Attachment 6

Approved Surveys (screenshots)

(16 Voluntary Survey Modules and Disease Progression Survey)

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.

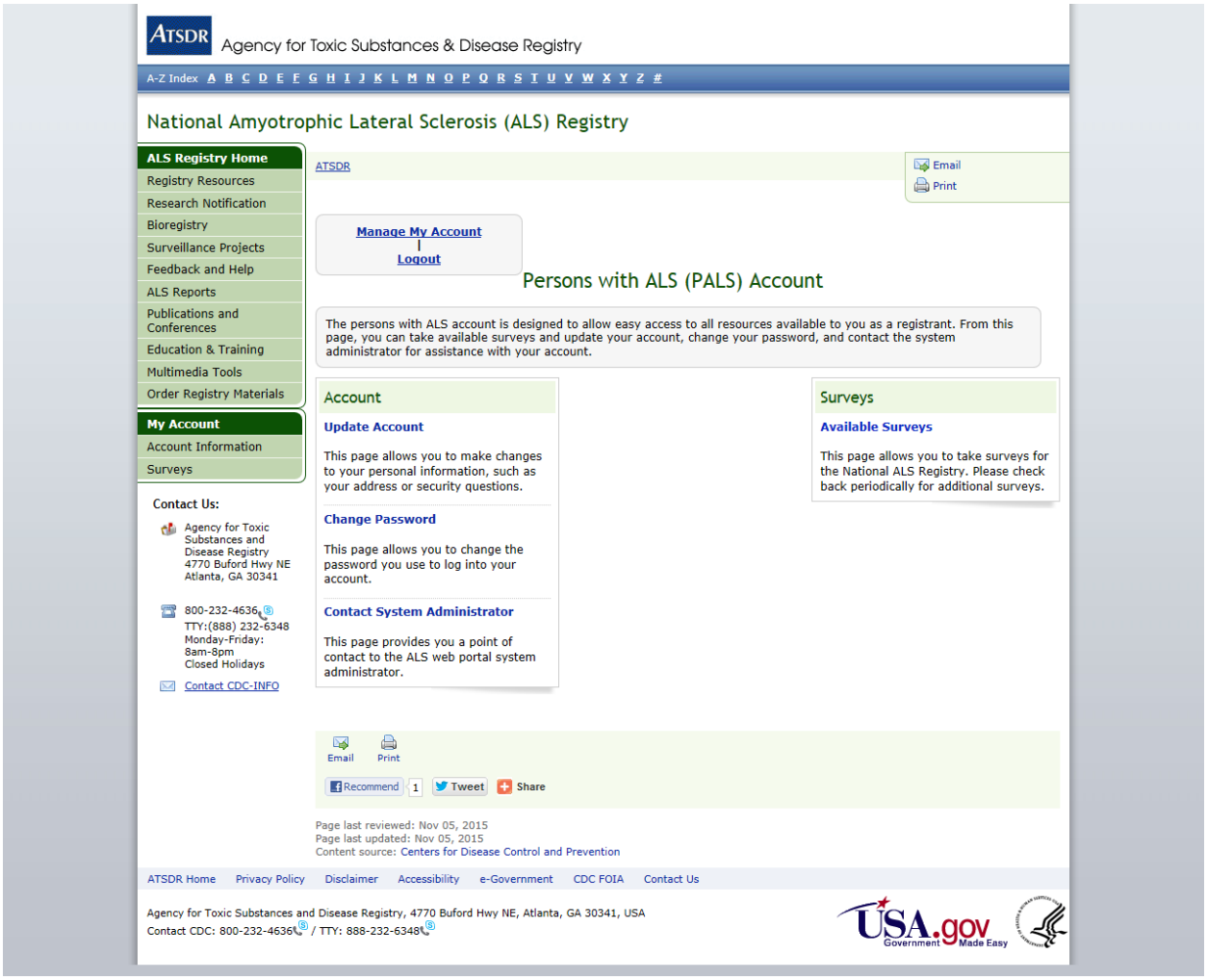

Figure 1: PALS Login Landing Page to Access Surveys

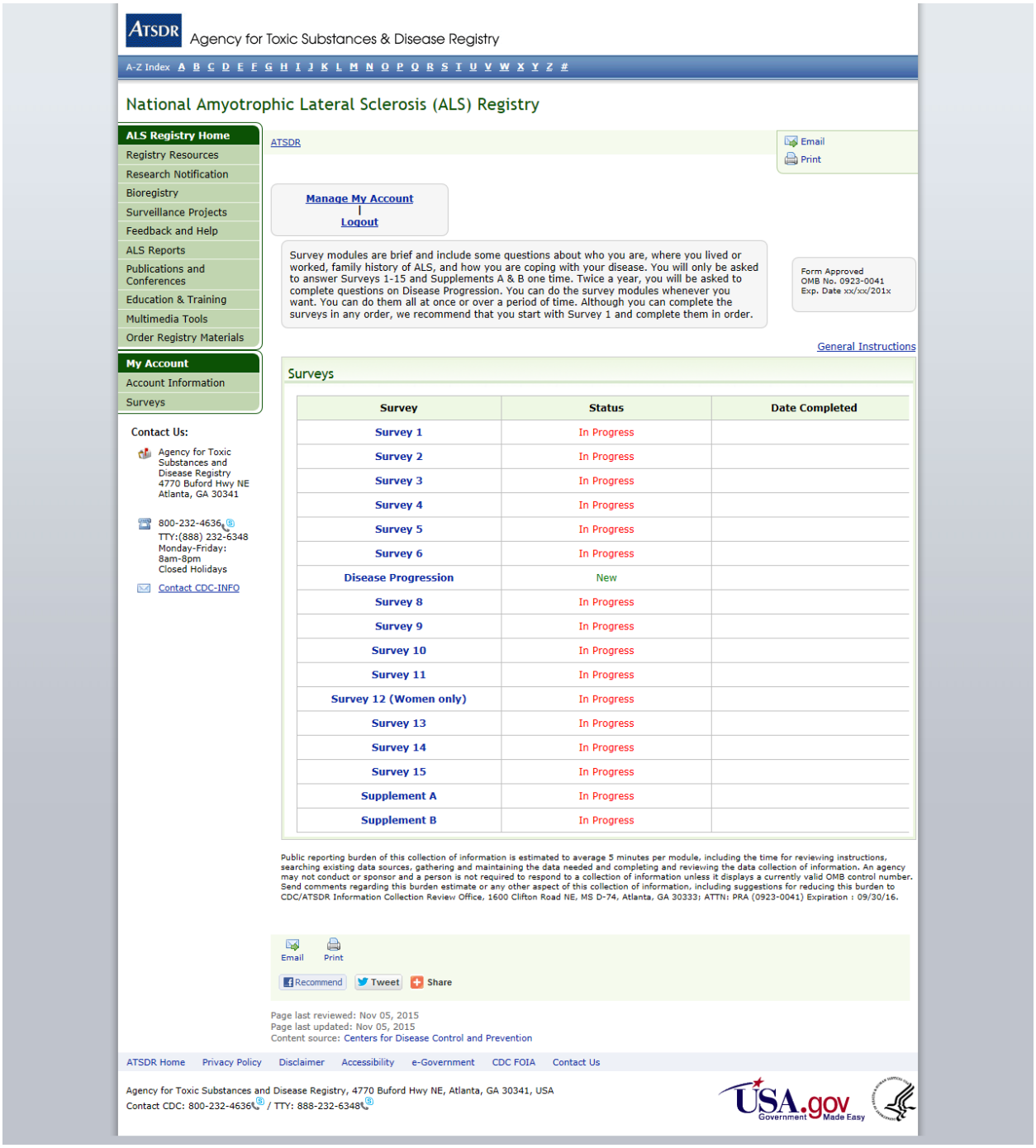

Figure 2: Select Survey to Take

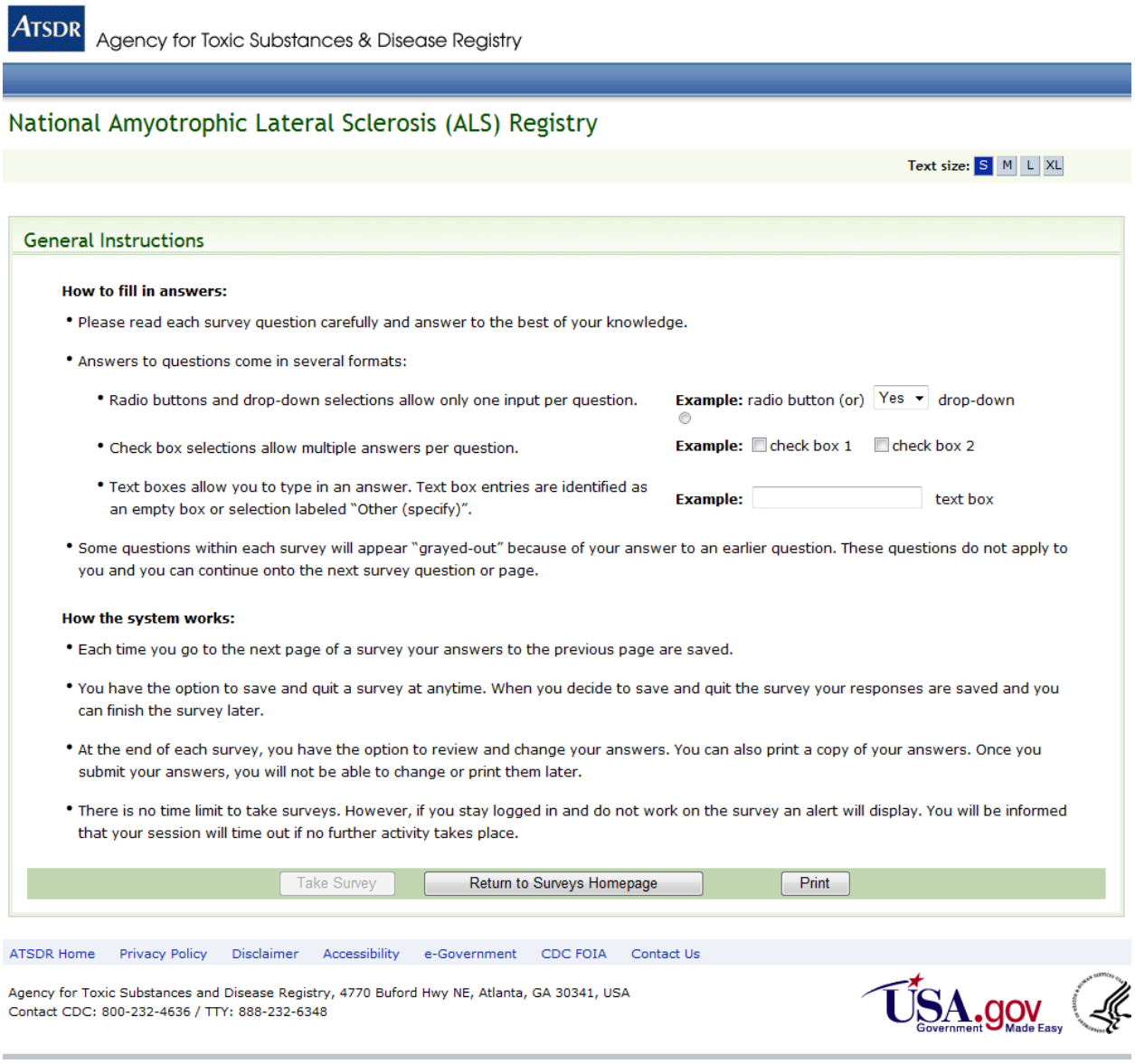

Figure 3: General Instructions

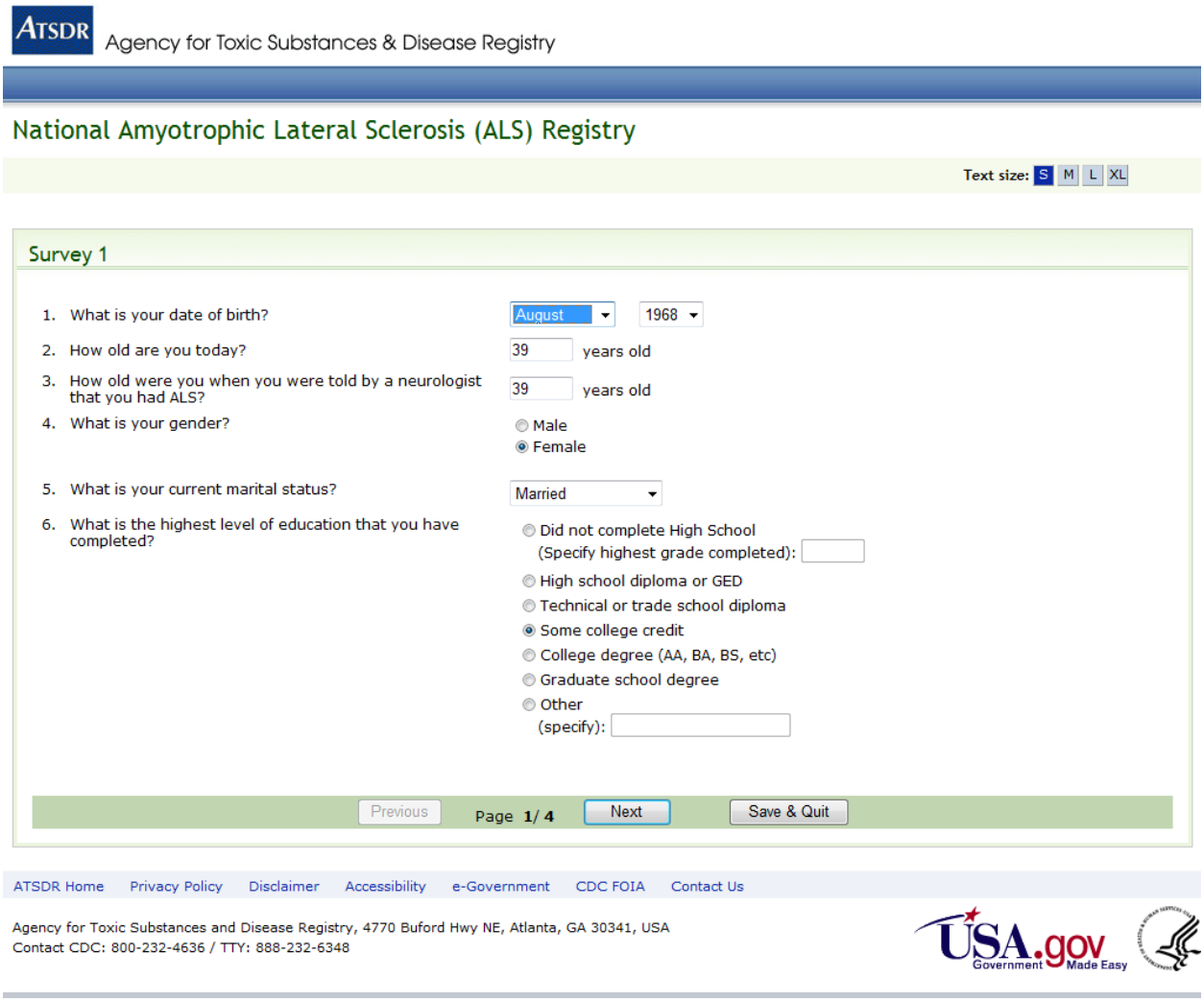

Figure 4: Survey 1, Page 1 of 4

Figure 5: Survey 1, Page 2 of 4

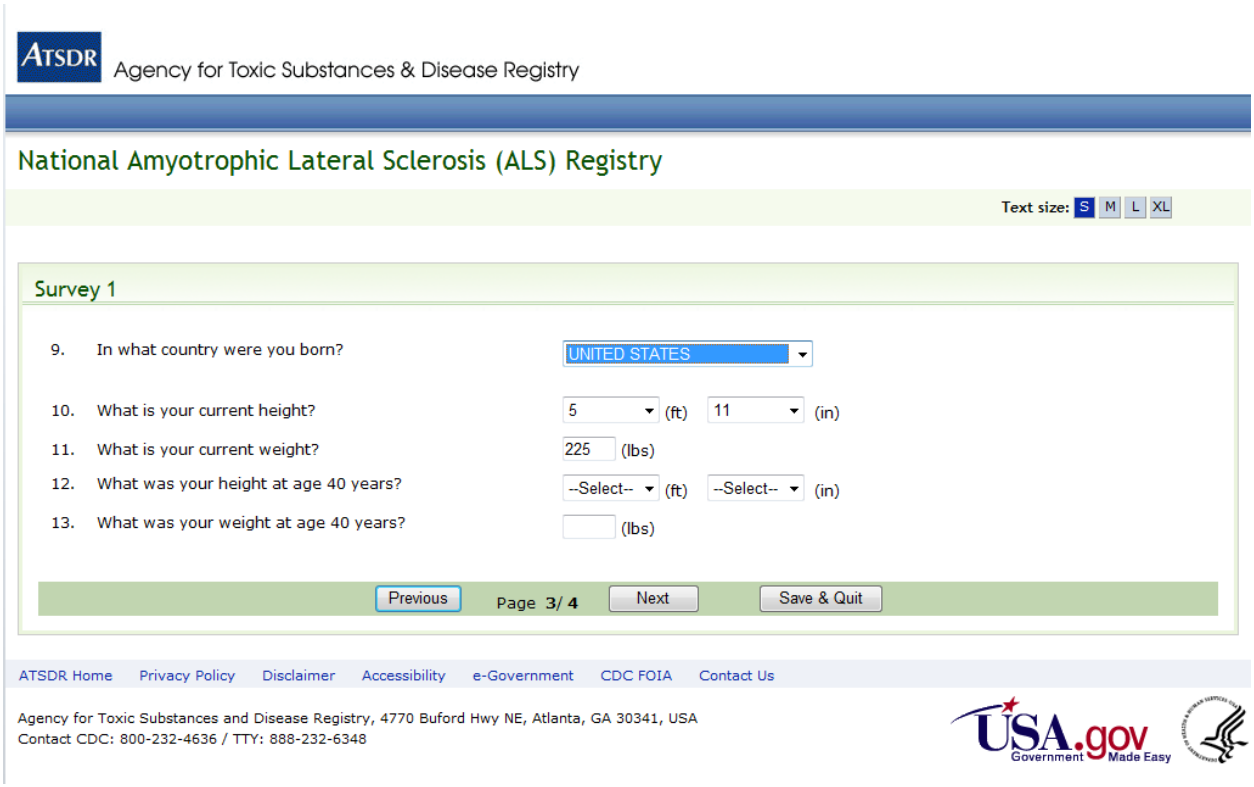

Figure 6: Survey 1, Page 3 of 4

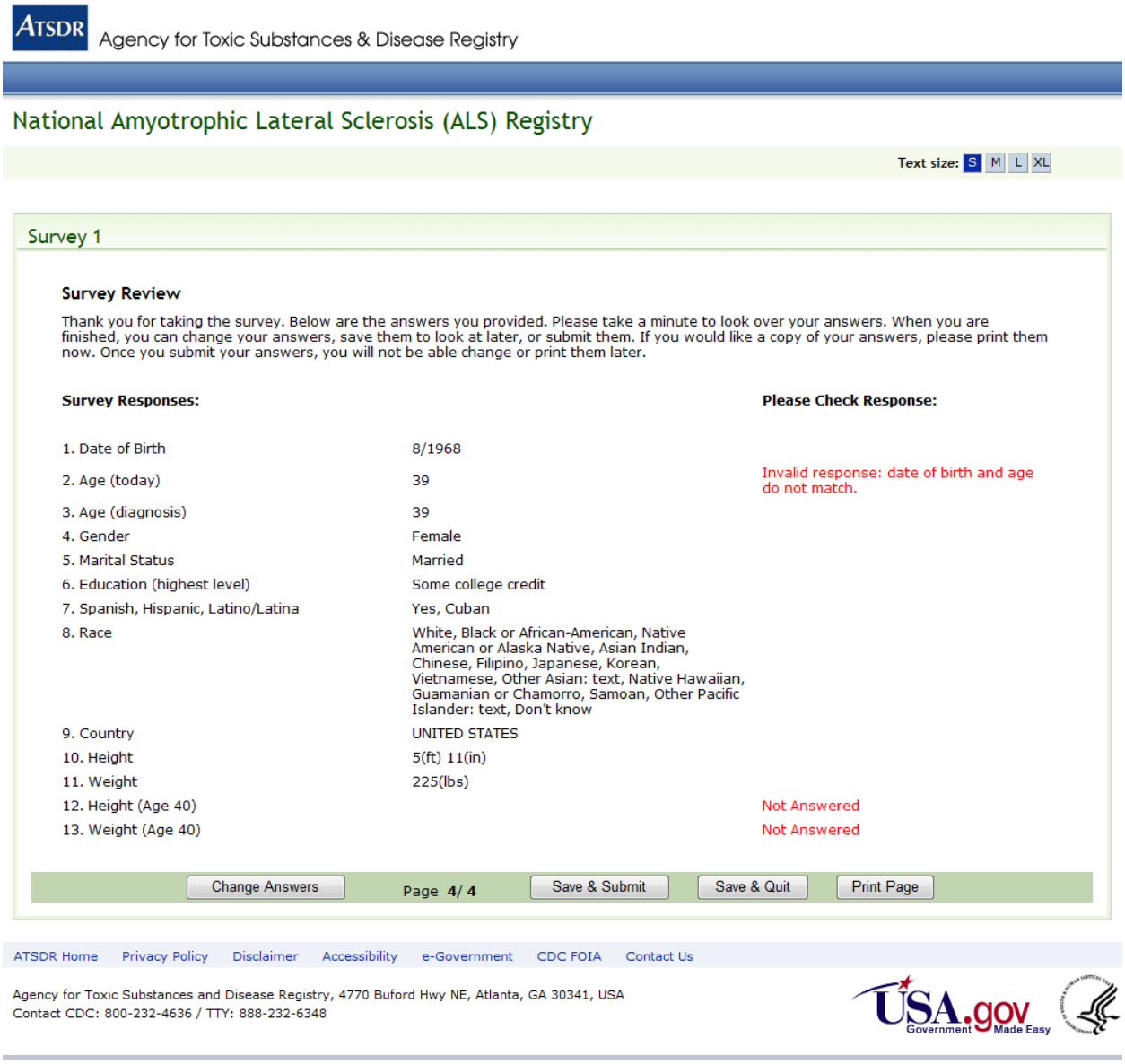

Figure 7: Survey 1, Page 4 of 4

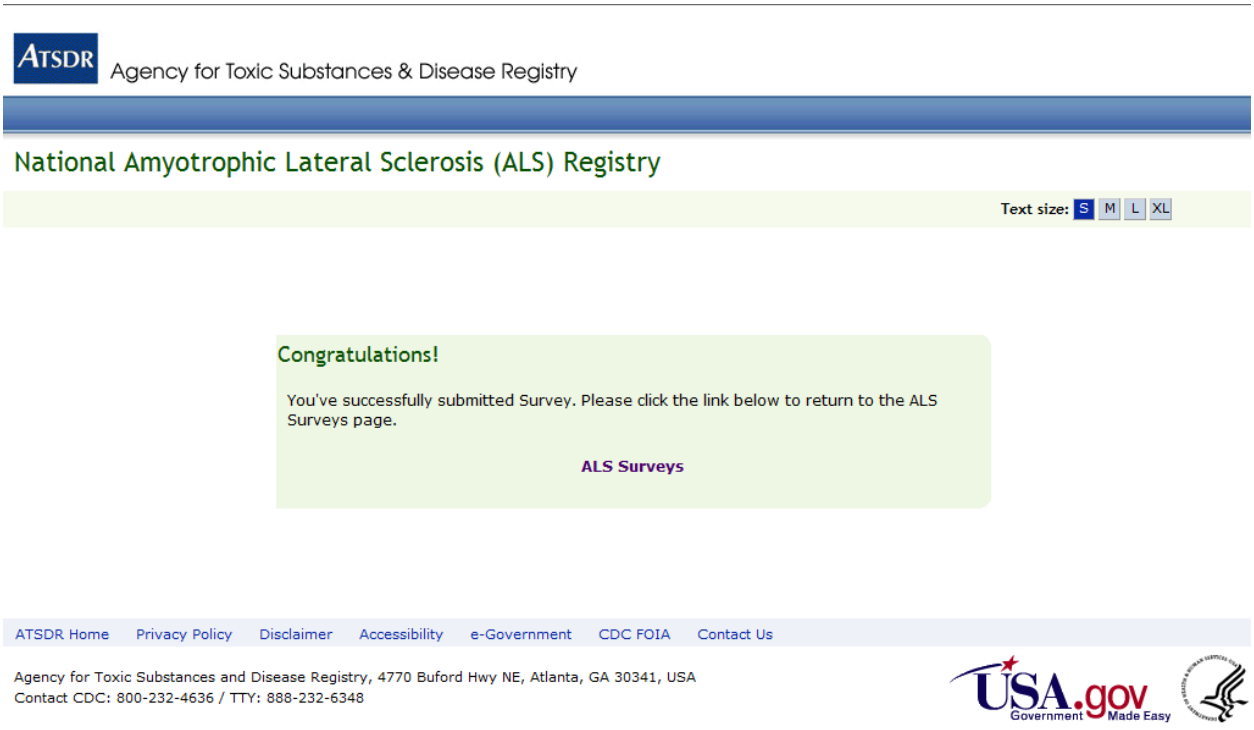

Figure 8: Survey Taken Confirmation Page (Same for ALL Surveys)

