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# Patients with rheumatoid arthritis facing sick leave or work disability meet varying regulations: a study among rheumatologists and patients from 44 European countries

Polina Putrik <sup>1</sup>, Sofia Ramiro <sup>2,3</sup>, Francis Guillemin,<sup>4</sup> Márta Péntek,<sup>5,6</sup> Francisca Sivera,<sup>7</sup> Tuulikki Sokka,<sup>8</sup> Maarten de Wit,<sup>9</sup> Anthony D Woolf,<sup>10</sup> Angela Zink,<sup>11</sup> Daina Andersone,<sup>12</sup> Florian Berghea,<sup>13</sup> Irena Butrimiene,<sup>14</sup> Sandra Brouwer,<sup>15</sup> Karen Cassar,<sup>16</sup> Paraskevi Charalambous,<sup>17</sup> Roberto Caporali,<sup>18,19</sup> Elena Deseatnicova,<sup>20</sup> Nemanja S Damjanov,<sup>21</sup> Axel Finckh,<sup>22</sup> Oliver FitzGerald,<sup>23</sup> Gerður Gröndal,<sup>24</sup> Nino Gobejishvili,<sup>25</sup> Piotr Gluszko,<sup>26</sup> Marco Hirsch,<sup>27</sup> Igor Jovanovic,<sup>28</sup> Jiří Vencovský,<sup>29</sup> Xavier Janssens,<sup>30</sup> Andras P Keszei,<sup>31</sup> Maria Kovarova,<sup>32</sup> Mart Kull,<sup>33,34</sup> Luís Cunha Miranda,<sup>35</sup> Miroslav Mayer,<sup>36,37</sup> Snezana Misevska - Percinkova,<sup>38</sup> Nevsun Inanc,<sup>39</sup> Oleg Nadashkevich,<sup>40</sup> Ingemar F Petersson,<sup>41,42</sup> Kari Puolakka <sup>43</sup>, Bernadette Rojkovich,<sup>44</sup> Helga Radner,<sup>45</sup> Fruzsina Szabados,<sup>46</sup> Gleb Slobodin,<sup>47</sup> Ivan Shirinsky,<sup>48</sup> Nikolay Soroka,<sup>49</sup> Prodromos Sidiropoulos <sup>50</sup>, Russka Shumnalieva,<sup>51</sup> Sekib Sokolovic,<sup>52</sup> Surayo Shukurova,<sup>53</sup> Argjend Tafaj,<sup>54</sup> Matija Tomšič,<sup>55</sup> Till Uhlig,<sup>56</sup> Suzanne M M Verstappen,<sup>57,58,59</sup> Annelies Boonen<sup>1</sup>

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For numbered affiliations see end of article.

## Correspondence to

Dr Polina Putrik, Rheumatology, Maastricht University, Maastricht, Netherlands; [polina.putrik@gmail.com](mailto:polina.putrik@gmail.com)

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## ABSTRACT

**Objectives** To describe and explore differences in formal regulations around sick leave and work disability (WD) for patients with rheumatoid arthritis (RA), as well as perceptions by rheumatologists and patients on the system's performance, across European countries.

**Methods** We conducted three cross-sectional surveys in 50 European countries: one on work (re-)integration and social security (SS) system arrangements in case of sick leave and long-term WD due to RA (one rheumatologist per country), and two among approximately 15 rheumatologists and 15 patients per country on perceptions regarding SS arrangements on work participation. Differences in regulations and perceptions were compared across categories defined by gross domestic product (GDP), type of social welfare regime, European Union (EU) membership and country RA WD rates.

**Results** Forty-four (88%) countries provided data on regulations, 33 (75%) on perceptions of rheumatologists (n=539) and 34 (77%) on perceptions of patients (n=719). While large variation was observed across all regulations across countries, no relationship was found between most of regulations or income compensation and GDP, type of SS system or rates of WD. Regarding perceptions, rheumatologists in high GDP and EU-member countries felt less confident in their role in the decision process towards WD ( $\beta=-0.5$  (95% CI  $-0.9$  to  $-0.2$ ) and  $\beta=-0.5$  (95% CI  $-1.0$  to  $-0.1$ ), respectively). The Scandinavian and Bismarckian system scored best on patients' and rheumatologists' perceptions of regulations and system performance.

**Conclusions** There is large heterogeneity in rules and regulations of SS systems across Europe in relation to WD

## Key messages

### What is already known about this subject?

- Rheumatoid arthritis (RA) has a high impact on functional ability and work participation.

### What does this study add?

- Large variation in social security regulations for sick leave and work disability for patients with RA was observed across countries.
- This heterogeneity cannot be explained by existing welfare regimes, European Union membership or country's wealth.

### How might this impact on clinical practice or future developments?

- Heterogeneity between countries regarding regulations for sick leave and work disability can affect patients' chances to return to work.
- These differences call for a platform to consider harmonisation of policies for patients with RA who experience restrictions in work participation.

of patients with RA, and it cannot be explained by existing welfare regimes, EU membership or country's wealth.

