Better together

Inflammatory Arthritis

santeon

October 2021

Santeon is a group of seven top-class clinical hospitals in the Netherlands. Together, we are committed to improving care in our hospitals and throughout the Netherlands by looking at each other's work, learning from each other and pursuing continuous improvement.

Santeon Utrecht, www.santeon.nl
Canisius Wilhelmina Hospital Nijmegen • Catharina Hospital Eindhoven
Maasstad Hospital Rotterdam • Martini Hospital Groningen
Medisch Spectrum Twente Enschede • OLVG Amsterdam
St. Antonius Hospital Utrecht/Nieuwegein

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In this publication, we will refer to three Santeon hospitals throughout: Maasstad Hospital, Medisch Spectrum Twente and St. Antonius Hospital. The other Santeon hospitals do not participate in the improvement cycle, because they cooperate with a chain partner for rheumatology care (Catharina Hospital, OLVG and Canisius Wilhelmina Hospital) or because they have chosen to join at a later stage (Martini Hospital).

Summary

In the Better Together programme for Rheumatoid Arthritis (RA), a condition belonging to the umbrella disease Inflammatory Arthritis, we strive to improve rheumatology care through the Value-Based Healthcare methodology. The Santeon hospitals (Maasstad Hospital, Medisch Spectrum Twente and St. Antonius Hospital) treat over 4,500 RA patients annually. By comparing real-life outcomes and practices, the hospitals can learn from each other's challenges and successes. The basis for making these comparisons is clean and consistent record-keeping and extensive data analysis.

Within the RA improvement cycle, we measure outcomes and costs for a defined patient group every six months, namely patients over 18 years of age who have been diagnosed with RA. Since the launch of the programme in mid-2018, the hospitals have now completed six iterations of the improvement cycle. Until now, there has been no actionable information at all at the group level with regard to disease activity within daily rheumatism care, which makes the insights gained from the RA Better Together programme unique and particularly valuable. The main topics covered were:

1 Disease activity and optimising medication use

Medication plays a key part of treating rheumatism. The hospitals therefore examined the process of escalating medication for new patients, the use and possible phasing out of biologicals in chronic patients and the dispensing of repeat medication.

A comparison (including case-mix adjustment) of treatment effectiveness in new patients showed that all hospitals managed to achieve the goal (at least low disease activity) and that the outcomes between the Santeon hospitals were very similar. However, the treatment protocols (choice of medication and dosage) appeared to be different. The hospitals therefore agreed to work towards a common treatment protocol, while seeking to optimise patient comfort and costs while maintaining at least the same level of quality.

If patients do not respond well to conventional DMARDs, they are switched to a biological until disease activity is, at least, low. Using these biologicals has many side effects and they are very expensive, which is why the official guidelines recommend scaling back the medication in case of prolonged low disease activity. However, strict de-escalation schedules have not yet been established, which is why the hospitals decided to investigate reducing the use of biologicals (including biosimilars), while focusing on optimising the care given to the patient.

This study focuses mainly on developing a joint phasing-out protocol. By analysing the current phasing-out schedules and the incidence of flares, the first steps towards developing such a protocol have now been taken. The next step is an extensive study to develop a predictive model that can be used to determine the optimal phasing-out schedule based on patient characteristics and disease progression parameters.

Both data and patient feedback showed that the hospitals could improve the process surrounding repeat medication. The goal is to make the process more pleasant for patients while gaining more insight into individual medication use at the same time.

2 PROMs for personalised care and Deciding Shared decision-making

One of the principles of Value-Based Health Care is that it revolves around the healthcare outcomes that are most important to the patient. That is why patients are also part of the improvement team and why they are involved in drawing up the scorecard. PROMs also play a major role. The PROMs are used to provide insight into patient outcomes and address the following five topics: pain, fatigue, activity limitation, general health, and ability to do (domestic) work and productivity. The PROMs are used during consultations to help focus on the topics that really matter to the patient, and because they give patients tools to help decide on their own care pathway. An important step that the hospitals are working on is increasing the PROMs response rates e.g. by sending automatic reminders and explaining why they matter. Improving the use of PROMs in the hospital is an important focus point.

3 Digitising care in the hospital and at home

Hospitals have long been working on digitising healthcare, and COVID-19 has only made the urgency of digitising healthcare more apparent. The number of physical consultations decreased rapidly from March 2020, while the number of remote consultations skyrocketed. An extensive evaluation among patients and healthcare providers has shown that there is support for the continuation of digital consultations in the future. However, this will always require a bespoke approach, as digital appointments are not appropriate for every patient and for every consultation. For RA patients who are in remission, (additional) digital care at home can have significant added value.

The acceleration of digitisation underlines the urgent need for an outcome measure that can be remotely monitored, replacing or complementing the DAS28 assessments that are now performed physically. With the transition to digital care, there were significantly fewer DAS28 assessments in hospitals, thus clouding the view of the course of the disease. The hospitals are therefore exploring their options for assessing DAS28 remotely, while also working on ways to structurally and periodically assess DAS28 scores during physical consultations. Remote solutions currently being explored include PROs, which allow patients to measure disease activity themselves, as well as PROMs as an indication of disease activity.

In addition to the guidance provided by the rheumatologist, rheumatism patients are also supported by rheumatology nurses. These nurses are responsible for collecting DAS28 scores, providing information on medication, helping to monitor disease activity and discussing other facets of PRO. Given the importance of this guidance, the Santeon hospitals have jointly agreed that every patient must be seen by a rheumatology nurse at least once a year. Unfortunately, due to COVID-19, the number of consultations with the rheumatology nurse has decreased, but active efforts are currently underway to bring this number back up.

4 Future perspectives

For the Santeon hospitals, the move towards personalised healthcare is a major development in rheumatism care. Part of this development revolves around the practical and logistical aspects of care, e.g. who do we see in the outpatient clinic and when do they come, and when do we opt for a digital appointment? Personalised care also means tailoring the treatment of each individual patient towards the care outcomes that matter most to them and that are best suited to their specific situation and wishes. The use of PROMs in the hospital and the living room, encouraging shared decision-making and the development of personalised protocols based on predictive models are giving healthcare providers more and more opportunities to do just this.

Taking steps towards a fully personalised care pathway requires broad cooperation, both in the Netherlands and abroad. Santeon hopes to contribute to closer cooperation in healthcare through its Together Better model in general, and with this publication in particular. This will give us the strength to tackle the challenges ahead more effectively.

We hope to inspire other hospitals with our approach

“The improvement programme has engendered a lot of positive energy. The Santeon project marks the first time that we have gained insight into the data on outcomes, medication and care processes of our own patients on this scale. We can now effectively compare our hospitals and understand variations within individual hospitals.
The process of making the results transparent and discussing them openly with each other may seem simple, but it is certainly not.

The most important lessons we have learned are:

- It starts with good record-keeping. Without using exactly the same definitions and completely cleaned data, the results cannot be interpreted correctly. For example, it did not take us long to find that our data included patients who had wrongly been listed as rheumatoid arthritis patients in the DBC system. We now use a common dataset with cleaned data at patient level. This makes the data even more comparable and allows us to perform more extensive analyses, including case-mix corrections.
- Focus on the most relevant indicators. It is not feasible to collect, analyse and discuss all parameters. The trick is to measure only what matters. The patient is a good source of information on what is important. What outcomes are most important to them? You could also take a hypothesis-driven approach. Where do you expect to find the most variation? Or which improvements have the greatest potential impact on quality of care or healthcare costs?
- Support is necessary. Support is essential for all data challenges and for organising all necessary practical matters. Our data analysts and project managers make thorough preparations down to the last detail, so that we, healthcare professionals, can cut right to the core during our improvement meetings.
- Take a multidisciplinary approach. Involving people other than medical specialists in discussions about quality of care is a great way to enrich them. Rheumatology nurses, pharmacists, radiologists and patients can provide insights that we would otherwise have missed.

I hope that our approach and results will inspire other hospitals, both in the Netherlands and abroad, to adopt a similar structural and data-driven approach to their practices and outcomes. Because that is, ultimately, the goal: improving healthcare, the care we provide together as individual doctors, departments, Santeon hospitals. We will continue along this path with undiminished enthusiasm, because there is always room for improvement.”

Angelique Weel-Koenders
Medical lead of the Inflammatory Arthritis improvement programme rheumatologist at Maasstad Hospital and Professor at Erasmus University (ESHPM)

“The mission of our hospital is to improve the quality of life of our patients. The Better Together programme plays a distinct role in this pursuit, as involving patients in improvement processes and taking a multidisciplinary approach have added real value. Because the programme addresses both aspects of VBHC (adding value for patients and cutting costs), it also helps us tackle the major budgetary challenge our hospital is currently facing. I have seen both healthcare outcomes and costs improved. The programme has had terrific results!”

Peter Langenbach, Chairman of the Board of Maasstad Hospital

Chapter 1

Improvement methodology

Santeon strives to provide the highest possible quality of care and lead the way in how Dutch hospital care is organised. To achieve this, we are pursuing five ambitions:

1 Patients are actively involved in choosing their treatment
2 Professionals work closely together, develop and improve
3 We join forces with others for research and innovation
4 Quality of care is transparent to patients
5 Healthcare remains affordable and accessible

The Better Together programmes are an important part of our approach. In these programmes, we take a closer look at specific conditions and openly discuss practices and outcomes, so that we can learn from each other’s challenges and successes. We then share our insights with the rest of the healthcare field to give other healthcare professionals the opportunity to learn from our experiences.

In the short term, we are improving outcomes and aiming to reduce costs. In the long run, we are bringing about a culture change. We are working to create an environment in which healthcare providers openly share results and have the opportunity to learn from each other, and an environment in which patients and healthcare providers decide together - based on outcomes - which treatment is best for the patient.

Starting from Value-Based Healthcare

The Santeon Better Together programmes are based on the principles of Value-Based Healthcare, which revolves around maximising patient care outcomes and then designing this care as efficiently as possible. Questions to be asked include: ‘Is there a way to make this procedure or treatment less taxing? Which surgical technique or medication is least likely to cause complications? And, does this treatment contribute to the patient’s quality of life? We do not look solely at medical outcomes and costs, but also consider factors that matter to our patients, creating an efficiently organised care process that delivers the best possible results and is fully tailored to patients’ needs.

Data and transparency at the fore

Transparency is the driving force behind our approach to improve our care. We make the results of treatments transparent and compare our practices with each other by using data and objective indicators. We use data as a mirror to find differences and formulate hypotheses about how we can do better. It helps direct our search for ways to explain differences between us, creating a continuous learning experience, in which we improve our care by harnessing data and transparency.

“Comparing data starts with clean record-keeping, and we have already managed to make major headway together.”

Marjan Ghiti Moghadam, rheumatologist at Medisch Spectrum Twente

We use real-life data to provide insight into the outcomes of care, so the conclusions we draw relate to daily practice and can therefore also be used for predictive models tailored tothis group of patients. In this respect, the methodology used by the Santeon hospitals differs from, for example,

scientific studies, which often examine a specific patient group with relatively few comorbidities.

Multidisciplinary improvement teams and six-month cycles

We work with six-month improvement cycles and multidisciplinary improvement teams consisting of medical specialists, nurses, data analysts, project leads, other healthcare professionals and patients. Every improvement cycle consists of three steps (see Figure 1):

1 Collecting data and finding differences
2 Analysing differences
3 Implementing improvements

Prior to the first cycle, the improvement teams draw up a scorecard together, which consists of a set of indicators relevant to the patient for which data is retrieved during the cycles, after which the results are compared. A scorecard consists of three components:

- **Clinical outcomes** - e.g. disease activity
- **Costs** - e.g. use of medication
- **Processes** - e.g. number of DAS28 measurements per year

Using a scorecard ensures data continuity, provides insight into how indicators evolve over time, and makes it easier to share information across Santeon more widely and efficiently. For each improvement cycle, specific indicators can be selected for in-depth analysis.

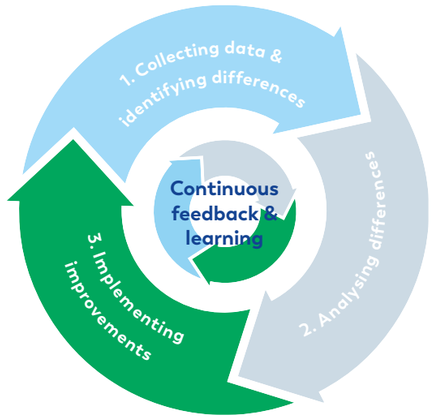
Joint meeting to coordinate improvement initiatives

Every six months, the improvement cycle ends with a meeting with representatives from the Santeon hospitals, usually medical specialists, data analysts and project leads. In this meeting, they discuss the analyses and insights and scrutinise the differences between them. In order to interpret observed variations in a structured and careful way, they go through four steps (see Figure 2). The result of these sessions is a shared understanding of the next steps to be taken and improvement initiatives to be implemented.

During these meetings, topics other than the indicators on the scorecard are also discussed. This includes current issues or innovative ideas about healthcare itself, but also ideas about the organisation of data and care systems, such as data cleansing. In-depth analyses and bottlenecks in the implementation of improvements are also discussed. Anchoring is always a key concern in these sessions. How do we ensure that the improvement methodology is implemented more widely in hospitals?

