

Dear OMERACT Patient Research Partner,

On behalf of everyone at OMERACT, we are delighted to welcome you as a new Patient Research Partner (PRP) and member of our community. We're thrilled you've joined us in our mission to improve the measurement of health outcomes in rheumatology and related fields through patient-centered research.

Purpose of this Toolkit

This PRP Toolkit is a living resource designed to support you at every stage of your journey with OMERACT. It draws on the structure of the widely used Patient Engagement in Research Toolkit and integrates key guidance from the OMERACT Handbook and Policy Manual. Its purpose is to:

- Introduce you to OMERACT's mission, values, and ways of working.
- Explain the vital role of PRPs in shaping Core Outcome Sets.
- Equip you with tools to help you participate effectively and confidently.

How to Use this Toolkit

Think of this toolkit as your companion guide. Use it to:

- Orient yourself — learn about OMERACT's structure, decision-making processes, and working groups.
- Deepen your understanding — explore the glossary, online learning modules (OMER-ED), and selected readings to build your knowledge base.

What You'll Find Inside

- PRP Roles & Responsibilities — a clear overview of expectations and opportunities.
- Access to OMER-ED — our online learning modules on Core Domain Set development and Instrument Selection.
- The OMERACT Glossary — plain-language definitions of common terms and acronyms.
- Selected Articles and Resources — curated to help you deepen your understanding of OMERACT and patient-centred outcomes research.

Our Commitment to You

We recognize that stepping into a new role can feel overwhelming. This toolkit was created specifically to help you feel welcomed, informed, and confident. It reflects OMERACT's belief that your experiential knowledge and lived experience are essential to improving research outcomes.

We're looking forward to collaborating with you, learning from your insights, and building a stronger OMERACT together.



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WHAT IS OMERACT?

OMERACT is a global, volunteer-driven, not-for-profit organization committed to improving outcomes for patients with autoimmune and musculoskeletal diseases through advancing the design and quality of clinical studies.

Through rigorous methodology and our global Working Groups, OMERACT supports the development of Core Outcome Sets (COS), identifying patient and disease-relevant areas to be measured (domains) and the corresponding measurement instruments for use in clinical trials, including those for regulatory approval of new treatments.

<https://omeract.org/>.

WHAT IS PATIENT ENGAGEMENT IN RESEARCH?

Patient engagement is a structured approach to include people with lived experience of a condition as partners in research decision-making. This can happen at every stage from identifying what should be studied, to designing and conducting the study, to interpreting results and sharing them.

Core Principles

- Respect & Partnership – Recognizing patients as experts in their own lived experience.
- Co-creation – Patients help shape study questions, methods, and dissemination.
- Transparency – Clear communication about roles, expectations, and decision-making.
- Support & Training – Providing resources so patient partners can contribute effectively.

Benefits

- Ensures research addresses Core Outcome Sets that matter to patients.
- Improves study design (making recruitment, measures, and interventions more relevant).
- Enhances trust and uptake of findings.

OMERACT calls these individuals Patient Research Partners (PRPs). They're embedded in working groups, help define core domains, lead working groups, and shape conference sessions. This is a model widely cited internationally as best practice for patient engagement in outcomes research.

WHAT IS AN OMERACT PATIENT RESEARCH PARTNER?

Patient Research Partner (PRP)

noun — PAY-shent REE-search PART-ner

an individual who has lived experience with a rheumatic or musculoskeletal condition and actively participates within OMERACT. Their role is to infuse the research process with their unique PRP perspective, ensuring that OMERACT's initiatives are truly patient-centred, address real-world concerns and enhance the relevance of outcomes. By working alongside researchers, clinicians, and other collaborators and partners, OMERACT PRPs play a pivotal role in shaping research that resonates with the needs and experiences of patients in general.

OMERACT GUIDING PRINCIPLES FOR PRP INVOLVEMENT

To effectively capture the invaluable insights and lived experiences that PRPs bring, it is imperative to establish clear guidelines that ensure meaningful and practical engagement outlined in the figure below. These guidelines constitute OMERACT's commitment to a collaborative research environment. Acting as a roadmap, they provide substantive and impactful collaboration with PRPs. Embracing the PRP perspective is central to OMERACT's philosophy, underscoring the essentiality of active PRP-researcher collaboration. By adhering to these guidelines, OMERACT aims to ensure that PRP engagement is meaningful, effective, and patient-centred, aligning with the organization's vision and values.

