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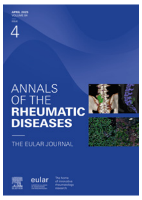

Recommendation

EULAR points to consider for patient education in physical activity and self-management of pain during transitional care

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ABSTRACT

Objectives: A EULAR task force was convened to develop points to consider (PtC) for patient education in physical activity and self-management of pain in young people with juvenile-onset rheumatic and musculoskeletal diseases during transitional care.

Methods: A task force of 26 people from 10 European countries followed the EULAR Standardised Operating Procedures to establish overarching principles (OAPs) and PtC based on a literature review and expert consensus. Level of evidence (LoE), grade of recommendation (GoR) and level of agreement (LoA) were determined.

Results: Two OAPs and seven PtC were formulated. The OAPs highlight the importance of personalised transitional care in rheumatology, ideally based on shared decision-making and incorporate interactive education to empower young individuals in managing their physical activity and pain. The PtC emphasise the clinical importance of patient education in these areas to improve readiness to transfer from paediatric to adult care. For two PtC, the GoR was moderate (grade B), based on individual cohort study (LoE 2b). For the remaining five PtC, the GoR was weak (grade D), based on expert opinion (LoE 5). The LoA among the task force was high, ranging from 9.4 to 9.8, except for one PtC that was 8.7.

Conclusion: These EULAR PtC establish guidance on best practices for delivering patient education in physical activity and self-management of pain during transitional care in rheumatology. The adoption of these PtC in clinical settings is recommended to standardise and optimise transitional care across European healthcare systems. Additionally, the task force expects that these PtC will drive future research and potentially shape policies across Europe.

INTRODUCTION

The transition from adolescence to adulthood is a critical period characterised by rapid and extensive biopsychosocial changes. This transition is particularly challenging for individuals growing up with juvenile-onset rheumatic and musculoskeletal diseases (jRMDs) [1], which may limit them from having a healthy and satisfactory life [2−4]. Children, adolescents and young adults (hereinafter referred to as young people) with jRMDs have a particular medication and face a health burden [5], distinct from adults [6] and require specialised care [5,6]. Although remission of jRMDs is possible [7], still 50% of cases persist with active disease into adulthood, requiring a transition from paediatric to adult care to continue their treatment [8,9]. During this transition, 20%−50% of young people with jRMDs discontinue treatment, leading to worsening outcomes [10−12]. Thus, in 2017, EULAR/PReS launched general standards and recommendations for transitional care in rheumatology [13]. These guidelines highlighted the importance of early access to developmentally appropriate transitional care provided by specialised and coordinated multidisciplinary teams. While the 2017 EULAR/PReS standards have inspired meaningful progress in the field [14−16], our task force identified a clinically relevant and timely gap: the need for specific guidelines focused on patient education in physical activity and self-management of pain.

First, young people with jRMDs often are at risk of worse overall health and an increased risk of comorbidity in adulthood [9]. In this context, physical activity has well-known, broad benefits for health, including those related to cardiovascular health [17], inflammation [18], cancer [19], sleep quality [20], mental health [21] and health-related quality of life [22]. Physical activity has also specific benefits for RMDs, with improvements in disease activity [23] and symptoms [24]. Therefore, patient education promoting regular physical activity is important and particularly timely now that 81% of adolescents worldwide do not meet the minimum physical activity levels recommended by the WHO [25]. Importantly, this figure seems to be even worse in young people with jRMDs [26]. Second, despite good pharmacological control, an average of 60% of young people with jRMDs continue to experience pain [27]. Persistent pain may negatively impact school attendance [28,29], academic performance [30], social participation [31] and employment rates [4,32], all of which may affect adulthood. In this context, patient education that improves self-management of pain may help young people with jRMDs navigate key outcomes such as educational and vocational achievement, emotional management, intimate relationships and social life [33]. Thus, patient education in physical activity and self-management of pain is essential to manage their health proactively as they transition from paediatric to adult care, offering potential long-lasting benefits.

WHAT IS ALREADY KNOWN ON THIS TOPIC

- The 2017 EULAR/PReS standards and recommendations provide general guidance for transitional care in rheumatology.
- The potentially long-lasting benefits of patient education in physical activity and self-management of pain during transitional care are widely acknowledged.
- However, there is currently a lack of consensus on how best to deliver patient education in these areas during transitional care.

