

Well Being 46

IF R Gender = EMPTY THEN

|

| **gender** R Gender

| What is your gender?

| 1 Male

| 2 Female

|

ENDIF

IF R Age = EMPTY THEN

|

| **calcage** R Age

| What is your age?

| Range: 0..120

|

ENDIF

BH_Intro Survey intro

In this survey, we would like to know more about how people make decisions about their own health care.

BH1 Rate health

First, we have some questions about your health. Would you say your health is excellent, very good, good, fair, or poor?

1 Excellent

2 Very good

3 Good

4 Fair

5 Poor

BH2 Rate health compared to year ago

Compared with one year ago, would you say that your health is much better now, somewhat better now, about the same, somewhat worse, or much worse than it was then?

1 Much better

2 Somewhat better

3 Same

4 Somewhat worse

5 Much worse

BH3 Rate emotional health

What about your emotional health - how good you feel or how stressed, anxious, or depressed you feel? Is it excellent, very good, good, fair, or poor?

1 Excellent

2 Very good

3 Good

4 Fair

5 Poor

IF R Gender = Male THEN

|

| **BH4_M** diagnosed prostate cancer

| Have you ever been diagnosed with prostate cancer?

| 1 Yes

| 2 No

| IF diagnosed prostate cancer = Yes THEN

| | **BH4_MC_Date** Year diagnosed prostate cancer

| | In what year were you diagnosed? Please write in 4 digits, for example 1973.

| | Range: 1900..2009

| | ENDIF

| ENDIF

IF R Gender = Female THEN

| **BH4_F** diagnosed breast cancer?

| Have you ever been diagnosed with breast cancer?

| 1 Yes

| 2 No

| IF diagnosed breast cancer? = Yes THEN

| | **BH4_FC_Date** Year diagnosed breast cancer

| | In what year were you diagnosed? Please write in 4 digits, for example 1973.

| | Range: 1900..2009

| | ENDIF

| ENDIF

BH5 diagnosed alzheimers disease

Have you ever been diagnosed with Alzheimer's disease?

1 Yes

2 No

IF diagnosed alzheimers disease = Yes THEN

| **BH5_A_Date** Year diagnosed breast cancer

| In what year were you diagnosed? Please write in 4 digits, for example 1973.

| Range: 1900..2009

| ENDIF

IF R Gender = Male THEN

| **CE1_M** family had prostate cancer

| Do you know of any living or deceased male family members - related to you by blood - who have had prostate cancer?

| 1 Yes

| 2 No

| IF family had prostate cancer = Yes THEN

[Questions CE1_M_Table to CE1_M_Table_Deceased[4] are displayed as a table]

CE1_M_Table family had prostate cancer table intro

Please tell us how you are/were related to each of your family members with prostate cancer; approximately how old he was when he first was told they had prostate cancer; and if this person is living or deceased. Please answer as best you can.

CE1_M_Table_Rel family had prostate cancer table relationship

Relationship:

- 1 Grandfather
- 2 Father
- 3 Uncle
- 4 Brother
- 5 Cousin
- 6 Other

CE1_M_Table_OnsetAge family had prostate cancer table onset age

Age of onset:

Range: 0..120

CE1_M_Table_Living family had prostate cancer table living

Living:

- 1

CE1_M_Table_CurrentAge family had prostate cancer table onset age

Current age:

Range: 0..120

CE1_M_Table_Deceased family had prostate cancer table deceased

Deceased:

- 1

CE1_M_Table_Rel family had prostate cancer table relationship

Relationship:

- 1 Grandfather
- 2 Father
- 3 Uncle
- 4 Brother
- 5 Cousin
- 6 Other

CE1_M_Table_OnsetAge family had prostate cancer table onset age

Age of onset:

Range: 0..120

CE1_M_Table_Living family had prostate cancer table living

Living:

- 1

CE1_M_Table_CurrentAge family had prostate cancer table onset age

Current age:

Range: 0..120

||
|| **CE1_M_Table_Deceased** family had prostate cancer table deceased
|| Deceased:
|| 1
||
|| **CE1_M_Table_Rel** family had prostate cancer table relationship
|| Relationship:
|| 1 Grandfather
|| 2 Father
|| 3 Uncle
|| 4 Brother
|| 5 Cousin
|| 6 Other
||
|| **CE1_M_Table_OnsetAge** family had prostate cancer table onset age
|| Age of onset:
|| Range: 0..120
||
|| **CE1_M_Table_Living** family had prostate cancer table living
|| Living:
|| 1
||
|| **CE1_M_Table_CurrentAge** family had prostate cancer table onset age
|| Current age:
|| Range: 0..120
||
|| **CE1_M_Table_Deceased** family had prostate cancer table deceased
|| Deceased:
|| 1
||
|| **CE1_M_Table_Rel** family had prostate cancer table relationship
|| Relationship:
|| 1 Grandfather
|| 2 Father
|| 3 Uncle
|| 4 Brother
|| 5 Cousin
|| 6 Other
||
|| **CE1_M_Table_OnsetAge** family had prostate cancer table onset age
|| Age of onset:
|| Range: 0..120
||
|| **CE1_M_Table_Living** family had prostate cancer table living
|| Living:
|| 1
||
|| **CE1_M_Table_CurrentAge** family had prostate cancer table onset age
|| Current age:
|| Range: 0..120
||
|| **CE1_M_Table_Deceased** family had prostate cancer table deceased
|| Deceased:

```

|| 1
||
| ENDIF
|
| IF (CE1_M_Table_Rel[1] <> empty and CE1_M_Table_Living[1] = 1 and CE1_M_Table_CurrentAge[1]
=
| empty) or (CE1_M_Table_Rel[2] <> empty and CE1_M_Table_Living[2] = 1 and
| CE1_M_Table_CurrentAge[2] = empty) or (CE1_M_Table_Rel[3] <> empty and CE1_M_Table_Living[3]
= 1
| and CE1_M_Table_CurrentAge[3] = empty) or (CE1_M_Table_Rel[4] <> empty and
CE1_M_Table_Living[4]
| = 1 and CE1_M_Table_CurrentAge[4] = empty) THEN
||
|| checkCurrentAge check current age
|| For one or more living relatives you did not enter a current age. Your answers are important to
|| us. Please go back and enter the current age(s) or your best guess(es) for them.
||
| ENDIF
|
| CE2_M Know others that had prostate cancer
| Do you know of any loved ones - close friends or non-blood-related family members other than the
| family members you just told us about - who have had prostate cancer?
| 1 Yes
| 2 No
|
| ENDIF

IF R Gender = Female THEN
|
| CE1_F family had breast cancer
| Do you know of any living or deceased female family members - related to you by blood - who have
| had breast cancer?
| 1 Yes
| 2 No
|
| IF family had breast cancer = Yes THEN
||
|| [Questions CE1_F_Table to CE1_F_Table_Deceased[4] are displayed as a table]
||
|| CE1_F_Table family had breast cancer table intro
|| Please tell us how you are/were related to each of your female family members with breast
|| cancer; approximately how old she was when she first was told they had breast cancer; and if
|| this person is living or deceased. Please answer as best you can.
||
|| CE1_F_Table_Rel family had breast cancer table relationship
|| Relationship:
|| 1 Grandmother
|| 2 Mother
|| 3 Aunt
|| 4 Sister
|| 5 Cousin
|| 6 Other
||