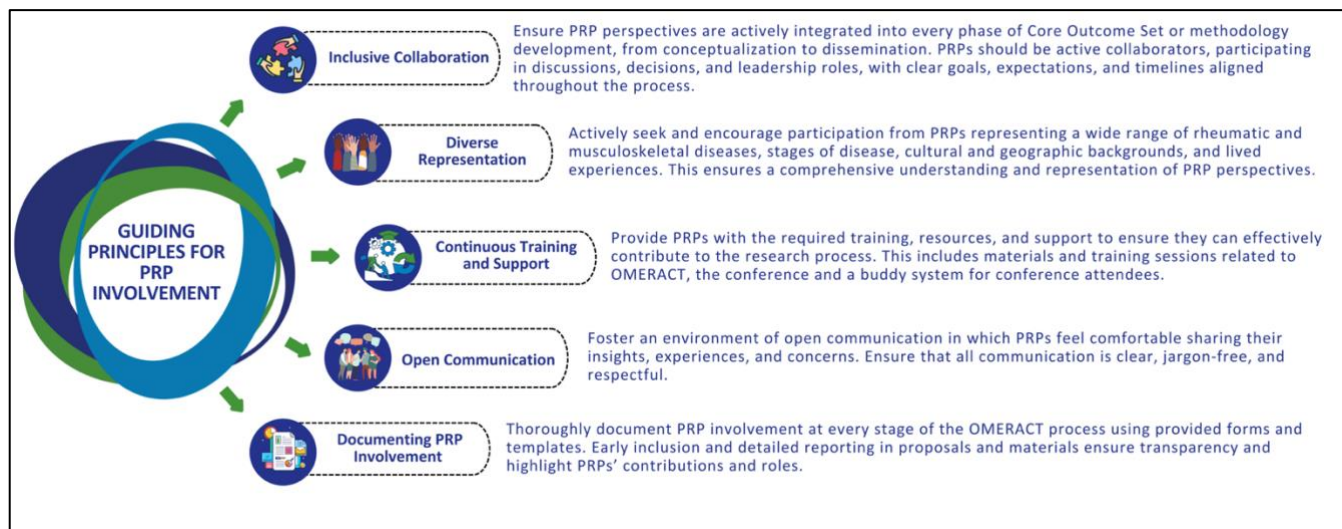


Figure 1: OMERACT Guiding Principles for PRP Involvement

GETTING STARTED AS AN OMERACT PRP

Joining an OMERACT Working Group as a PRP is both exciting and rewarding. You'll bring your lived experience to international research teams made up of clinicians, methodologists, and other patients. For those new to patient engagement in research, it's normal to feel uncertain about how a team works or what your role will be. This section is designed to help you settle in, understand the team, and build effective working relationships from the start.

Building Connections

Most OMERACT Working Groups include people who already know each other, so taking the initiative to introduce yourself helps break the ice. A brief personal introduction—your name, your role, and a little about your interests—can make the team more approachable and human. This not only clarifies who does what but also helps dismantle any perceived hierarchy. At OMERACT, every voice is valued; as the saying goes, *we all put our pants on one leg at a time*.

Roles and Expectations for OMERACT Patient Research Partners PRPs

OMERACT PRP Roles & Responsibilities

OMERACT PRPs have a central role in the research process. Their primary responsibilities include:

- Providing a 'Lived Experience' perspective:**
 - Provide their perspective as a person with 'lived experience' or caregiver on the research topic, including what matters most as a PRP.
 - Help ensure that the research question is relevant to people living with the condition and that the measured outcomes are meaningful and impactful.



- PRPs may be asked to help develop or review materials, such as survey questions or discussion guides, to ensure they are clear, understandable, and respectful of people with ‘Lived Experience’.
2. **Collaborating with researchers:**
- Work collaboratively with the research team, including attending meetings and providing feedback on study materials and manuscripts.
 - Help ensure that PRP perspectives are integrated throughout the research process, from study design to data analysis and interpretation.
 - An active contributor to discussions and decision-making based on unique perspectives and lived experience with their rheumatic disease.
 - Actively promote participation in essential surveys and Delphi studies within patient communities, enhancing engagement and ensuring diverse representation in OMERACT research initiatives.
3. **Contributing to dissemination:**
- Help disseminate the study results to the broader community, including presenting at conferences, writing papers, or participating in social media campaigns.
 - Help ensure that the study results are communicated in a way that is accessible and meaningful to people with ‘Lived Experience’ and the broader community.

Overall, the role of a PRP is critical to ensuring that the research is patient-centred and reflects the priorities of PRPs. PRPs work collaboratively with the research team to ensure the research is conducted ethically and respectfully.

Clarity of Role and Commitment

Before you begin, understand what is expected of you, including:

- How often, where, and how long meetings will be.
- The overall duration of the project.
- The time and effort the team expects from you.

Expressing Your Needs and Expectations

Share your needs and expectations openly with your Working Group. Consider:

- What you need to participate fully (technology, accessibility, time of day, etc.).
- What support or training would help you contribute confidently.
- How your personal health or life circumstances may affect your participation.

It’s normal for your needs to evolve. Communicate changes so the team can respond and support you effectively.

Roles in an OMERACT Working Group

Working Groups are the foundation of OMERACT’s mission, implementing the organization’s methodology to develop Core Outcome Sets and related research. Each group includes international collaborators from diverse fields, ensuring well-rounded perspectives and impactful research.

As a first step in a research partnership, it is important to know the research team. The following table provides a general description of some of the roles in OMERACT Working Groups:

Role in OMERACT Working Group	Description	Examples of What They May Be Doing
Business Advisory Committee (BAC) Member	Formal group within OMERACT composed of representatives from sponsoring organisations.	<ul style="list-style-type: none"> • Fund activities such as Delphi surveys, patient participation, or translation. • Avoid undue influence on methods or findings. • Receive



