

Rheuma SPACE - Standard Practice Aiming Clinical Excellence: description of the methodological approach

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ABSTRACT

Background: Quality of care is a key component of the right to health, and the route to equity and dignity. The aim of the project Rheuma SPACE - Standard Practice Aiming Clinical Excellence was to develop a set of quality indicators focused in rheumatoid arthritis care and apply them to rheumatology departments of the Portuguese National Health Service in order to benchmark the care for these patients. This article details the methodology that was applied.

Methodology: This was a single country, three-phase project, each phase comprising multiple steps. The first step defined quality indicators and the excellence quality model to be used. It involved a literature search for international benchmarking of quality of care initiatives and indicators, followed by a pre-selection of an initial set of indicators. The set of indicators was later on narrowed after an online Delphi round with all Portuguese rheumatologists and two consensus meetings involving the study task force. A set of 26 quality indicators was defined, within the three classic Donabedian dimensions of healthcare quality: Structure (9), Pro-

cesses (11), and Outcomes (6). These indicators cover eleven domains of quality of care: personnel and organizational structure, training and research, facilities, equipment and information technology, budgeting and financial resources, access to care, clinical records, patient communication, multidisciplinary management, clinical outcomes, and patient and personnel satisfaction. Decision on quality and excellence thresholds for each of the 26 quality indicators was agreed upon a consensus meeting gathering principal investigators of the eight Rheumatology Departments that decided to participate, task force core set members and invited representatives of all Portuguese Departments/Units. Rheumatoid arthritis was the chosen disease model of the project based on the reliability of the outcomes to be measured in the context of this condition. The second step was the assessment of the participating Rheumatology Departments. During eighteen months, research teams applied the 26 quality indicators to their own Departments. The third step comprised data analysis and the elaboration of individual Rheumatology Department reports and of a global public report.

Results: Eight Departments, comprising 80 specialists,

1. Serviço de Reumatologia, Hospital de Santa Maria – Centro Hospitalar Universitário de Lisboa Norte, Centro Académico de Medicina de Lisboa
2. Instituto Português de Reumatologia
3. Serviço de Reumatologia, Hospital CUF Descobertas
4. Merck Sharp & Dome, since 2017 Novartis Farma and Centro de Investigação em Saúde Pública, Escola Nacional de Saúde Pública, Universidade NOVA de Lisboa
5. Roche
6. AbbVie
7. Pfizer
8. IQVIA (IMS Health and Quintiles are now IQVIA)
9. Associação Portuguesa de Profissionais de Saúde em Reumatologia
10. Liga Portuguesa Contra as Doenças Reumáticas
11. Serviço de Reumatologia, Hospital Garcia de Orta
12. Unidade de Investigação em Reumatologia, Instituto de Medicina Molecular, Faculdade de Medicina, Universidade de Lisboa, Centro Académico de Medicina de Lisboa
13. Associação Portuguesa de Administradores Hospitalares: Alexandre Lourenço; Associação Portuguesa de Profissionais de

Saúde em Reumatologia: Lurdes Barbosa, Lurdes Narciso; Centro Hospitalar Universitário do Algarve - Hospital de Faro: Célia Ribeiro, Graça Sequeira, Lígia Silva; Centro Hospitalar do Baixo Vouga - Hospital de Aveiro: Anabela Barcelos, Catarina Ambrósio, Renata Aguiar; Centro Hospitalar Lisboa Ocidental - Hospital de Egas Moniz: Fernando Pimentel dos Santos, Jaime Branco, João Gomes, Sofia Serra, Teresa Pedrosa, Tiago Costa; Centro Hospitalar Universitário de Lisboa Norte - Hospital de Santa Maria: Carla Macieira, JA Pereira da Silva, José Carlos Romeu, Maria Inês Seixas; Centro Hospitalar de São João - Hospital de São João: Maria Lúcia Costa, Miguel Bernardes, Pedro Madureira; Centro Hospitalar Tondela-Viseu: Maura Couto, Paulo Monteiro; Centro Hospitalar Cova da Beira - Hospital Pêro da Covilhã: Margarida Oliveira; Hospital do Divino Espírito Santo: Guilherme Figueiredo; Hospital Garcia de Orta: Sandra Sousa; Hospital Ortopédico de Sant'Ana: Filipe Araújo; Instituto Português de Reumatologia: Augusto Faustino, Luís Cunha Miranda; Unidade Local de Saúde Alto Minho: Daniela Faria, Filipa Teixeira, Maria do Carmo Afonso; Unidade Local de Saúde Guarda: Cláudia Vaz; Unidade Local de Saúde de Castelo Branco: Pedro Abreu

20 residents and 30 nurses, covering 5.904.080 inhabitants, underwent quality evaluation. More than one thousand patients (1.325) and 113 health professionals' surveys were analysed, as well as data from 570 clinical records and 3.927 medical appointments on rheumatoid arthritis patients.

