Form approved OMB # 0920-#### Exp. date MM/DD/YYYY

# ATTACHMENT 4A Caregiver Survey (online, English)

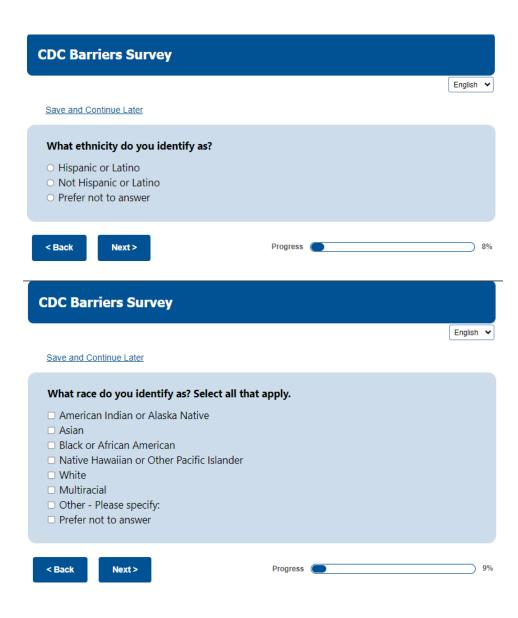
Public reporting burden of this collection of information is estimated to average of 15 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-####).

# For Caregivers of Patients with Breast Cancer

Save and Continue Later Si desea completer la encuesta en español, seleccione español en el menu despegable en la parte superior derecha de la pantalla. Thank you for agreeing to participate in this study. This survey will take you about 15 minutes to complete. After you submit the survey, you will receive a \$40 check or electronic gift card as a token of appreciation for your time. A goal of this study is to collect information about your experience as a caregiver for someone who was diagnosed with cancer. We are also interested in learning about any barriers your care recipient may have faced during their treatment. This survey includes questions on several topics. For example, you will be asked about where you live, your health, and how caregiving has impacted you. Some of these questions ask you to think back to events that may have occurred a few years ago. Although the answers may be hard to remember, please do the best you can. There are no right or wrong answers to any of these questions. You should just report what you have been through as a caregiver. Participation in this study is voluntary. Questions answered in this study will not affect your health care. You can skip any question you do not want to answer. Just go on to the next question. You may exit the survey at any time. You may also complete the survey in multiple sittings; your answers will be saved. Joining this study has minimal risks. Some of the questions are in the tore were them.		Engli	ish
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Save and Continue Later	
How old are you?	
○ 21-24 years old	
<ul> <li>25–29 years old</li> </ul>	
○ 30–34 years old	
<ul> <li>35–39 years old</li> <li>42 44 years old</li> </ul>	
<ul> <li>40-44 years old</li> <li>45 49 years old</li> </ul>	
<ul> <li>45-49 years old</li> <li>50-54 years old</li> </ul>	
<ul> <li>55–59 years old</li> </ul>	
0 60–64 years old	
○ 65–69 years old	
○ 70–74 years old	
<ul> <li>75 years old or older</li> </ul>	
< Back Next >	Progress 🔵
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	70
DC Barriers Caregiver Survey	70
DC Barriers Caregiver Survey Save and Continue Later What is your relationship to the individ	
DC Barriers Caregiver Survey Save and Continue Later What is your relationship to the individ 2021?	
DC Barriers Caregiver Survey Save and Continue Later What is your relationship to the individ 2021? They are your: Spouse (husband/wife) O domestic partner	
DC Barriers Caregiver Survey Save and Continue Later What is your relationship to the individ 2021? They are your:      spouse (husband/wife)     domestic partner     child	
DC Barriers Caregiver Survey Save and Continue Later What is your relationship to the individ 2021? They are your:      spouse (husband/wife)     domestic partner     child     parent	
DC Barriers Caregiver Survey Save and Continue Later What is your relationship to the individ 2021? They are your:      spouse (husband/wife)     domestic partner     child     parent     sibling	
DC Barriers Caregiver Survey Save and Continue Later What is your relationship to the individ 2021? They are your:      spouse (husband/wife)     domestic partner     child     parent	

CDC Barriers Caregiver Surv	
Save and Continue Later	English 🗸
For the rest of the survey, we will ref during their cancer treatment as a "c	er to the individual to whom you provided care are recipient."
< Back Next >	Progress 🛑 119
CDC Barriers Caregiver Surv	ey
Save and Continue Later	English 🗸
Do you live in the same household w • Yes • No	ith the care recipient?
< Back Next >	Progress ( 12%
CDC Barriers Caregiver Surv	ey <b>SERTI</b>
Save and Continue Later	English 💙
What is your biological sex? This is a certificate. Male Female Prefer not to answer	category that is based upon your original birth
< Back Next >	Progress 14%





#### Save and Continue Later

What was your marital status when the care recipient was <u>first diagnosed</u>?

- Never married
- Married
- O Living together with a partner as an unmarried couple / cohabitating
- Widowed
- Separated or divorced

#### What is your <u>current</u> marital status?

- Never married
- Married
- O Living together with a partner as an unmarried couple / cohabitating
- Widowed
- Separated or divorced



Next >

Progress 19%



#### Save and Continue Later

#### What was your employment status when the care recipient was first diagnosed?

- O Employed for pay (including self-employed) 40 hours or more per week
- O Employed for pay (including self-employed) Less than 40 hours per week
- O Retired
- O Homemaker
- O Student
- Out of work
- O Unable to work (e.g., due to disability, work authorization)

#### What is your current employment status?

- O Employed for pay (including self-employed) 40 hours or more per week
- O Employed for pay (including self-employed) Less than 40 hours per week
- Retired
- O Homemaker
- Student
- Out of work
- O Unable to work (e.g., due to disability, work authorization)

< Back	Next >	Progress (	219

#### **CDC Barriers Survey**

			English 🗸
Save and Conti	nue Later		
What is your	r <u>current</u> employmen	it status?	
<ul> <li>Employed</li> <li>Retired</li> <li>Homemake</li> <li>Student</li> <li>Out of wor</li> <li>Out of wor</li> </ul>	for pay (including self- er rk for 1 year or more rk for less than 1 year	-employed) – 40 or more hours per week -employed) – Less than 40 hours per week bility, work authorization)	
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## **CDC Barriers Survey**

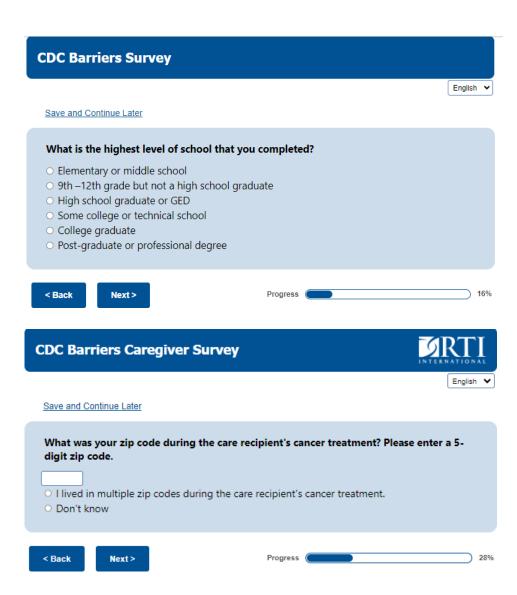


#### What is your current health insurance status? Please select all that apply.

- No insurance
- Lapse in coverage
- Private health insurance (purchased on your own or from your job or from your spouse's / partner's / parent's job)
- Medicaid
- Medicare/Medicare Advantage
- Military (Tricare, Champ-VA, or some other military insurance)
- Other Please specify:

< Back Next >

Progress 25%



Please enter the zip codes where you l	ived.				
Zip Code 1:					
Zip Code 2:					
Zip Code 3:					
< Back Next >	Progress (21)	1%			
CDC Barriers Caregiver Survey					
Save and Continue Later	English 🗸	·			
<ul> <li>Which best describes your home during your time as a caregiver to the care recipient?</li> <li>A one-family house detached from any other house (including mobile homes)</li> <li>A one-family house attached to one or more houses (e.g., townhome, duplex)</li> <li>An apartment building, apartment complex, or condo</li> <li>I did not have stable housing (staying in a hotel, in a shelter, living outside on the street or in a park, etc.).</li> <li>Other - Please specify:</li> </ul>					
< Back Next >	Progress ( 34	%			

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				rrie		 
-	_	<u> </u>				 

	English 🗸
Save and Continue Later	
Think about your household, which includes everyone who lives with you.	
Please indicate whether the following statements are often true, sometimes true, o true.	r never
"Within the past 12 months, we worried whether our food would run out before we money to buy more."	e had
Often true	
Sometimes true     Never true	
"Within the past 12 months, the food we bought just didn't last and we didn't have money to get more." • Often true	•
<ul> <li>Sometimes true</li> <li>Never true</li> </ul>	
< Back Next > Progress	23%



#### Save and Continue Later

# What condition(s) had <u>you</u> been dealing with shortly before the care recipient's breast cancer diagnosis? Select all that apply.