	Provides input on sustainability, engagement, and mutual priorities.	regular updates and reports from the Working Group Lead.
Caregiver	Provide assistance and support to someone who cannot fully manage their daily activities, health care, or other needs. May be family members, friends, or professionals.	<ul style="list-style-type: none"> • Contribute caregiver perspectives to ensure outcomes and processes are realistic and acceptable. • Participate in focus groups or consensus discussions.
Clinician	Healthcare professional providing direct patient care (diagnosing, treating, and managing illnesses or injuries). Brings front-line clinical insight to OMERACT work.	<ul style="list-style-type: none"> • Advise on feasibility of proposed outcomes or measures. • Contribute clinical expertise to domain definitions and instrument selection. • Help interpret clinical relevance of results.
Emerging Leader	Early- to mid-career professional showing strong commitment to advancing rheumatology within the OMERACT framework. They take on leadership roles, refine core outcome sets, contribute to working groups, and mentor newer members.	<ul style="list-style-type: none"> • Learn OMERACT processes by co-facilitating Working Group activities. • Help bridge new participants and experienced members. • Support consensus-building, documentation, and communications. • Lead small projects or initiatives to strengthen OMERACT.
Fellow	Early-career professional selected for their potential to become a future leader in outcomes research. Fellows actively participate in Working Groups, mentorship, and educational activities to develop skills and networks.	<ul style="list-style-type: none"> • Assist with methodological development, data analysis, or patient engagement activities. • Gain hands-on experience in Core Outcome Set development under senior mentors. • Contribute to preparing endorsement packages or presentations.
Members at Large	People likely to apply OMERACT outputs—policy makers, regulators, clinicians, health system leaders, or patient organisations.	<ul style="list-style-type: none"> • Ensure Core Domain Sets and instruments are relevant and implementable. • Provide feedback on feasibility, acceptability, and policy implications. • Champion uptake of OMERACT recommendations.
Methodologist	Specialist who develops, evaluates, and applies research methods to ensure studies are designed, conducted, and analysed rigorously.	<ul style="list-style-type: none"> • Guide Working Groups on study design, measurement, and statistical analysis. • Ensure instruments meet reliability, validity, and feasibility standards. • Support preparation of endorsement documentation.
Patient Research Partner (PRP)	An individual with lived experience of a rheumatic or musculoskeletal condition who actively participates in OMERACT. Brings the patient perspective to ensure initiatives are truly patient-centred, address real-world concerns, and enhance the relevance of outcomes.	<ul style="list-style-type: none"> • Help define domains and outcomes for Core Outcome Sets. • Participate in Delphi surveys, qualitative work, and consensus sessions. • Co-develop patient-friendly summaries and dissemination materials. • Bring the patient lens to all Working Group decisions.
Research Staff	Coordinators, assistants, or managers who handle the daily operations of the Working Group.	<ul style="list-style-type: none"> • Schedule meetings and prepare agendas, minutes, and reports. • Support recruitment of participants for Delphi rounds or qualitative studies. • Manage documentation and compliance with OMERACT policies.



Researchers	Individuals who systematically investigate questions, develop and test new methods, or validate existing ones. May be based in academic, clinical, governmental, or industry settings.	<ul style="list-style-type: none"> • Plan and conduct studies within OMERACT projects. • Collect and analyse data, draft manuscripts, and present findings at meetings. • Collaborate across disciplines to strengthen evidence.
Statistician & Methodologist	Often co-investigators whose contribution relates to minimising bias and ensuring scientific credibility.	<ul style="list-style-type: none"> • Advise on study design, sample size, endpoint selection, and analytic plans. • Ensure alignment with the OMERACT Filter and Handbook guidance. • Help interpret findings for endorsement packages.
Working Group Lead / Principal Investigator / Co-Chair	Provides overall leadership of the Working Group. Shapes the vision, defines objectives, and secures funding or resources for OMERACT activities.	<ul style="list-style-type: none"> • Guide the group through OMERACT methodology processes. • Oversee planning, timelines, and deliverables. • Ensure patient perspectives are integrated at every stage. • Administer reporting requirements to OMERACT.

Areas of Involvement for Patient Research Partners in OMERACT

This section outlines the OMERACT projects where Patient Research Partners (PRPs) can make a difference. OMERACT Working Groups follow a consistent but flexible process—whether developing a Core Domain Set, selecting instruments, creating composite measures, or refining methodology—and at every stage PRPs can shape the work so it remains relevant, feasible, and patient-centred.

These examples are not prescriptions—they are starting points for a conversation between Working Group leaders and each PRP to identify the best fit between the PRP’s knowledge, skills, experience, interests, and time, and the needs of the project. By using these lists as a guide, groups can plan for meaningful patient engagement across study design, recruitment, data collection, interpretation, and dissemination.

Development or Updating of a Core Domain Set

- Confirm the need for a new or updated Core Domain Set from the patient perspective.
- Identify research gaps and flag missing or outdated domains.
- Advise on which patient populations and collaborators should be included.
- Ensure outcomes reflect lived experience and patient priorities.
- Review and co-develop patient-facing materials for clarity and accessibility.
- Contribute to scoping reviews, qualitative work, and consensus activities (e.g., Delphi surveys).
- Help shape and refine definitions of core domains.
- Co-present draft Core Domain Sets to PRP networks and Working Groups.
- Support endorsement and dissemination by tailoring messages, recruiting participation, and co-authoring lay summaries.

Instrument Selection: Part A

- Confirm adequate patient representation in the Working Group.
- Review endorsed domain definitions and advise on relevant populations and collaborators.
- Refine search criteria for potential instruments and suggest patient-facing sources.
- Review candidate tools for missing patient-relevant aspects.
- Co-create feasibility checklists and give feedback on clarity and burden of patient-facing materials.
- Assess whether instruments are both relevant to the domain and practical for patients to use.
- Contribute to decision-making on domain match and feasibility.
- Interpret plain-language summaries of psychometric evidence.
- Co-author lay summaries or presentations for the OMERACT community.

