One size does not fit all

Document status and date:
Published: 07/07/2023

DOI:
10.26481/dis.20230707mb

Document Version:
Publisher's PDF, also known as Version of record

Download date: 02 Oct. 2023

ONE SIZE DOES NOT FIT ALL

Moving towards health literacy responsive rheumatology care

Mark Matthijs Bakker

ONE SIZE DOES NOT FIT ALL

Moving towards health literacy responsive rheumatology care

by Mark Matthijs Bakker

ONE SIZE DOES NOT FIT ALL
Moving towards health literacy responsive rheumatology care

PROEFSCHRIFT

ter verkrijging van de graad van doctor aan de Universiteit Maastricht,
op gezag van de Rector Magnificus, Prof. dr. Pamela Habibović,
volgens het besluit van het College van Decanen, in het openbaar te verdedigen
op vrijdag 7 juli 2023 om 13:00 uur

door

Mark Matthijs Bakker

TABLE OF CONTENTS

CHAPTER 1

General Introduction

HEALTH INEQUITIES, HEALTH POTENTIAL, AND HEALTH LITERACY

Substantial inequalities in health are present within and between countries, and much of these inequalities are rooted in socioeconomic differences rather than medical factors [1, 2]. According to the World Health Organization (WHO), these underlying social determinants of health (SDH) comprise "*the social, cultural, political, economic and environmental conditions in which people are born, grow up, live, work and age, and their access to power, decision-making, money and resources that give rise to these conditions of daily life*" [3]. When differences in health status are deemed unfair and avoidable, they are labelled health inequities [3]. These inequities are extensively studied in public health and clinical care. People with so-called 'lower socioeconomic status' have a lower life expectancy, live fewer years in good health, are more likely to acquire one or multiple chronic illnesses, and have worse disease outcomes than people of higher socioeconomic status [1, 4, 5]. International recognition of health inequalities originally came with the 1978 Alma-Ata declaration, which stated that "*gross inequality in the health status of the people, particularly between developed and developing countries as well as within countries, is politically, socially, and economically unacceptable*" [6].

Since Alma-Ata, a lot of effort has been made to reduce health inequities, with the aim of 'closing the gap'. However, a focus on SDH and 'closing the gap' may not necessarily lead to equitable health outcomes. In European countries, improvements in absolute mortality rates were achieved over time [7]. In absolute numbers, these improvements were usually (although not always significantly) bigger in groups in disadvantaged positions, thereby reducing absolute inequality. However, looking at the percentage decline in mortality, relative to the pre-existing differences in mortality rates between socioeconomic groups, these were usually smaller in groups in disadvantaged positions [7], thereby increasing relative inequality between groups. Further studies on individual European countries confirm this trend. In Germany, health improvements were seen across all socioeconomic groups, but absolute health inequalities remained constant or even widened over time [8]. In England, an evaluation of a systematic strategy to reduce health inequalities showed that despite making extensive efforts, 'closing the gap' remained a utopia; the target of a 10% reduction of the relative inequality gap in life expectancy and infant mortality was not achieved [9]. Again, while absolute improvements were made in all groups, these were equal or even bigger in the already advantaged socioeconomic group, thereby increasing relative inequality over time, rather than reducing it [9]. In other words, efforts to improve the health of those who need it most predominantly seem to benefit people who are already in a better position. Furthermore, the emergence of Coronavirus Disease 2019 (COVID-19) showed that when health outcomes universally worsen, people in vulnerable positions are hit the hardest. A study conducted in California, USA, suggested that the life expectancy gap between income groups significantly increased, even as all groups faced declines in life expectancy [10]. These examples show that we require interventions that more specifically address the needs of the (disadvantaged)

1

target population. This includes investigating how existing interventions work, and making them work for people with specific needs as well.

In addition to challenges in 'closing the gap', there are challenges related to the conceptualisation of SDH in research and clinical practice. For example, Westbrook and Harvey [11] show that SDH are still widely misunderstood and misrepresented. Despite the admirable intentions of focusing on SDH, public health students and scholars generally get probed to link these to individualised health behaviour rather than taking a holistic approach to the challenges posed by SDH [1, 11]. Moreover, Dijkstra and Horstman [12] argue that some of the findings relating to socioeconomic inequities in health may be produced directly as a result of the categorisation and operationalisation of 'low socioeconomic status' in research. Groups that are considered 'known to be unhealthy' may be framed as such, regardless of the realities found in the data [12]. For example, this is done by placing emphasis only on the results that confirm the hypothesis that lower socioeconomic groups have worse health behaviour and poorer health outcomes. Poorer outcomes that were found on some indicators for higher socioeconomic groups (such as higher specific mortality rates and lower nutritional skills) were either underreported or reinterpreted using additional theory, thereby avoiding 'blame' for the individual with higher socioeconomic status [12]. These studies challenge us to reflect more critically about socioeconomic health inequities, think of new ways to conceptualise and study the underlying causes, and identify factors that can be acted upon.

In 2018, the Dutch Scientific Council for Government Policy (*Dutch: Wetenschappelijke Raad voor het Regeringsbeleid, WRR)* controversially suggested to rethink how to deal with health inequities. Rather than a focus on 'closing the gap' (which had now been attempted but not achieved for decades), it argued to centralise 'health potential': how can we maximise health gains while minimising health loss? [13]. While at first glance this policy brief seems to suggest halting efforts to reduce health inequities, this is not the case per se. Quite the contrary; it argued extra attention be paid to those in worse health or vulnerable positions as one of the three key priorities [13]. Mackenbach [14] argued similarly to rethink health inequalities. Rather than trying to address relative inequity (which is almost mathematically impossible when overall health outcomes are improving), we should focus on reducing absolute inequities: improving the health of those in disadvantaged positions as much as possible [14]. To prevent the relative gap from widening, we should ensure that any interventions or actions reach and benefit these groups. The choices of what interventions or actions to deploy and whom to focus on specifically can differ between contexts.

As argued by different scholars, indeed, the biggest impact might not be made by trying to achieve equal outcomes, but by taking specific action there where the most gains can be made. While people with low socioeconomic status or in worse health might mathematically have the most potential, looking beyond socioeconomic status as the sole, unchangeable cause of their adverse health outcomes is necessary. There is diversity within socioeconomic groups, and efforts to maximise health potential will require us to look beyond these

categorisations to identify specific needs that can be addressed. Three short patient cases illustrate this opportunity:

1. Mike is a sociable man in his early fifties who works at a building site. The other guys there have come to respect him a lot over the years, so he's tasked with some leadership responsibilities. This is great for him, because it means he does not have to do as much of the heavier manual labour anymore. His colleagues have become his friends; they regularly hang out for beers & barbecue. Not all is going well for Mike though, as he was recently diagnosed with gout. The flares cause him a lot of pain, making it difficult to do much at work, but after taking medication for a couple of days, the problem seems to be resolved and he returns to work like nothing happened. His rheumatologist suggested he start urate-lowering therapy and change some of his dietary habits, but Mike has not really engaged with that. "When I do get an attack, the medication works well, so why do they want me to take these meds for months on end? I just wanna live my life." Mike's rheumatologist wonders if there is anything she could do to better help Mike manage his gout.

2. Linda, a single mother of two in her late thirties, is on welfare. She lives in subsidised housing and volunteers a few hours a week at the local community centre. Linda has always struggled to make ends meet and has put her children's needs before her own at every turn in life. In her free time, she used to work a simple sewing machine to make clothes for her children and herself, saving her money while still being able to give her children something new to wear sometimes. When her hands started to hurt, she avoided seeing a doctor for the longest time, afraid she would not be able to afford care. Now, there is radiographic damage to her joints, caused by rheumatoid arthritis, which was left undiagnosed for too long. Linda is now receiving treatment to keep her disease under control, but the damage cannot be undone. Her general practitioner (GP) wonders if anyone (i.e. a medical professional, someone at the community centre, or perhaps someone in Linda's personal network) could have picked up on Linda's issues earlier to prevent some of her health problems. If people like Linda are diagnosed at an earlier stage, their disease outcomes would be significantly better, which actually saves money in the long run, both at an individual and a societal level.

3. John, 42 years old, makes long hours at an accounting firm. "I've always been good with numbers, and I come from a family of entrepreneurs, so getting my finance degree at university was easy for me." What is not as easy for John, was adapting to the new reality of living with a chronic illness. He was diagnosed with axial spondyloarthritis (axSpA) last year. John finds it difficult to find the time to go see his doctor, and he does not always see the point of having a consultation. "If nothing about my treatment changes, why do I have to spend time talking to the doctor?" Conversations with his healthcare providers are in line with his way of life: efficiency is key, so he rarely asks questions. John focuses on taking his medication as prescribed, but he otherwise engages as little as possible with

his disease. His healthcare providers trust he is knowledgeable about important things like medication regimens and cardiovascular risk management, so there does not seem to be much attention for John's health information needs.

These three cases (inspired by real-life examples) illustrate missed health potential in people living with a rheumatic disease. The cases of Mike and Linda clearly show the relationship between their income, work environment, and education background, and adverse health outcomes, as often seen in research on health inequalities. What could help them is not as clear-cut, as changing their socioeconomic background is not immediately possible, and trying to 'close the health gap' and achieve outcomes equal to more affluent patients seems unattainable. So what are the specific needs of Linda and Mike? Equally important, what could health professionals or organisations do to better fit those needs at the time it matters most, and achieve the best outcomes possible for these individuals, without problematising and blaming them as individuals? The case of John is different. By socioeconomic measurements, he may have hit the jackpot, but his story illustrates that education level as a proxy for socioeconomic status may not always tell the whole story. Having obtained a university degree and being classified as a 'highly educated' individual does not help him manage the new challenge that is his chronic illness. On the contrary; his high education level and eloquent speech may trick his healthcare providers into thinking that no additional support is necessary. However, his self-management skills are insufficient, and the main problem is that neither he nor his doctor realises that he does not know all there is to know. In case of a flare, or occurrence of comorbidities, John will not know what to do. John's case may not be a case of inequity per se, and it will not contribute to the 'socioeconomic health gap'. Nevertheless, in John's case, as in Mike and Linda's, there is room to fulfil more 'health potential'. The question is how that could best be achieved.

This thesis focuses on the role of health literacy in this process of maximising health potential, beyond recognition of the role of socioeconomic status, specifically in people with rheumatic and musculoskeletal diseases (RMDs). Health literacy is increasingly recognised as a critical determinant of health [15] and could be a useful asset in maximising health potential. This is especially true for groups in vulnerable socioeconomic positions, because a clear social gradient exists in the relationship between health literacy and health outcomes [16]. Therefore, especially for people like Mike and Linda, but also for people like John, health literacy thinking could provide actionable insights to improve their health. The following sections will further introduce the background of this thesis research by exploring definitions and conceptual models of health literacy impact, measurement tools and associated health outcomes of health literacy, and the background on RMDs and the role of health literacy in this group of medical conditions. After, the current knowledge gaps and subsequently the aims of this thesis will be described.

Definitions

Health literacy was first introduced in 1974 by Simonds [17], in the context of health education programmes in schools (kindergarten through high school). Simonds [17] considered 'health literacy' as a minimum standard that should be achieved at the school level, to be used to identify schools that would need support for better health education teaching. One could say it was used as an indicator on a population level only. Over time, the definition has been refined by many different scholars towards more layered and comprehensive definitions. At times it remained a population-level indicator; other times it was used at an individual level. A pivotal publication in this field was written in 2000 by Nutbeam [18], who first proposed that different levels of health literacy exist within individuals. The first, basic level, 'functional health literacy', is most closely related to general literacy, as it refers to the basic reading and writing skills needed to be able to function in everyday health-related situations [18]. The second, communicative level, 'interactive health literacy', represents more advanced cognitive, literacy and social skills required to extract meaning from different forms of communication, including interactions with health professionals or other people [18]. The third level; 'critical health literacy' represents more advanced cognitive and social skills that can be applied to critically analyse information, and use this information to take control over one's health, as well as advocate for others [18].

Definitions commonly used in the 2000s by the American Medical Association *("The constellation of skills, including the ability to perform basic reading and numeral tasks required to function in the healthcare environment"* [19]) and Institute of Medicine *("The individuals' capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions"* [20]) are clearly linked to Nutbeam's 'functional health literacy' level. In the more comprehensive, multidimensional definitions of health literacy proposed later, all three of Nutbeam's levels of health literacy are more easily recognised [3, 21, 22]. In 2012, Sørensen et al. [21] proposed a comprehensive definition for use in public health, which captured the essence of previously identified definitions: *"Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course".* The most recent definition by WHO in its Health Promotion Glossary of Terms 2021 also acknowledges the importance of an individual's environment, as well as the dynamic nature of health literacy over time: *"Health literacy represents the personal knowledge and competencies that accumulate through daily activities, social interactions and across generations. Personal knowledge and competencies are mediated by the organizational structures and availability of resources that enable people to access, understand, appraise and use information and services in ways that promote and maintain good health and well-being for themselves and those around them."* [3] The definition that inspired the research in this thesis was proposed in 2018 by the International Union for

1

Health Promotion and Education [22]. It is more in line with the clinical nature of this thesis, as it acknowledges the importance of situational resources (including professional and social support), as well as health literacy responsiveness of the healthcare environment: *"Health literacy is the combination of personal competencies and situational resources needed for people to access, understand, appraise and use information and services to make decisions about health. It includes the capacity to communicate, assert and act upon these decisions. Health literacy responsiveness describes the way in which services, organisations and systems make health information and resources available and accessible to people according to health literacy strengths and limitations"* [22]. Other scholars may refer to health literacy responsiveness as 'organisational health literacy', which relates to the existence of 'health literate organisations' [23, 24].

While trends in health literacy definitions indicate a move towards 'more comprehensive, more multidimensional, more holistic' over time, in recent years several more narrow, specific definitions of subtypes of health literacy have been proposed. Some subtypes include mental health literacy [25], oral health literacy [26], COVID-19-related health literacy [27], e-health literacy [28], and navigational health literacy [29]. These subtypes are not subject to further study in this thesis, but they may help to understand the contextual nature of health literacy. Someone may be generally health literate and capable of managing their own health and services, but when a new, unknown health challenge occurs, it may turn out that in this new context, they are not health literate at all.

Finally, while it seems more applicable to a public health or population context than a clinical rheumatology context, 'distributed health literacy' has recently emerged as *"…the health literacy abilities, skills and practices of others that contribute to an individual's level of health literacy"* [30]. This definition acknowledges that health literacy is not merely an individual patient characteristic, but rather a characteristic of a patient in its social and professional environment. In a clinical rheumatology context, distributed health literacy may be helpful in understanding the dynamic between the patient with a chronic condition and their family, friends, and acquaintances [31].

Health literacy impact on health outcomes

Health literacy is hypothesised to impact health outcomes in different ways. Several conceptual models to describe these processes have been proposed by multiple authors. For the purpose of this thesis, three of the main papers are highlighted here.

First, Paasche-Orlow and Wolf [32] described three main causal pathways between health literacy and health outcomes for individuals: access to and utilization of health care, provider-patient interaction, and self-care [Figure 1.1]. Within these three pathways, from a patient's point of view, there are intrinsic factors of relevance (e.g. self-efficacy, knowledge, motivation), and extrinsic or system factors of relevance (e.g. health system complexity, healthcare provider communication skills, support technologies). It also acknowledges the personal and

socioeconomic characteristics that are interconnected with a person's health literacy, such as income level, social support, education level, age, verbal ability and memory [32].
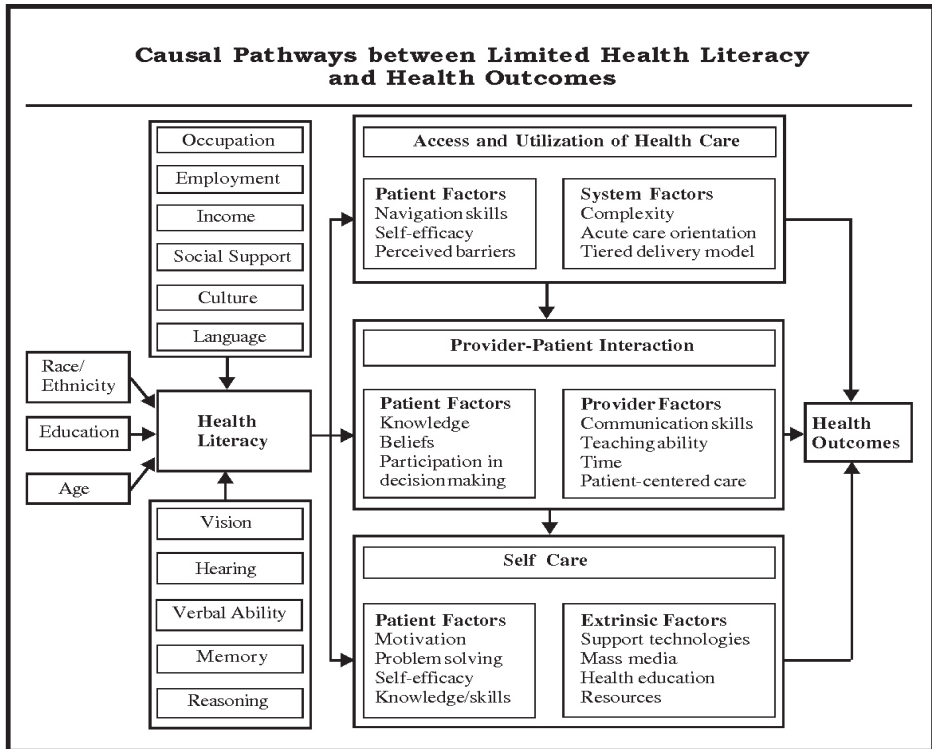
Figure 1.1 Causal Pathways between Limited Health Literacy and Health Outcomes, a model as proposed by Paasche-Orlow and Wolf [32]

Second, Sørensen et al. [21] proposed an integrated model of multiple previous definitions to look at health literacy from a public health perspective, ranging from the individual level (in healthcare; medical literacy) to the population level (disease prevention, health promotion; public health literacy) [Figure 1.2]. The model incorporates the three levels of health literacy according to Nutbeam [18] by considering people's knowledge, motivation and skills to access, understand, appraise and apply health information in the three domains of relevance to public health: healthcare, prevention, and health promotion. Shaped by situational and personal determinants, health literacy is considered an asset to patient empowerment in these three domains, with the aim to impact health behaviour, service use, participation and equity, and thereby improve outcomes [21].
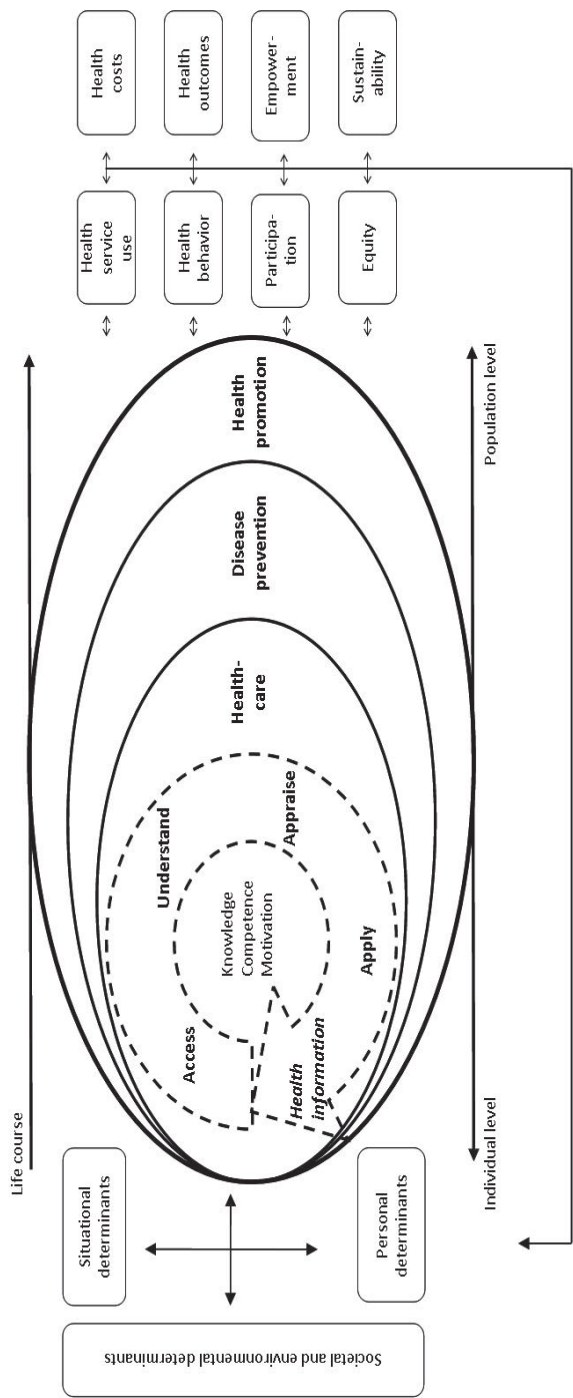
Figure 1.2 Integrated model of health literacy, as proposed by Sørensen et al. [21]

Third, the influential systematic review by Stormacq et al. [33] further explored the role of health literacy as a mediator in the relationship between socioeconomic status and health status, quality of life, health-related outcomes, health behaviours, and the use of preventive services. Where Sørensen et al. [21] & Paasche-Orlow and Wolf [32] proposed conceptual models based on a review of definitions, Stormacq et al. [33] reviewed empirical studies that quantified the role of health literacy. The paper emphasises the modifiable nature of health literacy as a risk factor, and thereby the potential for impact on health outcomes through improving the health literacy of people as well as taking people's health literacy needs into account [33]. The review conceptualised health literacy as a mediator, thereby supporting the existing conceptual models that hypothesised this relationship. Health literacy can function as potential leverage for action on the relationship between social determinants (which can be difficult to influence directly) and health outcomes [33]. However, addressing health literacy needs does not alleviate the underlying socioeconomic conditions themselves, nor does it counteract all possible negative effects, and health literacy initiatives should not be seen as a replacement for action to improve people's socioeconomic position, but rather as a complementary strategy in achieving equity in health [33].

Looking at the three patient cases again now, it becomes apparent that there may be a health literacy issue in each of them. For Mike, it is about having the capacity to understand and oversee long-term consequences, and the ability to act upon his health issues (competencies). For Linda, things may have been different if she would have had someone (situational resources) who could help her find out about ways to seek help free-of-charge, for instance by seeing a specialist at her GP's office, or about the long-term consequences of care avoidance, both medically and financially. Lastly, in John's case, his lack of engagement with his healthcare providers is rooted in his lacking capacity to adequately communicate about health issues, and his inability to appraise the information that is available to him, as a 'newbie' in the medical field (competencies). This dissertation explores how we could improve support to people like Mike, Linda and John through health literacy thinking.

MEASUREMENT AND ASSOCIATED HEALTH OUTCOMES

Tools for research and practice

Much like the evaluation of definitions and conceptual models, measurement tools of health literacy have developed over time. Haun et al. [34] provide a comprehensive overview of the scope and characteristics of 51 health literacy measurements, reflecting this development. Initial measures were closely linked to literacy (i.e. reading ability), such as the (Short-Form) Rapid Estimate of Adult Literacy in Medicine (REALM(-SF)) [35, 36] or Medical Achievement Reading Test (MART) [37], and/or comprehension, such as Samora et al. [38]'s 'Comprehension

of 50 medical terms' and the (Short) Test of Functional Health Literacy for Adults ((S-)TOFHLA) [39, 40]. Notably, the early measurement scales often reflected a unidimensional definition of health literacy, most closely related to Nutbeam's functional health literacy level.

Other tools commonly used in research are the performance-based Newest Vital Sign (NVS) and the Single Item Literacy Screener (SILS). The NVS has people interpret a nutritional label and answer six questions. People who answer less than four questions correctly are at high risk of having limited health literacy. The NVS has been applied in diverse settings, but its use is controversial as people may feel like they are being tested and judged, and the relation to nutrition may not be relevant to all health settings. The SILS has people answer the question "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?" on a 5-point Likert scale (1=never, 2=rarely, 3=sometimes, 4=often, 5=always) with any score higher than 2 considered as limited reading ability. The SILS can act as a screening tool to assess which patients may need additional support in clinical practice, because it is easy to administer and relates to difficulty with health information specifically, rather than reading ability or education level alone. However, while the construct validity of the SILS was found to be adequate [41], correlations with REALM and S-TOFHLA scores were found to be weak [41, 42].

More recently, there has been a push towards using multidimensional measurement tools, reflecting the complex nature of health literacy beyond unidimensional categorisations of 'high' and 'low' health literacy. Most well-known are the European Health Literacy Survey (HLS-EU-Q [16, 43]) and the Health Literacy Questionnaire (HLQ [44, 45]). The HLS-EU-Q was developed by Sørensen et al. [43] to measure and compare health literacy in populations in different European countries. In contrast with most tools available at the time, the HLS-EU-Q was specifically designed to be used in the public health context rather than a clinical context [43]. The original 47-item version measures health literacy in relation to the key processes of 1) accessing, 2) understanding, 3) appraising and 4) applying health-related information, in the context of a) health care, b) disease prevention, and c) health promotion. People are assigned an index score (0-50, where 0 represents 'least possible' and 50 represents 'best possible' health literacy) for their general health literacy, as well as scores for their health literacy in the context of health care, diseases prevention, and health promotion separately. Index thresholds have been proposed, resulting in four levels: 1) 'inadequate' (0-25 points), 2) 'problematic' (>25-33 points), 3) 'sufficient' (>33-42), and 'excellent' (>42-50) health literacy. The lowest two levels are commonly combined as 'limited health literacy' [16]. Short-form versions of the HLS-EU-Q (16, 12 or 6 items) have been developed and validated, only providing an index score for general health literacy [46-48].

Health Literacy Questionnaire

The HLQ, central to the work in this thesis, was developed in Australia by Osborne et al. [44] to provide actionable insights to improve individuals' health literacy as well as identify ways

for services to accommodate people with different health literacy needs. In the development process, the authors combined data from concept mapping workshops and patient interviews with input from Outcome Measures in Rheumatology (OMERACT) expert workshops [44], to respond to a clear need seen in the field. Rather than providing a single summary score or categorisations of 'high' and 'low' health literacy, the HLQ provides a score on nine distinct domains of health literacy (Table 1.1).

Table 1.1 Nine domains of the Health Literacy Questionnaire

Domain	Description
Part I	
1	Feeling understood and supported by healthcare providers (4 items)
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)
Part II	
6	Ability to actively engage with healthcare providers (5 items)
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)

Legend: Part I measures the 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 the 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).

The HLQ requires for an individual to answer 44 questions (4 to 6 questions per domain). In case of limited missing data (no more than 2 for domains with 4 or 5 items, no more than 3 for domains with 6 items), the developers of the HLQ suggest using Expectation Maximization algorithm syntax to compute domain scores. Domain scores reflect the mean score of all items within that domain [49]. Together, the nine domain scores form a patient's health literacy profile, showing limitations, as well as possible strengths that can be used to compensate for limitations. The HLQ has been translated and cross-culturally validated in multiple languages and is being used in research and practice all over the world. The validation process in the Dutch language was conducted in a sample of people living with chronic illness, and the authors concluded the questionnaire was a real asset in clinical care and public health research [45].

1

Empirical evidence of the impact of health literacy on health outcomes

In recent years, the body of research in the field of health literacy has been expanding rapidly [50]. As Paasche-Orlow and Wolf [32] pointed out in their paper outlining the causal pathways between health literacy and health outcomes, this comprised a theoretical model, and research should strive to confirm the hypothesised associations. Researchers have followed this recommendation and since 2017, WHO indeed recognises health literacy as a critical determinant of health, officially since the 9th Global Conference on Health Promotion in Shanghai, China [15], following the ever-increasing evidence on the role of health literacy in health behaviours and outcomes. For example, Jayasinghe et al. [51] found 'limited' health literacy to be associated with health behaviours such as smoking and insufficient physical activity, as well as physical and mental health outcomes. An influential review by Berkman et al. [52] from 2011 showed that 'limited' health literacy was consistently associated with poorer health outcomes and less adequate use of healthcare services (such as increased use of emergency services and inadequate intake of medication). At the same time, their team found that not all health literacy interventions were successful in alleviating the burden of 'limited' health literacy on health outcomes [53], indicating that there is no 'quick fix' for the problem at hand. A paper by van der Heide et al. [54] later confirmed that the association between health literacy and health outcomes was also relevant to the Dutch context. In light of this evidence, it is unsurprising that WHO has made health literacy an integral concept in the fight against non-communicable diseases (NCDs) [55, 56].

With the emergence of the Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) leading to the COVID-19 pandemic, it became abundantly clear that health literacy is as important in the prevention of communicable diseases as it is in NCDs [57]. Simply knowing or understanding health risks (having functional health literacy) was insufficient in light of scientific uncertainty, complex interventions, competing interests (public health vs individual interests) and an overflow of information of differing quality [57, 58]. An extensive study in Germany showed that while people generally felt like they had enough information and that it was easy to find, they also found it difficult to judge whether information was reliable, and more than half of the respondents reported feeling confused about coronavirus information [27]. More comprehensive, critical health literacy (i.e. Nutbeam's third level [18]) was required to navigate the complex health challenges related to COVID-19 [27, 58]. This was true for people who were generally healthy, as they were presented with a novel challenge of navigating the risk of acquiring an infectious disease, but especially for people with pre-existing conditions, who were perhaps more vulnerable to infection or a severe disease course [59-61]. Patients with pre-existing NCDs faced the additional challenge of having to manage their illness in an environment that had now changed. In light of the dynamic and context-specific nature of health literacy, this was a demanding endeavour, even for patients who were generally considered to have 'adequate' or 'good' health literacy. Additionally considering the role of health literacy in vaccine hesitancy [62], the perceived susceptibility to infection [63,

64], and the likelihood of taking preventive measures [65], the relevance of including health literacy thinking in policy for patients with NCDs, also in times of crisis, is imperative.

HEALTH LITERACY AND RMDs

Background on RMDs

Increasingly seen as a critical determinant of health, health literacy constitutes a promising pathway to reducing the burden of NCDs [15]. This is highly relevant in the context of rheumatology, with RMDs (chronic RMDs in particular) often requiring long-term, complex care leading to complex interactions between patients and health professionals. Patients are increasingly expected to take up an active role in decisions about medication, lifestyle, and support [66, 67], making addressing patient health literacy needs a potential key component to success.

Rheumatic and musculoskeletal diseases (RMDs) are highly prevalent across the globe and account for a significant proportion of the burden of NCDs. According to the 2019 Global Burden of Disease (GBD) study, all RMDs combined (explicitly including rheumatoid arthritis (RA), osteoarthritis (OA), low back pain, neck pain, gout and other musculoskeletal disorders) account for 17.1% of the total years lived with disability (YLDs) [68]. Moreover, 9.3% of disability-adjusted life years (DALYs) attributed to NCDs are caused by RMDs [68]. The proportion of overall disease burden caused by RMDs has slowly but surely increased since the first measurements in 1990, and is expected to increase further as a result of global population ageing [69, 70] and improved diagnostics in low- and middle-income countries (LMICs) [71]. It is therefore unsurprising that researchers and practitioners across the world are working to reduce or prevent further growth of the burden of RMDs. This thesis primarily focuses on three of the most common inflammatory rheumatic conditions: rheumatoid arthritis (RA), spondyloarthritis (SpA) and gout.

The global prevalence of RA is about 0.25%, and it affects more women than men [68]. In Western countries, a prevalence of up to 1% is reported [72, 73]. RA is an autoimmune disease; the immune system mistakenly attacks the body's own cells, causing inflammation in (multiple) joints and surrounding tissues, such as tendons, entheses and bursae. Characteristic symptoms include painful and swollen joints and general fatigue. If remained untreated, RA can cause long-term joint damage, disability, and characteristic rheumatic deformities. However, owing to significant improvements in treatment options for RA in the past decades, it is now possible to reach low disease activity or even clinical remission in most patients [74], which in turn significantly improves long-term outcomes for patients with RA. Recent guidelines recommend treatment with Disease-Modifying Anti-rheumatic Drugs (DMARDs) of patients with RA is started early, i.e. as soon as the diagnosis is made [74]. Firstly, conventional

synthetic DMARDs (csDMARDs) (primarily methotrexate) are considered. If treatment targets are not achieved with csDMARDs, a biological (bDMARD) or targeted synthetic (tsDMARD) can be added. Initiating a bDMARD is a significant step, both from a societal (high costs) and medical (risk of infection) perspective. At the Maastricht University Medical Center (MUMC+), patients who are prescribed a biological for the first time are therefore supported by a specialised team of nurses before initiating the new therapy.

The prevalence of SpA is less studied than that of RA, and is not explicitly mentioned in GBD data. Nevertheless, a 2016 systematic review of prevalence estimates found that it ranges from 0.20% to 1.61% [75]. SpA is an umbrella term for a group of rheumatoid factor negative conditions related to human leukocyte antigen (HLA) B27 and encompasses axial SpA, with symptoms primarily manifesting around the spine and sacroiliac joint, and peripheral SpA with symptoms primarily manifesting in peripheral joints and entheses. A specific subtype of peripheral SpA is psoriatic arthritis (PsA), in which arthritis symptoms are accompanied by (risk of developing) the skin condition psoriasis. The different subtypes of SpA require different types of treatment strategies. Some treatment regimens also involve bDMARDs, which brings along the same concerns as mentioned above for RA. In comparison to RA, SpA generally manifests earlier in life, and affects more men. The different demographics of the disease population also mean that patients may have different needs.

Gout is the most common inflammatory rheumatic disease with a global prevalence of about 0.72% according to GBD 2019 data [68], although Dehlin et al. [76] argued the prevalence may range between <1% and 6.8% depending on the study population. Gout is a metabolic disorder, resulting from a disrupted balance of serum uric acid and is characterised by the deposition of monosodium urate crystals in the synovial fluid and other tissues surrounding the joints. Commonly, the first gout flare manifests itself in the big toe, but it may extend to other joints when the disease remains untreated. Advanced gout is characterised by tophi, an organised chronic foreign body granulomatous inflammatory response to the deposition of monosodium urate crystals [77]. Contrary to RA and SpA, lifestyle-related factors (specifically overweight and obesity) are strongly related to the occurrence of hyperuricaemia (and thus gout). Compared to RA and SpA, drug treatment of gout is less complex. Inflammation during acute attacks can be tackled by nonsteroidal anti-inflammatory drugs (NSAIDs), colchicine, corticosteroids, or a combination of medications, while long-term gout management may be done using urate-lowering therapy (ULT) [78]. Besides pharmacological intervention, changes in lifestyle are an important component of gout management, as well as in the prevention and/or management of comorbidities such as cardiovascular disease and diabetes mellitus. Despite gout generally being well-understood and treatable, both patient factors (i.e. experience and beliefs, adherence) and physician factors (i.e. knowledge of management guidelines and information provision to patients) can be barriers to optimal disease management [79, 80].

All three conditions described above require different but consistently complex interactions between patients and the healthcare system, and patients and health professionals, thereby making it difficult to achieve optimal outcomes (i.e. remission). In that light, exploring the role of health literacy in this care process can be of interest. To improve healthcare delivery to patients with RA, SpA and gout, the first knowledge gap this thesis aims to fill is: What **are** the health literacy needs of patients with RMDs?

Health literacy and RMDs

The conceptual models of health literacy impact and the known associations of health literacy and health outcomes related to NCDs and COVID-19 foreshadow the impact in rheumatology. Why would it be relevant to address the health literacy needs of people with RMDs? Research into the relationship between health literacy and outcomes in rheumatic diseases is rapidly emerging, and an increasing number of scholars investigated the role of health literacy in rheumatology. While different measurement scales are used and comparison between studies is difficult, a review of the literature sheds light on the overall impact of health literacy in rheumatology care. For example, Caplan et al. [81] found a strong association between limited health literacy (measured with the SILS) and worse functional status in patients with RA, also after adjusting for educational attainment. Hirsh et al. [82] found that health literacy (measured with SILS, S-TOFHLA and REALM) was associated with disease severity in multivariable analysis. Kuipers et al. [83] found health literacy (measured with the health education literacy (HELP) scale)) to be associated with disease activity and quality of life indicators. Maheswaranathan et al. [84] linked limited health numeracy to higher disease activity in systemic lupus erythematosus (SLE), and Katz et al. [85] found associations of health literacy with multiple diverse patient-reported outcomes. Nevertheless, health literacy should not be seen as the 'one concept solving all inequities'. Loke et al. [86] reviewed multiple studies using measures of functional health literacy that did not show a significant association between limited health literacy and worse health outcomes, even though limited functional health literacy was common in patients with RMDs. It appears that associations of health literacy may be dependent on the definition of health literacy and the measurement tools used. Moreover, in all these studies it is important to note that while health literacy explains some of the variability, it is not the sole predictor of disease outcomes.

Health literacy is not only a relevant predictor of health outcomes, but also one of successful patient-provider interaction and patient participation, for example in shared decision-making (SDM). For example, Hirsh et al. [87] discovered that higher functional health literacy (as measured with the REALM and S-TOFHLA) of patients with RA was associated with lower discordance between the patient's and provider's global assessment of disease activity. Martin et al. [88] suggested people with limited health literacy were less likely to accept a change in DMARD, if given the option. Barton et al. [89] found that in patients with RA, SDM was less common in patients with limited health literacy. Similarly, Mattukat et al. [90] found

that patients with more health literacy difficulties were more likely to prefer not to participate in clinical decision-making. Edmonds et al. [91] found that among older patients, patients with limited health literacy (as screened with the SILS) were less likely to use a web-based portal to access their bone density test results. Hirsh et al. [92] suggested that patient-reported measures of disease activity or general health in patients with RA may be confusing to people with limited health literacy, which could lead to unreliable results. Patients with limited health literacy (as measured with S-TOFHLA) more often require help with administering a patient global visual analogue scale [92]. Similar issues may occur in goalsetting: Barton et al. [93] found evidence that patients with limited health literacy and their physicians might not always agree on the treatment goals, which could lead to further problems in communication and adherence. The OMERACT Equity Special Interest Group also suggested the importance of acknowledging health literacy in research, as people with limited health literacy may not respond to standardised questionnaires the same way as people with higher levels of health literacy (with whom questionnaires are often developed and validated), or at all [94]. This could lead to biased results. The OMERACT group also argued that measures should be tested for cultural equivalence and understandability [95].

As hypothesised in the conceptual models, several studies also confirmed the role of health literacy in motivation. Park et al. [96] identified limited health literacy (although subjectively defined as researcher-reported reason for non-adherence) as a major reason for women with RA to discontinue oral bisphosphonates for the treatment of osteoporosis. Similarly, Kim et al. [97] point to limited health literacy (as assessed by (suspected) reason of non-adherence) as the major reason for patients with gout to discontinue their long-term urate-lowering therapy, and Hunter et al. [98] found that patients with osteoarthritis were less likely to adhere to guideline-recommended self-care strategies if they had limited health literacy.

Health literacy interventions and RMDs
Due to the diverse nature of health literacy needs and the complexity of potential interventions to address them, it is to be expected that health literacy programmes show conflicting results in RCT studies. Rudd et al. [99] described an intervention focusing on the use of plain language materials and two sessions with a health educator intended to reduce low literacy barriers, but found no different outcomes to regular care after one year of follow-up. Two main lessons were derived from this study: first, participants had high health literacy levels and perhaps did not need the intervention; second, the long disease duration of participants may mean that patient-provider interactions and patient knowledge and experience may have already been firmly established, waiving the need for a health literacy intervention at that stage in the disease. This study highlights both the difficulty and importance of providing health literacy responsive care to those who need it most. In addition, it shows the role of selection bias in health literacy work. It is crucial to set up studies as inclusive as possible, in order to

successfully include people of the target population (with health literacy needs) and make sure the findings reflect their values and needs.

Among other interventions tested, Lopez-Olivo et al. [100] found that providing multiple modes of information (multimedia tool and printed booklet) to women with limited health literacy (as measured with a single item screener based on Chew's items) increased decisional conflict, i.e. made things more confusing than just offering one type: a printed booklet. Egerton et al. [101] found that people with limited health literacy reaped less immediate benefits from an instruction video that was supposed to foster self-management in patients with knee osteoarthritis, indicating that standard interventions may be less effective in patients with limited health literacy. Hirsh et al. [102] showed that adopting a Universal Precautions strategy in rheumatology, specifically using teach-back, can improve medication adherence in patients with RA, and possibly reduce disease activity.

The evidence listed above highlights the relevance of health literacy in rheumatology care, showing many associations between health literacy and intermediate and long-term health outcomes. However, it also shows the complexity of these associations, and how they are dependent on the measurement tool used, the population included in the study, and the adaptation to patients' needs in the local context. Furthermore, associations between health outcomes and multidimensional measures of health literacy, and the explicit health literacy needs of patients remain understudied. There is also a lack of clarity about what health professionals and organisations could do to help patients with specific health literacy needs. Therefore, the second knowledge gap this thesis aims to fill is: How can we **address** health literacy needs in rheumatology practice?

Addressing health literacy needs

Owing to the multidimensional nature of health literacy, and the diverse pathways through which health literacy may impact outcomes, there are multiple ways to go about addressing health literacy needs. A first possible strategy would be to *improve the health literacy of individuals or populations through health education programmes*. These can target broad health literacy skills (e.g. understanding the basics of a healthy lifestyle to promote good health as well as how to self-manage your health) or be targeted at managing some (chronic) conditions. The first type of intervention is commonly conducted in a school setting, where they are successful in improving participants' health literacy as well as relevant health indicators. Well-known examples include the HealthLit4Kids programme in Australia [103], and the Healthy Primary School of the Future in the Netherlands [104]. While the latter only implicitly addresses improving health literacy, it is a core value of the HealthLit4Kids programme [103], which advocates for embedding health literacy in the school curriculum, rather than teaching health literacy as an 'add-on' [103, 105]. An example of an intervention targeted at a specific condition or health problem (often later in life), is the 'Voel je goed!' (*English:* 'Feel good!') programme in the Netherlands [106]. This is a group-based intervention

1

for adults with limited literacy and overweight (defined as a Body Mass Index over 25,0), in which they follow twenty weekly classes geared towards improving physical activity, dietary habits and literacy of the participants under the supervision of a trained volunteer and a dietician. Besides improving health outcomes, the pilot programme proved to be successful in improving participants' critical health literacy (Nutbeam's third level of health literacy [18]) in particular [106]. While these examples show that improving individuals' health literacy can be useful, this may not be as applicable to a clinical setting, where time with individual patients is limited.

A second possible strategy would be to *organise health care and public health services in such a way that the health literacy of the population is not a limiting factor* in using these services successfully. This is best exemplified in the Universal Precautions approach, in which care is improved and simplified for all patients regardless of their health literacy level. Essentially, it assumes that all patients may have (hidden) health literacy needs, and healthcare delivery should take that into account. For this purpose, a 'Universal Precautions Toolkit' was developed by the Agency for Healthcare Research and Quality (AHRQ) [107]. This toolkit was later specifically adapted to the rheumatology context [108], containing 22 implementable tools in rheumatology care, albeit in the context of United States health care. While this validated approach could likely improve care in many healthcare organisations, it constitutes a 'one-size-fits-all' policy that may not be a good fit with local needs. Furthermore, this strategy is limited to the users of these services, and may not reach individuals who do not engage with the services to begin with.

A third possible strategy would be to *identify and address every individual's health literacy needs at the point of care*. However, identifying each individual's health literacy needs and coming up with tailor-made interventions is generally considered unfeasible due to constraints in time and resources. Therefore, a fourth and last possible strategy comes to mind. One could consider this *a population needs-based approach*. Rather than trying to develop interventions that consider the health literacy of a single individual at the point of care, they would aim to identify the health literacy needs of the specific patient population, in order to develop healthcare delivery in such a way that it addresses those population needs. To this end, the OPtimising HEalth LIteracy and Access (Ophelia) approach was developed [109-111]. This approach, originally applied in general health and community service organisations in the state of Victoria, Australia, is a systematic outcomes-oriented health literacy intervention development process [109]. The approach focuses on two questions: 1) what are the health literacy needs of the population?; and 2) how can health services interpret and respond to these needs to achieve positive health and equity outcomes for their patients? [109]. To answer the first question, the approach leans on the Health Literacy Questionnaire to identify context-specific needs. Qualitative interactions with patients and healthcare providers are primarily used to answer the second question, leading to implementable 'solutions' to identified patients' health literacy needs [109, 110]. This may lead to the establishment of 'health literacy

interventions', specific activities or formalised programmes to improve health literacy and/or health literacy responsiveness. However, oftentimes the described 'solutions' pertain to small changes or integration of existing tools into daily practices of healthcare professionals or organisations, or adjustments to health and social policy. In this case, we speak of 'health literacy actions'. Implementation of the Ophelia approach permits considerable flexibility; practical needs may differ between countries, settings, and medical specialties. However, there are eight core principles always underlying Ophelia work: focus on outcomes, driven by equity, co-design, diagnosing needs, driven by local wisdom, sustainability, responsiveness, and systematic application [110, 111]. Ophelia projects are being conducted all over the world in diverse contexts [112], including mental health services [112, 113], schools [103, 114], cardiac rehabilitation [115], primary care [116], and services for people with specific NCDs such as inflammatory bowel disease [117], diabetes [118, 119], or Chronic Obstructive Pulmonary Disease (COPD) [120].

This thesis describes the first application of the Ophelia approach in The Netherlands, aiming to identify health literacy needs and uncover strategies to address the patient population's health literacy needs in rheumatology. However, successfully implementing interventions and achieving organisational change is highly dependent on the organisation or system and the professionals working within them [121]. Therefore, the third knowledge gap this thesis aims to fill is: How ready are rheumatology *organisations* in the Netherlands for addressing health literacy needs?

The organisational perspective

Addressing health literacy needs in clinical practice requires action from an organisational perspective. This implies organisational readiness as well as awareness among individual healthcare providers. Regarding the latter, research shows that health professionals in The Netherlands want to take patients' health literacy needs into account, but do not always know how to do so [122]. Additionally, it can be difficult to recognise patients' health literacy needs in practice. Studies in various settings reported significant under- and overestimation of patients' health literacy by health professionals [123, 124]. This appears to be especially true when the patient-professional relationship still needs more time to develop [124]. However, available studies have not been conducted in the Netherlands, among patients with RMDs, or using multidimensional measures of health literacy such as the HLQ.

Organisational readiness for health literacy interventions is highly dependent on the baseline health literacy responsiveness of an organisation. Brach et al. [24] argued that a health literate organisation is one that sees health literacy as a core organisational value, not one that just implements health literacy interventions. They defined 10 attributes for a health literate organisation, relating to communication, leadership, planning and evaluation, preparing the workforce, involving consumers and ensuring easy access. Trezona et al. [23] developed a framework for organisation health literacy responsiveness, which summarised and further

defined some of the factors discussed by Brach et al. [24] but additionally included the external policy and funding environment, and partnerships with other organisations. Both frameworks refer to health literate organisations as those who have implemented health literacy thinking in a whole-of-organisation approach. Accordingly, Trezona et al. [23] suggested a definition of health literacy responsiveness that goes beyond that of Bröder et al. [22]; *"The provision of services, programs and information in ways that promote equitable access and engagement, that meet the diverse health literacy needs and preferences of all people, and that support individuals and communities to participate in decisions regarding their health and wellbeing, which is achieved through supportive culture and leadership, supportive systems, policies and practices, and an effective workforce."* A truly health literacy responsive organisation has health literacy thinking embedded throughout, meaning that the population's health literacy needs are taken into account by default, no matter the context. It is thereby crucial to acknowledge that this responsiveness may look different in other countries, sectors or medical specialties. Health literacy responsiveness implies responsiveness to the needs of people in the local system.

The emergence of COVID-19 organically presented a test case of organisational readiness for health literacy thinking for us to explore, as it required swift action from healthcare organisations. Taking health literacy into account is admittedly difficult on short notice in a crisis situation, although it is possible [57]. This is especially true if health literacy thinking is already embedded in an organisation, or if at least some efforts to adapt to patients' health literacy needs are already being made. The COVID-19 crisis showcased how responsive to health literacy needs organisations really are by default, when time and resources for carefully planned interventions are lacking, and thus provided a new angle to health literacy research from an organisational perspective.

Aims of the thesis

Contributing to emerging health literacy research with regard to the mentioned knowledge gaps, this thesis has the following aims:

1. To identify health literacy needs of patients with RMDs in Dutch rheumatology clinics.
2. To co-create solutions to better align rheumatology care with the health literacy needs of patients.
3. To explore current awareness of health literacy needs in rheumatology care from an organisational perspective.

THESIS OUTLINE

Part I: Identifying health literacy needs

Identifying the health literacy needs of the patient population is a key first step towards health literacy responsive rheumatology clinics. In Part I, **Chapter 2** describes 10 distinct health literacy profiles among patients with rheumatic diseases attending outpatient rheumatology clinics using cluster analyses of HLQ data. **Chapter 3** confirms the relevance of these health literacy profiles in clinical practice, by describing associations with disease activity and medication prescriptions in patients with RA.

Part II: Opportunities for improvement

Having discussed the population's health literacy needs, Part II of this thesis is focused on how to address those needs. To this end, **Chapter 4** describes the systematic process of needs assessment and co-creation with patients and health professionals in a process towards health literacy actions. **Chapter 5** contextualises the work in this thesis by presenting diverse health literacy intervention development projects addressing non-communicable diseases (NCDs) in different European countries under the WHO National Health Literacy Development Projects (NHLDP) initiative.

Part III: Organisational perspectives

Health literacy responsiveness includes organisational readiness for health literacy thinking. The focus of Part III of this thesis is therefore on these organisational perspectives, and the current readiness of healthcare professionals and organisations. Firstly, implementing individualised health literacy interventions at the point of care would require measurement of the patient's health literacy or accurate estimation of the patients' needs by the health professional. To investigate whether health professionals are aware of their patients' health literacy levels and thereby comment on the feasibility of relying on professionals' estimations, **Chapter 6** explores the discordance between patients' health literacy scores and professionals' estimations of patients' health literacy. Secondly, while work on this thesis was ongoing, the Coronavirus Disease 2019 (COVID-19) pandemic created a major challenge for patients, professionals, and health systems. We took this unique opportunity to learn about the way rheumatology organisations already consider patients' health literacy needs in practice. Therefore, **Chapter 7** explores the consideration of patients' health literacy needs in COVID-19 crisis communication during the first wave of the pandemic.

Finally, **Chapter 8** comprises a summary and general discussion of the findings presented in this thesis, including contextualisation of our findings, and future implications for health literacy and rheumatology research and clinical practice.

1

REFERENCES

1. Commission on Social Determinants of Health. *Closing the gap in a generation: health equity through action on the social determinants of health.* Final Report of the Commission on Social Determinants of Health. Geneva, Switzerland: World Health Organization; 2008.

2. Marmot M. Social determinants of health inequalities. *Lancet.* 2005;365(9464):1099-104. doi:10.1016/S0140-6736(05)71146-6.

3. *Health Promotion Glossary of Terms 2021.* Geneva, Switzerland: World Health Organization; 2021.

4. Marmot M, Allen J, Bell R, Bloomer E, Goldblatt P. WHO European review of social determinants of health and the health divide. *Lancet.* 2012;380(9846):1011-29. doi:10.1016/s0140-6736(12)61228-8.

5. van der Heijden P. *Sociaal-economische status en gezondheid.* Utrecht, The Netherlands: Nivel; 1990.

6. World Health Organization. *Declaration of Alma-Ata.* International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978. http://www.who.int/publications/almaata_declaration_en.pdf

7. Mackenbach JP, Kulhánová I, Artnik B, Bopp M, Borrell C, Clemens T, et al. Changes in mortality inequalities over two decades: register based study of European countries. *BMJ.* 2016;353:i1732. doi: 10.1136/bmj.i1732.

8. Lampert T, Kroll LE, Kuntz B, Hoebel J. Health inequalities in Germany and in international comparison: trends and developments over time. *J Health Monit.* 2018;3(Suppl 1):1-24. doi: 10.17886/rki-gbe-2018-036.

9. Mackenbach JP. Can we reduce health inequalities? An analysis of the English strategy (1997–2010). *J Epidemiol Community Health.* 2011;65(7):568-75. doi:10.1136/jech.2010.128280.

10. Schwandt H, Currie J, von Wachter T, Kowarski J, Chapman D, Woolf SH. Changes in the Relationship Between Income and Life Expectancy Before and During the COVID-19 Pandemic, California, 2015-2021. *JAMA.* 2022;328(4):360-6. doi:10.1001/jama.2022.10952.

11. Westbrook M, Harvey M. Framing health, behavior, and society: a critical content analysis of public health social and behavioral science textbooks. *Crit Public Health.* 2022:1-12. doi:10.1080/09581596.2022.2095255.

12. Dijkstra I, Horstman K. 'Known to be unhealthy': Exploring how social epidemiological research constructs the category of low socioeconomic status. *Soc Sci Med.* 2021;285:114263. doi:10.1016/j.socscimed.2021.114263.

13. Broeders D, Das D, Jennissen R, Tiemeijer W, de Visser M. *Van verschil naar potentieel: een realistisch perspectief op de sociaaleconomische gezondheidsverschillen.* WRR-Policy Brief. The Hague, The Netherlands: WRR; 2018;7.

14. Mackenbach JP. Re-thinking health inequalities. *Eur J Public Health.* 2020;30(4):615-. 10.1093/eurpub/ckaa001.

15. World Health Organization. Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development. *Health Promot Int.* 2017;32(1):7-8. doi:10.1093/heapro/daw103.

16. 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. doi:10.1093/eurpub/ckv043.

17. Simonds SK. Health Education as Social Policy. *Health Educ Behav*. 1974;2:1-10.

18. Nutbeam D. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promot Int*. 2000;15(3):259-67. doi:10.1093/heapro/15.3.259.

19. Parker RM, Williams MV, Weiss BD, Baker DW, Davis TC, Doak CC, et al. Health literacy: report of the Council on Scientific Affairs. *JAMA*. 1999;281(6):552-7. doi:10.1001/jama.281.6.552

20. Institute of Medicine. *Health literacy: a prescription to end confusion*. Washington DC: The National Academies Press; 2004. doi:10.17226/10883

21. Sørensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, et al. Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health*. 2012;12:80. doi:10.1186/1471-2458-12-80.

22. 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. doi:10.1177/1757975918814421.

23. Trezona A, Dodson S, Osborne RH. Development of the organisational health literacy responsiveness (Org-HLR) framework in collaboration with health and social services professionals. *BMC Health Serv Res*. 2017;17(1):513. doi:10.1186/s12913-017-2465-z.

24. Brach C, Keller D, Hernandez L, Baur C, Parker R, Dreyer B, et al. *Ten attributes of health literate health care organizations*. 2012.

25. Jorm AF, Korten AE, Jacomb PA, Christensen H, Rodgers B, Pollitt P. "Mental health literacy": a survey of the public's ability to recognise mental disorders and their beliefs about the effectiveness of treatment. *Med J Aust*. 1997;166(4):182-6.

26. Horowitz AM, Kleinman DV. Oral Health Literacy: The New Imperative to Better Oral Health. *Dent Clin North Am*. 2008;52(2):333-44. doi:10.1016/j.cden.2007.12.001.

27. Okan O, Bollweg TM, Berens EM, Hurrelmann K, Bauer U, Schaeffer D. Coronavirus-Related Health Literacy: A Cross-Sectional Study in Adults during the COVID-19 Infodemic in Germany. *Int J Environ Res Public Health*. 2020;17(15). doi:10.3390/ijerph17155503.

28. Norman CD, Skinner HA. eHealth Literacy: Essential Skills for Consumer Health in a Networked World. *J Med Internet Res*. 2006;8(2):e9. doi:10.2196/jmir.8.2.e9.

29. Griese L, Berens EM, Nowak P, Pelikan JM, Schaeffer D. Challenges in Navigating the Health Care System: Development of an Instrument Measuring Navigation Health Literacy. *Int J Environ Res Public Health*. 2020;17(16). doi:10.3390/ijerph17165731.

30. Edwards M, Wood F, Davies M, Edwards A. 'Distributed health literacy': longitudinal qualitative analysis of the roles of health literacy mediators and social networks of people living with a long-term health condition. *Health Expect*. 2015;18(5):1180-93. doi:10.1111/hex.12093.

1

31. Muscat DM, Gessler D, Ayre J, Norgaard O, Heuck IR, Haar S, et al. Seeking a deeper understanding of 'distributed health literacy': A systematic review. *Health Expect.* 2022;n/a(n/a). doi:10.1111/hex.13450.

