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# BMJ Open Patients' experiences regarding self-monitoring of the disease course: an observational pilot study in patients with inflammatory rheumatic diseases at a rheumatology outpatient clinic in The Netherlands

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## ABSTRACT

**Objectives** Self-monitoring the disease course is a relatively new concept in the management of patients with inflammatory rheumatic diseases (IRDs). The aims of this pilot study were to obtain patients' experiences with online self-monitoring, to assess information about the agreement between the disease course assessed with patient-reported outcome measures (PROMs) and an objectively measured Disease Activity Score 28 (DAS28) by the rheumatologist, and to assess adherence to predetermined PROM frequency intervals.

**Design** Observational study using qualitative and quantitative methods.

**Setting** The rheumatology outpatient clinic of a teaching hospital in The Netherlands (secondary care).

**Participants** 47 patients with an IRD who regularly attended the outpatient clinic.

**Methods** Patients completed PROMs by using an online self-monitoring program. Their experiences regarding self-monitoring were qualitatively assessed through a focus group discussion and telephone interviews using a thematic analysis approach. Adherence to the predefined PROM frequency (completed PROM assessments within the predetermined frequency) and the agreement between the DAS28 course and PROM values (Rheumatoid Arthritis Disease Activity Index-5 and the Rheumatoid Arthritis Impact of Disease (RAID)) were quantitatively assessed using descriptives.

**Results** Forty-seven patients participated, most of them diagnosed with rheumatoid arthritis (n=38, 80.9%). Three themes were identified: knowledge about and insight into the disease (activity), patient-professional interaction and functionality of the program. Mean adherence to the predetermined PROM frequency was 68.1%. The RAID showed the best agreement with the DAS28 course. Mean participation time was 350 days.

**Conclusion** Patients were predominantly positive about online self-monitoring. They indicated that they gained more knowledge about their disease, felt less dependent on the healthcare professional and valued the insight into their long-term disease course. Barriers were

## Strengths and limitations of this study

- A strength of this study is the use of both qualitative and quantitative research methods, providing a rich description of factors associated with self-monitoring.
- Patients were closely involved during the development stage, execution and evaluation stage of this study, which increases the clinical relevance according to a user perspective.
- Using validated patient-reported outcome measures (PROMs) assessing disease activity and disease impact allowed us to compare these PROM scores with objective, health professional assessed scores.
- The selective and small study population might have influenced the generalisability and applicability of the study.

mostly related to technical factors. Patients were able to and willing to self-monitor their disease, which could contribute to a more efficient allocation of outpatient consultations in the future.

## INTRODUCTION

In chronic care, there is a tendency towards personalised healthcare. Patients have become more empowered and are increasingly involved in the planning and development of healthcare.<sup>1-4</sup> There is a shift from a paternalistic model (in which the doctor is dominant and believes that patients need to be guided through the decision-making process) to a shared decision-making model (in which doctor and patient make mutual, collaborative decisions). This shift requires an engaged patient who takes responsibilities regarding day-to-day disease management.<sup>5-8</sup> As a result of this shift, new roles for



both patients and healthcare professionals (HCPs) have arisen. An example of what this new role entails for a patient is self-monitoring, in which a patient undertakes self-measurement of vital signs, symptoms, behaviour or psychological well-being through patient-reported outcome measures (PROMs).<sup>9 10</sup> In some patients with inflammatory rheumatic diseases (IRDs) such as rheumatoid arthritis (RA), psoriatic arthritis (PsA) or ankylosing spondylitis (AS), self-monitoring may gradually replace the traditional monitoring by HCPs.<sup>11</sup> Examples of disease-specific and validated PROMs in IRDs that can be used in self-monitoring are the Rheumatoid Arthritis Impact of Disease<sup>12 13</sup> (RAID), which measures disease impact, and the Rheumatoid Arthritis Disease Activity Index-5<sup>14-16</sup> (RADAI-5), which measures disease activity. An example of a general or non-specific PROM is the Health Assessment Questionnaire (HAQ), measuring functional status.