WHAT THIS STUDY ADDS

- This EULAR task force establishes two overarching principles and seven points to consider (PtC) for patient education in physical activity and self-management of pain during transitional care.
- The task force also proposed a research agenda to increase evidence-based knowledge and improving practice to enhance the quality of transitional care.
- These PtC provide guidance for clinical practice in these areas, aiming at facilitating continuity of care in the transition from paediatric to adult services.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- This task force encourages future well-designed randomised controlled trials to evaluate existing patient education programmes in physical activity and self-management of pain during transitional care and, if needed, optimise them or develop new programmes.
- Implementing these PtC in practice may lead to innovative approaches to promote physical activity and self-management of pain during transitional care.
- This PtC may influence policy by advocating for quality of care in rheumatology during the transition from paediatric to adult services across Europe.

Therefore, a task force was convened to establish the EULAR overarching principles (OAPs) and points to consider (PtC) for patient education in physical activity and self-management of pain in jRMDs during transitional care. This task force aimed to complement, rather than update, the 2017 EULAR/PReS general standards. The target audience comprises adult and paediatric rheumatologists, health professionals in rheumatology (HPRs), young people with jRMDs, their families, patient organisations and policy-makers across Europe.

METHODS

The work of this task force was conducted in accordance with the EULAR updated Standardised Operating Procedures [34]. After approval, from the EULAR Executive Committee, a steering committee was established, including the convenor (FE-L), two co-methodologists (FE-L and LC) and two fellows (JC-I and RP-M). The multidisciplinary task force (n = 26) included paediatric and adult rheumatologists, HPRs, people with RMDs and representatives from the Emerging EULAR Network from 10 European countries (Belgium, Czech Republic, Hungary, Germany, the Netherlands, Portugal, Spain, Switzerland, Turkey and the UK). All members disclosed their conflicts of interest upfront. All task force meetings were conducted online.

The steering committee convened in March 2021 to set out the whole process, establishing the protocol to develop the PtC. In line with the meeting's agenda, the fellows conducted a scoping review to create a preparatory material offering insights into current practices of transitional care in young people with jRMDs. Previous EULAR recommendations focused on adults and related to the scope of this task force were also reviewed (eg, patient education [35], pain management [36], physical activity [37] and self-management of inflammatory arthritis) [38]. During the first task force meeting, this preparatory material was discussed, with the final aim of defining the research question for the systematic literature review (SLR), a matter for a separate publication. Within this meeting, we identified the clinical gaps, which would serve as the basis for adopting the Population Intervention Comparison Outcome approach. This approach supported the development of the search strategy for the SLR, conducted in different databases (ie, Cochrane Library, Medline). The SLR was conducted by fellows, with the supervision of the convenor and co-methodologists, to collect qualitative and quantitative studies conducting or describing a structured transitional care programme for young people with jRMDs. Although the primary aim of the SLR was to inform the PtC for patient education in physical activity and self-management of pain, we intentionally broadened the scope of the SLR. This approach aligned with the research agenda developed during our first meeting, ensuring a more comprehensive summary of the current state of the art of transitional care in rheumatology. By including a wider range of studies, we aimed not only to address immediate priorities but also to provide insights that may optimise existing strategies and support the development of more effective, evidence-based approaches. Additionally, this broader review may facilitate the implementation of these approaches in clinical practice by identifying gaps and areas for improvement. In the second meeting, the task force discussed the SLR results and the first list of OAPs and PtC, drafted by the steering committee based on the preparatory material and the semistructured interviews carried out individually with each task force member, where relevant findings were discussed and additional literature was identified. The first two Delphi rounds were performed during the second meeting, where each member of the task force was asked to indicate their level of agreement (LoA) on each recommendation, which was rated anonymously through a survey on an 11-point Likert scale from 0 to 10 (0: completely disagree, 10: completely agree). Items scored over 7 mean points were considered for the next round. Items below 7 mean points were further discussed to decide whether to change the wording/contents or to dismiss them from the list. Additionally, related items were discussed to be grouped. After the meeting, a second list of OAPs and PtC was formulated and LoA asked to be rated anonymously. In the third Delphi round, each member of the task force gave their final rating on every item. The consensus was reached if ≥75% of the members voted in favour of the recommendations and gave ≥8 mean points. The mean and SD of the LoA, as well as the percentage of agreement ≥8, were presented. Lastly, the task force was consulted to revise and provide feedback on the final document. The steering committee appraised the level of evidence (LoE) and grade of recommendation (GoR), according to the standards of the Oxford Centre for Evidence-Based Medicine [39].

