

We4Us-GBM

Patient-Driven Data Sharing Platform for Glioblastoma

Foundation Research Synthesis

Understanding Patient Experience, Community Dynamics, and Ethical
Frameworks for Platform Design

Phase 0: Landscape Analysis

December 2025

Abstract

This comprehensive research synthesis examines the landscape for designing We4Us-GBM, a patient-driven platform where people facing Glioblastoma Multiforme share treatment journeys, outcomes, and insights with each other. By combining community-generated knowledge with published research, the platform aims to help patients and caregivers make more informed decisions alongside their medical teams.

This document synthesizes findings across seven critical research domains: patient experience and needs, competitive landscape analysis, regulatory requirements, clinical understanding of GBM, data sharing psychology and trust, community dynamics, and ethical frameworks. Each section distinguishes between patients, caregivers, and newly-diagnosed versus long-term survivors, surfaces non-obvious emotional and practical needs, flags assumptions requiring validation through direct interviews, and provides specific interview questions to test hypotheses.

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Executive Summary

Glioblastoma Multiforme (GBM) represents one of the most devastating diagnoses in oncology, with median survival of 14–16 months despite aggressive treatment. The profound impact of this diagnosis extends far beyond the patient, affecting families, caregivers, and entire support networks. Current information resources for GBM patients remain fragmented, scattered across waiting rooms, support groups, and disparate online communities.

We4Us-GBM aims to address this gap by creating a patient-driven data-sharing platform that aggregates treatment experiences, outcomes, and lifestyle interventions while synthesizing published research. This foundation research synthesis examines the full landscape necessary to design such a platform responsibly and effectively.

Key Findings:

- **Patient Experience:** Between 50–74% of brain tumor patients experience behavioral health disorders. The GBM journey is characterized by chaos, loss of autonomy, and isolation. Patients and caregivers express strong desires for peer connection and information that helps them understand “what to expect.”
- **Competitive Landscape:** Platforms like PatientsLikeMe demonstrate the value of structured, quantitative patient-reported data. Key success factors include matching patients on clinical characteristics, enabling aggregated insights, and facilitating peer connections. Failures often stem from insufficient trust-building, lack of perceived value, or privacy breaches.
- **Regulatory Environment:** Patient-generated health data platforms face complex compliance requirements. Depending on platform architecture, HIPAA, FTC regulations, and state-specific laws may apply. Transparency about data use is essential for maintaining user trust.
- **Clinical Context:** The Stupp protocol (surgery, concurrent radiation/temozolomide, adjuvant temozolomide) remains standard of care. MGMT methylation status is the strongest prognostic/predictive biomarker. Platform data structures must accommo-

date treatment complexity, biomarker status, and outcome metrics meaningful to patients.

- **Data Sharing Psychology:** Privacy concerns are the primary barrier to health data sharing, but personal health relevance, trust in the platform, perceived benefit to others with the same condition, and control over data use are strong motivators. Pseudonymous sharing facilitates participation.
- **Community Dynamics:** Terminal illness communities require special protocols for handling member death, maintaining hope while being realistic, and preventing misinformation. Successful communities develop clear roles (veterans, advocates, newly-diagnosed) and moderation practices.
- **Ethical Framework:** The Belmont principles (respect for persons, beneficence, justice) provide foundational guidance. Specific challenges include posthumous data management, surfacing potentially distressing patterns, and protecting vulnerable users from exploitation.

Critical Assumptions Requiring Validation:

This research synthesis is based on published literature and analogous platform experiences. Many assumptions about GBM patient-specific preferences and behaviors require direct validation through interviews. Particular areas of uncertainty include optimal identity management (anonymous vs. identified), acceptable data granularity, caregiver-specific platform needs, and willingness to share data for various secondary purposes.

Chapter 1

Patient Experience and Needs

1.1 The GBM Journey: From Diagnosis to Treatment

The glioblastoma journey represents one of the most challenging patient experiences in oncology. Research reveals a trajectory marked by profound psychological, social, and existential challenges that evolve across distinct phases: pre-diagnosis uncertainty, acute crisis at diagnosis, chronic illness adaptation, and terminal decline.

1.1.1 Pre-Diagnosis: The Shadow of Uncertainty

Patients typically present with symptoms that may initially be attributed to benign causes—headaches, personality changes, cognitive difficulties. The period awaiting diagnosis is characterized by maximum uncertainty and acute anxiety. Research from UK-based qualitative studies indicates that patients’ anxiety is “most acute while waiting for a formal confirmation of a malignant growth.”

Key Insight: Many patients later report wishing they had known what questions to ask during this phase. The platform might consider specific resources for those in the “diagnostic limbo” phase.

1.1.2 Diagnosis: The Shattering of Assumptions

Receiving a GBM diagnosis precipitates what researchers describe as “a shattering of preconscious assumptions about their life and its meaning.” Studies report that up to 74% of primary brain tumor patients experience significant distress at some point during their illness trajectory.

The diagnosis phase is characterized by:

- Information overload combined with difficulty processing information due to shock

- Immediate pressure to make treatment decisions
- Cognitive impairment from the tumor itself affecting decision-making capacity
- Family system disruption as roles and expectations shift rapidly

Research from focus groups with brain tumor patients identifies critical needs during this phase:

- Clear, honest information delivered at an appropriate pace
- Connection with others who have traveled this path
- Practical guidance on navigating the healthcare system
- Emotional support that acknowledges the weight of the diagnosis

1.1.3 Treatment Phase: Living with Chaos

A 2024 Swedish study examining glioblastoma patient and caregiver experiences found three dominant themes: *chaos*, *loss of autonomy*, and *isolation*. Patients described “dramatic changes in their life situation” requiring constant adaptation.

The standard Stupp protocol involves:

- Surgical resection (when feasible)
- Six weeks of concurrent radiation therapy and daily temozolomide
- Six cycles of adjuvant temozolomide (5 days every 28 days)

During this phase, patients report needing:

- Specific information about what to expect from each treatment phase
- Practical tips for managing side effects (fatigue, nausea, cognitive changes)
- Ways to maintain normalcy and meaningful activities
- Support for the “scan anxiety” experienced before each MRI

1.1.4 Disease Progression: Navigating Uncertainty

For most GBM patients, disease progression occurs within 6–9 months. This phase brings renewed uncertainty and difficult decisions about second-line treatments, clinical trials, or shifting focus to quality of life.

