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PROMIS in Rheumatoid Arthritis Care and Research: Lessons Learned

Clifton Bingham, MD

Professor of Medicine, Division of Rheumatology

Johns Hopkins University, Baltimore, Maryland

This program covers the importance of patient-reported outcomes (PROs), practical implementation strategies, interpreting PROMIS data, and the impact on patient care and clinical trials.

1. What Matters to RA Patients

- **Key Patient Concerns:** Pain, physical function, and fatigue are the top concerns, but sleep, emotional well-being, and participation in life activities are also important.
- **Current Clinical Measures:** Traditional RA measures (S-DAS, C-DAS, DAS-28) focus on joint counts and global assessments, often missing domains patients value.

2. Integrating PROMIS into Clinical Care

- **Study Design:**
  - Implemented at Johns Hopkins Arthritis Center.
  - Patients completed PROMIS questionnaires via iPad or patient portal.
  - Scores were shared with both patients and providers during visits.
- **Outcomes Evaluated:** Feasibility, acceptability, relevance, impact on communication, shared decision-making, satisfaction, and performance of PROMIS over time.

3. Impact and Lessons Learned

- **Feasibility:** PROMIS covered a wide range of symptoms with no floor/ceiling effects.
- **Correlation with Disease Activity:** Higher PROMIS symptom scores aligned with higher disease activity; remission returned scores to normative levels.
- **Patient Example:** PROMIS tracked dramatic improvements and flares in an individual patient, aligning with clinical changes.
- **Provider Actions:** In up to 20% of visits, PRO data led to treatment changes; 35% identified new symptoms; 4–11% led to non-pharmacological interventions.

4. Interpreting PROMIS Results

- **Thresholds for Symptoms:**
  - T-scores: 45–55 (mild/normal), 55–65 (moderate), >65 (severe).
  - Minimal clinically important difference: 5–6 points for "a lot better"; patients/clinicians often expect 10-point changes for meaningful improvement.
- **Individual Variation:** Patients' perception of severity is highly individualized; consensus is difficult.

5. Implementation Strategies

- **Key Requirements:**
  - Administrative, clinical, and staff buy-in.
  - Provider and staff education on value and use of PROs.
  - Technical infrastructure (Wi-Fi, tablets, EHR integration).
  - Workflow planning (timing, frequency, communication of results).
- **Data Visualization:** Developed dashboards and heatmaps for easy interpretation; alerts for severe depression.

6. Value in Clinical Care

- **Benefits:**
  - Enhances understanding of patient experience.
  - Fosters shared decision-making and collaboration.
  - Identifies new or worsening symptoms.
  - Supports goal setting and treatment matching.
- **Patient and Provider Feedback:** Both groups report increased insight, improved communication, and actionable data.

7. PROMIS in Clinical Trials and Registries

- **Responsiveness:** PROMIS measures are sensitive to clinical changes and treatment effects in trials (pain, fatigue, sleep, anxiety, depression).
- **Application:** Used to identify patient clusters and individualize treatment.
- **Examples:** Trials show 5–8 point improvements in PROMIS domains with effective therapies.

Key Concepts

- **PROMIS:** A comprehensive system for measuring physical, mental, and social health through patient-reported outcomes.
- **PROs (Patient-Reported Outcomes):** Direct reports from patients about their health, symptoms, and quality of life.
- **T-score Metric:** Standardized scoring system (mean=50, SD=10) used in PROMIS for interpreting symptom severity.

- **Shared Decision-Making:** Collaborative process where patients and providers use PRO data to guide care.

Implementation Insights
- **Staff Training:** Essential to explain the purpose and impact of PRO collection to all staff, especially front desk and support staff.
- **Patient Engagement:** Sharing results with patients increases buy-in and completion rates.
- **Technical Integration:** Embedding PROMIS in EHR (e.g., Epic) streamlines workflow and data access.
- **Pilot Testing:** Recommended before full-scale implementation to identify and address workflow barriers.

Examples/Applications
- **Clinical Practice:** Used for screening, monitoring, and shared decision-making.
- **Alerts:** Automated notifications for severe depression trigger appropriate referrals.
- **Longitudinal Tracking:** Visualization tools allow providers and patients to track progress over time.
- **Training:** Ongoing need for training and adaptation as new staff join and as systems evolve.

Key Takeaways
- **PROMIS captures what matters most to RA patients and fills gaps left by traditional clinical measures.**
- **Integrating PROMIS into routine care is feasible, valuable, and enhances patient-provider communication.**
- **Meaningful changes in PROMIS scores are typically larger than the minimal detectable difference, reflecting patient expectations.**
- **Education and engagement of all stakeholders are crucial for successful implementation.**
- **PROMIS is responsive to clinical changes and useful in both practice and research, supporting individualized care.**

Additional Note
- PROMIS tools are endorsed by the American College of Rheumatology as alternatives to traditional measures.