

**Postprint version** :  
**Journal website** : <https://www.sciencedirect.com/science/article/pii/S0738399118304877>  
**Pubmed link** : <https://www.ncbi.nlm.nih.gov/pubmed/30638903>  
**DOI** : 10.1016/j.pec.2019.01.005

This is a Nivel certified Post Print, more info at [nivel.nl](http://nivel.nl)

## Lessons learned from patients with access to an online self-management enhancing program for RA patients: Qualitative analysis of interviews alongside a randomized clinical trial

R.M. Zuidema a, S. Van Dulmen b, c, d, M.W.G Nijhuis-van der Sanden a, J. Fransen e, B.G.I Van Gaal a, f

### Abstract

**Objective:** This study aims to explain the earlier findings of a Randomized Controlled Trial (RCT), which showed that rheumatoid arthritis (RA) patients did not benefit from an online self-management program. Moreover, less patients than expected used the program.

**Methods:** As part of an explorative RCT, patients were interviewed to explore their (non) usage of the program. Purposive sampling (n = 21) was used to select patients from four groups of patients (n = 49): 1) non-users; 2) low users; 3) high users basic; 4) high users plus.

**Results:** The program supported only a small group of patients because: 1) not all patients were motivated to use the program, 2) patients had no clear expectation or had differing expectations of the program, 3) there was a mismatch between individual patients' support needs and the needs included in the program, 4) reminders were only sent to fill in the diaries for pain and fatigue, not to use the program modules.

**Conclusion:** This study offers insights in the (non-) usage of online programs and how usage could be increased in practice.

**Practical implications:** Health professionals should be involved in the implementation of this online programs and should inform patients what the program could bring them.

### 1. Introduction

Over the past decade, online self-management enhancing programs have been developed for patients to better manage their chronic illnesses. These programs can support patients in taking responsibility for improving their health status, e.g. reducing pain or increasing physical activity, by strengthening

Zuidema, R., Dulmen, S. van, Nijhuis-van der Sanden M.W.G., Fransen, J., Gaal, B.G.I. van. Lessons learned from patients with access to an online self-management enhancing program for RA patients: qualitative analysis of interviews alongside a randomized clinical trial. *Patient Education and Counseling*: 2018

self-management behaviours such as physical exercise and medication adherence, which can optimize their social participation and working capabilities [[1], [2], [3], [4], [5]]. Most online self-management enhancing programs are complex interventions characterized by a number of components (e.g. modelling video's for instruction or medication schedules aimed to enhance self-efficacy) to actively induce behavioural change. These components differ in the underlying social theories. A social theory can inform the intervention about which theoretical constructs need to be targeted (for example attitude and/or self-efficacy) and which behavioral change techniques need to be used to change these theoretical constructs such as using modelling to increase self-efficacy [1,6]. To be effective, online self-management programs need to be used regularly [7]. Research shows that currently, the actual usage (first visit, stay on the website and re-visits) of online self-management programs in experimental settings is quite low [8], and it is expected that usage may be even lower when these programs are implemented in real-life settings [6,9]. One explanation for the underuse of such programs could be that they are developed without input from patients [10] and without an underlying social theory [11]. Also, patients can experience various barriers to perform self-management behaviour, e.g. a lack of motivation or knowledge about the program, physical symptoms or difficulties with program use, such as log-in problems [[12], [13], [14]] Knowing that, we developed, together with patients and professionals, an online self-management enhancing program targeting patients with Rheumatoid Arthritis (RA), based on the Intervention Mapping (IM) framework [15] and the Theory of Planned Behaviour to induce behavioural change [16,17]. It was expected that patients' input would lead to high engagement, positive effects and higher usage. An explorative Randomised Controlled Trial (RCT) was conducted to explore the potential efficacy of the online program versus 'usual care', in preparation of a larger trial on the following outcome measurements: self-management behavior, self-efficacy, general health status, focus on fatigue, perceived pain and fatigue [15,18]. This explorative RCT showed that patients did not benefit from the program. Moreover, patients used the program less often than expected. From the patients in the intervention group (n = 78), only n = 40 patients used the program 6 or more times, while n = 29 patients used the program not or only once. Because of the importance of increasing usage, we interviewed patients from the intervention group of the exploratory RCT (non-users and users of the program as well) to obtain insight into: 1) why patients used or disused the online program and 2) the experiences with the program among users. The results of this study can be regarded when performing future studies with this and other online programs.

## 2. Materials and methods

### 2.1. Design

The participants in this qualitative study were the patients that were randomized to the intervention group of the explorative RCT [10]. Inclusion criteria of the explorative RCT were described elsewhere [11]. In short, all patients were diagnosed with RA, aged 18 years or older, were able to speak and read Dutch and had access to a computer with an internet connection. Patients who received psychiatric or psychological treatment were excluded. The medical ethics committee of Arnhem-Nijmegen approved this study (number 2014-1208). The study is performed in conformity with the declaration of Helsinki.

### 2.2. Intervention

#### 2.2.1. Development of the program

The intervention was developed between January 2013 and July 2014, using the Intervention Mapping (IM) framework, and aimed to increase self-management behaviour of adult Dutch RA patients. The repeated inputs of five patients and six health professionals were used in each step of IM [15]. Table 1

Zuidema, R., Dulmen, S. van, Nijhuis-van der Sanden M.W.G., Fransen, J., Gaal, B.G.I. van. Lessons learned from patients with access to an online self-management enhancing program for RA patients: qualitative analysis of interviews alongside a randomized clinical trial. *Patient Education and Counseling*: 2018

shows an overview of how the program was created, by mentioning patients' and professionals' input in each step.