There are however also other reasons why self-monitoring in patients with IRD has gained more interest. Usual care in patients with IRDs is primarily aimed at suppressing disease activity, in order to prevent structural damage.<sup>17 18</sup> The disease activity can be measured using a composite index, the Disease Activity Score (DAS) using 28 joint counts,<sup>19</sup> which measures tender and swollen joint counts, acute phase response and a patient's general health assessment. The Treat-to-Target Task Force recommends rheumatologists to monthly assess patients with moderate or high disease activity, and patients with controlled and low disease activity every 3 to 6 months.<sup>20</sup> In practice, however, these frequencies are not always met for various reasons. This strategy causes time constraints and a growing workload among rheumatologists, making it not manageable for all rheumatologists to comply fully to the frequent assessments.<sup>21</sup> Another reason is connected to the ageing population. The number and proportion of patients with IRDs aged 65 and over will increase in the near future.<sup>22</sup> Self-monitoring of the disease course using disease-specific PROMs such as RAID or RADAI-5 could prove to be a solution in diminishing the number of consultations.<sup>23</sup> As disease activity can only be objectively assessed during outpatient consultations, it remains unclear what happens to the disease activity in-between consultations. Fluctuations and peaks in disease activity are easily missed or they remain unnoticed, which could have disastrous consequences regarding joint damage.<sup>17</sup> Self-monitoring might also give a better insight into these fluctuations of disease activity in-between outpatient clinical consultations. Moreover, some patients visit their rheumatologist while their disease activity is under control, thereby contributing to unnecessary outpatient consultations. Summarising, self-monitoring of disease activity in IRDs as a first step towards personalised healthcare enables patients as well as HCPs to get insight into the disease activity course over time. Moreover, it may lead to a more consistent reporting in the long term and may contribute to optimising the number, timing and efficiency of consultations.<sup>11 23</sup> By completing PROMs,

patients who need further medical attention can be identified and receive additional medical attention. Moreover, completion of a PROM will help a patient to prepare for a visit and it could improve the communication between physician and patient.<sup>24 25</sup>

In the present study an online self-monitoring program was pilot-tested in order to test the feasibility of self-monitoring before implementation of a self-monitoring program in daily clinical practice. The aims of this study were to obtain patients' experiences regarding online self-monitoring, to assess the agreement between the disease course assessed with disease-specific PROMs (RAID and RADAI-5) and an objectively measured DAS28 by the rheumatologist, and to assess the adherence to predetermined PROM frequency intervals.

## METHODS

### Study design

This observational pilot study, using quantitative and qualitative research methods, was conducted at a teaching hospital in Uden (The Netherlands) at the rheumatology outpatient clinic from 6 July 2015 until 9 May 2017.

### Inclusion criteria

In order to be eligible for this study, patients had to be diagnosed with an IRD according to the American College of Rheumatology (ACR)/the European League Against Rheumatism (EULAR) criteria.<sup>26</sup> Furthermore, they needed to have an electronic device (laptop/PC, tablet or Smartphone) with access to the internet, and they needed to be able to sufficiently read and write Dutch. Patient inclusion started in July 2015 and we included the last patient in October 2016.

### Follow-up duration

Patients were able to withdraw from the program at any time point. We defined early study termination in two manners: when a patient reported to withdraw from the self-monitoring program, this was evaluated as the end date; some patients did not report dropping out of the study but did stop completing PROMs. End of study in these cases was set by adding the interval time to the date the last PROM was filled in. For example, a patient with a 4-week PROM frequency (28 days) completed the last PROM on 1 March 2017. For this patient, end of study date was set on 29 March 2017.

Self-monitoring program iMonitor, the online self-monitoring program tested in this study, was developed by Pfizer.<sup>27</sup> The program was accessible through a laptop, tablet or Smartphone by filling in a user name, password and pin code. The program complied with the required privacy standards. Because the program was intended to stimulate patient involvement, personalised healthcare and patient self-management, patients selected their preferred PROMs and PROM frequency (one, two, four, six or eight weekly) in advance and the system generated an email alert for filling in a PROM (or PROMs)

accordingly. Patients were able to complete one or more PROMs within a timeframe of 24 hours. They could send a message to the HCPs in case of questions or notifications by using the message option. In case of urgent matters, they could contact the outpatient clinic by telephone.

