

# Exploring discordance between Health Literacy Questionnaire scores of people with RMDs and assessment by treating health professionals

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**TITLE:** Exploring discordance between Health Literacy Questionnaire scores of people with RMDs and assessment by treating health professionals

**AUTHORS:** Mark M. Bakker<sup>1,2\*</sup>, Polina Putrik<sup>1,2</sup>, Cédric Dikovec<sup>1</sup>, Jany Rademakers<sup>2,3</sup>, Harald E. Vonkeman<sup>4,5</sup>, Marc R. Kok<sup>6</sup>, Hanneke Voorneveld-Nieuwenhuis<sup>6</sup>, Sofia Ramiro<sup>7,8</sup>, Maarten de Wit<sup>9</sup>, Rachelle Buchbinder<sup>10,11</sup>, Roy Batterham<sup>12</sup>, Richard H. Osborne<sup>13</sup>, Annelies Boonen<sup>1,2</sup>

\* Corresponding author

Mark Matthijs Bakker

c/o Maastricht UMC+, Div. of Rheumatology

PO Box 5800

6202 AZ Maastricht, the Netherlands

Fax: +31 43 387 5006

Telephone: +31 43 387 5026

[mark.bakker@mumc.nl](mailto:mark.bakker@mumc.nl)

<https://orcid.org/0000-0002-8972-1300>

#### **AFFILIATIONS:**

<sup>1</sup> Dept. of Internal Medicine, Div. of Rheumatology, Maastricht UMC+, Maastricht, the Netherlands, <sup>2</sup> CAPHRI Care and Public Health Research Institute, Maastricht University, Maastricht, the Netherlands, <sup>3</sup> Nivel Netherlands Institute for Health Services Research, Utrecht, the Netherlands, <sup>4</sup> Dept. of Psychology, Health and Technology, University of Twente, Enschede, the Netherlands, <sup>5</sup> Dept. of Rheumatology and Clinical Immunology, Medisch Spectrum Twente, Arthritis Center Twente, Enschede, the Netherlands, <sup>6</sup> Dept. of Rheumatology and Clinical Immunology, Maasstad Hospital, Rotterdam, the Netherlands, <sup>7</sup> Dept. of Rheumatology, Leiden UMC, Leiden, the Netherlands, <sup>8</sup> Dept. of Rheumatology, Zuyderland Medical Center, Heerlen, the Netherlands, <sup>9</sup> Tools2Use Patient Association, Amsterdam, the Netherlands, <sup>10</sup> Dept. of Epidemiology and Preventive Medicine, School of Public Health and Preventive Medicine, Monash University, Melbourne, Australia, <sup>11</sup> Monash Dept. of Musculoskeletal Health and Clinical Epidemiology, Cabrini Health, Melbourne, Australia, <sup>12</sup> Faculty of Public Health, Thammasat University, Bangkok, Thailand, <sup>13</sup> Centre for Global Health and Equity, Swinburne University of Technology, Melbourne, Australia

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**ABSTRACT**

**Objectives:** We studied discordance between health literacy of people with rheumatic and musculoskeletal diseases (RMDs) and assessment of health literacy by their treating health professionals, and explored whether discordance is associated with the patients' socioeconomic background.

**Methods:** Patients with rheumatoid arthritis (RA), spondyloarthritis (SpA), or gout from three Dutch outpatient rheumatology clinics completed the nine-domain Health Literacy Questionnaire (HLQ). Treating health professionals assessed their patients on each HLQ domain. Discordance per domain was defined as a  $\geq 2$ -point difference on a 0-10 scale (except if both scores were below three or above seven), leading to three categories: "negative discordance" (i.e. professional scored lower), "probably the same", or "positive discordance" (i.e. professional scored higher). We used multivariable multilevel multinomial regression models with patients clustered by health professionals to test associations with socioeconomic factors (age, gender, education level, migration background, employment, disability for work, living alone).

**Results:** We observed considerable discordance (21 – 40% of patients) across HLQ domains. Most discordance occurred for "Critically appraising information" (40.5%, domain 5). Comparatively, positive discordance occurred more frequently. Negative discordance was more frequently and strongly associated with socioeconomic factors, specifically lower education level and non-Western migration background (for five HLQ domains). Associations between socioeconomic factors and positive discordance were less consistent.

**Conclusion:** Frequent discordance between patients' scores and professionals' estimations indicates there may be hidden challenges in communication and care, which differ between socioeconomic groups. Successfully addressing patients' health literacy needs cannot solely depend on health professionals' estimations but will require measurement and dialogue.

**KEYWORDS:** health literacy, professionals' estimations, discordance, socioeconomic status, health inequalities.

**KEY MESSAGES:**

- Discordance between patients' health literacy scores and professionals' assessment occurs frequently across HLQ domains.
- Low education and migration background are associated with negative discordance; patterns for positive discordance vary.
- Discordance and associated factors vary across HLQ domains, highlighting the multidimensional nature of health literacy.

**Video abstract**

## INTRODUCTION

Health literacy, a multidimensional concept defined as “*the combination of personal competencies and situational resources needed for individuals to access, understand, appraise and use information and services to make decisions about health*” which “*includes the capacity to communicate, assert and act upon these decisions*” [1], is increasingly recognised as a critical determinant of health [2] that should be considered in delivering appropriate health care to patients [3-5]. ‘Limited’ health literacy, indicating people’s difficulty with one or more dimensions of health literacy, is prevalent across the globe and concerns about one in every three adults in the Netherlands [6]. A clear social gradient exists, with people in vulnerable circumstances being disproportionately affected [7].

People with ‘limited’ health literacy are at risk of poor health outcomes, for example through reduced access to and utilization of healthcare services, inadequate provider-patient interactions, and suboptimal self-management [4]. This is highly relevant considering the complexity of rheumatology care [8], which concerns chronic conditions and often long-term patient-professional relationships, requiring decision-making about medication, changes in lifestyle, and adequate support [9, 10], all highlighting how important it is for health professionals to understand patients’ health literacy needs. Several studies in rheumatology indeed discuss the role of health literacy in patient activation and self-management [11], medication adherence [12, 13], functional status [14], and disease severity [15], but also in access to biological disease modifying antirheumatic drugs (bDMARDs) [16]. To minimise these potential adverse effects of ‘limited’ health literacy, we advocate for tailoring rheumatology care to patients’ health literacy needs [17]. Accommodating an individual patient’s health literacy needs at the point of care would require either *measurement* of the health literacy of each patient with a robust tool (which might be not feasible in many contexts) or an *ad hoc estimation* of the patient’s literacy needs by the treating healthcare professional. The feasibility and accuracy of such estimations are the subject of this paper.

Research in various settings shows that health professionals tend to over- and/or underestimate patients’ [18] and their caregivers’ [19] health literacy. A study conducted among general practitioners (GPs) in Belgium showed that inaccurate estimation was more likely to occur in patients with lower education levels and patients who had been under the GP’s care for a shorter period of time [20]. In

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3 addition, a gender gap was observed, as male GPs were more likely to underestimate patients' health  
4 literacy [20]. Hawkins et al. [21] explored differing perspectives on health literacy between patients and  
5 health professionals on an item level, in a qualitative study using the Health Literacy Questionnaire  
6 (HLQ). In contrast to the studies referenced above, the authors did not conceptualize differences in  
7 assessment as over- or underestimation, but as discordance [21]. When discordance occurs, this may be  
8 due to differences in understanding specific wordings, perspectives on changing circumstances over  
9 time, expectations and criteria for assigning scores, or perspectives on the patients' reliance on  
10 healthcare providers [21]. No matter whether discordance is due to estimation errors or differing  
11 perspectives, it is important to signal these differences and the direction of any discordance in order to  
12 prevent potential communication gaps [22] and/or address them in the delivery of care.  
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24 To learn more about the prevalence and potential drivers of discordance in health literacy  
25 assessment in rheumatology, the two-fold aim of this study was 1) to investigate the discordance  
26 between health literacy of people with rheumatic and musculoskeletal diseases (RMDs) and assessment  
27 of health literacy by their treating health professionals, and 2) to explore whether discordance was  
28 associated with the patients' socioeconomic background.  
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## 39 **METHODS**

### 40 **Study design**

41 We conducted an observational cross-sectional study, as part of a health literacy project in rheumatology  
42 following the Optimising Health Literacy and Access (Ophelia) process [23]. A more extensive account  
43 of the methods of patient recruitment and data collection is described elsewhere [17]. One patient  
44 research partner (MdW) was involved throughout the research process.  
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### 54 **Population and setting**

55 This study was conducted in three outpatient rheumatology clinics in the Netherlands (in the South,  
56 West and East). We recruited adult patients diagnosed by a rheumatologist with rheumatoid arthritis  
57 (RA), spondyloarthritis (SpA), or gout, and their treating healthcare professional (rheumatologist,  
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3 rheumatology fellow, nurse practitioner/physician assistant, or rheumatology nurse). Data collection  
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5 took place between May 2018 and May 2019.  
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### 8 9 **Procedures and measurements**

