This is a sample version of the 2018 CF Health Insurance Survey intended for a person with cystic fibrosis to complete.

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A request form for paper surveys is available at cff.org/coveragestudy

You will be answering questions about insurance coverage, access to care, and quality of life. Please answer the following questions to the best of your ability. Answer questions about coverage and costs for the household in which the person with CF lives or is a dependent. The survey includes several questions about health insurance coverage and costs. Some of this information can be found on an Explanation of Benefits form (for information on deductibles) and on paystubs (for information on premium costs). Please access this information now so you can provide responses during the survey.

Please note: You will be able to save responses and return later to the survey by clicking “Save and Return Later” at the bottom of any survey page. If you need to save and return, please save the RETURN CODE that is generated for you so you can return to the survey. If you do not use this code, you will have to re-start the survey from the beginning, and your previous responses will be deleted. Please contact marshar@gwu.edu or call 202-994-8662 if you have questions or trouble returning to the survey.

This survey is expected to take 20 minutes to complete. Participation in this study is entirely voluntary. You may choose not to participate. You may quit the survey at any time or skip any questions you do not want to answer. Please take a moment to review the consent form below and indicate your willingness to participate.

[Attachment: "Written Informed Consent Form.pdf"]

By selecting yes, you agree that you have read the consent form and agree to participate.

◯ Yes, I agree to participate
◯ No, I do not agree to participate

The first set of questions ask about you. Remember this is an anonymous survey and your name is not linked in any way to your responses.

What is your gender?

◯ Male
◯ Female
◯ Other

What is your age, in years?

_____

What is the highest grade or level of school you have completed?

◯ 8th grade or less
◯ Some high school, but did not graduate
◯ High school graduate or GED
◯ Some college or 2-year degree
◯ 4-year college graduate
◯ More than 4-year college degree

Are you of Hispanic or Latino origin or descent?

◯ Yes
◯ No

What is your race?
(Please choose all that apply.)

☐ White
☐ Black or African American
☐ American Indian or Alaska Native
☐ Asian
☐ Native Hawaiian or other Pacific Islander
☐ Other

Other, please specify

_____

What is your current marital status?

◯ Single (never married)
◯ Living with partner
◯ Married
◯ Separated
◯ Divorced
◯ Widowed

Which of the following best describes your current employment status?

◯ Part time employment
◯ Full time employment
◯ Not currently employed outside the home
◯ Full time homemaker/ parent
◯ Student
◯ Retired

What was your total household income in 2017 (before taxes)?

◯ Less than $30,000
◯ $30,000 to $59,999
◯ $60,000 to $89,999
◯ $90,000 to $119,999
◯ $120,000 to $149,999
◯ $150,000 or more
◯ Don't know

How many people live in your household, including children in college who live away from home?

◯ 1
◯ 2
◯ 3
◯ 4
◯ 5
◯ 6
◯ 7
◯ 8
◯ 9
◯ 10
◯ 11 or more

In what state is your CF care center?
(If you attend a care center in more than one state, please select the state of the center you go to more frequently.)

◯ Alabama
◯ Alaska
◯ Arizona
◯ Arkansas
◯ California
◯ Colorado
◯ Connecticut
◯ Delaware
◯ District of Columbia
◯ Florida
◯ Georgia
◯ Hawaii
◯ Idaho
◯ Illinois
◯ Indiana
◯ Iowa
◯ Kansas
◯ Kentucky
◯ Louisiana
◯ Maine
◯ Maryland
◯ Massachusetts
◯ Michigan
◯ Minnesota
◯ Mississippi
◯ Missouri
◯ Montana
◯ Nebraska
◯ Nevada
◯ New Hampshire
◯ New Jersey
◯ New Mexico
◯ New York
◯ North Carolina
◯ North Dakota
◯ Ohio
◯ Oklahoma
◯ Oregon
◯ Pennsylvania
◯ Rhode Island
◯ South Carolina
◯ South Dakota
◯ Tennessee
◯ Texas
◯ Utah
◯ Vermont
◯ Virginia
◯ Washington
◯ West Virginia
◯ Wisconsin
◯ Wyoming
◯ Puerto Rico
◯ Do not seek CF care at a CF care center

Which of the following best describes the place where you now live?

