Community-Driven Survival Analysis of Penile Implant Outcomes: A 15-Year Retrospective Study of Online Forum Data

principles (FrankTalk.org community member)

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Introduction

Background

I am a member of FrankTalk.org, the largest English-language online community for men with erectile dysfunction, with particular focus on penile prostheses. Over years of participating in the Implants subforum, I noticed a recurring theme: skepticism toward published revision rates.

Forum veterans often expressed a sentiment that "the numbers don't match reality." Users would point to their own experiences—friends who had revisions, multiple posts documenting failures within the first year, and a general sense that manufacturer-reported survival rates of 95%+ at 5 years seemed disconnected from the lived experience of the community. This disconnect bred mistrust of both device manufacturers and the published literature.

The published data do have limitations. Most studies originate from single-center retrospectives or industry-sponsored registries with median follow-up of 3-5 years. Patients lost to follow-up are typically censored as "survived," yet those who experience complications may seek care elsewhere, never returning to the original surgeon. Publication lag means that devices implanted in 2015 appear in papers published in 2022, reflecting outdated surgical techniques and older device generations. Selection bias is inherent: high-volume academic centers publishing in prestigious journals may not represent the broader landscape of community urologists performing 10-20 implants per year.

But forum perceptions can be equally biased. Users experiencing complications are more likely to post frequently, creating an availability heuristic that overrepresents negative outcomes. The question remained: **What would the actual data show if we systematically analyzed what forum users themselves are reporting?**

I decided to investigate. FrankTalk.org users document their implant journeys in persistent signature files visible across all their posts. These signatures serve as informal medical timelines: "Titan 01/20, revised 08/22 for mechanical failure, Titan 09/22 ongoing." Thousands of users have maintained these signatures since the forum's inception around 2010, creating an unintentional longitudinal dataset spanning 15 years.

This study represents my attempt to answer the forum's question with the forum's own data: Are the published numbers misleading, or are community perceptions skewed by negativity bias?

Methodological Rationale

Online patient communities offer distinct advantages over traditional clinical follow-up. Unlike clinic-based studies that depend on patients returning to the original surgeon, online forums capture longitudinal

outcomes from geographically diverse populations with varying levels of medical engagement. Patients who experience complications and seek care elsewhere—a common source of censoring bias in single-center studies—often remain active forum participants and continue updating their signatures.

Forum data introduces its own biases: selection toward tech-savvy users, overrepresentation of complications (users seeking support), and incomplete medical detail. However, aggregating thousands of self-reported timelines may produce population-level estimates that complement—rather than replace—traditional research. This study tests that hypothesis by comparing forum-derived survival curves to the published clinical literature.

Study Objectives

I sought to determine whether systematic analysis of user signatures from FrankTalk.org could:

1. Provide reliable estimates of all-cause revision rates and device survival for modern penile prostheses
2. Generate Kaplan-Meier survival curves comparable to published clinical literature
3. Identify differences in survival across major device manufacturers and models
4. Validate the use of online forum data as a proxy for real-world outcomes research

This study represents, to my knowledge, the largest community-driven analysis of penile implant outcomes and the first to apply rigorous survival analysis methods to forum-sourced data.

Methods

Data Source and Collection

Web Scraping

I developed a custom Python-based web scraper specifically designed for the phpBB forum software used by FrankTalk.org. The scraper targeted the Implants subforum (forum ID 6) and executed the following protocol:

- **Temporal scope:** All threads from forum inception (~2010) through November 12, 2025
- **Scraping method:** Multi-threaded concurrent requests (up to 16 parallel threads) with exponential backoff retry logic
- **Rate limiting:** Compliant with robots.txt; implemented intelligent request throttling to minimize server load
- **Data captured:** Thread metadata, post content, post timestamps, and user signature text
- **Update detection:** Implemented smart differential scraping to identify threads with new posts, avoiding redundant full-thread rescans

The scraper ultimately processed approximately 15,000 threads containing hundreds of thousands of individual posts and extracted 1,639 unique user signatures containing implant-related information.

Signature Extraction and Deduplication

User signatures in phpBB forums persist across all posts by that user. I extracted signature text from each post and implemented hash-based deduplication to retain only the most recent signature per user. If a user updated their signature across multiple posts (e.g., after a revision), I retained the chronologically latest version based on post timestamps.

Data Processing and Extraction

Large Language Model (LLM) Validation

Manual parsing of 1,639 free-text signatures would be time-prohibitive and error-prone. I employed large language models (LLMs) for structured data extraction with the following protocol:

Primary extraction (OpenAI GPT-5): - Signatures processed in batches of 10 - Custom prompt engineering specifying exact extraction rules - Focus on completed procedures only (excluding planned or consultative mentions) - Extraction of: user identifier, procedure date(s), device model(s), and temporal sequence

Dual verification (Anthropic Claude Sonnet 4.5): - Independent re-analysis of all extracted records by a second LLM from a different provider - Cross-validation to identify discrepancies - Manual review of flagged cases for final adjudication

Disclaimer regarding LLM-related errors: Even with two independent LLM passes and human adjudication, occasional extraction errors (e.g., swapped months, mis-typed device names, or incorrectly parsed dates) almost certainly persist in individual records. Large language models can hallucinate, misinterpret ambiguous text, or make systematic parsing errors. I treated the output as best-effort community data with inevitable noise, then validated aggregate revision rates against published clinical series. The close match to Miller et al. (2022) at all time points (within 1-3%) indicates that any residual LLM-related errors do not materially affect population-level survival estimates, though individual entries may contain inaccuracies. This convergence suggests that random LLM errors average out at scale, but readers should interpret specific case-level data with appropriate caution.