RESULTS

The task force agreed on two OAPs and seven PtC (table 1). Most PtC were based on expert opinion (GoR = D, LoE = 5) due to the limited evidence available in the literature. However, PtC 5 and PtC 6 were based on individual cohort study (GoR = B, LoE = 2 b). Overall, the LoA on the present PtC was high, with scores ranging from 9.4 to 9.8, except for PtC 4 (LoA = 8.7). The

Table 1

Overarching principles (OAPs) and points to consider (PtC) for patient education in physical activity and self-management of pain in juvenile-onset rheumatic and musculoskeletal diseases (jRMDs) during transitional care in rheumatology

		LoA	
OAPs		Mean (SD)	% with score ≥8
1	Transitional care has clear personalised aims, ideally based on shared decision-making and periodically monitored by both objective and patient-reported outcomes	9.9 (0.8)	100
2	Patient education is a planned interactive learning process designed to support and enable young people with jRMDs to manage their health and chronic condition and optimise their well-being during transitional care	9.5 (0.8)	100

PtC		LoE	GoR	Mean (SD)	% with score ≥8
1	Patient education in physical activity and self-management of pain should be prioritised for newly diagnosed patients and for those in transitional care	5	D	9.6 (0.5)	100
2	Patient education in physical activity and self-management of pain should be tailored and needs-based according to the young people's priorities, preferences, capabilities and resources	5	D	9.6 (0.9)	95
3	Patient education during transitional care should consist of a variety of learning formats, including digital health	5	D	9.4 (1.4)	91
4	Patient education during transitional care should include the evaluation of both young people's health literacy and, most importantly, their behavioural changes	5	D	8.7 (0.8)	87
5	All patients and their caregivers should be offered education on the importance of maintaining a healthy lifestyle to better self-manage jRMDs	2b-5	B	9.8 (0.7)	100
6	Physical activity has health benefits for young people with jRMDs and should be promoted during transitional care	2b	B	9.8 (1.0)	95
7	Rheumatologists and health professionals in rheumatology should consider offering a variety of physical activity formats that align with young people's preferences and disease requirements	5	D	9.6 (0.4)	100

GoR, ranging from A ('consistent level 1') to D ('level 5 evidence'). LoA, ranging from 0 ('completely disagree') to 10 ('completely agree'). LoE, ranging from 1('high quality randomised controlled trials') to 5 ('expert opinion'). 2b = individual cohort study.
GoR, grade of recommendation; LoA, level of agreement; LoE, level of evidence.

task force attributed the lower LoA for PtC 4 to challenges in identifying a feasible and practical method for measuring health literacy in daily clinical practice during transitional care in rheumatology.

Overarching principles

The task force emphasises that both OAPs are relevant to all the PtC. These OAPs stress the importance of personalised and interactive patient education processes that empower young people with jRMDs to actively manage their health during the transition from paediatric to adult care [35]. A biopsychosocial approach is emphasised, considering not only medical but also psychological and social factors to ensure holistic support. These OAPs encourage shared decision-making, aligning care with individual needs, preferences and resources (ie, patient-centred care), ensuring regular monitoring of both objective and patient-reported outcomes [13].

Points to consider

PtC 1: patient education in physical activity and self-management of pain should be prioritised for newly diagnosed patients and for those in transitional care

Improving young people's knowledge and health literacy in physical activity and self-management of pain early in transitional care may be meaningful [40,41]. Thus, the task force suggests to consider providing patient education in these areas as the starting point of transitional care [42,43]. In this context, patient education may promote an active lifestyle and help young people cope with the consequences of pain [44]. Equipping young people with jRMDs with early health literacy and self-care skills may empower them to manage their own health independently [45], achieve self-efficacy and parental independence [46], prevent consequences of sedentarism [47], mitigate lifelong pain-related disability [48] and improve both their social and vocational development [49]. Additionally, providing education in both physical activity and self-management of pain may have a synergist effect, yielding larger effects when combined together than when addressed separately [50].

