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MaskTogetherAmerica

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Abstract Topic: **Long COVID Patient Community-Led Communication Model**

Title: A Grassroots Digital Communication Model for Long COVID Public Health and Prevention

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Background: Long COVID (LC) is an escalating global health and disability crisis. Patient needs are often minimized due to a significant lack of diagnostic standards and biomarkers [1]. Despite its scale, public health outreach [3] faces chronic underfunding [2], and the communication vacuum is exacerbated by algorithmic filtering of content concerning vulnerable groups—specifically youth and transgender communities-and pandemic mitigation [5, 8]. Dissemination barriers and misinformation ecosystems [6, 7, 9] limit the visibility of evidence-based data, rendering outreach infrequent and failing to communicate LC susceptibility or the benefits of layered prevention [4]. This systemic marginalization compounds the scarcity of research on effective strategies for disseminating evidence-based LC data on social media.

Objective: MaskTogetherAmerica (MTA) has developed a community-led multi-pronged digital communication model to increase visibility of Long COVID. This study evaluates how the framework achieves organic reach, amplifies diverse patient experiences, and fosters self-advocacy through prevention-centered messaging.

Methods: We conducted a retrospective analysis of 93 digital Long-COVID-centered content samples published by MTA between 2023 and 2026 on Facebook and Instagram. We categorized the samples into a five-prong communication model: Strategy 1 (Annotations), Strategy 2 (Expert-Patient Forums), Strategy 3 (Inclusive Representation), Strategy 4 (Storytelling), and Strategy 5 (Mobilization). We further subanalyzed the data by specific focus (organ systems and marginalized cohorts) to determine strategy-specific success in overcoming medical stigma and algorithmic filtering.

We examined raw metrics (Views, Reach, Saves, Shares, and Reposts) and 3 key ratios: Engagement Value (Views-to-Reach), Information Utility (Saves-to-Reach), and Dissemination Power ([Shares + Reposts]/Reach). We also evaluated the overall performance of the integrated model on Facebook and Instagram since 2020 based on data available on Meta's dashboard.

Results: Analysis of 93 samples shows that each strategy plays a distinct role in overcoming barriers. Strategy 1 (Annotations) and Strategy 2 (Expert Forums) achieved exceptional

Engagement Value (up to 87x ratio); specifically, scientific annotations explaining invisible symptoms (e.g., ocular health impacted by LC) achieved a 93.2% Information Utility rate. This demonstrates that our audience archives data, potentially utilizing our platform as a source. Strategy 3 (Inclusive Representation) was essential for lifting marginalized groups; by targeting the "double barriers" of stigma and censorship, the model achieved high Dissemination Power, reaching 2.7% for the transgender cohort and as high as 4.9% for the youth cohort, exceeding the average rate of 2.5% across all 93 samples. When content shines a light on marginalized communities, our members rise up as a distribution engine to support health equity awareness. Strategy 4 (Storytelling) and Strategy 5 (Mobilization) served as reach and action engines; the "Bane" reel (featuring an athlete masking after his father's heart attack during infection) reached 80,971 accounts, while the "Long COVID Swiss Cheese Defense" guidance earned nearly 1,000 saves. As of May 2026, the model built a community of over 36,034 followers, generating 11 million views with $0 ad-spend between Jan 1, 2026 and May 18, 2026.

Conclusion: These findings suggest that integrated, community-led digital communication strategies may serve as scalable tools for Long COVID public health engagement and prevention awareness.

Citation:

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What is the Big Question?

Why is it necessary to use 5 strategies to create a grassroots digital communication model for Long COVID public health and prevention?

Background

Long COVID: A Hidden Global Threat

Long COVID (LC) is an escalating global health and disability crisis. Gaps in diagnostic standards and biomarkers lead to patients' needs being overlooked.[1]

Public Health Communication Gaps

Underfunded public health outreach and barriers to digital visibility complicate access to LC information. [2-3]

Platform Visibility and Representation

Content filtering limits visibility of pandemic prevention information[2, 4] and perspectives from marginalized communities, including youth and trans people.[5, 8]

Misinformation and Prevention Awareness

Misinformation further complicates efforts to communicate Long COVID risks and the benefits of layered prevention.[6, 7, 9]

Research Gap

More research is needed on social media strategies that communicate Long COVID evidence and reach underserved communities.

Objective

To evaluate a community-led, five-prong digital communication model by MaskTogetherAmerica (MTA) designed to increase Long COVID visibility, amplify patient experiences, and promote prevention awareness on Instagram and Facebook.

Methodology

The 5-Prong Strategy Framework

🔴 Strategy 1 (**S1**)**: Scientific Annotations —** Translate and summarize peer-reviewed research.

🟠 Strategy 2 (**S2**): **Expert-Patient Forums —** Convene patients, researchers, & healthcare providers for virtual discussions.

🟡 Strategy 3 (**S3**): **Inclusive Representation** — Amplify perspectives from underrepresented groups, including youth and transgender communities.

🟢 Strategy 4 (**S4**): **Storytelling** — Share individual experiences of COVID-19 and Long COVID.

🔵 Strategy 5 (**S5**): **Mobilization** — Equip communities to share data, resources, and prevention toolkits, build solidarity, and empower collective action to advocate for systemic visibility, government support, and funding for Long COVID.

Social media is interactive. To evaluate the MTA model, we randomly selected and retrospectively evaluated 93 posts from a database of 4,545 Instagram assets (April 2020 – May 16, 2026), considering the level of partnerships. These Instagram posts were cross-shared to Facebook, and metrics from both platforms were analyzed across four supplemental tables:

- **Supplemental Table 1:** Comparing 47 posts that center on the definition and understanding of Long COVID (🔴 S1 vs. 🟠 S2)
- **Supplemental Table 2:** Comparing 16 posts that expose Long COVID's impact on organ systems (🔴 S1 vs. 🟢 S4)
- **Supplemental Table 3:** Comparing 13 youth and 2 transgender cohort posts that focus on vulnerable communities (🟡 S3)
- **Supplemental Table 4:** Comparing 18 posts focused on increasing MTA's credibility and community mobilization (🔵 S5)

Ratioed Categories

We assessed raw metrics (views, reach, saves, shares, and reposts) alongside 3 performance ratios.

💟 **Category 1:** Engagement Value = Views ÷ Reach
Indicates views relative to accounts reached; higher frequency may reflect repeat viewing but not direct comprehension.
🍎 **Category 2:** Information Utility = Saves ÷ Reach × 100%
Measures content saving rate, indicating a potential intent to retain information for future reference.
⭐ **Category 3:** Dissemination Power = (Shares + Reposts) ÷ Reach × 100%

Measures sharing relative to reach, indicating audience participation in content distribution.

For presentation purposes, we share the high-performing samples in two comparative indices, which include contextual descriptions for each selected post:

- **Supplemental Table 5:** Examples of High Raw Metrics
- **Supplemental Table 6:** Examples of Strong Ratioed Metrics

Lastly, cumulative account performance is summarized in **Supplemental Table 7: Cross-Platform Performance Metrics (January 1 – May 18, 2026).** This summary provides an overview of MaskTogetherAmerica's 6-year-old social media campaign initiated to serve public health at the start of the SARS-CoV-2 pandemic, which is now dedicated to educating people about Long COVID.

Social Media Communication cannot be measured by numbers. It's a form of art. It's about human connection. MaskTogetherAmerica's platform is an evolving canvas. Find the links to our educational campaign through our website: MaskTogetherAmerica.org, where you can not only see how all the strategies are integrated organically by a community with volunteers around the world, but also interact with them and participate in this work that serves both the science and the stakeholders.