32. Paasche-Orlow MK, Wolf MS. The causal pathways linking health literacy to health outcomes. *Am J Health Behav.* 2007;31 Suppl 1:S19-26. doi:10.5555/ajhb.2007.31.supp.S19.

33. Stormacq C, Van den Broucke S, Wosinski J. Does health literacy mediate the relationship between socioeconomic status and health disparities? Integrative review. *Health Promot Int.* 2019;34(5):e1-e17. doi:10.1093/heapro/day062.

34. Haun JN, Valerio MA, McCormack LA, Sorensen K, Paasche-Orlow MK. Health literacy measurement: an inventory and descriptive summary of 51 instruments. *J Health Commun.* 2014;19 Suppl 2:302-33. doi:10.1080/10810730.2014.936571.

35. Davis TC, Crouch MA, Long SW, Jackson RH, Bates P, George RB, et al. Rapid assessment of literacy levels of adult primary care patients. *Fam Med.* 1991;23(6):433-5.

36. Arozullah AM, Yarnold PR, Bennett CL, Soltysik RC, Wolf MS, Ferreira RM, et al. Development and Validation of a Short-Form, Rapid Estimate of Adult Literacy in Medicine. *Med Care.* 2007;45(11):1026-33.

37. Hanson-Divers EC. Developing a medical achievement reading test to evaluate patient literacy skills: A preliminary study. *J Health Care Poor Underserved.* 1997;8(1):56-69.

38. Samora J, Saunders L, Larson RF. Medical Vocabulary Knowledge Among Hospital Patients. *J Health Hum Behav.* 1961;2(2):83-92. doi:10.2307/2948804.

39. Parker RM, Baker DW, Williams MV, Nurss JR. The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *J Gen Intern Med.* 1995;10(10):537-41. doi:10.1007/bf02640361.

40. Baker DW, Williams MV, Parker RM, Gazmararian JA, Nurss J. Development of a brief test to measure functional health literacy. *Patient Educ Couns.* 1999;38(1):33-42. doi:10.1016/S0738-3991(98)00116-5.

41. Quinzanos I, Hirsh JM, Bright C, Caplan L. Cross-sectional correlation of single-item health literacy screening questions with established measures of health literacy in patients with rheumatoid arthritis. *Rheumatol Int.* 2015;35(9):1497-502. doi:10.1007/s00296-015-3238-9.

42. Gong Z, Haig SL, Pope JE, Rohekar S, Rohekar G, LeRiche NGH, et al. Health Literacy Rates in a Population of Patients with Rheumatoid Arthritis in Southwestern Ontario. *J Rheumatol.* 2015;42(9):1610-5. doi:10.3899/jrheum.141509.

43. Sørensen K, Van den Broucke S, Pelikan JM, Fullam J, Doyle G, Slonska Z, et al. Measuring health literacy in populations: illuminating the design and development process of the European Health Literacy Survey Questionnaire (HLS-EU-Q). *BMC Public Health.* 2013;13(1):948. doi:10.1186/1471-2458-13-948.

44. Osborne RH, Batterham RW, Elsworth GR, Hawkins M, Buchbinder R. The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health.* 2013;13:658. doi:10.1186/1471-2458-13-658.

45. Rademakers J, Waverijn G, Rijken M, Osborne R, Heijmans M. Towards a comprehensive, person-centred assessment of health literacy: translation, cultural adaptation and psychometric test of the Dutch Health Literacy Questionnaire. *BMC Public Health*. 2020;20(1):1850. doi:10.1186/s12889-020-09963-0.

46. Pelikan J, Ganahl K, Van den Broucke S, Sørensen K. Measuring health literacy in Europe: Introducing the European Health Literacy Survey Questionnaire (HLS-EU-Q). In: Okan O, Bauer U, Levin-Zamir D, Pinheiro P, Sørensen K, editors. *International Handbook of Health Literacy Research, practice and policy across the lifespan*. Bristol, UK: Policy Press; 2019. p. 115-38.

47. Finbråten HS, Wilde-Larsson B, Nordström G, Pettersen KS, Trollvik A, Guttersrud Ø. Establishing the HLS-Q12 short version of the European Health Literacy Survey Questionnaire: latent trait analyses applying Rasch modelling and confirmatory factor analysis. *BMC Health Serv Res*. 2018;18(1):506. doi:10.1186/s12913-018-3275-7.

48. Duong TV, Aringazina A, Kayupova G, Nurjanah, Pham TV, Pham KM, et al. Development and Validation of a New Short-Form Health Literacy Instrument (HLS-SF12) for the General Public in Six Asian Countries. *Health Lit Res Pract*. 2019;3(2):e91-e102. doi:10.3928/24748307-20190225-01.

49. Beauchamp A, Buchbinder R, Dodson S, Batterham RW, Elsworth GR, McPhee C, et al. Distribution of health literacy strengths and weaknesses across socio-demographic groups: a cross-sectional survey using the Health Literacy Questionnaire (HLQ). *BMC Public Health*. 2015;15(1):678. doi:10.1186/s12889-015-2056-z.

50. Wang J, Shahzad F. A Visualized and Scientometric Analysis of Health Literacy Research. *Front Public Health*. 2021;9:811707. doi:10.3389/fpubh.2021.811707.

51. Jayasinghe UW, Harris MF, Parker SM, Litt J, van Driel M, Mazza D, et al. The impact of health literacy and life style risk factors on health-related quality of life of Australian patients. *Health Qual Life Outcomes*. 2016;14(1):68. doi:10.1186/s12955-016-0471-1.

52. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med*. 2011;155(2):97-107. doi:10.7326/0003-4819-155-2-201107190-00005.

53. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Viera A, Crotty K, et al. Health literacy interventions and outcomes: an updated systematic review. *Evid Rep Technol Assess (Full Rep)*. 2011(199):1-941.

54. van der Heide I, Wang J, Droomers M, Spreeuwenberg P, Rademakers J, Uiters E. The relationship between health, education, and health literacy: Results from the dutch adult literacy and life skills survey. *J Health Commun*. 2013;18 Suppl 1:172-84. doi:10.1080/10810730.2013.825668.

55. Drapkina O, da Graça Freitas M, Mikkelsen B, Breda J, Salakhov E, Lopatina M, et al. The WHO European Action Network on Health Literacy for Prevention and Control of Noncommunicable Diseases. *Public Health Panorama*. 2019;5(2-3):197-200.

56. World Health Organization. Regional Office for Europe. *Setting up behavioural insights units for improved health outcomes: considerations for national health authorities*. Copenhagen, Denmark: World Health Organization. Regional Office for Europe; 2022

1

57.   Paakkari L, Okan O. COVID-19: health literacy is an underestimated problem. *Lancet Public health.* 2020;5(5):e249-e50. doi:10.1016/s2468-2667(20)30086-4.

58.   Abel T, McQueen D. Critical health literacy and the COVID-19 crisis. *Health Promot Int.* 2020;35(6):1612-3. doi:10.1093/heapro/daaa040.

59.   Philip KEJ, Lonergan B, Cumella A, Farrington-Douglas J, Laffan M, Hopkinson NS. COVID-19 related concerns of people with long-term respiratory conditions: a qualitative study. *BMC Pulm Med.* 2020;20(1):319. doi:10.1186/s12890-020-01363-9.

60.   Hennessy MA, Linehan A, Cowzer D, Coyne ZL, Fitzpatrick O, Barrett F, et al. Chemotherapy in the Covid-19 era: the patient's perception. *Ir J Med Sci.* 2021:1-6. doi:10.1007/s11845-020-02457-3.

61.   Michaud K, Wipfler K, Shaw Y, Simon TA, Cornish A, England BR, et al. Experiences of Patients With Rheumatic Diseases in the United States During Early Days of the COVID-19 Pandemic. *ACR Open Rheumatol.* 2020;2(6):335-43. doi:10.1002/acr2.11148.

62.   Montagni I, Ouazzani-Touhami K, Mebarki A, Texier N, Schück S, Tzourio C. Acceptance of a Covid-19 vaccine is associated with ability to detect fake news and health literacy. *J Public Health (Oxf)*. 2021. doi:10.1093/pubmed/fdab028.

63.   Bailey SC, Serper M, Opsasnick L, Persell SD, O'Conor R, Curtis LM, et al. Changes in COVID-19 Knowledge, Beliefs, Behaviors, and Preparedness Among High-Risk Adults from the Onset to the Acceleration Phase of the US Outbreak. *J Gen Intern Med.* 2020;35(11):3285-92. doi:10.1007/s11606-020-05980-2.

64.   Wolf MS, Serper M, Opsasnick L, O'Conor RM, Curtis L, Benavente JY, et al. Awareness, Attitudes, and Actions Related to COVID-19 Among Adults With Chronic Conditions at the Onset of the U.S. Outbreak: A Cross-sectional Survey. *Ann Intern Med.* 2020;173(2):100-9. doi:10.7326/m20-1239.

65.   Itaya T, Torii M, Hashimoto M, Jindai K, Yamamoto W, Tanigawa K, et al. Perceptions and behaviours related to COVID-19 in patients with rheumatoid arthritis: a cross-sectional study. *Clin Rheumatol.* 2021:1-7. doi:10.1007/s10067-021-05840-2.

66.   Nikiphorou E, Santos EJF, 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. doi:10.1136/annrheumdis-2021-220249.

67.   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. doi:10.1136/annrheumdis-2016-210770.

68.   Global Burden of Disease Collaborative Network. *Global Burden of Disease Study 2019 (GBD 2019) Results.* Seattle, United States: Institute for Health Metrics and Evaluation (IHME); 2020.

69.   Smith E, Hoy DG, Cross M, Vos T, Naghavi M, Buchbinder R, et al. The global burden of other musculoskeletal disorders: estimates from the Global Burden of Disease 2010 study. *Ann Rheum Dis.* 2014;73(8):1462-9. doi:10.1136/annrheumdis-2013-204680.

70. Hoy DG, Smith E, Cross M, Sanchez-Riera L, Blyth FM, Buchbinder R, et al. Reflecting on the global burden of musculoskeletal conditions: lessons learnt from the Global Burden of Disease 2010 Study and the next steps forward. *Ann Rheum Dis.* 2015;74(1):4-7. doi:10.1136/annrheumdis-2014-205393.

71. Hoy D, Geere JA, Davatchi F, Meggitt B, Barrero LH. A time for action: Opportunities for preventing the growing burden and disability from musculoskeletal conditions in low- and middle-income countries. *Best Pract Res Clin Rheumatol.* 2014;28(3):377-93. doi:10.1016/j.berh.2014.07.006.

72. Alamanos Y, Voulgari PV, Drosos AA. Incidence and prevalence of rheumatoid arthritis, based on the 1987 American College of Rheumatology criteria: a systematic review. *Semin Arthritis Rheum.* 2006;36(3):182-8. doi:10.1016/j.semarthrit.2006.08.006.

73. Silman AJ, Pearson JE. Epidemiology and genetics of rheumatoid arthritis. *Arthritis Res.* 2002;4 (Suppl 3):S265-72. doi:10.1186/ar578.

74. Smolen JS, Landewé RBM, Bijlsma JWJ, Burmester GR, Dougados M, Kerschbaumer A, et al. EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2019 update. *Ann Rheum Dis.* 2020;79(6):685-99. doi:10.1136/annrheumdis-2019-216655.

75. Stolwijk C, van Onna M, Boonen A, van Tubergen A. Global Prevalence of Spondyloarthritis: A Systematic Review and Meta-Regression Analysis. *Arthritis Care Res.* 2016;68(9):1320-31. doi:10.1002/acr.22831.

76. Dehlin M, Jacobsson L, Roddy E. Global epidemiology of gout: prevalence, incidence, treatment patterns and risk factors. *Nat Rev Rheumatol.* 2020;16(7):380-90. doi:10.1038/s41584-020-0441-1.

77. Chhana A, Dalbeth N. The gouty tophus: a review. *Curr Rheumatol Rep.* 2015;17(3):19. doi:10.1007/s11926-014-0492-x.

78. Richette P, Doherty M, Pascual E, Barskova V, Becce F, Castañeda-Sanabria J, et al. 2016 updated EULAR evidence-based recommendations for the management of gout. *Ann Rheum Dis.* 2017;76(1):29-42. doi:10.1136/annrheumdis-2016-209707.

79. Spencer K, Carr A, Doherty M. Patient and provider barriers to effective management of gout in general practice: a qualitative study. *Ann Rheum Dis.* 2012;71(9):1490-5. doi:10.1136/annrheumdis-2011-200801.

80. Doherty M, Jansen TL, Nuki G, Pascual E, Perez-Ruiz F, Punzi L, et al. Gout: why is this curable disease so seldom cured? *Ann Rheum Dis.* 2012;71(11):1765-70. doi:10.1136/annrheumdis-2012-201687.

81. Caplan L, Wolfe F, Michaud K, Quinzanos I, Hirsh JM. Strong association of health literacy with functional status among rheumatoid arthritis patients: A cross-sectional study. *Arthritis Care Res.* 2014;66(4):508-14. doi:10.1002/acr.22165.

82. Hirsh JM, Boyle DJ, Collier DH, Oxenfeld AJ, Nash A, Quinzanos I, et al. Limited health literacy is a common finding in a public health hospital's rheumatology clinic and is predictive of disease severity. *J Clin Rheumatol.* 2011;17(5):236-41. doi:10.1097/RHU.0b013e318226a01f.

1

83. Kuipers JG, Koller M, Zeman F, Müller K, Rüffer JU. Adherence and health literacy as related to outcome of patients treated for rheumatoid arthritis: Analyses of a large-scale observational study. *Z Rheumatol.* 2019;78(1):74-81. doi:10.1007/s00393-018-0449-y.

84. Maheswaranathan M, Eudy AM, Bailey SC, Rogers JL, Clowse ME. Low health numeracy is associated with higher disease activity in systemic lupus erythematosus. *Lupus.* 2021;30(3):489-94. doi:10.1177/0961203320979044.

85. Katz P, Dall'Era M, Trupin L, Rush S, Murphy LB, Lanata C, et al. Impact of Limited Health Literacy on Patient-Reported Outcomes in Systemic Lupus Erythematosus. *Arthritis Care Res.* 2021;73(1):110-9. doi:10.1002/acr.24361.

86. Loke YK, Hinz I, Wang X, Rowlands G, Scott D, Salter C. Impact of health literacy in patients with chronic musculoskeletal disease-systematic review. *PLoS One.* 2012;7(7):e40210. doi:10.1371/journal.pone.0040210.

87. Hirsh JM, Boyle DJ, Collier DH, Oxenfeld AJ, Caplan L. Health literacy predicts the discrepancy between patient and provider global assessments of rheumatoid arthritis activity at a public urban rheumatology clinic. *J Rheumatol.* 2010;37(5):961-6. doi:10.3899/jrheum.090964.

88. Martin RW, McCallops K, Head AJ, Eggebeen AT, Birmingham JD, Tellinghuisen DJ. Influence of patient characteristics on perceived risks and willingness to take a proposed anti-rheumatic drug. *BMC Med Inform Decis Mak.* 2013;13:89. doi:10.1186/1472-6947-13-89.

89. Barton JL, Trupin L, Tonner C, Imboden J, Katz P, Schillinger D, et al. English language proficiency, health literacy, and trust in physician are associated with shared decision making in rheumatoid arthritis. *J Rheumatol.* 2014;41(7):1290-7. doi:10.3899/jrheum.131350.

90. Mattukat K, Boehm P, Raberger K, Schaefer C, Keyszer G, Mau W. How Much Information and Participation Do Patients with Inflammatory Rheumatic Diseases Prefer in Interaction with Physicians? Results of a Participatory Research Project. *Patient Prefer Adherence.* 2019;13:2145-58. doi:10.2147/PPA.S209346.

91. Edmonds S, Lou Y, Robinson B, Cram P, Roblin DW, Wright NC, et al. Characteristics of older adults using patient web portals to view their DXA results. *BMC Med Inform Decis Mak.* 2019;19(1):187. doi:10.1186/s12911-019-0904-y.

92. Hirsh J, Wood P, Keniston A, Peng M, Ramaswami S, Caplan L, et al. Limited health literacy and patient confusion about rheumatoid arthritis patient global assessments and model disease states. *Arthritis Care Res.* 2019;71(5):611-9. doi:10.1002/acr.23692.

93. Barton JL, Markwardt S, Niederhausen M, Schue A, Dougherty J, Katz P, et al. Are We on the Same Page? A Cross-Sectional Study of Patient-Clinician Goal Concordance in Rheumatoid Arthritis. *Arthritis Care Res.* 2021. doi:10.1002/acr.24794.

94. O'Neill J, Rader T, Guillemin F, Boonen A, Christensen R, Lyddiatt A, et al. Including health equity considerations in development of instruments for rheumatology research: An introduction to a novel OMERACT paradigm. *J Rheumatol.* 2014;41(1):150-2. doi:10.3899/jrheum.130812.

95. Petkovic J, Epstein J, Buchbinder R, Welch V, Rader T, Lyddiatt A, et al. Toward Ensuring Health Equity: Readability and Cultural Equivalence of OMERACT Patient-reported Outcome Measures. *J Rheumatol.* 2015;42(12):2448-59. doi:10.3899/jrheum.141168.

96. Park J-H, Park E-K, Koo D-W, Lee S, Lee S-H, Kim G-T, et al. Compliance and persistence with oral bisphosphonates for the treatment of osteoporosis in female patients with rheumatoid arthritis. *BMC Musculoskelet Disord.* 2017;18(1):152-. doi:10.1186/s12891-017-1514-4.

97. Kim A, Kim Y, Kim G-T, Ahn E, So MW, Lee S-G. Comparison of persistence rates between allopurinol and febuxostat as first-line urate-lowering therapy in patients with gout: an 8-year retrospective cohort study. *Clin Rheumatol.* 2020;39(12):3769-76. doi:10.1007/s10067-020-05161-w.

98. Hunter DJ, McLachlan AJ, Carroll PR, Wakefield TA, Stosic R. Health literacy and appropriateness of self-care and pain management in osteoarthritis: An understanding of the patient's perspective. *Arthritis Care Res.* 2021. doi:10.1002/acr.24851.

99. Rudd RE, Blanch DC, Gall V, Chibnik LB, Wright EA, Reichmann W, et al. A randomized controlled trial of an intervention to reduce low literacy barriers in inflammatory arthritis management. *Patient Educ Couns.* 2009;75(3):334-9. https://doi.org/10.1016/j.pec.2009.03.001.

100. Lopez-Olivo MA, des Bordes JKA, Lin H, Rizvi T, Volk RJ, Suarez-Almazor ME. Comparison of multimedia and printed patient education tools for patients with osteoporosis: a 6-month randomized controlled trial. *Osteoporos Int.* 2020;31(5):857-66. doi:10.1007/s00198-019-05210-4.

101. Egerton T, Bolton J, Short CE, Bennell KL. Exploring changes, and factors associated with changes, in behavioural determinants from a low-cost, scalable education intervention about knee osteoarthritis: An observational cohort study. *BMC Musculoskelet Disord.* 2021;22(1):862. doi:10.1186/s12891-021-04751-2.

102. Hirsh J, Wood P, Keniston A, Boyle D, Quinzanos I, Caplan L, et al. Universal Health Literacy Precautions Are Associated With a Significant Increase in Medication Adherence in Vulnerable Rheumatology Patients. *ACR Open Rheumatol.* 2020;2(2):110-8. doi:10.1002/acr2.11108.

103. Nash R, Elmer S, Thomas K, Osborne R, MacIntyre K, Shelley B, et al. HealthLit4Kids study protocol; crossing boundaries for positive health literacy outcomes. *BMC Public Health.* 2018;18(1):690. doi:10.1186/s12889-018-5558-7.

104. Bartelink N, van Assema P, Kremers S, Savelberg H, Jansen M. De invloed van de schoolcontext op de effecten van de Gezonde Basisschool van de Toekomst. *TSG - Tijdschrift voor gezondheidswetenschappen.* 2020;98(2):34-41. doi:10.1007/s12508-020-00274-8.

105. Kickbusch I, Wait S, Maag D. *Navigating health. The role of Health Literacy.* London, UK: Alliance for Health and the Future; 2005.

106. Daalder NR, Martens M, Wiebing M. Voel je goed! *TSG - Tijdschrift voor gezondheidswetenschappen.* 2021;99(3):101-9. doi:10.1007/s12508-021-00298-8.

107. DeWalt DA, Broucksou KA, Hawk V, Brach C, Hink A, Rudd R, et al. Developing and testing the health literacy universal precautions toolkit. *Nurs Outlook.* 2011;59(2):85-94. doi:10.1016/j.outlook.2010.12.002.

108. Callahan LF, Hawk V, Rudd R, Hackney B, Bhandari S, Prizer LP, et al. Adaptation of the health literacy universal precautions toolkit for rheumatology and cardiology - applications for pharmacy professionals to improve self-management and outcomes in patients with chronic disease. *Res Social Adm Pharm.* 2013;9(5):597-608. doi:10.1016/j.sapharm.2013.04.016.

1

109. Batterham RW, Buchbinder R, Beauchamp A, Dodson S, Elsworth GR, Osborne RH. The OPtimising HEalth LIterAcy (Ophelia) process: Study protocol for using health literacy profiling and community engagement to create and implement health reform. *BMC Public Health*. 2014;14:694. doi:10.1186/1471-2458-14-694.

110. Dodson S, Beauchamp A, Batterham R, Osborne R. *Ophelia toolkit: A step-by-step guide for identifying and responding to health literacy needs within local communities*. Melbourne, Australia: Swinburne University of Technology; 2015.

111. Beauchamp A, Batterham RW, Dodson S, Astbury B, Elsworth GR, McPhee C, et al. Systematic development and implementation of interventions to OPtimise Health Literacy and Access (Ophelia). *BMC Public Health*. 2017;17(1):230. doi:10.1186/s12889-017-4147-5.

112. World Health Organization. *Health literacy development for the prevention and control of noncommunicable diseases*. Geneva, Switzerland; 2022.

113. New South Wales Mental Health Commission. *Health literacy development programme 2021* [Available from: https://www.nswmentalhealthcommission.com.au/advocacy-work/health-literacy-development.

114. Goss HR, McDermott C, Hickey L, Issartel J, Meegan S, Morrissey J, et al. Understanding disadvantaged adolescents' perception of health literacy through a systematic development of peer vignettes. *BMC Public Health*. 2021;21(1):593. doi:10.1186/s12889-021-10634-x.

115. Aaby A, Simonsen CB, Ryom K, Maindal HT. Improving Organizational Health Literacy Responsiveness in Cardiac Rehabilitation Using a Co-Design Methodology: Results from The Heart Skills Study. *Int J Environ Res Public Health*. 2020;17(3):1015. doi: 10.3390/ijerph17031015

116. Cheng C, Elsworth GR, Osborne RH. Co-designing eHealth and Equity Solutions: Application of the Ophelia (Optimizing Health Literacy and Access) Process. *Front. Public Health*. 2020;8. doi:10.3389/fpubh.2020.604401.

117. Hawkins M, Massuger W, Cheng C, Batterham R, Moore GT, Knowles S, et al. Codesign and implementation of an equity-promoting national health literacy programme for people living with inflammatory bowel disease (IBD): a protocol for the application of the Optimising Health Literacy and Access (Ophelia) process. *BMJ Open*. 2021;11(8):e045059. doi:10.1136/bmjopen-2020-045059.

118. Debussche X. Addressing health literacy responsiveness in diabetes. *Diabetes Epidemiology and Management*. 2021;4:100033. doi:10.1016/j.deman.2021.100033.

119. Do Ó DN, Goes AR, Elsworth G, Raposo JF, Loureiro I, Osborne RH. Cultural Adaptation and Validity Testing of the Portuguese Version of the Health Literacy Questionnaire (HLQ). *Int J Environ Res Public Health*. 2022;19(11):6465. doi:10.3390/ijerph19116465

120. Borge CR, Larsen MH, Osborne RH, Engebretsen E, Andersen MH, Holter IA, et al. Exploring patients' and health professionals' perspectives on health literacy needs in the context of chronic obstructive pulmonary disease. *Chronic Illness*. 2021:1742395321999441. doi:10.1177/1742395321999441.

121. Greenhalgh T, Robert G, Macfarlane F, Bate P, Kyriakidou O. Diffusion of innovations in service organizations: systematic review and recommendations. *Milbank Q.* 2004;82(4):581-629. doi:10.1111/j.0887-378X.2004.00325.x.

122. Murugesu L, Heijmans M, Fransen MP, Rademakers J, editors. *Beter omgaan met beperkte gezondheidsvaardigheden in de curatieve zorg: kennis, methoden en tools.* Utrecht, The Netherlands: Nivel; 2018.

123. Voigt-Barbarowicz M, Brütt AL. The Agreement between Patients' and Healthcare Professionals' Assessment of Patients' Health Literacy-A Systematic Review. *Int J Environ Res Public Health.* 2020;17(7). doi:10.3390/ijerph17072372.

124. Storms H, Aertgeerts B, Vandenabeele F, Claes N. General practitioners' predictions of their own patients' health literacy: a cross-sectional study in Belgium. *BMJ Open.* 2019;9(9):e029357. doi:10.1136/bmjopen-2019-029357.

1

PART I

Identifying health literacy needs
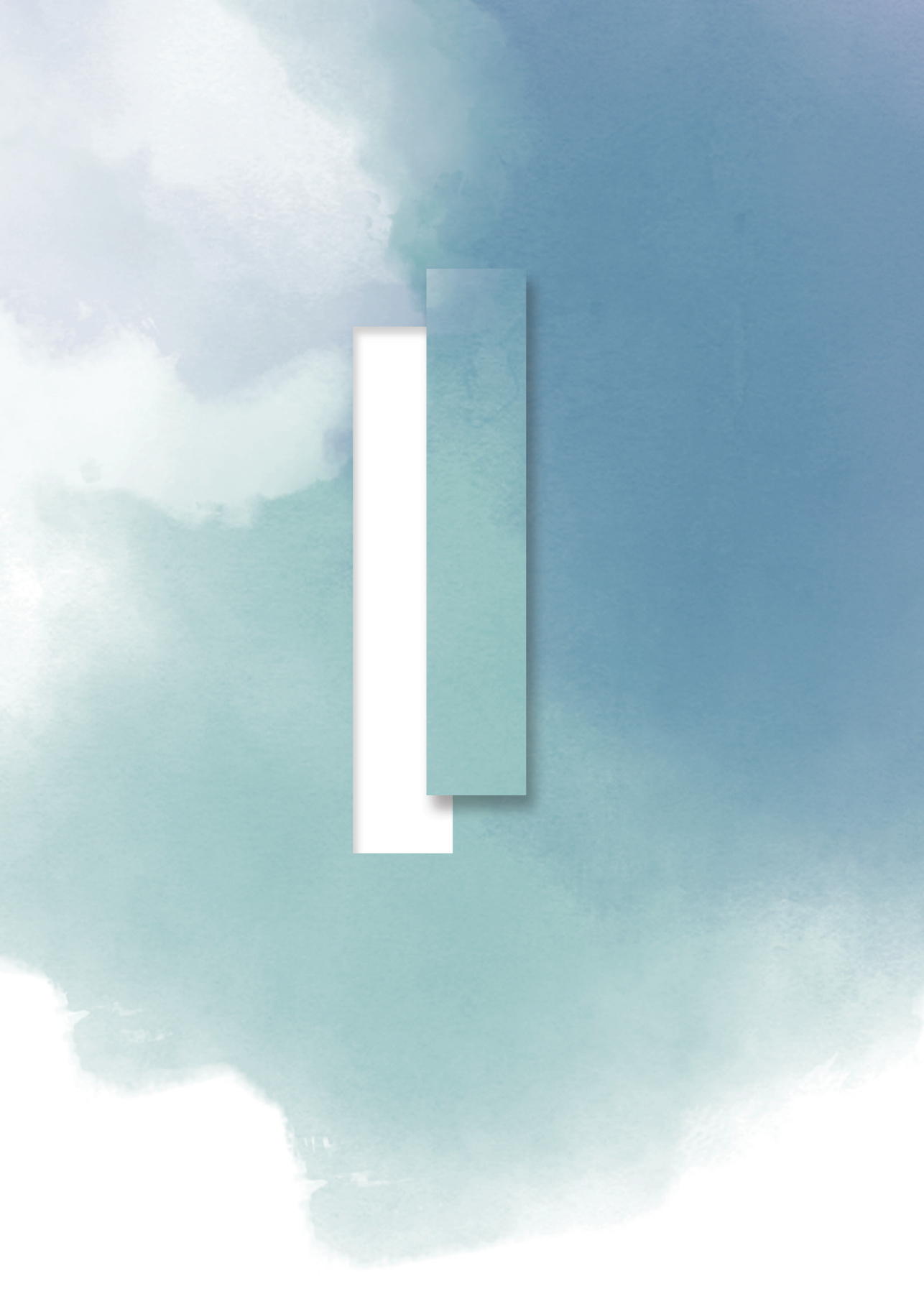
CHAPTER 2

Addressing health literacy needs in rheumatology – which patient health literacy profiles need the attention of health professionals?

Mark M. Bakker, Polina Putrik, Jany Rademakers, Mart van de Laar, Harald E. Vonkeman, Marc R. Kok, Hanneke Voorneveld-Nieuwenhuis, Sofia Ramiro, Maarten de Wit, Rachelle Buchbinder, Roy Batterham, Richard H. Osborne, Annelies Boonen

ABSTRACT

Objectives
To identify and describe health literacy profiles of patients with rheumatic diseases and explore whether the identified health literacy profiles can be generalised to a broader rheumatology context.

Methods
Patients with rheumatoid arthritis, spondyloarthritis and gout from three hospitals in different regions in the Netherlands completed the Health Literacy Questionnaire (HLQ). Hierarchical cluster analysis was used to identify patients' health literacy profiles based on nine HLQ domains. A multinomial regression model with the identified health literacy profiles as the dependent variable was fitted to assess whether patients with a given disease type or attending a given hospital were more likely to belong to a specific profile.

Results
Among 895 participating patients, lowest mean HLQ domain scores (indicating most difficulty) were found for 'Critical appraisal', 'Navigating the health system' and 'Finding good health information'. The ten identified profiles revealed substantial diversity in combinations of strengths and weaknesses. While 42% of patients scored moderate to high on all nine domains (profiles 1 and 3), another 42% of patients (profiles 2, 4, 5 and 6) clearly struggled with one or several aspects of health literacy. Notably, 16% (profiles 7 to 10) exhibited difficulty across a majority of health literacy domains. The probability of belonging to one of the profiles was independent of hospital attended or type of rheumatic disease.

Conclusion
Ten distinct health literacy profiles were identified among patients with rheumatic diseases, independent of disease type and treating hospital. These profiles can be used to facilitate health literacy intervention development in rheumatology.

KEY MESSAGES
— This is the first study to identify and describe a diversity of health literacy profiles of patients with RA, SpA and gout.
— Identified health literacy profiles are independent of the type of rheumatic disease and the treating hospital and thus potentially generalisable to a broader rheumatology context.
— Health literacy profiles can be used to facilitate health literacy intervention development.

BACKGROUND

Health literacy is increasingly recognised as a critical determinant of health [1], and has been hypothesised as a potential pathway leading to socioeconomic inequity in access to and outcomes of care [2-6]. Health literacy is a complex, multidimensional concept related to literacy [7]. The International Union for Health Promotion and Education (IUPHE) defined health literacy as *"the combination of personal competencies and situational resources needed for people to access, understand, appraise and use information and services to make decisions about health. It includes the capacity to communicate, assert and act upon these decisions"* [8]. While health literacy is related to education, it is critical to note that measuring education level alone as a proxy for health literacy would lead to both under- and overestimation of patients' health literacy in rheumatology [9].

Limited health literacy is associated with poorer health outcomes [10] and harmful health behaviour [11], caused for example by suboptimal utilisation of health care, less adequate patient-provider interactions and less adequate self-care [6]. Moreover, patients with limited health literacy are found to have reduced knowledge and understanding of their medical condition(s) and how they should be managed [5]. Health literacy difficulties disproportionally affect vulnerable groups including older adults, ethnic minorities, people with disabilities and socioeconomically disadvantaged populations [8].

Estimations of the prevalence of limited health literacy in the Netherlands range between 29 and 36% in the general population [3, 12, 13], shedding light on the magnitude of the challenge that patient health literacy may pose to our health system, health professionals, and patients. In rheumatology specifically, limited health literacy was shown to be associated with worse functional status of patients with rheumatoid arthritis (RA) [14]. Another study hypothesised health literacy as a possible pathway explaining reduced access to initial biological disease-modifying anti-rheumatic drugs (bDMARD) prescription for persons with lower educational level or older age [15].

Despite increasing attention for the impact of health literacy throughout the life course of (groups of) individuals [1, 8, 16-18], limited practical action has been taken to address limited health literacy as a way of reducing inequalities in access to care and disease outcomes. Innovative interventions, including digitalisation of health, might not be tailored to vulnerable patients' health literacy [19] or reach these persons in a timely fashion. If interventions do not account for specific health literacy needs in the target population, these already vulnerable patients are at higher risk to be left behind, while average improvements in population health could conceal these health inequalities.

Although action to address health literacy is critical, many existing studies in rheumatology merely describe associations between health literacy and health outcomes without offering practical solutions [20-22]. Identifying focal points for action and developing health literacy interventions is, therefore, imperative. However, the multidimensional nature

2

of health literacy causes people to experience different challenges and limitations depending on their individual health literacy strengths and weaknesses [5]. Someone who has difficulty reading and understanding written health information might face other challenges than someone who is highly educated but has difficulty engaging with healthcare professionals. Strengths and weaknesses can occur in different patterns, and understanding these dynamics is crucial to the success of newly developed interventions. To facilitate this, the OPtimising HEalth LIteracy and Access (Ophelia) process offers a guide to systematic development and implementation of interventions that can improve health and equity outcomes in communities [23, 24]. Ophelia was developed in Australia to inform health system strengthening through optimising the health literacy of individuals and optimising the way organisations respond to health literacy needs by giving a voice to people with particular health literacy difficulties [23]. The first and key phase of this approach constitutes an assessment of the health literacy of the target population that acknowledges the multidimensional nature of health literacy. Merely categorising patients as having 'high' or 'low' health literacy is not sufficient to inform the development of interventions. Rather, we should consider the diversity of health literacy profiles and the resulting health literacy needs of our patient population to inform meaningful improvements in care.

With this purpose in mind, the primary aim of this study was to identify health literacy profiles of patients with rheumatic diseases that uncover patterns of strengths and weaknesses across different domains of health literacy. The secondary aim was to explore whether the identified health literacy profiles are hospital- or disease-specific, or potentially generalisable to a broader rheumatology context.

METHODS

Study design
An observational cross-sectional study was conducted. It constitutes the first phase of a health literacy intervention development project in the rheumatology setting following the Ophelia process [23].

Population and setting
To capture potential differences in health literacy between patients with different rheumatic diseases and living in regions with diverse sociodemographic and geographic backgrounds, we recruited patients with rheumatoid arthritis (RA), spondyloarthritis (SpA), and gout attending the outpatient rheumatology clinics of 3 hospitals in the Netherlands with diverse populations (in the South, West and East). We aimed to recruit 100 patients per disease group per hospital as suggested in Ophelia to enable cluster analysis [25]. All patients ages ≥18 able

to answer questions in Dutch, English, German or Arabic were eligible for participation. Data collection took place between May 2018 and May 2019.

Procedures and measurements

Consecutive patients with RA, SpA or gout scheduled for a consultation at the outpatient clinic were informed about the study on behalf of their healthcare provider by regular mail 1-2 weeks prior to their consultation. Patients with limited health literacy often opt out of research projects and do not fill out questionnaires. Therefore, several strategies were employed to encourage their participation. First, front office staff reminded patients about the study upon arrival and/or after the consultation. Second, whenever possible, the treating healthcare provider personally introduced the patient to a researcher who was present in the waiting room at all times for face-to-face communication. Third, patients could choose their preferred way of completing the questionnaire, whether on paper or digitally, at the clinic or at home, and with the assistance of a researcher or relative. It was also possible to complete the questionnaire orally in an interview with a researcher, thus allowing the participation of patients who might have difficulty reading. Moreover, the data collection strategy and the questionnaire were tested with a panel of patient research partners to ensure this study was appropriate for an audience with diverse health literacy levels. A small token of appreciation in the form of a "thank you" pen was provided to encourage participants to return the questionnaire after taking it home. Patients who opted to fill out the questionnaire at home were reminded to return the questionnaire 2-3 weeks after their consultation. For returned questionnaires containing unanswered questions, the researcher contacted the patients by telephone to inquire about the missing items.

Health literacy was assessed using the Dutch version of the Health Literacy Questionnaire (HLQ), which was previously translated and cross-culturally adapted from the original English-language version [26, 27]. The original version and validated translations in German and Arabic were available to allow patients with diverse cultural backgrounds to participate. The HLQ comprises nine distinct domains of health literacy (Box 2.1) providing a separate score for each domain (the higher the score, the better), as it was developed to identify strengths and weaknesses across domains that would not be uncovered by a single summary score. Missing data were treated according to the expectation maximisation algorithm used in Ophelia before computing mean domain scores [28].

The questionnaire included additional questions on sociodemographics, self-reported health, mastery, and self-reported comorbidities. Sociodemographic information included age (years), gender, migration background (native Dutch, western migrant, non-western migrant [29]), marital status (married, unmarried living together, single, divorced, widower), employment status (studying, employed, unemployed, [partly] disabled for work, housewife/homemaker, retired, other [multiple answers possible]), household composition (living alone, with a partner, with children under and over 18 years of age, with parents, other (multiple

answers possible)) and language(s) spoken at home (Dutch, English, German, Arabic, Turkish, other [multiple answers possible]). For analysis, the following dichotomous variables were created: employed (yes/no), disabled for work (yes/no), living alone (yes/no), and speaking Dutch at home (yes/no). The highest level of completed education (using standardised Dutch category definitions) was dichotomised into low (primary or lower secondary education) versus medium/high [30]).

Box 2.1 Health Literacy Questionnaire domains

Domain number and description

1. Feeling understood and supported by healthcare providers (4 items)	Part I
2. Having sufficient information to manage my health (4 items)	(score range
3. Actively managing my health (5 items)	1 − 4)
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
7. Navigating the healthcare system (6 items)	(score range
8. Ability to find good health information (5 items)	0 − 5)
9. Understanding health information well enough to know what to do (5 items)	

Legend: Part I measures the 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 the 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).

Self-reported health was measured using a 0-10 visual analogue scale with higher scores indicating better health. Mastery, defined as the extent to which a person feels like they have control over life opportunities, was measured using the Pearlin Mastery Scale (range 7 to 28) [31]. The Rheumatic Disease Comorbidity Index (RDCI, range 0 to 9) was used to be informed about the presence of ten common types of comorbidities that are known to affect daily functioning and healthcare utilisation [32].

Statistical analysis

Descriptive statistics were used to characterise the total sample and by hospital and disease group. Next, we conducted hierarchical cluster analysis based on the 9 health literacy domains using Ward's linkage as the clustering method and the squared Euclidean distance as the distance measure [33]. To account for different score ranges between domains of the HLQ, the analyses were performed using Z-scores per domain. Three researchers (MMB, PP, and AB) jointly examined the upper 24 cluster solutions by seeking meaningful differences between the clusters' HLQ domains and patient characteristics while aiming to minimise within-cluster

domain variance. Distinct, meaningful clusters were selected as health literacy profiles. Of note, each patient could be assigned to one profile only. Profiles were presented in a heat map reflecting mean HLQ domain scores and further described using distinctive patterns of HLQ domain scores and sociodemographic characteristics of each cluster. In a 2-hour session, we presented and discussed the profiles and their interpretation with our patient research partner.

A multinomial regression model with the identified health literacy profiles as the dependent categorical variable was fitted to assess whether patients with 1 of the 3 rheumatic diseases or attending 1 of the 3 participating hospitals were more likely to belong to a specific profile. The base model was always adjusted for age, gender and education. Other factors (migration background, Dutch spoken at home, living alone, marital status, disability for work, employment, mastery, comorbidities and self-reported health) were first added one by one and then in combinations to assess direct and confounding effects. Factors that had a significant contribution or were confounders were retained in the model. Marginal probabilities of belonging to each profile given disease or hospital were computed from the final model. Analyses were performed in IBM SPSS Statistics 25 and Stata 15. The significance level was assumed at α = 5%.

RESULTS

Of the 989 patients who consented to participate, 895 patients completed the questionnaire (for flowchart, see Supplementary figure 2.1). The mean ± SD age of participants was 61 ± 14 years, 49% were female (n=436), and notably, only 56% of participants of working age had a paid occupation, while 51% of all participants reported having only completed low levels of education (Table 2.1). Recruitment of 100 patients per disease per hospital was reached for RA and SpA patients in all three hospitals. Recruitment of gout patients did not reach 100 patients per hospital but was large enough to have gout patients well represented in the total sample (n= 207, 23%). No substantial differences across diseases or hospitals were observed in age, education level, mastery and self-reported health (Table 2.1, Supplementary table 2.1). A relatively smaller proportion of non-Western migrants was observed at the centre in the South (3.2%) in comparison to the centres in the East and West (8.1 and 14.4% respectively; p<0.001).

Across the HLQ domains, notable differences were observed (Table 2.2). Highest mean ± SD scores were found for 'Healthcare provider support' (3.14 ± 0.45 for domain 1 [range 1-4]) and 'Active engagement with healthcare providers' (3.98 ± 0.62 for domain 6 [range 1-5]). Lowest mean ± SD scores were found for 'Critical appraisal' (2.71 ± 0.50 for domain 5 [range 1-4]), 'Navigating the health system' (3.77 ± 0.62 for domain 7 [range 1-5]) and 'Ability to find good health information' (3.77 ± 0.72 for domain 8 [range 1-5]).

2

Domain scores were largely independent from hospital or type of rheumatic disease, although for domains 4 (Social support), 6 (Engaging with providers), 7 (Navigating the healthcare system) and 9 (Understanding health information), patients treated at the centre in the East tended to score slightly higher compared with patients from the other hospitals (Table 2.2). Moreover, for domains 1 (Feeling supported by providers), 3 (Actively managing health), 8 (Finding health information) and 9 (Understanding health information), patients with gout tended to have lower scores (Supplementary table 2.2).

Health literacy profiles

Cluster analysis followed by researchers' appraisal resulted in retaining 10 distinct health literacy profiles (Figure 2.1). Patients in 2 profiles scored moderate to high on all 9 domains: *profile 1* (all very high scores) and *profile 3* (high). Other profiles showed different patterns of strengths and weaknesses across the HLQ domains. Patients in *profiles 2, 4, 5 and 6* struggled with 1 or several aspects of health literacy. For example, *profile 4* corresponds to patients who generally fare well in engaging with health and the health system (for domains 6-9, scores ranged from 3.91 to 4.12) and have good relations with their healthcare provider (2.99 for domain 1) and their social network (2.98 for domain 4). However, they do not take ownership of their own health (2.49 for domain 3) and lack a critical attitude toward health information (2.34 for domain 5). Patients in *profiles 7 – 10* exhibited difficulty across a majority of health literacy domains. Detailed profile descriptions are provided in Table 2.3. Distribution of age, mastery, RDCI, and proportions of patients living alone, employment status, migration background and education level differed across profiles (see Supplementary table 2.3). Of note, patients in more problematic health literacy profiles reported poorer self-rated health (6.8±1.7 for *profile 1;* 5.3±2.1 for *profile 10*, p<0.0001 for differences across all profiles) (see Supplementary table 2.3).

Health literacy profiles in relation to hospital and disease

The final multinomial model assessing the distribution of profiles across diseases and hospitals was adjusted for age, gender, education, mastery, living alone and migration background (see Supplementary table 2.4). Table 2.4 shows a patient's marginal probability of belonging to 1 of the 10 identified health literacy profiles, given rheumatic disease and hospital after adjusting for covariates. There are some differences in probabilities between hospitals and disease groups for some of the health literacy profiles. However, the model showed that these differences are not statistically significant overall; having a particular health literacy profile is independent of rheumatic disease (p=0.20) or the hospital attended (p=0.07) (see Supplementary table 2.4).

	1. Healthcare provider support	2. Having sufficient information	3. Actively managing health	4. Having social support for health	5. Critical appraisal of information	6. Actively engaging with providers	7. Navigating the health system	8. Finding health information	9. Understanding health information
1	3.75	3.62	3.50	3.57	3.37	4.58	4.38	4.52	4.56
2	3.87	3.30	2.63	3.56	2.37	4.70	4.41	4.39	4.65
3	3.21	3.09	2.98	3.00	2.84	4.24	4.04	4.06	4.17
4	2.99	2.96	2.49	2.98	2.34	4.12	3.96	3.91	4.01
5	3.03	2.88	2.92	2.82	2.88	3.81	3.60	3.65	3.69
6	2.96	2.80	2.84	2.99	2.40	3.53	3.27	3.18	3.39
7	3.04	2.76	2.20	2.87	2.06	3.80	2.95	2.04	2.86
8	2.63	2.62	2.78	2.22	2.51	3.53	3.30	3.62	3.88
9	2.47	2.44	2.73	2.23	2.32	2.86	2.85	2.94	3.25
10	2.88	2.53	2.75	2.70	2.39	2.22	2.22	1.90	2.09

Identified health literacy profiles (row axis label)

Distribution of scores across Health Literacy Questionnaire domains

Figure 2.1 Identified health literacy profiles and mean HLQ scores per domain for each profile. Scores marked in red indicate very low scores, orange indicates low scores, yellow indicates moderate scores, and green indicates higher scores.

2

Table 2.1 Demographic characteristics of the overall sample and per treating hospital

	Total (n=895)	South (n=317)	West (n=271)	East (n=307)	p-value*
% female (n)	48.7 (436)	48.9 (155)	52.4 (142)	45.3 (139)	p=0.23
Age (SD)	61.1 (13.9)	63.0 (13.2)	59.9 (13.5)	60.1 (14.8)	p=0.01
[range]	[18-91]	[18-91]	[25-88]	[21-89]	
Rheumatic disease					p=0.22
% RA (n)	41.2 (369)	42.0 (133)	42.1 (114)	39.7 (122)	
% SpA (n)	35.6 (319)	33.8 (107)	39.5 (107)	34.2 (105)	
% gout (n)	23.1 (207)	24.3 (77)	18.5 (50)	26.1 (80)	
Education level					p=0.02
% Low (n)	50.7 (454)	47.0 (149)	58.7 (159)	47.6 (146)	
% Medium (n)	24.8 (222)	24.6 (78)	22.9 (62)	26.7 (82)	
% High (n)	24.5 (219)	28.4 (90)	18.5 (50)	25.7 (79)	
Migration background					p<0.001
% Native Dutch (n)	82.5 (738)	84.8 (269)	78.2 (212)	83.7 (257)	
% Western migrant (n)	9.3 (83)	12.0 (38)	7.4 (20)	8.1 (25)	
% Non-western migrant (n)	8.3 (74)	3.2 (10)	14.4 (39)	8.1 (25)	
Employment					
% Working (n)	33.3 (298)	29.0 (92)	33.6 (91)	37.5 (115)	p=0.08
% Working <65 (n)	56.1 (280)	55.3 (89)	52.1 (85)	60.6 (106)	p=0.29
% Work disabled <65 (n)	29.2 (146)	29.8 (48)	31.9 (52)	26.3 (46)	p=0.52
% Retired (n)	40.0 (358)	45.1 (143)	35.4 (96)	38.8 (119)	p=0.05
Household composition					
% Living alone (n)	24.6 (220)	27.1 (86)	24.7 (67)	21.8 (67)	p=0.31
Patient-reported outcomes					
Mastery (SD)	20.0 (3.4)	19.8 (3.2)	19.7 (3.3)	20.5 (3.6)	p=0.01
[range]	[9-28]	[9-28]	[12-28]	[10-28]	
RDCI (SD)	1.2 (1.3)	1.1 (1.3)	1.1 (1.4)	1.2 (1.4)	p=0.91
[range]	[0-7]	[0-6]	[0-6]	[0-7]	
Self-reported health (SD)	6.4 (1.8)	6.6 (1.6)	6.2 (1.8)	6.4 (1.8)	p=0.02
[range]	[0-10]	[2-10]	[0-10]	[1-10]	

*Legend: * ANOVA/X2 for differences across hospitals. RA = Rheumatoid Arthritis, SpA = Spondyloarthritis, SD = standard deviation, RDCI = Rheumatic Disease Comorbidity Index.*

Table 2.2 Health Literacy Questionnaire (HLQ) scores per domain for the overall sample and per treating hospital

Domain number [range]	Total (n=895)	South (n=317)	West (n=271)	East (n=307)	p-value*
	Mean (SD) [range]				
1. Healthcare provider support [1-4]	3.14 (0.45) [1.25-4.00]	3.14 (0.43) [1.75-4.00]	3.10 (0.46) [1.25-4.00]	3.18 (0.46) [1.75-4.00]	p=0.09
2. Having sufficient information [1-4]	3.01 (0.42) [1.00-4.00]	2.99 (0.40) [1.50-4.00]	2.98 (0.42) [1.75-4.00]	3.06 (0.44) [1.00-4.00]	p=0.05
3. Actively managing health [1-4]	2.90 (0.45) [1.00-4.00]	2.87 (0.44) [1.00-4.00]	2.93 (0.48) [1.40-4.00]	2.90 (0.42) [1.80-4.00]	p=0.21
4. Having social support for health [1-4]	2.97 (0.50) [1.20-4.00]	2.93 (0.47) [1.20-4.00]	2.93 (0.55) [1.20-4.00]	3.05 (0.48) [1.40-4.00]	p<0.01
5. Critically appraising information [1-4]	2.71 (0.50) [1.00-4.00]	2.67 (0.48) [1.00-4.00]	2.76 (0.49) [1.60-4.00]	2.70 (0.53) [1.00-4.00]	p=0.07
6. Actively engaging with providers [1-5]	3.98 (0.62) [1.00-5.00]	3.94 (0.62) [1.00-5.00]	3.89 (0.65) [1.80-5.00]	4.09 (0.59) [1.60-5.00]	p<0.001
7. Navigating the health system [1-5]	3.77 (0.62) [1.50-5.00]	3.69 (0.64) [1.50-5.00]	3.74 (0.62) [1.50-5.00]	3.86 (0.58) [1.67-5.00]	p<0.01
8. Finding health information [1-5]	3.77 (0.72) [1.00-5.00]	3.75 (0.69) [1.00-5.00]	3.77 (0.69) [1.00-5.00]	3.79 (0.78) [1.00-5.00]	p=0.75
9. Understanding health information [1-5]	3.91 (0.64) [1.60-5.00]	3.86 (0.68) [1.80-5.00]	3.89 (0.61) [1.80-5.00]	3.99 (0.62) [1.60-5.00]	p=0.02

*Legend: *ANOVA for differences across hospitals. SD = standard deviation*

2

Table 2.3 Descriptions of health literacy profiles

Profile	N (%)	Label	Description of the health literacy profile
Profile 1	115 (13%)	High scores – no difficulty	Patients score highly across all domains, which means that they confidently work their way through health challenges without any difficulties.
Profile 2	32 (4%)	High scores but no active role taken	Patients score low on critical attitude towards health information (domain 5 = 2.37) and take limited ownership of their own health (domain 3 = 2.63). On the other hand, these (often female (75%)) patients have a good relationship with their healthcare provider (domain 1 = 3.87). They engage well with their physicians (domain 6 = 4.70) to receive support and relevant information.
Profile 3	262 (29%)	Moderate to high scores –minor to no difficulty	Patients show a pattern of moderate to high scores across the spectrum. They most often have a native Dutch background (89%). Many are still working (38%) or of retirement age (42%). The profile scores suggest they are able to process health information and manage their health with little to no difficulty.
Profile 4	110 (12%)	Moderate to high scores but no active role taken	Patients generally fare quite well. However, they have a passive attitude towards their health (domain 3 = 2.49) and are not critical towards health information (domain 5 = 2.34), which possibly indicates that health is not their main concern in life.
Profile 5	133 (15%)	Moderate scores across the spectrum	Patients report potential difficulty across multiple domains, including in particular social support for health (domain 4 = 2.82) and navigating the health system (domain 7 = 3.60), despite often living with a partner (71%).
Profile 6	103 (12%)	Lacking a critical attitude and ability to acquire good information	Patients take only moderate ownership of their own health (domain 3 = 2.84), and reportedly have experienced difficulty finding health information (domain 8 = 3.18) and navigating the health system (domain 7 = 3.27). Patients in this profile often have some form of comorbidity (RDCI = 1.55) and might struggle when unexpected changes in their health status occur.

Table 2.3 (Continued)

Profile	N (%)	Label	Description of the health literacy profile
Profile 7	25 (3%)	Take no active role in their health and struggle to find and understand information	Patients struggle to manage their own health (domain 3 = 2.20) and have difficulty finding and appraising health information (domain 8 = 2.04 and 5 = 2.06), navigating the health system (domain 7 = 2.95) and understanding health information (domain 9 = 2.86). These patients are low-educated (92%) older adults (mean age = 72), who often speak in local dialect at home (44%). They often have multiple comorbidities (mean RDCI = 2.2). Their moderate to good relations with healthcare providers (domains 1 = 3.04 and 6 = 3.80) may partly compensate for weaknesses across other domains.
Profile 8	62 (7%)	Moderate understanding, but lack of professional and personal support	Patients generally understand health information (domain 9 = 3.88) and know how to interact with their doctor and ask the right questions (domain 6 = 3.53). However, they lack social support (half reported living without a partner, domain 4 = 2.22), feel like do not have enough information about their health (domain 2 = 2.62) and seem somewhat dissatisfied with their healthcare provider (domain 1 = 2.63).
Profile 9	30 (3%)	Lacks understanding, lacks support	Patients score poorly across all nine domains. Particularly poor scores occur in domains 1-5, which mostly describe attitudes towards managing health. This profile occurs in patients of both native Dutch and immigrant backgrounds. They report being in poor health (mean = 5.4 out of 10) and experiencing a lack of support from both their social network (domain 4 = 2.23, 47% lives alone) and healthcare providers (domain 1 = 2.47). This implies that patients struggle to manage their health and receive little to no help.
Profile 10	23 (3%)	Low scores across all domains	Patients score poorly across all nine domains, but particularly across domains 6-9, capturing their poor ability to perform tasks related to their health (score range = 1.90-2.22). A third of the patients in this profile have a non-Western background (35%). The majority have low education levels (96%) and are disabled for work (54% of the working-age subgroup). Most problematic is their severe difficulty finding (domain 8 = 1.90) and understanding health information (domain 9 = 2.09), showing they need significant assistance.

Table 2.4 Probability for fitting each of the identified profiles per rheumatic disease and treating hospital

Profile	1	2	3	4	5	6	7	8	9	10
N	115	32	262	110	133	103	25	62	30	23
(%)	(13%)	(4%)	(29%)	(12%)	(15%)	(12%)	(3%)	(7%)	(3%)	(3%)
Rheumatic disease										
RA	0.11	0.05	0.31	0.15	0.16	0.11	0.01	0.05	0.03	0.03
SpA	0.16	0.03	0.26	0.10	0.15	0.11	0.04	0.08	0.05	0.03
Gout	0.11	0.03	0.31	0.12	0.13	0.14	0.04	0.08	0.02	0.02
Treating hospital										
South	0.11	0.03	0.30	0.15	0.14	0.08	0.04	0.07	0.04	0.05
West	0.14	0.03	0.28	0.10	0.16	0.13	0.02	0.09	0.03	0.01
East	0.14	0.04	0.30	0.12	0.14	0.14	0.02	0.05	0.02	0.02

Legend: Estimates of marginal probabilities (between 0 and 1) for persons with a specific disease or under care in a specific hospital to belong to one of the health profiles, derived from a fully adjusted multinomial model (Supplementary table 2.4). RA = Rheumatoid Arthritis, SpA = Spondyloarthritis.

DISCUSSION

The aim of this study was to identify and describe health literacy profiles of patients with RA, SpA, and gout, and to explore whether the profiles are specific to a hospital or rheumatic disease type. We distinguished 10 distinct health literacy profiles, covering a range of health literacy-related strengths and weaknesses. The profiles were independent of the type of rheumatic disease or the treating hospital.

While profiles differed in the type of domains for which strengths or weaknesses were seen, common weaknesses were found for 'Actively managing health' (domain 3) and 'Critical appraisal of information' (domain 5). These aspects deserve specific attention in the majority of our patients, as only patients with profile 1 (13% of our sample) scored consistently well on these domains. Of further interest, we observed lower self-reported health in profiles with more problematic scores across health literacy domains, hinting towards the relevance of the profiles in relation to health outcomes.

