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Experience of co-creation of a health plan and support for sustainable physical activity among people with chronic widespread pain: a qualitative interview study in Sweden

Caroline Feldthusen ,[1,2] Anna Bergenheim,[1,3] Emmelie Barenfeld ,[2,4] Inger Gjertsson,[5] Anette Larsson ,[1,3] Kaisa Mannerkorpi[1]

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For numbered affiliations see end of article.

Correspondence to
Dr Caroline Feldthusen; caroline.feldthusen@vgregion.se

ABSTRACT

Objectives The aim of this study was to gain deeper knowledge about how people with chronic widespread pain (CWP) experience the co-creation of a health plan for sustainable physical activity, working in partnership with a physiotherapist, supported by a digital platform.

Design Qualitative semistructured in-depth individual interviews were analysed with qualitative content analysis.

Setting Five primary healthcare centres in western Sweden.

Participants The interviewees comprised 19 individuals with CWP who had previously participated in a person-centred intervention involving co-creation of a health plan and support via a digital platform. The interviews were carried out from late 2019 to spring 2020, 1–6 months after the respondents' final follow-up.

Results The analysis resulted in an overarching theme; hope for physical activity that actually works, illustrating the experience of taking part in co-creating a reasonable health plan, based on the respondents' own goals and interests with the potential to actually work. This theme was based on two categories: a plan tailored for me and a frame for participation and accessibility to help fulfil the plan. The digital platform provided a way to participate and an assurance that there was someone there for them if necessary.

Conclusions The co-creation of a health plan nurtured hope of having developed a manageable plan for physical activity that could lead to improved future health and well-being. Digital support may serve as a valuable complement in order to sustain and adjust the planned physical activity.

Trial registration number ClinicalTrials.gov Identifier: NCT03434899.

Strengths and limitations of this study

- This study provides in-depth knowledge about how people with chronic widespread pain value the co-creation of a health plan for sustainable physical activity, supported by a digital platform.
- The study used a well-established qualitative method increasing the trustworthiness of the results.
- The number of male respondents was low, which limits the generalisability of the results to the male population.

INTRODUCTION

Approximately 10%–15% of the population worldwide suffer from chronic widespread pain (CWP),[1 2] and it is more common in women than in men.[1] According to the American College of Rheumatology, widespread pain is defined as pain that is present for at least 3 months and is located in both the upper and lower part of the body, both the left and right side of the body and together with axial pain.[3] As well as the challenge of pain, people with CWP suffer from fatigue, other health problems, impaired physical capacity, activity limitations and reduced quality of life.[4–7]

Physical activity is recommended as first choice treatment in CWP, and individually adjusted regular physical activity has been shown to improve pain, physical capacity, and ability to manage activities of daily life.[8–10] However, physical activity is challenging for people with CWP due to impaired endogenous pain inhibition, which often causes increased pain during or following physical loading.[11] It is therefore essential to develop strategies for long-term sustainability of physical activity for people with CWP.

Person-centredness is an ethical standpoint that guides our actions both as humans and as professionals. Person-centred rehabilitation encompasses the patient's experience of living with a condition together with the knowledge and experience of the professional.[12] The patient is seen as an expert on their condition and its consequences, and as a partner in the rehabilitation process.[13]

The patient and the professional co-create the rehabilitation, and document the agreement as a health plan. Involving the patient as an active partner in the treatment can strengthen their resources[14] and enhance their self-efficacy and the ability to manage symptoms.[12] Co-creation of rehabilitation has previously been shown to contribute to improved self-management of physical activity in patients with rheumatoid arthritis,[14] but no previous study has to our best knowledge explored experiences of a person-centred approach to health-planning for sustainable physical activity among people with CWP.

Moreover, eHealth, defined as 'health services and information delivered or enhanced through the internet and related technologies'[15] can be used to support the management of chronic illness.[16] They offer a way to deliver disease-specific interventions, give support, and improve communication between patients and healthcare providers.[17] However, it is not clear if eHealth should be viewed as a replacement for face-to-face treatment, nor when or to whom they should be offered.[18] There are knowledge gaps regarding how patients engage in eHealth. Previous research has suggested that motivation, understanding of the intervention, lifestyle and support may act as facilitators and barriers in eHealth interventions.[19] The aim of this study was to gain deeper knowledge about how people with CWP experience co-creating a health plan for sustainable physical activity, working in partnership with a physiotherapist, supported by a digital platform.