Supplemental Table 1: Comparing 47 posts that center on the definition and understanding of Long COVID (🔴Strategy 1 vs. 🟠Strategy 2)

Posts utilizing Strategy 1 (Scientific Annotation) and Strategy 2 (Expert-Patient Forums) were evaluated using raw and ratioed metrics. The matrix contrasts the specific roles of peer-reviewed data (Strategy 1) against the lived experiences shared by experts and stakeholders in virtual forums (Strategy 2), illustrating how both strategies function as vital components within a multi-pronged public health communication model.

Date Published	Strategy	Contributor / Subject	Reach	Total Views	Total Interactions	Likes	Comments	Shares	Reposts	Saves
June 16, 2024	**S1**	NASEM Definition (Post)	4,635	N/A	636	402	18	133	1	125
June 11, 2024	**S1**	NASEM Definition (Reel)	2,049	4,000	289	179	12	55	0	43
May 1, 2025	**S1**	NHLBI (Blood Clots)	7,885	17,000	1,180	785	36	222	11	255
April 30, 2025	**S1**	Cleveland Clinic (Blood Clots)	8,438	60,674	1,025	1,147	23	158	1	175
Sep 29, 2023	**S1**	NIH: Heart/Plague	42	N/A	685	521	24	0	0	140

May 7, 2025	**S1**	Weill_Cornell: Diabetes after COVID	9,316	25,013	1,202	1,020	22	183	2	212
May 14, 2026	**S1**	Studies: LC Sjögren's: The Hidden Driver	4,684	28,287	528	421	78	46	26	157
April 14, 2026	**S1**	Dr. Avindra Nath: the Ondine's Curse	5,301	49,556	559	614	47	46	33	174
March 17, 2026	**S1**	Studies: Persistent SARS-CoV-2	8,812	79,167	1,183	1,410	117	109	91	281
Dec 22, 2025	**S1**	Dr. Eric Topol: LC Autoimmune Diseases	2,187	40,036	200	494	58	20	9	40
Dec 4, 2025	**S1**	Irish Farmers Journal: More that 200 LC Symptoms	3,466	173,240	506	1,771	497	63	42	52
July 23, 2025	**S1**	Review: LC persists beyond 3 years	13,345	13,345	211	196	4	30	0	35
July 8, 2025	**S1**	Study: Neuro-Long-COVID	4,924	26,753	512	493	20	55	0	119
May 9, 2025	**S1**	LC Prevalence: 25%-30% in 14 nations	8,127	22,386	1,063	762	9	223	1	164
April 17, 2025	**S1**	UPenn Study: LC Kidneys	9,228	20,690	682	637	13	81	1	101
Mar 29, 2025	**S1**	LC POTS	20,448	67,814	2,555	1,923	77	481	1	476
Dec 29, 2024	**S1**	LC Bones	83,667	156,600	4,454	2747	116	1,037	2	892
Nov 26, 2024	**S1**	LC Brain (SCI-AM)	31,374	47,006	3,473	1,876	37	800	1	811
Oct 11, 2024	**S1**	LC Kidneys	7,181	17,655	779	629	19	120	0	106
Sep 20, 2024	**S1**	LC Male Fertility	10,219	16,153	1,052	758	23	201	1	146
Mar 26, 2024	**S1**	HHS: Long COVID	90	N/A	387	310	43	0	0	65
Mar 14, 2024	**S1**	Prevent LC	230	N/A	934	811	9	2	0	140
Mar 10, 2024	**S1**	LC Rheumatic Disease	250	N/A	991	861	8	2	0	233
Feb 26, 2024	**S1**	Dr. Al-Aly & Dr. Eric Topol: LC	428	N/A	1,176	862	23	9	0	351
Feb 23, 2024	**S1**	Neuro LC: Brain Fog	103	N/A	1,868	1,432	47	0	0	459
Sep 11, 2023	**S1**	NPR: Unraveling LC	17	N/A	444	353	7	0	0	84

Sep 2, 2023	**S1**	LC: Shorter Life	31	N/A	567	452	20	0	0	95
July 17, 2023	**S1**	Northwestern: LC	52	N/A	813	610	28	0	0	175
Nov 18, 2025	**S2**	Adam Van Bavel (IAQ)	3,014	32,000	452	866	84	76	39	74
Nov 15, 2025	**S2**	Solenn Tanguy (Winslow SP)	2,761	15,000	407	521	41	48	48	54
Nov 20, 2025	**S2**	Ann Wallace (NIH RECOVER)	2,036	12,749	288	384	32	33	34	30
Mar 18, 2026	**S2**	Devin Russel (LC Foundation)	1,171	11,000	126	289	66	7	16	8
Sep 19, 2025	**S2**	Devin Russel (HHS Round Table)	13,200	84,000	2,391	3,200	225	47	168	377
Jan 30, 2026	**S2**	Miles Griffis (The Sick Times)	1,545	46,000	205	1,262	149	23	19	28
Nov 27, 2025	**S2**	Becky Ancira Robertson (WHN)	1,422	11,000	198	296	29	27	19	24
Mar 21, 2026	**S2**	Delphine Crespo (Spain)	2,104	4,762	160	159	25	8	18	14
April 2, 2026	**S2**	Pamela Morrison (Ireland)	985	3,051	98	107	5	9	12	8
Jan 31, 2026	**S2**	Dr. Akiko Iwasaki (Trials)	2,082	41,000	336	976	77	55	28	73
April 28, 2024	**S2**	Dr. Akiko Iwasaki (Prevent LC)	1,264	16,471	1,144	771	58	13	1	301
Feb 6, 2026	**S2**	Dr. Akiko Iwasaki (Biomarkers)	2,776	11,000	153	238	20	9	11	17
Nov 24, 2025	**S2**	Dr. Angelique Corthals (Definition)	4,443	48,000	704	1,065	147	93	56	121
Dec 28, 2025	**S2**	Dr. Angelique Corthals (Symptom Index)	3,703	10,000	192	229	12	17	14	31
Oct 9, 2023	**S2**	Dr. Angelique Corthals: Viral Reservoir	595	6,771	493	325	18	13	5	132
Oct 1, 2025	**S2**	Dr. Robi Tamargo on Serious Neuro Outcomes	7,185	17,000	1,115	668	22	279	71	197
Mar 14, 2025	**S2**	Dr. Richard Corsi (Prevention)	15,000	21,500	1,338	896	23	178	1	240

Performance Analysis: Top 3 Examples from Supplemental Table 1

1. Top Performers by Views (Interest)

These posts broke the "echo chamber" and commanded the most attention.

- Irish Farmers Journal (Strategy 1): 173,240 Views (Broad awareness of the 200+ LC symptoms).
- LC Bones (Strategy 1): 156,600 Views (Validation of a major "invisible" risk).
- Devin Russell / HHS (Strategy 2): 84,000 Views (High interest in patient representation at the federal level).

2. Top Performers by Save/Reach (Information Utility)
These posts were deemed essential for medical reference and self-advocacy.

- LC Rheumatic Disease (Strategy 1): 93.2% Information Utility (Nearly every person who saw it, saved it).
- Dr. Ziyad Al-Aly & Dr. Eric Topol (Strategy 1): 82.0% Information Utility (Indispensable clinical reporting).
- Dr. Akiko Iwasaki / Prevent LC (Strategy 2): 23.8% Information Utility (Highly actionable expert guidance).

3. Top Performers by (Share + Repost) / Reach (Dissemination Power)
These posts leveraged community trust to fight algorithmic suppression.

- Studies: LC Sjögren's (Strategy 1): 1.5% Dissemination Power (46 shares + 26 reposts).
- Devin Russell / HHS (Strategy 2): 1.6% Dissemination Power (47 shares + 168 reposts).
- Dr. Robi Tamargo (Strategy 2): 4.8% Dissemination Power (279 shares + 71 reposts).