[\[table 1\]](#)

### **2.2.2. Content of the online program**

The content of the program is shown in Table 2. The program was followed by the patients independently after receiving a log-in code. They were able to use the program at their own time over a period of 12 months. For technical problems a helpdesk was available. For each module, performance objectives were formulated to specify the pursued behavioural change. Information about the Theory of planned behaviour, the Behavioural Change Strategies (BCTs) and the practical applications are shown in Table 3.

[\[table 2\]](#) [\[table 3\]](#)

### **2.3. Patient recruitment**

For this interview study, patients randomized to the intervention group of the 12 months explorative RCT were recruited by telephone after they filled in the questionnaire at 6 months after baseline. Thus, patients were recruited for the interview during their participation in the explorative RCT. Written informed consent had to be provided by the patient before inclusion in the qualitative study.

### **2.4. Procedure**

Purposive sampling was used to select patients regarding the degree in which they used the program. Four patient groups were recruited: 1) non-users 2) low users: patients who logged in between 1–5 times, 3) moderate users: patients who logged in 6 or more times for mainly using the diary for pain and fatigue, 4) high users: patients who logged in 6 or more times, using the modules as well as the diary. The cut-off point between 'low users' and 'moderate' and 'high users' was arbitrarily set on 5 times as a reflection of active involvement. It was expected that 'moderate' users, who mainly used the diary for monitoring pain and fatigue, had different experiences than 'high users', who used both the diary and the modules.

After giving written consent, each patient was interviewed once by telephone between February and May 2016 by the same researcher (sociologist/female). An interview guide was used to focus on three phases of (non) usage: 1) before using the online program, 2) while using of the program, 3) after using the program, i.e. to determine the outcomes of the program (appendix). The interview guide was pilot-tested; in addition, a test interview was held. The semi-structured interviews, lasting no longer than 30 minutes, were audio-recorded, anonymised and transcribed verbatim. After interviewing two participants per subgroup, members of the research team (RN, BvG, SvD) read the transcript of the interviews to optimise it and to add questions. The first 10 interviewed participants also received a summary of their own interview for a global check.

### **2.5. Data analysis**

Interview transcripts were uploaded to the software program AtlasTi for coding. The first six transcripts were independently coded in an inductive way by two researchers (RMZ and AOB). Codes were identified from the data and were related to the questions that were asked of the participants. After comparing the coded transcripts, code differences were resolved until the two researchers reached consensus. Codes were brought together in themes. Interviews were continued until data saturation was reached.

Zuidema, R., Dulmen, S. van, Nijhuis-van der Sanden M.W.G., Fransen, J., Gaal, B.G.I. van. Lessons learned from patients with access to an online self-management enhancing program for RA patients: qualitative analysis of interviews alongside a randomized clinical trial. *Patient Education and Counseling*: 2018

### 3. Results

In total, 78 patients were randomised to the intervention group in the exploratory RCT. At month 6 (T1), 59 patients had returned the questionnaire from the exploratory RCT. For the interviews, 49 patients were invited, 31 could be reached by telephone and 22 consented to participate, of whom 1 withdrew consent without providing a reason. The remaining ten eligible patients were not recruited because data saturation was reached. Consequently, 21 patients participated in the interviews, belonging to four user-groups (Table 4). Codes were combined according to the following themes: 'motivation', 'expectations of the program' and 'support needs for self-management' to analyse the phase before (not) using the program. The themes 'usability' and 'usage of the program' were used to analyse the phase of program use. Subsequently, the themes 'experiences' and 'satisfaction with the program' were used to analyse the phase after using the program. The final transcript (n = 21) yielded no new information and codes, indicating data saturation. The results are presented below under the four themes as described.

#### [table 4]

The results are presented under the themes as described in the method section. In this section, the group "high users" refers to both groups of high users (high users basic and high users plus). Different results between these two groups are indicated in the text.

#### 3.1. Patient motivation

Some high users felt intrinsically motivated to use the self-management enhancing program. These patients had an internal drive to increase their self-management behaviour, e.g. they because wanted to be more responsible for their own health or used the online program to refresh their knowledge.

"A month after a visit to the website, I refreshed my knowledge. For example, how do I need perform my exercises (high user plus)"

Also, curiosity whether the program could help them to find more information about RA or could support them to perform self-management behaviour was a reason to use the program. Another part of the patients, both low users and high users felt extrinsically motivated by the advice of the rheumatologist or by the invitation letter of the research team. Improving healthcare was another reason to use the program.

"The rheumatologist asked me to participate (low user)". I thought this study could lead to improvements in healthcare (high user)".

Reasons for not being motivated to use the program were: finding the online program not important enough, laziness, lack of time, personal circumstances and ICT problems. The password, with a required number of letters, capital letters, signs and numbers, was experienced as difficult and forced patients to use an alternative password. To open the homepage on the iPad also appeared to be difficult. All these difficulties decreased the motivation.

#### 3.2. Expectations of the program

All patients were asked whether they have had a priori expectations of the program, and if so, which expectations they had. Most users had no specific expectations and started using the program without having a clear idea.

"I had no priori expectations of the program, I could not make an imagination of the program (high user)"

Some high users expected to find information about topics which were not discussed in the program, namely information about the causes of RA or new medicines and their effects. Also, some patients expected a possibility to interact with other patients, which was not the case. Non-users expected that the program could help them to find information about medications and the prevention of physical impairment.