Instrument Selection: Part B

- Ensure ongoing patient representation and bring additional perspectives (e.g., low literacy, underrepresented populations).
- Provide feedback on clarity of systematic review protocols and plain-language summaries.
- Confirm the relevance of studies and suggest visual aids to make processes understandable.
- Review and interpret plain-language evidence; highlight gaps that matter to patients.
- Contribute to final selection decisions and ensure patient voice in recommendations.
- Edit patient-facing sections of TAG submissions.
- Help recruit participants for community endorsement and advise on realistic update timelines.
- Co-develop dissemination materials such as lay summaries, presentations, and messaging for newsletters and workshops.

Developing or Validating a Composite Measure

- Confirm whether a composite measure is needed and highlight where single-domain measures miss key aspects of lived experience.
- Help ensure diversity and relevance in the Working Group by connecting teams with advocacy groups and patient networks.
- Advise on which components and populations should be included in the composite.
- Provide feedback on patient-facing materials to keep burden manageable.
- Assist in identifying and defining domains and selecting appropriate instruments.
- Participate in weighting exercises to reflect patient priorities.
- Review plain-language summaries of the composite structure.
- Co-create messaging for community endorsement and record or present outreach materials.

Developing or Refining Core Outcome Set Methodology

- Confirm whether a methodological update is truly needed and highlight issues such as survey burden or gaps in guidance.
- Advise on which collaborator groups to include and connect with underrepresented patient populations.
- Provide input on how methodological issues affect feasibility from a patient perspective.
- Help shape work plans, clarify where they can contribute, and review patient-facing materials for clarity and accessibility.
- Select tasks that match their skills and time; ensure multiple PRPs are involved.
- Co-present findings in accessible formats and help tailor key messages for dissemination.
- Advocate for accessible summaries, training modules, and quick guides to make new methods understandable to other PRPs.



RESOURCES

OMERACT offers a range of supports to help Patient Research Partners participate confidently and meaningfully in its work. The resources below are designed to orient you, connect you with others, and give you practical tools and training.

OMERACT PRP Advisory Council

The PRP Advisory Council is a volunteer-led group dedicated to integrating and supporting PRPs across OMERACT. It includes international members and a Chair who sits on the OMERACT Management Group, ensuring PRP perspectives are represented at the highest level.

Through regular meetings the team:

- Creates a welcoming environment for PRPs.
- Advocates for active PRP involvement in decision-making.
- Develops educational resources and mentoring to build capacity.
- Works with other OMERACT groups so PRP insights are consistently reflected in research.

Online Hubs – Stay Connected and Informed

[OMERACT PRP Network Website](#)

The PRP Network site is the central hub for Patient Research Partners. It helps you stay informed, engaged, and connected with the OMERACT community. Key features include:

- **PRP Profiles** to share your background, experience, and areas of interest with other members.
- **News and Updates** about OMERACT activities and events.
- **Resources and Training Materials**, including webinars on patient-centred outcomes research and your role within OMERACT.

[OMERACT Website](#)

The main OMERACT website provides a comprehensive overview of the initiative, its history, and its mission. It offers:

- Information on OMERACT – who we are, what we do, and how to get involved.
- News and Updates on events, projects, and opportunities.
- Resources and Tools such as the OMERACT Glossary, conference publications, working group information, and training materials.
- Opportunities for Engagement – details on joining Working Groups and attending meetings.

Guidance Documents – Frameworks for Your Work

[OMERACT Handbook](#)

The Handbook is your roadmap to OMERACT's methodology. It explains how Core Domain Sets are developed and how instruments are selected. Chapters include:

- Chapter 1: Foundations, Achievements, and Aspirations
- Chapter 2: The Spirit of OMERACT
- Chapter 3 – Patient Research Partner Engagement
- Chapter 4: Developing Core Domain Sets
- Chapter 5. Evidence-Based Decision Making For The Selection Of Instruments For Core Outcome Sets: Part A & B



- Chapter 6 – Supporting OMERACT Working Groups In Developing And Refining Core Outcome Set Methodologies

OMERACT Policy Manual

This manual outlines the policies that guide OMERACT activities and protect PRPs. It covers:

- Governance and organisational structure (Management Group, Technical Advisory Group, PRP Advisory Council).
- Diversity, Equity, Inclusion and Accessibility (DEIA) principles.
- Codes of ethics, transparency, and confidentiality.
- Publication and authorship policies.
- Reimbursement policies for travel, meals, accommodations, childcare, and other supports

OMER-ED

OMERACT's eLearning modules introduce you to patient-centred outcomes research and OMERACT's methods. They are self-paced, interactive, and designed for PRPs, researchers, and clinicians alike. Currently available modules include:

1. An overview of what OMERACT is & how we work
2. Spirit of OMERACT
3. What to Expect at an OMERACT Conference
4. Advocating for Meaningful Engagement in OMERACT: A Practical Guide for PRPs
5. The OMERACT Pathway for developing a Core Domain Set
6. Overview of the OMERACT Pathway for Selecting Instruments in Core Outcome Set Development
7. Understanding the Delphi Survey and Its Role in Core Domain Set Development
8. Domain Match & Feasibility: The Goals of OMERACT Instrument Selection Part A

Each module includes interactive elements, such as quizzes, to help reinforce key concepts and facilitate learning. The modules are self-paced, allowing users to complete them at their own speed and convenience.

Setting Up an Account & Adding Courses on OMER-ED

1. **Go to the OMER-ED platform**
Click this link to browse the available courses: <https://omeract.org/elearning/>. Choose the course you'd like to start with.