Research indicates patients at this phase often seek:

- Information about others’ experiences with recurrence

- Guidance on clinical trial opportunities
- Peer support from those who have faced similar decisions
- Resources for advance care planning conversations

1.2 Psychological and Emotional Dimensions

1.2.1 Prevalence of Psychological Distress

Research consistently demonstrates high rates of psychological distress among GBM patients:

- 50–75% experience behavioral health disorders related to diagnosis and treatment
- 15–20% develop major depressive symptoms within eight months of diagnosis
- Depression rates exceed those in other oncology populations
- Patients with frontal lobe tumors show particular susceptibility to personality changes and loss of emotional control

Notably, very few patients receive psychiatric care despite high distress levels. This represents both a need and an opportunity for peer support platforms.

1.2.2 Existential Concerns

Qualitative research identifies profound existential challenges:

- Confrontation with mortality
- Loss of identity as cognitive and physical capacities change
- Disruption of future plans and life narratives
- Questions about meaning and purpose
- Fear of burdening loved ones

Platform Implication: Users may need spaces to discuss existential concerns alongside clinical information. The platform tone must balance hope with realism.

1.3 Patient Archetypes

Based on literature review and community observation, several distinct patient archetypes emerge:

1.3.1 The Information Seeker

Characteristics:

- Wants comprehensive data about treatments, outcomes, side effects
- Appreciates quantitative information and statistics
- May have scientific or technical background
- Copes through understanding and control

Platform Needs:

- Detailed outcome data with appropriate confidence intervals
- Access to clinical literature summaries
- Ability to filter and compare treatment protocols
- Structured data visualization

1.3.2 The Connection Seeker

Characteristics:

- Primary need is emotional support and understanding
- Values peer relationships over data
- May share more openly about feelings and fears
- Finds comfort in knowing others face similar challenges

Platform Needs:

- Easy connection with “patients like me”
- Forum/community features for discussion
- Ability to share and receive emotional support
- Less emphasis on statistics, more on stories

1.3.3 The Action-Oriented Optimizer

Characteristics:

- Focused on “what can I do?”
- Interested in complementary approaches, lifestyle interventions
- May pursue aggressive multi-modal treatment

- Values agency and control

Platform Needs:

- Information about complementary treatments tried by others
- Lifestyle intervention tracking (diet, exercise, supplements)
- Clinical trial matching and information
- Tools for self-experimentation and tracking

1.3.4 The Newly Diagnosed

Characteristics:

- Overwhelmed and in shock
- Needs basic orientation to the GBM landscape
- Time-pressured for treatment decisions
- May have cognitive impairment affecting information processing

Platform Needs:

- Clear, simple onboarding
- “What to expect” guides
- Connection with veteran patients who can provide guidance
- Curated, essential information (not overwhelming)

1.4 Caregiver-Specific Needs

Research reveals that caregivers of GBM patients face unique and often underappreciated challenges that differ substantially from the patient experience.

1.4.1 The Caregiver Burden

Studies document extraordinary caregiver burden in GBM:

- Caregivers provide substantial uncompensated care for months or years
- Tasks are physically, emotionally, socially, and financially demanding
- The rapid progression of GBM gives little time to adjust or adapt
- Cognitive and behavioral changes in patients create unique challenges

- One in five caregivers report “high levels of financial strain”
- One in four have taken on additional debt due to caregiving

Critical Finding: Research demonstrates that caregiver mastery (sense of competence and control) is *predictive of patient survival*. Supporting caregivers is not merely compassionate—it may improve patient outcomes.

1.4.2 Caregiver Information Needs

Caregivers report information gaps that differ from patient needs:

- What to expect as the disease progresses
- How to manage behavioral and cognitive changes
- When and how to access palliative care
- How to balance caregiving with their own needs
- Resources for financial assistance
- Guidance on difficult conversations (end of life, advance directives)

1.4.3 Caregiver Emotional Needs

Qualitative research reveals caregivers often:

- Feel isolated—“no one understands what we’re going through”
- Need permission to care for themselves
- Struggle with anticipatory grief while maintaining hope
- Experience role confusion as they become decision-makers
- Hide their own distress to “be strong” for the patient

Platform Implication: The platform needs dedicated caregiver spaces and resources. Caregivers may have different privacy concerns (sharing about their loved one’s condition) and different support needs.

1.5 Language and Terminology

Research reveals meaningful gaps between clinical terminology and patient language:

Clinical Term	Patient Language	Design Implication
Progression-free survival (PFS)	“Time until it comes back”	Define metrics in accessible terms
MGMT methylation	“The gene thing that affects chemo”	Provide explanations alongside technical terms
Temozolomide	“Temodar” or “TMZ”	Support multiple terms/synonyms
Adverse events	“Side effects”	Use patient-preferred language
Cognitive dysfunction	“Brain fog,” “memory problems”	Capture symptom experience in patient terms
Palliative care	“Comfort care” (often misunderstood as “giving up”)	Address misconceptions

1.6 Assumptions Requiring Interview Validation

1. Patients want to share treatment data with peers (vs. only receiving information)
2. Newly diagnosed patients will engage with platform during acute crisis
3. Quantitative outcome data is desired and not distressing
4. Caregivers want separate spaces vs. integrated discussion
5. Patients will share MGMT status and other biomarkers
6. Hope and realistic information can coexist on same platform

1.7 Suggested Interview Questions

For Patients:

1. Walk me through when you were first diagnosed. What information did you wish you had?
2. Where do you currently go for information and support about your GBM?
3. What would make you comfortable sharing your treatment experience with others?
4. What information about other patients’ experiences would be most helpful to you?

5. How do you feel about seeing outcome statistics for people with similar situations?

For Caregivers:

1. What aspects of caregiving have been most challenging?
2. What information do you wish you'd had earlier?
3. Where do you turn for support? What's missing?
4. Would you be comfortable sharing information about your loved one's journey?
5. What would a helpful platform for caregivers look like?

Chapter 2

Competitive and Adjacent Landscape

2.1 PatientsLikeMe: A Model Analysis

2.1.1 Platform Overview

PatientsLikeMe, founded in 2006 for ALS patients, pioneered the patient-generated health data platform model. It has grown to include over 830,000 members across 2,900+ health conditions, with approximately 43 million data points.

Core Value Proposition: Help patients answer “Given my status, what is the best outcome I can hope to achieve, and how do I get there?”