### **3.3. Support needs for self-management**

Users as well as non-users indicated a need for support in setting boundaries in daily life, finding balance in daily activities and prevention for physical impairment, which were all topics of the online program. There were also patients who had support needs that were not met by the program. These patients, mostly suffering from a long-term disease, expressed a need for more (scientific) in-depth information about the newest developments in medication, nutrition in relation to RA, non-conventional medicines and an explanation of eye problems related to RA.

"That issue (about developments in medication) was in the media, that's one example, but I really have a need for this information about this issue. What is new about it and what could I do with it? (high user plus)"

They mentioned that the information they read in the online program would be helpful when RA is just diagnosed.

"I think when someone gets rheumatism, I would recommend this as this program could be a guidance" (high user).

The possibility to interact online with other patients to give each other advice in how to cope with RA, and an option to chat with a health professional, were also mentioned as a need for support.

Even though the program did not fulfil the support needs for all patients with a long-term disease, they did re-visit the program several times due to curiosity, refreshing knowledge and a sense of obligation. Among patients who experienced only few symptoms of RA, both users and non-users reported no support need. Should symptoms of RA arise, a visit to the rheumatologist and rheumatology nurse would suffice for them. Some patients, mostly with a long-term disease, had followed a course previously, had their own physical exercise program in the fitness centre or participated in a fitness group; the information provided in the online program was therefore not new for them. Moreover, they felt that the social support of family and friends was adequate.

### **3.4. Satisfaction with the online program**

The attractive 'look and feel' of the online program, such as the clear lay-out, the possibilities to easily navigate through the program and to easily click on topics, a good overview of the content and the use of concise texts and ordered information were mentioned as attractive features. Patients were also satisfied with very two weeks automatically sent emails to remind them to fill in the diary for pain and fatigue. The diary did encourage patients to think and evaluate why pain had occurred.

"And then, an e-mail and such a program, where you can automatically insert pain and fatigue, is very nice and I also find that you can evaluate yourself: How did it come that I had so pain in the elbow? What did I do? Those kinds of things are very nice (high user)".

Zuidema, R., Dulmen, S. van, Nijhuis-van der Sanden M.W.G., Fransen, J., Gaal, B.G.I. van. Lessons learned from patients with access to an online self-management enhancing program for RA patients: qualitative analysis of interviews alongside a randomized clinical trial. Patient Education and Counseling: 2018

Other patients, high and low users, were unsatisfied with the program. For some of them, parts of the program were confronting, namely the modules worrying, coping with RA and the pain and fatigue diary. These topics forced them to think about their disease, even when they did not want to.

"I'm not a person who exactly knows how they feel every day; you need to fill in something and then you have too many thoughts about it while you are actually trying to minimise thinking (low user)".

Also, some patients found the problem was too long and found it difficult to figure out how the program works and to fill in certain components of the program.

### **3.5. Usage of the program**

The bi-weekly reminders for the pain and fatigue diary were triggers to re-visit the program. A part of the high users visited modules of the program after filling in the diary because they were curious if there were any tasks in the modules for them.

"No, in the first instance, I visited the website when I wanted, but later, when I received emails....yes, then you visit the program more frequently (high user)".

Other high users mentioned that the emails every two weeks were a reason to re-visit the diary (not necessarily the program).

"Because of my busy daily life, I forget it. You should have a pattern. I certainly would not have continued without receiving an email (high user)".

High-users and low-users gave various reasons for not re-visiting the program. High users did not take the initiative (after a while) to fill in the diary of daily activities or the pain and fatigue diary because this was not in their system.

"Yes, difficult if it is not in your system. Every day you check your email, but you don't visit the site to fill in [the diary of daily activities] (high user plus)".

Reasons for not re-visiting the program for high users were, having physical problems, not needing any support or needing other support than the program offered. For low-users, problems with logging in, being unfamiliar with the internet and even finding the internet scary were reasons for no re-visit. Patients visited the modules 'finding daily balance', 'setting boundaries', 'assistive devices' for more information, learning skills about setting boundaries and applying for a wheelchair and domestic help. The reasons for not visiting the modules were as follows: experiencing no problems around these topics ('medication' and 'assistive devices'), already having the skills ('asking for social support', 'setting boundaries', 'coping with RA'). The module 'coping with worries' was too confronting for some patients, because it forced them to think about their worries when they did not want that.

### **3.6. Experienced support of the program**

Some users, mainly high users, experienced support by the program, according to the drafted performance objectives of the program (Table 2) The module 'balancing daily life activities' supported them in finding more rest during the day, thereby gaining more energy. The module 'setting boundaries' supported patients in communicating their boundaries to others. Also, patients talked in their social environment about their illness to make sure the environment knew what to expect.

"After using the program, I started to communicate about my illness to others. I explained them what RA is and requested that they do not ask too much (low user)".

The module 'physical exercises' gave patients insight into which exercises they could do and stimulated them to find a balance between daily activities. This ensured that patients performed physical exercises as part of their daily life. Patients were more physically active than prior to using the online program, and because of this, patients were less tired, had less pain, and their stiffness decreased.

"I learned which exercises I could do. I fit this in my daily schedule and take the time to stretch and strength my muscles every morning. I'm not tired anymore and do not have any pain anymore (high user)".