Inclusion and Exclusion Criteria

Included procedures: - Penile prosthesis implantation (inflatable or malleable) - Revision surgeries (any cause: mechanical failure, infection, malposition, erosion, or elective upgrade) - Procedures with identifiable dates (at minimum, month and year)

Excluded mentions: - Future planned procedures (“scheduled for April 2026”) - Non-implant procedures (prostatectomy, Peyronie’s surgery, injection therapy) - Consultations without confirmed procedures - Ambiguous signatures lacking temporal information

Device Normalization

Device names were normalized according to the following schema:

- **Titan**: All Coloplast Titan variants (Titan, Titan Touch, Titan OTR, Titan XL, Titan Narrow)
- **LGX**: AMS 700 LGX when explicitly stated
- **CX**: AMS 700 CX and CXR variants
- **700**: Generic AMS 700 when subtype not specified
- **Genesis**: Coloplast Genesis malleable
- **Tactra**: Coloplast Tactra malleable
- **Rigi10**: Rigicon Rigi10 malleable (all variants)

- **Infla10X, Infla10AX**: Rigicon inflatables with specified model
- **Infla10**: Generic Rigicon inflatable when model not specified
- **others**: Uncommon devices (e.g., AMS 600, AMS Ambicor)
- **unknown**: Implant confirmed but specific device not documented

Date Normalization and Time-to-Revision Calculation

Dates were extracted from free-text signatures in various formats (e.g., "August 2020," "8/20," "2020-08") and normalized to MM/YY format. For year-only dates, January was assumed as the reference month.

Time to Revision (TTR) was calculated as:

$$TTR_{months} = (Year_{revision} - Year_{implant}) \times 12 + (Month_{revision} - Month_{implant})$$

Two-digit years were pivoted around 1950-2049 (years 50-99 = 1950-1999; 00-49 = 2000-2049).

For users with multiple documented procedures, each implant-to-revision interval was treated as an independent observation. The most recent procedure in each signature had unknown TTR and was treated as right-censored at the data cutoff date (November 12, 2025).

Ongoing duration for unrevised implants was calculated as time from procedure date to data cutoff.

Statistical Analysis

Survival Analysis Methods

I employed Kaplan-Meier product-limit estimation to calculate revision-free survival probabilities. The Kaplan-Meier estimator is appropriate for time-to-event data with censoring and does not assume any particular failure distribution.

Primary outcome: Time to revision for any cause (all-cause TTR)

Censoring: Implants without documented revision were right-censored at the data cutoff date. I assumed non-informative censoring—i.e., the probability of being censored is independent of the probability of future revision.

Event definition: Any documented second procedure following the index implantation, regardless of cause (mechanical failure, infection, erosion, malposition, cosmetic revision).

I calculated: - Overall survival function S(t) = probability of remaining revision-free at time t - Survival probabilities at clinically relevant time points (1, 3, 5, 10 years) - 95% confidence intervals using Greenwood's formula - Median TTR for revised cases

Device-specific analyses were stratified by normalized device type. I did not perform formal statistical comparisons (e.g., log-rank tests) between devices, as this was a descriptive study without hypothesis testing.

All analyses were conducted in Python 3.13.5 using: - `lifelines` (v0.30.0) for Kaplan-Meier estimation - `pandas` (v2.3.0) for data manipulation - `matplotlib` (v3.10.3) and `seaborn` (v0.13.2) for visualization

Comparison to Published Literature

I compared these survival estimates to the most comprehensive published meta-analysis (Miller et al., 2022, *Urology*) which pooled 12 studies encompassing 20,161 patients. I also compared device-specific mechanical failure rates to relevant clinical studies.

Limitations and Bias Considerations

Signature-based proxy methodology: I analyzed signatures, not full thread content. Users who document outcomes in posts but not signatures would be missed.

Selection bias: Forum users may not represent the general implant population. Patients with complications may be more likely to join and post.

Reporting bias: Users may be more likely to update signatures after complications than after uncomplicated courses.

Signature currency: Some users may cease forum participation without documenting late complications.

All-cause revision definition: The primary outcome includes infections, erosions, and malpositions in addition to mechanical device failure. This differs from studies reporting mechanical failure rates alone.

Follow-up truncation: Recent implants contribute limited person-time at risk, widening confidence intervals for long-term estimates.

I did not adjust for these biases statistically but discuss their likely impact on interpretation.

Ethical Considerations

All analyzed data were publicly posted by users to a public forum. No protected health information was collected. Usernames were retained for data quality purposes but are not reported in this manuscript. This study did not require institutional review board approval as it analyzed de-identified publicly available data.

Results

Dataset Characteristics

Overall Cohort

From 15,000 scraped threads, I identified **1,639 unique user signatures** containing implant-related information. After LLM-based validation and dual verification:

- **1,255 signatures** (76.6%) contained sufficient information for survival analysis
    - Clear documentation of completed penile prosthesis procedure
    - Identifiable procedure date (minimum: month and year)
    - Device information (specific model or generic category)
- **384 signatures** (23.4%) were excluded:
    - **320** mentioned planned but not completed procedures
    - **64** documented procedures but lacked extractable dates

Patient-Level Analysis: Unique Users vs. Implants

The 1,255 implant procedures corresponded to **1,056 distinct patients** (unique forum user accounts). This distinction is critical for understanding the data structure and independence assumptions underlying the survival analysis, as some users documented multiple revisions in their signatures.