```

|| **CE1_F_Table_OnsetAge** family had breast cancer table onset age
|| Age of onset:
|| Range: 0..120
||
|| **CE1_F_Table_Living** family had breast cancer table living
|| Living:
|| 1
||
|| **CE1_F_Table_CurrentAge** family had breast cancer table onset age
|| Current age:
|| Range: 0..120
||
|| **CE1_F_Table_Deceased** family had breast cancer table deceased
|| Deceased:
|| 1
||
|| **CE1_F_Table_Rel** family had breast cancer table relationship
|| Relationship:
|| 1 Grandmother
|| 2 Mother
|| 3 Aunt
|| 4 Sister
|| 5 Cousin
|| 6 Other
||
|| **CE1_F_Table_OnsetAge** family had breast cancer table onset age
|| Age of onset:
|| Range: 0..120
||
|| **CE1_F_Table_Living** family had breast cancer table living
|| Living:
|| 1
||
|| **CE1_F_Table_CurrentAge** family had breast cancer table onset age
|| Current age:
|| Range: 0..120
||
|| **CE1_F_Table_Deceased** family had breast cancer table deceased
|| Deceased:
|| 1
||
|| **CE1_F_Table_Rel** family had breast cancer table relationship
|| Relationship:
|| 1 Grandmother
|| 2 Mother
|| 3 Aunt
|| 4 Sister
|| 5 Cousin
|| 6 Other
||
|| **CE1_F_Table_OnsetAge** family had breast cancer table onset age
|| Age of onset:
|| Range: 0..120

```

|
|
| CE1_F_Table_Living family had breast cancer table living
| Living:
| 1
|
| CE1_F_Table_CurrentAge family had breast cancer table onset age
| Current age:
| Range: 0..120
|
| CE1_F_Table_Deceased family had breast cancer table deceased
| Deceased:
| 1
|
| CE1_F_Table_Rel family had breast cancer table relationship
| Relationship:
| 1 Grandmother
| 2 Mother
| 3 Aunt
| 4 Sister
| 5 Cousin
| 6 Other
|
| CE1_F_Table_OnsetAge family had breast cancer table onset age
| Age of onset:
| Range: 0..120
|
| CE1_F_Table_Living family had breast cancer table living
| Living:
| 1
|
| CE1_F_Table_CurrentAge family had breast cancer table onset age
| Current age:
| Range: 0..120
|
| CE1_F_Table_Deceased family had breast cancer table deceased
| Deceased:
| 1
|
| ENDIF
|
| IF (CE1_F_Table_Rel[1] <> empty and CE1_F_Table_Living[1] = 1 and CE1_F_Table_CurrentAge[1] =
| empty) or (CE1_F_Table_Rel[2] <> empty and CE1_F_Table_Living[2] = 1 and
| CE1_F_Table_CurrentAge[2] = empty) or (CE1_F_Table_Rel[3] <> empty and CE1_F_Table_Living[3] =
| 1
| and CE1_F_Table_CurrentAge[3] = empty) or (CE1_F_Table_Rel[4] <> empty and
| CE1_F_Table_Living[4]
| = 1 and CE1_F_Table_CurrentAge[4] = empty) THEN
|
| checkCurrentAge check current age
| For one or more living relatives you did not enter a current age. Your answers are important to
| us. Please go back and enter the current age(s) or your best guess(es) for them.
|
| ENDIF

```

```
|  
| CE2_F Know others that had breast cancer  
| Do you know of any loved ones - close friends or non-blood-related family members other than the  
| family members you just told us about - who have had breast cancer?  
| 1 Yes  
| 2 No  
|  
ENDIF
```

AE1_intro Alzheimer intro

As you may know, Alzheimer's disease is a brain disorder that causes dementia - a serious decline a person's memory, thinking, and ability to carry out daily activities. Alzheimer's disease is the most common cause of dementia among older adults. Many people have had one or more family members affected by Alzheimer's disease.

AE1 family diagnosed with Alzheimer

Do you know of any living or deceased family members - related to you by blood - who have been diagnosed with Alzheimer's disease?

1 Yes

2 No

IF family diagnosed with Alzheimer = Yes THEN

```
|  
| [Questions AE1_Table to AE1_Table_Deceased[4] are displayed as a table]
```

```
|  
| AE1_Table family had Alzheimer table intro
```

```
| Please tell us how you are/were related to each of your family members with Alzheimer's disease;  
| approximately how old he/she was when he/she first showed signs of Alzheimer's disease; and if  
| this person is living or deceased. Please answer as best you can.
```

```
| AE1_Table_Rel family had Alzheimer table relationship
```

```
| Relationship:
```

```
| 1 Grandparent
```

```
| 2 Parent
```

```
| 3 Parent's sibling
```

```
| 4 Sibling
```

```
| 5 Cousin
```

```
| 6 Other
```

```
| AE1_Table_OnsetAge family had Alzheimer table onset age
```

```
| Age of onset:
```

```
| Range: 0..120
```

```
| AE1_Table_Living family had Alzheimer table living
```

```
| Living:
```

```
| 1
```

```
| AE1_Table_CurrentAge family had Alzheimer table onset age
```

```
| Current age:
```

```
| Range: 0..120
```

```
| AE1_Table_Deceased family had Alzheimer table deceased
```

```
| Deceased:
```