One patient mentioned that the module 'taking medication', in which patients receive more insight in their medication use and learn how to discuss medication use with their rheumatologist or pharmacist, has led to a lower usage of pain medication, which was a positive sign, because less medication use leads to less side-effects. Each module consisted of certain elements, the so-called "operationalised BCT's": texts, a number of modelling videos in which patients reported their experiences or gave an explanation on how to cope with a certain topic and with exercises. Patients were asked which of these elements supported them. Videos confirmed that patients adequately coped with RA or gave them the feeling they were not the only ones with RA. The diary for pain and fatigue gave patients an overview about their patterns of pain and fatigue over time, enabling them to reflect upon the course of the disease. As a result, the patients made better decisions about when to take more rest and also discussed their results with the rheumatologist. In some patients, however, the modelling videos had a negative effect on their mood.

"I feel bad that other people have RA, but do not focus on your limitations, but focus on the things you can do" (high user).

The shown physical exercises were difficult to perform for older patients. The diary for daily activities required a lot of daily input, and for some patients, this was too time-consuming. Some patients thought that a program could be supportive when it includes a group-based face-to-face approach to share needs with other RA patients and to obtain more information about new developments in the field of RA.

## 4. Discussion and conclusions

### 4.1. Discussion

The most important reasons our online program supports only a small number of patients in their self-management behaviour were as follows: 1) some patients were not (intrinsically) motivated to start using the program (first phase of behavioural change) and because the behavioural change strategies (BCTs) in the online program did not motivate them, 2) patients had no clear or a different expectation of the program, 3) there was a mismatch between individual support needs and the needs included in the program and 4) no triggers were sent to use the modules of the program.

#### 4.1.1. Motivation

Not all non-users, low-users and high users were equally motivated or felt only extrinsically motivated by the advice of the rheumatologist or by the invitation letter of the research team. Extrinsically motivated patients often experience barriers to (re)-use the program that are difficult to overcome when patients are not intrinsically motivated [19,20]. However, in our study some of the patients who were extrinsically motivated used the program frequently. It may be that these patients felt obligated



Zuidema, R., Dulmen, S. van, Nijhuis-van der Sanden M.W.G., Fransen, J., Gaal, B.G.I. van. Lessons learned from patients with access to an online self-management enhancing program for RA patients: qualitative analysis of interviews alongside a randomized clinical trial. *Patient Education and Counseling*: 2018

to re-use the program often after agreeing to participate. The BCTs in the online program aimed to change the behaviour of users, but patients who did not visit the program were not reached by the strategies. Thus, to reach less motivated patients, it is necessary to add strategies to increase the awareness that self-management can be supported by an online program. A part of the patients had already experienced support from the rheumatologist and the nurse, which was considered sufficient. It is also possible that patients were not aware of their active role in the management of their illness. In that case, the role of the nurse could be to explain in which ways they can actively manage their disease.

#### **4.1.2. Expectations**

Most patients did not know what to expect from the program, while some found that the program did not match with their expectations (they expected, for example, in-depth information about medication). A part of these patients expected to find information about various topics and were not aware that this online program could support them to change their behaviour. A reason that patients had no expectation of the program could be the result of our focus on the implementation of the program, thereby neglecting to attract potential users. Although patients received an instruction manual of the program, this manual was mainly focused on how to use the program and less on what the program could bring them, for example: more balance in daily life or less fatigue. Considering the Technology Acceptance Model and the Unified Theory of Acceptance and Use of Technology, clear expectations are important in the decision to use the program. That is, when patients have no expectation about the pursued effects of the program and the effort expected from them, they tend to use the program less frequently [21]. Thus, it is crucial to clarify what patients can expect from the program, how much effort is needed and what effect can be reached.

#### **4.1.3. Patient needs**

Most patients had a need for more information and contact with other patients and health professionals. This result was unexpected, as we conducted a thorough need assessment, recommended by the Intervention Mapping framework to receive insights into the support needs for the self-management of RA patients [[22], [23], [24]]. Therefore, it seems that a general need assessment is not sufficient to match the individual support needs with the program.

#### **4.1.4. Reminders**

Reminders were linked to the pain and fatigue diary and not directly to the modules. Patients found reminders a trigger to re-use the program, but re-visited only the diary and not the modules. Earlier research showed that reminders can be effective to re-use a program [20,25]. It seems that the lack of a direct link between the diaries to the behavioural change techniques in the modules was a reason for not visiting the modules in the program.

#### **4.1.5. Advances and limitations**

Although we assumed that an interview study is the best approach to explore the use of the program, this study has some limitations. Firstly, patients were asked for an interview after they filled in the questionnaire at 6 months follow-up, while they had a 12 months access to the program. Patients could be triggered to re-use the program after the interview, but our log-in data did not show that interviewed patients logged in directly after the interviews. Secondly, most of the patients had not used the program for a while, and consequently, some patients could not remember how to use the program correctly. The third limitation is that the program is delivered to patients without the involvement of health professionals, which is essential to inform the patients what they can expect and guide patients through the program based on their needs and competences.



Zuidema, R., Dulmen, S. van, Nijhuis-van der Sanden M.W.G., Fransen, J., Gaal, B.G.I. van. Lessons learned from patients with access to an online self-management enhancing program for RA patients: qualitative analysis of interviews alongside a randomized clinical trial. *Patient Education and Counseling*: 2018

#### **4.2. Implications for practice**

Based on the results of this interview study, some implications can be made for further research and practice. It is recommended to deliver the online program in combination with face-to-face treatment (blended care). Alternative approaches to increase the efficacy and use of the program might be the involvement of health professionals such as nurses to implement the program and to guide patients in their usage of the program. To reach patients, it is recommended to assess their motivation. Health professionals can use the answers from a questionnaire according to the Trans Theoretical Model (TTM) to identify the behavioural change stage [26]. Depending on this stage, the health professionals can decide to use Motivational Interviewing (MI) to increase patient motivation or give patients who are already motivated access to the program [27]. To clarify what the patients can expect from an online self-management program, instructions from health professionals are needed in terms of the goals of the program, the expected outcomes and the effort expected from the patients. To assess patients' needs, it would be helpful for patients to discuss their support needs with a nurse. Besides formulating a support need, a health professional can help to specify a support need to tailor the program to the needs of the patient. That is, an information need about treatment or medication might be too general and needs to be more specific. Based on patients' support needs, the program could be tailored to the individual patient (e.g. offer a specific module from the online program adjusted to individual needs).

