

National Survey Among Catheter Users:

*A Study to Examine Catheter Usage and
Catheter Coverage by Health Plan*

Sponsored by:



DukeHealth



Survey Background and Purpose

Who was surveyed?

- Populations surveyed included community members represented by four sponsoring nonprofit organizations (whose communities include significant numbers of catheter users):
 - Spina Bifida Association
 - Christopher & Dana Reeve Foundation
 - Paralyzed Veterans of America
 - United Spinal Association

Why was the survey conducted?

The survey was conducted to determine:

- How much in out-of-pocket costs do catheter users incur monthly and annually?
- Does the amount catheter users pay out-of-pocket vary by the health plan they have?

What was the criteria to be included in the survey? All had to:

- Be a regular intermittent urinary catheter user over age 18, or adult caregiver for a child or adult who regularly uses catheters, **and**
- Be covered by any type of health insurance/plan (either commercial/private, public/government or Military/VA), **and**
- Live in the US, or a US territory.

Survey Methodology

This catheter survey was conducted as follows:

- Institutional Review Board (IRB) approval for survey was obtained through Duke University.
 - Duke University programmed the survey and was responsible for data collection and management.
- Questionnaire topics were developed collaboratively by sponsoring organizations.
- On January 19, 2021, links to survey were emailed to 143,905 people representing each of the four non-profit organizations' community lists. Links were also posted on the organizations' social media sites.
 - Emails included links to the survey in both English and Spanish
 - Data collection closed/ended on February 15, 2021
 - A total of 2,510 people participated in the survey; all met the inclusion criteria.

Survey Methodology (continued)

Survey Responses and Response Rates by Organization

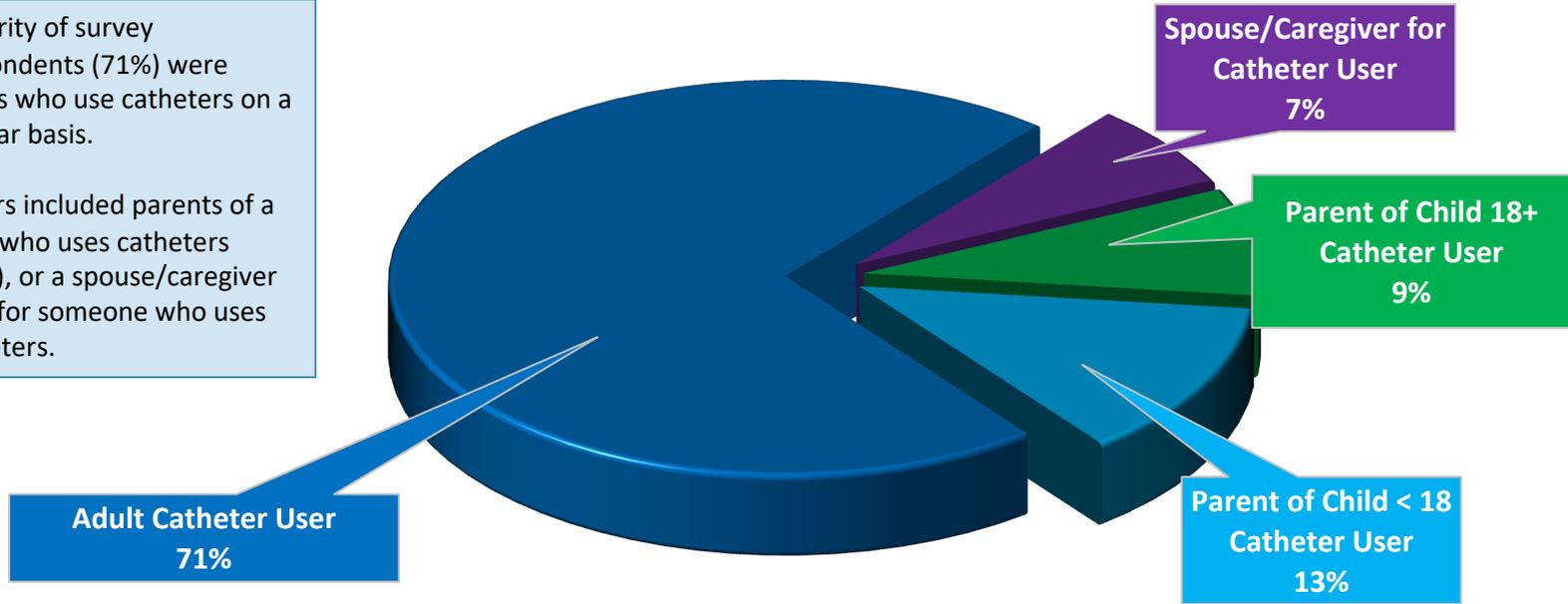
- A total of 2,510 regular intermittent catheter users participated in the survey; all met the inclusion criteria.