## INTRODUCTION

Rheumatoid arthritis (RA) is a chronic inflammatory joint disease that often starts during working life of

patients.<sup>1–3</sup> RA has a high impact on functioning and ability to participate in social roles.<sup>4,5</sup> Despite substantial improvements in treatment options in the last decades, still 20% of the patients are unable to continue to work in the first 3 years of disease and over 30% of patients become work disabled after 10 years.<sup>6–9</sup>

For patients, work disability (WD) implies exclusion from an essential role in society, but also loss of income and reduced economic self-sufficiency.<sup>5, 10</sup> To prevent individuals from poverty in case of WD, substitution of income has been introduced in some European countries in the 19th century. By now, most countries have some form of social security (SS) system in place to regulate income substitution. However, these systems are not uniform, as they have been shaped by national political and social developments throughout the 20th century. Policies targeted at income substitution balance between provision of a fair income, on one hand, and control of expenditures by restricting social security benefits only to individuals with specific levels of work restrictions, on the other hand.<sup>11</sup> More recently, the increasing economic burden of WD, and also the insight into social and health benefits of work participation stimulated in many countries stricter gate-keeping on the one hand and stronger employment support to enhance endurable work participation of persons with chronic disease on the other hand.<sup>12</sup>

SS arrangements have been suggested to result in differences in overall patterns of employment, WD and retirement.<sup>13, 14</sup> A recent worldwide multinational study (COMORA) has shown that lower economic wealth and human development of countries is associated with higher rates of unemployment and higher absenteeism.<sup>15</sup> Earlier, QUEST RA study has observed that in low gross domestic product (GDP) countries, people remain working with higher levels of disability and disease activity compared with high GDP countries.<sup>16</sup> The regulations around the sick leave and WD may be, at least partially, responsible for these differences; however, they have not been studied.

Policies with regard to work participation, however, go far beyond income substitution only. Criteria for access to WD benefits as well as levels of income substitution likely depend, among others, on economic, political and cultural factors. While the European Union (EU) and WHO accept the historical differences in the way health and social systems are organised and function in their member states, there is a universal agreement that differences should not result in inequalities in health and quality of life of people across nations.<sup>17</sup> It is unclear whether EU-member states achieved any degree of homogeneity in the key regulations around social policies with regards to WD. In addition to system-level factors, there is evidence that personal contextual and disease-related factors<sup>6, 18, 19</sup> influence the decision of an individual to take sick leave or apply for long-term WD.

The aim of this study was to describe and explore differences in formal regulations around sick leave and WD for patients with RA, as well as perceptions by rheumatologists and patients on the system's performance, across European countries. We hypothesised that (1) lower GDP countries have stricter rules with regard to obtaining WD and lower income substitution once WD is granted, (2) EU countries have more homogeneous regulations compared with non-EU countries, and (3) patients and rheumatologists in high GDP and EU-member states are more satisfied with the performance of the social security system.

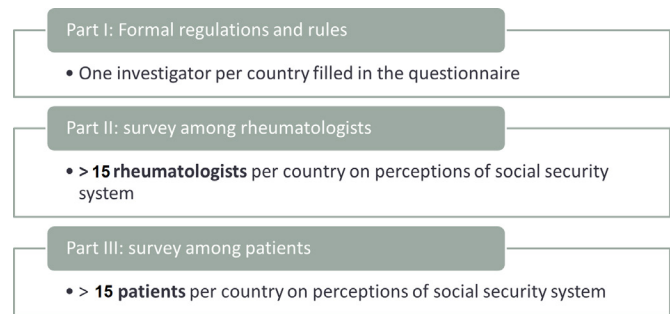


Figure 1 Study design.

## METHODS

### Design and framework

We conducted a cross-sectional observational study consisting of three surveys in 50 of the 53 countries of the European WHO Region (in three countries, no contact person could be found), in 2014–2016 (figure 1). The questionnaires were designed following the framework of access (originally applied in health-care<sup>20, 21</sup>), with three dimensions: (1) *availability* of re-integration plans or other systems/policies to facilitate work and/or prevent WD, as well as the eligibility criteria that a patient should meet to receive SS benefits; (2) *affordability*, that is, the level of income substitution granted in case of sick leave and permanent disability; (3) *acceptability*, that is, professional and individual perceptions of rheumatologists and patients, respectively, around the system performance on these issues.

### Participants

For each of the 50 European countries, one rheumatologist was invited as principal investigator (PI) to complete the questionnaire on SS arrangements in his/her country in case of sick leave and long-term WD due to RA (survey 1; availability and affordability). Additionally, each PI was asked to invite at least 15 rheumatologists (survey 2; acceptability) and at least 15 patients (survey 3; acceptability) to complete a questionnaire on professional and individual perceptions of the system. To recruit rheumatologists, PIs were instructed to ensure a diverse sample in terms of gender, years of professional experience and clinical setting. Patients could also be recruited via patient organisations and aimed at representing the spectrum of patients with RA, assuring that at least half of them had experience with (applying for a) WD pension.

### Questionnaires

The questionnaire for PIs addressed national regulations (in 2014) on benefits separately for sick leave and WD (online supplementary text S1a: availability and affordability), as well as calculations of the level of income for nine prespecified scenarios (vignettes), one on sick leave and two for long-term WD across the three levels of income (online supplementary text S1b). In countries where a patient research partner was available (n=21), he/she was invited to comment on any inconsistencies in the answers on the main questionnaire about the formal regulations. In this case, answers were double checked with the PI.

The questionnaire for rheumatologists (online supplementary text s2; acceptability) contained questions about perceptions on appropriateness of the SS arrangements, practical aspects of the application process for benefits and the role of rheumatologists in the process. The questionnaire for patients (online supplementary text S3; acceptability) addressed perceptions about the importance and adequacy of the existing arrangements. Additional questions

were included on age, gender and work environment (non-university hospital, university hospital, private practice, other) for rheumatologists; and on age, gender, disease duration, work status (paid work, no paid work but not work disabled, partially or fully work disabled) and history of sick leave and WD. The PI decided on whether questionnaires could be applied in English, otherwise translated them, wherever possible, with patient partners involved in checking the translation.

