A SURVEY AMONG PATIENTS
EU – THE NETHERLANDS
A QUANTITATIVE STUDY ABOUT THE PATIENT PERSPECTIVE ON COMMUNICATION ABOUT AND MANAGEMENT OF RHEUMATOID ARTHRITIS (RA)
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BACKGROUND & OBJECTIVES
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The RA NarRAtive is an international initiative, aimed at elevating the important role of the patient in the successful management of RA. In collaboration with Pfizer, the RA NarRAtive is supported by a global Advisory Panel comprised of 39 healthcare providers and patient group leaders from 17 countries. Its purpose is to improve rheumatoid arthritis disease management through harnessing the experience of people with RA, physicians and patient advocates to develop solutions that break down communication barriers and create positive change within the RA community.

This report represents the perspective of RA patients in the Netherlands. All patients were diagnosed with RA by a healthcare professional and were seen by a rheumatologist. The results are, were possible, split up into the severity of symptoms as determined by a health care professional.

As background, in 2014 and 2015, the RA NarRAtive completed a major survey of adult RA patients worldwide.
RESEARCH METHOD

Method
Online (CAWI) on the GfK online panel

Fieldwork
August 18th – September 12th 2016

Target group
Patients with RA diagnosed by a health care professional, and they have to visit a rheumatologist.

Sample
A total of **424 respondents**, of which:
- 50 respondents with mild RA according to their health care professional
- 306 respondents with moderate to severe RA according to their health care professional
- 68 respondents with severe RA according to their health care professional

Questionnaire
Length of questionnaire: ± 22 minutes
KEY FINDINGS FROM PATIENTS IN THE NETHERLANDS
KEY MESSAGE 1: GAPS BETWEEN BELIEF AND PRACTICE IN SETTING GOALS

Patients are affected quite severely by their RA and most of them have set goals for managing their disease. However, the majority have not set treatment goals with their physician.

- RA has a major influence on the patients with this disease:
  - Only a third can perform all activities in daily life without assistance;
  - More than half (53%) has stopped participating in certain activities due to the RA;
  - Also, 25% of the patients are unable to work due to a disability or illness and for 62% this was caused by the RA.

- In the Netherlands, 94% of RA patients indicate they have goals for managing their RA (of people with severe RA this is even 96%), however, only about 4 in 10 (43%) have set treatment goals with their health care professional. With the severe RA patients, treatment goals are set somewhat more often but still only in 53%.

- Furthermore, only 35% of the Dutch RA patients report having developed a disease management plan with their physician.
KEY MESSAGE 2: SEVERE PATIENTS INDICATE THEY CAN BE TREATED BETTER; OTHER PATIENTS ARE SETTLING

Many patients with severe RA are not completely satisfied with their medication regimen. The patients with moderate or mild RA seem to be settling but improvement is possible for part of them as well.

• Only 53% of the patients with severe RA in the Netherlands report being satisfied with their current medication. 34% of the severe RA patients have clear negative feelings about their medication: they feel concerned (13%), burdened (7%), frustrated (5%), confused (5%) or uncertain (4%) about their medication. In addition to this, almost half of the patients with severe RA (49%) indicates that their RA is active and a third (34%) that this is not under control.

• Feelings of patients with moderate or mild RA about their medication are more positive: 58% of patients with moderate RA and 76% of patients with mild RA are satisfied; also the RA is more often under control, in remission or on low activity. Still, for patients with moderate RA, for 36%, their RA is active and for 11% the RA is not under control. For patients with mild RA, in 16% their RA is active.

• 53% of the patients with severe RA indicate areas they would ideally change about RA medications (for moderate to severe 49% and for mild RA 42%). These areas are the following. Patients who are currently taking Rx medications say that they:
  • Wish the number of side effects could be reduced (21%)
  • Wish the severity of side effects could be reduced (16%)
  • Wish they could take fewer medications for their RA (15%)

• Many patients (66% of the total group of patients and 68% of the patients with severe RA) note areas where their relationship with the rheumatologist could be improved in order to help more successfully manage their RA. Suggestions made most often are:
  • Discussing new symptoms or experiences since their last visit (35%)
  • More information about the RA treatment options that are available to the specific patient (21%)
KEY MESSAGE 3: TREATMENT AND COMMUNICATION FOCUS VARIES BETWEEN PHYSICIAN AND PATIENT

Data indicate that one reason for a disconnect between patient and physician communication in the Netherlands is the focus of the physician on the medication and possible side effects and less focus on important aspects for the patient as pain and ability to participate normally in daily life.

• When thinking about what “successful” treatment means, patients want to eliminate the pain (70%), reduce interference with daily activities (61%) and decrease joint swelling/inflammation (62%).

• Additionally, when it comes to discussing the medication with their physician:

  **Physicians are more likely to discuss:**
  • How the medication works (71%)
  • Side effects (70%)
  • The importance of taking my medication/following my treatment plan exactly as prescribed (70%)

  **Physician are less likely to discuss:**
  • Restrictions on the patients life due to the medication(s) (38%)
  • Practical aspects of the medication, like oral or injectable (38%), how to receive it (36%), differences between various biologicals (39%)
KEY MESSAGE 4: DISCONNECT BETWEEN COMMUNICATION SATISFACTION AND RAISING CONCERNS

Despite the fact that quite some patients feel uncomfortable raising concerns and fears with their physician, many patients and physicians in the Netherlands indicate that they are satisfied with their communication about RA treatment.