OMERACT Glossary

Starting work with OMERACT can feel like learning a new language. Patient-centred outcomes research has its own terms, acronyms, and shorthand that researchers often use without realising it. Without a reference, it can be discouraging—but the OMERACT Glossary makes it easy.

The OMERACT Glossary is a comprehensive, plain-language list of key terms and definitions used across OMERACT and patient-centred outcomes research. It includes clear explanations of concepts such as outcome measures, domains, responsiveness, validity, and many more. Definitions are written in accessible language and are based on OMERACT community consensus.

The Glossary is regularly updated to reflect changes in terminology and feedback from members, ensuring it stays relevant and useful. It is an essential resource for anyone participating in OMERACT activities—especially new PRPs.

You can explore the full glossary online at omeract.org/glossary.

To help you get started, we’ve also included a list of some key terms from the Glossary in this toolkit. Use it as a quick-reference sheet during meetings or when reading OMERACT materials. And remember: if you come across an unfamiliar term or acronym, don’t hesitate to ask for clarification—new terms are introduced all the time, and questions are always welcome at OMERACT.

Term	Description	Synonyms	Abbreviation	Examples
Composite Outcome	an outcome measure in clinical research that combines two or more individual, clinically relevant events, domains, or endpoints into a single measure. By grouping multiple outcomes together, a composite outcome captures a broader concept of disease status or treatment effect than any single endpoint alone. Composite outcomes are especially useful when individual events are rare, when a multidimensional view of disease is needed, or when measuring overall treatment benefit.	Composite, Composite Instrument, Composite Outcome Measure, Composite Measure, Combined Endpoint		In rheumatoid arthritis (RA) research, the DAS28 (Disease Activity Score 28-joint count) is a composite outcome combining tender and swollen joint counts, patient-reported global health, and an inflammatory marker (ESR or CRP) into a single score to assess disease activity.
Consensus	a general agreement or shared understanding reached by a group of people through mutual discussion, collaboration, and compromise. It involves integrating diverse viewpoints to arrive at a decision that reflects the collective judgment of all participants. At OMERACT, consensus is central to its methodology and one of the 8 Cs in the Spirit of OMERACT			During the development of a new Core Domain Set at OMERACT, a working group uses the Delphi method to gather feedback from Patient Research Partners, clinicians, researchers, and policymakers. After several rounds of rating candidate domains and reviewing aggregated feedback, 75% of participants agree that “Fatigue” should be included as a core domain. This agreement meets the

				predefined consensus threshold, and the domain is formally added to the Core Domain Set.
Core Area	<p>a broad aspect of health or a health condition that must be measured to properly assess the effects of a health intervention. Each Core Area consists of more specific outcome domains and plays a distinct role in capturing the full impact of an intervention. Collectively, the Core Areas represent the entire “universe” of concepts that could be measured to understand the effects of an intervention.</p> <p>There are four universally recognized Core Areas that every Core Domain Set (CDS) — and ultimately every Core Outcome Set (COS) — should address:</p> <ol style="list-style-type: none"> 1. Death/Lifespan 2. Life Impact 3. Pathophysiological Manifestations (Manifestations/Abnormalities) 4. Resource Use/Economic Impact (Societal/Resource Use) 			<p>When developing a Core Outcome Set for rheumatoid arthritis, the working group ensures that all four Core Areas are represented:</p> <p>Death/Lifespan: Mortality during long-term follow-up.</p> <p>Life Impact: Patient-reported pain, fatigue, and quality of life.</p> <p>Pathophysiological Manifestations: Joint swelling and inflammatory biomarkers.</p> <p>Resource Use/Economic Impact: Costs related to medications, hospitalizations, and lost productivity.</p> <p>This guarantees that the Core Outcome Set captures not just clinical signs but also the full impact of the disease and its treatment on patients and society.</p>
Core Domain Set	<p>an agreed-upon group of outcome domains considered essential to define and report in all clinical trials and other research studies related to a specific health condition or disease. It represents “what to measure,” not “how to measure it.”</p> <p>At this stage, no specific instruments have been selected to assess the domains. The CDS is developed through systematic evidence review, input from patients and other stakeholders, and formal consensus methods (e.g., Delphi surveys). Establishing a CDS ensures that the most important aspects of health are</p>	Core Outcome Domain Set	CDS	The Psoriatic Arthritis Core Domain Set (CDS) includes domains such as pain, skin disease activity, fatigue, and physical function. These domains are considered critically important and must be measured and reported in all clinical trials for psoriatic arthritis to ensure consistent and meaningful outcomes. At this stage, no instruments have been chosen to measure these domains — only the domains

	consistently captured across studies, improving comparability and relevance.			themselves have been defined.
Core Outcome Set	<p>an agreed minimum collection of outcomes — defined as domains and their corresponding measurement instruments — that should be measured and reported in all clinical trials, longitudinal outcome studies, or other research within a specific health condition.</p> <p>COS are developed through a rigorous consensus process involving diverse stakeholders such as patient research partners, clinicians, researchers, regulators, and other decision-makers. The process typically involves:</p> <p>Identifying what to measure (domains) — resulting in a Core Domain Set.</p> <p>Determining how to measure these domains — selecting validated outcome measurement instruments.</p> <p>By standardizing outcomes across studies, a COS improves comparability, reduces selective outcome reporting, enhances the quality of evidence synthesis, and facilitates meta-analysis.</p>	Core Set, COS, Core Outcome Measurement Set	COS	The RA Core Set in rheumatoid arthritis research — including pain, physical function, and joint counts — is a widely adopted Core Outcome Set. It ensures that these key outcomes are consistently measured and reported in all clinical trials evaluating treatments for rheumatoid arthritis.
Delphi	a structured, anonymous, and iterative consultation method used to achieve consensus among a group of experts or stakeholders. It involves multiple rounds of questioning, feedback, and re-rating to refine opinions and move toward agreement on key issues.	Delphi Survey, Delphi Method		An OMERACT working group uses the Delphi Method to identify which patient-reported outcomes are most important for a new core domain set. Participants anonymously rate the importance of each domain over several rounds until consensus is reached.