Figure 1

Improvement cycle



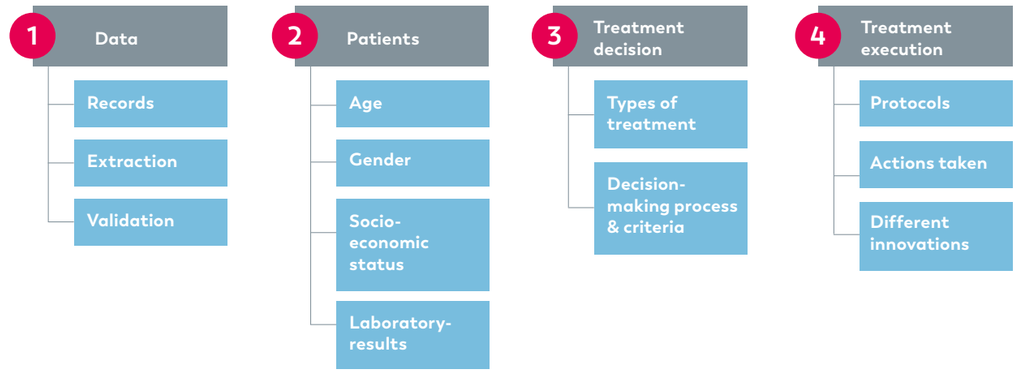
In the following chapters, we will elaborate on the scorecard, patient selection, specific analyses, insights and improvement initiatives. A glossary is attached in Appendix 1 describing some specific terms relating to rheumatism.

"We also involve our patients in the improvement process as much as possible. For example, a number of patients are members of our local improvement team and we set up focus groups for specific topics to poll their thoughts."

Annemiek Kwast, project lead at Medisch Spectrum Twente

Figure 2

What are the possible causes of the variation?



For a list of participants in the improvement teams for the Better Together Rheumatoid Arthritis programme, please turn to the Annex on page 57.

"PROMS provide insight to patients even before the consultation, while they fill out the questionnaires. They also serve as a good springboard for the consultation with the doctor. Visualising PROMs, which is becoming more and more common, is very effective, as it paints a clearer picture."

Clementine Ophuis,
Expert by Experience Medisch Spectrum Twente

Chapter 2

Focus of the Inflammatory Arthritis improvement cycle

Care pathway

Past improvement cycles have focused on patients with rheumatoid arthritis. For most of them, the care pathway begins with a referral from the general practitioner or another specialist because of a suspicion of rheumatism. The subsequent diagnostics usually consist of three parts: patient history, physical examination and/or imaging (supplemented by blood tests where necessary). Based on the outcome of these diagnostics, the rheumatologist diagnoses the patient and determines the disease activity, which is expressed as a DAS28 score. This score depends on the number of swollen and painful joints, as well as a score for overall health and blood values. Based on the DAS28 score, disease activity can be classified into four categories (see Figure 3).

The first six months after diagnosis, we classify the patient as 'new'. In this phase, treatment is aimed at controlling inflammation and lowering the DAS28 score (aiming for at least low disease activity <3.2). Initially, conventional DMARDs are used for this purpose, often in combination with steroids. Information provided by the treating physician and rheumatology nurse about the condition and discussing the various treatment options (including the advantages and disadvantages of each option) are also important parts of the process and contribute to the guidance given. The main aim is to help patients cope with the disease effectively and to help them prepare for treatment.

After six months, we classify the patient as 'chronic'. From then on, the aim of treatment is to strike an optimum balance between a stable low level of disease activity and the greatest level of comfort, e.g. giving as little medication as possible to minimise side effects, and if the DAS28-score allows, even phasing out medication. Medication, education and guidance by a rheumatology nurse remain part of the treatment.

Figure 3

Disease activity classified into four categories

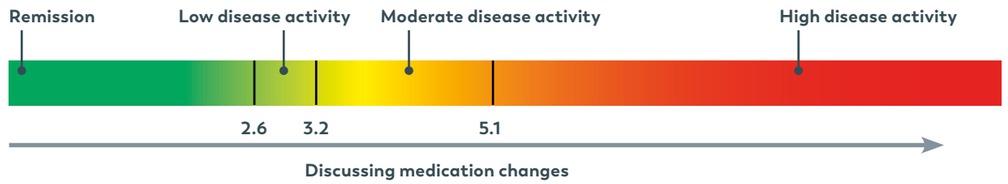


Figure 4 shows a diagram of the described care pathway. The colours for new patients (blue) and chronic patients (yellow-green) return in the various figures in the rest of this publication.

"Although the guidelines are not clear on this, we now only perform scans if there is a reason to do so. As we hardly see any damage nowadays due to improved treatment methods, we think this is justified."

Angelique Weel-Koenders, rheumatologist at theMaasstad Hospital

Patient selection

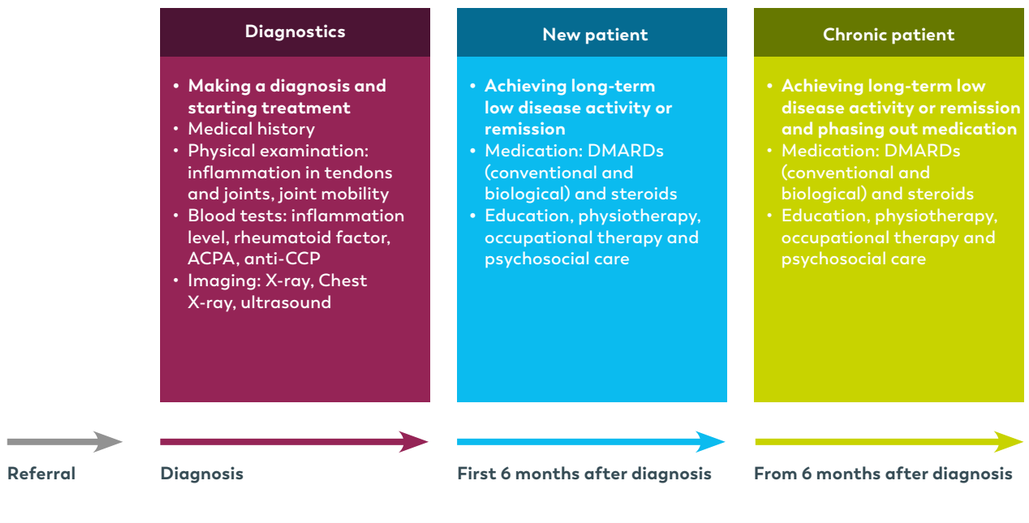
In the improvement programme, we focus on all patients aged 18 and over who have been diagnosed with rheumatoid arthritis and are being treated by a rheumatologist. As described in the previous section, we make a distinction between new patients (first six months after diagnosis) and chronic patients (after six months of treatment) in our analyses.

For the selected patient group (see Figure 5), we also collect - in addition to the various indicators on the scorecard (see the last section of this chapter) - a set of case-mix variables, including demographic features such as age, gender, BMI, socioeconomic status and smoking behaviour, as well as characteristics of the disease course, e.g. comorbidity, time since diagnosis and immunological status.

The periods used in our data analyses span a year. For chronic patients, they correspond to calendar years (2018, 2019 and 2020 for most analyses). For new patients, the periods run from 1 July to 30 June of the following year. In the analyses, we call these periods H2 2017 - H1 2018, H2 2018 - H1 2019, etc.

Figure 4

Care pathway diagram



"Data give us lots of insight, both across the group and in individual hospitals. We now have a better handle on our own data, and therefore on our own patients and our own care process."

Anna Jamnitski, rheumatologist at St. Antonius Hospital

Figure 5

Definition of patient group

Inclusion criteria	All patients diagnosed with Inflammatory Arthritis (Rheumatoid Arthritis) who are undergoing treatment by a rheumatologist. This does not include patients with psoriatic Arthritis (PsA) or spondyloarthritis. Definition: Patients diagnosed with RA by the rheumatologist.
Exclusion criteria	Patients < 18 years

Key figures

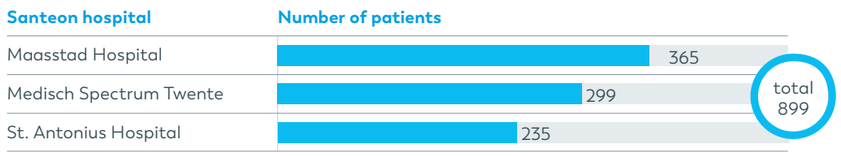
In the Santeon hospitals, data were collected during six cycles and outcomes were made transparent. Figures 6 and 7 show the characteristics of the population. From July 2017 through June 2020, nearly900 new RA patients were added. In 2020, the chronic group consisted of over 4,500 patients.

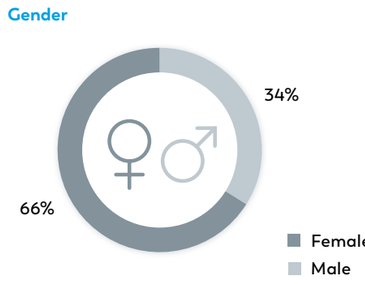
As expected, more women are diagnosed with RA than men, which is consistent with international literature. Naturally, new RA patients seen in Santeon hospitals are, on average, younger than the chronic group, with 32% of new patients being younger than 50 years. For chronic patients, socioeconomic status, estimated from the patient's postcode, is more often above average in the St. Antonius Hospital (58%) than in Maasstad Hospital (29%) and in Medisch Spectrum Twente (10%). A similar picture emerges for new patients. Looking at time since diagnosis, we can see that 31% have been under treatment for at least ten years (see Figure 7).

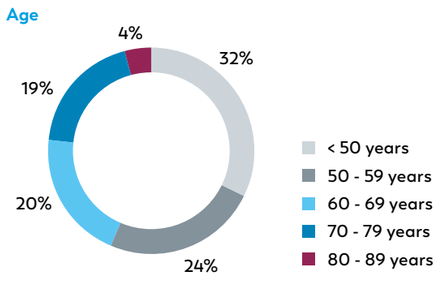
Figure 6

Characteristics of new patients

H2 2017 through H1 2020







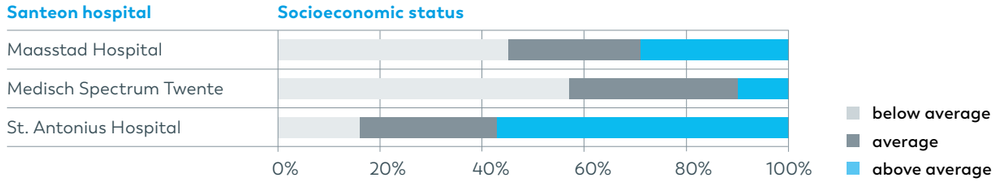
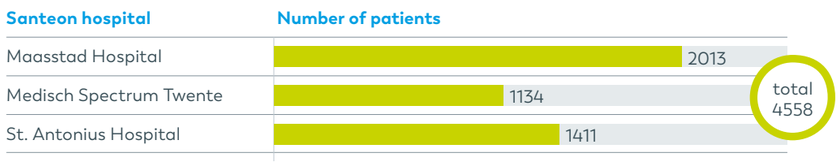
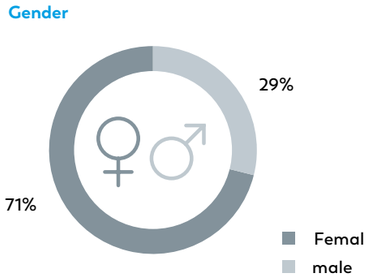


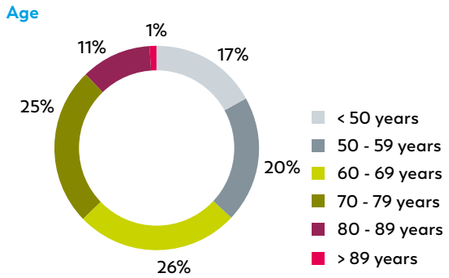
Figure 7

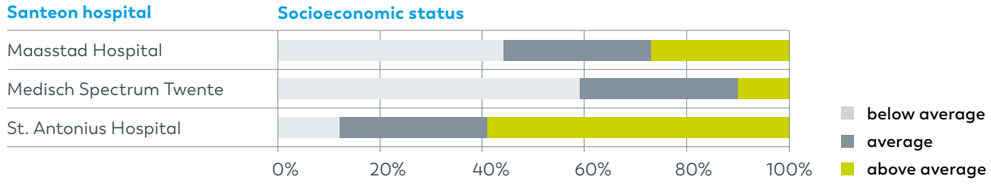
Characteristics of chronic patients

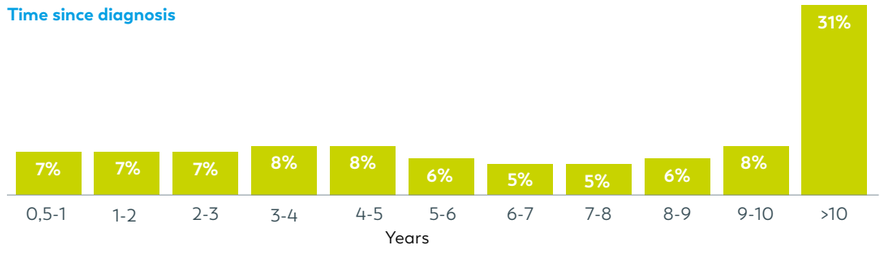
2020











Scorecard

Figure 8 shows the indicators used in the improvement cycles, most of which applied to both new and chronic patients. Two process indicators were only examined for new patients, as they are irrelevant for chronic patients.