METHODS

Study design

Qualitative semistructured in-depth individual interviews[20] were analysed with qualitative content analysis.[21]

Participants

The respondents in this study were individuals with CWP who had previously participated in a multicentre randomised controlled trial (RCT) evaluating the effects of a person-centred intervention which comprised co-creation of a health plan and support by a digital platform.[22] Inclusion criteria were, fulfilling the criteria of CWP according to the American College of Rheumatology,[3] and participating in the intervention group allocated to digital support. Respondents were recruited from the three study sites, 1–6 months after their final follow-up. Eligible respondents were informed about the study by telephone and invited to participate. If they agreed to participate, they received additional written and oral information about the study and an interview was scheduled. According to our experiences from previous studies, 15–20 interviews were estimated to be sufficient to answer the research question.

Intervention

The intervention in the multicentre trial[22] comprised two individual face-to-face meetings with a physiotherapist. The interval between the two meetings was 2 weeks. During the first meeting, the participant and the physiotherapist co-created a health plan for physical activity and, if needed, stress management, according to person-centred ethics. The physical activity had individual health promotional goals aimed at achieving the level of physical activity recommended by the WHO.[23] The health plan was based on the participant's goals, preferences, resources and barriers, and adjusted to the participant's limitations. At the second meeting the participant was introduced to the digital platform, a web-based tool that also could be reached through the participant's smartphone. The patient together with the physiotherapist adjusted the health plan if needed, and the plan was uploaded to the digital platform, where it would be accessible to the participant for 12 months. The digital platform was applied both as a tool for interaction between the participant and the physiotherapist, and as a tool for the participants to monitor their health. The platform contained questions regarding the participants perceived health and to what extent they had managed to follow their health-plan, and the participants was asked to fill in the questions once a week. Participants were able to send messages to and receive messages from the physiotherapist on the digital platform. During the study period, the participants received three information letters: exercise and pain, stress and pain and how to increase physical activity level to enhance physical capacity. During the 12 months study period, communication between the participant and physiotherapist took place through the platform pursuant to the participant's individual preferences and needs.

Patient and public involvement

The intervention was created by physiotherapists and scientists together with a patient research partner with chronic pain from the Swedish Rheumatoid Association. The patient research partner was involved in the planning of the RCT as well as planning of the interview study but no patient or public partner was involved in the conduct or analysis of the interview study.

Data collection

The interviews were performed by two experienced physiotherapists (CF and AB), who were not involved in the previous intervention and who both worked as healthcare professionals as well as researchers. Interview data were gathered through semi-structured individual interviews that took place either in a healthcare setting or by telephone.

An interview guide with open-ended questions was developed (box 1). All interviews began with the introductory statement '*We are interested in hearing about your experience of using e-health during the project,*' and the opening question '*I thought we would start by talking about the health plan itself, the one that you and the physiotherapist designed. -Would you like to tell us about the health plan?*'

Box 1 Interview guide

We are interested in hearing about your experience of using e-health during the project. Would you like to tell us about it?

The health plan

I thought we would start by talking about the health plan itself, the one that you and the physiotherapist designed. Would you like to tell us about the health plan?

- Would you like to tell us about the first meeting when the health plan was designed?
- How has the health plan changed in the meantime?
- How do you exercise today?
- How do you think about your health and how you feel today?
- Is there anything else you want to say about the health plan?

The e-health platform

Now I wonder if you would like to tell us about the e-health platform you used that was meant to serve as a support.

- What does it mean for you to have the opportunity to use e-health?
- Many people with widespread pain describe a need for support to be able to be physically active. What kind of support do you need?
- What do you think about having e-health as a complement to the health plan?
- Is there anything else you want to say about e-health as support?

Concluding

Is there anything else you would like to tell us?

- In general or related to the study? About physical activity, pain, support?
- Or something else that could be of value?

The interviewers followed the respondent's reasoning and invited the respondent to add, confirm and clarify any aspects discussed. A pilot interview was conducted and did not result in any changes to the interview guide. Each interview lasted for approximately 1 hour and was audiorecorded and then transcribed verbatim by a professional transcriber. All interviews were conducted and transcribed before data analyses started.[24 25] The interview material was rich and expected to be extensive enough to answer the research question.