### Patient-reported outcome measures

Available disease-specific PROMs for patients with RA were the RAID and the RADAI-5, measuring disease impact (0–10; 10=severe impact of disease activity) and disease activity (0–10; 10=severe disease activity). Patients with AS could fill in the disease-specific Bath Ankylosing Spondylitis Disease Activity Index, measuring disease activity (0–10; 10=severe disease activity) and/or the Bath Ankylosing Spondylitis Functional Index, measuring physical function (0–10; 10=severe functional limitation). The HAQ, general PROM that measures physical function, was available for all patients (0–3; 3=severe disability). Patients could opt to assess one to three PROMs. Completion of all PROMs took about 5 min. After completion, the PROM scores were subsequently displayed in a graph. Additionally, DAS28 scores (0–10; remission: DAS28 <2.6, low disease activity:  $\geq 2.6$  DAS28 <3.2, moderate disease activity:  $\geq 3.2$  DAS28  $\leq 5.1$ , high disease activity: DAS28 >5.1) could be added to the graph by the HCP. These DAS28 scores were obtained by the HCPs during outpatient consultations and were kept in the electronic medical files in the hospital.

### Procedure: recruitment

Patients were informed about this pilot study and recruited in several ways. First, we used purposive sampling: rheumatologists themselves asked possible suitable patients to participate during outpatient consultations during the entire study period. Second, during general information meetings at the hospital, patients were informed about the study and were able to sign up. Lastly, leaflets about the study were available in the waiting room and patients were informed about the study through the hospital's website. Patients received a manual containing information regarding access to and use of the program. However, a substantial number needed additional training, which was provided by instruction classes. After patients had been instructed how to use the program, they could indicate which PROM(s) they preferred to fill in by showing them the paper versions. Moreover, they were asked to indicate their desired frequency option. Patients who agreed to take part in the study were asked to sign a consent form. During the regular outpatient consultations, rheumatologists were expected to provide feedback to the patient about the patient's disease course and PROM results.

### Data collection and analysis

#### Quantitative methods

#### Adherence and agreement

First, we determined adherence to the predetermined PROM frequency by assessing whether a patient had

completed (yes or no) the PROMs in the predetermined time interval. Adherence was calculated as the number of completed assessments by the patient divided by the number of PROM assessments that should have been completed according to the chosen interval of the patient times 100%. For example, a patient with a weekly PROM frequency participated for 1 year. This patient should have received 52 email alerts, so 52 PROM assessments should have been completed. This patient completed 40 PROM assessments, so adherence is  $(40/52 \times 100)$  76.9%. Second, we determined the agreement between the DAS28 course and PROM values. Two researchers (LR and PLCMvR) independently assessed agreement by comparing the DAS28 course with the corresponding PROM values from the RAID and/or RADAI-5 using two categories (poor and good) and discussed discrepancies. The RAID and the RADAI-5 were used, because these two disease-specific PROMs measure disease impact and activity, whereas the HAQ is non-disease specific. 'Good' was used in cases where the DAS28 course and the PROM scores showed the same direction (ie, the DAS28 course increased and PROM scores as well). 'Poor' was used in cases where the DAS28 course and PROM scores showed opposite directions (the DAS28 course increased and PROM scores decreased or the other way around). Data from patients with at least three PROM values (falling within a 14-day-window with DAS28 assessment) were assessed.

#### Qualitative methods

Patients' experiences with the self-monitoring program were obtained via a focus group and semistructured interviews. The purpose of the focus group and interviews was to gain insight into relevant factors that might hinder or facilitate patients using the self-monitoring program. The checklist from Flottorp *et al.*<sup>28</sup> served as an inspiration for a semistructured topic guide (see online supplementary appendix 1). Relevant domains for our topic guide were program factors, patient factors, professional–patient interaction factors and resources. Prior to the start of the focus group discussion, we conducted a telephone interview with one patient to check the appropriateness of the topic guide and to check whether the questions were clear. During the focus group discussion, an experienced moderator (PLCMvR) guided the discussion. Patients unable to attend the focus group were interviewed by telephone, using the same topic guide. All participating patients had at least 6 months experience with the self-monitoring program.

#### Qualitative analysis

The interviews and focus group discussion were recorded. The recordings were transcribed *ad verbum* by an independent agency. One of the researchers (LR) and a research assistant independently coded the transcripts, in order to enhance the coding process, data interpretability and trustworthiness. They used the method 'thematic analysis' in which the codes were derived from the data with

the purpose to describe relevant factors regarding self-monitoring and to identify categories and themes. A constant comparative method was used for the analysis of the emerging themes. Any discrepancies in the analysis were discussed until consensus was reached.<sup>29</sup> Afterwards, two researchers (LR and AMPH) agreed on a provisional categorisation and overarching themes. These categories and overarching themes were also discussed with a third and fourth researcher (SAAR-vD and PLCMvR). The COnsolidated criteria for REporting Qualitative research (COREQ) checklist<sup>30</sup> was mainly used as guidance for the reporting of our qualitative research. We conducted coding and analysis by using a qualitative software program (Atlas.ti).