Data on GDP per capita (in international dollars, 2013) were extracted from the World Development Indicators report by the World Bank<sup>22</sup> and used as a continuous variable or dichotomised around the median (27 000 int.\$). The welfare regimes taxonomy included five groups, namely the Anglo-Saxon, Bismarckian, Mediterranean, Post-Communist and Scandinavian type of system.<sup>23</sup> Rates of WD among patients with RA have been collected by the QUEST-RA study (2009) and were available for 21 countries from our sample.<sup>16 24</sup>

### Statistical analysis

#### Arrangements to support work and SS regulations in case of sick leave or WD due to RA (questionnaire 1)

Collected data on formal rules and policies were first presented through descriptive statistics. To investigate whether the regulations differed by the type of welfare regime,<sup>23</sup> GDP, EU membership (EU-15, new EU-member states and non-EU countries) or were associated with country-level WD rates among patients with RA,<sup>16</sup> subgroup comparisons were performed using Pearson correlations, t-test/Mann-Whitney U test and  $\chi^2$ /Fisher's test, as appropriate.

#### Patients' and rheumatologists' perceptions of the SS system (questionnaires 2 and 3)

Answers of rheumatologists on their perspective of SS arrangements were summarised and scored (the higher is the better) around the two domains: (1) 'Performance of the system' (score 0–4) and (2) 'Role of the rheumatologists' (score 0–4). Additionally, a single item on the perceived standardisation in the decision-making process was analysed separately. Input from patients was summarised following three domains: (1) 'Importance and support to remain employed' (score 0–5); (2) 'Process of applying for WD' (score 0–4); (3) 'Obtaining and living with work disability pension' (score 0–6) (complete questionnaires are provided in online supplementary texts S2 and S3). Each domain consisted of four to six questions (each on a 1 (totally agree) to 5 (totally disagree) Likert scale, dichotomised as 1 ("totally agree") and 0 ("not agree/not disagree", "(totally) disagree"). The dichotomised scores per question were summed into the five domain scores (two for rheumatologists and three for patients).

Rheumatologists' and patients' characteristics were compared across the type of SS system, EU membership and GDP. Small numbers of surveyed patients and rheumatologists in each country hindered analyses of country-level means and thus were not related to national RA WD rates. The domain 'Importance and support to remain employed' was assessed in patients currently or ever having worked. Analyses in domains 'Process of applying for work disability' and 'Obtaining and living with work disability' were limited to patients currently work disabled or ever considered applying for WD.

Finally, we conducted multilevel (with individuals clustered in countries) multiple regression analysis with each of the domains as an outcome and type of SS system, EU membership or GDP

as the independent variable of interest. Models with patient perceptions as outcome were adjusted for age, gender, education, disease duration and ever having had sick leave due to RA. When rheumatologists' perceptions were the outcome, analyses were adjusted for age, gender and work setting.

### RESULTS

Forty-four (28 EU and 16 non-EU-member states) countries (88%) provided data on formal rules and regulations for sick leave and WD. Of these, 33 (75%) countries collected data from rheumatologists (n=539), and 34 (77%) countries collected data from patients (n=719) (missing countries were all non-EU members except Luxembourg).

#### Arrangements to support work and SS regulations in case of sick leave or WD due to RA

While nearly all countries had arrangements to support patients with restrictions to work, a large heterogeneity was observed in the type of arrangements (table 1, online supplementary tables S1–3). All except for 12 countries had facilities to support patients with RA in paid employment (n=32, 73%), but only in a quarter of countries (n=11, 25%) rehabilitation efforts were obligatory prior to the decision about long-term WD. Twenty-five (57%) and 30 (68%) countries had a requirement for employment history or social insurance contributions in order to be eligible for sick leave or long-term WD compensation, respectively. The maximum sick leave length before transition to long-term WD varied from 3 to 36 months (mean (SD) 13 (9)). In eight (18%) and five (11%) of the countries, participation of a rheumatologist was mandatory in the process of application or decision-making process on long-term WD, respectively. In addition to a functional assessment (degree of (dis)ability), prior profession (n=25 (57%) of countries), diagnosis (n=32 (73%)), earning capacity (n=12 (27%)), age (n=20 (45%)) and gender (n=5 (11%)) were reported to be accounted for when a decision was taken about (the degree of) WD. Prognosis, education and place of residence were mentioned as additional factors by few countries.

All countries except the former Yugoslav Republic of Macedonia, Bosnia-Herzegovina and Serbia reported to recognise partial WD, a status that partially substitutes income while the person can continue in (reduced) employment. Of the 26 countries providing data on income substitution, in eight countries (31%) income substitution (averaged over the first 6 months of disability) in case of sick leave was less than 70% of previous income. Income substitution averaged over the first 12 months of disability was less than 70% in 18 (69%) and 15 (58%) in case of moderate (partial) or severe (full) long-term disability, respectively (table 2). While wealthier countries as expected provided higher benefits in absolute terms, when converted to percentage of the previously earned income, no relationship was found between income compensation and neither GDP nor the type of SS system, or rates of WD. In richer countries and in countries with the Bismarckian type of welfare regime, the WD pension burden was more likely to be shared between SS and a private insurance, while countries with lower GDP and other welfare regimes had social insurance as the main source of WD allowances (data not shown). In countries with lower GDP, a rheumatologist was more frequently necessarily involved in the application and decision-making. Other aspects of the system revealed no statistically significant patterns with country-level characteristics or national WD rates.