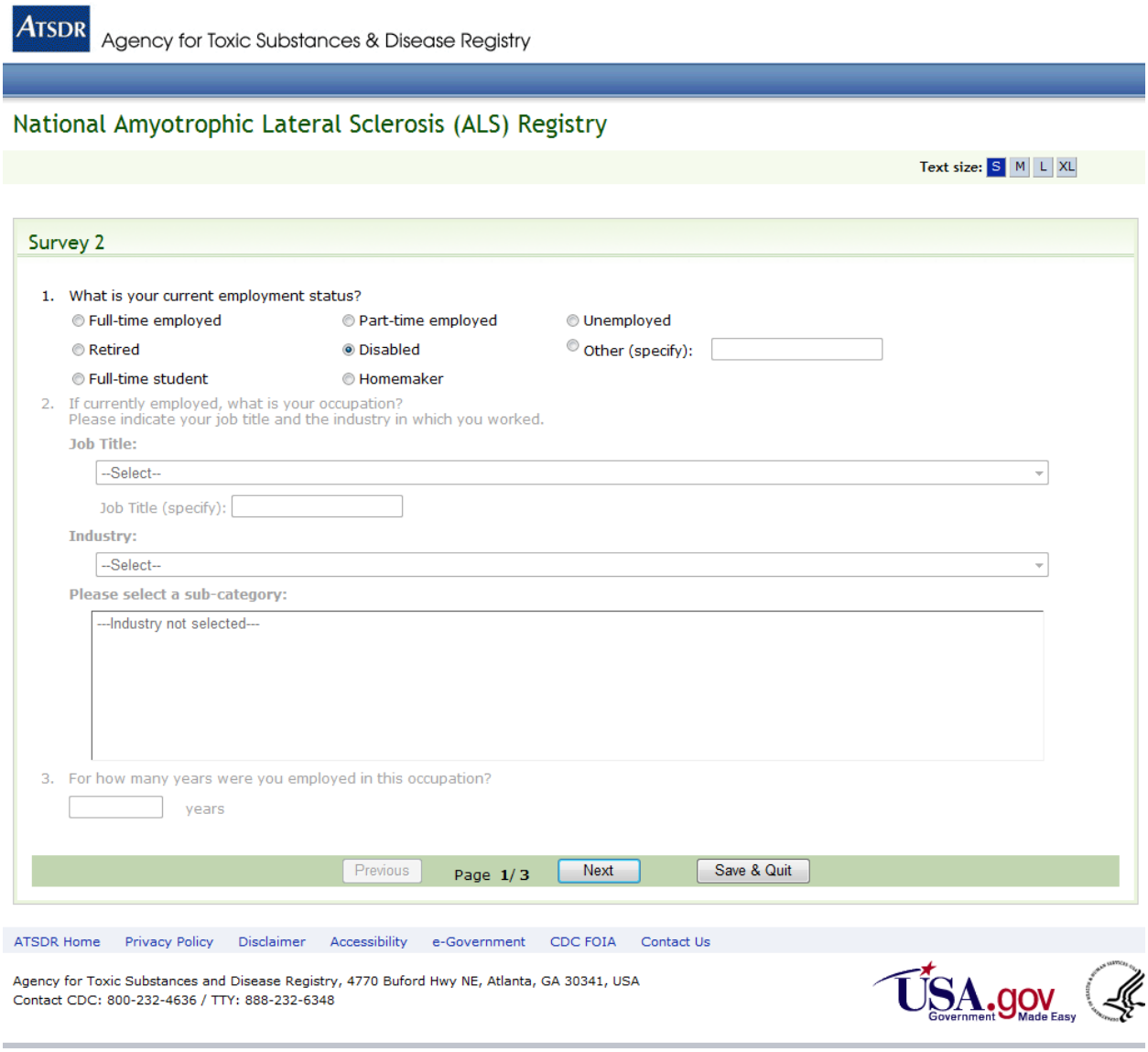

Figure 9: Survey 2, Page 1 of 3

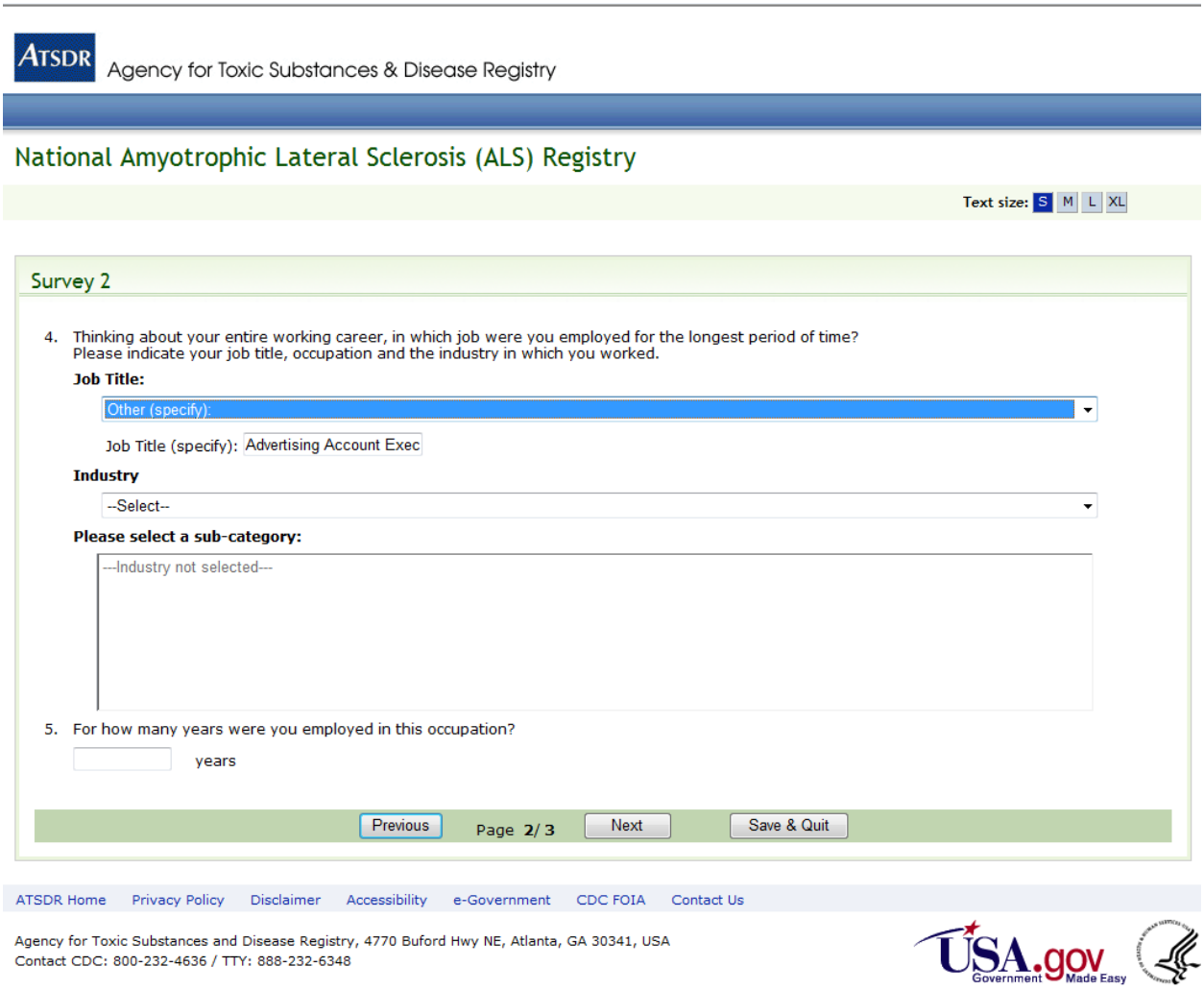

Figure 10: Survey 2, Page 2 of 3

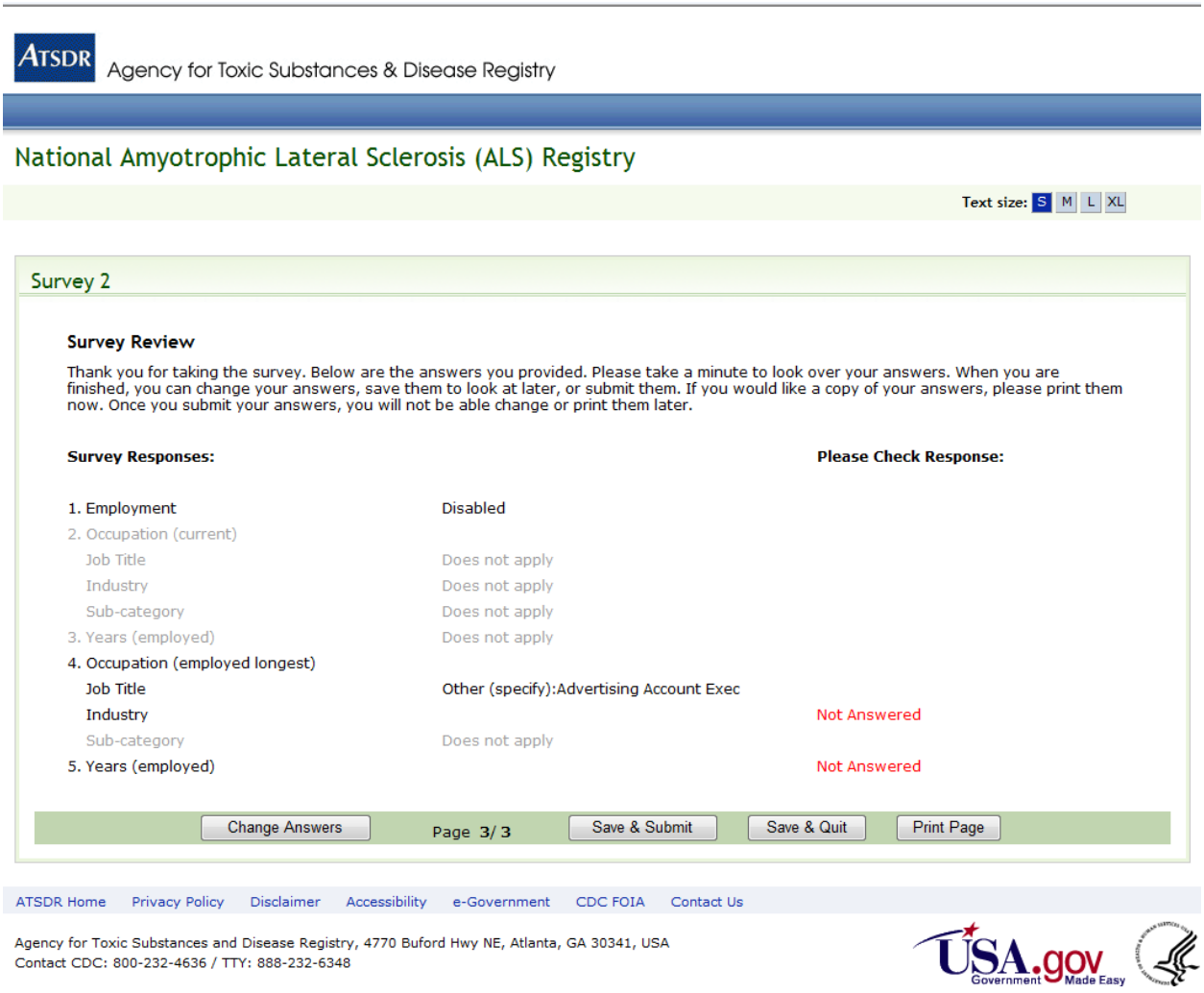

Figure 11: Survey 2, Page 3 of 3

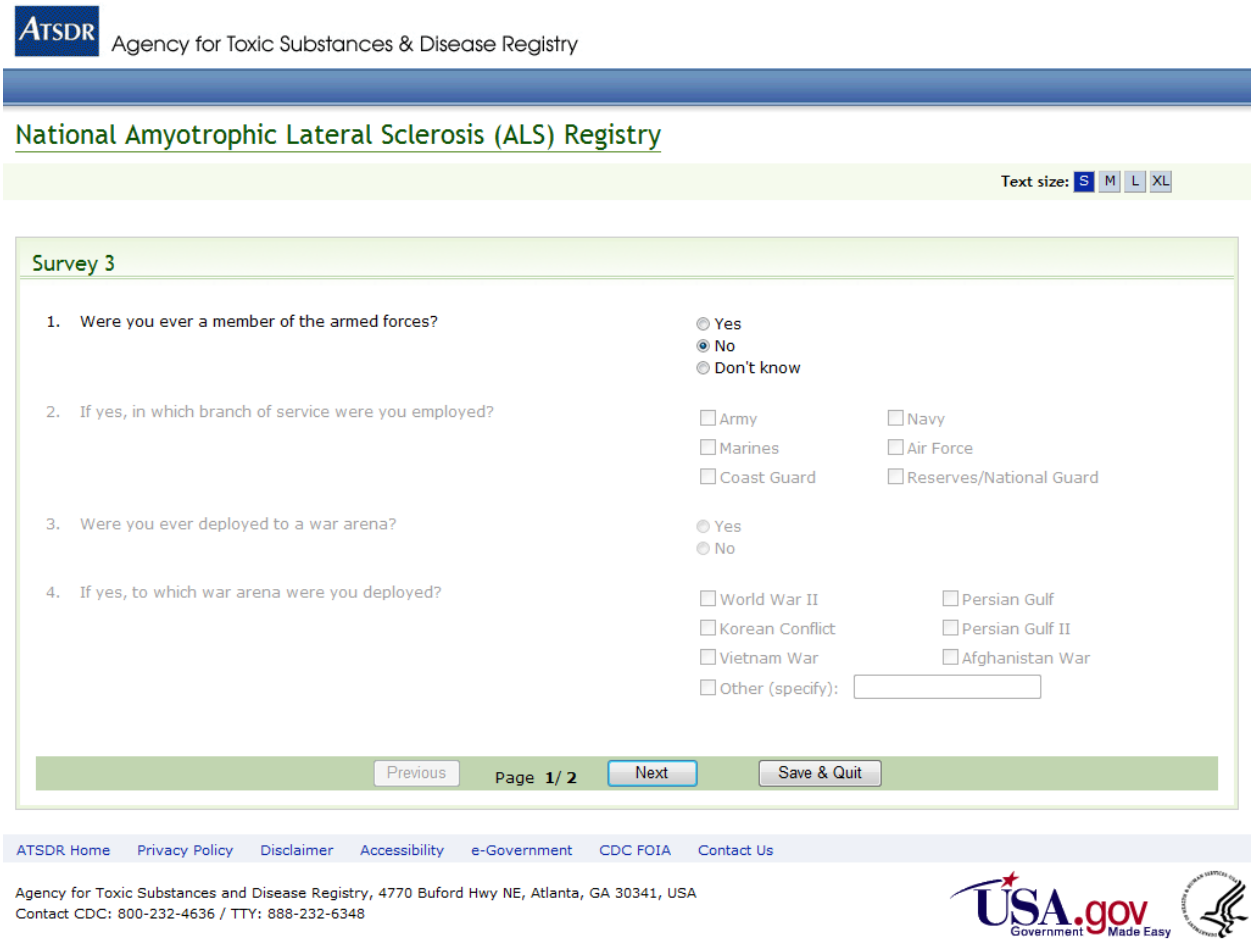

Figure 12: Survey 3, Page 1 of 2

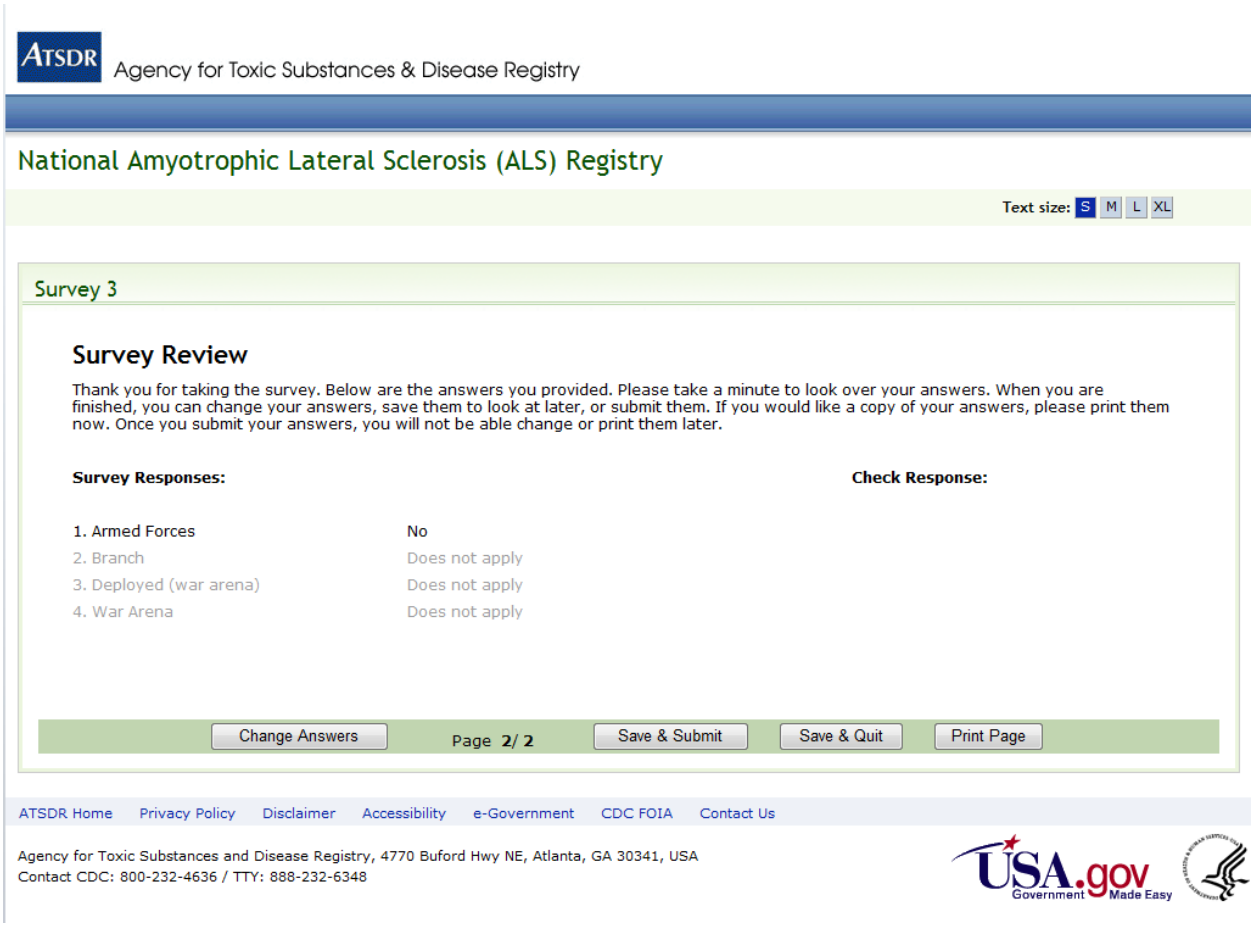

Figure 13: Survey 3, Page 2 of 2

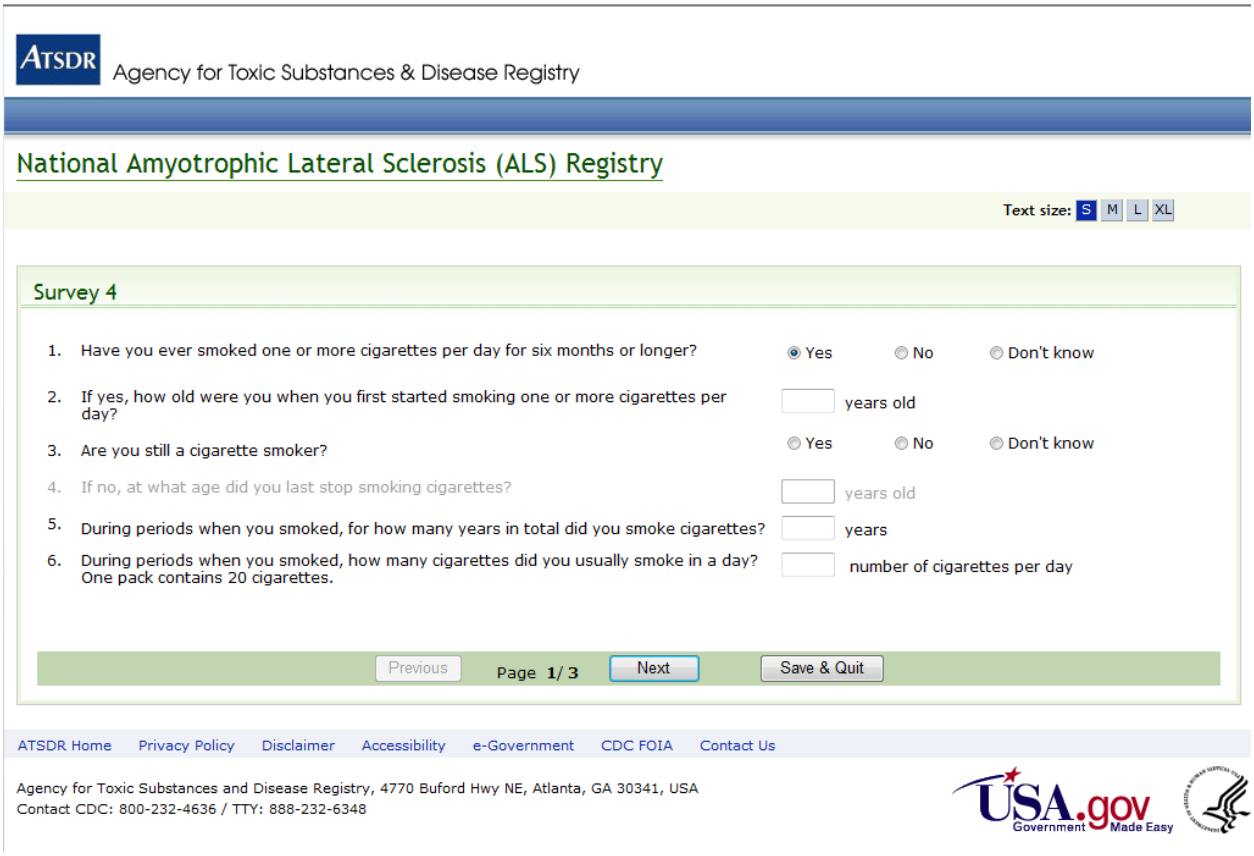

Figure 14: Survey 4, Page 1 of 3

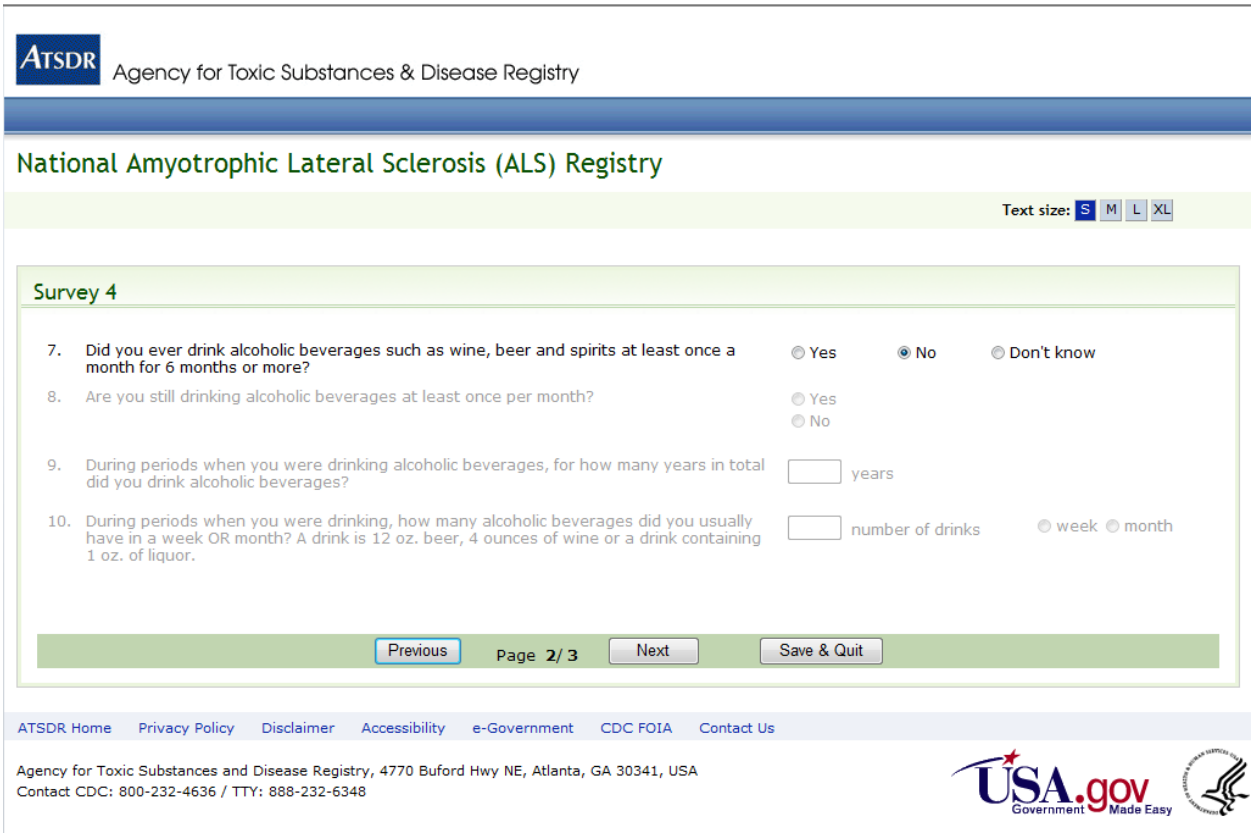

Figure 15: Survey 4, Page 2 of 3

Figure 16: Survey 4, Page 3 of 3

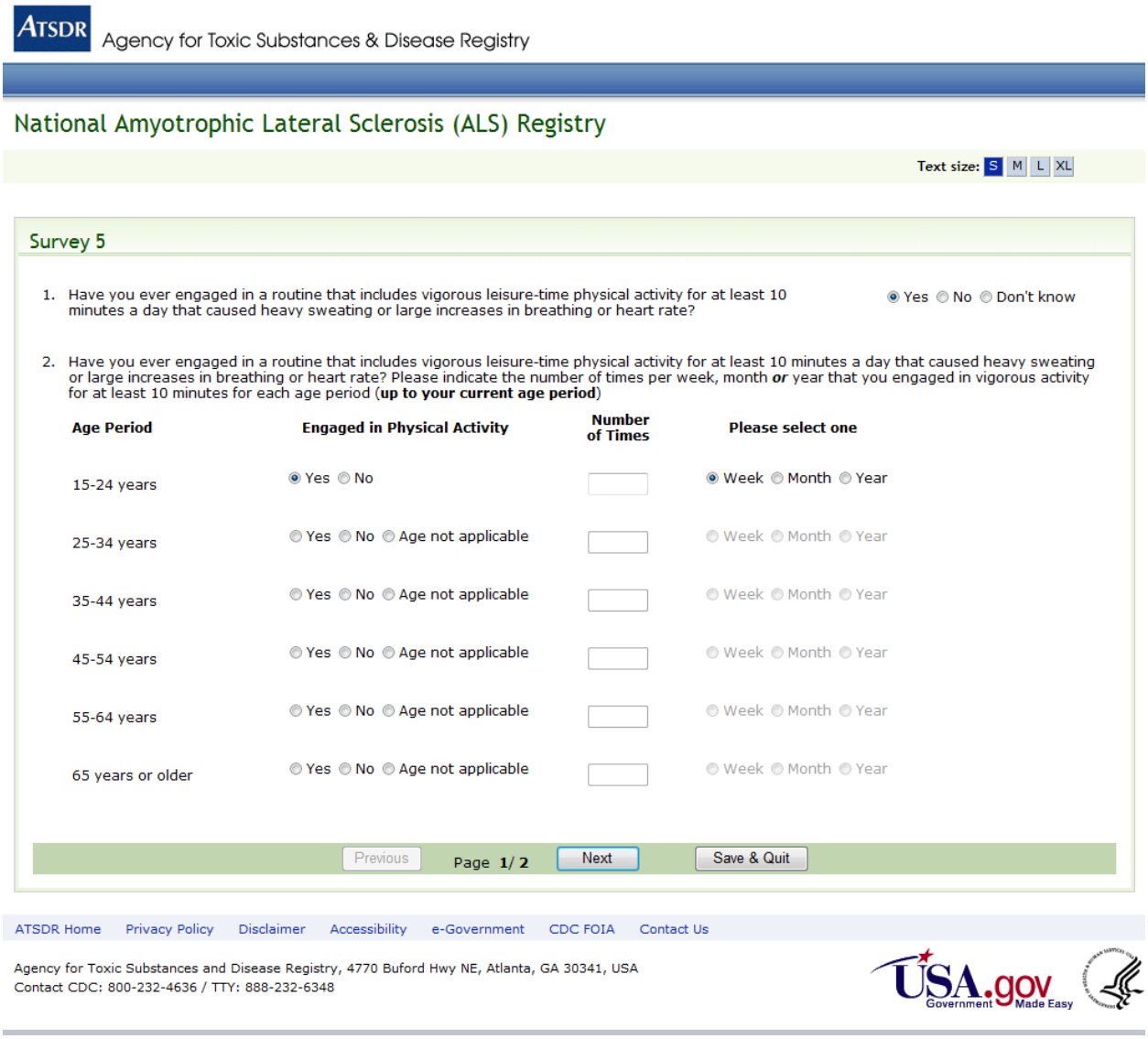

Figure 17: Survey 5, Page 1 of 2

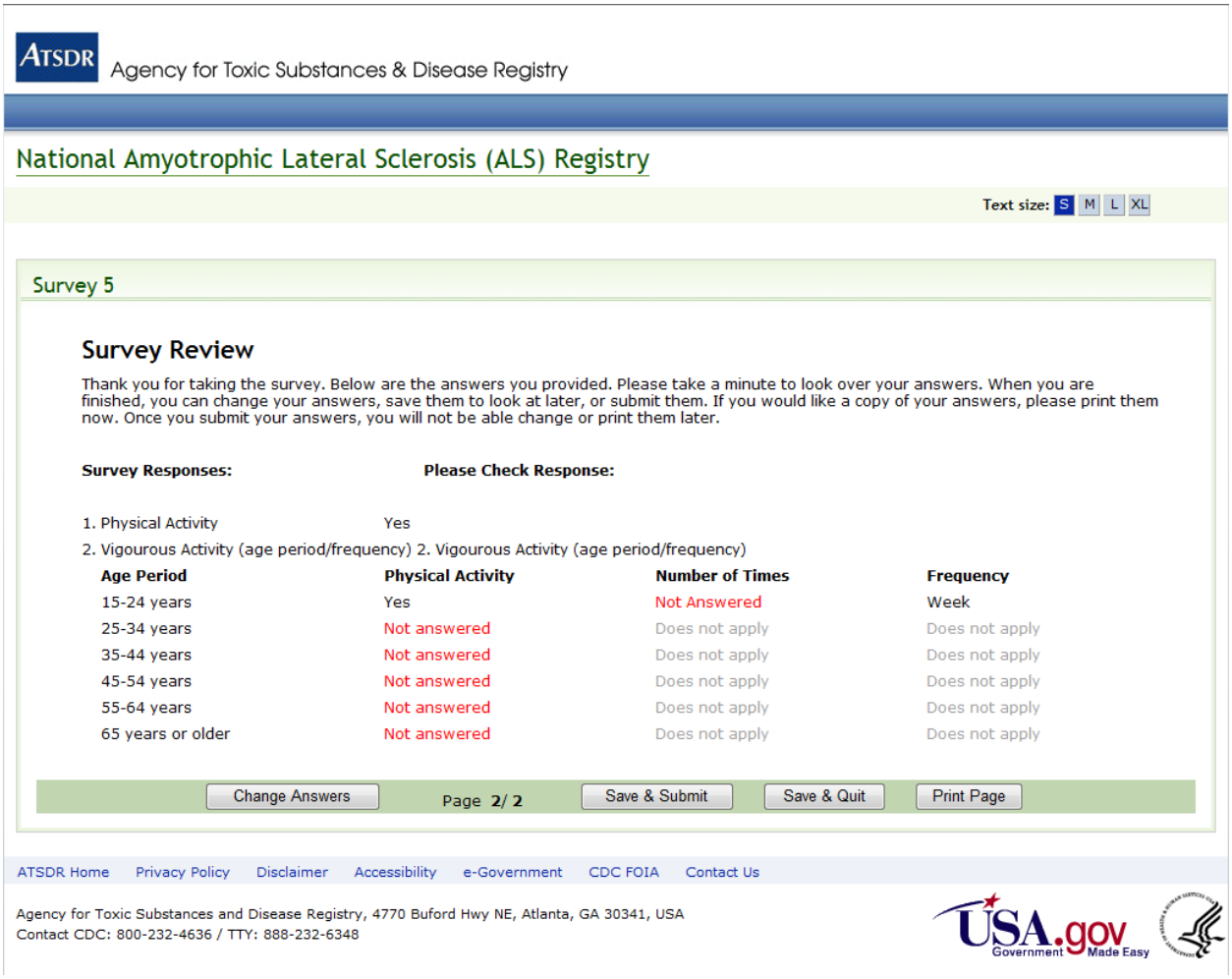

Figure 18: Survey 5, Page 2 of 2

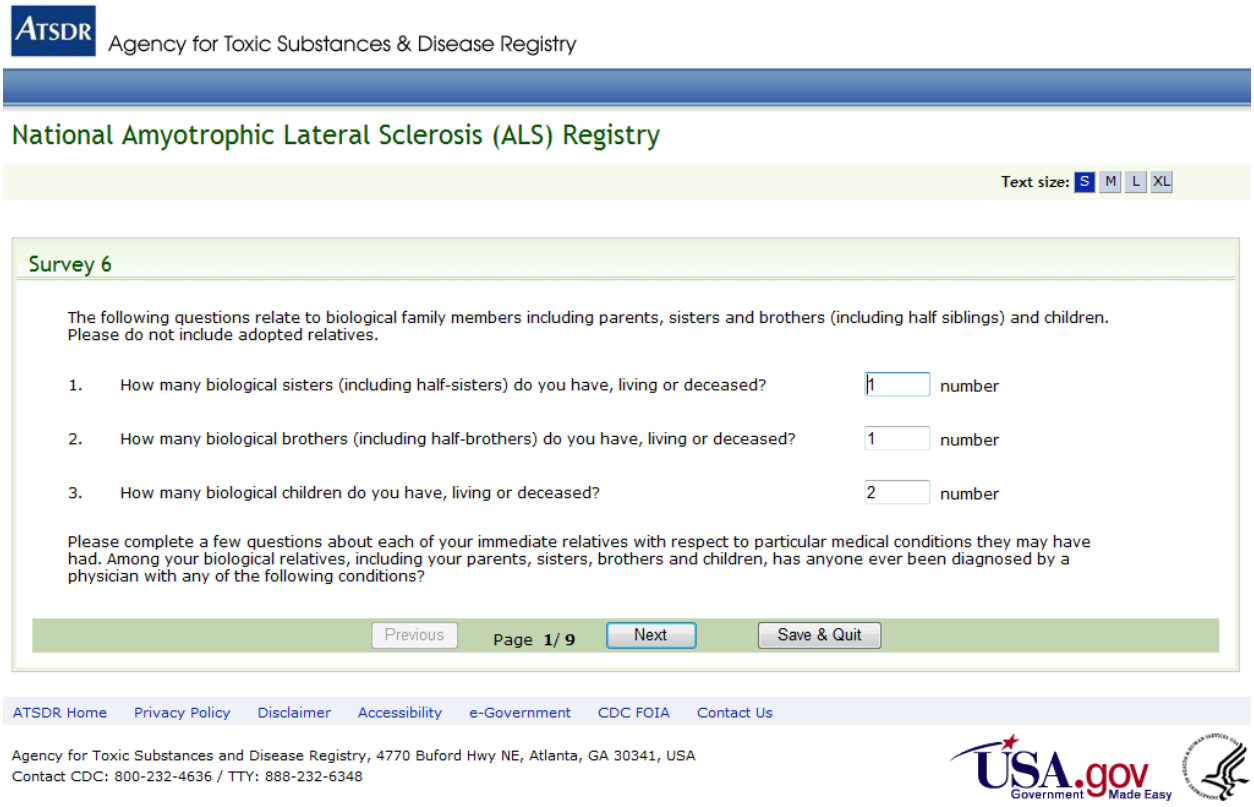

Figure 19: Survey 6, Page 1 of 9

