: Messung the Lebensqualität von Hochbetagten mit schwerer Demenz.

In: Porzsolt F, Williams AR, Kaplan RM (Hrsg.): Klinische Ökonomik. Effektivität & Effizienz the Gesundheitsversorgung in Klinik and Praxis. Ecomed Verlag, 310-321, ISBN 3-609-16148-5 (2003)

4. Sigle J

Elektronische Erfassung von Daten zur Lebensqualität.

In: Porzsolt F, Williams AR, Kaplan RM (Hrsg.): Klinische Ökonomik. Effektivität & Effizienz the Gesundheitsversorgung in Klinik and Praxis. Ecomed Verlag, 292-309, ISBN 3-609-16148-5 (2003)

5. Sigle J

Lebensqualitäts-Recorder.

In: Viethen JG (Hrsg.): QM-Checklisten for the Gesundheitswesen. Forum Verlag (aktualisierte Auflage, 2002)

6. Sigle J

Elektronisch unterstütztes Outcome Measurement.

In: Beuth J (Hrsg.):

 $Grundlagen \ the \ Komplement \" aronkologie.$

Hippokrates Verlag/Thieme Verlagsgruppe, ISBN 3-8304-5261-6 (2002)

7. Sigle J, Wilhelm HJ

Medizinisches Qualitätsmanagement.

In: Lehman T, Meyer zu Bexten E (Hrsg.): Handbuch the medizinischen Informatik. Carl Hanser Verlag, ISBN 3-446-21589-1 (2002)

8. Sigle J

Lebensqualitäts-Recorder.

In: Wilhelm HJ (Hrsg.): Direkt übernehmbare Vorlagen zum Qualitätsmanagement im Gesundheitsand Sozialwesen. Forum Verlag (2001)

- 9. Porzsolt F, Greimel E, Sigle J, Eisemann M
 - Lebensqualität.

In: Höffken, K, Kolb G, Wedding U (Hrsg.): Geriatrische Onkologie. Springer Verlag, ISBN 3-540-67411-X, 141-151 (2001)

10. Sigle, JM, Porzsolt, F

Znormalizowana ocena jakosci zycia w ambulatorium Ocena konstrukcji i przydatnosci elektronicznego rejestratora jakosci zycia.

In: Meyza L (Hrsg.): Jakosc Zycia W Chorobie Nowotworowej. Centrum Onkologii, Warzsawa, 147-166 (1997)

2.1.4 Personal published abstracts of contributions to scientific meetings

Lecture: Preuss C, Klimm HD, Streibl W, Klimm-Peters F, Sigle JM
 Patientenbefragung zur Lebensqualität and Behandlungszufriedenheit for Disease-Management
 Programme bei Diabetes mellitus: Erste Ergebnisse.
 41. Kongress the Deutschen Gesellschaft for Allgemein- and Familienmedizin (DEGAM), Berlin.
 Z Allg Med 82:1-24, V43 (2007)

The underlying doctoral thesis was awarded the Schwank-Preis 2007 of the Landesärztekammer Nordbaden. JS conceived the used platform with software and processes to perform patient assessments with questionnaires via mail.

 Lecture: Chen T, Li L, Sigle J, Du Y
 Feasibility and reliability of the electronic version of Chinese SF-36 administered using the Quality-of-Life-Recorder.
 2007 International Society for Quality of Life Research meeting abstracts Quality of Life Research, Supplement A-86, Abstract #1288 (2007)

www.isoqol.org/2007mtgabstracts.pdf

3. Poster: Rogausch A, Sigle J, Thüring S, Kochen MM, Himmel W and the MedViP-II-Studiengruppe Elektronische Erhebung the Lebensqualität in the hausärztlichen Praxis: Erste Ergebnisse.

40. Kongress the Deutschen Gesellschaft for Allgemein- and Familienmedizin (DEGAM), Potsdam.
Abstract in Z Allg Med, 82:19 (2006)
Awarded the poster prize (2. rank) of the congress.

4. Lecture: Sigle J, Surhoff M, Kochen MM for the MedViP-Arbeitsgruppe (Abteilung Allgemeinmedizin, Göttingen)

Entwicklung einer universellen Plattform for elektronische Leitlinien and Adaptation the DEGAM Leitlinie #1: Brennen beim Wasserlassen.