- Patients are in general satisfied with the communication with their rheumatologists about RA treatment (87%). However, patients with severe RA are somewhat less satisfied (80%) than the group moderate to severe (86%) and mild (92%).
- Yet, there are some aspects that could be improved:
  - 34% wish their rheumatologist and they themselves talked more about the RA goals and treatment;
  - 28% wish they could visit their rheumatologist more often;
  - 15% feel that their rheumatologist often ignores their concerns about medications or alternative treatment plans.

- More than 4 in 10 patients in the Netherlands (44%) report feeling uncomfortable raising concerns and fears with their rheumatologist. Nearly 1 in 5 (19%) worry that if they ask too many questions, their physician will see them as a difficult patient and it will affect the quality of their care.
KEY MESSAGE 5: UNDERUTILIZATION OF VALUABLE COMMUNITY RESOURCES

Time represents a barrier to the success of any medical visit. While also patient advocacy groups and patient support groups can be used as a way to gather more information and support, few patients utilize these local resources.

- The health care professional is seen as the most important source of information and advice about the RA treatment. However, more than a quarter of the patients (28%) wish they could see their health care professional more often.

- RA advocacy groups and RA patient support groups seem to be underused as source of information: only 28% of the RA patients use RA advocacy groups and 10% RA support groups. The patients with severe RA make use of the RA support groups a bit more often: 18% of the patients with severe RA rely on them as one of their information sources.
DETAILED FINDINGS
PATIENT PROFILE AND ASSESSMENT METRICS
MOST COMMON CO-MORBIDITIES ARE DIABETES, HEART DISEASE AND IBS. 70% OF RA PATIENTS WERE FIRST DIAGNOSED ON THE AGE OF 35 – 65 YEAR

Diagnosed health conditions + Age

Q600. Have you ever been diagnosed by a doctor or health care professional with any of the following health conditions?

Q710. How old were you when you were first diagnosed with RA?

Base Q600 & Q710: All respondents (n = 424)

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PATIENTS DESCRIBE THEIR RA MORE OFTEN AS MILD THAN HEALTH CARE PROFESSIONALS

Q715. How would you currently describe your RA? And how would your doctor or healthcare professional describe your RA?

Base: All respondents (n = 424)
Q716. How would you currently describe your RA? And how would your doctor or healthcare professional describe your RA?

Base: All respondents (n = 424)
MORE THAN A QUARTER OF PATIENTS WITH SEVERE RA NEED SOME HELP EACH DAY FOR MOST PHYSICAL ACTIVITIES

Ability to perform everyday activities

I can perform most physical activities without assistance but need some help with more strenuous activities such as cleaning and grocery shopping

- Severe: 60%
- Moderate to severe: 59%
- Mild: 36%

I need some help each day for most physical activities (e.g., walking up and down stairs, rising from sitting) but do not necessarily require around-the-clock care

- Severe: 26%
- Moderate to severe: 8%
- Mild: 0%

I can perform all physical activities of daily living without assistance

- Severe: 32%
- Moderate to severe: 10%
- Mild: 32%

I need around-the-clock care to help me with nearly all activities of daily living, including dressing, grooming (e.g., brushing hair/teeth), and cooking

- Severe: 64%
- Moderate to severe: 10%
- Mild: 3%

Q725. Which of the following best describes your current ability to perform everyday activities?

Base: All respondents (n = 424)
RA HAS A PROFOUND IMPACT ON THE WORKING LIFE OF THE PATIENTS

Employment status + consequences of RA

Q1410a. Which one of the following best describes your employment status?

Q1410b. Do you have to report sick more than average because of your RA?

Q1410d. Did you retire earlier than you planned to retire due to your RA?

Q1410c. Are you unable to work due to your RA?

Base Q1410a: All respondents (n = 424)
Base Q1410b: Is employed (full time/part time/self-employed) (n = 100)
Base Q1410d: Is retired (n = 167)
Base Q1410c: Is unemployed (n = 106)
MOST OF THE PATIENTS HAVE MADE ADJUSTMENTS IN THEIR LIVES DUE TO THEIR RA

Q726. Have you done any of the following as a result of your RA?

Base: All respondents (n = 424)
RA MANAGEMENT
ABOUT HALF OF THE PATIENTS DON’T SET TREATMENT GOALS WITH THEIR RHEUMATOLOGIST FOR THEIR RA

Actions with rheumatologist

Discuss how my current medication may help reach my treatment goals
- 65% - 60% - 64%

Set treatment goals for my RA
- 53%

Discuss how complementary therapies may or may not help me achieve my treatment goals
- 46%

Discuss my progress towards my treatment goals during every visit
- 44%

Developed a disease management plan
- 35%

None of these
- 13%

Q818. Which of the following, if any, have you done/do you do with your rheumatologist?

Severe
Moderate to severe
Mild

Base: All respondents (n = 424)
### Actions with rheumatologist

<table>
<thead>
<tr>
<th>Action</th>
<th>Total</th>
<th>Severe</th>
<th>Moderate to severe</th>
<th>Mild</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assess the current status of my RA</td>
<td>80%</td>
<td>85%</td>
<td>79%</td>
<td>82%</td>
</tr>
<tr>
<td>Discuss my progress toward my treatment goals</td>
<td>60%</td>
<td>72%</td>
<td>57%</td>
<td>60%</td>
</tr>
<tr>
<td>Prepare for visits in advance</td>
<td>56%</td>
<td>65%</td>
<td>55%</td>
<td>50%</td>
</tr>
<tr>
<td>Evaluate/update my disease activity score</td>
<td>42%</td>
<td>57%</td>
<td>40%</td>
<td>36%</td>
</tr>
<tr>
<td>Assess the progression of joint damage by evaluating my x-rays/ultrasounds/MRI</td>
<td>28%</td>
<td>40%</td>
<td>26%</td>
<td>24%</td>
</tr>
</tbody>
</table>

**Base:** All respondents (n = 424)

- **Q819.** How often do you do each of the following with your rheumatologist?