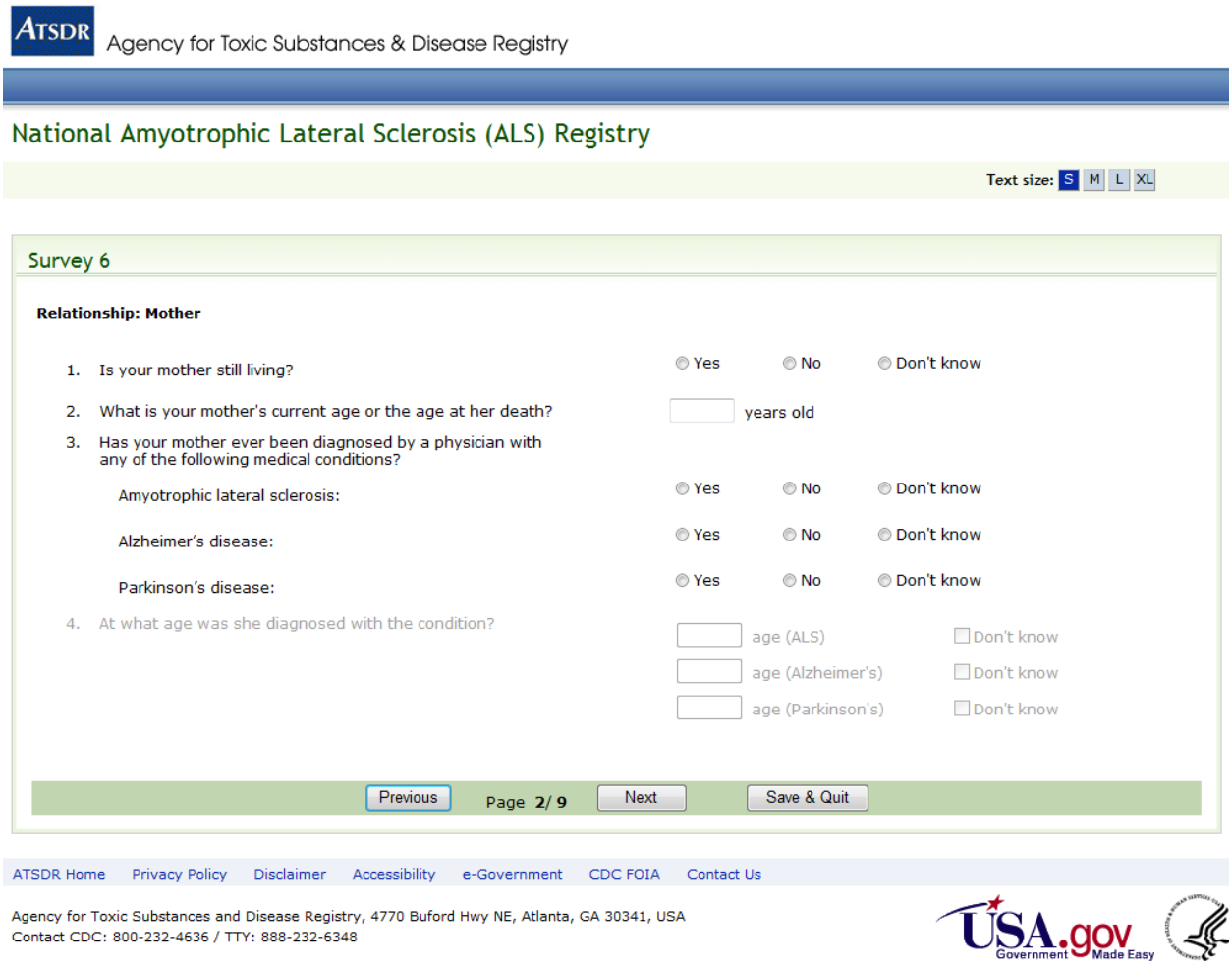

Figure 20: Survey 6, Page 2 of 9

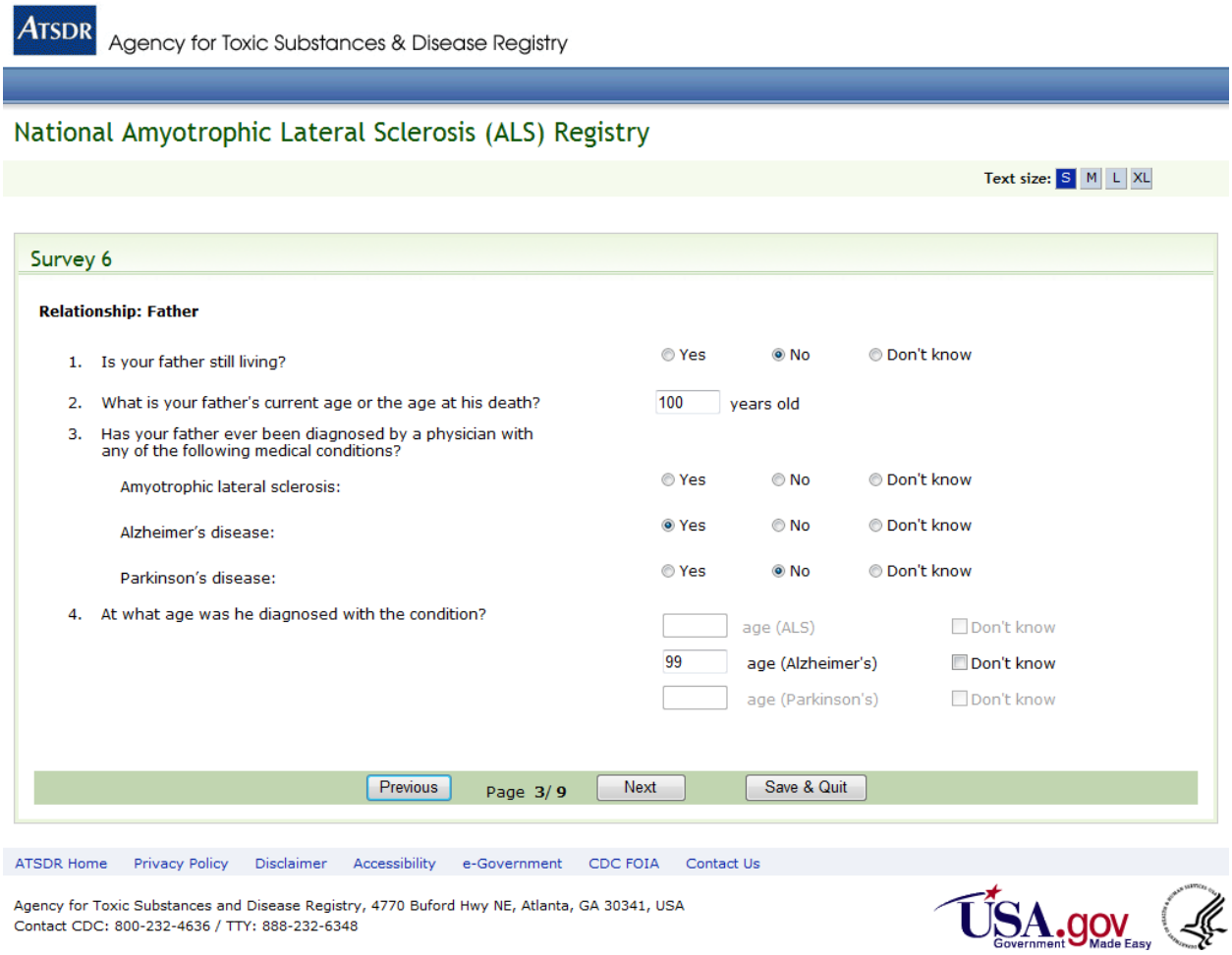

Figure 21: Survey 6, Page 3 of 9

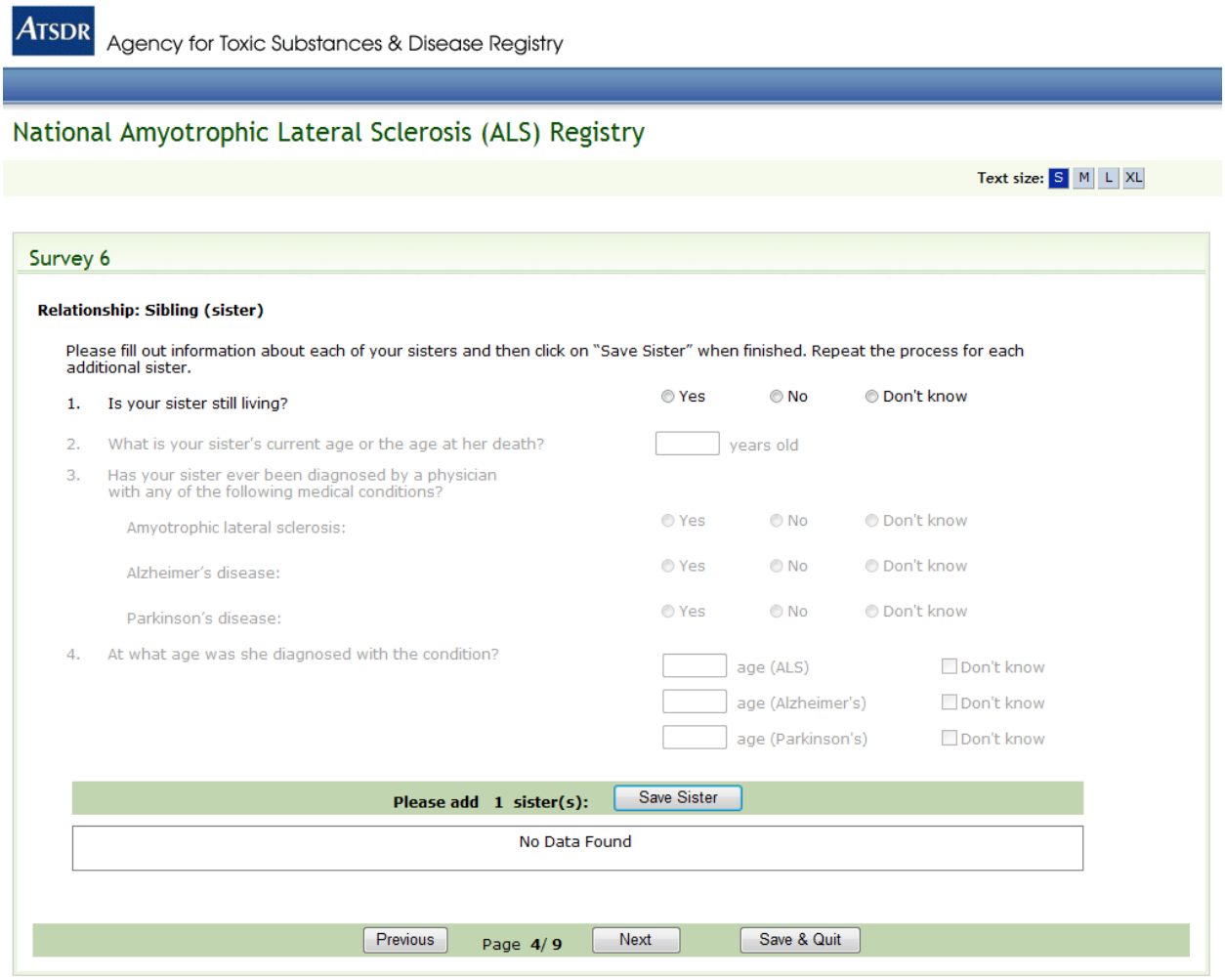

Figure 22: Survey 6, Page 4 of 9

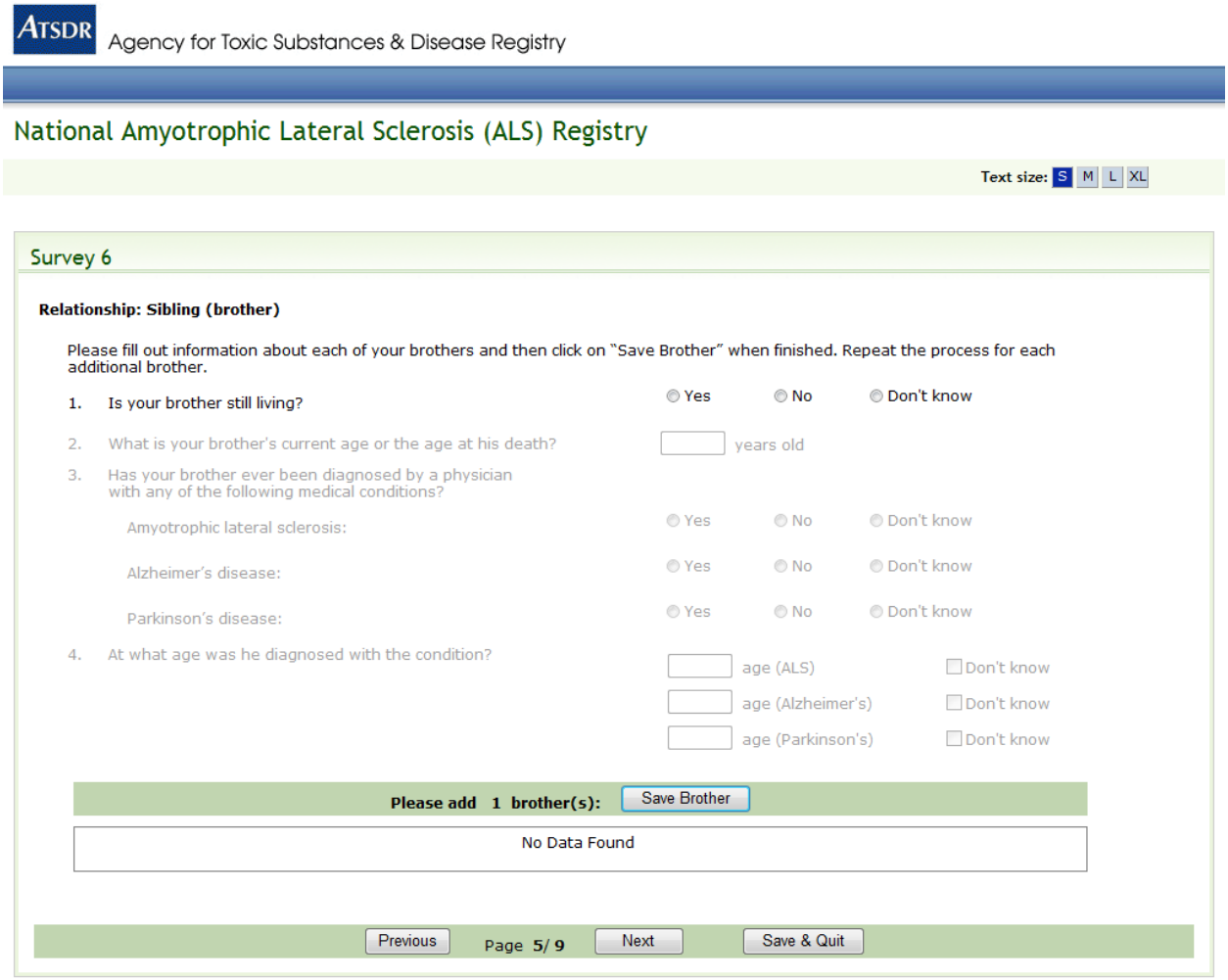

Figure 23: Survey 6, Page 5 of 9

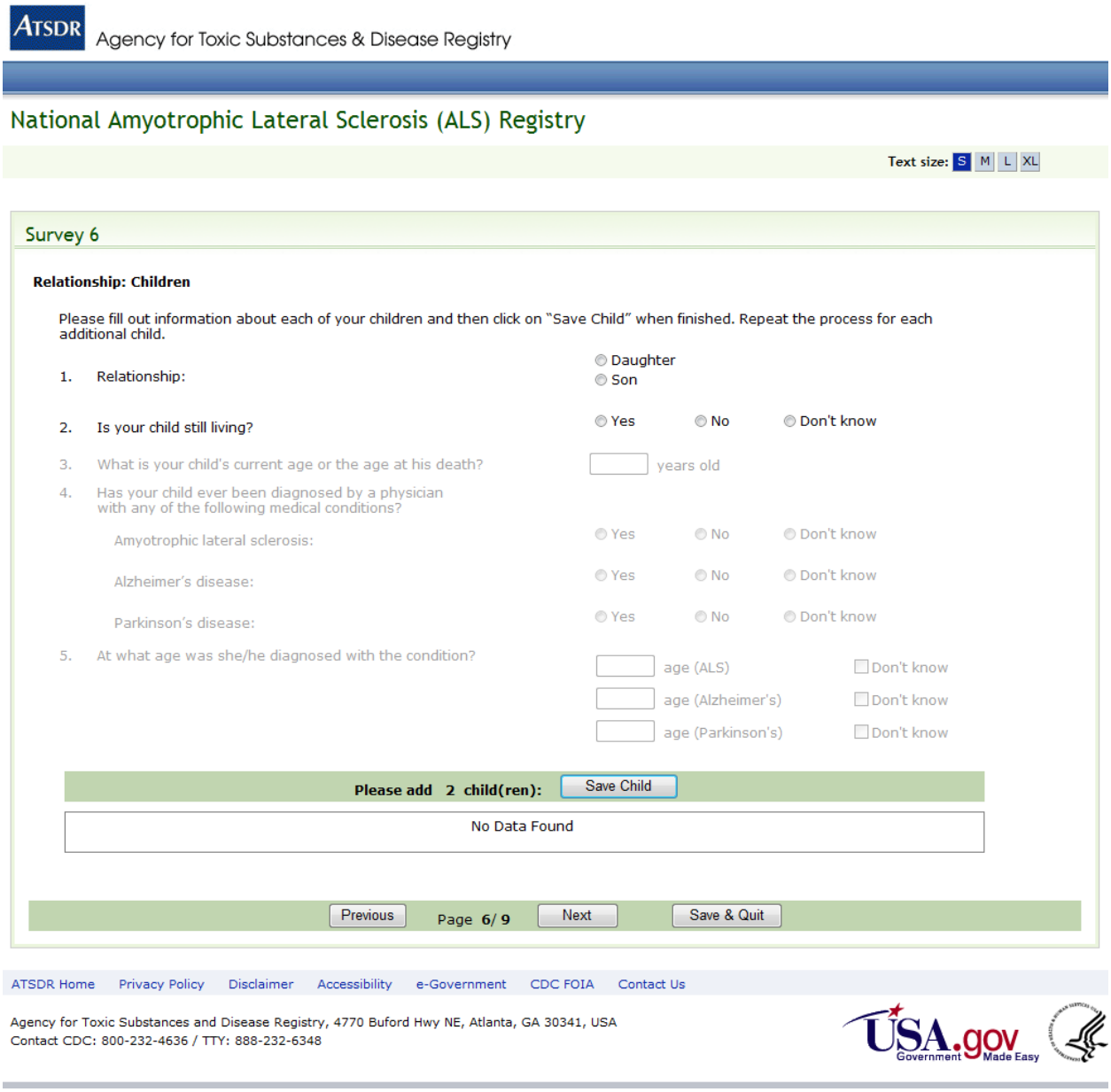

Figure 24: Survey 6, Page 6 of 9

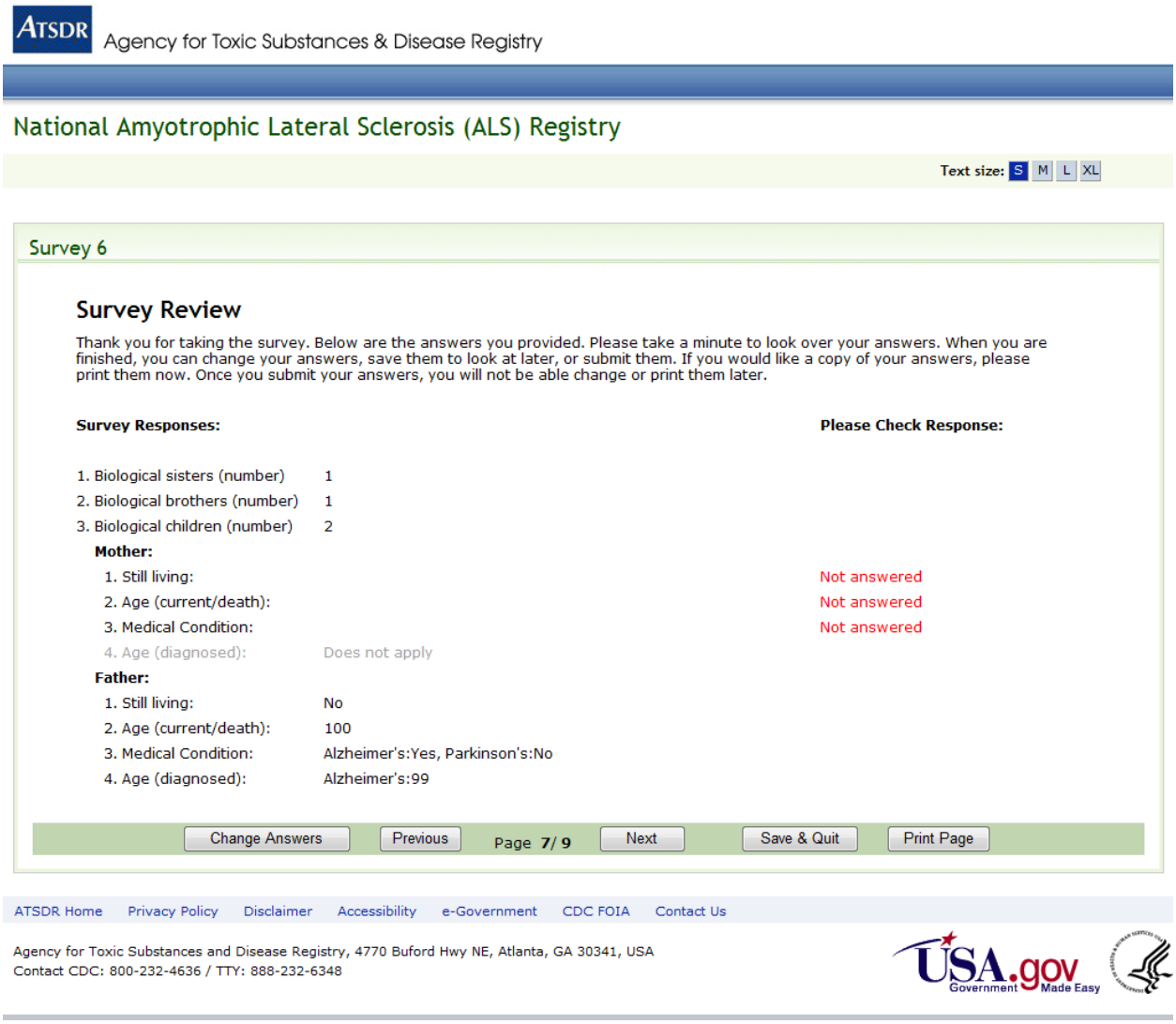

Figure 25: Survey 6, Page 7 of 9

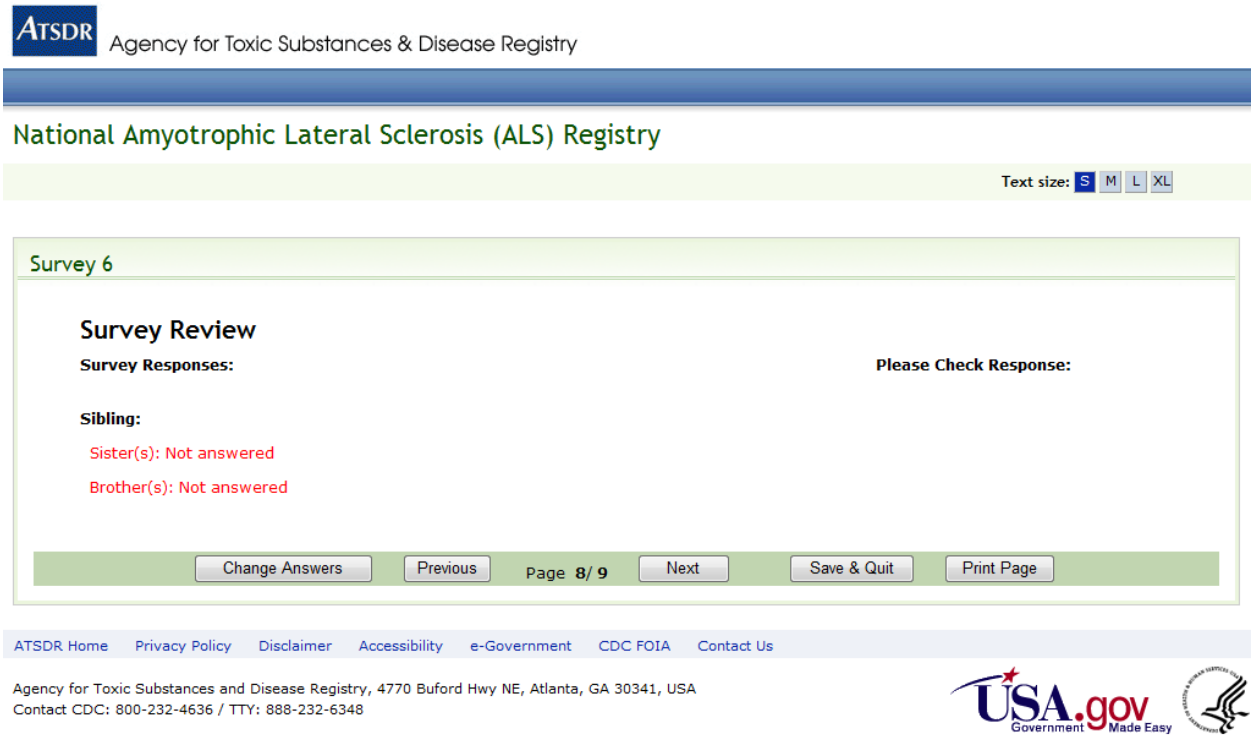

Figure 26: Survey 6, Page 8 of 9

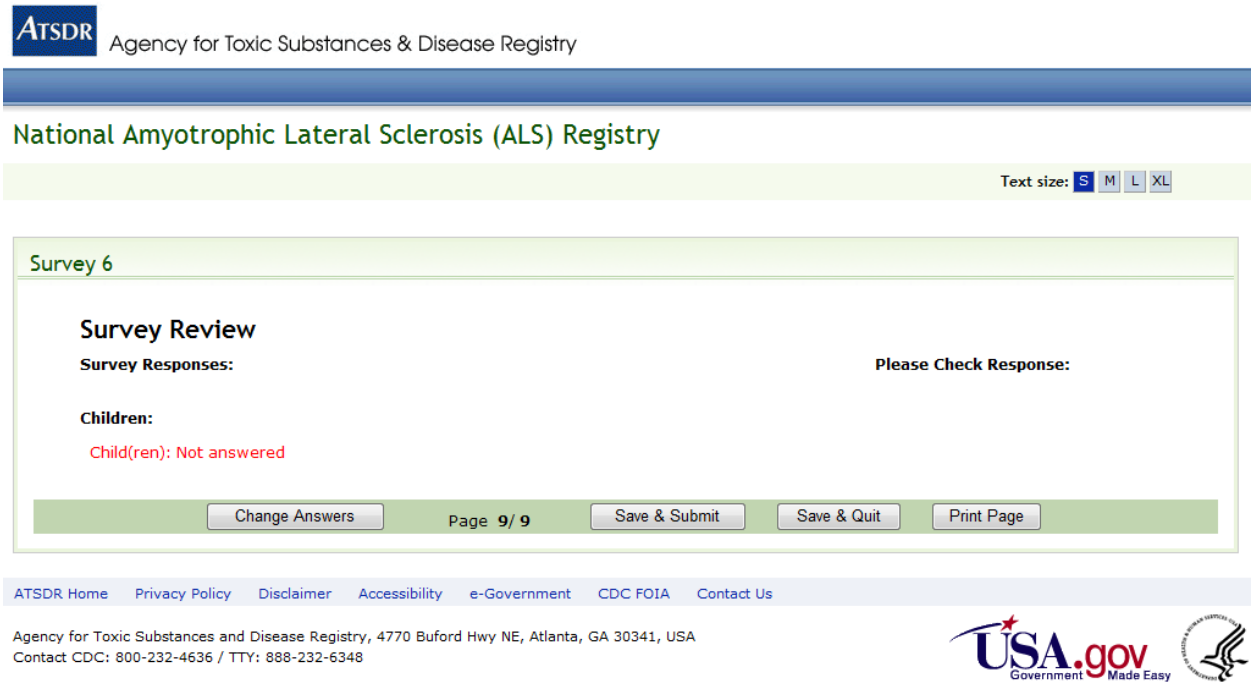

Figure 27: Survey 6, Page 9 of 9

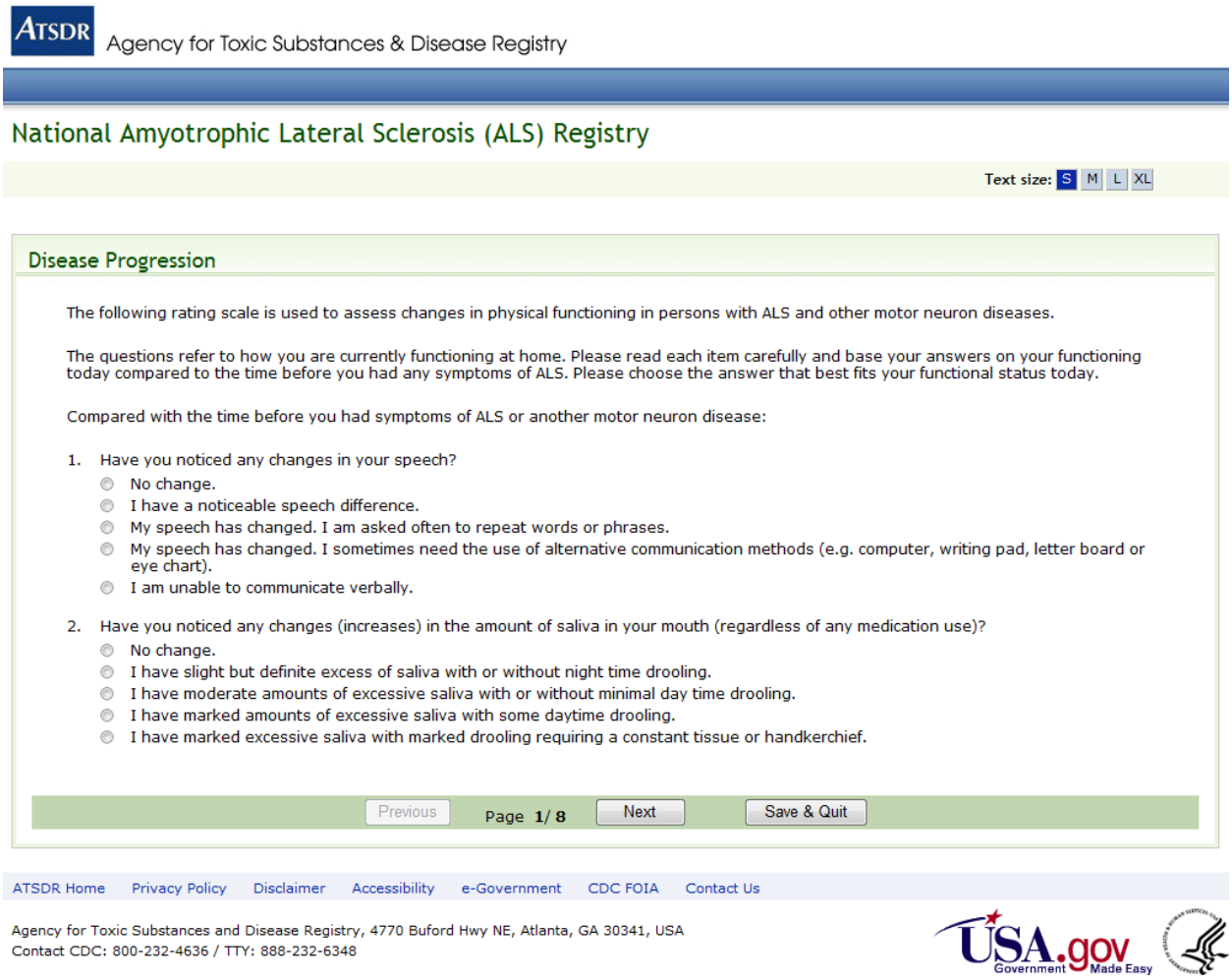

Figure 28: Disease Progression Survey, Page 1 of 8

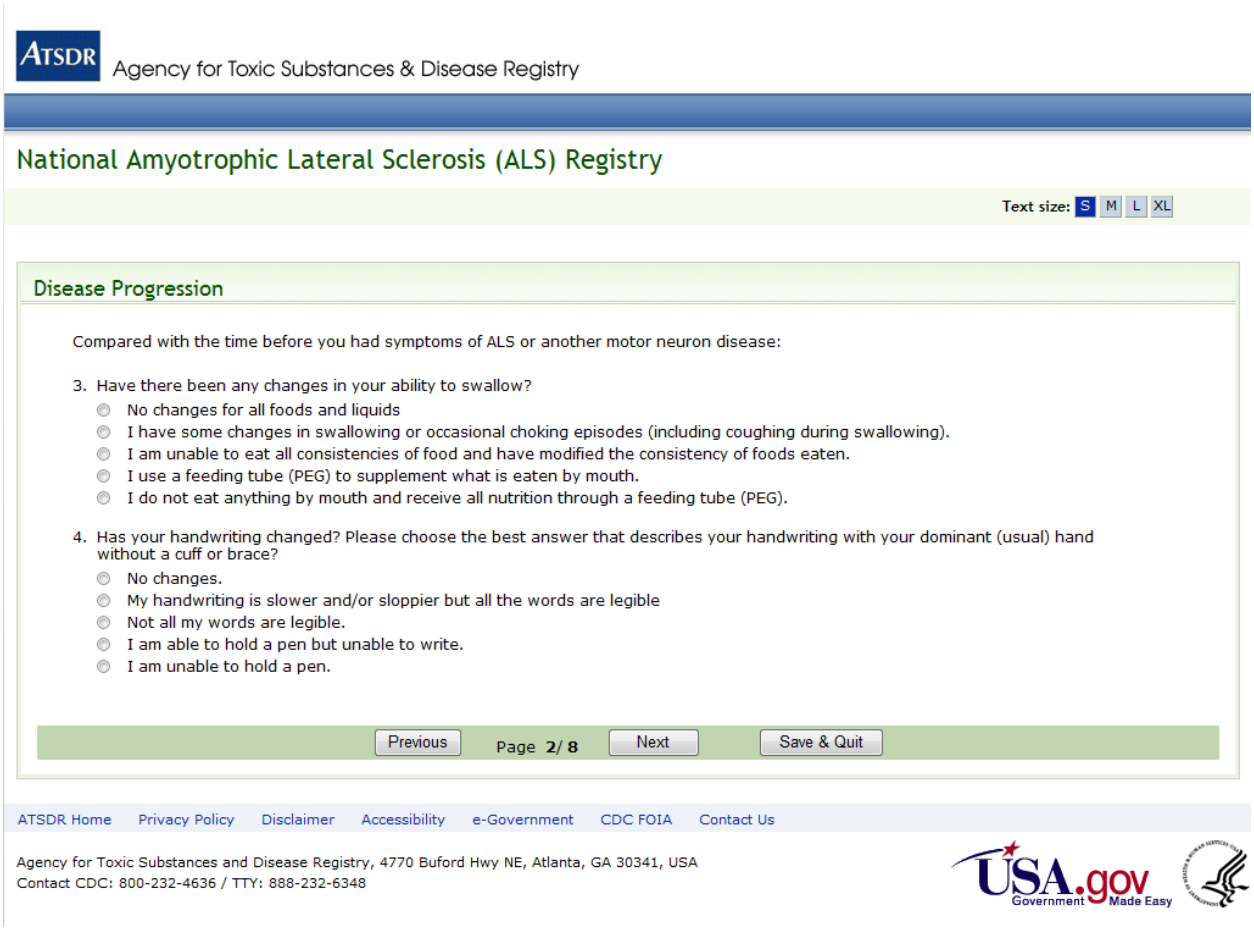

