

Delivering a one-stop, integrated, and patient-centered service for patients with rheumatic diseases

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Abstract

Objective: To describe a one-stop, integrated rheumatology service and assess patient satisfaction.

Methods: A descriptive report and patient satisfaction survey of a rheumatology clinic model first developed in 1996 to enhance the patient “journey” through rheumatology services. A patient-satisfaction survey over a 3-week period assessed several aspects of care including quality of services, consultations, and patient education.

Results: All referrals are screened by a rheumatologist to pre-schedule laboratory/radiology/other tests for the visit. Upon arrival to the clinic, patients check-in at an electronic desk, and then complete the electronic GoTreatIT monitoring system which assesses patient-reported outcomes. The patient is reviewed by a doctor in a 30- to 60-min consultation, and then by a nurse (for diagnosis/treatment education, vaccinations). An ultrasound machine and capillaroscopy are available for use in the clinic. Patients can be scheduled on the same day to see a nutritionist, physiotherapist, or other health professionals as necessary. An “early-rheumatoid arthritis treatment path” is available to ensure early, intensive treatment. A patient satisfaction survey revealed high rating of the overall service (90.6/100). None of the patients felt that they lacked education on their disease or medication. Only 6% of the respondents gave negative feedback, reasons including feeling overwhelmed with information or not being given a cause for their symptoms. The multi-disciplinary approach was highly valued and only 3% would rather see a doctor and nurse on separate days.

Conclusion: The specific clinic model provides an ideal setting for a one-stop service, avoiding unnecessary visits, collecting patient data, and enhancing the patient experience and journey through the system. Where possible, the specific clinic model could be used or adapted to build similar models in other rheumatology departments. The clinic model could also form the basis for services in other specialties dealing with chronic conditions.

Keywords

Clinic model, rheumatology, patient satisfaction, integrated service

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Introduction

Rheumatology is predominantly an outpatient, multi-disciplinary medical specialty dealing with multiple disorders of the joints, bones, muscles, and connective tissues. Conditions range from simple soft tissue disorders to complex systemic, autoimmune diseases. Inflammatory arthritis patients represent an important group of patients seen in rheumatology clinics and over the years emphasis has been placed on early diagnosis and treatment to improve long-term outcomes.^{1–4} With chronic diseases representing the bulk of rheumatology, an integrated, multi-disciplinary, and patient-centered approach to the management of patients is

essential.^{5,6} Care does not stop at the point of diagnosis and acute treatment but continues in the long-term with frequent monitoring and careful examination of disease and

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patient-reported outcomes.⁷ In reality though, not many rheumatologic units are able to provide this level of service; reasons include financial pressures and restrictions in resource availability. However, providing this level of service does not always necessitate more resources; a simple restructure of service provision may be adequate.

There are two objectives to this article: first, to provide a descriptive report of a one-stop, integrated rheumatology clinic model currently in practice and, second, to assess this model by a patient satisfaction survey.

Jyvaskyla Central Hospital is Finland's biggest non-universal hospital, covering the secondary level health care for 250,000 inhabitants. The development of the rheumatology clinic model in 1996 stemmed from the initiative of two rheumatologists working at the clinic: T.S. and P.H. However, the roots of the development of rheumatology care in this hospital and its scientific reporting date back many decades to the historical Finnish Rheumatism Foundation Hospital in Heinola.⁵ The goal was to enhance the patient "journey" through rheumatology services by providing all necessary education, treatment, and care in one visit, avoiding unnecessary visits, and optimizing the overall quality of care provided.

The ideology behind the Jyvaskyla clinic model is similar to that of a historical Finnish rheumatology center, the Rheumatism Foundation Hospital in Heinola.⁵ The famous Heinola Hospital was founded in 1951 and closed in 2010 due to financial constraints and diminished need of in-hospital services for rheumatoid patients following the era of biological medications. The hospital acted as Finland's rheumatology center of excellence, caring for patients with rheumatic diseases and also participating actively in scientific research. The Heinola patient-care model was based on the principles of prompt and multi-disciplinary care which was found to be most beneficial to patients. As part of the service, patients received active treatment right from the onset of disease which included cryotherapy, physiotherapy, rehabilitation, and provision of orthoses by a multi-disciplinary team consisting of adult and pediatric rheumatologists, orthopedic surgeons, radiologists, physiotherapists, and importantly, specialist nurses. The Jyvaskylä clinic structure is essentially a modernized version of the Heinola clinic model based on the same principles.