Distribution of documented revisions per user:

- **910 users (86.2%)** had **0 revisions** (primary implant only, no documented revision)
- **115 users (10.9%)** had **1 revision** (one documented revision surgery)
- **18 users (1.7%)** had **2 revisions**
- **5 users (0.5%)** had **3 revisions**
- **7 users (0.7%)** had **4 revisions**
- **1 user (0.1%)** had **5 revisions** (maximum observed)

In total, **146 users (13.8%)** documented at least one revision surgery during their time on the forum, while the vast majority (86.2%) documented only their primary implant without subsequent revision.

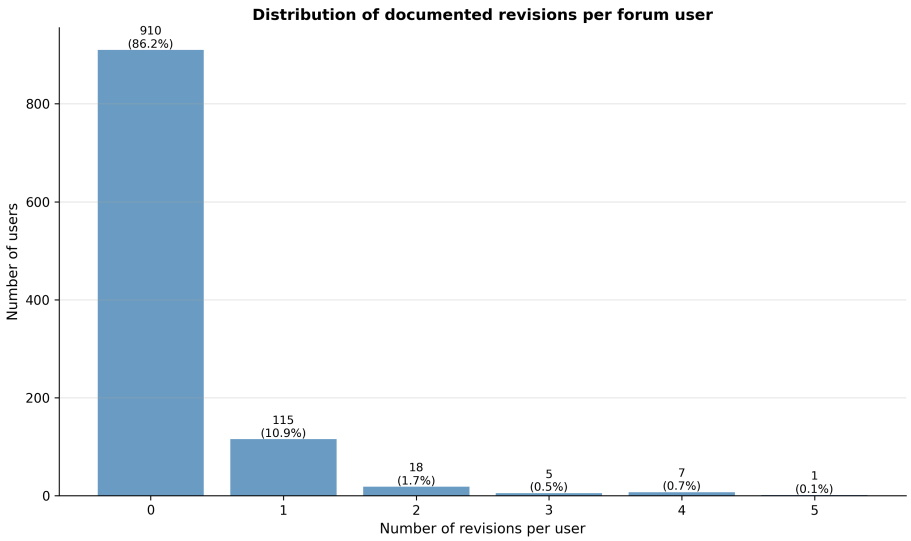

Figure 1. Distribution of documented revisions per forum user. Bar chart showing the number and percentage of users stratified by number of revisions. The majority of users (86.2%) documented no revisions, while progressively smaller proportions documented 1, 2, 3, 4, or 5 revisions. This distribution provides transparency about data independence and ensures no single patient dominates the dataset.

Implant-level summary: The 1,056 users contributed a total of **1,255 implant procedures** (including both primary implants and revisions). This represents **199 revision surgeries** performed in total (1,255 total implants − 1,056 primary implants = 199 revisions).

Methodological note on independence: For users with multiple documented procedures, each implant-to-revision interval was treated as an independent observation in the survival analysis. This approach assumes that the probability of one implant requiring revision does not systematically alter the hazard of subsequent implant revision (beyond measured covariates like time and device type). While this assumption is common in device surveillance studies, readers should note that unobserved patient-level factors (anatomy, surgical technique, immune response) could introduce correlation between successive implants in the same individual. The relatively small percentage of users with multiple revisions (13.8% total, with only 3.0% having ≥2 revisions) suggests that any such correlation does not dominate the dataset, and most survival information comes from primary implants in unique patients.

Implant-Level Outcomes

Of the 1,255 documented implant procedures:

- **162 implants (12.9%)** required revision and were replaced during the observation period

- **1,029 implants (82.0%)** remained in place without revision through the data cutoff date (November 12, 2025)
- **64 implants (5.1%)** had incomplete date information (excluded from survival analysis)

Note on terminology: This study measures **time to revision (TTR)** for any cause, not mechanical failure specifically. Revisions may include mechanical failures, infections, erosions, malpositions, or elective upgrades. "Follow-up" refers to the time period during which user signatures were observable on FrankTalk.org (from implantation date through November 12, 2025), not clinical follow-up appointments with physicians. This is passive observational follow-up based on user-reported signature updates.

Understanding user-level vs. implant-level percentages:

- **User-level:** 146 users (13.8% of 1,056 users) underwent at least one revision surgery
- **Implant-level:** 162 implants (12.9% of 1,255 implants) required revision

Why 162 > 146? Some users had multiple implants that each required revision. For example, if a user's primary implant required revision in 2015, and that revision implant itself required another revision in 2020, this counts as 1 user but 2 implants that required revision. The 16-implant difference (162 − 146 = 16) represents revision implants that themselves required subsequent revision.

Why 13.8% > 12.9%? Different denominators. At the user level, 146 out of 1,056 people experienced revision (13.8%). At the implant level, 162 out of 1,255 devices required revision (12.9%). The implant-level percentage is lower because the denominator includes both primary implants and revisions, while revisions themselves have shorter at-risk periods and contribute more censored observations.