39. Kongress the Deutschen Gesellschaft for Allgemein- and Familienmedizin (DEGAM), Potsdam. Abstract in Z Allg Med, 81:1-20, Abstract V 22 (2005)

5. Poster: Heidenreich R, Böckmann H, Himmel W, Hummers-Pradier E, Kochen MM, Niebling W, Rogausch A, Sigle J, Wetzel D, Scheidt-Nave C for the MedViP Studiengruppe, the teilnehmenden Ärzte and Ärztinnen im KV-Bezirk Göttingen sowie the Mitglieder the Qualitätspraxen GmbH, Freiburg

To 6205 or not to 6205? EDV-Dokumentation in the Hausarztpraxis: Wer, was, wie, wann?

37. Kongress the Deutschen Gesellschaft for Allgemein- and Familienmedizin (DEGAM), Travemünde. Abstract in Z Allg Med, 79:2-38 (2003)

6. Lecture: Sigle JM, Porzsolt F

Practical aspects of measuring quality of life: design and feasibility of a Quality-of-Life-Recorder and representative data collection in an out-patient clinic.

Jahrestagung the Deutschen and Österreichischen Gesellschaft for Hämatologie and Onkologie, Hamburg.

Abstract in Onkologie, 18 (supplement 2):74 (1995)

2.1.5 Doctoral and master theses

The following examples, compiled from my current knowledge, further support the contribution of the QL-Recorder to the advancement of research - and especially, that it also performs with small budgets:

1. Seibert, Anna

Akzteptanz elektronischer Befragung zur Lebensqualität in the Hausarztpraxis. Universität Göttingen. (Laufendes Promotionsverfahren)

2. Mautner, Eva

Schwangerschaft and Geburt, medizinische and psychosoziale Einflussfaktoren auf the Lebensqualität and Befindlichkeit.

Universität Graz, 2008.

3. Thüring, Sabine

Kommunikation von Ergebnissen individueller Lebbensqualitätsmessungen in the Hausarztpraxis.

Medizinische Hochschule Hannover, 2006.

4. Chen, Tian-hui

The effect of Health-Related Quality of Life (HRQoL) on Health Service Utilization of patients with chronic disease.

Universität Zhejiang, China, 2005.

5. Braun, Reiner

LQ-KID: Entwicklung einer computerbasierten Methode zur Evaluation the Lebensqualität bei chronisch kranken Kindern and Jugendlichen. University of Ulm, 200?.

6. Höhmann, Dirk

Klinische Signifikanz von von EORTC QLQ-C30 Daten for the Prognose von Patienten mit Mamma-, Pankreas-, Ovarial- and kolerektalem Karzinom. Universität Witten-Herdecke, 2000. 7. Holch, Sibylle

Praktische Aspekte the Lebensqualitäts-Messung: the standardisierte Messung the Lebensqualität bei stationären Patienten mit einem elektronischen Lebensqualitäts-Recorder.

University of Ulm, 2000.

8. Schimitzek, Claudia

Patientenpräferenzen bei the Mitwirkung an Therapieentscheidungen in the palliativen Onkologie.

University of Ulm, 1999.

- Gebhard, Ursula Grenzen the QL-Messung. University of Ulm, 1997.
- 10. Sigle, Jörg-Michael

Praktische Aspekte the Lebensqualitäts-Messung: the standardisierte Messung the Lebensqualität bei Ambulanzpatienten mit einem elektronischen Lebensqualitäts-Recorder. University of Ulm, 1996.

Some of these works are available on www.ql-recorder.com/document as PDF-documents.

2.1.6 Publications of other authors

There is no obligation of QL-Recorder users to report their publications; and unfortunately the used platform is not reliably mentioned, nor the original publication reliably cited, in all publications.

Consequentially, the following list is not conclusive.

 Mautner E, Greimel E, Egger J, Trutnovsky G., U. Lang Quality of life outcomes in pregnancy and postpartum complicated by hypertensive disorders, gestational diabetes and preterm birth.

Journal of Psychosomatic Obstetrics and Gynecology (2009, zur Publikation angenommen, im Druck)

2. Walker J, Waters RA, Murray G, Swanson H, Hibberd CJ, Rush RW, Storey DJ, Strong VA, Fallon MT, Wall LR, Sharpe M

Better off dead: suicidal thoughts in cancer patients.

