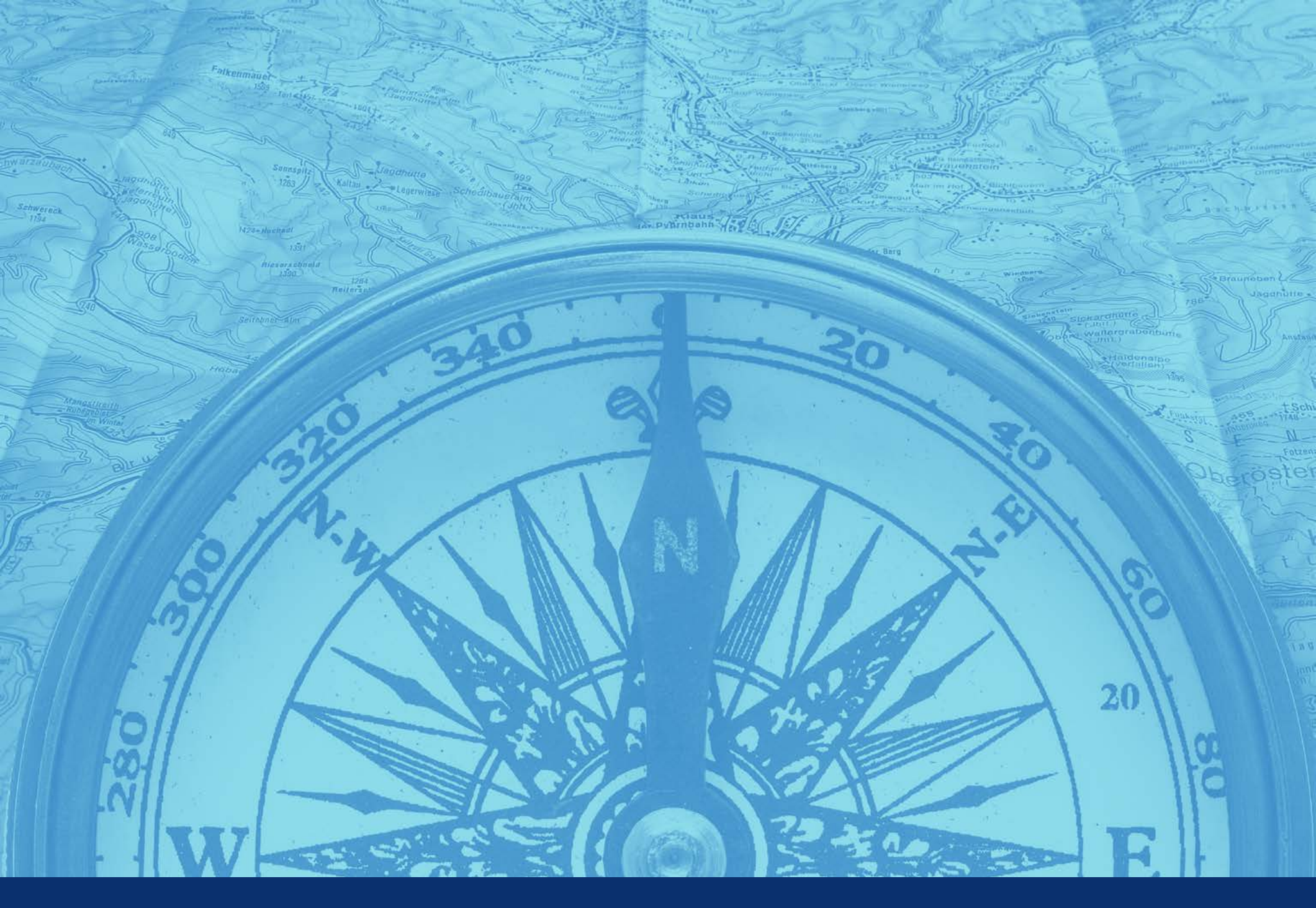

RA EVEREST

Striving for the highest level of care

COMPASS

Your guide on your journey in rheumatoid arthritis

This booklet 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. Please reach out to your doctor if you need any help with managing your rheumatoid arthritis.

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Contents

Appendix

Introduction

You and your doctor are partners on your journey in rheumatoid arthritis (RA), working closely together to ensure the success of this journey.

Through shared decision-making, you and your doctor can make decisions together by discussing your preferences and drawing on clinical knowledge from your doctor.[1,2] Together, you can develop a treatment plan that works best for you, enabling you to live with RA more easily moving forward.

Using COMPASS

Similar to how mountaineers prepare for their expeditions, preparation is the foundation of successfully managing your RA. This is especially important because you don't always have a lot of time with your doctor during each visit.

We want to help you to get the most out of your appointments with your doctor, so that you can achieve your clinical goals like remission or low disease activity, or personal goals, like feeling less pain or returning to your way of life before RA.

COMPASS is a guide for people living with RA to read in your own time between visits or at home. It is designed to help you practice shared decision-making with your doctor or nurse by:

- Providing **information** about your potential treatment goals and options in RA
- Helping you **prepare** for your visit through checklists and pre-visit questionnaires
- Sharing tips on how you can be more **involved** during your visit
- **Connecting** you to educational resources and support groups

You are invited to review this workbook between visits in your own time and at your own pace. All the key information is covered in the main section of the workbook. However, you can refer to the **Appendix** if you want to learn more.