The striking diversity of the identified profiles further emphasises that health literacy does not simply range from 'high to low'. Rather, it is an individual combination of strengths and weaknesses (either of the patient or in their surroundings), where strengths might function

as compensation mechanisms for weaknesses. For example, a high score on social support might indicate this patient has someone in their network who could help with understanding health information and making health decisions, thereby compensating for a lack of self-reported ability in these domains. From the diverse profiles in our study, patients that score poorly across domains without clear compensation mechanisms (mostly but not exclusively reflected by *profiles 6-10*) likely need the most attention in healthcare settings to ensure they are able to receive – and make use of – the care they need. Notably, patients with lower education and of migrant background are overrepresented in *profiles 7, 9 and 10* (8.7% of our sample). These patients reported difficulty finding good health information and navigating the health system. While for patients in *profile 7*, this might be mitigated by their better relationship with healthcare providers (domain 1), it remains of big concern for patients with *profiles 9 and 10*. It is both the high prevalence of limited health literacy and this diversity in patterns that professionals in clinical practice should be aware of in their communication with and treatment of patients.

In an era where patients are invited (and even expected) to participate actively in their health and in disease management decisions, we need to tailor our approaches and interventions (related to information delivery, decision-making and support) to our patients' health literacy needs [8, 19], and make sure our efforts actually reach those with limited health literacy [5]. In daily practice, however, it is neither feasible nor desirable to measure the health literacy of every individual patient using the HLQ and tailor care accordingly. Rather, health literacy profiles can be used to facilitate organisational change towards health literate organisations in which health literacy needs are addressed by design. Key strategies emerging from Ophelia processes involve: 1) implementing changes that make services user-friendly to people with limited health literacy (often called a universal precautions approach [34]); 2) addressing the specific barriers that patients with common health literacy profiles face; 3) improving awareness and building sensitivity to health literacy diversity among healthcare providers and developing skills and techniques to rapidly adapt communication approaches to the needs of different people; and 4) enhancing the ways in which families and communities support each other in acquiring and using health information.

Along these lines, this study is the first step in a care improvement process using the Ophelia process [23]. In the steps to follow, health literacy profiles will be combined with qualitative information from patient interviews to create short patient stories, or 'vignettes'. These vignettes will be used to facilitate group discussions with key stakeholders in patient care (including patients, physicians, nurses, management and clinic staff) to generate ideas that could improve care. These ideas will be assessed and developed into workable packages to be implemented and evaluated in our clinics, contributing to improved and more equitable care. A recent study showed promising effects of health literacy interventions, particularly the use of teach-back communication, on medication adherence and disease activity in the rheumatology setting [35]. In addition, Ophelia studies in other settings have shown the

potential for intervention development using health literacy profiles to achieve organisational change [23, 36].

When conducting this study, we did not foresee the Coronavirus Disease 2019 (COVID-19) pandemic accelerating remote and digital healthcare delivery. An Australian survey showed that while the pandemic has left patients with rheumatic diseases concerned and in need of information, telehealth was deemed an appropriate alternative [37]. However, digitalisation and the use of telehealth require skills and attitudes only partially captured in the HLQ – more specifically necessitating e-health literacy [38]. While e-health literacy was not measured in this study, challenges related to digitalisation and telehealth should nevertheless be considered when developing health literate organisations.

This study is the first of its kind in the field of rheumatology and among the largest of studies classifying patients into health literacy profiles based on their scores across health literacy domains. While an increasing number of projects identify health literacy patterns using the HLQ [39-41] or adopt the Ophelia process in a variety of settings across the world [23, 42], much work is still in progress, and data on health literacy profiles and success of developed interventions remains scarce. Other authors have reported on health literacy profiles identified in primary care [43], hospital care [44], and cardiac rehabilitation [36]. These studies also revealed a high diversity in the identified health literacy profiles. In this study, we observed that the distribution of patients into health literacy profiles was similar across the 3 studied rheumatic diseases and the diverse participating hospitals. While on average patients with gout reported lower and patients treated at the centre in the East reported higher scores for some individual HLQ domains, these statistically significant differences did not lead to meaningful differences in probabilities for patients to have a specific health literacy profile after adjusting for covariates. We therefore suggest that the health literacy profiles identified in this study could potentially be generalised across rheumatic diseases and to other hospitals in The Netherlands.

The results of this study should be interpreted in light of a few limitations. First, despite our efforts to accommodate participation of individuals with diverse health literacy needs, we may have failed to capture some patients with the most critical levels of health literacy because they did not participate. We deployed several strategies to minimise this recruitment bias by significantly lowering the threshold to participate and encouraging responses, which resulted in the inclusion of many older adults (44% age >65 and 17% age >75) and 51% of patients with low education, significantly more than the 30% in the general Dutch population [45]. Furthermore, we minimised missing data by contacting respondents to answer remaining items. Despite these steps, it is likely that the small number of patients in profiles with lower levels of health literacy may represent much larger and more problematic numbers in the community. Second, the selection of profiles, a dual quantitative and qualitative process based on Ward's hierarchical cluster analysis and appraisal of results by researchers is sensitive to subjectivity. This method does not use statistical criteria alone to determine the optimal

number of clusters; rather, it involves clinical, qualitative judgements. Moreover, no evidence-based guidelines on what constitutes a relevant difference between HLQ domain scores currently exist. However, 3 researchers (MMB, PP, and AB) jointly agreed on the most clinically meaningful cluster solution. In addition, our patient research partner (MdW) confirmed the proposed profiles as being distinct and reasonable, strengthening the face validity of our findings and contributing to our aim of identifying clinically meaningful profiles that can be used to uncover health literacy needs in our population and facilitate organisational change.

In summary, we identified and described a diversity of health literacy profiles of patients with rheumatic diseases. The profiles are independent of rheumatic disease and treating hospital, and thus potentially generalisable to a broader rheumatology context. These profiles can facilitate the development of tailored care improvement interventions in different rheumatology settings.

DECLARATIONS

Ethics
All respondents provided written informed consent. This study was approved by the Medical Ethics Research Committee at Maastricht UMC+ (2018-0327) as well as by the designated committees at each participating hospital for local approval (South: Maastricht University Medical Center+, Maastricht: 18–4-037, West: Maasstad Hospital, Rotterdam: L2018057, East: Medisch Spectrum Twente, Enschede: KH18-23). One patient research partner (MdW) was involved throughout the research process.

Acknowledgements
We thank Mirjam Hegeman for her significant contribution to the coordination of the study in Medisch Spectrum Twente. Furthermore, we thank our panel of patient research partners for their input throughout the project, and the health professionals and clinic staff at all three centres for their efforts in patient recruitment.

REFERENCES

1. World Health Organization. Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development. *Health Promot Int*. 2017;32(1):7-8. doi:10.1093/heapro/daw103.

2. Greenhalgh T. Health literacy: towards system level solutions. *BMJ.* 2015;350:h1026. doi:10.1136/bmj.h1026

3. 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. doi:10.1093/eurpub/ckv043.

4. Kickbush, I, Pelikan, JM, Apfel, F, Tsouros, AD. *Health literacy: the solid facts.* Copenhagen, Denmark: World Health Organization. Regional Office for Europe; 2013.

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. doi:10.1016/j.puhe.2016.01.001

6. Paasche-Orlow MK, Wolf MS. The causal pathways linking health literacy to health outcomes. *Am J Health Behav.* 2007;31 Suppl 1:S19-26. doi:10.5555/ajhb.2007.31.supp.S19.

7. Sørensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, et al. Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health.* 2012;12:80. doi:10.1186/1471-2458-12-80.

8. 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. doi:10.1177/1757975918814421.

9. Buchbinder R, Hall S, Youd JM. Functional health literacy of patients with rheumatoid arthritis attending a community-based rheumatology practice. *J Rheumatol.* 2006;33(5):879-86.

10. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med.* 2011;155(2):97-107. doi:10.7326/0003-4819-155-2-201107190-00005.

11. Geboers B, Reijneveld SA, Jansen CJM, de Winter AF. Health Literacy Is Associated With Health Behaviors and Social Factors Among Older Adults: Results from the LifeLines Cohort Study. *J Health Commun.* 2016;21(sup2):45-53. doi:10.1080/10810730.2016.1201174.

12. Heijmans M, Brabers A, Rademakers J. *Health Literacy in Nederland.* Utrecht, The Netherlands: Nivel; 2018. Available from: https://nivel.nl/sites/default/files/bestanden/Gezondheidsvaardigheden_in_Nederland.pdf

13. Heijmans M, Brabers A, Rademakers J. *Hoe gezondheidsvaardig is Nederland? Factsheet Gezondheidsvaardigheden − Cijfers 2019.* Utrecht, The Netherlands: Nivel; 2019. Available from: https://nivel.nl/sites/default/files/bestanden/1003631.pdf

14. Caplan L, Wolfe F, Michaud K, Quinzanos I, Hirsh JM. Strong association of health literacy with functional status among rheumatoid arthritis patients: A cross-sectional study. *Arthritis Care Res.* 2014;66(4):508-14. doi:10.1002/acr.22165.

15. Putrik P, Ramiro S, Lie E, Keszei AP, Kvien TK, van der Heijde D, et al. Less educated and older patients have reduced access to biologic DMARDs even in a country with highly developed social welfare (Norway): Results from Norwegian cohort study NOR-DMARD. *Rheumatology*. 2016;55(7):1217-24. doi:10.1093/rheumatology/kew048.

16. World Health Organization. Regional Office for Europe. *Health 2020: A European policy framework and strategy for the 21st century.* Copenhagen, Denmark: World Health Organization. Regional Office for Europe; 2013. Available from: https://www.euro.who.int/__data/assets/pdf_file/0011/199532/Health2020-Long.pdf

17. Mikkelsen, B, Mauer-Stender, K. Health literacy: working together to improve health [Editorial]. *Public Health Panorama*. 2019;5(2-3):133-5.

18. Sørensen K, Karuranga S, Denysiuk E, McLernon L. Health literacy and social change: exploring networks and interests groups shaping the rising global health literacy movement. *Glob Health Promot*. 2018;25(4):89-92. doi:10.1177/1757975918798366.

19. Visscher BB, Steunenberg B, Heijmans M, Hofstede JM, Devillé W, van der Heide I, et al. Evidence on the effectiveness of health literacy interventions in the EU: a systematic review. *BMC Public Health.* 2018;18(1):1414. doi:10.1186/s12889-018-6331-7.

20. Quinlan P, Price KO, Magid SK, Lyman S, Mandl LA, Stone PW. The relationship among health literacy, health knowledge, and adherence to treatment in patients with rheumatoid arthritis. *HSS J.* 2013;9(1):42-9. doi:10.1007/s11420-012-9308-6.

21. Hirsh JM, Boyle DJ, Collier DH, Oxenfeld AJ, Nash A, Quinzanos I, et al. Limited health literacy is a common finding in a public health hospital's rheumatology clinic and is predictive of disease severity. *J Clin Rheumatol.* 2011;17(5):236-41. doi:10.1097/RHU.0b013e318226a01f.

22. Martin RW, McCallops K, Head AJ, Eggebeen AT, Birmingham JD, Tellinghuisen DJ. Influence of patient characteristics on perceived risks and willingness to take a proposed anti-rheumatic drug. *BMC Med Inform Decis Mak*. 2013;13:89. doi:10.1186/1472-6947-13-89.

23. Beauchamp A, Batterham RW, Dodson S, Astbury B, Elsworth GR, McPhee C, et al. Systematic development and implementation of interventions to OPtimise Health Literacy and Access (Ophelia). *BMC Public Health.* 2017;17(1):230. doi:10.1186/s12889-017-4147-5.

24. Batterham RW, Buchbinder R, Beauchamp A, Dodson S, Elsworth GR, Osborne RH. The OPtimising HEalth LIterAcy (Ophelia) process: Study protocol for using health literacy profiling and community engagement to create and implement health reform. *BMC Public Health*. 2014;14:694. doi:10.1186/1471-2458-14-694.

25. Dodson S, Beauchamp A, Batterham R, Osborne R. *Ophelia toolkit: A step-by-step guide for identifying and responding to health literacy needs within local communities.* Melbourne, Australia: Swinburne University of Technology; 2015.

26. Osborne RH, Batterham RW, Elsworth GR, Hawkins M, Buchbinder R. The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health.* 2013;13:658. doi:10.1186/1471-2458-13-658.

2

27. Rademakers J, Waverijn G, Rijken M, Osborne R, Heijmans M. Towards a comprehensive, person-centred assessment of health literacy: translation, cultural adaptation and psychometric test of the Dutch Health Literacy Questionnaire. *BMC Public Health.* 2020;20(1):1850. doi:10.1186/s12889-020-09963-0.

28. Beauchamp A, Buchbinder R, Dodson S, Batterham RW, Elsworth GR, McPhee C, et al. Distribution of health literacy strengths and weaknesses across socio-demographic groups: a cross-sectional survey using the Health Literacy Questionnaire (HLQ). *BMC Public Health.* 2015;15(1):678. doi:10.1186/s12889-015-2056-z.

29. Alders M. *Classification of the population with a foreign background in the Netherlands.* Presented at the conference: The Measure and Mismeasure of Populations: the statistical use of ethnic and racial categories in multicultural societies; 2001 December 17–18; Paris, France. Available from: https://www.cbs.nl/-/media/imported/documents/2002/05/classification-foreign.pdf?la=nl-nl

30. Statistics Netherlands. *Standaard onderwijsindeling: Editie 2016/'17.* Den Haag/Heerlen, The Netherlands: CBS; 2017. Available from: https://www.cbs.nl/-/media/_pdf/2017/13/pubsoi2016ed1617.pdf

31. Pearlin LI, Schooler C. The Structure of Coping. *J Health Soc Behav.* 1978;19(1):2-21.

32. England BR, Sayles H, Mikuls TR, Johnson DS, Michaud K. Validation of the rheumatic disease comorbidity index. *Arthritis Care Res.* 2014;67(6):865-72. doi:10.1002/acr.22456.

33. Ward Jr JH. Hierarchical grouping to optimize an objective function. *J Am Stat Assoc.* 1963;58(301):236-44.

34. DeWalt DA, Broucksou KA, Hawk V, Brach C, Hink A, Rudd R, et al. Developing and testing the health literacy universal precautions toolkit. *Nurs Outlook.* 2011;59(2):85-94. doi:10.1016/j.outlook.2010.12.002.

35. Hirsh J, Wood P, Keniston A, Boyle D, Quinzanos I, Caplan L, et al. Universal Health Literacy Precautions Are Associated With a Significant Increase in Medication Adherence in Vulnerable Rheumatology Patients. *ACR Open Rheumatol.* 2020;2(2):110-8. doi:10.1002/acr2.11108.

36. Aaby A, Simonsen CB, Ryom K, Maindal HT. Improving Organizational Health Literacy Responsiveness in Cardiac Rehabilitation Using a Co-Design Methodology: Results from The Heart Skills Study. *Int J Environ Res Public Health.* 2020;17(3):1015. doi: 10.3390/ijerph17031015

37. Antony A, Connelly K, De Silva T, Eades L, Tillett W, Ayoub S, et al. Perspectives of patients with rheumatic diseases in the early phase of COVID-19. *Arthritis Care Res.* 2020;72(9):1189-95. doi:10.1002/acr.22456

38. Norgaard O, Furstrand D, Klokker L, Karnoe A, Batterham R, Kayser L, et al. The e-health literacy framework: A conceptual framework for characterizing e-health users and their interaction with e-health systems. *Knowl. Manag. E-Learn.* 2015;7(4):522-40. doi:10.34105/j.kmel.2015.07.035

39. Jessup RL, Osborne RH, Beauchamp A, Bourne A, Buchbinder R. Differences in health literacy profiles of patients admitted to a public and a private hospital in Melbourne, Australia. *BMC Health Serv Res.* 2018;18(1):134. doi:10.1186/s12913-018-2921-4.

40. Bourne A, Peerbux S, Jessup R, Staples M, Beauchamp A, Buchbinder R. Health literacy profile of recently hospitalised patients in the private hospital setting: a cross sectional survey using the Health Literacy Questionnaire (HLQ). *BMC Health Serv Res.* 2018;18(1):877. doi:10.1186/s12913-018-3697-2

41. van der Gaag M, van der Heide I, Spreeuwenberg PMM, Brabers AEM, Rademakers J. Health literacy and primary health care use of ethnic minorities in the Netherlands. *BMC Health Serv Res.* 2017;17(1):350. doi:10.1186/s12913-017-2276-2

42. Bakker MM, Putrik P, Aaby A, Debussche X, Morrissey J, Borge CR, et al. Acting together – WHO National Health Literacy Demonstration Projects (NHLDPs) address health literacy needs in the European Region. *Public Health Panorama.* 2019;5(2-3):233-43.

43. Aaby A, Beauchamp A, O'Hara J, Maindal HT. Large diversity in Danish health literacy profiles: perspectives for care of long-term illness and multimorbidity. *Eur J Public Health.* 2019;30(1):75-80. doi:10.1093/eurpub/ckz134.

44. Jessup RL, Osborne RH, Buchbinder R, Beauchamp A. Using co-design to develop interventions to address health literacy needs in a hospitalised population. *BMC Health Serv Res.* 2018;18(1):989. doi:10.1186/s12913-018-3801-7.

45. Statistics Netherlands. *Bevolking; onderwijsniveau; geslacht, leeftijd en migratieachtergrond* [Database]. Den Haag/ Heerlen, The Netherlands: CBS; 2020. Available from: https://opendata.cbs.nl/statline/#/CBS/nl/dataset/82275NED/table?fromstatweb

2

SUPPLEMENTARY MATERIALS
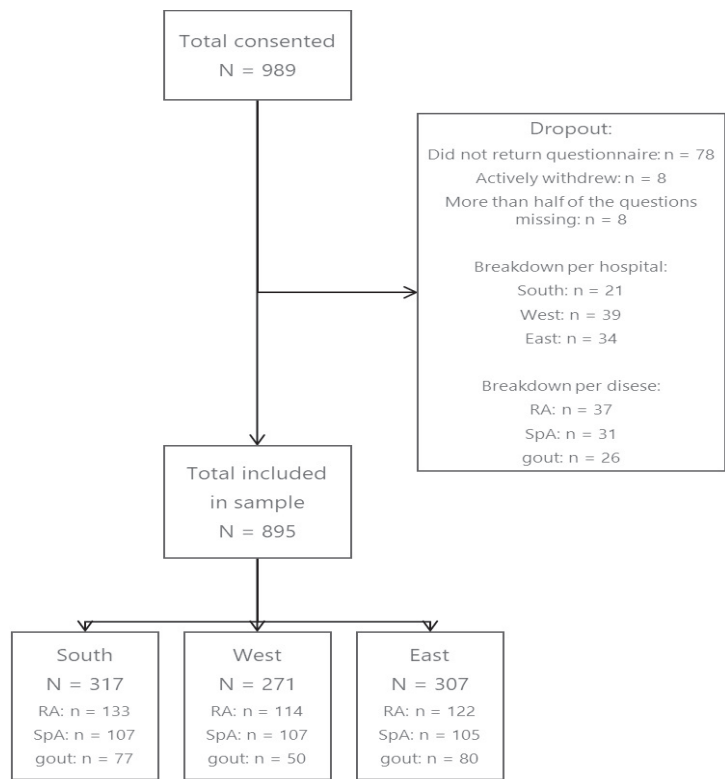
Supplementary figure 2.1 Study participation flowchart

Supplementary table 2.1 Demographic characteristics of the overall sample and per disease group*

	Total (n=895)	RA (n=369)	SpA (n=319)	Gout (n=207)	p-value†
Female gender	48.7 (436)	70.2 (259)	46.1 (147)	14.5 (30)	**<0.001**
Age, mean ± SD (range)	61.1 ± 13.9 (18-91)	64.1 ± 12.9 (18-89)	55.1 ± 13.5 (21-91)	64.8 ± 13.3 (29-88)	**<0.0001**
Treating hospital					0.22
South	35.4 (317)	36.0 (133)	33.5 (107)	37.2 (77)	
West	30.3 (271)	30.9 (114)	33.5 (107)	24.2 (50)	
East	34.3 (307)	33.1 (122)	32.9 (105)	38.7 (80)	
Education level					0.02
Low	50.7 (454)	55.0 (203)	43.3 (138)	54.6 (113)	
Medium	24.8 (222)	22.2 (82)	27.6 (88)	25.1 (52)	
High	24.5 (219)	22.8 (84)	29.2 (93)	20.3 (42)	
Migration background					0.41
Native Dutch	82.5 (738)	84.8 (313)	80.6 (257)	81.2 (168)	
Western migrant	9.3 (83)	8.9 (33)	10.0 (32)	8.7 (18)	
Non-western migrant	8.3 (74)	6.2 (23)	9.4 (30)	10.1 (21)	
Employment					
Working	33.3 (298)	24.1 (89)	45.1 (144)	31.4 (65)	**<0.001**
Working <65	56.1 (280)	47.5 (84)	58.8 (137)	66.3 (59)	**<0.01**
Work disabled <65	29.3 (146)	33.3 (59)	28.8 (67)	22.5 (20)	0.18
Retired	40.0 (358)	45.8 (169)	24.1 (77)	54.1 (112)	**<0.001**
Household composition					
Living alone	24.6 (220)	27.6 (102)	21.3 (68)	24.2 (50)	0.16
Patient-reported outcomes					
Mastery, mean ± SD (range)	20.0 ± 3.4 (9-28)‡	20.0 ± 3.3 (10-28)‡	20.1 ± 3.5 (9-28)	19.9 ± 3.4 (11-28)	0.81
RDCI, mean ± SD (range)	1.2 ± 1.3 (0-7)	1.1 ± 1.3 (0-6)	0.9 ± 1.3 (0-7)	1.6 ± 1.4 (0-7)	**<0.0001**
Self-reported health score, mean ± SD (range)	6.4 ± 1.8 (0-10)	6.5 ± 1.6 (1-10)	6.1 ± 2.0 (1-10)	6.7 ± 1.5 (0-10)	**<0.001**

*Legend: * Values are % (n) unless indicated otherwise. RA = Rheumatoid Arthritis; SpA = Spondyloarthritis; RDCI = Rheumatic Disease Comorbidity Index. † Analysis of variance / chi-square test was used for differences across disease groups. ‡ One respondent did not complete the Pearlin Mastery Scale as it was not available in Arabic.* **Bold** *values indicate p<0.05.*

2

Supplementary table 2.2 Health Literacy Questionnaire (HLQ) scores per domain for the overall sample and per disease group*

Domain	Total (n=895)	RA (n=369)	SpA (n=319)	Gout (n=207)	p-value†
1. Healthcare provider support (range 1-4)	3.14 ± 0.45 (1.25-4.00)	3.18 ± 0.44 (1.75-4.00)	3.14 ± 0.47 (1.75-4.00)	3.06 ± 0.43 (1.25-4.00)	**0.01**
2. Having sufficient information (range 1-4)	3.01 ± 0.42 (1.00-4.00)	3.05 ± 0.40 (1.75-4.00)	2.97 ± 0.46 (1.00-4.00)	3.00 ± 0.40 (1.75-4.00)	0.07
3. Actively managing health (range 1-4)	2.90 ± 0.45 (1.00-4.00)	2.91 ± 0.41 (1.00-4.00)	2.93 ± 0.48 (1.40-4.00)	2.83 ± 0.47 (1.40-4.00)	**0.04**
4. Having social support for health (range 1-4)	2.97 ± 0.50 (1.20-4.00)	2.98 ± 0.50 (1.20-4.00)	2.96 ± 0.49 (1.20-4.00)	2.98 ± 0.52 (1.20-4.00)	0.76
5. Critically appraising information (range 1-4)	2.71 ± 0.50 (1.00-4.00)	2.71 ± 0.49 (1.00-4.00)	2.75 ± 0.51 (1.00-4.00)	2.65 ± 0.51 (1.40-4.00)	0.09
6. Actively engaging with providers (range 1-5)	3.98 ± 0.62 (1.00-5.00)	4.02 ± 0.61 (1.00-5.00)	3.94 ± 0.65 (1.60-5.00)	3.98 ± 0.60 (2.20-5.00)	0.23
7. Navigating the health system (range 1-5)	3.77 ± 0.62 1.50-5.00)	3.81 ± 0.62 (1.50-5.00)	3.74 ± 0.62 (1.50-5.00)	3.73 ± 0.62 (1.50-5.00)	0.20
8. Finding health information (range 1-5)	3.77 ± 0.72 (1.00-5.00)	3.78 ± 0.71 (1.00-5.00)	3.83 ± 0.70 (1.00-5.00)	3.66 ± 0.75 (1.00-5.00)	**0.03**
9. Understanding health information (range 1-5)	3.91 ± 0.64 (1.60-5.00)	3.96 ± 0.60 (1.80-5.00)	3.94 ± 0.65 (1.60-5.00)	3.79 ± 0.67 (1.80-5.00)	**<0.01**

Legend: * Values are the mean ± SD (range) unless indicated otherwise. RA = Rheumatoid Arthritis; SpA = Spondyloarthritis. † Analysis of variance was used for differences across disease groups. **Bold** values indicate p<0.05.

2

Supplementary table 2.3 Patients' demographic characteristics per profile*

Variables / Profiles	1 (n=115)	2 (n=32)	3 (n=262)	4 (n=110)	5 (n=133)	6 (n=103)	7 (n=25)	8 (n=62)	9 (n=30)	10 (n=23)	p-value†
Female gender	54.8 (63)	75.0 (24)	48.9 (128)	40.0 (44)	45.9 (61)	46.6 (48)	40.0 (10)	56.5 (35)	43.3 (13)	43.5 (10)	**0.04**
Age, mean ± SD	59.0	55.3	60.8	61.1	61.4	64.2	72.2	57.7	60.3	64.8	**<0.0001**
(range)	(12.7)	(15.0)	(13.7)	(14.6)	(14.0)	(13.8)	(11.6)	(13.1)	(12.6)	(15.1)	
Education level											**<0.001**
Low	35.7 (41)	46.9 (15)	46.9 (123)	48.2 (53)	52.6 (70)	58.3 (60)	92.0 (23)	50.0 (31)	53.3 (16)	95.7 (22)	
Medium	24.3 (28)	21.9 (7)	26.3 (69)	28.2 (31)	25.6 (34)	24.3 (25)	4.0 (1)	29.0 (18)	30.0 (9)	- (0)	
High	40.0 (46)	31.3 (10)	26.7 (70)	23.6 (26)	21.8 (29)	17.5 (18)	4.0 (1)	21.0 (13)	16.7 (5)	4.3 (1)	
Migration background											**<0.001**
Native Dutch	80.0 (92)	87.5 (28)	88.9 (233)	85.5 (94)	76.7 (102)	83.5 (86)	76.0 (19)	80.6 (50)	70.0 (21)	56.5 (13)	
Western migrant	11.3 (13)	6.3 (2)	7.6 (20)	10.9 (12)	9.8 (13)	10.7 (11)	8.0 (2)	9.7 (6)	6.7 (2)	8.7 (2)	
Non-western migrant	8.7 (10)	6.3 (2)	3.4 (9)	3.6 (4)	13.5 (18)	5.8 (6)	16.0 (4)	9.7 (6)	23.3 (7)	34.8 (8)	
Employment											
Working	33.9 (39)	50.0 (16)	38.2 (100)	35.5 (39)	29.3 (39)	23.3 (24)	16.0 (4)	40.3 (25)	30.0 (9)	13.0 (3)	**0.01**
Working under 65	51.4 (36)	69.6 (16)	63.4 (92)	58.7 (37)	50.7 (37)	50.0 (23)	40.0 (2)	58.1 (25)	50.0 (9)	23.1 (3)	0.13
Work disabled under 65	35.7 (25)	21.7 (5)	28.3 (41)	20.6 (13)	28.8 (21)	30.4 (14)	40.0 (2)	30.2 (13)	27.8 (5)	53.8 (7)	0.48
Retired	34.8 (40)	28.1 (9)	41.6 (109)	38.2 (42)	37.6 (50)	47.6 (49)	76.0 (19)	33.9 (21)	30.0 (9)	43.5 (10)	**<0.01**
Household composition											
Living alone	20.0 (23)	31.3 (10)	22.9 (60)	12.7 (14)	24.1 (32)	28.2 (29)	44.0 (11)	32.3 (20)	46.7 (14)	30.4 (7)	**0.001**

Supplementary table 2.3 (Continued)

Variables / Profiles	1 (n=115)	2 (n=32)	3 (n=262)	4 (n=110)	5 (n=133)	6 (n=103)	7 (n=25)	8 (n=62)	9 (n=30)	10 (n=23)	p-value†
Patient-reported outcomes											
Mastery, mean ± SD	22.2	22.3	20.6	20.6	19.2	19.0	18.2	18.4	17.0	15.8	**<0.0001**
(range)	(3.3)	(3.7)	(3.1)	(2.9)	(2.9)	(2.7)	(3.9)‡	(2.7)	(2.6)	(3.8)	
RDCI, mean ± SD	0.93	0.59	1.16	0.95	1.02	1.55	2.20	1.16	1.33	1.48	**<0.0001**
(range)	(1.1)	(0.9)	(1.3)	(1.1)	(1.3)	(1.6)	(1.4)	(1.4)	(1.2)	(1.3)	
Self-reported health	6.8	6.9	6.7	6.8	6.2	6.2	5.8	5.7	5.4	5.3	**<0.0001**
score, mean ± SD											
(range)	(1.7)	(2.2)	(1.5)	(1.6)	(1.8)	(1.6)	(2.0)	(1.6)	(2.2)	(2.1)	

*Legend: * Values are % (n) unless indicated otherwise. RA = Rheumatoid Arthritis; SpA = Spondyloarthritis; RDCI = Rheumatic Disease Comorbidity Index. † Analysis of variance / chi-square test was used for differences across profiles. ‡ One respondent did not complete the Pearlin Mastery Scale as it was not available in Arabic.* **Bold** *values indicate p<0.05.*

2

Supplementary table 2.4 Relative risk per factor for belonging to each of the 10 health literacy profiles, computed using a fully adjusted multivariable multinomial regression model (n = 894)*

Factors / Profiles	1	2	3	4	5
Age	[ref]	0.96 (0.93-0.99)	0.99 (0.97-1.01)	0.99 (0.97-1.01)	1.00 (0.98-1.02)
Gender					
Female	[ref]	[ref]	[ref]	[ref]	[ref]
Male	[ref]	0.48 (0.17-1.34)	1.41 (0.85-2.34)	2.03 (1.11-3.72)	1.77 (0.98-3.17)
Education					
Middle/high	[ref]	[ref]	[ref]	[ref]	[ref]
Low	[ref]	2.05 (0.88-4.79)	1.52 (0.94-2.46)	1.66 (0.94-2.92)	1.65 (0.95-2.86)
Rheumatic disease					
RA	[ref]	[ref]	[ref]	[ref]	[ref]
SpA	[ref]	0.39 (0.15-1.02)	0.59 (0.34-1.01)	0.45 (0.24-0.88)	0.69 (0.37-1.30)
Gout	[ref]	0.77 (0.19-3.08)	1.07 (0.53-2.16)	0.88 (0.40-1.97)	0.87 (0.39-1.95)
Treating hospital					
South	[ref]	[ref]	[ref]	[ref]	[ref]
West	[ref]	0.67 (0.22-2.02)	0.67 (0.37-1.22)	0.49 (0.24-0.98)	0.77 (0.40-1.51)
East	[ref]	1.04 (0.39-2.75)	0.73 (0.42-1.27)	0.57 (0.30-1.10)	0.69 (0.36-1.33)
Household composition					
Living with others	[ref]	[ref]	[ref]	[ref]	[ref]
Living alone	[ref]	1.94 (0.77-4.93)	1.21 (0.68-2.15)	0.60 (0.28-1.29)	1.20 (0.63-2.32)
Migration background					
Native Dutch	[ref]	[ref]	[ref]	[ref]	[ref]
Western migrant	[ref]	0.49 (0.10-2.39)	0.65 (0.30-1.39)	0.93 (0.39-2.20)	0.98 (0.41-2.35)
Non-western migrant	[ref]	0.46 (0.09-2.40)	0.35 (0.13-0.94)	0.44 (0.12-1.55)	1.65 (0.65-4.18)
Mastery	[ref]	1.03 (0.90-1.17)	0.86 (0.80-0.93)	0.86 (0.78-0.94)	0.74 (0.68-0.81)

*Legend: * Values are relative risk (95% CI) unless indicated otherwise. RA = Rheumatoid Arthritis; SpA = Spondyloarthritis. † Chi-square test statistic for differences across profiles. **Bold** values indicate p<0.05.*

6	7	8	9	10	p-value†
1.01 (0.99-1.03)	1.08 (1.03-1.14)	0.98 (0.95-1.00)	1.00 (0.96-1.04)	1.03 (0.98-1.08)	**<0.01**
					0.09
[ref]	[ref]	[ref]	[ref]	[ref]	
1.57 (0.84-2.93)	2.28 (0.76-6.86)	1.06 (0.51-2.21)	2.53 (0.95-6.74)	2.34 (0.72-7.59)	
					0.01
[ref]	[ref]	[ref]	[ref]	[ref]	
1.87 (1.04-3.38)	13.35 (2.81-63.36)	1.58 (0.80-3.13)	1.43 (0.58-3.53)	26.76 (3.26-219.75)	
					0.20
[ref]	[ref]	[ref]	[ref]	[ref]	
0.71 (0.36-1.42)	2.70 (0.70-10.40)	1.08 (0.50-2.36)	1.18 (0.42-3.34)	0.93 (0.26-3.36)	
1.35 (0.60-3.08)	3.65 (0.95-14.05)	1.59 (0.57-4.40)	0.72 (0.18-2.89)	0.65 (0.14-3.00)	
					0.07
[ref]	[ref]	[ref]	[ref]	[ref]	
1.11 (0.54-2.31)	0.36 (0.11-1.19)	0.93 (0.42-2.05)	0.52 (0.18-1.47)	0.11 (0.02-0.48)	
1.20 (0.60-2.40)	0.37 (0.11-1.21)	0.49 (0.21-1.14)	0.31 (0.10-0.98)	0.19 (0.05-0.74)	
					0.03
[ref]	[ref]	[ref]	[ref]	[ref]	
1.45 (0.73-2.86)	2.39 (0.86-6.70)	2.00 (0.94-4.28)	3.30 (1.29-8.45)	1.13 (0.35-3.70)	
					<0.01
[ref]	[ref]	[ref]	[ref]	[ref]	
1.06 (0.42-2.64)	0.86 (0.16-4.70)	0.89 (0.30-2.64)	0.52 (0.10-2.80)	0.99 (0.17-5.79)	
0.63 (0.20-1.99)	2.94 (0.57-15.06)	0.81 (0.25-2.63)	3.23 (0.91-11.51)	14.79 (3.02-72.42)	
0.72 (0.66-0.79)	0.70 (0.59-0.82)	0.68 (0.61-0.75)	0.58 (0.50-0.67)	0.51 (0.42-0.61)	**<0.0001**

2

CHAPTER 3

The impact of health literacy: Associations with disease activity and medication prescription in patients with rheumatoid arthritis

Mark M. Bakker*, Anne Gorter*, Peter M. ten Klooster, Annelies Boonen, Harald E. Vonkeman

* These authors contributed equally

ABSTRACT

Objective

The aim of this study was to explore the longitudinal associations between health literacy profiles and disease activity and medication prescription in patients with rheumatoid arthritis (RA).

Methods

Patients with RA who previously completed the Health Literacy Questionnaire (HLQ) and were assigned one of ten distinct health literacy profiles based on cluster analysis were further aggregated into three groups: 'several health literacy limitations', 'some health literacy limitations' and 'good health literacy'. Linear mixed modelling (LMM) was used to analyse the association between health literacy groups and disease activity over the course of 1 year. Chi-square tests and logistic regression analyses were used to compare medication prescriptions between the groups.

Results

108 patients with RA were included. LMM showed a significant effect of health literacy group on disease activity over time (p=0.010). Patients with 'good health literacy' had significantly lower disease activity over time (DAS28-ESR=2.4) than patients with 'several health literacy limitations' (DAS28-ESR=3.1), independent of age, gender and education level. Patients with 'good health literacy' were most often prescribed a bDMARD (50%), whereas patients with 'some health literacy limitations' more commonly received a csDMARD only (72.7%, OR 4.24), and patients with 'several health literacy limitations' were more often prescribed prednisolone (52.4%, OR 3.56).

Conclusion

Significant differences in longitudinal disease activity and medication prescription were observed between groups with different health literacy levels. These results stress the importance of insight into the role of health literacy in treatment and outcomes in patients with rheumatoid arthritis.

KEY MESSAGES

— Patients with RA experiencing health literacy limitations have higher disease activity and are prescribed more prednisolone.
— Patients with 'good health literacy' have lower disease activity and are most often prescribed a biological DMARD.
— This study underscores the importance of insight into health literacy in patients with rheumatoid arthritis.

INTRODUCTION

Patients' health literacy is increasingly recognised as a critical determinant of health [1]. Health literacy comprises "*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*" [2].

The importance of health literacy has been demonstrated in multiple studies across diverse patient populations, linking 'limited' health literacy with problems seeking preventive care [3], delayed diagnosis of chronic illnesses [4], low adherence to treatment [5] and poorer health outcomes [4]. Health literacy follows a social gradient, with difficulties most often (but not exclusively) observed in societal groups in vulnerable positions, including older adults [6], ethnic minorities [3] and socio-economically disadvantaged populations [6, 7]. In the Netherlands, 'limited' health literacy is estimated to affect about a quarter of the general adult population [8].

This study focuses on patients with rheumatoid arthritis (RA). Previous studies on RA and health literacy specifically described a worse functional status [9] and reluctance to change prescription in patients with 'limited' health literacy [10]. Nevertheless, research in this field is still limited and predominantly focused on unidimensional definitions of health literacy, primarily targeting patients' levels of functional health literacy [11]. Further studies into the role of health literacy in the treatment and outcomes of patients with RA, particularly using multidimensional tools, are warranted.

We expand upon the research of Bakker et al. [12] who identified ten distinct health literacy profiles of patients with rheumatic diseases. These profiles categorised patients based on their health literacy strengths and weaknesses, thereby unveiling clusters of patients who might benefit from specific types of support. The profiles indicating more limitations were associated with lower self-rated health, but the clinical relevance of the identified profiles needs further substantiation; associations with disease activity trajectories and medication prescription have yet to be explored.

To gain more insight into the predictive role of health literacy profiles on treatment and treatment outcomes in patients with RA, the aim of this study was to explore the longitudinal associations between health literacy profiles, disease activity and medication prescription in patients with RA.

3

PATIENTS AND METHODS

Study design

We conducted a single centre, retrospective cohort study among patients with RA at Medisch Spectrum Twente (MST) hospital (Enschede, the Netherlands) who had previously completed the Health Literacy Questionnaire (HLQ [13, 14]) between February and May 2019 [12]. Up to 1 year of follow-up data was obtained from patients' electronic health records.

Patients and patient selection

The original study by Bakker et al. [12] included 895 adult patients with gout, spondyloarthritis or rheumatoid arthritis from three different hospitals in the Netherlands, representing diverse socio-economic backgrounds. From this pre-existing dataset, 307 patients were being treated at MST Enschede, of which 122 were diagnosed with RA. For the current study, we included those with available disease activity scores and medication prescription data in their patient records, resulting in a final sample of 108 patients.

The included patients had previously been assigned to one of ten possible health literacy profiles, ranging from patients who could manage their health and health care with minimal difficulty (group 1) to patients who had several limitations (group 10). A more elaborate description of health literacy profiles and demographic characteristics can be found in the original paper [12]. For the current study, the ten profiles were further aggregated, based on similarities in profile characteristics. The resulting three groups were labelled; 1) 'several health literacy limitations' (profiles 6-10), 2) 'some health literacy limitations' (profiles 2, 4 and 5) and 3) 'good health literacy' (profiles 1 and 3).

Data collection & dataset formation

We retrieved up to 1 year of follow-up data on disease activity and medication prescription from patients' electronic health records. The date at which the patient filled out the HLQ was taken as the baseline for the current study. Disease activity was assessed using routinely collected 28-joint disease activity scores-erythrocyte sedimentation rate (DAS28-ESR) scores. The DAS28-ESR score comprises the tender joint count, swollen joint count, a patient's indication of their global assessment of health (between 0-10), and erythrocyte sedimentation rate (ESR). A DAS28-ESR score higher than 5.1 implies active disease, lower than 3.2 implies low disease activity, and lower than 2.6 implies remission. We retrieved follow-up DAS28-ESR scores as collected 6 and 12 months after baseline. These time points were based on routine rheumatological care appointments. A range of +/- 4 months per time point was used to minimise missing data. Information on medication prescription (prednisolone yes/no, csDMARDs yes/no, bDMARDS yes/no) and medication changes (switching type or all-out stopping of medication) was retrieved over a period of 12 months after baseline.

Statistical analysis

Differences between the three health literacy groups at baseline were tested using one-way ANOVA (or where appropriate Kruskal-Wallis) tests for continuous data and chi-square tests for categorical data.

We used linear mixed modelling (LMM) with restricted maximum likelihood estimation to analyse the association between health literacy groups and DAS28-ESR scores over time, using health literacy group, time, and their interaction term as fixed effects with the 'good health literacy' group as the reference category, and gender and age as random effects. A first-order autoregressive (AR1) covariance structure was selected for the repeated covariance structure, because it was the best-fitting pattern of covariance matrices, based on Akaike's information criterion (AIC) and Schwartz's Bayesian information criterion (BIC) values. Least Significant Difference was used for post hoc contrast analysis. A sensitivity analysis was performed to observe the effect of education (as a fixed effect) on the association of health literacy and DAS28-ESR. Because no changes in type of medication prescribed were observed over time, we used chi-square tests to compare the health literacy groups at baseline. For medication variables with significant differences, we performed logistic regression models with medication prescription (yes/no) as the dependent variable and health literacy group as the independent variable, adjusted for gender, age, and education.

Missing data ranged from 0-16 patients for DAS28-ESR scores at the different time points, which were left missing. No medication prescription data were missing. All statistical analyses were performed using IBM SPSS Statistics Version 27. A two-sided p-value of 0.05 was considered statistically significant for all tests.

RESULTS

A total of 108 patients with RA were included in the study and assigned to the 'several health literacy limitations' (n=21), 'some health literacy limitations' (n=33) or 'good health literacy' (n=54) group.

Baseline characteristics

Mean age at baseline was 66.0 ± 12.7 years, and 62.0% were female. Persons belonging to the group with 'several health literacy limitations' were older on average, more frequently female, and comprised more persons with lower education levels compared to the other two groups. Moreover, patients with 'good health literacy' on average had lower disease activity scores (DAS28-ESR) at baseline. More than half of the participating patients had a positive rheumatoid factor (RF) (57%) and/or anti-cyclic citrullinated peptide (CCP) (54%). The majority of patients used a conventional disease-modifying anti-rheumatic drug (csDMARD) (56%)

and/or biological disease-modifying anti-rheumatic drug (bDMARD) (18%). Table 3.1 shows the baseline characteristics per health literacy group.

Longitudinal analyses of disease activity

Figure 3.1 displays the trajectories of mean DAS28-ESR scores over 12 months time for the three health literacy groups. LMM showed a significant main effect of health literacy group on DAS28-ESR scores over time (p=0.010, table 3.2, main model). Post hoc contrast analysis showed that patients with 'good health literacy' had significantly lower disease activity scores than patients with 'several health literacy limitations' (p=0.019) or 'some health literacy limitations' (p=0.009). The difference between the two groups with health literacy limitations was not significant.

In addition, DAS28-ESR scores changed significantly over time (p=0.007) in the total sample, owing to significantly lower scores at the 6-month follow-up. There was no significant interaction between group and time (p=0.541), indicating that the changes over time were not different between health literacy groups. Sensitivity analysis (Table 3.2) showed that controlling for education had no significant impact on the association between health literacy group and DAS28-ESR scores.
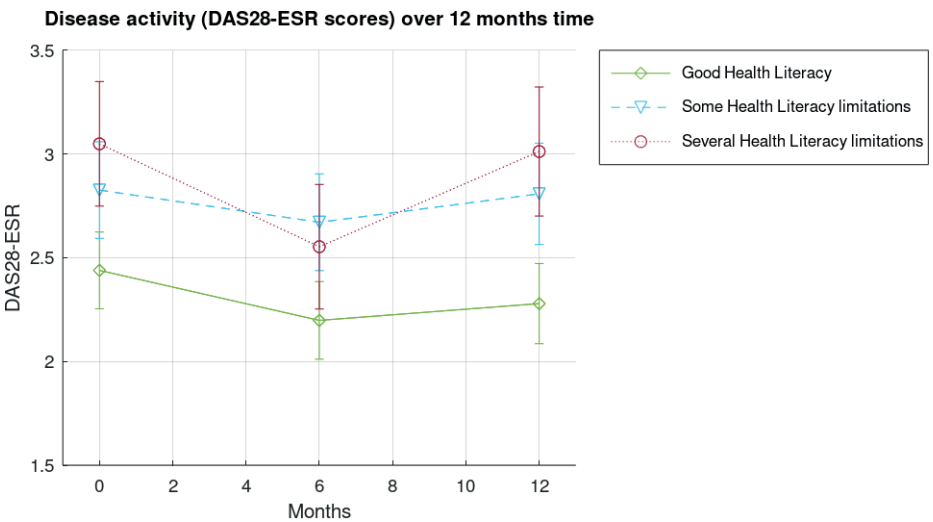
Figure 3.1 Disease activity (DAS28-ESR) per health literacy group over 12 months time

Table 3.1 Patient characteristics at baseline by health literacy group (n = 108).

	Good health literacy (n=54)	Some health literacy limitations (n=33)	Several health literacy limitations (n=21)	p-value
Demographic characteristics				
Female, n (%)	35 (64.8)	17 (51.5)	15 (71.4)	0.284[a]
Age (years), mean (SD)	65.1 (12.5)	65.0 (12.5)	69.5 (13.3)	0.542[b]
Education level, n (%):				0.059[a]
High education	16 (29.6)	7 (21.2)	4 (19)	
Medium education	13 (24.1)	7 (21.2)	0 (0)	
Low education	25 (46.3)	19 (57.6)	17 (81)	
Clinical characteristics				
Anti-CCP positive, n (%)†	25 (51.0)	14 (51.9)	11 (64.7)	0.604[a]
RF positive, n (%)‡	31 (58.5)	17 (54.8)	11 (57.9)	0.946[a]
ESR, median (IQR)	10.0 (21.0)	15.0 (19.0)	12.0 (27.0)	0.687[c]
TJC, median (IQR)	0 (0-2)	0 (0-1)	0.5 (0-5)	0.268[c]
SJC, median (IQR)	0 (0-1)	1 (0-3)	1 (0-3)	**0.010[c]**
Disease activity				
Remission (<2.6), n (%)	35 (64.8)	15 (45.5)	7 (33.3)	**0.030[a]**
DAS28-ESR, mean (SD)	2.4 (1.1)	2.9 (1.2)	3.1 (1.5)	**0.042[b]**
Medication prescription, n (%)				
Any DMARD	48 (88.9)	30 (90.9)	20 (95.2)	0.695[a]
Both csDMARD & bDMARD	15 (27.8)	4 (12.1)	4 (19.0)	0.215[a]
csDMARD only*	21 (38.9)	24 (72.7)	12 (57.1)	**0.008[a]**
bDMARD only*	12 (22.2)	2 (6.1)	4 (19.0)	0.138[a]
Any csDMARD	36 (66.7)	28 (84.8)	16 (76.2)	0.166[a]
Any bDMARD	27 (50.0)	6 (18.2)	8 (38.1)	**0.012[a]**
Prednisolone	12 (22.2)	7 (21.21)	11 (52.4)	**0.019[a]**

*Legend: n = number, SD = standard deviation, IQR = interquartile range, Anti-CCP = anti-cyclic citrullinated peptide, RF = rheumatoid factor, ESR = erythrocyte sedimentation rate, TJC = tender joint count, SJC = swollen joint count, DAS28 = disease activity score, csDMARD = conventional disease-modifying anti-rheumatic drug, bDMARD = biological disease-modifying anti-rheumatic drug. †Anti-CCP was available for 93 patients. ‡ RF was available for 103 patients. * refers to a single type of DMARD, but could still be prescribed with other medication, such as prednisolone. a Chi-square test; b One way ANOVA; c Kruskal-Wallis test. **Bold** values indicate p<0.05.*

3

Analyses of medication prescription

No changes in prescriptions occurred during the study period, so we present medication prescription data at baseline. Fifty percent of patients in the 'good health literacy' group were prescribed a bDMARD, compared to 18.2% and 38.1% in the 'some health literacy limitations' (adjusted OR 0.22 [0.08-0.65]) and 'several health literacy limitations' (adjusted OR 0.81 [0.27-2.47], not significant) groups respectively. Patients with 'some health literacy limitations' were prescribed csDMARDs only significantly more often (72.7%, OR 4.24 [1.57-11.51]) than patients with 'good health literacy' (38.9%). Patients with 'several health literacy limitations' were prescribed prednisolone significantly more often (52.4%, OR 3.56 [1.13-11.15] compared with 'good health literacy') than patients with 'some health literacy limitations' (21.2%) or 'good health literacy' (22.2%). Tables 3.1 and 3.3 display all data on medication prescriptions.

Table 3.2 Factors associated with disease activity scores. Results from linear mixed models (n = 108).

	Main model				**Sensitivity analysis**			
	β	SE	95% CI	p-value	β	SE	95% CI	p-value
Health literacy group				**0.010**				**0.011**
Good HL	(ref)	(ref)	(ref)	(ref)	(ref)	(ref)	(ref)	(ref)
Some HL limitations	0.617	0.265	0.096, 1.140	**0.021**	0.597	0.262	0.080, 1.114	**0.024**
Several HL limitations	0.765	0.309	0.155, 1.375	**0.014**	0.797	0.313	0.180, 1.413	**0.012**
Time				**0.007**				**0.008**
Baseline	0.155	0.184	-0.208, 0.518	0.400	0.159	0.184	-0.203, 0.521	0.387
6-month follow-up	-0.082	0.151	-0.381, 0.216	0.587	-0.075	0.152	-0.374, 0.224	0.622
12-month follow-up	(ref)	(ref)	(ref)	(ref)	(ref)	(ref)	(ref)	(ref)
Time * HL group				0.541				0.537
Education								**0.046**
High education					(ref)	(ref)	(ref)	(ref)
Medium education					0.661	0.274	0.119, 1.203	**0.017**
Low education					0.412	0.221	-0.027, 0.851	0.065

Legend: *HL= health literacy, (ref) = reference group. Dependent variable: disease activity scores, random effects: gender, age. Displayed are adjusted coefficients from multivariable models.* **Bold** *values indicate p<0.05*

Table 3.3 Odds ratios for medication prescription. Results from multivariable logistic regression models (n = 108).

	Any bDMARD		csDMARD only		Prednisolone	
	OR [95% CI]	p-value	OR [95% CI]	p-value	OR [95% CI]	p-value
Health literacy group						
Good HL	(ref)	(ref)	(ref)	(ref)	(ref)	(ref)
Some HL limitations	0.22 [0.08, 0.65]	**0.006**	4.24 [1.57, 11.51]	**0.004**	0.99 [0.34, 2.92]	0.989
Several HL limitations	0.81 [0.27, 2.47]	0.717	1.58 [0.53, 4.75]	0.412	3.56 [1.13, 11.15]	**0.029**
Education						
High education	(ref)	(ref)	(ref)	(ref)	(ref)	(ref)
Medium education	1.69 [0.47, 6.03]	0.420	0.44 [0.12, 1.60]	0.212	1.85 [0.43, 7.97]	0.410
Low education	0.75 [0.26, 2.17]	0.599	1.21 [0.43, 3.40]	0.720	1.67 [0.51, 5.50]	0.401
Female gender	1.63 [0.67, 3.94]	0.283	0.54 [0.23, 1.27]	0.158	1.60 [0.62, 4.18]	0.334
Age	0.98 [0.94, 1.01]	0.178	1.02 [0.99, 1.06]	0.179	1.02 [0.98, 1.06]	0.372

Legend: *HL = health literacy, bDMARD = biological disease-modifying anti-rheumatic drug, csDMARD = conventional disease-modifying anti-rheumatic drug, (ref) = reference group. Dependent variable: medication prescription, defined for each column.* **Bold** *values indicate p<0.05*

3

DISCUSSION

The aim of this study was to explore the longitudinal associations between health literacy profiles and disease activity as well as medication prescription in patients with RA. We found differences between the health literacy groups for both disease activity and medication prescription over the course of a year.

Disease activity scores were consistently higher over time in patients with more health literacy needs. In sensitivity analysis, this relationship proved independent of patients' education level. Previous cross-sectional studies on the relationship between health literacy and disease activity in patients with RA yielded mixed results. Hirsh et al. [15] did not find an association of disease activity with health literacy (as measured with three different unidimensional measures of health literacy, primarily targeting Nutbeam's first level of functional health literacy [11]). They attributed this lack of association to the variable nature of DAS28 scores and a relatively small sample size (n=110). In contrast, a larger study by Swearingen et al. [16] was consistent with our findings, linking higher disease activity to worse scores on the Rapid Estimate of Adult Literacy in Medicine (REALM, measuring functional

health literacy) and Health Education Literacy of Patients (HELP, measuring 'comprehension', 'applying medical information', and 'communicative competence') questionnaire. Our study complements these findings by establishing a link between DAS28-ESR scores and health literacy as measured with a comprehensive multidimensional tool, which considers Nutbeam's levels of interactive and critical health literacy, in addition to functional health literacy [11]. The underlying mechanism for this association remains unknown, but explanatory factors are most likely multifaceted. Examples include the (in-)adequacy of the history-taking by the physician and the relay of information by the patient, the difficulty with appraisal of the severity of the experienced symptoms by physician and patient, and the lacking reliability and validity of subjective (components of) outcome measures used to determine disease activity in people with 'limited' health literacy [17]. For this last challenge, it may be necessary to simplify measurement tools [17, 18], and provide patients with additional guidance and support [17]. In addition, adherence to treatment could play a role in the relationship between health literacy and disease activity scores. Adherence in itself is dependent on a multitude of factors, of which understanding the necessity is key. Several studies have indeed explicated the relationship between 'limited' health literacy and lack of medication adherence, resulting in reduced disease control and higher disease activity levels [19].

Medication prescriptions also differed between the health literacy groups. Most remarkably, we found that patients with 'several health literacy limitations' were prescribed prednisolone more often. No previous studies have reported on this phenomenon. Prednisolone was recommended by the American College of Rheumatology in 2015, to treat disease flare-ups to relieve swelling and pain [20]. In our practice, prednisolone is mainly used in the initial remission induction treatment of RA and as bridging therapy when switching between different DMARDs. The difference in prednisolone prescriptions suggests RA is not sufficiently under control in these patients, leading to prednisolone initially being prescribed as a practical short-term solution, but continued as a long-term maintenance dose. Patients with more health literacy needs may also ask for prednisolone more easily because they may not be as able to anticipate the adverse effects in the long-term. Additionally, we found significantly more bDMARD prescriptions in the 'good health literacy' group. In the 'some health literacy limitations' group, this was likely to be compensated by prescription of csDMARDs only, while the 'several health literacy limitations' group, as stated before, received more prednisolone. This finding could partly be explained by the reluctance of patients to switch to bDMARDs [10]. The causes of this reluctance are multifactorial, but likely include patients' concerns about new medication and overall satisfaction with their current treatment regimen (even if disease activity levels indicate a medication switch is required) [21]. Furthermore, a previous study in the United States showed that patients in socio-economically disadvantaged positions (as associated with 'limited' health literacy) were often not informed about or prescribed bDMARDs, albeit primarily due to high patient costs [22]. Nonetheless, a study conducted in Norway (where financial barriers are absent) also hypothesised that health literacy may play

a role as a barrier to bDMARD prescription in patients of older age and with lower education levels [23]. The present study further establishes this prescription divide in a health system where financial barriers generally play only a small role, as all medication discussed here is covered under mandatory basic health insurance in the Netherlands. Of note, patients with 'good health literacy' were prescribed most bDMARDs (Table 3.1), but differences were only significant compared with the 'some health literacy limitations' group (Table 3.3). Due to the relatively small size of the groups with health literacy limitations, we should be careful in drawing strong conclusions from comparisons between the two as they may also be due to chance, and further research is needed to confirm our findings. Nevertheless, different attitudes of healthcare professionals and patients towards decision-making between the groups [24], or higher disease activity in the 'several health literacy limitations' group might have prompted the prescription of prednisolone and earlier initiation of bDMARDs. Further (qualitative) research into the roles and attitudes of patients and rheumatologists in treatment decisions for bDMARDs in relation to health literacy is warranted.