| 1
|
| **AE1_Table_Rel** family had Alzheimer table relationship
| Relationship:
| 1 Grandparent
| 2 Parent
| 3 Parent's sibling
| 4 Sibling
| 5 Cousin
| 6 Other
|
| **AE1_Table_OnsetAge** family had Alzheimer table onset age
| Age of onset:
| Range: 0..120
|
| **AE1_Table_Living** family had Alzheimer table living
| Living:
| 1
|
| **AE1_Table_CurrentAge** family had Alzheimer table onset age
| Current age:
| Range: 0..120
|
| **AE1_Table_Deceased** family had Alzheimer table deceased
| Deceased:
| 1
|
| **AE1_Table_Rel** family had Alzheimer table relationship
| Relationship:
| 1 Grandparent
| 2 Parent
| 3 Parent's sibling
| 4 Sibling
| 5 Cousin
| 6 Other
|
| **AE1_Table_OnsetAge** family had Alzheimer table onset age
| Age of onset:
| Range: 0..120
|
| **AE1_Table_Living** family had Alzheimer table living
| Living:
| 1
|
| **AE1_Table_CurrentAge** family had Alzheimer table onset age
| Current age:
| Range: 0..120
|
| **AE1_Table_Deceased** family had Alzheimer table deceased
| Deceased:
| 1
|
| **AE1_Table_Rel** family had Alzheimer table relationship

| Relationship:
| 1 Grandparent
| 2 Parent
| 3 Parent's sibling
| 4 Sibling
| 5 Cousin
| 6 Other
|

| **AE1_Table_OnsetAge** family had Alzheimer table onset age
| Age of onset:
| Range: 0..120
|

| **AE1_Table_Living** family had Alzheimer table living
| Living:
| 1
|

| **AE1_Table_CurrentAge** family had Alzheimer table onset age
| Current age:
| Range: 0..120
|

| **AE1_Table_Deceased** family had Alzheimer table deceased
| Deceased:
| 1
|

ENDIF

IF (AE1_Table_Rel[1] <> empty and AE1_Table_Living[1] = 1 and AE1_Table_CurrentAge[1] = empty) or
(AE1_Table_Rel[2] <> empty and AE1_Table_Living[2] = 1 and AE1_Table_CurrentAge[2] = empty) or
(AE1_Table_Rel[3] <> empty and AE1_Table_Living[3] = 1 and AE1_Table_CurrentAge[3] = empty) or
(AE1_Table_Rel[4] <> empty and AE1_Table_Living[4] = 1 and AE1_Table_CurrentAge[4] = empty)
THEN

| **checkCurrentAge** check current age
| For one or more living relatives you did not enter a current age. Your answers are important to
| us. Please go back and enter the current age(s) or your best guess(es) for them.
|

ENDIF

AE2 Know others that had Alzheimer

Do you know of any loved ones - close friends or non-blood-related family members other than the
family members you just told us about - who have been diagnosed with Alzheimer's disease?

1 Yes
2 No

[Questions AE3 to AE3_other are displayed as a table]

AE3 heard about Alzheimer

Where have you previously heard about Alzheimer's disease? Please list all information sources that
apply - including print, television, the internet, and radio.

1 Television

2 Radio

3 Newspaper

4 Internet

5 Other information source:

6 I have not heard of Alzheimer's disease before.

AE3_other heard about Alzheimer other

String

AE4_intro example true false question

Next, we would like to know how strongly you agree with some true or false statements. We want to know if you think the statements are generally true or generally false, and how strongly you believe this. An example of a true-false statement is below: Example question: A person who smokes is more likely to develop lung cancer. If you think this statement is most likely to be true, choose a number on the scale on the right. If you think it is definitely true, select Surely True, 100%. If you think it is 80% true, then select 80% on the right side of the scale. If you think this statement is most likely to be false, choose a number on the scale on the left. If you think it is definitely false, select Surely False, 100%. If you think it is 80% likely to be false, then select 80% on the left side of the scale. If you are absolutely unsure, please make your best guess, and indicate whether you would guess false or guess true.

[Questions AE4 to AE6 are displayed as a table]

AE4 Alzheimer involves only memory loss

Alzheimer's disease involves only memory loss.

1 100%

2 90%

3 80%

4 70%

5 60%

6 50%

7 50%

8 60%

9 70%

10 80%

11 90%

12 100%

AE5 Cannot get Alzheimer when healthy lifestyle

Living a healthy lifestyle and staying mentally active can ensure that one does not get Alzheimer's disease.

1 100%

2 90%

3 80%

4 70%

5 60%

6 50%

7 50%

8 60%

9 70%

10 80%

11 90%
12 100%

AE6 no treatment can reverse Alzheimer

Once diagnosed, no treatment can reverse Alzheimers disease.

1 100%
2 90%
3 80%
4 70%
5 60%
6 50%
7 50%
8 60%
9 70%
10 80%
11 90%
12 100%

IF diagnosed alzheimers disease = Yes THEN

| **IC_A_Intro1** what insurance prior to being diagnosed

| Now we will ask you some questions about the types of insurance you held prior to being diagnosed with Alzheimer's, and any changes that you made after your diagnosis. Prior to your diagnosis, which of the following types of insurance did you have? Please check all that apply.

| 1 Health insurance through employer (yours or any household member's)
| 2 Life insurance through employer (yours or any household member's)
| 3 Disability insurance through employer (yours or any household member's)
| 4 Long-term care insurance through employer (yours or any household member's)
| 5 Personal health insurance
| 6 Personal life insurance
| 7 Personal disability insurance
| 8 Personal long-term care insurance
| 9 Medicare coverage

| [Questions IC_A_Intro2 to IC8_Change_A are displayed as a table]

| **IC_A_Intro2** Alzheimer disease changes insurance

| After you were diagnosed with Alzheimer's disease, did you make changes such as researching and purchasing any new or additional insurance policies? Please check all that apply.