- Arthritis, rheumatism, or gout
- Benign tumors or cysts
- Cancer
- Chronic pain
- Circulation problems (including blood clots)
- Dementia or Alzheimer's
- Depression, anxiety, or emotional problem
- Diabetes
- Epilepsy or seizures
- Fibromyalgia or lupus
- Gastrointestinal conditions or disorders
- Hearing problem
- Heart problem
- Hernia
- Hypertension or high blood pressure
- □ Kidney, bladder, or renal problems
- Lung or breathing problem (for example, asthma and emphysema)
- Migraine headaches (not just headaches)
- Multiple Sclerosis (MS) or Muscular Dystrophy (MD)
- Osteoporosis or tendinitis
- Parkinson's disease or other tremors
- Stroke
- Thyroid problems or Graves' disease
- Ulcer
- Vision problem or problem seeing
- Weight problem
- Other impairment or problem Please specify one:
- None of the above

< Back

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Progress 38%



#### Save and Continue Later

The next questions are about your experiences during the care recipient's cancer treatment.

Were you the primary caregiver for the care recipient, taking responsibility for most of the care recipient's needs during their treatment?

YesNo

< Back

Progress 39%

# **CDC Barriers Caregiver Survey**

Next >



#### Save and Continue Later

During the care recipient's cancer treatment, what type(s) of support did you provide? Select all that apply.

- Provided emotional support
- Provided financial support
- Helped manage finances
- Accompanied care recipient to medical appointments
- Helped with medical decision-making
- Coordinated medical care (e.g., finding health care providers, making appointments, helping with prescriptions/medications)
- Provided transportation to and from doctor, for errands, etc.
- Assisted with daily tasks (e.g., cooking, cleaning, childcare)
- Other Please specify:



Progress 41%



#### Save and Continue Later

During t	he care recipi	ent's cancer treatment, were you paid for your role as a caregiver?	
○ Yes ○ No			
< Back	Next >	Progress 44	2%

## **CDC Barriers Caregiver Survey**



Save and Continue Later

# During the care recipient's <u>cancer treatment</u>, what were your household's source(s) of income? Select all that apply.

- Income from employment
- Pension or retirement
- Government assistance (disability, social security)
- Paid leave from work
- Stipends or financial assistance from nonprofit organizations or charitable organizations
- Other Please specify:

#### Currently, what are your household's sources of income? Select all that apply.

- Income from employment
- Pension or retirement
- Government assistance (disability, social security)
- Paid leave from work
- Stipends or financial assistance from nonprofit organizations or charitable organizations
- Other Please specify:

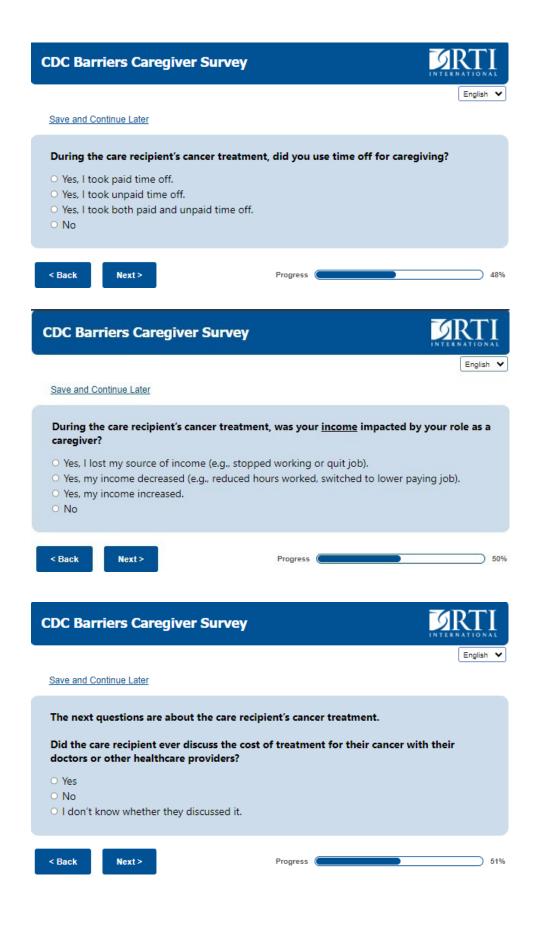


Progress 44%



#### Save and Continue Later

During the care recipient's cancer treatment, how many hours per week on average did you spend caring for them (e.g., attending doctor's appointments, helping them manage side effects, assisting with daily tasks like cooking or cleaning, spending time together, praying)? O Less than 5 hours Between 5 to 10 hours Between 11 to 15 hours Between 16 to 20 hours More than 20 hours Don't know < Back Next > Progress 🔵 46% **CDC Barriers Caregiver Survey** English ¥ Save and Continue Later During the care recipient's cancer treatment, was your employment impacted by your role as a caregiver? O Yes, my work schedule changed (e.g., went from full to part-time or my hours were reduced or increased) O Yes, my employment status changed (e.g., changed jobs, quit job, retired, or got an additional job). O No (e.g. job stayed the same, was already retired) < Back 47% Next > Progress





#### Save and Continue Later

When the care recipient was choosing a treatment course for their cancer, did they consider the costs of specific treatments?

- A great deal
- $\odot$  Somewhat
- Not at all
- O Not applicable; the care recipient did not receive information about treatment costs.
- Don't know

< Back Next >

Progress 52%



#### Save and Continue Later

How much money would you estimate your care recipient/care recipient's household has paid out-of-pocket in the past 12 months for medical expenses related to their breast cancer, including co-payments, hospital bills, deductibles, and medication costs including hormonal therapy and other medications to help prevent cancer recurrence?

For this question, please think of out-of-pocket money that they spent and not money provided by the insurance company.

- Less than \$500
- \$500-\$2,000
- \$2,001-\$5,000
- \$5,001-\$10,000
- More than \$10,000
- Don't know

How much money would you estimate your care recipient has paid out-of-pocket in the past 12 months for other expenses related to their breast cancer, such as travel costs, parking, child/elderly care, special diet/food/drinks, etc.?

For this question, please think of out-of-pocket money that they spent and not money provided by the insurance company.

- Less than \$500
- \$500-\$2,000
- \$2,001-\$5,000
- \$5,001-\$10,000
- More than \$10,000
- Don't know

< Back

Next >

Progress (

55%



#### Save and Continue Later

How would you describe the care recipient's reaction to the money they spent for cancer treatment?

#### They spent...

- $\odot$  ...more money than they expected
- $\, \odot \,$  ...about as much money as they expected
- …less money than they expected
- Don't know



Progress 56%



#### Save and Continue Later

What were the top non-medical issues the care recipient faced during their cancer treatment?

You may select up to 5 issues.

- Afraid the treatment will be too painful or unpleasant
- Could not afford care (e.g., cost too much; other competing expenses)
- Could not afford food
- Lack of permanent, stable housing
- No insurance coverage, or insurance company would not approve, cover or pay for care
- Problems getting transportation to doctor's office for treatment or office was too far away
- Could not get time off work for appointments and care (e.g., no paid sick leave, no flexible work schedule, no medical leave)
- Didn't know where to go to get care (e.g., no primary doctor or usual source of care to make referral; unfamiliar with local providers; local specialty practice closed)
- Was refused services (e.g., out of network provider, not accepting new patients)
- Took too long to get an appointment that worked for their schedule
- Experienced discrimination (e.g., racial or ethnic discrimination, gender, weight, sexual orientation, disability status)
- Unable to understand the doctor's language (e.g., different language without access to interpretation)
- Medical information was too hard to understand
- Couldn't get dependent care (e.g., for child, elderly relative, or relative with a disability)
- Could not get a friend or family member to go with them to appointment
- Other
- Did not encounter any issues
- I was not aware of any issues.

< Back

Next >

Progress 🤇

) 57%



#### Save and Continue Later

Af	raid the treatment will be too painful or unpleasant
Co	uld not afford care (e.g., cost too much; other competing expenses)
Co	uld not afford food
La	ck of permanent, stable housing
No	o insurance coverage, or insurance company would not approve, cover or pay re

If respondent selected "Did not encounter any issues", they will see:

Please select the top 5 factors <u>that made it easier for the cancer recipient to get medical</u> <u>care</u> for their cancer treatment.

- Worked with a nurse/patient navigator who provided additional support
- Had support of a caregiver
- Was able to manage side effects
- Was able to afford care
- Was able to cover all non-medical expenses like food
- Had permanent, stable housing
- Insurance covered most of their medical costs
- Easy access to transportation
- Convenient location of healthcare provider
- Was able to take time off work for appointments and care (e.g., paid sick leave, flexible work schedule, medical leave available)
- Connected to a provider by someone they knew (e.g., doctor, nurse, family member, friend, others on social media)
- Was able to get an appointment with a doctor or specialist within a reasonable timeframe
- Was able to make arrangements for dependent care (e.g., for child, elderly relative, or relative with a disability), if needed
- Was treated with respect by their doctor
- Was able to understand medical information that was shared with them
- Other Please specify:



Progress

) 61%



Save and Continue Later

During the care recipient's cancer treatment, was your health impacted by your role as caregiver?