Your doctor or nurse may also ask you to complete and share specific sections in the **Appendix** to help you prepare for your visits, as needed, and they may discuss these with you at the next visit.

Understanding your diagnosis: Be informed

For a brief refresher on RA, refer to Appendix 1A

Aim high with treat-to-target

The treat-to-target (or T2T) approach was developed to help you achieve your treatment goals in RA and prevent further joint damage.[3,4] It is based on the following principles:[2,4]

A. You and your doctor decide on your goal and how to achieve your goal together

B. The most important goal is to maximize your long-term quality of life by:

- Reducing symptoms, such as pain, fatigue, and stiffness
- Preventing damage to the joints
- Regaining physical function and ability to participate in daily activities

C. The most important way to achieve your goal is by stopping joint inflammation

D. By setting a clear treatment target, such as remission, and regularly measuring how active your RA is, you and your doctor can decide how to adjust your treatment if you haven't reached your goal after a certain time

Find out more about T2T recommendations in Appendix 1B

Set your treatment goals

The primary treatment goal of RA is clinical remission, whenever possible.[2,4] Remission significantly slows down joint damage and can make your life more enjoyable.[5] Not everyone living with RA will reach remission. If you have had RA for a long time, low disease activity may be recommended as an alternative goal.

Explore your potential goals in Appendix 2

Define your treatment plan

It is important to work with your doctor to develop a treatment plan tailored to you. Your plan may involve prescribed medication(s), lifestyle changes (eg, healthy diet, physical activity), and complementary therapies.

Explore your treatment options in Appendix 1C

Track your progress

To help you monitor your progress with treatment, your RA will be regularly assessed using disease activity measures, which include your signs and symptoms of disease, and patient-reported outcomes (PROs), which are your own feedback on how you feel and how well you can do everyday activities. These are usually represented by numbers that reflect how well your RA is being controlled.

Explore what your numbers mean in Appendix 1D

Before your visit: Be prepared

Your consultation time with your doctor or nurse may be limited so it is important to prepare beforehand to get the most out of your visits.

You are welcome to bring a family member or caregiver with you to your visit if you are comfortable with it.

What to expect at visits

- Your doctor or nurse will ask you about your medical history, symptoms, and medications
- Your doctor may conduct a physical examination and assess your disease activity
- You will work together to set or revise your treatment
- You will have the opportunity to ask your doctor questions about your condition, treatment options, and treatment plan

What to bring to visits

- Name, address, and contact details of your family doctor
- List of questions or concerns you may have **(Appendix 3A)**
- Pre-visit questionnaires (if these were requested from your doctor or nurse) which you should have completed before your visit **(Appendix 3B–D)**
- A notebook and pen
- If you prefer, a family member or friend to come with you to your consultation

What to expect and how to prepare for your telehealth visit

Some of your visits may be conducted via telehealth. This means you have a consultation with your doctor or nurse by using your computer or phone. Your doctor will usually determine whether a telehealth visit is appropriate and contact you to ask for your consent first. You will then receive instructions on how to attend your telehealth visit.

Telehealth visits can be just as effective as a face-to-face consultation.

Refer to Appendix 4 for more information on telehealth visits

During your visit: Be involved

Get the most from speaking with your doctor or nurse

- Ask the most important questions first from the list you have prepared before the visit **(Appendix 3A)**
- Be open and honest—ask questions and share your concerns clearly
- Share (show or email) any completed pre-visit questionnaires **(Appendix 3B–D)** if these have been requested by your doctor or nurse. These have important information about how you are doing and help focus your conversation with your doctor or nurse at visits
- Do not be afraid to ask your doctor to repeat or explain further if you do not understand
- Take notes during your discussion and keep them for reference

Your doctor or nurse may use aids to discuss your treatment goals and/or help you choose the best treatment option for you.

Discuss your treatment targets

Discuss what you would like to get from your treatment plan and agree on your short- and long-term treatment goals with your doctor. Your doctor will help you identify a clinical goal, which will focus on reducing inflammation, relieving symptoms, and reducing joint damage **(Appendix 2A).**

You may also include any personal goals, like getting back to work and returning to a hobby you enjoy, being able to get around independently, thinking about having children, or being able to wear your wedding ring again **(Appendix 2B).** This will help your doctor understand what is most important to you when managing your disease as these goals are different for each individual.

Develop your treatment plan

Your doctor will work with you to develop a treatment plan that best suits your individual needs and preferences. These questions may help you decide on a treatment together:

- What are my options?
- What are the pros and cons of these options?
- What does this mean in my situation?

If needed, ask your doctor or nurse how much time you have to consider your options. If you don't think your treatment is working well, tell your doctor or nurse to find out if a change is needed.

Refer to Appendix 2C to fill out details of your treatment plan

Between your visits: Stay informed and connected

Take control of your RA journey

Your RA journey continues after your visits and the following can make a difference on how quickly you can achieve your treatment targets:

- Taking your treatment on time
- Attending appointments for blood tests and follow-up visits
- Calling for test results if you do not hear from your doctor
- Having a healthy lifestyle, such as exercising and eating healthily
- Contacting your doctor or nurse if you have any questions or concerns about your treatment (especially if you are experiencing any unexpected side effects)
- Talking with your doctor or nurse about other health conditions you have that can influence your ability to cope with RA, such as diabetes or heart problems
- Talking with your doctor about a referral to another healthcare professional if needed, such as a physiotherapist or psychologist

Reach out for support

Family and friends

Your family and friends can offer practical and emotional support in your daily activities. Feel free to invite a family member or caregiver to attend a visit with you or support you with preparing for a visit, as needed.