- **Never**
- **Not sure**

- During every visit / during more than half of visits
Patients have lots of concerns about their RA, especially about the consequences for their lifestyle and for their body.

Q730. Which of the following, if any, do you worry about because of your RA?

Base: All respondents (n = 424)

NB. These are the most mentioned worries, the other worries can be found in the appendix.
COMMUNICATION: TOPICS DISCUSSED
13% OF THE PATIENTS WITH SEVERE RA SAY THAT THEIR RHEUMATOLOGIST HAS NOT FULLY EXPLAINED ANY ASPECT OF MANAGING RA

Aspects fully explained by rheumatologist

- My current RA status/whether my RA has gotten better/worse
  - Severe: 66%
  - Moderate to severe: 60%
  - Mild: 56%

- What I should expect from my RA medication(s) in particular
  - Severe: 60%
  - Moderate to severe: 60%
  - Mild: 58%

- My test results
  - Severe: 49%
  - Moderate to severe: 55%
  - Mild: 54%

- What I should expect from my overall RA management plan
  - Severe: 34%
  - Moderate to severe: 32%
  - Mild: 31%

- The various medications available for RA
  - Severe: 40%
  - Moderate to severe: 39%
  - Mild: 32%

- Lifestyle changes
  - Severe: 31%
  - Moderate to severe: 32%
  - Mild: 32%

- How my RA management plan helps me meet my personal RA management goals
  - Severe: 28%
  - Moderate to severe: 25%
  - Mild: 28%

- Complementary (non-medication) therapies
  - Severe: 25%
  - Moderate to severe: 22%
  - Mild: 26%

- How to fill my prescription(s) and receive my medication(s)
  - Severe: 25%
  - Moderate to severe: 25%
  - Mild: 25%

- None
  - Severe: 4%
  - Moderate to severe: 6%
  - Mild: 13%

Q815. Which of the following aspects of managing your RA, if any, has your doc rheumatologist fully explained to you?

Base: All respondents (n = 424)

NB. These are the most mentioned aspects, the other aspects can be found in the appendix.
AT LEAST A QUARTER OF THE PATIENTS DID NOT GET AN EXPLANATION ABOUT BASIC INFORMATION, LIKE HOW MEDICATION WORKS AND THE SIDE EFFECTS

Medications explained by rheumatologist

- How the medication(s) work: 71%
- Side effects of medication(s): 70%
- The importance of taking my medication/following my treatment plan exactly as prescribed: 70%
- How to manage my medication regimen properly (i.e., dosage, schedule): 64%
- What to do if I experience a side effect from a medication: 61%
- The differences between biologic/nonbiologic DMARDs that can be used on their own/that must be taken in combination with other DMARDs: 43%
- The differences between the various biologics available for RA: 39%
- How to know if the medication is working or not working: 38%
- Restrictions on my life due to the medication(s): 38%
- Oral versus injectable medication(s): 38%
- How to fill my prescription(s) and receive my medication(s) (e.g., what paperwork to complete, where to go): 36%
- Other: 1%

Q817. Which of the following did your rheumatologist explain about the medications available for RA?

Base: Is informed of medication that is available for the treatment of RA (n = 160)

NB. Chart is reported on total, because the n of the subgroups is too small.
COMMUNICATION:
SATISFACTION
ONE THIRD OF THE PATIENTS WISHES THEIR RHEUMATOLOGIST TALKED MORE WITH THEM ABOUT THEIR RA TREATMENT AND GOALS

<table>
<thead>
<tr>
<th>Statements communication with rheumatologist</th>
<th>Total</th>
<th>Severe</th>
<th>Moderate</th>
<th>Mild</th>
</tr>
</thead>
<tbody>
<tr>
<td>I understand my disease and the treatment options available</td>
<td>92%</td>
<td>93%</td>
<td>92%</td>
<td>90%</td>
</tr>
<tr>
<td>When I leave an appointment/consultation with my rheumatologist, I feel confident that I can follow his/her treatment recommendations</td>
<td>89%</td>
<td>85%</td>
<td>89%</td>
<td>94%</td>
</tr>
<tr>
<td>I am satisfied with the communication with my rheumatologist about my RA treatment</td>
<td>87%</td>
<td>81%</td>
<td>87%</td>
<td>92%</td>
</tr>
<tr>
<td>The paperwork my rheumatologist has to complete for me to receive/continue treatment takes time away from discussing my RA</td>
<td>36%</td>
<td>49%</td>
<td>34%</td>
<td>26%</td>
</tr>
<tr>
<td>I wish my rheumatologist and I talked more about my RA goals/treatment</td>
<td>34%</td>
<td>38%</td>
<td>34%</td>
<td>26%</td>
</tr>
<tr>
<td>I wish I could visit my rheumatologist more often</td>
<td>28%</td>
<td>34%</td>
<td>28%</td>
<td>18%</td>
</tr>
<tr>
<td>It is not important to me to be knowledgeable about RA</td>
<td>26%</td>
<td>18%</td>
<td>30%</td>
<td>14%</td>
</tr>
<tr>
<td>I worry that, if I ask too many questions, my rheumatologist will see me as a difficult patient and it will affect the quality of care I receive</td>
<td>19%</td>
<td>26%</td>
<td>19%</td>
<td>10%</td>
</tr>
<tr>
<td>My rheumatologist often ignores my concerns about medications/alternative treatment plans</td>
<td>15%</td>
<td>24%</td>
<td>14%</td>
<td>12%</td>
</tr>
<tr>
<td>My rheumatologist often makes changes to my treatment plan without consulting/involving me</td>
<td>9%</td>
<td>13%</td>
<td>8%</td>
<td>10%</td>
</tr>
</tbody>
</table>