Sponsoring Non-Profit Organizations	# Emails Sent 1/19/21 with Survey Link	Number of Qualified* Responses Rec'd by Organization By 2/15/21	Percent of Responses Rec'd by Organization	Response Rates by Organization
Christopher & Dana Reeve Foundation	85,000	629	25%	0.7%
Paralyzed Veterans of America	7,435	294	12%	3.9%
Spina Bifida Association	21,223	853	34%	4.0%
United Spinal Association	30,247	734	29%	2.4%
Totals	143,905	2510	100%	1.74%

Catheter Survey Respondents

Majority of survey respondents (71%) were adults who use catheters on a regular basis.

Others included parents of a child who uses catheters (22%), or a spouse/caregiver (7%) for someone who uses catheters.

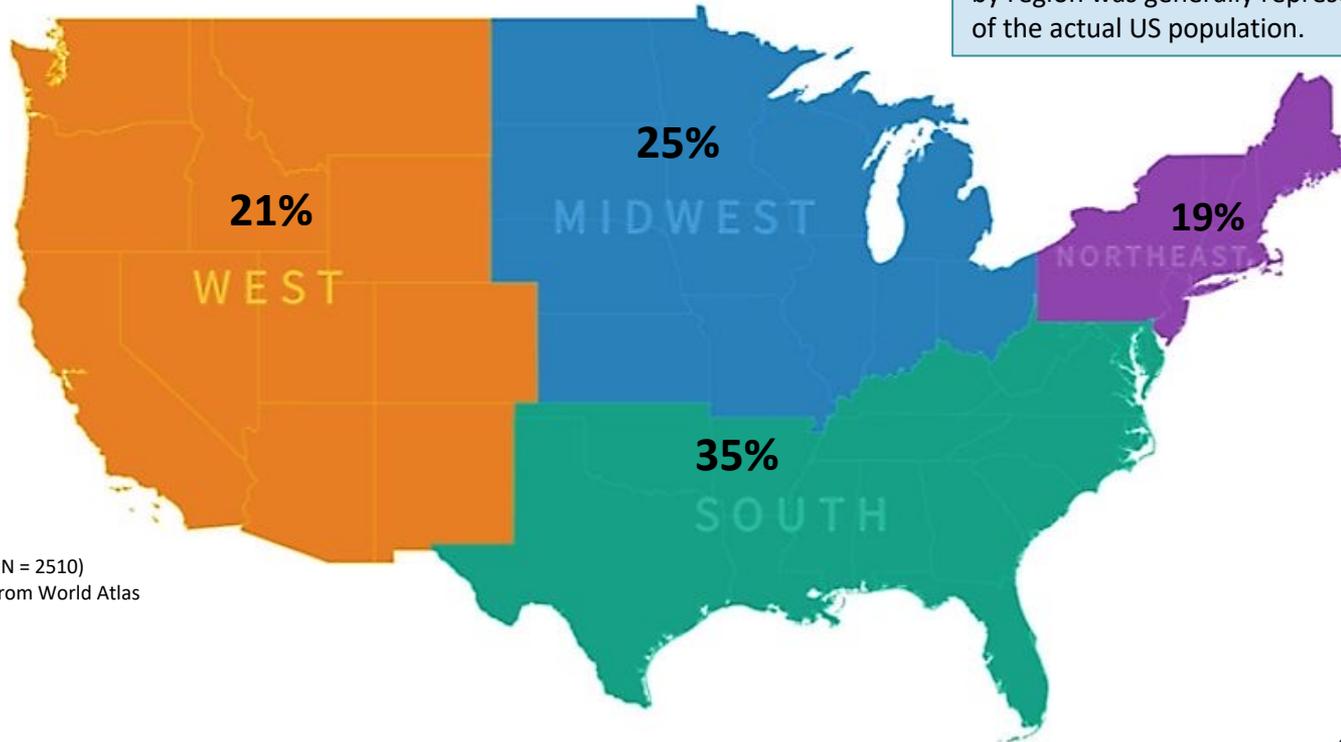


Base = All respondents (N = 2510)

Q 4

Catheter Survey Respondents by Region

Survey respondents reflected all 50 US states. The proportion of respondents by region was generally representative of the actual US population.

