

Original Article

Quality of Care Standards for Nursing Clinics in Rheumatology[☆]

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ARTICLE INFO

Article history:

Received 2 July 2012

Accepted 24 October 2012

Available online 3 July 2013

Keywords:

Rheumatology

Nursing

Quality of care

ABSTRACT

Background: Nursing clinics in rheumatology (NCR) are organizational models in the field of nursing care. There are various NCR models, but there is no consensus on its operational definition. Our objective is to develop quality standards to define and characterize a NCR.

Method: Two-round Delphi method. The panel consisted of 67 experts: rheumatologists and nurses of the nursing working group of the Spanish Society of Rheumatology (SSR). The Delphi questionnaire was developed after a literature and experience review from previous SSR projects. The questionnaire consists of 7 sections: general considerations, standards of structure, process, treatment and monitoring, health education, training and research and quality of care. Each item was scored from 1 (least important) to 9 (most important) or by assigning a number (e.g. waiting days). The degree of agreement among the experts was categorized according to the coefficient of variation (CoV) between very high (CoV \leq 25%) and very low (CoV>100%).

Results: The second round questionnaire (182 items) was answered by 46 panelists (34 rheumatologists and 12 nurses). A very important agreement was reached on the general standards of structure, process, treatment and monitoring, health education and quality of care. Less agreement was observed on standards related to training time, number of recommended nurses' research projects and publications.

Conclusion: The standards developed in this study would be useful for establishing desirable quality standards of structure and process, and criteria for clinical work, research and teaching that can be used to develop and evaluate the NCRs.

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[☆] Please cite this article as: Muñoz Fernández S, et al. Estándares de calidad asistencial para las consultas de enfermería en reumatología. Reumatol Clin. 2013;9:206–15.

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Estándares de calidad asistencial para las consultas de enfermería en reumatología

R E S U M E N

Palabras clave:
Reumatología
Enfermería
Calidad asistencial

Introducción: Las consultas de enfermería en reumatología (CER) son modelos organizativos asistenciales en el ámbito de competencias de enfermería. Hay diversos modelos de CER, pero no existe una definición operacional. El objetivo del proyecto es elaborar estándares de calidad para definir y caracterizar una CER. **Método:** Estudio Delphi a dos rondas. El panel estuvo constituido por 67 expertos: reumatólogos y enfermeras del grupo de trabajo de enfermería de la Sociedad Española de Reumatología (SER). El cuestionario se elaboró tras revisión bibliográfica y experiencias de proyectos previos de la SER. El cuestionario consta de 7 apartados: consideraciones generales, estándares de estructura, de proceso, de tratamiento y seguimiento, educación sanitaria, formación e investigación y calidad asistencial. Cada ítem se puntuó de 1 (menos importante) a 9 (más importante) o mediante una cifra. El grado de acuerdo de los expertos se categorizó según el coeficiente de variación (CV) entre muy alto ($CV \leq 25\%$) y muy bajo ($CV > 100\%$).

Resultados: El cuestionario de la segunda ronda (182 ítems) fue respondido por 46 panelistas (34 reumatólogos y 12 enfermeras). Se obtuvo un grado de acuerdo muy importante en los estándares generales, de estructura, de proceso, de tratamiento y seguimiento, educación sanitaria y calidad asistencial. Se encontró menor acuerdo en los estándares relacionados con el tiempo para formación, número de proyectos de investigación propios de enfermería y de publicaciones recomendables.

Conclusión: Los estándares desarrollados en este estudio permitirían establecer mínimos deseables de calidad de estructura, proceso, labor asistencial, investigadora y docente que se pueden utilizar para desarrollar y evaluar CERs.

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Introduction

Nursing consultations in rheumatology (NCR) are organizational patient-centered models of care in the field of rheumatology nursing skills. NCRs have been developed in recent years, but their implementation in Spain is still piecemeal. There are various models of NCR but there is no operational definition. Although there is little scientific evidence, one might assume that the NCR optimize each professional skill and contribute to improve the efficiency and quality of care by decreasing costs, especially medical, improving outcomes and quality of life effectiveness and perceived patient outcomes. Given the difficulty to find a definition of NCR in the existing literature and its potential relevance to quality of care, we designed this research project with the overall aim of contributing to the operational definition of an NCR and advance the exploration of those aspects of care, teaching and research of the NCR that could help measure quality.

To address this, Delphi rounds were considered the most appropriate method by experts in the field. The Delphi method was initially developed by the Rand Corporation in the United States to make provisions on military matters after World War II. It has subsequently been used in various areas, both as a predictive tool or as a prioritization strategy formulation.^{1,2} The objective of this technique is to improve judgments and forecasts on issues where there is uncertainty through expert opinion. It is based on the idea that the degree of consensus reached among a group of experts who are familiar with the topics under study gives a very rough idea of the actual size of these items.³ This technique is very useful to know a problem when it cannot be addressed with experimental approaches. The Delphi technique has been used in a variety of health-related studies. For example, it has been used to make predictions,^{4–7} prioritize design strategies,^{8–12} and especially to develop standards of quality of care and appropriate use of medical technology.^{13–20} This method was designed for this project, which aims to develop quality criteria and standards for defining and characterizing the NCR.

Methods

The project was an initiative of the Nursing Task Force of the Spanish Society of Rheumatology (GTESER), carried out by a

scientific committee (CC) consisting of 10 rheumatologists and 3 nurses. In addition, two experienced researchers participated in the methodology design. The project development schedule is shown in Fig. 1.