**Table 1** Summary of social security regulations to support stay at work and work disability arrangements for persons with rheumatoid arthritis (RA)

Regulation	N (%)*	Anglo-Saxon	Scandinavian	Bismarckian	Mediterranean	Post-Communist
Support to stay at work						
Facilities for persons with RA that aimed at keeping the patient in paid employment are available	Yes 32 (73%) No 12 (27%)	IE, GB	DK, FI, IS, NO, SE	AU, BE, DE, IL, LU, CH, NL, FR	CY, IT, PT, GR, MT, ES, TR	AL, BY, BG, CR, CZ, IT, MK, MD, ME, PL, RO, RS, SK, SL, TJ, BA, EE, GE, HU, RU, LV, UA
Access to sick leave or short-term absence						
Requirement for length of previous employment AND/OR certain income earned AND/OR certain amount of social insurance tax paid in order to be eligible for sick-leave compensation	Yes 25 (57%) No 18 (41%)	IE, GB	DK, NO, SE, FI, IS	BE, FR, IL, CH, AU, DE, LU, NL	CY, GR, PT, ES, IT, MT, TR	AL, BY, BA, BG, HR, CZ, IT, MD, PL, RO, SK, TJ, EE, GE, HU, LV, MK, ME, RU, RS, SL, UA
The rheumatologist is authorised to certify short-term absence from work due to RA	Yes 33 (75%) No 10 (23%) Yes 11 (25%) No 32 (73%)	IE	DK, FI, IS, NO, SE	AU, BE, FR, DE, IL, LU, CH, NL	CY, GR, MT, PT, ES, TR, IT	AL, BY, BA, CZ, EE, HU, IT, MK, ME, PL, RO, RU, TJ, UA, BG, CR, GE, IV, MD, RS, SK, SL, CZ, EE, LV
First 1–3 days of sick leave are unpaid	Yes 35 (80%) No 8 (18%) Yes 10 (23%) No 31 (70%)	GB	DK, IS, SE	AU, FR, DE, IL, LU	CY, GR, IT, MT, PT, ES, TR	AL, BY, BG, CR, EE, IV, IT, HU, MK, MD, ME, PL, RO, RU, RS, SL, TJ, UA, BA, CZ, SK
Decision about long-term work disability						
Maximum length of sick leave before a WD can be granted	<12 months					
Is it obligatory that a rheumatologist is involved in application process (ie, providing information about the disease)?†	Yes 36 (82%) No 5 (11%)	IE, GB, SE	DK, FI, NO	BE, CH, NL, AU, BE, FR, IL, LU, CH, NL, DE	CY, GR, IT, MT, PT, ES, TR, GR, II, MT, PT, ES, TR	AL, BG, SK, TJ, BY, BA, CR, CZ, EE, HU, LV, IT, MK, MD, PL, RO, RS, SL, UA
Is the rheumatologist also in an obligatory way involved in the decision-taking about the long-term work disability? (ie, is part of the commission or expert committee)?†	Yes 11 (25%) No 32 (73%)	IE, GB	DK, FI, SE, NO, IS	AU, CH, NL, BE, FR, DE, IL, LU	CY, GR, IT, MT, PT, ES, TR	IT, MD, ME, RO, SL, AL, BY, BA, BG, CR, CZ, EE, HU, LV, MK, PL, RU, RS, SK, TJ, UA

European Union countries are in **bold**, high GDP (>27 000 int.\$, based on median) countries are underscored.

\*Data provided by 44 countries, Georgia reported to not have any effective social security system in place.

†Data missing for IS, ME.

AL, Albania; AT, Austria; BA, Bosnia and Herzegovina; BE, Belgium; BG, Bulgaria; BY, Belarus; CH, Switzerland; CY, Cyprus; CZ, Czech Republic; DE, Germany; DK, Denmark; EE, Estonia; ES, Spain; FI, Finland; FR, France; GE, Georgia; GR, Greece; HR, Croatia; HU, Hungary; IE, Ireland; IL, Israel; IS, Iceland; IT, Italy; LV, Lithuania; LU, Luxembourg; LV, Latvia; MD, Moldova; ME, Montenegro; MK, Macedonia (the former Yugoslav Republic of Macedonia); MT, Malta; NL, The Netherlands; NO, Norway; PL, Poland; RO, Romania; RS, Serbia; RU, Russia; SE, Sweden; SK, Slovakia; SL, Slovenia; TJ, Tajikistan; TR, Turkey; UA, Ukraine; UK, United Kingdom.

**Table 2** Income compensation in case of work disability for an employee with average income\*

Type of disability	Income compensation	Anglo-Saxon	Scandinavian	Bismarckian	Mediterranean	Post-Communist
In case of sick leave	≤70% of earned income	<b>IE</b>	–	<b>BE</b>	<b>CY, PT, TR</b>	<b>CZ, EE, SK</b>
	>70% of earned income	–	<b>FI, NO</b>	<b>LU, NL, SE</b>	<b>FR, IT, ES</b>	<b>BG, LT, LV, MD, PL, RO, RS, SL</b>
In case of moderate (50%) work disability†	≤70% of earned income	<b>IE</b>	<b>FI, NO</b>	<b>BE, SE, CH</b>	<b>CY, TR</b>	<b>BY, BG, CZ, EE, LV, LT, MD, PL, RO, RS, SK</b>
	>70% of earned income	–	–	<b>LU, NL</b>	<b>FR, IT, PT, ES</b>	AL
In case of severe (75%) work disability†	≤70% of earned income	–	<b>FI, NO</b>	<b>BE, LU, SE, CH</b>	<b>CY</b>	<b>CZ, EE, LV, LT, MD, PL, RO, RS, SK</b>
	>70% of earned income	<b>IE</b>	–	<b>NL</b>	<b>FR, IT, PT, ES, TR</b>	AL, BY, BG

European Union countries are in **bold**, high GDP (>27 000 int.\$, based on median) countries are underscored.

