Rheuma SPACE - Standard Practice Aiming Clinical Excellence: the first Portuguese Rheumatology Department evaluation

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ABSTRACT

The Portuguese Rheumatology Society (SPR) embraced quality as a major goal and launched, in early 2015, a program to aim for excellence in global clinical care: Rheuma SPACE - Standard Practice Aiming Clinical Excellence. Evaluating daily reality is the first step in a quality development timeline, ultimately contributing for health gains. Herein we describe the results of the evaluation of the quality indicators defined for this project and the improvement strategies identified.

The Rheuma SPACE project included three phases: 1) establishing a set of quality indicators and an excellence quality model; 2) assessment of the current care at Rheumatology departments concerning the defined quality indicators in the scope of the excellence model; and 3) elaboration of global and customized reports for each participating Rheumatology department, resulting in the identification of improvement opportunities. Ten Rheumatology departments, countrywide, including larger and smaller institutions, were asked to participate in Rheuma SPACE. This resulted in an individual report for each department along with global benchmarking practices analysis. Furthermore, a list of improvement initiatives was developed.

We concluded that departments lack physicians and need exclusively dedicated nurses. Time dedicated to research and audit activities should be specifically allocated. Internal contracting is well established, and professionals are committed to targets. Processes are still suboptimal, needing standardization of triage criteria, more frequent follow-up, as well as better medical records and multidisciplinary coverage. Regarding outcomes, patients are satisfied with the provided care and professionals with the working environment. However, department facilities for the former, and career related aspects, for the latter should improve. With this innovative study conducted in Portugal we expect to have enlightened tailored opportunities for improvement, ensure patient-focused practices and be able to define the indispensable quality requirements for excellence.

Keywords: Rheumatology Practice; Quality Criteria; Quality of Care.

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INTRODUCTION

Health care professionals and stakeholders in general are increasingly facing scientific and technological advances, leading to constant and frequent changes in clinical practice worldwide. To ensure that the progress in medical science represents an effective contribution for high standards of care, assessment of the *Quality of Care* is an indispensable additional tool[1]. This can be achieved evaluating general aspects of global care in rheumatic diseases[2–5] or by applying measures of quality for specific diseases[6,7]. Rheumatoid arthritis (RA) represents a niche of opportunity, as healthcare quality indicators and standards of care for this disease have been drafted across Europe, mainly focusing on disease activity and outcomes[8–13].

In the specific field of Rheumatology, evaluating the practice of day care units/infusion rooms has been a preferential investigational line of work, pioneering quality of care in different clinical settings[14,15].

The Portuguese Rheumatology Society (SPR) embraced quality as a major goal and launched, in early 2015, a program to aim for excellence in global clinical care: Rheuma SPACE - Standard Practice Aiming Clinical Excellence[16,17]. This program ultimately envisages improving the performance of Portuguese Rheumatology departments focused on RA care, involving a multi-stakeholder approach with patients playing an active and important role.

The main purpose of Rheuma SPACE was to increase quality, effectiveness, and efficiency of the Standards of Care for rheumatic patients. Evaluating daily reality is the first step in a quality development timeline, ultimately contributing for health gains. Herein we describe the results of the evaluation of the quality indicators defined for this project and the improvement strategies identified.

METHODS

The Rheuma SPACE project included three phases: 1) establishing a set of quality indicators and an excellence quality model; 2) assessment of the current care at Rheumatology departments concerning the defined quality indicators in the scope of the excellence model; and 3) elaboration of global and customized reports for each participating Rheumatology department, resulting in the identification of improvement opportunities. Detailed methodology of the steps followed in each phase was previously detailed[18].

Summarily, after a four-stage RAND-modified Delphi approach, a set of 26 quality indicators for Rheumatology care were defined, as well as their quality and excellence thresholds, divided by three dimensions according to the Donabedian framework: Structure, Processes, and Outcomes[19] (Table I).

Ten Rheumatology departments, countrywide, including larger and smaller institutions, were asked to participate in Rheuma SPACE to ensure national representability. Authorization from Administration Boards and Ethics Committees was previously obtained.

Measurement of quality indicators required several data sources: 1) Department opinion; 2) Clinical records from RA patients (RA was defined as a case study); 3) Questionnaires applied to both patients and staff; 4) Inputs related to administrative procedures, equipment and other structural department standards, collected by research teams. After twelve months of data collection (phase I), Rheuma SPACE executor IQVIA proceeded with confidential data analysis, characterization of each department according to the defined criteria and analysis of each center results. A gap analysis versus excellence model was performed. This resulted in an individual report for each department along with global benchmarking practices analysis. Furthermore, a list of improvement initiatives was developed comprising 3 steps: 1) Problem identification and brainstorming; 2) Intervention definition and planning and 3) Prioritization.

RESULTS

A total of 1325 patient surveys were collected, from a representative sample of the Rheumatology patients' population, 75% were female, with a median age of 50-59 years, 45% employed, 40% retired and 13% unemployed. About one third (33%) of patients had RA, 22% had non-inflammatory pain related diagnosis, such as fibromyalgia and osteoarthritis, 11% had spondyloarthritis, 8% systemic lupus erythematosus, and 6% psoriatic arthritis. The majority of surveys (80%) were collected in outpatient appointments, 18% in day care hospitals and 2% in procedures units. Health professionals' surveys were also analyzed (n=113), as well as data from 570 clinical records and 3927 medical appointments.