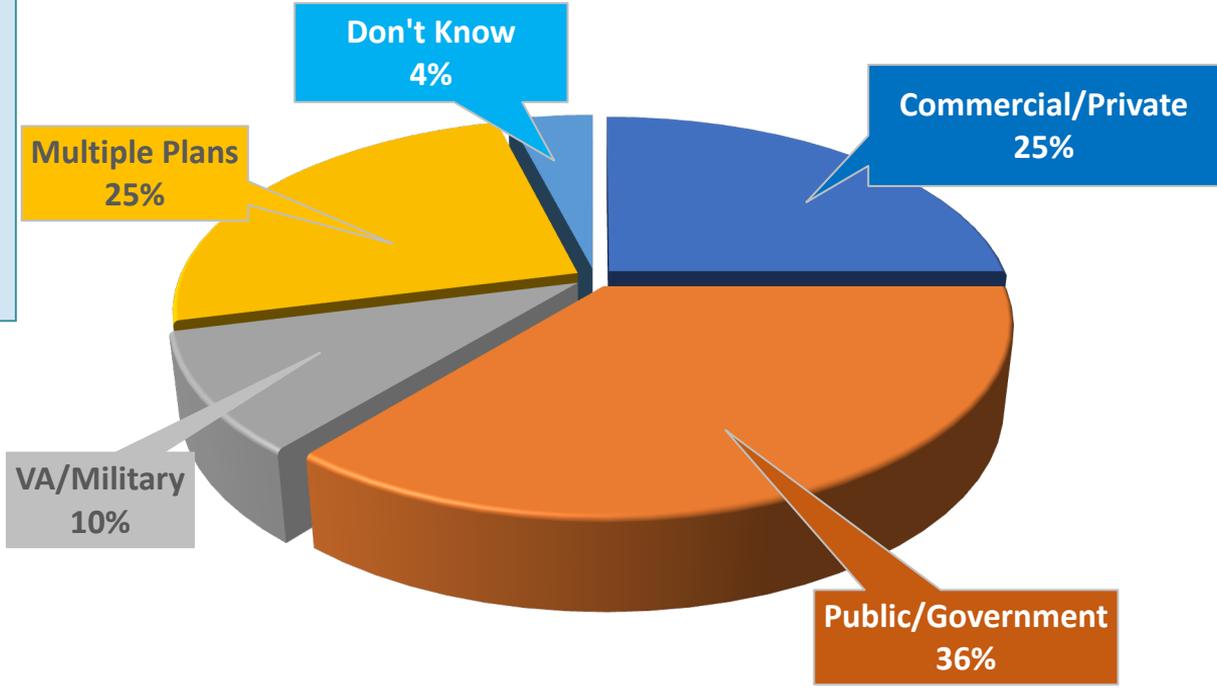


Base = All respondents (N = 2510)
Source: Regional map from World Atlas
Q 7

Type/Category of Health Plans

More than one-third (36%) had some type of public or government health plan (e.g., Medicare, Medicaid),

One in four (25%) had a commercial or private plan.



Base = All respondents
Q 12

Commercial/Private Public/Government VA/Military Multiple Plans Don't Know

Commercial/Private Health Plan Distribution

More than four in ten (45%) of those who were covered by a commercial/private health plan had a BlueCross Blue Shield plan.

