

# Patient Self-Management and Tracking

## A European Experience



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### KEYWORDS

- Self-management • Inflammatory rheumatic diseases • Digital tool • PROMs
- Education • Patients' experiences • Personalized health care

### KEY POINTS

- There is a shift from a paternalistic model of health care toward more personalized health care in which disease management is conducted by the patient together with his or her health professional.
- Self-management by patients can be performed in various levels including being prepared for an outpatient clinic visit with a list of current medications and suggesting to the health care professional to lower the dosage of a prescribed medication.
- Remote control by self-monitoring might give important information about the disease course between outpatient clinic visits. Outpatient visits can be minimized when patients monitor their disease activity themselves using a digital tool like Reumanet.
- For self-management, it is important to have an easy to understand electronic health record with a well-organized dashboard informing both the patient as well as the health professional about the status of the different domains.
- At the outpatient clinic, the doctor should discuss the results of the self-management and self-monitoring with the patient.

### INTRODUCTION

More than 2500 years ago, the ancient Greeks like Hippocrates realized that maintaining good health and managing diseases depended on the natural causes and lifestyle issues like diet and exercise as well as on the environment.<sup>1</sup> Already at that time, a lot of attention was being given to educate the population, to teach them that diseases

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are influenced by emotional factors, and that human behavior has a strong influence on the course of diseases. Special educators went to villages to increase the so-called self-sufficiency of the population, which we now would call patient self-management. In the twentieth century, due to the 1948 World Health Organization definition of health, “health is a state of *complete* physical, mental and social well-being and not merely the absence of disease or infirmity,” the focus was to find medical solutions to cure each disease. This fitted in the paternalistic approach, which was the standard procedure for how medicine was practiced: the doctor is dominant and makes decisions for the patient.

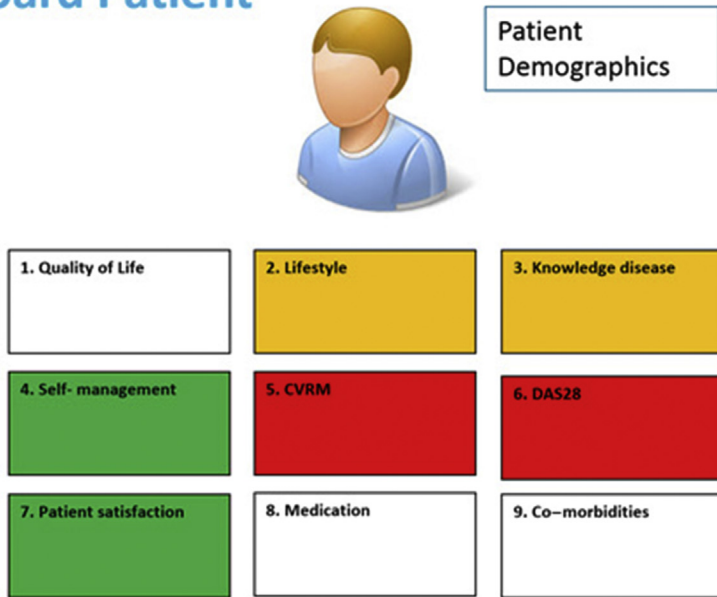
In the past decade, we moved from this paternalistic approach to a shared decision model in which the patient together with the health care professional make the decisions. This fits more in the new definition for positive health, which “is the ability to *adapt* and to *self-manage*, in the face of social, physical and emotional challenges.”<sup>2</sup> In the same period, it has been shown that lifestyle factors do influence the development of the disease, the course, and the response to treatments.<sup>3–7</sup> All these factors have caused more attention to be given to the role of the patient in the management of the disease. An important component of self-management is called self-monitoring, a patient undertakes self-measurement of, for instance, vital signs like weight and blood pressure or symptoms like pain, fatigue, and disease activity by Patient Reported Outcome Measures (PROM).<sup>8,9</sup>

The degree of self-management can vary per patient and depends for instance also on the situation the patient is facing. In an acute, life-threatening situation like a myocardial infarction, the degree of self-management of a patient at the emergency department will be minimal, whereas for patients with a chronic disease, the degree of self-management might vary between attending the outpatient clinic prepared with a list of their current medication usage to even suggesting to the health care professional to lower the dosage of a prescribed medication because their disease activity is low. Several studies have shown that patients with a chronic disease who practice self-monitoring do have a better outcome of their disease.<sup>10</sup> This, together with an improved cost-effectiveness of this approach, is the reason that self-management should be stimulated in patients with chronic diseases. Different studies, however, have shown that the percentage of patients with inflammatory rheumatic diseases (IRDs) that perform self-monitoring in daily clinical practice is still quite low.<sup>11</sup> In this article, we share our experiences with how we educated and motivated our patients with IRDs to participate in a self-monitoring program.