- Yes, it was negatively impacted.
- $\odot$  Yes, it was positively impacted.
- $\odot\,$  No, my health was not impacted.



Progress 62%



66%

#### Save and Continue Later

During the care recipient's cancer treatment, how much support did you get from your <u>family</u>?

- All of the support I needed
- Some of the support I needed
- No support
- O Prefer not to answer

During the care recipient's cancer treatment, how much support did you get from your <u>friends</u>?

- All of the support I needed
- Some of the support I needed

Next >

- No support
- Prefer not to answer

< Back

Progress 🤇



#### Save and Continue Later

The next three questions will ask about how you have felt more recently, in the past week.

Below is a list of statements that other people facing an illness have said are important.

For each of the following statements, please select your response as it applies to the <u>past</u> <u>7 days</u>.

	1 – Not at all	2 - A little bit	3 - Somewhat	4 - Quite a bit	5 - Very much
I have a lack of energy.	0	0	0	0	0
l have nausea.	0	0	0	0	0
Because of my physical condition, I have trouble meeting the needs of my family.	0	0	0	0	0
l have pain.	0	0	0	0	0
l feel ill.	0	0	0	0	0
I am able to enjoy life.	0	0	0	0	0
I am forced to spend time in bed.	0	0	0	0	0

< Back

Next >

Progress		69%

English 💙

# CDC Barriers Caregiver Survey Save and Continue Later Are you currently taking any medication or receiving other medical treatments? No

Yes

< Back Next >

Progress 70%



Save and Continue Later

Please select your response to the following statement as it applies to the <u>past 7 days</u> .					
	1 – Not at all	2 - A little bit	3 - Somewhat	4 - Quite a bit	5 – Very much
I am bothered by the side effects of treatment.	0	0	0	0	0
< Back Next >		Progress			

# **CDC Barriers Caregiver Survey**

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English	~

Save and Continue Later

Below is a list of statements that other people facing an illness have said are important.

For each of the following statements, please select your response as it applies to the <u>past</u> <u>7 days</u>.

	1 – Not at all	2 - A little bit	3 - Somewhat	4 - Quite a bit	5 – Very much
I am satisfied with how I am coping with my loved one's illness.	0	0	0	0	0
I am losing hope in the fight against my loved one's illness.	0	0	0	0	0
I feel nervous.	0	0	0	0	0
I worry about my loved one dying.	0	0	0	0	0
I worry that my loved one's condition will get worse.	0	0	0	0	0



	1775	
Progress		739



#### Save and Continue Later

Below is a list of statements that other people facing an illness have said are important.

For each of the following statements, please select your response as it applies to the <u>past</u> <u>7 days</u>.

	1 – Not at all	2 - A little bit	3 - Somewhat	4 - Quite a bit	5 – Very much
I am able to work (include work at home).	0	0	0	0	0
My work (include work at home) is fulfilling.	0	0	0	0	0
I am able to enjoy life.	0	0	0	0	0
I have accepted my loved one's illness.	0	0	0	0	0
I am sleeping well.	0	0	0	0	0
I am enjoying the things I usually do for fun.	0	0	0	0	0
I am content with the quality of my life right now.	0	0	0	0	0

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Progress 74%

# **CDC Barriers Caregiver Survey**



75%

#### Save and Continue Later

During the care recipient's cancer treatment, were you provided with information or resources specifically for caregivers? Select all that apply.

- Yes, from my care recipient's doctor or health care team
- Yes, from a nonprofit organization (e.g., American Cancer Society)
- Yes, from another source Please specify:

Next >

- □ No
- Don't know

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Progress

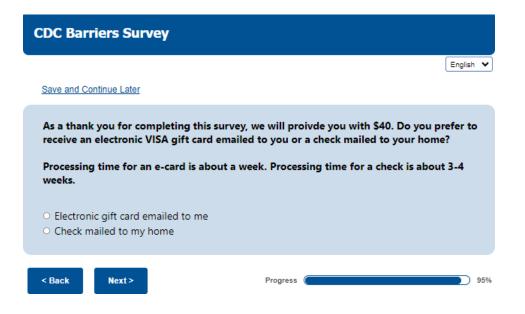
CDC Barriers Caregiver Survey	
Save and Continue Later	English 🗸
How informed did you feel about the <u>pot</u> treatment?	tential side effects from the care recipient's
<ul> <li>Very</li> <li>Somewhat</li> <li>Not at all</li> </ul>	
How informed did you feel about the <u>pot</u> wounds not healing) from the care recipie	<u>ential complications</u> (e.g., drains blocking, ent's treatment?
<ul> <li>Very</li> <li>Somewhat</li> <li>Not at all</li> </ul>	
< Back Next >	Progress 78%
CDC Barriers Caregiver Survey	
Save and Continue Later	English 🗸
How often did the care recipient's doctors much cancer-related information as you w	and other healthcare providers give you as vanted?
<ul> <li>Never</li> <li>Sometimes</li> <li>Usually</li> <li>Always</li> <li>Not applicable (I did not ask for cancer-rel</li> </ul>	lated information.)
< Back Next >	Progress 80%

Please describe your experience (o	ptional):
	Æ
< Back Next >	Progress 80
DC Barriers Caregiver Sur	
Save and Continue Later	English 🛰
How often did the care recipient's o for what you had to say?	doctors and other healthcare providers show respect
<ul> <li>Never</li> <li>Sometimes</li> <li>Usually</li> <li>Always</li> <li>Not applicable (I did not speak with</li> </ul>	h my loved one's doctor.)
< Back Next >	Progress ( 83
Please describe your experience (op	ptional):
< Back Next >	Progress 80%



#### Save and Continue Later

How often did the care recipient's other family members and/or friends show respect or appreciate your efforts (e.g., help with decision-making, house chores, emotional support, transportation, etc.)? O Never Sometimes Usually Always Not applicable (I did not speak with other family members and/or friends.) < Back Next > Progress ( 85% Please describe your experience (optional): 80% < Back Next > Progress (



# **CDC Barriers Survey**

Save and Continue Later
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Please enter <u>your con</u>	tact information so th	hat we may	send you a \$40 ch	eck.	
Full name:					
Street address 1:					
Street addres 2:					
City:					
State:					
Zip code:					
< Back Next >		Progress (			96%
CDC Barriers Surv	vey				
Save and Continue Later				English	<b>~</b>
Please enter your ema	il address for the elec	tronic gift c	ard:		

English 🗸

Please re	type the email a	ddress for confirmation:
< Back	Next >	Progress 98%



#### Save and Continue Later

We will be conducting 1-hour phone or online interviews with a subset of caregivers who complete this survey and are willing to volunteer their time. Would you like to be considered to participate in a 1-hour phone/online interview? Yes O No < Back Next > Progress 🤇 93% **CDC Barriers Caregiver Survey** -9 English 💙 Save and Continue Later Please provide your phone number: Please provide your email address: Please retype the email address for confirmation: < Back Next > Progress 🤇 97%



#### Thank you!

If you have any questions about the survey, please do not hesitate to call us toll free at (833) 997-2714 or email us at <u>CDC CancerSurvey@rti.org</u>

Please click [SUBMIT] to submit your responses.

Submit

Progress (

100%

# For Caregivers of Patients with Cervical Cancer

# CDC Barriers Caregiver Survey

Save and Continue Later

Si desea completer la encuesta en español, seleccione español en el menu despegable en la parte superior derecha de la pantalla.

English V

Thank you for agreeing to participate in this study. This survey will take you about 15 minutes to complete. After you submit the survey, you will receive a \$40 check or electronic gift card as a token of appreciation for your time.

A goal of this study is to collect information about your experience as a caregiver for someone who was diagnosed with cancer. We are also interested in learning about any barriers your care recipient may have faced during their treatment.

This survey includes questions on several topics. For example, you will be asked about where you live, your health, and how caregiving has impacted you. Some of these questions ask you to think back to events that may have occurred a few years ago.

Although the answers may be hard to remember, please do the best you can. There are no right or wrong answers to any of these questions. You should just report what you have been through as a caregiver.

Participation in this study is voluntary. Questions answered in this study will not affect your health care. You can skip any question you do not want to answer. Just go on to the next question. You may exit the survey at any time. You may also complete the survey in multiple sittings; your answers will be saved. Joining this study has minimal risks. Some of the questions on the survey may be upsetting, but you don't have to answer them. Protections are in place to keep your data as safe as possible.