### Patient and public involvement

First, patient involvement was needed during the establishment of the topic guide, which was pretested among one patient in order to check if the questions were comprehensible and clear. Second, patients were encouraged to give suggestions and comments regarding the use of the program during the entire study period. This feedback was used as input for the implementation of a revised version of the program at a later stage. Lastly, the study participants exchanged their experiences with the self-monitoring program with other patients (users and non-users) during research meetings at the hospital.

## RESULTS

### Study population

In this pilot study, slightly more women than men participated ( $n=27$ ; 57.4%). Mean ( $\pm$ ) age was 57.3 (10.7) years. Most patients ( $n=38$ ) were diagnosed with RA (80.9%), while nine patients were diagnosed with a spondylarthropathy (eight patients with PsA and one patient with AS). Other baseline characteristics are given in table 1. Of over 1800 patients with an IRD, we included 47 patients during the study period. Two patients eventually signed the informed consent form but did not complete any PROMs and were withdrawn from the study. An overview of the follow-up duration is presented in figure 1. In total, 23 patients participated from the start (different start dates were possible) until the end of the study (48.9%). The follow-up duration of the 45 patients who completed PROMs varied between 14 and 597 days, with a mean of 350 days.

### Quantitative

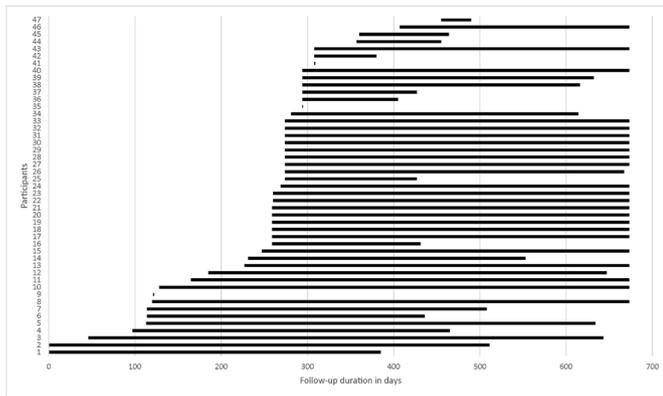
#### Adherence and agreement

Twenty-seven (57.4%) patients were able to use the self-monitoring program without additional training, whereas 20 (42.6%) patients attended the instruction classes. With regard to the PROM preferences, RAID was chosen most often, namely 34 times. HAQ and RADAI-5 were chosen

**Table 1** Baseline characteristics of the 47 patients using the self-monitoring program

Characteristics	RA, n=38	SpA group, n=9
Patient and disease characteristics		
Age, years, mean (SD)	57.74 (11.17)	55.67 (8.69)
Female, n (%)	20 (52.6%)	7 (77.8%)
Disease duration, years, mean (SD)	8.08 (4.74)	9.89 (7.25)
DAS28 score, mean (SD)	3.19 (1.25)	n.a.
Educational level		
Low, n (%)	12 (34.3)	3 (37.5)
Middle, n (%)	11 (31.4)	3 (37.5)
High, n (%)	12 (34.3)	2 (25.0)
Baseline PROM values		
HAQ (0.00–3.00) (n=27), mean, SD, range	0.78 (0.61) (0.00–2.38)	0.98 (0.60) (0.13;1.88)
RADAI-5 (0.00–10.00) (n=24), mean, SD, range	3.49 (2.32) (0.00–7.40)	n.a.
RAID (0.00–10.00) (n=35) mean, SD, range	3.47 (2.28) (0.00–7.61)	n.a.
BASFI (0.00–10.00) (n=1), mean, SD	n.a.	5.05
BASDAI (0.00–10.00) (n=1), mean, SD	n.a.	4.60
Medication use		
csDMARD, n (%)	36 (94.7%)	8 (88.9%)
bDMARD, n (%)	12 (32.0%)	3 (33.3%)

BASDAI, Bath Ankylosing Spondylitis Disease Activity Index (10=severe disease activity); BASFI, Bath Ankylosing Spondylitis Functional Index (10=severe functional limitation); bDMARD, biological disease-modifying antirheumatic drug; csDMARD, conventional synthetic disease-modifying antirheumatic drug; DAS, disease activity score; HAQ, Health Assessment Questionnaire (3=severe disability); RA, rheumatoid arthritis; RADAI-5, Rheumatoid Arthritis Disease Activity Index-5 (10=severe disease activity); RAID, Rheumatoid Arthritis Impact of Disease (10=severe impact of disease activity); SpA, spondylarthropathy.