\*A person 50 years old recently diagnosed with rheumatoid arthritis, who is a citizen and has worked for 25 years full time.

†SL did not provide data for long-term work disability.

AL, Albania; BE, Belgium; BG, Bulgaria; BY, Belarus; CH, Switzerland; CY, Cyprus; CZ, Czech Republic; EE, Estonia; ES, Spain; FI, Finland; FR, France; IE, Ireland; IT, Italy; LT, Lithuania; LU, Luxembourg; LV, Latvia; MD, Moldova; NL, The Netherlands; NO, Norway; PL, Poland; PT, Portugal; RO, Romania; RS, Serbia; SK, Slovakia; SL, Slovenia; TR, Turkey.

### Rheumatologists' and patients' perceptions of SS system

In total, 539 rheumatologists (mean age (SD) 48 (10), 284 (53%) female, 278 (51%) working in university hospitals) from 33 countries filled in the questionnaires (online supplementary table S4). Scores on 'Role of the rheumatologists' (0–4) and 'Performance of the system' (0–4) ranged from 1.4 (SD 0.9) (Anglo-Saxon) to 2.4 (1.1) (Post-Communist) and 0.8 (0.9) (Anglo-Saxon) to 2.3 (1.2) (Scandinavian), respectively. Perceived level of standardisation around decision-taking revealed that only 26% (n=135) of rheumatologists consider decisions on WD to be objective. Of note, those who perceived standardisation as poor (vs good) scored worse on both 'Role of the rheumatologists' (–0.4 points) and 'Performance of the system' (–2.6 points) domains (t-test p value for both scores <0.05). Multilevel analyses revealed that rheumatologists in high GDP (vs low GDP) and EU-member (vs non-EU-member) countries felt less confident in having an active role in WD decisions ( $\beta = -0.5$  (95% CI –0.9 to –0.2)

and  $\beta = -0.5$  (95% CI –1.0 to –0.1), respectively). In addition, significant differences were observed across the system types with the Scandinavian type (Denmark, Iceland, Sweden, Norway, Finland) consistently scoring higher than the others on domains 'Importance and support to remain employed' and 'Process of applying for work disability pension' (table 4 and online supplementary table S5).

The patient sample consisted of 719 patients from 34 countries (mean age (SD) 53 (12), 76% female, 519 (78%) ever worked). The highest (=most satisfied) patient scores on all three domains were consistently observed in countries with Scandinavian and Bismarckian type of security system (table 3). In multilevel adjusted regression models, neither country wealth nor EU status were associated with patients' perceptions (table 4 and online supplementary table S5). The findings across the system type were notably consistent across patient and rheumatologist domains.

**Table 3** Patients' and rheumatologists' characteristics per type of security system

	Total	Anglo-Saxon	Scandinavian	Bismarckian	Mediterranean	Post-Communist	P value
Rheumatologists' characteristics (questionnaire 2)							
N of rheumatologists (N of countries)	539 (33)	22 (2)	58 (5)	88 (6)	87 (6)	284 (14)	
Role of the rheumatologists (0–4)	2.1 (1.1)	1.4 (0.9)	1.3 (0.9)	2.1 (1.3)	1.9 (1.0)	2.4 (1.1)	<0.001
Performance of the system (0–4)	1.5 (1.1)	0.8 (0.9)	2.3 (1.2)	2.0 (1.1)	1.1 (1.0)	1.4 (1.1)	<0.001
Patient characteristics (questionnaire 3)							
N of patients (N of countries)	719 (34)	47 (2)	60 (4)	137 (5)	119 (7)	356 (16)	
Importance and support to remain employed (0–5)	2.1 (1.2)	1.6 (0.8)	2.6 (1.2)	2.3 (1.4)	2.1 (1.2)	2.0 (1.1)	<0.001
Process of applying for work disability (WD) (0–4)	2.2 (1.8)	1.3 (1.8)	3.2 (3.0)	2.4 (1.9)	2.0 (1.6)	2.3 (1.7)	<0.001
Obtaining and living with WD pension (0–6)	1.1 (1.1)	0.7 (0.8)	1.2 (1.1)	1.2 (1.4)	1.0 (1.1)	1.1 (1.1)	0.22

Anglo-Saxon: UK, Ireland; Scandinavian: Denmark, Iceland, Sweden, Norway, Finland; Bismarckian: Austria, Belgium, Germany, France, Israel, Netherlands, Switzerland; Mediterranean: Cyprus, Greece, Italy, Portugal, Spain, Turkey; Post-Communist: Albania, Bulgaria, Czech Republic, Croatia, Estonia, Georgia, Hungary, Latvia, Lithuania, Poland, Romania, Russian Federation, Serbia, Tajikistan, Slovak Republic, Slovenia.