Another model in use is in the United Kingdom, in the Haywood Rheumatology Centre.⁶ The center serves a population of 600,000 to 1 million patients with in-patient and out-patient rheumatology and musculoskeletal services. Haywood is a treatment and rehabilitation center, with physiotherapy and occupational therapy services and diagnostic imaging possibilities emphasizing a multi-disciplinary approach. Rheumatologists and consultant nurses lead and run the clinic in clinical equal partnership. General practitioners with special interest in rheumatology work part-time in the clinic developing skills and then benefitting their community at their own practice and reducing the need of hospital services. The center also holds an osteoporosis clinic and a clinic for

chronic pain. At the university hospital there are services of orthopedic rheumatology. Haywood center also hosts medical trainees and is active on scientific research in collaboration with the neighboring universities.

Clinic model

The description of the structure of the clinic model in this article is based on personal experience and on interviews with clinicians, nurses, and other health-care professionals.

Pre-clinic investigations. Patients are usually first seen by their primary care physician, who initiates the referral to rheumatology. Less than 10% of patients are referred directly from other secondary care professionals. All incoming referrals are screened by a senior rheumatologist. The majority are usually accepted for review with additional laboratory investigations and radiographs, including magnetic resonance imaging (MRI) scans organized prior to the review. The screening of referrals aims to reduce unnecessary visits to rheumatology hospitals and to enable a pre-clinic work-up that would enhance the patient's first appointment with the rheumatologist, leading to a confirmed diagnosis and initiation of treatment without delays.

Clinic setting, data collection, and monitoring tool

Integrated into the every-day clinical work since 2007 is an electronic monitoring tool for continuing treatment-data collection via a computer-based program, GoTreatIT (Figure 1). The program is developed by rheumatologists with a Norwegian company DiaGraphIT⁸ and is used to support systematic collection of data at every visit and during the entire length of the patient's illness.

Upon arrival to the clinic, the patient first reports either to the electronic self-check-in stations or to the receptionists and is then directed to complete a questionnaire at every visit on their symptoms and performance status before seeing the doctor. There are computers and tablets for this purpose in the waiting lobby. The receptionist assists elderly patients, who might have difficulties with electronic devices. The questionnaire comprises of several questions, aimed at identifying the patient's current performance status, quality of life, level of pain, and other issues. Commonly used questionnaires and measures such as Health Assessment Questionnaire (HAQ), 28-joint-count Disease Activity Score (DAS28), and Bath Ankylosing Spondylitis Functional Index (BASFI) are integrated in the GoTreatIT questionnaire.

At every visit, the doctor undertakes a complete joint assessment, denoting on GoTreatIT all tender and swollen joints and any intra-articular injections completed using a visual map of joints (Figure 1). In the same way, doctor can easily compare the current joint status to that of previous visits. The doctor also updates the C-reactive protein (CRP) and erythrocyte sedimentation rate (ESR) on the GoTreatIT