Analysis of Supplemental Table 1:

Strategy 1 (Data Annotation) with Strategy 2 (Expert-Patient Forums)

Rank	Date	Strategy	Subject	Reach	Views	Saves	Shares + Reposts	Engagement Value(View / Reach)	Info Utility (Save / Reach)	Dissemination Power [(Sh + Rp) / Reach]
Cat 1			**Engagement Value (Views ÷ Reach)**							
1	Dec 4, 2025	🔴**S1**	**Irish Farmers Journal** *[Annotation of an article by Rosalind Skillen reveals that Long COVID has more than 200 symptoms and the power to shatter human lives. https://bit.ly/LC_FarmersJournal]*	3,466	173,240	52	105	**50.0x**	1.5%	3.0%
2	Sep 19, 2025	🟠**S2**	**Devin Russell / HHS** *[Devin Russell, a Long COVID patient and co-founder of Long COVID Foundation spoke at the Long COVID Round Table Forum/Discussion hosted by the HHS.]*	13,200	84,000	377	215	**6.4x**	2.8%	1.6%

3	Dec 29, 2024	🔴**S1**	**LC Bones** *[Cleveland Clinic shares a study that connects Long COVID to bone health issues. https://insight.jci.org/articles/view/178820]*	83,667	156,600	892	1,039	**1.9x**	1.1%	1.2%
Cat 2			**Info Utility (Save ÷ Reach)**							
1	Mar 10, 2024	🔴**S1**	**LC Rheumatic Disease** *[This annotation exposed the risk of developing autoimmune inflammatory rheumatic disease (AIRD), highlighted by a study. https://doi.org/10.7326/M23-1831]*	250	N/A	233	2	N/A*	**93.2 %**	0.8%
2	Feb 26, 2024	🟠**S2**	**Dr. Al-Aly & Dr. Topol** *[This annotation of "Solving the puzzle of Long COVID" shares compelling insights on the escalating LC crisis by two experts.]*	428	N/A	351	9	N/A*	**82.0 %**	2.1%
3	April 28, 2024	🟠**S2**	**Dr. Akiko Iwasaki** *[Expert Forum: Yale Professor Akiko Iwasaki discusses possible root causes and the need for the layered approach in prevention]*	1,264	16,471	301	14	13.0x	**23.8 %**	1.1%
	Oct 9, 2023	🟠**S2**	**Dr. Angelique Corthals: Viral Reservoir** *[Expert Forum: CUNY Professor Dr. Angelique Corthals discusses how SARS-CoV-2 can persist in human cells, create reinfection and more transmission.]*	595	6771	132	18	11.38x	**22.18 %**	3.03%
Cat 3			**Dissemination Power (Shares + Reposts) ÷ Reach**							
1	Oct 1, 2025	🟠**S2**	**Dr. Robi Tamargo** *[Expert Forum: Analysis of the serious neurological impacts of COVID on the youth cohort.]*	7,185	17,000	197	350	2.4x	2.7%	**4.8%**
2	Dec 22, 2025	🔴**S1**	**Dr. Eric Topol: LC Autoimmune Diseases** *[An annotation of Dr. Topol's substack article on treatments and cures for autoimmune diseases]*	2,187	40,036	40	29	18.3x	1.8%	**1.3%**
3	May 14, 2026	🔴**S1**	**Studies: LC Sjögren's: The Hidden Driver** *[An annotation of studies that link Long COVID to Sjögren's.]*	4,684	28,287	157	72	6.0x	3.3%	**1.5%**

** Data for certain early static posts was unavailable due to platform data retention limits and algorithmic visibility restrictions. Instagram maintains specific data retention windows; older content—particularly that subjected to algorithmic suppression—may have irretrievable engagement metrics.*

Key Analytical Takeaways for Supplemental Table 1:

- Make the Content Worth Watching (Attention Density): The annotation of the Irish Farmers Journal article provides evidence that a modest reach (~3,500) can still generate over 173,000 views. This indicates that a high-interest topic can drive massive educational impact through repeated engagement and "study-like" viewing by a dedicated audience.
- Make the Content Useful (Portable Medical Evidence): The high utility rate (93.2%) of the annotation of *"COVID-19 Increases Risk for Autoimmune Inflammatory Rheumatic Disease"* in Inside Precision Medicine suggests that when algorithmic friction restricts reach, the 'Save' metric becomes the primary indicator of value. This post isn't "viral," but it was likely being used as a clinical tool for medical reference and self-advocacy—as nearly every viewer archived the data.
- Make the Content Worth Sharing (The Credibility Shield): Content featuring Dr. Robi Tamargo's Q&A segment at the Back-to-School Forum regarding the serious consequences of Neuro Long COVID and the annotation of Dr. Topol's substack article on treatments and cures for autoimmune diseases that follow COVID-19 earned the highest Dissemination Power in the dataset. The findings suggest that users might have shared the content because it is anchored by established medical professionals—a "Credibility Shield" that turns a community into a reliable distribution engine that can help bypass algorithmic filters.

Supplemental Table 2: Comparing 16 posts that expose Long COVID's impact on organ systems (🔴Strategy 1 vs. 🟢Strategy 4)

Posts that raise awareness about the clinical impact of Long COVID on specific organ systems (Cardiovascular, Sensory/Neurological and Immunological) were selected and categorized by strategy. This analysis evaluates the relative effectiveness and specific roles of Strategy 1 (Scientific Annotation) versus Strategy 4 (Storytelling) within a multi-pronged public health communication model.

Cardiovascular

Date Published	Strategy	Contributor / Subject	Reach	Total Views	Total Interactions	Likes	Comments	Shares	Reposts	Saves
Nov 1, 2025	**S1**	**"Long COVID Heart"**	11,923	266,085	1,550	2,295	89	243	1	270
Oct 26, 2025	**S1**	**"Cardiac Long COVID"**	9,533	103,865	1,082	1,100	104	151	70	177

May 3, 2026	**S1**	"Cardiovascular Long COVID"	4,010	56,788	358	564	81	15	34	82
March 20, 2024	**S1**	LC Heart	102	N/A	767	628	15	0	0	164
Sep 29, 2023	**S1**	NIH: Heart/Plague	42	N/A	685	521	24	0	0	140
Oct 2, 2024	**S4**	"Bane" Reel	80,971	80,971	11,722	8,600	286	1,598	8	1,250

Sensory/Neurological

Date Published	Strategy	Contributor / Subject	Reach	Total Views	Total Interactions	Likes	Comments	Shares	Reposts	Saves
April 23, 2026	**S1**	"LC Ear"	88,702	301,696	4,534	1,983	370	1,610	128	1,291
April 29, 2026	**S4**	Marc Redding With LC Ears	2,888	15,720	414	1,040	81	15	15	28
April 20, 2026	**S1**	"LC Eye"	6,924	328,577	595	1,370	403	59	42	147
April 18, 2026	**S4**	Erin Ahrens With LC Eyes	4,775	47,367	511	398	167	15	20	68
March 5, 2025	**S4**	"Phytocene" Reel	25,904	40,785	4,408	3,127	124	607	6	544
Feb 6, 2026	**S4**	Kristina with Parosmia	3,989	27,009	459	814	40	26	21	21
Sep 19, 2024	**S4**	Dr. Bailey Reel	13,106	25,665	2,755	1,954	129	330	4	338

Immunological

Date Published	Strategy	Contributor / Subject	Reach	Total Views	Total Interactions	Likes	Comments	Shares	Reposts	Saves
Dec 9, 2025	**S1**	"Risk of Lymphopenia"	11,577	42,614	1,204	908	75	140	71	287
Dec 24, 2025	**S1**	Independent News: Hidden Infections Could Fuel LC	5,763	34,820	590	625	33	39	32	139
April 28, 2026	**S4**	"Drew Empire" Reel	13,802	30,247	3,119	2,645	209	296	322	319

Summary of Findings

Analysis of Supplemental Table 2 shows that Strategy 1 (Annotations) provides evidence that people need to understand "invisible" symptoms, likely leading to high Engagement Value (up to

47.4x) as people study the data. Strategy 4 (Storytelling) acts as the main driver for sharing, as personal stories help humanize the science and push the information to new people.