Q830. With respect to your communication with the rheumatologist responsible for managing your RA, how much do you agree or disagree with each of the following statements?

Base: All respondents (n = 424)
For more successfully managing their RA, patients like to discuss their experiences and whether or not they take their medication as prescribed.

Means to more successfully manage RA

- Discussing my symptoms or experiences since my last visit: 35%
- Discussing whether or not I take my medication(s) exactly as prescribed: 26%
- More information about the RA treatment options that are available to me: 21%
- Clarity on my personal treatment goals and whether or not I am meeting them: 19%
- Clarity on what different treatment goals mean: 16%
- Supplemental or additional visits with other health care professionals: 16%
- More information about RA in general: 15%
- Advice on where to get reliable information to help me manage my disease: 14%
- Easier access to doctor visits: 13%
- Nothing would help me more successfully manage my RA: 13%

Q825. In thinking about your relationship with your rheumatologist, which of the following, if any, would help you more successfully manage your RA?

- Base: All respondents (n = 424)

NB. These are the most mentioned means, the other means can be found in the appendix.
About 40% of the patients don’t experience a partnership with their rheumatologist in making decisions about the course of treatment.

Q812. Which of the following, if any, best describes the role of the rheumatologist responsible for managing your RA?

- My rheumatologist and I make decisions in partnership together about the course of treatment
- My rheumatologist involves me in a discussion and considers my concerns when determining the course of treatment
- My rheumatologist recommends a treatment plan for me without involving me in a discussion
- I request specific treatments from my rheumatologist, and he/she considers my requests when determining the course of treatment
- None of these

Base: All respondents (n = 424)
COMMUNICATION:
BARRIERS
MORE THAN 20% OF THE PATIENTS FEEL UNCOMFORTABLE RAISING CONCERNS, BECAUSE THEY THINK THEIR RHEUMATOLOGIST KNOWS BEST

Reasons for feeling uncomfortable raising concerns

- My rheumatologist knows best so I defer to whatever he/she recommends: 26%
- I don't want to be seen as a difficult patient: 21%
- I don’t feel there is much I can control or change about my treatment: 12%
- I don’t have enough time with him/her: 12%
- Don't feel there is much my rheumatologist can control/change about my treatment: 10%
- Feel like my rheumatologist just tells me what to do and I am supposed to follow: 9%
- I don’t see him/her as often as I would like: 8%
- I don’t know enough about RA to know what I should be concerned about: 8%
- Don't always see the same rheumatologist at the clinic where my rheumatologist is: 6%
- None: 54%

Q840. For which of the following reasons, if any, do you feel uncomfortable raising concerns and fears with your rheumatologist?

**Base: All respondents (n = 424)**

*NB. These are the most mentioned reasons, the other reasons can be found in the appendix.*
COMMUNICATION:
GOAL-SETTING
Q727. What are your goals for managing your RA? Please select all that apply.

**Base: All respondents (n = 424)**

*NB. These are the most mentioned goals, the other goals can be found in the appendix.*
TREATMENT: GENERAL
ALMOST 20% OF THE PATIENTS DON’T USE ANY PRESCRIPTION MEDICATION(S) CURRENTLY

Q905. Which of the following, if any, are you currently doing, using, planning, or taking to treat your RA?

**Base: All respondents (n = 424)**
Patients with more severe symptoms are more often treated by a health care professional other than a rheumatologist.

**Health care professional seen to manage RA**

- Rheumatologist/Rheumatoid Arthritis specialist: 51%
- Primary care physician/General practitioner/Internist: 18%
- Physical therapist/Physiotherapist: 13%
- Nurse: 9%
- Pharmacist: 3%
- Pain specialist: 3%
- Orthopedist/Orthopedic surgeon: 2%
- Nurse practitioner/Physician’s assistant: 1%
- Other: 1%
- None: 0%

**Health care professional mostly responsible for managing RA**

- Rheumatologist/Rheumatoid Arthritis specialist: 67%
- Primary care physician/General practitioner/Internist: 10%
- Physical therapist/Physiotherapist: 13%
- Pain specialist: 3%
- Orthopedist/Orthopedic surgeon: 2%
- Nurse practitioner/Physician’s assistant: 0%
- Other: 3%
- None: 0%

Q805. Which health care professionals, if any, do you currently see to manage your RA?

Q807. Which health care professional is mostly responsible for managing your RA?

Base Q805 & Q807: All respondents (n = 424)

NB. Only mentioned options are displayed.
THE MORE SEVERE THE RA, THE MORE A PATIENT VISITS THE RHEUMATOLOGIST

Visits rheumatologist

Q810. How many times per year do you visit your rheumatologist as part of treating your RA? If you are not sure, please provide your best estimate.