Figure 29: Disease Progression Survey, Page 2 of 8

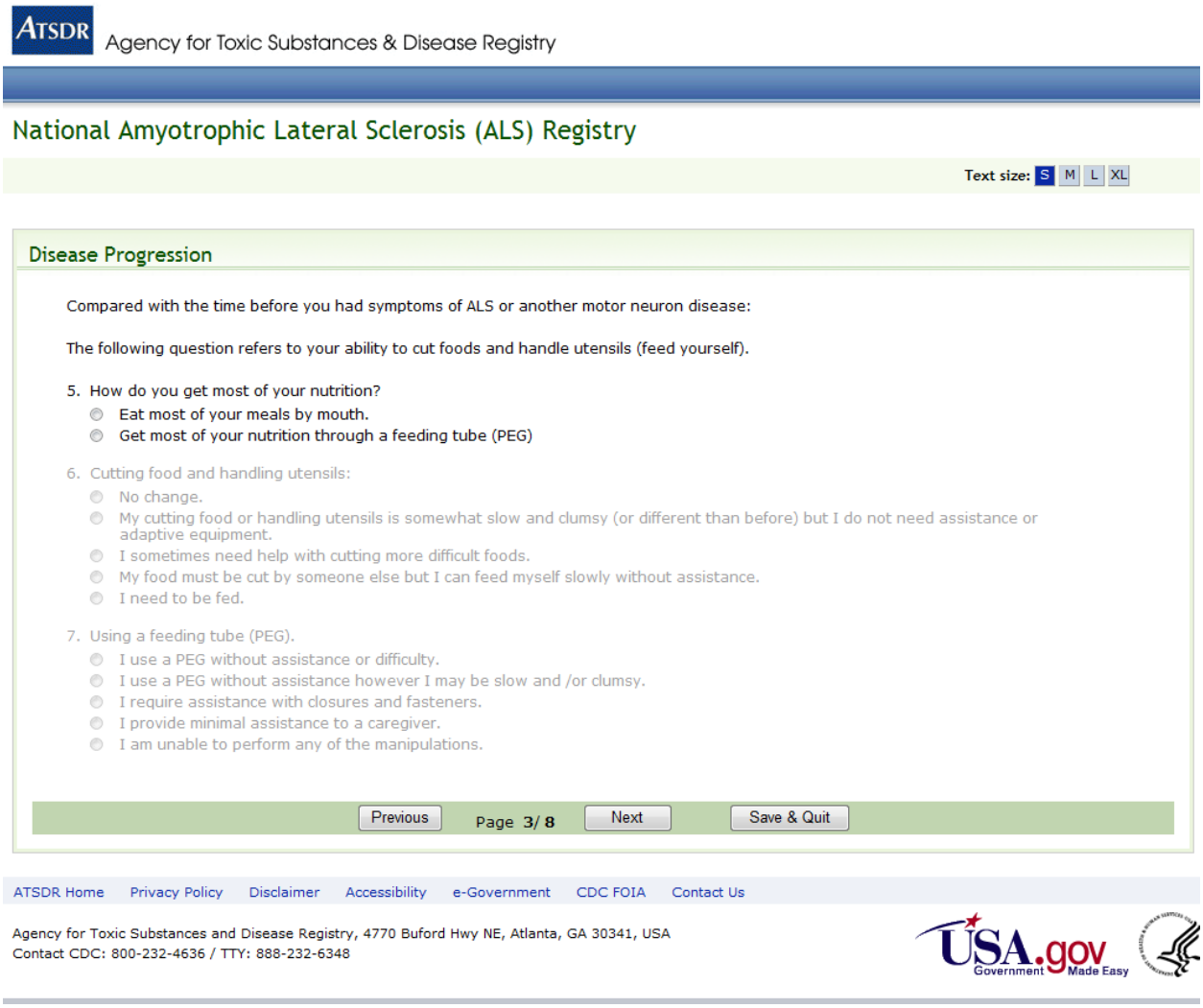

Figure 30: Disease Progression Survey, Page 3 of 8

Figure 31: Disease Progression Survey, Page 4 of 8

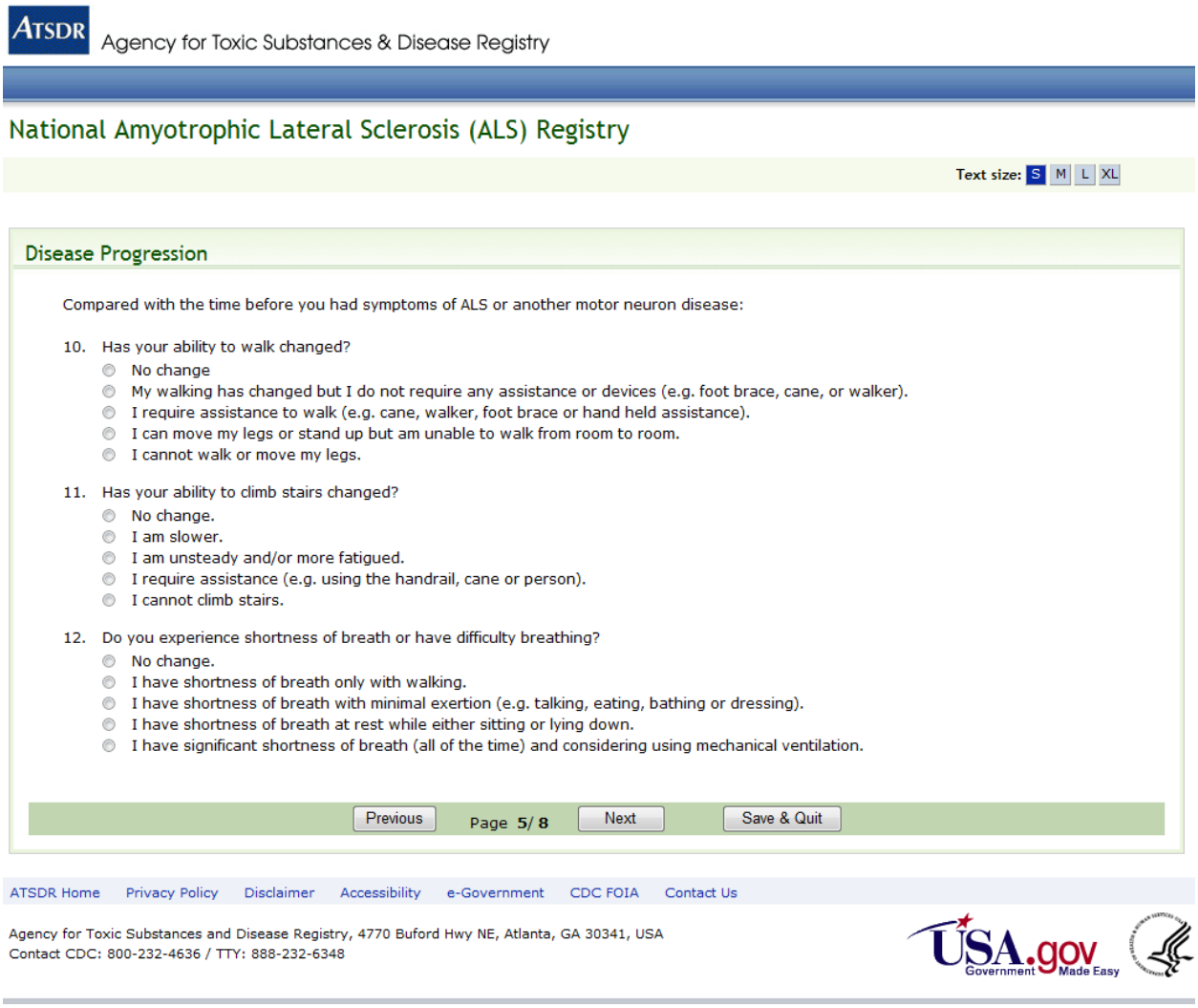

Figure 32: Disease Progression Survey, Page 5 of 8

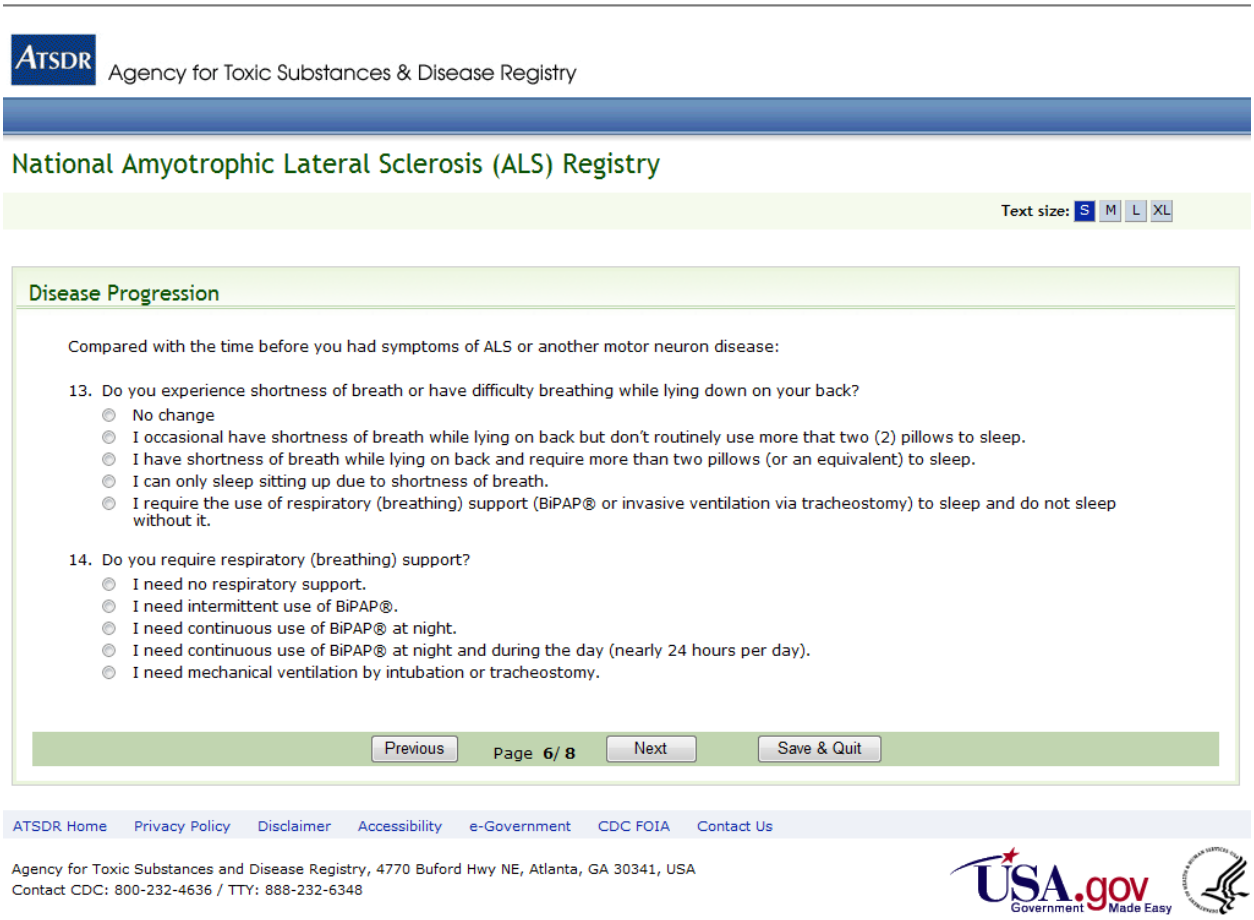

Figure 33: Disease Progression Survey, Page 6 of 8

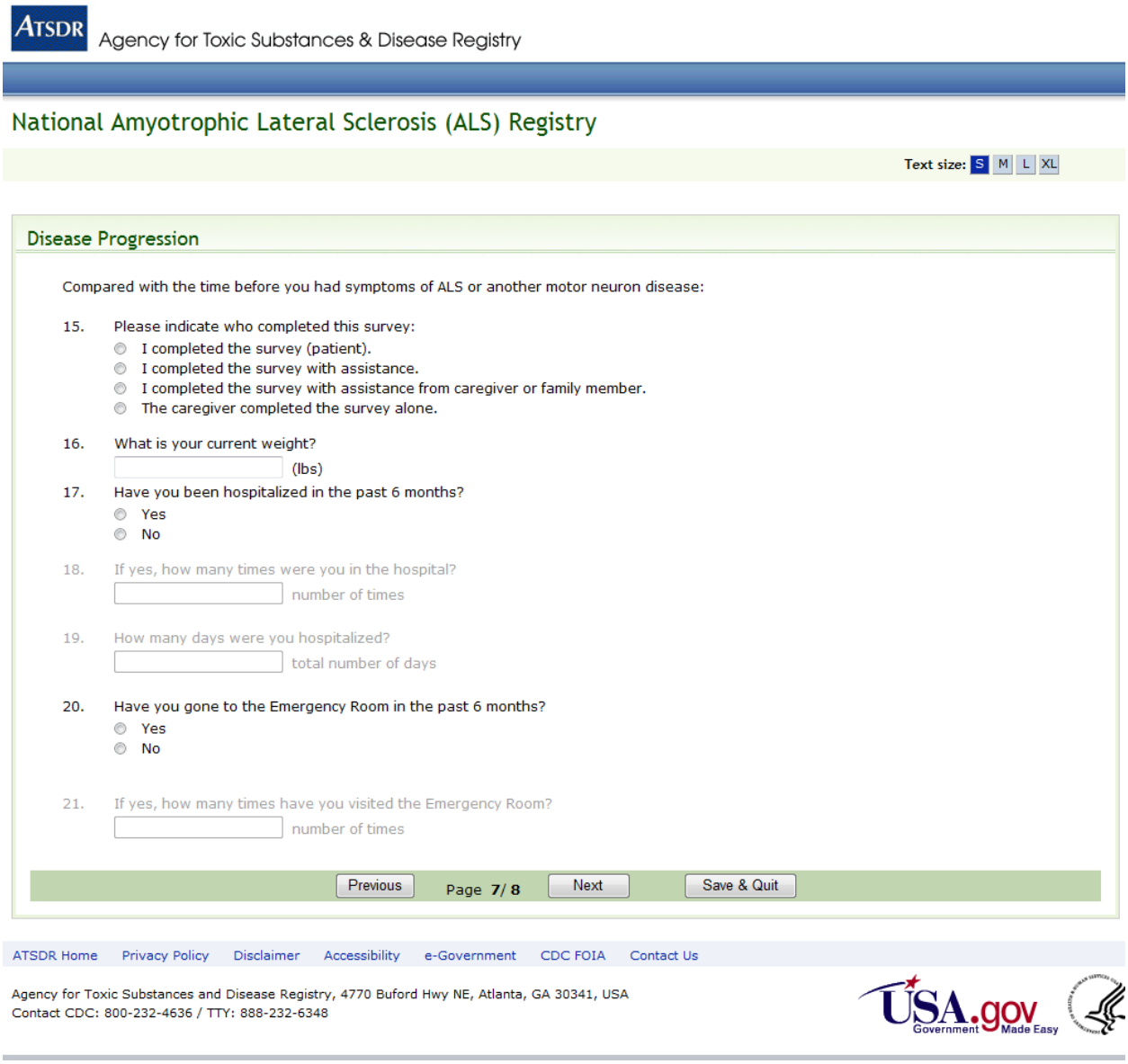

Figure 34: Disease Progression Survey, Page 7 of 8

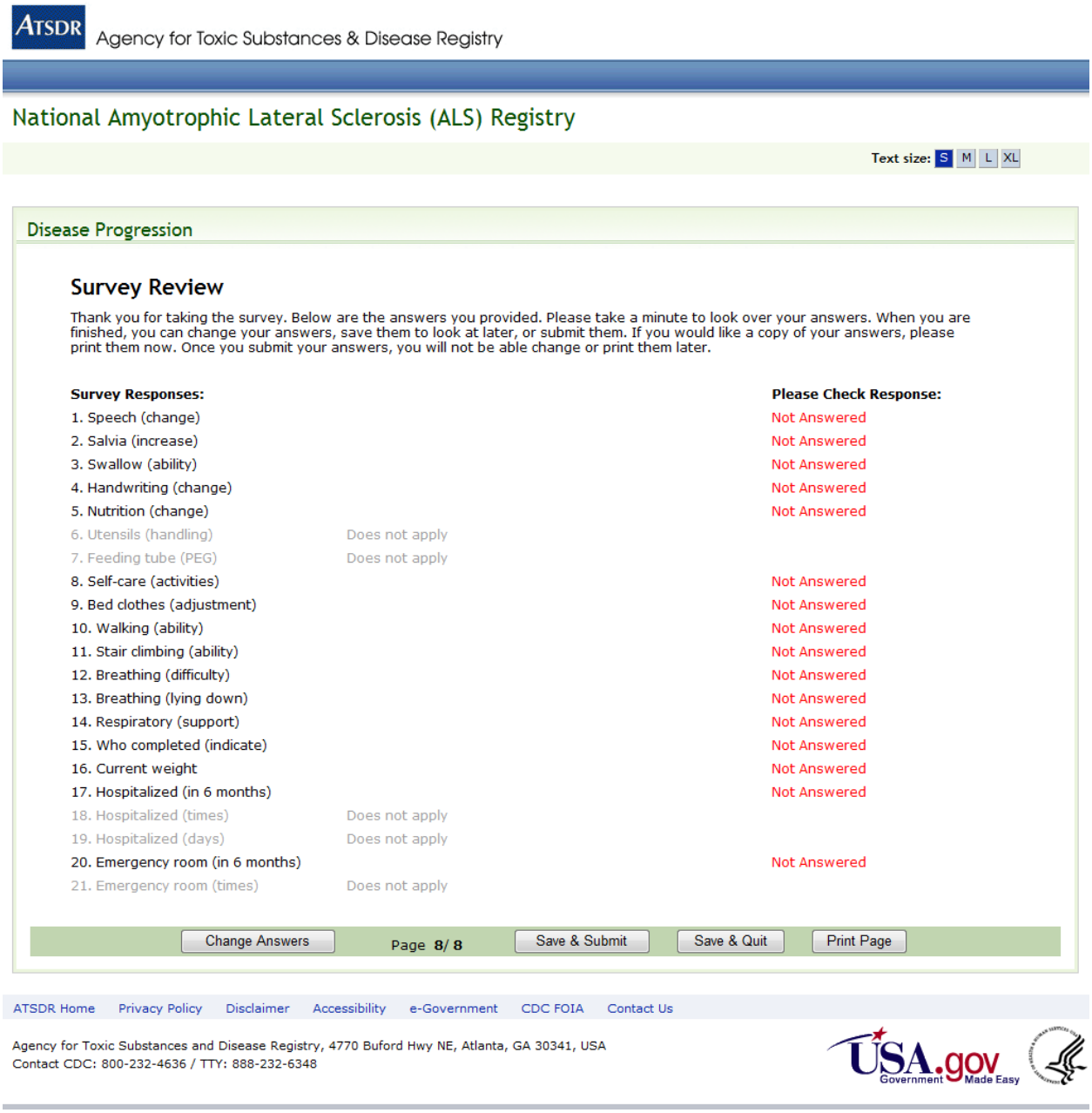

Figure 35: Disease Progression Survey, Page 8 of 8

Figure 36: Survey 8, Page 1 of 2

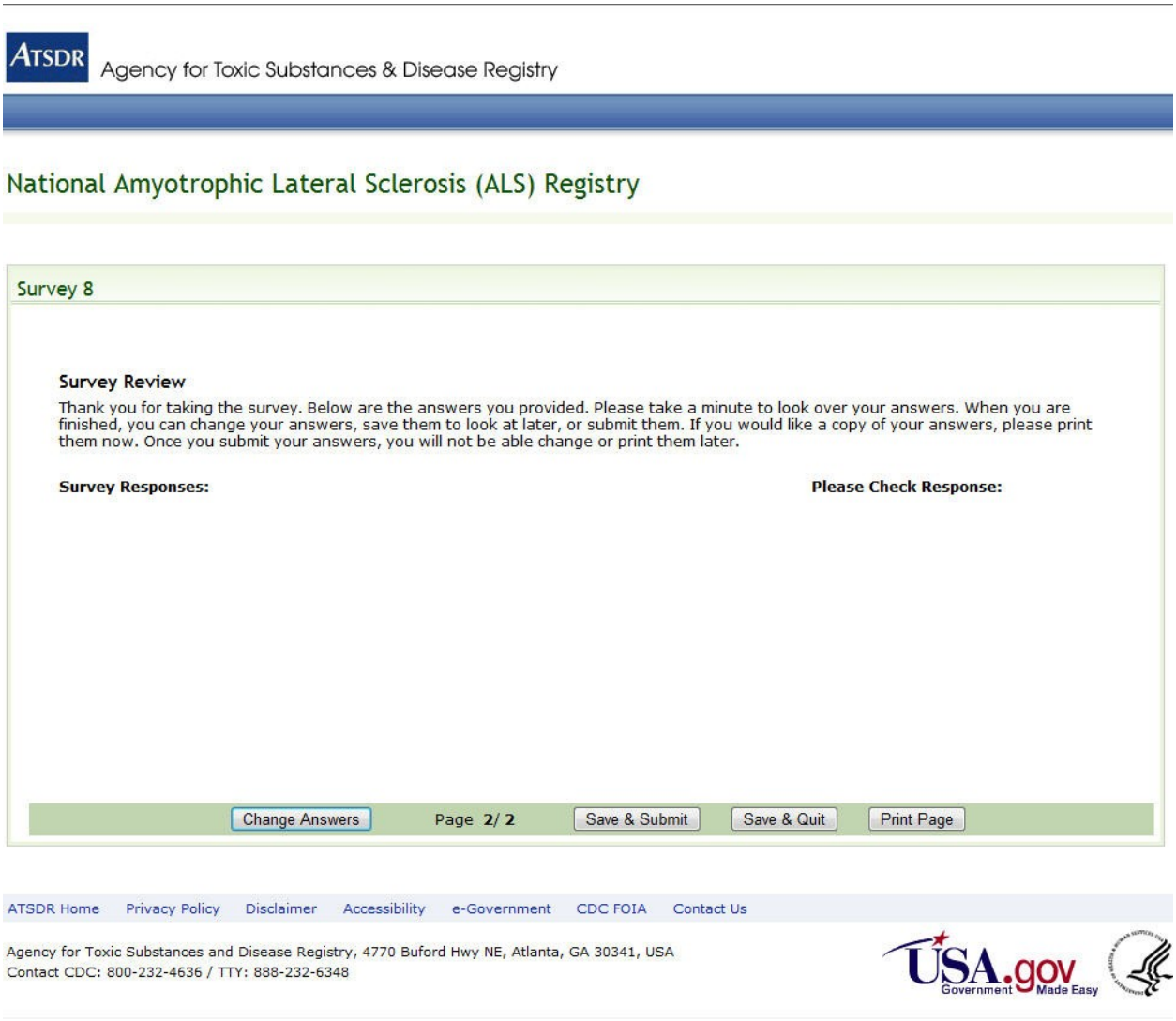

Figure 37: Survey 8, Page 2 of 2

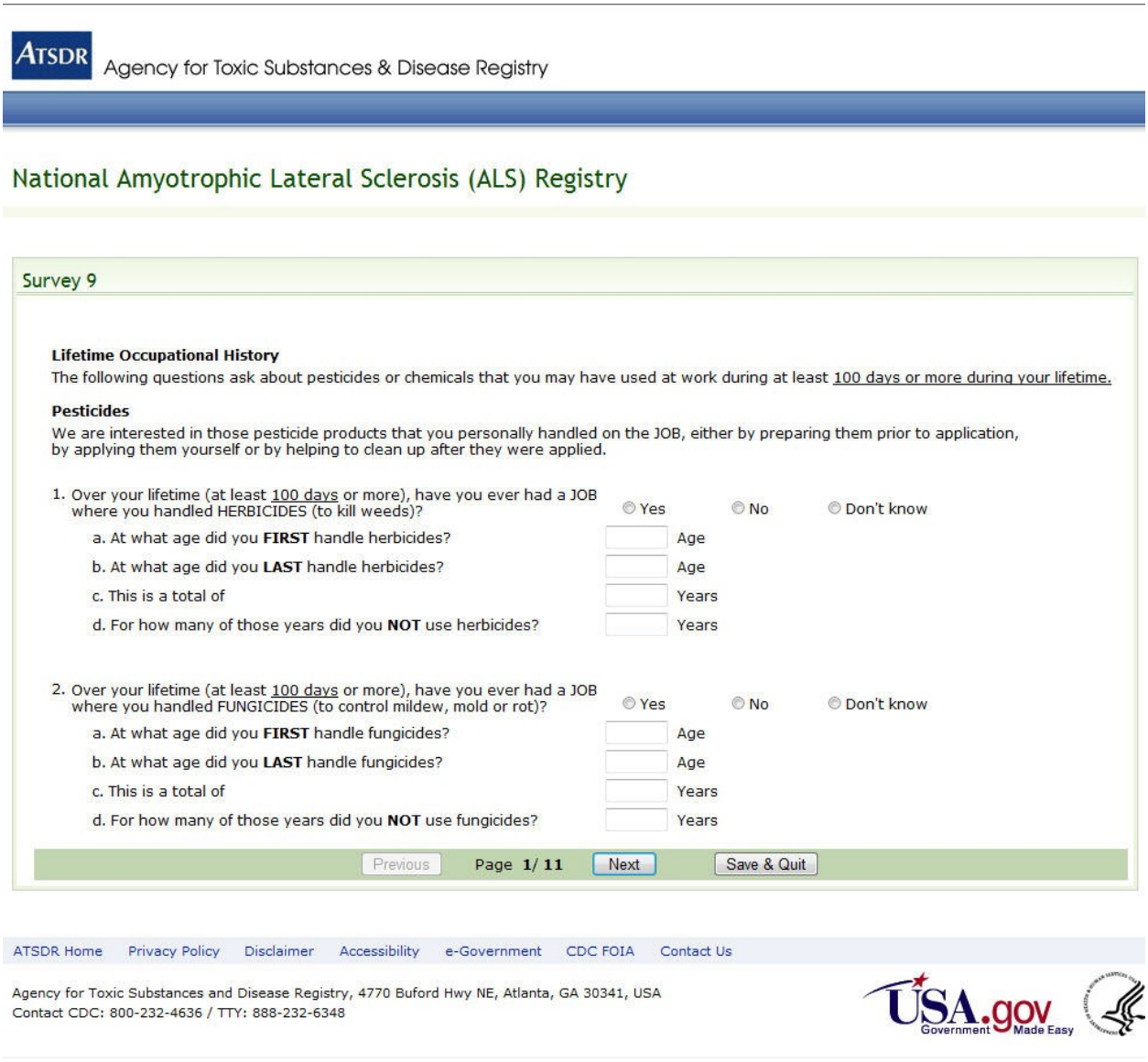

Figure 38: Survey 9, Page 1 of 11

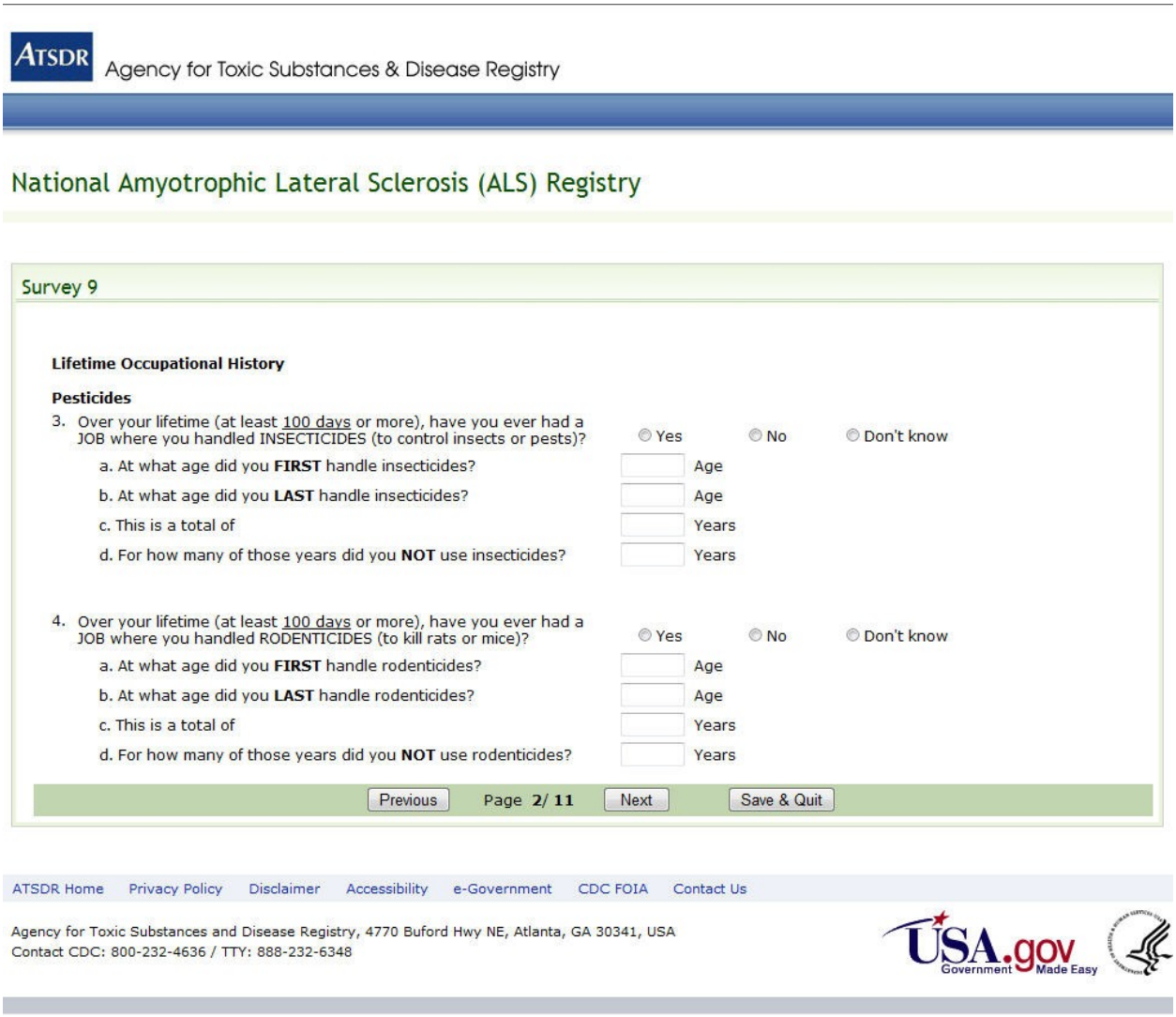