TABLE I. QUALITY CRITERIA

Structure Domains

Domain	Indicator	Quality threshold	Excellence threshold
Personnel and organizational structure	1. Number of Rheumatologists per population covered	1 Rheumatologist per ≤ 60.000 and >40.000 inhabitants	1 Rheumatologist per ≤40.000 inhabitants
	2. Number of nurses dedicated to Rheumatology service per population covered	1 nurse per ≤ 240.000 and > 120.000 inhabitants	1 nurse per ≤ 120.000 inhabitants
	3. Existence and frequency of medical audits assessing the compliance with those guidelines that are accepted by Rheumatology	≥50%* and <85%*	≥85%*
Training and research	4. Existence and implementation of an annual training plan for healthcare professionals, including monthly clinical sessions for continued scientific training	≥50%* and <85%*	≥85%
	5. Percentage of Rheumatologists' time dedicated to research and audit	≥10% and <20%	≥20%
Facilities, equipment and information systems	6. Access to medical and information technology equipment (ultrasonography, polarized light microscope, capillarosoopy instrument densitometer, and computers with internet access)	≥60%* and< 85%*	≥85%*
	7. Existence of a patient electronic medical reoord (EMR) with data protection systems and its availability across Rheumatology services to healthcare	≥ 50%* and <85%*	≥85%*
	professionals		
	8. Physical access (distance, physical barriers and orientation boards/signs) to hospital and to different services related to Rheumatology care, particularly to patients wilh disabilities	≥ 60%* and <90%*	≥90%*
Structure budgeting and financial resources	9. Annual implementation of an internal contract between Service and Administration, including budget and activity planning, quality indicators and funds for research and training	≥ 50%* and <85%*	≥85%*
Process Domains			
Access to care and productivity	10. Patient triage is performed by a rheumatologist, according to criteria defined by Rheumatology	≥60%" and< 80%*	≥85%*
	11. Percentage of patients who get a first appointment in Rheumatology within due waiting time, according to prioritization criteria established by Rheumatology 11.1. High Priority (1st appointment within 30 days} 11.2. Priority (1st appointment within 90 days) 11.3. Normal Priority (1st appointment within 180 days)	≥80% and <90%	≥90%
	12. Percentage of patients with disease flares or potential drug related side effects that received advice within one working day of contacting the service	≥85% and <95%	.≥95%

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TABLE I. CONTINUATION

Domain	Indicator	Quality threshold	Excellence threshold
Medical care and clinical records	13. Frequency of follow up appointments (rheumatoid arthritis as a case study)		
	13.1. Active disease (DAS28 ≥3.2)	≤10 and >6 weeks	≤6 weeks
	13.2. In Remission (DAS28 <2.6)	≤16 and >12 weeks	≤12 weeks
	13.3. Under Biologic Therapy	≤10 and >6 weeks	≤6 weeks
	13.4. No Biologic Therapy	≤16 and >12 weeks	≤12 weeks
	14. Frequency of assessment of pain, disease activity, patient function, quality of life and co-morbidities (rheumatoid arthritis as a case study)		
	14.1.Active disease (DAS28 ≥3.2)	≤10 and >6 weeks	≤6 weeks
	14.2. In Remission (DAS28 <2.6)	≤16 and >12 weeks	≤12 weeks
	15. Frequency of pharrnaoological therapy review for all rheumatology specific medication, including toxicity monitoring in a patient with active disease (rheumatoid arthritis as a case study}	≤9,5 and >6 weeks	≤6 weeks
	16. Percentage of patients with a frequently updated reoord on REUMA.PT with a set of minimum criteria {rheumatoid arthritis as a case study)	≥60% and <80%	≥80%
Patient communication	17. Percentage of patients who were given educational materials regarding the disease and/or treatment		
	17.1. Biologic Therapy	≥80% and <95%	≥95%
	17.2. No Biologic Therapy	≥50% and <80%	≥80%
	18. Percentage of patients followed in a day hospital or Rheumatology techniques unit who were given a direct telephone access of the Rheumatology service healthcare professional	≥80% and <95%	≥95%
Multidisciplinary	19. Ability to provide a multidisciplinary approach according to patients' needs	≥50%* and <75%*	≥75%*
	20. Percentage of diagnosed patients given a written communication addressing their GP or other relevant HCP, explaining the clinical situation and including the patient oontact of the rheumatologist management	≥80% and <95%	≥95%*
	20.1. Patients perspective		
	20.2. Physicians perspective		
Outcomes domains			
Clinical outcomes	21. Percentage of rheumatoid arthritis patients with significant improvement in disease activity, disability and quality of life (acoording to international validated criteria), after 6 months of treatment	≥60% and >80%	≥80%

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TABLE I. CONTINUATION

Domain	Indicator	Quality threshold	Excellence threshold
Patient satisfaction	22. Number of absent days per rheumatologic patient, per year, from patients' perspective	≤15 and >7 days	≤7 days
	23. Percentage of rheumatology patients that were granted early retirement due to illness	≤20% and >10%	≤10%
	24. Patients overall satisfaction with Rheumatology care	≥70%* and <90%*	≥90%*
	25. Patients satisfaction with service facilities (consultations and waiting room, privacy, toilets, etc.)	≥70%* and <90%*	≥90%*
Personnel satisfaction	26. Healthcare professionals' overall satisfaction with department environment, team work and cooperation within department professionals	≥70%* and <90%*	≥90%*

* Composite score from an ad hoc instrument developed specifically for project SPACE
DAS=Disease Activity score; GP=general practioner; HCP= Healthcare professionals; IT = information technology

1. STRUCTURE DIMENSION - HOW WELL EQUIPPED ARE RHEUMATOLOGY DEPARTMENTS? (Figure 1)

Criterion 1. Number of rheumatologists per population covered

Most hospitals (75%) lack rheumatologists taking into consideration the population covered, even when residents were considered, with only 2 hospitals above the quality threshold, defined as 1 rheumatologist per 40000-60000 inhabitants.

Criterion 2. Number of nurses dedicated to rheumatology per population covered

Hospitals tend to have enough nursing hours allocated to Rheumatology duties, but exclusive allocation is rare, with nursing staff usually shared in multidisciplinary day care hospitals or large inpatient wards. Some hospitals, nonetheless, had only residual nursing hours in outpatient appointments.

Criterion 3. Existence and frequency of medical audits assessing the compliance with those guidelines that are accepted by Rheumatology

Significant discrepancies were found between departments. Half of the departments had systematic clinical audits, implemented in the context of external accreditation or internal contracting, but many hospitals do not employ a regular clinical audit practice.

Criterion 4. Existence and implementation of an annual training plan for healthcare professionals, including monthly clinical sessions for continued scientific training

In general, there was a commitment towards annual training plans, although plan development and coverage could be improved, namely with the development of training plans for nurses and better definition of individual objectives with respective monitoring.

Criterion 5. Percentage of Rheumatologists' time dedicated to research and audit

Considering Rheumatologists' time dedicated to research and audit, only 4 hospitals formally designated hours for research and audit, with an average of <2H/week per physician allocated to research and audit. Six hospitals had access to scientific databases and developed ~1.3 research projects per full-time specialist (FTS), on average.