After defining the objectives of the project, we developed a specific questionnaire addressed to experts in the field, to be applied by Delphi methodology. Basically, the Delphi method is carried out through a series of rounds in each of which questionnaires are distributed with specific questions made to a panel of experts who score their opinions on a quantitative scale. In the second round, and the following if any, experts receive “feedback” on the scores of the rest of the group (in the form of the mean score for each question) and have the opportunity to review and change their score if they wish. The process ends when it is considered that it has reached a certain level of consensus or that the information obtained is sufficient. This method ensures the anonymity of responses for each respondent (each responder knows what he has responded, how many have responded to what question, but does not know who has answered what). The anonymity of responses prevents the group from being dominated by powerful or vehement individuals, which sometimes are characteristics not necessarily associated to knowledge. In addition, one of the strengths of the Delphi method is that it identifies the degree of agreement, but does not force consensus, but rather weights the views expressed by the number of respondents and the intensity of their responses.

In this project, we used the Delphi method for 2 rounds, with the distribution of questionnaires via email. To prepare the questionnaire for the first round, we constructed a list of features that could describe an NCR or standards that should be met. To do this, we started from the results and experiences of several SER projects: SERAP,²¹ ESPERANZA,²² EMAR²³ from clinical practice guidelines of the SER^{24,25} and publication of standards of quality of care in rheumatology.¹⁵ The list of features or standards are grouped into the following sections: (1) initial considerations, (2) structural standards, (3) process standards, (4) treatment and monitoring, (5) health education; (6) training/research by the nursing staff of the NCR, and (7) quality of care.

This produced a first draft of the questionnaire sent to members of the CC to verify the relevance of the items, that the statement was not ambiguous and that the way to answer them was appropriate. With the contributions of the CC, the final questionnaire was desig-

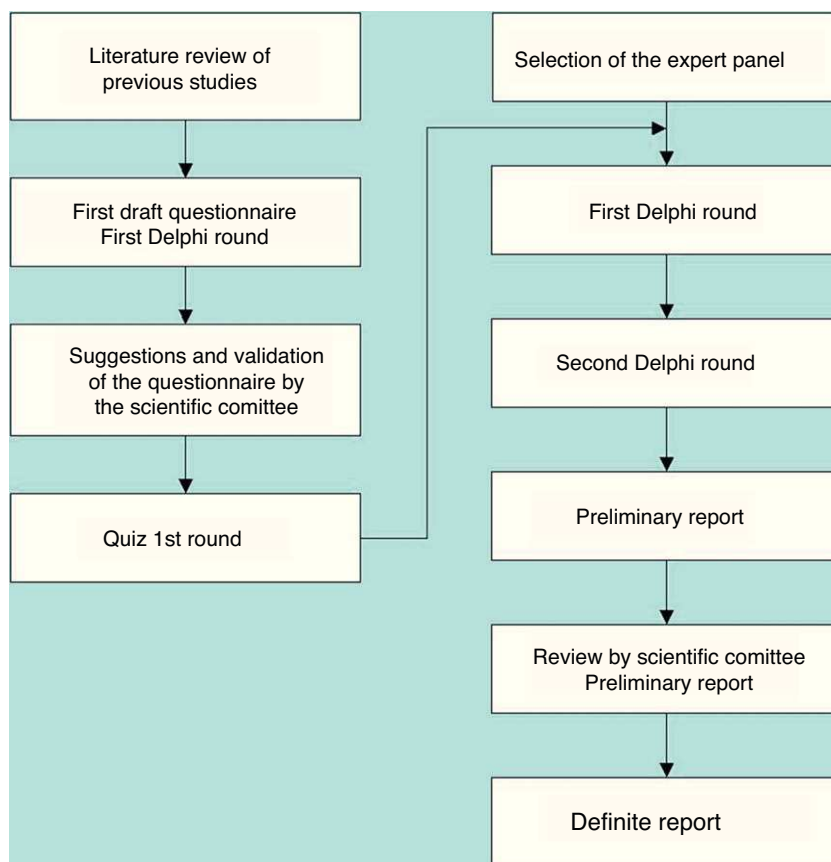


Fig. 1. Overview of the development of the project.

ned during the first round consisting of 159 items grouped into 7 sections above, and within each section, grouped according to the type of response.

To respond to the questionnaire, a panel of 13 members of the CC and 54 experts (rheumatologists and nurses) was formed.

To rate indicators, the Delphi method was used for 2 rounds.⁸ Each panelist received by email, in October 2010, an Excel workbook with 3 sheets: (1) introduction and explanation of the project, (2) instructions on how to complete the questionnaire, and (3) the questionnaire of the first round. They set a deadline of 15 days in order to respond to it.

For each of the indicators, the panelists rated a number, depending on the chosen indicator. Sometimes they had to rate on a scale of 1–9 (1=not important and 9=very important), according to the importance they attached to the statement regarding this item. At other times, they were asked to quantify the value of an indicator (e.g. the maximum number of people per nurse at the NCR). To develop the questionnaire for the second round, a descriptive analysis was performed by calculating the mean and standard deviation (SD) of the responses of each indicator. This analysis produced a specific sheet in Excel format, for each of the panelists. This sheet included, for each indicator, the mean, SD and the answer the panelist gave in the first round. Therefore, there were as many different questionnaires as panelists responded to the first round. In addition, with the suggestions given by the panelists in the first round, the final questionnaire was prepared for the second round.

On December 17, 2010, we emailed the questionnaire of the second round to the panelists who responded to the first. This questionnaire consisted of 182 items. Each group included scores (mean and SD) and the actual score of the first round. Each panelist was asked to score points over each item and could maintain the same

score of the first round, or modify it.^{13–15} The panelists were given 15 days to respond.