Base: All respondents (n = 424)
Q907. Which of the following types of prescription medication(s) are you currently taking for your RA?

- Pain relievers
- Disease-modifying antirheumatic drugs (DMARDs)
- Steroids or corticosteroids
- Biologics
- Other
- Not sure

Base: Uses medication (n = 361)
TREATMENT:
ADHERENCE
ABOUT 20% OF THE PATIENTS DON’T ALWAYS TAKE THEIR RA MEDICATION EXACTLY AS PRESCRIBED

Q925. What are the most important reasons why you don’t take your RA medication(s) exactly as prescribed?

Base: All respondents (n = 424)

NB. These are the most mentioned reasons, the other reasons can be found in the appendix.
TREATMENT: SATISFACTION
Almost three quarter of the patients wishes they could take fewer medications for their RA

Statements about RA medication(s)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Total</th>
<th>Severe</th>
<th>Moderate to severe</th>
<th>Mild</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am satisfied with my RA medication regimen</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I would rather be on a medicine that I took once per day rather than more than once per day, if they were both equally effective</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I wish I could take fewer medications for my RA</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treating my RA is as difficult as living with the disease</td>
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</tr>
<tr>
<td>If my rheumatologist wanted to change my medication(s) that I felt were working, I wouldn’t be concerned about it</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I sometimes worry my RA medication(s) will fail</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I wish I had more medication choices</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I don’t think any pill that is taken orally can be effective</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The paperwork that my rheumatologist must complete makes it more difficult for me to get the treatment I need</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My rheumatologist underestimates the pain and discomfort of injected medications</td>
<td></td>
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<tr>
<td>My RA medication regimen does not accommodate my busy lifestyle</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My RA medication regimen is too complex</td>
<td></td>
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</tbody>
</table>

Q940: How much do you agree or disagree with each of the following statements about your RA medication(s)?

Base: All respondents (n = 424)
ONLY 60% OF THE PATIENTS ARE SATISFIED WITH THEIR PRESCRIPTION MEDICATION

Feelings about medication for RA

- Satisfied: 53% (Severe n=55), 58% (Moderate to severe n=265), 76% (Mild n=41)
- Hopeful: 29%
- Thankful: 16%
- Concerned: 13%
- Burdened: 7%
- Frustrated: 5%
- Confused: 5%
- Confident: 12%
- Uncertain: 4%
- Indifferent: 2%
- Overwhelmed: 0%
- Other: 4%

Q920. In general, how do you feel about the prescription medication regimen you are currently taking for your RA?

Base: Uses medication (n = 361)
TREATMENT:
CHANGES IN MEDICATION REGIMEN
ALMOST ONE THIRD OF THE PATIENTS HAD TO SWITCH MEDICATION BECAUSE THEIR RHEUMATOLOGIST THOUGHT A DIFFERENT MEDICATION WORKS BETTER

Reasons for changing medication by rheumatologist

- My rheumatologist felt a different medication would work better: 32%
- I couldn’t tolerate or manage the side effects: 28%
- The medication was not working, or stopped working: 24%
- My lab tests or joint x-rays/MRIs showed a need to change medication: 20%
- A new or better medication became available: 11%
- I requested a change in my medication: 11%
- The medication interacted with other medications I was/am taking: 9%
- Had to change medication, because the medication I was using was too expensive: 8%
- My RA achieved a state of low disease activity: 6%
- My RA had gone into remission: 2%
- I became, or wanted to become, pregnant: 2%
- Not sure – my rheumatologist did not tell me why he/she changed my medication: 2%
- Don’t recall: 10%

Q909. For which of the following reasons, if any, did your rheumatologist change your medication?

Base: Worries about changes in medication (n = 133)

NB. Chart is reported on total, because the n of the subgroups is too small.
MOST MENTIONED REASON FOR BEING RELUCTANT ABOUT CHANGES IN THE MEDICATION REGIMENT IS WORRIES ABOUT THE SIDE EFFECTS OF THE NEW MEDICATION

Q910. For which of the following reasons, if any, have you been reluctant when your rheumatologist has recommended or made a change in your medication regimen?

Reasons for being reluctant

- I have never felt reluctant when rheumatologist has recommended a change in medication
- I was worried the side effects from the new medication would be difficult to manage
- I thought my current medication was treating my RA well enough
- I don’t want to “start over” learning to manage the side effects of a new medication
- The new medication had restrictions that I didn’t like (e.g., can’t drink alcohol, special diet, etc.)
- I didn’t think I needed to change
- I didn’t like the way the new treatment would be administered
- The medications my rheumatologist recommended were expensive
- N/A – my rheumatologist has never recommended or made a change in my medication regimen

Base: Uses medication (n = 361)

Severe (n=55)
Moderate to severe (n=265)
Mild (n=41)
TREATMENT: IDEAL CHANGES, SUCCESS VS. FAILURE
PATIENTS WOULD LIKE TO CHANGE THE SIDE EFFECTS OF THEIR CURRENT RA MEDICATION(S), BOTH NUMBER AND SEVERITY

Desire to change about current medication

- Number of side effects: 25% Moderate to severe, 21% Severe
- Severity of side effects: 22% Moderate to severe, 15% Severe
- The number of medications I need to take: 21% Others, 15% Number of medications
- How well the medication(s) works to relieve my symptoms: 18% Others, 12% Number of medications
- Picking up my medication closer to my home: 18% Others, 12% Number of medications
- My rheumatologist to complete less paperwork for me to receive/continue treatment: 15% Others, 9% Number of medications
- Delivering of my medication at home: 9% Others, 6% Number of medications
- How often I need to take oral medication(s): 9% Others, 6% Number of medications
- Being able to take it without other medications for my RA: 6% Others, 4% Number of medications
- There is nothing I would change about my current RA medication(s): 58% Others, 51% Number of medications

Q935. Ideally, what would you most like to change, if anything, about your current RA medication(s)?