Our findings may raise questions about what could be done to level the playing field through health literacy. While health literacy is seen as a modifiable determinant of health, improving individuals' health literacy is difficult in a clinical setting, where time with a patient is limited. Rather, we should identify how our services can better respond to the health literacy limitations of our patients. Ongoing research based on the study by Bakker et al. [12] currently focuses on what so-called 'health literacy actions' could be implemented in rheumatology care. The project follows the OPtimising HEalth LIteracy and Access (Ophelia) process [25], a methodology endorsed by the World Health Organization, which generates solutions to health literacy challenges in diverse (medical) settings all over the world [26]. Examples of health literacy solutions include using the Conversational Health Literacy Assessment Tool (CHAT) to identify a patient's specific challenges [27], developing understandable and actionable information materials (for example by using plain language or illustrations [28]), and offering patients additional guidance and support, for example by discussing questions and treatment decisions with a rheumatology nurse.

Another initiative that could potentially address the health literacy divide in rheumatology is the 'universal precautions' approach [29]. This approach assumes that every patient is at risk of reduced access to and outcomes of care due to 'limited' health literacy. A rheumatology-specific toolkit that can help organisations in providing care that connects with patients of all health literacy levels is publicly available [30]. Applying this approach can lead to increased adherence to rheumatology-related medications [31]. No matter which approach is taken, we should look beyond one-size-fits-all solutions: health literacy needs are context-specific, and therefore solutions need tailoring to the local context as well.

A strength of this paper is the use of a multidimensional approach to health literacy. This study is the first to explore associations of health literacy with disease activity and medication prescription in patients with RA using the HLQ, a multidimensional tool for health

literacy. Additionally, the use of patients' data from routine visits (without additional lab tests or measurements) provides a true-to-life representation of RA treatment and outcomes. Nevertheless, there are some limitations to take into account. First, due to the relatively small sample size, we aggregated the ten health literacy profiles into three health literacy groups for comparison. Variation of the effect of different health literacy profiles within these three groups on disease activity or medication prescription may exist, but a bigger sample size would be required for such analyses. Second, due to the single-centre study design, the population was rather homogenous, with all patients included being from the Twente region in The Netherlands. This limited the socioeconomic diversity thereby hindering broader generalisation of the results. Previous research in the field of health literacy showed a distinct connection between ethnicity and the level of health literacy [3] so a more diverse sample may yield different results. Last, this study only assessed medication prescriptions and did not look into adherence. Medication adherence in patients with 'limited' health literacy is a widely researched topic and there is general consensus about an existing negative association between the two [5, 19]. Studying medication prescription and adherence patterns in tandem could provide more insight into the reasons behind higher DAS28-ESR and prednisolone use.

In conclusion, in a population of patients with RA, we found that patients with 'several health literacy limitations' had higher disease activity scores over time, even when adjusted for education level, and used prednisolone significantly more often than patients with higher health literacy levels. Patients with 'good health literacy' were most often prescribed a bDMARD. These results support the clinical relevance of the previously identified health literacy profiles, and provide more insight into the role of health literacy in treatment and outcomes of patients with RA. This study suggests that better recognition of and attention for patients' health literacy needs by health professionals is necessary for more optimal disease management and patient understanding.

STATEMENTS

Funding

Conflicts of interest

The authors have no financial or other interest to declare.

Ethics

This study complies with the Declaration of Helsinki. All patients treated at MST have given their written informed consent for the use of their routinely collected data in patient files for (pseudo-anonymised) research purposes, and have previously provided informed consent for the collection of health literacy data in the original study [12]. No additional data were collected. Therefore, renewed ethical review was not necessary in accordance with Dutch regulations. The relevant Dutch law (Medical Research Involving Human Subjects Act (in Dutch: Wet medisch-wetenschappelijk onderzoek met mensen (WMO)) requires only certain research to be reviewed. Research is subject to the WMO if it concerns 1) medical scientific research, and 2) participants are subject to procedures or are required to follow rules of behaviour (Article 1.1b. Available from: https://wetten.overheid.nl/BWBR0009408/2022-01-31 (in Dutch)). An explanation of this law in English can be found on the website of the Central Committee on Research Involving Human Subjects (CCMO, the Committee created in Dutch law to administer the operation of the law): https://english.ccmo.nl/investigators/legal-framework-for-medical-scientific-research/your-research-is-it-subject-to-the-wmo-or-not. Analyses of pseudo-anonymised routinely collected patient data (accessed with written informed consent of the patient) and secondary analyses of previously collected research data (as undertaken in this study) are not within the meaning of medical scientific research, nor do they place the participants under a particular process or behaviour change. Therefore, the research undertaken here did not require further review under Dutch law. The original study by Bakker et al. [12] was reviewed by the Medical Ethics Review Committee at Maastricht University Medical Center (2018-0327) and the locally responsible committee at Medisch Spectrum Twente (KH18-23).

Data availability

The data underlying this article will be shared on reasonable request to the corresponding author, M.M. Bakker. The data cannot be shared publicly, as they contain information that could compromise the privacy of research participants. They did not consent to have their data shared.

REFERENCES

1. World Health Organization. Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development. *Health Promot Int*. 2017;32(1):7-8. doi:10.1093/heapro/daw103.

2. 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. doi:10.1177/1757975918814421.

3. Bennett IM, Chen J, Soroui JS, White S. The contribution of health literacy to disparities in self-rated health status and preventive health behaviors in older adults. *Ann Fam Med*. 2009;7(3):204-11. doi:10.1370/afm.940.

4. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med*. 2011;155(2):97-107. doi:10.7326/0003-4819-155-2-201107190-00005.

5. Miller TA. Health literacy and adherence to medical treatment in chronic and acute illness: A meta-analysis. *Patient Educ Couns*. 2016;99(7):1079-86. doi:10.1016/j.pec.2016.01.020.

6. 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. doi:10.1093/eurpub/ckv043.

7. Svendsen MT, Bak CK, Sørensen K, Pelikan J, Riddersholm SJ, Skals RK, et al. Associations of health literacy with socioeconomic position, health risk behavior, and health status: A large national population-based survey among Danish adults. *BMC Public Health*. 2020;20(1):565. doi:10.1186/s12889-020-08498-8.

8. Willems AEM, Heijmans M, Brabers AEM, Rademakers J. *Gezondheidsvaardigheden in Nederland: Factsheet cijfers 2021*. Utrecht, The Netherlands: Nivel; 2022.

9. Caplan L, Wolfe F, Michaud K, Quinzanos I, Hirsh JM. Strong association of health literacy with functional status among rheumatoid arthritis patients: A cross-sectional study. *Arthritis Care Res*. 2014;66(4):508-14. doi:10.1002/acr.22165.

10. Martin RW, McCallops K, Head AJ, Eggebeen AT, Birmingham JD, Tellinghuisen DJ. Influence of patient characteristics on perceived risks and willingness to take a proposed anti-rheumatic drug. *BMC Med Inform Decis Mak*. 2013;13:89. doi:10.1186/1472-6947-13-89.

11. Nutbeam D. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promot Int*. 2000;15(3):259-67. doi:10.1093/heapro/15.3.259.

12. Bakker MM, Putrik P, Rademakers J, van de Laar M, Vonkeman H, Kok MR, et al. Addressing health literacy needs in rheumatology: Which patient health literacy profiles need the attention of health professionals? *Arthritis Care Res*. 2021;73(1):100-9. doi:10.1002/acr.24480.

13. Osborne RH, Batterham RW, Elsworth GR, Hawkins M, Buchbinder R. The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health*. 2013;13:658. doi:10.1186/1471-2458-13-658.

14. Rademakers J, Waverijn G, Rijken M, Osborne R, Heijmans M. Towards a comprehensive, person-centred assessment of health literacy: translation, cultural adaptation and psychometric test of the Dutch Health Literacy Questionnaire. *BMC Public Health*. 2020;20(1):1850. doi:10.1186/s12889-020-09963-0.

15. Hirsh JM, Boyle DJ, Collier DH, Oxenfeld AJ, Nash A, Quinzanos I, et al. Limited health literacy is a common finding in a public health hospital's rheumatology clinic and is predictive of disease severity. *J Clin Rheumatol*. 2011;17(5):236-41. doi:10.1097/RHU.0b013e318226a01f.

16. Swearingen CJ, McCollum L, Daltroy LH, Pincus T, DeWalt DA, Davis TC. Screening for low literacy in a rheumatology setting: more than 10% of patients cannot read "cartilage," "diagnosis," "rheumatologist," or "symptom". *J Clin Rheumatol*. 2010;16(8). doi:10.1097/RHU.0b013e3181fe8ab1

17. Hirsh J, Wood P, Keniston A, Peng M, Ramaswami S, Caplan L, et al. Limited health literacy and patient confusion about rheumatoid arthritis patient global assessments and model disease states. *Arthritis Care Res*. 2019;71(5):611-9. doi:10.1002/acr.23692.

18. Petkovic J, Epstein J, Buchbinder R, Welch V, Rader T, Lyddiatt A, et al. Toward Ensuring Health Equity: Readability and Cultural Equivalence of OMERACT Patient-reported Outcome Measures. *J Rheumatol*. 2015;42(12):2448-59. doi:10.3899/jrheum.141168.

19. Joplin S, van der Zwan R, Joshua F, Wong PKK. Medication adherence in patients with rheumatoid arthritis: The effect of patient education, health literacy, and musculoskeletal ultrasound. *Biomed Res Int*. 2015. doi:10.1155/2015/150658.

20. Singh JA, Saag KG, Bridges Jr. SL, Akl EA, Bannuru RR, Sullivan MC, et al. 2015 American College of Rheumatology Guideline for the Treatment of Rheumatoid Arthritis. *Arthritis Care Res*. 2016;68(1):1-25. doi:10.1002/acr.22783.

21. Barton JL, Trupin L, Schillinger D, Evans-Young G, Imboden J, Montori VM, et al. Use of low-literacy decision aid to enhance knowledge and reduce decisional conflict among a diverse population of adults with rheumatoid arthritis: Results of a pilot study. *Arthritis Care Res*. 2016;68(7):889-98. doi:10.1002/acr.22801.

22. Heidari P, Cross W, Weller C, Team V, Nazarinia M, Crawford K. Rheumatologists' insight into medication adherence in patients with rheumatoid arthritis: A qualitative study. *Int J Rheum Dis*. 2019;22(9):1695-705. doi:10.1111/1756-185X.13660.

23. Putrik P, Ramiro S, Lie E, Keszei AP, Kvien TK, van der Heijde D, et al. Less educated and older patients have reduced access to biologic DMARDs even in a country with highly developed social welfare (Norway): Results from Norwegian cohort study NOR-DMARD. *Rheumatology*. 2016;55(7):1217-24. doi:10.1093/rheumatology/kew048.

24. Naik AD, Street RL, Castillo D, Abraham NS. Health literacy and decision making styles for complex antithrombotic therapy among older multimorbid adults. *Patient Educ Couns*. 2011;85(3):499-504. doi:10.1016/j.pec.2010.12.015.

3

25. Batterham RW, Buchbinder R, Beauchamp A, Dodson S, Elsworth GR, Osborne RH. The OPtimising HEalth LIterAcy (Ophelia) process: Study protocol for using health literacy profiling and community engagement to create and implement health reform. *BMC Public Health*. 2014;14:694. doi:10.1186/1471-2458-14-694.

26. World Health Organization. *Health literacy development for the prevention and control of noncommunicable diseases*. Geneva, Switzerland; 2022.

27. O'Hara J, Hawkins M, Batterham R, Dodson S, Osborne RH, Beauchamp A. Conceptualisation and development of the Conversational Health Literacy Assessment Tool (CHAT). *BMC Health Serv Res*. 2018;18(1):199. doi:10.1186/s12913-018-3037-6.

28. Shoemaker SJ, Wolf MS, Brach C. Development of the Patient Education Materials Assessment Tool (PEMAT): A new measure of understandability and actionability for print and audiovisual patient information. *Patient Educ Couns*. 2014;96(3):395-403. doi:10.1016/j.pec.2014.05.027.

29. DeWalt DA, Broucksou KA, Hawk V, Brach C, Hink A, Rudd R, et al. Developing and testing the health literacy universal precautions toolkit. *Nurs Outlook*. 2011;59(2):85-94. doi:10.1016/j.outlook.2010.12.002.

30. Callahan LF, Hawk V, Rudd R, Hackney B, Bhandari S, Prizer LP, et al. Adaptation of the health literacy universal precautions toolkit for rheumatology and cardiology - applications for pharmacy professionals to improve self-management and outcomes in patients with chronic disease. *Res Social Adm Pharm*. 2013;9(5):597-608. doi:10.1016/j.sapharm.2013.04.016.

31. Hirsh J, Wood P, Keniston A, Boyle D, Quinzanos I, Caplan L, et al. Universal Health Literacy Precautions Are Associated With a Significant Increase in Medication Adherence in Vulnerable Rheumatology Patients. *ACR Open Rheumatol*. 2020;2(2):110-8. doi:10.1002/acr2.11108.

3

PART II

Opportunities for improvement

EMBARGOED

CHAPTER 4

Patients' and professionals' ideas to address
health literacy challenges in rheumatology care:
a qualitative study

Mark M. Bakker, Annelies Boonen, Jany Rademakers, Harald E. Vonkeman, Marc
R Kok, Hanneke Voorneveld-Nieuwenhuis, Maarten de Wit, Richard H. Osborne,
Polina Putrik

CHAPTER 5

Acting together – WHO National Health Literacy Demonstration Projects (NHLDPs) address health literacy needs in the European Region

Mark M. Bakker*, Polina Putrik*, Anna Aaby, Xavier Debussche, Janis Morrissey, Christine Råheim Borge, Dulce Nascimento do Ó, Peter Kolarčik, Roy Batterham, Richard H. Osborne, Helle Terkildsen Maindal

* These authors contributed equally

ABSTRACT

The burden of noncommunicable diseases (NCDs) is increasing worldwide with the European Region of no exception. This poses economic and social challenges, which contribute to persisting health inequities. Sustainable Development Goal (SDG) target 3.4 specifically focuses on reducing premature mortality from NCDs by a third through prevention and treatment, and promoting mental health and well-being. The promising role of health literacy is increasingly recognised in relation to the prevention and treatment of NCDs throughout the life course. In support of this, WHO has initiated National Health Literacy Demonstration Projects (NHLDPs) in the European Region to generate evidence and accelerate NCD intervention development. The current European NHLDPs use the OPtimising HEalth LIteracy and Access (Ophelia) approach. This manuscript presents the methods, aims, status and preliminary outcomes of the seven flagship European NHLDPs, which cover a broad scope of settings (such as schools, hospitals and communities), health conditions (such as cardiovascular disease, renal failure and chronic obstructive pulmonary disease) and life stages. While the long-term impact of these NHLDPs on the NCD curve is too early to predict, the processes of engagement and action in each of the projects are promising.

INTRODUCTION

The burden of non-communicable diseases (NCDs) is increasing worldwide due to population growth, ageing and lifestyle-related factors, and the European Region is no exception [1]. NCDs are the leading cause of death around the world, contributing to 73.4% of total deaths in 2017 [2]. NCDs affect individuals and their families throughout the life course and impede both social and economic growth [3, 4]. The burden of NCDs hits hardest on socially or economically disadvantaged people and contributes to persisting health inequities [5, 6]. One of the Sustainable Development Goal targets (SDG target 3.4), is focused on reducing premature mortality from NCDs by one third through prevention and treatment, and promoting mental health and well-being [7].

At the 9th Global Conference on Health Promotion in Shanghai in 2016, health literacy was recognised as one of the key health promotion pillars to achieve the 2030 Agenda for Sustainable Development [8]. Multiple definitions of health literacy have been proposed over the last decade. A particularly comprehensive definition − acknowledging both individual and organisational health literacy − was put forward by the International Union for Health Promotion and Education: *"Health literacy is the combination of personal competencies and situational resources needed for people to access, understand, appraise and use information and services to make decisions about health. It includes the capacity to communicate, assert and act upon these decisions. Health literacy responsiveness describes the way in which services, organisations and systems make health information and resources available and accessible to people according to health literacy strengths and limitations"* [9].

Rapid advances in health technologies and treatment options inevitably result in increased health systems complexity. This poses a risk for vulnerable people and communities, with lower health literacy, to be left behind through reduced access, knowledge and understanding [9]. Vulnerable groups include people who have limited education, a migration background, multiple morbidities, or experience loneliness, as well as others whose voices are often left unheard [10]. When interventions fail to address the specific needs of these groups and communities, average improvements in population health can conceal widening health inequalities. Therefore, we should always question whether new interventions reach those who are often not considered, in order to prevent the unintentional widening of the health gap.

Innovative approaches — accounting for the variable health literacy needs of individuals and communities — could accelerate the development of effective interventions and improve the reach and impact of interventions currently in place. As health literacy is associated with health outcomes through different pathways [11], multilevel solutions of a diverse nature are required. By genuinely and effectively involving all stakeholders, including vulnerable groups, interventions are likely to be more appropriate for a wider number of people and thus support WHO's mission to leave no one behind [12].

5

In their mission to reduce the impact of NCDs, WHO and member states are investing in several initiatives to address health literacy. One of these is led by the WHO Global Coordination Mechanism for the Prevention and Control of NCDs (GCM/NCD) through its Global Working Group 3.3 on Health Education and Health Literacy for NCDs [13]. The Working Group developed the innovative concept of WHO National Health Literacy Demonstration Projects (NHLDPs). NHLDPs are local case studies that are proof of concept projects, which measure and improve health literacy in a local or regional context, and which have the potential and intention to be scaled up to improve health literacy at a national level [14]. The first NHLDP was initiated in Egypt and they are now being implemented in the European Region and beyond to generate evidence on how health literacy can accelerate NCD intervention development, implementation and scale-up. To date, seven research and implementation projects in Europe have been designated as WHO NHLDPs. This paper focuses on the development of these flagship European NHLDPs and has the following objectives:

— To describe the methodological approach for health literacy intervention development used in the NHLDPs;
— To describe the aims and status of seven NHLDPs currently underway, based in Denmark, France (Réunion Island), Ireland, the Netherlands, Norway, Portugal, and Slovakia, across diverse health settings, in populations with a diversity of NCDs, and at different life stages;
— To discuss the potential role of WHO NHLDPs to advance health and equity.

METHODOLOGICAL APPROACH: THE OPTIMISING HEALTH LITERACY AND ACCESS (OPHELIA) PROCESS

All of the current NHLDPs are inspired by the OPtimising HEalth LIteracy and Access (Ophelia) process for intervention development [15, 16]. The Ophelia process involves the collaboration of a wide range of community members, community leaders, and health workers to develop health literacy interventions that are based on the diverse health literacy strengths and weaknesses identified within a community [16]. Ophelia projects build on eight core principles (as presented in Table 5.1) [15].

The Ophelia process includes three phases (Figure 5.1), with the eight principles strongly embedded from the outset in order to maximise the potential impact on equity and health outcomes [15]. Phase 1 involves a local needs assessment, using multidimensional tools such as the Health Literacy Questionnaire (HLQ) [17] or the Information and Support for Health Actions Questionnaire (ISHA-Q) [18], combined with local data such as on service engagement or organisational responsiveness. This is followed by workshops with stakeholders including local professionals (health professionals, community workers, managers etc.) and members of the community, in which so-called vignettes, generated from the locally collected data,

are presented and discussed. The vignettes capture groupings of strengths and weaknesses across health literacy domains, as well as demographic background and lived experience of a diverse range of individuals within the population, by creating narratives about individuals within each grouping. The vignettes ensure the data collected come across as real-life examples of the diversity of individuals living in the community. Stakeholders reflect on the vignettes, utilising local wisdom to address the identified challenges, needs and strengths of a range of community members. Phase 2 entails the co-design of interventions into implementable packages, in collaboration with local stakeholders, using the results from Phase 1. Phase 3 then focuses on the testing, implementation and quality improvement, evaluation and embedding of selected interventions [15, 16]. A more thorough description of the different phases has been published elsewhere [15, 16, 19].

Table 5.1 Ophelia (OPtimising HEalth LIteracy and Access) core principles [15]

1. Outcomes focused	Improved health and reduced health inequities
2. Equity driven	All activities at all stages prioritise disadvantaged groups and those experiencing inequity in access and outcome
3. Co-design approach	In all activities at all stages, relevant stakeholders engage collaboratively to design solutions
4. Needs-diagnostic approach	Participatory assessment of local needs using local data
5. Driven by local wisdom	Intervention development and implementation is grounded in local experience and expertise
6. Sustainable	Optimal health literacy practice becomes normal practice and policy
7. Responsiveness	Recognise that health literacy needs and appropriate responses vary across individuals, contexts, countries, cultures and time
8. Systematically applied	A multilevel approach in which resources, interventions, research and policy are organised to optimise health literacy

5

PHASE 1 Identifying local strenghts, needs and issues	PHASE 2 Co-design of interventions	PHASE 3 Implementation, evaluation and ongoing improvement
Local data about health, health behaviour, service engagement, organisational responsiveness, and health literacy are systematically collected (or extracted from existing data sources). These data are analysed and presented to stakeholders for discussion and interpretation. Effective local practices and innovative intervention ideas are then identified.	Local stakeholders make decisions about local priorities for action. Interventions with potential to respond to local health literacy challenges, or to improve information and service access and availability, are designed and implementation is planned.	Health literacy interventions are applied within quality improvement cycles: organisations develop and implement trials, and actively evaluate and improve the effectiveness, local uptake and sustainability of the interventions.

Figure 5.1 The three phases of the Ophelia (OPtimising HEalth LIteracy and Access) process. Adapted from Beauchamp et al. [15]

WHO NATIONAL HEALTH LITERACY DEMONSTRATION PROJECTS (NHLDPS)

As of today, seven European projects have been designated as WHO NHLDP. They are united under the newly established WHO European Action Network on Health Literacy for Prevention and Control of NCDs, launched in January 2019 [20]. This Action Network seeks to generate a European community of practice and build up evidence on the NHLDP approach's impact on tackling the burden of NCDs. The seven initial projects are diverse in nature, dealing with a broad range of health settings, in populations with diverse health conditions and at different life stages (Table 5.2). These projects explore the utility of the Ophelia process in generating better care, more sustainable healthcare services, better health, and equity for people with NCDs. The network also enables teams to exchange experiences and build expertise and capacity within the European region. We briefly introduce the seven projects below.

NHLDP Denmark

The Heart Skills Project in Denmark aims to develop specific health literacy interventions targeting participation and health outcomes in people referred to a cardiac rehabilitation unit in a Danish municipality. The strong positive impact of cardiac rehabilitation on health outcomes, including quality of life following cardiac disease onset, is well documented [21]. Understanding the condition, self-management and the ability to navigate the health system by patients all play a central role in recovery and prevention of complications. These

competences are dimensions of health literacy and low health literacy is strongly associated with the prevalence of cardiac conditions and with cardiac risk behaviour [22].

The needs assessment of the Heart Skills project focused on both the health literacy of individuals and on the health literacy responsiveness of the unit. HLQ profiles of 161 people referred to a cardiac rehabilitation unit were generated, along with an organisational self-assessment based on the 'Organisational Health Literacy Responsiveness' (Org-HLR) framework [23]. The latter provided an overview of the capacity for health literacy responsiveness of the unit and initiated a transformation: to use health literacy to guide future approaches in identifying and managing vulnerable patients. Patients, staff and managers participated in co-design workshops, generating many improvement ideas. These ideas were incorporated into programme theory, which included several new initiatives for improving attendance and participation. Based on these processes, the Heart Skills Project is currently testing two interventions in the rehabilitation unit focusing on patients' social support and support by healthcare providers.

NHLDP France

The French project aims to design interventions to improve digital health literacy and health equity on Réunion Island, where the Indian Ocean health Innovation digital platform is currently being developed to address the burden of the most prevalent chronic diseases in the region. Digital health literacy is an individual's ability to successfully search for, access, understand and evaluate desired health information and services from electronic sources, and then use this information to manage a health problem [24].

The needs assessment (using the HLQ, eHLQ and qualitative interviews) includes people with chronic diseases such as diabetes, cardiovascular disease, and kidney disease in outpatient hospital settings, healthcare management networks, dialysis centres, and pharmacies (n=600). Early results from the assessment of health literacy needs and strengths of people living with long-standing diabetes on Réunion Island show difficulties in getting and appraising health information. It also revealed great diversity in people's ability to navigate health services, depending on location (for example, limited access to specialists in remote areas) and the presence of a primarily functional (or one-way) relationship to treatment and disease follow-up, where patients leave it up to health professionals to provide directions and initiatives. In contrast, respondents actively engaged in exercise and healthy food practices. The study also demonstrated that social support for health, as well as relationships with professionals and healthcare services, are important determinants for successfully managing health [25]. In Phase 2, these data will be used to provide the essential elements for co-design, engaging all professional, institutional and consumer stakeholders in generating interventions to improve access and equity in health for people with chronic diseases.

5

Table 5.2 The seven WHO National Health Literacy Demonstration Projects (NHLDP) in the European Region (as of April 2019)

Country	Focus disease(s) and target population	Setting	Lead and partner organisations	Reason for project
Denmark	Cardiac conditions Targets patients undergoing cardiac rehabilitation	A municipal rehabilitation unit	Lead: Department of Public Health, Aarhus University. Partners: Randers Municipality and their collaborators	Suboptimal attendance and adherence to recommended cardiac rehabilitation programme
France (Réunion Island)	Chronic illness (kidney failure, diabetes, CVD) Targets patients representing the general population of Réunion, as an example for Metropolitan France	Local pharmacies, dialysis centres, primary care network, and specialised outpatient clinics (diabetes, nephrology, cardiology)	Lead: CIC-EC 1410 INSERM, CHU Réunion Partners: ICARE unit, University of Réunion, OIIS eHealth platform, HCP associations, Regional Health Agency of Réunion,	Inequality in access, accessibility, and use of digital health information and tools, and the development of the OIIS regional eHealth platform
Ireland	Obesity and CVD in children and adolescents Targets young people (aged 12-16) and their families in schools and communities	Secondary schools and communities in disadvantaged areas The project will be scalable nationally and have international transferability	Lead: Irish Heart Foundation Partners: Dublin City University; University College Dublin	High levels of childhood obesity, affecting children's health immediately, and throughout the life course
The Netherlands	Rheumatic conditions (RA, SpA, gout) Targets patients in three hospital-based centres, representative of the national diversity in specialised rheumatic care	Specialised outpatient rheumatology clinics	Lead: Maastricht UMC+ (South) Partners: Medisch Spectrum Twente Enschede (East), Maasstad Hospital Rotterdam (West)	Increasing burden of rheumatic diseases and inequity in prescription of costly anti-rheumatic drugs

Aims	Current Ophelia phase	Progress to date	Funding
To develop a specific health literacy intervention targeting participation and health outcomes in people recovering from cardiac disease.	Phase 2	Performed organisation- and user-based health literacy needs assessments Co-designed interventions based on vignettes, focusing on social support and support from healthcare professionals. Pilot test of interventions based on PDSA-cycle is underway	External grants from the Danish Heart Association, regional authorities and a private fund along with internal research grant
To assess health literacy and digital health literacy in chronically ill populations, disadvantaged for geographical, social or psycho-social, economic, educational or cultural reasons To assess the potential contribution of existing tools, via the OIIS digital platform To improve access and equity in health for chronically ill	Phase 1	Performed health literacy and digital health literacy needs assessments	French interregional fund for health research
To assess adolescent health literacy levels To co-design a curriculum-based health literacy intervention, using cutting-edge technology in disadvantaged secondary schools to address cardiovascular health inequalities	Phase 1	Performed literature review of adolescent health literacy Establishment of project working group Dialogue with technology partner is ongoing	Irish Heart Foundation funding Additional funding being sought
To tailor care to health literacy needs of the patients, and improve equity in care by co-designing 'health literate' clinics To explore health professionals' perceptions of patient health literacy in regular care	Phase 1	Performed health literacy needs assessment Observed increased awareness of health literacy among clinical staff	Internal research budgets of the participating centres & Niels Stensen Fellowship Additional funding being sought

5

Table 5.2 (Continued)

Country	Focus disease(s) and target population	Setting	Lead and partner organisations	Reason for project
Norway	COPD Targets patients after hospitalisation and follow-ups in four community sites in the Oslo region	Cooperation hospital and community care	Lead: Lovisenberg Diaconal Hospital. Partners: University of Oslo and the community sites; Grünerløkka, Gamle Oslo, St.Hanshaugen and Sagene	High readmission rates for COPD patients, as well as high disease impact: multiple symptoms, low quality of life and limitation of coping
Portugal	Type 2 Diabetes Mellitus Targets patients in communities and from a national patient organisation	Diabetes outpatient Clinic Community involvement	Lead: NOVA School of Public Health and APDP – Diabetes Portugal Partners: Health centres and municipalities	Increased prevalence of type 2 diabetes and low health literacy levels in the population, especially among those with low socioeconomic status
Slovakia	Chronic illness, primary focus on dialysed patients Targets patients from twenty dialysis centres across Slovakia	Specialised dialysis centres	Lead: Department of Health Psychology, Faculty of Medicine, P.J. Šafárik University in Kosice Partners: Fresenius Medical Care – dialysis services	Suboptimal adherence of dialysed patients to recommended treatment

Legend: CVD = cardiovascular disease, RA = rheumatoid arthritis, SpA = spondyloarthritis, COPD = chronic obstructive pulmonary disease, CIC-EC 1410 INSERM = Centre of Clinical and Epidemiological Investigations, French National Institute of Health and Medical Research, CHU = University Hospital, ICARE = Austral Cooperative Institute for Research in Education, OIIS = Indian Ocean Health Innovation, HCP = Health Care Providers, UMC = University Medical Centre, APDP = Associação Protectora dos Diabéticos de Portugal, PDSA = plan, do, study, act, RCT = randomised controlled trial, HLQ = Health Literacy Questionnaire

Aims	Current Ophelia phase	Progress to date	Funding
To develop and evaluate a health literacy partnership health promotion intervention, in collaboration with patients, hospitals, municipalities and the university	Phase 3	Performed health literacy needs assessment Co-designed intervention, currently being evaluated in an RCT.	Norwegian Extra Foundation for Health and Rehabilitation through the Norwegian organisation for heart and lung, internal budgets of lead and partner organisations
To reduce the incidence of type 2 diabetes To improve the responsiveness of the health services to health literacy and self-care management To promote healthy lifestyles and improve diabetes disease control	Phase 1	Performed literature review of diabetes and health literacy Translation and validation of HLQ for Portuguese population. Evaluation of organisational responsiveness of APDP – Diabetes Portugal underway	Internal research budgets at APDP and NOVA School of Public Health Additional funding being sought
To improve the efficiency of chronic disease management and responsiveness of the health care system and health care providers	Phase 1	Performed health literacy needs assessment	Slovak Research and Development Agency

5

NHLDP Ireland

The project in Ireland addresses cardiovascular disease and obesity in children and adolescents. Childhood obesity has been acknowledged as one of the most serious public health challenges of the 21st century due to its increasing prevalence and associated health consequences [26]. Obesity can affect a child's immediate health, educational attainment and quality of life [27] as well as tracking into adulthood, bringing the negative consequences of NCDs [28]. Despite health literacy being identified as a critical factor in preventing NCDs and addressing heath inequalities, there is little research exploring the effectiveness of health literacy interventions, especially amongst adolescents. The 'Irish Heart Foundation Schools Health Literacy Project' aims to conduct research on adolescent health literacy levels and develop a school-based intervention addressing health literacy in disadvantaged communities. The project will use the Ophelia process to develop a health literacy intervention for students aged 12-16 years in DEIS (delivering equality of opportunity in schools) schools. Data on the health literacy needs of the students, parents and teachers will be gathered, followed by co-design workshops with relevant stakeholders. It is envisaged that the intervention will encompass a whole-school approach using cutting-edge technology, embedded within the Wellbeing curriculum. Scalability and transferability are being factored in from the outset.

NHLDP the Netherlands

The project in the Netherlands is focused on addressing the needs of patients with the three most common rheumatic conditions (rheumatoid arthritis, spondyloarthritis (SpA) and gout) in specialised outpatient rheumatology care in a hospital setting. Rheumatic and musculoskeletal diseases are highly prevalent and their impact on the global burden of disease has increased by 65.9% between 1990 and 2017 due to population growth, population ageing and improved diagnostics [1]. Considering that one in every three people in the Netherlands has limited health literacy [29], and that there is a large equity gap in the prescription of costly rheumatic medication [30], there is potential to reduce the burden of rheumatic conditions by addressing health literacy needs.

The HLQ-based needs assessment involved a clinically diverse sample of nearly 900 patients from three geographically and sociodemographically diverse regions. Additionally, this project measured health professionals' perceptions of their patients' health literacy to explore patterns in eventual under- or overestimation of health literacy by rheumatologists. During the needs assessment phase, the study team observed a remarkable increase in clinical staff's awareness of health literacy and their engagement in the project. Collaboration with primary care and public health professionals will be sought to achieve maximum impact during Phases 2 and 3 of the project.

NHLDP Norway

The Norwegian project targets people with chronic obstructive pulmonary disease (COPD), a disease with serious symptoms such as breathlessness, fatigue, depression, anxiety and pain, as well as physical impairment and low quality of life. Exacerbations and repeated readmission to hospitals are common [31]. Accessing, utilising and following up on treatment is complex for these patients. Thus, people with COPD may have many health literacy challenges, but health literacy has been little investigated in this population.

NHLDP Norway is the only European NHLDP in Phase 3 as of June 2019. It followed the Ophelia phases with the following activities. First, a cross-sectional needs assessment study was performed among 158 patients, using the HLQ and focus group interviews of patients with COPD and healthcare professionals. Focus group interviews identified four main focal areas of health literacy to be addressed: 1) to increase security to feel less anxious; 2) to increase knowledge of patients and professionals, improve follow-up and maintain information flow between patients and professionals, as well as between specialist healthcare services and community healthcare services; 3) to increase motivation for endurance and self-management; and 4) to increase dignity. Further analysis from the cross-sectional study showed that low health literacy was associated with higher readmission rates, more disease-related problems, low wellbeing, low self-efficacy, living alone, smoking habits and poor handling of medication. In Phase 2, these factors were discussed in workshops with health professionals from the community and specialist services, patients with COPD, and researchers. This led to the development of a health literacy intervention that is currently being tested in comparison to the standard care in Phase 3. After hospitalisation, the intervention group receives follow-up by specialised COPD nurses who are trained in motivational interviewing. Follow-up includes weekly home visits for eight weeks, and monthly telephone calls for an additional four months. Additionally, medical specialists and community healthcare services collaborate to provide patients with a supporting intervention, tailored to the individual. This may include tools to improve knowledge of COPD, use of medication and technical equipment (such as oxygen therapy or respiratory support), aid to quit smoking, nutritional support, psychosocial support, or assistance in finding and participating in healthcare-related activities in the community. Effects on hospital re-admission, health literacy, self-management, quality of life and health expenditure are currently being investigated in a randomised controlled trial.

NHLDP Portugal

The main objective of the NHLDP in Portugal is to develop innovative, responsive approaches to promote health literacy, focused on the prevention of Diabetes Mellitus Type 2 (T2DM) and its complications, as well as the promotion of wellbeing in the general population. T2DM represents a serious public health problem with increasing worldwide incidence and prevalence [32]. T2DM is considered a health priority because of its human, social and economic burden, its chronicity and its association with serious complications [33, 34]. Both

5

prevention and treatment of T2DM can be a daunting task, requiring people to have substantial health literacy to manage adequate self-care and be motivated and able to make informed decisions regarding their health.

The needs assessment using the HLQ [17] involved 453 patients from the Portuguese Diabetes Association (APDP – Diabetes Portugal). The health literacy profiles resulting from these data will be used in co-design workshops with patients and professionals to identify priorities, strategies and activities APDP should focus on. Simultaneously, stakeholder working groups (with staff and people with T2DM) guided by the Org-HLR framework [23] will determine priorities for organisational improvement. Phase 2 will be community-based, involving the Lisbon and Oeiras municipalities and their health centres. Therefore, the Phase 1 needs assessment will be replicated in these settings with local participants with diabetes or pre-diabetes, community stakeholders, and healthcare professionals. Besides health literacy, the project will assess diabetes empowerment and self-care activities through questionnaires. Overall, these partnerships will allow a thorough diagnosis of needs, identification of priorities, and co-design of innovative solutions with scaling-up potential.

NHLDP Slovakia

The Slovakian project targets people with various chronic health conditions. While people with chronic renal failure receiving dialysis are the primary focus, people with cervical dystonia, periodontitis, precancerous conditions or endometrial cancer, and endometriosis are also included.

The number of people referred to dialysis treatment is continuously increasing because of an increasing prevalence of chronic kidney disease, although recently growth has slowed [35]. Dialysed patients require complicated therapeutic care, and adherence to treatment protocols is crucial for their successful management [36, 37]. Health literacy is known to be associated with treatment adherence [38]. In this project, health literacy profiles will be used to guide the process to improve healthcare efficiency and increase the responsiveness of the Slovakian healthcare system.

Needs assessment involved 565 patients from 20 dialysis clinics across Slovakia. Self-reported data were collected on health literacy, using the HLQ, and quality of life and adherence through additional questionnaires. Diverse clinical data (for example, fluid overload, phosphoremia, kalaemia, blood pressure, and haemodynamic status) were obtained from medical records. Data are currently being analysed to generate vignettes to facilitate Phase 2, which will be in collaboration with patients and healthcare providers from dialysis centres. Stakeholders will be invited to participate in several workshops to co-design interventions based on real-life data.

DISCUSSION

The global burden of NCDs is increasing; it poses economic and social challenges through ever-increasing health system expenditure and persisting health inequities [1, 4-6]. Health literacy is increasingly recognised as a means of addressing inequity – especially in relation to the prevention of NCDs in all phases of the life course, and in population groups that have been insufficiently engaged with in the past [39]. The problem is apparent; now is the time to act.

In this report, we have outlined the basis of the emerging NHLDP Action Network, initiated under the auspices of WHO. Through the eight guiding principles embedded in the Ophelia approach (Table 5.1), NHLDPs work to improve health outcomes and equity [15]. While each of the NHLDPs is at a different stage, they each highlight specific principles in achieving this goal. The Norwegian project, for example, currently best showcases the focus on outcomes (Principle 1), with an ongoing randomised controlled trial measuring the effects on hospital readmission, quality of life, self-management and health expenditure. The French project, on the other hand, best emphasises the equity-driven approach (Principle 2), as data are collected in a disadvantaged population of Réunion Island [40]. NHLDP Slovakia notably focuses on involving stakeholders from multiple levels (for example, consumers, clinicians and managers) (Principle 3) to address low treatment adherence. The NHLDPs of Portugal and The Netherlands are making particular efforts to undertake needs assessments in multiple settings to get data specific to local needs (Principles 4 and 5) while aiming to inform policy and practice for wider populations. Meanwhile, NHLDP Ireland demonstrates responsiveness (Principle 7) well, by adapting the methodology to measure the health literacy needs of a younger generation. Last but not least, systematic project application through a multilevel approach (Principle 8) is exemplified by NHLDP Denmark, were patient health literacy is addressed alongside organisational health literacy responsiveness. This opens the door for interventions and developments at the level of patient-physician interaction, as well as the organisational and policy-making level, recognising the multiple pathways through which health literacy is associated with health outcomes [11]. As the NHLDPs are all still currently within their project period, sustainability (Principle 6), where optimal health literacy practice becomes standard practice and policy, has yet to be demonstrated. However, the projects in phases 2 and 3 have shown that all stakeholders involved take ownership of the intervention, which makes for a well-integrated comprehensive strategy and bodes well for their long-term impact, after the initial project period comes to a close.

The NHLDP Network offers a number of opportunities, by simultaneously implementing the NHLDP projects in multiple settings and contexts, and showing potential for promising interventions to develop from small pilots to larger-scale programmes. Moreover, the network of researchers and clinicians from different backgrounds working on projects based on similar principles offers a wealth of opportunities for mutual support, ideas, and expertise exchange. Within the NHLDP Network, important methodological discussions are already under way

5

regarding robust process development and outcome measures of the ongoing projects. Sharing and reflecting on the upcoming results of Phases 2 and 3 from multiple projects will shed much-needed light on what are potentially generalisable processes to tackle health and inequality among vulnerable groups in Europe, which would be hard to ascertain from a single project.

In conclusion, the European NHLDPs successfully apply the Ophelia principles to generate knowledge and develop interventions that aim to advance health and equity through health literacy. One of the most promising aspects in all the NHLDPs is the observed engagement from local partners at all stages of the intervention development process. This bodes well for the NLHDPs to generate wanted, effective, and sustainable interventions that have a lasting effect on NCD outcomes. Project teams also report that extensive local capacity building is taking place. The NHLDPs currently in the most advanced phases (Norway and Denmark) highlight the potential of practical outcomes of the co-design phase, such as new communication strategies and coping tools. The long-term outcomes of the NHLDPs' ability to bend the NCD curve are still too early to predict. However, the processes of engagement and action are promising for the future.

DECLARATIONS

Ethics

All individual projects described in this paper have been individually assessed and approved by the ethics committees of the lead organisations in each country. All participants in each of the projects have provided informed consent.

Acknowledgements

The authors acknowledge the project teams in each country for their contribution to the NHLDP Network and this paper (Table 5.3).

Table 5.3 All National Health Literacy Demonstration Project (NHLDP) teams.

| Country	Project team	Contact email
Denmark	Helle Terkildsen Maindal, Anna Aaby	aaby@ph.au.dk
France (Réunion Island)	Xavier Debussche, Maryvette Balcou-Debussche, Emmanuel Chirpaz, Delphine Ballet, Fanny David, Jessica Caroupin, Roselyne Coppens	xavier.debussche@chu-reunion.fr
Ireland	Tim Collins, Laura Hickey, Janis Morrissey, Sarahjane Belton, Johann Issartel, Celine Murrin, Clare McDermott	jmorrissey@irishheart.ie
The Netherlands	Annelies Boonen, Polina Putrik, Mark Matthijs Bakker, Marc Kok, Hanneke Voorneveld, Mart van de Laar, Harald Vonkeman	mark.bakker@mumc.nl
Norway	Astrid Wahl, Christine Råheim Borge, Marie H. Larsen, Marit Andersen	chrr@lds.no
Portugal	Maria Isabel Loureiro, Dulce do Ó, Ana Rita Goes, Sónia Dias, João Filipe Raposo	dulce.o@apdp.pt
Slovakia	Peter Kolarčik, Ivana Skoumalová, Jaroslav Rosenberger	peter.kolarcik@upjs.sk

5

REFERENCES

1. Global Burden of Disease Study 2017 Disease and Injury Incidence and Prevalence Collaborators. Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990-2017: a systematic analysis for the Global Burden of Disease Study 2017. *Lancet*. 2018;392(10159):1789-858. Doi: 10.1016/s0140-6736(18)32279-7.

2. Global Burden of Disease Study 2017 Causes of Death Collaborators. Global, regional, and national age-sex-specific mortality for 282 causes of death in 195 countries and territories, 1980-2017: a systematic analysis for the Global Burden of Disease Study 2017. *Lancet*. 2018;392(10159):1736-88. doi:10.1016/S0140-6736(18)32203-7.

3. Bloom DE, Cafiero, E.T., Jané-Llopis, E., Abrahams-Gessel, S., Bloom, L.R., Fathima, S., et al. *The Global Economic Burden of Noncommunicable Diseases.* Geneva, Switzerland: World Economic Forum; 2011.

4. Chaker L, Falla A, van der Lee SJ, Muka T, Imo D, Jaspers L, et al. The global impact of non-communicable diseases on macro-economic productivity: a systematic review. *Eur J Epidemiol*. 2015;30(5):357-95. doi:10.1007/s10654-015-0026-5.

5. World Health Organization. *Global status report on noncommunicable diseases.* Geneva, Switzerland; 2014.

6. Mackenbach JP, Valverde JR, Artnik B, Bopp M, Bronnum-Hansen H, Deboosere P, et al. Trends in health inequalities in 27 European countries. *Proc Natl Acad Sci U S A*. 2018;115(25):6440-5. doi:10.1073/pnas.1800028115.

7. United Nations. Transforming our world: The 2030 agenda for sustainable development. *Resolution adopted by the General Assembly*. 2015.

8. World Health Organization. Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development. *Health Promot Int*. 2017;32(1):7-8. doi:10.1093/heapro/daw103.

9. 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. doi:10.1177/1757975918814421.

10. Beauchamp A, Buchbinder R, Dodson S, Batterham RW, Elsworth GR, McPhee C, et al. Distribution of health literacy strengths and weaknesses across socio-demographic groups: a cross-sectional survey using the Health Literacy Questionnaire (HLQ). *BMC Public Health*. 2015;15(1):678. doi:10.1186/s12889-015-2056-z.

11. Paasche-Orlow MK, Wolf MS. The causal pathways linking health literacy to health outcomes. *Am J Health Behav*. 2007;31 Suppl 1:S19-26. doi:10.5555/ajhb.2007.31.supp.S19.

12. Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, et al. Patient engagement in research: a systematic review. *BMC Health Serv Res*. 2014;14:89-. doi:10.1186/1472-6963-14-89.

13. World Health Organization. *The WHO GCM/NCD Working Group on health education and health literacy for NCDs (Working Group 3.3, 2016-2017)*; 2018. Available from: https://www.who.int/global-coordination-mechanism/working-groups/working-group-3-3/en/.

14. World Health Organization Global Coordination Mechanism on the Prevention and Control of Noncommunicable Diseases. *Considerations for setting up a National Health Literacy Demonstration Project (NHLDP).* Melbourne, Australia: Deakin University; 2017.

15. Beauchamp A, Batterham RW, Dodson S, Astbury B, Elsworth GR, McPhee C, et al. Systematic development and implementation of interventions to OPtimise Health Literacy and Access (Ophelia). *BMC Public Health.* 2017;17(1):230. doi:10.1186/s12889-017-4147-5.

16. Batterham RW, Buchbinder R, Beauchamp A, Dodson S, Elsworth GR, Osborne RH. The OPtimising HEalth LIterAcy (Ophelia) process: Study protocol for using health literacy profiling and community engagement to create and implement health reform. *BMC Public Health.* 2014;14:694. doi:10.1186/1471-2458-14-694.

17. Osborne RH, Batterham RW, Elsworth GR, Hawkins M, Buchbinder R. The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health.* 2013;13:658. doi:10.1186/1471-2458-13-658.

18. Dodson S, Beauchamp A, Batterham R, Osborne R. Information sheet 10: About the Information and Supports for Health Actions Questionnaire (ISHA-Q). In: *Ophelia toolkit: A step-by-step guide for identifying and responding to health literacy needs within local communities.* Melbourne, Australia: Swinburne University of Technology; 2015.

19. 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. doi:10.1016/j.puhe.2016.01.001

20. World Health Organization. *Health literacy as a lever to prevent and control NCDs – workshop in Portugal*; 2019 Available from: http://www.euro.who.int/en/media-centre/events/events/2019/01/health-literacy-as-a-lever-to-prevent-and-control-ncds-workshop-in-portugal.

21. Anderson L, Taylor RS. Cardiac rehabilitation for people with heart disease: an overview of Cochrane systematic reviews. *Cochrane Database Syst Rev.* 2014(12):Cd011273. doi:10.1002/14651858.CD011273.pub2.

22. Aaby A, Friis K, Christensen B, Rowlands G, Maindal HT. Health literacy is associated with health behaviour and self-reported health: A large population-based study in individuals with cardiovascular disease. *Eur J Prev Cardiol.* 2017;24(17):1880-8. doi:10.1177/2047487317729538.

23. Trezona A, Dodson S, Osborne RH. Development of the Organisational Health Literacy Responsiveness (Org-HLR) self-assessment tool and process. *BMC Health Serv Res.* 2018;18(1). doi:10.1186/s12913-018-3499-6.

24. Kayser L, Karnoe A, Furstrand D, Batterham R, Christensen KB, Elsworth G, et al. A Multidimensional Tool Based on the eHealth Literacy Framework: Development and Initial Validity Testing of the eHealth Literacy Questionnaire (eHLQ). *J Med Internet Res.* 2018;20(2):e36. doi:10.2196/jmir.8371.

25. Debussche X, Balcou-Debussche M. Analyse des profils de littératie en santé chez des personnes diabétiques de type 2: la recherche ERMIES-Ethnosocio. *Sante Publique.* 2018;S1(HS1):145-56. doi:10.3917/spub.184.0145.

5

26. World Health Organization. *Prioritizing areas for action in the field of population-based prevention of childhood obesity*. Geneva, Switzerland; 2012.

27. World Health Organization. *Report of the Commission on Ending Childhood Obesity*. Geneva, Switzerland; 2016.

28. Han JC, Lawlor DA, Kimm SY. Childhood obesity. *Lancet*. 2010;375(9727):1737-48. doi:10.1016/s0140-6736(10)60171-7.

29. Heijmans M, Brabers A, Rademakers J. *Health Literacy in Nederland*. Utrecht, The Netherlands: Nivel; 2018. Available from: https://nivel.nl/sites/default/files/bestanden/Gezondheidsvaardigheden_in_Nederland.pdf

30. Putrik P, Ramiro S, Lie E, Keszei AP, Kvien TK, van der Heijde D, et al. Less educated and older patients have reduced access to biologic DMARDs even in a country with highly developed social welfare (Norway): Results from Norwegian cohort study NOR-DMARD. *Rheumatology*. 2016;55(7):1217-24. doi:10.1093/rheumatology/kew048.

31. Global Initiative for Chronic Obstructive Lung Disease. *Global Strategy for the Diagnosis, Management and Prevention of Chronic Obstructive Pulmonary Disease*. 2019. Available from: https://goldcopd.org/wp-content/uploads/2018/11/GOLD-2019-v1.7-FINAL-14Nov2018-WMS.pdf

32. IDF. *Diabetes Atlas 7th Edition*. Brussels, Belgium: International Diabetes Federation; 2015.

33. American Diabetes Association. Introduction: Standards of Medical Care in Diabetes—2018. *Diabetes Care*. 2018;41(Supplement 1):S1-S2. doi:10.2337/dc18-Sint01.

34. Sociedade Portuguesa de Diabetologia. *Diabetes: Factos e Números. Relatório Anual do Observatório Nacional da Diabetes*. Lisbon, Portugal; 2015.

35. Heaf J. Current trends in European renal epidemiology. *Clinical Kidney Journal*. 2017;10(2):149-53. doi:10.1093/ckj/sfw150.

36. Ghimire S, Castelino RL, Jose MD, Zaidi STR. Medication adherence perspectives in haemodialysis patients: a qualitative study. *BMC Nephrol*. 2017;18(1):167. doi:10.1186/s12882-017-0583-9.

37. Kammerer J, Garry G, Hartigan M, Carter B, Erlich L. Adherence in patients on dialysis: strategies for success. *Nephrol Nurs J*. 2007;34(5):479-86.

38. Miller TA. Health literacy and adherence to medical treatment in chronic and acute illness: A meta-analysis. *Patient Educ Couns*. 2016;99(7):1079-86. doi:10.1016/j.pec.2016.01.020.

39. Vamos S, Rootman I. Health Literacy as a Lens for Understanding Non-communicable Diseases and Health Promotion. In: McQueen D, editor. *Global Handbook on Noncommunicable Diseases and Health Promotion*. New York, NY, USA: Springer; 2013. p. 169-87.

40. Balcou-Debussche M, Rogers C. Promoting health education in a context of strong social and cultural heterogeneity : the case of the Reunion island. In: Simovska, Venka, Mannix M, Patricia, editors. *Schools for Health and Sustainability*. Dordrecht, The Netherlands: Springer Netherlands; 2015. p. 291-312.

5
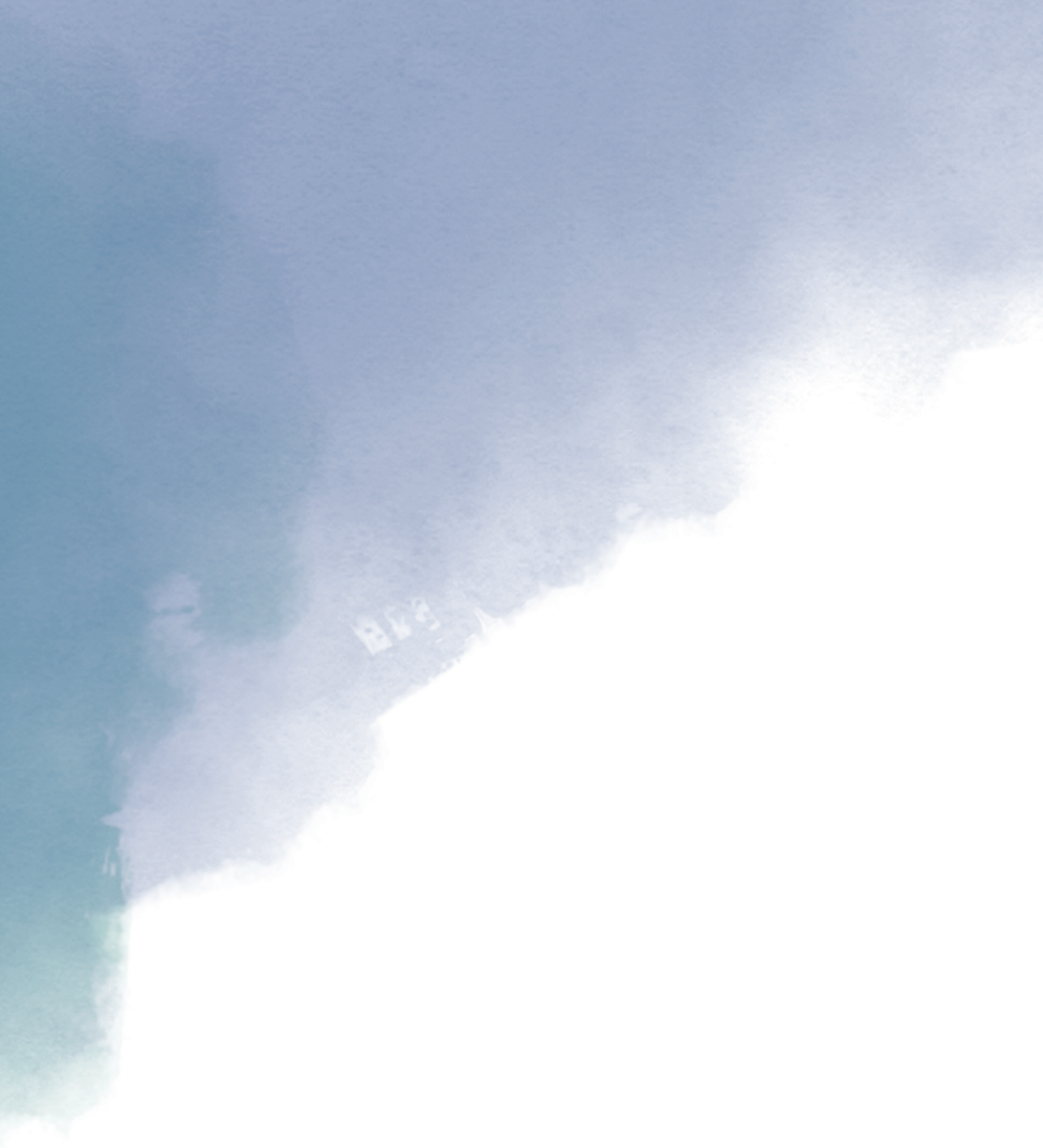
PART III

Organisational perspectives

CHAPTER 6

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

Mark M. Bakker, Polina Putrik, Cédric Dikovec, Jany Rademakers, Harald E. Vonkeman, Marc R. Kok, Hanneke Voorneveld-Nieuwenhuis, Sofia Ramiro, Maarten de Wit, Rachelle Buchbinder, Roy Batterham, Richard H. Osborne, Annelies Boonen

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 ≥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.

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.

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 disproportionally affected [7].

People with 'limited' health literacy are at risk of poor health outcomes, for example through reduced access to and utilisation 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 anti-rheumatic 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 addition, a gender gap was observed, as male GPs were more likely to underestimate patients' health literacy [20]. Hawkins et al. [21] explored differing perspectives on health literacy between patients and health professionals on an item level, in a qualitative study using the Health Literacy Questionnaire (HLQ). In contrast to the studies referenced above, the authors did not conceptualise differences in assessment as over- or underestimation, but as discordance [21]. When discordance occurs, this may be due to differences in understanding specific wordings, perspectives on changing circumstances over time, expectations and criteria for assigning scores, or perspectives on the patients'

6

reliance on healthcare providers [21]. No matter whether discordance is due to estimation errors or differing perspectives, it is important to signal these differences and the direction of any discordance in order to prevent potential communication gaps [22] and/or address them in the delivery of care.