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11 Consenting patients filled out a survey on paper, digitally, or orally in an interview format with a  
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13 researcher, in their preferred language (Dutch, English, German, or Arabic). The survey primarily  
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15 included the Health Literacy Questionnaire (HLQ) [24, 25], which comprises 44 items addressing nine  
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17 distinct domains of health literacy (Box 1). The HLQ provides a score for each domain (the higher the  
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19 better) [24], as it was developed to identify strengths and weaknesses across domains that would not be  
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21 revealed by a single summary score. Other survey questions included the Pearlin Mastery Scale (which  
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23 assesses the extent to which a person feels like they have control over life's opportunities, score range  
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25 7 – 28 [26]) and questions on sociodemographic background and health status. Sociodemographic  
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27 information included age (in years), gender, education level (low (no more than primary or lower  
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29 secondary education) / medium / high (graduated tertiary education) using Dutch standardized  
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31 categories [27]), migration background (Native Dutch, Western migrant, or non-Western migrant [28]),  
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33 employed (yes/no), (partially) work disabled (yes/no), and living alone (yes/no).  
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37 Following the clinical visit, the health professional who performed the consultation provided  
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39 their assessment of the patient's level (or answered "I do not know") on each of the nine domains of the  
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41 HLQ using a 0-10 numeric rating scale (NRS). In addition, professionals indicated how well they knew  
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43 the patient (not at all/barely, somewhat, fairly well, very well) and provided a professional's global  
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45 assessment of the impact of the rheumatic disease on the functioning and health of the patient (NRS 0-  
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47 10, 10 being maximum impact). Additionally, we documented the healthcare professionals' gender and  
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49 profession. Before the start of the study, all participating health professionals attended a one-hour  
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51 session to discuss health literacy, the study setup, and how to fill out the survey. An explanation of the  
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53 meaning of high and low scores on the nine domains [24] was provided to health professionals whenever  
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55 they were assessing patients.  
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### 58 **Ethics**

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3 This study was reviewed by the Medical Ethics Review Committee at Maastricht University Medical  
4 Center + (2018-0327) as well as by the designated committees at each participating hospital for local  
5 permission (Maastricht University Medical Center +, Maastricht: 18-4-037, Maasstad Hospital,  
6 Rotterdam: L2018057, Medisch Spectrum Twente, Enschede: KH18-23). All patients and professionals  
7 provided written informed consent.  
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### 14 15 **Statistical analysis**

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17 In case of missing data, we contacted patients and healthcare professionals to complete missing items.  
18 Remaining missing HLQ data were treated according to the expectation maximization algorithm used  
19 in Ophelia [29], before computing domain scores. We analysed discordance data using three categories:  
20 1) “The professional’s assessment was lower than the patient’s HLQ score” (negative discordance), 2)  
21 “The professional’s assessment and patient’s HLQ score were probably the same”, and 3) “The  
22 professional’s assessment was higher than the patient’s HLQ score” (positive discordance). Before  
23 categorisation, patients’ HLQ domain scores were converted to a 0-10 scale to enable comparisons with  
24 the health professionals’ assessments. Discordance was defined as a  $\geq 2$ -point difference (in either  
25 direction). Given a  $\geq 2$ -point difference at the extremes of the 0-10 scale implies the patient and health  
26 professional agree the score is either “very high” or “very low”, such discordance is unlikely to be  
27 relevant. Therefore, we classified observations where both the professional and the patient scored  $\leq 3$  or  
28  $\geq 7$  as “probably the same” (i.e., no relevant discordance).  
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43 We used multilevel multinomial regression (mixed) models to test the role of socioeconomic  
44 factors in negative (i.e., professional scored lower than the patient) and positive (i.e., professional scored  
45 higher than the patient) relevant discordance in each of the nine HLQ domains (reference = “probably  
46 the same”). To account for clustering within individual health professionals, we added a random  
47 intercept to the models. Intraclass correlation coefficients (ICCs) were computed. The base model  
48 included all socioeconomic factors of interest (age, gender, education level, migration background,  
49 being employed or (partially) work disabled, living alone). Other potential predictors or confounding  
50 variables (type of rheumatic disease, patient-reported mastery, professionals’ global assessment of  
51 disease impact, type of healthcare professional, gender of healthcare professional, and how well the  
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3 healthcare professional knew the patient) were each tested separately in the base model. The final model  
4 was selected by retaining all base model variables and performing a backwards selection procedure for  
5 other variables that proved significant predictors or confounders when added to the base model.  
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7 Analyses were performed in IBM SPSS Statistics 27 and Stata 15. Statistical significance was assumed  
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9 at  $\alpha=5\%$ .  
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## 15 **RESULTS**

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17 Treating health professionals filled out questionnaires for 778 out of 895 participating patients [17].  
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19 There were no important differences between the 778 patients included in analysis and those for whom  
20 a professional's questionnaire was not completed (Supplementary Table S1, available at *Rheumatology*  
21 online). Included patients had a mean age of 61.2 (SD 13.9); 52.1% were male; 51.7% reported to have  
22 a low education level; 17.5% had a Western or non-Western migration background; 32.5% were  
23 employed; 14.3% were (partially) work disabled; and 23.9% lived alone (Table 1). Thirty-nine  
24 healthcare professionals assessed between 1 and 85 patients; 23.1% of professionals were male; and  
25 60% were rheumatologists (Table 1).  
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### 36 **Discordance**

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38 Total relevant (negative and positive) discordance between patients' HLQ scores and professionals'  
39 assessments occurred in 161 (20.7%) to 315 (40.5%) patients per domain (Figure 1). Professionals  
40 answered: "I do not know" most often for "Having social support for health" (19.4%, domain 4).  
41 Relevant positive discordance was observed more frequently than negative discordance. Most positive  
42 discordance was observed for "Critically appraising information" (domain 5, 31.9% positive  
43 discordance), while most negative discordance was observed for "Actively engaging with providers"  
44 (domain 6, 19.0% negative discordance).  
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### 55 **Exploring the role of socioeconomic factors**

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57 Results of univariable associations between socioeconomic factors and discordance are provided as  
58 Supplementary Table S2, available at *Rheumatology* online. Tables 2 and 3 and Figures 2A and 2B  
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3 show the multivariable multilevel multinomial models. Socioeconomic factors played a role in  
4 discordance in all domains except “Healthcare provider support” (domain 1). Patients’ gender was not  
5 associated with relevant discordance in health literacy scores. Observed ICCs exposed clustering of  
6 discordance by professional.  
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### 10 11 12 13 ***Negative discordance (i.e. professional scored lower than the patient)***

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15 Figure 2A and Table 2 present odds ratios of negative discordance (compared to “probably the same”)  
16 per domain. Education level and migration background were most frequently and strongly associated  
17 with negative discordance. Having *low education level* or *medium education level* (compared to *high*  
18 *education level*) was associated with negative discordance in five and three domains, respectively, with  
19 highest odds observed for “Actively engaging with providers” (domain 6, OR low education 3.97 [2.06  
20 – 7.64], OR medium education 3.03 [1.47 – 6.24]). *Non-Western migration background* (compared to  
21 *Native Dutch*) was associated with negative discordance in five domains, with the highest odds observed  
22 for “Understanding health information” (domain 9, OR 8.52 [4.12 – 17.61]), the only domain in which  
23 *Western migration background* was additionally associated with professionals underscoring patients  
24 (OR 2.41 [1.12 – 5.21]).  
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37 Other observed associations were less consistent across domains. Living alone and not being  
38 employed were each associated with negative discordance in single HLQ domains. People *living alone*  
39 were more likely to be underscored by professionals for “Having social support” (domain 4, OR 3.51  
40 [1.52 – 8.10]). People *not employed* were more likely to be underscored by professionals for “Navigating  
41 the health system” (domain 7, OR 2.28 [1.09 – 4.78]). People who were (*partially*) *work disabled* had  
42 higher odds of being underscored only for “Actively managing health” (domain 3, OR 2.09 [1.02 –  
43 4.30]). Age was not associated with negative discordance in any domain.  
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### 53 ***Positive discordance (i.e. professional scored higher than the patient)***

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55 Figure 2B and Table 3 present odds ratios of positive discordance (compared to “probably the same”)  
56 per domain. While positive discordance occurred more frequently than negative discordance (mean 17.1  
57 and 10.5% per domain respectively, Figure 1), it was less often and less strongly associated with  
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3 socioeconomic determinants. Having *low education level* (compared to *high education level*) was  
4 negatively associated with positive discordance for “Having sufficient information” (domain 2, OR 0.45  
5 [0.28 – 0.73]), “Actively managing health” (domain 3, OR 0.65 [0.42 – 0.99]), and “Critically appraising  
6 information” (domain 5, OR 0.53 [0.35 – 0.79]), and positively associated with positive discordance for  
7 “Finding health information” and “Understanding health information” (domains 8 and 9, OR 2.89 [1.41  
8 – 5.93] and 2.34 [1.12 – 4.90]). Having *medium education level* (compared to *high education level*) was  
9 negatively associated with positive discordance in two domains: “Having sufficient information”  
10 (domain 2, OR 0.57 [0.34 – 0.96]) and “Navigating the health system” (domain 7, OR 0.43 [0.22 –  
11 0.85]). Of note, migration background was not associated with positive discordance in any of the  
12 domains.  
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24 While not a factor in negative discordance, being of *higher age* was associated with positive  
25 discordance in three domains, although the direction of the effect was inconsistent. Professionals were  
26 more likely to overscore *older patients* for “Finding health information” and “Understanding health  
27 information” (domains 8 and 9, 10-year difference OR 1.32 [1.01 – 1.75] and 1.49 [1.09 – 2.03]  
28 respectively), and *younger patients* for “Having sufficient information” (domain 2, 10-year difference  
29 OR 0.81 [0.68 – 0.98]). People *not employed* had lower odds of being overscored by professionals only  
30 for “Understanding health information” (domain 9, OR 0.45 [0.21 – 1.00]).  
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### 41 **Exploring the role of other factors**

