Attachment 6

Approved Surveys (screenshots)

(16 Voluntary Survey Modules and Disease Progression Survey)

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Please Note: OMB Burden Statement appears on the individual's Survey Accounts page. Because participants can take surveys in any order, the OMB Burden Statement was placed on the one page that everyone has to view.



Figure 1: PALS Login Landing Page to Access Surveys



Figure 2: Select Survey to Take

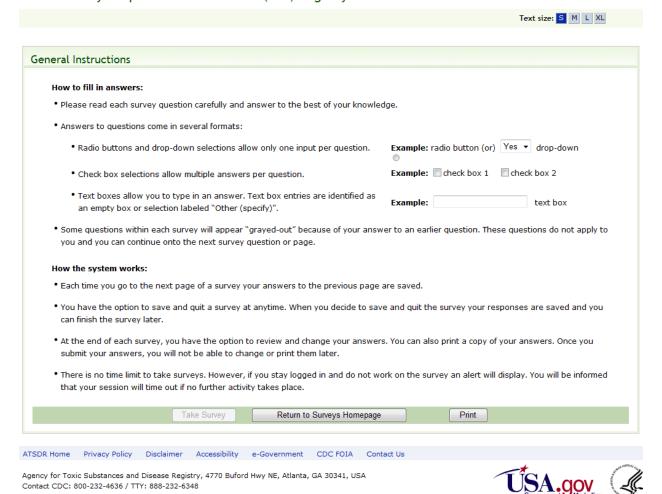


Figure 3: General Instructions

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	Text size: S M L XL
Survey 1	
1. What is your date of birth?	August ▼ 1968 ▼
2. How old are you today?	39 years old
How old were you when you were told by a neurologist that you had ALS?	39 years old
4. What is your gender?	○ Male● Female
5. What is your current marital status?	Married ▼
What is the highest level of education that you have completed?	 Did not complete High School (Specify highest grade completed): High school diploma or GED Technical or trade school diploma Some college credit College degree (AA, BA, BS, etc) Graduate school degree Other (specify):
Previous Pag	ge 1/4 Next Save & Quit
, ,	ernment CDC FOIA Contact Us
Agency for Toxic Substances and Disease Registry, 4770 Buford Hwy NE Contact CDC: 800-232-4636 / TTY: 888-232-6348	, Atlanta, GA 30341, USA USA. GOVERNMENT OF MADE Easy WAS GOVERNMENT OF MADE EASY

Figure 4: Survey 1, Page 1 of 4



Figure 5: Survey 1, Page 2 of 4

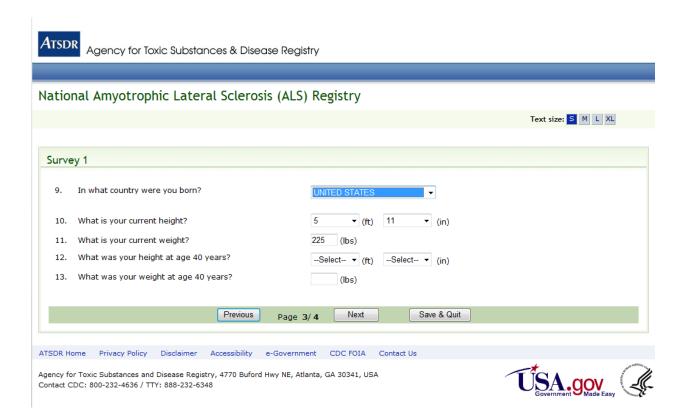
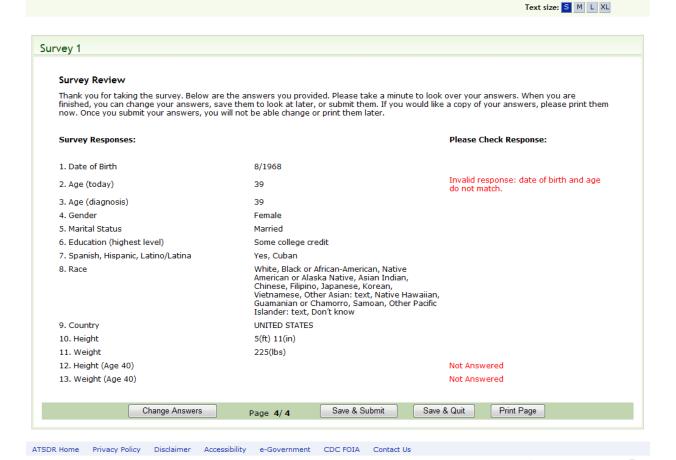


Figure 6: Survey 1, Page 3 of 4

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Figure 7: Survey 1, Page 4 of 4

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Figure 8: Survey Taken Confirmation Page (Same for ALL Surveys)

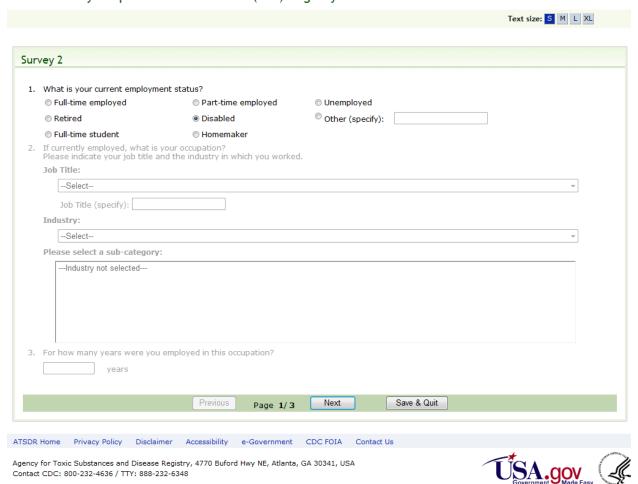


Figure 9: Survey 2, Page 1 of 3

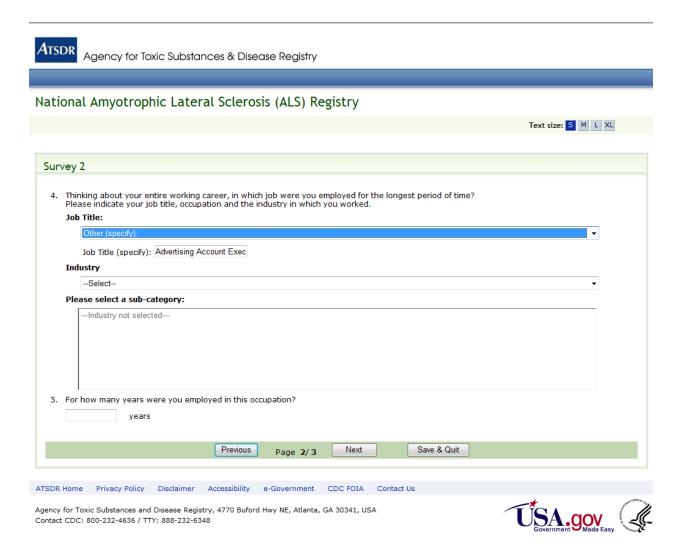
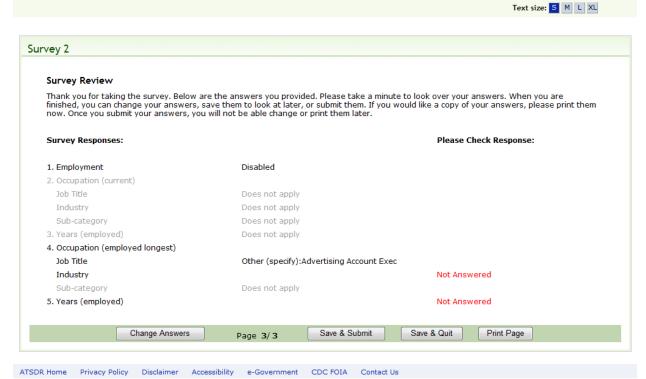


Figure 10: Survey 2, Page 2 of 3





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Figure 11: Survey 2, Page 3 of 3