RA support groups and organizations

You could also consider speaking to others with the same condition via support groups for people with RA, particularly if you find it difficult to share with family and friends.

Online resources

When you are looking for online resources to learn more about RA by yourself, consider the following tips to find information that you can trust:

- Look for websites developed by hospitals or patient organizations, which tend to be more trustworthy than personal websites
- Check when the pages were last updated to find up-to-date information
- Look for evidence, references, and citations to support the information provided
- Watch out for advertisements that resemble a source of health information
- If needed, compare information from multiple websites

Mobile apps

Your doctor may also ask you to track and manage your RA regularly using a mobile app

Ask your doctor to recommend relevant sources of support between your visits (Appendix 5)

References

1. Florin J, et al. Clinical decision-making: Predictors of patient participation in nursing care. J Clin Nurs 2008;17:2935–44
2. de Wit MP, et al. Treating rheumatoid arthritis to target: The patient version of the international recommendations. Ann Rheum Dis 2011; 70:891–5
3. Smolen JS, et al. Treating rheumatoid arthritis to target: Recommendations of an international task force. Ann Rheum Dis 2010;69:631–7
4. Smolen JS, et al. Treating rheumatoid arthritis to target: 2014 update of the recommendations of an international task force. Ann Rheum Dis 2016;75:3–15
5. Ostor AJ, et al. Value of remission in patients with rheumatoid arthritis: A targeted review. Adv Ther 2022;39:75–93
6. Bullock J, et al. Rheumatoid arthritis: A brief overview of the treatment. Med Princ Pract 2018;27:501–7
7. Shams S, et al. The therapeutic landscape of rheumatoid arthritis: Current state and future directions. Front Pharmacol 2021;12:680043
8. Ma X, Xu S. TNF inhibitor therapy for rheumatoid arthritis. Biomed Rep 2013;1:177–84
9. EMA. EMA recommends measures to minimise risk of serious side effects with Janus kinase inhibitors for chronic inflammatory disorders. Available at: https://www.ema.europa.eu/en/news/ema-recommends-measures-minimise-risk-serious-side-effects-janus-kinase-inhibitors-chronic (last accessed December 2022)
10. Fries JF, et al. The dimensions of health outcomes: The health assessment questionnaire, disability and pain scales. J Rheumatol 1982;9:789–93
11. Gossec L, et al. Elaboration of the preliminary Rheumatoid Arthritis Impact of Disease (RAID) score: A EULAR initiative. Ann Rheum Dis 2009;68:1680–5
12. Pincus T, et al. RAPID3 (Routine Assessment of Patient Index Data 3), a rheumatoid arthritis index without formal joint counts for routine care: Proposed severity categories compared to disease activity score and clinical disease activity index categories. J Rheumatol 2008;35:2136–47
13. Taylor PC, et al. Treatment satisfaction, patient preferences, and the impact of suboptimal disease control in a large international rheumatoid arthritis cohort: SENSE study. Patient Prefer Adherence 2021;15:359–73
14. de Thurah A, et al. 2022 EULAR points to consider for remote care in rheumatic and musculoskeletal diseases. Ann Rheum Dis 2022;81:1065–71

Appendix 1:

Basics of RA management

A) An overview of RA[2,6]

Your body's immune system protects you against harm from the outside world. Rheumatoid arthritis (RA) is a disease that occurs when your immune system is switched on by mistake.

This causes inflammation in your joints (often in your hands, feet, wrists, elbows, knees, or ankles), leading to pain, swelling, stiffness, and tenderness. It also leads to symptoms outside your joints like fatigue, weight loss, or a low fever.

You should always tell your doctor about your symptoms because:

- Symptoms can vary from person to person and may appear without a pattern
- Your doctor can't see most of these symptoms, so if you don't say how you feel, your doctor won't know how best to treat you
- Symptoms can be a sign that joint damage is happening, so it is important not to wait to say something

As RA is a chronic (lasting a long time) condition, it can lead to permanent joint damage if it is not well managed. Early diagnosis is very important because studies have shown that delaying treatment can result in more pain and disability in the future.

B) Summary of T2T recommendations[2,4]

1. **Your recommended treatment goal** will usually be either clinical remission, which is the absence of signs and symptoms of RA caused by inflammation, or **low disease activity** as an alternative, especially if you have had RA for a long time
2. **Your disease activity** (including your joints) should be measured as frequently as monthly if you have high or moderate disease activity and every 6 months if you are in low disease activity or remission
3. **Your treatment plan is based on your treatment goals.** This means that until your goal is reached, your medication should be adjusted at least every 3 months. Once you have achieved your goal, your aim is to stay at this level of disease activity moving forward
4. **Factors for treatment decisions** include your disease activity, how much joint damage you have, how well you function in daily activities, and your individual situation (eg, if you have other diseases, if you have drug-related safety risks, and your personal preferences)
5. **You and your doctor (or nurse) should decide together** on what your treatment goals are and how to reach them

Read the full T2T recommendations

C) Explore your treatment options

These are the main types of medications used to treat RA:[6-9]