Criterion 6. Access to medical and IT equipment (echography, polarized light microscope, capilaroscope, densitometer, and functional computers with internet access)

Regarding access to medical and information technology equipment, all departments met the quali-

FIGURE 1. Structure – Criterion 1: Population (thousands) covered by Rheumatologist (blue square – average of all hospitals, blue bullets – hospitals without residents, green bullet – hospitals with residents); Criterion 2: Number of nurses dedicated to Rheumatology department per population covered (blue square – average of all hospitals, blue bullets – each hospital); Criterion 3: Existence and frequency of medical audits assessing the compliance with those guidelines that are accepted by Rheumatology (blue bullets – each hospital, blue square - average of all hospitals); Criterion 4: Existence and implementation of an annual training plan for healthcare professionals, including monthly clinical sessions for continued scientific training (blue square – average of all hospitals, blue bullets – each hospital); Criterion 5: Percentage of Rheumatologists' time dedicated to research and audit (blue bullets – total physicians, green bullet – physicians with research hours, blue square – average); Criterion 6: Access to medical and IT equipment - ultrasonography, polarized light microscope, capillaroscopy instrument, densitometer, and computers with internet access (blue square – average of all hospitals, blue bullets – each hospital); Criterion 7: Existence of a patient electronic medical record (EMR) with data protection systems and its availability across Rheumatology departments to healthcare professionals (blue square – average of all hospitals, blue bullets – each hospital); Criterion 8: Physical access to hospital and to different departments related to Rheumatology care, particularly to patients with disabilities (blue square – average of all hospitals, blue bullets – each hospital); Criterion 9: Annual implementation of an internal contract between Department and Administration, including budget and activity planning, quality indicators and funds for research and training (blue square – average of all hospitals, blue bullets – each hospital).

ty threshold. Microscopes and densitometers were missing in a few cases.

Criterion 7. Existence of a patient electronic medical record (EMR) with data protection systems and its availability across Rheumatology services to healthcare professionals

Patient electronic medical record was well implemented across most departments, with only one still working with paper medical records. Rheumatic Diseases Portuguese Register (Reuma.pt) records were not always documented in the electronic medical record (EMR). *Plataforma de Dados da Saúde (PDS)*, which allows information sharing with primary care units, was not always available.

Criterion 8. Physical access (distance, physical barriers and orientation boards/signs) to hospital and to different services related to Rheumatology care, particularly to patients with disabilities

Overall, departments had adequate accessibility conditions for patients with disabilities, namely parking spaces, entrance, and sanitary facilities. Signage was the domain with lower quality score.

Criterion 9. Annual implementation of an internal contract between Service and Administration, including budget and activity planning, quality indicators and funds for research & training

Annual contracts were a common practice, but the standards negotiated differed between departments and in some cases excluded department costs. Criteria related to staff training, research projects and patient satisfaction were usually disregarded. Annual productivity per FTS was analyzed in a complementary evaluation, and different numbers were found between departments in day care hospital sessions, technics unit and inpatient admissions, with outpatient appointments having the lowest dispersion.

Initiatives to improve the main issues found in the structure dimension are specified in Table II.

TABLE II. INITIATIVES RELATED TO THE STRUCTURE DIMENSION

Create partnerships between different departments to share and benefit from physicians with higher availability or with certain expertise.
Promote Nurses specialization and training in Rheumatology, including Nurses in the departments clinical sessions and negotiating that nurses allocated to Day Hospital or Procedures Unit are exclusively dedicate to Rheumatology to promote specialization via adequate training.
Partnership with "Associação Portuguesa de Profissionais de Saúde em Reumatologia" to develop a specific nurse training program.
Create a clinical audit algorithm in Rheumatic Diseases Portuguese Register (Reuma.pt)
Train department Directors (and other relevant physicians) on hospital management practices and working tools; additionally, promote best practices sharing and discuss their impact on department's budget (e.g. Day Hospital biologics subcutaneous appointments).
Develop partnerships with other Universities to create hospital management tools and post-graduation courses in line with the Medical society criteria for competence certification and credits attribution.

2. PROCESSES DIMENSION - HOW IS CARE PROVIDED TO RHEUMATIC PATIENTS? (Figures 2-4)

Criterion 10. Patient triage is performed by a rheumatologist, according to criteria defined by Rheumatology

Triage process met quality standards in most departments (Figure 2), but triage criteria used should be revised and harmonized to provide patients equal clinical accessibility.

Most hospitals dedicated few hours to triage and these were not formally defined in physicians' schedules.

Criterion 11. Percentage of patients who get a first appointment in Rheumatology within due waiting time, according to prioritization criteria established by Rheumatology

Compliance with *Consulta a tempo e horas* (CTH) imply that waiting times varied with the priority attributed to the patient. High priority patients were usually observed in due time, but this included a very small percentage of referrals. Referral distribution per priority level varied significantly between departments (11% high priority patients in larger departments vs 1% in smaller ones; 53% normal priority patients in larger departments vs 91% in smaller ones), suggesting the existence of different triage criteria, since case-mix differences unlikely justify such disparities (Figure 2).

Criterion 12. Percentage of patients with disease flares or potential drug related side effects that received advice within one working day of contacting the service

In the context of an urgent referral, roughly half of patients received counseling within <1 day and had an appointment scheduled within <1 week (Figure 2).

Rheumatoid arthritis was defined as a case study for the evaluation of medical care and clinical records. Clinical data was collected from 570 patients and 3927

appointments. Of the total 570 patients, 158 were under biologic therapy, 29% of which initiated this treatment during the analysis period. Roughly 60% of patients that met clinical criteria initiated biologic therapy, yet first drug administration took in average 3 months to occur after prescription. Reasons for not initiating therapy in patients that met criteria (n= 28) were physician's decision (29%), comorbidities (25%) and patient refusal (21%).

Criterion 13. Frequency of follow up appointments (rheumatoid arthritis as a case study)

Three departments met the defined quality follow--up frequency for appointments of patients with disease activity-score-28 (DAS28) ≥3.2 (Figure 3). Thirty-one percent of total appointments occurred within 12 weeks. For most hospitals, the time interval between visits did not shorten significantly when DAS28 ≥3.2 (average 2.2 weeks shortening). However, patients under biologics were seen much more frequently (shortening of 4.9 weeks between visits).

Criterion 14. Frequency of assessment of pain, disease activity, patient function, quality of life and co-morbidities (rheumatoid arthritis as a case study)

Disease activity registry occurred in only 31% of appointments, with an average frequency of every 16 weeks for patients with active disease and every 20 weeks for patients in remission (Figure 3).

Criterion 15. Frequency of pharmacological therapy review for all Rheumatology specific medication, including toxicity monitoring in a patient with active disease (rheumatoid arthritis as a case study)

Drug review and prescription were not registered with appropriate frequency, but most appointments included these criteria (Figure 3).

Criterion 16. Percentage of patients with a frequently updated record on REUMA.PT with a set of minimum criteria (rheumatoid arthritis as a case study)

All departments missed quality regarding Reuma.pt registration, with less than half of patients having at least 1 appointment in the registry (Figure 3). However, more than 70% of patients under biologics complied with Reuma.pt minimal requirements (DAS28 + visual analogic scale every 6 months).