Save and Continue Later	
How old are you?	
○ 21-24 years old	
<ul> <li>25–29 years old</li> </ul>	
○ 30–34 years old	
• 35–39 years old	
<ul> <li>40-44 years old</li> <li>45 40 years old</li> </ul>	
<ul> <li>45-49 years old</li> <li>50-54 years old</li> </ul>	
<ul> <li>55–59 years old</li> </ul>	
0 60–64 years old	
○ 65–69 years old	
○ 70–74 years old	
<ul> <li>75 years old or older</li> </ul>	
< Back Next >	Progress 🔵
< Back Next>	70
	70
DC Barriers Caregiver Survey	70
DC Barriers Caregiver Survey Save and Continue Later What is your relationship to the individ	
DC Barriers Caregiver Survey Save and Continue Later What is your relationship to the individ 2021?	
DC Barriers Caregiver Survey Save and Continue Later What is your relationship to the individ 2021? They are your: Spouse (husband/wife) O domestic partner	
DC Barriers Caregiver Survey Save and Continue Later What is your relationship to the individ 2021? They are your:      spouse (husband/wife)     domestic partner     child	
DC Barriers Caregiver Survey Save and Continue Later What is your relationship to the individ 2021? They are your:      spouse (husband/wife)     domestic partner     child     parent	
DC Barriers Caregiver Survey Save and Continue Later What is your relationship to the individ 2021? They are your:      spouse (husband/wife)     domestic partner     child     parent     sibling	
DC Barriers Caregiver Survey Save and Continue Later What is your relationship to the individ 2021? They are your:      spouse (husband/wife)     domestic partner     child     parent	

CDC Barriers Caregiver Surv	
Save and Continue Later	English 🗸
For the rest of the survey, we will ref during their cancer treatment as a "c	er to the individual to whom you provided care are recipient."
< Back Next >	Progress 🛑 119
CDC Barriers Caregiver Surv	ey
Save and Continue Later	English 🗸
Do you live in the same household w • Yes • No	ith the care recipient?
< Back Next >	Progress ( 12%
CDC Barriers Caregiver Surv	ey <b>DIRECTIONAL</b>
Save and Continue Later	English 💙
What is your biological sex? This is a certificate. Male Female Prefer not to answer	category that is based upon your original birth
< Back Next >	Progress 14%



#### Save and Continue Later

What was your marital status when the care recipient was <u>first diagnosed</u>?

- Never married
- Married
- O Living together with a partner as an unmarried couple / cohabitating
- Widowed
- Separated or divorced

#### What is your <u>current</u> marital status?

- Never married
- Married
- O Living together with a partner as an unmarried couple / cohabitating
- Widowed
- Separated or divorced



Next >

Progress 19%



#### Save and Continue Later

#### What was your employment status when the care recipient was first diagnosed?

- O Employed for pay (including self-employed) 40 hours or more per week
- O Employed for pay (including self-employed) Less than 40 hours per week
- O Retired
- O Homemaker
- O Student
- Out of work
- O Unable to work (e.g., due to disability, work authorization)

#### What is your current employment status?

- O Employed for pay (including self-employed) 40 hours or more per week
- O Employed for pay (including self-employed) Less than 40 hours per week
- Retired
- O Homemaker
- Student
- Out of work
- O Unable to work (e.g., due to disability, work authorization)

< Back	Next >	Progress (	219

### **CDC Barriers Survey**

			English 🗸
Save and Conti	nue Later		
What is your	r <u>current</u> employmen	it status?	
<ul> <li>Employed</li> <li>Retired</li> <li>Homemake</li> <li>Student</li> <li>Out of wor</li> <li>Out of wor</li> </ul>	for pay (including self- er rk for 1 year or more rk for less than 1 year	-employed) – 40 or more hours per week -employed) – Less than 40 hours per week bility, work authorization)	
< Back	Next >	Progress	13%

## **CDC Barriers Survey**

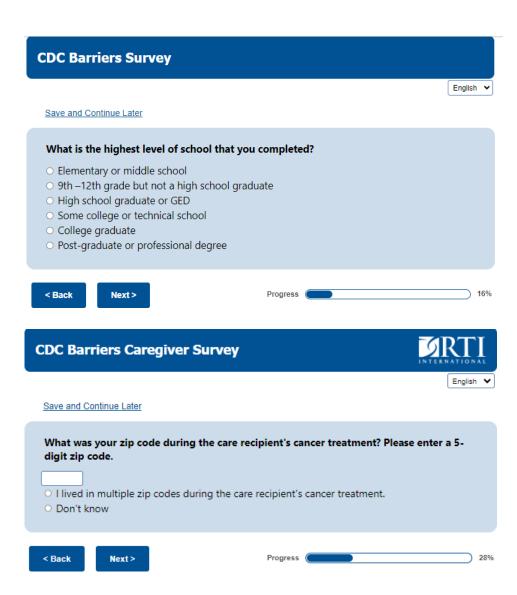


#### What is your current health insurance status? Please select all that apply.

- No insurance
- Lapse in coverage
- Private health insurance (purchased on your own or from your job or from your spouse's / partner's / parent's job)
- Medicaid
- Medicare/Medicare Advantage
- Military (Tricare, Champ-VA, or some other military insurance)
- Other Please specify:

< Back Next >

Progress 25%



Please enter the zip codes where you l	ived.	
Zip Code 1:		
Zip Code 2:		
Zip Code 3:		
< Back Next >	Progress (21)	1%
CDC Barriers Caregiver Survey		
Save and Continue Later	English 🗸	·
<ul> <li>A one-family house detached from any</li> <li>A one-family house attached to one or</li> <li>An apartment building, apartment com</li> </ul>	more houses (e.g., townhome, duplex)	
< Back Next >	Progress ( 34	%

_	_	_	_		_	
				Distance of the		 <b>CONT</b>
				rrie		 
-	_	<u> </u>				 

	English 🗸
Save and Continue Later	
Think about your household, which includes everyone who lives with you.	
Please indicate whether the following statements are often true, sometimes true, o true.	r never
"Within the past 12 months, we worried whether our food would run out before we money to buy more."	e had
Often true	
Sometimes true     Never true	
"Within the past 12 months, the food we bought just didn't last and we didn't have money to get more." • Often true	•
<ul> <li>Sometimes true</li> <li>Never true</li> </ul>	
< Back Next > Progress	23%

# What condition(s) had <u>you</u> been dealing with shortly before the care recipient's cervical cancer diagnosis? Select all that apply.

- Arthritis, rheumatism, or gout
- Benign tumors or cysts
- Cancer
- Chronic pain
- Circulation problems (including blood clots)
- Dementia or Alzheimer's
- Depression, anxiety, or emotional problem
- Diabetes
- □ Epilepsy or seizures
- Fibromyalgia or lupus
- Gastrointestinal conditions or disorders
- Hearing problem
- Heart problem
- 🗆 Hernia
- Hypertension or high blood pressure
- □ Kidney, bladder, or renal problems
- Lung or breathing problem (for example, asthma and emphysema)
- Migraine headaches (not just headaches)
- Multiple Sclerosis (MS) or Muscular Dystrophy (MD)
- Osteoporosis or tendinitis
- □ Parkinson's disease or other tremors
- Stroke
- Thyroid problems or Graves' disease
- Ulcer
- □ Vision problem or problem seeing
- Weight problem
- Other impairment or problem Please specify one:
- None of the above



#### Save and Continue Later

The next questions are about your experiences during the care recipient's cancer treatment.

Were you the primary caregiver for the care recipient, taking responsibility for most of the care recipient's needs during their treatment?

YesNo

< Back

Progress 39%

# **CDC Barriers Caregiver Survey**

Next >



#### Save and Continue Later

During the care recipient's cancer treatment, what type(s) of support did you provide? Select all that apply.

- Provided emotional support
- Provided financial support
- Helped manage finances
- Accompanied care recipient to medical appointments
- Helped with medical decision-making
- Coordinated medical care (e.g., finding health care providers, making appointments, helping with prescriptions/medications)
- Provided transportation to and from doctor, for errands, etc.
- Assisted with daily tasks (e.g., cooking, cleaning, childcare)
- Other Please specify:



Progress 41%



#### Save and Continue Later

During t	he care recipi	ent's cancer treatment, were you paid for your role as a caregiver?	
○ Yes ○ No			
< Back	Next >	Progress 44	2%

## **CDC Barriers Caregiver Survey**



Save and Continue Later

# During the care recipient's <u>cancer treatment</u>, what were your household's source(s) of income? Select all that apply.