Medications	Benefits	Common side effects
Nonsteroidal anti-inflammatory drugs (NSAIDs) Examples: Over-the-counter painkillers (such as aspirin and ibuprofen), prescription NSAIDs, COX-2 inhibitors	• Reduce pain and swelling • Lower fever	• Upset stomach • Stomach ulcer • Nausea
Corticosteroids Example: Prednisone	• Usually used for short periods to reduce inflammation in severe RA	• Weight gain • Increased risk of infection • Bone loss
Conventional disease-modifying antirheumatic drugs (DMARDs) Example: Methotrexate	• Prevent long-term joint damage • Can be taken alone or with NSAIDs	• Upset stomach • Liver problems • Skin problems • Fatigue • Anemia
Biologic DMARDs Examples: TNF inhibitors, IL-6 inhibitors, B-cell inhibitors, T-cell inhibitors	• Target a specific part of the immune system to reduce inflammation • Help prevent damage to joints and improve physical function • Can be taken alone or with conventional DMARDs	• Allergic reactions • Mild skin reaction at injection site • Infection in the upper part of the airway • Increased infection risk • Increased risk of certain types of cancer
Targeted synthetic DMARDs Examples: JAK inhibitors	• Target a specific part of the immune system to reduce inflammation • Help prevent damage to joints and improve physical function • Can be taken alone or with conventional DMARDs	• Infection in the upper part of the airway • Increased infection risk • Increased risk of certain types of cancer • In specific patients, increased risk of cardiovascular events

It is important to understand the pros and cons of these medications to ensure that the benefit from a treatment outweighs the potential side effects that you may experience. Ask your doctor about individual safety concerns on any medication you are taking or are considering taking. You may refer to the most up-to-date Patient Information Leaflets for details on the side effects of a particular RA drug.

D) Tracking disease control[2]

Disease activity is a term doctors use to describe your current level of inflammation, signs (eg, swelling), and symptoms (eg, pain). The most common ways of measuring your RA disease activity are:

- Clinical Disease Activity Index (CDAI)
- Simple Disease Activity Index (SDAI)
- Disease Activity Score in 28 joints (DAS28)

These are represented by a single number and are based on a combination of the following:

- Joint examination by your doctor
- How controlled you think your RA is on a scale of 1–10 (where 10 is the worst)
- How controlled your doctor thinks your RA is on a scale of 1–10 (where 10 is the worst)
- Blood tests

By tracking your disease score over time, your doctor or nurse will be able to evaluate how effective your current treatment is.

How do my numbers correspond to my disease activity?[2]				
How is it measured?				
CDAI	**≤2.8**	**>2.8–10**	**>10–22**	**>22**
SDAI	**≤3.3**	**>3.3–11**	**>11–26**	**>26**
DAS28	**<2.6**	**≥2.6–3.2**	**>3.2–5.1**	**>5.1**
What does it mean?	**REMISSION**	**LOW**	**MODERATE**	**HIGH**
Inflammation	**None**	**Reduced**	**Present**	**High**
Symptoms	**Absent**	**Weak**	**Strong**	**Severe**
Physical function	**Good**	**Improved**	**Limited**	**Poor**
Progression of joint damage	**None**	**Limited**	**Present**	**Often**

< less than. ≤ less than or equal to. > more than. ≥ more than or equal to.

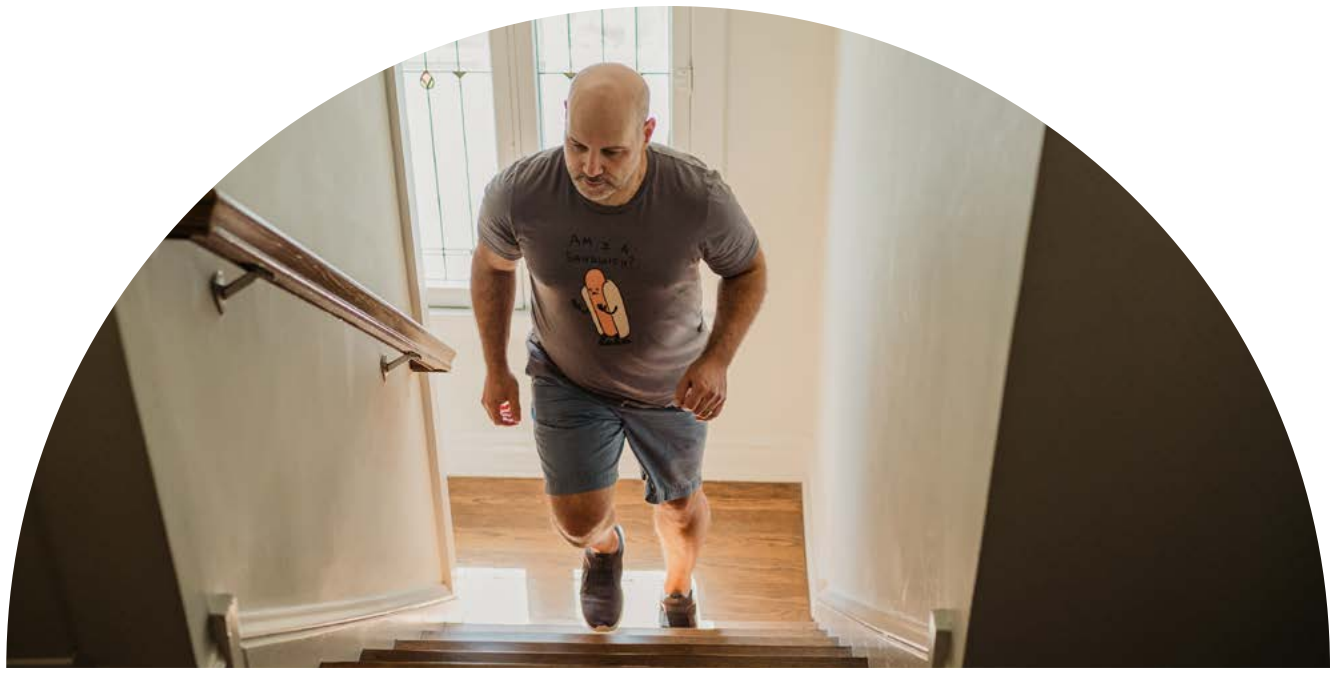
Appendix 2:

Treatment goals and treatment plan

A) Disease activity goals

Disease activity goals are based on achieving the lowest level of disease activity possible (usually remission or low disease activity) through reducing inflammation, relieving symptoms, and reducing joint damage. Ask your doctor or nurse to help you complete this information.

Date:	
Disease activity measure (please circle one):	CDAI / SDAI / DAS28-CRP / DAS28-ESR / RAPID3 / Other (please specify):
Current disease activity (please circle one):	Remission / Low disease activity / Moderate disease activity / High disease activity
Current target (please circle one):	Remission / Low disease activity / Other (please specify):
Date to be achieved by:	
Next target (please circle one):	Remission / Low disease activity / Other (please specify):
Date to be achieved by:	



B) Personal goals

Think about how RA has affected your life, from the daily challenges that you face to the long-term impact on your life. In what ways do you hope to improve your quality of life and what are specific goals that you and your doctor can work toward? Please prioritize 1–3 goals from the suggested areas below and explain what you would like to achieve specifically.

Categories	Suggested areas to consider	Specific details (please add below)
Physical wellbeing	☐ Daily activities (eg, shopping, cleaning)	
	☐ Independence/mobility	
	☐ Quality of sleep; fatigue	
	☐ Exercise/sport	
	☐ Pain	
	☐ Weight loss or gain; appetite	
	☐ Other	
Emotional wellbeing	☐ Stress/mental wellbeing	
	☐ Concern over appearance	
	☐ Mood (eg, loneliness, feeling down or misunderstood)	
	☐ Other	
Social life	☐ Hobbies	
	☐ Family, friends, and other relationships	
	☐ Travel, going out	
	☐ Other	
Work life and study	☐ Study and student life	
	☐ Applying for, keeping, or switching, a job	
	☐ Traveling to and from work	
	☐ Daily tasks, work performance	
	☐ Other	
Personal	☐ Self-care: Personal hygiene, getting dressed	
	☐ Intimacy (eg, sexual intimacy)	
	☐ Pregnancy	
	☐ Caregiving	
	☐ Other	
Other (please specify)		

C) Treatment plan

Note down what you have discussed and the decisions you made with your doctor or nurse regarding your treatment plan and next steps during your visit.

Treatment plan and next steps

Notes

Appendix 3:

Pre-visit questionnaires

A) List of questions or concerns

The consultation is a two-way discussion between you and your doctor. This is the best opportunity for you to raise any concerns or clarify any questions you may have.

It is helpful to prepare a list of questions before each visit and prioritize up to three questions or concerns that are most important to you. These may be based on the following example questions, or you may prefer to write down your own questions in the space provided below.

Example questions

- How is my RA condition now?
- Has my RA improved since my last visit?
- How can I achieve my treatment goals?
- What treatment options are available?
- Why are you recommending this particular medicine?
- How often and for how long do I need to take my medication?
- How long will it take before I will experience an improvement in my condition?
- What are potential side effects of this medicine?
- What can I do to reduce these side effects if they occur?
- Are there any lifestyle changes that I need to consider?
- What if I don't reach my treatment goal?
- Is it possible that I could develop new symptoms?

Your own questions or concerns

B) Current medications

Please fill out the table below to keep your doctor or nurse informed about the treatment that you are currently on (including medications that are prescribed by another doctor or that you started taking yourself, eg, NSAIDs); if you have any allergies; or if you have any conditions other than RA.

Medication	Dose	Frequency	Notes

Allergies (please add below, if any)	**Conditions other than RA** (please add below, if any)

Response to your current treatment

Think about how you are feeling about your current treatment. It is important to be open about this.

Please check (✓) below the smiley face that best represents your thoughts about the following:

Current treatment How do you feel about your medications?					
Medication adherence Have you been able to take your medications as advised?					
Side effects Are you experiencing any side effects? (Please add below, if any)					

C) Track your symptoms

If you are experiencing symptoms such as pain, stiffness and fatigue, or any challenges with your daily activities since your last visit, please let your doctor know by describing them in this table.

Symptoms (What they were)	**Frequency** (How often I experienced symptoms)	**Duration** (How long symptoms lasted)

Please complete one of the following questionnaires (your doctor or nurse will advise on which one) to help your doctor or nurse understand how your symptoms are affecting your daily activities.

HAQ-DI[10]

Please check (✓) the one that best describes your abilities.