42 Besides associations with socioeconomic determinants, we observed several relevant associations  
43 between discordance and other patient and health professionals’ characteristics. These associations  
44 differed between negative and positive discordance.  
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#### 51 ***Negative discordance (i.e. professional scored lower than the patient)***

52 The most common factor associated with negative discordance (Table 2) was *professionals’ global*  
53 *assessment of disease impact*, with higher impact increasing the odds of negative discordance in the first  
54 seven HLQ domains. Compared to rheumatologists, *fellows* were more likely to underscore their patient  
55 on “Healthcare provider support” (domain 1), “Having social support for health” (domain 4), and  
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3 “Critically appraising information” (domain 5). In cases where health professionals stated they *knew the*  
4 *patient very well* (compared to *not at all/barely*), negative discordance was less likely for “Actively  
5 managing health” (domain 3). Patients with *gout* (compared to patients with RA) were more likely to be  
6 underscored for “Actively engaging with providers” (domain 6). The gender of the health professional  
7 was only of relevance in one domain: male professionals were more likely to underscore patients on  
8 “Having social support for health” (domain 4).  
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### 15 ***Positive discordance (i.e. professional scored higher than the patient)***

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17 The most relevant factor associated with positive discordance was *patients’ mastery*. *Lower mastery*  
18 was associated with positive discordance in six domains (Table 3). In cases where health professionals  
19 stated they *knew the patient very well*, positive discordance was more likely for “Actively managing  
20 health” (domain 3) and “Navigating the health system” (domain 7). Patients with *gout* (compared to  
21 patients with RA) were more likely to be overscored by professionals for “Healthcare provider support”  
22 (domain 1) and “Navigating the health system” (domain 7).  
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## 35 **DISCUSSION**

36 We found discordance between Health Literacy Questionnaire scores of people with RMDs and  
37 assessment of health literacy by their treating health professionals in more than a quarter of all cases.  
38 This indicates hidden challenges in communication and care. Most positive discordance (i.e.  
39 professional scored higher than the patient) occurred for “Critically appraising information” (domain 5,  
40 31.9%), while most negative discordance (i.e. professional scored lower than the patient) was observed  
41 for “Actively engaging with providers” (domain 6, 19.0%). Professionals were most often unsure about  
42 their patient “Having social support for health” (domain 4, 19.4% “I do not know”). In addition, we  
43 found that risks of discordance were not equal across socioeconomic groups. Discordance was  
44 frequently associated with patients’ socioeconomic background, particularly education level and  
45 migration background. Risk of negative discordance was higher in patients with low education level  
46 and/or non-Western migration background. Risk of positive discordance was higher in patients with low  
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3 education level for finding and understanding health information (domains 8 and 9) and higher in  
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5 patients with high education level in four other domains.  
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7 Our findings support and expand upon findings from previous studies. Voigt-Barbarowicz and  
8 Brütt [18] systematically reviewed health literacy assessment studies (using other measurement tools  
9 than the HLQ [18, 20, 22, 30-34]) in hospital-based and primary care populations with somatic  
10 conditions. In these studies, misclassification by professionals was also common, and while the biggest  
11 concern was overestimation (ranging from 9 to 58% of all patients per study), six out of seven studies  
12 also reported underestimation in 5 to 29% of all patients [20, 22, 30-33]. Storms et al. [16] additionally  
13 investigated the impact of patients' and GPs' characteristics on discordance in single-score health  
14 literacy assessment and noted the GPs were more likely to have discordant judgement (over- or  
15 underestimation) for patients with low education. Our work expanded on these findings, showing  
16 positive discordance occurred more frequently, but negative discordance was more strongly associated  
17 with socioeconomic factors. Furthermore, the multidimensional nature of the HLQ allowed us to  
18 conduct more nuanced analyses, suggesting that (associations with) discordance may be domain  
19 dependent. For example, contrasting conclusions that particularly underestimation was more likely in  
20 patients who had been under the GP's care for a shorter period of time and in patients treated by a male  
21 GP [20], we only observed these effects in single domains ("Actively managing health" (domain 3) and  
22 "Having social support for health" (domain 4), respectively).  
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41 This paper describes the first study to quantify discordance between patients' health literacy  
42 scores and professionals' assessment using the multidimensional HLQ. In a qualitative study, Hawkins  
43 et al. [21] showed that differing perspectives can be a reason for discordance in HLQ scores between  
44 patients and professionals. For example, some patients saw goalsetting and making plans to be healthy  
45 as "Actively managing health" (domain 3), while clinicians expected patients to convert these goals and  
46 plans into action. Lacking a gold standard for objective health literacy measurement, we do not know if  
47 the discordance in this study means professionals over- or underestimate patients, patients over- or  
48 underestimate themselves, or that the truth is somewhere in the middle. Notwithstanding, the present  
49 data uncover a considerable disconnect between patients' and professionals' views on patients' health  
50 literacy needs. Moreover, professionals strikingly often answered "I do not know" in estimating "Having  
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3 social support for health” (domain 4), indicating this may not receive sufficient attention in clinical  
4 consultations. The findings highlight that we cannot expect all health professionals to accurately  
5 understand and address all patients’ health literacy needs adequately at the point of care based on  
6 subjective estimations alone. Instead, we require strategies to address health literacy needs that rely on  
7 health literacy measurement and dialogue with patients and professionals, either at the point of care, or  
8 in the development of organisational interventions based on patients’ needs [23]. The Conversational  
9 Health Literacy Assessment Tool (CHAT) could assist health professionals in this process [35].

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18 Knowing that health literacy needs are not static but can change over time or between contexts  
19 [36, 37], and that risk of discordance differs between socioeconomic groups, we also need to reflect on  
20 the assumptions we make in research and practice to fill the discordance gap. Dijkstra and Horstman  
21 [38] discussed that we should challenge the construction and characterisation of socioeconomic  
22 background to understand health inequalities, to prevent perpetuating (possibly inaccurate) negative  
23 notions of ‘low socioeconomic status’ and break away from the narrative of groups “known to be  
24 unhealthy”. The differing risks of discordance based on education level and migration background  
25 suggest that pre-existing notions of what health literacy entails in people belonging to specific  
26 socioeconomic groups indeed play a role in assessment by health professionals. In order for patients and  
27 health professionals to better understand each other, we may need to challenge these pre-existing notions  
28 of health literacy and socioeconomic background in our daily work. Of note, discordance between  
29 patients’ and professionals perspectives is not unique to health literacy, but has also been documented  
30 in concepts such as patient activation [39] and goal-setting [40], which highlights general challenges in  
31 clinical communication.

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There are additional implications of this study for health literacy and discordance research and  
practice. First, the ICCs indicated substantial clustering by professional, supporting our assumption that  
professionals’ assessments are highly dependent on the assessor. While many past discordance studies  
in rheumatology (focusing on other outcomes) did not adjust for possible correlation of scores within  
health professionals [41-45], our results suggest the clustered nature of the data should be considered in  
the statistical analyses of future discordance research. Second, we saw clear diversity in discordance and  
associations with discordance across domains. This further highlights that assessing or estimating single