After receiving the scores, we performed statistical analysis of the second round of ratings. To categorize the variability in responses and its opposite (the agreement), we used the coefficient of variation (CV) categorized with the following breakpoints: CV less than or equal to 25%=very low variability (high agreement), CV greater than 25% and less than or equal to 50%=low variability (high agreement), CV greater than 50% and less than or equal to 75%=average variability (medium agreement), CV greater than 75% and less than or equal to 100%=high variability (low agreement), and greater than 100% CV=very high variability (very low agreement).

Due to the circumstances of this study, which only reflects the views of health professionals and patients, it was not submitted for review by the ethics committee.

Results

Of the 67 panelists initially contacted for the first round of the study, responses were received from 49 (73%): 37 rheumatologists (71%) and 12 nurses (92%).

Of these, 46 panelists (34 rheumatologists and 12 nurses) from 12 Spanish autonomous communities responded to the second round (93% of respondents from the first round).

In Tables 1–7 specifies the items distributed in each domain, with their average score, SD, median, minimum, maximum, CV and degree of agreement.

In the items related to general considerations (Table 1) it is worth highlighting the very high degree of agreement in all cases. The panelists believe that an NCR is needed in the Rheumatology department and that it contributes to improving quality of care,

Table 1
Standards on NCR Initial Considerations (Scale of 1–9).

Standard	Mean	SD	Median	Lo	Hi	CV, %	Agreement
An NCR is needed in a department of Rheumatology	8.4	0.9	9.0	6.0	9.0	10.2	Very high
NCR help improve the quality of care in Rheumatology	8.4	0.7	8.0	7.0	9.0	8.1	Very high
NCR help improve waiting times in Rheumatology	7.8	1.0	8.0	6.0	9.0	12.5	Very high
NCR improve the use of resources in the department (cost/effective)	7.9	1.1	8.0	5.0	9.0	13.7	Very high
NCR reduce costs in the department	7.3	1.4	7.0	4.0	9.0	18.7	Very high
NCR improve clinical outcomes in patients	7.8	1.0	8.0	5.0	9.0	13.2	Very high
NCR improve patient satisfaction	8.2	0.8	8.0	6.0	9.0	9.9	Very high

waiting times, resource use, costs, clinical outcomes and patient satisfaction.

Regarding structural standards (Table 2), this showed less agreement on the need for a crash cart (Table 2.1, subcategory of equipment) and the maximum number of people per NCR in a health area and for every nurse (Table 2.3, subcategory of population). There was a very high agreement on standards relating to the training the nurses should have to administer different questionnaires, especially the visual analog scale (VAS) and the *Health Assessment Questionnaire* (HAQ) and metrology training in rheumatoid arthritis regarding the *Disease Activity Score 28* (DAS28) and the *Bath Ankylosing Spondylitis Ankylosing Spondylitis Disease Activity Index* (BASDAI) and the *Bath Ankylosing Spondylitis Functional Index* (BASFI).

In the items related to process standards we found a very high degree of agreement in all those included in the subcategories of Tables 3.1–3.3, except for the minimum number of days per week that the NCR should be available (Table 3.2)

and the need for an appointment reminder to the patient the previous day (Table 3.3). As can be seen in Table 3.5, regarding the time of visit standards, we found a much lesser degree of agreement according to numerous items, highlighting a very low agreement in the minimum estimated time before scheduling appointments.

The items related to standards of care and follow-up (Table 4) and health education (Table 5) had a very high degree of agreement except an agreement only measured as high in “nursing training in relaxation techniques for application to patients” (Table 5).

The items in Table 6, relating to training and research standards, had a greater variability, being medium, low or very low in those regarding days required for continuing education and auxiliary nursing, number of research projects by nursing and number of national publications, respectively. For all other items there was a very high degree of agreement.

The items related to care quality standards (Table 7) had a very high agreement, except the maximum time to resolve claims, the

Table 2
Structure Standards.

2.1. Equipment/Materials in an NCRC (Scale of 1–9)							
Standard	Mean	SD	Median	Lo	Hi	CV, %	Agreement
Office	8.4	0.8	9.0	7.0	9.0	9.2	Very high
Computer	8.4	0.7	8.5	6.0	9.0	8.9	Very high
Phone	8.7	0.5	9.0	7.0	9.0	6.0	Very high
Specialized software	7.4	1.1	7.5	5.0	9.0	14.9	Very high
Databases	7.6	1.1	8.0	5.0	9.0	14.0	Very high
Educational material for patients	8.7	0.5	9.0	7.0	9.0	5.9	Very high
Sphygmomanometer	8.6	0.6	9.0	7.0	9.0	7.2	Very high
Scale to weigh and measure patients	8.6	0.7	9.0	6.0	9.0	8.0	Very high
Crash cart	5.4	1.9	6.0	1.0	9.0	35.2	High
The location of the NCR must be within the Rheumatology department, next to that of the rheumatologists	8.7	0.5	9.0	7.0	9.0	6.2	Very high
2.2. Personal/Competency in an NCR (Scale of 1–9)							
Standard	Mean	SD	Median	Lo	Hi	CV, %	Agreement
<i>The NCR nursing staff should be trained to perform:</i>							
Visual analog scale	8.8	0.4	9.0	8.0	9.0	4.9	Very high
Functional capacity Questionnaire: HAQ	8.8	0.4	9.0	8.0	9.0	4.7	Very high
Painful joint count	7.9	1.3	8.0	4.0	9.0	15.8	Very high
Swollen joint count	7.9	1.3	8.0	4.0	9.0	16.5	Very high
RADAI	7.5	1.5	8.0	3.0	9.0	19.9	Very high
BASFI	8.3	1.0	9.0	4.0	9.0	11.6	Very high
BASDAI	8.5	0.7	9.0	7.0	9.0	7.7	Very high
DAS 28	8.0	1.1	8.0	5.0	9.0	13.4	Very high
SDAI	7.7	1.3	8.0	4.0	9.0	16.5	Very high
CDAI	7.5	1.3	7.0	4.0	9.0	17.2	Very high
BASMI	7.6	1.5	8.0	4.0	9.0	19.4	Very high
Generic health questionnaires (e.g. EuroQoL, SF-12)	8.2	0.9	8.0	6.0	9.0	10.7	Very high
2.3. Population Needed to Establish an NCR (Continuous Variable)							
Standard	Mean	SD	Median	Lo	Hi	CV, %	Agreement
Maximum number of people per NCR in a health area	212 614	76 177	200 000	50 000	400 000	35.8	High
Maximum number of people per NCR nurse	165 833	85 675	150 000	20 000	400 000	51.7	Intermediate
Maximum number of rheumatologists who share an NCR nurse	3.9	1.0	4.0	2.0	6.0	24.8	Very high