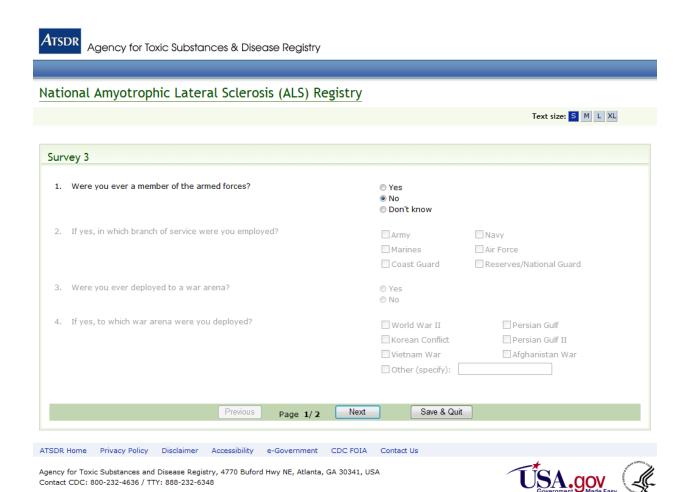


Figure 12: Survey 3, Page 1 of 2

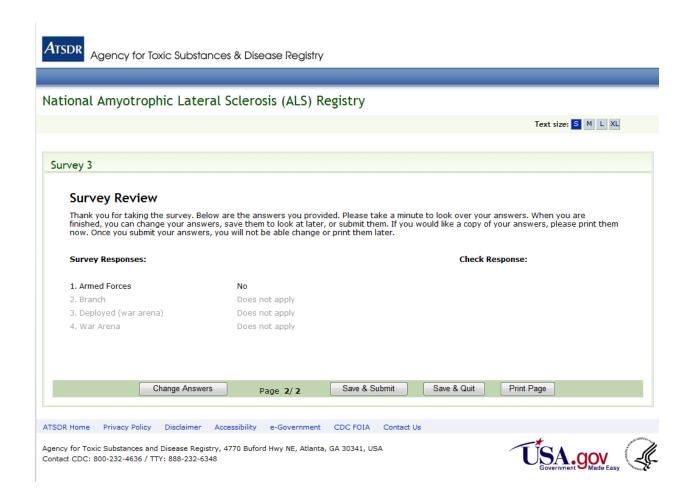


Figure 13: Survey 3, Page 2 of 2



Figure 14: Survey 4, Page 1 of 3

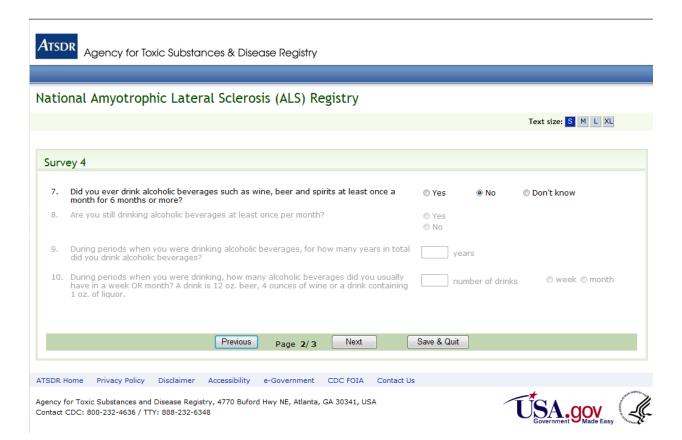
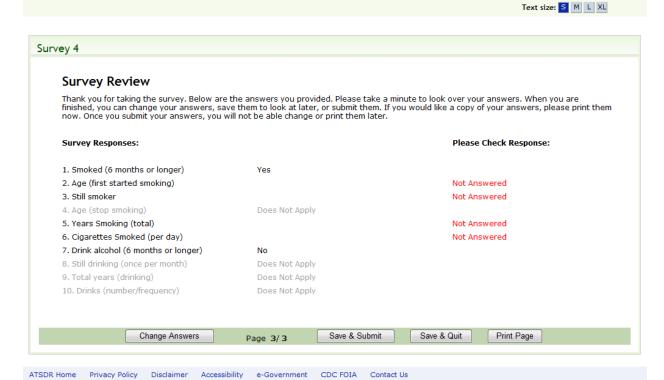


Figure 15: Survey 4, Page 2 of 3



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Figure 16: Survey 4, Page 3 of 3

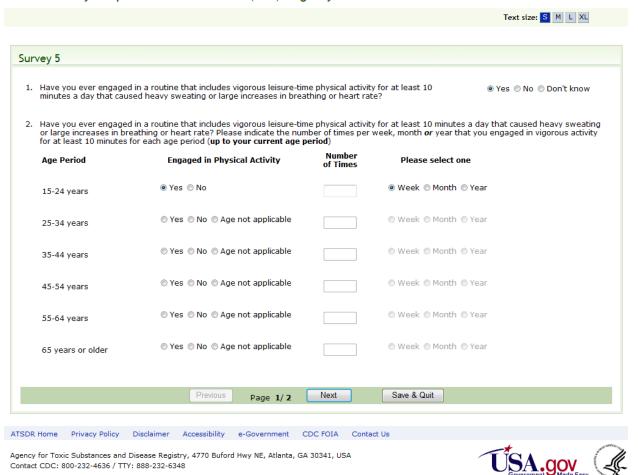


Figure 17: Survey 5, Page 1 of 2

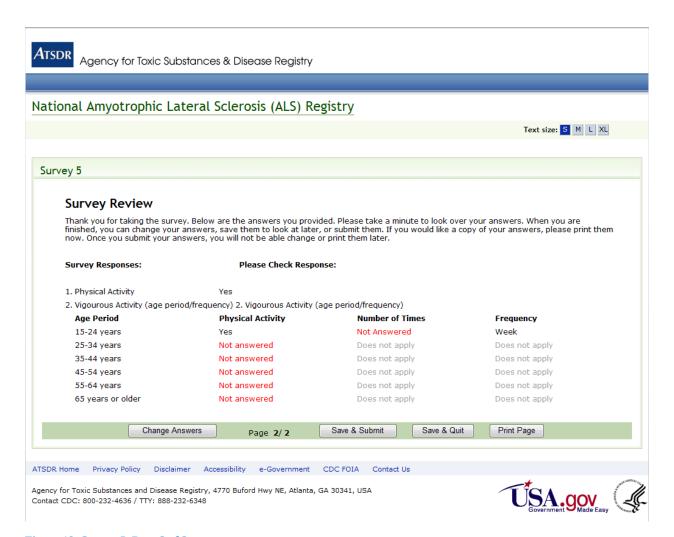


Figure 18: Survey 5, Page 2 of 2

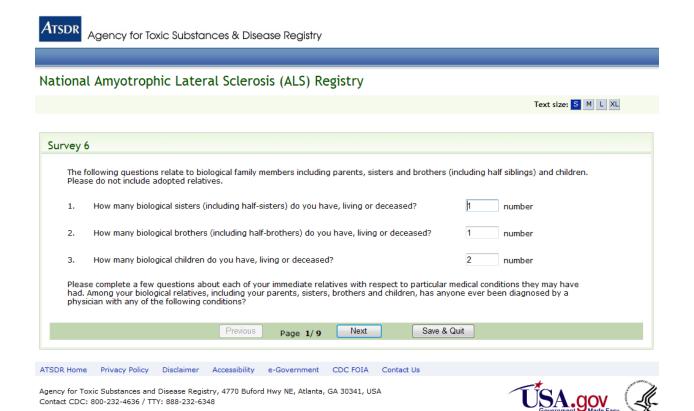


Figure 19: Survey 6, Page 1 of 9

				Text size: S M L XL
urve	<i>y</i> 6			
Relatio	onship: Mother			
1.	Is your mother still living?	⊚ Yes	⊚ No	Don't know
2.	What is your mother's current age or the age at her death?		years old	
3.	Has your mother ever been diagnosed by a physician with any of the following medical conditions?			
	Amyotrophic lateral sclerosis:	© Yes	⊚ No	O Don't know
	Alzheimer's disease:	⊚ Yes	⊚ No	○ Don't know
	Parkinson's disease:	⊚ Yes	⊚ No	O Don't know
4.	At what age was she diagnosed with the condition?		age (ALS)	Don't know
			age (Alzheime	_
			age (Parkinso	on's) Don't know
	Previous Page 2/9	Next	Save & Quit	
	Page 2/ 9			

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Figure 20: Survey 6, Page 2 of 9

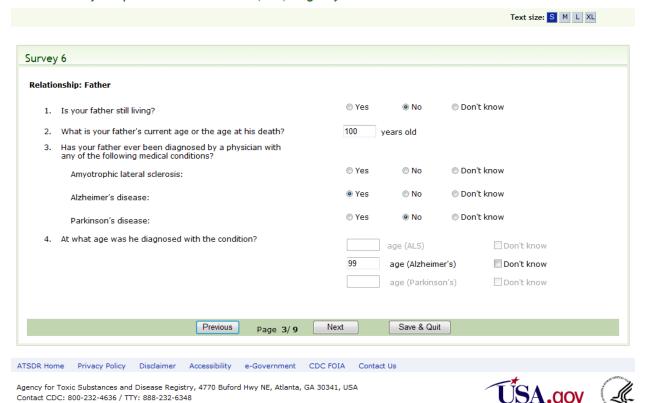


Figure 21: Survey 6, Page 3 of 9



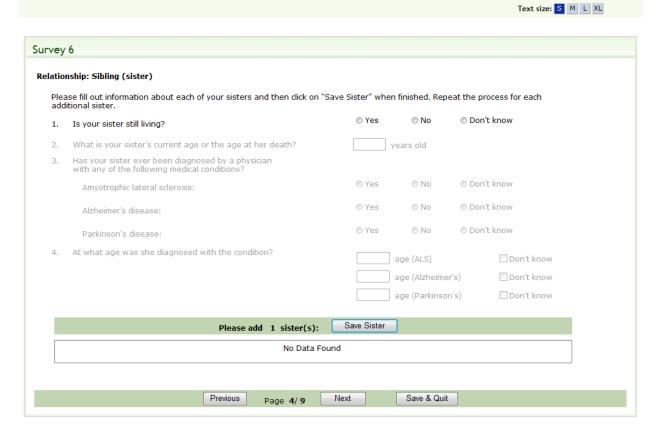


Figure 22: Survey 6, Page 4 of 9



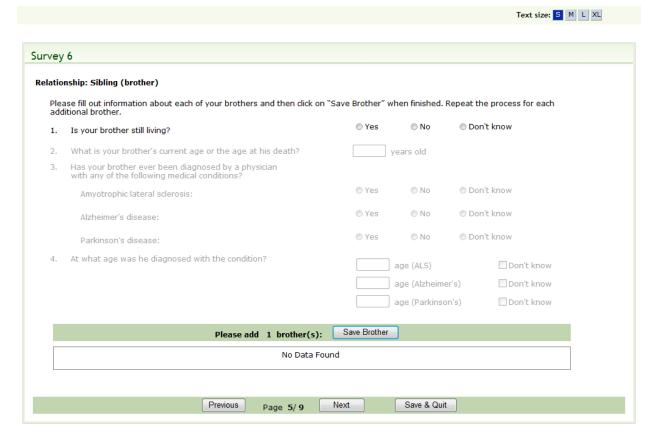


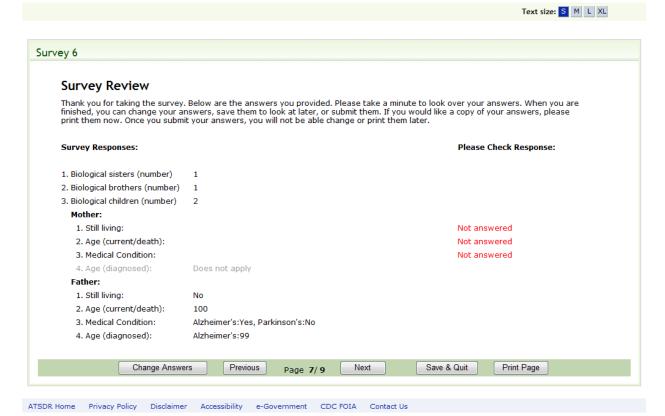
Figure 23: Survey 6, Page 5 of 9

ea	nship: Children ase fill out information about each of your children and then click on "Sa litional child.	ive Child" w	hen finished. Rep	eat the process for each
ι.	Relationship:	© Daug © Son	hter	
2.	Is your child still living?	⊚ Yes	⊚ No	○ Don't know
3.	What is your child's current age or the age at his death?		years old	
4.	Has your child ever been diagnosed by a physician with any of the following medical conditions?			
	Amyotrophic lateral sclerosis:	Yes	⊚ No	O Don't know
	Alzheimer's disease:	Yes	◎ No	○ Don't know
	Parkinson's disease:	Yes	◎ No	O Don't know
5.	At what age was she/he diagnosed with the condition?		age (ALS)	☐ Don't know
			age (Alzheime	's) Don't know
			age (Parkinsor	's) Don't know
	Please add 2 child(ren):	Save Child	i	
Е	No Data Found	-	_	
	No Data Found			
	Previous Page 6/9	lext	Save & Quit	