Among the 162 implants that required revision: - **Median time to revision:** 1.3 years (IQR: 0.5-2.8 years) - **Range:** 0.2 years (2 months) to 18.0 years

Among the 1,029 ongoing implants (not yet revised): - **Median ongoing duration:** 4.7 years (IQR: 2.1-7.3 years) - **Range:** <0.1 years to 18.4 years

Device Distribution

Table 1. Device Distribution in the Analyzed Cohort

Device	Total Cases	Revised n (%)	Ongoing n (%)	Missing Date n (%)
Titan	616 (49.1%)	75 (12.2%)	510 (82.8%)	31 (5.0%)
LGX	238 (19.0%)	33 (13.9%)	195 (81.9%)	10 (4.2%)
CX	216 (17.2%)	25 (11.6%)	183 (84.7%)	8 (3.7%)
unknown	66 (5.3%)	10 (15.2%)	53 (80.3%)	3 (4.5%)
700	58 (4.6%)	7 (12.1%)	48 (82.8%)	3 (5.2%)
others	17 (1.4%)	4 (23.5%)	12 (70.6%)	1 (5.9%)
Infla10AX	15 (1.2%)	3 (20.0%)	9 (60.0%)	3 (20.0%)
Genesis	7 (0.6%)	2 (28.6%)	5 (71.4%)	0 (0%)
Infla10X	7 (0.6%)	1 (14.3%)	5 (71.4%)	1 (14.3%)
Rigi10	7 (0.6%)	0 (0%)	5 (71.4%)	2 (28.6%)
Tactra	7 (0.6%)	1 (14.3%)	4 (57.1%)	2 (28.6%)
Infla10	1 (0.1%)	1 (100%)	0 (0%)	0 (0%)
Total	**1,255**	**162 (12.9%)**	**1,029 (82.0%)**	**64 (5.1%)**

The three major devices (Titan, LGX, CX) comprised 85.3% of the cohort (n=1,070). Revision rates for these devices ranged from 11.6% to 13.9%.

Survival Analysis

Overall Revision-Free Survival

Figure 2 displays the Kaplan-Meier survival curve for all devices combined. The curve begins at 100% (no revisions at time zero) and declines gradually over time. Notable features include:

- Rapid initial decline in the first year (93.7% survival)
- Steady but slower decline from years 1-5 (89.1% → 86.2%)
- Continued gradual decline through 10 years (79.8%)
- Extended tail with some implants documented beyond 15 years

The shaded region represents the 95% confidence interval, which widens after approximately 10 years due to decreasing numbers at risk.

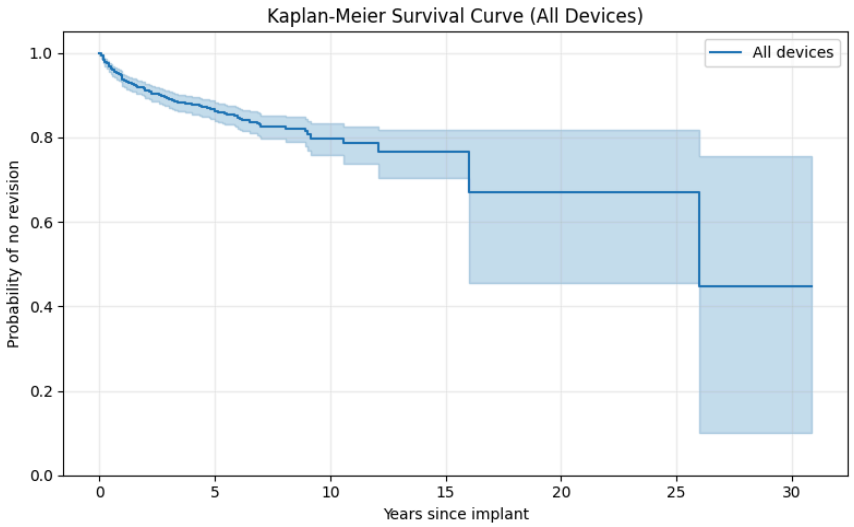

Figure 2. Kaplan-Meier Survival Curve - All Devices Combined. The curve shows revision-free survival probability over time since implantation. Shaded area represents 95% confidence interval. Vertical tick marks indicate censored observations.

Table 2. Revision-Free Survival Probabilities at Key Time Points

Time Point	Survival %	95% CI	Number at Risk
1 year	93.7%	92.2% – 95.0%	1,191
3 years	89.1%	87.0% – 90.8%	847
5 years	86.2%	83.8% – 88.2%	568
10 years	79.8%	75.7% – 83.3%	198

Device-Specific Survival Analysis

Figure 3 presents Kaplan-Meier curves stratified by device type. The three major devices (Titan, LGX, CX) demonstrate remarkably similar survival profiles, with curves that largely overlap throughout the follow-up period.