**Table 4** Patients' and rheumatologists' perceptions across several domains according to (1) GDP per capita purchasing power parity, (2) EU membership status and (3) type of social security system (models adjusted for sociodemographic confounders)

	Patients' perceptions (N of countries=34)*			Rheumatologists' perceptions (N of countries=33)*	
	Importance and support to remain employed (0–5) n=491	Process of applying for work disability pension (0–4) n=342	Obtaining and living with work disability pension (0–6) n=341	Performance of the system (0–4) n=390	Role of the rheumatologists (0–4) n=393
GDP per capita (int.\$) High vs low GDP	0.21 (–0.07 to 0.50)	0.39 (–0.20 to 0.98)	–0.09 (–0.44 to 0.25)	0.30 (–0.08 to 0.72)	–0.55 (–0.94 to –0.16)
EU membership EU vs non-EU member	0.20 (–0.14 to 0.53)	–0.41 (–1.10 to 0.29)	–0.16 (–0.57 to 0.26)	–0.12 (–0.56 to 0.32)	–0.54 (–0.95 to –0.13)
Type of system					
Scandinavian	Reference	Reference	Reference	Reference	Reference
Anglo-Saxon/liberal	–1.02 (–1.64 to –0.39)	–1.41 (–2.73 to –0.09)	–0.47 (–1.30 to 0.36)	–1.49 (–2.22 to –0.77)	–0.57 (–1.49 to 0.35)
Bismarckian/conservative	–0.40 (–0.90 to 0.10)	–0.74 (–1.84 to 0.40)	–0.04 (–0.73 to 0.65)	–0.41 (–0.94 to 0.12)	–0.39 (–1.09 to 0.31)
Mediterranean/southern	–0.56 (–1.06 to –0.07)	–1.29 (–2.33 to –0.25)	–0.20 (–0.86 to 0.46)	–1.19 (–1.70 to –0.69)	–0.11 (–0.78 to 0.56)
Post-Communist/eastern	–0.63 (–1.06 to –0.19)	–1.02 (–1.91 to –0.13)	–0.04 (–0.62 to 0.53)	–0.98 (–1.44 to –0.51)	0.21 (–0.40 to 0.83)

Coefficients are derived from separate multilevel multiple models (with individuals clustered in countries and each independent variable (ie, gross domestic product (GDP), European Union (EU) membership or type of system), adjusted for age, gender, education, disease duration and ever having had sick leave due to rheumatoid arthritis; analyses on the rheumatologist domains were adjusted for age, gender and work setting.

Statistically significant ( $p < 0.05$ ) regression estimates are in **bold**.

Anglo-Saxon: UK, Ireland; Scandinavian: Denmark, Iceland, Sweden, Norway, Finland; Bismarckian: Austria, Belgium, Germany, France, Israel, Netherlands, Switzerland;

Mediterranean: Cyprus, Greece, Italy, Portugal, Spain, Turkey; Post-Communist: Albania, Bulgaria, Czech Republic, Croatia, Estonia, Georgia, Hungary, Latvia, Lithuania, Poland, Romania, Russian Federation, Serbia, Tajikistan, Slovak Republic, Slovenia.

\*The higher the score, the more positive are the perceptions.

## DISCUSSION

To our knowledge, this is the first study to provide an extended overview of systems to support work or WD in RA. With regard to the system rules and regulations, that is, availability and affordability of WD arrangements, a large heterogeneity across countries was observed for most regulations including income compensation. While research and judgement on which system is preferable is complex and beyond the aim of this study, it is striking that a person with RA, on becoming disabled, will face very different perspectives on future work participation, depending on his/her country of residence. Only in a minority of countries work re-integration plans were obligatory before starting a procedure towards WD.

Despite important variation, we could not detect patterns explaining differences in the formal rules and regulations of the SS systems, with only few exceptions. We could not find support to our first hypothesis that lower GDP countries would have stricter rules around WD or lower relative income substitution when WD is granted, nor did we find any common features of systems in lower GDP countries or EU-member versus non-EU-member states. Moreover, the rules of the SS system did not seem to have a large role in explaining differences in WD in RA. Earlier research—mainly in general population and above 50 years of age in a number of European countries and dating back to 2007—suggested that the national SS system and, in particular, generosity of benefits explains a large proportion of between-country variations in disability rates.<sup>25</sup> We could not reproduce these results in our study among patients with RA. It is worth noting that data on WD rates in RA were available for 21 countries only and collected almost a decade earlier, and was based on a sample of patients rather than national statistics.<sup>16</sup>

In contrast to findings on formal regulations (availability and affordability), patients' and rheumatologists' perceptions of systems to support persons with RA encountering work restrictions (acceptability) showed an apparent variation according to the type of the social security system: the Scandinavian and

Bismarckian employment support and social security system consistently appeared to most adequately meet the expectations of patients and rheumatologists regarding remaining at work and application for a WD pension. At the same time, little differences were related to country's wealth or EU membership, and only a weak signal suggested that rheumatologists in lower-income countries are more confident in their role to support patient in WD issues. The latter may indicate that rheumatologists in low-income countries interact more intensively with patients on these issues and accept WD questions as part of their responsibility. Alternatively, other cultural and system factors could be considered, for example, patients referring to other professionals within the system (such as primary care or state agencies) for advice and support regarding WD decisions.<sup>26</sup> Overall, a lack of standardisation in the decision-making process on WD was reported by nearly three quarters of the rheumatologists, and reinforces earlier calls for efforts for standardisation and homogenisation.<sup>27</sup> Therefore, our third hypothesis that levels of satisfaction with the system is higher in EU-member states and higher GDP countries was not supported by the available data, while initial insight was generated with respect to the SS system type where no hypotheses were formed a priori.

This study has some notable limitations. First, the complexity of access to SS related to work and disability is hard to capture with a questionnaire that unavoidably simplifies reality. In absence of a validated tool to measure formal social security regulations and perceptions around the system performance, we used self-developed questionnaires. These happened in intensive collaboration with several international experts on work participation studies. We did not follow a formal translation procedure and the decision and responsibility to translate was left with the PI; however, the translations were double checked by patient partners. While government authorities would be the most knowledgeable parties to enquire about rules and regulations, the feasibility issues around establishing a direct contact with agencies from >30 European countries, in different languages,

and where they likely have little or no interest to contribute to a research project, the well-established network of rheumatologists active in research was approached instead. To improve data quality and accuracy, PIs were encouraged to seek help from other experts in their country; the summary was sent to available patient partners for a face-validity check of data in their country, and the results showed a good agreement. It is emphasised in the discussion that this study has an explorative nature and limited conclusions should be drawn.

