



Mass General Brigham

 Fuel Cycle

From Patient Voice to Strategic Decision

How Mass General Brigham Gives Patients a Seat at the Table

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Who is Mass General Brigham



Not-for-profit integrated healthcare system based in Greater Boston, and a principal teaching affiliate of Harvard Medical School



Five academic medical centers: Massachusetts General Hospital, Brigham and Women's Hospital, Mass Eye & Ear, Spaulding Rehabilitation, and McLean Hospital



Member hospitals include Newton-Wellesley, Salem Hospital, Wentworth-Douglass, Cooley Dickinson, Martha's Vineyard Hospital, and Nantucket Cottage Hospital



~82,000 employees - Massachusetts' largest private employer



Services span inpatient, outpatient, virtual, home care, urgent care, and a licensed health plan across MA and southern NH



AMY'S ROLE

Director of Market Research & Consumer Insights

Responsible for the full research function at one of the largest health systems in the country

Limited team.

Lean by design - minimal internal programming support, coordination, or project management resources underneath her.

THE RESEARCH CHALLENGE

The Challenge:

Mass General Brigham's stakeholders across hospitals, service lines, and corporate functions all need patient insight to make decisions - on communications, patient experience, digital experience, policy, and more

The Constraint:

Traditional research approaches - slow, expensive, vendor-dependent - couldn't keep pace with the volume and variety of questions coming in

What Was Needed:

A flexible, always-on, patient-first research capability that Amy could direct, and that could scale up or down depending on the question

The Patient Voice Community: At a Glance

2019

Year Founded

4,500+

Community Members

80%

Avg Participation Rate*

How It Started:

Launched in 2019 under Mass General Brigham's Strategy & Business Development team. Migrated to Fuel Cycle from a prior vendor in May 2023.

CRM-recruited, verified Mass General Brigham patients across the Greater Boston area (MA, NH, RI).

Zero Monetary Incentives:

Participation is driven entirely by purpose and the patient's connection to the mission. No points, no payments, no gift cards

English & Spanish Communities:

Research is conducted in both English and Spanish, reflecting commitment to serving a diverse patient population.

Powered by Fuel Cycle:

Expanded capacity (up to 20,000), enhanced analytics, multilingual support, and the ability to layer in non-patients for a more balanced research engine. Full-service infrastructure behind a lean team.

Fuel Cycle serves as a critical support system enabling Mass General Brigham's insights team to have an outsized impact on the organization

How Mass General Brigham Uses the Community: Built for Breadth

The community flexes across a range of research needs – spanning clinical, operational, communications, and patient experience topics.

Access & Navigation

- Barriers to care
- ER e-check-in UX, walk-in care
- Visitation policy

How We Communicate

- Naming & language studies
- Website content testing
- Communication effectiveness

Perception & Experience

- Social determinants of health
- Vaccine perceptions
- Perceptions of AI usage in healthcare

Condition & Service Line Research

- AVM awareness, Parkinson's, CAD
- Stress management, neurology, cancer
- Mental health needs



The Value Exchange

This is what patient-centered care looks like when it extends into the research relationship.

No Money. Ever.

A fully unincentivized community - rare in market research. No points, no payments, no gift cards. Participation driven entirely by purpose.

Trust Over Transactions.

The result: an organic, trust-based relationship that produces more honest, more engaged responses than panels built on points or payments.

Deeply Engaged.

Largely older patients who show up consistently at high participation rates, sustained over years. That kind of engagement doesn't happen by accident - it's a function of how this community is built.

Patients Feel Heard.

They participate because they see their feedback reflected in real decisions about their care.

A Closed Loop.

Fuel Cycle supports with a member engagement survey and quarterly share-backs. Patients told us they wanted to know how their feedback was being used - so Mass General Brigham closes that loop every quarter.

When Data Changes the Conversation Internally

The Challenge	Mass General Brigham's medical experts - among the leading clinicians in the country - were defaulting to clinical jargon for patient-facing content. Department names, website headers, and service descriptions were written for clinicians, not patients
How the Community Was Used	Naming and language studies - unaided awareness, open-ended description, head-to-head preference testing - to understand how patients actually describe and recognize our services
What Came Back	Patients didn't recognize clinical terminology, e.g. Pulmonology, Nephrology. Plain, accessible language – Lung, Kidney – consistently outperformed technical naming across segments
The Outcome	The data gave the team the credibility to push back on internal subject matter experts. It changed how we name departments, write copy, and present services to the people we're trying to reach
The Broader Takeaway	This wasn't just research informing a decision - it shifted an internal dynamic. Patient data became the tie-breaker in conversations that previously defaulted to clinical authority

Patient data didn't just inform the decision - it changed it.