**Figure 1** Follow-up duration in days of the 47 iMonitor participants. Y-axis: 47 patients who participated in the self-monitoring program, each line represents a patient; X-axis: days since start of study (different start days possible for patients).

27 and 23 times, respectively. Seventeen patients chose to complete one PROM, 21 patients chose to complete two PROMs and 9 patients chose to complete three PROMs. Mean adherence to the predetermined PROM frequency was 68.1%, see [table 2](#). With regard to the agreement between the DAS28 course and PROM values, RAID scored best (from 25 assessments, 17 times a score of ‘good’, 68.0%). RADAI-5, on the other hand, scored ‘good’ in 10 (58.8%) out of 17 assessments, see [table 3](#). [Figure 2](#) shows two examples of assessments regarding the agreement between the DAS28 course and PROM values.

**Qualitative**

We conducted the focus group discussion and telephone interviews between December 2016 and June 2017. The interviews lasted between 24 and 42 min, while the focus

**Table 2** Data regarding PROM frequency, PROM scores and adherence rates, n=47

Item	N (%)
<b>PROM frequency</b>	
1 week	4 (8.5)
2 weeks	10 (21.3)
4 weeks	31 (66.0)
≥6 weeks	2 (4.3)
<b>Number of PROMs to complete, chosen by patient</b>	
One	17 (36.17)
Two	21 (44.68)
Three	9 (19.15)
Mean adherence (%) to the predetermined PROM frequency	68.1%

Adherence to the predefined PROM frequency calculated by dividing the number of completed PROMs by the number of PROM assessments (based on the reminder emails) that should have been completed according to the chosen PROM frequency by the patient, times 100.  
PROMs, patient-reported outcome measures.

**Table 3** Agreement (poor or good) between the DAS28 course and disease-specific PROMs (RAID and RADAI-5), assessed in n=33 patients

PROMs	Poor	Good	Total
RAID	8 (32.0%)	17 (68.0%)	25
RADAI-5	7 (41.2%)	10 (58.8%)	17

DAS28 course, disease activity score using 28 joint counts, assessed by rheumatologists.  
Good, DAS28 course and the PROM scores showed the same direction.  
Poor, DAS28 course and PROM scores showed opposite direction.  
DAS28, Disease Activity Score 28; PROMs, patient-reported outcome measures; RADAI-5, Rheumatoid Arthritis Disease Activity Index-5; RAID, Rheumatoid Arthritis Impact of Disease.

group discussion lasted 1 hour and 22 min. Six patients attended the focus group discussion, and four patients participated in a telephone interview (five female and five male patients).

**Patients’ experiences regarding the self-monitoring program**

Three main themes emerged from the focus group discussion and interviews: knowledge about and insight into disease (activity), patient–professional interaction and functionality of the program. Five subcategories emerged: disease (self)management, discussing results with HCPs, technical factors, user interface and PROMs and patients’ suggestions for improvement. [Table 4](#) provides an overview of the themes and subcategories regarding the qualitative analysis.

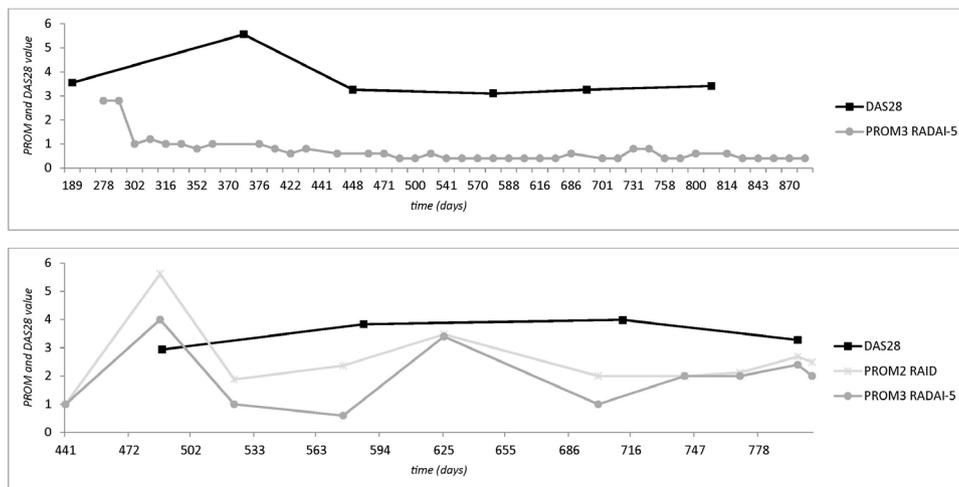
**Theme I: knowledge about and insight into disease (activity)**