- J Clin Oncol. 2008 Oct 10;26(29):4725-30. Epub 2008 Aug 11. PMID: 18695258
- Storey DJ, Waters RA, Hibberd CJ, Rush RW et al Clinically relevant fatigue in cancer outpatients: the Edinburgh Cancer Centre symptom study. Ann Oncol. 2007 Nov;18(11):1861-9. Epub 2007 Sep 5. PMID: 17804467
- Strong V, Waters R, Hibberd C, Rush R, et al Emotional distress in cancer patients: the Edinburgh Cancer Centre symptom study. Br J Cancer. 2007 Mar 26;96(6):868-74. Epub 2007 Feb 20. PMID: 17311020
- 5. Herschbach P, Berg P, Pirker C, Henrich G, U Emmrich, Sehlen S, Dühmke E, Geinitz H, Molls M Computer based evaluation of a screening procedure for psycho-oncological treatment during radiotherapy.

In: Abstracts of the 8th World Congress of Psycho-Oncology, 2006, Ferrara-Venice, Italy. Psycho-oncology 2006; 15(iss 2 Suppl): S1-462; PMID: 1733807

- Bjelic-Radisic V, Dorfer M, Greimel E, Frudinger A, Tamussino K, Winter W
 Quality of life and continence 1 year after the tension-free vaginal tape operation. Am J Obstet Gynecol 195:1784-8, 2006. PMID: 17132481
- Keller F, Peter S, Fegert JM, Naumann A, Goldbeck L
 Behandlungsbewertungen von Jugendlichen im Verlauf einer stationär-psychiatrischen Behandlung.

Klinik for Kinder- and Jugendpsychiatrie/Psychotherapie, University of Ulm, 2006. http://vts.uni-ulm.de/docs/2006/5732/vts_5732_7613.pdf (Several publications in scientific journals also available, to be added later)

- 8. Lutz K, Keller F, Stiller K, Ziegenhain U, Fegert JM Entwicklung and Implementierung eines Instruments zur Erhebung pädagogischer Effekte and zur Unterstützung im Zielerreichungsprozess. Cooperation project of the CJD and the Klinik for Kinder- and Jugendpsychiatrie/Psychotherapie, University of Ulm, 2003-2005. http://www.uniklinik-ulm.de/fileadmin/Kliniken/Kinder_Jugendpsychiatrie/ Praesentationen/lu_CJD_041104.pdf (Several publications in scientific journals also available, to be added later)
- 9. Goldbeck L, Melches J
 - Quality of Life in Families of Children with Congenital Heart Disease. Quality of Life Research, 14(8): 1915-1924 (2005)
- 10. Goldbeck L, Braun R
 LQ-KID: ein computergestütztes Verfahren zur Erfassung the Lebensqualität chronisch kranker Kinder and Jugendlicher.
 Prävention and Rehabilitation 15(3): 117-128 (2003)
- Lecture: von Bültzingslöwen, F **TREG - a clinical tumor data base with instruments for medical reporting, measure- ment of quality of life and statistical analysis.** EMBEC-Kongress 1999, Wien. Cancer Research and Management, Proc EMBEC, 1999, II, 1560-1561.

All projects listed above, or their preparation, received technical support or consultation from JS.

2.2 General publications

This article is cited in the introction above, but does *not* specifically refer to the QL-Recorder:

1. Black N, Jenkinson C

Measuring patients' experiences and outcomes. BMJ 2009;339:b2495. doi:10.1136/bmj.b2495.

3 Questionnaires adopted to the QL-Recorder

3.1 Significance of available questionnaire definition files

The following listing documents the broad usability of the platform. It is not conclusive.

Data collected on any of the named electronic questionnaires are stored in the same file format. Results from a single administration, as well as course over time for an individual patient as well as for series of questionnaire administrations, static and dynamically computed reference values, descriptive statistics and boxplots can be used in a similar way for all adopted instruments. Data from all instruments can be made available to statistical software or other analysis environments in a similar way.

Questionnaire definition files for multiple instruments can be combined, and additionally required items can be added.