## TOOL REUMANET

To stimulate patients in their self-management behavior, a digital tool can be helpful in which the patient can monitor and manage his or her disease outcomes. For this purpose, we developed at the department of Rheumatology of Bernhoven, a teaching hospital in Uden, The Netherlands, Reumanet Bernhoven. This is an online 2-factor authentication protected-personal health environment with several functions to support patients with IRD in their self-management behavior. This online personal health environment is available for the patient and the rheumatologist, but also the nurse, general practitioners, and/or physiotherapist can have access (with permission of the patient). The online personal health environment includes all patient characteristics, questionnaires, graphical overviews, lifestyle advices, and feedback opportunities, which include e-health modules and other relevant information adjusted for the individual patient with an IRD. This information is summarized in the dashboard (Fig. 1).

## Dashboard Patient



**Fig. 1.** Example of a personalized dashboard for patients in Reumanet. Green button: under control, no action needed. Red button: not under control, further action is needed. CVRM, cardio vascular risk management.

In more detail, first, patients can find an overview of their current and past medicines and blood values. Second, a monitoring function is available to track patients' disease activity. Patients can complete PROMs in this online system as preparation for the consultation with the rheumatologist and these scores are displayed in a graph. The patients can choose from scores such as the Rheumatoid Arthritis Disease Activity Index (RADAI) and the Rheumatoid Arthritis Impact Disease activity (RAID). These PROMs have shown to correlate well with objectively assessed measures and have good psychometric properties. In case the disease activity according to these PROMs and together with the patient set, exceeds a predetermined threshold, an alert appears in the online system. This enables identification of patients whose disease activity is not in line with the target and who might need further medical attention. Third, patients can self-add measurements of body weight or blood pressure and the results are also visible in a graph. Fourth, a chat function is available to send messages to health professionals. Last, patients can make use of the educational part of the program, called the library, which contains several leaflets and videos with information about various topics including information about their disease, medication use, fatigue, or working with RA.

### PERSONALIZED DASHBOARD

For the different health professionals involved in the management of IRD, it is mandatory to have an overview of the status of the different domains of disease management (see Fig. 1). For example, the personalized dashboard contains the following domains: (1) *Quality of life*, in which different questionnaires will be filled in by patients about their current quality of life. (2) *Lifestyle factors*, such as physical activity behavior, smoking

status, and diet of the patient will be followed over time. (3) *Knowledge of disease* by the patient will be inquired by questionnaires. (4) *Self-management*, using the self-management questionnaire SEMAS, the different domains of self-management will be measured that can be used as a screening instrument for nurses to assess patients' individual capabilities or barriers for self-management. (5) *Cardiovascular risk management (CVRM)*, the cardiovascular risk profile of the patient will be checked at least once a year. (6) *Disease activity*, such as the DAS28 in patients with RA, will be monitored. (7) *Patient satisfaction* and perceived quality of rheumatology care will be asked by questionnaires. (8) *Medication use* and adverse events will be documented in the system. (9) *Comorbidities*.

It is important for patients to have an overview of the disease process as well and to get feedback about actions they have taken. For instance, to make sure that the patient will continue with an exercise program, it is important to set a target, to give feedback to the patient, and to encourage the patient to reach the target. Therefore, it is important that in addition to the patient and the rheumatologist, the nurse, general practitioners, and/or physiotherapist also have access to this Web-based program (only with patient permission). In this way, both the patient and the rheumatologist and other health professionals are involved in managing the disease and are aware of each other's actions. In the case of a red button, the health professional or the patient should be aware that some action is needed in that domain. In the case of a green button, that domain is recently checked and under control and no further action is needed at this moment.

## EDUCATION

To increase the number of patients participating in the self-management program, education of both the patients and the health professionals is important. Next to leaflets in the waiting room and general educational meetings, instruction classes have been organized to give patients a general instruction on how to use Reumanet. Patients can call or e-mail the help desk in case of any additional inquiries. The staff at the outpatient clinic is also available to assist the patients in case they are needed before or after their visit to the rheumatologist.