Data analyses

The transcribed interviews were analysed by qualitative content analysis.[21 25] Qualitative content analysis includes interpretations of the manifest content close to the text as well as deeper interpretations of its underlying latent meaning.[24] The unit of analysis consisted of the whole interviews, and no parts were excluded from the analyses. First, the transcripts were read several times to obtain a sense of the whole. Then, meaning units answering the aim of the study were derived from the texts and abstracted without being separated from the context. These two steps were performed by CF. Subcategories, categories, and themes were formed from the abstracted meaning units by continuously moving back and forth between the whole text and its parts. Tentative subcategories and categories were discussed and elaborated between all authors until consensus was reached. Cooperation between the researchers was assumed to increase the credibility of the analysis. The results from the analysis are presented as a theme, categories and subcategories, illustrated by quotations from the interviews.

Table 1 Demographics of the respondents (n=19)

	Median (min;max)	N (%)
Sex (female)		16 (84)
Age (years)	47 (26;60)	
Symptom duration (years)	13 (2;22)	
Education		
10–12 years		7 (37)
>12 years		12 (63)
Living with another adult (yes)		13 (69)
Born in Sweden (yes)		15 (79)
Working (yes)		12 (75)
Pain (VAS 0–100)	66 (30;99)	
FIQ total (0–100)	55.1 (33.5;93.5)	

Missing: Symptom duration n=1, working n=3.
VAS, Visual Analogue Scale; FIQ, Fibromyalgia Impact Questionnaire.;

RESULTS

Of the 27 women and men who were asked to participate, 20 agreed to this and scheduled a meeting. One respondent was unable to attend the scheduled meeting due to illness, and so 19 respondents (16 women and 3 men) participated in the interviews: 10 in person in a healthcare setting and 9 by telephone (due to the COVID-19 pandemic). The interviews were carried out from late 2019 to spring 2020.

Demographic characteristics of the respondents are presented in table 1. Seventy-five per cent of the respondents were employed. Self-estimated pain was 66 mm on a 0–100 mm Visual Analogue Scale[26] and the Fibromyalgia Impact Questionnaire showed moderate impact on health.[27]

The analysis resulted in one theme: hope for physical activity that actually works. This was comprised of two categories: a plan tailored for me and a frame for participation and accessibility to help fulfil the plan. Each category had several subcategories elaborating on the striving towards sustainable health-enhancing physical activity when living with CWP (figure 1).

Theme

Hope for physical activity that actually works

The respondents described positive experiences of taking part in co-creating the health plan, and many of them expressed hopefulness about the opportunity to develop 'a reasonable plan with the potential to actually work'. They all described difficulties performing physical activity according to health recommendations, and worried

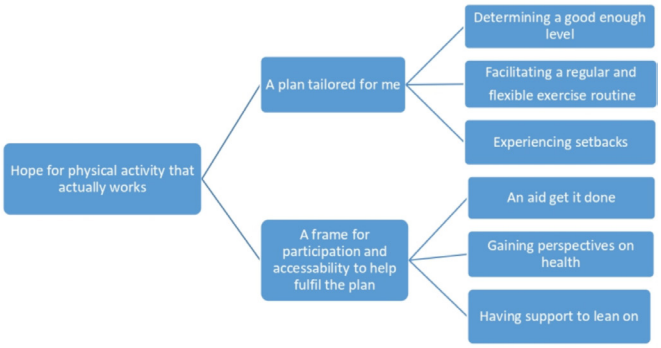

Figure 1 Theme, categories and subcategories.

about their present and future health. They expressed that their goal was not primarily to reduce their symptoms but to be able to perform health-enhancing physical activity despite the symptoms. However, a few respondents nurtured hope about the possibility to get rid of their pain.

Finding a plan that worked referred to their ability not only to manage the plan, but also to affect their future health and well-being and avoid deterioration in health.

Categories with subcategories

A plan tailored for me

The co-creation of the health plan was described as the most valuable part of the intervention. This health plan was perceived to be based on the respondents' own goals and interests, and according to their individual life conditions, resources and limitations. They described that the plan as being mutually tailored for themselves, rather than a predesigned programme according to general guidelines. The goal was not only to exercise but also to feel well and focus was on health instead of pain. One aspect highlighted as a prerequisite for the development of the health plan, was that the physiotherapist was knowledgeable, interested and willing to listen. Many of the respondents had experiences of being mistrusted regarding their symptoms, and said it was a relief to be believed and to not have to fight and defend themselves in order to gain understanding of their difficulties in performing physical activity according to the norm. This created feelings of trust and security.

