

EULAR/eumusc.net standards of care for rheumatoid arthritis

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EULAR/eumusc.net standards of care for rheumatoid arthritis: cross-sectional analyses of importance, level of implementation and care gaps experienced by patients and rheumatologists across 35 European countries

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ABSTRACT

Objective As part of European League against Rheumatism (EULAR)/European Musculoskeletal Conditions Surveillance and Information Network, 20 user-focused standards of care (SoCs) for rheumatoid arthritis (RA) addressing 16 domains of care were developed. This study aimed to explore gaps in implementation of these SoCs across Europe.

Methods Two cross-sectional surveys on the importance, level of and barriers (patients only) to implementation of each SoC (0–10, 10 highest) were designed to be conducted among patients and rheumatologists in 50 European countries. Care gaps were calculated as the difference between the actual and maximum possible score for implementation (ie, 10) multiplied by the care importance score, resulting in care gaps (0–100, maximal gap). Factors associated with the problematic care gaps (ie, gap \geq 30 and importance \geq 6 and implementation $<$ 6) and strong barriers (\geq 6) were further analysed in multilevel logistic regression models.

Results Overall, 26 and 31 countries provided data from 1873 patients and 1131 rheumatologists, respectively. 19 out of 20 SoCs were problematic from the perspectives of more than 20% of patients, while this was true for only 10 SoCs for rheumatologists. Rheumatologists in countries with lower gross domestic product and non-European Union countries were more likely to report problematic gaps in 15 of 20 SoCs, while virtually no differences were observed among patients. Lack of relevance of some SoCs (71%) and limited time of professionals (66%) were the most frequent implementation barriers identified by patients.

Key messages

What is already known about this subject?

- Twenty user-focused standards of care (SoCs) for rheumatoid arthritis (RA) addressing 16 important domains of care were developed by European League against Rheumatism (EULAR)/European Musculoskeletal Conditions Surveillance and Information Network.

What does this study add?

- Problematic gaps were reported across essential aspects of RA care that are reflected in SoC.
- In non-European Union countries and those with lower gross domestic products, rheumatologists were more likely than patients to identify problematic care gaps.

How might this impact on clinical practice or future developments?

- A consolidated action from the rheumatology community, national rheumatology societies and EULAR is needed to further improve healthcare in rheumatic and musculoskeletal diseases by addressing the implementation of SoCs.

Conclusions Many problematic gaps were reported across several essential aspects of RA care. More efforts need to be devoted to implementation of EULAR SoCs.

INTRODUCTION

The European Musculoskeletal Conditions Surveillance and Information Network (eumusc.net), a 5-year project cofunded by the European League against Rheumatism (EULAR) and the European Union (EU), was established in 2008. The project aimed at raising and harmonising quality of care for patients with rheumatic and musculoskeletal diseases (RMDs) across Europe. As part of eumusc.net, 20 user-focused standards of care (SoCs) for rheumatoid arthritis (RA) addressing 16 important domains of care were developed.^{1 2} These were based on existing clinical practice guidelines, evidence regarding the effect of disease management on patients' outcomes and expert opinion from different stakeholders, including patient research partners.³ Examples of SoCs include standard on time to diagnosis 'People with symptoms of RA should have timely access to a clinician/health professional competent in making a (differential) diagnosis (6 weeks according to EULAR recommendations)' or standards around communication, education and assessment when starting treatments 'At the start of any disease specific treatment, people with RA should be fully educated about the expected benefits and any potential risks, and fully evaluated to assess both clinical status and safety aspects'.⁴ To facilitate the use by patient and advocacy organisations, as well as by individual patients in their efforts to be involved in their own care, lay versions have been made available in 23 languages.⁵

The eumusc.net SoCs present an important reference point and benchmark to monitor quality of care. Uptake and adherence to these standards can be impeded not only by a variety of factors, such as country-specific health system characteristics, but also by individual patient and professional beliefs and preferences. A recent study assessed level of implementation and importance of each of the 20 SoCs as perceived by patients, rheumatologists and rheumatology nurses in the Netherlands.⁶ Patients and professionals had an overall high level of agreement on the priorities among SoCs and reported satisfactory levels of implementation. Notably, patients with poorer health and/or a higher level of education were less satisfied with received care, particularly care related to early diagnosis, availability of a treatment plan and regular assessment of health status.⁶

On the level of healthcare systems, implementation of care standards was expected to vary substantially, depending on financial and organisational capacities of the system. It has been documented that initiation of biological disease-modifying antirheumatic drugs (bDMARDs) following the EULAR treatment recommendations for RA is not equally implemented across Europe, being strongly linked to the country's socioeconomic status.⁷⁻⁹ Determining and consequently monitoring the implementation of available SoCs across countries would be an important step towards improving and harmonising care.

The objectives of this study were (1) to assess the gaps in the implementation of the EULAR SoC for RA among patients and rheumatologists across Europe, (2) to investigate the contribution of individual-level and country-level characteristics to care gaps, and (3) to explore the perceived barriers to implementation of SoC.

METHODS

Design

This study consisted of two cross-sectional surveys aiming at obtaining responses from 50 patients and 50 rheumatologists in each of the 53 countries of the European WHO region. In three of these (Kyrgyzstan, Azerbaijan and Turkmenistan), no

person who could act as a country principal investigator (PI) was identified.