The most cited reason for using the self-monitoring program was that patients gained insight into their (long-term) disease activity course. Most patients indicated that using the program led to more knowledge and awareness about their disease. Some patients reported that they recognised peaks in disease activity earlier and could subsequently prepare for an exacerbation. Patients also mentioned that they became more prudent when noticing a flare. When asked more specifically about patients’ experiences with the agreement between their PROM values and DAS28 scores, most patients thought their PROM values were in line with their DAS28. One patient noted: ‘*By consciously using the program, it was easier to find things about rheumatism and to gain more insight into the question ‘What is rheumatism?’*’

**Theme II: patient–professional interactions**

**Disease (self)management**

By using the self-monitoring program, most patients felt less dependent on their HCP. Patients appreciated the fact that they were able to influence their own disease management. Overall, patients thought that the self-monitoring program could contribute to a reduction in the number of outpatient consultations.



**Figure 2** Example of a positive (above) and negative (below) rating regarding the agreement between the PROMs and DAS28 course. Above: good congruence between PROM values and DAS28 scores; Below: poor congruence between PROM values and DAS28 scores; good, DAS28 course and the PROM scores show the same direction; poor, DAS28 course and PROM scores show opposite direction. DAS28, disease activity score 28; PROM, patient-reported outcome measure; RADAI-5, Rheumatoid Arthritis Disease Activity Index-5; RAID, Rheumatoid Arthritis Impact of Disease.

A patient told: *I can monitor my disease course, keep record of my disease activity in-between consultations, without being dependent on the professional*

#### Discussing results with HCPs

Patients emphasised the importance of discussing the results of online monitoring (eg, PROM values) with their HCP (rheumatologist or nurse). Most of all, they wanted to know if they were ‘doing it right’. Some patients expressed the value of discussing their results with their HCP. One patient provided the following scenario: *I used to look at the back of a computer screen during an outpatient visit. Now, I’m looking at the computer screen together with my HCP, sharing and discussing the PROM values and our ideas about my treatment*. Patients who did not discuss their values felt the need to do so in the future.

**Table 4** Themes and subcategories with regard to the qualitative analysis of patients’ experiences with iMonitor

Theme	Subcategory
Knowledge about and insight into disease (activity)	n.a.
Patient–professional interactions	<ul style="list-style-type: none"> <li>▶ Disease (self)management</li> <li>▶ Discussing results with HCPs</li> </ul>
Functionality of the program	<ul style="list-style-type: none"> <li>▶ Technical factors</li> <li>▶ User interface and PROMs</li> <li>▶ Patients’ suggestions for improvement</li> </ul>

Three main themes and five subcategories emerged from the qualitative analysis. The checklist from Flottorp *et al*<sup>28</sup> served as a guide for the establishment of the topic guide. HCPs, healthcare professionals.

#### Theme III: functionality of the program

##### Technical factors

Barriers regarding the use of the self-monitoring program were mostly related to technical aspects. Some patients had problems with the login system, which hindered them from accessing the website. Regarding the PROM reminder emails: the system generated an email alert at fixed time points (eg, 4 weekly). Some patients noticed that the system generated an alert at unfortunate time points or even no alert at all.

##### User interface and PROMs

Twenty-seven patients joined the instruction classes, which were perceived to be very helpful. Overall, patients were satisfied with the user interface of the program. They reviewed the layout as clear and comprehensible. Some patients experienced difficulties with the content and layout of the PROMs. For example, some patients thought the questions were not specific enough. Furthermore, the program did not use a progress bar and there was no ‘Accomplish’ sign after completing a PROM. As a result—in case of completing more than one PROM—some patients did not know how many PROMs they had actually completed.

