




Primary Immunodeficiencies / Autoinflammatory Disorders
Autoimmune Diseases / Paediatric Rheumatic Diseases

PATIENT JOURNEY HANDBOOK



European Reference Network

for rare or low prevalence
complex diseases

 **Network**
Immunodeficiency,
Autoinflammatory and
Autoimmune Diseases
(ERN RITA)



Funded by
the European Union

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PATIENT EUROPEAN JOURNEY PROJECT

Background and objectives

A Patient journey encompasses the various stages, interactions, and experiences encountered by individuals within the healthcare system. Understanding these journeys is pivotal for healthcare providers, policymakers, and researchers to optimize care delivery, improve patient outcomes, and enhance the overall healthcare experience. It delves into the diverse stages, challenges, and experiences encountered by patients throughout their healthcare interactions, aiming to enhance healthcare delivery and patient-centred care.

Within rare and/or chronic disease, patient journeys are even more difficult due to the lack of awareness, leading to complications from delayed diagnosis and treatment. The establishment of the European Reference Networks in 2017 has allowed Healthcare and Patient experts to connect and share their experience and expertise of managing rare conditions, with the aim of ensuring no one is disadvantaged by where they live.

The ultimate objective of developing Patient Journeys within each RITA stream is to improve future patient care in these areas – Autoinflammatory Disorders, Primary Immunodeficiencies, Auto-immune diseases (Vasculitis, Neuro-inflammation), and Paediatric Rheumatic diseases,

<< as patient involvement in the design, evaluation and designation of healthcare services, improves the relevance and quality of the services, as well as improves their ability to meet patient needs >>.'!

Governance of the Patient journey working group

The working group leading the patient journey project, is made up of:

- one patient representative from each stream,
- ERN RITA Physicians who oversee medical aspects of project design,
- members of the coordination team

Each patient representative in turn creates working teams within their stream to elaborate their specific Patient Journeys.

Country inclusion: Representatives from the different EU members, but non-RITA/non-EU members can join (i.e. UK, Norway, Switzerland, Turkey and beyond if deemed relevant)

The working group meets on a regular basis to choose the diseases, to follow up on the ongoing work, to establish plans and to update the ERN-RITA board.