Figure 39: Survey 9, Page 2 of 11

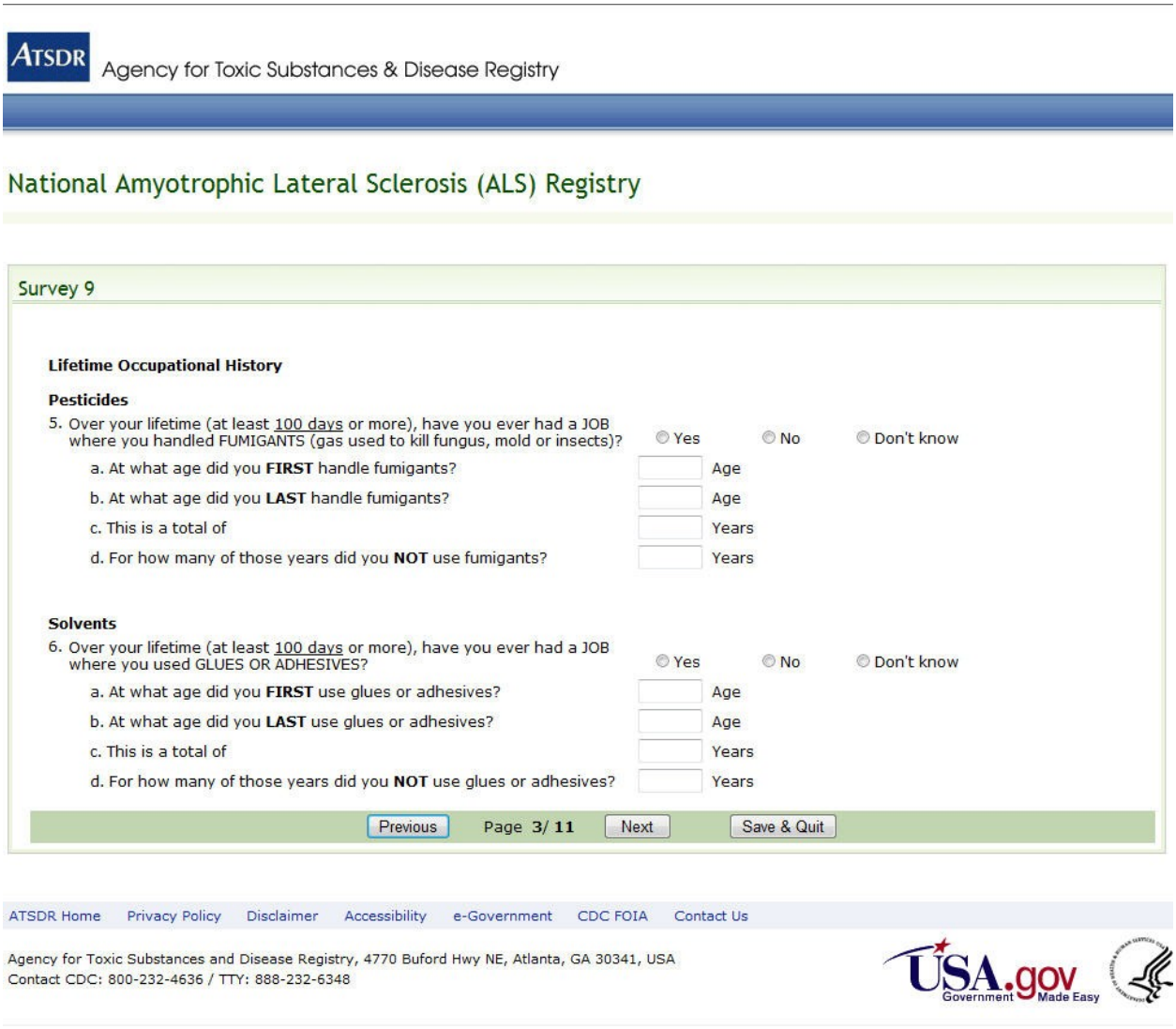

Figure 40: Survey 9, Page 3 of 11

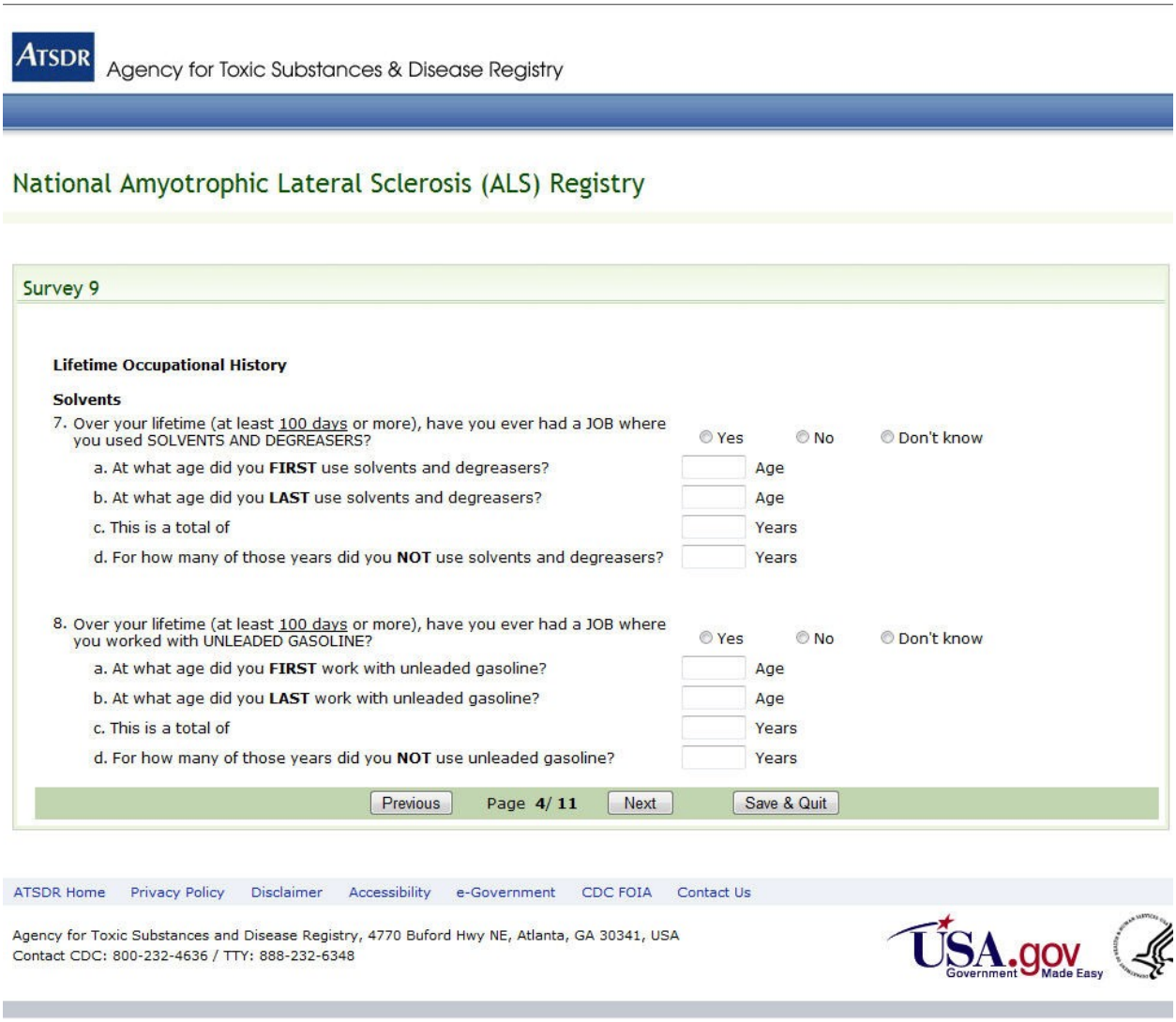

Figure 41: Survey 9, Page 4 of 11

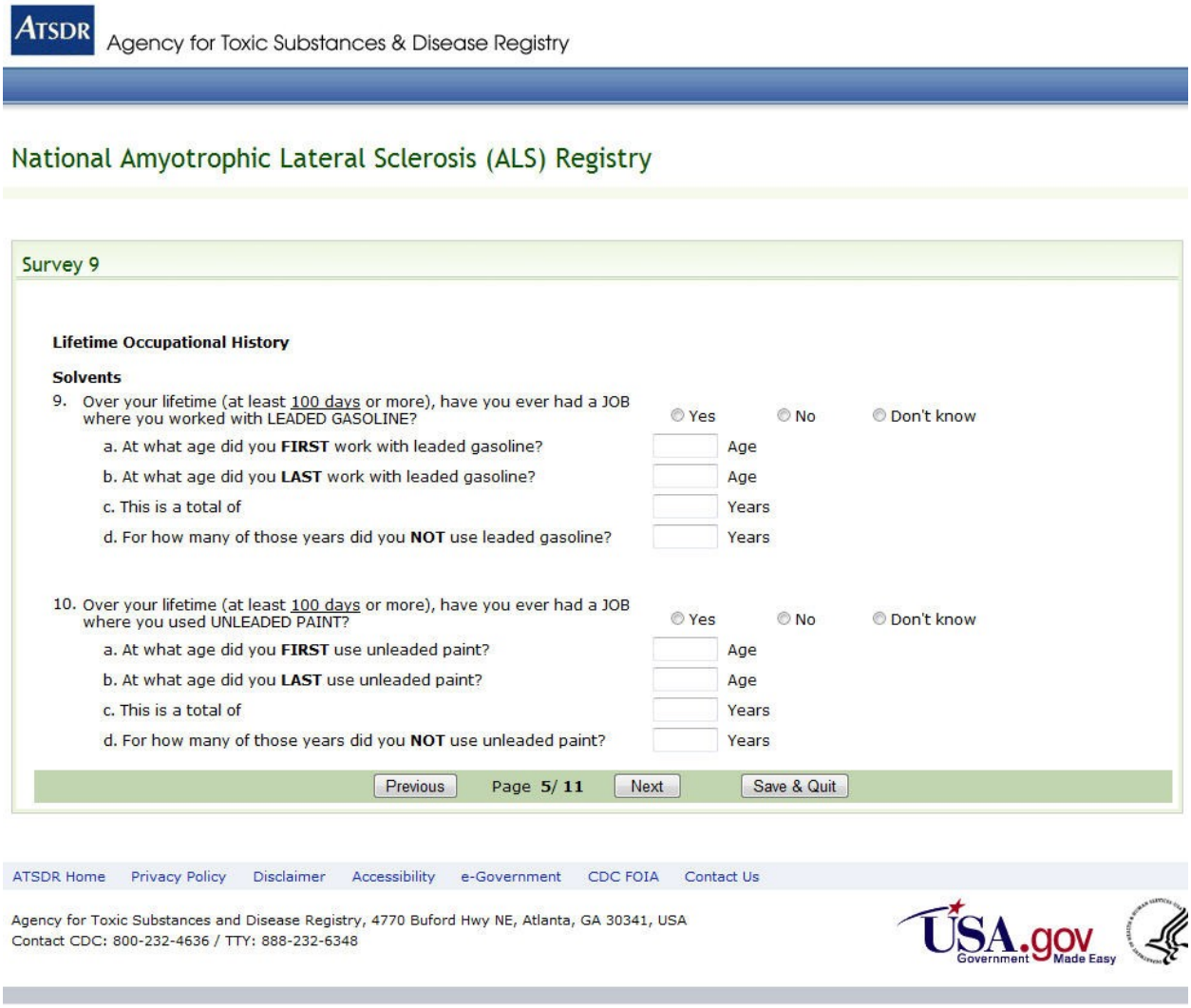

Figure 42: Survey 9, Page 5 of 11

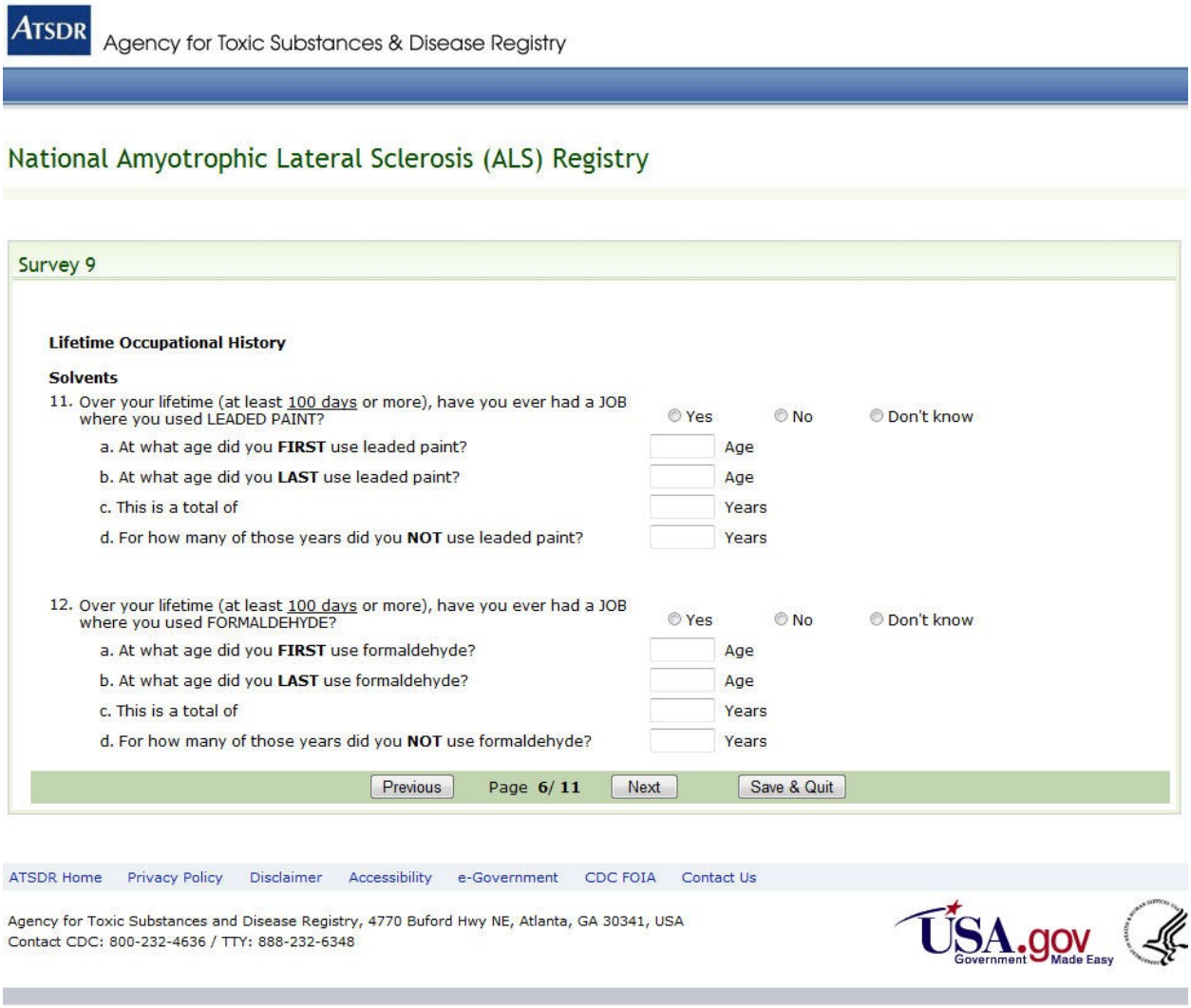

Figure 43: Survey 9, Page 6 of 11

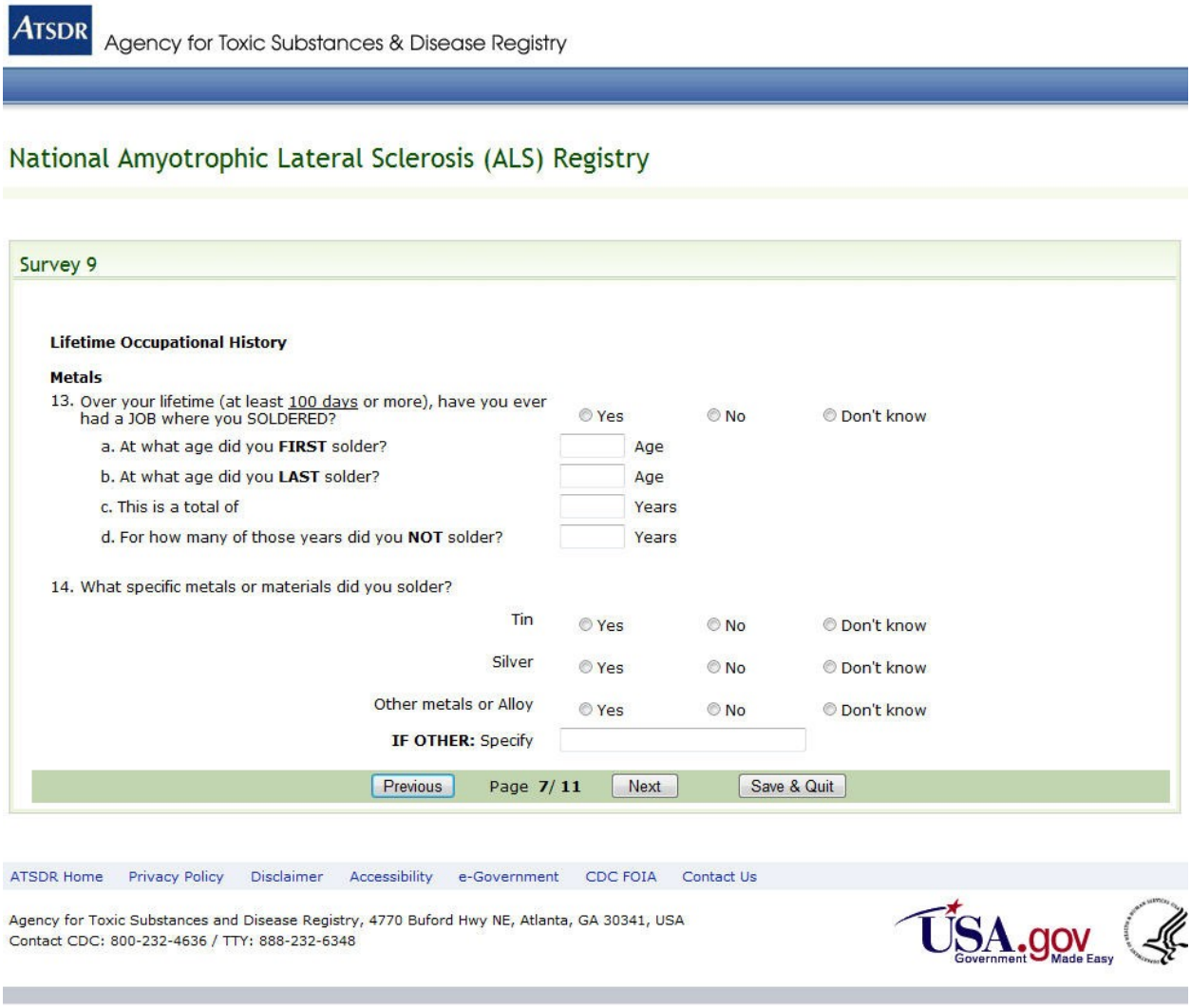

Figure 44: Survey 9, Page 7 of 11

ATSDR Agency for Toxic Substances & Disease Registry

National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 9

Lifetime Occupational History

Metals

15. Over your lifetime (at least 100 days or more), have you ever had a JOB where you WELDED, BRAZED OR FLAME CUT METALS? ○ Yes ○ No ○ 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