##### Patients’ suggestions for improvement

Most commonly mentioned suggestions concerned adjustments to clarify PROM values, for example a textbox to type a comment in case of an exacerbation. Additionally, patients provided suggestions concerning the possibility of also having access to their lab values in the self-monitoring program, as well as the possibility of having a more detailed look at a certain time period.

#### DISCUSSION

This study collected experiences from patients with IRDs regarding online self-monitoring. Moreover, we assessed

adherence to the predefined PROM frequency to measure disease activity and the agreement between the PROMs and the DAS28 course. The qualitative analysis revealed three themes: knowledge about and insight into disease (activity), patient–professional interaction and functionality of the program. Overall, patients were mainly positive about the program and were willing to continue. Most of them participated for an extended period: mean follow-up duration was almost 1 year. Mean adherence to the predefined PROM frequency was 68.1%, and the disease-specific and patient-reported RAID showed best agreement with the DAS28 assessed by the rheumatologist. Patients reported that they gained more knowledge about their disease and felt less dependent on their HCP.

By self-monitoring disease activity, patients obtained a graphic overview of their PROM values over time, which gave them insight into their disease course. Patients reported that they appreciated both this long-term insight into their disease pattern, and the ability to anticipate on an exacerbation. They also indicated that they gained more knowledge about their disease, they felt better prepared for a consultation and felt less dependent on their HCP in handling their disease. Literature about self-monitoring in diabetes already showed that knowledge about the disease and self-monitoring is related.<sup>10</sup> Although some knowledge is a prerequisite for self-monitoring, the process of self-monitoring contributes to the further expansion of disease-related knowledge. Adequate disease-related knowledge is important, since it may influence patients' decisions regarding treatment, compliance and self-management performance,<sup>31</sup> as well as the ability to recognise signs, symptoms and patterns,<sup>10</sup> which is supported by a study about experiences with telehealth in patients with RA.<sup>32</sup> All of these aspects are essential in shared decision-making,<sup>33</sup> while also being beneficial to the efficiency of consultations. From the perspective of the HCP, it is important to give feedback to the patients about the results of self-monitoring during outpatient consultations, a fact that was emphasised by our study participants during the interviews. Those who had not received feedback about their PROM values and/or disease activity course were less motivated to continue with the program. The importance of feedback was emphasised in a study in which patients with early RA received visual feedback by their HCP about their disease progression. Compared with patients who received standard care, patients who received feedback showed significant differences regarding disease activity parameters.<sup>34</sup> Obtaining insight into the long-term disease activity course, and being able to anticipate on an exacerbation, might benefit the effectiveness of the delivered care as well. Patients will be able to respond to a deterioration in a timely manner and will have a greater chance to receive the care they need at the right time, resulting in a decrease of the cumulative disease activity. On the other hand, fewer consultations are possible if the disease activity is stable, which will eventually lead to less frequent outpatient visits. That reduction of healthcare

costs can be obtained by introducing patient-report outcomes (PROs) in the follow-up was shown by a study on tele-health in RA. Patients received PRO-based health follow-up and were scheduled for telephone consultations by a rheumatologist or nurse. Similar results regarding disease control were found for the telehealth group compared with conventional follow-up.<sup>35</sup> Studies on self-monitoring in other chronic diseases have already proven its effectiveness, such as better control of blood glucose levels in diabetes,<sup>36 37</sup> reduction in mortality rates in heart failure,<sup>38 39</sup> reductions in blood pressure in hypertension<sup>40 41</sup> and reductions in thromboembolic events in patients using anticoagulation therapy.<sup>42</sup> The effectiveness of self-monitoring resulted in a reduction in hospital readmissions in patients with hypertension, Chronic Obstructive Pulmonary Disease (COPD) and heart failure.<sup>43</sup> Patients in our study believed that self-monitoring could lead to a reduction in consultations, although they stressed the need and possibility for contacting the outpatient clinic when necessary. To our knowledge, there are no studies in IRDs on the efficiency of online remote self-monitoring of the disease activity by completing PROMs using an online program on reduction in consultations. Further research will therefore be needed.