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3 summary scores may fail to capture the complexity of the role of health literacy in health care delivery.  
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5 Health literacy needs are not grounded in scores on a single domain, but rather follow from a pattern of  
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7 strengths and weaknesses across health literacy domains [17, 29]. We therefore second Voigt-  
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9 Barbarowicz and Brütt [18], recommending the use of multidimensional health literacy assessment tools  
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11 in research and practice.  
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14 Our paper reports on a large, inclusive, multi-centre study in rheumatology using a  
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16 multidimensional health literacy tool, giving valuable new insights into health literacy assessment and  
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18 the role of socioeconomic factors. Nevertheless, it should be seen in light of a few limitations. First, in  
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20 contrast to Hawkins et al. [21], health professionals did not fill out the full HLQ, but estimated domain  
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22 scores (for feasibility reasons). This may have exacerbated discordance, also because HLQ scores had  
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24 to be converted to a 0-10 scale. Second, the choice of categorisation and threshold of “discordance” as  
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26 a 2-point difference in observations could be debated. We made this decision based on commonly used  
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28 cut-offs in rheumatology research [43-46], but no true consensus exists [47], and future studies should  
29  
30 determine what difference in health literacy scoring could impact patient-professional relationships and  
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32 communication. Third, we explored many associations, risking that some of our observations may be  
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34 due to chance. Therefore, the strong, consistent findings are more likely to reflect true patterns, while  
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36 less consistent patterns need to be validated in further research. Fourth, some of the associations  
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38 observed in this cross-sectional study were not consistent between domains, such as the increased risk  
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40 of both negative and positive discordance in people with low education level for finding and  
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42 understanding health information (domains 8 and 9), and not consistent with previous research [18, 20].  
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44 While these inconsistencies hint at the complexity of health literacy assessment, we cannot be sure if  
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46 the role of socioeconomic factors in discordance is indeed inconsistent or if there may be other factors  
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48 (not explored in this study) that can explain discordance patterns and confound the observed  
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50 associations. Last, we were unable to explore the impact of discordance on outcomes such as quality of  
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52 care, health status or the occurrence of adverse events. We hypothesize these associations exist, but  
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54 future research on this topic is warranted.  
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58 In conclusion, our study shows that accurate estimation of patients’ health literacy by  
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60 professionals in rheumatology is not a given. Discordance between patients’ health literacy scores and

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3 professionals' estimations indicates that there may be hidden challenges in communication and care in  
4 about a quarter of all patients. Risks are not equal across socioeconomic groups (particularly higher for  
5 people with low education level and/or non-Western migration background) and domains of health  
6 literacy, which highlights the multidimensional nature of health literacy and indicates that challenges in  
7 addressing health literacy needs may be unequal between socioeconomic groups as well. While  
8 increasing awareness among health professionals could potentially reduce discordance and improve  
9 understanding between patients and professionals, we suggest health literacy measurement and dialogue  
10 with patients and health professionals are vital to addressing health literacy needs, which cannot rely on  
11 health professionals' estimations alone.  
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## 26 **DECLARATIONS**

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36 carry out the work described in this article.  
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### 41 **Conflicts of interest**

42 The authors have declared no conflict of interest.  
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### 45 **Data availability**

46 The data underlying this article cannot be shared publicly due to privacy of individuals that participated  
47 in the study. They did not consent to have their data shared.  
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**REFERENCES**

1. Bröder J, Chang P, Kickbusch I, Levin-Zamir D, McElhinney E, Nutbeam D, et al. IUHPE Position Statement on Health Literacy: a practical vision for a health literate world. *Glob Health Promot*. 2018;25(4):79-88.
2. World Health Organization. Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development. *Health Promot Int*. 2017;32(1):7-8.
3. van der Heide I, Rademakers J, Schipper M, Droomers M, Sorensen K, Uiters E. Health literacy of Dutch adults: A cross sectional survey. *BMC Public Health*. 2013;13:179.
4. Paasche-Orlow MK, Wolf MS. The causal pathways linking health literacy to health outcomes. *Am J Health Behav*. 2007;31 Suppl 1:S19-26.
5. Batterham RW, Hawkins M, Collins PA, Buchbinder R, Osborne RH. Health literacy: Applying current concepts to improve health services and reduce health inequalities. *Public Health*. 2016;132:3-12.
6. Heijmans M, Brabers A, Rademakers J. Hoe gezondheidsvaardig is Nederland? Factsheet Gezondheidsvaardigheden – Cijfers 2019. Utrecht: Nivel; 2019.
7. Sørensen K, Pelikan JM, Röthlin F, Ganahl K, Slonska Z, Doyle G, et al. Health literacy in Europe: comparative results of the European health literacy survey (HLS-EU). *Eur J Public Health*. 2015;25(6):1053-8.
8. Kahn KL, MacLean CH, Liu H, Rubenstein LZ, Wong AL, Harker JO, et al. The Complexity of Care for Patients with Rheumatoid Arthritis: Metrics for Better Understanding Chronic Disease Care. *Med Care*. 2007;45(1):55-65.
9. Nikiphorou E, Santos E, Marques A, Böhm P, Bijlsma JW, Daien CI, et al. 2021 EULAR recommendations for the implementation of self-management strategies in patients with inflammatory arthritis. *Ann Rheum Dis*. 2021;80(10):1278-85.
10. van der Heijde D, Ramiro S, Landewé R, Baraliakos X, Van den Bosch F, Sepriano A, et al. 2016 update of the ASAS-EULAR management recommendations for axial spondyloarthritis. *Ann Rheum Dis*. 2017;76(6):978-91.

- 1  
2  
3 11. Jones B, Ndosi M, Hunt A, Harcourt D, Dures E. Factors associated with patient activation in  
4  
5 inflammatory arthritis: a multisite cross-sectional study. *Rheumatology Advances in Practice*.  
6  
7 2021;5(Supplement\_2):ii35-ii44.
- 8  
9 12. Joplin S, van der Zwan R, Joshua F, Wong PKK. Medication Adherence in Patients with  
10  
11 Rheumatoid Arthritis: The Effect of Patient Education, Health Literacy, and Musculoskeletal  
12  
13 Ultrasound. *BioMed Research International*. 2015;2015.
- 14  
15 13. Hirsh J, Wood P, Keniston A, Boyle D, Quinzanos I, Caplan L, et al. Universal Health  
16  
17 Literacy Precautions Are Associated With a Significant Increase in Medication Adherence in  
18  
19 Vulnerable Rheumatology Patients. *ACR Open Rheumatol*. 2020;2(2):110-8.
- 20  
21 14. Caplan L, Wolfe F, Michaud K, Quinzanos I, Hirsh JM. Strong association of health literacy  
22  
23 with functional status among rheumatoid arthritis patients: A cross-sectional study. *Arthritis Care Res*  
24  
25 *(Hoboken)*. 2014;66(4):508-14.
- 26  
27 15. Hirsh JM, Boyle DJ, Collier DH, Oxenfeld AJ, Nash A, Quinzanos I, et al. Limited health  
28  
29 literacy is a common finding in a public health hospital's rheumatology clinic and is predictive of  
30  
31 disease severity. *J Clin Rheumatol*. 2011;17(5):236-41.
- 32  
33 16. Putrik P, Ramiro S, Lie E, Keszei AP, Kvien TK, van der Heijde D, et al. Less educated and  
34  
35 older patients have reduced access to biologic DMARDs even in a country with highly developed  
36  
37 social welfare (Norway): Results from Norwegian cohort study NOR-DMARD. *Rheumatology*  
38  
39 *(Oxford)*. 2016.
- 40  
41 17. Bakker MM, Putrik P, Rademakers J, van de Laar M, Vonkeman H, Kok MR, et al.  
42  
43 Addressing Health Literacy Needs in Rheumatology: Which Patient Health Literacy Profiles Need the  
44  
45 Attention of Health Professionals? *Arthritis Care Res (Hoboken)*. 2021;73(1):100-9.
- 46  
47 18. Voigt-Barbarowicz M, Brütt AL. The Agreement between Patients' and Healthcare  
48  
49 Professionals' Assessment of Patients' Health Literacy-A Systematic Review. *Int J Environ Res Public*  
50  
51 *Health*. 2020;17(7).
- 52  
53 19. Cooper M, Jr., Blucker R, Thompson D, Griffeth E, Grassi M, Damron K, et al. Health  
54  
55 Literacy Estimation of English and Spanish Language Caregivers. *Health literacy research and*  
56  
57 *practice*. 2018;2(2):e107-e14.
- 58  
59  
60

- 1  
2  
3 20. Storms H, Aertgeerts B, Vandenabeele F, Claes N. General practitioners' predictions of their  
4 own patients' health literacy: a cross-sectional study in Belgium. *BMJ Open*. 2019;9(9):e029357.  
5  
6  
7 21. Hawkins M, Gill SD, Batterham R, Elsworth GR, Osborne RH. The Health Literacy  
8 Questionnaire (HLQ) at the patient-clinician interface: A qualitative study of what patients and  
9 clinicians mean by their HLQ scores. *BMC Health Serv Res*. 2017;17(1):309.  
10  
11  
12  
13 22. Kelly PA, Haidet P. Physician overestimation of patient literacy: a potential source of health  
14 care disparities. *Patient Educ Couns*. 2007;66(1):119-22.  
15  
16  
17  
18 23. Beauchamp A, Batterham RW, Dodson S, Astbury B, Elsworth GR, McPhee C, et al.  
19 Systematic development and implementation of interventions to OPTimise Health Literacy and Access  
20 (Ophelia). *BMC Public Health*. 2017;17(1):230.  
21  
22  
23  
24 24. Osborne RH, Batterham RW, Elsworth GR, Hawkins M, Buchbinder R. The grounded  
25 psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC*  
26 *Public Health*. 2013;13:658.  
27  
28  
29  
30 25. Rademakers J, Waverijn G, Rijken M, Osborne R, Heijmans M. Towards a comprehensive,  
31 person-centred assessment of health literacy: translation, cultural adaptation and psychometric test of  
32 the Dutch Health Literacy Questionnaire. *BMC Public Health*. 2020;20(1):1850.  
33  
34  
35  
36 26. Pearlin LI, Schooler C. The Structure of Coping. *J Health Soc Behav*. 1978;19(1):2-21.  
37  
38  
39 27. Statistics Netherlands. Standaard onderwijsindeling: Editie 2016/'17 (The Dutch Standard  
40 Classification of Education). *Den Haag/Heerlen, the Netherlands: CBS*. 2017.  
41  
42  
43 28. Alders M. Classification of the population with a foreign background in the Netherlands.  
44 Presented at the conference: The Measure and Mismeasure of Populations: the statistical use of ethnic  
45 and racial categories in multicultural societies; 2001 December 17–18; Paris, France. Available from:  
46 <https://www.cbs.nl/-/media/imported/documents/2002/05/classification-foreign.pdf?la=nl-nl>  
47  
48  
49  
50 29. Beauchamp A, Buchbinder R, Dodson S, Batterham RW, Elsworth GR, McPhee C, et al.  
51 Distribution of health literacy strengths and weaknesses across socio-demographic groups: a cross-  
52 sectional survey using the Health Literacy Questionnaire (HLQ). *BMC Public Health*. 2015;15(1):678.  
53  
54  
55  
56 30. Lindau ST, Basu A, Leitsch SA. Health literacy as a predictor of follow-up after an abnormal  
57 Pap smear: a prospective study. *J Gen Intern Med*. 2006;21(8):829-34.  
58  
59  
60