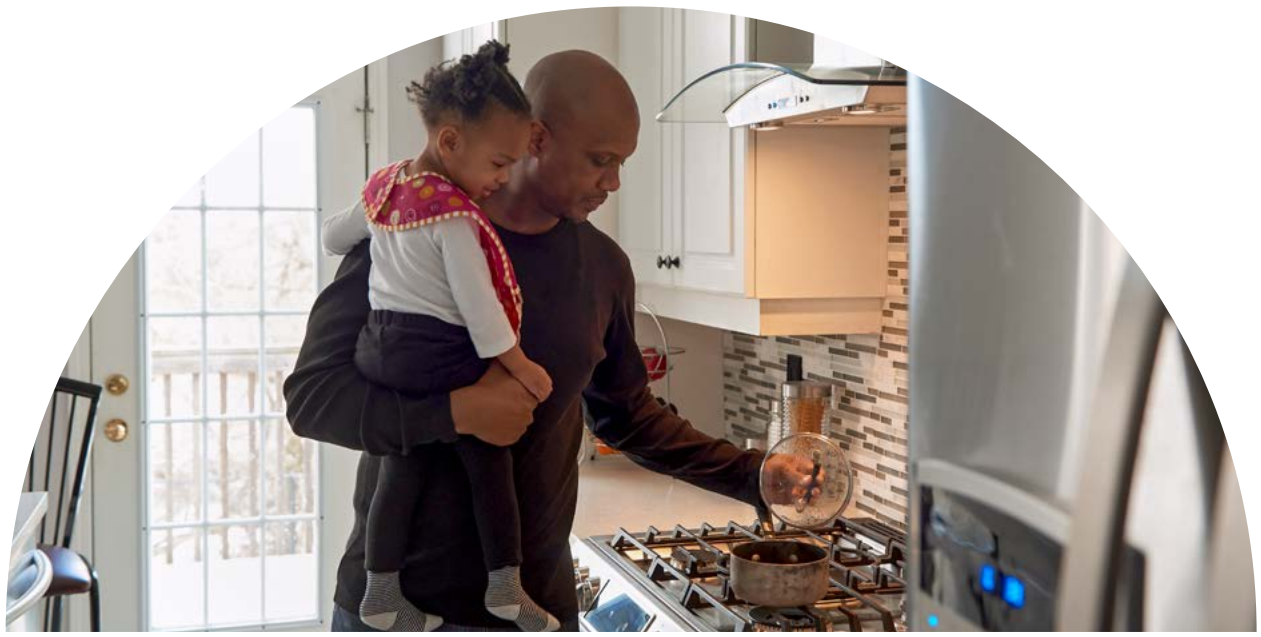
Over the last week, were you able to:	Without **ANY** difficulty	With **SOME** difficulty	With **MUCH** difficulty	**UNABLE** to do
Dressing and grooming Dress yourself, including shoelaces and buttons?				
Shampoo your hair?				
Arising Stand up from a straight chair?				
Get in and out of bed?				
Eating Cut your own meat?				
Lift a full cup or glass to your mouth?				
Open a new milk carton?				
Walking Walk outdoors on flat ground?				
Climb up five steps?				

Please check any AIDS OR DEVICES that you usually use for any of the above activities:

- ☐ Devices used for dressing (button hook, zipper pull, etc.)
- ☐ Built up or special utensils
- ☐ Crutches
- ☐ Special or built up chair
- ☐ Cane
- ☐ Walker
- ☐ Wheelchair

Please check any categories for which you usually need HELP FROM ANOTHER PERSON:

- ☐ Dressing and grooming
- ☐ Arising
- ☐ Eating
- ☐ Walking



HAQ-DI[10] (continued)

Please check (✓) the one that best describes your abilities.

Over the last week, were you able to:	Without **ANY** difficulty	With **SOME** difficulty	With **MUCH** difficulty	**UNABLE** to do
Hygiene Wash and dry your body?				
Take a tub bath?				
Get on and off the toilet?				
Reach Reach and get down a 5-pound object (such as a bag of sugar) from above your head?				
Bend down to pick up clothing from the floor?				
Grip Open car doors?				
Open previously opened jars?				
Turn faucets on and off?				
Activities Run errands and shop?				
Get in and out of a car?				
Do chores such as vacuuming or yard work?				

Please check any AIDS OR DEVICES that you usually use for any of the above activities:

☐ Raised toilet seat
☐ Bathtub bar
☐ Long-handled appliances for reach
☐ Bathtub seat
☐ Long-handled appliances in bathroom
☐ Jar opener (for jars previously opened)

Please check any categories for which you usually need HELP FROM ANOTHER PERSON:

☐ Hygiene
☐ Reach
☐ Gripping and opening things
☐ Errands and chores

Your ACTIVITIES:
To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?

☐ Completely ☐ Mostly ☐ Moderately ☐ A little ☐ Not at all

Your PAIN: How much pain have you had IN THE PAST WEEK?
On a scale of 0 to 100 (where zero represents “no pain” and 100 represents “severe pain”), please record the number below.

Your HEALTH:
Please rate how well you are doing on a scale of 0 to 100 (0 represents “very well” and 100 represents “very poor” health). Please record the number below.

Rheumatoid Arthritis Impact of Disease (RAID)[11]

Please check (✓) the number that best describes how your RA has affected you during the last week.

1. Pain
Please check (✓) the number that best describes the pain you felt due to your RA during the last week.

None	◯ 0	◯ 1	◯ 2	◯ 3	◯ 4	◯ 5	◯ 6	◯ 7	◯ 8	◯ 9	◯ 10	Extreme

2. Functional disability assessment
Please check (✓) the number that best describes the difficulty you had in doing daily physical activities due to your RA during the last week.

None	◯ 0	◯ 1	◯ 2	◯ 3	◯ 4	◯ 5	◯ 6	◯ 7	◯ 8	◯ 9	◯ 10	Extreme difficulty

3. Fatigue
Please check (✓) the number that best describes how much fatigue you felt due to your RA during the last week.