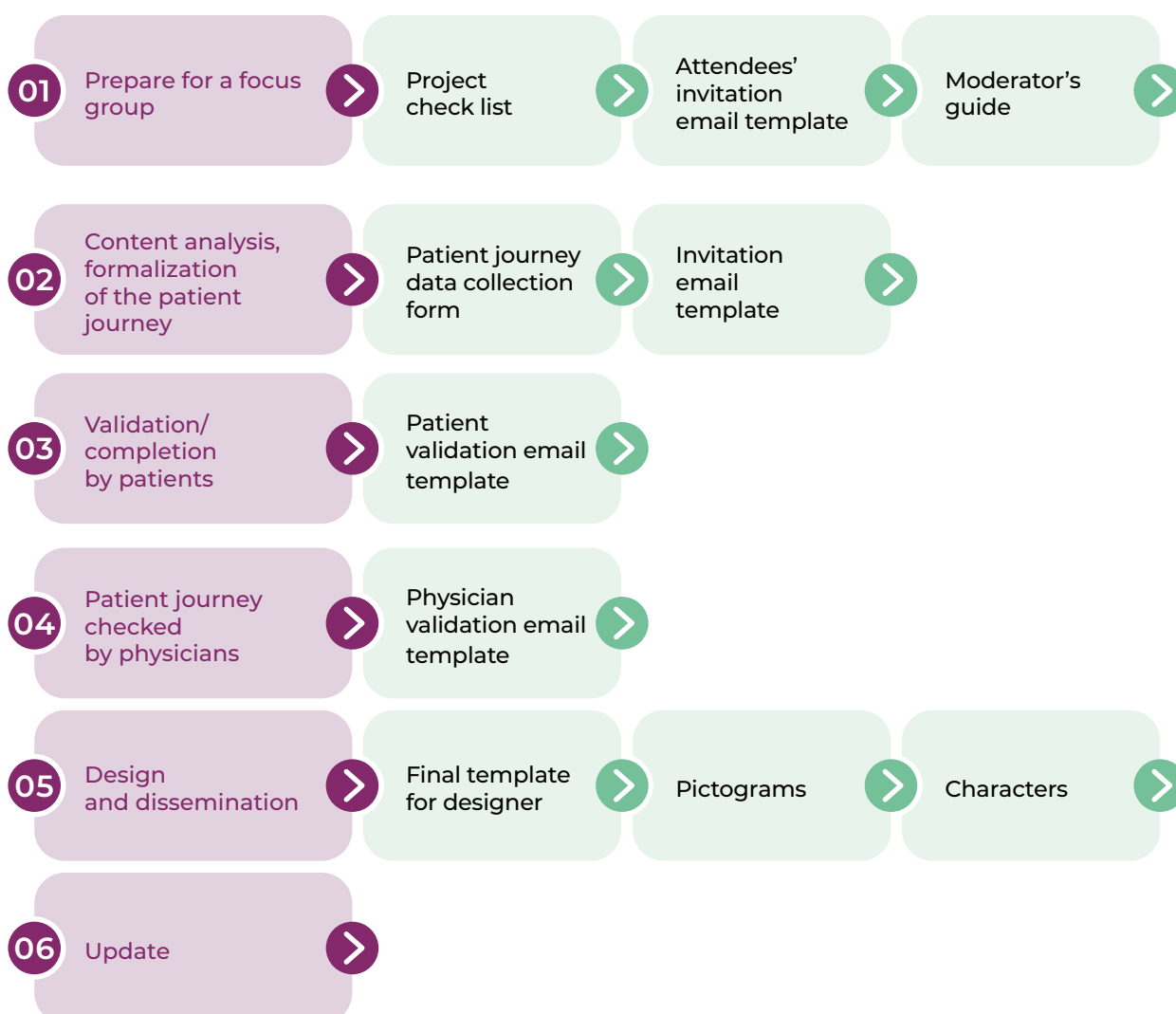
These meetings are not exclusive to the working group and are joined by invited others when necessary to ongoing work.

METHODOLOGY: QUALITATIVE DATA COLLECTION METHOD WITH FOCUS GROUPS

To release Patient journeys, WG uses a qualitative data collection method based on focus groups, that facilitates the collection of information on experiences, perceptions, insights, attitudes, from a given population².

Methodology step by step

Legend:  Step  Tool



1. Prepare for a Patient focus group

A focus group is a group interview of around twelve people who share similar characteristics. A moderator guides the group based on a predetermined set of topics summarized in a Moderator's guide.

1.1 Plan your Focus group

- Establish a calendar for a series of meetings.
- Decide if to hold several dedicated language groups or a multinational group in a single language.
- Decide if the focus group will be conducted as a face-to-face meeting (taking the opportunity of a meeting) or via videoconference.
- Consider a moderator fluent in the language of the group. They will guide the attendees through the discussion and keep the group focused on the topics for discussion.
- Identify and invite attendees to the focus group. Consider around 12 attendees (More may be invited in case some are unable to attend).
- Notes can be recorded by any method or a combination of the following:
 - a designated note taker who will attend for this role only and not interact with the group,
 - a flip chart (face-to-face meeting) or online white board with multi-user access, so that attendees can write their responses/opinions,
 - AI script or a recording but the attendees must be made aware of this beforehand and the recording deleted once transcript has been obtained.

1.2 Invite possible attendees

- Send an invitation explaining the objective of the focus group why we want this information, how this information will be used and the impact this will have in future care. This invitation should be engaging, short and clear. If available a link may be provided to a Patient journey to demonstrate what is involved
 - The patients/parents/carers may come from different EU countries or beyond.

 See Invitation template.

1.3 Adapt the moderator's guide to the condition you want to address

- See the example and adapt the questions to the condition and the group you will address. It will then be used as a support to collect the data from the different focus groups

 See moderation guide

1.4 Duration of the focus group: 1 to 2 hours

(depending on the number of attendees and how they are engaged)

- 10 mins for Introduction of the meeting and of the attendees (short)
- 15/20 mins for each section of the moderation guide:
First Symptoms, Diagnosis, Treatment, and Follow up and aging
- 20 mins for feedback/comments on the meeting, conclusions and next steps.

