



CHANGING THE  
nar**R**ative

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Enhancing dialogue between  
healthcare providers and patients

## About Changing the RA NarRAtive

*Changing the RA NarRAtive* is an international initiative aimed at elevating the important role of the patient in the management of RA. Supported by Pfizer, the RA NarRAtive initiative is directed by a global Advisory Panel comprised of 39 healthcare providers and patient support group leaders from 17 countries. The purpose of *Changing the RA NarRAtive* is to create positive change within the RA community by harnessing the experience of people living with RA, physicians and patient advocates, to develop resources that break down communication barriers and change expectations to improve RA disease management.

The RA NarRAtive gathered insights from physician and patient perspectives in the management of RA through two global surveys fielded to almost 4,000 adults with RA and nearly 1,700 physicians.<sup>1</sup> To learn more about *Changing the RA NarRAtive*, visit [Pfizer.com/RANarRAtive](http://Pfizer.com/RANarRAtive).

In reviewing and discussing the findings of both surveys, the Advisory Panel suggests that people with RA and healthcare providers can establish a new narrative, a new conversation around RA by recognizing the unique and important perspective of each.

### An HCP's perspective may focus on<sup>1</sup>:



Running tests to determine swollen joint counts or level of inflammatory markers



Utilizing scientific literature to determine the best course of disease management



### A patient's perspective may focus on:



Tracking their RA symptoms and sharing the results with their HCP



Voicing if they need help to complete daily activities

While healthcare providers bring their perspective to this relationship at all times, patients may not for a variety of reasons. This means a critical, complementary piece of this dynamic can be absent. When the patient doesn't voice the unique self-perspective that is inherent within them, it complicates the HCP's ability to manage their RA.<sup>1</sup>

## RA NarRAtive Weighted Survey Methodology

### The RA Narrative Patient Survey

The RA Narrative patient survey was conducted online by Harris Poll on behalf of Pfizer between September 4 and December 24, 2014, January 9 and 13, 2015 and September 3, 2015 and January 13, 2016 among 3987 adults ages 18+ who have been diagnosed with rheumatoid arthritis (RA) in the US (n=526), Canada (n=237), Brazil (n=324), Argentina (n=217), Australia (n=481), South Korea (n=224), Japan (n=354), Germany (n=525), France (n=122), Spain (n=122), the UK (n=246), Italy (n=204), Turkey (n=123), Hong Kong (n=192), and Taiwan (n=90).

Raw data were weighted where necessary to reflect the general adult (or online adult) population in each country (sample sizes noted above). For the global, 15-country total, a post-weight was applied to adjust for the relative size of each country's adult population within the total adult population across all countries surveyed. The unweighted sample sizes above reflect the total number of patients who completed the survey in each country, while all reported percentages are calculated based on the weighted global total described here.

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## The RA Narrative Physician Survey

The RA Narrative physician survey was conducted online by Harris Poll on behalf of Pfizer between August 14 and October 2, 2015 among 1666 rheumatologists ages 18+ who have seen at least five (5) RA patients in the past month whose RA is moderately to severely active or severely active in the US (n=208), Canada (n=50), Brazil (n=150), Argentina (n=130), Australia (n=60), South Korea (n=100), Japan (n=139), Germany (n=150), France (n=149), Spain (n=100), the UK (n=150), Italy (n=100), Turkey (n=50), Hong Kong (n=30), and Taiwan (n=100).

Physician results in the US were weighted by region and years in practice by gender. In all other countries, raw data were not weighted at the individual country level (sample sizes noted above), and therefore are only representative of the individuals who completed the survey. For the global, 15-country total, a post-weight was applied to adjust for the relative size of each country's adult population within the total adult population across all countries surveyed. The unweighted sample sizes above reflect the total number of HCPs who completed the survey in each country, while all reported percentages are calculated based on the weighted global total described here.