Criterion 17. Percentage of patients who were given educational materials regarding the disease and/or treatment

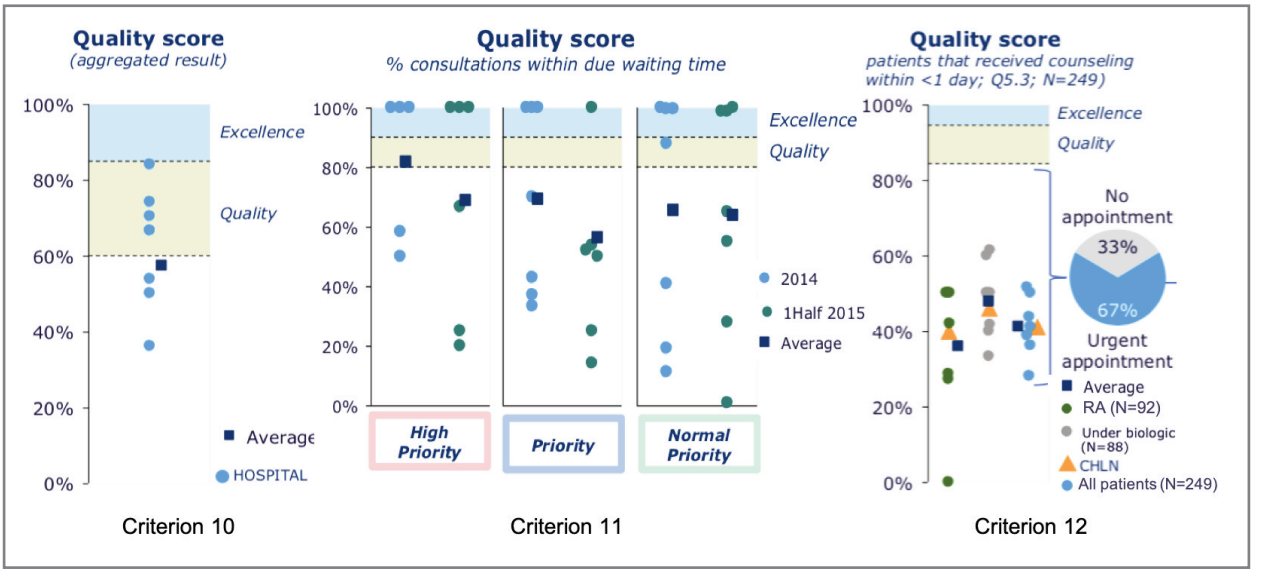
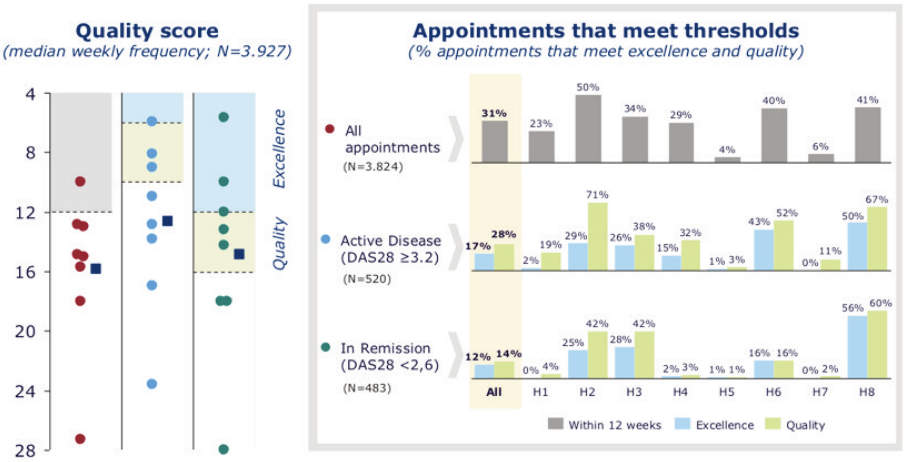
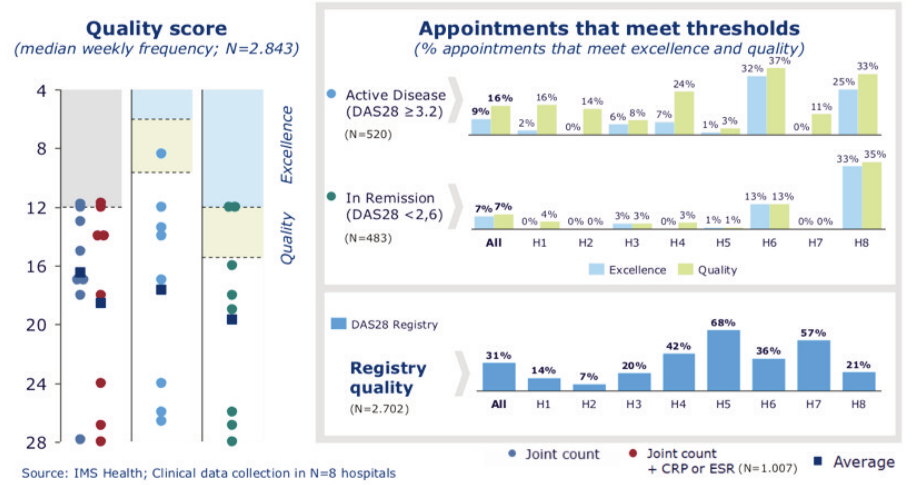


FIGURE 2. Processes (1): Criterion 10: Patient triage is performed by a rheumatologist, according to criteria defined by Rheumatology (blue square – average of all hospitals, blue bullets – each hospital); Criterion 11: Percentage of patients who get a first appointment in Rheumatology within due waiting time, according to prioritization criteria established by Rheumatology – first panel - High Priority (1st appointment within 30 days); second panel - Priority (1st appointment within 90 days); third panel - Normal Priority (1st appointment within 180 days) (blue bullets refer to data from 2014 from each hospital; green bullets refer to data from the first half of 2015 from each hospital, blue squares – average); Criterion 12: Percentage of patients with disease flares or potential drug related side effects that received advice within one working day of contacting the department (green bullet – rheumatoid arthritis patients, grey bullet – patients under biologics, yellow triangle – data from central department; blue bullet – all patients; blue square – average).