16. What specific metals or materials did you weld, braze or flame cut?

Steel	○ Yes	○ No	○ Don't know
Iron, copper or aluminum	○ Yes	○ No	○ Don't know
Brass or bronze	○ Yes	○ No	○ Don't know
Lead	○ Yes	○ No	○ Don't know
Other metals or Alloy	○ Yes	○ No	○ Don't know

IF OTHER: Specify ____

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Figure 45: Survey 9, Page 8 of 11

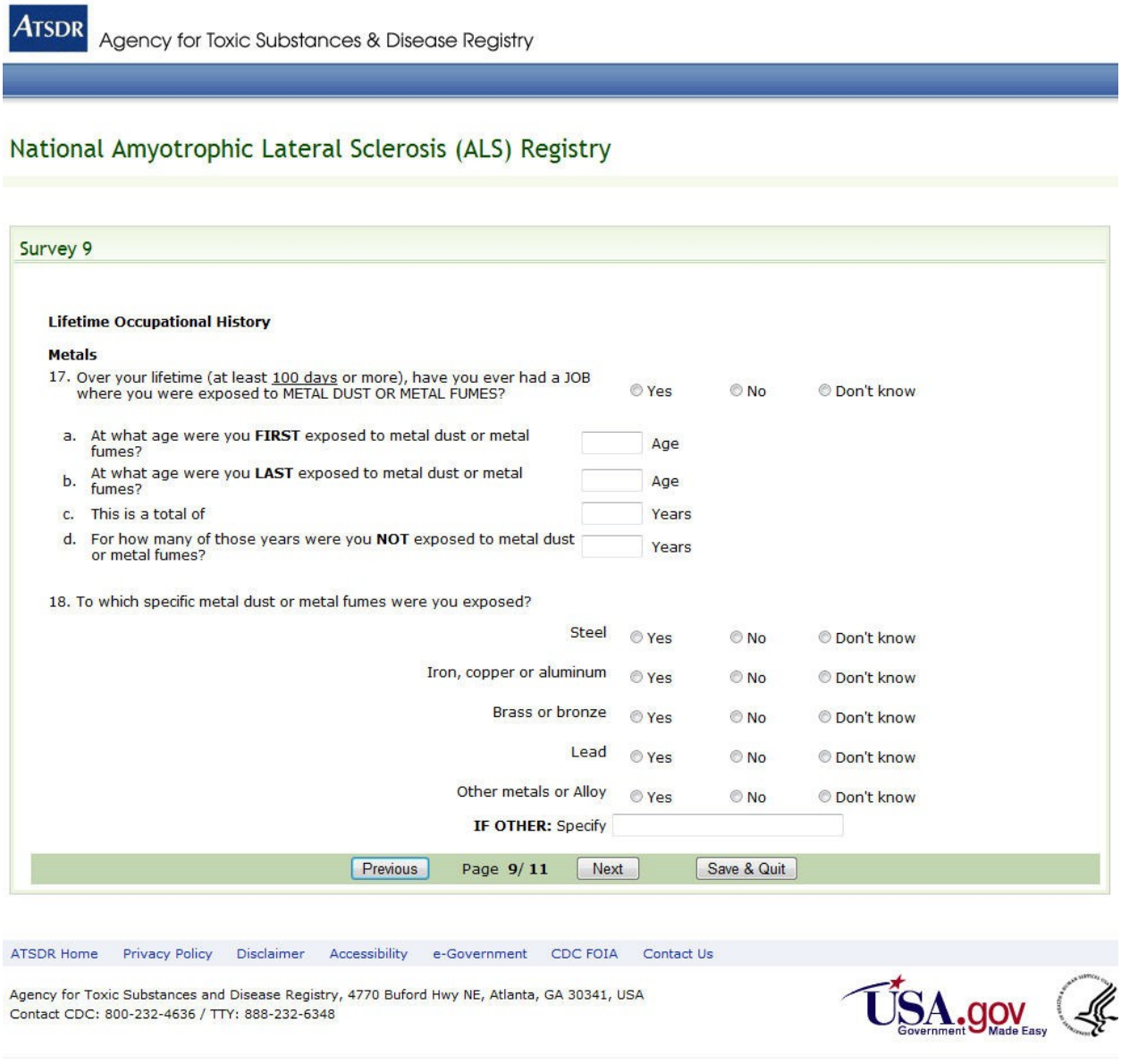

Figure 46: Survey 9, Page 9 of 11

ATSDR Agency for Toxic Substances & Disease Registry

National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 9

Lifetime Occupational History

Other occupational exposure

19. Over your lifetime (at least 100 days or more), have you ever had a JOB where you worked with ANY OTHER CHEMICAL? ○ Yes ○ No ○ Don't know

Specify

a. At what age did you **FIRST** work with this chemical? Age

b. At what age did you **LAST** work with this chemical? Age

c. This is a total of Years

d. For how many of those years did you **NOT** use this chemical? Years

20. Over your lifetime (at least 100 days or more), have you ever had a JOB where you worked with ANY OTHER CHEMICAL? ○ Yes ○ No ○ Don't know

Specify

a. At what age did you **FIRST** work with this chemical? Age

b. At what age did you **LAST** work with this chemical? Age

c. This is a total of Years

d. For how many of those years did you **NOT** use this chemical? Years

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Figure 47: Survey 9, Page 10 of 11

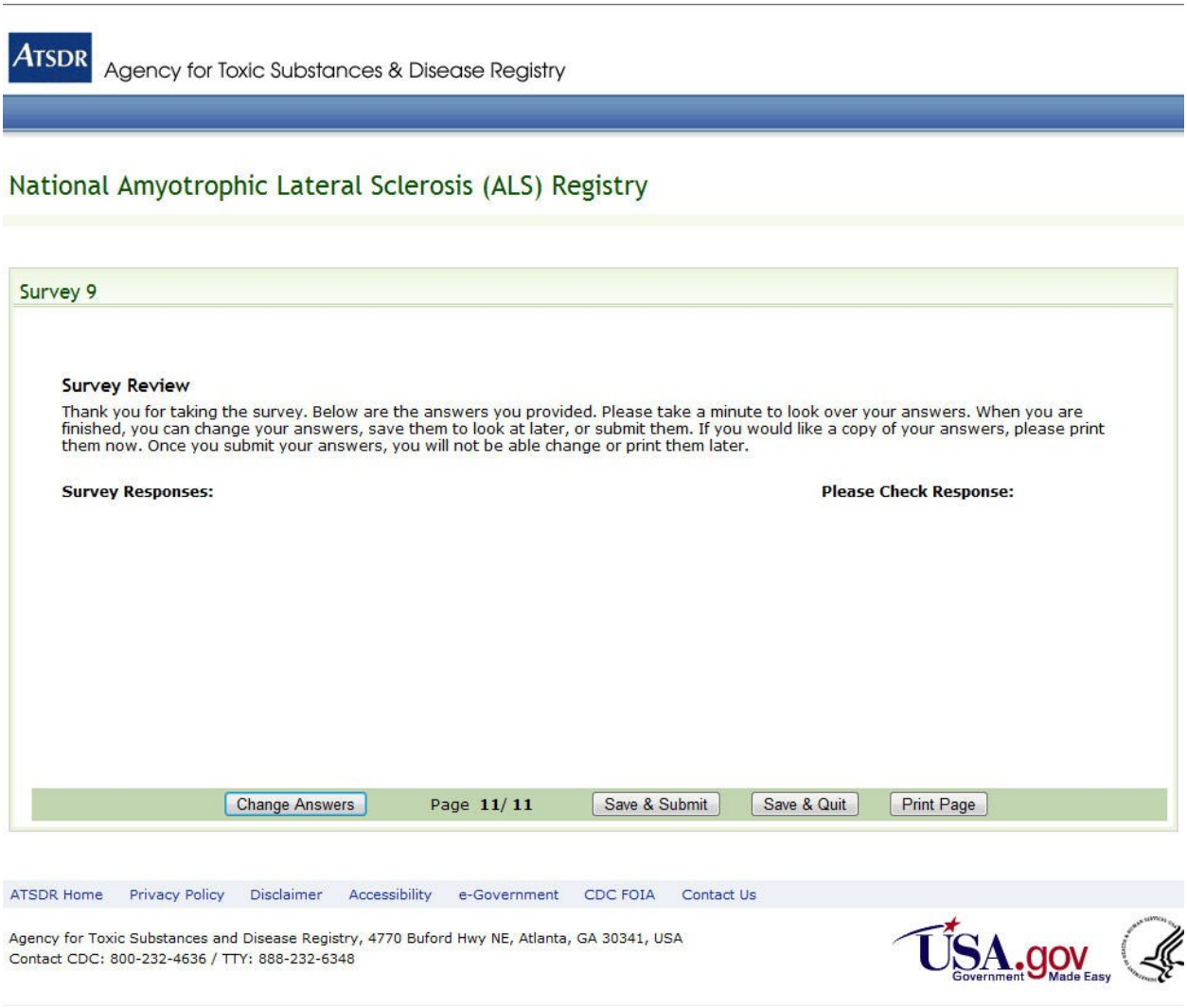

Figure 48: Survey 9, Page 11 of 11

ATSDR Agency for Toxic Substances & Disease Registry

National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 10

Home Pesticide Use

The following questions are about chemicals or home pesticides that you used to kill insects, plants, weeds, mold or mildew, or other pests in or around any house or apartment where you lived. We are interested only in those products that you personally handled, either by preparing them prior to application, by applying them yourself, or by helping to clean up after they were applied. Please consider products that you have personally handled at any time in your life. Please consider only the time from 10 years of age to the present.

1. Have you ever personally handled insecticides to control insects and pests in your home? ○ Yes ○ No ○ Don't know

   a. At what age did you **FIRST** handle insecticides in the home? ____ Age
   b. At what age did you **LAST** handle insecticides in the home? ____ Age
   c. This is a total of ____ Years
   d. For how many of those years did you **NOT** handle insecticides in your home? ____ Years
   e. During the periods when you did use insecticides in the home, how many days per year did you use them? ____ Days per year

2. Have you ever personally handled insecticides to control insects and pests in your lawn or garden? ○ Yes ○ No ○ Don't know

   a. At what age did you **FIRST** handle insecticides in the lawn or garden? ____ Age
   b. At what age did you **LAST** handle insecticides in the lawn or garden? ____ Age
   c. This is a total of ____ Years
   d. For how many of those years did you **NOT** handle insecticides in the lawn or garden? ____ Years
   e. During the periods when you did use insecticides in the lawn or garden, how many days per year did you use them? ____ Days per year

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Figure 49: Survey 10, Page 1 of 3

ATSDR Agency for Toxic Substances & Disease Registry

National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 10

Home Pesticide Use

3. Have you ever used herbicides or weed killers to control weeds or plants in your lawn, garden, or other areas around the home? ○ Yes ○ No ○ 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 per year did you use them? ____ Days per year

4. Have you ever used fungicides to control mildew or rot in your home or plant mold in the garden? ○ Yes ○ No ○ Don't know

   a. At what age did you **FIRST** handle fungicides in the home or garden? ____ Age
   b. At what age did you **LAST** handle fungicides in the home or garden? ____ Age
   c. This is a total of ____ Years
   d. 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 per year did you use them? ____ Days per year

5. Have you ever personally applied chemical soaps, shampoos, dips or powders to kill fleas, ticks or other insects on a pet, such as a dog or a cat? ○ Yes ○ No ○ Don't know

   a. At what age did you **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 per year did you apply them to your pet(s)? ____ Days per year

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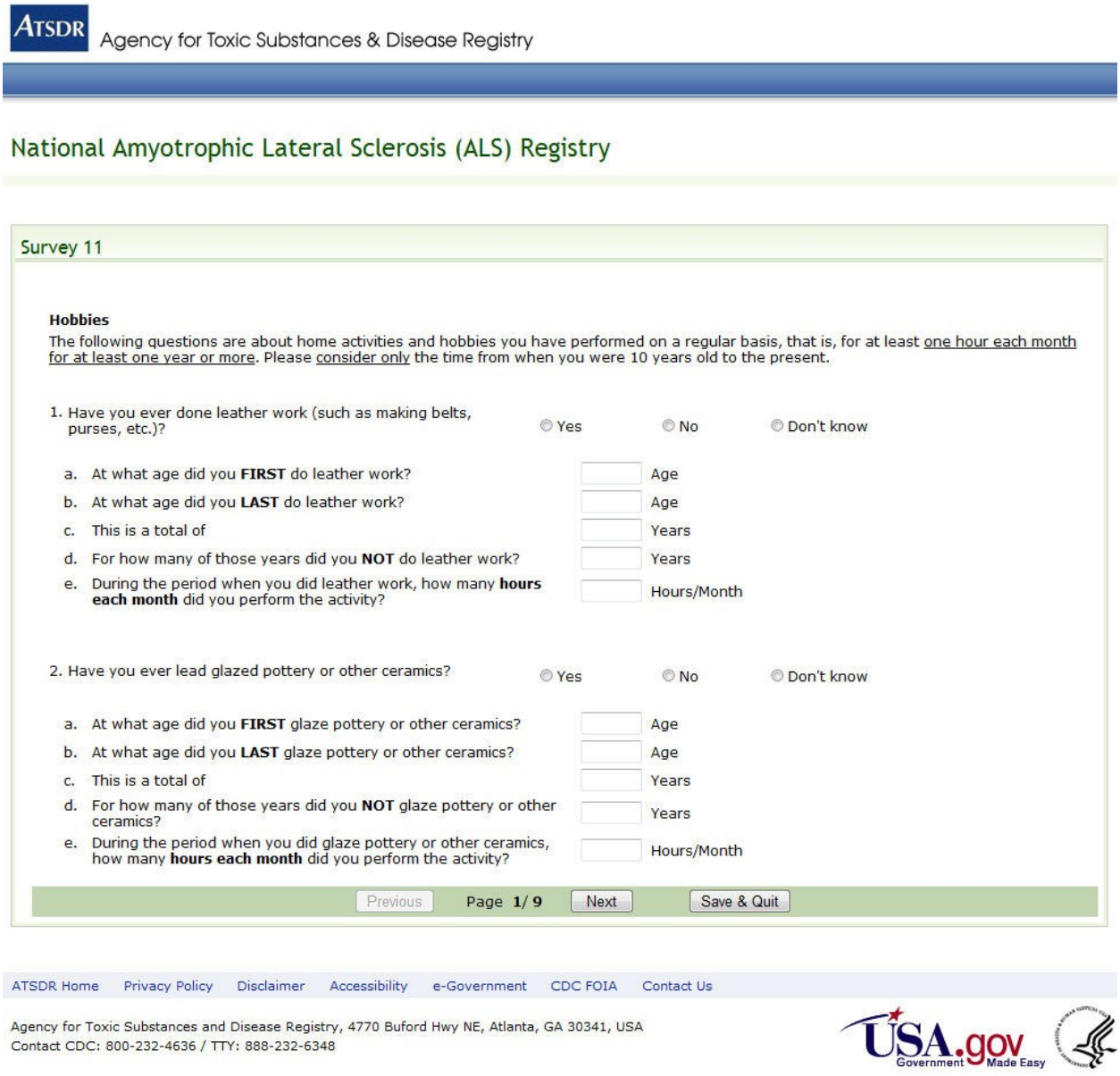
Figure 50: Survey 10, Page 2 of 3

Figure 51: Survey 10, Page 3 of 3



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Survey 11

Hobbies

3. Have you ever painted pictures or furniture with oil-based paint? ○ Yes ○ No ○ Don't know

a. At what age did you **FIRST** paint pictures or furniture with oil-based 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

4. Have you ever done home remodeling projects that involved scraping, stripping, burning and sanding paint? Please count only houses built before 1960. ○ Yes ○ No ○ 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
c. This is a total of ____ Years
d. For how many of those years did you **NOT** do home remodeling projects that involved scraping, stripping, burning and sanding paint on houses built before 1960? ____ Years
e. During the period when you did home remodeling projects that involved scraping, stripping, burning and sanding paint on houses built before 1960, how many **hours each month** did you perform the activity? ____ Hours/Month

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Survey 11

Hobbies

5. Have you ever done woodworking? ○ Yes ○ No ○ 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, how many **hours each month** did you perform the activity?	Hours/Month

6. Have you ever painted, repaired or restored old cars, other than fixing a flat tire or changing oil? ○ Yes ○ No ○ Don't know

a.	At what age did you **FIRST** paint, repair or restore old cars, other than fixing a flat tire or changing oil?	Age
b.	At what age did you **LAST** paint, repair or restore old cars, other than fixing a flat tire or changing oil?	Age
c.	This is a total of	Years
d.	For how many of those years did you **NOT** paint, repair or restore old cars, other than fixing a flat tire or changing oil?	Years
e.	During the period when you did paint, repair or restore old cars, other than fixing a flat tire or changing oil, how many **hours each month** did you perform the activity?	Hours/Month

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Hobbies

7. Have you ever built wooden or plastic models using glue? ○ Yes ○ No ○ Don't know

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. Have you ever developed photographs? ○ Yes ○ No ○ Don't know

a. At what age did you **FIRST** develop photographs? ____ Age
b. 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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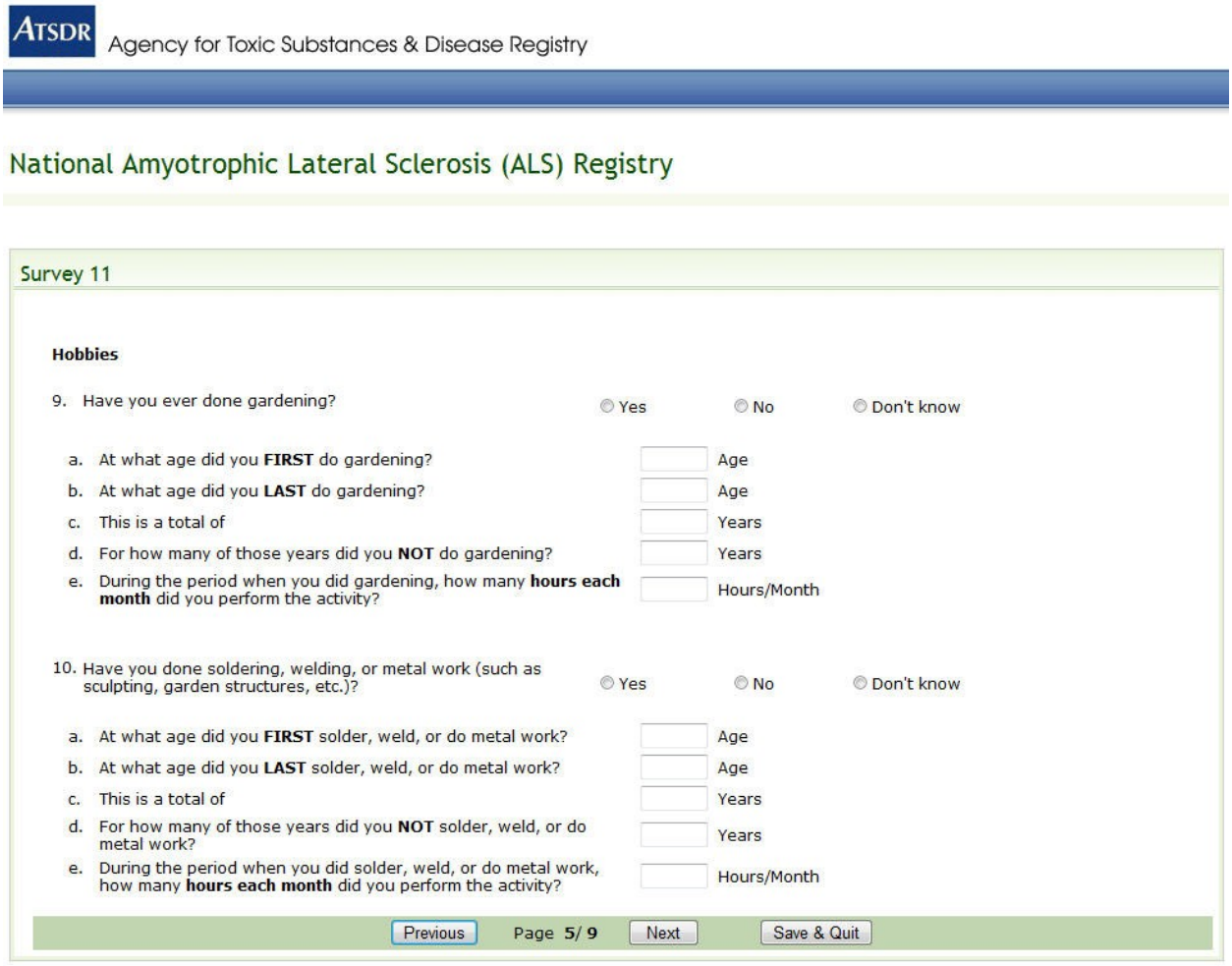

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Survey 11

Hobbies

11. Have you ever done outdoor hunting or shooting with guns, including animals, skeet, trap or targets? ○ Yes ○ No ○ 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. Have you ever done gun shooting in an indoor pistol or rifle range? ○ Yes ○ 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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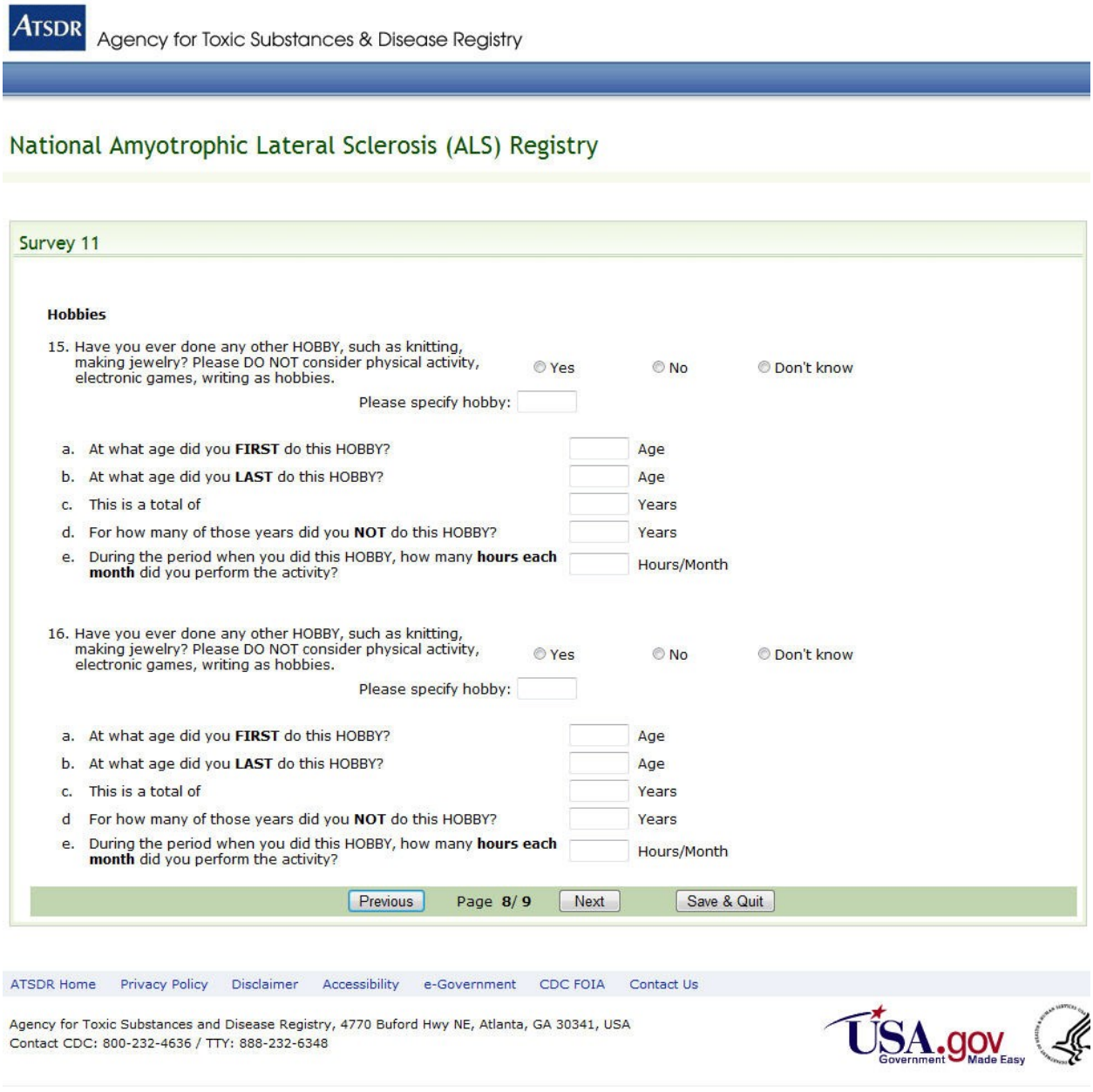

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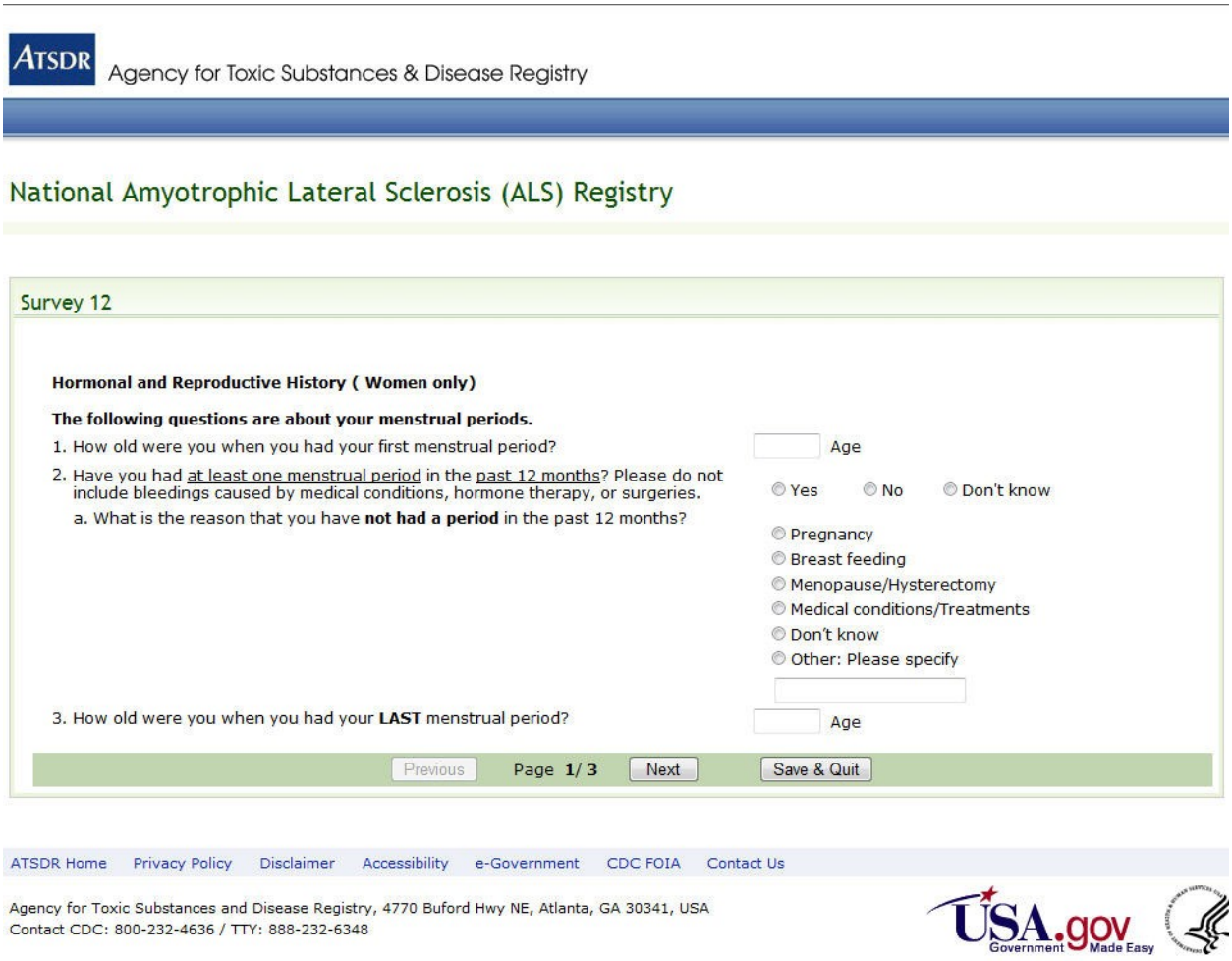