PtC 2: patient education in physical activity and self-management of pain should be tailored and needs-based according to the young people's priorities, preferences, capabilities and resources

The task force suggests tailoring patient education in physical activity and self-management of pain to meet young people's care needs according to their developmental changes in perceptions, interests and maturity during transitional care [49]. Importantly, young people of the same age may have different self-management skills and readiness to transition [51]. Thus, patient education may consider biopsychosocial and environmental needs over age-based approaches [52]. Accordingly, educational needs for physical activity and self-management of pain may be flexible, regularly revised and adjusted to the evolving challenges young people face during transitional care, such as changes in self-advocacy, self-confidence, school demands, body image and sexuality [53,54]. In this context, introducing activity pacing may help young people with jRMDs manage daily activities more sustainably by adapting to the fluctuating nature of their symptoms, including pain. Activity pacing involves breaking activities into realistic goals to prevent overexertion and avoid the boom-and-bust cycle, where overactivity leads to flare-ups and subsequent decreases in physical activity.

PtC 3: patient education during transitional care should consist of a variety of learning formats, including digital health

The task force suggests offering young people with jRMDs a variety of options, allowing them to choose based on their preferred learning style. The main modes of delivering patient education explored in transitional care in rheumatology, include combinations of face-to-face or remote interventions with individual or group-based approaches [55]. Gamification strategies (eg, avatars, progress indicators and rewards) [56,57], narrative medicine interventions (storytelling) [58] and peer-mentoring [59] may also be considered, given the intrinsic interest shown by young people. Social media-based programmes [60] and video games [61] often show good acceptability and provide engaging alternatives for promoting physical activity in young people with jRMDs. Smartphone-based pain self-management programmes seem to be both feasible and beneficial for young people with jRMDs [44].

The task force advises education providers to be skilled in the delivery formats preferred by young people with jRMDs and be flexible in adapting their approach as the young person develops [35]. Education providers are also encouraged to engage young people in informed shared decision-making, particularly regarding patient education in physical activity and self-management of pain. When needed, the task force highlights the importance of offering training in these areas to education providers, including but not limited to, rheumatologists, HPRs, families and teachers.

PtC 4: patient education during transitional care should include the evaluation of both young people's health literacy and, most importantly, their behavioural changes

Health literacy, defined as the ability to find, understand and use health-related information, is crucial for making informed decisions regarding physical activity and self-management of pain. In young people with jRMDs, insufficient health literacy is associated with worse outcomes including poorer transition readiness [62] and ineffective self-management, often resulting in parents having a more central role during consultations [63,64]. Enhancing health literacy equips young people to make informed decisions, supporting them to have better control of their disease management. In transitional care, it may be important to equip young people with jRMDs with health literacy skills to critically appraise the quality of information available on the internet [65]. In addition to enhance health literacy, patient education may have potential to promote long-lasting behavioural changes that integrate healthy practices, such as engaging in physical activity and self-managing pain, into daily routines [9,45]. Educational programmes tailored to the individual health concerns and life experiences of young people with jRMDs may be beneficial in increasing health literacy and helping them better understand the potential risks related to their condition [66] while also encouraging sustainable behavioural changes [67].

Therefore, the task force emphasises the importance of patient education in physical activity and self-management of pain during transitional care, focusing not only on improving health literacy but also on supporting long-lasting behavioural changes and their integration into daily routines [67−69].

PtC 5: all patients and their caregivers should be offered education on the importance of maintaining a healthy lifestyle to better self-manage jRMDs

Patient education in physical activity and self-management of pain should raise awareness and promote specific behavioural changes in young people with jRMDs during transitional care, helping them and their caregivers understand the importance of a healthy lifestyle for reducing disease activity, preventing comorbidities and achieving other general benefits such as improved well-being [43,70,71]. In this context, a systematic review [72] concluded that there is evidence supporting that adopting a healthy lifestyle may be beneficial for young people with jRMDs. For instance, nutritional interventions such as omega-3 fatty acids and iron supplementation have been shown to strengthen immune status markers, including cytokines [73] and haemoglobin levels [74]. In addition, educational programmes focused on healthy nutrition for both patients and their parents have been found to promote greater calcium intake [75], which may have long-lasting benefits supported by better bone health [76]. Although the existing evidence is limited, the task force also emphasises the importance of offering guidance on avoiding unhealthy habits such as smoking and alcohol consumption [77−79], as well as other important topics like sleep hygiene [3,80], sexual health [81,82] and healthy body composition [83,84], as addressing these behaviours may further enhance long-term health outcomes. To support this, it may be important guiding families in reducing overprotective behaviours, encouraging a gradual transfer of responsibility to young people, fostering independence, better self-management and improved health outcomes [15,16,85].

