


# BMJ Open Making space for patients' preferences in precision medicine: a qualitative study exploring perspectives of patients with rheumatoid arthritis

Karin Schölin Bywall <sup>1</sup>, Jennifer Viberg Johansson,<sup>1,2</sup> Inger Erlandsson,<sup>3</sup> Marie Heidenvall,<sup>3</sup> Marta Lason,<sup>4</sup> Bente Appel Esbensen<sup>5,6</sup>

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For numbered affiliations see end of article.

**Correspondence to**  
Karin Schölin Bywall;  
karin.bywall@crb.uu.se

## ABSTRACT

**Objective** Precision medicine in rheumatoid arthritis (RA) creates new opportunities to involve patients in early identification of accurate indicators of health trajectories. The aim of this study was to explore patient perspectives on patient-centredness in precision medicine for RA treatment.

**Design** Semistructured interviews were conducted to explore patients' perspectives on a new personalised approach to RA treatment. The interview guide was developed together with patient research partners and health care professionals.

**Setting** An invitation to the interviews was sent through a mobile application. The interviews were one-on-one, using an interview guide with open-ended questions. Interviews were conducted digitally (October 2020–February 2021) via Zoom or telephone, depending on each participant's preferences.

**Participants** Patients with RA (N=12) were purposively recruited. Patients were eligible if they had an RA diagnosis, were aged 18–80 years, and understood and expressed themselves in Swedish. Participants and researchers did not know each other prior to the interviews.

**Results** Participants expressed desires and needs for patients to have an active role in precision medicine by making shared treatment decisions together with a healthcare professional. In order for that to work, patients need information on potential treatment options, an ability to express their preferences, an individual treatment plan and identification of personal treatment goals. Patients also identified two requirements of healthcare professional in precision medicine: a safe environment to express personal matters and two-way communication with healthcare professionals.

**Conclusion** Communication between patients and healthcare professionals needs to be more focused on patients' individual treatment preferences and expressed needs, in order to increase patient-centredness in treatment decisions, so shared decision-making can become a reality. More research is needed to design multifaceted implementation strategies to support patients and healthcare professionals to increase patient-centredness throughout treatment personalisation.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ A multidisciplinary team of academics, clinicians and patient research partners developed the study.
- ⇒ Patient perspectives on patient-centredness in precision medicine for rheumatoid arthritis (RA) treatment was explored through semistructured interviews.
- ⇒ A possible limitation of this study may be that the invitation was distributed to potential participants via a mobile application and consequently a selected group of patients with RA.

## INTRODUCTION

Currently, pharmacological treatment of rheumatoid arthritis (RA) aims mainly to achieve remission (ie, inactive disease) or as low disease activity as possible in patients with RA.<sup>1</sup> Such treatment approach implies avoiding joint damage, disability and systemic manifestations by a treat-to-target approach which includes tight disease control. Such approach around treatment can vary depending on the treatment goals of the patient (ie, increasing functional capacity or avoiding side effects) and the rheumatologist (ie, slow down disease progression or remission), and which individual outcomes can be achieved.<sup>2</sup> Treating to target requires frequent assessments of the patient (eg, regular blood tests) and modification of treatment until the target is achieved and sustained.<sup>3</sup> The current treat-to-target approach does not use biomarkers to personalise treatment by stratifying the individual to the most appropriate treatment.<sup>1</sup>

In the future, precision medicine may enable treatment that is highly personalised and tailored for patient management.<sup>4</sup> The primary goals of precision medicine are to identify accurate and earlier indicators of health trajectories for individuals, detect



early stages of the disease, reverse disease development, slow disease progression and adjust health trajectories through targeted and more effective pharmacological treatments or lifestyle interventions.<sup>5</sup> Precision medicine encompasses multiple layers of precision, with patient history and lab tests considered to improve tailoring of treatment to the individual. A newer and more narrow approach to precision medicine involves the use of biomarkers: multidimensional sources of patient data that mainly include ‘omics’ (genomics, epigenomics, transcriptomics, proteomics, metabolomics, metagenomics, etc) to generate prediction algorithms. Non-molecular sources may also be included in the algorithms, such as sociodemographic and lifestyle factors extracted from various technical aids, including electronic health records, social media, and mobile phone applications.<sup>4</sup>