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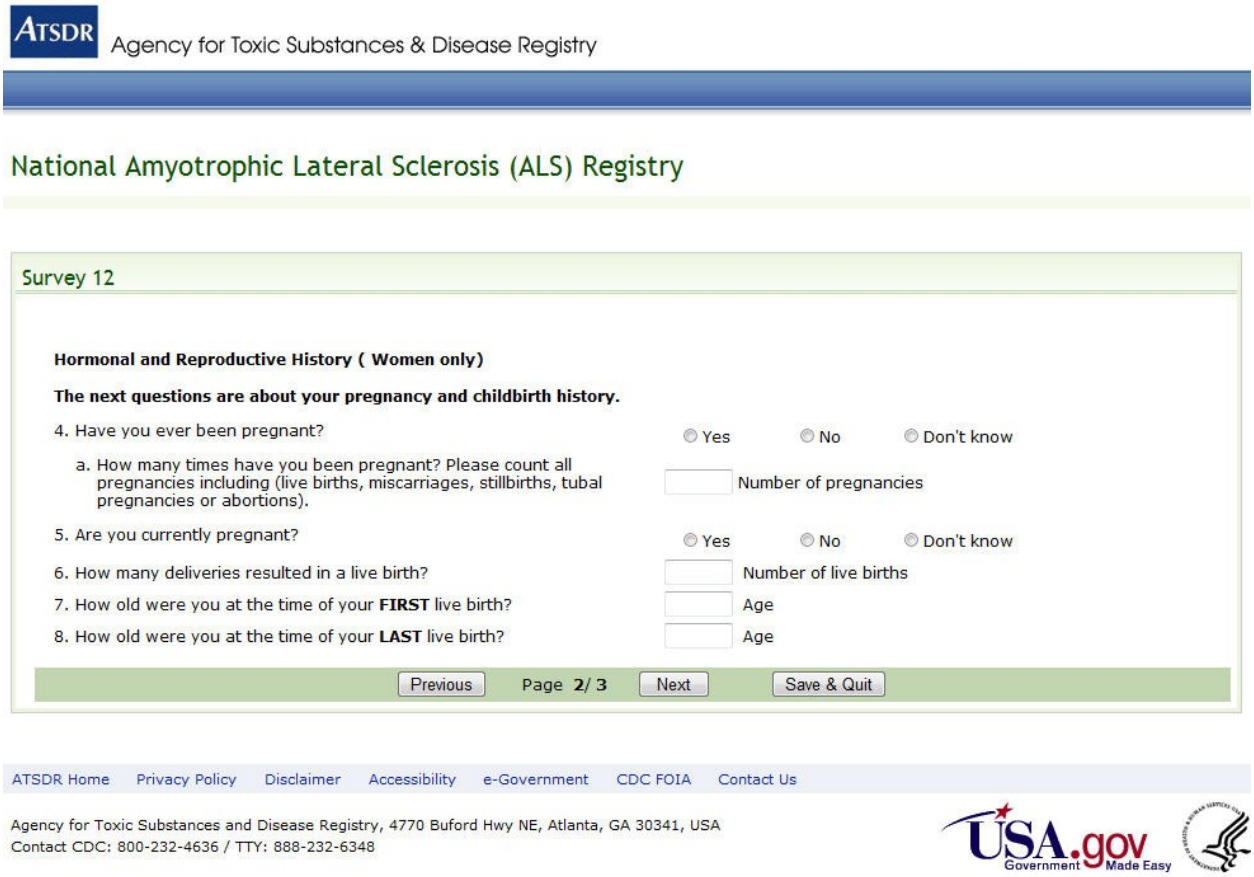

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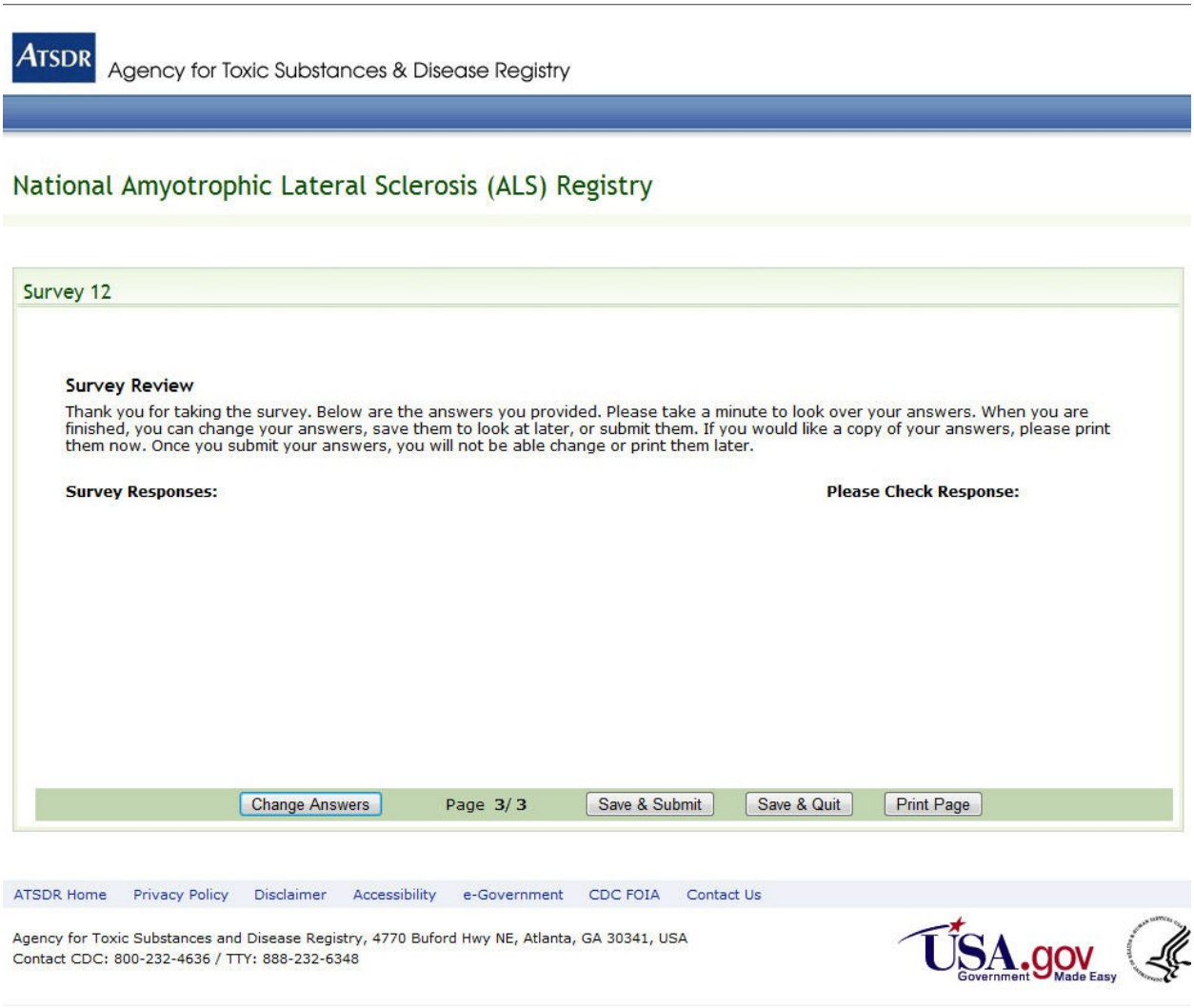

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Survey 13

Caffeine

The next questions pertain to your usual caffeine habits as an adult. By usual, we mean drinking the beverage at least once a month for six months or more.

1. Did you ever drink espresso or espresso drinks (Latte, Mocha, Americano)? A serving of espresso is 1 shot. ○ Yes ○ No ○ 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 ○ 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 of drinks per ○ day ○ week ○ month ○ year

2. Did you ever drink caffeinated coffee? A serving of coffee is 8 ounces. ○ Yes ○ No ○ Don't know

   a. At what age did you **FIRST** drink caffeinated coffee at least once per month? ____ Age
   b. Are you still drinking caffeinated coffee at least once per month? ○ Yes ○ No ○ 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? ____ Number of drinks per ○ day ○ week ○ month ○ year

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Survey 13

Caffeine

3. Did you ever drink caffeinated tea (green or black), hot or iced? A serving of tea is 8 oz. ○ Yes ○ No ○ 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 of drinks per ○ day ○ week ○ month ○ year

4. Did you ever drink highly caffeinated drinks, including Jolt®, Surge®, Mountain Dew MDX®, Red Bull®? A serving of these drinks is a 12 oz can. ○ Yes ○ No ○ Don't know

   a. At what age did you **FIRST** drink highly caffeinated drinks at least once per month? ____ Age
   b. Are you still drinking highly caffeinated drinks at least once per month? ○ Yes ○ No ○ Don't know
   c. At what age did you **LAST** drink highly caffeinated drinks at least once per month? ____ Age
   d. This is a total of ____ Years
   e. For how many of those years did you **NOT** drink highly caffeinated drinks? ____ Years
   f. During the periods when you did drink highly caffeinated drinks, how often (per day, week, month **or** year) did you drink them? ____ Number of drinks per ○ day ○ week ○ month ○ year

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Survey 13

Caffeine

5. Did you ever drink caffeinated soda, including colas, Barq's Root Beer ® or regular Mountain Dew®? A serving of colas or root beer is a 12 oz can. ○ Yes ○ No ○ Don't know

a. At what age did you **FIRST** drink caffeinated soda at least once per month? ____ Age

b. Are you still drinking caffeinated soda at least once per month? ○ Yes ○ No ○ Don't know

c. At what age did you **LAST** drink caffeinated soda 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 soda? ____ Years

f. During the periods when you did drink caffeinated soda, how often (per day, week, month **or** year) did you drink them? ____ Number of drinks per ○ day ○ week ○ month ○ year

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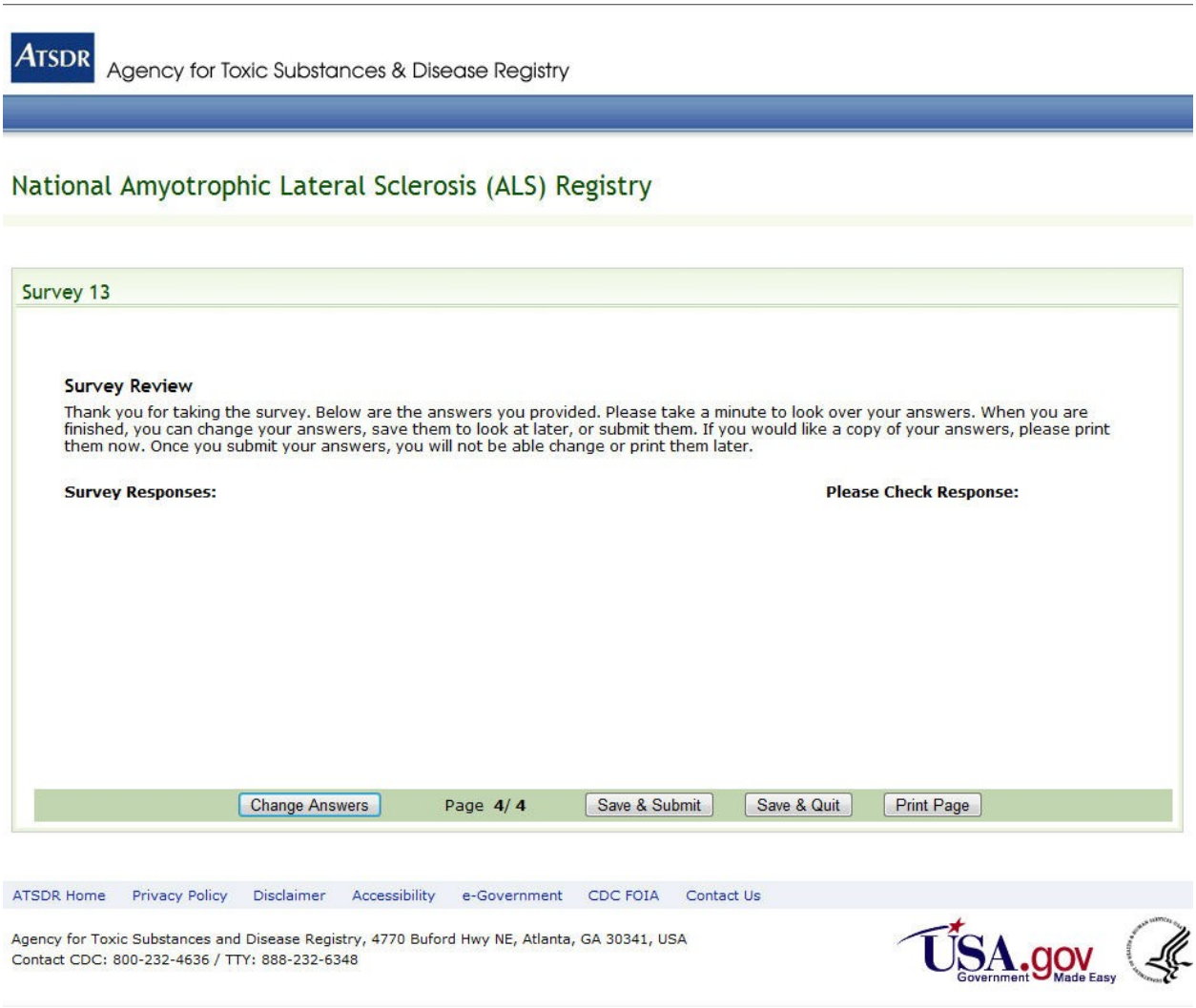

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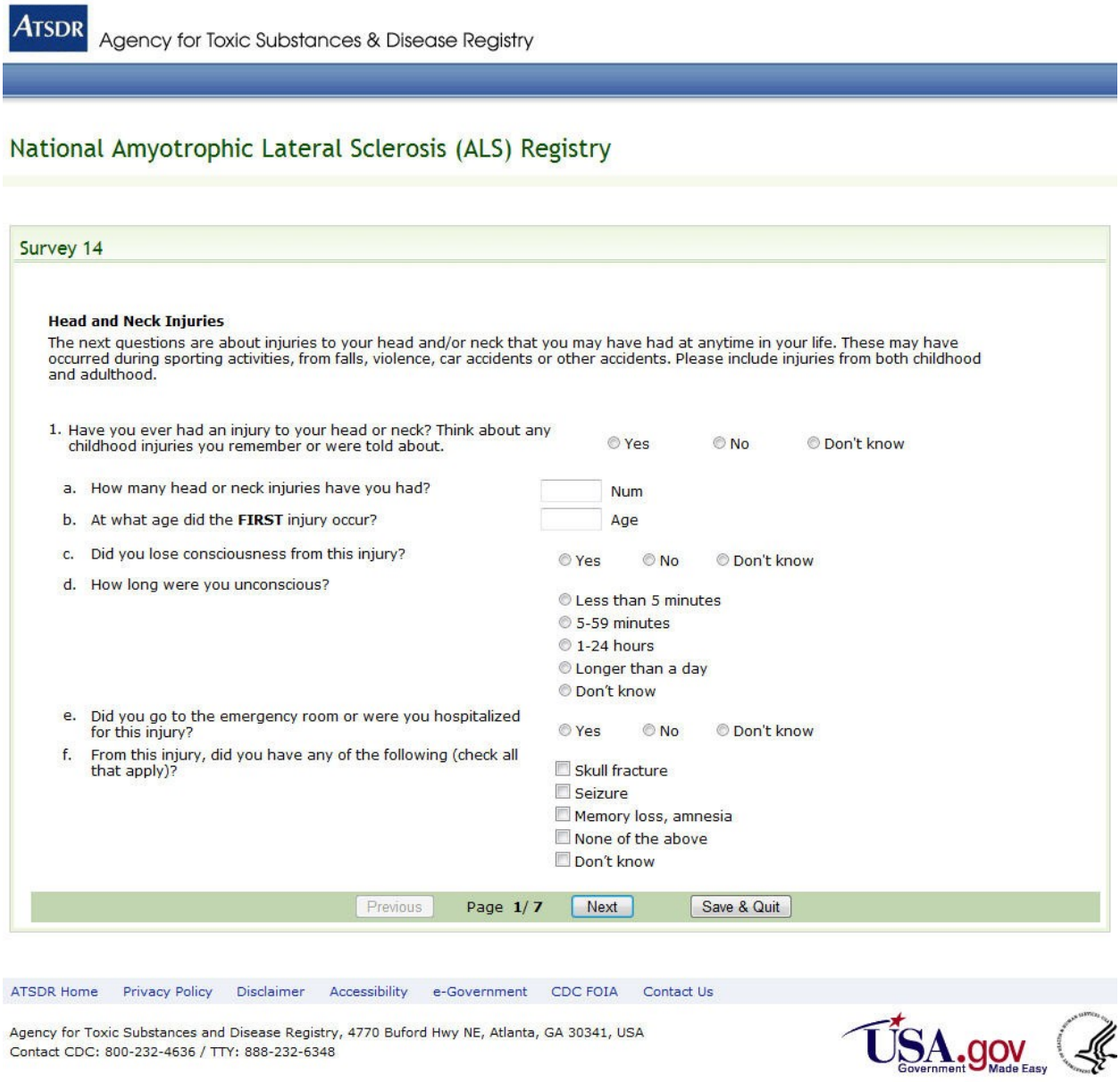

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National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 14

Head and Neck Injuries

2. Have you ever injured your head or neck in a car accident or from some other moving vehicle accident (e.g. motorcycle, ATV)? ○ Yes ○ No ○ Don't know

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 day
- ○ Don't know

e. Did you go to the emergency room or were you hospitalized for this injury? ○ Yes ○ No ○ Don't know

f. From this injury, did you have any of the following (check all that apply)?
- ☐ Skull fracture
- ☐ Seizure
- ☐ Memory loss, amnesia
- ☐ None of the above
- ☐ Don't know

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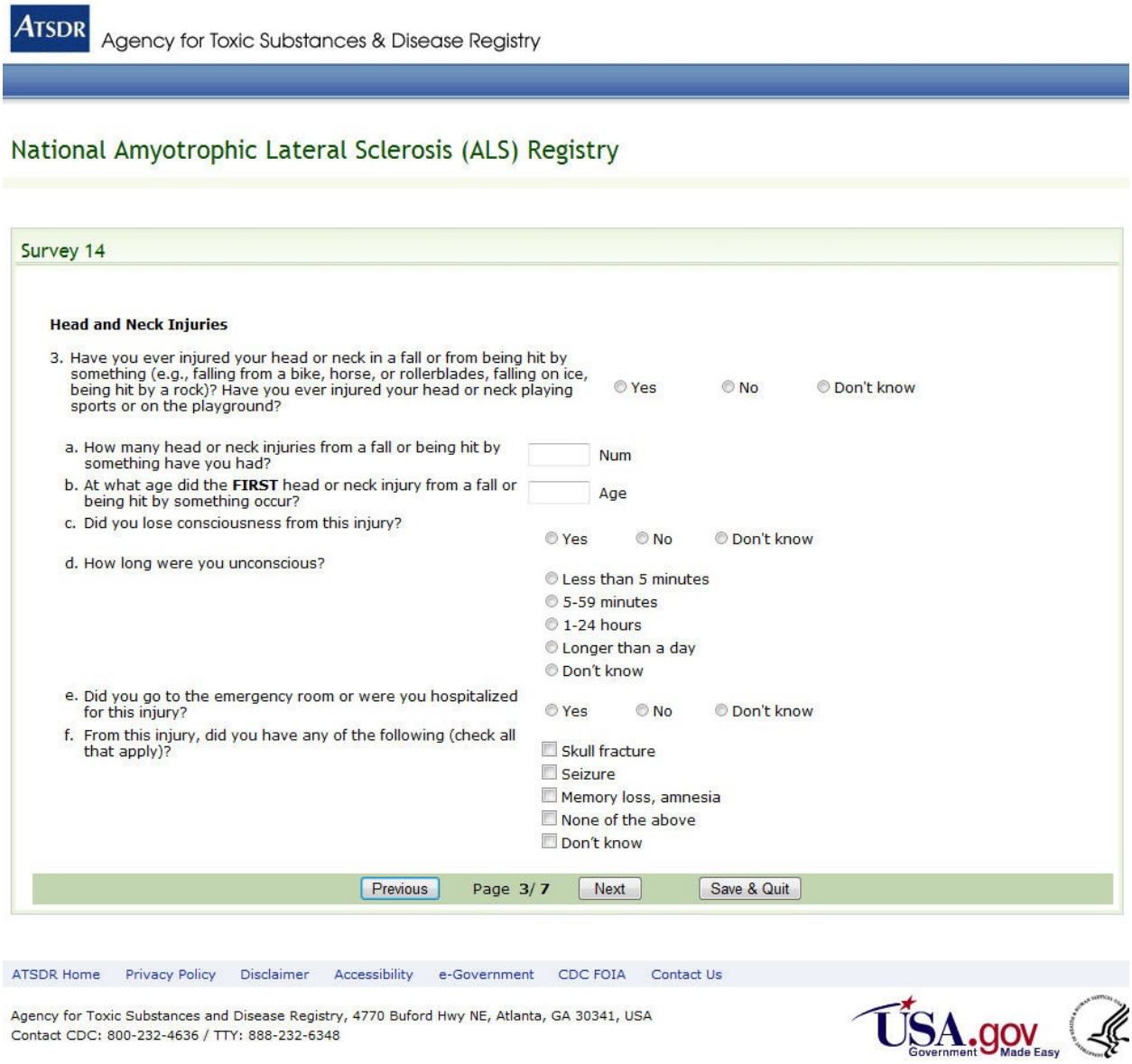

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Survey 14

Head and Neck Injuries

4. Have you ever injured your head or neck in a fight, from being hit by someone, or from being shaken violently? Have you ever been shot in the head? ○ Yes ○ No ○ Don't know

a. How many head or neck injuries have you had in a fight or from other violence? ____ Num

b. At what age did the **FIRST** head or neck injury in a fight or from other violence occur? ____ Age

c. Did you lose consciousness from this injury? ○ Yes ○ No ○ Don't know

d. How long were you unconscious?
- ○ Less than 5 minutes
- ○ 5-59 minutes
- ○ 1-24 hours
- ○ Longer than a day
- ○ Don't know

e. Did you go to the emergency room or were you hospitalized for this injury? ○ Yes ○ No ○ Don't know

f. From this injury, did you have any of the following (check all that apply)?
- ☐ Skull fracture
- ☐ Seizure
- ☐ Memory loss, amnesia
- ☐ None of the above
- ☐ Don't know

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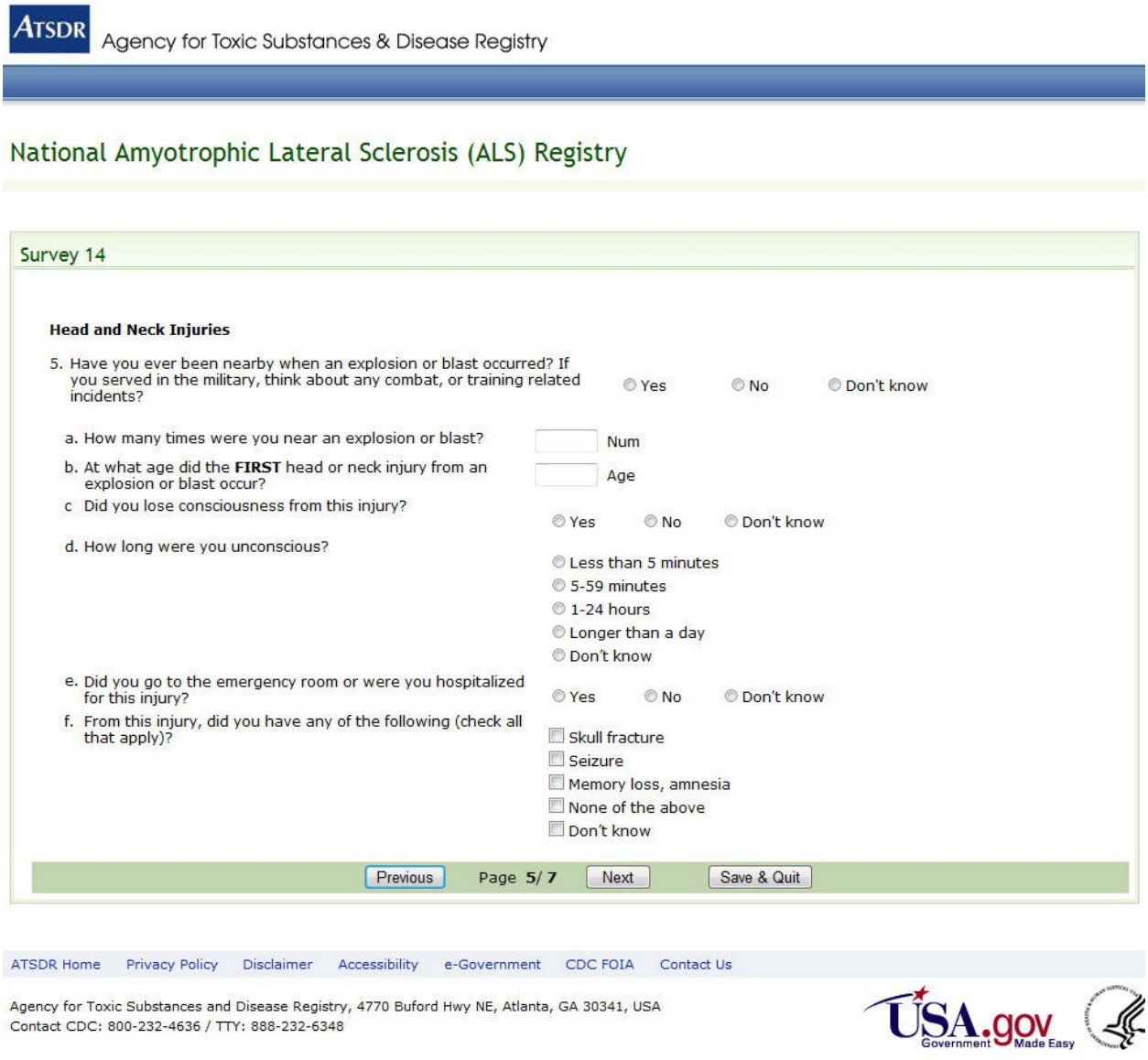