- Income from employment
- Pension or retirement
- Government assistance (disability, social security)
- Paid leave from work
- Stipends or financial assistance from nonprofit organizations or charitable organizations
- Other Please specify:

#### Currently, what are your household's sources of income? Select all that apply.

- Income from employment
- Pension or retirement
- Government assistance (disability, social security)
- Paid leave from work
- Stipends or financial assistance from nonprofit organizations or charitable organizations
- Other Please specify:

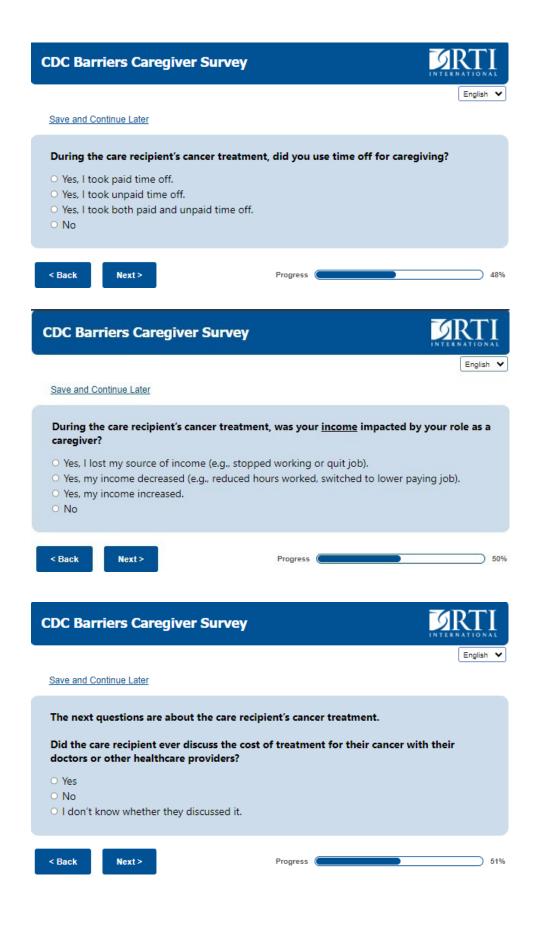


Progress 44%



#### Save and Continue Later

During the care recipient's cancer treatment, how many hours per week on average did you spend caring for them (e.g., attending doctor's appointments, helping them manage side effects, assisting with daily tasks like cooking or cleaning, spending time together, praying)? O Less than 5 hours Between 5 to 10 hours Between 11 to 15 hours Between 16 to 20 hours More than 20 hours Don't know < Back Next > Progress 🔵 46% **CDC Barriers Caregiver Survey** English ¥ Save and Continue Later During the care recipient's cancer treatment, was your employment impacted by your role as a caregiver? O Yes, my work schedule changed (e.g., went from full to part-time or my hours were reduced or increased) O Yes, my employment status changed (e.g., changed jobs, quit job, retired, or got an additional job). O No (e.g. job stayed the same, was already retired) < Back 47% Next > Progress





#### Save and Continue Later

When the care recipient was choosing a treatment course for their cancer, did they consider the costs of specific treatments?

- A great deal
- $\odot$  Somewhat
- Not at all
- O Not applicable; the care recipient did not receive information about treatment costs.
- Don't know

< Back Next >

Progress 52%

How much money would you estimate your care recipient/care recipient's household has paid out-of-pocket in the past 12 months for <u>medical expenses</u> related to their cervical cancer, including co-payments, hospital bills, deductibles, and medication costs – including hormonal therapy and other medications to help prevent cancer recurrence?

For this question, please think of out-of-pocket money that they spent and not money provided by the insurance company.

- Less than \$500
- \$500-\$2,000
- \$2,001-\$5,000
- \$5,001-\$10,000
- More than \$10,000
- Don't know

How much money would you estimate your care recipient has paid out-of-pocket in the past 12 months for <u>other expenses</u> related to their cervical cancer, such as travel costs, parking, child/elderly care, special diet/food/drinks, etc.?

For this question, please think of out-of-pocket money that they spent and not money provided by the insurance company.

- Less than \$500
- \$500-\$2,000
- \$2,001-\$5,000
- \$5,001-\$10,000
- More than \$10,000
- Don't know

< Back

Next >

Progress (

54%



#### Save and Continue Later

How would you describe the care recipient's reaction to the money they spent for cancer treatment?

#### They spent...

- $\odot$  ...more money than they expected
- $\, \odot \,$  ...about as much money as they expected
- …less money than they expected
- Don't know



Progress 56%



#### Save and Continue Later

What were the top non-medical issues the care recipient faced during their cancer treatment?

You may select up to 5 issues.

- Afraid the treatment will be too painful or unpleasant
- Could not afford care (e.g., cost too much; other competing expenses)
- Could not afford food
- Lack of permanent, stable housing
- No insurance coverage, or insurance company would not approve, cover or pay for care
- Problems getting transportation to doctor's office for treatment or office was too far away
- Could not get time off work for appointments and care (e.g., no paid sick leave, no flexible work schedule, no medical leave)
- Didn't know where to go to get care (e.g., no primary doctor or usual source of care to make referral; unfamiliar with local providers; local specialty practice closed)
- Was refused services (e.g., out of network provider, not accepting new patients)
- Took too long to get an appointment that worked for their schedule
- Experienced discrimination (e.g., racial or ethnic discrimination, gender, weight, sexual orientation, disability status)
- Unable to understand the doctor's language (e.g., different language without access to interpretation)
- Medical information was too hard to understand
- Couldn't get dependent care (e.g., for child, elderly relative, or relative with a disability)
- Could not get a friend or family member to go with them to appointment
- Other
- Did not encounter any issues
- I was not aware of any issues.

< Back

Next >

Progress 🤇

) 57%



#### Save and Continue Later

 Of the top issues you selected, please rank them, with "1" being the most important.

 Afraid the treatment will be too painful or unpleasant

 Could not afford care (e.g., cost too much; other competing expenses)

 Could not afford food

 Lack of permanent, stable housing

 No insurance coverage, or insurance company would not approve, cover or pay for care

If caregiver selects "Did not encounter any issues", will see:

Please select the top 5 factors <u>that made it easier for the cancer recipient to get medical</u> <u>care</u> for their cancer treatment.

Worked with a nurse/	patient navid	ator who	provided a	additional	support
- worked with a huise/	patient navig	Jacor wino	provided	additional	support

- Had support of a caregiver
- Was able to manage side effects
- Was able to afford care
- Was able to cover all non-medical expenses like food
- Had permanent, stable housing
- Insurance covered most of their medical costs
- Easy access to transportation
- Convenient location of healthcare provider
- Was able to take time off work for appointments and care (e.g., paid sick leave, flexible work schedule, medical leave available)
- Connected to a provider by someone they knew (e.g., doctor, nurse, family member, friend, others on social media)
- Was able to get an appointment with a doctor or specialist within a reasonable timeframe
- Was able to make arrangements for dependent care (e.g., for child, elderly relative, or relative with a disability), if needed
- Was treated with respect by their doctor
- Was able to understand medical information that was shared with them
- □ **Other** Please specify:



Progress (

61%



Save and Continue Later

During the care recipient's cancer treatment, was your health impacted by your role as caregiver?

- Yes, it was negatively impacted.
- $\odot$  Yes, it was positively impacted.
- $\odot\,$  No, my health was not impacted.



Progress 62%



66%

#### Save and Continue Later

During the care recipient's cancer treatment, how much support did you get from your <u>family</u>?

- All of the support I needed
- Some of the support I needed
- No support
- O Prefer not to answer

During the care recipient's cancer treatment, how much support did you get from your <u>friends</u>?

- All of the support I needed
- Some of the support I needed

Next >

- No support
- Prefer not to answer

< Back

Progress 🤇



#### Save and Continue Later

The next three questions will ask about how you have felt more recently, in the past week.

Below is a list of statements that other people facing an illness have said are important.

For each of the following statements, please select your response as it applies to the <u>past</u> <u>7 days</u>.

1 – Not at all	2 - A little bit	3 - Somewhat	4 - Quite a bit	5 - Very much
0	0	0	0	0
0	0	0	0	0
0	0	0	0	0
0	0	0	0	0
0	0	0	0	0
0	0	0	0	0
0	0	0	0	0
	at all 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0	at alllittle bitOOOOOOOOOOOOOOOOOO	at all         little bit         Somewhat           O         O         O           O         O         O           O         O         O           O         O         O           O         O         O           O         O         O           O         O         O           O         O         O           O         O         O           O         O         O           O         O         O	at all         little bit         Somewhat         a bit           O         O         O         O           O         O         O         O           O         O         O         O           O         O         O         O           O         O         O         O           O         O         O         O           O         O         O         O           O         O         O         O           O         O         O         O           O         O         O         O           O         O         O         O

Progress (

< Back Next >

**CDC Barriers Caregiver Survey** 



69%

Save and Continue Later





Save and Continue Later

lease select your response to th	e followir 1 – Not at all	<b>ig statemen</b> 2 - A little bit	3 - Somewhat	s to the <u>past</u> 4 - Quite a bit	<u>7 days</u> . 5 – Very much
I am bothered by the side effects of treatment.	0	0	0	0	0
Back Next>		Progress	(		

# **CDC Barriers Caregiver Survey**

SI		ļ
TRIERR	English	-

Save and Continue Later

Below is a list of statements that other people facing an illness have said are important.

For each of the following statements, please select your response as it applies to the <u>past</u> <u>7 days</u>.

	1 – Not at all	2 - A little bit	3 - Somewhat	4 - Quite a bit	5 – Very much
I am satisfied with how I am coping with my loved one's illness.	0	0	0	0	0
I am losing hope in the fight against my loved one's illness.	0	0	0	0	0
I feel nervous.	0	0	0	0	0
I worry about my loved one dying.	0	0	0	0	0
I worry that my loved one's condition will get worse.	0	0	0	0	0

< Back

Next >

Progress 🦲 73% 



#### Save and Continue Later

Below is a list of statements that other people facing an illness have said are important.