Base: All respondents (n = 424)

NB. These are the most mentioned changes, the other changes can be found in the appendix.
TREATMENT SUCCESS IS ASSOCIATED WITH NO PAIN AND BEING ABLE TO PERFORM DAILY ACTIVITIES NORMALLY

**Meaning of ‘successful’ by medication**

<table>
<thead>
<tr>
<th>Meaning</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am no longer in pain</td>
<td>70%</td>
</tr>
<tr>
<td>My RA does not interfere with my daily activities</td>
<td>68%</td>
</tr>
<tr>
<td>My joint swelling or inflammation has decreased</td>
<td>61%</td>
</tr>
<tr>
<td>I am better able to move</td>
<td>60%</td>
</tr>
<tr>
<td>Being unable to perform basic physical activities of daily life</td>
<td>50%</td>
</tr>
<tr>
<td>My rheumatologist tells me my RA is in a state of low disease activity</td>
<td>34%</td>
</tr>
<tr>
<td>I am able to take it without other medications for my RA</td>
<td>27%</td>
</tr>
<tr>
<td>My rheumatologist tells me my RA is in a state of remission</td>
<td>22%</td>
</tr>
<tr>
<td>I meet the specific treatment goals discussed with my rheumatologist I will increase my level of physical activity</td>
<td>18%</td>
</tr>
</tbody>
</table>

Q955. When thinking about your RA medication(s), what does “successful” treatment mean to you?

*Base: All respondents (n = 424)*
FAILURE IS ASSOCIATED WITH NOT IMPROVING OR WORSENING (JOINT) PAIN AND JOINT DAMAGE

Meaning of ‘failure’ by medication

- Joint pain is worsening or not improving:
  - Severe: 62%
  - Moderate to severe: 60%
  - Mild: 51%

- Having continued pain:
  - Severe: 44%
  - Moderate to severe: 53%
  - Mild: 51%

- Joint damage continues:
  - Severe: 52%
  - Moderate to severe: 53%
  - Mild: 51%

- Being unable to stay as active as I want to be:
  - Severe: 38%
  - Moderate to severe: 47%
  - Mild: 51%

- Joint swelling or inflammation is worsening or not improving:
  - Severe: 48%
  - Moderate to severe: 54%
  - Mild: 53%

- Being unable to perform basic physical activities of daily life:
  - Severe: 46%
  - Moderate to severe: 56%
  - Mild: 53%

- Having to stop taking a medication because I cannot tolerate the side effects:
  - Severe: 37%
  - Moderate to severe: 28%
  - Mild: 38%

- Having continued flare-ups:
  - Severe: 26%
  - Moderate to severe: 26%
  - Mild: 16%

- When the medication doesn’t help me meet my specific treatment goals:
  - Severe: 16%
  - Moderate to severe: 26%
  - Mild: 28%

- None:
  - Severe: 20%
  - Moderate to severe: 16%
  - Mild: 15%

Q950. When thinking about your RA medication(s), what does “failure” mean to you?

Base: All respondents (n = 424)

NB. These are the most mentioned meanings, the other meanings can be found in the appendix.
KNOWLEDGE AND RESOURCES
**MOST PATIENTS RELY ON HEALTH CARE PROFESSIONALS FOR INFORMATION AND ADVICE ABOUT THEIR RA TREATMENT**

Q800. What resources, if any, do you rely on regularly for information and advice about your RA treatment?

*Base: All respondents (n = 424)*

<table>
<thead>
<tr>
<th>Resources</th>
<th>Severe</th>
<th>Moderate to severe</th>
<th>Mild</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health care professionals</td>
<td>81%</td>
<td>29%</td>
<td>28%</td>
</tr>
<tr>
<td>Online resources</td>
<td>26%</td>
<td>20%</td>
<td>22%</td>
</tr>
<tr>
<td>RA advocacy groups</td>
<td>28%</td>
<td>26%</td>
<td>18%</td>
</tr>
<tr>
<td>News</td>
<td>19%</td>
<td>4%</td>
<td>18%</td>
</tr>
<tr>
<td>Other people (friends, family, acquaintances) who have RA</td>
<td>19%</td>
<td>10%</td>
<td>18%</td>
</tr>
<tr>
<td>RA patient support groups</td>
<td>12%</td>
<td>18%</td>
<td>8%</td>
</tr>
<tr>
<td>Materials in doctor or health care professional waiting rooms</td>
<td>18%</td>
<td>18%</td>
<td>8%</td>
</tr>
<tr>
<td>Adherence or patient support programs offered by pharmaceutical companies</td>
<td>12%</td>
<td>18%</td>
<td>8%</td>
</tr>
<tr>
<td>Educational seminars</td>
<td>6%</td>
<td>6%</td>
<td>6%</td>
</tr>
<tr>
<td>Friends and/or family</td>
<td>10%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Other</td>
<td>6%</td>
<td>8%</td>
<td>0%</td>
</tr>
<tr>
<td>None</td>
<td>7%</td>
<td>8%</td>
<td>10%</td>
</tr>
</tbody>
</table>
MORE THAN 90% OF THE PATIENTS RELY ON A RHEUMATOLOGIST OR A RHEUMATOID ARTHRITIS SPECIALIST FOR INFORMATION