1.5 Identify physicians who will be involved in the process

- Identify physicians who are specialists on the conditions, addressing children and/or adult patients depending on the condition.
- They belong from different EU countries and beyond.
- They may be able to support for patient engagement in the focus groups
- They will review the final version of the patient journey

1.6 Conduct of the Focus Group

- Manage the focus group and collect the information
- The moderator creates an environment that encourages participants to share their perceptions and points of view without entering debates: what matters is to collect as much information as possible.
- You can discuss with the whole focus group, eventually using a whiteboard with post it notes. Attendees can also work in subgroups by topics using breakout rooms (when digital).
- Data collection will follow the same route, as mentioned in the moderator's guide.

2. Content analysis, formalization of the patient journey of the patient journey

- Gather all the information collected during the focus group(s) in the “data journey collection form”

 Patient Journey data collection form

3. Validation/completion by patients of the patient journey

- Send the completed data collection form to all the attendees, asking them to validate, or complete the form (often attendees have other insights coming up after the meeting).
- Mention a deadline
 - Take the feedback and incorporate it into final work.

4. Patient journey checked by physicians

- Liaise with the physicians involved in the Patient journey project so that they can review the collected data. They are expected to validate (sometimes patients may mention aspects that don't belong to the disease per say but to comorbidities) and complete the collected information. They may add appropriate medical resources (i.e. guidelines)
- Mention a deadline.

5. Design and dissemination of the patient journey

- Organise all the data in the different sections using the pictograms.
- Choose the main character, and the other ones you wish in the background.
- Have a look at existing patient journeys on ERN RITA website, they may help you to apply this.

 Pictograms

 Characters

 Final template for designer

- After designing, it will be necessary to check the patient journey and make corrections if necessary.
- The released patient journey will be sent to the coordination team to be made available online and disseminated.

6. Follow up on the patient journey

- The patient journey needs reviewing and updating every 2–3 years.

PATIENT JOURNEY HANDBOOK – TOOLBOX



Project check list

1. Prepare for a Patient focus group

- Decide if to hold several dedicated language groups or a multinational group in a single language.
- Decide if the focus group will be conducted in person or online.
- Establish a calendar with a series of meetings.
- Consider a moderator fluent in the language of the group.
- Decide how to take notes.
- Identify attendees to the focus group.
- Send out the invitations... and plan the reminders
- Identify physicians, specialists of the condition.

See Invitation template

- Adapt the question of the moderator's guide to the condition you are addressing

See moderation guide

2. Conduct the Focus Group

- Manage the focus group
- Collect the information

Patient Journey data collection form

3. Formalize the patient journey

- Summarize the information collected during the focus group(s) in the “Patient journey data collection form”

Patient Journey data collection form

4. Validate the patient journey

- By the patients.
- By the physicians.

5. Design

- Organise all the data in the different sections using the pictograms.
- Choose the main character, and the other ones you wish in the background.

Pictograms

Characters

Final template for designer

- After designing, check your patient journey and make corrections if necessary.

6. Dissemination of the patient journey

- Send to the coordination team to be made available online and disseminated.

 Final template for designer

Attendees invitation template

(email the patients on the list, affected by the condition)

New message



To:

Subject:

Dear [appropriate title]

[Name of Patient org, or person who is inviting] participates in an European project aimed at defining the journey of patients affected by [Name of the disease], in the frame of [ERN RITA](#).

Studies have demonstrated that involving patients in the design, implementation and for the evaluation of health services improve the relevance and the quality of these services, as well as their ability to meet the needs of patients.

With this in mind, we are organizing a focus group aimed at designing the journey of a patient affected by [Name of the disease]. This will be a 90 minute meeting, collecting information on what exists now and what would make the patient journey better for us. This information will be used to help direct care and improve services in the future.

We would be very happy to count on your participation as a patient or as a parent/carer, affected by [Name of the disease].

This meeting will be held in-person/online and will be moderated by [Name and title of the moderator]

[Venue address if in-person]

[Date] from [Hour] to [Hour] p.m.

If you are interested and can participate, please register at this [\[link\]](#) by [\[Deadline\]](#)

This initiative will gather the experience from patients coming from various European countries with the aim to offer patients the same chance of care no matter which country they live in.

