Patient Engagement Barriers

Lack of awareness

Lack of awareness impedes patient engagement in clinical trials due to unfamiliarity with rights, trial processes, and available technologies. Sponsors and sites may also not fully understand effective engagement strategies or how to ensure patient satisfaction. To tackle this, we need to create educational and engagement programs to boost patient awareness and participation in clinical trials.

Limited access to information & resources

Data privacy restrictions, limiting information and resource access, pose a significant obstacle to patient engagement in clinical trials. Regulatory constraints impact technology use, data sharing, privacy, and interoperability. To overcome this, sponsors and sites should create engagement strategies that comply with regulations yet personalize and humanize the experience. Effective communication of data privacy rules to patients, clarifying why some information can't be shared, is crucial.

Patient burden and inconvenience

Patient burden hinders engagement in clinical trials, which can be due to numerous site visits or complex treatment procedures. To mitigate this, sponsors and sites must collaborate to modify the approach, identifying perceived versus real burdens, and developing methods for their measurement. A system should be set up to collect and incorporate feedback into planning, with more flexibility in protocol design to offer patients increased participation choices.

Lack of diversity & inclusion

Access to diverse sites is crucial for different populations. Patient burden, including potential wage loss due to site visits, must be considered, and reimbursements could be a solution. Building trust in marginalized communities is challenging yet critical for their representation in trials. To ensure successful patient engagement in trials, these barriers must be addressed, not on a study-by-study basis, but through a consistent, top-down approach involving ongoing engagement and education.

Datacubed Health