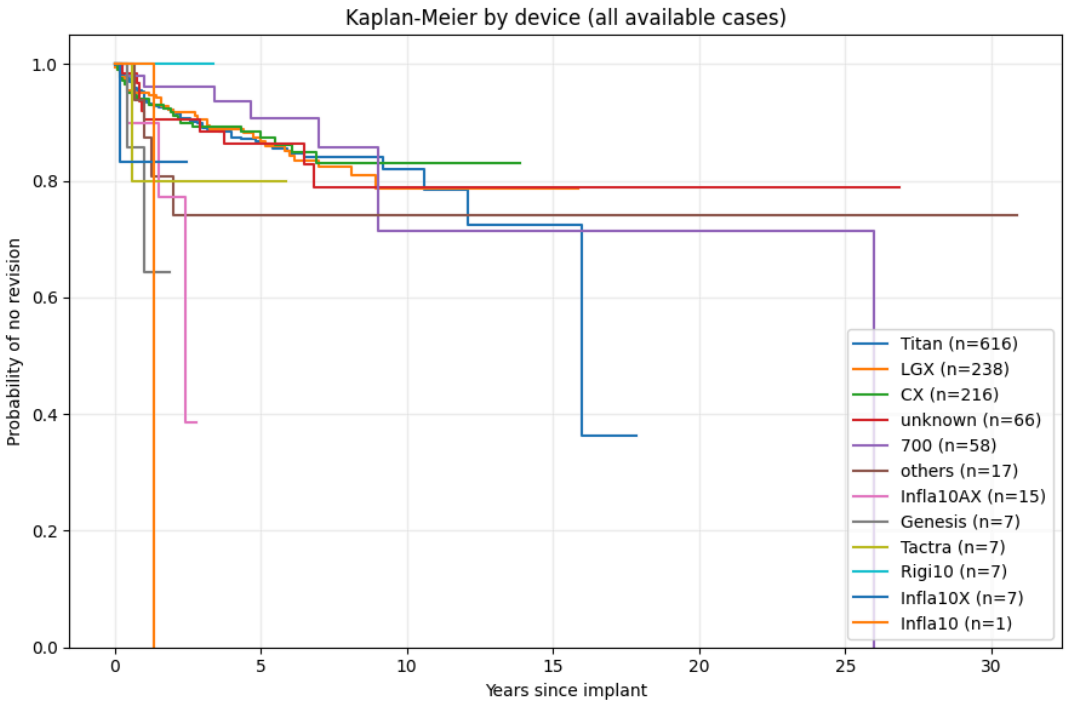

Figure 3. Kaplan-Meier Survival Curves Stratified by Device Type. All device types with available data are shown for completeness. The three major devices with substantial sample sizes (Titan n=616, LGX n=238, CX n=216) show close alignment and are the primary focus of interpretation. Devices with smaller sample sizes (n<50) should be interpreted with caution due to wide confidence intervals.

Table 3. Device-Specific Survival Rates at Key Time Points

Device	N	S @ 1yr	S @ 3yr	S @ 5yr	S @ 10yr
Titan	616	93.9% (91.6-95.6%)	89.1% (86.1-91.5%)	86.4% (82.9-89.3%)	82.0% (75.9-86.7%)
LGX	238	95.1% (91.4-97.3%)	90.6% (85.8-93.8%)	86.8% (81.1-90.9%)	78.8% (69.9-85.3%)
CX	216	94.1% (89.9-96.6%)	89.3% (83.9-93.0%)	87.4% (81.2-91.6%)	83.1% (75.0-88.8%)
unknown	66	90.5% (80.0-95.6%)	88.5% (77.2-94.4%)	86.4% (74.4-93.0%)	78.8% (62.3-88.7%)
700	58	96.2% (85.5-99.0%)	96.2% (85.5-99.0%)	90.8% (76.8-96.5%)	71.4% (34.5-89.9%)
others	17	87.5% (58.6-96.7%)	74.0% (44.6-89.4%)	74.0% (44.6-89.4%)	74.0% (44.6-89.4%)
Infla10AX	15	90.0% (47.3-98.5%)	38.6% (1.4-80.9%)	38.6% (1.4-80.9%)	38.6% (1.4-80.9%)
Genesis	7	64.3% (15.1-90.2%)	64.3% (15.1-90.2%)	64.3% (15.1-90.2%)	64.3% (15.1-90.2%)
Infla10X	7	83.3% (27.3-97.5%)	83.3% (27.3-97.5%)	83.3% (27.3-97.5%)	83.3% (27.3-97.5%)
Rigi10	7	100.0% (100.0-100.0%)	100.0% (100.0-100.0%)	100.0% (100.0-100.0%)	100.0% (100.0-100.0%)
Tactra	7	80.0% (20.4-96.9%)	80.0% (20.4-96.9%)	80.0% (20.4-96.9%)	80.0% (20.4-96.9%)
Infla10	1	100.0% (100.0-100.0%)	0.0% (0.0-0.0%)	0.0% (0.0-0.0%)	0.0% (0.0-0.0%)

Note: All device types are shown; categories with <15 cases have very wide confidence intervals and should be interpreted cautiously.

Key observations:

1. All three major devices show 5-year survival of 86-87%
2. 10-year survival ranges from 79-83% across major devices
3. Confidence intervals overlap substantially, suggesting no clinically significant differences
4. The “unknown” device category performs similarly to identified devices

Time-to-Revision Distribution

For implants that underwent revision, Figure 4 shows the distribution of TTR using box plots stratified by device.