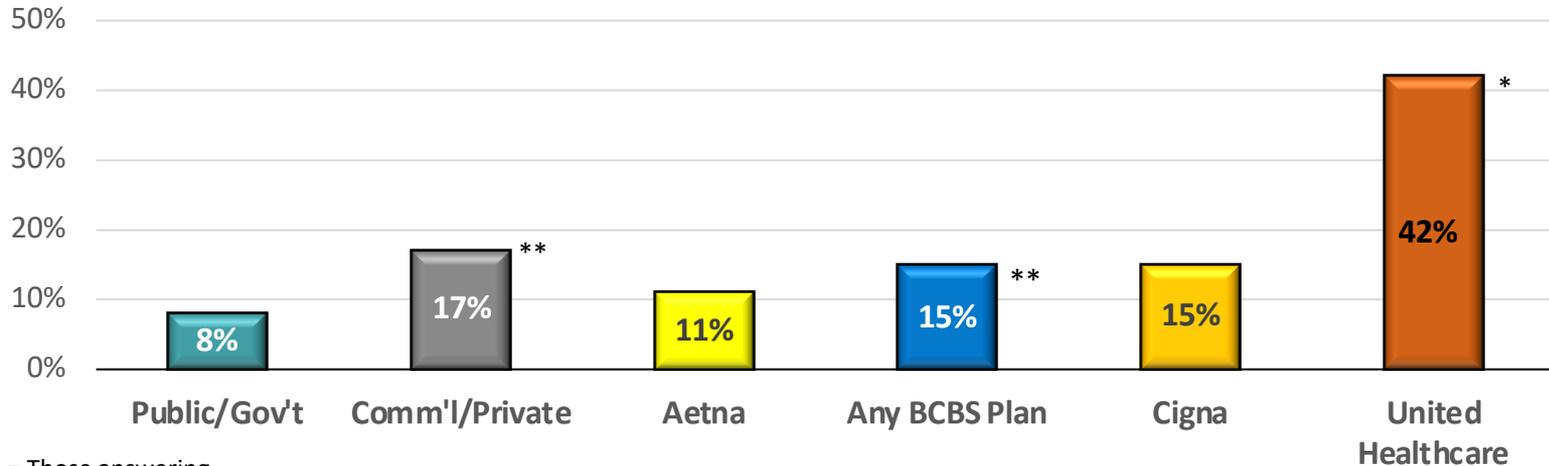
Other plans which covered a significant percentage of catheter users included United Healthcare (13%), Aetna (10%), and Cigna (7%)

Base = Those who were covered by any commercial/private health plan
Q 14

	Commercial/Private Health Plans
Any BCBS Plan	45%
UnitedHealthcare	13%
Aetna	10%
Cigna	7%
Kaiser	3%
Humana	2%
Any other Commercial/Private Health Plans	18%
Don't Know/Not Sure	1%

Proportion of Respondents who Reported their Health Plan *Does Not Cover Any Costs* for Catheters

Catheter users were asked whether their health plan covered *all, some, or none* of the costs of the catheter types they use most often. This chart shows those who said that their plan did not cover any of the costs for the types of catheters they use.



Base = Those answering

*Statistically significantly higher than all others at 95% confidence level

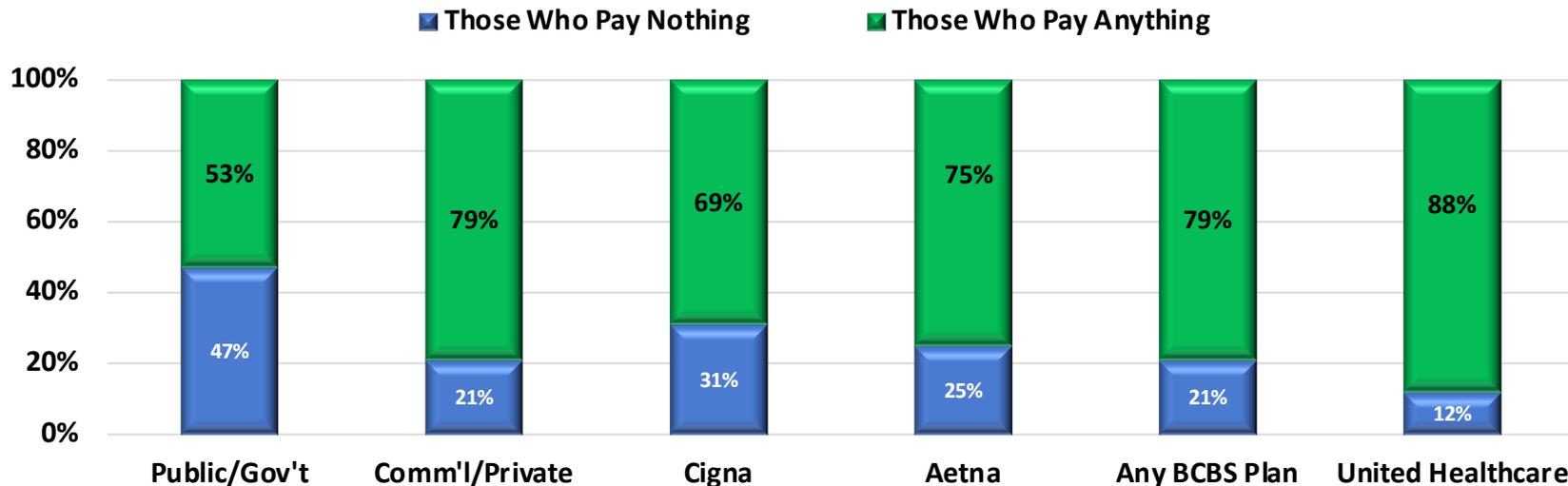
**Statistically significantly higher than Public/Gov't Plans at 95% confidence level