Text size: S M L XL

Figure 24: Survey 6, Page 6 of 9

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Figure 25: Survey 6, Page 7 of 9

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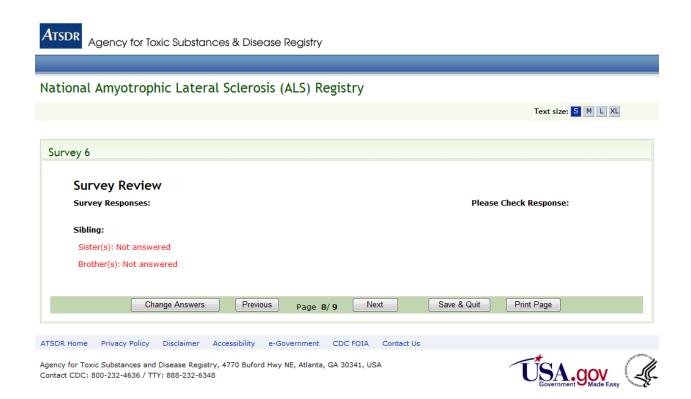


Figure 26: Survey 6, Page 8 of 9

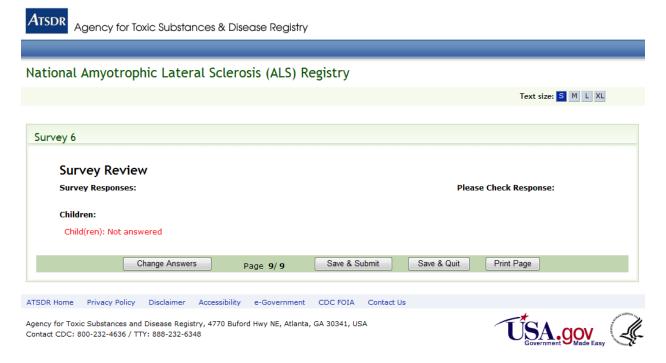
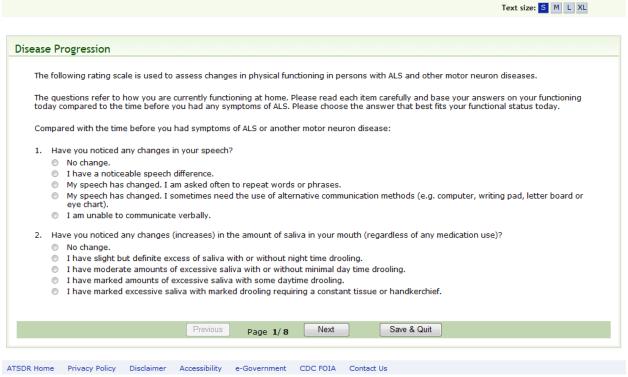


Figure 27: Survey 6, Page 9 of 9



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Figure 28: Disease Progression Survey, Page 1 of 8

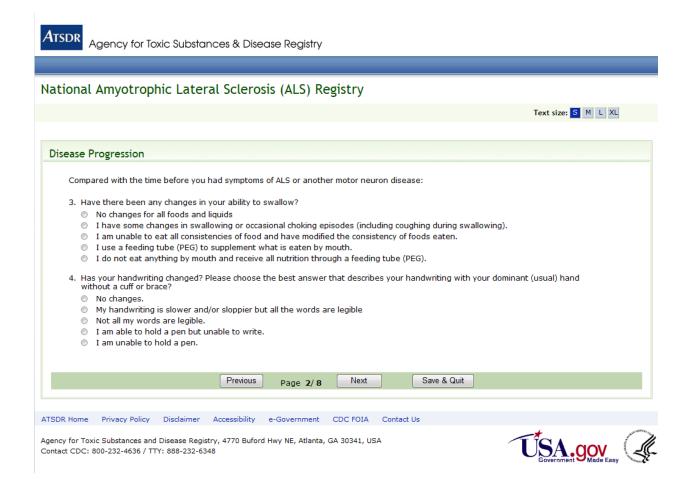


Figure 29: Disease Progression Survey, Page 2 of 8

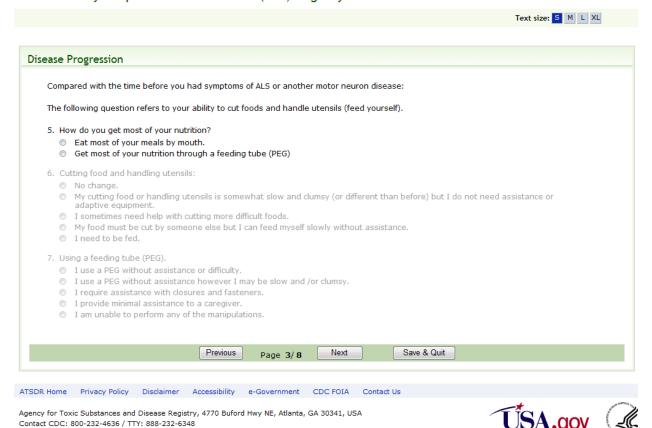
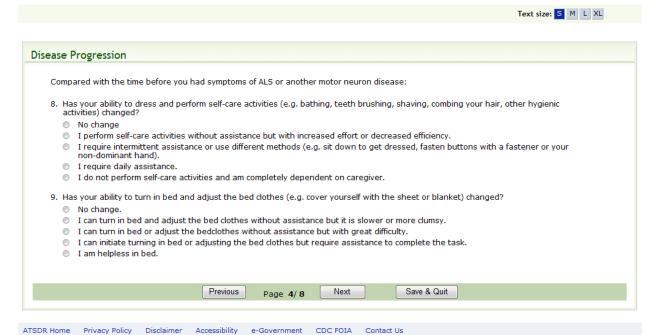


Figure 30: Disease Progression Survey, Page 3 of 8



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Figure 31: Disease Progression Survey, Page 4 of 8