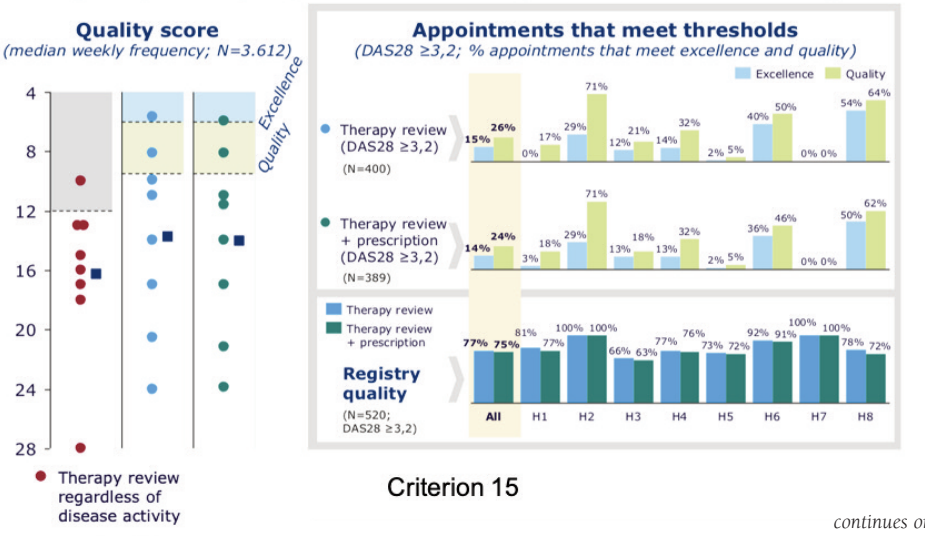


Criterion 13



Source: IMS Health; Clinical data collection in N=8 hospitals

Criterion 14



Criterion 15

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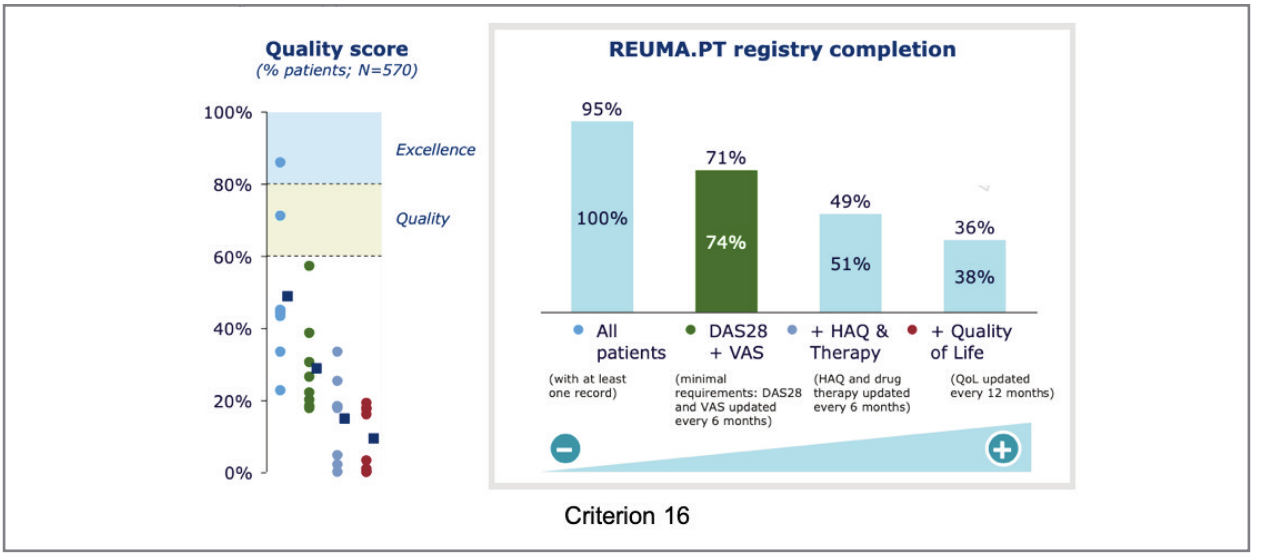

FIGURE 3. Processes (2) – Criterion 13: Left panel - frequency of follow up appointments (red bullets – all patients, blue bullets – patients with active disease, green bullets – patients in remission); Right panel – percentage of appointments that meet quality (green bars) and excellence (blue bars) threshold in each hospital; Criterion 14: Left panel - frequency of assessment of pain, disease activity, patient function, quality of life and co-morbidities (grey bullets - joint count, red bullets - joint count and ESR or CRP, blue bullets – patients with active disease, green bullets – patients in remission, blue squares - average in all hospitals); Right panel - percentage of appointments that meet quality (green bars) and excellence (blue bars) threshold in each hospital; Criterion 15: Left panel - frequency of pharmacological therapy review for all Rheumatology specific medication (red bullets – data from all patients, regardless of disease activity; blue bullets – therapy review in patients with high disease activity; green bullets - therapy review and new prescriptions in patients with high disease activity); Right panel - percentage of appointments that meet quality (green bars) and excellence (blue bars) threshold in each hospital; Criterion 16 – Left panel - percentage of patients with a frequently updated record on Reuma.pt with a set of minimum criteria (blue bullets – all patients with at least one record with minimum criteria, green bullets – patients with DAS28 and VAS updated every 6 months, grey bullets - patients with DAS28, VAS, HAQ and therapy updated every 6 months, red bullets – patients with DAS28, VAS, HAQ and therapy updated every 6 months and quality of life evert 12 months); Right panel – data for the subset of patients under biologic therapy CRP – C-reactive protein; DAS – disease activity score; ESR – erythrocyte sedimentation rate; HAQ – health assessment questionnaire; VAS – visual analogic scale

Educational materials were given to ~35% of patients (Figure 4), mainly at diagnosis or at beginning/switching of therapies, which are critical points in the patient journey. Patients under biologic therapy tended to receive more educational materials, still only ~60% patients recalled receiving them. Almost 90% of the patients considered the materials "useful" or "very useful", although they disregard lifestyle topics and patients' continuous educations, limiting their scope to diagnosis and therapy.

Criterion 18. Percentage of patients followed in a Day Hospital or Rheumatology Techniques Unit who were given a direct telephone access of the Rheumatology service healthcare professional

Roughly 2/3 of patients followed in a day hospital or Rheumatology techniques unit were given a direct contact (Figure 4) and reaching a healthcare professional through that contact took less than 10 minutes.

Criterion 19. Ability to provide a multidisciplinary approach according to patients' needs

In most departments, multidisciplinary approach was provided according to patient's needs, but only included <5% of patients (Figure 4). Team meetings were more common than patient appointments with multiple health professionals. Teams were mainly constituted by medical staff, with only 2 hospitals referring non-medical professionals.