Participants

In 50 countries, one rheumatologist was invited as a PI. The PI was responsible for recruiting 50 patients (from own practice or outside) with a rheumatologist-diagnosed RA without specific eligibility criteria except for being able to read and understand the country's language. In addition, 50 rheumatologists of different age, gender and work setting were invited to participate in this study. Rheumatologists completed the questionnaire online, whereas patients did so either online or on paper.

Questionnaires

The questionnaires (available on request) addressed each of the 20 SoC (online supplementary figure 1), starting with rating the perceived level of importance of each. Participants had to indicate the level at which they had received (patients) or provided (rheumatologists) care according to each SoC (perceived implementation). All answers were to be scored on a 0–10 numerical rating scale (10=highest importance or best received/provided care). Questions on importance offered an answer option 'no opinion', and questions on care received or care provided an answer option 'not applicable to me/my patients'. For feasibility reasons, only the patient questionnaire included additionally seven questions on potential barriers to implementation of SoC (0–10, 10=full agreement).

The questionnaire further included questions about the background of the respondent. For *patients*, sociodemographic questions included age, gender, level of education (completed primary school, secondary education or university education) and work status (working full-time or part-time; retired due to age; officially work disabled; currently not working for other reasons (eg, student, homemaker, or unemployed)). Next, three questions on health literacy were included (ie, help needed to read medical materials, confidence to fill out medical forms or difficulty understanding written information).¹⁰ Each question contained a 5-point Likert scale (5=extremely problematic). The questionnaire also inquired about time since RA diagnosis (disease duration of ≤ 2 vs > 2 years) and self-rated health (well-being considering impact of RA and other present illnesses, 0–10, 10=best health), as well healthcare use (low, ≤ 2 visits/year; middle, 3–6 visits/year; and high, ≥ 7 visits/year). For *rheumatologists*, data on age, gender and work environment (academic setting, non-university hospital or private practice) were collected.

Questionnaires to rheumatologists were administered in English. For patients, the official translations of the lay version of the SoC were used.⁴ The PIs were responsible for the translation of the remaining parts, and where possible (n=14 countries), a patient research partner checked it.

Statistical analysis

The distribution of scores (ratings) for importance and implementation of SoC as well as perceived barriers varied from symmetric unimodal, skewed to bimodal. To facilitate interpretation, the percentages of participants indicating an SoC is *important* (score ≥ 6), a SoC is *insufficiently implemented* (score < 6), or a *barrier* is *strong* (score ≥ 6 , patients only), were provided. Average percentage was computed from country-specific percentages.

Care gaps were then defined as the difference between the actual and the maximum possible score for implementation of

care (ie, 10) multiplied by the score for the importance of care, resulting in a score between 0 (no gap) and 100 (maximal gap) (see online supplementary figure 1). Care gaps were defined as problematic when the following three conditions were all fulfilled: (1) the care gap was ≥ 30 ; (2) importance was scored as ≥ 6 ; and (3) implementation of care (care received or provided) was < 6 (online supplementary figure 2). Problematic care gaps were presented as average proportion across all countries, for patients and rheumatologists.

Factors associated with the problematic care gaps (yes vs no) and strong barriers (yes vs no) were analysed in multi-level logistic regression models, with respondents clustered by country of residence. Separate models were computed for patients and rheumatologists. For patients, models were adjusted for gender, age, disease duration, level of education, work status, confidence with filling in medical forms (proxy to health literacy, none or little vs quite, somewhat or extremely), overall health and healthcare use. For rheumatologists, adjustment was done for gender, age, work setting and years of experience. Gross domestic product (GDP) and EU status were entered separately in fully adjusted models. Data on GDP per capita from 2016, adjusted for purchasing power parity (international dollars), were extracted¹¹ and split into tertiles (low: $< \text{int. } \$24\,157$, middle: $> \text{int. } \$24\,157$ and $< \text{int. } \$38\,212$, high: $> \text{int. } \$38\,212$). EU status was categorised into three groups: the first 15 members, new members and non-EU members (online supplementary table 7). Analyses were performed in STATA V.15.¹²

Patient and public involvement

Patient research partners were consulted at the study design stage, piloting and verifying translations of the study questionnaires, as well as interpretation of the findings. In a few countries, patient partners assisted recruitment of patient respondents through patient organisations.

RESULTS

Study sample

In total, 27 (54%) and 35 (70%) of 50 approached countries provided data, 1873 patients (range 9–385 per country) and 1131 rheumatologists (range 5–107 per country) participated in the survey. Fourteen countries did not meet the recruitment objective of 50 patients and/or 50 rheumatologists per country. Of these, less than five patient questionnaires were provided from Belgium and less than five rheumatologists questionnaires were provided from Armenia, Cyprus, Moldavia, and Norway; these countries were excluded from the analyses, leaving data from 26 and 31 countries for analysis.

Of all patients, 447 (24%) were male; the mean age was 57.2 (SD 13.2) years. Twenty-two per cent had completed primary education only, and 576 (31%) were working. Mean self-rated health was 6.0 (SD 2.3). Most of patients had established RA, with only 168 (9%) having a diagnosis of < 2 years, mean 13.9 (SD 11.2) years. Participating rheumatologists comprised 50% women and, 48% were working in a university hospital. The mean age of the participating rheumatologists was 47.7 (SD 10.5) years (table 1 and online supplementary table 1).