Table 3
Processing Standards.

3.1. NCR Nurse (Scale of 1–9)							
Standard	Mean	SD	Median	Lo	Hi	CV, %	Agreement
Apply protocols for the management of rheumatology patients	8.1	1.0	8.0	5.0	9.0	12.0	Very high
Established communication circuits between the NCR nursing staff with the rheumatologist, physiotherapist, occupational therapist, psychologist, social worker	8.0	0.9	8.0	5.0	9.0	11.1	Very high
Participate in regular meetings with other health professionals (rheumatologist, physiotherapist, occupational therapist, psychologist, social worker)	7.9	1.2	8.0	4.0	9.0	14.9	Very high
Interact with PC physicians	6.8	1.4	7.0	4.0	9.0	21.2	Very high
Interact with PC nurses	7.5	1.4	8.0	4.0	9.0	18.3	Very high
Participates with other departments and a multidisciplinary service team	7.4	1.4	8.0	3.0	9.0	19.2	Very high
Participates in interdepartmental multidisciplinary teams with PC	6.8	1.5	7.0	3.0	9.0	21.7	Very high
Keeps track of the patients treated	8.4	0.9	9.0	5.0	9.0	10.5	Very high
Has own agenda	8.5	1.0	9.0	4.0	9.0	11.6	Very high
3.2. Availability of NCR Appointments (Continuous Variable)							
Standard	Mean	SD	Median	Lo	Hi	CV, %	Agreement
The availability of appointments in the NCR should be immediate (days/week)	3	2	3.0	1.0	10.0	44.9	High
3.3. Essential Assistance Nursing Activities in an NCR (Scale of 1–9)							
Standard	Mean	SD	Median	Lo	Hi	CV, %	Agreement
<i>Overall health assessment by the patient (VAS)</i>	8.5	0.8	9.0	5.0	9.0	9.5	Very high
<i>VAS pain</i>	8.5	0.8	9.0	5.0	9.0	9.8	Very high
<i>Rate the quality of life of patients through questionnaires (e.g. Euroqol 5 D, SF-12)</i>	8.2	1.0	8.0	4.0	9.0	12.8	Very high
<i>Collaboration with doctor in: arthrocentesis/infiltration</i>	8.2	1.2	9.0	3.0	9.0	14.9	Very high
<i>Resolution of unsolicited consultations</i>	8.0	1.1	8.0	5.0	9.0	13.2	Very high
<i>Emotional support to patients and families</i>	7.9	1.2	8.0	4.0	9.0	14.7	Very high
<i>Advice regarding nutrition, exercise</i>	8.3	0.9	8.5	5.0	9.0	10.4	Very high
<i>Telephone Support</i>	8.6	0.5	9.0	7.0	9.0	6.2	Very high
<i>Registration of nursing performance</i>	8.5	0.8	9.0	5.0	9.0	9.5	Very high
<i>Health education to patients and families</i>	8.7	0.6	9.0	7.0	9.0	6.4	Very high
<i>Patient appointment reminder on the previous day</i>	5.3	1.8	5.0	1.0	9.0	33.1	High
<i>Mantoux and Booster during the NCR query itself</i>	7.4	1.7	8.0	1.0	9.0	22.4	Very high
<i>Participation in additional examinations (muscle biopsy of subcutaneous fat)</i>	7.4	1.3	7.5	5.0	9.0	17.2	Very high
<i>Administering alidated patient self-management and self-efficacy questionnaires and initiating contact with the NCR and periodical follow ups (e.g. Self-efficacy scale for arthritis)</i>	7.7	1.0	8.0	4.0	9.0	13.5	Very high
<i>For patients with rheumatoid arthritis</i>							
Assessment of disease activity: RADA1	7.6	1.3	8.0	3.0	9.0	16.6	Very high
Collaboration with doctor in the assessment of disease activity: DAS28	7.9	1.1	8.0	4.0	9.0	14.2	Very high
Assessment of disease activity with DAS28	7.8	1.3	8.0	4.0	9.0	17.3	Very high
Assessment of disease activity with the SDAI	7.5	1.3	8.0	4.0	9.0	17.4	Very high
Assessment of disease activity with CDAI	7.3	1.4	7.0	4.0	9.0	18.7	Very high
functional capacity evaluation: HAQ	8.3	0.9	9.0	6.0	9.0	11.1	Very high
number of painful joints	7.7	1.4	8.0	3.0	9.0	18.5	Very high
number of swollen joints	7.5	1.5	8.0	3.0	9.0	20.3	Very high
<i>For patients with ankylosing spondylitis</i>							
Assessment of disease activity: BASDAI	8.4	0.8	9.0	6.0	9.0	9.5	Very high
functional capacity evaluation: BASFI	8.3	0.7	8.0	6.0	9.0	8.8	Very high
Collaboration with the performance of BASMI with the rheumatologist	7.8	1.2	8.0	5.0	9.0	15.1	Very high
<i>For patients with osteoarthritis</i>							
Individual information	7.5	1.3	8.0	5.0	9.0	17.4	Very high
Information in patient groups	7.4	1.4	8.0	1.0	9.0	19.0	Very high
Information on physical measures (hot-cold)	7.7	1.1	8.0	5.0	9.0	14.8	Very high
<i>For patients with chronic low back pain</i>							
Individual information	7.7	1.3	8.0	5.0	9.0	16.9	Very high
Information in patient groups	7.3	1.5	8.0	1.0	9.0	20.4	Very high
Recommendations and individualized advice on exercise and posture	7.7	1.3	8.0	5.0	9.0	17.2	Very high
Recommendations to groups of patients on exercise and posture	7.4	1.4	8.0	1.0	9.0	18.5	Very high
<i>For patients with osteoporosis</i>							
Individual information	7.7	1.2	8.0	5.0	9.0	15.8	Very high