Several indicators were mainly analysed in the first few cycles and were not collected in the later cycles, because no improvement potential was seen after in-depth consideration. This specifically concerns: adverse events, number of days from referral to first consultation and number of days from first consultation to start of treatment. This created room for in-depth analyses on other themes, such as disease activity and medication use. Some data could not be retrieved automatically in all hospitals, which made it more difficult to shed light on differences between hospitals. Where possible, the scorecard was harmonised with existing indicator sets, in particular those of the International Consortium for Health Outcomes Measurement (ICHOM), ensuring that the indicator definitions match those used in international standards and enabling the international comparison of outcomes in the future.

"Before we started collaborating with other Santeon hospitals, we thought we were doing so well that there would be little room for improvement. After taking a deep dive together, though, it turned out that there were still wins out there for all of us."

Marjan Ghiti Moghadam, rheumatologist at Medisch Spectrum Twente

Figure 8

Rheumatoid Arthritis Scorecard

OUTCOME	Patients in remission or with low disease activity
	Disease activity per patient
	Percentage of patients experiencing adverse events
	Pain*
	Fatigue*
	Activity limitation*
	Impact on overall health*
	Ability to do (domestic) work and productivity*
COSTS	Use of DMARDs (conventional and biological)
	Number of outpatient consultations per patient per year
	Diagnostic activities per patient per year
PROCES	Number of days from referral by GP to first consultation with rheumatologist **
	Number of days from first consultation with rheumatologist to start of treatment **
	Percentage of patients who had an appointment with a clinical nurse specialist or a rheumatology nurse
	Number of DAS measurements per patient per year

** Obtained from PROMs.* *** Only collected for new patients.*

Chapter 3

Insights and improvement initiatives

The main insights and improvement initiatives that emerged in recent improvement cycles can be classified into three themes:

1 Disease activity and medication use
2 PROMs for personalised care and Shared decision-making
3 Digitising care in the hospital and at home

In this chapter, we will explore each of these themes in greater detail and illustrate the insights with data and analyses.

1 Disease activity and medication use

Patient-friendly treatment protocol for new patients

The first six months after diagnosis are dedicated to reducing disease activity. The international guideline sets the goal of reducing disease activity in new patients to a level below at least 3.2, or low disease activity, within the first six months.

Figure 9 and 10 show the mean DAS28 score at diagnosis and six months after diagnosis, both unadjusted and adjusted for age, gender, rheumatoid factor, anti-CCP and socioeconomic status. This case-mix adjustment was performed using a generalised least squares linear model. The adjusted DAS28 scores in the figure are to be interpreted as the estimated mean DAS28 score for a 60-year-old male, of average socioeconomic status and with a negative rheumatoid factor and anti-CCP. All RA patients who had at least one registered DAS28 measurement at baseline and 6 months later between 2016 and 2019, and for whom rheumatoid factor and anti-CCP were known were selected for the case-mix adjustment.

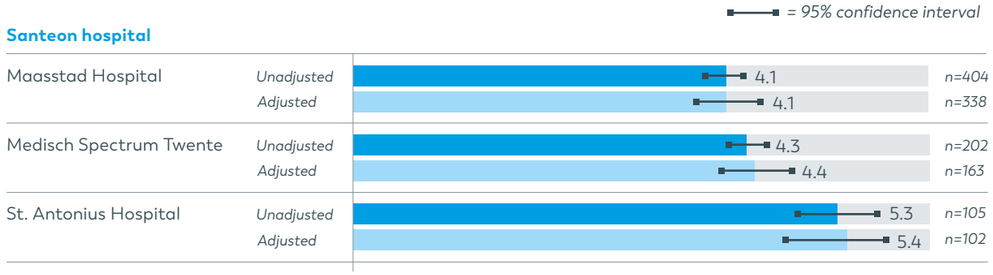
The corrected DAS28 scores six months after diagnosis show that after the first six months of treatment, hospitals averaged a DAS28 score between 2.0 and 2.5, or remission. This means that the majority of patients comply with the aforementioned international guideline, which aims to reduce disease activity in the first six months to a level below at least 3.2. Furthermore, from the adjusted DAS28 scores six months after diagnosis, we can conclude that the results across Santeon hospitals are very similar. On the face of it, the Medisch Spectrum Twente achieves a slightly lower mean DAS28 score than the other two hospitals, but if we consider the 95% confidence interval, the differences seem small. Two important caveats in interpreting mean DAS28 scores are that hospitals measure the DAS28 scores of of worse-off patients more often, in order to gain more accurate and more frequent insight into the course of the disease and that DAS28 scores are also influenced by factors such as compliance, pharmacogenetics and comorbidity. Finally, it is striking that St. Antonius Hospital has a higher DAS28 score at the start. This has been investigated, but no clear reason has been found.

Figures 11 and 12 show the percentage of patients who had lowdisease activity or were in remission.

Figure 9

Mean DAS28 score at diagnosis - new patients

2016 to 2019

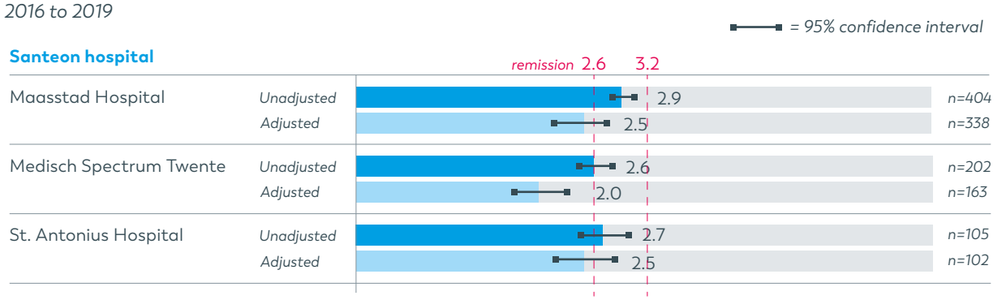


Adjusted for age, gender, rheumatoid factor, anti-CCP and SES.

Figure 10

Mean DAS28 score 6 months after diagnosis - new patients

2016 to 2019



Adjusted for age, gender, rheumatoid factor, anti-CCP and SES.

Figure 11

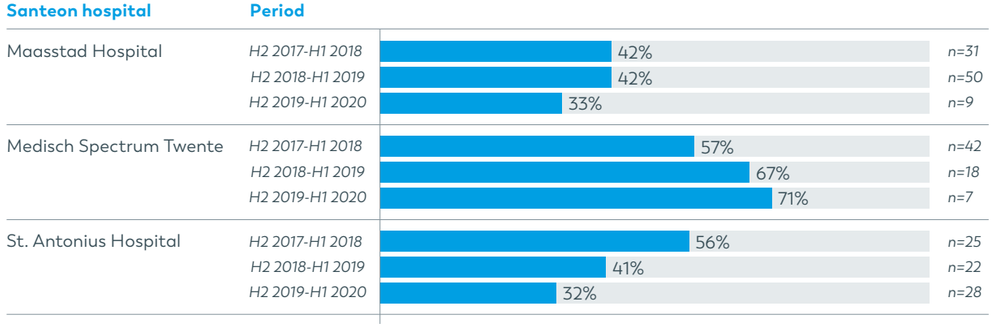
% New patients with low disease activity 6 months after diagnosis

H2 2017 through H1 2020

Figure 12

% New patients in remission 6 months after diagnosis

H2 2017 through H1 2020



As can be seen in Figure 11, the recommendations of the international guidelines, which stipulate that disease activity should be brought to a level below at least 3.2, or low disease activity, within 6 months, are achieved in the majority of patients. In some new patients, disease activity is even brought to a level below 2.6, or remission, in the first 6 months (see Figure 12). Two important caveats for interpreting the data are that the results in the final cycle are less reliable, as fewer DAS28 scores were measured as a result of COVID-19, and that the results were not adjusted for differences in core demographic characteristics and core disease characteristics, which we have previously seen differ between hospitals.

Goal: joint treatment protocol

For the treatment of new patients with rheumatoid arthritis, the Santeon hospitals follow European and Dutch guidelines. However, these guidelines leave some latency, e.g. with regard to medication, dose and method of administration. As as a result, the working methods used do not just differ between the three Santeon hospitals (see Figure 13), but also between different practitioners within the hospitals.

Based on the protocols and the comparable outcomes, which all fall well within the set international guidelines, the hospitals have set themselves the goal of arriving at a joint, patient-friendly treatment protocol, optimised for patient comfort and costs, among other factors, while maintaining or increasing quality of care.

Figure 13

Protocols prior to the start of treatment

Maasstad Hospital	**Start**	• MTX 15mg and escalate to 25mg within 3 months
	Bridging	• Steroids: de-escalation schedule: 15mg within 8 weeks to 0 or depomedrol 120mg intramuscular
	Continuation	• Switch to bDMARD after three months based on disease activity and prognosis • If not, add sulfazanin • At DAS28 above 2.6 bDMARD or TS
Medisch Spectrum Twente	**Start**	• MTX 20mg subcutaneous i.c.w. plaquinil (HCQ) 400mg • After 1 month MTX increased to 25mg • After 2 months MTX increased to 30mg (if needed based on DAS28 score) • Optional: one-off steroids - 120mg of triamcinolone intramuscular
	Bridging	• Next step may include systemic steroids
	Continuation	• After 4 months, option to add TNF-blocker based on DAS28 score • Bridging: add steroids or sulfasalazine
St. Antonius Hospital	**Start**	• MTX 15mg and escalate to 25mg within 2 months
	Bridging	• In case of high disease activity and/or rheumatoid factor and/or anti-ccp positive: prednisone oral or IM - starting dose varies
	Continuation	• No further action if low disease activity • If DAS28 above 3.2, start HCQ and/or sulfasalazine and/or steroids

Phasing out biologicals for chronic patients

The mean disease activity of chronic patients calculated with the area under the curve (AUC) method, taking into account the time between different measurements, is shown in Figure 14. All three hospitals have a mean DAS28 score lower than 3.2, indicating that the majority of chronic patients have low disease activity. Although the averages have not been adjusted for case mix and should be interpreted with caution, the differences between hospitals are again small.

In general, rheumatologists strive to minimise medication due to the side effects and high cost of anti-rheumatic medication. This mainly involves minimising the use of so-called DMARDs. That is why the Santeon hospitals, if the patient's situation allows, also strives to taper off or even discontinue medication use at an early stage.

Figure 15 shows that in 2018, 2019 and 2020, around 20% to 30% of chronic patients in the Santeon hospitals used biologicals. As a result of this percentage, the hospitals have decided to investigate whether the use of biologicals can be cut back without jeopardising outcomes. Naturally, this mainly applies to patients with low disease activity.

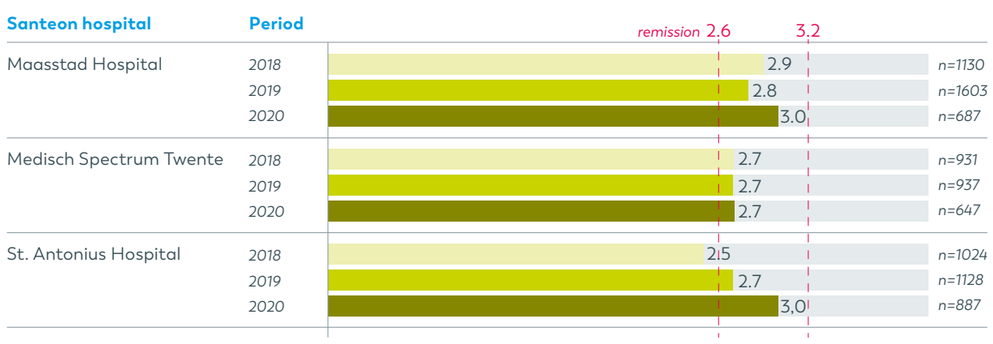
Approach to medication tapering differs across hospitals and rheumatologists

To improve their understanding of the subject, the hospitals looked at how they currently deal with phasing out biologicals in chronic patients. The results are shown in Figure 16. For this analysis, the teams examined in which part of the patients biologicals were tapered off and to what extent this was done between 2016 and 2019. A dose reduction >0% means biologicals were tapered off, either by reducing the default user frequency or by reducing the default dose, but that no information is available on the extent to which this was done compared to the standard dosage. A dose reduction of >30%, >50% and >70% indicates the degree of reduction compared to the standard dose.

Figure 14

Average DAS28 score - chronic patients

2018 to 2020



Unadjusted for differences in demographic and disease characteristics.