SoC according to patients and rheumatologists

Among the 20 SoCs, the most frequent *problematic care gap* was for SoC₁ ‘diagnosis within 6 weeks of symptom onset by professional’ by both patients (52%) and rheumatologists (59%) (table 2). Other shared priorities (top five for both) were ‘info about relevant patient organisations and trusted sources of

Table 1 Characteristics of patients and rheumatologists

		n (%) / mean (SD)†
Patients (n=1873)*		
Gender	Female	1264 (67)
Age		57.2 (13.2)
Disease duration	2 years or less	168 (9)
Education	Primary	408 (22)
	Secondary	722 (39)
	University	558 (30)
Work	Not working	199 (11)
	Work disabled	282 (15)
	Retired	561 (30)
	Working	576 (31)
Confidence to fill out medical forms	None or little confidence	314 (17)
Visits to healthcare professionals	Low (0–2 visits/year)	661 (35)
	Middle (3–6 visits/year)	724 (39)
	High (≥ 7 visits/year)	163 (9)
Self-rated health (0–10)		6.0 (2.3)
EU membership	First member states (n=10)	1232 (66)
	New member states (n=7)	253 (14)
	Non-member states (n=7)	273 (15)
GDP per capita, category	Low (GDP PPP/capita $< \$24\,157$)	235 (13)
	Middle (GDP PPP/capita $> \$24\,157$ & $< \$38\,212$)	680 (36)
	High (GDP PPP/capita $> \$38\,212$)	958 (51)
Rheumatologists (n=1131)*		
Gender	Female	561 (50)
Age		47.7 (10.5)
Work environment	University hospital	548 (48)
	Non-university hospital or private practice	495 (44)
Years of experience		14.7 (17.5)
EU membership	First member states (n=14)	658 (58)
	New member states (n=9)	205 (18)
	Non-member states (n=7)	196 (17)
GDP per capita, category	Low (GDP PPP per capita $< \$24\,157$)	232 (21)
	Middle (GDP PPP/capita $> \$24\,157$ and $< \$38\,212$)	430 (38)
	High (GDP PPP/capita $> \$38\,212$)	469 (41)

*Number of missing data is provided in online supplementary table S1.

† as appropriate

EU, European Union; GDP, gross domestic product; PPP, purchasing power parity.

information’ (SoC_{2,4}, 41% and 38% for patients and rheumatologists, respectively), ‘info about vaccination’ (SoC_{4,2}, 39% and 29%) and ‘training on aids, devices, ergonomic principles’ (SoC₁₄, 40% in both groups). Notably, patients reported problematic care gaps more frequently than rheumatologists with 19 out of 20 SoC showing problematic care gaps for more than 20% of patients, and 10 out of 20 SoC for more than 20% of rheumatologists. Nearly all SoCs were rated as important by patients and rheumatologists, 15 and 17 being identified as *important* by over 90% of patients and rheumatologists, respectively. However, *implementation* of standards was considered insufficient for many SoCs, ‘info about relevant patient organisations and trusted sources of information’ (SoC_{2,4}) and ‘info about limited evidence of alternative therapies’ (SoC₁₆) being least implemented according to patients, and ‘diagnosis within 6 weeks of symptom onset by professional’ (SoC₁) and ‘info about relevant patient organisations and trusted sources of information’ (SoC_{2,4}) according to rheumatologists (table 2, online supplementary table 2 and figure 1).

Table 2 Implementation, importance and relevant care gaps for each EULAR care standard of care according to patients and rheumatologists

% (n)	Patients (n=1097–1737)			Rheumatologists (n=1021–1104)		
	Implementation (<6)	Importance (≥6)	Problematic care gap*	Implementation (<6)	Importance (≥6)	Problematic care gap*
1. Diagnosis within 6 weeks of symptom onset by professional.	57%	94%	52%	69%	92%	59%
2.1. Info/education about disease.	27%	99%	30%	31%	96%	28%
2.2. Info/education on treatment benefits/risks.	33%	96%	32%	16%	98%	13%
2.3. Info/education on relevant patient's needs.	34%	95%	34%	18%	98%	15%
2.4. Info about relevant patient organisations and trusted sources of information.	68%	72%	41%	62%	82%	38%
3. Availability of a treatment plan.	44%	92%	39%	28%	94%	18%
4.1. Clinical status assessment prior treatment.	30%	94%	26%	9%	99%	9%
4.2. Info about vaccination.	61%	79%	39%	38%	91%	29%
5. Schedule provided of regular assessment of disease.	42%	93%	37%	35%	91%	23%
6. Info on access to emergency contact (flare, side effect).	27%	96%	26%	10%	99%	8%
7. Adequate DMARD received.	15%	94%	10%	5%	98%	3%
8. Regular reappraisal of treatment targets in case of treatment failure.	27%	94%	24%	17%	98%	13%
9. Info on how to control pain.	31%	95%	31%	42%	99%	19%
10. Info about options (benefit/risk) of surgery.	63%	77%	38%	40%	85%	18%
11. Access to treatments (pharmaceutical and non-pharmaceutical).	26%	96%	22%	24%	98%	20%
12. Access to other HCPs (occupational therapist and physiotherapist).	39%	93%	34%	44%	95%	37%
13. Info on adequate physical exercise.	45%	90%	37%	28%	96%	20%
14. Training on aids, devices, and ergonomic principles.	57%	82%	40%	45%	94%	40%
15. Info on healthy lifestyle.	43%	91%	36%	26%	95%	19%
16. Info about limited evidence of alternative therapies.	75%	70%	45%	61%	66%	21%

Top five most frequent problematic care gaps in bold. Average proportion across all countries for complete pairs. Complete pairs of rating both implementation and importance between 0 and 10, excluding answer options 'I don't know', 'not applicable' or 'no opinion' (these are provided in online supplementary table 2).