2.1.2 Strengths

Structured Quantitative Data: PatientsLikeMe distinguishes itself from qualitative forums by collecting structured data on symptoms, treatments, and outcomes. This enables:

- Matching patients on demographic and clinical characteristics
- Aggregated reports showing treatment effectiveness across populations
- Individual longitudinal tracking with visualization
- Comparison of one’s experience to similar patients

Perceived Patient Benefits: Survey research with PatientsLikeMe members found:

- 72% found the site “moderately” or “very helpful” in learning about symptoms
- 57% found it helpful for understanding treatment side effects

- 42% found another patient who helped them understand what taking a specific treatment was like
- 37% found it helpful for decisions about starting medication
- Members reported improved psychological experience of living with their conditions

Data Integrity: The platform employs a Health Data Integrity team of clinical pharmacists and nurses who:

- Connect patient-reported experiences to standardized medical coding (ICD-10, MedDRA)
- Ensure data can be “rolled up” for meaningful aggregate analysis
- Bridge patient language to clinical terminology

2.1.3 Limitations and Challenges

Representativeness: Research notes that PatientsLikeMe users “may not be representative of the larger patient population.” Users tend to be:

- More educated
- More engaged in their health
- Better access to healthcare
- More comfortable with technology

Misinformation Risk: Content is not reviewed by medical professionals, creating risk of:

- Spreading medical misinformation
- Dangerous advice for patients with complex conditions
- Misinterpretation of aggregated data

Commercial Model Concerns: PatientsLikeMe sells aggregated, de-identified data to pharmaceutical companies and other partners. Research shows:

- 87% of members expressed concern about data being “stolen by hackers”
- Commercial data use remains controversial among some users
- Transparency about partnerships is essential but may not fully address concerns

Transition Challenges: The platform’s 2011 transition from disease-specific “vertical” communities to a “generalized platform” diluted some of the intimate community feel that characterized early condition-specific groups.

2.1.4 Key Takeaways for We4Us-GBM

1. Structured data collection enables unique value proposition
2. Matching patients on clinical characteristics is highly valued
3. Data integrity requires investment (clinical coding, standardization)
4. Trust and transparency about data use is essential
5. Disease-specific focus may enable deeper community than generalized platforms
6. Active engagement correlates with perceived benefit

2.2 GBM-Specific Communities

2.2.1 Current Landscape

Several resources exist specifically for the GBM community:

National Brain Tumor Society (NBTS):

- Advocacy organization with patient resources
- Hosts Glioblastoma Awareness Day (July 16)
- Provides support group information and educational materials
- Focus on advocacy and research funding

American Brain Tumor Association (ABTA):

- Patient education and support
- Peer-to-peer mentoring programs
- Focus on coping strategies and quality of life

Glioblastoma Support Network:

- Caregiver-focused 501(c)(3)
- Founded by caregivers who “have walked the same path”
- Provides caregiver kits and resources
- Focus on practical support

Facebook Support Groups:

- Multiple private groups with thousands of members

- High engagement and peer support
- Unstructured information sharing
- Variable quality of medical information

Reddit (r/glioblastoma, r/braincancer):

- Pseudonymous peer support
- Questions and experience sharing
- Mixed patient/caregiver community
- Variable moderation quality

2.2.2 Gaps in Current Landscape

1. **Structured Data:** No platform collects structured treatment and outcome data specifically for GBM
2. **Peer Matching:** Limited ability to find “patients like me” based on clinical characteristics (MGMT status, age at diagnosis, treatment protocol)
3. **Outcome Insights:** Aggregated learning from community experience is not systematically captured
4. **Research Integration:** Patient experiences are not connected to published clinical evidence
5. **Caregiver-Patient Integration:** Most resources serve one group or the other

2.3 Lessons from Platform Failures

2.3.1 Google Health (2008–2012)

Google’s personal health record failed despite massive resources. Key failure factors:

- Insufficient value proposition for users
- Friction in data entry with limited payoff
- Privacy concerns about Google’s data practices
- Lack of integration with healthcare system

Lesson: Data entry burden must be offset by clear, immediate value to users.

2.3.2 Microsoft HealthVault (2007–2019)

Another tech giant’s failed health record platform:

- Limited ecosystem adoption
- Unclear use cases for patients
- Competition from hospital patient portals

Lesson: Platform must fit into existing patient workflows and provide unique value.

2.4 Trust-Building from Successful Health Communities

Research on successful rare disease and patient communities identifies key trust-building elements:

Governance and Transparency:

- Clear data use policies, prominently displayed
- Patient involvement in governance decisions
- Regular communication about how data is used
- Transparent partnerships and funding sources

Community Ownership:

- Patients as partners, not subjects
- Feedback mechanisms that influence platform development
- Recognition of contributor value
- Return of insights to the community

Safety and Moderation:

- Clear community guidelines
- Responsive moderation
- Handling of crisis situations (suicidality, medical emergencies)
- Protection from scams and exploitation

2.5 Assumptions Requiring Validation

1. GBM patients/caregivers are dissatisfied with current resources
2. Structured data collection is acceptable burden given perceived value
3. A GBM-specific platform is preferable to general cancer/brain tumor platforms
4. Users will contribute data, not just consume
5. Peer matching on clinical characteristics is valued

2.6 Suggested Interview Questions

1. What resources have you used to learn about GBM and connect with others?
2. What has been most and least helpful about these resources?
3. What's missing that you wish existed?
4. Would you prefer a platform specifically for GBM vs. all brain tumors vs. all cancers?
5. What would make you trust a new platform with your health information?

Chapter 3

Regulatory and Legal Landscape

3.1 HIPAA: Applicability and Requirements

3.1.1 When HIPAA Applies

HIPAA (Health Insurance Portability and Accountability Act) applies to “covered entities” and their “business associates”:

- Covered entities: health plans, healthcare clearinghouses, healthcare providers conducting certain electronic transactions
- Business associates: entities performing functions on behalf of covered entities

Critical Distinction for We4Us-GBM:

A patient-driven data platform where individuals directly share their own health information is *generally not* a covered entity under HIPAA. This is a significant regulatory distinction:

- Consumer-facing health apps and platforms collecting data directly from users typically fall outside HIPAA
- This creates both flexibility and responsibility—HIPAA’s protections don’t automatically apply
- Other regulations (FTC Act, state privacy laws) may apply instead

Exception: If the platform receives protected health information from a healthcare provider or health plan (e.g., integration with electronic health records), HIPAA business associate requirements would apply.