| **IC1_Change_A** Alzheimer changes health insurance through employer

| Health insurance through employer (yours or any household member's)

| 1 Bought new policy
| 2 Decreased coverage under existing policy
| 3 Increased coverage under existing policy
| 4 Terminated existing policy
| 5 Did Research but Took No Action
| 6 No change

| **IC2_Change_A** Alzheimer changes life insurance through employer

| Life insurance through employer (yours or any household member's)

| 1 Bought new policy
| 2 Decreased coverage under existing policy

- | 3 Increased coverage under existing policy
- | 4 Terminated existing policy
- | 5 Did Research but Took No Action
- | 6 No change

| **IC3_Change_A** Alzheimer changes disability insurance through employer
| Disability insurance through employer (yours or any household member's)

- | 1 Bought new policy
- | 2 Decreased coverage under existing policy
- | 3 Increased coverage under existing policy
- | 4 Terminated existing policy
- | 5 Did Research but Took No Action
- | 6 No change

| **IC4_Change_A** Alzheimer changes long-term care
| Long-term care insurance through employer (yours or any household member's)

- | 1 Bought new policy
- | 2 Decreased coverage under existing policy
- | 3 Increased coverage under existing policy
- | 4 Terminated existing policy
- | 5 Did Research but Took No Action
- | 6 No change

| **IC5_Change_A** Alzheimer changes personal health insurance
| Personal health insurance

- | 1 Bought new policy
- | 2 Decreased coverage under existing policy
- | 3 Increased coverage under existing policy
- | 4 Terminated existing policy
- | 5 Did Research but Took No Action
- | 6 No change

| **IC6_Change_A** Alzheimer changes personal life insurance
| Personal life insurance

- | 1 Bought new policy
- | 2 Decreased coverage under existing policy
- | 3 Increased coverage under existing policy
- | 4 Terminated existing policy
- | 5 Did Research but Took No Action
- | 6 No change

| **IC7_Change_A** Alzheimer changes personal disability insurance
| Personal disability insurance

- | 1 Bought new policy
- | 2 Decreased coverage under existing policy
- | 3 Increased coverage under existing policy
- | 4 Terminated existing policy
- | 5 Did Research but Took No Action
- | 6 No change

| **IC8_Change_A** Alzheimer changes personal long-term insurance
| Personal long-term care insurance

- | 1 Bought new policy

- | 2 Decreased coverage under existing policy
- | 3 Increased coverage under existing policy
- | 4 Terminated existing policy
- | 5 Did Research but Took No Action
- | 6 No change

| **IC10_A** other changes made to insurance status

| Please tell us about any other changes you made to your insurance status?

| Memo

|
ENDIF

IF diagnosed alzheimers disease = No THEN

| **INS_NA_Intro1** what types of insurance currently holding

| Now we will ask you some questions about the types of insurance you are currently holding. Please check all that apply.

- | 1 Health insurance through employer (yours or any household member's)
- | 2 Life insurance through employer (yours or any household member's)
- | 3 Disability insurance through employer (yours or any household member's)
- | 4 Long-term care insurance through employer (yours or any household member's)
- | 5 Personal health insurance
- | 6 Personal life insurance
- | 7 Personal disability insurance
- | 8 Personal long-term care insurance
- | 9 Medicare coverage

| IF family diagnosed with Alzheimer = Yes OR Know others that had Alzheimer =Yes THEN

| |
| | [Questions IC_NA_Intro2_FF to IC8_Change_NA are displayed as a table]

| | **IC_NA_Intro2_FF** friend Alzheimer disease changes insurance

| | After you found out about your friends or family members being diagnosed with Alzheimer's disease, did you make any changes such as researching and purchasing any new or additional insurance policies for yourself? Please check all that apply.

| | **IC1_Change_NA** f Alzheimer changes health insurance through employer

| | Health insurance through employer (yours or any household member's)

- | | 1 Bought new policy
- | | 2 Decreased coverage under existing policy
- | | 3 Increased coverage under existing policy
- | | 4 Terminated existing policy
- | | 5 Did Research but Took No Action
- | | 6 No change

| | **IC2_Change_NA** f Alzheimer changes life insurance through employer

| | Life insurance through employer (yours or any household member's)

- | | 1 Bought new policy
- | | 2 Decreased coverage under existing policy
- | | 3 Increased coverage under existing policy
- | | 4 Terminated existing policy
- | | 5 Did Research but Took No Action
- | | 6 No change

||
|| **IC3_Change_NA** f Alzheimer changes disability insurance through employer
|| Disability insurance through employer (yours or any household member's)

- || 1 Bought new policy
- || 2 Decreased coverage under existing policy
- || 3 Increased coverage under existing policy
- || 4 Terminated existing policy
- || 5 Did Research but Took No Action
- || 6 No change

||
|| **IC4_Change_NA** f Alzheimer changes long-term care
|| Long-term care insurance through employer (yours or any household member's)

- || 1 Bought new policy
- || 2 Decreased coverage under existing policy
- || 3 Increased coverage under existing policy
- || 4 Terminated existing policy
- || 5 Did Research but Took No Action
- || 6 No change

||
|| **IC5_Change_NA** f Alzheimer changes personal health insurance
|| Personal health insurance

- || 1 Bought new policy
- || 2 Decreased coverage under existing policy
- || 3 Increased coverage under existing policy
- || 4 Terminated existing policy
- || 5 Did Research but Took No Action
- || 6 No change

||
|| **IC6_Change_NA** f Alzheimer changes personal life insurance
|| Personal life insurance

- || 1 Bought new policy
- || 2 Decreased coverage under existing policy
- || 3 Increased coverage under existing policy
- || 4 Terminated existing policy
- || 5 Did Research but Took No Action
- || 6 No change

||
|| **IC7_Change_NA** f Alzheimer changes personal disability insurance
|| Personal disability insurance

- || 1 Bought new policy
- || 2 Decreased coverage under existing policy
- || 3 Increased coverage under existing policy
- || 4 Terminated existing policy
- || 5 Did Research but Took No Action
- || 6 No change

||
|| **IC8_Change_NA** f Alzheimer changes personal long-term insurance
|| Personal long-term care insurance

- || 1 Bought new policy
- || 2 Decreased coverage under existing policy
- || 3 Increased coverage under existing policy
- || 4 Terminated existing policy
- || 5 Did Research but Took No Action

6 No change

IC10_NA other changes made to insurance status

Please tell us about any other changes you made to your insurance status?