- 1  
2  
3 31. Bass PF, 3rd, Wilson JF, Griffith CH, Barnett DR. Residents' ability to identify patients with  
4 poor literacy skills. *Acad Med*. 2002;77(10):1039-41.  
5  
6  
7 32. Rogers ES, Wallace LS, Weiss BD. Misperceptions of Medical Understanding in Low-  
8 Literacy Patients: Implications for Cancer Prevention. *Cancer Control*. 2006;13(3):225-9.  
9  
10  
11 33. Zawilinski LL, Kirkpatrick H, Pawlaczyk B, Yarlagadda H. Actual and perceived patient  
12 health literacy: How accurate are residents' predictions? *Int J Psychiatry Med*. 2019;54(4-5):290-5.  
13  
14  
15 34. Dickens C, Lambert BL, Cromwell T, Piano MR. Nurse Overestimation of Patients' Health  
16 Literacy. *J Health Commun*. 2013;18(sup1):62-9.  
17  
18  
19 35. O'Hara J, Hawkins M, Batterham R, Dodson S, Osborne RH, Beauchamp A.  
20 Conceptualisation and development of the Conversational Health Literacy Assessment Tool (CHAT).  
21  
22 *BMC Health Serv Res*. 2018;18(1):199.  
23  
24  
25 36. Berkman ND, Davis TC, McCormack L. Health literacy: what is it? *J Health Commun*.  
26  
27 2010;15 Suppl 2:9-19.  
28  
29  
30 37. Sørensen K, Van den Broucke S, Pelikan JM, Fullam J, Doyle G, Slonska Z, et al. Measuring  
31 health literacy in populations: illuminating the design and development process of the European  
32 Health Literacy Survey Questionnaire (HLS-EU-Q). *BMC Public Health*. 2013;13(1):948.  
33  
34  
35 38. Dijkstra I, Horstman K. 'Known to be unhealthy': Exploring how social epidemiological  
36 research constructs the category of low socioeconomic status. *Soc Sci Med*. 2021;285:114263.  
37  
38  
39 39. Ledford CJ, Ledford CC, Childress MA. Exploring patient activation in the clinic:  
40 measurement from three perspectives. *Health Educ Behav*. 2013;40(3):339-45.  
41  
42  
43 40. Barton JL, Markwardt S, Niederhausen M, Schue A, Dougherty J, Katz P, et al. Are We on the  
44 Same Page?: A Cross-Sectional Study of Patient-Clinician Goal Concordance in Rheumatoid Arthritis.  
45  
46  
47 *Arthritis Care Res (Hoboken)*. 2021.  
48  
49  
50 41. Challa DN, Kvrjic Z, Cheville AL, Crowson CS, Bongartz T, Mason TG, et al. Patient-  
51 provider discordance between global assessments of disease activity in rheumatoid arthritis: a  
52 comprehensive clinical evaluation. *Arthritis Res Ther*. 2017;19(1):212.  
53  
54  
55  
56  
57  
58  
59  
60

- 1  
2  
3 42. Barton JL, Imboden J, Graf J, Glidden D, Yelin EH, Schillinger D. Patient-physician  
4 discordance in assessments of global disease severity in rheumatoid arthritis. *Arthritis Care Res*  
5 *(Hoboken)*. 2010;62(6):857-64.  
6  
7  
8  
9 43. Castrejon I, Shakoor N, Chua JR, Block JA. Discordance of global assessment by patients and  
10 physicians is higher in osteoarthritis than in rheumatoid arthritis: a cross-sectional study from routine  
11 care. *Rheumatol Int*. 2018;38(11):2137-45.  
12  
13  
14 44. Khan NA, Spencer HJ, Abda E, Aggarwal A, Alten R, Ancuta C, et al. Determinants of  
15 discordance in patients' and physicians' rating of rheumatoid arthritis disease activity. *Arthritis Care*  
16 *Res (Hoboken)*. 2012;64(2):206-14.  
17  
18  
19 45. Floris A, Espinosa G, Serpa Pinto L, Kougkas N, Lo Monaco A, Lopalco G, et al. Discordance  
20 between patient and physician global assessment of disease activity in Behçet's syndrome: a  
21 multicenter study cohort. *Arthritis Res Ther*. 2020;22(1):278.  
22  
23  
24 46. Lindström Egholm C, Krogh NS, Pincus T, Dreyer L, Ellingsen T, Glintborg B, et al.  
25 Discordance of Global Assessments by Patient and Physician Is Higher in Female than in Male  
26 Patients Regardless of the Physician's Sex: Data on Patients with Rheumatoid Arthritis, Axial  
27 Spondyloarthritis, and Psoriatic Arthritis from the DANBIO Registry. *J Rheumatol*.  
28 2015;42(10):1781-5.  
29  
30  
31 47. Desthieux C, Hermet A, Granger B, Fautrel B, Gossec L. Patient-Physician Discordance in  
32 Global Assessment in Rheumatoid Arthritis: A Systematic Literature Review With Meta-Analysis.  
33 *Arthritis Care Res (Hoboken)*. 2016;68(12):1767-73.  
34  
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## BOXES, TABLES & FIGURES

### Box 1. Health Literacy Questionnaire (HLQ) domains

Domain number and description	
1. Feeling understood and supported by healthcare providers (4 items)	Part I (score range 1 – 4)
2. Having sufficient information to manage my health (4 items)	
3. Actively managing my health (5 items)	
4. Having social support for health (5 items)	
5. Critical appraisal of health information (5 items)	
6. Ability to actively engage with healthcare providers (5 items)	Part II (score range 1 – 5)
7. Navigating the healthcare system (6 items)	
8. Ability to find good health information (5 items)	
9. Understanding health information well enough to know what to do (5 items)	

Part I measures level of agreement with items on a 4-point Likert scale: strongly disagree (1), disagree (2), agree (3) and strongly agree (4). Part II measures difficulty experienced with items on a 5-point Likert scale: always difficult/cannot do (1), usually difficult (2), sometimes difficult (3), usually easy (4) and always easy (5).

**Table 1.** Participant characteristics

<i>Patient characteristics (n = 778)</i>	Mean (SD) [min-max] <sup>†</sup> / % (n) <sup>‡</sup>
<b>Age</b>	61.2 (13.9) [18-89]
<b>Gender: male</b>	52.1 (405)
<b>Education level</b>	
Low	51.7 (402)
Medium	24.4 (190)
High	23.9 (186)
<b>Migration background</b>	
Non-Western migrant	8.9 (69)
Western migrant	8.6 (67)
Native Dutch	82.5 (642)
<b>Occupation status*</b>	
Employed	32.5 (253)
(Partially) work disabled	14.3 (111)
<b>Household type*</b>	
Living alone	23.9 (186)
<b>Rheumatic disease</b>	
RA	41.0 (319)
SpA	34.2 (266)
Gout	24.8 (193)
<b>Treating hospital</b>	
South	31.7 (247)
West	28.8 (224)
East	39.5 (307)
<b>Treated by type of healthcare professional</b>	
Rheumatologist	55.3 (430)
Rheumatology fellow	7.5 (58)
Nurse practitioner/physician assistant	21.0 (163)
Rheumatology nurse	16.3 (127)
<b>Mastery</b>	20.06 (3.44) [9-28] <sup>§</sup>
<i>Healthcare professional-reported outcomes</i>	
<b>Professionals' global assessment of disease impact</b>	4.28 (2.39) [0-10]
<b>How well professional knew the patient</b>	
Not at all/barely	10.9 (85)
Somewhat	30.1 (234)
Fairly well	46.5 (362)
Very well	12.5 (97)
<i>Health professional characteristics (n = 39)</i>	
<b>Gender: male</b>	23.1 (9)
<b>Type of professional</b>	
Rheumatologist	60.0 (23)
Rheumatology fellow	20.5 (8)
Nurse practitioner/physician assistant	10.3 (4)
Rheumatology nurse	10.3 (4)
<b>Employing hospital</b>	
South	30.8 (12)
West	30.8 (12)
East	38.5 (15)
<b>Number of patients assessed</b>	19.9 (16.8) [1-85]

**Legend:** <sup>†</sup> for continuous variables. <sup>‡</sup> for categorical variables. \* described as yes/no variable. For occupation status, patients may belong to both or neither of these groups. <sup>§</sup> n = 777 (1 questionnaire administered in Arabic without Mastery scale because no validated translation is available). RA = rheumatoid arthritis, SpA = spondyloarthritis.