A direct cross validation between the paper based and the QL-Recorder based versions was performed for the eSIRO (German) and the eSF-36 (Chinese). Patient preferences were also compared. For the QLQ-C30, selected aspects of validity and reliability have been studied; and according to my knowledge, a relevant study is currently running at multiple sites in Sweden.

An included editor for electronic questionnaires enables users to generate their own questionnaire definition files in a comfortable way. Moreover, these can be generated by third party software or synthesized from data base content (e.g. from an Item-Bank) ad-hoc via a text format. This mechanism is even available while a questionnaire definition file is being deployed (-> IRT, CAT, Morphing Questionnaires).

3.2 Questionnaires on Health Related Quality-of-Life

ACT Asthma Control Test (de)⁵, BI Barthel Index (de), BORG Scale (de), EORTC QLQ-C30 Version 3.0 Kernfragebogen (de, en, fr, ho, sw, u.a.m.), EORTC QLQ-C30 Version 2.0 Core Questionnaire (de, en, fr), EORTC QLQ-BR23 Breast Cancer Module (de, en, fr), EORTC QLQ-LC13 Lung Cancer Module (de, en, fr), EORTC modified QLQ-LC13 Lung Cancer Module (de), EPDS - Edinburgh Postnatal Depression Scale (de), Epworth Scale (fr), EuroQOL, EuroQOL-LASA (de), FLZ-M Fragebogen zur Lebenszufriedenheit (de), GDS Global Deterioration Scale (de), GCSS Green Climacteric Symptom Scale (de), GCSS LASA Green Climacteric Symptom Scale LASA/VAS-Version (de), HADS Hospital Anxiety and Depression Scale (de, en, fr), IBCT International Breast Cancer Trials Group Visual Analog Scales (en), IBSQOL Irritable Bowel Syndrome Quality of Life Questionnaire (19 languages, including Greek), KHQ King's Health Questionaire (de), MFI-20 Multidimensional Fatigue Inventory (de, en), MLHFQ Minnesota Living with Heart Failure Fragebogen (de, en), MOS SF-36 - Medical Outcomes Trust Short Form (ch, de, en, fr), MOS SF-12 Medical Outcomes Trust Short Form (de, en), MRF-28, Magueri Foundation Respiratory Failure Item Set (fr), QSQ - Quebec Sleep Apnea Quality of Life Scale (fr), QSQA - Quebec Sleep Apnea Quality of Life Scale, Kurzfassung (fr), QWB-SA Quality of Well-Being Scale, Self Administered Version (en), Pain VAS Visuelle analoge Schmerz-Skala (de, en), Pain VAS sm Visuelle analoge Schmerz-Skala mit Smileys (de, en), SUB_PAIN Schmerzprotokoll the Palliativistation the Uniklinik Göttingen (de), PHQ-D Patients' Health Questionnaire, short version (de), PHQ-9 Patient-Health-Questionnaire (en), SAQLI Calgary Sleep Apnea Quality of Life Inventory (en, ho), SES Pain-Susception-Scale (de), SGRQ St. George's Hospital Respiratory Distress Questionnaire (fr), SI Spitzer Index (de), SIRO Stress-Index Radio-Onkologie (de), WHOQOL-BREF (de).

 $^{^{5}}$ de=German, ch=Chinese, en=Englisch, fr=French, gr=Greek, ho=Netherlands, sw=Swedish; the eIBSQOL is available in 19 language versions, the QLQ-C30 in 20, these are not listed in further detail.

3.3 Questionnaires from other fields

3.3.1 From psychiatric/psychotherapeutic applications

Point of time of assessment, Base documentation (2 Teile), History, Severity (or impact) of burden score, GBB 24 Giessener Beschwerdebogen (short form), IIP-D (64 Items), Usage of various sources of help, Physical (bodily) symptoms, Questions on Quality-of-Life, Current Problems, Current Well-Being, Psychic and social Symptoms, SCL-90-R, Questions on the course of therapy (Patient), Questions on the course of therapy (Therapist), Questions for demission (Patient), Questions for demission (Therapeut), ILK9 modified, CBCL, PADZI, YABCL, YASR, YSR, Satisfaction questionnaire (de), EVAL Evaluation of the computer based assessment by adolescents (de), MOCI Obsessive Compulsive Tendency (en), EMQ4 E.M.'s Questions on giving birth (de).