<p>Discrimination</p>	<p>In the OMERACT framework, Discrimination refers to an outcome measure’s ability to distinguish between situations of interest. This includes detecting differences:</p> <ol style="list-style-type: none"> 1. Between groups (e.g., treatment vs. control/placebo groups). 2. Over time (e.g., responsiveness to change within individuals). 3. Within individuals (e.g., change in a single patient’s status). <p>It encompasses reliability (consistency across raters or occasions), sensitivity to change (responsiveness), and thresholds of meaning (the smallest change that is clinically important).</p>		<p>D</p>	<p>An instrument measuring fatigue in rheumatoid arthritis is tested in a clinical trial. It successfully detects:</p> <p>A difference between groups (patients receiving the new therapy report significantly less fatigue than those on placebo).</p> <p>A change over time (fatigue scores decrease within the same patients as treatment progresses).</p> <p>This demonstrates good discrimination, meaning the instrument can reliably distinguish between situations of interest.</p>
<p>Domain</p>	<p>a single, clearly defined aspect of health, disease impact, or well-being that is considered important to measure. Domains represent distinct concepts such as symptoms (e.g., pain), functions (e.g., mobility), biological processes (e.g., biomarkers like C-reactive protein), or broader life impacts (e.g., quality of life).</p>	<p>Outcome Domain, concept, item</p>		<p>In a clinical trial testing a new treatment for rheumatoid arthritis, researchers include several domains to capture the treatment’s impact:</p> <p>Pain Physical function Fatigue</p> <p>Each of these represents a distinct domain that reflects a specific aspect of the patient’s health and the treatment’s effect.</p>
<p>Endorsement</p>	<p>the formal recognition or approval of a measure, instrument, process, or standard by an authoritative or credible body. In research and health care, endorsement signals that the item has undergone evaluation and meets agreed-upon criteria (e.g., methodological rigor, relevance, feasibility). It often represents a seal of quality, credibility, or acceptance for broader use.</p>	<p>Approval, ratification</p>		<p>The OMERACT community provided endorsement of a new core outcome set for psoriatic arthritis after a rigorous multi-collaborator development process. This formal recognition signals to researchers, clinicians, and regulators that the set meets OMERACT’s methodological standards and is recommended for use in clinical trials.</p>

<p>Equity, Diversity, and Inclusion</p>	<p>Equity, Diversity, and Inclusion (EDI) refers to the principles and practices that ensure fair treatment, access, opportunity, and advancement for all people, while striving to identify and eliminate barriers that have historically led to unequal participation or outcomes.</p> <p>Equity means providing resources and opportunities based on individual needs to achieve fairness (not just sameness).</p> <p>Diversity encompasses the presence of differences among people (such as race, gender, ethnicity, age, disability, sexual orientation, socioeconomic status, and lived experiences).</p> <p>Inclusion ensures that all individuals feel respected, valued, and able to contribute fully in a given environment.</p> <p>Together, EDI represents a commitment to creating and sustaining environments where all people can thrive.</p>	<p>Fairness, inclusiveness, belonging; EDI (common abbreviation)</p>	<p>EDI</p>	<p>A research team develops recruitment strategies to improve EDI in clinical trials.</p>
<p>Feasibility</p>	<p>one of the key components of the OMERACT Filter. It refers to the practicality and acceptability of using an outcome measure or instrument in research or clinical practice. An instrument with good feasibility is realistic to implement without undue burden or cost. This includes being easy to administer, score, and interpret; requiring minimal time, equipment, or training; and being acceptable to patients, clinicians, and researchers alike. Even if an instrument demonstrates strong Truth and Discrimination, it must also be feasible to use.</p>	<p>Practicality, Suitability</p>	<p>F</p>	<p>VAS Pain Scale: This instrument is considered to have high feasibility because it is low-cost, quick to administer, requires no special equipment or training, and is easily understood by both patients and clinicians.</p>