## CHANGING ROLE OF HEALTH CARE PROFESSIONALS

The introduction of a self-management outpatient clinic has, in addition to patients, also had consequences for the health care professionals. It requires a different approach, instead of the usual, old-fashioned paternalistic relationship, the role of the health care professional has changed to one in which the patient is coached to manage his or her disease. Different skills are required for this role, for instance motivational interviewing to help stimulate the patients to take their disease management role. For this purpose, a training program has been developed in which patients, health care professionals, and students learn together by exchanging experiences, knowledge, and skills.<sup>12</sup>

## SELF-MANAGEMENT OUTPATIENT CLINIC

The traditional approach to monitoring IRD patients 2 to 4 times a year to assess disease activity is no longer necessary or appropriate but should be tailored. As long as remission is not reached, frequent assessments need to be done to adapt the medication according to the Treat to Target guidelines. When the disease is under control, these measurements can be done less frequently and even remote self-monitoring

would be feasible. Remote control by self-monitoring might also give important information about the disease course between outpatient clinic visits, as it has been shown that this information might have an important impact on the outcome of the disease. Therefore, self-monitoring in IRDs as a first step toward personalized health care enables patients as well as health care providers to get insights into the disease activity course over time.

In November 2017 we started with a “self-management outpatient clinic” to find if the monitoring frequency of patients can be decreased to 1 visit a year. Patients with IRDs are included if they fulfill the following inclusion criteria: (1) the patient is in remission or has low disease activity, (2) is motivated to take part in the self-management program, and (3) is able to use Reumanet. After consent, the patient receives information about (1) the aim of the self-management program and how to use Reumanet, (2) what the patient can expect from the health professionals, and (3) how to contact the outpatient clinic in case of questions. At the start, the self-management screening questionnaire is filled out by the patients to get to know if the patient encounters barriers in self-management behavior.<sup>13</sup> If appropriate, these barriers are solved before the start of the program or, in case this is impossible, the patients will not be included.

The patients can choose to track their disease activity by filling in the RAID or RADAI questionnaire. Patients can decide by themselves the frequency to fill in the RAID, for example, every week or every month. The results of the questionnaires are shown in a graph together with the DAS28 values performed by the health professional at the outpatient clinic visits (Fig. 2). To manage their disease, it is essential for them to perform self-management behavior: they need to remind themselves to fill in the questionnaire multiple times and based on the insight they gain in the graph and the preset target, they need to decide when to make an in-between appointment for a visit to the outpatient clinic. After 1 year, the rheumatologist and patient will evaluate the participation with a questionnaire to assess the patient’s satisfaction.

## FIRST RESULTS

By November 2017, 1125 patients with an IRD were already active in Reumanet Bernhoven. The degree to which patients make use of Reumanet Bernhoven differed

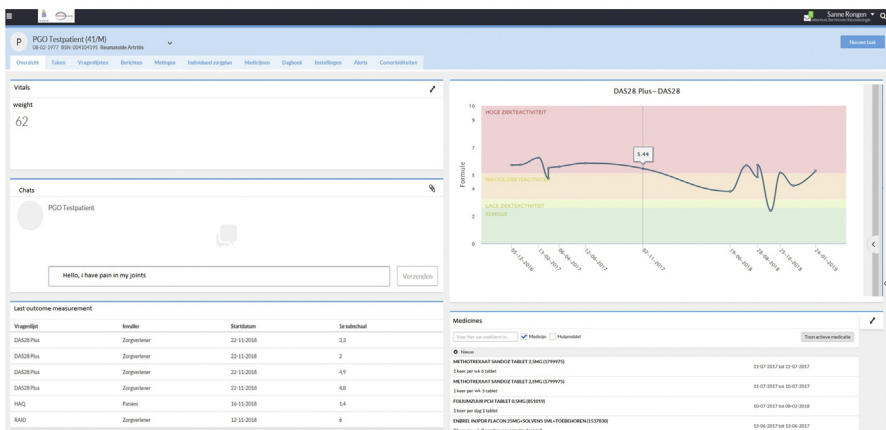
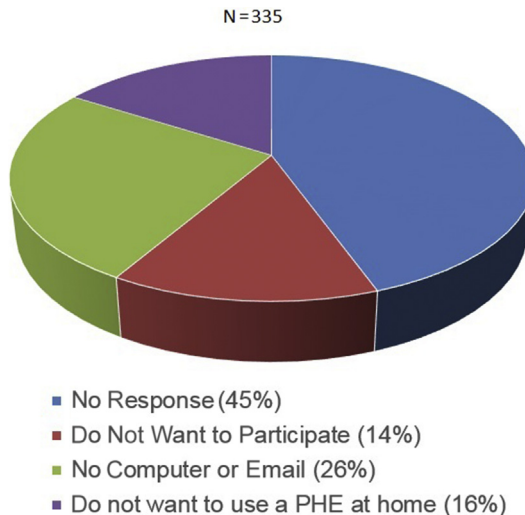


Fig. 2. Current Dashboard.