◯ A large city
◯ A suburb near a large city
◯ A small city or town
◯ A rural area

The next questions ask about your health status.

In general, how would you rate your overall health?

◯ Excellent
◯ Very good
◯ Good
◯ Fair
◯ Poor
◯ Don't know

In general, how would you rate your overall mental health and well-being?

◯ Excellent
◯ Very good
◯ Good
◯ Fair
◯ Poor
◯ Don't know

Please select all of the following chronic conditions for which you are receiving treatment.

☐ Cystic Fibrosis related diabetes (CFRD)
☐ Cystic Fibrosis related liver disease (CFLD)
☐ Evaluated or listed for lung transplant
☐ Kidney disease
☐ Bone disease (Osteoporosis)
☐ Pancreatic disease (Pancreatitis or pancreatic insufficiency)
☐ Joint disease
☐ Cancer
☐ Malnutrition
☐ Gastric reflux (GERD)
☐ Chronic constipation
☐ Post-transplant health issues
☐ Heart disease
☐ Anxiety and/or depression
☐ Substance/Alcohol abuse
☐ Other conditions

Please specify

_____

In the last 12 months, how many pulmonary exacerbations have you had?

◯ 0
◯ 1
◯ 2
◯ 3
◯ 4
◯ 5 or more
◯ Don't know

Have you had an organ transplant?

◯ Yes
◯ No

Please specify what type of organ transplant.
(Select all that apply.)

☐ Lung
☐ Liver
☐ Kidney

Have you been referred to an organ transplant center in the last 2 years?

◯ Yes
◯ No

Please specify what type of organ transplant.

☐ Lung
☐ Liver
☐ Kidney

The following questions ask about your use of medical care. Please answer to the best of your ability.

In the last 12 months, how many times did you...?

	0	1	2	3	4	5 or more	Don't know
Visit your CF care center	◯	◯	◯	◯	◯	◯	◯
Have a hospitalization for CF or another health reason	◯	◯	◯	◯	◯	◯	◯
Go to the Emergency Department (ED) for CF or another health reason	◯	◯	◯	◯	◯	◯	◯
See a doctor or other health professional NOT at your CF care center (Please do not include Emergency Department visits)	◯	◯	◯	◯	◯	◯	◯

In the last 12 months, did you see a mental health professional (social worker, psychologist, psychiatrist, or mental health coordinator) for treatment at any location?

◯ Yes
◯ No
◯ Don't know

The next set of questions are about your insurance plan and any other assistance programs you may utilize.

What kind of health insurance or health care coverage do you have?
(Please select all that apply.)

☐ An insurance plan through my employer or my family member's employer
☐ Medicaid
☐ Medicare (including Medigap)
☐ Children's Health Insurance Program (CHIP)
☐ A plan purchased through healthcare.gov or the health insurance marketplace (also known as a health exchange)
☐ A plan purchased through an individual market (not through the health exchange)
☐ A state special needs program that provides additional financial assistance to individuals and families with special health care needs including CF
☐ TriCare, VA, or Other military health plan
☐ Indian Health Service
☐ COBRA (provides retirees, former employees and their families a limited period of continued coverage at group rates)
☐ Other
☐ I do not have insurance
☐ Don't know
☐ Prefer not to answer

Please specify

_____

Please select the sentence that best describes your health insurance coverage.

◯ I am on a family member's plan and not the primary policyholder
◯ I am the primary policyholder on my own individual plan
◯ I am the primary policyholder with other family members on my plan
◯ Don't know

Have you been determined to be medically disabled by any organization that provides disability services or benefits?

◯ Yes
◯ No
◯ Don't know

Please select the type of disability services or benefits.