Criterion 20. Percentage of diagnosed patients given a written communication addressing their GP or other relevant HCP, explaining the clinical situation and including the contact of the rheumatologist

More patients should receive a communication addressing general practitioners (Figure 4). Rheumatologists were relying on electronic medical records (EMR) such as PDS for this purpose, but not all departments had PDS integration working fully.

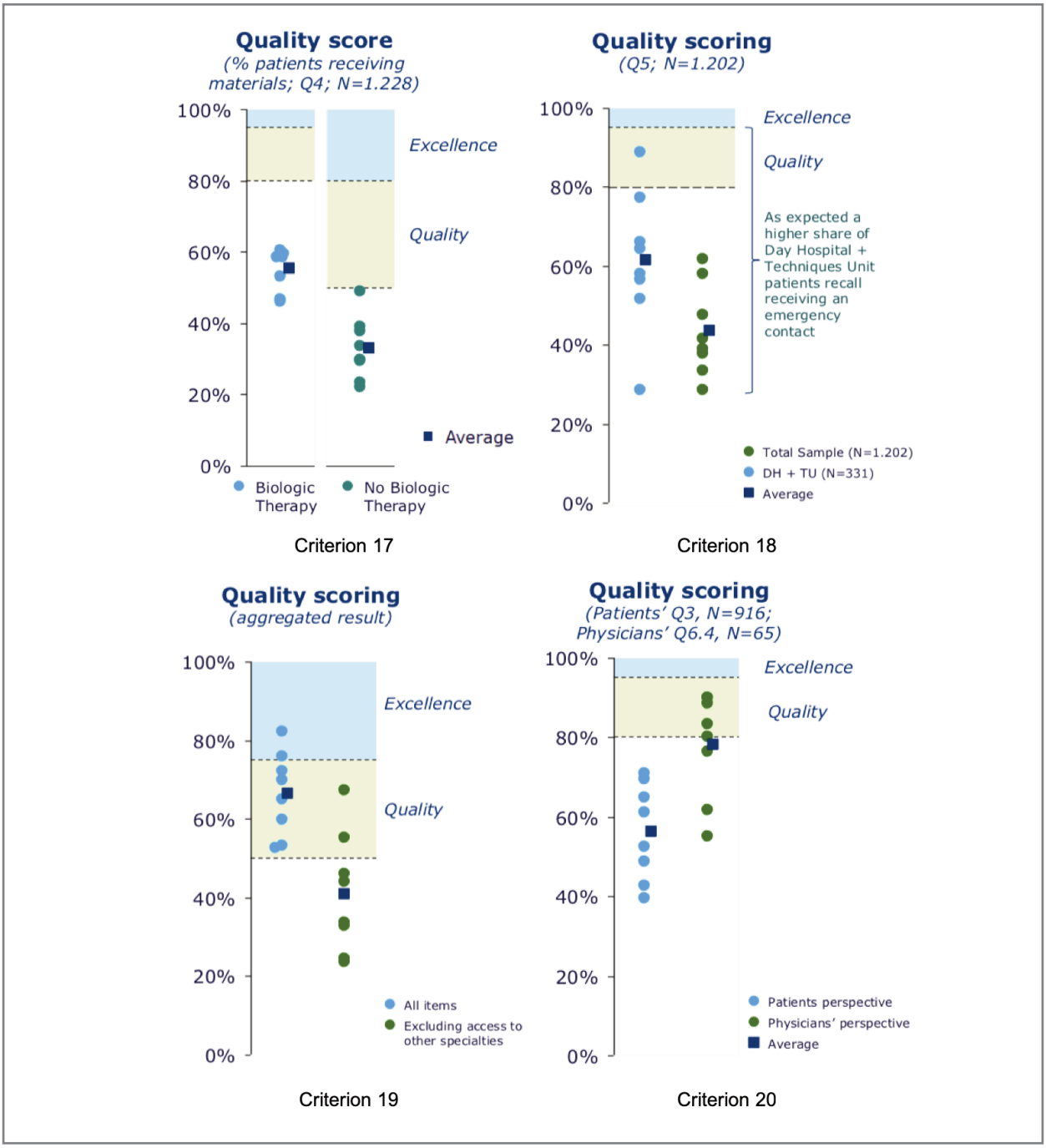

FIGURE 4. Processes (3) – Criterion 17: Percentage of patients who were given educational materials regarding the disease and/or treatment (blue bullets – patients under biologics; green bullets – patients not under biologic therapy, blue square – average of all hospitals); Criterion 18: Percentage of patients followed in a day hospital or Rheumatology techniques unit who were given a direct telephone access of the Rheumatology department healthcare professional (green bullets – all patients, blue bullets – patients that had an appointment at the day hospital or techniques unit, blue square – average of all hospitals); Criterion 19: Ability to provide a multidisciplinary approach according to patients' needs (blue bullets – all items; green bullets – data excluding access to other specialties, blue square – average of all hospitals); Criterion 20: Percentage of diagnosed patients given a written communication addressing their general practitioner explaining the clinical situation and including the contact of the rheumatologist (blue bullets - patients perspective, green bullets - physicians perspective, blue square – average of all hospitals). DH – day hospital; TU – techniques unit

TABLE III. INITIATIVES RELATED TO THE PROCESSES DIMENSION

Develop a "national consensus" on triage criteria in order to standardize practices, with annual revision in a meeting with triage professionals and multidisciplinary approach with a partnership between SPR and General Practitioner's associations.
Adapt Reuma.pt to better distinguish mandatory from complementary parameters and create "alert pop-ups" when critical information is missing.
Upgrade Reuma.pt to include more qualitative insights such as clinical recommendations and follow-up/ /exams/therapy suggestions.
Promote paperless Day Hospitals, namely via online self-answering patient reported outcomes and full adoption of electronic medical records.
Adapt SPR website for quick access to patient education materials in printable format and with a more common language, that also include references to validated websites.
Empower the Patient Associations' roles in the life and education of the patient.
Modular courses for General Practitioners in the field of Rheumatology.
Develop the option to create a standardized formulary from the patient clinical record to be printed and delivered to the patient to facilitate information diffusion between Primary and Secondary Care.

Initiatives to improve the main issues found in the processes dimension are specified in Table III.

