

## **Appendix B: Pre- and Post-surveys**

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# Pre-survey for Autistic Participants

[order\_num: 2; slide\_id: 0] type: statement

## Introduction

Thank you for volunteering to participate in this study. This first survey will take about 10 - 15 minutes. It asks for some basic information about you, and then asks some questions about your health and your experiences with healthcare.

At the end of this survey, you will be directed automatically to the next part of the study, which is the customized accommodations report.

(chapter: basic\_information: )

[order\_num: 0; slide\_id: 0] type: statement

## Basic Information

We will use your email address to communicate with you during the study. We will also use it to send you your gift card at the end of the study.

[order\_num: 1; slide\_id: 1] type: fillinblank

**What is your email address?**

[order\_num: 2; slide\_id: 2] type: birthdate

**When were you born?**

birthdate

[order\_num: 3; slide\_id: 3] type: question

**What is your sex?**

- Male
- Female
- Other, but prefer to be referred to as “he”
- Other, but prefer to be referred to as “she”
- I do not wish to say

[order\_num: 4; slide\_id: 4] type: question

**Did you finish high school?**

- Yes
- No
- I do not wish to say

[order\_num: 5; slide\_id: 5] type: question

**Did you get a regular diploma or a modified diploma?**

- Regular
- Modified
- I don't know / I do not wish to say

[order\_num: 6; slide\_id: 6] type: question

**Were you ever enrolled in college?**

- Yes
- No
- I do not wish to say

[order\_num: 7; slide\_id: 7] type: question

**Did you get a degree?**

- Yes
- No
- I do not wish to say

[order\_num: 8; slide\_id: 8] type: question

**What is the highest degree you got?**

- Associates
- Bachelors
- Masters / Graduate Certificate
- Doctorate
- Other

- I do not wish to say

[order\_num: 9; slide\_id: 9] type: question

**What type of Autism Spectrum Disorder diagnosis do you have? (If you have been given more than one diagnosis, please pick the one you got most recently.)**

- Autistic Disorder
- Asperger's Disorder
- Autism Spectrum Disorder
- Pervasive Developmental Disorder not otherwise specified
- Other

- I do not wish to say

[order\_num: 10; slide\_id: 10] type: question

**Where do you live?**

- Place I own or rent.
- With family.
- Group home / foster home.
- Other

I do not wish to say

[order\_num: 11; slide\_id: 11] type: question

**What is your race? (Check one)**

- White
- Black / African American
- Asian / Pacific Islander
- Native American / Native Alaskan
- Biracial or multi-racial
- Other

I do not wish to say

[order\_num: 12; slide\_id: 12] type: question

**Are you Latino or Hispanic?**

- Yes
- No
- I do not wish to say

[order\_num: 13; slide\_id: 13] type: question

**Do you need assistance from someone to get medical or dental care?**

- Always or often
- Sometimes
- Rarely or never
- I do not know / I do not wish to say

[order\_num: 14; slide\_id: 15] type: question

**Think about your office visits. How much help do you get from your supporters to communicate with providers?**

- I mostly communicate with providers myself.
- I mostly communicate with providers myself, but someone helps me some of the time.
- Someone besides me does most or all of the communication.
- I do not wish to say.

[order\_num: 15; slide\_id: 14] type: question

**Think about your office visits with doctors, nurses, or other healthcare professionals. Do you usually talk with the healthcare providers or do you usually communicate in other ways? For example, do you usually sign, use pictures, use an interpreter, or use a speech device to communicate with them?**

- Talk
- Something else
- N/A (For example, I don't communicate with healthcare providers at all).
- I do not wish to say

[order\_num: 16; slide\_id: 16] type: question

**In general, how would you rate your health?**

- Excellent
- Very good
- Good
- Fair

- Poor
- I do not wish to say

[order\_num: 17; slide\_id: 17] type: question

**Have you been told by a doctor or other health professional that you have a chronic physical health condition? Some examples are high blood pressure, diabetes, congestive heart failure, epilepsy or seizures, emphysema, asthma, chronic bowel problems, and chronic pain.**