*Problematic care gap if $[(10 - \text{implementation}) \times \text{importance}]$ equals 30 or higher.

DMARD, disease-modifying anti-rheumatic drug; EULAR, European League Against Rheumatism; HCP, healthcare professional.

Among the perceived barriers to implementation of SoC, lack of relevance of some SoC for the actual patient situation (71%) and limited time of professionals (66%) were among the most frequently mentioned barriers. Furthermore, approximately a half of patients identified insufficient insurance coverage (55%) and limited access to healthcare professionals (HCPs) (46%) as barriers. Only 6% of respondents indicated lack of personal engagement (of patients) in their own care was a barrier (table 3).

Associations of country-level and patient-level characteristics with problematic care gaps and barriers

Rheumatologists in lower compared with high GDP countries, and in new EU or non-EU member states (vs EU first 15 states) had higher odds to report problematic gaps in 15 SoCs (table 4). The strongest discrepancies disfavouring poorer countries and new/non-EU member states were observed for 'info about relevant patient organisations and trusted sources of information' (SoC_{2.4}), 'clinical status assessment prior treatment' (SoC_{4.1}), 'info about vaccination' (SoC_{5.2}), 'access to emergency contact' (SoC₆), 'DMARD received' (SoC₇) and 'access to other HCPs' (SoC₁₂). No clear patterns were observed for rheumatologists' age, work environment, years of clinical practice or gender (online supplementary table 5).

Patients in non-EU and (although not reaching statistical significance) new-EU countries, compared with patients from the first EU members, reported less frequently problematic gaps for 'access to HCP' (SoC₁₂), 'info on adequate physical exercise' (SoC₁₃),

'info on healthy lifestyle' (SoC₁₅) and 'info on limited evidence of alternative treatments' (SoC₁₆). Further exploration revealed that this can be driven by lower scores on *importance* of some SoCs (online supplementary table S3). Patients with poorer self-rated health consistently identified more frequently problematic care gaps in all 20 SoCs (online supplementary table S4) and were also more likely to report barriers to achieve these standards (table 5). Further, highly educated patients and patients who rarely consulted the doctor reported more frequently problematic care gaps, and in approximately half of the SoCs this association reached statistical significance. For approximately half of the SoCs, differences were observed between patients with established disease versus newly diagnosed patients. In all but one of these SoCs, newly diagnosed patients were more critical about level of implementation and, as a result, identified more care gaps.

In terms of barriers to implementation of SoCs, patients in lower income countries were more likely to indicate that 'rheumatologists do not see the need to implement SoC' (OR 3.3, 95% CI 1.1 to 9.8 and 2.9 (1.2–7.3) for low and medium GDP countries vs high GDP, respectively). There was also a signal that patients in lower GDP countries perceived more challenges in 'insurance coverage' and 'access to specialists' (table 5). EU membership did not clearly distinguish between perceptions of the barriers to SoC implementation. Men, patients not in paid work (ie, retired, disabled and not working for other reasons) and those not attending physicians frequently were substantially more likely to indicate that their own engagement in care was not important (table 5).

