



Striving for the highest level of care

Patient–HCP pocket translator

Disclaimer: This material has been developed by a group of expert rheumatologists and patient representatives, as part of the EVEREST initiative, to help patients with rheumatoid arthritis manage their condition, and does not replace medical examination and/or advice. If you are a person living with rheumatoid arthritis, please reach out to your healthcare professional if you need any help with managing your condition.

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Patient-Doctor/Nurse communication disconnect: A real-life example

Ms. S, who is living with rheumatoid arthritis (RA), is visiting her rheumatologist/rheumatology HCP (M) and would like to seek advice on a new medication, since she feels her current drugs do not work any more...

Ms. S (Patient)



1. I have this pain in my ankles and feel completely exhausted.

3. M, I am glad that you are happy with my treatment, but I have been feeling so tired lately that I can no longer go shopping or play with my grandchildren.

5. And M, what do you think about my pain and why am I feeling so exhausted?

7. M, thank you very much. I hope you can help me...

Doctor/Nurse (M)



2. I saw that your CRP was normal last time, your ultrasound did not show any Power Doppler signals, and your joint count has improved. It looks like your treatment is working fine.

4. Do you really think we should try a new treatment strategy now, or should we wait for another three months and decide? I will now perform a detailed laboratory analysis, and we might change your treatments next time based on your acute-phase reactants.

6. I am sorry, but don't worry - I will call you if your CRP is elevated.

Does this sound familiar?

This is just one real-life example to illustrate how it can be challenging for patients and healthcare professionals to speak the same language when discussing the patient's condition and treatment strategies.

According to a systematic literature review conducted as part of the EVEREST initiative, we found that patient- HCP disconnect and miscommunication are key barriers to applying treat-to-target (T2T) in RA clinical practice¹

In this patient - HCP translator, we have identified common scenarios related to T2T in RA where patients and HCPs may struggle to reach alignment on, and provide suggestions on what they can say instead, to help both sides better understand each other when practicing shared decision-making

CRP, C-reactive protein, HCP, Healthcare Professional
1. Gossec L, et al. EULAR 2022 [POS0607]



Objective of this tool

This translator aims to help patients and HCPs better understand each other's perspectives and speak the same language when practicing T2T in RA¹

There are 4 key areas of practicing T2T, but patients and HCPs don't always speak the same language within these areas.

This translator gives you some suggestions on what you can say to understand each other better.

- We have selected **4 key areas of practicing T2T as symbolised by climbing gear (see figure below)** to indicate what patients and HCPs need to bring on their journey to achieve their treatment goals, similar to how mountaineers use these to reach their summits
- Based on these areas, we have identified several **typical scenarios where misalignment is frequently reported (see figure below)**
- We have collected examples of what patients and HCPs may commonly say in these situations (**"When I say..."**) and suggested things they could say instead to help them understand each other better (**"Instead, maybe I could say..."**)
- Please note that these are not intended to be a dialogue between the patient and HCP, but instead aim to highlight how they can be more clear in communicating their perspectives in situations where they might disagree



Align on treatment goals

GPS: Identify your target

Scenario: Misalignment on the definitions of RA treatment goals



Select and adjust treatment as needed

Ascender device: Jointly adjust your trajectory

Scenario: Disagreement on adjusting RA treatment(s)



Assess disease activity regularly

Altitude meter: Check your progress together regularly

Scenario: Disagreement on the level of RA disease activity



Practice shared decision-making

Carabiner: Connect with your patient or HCP

Scenario: Reluctance to participate in shared decision-making

Please note that these are illustrative examples and do not reflect the thoughts of every patient or HCP; HCP, Healthcare Professional

1. de Wit MP, et al. Ann Rheum Dis 2011;70:891-5



Align on treatment goals

GPS: Identify your target



Patient



When I say...

I want my RA cured

Scenario:

Misalignment on
the definitions of
RA treatment
goals

HCP



When I say...

Your goal should be clinical remission

Instead, maybe I could say...

I would like to have no pain in my joints, feel less tired, and be able to return to my day-to-day activities at home, in my social life, or at work as before I was diagnosed with RA¹⁻³

Suggestions
on how to speak
the same
language

Instead, maybe I could say...

We need to aim for clinical remission, which means you should have no (or almost no) signs and symptoms of inflammation, according to the numbers calculated from your clinical assessments^{4,5}

Please tell me if you are still experiencing any symptoms and we can look into the reasons why

1. Gibofsky A, et al. Health Qual Life Outcomes 2018;16:211;
2. Hulen E, et al. Musculoskeletal Care 2017;15:295-303;
3. van Tuyl LHD, et al. J Rheumatol 2011;38:1735-8;
4. Smolen JS, et al. Ann Rheum Dis 2020;79:685-99;
5. Smolen JS, et al. Ann Rheum Dis 2016;75:3-15

HCP, Healthcare Professional



Assess disease activity regularly

Altitude meter: Check your progress together regularly



Patient



When I say...

I feel that my RA is worse than you think it is

Scenario:

Disagreement on the level of RA disease activity

HCP



When I say...

Based on your disease activity, your RA seems to be under control, and is not as bad as you think it is

Instead, maybe I could say...