Memo

[Questions IC_NA_Intro2_NFF to IC8_Change_NA are displayed as a table]

IC_NA_Intro2_NFF No friend Alzheimer disease changes insurance

Please think back to when you first heard about Alzheimers' disease. Did you make any changes such as researching and purchasing any new or additional insurance policies for yourself? Please check all that apply.

IC1_Change_NA f Alzheimer changes health insurance through employer

Health insurance through employer (yours or any household member's)

1 Bought new policy

2 Decreased coverage under existing policy

3 Increased coverage under existing policy

4 Terminated existing policy

5 Did Research but Took No Action

6 No change

IC2_Change_NA f Alzheimer changes life insurance through employer

Life insurance through employer (yours or any household member's)

1 Bought new policy

2 Decreased coverage under existing policy

3 Increased coverage under existing policy

4 Terminated existing policy

5 Did Research but Took No Action

6 No change

IC3_Change_NA f Alzheimer changes disability insurance through employer

Disability insurance through employer (yours or any household member's)

1 Bought new policy

2 Decreased coverage under existing policy

3 Increased coverage under existing policy

4 Terminated existing policy

5 Did Research but Took No Action

6 No change

IC4_Change_NA f Alzheimer changes long-term care

Long-term care insurance through employer (yours or any household member's)

1 Bought new policy

2 Decreased coverage under existing policy

3 Increased coverage under existing policy

4 Terminated existing policy

5 Did Research but Took No Action

6 No change

IC5_Change_NA f Alzheimer changes personal health insurance

Personal health insurance


```

| 1 Bought new policy
| 2 Decreased coverage under existing policy
| 3 Increased coverage under existing policy
| 4 Terminated existing policy
| 5 Did Research but Took No Action
| 6 No change
|
| IC6_Change_NA f Alzheimer changes personal life insurance
| Personal life insurance
| 1 Bought new policy
| 2 Decreased coverage under existing policy
| 3 Increased coverage under existing policy
| 4 Terminated existing policy
| 5 Did Research but Took No Action
| 6 No change
|
| IC7_Change_NA f Alzheimer changes personal disability insurance
| Personal disability insurance
| 1 Bought new policy
| 2 Decreased coverage under existing policy
| 3 Increased coverage under existing policy
| 4 Terminated existing policy
| 5 Did Research but Took No Action
| 6 No change
|
| IC8_Change_NA f Alzheimer changes personal long-term insurance
| Personal long-term care insurance
| 1 Bought new policy
| 2 Decreased coverage under existing policy
| 3 Increased coverage under existing policy
| 4 Terminated existing policy
| 5 Did Research but Took No Action
| 6 No change
|
| IC10_NA other changes made to insurance status
| Please tell us about any other changes you made to your insurance status?
| Memo
|
| ENDIF
|
ENDIF

```

IF family diagnosed with Alzheimer = No AND before or after alzheimers disease in lifetime = before
THEN

```

| BD0_Alzheimers develop alzheimers disease in lifetime
| What do you think is the percent chance that you will develop Alzheimer's disease in your
| lifetime? Please click on the scale at the point that indicates your answer.
| Range: 0.0..100.0
|
ENDIF

```

BD1_Alzheimers average lifetime chance developing Alzheimers

What do you think is the average person's lifetime percent chance of developing Alzheimer's disease?
Please click on the scale at the point that indicates your answer.
Range: 0.0..100.0

BD2_Alzheimers all same age olds in US 100 people
Now think of all the [R Age]-year olds in the United States. Out of all the people in that group,
what percentage do you think will develop Alzheimer's disease?
String

IF family diagnosed with Alzheimer = after AND before or after alzheimers disease in lifetime =
after THEN

|
| **BD0_Alzheimers** develop alzheimers disease in lifetime
| What do you think is the percent chance that you will develop Alzheimer's disease in your
| lifetime? Please click on the scale at the point that indicates your answer.
| Range: 0.0..100.0
|
ENDIF

IF R Gender = Male THEN

|
| IF diagnosed prostate cancer = No AND before or after prostate cancer in lifetime = before THEN
||
|| **BD0_Cancer_M** develop prostate cancer in lifetime
|| What do you think is the percent chance of that you will develop prostate cancer in your
|| lifetime? Please click on the scale at the point that indicates your answer.
|| Range: 0.0..100.0
||
| ENDIF

| **BD1_Cancer_M** average lifetime chance getting prostate cancer
| What do you think is the average man's lifetime percent chance of getting prostate cancer?
| Please click on the scale at the point that indicates your answer.
| Range: 0.0..100.0
|

| **BD2_Cancer_M** all same age olds in US 100 people develop prostate
| Now think of all the [R Age]-year old men in the United States . Out of all the people in that
| group, what percentage do you think will develop prostate cancer?
| String

| IF diagnosed prostate cancer = after AND before or after prostate cancer in lifetime = after THEN
||
|| **BD0_Cancer_M** develop prostate cancer in lifetime
|| What do you think is the percent chance of that you will develop prostate cancer in your
|| lifetime? Please click on the scale at the point that indicates your answer.
|| Range: 0.0..100.0
||
| ENDIF

ENDIF

IF R Gender = Female THEN

|

```

| IF diagnosed breast cancer? = No AND before or after breast cancer in lifetime = before THEN
|
| BD0_Cancer_F develop breast cancer in lifetime
| What do you think is the percent chance of that you will develop breast cancer in your lifetime?
| Please click on the scale at the point that indicates your answer.
| Range: 0.0..100.0
|
|
| ENDIF
|
| BD1_Cancer_F average lifetime chance getting breast cancer
| What do you think is the average woman's lifetime percent chance of getting breast cancer?
| Please click on the scale at the point that indicates your answer.
| Range: 0.0..100.0
|
| BD2_Cancer_F all same age olds in US 100 people develop breast
| Now think of all the [R Age]-year old women in the United States . Out of all the people in that
| group, what percentage do you think will develop breast cancer?
| String
|
| IF diagnosed breast cancer? = after AND before or after breast cancer in lifetime = after THEN
|
| BD0_Cancer_F develop breast cancer in lifetime
| What do you think is the percent chance of that you will develop breast cancer in your lifetime?
| Please click on the scale at the point that indicates your answer.
| Range: 0.0..100.0
|
|
| ENDIF
|
| ENDIF

```

PA1 Measures to prevent diseases

The following are some measures that people take to prevent diseases or improve their physical or mental health. What types of preventive health measures are you currently taking?