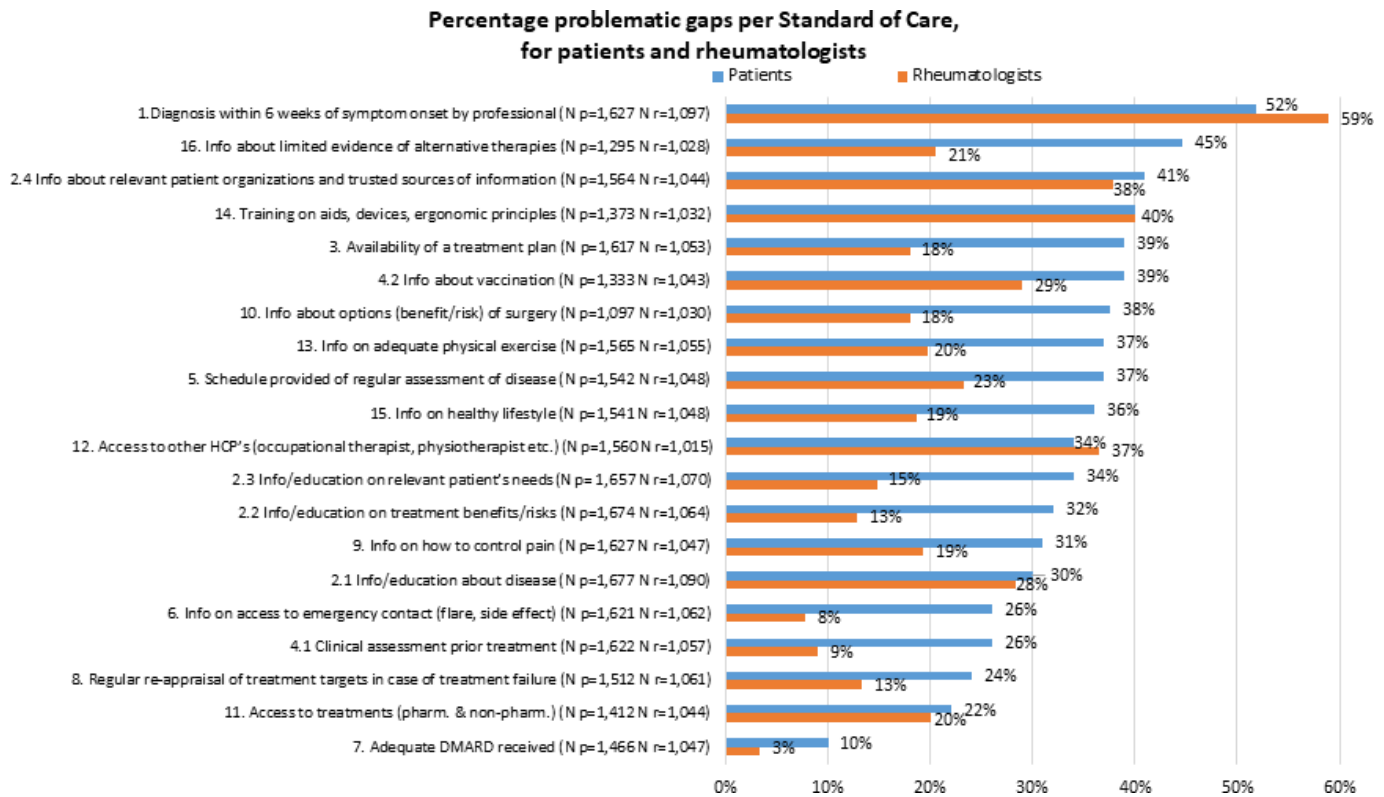


Figure 1 Problematic care gaps (%) for individual SoC, according to patients and rheumatologists.* SoCs are sorted by descending order of the patient's ranking of problematic care gaps. Calculations are based on available complete pairs of scores on importance and implementation. *Average proportion across all countries. DMARD, disease-modifying antirheumatic drug; HCP, healthcare professional; Np, number of patients; Nr, number of rheumatologists; SoC, standards of care.

DISCUSSION

In our survey across Europe, patients and rheumatologists confirmed that the 20 EULAR SoCs for RA are important: 15 and 17 of the 20 SoCs were identified as important by over 90% of patients and rheumatologists, respectively. Notably, patients reported problematic care gaps in a larger number of SoCs as compared with rheumatologists. With few exceptions, patients were more critical about the level of implementation (care received) compared with rheumatologists (care provided), which resulted in more problematic gaps. These findings point to the need for a better communication by healthcare providers about

the aspects of care that have been identified as 'standard care'. On this line, it is important to appreciate that 94% reported to be eager to actively engage in the management of their disease. However, access to and time of rheumatologists and other HCPs, as well as aspects of insurance coverage were perceived by patients as important barriers to receive care according to standards. The need to change reimbursement systems has been previously suggested as a facilitator to implement SoC,³ and digital innovations may also facilitate patient-centred care.¹³

Our results reveal that 'diagnosis within 6 weeks of symptom onset by professional' is the least achieved SoC with a problematic gap seen by 52% of patients and 59% of rheumatologists. With 59% of included patients diagnosed before 2000 when benefits of early diagnosis became common knowledge,^{14 15} it may not be surprising that half of the patients reported they were not diagnosed within 6 weeks. However, rheumatologists were asked about their current practice and the majority reporting insufficient implementation of this standard is alarming. This underlines the importance of recently initiated EULAR campaign 'Don't delay, connect today'.¹⁶

Other aspects around patient-centred care require further attention, particularly SoC around provision of appropriate information and training. Efforts are needed to ensure access to trustable and easy to understand information. Importantly, information only is not always sufficient, and training—specifically on ergonomic principles about how to deal with limitations in daily activities and participation—is an unmet need. It was striking that even for 'information and education on treatment benefits/risks', 'information about controlling pain', 'information on access to emergency contact (in case, eg, flares)' or 'availability of a personal treatment plan' and 'information on healthy

Table 3 Patients' perceived barriers to implementation of standards of care (n=996–1677)*

Barrier	Proportion averaged across all countries (%)
Not all SoCs are applicable or are useful for patient situation.	71
Time of HCP is limited.	66
Some of the services included in SoC are not covered by insurance.	55
Access to specialist and other HCP is limited.	46
Doctors think patients do not need to be educated about SoC.	38
Doctors do not see the need to implement SoC in clinical practice.	34
Patient active involvement as important.†	6

Patients who identified barrier as a percentage of all patients, averaged across countries.

*N missings per each variable is provided in online supplementary table S1.

†Reversed scale, score of <6 indicated a barrier.

HCP, healthcare professional; SoC, standard of care.

Table 4 Problematic care gaps in SoCs according to GDP and European Union membership status*

