

OurBrainBank case study

uMotif powers OurBrainBank's patient-led research initiative with engaging eCOA / ePRO platform to track glioblastoma symptoms



Opportunity: Patients leading research to advance treatments for glioblastoma (GBM)



GBM is the most invasive and lethal type of brain cancer. Less than 5% of patients survive for longer than 5 years from their diagnosis. While we've seen survival rates for many cancers improve significantly in recent years, overall GBM survival rates have remained nearly static for the last 30 years.

Given the lack of progress through traditional methods, it's critical to explore new approaches – including expanding patient-reported symptom tracking data, and how this is used by doctors and patients alike.

Patients are increasingly demanding enhanced solutions to put them in control of their treatment and provide more data to researchers. This desire among patients to do more was the impetus for Jessica Morris to create OurBrainBank (OBB), an innovative, patient-led movement designed to move GBM from terminal to treatable.



Challenge: Capture more accurate, timely, and extensive symptom reporting

Patients with GBM face a hugely challenging treatment regime, often with a highly complex set of medications, clinic visits, and diagnostics to manage. Patients can find it difficult to recall their symptoms and progress, particularly with the cognitive impacts of GBM.

Individualized, real-time symptom tracking offers a potential solution to the limitations of sporadic, patient

self-reporting in the doctor's office. Driven by her own experience, the OBB founder wanted an easy-to-use tool that would empower GBM patients to own and track their own symptom data over time and export reports to show to their medical teams. The patient community also wanted a way to provide more data to researchers – to help OBB's aim to turn GBM from terminal to treatable, powered by research.



Solution: uMotif eCOA / ePRO platform

The founder of OBB worked with uMotif and researchers at Columbia University and the Dana Farber Cancer Center to create the patient-led initiative, shape the initial research study, and define the datasets of most value to both patients and researchers.

The team selected the highly configurable uMotif eCOA / ePRO platform as the foundation for the pioneering research initiative – empowering patients and caregivers to effectively track symptoms, share data with clinicians, and donate data to medical research. Shaped by input from the GBM community, patients

used the uMotif app to report common symptoms – including sleep quality, exercise, mood, and fatigue – and capture quality of life ePRO instruments (EORTC, EQ-5D-5L).

The application also included an information tab that allowed users to view their own data and export it to their clinician, as well as in-app physical responsiveness and pattern recognition tests. To boost engagement, weekly mobile notifications reminded patients to track their symptoms.



Impact



630 patients participated in the initial study, with a community growing to over 1,000



>150,000 data points captured



Majority of patients reported finding symptom tracking useful in the management of their GBM treatment



Created a viable and scalable foundation for future research and discovery



Engaged and empowered patients in their GBM treatment

Find out more about how uMotif can help drive unparalleled patient engagement and data capture in your next study.

Contact us