<p>OMERACT</p>	<p>OMERACT is a global, volunteer-driven, not for profit organisation committed to improving outcomes for patients with autoimmune and musculoskeletal diseases through advancing the design and quality of clinical studies.</p> <p>Through rigorous methodology and our global Working Groups, OMERACT supports the development of Core Outcome Sets (COS), identifying patient and disease-relevant areas to be measured (domains) and the corresponding measurement instruments for use in clinical trials, including those for regulatory approval of new treatments.</p>			
<p>OMERACT Filter</p>	<p>an evidence-based conceptual framework and process used to guide the development and appraisal of core outcome measurement sets (Core Outcome Sets). It helps working groups decide what to measure (selecting appropriate domains) and how to measure them (selecting instruments).</p> <p>At its core, the Filter requires every outcome measurement instrument—whether a questionnaire, scale, or other tool—to be evaluated across three clinimetric pillars:</p> <p>Truth – Does the instrument measure the intended concept (face, content, construct, and criterion validity)?</p> <p>Discrimination – Can it reliably distinguish between groups, across time, and in situations of interest (reliability and sensitivity to change)?</p> <p>Feasibility – Can it be applied practically in research and clinical settings (burden, cost, time, and interpretability)?</p> <p>If an instrument passes all three pillars, it is considered valid for use in OMERACT-endorsed Core Outcome Sets.</p>		<p>TDF</p>	<p>A working group developing a core outcome set for psoriatic arthritis uses the OMERACT Filter to evaluate a fatigue questionnaire. They review evidence for Truth (does it truly measure fatigue?), Discrimination (does it detect meaningful changes over time and between treatment groups?), and Feasibility (is it short, low-cost, and easy for patients to complete?). Based on this evaluation, the group determines whether to include the questionnaire in the final Core Outcome Set.</p>

	<p>Revisions over time (Filter 2.0 in 2014, Filter 2.1 in 2019, and proposed refinements in Filter 2.2 in 2021) expanded the framework to include additional core areas (such as Death, Life Impact, Pathophysiological Manifestations, and Resource Use), clarified definitions, and improved decision-making processes for working groups.</p>			
<p>OMERACT Filter Instrument Selection Algorithm</p>	<p>a standardized, step-by-step tool developed by OMERACT to guide researchers in selecting the most appropriate measurement instruments for their studies. It provides a systematic framework for evaluating instruments against the OMERACT Filter (truth, discrimination, feasibility), taking into account the construct being measured, the target population, study setting, and feasibility considerations. By following OFISA, users can make transparent, evidence-based decisions on whether an instrument meets the OMERACT standards for inclusion in a core outcome set.</p>		<p>OFISA</p>	
<p>OMERACT Onion</p>	<p>a conceptual framework used to organize and prioritize outcome domains for Core Domain Sets in rheumatology and musculoskeletal research. It is visualized as three concentric circles (layers), representing the level of priority and evidence for each domain:</p> <p>Inner Circle: Mandatory core domains required in all trials. This layer is kept intentionally small (recommended 5–9 domains) to avoid overburdening studies.</p> <p>Middle Circle: Domains that are mandatory only in specific circumstances or for certain types of studies.</p> <p>Outer Circle: Domains on the research agenda—candidate domains requiring further validation or investigation before potential inclusion in the core set.</p>			

	<p>The Onion provides a shared language and structure for consensus-building, discussions, and voting when developing or updating Core Domain Sets.</p>			
<p>Outcome Measurement Instrument (OMI)</p>	<p>any tool, scale, questionnaire, or procedure used to measure an outcome domain in clinical research or practice. Instruments can be:</p> <p>Quantitative: e.g., blood pressure, laboratory values, physical performance tests.</p> <p>Qualitative: e.g., quality-of-life measures, patient satisfaction, or other subjective experiences.</p> <p>They may be disease-specific (tailored to a particular condition) or generic (applicable across multiple conditions). Organizations like OMERACT evaluate instruments to ensure they measure the intended domain accurately, detect meaningful differences, and are feasible to use.</p>	<p>Outcome Instrument, Outcome Measure, Clinical Outcome Assessment (COA) (FDA term, Instrument, Tool</p>	<p>OMI</p>	<p>Health Assessment Questionnaire–Disability Index (HAQ-DI) to measure physical function in rheumatology.</p> <p>MRI Scoring Systems to quantify inflammation in specific joints.</p> <p>(Both are OMI used to assess key domains of health outcomes.)</p>
<p>Patient Research Partner</p>	<p>an individual who has lived experience with a rheumatic or musculoskeletal condition and actively participates within OMERACT. Their role is to infuse the research process with their unique PRP perspective, ensuring that OMERACT's initiatives are truly patient-centred, address real-world concerns and enhance the relevance of outcomes. By working alongside researchers, clinicians, and other collaborators and partners, OMERACT PRPs play a pivotal role in shaping research that resonates with the needs and experiences of patients in general.</p>		<p>PRP</p>	

<p>Spirit of OMERACT</p>	<p>represents the foundational principles and values that drive the mission of OMERACT. It underpins everything from developing core outcome sets to shaping organizational practices. This spirit embodies a commitment to evidence-based, inclusive, and data-driven approaches that emphasize collaboration among patients, researchers, clinicians, industry, and regulators.</p> <p>It is captured by the 8 C's:</p> <ol style="list-style-type: none"> 1. Consensus 2. Careful/Conscientious 3. Communication 4. Collaboration 5. Concrete Outcomes 6. Continuous Learning 7. Continuity 8. Critical Thinking <p>Together, these values guide OMERACT's work to ensure rigor, transparency, and relevance in outcome measure development.</p>		<p>8C's</p>	
<p>Summary of Measurement Properties Table</p>	<p>a standardized dissemination tool developed by OMERACT to concisely present key evidence about an outcome measure's performance, measurement properties, and final disposition. It integrates all elements of the OMERACT Filter (truth, discrimination, and feasibility), making it easier for researchers, clinicians, and stakeholders to interpret and compare the quality and readiness of instruments for use in Core Outcome Sets.</p>		<p>SOMP</p>	
<p>Truth</p>	<p>the extent to which an instrument genuinely measures what it is intended to measure. An instrument must demonstrate that it is relevant (captures what matters for the target domain), comprehensive (covers all important aspects of the construct), and accurate (produces results that reflect reality) for the specified context and population.</p>		<p>T</p>	<p>If a questionnaire is designed to measure fatigue in people with rheumatoid arthritis, Truth means the items must genuinely capture the full experience of fatigue (not pain or mood), be relevant to patients' lives, and accurately reflect changes over time. For example,</p>

