

Dear Colleague,

The Center for Innovation & Value Research is pleased to share the draft ***Patient-Centered Value Research Checklist for Rare Disease***. This resource is primarily designed to support value researchers in integrating patient engagement into the processes, data, and methods of patient-centered value research for rare disease.

The Checklist was developed in partnership with an expert advisory group composed of patients, caregivers, researchers, advocates, health economists, and other stakeholders. It is organized into four key sections: **Initiation & Planning, Execution, Monitoring, and Dissemination & Assessment**. It includes practical considerations and reflective questions to help guide inclusive, relevant, and actionable research.

As a valued member of our community, we invite you to contribute to our efforts by reviewing this critical resource. The input received during this public comment period will shape and refine the Checklist to ensure the final version is practical, inclusive, and responsive to real-world needs.

During this public comment period, the Center is seeking input in three main areas:

- Feedback on the content, specifically comprehensiveness and response formats
- Comments regarding usability and adaptability to different rare diseases
- Additional resources that should be included

Feel free to respond to any or all of the areas above in your submission of comments. Please send question responses and comments in a Word document or PDF file to:
public.comment@valueresearch.org.

We are accepting comments through **August 18th, 2025**. The Center will post all comments on our website and will provide an overview of how we intend to incorporate the recommendations.

Thank you for your time and expertise in shaping this important resource. Your collaboration helps ensure this checklist supports more equitable and patient-centered value research in rare diseases.

Sincerely,

Center for Innovation & Value Research