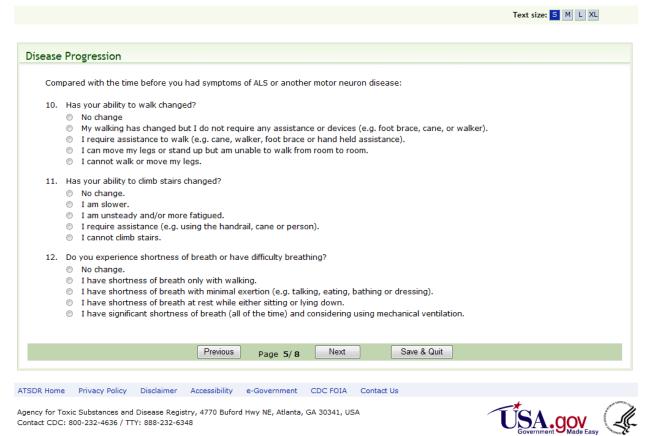


Figure 32: Disease Progression Survey, Page 5 of 8

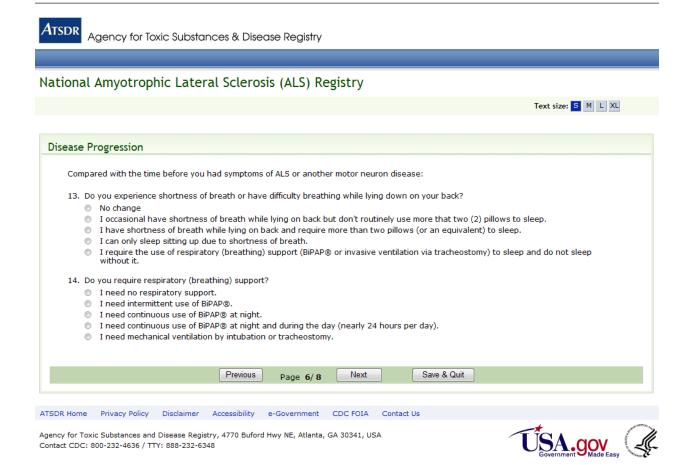


Figure 33: Disease Progression Survey, Page 6 of 8

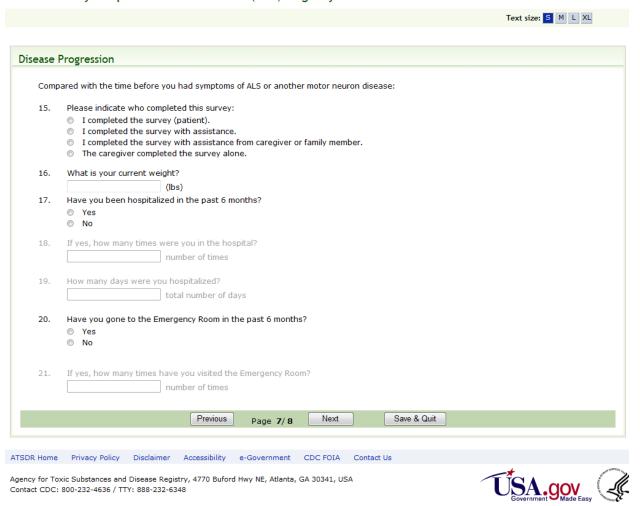


Figure 34: Disease Progression Survey, Page 7 of 8

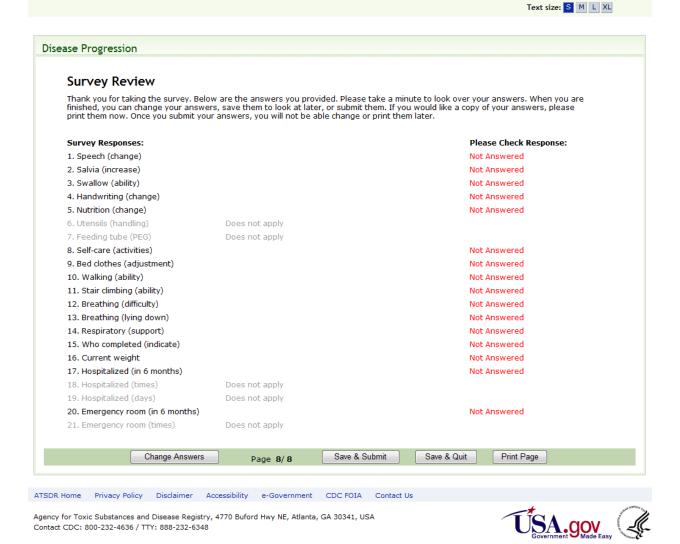


Figure 35: Disease Progression Survey, Page 8 of 8



Agency for Toxic Substances & Disease Registry

National Amyotrophic Lateral Sclerosis (ALS) Registry

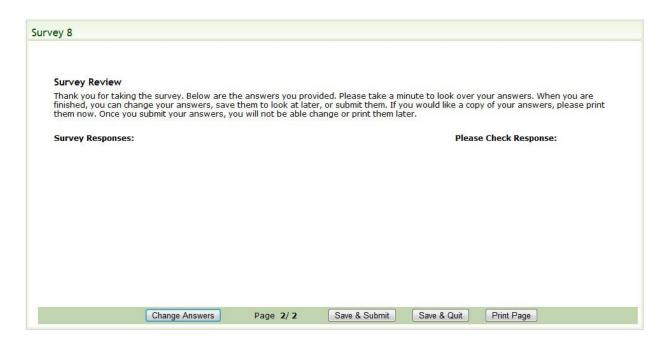
rvey 8			
Residence History			
We are interested in the location of your residences for all the plac where you were born, indicate the city and state (or country) of ea give the nearest city or town. If you moved to a different residence entry.	ch place whe	re you lived for 6	6 months or longer. If you lived on a farm, pleas
At what age did you move to your next residence of 6 months or longer?	Yea	rs old	
2. In what city or town was this residence?			
3. In what state (or country) was this residence?			•
4. Was this residence a farm or a ranch?	© Yes	◎ No	© Don't know
5. Was your main source of drinking water at this residence a private well?	○ Yes	⊚ No	O Don't know
6. Was this residence within ¼ mile of an agricultural area that was sprayed with pesticides or herbicides?	© Yes	⊚ No	O Don't know
a. How often did the pesticide or herbicide spraying happen?	0 <1 time/	voor.	
	○ 1-3 times		
	© ≥ 4 times	56 P. C.	
	O Don't kno		
7. Was this your current or most recent residence?	◎ Yes		
7. Was this your current of most recent residence:	© No		
Address(s):	Save Addres	s	
Previous Page 1/	/ 2 Next		& Quit

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Figure 36: Survey 8, Page 1 of 2



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Figure 37: Survey 8, Page 2 of 2



Lifetime Occupational History The following questions ask about pesticides or chemicals that you may hav	e used at wor	rk during at lea	st <u>100 days or more during your lifetime</u>
Pesticides			
We are interested in those pesticide products that you personally handled oby applying them yourself or by helping to clean up after they were applied.		ther by prepari	ng them prior to application,
Over your lifetime (at least 100 days or more), have you ever had a JOB where you handled HERBICIDES (to kill weeds)?	© Yes	⊚ No	O Don't know
a. At what age did you FIRST handle herbicides?	Age		
b. At what age did you LAST handle herbicides?	Age		
c. This is a total of	Year	rs	
d. For how many of those years did you NOT use herbicides?	Year	rs	
 Over your lifetime (at least 100 days or more), have you ever had a JOB where you handled FUNGICIDES (to control mildew, mold or rot)? a. At what age did you FIRST handle fungicides? 	© Yes	© No	O Don't know
b. At what age did you LAST handle fungicides?	Age		
	Year	rs	
c. This is a total of	Year	rs	
c. This is a total of d. For how many of those years did you NOT use fungicides?			
d. For how many of those years did you NOT use fungicides?	Next	Save & Quit	
d. For how many of those years did you NOT use fungicides?	Next	Save & Quit	
d. For how many of those years did you NOT use fungicides?	Next	Save & Quit	

Figure 38: Survey 9, Page 1 of 11



Lifetime Occupational History				
Pesticides				
 Over your lifetime (at least 100 days or more), have you ever had a JOB where you handled INSECTICIDES (to control insects or pests)? 	© Yes		© No	O Don't know
a. At what age did you FIRST handle insecticides?		Age		
b. At what age did you LAST handle insecticides?		Age		
c. This is a total of		Years		
d. For how many of those years did you NOT use insecticides?		Years		
JOB where you handled RODENTICIDES (to kill rats or mice)? a. At what age did you FIRST handle rodenticides? b. At what age did you LAST handle rodenticides? c. This is a total of		Age Age Years		
d. For how many of those years did you NOT use rodenticides?		Years		
Previous Page 2/11	Next	5	Save & Quit	

Figure 39: Survey 9, Page 2 of 11



Lifetime Occupational History				
Pesticides				
Over your lifetime (at least 100 days or more), have you ever had a JOB where you handled FUMIGANTS (gas used to kill fungus, mold or insects)?	© Yes		◎ No	O Don't know
a. At what age did you FIRST handle fumigants?		Age		
b. At what age did you LAST handle fumigants?		Age		
c. This is a total of		Years		
d. For how many of those years did you NOT use fumigants?		Years		
5. Over your lifetime (at least <u>100 days</u> or more), have you ever had a JOB where you used GLUES OR ADHESIVES?	© Yes		© No	O Don't know
a. At what age did you FIRST use glues or adhesives?		Age		
b. At what age did you LAST use glues or adhesives?		Age		
c. This is a total of		Years		
d. For how many of those years did you NOT use glues or adhesives?		Years		

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Figure 40: Survey 9, Page 3 of 11



Lifetime Occupational History	
Solvents	
7. Over your lifetime (at least 100 days or more), have you ever had a JOB where you used SOLVENTS AND DEGREASERS?	◎ Yes ◎ No ◎ Don't know
a. At what age did you FIRST use solvents and degreasers?	Age
b. At what age did you LAST use solvents and degreasers?	Age
c. This is a total of	Years
d. For how many of those years did you NOT use solvents and degreasers?	Years
Over your lifetime (at least 100 days or more), have you ever had a JOB where you worked with UNLEADED GASOLINE?	
you worked with UNLEADED GASOLINE? a. At what age did you FIRST work with unleaded gasoline? b. At what age did you LAST work with unleaded gasoline?	Age Age
you worked with UNLEADED GASOLINE? a. At what age did you FIRST work with unleaded gasoline? b. At what age did you LAST work with unleaded gasoline? c. This is a total of	Age Age Years
you worked with UNLEADED GASOLINE? a. At what age did you FIRST work with unleaded gasoline? b. At what age did you LAST work with unleaded gasoline?	Age Age
you worked with UNLEADED GASOLINE? a. At what age did you FIRST work with unleaded gasoline? b. At what age did you LAST work with unleaded gasoline? c. This is a total of	Age Age Years
you worked with UNLEADED GASOLINE? a. At what age did you FIRST work with unleaded gasoline? b. At what age did you LAST work with unleaded gasoline? c. This is a total of d. For how many of those years did you NOT use unleaded gasoline?	Age Age Years Years
you worked with UNLEADED GASOLINE? a. At what age did you FIRST work with unleaded gasoline? b. At what age did you LAST work with unleaded gasoline? c. This is a total of d. For how many of those years did you NOT use unleaded gasoline?	Age Age Years Years

Figure 41: Survey 9, Page 4 of 11



Life	time Occupational History				
Solv	vents				
9.	Over your lifetime (at least <u>100 days</u> or more), have you ever had a JOB where you worked with LEADED GASOLINE?	© Yes		⊚ No	O Don't know
	a. At what age did you FIRST work with leaded gasoline?		Age		
	b. At what age did you LAST work with leaded gasoline?		Age		
	c. This is a total of		Years		
	d. For how many of those years did you NOT use leaded gasoline?		Years		
	a. At what age did you FIRST use unleaded paint? b. At what age did you LAST use unleaded paint? c. This is a total of		Age Age Years		
	d. For how many of those years did you NOT use unleaded paint?		Years		
	Previous Page 5/11 Ne:	xt	Sav	ve & Quit	
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					939