## Set a new narrative to better understand people living with RA

One aspect that both healthcare providers and patients inherently have the most influence over is the relationship and dialogue they have with one another. This relationship is critical for the implementation of disease management strategies, which should be based on a shared decision.<sup>1</sup> RA NarRAtive survey findings suggest that people who are comfortable raising concerns (indicating comfort with an open, honest dialogue) with their healthcare provider are more likely to have better perceived health outcomes.<sup>2</sup>

**To improve the narrative around RA management, the Advisory Panel uncovered four actions that healthcare providers can undertake to empower their patients to speak up about their RA experience:**

**1.** Help Patients to Expect More and Not Settle for Good Enough

**3.** Schedule Conversations, Not Appointments

**2.** Craft Goals and Set Expectations

**4.** Encourage a Strong Support Network

Read on to learn more about the findings uncovered through RA NarRAtive research, including how Advisory Panel members have changed their approach to improve the RA narrative with their patients.

# 1. Help patients to expect more and not settle for “good enough”

## Take Action: Dig deeper into how patients truly feel

As noted by Wolfe (*Arthritis Rheum* 2007) and Solomon (*Arthritis Rheumatol* 2014), once a medication is prescribed, and the person with RA begins to feel better than they used to, they may be reluctant to change therapies to seek additional improvement, for fear of side effects or of losing control of their disease, even if they are still experiencing symptoms and have active disease.<sup>3,4</sup> For them, it's better than it was, so it's "good enough."

## Not all patients that report feeling satisfied with their treatment feel that their RA is under control

Of 1263 patients on a prescription RA medication, survey results showed:



78% of patients who were on a RA prescription medication said they were satisfied with their RA medication regimen<sup>2</sup>  
n=1298/1667



36% would describe their RA as under control?<sup>2</sup>  
n=466/1298

- 14% would describe their RA as in remission [n= 176/1298]

- 5% would describe their RA as in a state of low disease activity [n= 66/1298]



70% of physicians said their patients settle for a treatment that makes them feel “good enough”<sup>1</sup>  
n=1169/1666

The RA NarRAtive surveys uncovered that asking the patient directly whether they are satisfied with their treatment regimen may not reflect true disease control. In fact, the majority of patients (78%, n=1298/1667) who were taking prescription medicines for their RA said they were satisfied with their medication regimen, yet only (36%, n=466/1298) of those individuals would self-describe their RA as “under control.”<sup>2</sup> In addition, half had stopped participating in certain activities (as a result of their RA) or needed some or daily help to complete activities (n=655/1298).<sup>2</sup>

Furthermore, *Changing the RA NarRAtive* findings showed that 2 out of 3 surveyed physicians (n=1094/1666) reported that their patients living with RA say they feel “good enough,” even though clinical assessments indicated their disease is active, and 70% of physicians (n=1169/1666) said their patients with RA often settle for a treatment that makes them feel “good enough” despite other treatment options that may make them feel better.<sup>1</sup>



Allan Gibofsky, MD, Rheumatologist (USA)

*“When I try to determine if my patients are settling, I look for the difference between how we both assess their disease. This is a frequent tip-off to the fact that a patient may be settling. If I assess that a patient has active RA and they say that ‘they’re fine and happy where they are,’ that’s a suggestion that they may be settling. It’s a prompt for me to ask additional questions and to probe further, to not take ‘I’m fine’ at face value.”*

## ACTIONS TO DIG DEEPER



It’s not uncommon for people living with RA to settle into a new reality. Healthcare providers shouldn’t take “satisfied” or “I’m fine” at face value and should encourage their patients to tell them how they are truly feeling.



Dig deeper into their patients’ stories, encourage them to be open and ask for specific instances when RA interfered with their life.



It could be as simple as asking: Are you really fine?