For each of the following statements, please select your response as it applies to the <u>past</u> <u>7 days</u>.

	1 – Not at all	2 - A little bit	3 - Somewhat	4 - Quite a bit	5 – Very much
I am able to work (include work at home).	0	0	0	0	0
My work (include work at home) is fulfilling.	0	0	0	0	0
I am able to enjoy life.	0	0	0	0	0
I have accepted my loved one's illness.	0	0	0	0	0
I am sleeping well.	0	0	0	0	0
I am enjoying the things I usually do for fun.	0	0	0	0	0
I am content with the quality of my life right now.	0	0	0	0	0

< Back

Next >

Progress 74%

# **CDC Barriers Caregiver Survey**



75%

#### Save and Continue Later

During the care recipient's cancer treatment, were you provided with information or resources specifically for caregivers? Select all that apply.

- Yes, from my care recipient's doctor or health care team
- Yes, from a nonprofit organization (e.g., American Cancer Society)
- Yes, from another source Please specify:

Next >

- □ No
- Don't know

< Back

Progress

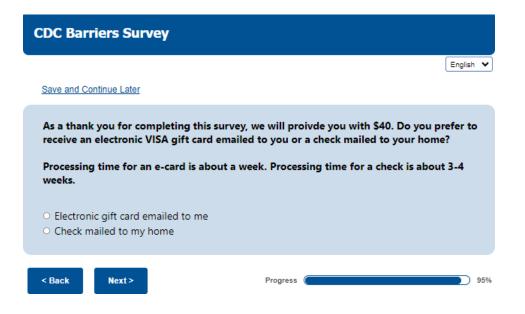
CDC Barriers Caregiver Survey	
Save and Continue Later	English 🗸
treatment?	tential side effects from the care recipient's
<ul> <li>Very</li> <li>Somewhat</li> <li>Not at all</li> </ul>	
How informed did you feel about the <u>pot</u> wounds not healing) from the care recipie	<u>tential complications</u> (e.g., drains blocking, ent's treatment?
<ul> <li>Very</li> <li>Somewhat</li> <li>Not at all</li> </ul>	
< Back Next >	Progress 78%
CDC Barriers Caregiver Survey	<b>VIRTUAL</b>
Save and Continue Later	English 🗸
How often did the care recipient's doctors much cancer-related information as you w	and other healthcare providers give you as vanted?
<ul> <li>Never</li> <li>Sometimes</li> <li>Usually</li> <li>Always</li> </ul>	
<ul> <li>Not applicable (I did not ask for cancer-rel</li> </ul>	lated mormation.)
< Back Next >	Progress 80%

Please describe your experience (op	ptional):
	~
< Back Next >	Progress ( 80
CDC Barriers Caregiver Sur	
Save and Continue Later	English 🛰
How often did the care recipient's d for what you had to say?	doctors and other healthcare providers show respect
<ul> <li>Never</li> <li>Sometimes</li> <li>Usually</li> <li>Always</li> <li>Not applicable (I did not speak with</li> </ul>	h my loved one's doctor.)
< Back Next >	Progress ( 83
Please describe your experience (op	otional):
	*
< Back Next >	Progress 80%



#### Save and Continue Later

How often did the care recipient's other family members and/or friends show respect or appreciate your efforts (e.g., help with decision-making, house chores, emotional support, transportation, etc.)? O Never Sometimes Usually Always Not applicable (I did not speak with other family members and/or friends.) < Back Next > Progress ( 85% Please describe your experience (optional): 80% < Back Next > Progress (



# **CDC Barriers Survey**

Save and Continue Later
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Please enter <u>your con</u>	<u>itact information</u> so	that we may	send you a \$40	check.		
Full name:						
Street address 1:						
Street addres 2:						
City:						
State:						
Zip code:						
< Back Next >		Progress	(			96%
CDC Barriers Surv	vey					
Save and Continue Later					English	<b>~</b>
Please enter your email address for the electronic gift card:						

English 🗸

Please re	type the email a	Idress for confirmation:
< Back	Next >	Progress 98%



#### Save and Continue Later

We will be conducting 1-hour phone or online interviews with a subset of caregivers who complete this survey and are willing to volunteer their time. Would you like to be considered to participate in a 1-hour phone/online interview? O Yes O No < Back Next > Progress 🤇 93% **CDC Barriers Caregiver Survey** -9 English 💙 Save and Continue Later Please provide your phone number: Please provide your email address: Please retype the email address for confirmation: < Back Next > Progress 🤇 97%



#### Thank you!

If you have any questions about the survey, please do not hesitate to call us toll free at (833) 997-2714 or email us at <u>CDC CancerSurvey@rti.org</u>

Please click [SUBMIT] to submit your responses.

Submit

Progress (

100%

For Caregivers of Patients with Colorectal Cancer

#### Save and Continue Later

Si desea completer la encuesta en español, seleccione español en el menu despegable en la parte superior derecha de la pantalla.

English V

Thank you for agreeing to participate in this study. This survey will take you about 15 minutes to complete. After you submit the survey, you will receive a \$40 check or electronic gift card as a token of appreciation for your time.

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\_\_\_\_

## **CDC Barriers Survey** English 🗸 Save and Continue Later How old are you? ○ 21-24 years old ○ 25–29 years old 30–34 years old ○ 35–39 years old ○ 40–44 years old ○ 45–49 years old ○ 50–54 years old ○ 55–59 years old 0 60–64 years old ○ 65–69 years old ○ 70–74 years old 75 years old or older < Back Next > Progress 🔵 7%

They are your:	
<ul> <li>spouse (husband/wife)</li> <li>domestic partner</li> <li>child</li> <li>parent</li> </ul>	
<ul> <li>sibling</li> <li>friend</li> <li>Other – Please specify:</li> </ul>	
< Back Next >	Progress
DC Barriers Caregiver	INTERNATIONAL
Save and Continue Later	English 🗸
For the rest of the survey, we w during their cancer treatment a	vill refer to the individual to whom you provided care as a "care recipient."
< Back Next >	Progress 11%
DC Barriers Caregiver S	Survey
	INTERNATIONAL
	English V
Save and Continue Later	English V
Save and Continue Later Do you live in the same househ	
<b>Do you live in the same househ</b> O Yes	old with the care recipient?
<b>Do you live in the same househ</b> O Yes O No	old with the care recipient?
Do you live in the same househ <ul> <li>Yes</li> <li>No</li> </ul> <li>CDC Barriers Caregiver S <ul> <li>Save and Continue Later</li> </ul> </li> <li>What is your biological sex? This</li>	old with the care recipient? Survey
Do you live in the same househ <ul> <li>Yes</li> <li>No</li> </ul> CDC Barriers Caregiver S Save and Continue Later	old with the care recipient? Survey



#### Save and Continue Later

What was your marital status when the care recipient was <u>first diagnosed</u>?

- Never married
- Married
- O Living together with a partner as an unmarried couple / cohabitating
- Widowed
- Separated or divorced

#### What is your <u>current</u> marital status?

- Never married
- Married
- O Living together with a partner as an unmarried couple / cohabitating
- Widowed
- Separated or divorced



Next >

Progress 19%



#### Save and Continue Later

#### What was your employment status when the care recipient was first diagnosed?

- O Employed for pay (including self-employed) 40 hours or more per week
- O Employed for pay (including self-employed) Less than 40 hours per week
- O Retired
- O Homemaker
- O Student
- Out of work
- O Unable to work (e.g., due to disability, work authorization)

#### What is your current employment status?

- O Employed for pay (including self-employed) 40 hours or more per week
- O Employed for pay (including self-employed) Less than 40 hours per week
- Retired
- O Homemaker
- Student
- Out of work
- O Unable to work (e.g., due to disability, work authorization)

< Back	Next >	Progress (	219

### **CDC Barriers Survey**

			English 🗸
Save and Co	ontinue Later		
What is yo	our <u>current</u> employme	ent status?	
<ul> <li>Employe</li> <li>Retired</li> <li>Homem</li> <li>Student</li> <li>Out of v</li> <li>Out of v</li> </ul>	ed for pay (including se laker vork for 1 year or more vork for less than 1 yea		
< Back	Next >	Progress (	13%

## **CDC Barriers Survey**

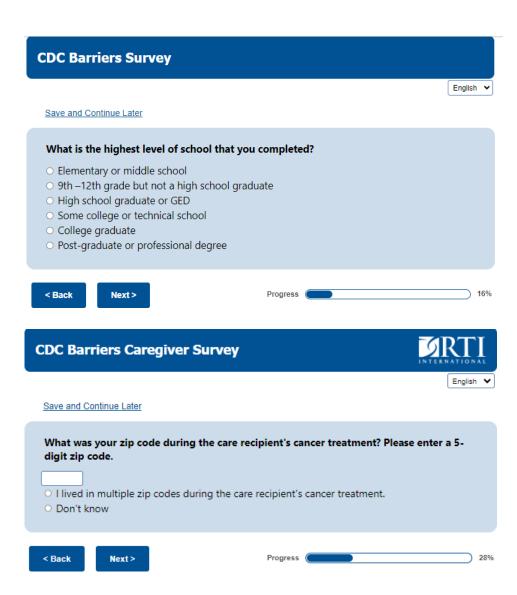


#### What is your current health insurance status? Please select all that apply.

- No insurance
- Lapse in coverage
- Private health insurance (purchased on your own or from your job or from your spouse's / partner's / parent's job)
- Medicaid
- Medicare/Medicare Advantage
- Military (Tricare, Champ-VA, or some other military insurance)
- Other Please specify:

< Back Next >

Progress 25%



Please enter the zip codes where you l	ived.	
Zip Code 1:		
Zip Code 2:		
Zip Code 3:		
< Back Next >	Progress (21)	1%
CDC Barriers Caregiver Survey		
Save and Continue Later	English 🗸	·
<ul> <li>A one-family house detached from any</li> <li>A one-family house attached to one or</li> <li>An apartment building, apartment com</li> </ul>	more houses (e.g., townhome, duplex)	
< Back Next >	Progress ( 34	%

-	_	_	_		_	
				Distance of the		 <b>CONT</b>
				rrie		 
-	_	<u> </u>				 

	English 🗸
Save and Continue Later	
Think about your household, which includes everyone who lives with you.	
Please indicate whether the following statements are often true, sometimes true, o true.	r never
"Within the past 12 months, we worried whether our food would run out before we money to buy more."	e had
Often true	
Sometimes true     Never true	
"Within the past 12 months, the food we bought just didn't last and we didn't have money to get more." • Often true	•
<ul> <li>Sometimes true</li> <li>Never true</li> </ul>	
< Back Next > Progress	23%

# What condition(s) had <u>you</u> been dealing with shortly before the care recipient's colorectal cancer diagnosis? Select all that apply.

- Arthritis, rheumatism, or gout
- Benign tumors or cysts
- Cancer
- 🗆 Chronic pain
- Circulation problems (including blood clots)
- Dementia or Alzheimer's
- Depression, anxiety, or emotional problem

Diabetes

- Epilepsy or seizures
- Fibromyalgia or lupus
- Gastrointestinal conditions or disorders
- Hearing problem
- Heart problem
- 🗆 Hernia
- Hypertension or high blood pressure
- Kidney, bladder, or renal problems
- Lung or breathing problem (for example, asthma and emphysema)
- Migraine headaches (not just headaches)
- Multiple Sclerosis (MS) or Muscular Dystrophy (MD)
- Osteoporosis or tendinitis
- $\hfill\square$  Parkinson's disease or other tremors
- Stroke
- Thyroid problems or Graves' disease
- Ulcer
- Vision problem or problem seeing
- Weight problem
- □ Other impairment or problem Please specify one:
- None of the above



#### Save and Continue Later

The next questions are about your experiences during the care recipient's cancer treatment.

Were you the primary caregiver for the care recipient, taking responsibility for most of the care recipient's needs during their treatment?

YesNo

< Back

Progress 39%

# **CDC Barriers Caregiver Survey**

Next >



#### Save and Continue Later

During the care recipient's cancer treatment, what type(s) of support did you provide? Select all that apply.

- Provided emotional support
- Provided financial support
- Helped manage finances
- Accompanied care recipient to medical appointments
- Helped with medical decision-making
- Coordinated medical care (e.g., finding health care providers, making appointments, helping with prescriptions/medications)
- Provided transportation to and from doctor, for errands, etc.
- Assisted with daily tasks (e.g., cooking, cleaning, childcare)
- Other Please specify:



Progress 41%



#### Save and Continue Later

During t	he care recipi	ent's cancer treatment, were you paid for your role as a caregiver?	
○ Yes ○ No			
< Back	Next >	Progress 44	2%

### **CDC Barriers Caregiver Survey**



Save and Continue Later

# During the care recipient's <u>cancer treatment</u>, what were your household's source(s) of income? Select all that apply.

- Income from employment
- Pension or retirement
- Government assistance (disability, social security)
- Paid leave from work
- Stipends or financial assistance from nonprofit organizations or charitable organizations
- Other Please specify:

#### Currently, what are your household's sources of income? Select all that apply.

- Income from employment
- Pension or retirement
- Government assistance (disability, social security)
- Paid leave from work
- Stipends or financial assistance from nonprofit organizations or charitable organizations
- Other Please specify:

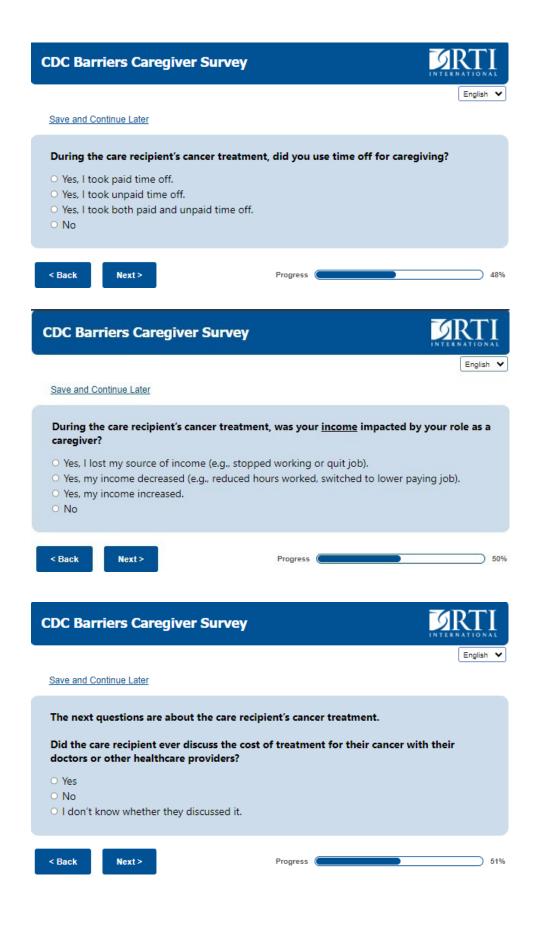


Progress 44%



#### Save and Continue Later

During the care recipient's cancer treatment, how many hours per week on average did you spend caring for them (e.g., attending doctor's appointments, helping them manage side effects, assisting with daily tasks like cooking or cleaning, spending time together, praying)? O Less than 5 hours Between 5 to 10 hours Between 11 to 15 hours Between 16 to 20 hours More than 20 hours Don't know < Back Next > Progress 🔵 46% **CDC Barriers Caregiver Survey** English ¥ Save and Continue Later During the care recipient's cancer treatment, was your employment impacted by your role as a caregiver? O Yes, my work schedule changed (e.g., went from full to part-time or my hours were reduced or increased) O Yes, my employment status changed (e.g., changed jobs, quit job, retired, or got an additional job). O No (e.g. job stayed the same, was already retired) < Back 47% Next > Progress





#### Save and Continue Later

When the care recipient was choosing a treatment course for their cancer, did they consider the costs of specific treatments?

- A great deal
- $\odot$  Somewhat
- Not at all
- O Not applicable; the care recipient did not receive information about treatment costs.
- Don't know

< Back Next >

Progress 52%

How much money would you estimate your care recipient/care recipient's household has paid out-of-pocket in the past 12 months for <u>medical expenses</u> related to their colorectal cancer, including co-payments, hospital bills, deductibles, and medication costs – including hormonal therapy and other medications to help prevent cancer recurrence?

For this question, please think of out-of-pocket money that they spent and not money provided by the insurance company.

- Less than \$500
- \$500-\$2,000
- \$2,001-\$5,000
- \$5,001-\$10,000
- More than \$10,000
- Don't know

How much money would you estimate your care recipient has paid out-of-pocket in the past 12 months for <u>other expenses</u> related to their colorectal cancer, such as travel costs, parking, child/elderly care, special diet/food/drinks, etc.?

For this question, please think of out-of-pocket money that they spent and not money provided by the insurance company.

- Less than \$500
- \$500-\$2,000
- \$2,001-\$5,000
- \$5,001-\$10,000
- O More than \$10,000
- Don't know

< Back

Next >

Progress (

54%



#### Save and Continue Later

How would you describe the care recipient's reaction to the money they spent for cancer treatment?

#### They spent...

- $\odot$  ...more money than they expected
- $\, \odot \,$  ...about as much money as they expected
- …less money than they expected
- Don't know



Progress 56%



#### Save and Continue Later

/ou m	ay select up to 5 issues.
Afra	id the treatment will be too painful or unpleasant
	Id not afford care (e.g., cost too much; other competing expenses)
Cou	ld not afford food
Lack	of permanent, stable housing
No i care	insurance coverage, or insurance company would not approve, cover or pay for
Prol	plems getting transportation to doctor's office for treatment or office was too far y
	Id not get time off work for appointments and care (e.g., no paid sick leave, no ble work schedule, no medical leave)
	n't know where to go to get care (e.g., no primary doctor or usual source of care to e referral; unfamiliar with local providers; local specialty practice closed)
Was	refused services (e.g., out of network provider, not accepting new patients)
Tool	k too long to get an appointment that worked for their schedule
	erienced discrimination (e.g., racial or ethnic discrimination, gender, weight, sexual ntation, disability status)
	<b>ble to understand the doctor's language</b> (e.g., different language without access to pretation)
Mec	lical information was too hard to understand
Cou	Idn't get dependent care (e.g., for child, elderly relative, or relative with a disability)
Cou	ld not get a friend or family member to go with them to appointment
Oth	er
Did	not encounter any issues
l wa	s not aware of any issues.