We have to acknowledge that *application* of the formal rules and regulations can differ substantially from the formal rules, and hence patients in countries with similar rules could potentially have different experiences when rules are applied. For example, partial WD (which formally implies that a patient can work part of the time) may be a barrier to any employment in some countries and thus perceived differently compared with countries where patients deemed partially disabled are able to use their right for part-time work. We have attempted to get the initial insight into this through the surveys among patients and rheumatologists. Furthermore, it was challenging to select the best country-level characteristics that should be related to indicators of access. On this line, the SS system taxonomy used<sup>23</sup> is most likely an oversimplification of the complex systems that are constantly changing and developing, but to our knowledge, no alternative taxonomy exists. Recourse to (official) disability is a complex construct in which social security has a limited role. Alternative approaches to gain insight into international variation should be considered to study the performance and impact or social security systems. One of the potentially promising methods could consist of a series of clinical vignettes. By considering the rules and regulations that are to be applied to a hypothetical patient with given characteristics in terms of disease, work situation and disability, as well as attitudes and values about role of work in life and society, countries could be compared and further classified. Despite limitations, we present the first attempt to understand whether patterns in regulations can be found to help to understand differences in employment, sick leave and WD. We found differences in regulations and income substitution that are challenging our perceptions of equity and call for further research to justify them or for efforts to define the acceptable standards. Cost-effectiveness models in RA often count with an improvement of WD in parallel with the improvement of the health status of the patient (eg, Health Assessment Questionnaire-based Markov models). Our study suggests that large variations exist between countries regarding regulations of short-term absence or WD that can affect their chances to return to work, a point to consider in economic evaluations. Although we did not find clear relations between regulations and work participation rates, we should keep in mind the previous research that suggested that patients continue to work at different health status across countries.<sup>16</sup> As system type appears to have a rather limited impact on regulations and perceptions on them, this might indicate that interventions to support work retention in patients with RA could in principle be considered irrespective of SS system. Moreover, the ageing of the population worldwide urges policy-makers to increase the age of retirement, meaning that people with RA will also be expected to work longer in the years to come.

In conclusion, we observed large heterogeneity in rules and regulations of SS systems across Europe in relation to WD of patients with RA, and these cannot be explained by existing welfare regimes, EU membership or country's wealth. These differences call for a platform to consider harmonisation of policies for patients with RA who experience restrictions in work

participation. While remarkably little differences of patients' and rheumatologists' perceptions are related to country's wealth and membership in EU, Scandinavian employment support and SS system appears to most adequately meet the expectations of patients and rheumatologists regarding endurable work participation and access to WD pension.