PtC 6: physical activity has health benefits for young people with jRMDs and should be promoted during transitional care

EULAR recognises promoting physical activity is a core component of RMDs care [13,37,86] with its health benefits extending to young people with jRMDs [47]. In this context, there is evidence supporting that physical activity interventions may have benefits in functional status (eg, dressing, walking) [87], health-related quality of life [2], pain [88], multimorbidity [71] and disability [89]. The task force suggests that the WHO 2020 guidelines on physical activity and sedentary behaviour are also applicable to young people with jRMDs during transitional care [25]. We also highlight that, to promote adherence to physical activity, strategies may address barriers faced by young people with jRMDs (eg, fear of worsening symptoms, parental overprotection and low self-efficacy) while maximising facilitators (eg, enjoyment, parental and peer support and positive reinforcement) [47,90,91].

PtC 7: rheumatologists and HPRs should consider offering a variety of physical activity formats that align with young people's preferences and disease requirements

Although the WHO guidelines emphasise quantitative aspects of physical activity (frequency, duration and intensity), the task force underscores the importance of considering qualitative factors (ie, contextual elements) to optimise enjoyment [92], improve self-esteem [93] and to achieve a better adherence to physical activity in young people with jRMDs. Thus, rheumatologists, HPRs and any other caregivers (eg, families, teachers) may consider contextual factors when offering physical activity for young people with jRMDs, including but not limited to, the type of activity (eg, aerobic activity, bone-strengthening and muscle-strengthening exercise, mind-body activities and sports), level of supervision (ie, supervised or unsupervised), delivery mode (eg, face to face or remote), physical environment (ie, schools, community settings or sports clubs; indoors vs outdoors), social environment (eg, individual sports or team sports) and equipment (eg, ropes, balls).

The task force highlights the need for specialised assistance in offering variations in contextual factors of physical activity to reduce monotony, while ensuring the activity is safe and well-tolerated [90]. Patient education for physical activity may help young people with jRMDs to self-regulate physical activity levels according to their capabilities and daily symptoms fluctuations. Importantly, engaging in a variety of physical activity may help them discover their personal preferences.

DISCUSSION

This manuscript presents the EULAR PtC for patient education in physical activity and self-management of pain in young people with jRMDs during transitional care, establishing two OAPs and seven PtC. These PtC are the consensus of a diverse, multidisciplinary and international panel of 26 members including paediatric and adult rheumatologists, HPRs and people with RMDs. The discussions of this task force were informed by a broad review of the available literature (including previous guidelines [35–38]) and semistructured individual interviews with each task force member. Most PtC were based on weak evidence (ie, expert opinion) due to the limited evidence available in the literature. PtC 5 and PtC 6, in contrast, were based on moderate evidence (ie, individual cohort study). Overall, task force agreement was high, except for PtC 4, which was lower due to challenges in identifying a practical method for measuring health literacy in daily clinical practice in transitional care.

The 2017 EULAR/PReS task force introduced general guidelines for transitional care in young people with jRMDs. Building on the progress initiated by those general guidelines, our task force viewed it as a next step to provide specific guidance on patient education in physical activity and self-management of pain during transitional care in rheumatology. We identified these areas as particularly urgent due to the high prevalence of physical inactivity and poor self-management of pain among young people with jRMDs, which may negatively impact their long-term outcomes and health-related quality of life. Thus, addressing these two key issues offers a valuable step forward in promoting continuity of care in rheumatology. To further advance transitional care in rheumatology, the task force outlined a research agenda emphasising the importance of experimentally evaluating the effects of existing transitional care programmes and, if needed, optimise them or develop new programmes (box 1).