To improve the content of the program, more (scientific) in-depth information about the newest developments in medication, nutrition in relation to RA, non-conventional medicine and an explanation about the eye problems associated with RA could be added. Also, an interactive component, facilitating contact with other RA patients and health professionals, could be added as part of the program. Regarding the reminders, it is important to assess patients' preferences regarding reminders and to link reminders directly to the modules in the program.

#### **4.3. Overall conclusion**

This interview study contributes to our understanding of the (non-) usage of this online self-management enhancing program. The results suggest that the involvement of health professionals is important for a successful implementation of the program. The program can be improved as follows 1) providing a more profound individual need assessment, 2) assessment of patients' motivational stage before usage, 3) providing a clear outline of realistic expectations from the program and 4) integrating reminders into program modules. Already effective proven online programs can use the results of this study as pre-conditions for a successful implementation.

#### ***Funding***

This study was funded by ZonMw, The Netherlands Organization for Health Research and Development (520001001). Additional funding for the development of 'Reuma zelf te lijf' was obtained from Roche Pharmaceuticals, Janssen-Gilag BV and Pfizer BV. Only the authors were involved in the design, analyses, interpretation of results and the writing of the manuscript. The trial is registered at the Dutch Trial Register (ID: NTR4871).

Zuidema, R., Dulmen, S. van, Nijhuis-van der Sanden M.W.G., Fransen, J., Gaal, B.G.I. van. Lessons learned from patients with access to an online self-management enhancing program for RA patients: qualitative analysis of interviews alongside a randomized clinical trial. Patient Education and Counseling: 2018

## **Appendix A: Interview guide**

The interviewer repeated briefly the information that the patient received and agreed with in the written consent. Also, she explained in short the aim of the interview and that answers of the patient are not considered as being right or wrong. Each question was introduced to the patient and described in this interview guide between brackets.

[We want to receive more insight in why patients used the online program 'coping with RA' or not. Thus the reasons why you decided the use the program or not]

### **Question 1: What are the reasons for using the online program 'coping with RA' (or not)?**

[We also want to receive more information about patients' expectations of the program]

### **Question 2. What were your expectations of the program 'coping with RA'?**

Did you're expectation met the program and can you explain why (not)?

[You could choose by yourself how many times you use the program]

### **Question 3. How many times do you visit the program and why do you (re-use) the program?**

What is/are the reason(s) for re-using of the program

What is/are the reasons(s) for not re-using the program

What is the reason for non-usage of the program?

[The next questions are about the usage of the program. Can you remember how many time you logged-in until now? If patients did not remember, we explained to them how many times they used the program based on their user data].

### **Question 4. What is/are the reason(s) for re-use of the program, or what is/are the reason(s) for no re-use**

What can help you to overcome barriers to use the program

[The next questions are about the usage of program components. The modules and diary of pain and fatigue. Can you remember which program components u used until now? If patients did not remember, we showed them which modules they had used based on their user data].

### **Question 5: Can you explain why you visit these components?**

Why did you not visit the other program components

Did you finish the complete module? Why did you finish the module (not)?

[To optimize the program, it is important to know your user experiences with the program. The following questions are about your user experiences].

Zuidema, R., Dulmen, S. van, Nijhuis-van der Sanden M.W.G., Fransen, J., Gaal, B.G.I. van. Lessons learned from patients with access to an online self-management enhancing program for RA patients: qualitative analysis of interviews alongside a randomized clinical trial. *Patient Education and Counseling*: 2018

### **Question 6. Are you satisfied about the program?**

About which program components are you satisfied? Why are you satisfied about this?

About which program components are you unsatisfied? Why are you unsatisfied about this?

[The program 'coping with RA was developed to support you in daily life].

### **Question 7. Did the program you support in daily life?**

How supports the program you (or) not? Why (not)?

Which support do you receive from the program?

From which components do you receive support?

If the program did not support you, need the program be change to support you? If yes, how need the program chang

If the program did not support you, what kind of other support can help you?