Analysis of Supplemental Table 2: Strategy 1 (Annotations) vs. Strategy 4 (Storytelling)

Category	Date	Strategy	Subject	Reach	Views	Saves	Sh + Rp	Engagement Value (View/ Reach)	Info Utility (Save/ Reach)	Dissemination Power [(Sh+Rp)/ Reach]
Cat 1:			**Engagement Value (Views ÷ Reach)**							
	Apr 20, 2026	🔴**S1**	**LC Eye** *[Annotation: Long COVID research on ocular manifestations associated with SARS-CoV-2, drawing attention to symptoms and effects that may be overlooked.]*	6,924	328,577	147	42	**47.4x**	2.1%	0.6%
	Nov 1, 2025	🔴**S1**	**Long COVID Heart** *[Annotation of research linking COVID infection to inflammation in organ system, and risk of heart attack, stroke, and Long COVID.]*	11,923	266,085	270	244	**22.3x**	2.3%	2.0%
	Apr 23, 2026	🔴**S1**	**LC Ear** *[Annotation: Long COVID research on ear-related manifestations associated with SARS-CoV-2, including tinnitus, vertigo, and hearing loss.]*	88,702	301,696	1,291	1,738	**3.4x**	1.5%	2.0%
Cat 2:			**Info Utility (Save ÷ Reach)**							
	Sep 29, 2023	🔴**S1**	**NIH: Heart/Plague** *[Annotation of NIH report linking SARS-CoV-2 to plague inflammation inside arteries.]*	42	N/A*	140	0	N/A*	**333.3 %**	0.0%
	Mar 20, 2024	🔴**S1**	**LC Heart** *[Annotation of research linking COVID infection to inflammation in organ system, and risk of heart attack, stroke, and Long COVID.]*	102	N/A*	164	0	N/A*	**160.7 %**	0.0%
	Sep 19, 2024	🟢**S4**	**Dr. Bailey Reel** *[A self-employed doctor/athlete shares why she masks at the gym to prevent Long COVID and its associated conditions.]*	13,106	25,665	338	334	2.0x	**2.6%**	2.5%
Cat 3:			**Dissemination Power (Shares + Reposts) ÷ Reach**							

	Apr 28, 2026	🟢**S4**	**"Drew Empire"** *[A Hip-hop musician shares why they organize mask-required events to protect the community from immune disruption by infections.]*	13,802	30,247	319	618	2.2x	2.3%	**4.5%**
	Apr 23, 2026	🔴**S1**	**LC Ear** *[Annotation: Long COVID research on ear-related manifestations associated with SARS-CoV-2, including tinnitus, vertigo, and hearing loss.]*	88,702	301,696	1,291	1,738	3.4x	1.5%	**2.0%**
	Oct 2, 2024	🟢**S4**	**"Bane" Reel** *[Bodybuilder Bane shares his account of COVID-19 –related illness and loss in his family, highlighting the personal impact of infection.]*	80,971	80,971	1,250	1,606	1.0x	1.5%	**2.0%**

**Data for certain early static posts was unavailable due to platform data retention limits and algorithmic visibility restrictions.*

Key Analytical Takeaways for Supplemental Table 2:

- Annotations make people pay attention: The "LC Eye" and "LC Heart" Annotations had huge View/Reach ratios (47.4x and 22.3x). This suggests that when scientific data explains organ damage, the audience studies the content with repeated viewing.
- Annotations act as a Medical Library: The NIH "Heart/Plaque" post reached only 42 people but got 140 saves (333.3% Information Utility). This demonstrates that Annotations are likely saved and shared as portable medical evidence, even when the platform hides the post.
- The Power of both Annotations and Storytelling: The "Bane" reel (Storytelling) and the "LC Ear" post (Annotations) both earned the same 2.0% share rate. One used a personal story and the other used scientific facts, but both were equally strong at getting the community to share the data. Both the Bane reel and the LC Ear annotation reached over 80K accounts, indicating that both content were promoted by the platform and the community.
- Storytelling for Self-Advocacy: Dr. Bailey's reel (storytelling) had a high save rate (2.6%). This indicates that her story about being "self-employed and unable to afford illness" resonates with others in similar socio-economic positions who prioritize their health.

Supplemental Table 3: Comparing 13 youth and 2 transgender cohort posts that focus on vulnerable communities (🟡Strategy 3)

A total of 15 samples (13 focused on the youth cohort and 2 on the transgender cohort) were evaluated across two separate comparative analyzes. The matrices show which communication strategies (🔴S1, 🟠S2, or 🟢S4) were paired to achieve 🟡Strategy 3 (Inclusive Representation). The technical and ethical rationales for centering these marginalized communities are provided below.

Diversity is MTA's cornerstone. To promote health equity and inclusion, MTA's communication model emphasizes the marginalized cohorts to increase visibility of their struggles for diagnosis and care.

Stigma, Algorithmic Suppression, and Multi-Demographic Barriers

Raising awareness about Long COVID presents profound challenges, particularly the urgent need to battle public stigma and systemic social media censorship of marginalized communities (Vazquez et al., 2023). In June 22, 2022, Meta acknowledged in a document submitted to its Oversight Board regarding modifying its algorithms and content moderation standards to censor pandemic content under governmental pressure, resulting in the systemic suppression of posts regarding COVID-19 mitigations. In response, the board concluded that, "as long as the World Health Organization (WHO) continues to declare COVID-19 an international public health emergency, Meta should maintain its current policy." [1, 2, 3, 4, 5, 6]

In its "*complete set of rules*" regarding what would be censored, it listed COVID-related health practices including "getting tested, social distancing, wearing a face mask, and getting a vaccine for COVID-19." As a result, automated moderation systems flag specific high-risk keywords (e.g., "COVID-19," "Vaccine," "Mask"), drastically downgrading a post's reach and penalizing accounts via "shadowbanning"—silently reducing content visibility without notifying the creator.

In Appendix C (page 21), Meta openly admits that it systematically reduces the distribution (demotes) of vaccine-related content. When Meta's algorithm demotes a post, it launches "Algorithm Suppression" and "Recommendation Blocking." The post is buried at the very bottom of the news feed, meaning that regular followers will almost never see it unless they manually go directly to your profile page. In addition, Meta explicitly bars these posts from appearing in "Suggested for You" feeds, Instagram Explore, or group recommendations. The posts get labeled.

Because Meta's automated keyword systems cannot reliably distinguish context, a regular user sharing an accurate, positive news story about vaccines would often have their post automatically flagged by the system. Once flagged, the post is slapped with a label and quietly demoted by the algorithm.

So while Meta's public stance was that they only "removed" 80 specific dangerous claims, their background algorithmic "demotions" meant that millions of everyday user posts were effectively silenced and prevented from reaching an audience. For the average person trying to share information, an algorithmic demotion functions exactly like censorship because it kills the post's reach completely.

Simultaneously, pervasive medical stigma denies patients equitable access to care across all ages and identities. Women face a 31% higher risk of Long COVID (peaking ages 40–54), but their Long COVID symptoms are frequently dismissed as "psychosomatic" or "hormonal." Conversely, labeling Long COVID as a specialized gender issue discourages men from seeking testing and treatment despite high disease severity. Furthermore, children are often dismissed as unaffected due to low acute mortality rates, even though 2025 JAMA Pediatrics data reveals that

Long COVID has surpassed asthma as the most common chronic illness among U.S. children. Transgender and non-binary individuals remain the most vulnerable demographic, reporting Long COVID at four times the rate of cisgender individuals while facing profound barriers to finding informed providers.