widely, and depended on patient needs, abilities, and skills. The results of Reumanet Bernhoven showed that 70% ( $n = 790$ ) of the patients used it at least once a year, but only 13% ( $n = 100$ ) of the patients used the self-monitoring tool. The remaining patients ( $n = 335$ ) were questioned for not using Reumanet at home. The most common reason for not using Reumanet was not having a computer or e-mail address or the patient did not want to use a digital environment at home (Fig. 3). To increase the chance that patients are using the self-monitoring tool, it is important that they find useful information in this digital environment and therefore it is important to involve patients in the development of such a tool. It is also important to teach patients how to use it; to enhance continuous usage, patients need to receive feedback about it from their health care professionals at the outpatient clinic visits. Therefore, to increase the usage of Reumanet, the program will be continuously optimized and extended in accordance with patients' support needs and preferences. Earlier research shows that the patients' input is essential in the development of online tools<sup>14,15</sup> and that patients have various educational support needs.<sup>16-18</sup> To assess patients' support needs and preferences regarding the educational part of the online tool in our patient population, patients filled out a questionnaire with questions about their usage and their opinion about optimizing the content of the program. For instance, patients were asked what kind of functions should be added to Reumanet (eg, a newsletter, informational texts, or instructional videos). Also, patients were asked about which topics should be dealt with in the program (eg, new treatment options, the influence of nutrition on IRD, or medication usage).

#### ***Reasons Given by Patients for Not Using Reumanet***

The first results ( $n = 35$ ) showed that patients have several informational needs regarding physical impairments (pain, fatigue, and stiffness), and their treatment (how to prepare a visit to the outpatient clinic, improve their communication with health professional, usage of medicines, and being up to date on the newest treatment options). Informational texts, more graphical overviews, newsletters, instructional videos, and exercises should be added as functions to support patients in their



**Fig. 3.** Reasons Given by Patients for Not Using Reumanet. PHE, personal health environment.

informational needs. In addition to the questionnaire, we will conduct qualitative interviews to explore what patients exactly want; for instance, what kind graphical overviews they may want and which topics should be discussed in newsletters. Based on the results of the questionnaire and qualitative interviews, program material will be developed and added to the program to provide patients support in their self-management.

## EXPERIENCES OF PATIENTS

The following quotes are from one of the patients who participated in the self-management program from the beginning of the program:

*After the diagnosis of rheumatoid arthritis (RA) was made, my biggest fear for the rest of my life was to be dependent on others, but nothing is less true. I am using Reumanet, on which I regularly fill out questionnaires. I do that at home at a time that suits me. I determine the frequency myself, the moment and the time, no pressure from outside or a planned "quarter of an hour" in the hospital where it has to be done. I have direct insight into my medication, laboratory results, a library full of useful information, and there is room to add personal matters. Data from completed questionnaires are immediately processed and displayed in graphs that are readable and clear to me. The diagrams show progressive information in which I can set the period for which I want to look back.*

*All of this really gives me the feeling of being in control of my own life and I don't feel myself a patient anymore but a human being. Meanwhile, I take the initiative to adjust the medication myself, of course under supervision and with the permission of my rheumatologist. If the disease activity values remain below the predefined target level, I don't plan a visit to the outpatient clinic. Because I only use a consultation with the rheumatologist when it is necessary, I can reduce the visits to the hospital to the minimum.*

*Since last year, I go to the hospital much more often than before I had RA, but not as a patient but to help others how to deal with it. With this I have given it a place, accepted and enjoy the nice things in life despite my chronic disease.*

## EXPERIENCES OF HEALTH CARE PROFESSIONALS

For the health care professional, the self-management program has changed the character of the outpatient visits significantly. Sometimes patients will start the consultation with a proposal to change their treatments based on their outcomes. The health care professional will discuss the pros and cons of the proposal with the patient and a truly shared decision will finally be made. Of course, there is a wide range in the degree of self-management between the different patients, similar to a visual analogue scale it can vary from a situation in which the health care provider decides alone, to a situation in which the patients tells the health care professional what he or she decided. It is a continuous learning process for both the patients and health care professionals, and because of this, the discussions during the outpatient clinic become more and more well matched.

## SUMMARY

Currently in the management of patients with chronic diseases, more attention is being given to the patients' ability to adapt and self-manage their disease. The consequence of this is a change in the relationship between health care professional and

patient: from a paternalistic to a shared decision approach. Currently the percentage of patients with chronic disease who practice self-management is still quite low. The rising health care costs and the decreasing number of available health care professionals in the near future compels us to find solutions in the short term. It would be very helpful if we are able to increase the percentage of patients who can manage and monitor themselves. In this respect, the following aspects are important takeaways:

- An easy to understand electronic health record with a well-organized dashboard informing both the patient as well as the health care professional about the status of the different health domains
- Attention should be paid to educate patients as well as health care professionals
- Use one electronic system for both the patient and health care professional
- The health care professional should discuss with the patient the results of the self-management and self-monitoring process.

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