Changing Our Own Assumptions About Patient Preferences

The negative connotation associated with the phrase “altering genes” changes to a positive one by qualifying it to “altering defective gene with corrected version in Definition II”.

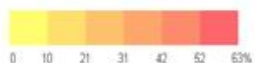
Gene and Cell Therapy involves altering defective genes or cells with targeted treatments to treat or stop disease progression. Gene therapy replaces or modifies a faulty gene with a corrected version while cell therapy introduces cells to replace or repair existing damaged cells. These treatments are available now for some conditions with the potential for more treatments to be delivered in the future.

Like	Dislike	Compelling	Confusing
<ul style="list-style-type: none"> ▪ Simple and Understandable ▪ Altering defective genes with a corrected version ▪ Modifies faulty genes ▪ Purpose of therapy explained ▪ Direct and clear information ▪ Stop disease progression ▪ Replaces or repairs something broken ▪ Treatments available now ▪ Future potential of therapy ▪ Targeted treatment ▪ Stop disease progression ▪ Replaces or modifies genes 	<p>Wordy, complex information, no examples of what type of diseases, not simple for lay people</p>	<ul style="list-style-type: none"> ▪ Simple and Understandable ▪ Altering defective genes with a corrected version ▪ Modifies faulty genes ▪ Purpose of therapy explained ▪ Direct and clear information ▪ Stop disease progression ▪ Replaces or repairs something broken ▪ Treatments available now ▪ Future potential of therapy ▪ Targeted treatment ▪ Replaces or repairs ▪ Stop disease progression ▪ Replaces or modifies genes 	<p>Wordy, complex information, no examples of what type of diseases, not simple for lay people</p>

Gene & Cell Therapy Part 2: Messaging to the Masses

Patients were most inspired by phrases that highlight the positive impact of GCT, while less enthused by technical jargon or 'flowery language'

Total: 435 participants



Innovators

At Mass General Brigham, innovators lead and discover. They aim tirelessly for progress. In search of something greater.

At the Gene and Cell Therapy Institute, we stand at the forefront of this exciting field of gene and cell therapy. Here hundreds of researchers and doctors push boundaries, using advanced technology and scientific expertise.

Our mission: develop and deliver new gene and cell therapies, harnessing the power of targeted treatments to slow or stop disease progression.

Innovators are the masters of unlocking potential, today and in the future. Today, we offer patients the latest FDA-approved treatments, revolutionizing the way we combat devastating diseases.

Using gene therapy for rare brain disease and inherited forms of blindness. Transforming the fight against cancer using the latest CAR T-cell therapies.

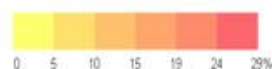
Today patients are offered first-of-its-kind clinical trials. Accelerating the promise of improved medicine. Today - and every day - we are focused on changing the lives of patients.

Our team of brilliant minds relentlessly pursues new discoveries. Shaping next-generation technology and treatments, such as prime editing and in-vivo cell therapy.

Our goal: create a better tomorrow. Striving to solve some of our most challenging medical conditions, like cancer, neurological disorders, and genetic disease of the heart, liver, and lungs.

We are the Gene and Cell Therapy Institute at Mass General Brigham. Innovators pioneering the future of medicine.

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Gene & Cell Therapy Part 2: Where we landed



What We Tried, What We Learned

On-Camera UX Testing

Patients weren't comfortable discussing health on camera. We adapted - shifted to unmoderated qual formats. Better fit, better data.

Engagement Experimentation

We tested patient-nominating-patient recruitment and a badge system to gamify participation. Neither resonated. The learning: these patients show up because the mission feels real, not because of mechanics - and that's actually a strength.

Building a Spanish-Speaking Community

Digital recruitment alone isn't enough in healthcare. The solution is in-person, community-level outreach - meeting patients where they actually are, not where it's easiest to reach them.

AI Perceptions

Patients expressed distrust of AI in healthcare - but were often already using it without knowing. The community helped MGB understand where the education gap lives and how to start closing it.

We don't expect every method to work perfectly out of the gate. What matters is having a partner willing to adapt. That flexibility is what makes the research practice sustainable.

Key Takeaways

Scale doesn't have to mean slow. Mass General Brigham is one of the largest health systems in the country, powered by a small but nimble market research team. The Patient Voice community - backed by Fuel Cycle's infrastructure - is how that team punches above its weight

Meeting your audience where they are is a research design principle, not a tagline. It shows up in language choices, methodology selection, recruitment strategy, and how you share findings back. Apply it at every step, not just in the research instrument

The most valuable research infrastructure is the one that's always on, always accessible, and built on genuine patient trust. For Mass General Brigham, the Patient Voice community has become exactly that.



Thank You

Questions?

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