Figure 15

% Chronic patients using biological DMARDs

2018 to 2020

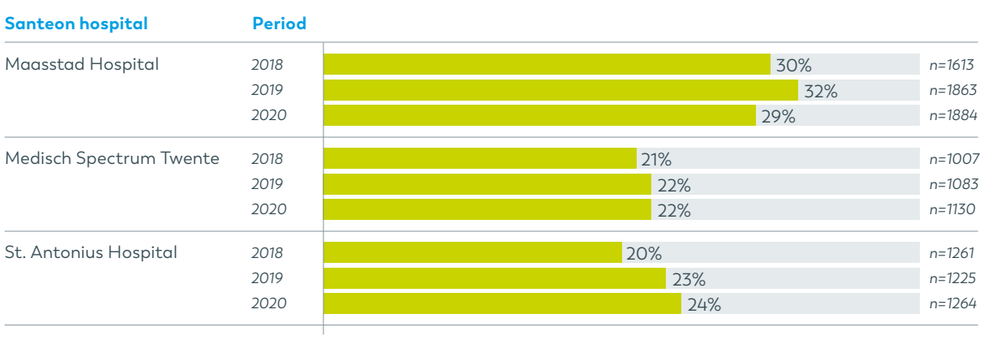
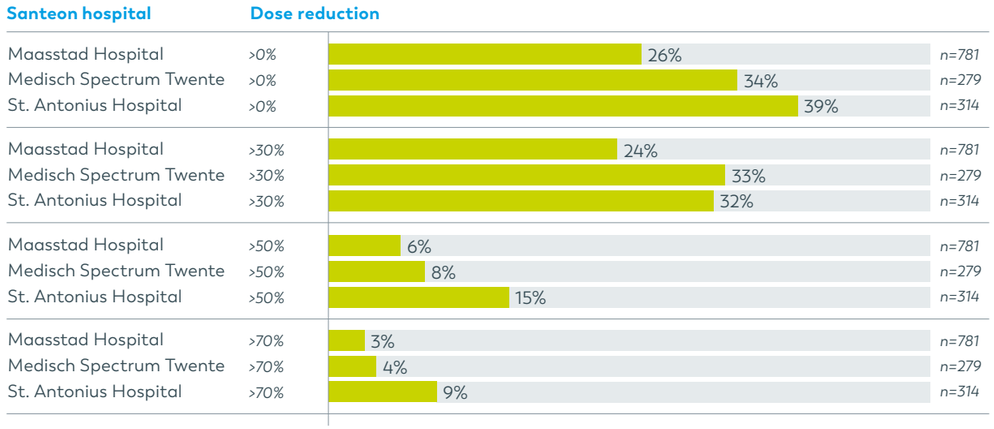


Figure 16

% Chronic patients with reduced dose compared to standard dose

2016 to 2019



Medication	Standard dosage
Abatacept	125mg once a week
Adalimumab	40mg once every 2 weeks or 20mg once a week
Etanercept	50mg once a week / 25mg twice a week
Tocilizumab	162mg once a week

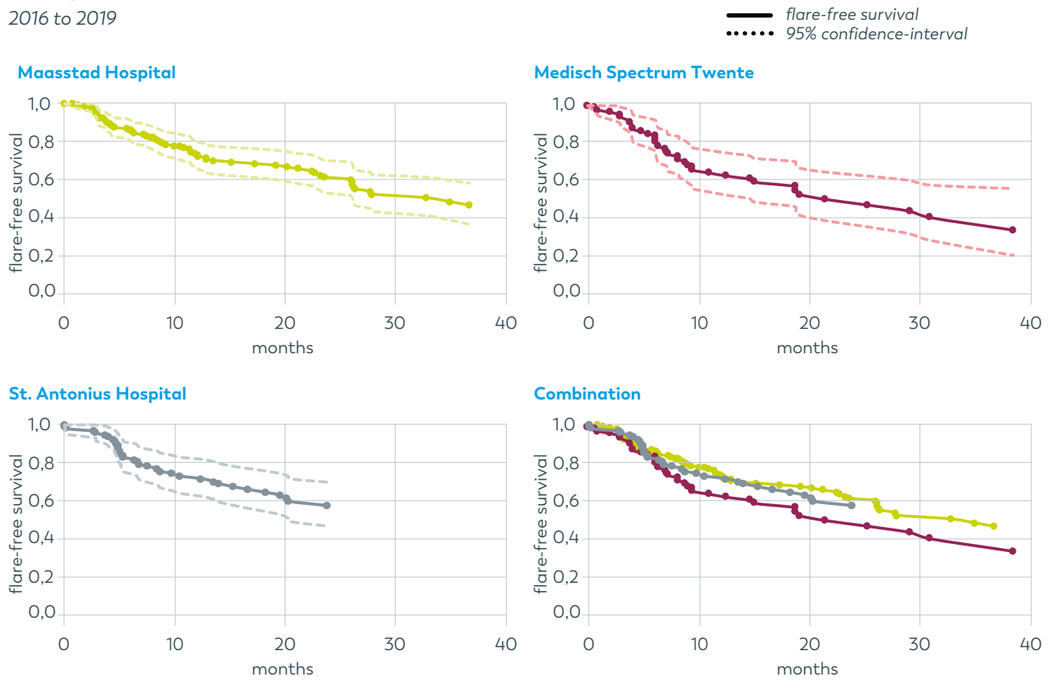
The figure shows that not all Santeon hospitals approach tapering off biologicals the same way, with the de-escalation process appearing to be more frequent and quicker in St. Antonius Hospital than in Maasstad Hospital and Medisch Spectrum Twente. The medicines included in this analysis and their standard dosages can be found in the table. This analysis only considered the subcutaneous administration of medication, i.e. injection into subcutaneous tissue.

The analysis shows that not all Santeon hospitals approach tapering biologicals the same way. From discussions with the rheumatologists and from various publications (e.g.: *"Doctors' preferences in de-escalating DMARDs in rheumatoid arthritis: a discrete choice experiment"; Arthritis Research & Therapy; (2017) 19:78*) shows that the approach varies not only between hospitals, but also between individual rheumatologists in the same hospital. There are many possible causes for this variation, including, for example, different starting points in terms of numbers of swollen joints, a patient's history with erosive diseases, duration of remission and patient preferences. In addition, the involvement of the relevant rheumatologist in studies on the de-escalation of biologicals also seems to have been an influencing factor.

Figure 17

Kaplan-Meier curves: flare-free survival after start of tapering biologicals - chronic patients

2016 to 2019



	Flare occured in >25% of population	Flare occured in >50% of population
Maasstad Hospital	11.5 months	34.9 months
Medisch Spectrum Twente	7.3 months	25.3 months
St. Antonius Hospital	8.3 months	No data available

Goal: joint de-escalation protocol

A more fundamental cause of variation is the lack of international guidelines and standards for de-escalating biologicals in chronic patients, which is why the Santeon hospitals have agreed to work towards a joint de-escalation protocol for their own hospitals. It is critical that any such protocol leaves room for patients' wishes and characteristics. However, in order to arrive at a joint de-escalation protocol, several in-depth studies are necessary.

Link between de-escalating biologicals and disease activity

Figure 16 shows that not all Santeon hospitals approach tapering biologicals the same way. As a first step towards a joint de-escalation protocol, the Santeon hospitals have examined how often and how quickly a flare occurs in chronic patients in whom biologicals are being tapered off (Figure 17). Specifically, we examined what percentage of chronic patients who used one of the biologicals (from the table in Figure 16) between 2016 and 2019 experienced a flare at a certain point after the start of the de-escalation process The definition of flare is: a DAS28 score above 3.2. The degree of de-escalation has not been taken into account in this analysis. The results are shown in Figure 17 and in the table. This shows that there seems to be little variation between hospitals in terms of when a flare occurs, but more research is needed to draw sound conclusions.

Next steps: study started to create a predictive model

In order to lay a solid foundation for a common de-escalation protocol, the Santeon hospitals followed up on the above analysis by launching various follow-up studies to create a prospective predictive model.

One of the follow-up studies is a repeat of the above analysis on flares, but with a control group. Putting together a representative control group - with similar DAS28 scores without de-escalation - is a challenge. Another follow-up study focuses on the period after a flare occurs. To create an effective protocol, it is not only important whether a flare occurs, but also how quickly disease activity can be reduced and how much medication is needed.

The ultimate goal of the study is to use real-life outcomes from the past few years to develop a model that, based on patient characteristics (comorbidity, smoking behaviour and BMI) and parameters of the course of the disease (disease activity, rheumatoid factor, duration of remission and previous flares), predicts the most appropriate time for de-escalation and the most appropriate de-escalation schedule. The researchers are also studying the possibility of including PROMs as an important predictive parameter, thus contributing to personalising care for rheumatism patients. The more information we can get from prediction models, the better healthcare providers will be able to assess which care is best suited to patients' specific symptom patterns.

Whereas previous studies used a randomised population, the strength of this study is that - thanks to collaboration across Santeon - the population to be studied is large enough to conduct the study using real-life data. Once the prospective model is ready, it will be validated in the second phase of the study.

The Santeon hospitals aim to produce a scientific publication in order to contribute to a convergent approach throughout the healthcare sector.

"Patients are often apprehensive when it comes to de-escalating biologicals and tend to think that cutting costs is the main motivation. However, an overall desire to taper off medication is often the actual primary reason. Nowadays, there is a lot of room for patients' own input, which has made providing information about the reason for de-escalating drugs and the process very important. Doing so inspires trust."

Clementine Ophuis, , Expert by Experience
Medisch Spectrum Twente

Improvement actions already in place

The studies and follow-up analyses described above focus on structurally improving the process of de-escalating biologicals in chronic patients. The Santeon hospitals also seek to directly implement concrete measures to encourage the de-escalation of biologicals and taper off their overall use, depending on disease activity levels. The hospitals, for example, promote active dialogue within departments, so that rheumatologists stay up-to-date with each other's thoughts on whether or not to start tapering off and to foster close discussions. In addition, the hospitals focus on providing good information to patients, to ensure that that every patient, from the start of treatment, can oversee the entire process and begin to accept that the medication will also be tapered off at a later time. This can make patients less apprehensive or reluctant and will make it easier to make the decision to de-escalate biologicals.

In St. Antonius Hospital, the care pathway for rheumatism has been integrated into Epic. The system looks at the DAS28 score and whether, based on this score, the policy chosen by rheumatologists corresponds to the general policy. If not, it displays an alert indicating the expected policy and prompting the physician to explain their reason for deviating from said policy. This encourages rheumatologists to actively consider tapering off medication, as they are asked to explicitly state their reasons for deviating from the expected policy in certain cases (see Figure 18).

"Entering a policy that deviates from the recommended policy for the DAS28 score in question automatically triggers an alert. This helps ensure that physicians always make a conscious, deliberate choice with regard to what treatment protocol to follow."

Anièla White, Epic Innovation Advisor at St. Antonius Hospital

Improving the process around repeat medication

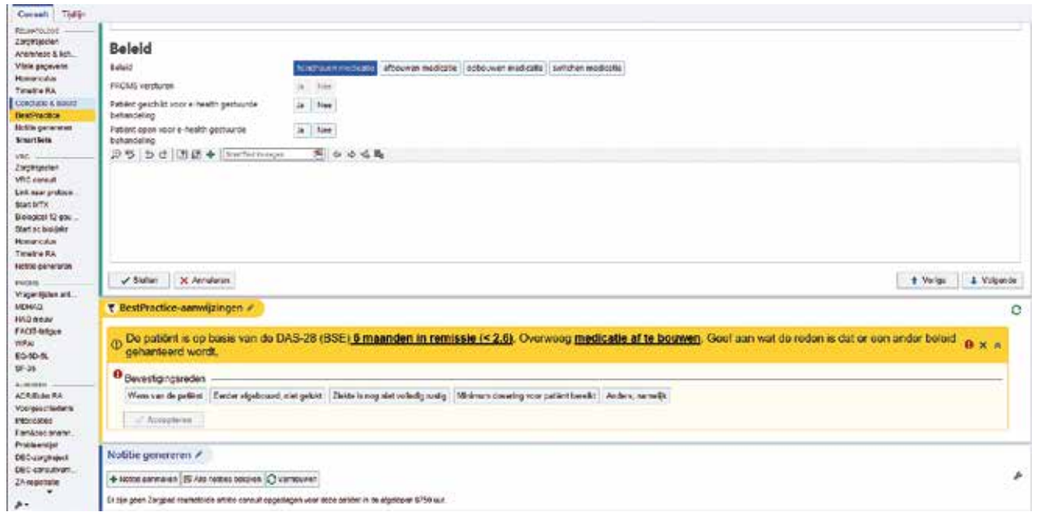
Chronic rheumatism patients are largely treated with medication, including biologicals. This type of medication is provided only by the hospital pharmacy and cannot be obtained from local pharmacies. The Santeon hospitals have looked at how they can improve the process of requesting and issuing repeat medication, making the process more comfortable for patients, reducing wastage and providing more accurate insight into the patient's current situation.

Improvement action based on patient signals

At St. Antonius Hospital, the improvement team was prompted to delve deeper into the topic of repeat medication after receiving several signals from patients. In this hospital, patients can request their repeat medication themselves via an online portal. After the rheumatologist signs off on the request digitally, the patient is notified that they

Figure 18

Example of decision support in EPIC



can pick up their medication. However, there were several instances in which the hospital pharmacy was unaware of the new order and had therefore not prepared the medication yet, forcing the patient to return a day later. A multidisciplinary team consisting of the hospital pharmacy, the rheumatology department and lean experts mapped out the entire repeat medication process, after which they eliminated process steps that did not have any added value. In the past, for example, prescriptions would be printed and sent to the hospital pharmacy, where they would be scanned and discarded. This process was not only inefficient but also entailed personal data protection risks.