☐ Supplemental Security Income (SSI)/Social Security Disability Insurance (SSDI)
☐ Private disability benefits (e.g. through your employer or purchased by you)

In the last 12 months, was there ever a time when you did NOT have ANY health insurance or coverage?

◯ Yes
◯ No
◯ Don't know

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How many months were you without coverage?

◯ 1
◯ 2
◯ 3
◯ 4
◯ 5
◯ 6
◯ 7
◯ 8
◯ 9
◯ 10
◯ 11
◯ 12

What was the main reason you did not have health insurance?

◯ Change in employment
◯ Change in family circumstance (for example death or divorce)
◯ Change in insurance affordability
◯ Ineligible for public program
◯ Aged out of parent's plan
◯ Chose not to be insured
◯ Other

Please specify

_____

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Now you will be asked to answer a series of questions about your insurance benefits for specific CF care services. Please answer to the best of your ability.

Does your insurance pay for the following services and treatments?

	Yes, it covers all costs	Yes, it covers some costs	No, it doesn't cover anything	Does not apply
Vitamins and supplements	○	○	○	○
GI therapies (Pancreatic enzyme replacement therapy, proton pump inhibitor (PPI), antacids)	○	○	○	○
G-tube or NG-tube equipment	○	○	○	○
G-tube or NG-tube formula	○	○	○	○
Diabetes supplies (Insulin pump, test strips)	○	○	○	○
Insulin	○	○	○	○
IV treatment for pulmonary exacerbations	○	○	○	○
Chronic inhaled antibiotics (Cayston, Bethkis, Kitabis Pak, TOBI, TOBI Podhaler, inhaled tobramycin)	○	○	○	○
Pulmozyme	○	○	○	○
Hypertonic saline	○	○	○	○
Nebulizers (including replacements)	○	○	○	○
Airway clearance devices (Vest, PEP/OSCPEP, Acapella, Flutter devices)	○	○	○	○
CFTR modulators (Kalydeco, Orkambi)	○	○	○	○
Transplant services and medications	○	○	○	○
Home health care	○	○	○	○

In the last 12 months did you/ anyone in the family have problems paying or were unable to pay any medical bills related to the following services or treatments?

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	Yes	No	Does not apply	Don't know
CF routine visits	◯	◯	◯	◯
CF sick visits	◯	◯	◯	◯
Other doctor visits	◯	◯	◯	◯
Hospital care	◯	◯	◯	◯
Emergency room visits	◯	◯	◯	◯
Mental health care	◯	◯	◯	◯
Home health care	◯	◯	◯	◯
Vitamins and supplements	◯	◯	◯	◯
GI therapies (Pancreatic enzyme replacement therapy, proton pump inhibitor (PPI), antacids)	◯	◯	◯	◯
G-tube or NG-tube equipment	◯	◯	◯	◯
G-tube or NG-tube formula	◯	◯	◯	◯
Diabetes supplies (Insulin pump, test strips)	◯	◯	◯	◯
Insulin	◯	◯	◯	◯
IV treatment for pulmonary exacerbations	◯	◯	◯	◯
Chronic inhaled antibiotics (Cayston, Bethkis, Kitabis Pak, TOBI, TOBI Podhaler, inhaled tobramycin)	◯	◯	◯	◯
Pulmozyme	◯	◯	◯	◯
Hypertonic saline	◯	◯	◯	◯
Nebulizers (including replacements)	◯	◯	◯	◯
Airway clearance devices (Vest, PEP/OSCPEP, Acapella,Flutter devices)	◯	◯	◯	◯
CFTR modulators (Kalydeco, Orkambi)	◯	◯	◯	◯
Transplant services and medications	◯	◯	◯	◯

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The next questions ask about the costs of your health insurance and any medical costs that are not covered by health insurance. If you are unsure of what the costs are, then please respond to the best of your ability. If you do not know the answer please indicate 'Don't know' rather than skip the question.

The first question asks about your health insurance premiums. A health insurance premium is the monthly amount paid by the policy holder (either you or a family member).