Discussion: 26 quality indicators were used for the first evaluation of Portuguese Rheumatology Departments, turning Rheuma SPACE into a pioneer project. Data analysis and benchmarking will be the subject of a further publication.

Keywords: Quality of Care; Quality Indicators.

INTRODUCTION

Health care professionals and stakeholders are increasingly faced with scientific and technological advances, leading to constant and frequent changes in clinical practice. 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 tool¹. Quality of Care is a key component of the right to health, and the route to equity and dignity. In order to achieve this, health care must be safe, effective, timely, efficient, equitable and people-centred². In addition, quality of care evaluation is the only way to ensure that the programmed measures are being effective in achieving the proposed outcomes.

In the specific field of Rheumatology evaluating the practice of day care units/infusion rooms has been the main line of work, pioneering quality of care in different clinical settings³⁻⁵. The Spanish Society of Rheumatology published an interesting project almost exclusively focused on day care units/infusion rooms. They started by implementing a cross-sectional characterization of existing shortcomings and then evolved into the application of a model of excellence, the "Reumatolex Project"⁶. Finally, they established the indicators and other management tools to ensure a patient-oriented practice, based on both evidence and clinical experience^{6,7}, considering stakeholders' opinions and patients' perspectives. Two other publications explored, under the same perspective, disease course monitoring⁸ and patients' satisfaction⁹. Alternative approaches to quality assessment in the field of rheumatic diseases have characterized general aspects of global care in rheumatic diseases¹⁰⁻¹³ or have applied measures of quality for specific diseases, such as juve-

nile idiopathic arthritis¹⁴ or lupus¹⁵. In the case of rheumatoid arthritis (RA) healthcare quality indicators and standards of care for this disease have been drafted across Europe, mainly focusing on disease activity and outcomes¹⁶⁻²².

An additional concern in the context of quality of care implementation and evaluation is the balanced involvement of patients as they are now perceived as active recipients of care, welcoming equal dialogue with health care staff^{23,24}.

The Portuguese Society of Rheumatology (SPR) embraced quality as a major goal and launched in early 2015, a program to aim at excellence in global clinical care: Rheuma SPACE - Standard Practice Aiming Clinical Excellence^{25,26}. This program 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. RA was chosen as the disease model due to the comprehensive set of quality indicators already proposed in the literature and for being a relatively homogenous disease that facilitate the process of quality of care assessment.

The main purpose of Rheuma SPACE was to develop a set of quality indicators focused in RA care and apply them to rheumatology departments of the National Health Service in order to benchmark the care for these patients. Herein we describe the methodology followed to develop the evaluating tool of this program.

METHODS

Rheuma SPACE was initially thought as a three-phase project:

1. Establishing a set of quality indicators and an excellence quality model focused on RA care. The selection of quality indicators was done in 2015.
 2. Assessment of the current care at Rheumatology Departments using the defined quality indicators. This fieldwork was performed over 2015 and 2016.
 3. Elaboration of global and customized reports for each participating Rheumatology Department. This data analysis phase was done over 2016 and 2017.
- Each of these three phases comprised multiple steps.

PHASE 1: DEFINING QUALITY INDICATORS AND AN EXCELLENCE QUALITY MODEL

STEP 1: PROJECT'S TEAM

Rheuma SPACE project started by participants' selec-

tion and defining a project team:

- Promotor: SPR was responsible for the project leadership, methodology definition and technical coordination.
- Task force: a) a central core of five rheumatologists, including the SPR president (JEF) and the SPR president elect (JCS), two rheumatology specialists from two large Rheumatology Departments (CM, LCM) and one specialist with former experience of working in a medium size Rheumatology Department (PN); b) rheumatologists representing smaller centres who collaborated in selected parts of the project (Rheuma SPACE study group); c) other professionals, including a rheumatologist MD (MB), pharm D (SF,IF) and an epidemiologist (PL) working at the medical departments of four pharmaceutical companies also gave an important and original input at different phases of the project.^{fn1}
- Enablers: AbbVie, Merck Sharp & Dome, Pfizer and Roche, gave the necessary budgetary support.
- Executor: IQVIA (IMS Health and Quintiles are now IQVIA) was the executor agent, responsible for methodological executive support in all participating centres, organization details and data keeping analysis and synthesis, and finally, elaboration of a global and customized Department reports. Execu-

fn1. JEF- João Eurico Fonseca, JCS- José Canas da Silva, CM- Carla Macieira, LCM- Luís Cunha Miranda, PN- Patrícia Nero, MB- Mónica Bogas, SF- Sara Farinha, IF- Isabel Freitas, PL- Pedro Laires, PLU- Pedro Lucas, JS- Joana Sousa

fn2. LN-Lurdes Narciso, LB-Lurdes Barbosa, EM-Elsa Mateus

tor IQVIA always assured total data anonymity and confidentiality (PLu, JS).^{fn1}