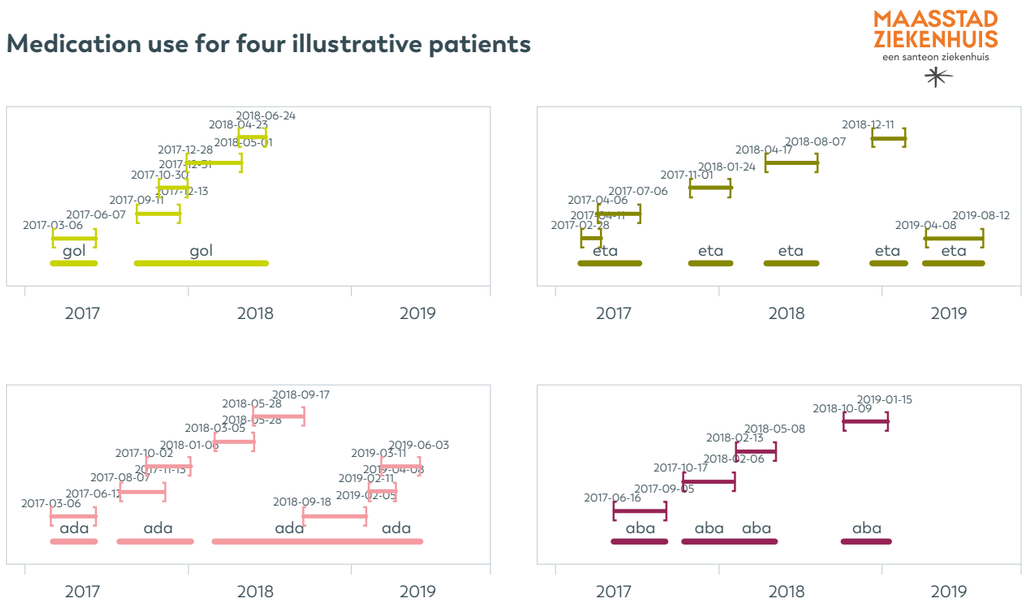
The new process is controlled by the hospital pharmacy, who can dispense up to three-month supplies of biologicals to patients and automatically notify patients when they need new medication. The patient can then choose to pick up their new prescription, and if they do not do so, the treating rheumatologist is notified so that they can contact the patient immediately.

Improvement action based on in-depth analysis

Maasstad Hospital also took a close look at repeat medication, following an in-depth analysis into the use of biologicals. The hospital mapped out when medication was dispensed to a particular set of patients, as well as how long this prescription would last. Figure 19 shows the results of this analysis for four illustrative patients. The small bars in each of the figures show the dispensed dates and the period covered by the prescription. The large bars at the bottom of each figure represent the cumulative total of the small bars. The apertures between the large bars represent periods in which the patient - if they adhered to the recommended medication schedule - did not have any medication at their disposal.

Figure 19

Medication use for four illustrative patients



The conclusion shown by the figure is that not all patients picked up their medication with the frequency you would expect, with the analysis indicating that 10% of patients on biologicals did not pick up their medication on time. There may be various reasons for this, such as temporarily discontinuing medication due to other therapy, not taking the medication on time, tapering off medication without adjusting the prescription or simply failing to pick up the medication from the pharmacy.

Together with a number of patients from the patient panel, Maasstad Hospital has devised and prioritised a number of possible solutions to improve the situation, such as linking new patients to chronic patients who have experience with biologicals to give them access to good information and answers to their questions. The hospital also improved the process of dispensing repeat medication. These solutions are currently being fleshed out and implemented by the improvement team in close cooperation with patients.

Tessa Bosch, hospital pharmacist and Clinical Pharmacologist at Maasstad Hospital, believes there are various ways to improve the use of biologicals. "An interesting option would be for us, at the outpatient pharmacy, to trigger an alert if we notice that a rheumatism patient is not taking any or less medication than actually prescribed. We sometimes find that there are gaps in the use of biologicals, which are very expensive, and that a patient may not adhere to their treatment plan, even though the rheumatologist may not have noticed this yet. Another idea would be to consistently monitor patients' medicine blood levels to see if the medication is being used and whether it is being used in the right amount." These ideas are currently being discussed and developed in the improvement team.

At Medisch Spectrum Twente, rheumatologists prescribe expensive medication until the date of the next consultation. They recognise the issues with repeat medication and copy the improvement actions and developments of St. Antonius Hospital and Maasstad Hospital.

2 PROMs for personalised care and Shared Decision-making

One of the principles of Value-Based Health Care is that it revolves around the healthcare outcomes that are most important to the patient. PROMs play a major role in personalised care. The PROMs used in this improvement cycle are based on the standard ICHOM set. PROs are collected through questionnaires, in which patients clarify how they feel with regard to the various PROM domains.

Research shows that doctors and patients do not always consider the same outcomes to be equally important (*see, for example: Studenic Arthritis Rheum. 2012; 64(9):2814-23*). While doctors typically stress disease activity (DAS28), swollen joints and lab results, patients tend to value participation, self-efficacy and sleep problems more highly. These indicators can be closely related, but this is not the case for every patient in every situation. PROMs thus provide tools to focus the dialogue between patients and healthcare providers on the patient's personal situation and the issues that really matter to them at that moment.

Using PROMs during consultations

Using PROMs to support daily rheumatology care is a relatively new field. To make optimal use of the PROMs in the dialogue between patients and healthcare providers, the Santeon hospitals have developed a joint training course to assist their employees. This accredited course explains how best to usePROMs in the doctor's office and how they can help foster shared decision-making between the doctor and patient, using accurate information.

More than 30 healthcare professionals, including rheumatologists, rheumatology nurses, clinical nurse specialists, junior doctors, doctor's assistants, general practitioners in training, RA patients, project leads and data analysts participated in the first training course. The Santeon hospitals are now working on a follow-up to this initial session. In addition, as part of the Santeon Outcome Indicators Experiment, an e-learning course has been developed on 'Conversational skills for joint decision-making and the use of care outcomes'.

"PROMs allow you to empathise more with the situation and complaints of individual patients. You can immediately focus the conversation on what they find difficult and where they need help."

Jacqueline Luttikholt, rheumatology nurse in Medisch Spectrum Twente

Visualisation tools

Visualisations can contribute to and support the effective discussion of PROMs during a consultation, as they give both patients and healthcare providers clear, immediate insight into the current situation, striking outcomes requiring attention and, possibly, historical patterns. The three Santeon hospitals each work with a system to visualise PROMs in the doctor's office. Unfortunately, it is not yet possible to adopt a uniform system, because the hospitals work with different EPRs and collect and process PROMs in different ways, e.g. because some hospitals do work with online care pathways while others do not. Of course, the hospitals do strive to make uniform recommendations with regard to PROMs.

Medisch Spectrum Twente uses a dashboard on mijnreumacentrum.nl, developed as a research database, benchmarking tool and patient portal, which combines various indications,including disease activity, PROMs and medication use (see Figure 20). Maasstad Hospital uses the Joint Decision Dashboard in the HiX EPR package, which was funded by a grant from the Healthcare Institute and provides transparent insight into PROMs outcome indicators, clinical parameters such as the DAS28 score, and lab values (see Figure 21). The dashboard also displays the patient's current medication summary. St. Antonius Hospital is working on a similar visualisation tool in the Epic electronic patient record.

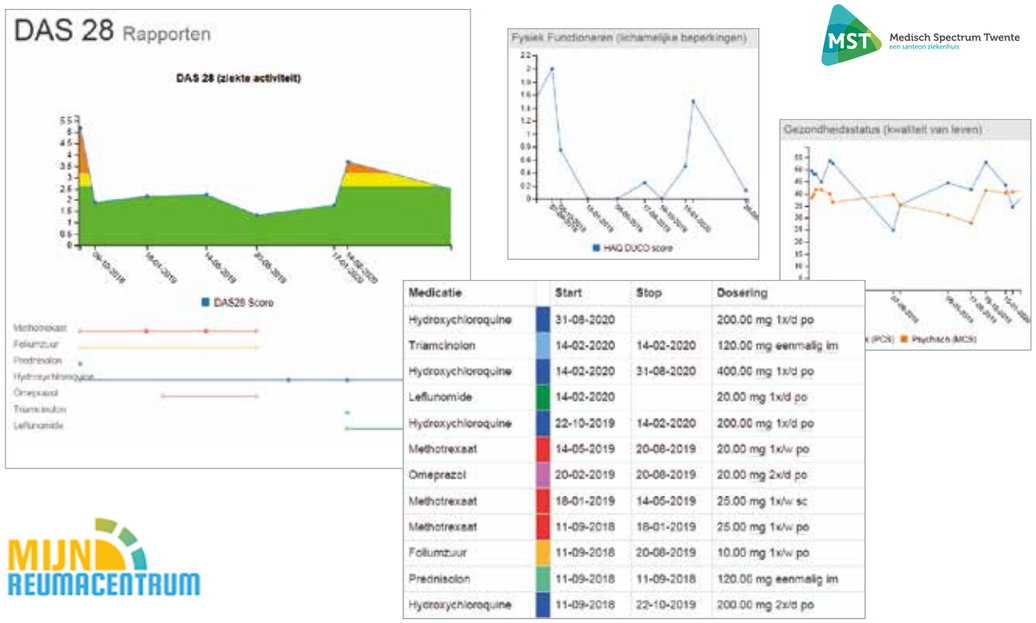
"We asked patients for feedback on our PROMs dashboards. It was very important to us to consider their input, because they have a different perspective than medical professionals. These sessions showed, for example, that they preferred simpler overviews."

Angelique Weel-Koenders, rheumatologist at Maasstad Hospital

The PROMs dashboards also enable patients to review their own disease progress over time, which can provide valuable information. Thanks to the vast quantities of data generated by the group, the dashboards may even allow patients to compare themselves with similar patients, or so-called patients like me, in the future. This will give patients a better idea of what to expect in the future and it can be reassuring to see that their situation is no exception.
Maasstad Hospital has already launched this feature. Conversations with patients have shown that not every patient values this information, which is why the hospitals are now working towards a situation in which they can further personalise dashboards based on patients' specific situation, needs and wishes.

Figure 20

Illustrative selection from Medisch Spectrum Twente's PROMs dashboard



Medicatie	Start	Stop	Dosering
Hydroxychloroquine	31-08-2020		200.00 mg 1x/d po
Triamcinolon	14-02-2020	14-02-2020	120.00 mg eenmalig im
Hydroxychloroquine	14-02-2020	31-08-2020	400.00 mg 1x/d po
Leflunomide	14-02-2020		20.00 mg 1x/d po
Hydroxychloroquine	22-10-2019	14-02-2020	200.00 mg 1x/d po
Methotrexaat	14-05-2019	20-08-2019	20.00 mg 1x/w po
Omeprazol	20-02-2019	20-08-2019	20.00 mg 2x/d po
Methotrexaat	18-01-2019	14-05-2019	25.00 mg 1x/w sc
Methotrexaat	11-09-2018	18-01-2019	25.00 mg 1x/w po
Folliumzuur	11-09-2018	20-08-2019	10.00 mg 1x/w po
Prednisolon	11-09-2018	11-09-2018	120.00 mg eenmalig im
Hydroxychloroquine	11-09-2018	22-10-2019	200.00 mg 2x/d po

Figure 21

Illustrative selection from Maasstad Hospital's PROMs dashboard

Shared decision-making

The dashboards used by the Santeon hospitals provide insight into the situation of an individual patient. These insights support shared decision-making, in which the doctor and patient discuss which treatment is best. Healthcare providers are trained in this and all three hospitals try to provide good information about the importance of shared decision-making. Maasstad, for example, has a specific page on their website for rheumatism patients about shared decision-making, including an animation that explains how shared decision-making is organised and what the benefits are. They also use the so-called rheumatism web during consultations, which serves to help determine treatment goals together with the patient and to organise the treatment plan.
Other ways in which the Santeon hospitals engage in shared decision-making include using the website rheumedicatiekeuzehulp.nl, where patients can compare different types of medication and weigh up their pros and cons. They can then print out a summary of their preferences and discuss it with their doctor. Together with a patient panel, Medisch Spectrum Twente is also working on an app that will make it possible to monitor patients remotely, while giving patients the option to schedule consultations with their doctor on their own accord.

Questionnaire selection

The Santeon hospitals use PROMs to gain more insight into the following five domains: pain, fatigue, activity limitation, general health, and ability to do (domestic) work and productivity, but not all hospitals use the same questionnaire for the same topic. There are various reasons for this, such as the link with the hospital information system, scientific collaborations and coordination with other specialisms within the same hospital. This makes it difficult to compare the results between the hospitals, but as soon as the total number of PROMs measurements in the Santeon hospitals reaches a certain critical mass, this issue can be solved with translation tables. Figure 22 shows which questionnaires the hospitals now use for each of the domains.

Challenge: increasing the response rate

The Santeon hospitals aim to receive a fully completed questionnaire from every patient on each of the five domains at least once a year. For new patients, it is best to receive all completed questionnaires after six months. In 2020, the hospitals failed to achieve this goal due to COVID-19, but all three hospitals were very actively involved nonetheless. The completed PROMs meant that, despite there being fewer DAS28 scores due

Figure 22

PROMs collected for scorecard

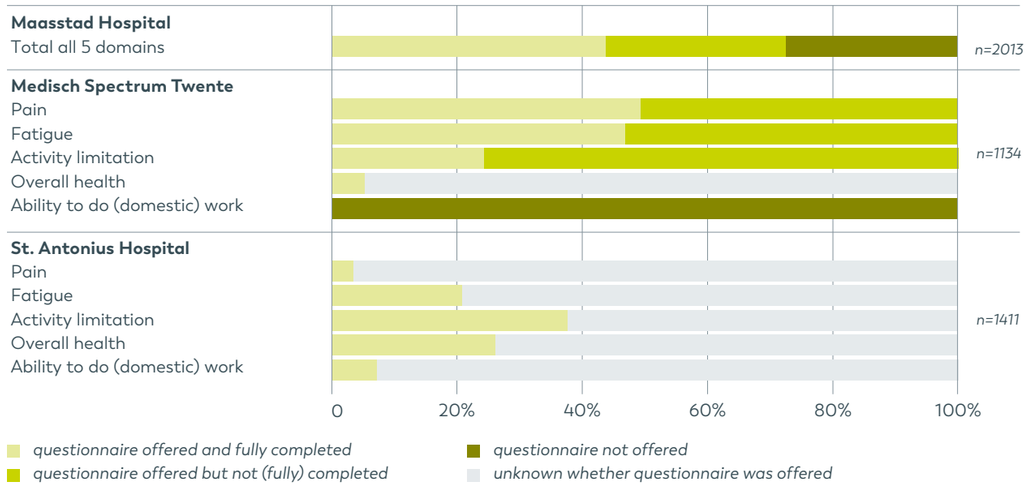
	Pain	Fatigue	Activity limitation	Overall health	Ability to do (domestic) work and productivity
Maasstad Hospital	RAID	FACIT-F	HAQ-di	EQ5D-VAS	WPAI
Medisch Spectrum Twente	VAS	VAS	HAQ-di	EQ5D-VAS	Not currently used
St. Antonius Hospital	VAS	FACIT-F	HAQ-di	EQ5D-VAS	WPAI

This concerns the set of PROMs for the scorecard. Hospitals use several questionnaires.