#### Author affiliations

- <sup>1</sup>Internal Medicine, Division of Rheumatology, Maastricht University, CAPHRI and Maastricht University Medical Center (MUMC), Maastricht, The Netherlands
- <sup>2</sup>Rheumatology, Leiden University Medical Center, Leiden, The Netherlands
- <sup>3</sup>Rheumatology, Zuyderland Medical Center, Heerlen, The Netherlands
- <sup>4</sup>APEMAC unit, University of Lorraine, Nancy, France
- <sup>5</sup>Department of Health Economics, Corvinus University of Budapest, Budapest, Hungary
- <sup>6</sup>Rheumatology, Flór Ferenc County Hospital, Kistarcsa, Hungary
- <sup>7</sup>Rheumatology, Hospital General Universitario de Elda, Alicante, Spain
- <sup>8</sup>Department of Medicine, Jyväskylä Central Hospital, Jyväskylä, Finland
- <sup>9</sup>Medical Humanities, Amsterdam University Medical Centre, Amsterdam, The Netherlands
- <sup>10</sup>Rheumatology, Royal Cornwall Hospital, Truro, UK
- <sup>11</sup>Epidemiology, German Rheumatism Research Centre and Rheumatology, Charité University Medicine, Berlin, Germany
- <sup>12</sup>Rheumatology, Pauls Stradina Clinical University Hospital, Riga, Latvia
- <sup>13</sup>Department of Internal Medicine and Rheumatology, Carol Davila University of Medicine and Pharmacy, Bucharest, Romania
- <sup>14</sup>Clinic of Rheumatology, Orthopedics Traumatology and Reconstructive Surgery, Institute Clinical Medicine, Vilnius University, Vilnius, Lithuania
- <sup>15</sup>Department of Community and Occupational Medicine, Groningen UMC, Groningen, The Netherlands
- <sup>16</sup>Faculty of Medicine and Surgery, University of Malta, Msida, Malta
- <sup>17</sup>Cyprus Society for Rheumatology, Nicosia, Cyprus
- <sup>18</sup>IRCCS Policlinico San Matteo Foundation, Pavia, Italy
- <sup>19</sup>Department of Clinical Sciences and Community Health, University of Milan, Milan, Italy
- <sup>20</sup>Rheumatology, State Medical and Pharmaceutical University Nicolae Testemitanu, Chisinau, Moldova (the Republic of)
- <sup>21</sup>Rheumatology, University of Belgrade School of Medicine, Belgrade, Serbia
- <sup>22</sup>Division of Rheumatology, University Hospital of Geneva, Geneva, Switzerland
- <sup>23</sup>Rheumatology, St Vincents University Hospital, Dublin, Ireland
- <sup>24</sup>Center for Rheumatology Research, Landspítali University Hospital, Reykjavik, Iceland
- <sup>25</sup>Rheumatology, Health Center of Georgia, Tbilisi, Georgia
- <sup>26</sup>Department of Rheumatology, National Institute of Geriatrics, Rheumatology and Rehabilitation, Warsaw, Poland
- <sup>27</sup>Rheumatology, Hôpitaux Robert Schuman, Luxembourg, Luxembourg
- <sup>28</sup>Rheumatology, Filipovic polyclinic, Podgorica, Montenegro
- <sup>29</sup>Institute of Rheumatology and Dept. of Rheumatology, 1st Medical Faculty, Charles University, Prague, Czech Republic
- <sup>30</sup>Rheumatology, Ghent University Hospital, Ghent, Belgium
- <sup>31</sup>Center for Translational & Clinical Research Aachen (CTC-A), Medical Faculty RWTH Aachen University, Aachen, Germany
- <sup>32</sup>Rheumatology, St.CM University, Trnava, Slovakia
- <sup>33</sup>Rheumatology, Tartu University, Tartu, Estonia
- <sup>34</sup>Internal Medicine, Viljandi Hospital, Tartu, Estonia
- <sup>35</sup>Rheumatology, Portuguese Institute of Rheumatology, Lisbon, Portugal
- <sup>36</sup>Division of Clinical Immunology and Rheumatology, Department of Internal Medicine, University Hospital Centre Zagreb, Zagreb, Croatia
- <sup>37</sup>School of Medicine, University of Zagreb, Zagreb, Croatia
- <sup>38</sup>Rheumatology, University Rheumatology Clinic, Skopje, North Macedonia
- <sup>39</sup>Division of Rheumatology, Marmara University, School of Medicine, Istanbul, Turkey
- <sup>40</sup>Danylo Halytsky Lviv National Medical University, Lviv, Ukraine
- <sup>41</sup>Orthopedics, Clinical Sciences Lund, Lund University, Lund, Sweden
- <sup>42</sup>Skåne University Hospital, Lund and Malmö, Lund, Sweden
- <sup>43</sup>Department of Medicine, South Karelia Central Hospital, Lappeenranta, Finland
- <sup>44</sup>Rheumatology, Polyclinic of the Hospitalier Brothers of St. John of God, Semmelweis University, Budapest, Hungary
- <sup>45</sup>Internal Medicine III, Department of Rheumatology, Medical University Vienna, Vienna, Austria
- <sup>46</sup>Rheumatology, North Denmark Regional Hospital, Hjørring, Denmark
- <sup>47</sup>Rheumatology Unit, Bnai Zion Medical Center, Haifa, Israel
- <sup>48</sup>Laboratory of Clinical Immunopharmacology, Institute of Fundamental and Clinical Immunology, Novosibirsk, Russian Federation
- <sup>49</sup>Internal Medicine, Society of Internal Medicine of Belarus, Minsk, Belarus
- <sup>50</sup>Rheumatology, University of Crete School of Medicine, Heraklion, Greece



- <sup>51</sup>Clinic of Rheumatology, Department of Internal Medicine, Medical University, Sofia, Bulgaria
- <sup>52</sup>Rheumatology, Clinic of Heart and Rheumatic Diseases, Clinical Center University of Sarajevo, Sarajevo, Bosnia and Herzegovina
- <sup>53</sup>Internal Medicine, Medical Science Academy, Dushanbe, Tajikistan
- <sup>54</sup>Rheumatology clinic, Medical University Of Tirana, "Nene Tereza" Hospital, Tirane, Albania
- <sup>55</sup>Rheumatology, University Medical Centre Ljubljana, Ljubljana, Slovenia
- <sup>56</sup>Rheumatology, Diakonhjemmet Hospital, Oslo, Norway
- <sup>57</sup>Centre for Epidemiology Versus Arthritis, Centre for Musculoskeletal Research, Faculty of Biology, Medicine and Health, University of Manchester, Manchester Academic Health Science Centre, Manchester, UK
- <sup>58</sup>NIHR Manchester Biomedical Research Centre, Manchester University Hospitals NHS Foundation Trust, Manchester Academic Health Science Centre, Manchester, UK
- <sup>59</sup>Arthritis Research UK/MRC Centre for Musculoskeletal Health and Work, University of Southampton, Southampton, UK

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**Collaborators** Working group 'Working Group Access to Social Security for Patients with RA across Europe': Ermir Tafaj (Albania), Edi Rembeci (Albania), Saskia Decuman (Belgium), Anastasia Tushina (Belarus), Iva Miteva (Bulgaria), Šárka Forejtová (Czech Republic), Esben Toftegaard Knudsen (Denmark), Maxime Wach (France), Matthieu Mangin (France), Márta Fekete (Hungary), Antonella Celano (Italy), Grainne O'Leary (Ireland), Giedre Dereševiciene (Lithuania), Mona Thorekildsen (Norway), Leszek Roszkowski (Poland), Claudia Handra (Romania), Inessa Samko (Russia), Jenny Hubertsson (Sweden), Tapparel Ludovic (Switzerland), Zumrad Hamroeva (Tajikistan), Ilker Yagci (Turkey), Ana Zekovic (Serbia), James Anderson (UK)

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#### ORCID iDs

Polina Putrik <http://orcid.org/0000-0002-9342-1861>  
Sofia Ramiro <http://orcid.org/0000-0002-8899-9087>  
Kari Puolukka <http://orcid.org/0000-0003-1307-7421>  
Prodromos Sidiropoulos <http://orcid.org/0000-0001-9607-0326>

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