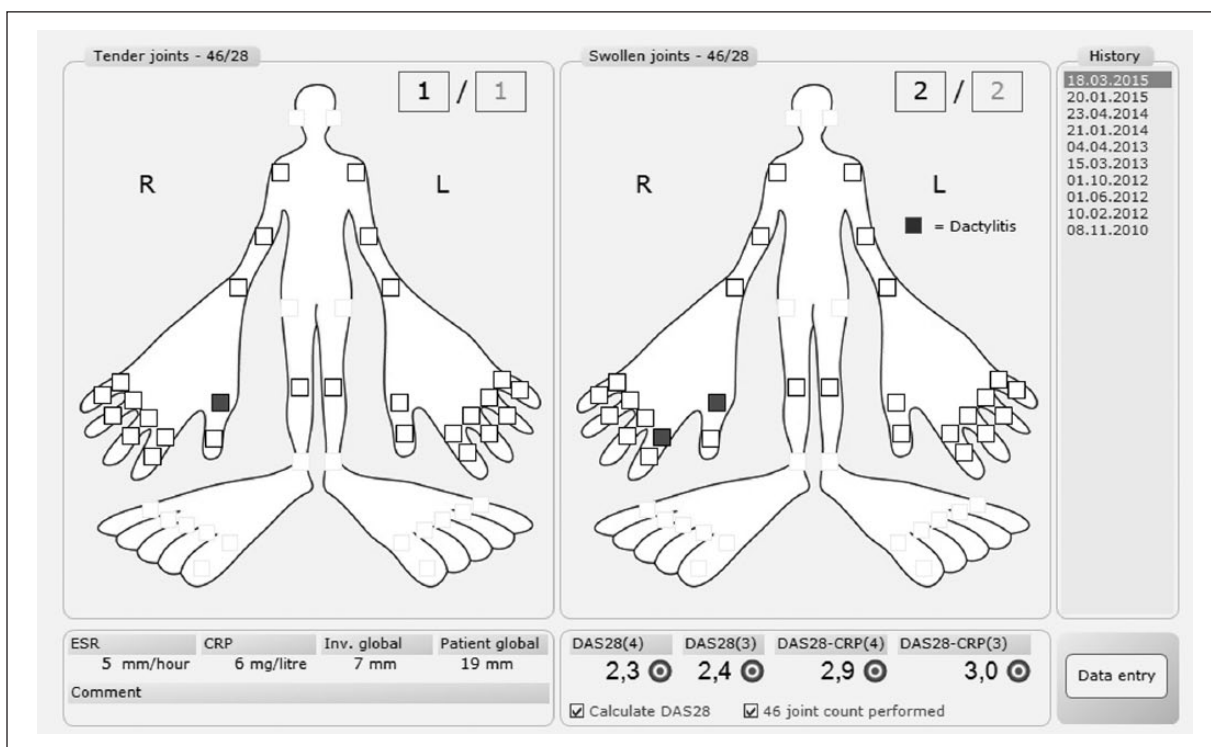


Figure 1. Extract from GoTreatIT demonstrating an example of electronic recording for tender and swollen joint counts.

system. Entering the data to the system is simple and doesn't take more than a minute.

In addition to the patient's self-assessment and doctor's observation, socio-demographic data, diagnostic tests, and comorbidities are completed to GoTreatIT by a research coordinator. Any changes in the type and dose of medications during the course of the disease and reasons for including any adverse events are indicated on GoTreatIT, allowing the doctor to see the complete history of medications used at a glance.

Using the questionnaire completed by the patient, current laboratory values and joint status completed by doctor, the program then generates commonly used comparable values such as HAQ, DAS28, and BASFI for every visit. These values can then be viewed graphically, visually making it easy to see trends and the patients' progress over time. GoTreatIT is used in 10 other cities in Finland as well as other countries, including Greece, Norway, and Czech Republic.⁹

Staff. The rheumatology department in the hospital consists of two main areas: a day care-unit where infusions are given and an outpatient clinic area. In-patient beds for rheumatology patients are provided within the general medical ward. The outpatient clinic area consists of 12 clinic rooms, 2–5 used by doctors and 5–7 by nurses and research co-ordinators.

At any time, 2–4 senior rheumatologists and 1–3 trainees are present in the department. There are 5–6 rheumatology nurses working closely with the doctors. Radiology as well as pharmacy services are provided within close proximity in

the main hospital. Patients can be referred to a physiotherapist, social worker, a nutritionist, podiatrist, and any other health specialist as necessary. An orthopedic surgeon visits the clinic every 2 weeks.

Doctor review. Doctor review lasts from 30 to 60 min. At every visit, whether a first or a follow-up visit, the patient is assessed for important comorbidities including cardiovascular disease and related risk factors. Osteoporosis-screening using bone densitometry can be arranged within 1 month if needed. Blood pressure, lipid profile, and vitamin D levels are screened and recorded on a routine basis with follow-up instructions as necessary. Doctors can initiate referrals directly to other secondary care services such as orthopedic surgery and health care professionals including podiatrists, nutritionists, occupational therapists, physiotherapists, and others. These reviews are mainly scheduled on the same day patients visit the clinic for doctor or nurse review.

An ultrasound machine is available in most rheumatologists' rooms; furthermore, nailfold capillaroscopy is available in two of the rooms. Inflamed joints can be injected with glucocorticoids. The working diagnosis and treatment plan are discussed with patients, but a more detailed education on their diagnosis and treatment is further provided by nurses following the doctor review.