Figure 23

Response to PROMs - chronic patients

January through December 2020



Registration method

Maasstad Hospital	Medisch Spectrum Twente	St. Antonius Hospital
The JDS dashboard makes it possible to send patients the full set of questionnaires in one go, which is why the aggregate response rate is shown. If necessary, the response rate can be broken down by domain.	Does not actively send out questionnaires, but these are available to all patients via mijnrheumacentrum. The response rate for the general health domain was calculated based on the EQ5D-VAS, which was temporarily deployed as part of the study.	Number of completed questionnaires is available as control information. Control information on questionnaires and the availability of an active MijnAntonius account (required for digital questionnaires) is available.

to COVID restrictions, it was still possible to monitor the disease progression of patients. This unforeseen situation demonstrated clearly how great the added value of PROMs is, especially with the advent of digital healthcare. They provide the opportunity to ensure that, if physical care is scaled down for a certain period of time, whether intentionally or not, quality of care is not jeopardised. This of course applies to all conditions, but particularly to RA, as less physical care makes DAS28 scores more difficult to determine, which can jeopardise the availability of control information (see chapter 3). PROMs could partly help overcome this issue.

Figure 23 shows the PROMs response rate for chronic patients in 2020. All three hospitals now track the response rate, but they do not (yet) do this in a uniform way (see Table).

The hospitals are trying in various ways to increase the response rate to PROMs and to find the right timing, with the main objective of improving relevant use in the doctor's office. One way hospitals are attempting to do so is by reducing the time and effort it takes for patients to complete the questionnaires by making them as easy as possible to complete. All Santeon hospitals are investigating the possibility of merging PROMs for patients with various comorbidities, to ensure that they do not need answer the same question twice. In Maasstad, (extra) questionnaires are sent, for example, if the discussion with the patient reveals that more attention is needed for a domain such as fatigue. This also enables them to increasingly focus on outcome indicators that are relevant to the patient.

In the future, hospitals also expect to use computer adaptive testing (CAT) questionnaires, which adjust the follow-up question based on the answer to previous questions. This would make it possible to generate a reliable answer with far fewer questions. Especially with a chronic condition like RA, where patients basically get the same questionnaire year after year, this can increase the motivation to complete the questionnaire. The hospitals are also working on improving various processes to remind patients more often and more actively to complete the questionnaires. This starts with explaining PROMs and underlining their added value for the patient. Next, it is important that rheumatologists, nurses, secretaries and receptionists repeatedly ask the patientabout the questionnaires and remind them or compliment them for completing them. The hospitals are also working on a new initiative that will allow patients to complete PROMs on a tablet while waiting for their appointment. St.Antonius Hospital has set up automatic reminders via Epic and the other hospitals are also working on a system for sending automatic digital reminders.

The most important factor in increasing the response rate is probably the increasing use of PROMs in the doctor's office. If patients fully understand why PROMs are so important, experience so for themselves during a consultation and realise that their treatment is tailored to their response to a questionnaire, they will be more likely to complete the questionnaires.

Together, these steps should ultimately lead to PROMs playing a key role in gaining insight into treatment outcomes and discussing them at home and in the hospital, allowing for increasingly personalised rheumatism care.

A higher response rate to PROMs will also enable Santeon hospitals to use the overall results to compare outcomes and learn from each other at the group level.

First results

Figure 24 shows the first Santeon-wide results for the two PROM topics for which the Santeon hospitals use the same questionnaire. No conclusions about outcome variance can be drawn from these results at this time, as differences in demographic and disease course characteristics have not yet been adjusted for.

The response rate for 2020 was not yet high enough to adjust for case mix, but as soon as the requisite responserate is reached, we will adjust the results to allow us to draw up hypotheses about care quality and possible improvement initiatives in the future. An important addition is that PROMs are gaining an increasingly prominent position in Rheumatism care both in the Netherlands and abroad. In time, this will make it possible to compare the results of the Santeon hospitals with national and international PROM standards and scientific guidelines.

3 Digitising care in the hospital and at home

Replacing outpatient visits with digital and telephone consultations

The digitisation of healthcare is not a new topic, and even before COVID-19, the Santeon hospitals were already experimenting with digital consultations and remote care. However, the COVID-19 pandemic has laid bare the urgent need for digitising healthcare. Figure 25 shows that, for both new patients and chronic patients in all three Santeon hospitals, the mean number of teleconsultations increased significantly in the last cycle.

An in-depth analysis was carried out to gain a more precise insight. Figure 26 shows the mean number of consultations for chronic patients in the first half of 2020 per month, broken down into outpatient appointments and remote consultations. The figure shows that after the official outbreak of COVID-19 in the Netherlands (March 2020), the number of remote consultations increased significantly.

This increase in digital rheumatology care, mostly by telephone, has its benefits, also raises questions.

Figure 24

First results PROMs - chronic patients

2020

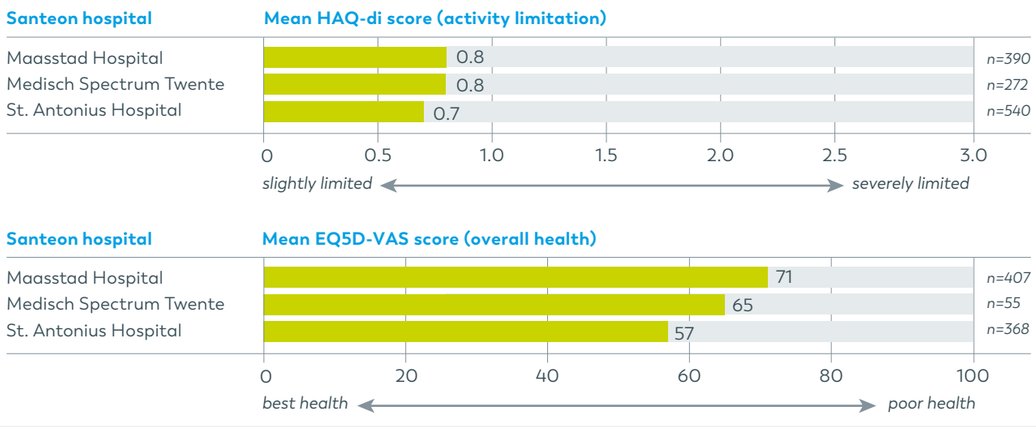
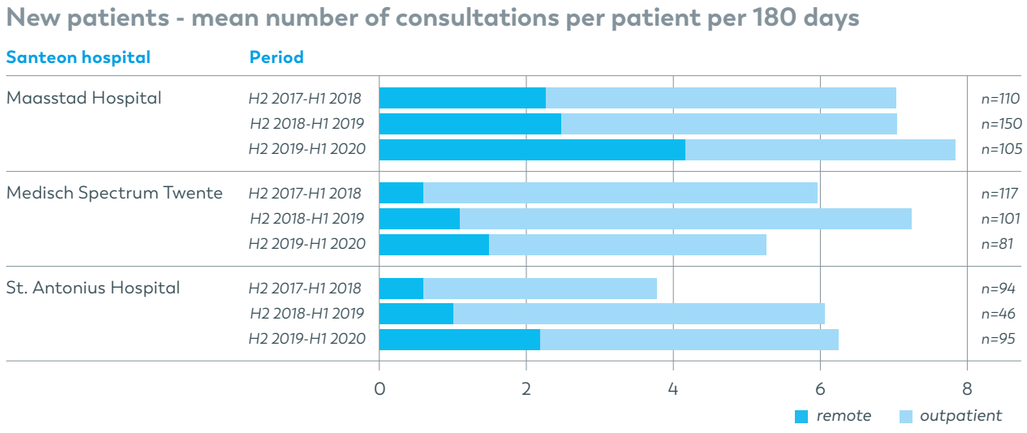
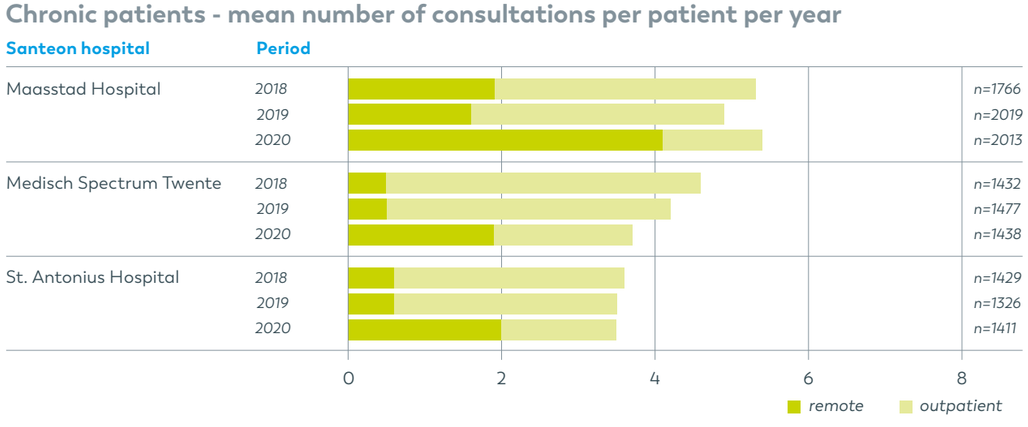


Figure 25

Mean number of (remote) consultations per patient with a rheumatologist, clinical nursing specialist, doctor's assistant or rheumatology nurse

H2 2017 through H1 2020 and 2018 through 2020





How can we continue to focus on quality when we see patients less often, conduct fewer DAS28 measurements and face the spectre of a shortage of control information? COVID-19 underlined this problem, intensifying the search for possible alternatives to gain access to information about outcomes that matter to the patient.

The importance of determining the DAS28 score

Disease activity - expressed as a DAS28 score - is the most important outcome measure in the RA care pathway. It is one of the primary parameters on which treatment choices are based, such as whether to escalate or de-escalate medication. Regularly determining a DAS28 score in a structural manner also makes it possible to monitor the progression of the disease over time. That is why the Santeon hospitals have set out to increase the number of DAS28 assessments per patient to at least one assessment per six months for new patients and one per year for chronic patients. Figure 27 shows that Santeon hospitals determined at least one DAS28 score per year for 64% to 89% of chronic patients in 2018 and 2019.

Number of DAS28 scores significantly down due to COVID-19

By 2020, the percentage of chronic patients with at least one annual DAS28 score has decreased significantly, as, healthcare experienced a shift to the digital realm. Accurately determining a DAS28 score, however, requires blood tests and a precise determination of the number of painful and swollen joints. These factors are impossible or more difficult for a rheumatologist to determine without a physical visit to the outpatient clinic.

Figure 28 shows that after the COVID-19 outbreak, the number of DAS28 scores determined per chronic patient per month decreased. In the Medisch Spectrum Twente and St. Antonius Hospital, the number of DAS28 scores slowly started to increase again after April 2020. This was mainly due to the fact that these hospitals were able to see more patients in person during the COVID-19 pandemic than Maasstad hospital, where fewer in-person consultations were possible due to waiting room restrictions.

Remote scoring of disease activity precondition for further digitisation

To make remote care future-proof without jeopardising quality, the Santeon hospitals are investigating ways to improve the way to carefully map disease activity in a structured manner during remote consultations. They are currently looking into several directions. For example, they are exploring the aforementioned possibility of having PROMs play a greater role in determining disease activity and outcomes. Other options that hospitals are looking at include modifying the components of a DAS28 assessment to make them easier to perform remotely or allowing patients to carry out their own assessment of disease activity with certain tools, such as apps.

Evaluation of digital consultations: generally positive

Between 29 April and 1 September 2020, Medisch Spectrum Twente comprehensively evaluated care providers' and patients' attitudes towards digital consultations. In total, Medisch Spectrum Twente surveyed the people involved in 150 video consultations.