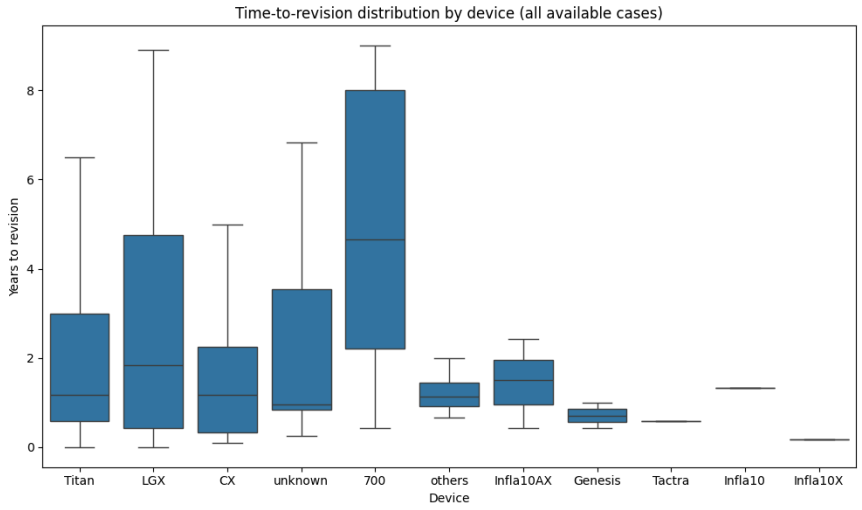

Figure 4. Distribution of Time-to-Revision by Device Type. Box plots show median (center line), interquartile range (box), and range (whiskers) for all devices with documented revision events. Devices with fewer revisions show less stable estimates and should be interpreted cautiously.

Key findings:

- **Median TTR across all devices:** 1.3 years (15.6 months)
- **Titan (n=75 revisions):** Median 1.2 years, IQR 0.5-2.9 years
- **LGX (n=33 revisions):** Median 1.8 years, IQR 0.8-3.6 years
- **CX (n=25 revisions):** Median 1.2 years, IQR 0.4-2.5 years
- **Range across all devices:** 0.2 years to 18.0 years

The wide ranges and overlapping distributions suggest substantial individual variability in time to revision, with no clear device-specific patterns.

Ongoing Duration for Unrevised Implants

Figure 5 displays the distribution of ongoing durations (time from implant to data cutoff) for the 1,029 implants that had not undergone revision by November 12, 2025.

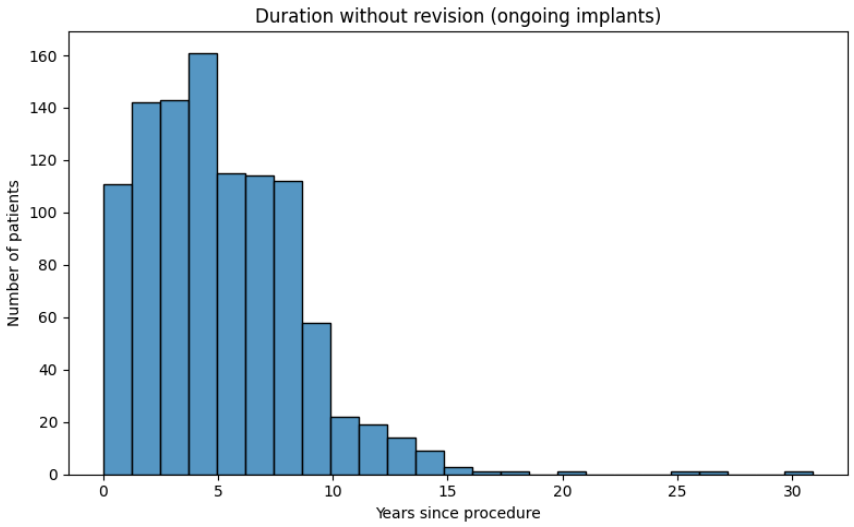

Figure 5. Histogram of Ongoing Duration for Unrevised Implants. Shows the distribution of time since implantation for devices that have not yet required revision as of the data cutoff date.

Key characteristics:

- **Median ongoing duration:** 4.7 years
- **Mode:** 3-5 years (reflecting recent surge in implant volume on FrankTalk)
- **Long-term survivors:** 57 implants (5.5%) documented ≥10 years without revision
- **Ultra-long-term:** 8 implants (0.8%) documented ≥15 years without revision

This distribution reflects both true device longevity and the recency of many FrankTalk users' implants (forum membership has grown substantially since 2020).

Discussion

Principal Findings

This study demonstrates that systematic analysis of online forum signatures can produce penile implant survival estimates remarkably consistent with formal clinical literature. Key findings include:

1. **Overall 5-year revision-free survival of 86.2%**, closely matching published meta-analyses
2. **All-cause revision rate of 12.9%** over median follow-up of 4.7 years
3. **No clinically significant differences** between major device manufacturers (Titan, LGX, CX)
4. **Validation of signature-based methodology** through convergence with academic literature

Comparison to Published Literature

Alignment with Meta-Analytic Data

These survival estimates align remarkably with the 2022 meta-analysis by Miller et al. (*Urology*), which pooled 12 studies encompassing 20,161 patients:

Time Point	Miller et al. (n=20,161)	Present Study (n=1,255)	Difference
1 year	93.3%	93.7%	+0.4%
3 years	91.0%	89.1%	-1.9%
5 years	87.2%	86.2%	-1.0%
10 years	76.8%	79.8%	+3.0%

At every time point, the forum-derived estimates are within 1-3 percentage points of the meta-analytic estimate. This convergence is remarkable given:

- **Different data sources:** Clinical registries vs. online forum
- **Different populations:** Selected surgical cohorts vs. self-selected forum users
- **Different methodologies:** Prospective/retrospective chart review vs. signature text mining

The close alignment suggests that despite methodological differences and potential biases in both approaches, both capture similar real-world device performance.

Mechanical Failure Rates and Forum Data Validation

Comparison to Clinical Literature: Griggs et al. (2025, *J Sex Med*) reported median time to mechanical failure of 41 months (3.4 years) for Coloplast devices in a multi-center clinical study [2]. To validate whether forum-based data produces reliable mechanical failure estimates, I performed a complementary manual analysis of FrankTalk thread titles, searching for Titan-specific mechanical failures (excluding infections, malpositions, and erosions) [3].