				<p>questions about “level of tiredness after daily activities” would show high truth for fatigue, while questions about “number of steps walked” alone might not.</p>
<p>Working Group (WG)</p>	<p>a focused, task-oriented subcommittee of the larger OMERACT community created to address specific research questions or areas of interest . These groups bring together diverse collaborators—such as clinicians, researchers, patients, regulators, and industry representatives—to collaboratively develop Core Outcome Sets for use in clinical trials, observational studies, and other research settings.</p>		<p>WG</p>	

UNDERSTANDING AUTHORSHIP AS A PATIENT RESEARCH PARTNER

It is important for patient research partners to be authors in publications for several reasons, your involvement contributes to more meaningful, relevant, and impactful research outcomes. Some key benefits of including patient research partners as authors are:

1. **Enhancing the relevance of research:** Patient research partners bring unique perspectives and experiences to the research process, helping to ensure that research questions, study designs, and outcome measures are relevant and meaningful to the people most affected by the health conditions being studied.
2. **Improving the quality of research:** Patient research partners can identify potential barriers and facilitators to research implementation, recruitment, and data collection, as well as contribute to the development of more accessible and understandable study materials. Their insights can lead to more efficient, effective, and inclusive research designs.
3. **Promoting patient-centered research:** Including patient research partners as authors emphasizes the value of patient-centered research and the need to consider patients' needs, preferences, and experiences throughout the research process. This approach contributes to a shift in research culture towards more equitable and patient-focused practices.
4. **Increasing the credibility and impact of research:** Patient research partners' contributions enhance the credibility and real-world applicability of research findings, as their involvement demonstrates that the research has been informed by the lived experiences of those directly affected by the health condition. This can ultimately lead to more impactful research outcomes and more effective translation of research findings into practice and policy.
5. **Fostering transparency and trust:** Involving patient research partners as authors promotes transparency and trust in the research process, as it signals to readers and stakeholders that patients have been engaged as equal partners in the research, and that their perspectives and experiences have been taken into account.
6. **Empowering patients:** Recognizing patient research partners as authors acknowledges their contributions and expertise, empowering them to continue advocating for patient-centered research and ensuring that research remains focused on addressing the needs and priorities of patients.

If you believe that you qualify for co-authorship, please make sure to:

1. Carefully review the International Committee of Medical Journal Editors (ICMJE) criteria. ICMJE recommends that authorship be based on the following 4 criteria:
 - Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
 - Drafting the work or revising it critically for important intellectual content; AND
 - Final approval of the version to be published; AND
 - Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

When you receive the manuscript from the Working Group Leaders

- Carefully review the CRediT** <https://credit.niso.org/> author statement and fill out the form, i.e. indicate your contributions to the work described in the manuscript which is a requirement from the journal. This could include but not limited to: attending working group meetings and participating in the discussions; attending a SIG or Workshop either in person or virtually; helping to develop a survey; distribution of a survey to your networks, or any other substantive engagement with the working group.
- Review the manuscripts in detail and provide your suggestions and comments to the corresponding author. Even if you have no suggestions to make, acknowledge that you have read it and have no additional comments to make.
- Fill out the COI disclosure form and send back to the corresponding author



**CRediT (Contributor Roles Taxonomy) was introduced with the intention of recognizing individual author contributions, reducing authorship disputes and facilitating collaboration. CRediT offers authors the opportunity to share an accurate and detailed description of their diverse contributions to the published work.



NEW PRP CHECKLIST

Step	Actions to Take	Done
Welcome & Orientation	<ul style="list-style-type: none"> • Read the Welcome Letter and Purpose of the Toolkit. • Explore “What is OMERACT?” and “Why Patient Research Partners Matter.” 	<input type="checkbox"/>
Know Your Role	<ul style="list-style-type: none"> • Identify your Working Group and its focus area. • Clarify meeting frequency, duration, and expectations with the group lead. • Review the “Roles in an OMERACT Working Group” table. 	<input type="checkbox"/>
Build Connections	<ul style="list-style-type: none"> • Introduce yourself to your Working Group. • Ask who your key contacts are (co-chair, staff support, other PRPs). 	<input type="checkbox"/>
Prepare to Participate	<ul style="list-style-type: none"> • Review the OMERACT Handbook and Policy Manual. • Complete the OMER-ED eLearning modules. • Familiarize yourself with the OMERACT Glossary—highlight terms new to you. 	<input type="checkbox"/>
Express Needs & Get Support	<ul style="list-style-type: none"> • Share any accessibility, scheduling, or support needs. • Connect with the PRP Advisory Council if you have questions or need a mentor. 	<input type="checkbox"/>
Engage & Contribute	<ul style="list-style-type: none"> • Identify which phases of the project match your skills. • Volunteer for tasks that fit your time and interests. 	<input type="checkbox"/>
Track Your Contributions	<ul style="list-style-type: none"> • Keep notes on meetings, tasks, and outputs (useful for authorship). 	<input type="checkbox"/>
Stay Connected	<ul style="list-style-type: none"> • Sign up for the PRP Network Website and create your profile. • Follow OMERACT news and updates for opportunities to participate. 	<input type="checkbox"/>