SoCs	Patients (n=821–1279)†				Rheumatologists (n=907–997)†			
	GDP (ref=high)		EU status (ref=first members)		GDP (ref=high)		EU status (ref=first members)	
	Low	Middle	New EU	Non-EU	Low	Middle	New EU	Non-EU
	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
1. Diagnosis within 6 weeks of symptom onset by professional.	1.65 (0.84 to 3.27)	1.26 (0.71 to 2.22)	0.57 (0.30 to 1.10)	0.90 (0.48 to 1.71)	1.34 (0.67 to 2.65)	1.61 (0.87 to 2.96)	1.54 (0.80 to 2.99)	1.07 (0.52 to 2.20)
2.1. Info/education about disease.	1.73 (0.86 to 3.50)	1.25 (0.69 to 2.26)	0.77 (0.39 to 1.52)	0.98 (0.51 to 1.90)	3.30 (2.06 to 5.26)	2.14 (1.43 to 3.21)	2.23 (1.35 to 3.69)	2.48 (1.44 to 4.27)
2.2. Info/education on treatment benefits/risks.	1.00 (0.46 to 2.21)	0.99 (0.51 to 1.91)	0.74 (0.38 to 1.47)	0.59 (0.30 to 1.14)	3.64 (1.89 to 7.01)	1.97 (1.07 to 3.61)	2.27 (1.12 to 4.59)	1.81 (0.83 to 3.94)
2.3. Info/education on relevant patient's needs.	1.20 (0.45 to 3.21)	0.80 (0.35 to 1.84)	0.62 (0.27 to 1.43)	0.61 (0.27 to 1.39)	1.81 (1.02 to 3.20)	1.42 (0.85 to 2.37)	1.15 (0.65 to 2.01)	1.42 (0.78 to 2.58)
2.4. Info about relevant patient organisations and trusted sources of information.	1.26 (0.41 to 3.91)	1.72 (0.66 to 4.48)	0.83 (0.31 to 2.23)	0.54 (0.21 to 1.44)	5.85 (3.34 to 10.27)	2.29 (1.41 to 3.72)	2.89 (1.56 to 5.34)	4.05 (2.04 to 8.04)
3. Availability of a treatment plan.	0.98 (0.39 to 2.47)	0.90 (0.41 to 1.96)	0.55 (0.26 to 1.16)	0.53 (0.25 to 1.11)	1.61 (0.93 to 2.77)	1.20 (0.73 to 1.97)	1.16 (0.67 to 1.99)	1.64 (0.93 to 2.90)
4.1. Clinical status assessment prior to treatment.	0.63 (0.23 to 1.69)	0.60 (0.26 to 1.39)	0.56 (0.23 to 1.34)	0.52 (0.22 to 1.22)	10.66 (4.92 to 23.09)	3.86 (1.79 to 8.30)	2.06 (0.96 to 4.39)	5.78 (2.88 to 11.63)
4.2. Info about vaccination.	1.23 (0.40 to 3.72)	1.47 (0.58 to 3.73)	1.06 (0.46 to 2.43)	0.53 (0.23 to 1.23)	5.19 (2.54 to 10.61)	1.55 (0.81 to 3.00)	3.15 (1.63 to 6.10)	4.60 (2.23 to 9.48)
5. Schedule provided of regular assessment of disease.	1.39 (0.37 to 5.30)	1.00 (0.32 to 3.12)	0.77 (0.24 to 2.51)	0.75 (0.23 to 2.42)	2.66 (1.44 to 4.92)	1.83 (1.05 to 3.16)	1.36 (0.75 to 2.45)	2.60 (1.39 to 4.84)
6. Info on access to emergency contact (flare, side effect).	1.08 (0.40 to 2.95)	1.24 (0.53 to 2.88)	1.00 (0.43 to 2.30)	0.53 (0.23 to 1.22)	8.37 (2.37 to 29.59)	4.5 (1.34 to 15.17)	2.51 (0.84 to 7.50)	4.30 (1.35 to 13.70)
7. Adequate DMARD received.	0.54 (0.12 to 2.46)	1.16 (0.34 to 3.88)	0.70 (0.20 to 2.52)	0.27 (0.07 to 1.01)	8.59 (3.07 to 24.06)	2.91 (1.01 to 8.40)	1.59 (0.51 to 4.95)	4.40 (1.48 to 13.08)
8. Regular reappraisal of treatment targets in case of treatment failure.	0.71 (0.15 to 3.35)	0.56 (0.15 to 2.12)	0.36 (0.09 to 1.34)	0.30 (0.08 to 1.04)	2.17 (0.89 to 5.31)	1.33 (0.58 to 3.08)	1.61 (0.73 to 3.52)	1.45 (0.61 to 3.44)
9. Info on how to control pain.	0.80 (0.38 to 1.68)	0.77 (0.42 to 1.43)	0.49 (0.26 to 0.94)	0.66 (0.35 to 1.22)	1.69 (0.97 to 2.94)	0.99 (0.61 to 1.63)	0.86 (0.52 to 1.45)	1.67 (0.99 to 2.83)
10. Info about options (benefit/risk) of surgery.	0.55 (0.26 to 1.18)	0.93 (0.51 to 1.70)	0.65 (0.35 to 1.20)	0.50 (0.27 to 0.95)	2.60 (1.48 to 4.57)	1.45 (0.86 to 2.44)	1.29 (0.71 to 2.37)	1.97 (1.04 to 3.73)
11. Access to treatments (pharmaceutical and non-pharmaceutical).	0.88 (0.27 to 2.93)	0.55 (0.20 to 1.54)	0.63 (0.20 to 2.01)	0.56 (0.18 to 1.74)	3.67 (1.65 to 8.15)	2.48 (1.19 to 5.16)	2.69 (1.42 to 5.09)	3.19 (1.60 to 6.35)
12. Access to other HCPs (occupational therapist and physiotherapist).	0.89 (0.28 to 2.85)	1.20 (0.45 to 3.22)	0.58 (0.23 to 1.48)	0.33 (0.13 to 0.83)	5.55 (3.00 to 10.28)	4.96 (2.86 to 8.60)	3.16 (1.52 to 6.60)	2.54 (1.13 to 5.70)
13. Info on adequate physical exercise.	0.74 (0.31 to 1.76)	0.83 (0.41 to 1.71)	0.61 (0.32 to 1.18)	0.42 (0.22 to 0.79)	1.51 (0.89 to 2.57)	1.63 (1.03 to 2.57)	1.17 (0.69 to 1.98)	1.26 (0.72 to 2.23)
14. Training on aids, devices, ergonomic principles.	1.64 (0.45 to 5.95)	1.24 (0.42 to 3.67)	0.88 (0.27 to 2.84)	0.73 (0.23 to 2.33)	4.68 (3.03 to 7.21)	4.45 (3.08 to 6.43)	2.37 (1.33 to 4.22)	2.84 (1.51 to 5.35)
15. Info on healthy lifestyle.	0.55 (0.19 to 1.56)	0.68 (0.28 to 1.63)	0.62 (0.26 to 1.48)	0.37 (0.16 to 0.87)	1.88 (1.08 to 3.28)	1.45 (0.89 to 2.37)	1.33 (0.84 to 2.12)	2.20 (1.39 to 3.49)
16. Info about limited evidence of alternative therapies.	0.46 (0.20 to 1.07)	0.83 (0.41 to 1.66)	0.54 (0.28 to 1.05)	0.37 (0.19 to 0.71)	2.01 (1.32 to 3.06)	1.17 (0.80 to 1.71)	1.50 (1.01 to 2.23)	1.89 (1.26 to 2.84)