Q 15 & Q 41

Catheter Users Paying Anything Out-of-Pocket for Catheters & Catheter Supplies (By Type of Health Coverage)

Most of those with a commercial/private health plan (79%) had to pay something out of pocket for catheters.

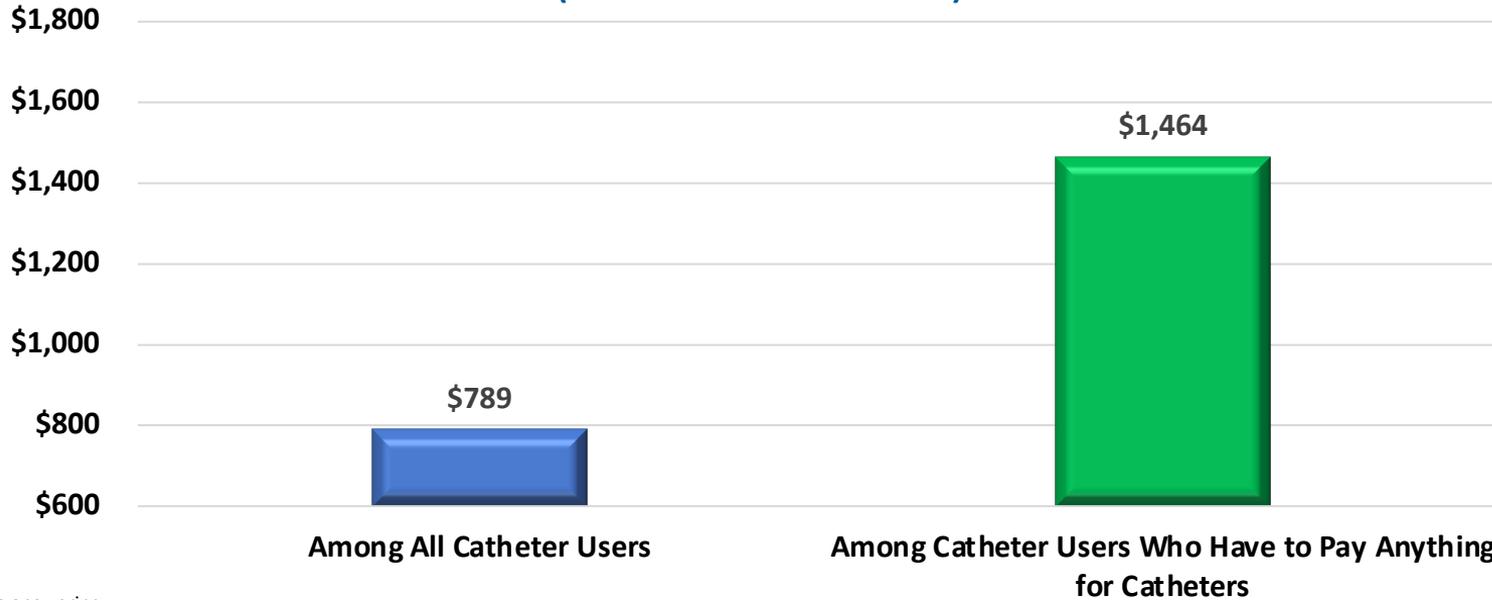
In comparison, only 53% of those with government/public plans incurred out-of-pocket costs for catheters.