3.3.2 From other fields

BB Questionnaire on Patient Satisfaction with Outpatient Care (de), KombiDox Questionnaire on Patient Satisfaction with Inpatient Care (de), EMSOZDEM E.M.'s Soziodemographische Fragen (de), Soziodemographische Daten (fr), Evaluation of a course (de), Evaluation of a course for students (de), Evaluation of a workshop (de), SECT Assessment of the quality of clinical studies (de), Glasgow Coma Scale (de, en).

4 Illustrations

The WWW-site of the QL-Recorder includes - in addition to software-packages with several electronic questionnaires which can be downloaded and tried out - a large number of images (showing various electronic questionnaires and printouts), videos, illustrated manuals and many more.

Here are merely two examples:



Figure 1: Example of an electronic questionnaire (EORTC QLQ-C30) using AnyQuest for Windows on a Tablet-PC. This computer measures about 33 cm x 22 cm x 2 cm (a little larger than a sheet of A4 paper) and can be linked to a practice- or hospital-IT-system via WLAN. The same software, however, also works on any older PC from 386/Windows 3.x/Linux etc., with or without a Touch-Screen.

,					
	Messung nach Tummes' The	arapia Monitoring garqdw 0.2	Monitoring ger qdw 0.2		
Gruppe/PID: Name: Gebutisdatum: Akter:	123 Max Mustermann 03.04.1956 52.4 Jahre				
1:01.09.2008 2:01.09.2 22:34:25 22:37:3	008 D				
Ergebnisse:					
Funktionen: Werte im QBE	REN Bereich sind günstiger.				
·•					
41 r©1					
02					
°					
01					
Giobale LQ					
Symptome: Wene im UNTI	REN Bereich sind günstiger.				
04 m	04	04	04		
	03 02				
Müdiskeit	Übelkeit und Erbrechen	Atempot	Appelitmappel		
04	04	100 04	100 04		
03 02	03 02	03 02	03 02		
1			0		
Versiopiung	Duchiali	Schmerzen/Wund Mund	Geschmacksv.		
04 03 1	04 03	04 03			
02 01	02	02			
Haarausiali	Gewichtsverlust	Gewichtszunahme			

Figure 2: Example for automatically computed scores, available immediately after an assessment (as true printout or PDF-document): Results of a patient over time. Content, distribution, reference values, page layout etc. can be configured to a some extent. The example includes those dimensions from the QLQ-C30 and some of its modules, which an oncologist selected to be regularly observed in his own practice. Green bars = functions; Red bars = symptoms.

5 Contact

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6 Curriculum Vitae

Dr. med. Jörg Sigle

Education and professional training

- 1990 1997 Studies of Medicine at the University of Ulm
- 1997 1998 Scientific assistant at the AG Klinische Ökonomik the University of Ulm, Prof. Franz Porzsolt
- 2001 2002 Assistant physician in a rural general practice, Dr. Wolfgang Streibl
- 2003 2005 Scientific assistant at the Department for Family Medicine / General Practice at the University of Göttingen, Prof. Michael M. Kochen
- Since 1992 Freelancer in the field of IT and Medicine

Professional emphasis

Development of software to meet specialized requirements e.g. in the medical field

Measurement of the benefit of medical interventions

Improvement of student education at the University of Ulm

- 1996 participation in the course "How to teach and practice Evidence based Medicine" by Prof. David Sackett, Oxford
- Participation in student education at the Universities of Ulm, Bayreuth and Göttingen

Conzept of the Quality-of-Life-Recorder at the Cancer Center of the Uni of Ulm; and consequentially:

- 1993: Practical implementation by the software AnyQuest for DOS
- 1996: Development of AnyQuest for Windows during a PJ-Tertials (internship) with Prof. Alan Coates, Sydney
- 1998: Doctoral thesis: "Practical aspects of quality-of-life measurement: The standardized measurement of quality-of-life in outpatients using an electronic Quality-of-Life-Recorder"
- Conception and maintenance of the WWW Site www.ql-recorder.com
- Generation of various electronic adaptions of questionnaires on health related quality of life and patient satisfaction with care
- Addition of interfaces to IT systems for practices and clinics, and QM-systems, analysis tools, documentation and training materials, online-database for assessment results
- Participation in studies deploying the QL-Recorder in routine care and research projects, including the support of a number of doctoral theses