

OMERACT PATIENT RESEARCH PARTNER TOOLKIT

Dear OMERACT Patient Research Partner,

On behalf of OMERACT, we would like to welcome you as a new Patient Research Partner (PRP) and member of the OMERACT community. We are excited to have you join us in our mission to improve the measurement of health outcomes in rheumatology through patient-centered research.

As a new PRP, we understand that you may be unfamiliar with OMERACT and the role of Patient Research Partners in this work. To help you get started, we have developed an OMERACT PRP Toolkit that includes a range of resources and tools to support your participation. These resources have been designed to provide you with an introduction to patient-centered research and OMERACT, as well as practical guidance on how to contribute to this work as a PRP.

The OMERACT PRP Toolkit includes a range of resources, such as PRP Roles & Responsibilities, the OMERACT Primer, which provides an overview of OMERACT and its goals, online learning modules focused on Core Domain Set Development and Instrument Selection, an OMERACT Glossary and articles of interest.

We hope that you find the OMERACT PRP Toolkit to be a valuable resource as you begin your work as a PRP within the OMERACT community. We look forward to working with you and learning from your unique experiential knowledge and insights as a patient with a rheumatic disease.

Best regards,



Catherine Hofstetter(chair), Mary Cowern, Ingrid de Groot, Maya Desai & Ben Horgan
OMERACT Patient Research Partner Support Team



Table of Contents

GUIDING PRINCIPLES OF THE OMERACT PATIENT RESEARCH PARTNER	2
OMERACT PATIENT RESEARCH PARTNER ROLES & RESPONSIBILITIES	3
OMERACT eLEARNING MODULES	4
<i>Setting up an Account & Adding Courses</i>	4
OMERACT GLOSSARY	6
OMERACT PRP NETWORK WEBSITE	7
OMERACT WEBSITE	7
KEY PUBLICATIONS	8
UNDERSTANDING AUTHORSHIP AS A PATIENT RESEARCH PARTNER	8

Guiding Principles of the OMERACT Patient Research Partner

- At all times to keep foremost in mind the health, safety and well-being of the Patient Research Partners engaged in OMERACT
- To preserve and maintain the privacy, dignity and integrity of all Patient Research Partners engaged in OMERACT
- To work together in a spirit of respect, collaboration and support, and to achieve consensus through open and transparent dialogue and decision making
- To be mindful of the health challenges each of us face day to day and the limitations they may impose on our ability to contribute to OMERACT's work
- To continually strive to motivate and inspire new Patient Research Partners and one another, through education, knowledge dissemination and open and regular communication
- To be forthright and courageous when sharing our perspective as people living with a rheumatic disorder
- To work in harmony and mutual respect with the fellows, researchers and clinicians, and the administrative staff toward optimal outcomes for all people living with a rheumatic disorders



OMERACT Patient Research Partner Roles & Responsibilities

As a Patient Research Partner (PRP) with OMERACT, you will have a crucial role in the research process. Your main responsibilities include:

1. Providing a patient perspective:

- provide your personal perspective as a patient or caregiver on the research topic, including what matters most to you.
- help ensure that the research question is relevant to patients and that the outcomes being measured are meaningful and impactful to patients.
- you may be asked to help develop or review materials, such as survey questions or discussion guides, to ensure that they are clear, understandable, and respectful of patients.

2. Collaborating with researchers:

- work collaboratively with the research team, including attending meetings and providing feedback on study materials.
- help ensure that patient perspectives are integrated throughout the research process, from study design to data analysis and interpretation.
- be an active contributor to discussions and decision-making, based on your unique perspectives and experiences as a patient.

3. Contributing to dissemination:

- help disseminate the study results to the wider 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 patients and the broader community.

Overall, your role as a PRP is critical to ensuring that the research is patient-centered and reflects the needs and priorities of patients. You will work collaboratively with the research team to ensure that the research is conducted in an ethical and respectful manner, and that the outcomes are meaningful and impactful to patients.

OMERACT eLearning Modules

OMERACT eLearning modules are a series of online educational resources that introduce patient-centered outcomes research and OMERACT. These modules are designed to be accessible and engaging for a wide range of audiences, including Patient Research Partners (PRPs), researchers, clinicians, and other stakeholders.