Nurse review. Patients are seen by the same nurse at every clinic visit, to ensure consistency of treatment. The nurse-doctor ratio is 1:1. Nurses provide detailed education on any

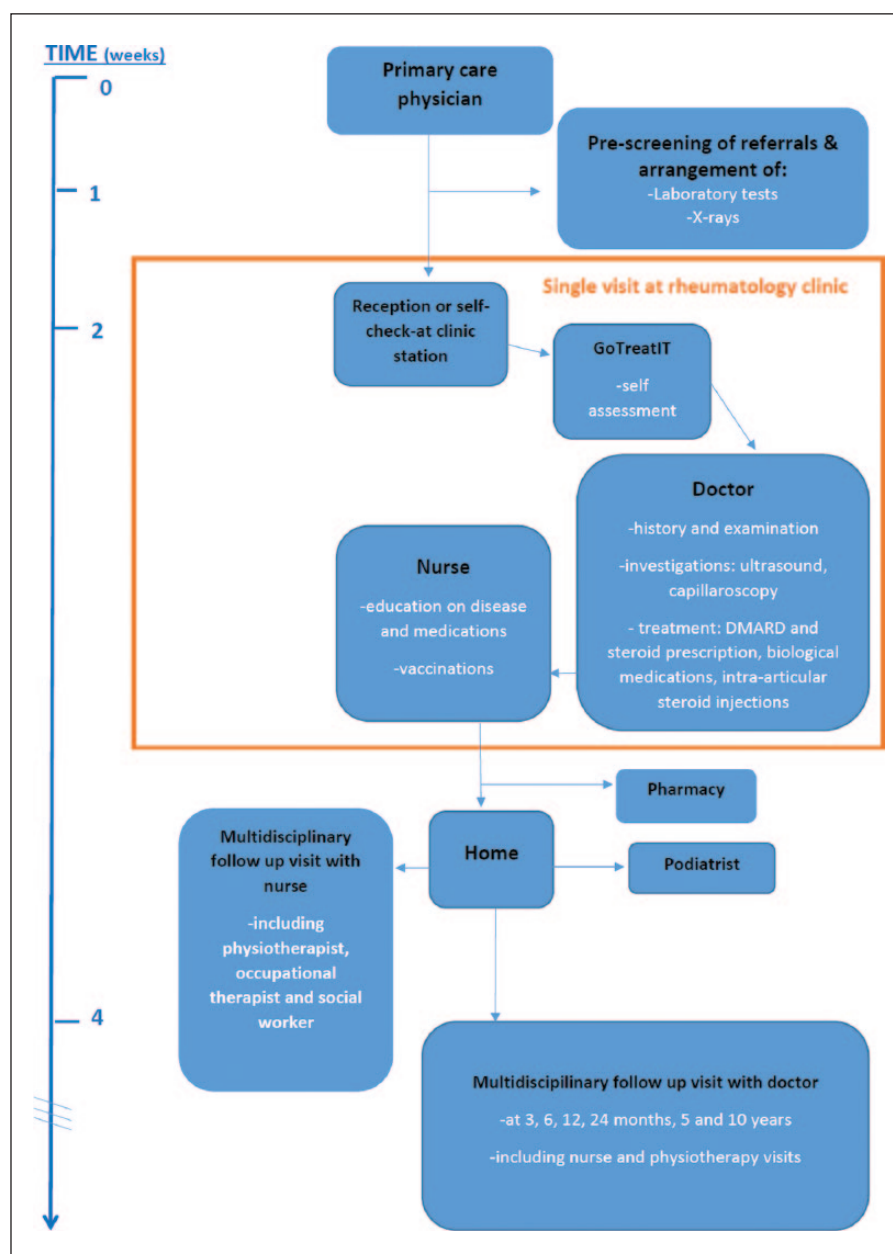


Figure 2. Treatment pathway for newly-diagnosed rheumatoid arthritis patients in the Jyvaskyla rheumatology clinic model.

new diagnoses given to the patient and treatments started. If injectable drugs are used, patients are taught the injection technique. When biological drugs are considered a pneumococcus vaccine will be administered aside from detailed education on the specific drug, its use, benefits, and potential adverse effects. Rheumatoid arthritis (RA) patients on conventional synthetic anti-rheumatic drugs including methotrexate have pre-arranged laboratory testing supervised by nurses.

Allied health professionals. Two physiotherapists are involved in the care of rheumatology patients. All new and follow-up patients needing review by physiotherapy, occupational

therapy, or other health care professionals can be referred directly by the doctor. Orthotic devices are ordered when needed and new insoles are provided routinely by the clinic every 2 years to prevent foot malalignments. At the physiotherapy visit, patients' aerobic performance capacity as well as muscle strength is tested and they receive basic education on healthy exercise habits accordingly.