> I thought it was really good. It worked great. Because … Then I knew all the time, that I had a plan and it was just for me. I didn't need to compare myself with anyone else, and so on. It was aimed at me[8]

However, one respondent found the preparation of the health plan to be demanding, mainly because of the many questions to respond to during the meeting.

Determining a good enough level

The respondents said that the plan helped them to start gently and then progress while still keeping the load at a reasonable level. Many respondents described previous experiences of overload and feelings of failure when they were not able to exercise according to the norm. Setting the standard together with a knowledgeable physiotherapist made the plan legitimate, and so when they had fulfilled the plan the respondents could feel successful in knowing that they had done enough. The goals they set were described as good, and as aimed at healthy exercise that was integrated as a part of their life. They said that setting these goals increased their ability to exercise instead of constantly trying to recover after exercise-related overload.

> Well, I guess we decided together what was reasonable. And we were pretty careful about me not biting off more than I could chew right away, but instead increasing gradually. Because it's so easy to feel defeated. And then it so easily falls apart, all of it.[16]

Facilitating a regular and flexible exercise routine

The health plan was described as providing support to maintain a regular exercise routine with reasonable expectations on continuity. The respondents described their plan as flexible, with multiple opportunities and the ability to continuously change exercises accordingly. They explained that the focus was on physical activity in itself, rather than any specific achievement, as the overall goal was a sustainable health-enhancing level of physical activity. The health plan was a starting plan, and the respondents had the opportunity to discuss with the physiotherapist how to elaborate the plan and think about exercise. They described becoming more aware about what they did, and more aware that all physical activity counted and influenced their health.

> …but if I feel I'd like to take a proper walk, I mean if I go for a walk longer than half an hour and in normal speed, that can be something instead of the things we wrote down, swimming or…? …she (the physiotherapist) just said "Yes, absolutely." Good, then I know and can think about it later, that I don't need to dance today because I went for a walk. I can do that too but that walk… even a short walk may count as such an element.[2]

Experiencing setbacks

All respondents experienced some level of difficulty in maintaining their exercise routine, and described setbacks in their ability to exercise according to their plan. These setbacks included fluctuation in symptoms as well as exacerbation of symptoms due to exercise, but also other health issues or life events that caused disruption. Many respondents described their struggle to repeatedly pull themselves together and start over.

Ways of coping with these setbacks varied among the respondents, as did the ability to start over. Reflecting on one's resources and misgivings was part of tailoring the health plan, and the respondents said that this reflection prepared them for eventual setbacks and provided a plan about how to overcome them. Some respondents described having the strength and ability to adjust their

health plan on their own and get going again. Others said that discussing and adjusting the plan together with the physiotherapist helped them overcome the difficulties and start over. A few respondents described being unable to overcome their difficulties and fulfil their plan. Of these, some did not seek help from the physiotherapist as they could not see what this would add, while others said they were still not able to move on despite close contact with the physiotherapist.

> …but there are bad days and good days, and things happened that even I couldn't influence, and it's good to see how you react upon such things when you have (support)… how to do and what things work.[18]

A frame for participation and accessibility to help fulfil the plan

Most of the respondents reported positive experiences using the digital platform, and they appreciated that it had many functions gathered in the same place. They liked the idea of using eHealth to support their health plan and interaction with healthcare. The platform was described as acting as a frame for the health plan, giving them a way to participate and an assurance that there was someone there for them if needed.

> The app was kind of there all the time, and you felt involved in some way even if you were still do everything yourself.[4]

Many of the respondents were familiar with using functions in their smartphone and social media, and this way of registering and communicating felt natural. A minority of the respondents did not use the platform. The reasons for this included technical difficulties, the platform not meeting their needs, or just forgetting to use it. Most of these respondents still liked the idea of a digital platform for communication and support, and acknowledged that this could be a significant support for many people even if it was not suitable for themselves at that time.

An aid to get it done

The respondents found that self-reporting achievements of physical activity in the digital platform gave them motivation to get the exercise done, since they had to do it in order to be able to report it. The display showed what they had done, and many respondents felt good about themselves when they ticked off that their exercise had been performed according to the plan. However, when they were not able to fulfil their plan, they experienced it as hard to register this in the platform, even though some said that the registration was helpful in getting back to the plan after a setback. They saw it as positive that there was a real person to report to, not just a digital reminder for themselves. Although the respondents knew they were exercising for their own well-being, the feeling of being required to report on their exercise and receive feedback increased their motivation and ability to accomplish their plan.