No fatigue	◯ 0	◯ 1	◯ 2	◯ 3	◯ 4	◯ 5	◯ 6	◯ 7	◯ 8	◯ 9	◯ 10	Totally exhausted

4. Sleep
Please check (✓) the number that best describes the sleep difficulties (ie, resting at night) you felt due to your RA during the last week.

No difficulty	◯ 0	◯ 1	◯ 2	◯ 3	◯ 4	◯ 5	◯ 6	◯ 7	◯ 8	◯ 9	◯ 10	Extreme difficulty

5. Physical wellbeing
Considering your arthritis overall, how would you rate your level of physical wellbeing during the past week? Please check (✓) the number that best describes your level of physical wellbeing.

Very good	◯ 0	◯ 1	◯ 2	◯ 3	◯ 4	◯ 5	◯ 6	◯ 7	◯ 8	◯ 9	◯ 10	Very bad

Rheumatoid Arthritis Impact of Disease (RAID)[11] (continued)

Please check (✓) the number that best describes how your RA has affected you during the last week.

6. Emotional wellbeing

Considering your arthritis overall, how would you rate your level of emotional wellbeing during the past week? Please check (✓) the number that best describes your level of emotional wellbeing.

Very good	○ 0	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7	○ 8	○ 9	○ 10	Very bad

7. Coping

Considering your arthritis overall, how well did you cope (manage, deal, make do) with your RA during the last week?

Very well	○ 0	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7	○ 8	○ 9	○ 10	Very poorly

RAPID3[12]

Please check (✓) the one best answer for your abilities at this time.

Over the last week, were you able to:	Without **ANY** difficulty	With **SOME** difficulty	With **MUCH** difficulty	**UNABLE** to do
A. Dress yourself, including tying shoelaces and doing up buttons?				
B. Get in and out of bed?				
C. Lift a full cup or glass to your mouth?				
D. Walk outdoors on flat ground?				
E. Wash and dry your entire body?				
F. Bend down to pick up clothing from the floor?				
G. Turn regular faucets on and off?				
H. Get in and out of a car, bus, train, or airplane?				
I. Walk two miles or three kilometers, if you wish?				
J. Participate in recreational activities and sports as you would like, if you wish?				
K. Get a good night's sleep?				
L. Deal with feelings of anxiety or being nervous?				
M. Deal with feelings of depression or feeling down?				

1. How much pain have you had because of your condition over the past week?

Please check (✓) below how severe your pain has been:

No pain	○ 0	○ 0.5	○ 1.0	○ 1.5	○ 2.0	○ 2.5	○ 3.0	○ 3.5	○ 4.0	○ 4.5	○ 5.0	○ 5.5	○ 6.0	○ 6.5	○ 7.0	○ 7.5	○ 8.0	○ 8.5	○ 9.0	○ 9.5	○ 10	Pain as bad as it could be

2. Considering all the ways in which illness and health conditions may affect you at this time:

Please check (✓) below how you are doing:

Very well	○ 0	○ 0.5	○ 1.0	○ 1.5	○ 2.0	○ 2.5	○ 3.0	○ 3.5	○ 4.0	○ 4.5	○ 5.0	○ 5.5	○ 6.0	○ 6.5	○ 7.0	○ 7.5	○ 8.0	○ 8.5	○ 9.0	○ 9.5	○ 10	Very poorly

D) Treatment expectations and preferences[13]

Think about the following areas of your health related to RA in which you would like to see improvement, then please check (✓) the number that best describes your expectations.

	1	2	3	4	5	6	7
	No improvement needed			Some improvement needed			The most improvement needed
General improvement of arthritis							
Less joint pain							
Less joint swelling							
Lasting relief of RA symptoms							
More joint flexibility							
Improvement in morning stiffness in the limbs							
Less tiredness and less fatigue							
Improvement in mood							
Improvement in self-care							
Improvement in workability							
Improvement in sleep							
Other (please specify):							

Please check (✓) your medication preferences below and add any additional comments into the space provided.

Route of administration	Frequency
☐ By mouth	☐ Once daily
☐ By self-injection (medication injected by yourself or caregiver; requires less than 10 minutes to complete)	☐ Once weekly
☐ By infusion (medication infused through a vein by a trained professional; requires 2 hours to complete)	☐ Once monthly

Side effects that you consider most undesirable (please rank, if appropriate)

- ☐ Weight gain
- ☐ Hair thinning or loss
- ☐ Skin symptoms, eg, injection-site reaction, rash
- ☐ Allergic reactions
- ☐ Negative effect on your blood test results
- ☐ Effect on fertility
- ☐ Increased risk of infections
- ☐ Increased risk of cancer
- ☐ Increased risk of cardiovascular disease
- ☐ Other (please specify, if any)

Any additional preferences or comments (please add below, if any)

Appendix 4:

Preparing for telehealth visits[14]

A) What to expect at telehealth visits

Telehealth allows you to have a medical consultation when you and your doctor are in different locations. Essentially, telehealth connects the two of you using telecommunications, usually via phone calls or video conferencing over the internet

- If you're new to video conferencing, don't worry—your doctor or nurse will give you all the information you need to set up prior to your appointment, including the video link so you can log in to the telehealth platform using the device (laptop, desktop computer, tablet, or phone) most suitable for you
- Before your telehealth visit, your doctor might send you a link to a video tutorial on a self-assessment technique or other information to help you prepare for your consultation
- Make sure your doctor or nurse has your correct contact information, as they may call you by telephone if you become disconnected during the appointment