To learn more about the prevalence and potential drivers of discordance in health literacy assessment in rheumatology, the two-fold aim of this study was 1) to investigate the discordance between health literacy of people with rheumatic and musculoskeletal diseases (RMDs) and assessment of health literacy by their treating health professionals, and 2) to explore whether discordance was associated with the patients' socioeconomic background.

METHODS

Study design
We conducted an observational cross-sectional study, as part of a health literacy project in rheumatology following the OPtimising HEalth LIteracy and Access (Ophelia) process [23]. A more extensive account of the methods of patient recruitment and data collection is described elsewhere [17]. One patient research partner (MdW) was involved throughout the research process.

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

Procedures and measurements
Consenting patients filled out a survey on paper, digitally, or orally in an interview format with a researcher, in their preferred language (Dutch, English, German, or Arabic). The survey primarily included the Health Literacy Questionnaire (HLQ) [24, 25], which comprises 44 items addressing nine distinct domains of health literacy (Box 6.1). The HLQ provides a score for each domain (the higher the better) [24], as it was developed to identify strengths and weaknesses across domains that would not be revealed by a single summary score. Other survey questions included the Pearlin Mastery Scale (which assesses the extent to which a person feels like they have control over life's opportunities, score range 7-28 [26]) and questions on sociodemographic background and health status. Sociodemographic information included age (in years), gender, education level (low (no more than primary or

lower secondary education) / medium / high (graduated tertiary education) using Dutch standardized categories [27]), migration background (Native Dutch, Western migrant, or non-Western migrant [28]), employed (yes/no), (partially) work disabled (yes/no), and living alone (yes/no).

Box 6.1 Health Literacy Questionnaire (HLQ) domains

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

Part I measures the 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 the 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).

Following the clinical visit, the health professional who performed the consultation provided their assessment of the patient's level (or answered "I do not know") on each of the nine domains of the HLQ using a 0-10 numeric rating scale (NRS). In addition, professionals indicated how well they knew the patient (not at all/barely, somewhat, fairly well, very well) and provided a professional's global assessment of the impact of the rheumatic disease on the functioning and health of the patient (NRS 0-10, 10 being maximum impact). Additionally, we documented the healthcare professionals' gender and profession. Before the start of the study, all participating health professionals attended a one-hour session to discuss health literacy, the study setup, and how to fill out the survey. An explanation of the meaning of high and low scores on the nine domains [24] was provided to health professionals whenever they were assessing patients.

Statistical analysis

In case of missing data, we contacted patients and healthcare professionals to complete missing items. Remaining missing HLQ data were treated according to the expectation maximisation algorithm used in Ophelia [29], before computing domain scores. We analysed discordance data using three categories: 1) 'The professional's assessment was lower than

6

the patient's HLQ score' (negative discordance), 2) 'The professional's assessment and patient's HLQ score were probably the same', and 3) 'The professional's assessment was higher than the patient's HLQ score' (positive discordance). Before categorisation, patients' HLQ domain scores were converted to a 0-10 scale to enable comparisons with the health professionals' assessments. Discordance was defined as a ≥2-point difference (in either direction). Given a ≥2-point difference at the extremes of the 0-10 scale implies the patient and health professional agree the score is either 'very high' or 'very low', such discordance is unlikely to be relevant. Therefore, we classified observations where both the professional and the patient scored ≤3 or ≥7 as 'probably the same' (i.e., no relevant discordance).

We used multilevel multinomial regression (mixed) models to test the role of socioeconomic factors in negative (i.e., professional scored lower than the patient) and positive (i.e., professional scored higher than the patient) relevant discordance in each of the nine HLQ domains (reference = 'probably the same'). To account for clustering within individual health professionals, we added a random intercept to the models. Intraclass correlation coefficients (ICCs) were computed. The base model included all socioeconomic factors of interest (age, gender, education level, migration background, being employed or (partially) work disabled, living alone). Other potential predictors or confounding variables (type of rheumatic disease, patient-reported mastery, professionals' global assessment of disease impact, type of healthcare professional, gender of healthcare professional, and how well the healthcare professional knew the patient) were each tested separately in the base model. The final model was selected by retaining all base model variables and performing a backwards selection procedure for other variables that proved significant to be predictors or confounders when added to the base model. Analyses were performed in IBM SPSS Statistics 27 and Stata 15. Statistical significance was assumed at α=5%.

RESULTS

Treating health professionals filled out questionnaires for 778 out of 895 participating patients [17]. There were no important differences between the 778 patients included in the analysis and those for whom a professional's questionnaire was not completed (see Supplementary Table 6.1). Included patients had a mean age of 61.2 (SD 13.9); 52.1% were male; 51.7% reported to have a low education level; 17.5% had a Western or non-Western migration background; 32.5% were employed; 14.3% were (partially) work disabled; and 23.9% lived alone (Table 6.1). Thirty-nine healthcare professionals assessed between 1 and 85 patients; 23.1% of professionals were male; and 60% were rheumatologists (Table 6.2).

Discordance

Total relevant (negative and positive) discordance between patients' HLQ scores and professionals' assessments occurred in 161 (20.7%) to 315 (40.5%) patients per domain (Figure 6.1). Professionals answered 'I do not know' most often for 'Having social support for health' (19.4%, domain 4). Relevant positive discordance was observed more frequently than negative discordance. Most positive discordance was observed for 'Critically appraising information' (domain 5, 31.9% positive discordance), while most negative discordance was observed for 'Actively engaging with providers' (domain 6, 19.0% negative discordance).

Table 6.1 Patient characteristics (n = 778)

	Mean (SD) [min-max]† / % (n)‡
Age	61.2 (13.9) [18-89]
Gender: male	52.1 (405)
Education level	
Low	51.7 (402)
Medium	24.4 (190)
High	23.9 (186)
Migration background	
Non-Western migrant	8.9 (69)
Western migrant	8.6 (67)
Native Dutch	82.5 (642)
Occupation status*	
Employed	32.5 (253)
(Partially) work disabled	14.3 (111)
Household type*	
Living alone	23.9 (186)
Rheumatic disease	
RA	41.0 (319)
SpA	34.2 (266)
Gout	24.8 (193)
Treating hospital	
South	31.7 (247)
West	28.8 (224)
East	39.5 (307)

Table 6.1 (Continued)

	Mean (SD) [min-max]† / % (n)‡
Treated by type of healthcare professional	
Rheumatologist	55.3 (430)
Rheumatology fellow	7.5 (58)
Nurse practitioner/physician assistant	21.0 (163)
Rheumatology nurse	16.3 (127)
Mastery	20.06 (3.44) [9-28]§
Healthcare professional-reported outcomes	
Professionals' global assessment of disease impact	4.28 (2.39) [0-10]
How well professional knew the patient	
Not at all/barely	10.9 (85)
Somewhat	30.1 (234)
Fairly well	46.5 (362)
Very well	12.5 (97)

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

Table 6.2 Health professional characteristics (n = 39)

	Mean (SD) [min-max]† / % (n)‡
Gender: male	23.1 (9)
Type of professional	
Rheumatologist	60.0 (23)
Rheumatology fellow	20.5 (8)
Nurse practitioner/physician assistant	10.3 (4)
Rheumatology nurse	10.3 (4)
Employing hospital	
South	30.8 (12)
West	30.8 (12)
East	38.5 (15)
Number of patients assessed	19.9 (16.8) [1-85]

Legend: † for continuous variables. ‡ for categorical variables.

	Professional scored lower	Probably the same	Professional scored higher	Professional did not know
1. Healthcare provider support	4.9%	77.9%	15.9%	1.3%
2. Having sufficient information	8.9%	72.1%	18.1%	0.9%
3. Actively managing health	9.5%	62.3%	26.3%	1.8%
4. Having social support for health	4.6%	54.4%	21.6%	19.4%
5. Critically appraising information	8.6%	59.3%	31.9%	0.3%
6. Actively engaging with providers	19.0%	73.5%	7.1%	0.4%
7. Navigating the health system	11.7%	73.9%	12.9%	1.5%
8. Finding health information	15.8%	70.6%	10.4%	3.2%
9. Understanding health information	11.3%	77.8%	9.4%	1.5%

Figure 6.1 Classification by occurrence and direction of relevant discordance between patients' Health Literacy Questionnaire scores and their healthcare professionals' estimation per domain

Exploring the role of socioeconomic factors

Results of univariable associations between socioeconomic factors and discordance are provided in Supplementary Table 6.2. Tables 6.3 and 6.4 and Figures 6.2A and 6.2B show the multivariable multilevel multinomial models. Socioeconomic factors played a role in discordance in all domains except 'Healthcare provider support' (domain 1). Patients' gender was not associated with relevant discordance in health literacy scores. Observed ICCs exposed clustering of discordance by professional.

Negative discordance (i.e. professional scored lower than the patient)
Figure 6.2A and Table 6.3 present odds ratios of negative discordance (compared with 'probably the same') per domain. Education level and migration background were most frequently and strongly associated with negative discordance. Having *low education level* or *medium education level* (compared with *high education level*) was associated with negative discordance in five and three domains, respectively, with the highest odds observed for 'Actively engaging with providers' (domain 6, OR low education 3.97 [2.06 – 7.64], OR medium education 3.03 [1.47 – 6.24]). *Non-Western migration background* (compared with *Native Dutch*) was associated with negative discordance in five domains, with the highest odds observed for 'Understanding health information' (domain 9, OR 8.52 [4.12 – 17.61]), the only domain in which *Western migration background* was additionally associated with professionals underscoring patients (OR 2.41 [1.12 – 5.21]).

Other observed associations were less consistent across domains. Living alone and not being employed were each associated with negative discordance in single HLQ domains.

People *living alone* were more likely to be underscored by professionals for 'Having social support' (domain 4, OR 3.51 [1.52 − 8.10]). People *not employed* were more likely to be underscored by professionals for 'Navigating the health system' (domain 7, OR 2.28 [1.09 − 4.78]. People who were (*partially) work disabled* had higher odds of being underscored only for 'Actively managing health' (domain 3, OR 2.09 [1.02 − 4.30]. Age was not associated with negative discordance in any domain.

Positive discordance (i.e. professional scored higher than the patient)
Figure 6.2B and Table 6.4 present odds ratios of positive discordance (compared with 'probably the same') per domain. While positive discordance occurred more frequently than negative discordance (mean 17.1 and 10.5% per domain, respectively, Figure 6.1), it was less often and less strongly associated with socioeconomic determinants. Having *low education level* (compared with *high education level*) was negatively associated with positive discordance for 'Having sufficient information' (domain 2, OR 0.45 [0.28 − 0.73]), 'Actively managing health' (domain 3, OR 0.65 [0.42 − 0.99]), and 'Critically appraising information' (domain 5, OR 0.53 [0.35 − 0.79]), and positively associated with positive discordance for 'Finding health information' and 'Understanding health information' (domains 8 and 9, OR 2.89 [1.41 − 5.93] and 2.34 [1.12 − 4.90], respectively). Having *medium education level* (compared with *high education level*) was negatively associated with positive discordance in two domains: 'Having sufficient information' (domain 2, OR 0.57 [0.34 − 0.96]) and 'Navigating the health system' (domain 7, OR 0.43 [0.22 − 0.85]). Of note, migration background was not associated with positive discordance in any of the domains.

While not a factor in negative discordance, being of *higher age* was associated with positive discordance in three domains, although the direction of the effect was inconsistent. Professionals were more likely to overscore *older patients* for 'Finding health information' and 'Understanding health information' (domains 8 and 9, 10-year difference OR 1.32 [1.01 − 1.75] and 1.49 [1.09 − 2.03], respectively), and *younger patients* for 'Having sufficient information' (domain 2, 10-year difference OR 0.81 [0.68 − 0.98]). People *not employed* had lower odds of being overscored by professionals only for 'Understanding health information' (domain 9, OR 0.45 [0.21 − 1.00]).

Exploring the role of other factors
Besides associations with socioeconomic determinants, we observed several relevant associations between discordance and other patient and health professionals' characteristics. These associations differed between negative and positive discordance.
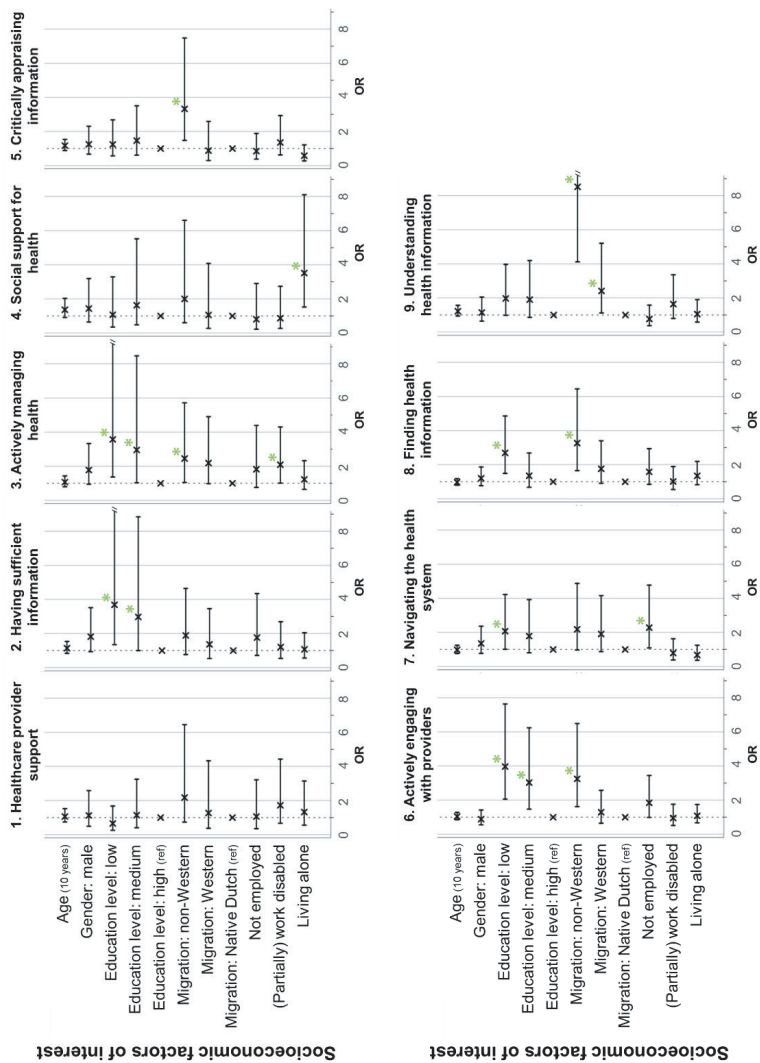
Negative discordance (i.e. professional scored lower than the patient)
The most common factor associated with negative discordance (Table 6.3) was *professionals' global assessment of disease impact*, with higher impact increasing the odds of negative

discordance in the first seven HLQ domains. Compared with rheumatologists, *fellows* were more likely to underscore their patients on 'Healthcare provider support' (domain 1), 'Having social support for health' (domain 4), and 'Critically appraising information' (domain 5). In cases where health professionals stated they *knew the patient very well* (compared with *not at all/barely*), negative discordance was less likely for 'Actively managing health' (domain 3). Patients with *gout* (compared with patients with RA) were more likely to be underscored for 'Actively engaging with providers' (domain 6). The gender of the health professional was only of relevance in one domain: male professionals were more likely to underscore patients on 'Having social support for health' (domain 4).

Positive discordance (i.e. professional scored higher than the patient)
The most relevant factor associated with positive discordance was *patients' mastery. Lower mastery* was associated with positive discordance in six domains (Table 6.4). In cases where health professionals stated they *knew the patient very well*, positive discordance was more likely for 'Actively managing health' (domain 3) and 'Navigating the health system' (domain 7). Patients with *gout* (compared to patients with *RA*) were more likely to be overscored by professionals for 'Healthcare provider support' (domain 1) and 'Navigating the health system' (domain 7).

6

Figure 6.2A Odds ratios (ORs) and 95% confidence intervals of socioeconomic factors associated with negative discordance

Legend: negative discordance means professionals scored lower vs. 'probably the same'. * indicates higher odds with p<0.05, // indicates upper limit exceeds 0-9 scale.
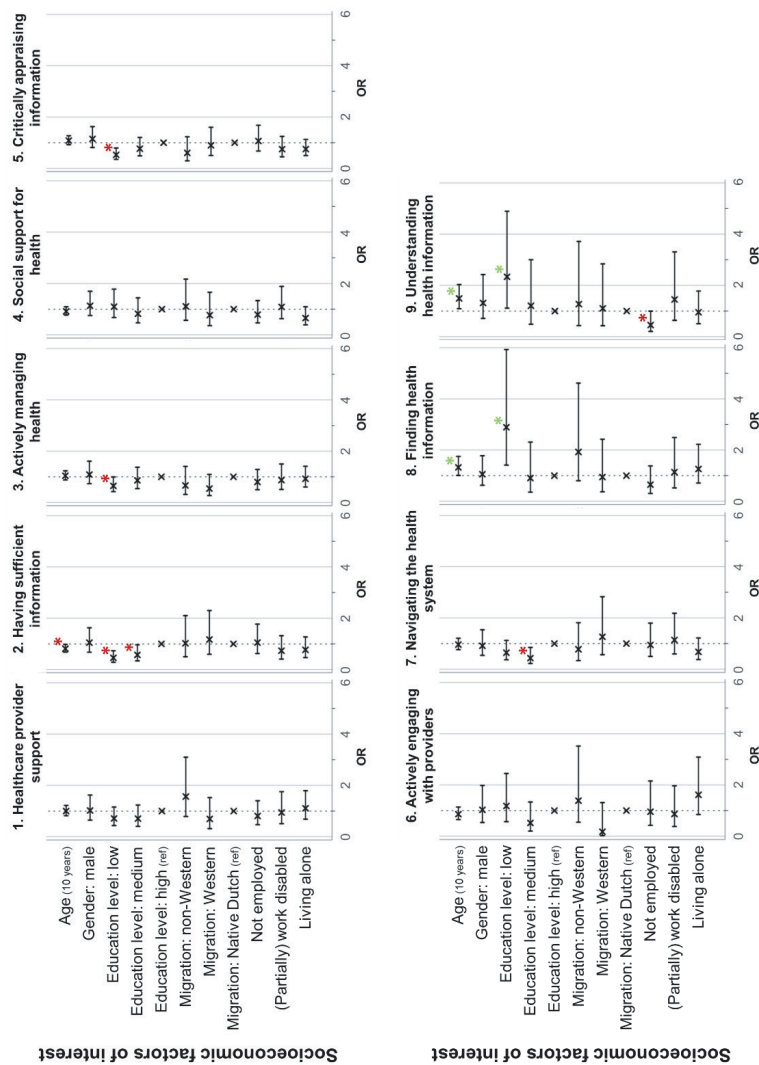
Figure 6.2B Odds ratios (ORs) and 95% confidence intervals of socioeconomic factors associated with positive discordance

Legend: positive discordance means professionals scored higher vs. 'probably the same'. * indicates lower odds with p<0.05 and * indicates higher odds with p<0.05.

Table 6.3 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)
Variables of interest:	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
Age (10 years)	1.06 [0.74 - 1.52]	1.14 [0.84 - 1.54]	1.07 [0.80 - 1.43]	1.36 [0.91 - 2.03]
Gender: male (female = ref)	1.13 [0.49 - 2.58]	1.81 [0.94 - 3.52]	1.78 [0.95 - 3.33]	1.44 [0.65 - 3.19]
Education level (high level = ref):				
Low education level	0.65 [0.25 - 1.68]	**3.69 [1.35 - 10.11]**	**3.58 [1.37 - 9.33]**	1.07 [0.35 - 3.29]
Medium education level	1.14 [0.40 - 3.25]	**2.97 [1.00 - 8.84]**	**2.96 [1.03 - 8.47]**	1.63 [0.48 - 5.52]
Migration background (Native Dutch = ref):				
Non-Western migrant	2.18 [0.73 - 6.45]	1.89 [0.77 - 4.65]	**2.45 [1.05 - 5.72]**	2.00 [0.61 - 6.60]
Western migrant	1.27 [0.37 - 4.33]	1.36 [0.54 - 3.46]	2.19 [0.98 - 4.91]	1.06 [0.28 - 4.08]
Not employed (employed = ref)	1.06 [0.35 - 3.22]	1.76 [0.72 - 4.35]	1.83 [0.76 - 4.39]	0.81 [0.23 - 2.90]
(Partially) work disabled: yes (no = ref)	1.72 [0.67 - 4.43]	1.21 [0.54 - 2.69]	**2.09 [1.02 - 4.30]**	0.87 [0.28 - 2.74]
Living alone: yes (no = ref)	1.32 [0.56 - 3.15]	1.07 [0.56 - 2.05]	1.23 [0.65 - 2.33]	**3.51 [1.52 - 8.10]**
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]
Other predictors / confounders:				
Disease (RA = ref):				
Gout	0.85 [0.24 - 3.03]	1.84 [0.79 - 4.31]	1.33 [0.54 - 3.27]	N/A
SpA	1.00 [0.41 - 2.44]	0.90 [0.42 - 1.93]	2.05 [1.00 - 4.20]	N/A
Mastery	N/A	1.02 [0.94 - 1.12]	0.94 [0.86 - 1.02]	0.97 [0.87 - 1.09]
Professionals' global disease impact	**1.36 [1.11 - 1.67]**	**1.27 [1.10 - 1.46]**	**1.23 [1.07 - 1.43]**	**1.24 [1.01 - 1.51]**
Professional type (rheumatologist = ref):				
Rheumatology nurse	2.41 [0.38 - 15.20]	N/A	N/A	1.33 [0.27 - 6.66]
Nurse practitioner / physician assistant	0.65 [0.09 - 4.75]	N/A	N/A	1.65 [0.45 - 6.08]
Rheumatology fellow	**4.55 [1.04 - 19.91]**	N/A	N/A	**6.92 [2.02 - 23.71]**
Rheumatologist (ref)	-	N/A	N/A	-
Professional gender: male (female = ref)	N/A	N/A	N/A	**3.21 [1.14 - 9.05]**

	HLQ domains	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)
		OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
Variables of interest:						
Age		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]
Gender: male		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]
Education level						
Low		1.24 [0.57 - 2.69]	**3.97 [2.06 - 7.64]**	**2.07 [1.02 - 4.22]**	**2.69 [1.49 - 4.86]**	1.97 [0.98 - 3.97]
Medium		1.47 [0.61 - 3.51]	**3.03 [1.47 - 6.24]**	1.79 [0.81 - 3.92]	1.35 [0.68 - 2.69]	1.90 [0.86 - 4.20]
Migration background						
Non-Western		**3.33 [1.48 - 7.48]**	**3.25 [1.62 - 6.49]**	2.18 [0.97 - 4.88]	**3.27 [1.66 - 6.44]**	**8.52 [4.12 - 17.61]**
Western		0.88 [0.30 - 2.59]	1.29 [0.65 - 2.57]	1.91 [0.88 - 4.16]	1.76 [0.91 - 3.40]	**2.41 [1.12 - 5.21]**
Not employed		0.85 [0.38 - 1.88]	1.85 [0.99 - 3.44]	**2.28 [1.09 - 4.78]**	1.58 [0.85 - 2.94]	0.77 [0.37 - 1.58]
(Partially) work disabled:		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]
Living alone:		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]
Fixed intercept		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]
Other predictors / confounders:						
Disease						
Gout		N/A	**2.43 [1.26 - 4.67]**	0.86 [0.38 - 1.92]	N/A	1.53 [0.71 - 3.32]
SpA		N/A	0.86 [0.50 - 1.46]	0.78 [0.42 - 1.46]	N/A	0.74 [0.38 - 1.44]
Mastery		N/A	**1.09 [1.02 - 1.16]**	**1.12 [1.04 - 1.21]**	1.07 [1.00 - 1.14]	1.01 [0.94 - 1.09]
Disease impact		**1.27 [1.10 - 1.47]**	**1.18 [1.06 - 1.30]**	**1.24 [1.09 - 1.41]**	N/A	N/A
Professional type						
Nurse		0.68 [0.14 - 3.27]	N/A	N/A	N/A	N/A
Practitioner / assistant		1.00 [0.27 - 3.70]	N/A	N/A	N/A	N/A
Fellow		**4.22 [1.32 - 13.44]**	N/A	N/A	N/A	N/A
Rheumatologist		-	N/A	N/A	N/A	N/A
Professional gender: male		N/A	N/A	N/A	N/A	N/A

6

Table 6.3 (Continued)

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)
How well the professional knew the patient (not/barely = ref):				
Very well	N/A	N/A	**0.25 [0.07 - 0.96]**	N/A
Fairly well	N/A	N/A	0.51 [0.20 - 1.27]	N/A
Somewhat	N/A	N/A	0.74 [0.31 - 1.79]	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]

Legend: Results from adjusted multilevel multinomial models, 'no discordance' as reference category.
* n differs between domains due to the 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, OR = odds ratio, RA = rheumatoid arthritis, SpA = spondyloarthritis, 95% CI = 95% confidence interval. **Bold** *values indicate p<0.05.*

Table 6.4 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)
Variables of interest:	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
Age (10 years)	1.00 [0.82 - 1.22]	**0.81 [0.68 - 0.98]**	1.04 [0.88 - 1.23]	0.91 [0.77 - 1.09]
Gender: male (female = ref)	1.02 [0.65 - 1.62]	1.05 [0.67 - 1.63]	1.09 [0.73 - 1.61]	1.13 [0.75 - 1.70]
Education level (high level = ref):				
Low education level	0.71 [0.44 - 1.16]	**0.45 [0.28 - 0.73]**	**0.65 [0.42 - 0.99]**	1.10 [0.68 - 1.78]
Medium education level	0.71 [0.40 - 1.24]	**0.57 [0.34 - 0.96]**	0.86 [0.54 - 1.37]	0.82 [0.47 - 1.44]
Migration background (Native Dutch = ref):				
Non-Western migrant	1.57 [0.79 - 3.10]	1.02 [0.50 - 2.10]	0.66 [0.31 - 1.41]	1.11 [0.57 - 2.17]
Western migrant	0.69 [0.32 - 1.53]	1.17 [0.60 - 2.30]	0.54 [0.27 - 1.09]	0.77 [0.36 - 1.66]
Not employed (employed = ref)	0.81 [0.47 - 1.40]	1.05 [0.62 - 1.77]	0.80 [0.50 - 1.29]	0.79 [0.46 - 1.33]

HLQ domains	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)
How well the professional knew the patient (not/barely = ref):					
Very well	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]
Fairly well	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]
Somewhat	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]
ICC	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]

HLQ domains	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)
Variables of interest:	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
Age (10 years)	1.08 [0.92 - 1.27]	0.86 [0.65 - 1.14]	0.96 [0.76 - 1.21]	1.32 [1.01 - 1.75]	1.49 [1.09 - 2.03]
Gender: male	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]
Education level					
Low	**0.53 [0.35 - 0.79]**	1.18 [0.57 - 2.45]	**0.64 [0.37 - 1.12]**	**2.89 [1.41 - 5.93]**	**2.34 [1.12 - 4.90]**
Medium	0.77 [0.49 - 1.20]	0.52 [0.20 - 1.34]	**0.43 [0.22 - 0.85]**	0.91 [0.36 - 2.31]	1.21 [0.49 - 3.00]
Migration background					
Non-Western	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]
Western	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]
Not employed	1.07 [0.68 - 1.68]	0.96 [0.42 - 2.16]	0.95 [0.50 - 1.80]	0.65 [0.31 - 1.38]	**0.45 [0.21 - 1.00]**

6

Table 6.4 (Continued)

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)
(Partially) work disabled: yes (no = ref)	0.95 [0.51 - 1.76]	0.73 [0.41 - 1.32]	0.87 [0.51 - 1.50]	1.09 [0.63 - 1.89]
Living alone: yes (no = ref)	1.11 [0.69 - 1.79]	0.77 [0.46 - 1.27]	0.92 [0.60 - 1.41]	0.65 [0.39 - 1.09]
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]
Other predictors / confounders:				
Disease (RA = ref):				
Gout	**1.82 [1.01 - 3.29]**	1.18 [0.63 - 2.18]	0.88 [0.50 - 1.57]	N/A
SpA	1.18 [0.70 - 1.98]	1.36 [0.83 - 2.22]	1.08 [0.70 - 1.67]	N/A
Mastery	N/A	**0.87 [0.82 - 0.93]**	0.97 [0.92 - 1.03]	**0.86 [0.81 - 0.92]**
Professionals' global disease impact	0.95 [0.86 - 1.04]	0.94 [0.85 - 1.03]	**0.90 [0.83 - 0.98]**	0.97 [0.88 - 1.07]
Professional type (rheumatologist = ref):				
Rheumatology nurse	0.74 [0.38 - 1.46]	N/A	N/A	0.77 [0.33 - 1.84]
Nurse practitioner / physician assistant	0.73 [0.39 - 1.37]	N/A	N/A	0.92 [0.41 - 2.09]
Rheumatology fellow	0.67 [0.27 - 1.64]	N/A	N/A	0.72 [0.28 - 1.85]
Rheumatologist (ref)	-	N/A	N/A	-
Professional gender: male (female = ref)	N/A	N/A	N/A	-
How well the professional knew the patient (not/barely = ref):				
Very well	N/A	N/A	**2.60 [1.19 - 5.70]**	N/A
Fairly well	N/A	N/A	1.49 [0.78 - 2.87]	N/A
Somewhat	N/A	N/A	1.11 [0.57 - 2.13]	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]

Legend: Results from adjusted multilevel multinomial models, 'no discordance' as reference category.
** n differs between domains due to the 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, OR = odds ratio, RA = rheumatoid arthritis, SpA = spondyloarthritis, 95% CI = 95% confidence interval. **Bold** values indicate p<0.05.*

HLQ domains	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)
(Partially) work disabled	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]
Living alone	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]
Fixed intercept	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]
Other predictors / confounders:					
Disease (RA = ref):					
Gout	N/A	1.40 [0.56 - 3.52]	**2.73 [1.31 - 5.71]**	N/A	1.53 [0.67 - 3.50]
SpA	N/A	1.26 [0.60 - 2.63]	1.37 [0.75 - 2.50]	N/A	1.16 [0.57 - 2.38]
Mastery	N/A	**0.82 [0.74 - 0.90]**	**0.84 [0.78 - 0.91]**	**0.91 [0.84 - 0.98]**	**0.87 [0.80 - 0.94]**
Disease impact	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	1.10 [0.54 - 2.21]	N/A	N/A	N/A	N/A
Practitioner / assistant	0.73 [0.37 - 1.44]	N/A	N/A	N/A	N/A
Fellow	1.36 [0.62 - 2.98]	N/A	N/A	N/A	N/A
Rheumatologist	-	N/A	N/A	N/A	N/A
Professional gender: male	N/A	N/A	N/A	N/A	N/A
How well the professional knew the patient (not/barely = ref):					
Very well	1.54 [0.76 - 3.15]	0.74 [0.22 - 2.57]	**3.83 [1.45 - 10.09]**	N/A	1.40 [0.43 - 4.56]
Fairly well	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]
Somewhat	**0.56 [0.31 - 1.00]**	0.56 [0.20 - 1.62]	0.95 [0.41 - 2.21]	N/A	0.87 [0.35 - 2.16]
ICC	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]

6

DISCUSSION

We found discordance between Health Literacy Questionnaire scores of people with RMDs and assessment of health literacy by their treating health professionals in more than a quarter of all cases. This indicates hidden challenges in communication and care. Most positive discordance (i.e. professional scored higher than the patient) occurred for 'Critically appraising information' (domain 5, 31.9%), while most negative discordance (i.e. professional scored lower than the patient) was observed for 'Actively engaging with providers' (domain 6, 19.0%). Professionals were most often unsure about their patient 'Having social support for health' (domain 4, 19.4% 'I do not know'). In addition, we found that risks of discordance were not equal across socioeconomic groups. Discordance was frequently associated with patients' socioeconomic background, particularly education level and migration background. Risk of negative discordance was higher in patients with low education level and/or non-Western migration background. Risk of positive discordance was higher in patients with low education level for finding and understanding health information (domains 8 and 9) and higher in patients with high education level in four other domains.

Our findings support and expand upon findings from previous studies. Voigt-Barbarowicz and Brütt [18] systematically reviewed health literacy assessment studies (using other measurement tools than the HLQ [18, 20, 22, 30-34]) in hospital-based and primary care populations with somatic conditions. In these studies, misclassification by professionals was also common, and while the biggest concern was overestimation (ranging from 9 to 58% of all patients per study), six out of seven studies also reported underestimation in 5 to 29% of all patients [20, 22, 30-33]. Storms et al. [20] additionally investigated the impact of patients' and GPs' characteristics on discordance in single-score health literacy assessment and noted the GPs were more likely to have a discordant judgement (over- or underestimation) for patients with low education. Our work expanded on these findings, showing positive discordance occurred more frequently, but negative discordance was more strongly associated with socioeconomic factors. Furthermore, the multidimensional nature of the HLQ allowed us to conduct more nuanced analyses, suggesting that (associations with) discordance may be domain dependent. For example, contrasting conclusions that particularly underestimation was more likely in patients who had been under the GP's care for a shorter period of time and in patients treated by a male GP [20], we only observed these effects in single domains ('Actively managing health' (domain 3) and 'Having social support for health' (domain 4), respectively).

This paper describes the first study to quantify discordance between patients' health literacy scores and professionals' assessment using the multidimensional HLQ. In a qualitative study, Hawkins et al. [21] showed that differing perspectives can be a reason for discordance in HLQ scores between patients and professionals. For example, some patients saw goalsetting and making plans to be healthy as 'Actively managing health' (domain 3), while clinicians

expected patients to convert these goals and plans into action. Lacking a gold standard for objective health literacy measurement, we do not know if the discordance in this study means professionals over- or underestimate patients, patients over- or underestimate themselves, or that the truth is somewhere in the middle. Notwithstanding, the present data uncover a considerable disconnect between patients' and professionals' views on patients' health literacy needs. Moreover, professionals strikingly often answered 'I do not know' in estimating 'Having social support for health' (domain 4), indicating this may not receive sufficient attention in clinical consultations. The findings highlight that we cannot expect all health professionals to accurately understand and address all patients' health literacy needs adequately at the point of care based on subjective estimations alone. Instead, we require strategies to address health literacy needs that rely on health literacy measurement and dialogue with patients and professionals, either at the point of care or in the development of organisational interventions based on patients' needs [23]. The Conversational Health Literacy Assessment Tool (CHAT) could assist health professionals in this process [35].

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

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 summary scores may fail to capture the complexity of the role of health literacy in health care delivery. Health literacy needs are not grounded in scores on a single domain, but

6

rather follow from a pattern of strengths and weaknesses across health literacy domains [17, 29]. We therefore second Voigt-Barbarowicz and Brütt [18], recommending the use of multidimensional health literacy assessment tools in research and practice.

Our paper reports on a large, inclusive, multi-centre study in rheumatology using a multidimensional health literacy tool, giving valuable new insights into health literacy assessment and the role of socioeconomic factors. Nevertheless, it should be seen in light of a few limitations. First, in contrast to Hawkins et al. [21], health professionals did not fill out the full HLQ, but estimated domain scores (for feasibility reasons). This may have exacerbated discordance, also because HLQ scores had to be converted to a 0-10 scale. Second, the choice of categorisation and threshold of 'discordance' as a 2-point difference in observations could be debated. We made this decision based on commonly used cut-offs in rheumatology research [43-46], but no true consensus exists [47], and future studies should determine what difference in health literacy scoring could impact patient-professional relationships and communication. Third, we explored many associations, risking that some of our observations may be due to chance. Therefore, the strong, consistent findings are more likely to reflect true patterns, while less consistent patterns need to be validated in further research. Fourth, some of the associations observed in this cross-sectional study were not consistent between domains, such as the increased risk of both negative and positive discordance in people with low education level for finding and understanding health information (domains 8 and 9), and not consistent with previous research [18, 20]. While these inconsistencies hint at the complexity of health literacy assessment, we cannot be sure if the role of socioeconomic factors in discordance is indeed inconsistent or if there may be other factors (not explored in this study) that can explain discordance patterns and confound the observed associations. Last, we were unable to explore the impact of discordance on outcomes such as quality of care, health status or the occurrence of adverse events. We hypothesise these associations exist, but future research on this topic is warranted.

In conclusion, our study shows that accurate estimation of patients' health literacy by professionals in rheumatology is not a given. Discordance between patients' health literacy scores and professionals' estimations indicates that there may be hidden challenges in communication and care in about a quarter of all patients. Risks are not equal across socioeconomic groups (particularly higher for people with low education level and/or non-Western migration background) and domains of health literacy, which highlights the multidimensional nature of health literacy and indicates that challenges in addressing health literacy needs may be unequal between socioeconomic groups as well. While increasing awareness among health professionals could potentially reduce discordance and improve understanding between patients and professionals, we suggest health literacy measurement and dialogue with patients and health professionals are vital to addressing health literacy needs, which cannot rely on health professionals' estimations alone.

DECLARATIONS

Ethics
This study was reviewed by the Medical Ethics Review Committee at Maastricht University Medical Center+ (2018-0327) as well as by the designated committees at each participating hospital for local permission (South: Maastricht University Medical Center+, Maastricht: 18–4-037, West: Maasstad Hospital, Rotterdam: L2018057, East: Medisch Spectrum Twente, Enschede: KH18-23). All patients and professionals provided written informed consent.

Acknowledgements
We are grateful to the clinic staff at all three centres for their efforts in patient recruitment and to all patients and health professionals for participating in this study.

6

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. doi:10.1177/1757975918814421.

2. World Health Organization. Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development. *Health Promot Int*. 2017;32(1):7-8. doi:10.1093/heapro/daw103.

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. doi:10.1186/1471-2458-13-179.

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. doi:10.5555/ajhb.2007.31.supp.S19.

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. doi:10.1016/j.puhe.2016.01.001

6. Heijmans M, Brabers A, Rademakers J. *Hoe gezondheidsvaardig is Nederland? Factsheet Gezondheidsvaardigheden – Cijfers 2019.* Utrecht, The Netherlands: Nivel; 2019. Available from: https://nivel.nl/sites/default/files/bestanden/1003631.pdf

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. doi:10.1093/eurpub/ckv043.

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. doi:10.1097/01.mlr.0000237425.58554.66.

9. Nikiphorou E, Santos EJF, 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. doi:10.1136/annrheumdis-2021-220249.

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. doi:10.1136/annrheumdis-2016-210770.

11. Jones B, Ndosi M, Hunt A, Harcourt D, Dures E. Factors associated with patient activation in inflammatory arthritis: a multisite cross-sectional study. *Rheumatology Advances in Practice*. 2021;5(Supplement_2):ii35-ii44. doi:10.1093/rap/rkab053.

12. Joplin S, van der Zwan R, Joshua F, Wong PKK. Medication adherence in patients with rheumatoid arthritis: The effect of patient education, health literacy, and musculoskeletal ultrasound. *Biomed Res Int*. 2015. doi:10.1155/2015/150658.

13. Hirsh J, Wood P, Keniston A, Boyle D, Quinzanos I, Caplan L, et al. Universal Health Literacy Precautions Are Associated With a Significant Increase in Medication Adherence in Vulnerable Rheumatology Patients. *ACR Open Rheumatol.* 2020;2(2):110-8. doi:10.1002/acr2.11108.

14. Caplan L, Wolfe F, Michaud K, Quinzanos I, Hirsh JM. Strong association of health literacy with functional status among rheumatoid arthritis patients: A cross-sectional study. *Arthritis Care Res.* 2014;66(4):508-14. doi:10.1002/acr.22165.

15. Hirsh JM, Boyle DJ, Collier DH, Oxenfeld AJ, Nash A, Quinzanos I, et al. Limited health literacy is a common finding in a public health hospital's rheumatology clinic and is predictive of disease severity. *J Clin Rheumatol.* 2011;17(5):236-41. doi:10.1097/RHU.0b013e318226a01f.

16. Putrik P, Ramiro S, Lie E, Keszei AP, Kvien TK, van der Heijde D, et al. Less educated and older patients have reduced access to biologic DMARDs even in a country with highly developed social welfare (Norway): Results from Norwegian cohort study NOR-DMARD. *Rheumatology.* 2016;55(7):1217-24. doi:10.1093/rheumatology/kew048.

17. Bakker MM, Putrik P, Rademakers J, van de Laar M, Vonkeman H, Kok MR, et al. Addressing health literacy needs in rheumatology: Which patient health literacy profiles need the attention of health professionals? *Arthritis Care Res.* 2021;73(1):100-9. doi:10.1002/acr.24480.

18. Voigt-Barbarowicz M, Brütt AL. The Agreement between Patients' and Healthcare Professionals' Assessment of Patients' Health Literacy-A Systematic Review. *Int J Environ Res Public Health.* 2020;17(7). doi:10.3390/ijerph17072372.

19. Cooper M, Jr., Blucker R, Thompson D, Griffeth E, Grassi M, Damron K, et al. Health Literacy Estimation of English and Spanish Language Caregivers. *Health Lit Res Prac.* 2018;2(2):e107-e14. doi:10.3928/24748307-20180503-02.

20. Storms H, Aertgeerts B, Vandenabeele F, Claes N. General practitioners' predictions of their own patients' health literacy: a cross-sectional study in Belgium. *BMJ Open.* 2019;9(9):e029357. doi:10.1136/bmjopen-2019-029357.

21. Hawkins M, Gill SD, Batterham R, Elsworth GR, Osborne RH. The Health Literacy Questionnaire (HLQ) at the patient-clinician interface: A qualitative study of what patients and clinicians mean by their HLQ scores. *BMC Health Serv Res.* 2017;17(1):309. doi:10.1186/s12913-017-2254-8.

22. Kelly PA, Haidet P. Physician overestimation of patient literacy: a potential source of health care disparities. *Patient Educ Couns.* 2007;66(1):119-22. doi:10.1016/j.pec.2006.10.007.

23. Beauchamp A, Batterham RW, Dodson S, Astbury B, Elsworth GR, McPhee C, et al. Systematic development and implementation of interventions to OPtimise Health Literacy and Access (Ophelia). *BMC Public Health.* 2017;17(1):230. doi:10.1186/s12889-017-4147-5.

24. Osborne RH, Batterham RW, Elsworth GR, Hawkins M, Buchbinder R. The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health.* 2013;13:658. doi:10.1186/1471-2458-13-658.

6

25. Rademakers J, Waverijn G, Rijken M, Osborne R, Heijmans M. Towards a comprehensive, person-centred assessment of health literacy: translation, cultural adaptation and psychometric test of the Dutch Health Literacy Questionnaire. *BMC Public Health.* 2020;20(1):1850. doi:10.1186/s12889-020-09963-0.

26. Pearlin LI, Schooler C. The Structure of Coping. *J Health Soc Behav.* 1978;19(1):2-21.

27. Statistics Netherlands. *Standaard onderwijsindeling: Editie 2016/'17.* Den Haag/Heerlen, the Netherlands: CBS; 2017. Available from: https://www.cbs.nl/-/media/_pdf/2017/13/pubsoi2016ed1617.pdf

28. Alders M. *Classification of the population with a foreign background in the Netherlands.* Presented at the conference: The Measure and Mismeasure of Populations: the statistical use of ethnic and racial categories in multicultural societies; 2001 December 17–18; Paris, France. Available from: https://www.cbs.nl/-/media/imported/documents/2002/05/classification-foreign.pdf?la=nl-nl

29. Beauchamp A, Buchbinder R, Dodson S, Batterham RW, Elsworth GR, McPhee C, et al. Distribution of health literacy strengths and weaknesses across socio-demographic groups: a cross-sectional survey using the Health Literacy Questionnaire (HLQ). *BMC Public Health.* 2015;15(1):678. doi:10.1186/s12889-015-2056-z.

30. Lindau ST, Basu A, Leitsch SA. Health literacy as a predictor of follow-up after an abnormal Pap smear: a prospective study. *J Gen Intern Med. 2006*;21(8):829-34. doi:10.1111/j.1525-1497.2006.00534.x

31. Bass PF, 3rd, Wilson JF, Griffith CH, Barnett DR. Residents' ability to identify patients with poor literacy skills. *Acad Med.* 2002;77(10):1039-41. doi:10.1097/00001888-200210000-00021.

32. Rogers ES, Wallace LS, Weiss BD. Misperceptions of Medical Understanding in Low-Literacy Patients: Implications for Cancer Prevention. *Cancer Control.* 2006;13(3):225-9. doi:10.1177/107327480601300311.

33. Zawilinski LL, Kirkpatrick H, Pawlaczyk B, Yarlagadda H. Actual and perceived patient health literacy: How accurate are residents' predictions? *Int J Psychiatry Med.* 2019;54(4-5):290-5. doi:10.1177/0091217419860356.

34. Dickens C, Lambert BL, Cromwell T, Piano MR. Nurse Overestimation of Patients' Health Literacy. *J Health Commun.* 2013;18(sup1):62-9. doi:10.1080/10810730.2013.825670

35. O'Hara J, Hawkins M, Batterham R, Dodson S, Osborne RH, Beauchamp A. Conceptualisation and development of the Conversational Health Literacy Assessment Tool (CHAT). *BMC Health Serv Res.* 2018;18(1):199. doi:10.1186/s12913-018-3037-6.

36. Berkman ND, Davis TC, McCormack L. Health literacy: what is it? *J Health Commun.* 2010;15 Suppl 2:9-19. doi:10.1080/10810730.2010.499985.

37. Sørensen K, Van den Broucke S, Pelikan JM, Fullam J, Doyle G, Slonska Z, et al. Measuring health literacy in populations: illuminating the design and development process of the European Health Literacy Survey Questionnaire (HLS-EU-Q). *BMC Public Health.* 2013;13(1):948. doi:10.1186/1471-2458-13-948.

38. Dijkstra I, Horstman K. 'Known to be unhealthy': Exploring how social epidemiological research constructs the category of low socioeconomic status. *Soc Sci Med.* 2021;285:114263. doi:10.1016/j.socscimed.2021.114263

39. Ledford CJ, Ledford CC, Childress MA. Exploring patient activation in the clinic: measurement from three perspectives. *Health Educ Behav.* 2013;40(3):339-45. doi:10.1177/1090198112455173.

40. Barton JL, Markwardt S, Niederhausen M, Schue A, Dougherty J, Katz P, et al. Are We on the Same Page? A Cross-Sectional Study of Patient-Clinician Goal Concordance in Rheumatoid Arthritis. *Arthritis Care Res.* 2021. doi:10.1002/acr.24794.

41. Challa DN, Kvrgic Z, Cheville AL, Crowson CS, Bongartz T, Mason TG, et al. Patient-provider discordance between global assessments of disease activity in rheumatoid arthritis: a comprehensive clinical evaluation. *Arthritis Res Ther.* 2017;19(1):212. doi:10.1186/s13075-017-1419-5.

42. Barton JL, Imboden J, Graf J, Glidden D, Yelin EH, Schillinger D. Patient-physician discordance in assessments of global disease severity in rheumatoid arthritis. *Arthritis Care Res.* 2010;62(6):857-64. doi:10.1002/acr.20132.

43. Castrejon I, Shakoor N, Chua JR, Block JA. Discordance of global assessment by patients and physicians is higher in osteoarthritis than in rheumatoid arthritis: a cross-sectional study from routine care. *Rheumatol Int.* 2018;38(11):2137-45. doi:10.1007/s00296-018-4166-2.

44. Khan NA, Spencer HJ, Abda E, Aggarwal A, Alten R, Ancuta C, et al. Determinants of discordance in patients' and physicians' rating of rheumatoid arthritis disease activity. *Arthritis Care Res.* 2012;64(2):206-14. doi:10.1002/acr.20685.

45. Floris A, Espinosa G, Serpa Pinto L, Kougkas N, Lo Monaco A, Lopalco G, et al. Discordance between patient and physician global assessment of disease activity in Behçet's syndrome: a multicenter study cohort. *Arthritis Res Ther.* 2020;22(1):278. doi:10.1186/s13075-020-02362-1.

46. Lindström Egholm C, Krogh NS, Pincus T, Dreyer L, Ellingsen T, Glintborg B, et al. Discordance of Global Assessments by Patient and Physician Is Higher in Female than in Male Patients Regardless of the Physician's Sex: Data on Patients with Rheumatoid Arthritis, Axial Spondyloarthritis, and Psoriatic Arthritis from the DANBIO Registry. *J Rheumatol.* 2015;42(10):1781-5. doi:10.3899/jrheum.150007

47. Desthieux C, Hermet A, Granger B, Fautrel B, Gossec L. Patient-Physician Discordance in Global Assessment in Rheumatoid Arthritis: A Systematic Literature Review With Meta-Analysis. *Arthritis Care Res.* 2016;68(12):1767-73. doi:10.1002/acr.22902.

6

SUPPLEMENTARY MATERIALS

Supplementary Table 6.1 Characteristics of patients included in the present study compared to patients in the original study whose healthcare professional did not fill out a questionnaire

	Patients in present study (n = 778)	**Patients without questionnaire by healthcare professional** (n = 117)	**p-value¶**
	Mean (SD) [min-max]† / % (n)‡		
Age	61.2 (13.9) [18-89]	60.3 (13.9) [23-91]	0.505
Gender: male	52.1 (405)	46.2 (54)	0.234
Education level			0.338
Low	51.7 (402)	44.4 (52)	
Medium	24.4 (190)	27.4 (32)	
High	23.9 (186)	28.2 (33)	
Migration background			0.067
Non-Western migrant	8.9 (69)	4.3 (5)	
Western migrant	8.6 (67)	13.7 (16)	
Native Dutch	82.5 (642)	82.1 (96)	
Occupation status*			
Employed	32.5 (253)	38.5 (45)	0.204
(Partially) work disabled	14.3 (111)	19.7 (23)	0.047
Household type*			
Living alone	23.9 (186)	29.1 (34)	0.228
Rheumatic disease			0.004
_RA_	41.0 (319)	42.7 (50)	
SpA	34.2 (266)	45.3 (53)	
Gout	24.8 (193)	12.0 (14)	
Treating hospital			<0.001
South	31.7 (247)	59.8 (70)	
West	28.8 (224)	40.2 (47)	
East	39.5 (307)	0.0 (0)	

Supplementary Table 6.1 (Continued)

	Patients in present study (n = 778)	Patients without questionnaire by healthcare professional (n = 117)	p-value¶
Treated by type of healthcare professional			<0.001
Rheumatologist	55.3 (430)	95.7 (112)	
Rheumatology fellow	7.5 (58)	0.0 (0)	
Nurse practitioner/physician assistant	21.0 (163)	1.7 (2)	
Rheumatology nurse	16.3 (127)	2.6 (3)	
Mastery	20.06 (3.44) [9-28]§	19.71 (2.99) [13-28]	0.294

*Legend: † for continuous variables. ‡ for categorical variables. ¶ One-way ANOVA or X² test for differences between patients included or excluded in this study. * described as a yes/no variable. For occupation status, patients may belong to both or neither of these groups. § n = 777 (1 questionnaire administered in Arabic without Mastery scale because no validated translation is available). RA = rheumatoid arthritis, SpA = spondyloarthritis.*

6

Supplementary Table 6.2 Odds ratios for discordance per domain, results from univariable 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)
Negative discordance:	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
Age (10 years)	0.94 [0.75 - 1.20]	1.21 [0.98 - 1.49]	1.01 [0.84 - 1.22]	**1.34 [1.01 - 1.77]**
Gender: male (female = ref)	1.11 [0.55 - 2.24]	1.71 [0.97 - 3.00]	**1.71 [1.01 - 2.92]**	1.15 [0.57 - 2.34]
Education level (high level = ref):				
Low education	0.72 [0.31 - 1.71]	**4.41 [1.67 - 11.63]**	**3.84 [1.58 - 9.32]**	1.85 [0.67 - 5.15]
Medium education	0.91 [0.34 - 2.41]	2.75 [0.95 - 7.97]	2.51 [0.93 - 6.75]	1.79 [0.57 - 5.64]
Migration background (Native Dutch = ref):				
Non-Western migrant	**3.01 [1.16 - 7.82]**	**2.22 [1.00 - 4.94]**	**3.33 [1.64 - 6.75]**	1.94 [0.72 - 5.24]
Western migrant	1.32 [0.41 - 4.21]	1.34 [0.55 - 3.27]	1.85 [0.87 - 3.92]	1.17 [0.32 - 4.24]
Not employed (employed = ref)	1.47 [0.64 - 3.35]	**2.59 [1.28 - 5.20]**	**2.55 [1.29 - 5.04]**	2.03 [0.81 - 5.08]
(Partially) work disabled: yes (no = ref)	**2.43 [1.13 - 5.23]**	1.48 [0.77 - 2.82]	**2.81 [1.60 - 4.94]**	0.97 [0.38 - 2.48]
Living alone: yes (no = ref)	1.40 [0.65 - 3.00]	1.40 [0.78 - 2.52]	1.46 [0.84 - 2.56]	**3.50 [1.70 - 7.19]**
Positive discordance:				
Age (10 years)	0.94 [0.82 - 1.08]	**0.80 [0.70 - 0.91]**	0.98 [0.88 - 1.11]	0.92 [0.81 - 1.05]
Gender: male (female = ref)	1.24 [0.83 - 1.85]	1.15 [0.78 - 1.69]	1.10 [0.79 - 1.55]	1.19 [0.82 - 1.74]
Education level (high level = ref):				
Low education	0.69 [0.43 - 1.09]	**0.49 [0.32 - 0.77]**	**0.60 [0.40 - 0.89]**	1.14 [0.73 - 1.78]
Medium education	0.71 [0.41 - 1.23]	0.68 [0.41 - 1.12]	0.83 [0.53 - 1.30]	0.92 [0.54 - 1.57]
Migration background (Native Dutch = ref):				
Non-Western migrant	1.56 [0.81 - 3.01]	1.48 [0.77 - 2.84]	0.67 [0.33 - 1.36]	1.27 [0.68 - 2.36]
Western migrant	0.72 [0.33 - 1.57]	1.17 [0.61 - 2.25]	0.54 [0.27 - 1.08]	0.78 [0.37 - 1.65]
Not employed (employed = ref)	0.74 [0.50 - 1.12]	0.76 [0.51 - 1.12]	0.75 [0.53 - 1.06]	0.90 [0.61 - 1.34]
(Partially) work disabled: yes (no = ref)	0.86 [0.49 - 1.51]	0.99 [0.59 - 1.66]	0.84 [0.52 - 1.36]	1.26 [0.78 - 2.03]
Living alone: yes (no = ref)	1.01 [0.63 - 1.60]	0.65 [0.40 - 1.05]	0.84 [0.56 - 1.26]	0.68 [0.42 - 1.10]

*Legend: Results from unadjusted univariable multilevel multinomial models, 'no discordance' as reference category. * n differs between domains due to the exclusion of "I do not know". ref = reference category (no OR), HLQ = Health Literacy Questionnaire, OR = odds ratio, 95% CI = 95% confidence interval. **Bold** values indicate p<0.05.*

HLQ domains	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)
Negative discordance:	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
Age	1.00 [0.83 - 1.21]	**1.16 [1.01 - 1.34]**	1.07 [0.91 - 1.27]	1.08 [0.93 - 1.25]	1.07 [0.90 - 1.27]
Gender: male	1.41 [0.82 - 2.45]	0.99 [0.67 - 1.46]	1.23 [0.76 - 1.99]	1.12 [0.74 - 1.70]	1.45 [0.90 - 2.34]
Education level					
Low	1.18 [0.58 - 2.42]	**4.28 [2.33 - 7.86]**	**2.00 [1.04 - 3.86]**	**2.55 [1.47 - 4.44]**	1.85 [0.99 - 3.46]
Medium	1.14 [0.50 - 2.60]	**2.61 [1.32 - 5.16]**	1.53 [0.72 - 3.23]	1.17 [0.60 - 2.26]	1.36 [0.66 - 2.82]
Migration background					
Non-Western	**3.08 [1.52 - 6.26]**	**2.86 [1.58 - 5.18]**	2.03 [0.99 - 4.17]	**3.16 [1.70 - 5.89]**	**6.46 [3.44 - 12.15]**
Western	0.87 [0.31 - 2.41]	1.25 [0.66 - 2.37]	1.94 [0.93 - 4.09]	1.82 [0.96 - 3.45]	**2.34 [1.11 - 4.95]**
Not employed	1.14 [0.63 - 2.07]	**2.44 [1.53 - 3.87]**	**2.05 [1.17 - 3.59]**	**1.80 [1.13 - 2.87]**	1.31 [0.78 - 2.21]
(Partially) work disabled	1.58 [0.83 - 3.02]	1.14 [0.70 - 1.88]	1.14 [0.62 - 2.10]	1.17 [0.69 - 1.98]	1.39 [0.77 - 2.50]
Living alone	0.71 [0.37 - 1.38]	1.51 [0.99 - 2.30]	0.87 [0.50 - 1.52]	**1.61 [1.03 - 2.52]**	1.34 [0.80 - 2.25]
Positive discordance:					
Age	1.06 [0.94 - 1.19]	0.96 [0.79 - 1.17]	1.00 [0.85 - 1.17]	**1.38 [1.14 - 1.67]**	**1.38 [1.13 - 1.70]**
Gender: male	1.16 [0.84 - 1.61]	1.02 [0.59 - 1.79]	1.09 [0.70 - 1.70]	0.96 [0.59 - 1.56]	1.35 [0.79 - 2.30]
Education level					
Low	**0.51 [0.35 - 0.75]**	1.56 [0.80 - 3.06]	0.76 [0.46 - 1.25]	**3.69 [1.86 - 7.31]**	**2.88 [1.44 - 5.78]**
Medium	0.72 [0.46 - 1.11]	0.65 [0.26 - 1.63]	**0.51 [0.27 - 0.97]**	0.91 [0.36 - 2.28]	1.15 [0.48 - 2.79]
Migration background					
Non-Western	0.57 [0.29 - 1.13]	1.99 [0.84 - 4.75]	1.17 [0.53 - 2.55]	1.68 [0.75 - 3.74]	1.10 [0.41 - 2.99]
Western	0.91 [0.52 - 1.60]	0.20 [0.03 - 1.51]	1.28 [0.60 - 2.76]	0.95 [0.38 - 2.35]	1.05 [0.42 - 2.59]
Not employed	0.92 [0.66 - 1.28]	1.27 [0.70 - 2.31]	1.22 [0.76 - 1.94]	**1.76 [1.02 - 3.04]**	1.38 [0.79 - 2.40]
(Partially) work disabled:	0.72 [0.46 - 1.13]	1.32 [0.66 - 2.67]	1.49 [0.87 - 2.57]	0.90 [0.46 - 1.75]	0.98 [0.49 - 1.96]
Living alone	0.70 [0.48 - 1.03]	1.74 [0.95 - 3.16]	0.73 [0.43 - 1.26]	1.75 [1.04 - 2.95]	1.22 [0.69 - 2.15]

6

CHAPTER 7

Consideration of health literacy in patient information: a mixed-methods study of COVID-19 crisis communication in Dutch rheumatology

Mark M. Bakker, Tess Luttikhuis, Polina Putrik, Isabelle Jansen, Jany Rademakers, Maarten de Wit, Annelies Boonen

ABSTRACT

Background
The rapid spread of COVID-19 required swift action to provide people with rheumatic and musculoskeletal diseases (RMDs) with reliable information. People with limited health literacy constitute a vulnerable group that might have difficulty accessing, understanding, and applying health information, particularly in times of crisis.