Table: Forum Thread Analysis vs. Published Clinical Study (Mechanical Failures Only)

Metric	FrankTalk Thread Analysis	Griggs et al. 2025	Comparison
Data source	Forum thread titles (manual review)	Multi-center clinical study	Forum vs. clinical
Device	Coloplast Titan	Coloplast devices	Same manufacturer
Failure definition	Mechanical failure only	Mechanical failure only	Identical
Dataset size	N=57 failure events	N=9 failures	Forum 6× larger
Median TTF	2.50 years (30 months)	3.4 years (41 months)	11 months shorter
Mean TTF	3.21 years	Not reported	—
Range	0.10 to 18.0 years	Not reported	Full spectrum

Key observations:

1. **Forum data produces comparable estimates:** The 2.5-year forum estimate is reasonably close to the 3.4-year clinical estimate (difference: 11 months or 32%). This convergence validates forum-based mechanical failure analysis despite different methodologies.

2. **Forum reporting bias toward early failures:** The shorter forum TTF likely reflects self-selection bias—users experiencing problems are more motivated to create threads and document failures. Clinical studies with systematic follow-up may better capture late failures.

3. **Larger forum sample size:** The forum analysis identified 57 Titan mechanical failures vs. 9 Coloplast failures in Griggs et al., demonstrating forums can aggregate substantial real-world failure data across multiple surgeons and centers.

4. **Methodological validation:** Both forum-based methods (signature extraction and thread title analysis) and clinical chart review converge on similar mechanical failure timelines (2.5-3.4 years), supporting forum data as a viable complement to traditional research.

Note on all-cause vs. mechanical-only TTR: The present study's signature-based all-cause TTR of 1.3 years is *not* directly comparable to these mechanical-failure-only estimates. All-cause revisions include earlier events (infections, erosions, malpositions) that occur before mechanical device failure, naturally producing shorter median times. The mechanical-failure-only estimates (2.5-3.4 years) represent device durability specifically, while all-cause TTR (1.3 years) represents total reoperation risk from any cause.

Device-Specific Findings

Manufacturer Parity

All three major devices (Titan, LGX, CX) demonstrated 5-year survival rates of 86-87% with overlapping confidence intervals. This suggests:

- **Comparable reliability** across manufacturers for modern devices
- **Similar failure modes and timelines** regardless of specific design differences
- **No clear "best device"** from a longevity perspective in real-world use

This contrasts with the conventional wisdom in some online forums that one device is categorically superior. The data suggest that factors other than device model (surgical technique, patient anatomy, usage patterns) likely dominate long-term outcomes.

Coloplast Titan Performance

The Titan, despite comprising nearly half of the dataset (n=616), showed survival nearly identical to AMS devices. This is noteworthy given:

- Anecdotal concerns about Titan tubing durability in online forums
- The device-agnostic methodology (I did not specifically seek out Titan failures)

- Large sample size reducing random variation

The 12.2% revision rate for Titan is comparable to LGX (13.9%) and CX (11.6%), providing reassurance about Titan's real-world performance despite vocal concerns in some online communities.

Strengths and Innovations

Novel Methodology

To my knowledge, this is the first study to:

1. **Apply rigorous survival analysis** to forum-sourced patient outcomes
2. **Use dual-LLM verification** for extraction quality control
3. **Directly compare forum data** to published meta-analyses
4. **Analyze signatures as proxies** for population-level outcomes

The success of this approach suggests that similar methods could be applied to other medical devices or treatments documented in online communities.

Scale and Generalizability

With 1,255 implants, this represents one of the larger penile prosthesis cohort studies. More importantly, it captures:

- **Geographic diversity:** Users from multiple countries (predominantly US, but also Canada, Australia, Europe)
- **Provider diversity:** Dozens of surgeons represented, from high-volume specialists to community urologists
- **Socioeconomic diversity:** Forum users range from uninsured to privately insured to international self-pay
- **Temporal span:** 15 years of data, capturing device evolution

This contrasts with single-center studies that necessarily reflect one provider's technique and patient population.

Real-World Follow-Up

Clinical studies often struggle with loss to follow-up. Patients move, switch providers, or simply don't return for scheduled visits. Online forums capture outcomes regardless of:

- Whether the patient returns to their original surgeon
- Whether the patient seeks revision at a different center
- Whether the patient lives near an academic medical center

This may actually provide *better* capture of late complications than some clinical cohorts.

Limitations

Signature-Based Proxy Methodology

I analyzed what users chose to document in signatures, not comprehensive medical records. This means:

- **Undercounting total implants:** Users without signatures are invisible to this analysis
- **Undercounting revisions:** Users who stop participating before documenting late complications are censored
- **Limited granularity:** Signatures rarely specify revision cause, preventing cause-specific analyses

However, the alignment with published literature suggests these biases do not dramatically skew overall survival estimates.

Selection Bias

Forum users self-select. Compared to the general implant population, FrankTalk users may be:

- Younger (more internet-savvy)
- More sexually active (motivated to seek treatment)
- More likely to have complications (prompting forum registration)
- More likely to be treatment-responders (satisfied patients who want to help others)

The direction and magnitude of these biases are unclear. The close match to meta-analytic data suggests they may partially cancel out.