Health care professionals to rely on for information about RA

<table>
<thead>
<tr>
<th>Professional</th>
<th>Severe</th>
<th>Moderate to severe</th>
<th>Mild</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rheumatologist/Rheumatoid Arthritis specialist</td>
<td>91%</td>
<td>93%</td>
<td></td>
</tr>
<tr>
<td>Primary care physician/General practitioner/Internist</td>
<td>49%</td>
<td>45%</td>
<td>42%</td>
</tr>
<tr>
<td>Physical therapist/Physiotherapist</td>
<td>43%</td>
<td>35%</td>
<td>32%</td>
</tr>
<tr>
<td>Nurse</td>
<td>38%</td>
<td>30%</td>
<td>26%</td>
</tr>
<tr>
<td>Orthopedist/Orthopedic surgeon</td>
<td>22%</td>
<td>14%</td>
<td></td>
</tr>
<tr>
<td>Pain specialist</td>
<td>21%</td>
<td>15%</td>
<td>10%</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>16%</td>
<td>17%</td>
<td>16%</td>
</tr>
<tr>
<td>Nurse practitioner/Physician’s assistant</td>
<td>12%</td>
<td>11%</td>
<td></td>
</tr>
<tr>
<td>Dermatologist</td>
<td>6%</td>
<td>5%</td>
<td>2%</td>
</tr>
<tr>
<td>Psychiatrist/Psychologist/Therapist</td>
<td>6%</td>
<td>4%</td>
<td>2%</td>
</tr>
<tr>
<td>Other</td>
<td>9%</td>
<td>2%</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>3%</td>
<td>3%</td>
<td>2%</td>
</tr>
</tbody>
</table>

Q802. Which health care professionals in particular do you rely on regularly for information and advice about your RA treatment?

Base: All respondents (n = 424)
AT LEAST ONE THIRD OF THE PATIENTS THINK THERE IS ANY STIGMA ASSOCIATED WITH RA

Q860. Do you think there is any stigma associated with having RA? By stigma, we mean social shame or disapproval

*Base: All respondents (n=424)*
DEMOGRAPHICS
### DEMOGRAPHICS

**GENDER**

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Severe</th>
<th>Moderate to severe</th>
<th>Mild</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>30%</td>
<td>26%</td>
<td>29%</td>
<td>40%</td>
</tr>
<tr>
<td>Female</td>
<td>70%</td>
<td>74%</td>
<td>71%</td>
<td>60%</td>
</tr>
<tr>
<td>Respondent left blank</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

**AGE**

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Severe</th>
<th>Moderate to severe</th>
<th>Mild</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-44</td>
<td>8%</td>
<td>10%</td>
<td>7%</td>
<td>6%</td>
</tr>
<tr>
<td>45-54</td>
<td>14%</td>
<td>16%</td>
<td>14%</td>
<td>14%</td>
</tr>
<tr>
<td>55-64</td>
<td>35%</td>
<td>40%</td>
<td>34%</td>
<td>36%</td>
</tr>
<tr>
<td>65+</td>
<td>43%</td>
<td>34%</td>
<td>44%</td>
<td>44%</td>
</tr>
<tr>
<td><strong>MEAN</strong></td>
<td><strong>61.3</strong></td>
<td><strong>59.7</strong></td>
<td><strong>61.4</strong></td>
<td><strong>62.3</strong></td>
</tr>
</tbody>
</table>

**MARITAL STATUS**

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Severe</th>
<th>Moderate to severe</th>
<th>Mild</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never married</td>
<td>8%</td>
<td>15%</td>
<td>8%</td>
<td>4%</td>
</tr>
<tr>
<td><strong>MARRIED/ LIVING WITH PARTNER (NET)</strong></td>
<td><strong>70%</strong></td>
<td><strong>62%</strong></td>
<td><strong>70%</strong></td>
<td><strong>78%</strong></td>
</tr>
<tr>
<td>Married or civil union</td>
<td>64%</td>
<td>56%</td>
<td>64%</td>
<td>74%</td>
</tr>
<tr>
<td>Living with partner</td>
<td>5%</td>
<td>6%</td>
<td>6%</td>
<td>4%</td>
</tr>
<tr>
<td>Divorced/ separated</td>
<td>14%</td>
<td>15%</td>
<td>14%</td>
<td>12%</td>
</tr>
<tr>
<td>Widow/Widower</td>
<td>9%</td>
<td>9%</td>
<td>9%</td>
<td>6%</td>
</tr>
<tr>
<td>Respondent left blank</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Q364. What is your current marital status?