- Partners: they've collaborated in all Rheuma SPACE' phases as team partners of the task force, assuring that other health care stakeholders' perspectives were taken into consideration. Representatives of the following organizations were involved in the project: Portuguese Association of Hospital Managers, nurses from the Portuguese Rheumatology Health Care Professionals Association (LN, LB), patients' representatives from the Portuguese League against Rheumatic Diseases (EM)^{fn2}. Also relevant to the project was the work already done by the eumusc.net project^{21,22} supported by the European Union and European League against Rheumatism. A representative of this project gave feedback regularly during the development of Rheuma Space^{fn3}.
- Participants: a total of ten Rheumatology Departments belonging to the National Health Service, country-wide, including large and smaller centres, were invited to participate in the project. One Department was unable to allocate time and resources to participate and another one failed to complete all project phases. At the end, eight Departments were evaluated.

STEP 2: SELECTION OF QUALITY INDICATORS

The definition of quality indicators of care provided by

fn3. AW-Anthony Wolf

fn4. TM-Tolero Molina, RGV-Rosario Garcia de Vicuña

TABLE I. EUROPEAN QUALITY ASSESSMENT BENCHMARKS

	Rheumatology standards of care, quality guidelines and indicators initiatives
eumusc.net	eumusc.net aims to harmonize quality of care of rheumatic diseases across Europe and defined 14 quality indicators
DANBIO	In Denmark the patient registry is used to evaluate quality according to 7 clinical processes and outcomes - related criteria
Le Point	Le Point's Hospitals and Clinics' ranking aims to support patient's selection of healthcare units based on their quality
DRFZ	The German rheumatologic database has been gathering information since 1993 to evaluate care in Rheumatology
DREAM	The DREAM collaboration is an established patient registry used to benchmark hospitals on rheumatoid arthritis care outcomes and efficiency
ÍCARO	The Spanish Rheumatology Society has work on quality of care evaluation since 2006 focusing on Hospital's day care practice, resulting in several publications
NICE	NICE defined 7 quality statements for rheumatoid arthritis, across different stages of patient pathway

TABLE II. DONABEDIAN'S DIMENSIONS AND DOMAINS

Dimensions	Domain
Structure	Personnel and organizational structure
	Training and research
	Facilities, equipment and information systems
	Structure budgeting and financial resources
Process	Access to care and productivity
	Medical care and clinical records
	Physician - patient communication
	Multidisciplinary patient management
Outcomes	Clinical outcomes
	Patient satisfaction
	Personnel satisfaction
	Therapeutic costs and care efficiency

Rheumatology Departments, along with a model of excellence was settled over four sub-steps.

Sub-step 2.1: literature search

The task force performed an extensive process of literature search for international publications on rheumatology standards of care, quality guidelines and indicators. However, the publications on this subject were scarce. Table I summarizes the work developed by some Rheumatology Societies in Europe. Of note, the Spanish Rheumatology Society, over the last two decades, developed and published data centred on hospital's day care practice⁶⁻⁷. Specific indicators for RA^{16,18-20} patients' care have been detailed^{16,18-22}, but juvenile idiopathic arthritis¹⁴ and lupus¹⁵ quality of care indicators were also found.

Sub-step 2.2: stakeholders' interviews

At the same time, the characteristics of the patients flowing within Rheumatology Departments were mapped. Interviews with doctors, nurses and hospital managers at several institutions took place. The opinion and feedback of several stakeholders was valuable and considered. A preliminary list of Rheumatology care related topics was gathered, compiled and translated into quality indicators, each one measurable and pertinent to the Portuguese reality. Globally, 412 different indicators were collected throughout this project phase. At the end of this stage, interviews with in-

ternational key opinion leaders were made to gather additional expertise from previous experiences^{fn4}.

Sub-step 2.3: quality indicators selection

The 412 collected indicators were organized according to the *Donabedian* framework²⁷ comprising three dimensions: *structure* - resources and administration, *process* - culture and professional cooperation, and *outcomes* - competence development and goal achievement.

This was structured in 3 major questions:

Structure – how well equipped are Rheumatology Departments in terms of personnel, training and research, facilities, equipment and information systems, budgeting and financial resources?