Compounding these issues, social media platforms deploying sensitive content filters to comply with children's online safety laws frequently over-moderate and hide content featuring LGBTQ+ identities and youth. This reliance on silent algorithmic downgrades makes digital advocacy for youth and transgender health unprecedentedly challenging.

To give high-risk and marginalized communities urgently needed support and visibility on this highly censored social media topic, scientific evidence and expert voices are required.

We selected 13 posts that centered on the youth cohort and 2 posts that featured the transgender cohort to compare the effectiveness of different communication strategies including Annotations, Expert-Patient Forums and Storytelling—based on their views, utility and dissemination.

Youth Cohort

Date Published	Strategy	Contributor / Subject	Reach	Total Views	Total Interactions	Likes	Comments	Shares	Reposts	Saves
Nov 8, 2025	**S1, S3**	Pediatric LC Prevalence and Impact On Children	7,358	27,296	941	680	18	173	65	124
Oct 3, 2025	**S1, S3**	Pediatric LC Risk from ReInfection	22,690	65,170	2,628	1,866	38	536	167	345
July 15, 2025	**S1, S3**	LC Associated Conditions in Children	7,521	29,860	1,046	906	26	170	2	145
June 14, 2025	**S1, S3**	Common Pediatric LC Symptoms	5,649	24,901	325	360	0	53	1	68
Sep 2, 2024	**S1, S3**	NJ News on LC Kids Reel	9,213	14,890	1,196	722	21	241	0	212
Sep 6, 2024	**S1, S3**	NBC 4 on LC Kids Reel	6,609	9,673	884	561	22	155	0	146
Dec 2, 2025	**S2, S3**	Ann Wallace, LCK Caretaker and LC Patient	3,279	13,353	370	441	37	46	34	61
Jan 23, 2026	**S2, S3**	Sinead O'Brien_Clean air Ireland	3,090	6,986	287	233	18	30	37	34
Oct 1, 2025	**S2, S3**	Dr. Robi Tamargo on Serious Neuro Outcomes	7,185	17,212	1,115	668	22	279	71	197

Sep 8, 2025	**S2, S3**	Dr. Michael Hoerger sharing LCK's struggles	5,689	5,689	486	385	19	48	33	76
Aug 31, 2025	**S2, S3**	Dr. Robi Tamargo On Neuroinflammation	6,169	12,754	593	452	17	83	25	124
Oct 10, 2023	**S2, S3**	Dr. Robi Tamargo's Insights on Long COVID Kids	51	4,439	410	344	10	0	0	56
Jan 25, 2026	**S4, S3**	"Tina Sugandh & Kids" Reel	75,354	135,898	15,669	10,900	605	2,085	1,400	1,648

Transgender Cohort

Date Published	Strategy	Contributor / Subject	Reach	Total Views	Total Interactions	Likes	Comments	Shares	Reposts	Saves
Feb 18, 2025	**S1, S3**	Long COVID Trans Risk Awareness *[Annotation: Sharing data on why research and guidance on transgender health is critical.]*	20,597	39,553	2,475	1,698	33	553	1	349
July 16, 2025	**S4, S3**	Sirus Bouchat Reel *[Narrative of a transgender acrobatic coach and educator shares why everyone, especially the high risk communities need to take precautions.]*	32,289	76,063	5,193	4,627	183	758	13	585

Analysis of Supplemental Table 3: Youth Cohort (13 samples)

This analysis focuses on how your three strategies—**Annotations, Expert-Patient Forums, and Storytelling**— to address the dismissal of pediatric Long COVID.

Category	Strategy	Date	Subject	Reach	Views	Saves	Sh + Rp	Engagement Value (View/Reach)	Info Utility (Save/Reach)	Dissemination Power [(Sh+Rp)/Reach]
Cat 1:			**Engagement Value (Views ÷ Reach)**							
	🟠🟡 **S2 /S3**	Oct 10, 2023	Dr. Rob Tamargo'si Insights on Long COVID Kids *[Expert Forum: Dr. Robi Tamargo discusses Pediatric Long COVID and challenges viewpoints that attribute symptoms solely to the psychological effects of lockdowns and precautions.]*	51	4,439	56	0	**87.0x**	109.8 %	0.0%

	🔴🟡 **S1/ S3**	June 14, 2025	**Common Pediatric LC Symptoms** *[Annotation: Clinical breakdown of the most frequent Long COVID symptoms found in children.]*	5,649	24,901	68	54	**4.4x**	1.2%	1.0%
	🟠🟡 **S2/ S3**	Nov 8, 2025	**Pediatric LC Prevalence and Impact On Children** *[Annotation: Data regarding the rising prevalence of Long COVID in the pediatric population.]*	7,358	27,296	124	238	**3.7x**	1.7%	3.2%
Cat 2:			**Info Utility (Save ÷ Reach)**							
	🟠🟡 **S2/ S3**	Oct 10, 2023	**Dr. Robi Tamargo's Insights on Long COVID Kids** *[Expert Forum: Dr. Robi Tamargo discusses Pediatric Long COVID and challenges viewpoints that attribute symptoms solely to the psychological effects of lockdowns and precautions.]*	51	4,439	56	0	87.0x	**109.8 %**	0.0%
	🟠🟡 **S2/ S3**	Oct 1, 2025	**Dr. Robi Tamargo on Serious Neuro Outcomes** *[Expert Forum: Dr. Robi Tamargo discusses potential neurological effects of COVID-19 in young people and their implications for prevention awareness.]*	7,185	17,212	197	350	2.4x	**2.7%**	4.9%
	🔴🟡 **S1/ S3**	Sep 2, 2024	**NJ News on LC Kids Reel** *[Annotation: Local news report highlighting the lack of pediatric LC clinics in New Jersey.]*	9,213	14,890	212	241	1.6x	**2.3%**	2.6%
Cat 3:			**Dissemination Power (Shares + Reposts) ÷ Reach**							
	🟠🟡 **S2/ S3**	Oct 1, 2025	**Dr. Robi on Serious Neuro Outcomes** *[Expert Forum: Dr. Robi Tamargo discusses potential neurological effects of COVID-19 in young people and their implications for prevention awareness.]*	7,185	17,212	197	350	2.4x	2.7%	**4.9%**
	🟢🟡 **S4/ S3**	Jan 25, 2026	**"Tina Sugandh & Kids" Reel** *[Feature: Taekwondoin Tina Sugandh and her black belt kids share practical tips for competing in masks and explain why pediatric Long COVID awareness is so urgent.]*	75,354	135,898	1,648	3,485	1.8x	2.2%	**4.6%**

	🔴🟡 **S1/ S3**	Oct 3, 2025	**Pediatric LC Risk from ReInfection** *[Annotation: Study highlighting how repeated infections increase the risk of Long COVID in children.]*	22,690	65,170	345	703	2.9x	1.5%	**3.1%**

**Sh + Rp = Shares + Reposts combined.*
***Data for certain early static posts was unavailable due to platform data retention limits and algorithmic visibility restrictions.*

Key Analytical Takeaways for Youth Cohort:

- Expert-Patient Forums (🟠Strategy 2), targeting youth (🟡Strategy 3) provide the highest educational value: The Expert-Patient Forum featuring Dr. Robi Tamargo (Oct 10, 2023) shows the highest Engagement Value (87.0x). Even when reach was extremely suppressed (only 51 people), the content was watched thousands of times. This suggests that the audience study expert videos repeatedly potentially to understand the risks to their children.
- Annotations (🔴Strategy 1) that target the youth cohort (🟡Strategy 3) act as a "Fact Shield" for parents: Annotations like Pediatric Prevalence and Common Pediatric Symptoms provide high Information Utility. This suggests that caregivers use these facts as portable medical evidence to fight the common stigma that "children are not affected by COVID."
- Storytelling (🟢Strategy 1) made for a youth audience (🟡Strategy 3) breaks through visibility barriers: The Tina Sugandh & Kids reel reached over 75,000 people. While Annotations and Expert Forums provide the facts, Storytelling is the strategy that successfully drives mass visibility for the youth cohort, bypassing algorithmic suppression through high Dissemination Power (4.6%). The reel showing Tina and her three martial artist children competing in their masks and talking about strategies to protect themselves from Long COVID earned over 75K reach, validating the power of creativity and entertainment values.