Still, the main principle for management of RA is that treatment of patients ‘should aim at the best care and must be based on a shared decision between the patient and the healthcare professional’.<sup>1</sup> Shared decision-making requires that healthcare professionals and patients evaluate potential treatment alternatives to align decisions with both clinical goals and individual treatment preferences.<sup>6</sup> Precision medicine should account for individuals’ perspectives, to align medical decision-making with patients’ preferences. Because social and therapy-related factors play an essential role in treatment adherence.<sup>7</sup> It is essential that personalisation of treatment takes account of patients’ perspectives on the use of precision medicine to increase patient-centredness.<sup>8–10</sup> Therefore, the aim of this study is to explore patient perspectives on patient-centredness in precision medicine for RA treatment.

## Methods and participants

Patients with RA in Sweden were invited to explore their perspectives on a new personalised approach to RA treatment. The invitation was sent through the mobile application [www.elsa.science.se](http://www.elsa.science.se) for patients with established RA diagnosis (patients can assess the app via clinic or via digital platforms) and contained an introduction to the research project and ethical declarations. Patients could sign up themselves if they were interested in being interviewed to KSB. Participants were then recruited purposively. Patients were eligible if they had an RA diagnosis, were aged 18–80 years, and understood and expressed themselves in Swedish. Participants and researchers did not know each other prior to the interviews. KSB contacted each potential participant via email when provided their contact information to the researchers, to schedule a 1-hour interview. We followed the COnsolidated criteria for REporting Qualitative research checklist (online supplemental file 1).

The interviews were one-on-one, using a semistructured interview guide with open-ended questions. The interview guide was developed together with patient research partners and healthcare professionals (online supplemental file 2). The guide was pilot-tested in one patient with RA and contained questions regarding individuals’

perspectives on patient-centredness in precision medicine and experience (or lack of experience) of shared decision-making in treatment decisions. Interviews were conducted digitally (October 2020–February 2021) via Zoom or telephone, depending on each participant’s preferences. The interviews were conducted by the female first author KSB, that is a researcher in patient preference science experienced in interviewing patients with RA.<sup>11</sup> The duration of was ~1 hour and KSB made field notes during the interviews. The interviews were conducted in Swedish, audiorecorded, transcribed and analysed using qualitative content analysis.<sup>12</sup> Extracted quotes from the analysis to be presented in this article was translated by a professional agency prior to the submission. All participants provided informed consent before starting the interviews.

All of the authors were involved in the manifest qualitative content analysis.<sup>13</sup> The transcripts were organised using NVivo V.11. As a first step, all the transcripts were read through, with meaning units extracted for further inductive exploration. Meaning units (ie, quotes from the interviewees) were extracted if they corresponded to the aim. The meaning units were then ‘condensed’ by summarising the text while still preserving the core content and meaning. Each condensed meaning unit was then labelled with a code (see [table 1](#) for extraction of condensed meaning units). The codes were abstracted by grouping condensed meaning units under higher order subcategories and main categories (online supplemental file 3). Data saturation was obtained after performance of ten interviews. Two additional interviews were conducted to confirm saturation among the research team.

In all, the condensed meaning units revealed 15 manifest codes that were organised under seven subcategories after discussions among the research team. The subcategories revealed two main categories: (1) patients’ desires and needs in precision medicine and (2) patients’ requirements of healthcare professionals. The condensed meaning units corresponding to the subcategories and main categories were organised into a summarised content area presented in the result section.

## Patient and public involvement

Patient research partners MH and IE from the Swedish Rheumatism Association were involved throughout all steps of the research process and stated as authors of this article. Patient research partners contributed in monthly meetings to discuss the research questions, patient information letter and interview guide. The content analysis of the interviews was discussed and revised based on the patient research partners input. For example, the patient research partners assigned the most important findings in the study and supported the discussion.