- Yes
- No
- I do not wish to say

[order\_num: 18; slide\_id: 18] type: question

**Have you been told by a doctor or other health professional that you have a mental health condition (not including Autism Spectrum Disorders). Some examples are depression, anxiety, post-traumatic stress disorder (PTSD), schizophrenia, and bipolar disorder.**

- Yes
- No
- I do not wish to say

[order\_num: 19; slide\_id: 19] type: checkall

**What type(s) of health insurance do you have?**

- Private insurance (for example, Blue Cross Blue Shield, Aetna, Kaiser, Group Health)
- Medicare
- Medicaid
- Other government insurance (for example, Veterans Administration)
- I have insurance, but I'm not sure what type
- None
- Other
- 
- I do not know
- I do not wish to say

(chapter: healthcare\_use: )

[order\_num: 0; slide\_id: 0] type: statement

## Healthcare Use

The next section asks about your use of healthcare services. If you are certain that you do not know the answer to a question, answer "Do not know." Otherwise, please give your best guess from the provided answers.

[order\_num: 1; slide\_id: 1] type: checkall

**During the past 12 months, was there a time when you felt that you needed one or more following types of healthcare, but did not receive it? Check all the types of healthcare you felt you needed but did not get.**

- Medical care for a physical health problem
- Preventive healthcare (including routine physical examinations)
- Mental healthcare or counseling
- Dental care (including dental checkups)
- Prescription medicines

Eyeglasses or contact lenses

Other

None of the above

Do not wish to say

Popup for Preventive healthcare:

Preventive healthcare is healthcare that is aimed at early detection and treatment or prevention of disease. Examples of preventive healthcare may include visits where a healthcare worker performs screening tests such as pap smears, mammograms, colonoscopies; draws blood to check a cholesterol level; counsels a patient about diet, exercise, tobacco, or alcohol; or performs a routine physical examination.

[order\_num: 2; slide\_id: 2] type: question

**During the past 12 months, how many times did you go to a hospital emergency room about your own health? (This includes emergency room visits that did or did not result in a hospital admission.)**

0 times

1 time

2-3 times

4 or more times

I do not wish to say

[order\_num: 3; slide\_id: 6] type: question

**During the past 12 months, how many times did you see a doctor or other healthcare professional about your own health at a doctor's office, a clinic, or some other place?**

0 times

1 time

2-3 times

4 or more times

I do not wish to say

[order\_num: 4; slide\_id: 3] type: question

**Within the past 3 years, have you had a [pelvic exam](#) and/or [pap smear](#)?**

Yes

No

Not applicable (for example, hysterectomy)

I do not know

I do not wish to say

Popup for pap smear:

A pap smear is done as part of a pelvic exam. It looks for early signs of cervical cancer. The healthcare provider takes a sample of cells from the uterine cervix and sends them to the lab for examination.

Popup for pelvic exam:

In a pelvic exam, a speculum (an instrument for opening and widening certain passages of the body) is used to open the vagina and aid in visualizing the uterine cervix.

[order\_num: 5; slide\_id: 4] type: question

**Within the past 2 years, have you had your blood pressure checked?**

- Yes
- No
- I don't know
- I do not wish to say

[order\_num: 6; slide\_id: 5] type: question

**Within the past 10 years, have you had a [tetanus vaccine](#)?**

- Yes
- No
- I don't know
- I do not wish to say

Popup for tetanus vaccine:

A tetanus vaccine is a type of immunization that prevents you from getting tetanus. Tetanus vaccines are given as shots. Tetanus is a possibly fatal medical condition, also called lockjaw, which causes severe and long-lasting muscle contractions. Tetanus infections are usually caused by contamination of wounds.