Process – how is care provided to rheumatic patients in terms of access to care and productivity, medical care and clinical records, physician-patient communication and multidisciplinary patient management?

Outcomes – what results have been achieved across stakeholders in terms of outcomes, patient and personnel satisfaction?

These three dimensions aggregate twelve domains of healthcare quality (Table II).

Starting from the 412 selected items, 2 crucial outcomes had to be obtained:

- Indicators selection
- Quality/excellence definition

In order to obtain a concise list of *quality indicators* for Rheumatology care, the team proceeded with a four-stage RAND-modified Delphi²⁸ approach (Figure 1).

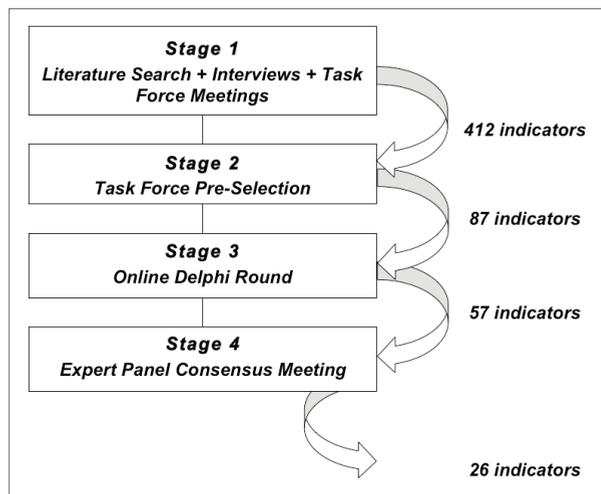


FIGURE 1. Four-stage RAND-modified Delphi methodology used to identify and select quality indicators

RAND-modified Delphi approach**Stage 1 and 2: literature search and task force pre-selection**

Items from the preliminary list (412 indicators) were pre-selected by the task force over the course of two meetings. Before the first meeting, task force members gave their individual scores to each indicator based on plausibility, applicability and their individual experience. Individual work was compiled by IQVIA and discussed in the first meeting, with a focus on criteria for which the range of relevance was higher (least consensual items). All indicators were further re-evaluated in a second meeting, resulting in a shorter list of 87 items.

Stage 3: online 1st Delphi round – all rheumatologists

Since its start, the project aimed to be inclusive and to incorporate the view of most SPR members. An online Delphi questionnaire tool was designed and shared with all rheumatologists. SPR members with an email address registered (146 rheumatology experts) were invited to participate in the Delphi questionnaire round. They were asked to rate all indicators in a Likert scale (from 1 - not important at all, up to 9 - crucial). To ensure a proper prioritization a benchmark indicator was defined, one for each *Donabedian* dimension of quality. Indicators were grouped into these three categories and received a classification for their relevance in comparison to the benchmark. Fifty rheumatologists gave complete scores in the Delphi questionnaire round - a 34% response rate. Eighty-seven indicators were voted, and after the online Delphi meeting output, 57 moved on to a second selection round.

Stage 4: consensus meeting 2nd Delphi round - expert panel

A second consensus meeting was required to obtain a smaller set of indicators to be used, to agree on the inclusion of the highest scored indicator, exclusion of the lowest ones and at the end, the determination of the final list of quality indicators. The panel included the task force, eight department directors, a patient representative, two members of the Rheumatology Health Care Professionals Association and the head of the international project eumusc.net^{21,22}, who shared his experience and best practices²³. Experts were required to vote for the exclusion of indicators within each of the twelve domains of quality of care, discussed the results of the voting, had a second voting round after the discussion and collectively agree on the final set to be in-

cluded in the project's list. Some indicators were grouped together, rephrased or further detailed. A final set of 26 quality indicators that reflected the quality of care envisioned for the Portuguese Rheumatology was reached.

Sub step 2.4: quality indicators thresholds definition - quality/excellence

A measurement scale and quality/excellence thresholds were developed for each of the 26 selected quality indicators and again the Delphi method was used. Published evidence was valuable but scarce and Delphi provided a good starting point for some indicators. Decision on quality and excellence thresholds was agreed at a second consensus meeting gathering principal investigators of the eight Rheumatology Departments, task force members and representatives from all Portuguese Departments/Units.

PHASE 2: ASSESSMENT OF RHEUMATOLOGY DEPARTMENTS

Ten Rheumatology Departments country-wide, large and smaller institutions were asked to participate in Rheuma SPACE to ensure national coverage.

Departments were asked to set up a research team including one to three rheumatologists and residents – Rheuma SPACE study group, that assured data access and collection. All clinical data needed was obtained from Reuma.pt, the Rheumatic Diseases Portuguese Register. No face-to-face interviews were performed.