## RESULTS

In total, 12 interviews (10 female) were conducted with patients with RA in Sweden. Disease duration ranged from 2 to 40 years. Participants were aged 18–80 years and from

**Table 1** Extract from analysing meaning units and condensed meaning units from content analysis

Meaning units	Condensed meaning units	Codes
<ul style="list-style-type: none"> <li>▶ I am willing to try it, because of the promising research, I believe in the results.</li> <li>▶ I would try it at once, I have read about it and I would like to start upfront with precision medicine instead of going the standardized way.</li> <li>▶ As a patient you need to take tests all the time, I would accept a blood test and additional exams.</li> </ul>	Patients trust research and they are willing to try precision medicine because they are already used to tight controls.	Positive to new approach
<ul style="list-style-type: none"> <li>▶ We did have a discussion they wanted a much higher dose for me. I felt like she already had a plan for me.</li> <li>▶ I think you should have some influence, defiantly. It is important to know that there are options and to start discussions with 'what is important for you?'</li> <li>▶ I would rather go for a more personalized precision medicine than a standardized approach.</li> </ul>	An individualises treatment approach requires rheumatologists to be more patient-centred by asking patient's what is most important instead of just following the standardised approach.	Questioning standardised approach
<ul style="list-style-type: none"> <li>▶ Patients influencing precision medicine requires patients to get a lot of information from the healthcare professional.</li> <li>▶ My rheumatologist just gave me a folder and said 'go home and read'.</li> <li>▶ There is a big knowledge gap if you don't even know the disease. You also need easier explanations.</li> </ul>	Patients' need to be properly informed to increase patient-centredness in precision medicine.	Information format
<ul style="list-style-type: none"> <li>▶ I would have needed some kind of explanations, what are my alternatives?</li> <li>▶ I would have needed more information on the disease</li> <li>▶ I have read a lot about treatment by myself, but it is hard to find information.</li> </ul>	Patients need to be prepared to be able to discuss treatment. They need to know that there are potential treatment alternatives, and what they are.	Available treatment alternatives

different demographic locations in Sweden. The qualitative content analysis revealed two main categories, which are presented below: (1) patients' desires and needs in precision medicine and (2) patients' requirements of healthcare professionals (table 2).

### Patients' desires and needs in precision medicine

#### A positive attitude towards a new approach

In general, participants stated that they were positive to a more personalised treatment approach by means of identifying biomarkers for immediate stratification of an individual patient to the most appropriate treatment (ie, precision medicine). Participants would be positive to the new approach because they trusted researchers and felt it would be easy to take a blood sample, or any other sample, as they were used to this:

Yes, absolutely. I mean, a blood sample, which is nothing, you have to take blood samples all the time and... I would accept more than a blood sample too, plus any specialised examination or whatever.

Participants discussed the importance for patients with RA of being involved in treatment discussions and having an active role in treatment decisions. Some mentioned that they wanted to have a significant influence on all treatment decisions. Some participants said that the reason for being positive to the new approach 'precision medicine' was related to questioning the standardised approach, as it did not take account of a patient's own treatment preferences in medical decisions:

I think you should have some influence, absolutely. I don't know how much, but I think that it's important that you understand that there are different options and that the discussion starts with, what is most important for you?

#### To be properly informed

The participants also identified some obstacles for them getting involved, such as the importance of being properly informed and getting the chance to ask questions. Participants highlighted the lack of knowledge regarding the disease and treatment options as an obstacle to identifying and communicating personal preferences. It was suggested that simpler explanations of medicines should be used in communication with patients:

The knowledge gap, because it's hard if you don't even... know the disease, and it's also hard, when you are talking to a specialist it's just... Yeah, that is like a bridge you have to... Well, you also need explanations that you are able to understand in a simpler way.

#### To be able to express one's preferences

The availability of healthcare professionals was mentioned as a central part of treatment personalisation. Having tight controls and meeting the same rheumatologist over time were emphasised as important components for communication and for feeling comfortable in bringing up personal questions and preferences. Both positive and

**Table 2** Codes and sub-categories corresponding to main categories

Codes	Subcategories	Main categories
Positive to new approach	A positive attitude towards a new approach	Patients' desires and needs in precision medicine
Questioning standardised approach		
Information format	To be properly informed	
Available treatment alternatives		
Someone to talk to	To be able to express one's preferences	
Being able to communicate		
Considering patient preferences	Have an individual treatment plan	
Time frame		
Physical functional capacity	Identifying patients' needs for support and personal goals	
Psychosocial functional capacity		
Have confidence	Having a safe environment to express personal matters	Patients requirements of healthcare professionals
Be reassured		
Adapt communication	Having a two-way communication with healthcare professionals	
Including patients in decisions		
Considering patients' daily life		

negative experiences from communication with a healthcare professional were mentioned:

Then I got this appointment just a few months later, I got an appointment with my doctor and a nurse. And they were like, you can always give us a call, it felt like I was in good hands.