Objectives
This study explored (a) key aspects of crisis communication and (b) explicit consideration of people's health literacy needs in communication to people with RMDs during the first wave of COVID-19 in the Netherlands.

Methods
We conducted a convergent, qualitatively driven mixed-methods study comprising seven qualitative interviews with professional representatives of organisations responsible for information provision to people with RMDs, and quantitative analysis of 15 patient information materials distributed by these organisations. The study was guided by principles of crisis communication and health literacy. We assessed understandability and actionability of information materials using the Dutch version of the Patient Education Materials Assessment Tool (PEMAT, resulting in a percentage of quality criteria met), and language difficulty level using an online application (assessing difficult words, jargon, passive, complex and long sentences, and long paragraphs, and difficulty levels according to the Common European Framework of Reference for Languages (CEFR, from A1 (basic) to C2 (proficient)).

Results
Respondents reported lack of preparedness, challenges related to scientific uncertainty and reaching the target group, difficulty simplifying information, and uncertainty regarding adequacy of the communication approach. Patient information materials (written and video) showed variation in actionability (range 60-100%) and understandability (range 58-100%), and 69% of written materials were too difficult, mostly due to the use of long sentences and difficult words. The quantitative findings were in coherence with the limitations in communication reported by respondents. Several potential improvements were formulated in 'lessons learned'.

Conclusions
Although rheumatology organisations mostly adhered to principles of crisis communication and made efforts to adapt information to their audience's needs, we propose recommendations to improve preparedness, strategy, content, reach, and consideration of health literacy needs in future crisis communication.

KEY MESSAGES

— Rheumatology organisations reported efforts to align with principles of crisis communication and health literacy.

— Patients' health literacy needs were insufficiently considered and patient information materials were too difficult.

— Improving preparedness, collaboration between organisations and disciplines, and adaptation to patients' needs is necessary.

7

INTRODUCTION

The rapid global spread of Coronavirus Disease 2019 (COVID-19) raised acute concern among the general population [1], especially among people with pre-existing conditions that possibly made them more vulnerable to infection or prone to a severe course of COVID-19 [2, 3]. Lee and You [4] observed higher levels of perceived susceptibility and perceived severity of disease among people with lower health status. Particular groups of concern include people with pre-existing respiratory problems [5], people undergoing chemotherapy [6], and people with inflammatory rheumatic and musculoskeletal diseases (RMDs) treated with immunosuppressive drugs, including people with Rheumatoid Arthritis (RA), Spondyloarthritis (SpA), and systemic diseases [7, 8]. At the Maastricht University Medical Center+ (Maastricht UMC+), the first phone calls and emails with questions and concerns from patients reached the outpatient clinic on February 27th, 2020, the day of the first confirmed case of COVID-19 in the Netherlands. Immediate action by healthcare providers and organisations was required to provide reliable, timely information to people with RMDs. Important issues included the risk of infection and severe COVID-19 in subgroups of patients, continuation of non-steroidal anti-inflammatory drugs (NSAIDs) and specific anti-rheumatic drugs such as disease-modifying anti-rheumatic drugs (DMARDs) or glucocorticoids, safety at work, temporary closure of clinics and organisation of (semi-) virtual care, and the alleged role of anti-rheumatic drugs in the treatment of COVID-19.

The World Health Organization (WHO) and Centers for Disease Control and Prevention (CDC) set out principles to consider in crisis communication at the time of an outbreak [9, 10]. Among others, these documents provide governments and organisations with advice on being prepared, being credible, and achieving reach and impact through a communication strategy that fits the needs of the targeted audience [9, 10].

The needs of the audience can be diverse and depend on, for example, people's clinical profile or socioeconomic background. People with limited health literacy constitute a vulnerable group that might have specific health information needs, particularly in times of crisis [11-13]. Health literacy is defined as *"the combination of personal competencies and situational resources needed for people to access, understand, appraise and use information and services to make decisions about health. It includes the capacity to communicate, assert and act upon these decisions"* [14]. Adequate health literacy is of vital importance to be able to navigate the abundance of health information of differing quality, deal with scientific uncertainty, and adequately assess risks and adapt health behaviour accordingly [11-13]. In realisation that limited health literacy is prevalent both in the general Dutch population [15] and among patients with rheumatic diseases [16], consideration of health literacy principles in crisis communication is required. In this paper, we therefore explored (a) key aspects of crisis communication and (b) the explicit consideration of people's health literacy needs in communication with people with RMDs during the first wave of COVID-19 in the Netherlands.

METHODS

We conducted a convergent, qualitatively driven mixed-methods study [17, 18] in which we interviewed professional representatives of organisations with different roles in providing information to persons with RMDs in the Netherlands during the COVID-19 pandemic. The qualitative findings, distilled from a generic qualitative approach [19], are combined with a quantitative assessment of patient information materials provided by these organisations in the first months of the pandemic, to further understand how principles of crisis communication and health literacy were applied in communication to persons with RMDs. We used a separative approach, in which qualitative data and quantitative data analyses are conducted independently before integrating the datasets for further interpretation [18].

Sampling of organisations

We purposefully sampled four organisations: two large patient organisations, the national association of rheumatology professionals, and the rheumatology department of one academic medical centre to gain insight into crisis communication on a national and hospital level. While the primary audience differed between organisations, communications by all four organisations were used to inform patients with RMDs with diverse health literacy needs, and therefore fit the scope of this study. Each organisation was asked to refer us to one or several professional spokesperson(s) on this topic. All respondents were involved in one-on-one or mass communication with patients, and/or responsible for coordinating COVID-19 communication, and could therefore reflect upon the process as 'expert insiders'.

Qualitative data collection – interviews

In May and June 2020, two researchers (TL & IJ) conducted semi-structured interviews via video- or telephone call using an interview guide (Supplementary material 7.1). Respondents were asked to describe the crisis communication of their organisation in light of key principles of crisis communication [9, 10], and identify points for improvement. Moreover, we enquired about whether explicit efforts were made to adapt crisis communication to populations with health literacy needs.

Qualitative data processing and analysis – interviews

Upon the respondent's consent, the interviews were recorded and transcribed. In one case, extensive notes were taken instead, as close to verbatim as possible. Two researchers (TL & IJ) independently performed open line-by-line coding [20], using Atlas.ti software. We initially developed a coding tree based on the interview guide (deductive coding [20]), but expanded and adapted it after every interview, with emerging codes added (inductive coding [20]). After agreeing on the final coding tree with a third researcher (MB), all interviews were recoded where necessary. In case of disagreement between the researchers, differences were

7

discussed and resolved. Through further axial coding [20], a thematic structure emerged [21]. This thematic structure led us to create a framework comprising four core pillars of crisis communication, i.e. (1) *preparedness,* (2) *strategy,* (3) *reach,* and (4) *content of communication* (Box 7.1), which we used to describe and structure the results.

The framework was inspired by key publications [9, 10, 22], and encompasses known principles of crisis communication and health literacy that help contextualise and understand our results. While using this framework enhances the interpretability of our findings, note that there is some dependency and overlap of principles between and across core pillars, indicating that crisis communication is more complex than the pillars in this framework seem to suggest. Consideration of health literacy throughout the process was described and evaluated separately, because the analysis suggested it was a recurring theme across the other themes, rather than a separate pillar. Whenever relevant, we distinguish between mass communication and one-on-one communication in describing the results.

Quantitative data collection – patient information materials

To complement the qualitative findings and gain insight into the outputs of the crisis communication efforts described by the respondents, we conducted a quantitative assessment of patient information materials used by the four organisations, in parallel with the qualitative data collection and analyses. We identified patient information materials (texts and videos) provided on websites and social media (Twitter and Facebook) pages of the organisations between February 27th and June 1st 2020 for assessment. Materials were selected if they a) aimed specifically at an RMD patient audience, and b) provided information or health advice related to COVID-19. We further included a standardised written communication used at the hospital to support nurses in answering patients' questions by telephone and individual emails.

Quantitative data processing and analysis – patient information materials

Written materials were assessed for *difficulty level* using '*Klinkende Taal'* [English-language version: SonaLing] [23]. This online application assesses the use of difficult words, jargon, passive, complex and long sentences, and long paragraphs, and assigns difficulty levels according to the Common European Framework of Reference for Languages (CEFR, from A1 (basic) to C2 (proficient)). There is broad consensus that difficulty should not exceed B1 level (lowest level of independent proficiency, indicative of adequate literacy) for the majority of the population to be able to read and understand everything that is written [24-27]. Figure 7.1 displays an excerpt of an assessment for the reader's insight.

Box 7.1 Core pillars and underlying principles of crisis communication and health literate communication [9, 10, 22]. Note: Accessibility refers to different aspects, some related to reach, others to content.

Pillar 1: preparedness
Planning & guidelines: A crisis communication plan, developed in non-crisis time, should be readily available [9].

Pillar 2: strategy
Announcing early: Accurate, comprehensive, transparent information should be shared early to build trust and facilitate behavioural change [9, 10].
Frequency: Information should be updated regularly, to reinforce earlier messages and keep the attention as a credible source [10].
Consistency: Messages across organisations should be consistent, as people inform themselves using different sources [10].
Transparency: Information should include acknowledgement of uncertainty, what is known and (still) unknown, and what actions are being undertaken to deal with the crisis, to maintain public trust and promote more deliberate decision-making [9, 10].

Pillar 3: reach
Trust: Communication with the public depends on building, maintaining and/or restoring trust as a precondition for medical advice to be believed and followed, and to ensure it truly reaches the intended audience. Trust is built through long-term relations with the public, acknowledging people's struggles as well as, counterintuitively, scientific uncertainty [9, 10].
Accessibility (1/2): Information should be accessible through multiple channels (besides oral communication in clinical encounters) to enhance reach and impact, as a diverse audience is best reached in diverse ways [10].

Pillar 4: content of communication
Understanding the public: Crisis communication should be a dialogue, where providers communicate a message that is adapted towards the needs of their intended audience. Messages should address the concerns that live among the population [9, 10].
Actionability: Communication should include information on what the public can do themselves (for example in prevention, treatment, or coping). Materials are actionable when consumers of diverse backgrounds and varying levels of health literacy can identify what they can do based on the information presented [9, 10, 22].
Accessibility (2/2): Information should be accessible in terms of understandability and difficulty, to promote the audience's understanding [10, 22].

Recurring theme: health literacy
Health literacy needs of the audience should be considered throughout. This specifically refers to actionability and understandability, but also considers people's health literacy needs across all principles, such as by using appropriate channels, building trust, and providing tailored guidance and support as a strategy to make sure the communication is understood and acted upon by the audience.

Both video and written materials were assessed for *actionability* and *understandability* using the '*Voorlichtingsmateriaal BeoordelingsInstrument*' (VBI) [Translated and cross-culturally adapted version of the English-language Patient Education Materials Assessment Tool (PEMAT)] [22, 28]. *Actionability* refers to the extent to which the audience would be able to identify a specific course of action. *Understandability* comprises difficulty of words and sentences, but also factors such as layout, clarity of what concept is discussed, distracting content, and use of illustrations. *VBI* is an easy-to-use freely available Dutch-language checklist in two versions: one for written materials and one for audio-visual materials, comprising 24 (17 for understandability and 7 for actionability) and 17 (13 for understandability and 4 for actionability) criteria, respectively. Two assessors (TL, IJ) separately judged for each applicable criterion whether or not it was met. Discrepancies were discussed and resolved. For each material, the proportion of (applicable) criteria met is given as a percentage for actionability and understandability separately. Hence, a higher percentage score indicates a more understandable or actionable information material. The number of applicable criteria may differ between materials and thus is not comparable across materials.
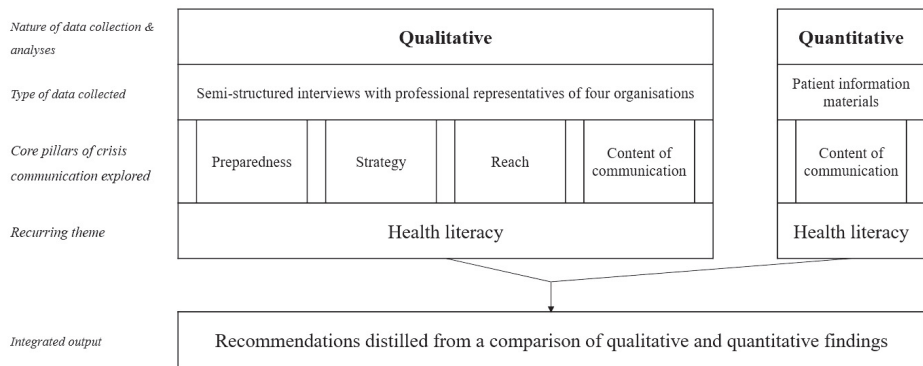

Figure 7.1 Example of textual assessment using the 'Klinkende Taal' [SonaLing] application. Note: Dutch-language text was used for analysis; the English translation is provided as a reference only and may not be equivalent in difficulty level.

Data integration

The convergent, qualitatively driven study design and methods used in relation to the pillars of the framework are displayed in Figure 7.2 [17, 18]. While the qualitative data describe the perspectives of professionals on the crisis communication efforts of their organisation in light of key principles, the quantitative data were used to assess the outputs of these efforts, specifically with regard to actionability, understandability, and language difficulty of the patient information materials delivered by the organisations ('content of communication pillar' and

recurring theme of health literacy). We merged our qualitative and quantitative datasets at the stage of data analysis [17], to enable mixed-methods analysis and comparison of the 'content of communication' pillar and the recurring theme of health literacy. The mixed-methods research question answered in this paper is: to what extent are the outcomes of the quantitative assessment of patient information materials in coherence with the perceptions of professionals working for the organisations who produced these materials? [17, 29] We used a contiguous 'integrating through narrative' approach, in which the qualitative findings are described first, followed by the quantitative findings [29]. Lessons learned, summarised in the discussion as recommendations, are distilled from a combination of both types of data.

Nature of data collection & analyses	Qualitative				Quantitative
Type of data collected	Semi-structured interviews with professional representatives of four organisations				Patient information materials
Core pillars of crisis communication explored	Preparedness	Strategy	Reach	Content of communication	Content of communication
Recurring theme	Health literacy				Health literacy
Integrated output	Recommendations distilled from a comparison of qualitative and quantitative findings				

Figure 7.2 Overview of study design and methods used in relation to the pillars of the crisis communication framework.

Ethics and quality considerations

No ethical approval was sought for this study given it involved interviews with professionals in the field and analyses of public information. Respondents provided informed consent before participation, and their anonymity was ensured. Researchers conducting the interviews (TL, IJ) and analyses (MB, TL, IJ) were not involved in the crisis communication, and worked independently from the respondents. The corresponding author (MB) was acquainted with five of the respondents prior to the study. Interviewees were asked to review the manuscript to check the interpretation of their statements, which did not result in significant changes.

RESULTS

All persons invited accepted the invitation to be interviewed. Interviews lasted between 30 minutes and 1 hour. Seven interviews were conducted, one with a spokesperson of patient communication from each of the three invited national organisations, two with rheumatologists responsible for clinical care and overall management of the department of rheumatology of the academic medical centre, and two with rheumatology nurses from the same department who were in direct contact with patients.

Preparedness

All respondents revealed their organisation had no pre-existing plans, *guidelines* or previous training on the concept of and skills required for crisis communication, and confirmed that this contributed to chaos in the early stages.

"There was absolutely no preparation on what to share with patients or not, what objective, credible information is. It was complete chaos, to be honest. (…). We did not have a crisis protocol available telling us what to do when there's an outbreak or something heavy happens. Nothing." (Respondent 1)

Respondents indicated that having a plan with clearly defined responsibilities assigned to specific individuals, and advice on what and how to communicate with patients at times of crisis would be of benefit. In addition, *crisis communication training* should be offered to those responsible for patient communication.

"Imagine a new crisis occurs, then you should have a protocol ready, to have your information provision run smoothly from the beginning. (…). You can never predict exactly what a crisis situation is going to be like, but with the experience of the COVID-19 pandemic, we can make a more general crisis protocol." (Respondent 5)

Strategy

All organisations immediately started screening the available information from scientific sources, as well as documenting incoming questions from patients and professionals, to provide patients with answers to frequently asked questions in a timely fashion.

"We established that information rather quickly, and those frequently asked questions were updated as time passed, for example when schools partially reopened we added some specific information." (Respondent 4, referring to mass communication)

Nevertheless, only one organisation provided information *early*, i.e. on the day of the first confirmed case in the Netherlands, while the other organisations took over a week for the first public announcements.

All organisations strived to update patients *frequently* regarding new developments. However, respondents from the hospital revealed that technical and time constraints at the organisational level hindered regular updating of disease-specific information on the website.

The organisations made efforts to ensure *consistency* of information across organisations. Although the association of rheumatology professionals answered questions from individuals that contacted them directly, they did not seek to inform patients themselves. Instead, they *collaborated* closely with one patient organisation and the hospitals by providing information that was agreed upon by a COVID-19 working group, which in turn ensured consistency with communications by the Dutch government and EULAR COVID-19 working group. Information was then disseminated to a wide patient audience by the patient organisation and healthcare providers. One patient organisation did not collaborate explicitly with other organisations, but contributed to consistency by adapting information from other Dutch and European resources for their audience. Respondents suggested coordination between partners could be improved by: 1) appointing a single point of contact in each organisation and governmental agencies (to be included in a crisis protocol), 2) sharing developed audio-visual materials between organisations, and 3) further increasing collaboration on a European level.

"We should have that. If something happens, which person is the one to talk to? Then you can immediately get together. Direct communication. We already had that, we already had direct communication with the professionals' association, but I still think it is good to appoint one person." (Respondent 6, referring to mass communication)

Several respondents emphasised that in mass communication, they remained *transparent* with their audience about scientific uncertainty and that scientific developments followed each other rapidly. In most cases, they explicitly referenced where information came from, and specified that information was based on the most recent insights, implying these might change over time. In clinical encounters at the hospital, however, information was sometimes personalised and presented in a more certain, directive manner, to avoid further confusion or unnecessary anxiety. This relied on the treating professional's judgement of whether the patient would benefit from strong recommendations as opposed to transparency and acknowledgement of uncertainty.

"I try to read my patients, and well, some people can or cannot handle uncertainty, they can or cannot assess the impact of uncertainty. Of course, I can misread my patients, but I do try to add nuance. And if I feel like this person is not going to understand, I did it [provide information] in a more direct way." (Respondent 7, referring to one-on-one communication)

Reach

Organisations used *multiple channels* to share information. Healthcare professionals provided information one-on-one during (usually remote) consultations, by telephone, or by email, and all organisations used their websites. However, interviewees mentioned this was not sufficient, as it relies on patients to actively search for the information. The patient organisations used digital newsletters to reach their members, and their social media pages (Twitter, Facebook, and Instagram) to reach a wider audience. One organisation hosted a video livestream combined with questions & answers (Q&A) with a physician.

7

Organisations indicated they likely benefitted from established *trust* of their audience. The national organisations often communicated directly with their formal members, and healthcare professionals acknowledged the importance of trust and the personal relationship with their patients to ensure adherence to health advice, despite *scientific uncertainty.*

"We explained time and time again that while the medication perhaps could negatively impact their risk, the risk of a flare of their rheumatic disease would be more dangerous, because you might need a lot more medication [immunosuppressive medication to control a flare]. And those are definitely bad for you." (Respondent 7, referring to one-on-one communication)

At the same time, respondents noted that they also communicated with patients that were new to them, because they were new to the clinic or normally under regular care of a colleague, making it more difficult to use a personalised *trust-based approach.*

"Most patients who contacted me knew me, and I knew them. That creates confidence. It is nice to be in contact with people you know, so you can give personalised advice. But there are also people who had recently been diagnosed who are not familiar with everything yet, these people are more difficult to reassure. That is much more difficult." (Respondent 5, referring to one-on-one communication)

Respondents indicated that the reach of information could have been better. For example, healthcare professionals wished *tailored* letters had been sent out to specific patient groups to increase reach, also allowing for more specification and nuance, for example about using specific medication. Other respondents wondered how to reach people who might not seek out information themselves.

"And yeah, then it is good to realise, like oh, if you want to reach two million people [= total potential audience of interest in the Netherlands], that you will have to use more social media. That you have a plan for that. A social media plan. A press list. That you can work through very different channels (…) outside the rheumatology channels. (…) I think such a list of networks and contacts, that you can use that to distribute information in such occasions. Actually, always, I have to say. Actually we could do a lot better in daily practice as well, when it comes to distribution of news." (Respondent 1, referring to mass communication)

Content of communication

The respondents agreed that they *prioritised* repeating the key messages of risk reduction (hygiene, physical distancing, and avoiding people with symptoms) and continuation of rheumatic medication. Furthermore, they tried to adapt information to the *needs of the audience*, taking into account both the patients' and professionals' perspectives on these needs. However, only limited initiative was undertaken to actively uncover information needs from a patient perspective. One organisation actively monitored social media to uncover *patient information needs*; other respondents stated they found out about patients' needs through their questions, which made adaptation primarily a reactive process. Moreover, there

was no system in place to find out if the population deemed the information provision to be adequate, with the exception of feedback during the Q&A session, which clearly filled a need.

"What really helped was the Q&A session with a rheumatologist. (…) All those questions about medication and corona were asked. And since that session, we typed out all frequently asked questions. Everything we encountered, all those questions, yeah, that really took the pressure off." (Respondent 6, referring to mass communication)

Especially in the earliest stages, respondents noticed that information materials were *difficult to understand*. Materials were heavily text-based, as visual materials took longer to develop.

"We worked on a (…), a general poster to share on social media. With icons for hand hygiene, sneeze in your elbow, continue using your medication. We worked on that, but by the time that was completely done, with the right pictures and everything, it was a month and a half later." (Respondent 1, referring to mass communication)

One organisation explicitly said they attempted to send out information at a B1 *difficulty* level only. Other respondents said that they tried to use simple language, but acknowledged it may have been too difficult for some patients.

"The emails, definitely, that was just plain text, (…) quite an extensive piece of plain text. I think it was communicated like that on the website too, which is indeed unfortunate." (Respondent 3, referring to mass communication)

Respondents suggested further identification of and adaptation to the needs of patients would be necessary in future crises, for example by considering patients with *multi-morbidity*. Collaboration with experts from other medical specialties is required to achieve this. Another specific suggestion was the issue of dealing with *fake news* about medication often used by patients with rheumatic diseases.

"When it came to ace-inhibitors, chloroquine, or anti-inflammatories, there was quite a bit of fake news about those at some point. And for some patient groups, specifically our patients, (…) we could have specifically targeted this group, actively informed them…" (Respondent 3, referring to mass communication)

Health literacy

All interviewees acknowledged that this crisis was particularly difficult for people with limited health literacy. There were substantial amounts of information to process and many of the guidelines were difficult to understand.

"We did not manage to do that [about adapting to health literacy needs]. We were happy to even be able to share information at all. (…) But the information is so incredibly complicated, no matter how hard you've worked on a clear message. You notice, especially when explaining medical information, that you lose people" (Respondent 1)

Furthermore, the majority of information was shared online, while patients with lower (e-) health literacy might struggle to use digital services. As there were no crisis communication

7

plans in place, health literacy needs were not explicitly taken into account from the onset. Notwithstanding, all four organisations had already initiated efforts to address health literacy needs before the pandemic, mainly with regard to understandability of materials, and continued these during the pandemic. On that line, respondents adopted a one-size-fits-all approach by aiming to use easier vocabulary in conversations with patients, writing patient information at B1-level, and experimenting with social media and interactive webinars. One patient organisation consulted patient language ambassadors and health equity experts to review their website and some information materials. Nevertheless, these intentions did not always result in accessible information for people with limited health literacy, due to *time-pressure*.

"I do think people with limited health literacy get the short end of the stick. (…). We were not able to, considering the pace at which information was delivered and the pace we had to make decisions and share information in our own words, I think it happened at the expense of readability." (Respondent 1, referring to mass communication)

Respondents at the hospital tried to adapt information to the health literacy needs of individual patients by speaking in clear language, keeping instructions as simple as possible and focusing only on the most important issues. Two respondents noted they strongly preferred telephone calls to emails, as it allowed them to check if their message had come across. A challenge, however, was to *judge* the patient's health literacy struggles.

"If you know your patients, it is easier than if you have a patient you do not know that well. That is a lot more difficult to estimate, like, have they really understood or are they just afraid to tell me that they have not understood." (Respondent 2, referring to one-on-one communication)

One respondent noted the importance of using as many channels as possible, to increase reach and allow people to ask questions in a way they prefer. Another respondent suggested that in the future, patients should be able to opt for instructions at their preferred difficulty level. Further collaboration between organisations as well as training or guidelines on how to reach people with health literacy needs were recommended. Importantly, one respondent reminded us always to include the *patient perspective*.

"So to always keep the critical view of the patient involved. Keep an eye on what's going on here, what's going on there? (…). And don't think that you already know! That happens a lot in healthcare, certainly also in rheumatology, where the specialists are real people's doctors, who might feel like they know what patients think. But it really is different if you're a patient yourself." (Respondent 6, referring to health literate communication)

Quantitative assessment of patient information materials

Thirteen texts and two videos (between two and five per organisation) were analysed (Table 7.1 and Supplementary material 7.2). Assessment of *difficulty* of texts revealed that only four out of thirteen texts (31%) shared with patients were written at the aspired B1-level, despite several respondents indicating they aim to write at this level. Admittedly, the professionals' association wrote their two texts primarily for a professional audience, but these texts were

also provided to patients. Most problematic across different texts was the use of difficult words and long sentences. The use of long paragraphs was only a problem in the materials of one organisation.

Assessment of *actionability* revealed that while some materials allowed the audience to clearly identify a specific course of action, others lacked a direct appeal for action or clear steps to take. Median actionability of the assessed materials was 80% (range 60% - 100%). Lower actionability was observed in more general materials about dealing with fake news, and the effects and availability of rheumatic medication, provided by a patient organisation.

Table 7.1 Summary of assessment of patient information materials per organisation

	VBI [PEMAT]		Klinkende Taal [SonaLing] Online application
	Actionability	Understandability	Difficulty level
Hospital (n=4)	80 − 100%	67 − 89%	B1 − C1
Patient organisation A (n=4)	100%	67 − 100%	B2*
Patient organisation B (n=5)	60 − 100%	58 − 87%	B1 − C1
Professionals' association (n=2)	80%	75 − 89%	B2

*Legend: Displayed results represent the range of scores (difficulty levels or percentages, depending on the tool applied) for all materials per organisation. Percentages indicate the proportion of applicable quality criteria for actionability and understandability that were met. The number of applicable criteria may differ between materials. VBI = Voorlichtingsmateriaal BeoordelingsInstrument [Patient Education Materials Assessment Tool (PEMAT)]. Further details in Supplementary material 7.2. * only written information materials (n=2)*

The texts with lowest *understandability* were those that also scored poorly in terms of language difficulty. Least understandable were the text provided to patients by email and on the website of the hospital, and the texts about fake news and medication. Median understandability of texts was 83% (range 58% - 100%). Both videos scored 67%. While many materials were highly understandable (8 materials scored between 80-100%), almost all left room for improvement. In addition to using easier language, texts would benefit from a better use of images, visual cues such as bullet points or bold text to highlight importance, and removal of distracting information. Both videos lacked a clear thematic structure and a summary.

The quantitative analyses supported the respondents' qualitative reflections that efforts to provide understandable information were made. At the same time, these analyses also confirmed the limitations in communication acknowledged by the respondents in the qualitative interviews.

7

DISCUSSION

This study explored key aspects of crisis communication and the explicit consideration of people's health literacy needs in communication to people with RMDs during the first wave of COVID-19 in the Netherlands. Furthermore, it explored whether professionals' perceptions of the quality of patient information materials were in coherence with quantitative assessment. In summary, the patient organisations, the professionals' association and the academic hospital reported explicit efforts to provide people with RMDs with relevant, timely and accurate information through multiple channels. While these efforts generally aligned with principles of good crisis communication, the respondents acknowledged several limitations such as a lack of preparedness, lack of reach to specific groups, lack of insight into patients' needs, and high difficulty and low understandability of patient information materials. The quantitative assessment confirmed that the majority of texts were too difficult to understand, and often lacked actionability. Therefore, we propose we propose several recommendations for future crises, especially in informing patients with diverse health literacy needs (Box 7.2). We deem these lessons learned transferable across countries and medical specialities.

We argue for the consideration of broader aspects of health literacy needs in a crisis communication approach, beyond readability of information only. While we asked respondents whether the health literacy of patients was explicitly considered, implying a broad definition, most reflections focused specifically on difficulty and understandability of information. However, simplifying texts to a B1-level is insufficient for a proportion of the population with a lower reading level (people with low literacy or illiteracy, estimated at 14%) [24, 25, 27]. Moreover, health literacy needs manifest in diverse ways in practice, with patients exhibiting different strengths and weaknesses across domains of health literacy, thus understanding information might not be the main problem [16]. None of the organisations reported having accounted for this diversity in health literacy needs by considering tailored guidance and support. This is unfortunate because besides a general risk of patients being underinformed and underprepared [11-13], recent research further emphasises the importance of considering health literacy needs in crisis communication. While several studies reported that people with lower health status [4] and people with rheumatic diseases [30] were aware of their vulnerability and therefore took precautions [30], this may not have been true for people with limited health literacy within those groups, who were found to perceive themselves less susceptible to COVID-19 infection [31, 32], and were possibly less likely to take preventive measures [33]. A Dutch qualitative study on the COVID-19-related challenges of people with a chronic illness and limited health literacy highlighted the important role of one-on-one communication by trusted healthcare professionals, especially in providing information tailored to the health literacy needs and clinical profile of the individual [34]. Knowing that COVID-19 has exacerbated health inequalities [35-37], and health literacy plays a role in vaccine hesitancy [38, 39], the need to consider health literacy in crisis communication is imperative.

Box 7.2 Recommendations for improvement of crisis communication. In brackets, it is indicated what source data the recommendation was based on *(qualitative or mixed-methods)*.

Preparedness *(qualitative)*

Use the experience of this pandemic to establish a future crisis communication plan, by reviewing and amending the ad hoc protocols that were established.

Train staff and management in crisis communication and health literate communication.

Strategy *(qualitative)*

Build sustainable relationships with relevant organisations to ensure consistency in messages.

Inform people early and frequently, preferably in a way tailored to clinical profiles.

Remain transparent about uncertainty.

Reach *(qualitative)*

Use multiple channels to communicate your messages, including those that do not rely on the patient's initiative (active outreach).

Use different outreach strategies to cater to a diverse audience, also beyond the clinic's regular patients and the associations' own members.

Content of communication *(qualitative + quantitative)*

Adapt information to different people's needs, considering e.g. age, cultural background. Actively discover these needs from the patient perspective. *(qualitative)*

Ask your audience for suggestions and feedback and use it to revise your strategy and provided information. *(qualitative)*

Combat fake news through acknowledgement and counterarguments. *(qualitative)*

Check difficulty level of written information (aim at A2/B1) and adapt accordingly. *(quantitative + qualitative)*

Make sure information is directly applicable in practice. *(quantitative + qualitative)*

Health literacy *(quantitative + qualitative)*

Explicitly consider people's health literacy needs throughout and provide tailored guidance and support, beyond merely simplifying written health information.

Admittedly, the principles of crisis communication as suggested by the WHO and CDC [9, 10] implicitly overlap with principles of health literate communication. Communication with the public should in both cases be timely, simple, coherent and consistent, and provided messages should be understandable, actionable and adjusted to the audience's needs, which implies consideration of health literacy diversity. Nevertheless, this study shows that consideration of the specific needs of people with limited health literacy was delayed and limited to a basic

definition, rather than explicitly and consistently taken into account from the start. Knottnerus, Heijmans and Rademakers [34] showed that this was not unique to the rheumatology context, but extends across people with chronic diseases in the Netherlands. While the intersection between crisis communication and health literacy should be further explored, investing in training and guidelines for health literate communication for organisations and health professionals will potentially be useful in general patient communication as well as in times of crisis.

This paper contributes to the fast-increasing body of scientific literature about the role of health literacy in COVID-19 communication. Levin-Zamir et al. [40] described multiple case studies showing the need to focus on health literacy at multiple levels of the social-ecological model (individual, interpersonal, organisational, community, and policy level) in order to be more prepared for future crises, and prevent problems such as care avoidance, mental health issues, or lack of adherence to public health guidelines. Ratzan, Sommariva and Rauh [41] offer lessons learned in global health communication early in the pandemic, summarised as 'be proactive', 'plan ahead' and 'focus on people'. In the age of social media, this means considering not only people's health literacy needs, but also their media literacy needs to help people appraise content and consequently make sound health decisions [41]. Along this line, Hamaguchi, Nematollahi and Minter [42] argue for the use of visual aids to leverage the power of social media and reach a wide audience with simple, accessible health information. The recommendations proposed in the present paper reinforce those made by these scholars.

The findings in this study should be seen in light of a few limitations. First, this study explores the application of key principles of crisis communication and health literacy based on the views of a limited number of respondents, and does not provide a comprehensive assessment of the national information provision in rheumatology. Moreover, the focus of our study was the Dutch context, and we only assessed Dutch-language materials. Our findings may therefore not be directly transferable to non-Dutch speakers in the Netherlands. Nevertheless, we sampled diverse actors of importance in the Dutch context to get a broad idea of the quality of the initial response to the COVID-19 pandemic while minimising the burden for respondents and organisations, and have uncovered general lessons learned to inform future improvements. Because these lessons are generally not context-specific, they may also be of inspiration to other countries and medical specialties to critically reflect on their crisis communication. Second, we cannot be sure of the full reach and impact of the strategies employed by the organisations, because we did not interview patients. We decided against patient interviews for feasibility and desirability reasons, to not further burden patients at a very high-stress period in time. Reflections of difficulty are therefore based on the expert respondents' observations, supported by quantitative evidence. Future research should nevertheless focus on the patient perspective to complement our findings and recommendations, as was also recommended by a respondent. As a promising starter, while there was no mention of the reach and impact of communication, Décary et al. [43] draw attention to the patients' perspective throughout and beyond the pandemic, particularly

in considering the most vulnerable patients in the implementation of new care models, and investigation into the uncertainties that people with RMDs face in different aspects of their lives. In addition, the REUMAVID study, a cross-sectional online survey conducted among patients with RMDs in several European countries (not including the Netherlands), showed that 45.6% of surveyed patients had not received rheumatology-specific information at all [44]. Patient associations were reported as the most frequent source of information [44]. While this study did not assess actionability, understandability and difficulty of information and communication from the patient perspective, the results are indeed indicative of overall room for improvement in crisis communication.

CONCLUSIONS

In conclusion, despite being underprepared for a crisis communication campaign, the patient organisations, professionals' association and an academic hospital demonstrated aspects of good crisis communication with some consideration of health literacy. Analyses of their experience resulted in several lessons learned for future crises, to improve crisis communication in general, but particularly to consider patients' health literacy needs.

7

DECLARATIONS

Ethics

This study complies with the Declaration of Helsinki. Ethics approval was deemed unnecessary in accordance with Dutch regulations. The relevant Dutch law (Medical Research Involving Human Subjects Act (in Dutch: Wet medisch-wetenschappelijk onderzoek met mensen (WMO)) requires only certain research to be reviewed. Research is subject to the WMO if it concerns 1) medical scientific research, and 2) participants are subject to procedures or are required to follow rules of behaviour (Article 1.1b. Available from: https://wetten.overheid.nl/BWBR0009408/2022-01-31 (in Dutch)). This is explained by the Central Committee on Research Involving Human Subjects (the Committee created in Dutch law to administer the operation of this law) - the 'CCMO' - on its website: https://english.ccmo.nl/investigators/legal-framework-for-medical-scientific-research/your-research-is-it-subject-to-the-wmo-or-not (in English). Expert interviews and analyses of public information (as those undertaken in this study) are not within the meaning of medical scientific research, nor do they place the participants under a particular process or behaviour change. Therefore, the research undertaken here is not required to be reviewed under Dutch law. Respondents provided informed consent before participation, and their anonymity was ensured. The personal data collected through the study was and is subject to the personal data management requirements of the University.

Acknowledgements

REFERENCES

1.   Leão T, Amorim M, Fraga S, Barros H. What doubts, concerns and fears about COVID-19 emerged during the first wave of the pandemic? *Patient Educ Couns*. 2021;104(2):235-41. doi:10.1016/j.pec.2020.11.002

2.   Ozamiz-Etxebarria N, Dosil-Santamaria M, Picaza-Gorrochategui M, Idoiaga-Mondragon N. Stress, anxiety, and depression levels in the initial stage of the COVID-19 outbreak in a population sample in the northern Spain. *Cad Saude Publica*. 2020;36(4):e00054020. doi:10.1590/0102-311X00054020.

3.   Özdin S, Bayrak Özdin Ş. Levels and predictors of anxiety, depression and health anxiety during COVID-19 pandemic in Turkish society: The importance of gender. *Int J Soc Psychiatry*. 2020;66(5):504-11. doi:10.1177/0020764020927051.

4.   Lee M, You M. Psychological and Behavioral Responses in South Korea During the Early Stages of Coronavirus Disease 2019 (COVID-19). *Int J Environ Res Public Health*. 2020;17(9). doi:10.3390/ijerph17092977

5.   Philip KEJ, Lonergan B, Cumella A, Farrington-Douglas J, Laffan M, Hopkinson NS. COVID-19 related concerns of people with long-term respiratory conditions: a qualitative study. *BMC Pulm Med*. 2020;20(1):319. doi:10.1186/s12890-020-01363-9.

6.   Hennessy MA, Linehan A, Cowzer D, Coyne ZL, Fitzpatrick O, Barrett F, et al. Chemotherapy in the Covid-19 era: the patient's perception. *Ir J Med Sci*. 2021:1-6. doi:10.1007/s11845-020-02457-3

7.   Michaud K, Wipfler K, Shaw Y, Simon TA, Cornish A, England BR, et al. Experiences of Patients With Rheumatic Diseases in the United States During Early Days of the COVID-19 Pandemic. *ACR Open Rheumatol*. 2020;2(6):335-43. doi:10.1002/acr2.11148.

8.   Duculan R, Jannat-Khah D, Mehta B, Mandl LA, Barbhaiya M, Bass AR, et al. Variables Associated With Perceived Risk of Contracting SARS-CoV-2 Infection During the COVID-19 Pandemic Among Patients With Systemic Rheumatic Diseases. *J Clin Rheumatol*. 2021;27(3):120-6. doi:10.1097/RHU.0000000000001686.

9.   World Health Organization. *WHO outbreak communication guidelines*. Geneva, Switzerland; 2005.

10.   Centers for Disease Control and Prevention. *Crisis and Emergency Risk Communication: 2014 Edition*. Atlanta, GA, USA; 2014.

11.   Abel T, McQueen D. Critical health literacy and the COVID-19 crisis. *Health Promot Int*. 2020;35(6):1612-3.

12.   Paakkari L, Okan O. COVID-19: health literacy is an underestimated problem. *Lancet Public health*. 2020;5(5):e249-e50. doi:10.1016/s2468-2667(20)30086-4.

13.   Okan O, Bollweg TM, Berens EM, Hurrelmann K, Bauer U, Schaeffer D. Coronavirus-Related Health Literacy: A Cross-Sectional Study in Adults during the COVID-19 Infodemic in Germany. *Int J Environ Res Public Health*. 2020;17(15). doi:10.3390/ijerph17155503.

7

14. 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. doi:10.1177/1757975918814421.

15. Heijmans M, Brabers A, Rademakers J. *Hoe gezondheidsvaardig is Nederland? Factsheet Gezondheidsvaardigheden – Cijfers 2019.* Utrecht, The Netherlands: Nivel; 2019. Available from: https://nivel.nl/sites/default/files/bestanden/1003631.pdf

16. Bakker MM, Putrik P, Rademakers J, van de Laar M, Vonkeman H, Kok MR, et al. Addressing health literacy needs in rheumatology: Which patient health literacy profiles need the attention of health professionals? *Arthritis Care Res*. 2021;73(1):100-9. doi:10.1002/acr.24480.

17. Creswell JW. *A concise introduction to mixed methods research.* Thousand Oaks, CA, USA: SAGE publications; 2014.

18. Moseholm E, Fetters MD. Conceptual models to guide integration during analysis in convergent mixed methods studies. *Methodological Innovations*. 2017;10(2). doi:10.1177/2059799117703118.

19. Kahlke RM. Generic Qualitative Approaches: Pitfalls and Benefits of Methodological Mixology. Int J Qual Methods. 2014;13(1):37-52. doi:10.1177/160940691401300119.

20. Boeije H. *Analysis in Qualitative Research*. Los Angeles, CA, USA: SAGE Publications; 2010.

21. Grbich C. *Qualitative research in health: an introduction.* London, UK: Sage Publications; 1998.

22. van Bommel H, van Leeuwen M. *Voorlichtingsmateriaal BeoordelingsInstrument (VBI).* Utrecht, The Netherlands: Pharos; 2018.

23. Gridline, Loo van Eck. *Klinkende Taal - schrijf heldere teksten.* Available from: https://klinkendetaal.nl/.

24. Stichting Lezen en Schrijven. *Feiten & Cijfers Laaggeletterdheid. De invloed van lage basisvaardigheden op deelname aan de maatschappij*. The Hague, The Netherlands: Stichting Lezen en Schrijven; 2018.

25. Algemene Rekenkamer. Aanpak van laaggeletterdheid. The Hague, The Netherlands: Algemene Rekenkamer; 2016.

26. Pharos. Factsheet Laaggeletterdheid en beperkte gezondheidsvaardigheden. Utrecht, The Netherlands: Pharos; 2020. Available from: https://www.pharos.nl/factsheets/laaggeletterdheid-en-beperkte-gezondheidsvaardigheden/

27. Statistics Netherlands. *Bevolking op 1 januari en gemiddeld; geslacht, leeftijd en regio* [Database]. Den Haag/Heerlen, The Netherlands: CBS; 2021. Available from: https://opendata.cbs.nl/statline/#/CBS/nl/dataset/03759ned/table?fromstatweb

28. Shoemaker SJ, Wolf MS, Brach C. Development of the Patient Education Materials Assessment Tool (PEMAT): A new measure of understandability and actionability for print and audiovisual patient information. *Patient Educ Couns.* 2014;96(3):395-403. doi:10.1016/j.pec.2014.05.027.

29. Fetters MD, Curry LA, Creswell JW. Achieving Integration in Mixed Methods Designs—Principles and Practices. *Health Serv Res*. 2013;48(6pt2):2134-56. doi:10.1111/1475-6773.12117.

30. Hooijberg F, Boekel L, Vogelzang EH, Leeuw M, Boers M, van Vollenhoven R, et al. Patients with rheumatic diseases adhere to COVID-19 isolation measures more strictly than the general population. *Lancet Rheumatol.* 2020;2(10):e583-e5. doi:10.1016/S2665-9913(20)30286-1.

31. Bailey SC, Serper M, Opsasnick L, Persell SD, O'Conor R, Curtis LM, et al. Changes in COVID-19 Knowledge, Beliefs, Behaviors, and Preparedness Among High-Risk Adults from the Onset to the Acceleration Phase of the US Outbreak. *J Gen Intern Med.* 2020;35(11):3285-92. doi:10.1007/s11606-020-05980-2

32. Wolf MS, Serper M, Opsasnick L, O'Conor RM, Curtis L, Benavente JY, et al. Awareness, Attitudes, and Actions Related to COVID-19 Among Adults With Chronic Conditions at the Onset of the U.S. Outbreak: A Cross-sectional Survey. *Ann Intern Med.* 2020;173(2):100-9. doi:10.7326/M20-1239.

33. Itaya T, Torii M, Hashimoto M, Jindai K, Yamamoto W, Tanigawa K, et al. Perceptions and behaviours related to COVID-19 in patients with rheumatoid arthritis: a cross-sectional study. *Clin Rheumatol.* 2021:1-7. doi:10.1007/s10067-021-05840-2.

34. Knottnerus B, Heijmans M, Rademakers J. The role of primary care in informing and supporting people with limited health literacy in the Netherlands during the COVID-19 pandemic: a qualitative interview study. *BMC Prim. Care.* 2022;23(115). doi:10.1186/s12875-022-01723-w

35. Dorn AV, Cooney RE, Sabin ML. COVID-19 exacerbating inequalities in the US. *Lancet.* 2020;395(10232):1243-4. doi:10.1016/S0140-6736(20)30893-X.

36. Burström B, Tao W. Social determinants of health and inequalities in COVID-19. *Eur J Public Health.* 2020;30(4):617-8. doi:10.1093/eurpub/ckaa095.

37. Bambra C, Riordan R, Ford J, Matthews F. The COVID-19 pandemic and health inequalities. *J Epidemiol Community Health.* 2020;74(11):964-8. doi:10.1136/jech-2020-214401.

38. Montagni I, Ouazzani-Touhami K, Mebarki A, Texier N, Schück S, Tzourio C. Acceptance of a Covid-19 vaccine is associated with ability to detect fake news and health literacy. *J Public Health (Oxf).* 2021. doi:10.1093/pubmed/fdab028.

39. Lorini C, Santomauro F, Donzellini M, Capecchi L, Bechini A, Boccalini S, et al. Health literacy and vaccination: A systematic review. *Hum Vaccin Immunother.* 2018;14(2):478-88. doi:10.1080/21645515.2017.1392423.

40. Levin-Zamir D, Sorensen K, Su TT, Sentell T, Rowlands G, Messer M, et al. Health promotion preparedness for health crises - a 'must' or 'nice to have'? Case studies and global lessons learned from the COVID-19 Pandemic. *Glob Health Promot.* 2021;28(2):27-37. doi:10.1177/1757975921998639.

41. Ratzan SC, Sommariva S, Rauh L. Enhancing global health communication during a crisis: lessons from the COVID-19 pandemic. *Public Health Res Pract.* 2020;30(2):3022010. doi:10.17061/phrp3022010.

42. Hamaguchi R, Nematollahi S, Minter DJ. Picture of a pandemic: visual aids in the COVID-19 crisis. *J Public Health (Oxf).* 2020;42(3):483-5. doi:10.1093/pubmed/fdaa080.

43. Décary S, Barton JL, Proulx L, Richards DP, Paterson G, de Wit M, et al. How to Effectively Support Patients with Rheumatic Conditions Now and Beyond COVID-19. *ACR Open Rheumatol.* 2020;2(9):505-6. doi: 10.1002/acr2.11152.

44. Garrido-Cumbrera M, Marzo-Ortega H, Christen L, Plazuelo-Ramos P, Webb D, Jacklin C, et al. Assessment of impact of the COVID-19 pandemic from the perspective of patients with rheumatic and musculoskeletal diseases in Europe: results from the REUMAVID study (phase 1). *RMD Open.* 2021;7(1):e001546. doi:10.1136/rmdopen-2020-001546

7

SUPPLEMENTARY MATERIALS

Supplementary material 7.1 English translation of interview guide

1) **How were you prepared for providing information about COVID-19?**
a. Were there any guidelines for crisis communication which you could rely on?
b. Did you previously receive any training about crisis communication?
c. Where did you find the information that would be shared with patients?
→ Overall, did you feel well prepared to provide information about the Corona crisis? Can you imagine any improvements?

2) **How was the provision of information about COVID-19 to patients organised in your division or organisation?**
a. Were there any differences in how information was provided during the crisis compared to the normal communication of your organisation?
b. How were the tasks divided? Was there anyone specifically responsible for updating patients?
c. Was there any guarantee that all patients were reached with the information? / was there a strategy to reach as many patients as possible?
d. When did you start sharing information, how frequently and how was this determined?
e. Was there any communication with other organisations (such as ReumaNederland, NVR, MUMC+, hospitals, ReumaZorgNederland)?
i. How did you try to ensure information from these different organisations was consistent?
→ Overall, how would you evaluate the organisation of the information provision? Can you imagine any improvements?

3) **What was the content of the information which was provided to patients?**
a. What was the most important information to share with patients for you?
i. Were there any specific instructions you provided to patients?
ii. Were there any suggestions for patients to improve their own situation?
b. How did you deal with the uncertainty surrounding the information about COVID-19?
i. Did you provide any information about the source of information or any decisions made?
ii. Why did you or did you not choose to share information that was still uncertain?
c. What platforms did you use and what types of information did you provide?
i. Did you take the difficulty of language into account when providing this information? Did you use any explanatory images?
→ How would you evaluate the information provision and guidance for patients who might struggle to understand healthcare information? Can you imagine any improvements?

4) **How did you experience the contact with patients?**
a. To what extent did you know the patients you contacted?
b. Did you receive any questions from patients and were you prepared to answer them?
c. Did you use any specific strategies to help patients understand the information?
d. Was there a way for patients to provide any feedback on past information or on information they would like to receive?
→ Were there any difficulties in the contact with patients? Can you imagine any improvements?

5) **Closing questions:**
a. If there would be some other crisis where crucial information should be shared with patients, what would you like to see different from how you currently shared information and what you like to keep the same?
b. According to you, what could this crisis teach us about information provision to all patients?
c. Are there any other aspects you would like to discuss?

7

Supplementary material 7.2 Details of patient information materials assessment

| | VBI [PEMAT] | | Klinkende Taal [SonaLing] online application | | | | | |
	Actionability	Understandability	Difficult words	Passive sentences	Difficult sentences	Long sentences	Long paragraphs	Measured level
Hospital	80 – 100%	67 – 89%	2 – 17%	0 – 14%	0 – 11%	0 – 26%	0%	B1 – C1
Text 1	100% (2 n/a)	89% (8 n/a)	2.3%	0%	4.3%	21.7%	0%	B1
Text 2	100% (2 n/a)	83% (5 n/a)	7.5%	0%	0%	0%	0%	B1
Text 3	80% (2 n/a)	67% (5 n/a)	16.7%	14.3%	7.1%	21.4%	0%	B2
Text 4	80% (2 n/a)	67% (8 n/a)	10.5%	10.5%	10.5%	26.3%	0%	C1
Patient Organisation A	100%	67 – 100%	5%	7 – 12%	4 – 6%	20 – 23%	0%	B2
Text 1	100% (1 n/a)	92% (5 n/a)	4.5%	7.4%	5.8%	19.6%	0%	B2
Text 2	100% (2 n/a)	100% (8 n/a)	4.9%	11.5%	3.8%	23.1%	0%	B2
Webinar 1	100% (1 n/a)	67% (4 n/a)	-	-	-	-	-	-
Webinar 2	100% (1 n/a)	67% (4 n/a)	-	-	-	-	-	-
Patient Organisation B	60 – 100%	58 – 87%	7 – 12%	2 – 30%	2 – 20%	9 – 42%	0 – 33%	B1 – C1
Text 1	80% (2 n/a)	80% (2 n/a)	6.8%	7.4%	1.8%	9.3%	0%	B1
Text 2	80% (2 n/a)	87% (2 n/a)	7.7%	1.6%	1.6%	14.3%	33.3%	B1
Text 3	60% (2 n/a)	60% (2 n/a)	11.5%	29.6%	18.5%	33.3%	14.3%	C1
Text 4	100% (2 n/a)	83% (5 n/a)	9.4%	11.5%	11.5%	34.6%	0%	B2
Text 5	60% (2 n/a)	58% (5 n/a)	8.8%	9.7%	19.3%	41.9%	14.3%	C1

Supplementary material 7.2 (Continued)

	VBI [PEMAT]		Klinkende Taal [SonaLing] online application					
	Actionability	Understand-ability	Difficult words	Passive sentences	Difficult sentences	Long sentences	Long paragraphs	Measured level
Professionals' association	80%	75 – 89%	7 – 8%	0 – 2%	4 – 9%	8 – 37%	0%	B2
Text 1	80% (2 n/a)	89% (8 n/a)	7.6%	0%	3.8%	7.7%	0%	B2
Text 2	80% (2 n/a)	75% (5 n/a)	6.8%	2.3%	9.3%	37.2%	0%	B2

Legend: Displayed results represent the range of scores (difficulty levels or percentages, depending on the tool applied) of patient information materials assessed per organisation, and specified per material. Percentages for VBI assessment represent the proportion of applicable actionability / understandability criteria met. n/a represents the number of statements which were not applicable to the material. Percentages for the Klinkende Taal online application indicate the proportion of words, sentences or paragraphs deemed more difficult than at B1-level. VBI = Voorlichtingsmateriaal BeoordelingsInstrument [Patient Education Materials Assessment Tool (PEMAT)].

CHAPTER 8

Summary and General Discussion

With this thesis, I contributed to the development of rheumatology care towards health literacy responsive clinics. In light of the clinical nature of this thesis, I used the definition as posed by the International Union for Health Promotion and Education (IUHPE): *"Health literacy is the combination of personal competencies and situational resources needed for people to access, understand, appraise and use information and services to make decisions about health. It includes the capacity to communicate, assert and act upon these decisions. Health literacy responsiveness describes the way in which services, organisations and systems make health information and resources available and accessible to people according to health literacy strengths and limitations"* [1]. This is highly relevant in the context of rheumatic and musculoskeletal diseases (RMDs), because these usually require long-term engagement with healthcare services. Furthermore, patients are increasingly expected to participate actively in the decision-making and treatment process, and to self-manage their condition and general health in a true balancing act with their other daily life responsibilities [2]. Having adequate health literacy, or having access to healthcare services that are delivered in a way that is appropriate for one's health literacy, is therefore a crucial element in achieving good health outcomes. There is a social gradient in health literacy; people in disadvantaged socio-economic positions are more likely to experience health literacy limitations, although a high socio-economic position is not equivalent to high health literacy and vice versa [3, 4]. Because of this social gradient on the one hand and the relationship between health literacy and health outcomes on the other, addressing patients' health literacy needs could potentially help reduce health inequalities and maximise health potential. The work in this thesis helps us to better understand the role of health literacy in patients with RMDs, and shows what could be done in rheumatology care to better address the needs of our patient population. The work was inspired by the OPtimising HEalth LIteracy and Access (Ophelia) approach, a guidebook for researchers and clinicians to improve health outcomes through health literacy development [5-7]. This final chapter presents a summary of the main findings, showing how the previous chapters contribute to improved health literacy responsiveness of rheumatology care, followed by a general discussion of the lessons learned throughout this thesis. These include suggestions for future research and practice, contextualised by literature from the field.