(chapter: hcare\_satisfaction: )

[order\_num: 0; slide\_id: 0] type: statement

## Satisfaction With Healthcare

For the next set of questions, think about the last visit you had with your [primary care provider](#).

Popup for primary care provider:

Primary care providers are physicians, nurse practitioners or physician's assistants who deliver primary care services. Primary care providers evaluate and treat new medical problems, manage chronic illnesses, provide preventive healthcare, and make referrals to other specialists, as needed. Primary care providers are usually trained in family practice, internal medicine or pediatrics, but in some instances they may be trained in other specialties, such as gynecology.

[order\_num: 1; slide\_id: 1] type: question

**How strongly do you agree or disagree with the following statement? My primary care provider gave me the chance to ask all the health related questions I had.**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- I do not wish to say

[order\_num: 2; slide\_id: 2] type: question

**How strongly do you agree or disagree with the following statement? My primary care provider gave the attention I needed to my feelings and emotions.**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- I do not wish to say

[order\_num: 3; slide\_id: 3] type: question

**How strongly do you agree or disagree with the following statement? My primary care provider involved me in decisions about my healthcare as much as I wanted.**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- I do not wish to say

[order\_num: 4; slide\_id: 4] type: question

**How strongly do you agree or disagree with the following statement? My primary care provider made sure I understood the things I needed to do to take care of my health.**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- I do not wish to say

[order\_num: 5; slide\_id: 5] type: question

**How strongly do you agree or disagree with the following statement? My primary care provider helped me deal with feelings of uncertainty about my health or healthcare.**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- I do not wish to say

[order\_num: 6; slide\_id: 6] type: question

**How strongly do you agree or disagree with the following statement? My primary care provider understood what I was trying to communicate.**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- I do not wish to say

[order\_num: 7; slide\_id: 7] type: question

**How strongly do you agree or disagree with the following statement? My primary care provider communicated in a way that I could understand.**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree

- Strongly Disagree
- I do not wish to say

[order\_num: 8; slide\_id: 8] type: question

**How strongly do you agree or disagree with the following statement? I felt I could trust my primary care provider to take care of my healthcare needs.**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- I do not wish to say

[order\_num: 9; slide\_id: 9] type: question

**Overall, how would you rate the quality of healthcare you received from your primary care provider?**

- Excellent
- Good
- Fair
- Poor

(chapter: healthcare\_barriers: )

[order\_num: 0; slide\_id: 0] type: statement

## Barriers To Healthcare

The next section has a list of statements. Each statement describes a possible barrier that can sometimes prevent people from getting good healthcare.

[order\_num: 1; slide\_id: 1] type: checkall

**Which of the following barriers keep you from receiving good healthcare? (Select all that apply.)**

- I do not have a way to get to my doctor's office.
- It is too difficult to make appointments
- I have problems filling out paperwork
- I find it hard to handle the waiting room
- Sensory discomforts (for example, the lights, smells or sounds) get in the way of my healthcare
- I cannot find a healthcare provider who will accommodate my needs
- I have inadequate social, family, or caregiver support
- I don't understand the healthcare system
- Fear, anxiety, embarrassment, or frustration keeps me from getting primary care
- I have trouble following up on care (for example, going to pharmacy, taking prescribed drugs at the right time, or making a follow-up appointment)
- I have difficulty understanding how to translate medical information into concrete steps that I can take to improve my health
- When I experience pain and/or other physical symptoms, I have difficulties identifying them and reporting them to my healthcare provider
- Communication with my healthcare provider or the staff is difficult
- My providers or the staff do not include me in discussions about my health
- My behaviors are misinterpreted by my provider or the staff
- My providers or the staff do not take my communications seriously

Other

None of the above

I do not wish to say

(chapter: healthcare\_confident: )

[order\_num: 0; slide\_id: 0] type: statement

## Confidence with Health and Healthcare

The following set of questions ask about how confident you are in doing tasks related to your health and healthcare, with help from others if needed.