Base = Those answering Q.16

Average Annual Out-of-Pocket Costs for Catheters & Catheter Supplies

(Costs exclude deductible)



Base = Those answering

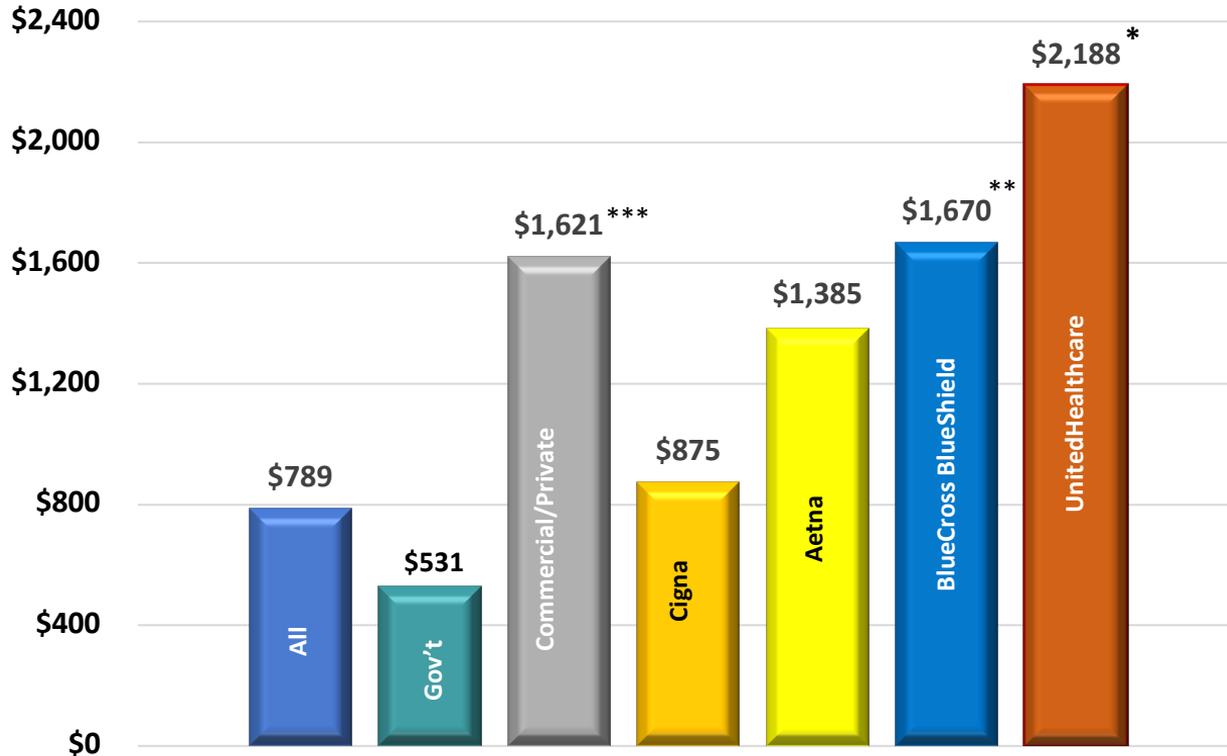
Note: Catheter users reported how much they spent out-of-pocket monthly for catheters.

From this, an average was calculated. Then, the average was multiplied by 12 to obtain the average annual out-of-pocket cost.

Q.16

Average Annual Out-of-Pocket Costs for Catheters & Catheter Supplies Among All Catheter Users by Type of Health Plan

(Costs exclude deductible)



Average annual amount catheter users pay out-of-pocket for catheters and supplies varies significantly by type of health plan and by brand of commercial plan. Those with a government/public plan incurred the lowest out-of-pocket costs at \$531.

Base = Those answering, *including those who pay \$0*
Note: Catheter users reported how much they spent out-of-pocket monthly for catheters. From this, the average was calculated. The average was multiplied by 12 to obtain the average annual out-of-pocket cost.