Quality indicators measurement required significant team effort in the use of different data sources:

1. Department opinion: the team was asked to evaluate current practices and resources and adapt the application of some criteria in accordance to local reality
2. Clinical records from RA patients: data was obtained from Reuma.pt in order to minimize “perception” bias and guarantee methodology uniformity
3. Surveys: questionnaires were applied to both patients and staff, inquiring about their satisfaction with current practices and other topics
4. Research teams were asked to collect inputs related to administrative procedures, equipment and other structural Department standards

PHASE 3: DATA ANALYSIS, GLOBAL AND INDIVIDUAL RHEUMATOLOGY DEPARTMENT REPORTS

At the end of a twelve months collection phase,

Rheuma SPACE executor IQVIA proceeded with confidential data analysis, resulting in a report for each Department along with global benchmarking practices analysis.

Results were first presented and discussed with each research team, and afterwards with each involved Departments. Final individual reports for each centre were developed, identifying positive aspects, best practices and improvement areas. On October 2016, at a meeting promoted by SPR, national results were presented and discussed.

Furthermore, the development of a list of improvement initiatives seemed crucial to ensure benefits from Rheuma SPACE and initiating a future process of defining key macro objectives and milestones. Two task force meetings took place. A three-step methodology aiming to identify and prioritize potential improvement initiatives was presented:

STEP 1: ITEMS SELECTION AND BRAINSTORMING

- Task force agreement on what quality indicators to focus on
- Listing down all potential ideas to tackle selected issues

STEP 2: DESCRIPTION AND ORGANIZATION

- Production of a short description statement for each selected idea
- Aggregation of groups of ideas according to agreed criteria into similarity clusters

STEP 3: PRIORITIZATION

- Discussion of each initiative's impact, as well as the implementation challenges
- Prioritizing and mapping improvement initiatives in a "wish timeline"

A list of potential initiatives was selected to be discussed as an improvement quality plan for each Department.

ETHIC ISSUES

Authorization from Administration Boards and Ethics Committees was obtained from the participating Hospitals. All clinical data needed was obtained from Reuma.pt, the Rheumatic Diseases Portuguese Register. A signed informed consent for participating in clinical research was collected from patients participating at the register. Reuma.pt is approved by all local ethics committees and the national board for the protection of personal data (Comissão Nacional de Proteção de dados)²⁹.

RESULTS

PHASE 1: DEFINING QUALITY INDICATORS AND AN EXCELLENCE QUALITY MODEL

With the four-step RAND-modified Delphi approach a final list of 26 quality indicators was obtained - nine structure, eleven processes and six outcomes indicators, from eleven domains of quality of care (Table III). The expert panel unanimously agreed at a consensus meeting, on the exclusion of therapeutic costs and care efficiency indicators.

At the end of Rheuma SPACE phase 1, task force members prepared individual indicators discussion at a second consensus meeting. As a result, quality and excellence thresholds were additionally defined (Table IV).

PHASE 2: ASSESSMENT OF RHEUMATOLOGY DEPARTMENTS

In the beginning of Rheuma SPACE phase 2 - assessment of Rheumatology Departments - eight of the 10 invited Departments accepted to participate and completed the evaluation process (Table V).

These eight Departments, comprising 80 specialists, 20 residents and 30 nurses, covering 5.904.080 inhabitants, underwent quality evaluation.

More than one thousand patients (1.325) and 113 health professionals' surveys were analysed, as well as data from 570 clinical records and 3.927 medical appointments. This information is listed in Table III: Rheuma Space final criteria list and concerns the Process Dimension in "Medical care and clinical records, criteria 13-16" and the Outcomes Dimension in "Clinical outcomes, criteria 21-23".

PHASE 3: DATA ANALYSIS, GLOBAL AND INDIVIDUAL RHEUMATOLOGY DEPARTMENT REPORTS

This information will be released in a separate publication addressing the outcome of the Rheuma SPACE project.