[order\_num: 1; slide\_id: 1] type: question

**How confident are you that you can make an appointment with your healthcare provider when needed?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 2; slide\_id: 2] type: question

**How confident are you that you can make it to a scheduled healthcare appointment?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 3; slide\_id: 3] type: question

**How confident are you that you can bring what is needed to a healthcare visit?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 4; slide\_id: 4] type: question

**How confident are you that you can feel prepared at a healthcare visit?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 5; slide\_id: 5] type: question

**How confident are you that you can get the accommodations you need for a successful healthcare visit?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 6; slide\_id: 6] type: question

**How confident are you that you can describe your symptoms or healthcare concerns to your provider?**

- Not at all confident

- A little confident
- Mostly confident
- Totally confident

[order\_num: 7; slide\_id: 7] type: question

**How confident are you that you can answer your healthcare provider's questions?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 8; slide\_id: 8] type: question

**How confident are you that you can understand what your healthcare provider tells you about your health?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 9; slide\_id: 21] type: question

**How confident are you that you can communicate effectively with your healthcare provider?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 10; slide\_id: 9] type: question

**How confident are you that you can be open with your healthcare provider about your feelings or concerns?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 11; slide\_id: 10] type: question

**How confident are you that you can handle (physically and/or emotionally) physical examinations, medical tests, or procedures?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 12; slide\_id: 11] type: question

**How confident are you that you can take part in healthcare decisions?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 13; slide\_id: 12] type: question

**How confident are you that you can make it through a healthcare visit without a melt-down, shut-down, or severe anxiety?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 14; slide\_id: 13] type: question

**How confident are you that you can take medications the way you are supposed to take them?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 15; slide\_id: 14] type: question

**How confident are you that you can do what is needed to follow-up after a visit (for example, make another appointment, get tests done, see a specialist, go to the pharmacy)?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 16; slide\_id: 15] type: question

**How confident are you that you can do what is needed to be as healthy as possible? For example, eat a healthy diet, exercise, relax, or brush your teeth.**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 17; slide\_id: 16] type: question

**How confident are you that you can do what is needed to take care of your health conditions (if you have any)?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 18; slide\_id: 17] type: question

**How confident are you that your provider will understand the role you want your supporter to play in your healthcare, if applicable?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident
- Not applicable

[order\_num: 19; slide\_id: 18] type: question

**How confident are you that you can change healthcare providers if you want to?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 20; slide\_id: 19] type: question

**How confident are you that your healthcare providers will keep your health information private or confidential?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 21; slide\_id: 20] type: question

**How confident are you that you can find reliable sources of information about your health and health conditions?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

(chapter: end: hidden from navigation; )

[order\_num: 0; slide\_id: 0] type: fillinblank

**Is there anything else you would like to tell the researchers?**

[order\_num: 1; slide\_id: 1] type: statement

Thank you for completing the first survey. When you press next, you will automatically go to the next part of the study.

The next part of the study is to create a personalized report about you and what makes healthcare go more smoothly for you. After you create the report, you will be able to look at it. With your permission, we will share the report with your healthcare provider, and ask them some questions about whether or not it is helpful to them.

[order\_num: 2; slide\_id: 2] type: next\_survey

New Slide

next\_survey

# Post-survey for Autistic Participants

[warning\_screen] #1

(chapter: introduction: )

[order\_num: 0; slide\_id: 0] type: statement

## Introduction

Thank you for your participation in this study so far. We hope that you have found some of the study materials useful.

This survey is the last part of the study. It will take about 15 minutes to complete.

This survey will ask you some questions about you and your health and healthcare experiences. This survey will also ask you what you thought about the Healthcare Toolkit.