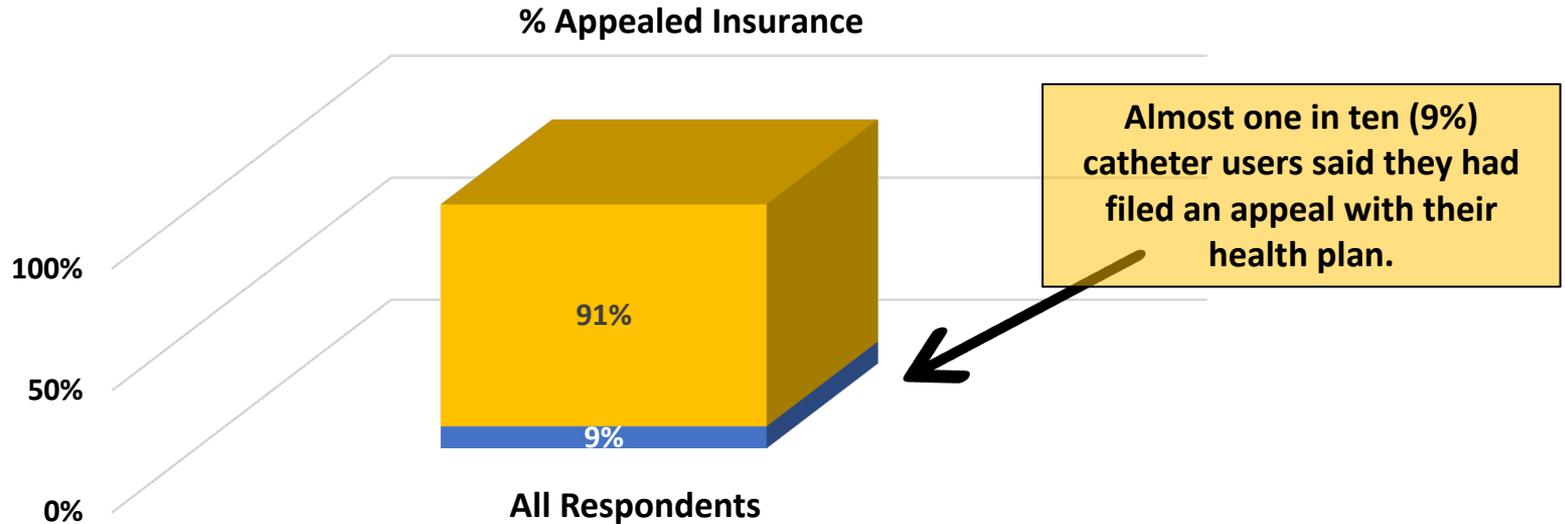
*Statistically significantly higher than all others at 95% confidence level