If the caregiver selects any problems, they will see:



#### Save and Continue Later

Of the top issues you selected, please rank them, with "1" being the most important.

 Afraid the treatment will be too painful or unpleasant

 Could not afford care (e.g., cost too much; other competing expenses)

 Could not afford food

 Lack of permanent, stable housing

 No insurance coverage, or insurance company would not approve, cover or pay for care

If caregiver selected "Did not encounter any issues", they will see:

Please select the top 5 factors <u>that made it easier for the cancer recipient to get medical</u> <u>care</u> for their cancer treatment.

Worked with a	nurse/patient	navigator who	provided additional	support

- Had support of a caregiver
- □ Was able to manage side effects
- Was able to afford care
- □ Was able to cover all non-medical expenses like food
- Had permanent, stable housing
- Insurance covered most of their medical costs
- Easy access to transportation
- Convenient location of healthcare provider
- Was able to take time off work for appointments and care (e.g., paid sick leave, flexible work schedule, medical leave available)
- Connected to a provider by someone they knew (e.g., doctor, nurse, family member, friend, others on social media)
- Was able to get an appointment with a doctor or specialist within a reasonable timeframe
- Was able to make arrangements for dependent care (e.g., for child, elderly relative, or relative with a disability), if needed
- Was treated with respect by their doctor
- Was able to understand medical information that was shared with them
- □ **Other** Please specify:



Progress (

61%



Save and Continue Later

During the care recipient's cancer treatment, was your health impacted by your role as caregiver?

- Yes, it was negatively impacted.
- $\odot$  Yes, it was positively impacted.
- $\odot\,$  No, my health was not impacted.



Progress 62%



66%

#### Save and Continue Later

During the care recipient's cancer treatment, how much support did you get from your <u>family</u>?

- All of the support I needed
- Some of the support I needed
- No support
- O Prefer not to answer

During the care recipient's cancer treatment, how much support did you get from your <u>friends</u>?

- All of the support I needed
- Some of the support I needed

Next >

- No support
- Prefer not to answer

< Back

Progress 🤇



#### Save and Continue Later

The next three questions will ask about how you have felt more recently, in the past week.

Below is a list of statements that other people facing an illness have said are important.

For each of the following statements, please select your response as it applies to the <u>past</u> <u>7 days</u>.

	1 – Not at all	2 - A little bit	3 - Somewhat	4 - Quite a bit	5 - Very much
I have a lack of energy.	0	0	0	0	0
l have nausea.	0	0	0	0	0
Because of my physical condition, I have trouble meeting the needs of my family.	0	0	0	0	0
l have pain.	0	0	0	0	0
l feel ill.	0	0	0	0	0
I am able to enjoy life.	0	0	0	0	0
I am forced to spend time in bed.	0	0	0	0	0

Progress (

< Back Next >

**CDC Barriers Caregiver Survey** 



69%

Save and Continue Later





Save and Continue Later

lease select your response to th	e followir 1 – Not at all	<b>ig statemen</b> 2 - A little bit	3 - Somewhat	s to the <u>past</u> 4 - Quite a bit	<u>7 days</u> . 5 – Very much
I am bothered by the side effects of treatment.	0	0	0	0	0
Back Next>		Progress	(		

# **CDC Barriers Caregiver Survey**



Save and Continue Later

Below is a list of statements that other people facing an illness have said are important.

For each of the following statements, please select your response as it applies to the <u>past</u> <u>7 days</u>.

	1 – Not at all	2 - A little bit	3 - Somewhat	4 - Quite a bit	5 – Very much
I am satisfied with how I am coping with my loved one's illness.	0	0	0	0	0
I am losing hope in the fight against my loved one's illness.	0	0	0	0	0
I feel nervous.	0	0	0	0	0
I worry about my loved one dying.	0	0	0	0	0
I worry that my loved one's condition will get worse.	0	0	0	0	0

< Back

Next >





#### Save and Continue Later

Below is a list of statements that other people facing an illness have said are important.

For each of the following statements, please select your response as it applies to the <u>past</u> <u>7 days</u>.

	1 – Not at all	2 - A little bit	3 - Somewhat	4 - Quite a bit	5 – Very much
I am able to work (include work at home).	0	0	0	0	0
My work (include work at home) is fulfilling.	0	0	0	0	0
I am able to enjoy life.	0	0	0	0	0
I have accepted my loved one's illness.	0	0	0	0	0
I am sleeping well.	0	0	0	0	0
I am enjoying the things I usually do for fun.	0	0	0	0	0
I am content with the quality of my life right now.	0	0	0	0	0

< Back

Next >

Progress 74%

## **CDC Barriers Caregiver Survey**



75%

#### Save and Continue Later

During the care recipient's cancer treatment, were you provided with information or resources specifically for caregivers? Select all that apply.

- Yes, from my care recipient's doctor or health care team
- Yes, from a nonprofit organization (e.g., American Cancer Society)
- Yes, from another source Please specify:

Next >

- □ No
- Don't know

< Back

Progress

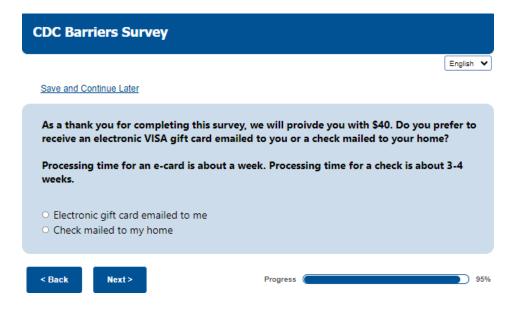
CDC Barriers Caregiver Survey	
Save and Continue Later	English 🗸
How informed did you feel about the <u>pot</u> treatment?	tential side effects from the care recipient's
<ul> <li>Very</li> <li>Somewhat</li> <li>Not at all</li> </ul>	
How informed did you feel about the <u>pot</u> wounds not healing) from the care recipie	<u>ential complications</u> (e.g., drains blocking, ent's treatment?
<ul> <li>Very</li> <li>Somewhat</li> <li>Not at all</li> </ul>	
< Back Next >	Progress 78%
CDC Barriers Caregiver Survey	
Save and Continue Later	English 🗸
How often did the care recipient's doctors much cancer-related information as you w	and other healthcare providers give you as vanted?
<ul> <li>Never</li> <li>Sometimes</li> <li>Usually</li> <li>Always</li> <li>Not applicable (I did not ask for cancer-rel</li> </ul>	lated information.)
< Back Next >	Progress 80%

Please describe your experience (o	ptional):
	Æ
< Back Next >	Progress 80
DC Barriers Caregiver Sur	
Save and Continue Later	English 🛰
How often did the care recipient's o for what you had to say?	doctors and other healthcare providers show respect
<ul> <li>Never</li> <li>Sometimes</li> <li>Usually</li> <li>Always</li> <li>Not applicable (I did not speak with</li> </ul>	h my loved one's doctor.)
< Back Next >	Progress ( 83
Please describe your experience (op	ptional):
< Back Next >	Progress 80%



#### Save and Continue Later

How often did the care recipient's other family members and/or friends show respect or appreciate your efforts (e.g., help with decision-making, house chores, emotional support, transportation, etc.)? O Never Sometimes Usually Always Not applicable (I did not speak with other family members and/or friends.) < Back Next > Progress ( 85% Please describe your experience (optional): 80% < Back Next > Progress (



# **CDC Barriers Survey**

Save and Continue Later
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Please enter <u>your contact inform</u>	ation so that we may send you a \$40 check.		
Full name:			
Street address 1:			
Street addres 2:			
City:			
State:			
Zip code:			
< Back Next >	Progress 96%		
CDC Barriers Survey			
	English 🗸		
Save and Continue Later			
Please enter your email address for the electronic gift card:			

English 🗸

Please re	type the email a	dress for confirmation:
< Back	Next >	Progress 98%



#### Save and Continue Later

We will be conducting 1-hour phone or online interviews with a subset of caregivers who complete this survey and are willing to volunteer their time. Would you like to be considered to participate in a 1-hour phone/online interview? O Yes O No < Back Next > Progress 🤇 93% **CDC Barriers Caregiver Survey** -9 English 💙 Save and Continue Later Please provide your phone number: Please provide your email address: Please retype the email address for confirmation: < Back Next > Progress 🤇 97%



#### Thank you!

If you have any questions about the survey, please do not hesitate to call us toll free at (833) 997-2714 or email us at <u>CDC CancerSurvey@rti.org</u>

Please click [SUBMIT] to submit your responses.

Submit

Progress (

100%