- 1 Diet
- 2 Exercise
- 3 Medications
- 4 Vitamins
- 5 Herbal supplements
- 6 Stress reduction
- 7 Mental activities (crossword puzzles, Sudoku, etc.)

IF R Gender = Male THEN

| **CT_Intro_M** Cancer testing Intro Male

| Suppose there is a genetic test available to the public that may tell some men if they have inherited a certain type of genetic change associated with a higher risk for prostate cancer. This genetic test could only tell you whether you possess the genetic condition associated with increased risk of developing prostate cancer. However it is important to remember that genes are only one of the factors that predict prostate cancer. Not all cases of prostate cancer would involve these genetic changes, and not all men with these genetic changes would develop prostate cancer. The test would not provide a 'yes' or 'no' answer about whether you would develop prostate cancer. Let's suppose that a fraction of the general population, say 15% of men, will be diagnosed with prostate cancer. Men who have inherited this known genetic condition, however, have an increased lifetime risk developing of prostate cancer, such that approximately 80% will be diagnosed with prostate cancer. [Show table in CT intro]

|
ENDIF

IF R Gender = Female THEN

| **CT_Intro_F** Cancer testing Intro Female

| Suppose that there is a genetic test available to the public that may tell some women if they have inherited a certain type of genetic change (changes in either one of two known genes, the BRCA1 and BRCA2 genes) associated with a higher risk for breast cancer. This genetic test could only tell you whether you possess the genetic condition associated with an increased risk of developing breast cancer. However it is important to remember that genes are only one of the factors that predict breast cancer. Not all cases of breast cancer would involve these genetic changes and not all women with these genetic changes would develop breast cancer. The test would not provide a 'yes' or 'no' answer about whether you would develop breast cancer. Let's suppose that a fraction of the general population, say 15% of women, will be diagnosed with breast cancer. Women who have inherited this known genetic condition, however, have an increased lifetime risk of developing breast cancer, such that approximately 80% will be diagnosed with breast cancer. []

|
ENDIF

IF diagnosed prostate cancer = Yes OR diagnosed breast cancer? = Yes THEN

| **CT_Intro_C** intro reliable test developed

| Suppose that a reliable test has been developed by a well-known drug company, and made available for sale to the public. Prior to your being diagnosed with cancer you are offered such a test. This test is completely safe, painless and accurate.

|
ENDIF

IF diagnosed prostate cancer = No OR diagnosed breast cancer? = No THEN

| **CT_Intro_NC** intro reliable test developed NC

| Suppose that a reliable test has been developed by a well-known drug company, and made available for sale to the public. Suppose that you are offered such a test. This test is completely safe, painless and accurate.

|
ENDIF

CT_100 test not covered willing to pay more than 100

This test is not covered by your insurance policy, flexible spending account, or any other kind of medical cost reimbursement plan you may have. Would you be willing to pay more than \$100 for the test?

- 1 Yes
- 2 No

IF test not covered willing to pay more than Yes00 = Yes THEN

| **CT_500** test not covered willing to pay more than 500
| What about \$500 - would you be willing to pay more than \$500 for the test?
| 1 Yes
| 2 No

| IF test not covered willing to pay more than 500 = Yes THEN

|| **CT_1000** test not covered willing to pay more than 1000
|| Would you be willing to pay more than \$1000 for the test?
|| 1 Yes
|| 2 No

|| IF test not covered willing to pay more than Yes000 = Yes THEN

||| **CT_1500** test not covered willing to pay more than 1500
||| How about \$1500 - would you be willing to pay \$1500 for the test?
||| 1 Yes
||| 2 No

||| IF test not covered willing to pay more than Yes500 = Yes THEN

|||| **CT_3000** test not covered willing to pay more than 3000
|||| Would you be willing to pay \$3000 or more to take the test?
|||| 1 Yes
|||| 2 No

||| ENDIF

|| ENDIF

| ENDIF

ENDIF

IF test not covered willing to pay more than 100 = No THEN

| **CT_Free** test not covered willing to take if free
| Would you be willing to take the test if it were free?
| 1 Yes
| 2 No

| IF test not covered willing to take if free = No THEN

|| [Questions CT_Free_F to CT_Free_F_other are displayed as a table]

|| **CT_Free_F** why not take test when free
|| Why would you choose not to take the genetic test for cancer? Please check all that apply.
|| 1 Concerns about emotional well-being

```

| 2 Lack of sufficient prevention options
| 3 Concerns about privacy/confidentiality/discrimination
| 4 Limitations of test information/lack of interest
| 5 Other, please write-in:
|
| CT_Free_F_Other why not take test when free other
|
| String
|
| ENDIF
|
ENDIF

```

AT_Intro intro alzheimer disease

Alzheimer's disease is a progressive brain disorder that impairs a person's ability to think and remember things, which, in turn, affects their ability to carry out daily activities. Alzheimer's disease is the most common cause of memory and language problems (sometimes referred to as 'senility' or 'dementia') among older people. As with breast and prostate cancer, many factors can raise an individual's risk of developing Alzheimer's, and one of these factors is genetic. There is a genetic test that may tell some people if they have inherited a certain form of a known gene, the apolipoprotein E (APOE) gene, which is associated with a higher risk of eventually developing Alzheimer's disease. The APOE gene comes in three forms: APOE e2, APOE e3, and APOE e4. Every person inherits two forms of the APOE gene - one form from each parent. Any person may therefore have one, two or no APOE e4 genes. People with one or two APOE e4 genes have been shown to have an increased lifetime risk of developing Alzheimer's disease. Of those aged 55 and older, 29% of people with one APOE e4 gene and 50% of people with two APOE e4 genes develop Alzheimer's disease during their lifetime, compared to 9% of people with no APOE e4 genes and 13.4% of the general population. [Show table in AT intro] This genetic test can only tell you which forms of the APOE gene you have and whether you possess the APOE e4 forms that are associated with increased risk of developing Alzheimer's disease. However it is important to remember that genes are only one of the factors that predict Alzheimer's disease. Not all cases of Alzheimer's occur in individuals with APOE e4 genes, and not all individuals with APOE e4 genes develop Alzheimer's disease. The test will not provide a 'yes' or 'no' answer about whether you will develop Alzheimer's disease.