Results of multilevel logistic regressions for patients. *Models in rheumatologists adjusted for age, gender, work environment and years of experience; regression coefficients for rheumatologist covariates are provided in online supplementary table S5. †In all models patients and rheumatologists from the same country are nested within their countries (N=26 countries for patients and 31 for rheumatologists). Significant associations in bold. Problematic care gap if [10-(importance) × importance] equals 30 or higher.

*Models in patients adjusted for age, gender, disease duration, education, working status, self-rated health, confidence with filling in medical forms, and healthcare use, regression coefficients for patient covariates are provided in online supplementary table S5.

†Range of number of subjects varies for each model due to missing values.

DMARD, disease-modifying anti-rheumatic drug; GDP, gross domestic product; HCP, healthcare professional; SoC, standard of care.

Table 5 Patient characteristics according to GDP or European Union status with reported barriers to implementing standards of care

OR (95% CI)	Rheumatologists see no need to implement	Rheumatologists see no need to educate	Active own patient involvement is important	Limited time of professional	Lack of insurance for some services	Lack of access to care providers	SoCs are not applicable to individual patient's situation
Age per year	1.01 (0.99–1.02)	1.00 (0.99–1.02)	0.98 (0.95–1.00)	0.98 (0.97–1.00)	1.00 (0.99–1.02)	1.00 (0.98–1.01)	1.01 (0.99–1.02)
Gender (female)	1.09 (0.75–1.58)	1.16 (0.84–1.60)	0.39 (0.21–0.70)	1.27 (0.95–1.72)	1.11 (0.81–1.53)	1.36 (0.97–1.93)	1.29 (0.90–1.84)
Disease duration, >2 years vs <2 years	0.76 (0.48–1.21)	0.87 (0.58–1.32)	0.81 (0.34–1.92)	1.35 (0.90–2.04)	0.96 (0.63–1.48)	0.68 (0.44–1.05)	0.45 (0.26–0.77)
Education							
Secondary versus primary	1.26 (0.81–1.97)	1.28 (0.87–1.87)	0.77 (0.37–1.59)	1.22 (0.86–1.73)	1.18 (0.81–1.71)	1.66 (1.10–2.51)	1.20 (0.78–1.85)
University versus primary	1.06 (0.67–1.69)	1.06 (0.71–1.59)	1.11 (0.52–2.40)	1.13 (0.78–1.64)	1.05 (0.71–1.55)	1.09 (0.70–1.71)	1.23 (0.80–1.91)
Working status							
Not working versus working	0.75 (0.45–1.24)	0.88 (0.56–1.38)	3.21 (1.29–7.99)	0.76 (0.48–1.20)	0.48 (0.30–0.77)	0.85 (0.53–1.36)	1.53 (0.90–2.58)
Disabled versus working	0.92 (0.61–1.39)	0.83 (0.57–1.21)	2.46 (0.99–6.10)	1.09 (0.74–1.61)	1.28 (0.86–1.90)	1.19 (0.80–1.78)	1.32 (0.86–2.04)
Retired versus working	0.66 (0.41–1.05)	0.54 (0.36–0.82)	3.52 (1.40–8.83)	1.02 (0.68–1.53)	0.55 (0.36–0.83)	0.84 (0.55–1.29)	1.70 (1.06–2.71)
Self-rated health	0.88 (0.82–0.94)	0.90 (0.84–0.95)	0.99 (0.87–1.12)	0.91 (0.85–0.96)	0.95 (0.89–1.01)	0.93 (0.87–0.99)	1.13 (1.06–1.22)
Confidence to fill out medical forms (not/little)	1.47 (0.88–2.43)	1.29 (0.83–2.01)	1.10 (0.47–2.58)	1.45 (0.94–2.25)	1.00 (0.64–1.56)	1.58 (1.02–2.45)	0.50 (0.30–0.83)
Visits to doctor							
Low versus high	1.28 (0.78–2.11)	1.30 (0.82–2.06)	8.41 (1.09–65.07)	1.51 (0.97–2.35)	1.08 (0.69–1.69)	1.46 (0.91–2.32)	1.11 (0.67–1.85)
Middle versus high	0.95 (0.58–1.55)	1.12 (0.72–1.75)	6.53 (0.85–50.41)	1.10 (0.72–1.68)	0.86 (0.56–1.32)	0.96 (0.61–1.52)	0.98 (0.60–1.59)
GDP							
Low versus high	3.32 (1.12–9.84)	1.44 (0.47–4.45)	0.42 (0.10–1.78)	0.93 (0.34–2.51)	2.06 (0.79–5.39)	1.28 (0.47–3.48)	1.14 (0.38–3.40)
Medium versus high	2.91 (1.16–7.34)	1.89 (0.73–4.93)	0.77 (0.26–2.28)	0.91 (0.40–2.09)	2.77 (1.22–6.31)	2.44 (1.05–5.66)	2.30 (0.92–5.72)
EU							
New versus old—15	1.51 (0.57–4.00)	0.95 (0.34–2.64)	0.47 (0.11–2.05)	1.50 (0.60–3.73)	2.03 (0.89–4.60)	2.61 (1.18–5.80)	1.12 (0.38–3.34)
Non-members versus old—15	2.32 (0.88–6.13)	1.28 (0.47–3.53)	0.98 (0.29–3.31)	0.84 (0.35–2.04)	1.81 (0.82–4.04)	0.87 (0.40–1.91)	0.84 (0.28–2.48)