[order\_num: 1; slide\_id: 1] type: birthdate

## When were you born?

birthdate

[order\_num: 2; slide\_id: 2] type: question

## What is your sex?

- Male
- Female
- Other
- I do not wish to say

[order\_num: 3; slide\_id: 3] type: question

## Have you seen your primary care provider since you started this study?

- Yes
- No, but I scheduled a visit to go see my primary care provider
- No, and I have not scheduled a visit
- I do not wish to say

(chapter: satisfaction\_with\_he: )

[order\_num: 0; slide\_id: 0] type: statement

## Satisfaction with Healthcare

For the next set of questions, think about the last visit you had with your [primary care provider](#).

Popup for primary care provider:

Primary care providers are physicians, nurse practitioners or physician's assistants who deliver primary care services. Primary care providers evaluate and treat new medical problems, manage chronic illnesses, provide preventive healthcare, and make referrals to other specialists, as needed. Primary care providers are usually trained in family practice, internal medicine or pediatrics, but in some instances they may be trained in other specialties, such as gynecology.

[order\_num: 1; slide\_id: 1] type: question

**How strongly do you agree or disagree with the following statement? My primary care provider gave me the chance to ask all the health related questions I had.**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- I do not wish to say

[order\_num: 2; slide\_id: 2] type: question

**How strongly do you agree or disagree with the following statement? My primary care provider gave the attention I needed to my feelings and emotions.**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- I do not wish to say

[order\_num: 3; slide\_id: 3] type: question

**How strongly do you agree or disagree with the following statement? My primary care provider involved me in decisions about my healthcare as much as I wanted.**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- I do not wish to say

[order\_num: 4; slide\_id: 4] type: question

**How strongly do you agree or disagree with the following statement? My primary care provider made sure I understood the things I needed to do to take care of my health.**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- I do not wish to say

[order\_num: 5; slide\_id: 5] type: question

**How strongly do you agree or disagree with the following statement? My primary care provider helped me deal with feelings of uncertainty about my health or healthcare.**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree

- Strongly Disagree
- I do not wish to say

[order\_num: 6; slide\_id: 6] type: question

**How strongly do you agree or disagree with the following statement? My primary care provider understood what I was trying to communicate.**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- I do not wish to say

[order\_num: 7; slide\_id: 7] type: question

**How strongly do you agree or disagree with the following statement? My primary care provider communicated in a way that I could understand.**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- I do not wish to say

[order\_num: 8; slide\_id: 8] type: question

**How strongly do you agree or disagree with the following statement? I felt I could trust my primary care provider to take care of my healthcare needs.**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- I do not wish to say

[order\_num: 9; slide\_id: 9] type: question

**Overall, how would you rate the quality of healthcare you received from your primary care provider?**

- Excellent
- Good
- Fair
- Poor

(chapter: barriers\_to\_healthca: )

[order\_num: 0; slide\_id: 0] type: checkall

**Which of the following barriers keep you from receiving good healthcare? (Select all that apply.)**

- I do not have a way to get to my doctor's office.
- It is too difficult to make appointments
- I have problems filling out paperwork
- I find it hard to handle the waiting room
- Sensory discomforts (for example, the lights, smells or sounds) get in the way of my healthcare
- I cannot find a healthcare provider who will accommodate my needs
- I have inadequate social, family, or caregiver support
- I don't understand the healthcare system
- Fear, anxiety, embarrassment, or frustration keeps me from getting primary care

- I have trouble following up on care (for example, going to pharmacy, taking prescribed drugs at the right time, or making a follow-up appointment)
- I have difficulty understanding how to translate medical information into concrete steps that I can take to improve my health
- When I experience pain and/or other physical symptoms, I have difficulties identifying them and reporting them to my healthcare provider
- Communication with my healthcare provider or the staff is difficult
- My providers or the staff do not include me in discussions about my health
- My behaviors are misinterpreted by my provider or the staff
- My providers or the staff do not take my communications seriously
- Other
- None of the above
- I do not wish to say

(chapter: confidence\_with\_heal: )

[order\_num: 0; slide\_id: 0] type: statement

### **Confidence with Health and Healthcare**

The following set of questions ask about how confident you are in doing tasks related to your health and healthcare, with help from others if needed.