IF family diagnosed with Alzheimer = Yes THEN

```

|
| AT_Intro1_A intro drug developen Alzheimer A
| Suppose a well-known drug company has developed this test for sale to the public, and prior to
| your being diagnosed with Alzheimer's you were offered this test. This test is completely safe,
| painless and accurate.
|
ENDIF

```

IF family diagnosed with Alzheimer = No THEN

```

|
| AT_Intro1_NA intro drug developen Alzheimer NA
| Suppose a well-known drug company has developed this test for sale to the public, and you are
| offered this test. This test is completely safe, painless and accurate.
|
ENDIF

```

AT_100 test not covered willing to pay more than 100 Alzheimer

Suppose these tests are not covered by your insurance policy, flexible spending account, or any

other kind of medical cost reimbursement plan you may have. Would you be willing to pay more than \$100 for the test?

1 Yes

2 No

IF test not covered willing to pay more than Yes00 Alzheimer = Yes THEN

|

| **AT_500** test not covered willing to pay more than 500 Alzheimer

| What about \$500 - would you be willing to pay more than \$500 for the test?

| 1 Yes

| 2 No

|

| IF test not covered willing to pay more than 500 Alzheimer = Yes THEN

||

|| **AT_1000** test not covered willing to pay more than 1000 Alzheimer

|| Would you be willing to pay more than \$1000 for the test?

|| 1 Yes

|| 2 No

||

|| IF test not covered willing to pay more than Yes000 Alzheimer = Yes THEN

|||

||| **AT_1500** test not covered willing to pay more than 1500 Alzheimer

||| How about \$1500 - would you be willing to pay \$1500 for the test?

||| 1 Yes

||| 2 No

|||

||| IF test not covered willing to pay more than Yes500 Alzheimer = Yes THEN

||||

|||| **AT_3000** test not covered willing to pay more than 3000 Alzheimer

|||| Would you be willing to pay \$3000 or more to take the test?

|||| 1 Yes

|||| 2 No

||||

||| ENDIF

|||

|| ENDIF

||

| ENDIF

|

ENDIF

IF test not covered willing to pay more than 100 Alzheimer = No THEN

|

| **AT_Free** test not covered willing to take if free Alzheimer

| Would you be willing to take the test if it were free?

| 1 Yes

| 2 No

|

| IF test not covered willing to take if free Alzheimer = No THEN

||

|| [Questions AT_Free_F to AT_Free_F_Other are displayed as a table]

||

|| **AT_Free_F** why test not covered willing to take if free Alzheimer

|| Why would you choose not to take the genetic test for Alzheimers? Please check all that apply.

|| 1 Concerns about emotional well-being

|| 2 Lack of prevention option for Alzheimer's disease

|| 3 Concerns about privacy/confidentiality/discrimination

|| 4 Limitations of test information/lack of interest

|| 5 Other, please write-in:

||

|| **AT_Free_F_Other** why test not covered willing to take if free Alzheimer other

||

|| String

||

| ENDIF

|

ENDIF

IF family diagnosed with Alzheimer = Yes THEN

|

| **AT_Intro2_A** Alzheimer intro A

| Suppose that prior to your diagnosis, you were to be tested. [Test result AT Intro] [General Alzheimer Intro fill]

|

ENDIF

IF family diagnosed with Alzheimer = No THEN

|

| **AT_Intro2_NA** Alzheimer intro NA

| Suppose that you were to be tested. [Test result AT Intro] [General Alzheimer Intro fill]

|

ENDIF

[Questions AT_Intro3 to AT8_Change are displayed as a table]

AT_Intro3 changes as result of test intro

[show results in rest of alzheimer questions on top] Now we want to ask about changes as a result of this test. After receiving this test result, what changes do you think you would have made to your insurance coverage? Please check all that apply.

AT1_Change changes as result of test health insurance through employer

Health insurance through employer (yours or any household member's)

1 Buy new policy

2 Decrease coverage under existing policy

3 Increase coverage under existing policy

4 Terminate existing policy

5 Do Research

6 No change

AT2_Change changes as result of test life insurance through employer

Life insurance through employer (yours or any household member's)

1 Buy new policy

2 Decrease coverage under existing policy

3 Increase coverage under existing policy

4 Terminate existing policy

5 Do Research

6 No change

AT3_Change changes as result of test disability insurance through employer
Disability insurance through employer (yours or any household member's)

- 1 Buy new policy
- 2 Decrease coverage under existing policy
- 3 Increase coverage under existing policy
- 4 Terminate existing policy
- 5 Do Research
- 6 No change

AT4_Change changes as result of test long term care through employer
Long-term care insurance through employer (yours or any household member's)

- 1 Buy new policy
- 2 Decrease coverage under existing policy
- 3 Increase coverage under existing policy
- 4 Terminate existing policy
- 5 Do Research
- 6 No change

AT5_Change changes as result of test personal health insurance
Personal health insurance

- 1 Buy new policy
- 2 Decrease coverage under existing policy
- 3 Increase coverage under existing policy
- 4 Terminate existing policy
- 5 Do Research
- 6 No change

AT6_Change changes as result of test personal life insurance
Personal life insurance

- 1 Buy new policy
- 2 Decrease coverage under existing policy
- 3 Increase coverage under existing policy
- 4 Terminate existing policy
- 5 Do Research
- 6 No change

AT7_Change changes as result of test disability insurance
Personal disability insurance

- 1 Buy new policy
- 2 Decrease coverage under existing policy
- 3 Increase coverage under existing policy
- 4 Terminate existing policy
- 5 Do Research
- 6 No change

AT8_Change changes as result of test personal long term care insurance
Personal long-term care insurance

- 1 Buy new policy
- 2 Decrease coverage under existing policy
- 3 Increase coverage under existing policy
- 4 Terminate existing policy

5 Do Research
6 No change

AT10_A other changes made to insurance status Alzheimer geno
[show results in rest of alzheimer questions on top] Please tell us about any other changes you think you would have made to your insurance status.
Memo

AT_PA what changes after receiving test result
[show results in rest of alzheimer questions on top] After receiving this test result, what health and wellness changes do you think you would have made? Please check all that apply.