## 2. Craft goals and set expectations

### Take Action: Identify your patients' goals

Most guidelines instruct patients and physicians to jointly set goals in an effort to obtain better disease management outcomes.<sup>5</sup> The RA NarRAtive survey findings reinforced that patients and physicians agree on the importance of setting goals and disease management. However, a gap was discovered between belief and practice:

About 3 in 4 surveyed physicians believed that setting treatment goals (78%, n=1300/1666) and developing a disease management plan (74%, n=1230/1666) with their patients is very important or absolutely essential for the successful management of RA.<sup>1</sup> Globally, 97% of surveyed people with RA indicated that they have goals for managing their RA (n=1621/1667); however, only 37% have actually set treatment goals with their healthcare professional.<sup>1,2</sup> (n=618/1667)

According to *Changing the RA NarRAtive* findings, patients and physicians alike wished they talked more about RA goals and treatment (physician: 68% (n=1137/1666); patient: 56% (n=927/1667), which is a great start.<sup>1,2</sup> Yet, research also shows physicians are more likely to discuss side effects and ability to adhere to prescribed medication than they are to discuss specific quality of life issues.<sup>1</sup> But these topics aren't what concerns most people with RA: approximately 3 in 4 of surveyed patients were worried that their RA will negatively affect their overall quality of life, ranging from impact of the disease on personal activities to patients' ability to work.<sup>2</sup>

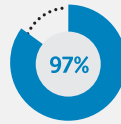
Despite these apparent differences in focus, both patients and physicians should be working toward the same end goal of remission or low disease activity, even if they are arriving at it from different paths.<sup>5</sup> It is reflective of the different perspectives that physicians (with their clinical expertise) and patients (with their knowledge of their body) bring to the relationship. It emphasizes the importance of ensuring both patient and physician perspectives are working together.



### Physicians and patients agree about the importance of goals<sup>1,2</sup>



of physicians say treatment goals are absolutely essential (n=1300/1666)



of patients have goals for managing their RA (n=1621/1667)



**Yet, only** of patients have actually set treatment goals with their HCP (n=618/1667)

- 44% of patients have discussed their progressed towards their treatment goals during every visit (n=737/1667)
- 44% of patients have discussed how their current medication may help reach their treatment goals (n=727/1667)



Ara Dikranian, MD,  
Rheumatologist (USA)

*There is immense value to setting goals with your patient at initiation of the relationship and regularly thereafter. These goals may create a meaningful result to the patient but also outline an objective endpoint that you can both work towards. In addition to making the disease management process less nebulous to your patient, setting goals together involves the patient in working towards a common goal. These goals also provide a safeguard towards patient settling, since they force the patient to continually evaluate their progress and make the determination whether their current management plan is working for them.*

### When setting goals, an HCP may say:



We need to reduce the number of your swollen joints



### When setting goals, a patient may say:



I want to be able to play with my grandchildren



I want to be able to get up in the morning and feel well enough to get to work

### What they are both saying:

We are both trying to accomplish the same goals: Remission or low disease activity

## ACTIONS TO CRAFT GOALS TOGETHER



Work together with the patient to establish goals that will move them in the direction of low disease activity. If the patient isn't bringing up goals they'd like to achieve, it can be beneficial for the HCP to proactively bring these points up in discussions.



Use unique clinical knowledge to work with patients to help them better understand their treatment goals and the measures that will collectively be taken to help them reach those goals.

### 3. Schedule conversations, not appointments

#### Take Action: Ensure patients have the tools to prepare for their visit

There's no denying that time is limited when it comes to medical visits. While findings from the RA NarRative surveys suggest that many physicians and patients wished they could meet more often (66% (n=1101/1666) and 45% (n=745/1667), respectively), appointment time will likely never allow for all questions and topics to be discussed in a single visit.<sup>1,2</sup> Given these limitations, what can be done to maximize the time that patients and healthcare providers have together?

One of the simplest answers to this question, and one that healthcare providers and their patients may have the most control over, is preparation. If a patient is prepared for their visit — knows their updates, questions, concerns and goals — the conversation with their healthcare provider can be more efficient. For these reasons, the Advisory Panel recommends that healthcare providers provide their patients with a [conversation guide](#) to ensure that they are prepared and ready to discuss the most important aspects of their RA during their meeting.