Analysis of Supplemental Table 3: Transgender Cohort (2 samples)

This demographic is particularly significant as they report Long COVID at four times the rate of cisgender individuals while facing unique "sensitive content" algorithmic filters. This analysis of the Transgender Cohort (Strategy 3) highlights how Annotations (Strategy 1) and Storytelling (Strategy 4) are used as targeted tools to validate the highest-risk demographic and overcome digital barriers.

Category	Strategy	Date	Subject	Reach	Views	Saves	Sh + Rp	Engagement Value (View/Reach)	Info Utility (Save/Reach)	Dissemination Power [(Sh+Rp)/ Reach)
Cat 1: Views	🟢🟡 **S4/ S3**	July 16, 2025	**Sirus Bouchat Reel** *[Narrative of a transgender acrobatic*	32,289	76,063	585	771	2.4x	1.8%	2.4%

			coach and educator shares why everyone, especially the high risk communities need to take precautions.]							
Cat 2: Utility	🟢🟡 **S4/ S3**	July 16, 2025	**Sirus Bouchat Reel**	32,289	76,063	585	771	2.4x	1.8%	2.4%
Cat 3: Power	🔴🟡 **S1/ S3**	Feb 18, 2025	**Long COVID Trans Risk Awareness** *[Annotation: Sharing data on why research and guidance on transgender health is critical.]*	20,597	39,553	349	554	1.9x	1.7%	2.7%

Key Analytical Takeaways for Transgender Cohort

- Annotations drive community power: The Long COVID Trans Risk Awareness annotation (🔴Strategy 1) achieved the highest Dissemination Power (2.7%) in the transgender cohort. This suggests that when scientific data validates the unique risks of the transgender community, users are highly motivated to share the content to ensure it bypasses "sensitive content" filters.
- Storytelling creates sustained interest: The reel featuring Sirus Bouchat (🟢Strategy 4) earned higher Engagement Value (2.4x) and Information Utility (1.8%). This indicates that personal narratives from a transgender educator help viewers connect with the content, leading them to watch the video repeatedly and save it as a reference.
- Targeting for Equity: Despite systemic censorship of LGBTQ+ content on social media, both strategies maintained strong performance. This shows that **inclusive representation** (🟡Strategy 3), connecting with the target audience, is an essential strategy for reaching vulnerable groups who are otherwise neglected by standard public health outreach.
- The finding indicates that even for a group facing the "double barrier" of pandemic censorship and sensitive content filters, the community of the targeted audience still managed to drive a high rate of sharing to ensure the data reached more people.

Supplemental Table 4: Comparing 18 posts focused on increasing MTA's credibility and community mobilization (🔵Strategy 5)

This matrix analyzes the role of Strategy 5 (Mobilization) within the multi-pronged communication model across 18 selected posts.

Date Published	Strategy	Contributor / Subject	Results	Reach	Total Views	Total Interactions	Likes	Comments	Shares	Reposts	Saves

Feb 21, 2026	S5	Right to Mask in IL	Right to Mask in Illinois passed the Senate	7,648	26,074	721	664	36	79	94	69
April 27, 2026	S5	Fight for Airborne Act	3,789 letters sent. https://admin.actionnetwork.org/petitions/petition-for-nyc-to-recognize-international-long-covid-awareness-day/manage	2,261	6,759	193	181	12	17	30	18
April 15, 2025	S5	Fight for Our Right to Mask	9 organizational co-sponsorship. 12,282 letters sent to government officials. https://admin.actionnetwork.org/letters/stop-mask-bans-defend-our-human-right-to-mask-protection/manage	5,660	12,471	792	780	17	119	0	44
Dec 5, 2024	S5	Meeting with the CDC	During a meeting with the CDC in August 2024, Pan End It!, MaskTogetherAmerica, and Long COVID Justice outlined critical steps to protect the health of high-risk Americans, resulted in the CDC promoting the layered approach for prevention against respiratory infections. A post shared on the CDC's social media on 17 October aims to promote the layered approach, emphasizing preventive strategies including using a mask, cleaning the air, and immunization.	3,081	9,534	333	328	5	29	0	25
June 20, 2024	S5	Test to Treat Campaign	A letter sent to former NIH Director Dr. Monica Bertagnolli to urge the government to ensure free COVID-10 testing and treatment was cosponsored by 36 public health advocacy organizations.	8,162	N/A	629	522	22	53	0	64
Mar 15, 2026	S5	LC Awareness Day	We highlighted the impact COVID continues to have on all people including children, contributing to est. 400 million LC cases and growing on Long COVID Awareness Day.	15,455	33,009	1,499	1,009	10	313	168	109
Mar 10, 2026	S5	Niagara Falls Lighting	We wrote to Governor Hochul, as a result, New York State lit up the Niagara Falls to recognize the International Long COVID Awareness Day.	9,156	26,605	1,134	976	24	128	87	63
Mar 9, 2026	S5	Light Up NYC Petition	Our petition to urge NYC Mayor to recognize Long COVID Day earned 526 signatures and 21 organizational sponsorships https://admin.actionnetwork.org/petitions/petition-for-nyc-to-recognize-international-long-covid-awareness-day/manage	1,739	7,624	149	208	26	12	19	8
Jan 4, 2026	S5	Light Up LA	Our support for Clean Air LA in getting signers for their petition resulted in the City of Los Angeles officially recognizing International Long COVID Awareness Day.	4,607	13,432	503	409	23	56	55	33
Mar 29, 2026	S5	B.A.3.2 Variant Report	B.A.3.2 (Cicada) may cause Syncope (Fainting). Data reporting saves lives.	57,867	153,686	7,112	4,396	102	1,323	691	1,052
Jan 5, 2026	S5	Dec 27 2025 Data Report	Data reporting saves lives. Super Flu Week 52 (ending Dec 27, 2025) report	17,076	343,714	1,307	1,693	372	354	95	143
Feb 8, 2025	S5	Feb 2025 Data Report	US Schools are closing amid an intense wave of Flu, COVID, RSV & Noro Feb, 2025. Data reporting saves lives.	28,389	118,521	2,847	2,249	204	890	0	286
Aug 16, 2025	S5	Swiss Cheese Defense	Our Long COVID Defense Guidance has been widely adopted by the public health advocacy community.	29,805	119,232	3,998	2,806	81	579	150	947
Mar 6, 2025	S5	LC Health Justice Toolkit	MaskTogetherAmerica provides letter templates for the high-risk community and their allies to advocate for funding Long COVID research & awareness, Telehealth, Medicaid, Equity & Accessibility Rights, Prevention Tools, and Federal Aid.	2,019	7,986	145	194	17	19	0	9
May 20, 2025	S5	Access Healthcare Barriers Poll	171 people responded to Long COVID Health Justice Poll conducted on March 15, 2025. We learned that LC patients are struggling to get care in the U.S. http://masktogetherамerica.org/blog/long-covid-health-justice-poll-march-15-2025	6,248	34,774	504	548	27	35	1	56
Mar 4, 2024	S5	Cure ID	We promote CURE ID so more patients and health care providers will participate in the online survey on drug repurposing efforts.	166	N/A	131	140	5	0	0	18
Mar 15, 2024	S5	Long COVID March	MaskTogetherAmerica team members and advisors joined as speakers at the Long COVID March to raise awareness about prevention.	404	N/A	869	928	52		0	50
June 29, 2025	S5	Pride Health Fair	Distributed masks at the Pride March to support the vulnerable communities.	4,754	23,972	1,044	1,305	44	42	0	20

March 22	**S5, S4**	Karina tells NYC to recognize LC	Narrative of Long Hauler Karina shares her grievances that NYC mayor's office refuses to recognize Long COVID through lighting the city hall in teal.	15,255	60,142	3,499	3,622	73	194	153	243

Analysis of Supplemental Table 4: Strategy 5 (Mobilization)

This final analysis of Supplemental Table 4 evaluates Strategy 5 (Mobilization). This strategy acts as the **"ignition"** of MTA's grassroots digital communication model for Long COVID public health and prevention. Strategy 5 mobilizes the community to turn the knowledge from Annotations and the empathy from Storytelling into collective action.