*Base: All respondents (n = 424)*
EXTRA SLIDES
### Current situation RA

**According to doctor/health care professional**

<table>
<thead>
<tr>
<th>According to me</th>
<th>Mild</th>
<th>Moderate to severe</th>
<th>Severe</th>
<th>In remission</th>
<th>In a state of low disease activity</th>
<th>Active</th>
<th>Under control</th>
<th>Not under control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>86%</td>
<td>14%</td>
<td>1%</td>
<td>77%</td>
<td>43%</td>
<td>11%</td>
<td>21%</td>
<td>4%</td>
</tr>
<tr>
<td>Moderate to severe</td>
<td>14%</td>
<td>83%</td>
<td>43%</td>
<td>23%</td>
<td>57%</td>
<td>72%</td>
<td>72%</td>
<td>60%</td>
</tr>
<tr>
<td>Severe</td>
<td>0%</td>
<td>3%</td>
<td>56%</td>
<td>0%</td>
<td>0%</td>
<td>17%</td>
<td>7%</td>
<td>36%</td>
</tr>
<tr>
<td>In remission</td>
<td>22%</td>
<td>1%</td>
<td>1%</td>
<td>92%</td>
<td>1%</td>
<td>0%</td>
<td>2%</td>
<td>0%</td>
</tr>
<tr>
<td>In a state of low disease activity</td>
<td>36%</td>
<td>21%</td>
<td>6%</td>
<td>8%</td>
<td>85%</td>
<td>10%</td>
<td>12%</td>
<td>2%</td>
</tr>
<tr>
<td>Active</td>
<td>16%</td>
<td>36%</td>
<td>49%</td>
<td>0%</td>
<td>12%</td>
<td>87%</td>
<td>19%</td>
<td>42%</td>
</tr>
<tr>
<td>Under control</td>
<td>38%</td>
<td>45%</td>
<td>22%</td>
<td>15%</td>
<td>21%</td>
<td>21%</td>
<td>86%</td>
<td>7%</td>
</tr>
<tr>
<td>Not under control</td>
<td>0%</td>
<td>11%</td>
<td>34%</td>
<td>8%</td>
<td>6%</td>
<td>10%</td>
<td>2%</td>
<td>82%</td>
</tr>
</tbody>
</table>

**According to me**

<table>
<thead>
<tr>
<th>According to me</th>
<th>Mild</th>
<th>Moderate to severe</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>49%</td>
<td>50%</td>
<td>1%</td>
</tr>
<tr>
<td>Moderate to severe</td>
<td>2%</td>
<td>88%</td>
<td>10%</td>
</tr>
<tr>
<td>Severe</td>
<td>0%</td>
<td>17%</td>
<td>83%</td>
</tr>
</tbody>
</table>

Q715 + Q716. How would you currently describe your RA? And how would your doctor or healthcare professional describe your RA?

*Base: All respondents (n = 424)*
Q815. Which of the following aspects of managing your RA, if any, has your doc rheumatologist fully explained to you?

Base: All respondents (n = 424)

Aspects fully explained by rheumatologist

- What different treatment goals mean
  - Severe: 22%
  - Moderate to severe: 17%
  - Mild: 14%

- My progress to my personal RA management goals
  - Severe: 19%
  - Moderate to severe: 20%
  - Mild: 6%

- Benefits/risks of aggressive treatment early on in the disease
  - Severe: 18%
  - Moderate to severe: 12%
  - Mild: 18%

- Where to turn for reliable information and advice
  - Severe: 16%
  - Moderate to severe: 18%
  - Mild: 10%

- The concept of “treat to target”
  - Severe: 9%
  - Moderate to severe: 8%
  - Mild: 6%

- What “failure” means with respect to my RA medication(s)
  - Severe: 3%
  - Moderate to severe: 8%
  - Mild: 0%

- Other
  - Severe: 0%
  - Moderate to severe: 2%
  - Mild: 0%

Severe
Moderate to severe
Mild

0% 25% 50% 75% 100%
Q825. In thinking about your relationship with your rheumatologist, which of the following, if any, would help you more successfully manage your RA?

- More tools to help me prepare for my visits with my rheumatologist: 12%
- Less paperwork for rheumatologist to complete for receiving continuing treatment: 10%
- Online tool/smartphone application to better monitor/track my activities and progress: 9%
- Longer visits: 10%
- Feeling more comfortable having an open dialogue about RA: 7%
- More frequent visits: 6%
- Disease management classes: 6%
- Other: 4%

**Base: All respondents (n = 424)**
Q840. For which of the following reasons, if any, do you feel uncomfortable raising concerns and fears with your rheumatologist?

Base: All respondents (n = 424)
Q727. What are your goals for managing your RA? Please select all that apply.

Base: All respondents (n = 424)
Q925. What are the most important reasons why you don’t take your RA medication(s) exactly as prescribed?

Base: All respondents (n = 424)
Q935. Ideally, what would you most like to change, if anything, about your current RA medication(s)?

Base: All respondents (n = 424)
Q950. When thinking about your RA medication(s), what does “failure” mean to you?

Base: All respondents (n = 424)
Q730. Which of the following, if any, do you worry about because of your RA?

Base: All respondents (n = 424)
CERTIFICATION
CERTIFICATION

- The study was conducted in accordance with GfK's quality system that is certified according to the standard of NEN-EN-ISO 9001, ISO 20252 and 23632. GfK abides by the code of conduct of ESOMAR (European Society for Opinion and Market Research) and is a member of the professional organization MOA (Center for Information Based Decision Making & Marketing Research) (see http://www.moaweb.nl).
- It is permitted to publish the outcomes of a study externally. Under the condition that in such a case the source is indicated as 'GfK <month and year of the study>'.
- Exclusivity of the collected data is based on the Code of Conduct of the MOA, art. 5 (see http://www.moaweb.nl).
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