Treatment path for new RA patients. Since 1997, the clinic has employed a standard management protocol (Figure 2) for patients with RA to ensure early, intensive, and uniform care as per existing recommendations.¹⁻⁴ After a patient is diagnosed with RA, combination therapy with

disease-modifying anti-rheumatic drugs (DMARDs) according to Finnish guidelines is started.¹⁰ All patients have their auto-antibodies (rheumatoid factor and anti-cyclic citrullinated peptide), inflammatory markers, and other baseline laboratory tests along with X-rays of the hands and feet arranged at baseline. Patients with RA have follow-up visits arranged at 3, 6, 12, and 24 months after the initial (baseline) appointment. Each time they are reviewed by both doctors and nurses. Physiotherapy and occupational therapy are organized within 1 month of initial appointment, physiotherapy continuing at every visit through the 24-month treatment-path. At 24 months, X-rays of the hands and feet are repeated. The goal of treatment is achievement of disease-remission by the 3-month, latest by the 6-month visit. If this is not achieved, treatment is intensified with addition of biologic DMARDs as indicated. At each visit, swollen joints are treated with local (intra-articular) long-lasting glucocorticoid injections with the patient's consent. To ensure adherence to treatment, automated mobile phone monitoring is employed for the first 6 months.¹¹

If after the 2-year follow-up patients are in stable remission, they are referred back to primary care for subsequent follow-up, up until the fifth year from diagnosis. If there is a flare of disease at any point thereafter, they can be referred straight back into the rheumatology clinic. At five and 10 years, patients are invited back for follow-up visits with the above procedures including laboratory tests and X-rays repeated.

Methods

This article also discusses the results of a patient satisfaction survey in relation to the specific service provided. The main objective of the study was to determine how patients experience the clinic model, what is their overall assessment, and to find out whether there are specific areas that need developing. The survey was developed by adapting a previous questionnaire on rheumatology patients in 2009 (unpublished). Epidemiological questions were presented, but otherwise the questionnaire was completely anonymous. It contained 14 questions, focusing on the main aspects of care and quality of treatment, friendliness of staff, and overall quality of care. Patients were asked to report what they benefited most from during the course of their illness. Concerning patient education, patients were asked whether they feel that they have received sufficient patient education from nurses, who provide most of the education. They were asked whether they receive too much information at once and whether they would rather see the doctor and nurse on different days. Patients answered different statements on a scale of 1 to 5 (1=agree completely, 2=agree mainly, 3=no opinion, 4=disagree mainly, and 5=disagree completely). The options "disagreed mainly" and "disagreed completely" were analyzed in the results as one option "disagreed," due

to the low number of responses. Patients also gave an overall score of the service (0–100). The survey included options for free-text feedback and critique (questionnaire available as supplementary material). The survey was distributed by the receptionist to all patients visiting the clinic for a doctor review over a period of 3 weeks, April–May 2015. The objective was to distribute 150–200 questionnaires. The latter were anonymously completed and returned by patients into a post box. The responses were recorded in an Excel file, where they were coded and analyzed. Descriptive statistics (including frequencies and mean values) were used to present the results.

Results

A total of 164 questionnaires were distributed, with 141 completed and returned (86% response rate). A total of 94 (67%) patients were females. Mean age was 54.3 years; 52 (37%) patients were retired. The majority of patients were diagnosed with RA (51%), 10 patients (7%) had ankylosing spondylitis, 8 (6%) psoriatic arthritis, and the rest had other diagnoses, including polymyalgia rheumatica, vasculitides, myositis, and lupus.

Of the responders, 90% "completely agreed" that they had sufficient education on their disease and medication and the rest "mainly agreed" with the statement. Only 6% of patients felt that they were overwhelmed with information, whereas 83% were content with the amount of information on their single visit. The multi-disciplinary approach was valued and only 3% reported they would rather see the doctor and nurse on separate days. In total, 92% of patients "agreed" that their medical care was of high quality, and of these patients 75% "completely agreed." None disagreed with the statement and 8% of patients had no opinion on the matter. Patients found nurses to be friendly and professional in 99% of visits and doctors in 96% of visits. The main results are presented in Table 1.

The mean score of the patients' overall assessment of the service at a scale of 0–100 was 90.6/100. The patients who had a visual analog scale (VAS) pain score over 50 at the scale of 0–100 (19% of all patients) still rated the service as 87.8/100.

On free-text feedback most valued was the information and education provided and addressing patients' current issues, with 26 positive free-text comments made. A total of 14 patients pointed out that the staff was friendly, the atmosphere in the clinic was very good, and that they got genuine and empathic care. A total of 13 patients found the staff to be professional and an equal number of patients reported benefiting from efficient treatment, such as intra-articular glucocorticoids and biological agents. Some patients were pleased that the service was quick, thorough, and that there was no feeling of rush during the visit.