## **References**

- [1] K.R. Lorig, P.L. Ritter, D.D. Laurent, K. Plant. The Internet-based Arthritis Self-Management Program: Aarthritis self-management program: a one-year randomized trial for patients with arthritis or fibromyalgia. *Arthritis & Rheumatism-Arthritis Care & ResearchRes.*, 59 (2008), pp. 1009-1017, 10.1002/Art.23817
- [2] A. Warsi, M.P. LaValley, P.S. Wang, J. Avorn, D.H. Solomon. Arthritis self-management education programs: a meta-analysis of the effect on pain and disability. *Arthritis Rheum.*, 48 (2003), pp. 2207-2213, 10.1002/art.11210
- [3] J.N. Stinson, J.N. Stinson, P.J. McGrath, E.D. Hodnett, B.M. Feldman, C.M. Duffy, A.M. Huber, L.B. Tucker, C.R. Hetherington, S.M. Tse, L.R. Spiegel, S. Campillo, N.K. Gill, M.E. White. An internet-based self-management program with telephone support for adolescents with arthritis: a pilot randomized controlled trial. *J. Rheumatol.*, 37 (2010), pp. 1944-1952, 10.3899/jrheum.091327
- [4] K.R. Lorig, P.D. Mazonson, H.R. Holman. Evidence Suggesting That Health-Education for Self-Management in Patients with Chronic Arthritis Has Sustained Health Benefits While Reducing Health-Care Csuggesting that health-education for self-management in patients with chronic arthritis has sustained health benefits while reducing health-care costs. *Arthritis and RheumatisRheum.*, 6 (1993), pp. 439-446, 10.1002/art.1780360403
- [5] M. van Vilsteren, C.R.L. Boot, D.L. Knol, D. van Schaardenburg, A.E. Voskuyl, R. Steenbeek, J.R. Anema. Productivity at work and quality of life in patients with rheumatoid arthritis *Bmc Musculoskeletal DisordersMC Musculoskelet. Disord.*, 16 (2005), 10.1186/S12891-015-0562-X
- [6] H. Spittaels, I. De Bourdeaudhuij, J. Brug, C. Vandelanotte. Effectiveness of an online computer-tailored physical activity intervention in a real-life setting. *Health Educ. Res.*, 22 (2007), pp. 385-396
- [7] R. Crutzen, W. Brouwer, J. Brug, N.K. de Vries, A. Oenema, J. de Nooijer. Gezondheidsbevorderende interventies via iInterventies Via Internet [Promotion of healthy behavior tHealthy Behavior Through the Internet]. (2008)

Zuidema, R., Dulmen, S. van, Nijhuis-van der Sanden M.W.G., Fransen, J., Gaal, B.G.I. van. Lessons learned from patients with access to an online self-management enhancing program for RA patients: qualitative analysis of interviews alongside a randomized clinical trial. *Patient Education and Counseling*: 2018

- [8] E. Leslie, A.L. Marshall, N. Owen. Baurman, Engagement and retention of participants in a physical activity website. *Preventive Medicine. Med.*, 40 (2005), pp. 54-59, 10.1016/j.yjmed.2004.05.002
- [9] K.E. Evers, J.M. Prochaska, J.O. Prochaska, M.M. Driskell, C.O. Cummins, W.F. Velicer. Strengths and weaknesses of health behavior change programs on the Internet. *Journal of Health Psychology. Health Psychol.* (2003), pp. 63-70, 10.1177/1359105303008001435
- [10] L.A. Olsen, R.S. Saunders, J.M. McGinnis. Patients Charting the Course: Citizen Engagement and the Learning Health System: Workshop Summary. (2011), 10.17226/12848 Washington (DC)
- [11] T.L. Webb, J. Joseph, L. Yardley, S. Michie. Using the Internet to Promote Health Behavior Change: A Systematic Review and Meta-analysis of the Impact of Theoretical Basis, Use of Behavior Change Techniques, and Mode of Delivery on Efficacy *Journal of Medical Internet Research* internet to promote health behavior change: a systematic review and meta-analysis of the impact of theoretical basis, use of behavior change techniques, and mode of delivery on efficacy. *J. Med. Internet Res.*, 12 (2010), 10.2196/Jmir.1376
- [12] A.M. Hazara, S. handari. Barriers to patient participation in a self-management and education website *Renal PatientView: Arenal patientview: a questionnaire-based study of inactive users. Int J Med Inform. J. Med. Inform.*, 87 (2016), pp. 10-14, 10.1016/j.ijmedinf.2015.12.004
- [13] J.J. Veldhuijzen van Zanten, P.C. Rouse, E.D. Hale, N. Ntoumanis, G.S. Metsios, J.L. Duda, G.D. Kitas. Perceived Barriers, Facilitators and Benefits for Regular Physical Activity and Exercise in Patients with Rheumatoid Arthritis: A Review of the Lbarriers, facilitators and benefits for regular physical activity and exercise in patients with rheumatoid arthritis: a review of the literature. *Sports Med.*, 45 (2015), pp. 1401-1412, 10.1007/s40279-015-0363-2
- [14] A.F. Jerant, M.M. von Friederichs-Fitzwater, M. Moore. Patients' perceived barriers to active self-management of chronic conditions. . *Patient Educ Couns.* 57 (2005) 300-7. [https://doi-org.proxy.library.uu.nl/Patient Educ. Couns.](https://doi-org.proxy.library.uu.nl/Patient%20Educ.%20Couns.,%2057%20(2005),%20pp.%20300-307,%2010.1016/j.pec.2004.08.004), 57 (2005), pp. 300-307, 10.1016/j.pec.2004.08.004
- [15] R.M. Zuidema, B.G.I. Van Gaal, S. van Dulmen, H. Repping-Wuts, L. Schoonhoven. An online tailored self-management program for patients with rheumatoid arthritis: a Developmental Study *JMIR Res developmental study. JMIR Res. Protoc.*, 4 (2015), Article e140, 10.2196/resprot.4571
- [16] I. Ajzen. The Theory of Planned Behavior *Organizational Behavior and Human Decision Processes* theory of planned behaviour. *Organ. Behav. Hum. Decis. Process.*, 50 (1991), pp. 179-211, 10.1016/0749-5978(91)90020-T
- [17] C. Abraham, S. Michie A taxonomy of behavior change techniques used in interventions *Health Psychol.*, 27 (2008), pp. 379-387, 10.1037/0278-6133.27.3.379
- [18] R.M. Zuidema, S. Van Dulmen, M.W.G. Nijhuis- van der Sanden, I. Meek, C.M.H. Van den Ende, J. Fransen, B.G.I. Van Gaal Efficacy of an Schoonhoven An Online Tailored Self-Management Program *Online Self-management Enhancing Programme for Patients With Rheumatoid Arthritis: n ean Explorative RCT Submitted.* (2018)
- [19] J. Michalak, M.A. Klapheck, J. Kosfelder Personal goals of psychotherapy patients: Tthe intensity and the "why" of goal-motivated behavior and their implications for the therapeutic process . *Psychotherapy Research. Res.*, 14 (2004), pp. 193-209, 10.1093/ptr/kph017
- [20] W. Brouwer, A. Oenema, R. Crutzen, J. de Nooijer, N.K. de Vries, J. Brug An exploration of factors related to dissemination of and exposure to internet-delivered behavior change interventions aimed at adults: a Delphi study approach *J Med. Med. Internet Res.*, 10 (2008), Article e10ARTN e1010.2196/jmir.956
- [21] V. Venkatesh, M.G. Morris, G.B. Davis, F.D. Davis User acceptance of information technology: Ttoward a unified view . *Mis Quarterly.*, 27 (2003), pp. 425-478
- [22] L.K. Bartholomew Planning health promotion programs : an intervention mapping a *Health Promotion Programs : an Intervention Mapping Approach .* (1st ed.), Jossey-Bass, San Francisco (2006)