Best wishes

[Signature]

Send



Email template validation for focus group attendees

New message



To:

Subject:

Dear all,

Some times ago, you took part in one of the x panel discussions on [Name of the disease] Patient journey organized by our ERN RITA patient Journey working group, bringing your experience and also the lessons (challenges and needs) you got out of it. This from different countries from Europe. We are now able to share with you the outcome of the very productive work done.

> May we kindly ask you to revise the attached document to ensure that none of your views or experiences have been missed?

We would be very grateful if you could do this before [Deadline].

Any corrections/additions can be made directly in the attached Word document, either using the track mode, another colour for the text or you may also write your changes in an email.

Many thank in advance! Kind wishes

[Signature]

Send



Email template validation for physicians

New message



To:

Subject:

Dear [Name of the physician],

I hope this email finds you well.

We are reaching out to you in the frame of a project group of ERN-RITA that aims to define Patient journeys to improve future patient care in these areas – Auto-Inflammatory Disorders, Primary Immunodeficiencies, Auto-immune diseases (Vasculitis, Neuro-inflammation), and Paediatric Rheumatology, << [as patient involvement in the design, evaluation and designation of healthcare services, improves the relevance and quality of the services, as well as improves their ability to meet patient needs](#) >>

A Patient Journey is the route followed by patients from their first contact with a health professional, through referral, diagnosis, investigation, treatment and management of their condition. '[The pathway provides an outline of the events likely to happen on the patient's journey and can be used to both inform the patient, as well as plan services as a template for common services and operations](#)'.

It encompasses the clinical pathway and the lived patient experience (including all aspects medical, social, psychological, regulatory, ...)

This work to date on [Name of the condition] is a culmination of information gathered from patients from all over Europe.

We would be grateful if you could check:

- if you think the journey is complete (patients in the panels may not represent all situations)
- if some aspects mentioned by the patients do truly belong to their [name of the condition] and not to another underlying disease, comorbidities, ...

This is a concise document and should not take long to review. After validation by physicians coming from different EU countries, we will disseminate it in an infographic format.

Many thanks in advance,
Kind regards,

[Signature]

Send



Moderators' guide

Introduction

This guide aims to support the moderator in leading the meeting, facilitating a comprehensive guide through all topics and avoid omitting any of them.

The moderator is there to allow people to express their ideas and experiences, they do not participate in the discussion, just collect the content, and ensure that everyone can share their perspective, without entering any debate, as the objective here is to collect as many experiences, perspectives as possible, even if they differ much from each other.

The moderator's guide goes along the journey from the onset of the condition to its management at present time.

It is not a questionnaire and only the topics in the 1st column are relevant. The questions are only intended to help the moderator keep the conversation flowing and to ensure that no topics have been forgotten.

Introduction	<ul style="list-style-type: none">■ The moderator (their role, other people not listed as attendees (note takers, observers)■ Participants■ Presentation of the objectives <p>This is a reminder of what has been sent in the invitation to attend the focus group.</p>
Presentation of the rules of the meeting	<ul style="list-style-type: none">■ Everyone is invited to share their experiences, feelings, expectations.■ The purpose of the group is not to come to an agreement since each experience is unique. The aim is to collect real-life stories from patients with different backgrounds.■ Thus, everyone is encouraged to participate without judgement.■ The moderator may also interrupt someone to ensure that everyone has the opportunity to participate in the conversation or also for the sake of time.■ Everyone should try to be concise

First symptoms	Possible questions (to be adapted to the condition at stake)
	How did your story begin?
	When, which ones? How long did the symptoms last?
	What reactions from environment (family, friends, school, work, ...)
	To which HC Provider did you reach out?
	What has been the main challenge during this pre-diagnosis period?
	List up to 3 supports/information that would have helped during this period

Diagnosis	Note that in some case, screening may be mentioned before diagnosis especially for conditions where diagnosis is made before first symptoms occur
	How did you get the diagnosis? How long did it take to get the diagnosis? Did you meet several doctors for this? Misdiagnosis? Accurate?
	Who (as in which healthcare professional) diagnosed you? Who played a key role in the diagnosis?
	What has been your first thoughts when knowing the name of your condition?
	What was clear, what was missing when you were told your diagnosis.
	What has been the main challenge during this period post-diagnosis?
	Who should have been involved (as a HCP, social service,...) at this stage of your journey?
	Did you ask for a second opinion?
	List up to 3 support /information that would have helped at this moment