Table 3 (Continued)

3.3. Essential Assistance Nursing Activities in an NCR (Scale of 1–9)							
Standard	Mean	SD	Median	Lo	Hi	CV, %	Agreement
Information in patient groups	7.5	1.4	8.0	1.0	9.0	18.6	Very high
Recommendations for individualized home adequacy to prevent falls	7.7	1.2	8.0	5.0	9.0	15.8	Very high
Recommendations to patient groups on adequacy of home conditions to prevent falls	7.5	1.3	8.0	1.0	9.0	17.9	Very high
Completing the FRAX questionnaire	7.1	1.6	7.5	1.0	9.0	23.2	Very high
<i>For patients with lupus</i>							
Individual information	7.6	1.3	8.0	4.0	9.0	16.7	Very high
Information in patient groups	6.8	1.7	7.0	1.0	9.0	24.6	Very high
Completing the SLEDAI questionnaire or others	6.9	1.4	7.0	3.0	9.0	20.3	Very high
3.4. Recording the Activity of the NCR Nurse (Scale of 1–9)							
Standard	Mean	DESD	Median	Lo	Hi	CV, %	Agreement
Assessing the patient (e.g. Annotations of relevant variables, VAS)	8.5	0.8	9.0	4.0	9.0	9.8	Very high
Nursing diagnosis	7.6	1.5	8.0	3.0	9.0	19.1	Very high
Activity planning	8.2	1.1	8.0	3.0	9.0	12.9	Very high
Running the activity	8.2	1.0	8.0	3.0	9.0	12.6	Very high
Evaluation of the activity	8.1	1.1	8.0	3.0	9.0	13.1	Very high
Drug sheet	8.3	1.0	9.0	3.0	9.0	12.2	Very high
<i>Quality of information on patient history regarding:</i>							
Objectivity of information (without prejudice of value or personal opinions)	8.2	1.0	8.0	4.0	9.0	12.1	Very high
Readability	8.3	0.8	8.0	6.0	9.0	9.7	Very high
The facts should be recorded in a clear and concise manner	8.5	0.7	9.0	6.0	9.0	8.5	Very high
Date and time should be noted	8.6	0.7	9.0	6.0	9.0	7.6	Very high
Appropriate use of acronyms	8.3	0.8	8.0	6.0	9.0	9.1	Very high
Ensure confidentiality of patient data	8.8	0.6	9.0	6.0	9.0	6.5	Very high
<i>Complete information on the patient history and in:</i>							
NCR treatment protocols	8.1	1.4	8.5	2.0	9.0	17.7	Very high
Reports and statistics	7.7	1.4	8.0	2.0	9.0	18.4	Very high
Documentats regarding administrative assistance related to clinical processes	7.9	1.4	8.0	2.0	9.0	18.1	Very high
Nurse signature of all records	8.1	1.5	8.5	2.0	9.0	18.6	Very high
3.5. Standards of Medical Visitation Time (Continuous Variable)							
Standard	Mean	SD	Median	Lo	Hi	CV, %	Agreement
Minimum time duration of the first visit to the NCR (min)	25	6	24	15	45	25.5	High
Minimum time duration of the second visit to the NCR (min)	15	3	15	10	20	21.2	Very high
Minimum time duration of the successive visits to the NCR (min)	13	3	13	5	20	23.2	Very high
Maximum waiting time of the patient in the waiting room after the time of appointment before being seen by nurses (min)	24	9	25	10	60	34.8	High
Minimum time of a family information session (min)	15	5	15	5	30	36.3	High
Minimum time of a session of family health education (min)	18	6	18	3	30	34.1	High
Maximum hours of nursing consultation by a nurse/day	5.3	1.7	5.0	3.0	15.0	31.3	High
Maximum waiting time (days) for the first ordinary visit to the rheumatologist	25	10	25	10	60	37.8	High
Maximum time (days) to wait for the preferential first visit to the rheumatologist	10	6	7	2	30	62.5	Intermediate
Maximum waiting time (days) between the first visit to the NCR and the second visit	35	15	30	10	100	43.9	High
Maximum waiting time (days) for successive visits	63	25	60	15	120	39.0	High
In the NCR appointments should be programmed with a minimum of (months)	6.8	12.4	2.5	0.3	70.0	181.9	Very low
Percentage of weekly time nurse must be dedicated to assistance in the NCR	61	15	60	20	90	23.9	Very high
Number of patients per day/nurse	14	3	15	9	20	19.4	Very high
Average desirable ratio of successive nursing consultations per each new visit (over a period of one year)	4.2	1.6	4.0	2.0	10.0	38.9	High
Desirable frequency of multidisciplinary team and NCR staff (sessions/month)	3.5	1.2	4.0	1.0	8.0	35.0	High

Table 4
Treatment and Follow Up Standards (Scale of 1–9).