Figure 42: Survey 9, Page 5 of 11



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Making One of the Luisters	
ifetime Occupational History	
Solvents	
11. Over your lifetime (at least 100 days or more), have you ever had a JOB where you used LEADED PAINT?	○ Yes ○ No ○ Don't know
a. At what age did you FIRST use leaded paint?	Age
b. At what age did you LAST use leaded paint?	Age
c. This is a total of	Years
d. For how many of those years did you NOT use leaded paint?	Years
12. Over your lifetime (at least 100 days or more), have you ever had a JOB where you used FORMALDEHYDE? a. At what age did you FIRST use formaldehyde?	
b. At what age did you LAST use formaldehyde?	Age
c. This is a total of	Years
d. For how many of those years did you NOT use formaldehyde?	Years
Previous Page 6/11 Ne	lext Save & Quit

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Figure 43: Survey 9, Page 6 of 11

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vey 9				
Lifetime Occupational History				
Metals				
13. Over your lifetime (at least 100 days or more), have you ever had a JOB where you SOLDERED?	⊚ Yes		◎ No	O Don't know
a. At what age did you FIRST solder?		Age		
b. At what age did you LAST solder?		Age		
c. This is a total of		Years		
d. For how many of those years did you NOT solder?		Years		
14. What specific metals or materials did you solder?				
Tin	O Yes		◎ No	O Don't know
Silver	⊚ Yes		◎ No	O Don't know
Other metals or Alloy	© Yes		◎ No	Don't know
IF OTHER: Specify				
Previous Page 7/	11	Next	Save	& Quit

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	me Occupational History			
1etal	-			
	ver your lifetime (at least 100 days or more), have you ever had a JOB	2278	Statement	TO THE PERSON WHEN THE PERSON WE WANTED
W	here you WELDED, BRAZED OR FLAME CUT METALS?	© Yes	◎ No	O Don't know
a.	At what age did you FIRST weld, braze or flame cut metals?	Age		
b.	At what age did you LAST weld, braze or flame cut metals?	Age		
C.	This is a total of	Years		
d.	For how many of those years did you NOT weld, braze or flame cut metals?	Years		
	Steel Iron, copper or aluminum	○ Yes	© No © No	Don't knowDon't know
	Brass or bronze	© Yes	◎ No	O Don't know
	Lead	© Yes	◎ No	O Don't know
	Other metals or Alloy	© Yes	◎ No	O Don't know
	IF OTHER: Specify			

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itet	ime Occupational History			
leta	ls			
7. C	Over your lifetime (at least <u>100 days</u> or more), have you ever had a JOB where you were exposed to METAL DUST OR METAL FUMES?	© Yes	◎ No	O Don't know
a.	At what age were you FIRST exposed to metal dust or metal fumes?	Age		
b.	At what age were you LAST exposed to metal dust or metal fumes?	Age		
C.	This is a total of	Years		
d.	For how many of those years were you NOT exposed to metal dust or metal fumes?	Years		
	Steel Iron, copper or aluminum Brass or bronze	© Yes © Yes	© No © No © No	Don't knowDon't knowDon't know
	Lead	© Yes	© No	O Don't know
	Other metals or Alloy	© Yes	⊚ No	O Don't know
	IF OTHER: Specify			
	Previous Page 9/11 Ne	ext	Save & Quit	

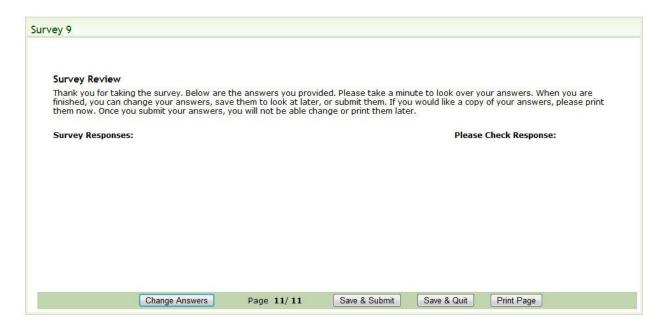
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ifetime Occupational History			
ther occupational exposure			
Over your lifetime (at least 100 days or more), have you ever had a JOB where you worked with ANY OTHER CHEMICAL?	© Yes	⊚ No	O Don't know
Specify			
a. At what age did you FIRST work with this chemical?	A	ge	
b. At what age did you LAST work with this chemical?	A	ge	
c. This is a total of	Y	ears	
d. For how many of those years did you NOT use this chemical?	Ye	ears	
where you worked with ANY OTHER CHEMICAL?	© Yes	© No	O Don't know
O. Over your lifetime (at least 100 days or more), have you ever had a JOB where you worked with ANY OTHER CHEMICAL? Specify a. At what age did you FIRST work with this chemical?	2 1000	© No	O Don't know
where you worked with ANY OTHER CHEMICAL? Specify	A	2832	© Don't know
Specify a. At what age did you FIRST work with this chemical?	A	ge	◎ Don't know
where you worked with ANY OTHER CHEMICAL? Specify a. At what age did you FIRST work with this chemical? b. At what age did you LAST work with this chemical?	A A	ge ge	◎ Don't know



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Figure 48: Survey 9, Page 11 of 11



rvey	10				
Hom	e Pesticide Use				
arou	ollowing questions are about chemicals or home pesticides that you u nd any house or apartment where you lived. We are interested only ir to application, by applying them yourself, or by helping to clean up aft onally handled at any time in your life. Please <u>consider only</u> the time fr	those proceer they we	ducts that your re applied. F	ou pers lease o	onally handled, either by preparing the consider products that you have
	ave you ever personally handled insecticides to control insects and per your home?	© Ye	es ©	No	O Don't know
a.	At what age did you FIRST handle insecticides in the home?	A	ge		
b.	At what age did you LAST handle insecticides in the home?	A	ge		
C.	This is a total of	Ye	ears		
d.	For how many of those years did you NOT handle insecticides in your home?	Ye	ears		
e.	During the periods when you did use insecticides in the home, how many days <u>per year</u> did you use them?	D	ays per yea	,	
in	ave you ever personally handled insecticides to control insects and per your lawn or garden? At what age did you FIRST handle insecticides in the lawn or	© Ye		No	O Don't know
	garden?	A	ge		
b.	At what age did you LAST handle insecticides in the lawn or garden?	A	ge		
C.	This is a total of	Ye	ears		
d.	For how many of those years did you NOT handle insecticides in the lawn or garden?	Ye	ears		
e.	During the periods when you did use insecticides in the lawn or garden, how many days <u>per year</u> did you use them?	D	ays per yea	r	
	Previous Page 1/3	Next	Save &	Quit	

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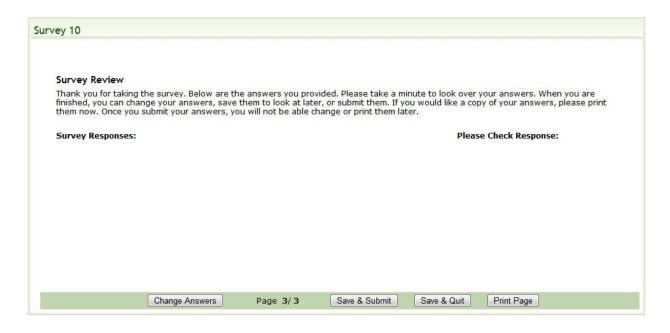
Figure 49: Survey 10, Page 1 of 3

urvey	10			
Hom	e Pesticide Use			
	ave you ever used herbicides or weed killers to control weeds or plan our lawn, garden, or other areas around the home?	ts <u>in</u>	⊚ Yes	O Don't know
a.	At what age did you FIRST handle herbicides in your lawn, garden, or other areas around the home?		Age	
b.	At what age did you LAST handle herbicides in your lawn, garden, or other areas around the home?		Age	
C.	This is a total of		Years	
d.	For how many of those years did you NOT use herbicides in your lawn, garden, or other areas around the home?		Years	
e.	During the periods when you did use herbicides in your lawn, garden, or other areas around the home, how many days <u>per year</u> did you use them?	Days per year		
m	ave you ever used fungicides to control mildew or rot <u>in your home</u> or old <u>in the garden?</u> At what age did you FIRST handle fungicides in the home or garden?	plant	◎ Yes ◎ No	© Don't know
b.	At what age did you LAST handle fungicides in the home or		Age	
	garden?		1 3 3 7	
	This is a total of		Years	
	For how many of those years did you NOT use fungicides?		Years	
e.	During the periods when you did use fungicides in the home or garden, how many days <u>per year</u> did you use them?		Days per year	
	ave you ever personally applied chemical soaps, shampoos, dips or po kill fleas, ticks or other insects <u>on a pet, such as a dog or a cat</u> ?	owders	◎ Yes ◎ No	© Don't know
a.	At what age did you \boldsymbol{FIRST} apply these substances to your pet(s)?		Age	
b.	At what age did you LAST apply these substances to your pet(s)?		Age	
C.	This is a total of		Years	
d.	For how many of those years did you NOT apply these substances to your pets?		Years	
e.	During the periods when you did use these substances, how many days <u>per year</u> did you apply them to your pet(s)?		Days per year	
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urvey	11			
	oles ollowing questions are about home activities and hobbies you ha t least one year or more. Please <u>consider only</u> the time from whe			
	ave you ever done leather work (such as making belts, irses, etc.)?	∂ Yes	⊚ No	O Don't know
a.	At what age did you FIRST do leather work?		Age	
b.	At what age did you LAST do leather work?		Age	
C.	This is a total of		Years	
d.	For how many of those years did you NOT do leather work?		Years	
e.	During the period when you did leather work, how many hours each month did you perform the activity?		Hours/Month	
2. Ha	ave you ever lead glazed pottery or other ceramics?	○ Yes	◎ No	O Don't know
a.	At what age did you FIRST glaze pottery or other ceramics?		Age	
b.	At what age did you LAST glaze pottery or other ceramics?		Age	
C.	This is a total of		Years	
d.	For how many of those years did you $\operatorname{\textbf{NOT}}$ glaze pottery or oth ceramics?	er	Years	
e.	During the period when you did glaze pottery or other ceramics how many hours each month did you perform the activity?	·	Hours/Month	
	Previous Page 1/9	Next	Save &	Quit

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lobl	pies				
. Ha	eve you ever painted pictures or furniture with oil-based paint?	⊚ Ye	s	◎ No	O Don't know
a.	At what age did you FIRST paint pictures or furniture with oilbased paint?		Age		
b.	At what age did you LAST paint pictures or furniture with oil-based paint?		Age		
C.	This is a total of		Years		
d.	For how many of those years did you NOT paint pictures or furniture with oil-based paint?		Years		
e.	During the period when you did paint pictures or furniture with oil- based paint, how many hours each month did you perform the activity?		Hours,	/Month	
st	ave you ever done home remodeling projects that involved scraping, ripping, burning and sanding paint? Please count only houses built fore 1960.	© Ye	S	◎ No	O Don't know
a.	At what age did you FIRST do home remodeling projects that involved scraping, stripping, burning and sanding paint on houses built before 1960?		Age		
b.	At what age did you LAST do home remodeling projects that involved scraping, stripping, burning and sanding paint on houses built before 1960?		Age		
	This is a total of		Years		
C.	For how many of those years did you NOT do home remodeling		Years		
OF RE	projects that involved scraping, stripping, burning and sanding paint on houses built before 1960?				