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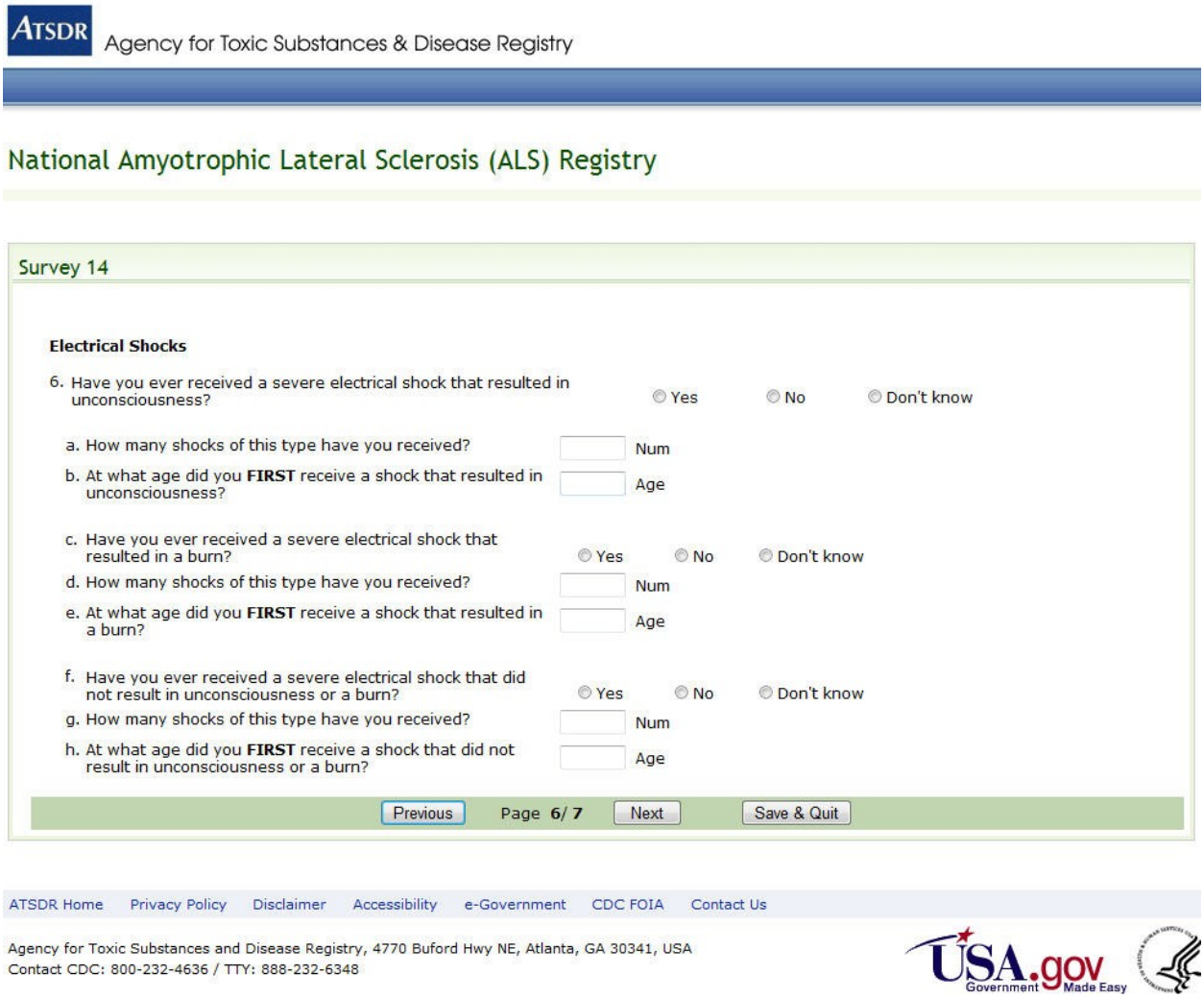

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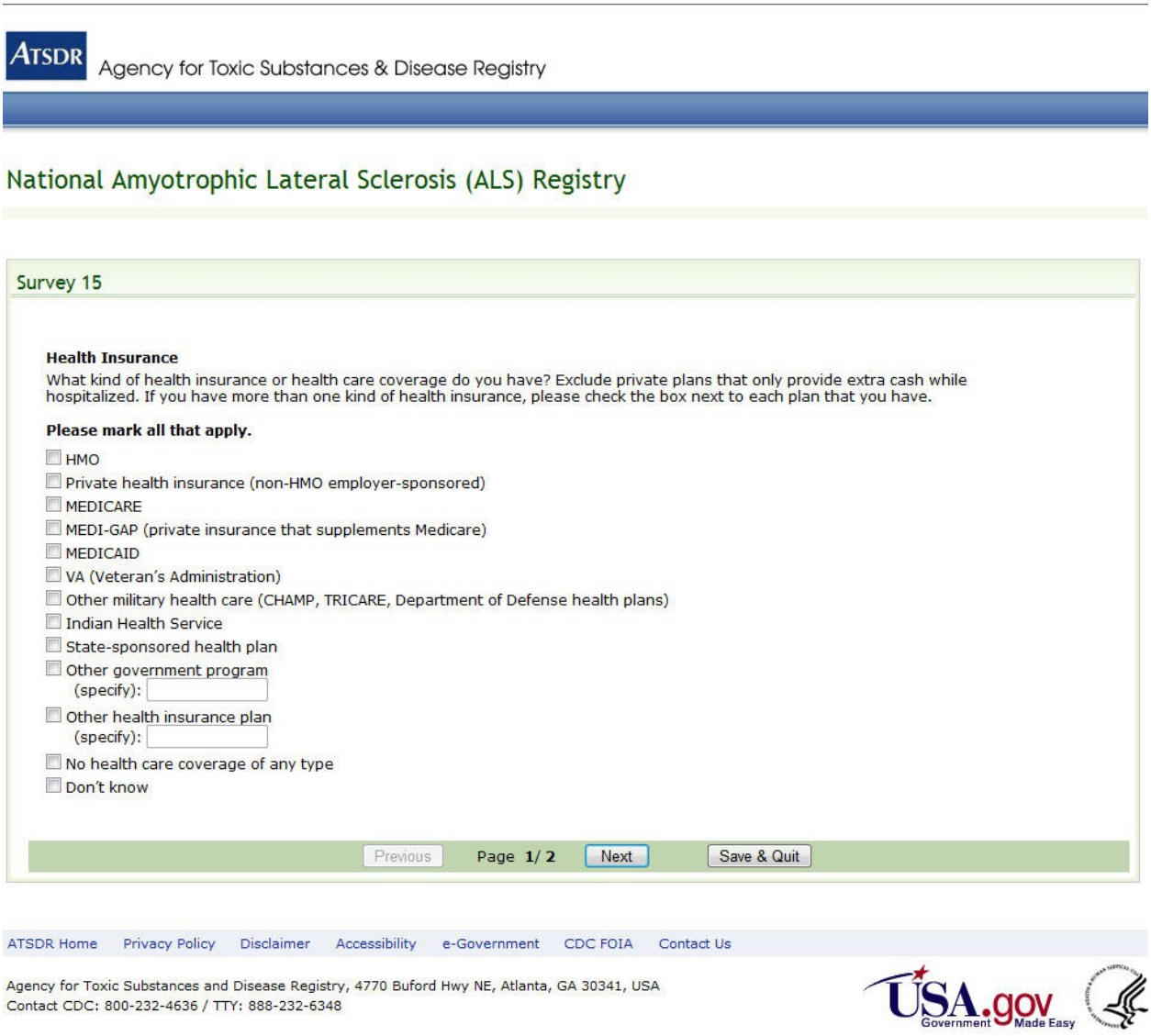

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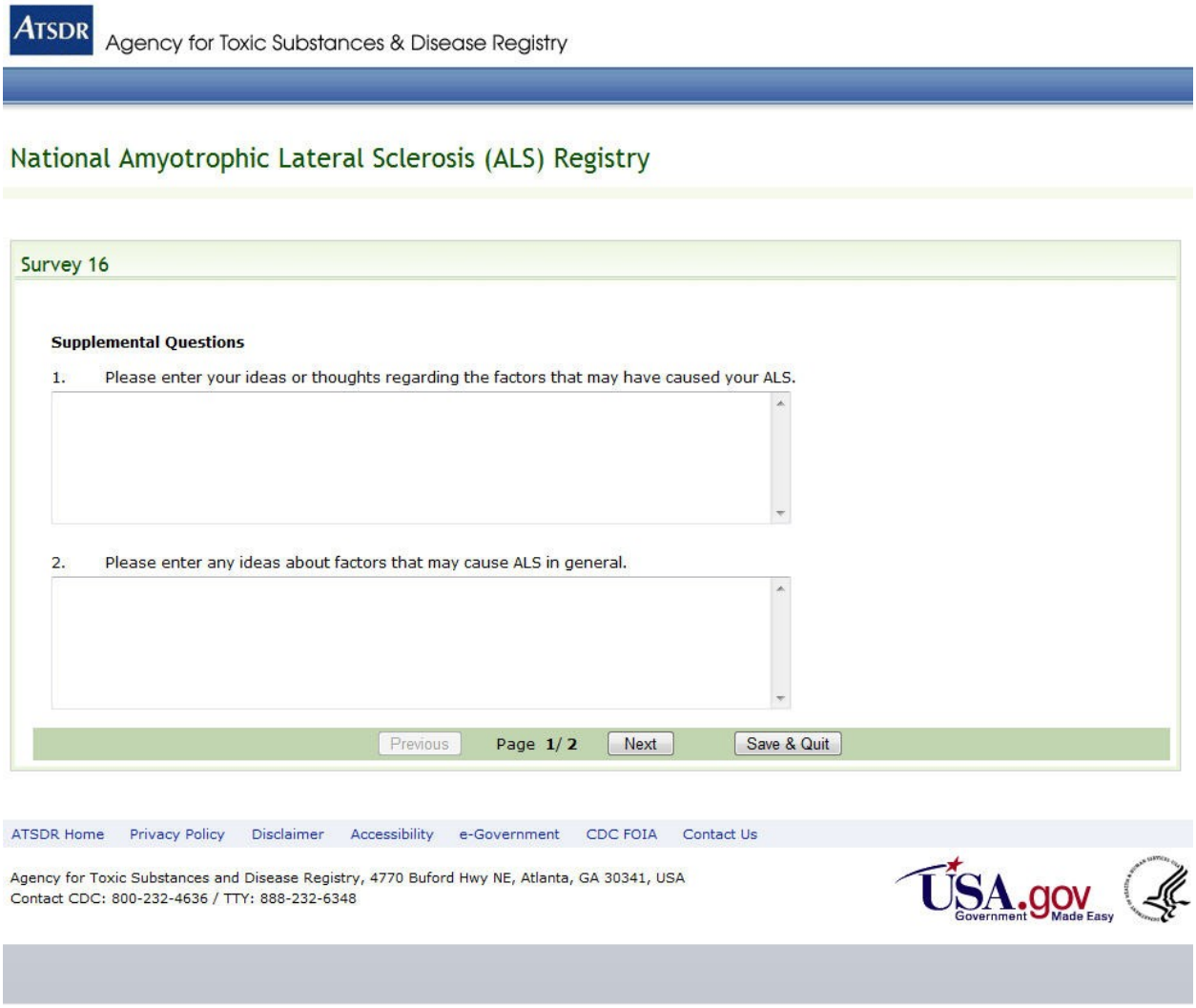

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National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 17

Clinical Module

3. Before you noticed weakness that turned out to be ALS, did you experience any of the following?

a. Cramps or muscle spasms? ○ Yes ○ No ○ Don't know

In what month and year did you first experience **cramps or muscle spasms?** Month / Year ☐ Don't Know

b. Scattered muscle twitching? ○ Yes ○ No ○ Don't know

In what month and year did you first experience **scattered muscle twitching?** Month / Year ☐ Don't Know

c. Difficulty swallowing? ○ Yes ○ No ○ Don't know

In what month and year did you first experience **difficulty swallowing?** Month / Year ☐ Don't Know

d. Problems with speech? ○ Yes ○ No ○ Don't know

In what month and year did you first experience **problems with speech?** Month / Year ☐ Don't Know

e. Difficulty controlling bowels or bladder? ○ Yes ○ No ○ Don't know

In what month and year did you first experience **difficulty controlling bowels or bladder?** Month / Year ☐ Don't Know

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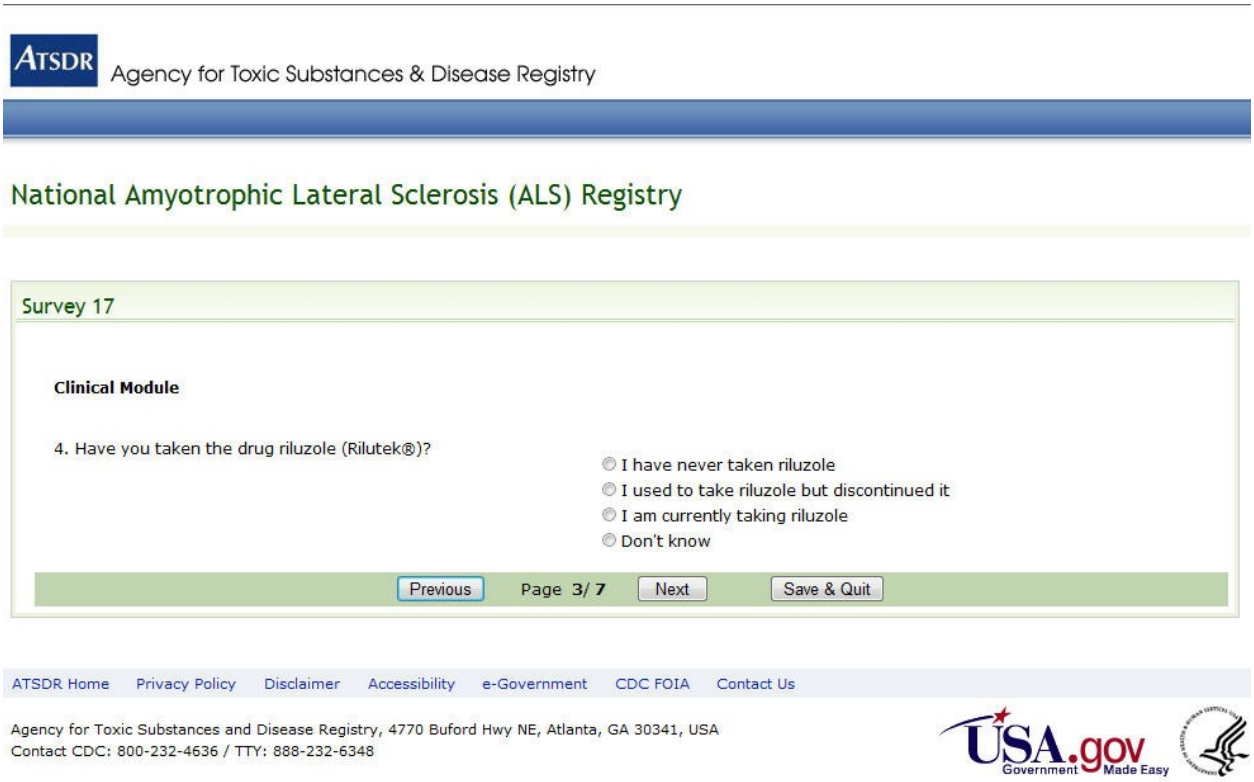

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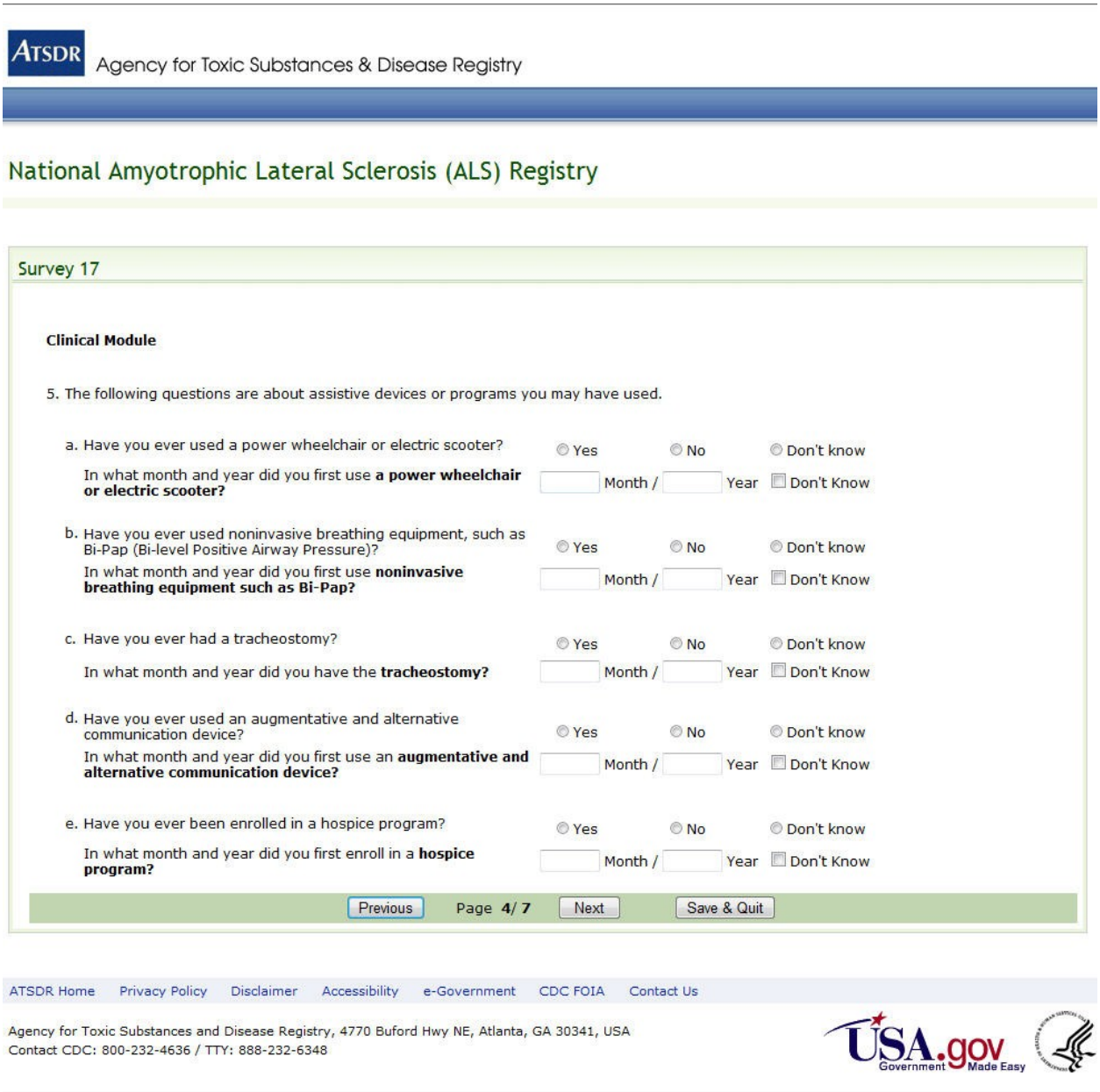

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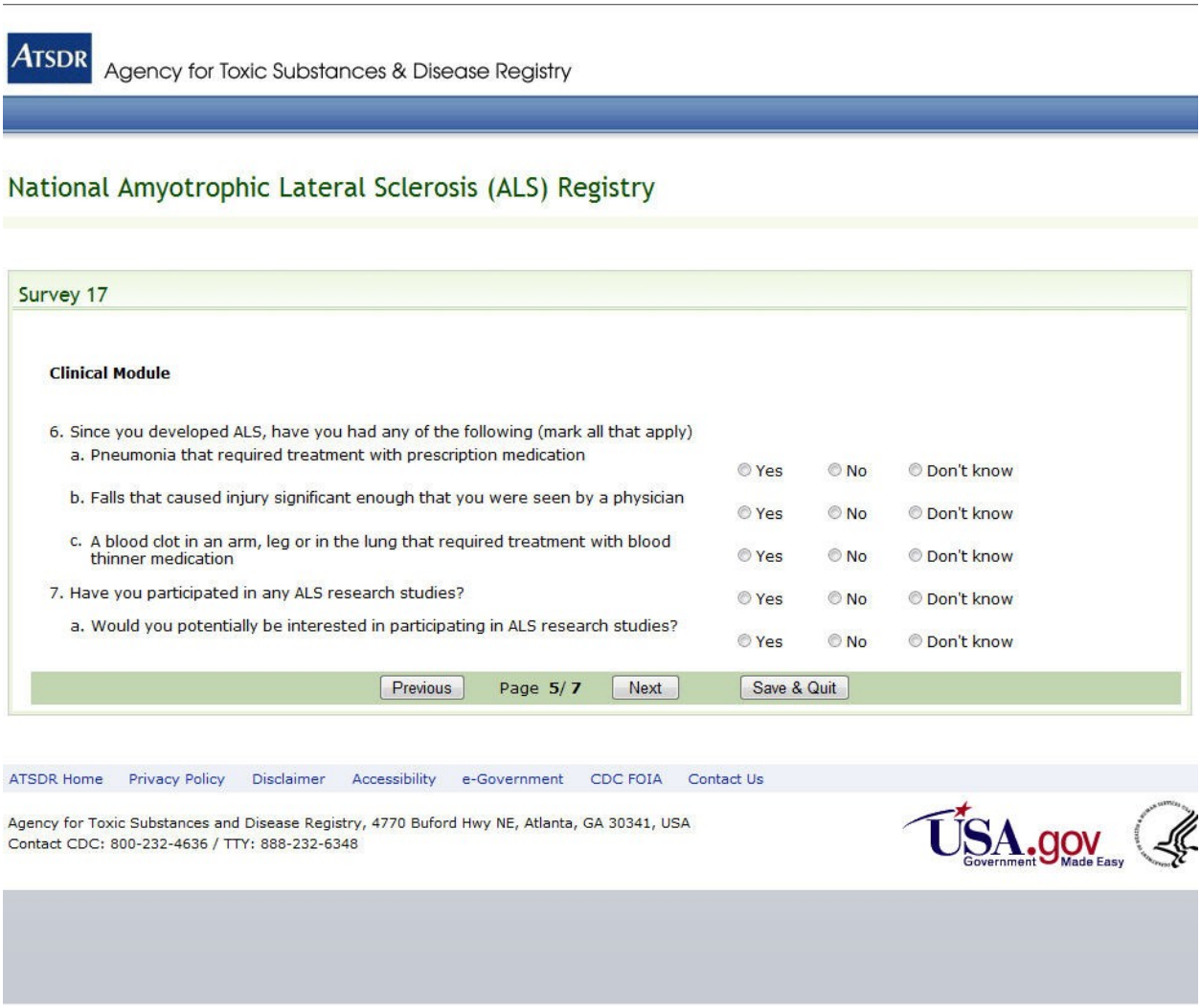

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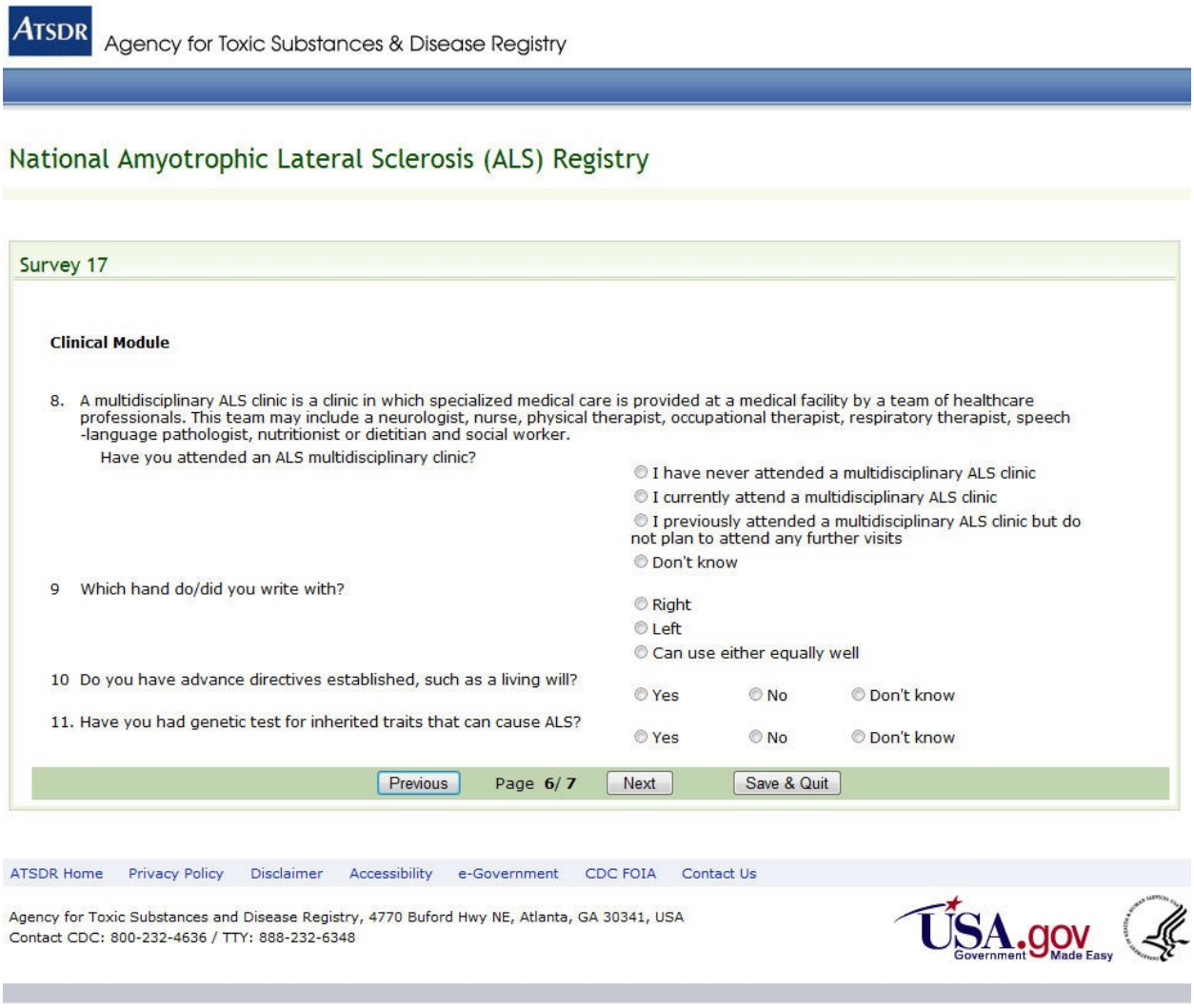

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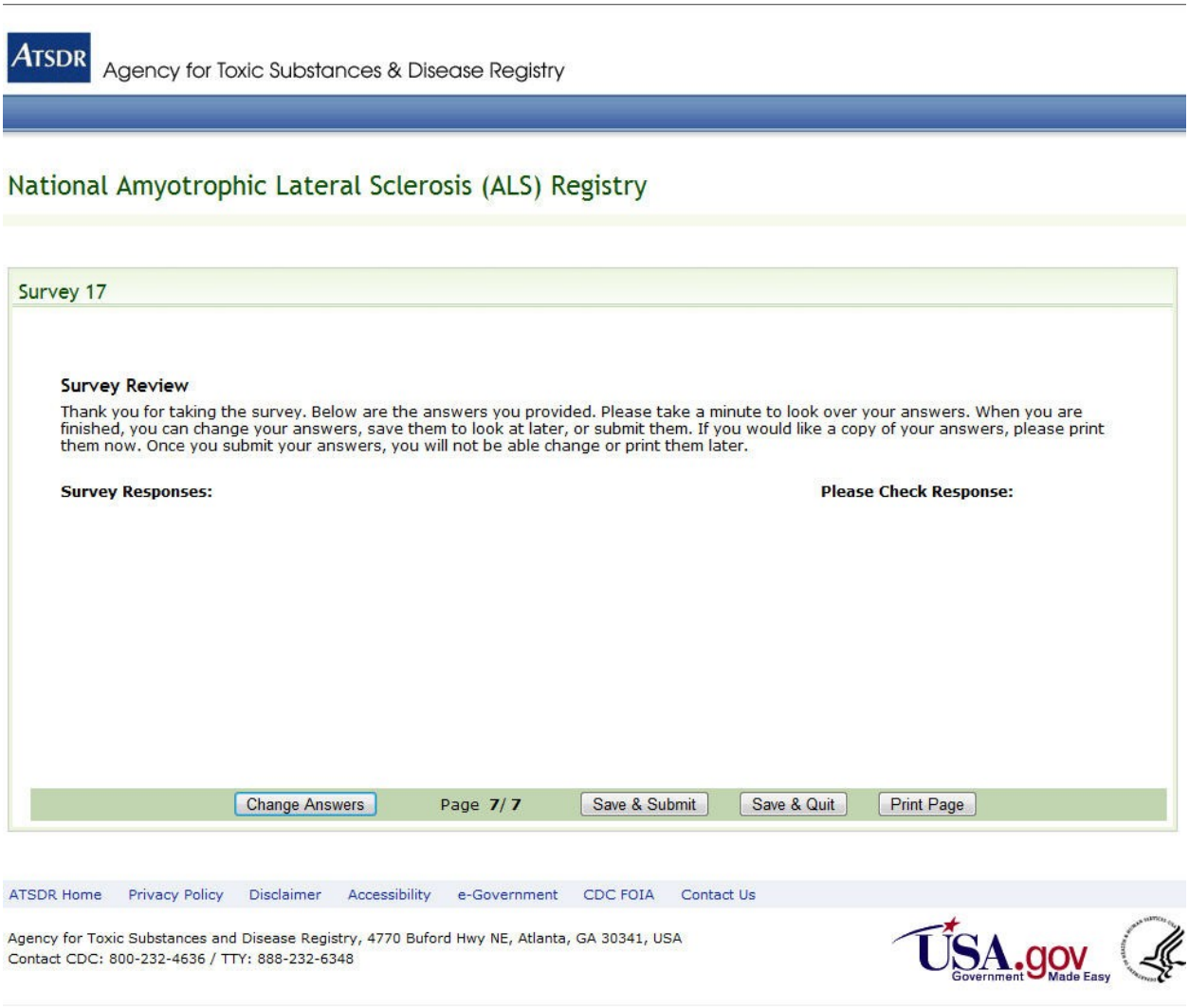

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