My RA symptoms are still making simple day-to-day activities like exercise or work painful and difficult. This is making me feel depressed and negatively affecting my social life and relationships¹⁻³

Suggestions on how to speak the same language

Instead, maybe I could say...

Based on your joint count and your laboratory test results, your disease seem to be under control²

However, it seems like your RA is still affecting you a lot. Can you tell me more about (or fill in a questionnaire to help me understand) how your RA is impacting your daily life or mental health?^{1,4,5}

1. Kvrjic Z, et al. Arthritis Care Res 2018;70:1439-47;
 2. Desthieux C, et al. Arthritis Care Res 2016;68:1767-73;
 3. Hulen E, et al. Musculoskeletal Care 2017;15:295-303;
 4. Bruce B, Fries JF. Clin Exp Rheumatol 2005;23:S14-8;
 5. Ware JE Sherbourne CD. Med Care 1992;30:473-83
- HCP, Healthcare Professional



Select and adjust treatment as needed

Ascender device:

Jointly adjust your trajectory



Patient



When I say...

I'm happy with the treatment I'm receiving and don't think it needs to be changed

Scenario:

Disagreement on adjusting RA treatment(s) (HCP-proposed treatment change)

HCP



When I say...

I think we should adjust your treatment

Instead, maybe I could say...

I want to continue with this treatment because I think it's helping with my RA. What are the pros and cons of switching to a new treatment versus staying on my current treatment?

It is important that I don't lose my progress and that any new side effects are manageable^{1,2}

Suggestions on how to speak the same language

Instead, maybe I could say...

It's been **<3-6 months>** and we still haven't reached our treatment goals yet, so I think it's time we try a different treatment^{3,4}

I understand that you are happy with your current treatment, but can we talk about the pros and cons of switching to another treatment that might help you even more?

1. Wolfe F, Michaud K. Arthritis Rheum 2007;56:2135-42;

2. Tan BE, et al. Rheumatol Int 2017;37:905-13;

3. Smolen JS, et al. Ann Rheum Dis 2020;79:685-99;

4. Smolen JS, et al. Ann Rheum Dis 2016;75:3-15

HCP, Healthcare Professional



Select and adjust treatment as needed

Ascender device:

Jointly adjust your trajectory



Patient



When I say...

I want to change my treatment

Scenario:

Disagreement
on adjusting RA
treatment(s)
(Patient-proposed
treatment
change)

HCP



When I say...

I think your treatment is working well,
so it doesn't need to be changed

Instead, maybe I could say...

I want to see if there are any alternative treatment options available for me because **<include one or more of the following common reasons or specify your own reasons>**.^{1,2}

- 1) I feel that my current treatment isn't working very well;
- 2) I don't like the side effects;
- 3) It is difficult for me to take my treatment;
- 4) I heard about an alternative treatment which might work better for me

Suggestions
on how to speak
the same
language

Instead, maybe I could say...

I don't think we should change treatments because **<include one or more of the following common reasons or specify your own reasons>**.²

- 1) Your treatment now is controlling your inflammation and I don't want you to lose that progress;
- 2) It's unlikely that another treatment will be more effective because **<add explanation>**;
- 3) There are limited treatment options available given your medical history and/or preferences

Could you please tell me more about the reasons why you are unhappy with your treatment and/or why you think a treatment change is needed so we can find a solution together?

1. Wolfe F, et al. Arthritis Rheum 2007;56:2135-42;

2. Taylor PC, et al. Patient Prefer Adherence 2021;15:359-7

HCP, Healthcare Professional



Practice shared decision-making

Carabiner: Connect with your patient or doctor



Patient



When I say...

I don't feel confident enough to make decisions about my RA treatment

Scenario:
Reluctance to participate in shared decision-making

HCP



When I say...

We don't have enough time to cover everything about your RA during our visits

Instead, maybe I could say...

I trust your decisions, but I feel I would be able to contribute more if I had resources or information that I can review between visits to help me understand my RA and treatment options better so I can make a more informed decision^{1,2}

Suggestions on how to speak the same language

Instead, maybe I could say...

I think it is really valuable for you to be involved in the decision-making process and for me to listen to your preferences and/or concerns³⁻⁵

To make sure we have enough time to cover everything, please read these resources, prepare some questions, and prioritize what you want to talk about before our next visit

1. Gibofsky A, et al. Health Qual Life Outcomes 2018;16:211;
2. Nota I, et al. Clin Rheumatol 2016;35:1225-35;
3. Barton JL, Décary S. Curr Opin Rheumatol 2020;32:273-8;
4. Mathijssen EGE, et al. Ann Rheum Dis 2020;79:170-5;
5. Elwyn G, et al. BMJ 2017;359:j4891

HCP, Healthcare Professional



Communication tips

Everyone has a slightly different way of understanding or interpreting a concept. It will help if you:

- Speak in your own words and be more direct about what you mean
- Try to explain the reason behind your opinion or position, whenever possible
- Use gestures or pictures to help you communicate
- Don't assume the other person always understands what you mean right away
- Ask the other person to clarify or elaborate if you don't understand something
- For key actions, repeat back what you understand to check that you are on the same page