8

SUMMARY OF THE MAIN FINDINGS

Chapter 1 constitutes an extensive introduction to the relationship between health literacy, health inequities and health potential, definitions and conceptual models of health literacy, health literacy measurement, the known impact of health literacy on outcomes (in general and within the field of RMDs), ways to address health literacy needs, and an organisational perspective on health literacy. These concepts are considered integral background information to the work presented in the subsequent chapters. They show how health literacy is ultimately an issue of health equity, and how addressing health literacy needs is necessary, and may help reduce the socio-economic health gap by maximising health potential. In the introduction, I also articulated the three main aims that guided this work. First, to identify health literacy needs of patients with RMDs. Second, to co-design solutions to better align rheumatology care with the health literacy needs of patients. Third, to explore current awareness of health literacy needs in rheumatology care from an organisational perspective. The subsequent chapters included in this thesis all correspond to one of the three research aims, and together contribute to advancing research and practice of health literacy within the field of rheumatology. The thesis is structured in three parts, each one primarily corresponding to one of the thesis aims.

Part I: Identifying health literacy needs

The first part of this thesis concerns the identification of health literacy needs of patients with RMDs. In **Chapter 2**, we studied patterns of health literacy strengths and weaknesses in a population of patients with RMDs. In this quantitative observational cross-sectional study, patients with rheumatoid arthritis (RA), spondyloarthritis (SpA), or gout filled out the Health Literacy Questionnaire (HLQ). Between the three participating geographically and socio-demographically diverse rheumatology clinics (South: Maastricht University Medical Center in Maastricht, West: Maasstad Hospital in Rotterdam, and East: Medisch Spectrum Twente in Enschede), 895 patients participated. HLQ scores in each of the nine domains were largely independent of hospital or type of rheumatic disease, although patients in one of the centres tended to score slightly better for domains 4 (social support), 6 (engaging with providers), 7 (navigating the health care system), and 9 (understanding health information), and patients with gout tended to score worse for domains 1 (feeling supported by providers), 3 (actively managing health), 8 (finding health information), and 9 (understanding health information).

Next, we used hierarchical clustering analysis to identify 'health literacy profiles' based on strengths and weaknesses, as reflected by higher and lower scores across the nine domains of the HLQ. We described 10 distinct 'health literacy profiles'. Two of those profiles represented 42% of patients who experienced little to no difficulty on all nine HLQ domains (profiles 1 and 3, high to very high scores on all domains). Another 42% of patients clearly struggled with 1 or several aspects of health literacy (profiles 2, 4, 5 and 6). The remaining profiles, representing

16% of our sample exhibited difficulties across a majority of health literacy domains (profiles 7-10). We described the strengths and weaknesses of the different 'health literacy profiles', by combining HLQ scores with sociodemographic data of the participants. Of note, patients with 'health literacy profiles' representing more health literacy difficulties self-reported worse health status than patients with higher health literacy scores. This showed the relevance of health literacy profiles in relation to health outcomes. Moreover, people with lower education and people with a migrant background are overrepresented in the more complex profiles, which relates to the social gradient that exists in the relationship between health literacy and health outcomes.

Using a multinomial regression model with health literacy profiles as the dependent variable, we assessed whether the 'health literacy profiles' were dependent on the clinic the patient attended, or the disease the patient had been diagnosed with. While some profiles occurred more often in one of the hospitals or one of the disease groups, we found that these differences were not statistically significant. Thus, the general lessons are potentially generalisable to a broader Dutch rheumatology context.

Chapter 3 constitutes a follow-up study of patients with RA who participated in the study described in Chapter 2 in one centre (East: Medisch Spectrum Twente). In a retrospective quantitative observational longitudinal design, we explored the association between the previously identified 'health literacy profiles' and disease activity and medication prescription, by extracting these data from the electronic patient files. Of the 122 patients with RA at this centre included in the original study, data on disease activity and medication prescription (biological disease-modifying anti-rheumatic drugs (bDMARDs), conventional DMARDs (csDMARDs) and prednisolone) was available for 108 of them. To enable between-groups comparisons, we further aggregated the 'health literacy profiles' into three groups, based on similarities between profile characteristics. In a slight diversion from the description in Chapter 2, the three groups were separated and labelled as follows: 1) 'several health literacy limitations' (profiles 6-10); 2) 'some health literacy limitations' (profiles 2, 4 and 5); and 3) 'good health literacy' (profiles 1 and 3).

We used linear mixed modelling with routinely collected 28-joint disease activity scores-erythrocyte sedimentation rate (DAS28-ESR) scores as the dependent variable to assess the relationship between health literacy group and disease activity over the course of 1 year, and Chi-square tests and logistic regression models to assess the relationship between health literacy group and medication prescription. We found that patients in the 'good health literacy' group had significantly (p=0.01) lower disease activity over time (mean DAS28-ESR: 2.4) than patients in the 'several health literacy limitations' group (mean DAS28-ESR: 3.1). This association was independent of education level. In addition, we found that fifty percent of the 'good health literacy' group was prescribed a bDMARD, compared to 18.2% and 38.1% in the 'some health literacy limitations' (adjusted OR 0.22 [0.08-0.65] and 'several health literacy limitations' (adjusted OR 0.81 [0.27-3.27], not significant) groups, respectively. Patients with

8

'some health literacy limitations' were more often prescribed a csDMARD only (OR 4.24 [1.57-11.51]) than patients with 'good health literacy', and patients in the 'several health literacy limitations' group were prescribed prednisolone significantly more often (52.4%, OR 3.56 [1.13-11.15] compared with 'good health literacy') than patients in the 'some health literacy limitations' (21.2%) and 'good health literacy' groups (22.2%). This difference suggests that the disease is insufficiently under control in these patients, which led to prednisolone initially being prescribed as a practical (short-term) solution, but continued as a long-term maintenance dose.

The study described in this chapter further confirmed the relevance of health literacy in clinical care. The results suggested that health literacy is an independent determinant of disease outcomes, meaning that education level is not an adequate proxy to understand health literacy needs. This study showed that the health literacy needs of patients are related to their disease activity, as well as the type of medication prescribed and used, independent of the education level of the patient. While we are not claiming to have established a causal link between health literacy and these health indicators, we do believe this study suggests that better recognition of and attention for patients' health literacy needs by health professionals is imperative to optimise disease management and patient understanding.

Part II: Opportunities for improvement

While quantitative data can help us define the magnitude of an issue, in the case of health literacy, we need qualitative data to understand the dynamics of the issue in the local context, to ensure the fit of interventions and solutions when moving from clinical studies to clinical care. Therefore, whereas Chapters 2 and 3 related to identifying health literacy needs from a quantitative perspective, Part II of this thesis provides further qualitative depth to these needs, while also discussing ways to address these needs. In **Chapter 4**, we describe further steps taken in the process towards health literacy responsive care, making recommendations for further research on and potential implementation of health literacy responsiveness in rheumatology care. Building upon the health literacy profiles described in Chapter 2, and using previously written field notes and additionally conducted semi-structured interviews, we developed six 'health literacy vignettes'; anonymised but recognisable patient stories reflecting their health literacy-related challenges. These vignettes were used as input for co-design consultations (focus groups and individual interviews) with patients (n=14) and health professionals (n=38). These consultations revolved around four questions: 1) Do you recognise this patient? 2) What are the challenges for this patient, or what challenges do you face in caring for this patient? 3) How could we better support this patient? 4) What should our clinic look like if there were 100 patients like this patient? Qualitative analysis was used to structure the outputs of the consultations, to describe challenges and potential solutions to these challenges in the shape of 'health literacy actions' (i.e. small changes on any level

in the process of healthcare delivery, or integration of existing tools or strategies into daily practices of healthcare organisations and professionals)

We identified eleven health literacy-related challenges that patients with RMDs face. Health professionals and patients suggested a wide range of possible solutions to these challenges, as well as solutions that could be considered generic or universal. Solutions were grouped into three categories, with seven subcategories: 1) responsive professional-patient interaction, subdivided into a) clarifying the patient's responsibilities, and b) applying communication strategies; 2) training programmes for health professionals or patients; and 3) organisational actions, subdivided in a) changes in how care delivery is organised, b) involvement of another health professional or organisation, and c) development and/or provision of materials to support clinical care. We provided a matrix that linked each of the individual health literacy challenges to the health literacy actions that could address the challenge. Further work is necessary to prioritise and further develop the proposed health literacy actions, and evaluate and integrate them into daily practice. Introduction of these health literacy actions, suggested by patients and health professionals, could enhance the health literacy responsiveness of our rheumatology clinics and potentially improve health outcomes.

In **Chapter 5**, we show that the work being done in rheumatology care is not a stand-alone project. Rather, it is embedded in an international network of researchers and practitioners supported by the World Health Organization (WHO), through the establishment of National Health Literacy Demonstration Projects (NHLDPs). In this report, we presented a common mission to reduce the burden of NCDs, described the methodological approach used to help achieve this, described the aims and context of each of the seven NHLDPs being conducted in the WHO European Region as of April 2019, and discussed how this work can help advance health and equity. We showed that an exchange of knowledge and practices can support work in the local context, while the outcomes of these projects together will help with the generalisability of health literacy practices, much more than an individual project could.

Part III: Organisational perspectives

The long-term aim of the work presented in this thesis is to contribute to health literacy responsive care in rheumatology clinics. This will require that organisations and professionals recognise patients' needs and deliver care and services in a way that matches those needs. Therefore, the final aim of this thesis was to investigate whether there is currently adequate awareness of health literacy among professionals and organisations to meet these expectations. Therefore, in **Chapter 6**, we explored discordance between the HLQ scores of patients with RMDs, and the intuitive assessment by their treating healthcare professional. For all patients who participated in the study described in Chapter 2, their treating health professional was asked to fill out a short questionnaire. They were asked to assess their patient's health literacy level on each of the nine domains of the HLQ on a 0-10 scale. In

8

addition, professionals reported how well they knew that patient, and scored their view on the impact of the disease on the functioning and health of that patient. To enable comparisons with the patients' HLQ scores, the patients' domain scores were also converted to a 0-10 scale. We collected data from 778 patient-professional pairs.

For analysis, we defined discordance per domain as a ≥2-point difference in either direction on the 0-10 scale, which led to three categories: 1) 'negative discordance' (i.e. professional scored lower than the patient); 2) both scores are 'probably the same'; and 3) 'positive discordance' (i.e. professional scored higher the patient). If both the patient and the professional scored below three or above seven, despite a ≥2-point difference, this was an indication that they agreed the score was either 'very high' or 'very low'. Therefore, these cases were classified as 'probably the same'. Because there is no gold standard for objective health literacy measurement, we do not know if discordance means that professionals over- or underestimate their patients, patients over- or underestimate themselves, or if the truth is somewhere in the middle. Nevertheless, significant discordance in the data still means that patients and health professionals are not on the same page about the patient's health literacy.

Depending on the HLQ domain, we found discordance in 20.7 to 40.5% of all cases. Moreover, health professionals indicated they did not know the patient's level of social support for health (HLQ domain 4) in one out of five (19.4%) cases, indicating this may not receive sufficient attention in clinical interactions. In addition, we used multilevel multinomial regression models to test the role of socioeconomic factors in negative and positive discordance in each of the nine HLQ domains. We found that particularly negative discordance was associated with socioeconomic factors, specifically lower education level and non-Western migration background (in five HLQ domains). We concluded that accurate estimation of patients' health literacy by professionals in rheumatology is not a given. Our results indicate that there may be hidden challenges in communication and care, and suggest these risks are not equal across socioeconomic groups and HLQ domains. This highlights both the multidimensional nature of health literacy, and that challenges in addressing health literacy needs may also be unequal between socioeconomic groups. Above all, these results teach us that addressing health literacy needs will require measurement and dialogue.

Lastly, in **Chapter 7**, we explored the consideration of health literacy in crisis communication. While work on this thesis was ongoing, the Coronavirus Disease 2019 (COVID-19) pandemic provided a unique opportunity to learn about the way rheumatology organisations already consider patients' health literacy needs in practice. We conducted a convergent, qualitatively driven mixed-methods study to explore key aspects of crisis communication and the explicit consideration of people's health literacy needs in communication with people with RMDs during the first wave of COVID-19 in the Netherlands. The study combined findings from seven qualitative interviews with (professional) representatives of organisations responsible for information provision to people with RMDs, and quantitative analysis of 15 patient information materials distributed by these organisations.

While analysing the qualitative data using common coding techniques, a thematic structure emerged. This led us to create a framework comprising four pillars of crisis communication; 1) preparedness; 2) strategy; 3) reach, and 4) content of communication. Health literacy was described and evaluated as a separate recurring theme. The quantitative analyses of patient information materials constituted an assessment of language difficulty using the 'Klinkende Taal' (English language version: SonaLing) online application, and an assessment of actionability and understandability using the 'Voorlichtingsmateriaal BeoordelingsInstrument' (VBI), the Dutch version of the Patient Education Materials Assessment Tool (PEMAT). 'Klinkende Taal' assesses the use of difficult words, jargon, passive, complex and long sentences, and long paragraphs, and assigns each text with a difficulty level inspired by the Common European Framework of Reference for Languages (CEFR), which ranges from A1 (basic) to C2 (proficient). It is widely believed that patient information materials should not exceed a B1-level in order for the majority of the population to understand what is meant. The 'VBI' is a checklist which results in a percentage of quality criteria adhered to, separately for actionability and understandability.

Despite extensive efforts by organisations as soon as the threat of the pandemic emerged, participants in our study reported a lack of preparedness for crisis communication, challenges related to scientific uncertainty and reaching the target group. Organisations also had difficulty simplifying information, and were uncertain whether their communication approach was adequate. Patient information materials varied greatly in actionability (quality score range 60–100%) and understandability (quality score range 58–100%), and we found that 69% of written materials were too difficult, mostly due to the use of long sentences and difficult words. The quantitative findings were in coherence with the qualitative findings, and we formulated several 'lessons learned' as opportunities for improvement. We argue that despite the best efforts of rheumatology organisations and healthcare providers, patients' health literacy needs were insufficiently considered and patient information materials were too difficult.

These final two empirical chapters show that a 'business as usual, with a little bit of health literacy in mind'-approach is insufficient to address people's health literacy needs. To make an impact through health literacy in rheumatology, we are going to need a conscious, integrated approach, which involves health professionals as well as rheumatology organisations. The work presented in this thesis can serve as a valuable starting point for these future efforts.

8

GENERAL DISCUSSION OF LESSONS LEARNED

While working on this research project, our research team learned a number of lessons, beyond the direct conclusions in each of the respective chapters. They relate to measurement, co-design methods, holistic & collaborative approaches, commitment, and training. Overlap between these lessons exists, and some have been touched upon in the previous chapters of this dissertation. Nevertheless, it is worthwhile to highlight several challenges of our studies in relation to existing literature and potential for future research and practice. The lessons are structured by theme and discussed in detail below.

Methodological considerations about measurement

We learned several methodological lessons about health literacy measurement. The first lesson is to independently and explicitly consider health literacy in research projects that aim to understand health inequalities, or mechanisms that aim to determine the success of (primarily non-pharmacological) interventions. As displayed in the WHO Report on Health Literacy Development for non-communicable diseases, the impact of interventions can be maximised by firstly considering health literacy in general (through more universal health literacy actions), and secondly considering health literacy diversity within and between individuals and communities (through health literacy actions targeting specific health literacy needs) [8]. This could ensure the fit of interventions to the needs of the target group, and help avoid the unnecessary development and uptake of more interventions that primarily work for those who do not need extra support. In health literacy projects, it may be tempting to use existing (i.e. readily available) data on concepts related to health literacy, rather than measuring health literacy. For example, van der Heide et al. [9] developed prediction models of health literacy scores, and suggested that education level could be used as a proxy for health literacy scores (while acknowledging that health literacy challenges may also occur in highly educated groups). Health literacy is related to a patient's socio-economic background [3, 10], as well as factors such as disease knowledge [11], engagement in shared decision-making [12], motivation and capacity to manage one's own health [13], and patient activation [14], indicating there are promising 'proxies' to use in lieu of health literacy measurements. However, while there are clear links with related concepts [5], health literacy is a distinct concept in itself. Our work indeed found a relationship between health literacy and education level or mastery in patients with RMDs (Chapter 2), but we should not forget that there are highly educated patients with significant health literacy needs and vice versa. Furthermore, Chapter 3 explicitly revealed that health literacy was an independent predictor of disease activity and medication prescription in patients with RA, even when adjusted for education level. To address health literacy needs, we will need to measure health literacy; not education level.

The second lesson, in line with what Osborne et al. [15] have proposed, is that using a simplified approach to health literacy assessment, for example by using single summary

scores, or quantitative cut-off points for categories with labels like 'high' and 'low' health literacy, is unlikely to result in a true representation of the research population's health literacy needs for a number of reasons. First, our work (and that of previous authors) convincingly shows that health literacy is a multidimensional concept, and persons can have strengths and weaknesses across health literacy domains. It is that pattern of strengths and weaknesses that determines the health literacy challenges that patients face in clinical care, and not their mean score across all domains. Second, the choice of cut-off values for categorisations and the wording of labels of the resulting categories can be problematic. For example, labelling anyone as 'low', is needlessly stigmatising, especially if the cut-off values are arbitrary [15]. Furthermore, such categorisations without further substantiation may lead to the inappropriate 'framing' of (groups of) persons, which in turn could lead to prejudiced research findings [16]. Third, single or unidimensional scores of health literacy are not actionable; they are unable to identify challenges that need to be addressed or the strengths that can be cultivated. In addition, health literacy is not a static determinant or personality trait, but a dynamic factor that can change over time (in either direction), and is related to the contextual factors of both the individual person and the health system. Proxy measurements or one-time recording of unidimensional measurement of health literacy are unable to capture this kind of complexity, and therefore the use of multidimensional tools that focus on change, such as the Health Literacy Questionnaire, should be encouraged. Notwithstanding, the choice of measurement tools depends on the aim of measurement and the context in which the measurement takes place [15]. Aims may differ between different types of studies (population-based epidemiological research vs. clinical action research) and different types of populations (different cultural contexts, age groups or disease groups), as well as between research and practice. For example, in daily practice, the Conversational Health Literacy Assessment Tool (CHAT) can be of use to identify a patient's health literacy needs in the moment [17], even if it does not provide a quantitative score.

The third lesson, closely related to the second, is that measuring health literacy with the HLQ is not enough in itself; we need to combine the quantitative data with qualitative methods. Using a self-reported measure for health literacy, as we did in this dissertation by using the HLQ, has limitations. No gold standard for health literacy measurement currently exists, and there is indeed ongoing debate about the selection of measurement tools in health literacy studies [15, 18-20]. For example, Schulz et al. [20] argue that only 'objective' measurement (in their case using the Newest Vital Sign (NVS)) of health literacy has the potential to prevent people from becoming victims of misinformation. However, we should not conceptualise self-reported health literacy data as 'subjective', and performance-based measurements (such as the NVS or Rapid Estimate of Adult Literacy in Medicine (REALM) as 'objective', because using these terms implies superiority of 'objective' measures compared to 'subjective' measures. This is not the case; both types of measurements serve a distinct purpose. Performance-based measurements can be used to assess performance on word recognition, calculations,

8

or interpretation of health information but they are simply unsuitable to assess health literacy performance for domains such as feeling supported by healthcare providers or having social support. In contrast, self-reported measurement tools are able to map health literacy needs across multiple domains of health literacy. However, patients may not be sufficiently aware of what is needed to manage their own health, which may result in the inflation of their scores; further conversations with the patient or their health professional could reveal that there are in fact health literacy weaknesses [21]. In other words, for a comprehensive understanding of health literacy needs in the local context, we need to look beyond quantitative outputs of measurement scales alone. Besides the need for actionable output mentioned above, there is also a need to capture more of the context in which the data are collected. To understand what the HLQ scores of patients with RMDs (Chapter 2) meant to these patients' real lives, we needed qualitative methods (Chapter 4). While quantitative data alone could not reveal the specific challenges of patients with RMDs in accessing information and services, the qualitative data would not have been as rich if there had not been quantitative data to feed into the co-design consultations with patients and professionals. The rich output of this thesis shows the value of combining methods to analyse a problem.

The fourth and final measurement-related lesson concerns the evaluation of implemented health literacy actions. The goal of health literacy actions is not to improve health literacy, but rather to improve health outcomes. In this context, (clinical) researchers do not need to measure health literacy, but measure the impact of health literacy actions on health. However, clinically relevant improvements in health outcomes are likely to manifest only after a longer period of time due to the cumulative effect of small improvements at each clinical encounter. This makes it difficult to quantitatively show improvement of health outcomes in a clinical study as a result of implemented health literacy actions, let alone a relevant reduction of the socioeconomic health gap. This might be problematic, because the dominant paradigm of evidence-based medicine has led to an environment where initiatives in health are required to be (cost-) effective, expressed in quantitative data. However, as outlined in the report "No evidence without context" [22], by the Dutch Council for Public Health and Society (Dutch: Raad voor Volksgezondheid en Samenleving, RVS), the context in which any intervention is proven effective may differ greatly from the daily reality on a clinical level. Furthermore, processes as well as outcomes of many health actions and tasks by health professionals used in caring for individual patients are difficult to assess through quantitative experimental studies. These are relevant considerations in both the continued effects in a post-study setting, and the translation of health literacy actions to rheumatology centres outside the study setting. In the case of health literacy, actions to support individuals (in relation to their needs) may vary from wildly complex to very simple, but in any case constitute components that are difficult to evaluate in isolation. Because of moving parts within the health literacy intervention as well as in the environment this intervention is implemented in, it begs the question whether we can speak of 'quantifying' effects at all. Perhaps quantifying health

outcomes should not be a primary goal of each health literacy action or intervention in itself, but rather, we would need (surrogate) evaluation methods that respect the 'context'. Partners in the NHLDP network provide best practice examples of evaluation methods, for example by conducting a qualitative process evaluation in a Danish cardiac rehabilitation centre [23], or conducting a randomised controlled trial with diverse short- and long-term outcomes in Norwegian patients with Chronic Obstructive Pulmonary Disease (COPD) [24, 25] (study ongoing). We suggest that using both components in mixed-methods research will be crucial to understand the role of health literacy in clinical practice.

Value and pitfalls of co-design approaches

Second, we learned about both the value and pitfalls of co-design methods. Jull et al. [26] have described how different co-design approaches foster a bi-directional exchange of information and promote shared learning. Indeed, both the study participants and researchers have gained significant health literacy knowledge through this co-design process. Through engagement with the stakeholders at the heart of the issue of health literacy in RMDs (people with RMDs and the health professionals who care for them) in quantitative and qualitative methods, we uncovered the health literacy needs in our local context. As described in Chapter 4, patients and health professionals have suggested a wealth of ideas (health literacy actions) to address those needs in the 'health literacy responsive' clinic of the future. Involving patients, health professionals, and other potential actors is crucial in developing interventions that will be successful, durable, and embedded in the local context [27].

Nevertheless, we also encountered limitations to this approach. For example, the overwhelming number of ideas generated in the qualitative phase of the study is challenging to distil back to tangible priorities for action. We will need to do further work before the outputs of our study are useful to clinical care, including the involvement of persons responsible for organising clinical care in this process. Furthermore, the co-design consultations showed it is difficult to truly address health literacy needs if the participants in the consultations are unfamiliar with the concepts underlying health literacy. A lack of focus on and common understanding of health literacy may cause the conversation to divert into different (although related) territory, such as details of the general functioning of the clinic (unrelated to the patient experience), training of healthcare professionals outside the chain of care (such as home-based nurses or first-line physiotherapists), or specific medical details of individual cases. In our co-design consultations, these diversions further exacerbated the previously mentioned challenge of the overwhelming number of suggestions for health literacy actions. In addition, the time investment required by participants is considerable, and adequate compensation for this time should be considered. The depth of our discussions, especially with health professionals, was at times hindered by the time constraints imposed by increasingly demanding clinical workloads and schedules. A review by Greenhalgh et al. [28] argued that the success of co-design methods depends on skilled leadership, ongoing

8

negotiation and dedicated resources (in terms of time, expertise and finances), which aligns with our experience. Indeed, for our co-design approach to achieve long-term success, further dedication of time, expertise and financial resources by researchers and clinical leadership is needed.

A final challenge in this process was the inclusion of perspectives of people with the most pressing health literacy needs in the co-design consultations. While our extensive recruitment efforts initially paid off, resulting in a diverse sample of participants in our quantitative study, it was much harder to find patients with health literacy needs willing to participate in further interviews and focus group discussions. Thankfully, these patients were represented in the 'health literacy vignettes', and their challenges were recognised by the participants in the co-design consultations. Nevertheless, the qualitative findings may not be fully transferable to our general patient population at the three centres, let alone to the wider European population of patients with RMDs. We therefore acknowledge that the suggested health literacy actions described in Chapter 4, even when further developed into readily implementable actions, may need further adaptations when piloted in rheumatology clinics to ensure they also serve the needs of patients who were not represented in the qualitative phases. This further emphasises the need to prioritise, evaluate and adapt proposed solutions during the implementation phase of Ophelia health literacy projects [5-7] to ensure the implemented health literacy actions work as intended. This applies to local implementation efforts, but also to making health literacy actions work in 'outside contexts', such as other patient populations or other countries. The concurrent processes of implementation, evaluation and adaptation in the local (practice) context align with the principles of action research [29, 30].

A need for holistic and collaborative approaches

Third, we learned that to truly maximise health potential through health literacy responsiveness of clinical care, it will require holistic and collaborative approaches. Health literacy challenges do not occur in a vacuum; they are inherently related to each other, as well as to socio-economic challenges that are outside the control of the individual healthcare professional. Taking a bird's eye view of the challenges at hand is necessary to find the right way forward. Solutions that target one specific aspect of a patient's challenges will be useful, but too simplistic to address the complexity of the patient's challenges. The co-design consultations described in Chapter 4 exemplified this; each vignette yielded many solutions at the patient-provider level, but numerous suggestions would require initiative at an organisational, regional or national level, such as the redesign of IT infrastructure, collaboration networks with other care providers, and better (financial) support for self-employed people with chronic illness, respectively. To maximise health potential by addressing the health literacy needs of patients, it is crucial that they are addressed at each of these levels. In fact, many solutions would not actually be solutions when implemented as a stand-alone intervention or action.

Clearly, a comprehensive approach to health literacy responsive care (both in development research and in daily practice) will require collaboration between individual healthcare providers as well as organisations. Several solutions offered in Chapter 4 require collaboration between healthcare professionals in organising care 'behind the scenes', or actively referring a patient to a colleague or other organisation. Furthermore, even if an individual healthcare professional aims to provide health literacy responsive care; if the rest of the system the patient functions in has not been taken into account, the effects of the individual healthcare professional's efforts are unlikely to make a difference. For example, Chapter 7 revealed that the emergence of the COVID-19 pandemic required alignment between different organisations to secure access to and understanding of information for patients. Organisations depend on each other, and patients reach out to multiple sources to get the information and support they need. Intervening at one organisation only will not solve the health literacy challenges at hand. Luckily, the organisations we interviewed indicated that further collaboration is possible and desirable. In addition, collaboration across medical specialties, such as is being done through the NHLDP network presented in Chapter 5 of this dissertation, can identify common challenges and solutions that transcend the local context. This also puts responsibility on the (clinical) researchers in this field to increase their collaboration efforts. Learning more about which health literacy actions and interventions work (and why) or not (and why not) will be crucial in the successful and efficient implementation of health literacy responsive care and systems. If we do not share and collaborate well, we are doomed to repeat mistakes and waste resources.

A need for conscious commitment

For the holistic and collaborative approach towards health literacy responsive care to be successful, a conscious commitment is required. As discussed in Chapter 1, Brach et al. [31] suggested that 'health literate organisations' are dependent on ten core attributes, which include having committed leadership. We learned that committed leadership, both within and between organisations, is not only needed at the top level. We also require local leadership and ownership of the proposed changes towards 'health literacy responsive care', to make implementation a success.

Over the last couple of years, awareness of the role of health literacy has increased among researchers, healthcare professionals and organisations [32]. Nevertheless, our study on information provision during the COVID-19 pandemic described in Chapter 7 showed that merely being aware of the importance does not translate into action. During the co-design consultations (Chapter 4), we found that it was not a given that health professionals were knowledgeable about health literacy and their role in addressing patients' health literacy needs in their work. Chapter 6 reinforced this finding, showing us that the current strategy of trusting the healthcare professionals' intuition and expertise on a case-by-case may not be enough. Recognising a patient's health literacy needs is difficult, and implementing health literacy

8

actions will only be possible if we consciously identify which actions are needed for each patient. Furthermore, health literacy needs are situational, meaning they can change over time (life phase or disease progression) or between contexts (different medical specialties, specific challenges), also depending on circumstances in the patient's life. Finding out what the patient needs at a particular time or in a particular situation will therefore require measurement and/or dialogue. Admittedly, we would have liked to be further along in our work towards implementation of health literacy actions. Two of the principles underlying the Ophelia process relate to the durability and local ownership of health literacy efforts [5, 7]. One of the challenges moving forward will be to facilitate that local ownership, moving away from the researcher-led thinking and project and towards efforts led by health professionals at the clinic.

A need for training

As the concept of health literacy is gaining traction in the clinical setting, we are coming to a point where awareness alone is not sufficient. Therefore, the fifth lesson of this thesis relates to the clear need for training of health professionals. Health professionals were almost unanimously interested in this research project, but often admitted they felt underprepared to do something with what they had learned about health literacy so far. Further training on the role of health literacy and potential ways to address health literacy needs is warranted, to complement health professionals' pre-existing knowledge of health communication strategies, acquired through previous training [33] and clinical experience.

Relatedly, health professionals reported a lack of time available to discuss health literacy issues with colleagues. Health professionals need to be given the time to reflect upon and develop their skills. The clinical setting is demanding, and health professionals often already feel pressed for time. Asking them to partake in further initiatives without providing appropriate support will not lead to a successful implementation of health literacy responsiveness. Another core attribute of a 'health literate organisation' suggested by Brach et al. [31] indeed concerns the commitment to prepare the workforce. The participants in our studies echoed these needs. In Chapter 4, they specifically called for training on communication strategies, shared decision-making, intercultural medicine, and complementary medicine. In one of the focus group consultations, respondents discussed the importance of intercollegiate consultation; an opportunity to discuss with a colleague not a patient's medical details, but rather the social and contextual factors that impact the patient's health and the professional's role in treating the patient. We believe these types of consultations can take many shapes and forms, but acknowledging they are needed beyond a focus on the medical perspective is an important first step.

Contributions to theoretical frameworks

Next, I want to reflect briefly on the theoretical frameworks discussed in Chapter 1 (pages 13-14). Looking back at the models by Paasche-Orlow and Wolf [34] and Sørensen et al. [35], and the mediation theory discussed by Stormacq et al. [36], the findings in this dissertation suggest additional factors should be considered, either by amending the models or by expanding upon the supporting information. Paasche-Orlow and Wolf [34] explicitly invite researchers to complement their model (preferably with empirical evidence). Firstly, I would propose that the concept of compensation mechanisms (health literacy strengths compensating for weaknesses) be explicated in either the model or the supporting text. The authors acknowledge that health literacy is a context-specific concept, which as such implies the dynamic nature of health literacy over time and between health tasks [34]. Nevertheless, further emphasis could be placed on the multidimensional nature of health literacy. The HLQ data in Chapter 2 showed a diversity of strengths and weaknesses, and both patients and health professionals referred to these mechanisms in qualitative consultations, in particular for social support. Admittedly, this could be considered a personal 'resource', and 'resources' are already listed as an extrinsic factor under 'self-care'. However, the supporting information in the paper does not state that it is indeed considered as such. I believe it deserves to be explicated as a different type of resource than strictly financial resources, as social capital and relations with health professionals represent very different kinds of resources, and would probably fit better under 'patient factors' than under 'extrinsic factors'. Adding 'compensation mechanisms' under 'patient factors' in each of the three pathways in the model, or amending the box 'health literacy' to include 'health literacy strengths and weaknesses' are two ways to account for these insights in the figure as well as the supporting information. Secondly, social capital does not only determine one's health literacy (as is currently indicated on the left side of the model), but participants in our interviews indicated it also influences the way a person's health literacy impacts health outcomes through access, interaction, or self-care. In other words, the model should also acknowledge that the pathways to health outcomes are not linear, but may be multidirectional. This may be reflected by making arrows bi-directional. Thirdly, we have suggested throughout this thesis that health systems and organisations should be responsive to patients' health literacy needs. Therefore, I propose adding 'health literacy responsiveness' to the system factors under 'Access and Utilization of Health Care'. Fourthly, in Chapter 6 specifically, we showed the importance of health professionals' awareness of their patient's health literacy needs in order to address them. I propose to explicitly list this as a 'provider factor' under 'Provider-patient interactions', to supplement the relevant factors of communication skills, teaching ability, time, and patient-centred care. Finally, the work in Chapter 4 resulted in a wealth of opportunities for health professionals to address health literacy needs, including tools such as decision aids, referral schemes, patient testimonials and personalised patient information materials. The availability and use of such tools that may support health professionals could also be explicated under 'provider factors'.

8

The integrated nature and public health focus of the model proposed by Sørensen et al. [35] make it difficult to apply it directly to our clinical case study. Nevertheless, participants in our studies argued that health literacy is not only relevant from a life course perspective but also from a disease course perspective. Health literacy needs change over time not (only) due to a change in age and life phase, but also due to the progression of disease or periods of flares, so amending the figure to state 'life/disease course' should be considered. Secondly, the concepts of health literacy action and responsiveness could be integrated into the societal and situational determinants. The original model presents antecedents (left side of the model) and impact (right side of the model) of health literacy, and shows health literacy as a process of accessing, understanding, appraising and applying health information in different settings. While it acknowledges health literacy as a process and not as a static determinant, the antecedents described (such as demographic situation, societal systems, socioeconomic status and family or peer influences) are framed as static determinants impacting outcomes through health literacy. Instead, we should explicitly acknowledge the dynamic nature of these antecedents; there is an opportunity to modify healthcare organisations and systems through health literacy actions and improved responsiveness. The authors have already described health literacy as a process [35]; I believe we should also view the system antecedents as such.

Finally, the quantitative mediation studies reviewed by Stormacq et al. [36] provided a welcome statistical justification to act upon health literacy needs as a way to address socioeconomic disparities in health. Nevertheless, mediation analysis is unable to account for the complexity and interrelatedness of health literacy antecedents and outcomes displayed in the conceptual models [34, 35]. For example, health literacy may in itself be an antecedent to socioeconomic factors, or may have a direct effect on health outcomes. The proportion of variance explained by health literacy as a mediator might therefore underestimate the potential role of health literacy as a modifiable factor, and perhaps more complex statistical models are needed to explore this. Notwithstanding, merely quantifying relations between health literacy and health outcomes does nothing to improve health outcomes themselves; for that, we need health literacy development and action. Therefore, future research should ideally focus primarily on achieving change (through intervention and action research), rather than merely quantifying existing relations. Stormacq et al. [36] argue health literacy is a promising modifiable factor to reduce inequalities in health outcomes, and indeed call for health literacy action; taking people's health literacy needs into account to reduce health inequalities. In addition, they justifiably call for continued work to tackle the root causes of health inequalities through societal change, because addressing health literacy needs does not undo social inequalities in greater society. In light of this, we need to utilise our (limited) human and financial resources to work towards change.

Where do we go from here?

To round off, let me take you, the reader, back to the beginning; the cases of Mike, Linda and John (described on pages 9-10). Throughout this thesis, I provided insight into the challenges they face, why they relate to health literacy, what factors come into play when they seek health information and care, and what healthcare professionals and organisations could do to better address their challenges and needs.

In Mike's case, this is related to a better understanding of the long-term impact of his illness, and the benefits and harms of medication. His healthcare professional could use some of the tools and strategies proposed in Chapter 4, such as group consultations, examples of patients like him (and how they benefited from taking medication), or additional time with a rheumatology nurse to discuss his concerns at his pace. For Linda, most of the damage has already been done by the time she reached the rheumatologist's office, due to the delays in her diagnostic process. People like her could benefit from improved skills of first-line healthcare workers regarding illness recognition and diagnosis, and likely from increased societal awareness (through television or community-based initiatives, giving insight into what complaints require medical attention, and what complaints are a normal part of ageing). Had someone been able to recognise her complaints, despite her inability to bring them up to the right person at the right time, she could have been referred much earlier. Even at this point in her disease course, however, Linda might still benefit from a referral to someone who can support her in her daily tasks, such as an occupational therapist, or someone who could help navigate the rules for available support from public funds. An organisational referral scheme, showing where a patient could go with specific questions (for example about financial support, or a change of career), could facilitate that, because Linda finds it difficult to navigate the health (and social services) system by herself. Linda's case is an example of how action is needed on multiple levels; a health professional will be unable to help her by supporting her in the clinical appointment only, we also should make our systems easier to navigate. Lastly, John's case is an example of what happens when health literacy is taken for granted, or when high education is used as a proxy for good health literacy. Ideas collected from co-design consultations suggested that John could benefit from peer-support sessions, because he could learn from how other patients cope with their illness. For example, he could learn that living his preferred fast-paced life is possible, but only if he makes the right adjustments. However, the availability of peer-support sessions alone will not suffice; John might not want to attend them, and thus a range of alternative solutions should be considered. This case also showed a clear need for professional awareness, the use of teach-back, and the use of patient testimonials (one of the respondents referred to these as a reality check), so that John can relate to 'someone like him', and learn how important it is to take his condition seriously.

In only one paragraph, I have reduced three patients' complex, contextual struggles and offered suggestions for solutions. Therefore, I believe a disclaimer paragraph is warranted. While patients like Mike, Linda and John are seen in rheumatology clinics on a daily basis,

8

their individual challenges differ as much as their personality and contextual factors differ. There is no easy solution to their health literacy-related challenges; rather, it is important for health literacy actions to be tailored to their needs, considering - to the extent possible - other contextual factors. What works for Linda, may not work for someone else in a similar situation. What works for Mike in his early 50s, may not have worked for Mike in his late 30s. The work in this dissertation has offered health professionals a number of tools, interventions and actions they could apply in care situations to maximise their patients' health potential, but is unable to prescribe what would be the right strategy to apply in any given moment. Only the healthcare professional and their patient can figure that out together. Thankfully, healthcare professionals do not have to start from scratch. This dissertation has identified several common health literacy challenges that patients with RMDs face, and a variety of solutions to each of these challenges. Being aware of these common challenges and potential ways to address them could help health professionals in providing better care.

Ultimately, the outputs of this dissertation should serve as input for the dissemination of health literacy thinking in the field of rheumatology and the implementation of health literacy responsiveness in rheumatology care. The lessons learned have been or will be distributed in scientific publications, but perhaps more importantly through educational sessions with (future) healthcare professionals. With regard to practical implementation, in Chapter 4 we described several health literacy actions and interventions to address specific health literacy challenges as proposed by patients and health professionals. As a next step in the Ophelia process [5], a project team at the principal centre (Maastricht UMC+, in the South) will further work on prioritising and developing these suggested actions into implementable work packages, to be piloted in the local clinical setting. In an attempt to make the clinic more health literacy responsive, the idea is that the rheumatology nurse's annual review with the patient provides an opportunity to initiate a conversation with a patient about their experiences. This conversation may be guided by the CHAT [17]. When patients' challenges come to the surface, the nurse will have a set of tools or strategies at their disposal to further support the patient by responding to the challenges that are specific to that individual patient. Should this pilot provide promising results, it can be expanded both within the rheumatology department at Maastricht UMC+ and to the partner centres. NHLDP colleagues in other countries have already shown that such sustainable implementation of health literacy actions is possible [8].

To conclude, I hope the findings described in this dissertation contribute to further awareness of health literacy diversity and health literacy development in the field of rheumatology. While the impact of this project and details of implementation have yet to be defined and realised, the work completed so far and the diversity and complexity of proposed health literacy actions have made clear: 'One size does not fit all'.

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. doi:10.1177/1757975918814421.

2. Kooiker S, Hoeymans N. *Burgers en gezondheid: Themarapport Volksgezondheid Toekomst Verkenning* 2014. Bilthoven, The Netherlands: RIVM; 2014.

3. 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. doi:10.1093/eurpub/ckv043.

4. Nutbeam D, Lloyd JE. Understanding and Responding to Health Literacy as a Social Determinant of Health. *Annu Rev Public Health*. 2021;42:159-73. doi:10.1146/annurev-publhealth-090419-102529.

5. Dodson S, Beauchamp A, Batterham R, Osborne R. *Ophelia toolkit: A step-by-step guide for identifying and responding to health literacy needs within local communities*. Melbourne, Australia: Swinburne University of Technology; 2015.

6. Batterham RW, Buchbinder R, Beauchamp A, Dodson S, Elsworth GR, Osborne RH. The OPtimising HEalth LIterAcy (Ophelia) process: Study protocol for using health literacy profiling and community engagement to create and implement health reform. *BMC Public Health*. 2014;14:694. doi:10.1186/1471-2458-14-694.

7. Beauchamp A, Batterham RW, Dodson S, Astbury B, Elsworth GR, McPhee C, et al. Systematic development and implementation of interventions to OPtimise Health Literacy and Access (Ophelia). *BMC Public Health*. 2017;17(1):230. doi:10.1186/s12889-017-4147-5.

8. World Health Organization. *Health literacy development for the prevention and control of noncommunicable diseases*. Geneva, Switzerland; 2022.

9. van der Heide I, Uiters E, Sørensen K, Röthlin F, Pelikan J, Rademakers J, et al. Health literacy in Europe: the development and validation of health literacy prediction models. *Eur J Public Health*. 2016;26(6):906-11. doi:10.1093/eurpub/ckw078.

10. 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. doi:10.1186/1471-2458-13-179.

11. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med*. 2011;155(2):97-107. doi:10.7326/0003-4819-155-2-201107190-00005.

12. Muscat DM, Shepherd HL, Nutbeam D, Trevena L, McCaffery KJ. Health Literacy and Shared Decision-making: Exploring the Relationship to Enable Meaningful Patient Engagement in Healthcare. *J Gen Intern Med*. 2021;36(2):521-4. 10.1007/s11606-020-05912-0.

8

13. Heijmans M, Waverijn G, Rademakers J, van der Vaart R, Rijken M. Functional, communicative and critical health literacy of chronic disease patients and their importance for self-management. *Patient Educ Couns*. 2015;98(1):41-8. doi:10.1016/j.pec.2014.10.006.

14. Smith SG, Curtis LM, Wardle J, von Wagner C, Wolf MS. Skill Set or Mind Set? Associations between Health Literacy, Patient Activation and Health. *PLoS One*. 2013;8(9):e74373. doi:10.1371/journal.pone.0074373.

15. Osborne RH, Cheng CC, Nolte S, Elmer S, Besancon S, Budhathoki SS, et al. Health literacy measurement: embracing diversity in a strengths-based approach to promote health and equity, and avoid epistemic injustice. *BMJ Glob Health*. 2022;7(9):e009623. 10.1136/bmjgh-2022-009623.

16. Dijkstra I, Horstman K. 'Known to be unhealthy': Exploring how social epidemiological research constructs the category of low socioeconomic status. *Soc Sci Med*. 2021;285:114263. doi:10.1016/j.socscimed.2021.114263

17. O'Hara J, Hawkins M, Batterham R, Dodson S, Osborne RH, Beauchamp A. Conceptualisation and development of the Conversational Health Literacy Assessment Tool (CHAT). *BMC Health Serv Res*. 2018;18(1):199. doi:10.1186/s12913-018-3037-6.

18. Pelikan J, Bobek J, Ganahl K. Health literacy: objective performance-based tests vs. subjective perception-based questionnaires? *Eur J Public Health*. 2018;28(suppl_4). doi:10.1093/eurpub/cky213.644.

19. Haun JN, Valerio MA, McCormack LA, Sorensen K, Paasche-Orlow MK. Health literacy measurement: an inventory and descriptive summary of 51 instruments. *J Health Commun*. 2014;19 Suppl 2:302-33. doi:10.1080/10810730.2014.936571.

20. Schulz PJ, Pessina A, Hartung U, Petrocchi S. Effects of Objective and Subjective Health Literacy on Patients' Accurate Judgment of Health Information and Decision-Making Ability: Survey Study. *J Med Internet Res*. 2021;23(1):e20457. doi:10.2196/20457.

21. Hawkins M, Gill SD, Batterham R, Elsworth GR, Osborne RH. The Health Literacy Questionnaire (HLQ) at the patient-clinician interface: A qualitative study of what patients and clinicians mean by their HLQ scores. *BMC Health Serv Res*. 2017;17(1):309. doi:10.1186/s12913-017-2254-8.

22. Raad voor Volksgezondheid en Samenleving. *Zonder context geen bewijs. Over de illusie van evidence-based practice in de zorg.* The Hague, The Netherlands: RVS; 2017.

23. Aaby A, Simonsen CB, Ryom K, Maindal HT. Improving Organizational Health Literacy Responsiveness in Cardiac Rehabilitation Using a Co-Design Methodology: Results from The Heart Skills Study. *Int J Environ Res Public Health*. 2020;17(3):1015. doi: 10.3390/ijerph17031015

24. Bakker MM, Putrik P, Aaby A, Debussche X, Morrissey J, Borge CR, et al. Acting together – WHO National Health Literacy Demonstration Projects (NHLDPs)address health literacy needs in the European Region. *Public Health Panorama*. 2019;5(2-3).

25. Borge CR, Larsen MH, Osborne RH, Engebretsen E, Andersen MH, Holter IA, et al. How to co-design a health literacy-informed intervention based on a needs assessment study in chronic obstructive pulmonary disease. *BMJ Open*. 2022;12(10):e063022. doi:10.1136/bmjopen-2022-063022.

26. Jull J, Giles A, Graham ID. Community-based participatory research and integrated knowledge translation: advancing the co-creation of knowledge. *Implement Sci.* 2017;12(1):150. doi:10.1186/s13012-017-0696-3.

27. Osborne RH, Elmer S, Hawkins M, Cheng CC, Batterham RW, Dias S, et al. Health literacy development is central to the prevention and control of non-communicable diseases. *BMJ Glob Health*. 2022;7(12):e010362. doi:10.1136/bmjgh-2022-010362.

28. Greenhalgh T, Jackson C, Shaw S, Janamian T. Achieving Research Impact Through Co-creation in Community-Based Health Services: Literature Review and Case Study. *The Milbank Q.* 2016;94(2):392-429. doi:10.1111/1468-0009.12197.

29. Cordeiro L, Soares CB. Action research in the healthcare field: a scoping review. *JBI Database System Rev Implement Rep.* 2018;16(4). doi:10.11124/JBISRIR-2016-003200.

30. Greenwood DJ, Levin M. Action research, science, and the co-optation of social research. *Cult Organ.* 1998;4(2):237-61. doi:10.1080/10245289808523514.

31. Brach C, Keller D, Hernandez L, Baur C, Parker R, Dreyer B, et al. *Ten attributes of health literate health care organizations*. 2012.

32. Qi S, Hua F, Xu S, Zhou Z, Liu F. Trends of global health literacy research (1995-2020): Analysis of mapping knowledge domains based on citation data mining. *PLoS One*. 2021;16(8):e0254988. doi:10.1371/journal.pone.0254988.

33. Kaper MS, Reijneveld SA, van Es FD, de Zeeuw J, Almansa J, Koot JAR, et al. Effectiveness of a Comprehensive Health Literacy Consultation Skills Training for Undergraduate Medical Students: A Randomized Controlled Trial. *Int J Environ Res Public Health*. 2019;17(1). doi:10.3390/ijerph17010081.

34. Paasche-Orlow MK, Wolf MS. The causal pathways linking health literacy to health outcomes. *Am J Health Behav.* 2007;31 Suppl 1:S19-26. doi:10.5555/ajhb.2007.31.supp.S19.

35. Sørensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, et al. Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health*. 2012;12:80. doi:10.1186/1471-2458-12-80.

36. Stormacq C, Van den Broucke S, Wosinski J. Does health literacy mediate the relationship between socioeconomic status and health disparities? Integrative review. *Health Promot Int*. 2019;34(5):e1-e17. 10.1093/heapro/day062.

8

ADDENDA

SCIENTIFIC AND SOCIAL IMPACT

What is the problem?

Health is not only determined by biological factors, but also by social determinants. Social determinants of health refer to the conditions in which people are born, grow, work, live, and age. Social determinants can lead to unfair and avoidable inequalities in health. The central topic of this dissertation is 'health literacy', which is increasingly seen as a concept that we can do something about, in order to reduce health inequalities We studied health literacy among patients with rheumatic and musculoskeletal diseases (RMDs). RMDs are complex chronic diseases that require intensive interaction with healthcare services, as well as efforts from patients to self-manage their health in daily life.

In a narrow sense, health literacy refers to people's capacity to access, understand and apply health information. In a broader sense, health literacy refers to the personal capacity and resources people require to be able to manage their own health, beyond reading and using health information. It includes several dimensions, such as being able to communicate with health professionals, having the social support you need, and being able to navigate the health system. Health literacy is seen as an asset, relevant in clinical situations, but also helping people live healthy lives. If you have 'limited' health literacy, you might have more trouble following health advice, knowing what to do when experiencing health issues, understanding your doctor, or taking medication in the 'right' way. All these things (and more) could lead to health problems that could otherwise have been prevented. As people do not choose to have 'limited' health literacy, supporting patients with health literacy needs is simply 'the right thing to do'.

There are two main approaches to improving health through health literacy. The first is *improving people's* health literacy. This can be done through education programmes, often starting early in life, teaching people how to manage their own health. The second approach is to change the way (public) health services are *delivered by professionals and organisations*, so that having 'limited' health literacy does not create barriers to benefitting from these services. This is called 'health literacy responsiveness': the healthcare environment 'responds' to the health literacy needs of patients through 'health literacy actions'. Examples of actions include providing simpler information to people who have difficulty reading (using shorter sentences or pictures), supporting people in making appointments, and taking additional time to check if patients understand their treatment plan. While several examples of these 'health literacy actions' exist, we did not yet know how best to support our own patients with RMDs.

To find out what to do in our clinics, we followed the OPtimising HEalth LIteracy and Access (Ophelia) approach, which was previously developed in Australia. Ophelia constitutes a guideline for health literacy development in the local context. It partly relies on quantitative data (numbers) from the Health Literacy Questionnaire (HLQ). A person fills out the questionnaire, which results in scores on nine distinct health literacy domains. Sometimes, a strength in one domain might compensate for weaknesses in others. For example, if you

have trouble understanding health information yourself, but have the support of a close friend or a trusted healthcare professional. Combinations of strengths and weaknesses differ between people, but previous research showed there may be common patterns in patients with similar conditions. Therefore, we need to think about how that affects the way we should deliver care. What are the needs of our patient population? What can we do to address them? To find answers to these questions, Ophelia relies on qualitative data (expression of views, experiences, needs and solutions) from patients and health professionals. This dissertation focused on the health literacy needs of our patients, and importantly, what 'health literacy actions' we could take in rheumatology care, so we can move away from the 'one size fits all' delivery of health information and services. Through this work, we contribute to fairer access to and outcomes of care for patients with RMDs.

What did we learn?

We focused on three main questions. First, we studied the health literacy needs of our patients. We identified 'common' patterns of strengths and weaknesses among patients with RMDs. They resulted in ten different 'health literacy profiles' of patients in our participating clinics, each representing different needs. We found that patients with more health literacy needs were more likely to have high disease activity over time. We also found differences in the medication they were prescribed. This emphasised the importance of addressing health literacy needs.

Second, we wanted to find out more about the specific health literacy challenges that patients experience, and what health professionals and organisations could do to address those challenges. We talked to patients and their health professionals, and learned that patients can face multiple challenges, such as difficulties remembering information or being able to balance their working life with their health condition. Luckily, patients and health professionals have many ideas and strategies to help solve these challenges! We described these as proposed 'health literacy actions'. These actions are required at different levels, from individual patient-provider interactions, to organisational change, to governmental social policies. Besides working locally, we collaborate with researchers in other European countries through the World Health Organization National Health Literacy Demonstration Projects (WHO NHDLPs). Through this collaboration, we can find out what strategies work in multiple places, and what strategies are unique to the local context.

Third, we wanted to explore whether healthcare professionals and organisations are well equipped to consider health literacy in their work. In order for healthcare professionals to improve care based on patients' health literacy, we need to know whether a doctor or nurse can identify patients' health literacy needs at the point of care. We found that 'educated guesses' are possible, but in 1 out of 4 patients, large differences between the health literacy scores of the patient and the professionals' estimations occurred. As the research in this dissertation took place during the COVID-19 pandemic, we were also able to study to what

extent rheumatology professionals and organisations adapted their crisis communication strategy during the first wave of the COVID-19 pandemic to the health literacy needs of their target audience. We learned that despite good intentions, health literacy was insufficiently considered. These findings show that we need to make explicit efforts to address health literacy needs in rheumatology care. This also means we will have to give health professionals the time and resources they need to do so.

Why is this relevant?

Our findings help to better understand the health literacy challenges of people with RMDs, their impact on health care and outcomes, and the potential approaches or 'health literacy actions' that could support healthcare professionals in providing better care to patients with different needs. We hypothesise that these actions can improve patients' health outcomes, improve patients' and professionals' experience and contain costs. More research is needed to further develop, integrate and evaluate the 'health literacy actions' in our clinics to ensure 'health literacy responsive care'. With this work, we hope to make access to and outcomes of rheumatology care more equal between (groups) of patients.

Who (potentially) benefits and how?

Both patients and health professionals benefit from the increased awareness and understanding of health literacy needs, through better health outcomes and improved experience. This dissertation should serve as a starting point in achieving 'health literacy responsive care'. In a future project, several of the identified 'health literacy actions' will be tried out and further developed in the rheumatology clinic at Maastricht UMC+. If this project shows the benefits of 'health literacy responsive care', we could scale up to other rheumatology clinics (nationally and internationally), and potentially to other clinical settings.

Lessons for (clinical) researchers include the need to use multidimensional tools to measure health literacy, and to include health literacy thinking in care (implementation) projects. Any programme or initiative aiming to improve the provision of health services should engage people with diverse health literacy needs. Otherwise, it is unlikely that the initiative will reach and benefit those patients who need it most.

Other stakeholders who benefit from this research include hospital management and health professionals outside our clinic. This project shows a way to act upon societal challenges (health inequalities and 'limited' health literacy) at a local level. We need actions on different levels, going much further than simplifying written information materials alone. Health literacy actions can support patients in managing their own health and navigating the health system, thereby improving adherence and making the best use of clinical appointments, for example. Lastly, through our work with the WHO NHLDP network, our lessons learned should serve as an example for health literacy action on both a local, national, and international level.

How were these stakeholders involved and informed?

The main stakeholders in this project, patients and health professionals (rheumatologists (in training), nurses, physician assistants & nurse practitioners), were involved in the study design and collection and interpretation of the data. We also asked a patient panel of 4 patients for feedback when setting up the study protocol and during data collection. Almost 900 patients and 39 health professionals completed our questionnaires. We also held 13 interviews with patients to capture patients' experiences, and then held focus groups and interviews with patients and professionals to discuss the health literacy data and patients' experiences. This engaged 38 professionals and 14 patients in thinking about health literacy challenges and solutions. In addition, three rheumatology organisations shared their experience with health literacy and crisis communication during the COVID-19 pandemic.

Several additional activities were performed to inform stakeholder groups and increase our impact. I shared our findings at two patient partner meetings organised by ReumaZorg Nederland (a national patient organisation), and as a keynote speaker at the EULAR PARE (Patient chapter of the European League Against Rheumatism) Conference 2022, where health literacy was a key theme. Patient representatives and professionals working for patient organisations from across Europe engaged with our findings and brainstormed how they could apply these lessons in their local context, thereby supporting patients across the continent. In addition, I delivered educational sessions for the Dutch Society for Rheumatology (NVR), Dutch Health Professionals in Rheumatology (NHPR), Nurses & Carers Netherlands (V&VN), medical students at Utrecht UMC, and Internal Medicine trainees at Maastricht UMC+, each attended by dozens of (future) health professionals. Furthermore, researchers and health professionals were informed through scientific publications and national and international conferences in health literacy and rheumatology. We successfully created a video abstract to increase the reach and impact of our paper. On two occasions, a medical journalist dedicated an article to our findings, once at DOQ.nl, and once in the EULAR Congress Report of 2020.