Despite the fact that almost half of the patients had no or little prior experience with video calls, almost 80% were satisfied with the software. However, some 33% of patients experienced difficulties making calls and getting their camera or microphone to work.
Overall, 69% of patients were satisfied with the quality of the digital consultation, as were 81% of healthcare providers. 99% of the healthcare providers participating in the survey considered video consultations to be a good and permanentaddition to regular care, and over 20% of patients and healthcare providers would even prefer digital consultations to outpatient appointments in the future. The main reason mentioned for this was efficiency, as digital consultations cost patients less time and, importantly, less energy. A major

Figure 26

Mean number of monthly (remote) consultations per chronic patient with a rheumatologist, clinical nursing specialist, doctor's assistant or rheumatology nurse

January through June 2020

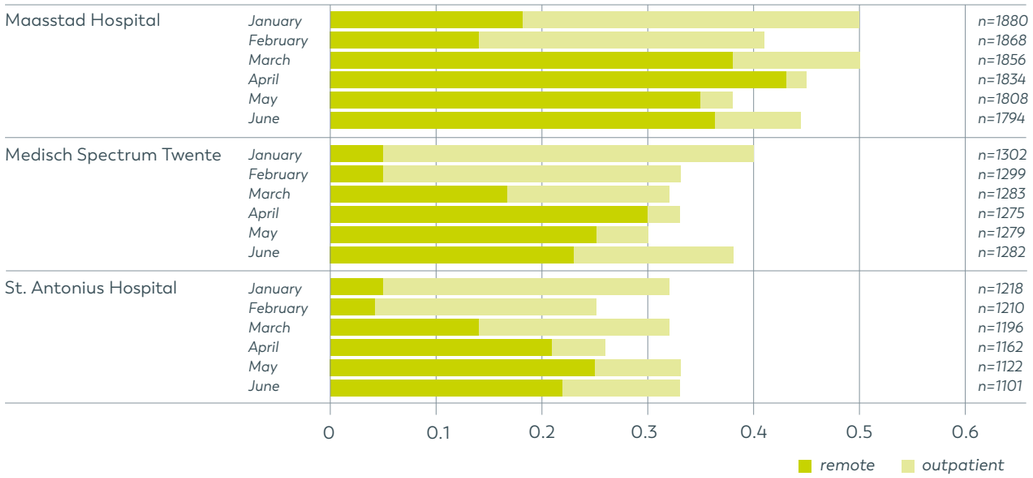


Figure 27

% Chronic patients with at least 1 DAS28 score

2018 to 2020

shortcoming of digital consultations is that they do not allow doctors to determine a DAS28 score, which ties in with the above-mentioned concerns about digitising rheumatology care.

Future demands personalised approach to healthcare

Figure 25 shows that the total number of consultations (outpatient and remote) rose slightly, particularly in Maasstad Hospital. This is because digital or remote consultations may reveal the need for an additional in-person appointment in order to safeguard quality of care. This is often the case when patients experience specific symptoms, such as pain or swollen joints, that a rheumatologist may have difficulty assessing remotely. Patients whose situation seems to be deteriorating may also have to be seen in the outpatient clinic. In general, this led to an increase in the total number of consultations at Maasstad Hospital and thus in the workload of the healthcare providers. Similar developments were noticed in the other two hospitals, although the increase is less clear in Figure 25.

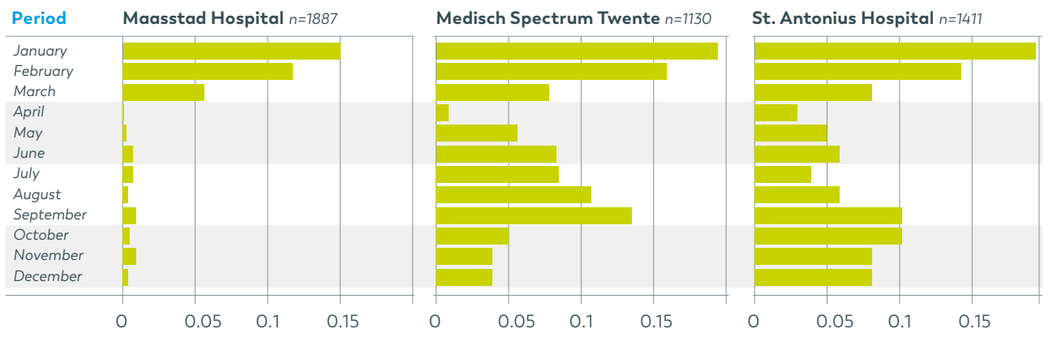
It is certain that digitising healthcare can help optimise rheumatism care, and personalisation is the next step. Digital consultations are not a good solution for all patients at all times, depending on the one hand on patients' digital skills and on the other hand on the course of the disease. For patients who have been in remission for a long time or who suffer from other forms of rheumatism, digital checkups or some other form of digital monitoring are a good solution. These digital checkups could also be supplemented with an annual visit to the outpatient clinic. For new patients, patients with extensive joint damage or new complaints or patients whose treatment plan may need to be adjusted, digital consultations do not seem to be the right solution.

By consciously checking with each patient whether a digital or physical consultation is the best solution at a particular point of the treatment process, healthcare can be organised more efficiently without having a negative impact on thequality of care. What is clear is that remote monitoring must be improved. One way of doing this is to encourage patients to completion of PROMs more frequently, so that practitioners have a better picture of the patient's situation, especially if this outcome information is incorporated into clear dashboards that aggregate different indicators. These dashboards can serve as a triage method and help patients prepare for the consultation. The Santeon hospitals will continue to work on this in the near future.

Figure 28

Mean number of DAS28 scores determined per patient per month - chronic patients

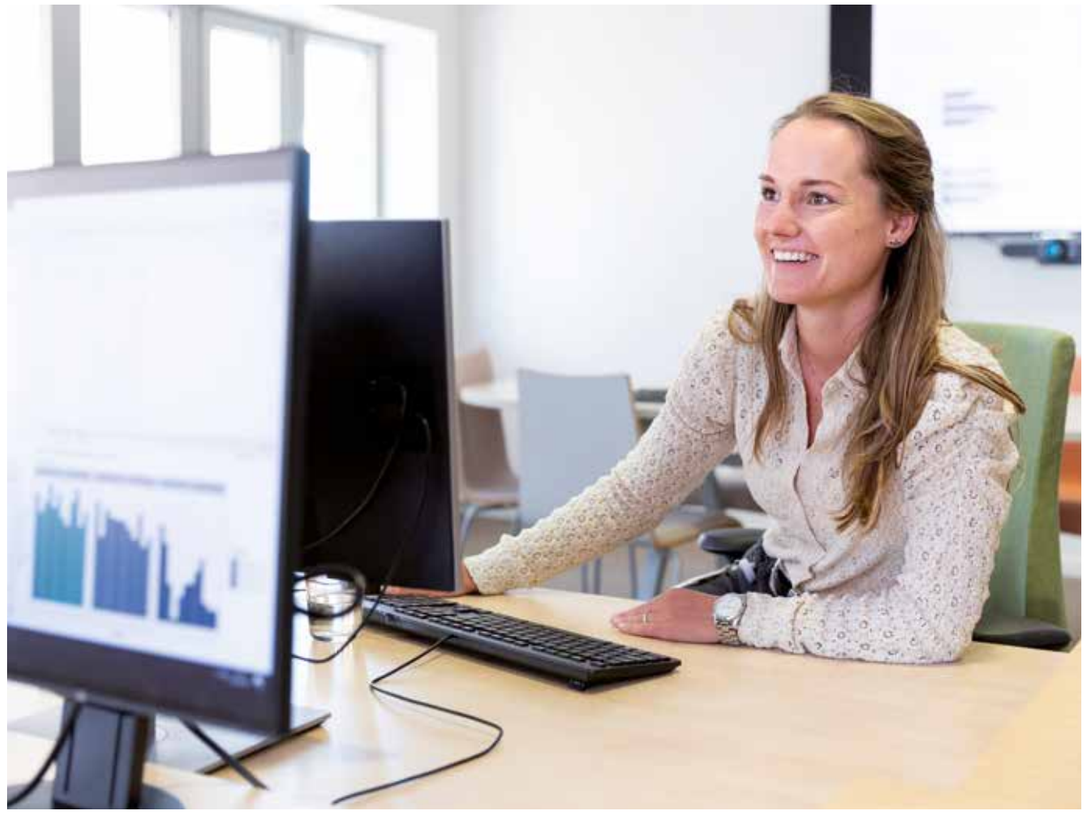
2020



Increase number of consultations with rheumatology nurse

RA has a severely negative impact on the daily life of patients, impairing them in everyday situations, at work and in their hobbies. It forces patients to significantly alter their lifestyle, which can, in some cases, even lead to depression.

To support and assist patients in coping with their disease, the Santeon hospitals, as described earlier, explicitly focus on broader rheumatism counselling, usually provided by a rheumatology nurse. These nurses determine DAS28 scores, provide information about medication, help monitoring disease activity and bring up PROMs with patients, among other things. The aim is to help patients enjoy their lives again and limit the impact that RA has on their daily lives. The three Santeon hospitals implement this counselling in slightly different ways, but the general idea is the same: supporting the patient in coping with the disease.
Special activities are also organised to inform and motivate patients. Maasstad, for instance, organisesa yearly 'RA Exercise' event, a day on which RA patients are given information about the



importance of exercise and introduced to inspiring exercise options.
Medisch Spectrum Twente organises a course on 'Living with purpose', which hands patients tools to cope with the disease in everyday life, as well as organising regular meetings for RA patients.

Good support improves adherence to therapy

The counselling provided by the rheumatology nurse also helps to improve compliance. By providing detailed explanations of the medication and paying attention to possible side effects, patients are given the opportunity, for example, to broach subjects they would not always feel comfortable with in a brief consultation with a rheumatologist, such as discussing the impact of medication on their libido, side effects such as weight gain, nausea and the impact of RA on their lives. By enabling patients o address these issues, hospitals avoid patients from discontinuing medication on their own accord because of side effects that were never discussed.

Effective counselling is a focus for both new patients and chronic patients, but new patients are given extra priority. Informing them about the possible consequences of their illness, the expected course of care and the challenges they will face from the outset reduces the chance of difficult situations arising later in the process.

Annual consultation with rheumatology nurse

The Santeon hospitals have agreed that every patient should have a consultation with the rheumatology nurse at least once a year. Since uttering this ambition, the improvement themes have shifted their focus to this indicator and now share developments and progress at the Santeon meetings. Figure 29 shows an increase from 2018 to 2019. However, the figures for 2020 are less positive, primarily due to COVID-19. The huge increase in the number of consultations with new patients at St. Antonius Hospital is due to the fact that healthcare providers at this hospital had been unable to work due to illness in 2017 and 2018, as a result of which they were able to see fewer patients.

Now that hospitals are once again making more room for in-person consultations, the aim is to increase the number of patients who see a rheumatology nurse in person at least once a year, depending, of course, on the patient's needs and wishes. As an example of a concrete action taken to improve this, counter clerks now pay specific attention to the number of consultations a given patient had with a rheumatology nurse when scheduling appointments.
If they have not had an appointment in the past year, an appointment is scheduled immediately.

"I thought that everyone saw the rheumatology nurse, but the data show that this was not the case. This just goes to show how important it is to gain insight into your own data and to work on improvements in a multidisciplinary manner. It's especially important for such an essential topic, because it really helps people regain control of their lives."

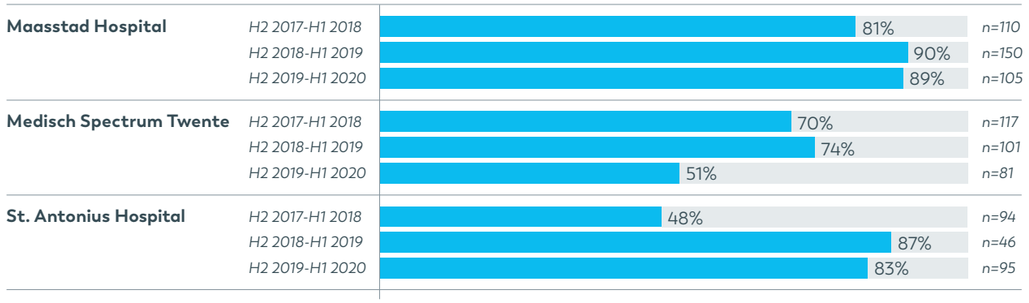
Marjan Ghiti Moghadam, rheumatologist at Medisch Spectrum Twente

Figure 29

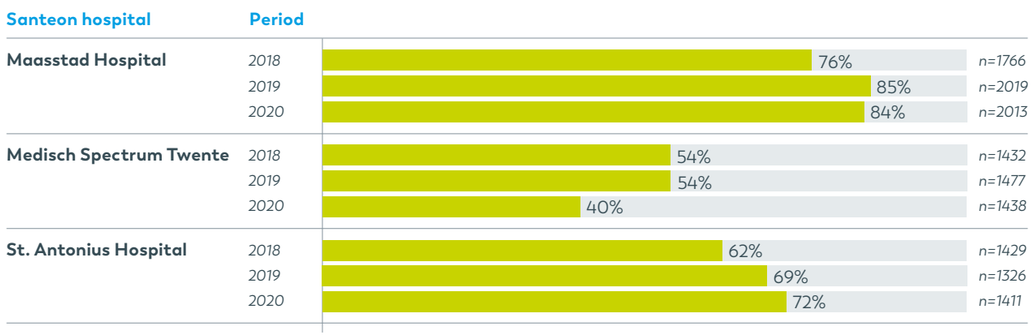
% Patients who had a (remote) consultation with a clinical nurse specialist, physician assistant or rheumatism nurse