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Survey 11			
Hobbies			
5. Have you ever done woodworking?	© Yes	⊚ No	O Don't know
a. At what age did you FIRST do woodworking?		Age	
b. At what age did you LAST do woodworking?		Age	
c. This is a total of		Years	
d. For how many of those years did you NOT do	woodworking?	Years	
e. During the period when you did wood working each month did you perform the activity?	, how many hours	Hours/Month	
6. Have you ever painted, repaired or restored old of than fixing a flat tire or changing oil?	ears, other © Yes	⊚ No	Don't know
 At what age did you FIRST paint, repair or resthan fixing a flat tire or changing oil? 	store old cars, other	Age	
b. At what age did you LAST paint, repair or rest than fixing a flat tire or changing oil?	tore old cars, other	Age	
c. This is a total of		Years	
For how many of those years did you NOT pai old cars, other than fixing a flat tire or changir		Years	
e. During the period when you did paint, repair of other than fixing a flat tire or changing oil, how month did you perform the activity?		Hours/Month	
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irvey	11						
Hobl	bies						
7. H	ave you ever built wooden or plastic models using glue?	es.	◎ No				
a.	At what age did you FIRST build wooden or plastic models using glue?		Age				
b.	At what age did you LAST build wooden or plastic models using glue?		Age				
C.	This is a total of		Years				
d.	For how many of those years did you NOT build wooden or plastic models using glue?		Years				
e.	During the period when you did build wooden or plastic models using glue, how many hours each month did you perform the activity?	Hours/Month					
8. Ha	ave you ever developed photographs?	·s	© No				
a.	At what age did you FIRST develop photographs?		Age				
ь.	At what age did you LAST develop photographs?		Age				
C.	This is a total of		Years				
d.	For how many of those years did you NOT develop photographs?		Years				
e.	During the period when you did develop photographs, how many hours each month did you perform the activity?		Hours/Month				
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Hobbies			
9. Have you ever done gardening?	© Yes	© No	O Don't know
a. At what age did you FIRST do gardening?		Age	
b. At what age did you LAST do gardening?		Age	
c. This is a total of		Years	
d. For how many of those years did you NOT do	gardening?	Years	
 During the period when you did gardening, hemonth did you perform the activity? 	ow many hours each	Hours/Month	
10 11-1	ork (such as	12	O Don't know
sculpting, garden structures, etc.)?	◎ Yes	◎ No	© Don't know
 Have you done soldering, welding, or metal wo sculpting, garden structures, etc.)? a. At what age did you FIRST solder, weld, or or 	© Yes	◎ No Age	© Don't know
sculpting, garden structures, etc.)?	○ Yes		© Don't know
sculpting, garden structures, etc.)? a. At what age did you FIRST solder, weld, or o	○ Yes	Age	© Don't know
a. At what age did you FIRST solder, weld, or do. At what age did you LAST solder, weld, or do.	o metal work?	Age Age	© Don't know

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Figure 56: Survey 11, Page 5 of 9



vey	11				
Hob	bies				
	Have you ever done outdoor hunting or shooting with guns, including animals, skeet, trap or targets?	© Ye	es	◎ No	O Don't know
a.	At what age did you FIRST do outdoor hunting or shooting with guns, including animals, skeet, trap or targets?		Age		
b.	At what age did you LAST do outdoor hunting or shooting with guns, including animals, skeet, trap or targets?		Age		
C.	This is a total of		Years		
d.	For how many of those years did you NOT do outdoor hunting or shooting with guns, including animals, skeet, trap or targets?		Years		
e.	During the period when you did outdoor hunting or shooting with guns, including animals, skeet, trap or targets, how many hours each month did you perform the activity?		Hours/	Month	
12. H	Have you ever done gun shooting in an indoor pistol or rifle range?	⊚ Ye	es	© No	⊚ Don't know
a.	At what age did you FIRST do gun shooting in an indoor pistol or rifle range?		Age		
b.	At what age did you LAST do gun shooting in an indoor pistol or rifle range?		Age		
C.	This is a total of		Years		
d.	For how many of those years did you NOT do gun shooting in an indoor pistol or rifle range?		Years		
e.	During the period when you did gun shooting in an indoor pistol or rifle range, how many hours each month did you perform the activity?		Hours/	Month	

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rvey	11			
Hobb	bies			
	Have you ever done casting of bullets or reloading of ammunition?	i	© No	O Don't know
a.	At what age did you FIRST do casting of bullets or reloading of ammunition?	А	ge	
b.	At what age did you LAST do casting of bullets or reloading of ammunition?	А	ge	
C.	This is a total of	Υ	ears	
d.	For how many of those years did you NOT do casting of bullets or reloading of ammunition?	Υ	ears	
e.	During the period when you did casting of bullets or reloading of ammunition, how many hours each month did you perform the activity?	Н	ours/Month	
a.	Have you ever done fishing using lead weights or sinkers? O Yes At what age did you FIRST do fishing using lead weights or sinkers?		© No ge	© Don't know
b.	At what age did you LAST do fishing using lead weights or sinkers?	А	ge	
C.	This is a total of	Y	ears	
d.	For how many of those years did you NOT do fishing using lead weights or sinkers?	Υ	ears	
e.	During the period when you did fishing using lead weights or sinkers, how many hours each month did you perform the activity?	Н	ours/Month	
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100	bies			
1	Have you ever done any other HOBBY, such as knitting, making jewelry? Please DO NOT consider physical activity, electronic games, writing as hobbies. Please specify hobby:	Yes	◎ No	⊚ Don't know
	Please specify hobby.			
a.	At what age did you FIRST do this HOBBY?		Age	
b.	At what age did you LAST do this HOBBY?		Age	
c.	This is a total of		Years	
d.	For how many of those years did you NOT do this HOBBY?		Years	
e.	During the period when you did this HOBBY, how many hours ea month did you perform the activity?	ch	Hours/Month	
	Have you ever done any other HOBBY, such as knitting, making jewelry? Please DO NOT consider physical activity,			
	electronic games, writing as hobbies.	Yes	◎ No	O Don't know
	Please specify hobby:			
			Age	
•	Salaranous Antonios		Age Age	
a.	At what age did you FIRST do this HOBBY?		- Louis	
a. b.	At what age did you FIRST do this HOBBY? At what age did you LAST do this HOBBY?		Age	

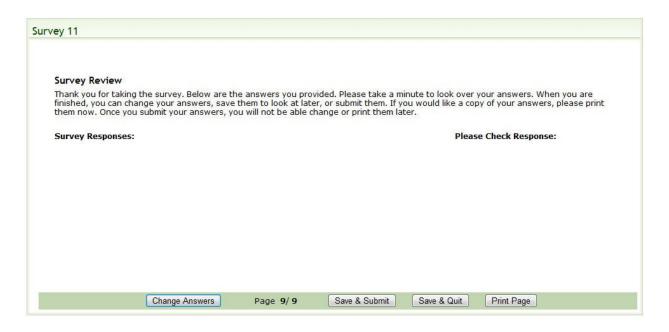
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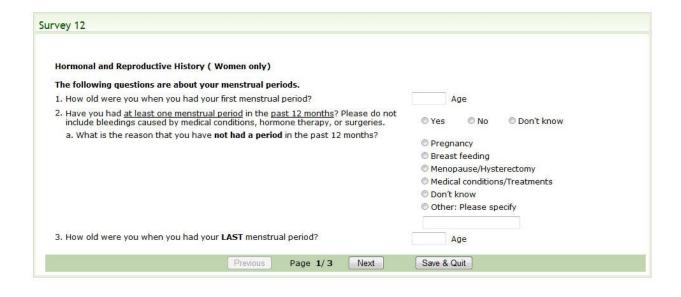


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National Amyotrophic Lateral Sclerosis (ALS) Registry



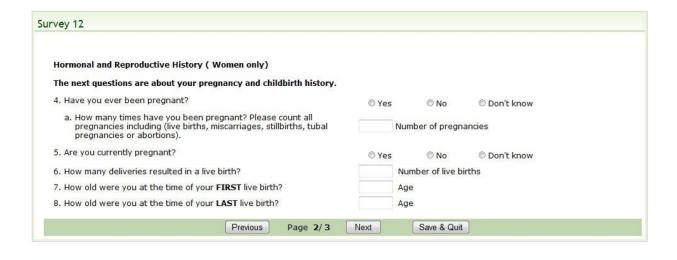
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Figure 61: Survey 12, Page 1 of 3