3.1.2 Key HIPAA Principles (If Applicable)

Even if not legally required, HIPAA provides useful guidance for platform design:

Privacy Rule:

- Establishes patient rights regarding their health information
- Requires minimum necessary use of protected health information
- Mandates privacy notices and patient consent for many disclosures

Security Rule:

- Administrative safeguards: policies, training, risk assessment
- Physical safeguards: facility access controls, workstation security
- Technical safeguards: access controls, audit logs, encryption

Breach Notification Rule:

- Requires notification to affected individuals within 60 days
- Media notification for breaches affecting 500+ individuals
- HHS notification requirements

3.2 FTC Regulation of Health Apps

The Federal Trade Commission Act Section 5 prohibits unfair or deceptive practices, including:

- Making false claims about data security
- Failing to honor privacy promises
- Inadequate data security leading to harm

FTC Health Breach Notification Rule: Applies to personal health record vendors and related entities not covered by HIPAA:

- Requires breach notification to consumers, FTC, and media
- Applies to “personal health records” provided by vendors
- Enforcement has increased for health apps

3.3 GDPR Considerations

If the platform serves EU users, GDPR applies with heightened requirements for health data (“special category data”):

Lawful Basis Required:

- Explicit consent is typically required for health data processing
- Consent must be freely given, specific, informed, and unambiguous
- Must be as easy to withdraw as to give

Data Subject Rights:

- Right to access personal data
- Right to rectification
- Right to erasure (“right to be forgotten”)
- Right to data portability
- Right to object to processing

Design Requirements:

- Data protection by design and default
- Data minimization
- Storage limitation
- Records of processing activities

3.4 FDA Digital Health Considerations

The FDA regulates “medical devices,” which may include some health software.

When FDA Applies:

- Software that diagnoses, treats, cures, mitigates, or prevents disease
- Clinical decision support that is not transparent or is not intended for independent review by healthcare professional

When FDA Typically Does Not Apply:

- Platforms for tracking and sharing health information
- Patient community and support tools

- General health and wellness applications
- Platforms that present information for user/clinician review without making recommendations

We4Us-GBM Implications:

The platform should avoid making diagnostic or treatment recommendations. Features should:

- Present data for user interpretation
- Encourage discussion with healthcare providers
- Avoid language suggesting platform insights are medical advice

3.5 State Privacy Laws

California (CCPA/CPRA):

- Applies to for-profit businesses meeting revenue/data thresholds
- Requires disclosure of data collection and sharing practices
- Provides consumer rights (access, deletion, opt-out of sale)
- Special provisions for “sensitive personal information” including health data

Other State Laws: A patchwork of state privacy laws is emerging (Virginia, Colorado, Connecticut, Utah, etc.) with varying requirements. Platform should monitor and plan for multi-state compliance.

3.6 Consent Framework Design

Based on research about patient preferences and regulatory requirements, We4Us-GBM should implement a robust consent framework:

Dynamic Consent Model:

- Allow users to specify and modify consent preferences over time
- Granular control over data types and uses
- Easy-to-understand interface, not buried legal language
- Regular re-engagement to confirm preferences

Transparency Requirements:

- Clear description of all data uses
- Identification of all data recipients
- Explanation of security measures
- Notice of any commercial arrangements

User Rights:

- Access to personal data in usable format
- Ability to correct inaccurate information
- Ability to delete data
- Ability to withdraw from platform

3.7 Research Partnerships and IRB

If platform data is used for formal research:

IRB Requirements:

- Institutional Review Board approval for human subjects research
- Informed consent specific to research use
- Ongoing oversight of research activities

Research Consent Best Practices:

- Separate consent for research use from platform participation
- Describe specific research purposes
- Allow users to opt-in to research opportunities
- Return research findings to community

3.8 Liability Considerations

Potential Liability Areas:

- Misinterpretation of platform data leading to harm
- Privacy breaches exposing sensitive health information
- Misinformation spread through platform
- Failure to intervene in user crisis situations

Risk Mitigation Strategies:

- Clear terms of service and disclaimers
- Statement that platform does not provide medical advice
- Encouragement to consult healthcare providers
- Robust data security measures
- Content moderation policies
- Protocols for handling crisis situations

3.9 Assumptions Requiring Validation

1. Users understand and accept that platform is not medical advice
2. Users will engage with consent processes (not just click through)
3. Granular consent options are valued vs. overwhelming
4. Users accept data use for platform improvement

3.10 Suggested Interview Questions

1. How do you feel about sharing your health information online?
2. What would you want to know about how your data is used?
3. Would you be comfortable with your data being used for research?
4. What would need to be true for you to trust a platform with this information?
5. How would you feel about your data being shared with pharmaceutical companies?

Chapter 4

Clinical Understanding of GBM

4.1 Disease Overview

Glioblastoma Multiforme (GBM) is the most common and aggressive primary brain tumor in adults, classified as WHO Grade IV. Key clinical characteristics:

- **Incidence:** Approximately 3 per 100,000 adults
- **Median age at diagnosis:** 64 years
- **Median survival:** 14–16 months with standard treatment
- **5-year survival rate:** Less than 10%
- **2-year survival rate:** Approximately 27%

4.2 Standard of Care: The Stupp Protocol

Established by the landmark 2005 Stupp trial published in the *New England Journal of Medicine*, the standard treatment protocol includes:

Phase 1: Surgical Resection

- Maximum safe resection when feasible
- Goal: reduce tumor burden while preserving function
- Extent of resection correlates with survival
- Some tumors are unresectable due to location

Phase 2: Concurrent Chemoradiation

- 60 Gy radiation in 30 fractions over 6 weeks

- Daily temozolomide 75 mg/m² during radiation
- Antibiotic prophylaxis (Pneumocystis prevention)

Phase 3: Adjuvant Chemotherapy

- Six cycles of temozolomide (150–200 mg/m²)
- 5 days on, 23 days off per cycle
- Some protocols extend beyond 6 cycles

Trial Results:

- Median overall survival: 14.6 months (vs. 12.1 months RT alone)
- 2-year survival: 26.5% (vs. 10.4%)
- Established temozolomide + radiation as standard of care

4.3 Molecular Markers and Prognosis

4.3.1 MGMT Methylation

O6-Methylguanine-DNA Methyltransferase (MGMT) promoter methylation is the most important prognostic/predictive biomarker in GBM:

- Present in approximately 45% of GBM
- MGMT enzyme repairs DNA damage caused by temozolomide
- Methylated promoter silences MGMT, improving temozolomide response
- Methylated vs. unmethylated median survival: 21.7 vs. 12.7 months
- 2-year survival: 46% vs. 13.8%

Platform Implications:

- MGMT status is critical for patient matching and outcome comparison
- Users should be able to indicate and filter by MGMT status
- Education about MGMT significance is needed

4.3.2 IDH Mutation Status

Isocitrate Dehydrogenase (IDH) mutation status:

- By current WHO classification, GBM is defined as IDH-wildtype

- IDH-mutant tumors (previously sometimes called GBM) have better prognosis
- Now classified as astrocytoma Grade 4 if IDH-mutant
- Important for accurate patient matching

4.3.3 Other Molecular Markers

- **EGFR amplification:** Common in GBM, potential therapeutic target
- **TERT promoter mutations:** Present in most GBM
- **ATRX loss:** More common in lower-grade gliomas
- **1p/19q codeletion:** Defines oligodendroglioma (not GBM)

4.4 Treatment Beyond Standard Protocol

4.4.1 Tumor Treating Fields (TTFields)

- Optune device delivering alternating electric fields
- Added to maintenance temozolomide
- Extended median survival by several months in trials
- Requires wearing device 18+ hours daily
- Controversial cost-benefit ratio

4.4.2 Bevacizumab

- Anti-angiogenic therapy (anti-VEGF)
- Approved for recurrent GBM
- Improves progression-free survival but not overall survival
- May improve quality of life, reduce steroid dependence

4.4.3 Clinical Trials

Common investigational approaches:

- Immunotherapies (checkpoint inhibitors, CAR-T cells, vaccines)
- Targeted therapies based on molecular profiling
- Novel radiation approaches

- Combination strategies

4.5 Common Symptoms and Side Effects

Tumor-Related Symptoms:

- Headaches (often worse in morning)
- Cognitive changes (memory, concentration, processing speed)
- Personality and behavioral changes
- Seizures (30–50% of patients)
- Focal neurological deficits (weakness, vision changes, speech problems)
- Fatigue

Treatment-Related Side Effects:

Radiation:

- Fatigue
- Hair loss in treatment area
- Skin changes
- Cognitive effects (may be delayed)

Temozolomide:

- Nausea
- Fatigue
- Myelosuppression (low blood counts)
- Increased infection risk

Steroids (commonly used):

- Weight gain, fluid retention
- Blood sugar elevation
- Mood changes, insomnia
- Muscle weakness

Anti-seizure medications:

- Levetiracetam (Keppra): fatigue, mood changes (“Keppra rage”)

- Other options with various side effect profiles

4.6 Outcome Metrics

Understanding outcome metrics is essential for meaningful data collection and presentation:

Clinical Trial Metrics:

- **Overall Survival (OS):** Time from diagnosis/treatment to death
- **Progression-Free Survival (PFS):** Time until tumor regrowth
- **Objective Response Rate (ORR):** Proportion with tumor shrinkage

Patient-Relevant Metrics:

- Quality of life measures
- Functional status (Karnofsky Performance Status)
- Symptom burden
- Time to functional decline
- Ability to maintain daily activities

Platform Consideration: Patients may value quality-of-life outcomes as much or more than survival metrics. Data collection should capture what matters to patients.

4.7 Complementary and Alternative Treatments

Research and community observation indicate common complementary approaches tried by GBM patients:

Dietary Interventions:

- Ketogenic diet (reducing glucose availability)
- Anti-inflammatory diets
- Fasting/caloric restriction
- Specific supplements

Supplements:

- Curcumin
- Boswellia

- CBD/cannabis products
- Medicinal mushrooms
- Various vitamins and antioxidants

Mind-Body Approaches:

- Meditation, mindfulness
- Yoga
- Acupuncture
- Counseling, psychotherapy

Platform Consideration: Evidence for complementary approaches varies widely. Platform should enable sharing of patient experiences without endorsing unproven treatments or discouraging evidence-based care.

4.8 Assumptions Requiring Validation

1. Patients understand and can report their MGMT status
2. Patients are willing to share detailed treatment protocols
3. Patients value outcome data from similar patients
4. Quality of life metrics are desired alongside survival data
5. Patients want to track and share complementary treatment use

4.9 Suggested Interview Questions

1. What do you know about your tumor’s molecular characteristics (MGMT, IDH)?
2. What outcomes matter most to you—how would you define “doing well”?
3. Are you using any complementary treatments or lifestyle approaches?
4. What would you want to know about other patients’ treatment experiences?
5. How do you feel about tracking and sharing symptom data?

Chapter 5

Data Sharing Psychology and Trust

5.1 Motivations for Sharing Health Data

Research on health data sharing reveals several key motivators:

5.1.1 Altruistic Motivations

Helping Others with Same Condition:

- Consistently ranked as strongest motivator
- “Knowing the study using my data could help patients with my health condition” rated most important
- Patients want their experience to benefit others on similar journeys
- Sense of community contribution

Advancing Research:

- Contributing to scientific understanding
- Potentially helping future patients
- “Leaving a legacy” especially relevant for terminal illness

5.1.2 Personal Benefit Motivations

Self-Understanding:

- Learning from patterns in own data
- Comparing experience to similar patients

- Better communication with healthcare providers

Social Support:

- Connection with peers
- Feeling less alone
- Sharing struggles and successes

Practical Information:

- Learning what to expect
- Treatment tips and strategies
- Managing symptoms and side effects

5.1.3 Issue Relevance and Personal Salience

Research consistently finds that willingness to share increases when:

- The condition is personally relevant
- The data use purpose is clearly connected to the condition
- Benefits return to the affected community

Implication for GBM: A GBM-specific platform may generate greater sharing willingness than a general cancer platform because of heightened issue relevance.

5.2 Barriers to Sharing Health Data

5.2.1 Privacy and Security Concerns

Privacy concerns are the most commonly identified barrier across studies:

Specific Concerns:

- Data being “stolen by hackers” (87% concerned in one study)
- Information reaching insurance companies
- Future discrimination based on health status
- Loss of control over personal information
- Potential for re-identification from “anonymous” data

Privacy-Protective Behaviors: Research shows that unaddressed privacy concerns lead patients to:

- Withhold clinically relevant information from providers
- Misreport or omit sensitive information
- Avoid using health platforms entirely

5.2.2 Concerns About Data Use

Commercial Use Concerns:

- Strong aversion to data reaching insurance companies
- Concern about pharmaceutical company access
- Perception that commercial entities prioritize profit over patient welfare
- Feeling of exploitation—“my data is valuable but I don’t benefit”

Research Use:

- Generally more acceptable than commercial use
- University research viewed more favorably than industry research
- Concerns about data use for projects that don’t align with values

5.2.3 Trust Deficits

Factors Eroding Trust:

- Negative past experiences with data breaches
- Lack of transparency about data practices
- Perceived misalignment between platform and user interests
- Not seeing benefit from data contribution
- Unfamiliar or unaccountable data recipients