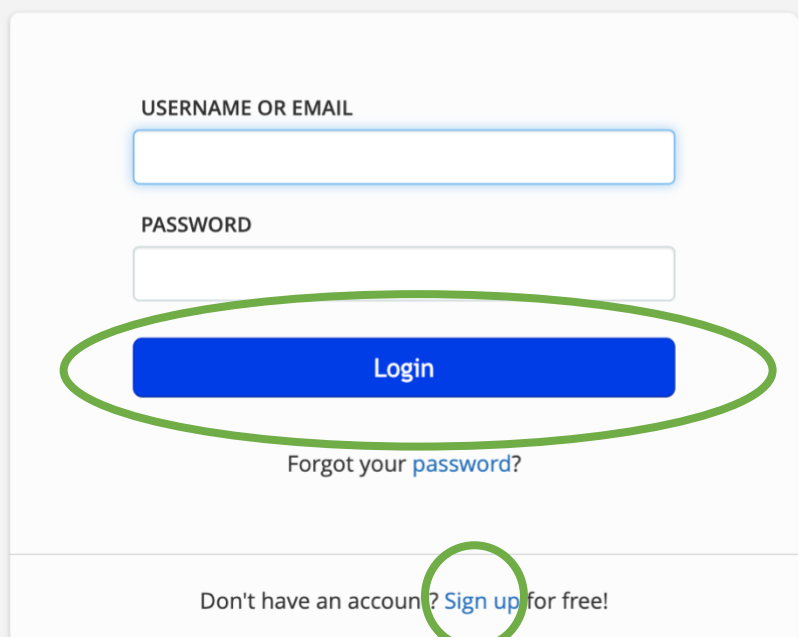
We are in the early phases of developing our online modules there are currently 3 available:

1. OMERACT Primer: provides an overview of what OMERACT is & how we work.
2. Overview of Developing OMERACT Core Domain Sets: the aim of this module is to provide an overview of the OMERACT Way of developing Core Domain Sets.
3. Overview of OMERACT Instrument Selection: the aim of this module is to provide an overview of the OMERACT way for Instrument Selection.

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

1. Click on the link and navigate to the OMERACT TalentLMS website: <https://omeract.talentlms.com/>
2. You will need to create an account by clicking the "Sign up now" link and following the prompts.
3. Once you've created your account you can enter your login credentials and click on the "Log in" button.



USERNAME OR EMAIL

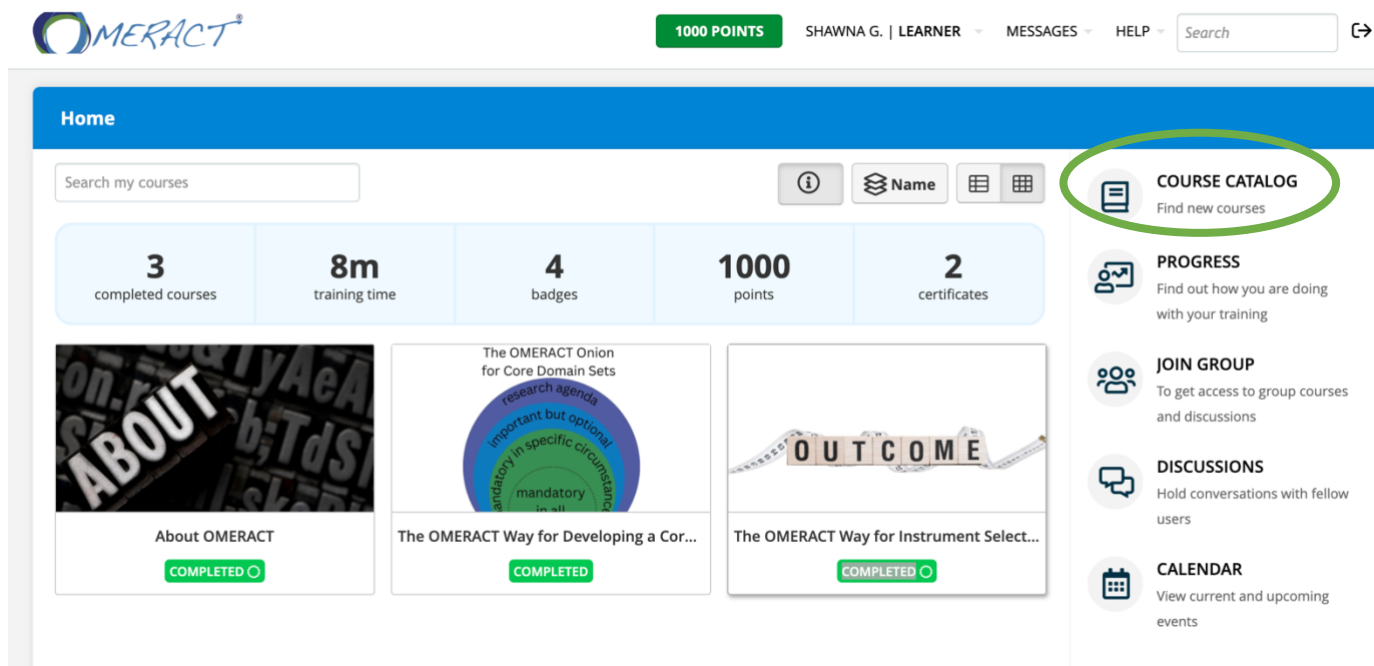
PASSWORD

Login

[Forgot your password?](#)

Don't have an account? [Sign up](#) for free!