[order\_num: 1; slide\_id: 1] type: question

**How confident are you that you can make an appointment with your healthcare provider when needed?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 2; slide\_id: 2] type: question

**How confident are you that you can make it to a scheduled healthcare appointment?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 3; slide\_id: 3] type: question

**How confident are you that you can bring what is needed to a healthcare visit?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 4; slide\_id: 4] type: question

**How confident are you that you can feel prepared at a healthcare visit?**

- Not at all confident
- A little confident
- Mostly confident

Totally confident

[order\_num: 5; slide\_id: 5] type: question

**How confident are you that you can get the accommodations you need for a successful healthcare visit?**

Not at all confident

A little confident

Mostly confident

Totally confident

[order\_num: 6; slide\_id: 6] type: question

**How confident are you that you can describe your symptoms or healthcare concerns to your provider?**

Not at all confident

A little confident

Mostly confident

Totally confident

[order\_num: 7; slide\_id: 7] type: question

**How confident are you that you can answer your healthcare provider's questions?**

Not at all confident

A little confident

Mostly confident

Totally confident

[order\_num: 8; slide\_id: 8] type: question

**How confident are you that you can understand what your healthcare provider tells you about your health?**

Not at all confident

A little confident

Mostly confident

Totally confident

[order\_num: 9; slide\_id: 9] type: question

**How confident are you that you can communicate effectively with your healthcare provider?**

Not at all confident

A little confident

Mostly confident

Totally confident

[order\_num: 10; slide\_id: 10] type: question

**How confident are you that you can be open with your healthcare provider about your feelings or concerns?**

Not at all confident

A little confident

Mostly confident

Totally confident

[order\_num: 11; slide\_id: 11] type: question

**How confident are you that you can handle (physically and/or emotionally) physical examinations, medical tests, or procedures?**

Not at all confident

A little confident

Mostly confident

Totally confident

[order\_num: 12; slide\_id: 12] type: question

**How confident are you that you can take part in healthcare decisions?**

Not at all confident

- A little confident
- Mostly confident
- Totally confident

[order\_num: 13; slide\_id: 13] type: question

**How confident are you that you can make it through a healthcare visit without a melt-down, shut-down, or severe anxiety?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 14; slide\_id: 14] type: question

**How confident are you that you can take medications the way you are supposed to take them?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 15; slide\_id: 15] type: question

**How confident are you that you can do what is needed to follow-up after a visit (for example, make another appointment, get tests done, see a specialist, go to the pharmacy)?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 16; slide\_id: 16] type: question

**How confident are you that you can do what is needed to be as healthy as possible? For example, eat a healthy diet, exercise, relax, or brush your teeth.**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 17; slide\_id: 17] type: question

**How confident are you that you can do what is needed to take care of your health conditions (if you have any)?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 18; slide\_id: 18] type: question

**How confident are you that your provider will understand the role you want your supporter to play in your healthcare, if applicable?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident
- Not applicable

[order\_num: 19; slide\_id: 19] type: question

**How confident are you that you can change healthcare providers if you want to?**

- Not at all confident
- A little confident

- Mostly confident
- Totally confident

[order\_num: 20; slide\_id: 20] type: question

**How confident are you that your healthcare providers will keep your health information private or confidential?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 21; slide\_id: 21] type: question

**How confident are you that you can find reliable sources of information about your health and health conditions?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

(chapter: toolkit\_evaluation: )

[order\_num: 0; slide\_id: 0] type: statement

## Toolkit Evaluation

The last questions are about what it was like to use the Healthcare Toolkit.