The need for own preparations before meeting with a healthcare professional was highlighted. For instance, it was suggested that it would be good to get some guidance in advance, to figure out preferences before an appointment:

I know that there are a lot of discussions going on about that you should ask the doctors questions, but I think, even before, to word your questions before the appointment, maybe you should try to get a lot of knowledge about the disease you have, some kind of ground to stand on before you meet with the doctor, so your mind isn't just a blank.

#### Have an individual treatment plan

Making an individual plan together with a healthcare professional would make the treatment approach more patient-centred, according to the participants. The individual plan could potentially be a way to initiate

discussions on alignment of treatment strategy with the patient's personal treatment goals and preferences:

To extend the actual visit at the rheumatologist to focus on different treatment paths. That you could make it more patient-centred. Some people do not like to talk about themselves, others may have a greater need for that, or some may focus on physical activities, what you can do to adjust for that.

#### Identifying patients' needs for support and personal goals

The main goals of the participants were related to increasing functional capacity to get a 'normal life'. Limitations in physical functional capacity were mentioned in all of the interviews as something that could affect quality of life. Some participants also mentioned limitations in their psychosocial functional capacity after being diagnosed and the need for appropriate support to reach their personal goals:

For me at least, you just get this (RA), and that it's... firstly, your whole life changes and then it's also very overwhelming, the inner crisis. To get them to pay any attention to this crisis, I had to deal with this crisis on my own.

#### Patients' requirements of healthcare professionals

##### Creating a safe environment to express personal matters

Participants said that the level of patient-centredness in treatment personalisation depended on their trust in healthcare professionals and their feeling of being safe and confident in expressing personal matters. The feeling of being reassured as in 'taken care of' was mentioned as an essential condition for making shared treatment decisions. Being reassured involved getting an understanding of the disease, feeling that the disease could be managed and that it is possible to live a good life with RA:

*That was the first thing my doctor said to me, there are a lot of great medicines, so you don't need to worry. That was reassuring to me. I felt glad that she understood my situation.*

##### Having a two-way communication with healthcare professionals

Participants described that communication with healthcare professionals was crucial for treatment decisions to be aligned with a patient's preferences, so the personalised approach was indeed 'personalised' to meet the individual patient's goals, not only to meet the clinical treatment goals. They described an asymmetry in communication and some of them had experience of a healthcare professional taking a paternalistic approach (ie, not including them) and making treatment decisions for them, not together with them:

Well, there was no room for that. It was like, not equal in any way, when you're in this thing that you don't quite understand and you are in shock and the person in front of you has so much expertise, which is unreachable. The prognosis is quite clear and how...

this person has so much clinical experience. But this exchange never happens.

The participants said that they felt excluded from treatment decisions. They wanted to get the opportunity to ask questions, feel that they had been heard, know how the treatment decisions were made and what potential treatment options there might be for them:

It was like, I felt so excluded in some way. It was very... my rheumatologist, I trusted her, she was extremely competent, but I would have needed... I would have needed to ask [get an opportunity to ask questions].

Some of the participants felt that the healthcare professional did not acknowledge their lifestyle and daily life activities when making treatment decisions for them. Some wanted healthcare professionals to consider a patient's own goals in life, for example, physical goals, not only the clinical goals. Others described a need for having their psychosocial treatment goals acknowledged:

There were some contradictions, my rheumatologist did not want to have shorter intervals, as she put it: it was not possible to change the medicine for me to be able to continue with my sport, that was not the main treatment goal. While to me, that is part of what makes me healthy.

## DISCUSSION

The aim of this study was to explore patient perspectives on patient-centredness in precision medicine for RA treatment. Overall, the participants were positive to making shared treatment decisions. However, healthcare professionals need to address several hindrances, such as patients' ability to express significant matters and healthcare professionals' responsibility to create a safe environment. Consequently, space for patient's preferences will have the opportunity to be acknowledged in treatment decisions.