Zuidema, R., Dulmen, S. van, Nijhuis-van der Sanden M.W.G., Fransen, J., Gaal, B.G.I. van. Lessons learned from patients with access to an online self-management enhancing program for RA patients: qualitative analysis of interviews alongside a randomized clinical trial. *Patient Education and Counseling*: 2018

[23] L.K. Bartholomew, G.S. Parcel, G. Kok Intervention mapping: a process for developing theory- and evidence-based health education programs *Health Educ. Behav.*, 25 (1998), pp. 545-563

[24] R.M. Zuidema, B.G.I. van Gaal, H. Repping-Wuts, A. Evers, T. van Achterberg What Is Known About Rheumatoid Arthritis Patients' Support Needs for Self-Management? A Scoping Review *Annals of the Rheumatic Diseases* is known about rheumatoid arthritis patients' support needs for self-management? A scoping review *Ann. Rheum. Dis.*, 73 (2012) 1194-1194

[25] W. Brouwer, W. Kroeze, R. Crutzen, J. de Nooijer, N.K. de Vries, J. Brug, A. Oenema Which intervention characteristics are related to more exposure to internet-delivered healthy lifestyle promotion interventions? A systematic review *J Med. Med. Internet Res.*, 13 (2011), p. e2ARTN e210.2196/jmir.1639

[26] J.O. Prochaska, W.F. Velicer The transtheoretical model of health behavior change *Am J. J. Health Promot.*, 12 (1997), pp. 38-48, 10.4278/0890-1171-12.1.38

[27] J. Percival Using motivational interviewing (MI) skills to help people change *Perspectives in Public Health.. Public Health*, 137 (2017), pp. 256-257, 10.1177/1757913917722665

## Tables

Table 1. An overview how the program was created

| Number of step | Aim of each step   | Input multidisciplinary panel of patients and professionals   |
|----------------|--|---|
| 1              | Conduct a needs assessment   | The multidisciplinary panel participated in a brainstorm session to identify the main health problems affecting RA patients. To select the most important health problems, the research team coded health problems identified during this brainstorm session and found in literature search. In preparation of step 2, the research team searched also in literature for problems affecting health related behaviors and their determinants. These were also identified by the multidisciplinary panel during a discussion about the following questions:<br>1) Why do patients have problems?<br>2) Why do patients have problems with this behavior (determinants of behavior)? |
| 2              | Create a matrix of performance objectives and change objectives based on the overall aim of the online program and the behaviors needed to be changed to achieve the overall aim | The multidisciplinary panel validated the matrix of performance objectives and change objectives constructed by the researcher  |
| 3              | Select theory-based intervention methods and practical applications  | After the research team selected the theory of planned behavior as underlying theory of the intervention, they independently coded behavioral change techniques (BCTs). The multidisciplinary panel decided whether the methods were suitable for the RA population.  |
| 4              | Production of program components   | After the program components were developed by the research team, the multidisciplinary panel pre-tested the program. Additional to this, three RA patients not involved in the development of the program tested the program using the 'think aloud' method.   |
| 5              | Design a plan for adoption, implementation and sustainability  | The multidisciplinary panel and research team identified and categorized barriers and facilitators to implement the online program.   |
| 6              | Generate an evaluation plan to conduct an effect and process evaluation  |   |

Table 2. Content of the program with the inserted BCT strategies and their practical applications.