> It was a swift kick in the butt, absolutely, having to fill in every week. Because you don't want to report that you haven't complied.[9]

The respondents did however raise some suggestions for improvements to the platform that could contribute to the support it provided, such as push notifications to remind them that it was time to register, and more frequent check-ups from the physiotherapist, especially when they had not registered for a while. Some respondents also suggested a forum which would allow them to interact with the other participants in the study and gain support from others in the same situation.

Gaining perspective on health

Some respondents said it was helpful that they were able to look back on their progress and how they felt and performed, including graphs and statistics which let them monitor their fluctuation in health and find patterns. Looking back helped them gain perspective on their health, both in visualising and acknowledging their progress; and when they felt worse, knowing they had had better periods gave them hope.

> Well, it is actually interesting. If I'd done this well, and responded to it, it would have been fantastic to be able to go back for, like, half a year, if you think everything is crap. 'No, but look here, I had a great stretch, what was I actually doing then?' Because you forget and only see the hard times.[3]

Having support to lean on

All respondents appreciated the possibility of sending messages to the physiotherapist through the chat function. Having support from a knowledgeable person was important for them to feel secure about adjusting exercises and loads to avoid increased pain. They felt trust in having access to this expertise, knowing where to turn in case of need.

The respondents described both positive and negative experiences of communicating through the chat function. Positive aspects including being able to easily receive responses to their questions and the ability to post questions whenever they arose. They also said their threshold for sending simple questions was lowered knowing that they would not be disturbing the physiotherapist in her clinical work. One negative aspect was not knowing when the response would come; sometimes they had to wait for a week.

Some respondents used the chat function on a regular basis, reporting on their achievements every week and receiving support and feedback from the physiotherapist. Others used it more seldom, or more frequently in periods of need, and some respondents did not use it at all as they felt they were not in need of contact.

A few respondents preferred communication through telephone or appointments.

And knowing this …I can write to her exactly when I want, and it's going to be like that for a year, that was absolutely wonderful. To have that access. It brings security in that maybe … the motivation to continue to exercise. Because you know that if things get difficult, you're not alone, she's still here in this and I can just contact her.[2]

DISCUSSION

The co-creation of the health plan for physical activity was described as the most valuable part of the intervention. The respondents experienced this as a new model that they had not previously encountered within healthcare. In the light of their limitations, disease and fears, they expressed hope of having developed a plan that they could manage and that could improve their health and well-being. Aspects that were valuable for this hope included the fact that the plan was individually and mutually tailored, and that it started with a load that was reasonable in the light of their resources and limitations.

Reflecting over their health together with a knowledgeable person who acknowledged their limitations and circumstances brought an experience of trust and security. This finding is in line with previous reports on the contributions of e-health to trust and security among other populations living with chronic conditions.[28 29] The category a plan tailored for me showed that the key elements from the respondents' perspective were creating a plan on a reasonable and good enough level, building flexibility into the activities in order to facilitate regular exercise and providing digital support in case of setbacks. The experiences of hope nurtured by working in partnership with a physiotherapist was a contrast to earlier experiences of being mistrusted and having to defend themselves. Experiences of difficulties and confusion over executing physical activity when living with chronic pain have been raised in earlier studies,[30 31] highlighting the need for guidance from a professional with adequate knowledge as well as extra support to overcome barriers and get the exercise done.

The co-creation of the health plan was based on the theoretical foundation of person-centredness. Person-centredness implies an ethical consciousness about the patient as a capable person; who they are rather than what health problem they have.[12] Mindful listening constitutes an important part of this,[32–34] as it is crucial in getting to know who the person is and 'sends a message to the patient that his or her experiences, feelings, beliefs and preferences are important considerations'.[12] One respondent found the tailoring of the health plan demanding, no other negative views about the co-creation of the health plan were raised.

A digital platform was introduced as a year-long support to implement the health plan.[22] The respondents liked the idea of digital support, both to fulfil their health plan and for interaction with healthcare. The digital platform gave them external motivation (described in the subcategory an aid to get it done), a tool to monitor their health (gaining perspectives of health), and a sense of accessibility and security (having support to lean on). However, perceptions of what the platform contributed varied widely among the respondents.