Standard	Mean	SD	Median	Lo	Hi	CV, %	Agreement
Continuous monitoring of patients according to drug protocol	8.3	0.9	9.0	5.0	9.0	11.1	Very high
Medication Management	8.3	0.8	8.0	6.0	9.0	9.1	Very high
Analytical control of protocolized treatments	8.4	0.9	9.0	4.0	9.0	11.1	Very high
Pharmacovigilance registration and monitoring of rheumatic disease related drugs	8.1	1.3	8.0	2.0	9.0	16.2	Very high
Provide and implement the monitoring protocol for biological and nonbiological disease modulating drugs	8.5	0.7	9.0	6.0	9.0	8.5	Very high
Patients with rheumatic diseases should have access to the NCR, where a nurse will be responsible for coordinating the multidisciplinary care required by the patient	7.5	1.7	8.0	2.0	9.0	22.7	Very high
Strategies to ensure the safety (adverse effects, interactions, incompatibilities, allergies)	8.4	0.9	9.0	4.0	9.0	10.8	Very high
Ask the patient about their adherence to treatment on each visit	8.5	0.8	9.0	6.0	9.0	9.2	Very high

maximum time for clinical queries and months the clinics should distribute questionnaires of perceived quality.

Discussion

To our knowledge, this is the first published study intended to clarify the features an NCR should have.

An important finding in this study was the high degree of agreement (CV<25%) achieved in most of the standards. Those related to initial considerations stand out as most important aspects considered, stating that the NCR is an essential component of Rheumatology departments and helps to improve the quality of care.

The structure standard underscores the need for the NCR to be located within the Rheumatology department. The most important minimum requirements are to have its own phone line, patient education materials, sphygmomanometer, and scales to weigh and measure patients. In addition, the NCR nursing staff should be trained primarily for the performance of the VAS, HAQ, DAS28, BASDAI and BASFI.

Within the structure standards, there was also good agreement in establishing the average maximum population (about 200 000 inhabitants) to justify establishing an NCR in a health area and the maximum number of rheumatologists who share an NCR nurse (3,

9). In contrast, the agreement was lower in deciding the average maximum population per nurse in an NCR (about 165 000 inhabitants).

In the standard process it is worth noting the high degree of agreement that exists in almost all of the items. In the section on the NCR nursing staff, the panelists considered essential that the nursing staff managed their own agenda, kept a patient registry, applied protocols for the management of patients with rheumatologic disease and coordinated communication with the rheumatologist, physical therapist, occupational therapist, psychologist and social worker. Furthermore, the availability of NCR appointments must be at least 3 days/week.

In point of care activities of NCR, health education to patients and families, telephone assistance, global health assessment by the patient (VAS), pain VAS assessment and recording different nursing activities are considered essential. In patients with rheumatoid arthritis, functional capacity assessment by the HAQ is considered necessary. For patients with ankylosing spondylitis, the most important is the assessment of disease activity through the BASDAI and functional capacity assessment using the BASFI. For patients with osteoarthritis, the most important care activities of nursing personnel in the NCR should be to provide information on physical measures (hot-cold) and provide information to patients on an individual basis. For patients with chronic low back pain, indi-

Table 5
Health Education Standards (Scale of 1–9).

Standard	Mean	SD	Median	Lo	Hi	CV, %	Agreement
Disease information	8.3	1.1	9.0	3.0	9.0	12.7	Very high
Information on diagnostic tests related to the disease	7.5	1.4	8.0	3.0	9.0	18.5	Very high
Drug Information	7.9	1.3	8.0	3.0	9.0	16.0	Very high
Training in self-medication	8.9)	0.3	9.0	8.0	9.0	3.8	Very high
Joint ergonomic measures	8.5	0.7	9.0	7.0	9.0	8.1	Very high
Help the patients to actively participate in the management of their disease	8.7	0.6	9.0	7.0	9.0	6.9	Very high
Health education for self-care	8.7	0.6	9.0	7.0	9.0	6.8	Very high
Information to contact patient associations	7.6	1.3	8.0	2.0	9.0	17.8	Very high
Explain precautions that the patient should take into account (e.g. fever, skin or mucosal ulcers)	8.7	0.7	9.0	6.0	9.0	8.2	Very high
Teaching patients treated to properly administer subcutaneous drugs through injection systems ("pens", etc.)	9.0	0.2	9.0	8.0	9.0	2.3	Very high
Provide immunization schedule	8.0	1.0	8.0	5.0	9.0	12.6	Very high
Verbal Education	8.3	1.2	9.0	2.0	9.0	14.1	Very high
Written education	8.3	0.8	8.0	6.0	9.0	9.1	Very high
Audiovisual information	7.0	1.4	7.0	2.0	9.0	19.9	Very high
Nurse training in relaxation techniques to apply to patients	6.3	1.9	7.0	2.0	9.0	30.0	High
Education of caregivers of patients with limited mobility	7.4	1.4	8.0	2.0	9.0	19.3	Very high

Table 6
Training Standards/Research of the NCR Nursing Staff.