Results of multilevel logistic regressions for patients, n=980–1305. Range of number of subjects varies for each model due to missing values. Significant associations in bold.
GDP, gross domestic product; SoC, standard of care.

lifestyle' a problematic care gap was revealed by 30%–40% of patients opposed to 8%–18% of providers. This emphasises the need to monitor whether the right information reached the patient at the right time, as supported by focus groups that were part of the eumusc.net project.³

Patients with higher education and worse self-reported health experienced problematic gaps more frequently. Assuming all patients are offered equal care, it is apparent that higher educated patients are more critical about the care or set higher expectations, which may signal that lower educated patients are less aware about the standards and potentially set lower expectations. Patients with worse health may have higher expectations of healthcare or have more exposure, and thus might sooner notice the discrepancies of care compared with agreed standards. These variations in perceived care gaps acknowledge the need to gain more insight into patient experiences and needs and how to deal with them.

Our findings also call for objective data on implementation of the SoC. In parallel to the development of the lay versions of the SoC, quality indicators were developed.^{17–19} Quality indicators are evidence-based measures of healthcare quality standard. These indicators specify the proportion of eligible patients that received this care. To our knowledge, such data are not available in Europe. A related matter of discussion is which proportion of patients should receive standards of care, in order to consider a SoC implemented. Although patient experience measures are gaining ground in initiatives for quality improvement, they reflect experiences and not the objective care provided.

An important finding of our study is that the SoCs are not equally implemented across countries. Rheumatologists in low GDP countries and new-/non-EU members reported higher care gaps than their colleagues in high income and/or EU member states. Reasons like insufficient infrastructure and funding are among the most plausible explanations and limited access to some treatments has been well-documented before.^{7,8} Although standards around treatments with DMARDs and regular monitoring of the disease have been identified as mostly achieved in an 'average' European country, they are still experienced as problematic by rheumatologists in low GDP countries. It is worth noticing that patients in lower income countries were much more likely to report that rheumatologists do not see the need to provide care according to the standards.

Surprisingly, patients in new or non-EU members have reported less problematic care gaps in six SoCs. Closer exploration showed that this was mainly driven by lower scores on perceived importance of these SoCs. Possibly, timely diagnosis and adequate disease control are considered relatively a much higher priority.

The results of this study should be interpreted in view of several limitations. First, the study design could not ensure representative samples per country (due to recruitment centred on the network of the PI) and despite the efforts to include sufficient respondents in each country, this could not always be achieved. While this prevented us from initially planned comparisons between the countries, our sample still allowed assessment of the current levels of care using agreed SoCs as a benchmark, as well as identification of patterns at supranational level—by countries' wealth and EU membership. Varying sample sizes per country were accounted for in statistical procedures. Funding restrictions did not allow a formal translation procedure; however, many translations done by PIs were double-checked by patient partners and few issues were raised. It is important to emphasise that the SoCs have been translated in 23 languages following the validated procedures, so potential imperfections in translation

only refer to survey instructions and few added questions. In the absence of validated cut-offs, the choice of cut-offs to define care gaps was arbitrary. An important limitation of our study is that we could not include nurses and potentially other clinical staff involved in rheumatic care in different countries. Since these professionals are not equally involved in RA care in all countries, it was too challenging to survey their perspectives in a uniform way and therefore left out of this study. Last but not least, evidence is still lacking that patient outcomes are better when care is provided according to all the standards.^{20–22}

In conclusion, problematic gaps are reported across essential aspects of RA care, as defined by the EULAR standards of care. The rheumatology community, national rheumatology societies and EULAR need to further work for improved healthcare in RMDs, addressing the implementation of SoC.

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Contributors AB conceived the idea; AB, SR, MH, PP, YvE-H, AW, JS, TAS, MS-M, TU, RHM and MdW contributed to the design of the work. Country collaborators (AT, VM, PS, PV, RS, PC, JV, MV, MK, KP, LG, NG, JD, PS, MP, DK, CAS, UA, DA, MvdL, AvdH-vM, PG, LCM, FB, NSD, MT, LC, CT, AC, SS, NI and SMMV) collected data and assisted in the interpretation of the findings; RM, AB, SR and PP performed analyses; APK provided statistical advice. RM and PP drafted the first draft, which was critically reviewed and approved for submission by all authors.

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