Category	Date	Strategy	Subject	Reach	Views	Saves	Sh + Rp	Engagement Value (View/Reach)	Info Utility (Save/ Reach)	Dissemination Power [(Sh+Rp)/Reach]
Cat 1:			**Engagement Value (Views ÷ Reach)**							
	Jan 5, 2026	🔵 **S5**	Dec 2025 Data Report	17,076	343,714	143	449	**20.1x**	0.8%	2.6%
	May 20, 2025	🔵 **S5**	Access Healthcare Barriers Poll	6,248	34,774	56	36	**5.6x**	0.9%	0.6%
	Feb 8, 2025	🔵 **S5**	Feb 2025 Data Report	28,389	118,521	286	890	**4.2x**	1.0%	3.1%
Cat 2:			**Info Utility (Save ÷ Reach)**							
	Mar 22, 2026	🔵🟢 **S5/S4**	Karina tells NYC to recognize LC	15,255	60,142	243	347	3.9x	**1.6%**	2.3%
	Aug 16, 2025	🔵 **S5**	Swiss Cheese Defense	29,805	119,232	947	729	4.0x	**3.2%**	2.4%
	Feb 21, 2026	🔵 **S5**	Right to Mask in IL	7,648	26,074	69	173	3.4x	**0.9%**	2.3%
Cat 3:			**Dissemination Power (Shares + Reposts) ÷ Reach**							
	Mar 29, 2026	🔵 **S5**	B.A.3.2 Variant Report	57,867	153,686	1,052	2,014	2.7x	1.8%	**3.5%**
	Mar 15, 2026	🔵 **S5**	LC Awareness Day	15,455	33,009	109	481	2.1x	0.7%	**3.1%**

	Feb 8, 2025	🔵 **S5**	**Feb 2025 Data Report**	28,389	118,521	286	890	4.2x	1.0%	**3.1%**

**Sh + Rp = Shares + Reposts combined.*
***Data for certain early static posts was unavailable due to platform data retention limits and algorithmic visibility restrictions.*

Key Analytical Takeaways for Strategy 5

- **Mobilization of Prevention:** The Dec 2025 Data Report achieved a massive 20.12x Engagement Value. The high view frequency suggests that during high-risk periods (like "Super Flu" weeks), the community repeatedly returns to MTA's report to track regional risks, establishing the foundation for collective action.
- **Mobilization through Storytelling:** The narrative interview featuring MaskTogetherAmerica coordinator Karina Halevy regarding the NYC Mayor's office achieved high utility and significant saves. Her disappointment at the city's rejection of the petition to recognize International Long COVID Awareness Day served as a rallying cry, illustrating how a single person's grievance can become portable medical evidence of government neglect and drive community-led advocacy.
- **Mobilization through Setting Guidance:** The Swiss Cheese Long COVID Defense guidance toolkit earned nearly 1,000 saves. This indicates that the public health community treats MTA's mobilization toolkits as essential reference material for organizing and protecting their own local groups.
- **Mobilization to Drive Support and Visibility:** The B.A.3.2 Variant Report and Long COVID Awareness Day activities saw the highest dissemination rates. This suggests that when information is tied to a specific call-to-action—like reporting a new variant or supporting a mask ban defense—the community acts as a reliable distribution engine to influence policy.
- **Mobilization to Drive Change:** Strategy 5 (Civic Mobilization) turns information into real-world action, driving policy changes and research funding, preserving the right to prevent infection, increasing global recognition of Long COVID, and helping make this "invisible" disability visible to the public and policymakers.

Results: Diverse Strategic Outcomes

Posts exhibited distinct performance patterns. While certain assets achieved broad public exposure, others generated high view or save rates relative to smaller, targeted audiences. Synthesizing these metrics provides a comprehensive evaluation of MTA's model.

(Note: To preserve data integrity, post selection accounted for Meta dashboard constraints by excluding assets missing critical metric data.)

Supplemental Table 5: Examples of High Raw Metrics

Selected posts illustrate strong performance across views, reach, and interactions.

High in Raw Metrics	Date	Strategy	Context & Educational Impact	Strategic Outcome
🏆 Top Views	Jan 5, 2026	🔵S5	"Dec 27 2025 Data Report" Infographic: Respiratory surveillance data for Dec 21-27, 2025—raising awareness of current illness trends and prevention.	👑**343,714** Total Views • 17,076 Unique Reach • **20.12x** Engagement Value • 0.84% Info Utility • 2.63% Dissemination Power
🏆 Top Reach	Apr 23, 2026	🔴S1	"LC Ear" Annotation: Long COVID research on ear-related manifestations associated with SARS-CoV-2, including tinnitus, vertigo, and hearing loss.	👑**88,702** Unique Reach • **301,696** Total Views • 1,291 Total Saves • **3.40x** Engagement Value • 1.46% Info Utility • 1.96% Dissemination Power
🏆 Top Interactions	Jan 25, 2026	🟢🟡 S4 / S3	"Tina Sugandh & Kids" Reel Feature: Taekwondoin Tina Sugandh and her black belt kids share practical tips for competing in masks and explain why pediatric Long COVID awareness is so urgent.	👑**15,669** Total Interactions 🥉**4.62%** Dissemination Power • **75,354** Unique Reach • **135,898** Total Views • 1,648 Total Saves • 1.80**x** Engagement Value • 2.19% Info Utility
🏆Top Storytelling	Oct 2, 2024	🟢S4	"Bane" Reel Feature: Bodybuilder Bane recalls the devastating impact of COVID-19–related illness and loss in his family, sharing a powerful, personal appeal for prevention.	👑**80,971** Unique Reach • **80,971** Total Views • **11,742** Total Interactions • 1,250 Total Saves • **1.00x** Engagement Value • 1.54% Info Utility • 1.98% Dissemination Power

Supplemental Table 6: Examples of Strong Ratioed Metrics

This matrix isolates top examples across Engagement Value, Information Utility, and Dissemination Power to illustrate why content filtering must be factored in when assessing communication effectiveness. Engagement relative to reach reveals distinct patterns shaped by dissemination barriers and a misinformation ecosystem that restricts data visibility.