3. OUTCOMES DIMENSION – WHAT RESULTS HAVE BEEN ACHIEVED ACROSS STAKEHOLDERS? (Figure 5)

Criterion 21. Percentage of rheumatoid arthritis patients with significant improvement in disease activity, disability and quality of life (according to international validated criteria), after 6 months of treatment

Analysis of criterion 21 was excluded because the disease activity outcome was evaluated for all patients without considering treatment start or switch, significantly biasing the analysis. Nevertheless, it was possible to consider a "baseline visit" with a DAS28 ≥3.2, and evaluate disease activity improvement after 6 and 12 months, which showed that an average of 42% of patients obtained remission or a 1.2 decrease in DAS28.

Criterion 22. Number of absent days per rheumatologic patient, per year, from patients' perspective

Most patients did not require working absences, but in those that did, time off reached almost 70 days per year. Half of the departments met quality threshold, by having <15 days of absence per each working-patient.

Criterion 23. Percentage of rheumatology patients that were granted early retirement due to illness

Almost 25% of patients were granted early retirement at a median age of 55 years, which had a considerable economic impact.

Criterion 24. Patients' overall satisfaction with Rheumatology care

Patient overall satisfaction with Rheumatology care was within quality threshold, with higher scores for interpersonal and communication aspects. Despite this, some patients showed concerns regarding financial and accessibility aspects with several patients feeling unable to afford access to medical care and/or complaining about waiting times.

Criterion 25. Patients' satisfaction with service facilities (consultations and waiting room, privacy, toilets, etc.)

Satisfaction with hospitals' facilities was positive, namely with consultation room's comfort and privacy, but could improve regarding waiting room, toilets and cafeteria.

Criterion 26. Healthcare professionals' overall satisfaction with Service environment, team work and cooperation within Service professionals

Health professionals were neutral regarding their overall job satisfaction, criticizing remuneration and career aspects. Coworkers, supervision and nature of work were the best quoted aspects.

Suggestions to improve the Outcomes dimension results can be found in Table IV.

TABLE IV. INITIATIVES RELATED TO THE OUTCOMES DIMENSION

Add absenteeism and retirement metrics to Reuma.pt, to be assessed in each appointment, considering these as relevant as clinical outcomes.
Organize cycle meetings off-site to promote team building, reflect on department's processes and develop soft skills (e.g. time management, conflict resolution, emotional intelligence, etc.), supported by "work psychologists".
Expand the support of administrative staff to physicians (e.g. filtering patients questions/requests regarding appointments booking/changes or prescriptions re-fills).

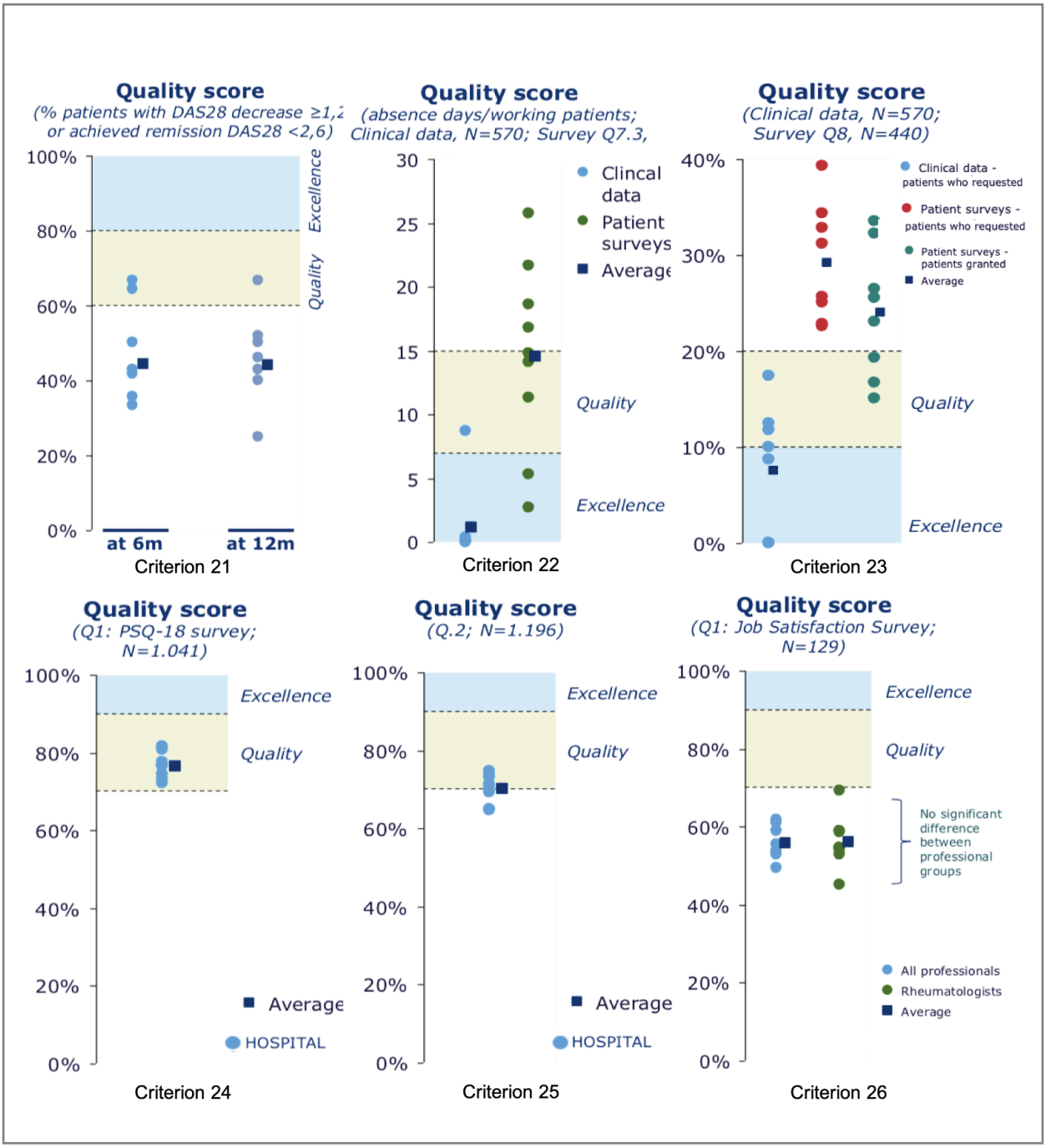

FIGURE 5. Outcomes – Criterion 21: Percentage of rheumatoid arthritis patients with significant improvement in disease activity (DAS28 decrease ≥1.2 or remission DAS28 <2.6), after 6 months of treatment (blue bullets) and 12 months (grey bullets); Criterion 22: Number of absent days per rheumatologic patient, per year, (blue bullets – data from clinical records, green bullets – data from patient surveys); Criterion 23: Percentage of rheumatology patients that were granted early retirement due to illness (blue bullets- data from clinical records containing patients requests, red bullets - data from patient surveys containing patients requests, green bullets - data from patient surveys containing patients who were granted early retirement); Criterion 24: Patients overall satisfaction with Rheumatology care (blue bullet – each hospital, blue square – average of all hospitals); Criterion 25: Patients satisfaction with department facilities (blue bullet – each hospital, blue square – average of all hospitals); Criterion 26: Healthcare professionals' overall satisfaction with Department environment, team work and cooperation within Department professionals (blue bullets – all professionals, green bullets – rheumatologists, blue square – average of all hospitals).