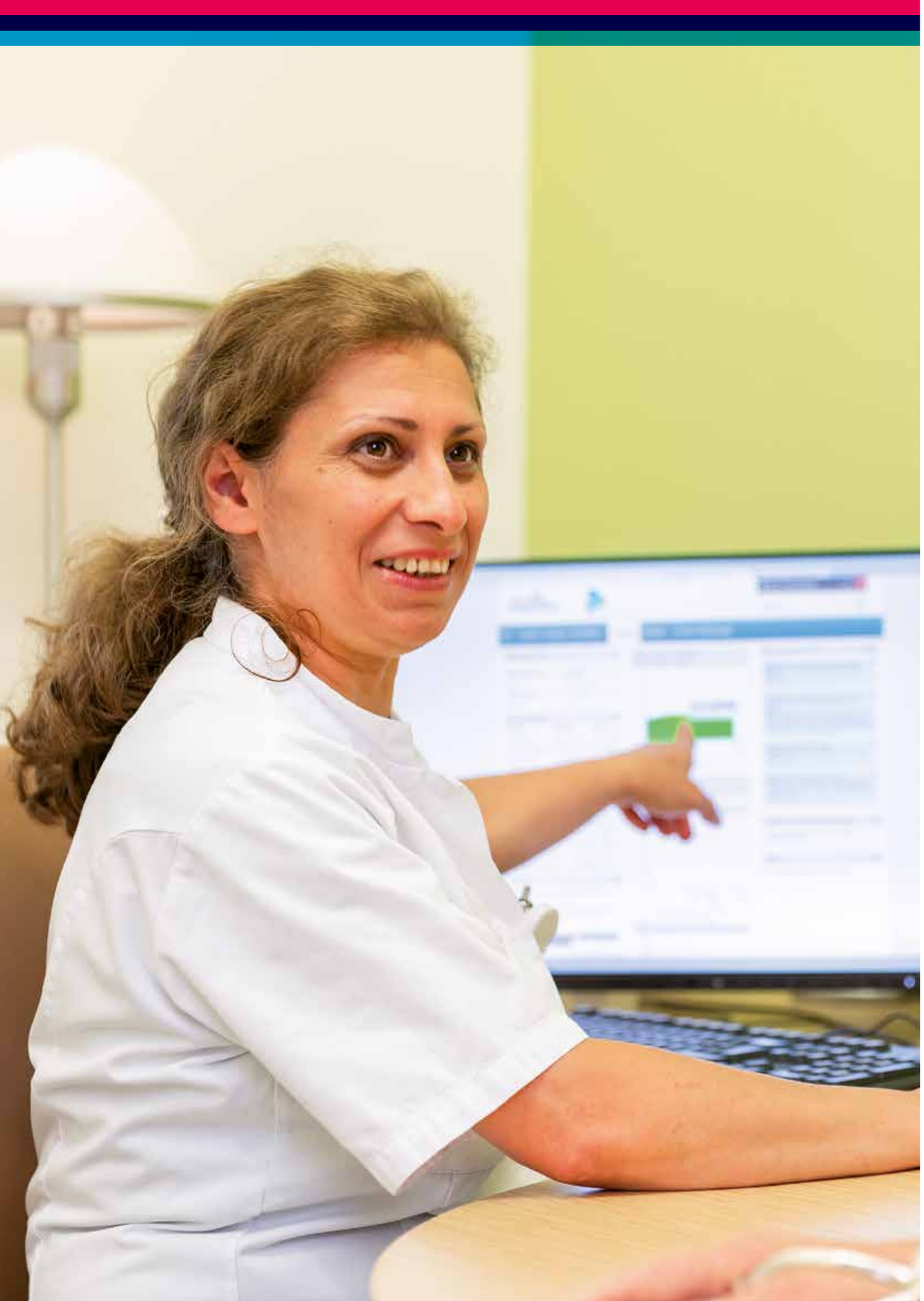
H2 2017 through H1 2020 and 2018 through 2020

New patients



Chronic patients





Chapter 4

Future perspectives

Personalised care for RA patients

For the Santeon hospitals, the move towards personalised healthcare is a major development in rheumatism care. Our ambition is to offer each patient the care that suits their specific situation and their personal needs and wishes. Given the chronic nature of the disease, this is a continuous and dynamic process. The hospitals are integrating this development into their daily practice by committing to using PROMs in the hospital and at home, encouraging shared decision-making and developing personalised protocols based on predictive models.

Partly thanks to the implementation of PROMs, the outcomes that matter most to patients are already becoming more and more transparent. Moreover, hospitals are developing more and more tools to measure these outcomes (digitally) and make them transparent, both to healthcare professionals and to patients. Thanks to the collaboration between Santeon hospitals, the hospitals now have access to large sets of “mirror data”, enabling them to show patients the expected outcomes per treatment option based on similar patients, the so-called patients like me.

The personalisation of rheumatism care is also reflected in how the care provided is organised. There are more and more ways to invite patients to come to the outpatient clinic in a targeted manner and for periodic appointments to take place digitally. In the future, hospitals will therefore offer patients the freedom to express their own preferences and examine a patient’s personal disease characteristics to determine whether they need to be seen in person or not. One way of achieving this is to make more intensive use of PROMs as a “triage tool”. Other ways to gain easy, remote insight into disease activity, parameters related to medication use and overall health indicators are also being explored.

Predictive models for personalised treatment protocols

Predictive models and the decision tools based on them are an important prerequisite for well implemented personalisation. In the future, the hospitals expect to use predictive models for, for example, medication choice, de-escalation schedules and other treatment options, such as physiotherapy. These models show exactly which treatment options are available for each patient and what the expected outcomes are for each choice. The input for these models consists of all measured disease indicators, including PROMs and specific personal characteristics that turn out to be relevant for the progression of the disease (e.g. BMI, smoking behaviour, rheumatoid factor and anti-CCP). This may also include multimorbidity, which is playing an increasingly important role in chronic care. Predictive models help optimise the effectiveness and costs of treatments, as well as giving patients access to even better information, allowing them to make decisions about their own care.

The first step is the development of two treatment protocols, namely:

- a patient-friendly medication escalation protocol for new patients
- a medication de-escalation protocol for chronic patients with long-term low disease activity

“The Santeon hospitals are exploring broader cooperation in the Netherlands and, where possible, internationally. It would be great if this initiative were followed upand attained the critical mass needed to accelerate the journey towards the outlined perspective for the future. After all, all healthcare professionals are united in the pursuit of the best possible care for patients.”

Anna Jamnitski, rheumatologist at St. Antonius Hospital

With the focus on learning and improving, combined with the availability of real-life, validated data on large patient groups, Santeon hospitals can continuously evaluate effects, enabling the creation of increasingly personalised treatment protocols. We also plan to publish the results of the study into a predictive model for the de-escalation of medication in chronic patients in order to contribute to a convergent approach throughout the healthcare sector.

“We would like patients treated in other hospitals to also receive the very best care, which is why we share what we have learned with other healthcare professionals.”

Marieke Oskam, data analyst at Santeon

Inspiring others and international collaboration

The aim of collaboration within Santeon is to use a data- and outcome-driven process to improve the quality of care at the same or lower cost. Initially, these efforts will focus on our own hospitals, but Santeon’s ambitions go above and beyond the group itself. By actively increasing the transparency of outcomes, working methods and improvement initiatives, the hospitals aim to inspire the healthcare sector to start measuring and improving as well.

Broader cooperation, in the Netherlands and internationally, could provide a further boost to the evolution of rheumatology care. Santeon can play a facilitating role by sharing its experience with improvement processes and offering support to other hospitals that wish to set up a similar process. Santeon would also like to contribute to the development of national standards and definitions to facilitate the comparison of outcomes between hospitals.

“Our group differs from, for example, the DQRA, because we do not only compare, but above all discuss the differences and then exchange improvement initiatives. Because the available data can be broken down right to the patient level, we are confident in each other’s results and are motivated to implement initiatives that have already proven to be effective in other hospitals.”

Suzanne van Lint,
project lead at St. Antonius Hospital

Epilogue

Valuable insight into the progression of my disease

“RA has far-reaching impact on my life, far beyond just taking medication and going to hospital every now and again. I had to quit my job and find new hobbies, but I am lucky to have a positive attitude and focus on what I can do. I enjoy participating in the Better Together programme, which compares healthcare outcomes. During meetings, I work with other patients to make sure that the outcomes being discussed actually matter to us.

At meetings, we patients are equal to healthcare professionals and are truly heard. We indicate which aspects of care could be improved, and contributed to ways to make more effective use of PROMs, for instance. After all, we know how these PROMs are communicated with patients and whether they are understandable. We have also indicated that providing context and feedback is important. If you understand why the questionnaires are useful, you will be more likely to complete them on a regular basis. In my opinion, the continued emergence of PROMs is a valuable development, as they provide insight into the course of your disease, both remotely, e.g. in an app, and during a consultation, when you can discuss visualised PROMs. By combining these visualisations with your medication history and the peaks and troughs in your disease activity, you can easily make connections.

An important change I have seen in rheumatology care is that shared decision-making is becoming increasingly common. Patients have a greater say in their treatment. I finally feel in control, which is a good feeling. I would like for other patients to feel the same way, which is one of the reasons I am committed to improving RA care.”

Clementine Ophuis,
expert by experience and patient at the Medisch Spectrum Twente

Annexes

“I enjoyed being part of the improvement team. My opinion was respected and my suggestions were acted upon. Moreover, it has given me insight I would never have had otherwise. It has allowed me to see both sides of the story, which can be very valuable.”

Karin Breukers, Expert by Experience at Medisch Spectrum Twente

Appendix 1

RA Glossary

Anti-CCP
Anti-CCP stands for antibodies against cyclic citrullinated peptides. These can be detected in the blood of patients with rheumatoid arthritis, often together with rheumatoid factor (RF). The presence of these antibodies can support the diagnosis.

DAS28
DAS stands for Disease Activity Score. The number 28 refers to the number of joints included in the score. The DAS28 score is used to measure disease activity in patients with rheumatoid arthritis. In this publication we use the DAS28-BSE (blood sedimentation rate).

DMARDs
DMARDs stand for Disease Modifying Anti-Rheumatic Drugs. This group of drugs has been scientifically proven to actively affect the inflammation of joints caused by an autoimmune response and thus prevents or slows down the progression of the disease and the occurrence of joint damage. Within DMARDs, a distinction can be made between conventional and biological DMARDs.

Flare
An exacerbation of the disease, characterised by active inflammation of the joints and associated symptoms.

Inflammatory Arthritis
Group of various rheumatic diseases, characterised by chronic inflammation of the joints, due to a autoimmune response. This group of diseases includes a.o. Rheumatoid Arthritis (RA), Psoriatic Arthritis (PsA) and Spondyloarthritis (SpA).

PROMs
PROMs stands for Patient Reported Outcome Measures. These are questionnaires measuring healthcare outcomes that patients perceive as being important (PROs). PROMs map out how patients fare before, during and after treatment and how they themselves experience their treatment and health. The results can be used to make treatment decisions together with the patient. In rheumatology, the domains measured by PROMs include pain, fatigue, activity limitation, general health, and ability to do (domestic) work and productivity.

Rheumatoid Arthritis
Rheumatological disease, characterised by chronic inflammation, especially of the small joints of the hands and feet, caused by an autoimmune response. The Better Together programme is called Rheumatoid Arthritis. For ease of reading, this publication uses RA or rheumatism throughout.

Rheumatology nurse
Specialist nurses who provide care to rheumatic patients, including lifestyle advice and counselling to help patients cope with the disease. This can also be provided by a clinical nursing specialist or doctor’s assistant.

Appendix 2

RA Improvement teams

Maasstad Hospital

Angelique Weel	Rheumatologist, VBHC medical lead
Natalja Basoski	Rheumatologist
Hanneke Voorneveld	Clinical nursing specialist
Tessa Bosch	Hospital pharmacist
Mitzy Homburg	Rheumatology nurse
Mirella van Kleij	Rheumatology nurse (until August 2020)
Lisanne Wijbrands	Doctor's assistant
Linda Kamphues	Doctor's assistant (until November 2020)
Patricia Zuidmeer	Team lead
Marieke Holtrop	Team lead (until November 2020)
Annemieke van Groenestijn	VBHC Project lead
Martijn Kuijper	Data analyst
Amber Kinkel	Data analyst
Patient panel	Various patients/experts by experience

Medisch Spectrum Twente

Marjan Ghiti Moghadam	Rheumatologist, VBHC medical lead
Marjan van het Spijker-Kerseboom	Doctor's assistant/secretary
Jolanda Delsing	Clinical nurse specialist
Joost Masselink	Pharmacist
Shasti Mooij	Assistant Physician (now Rheumatologist)
Herlinde Lenselink	Doctor's assistant/secretary
Annemiek Kwast	VBHC Project Lead
Chantal Storck	Data analyst
Clementine Ophuis	Patient/Expert by experience
Karin Breukers	Patient/Expert by experience

St. Antonius Hospital

Anna Jamnitski	Rheumatologist, VBHC medical lead
Karin Janssen	Pharmacist
Karin van den Berg	Outpatient clerk
Margriet Kroon	Rheumatologist
Eline van Ballegooijen	Team Head
Annette Hokke	Head of Department
Nathalie van Laar	Care Manager
Ite Priems	Data analyst
Veerle Reijnders	Data analyst
Suzanne van Lint	VBHC Project Lead
Peter Nieuwhof	Patient/Expert by experience

We would like to thank all healthcare providers involved in rheumatology in our hospitals, patients, IT departments, BI departments, PhD students and support staff for their time and perseverance in bringing Value-Based Health Care into practice. Without the commitment of these colleagues and patients, we would not have been able to gain the insights described and implement the improvements that followed.

Colophon

Text and editing
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Coco Levendag
Marieke Oskam
Tessa Linssen
Maartje Wielders

Design
Telvorm grafische vormgeving

Photography
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Annabel Jeuring
Geeske Stoker - Dijkman
Beeldbank Santeon

Publication: October 2021

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Santeon is a group of seven top-class clinical hospitals in the Netherlands. Together, we are committed to improving care in our hospitals and throughout the Netherlands by looking at each other's work, learning from each other and pursuing continuous improvement.

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