Where are we heading?

The findings of and thinking behind the research in this thesis have sparked conversations and increased awareness of the role of health literacy in rheumatology among patients, health professionals and researchers. We expect to see further impact of this work in the future. For example, in 2023, health literacy will be a key topic of a clinical science session at EULAR Congress (the leading conference for rheumatology in Europe) for the first time, and V&VN will organise further education on health literacy for nurses and nurse practitioners. Furthermore, we hope to receive funding to further develop and implement 'health literacy actions' in practice.

Developments are not limited to the field of rheumatology. Through our work with the NHLDPs and the Ophelia approach, our project is included in the important 2022 WHO report "Health literacy development for the prevention and control of non-communicable diseases".

The idea that patients' health literacy is key to health outcomes and healthy populations is also slowly gaining the attention of the Dutch Ministry of Health and research funders. Personally, I am affiliated with the Dutch Health Literacy Alliance, and an elected member of the Practice Standards Committee of the International Health Literacy Association. The lessons learned in this thesis could therefore impact healthcare access and outcomes in many different settings through improved 'health literacy responsiveness'. While there is a lot left unwritten, I hope that the work in this dissertation may indeed support this process.

ABOUT THE AUTHOR

Mark Matthijs Bakker was born in Lelystad on April 19th, 1994 and grew up in Zeewolde, the Netherlands. Mark comes from a caring family, in every sense of the word, with both his parents working as healthcare professionals and his two older sisters later choosing to work in the same field. In 2012, he graduated *with distinction* from secondary education (VWO) at Christelijk College Groevenbeek in Ermelo. He received an International Baccalaureate certificate in English language & literature as part of his bilingual education.

Mark went on to study Physiotherapy at the University of Applied Sciences Utrecht (HU). He graduated *with merit* in 2015, and simultaneously completed a premaster programme in Clinical Health Sciences (Physiotherapy Science) at Utrecht University (UU). He subsequently moved to Maastricht to pursue his two master's degrees in Global Health and Governance & Leadership in European Public Health (graduated *with distinction*) at Maastricht University (UM). His studies led him to Manipal, Karnataka, India, for an exchange programme on social work in public health, at the Manipal Academy of Higher Education (MAHE), and to Prishtina, Kosovo, for his thesis research on health system reform and implications for older adults at the National Institute of Public Health of Kosovo (NIPHK). He gained further work experience as a physiotherapist in care for older adults at Warande in Zeist and Sevagram in Heerlen.

Through his work and studies, Mark became passionate about improving health on group and population levels through transformation of healthcare systems, organisations, and delivery. In 2018, this led him to take a position as junior researcher in health literacy development at the Department of Internal Medicine (Rheumatology Division) at Maastricht University Medical Centre (Maastricht UMC+), working together with Prof. dr. Annelies Boonen and dr. Polina Putrik as part of the World Health Organization's National Health Literacy Demonstration Projects (WHO NHLDP) network. For this project, Mark conducted quantitative and qualitative research at Maastricht UMC+, Maasstad Hospital in Rotterdam, and Medisch Spectrum Twente in Enschede. During his time as a PhD candidate, Mark served as a PhD Representative at the Care and Public Health Research Institute (CAPHRI) of Maastricht University.

Having completed his PhD, Mark now works as a lecturer at the Department of International Health at Maastricht University while also continuing his work on health literacy responsiveness in rheumatology care on a part-time basis. He will continue to serve on the Practice Standards Committee of the International Health Literacy Association (IHLA) and as a member of the WHO NHLDP Network.

LIST OF PUBLICATIONS & PRESENTATIONS

Peer-reviewed publications

Bakker, M.M.*, Putrik, P.*, Aaby, A., Debussche, X., Morrissey, J., Borge C.R., . . . Terkildsen Maindal, H. Acting together – WHO National Health Literacy Demonstration Projects (NHLDPs) address health literacy needs in the European Region. *Public Health Panorama.* 2019; 5(2-3): 228-238. *These authors contributed equally*

Bakker, M.M., Putrik, P., Rademakers, J., van de Laar, M., Vonkeman, H., Kok, M.R., . . . Boonen, A. Addressing health literacy needs in rheumatology: Which patient health literacy profiles need the attention of health professionals? *Arthritis Care & Research (Hoboken).* 2021; 73(1), 100-109, https://doi.org/10.1002/acr.24480

Bakker, M.M., Luttikhuis, T., Putrik, P., Jansen, I., Rademakers, J., de Wit, M., Boonen, A. Consideration of health literacy in patient information: a mixed-methods study of COVID-19 crisis communication in Dutch rheumatology. *BMC Rheumatology.* 2022; 6:52, https://doi.org/10.1186/s41927-022-00283-x

Bakker, M.M., Putrik, P., Dikovec, C., Rademakers, J., Vonkeman, H.E., Kok, M.R., . . . Boonen, A. Exploring discordance between Health Literacy Questionnaire scores of people with RMDs and assessment by treating health professionals. *Rheumatology (Oxford).* 2023; 62(1), 52-64, https://doi.org/10.1093/rheumatology/keac248

Bakker, M.M.*, Gorter, A.*, ten Klooster, P., Boonen, A., Vonkeman, H.E. The impact of health literacy: Associations with disease activity and medication prescription in patients with rheumatoid arthritis. *Rheumatology (Oxford).* 2023; Advance online publication. https://doi.org/10.1093/rheumatology/kead094. *These authors contributed equally*

Manuscripts in preparation

Bakker, M.M., Boonen, A., Rademakers, J., Vonkeman, H.E., Kok, M.R., Voorneveld-Nieuwenhuis, H., de Wit, M., Osborne, R.H., Putrik, P. Patients' and professionals' ideas to address health literacy challenges in rheumatology care: a qualitative study. In preparation.

Jansen, M., Bakker, M.M., Boonen, A., Sepriano, A., Landewé, R., Shkedy, Z., Putrik, P. Using clustering techniques in clinical epidemiological research. Practical tips using examples from health literacy in rheumatology. In preparation.

Conference presentations

Abstract submissions

Bakker, M.M., Putrik, P., Rademakers, J., van de Laar, M., Vonkeman, H., Kok, M., . . . Boonen, A. Improving care for patients with rheumatic diseases, using the Optimising Health Literacy and Access (Ophelia) approach. Oral presentation at: 4th European Health Literacy Conference; 2019 March 14-15; Dublin, Ireland.

Bakker, M.M., Putrik, P., Rademakers, J., van de Laar, M., Vonkeman, H., Kok, M., . . . Boonen, A. SAT0558 Identifying Health Literacy profiles of RA and SpA patients using the Health Literacy Questionnaire. Poster presentation at: EULAR Congress; 2019 June 12-15; Madrid, Spain.

Bakker, M.M., Putrik, P., Rademakers, J., van de Laar, M., Vonkeman, H., Kok, M., . . . Boonen, A. Identifying Health Literacy profiles of RA and SpA patients using the Health Literacy Questionnaire. Oral presentation at: NVR Najaarsdagen; 2019 Sept 29; Arnhem, The Netherlands.

Bakker, M.M., Putrik, P., Rademakers, J., van de Laar, M., Vonkeman, H., Kok, M., . . . Boonen, A. OP0257-PARE Using patient Health Literacy profiles to identify solutions to challenges faced in rheumatology care. Oral presentation at: EULAR E-Congress; 2020 June 3-6; Frankfurt, Germany (virtual).

Bakker, M.M., Putrik, P., Dikovec, C., Rademakers, J., Vonkeman, H., Kok, M., . . . Boonen, A. Exploring discordance between Health Literacy Questionnaire scores of people with RMDs and assessment by treating health professionals. Poster tour presentation at: EULAR Virtual Congress; 2021 June 2-5; Paris, France (virtual).

Bakker, M.M., Luttikhuis, T., Jansen I., Rademakers, J., de Wit, M., Boonen, A., Putrik, P. OP0324-PARE Patient information in times of crisis: lessons learned from COVID-19 communication in rheumatology. Oral presentation at: EULAR Virtual Congress; 2021 June 2-5; Paris, France (virtual).

Bakker, M.M., de Wit, M., Mateus, E., Wiek, D., Boonen, A., Osborne, R. OP0184-PARE How representative are patient representatives? Health literacy scores and profiles of representatives of patient organisations as compared to an existing sample of people with RMDs. Oral presentation at: EULAR Congress; 2023 May 31-June 3; Milan, Italy

Invited speaker

Bakker, M.M., Putrik, P., Boonen, A. NHLDP Netherlands: Applying Ophelia in Rheumatology care. Presented at: WHO Regional Office for Europe - European workshop on developing, implementing and evaluating health literacy initiatives across the WHO European Region in support of NCDs prevention and control; 2019 Jan 17-18; Lisbon, Portugal.

Bakker, M.M., Putrik, P., Boonen, A. Gezondheidsvaardigheden, van local naar global. Ontwikkelen van interventies in de Nederlandse reumatologie en daarbuiten. Presented at: NVR Najaarsdagen – Best Practice Health Professionals; 2019 Sept 29; Arnhem, The Netherlands.

Bakker, M.M. Patient information in times of crisis. Lessons learned from COVID-19 communication in the Dutch Rheumatology setting. Presented at: IHLA Global Health Literacy Summit; 2021 Oct 3-5; Kaohsiung City, Taiwan (virtual).

Bakker, M.M. Beter omgaan met (beperkte) gezondheidsvaardigheden in de zorg voor mensen met reumatische aandoeningen. Presented at: V&VN Jaarcongres; 2022 May 10; Bunnik, The Netherlands.

Bakker, M.M. Health literacy in RMDs. Presented at: EULAR PARE Conference; 2022 Oct 19-22; Brussels, Belgium.

Other presentations (as invited speaker)

Bakker, M.M., Putrik, P., Rademakers, J., Vonkeman, H., Voorneveld, H., de Wit, M., Boonen, A. Reuma en gezondheidsvaardigheden [unpublished lecture]. Themabijeenkomst ReumaZorg Nederland; 2018 Sept 22; Utrecht, The Netherlands.

Bakker, M.M., Putrik, P., Boonen, A. Reuma en gezondheidsvaardigheden [unpublished lecture]. Themabijeenkomst ReumaZorg Nederland; 2020 Oct 24; Nijmegen, The Netherlands (virtual).

Bakker, M.M. The role of health literacy in (global) health [unpublished lecture]. M Medicine, Global Health II, Utrecht University; lecture given 2022 Oct 4; Utrecht, The Netherlands (virtual).

Bakker, M.M. The role of health literacy in (global) health [unpublished lecture]. M Medicine, Global Health II, University College Utrecht, Utrecht University; lecture given 2023 March 13; Utrecht, The Netherlands (virtual).

Bakker, M.M., Putrik, P., Boonen, A. Applying Ophelia in Rheumatology care. Experiences from the Netherlands [unpublished lecture]. Ophelia Masterclass; 2023 April 27-28; Aarhus, Denmark.

NEDERLANDSTALIGE SAMENVATTING

In dit proefschrift heb ik richting gegeven aan de ontwikkeling van de reumazorg, naar een situatie waarin deze zorg beter inspeelt op (ofwel meer ontvankelijk en responsief is voor) de gezondheidsvaardigheden van de patiëntpopulatie. Gezondheidsvaardigheden worden in sommige bronnen 'gezondheidsgeletterdheid' genoemd; de Engelstalige term is 'health literacy'. In lijn met de klinische aard van dit proefschrift, definieer ik gezondheidsvaardigheden als voorgesteld door de International Union for Health Promotion and Education (IUHPE): *Gezondheidsvaardigheden omvatten de combinatie van persoonlijke eigenschappen en omgevingsfactoren die men nodig heeft om toegang te krijgen tot gezondheidsinformatie en zorgvoorzieningen, en deze te kunnen begrijpen, beoordelen en te gebruiken om gezondheidsgerelateerde beslissingen te nemen. Dit omvat ook het vermogen om helder over deze beslissingen te communiceren, en om vervolgens actie te ondernemen. Responsiviteit met betrekking tot gezondheidsvaardigheden betreft de manier waarop zorgverleners, organisaties, en stelsels gezondheidsinformatie en ondersteuningsmiddelen beschikbaar en toegankelijk maken aan de hand van de sterktes en zwaktes van de populatie op het gebied van gezondheidsvaardigheden* (vrij vertaald). Dit is relevant in de context van reumatische en musculoskeletale aandoeningen (RMDs), omdat mensen met (een van) deze aandoeningen vaak langdurig behandeling door zorgverleners nodig hebben. Daarnaast wordt steeds meer van patiënten verwacht dat zij zelf actief betrokken zijn bij het besluitvormings- en behandelproces, en dat zij door middel van zelfmanagement hun aandoening en gezondheid in het algemeen in balans weten te houden met hun andere verantwoordelijkheden in het dagelijks leven. Gezondheidsvaardig zijn, of toegang hebben tot zorg die wordt geleverd op een manier die past bij de vaardigheden van een patiënt, is daarom een cruciale voorwaarde voor goede gezondheidsuitkomsten. Er bestaat een sociale gradiënt van gezondheidsvaardigheden: we zien verschillen in gezondheidsvaardigheden tussen (groepen van) mensen op basis van hun sociaaleconomische achtergrond, wat resulteert in verschillende gezondheidsuitkomsten. Echter, een sterke sociaaleconomische positie is nog geen garantie voor het hebben van gunstige gezondheidsvaardigheden. Vanwege het bestaan van deze gradiënt en de aangetoonde relatie tussen gezondheidsvaardigheden en gezondheidsuitkomsten is het in potentie mogelijk om gezondheidsverschillen te verminderen en gezondheidspotentieel te benutten, door in te spelen op de behoeften van patiënten op het gebied van gezondheidsvaardigheden. Het werk beschreven in dit proefschrift helpt ons om de rol van gezondheidsvaardigheden voor patiënten met RMDs beter te begrijpen, en laat zien wat we zouden kunnen doen om de reumazorg beter af te stemmen op de behoeften van de patiëntpopulatie, en daarmee gezondheidsuitkomsten gelijkwaardiger te maken. Het beschreven werk maakt gebruik van de OPtimising HEalth LIteracy and Access (Ophelia) aanpak. Ophelia betreft een leidraad voor onderzoekers en zorgverleners om gezondheidsuitkomsten te verbeteren door middel van ontwikkelingen op het gebied van

gezondheidsvaardigheden. Deze samenvatting van de voornaamste bevindingen in elk van de hoofdstukken laat zien hoe dit proefschrift bijdraagt aan mogelijke verbeteringen van de responsiviteit van de reumazorg met betrekking tot gezondheidsvaardigheden.

Hoofdstuk 1 vormt de inleiding van dit proefschrift, en bevat belangrijke concepten en achtergrondinformatie voor de overige hoofdstukken. Het hoofdstuk geeft een inkijk in de relatie tussen gezondheidsvaardigheden, gezondheidsverschillen en gezondheidspotentieel, definities en conceptuele modellen van gezondheidsvaardigheden, het meten van gezondheidsvaardigheden, de reeds bekende impact van gezondheidsvaardigheden op gezondheidsuitkomsten (in het algemeen en binnen de reumatologie), manieren om met gezondheidsvaardigheden om te gaan, en gezondheidsvaardigheden vanuit het perspectief van organisaties. In de inleiding wordt duidelijk dat gezondheidsvaardigheden alles te maken hebben met gezondheidsgelijkheid. Actie ondernemen is daarom noodzakelijk om mogelijk de sociaaleconomische kloof te versmallen door gezondheidspotentieel te benutten. Ook presenteerde ik in dit hoofdstuk de drie onderzoeksdoelen van dit proefschrit:

1. het in kaart brengen van behoeften van reumapatiënten op het gebied van gezondheidsvaardigheden;
2. het genereren van oplossingen om de reumazorg beter af te stemmen op de geïdentificeerde behoeften door middel van co-creatie;
3. het onderzoeken van het huidige bewustzijn van deze behoeften vanuit het perspectief van organisaties.

De hierop volgende hoofdstukken zijn elk verbonden aan een van de drie onderzoeksdoelen. Samen dragen ze bij aan de bevordering van gezondheidsvaardigheden binnen de reumatologie, zowel in onderzoek als in de praktijk. Het proefschrift is verdeeld in drie delen, in lijn met de drie onderzoeksdoelen.

Deel I: Patiëntbehoeften op het gebied van gezondheidsvaardigheden

Het eerste deel van dit proefschrift betreft het identificeren van behoeften van patiënten met RMDs op het gebied van gezondheidsvaardigheden. In **Hoofdstuk 2** bestudeerden we de bestaande patronen van sterktes en zwaktes met betrekking tot gezondheidsvaardigheden binnen een groep patiënten met reuma. Dit was een kwantitatief, observationeel, cross-sectioneel onderzoek, waarin patiënten met reumatoïde artritis (RA), spondyloartritis (SpA) of jicht een vragenlijst invulden. Het betrof de Nederlandstalige versie van de Health Literacy Questionnaire (HLQ). Liefst 895 patiënten in drie geografisch en sociaaleconomisch diverse centra (het Maastricht UMC+ (zuid) te Maastricht, Maasstad Ziekenhuis (west) te Rotterdam, en het Medisch Spectrum Twente (oost) te Enschede) namen deel. HLQ-scores van patiënten op elk van de negen domeinen van deze vragenlijst bleken grotendeels onafhankelijk te zijn van het type reumatische aandoening of het centrum waar de patiënt behandeld werd, al scoorden patiënten in één van de centra net iets beter op domeinen 4 (sociale steun), 6

(actieve betrokkenheid bij zorgverleners), 7 (de weg vinden in de gezondheidszorg), en 9 (schriftelijke gezondheidsinformatie lezen en begrijpen).

Vervolgens gebruikten we hiërarchische clusteranalyse om zogeheten 'profielen van gezondheidsvaardigheden' te identificeren, gebaseerd op sterktes en zwaktes (te zien aan respectievelijk hogere en lagere scores op de negen domeinen van de HLQ-vragenlijst). We vonden uiteindelijk tien verschillende profielen. Tweeënveertig procent van de deelnemers paste het best bij een van de twee profielen met weinig tot geen moeilijkheden over de negen domeinen (profiel 1 en 3, respectievelijk zeer hoge tot hoge scores op alle domeinen). Nog eens 42% van de deelnemers had duidelijk moeite met een of enkele domeinen van gezondheidsvaardigheden (profielen 2, 4, 5 en 6). De overige 16% van de deelnemers liet zien moeilijkheden te ervaren in het merendeel van de domeinen (profielen 7-10). We beschreven de sterktes en zwaktes van deze verschillende profielen door de HLQ-scores te combineren met demografische en sociaaleconomische kenmerken van de deelnemers. Een opvallende bevinding was dat de deelnemers met een profiel dat meer moeilijkheden op het gebied van gezondheidsvaardigheden indiceert ook aangaven minder gezond te zijn dan mensen met hogere scores op de HLQ-vragenlijst. Met andere woorden, deze profielen zijn een relevante factor als het gaat om gezondheidsuitkomsten. Daarnaast waren mensen met een 'lager' opleidingsniveau of een migratie-achtergrond oververtegenwoordigd in de meer complexe profielen. Deze bevinding heeft te maken met de bestaande sociale gradiënt van gezondheidsvaardigheden.

Door middel van een multinomiaal regressiemodel met de profielen als afhankelijke variabele hebben we ook onderzocht of de gevonden profielen afhingen van het type reuma of het centrum waar de patiënt behandeld werd. We vonden dat sommige profielen vaker voorkwamen in een van de centra of ziektegroepen, maar deze verschillen waren niet statistisch significant. Met andere woorden, de geleerde lessen zijn potentieel te generaliseren naar de bredere context van de reumazorg in Nederland.

Hoofdstuk 3 is een vervolgstudie onder patiënten met RA binnen het Medisch Spectrum Twente (oost) die hebben deelgenomen aan de vragenlijststudie beschreven in Hoofdstuk 2. In een retrospectief kwantitatief observationeel longitudinaal onderzoek onderzochten we de associatie tussen de eerder geïdentificeerde profielen van gezondheidsvaardigheden, ziekteactiviteit, en voorgeschreven medicatie, door die gegevens op te zoeken in de elektronische patiëntendossiers. Er werden dus geen nieuwe gegevens verzameld; we gebruikten de gegevens die in de standaardzorg verzameld worden. Hoewel er 122 patiënten met RA in dit centrum deelnamen aan de originele studie, waren er gegevens over ziekteactiviteit en voorgeschreven medicatie (biologische disease-modifying anti-rheumatic drugs (bDMARDs), conventionele synthetische DMARDs (csDMARDs), en prednison) beschikbaar voor 108 van hen. Om groepen te kunnen vergelijken hebben we de tien profielen samengevoegd tot drie groepen, gebaseerd op vergelijkbare eigenschappen tussen de profielen. De resulterende gezondheidsvaardighedengroepen, net iets anders dan de verdeling

beschreven in Hoofdstuk 2, werden als volgt gedefinieerd: 1) 'meerdere beperkingen op het gebied van gezondheidsvaardigheden' (profielen 6-10); 2) 'enkele beperkingen op het gebied van gezondheidsvaardigheden' (profielen 2, 4 en 5); en 3) 'gunstige gezondheidsvaardigheden' (profielen 1 en 3).

We gebruikten gemengde lineaire modellering met als afhankelijke variabele de ziekteactiviteit gemeten met de DAS28-ESR, een score die gevormd wordt aan de hand van 28 bekeken gewrichten, een zelfgerapporteerd cijfer voor de algehele gezondheid van de patiënt, en de bezinking. Hiermee onderzochten we de relatie tussen de gezondheidsvaardighedengroepen en de ziekteactiviteit over een periode van 1 jaar. Daarnaast gebruikten we chi-kwadraat toetsen en logistische regressiemodellen om de relatie tussen de gezondheidsvaardighedengroepen en de voorgeschreven medicatie te onderzoeken. We ontdekten dat patiënten met 'gunstige gezondheidsvaardigheden' significant (p=0.01) lagere ziekteactiviteit hadden gedurende het jaar (gemiddelde DAS28-ESR: 2.4) dan patiënten in de 'meerdere beperkingen' groep (gemiddelde DAS28-ESR: 3.1). Dit verband was onafhankelijk van het opleidingsniveau van de patiënten. Daarnaast ontdekten we dat vijftig procent van de patiënten met 'gunstige gezondheidsvaardigheden' een biological kreeg voorgeschreven, vergeleken met respectievelijk 18.2% en 38.1% in de groepen met 'enkele beperkingen' (gecorrigeerde Odds Ratio (OR) 0.22 [0.08-0.65]) of 'meerdere beperkingen' (gecorrigeerde OR 0.91 [0.27-3.27], niet significant). Aan patiënten met 'enkele beperkingen op het gebied van gezondheidsvaardigheden' werd vaker alleen een csDMARD voorgeschreven (OR 4.24 [1.57-11.51]) dan aan patiënten met 'gunstige gezondheidsvaardigheden', en aan patiënten met 'meerdere beperkingen' werd significant meer prednison voorgeschreven (52.4%, OR 3.56 [1.13-11.15] vergeleken met de 'gunstige gezondheidsvaardigheden' groep) dan aan patiënten met 'enkele beperkingen' (21.2%) of 'gunstige gezondheidsvaardigheden (22.2%). Dit verschil suggereert dat de ziekte niet voldoende onder controle is bij deze patiënten. In eerste instantie werd hen waarschijnlijk prednison voorgeschreven als praktische oplossing voor de korte termijn, maar uiteindelijk werd het gebruikt als langdurige onderhoudsdosering.

Dit hoofdstuk bevestigde opnieuw de relevantie van gezondheidsvaardigheden in de (poli)klinische reumazorg. De resultaten suggereren dat gezondheidsvaardigheden een onafhankelijke determinant van gezondheidsuitkomsten zijn, wat betekent dat opleidingsniveau geen goede vervangende maat is om gezondheidsvaardigheden in de praktijk te begrijpen. Deze studie toonde aan dat de behoeften van patiënten op het gebied van gezondheidsvaardigheden gerelateerd zijn aan de ziekteactiviteit en het soort voorgeschreven medicatie, onafhankelijk van opleidingsniveau. Hoewel we hiermee niet beweren een causaal verband te hebben aangetoond tussen gezondheidsvaardigheden en deze indicatoren van gezondheid, zijn we wel van mening dat betere herkenning van en aandacht voor gezondheidsvaardigheden door zorgverleners belangrijk is in het optimaliseren van de behandeling en de kennis van patiënten.

Deel II: Kansen voor verbetering

Waar kwantitatieve data geschikt is om de omvang van een probleem in kaart te brengen, hebben we kwalitatieve gegevens nodig om de dynamiek van gezondheidsvaardigheden in de lokale context te begrijpen. Dit is een belangrijke voorwaarde om ervoor te zorgen dat ontwikkelde interventies en oplossingen in klinisch onderzoek straks ook aansluiten op de klinische praktijk. Deel II van dit proefschrift richt zich daarom op het verdiepen van de kennis van de patiëntbehoeften op het gebied van gezondheidsvaardigheden (opgedaan in Deel I) door middel van kwalitatief onderzoek. Daarnaast behandelt dit deel ook mogelijke oplossingen om beter op deze behoeften in te spelen. In **Hoofdstuk 4** beschrijven we de verder genomen stappen in het proces richting responsieve reumazorg, met aanbevelingen voor vervolgonderzoek en mogelijk implementatie van responsiviteit met betrekking tot gezondheidsvaardigheden in de praktijk. Voortbouwend op de profielen van gezondheidsvaardigheden uit Hoofdstuk 2, en gebruikmakend van eerder verzamelde aantekeningen en aanvullende semigestructureerde interviews, hebben we zes 'gezondheidsvaardigheden vignetten' ontwikkeld. Deze vignetten zijn geanonimiseerde maar toch herkenbare patiëntverhalen, die een beeld geven van enkele uitdagingen van de patiënt op het gebied van gezondheidsvaardigheden. Deze vignetten werden gebruikt als input voor co-creatie overleggen (focusgroepen en individuele interviews) met patiënten (n=14) en zorgverleners (n=38). Deze overleggen draaiden om vier vragen: 1) Herken je deze patiënt?; 2) Wat zijn de uitdagingen voor deze patiënt (in overleg met patiënten en zorgverleners), en/of wat zijn jouw uitdagingen in het behandelen van deze patiënt? (alleen in overleg met zorgverleners); 3) Hoe kunnen we deze patiënt beter ondersteunen?; en 4) Hoe zou onze afdeling eruit moeten zien als er 100 patiënten als deze patiënt zouden zijn? We hebben de uitkomsten van deze overleggen door middel van kwalitatieve analysetechnieken gestructureerd, om zo de uitdagingen en mogelijke oplossingen voor deze uitdagingen (in de vorm van actiepunten) te beschrijven. Deze actiepunten varieerden van kleine en grote wijzigingen in aanpak op elk mogelijke niveau in het zorgproces tot het integreren van bestaande hulpmiddelen of strategieën in de dagelijkse praktijk van zorgorganisaties en zorgverleners.

We identificeerden elf uitdagingen met betrekking tot gezondheidsvaardigheden die van toepassing zijn op mensen met reuma. Zorgverleners en patiënten stelden een breed scala aan mogelijke oplossingen voor deze specifieke uitdagingen voor, alsmede een aantal generieke of universele oplossingen. Oplossingen werden beschreven in drie categorieën met zeven subcategorieën: 1) responsieve zorgverlener-patiënt communicatie, onderverdeeld in a) verduidelijken wat de patiënt zelf kan doen in het zorgproces, en b) toepassen van communicatiestrategieën; 2) cursussen voor a) zorgverleners, en b) patiënten; en 3) organisatorische actiepunten, onderverdeeld in a) verandering in de manier waarop zorgverlening wordt georganiseerd, b) het betrekken van een andere zorgprofessional of organisatie, en c) ontwikkelen en/of aanbieden van materialen om het zorgproces te ondersteunen. We presenteerden een matrix, waarin elke uitdaging op het gebied van

gezondheidsvaardigheden werd verbonden aan actiepunten die mogelijk van toepassing zouden zijn. Meer onderzoek is nodig om deze actiepunten verder te prioriteren en ontwikkelen, en daarna om ze te evalueren en integreren in de dagelijkse zorgpraktijk. Het opvolgen van deze actiepunten, die zijn voorgesteld door patiënten en zorgverleners, zou de responsiviteit met betrekking tot gezondheidsvaardigheden van de reumatologische zorg kunnen verbeteren, en heeft de potentie om gezondheidsuitkomsten te verbeteren.

In **Hoofdstuk 5** laten we zien dat het werk wat wij doen in de reumazorg niet op zichzelf staat. Integendeel, het project is ingebed in een internationaal netwerk van onderzoekers en zorgverleners, ondersteund door de Wereldgezondheidsorganisatie (WHO), onder de noemer van WHO National Health Literacy Demonstration Projects (NHLDPs). In dit rapport presenteren we onze gezamenlijke missie om iets te doen aan de ziektelast van niet-overdraagbare (chronische) ziekten, de methodologische aanpak om dit te bereiken, en het doel en de context van elk van de zeven Europese NHLDPs zoals die per april 2019 bestonden. Ook bespreken we hoe deze projecten kunnen bijdragen aan betere en meer gelijkwaardige gezondheidsuitkomsten. We laten zien dat het uitwisselen van kennis en handelingen de lokale projecten kan versterken. Daarnaast kunnen de gezamenlijke uitkomsten van meerdere projecten bijdragen aan de generaliseerbaarheid van de bevindingen, veel beter dan een enkel project dat zou kunnen.

Deel III: Het perspectief van organisaties

Het doel van dit proefschrift op de lange termijn is om bij te dragen aan de responsiviteit van reumatologische zorg met betrekking tot gezondheidsvaardigheden. Hiervoor is het van belang dat zorgorganisaties en zorgverleners de behoeften van patiënten herkennen, en zorg verlenen op een manier die bij die behoeften past. Het laatste doel van dit proefschrift was daarom om te onderzoeken of er in de huidige situatie genoeg bewustzijn is over gezondheidsvaardigheden onder zorgverleners en organisaties om aan deze verwachtingen te voldoen. In **Hoofdstuk 6** onderzochten we de discrepanties tussen de HLQ-scores van patiënten en de intuïtieve inschatting van deze scores door de behandelend zorgverlener. Voor alle patiënten die deelnamen aan de studie beschreven in Hoofdstuk 2, vroegen we aan de zorgverlener of die een korte vragenlijst over de patiënt wilde invullen. De zorgverleners gaven een inschatting van de gezondheidsvaardigheden van hun patiënt op elk van de negen domeinen van de HLQ, op een schaal van nul tot tien. Daarnaast gaven zorgverleners aan hoe goed ze de patiënt kenden, en beoordeelden ze de impact van de reumatologische aandoening op de algehele gezondheid en het functioneren van de patiënt. Om de scores van de zorgverleners te kunnen vergelijken met de scores van de patiënten werden de HLQ-scores omgerekend naar dezelfde schaal van nul tot tien. We hebben gegevens van 778 patiënt-zorgverlener paren.

Voor het analyseren hebben we 'discrepantie' (gebruikte term in het Engels: 'discordance') gedefinieerd als een verschil gelijk aan of groter dan twee punten. Omdat het verschil tussen

de twee scores in beide richtingen kan plaatsvinden, ontstonden er drie categorieën: 1) 'negative discrepantie' (d.w.z. de zorgverlener scoorde lager dan de patiënt); 2) beide scores zijn 'waarschijnlijk gelijkwaardig'; en 3) 'positieve discrepantie' (d.w.z. de zorgverlener scoorde hoger dan de patiënt). Als, ondanks een verschil van minimaal twee punten, zowel de patiënt als de zorgverlener een score lager dan drie of hoger dan zeven scoorden, dan was dit onzes inziens een indicatie dat ze het eens waren dat de score ofwel 'zeer laag', ofwel 'zeer hoog' was. Deze gevallen werden gecategoriseerd als 'waarschijnlijk gelijkwaardig'. Omdat er geen gouden standaard bestaat om objectief gezondheidsvaardigheden te kunnen meten, weten we niet of deze discrepanties betekenen dat zorgverleners patiënten over- of onderschatten, patiënten zichzelf over- of onderschatten, of dat ze waarheid ergens in het midden ligt. Desondanks betekent een aanmerkelijke discrepantie tussen beide scores dat patiënten en hun zorgverleners in elk geval niet op één lijn zitten betreffende de gezondheidsvaardigheden van de patiënt.

Er waren verschillen in het aantal discrepanties tussen de HLQ-domeinen; discrepanties kwamen voor in 20.7 tot 40.5% van de gevallen, afhankelijk van het specifieke domein. Daarnaast gaven zorgverleners in bijna een vijfde van de gevallen (19.4%) aan niet te weten in hoeverre de patiënt sociale steun had (HLQ-domein 4). Dit laat zien dat sociale steun mogelijk niet voldoende aandacht krijgt in het consult. We hebben door middel van multilevel multinomiale regressiemodellen ook de rol van sociaaleconomische factoren in zowel negatieve als positieve discrepanties onderzocht voor elk van de negen HLQ-domeinen. We vonden dat voornamelijk negatieve discrepanties gerelateerd waren aan sociaaleconomische factoren; met name een lager onderwijsniveau en een niet-Westerse migratieachtergrond (voor 5 HLQ-domeinen). We concludeerden hieruit dat een correcte inschatting van de gezondheidsvaardigheden van patiënten door zorgverleners niet vanzelfsprekend is. Onze resultaten laten zien dat er mogelijk verborgen uitdagingen liggen in de communicatie en de zorgverlening, en dat deze uitdagingen niet gelijk verdeeld zijn tussen bevolkingsgroepen en tussen de HLQ-domeinen. Hiermee willen we nog maar eens benadrukken dat gezondheidsvaardigheden dus een multidimensionaal karakter hebben, en dat ook eventuele uitdagingen met betrekking tot het omgaan met de gezondheidsvaardigheden van de patiënt mogelijk niet gelijk verdeeld zijn tussen verschillende bevolkingsgroepen. Bovenal hebben we hiervan geleerd dat het beter omgaan met gezondheidsvaardigheden niet af kan hangen van inschattingen. We zullen gezondheidsvaardigheden moeten meten, en met elkaar in gesprek moeten gaan.

Ten slotte hebben we in **Hoofdstuk 7** onderzocht in hoeverre gezondheidsvaardigheden werden meegenomen in crisiscommunicatie. Terwijl dit promotietraject liep, bood de Coronavirus Disease 2019 (COVID-19) pandemie een unieke kans om inzicht te krijgen in de manier waarop reuma-organisaties in de praktijk al rekening houden met gezondheidsvaardigheden van patiënten. We voerden een convergent, kwalitatief gedreven mixed-methods studie uit, waarin we keken naar belangrijke aspecten van goede

crisiscommunicatie, en het expliciet meenemen van gezondheidsvaardigheden in de communicatie met mensen met een reumatische aandoening, gedurende de eerste golf van COVID-19 in Nederland. Het onderzoek betrof een combinatie van bevindingen uit zeven kwalitatieve interviews met (professionele) vertegenwoordigers van organisaties met een rol in de informatievoorziening aan mensen met reuma, en een kwantitatieve analyse van vijftien voorlichtingsmaterialen voor patiënten die door deze zelfde organisaties werden verspreid.

Tijdens de analyse van de kwalitatieve gegevens met veelvoorkomende coderingstechnieken ontstond er een thematische structuur. Op basis hiervan hebben we een raamwerk gemaakt, bestaande uit vier pilaren van crisiscommunciatie: 1) voorbereid zijn; 2) strategie; 3) bereik; en 4) inhoud van de gecommuniceerde informatie. De bevindingen rondom gezondheidsvaardigheden werden apart beschreven en geëvalueerd, als een thema dat steeds terugkeerde. De kwantitatieve analyse van de patiëntinformatiematerialen bestond uit een beoordeling van het taalniveau door de 'Klinkende Taal' applicatie, en een beoordeling van de toepasbaarheid en begrijpelijkheid met behulp van het 'Voorlichtingsmateriaal BeoordelingsInstrument' (VBI). Klinkende Taal beoordeelt een tekst op het gebruik van moeilijke woorden, vakjargon, passieve, moeilijke, en lange zinnen, en lange paragrafen. Daarnaast geeft de applicatie een inschatting van het taalniveau van de tekst. Er zijn zes mogelijke taalniveaus, lopend van A1 (meest eenvoudig) tot C2 (hoogste niveau). Deze niveaus zijn aangegeven door het Common European Framework of Reference for Languages (CEFR). Er is brede consensus dat patiëntinformatiematerialen niet moeilijker zouden mogen zijn dan B1-niveau, om ervoor te zorgen dat het grootste deel van de bevolking de geschreven informatie kan begrijpen. De VBI is een checklist met verschillende criteria, waarvan niet alle criteria op elk materiaal van toepassing zijn. De uitkomst van de VBI is een percentage van alle relevante criteria waaraan is voldaan. Er is een aparte score voor toepasbaarheid en begrijpelijkheid.

Ondanks de uitgebreide inspanningen van de organisaties vanaf het moment dat de dreiging van de pandemie reëel werd, gaven de deelnemers in deze studie aan dat de organisaties niet voorbereid waren om goede crisiscommunicatie te garanderen. Ook waren er uitdagingen op het gebied van wetenschappelijke onzekerheden en het bereiken van de doelgroep. Daarnaast hadden de organisaties moeite met het versimpelen van informatie, en waren ze er niet zeker van dat hun communicatieaanpak het beoogde effect had. De onderzochte voorlichtingsmaterialen voor patiënten waren zeer divers in toepasbaarheid (aan 60-100% van de relevante criteria werd voldaan) en begrijpelijkheid (aan 58-100% van de relevante criteria werd voldaan). Daarnaast zagen we dat 69% van de materialen te moeilijk was qua taalniveau, voornamelijk door het gebruik van lange zinnen en moeilijke woorden. Deze kwantitatieve bevindingen waren in lijn met de kwalitatieve bevindingen uit de interviews. We hebben naar aanleiding van deze studie diverse 'geleerde lessen' geformuleerd, die je zou kunnen zien als kansen voor verbetering. We stellen dat ondanks de inspanningen van reuma-organisaties en individuele zorgverleners er onvoldoende aandacht was voor de

gezondheidsvaardigheden van de patiëntpopulatie, en dat de voorlichtingsmaterialen voor patiënten die werden gebruikt niet eenvoudig genoeg waren.

Deze laatste twee inhoudelijke hoofdstukken laten zien dat het niet genoeg is om dingen te doen zoals we ze altijd hebben gedaan, maar dan met gezondheidsvaardigheden in het achterhoofd. Zo'n aanpak zou onvoldoende zijn om adequaat op de behoeften van patiënten in te spelen. Om daadwerkelijk verschil te maken op het gebied van gezondheidsvaardigheden in de reumazorg is er een gerichte, integrale aanpak nodig. Hierbij moeten zowel zorgverleners als organisaties betrokken worden. Het onderzoek gepresenteerd in dit proefschrift kan hierbij dienen als veelbelovend begin van toekomstige inspanningen.

DANKWOORD / ACKNOWLEDGEMENTS

One day you will say, "I did it". Deze quote lieten we als CAPHRI PhD Representatives op koelkastmagneetjes drukken, om cadeau te doen aan alle binnenkomende promovendi. Ik ben heel blij en ook wel een beetje trots dat het voor mij nu ook zo ver is. Wat ze je aan het begin van je promotietraject echter niet vertellen, is dat je er nog helemaal niet bent op het moment dat je denkt dat je er bent. Dan komt namelijk het moeilijkste nog; het schrijven van het dankwoord. Bij dezen dan mijn dappere poging. Hieronder staan een aantal mensen specifiek genoemd, maar als je dit leest, dan is de kans groot dat ook jij de afgelopen 29 jaar een grote of kleine bijdrage hebt geleverd aan mijn reis die geleid heeft tot deze dag. Dat mijn naam voorop dit boekje staat, heb ik niet alleen aan mezelf, maar ook aan jou te danken. Vanuit de grond van mijn hart: Bedankt!

One day you will say, "I did it". As CAPHRI PhD Representatives, we printed this quote on fridge magnets, so we could gift them to incoming PhD candidates. I am delighted and even a little bit proud that I have gotten to this point. However… What they don't tell you at the beginning of your PhD-trajectory, is that you haven't actually done it yet when you think you've done it. The hardest thing is yet to come; writing your acknowledgements. I've given it my all, nonetheless. A couple of people are mentioned explicitly below, but if you read this, chances are that you contributed (in whatever way, large or small) to my journey that has led to this day. That my name is printed on the cover of this book is not just thanks to me, but also thanks to you. From the bottom of my heart: Thank you!

Veel mensen verdienen een speciale vermelding in dit hoofdstuk. Allereerst mijn promotieteam, **Prof. dr. Annelies Boonen** en **dr. Polina Putrik**. Ik bewonder jullie beiden om jullie analytisch vermogen en werkethiek, en ik ben dankbaar dat jullie mij steeds probeerden uit te dagen om kritisch te zijn op mijn eigen denken, handelen, en schrijven. Annelies, wat moet ik zeggen. Toen Polina me vertelde over een mogelijke vacature en ik om meer informatie vroeg, stelde ze voor om gelijk de hoogleraar maar te ontmoeten. In dat eerste gesprek raakte ik onder de indruk van uw kalm en zorgvuldig verwoorde inhoudelijke analyses. Onze afspraken zijn misschien niet altijd even efficiënt, omdat we er beiden genoegen in scheppen om complexe situaties uit te pluizen. Het was dan ook genieten om een aantal keer het halve land met u te doorkruisen naar de partnercentra, omdat dat ons de gelegenheid gaf om ruim drie uur door te praten. Het is zowel bij de UM als binnen de reumatologie fijn om te kunnen zeggen dat u mijn promotor bent, omdat men weet dat u als onderzoeker en als mens waarde hecht aan persoonlijke aandacht en het streven naar (gezondheids-)gelijkheid. Dank u wel dat u mij de kans heeft gegeven om aan uw doelen mee te werken.

Polina, we hebben elkaar ooit ontmoet via video-call, toen ik solliciteerde voor een stageplek voor mijn eerste masterscriptie terwijl ik nog in India zat. Ik was verrast dat ik aan de stage mocht beginnen, meer verrast dat je je als kwantitatief onderzoeker zo vast kon bijten in kwalitatief onderzoek, en nog meer verrast toen je bij een van onze bezoekjes aan een

buurtnetwerk in Maastricht liet vallen dat Nederlands je vierde taal was. Hoewel onze meeste gesprekken in het Engels verlopen, wil ik je graag in je vierde taal bedanken, juist omdat ik daar zo onder de indruk van ben. Bedankt dat je aan mij dacht toen jullie een onderzoeker zochten om op de poli reumatologie data te verzamelen, en bedankt voor je begeleiding de afgelopen jaren. Uit de manier waarop je (vooral in de laatste periode) je feedback verwoordde, kan ik zien dat je inzicht hebt gekregen in hoe ik denk, en daar meteen rekening mee hield. Dankjewel dat je die moeite neemt, en dankjewel voor het delen van al je kwantitatieve kennis.

Next, I'd like to thank the assessment committee for reading and approving my dissertation: **Prof. dr. Christian Hoebe**, **Prof. dr. Karin Faber**, **Prof. dr. Tim Huijts**, **dr. Elena Nikiphorou** and **Prof. dr. Orkan Okan**. Ook **dr. Yvonne van Eijk-Hustings** wil ik hartelijk bedanken voor het lezen van mijn proefschrift en deelnemen aan de verdediging. Dank ook voor je hulp bij het werven van patiënten met jicht tijdens je werk als reumaverpleegkundige.

To my co-authors, thank you for your support and input on the work presented in this thesis. I have grown as a researcher, thanks to you. **Hanneke Voorneveld-Nieuwenhuis**, **dr. Marc Kok, Prof. dr. Harald Vonkeman** en **Prof. dr. Mart van de Laar**, dank voor jullie hulp bij het uitvoeren van dit project in het Maasstad Ziekenhuis en het Medisch Spectrum Twente. **Prof. dr. Jany Rademakers**, ontzettend bedankt voor al uw advies over gezondheidsvaardigheden in de Nederlandse context. Het was fijn om op uw lokale expertise te kunnen bouwen. **Dr. Maarten de Wit**, veel dank voor het steeds opnieuw inbrengen van het patiëntperspectief, ook op momenten dat ik dit zelf soms uit het oog verloor. Dank ook voor je prettige introductie bij het EULAR PARE congres en de samenwerking daar. Thanks to **Prof. dr. Richard Osborne** for being a main contributor to the theory underlying this dissertation, for your tireless efforts in promoting health literacy development around the world in diverse settings, and for your appreciation of excellent vega(n) food. I hope to be part of your network for years to come. **Prof. dr. Rachelle Buchbinder**, **dr. Sofia Ramiro**, **dr. Roy Batterham**, **Prof. dr. Helle Terkildsen Maindal**, **dr. Anna Aaby**, **dr. Christine Råheim Borge**, **dr. Dulce Nascimento do Ó**, **dr. Peter Kolarčik**, **Janis Morrissey**, **dr. Peter ten Klooster**, thank you for your contributions to our scientific publications. Speciale dank ook aan de stagiairs die co-auteurs werden: **Cédric**, **Tess**, **Isabelle** & **Anne**. Jullie bijdragen zijn cruciaal geweest voor het vorderen van mijn project. Ik hoop dat jullie met plezier en tevredenheid terugkijken op jullie stageperiode.

Graag bedank ik ook alle **patiënten en zorgverleners** (reumatologen, reumaverpleegkundigen, verpleegkundig specialisten, physician assistants en natuurlijk de aiossen) die ik in de loop van de jaren heb gesproken in het kader van dit project. Velen van jullie hebben deelgenomen aan de studies, waarvoor veel dank. Nog dankbaarder ben ik voor de vele informele gesprekken tussen het onderzoek door. De tijd die ik op de polikliniek heb doorgebracht was ontzettend waardevol. Zonder jullie hadden we niet zoveel geleerd over het beter omgaan met gezondheidsvaardigheden in de reumatologie. Veel dank ook aan **Mirjam Hegeman** voor het regelen van de praktische zaken met betrekking tot dit onderzoek in Enschede.

Het secretariaat reumatologie, **Peggy Renckens** en **Patricia Munsters**, maar ook zeker **Sandra Kolkman** en **Yvonne Steijns**, super bedankt voor al jullie ondersteuning tijdens mijn promotietraject. Fijn dat jullie er voor Annelies en voor de afdeling zijn (of waren).

Alle collega's van de reumatologie, zowel in de zorg als in het onderzoek, dank jullie wel. In het bijzonder **Esther**, **Ritch**, **Kasper** en **Maarten**, de promovendi uit mijn 'lichting'; dank voor het delen van lief en leed, in ons ruime kantoor met premium uitzicht op St. Pieter in het Provisorium. We zijn allemaal erg verschillend en doen erg verschillend onderzoek, maar in mijn beleving paste dat heel fijn bij elkaar. Esther, ik beloof dat ik je nooit meer een half uur zal laten wachten tot ik gekozen heb welke HappySocks ik wil kopen. Kasper, ik ben erg voorzichtig geworden met proosten op succes (die ene METC-goedkeuringsborrel die gevolgd werd door een maandenlange lockdown komt terug in mijn nachtmerries), maar ik kijk er enorm naar uit om straks te proosten op de afronding van jouw gigantische project. **Casper**, bedankt voor het delen van je ervaringen als 'ouderejaars'; fijn dat je af en toe even langskwam om te printen (lees: een half uur te kletsen). **Marin** & **Saskia**, jullie waren zeer welkome versterking; veel succes met jullie verdere projecten!

I am grateful for the exchange of knowledge and ideas within the **WHO NHLDP Network** and both the Practice Standards Committee and Health Literacy Explorers group within the **International Health Literacy Association**. Veel dank ook aan de organisatoren en partners van de **Alliantie Gezondheidsvaardigheden** voor de netwerkbijeenkomsten die altijd weer leidden tot nieuwe inspiratie en energie. **Dr. Jan Custers**, bedankt dat je mij ooit als student fysiotherapie op de weg tot de wetenschap hebt gebracht.

Mijn mede PhD Representatives bij CAPHRI, lieve **Inez**, **Michelle** en **Raisa**. Het was me een eer om me samen met jullie te mogen inzetten voor meer verbinding naar en tussen CAPHRI-promovendi. Ondanks dat de pandemie al onze ideeën voor fysieke bijeenkomsten overhoopgooide, hebben we er samen een productieve en leuke tijd van gemaakt. Het was een zeer welkome variatie op het onderzoekswerk. Ik heb in de periode als Representative veel met en van jullie geleerd. Ik stel voor dat we onze regelmatige etentjes nog lang blijven voortzetten. Dank ook aan **dr. Hannerieke van der Boom**, **Hanneke Trines, Chantal Claessens, Prof. dr. Maurice Zeegers** en **Martijn Streefkerk** voor de fijne samenwerking bij CAPHRI in deze periode.

Dan kom ik langzaam maar zeker bij de belangrijkste groep mensen, te beginnen bij mijn geweldige paranimfen, **Ricky** and **Sander**. Dear Ricky, I'd write this in your preferred language if I could, but I'm just not proficient in Limburgian. From the moment you dropped my beer, trying to help this poor kid (was I really only 21?) on crutches at the Global Health introday in August 2015, I had a feeling we would become good friends. You have been a consistent source of inspiration, critical thinking, and red wine for the past 8 years, and I know both my dissertation and myself have become stronger because you were around. Sander, mijn Duits is van hetzelfde niveau als mijn Limburgs, dus voor jou doe ik dit stukje maar in het Nederlands. Lees dit anders maar met een Heydrich-accent in gedachten. Chronobiologie.

Kinderarts. Fijne kameraad. Ondanks dat we uitgebreid hebben geoefend met het schrijven van stukjes namens de PR in de Nijlpraad van MSKV De Hippo's, vind ik het elke keer weer een uitdaging om ook maar in de buurt te komen van het niveau van jouw poëtische schrijfsels. Ik bewonder de manier waarop je altijd weloverwogen kiest voor wat het beste bij jou past. Je hebt daarnaast het talent om mensen zich comfortabel te laten voelen, en om dan op precies het juiste moment de vraag te stellen die leidt tot nieuwe inzichten of een quarterlife-crisis; beide enorm gewaardeerd. Lieve Ricky en Sander, wat fijn dat jullie er ook tijdens dit laatste stukje promotietraject voor me zijn. Dank jullie wel voor alles.

Lieve **Lonne**, **Rose**, **Inez** en **Perla**, een PhD afmaken lukt alleen met de steun van lotgenoten. Zonder jullie was het niet half zo leuk geweest. Veel dank voor alle koffie, biertjes, afleiding en 'inspo'. Op een dag zullen we de Maas Bucketlist afstrepen! Aan de leden van '**Dansvereniging Staalin'** en de '**Pianostraat**': Lieve vrienden, fijn dat jullie het leven altijd een beetje leuker maken, en fijn dat jullie het me hebben vergeven als ik door mijn promotieonderzoek weer eens fysiek (of vooral mentaal…) afwezig was. Proost, op de vriendschap. Stuurt iemand een datumprikker? Members of '**Casa KFC'** (+) and the '**Geringverdiener**' (+), thank you all for the wonderful energy you bring into my life. It's exciting to watch all of you grow into full-fledged adults. You inspire me! Een speciale vermelding voor **Tessa**, die naast haar status als beste gids (ook wel het levend monument) in Maastricht voor de rest van ons leven mijn grote Global Health-voorbeeld zal zijn. Ik ben trots op je! Ik kijk uit naar onze eerstvolgende Bemmelse Dweildag, en het 'per ongeluk' bestelde extra rondje bij de Gouverneur. Dear **Olga**, **Cara**, **Rok** and **Nina**, you are living proof that personalised mugs are the glue to sustainable friendships, long after the memories of a certain Christmas party or nights out dancing at the Alla have faded. I cannot wait to further fuel my Vistaprint addiction for future life events, however large or small. Nina, thank you for consistently proving to be the best brunch host in the Northern Hemisphere. Olga & Cara, thank you for being my soundboard for virtually everything, and for always having another relatable meme in stock to make me scream "Same!"

Tot slot, mijn lieve familie, te beginnen met de speciale familieleden, **Judith** en **Kevin**. Lieve Judith, je weet hoe belangrijk onze vriendschap voor me is. Ruim 28 jaar 'Jip en Janneke', and counting! Ondanks dat we nu 200 kilometer uit elkaar wonen in plaats van de 5 meter die we vroeger gewend waren, zorgen we dat we op de hoogte blijven van elkaars leven, en altijd als we elkaar zien voelt het alsof ik thuis ben. Fijn dat je er altijd bent. Lieve Kevin, ik daag je een beetje uit door jouw stukje in het Nederlands te schrijven. Als je een week lang met Jord kan kletsen, dan moet het lezen van een paar regels ook wel lukken, toch? Van bijna zevenduizend kilometer afstand naar samenwonen (inclusief lockdown) in 1 ruimte; we hebben wel bewezen alles aan te kunnen. Bedankt dat je al die jaren mijn grootste supporter bent geweest, vooral als mijn impostor syndrome weer eens de kop op stak. Je weet precies wat je moet zeggen om me mijn zelfvertrouwen terug te geven. Vergeet niet dat jij nog steeds de slimste van ons tweeën bent! Ik kijk ernaar uit om te zien waar jouw pad je verder brengt. Ik hou van je.

Mijn lieve zussen, **Dianne** & **Marinka**, ik hoop dat jullie een beetje trots zijn op jullie kleine broertje, want ik ben zeker trots op jullie. Ik ben blij dat jullie me als moeder #2 en #3 hebben geholpen (een soort van) volwassen te worden. Marinka, jij bent degene geweest die mij echt enthousiast heeft gemaakt over het werk in de zorg. Hoewel ik de zorg (voorlopig) verlaten heb, ben ik nog steeds heel blij met deze praktische achtergrond in mijn onderzoek en onderwijs. Je bent een voorbeeld voor me, in je werk en als moeder voor Jord en Lars. Dianne, ik bewonder je creativiteit en intelligentie. Jij hebt echt voor elk praktisch probleem een oplossing! Je bent een aanwinst voor de dementiezorg, maar ook voor alle mensen die je om je heen verzamelt. Dank voor je wijze raad met betrekking tot mijn kledingkeuzes van vandaag.

Tot slot, **pap** & **mam**, sorry dat ik al jaren zo ver weg woon, ondanks dat ik maar voor vier maanden naar Maastricht zou gaan. Het voordeel daarvan is wel dat ik jullie al gauw met overnachting zie, ergens in Zuid-Limburg of thuis in Zeewolde. Jullie zijn als koppel en als individuen belangrijke voorbeelden voor me, zowel in mijn werk als in mijn persoonlijke leven. Het is fijn om altijd trots over mijn ouders te kunnen vertellen; ik realiseer me dat dat niet vanzelfsprekend is. Bedankt dat jullie ons altijd de ruimte geven om keuzes te maken die bij ons passen, en dat ik altijd met mijn verhalen en mijn zorgen bij jullie terecht kan. Lieve papa, (pas op, er komt een cliché aan…) ik lijk steeds meer op jou, en hoe ouder ik word, hoe blijer ik daar mee ben (al hoop ik nog steeds dat die terugtrekkende haarlijn me wat langer bespaard blijft…). Ik ben dankbaar dat ik wat van jouw kwaliteiten als geboren leraar heb geërfd, en dat ik zo vroeg in mijn carrière heb mogen ontdekken dat het lesgeven mij goed ligt. Lieve mama, voor altijd de belangrijkste vrouw in mijn leven. Het 'zorgen voor' zit bij jullie allebei in het bloed, maar bij jou staat ook nog eens 'vertel het me' op je voorhoofd geschreven. Dat ik daar een klein beetje van meegekregen heb, heeft me enorm geholpen, zowel in mijn sociale leven als in mijn (kwalitatieve) onderzoek. Ik kijk met veel bewondering naar hoe je je werk in de zorg doet en ervaart, en hoe je er bent voor de mensen om je heen, als het leven leuk is en als het moeilijk is. Lieve pap & mam, zonder jullie support was dit me nooit gelukt. Bedankt voor alles, ik hou van jullie.

"I did it!"