You may need to refer to your paycheck, the policyholder's paycheck, a statement of benefits, or other insurance paperwork to determine what this amount is. If you are paid more frequently than once a month (for example, twice a month or every other week), please estimate what the monthly amount is.

Approximately how much do you currently spend per month on health insurance premiums?
*Reference your payroll deductions or amounts you directly pay to the insurance company

◯ Under $250 per month
◯ $250 to $499 per month
◯ $500 to $749 per month
◯ $750 to $999 per month
◯ $1000 to $1249 per month
◯ $1250 to $1499
◯ $1500 or more per month
◯ Don't know
◯ Prefer not to answer

The next questions ask about your deductible. A deductible is a fixed amount that the policyholder (either you or a family member) must pay every year before the insurance company starts to make payments for covered services. You may need to refer to paperwork explaining your insurance benefits to determine this annual amount.

What is the annual deductible you pay for your care? If your plan has both an individual and family deductible, please include both. If there is a separate deductible for medical services and prescription drugs, please add them together.

Annual individual deductible

◯ Under $500
◯ $500- $1,499
◯ $1,500-$2,999
◯ $3000 or more
◯ Does not apply
◯ Don't know
◯ Prefer not to answer

Annual family deductible

◯ Under $3000
◯ $3000-$6000
◯ $6000 or more
◯ Does not apply
◯ Don't know
◯ Prefer not answer

To the best of your knowledge, when do you typically meet your annual deductible?

◯ First quarter of year (January, February or March)
◯ Second quarter of year (April, May or June)
◯ Third quarter of year (July, August or September)
◯ Fourth quarter of year (October, November or December)
◯ Never
◯ Does not apply
◯ Don't know

The next question asks about your out-of-pocket costs. Out-of-pocket costs are expenses that are not paid for by insurance, or that are paid by you because you do not have health insurance. For the purposes of these questions, out-of-pocket costs include:

• Copayments- the set amount you are required to pay for a health care service, such as a $20 co-pay for a routine visit at your doctor's office

• Co-insurance -the percentage of costs you are required to pay for a health care service, such as 20% of the cost of seeing a specialist

• Costs related to health care services that are not paid for by your health insurance because they are not part of your network or group of covered services, such as $10 for vitamins or supplements that are not covered by your insurance.

In the last 12 months, approximately how much were your out-of-pocket expenses excluding the amount you paid for your deductible?

◯ Under $1000
◯ $1,000 to $4,999
◯ $5000 to $9,999
◯ $10,000 to $14,999
◯ $15,000 or more
◯ Don't know
◯ Prefer not to answer

Do you receive additional coverage, subsidies or other financial assistance to help pay for any health care services or medications? Include assistance for premiums, deductibles, out-of-pocket costs, and programs specifically related to prescription medications, vitamins, supplements and enzymes.

	Yes	No	Don't know
Premium tax credits available for plans purchased through the health insurance marketplace	○	○	○
Patient assistance programs or copay assistance programs sponsored by drug companies to help cover the cost of prescription medications including enzymes	○	○	○
"Loyalty rewards" programs sponsored by drug companies that provide free vitamins or supplements	○	○	○
Non-profit foundations, like HealthWell, to help cover copays for the cost of prescription therapies such as medicines, vitamins, supplements, enzymes, hypertonic saline solution, and others	○	○	○
Grants or assistance from community organizations or non-profits, such as Breathing Easy, Garret Thomas Foundation, Living Breath Foundation)	○	○	○
Grants of assistance from my care center	○	○	○
Family/ friend	○	○	○

Other assistance, please specify

_____

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The next questions are about problems you may have paying for your health care services.

In the last 12 months, have you ever decided not to appeal or challenge a denial because of the amount of time it might take to do so?

◯ Yes
◯ No
◯ Don't know

Thinking about your current health insurance and the benefits it offers, does your health plan limit any of the following?