Ratioed Metric Category	Date	Strategy	Context & Educational Impact	Strategic Outcome
💟High Engagement Value 🍎High Info Utility	Oct 10, 2023	🟠🟡 S2 / S3	"Dr. Robi Tamargo's Insights on Long COVID Kids" Expert Forum: Dr. Robi Tamargo discusses Pediatric Long COVID and challenges viewpoints that attribute symptoms solely to the	🥇**87.04x Engagement Value** 🥇**109.8% Info Utility** • 51 Unique Reach • 4,439 Total Views • 56 Total Saves • 0% Dissemination Power

			psychological effects of lockdowns and precautions.	
💟High Engagement Value	Dec 4, 2025	🔴S1	**"Irish Farmers Journal: More that 200 LC Symptoms"** Annotation: An *Irish Farmers Journal* article by Rosalind Skillen highlights that Long COVID encompasses more than 200 symptoms, underscoring its capacity to shatter human lives.	🥈 **50x Engagement Value** • 3,466 Unique Reach • 173,240 Total Views • 52 Total Saves • 1.50 % Info Utility • 3.03 % Dissemination Power
💟High Engagement Value	Apr 20, 2026	🔴S1	**"LC Eye"** Annotation: Long COVID research on ocular manifestations associated with SARS-CoV-2 drawing attention to symptoms and effects that may be overlooked.	🥉 **47.45x Engagement Value** • 6,924 Unique Reach • 328,577 Total Views • 147 Total Saves • 2.12 % Info Utility • 1.46 % Dissemination Power
🍎High Info Utility	Apr 28, 2024	🟠S2	**"Dr. Akiko Iwasaki (Prevent LC)"** Expert Forum: Yale Prof. Akiko Iwasaki discusses possible Long COVID root causes and the need for a layered approach to prevention.	🥈 **23.81% Info Utility** • 1264 Unique Reach • 301 Total Saves • 16,471 Total Views • 13.03**x** Engagement Value • 1.11% Dissemination Power
🍎High Info Utility	Oct 9, 2023	🟠S2	**"Dr. Angelique Corthals: Viral Reservoir"** Expert Forum: CUNY Assoc. Prof. Dr. Angelique Corthals explains how cellular persistence of SARS-CoV-2 drives viral reinfection and transmission.	🥉 **22.18% Info Utility** • 595 Unique Reach • 132 Total Saves • 6771 Total Views • 11.38**x** Engagement Value • 3.03% Dissemination Power
🍎High Info Utility	Aug 16, 2025	🔵S5	**"Swiss Cheese Defense Guidance Toolkit"** Infographic: Layered prevention strategies designed to support community education.	👍**3.18% Info Utility** • 29,805 Unique Reach • 947 Total Saves • 119,232 Total Views • 4.00**x** Engagement Value • 2.45% Dissemination Power
⭐High Dissemination Power	Oct 1, 2025	🟠🟡 S2 / S3	**"Dr. Robi on Serious Neuro Outcomes (Youth)"** Expert Forum: Dr. Robi Tamargo discusses potential neurological effects of COVID-19 in young people and their implications for prevention awareness.	🥉 **4.87% Dissemination Power** • 7,185 Unique Reach • 17,212 Total Views • 350 Total Shares/Reposts • 2.4**x** Engagement Value

⭐High Dissemination Power	Apr 28, 2026	🟢S4	"Drew Empire" Reel Feature: Hip-hop musician Drew Empire shares his rationale for organizing mask-required events, emphasizing community protection against infection-induced immune dysregulation.	🥉**4.48% Dissemination Power** • 13,802 Unique Reach • 30,247 Total Views • 618 Total Shares/Reposts • 2.19**x** Engagement Value • 2.31% Info Utility

Supplemental Table 7: Cross-Platform Performance Metrics (Jan 1 – May 18, 2026)

To contextualize the 93-sample analysis, this table summarizes Facebook and Instagram performance metrics derived from the Meta dashboard. Total follower counts reflect lifetime cumulative data as of May 18, 2026, while views, reach, and content interactions represent accumulated activity between January 1, 2026 and May 18, 2026.

Metric	Instagram	Facebook	Total (2 Platforms)
Total Lifetime Followers	18,294	17,740	36,034
Total Views	6.4 Million	4.6 Million	11 Million
Organic Reach	475,000	1.5 Million+	1.975 Million
Content Interactions	150,800	94,000	244,800
Paid Ad Spend	$0	$0	$0

Key Analytical Takeaways for Cross-Platform Performance:

- **Deep Audience Immersion:** On Instagram, a **13.03x Engagement Value** confirms that users repeatedly return to the content to study the data. On Facebook, users accumulated **over 54 days of cumulative watch time** in under five months, demonstrating the platform's role as a primary educational resource.
- **Strategic Distribution Dynamics:** While Instagram serves as an informational repository, Facebook functions as the primary dissemination engine—achieving an organic reach of over **1.5 million users** with a **37.4% growth rate** during this period.

Demographic & Geographic Analysis (Inclusive Representation)

- **Female Majority & Clinical Correlation:** The audience across both platforms is overwhelmingly female (**80.8% on Instagram and 81.6% on Facebook**). This demographic profile strongly correlates with clinical literature indicating that women face a disproportionately higher risk of developing Long COVID.

- **Working-Age Concentration:** The primary age demographic across both platforms is **35–44 years old** (approx. 22–27%), followed closely by the **45–54 bracket on Facebook** (approx. 21%). These cohorts represent the demographic most vulnerable to the clinical, professional, and socioeconomic consequences of Long COVID.
- **Geographic Footprint:** While the United States remains the primary audience base (~82%), MTA maintains a global footprint, reaching patients and advocates across the UK, Canada, Australia, Germany, France, India, Argentina, Spain, New Zealand, the Netherlands, Sweden, Ireland, and beyond.

(*Note on Data Consistency: Individual metrics for the 93-sample dataset were collected and frozen on **May 16, 2026**. Cumulative cross-platform performance, follower counts, and global demographic data reflect metrics extracted from the Meta dashboard on **May 18, 2026**, with time-bound growth and reach metrics covering the active window of January 1 – May 18, 2026.*)

Conclusion

As of May 18, 2026, MaskTogetherAmerica achieved a combined follower count of 36,034 and approximately 11 million organic views accumulated since January 1, 2026, across Instagram and Facebook. These findings suggest that integrated, community-led communication may support Long COVID public health engagement and prevention awareness. Further research is warranted to assess the model's scalability and its effect on self-advocacy and prevention behavior.

Link to Supplemental Table Data:

MTA-Study_Supplemental_Table_Metrics.xlsx

Link to Raw Metric Data:

MTA_IG_raw_metrics_April20-May26.xlsx

Note on Raw Metrics:

This dataset comprises the cumulative tracking metrics of 4,545 assets published on the MaskTogetherAmerica Instagram platform between April 5, 2020, and May 31, 2026, alongside cross-shared Facebook data captured since January 2, 2024. Data extraction was conducted manually via post-level native dashboards on Instagram between May 15, 2026, and August 23, 2026. Because metrics dynamically compound in real-time on live social networks, this dataset represents a frozen baseline snapshot of available dashboard values at the designated times of manual extraction.

Taxonomy & Coding Framework

- **Core Content Strategies:**
  - **Strategy 0:** Documentary Photography or Film (Original assets by Julie Lam)
  - **Strategy 0, 4:** Combined Narrative Interview and Documentary Photography
  - **Strategy 1:** Scientific Annotations (Peer-reviewed literature translation)
  - **Strategy 2:** Expert-Patient Forums (Virtual stakeholder discussions)
  - **Strategy 3:** Targeted Awareness against Marginalized Long COVID Cohort Stigma
  - **Strategy 4:** Narrative & Storytelling (Individual lived experiences)

- **Strategy 5:** Mobilization, Branding, Tactical Toolkits, and Civic Action
- **Strategy 6:** Special Event Programming
- **Demographic Identifiers:**
- **Y:** Youth / Pediatric Cohorts
- **P.O.C.:** People of Color / Minoritized Groups
- **Feature:** Individual features authorized via direct personal communication (verbal, email, or institutional social messaging permissions).
- **Composite Calculation Model:**
- **Total Interactions:** Evaluated as a cross-platform aggregate consisting of Instagram Post Interactions (cumulative likes, comments, saves, and shares as native to the platform dashboard) combined with Facebook reactions and comments.

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