[order\_num: 1; slide\_id: 1] type: question

**When you used the Healthcare Toolkit, which type of device did you use most?**

- Regular computer (for example, desktop, laptop, notebook, etc.)
- Tablet (for example, iPad, Kindle Fire, Google Nexus, etc.)
- Smart phone or personal data assistant (PDA)
- Other

[order\_num: 2; slide\_id: 2] type: question

**When you used the Healthcare Toolkit, what web browser did you use most?**

- Chrome
- FireFox
- Internet Explorer version 9 or higher
- Internet Explorer version 8 or lower
- Safari
- Opera
- Other

[order\_num: 3; slide\_id: 3] type: question

**How much help, if any, did you get to use the Toolkit? (Note: it is OK if you got help. We just want to know how many people got help.)**

- None
- Someone helped me a little bit.
- Someone helped me a lot.

I do not wish to say.

[order\_num: 4; slide\_id: 4] type: checkall

**What kind of help, if any, did you get while you were using the Toolkit? (Check all that apply)**

- Someone helped me use the computer (for example, click on links).
- Someone helped me to find my way around the web site.
- Someone helped me understand what the information on the web site meant.
- Someone helped me read the information on the web site.
- Someone helped me use the Toolkit materials (for example, fill out a worksheet).
- I did not get any help using the Toolkit.
- I do not wish to say.

[order\_num: 5; slide\_id: 5] type: checkall

**How easy was it to use the Healthcare Toolkit web site (with help if needed)?**

- Very easy
- Somewhat easy
- Somewhat hard
- Very hard
- I do not wish to say

[order\_num: 6; slide\_id: 6] type: question

**How much of the information in the Healthcare Toolkit was easy to understand (with help if needed)?**

- Less than half
- About half
- Most
- All or almost all
- I do not wish to say

[order\_num: 7; slide\_id: 7] type: question

**How important is the information in the Healthcare Toolkit?**

- Not important
- Kind of important
- Very important
- I do not wish to say

[order\_num: 8; slide\_id: 8] type: question

**How useful was the information in the Healthcare Toolkit?**

- Very useful
- Somewhat useful
- Not useful
- I do not wish to say

[order\_num: 9; slide\_id: 9] type: question

**Would you recommend the Healthcare Toolkit to a friend?**

- Yes
- No
- I do not wish to say

[order\_num: 10; slide\_id: 10] type: question

**Would you recommend the Healthcare Toolkit to healthcare providers?**

- Yes
- No
- I do not wish to say

[order\_num: 11; slide\_id: 11] type: fillinblank

**What did you like best about the Healthcare Toolkit?**

[order\_num: 12; slide\_id: 12] type: fillinblank

**What did you like least about the Healthcare Toolkit?**

[order\_num: 13; slide\_id: 13] type: fillinblank

**What did you find most useful about the Healthcare Toolkit?**

[order\_num: 14; slide\_id: 14] type: fillinblank

**Do you have any suggestions for how we can improve the Healthcare Toolkit?**

[order\_num: 15; slide\_id: 15] type: fillinblank

**How did you use the Healthcare Toolkit materials or strategies when you saw your healthcare provider?**

[order\_num: 16; slide\_id: 16] type: fillinblank

**How did your visit with your healthcare provider go? Do you think what you learned from the Healthcare Toolkit made a difference in how the visit went?**

[order\_num: 17; slide\_id: 17] type: question

**Did you give permission for us to send the customized accommodations report to your healthcare provider? (Though the AASPIRE researchers know your answer, the survey program doesn't :-)**

- Yes  
 No  
 I do not wish to say

[order\_num: 18; slide\_id: 18] type: question

**Did you go over the accommodations report with your healthcare provider?**

- Yes  
 No  
 I do not wish to say

[order\_num: 19; slide\_id: 19] type: question

**What effect, if any, do you think the report had on your relationship with your healthcare provider?**

- It made things a lot worse  
 It made things a little worse  
 It didn't make a difference  
 It made things a little better  
 It made things a lot better

[order\_num: 20; slide\_id: 20] type: fillinblank

**Do you think your healthcare provider (or his or her team) will make any changes because of the accommodations report? Include anything they have promised or already done, as well as things you think they are likely to do.**

[order\_num: 21; slide\_id: 21] type: fillinblank

**Do you have any suggestions for how we can improve the accommodations report?**

[order\_num: 22; slide\_id: 23] type: question

**Is it OK for AASPIRE to contact you by email about our studies in the future?**

Yes

No

[order\_num: 23; slide\_id: 22] type: fillinblank

**Is there anything else you would like to tell the researchers?**

(chapter: end\_of\_study: )

[order\_num: 0; slide\_id: 0] type: statement

## **End of Study**

Thank you so much for participating in our research study. We hope that you found some part of it useful as well.