1 Diet

2 Exercise plan

3 Medication

4 Vitamins

5 Herbal supplements

6 Stress reduction

7 Mental activities (crossword puzzles, Sudoku, etc.)

IF Diet IN what changes after receiving test result THEN
|
| **AT_PA1_Writein** changes as result of test specific diet
| What specific dietary changes would you make in addition to your current activities?
| Memo
|
ENDIF

IF Exercise plan IN what changes after receiving test result THEN
|
| **AT_PA2_Writein** changes as result of test specific exercise
| What specific exercise changes would you make in addition to your current activities?
| Memo
|
ENDIF

IF Medication IN what changes after receiving test result THEN
|
| **AT_PA3_Writein** changes as result of test specific medication
| What specific medication changes would you make in addition to your current activities?
| Memo
|
ENDIF

IF Vitamins IN what changes after receiving test result THEN

| **AT_PA4_Writein** changes as result of test specific vitamins

| What specific vitamin changes would you make in addition to your current activities?

| Memo

ENDIF

IF Herbal supplements IN what changes after receiving test result THEN

| **AT_PA5_Writein** changes as result of test specific herbal

| What specific herbal supplement changes would you make in addition to your current activities?

| Memo

ENDIF

IF Stress reduction IN what changes after receiving test result THEN

| **AT_PA6_Writein** changes as result of test specific stress

| What specific changes would you make to reduce stress?

| Memo

ENDIF

IF Mental activities (crossword puzzles, Sudoku, etc.) IN what changes after receiving test result THEN

| **AT_PA7_Writein** changes as result of test specific mental activities

| What specific changes would you make to your mental activities?

| Memo

ENDIF

[Questions AT_Intro4 to AT_IN6 are displayed as a table]

AT_Intro4 who revealed result intro

If you had received these test results, who, if anyone, do you think you would have revealed your genetic test result information to? Please check all that apply.

AT_IN1 who revealed result spouse

Spouse or immediate family

1 Yes

2 No

9 [Show do not know]

AT_IN2 who revealed result other family

Other Family

1 Yes
2 No
9 [Show do not know]

AT_IN3 who revealed result friends

Friends

1 Yes
2 No
9 [Show do not know]

AT_IN4 who revealed result healthcare provider

Healthcare provider

1 Yes
2 No
9 [Show do not know]

AT_IN5 who revealed result colleagues

Work colleagues

1 Yes
2 No
9 [Show do not know]

AT_IN6 who revealed result employer

Employer

1 Yes
2 No
9 [Show do not know]

IF who revealed result spouse = No OR who revealed result spouse = ^AT_DK THEN

|

| **AT_IN1_Table** not reveal to spouse

| You indicated that you might not reveal your test information to your spouse or immediate family.

| Why not? Please check all that apply.

| 1 Concerns about emotional well-being

| 2 Lack of prevention options for AD

| 3 Concerns about privacy/confidentiality/discrimination

| 4 Limitations of test information/lack of interest

|

ENDIF

IF who revealed result other family = No OR who revealed result other family = ^AT_DK THEN

|

| **AT_IN2_Table** not reveal to other family

| You indicated that you might not reveal your test information to your family members other than
| your spouse or immediate family. Why not? Please check all that apply.

| 1 Concerns about emotional well-being

| 2 Lack of prevention options for AD

| 3 Concerns about privacy/confidentiality/discrimination

| 4 Limitations of test information/lack of interest

|

ENDIF

IF who revealed result friends = No OR who revealed result friends = ^AT_DK THEN

|
| **AT_IN3_Table** not reveal to friends
| You indicated that you might not reveal your test information to your friends. Why not? Please
| check all that apply.
| 1 Concerns about emotional well-being
| 2 Lack of prevention options for AD
| 3 Concerns about privacy/confidentiality/discrimination
| 4 Limitations of test information/lack of interest
|
ENDIF

IF who revealed result healthcare provider = No OR who revealed result healthcare provider = ^AT_DK
THEN
|
| **AT_IN4_Table** not reveal to healthcare provider
| You indicated that you might not reveal your test information to your healthcare provider. Why
| not? Please check all that apply.
| 1 Concerns about emotional well-being
| 2 Lack of prevention options for AD
| 3 Concerns about privacy/confidentiality/discrimination
| 4 Limitations of test information/lack of interest
|
ENDIF

IF who revealed result colleagues = No OR who revealed result colleagues = ^AT_DK THEN
|
| **AT_IN5_Table** not reveal to colleagues
| You indicated that you might not reveal your test information to your work colleagues. Why not?
| Please check all that apply.
| 1 Concerns about emotional well-being
| 2 Lack of prevention options for AD
| 3 Concerns about privacy/confidentiality/discrimination
| 4 Limitations of test information/lack of interest
|
ENDIF

IF who revealed result employer = No OR who revealed result employer = ^AT_DK THEN
|
| **AT_IN6_Table** not reveal to employer
| You indicated that you might not reveal your test information to your employer. Why not? Please
| check all that apply.
| 1 Concerns about emotional well-being
| 2 Lack of prevention options for AD
| 3 Concerns about privacy/confidentiality/discrimination
| 4 Limitations of test information/lack of interest
|
ENDIF

AD_Test_2 develop alzheimers disease in lifetime no APOE e4
Suppose now you are offered the same genetic test for Alzheimer's disease. This time, you receive
the news that you do not carry any APOE e4 gene. In other words, you do not carry any gene that
would increase your lifetime risk of developing Alzheimer's disease. Given this news, what do you
think is the chance that you would develop Alzheimer's disease in your lifetime?

Range: 0.0..100.0

Bonus bonus open-ended question

We would like to know your personal thoughts and opinions about genetic testing for common diseases. In your own words, please tell us if you feel genetic testing is a positive or negative scientific development. Do you have any moral or ethical objections to testing? What are the main factors that would drive your decisions to get tested or not for a particular disease?

Memo

CS_001 HOW PLEASANT INTERVIEW

Could you tell us how interesting or uninteresting you found the questions in this interview?

- 1 Very interesting
- 2 Interesting
- 3 Neither interesting nor uninteresting
- 4 Uninteresting
- 5 Very uninteresting

CS_003 COMMENTS

Do you have any other comments on the interview? Please type these in the box below.

Memo