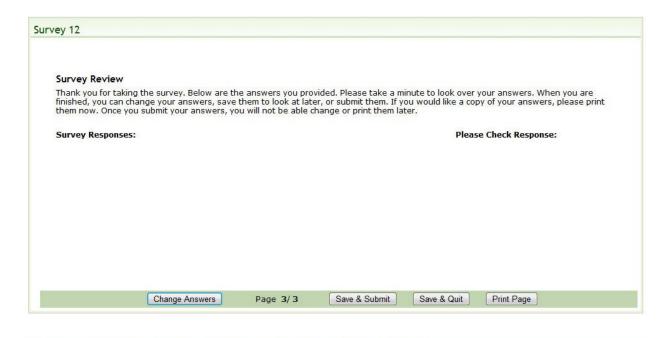


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Figure 63: Survey 12, Page 3 of 3

/ey	13						
Caffe	eine						
	next questions pertain to your usual caffeine habits a x months or more.	s an adul	t. By usu	ıal, we mean dri	nking the b	everage at least once	a month
	id you ever drink espresso or espresso drinks (Latte, mericano)? A serving of espresso is <u>1 shot.</u>	Mocha,		◎ Yes	◎ No	O Don't know	
a.	At what age did you FIRST drink espresso or espresso drinks at least once per month?		Age				
b.	Are you still drinking espresso or espresso drinks at least once per month?	© Yes	⊚ No	O Don't know			
C.	At what age did you LAST drink espresso or espresso drinks at least once per month?		Age				
d.	This is a total of		Years				
e.	Were there any periods of time during these years when you did NOT drink espresso or espresso drinks? If no, then record as (00 years).		Years				
f.	During the periods when you did drink espresso, how often (per day, week, month or year) did you drink them?		Number	r of drinks per	⊚ day	© week	⊚ year
	id you ever drink caffeinated coffee? A serving of coff At what age did you FIRST drink caffeinated coffee at least once per month?	ee is 8 ou	nces.	© Yes	◎ No	© Don't know	
b.	Are you still drinking caffeinated coffee at least once per month?	© Yes	◎ No	O Don't know			
C.	At what age did you LAST drink caffeinated coffee at least once per month?		Age				
d.	This is a total of		Years				
e.	For how many of those years did you NOT drink caffeinated coffee?		Years				
f.	During the periods when you did drink caffeinated coffee, how often (per day, week, month or year) did you drink it?		Numbe	r of drinks per	© day	⊚ week ⊚ month	© year
	ald you drink it?	Page 1/		Next	Save & Quit		CHA YES

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National Amyotrophic Lateral Sclerosis (ALS) Registry

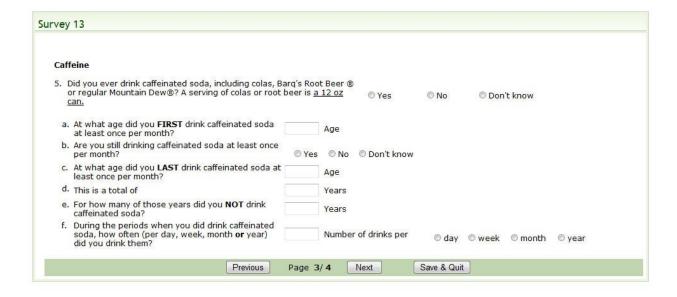
affe	eine						
D	id you ever drink caffeinated tea (green or black), hot	or iced?	Δ				
	erving of tea is <u>8 oz.</u>	or iccu.		O Yes	◎ No	O Don't know	
a.	At what age did you FIRST drink caffeinated tea at least once per month?		Age				
b.	Are you still drinking caffeinated tea at least once per month?	© Yes	◎ No 《	Don't know			
c.	At what age did you LAST drink caffeinated tea at least once per month?		Age				
d.	This is a total of		Years				
e.	For how many of those years did you NOT drink caffeinated tea?		Years				
f.	During the periods when you did drink caffeinated tea, how often (per day, week, month or year) did you drink them?		Number o	of drinks per	⊚ day	⊚ week ⊚ month	© year
M	id you ever drink highly caffeinated drinks, including J ountain Dew MDX®, Red Bull®? A serving of these dr <u>an</u> .			◎ Yes	⊚ No	O Don't know	
C	ountain Dew MDX®, Red Bull®? A serving of these dr			© Yes	◎ No	O Don't know	
a.	ountain Dew MDX®, Red Bull®? A serving of these dr an. At what age did you FIRST drink highly caffeinated		Age	YesDon't know	© No	© Don't know	
a. b.	lountain Dew MDX®, Red Bull®? A serving of these dr an. At what age did you FIRST drink highly caffeinated drinks at least once per month? Are you still drinking highly caffeinated drinks at	inks is a	Age	2.852	◎ No	⊚ Don't know	
a. b.	lountain Dew MDX®, Red Bull®? A serving of these dran. At what age did you FIRST drink highly caffeinated drinks at least once per month? Are you still drinking highly caffeinated drinks at least once per month? At what age did you LAST drink highly caffeinated	inks is a	Age	2.852	⊚ No	© Don't know	
a. b. c.	lountain Dew MDX®, Red Bull®? A serving of these dran. At what age did you FIRST drink highly caffeinated drinks at least once per month? Are you still drinking highly caffeinated drinks at least once per month? At what age did you LAST drink highly caffeinated drinks at least once per month?	inks is a	Age No Age	2.852	◎ No	⊚ Don't know	

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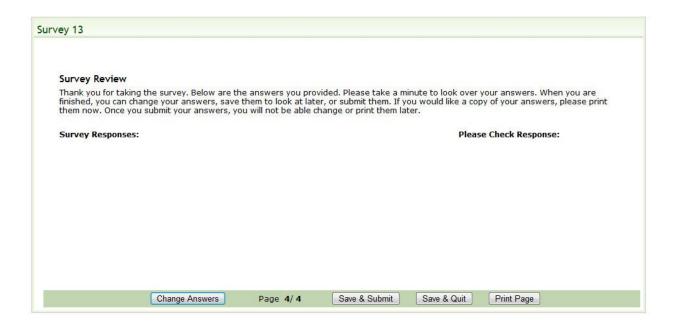


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Head	and Neck Injuries						
The occu	next questions are about injuries to your head and/or neck that y red during sporting activities, from falls, violence, car accidents or adulthood.						
	ave you ever had an injury to your head or neck? Think about any ildhood injuries you remember or were told about.	r.	© Yes	◎ No	⊚ Don't know		
a.	How many head or neck injuries have you had?		Num				
b.	At what age did the FIRST injury occur?		Age				
C.	Did you lose consciousness from this injury?	⊚ Yes	© No	O Don't kn	now		
d.	How long were you unconscious?	0.	Less than 5 minutes				
			s than 5 minu 9 minutes	tes			
		-	4 hours				
			ger than a da	V			
			't know	1.			
e.	Did you go to the emergency room or were you hospitalized for this injury?	© Yes	⊚ No	O Don't kn	now		
f.		=-					
	that apply)?	Sku Seiz	ll fracture				
		10000000	cure nory loss, amr	nocia			
			e of the abov				
		□ Don	't know				

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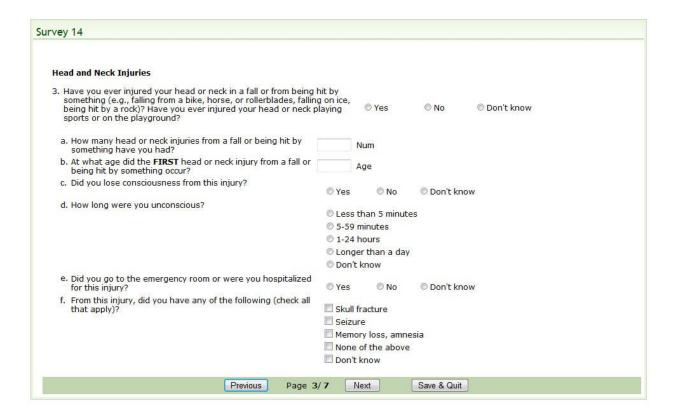
Survey 14			
Head and Neck Injuries			
Have you ever injured your head or neck in a car accident or fro other moving vehicle accident (e.g. motorcycle, ATV)?	om some	◎ Yes	
a. How many accidents have you had?		Num	
b. At what age did the FIRST accident occur?		Age	
c. Did you lose consciousness from this accident?	© Yes	⊚ No	© Don't know
d How long were you unconscious?	~		
© Less than 5 minutes			
© 5-59 minutes © 1-24 hours			
	Longer than a dayDon't know		
e. Did you go to the emergency room or were you hospitalized for this injury?	© Yes	⊚ No	O Don't know
f. From this injury, did you have any of the following (check all that apply)?	Cku	ll fracture	
Seizure			
Memory loss, amnesia			
None of the above			
Don't know			
250/2000			
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Contact CDC: 800-232-4636 / TTY: 888-232-6348

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ead and Neck Injuries				
. Have you ever injured your head or neck in a fight, from being h someone, or from being shaken violently? Have you ever been the head?		© Yes		
How many head or neck injuries have you had in a fight or from other violence?	N	lum		
b. At what age did the FIRST head or neck injury in a fight or from other violence occur?	Δ	ge		
c. Did you lose consciousness from this injury?	© Yes	◎ No	O Don't know	
d. How long were you unconscious?	2.000			
		han 5 minut	es	
	© 5-59 n	ninutes		
	1-24 h	nours		
	Conge	r than a day		
	O Don't	know		
e. Did you go to the emergency room or were you hospitalized for this injury?	O Yes	◎ No	O Don't know	
f. From this injury, did you have any of the following (check all	Skull fr	and the same		
that apply)?	Seizur			
	Total State of the last of the			
		ry loss, amn		
	1000000			
	Don't l	know		
	/7 N	ext	Save & Quit	