Standard (continuous variable)	Mean	SD	Median	Lo	Hi	CV, %	Agreement
<i>Number of days for training (a year) for nurses (DUE)</i>	11	8	10	5	60	75.3	Low
<i>Number of days for training (a year) for nursing assistant</i>	8	13	6	1	90	153.1	Very low
<i>Minimum number of scientific NCR communications at conferences a year</i>	1	1	1	1	4	48.7	High
<i>Minimum number of NCR projects in the last five years</i>	3	2	3	1	10	60.2	Intermediate
<i>Minimum number of national NCR publications in the last five years</i>	2	1	2	1	5	57.1	Intermediate
<i>Minimum number of international NCR publications in the last 5 years</i>	1	1	1	1	4	44.7	High
<i>Among the research areas in which the NCR could participate we found (scale of 1–9)</i>							
Diagnostic and prognostic factors	6.7	1.4	7.0	2.0	9.0	20.7	Very high
Efficacy studies (clinical trials) of treatments	7.4	1.2	7.0	3.0	9.0	15.7	Very high
Efficacy studies (in practice) of treatments	7.6	1.1	8.0	3.0	9.0	14.0	Very high
Safety Observatories	7.8	0.9	8.0	5.0	9.0	12.0	Very high
Observatories adherence	8.3	0.7	8.0	6.0	9.0	8.4	Very high
Genetic testing: biological sampling and clinical information	7.7	1.1	8.0	5.0	9.0	13.7	Very high
Obtaining blood samples for clinical trials	8.6	0.6	9.0	7.0	9.0	6.8	Very high
Economic NCR assessment studies	7.3	1.4	8.0	2.0	9.0	19.7	Very high
<i>The following should be included among the NCR nursing staff training topics (scale of 1–9)</i>							
Advances in pharmacological and non-pharmacological treatments	8.3	0.9	8.5	5.0	9.0	10.4	Very high
Update on diagnosis	7.3	1.4	7.0	2.0	9.0	19.1	Very high
Update on measurement tools (DAS28, CDAI, HAQ)	8.3	0.8	8.5	6.0	9.0	10.1	Very high
Healthcare Management	6.4	1.5	6.0	3.0	9.0	24.1	Very high
Research Methodology	6.9	1.3	7.0	3.0	9.0	19.1	Very high
Stress Management for monitoring the patient	7.7	1.2	8.0	3.0	9.0	15.9	Very high
Coaching through motivational talks, seminars, workshops	7.5	1.2	8.0	3.0	9.0	16.4	Very high
Communication skills to promote kindness, understanding, empathy, sympathy, and creating a climate of trust	8.1	1.3	8.0	2.0	9.0	15.8	Very high
The NCR should be able to train nursing students and other professionals	7.9	1.4	8.0	1.0	9.0	18.2	Very high

Table 7
Quality Care Standards (Scale of 1–9).

Standard (Scale of 1–9)	Mean	SD	Median	Lo	Hi	CV, %	Agreement
<i>Perform audits on NCR activity and nursing registries</i>	7.1	1.4	7.0	2.0	9.0	19.7	Very high
<i>Perform NCR management indicators</i>	7.3	1.4	8.0	2.0	9.0	18.4	Very high
<i>Have strategies for managing complaints and claims</i>	7.5	1.1	8.0	3.0	9.0	14.7	Very high
<i>Evaluate the agreement of the assessments performed by nurses (e.g. DAS 28, RADAI) with specialists in Rheumatology in order for the results to be reliable</i>	8.0	1.3	8.0	2.0	9.0	17.0	Very high
<i>If there is little agreement in the assessment between nurses and rheumatologists, carry out joint evaluations to increase the level of agreement</i>	8.0	1.4	8.0	2.0	9.0	17.2	Very high
<i>Assess the satisfaction of patients</i>	8.5	0.7	9.0	7.0	9.0	7.7	Very high
<i>Issues to consider in the satisfaction survey of patients seen in the NCR</i>							
Care, kindness	8.4	0.7	8.5	7.0	9.0	7.8	Very high
Information provided by the nursing staff	8.7	0.6	9.0	7.0	9.0	6.7	Very high
Frequency of visits	7.4	1.3	7.0	2.0	9.0	17.6	Very high
Visits duration	7.4	1.4	7.0	2.0	9.0	19.0	Very high
Waiting time to first NCR visit	7.8	1.0	8.0	4.0	9.0	12.3	Very high
waiting time to be seen once in the NCR office	7.7	1.1	8.0	4.0	9.0	14.9	Very high
Doubt resolution	8.6	0.7	9.0	6.0	9.0	8.0	Very high
Accessibility	8.2	1.2	8.0	2.0	9.0	15.1	Very high
Telephone contact availability	8.5	0.8	9.0	5.0	9.0	8.8	Very high
physical space in which the query takes place	7.8	1.2	8.0	4.0	9.0	15.3	Very high
Privacy consultation of the	8.3	0.9	8.5	4.0	9.0	11.3	Very high
nursing Coordination with physician	8.7	0.7	9.0	5.0	9.0	7.8	Very high
<i>Standard (continuous variable)</i>							
Maximum time to resolve the claims of a patient in the NCR (days)	13	7	10	2	30	51.4	Intermediate
Maximum time to answer any questions a patient has in by the NCR clinic (h)	14	12	12	1	72	86.0	Low
Number of months the health quality questionnaires are received by patients of the NCR	10	4	12	3	24	36.3	High

vidualized information and individualized advice on exercise and posture are the most prominent. For patients with osteoporosis this also applies, as individualized information and recommendations on adequacy of housing to prevent falls are the most necessary. For patients with lupus, individualized information stood out. In all conditions individualized information by the nurse stands over group information.