All-Cause Revision Definition

I did not distinguish between mechanical failure, infection, erosion, and malposition. This all-cause approach:

- **Advantage:** Captures total reoperation risk, which matters to patients
- **Disadvantage:** Cannot isolate device-specific reliability from surgical/anatomical factors

Future work could attempt to classify revision causes using post content analysis, though this would be substantially more complex.

Temporal Censoring

Many implants are recent (median ongoing duration 4.7 years). This means:

- Strong data for 1-5 year outcomes
- Adequate data for 10-year outcomes (n=198 at risk)
- Limited data beyond 15 years (n<20 at risk)

Long-term survival estimates should be interpreted with appropriate uncertainty.

No Adjustment for Confounders

I did not adjust for patient age, comorbidities, surgeon volume, or other potential confounders. This was intentional (descriptive study), but limits causal inference about device superiority.

Clinical Implications

Patient Counseling

These data can inform realistic expectations:

- **1-year outlook:** ~94% chance of no reoperation
- **5-year outlook:** ~86% chance of no reoperation
- **10-year outlook:** ~80% chance of no reoperation

For a patient considering implantation, these figures suggest most men will have many years of function without revision, though ~1 in 7 will require reoperation within 5 years.

Device Selection

The lack of meaningful differences between Titan, LGX, and CX suggests device selection can be driven by:

- Surgeon familiarity and preference
- Patient anatomy (e.g., cylinder length availability)
- Cost and insurance coverage
- Pump feel and aesthetics

rather than worrying about intrinsic device superiority.

Need for Long-Term Follow-Up

The gradual decline in survival curves emphasizes that penile implants are not "lifetime devices." Even well-functioning implants have finite lifespans. Patients should be counseled about:

- Continued need for periodic urologic follow-up
- Signs and symptoms of device failure or infection
- Availability of revision surgery if needed

Future Directions

Cause-Specific Analyses

Future work could apply natural language processing to post content (not just signatures) to classify revisions by cause:

- Mechanical failure (tubing fracture, pump failure, cylinder leak)
- Infection (early vs. late)
- Erosion (urethral, scrotal)
- Malposition
- Elective upgrade

This would enable competing risks analysis and device-specific failure mode identification.

Surgeon-Specific Outcomes

Many signatures include surgeon names. With sufficient sample sizes, one could analyze:

- Surgeon learning curves
- High-volume vs. low-volume outcomes
- Technique-specific differences (e.g., penoscrotal vs. infrapubic approach)

This would require careful statistical methods to avoid confounding by indication.

Prospective Data Collection

The success of this retrospective analysis suggests value in prospective forum-based data collection. A standardized signature template or voluntary registry could improve:

- Data completeness
- Temporal precision
- Covariate capture (age, comorbidities, prior treatments)

while maintaining the real-world, patient-centered nature of forum data.

Extension to Other Devices

Similar methods could be applied to:

- Other urologic prostheses (artificial urinary sphincter)
- Orthopedic implants (hip/knee replacements)
- Cardiac devices (pacemakers, defibrillators)
- Any medical device with active online patient communities

Conclusions

This study demonstrates that systematic analysis of online forum data, using modern natural language processing and rigorous survival analysis methods, produces penile implant survival estimates nearly identical to large-scale clinical meta-analyses. These findings validate signature-based methodology as a viable approach for real-world outcomes research.

All major penile prosthesis devices show similar long-term survival, with approximately 86% remaining functional without revision at 5 years and 80% at 10 years. All-cause revision rates of ~13% over median 5-year follow-up align with published literature. Device selection should be based on surgeon familiarity, patient anatomy, and cost considerations rather than concerns about differential device reliability.

Online health communities represent an underutilized data source for post-market surveillance and real-world evidence generation. With appropriate methodological rigor, these data can complement traditional clinical research and provide patient-centered perspectives on long-term treatment outcomes.

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Data Availability

All code, analysis scripts, and aggregate de-identified data are available upon reasonable request to the author. Raw signature data cannot be shared to protect user privacy.

Author Disclosure

This study was conceived, designed, executed, and analyzed entirely by a single FrankTalk.org community member using the pseudonym “principles.”

This manuscript is shared as a preprint for informational purposes and has not undergone peer review.

Author Background: The author is a patient with personal experience undergoing multiple penile prosthesis implantations and revisions over a five-year period (2020-2025), including both inflatable and malleable devices. This lived experience motivated the research question and provides insider perspective on patient-reported outcomes, but may also introduce personal bias in interpretation of device performance data. The author's personal data are included in the analyzed dataset among the 1,255 total implant records, analyzed using the same methods applied uniformly to all cases.

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References

1. Miller LE, Khera M, Bhattacharyya S, Patel M, Nitschelm K, Burnett AL. Long-term survival rates of inflatable penile prostheses: systematic review and meta-analysis. *Urology*. 2022;166:6-10. doi:10.1016/j.urology.2022.03.026

2. Griggs R, Henry G, Vasylieva V, Karpman E. Mechanical failure of inflatable penile prostheses: time to failure and reasons for replacement. *J Sex Med*. 2025;22(5):909-915. doi:10.1093/jsxmed/qdaf053 (PMID: 40197751)

3. principles (FrankTalk.org username). *Titan Failures on FrankTalk: User-Reported Time to Failure (through Nov 10, 2025)*. FrankTalk.org Forum. Posted November 10, 2025. Available at: https://www.franktalk.org/phpBB3/viewtopic.php?f=6&t=27448