DISCUSSION

Selection of quality indicators based on both published evidence and experience of several stakeholders offered guidelines for comparing quality standards. These 26 indicators were used for the first quality evaluation of Portuguese Rheumatology Departments, turning

TABLE III. RHEUMA SPACE 26 QUALITY INDICATORS**STRUCTURE – How equipped are Rheumatology Departments?**

Personnel and organizational structure	<ol style="list-style-type: none"> 1. Number of rheumatologists per population covered 2. Number of nurses dedicated to Rheumatology per population covered 3. Existence and frequency of medical audits assessing the compliance with guidelines that are accepted by Rheumatology
Training and research	<ol style="list-style-type: none"> 4. Existence and implementation of an annual training plan for healthcare professionals, including monthly clinical sessions for continued scientific training 5. Percentage of rheumatologists' time dedicated to research and audit
Facilities, equipment and information systems	<ol style="list-style-type: none"> 6. Access to medical and informatics technology equipment (ultrasonography, polarized light microscope, capillaroscopy instrument, densitometer, and computers with internet access) 7. Existence of a patient electronic medical record (EMR) with data protection systems and its availability across Rheumatology Departments' to healthcare professionals 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
Structure budgeting and financial resources	<ol style="list-style-type: none"> 9. Annual implementation of an internal contract between Department and Administration, including budget and activity planning, quality indicators and funds for research & training

PROCESSES – How is care provided to rheumatic patients?

Access to care and productivity	<ol style="list-style-type: none"> 10. Patient triage is performed by a rheumatologist, according to criteria defined by Rheumatology 11. Percentage of patients who get a first appointment in Rheumatology within due waiting time, according to prioritization criteria established by Rheumatology 12. Percentage of patients with disease flares or potential drug related side effects that received advice within 1 working day of contacting the service
Medical care and clinical records	<ol style="list-style-type: none"> 13. Frequency of follow up appointments - rheumatoid arthritis as a case study 14. Frequency of assessment of pain, disease activity, patient function, quality of life and co-morbidities - rheumatoid arthritis as a case study 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 16. Percentage of patients with a frequently updated record on REUMA.PT with a set of minimum criteria - rheumatoid arthritis as a case study
Patient communication	<ol style="list-style-type: none"> 17. Percentage of patients who were given educational materials regarding the disease and/or treatment 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
Multidisciplinary patient management	<ol style="list-style-type: none"> 19. Ability to provide a multidisciplinary approach according to patients' needs 20. Percentage of diagnosed patients given a written communication addressing their general practitioner or other relevant health care provider, explaining the clinical situation and including the contact of the rheumatologist

OUTCOMES – What results have been achieved across stakeholders?

Clinical outcomes	<ol style="list-style-type: none"> 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
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TABLE III. CONTINUATION

	22. Number of absent days per rheumatologic patient, per year - rheumatoid arthritis as a case study
	23. Percentage of rheumatology patients that were granted early retirement due to illness – rheumatoid arthritis as a case study
Patient satisfaction	24. Patient overall satisfaction with Rheumatology care 25. Patient satisfaction with service facilities (consultations and waiting room, privacy, toilets, etc.)
Personnel satisfaction	26. Healthcare professionals' overall satisfaction with Department environment, team work and cooperation within Department professionals

TABLE IV. QUALITY AND EXCELLENCE THRESHOLD DEFINITIONS FOR STRUCTURE, PROCESSES AND OUTCOMES QUALITY INDICATORS

Domain	Indicator	Quality threshold	Excellence threshold
STRUCTURE			
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	$\geq 50\%^*$ and $< 85\%^*$	$\geq 85\%^*$
Training and research	4. Existence and implementation of an annual training plan for healthcare professionals, including monthly clinical sessions for continued scientific training	$\geq 50\%^*$ and $< 85\%^*$	$\geq 85\%$
	5. Percentage of Rheumatologists' time dedicated to research and audit	$\geq 10\%$ and $< 20\%$	$\geq 20\%$
Facilities, equipment and information systems	6. Access to medical and IT equipment (ultrasonography, polarized light microscope, capillaroscopy instrument, densitometer, and computers with internet access)	$\geq 60\%^*$ and $< 85\%^*$	$\geq 85\%^*$
	7. Existence of a patient electronic medical record (EMR) with data protection systems and its availability across Rheumatology services to healthcare professionals	$\geq 50\%^*$ and $< 85\%^*$	$\geq 85\%^*$
	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	$\geq 60\%^*$ and $< 90\%^*$	$\geq 90\%^*$
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	$\geq 50\%^*$ and $< 85\%^*$	$\geq 85\%^*$

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TABLE IV. CONTINUATION

Domain	Indicator	Quality threshold	Excellence threshold
PROCESSES			
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	≥ 80% and <90%	≥ 90%
	11.1. High Priority (1 st appointment within 30 days)		
	11.2. Priority (1 st appointment within 90 days)		
	11.3. Normal Priority (1 st appointment within 180 days)		
	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%
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 pharmacological 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 record 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%

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TABLE IV. CONTINUATION

Domain	Indicator	Quality threshold	Excellence threshold
Multidisciplinary patient management	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 contact of the rheumatologist	≥ 80% and < 95%	≥ 95%
	20.1. Patients perspective		
	20.2. Physicians perspective		
OUTCOMES			
Clinical outcomes	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	≥ 60% and >80%	≥ 80%
	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%
Patient satisfaction	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