Panelists considered as important those aspects related to the registry of the NCR nursing staff. The most important item was to note either in the medical record (patient history) or in a database, patient assessment, medication sheet, activity planning, implementation of the activity and its assessment. It is of utmost importance to ensure patient confidentiality of the data. Furthermore, the patient history should always note the date and time in a clear and concise manner. The nurse's signature must appear on all medical records. All this information should also complete NCR treatment protocols.

There was also a high degree of agreement for some of the time standards, but not for the whole. Of note was the 'very low' degree of agreement when asked how far in advance the patient should be able to make an NCR appointment. At this point, the panelists issued responses ranging between 0.3 and 70 months. The lack of agreement on this point may be due to different mechanisms established in each department to meet the urgent demands or preference of patients, and the unscheduled tasks and availability for first appointment of different professionals (e.g. residents, physicians, nursing staff, secretary). It is desirable that these responsibilities are well defined to avoid delays or redundancies in unscheduled care.

By studying the results of treatment and monitoring standards, the majority of opinions highlighted the need for a protocol for monitoring disease modulating biological and nonbiological drugs, and applying it. It is also very important to ask the patient for their adherence to treatment at each visit.

Among the NCR health education standards, the panelists believe that it is essential to teach patients treated with subcutaneous drugs to administer them properly and train when in self-medication.

In the block of training and research standards of the NCR staff, there is little agreement among the panelists on how to quantify the value of the indicators. The agreement is very low at the time of deciding the number of days per year of training for nursing assistants, standard on which the panelists ranged from a day to 90 days (mean: 8 days). In the case of nursing training days, and showing better agreement, it scored, on average, 11 days a year. This variability may be explained by the different professionals that made up the group of experts who participated in the study, rheumatologists and nurses belonging to GTESER.

There was more consensus in deciding the research and staff training issues of the NCR. The most valuable lines of research were to obtain blood samples for clinical trials and adherence protocols. The most needed training topics were considered advances in pharmacologic and nonpharmacologic treatments, as well as metrology tools update. It is essential that, with the gradual implementation of NCR units, rheumatologists actively engage nursing staff in research tasks, which are not limited to mere procedure performance. This means minimal training in research methodology as part of the skills to be acquired by any member of the service.

Finally, there was also a low level of agreement to quantify time standards on quality of care. The agreement is low when setting the maximum time to answer any questions from a patient by the NCR. This time ranges from a minimum of one and a maximum of 72 h. On the contrary, the agreement is highest in consideration to quality of care. The most important aspect of quality of care is to assess the satisfaction of patients. Among the most important

aspects to consider in the satisfaction survey of patients seen in the NCR, information provided by the nursing staff, coordination with the attending physician, resolution of doubts and ease/availability for contacting the NCR stand out.

Although for this project followed the most appropriate methodology for developing such standards, the study is not without limitations. For example, a possible limitation may arise from the representation of the panelists. To avoid this limitation, we sent the questionnaire to rheumatologists and nurses across the country. In the end, panelists from 12 regions and different types of services participated, and it seems unlikely that there is any significant bias in the selection on the panelists and the results derived from their scores.

Another limitation may arise from the lack of completeness of the standards. To avoid missing potentially relevant standards, we searched all those available in previous publications, including¹⁵ those of SER itself. With the identified standards, we developed a preliminary list of those that should have an NCR. This list was corrected and extended by SER researchers who had participated in other projects such as the SERAP and ESPERANZA programs. It is therefore unlikely that this list missed any relevant standards, although it is possible that new standards may be defined with increased attention on NCR and their numbers.

Another possible limitations in the development of standards may be due to the influence of the opinions of some experts over others. In this project, influence among panelists was avoided using the Delphi method, since interactions occur in the second round to maintain the anonymity of responses. This method has proved its worth in the development of standards similar to those in this study.^{14,26–30}

In any case, the standards developed in our study are quite consistent with recent recommendations made recently by the *European League Against Rheumatism* (EULAR) on the role of nurses in the management of chronic inflammatory arthritis.³¹

In conclusion, the definition of these standards may allow us to establish minimum desirable qualities in different dimensions, such as structure, process and outcome, both in clinical work and in research and teaching. The usefulness of these standards can be multiple, not only for health professionals but also in relationships with patients and patient organizations, institutions and health services and administration.

Ethical Responsibilities

Protection of People and Animals. The authors state that no experiments were performed on humans or animals.

Data Confidentiality. The authors state that no patient data appear in this article.

Right to Privacy and Informed Consent. The authors state that no patient data appear in this article.

Funding

Project undertaken by the Spanish Foundation of Rheumatology and sponsored by Abbott.

Conflict of Interest

Dr. D. Santiago Muñoz states the following conflicts of interest: advisorships with Roche, Celgene, and Pfizer. President of the Spanish Society of Rheumatology. Current Participation in clinical

trials or studies sponsored by UCB, Roche, Abbott, MSD, Bioiberica, Celgene, Pfizer and the Spanish Foundation of Rheumatology. The other authors declare no conflicts of interest.

Acknowledgments

We thank the panel of experts who responded to the Delphi questionnaires for their time and dedication in preparing their responses, without which this study would not have been possible.

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