**Table 2.** Odds ratios for negative discordance (professional scored lower) per domain, results from adjusted multilevel multinomial models (n = 778)\*

HLQ domains	1. Healthcare provider support (n = 768)	2. Having sufficient information (n = 770)	3. Actively managing health (n = 763)	4. Having social support for health (n = 626)	5. Critically appraising information (n = 776)	6. Actively engaging with providers (n = 774)	7. Navigating the health system (n = 765)	8. Finding health information (n = 752)	9. Understanding health information (n = 765)
<i>Variables of interest:</i>	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
<b>Age (10 years)</b>	1.06 [0.74 - 1.52]	1.14 [0.84 - 1.54]	1.07 [0.80 - 1.43]	1.36 [0.91 - 2.03]	1.17 [0.89 - 1.54]	1.04 [0.85 - 1.28]	0.98 [0.77 - 1.25]	0.97 [0.80 - 1.19]	1.22 [0.94 - 1.57]
<b>Gender: male</b>	1.13 [0.49 - 2.58]	1.81 [0.94 - 3.52]	1.78 [0.95 - 3.33]	1.44 [0.65 - 3.19]	1.25 [0.68 - 2.31]	0.89 [0.55 - 1.42]	1.35 [0.77 - 2.37]	1.20 [0.78 - 1.87]	1.15 [0.64 - 2.05]
Gender: female (ref)	-	-	-	-	-	-	-	-	-
<b>Education level: low</b>	0.65 [0.25 - 1.68]	<b>3.69 [1.35 - 10.11]</b>	<b>3.58 [1.37 - 9.33]</b>	1.07 [0.35 - 3.29]	1.24 [0.57 - 2.69]	<b>3.97 [2.06 - 7.64]</b>	<b>2.07 [1.02 - 4.22]</b>	<b>2.69 [1.49 - 4.86]</b>	1.97 [0.98 - 3.97]
<b>Education level: medium</b>	1.14 [0.40 - 3.25]	<b>2.97 [1.00 - 8.84]</b>	<b>2.96 [1.03 - 8.47]</b>	1.63 [0.48 - 5.52]	1.47 [0.61 - 3.51]	<b>3.03 [1.47 - 6.24]</b>	1.79 [0.81 - 3.92]	1.35 [0.68 - 2.69]	1.90 [0.86 - 4.20]
Education level: high (ref)	-	-	-	-	-	-	-	-	-
<b>Migration background: non-Western</b>	2.18 [0.73 - 6.45]	1.89 [0.77 - 4.65]	<b>2.45 [1.05 - 5.72]</b>	2.00 [0.61 - 6.60]	<b>3.33 [1.48 - 7.48]</b>	<b>3.25 [1.62 - 6.49]</b>	2.18 [0.97 - 4.88]	<b>3.27 [1.66 - 6.44]</b>	<b>8.52 [4.12 - 17.63]</b>
<b>Migration background: Western</b>	1.27 [0.37 - 4.33]	1.36 [0.54 - 3.46]	2.19 [0.98 - 4.91]	1.06 [0.28 - 4.08]	0.88 [0.30 - 2.59]	1.29 [0.65 - 2.57]	1.91 [0.88 - 4.16]	1.76 [0.91 - 3.40]	<b>2.41 [1.12 - 5.21]</b>
Migration background: Native Dutch (ref)	-	-	-	-	-	-	-	-	-
<b>Not employed</b>	1.06 [0.35 - 3.22]	1.76 [0.72 - 4.35]	1.83 [0.76 - 4.39]	0.81 [0.23 - 2.90]	0.85 [0.38 - 1.88]	1.85 [0.99 - 3.44]	<b>2.28 [1.09 - 4.78]</b>	1.58 [0.85 - 2.94]	0.77 [0.37 - 1.58]
Employed (ref)	-	-	-	-	-	-	-	-	-
<b>(Partially) work disabled: yes</b>	1.72 [0.67 - 4.43]	1.21 [0.54 - 2.69]	<b>2.09 [1.02 - 4.30]</b>	0.87 [0.28 - 2.74]	1.36 [0.63 - 2.93]	0.95 [0.52 - 1.76]	0.79 [0.39 - 1.63]	1.02 [0.55 - 1.89]	1.64 [0.80 - 3.36]
(Partially) work disabled: no (ref)	-	-	-	-	-	-	-	-	-
<b>Living alone: yes</b>	1.32 [0.56 - 3.15]	1.07 [0.56 - 2.05]	1.23 [0.65 - 2.33]	<b>3.51 [1.52 - 8.10]</b>	0.58 [0.28 - 1.22]	1.08 [0.67 - 1.74]	0.68 [0.37 - 1.25]	1.35 [0.83 - 2.20]	1.06 [0.59 - 1.90]
Living alone: no (ref)	-	-	-	-	-	-	-	-	-
Fixed intercept	0.00 [0.00 - 0.05]	0.00 [0.00 - 0.03]	0.02 [0.00 - 0.32]	0.00 [0.00 - 0.08]	0.01 [0.00 - 0.08]	0.00 [0.00 - 0.01]	0.00 [0.00 - 0.02]	0.02 [0.00 - 0.14]	0.01 [0.00 - 0.15]
<i>Other predictors / confounders:</i>									
<b>Disease: gout</b>	0.85 [0.24 - 3.03]	1.84 [0.79 - 4.31]	1.33 [0.54 - 3.27]	N/A	N/A	<b>2.43 [1.26 - 4.67]</b>	0.86 [0.38 - 1.92]	N/A	1.53 [0.71 - 3.32]
<b>Disease: SpA</b>	1.00 [0.41 - 2.44]	0.90 [0.42 - 1.93]	2.05 [1.00 - 4.20]	N/A	N/A	0.86 [0.50 - 1.46]	0.78 [0.42 - 1.46]	N/A	0.74 [0.38 - 1.44]
Disease: RA (ref)	-	-	-	N/A	N/A	-	-	N/A	-
<b>Mastery</b>	N/A	1.02 [0.94 - 1.12]	0.94 [0.86 - 1.02]	0.97 [0.87 - 1.09]	N/A	<b>1.09 [1.02 - 1.16]</b>	<b>1.12 [1.04 - 1.21]</b>	1.07 [1.00 - 1.14]	1.01 [0.94 - 1.09]
<b>Professionals' global disease impact</b>	<b>1.36 [1.11 - 1.67]</b>	<b>1.27 [1.10 - 1.46]</b>	<b>1.23 [1.07 - 1.43]</b>	<b>1.24 [1.01 - 1.51]</b>	<b>1.27 [1.10 - 1.47]</b>	<b>1.18 [1.06 - 1.30]</b>	<b>1.24 [1.09 - 1.41]</b>	N/A	N/A
<b>Professional type: nurse</b>	2.41 [0.38 - 15.20]	N/A	N/A	1.33 [0.27 - 6.66]	0.68 [0.14 - 3.27]	N/A	N/A	N/A	N/A
<b>Professional type: NP/PA</b>	0.65 [0.09 - 4.75]	N/A	N/A	1.65 [0.45 - 6.08]	1.00 [0.27 - 3.70]	N/A	N/A	N/A	N/A
<b>Professional type: fellow</b>	<b>4.55 [1.04 - 19.91]</b>	N/A	N/A	<b>6.92 [2.02 - 23.71]</b>	<b>4.22 [1.32 - 13.44]</b>	N/A	N/A	N/A	N/A
Professional type: rheumatologist (ref)	-	N/A	N/A	-	-	N/A	N/A	N/A	N/A
<b>Professional gender: male</b>	N/A	N/A	N/A	<b>3.21 [1.14 - 9.05]</b>	N/A	N/A	N/A	N/A	N/A
Professional gender: female (ref)	N/A	N/A	N/A	-	N/A	N/A	N/A	N/A	N/A
<b>How well the professional knew the patient: very well</b>	N/A	N/A	<b>0.25 [0.07 - 0.96]</b>	N/A	0.61 [0.16 - 2.33]	1.02 [0.34 - 3.08]	0.96 [0.28 - 3.26]	N/A	0.60 [0.17 - 2.09]
<b>How well the professional knew the patient: fairly well</b>	N/A	N/A	0.51 [0.20 - 1.27]	N/A	1.03 [0.38 - 2.81]	2.37 [1.04 - 5.39]	1.29 [0.51 - 3.30]	N/A	1.05 [0.43 - 2.59]
<b>How well the professional knew the patient: somewhat</b>	N/A	N/A	0.74 [0.31 - 1.79]	N/A	1.11 [0.41 - 3.03]	2.63 [1.19 - 5.80]	1.73 [0.70 - 4.27]	N/A	1.12 [0.46 - 2.70]
How well the professional knew the patient: not barely (ref)	N/A	N/A	-	N/A	-	-	-	N/A	-
ICC	0.32 [0.16 - 0.54]	0.26 [0.14 - 0.44]	0.17 [0.07 - 0.36]	0.14 [0.03 - 0.47]	0.21 [0.09 - 0.42]	0.16 [0.08 - 0.31]	0.21 [0.10 - 0.40]	0.15 [0.06 - 0.31]	0.22 [0.10 - 0.40]

**Legend:** Results from adjusted multilevel multinomial models, “no discordance” as reference category. \* n differs between domains due to exclusion of “I do not know” and one patient with missing data for “Mastery”. (ref) = reference category (no OR), N/A = not applicable (variable not included in model), HLQ = Health Literacy Questionnaire, ICC = intraclass correlation coefficient, NP/PA = nurse practitioner/physician assistant, OR = odds ratio, RA = rheumatoid arthritis, SpA = spondyloarthritis, 95% CI = 95% confidence interval. **Bold values** indicate p<0.05.