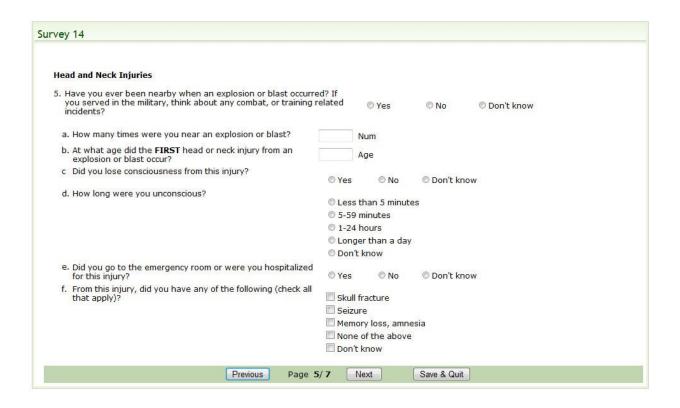
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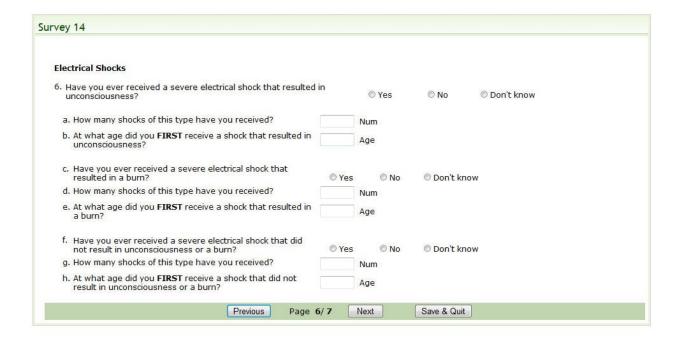


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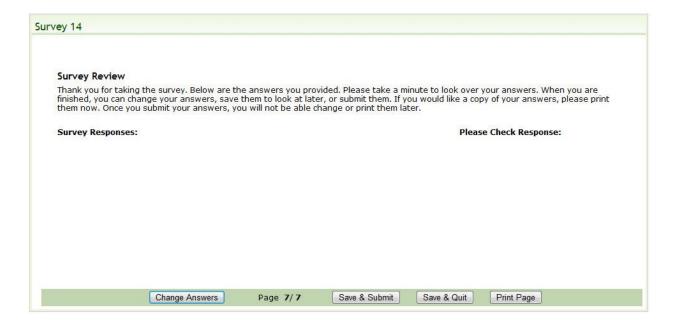
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Agency for Toxic Substances & Disease Registry

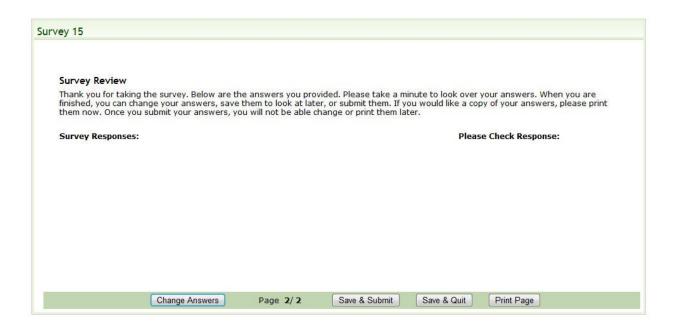
National Amyotrophic Lateral Sclerosis (ALS) Registry

rvey 15	
Health Insurance What kind of health insurance or health hospitalized. If you have more than one	care coverage do you have? Exclude private plans that only provide extra cash while kind of health insurance, please check the box next to each plan that you have.
Please mark all that apply.	
□ нмо	
Private health insurance (non-HMO en	nployer-sponsored)
■ MEDI-GAP (private insurance that sup	plements Medicare)
MEDICAID	
VA (Veteran's Administration)	
Other military health care (CHAMP, TR	ICARE, Department of Defense health plans)
Indian Health Service	
State-sponsored health plan	
Other government program (specify):	
Other health insurance plan (specify):	
☐ No health care coverage of any type ☐ Don't know	
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Figure 75: Survey 15, Page 1 of 2

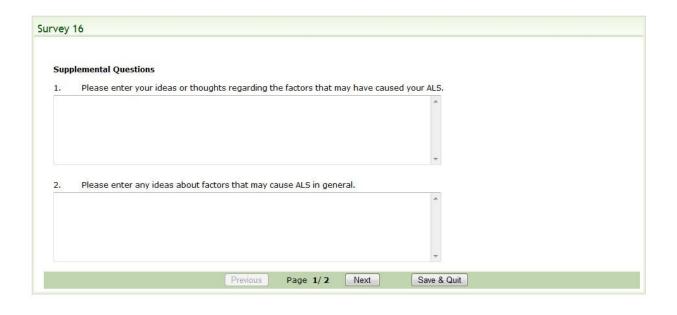


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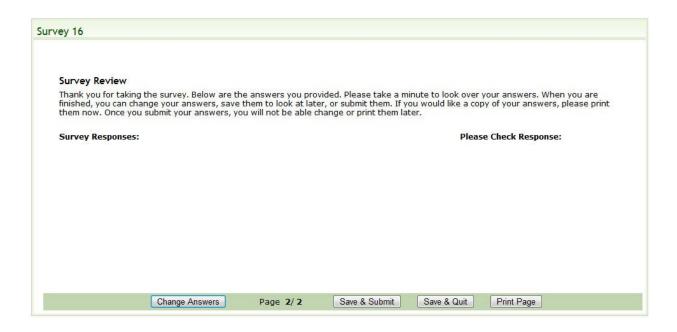
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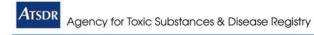
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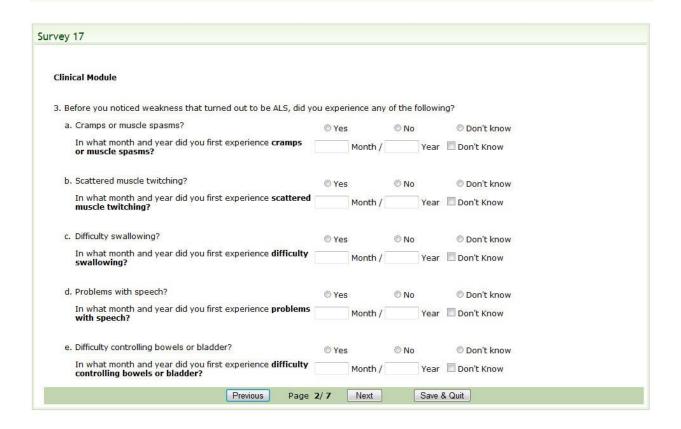
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Clinical I	Module						
1. When	did you first not	tice weaknes	s that was late	er diagnosed	Month	th / Year Don't Know	
	at part of the bo iagnosed as ALS		st notice weak	kness that	Arm or har	ck or abdominal area ot g muscles	
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urvey 17					
Clinical Module					
5. The following questions are about assistive devices or programs yo	u may ha	ive used.			
a. Have you ever used a power wheelchair or electric scooter?	⊚ Yes		© No		O Don't know
In what month and year did you first use a power wheelchair or electric scooter?		Month /		Year	☐ Don't Know
b. Have you ever used noninvasive breathing equipment, such as Bi-Pap (Bi-level Positive Airway Pressure)?	© Yes		© No		O Don't know
In what month and year did you first use noninvasive breathing equipment such as Bi-Pap?		Month /		Year	Don't Know
c. Have you ever had a tracheostomy?	© Yes		⊚ No		© Don't know
In what month and year did you have the tracheostomy?		Month /		Year	Don't Know
d. Have you ever used an augmentative and alternative communication device?	© Yes		⊚ No		O Don't know
In what month and year did you first use an augmentative and alternative communication device?		Month /		Year	Don't Know
e. Have you ever been enrolled in a hospice program?	© Yes		© No		O Don't know
In what month and year did you first enroll in a hospice program?		Month /		Year	Don't Know
Previous Page 4/7	Nex	t	Save	& Quit	

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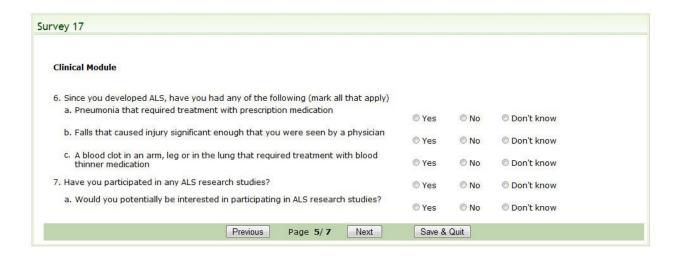
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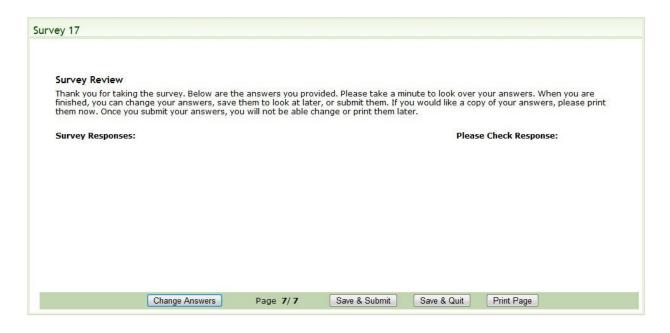
Figure 83: Survey 17, Page 5 of 7

Clinical Module			
 A multidisciplinary ALS clinic is a clinic in which specialized medical c professionals. This team may include a neurologist, nurse, physical -language pathologist, nutritionist or dietitian and social worker. 			
Have you attended an ALS multidisciplinary clinic?	@ I have r	never attende	d a multidisciplinary ALS clinic
			ultidisciplinary ALS clinic
	O I previo	The state of the s	a multidisciplinary ALS clinic but do
	O Don't kr	now	
9 Which hand do/did you write with?			
	Right		
	© Left		
	Can use	e either equall	y well
10 Do you have advance directives established, such as a living will?	© Yes	© No	O Don't know
11. Have you had genetic test for inherited traits that can cause ALS?	© Yes	◎ No	O Don't know

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