**Statistically significantly higher than Cigna and Public/Gov't plans at 95% confidence level

*** Statistically significantly higher than Public/Gov't plans at 95% confidence level

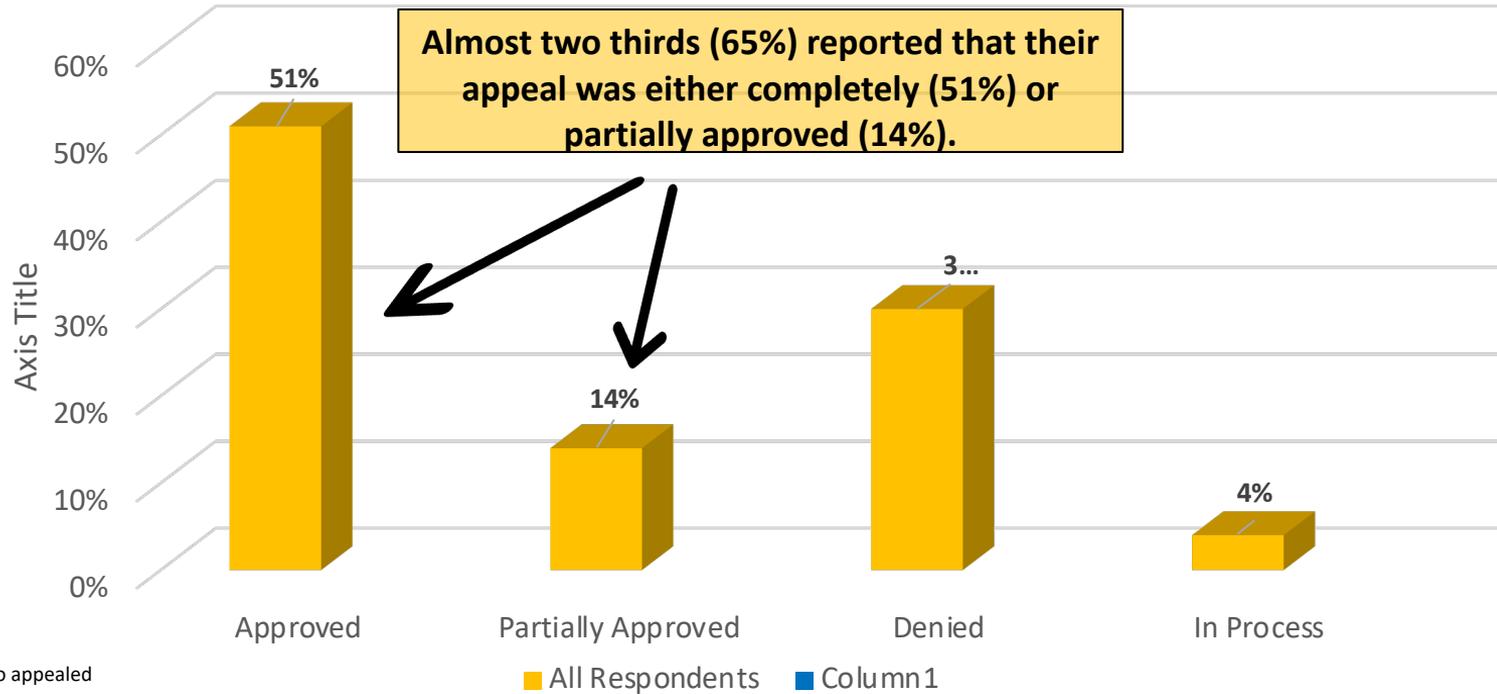
Q 16

Those Who Appealed Insurance



Base = All respondents (N = 2510)
Q. 25 & Q. 26

Results of Appeal



Base = Those who appealed
Q 27

Additional Comments About Catheters or Health Plan Coverage of Catheters

Open-ended survey question

“Do you have any other comments or suggestions that you would like to make regarding catheters, or about health insurance/health plan issues related to catheters?”

Overwhelming majority who answered made *negative* comments (72%).

- Most of the negative comments were about:
 - Costs of catheters/not being covered by insurance (46%),
 - A specific health insurance company regarding inadequate coverage for catheters (23%),
 - Having to pay out-of-pocket for catheters (21%),
 - Preferred catheter types/catheter supplies not being adequately covered by insurance (20%).

“It is ridiculous that healthcare doesn't cover the extra costs of having to pee when you have a health problem.”

-Survey Respondent

Catheter Survey Researchers

Maryellen S Kelly, DNP, CPNP, MHSc

- Dr. Kelly is an Assistant Professor at Duke University in the Healthcare of Women and Children Division within the School of Nursing
- She is a pediatric nurse practitioner with her Doctorate in Pediatric Nursing and a Masters of Health Sciences-Clinical Research.
 - Her clinical practice for the past decade has been focused on individuals with Spina Bifida and neurogenic bladder and bowel management.
 - She has a close relationship with the SBA as a member of the Research Advisory Council where she leads the subgroup on fecal continence.
 - She works with the CDC on the National Spina Bifida Patient Registry and UMPIRE studies.
 - She serves on the Executive Board of the Pediatric Urology Nurses and Specialists Society within the American Urologic Association.
 - She is also an editor of the *Journal of Pediatric Urology*.

Dawne Widener-Burrows

- Dawne is a professional market researcher with 35+ years experience conducting qualitative and quantitative market research. She specializes in conducting medical market research. In her career she has surveyed a variety of types of physicians and surgeons, nurses, pharmacists, other medical professionals, hospital and health plan administrators, as well as health plan members and patients.

Some of her clients have included:

- Johns Hopkins Hospitals, Johns Hopkins Medicine and Johns Hopkins Health Plans
- MedStar Health System and MedStar affiliated hospitals (Georgetown Hospital, Washington Hospital Center, Union Memorial, etc.)
- Multiple BlueCross BlueShield plans (CareFirst, Independence BlueCross, Highmark, etc.)
- Cedars-Sinai Hospital and HCA
- Between 2000-2007 she was full-time Affiliated Faculty Loyola University (MD). Previously, she was an Adjunct Faculty member at Johns Hopkins in the Masters of Marketing program.
- Dec 2020, she was elected a member of the Spina Bifida Association Board of Directors



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