- Navigate to the course catalogue to join the current courses that OMERACT has available. Select which course you would like to enrol in by clicking get this course.



The screenshot shows the OMERACT learner dashboard. At the top, there is a navigation bar with the OMERACT logo, a green '1000 POINTS' badge, and user information: 'SHAWNA G. | LEARNER', 'MESSAGES', and 'HELP'. A search bar is on the right. Below the navigation bar is a 'Home' header. A search bar for courses is on the left. In the center, there are five statistics: 3 completed courses, 8m training time, 4 badges, 1000 points, and 2 certificates. Below these are three course cards, each with a 'COMPLETED' badge. On the right, a vertical navigation menu includes 'COURSE CATALOG' (circled in green), 'PROGRESS', 'JOIN GROUP', 'DISCUSSIONS', and 'CALENDAR'.

- Once you're in the course, you can access the course materials.

If you have trouble logging in, you can click on the "Forgot your password?" link on the login page and follow the prompts to reset your password. If you need further assistance, you can contact admin@omeract.org



OMERACT Glossary

The OMERACT Glossary is a comprehensive list of terms and definitions related to patient-centered outcomes research and OMERACT. It is designed to help members of the OMERACT community understand and communicate effectively about key concepts and terminology used.

The OMERACT Glossary includes definitions for a range of terms, such as outcome measures, domains, responsiveness, and validity, among others. The definitions are written in clear, plain language and are based on the consensus of the OMERACT community.

The Glossary is regularly updated to reflect changes in terminology and to incorporate feedback from members of the OMERACT community. It is an important resource for anyone working in patient-centered outcomes research and is available to all members of the OMERACT community as part of the OMERACT toolkit.

You can find the Glossary online at <https://omeract.org/glossary/>.

We hope you find it helpful!



OMERACT PRP Network Website

The OMERACT PRP Network Website is designed to serve as a central hub for OMERACT Patient Research Partners (PRPs) who are involved in the OMERACT initiative. The website provides a range of resources and tools to help PRPs stay informed, engaged, and connected with the OMERACT community.

Some of the key features of the website include:

- **PRP Profiles:** PRPs can create a profile on the website to share information about their background, experience, and areas of interest. This allows other members of the OMERACT community to connect with PRPs and learn from their expertise.
- **News and Updates:** The website includes news and updates about the OMERACT initiative, upcoming events, and other relevant information for PRPs.
- **Resources and Training Materials:** The website provides access to a range of webinars to help PRPs better understand patient-centered outcomes research and their role in the OMERACT initiative.

The OMERACT PRP Network Website is an important tool for building and supporting the community of PRPs who are involved in the OMERACT initiative. It helps to ensure that PRPs have the resources and support they need to make meaningful contributions to patient-centered outcomes research.

You can find the website here: <https://omeractprpnetwork.org/>

OMERACT Website

The OMERACT website serves as the primary online resource for the OMERACT initiative, which is focused on developing and promoting the use of patient-centered outcomes in clinical research. The website provides a range of resources and tools to support the work of the OMERACT community, including researchers, clinicians, patients, and other stakeholders.

Some of the key features of the OMERACT website include:

- **Information about OMERACT:** The website provides an overview of OMERACT its history, and its mission.
- **News and Updates:** The website includes news and updates about OMERACT events, projects, and other activities.
- **Resources and Tools:** The website provides access to a range of resources and tools to support patient-centered outcomes research, including the OMERACT Glossary, conference publications, working group activities and training materials.
- **Opportunities for Engagement:** The website provides information about opportunities for individuals and organizations to get involved with OMERACT, including joining working groups and attending meetings.

Overall, the OMERACT website plays a critical role in advancing patient-centered outcomes research by providing a central hub for information, resources, and engagement for the OMERACT community.

You can find the website here: <https://omeract.org/>



Key Publications

Key publications can serve as a valuable resource for PRPs who are looking to increase their knowledge and understanding of patient-centered outcomes research, and who want to stay informed about the latest developments and best practices in the field. By identifying and promoting key publications, OMERACT helps to ensure that PRPs have access to the information and resources they need to make meaningful contributions to patient-centered outcomes research.

1. [Successful Stepwise Development of Patient Research Partnership: 14 Years' Experience of Actions and Consequences in Outcome Measures in Rheumatology \(OMERACT\)](#)
2. [Recommendations for the Involvement of Patient Research Partners \(PRP\) in OMERACT Working Groups. A Report from the OMERACT 2014 Working Group on PRP](#)
3. [The evolution of instrument selection for inclusion in core outcome sets at OMERACT: Filter 2.2](#)
4. [Core Domain Set Selection According to OMERACT Filter 2.1: The OMERACT Methodology](#)
5. [Instrument Selection Using the OMERACT Filter 2.1: The OMERACT Methodology](#)

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.