TABLE V. RHEUMA SPACE PARTICIPATING PORTUGUESE DEPARTMENTS

Department	Status
Unidade Local de Saúde Alto Minho	Completed data collection
Centro Hospitalar Universitário - Hospital de São João	Completed data collection
Centro Hospitalar Tondela Viseu	Completed data collection
Centro Hospitalar Universitário de Lisboa Norte - Hospital de Santa Maria	Completed data collection
Centro Hospitalar de Lisboa Ocidental - Hospital de Egas Moniz	Completed data collection
Instituto Português de Reumatologia	Completed data collection
Hospital Garcia de Orta	Completed data collection
Centro Hospitalar e Universitário do Algarve - Hospital de Faro	Completed data collection
Centro Hospitalar do Baixo Vouga - Hospital de Aveiro	Could not collect data
Centro Hospitalar Universitário de Coimbra	Choose not to participate

Rheuma SPACE into a pioneer project.

Rheuma SPACE methodology was designed on a RAND-modified Delphi approach based on literature evidence, but also expert and stakeholders' opinions, online Delphi rounds and consensus meetings open to all SPR members. We believe that the work developed resulted in solid indicators that went further beyond the previous evaluations of the practice of day care units previous done across Europe^{3,5-7,16}. In addition, it was an inclusive collaborative work: eight Departments, comprising 80 specialists, 20 residents and 30 nurses, covering 5.904.080 inhabitants.

This project allowed an in deep analysis of quality indicators adapted to the Portuguese reality, paving the way for subsequent studies. In addition, the field phase of the project enrolled local teams that became aware of the relevance of quality of care and motivated to further monitor it. Finally, this project set the seeds for benchmarking the quality of care of Rheumatology practice in Portugal.

The Rheuma SPACE project has some limitations. In line with previous studies^{16-22, 30}, we have chosen RA as a clinical model, though it may not represent the standard of care for all rheumatic patients. The 26 indicators have been developed based on evidence that have been published, reviewed by experts' panels and proved to be applicable to the Portuguese reality. However, they lack an independent validation, as well as, an external proof of reliability and feasibility. In addition, effective improvement initiatives may also turn hard to conduct.

CONCLUSIONS

The number of rheumatologists, patients, allied professionals, management personnel as well as the task force member's expertise, ensured a representative and solid view on the Standard of Practise Aiming for Clinical Excellence quality indicators. Improving quality of care is a continuous and resilient effort. Future stakeholders' partnerships may enhance and facilitate the development and implementation of selected improvement strategies as in other projects aiming at Quality of Care³¹.

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REFERENCES

1. Blumenthal D. Quality of health care. Part 4: The origins of the quality-of-care debate. *N Engl J Med* 1996, 335(15):1146-1149.
2. World Health Organization. Quality of Care. A Process for making strategic decisions in health systems. Available from https://www.who.int/management/quality/assurance/Quality-Care_B.Def.pdf.
3. Kunkel S, Rosenqvist U, Westerling R. The structure of quality systems is important to the process and outcome, an empirical study of 386 hospital departments in Sweden. *BMC Health Services Research* 2007, 7:104.
4. Saag KG, Yazdany J, Alexander C. Defining quality of care in rheumatology: the American College of Rheumatology white paper on quality measurement. *Arthritis Care Res (Hoboken)*. 2011 Jan; 63(1):2-9.
5. Román Ivorra JA, Gómez-Salazar JR, Calvo Catalá J. Current status of day care units where rheumatology treatments are administered in the autonomous community of Valencia. *Reumatol Clin*. 2010, 6(5):244-249.
6. Román Ivorra JA, Sanmarti R, Collantes-Estévez E. Model of Excellence in Rheumatology Day Hospitals in Spain: The HD – Reumatolex Project. *Reumatol Clin*. 2013, 9(3):142-147.
7. García-Vicuña R, Montoro M, Egües Dubuc CA. Quality Standards in a Rheumatology Day-Care Hospital Unit. The Proposal of the Spanish Society of Rheumatology Day Hospitals' Working Group. *Reumatol Clin*. 2014, 10(6):380-388.
8. van Hulst LT, Fransen J, den Broeder AA. Development of quality indicators for monitoring of the disease course in rheumatoid arthritis. *Ann Rheum Dis* 2009, 68:1805-1810.
9. Barbosa L, Ramiro S, Roque R. Patients s satisfaction with the rheumatology day care unit. *Acta Reumatol Port*. 2011, 36:377-338.
10. Muñoz Fernández S, Lázaro y De Mercado P, Alegre López J. Quality of Care Standards for Nursing Clinics in Rheumatology. *Reumatol Clin*. 2013, 9(4):206-215.
11. Ivorra JA1, Martínez JA, Lázaro P. Quality-of-care standards for early arthritis clinics. *Rheumatol Int* 2013 33:2459-2472.
12. MacLean CH, Saag KG, Solomon DH, et al. Measuring Quality in Arthritis Care: Methods for Developing the Arthritis Foundation's Quality Indicator Set. *Arthritis & Rheumatism (Arthritis Care & Research)* 2004, 51(2):193-202.
13. Alonso Ruiz A, Vidal Fuentes J, Tornero Molina J, et al. Assistance Quality Standards in Rheumatology 2007, 3(5):218-25.
14. Lovell DJ, Passo MH, Beukelman T, et al. Measuring Process of Arthritis Care: A Proposed Set of Quality Measures for the Process of Care in Juvenile Idiopathic Arthritis. *Arthritis Care & Research* 2011, 63(1): 10-16.
15. Dua AB, Aggarwal R, Mikolaitis RA. Rheumatologists' Quality of Care for Lupus: Comparison Study between a University and County Hospital. *Arthritis Care & Research* 2012; 64(8): 1261-1264.
16. Kennedy T, McCabe C, Struthers G, et al. British Society for Rheumatology Standards, Guidelines and Audit Working Group (SGAWG). BSR guidelines on standards of care for persons with rheumatoid arthritis. *Rheumatology (Oxford)* 2005; 44(4):553-556.
17. Lempp H, Scott DL, Kingsley GH. Patients' views on the quality of health care for rheumatoid arthritis. *Rheumatology* 2006, 45:1522-1528.
18. Khanna D, Arnold EL, Pencharz JN, et al. Measuring process of arthritis care: the Arthritis Foundation's quality indicator set for