	Yes	No	Don't know
The number of times you can visit your CF care center each year	◯	◯	◯
The number of times you can visit mental health providers each year	◯	◯	◯
The doctors in your insurance plan network	◯	◯	◯
The number of medical procedures you can get	◯	◯	◯
The type or number of Durable Medical Equipment you can get	◯	◯	◯
The type of prescription medications you can get (for example, generics or a less expensive medication)	◯	◯	◯
The number of prescription medications you can get per month	◯	◯	◯
The pharmacies where you can get your prescriptions filled	◯	◯	◯

Other benefits, please specify

_____

The next questions ask about care you delayed or never recevied.

In the last 12 months, were any of the following true for you?

	Yes	No	Does not apply	Don't know
You skipped medication doses to save money.	○	○	○	○
You took less medicine to save money.	○	○	○	○
You delayed filling a prescription to save money.	○	○	○	○
You asked your doctor for a lower-cost medication to save money.	○	○	○	○
You bought prescription drugs from another country to save money.	○	○	○	○
You used alternative therapies to save money.	○	○	○	○
You skipped or didn't take vitamins or nutritional supplements to save money.	○	○	○	○
You skipped a meal or ate less to save money.	○	○	○	○
You skipped one of your routine CF care center visits to save money.	○	○	○	○
You delayed a CF care center visit when you didn't feel well to save money.	○	○	○	○
You tried to delay or shorten a hospitalization to save money.	○	○	○	○

In the last 12 months, have you ever delayed or gone without medical care you needed for any of the following reasons? Please select all that apply.

☐ You were worried about the costs or having the claim denied
☐ You had difficulty finding a doctor that knows how to treat CF
☐ The doctor or hospital wouldn't accept your health insurance
☐ The doctor's office or CF care center is too far from where you live or work
☐ Your insurance declined or delayed approval for your treatment
☐ The costs of transportation or parking at your doctor's office or CF Care center are too high
☐ Other reasons
☐ None of the above

Please specify

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The next set of questions are about the impact of your health coverage on your quality of life.

Has paying for health care created financial problems for you or your family? This may involve large debt or losing assets (such as a home or savings) that are essential to your well-being.

◯ Yes
◯ No
◯ Don't know

Have you or your family ever been faced with the following issues because of medical bills?

	Yes	No	Does not apply	Don't know
Been contacted by a collection agency	◯	◯	◯	◯
Put off major purchases, such as a new home or car	◯	◯	◯	◯
Had difficulty paying for food	◯	◯	◯	◯
Had difficulty paying for other basic needs such as utilities or rent/ mortgage payment?	◯	◯	◯	◯

In the last 12 months, have concerns about keeping or getting insurance coverage affected your life in any of the following ways?

	Yes	No	Does not apply	Don't know
Affected your decision to go to school	◯	◯	◯	◯
Affected your decision to take a job, change jobs, or accept a raise	◯	◯	◯	◯
Affected your decision to get married	◯	◯	◯	◯
Affected your decision to move to another state	◯	◯	◯	◯

Thinking about your ability to get health care and health insurance coverage in future years, please identify your THREE biggest concerns from the list below.

☐ Rising health insurance premiums and out-of-pocket costs
☐ Rising drug costs
☐ Losing health insurance
☐ Health insurance companies not covering certain medications or other CF care
☐ Pre-existing condition will keep me from getting insurance coverage in the future
☐ Annual or lifetime limits will limit how my insurance covers in the future
☐ Assistance programs will end or I will not qualify for them
☐ Unsure
☐ Other concern

Please specify

_____

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The final questions are about how well you understand your health care coverage.

How well do you feel you understand the coverage benefits that your health insurance plan provides?

◯ Very
◯ Moderately
◯ Neutral
◯ Slightly
◯ Not at all

Where do you go to get information on health plans or patient assistance programs? Please select all that apply. (Please select all that apply.)

☐ CF care center
☐ Compass
☐ HealthWell Foundation
☐ Drug manufacturer
☐ Insurance company
☐ Family/friend
☐ Someone else with CF
☐ Your employer
☐ Internet search
☐ Other

Please specify

_____

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