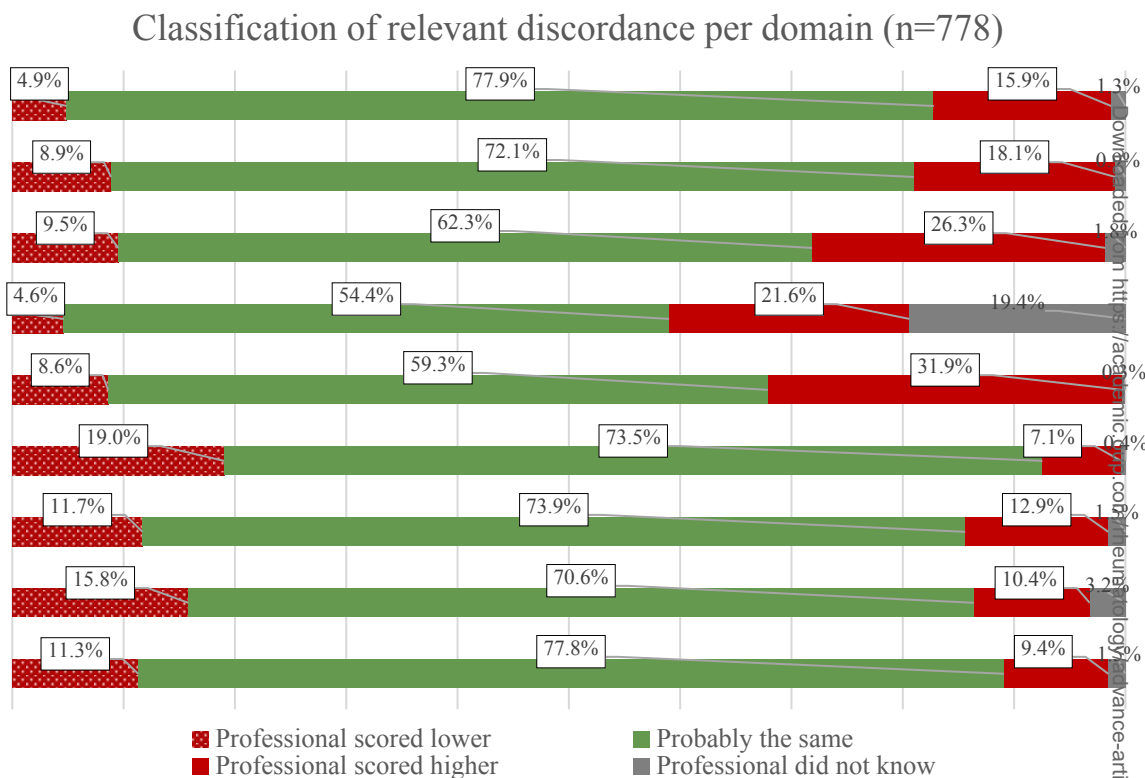
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**Table 3.** Odds ratios for positive discordance (professional scored higher) per domain, results from adjusted multilevel multinomial models (n = 778)\*

HLQ domains	1. Healthcare provider support (n = 768)	2. Having sufficient information (n = 770)	3. Actively managing health (n = 763)	4. Having social support for health (n = 626)	5. Critically appraising information (n = 776)	6. Actively engaging with providers (n = 774)	7. Navigating the health system (n = 765)	8. Finding health information (n = 752)	9. Understanding health information (n = 765)
<i>Variables of interest:</i>	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
Age (10 years)	1.00 [0.82 - 1.22]	<b>0.81 [0.68 - 0.98]</b>	1.04 [0.88 - 1.23]	0.91 [0.77 - 1.09]	1.08 [0.92 - 1.27]	0.86 [0.65 - 1.14]	0.96 [0.76 - 1.21]	<b>1.32 [1.01 - 1.75]</b>	<b>1.49 [1.09 - 2.03]</b>
Gender: male	1.02 [0.65 - 1.62]	1.05 [0.67 - 1.63]	1.09 [0.73 - 1.61]	1.13 [0.75 - 1.70]	1.15 [0.81 - 1.63]	1.03 [0.54 - 1.98]	0.91 [0.54 - 1.54]	1.06 [0.63 - 1.78]	1.31 [0.71 - 2.42]
Gender: female (ref)	-	-	-	-	-	-	-	-	-
Education level: low	0.71 [0.44 - 1.16]	<b>0.45 [0.28 - 0.73]</b>	<b>0.65 [0.42 - 0.99]</b>	1.10 [0.68 - 1.78]	<b>0.53 [0.35 - 0.79]</b>	1.18 [0.57 - 2.45]	0.64 [0.37 - 1.12]	<b>2.89 [1.41 - 5.93]</b>	<b>2.34 [1.12 - 4.90]</b>
Education level: medium	0.71 [0.40 - 1.24]	<b>0.57 [0.34 - 0.96]</b>	0.86 [0.54 - 1.37]	0.82 [0.47 - 1.44]	0.77 [0.49 - 1.20]	0.52 [0.20 - 1.34]	<b>0.43 [0.22 - 0.85]</b>	0.91 [0.36 - 2.31]	1.21 [0.49 - 3.00]
Education level: high (ref)	-	-	-	-	-	-	-	-	-
Migration background: non-Western	1.57 [0.79 - 3.10]	1.02 [0.50 - 2.10]	0.66 [0.31 - 1.41]	1.11 [0.57 - 2.17]	0.60 [0.29 - 1.23]	1.39 [0.55 - 3.52]	0.78 [0.34 - 1.82]	1.93 [0.80 - 4.62]	1.27 [0.44 - 3.72]
Migration background: Western	0.69 [0.32 - 1.53]	1.17 [0.60 - 2.30]	0.54 [0.27 - 1.09]	0.77 [0.36 - 1.66]	0.90 [0.50 - 1.60]	0.17 [0.02 - 1.31]	1.27 [0.57 - 2.83]	0.95 [0.37 - 2.42]	1.10 [0.43 - 2.84]
Migration background: Native Dutch (ref)	-	-	-	-	-	-	-	-	-
Not employed	0.81 [0.47 - 1.40]	1.05 [0.62 - 1.77]	0.80 [0.50 - 1.29]	0.79 [0.46 - 1.33]	1.07 [0.68 - 1.68]	0.96 [0.42 - 2.16]	0.95 [0.50 - 1.80]	0.65 [0.31 - 1.38]	<b>0.45 [0.21 - 1.00]</b>
Employed (ref)	-	-	-	-	-	-	-	-	-
(Partially) work disabled: yes	0.95 [0.51 - 1.76]	0.73 [0.41 - 1.32]	0.87 [0.51 - 1.50]	1.09 [0.63 - 1.89]	0.75 [0.45 - 1.25]	0.87 [0.38 - 1.97]	1.14 [0.60 - 2.18]	1.14 [0.52 - 2.49]	1.45 [0.64 - 3.31]
(Partially) work disabled: no (ref)	-	-	-	-	-	-	-	-	-
Living alone: yes	1.11 [0.69 - 1.79]	0.77 [0.46 - 1.27]	0.92 [0.60 - 1.41]	0.65 [0.39 - 1.09]	0.75 [0.50 - 1.13]	1.62 [0.85 - 3.09]	0.68 [0.38 - 1.22]	1.26 [0.71 - 2.23]	0.95 [0.51 - 1.78]
Living alone: no (ref)	-	-	-	-	-	-	-	-	-
Fixed intercept	0.33 [0.09 - 1.19]	23.31 [3.31 - 164.22]	1.01 [0.16 - 6.38]	17.40 [2.48 - 122.24]	0.78 [0.25 - 2.40]	12.35 [0.60 - 252.57]	5.55 [0.49 - 63.49]	0.09 [0.01 - 1.01]	0.09 [0.01 - 1.39]
<i>Other predictors / confounders:</i>									
Disease: gout	<b>1.82 [1.01 - 3.29]</b>	1.18 [0.63 - 2.18]	0.88 [0.50 - 1.57]	N/A	N/A	1.40 [0.56 - 3.52]	<b>2.73 [1.31 - 5.71]</b>	N/A	1.53 [0.67 - 3.50]
Disease: SpA	1.18 [0.70 - 1.98]	1.36 [0.83 - 2.22]	1.08 [0.70 - 1.67]	N/A	N/A	1.26 [0.60 - 2.63]	1.37 [0.75 - 2.50]	N/A	1.16 [0.57 - 2.38]
Disease: RA (ref)	-	-	-	N/A	N/A	-	-	N/A	-
Mastery	N/A	<b>0.87 [0.82 - 0.93]</b>	0.97 [0.92 - 1.03]	<b>0.86 [0.81 - 0.92]</b>	N/A	<b>0.82 [0.74 - 0.90]</b>	<b>0.84 [0.78 - 0.91]</b>	<b>0.91 [0.84 - 0.98]</b>	<b>0.87 [0.80 - 0.94]</b>
Professionals' global disease impact	0.95 [0.86 - 1.04]	0.94 [0.85 - 1.03]	<b>0.90 [0.83 - 0.98]</b>	0.97 [0.88 - 1.07]	0.94 [0.87 - 1.02]	0.97 [0.85 - 1.11]	0.98 [0.88 - 1.09]	N/A	N/A
Professional type: nurse	0.74 [0.38 - 1.46]	N/A	N/A	0.77 [0.33 - 1.84]	1.10 [0.54 - 2.21]	N/A	N/A	N/A	N/A
Professional type: NP/PA	0.73 [0.39 - 1.37]	N/A	N/A	0.92 [0.41 - 2.09]	0.73 [0.37 - 1.44]	N/A	N/A	N/A	N/A
Professional type: fellow	0.67 [0.27 - 1.64]	N/A	N/A	0.72 [0.28 - 1.85]	1.36 [0.62 - 2.98]	N/A	N/A	N/A	N/A
Professional type: rheumatologist (ref)	-	N/A	N/A	-	-	N/A	N/A	N/A	N/A
Professional gender: male	N/A	N/A	N/A	1.13 [0.55 - 2.32]	N/A	N/A	N/A	N/A	N/A
Professional gender: female (ref)	N/A	N/A	N/A	-	N/A	N/A	N/A	N/A	N/A
How well the professional knew the patient: very well	N/A	N/A	<b>2.60 [1.19 - 5.70]</b>	N/A	1.54 [0.76 - 3.15]	0.74 [0.22 - 2.57]	<b>3.83 [1.45 - 10.09]</b>	N/A	1.40 [0.43 - 4.56]
How well the professional knew the patient: fairly well	N/A	N/A	1.49 [0.78 - 2.87]	N/A	0.91 [0.51 - 1.60]	1.04 [0.39 - 2.78]	1.38 [0.60 - 3.18]	N/A	1.08 [0.42 - 2.78]
How well the professional knew the patient: somewhat	N/A	N/A	1.11 [0.57 - 2.13]	N/A	<b>0.56 [0.31 - 1.00]</b>	0.56 [0.20 - 1.62]	0.95 [0.41 - 2.21]	N/A	0.87 [0.35 - 2.16]
How well the professional knew the patient: not/barely (ref)	N/A	N/A	-	N/A	-	-	-	N/A	-
ICC	0.02 [0.00 - 0.47]	0.04 [0.01 - 0.18]	0.06 [0.02 - 0.16]	0.09 [0.03 - 0.22]	0.06 [0.02 - 0.18]	0.01 [0.00 - 1.00]	0.05 [0.01 - 0.23]	0.11 [0.04 - 0.28]	0.12 [0.04 - 0.30]