| <b>Content of the program [15]</b>   |
|--|
| <p>Based on needs assessment and patient input, we developed the following 10 modules with each one to five sessions and a diary with the following performance objectives:</p> <ol style="list-style-type: none"><li>0. Welcome (one session)</li><li>1. Balancing daily life activities (five sessions)<ul style="list-style-type: none"><li>- Finding balance between rest and activity</li><li>- Making choices in participating in daily life activities to keep balance</li></ul></li><li>2. Setting boundaries (four sessions)<ul style="list-style-type: none"><li>- Setting boundaries to partners, relatives, colleagues and the social environment</li></ul></li><li>3. Asking for help and support (four sessions)<ul style="list-style-type: none"><li>- Asking for social support or practical help from partners, relatives, colleagues and the social environment in daily life</li><li>- Asking for social support and practical help from colleagues</li><li>- Accepting social support or practical help from partners, relatives, colleagues and the social environment in daily life</li></ul></li><li>4. Using medication (four sessions)<ul style="list-style-type: none"><li>- Taking prescribed medication</li></ul></li><li>5. Communicating with health professionals (four sessions)<ul style="list-style-type: none"><li>- Preparing the visit to the health professionals</li><li>- Asking questions and/or expressing concerns during an appointment with a health professional</li></ul></li><li>6. Using assistive devices (four sessions)<ul style="list-style-type: none"><li>- Using, if necessary, assistive devices</li></ul></li><li>7. Performing physical exercises (four sessions)<ul style="list-style-type: none"><li>- Performing daily physical exercises</li></ul></li><li>8. Coping with worries (three sessions)<ul style="list-style-type: none"><li>- Coping with worries about RA</li></ul></li><li>9. Coping with RA (two sessions)<ul style="list-style-type: none"><li>- Coping with RA</li></ul></li></ol> <p>An online diary to track the levels of mean pain and fatigue during the last 2 weeks and the levels of pain and fatigue today.</p> |
| <p>*Each module takes on average 25 minutes to complete. Patients can choose which module(s) to work through and can do this at their own speed at any time.</p>   |
| <p>**Patients receive an email every other week with a hyperlink to the pain and fatigue diary.</p>  |



Table 3. Overview of the inserted BCT strategies and their practical applications.

| <b>Inserted BCTs and practical applications</b>   |
|---|
| <p>The theory of planned behaviour [16] was the underlying theory, and the following BCTs were inserted [17]:</p> <p>To enhance knowledge:</p> <ul style="list-style-type: none"> <li>- Providing general information about health behaviour (informational texts)</li> <li>- Increasing memory and/or understanding of transferred information (informational texts)</li> </ul> <p>To create awareness and insight:</p> <ul style="list-style-type: none"> <li>- Risk-communication (text about positive consequences of behaviour)</li> <li>- Self-monitoring of behaviour (diary pain and fatigue)</li> <li>- Self-report of behaviour (e.g. assignment to fill in daily activities)</li> </ul> <p>To provide social influence:</p> <ul style="list-style-type: none"> <li>- Providing information about peer behaviour (quotes from patients and texts, with experiences of patients)</li> </ul> <p>To strengthen positive beliefs:</p> <ul style="list-style-type: none"> <li>- Persuasive communication/belief selection (persuasive text)</li> <li>- Reinforcement on behavioural progress (feedback)</li> <li>- Providing contingent rewards (feedback)</li> </ul> <p>To enhance self-efficacy:</p> <ul style="list-style-type: none"> <li>- Modelling (videos from other patients)</li> <li>- Practicing (assignment to practice behaviour)</li> <li>- Planning coping responses (evaluating questions)</li> </ul> <p>To encourage patient intention:</p> <ul style="list-style-type: none"> <li>- Developing medication intake schedules (medication schedule to fill in)</li> </ul> <p>To encourage patient action control:</p> <ul style="list-style-type: none"> <li>- Using social support (instructions on how to use social support)</li> <li>- Using cues (instructions on how to use cues)</li> <li>- Self-persuasion (instructions on how to increase patient motivation)</li> </ul> |
| <p>BCTs = behavioural change techniques</p>   |



Zuidema, R., Dulmen, S. van, Nijhuis-van der Sanden M.W.G., Fransen, J., Gaal, B.G.I. van. Lessons learned from patients with access to an online self-management enhancing program for RA patients: qualitative analysis of interviews alongside a randomized clinical trial. *Patient Education and Counseling*: 2018

Table 2. Patients' demographic and disease-related characteristics

| <b>Group</b>   | <b>N</b> | <b>Gender</b>    | <b>Age median (range)</b> | <b>Disease duration in years median (range)</b> | <b>Education</b>            | <b>Work</b>                  |
|--|----------|------------------|---------------------------|---|-----------------------------|------------------------------|
| <b>Non-users<br/>0 times</b>   | 4        | 2 men<br>2 women | 57 (53-65)                | 6,5 (1-14)                                      | 1 low<br>2 middle<br>1 high | 2 yes<br>2 no                |
| <b>Low users<br/>1-5 times</b>   | 4        | 4 women          | 64 (54-74)                | 3.5 (3-6)                                       | 4 middle                    | 1 yes<br>1 part-time<br>2 no |
| <b>High users basic<br/>More than 6 times:<br/>mainly using the<br/>pain and fatigue<br/>diary</b>   | 7        | 3 men<br>4 women | 50 (44-63)                | 7 (2-34)  | 4 middle<br>3 high          | 3 yes<br>3 part-time<br>1 no |
| <b>High users plus<br/>More than 6 times:<br/>using both the<br/>modules and the<br/>diary frequently</b>  | 6        | 3 men<br>3 women | 66.5 (57-78)              | 13 (2-19)                                       | 1 low<br>4 middle<br>1 high | 2 yes<br>1 part-time<br>3 no |
| <p>* Work "yes" means: more than 12 hours per week paid work or more than 8 hours unpaid work,<br/>           "Part-time" work means 1 to 12 hours paid work or 1-8 hours unpaid work;<br/>           "No" work means no paid or unpaid work.<br/>           * Education "low" means no education or completed elementary school, education "medium" means completed preparatory secondary education, education "high" means completed a bachelor's degree in applied sciences or a university degree.</p> |          |                  |                           |   |                             |                              |