Go, go, GoTreatIT!

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ABSTRACT
Patient monitoring has been emphasised in rheumatology for decades. However, many obstacles must be overcome before successful monitoring is part of routine care. We describe one model: GoTreatIT.

Measuring of outcomes in rheumatology over time
In 1983, over 30 years ago, Verna Wright pointed out that ‘Clinicians may all too easily spend years writing ‘doing well’ in the notes of a patient who has become progressively crippled before their eyes…” (1). Thirty-three years later, at EULAR 2016 in London, when this was addressed to a full auditorium of rheumatologists who measure psoriatic arthritis outcomes, very few hands rose.

The role of measuring in clinical medicine
Medicine is not an exact science. Diseases manifest differently in different people; the experience of disease differs from one person to another. Disease feels different on a sunny day than on a rainy day, in outdoor temperature of +30°C or -30°C. A man is not a paper mill. Therefore, monitoring and measures can provide only a picture of the truth, a picture that requires interpretation. A rheumatologist is the specialist who must learn how to interpret the picture: his patient, patient’s symptoms, and many measures and the results of monitoring.

It is easiest not to measure at all
Traditionally, the doctor listens to a patient, observes, performs some basic examinations, orders some lab tests, draws a conclusion, writes a prescription; the patient gets along so and so, and the story continues. Or, with the current technology, all imaginable lab tests and imaging modalities are being used instead of listening and observing the patient. In the most unfortunate scenario, the doctor believes that she/he knows and the patient believes that the doctor knows. Many patients get better and some are cured, but many become “crippled before the doctor’s eyes”. It appears that until current times, rheumatologists remained prisoners of their traditions: not to measure. Or to replace a patient with technology. A literature review of disease-modifying anti-rheumatic drugs in cohorts of patients with rheumatoid arthritis (RA) around the world suggested that for decades, traditions dictated medications for rheumatoid arthritis (RA) (2).

What to measure?
Over many years, lectures and articles have addressed the issue of measures in rheumatology (3). There are measures of the state and measures of improvement. Measures may be considered as “objective” and some measures can be considered “subjective”. However, sometimes subjective measures are more objective than objective measures. Some measures are surrogates for actual outcomes. In the short term, disease activity matters, but over decades, measures of permanent damage matter. However, the patient’s functional capacity and ability to work matter most, from the point of the patient, health care, society, and the tax payers.

Why to measure?
Outcomes of chronic conditions do not appear to be on the priority list of health authorities. They ask for savings in health care when they should ask for outcomes, whether patients could maintain the ability to work. Furthermore, it appears that “hotel-based rheumatology”(4) remains the trend; randomised, controlled clinical trials (RCTs) that provided the best remission rates ever (5), are ignored by rheumatology opinion leaders (6). Doctors may be paid for performing procedures including patient monitoring although in settings of socialised medicine,
monitoring is not translated to greater earnings of health care providers.

Very few colleagues have the courage to ask an important question (7): which of many clinics scores the best in terms of treatment results? Seeking an answer to this question would help to identify the best practices and reveal the most effective treatment strategies. These results could be disseminated to all other clinics in order to improve disease outcomes. Routine patient monitoring in actual clinical care reveals inequality in patients’ disease activity and health status between countries (8), and provides insight into clinical cost-effectiveness of treatment strategies (9).

Patient monitoring stems from the basics of medicine: the primary goal of measuring is to optimise clinical decisions that maintain the patient in as good health as possible with minimal side effects from the therapies.

**How to measure?**

Patient monitoring as an order from an outsider – with financial or other benefits – will die as soon as the benefit loses its value. Patient monitoring for a specified project will continue as long as the project requires – after that, measuring becomes forgotten. Possibly the only approach to perform long term patient monitoring consistently is to build it into the infrastructure of the clinic, as an automatic procedure that is not affected by mood, doubts, trends or projects. Monitoring as part of infrastructure provides data for decision-making in clinical care for anyone who wishes to use it, and also accumulates big data that can be mined for many purposes over time.

**Information technology (IT) in patient monitoring**

In a Finnish story, in the beginning, there was swamp, a hoe, and Jussi. In patient monitoring in rheumatology, in the beginning, there was paper, a pencil and Pincus (10). Very few highly dedicated rheumatologists were able to arrange for the required machinery for patient monitoring before large scale use of IT. In fact, prior to IT, patient monitoring was beyond capacity of regular clinical rheumatologists. User-friendly IT solutions are a major advance for successful patient monitoring.

**Go: GoTreatIT!**

We describe below how patient monitoring is organised in a single clinic as part of a practical clinic model [text adapted from Vare et al. (11)].

**Vision**

The vision of the clinical model is based on “a Finnish treat-to-target” manifest from the 1970’s “We are treating not only the actual inflammation of the joints but also the quality of the patient’s life for many decades in the future” (12). In this model, treatment target is early and aims for early and permanent remission. The model aims at an informed patient and an informed health professional so that treatment decisions would not be based on the beliefs of the patient or the doctor.