Negative feedback was given by seven patients. The main complaint concerned the electronic self-reporting desk and

Table 1. Patient satisfaction across different areas.

	Agreed completely	Agreed mainly	Disagreed	No opinion
Received high-quality medical care overall	100 (75%)	23 (17%)	0	10 (8%)
Doctor gave appropriate attention to patient's overall medical care	118 (87%)	15 (11%)	0	2 (1%)
Received sufficiently nurses education on disease and medication	120 (90%)	11 (8%)	0	3 (2%)
The amount of information per visit was overwhelming	4 (3%)	4 (3%)	111 (83%)	15 (11%)
Would rather see a doctor and nurse on different days	3 (2%)	1 (1%)	113 (85%)	16 (12%)
Was treated friendly by doctors	123 (90%)	8 (6%)	3 (2%)	2 (1%)

difficulty in using it. Some patients expressed disappointment for the doctors not identifying an unambiguous cause for their symptoms.

Discussion

This report describes a well-functioning multi-disciplinary one-stop service integrating the services of all necessary professionals at the same patient visit. The pooling of skills in rheumatology in both assessing and managing disease is the key to optimal patient care. It is based on principles of good care and communication, with the patient at the core of care; a principle that applies to all other specialties especially those dealing with chronic diseases.

The results of the patient survey supports that the Jyvaskyla rheumatology clinic model results in high patient satisfaction. Positive feedback was obtained despite one in five patients having reported a pain VAS of over 50 on a scale of 0–100 at the time of completing the survey. The majority of patients felt that the doctors and nurses paid attention to their care and treatment and that they left the clinic having acquired good education on their condition and treatment. Good patient education is the key principle of the clinic, and aside from doctors, nurses have the necessary credentials and skills required to educate patients on various aspects of disease. This naturally leaves more time for the doctor to concentrate on important clinical aspects such as screening for comorbidities. Furthermore, the specialist nurses work closely and efficiently with the doctors, which further enhances the patient experience and outcomes. This was reflected in the responses of patients reporting a high quality of medical care received and scoring high on friendliness and professionalism of staff. The very low proportion of patients (<5%) giving negative feedback supports the success of this service. The survey demonstrated that the multi-disciplinary approach was highly regarded and valued and this was also reflected in the very positive free-text feedback. The negative feedback can be used to further improve the service.

GoTreatIT is a unique feature of the Jyvaskyla clinic model, enabling important collection of data. The GoTreatIT monitoring system can be used both for clinical and also for research purposes. It is simple and time-saving to use by professionals as patients can enter some of their own data prior to the doctor review. The electronic monitoring system

enables a quick review of the individual patient's history of presentation, medication used, examination findings, comorbidities, and any other patient or disease-related details. For example, all medications used, their adverse effects, and reasons for changing medication can be reviewed in one page, without the need to go through old medical files. GoTreatIT also provides clinically relevant measures such as HAQ, DAS28, and BASFI for each visit once necessary data have been entered.

To the authors knowledge there are no similar systems such as GoTreatIT. Parallel to GoTreatIT which is used in the rheumatology clinic, an electronic medical record is in use in the whole hospital and Jyvaskyla region. Usually, electronic medical records are considered outstanding in a modern clinic. However, they only store the data in a non-structured form and cannot be used as a data storage medium to illustrate the course of the disease over time in individual patients, or in groups of patients.

Whereas with GoTreatIT, while providing data for clinical purpose, it also provides data for research purposes. Data extraction from GoTreatIT is quick and easy and completed on the press of a button and can be limited to a certain period of time, certain disease, or diagnosis. Ongoing, active, scientific research is a further strength of the Jyvaskyla rheumatology center resulting in a number of publications to date on long-term outcomes of RA.^{12–14}

The Jyvaskyla model is applicable to any modern health care service. It necessitates a certain amount of staff resources and expertise. The treatment protocol based on principles of early treatment requires more resources at the beginning of treatment but with early remission, follow-up visits, and the need of rehabilitation diminish. Although the composition of the teams at different places may vary, emphasis should be placed on at least enabling easy access to relevant professionals even though this may not be provided on the same day and within the same department. The Jyvaskyla clinic model provides an example for building or adapting other clinic models, both in rheumatology and also in other specialties dealing with patients with chronic diseases.

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Ethics approval

Ethics approval is not applicable, because this was an anonymous survey and according to law in many countries including Finland, surveys can be performed without those.

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Informed consent

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