



Patient Engagement

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Patient Engagement

What is it?

“Patient engagement is the meaningful involvement of patients, caregivers, and the healthcare community at large throughout the research process, from planning and design to implementation and dissemination of results. This engagement ensures that the perspectives and experiences of patients drive research priorities, study design, and outcomes.”



Patient-Centered Outcomes Research Institute



Patient Engagement Examples

1. Real-World Symptom Tracking and Lifestyle Integration
2. Including Mental Health and Behavioral Support Metrics
3. Reducing the Burden of Invasive Procedures
4. Diverse Representation in MASH Trials

Patient Engagement Examples

1. Real-World Symptom Tracking and Lifestyle Integration

- MASH patients often report symptoms like fatigue and brain fog that may not be captured. Engaging patients in trial design helps ensure these symptoms are considered.
 - help add symptom-tracking measures and patient-reported outcomes
 - make trials more relevant to patient experiences and provide a fuller picture of therapeutic impact.

Patient Engagement Examples

2. Including Mental Health and Behavioral Support Metrics

- Many MASH patients experience stress, anxiety, and lifestyle challenges related to diet and exercise regimens. Patients have advocated for the inclusion of mental health assessments and behavioral support metrics as part of the trial.
 - patient input has led to the inclusion of mental health evaluations and support components (access to nutritional or psychological counseling)
 - helps evaluate the full impact of the treatment

Patient Engagement Examples

3. Reducing the Burden of Invasive Procedures

- Engaging patients in trial design has led to the reduction of certain invasive procedures, such as liver biopsies, and the inclusion of non-invasive liver assessments like FibroScan
 - MASH trials include imaging technologies like MRI-PDFF or FibroScan, allowing more comfortable and accessible liver assessments
 - shift may have been largely driven by patient feedback on reducing procedure-related stress and enhancing convenience

Patient Engagement Examples

4. Diverse Representation in MASH Trials

- Given the prevalence of MASH among those with type-2 diabetes and obesity, patient engagement has highlighted the need for trials to include a more diverse population representing varying metabolic profiles, ethnic backgrounds, and lifestyle factors.
 - trials in the MASH space increasingly incorporate input from diverse patient groups
 - study populations better reflect the broad demographics of those affected by MASH
 - provides more generalizable and equitable data

Patient Engagement Practical Strategies

1. Forming Patient Steering Committees and Advisory Boards
2. Patient Friendly Trial Materials and Processes
3. Incorporating Tool and Technology
4. Recognizing and Addressing Health Literacy Levels
5. Sharing Trial Results with Participants

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