5.2.4 Practical Barriers

- Data entry burden vs. perceived benefit
- Poor health literacy affecting ability to share accurately
- Cognitive impairment (especially relevant for GBM)
- Technical barriers for some users

5.3 Identity and Anonymity

Research reveals nuanced preferences around identity in health sharing:

5.3.1 Benefits of Anonymity

- Reduces fear of discrimination
- Enables sharing of stigmatized or embarrassing information
- Lowers barrier to participation
- Protects from real-world consequences

5.3.2 Benefits of Identity

- Enables deeper peer relationships
- Increases perceived authenticity of shared information
- Allows for personal connection and support
- May increase sense of accountability

5.3.3 Pseudonymous Option

Research suggests pseudonymous sharing (consistent identity not linked to real name) offers a middle ground:

- Enables relationship building
- Protects real-world identity
- Allows for reputation and history within community
- Facilitates ongoing support relationships

Recommendation: Offer flexible identity options—users may prefer anonymity for some sharing and pseudonymous/identified for other interactions.

5.4 Building Trust: Evidence-Based Strategies

5.4.1 Transparency

Required Elements:

- Clear, plain-language explanation of all data uses

- Specific identification of data recipients
- Explanation of how data is protected
- Regular communication about platform activities
- Honest acknowledgment of limitations and risks

5.4.2 User Control

Research strongly supports giving users control over:

- What data is shared
- Who can access data
- How data is used
- Duration of data retention
- Ability to modify or delete

Dynamic Consent: Rather than one-time consent, allow ongoing refinement of preferences with:

- Granular opt-in/opt-out for specific uses
- Easy-to-use preference management
- Regular prompts to review and update preferences

5.4.3 Feedback and Return of Value

Trust increases when users see tangible benefit from data sharing:

- Regular reports on how data is being used
- Sharing of insights generated from community data
- Notification when data contributes to research
- Making aggregated findings available to contributors

5.4.4 Governance and Accountability

- Patient/user representation in governance
- External oversight or advisory boards
- Clear policies with enforcement mechanisms

- Responsive complaint handling

5.5 Data Sensitivity Hierarchy

Research suggests varying comfort levels with sharing different data types:

More Comfortable Sharing:

- Diagnosis information
- Treatment protocols
- General health status
- Symptom experiences

Less Comfortable Sharing:

- Genetic/genomic information
- Mental health details
- Financial information
- Family medical history

GBM-Specific Considerations:

- MGMT status may feel sensitive (linked to prognosis)
- Cognitive symptoms may be embarrassing
- End-of-life preferences are deeply personal
- Family implications of diagnosis

5.6 What Destroys Trust

Case studies identify trust-breaking events:

Data Breaches:

- Healthcare breaches among most damaging
- Even minor incidents can permanently damage trust
- Recovery is extremely difficult

Undisclosed Commercial Arrangements:

- Discovery of hidden data sales

- Surprise partnerships with unpopular entities
- Perception of putting profit before users

Broken Promises:

- Changing privacy policies without clear notice
- Using data in ways not originally consented to
- Failing to honor deletion requests

Poor Crisis Response:

- Slow or inadequate breach notification
- Defensive rather than accountable posture
- Failure to remediate harm

5.7 Assumptions Requiring Validation

1. GBM patients are motivated to share data to help others
2. Privacy concerns are manageable with appropriate controls
3. Pseudonymous sharing is acceptable/preferred
4. Users will engage with consent management features
5. Trust can be built through transparency alone
6. Data sharing motivations are consistent across patient archetypes

5.8 Suggested Interview Questions

1. Have you ever shared health information online? What was that experience like?
2. What would motivate you to share your GBM experience with others?
3. What concerns would you have about sharing your health data?
4. How would you prefer to be identified—real name, username, anonymous?
5. What would you need to see to trust a new platform with your information?
6. How would you feel about your data being used for research? For commercial purposes?
7. What control would you want over who sees your information?

Chapter 6

Community Dynamics

6.1 Handling Death and Decline

In terminal illness communities, death is an ever-present reality that profoundly shapes community dynamics.

6.1.1 Challenges

- Grief affects entire community when members die
- Newly diagnosed may find death discussions distressing
- Long-term survivors may experience “survivor guilt”
- Caregivers may continue to need community after patient death
- Balance needed between acknowledging reality and maintaining hope

6.1.2 Best Practices from Existing Communities

Memorial Protocols:

- Designated spaces for remembering deceased members
- Clear processes for announcing deaths
- Opportunity for community to share memories
- Sensitivity to varying grief responses

Bereavement Support:

- Continued access for bereaved caregivers

- Bereavement-specific support spaces
- Connection to external grief resources
- Recognition that grief timeline varies

Hope and Realism Balance:

- Allowing honest discussion of prognosis
- Not censoring difficult conversations
- Highlighting long-term survivors without creating false expectations
- Acknowledging uncertainty

6.1.3 Posthumous Data Considerations

- Should data remain after member death?
- Can family access deceased member's account?
- How to handle ongoing contributions to aggregated insights?
- Privacy preferences after death

Policy Recommendations:

- Allow users to specify data handling preferences in advance
- Offer options: maintain data anonymously, remove data, designate data steward
- Default to privacy protection
- Clear communication about community norms around death

6.2 Misinformation and Dangerous Advice

6.2.1 The Challenge

Patient communities inevitably encounter:

- Anecdotal reports of unproven treatments
- Misunderstanding of clinical evidence
- Well-meaning but incorrect medical advice
- Occasional bad actors promoting fraudulent treatments

Specific Risks for GBM:

- Desperate patients vulnerable to exploitation
- Cognitive impairment may reduce critical evaluation
- Time pressure creates urgency around treatment decisions
- Complementary treatment discussions may delay evidence-based care

6.2.2 Moderation Strategies

Proactive Education:

- Clear explanation of evidence levels
- Distinguish anecdote from evidence
- Provide context for treatment discussions
- Connect community insights to published research

Community Guidelines:

- Prohibit guaranteed cure claims
- Require disclosure of financial interests
- Encourage “this is my experience, not medical advice” framing
- Provide clear guidelines about what discussions are welcome

Content Review:

- Community flagging mechanisms
- Review of potentially harmful content
- Clear escalation path for dangerous advice
- Balance moderation with free expression

Expert Input:

- Periodic expert review of common discussions
- Expert-authored content on frequent questions
- Clear identification of expert vs. peer input

6.3 Community Roles and Dynamics

Research on patient communities identifies emergent roles:

6.3.1 The Veteran/Elder

- Long-term survivor or experienced caregiver
- Provides guidance to newly diagnosed
- Shares institutional knowledge
- May hold formal or informal leadership role

Platform Support:

- Mentorship program matching
- Recognition of veteran contributors
- Training for peer support role

6.3.2 The Advocate

- Focused on awareness and policy change
- May connect community to external opportunities
- Often highly engaged and vocal

Platform Support:

- Advocacy information sharing
- Connection to research and policy opportunities
- Channels for advocacy-related discussions

6.3.3 The Information Curator

- Collects and shares resources
- Answers common questions
- May create guides or summaries

Platform Support:

- Tools for content curation
- Recognition of contributions
- Resource library integration

6.3.4 The Supporter

- Provides emotional support to others
- Responds to distress posts
- Creates welcoming atmosphere

Platform Support:

- Crisis response training
- Recognition of support contributions
- Tools for reaching out to isolated members

6.4 Balancing Hope and Realism

6.4.1 The Challenge

Terminal illness communities must navigate:

- Newly diagnosed need hope to cope
- False hope can lead to poor decisions
- Long-term survivors may create unrealistic expectations
- Honest prognosis discussion can be devastating
- Individual variation makes generalizations difficult

6.4.2 Principles

Accuracy:

- Present data honestly, including outcomes
- Acknowledge uncertainty
- Avoid cherry-picking survivor stories
- Provide context for individual experiences

Compassion:

- Allow space for hope
- Don't force confrontation with mortality
- Recognize individual coping styles

- Support those choosing different approaches

Empowerment:

- Focus on what patients can control
- Highlight quality of life alongside survival
- Support informed decision-making
- Respect patient autonomy

6.5 Moderation Practices

6.5.1 Community-Driven Moderation

- Clear community guidelines developed with member input
- Flagging and reporting mechanisms
- Peer-to-peer norm enforcement
- Graduated response to violations

6.5.2 Professional Moderation

- Trained moderators for sensitive issues
- Crisis response protocols
- Review of flagged content
- Consistency in enforcement

6.5.3 Special Situations

Crisis Situations:

- Suicide ideation protocols
- Medical emergency response
- Connection to crisis resources
- Training for community members to recognize and respond

Harassment and Conflict:

- Clear anti-harassment policies

- Confidential reporting mechanisms
- Fair investigation processes
- Account suspension/ban policies

6.6 Assumptions Requiring Validation

1. Users want community features alongside data sharing
2. Death/grief discussions are desired vs. avoided
3. Peer moderation is acceptable to community
4. Professional moderation is needed for specific issues
5. Hope and realism can coexist on same platform

6.7 Suggested Interview Questions

1. What kind of community support would be most helpful to you?
2. How do you feel about discussions of death and prognosis?
3. Have you encountered misinformation about GBM? How did you evaluate it?
4. What would make you feel safe and supported in an online community?
5. How do you think a community should handle it when a member passes away?
6. What kind of moderation would you expect in a GBM community?

Chapter 7

Ethical Framework

7.1 Foundational Principles: The Belmont Report

The Belmont Report (1979) established three core principles for ethical research involving human subjects that provide foundational guidance for patient data platforms:

7.1.1 Respect for Persons

Core Concept: Individuals should be treated as autonomous agents; persons with diminished autonomy are entitled to protection.

Application to We4Us-GBM:

- Informed consent: Users must understand what they're agreeing to
- Voluntary participation: No coercion or undue pressure to share data
- Right to withdraw: Easy exit with data deletion
- Special consideration for cognitive impairment: GBM patients may have reduced capacity; consent processes must accommodate this
- Caregiver consent considerations: When is it appropriate for caregivers to share patient information?

7.1.2 Beneficence

Core Concept: Maximize benefits and minimize harms.

Application to We4Us-GBM:

- Benefits: Peer support, information access, potential research contributions

- Potential harms: Privacy violations, psychological distress, misinformation
- Design obligation: Structure platform to maximize benefit/harm ratio
- Ongoing assessment: Monitor for unanticipated harms

7.1.3 Justice

Core Concept: Fair distribution of benefits and burdens of research.

Application to We4Us-GBM:

- Accessibility: Platform should serve diverse patients, not only privileged groups
- Benefit sharing: Insights should return to contributing community
- Avoiding exploitation: Vulnerable users should not bear disproportionate burden
- Equity: Consider barriers faced by underserved communities

7.2 Patient Data Ethics: Specific Considerations

7.2.1 Data Ownership and Stewardship

Key Questions:

- Who “owns” patient-generated health data?
- What obligations does the platform have as data steward?
- How should benefits from data use be distributed?

Ethical Position:

- Patients own their data
- Platform is steward, not owner
- Stewardship entails obligations: security, transparency, return of value
- Any commercial benefit should be transparent and, where possible, shared

7.2.2 Posthumous Data Ethics

Challenges:

- Deceased individuals cannot provide ongoing consent
- Data may have value for research and community

- Family members may have interests in data
- Privacy interests may persist after death

Ethical Framework:

- Respect advance directives about data handling
- Default to privacy protection
- Allow designation of data steward
- Consider family interests while protecting patient autonomy
- Data contribution to aggregated insights may continue with appropriate consent

7.2.3 Surfacing Distressing Information

The Dilemma: Aggregated data may reveal patterns that could distress individual patients (e.g., survival curves, treatment failure rates).

Ethical Considerations:

- Patients have right to know information relevant to their care
- Some patients may not want to see distressing statistics
- Information presentation affects emotional impact
- Individual variation means aggregate data may not apply to specific case

Recommendations:

- User control over exposure to potentially distressing data
- Contextualization of statistics (“this is average, individual cases vary”)
- Gradual disclosure with user control
- Support resources alongside difficult information

7.2.4 Protecting Vulnerable Users

Vulnerability Factors:

- Desperation from terminal diagnosis
- Cognitive impairment
- Financial stress
- Emotional distress affecting judgment

Protection Mechanisms:

- Screening for predatory content (scams, fraudulent treatments)
- Watchful community norms
- Crisis response protocols
- Connection to professional support resources
- Caregiver involvement options

7.3 Research Ethics Integration

7.3.1 When Platform Data Becomes Research

Research Activities:

- Formal studies using platform data
- Publications based on aggregated insights
- Partnership with academic researchers
- Collaborations with pharmaceutical companies

Ethical Requirements:

- Separate consent for research use
- IRB oversight for formal research
- Transparency about research activities
- Return of findings to community