Patient willingness to be more involved in treatment decisions has also been seen in recent quantitative preference research with patients with RA.<sup>14</sup> It was suggested by the participants in our study that patients with RA need to have an active role in treatment decisions and be able to express personal preferences and goals. These findings are in line with recent research revealing that there is a current lack in patient-tailored support tools for effective doctor-patient communication to support patients in adherence.<sup>7</sup> Aligning treatment decisions with patient preferences could potentially improve clinical outcomes and increase patient satisfaction and treatment adherence.<sup>15</sup>

Our findings underline that the participants want to be prepared and reflect on their own preferences before an appointment with a healthcare professional. This is also highlighted in general guidelines on treating RA.<sup>1</sup> Some of the participants suggested that making an individual

plan together with a healthcare professional might improve their communication. The individual plan could potentially be a way to initiate discussions on aligning the treatment strategy with a patient's personal preferences. Making an individual plan, sometimes called the 'patient journey' or the 'patient contract', is in line with current guidelines in Sweden.

The need for information to improve shared decision-making has also been identified in previous research.<sup>16</sup> A recent study interviewing people at risk of developing RA also stressed a need for further development of effective and tailored information to support medical decision-making.<sup>17</sup> Setting personal goals was described as necessary by the participants in our study. However, participants mentioned a tension between a patient's own treatment goals and healthcare professionals' goals. Currently, the care system is designed to deliver care and treatment supported by clinical goals.<sup>18</sup> Therefore, shared decision-making has the potential to support patients and healthcare professionals in translating clinical goals into meaningful patient goals.

Identifying treatment goals is already a key aspect of RA care, including when choosing targets at the start of the treat-to-target approach. Decision aids to support patients and healthcare professionals in identifying treatment goals may be one of the best known and most effective strategies in shared decision-making.<sup>19</sup> Therefore, newer decision aids should incorporate information on patients' relevant treatment options and reflection on patient preferences.

This study has some limitations. First, the invitation to participate in an interview was distributed to potential participants via a mobile application. Patients not using this mobile application were therefore excluded. Additionally, the sample consisted of mostly women, 10, out of 12. It can be argued that 12 interviews are few, but no further new information emerged after we had completed 10 interviews. To strengthen the validity, we conducted two additional interviews and were confirmed that we had achieved data saturation. Trustworthiness is a key challenge in qualitative research. Therefore, three concepts are important: credibility, transferability and dependability. Credibility was promoted in this study by recruiting participants with different disease stages and ages. Participants were informed about precision medicine to improve transferability. Dependability was promoted in the analysis of the results by collaboration between the authors.

Future research should design multifaceted implementation strategies that combine clinician training and tools to support patients and healthcare professionals in shared decision-making, in order to increase patient-centredness in treatment personalisation.

## CONCLUSIONS

Participants had a positive attitude toward taking on an active role in precision medicine by making shared



treatment decisions with a healthcare professional. They expressed a need to be informed about the treatment options and supported to express personal preferences and goals. Communication needs to focus on a patient's own treatment goals, to align treatment decisions with their preferences. Future research is needed to design multifaceted implementation strategies that combine clinician training and tools to support patients and healthcare professionals in shared decision-making in order to increase patient-centredness in treatment personalisation.

#### Author affiliations

<sup>1</sup>Centre for Research Ethics & Bioethics, Uppsala Universitet, Uppsala, Sweden

<sup>2</sup>Institute for Futures Studies, Stockholm, Sweden

<sup>3</sup>Swedish Rheumatism Association, Stockholm, Sweden

<sup>4</sup>Elsa Science, Stockholm, Sweden

<sup>5</sup>Department of Clinical Medicine, University of Copenhagen, Kobenhavn, Denmark

<sup>6</sup>Copenhagen Center for Arthritis Research (COPECARE), Center for Rheumatology and Spine Diseases, Centre of Head and Orthopaedics, Rigshospitalet, Kobenhavn, Denmark

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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** Consent obtained directly from patient(s)

**Ethics approval** The study was approved by the Ethics Review Authority in Sweden (Dnr 2020-00556). All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards. Participants gave informed consent to participate in the study before taking part.

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#### ORCID iD

Karin Schölin Bywall <http://orcid.org/0000-0002-5865-5590>

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