**Legend:** Results from adjusted multilevel multinomial models, "no discordance" as reference category. \* n differs between domains due to exclusion of "I do not know" and one patient with missing data for "Mastery". (ref) = reference category (no OR), N/A = not applicable (variable not included in model), HLQ = Health Literacy Questionnaire, ICC = intraclass correlation coefficient, NP/PA = nurse practitioner/physician assistant, OR = odds ratio, RA = rheumatoid arthritis, SpA = spondyloarthritis, 95% CI = 95% confidence interval. **Bold values** indicate p<0.05.



**Figure 1.** Classification of relevant discordance per Health Literacy Questionnaire domain.

Classification by occurrence and direction (i.e. negative (professional scored lower) or positive (professional scored higher) discordance) of relevant discordance between patients' Health Literacy Questionnaire scores and their healthcare professionals' estimation per domain (n = 778).

<https://doi.org/10.1093/rheumatology/keac248/6570604> by Universiteit Maastricht user on 17 May 2022

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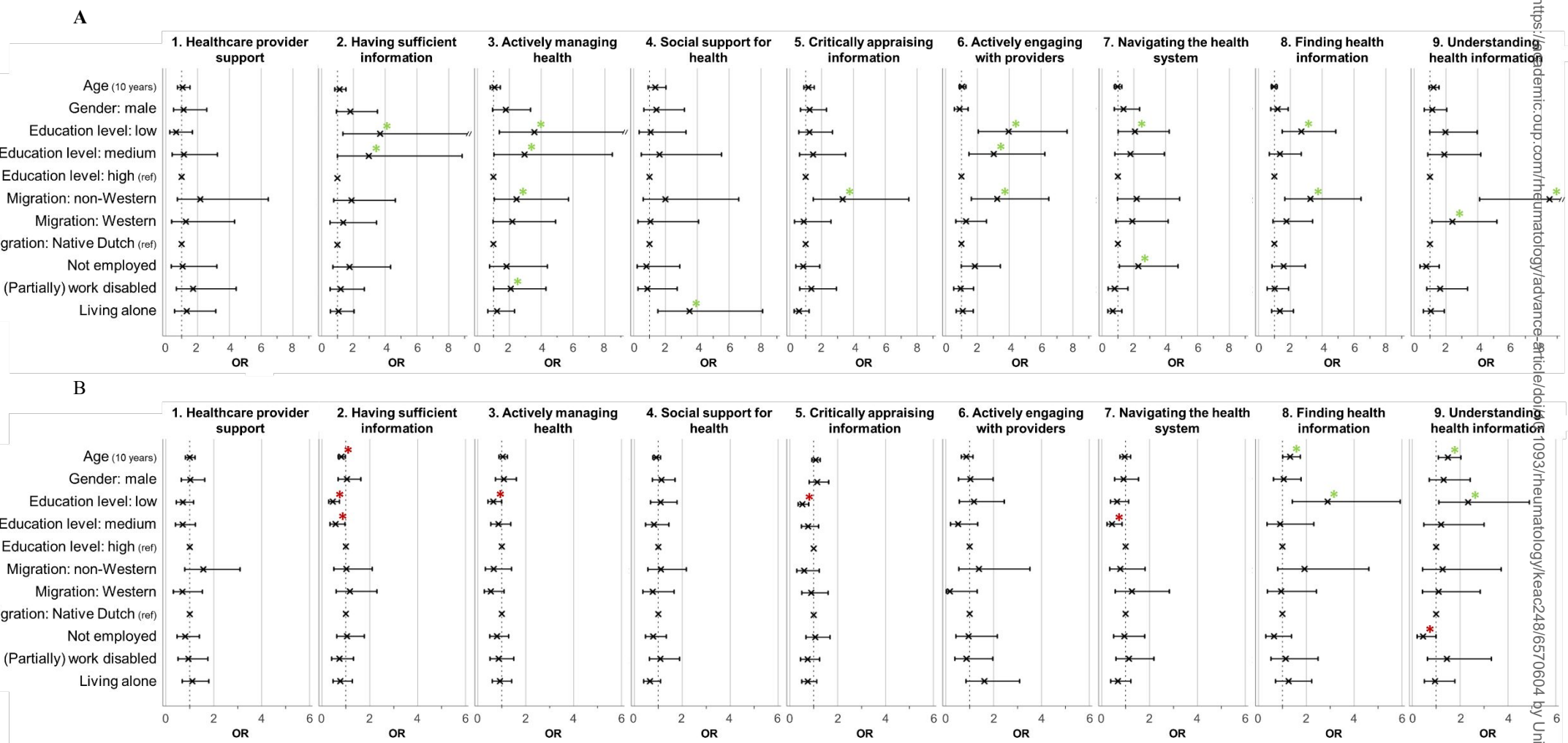


Figure 2. Associations of socioeconomic factors with negative (A) and positive (B) discordance.

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3 Odds ratios (ORs) and 95% Confidence intervals of socioeconomic factors associated with discordance. Figure 2A shows associations with negative  
4 discordance (professionals scored lower vs. “probably the same”). Figure 2B shows associations with positive discordance (professionals scored  
5 higher vs. “probably the same”). \* indicates higher odds with  $p < 0.05$ , \* indicates lower odds with  $p < 0.05$ , // indicates upper limit exceeds 0-9 scale.  
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