Digital support has the advantage of being highly accessible, and are suggested to be beneficial complements to clinical treatment,[17 35] but there is an evidence gap regarding efficacy.[36] Recent RCTs in people with chronic pain found no significant differences between standard treatment and treatment including web-based supplements,[18 22] and adherence to web-based interventions is often low.[18] However, promotion of physical activity is important for all patient groups and adherence to a physical activity plan is challenging for patients with chronic disease. A recent study indicates that the outcomes among those with low motivation and low adherence for physical activity plan can improve by increasing the number of individual appointments.[37] Further research on how to support regular physical activity is warranted.

Implications

This study indicates that the co-creation of a health plan for physical activity was a valued approach, based on the respondents goals and experiences, and anticipated to improve their health and well-being. The digital platform could be a significant support, providing motivation and a sense of security. However, it was clear that the platform as support for the health plan was not optimal for all. Combining face-to-face care with web-based options[36] could be considered for future research.

Although the respondents said that they had been introduced to the functions of the platform and encouraged to use these according to their needs and desires, several respondents requested more scheduled check-ups from the physiotherapists, especially in times of vulnerability; for example, to restart after setbacks. We, therefore, recommend that the co-creation of the health plan also includes an additional plan for follow-ups based on how the patient would prefer the collaboration to continue and the anticipated need of motivational support.

Strengths and limitations

To enhance credibility, respondents with various experiences were sought from a previous intervention study by recruiting from all study sites. Nineteen respondents participated, which can be regarded as a relatively large sample in a qualitative study. However, only three men agreed to participate, which limits the generalisability. Further, the age of the respondents ranged from 26 to 60 years, an age-group anticipated to be familiar with digital tools. The use of digital tools in an older population needs to be further outlined.

The interviews were performed by two physiotherapists, both experienced in interview methodology and conducting qualitative interviews. To ensure consistency in data collection, all interviews followed a semistructured

interview guide and were initiated with the same question. Due to the COVID-19 pandemic, the data collection method changed during the study from face-to-face interviews to telephone interviews. Face-to-face interviewing is considered the norm for qualitative interviews, but studies report positive experiences of telephone interviews and suggests that telephone interviews can be considered as first choice options.[38] We found that both the face-to-face interviews and the telephone interviews were rich and nuanced, indicating that the telephone has become a natural tool for communication. The respondents in this study appreciated the opportunity to participate from home especially due to the prevailing pandemic. The interview questions focused on concrete aspects (the health plan and the digital platform) rather than general perceptions and existential issues.

Recently, statistical models have been presented to estimate the number of interviews needed to estimate a new information threshold.[39] The statistical analysis requires, however, a specific codebook, which was not applied in our study. When scrutinising the categories developed in the analysis of the individual interviews, we found that no new codes emerged in the last four interviews (two for each interviewer), indicating that data saturation was achieved.

The interviews were analysed with qualitative content analysis, which is commonly used in healthcare and suitable for our research question. The analysis was performed by five researchers who reached agreement on the results through the whole analytical process, which contributes to the credibility of the study. We believe the results show that the health plan as it was constructed nurtured hope for physical activity that works. The generalisability to other populations must be judged by the reader.

CONCLUSION

The co-creation of a health plan nurtured hope of having developed a manageable plan for physical activity that could lead to improved health and well-being. Digital support may serve as a valuable complement in order to provide motivation and sense of security, but a predefined plan for follow-ups should be established.

Author affiliations
[1]Department of Health and Rehabilitation, Unit of Physiotherapy, University of Gothenburg Institute of Neuroscience and Physiology, Goteborg, Sweden
[2]Department of Occupational Therapy and Physical Therapy, Sahlgrenska University Hospital, Region Västra Götaland, Goteborg, Sweden
[3]Research, Education, Development & Innovation, Primary Health Care, Region Västra Götaland, Goteborg, Sweden
[4]University of Gothenburg Institute of Health and Care Sciences, Goteborg, Sweden
[5]Department of Rheumatology and Inflammation research, University of Gothenburg, Goteborg, Sweden

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Competing interests None declared.

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 applicable.

Ethics approval This study involves human participants and was approved by the Regional Ethics Review Board in Gothenburg, Sweden (Dnr 1025-17). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request.

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ORCID iDs
Caroline Feldthusen http://orcid.org/0000-0003-3467-6757
Emmelie Barenfeld http://orcid.org/0000-0002-4945-4623
Anette Larsson http://orcid.org/0000-0002-0405-3877

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