**Setting**

Jyväskylä Central Hospital is Finland’s biggest non-university hospital, covering the secondary level health care for 250,000 inhabitants. The rheumatology clinic model has its roots in the development of rheumatology care and its scientific reporting, which started many decades ago (13). The goal was to enhance the patient ‘journey’ through rheumatology services by providing all necessary education, treatment and care, avoiding unnecessary visits and optimising the overall quality of care provided.

**Pre-clinic investigations**

Patients are usually first seen by their primary care physician, who initiates the referral to rheumatology. All incoming referrals are screened by a senior rheu-
matologist. The majority are usually accepted for review with additional laboratory investigations and radiographs, including MRIs organised prior to the review. The screening of referrals aims to reduce unnecessary visits to rheumatology 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 delay.

**Patient monitoring**

An electronic monitoring tool for continuing treatment-data collection via software, GoTreatIT, has been integrated into the every-day clinical work since 2007. The programme was developed by rheumatologists in collaboration with a Norwegian company DiaGraphIT and is used to support the systematic collection of data at every visit and during the entire course of the patient’s illness (14).

Upon arrival at the clinic at every visit, the patient signs in to GoTreatIT with his/her unique identification number, to complete a questionnaire, before seeing the nurse or the doctor. The questionnaire consists of questions aimed at identifying the patient’s current performance status, quality of life, level of pain, fatigue, disease activity, and any other relevant issues. Several touch screen stations and tablets are reserved for patient self-report, to ensure availability of devices at the arrival of the patient. Questions appear on the screen one by one, with large font, to aid the elderly patient population. The number of questions varies between 20 and 120. The set of questions is pre-defined, depending on the diagnosis and patient’s capacities. For example, a young person with axial and peripheral symptoms completes a maximal number of questions and an elderly person with memory problems, completes a short one.

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. In the same way, the doctor can easily compare current joint status to that of previous visits. Entering the data to the system is simple and takes less than half a minute.

In addition to the patient’s self-assessment and doctor’s observation, socio-demographic data, diagnostic tests, comorbidities, joint surgeries and permanent joint damage are incorporated into GoTreatIT. Any changes in the type and dose of medications during the course of the disease and reasons for that including any adverse events are indicated in GoTreatIT, allowing the doctor to see the complete history of medications used at a glance.

Using the questionnaire completed by patient, current laboratory values and

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**Fig. 2.** Graphic presentation of patient data in GoTreatIT.
joint status completed by doctor, the programme then generates commonly used comparable values such as Health Assessment Questionnaire (HAQ), 28-joint count Disease Activity Score (DAS28) and Bath Ankylosing Spondylitis Functional Index (BASFI) for every visit.

**Doctor review**

The doctor review is conducted over 30 to 60 minutes. 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 if needed. Blood pressure, lipid profile, and vitamin D-levels are screened and recorded on a routine basis with follow-up instructions as necessary. Every doctor’s visit should be meaningful with long-haul treatment decisions; “see you back in three months” without an appropriate assessment and management plan is practically forbidden. Structured treatment paths have been built for early diseases with the goal of remission and scheduled patient education, which limits “random” visits to the clinic. Patients with stable systemic rheumatic diseases are seen by rheumatologists once a year. The pre-specified structure of the clinic and a strong input from the rheumatology nurse allows the rheumatologist to devote up to 60 minutes for a patient, which, in the long term may be more meaningful than 5 x 12 minutes over years.

**Nurse review**

The nurse provides detailed education on any new diagnoses given to the patient and treatments started. The goal of patient education is an informed patient, which is achieved through a motivational interview. The patient should understand the natural course of disease, and remission as the treatment target. Patient education facilitates patient’s adherence to the therapy.

**Review of data**

The electronic monitoring system enables a quick review of the individual patient’s history of presentation, medication used, examination findings, comorbidities, values of patient self-report, disease activity measures and any other patient or disease-related details in a table or a graph for individual patients (Fig. 1-2). Responses for patient self-report can also be reviewed one by one and compared to the previous responses. Patient self-report is simultaneously made available to the doctor or the nurse or other health professional while the patient is working on it, and can be reviewed and compared to values of previous visits before patient enters to...
Remote patient monitoring with GoTreatIT

In patients who are in stable remission, remote monitoring is a potential option. At certain intervals such as every half a year, reminder via text message or an e-mail to complete the GoTreatIT self-report and laboratory tests is sent to the patient. Results will be reviewed by the rheumatology nurse or the rheumatologist, comparing the patient’s previous values with remarks made in the electronic medical record, which the patient can review online. If disease activity is increased or other problems are identified, remote monitoring will lead to a telephone contact and/or patient visit to the clinic as judged appropriate.

Discussion

We have practiced the specific clinical model for 20 years with electronic patient monitoring using GoTreatIT already for a decade. The success of the clinical model may lie in the fact that it has been built with the ‘KISS’ principle: Keep It Simple Stupid (17). The work load for the rheumatologist is thus kept to a minimum. A principle for medications used in RA, “Strategy more important than the agent” (18), may also apply here. Indeed, the clinical model and strategy may be more important than patient monitoring itself. Patient monitoring per se is of limited value while patient monitoring as part of the infrastructure of the clinic, to maintain the patient’s quality of life for decades in the future (12), is beneficial in many ways.

Reference