Treatment	
	What stakeholders were/are included in your treatment?
	What (HCP, social services, ...) should have but were not included in your treatment?
	Access to treatment: were/are there challenges?
	What are the benefit of this treatment?
	And its drawback?
	What would you expect your treatment could be? Would do? How would it help (better)?
	Did you ask for a second opinion?
	List up to 3 support /information that would have helped at this moment

Disease course / Follow up / aging	
	In what does you follow up consist in?
	Did you experience many disease flares?
	If transitioning, aging, getting co-morbidities or other conditions, how is this managed?
	Which doctor manage your long term follow up
	What stakeholders should manage but are not included in your follow up
	The most important challenges you face at the moment in your patient's life?
	What kind of support care would be needed/did you get?
	List up to 3 support /information that would have helped at this moment

Medical Guidelines	
	Are you aware of any medical guidelines existing for this condition in your country/hospital?
Conclusion	What would be the 3 main aspects that you would like that the healthcare system takes into account in the whole management of your condition?

Patient Journey data collection form

STREAM:

Condition:

Children / Adults / Both

Journey	Description	What Health Care professional are involved	Challenges
Symptoms			
Diagnosis			
Treatment			
Management & Follow up (incl. Transition & aging)			
Other info/ comments			

Journey	Needs	Resources	Comments
Symptoms			
Diagnosis			
Treatment			
Management & Follow up (incl. Transition & aging)			
Other info/ comments			

Pictograms (1/3)

Legend: Symptoms Diagnostic Treatment Follow-up & aging



Haematology



ENT



Nutrition



Gastroenterology



Neurology



Respiratory



Rheumatology



Infections



Dermatology



Cardiology



Immunology



Orthopedic



Nephrology



Oral health



Ophthalmology



Imunology



Urology



Gynecology



Healthcare professionals awareness & Education



Medical awareness & Education



Medical education



HCP follow-up





HCP awareness & Education



Medical practice & Education

Pictograms (2/3)

Legend:  Symptoms  Diagnostic  Treatment  Follow-up & aging



Patient education & Empowerment



Patient empowerment



Medical practice



Lack of specialists



Access



Access to early, accurate diagnosis



Added risks



Emergency plan



Others needs



General Practice



Research



Chronicity of treatment



General



Genetic testing



Antibiotics



Imaging technics



Specifics medicines



Transitioning



Comorbidities linked to age



Health impact



Quality of life



Psychological & Social impact, mental health






Communication & Coordination



Digital health

Pictograms (3/3)

Legend:  Symptoms  Diagnostic  Treatment  Follow-up & aging



Support & Advocacy



Life Issues



Long-distance travel



Financial burden

Characters



Final template for designer

Journey	Description	What doctors/HCPs are involved?	Challenges	Needs	Resources
Home Page generic text	<ul style="list-style-type: none"> □ Precise the stream that the condition belongs to 				
The journey of a patient with... (page3)	<ul style="list-style-type: none"> ■ Please: <ul style="list-style-type: none"> □ provide a sentence <p>Example: Meet Riwanon, she is a child with Juvenile Idiopathic Arthritis, a group of auto-immune diseases characterized by inflamed and painful joints. The JIA may be oligoarticular, polyarticular, enthesitis related, psoriatic, systemic or undifferentiated. Depending on the type, other symptoms and characteristics are present.</p> □ select the main character among the 8 available □ give him/her a first name □ state if you want all the characters in the background in addition to the main one (this showcases which age of life a patient can be affected by the condition) 				

Journey	Description	What doctors/HCPs are involved?	Challenges	Needs	Resources
Symptoms	Category: Data collected under this category				
Diagnosis	Category: Data collected under this category				
Treatment					
Follow-up and ageing					
Other info/ comments					

Resources

Focus groups

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² extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.cdc.gov/healthyouth/evaluation/pdf/brief13.pdf