Barriers regarding online self-monitoring were mostly related to the functionality of the online monitoring system. Some patients experienced log-on problems, while others would like to have access in the system to more extensive information about their health status in general (eg, blood test results). Despite these barriers, almost half of the participants reached the end of the study, and the follow-up duration was almost 1 year. Literature in the field of technology and innovations indicates that factors such as compatibility, complexity and relative advantage influence the adoption of new innovations.<sup>44</sup> Therefore, a self-monitoring program should be comprehensible and user-friendly and preferably integrated into an existing hospital system. In addition, we recommend screening patients on motivation and computer skills and providing guided practice. We also recommend to let patients choose their own preferred interval and PROMs. Forcing patients to complete PROMs at predefined intervals set by researchers does not support our idea of self-management and might impede patients' motivation. Some patients opted for weekly self-assessments, which might seem to be too frequent for us as HCPs. However, especially in an early or active phase of the disease, this seems to provide some measure of support for some patients. Patients were willing and able to self-monitor their disease. The mean adherence to the predetermined PROM frequency was reasonably high: 68.1%. This could be partly explained by system-related factors such as the reminders, which were considered very useful in encouraging patients to complete the questionnaire. Next to this, patient-related factors such as intrinsic motivation might also have influenced this percentage. Since there was no real 'need' or urgency for



self-monitoring in our study, as opposed to blood glucose monitoring in diabetes, for example, reaching complete (100%) adherence was not a realistic option. Both the RAID and RADAI-5 had acceptable agreements with the DAS28, 68.0% and 58.8%, respectively. Due to the relatively small number of patients no conclusion can be drawn as to which PROM should be used to self-monitor the disease course.

By using qualitative methods we were able to examine the experiences and barriers that influence participation in self-monitoring programs. This resulted in a thorough description of factors related to self-monitoring, and guidance for further development of appropriate tools. The main limitation of this study was the selective, highly motivated study population due to the purpose sampling. Because of the small study sample, it remains unclear which percentage of the total population will be eligible for self-monitoring. However, the main purpose was to gather experiences about self-monitoring, which were provided by the extensive comments of the patients. With regard to difficulties in data interpretation in qualitative research, it remains unclear whether we actually truly grasped what patients were really thinking or feeling. Interpretations might have been influenced by the professional backgrounds and theoretical perspectives of the researchers. However, the coding process was done together with a collaborator who did not have a scientific background. Another limitation is connected to the fact that the moderator was the main care provider for some patients which might have influenced their responses. Despite these limitations, we extensively and thoroughly discussed our data several times in order to identify the relevant categories and emerging themes regarding self-monitoring.

By monitoring their disease activity at home, patients were involved in their own disease management and had individual control and responsibilities. During outpatient visits, patients might be better prepared to interact with their HCP, which will improve shared decision-making, contributing to the concept of personalised care. Self-monitoring—as a prerequisite of self-management—might benefit the cost-effectiveness of outpatient consultations. Efficiency gains are reflected in a reduction in the number of consultations without any increase in costs. At the same time, patient outcomes and patients' satisfaction should either remain stable or increase. This study is a first step toward personalised healthcare and involving the patient in decision-making about their disease treatment. Findings from our study were used to implement a self-monitoring program at our outpatient clinic using the Integrated Electronic Patient Record from the hospital.

The present study showed the potential of self-monitoring as a first step towards disease self-management. Patients reported that they gained more knowledge, felt less dependent on their HCP and most of them were able to monitor their disease. Therefore, we believe that self-monitoring can benefit the quality and efficiency of

healthcare. Further research will be needed to confirm the cost-effectiveness of self-monitoring.

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**Contributors** Study acquisition was done by PLCMvR. All authors helped in conception and design. LR obtained the ethical approval, helped in qualitative data collection and pretested the topic guide. Focus group discussion: PLCMvR functioned as moderator and LR as observer. Telephone interviews were conducted by LR. Quantitative data collection was done by PLCMvR and SAAR-vD (mainly clinical data), whereas LR obtained data derived from the self-monitoring program. Qualitative data analysis: LR was involved as one of the coders during the coding process, together with a research assistant. Provisional categorisation of themes was done by LR and AMPH. Final version of the categorisation of themes and categories was done by all the authors. Quantitative data analysis was done by all the authors. Writing: LR drafted the first version of the manuscript. PLCMvR, AMPH and SAAR-vD revised the manuscript. The final manuscript has been seen and approved by all the authors.

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**Patient and public involvement** Patients and/or the public were involved in the design, or conduct, or reporting or dissemination plans of this research. Refer to the Methods section for further details.

**Patient consent for publication** Not required.

**Ethics approval** The present study fulfils the Helsinki criteria and was approved by the Medical Ethical Committee of the Radboud University Medical Center Nijmegen (2016-2435) and concluded that no specific obligations were applicable to this research.

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