Clare Jacklin, Patient Advocate, UK

*"Although patients with RA can't be in control of everything, there are small changes that can make a big difference in the ownership over their disease. Being prepared for their health visit and asking the right questions can be very important steps to gaining more control. When a patient prepares to go into that examination room or clinic appointment, they shouldn't enter without preparation. That would be akin to going to the shop and having no idea of what you're going to buy. You're going to end up buying the wrong thing; so always make sure to go prepared. Think about it before you get there and ask "What do I want to get out of this visit?" Tools like the RA NarRative conversation guide are great resources to build prepared patients that are ready to ask the questions and discuss the issues that are important to them."*



#### Power Your Inner RA Voice Conversation Guide

To support the importance of preparation, the RA NarRative Advisory Panel has developed a conversation guide (available at [Pfizer.com/RANarRative](https://Pfizer.com/RANarRative)) to help patients prepare for visits.

Its purpose is to help elevate the patient's voice to ensure that their expertise is part of the discussion around the management of RA.

Consider reframing the patient's idea of attending a medical appointment to be: "I'm having a conversation about my RA goals with my doctor." By ensuring that patients are prepared for their medical visit and reframing it as a conversation – which always involves at least two people – healthcare providers can illustrate the value of the patient's input, further supporting the need to be open and honest.

#### Prepare your patients to be involved patients



Nearly **9 in 10 physicians** agree, patients who are involved with treatment decisions tend to be more satisfied with their treatment experience<sup>1</sup> (n=1469/1666)



#### Increase your patient comfort level



**61%** of patients report feeling uncomfortable raising concerns and fears<sup>2</sup> (n=1022/1667)



**32% worry** that if they ask too many questions, it will affect the quality of their care<sup>2</sup> (n=530/1667)



Patients who are more comfortable raising concerns and fears are more likely to describe their current overall health as excellent/good<sup>2</sup>

### ACTIONS TO ENSURE PATIENTS ARE PREPARED FOR CONVERSATIONS



Time is of the essence! Help ensure patients are prepared with their concerns, goals and questions in advance of the visit. Utilize this tool: Power Your Inner RA Voice Conversation Guide at [Pfizer.com/RANarRative](https://Pfizer.com/RANarRative)



Help foster a two-way conversation. A patient's perspective is an important piece of the puzzle, but patients may not always be open and may not realize it.



Recap key points and set expectations at the end of the conversation. Agree on achievable goals for the next appointment and ensure a mutual understanding of those goals.

## 4: Encourage a strong support network

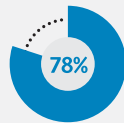
**Take Action:** *Recommend patient advocacy groups to support patients*

While the hope is that all of a patient's questions can be answered and their concerns abated during a single visit, the reality is often different. Sometimes, it is necessary for healthcare providers to investigate what can be done to support patients between visits. The good news is that healthcare providers believe there are solutions to further support patients.

Patient advocacy groups are viewed by many physicians as being integral to helping their patients better live with and manage their RA.<sup>1</sup> To maximize their time with patients to discuss their RA management, healthcare providers can make use of support groups to provide additional insight on how to live with RA that is complementary to physician care.



### Access to patient support networks must be encouraged



of physicians believe patients who participate in RA support groups might be better able to live and manage their RA<sup>1</sup>  
(n=1301/1666)

however,



of patients participate in a support or patient advocacy group<sup>2</sup>  
(n=387/1667)



James Galloway, MD,  
Rheumatologist, UK

*"I am heavily reliant on our patient advocacy support networks in the UK. Every patient that I diagnose, almost without fail, I will direct towards a patient advocacy group for support. As a patient continues to live with their disease, they will inevitably have questions to which I don't have the answers. Patient advocacy support groups are perfect for these situations. These groups allow people living with RA to connect with others who have shared their exact same experiences. The importance of these groups cannot be understated and should be intertwined with any rheumatology practice."*

## ACTIONS TO HELP SUPPORT PATIENTS OUTSIDE OF THEIR VISIT



Learn more about local patient advocacy group resources and what they offer to add to patients' disease management.

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5. Smolen J, Breedveld F, Burmester G, et al. Treating rheumatoid arthritis to target: 2014 update of the recommendations of an international task force. *Ann Rheum Dis.* 2016;75:3-15.