DISCUSSION

Rheuma SPACE allowed us to take a snapshot of Portuguese rheumatology practice according to specifically defined quality criteria, identifying major weaknesses and disparities that will help us in the pathway of improving quality of care to rheumatology patients.

1. STRUCTURE - HOW WELL EQUIPPED ARE RHEUMATOLOGY DEPARTMENTS?

Regarding structural domains, we verified that there were few FTS and rheumatology nurses for the population covered. Our rheumatologist per population ratio (1 per 90.000-100.000 inhabitants) was below the quality standard of 1 FTS per 60.000 inhabitants. The American College of Rheumatology (ACR) Workforce Study in the United States reported 1 FTS per 50.626 inhabitants in 2015[20] and in Canada, the ratio is 1:68.786[21]. In Europe, reported ratios are also better than the reported in our work, with 1:39.325 in Austria[22], 1:33.280 in Madrid[23] and 1:83.478 in the United Kingdom (UK)[24]. Nurses' exclusive allocation to Rheumatology departments is essential to promote specialization and expand responsibilities. Nurses may optimize outpatient consultations by having a patient education role and support disease activity assessment[25]. Reports on the ratio of rheumatology nurses per population are scarce. Data from Australia estimate 1 nurse for 462.777 inhabitants[26], and a UK survey states that each rheumatologist has at least 1 nurse[27].

Time dedicated to research and audit was below the quality threshold of 10%. In general, departments had access to appropriate equipment. Time for research and audit activities is low compared to other countries, with reported values of 21.6% in Madrid[23], 17.7% in the UK[24], 8.4% in Austria[22], and 10% in Canada[21].

EMR implementation met the excellence criteria of >85% coverage. EMR is a standard practice in Portuguese rheumatology, used by all professional, covering all patients and being available in all working locations. In Western Countries, EMR are also regular practice (ex: 70% in Canada[21]), and nowadays the ACR recommends the use of electronic clinical quality measures that rely on computer algorithms to extract data from electronic health records, in order to evaluate quality of care[28].

2. PROCESSES - HOW IS CARE PROVIDED TO RHEUMATIC PATIENTS?

Regarding processes, we verified that the triage process is well implemented in most departments. A significant delay existed in primary care referral for a first appointment, except for high priority patients.

Triage process met quality standards in most departments, but triage criteria should be consensual across all Rheumatology departments to provide patients with equal clinical accessibility. In 2015, a taskforce established the referral criteria for the main rheumatic diseases and musculoskeletal complaints[29]. High priority and priority patients should be seen in 30 and 90 days, respectively, and this was accomplished in more than 60% of cases. Median times for a first appointment differ across countries and are influenced by referral information quality and the priority attributed. In Canada, median waiting time from referral to rheumatologist consultation was 74 days, decreasing to 66 days for systemic inflammatory rheumatic diseases, not achieving predefined time benchmarks[30].

The quality of registers was still below quality thresholds, despite the use of a specific national database for rheumatic diseases. Frequency of follow-up appointments, assessment of disease activity and other outcome measures, as well as review of pharmacological therapy and completion of Reuma.pt registry was not appropriate in most centers, increasing in patients under biologics, but still below quality threshold. Evaluation of the METEOR database reported that information regarding function assessment was available for 49% of visits and regarding disease activity for 85% of visits[31].

Only 35 to 60% of patients' recall receiving educational materials. Access to educational material should expand to meet international recommendations[32] including websites and applications in order to be more engaging for patients.

3. OUTCOMES – WHAT RESULTS HAVE BEEN ACHIEVED ACROSS STAKEHOLDERS?

Evaluation of the Outcomes criteria met quality standards for criteria regarding patient's working absence, and patient satisfaction, but was below the expected threshold for rates of early retirement and professional's satisfaction.

42% of patients with high disease activity at baseline achieved remission or a decrease in DAS28 of >1.2, and in some departments this was accomplished for 60% of patients. These results are in line with results from major trials of drugs developed for RA[33–37], but leave be-

hind an important percentage of patients for whom solutions in order to achieve a state of low disease activity or remission are still an unmet need.

Working absence was very low when clinical records were evaluated, but reached 15% in the analysis of patient surveys, reflecting the reality that this certificate is commonly issued by the general practitioner and not by the rheumatologist. Other recent publications reported that 15-20% of RA patients require sick leaves during one year[38].

Results from this project, pointing to 25% of patients early retirement are in line with reported national data[39], according to which 22.4% of RA patients are early retired due to the disease, which is responsible for the loss of an average of 7 years of active work.

Professionals complain mainly about salary, benefits, rewards, career progression and operating conditions (workload and bureaucracy), with no significant difference between professional groups. Rheumatologists satisfaction was also evaluated in the UK[27] and Latin American countries[40], with reported global satisfaction ranging from 5-5.3 in a 7 point scale.

CONCLUSIONS

We believe that this innovative study conducted in Portugal, generating quality standards and evaluating them across departments, can contribute to the creation of an individualized and group quality plan.

We concluded that departments lack physicians and need exclusively dedicated nurses. Time dedicated to research and audit activities should be specifically allocated. Internal contracting is well established and professionals are committed to targets. Processes are still suboptimal, needing standardization of triage criteria, more frequent follow-up, as well as better medical records and multidisciplinary coverage. Regarding outcomes, patients are satisfied with the provided care and professionals with the working environment. However, department facilities for the former and career related aspects for the latter, should improve. Although day care hospitalization activities have suffered progressively increase in the last two decades in rheumatology departments, with an important part of daily work gaining importance at various levels, including as an essential basis for clinical research, there is still variability in their operation and features among different centers and an important framework standardization, expansion and specialized dedicated staffing may be need.

With this project we expect to have enlightened tailored opportunities for improvement, ensure patient-focused practices and be able to define the indispensable quality requirements for excellence.

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