Telehealth visits can be just as effective as a face-to-face consultation

On the day of your telehealth visit

- Make sure your computer or device is plugged in, charged, and switched on
- Check that your internet connection is working and you can access the telehealth platform
- Close all other applications that might slow down your internet connection or be a distraction
- If you are unsure how to access the consultation on your device, ask a family member or friend to check that everything is set up correctly; you might also want them to be with you during the consultation in case of technical problems
- Make sure you are in a quiet place with as little background noise as possible
- Have your medications ready to check that you are taking them as your doctor has prescribed
- Make sure you are ready with the questions that you want to ask your doctor or nurse

During the consultation

- For some appointments, you might be required to confirm your identity and give a brief verbal consent to ensure you understand and are happy to continue the consultation
- Much like an in-person consultation, your doctor will review your medical records and ask you questions to evaluate your condition; they might also discuss your treatment goals and options with you, as well as the outcomes of any self-assessments or questionnaires you have completed
- Your doctor may want to watch you moving or doing specific activities, in which case they might ask you to stand your device on a chair or shelf, so they can see you better; they might also ask you to take a picture and send it to them
- Your doctor may write a prescription, which is then sent directly to a pharmacy for home delivery, or for you to collect
- Your doctor may request for additional tests (eg, laboratory, radiology tests), which are sent directly to the test provider who will then follow up with you
- You will have the opportunity to ask questions and to talk about any concerns you have with your RA or your treatment
- If you do become disconnected from your doctor during the appointment, they may call you by telephone

Follow-up

- After your telehealth consultation, you should receive any resources that you talked about with your doctor. This might be a list of exercises you can practice or a link to a website with more information

B) Telehealth visit checklist

You may not always have the means to create an optimal environment for telehealth; the most important aspect is that you are able to communicate clearly with your physician. Please ask for help from family members, caregivers, friends, or the practice as needed to support you with this.

- [ ] If applicable, ask your nominated family member/ caregiver to attend the visit with you
- [ ] Check that you have completed and emailed your pre-visit questionnaires, or have them handy **(Appendix 3B–D)**
- [ ] Check that you have your questions that you want to ask your doctor or nurse ready
- [ ] Set up in a quiet and private space
  - [ ] Switch off or mute other sound-emitting devices
  - [ ] Check that there is adequate lighting in the room
  - [ ] Check that you have a pen and paper nearby for taking notes (if applicable)
- [ ] Set up your IT equipment
  - [ ] Choose the most suitable device (laptop, desktop computer, tablet, or phone)
  - [ ] Check that your device and browser support the telehealth platform or application
  - [ ] Ensure that your device is plugged in and charging
  - [ ] Check your internet is stable
  - [ ] Close other applications and turn off notifications
  - [ ] Log in to the telehealth platform using the weblink provided by your doctor
  - [ ] Check the sound from your headphones or speakers
  - [ ] Set up and test the sound on your microphone
  - [ ] Set up your webcam to show your head and shoulders
  - [ ] Check your webcam and microphone are set up correctly

Appendix 5:

Follow-up support information

To help you access the support you might need between visits, please ask your doctor to help you complete the relevant information.

Who to go to when I...	
Have questions about my medications?	
Am experiencing flares?	
Need to find out my test results?	
Need advice for managing my disease on holiday?	
Need technical assistance for telehealth visits?	
Other queries?	

Useful resources	
Patient clinic helpline number/email:	
Patient association:	
Websites for additional information: Examples: - Rheum for More - RA overview (National Health Service, UK) - Your guide to RA (WebMD)	
Recommended mobile health apps:	

Useful contacts	
Rheumatologist:	
Family doctor:	
Other:	

Next appointments		
Date	Time	Location (or online)

Glossary[2]

Keywords for managing your rheumatoid arthritis

- **Clinical remission or Remission:** The lowest level of disease activity
- **Comorbidities:** Other long-term conditions or diseases that a person with RA may have; for example, diabetes or high blood pressure
- **Disease activity:** Signs and symptoms caused by inflammation due to RA. It is usually categorized as four levels: high, moderate, low, and remission
- **Disease activity measures:** How RA disease activity is measured, based on a combination of information collected from joint examinations, blood tests, and patient feedback; and usually represented by a number
- **Inflammation:** What happens when your immune system is switched on; this leads to pain, swelling, stiffness, and loss of function in the joints, as well as fatigue in RA
- **Patient-reported outcomes or PROs:** Patients' assessments, in their own words, of how they feel and how well they can do everyday activities
- **Rheumatoid arthritis or RA:** A condition that occurs when the immune system is switched on by mistake, leading to inflammation that causes pain, swelling, stiffness, and loss of function in the joints, as well as fatigue
- **Signs:** Features that can be seen by physical examination, such as the number of swollen joints
- **Shared decision-making:** The process during which you and your doctor make treatment decisions together: 1) Your doctor presents your options with their pros and cons; 2) You share your thoughts about the different options; 3) Together, you decide on the option that best fits with your preferences
- **Symptoms:** Features of the disease as experienced by the patient, such as pain, fatigue, and stiffness
- **Treat-to-target or T2T:** Treating your RA until you achieve the lowest levels of disease activity (remission or low disease activity) and maintaining your RA at the same level once this is achieved