Given the urgent need to raise awareness about the importance of ensuring continuity of care in rheumatology, our immediate goal is to promote the present PtC. We plan to disseminate these guidelines to both academic and layperson audiences through various channels, including scientific manuscripts, presentations and leaflets, as well as participation in mass media such as interviews, podcasts and social media campaigns. To maximise their reach and visibility, these materials will be translated into as many languages as possible.

Considering the limited availability and access to transitional care programmes of excellence in rheumatology, promoting the broad implementation of these PtC is a key priority for our task force. While digital health solutions (eg, apps) offer potential for patient education in physical activity and self-management of pain, they must be approached with caution due to the need for individualised strategies and limited supporting evidence. Additionally, placing the burden on patients is always problematic and particularly without adopting system-wide changes to support them. For instance, we highlight the need for caregivers training and ensuring that educational resources are both accessible and affordable.

Box 1 Research agenda

- To conduct high-quality studies that generate evidence supporting or refuting the present points to consider for patient education in physical activity and self-management of pain in transitional care in rheumatology, which is primarily based on expert consensus.
- To analyse the effects of existing programmes in these areas through well-designed randomised controlled trials that assess key outcomes in transitional care (eg, readiness to transfer, continuity of care) and, if needed, optimise them or develop new programmes.
- To develop sustainable, customised educational interventions in these areas, with developmentally appropriate content that aligns with the evolving priorities of young people's with juvenile-onset rheumatic and musculoskeletal diseases (jRMDs) as they grow.
- To explore the barriers and facilitators to implementing patient education in these areas into the daily lives of young people with jRMDs, including school and leisure time.
- To examine how digital health tools may support young people with jRMDs—and their families, healthcare professionals and any other caregivers (eg, teachers)—as they transition from paediatric to adult care, while promoting responsible use of technology and addressing issues such as time management and avoiding sedentary behaviour.

A limitation of these PtC is that the task force decided to focus on patient education in physical activity and self-management of pain, thereby excluding other important areas, such as patient education in self-management of fatigue. Expanding the scope to include additional outcomes would have been excessively ambitious and could have compromised the feasibility of the task force's work. Additionally, most of the available literature is from studies conducted in relatively homogeneous populations; predominantly, white individuals with Juvenile Idiopathic Arthritis from developed countries, with scarce attention to individuals from minorities, populations at risk of social exclusion and those underrepresented in research or with limited access to care. In addition to raising questions about generalisability to other populations, this may be particularly relevant during transitional care as diversity continues to increase in younger populations. While these limitations should be acknowledged, the present PtC emphasise the importance of personalised transitional care tailored to individual needs, priorities, preferences, capabilities, resources and contexts. In addition, a potential limitation of the consensus process is the potential for bias in expert selection, which may lead to an overrepresentation of certain viewpoints, limiting the diversity of perspectives.

In conclusion, this EULAR PtC for patient education in physical activity and self-management of pain in young people with jRMDs during transitional care provide guidance to rheumatologists, HPRs, young people with jRMDs, families, any other caregivers (eg, teachers) and organisations. Our ultimate goal is to promote continuity of care in rheumatology, empowering young people with jRMDs to manage their health proactively and improve their long-term health outcomes. These PtC are intended to fill gaps in current practice, drive future research and potentially shape policies to ensure more standardised, person-centred transitional care across Europe.

Contributors

All authors are members of the EULAR's task force HPR051. JC-I and RP-M were the fellows. FE-L was the convenor (guarantor). LC and FE-L were the co-methodologists. All authors contributed to the work, read and finally approved the manuscript for submission.

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Competing interests

JC-I: none declared, RP-M: none declared, EB-V: none declared, PA-V: none declared, SA: none declared, JA: none declared, IB: none declared, DC: none declared, MC: none declared, WC: none declared, DDC: none declared, AD: none declared, LL: payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events from Pfizer; AM: none declared, KM: grant/research support from Pfizer, Novartis and Medac, AFM: none declared, AN: none declared, SO: none declared, GP: none declared, ZS: none declared, TV: none declared, NMW: none declared, AZC: none declared, YP: none declared, LC: none declared, FE-L: none declared.

Patient and public involvement statement

Patients as research partners were involved in the design, conduction, reporting and dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication

Not applicable.

Data availability statement

Data sharing is not applicable as no datasets were generated for this study. All data relevant to the study are included in the article or uploaded as online supplemental information.

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