7.3.2 Community-Based Participatory Research Model

- Involve community in research priority setting
- Patient partners in research design
- Community review of research proposals
- Accessible communication of findings
- Benefits return to community

7.4 Balancing Individual Privacy with Collective Benefit

7.4.1 The Tension

- Greater data sharing enables better community insights
- Individual privacy interests may limit data availability
- Aggregate benefit depends on sufficient individual contributions
- No individual is obligated to sacrifice privacy for collective good

7.4.2 Ethical Framework

Principles:

- Individual consent is paramount
- No coercion to share data
- Collective benefit is real but doesn't override individual rights
- Design should maximize benefit while respecting privacy choices

Implementation:

- Make privacy-respecting participation easy
- Communicate value of data sharing without pressure
- Offer graduated sharing options
- Return value to contributors

7.5 Platform Governance Ethics

7.5.1 Patient Voice in Governance

- Patients and caregivers should have meaningful input
- Advisory boards with patient representation
- Community feedback mechanisms
- Transparency about governance decisions

7.5.2 Conflict of Interest Management

- Disclose funding sources and partnerships
- Manage conflicts between commercial and patient interests
- Prioritize patient benefit in conflicting situations
- External oversight for major decisions

7.6 Preventing Exploitation

7.6.1 Types of Exploitation Risk

- Fraudulent treatment promoters targeting desperate patients
- Commercial entities extracting value without fair return
- Research that doesn't benefit the patient community
- Emotional manipulation of vulnerable users

7.6.2 Protective Measures

- Content policies prohibiting fraudulent claims
- Verification of any “expert” claims
- Transparent commercial relationships
- Community watch for suspicious actors
- Education about common scams
- Easy reporting mechanisms

7.7 Assumptions Requiring Validation

1. Users understand and value ethical principles
2. Privacy controls are sufficient for user comfort
3. Users want governance participation
4. Transparency is valued even if it reveals uncomfortable facts
5. Ethical operation is trusted

7.8 Suggested Interview Questions

1. What would you want to happen to your data if you were no longer able to manage it?
2. How do you feel about seeing survival statistics and outcome data?
3. Have you encountered anyone trying to take advantage of GBM patients?
4. What role would you want in how the platform is run?
5. What would make you confident that a platform is acting in patients' best interests?

Chapter 8

Synthesis: Design Principles for We4Us-GBM

Based on this comprehensive research synthesis, the following design principles emerge for the We4Us-GBM platform:

8.1 Core Design Principles

8.1.1 Patient-Centered Design

1. Design for crisis: Newly diagnosed users are overwhelmed; prioritize clarity and simplicity
2. Accommodate cognitive impairment: GBM affects cognition; design must be accessible
3. Serve multiple archetypes: Information seekers, connection seekers, and optimizers have different needs
4. Include caregivers: They have distinct needs and significantly impact patient outcomes
5. Respect the journey: Needs evolve from diagnosis through treatment through progression

8.1.2 Trust-First Architecture

1. Radical transparency: Every data use clearly explained
2. User control: Granular, easily managed privacy preferences
3. Return value: Insights flow back to those who contribute
4. Security by design: Protect data as if breach is inevitable

5. Patient ownership: Users own their data; platform is steward

8.1.3 Community-Centered Approach

1. Balance hope and realism: Acknowledge mortality while supporting hope
2. Handle death with dignity: Clear protocols for community grief
3. Protect from exploitation: Active defense against predators and misinformation
4. Foster peer support: Enable meaningful connection with similar patients
5. Involve community in governance: Patients shape platform direction

8.1.4 Clinical Relevance

1. Capture clinically meaningful data: MGMT status, treatment protocols, outcomes
2. Connect patient experience to medical evidence: Synthesize peer data with published research
3. Never replace medical care: Frame all insights as “questions for your doctor”
4. Outcome metrics that matter: Include quality of life, not just survival
5. Evidence context: Distinguish anecdote from evidence

8.2 Critical Success Factors

1. **Clear value proposition:** Users must quickly see what they get from participating
2. **Low friction data entry:** Make sharing easy despite the burden of illness
3. **Meaningful peer matching:** “Patients like me” based on clinically relevant characteristics
4. **Trustworthy data practices:** Build and maintain trust through consistent ethical operation
5. **Community safety:** Protect vulnerable users from harm
6. **Sustainable operation:** Business model that aligns with patient interests

8.3 Key Uncertainties Requiring User Research

This synthesis identifies numerous assumptions requiring validation through direct patient and caregiver interviews. Priority areas include:

1. Willingness to share detailed treatment and outcome data
2. Acceptable identity management (anonymous vs. pseudonymous vs. identified)
3. Tolerance for distressing information (survival statistics, outcomes data)
4. Caregiver-specific platform needs and willingness to share patient data
5. Preferred community features and moderation approaches
6. Attitudes toward data use for research and commercial purposes
7. Trust-building requirements specific to GBM community

8.4 Recommended Next Steps

1. **User Research:** Conduct interviews with GBM patients and caregivers using questions suggested throughout this document
2. **Competitive Deep Dive:** More detailed analysis of existing GBM community platforms
3. **Legal Review:** Formal legal analysis of regulatory obligations
4. **Technical Architecture:** Design data model to capture clinically meaningful information
5. **Advisory Board Formation:** Recruit patient advisors to guide development
6. **Pilot Planning:** Design limited pilot to test core assumptions

Conclusion

Glioblastoma patients and their caregivers navigate one of medicine’s most challenging diagnoses with fragmented information and scattered peer support. The research synthesized in this document reveals both the profound need for a platform like We4Us-GBM and the substantial challenges involved in creating one responsibly.

The opportunity is clear: patients want to learn from others’ experiences, share their own journeys, and make informed decisions alongside their medical teams. The challenges are equally clear: privacy concerns, trust deficits, vulnerable populations, regulatory complexity, and the profound emotional weight of terminal illness.

Success will require unwavering commitment to patient-centered design, radical transparency, robust privacy protections, and genuine community governance. It will require navigating the delicate balance between hope and realism, between individual privacy and collective benefit, between data-driven insights and human connection.

Most importantly, it will require listening—to patients, to caregivers, to the GBM community—and letting their voices guide the platform’s development. This research synthesis provides a foundation, but the real experts are those living with this disease.

The goal is ambitious but worthy: ensuring that no one navigates a GBM diagnosis alone, and that the collective experience of the GBM community becomes a resource for those who follow.

“Because no one should navigate this diagnosis alone, and collective experience is too valuable to stay scattered across waiting rooms and support groups.”