- rheumatoid arthritis. *Semin Arthritis Rheum*. 2006 Feb;35(4):211-237
19. NICE, National Institute for Health and Care Excellence. Quality standard for rheumatoid arthritis. NICE quality standard 33. Available from www.nice.org.uk/guidance/qs33
 20. Bombardier C, Mian S. Quality indicators in rheumatoid arthritis care: using measurement to promote quality improvement. *Ann Rheum Dis* 2013, 72: ii128–ii131.
 21. Petersson IF, Strömbeck B, Andersen L, et al. Development of healthcare quality indicators for rheumatoid arthritis in Europe: the eumusc.net project. *Ann Rheum Dis* 2014, 73:906–908.
 22. Stoffer MA, Smolen JS, Woolf A, et al. Development of patient-centred standards of care for rheumatoid arthritis in Europe: the eumusc.net project. *Ann Rheum Dis* 2014, 73:902–905.
 23. Lim AY, Ellis C, Brooksby A, et al. Patient Satisfaction with Rheumatology Practitioner Clinics: Can We Achieve Concordance by Meeting Patients' Information Needs and Encouraging Participatory Decision Making? *Ann Acad Med Singapore* 2007, 36:110-114.
 24. Hendriks AA, Oort FJ, Vrieling MR, Smets EM. Reliability and validity of the Satisfaction with Hospital Questionnaire. *Reumatol Clin*. 2013, 9(3):142–147.
 25. Macieira C, Cunha-Miranda L, Nero P, et al. Rheuma space: standard practice aiming clinical excellence in rheumatology. *Ann Rheum Dis*. 2017; 76:436.
 26. Macieira C. Standard practice aiming clinical excellence in rheumatology. *Acta Reumatol Port*. 2017 Oct-Dec; 42(4):285-286.
 27. Ayanian JZ, Markel H. Donabedian's Lasting Framework for Health Care Quality. *New England Journal of Medicine* 2016, 375:205-207.
 28. Khodyakov D, Grant S, Barber CE, et al. Acceptability of an online modified Delphi panel approach for developing health services performance measures: results from 3 panels on arthritis research. *Journal of Evaluation in Clinical Practice* 2017;23(2):354-360.
 29. Santos MJ, Canhão H, Faustino A, Fonseca JE. Reuma.pt - case study. *Acta Med Port*. 2016 Feb;29(2):83-4.
 30. Adhikesavan LG, Newman ED, Diehl MP, et al. American College of Rheumatology quality indicators for rheumatoid arthritis: benchmarking, variability, and opportunities to improve quality of care using the electronic health record. *Arthritis Rheum*. 2008; 59(12):1705-1712.
 31. Chow SL, Shojania KG. "Rheum to Improve": Quality Improvement in Outpatient Rheumatology. *J Rheumatol*. 2017 Sep; 44(9):1304-1310.