You will get an email asking how you would like to receive your \$30 for completing the study. If you do not get an email from us in the next two weeks, or if you have any additional comments or questions, you can

Call Angie at 503-725-9634

Email [studies@aaspire.org](mailto:studies@aaspire.org) .

Thank you again!

# Pre-survey for Supporter Participants

[order\_num: 2; slide\_id: 0] type: statement

## Introduction

Thank you for volunteering to participate in this study. This first survey will take about 10 - 15 minutes. It asks for some basic information about the person you support, and then asks some questions about his or her health and experiences with healthcare.

At the end of this survey, you will be directed automatically to the next part of the study, which is the customized accommodations report.

(chapter: sup\_pre\_support: )

[order\_num: 0; slide\_id: 0] type: statement

## Person You Support

These questions ask basic information about the person on the autistic spectrum you support.

[order\_num: 1; slide\_id: 1] type: question

**What type of Autism Spectrum Disorder diagnosis does he/she have? (If you have been given more than one diagnosis, please pick the one you got most recently.)**

- Autistic Disorder
- Asperger's Disorder
- Autism Spectrum Disorder
- Pervasive Developmental Disorder not otherwise specified
- Other

I do not wish to say

[order\_num: 2; slide\_id: 2] type: birthdate

**When was he/she born?**

birthdate

[order\_num: 3; slide\_id: 3] type: question

**What is the person's sex?**

- Male
- Female
- Other, but prefer to be referred to as "he"
- Other, but prefer to be referred to as "she"
- I do not wish to say

[order\_num: 4; slide\_id: 4] type: question

**Did he/she finish high school?**

- Yes
- No
- I do not wish to say

[order\_num: 5; slide\_id: 5] type: question

**Did he/she get a regular diploma or a modified diploma?**

- Regular
- Modified
- I don't know / I do not wish to say

[order\_num: 6; slide\_id: 6] type: question

**Was he/she ever enrolled in college?**

- Yes
- No
- I do not wish to say

[order\_num: 7; slide\_id: 7] type: question

**Did he/she get a degree?**

- Yes
- No
- I do not wish to say

[order\_num: 8; slide\_id: 8] type: question

**What is the highest degree he/she got?**

- Associates
- Bachelors
- Masters / Graduate Certificate
- Doctorate
- Other

- I do not wish to say

[order\_num: 9; slide\_id: 9] type: question

**Where does he/she live?**

- Place he/she owns or rents
- With family
- Group home / foster home
- Other

- I do not wish to say

[order\_num: 10; slide\_id: 10] type: question

**What is his/her race? (Pick one.)**

- White
- Black / African American
- Asian / Pacific Islander
- Native American / Native Alaskan
- Biracial or multi-racial
- Other

- I do not wish to say

[order\_num: 11; slide\_id: 11] type: question

**Is he/she Latino or Hispanic?**

- Yes
- No
- I do not wish to say

[order\_num: 12; slide\_id: 12] type: question

**Does he/she need assistance from someone to get medical or dental care?**

- Always or often
- Sometimes
- Rarely or never
- I do not know / I do not wish to say

[order\_num: 13; slide\_id: 14] type: question

**Think about office visits with doctors, nurses, or other healthcare professionals. Does he/she usually talk with the healthcare providers or does he/she usually communicate in other ways? For example, does he/she usually sign, use pictures, use an interpreter, or use a speech device to communicate with them?**

- Talk
- Something else
- N/A (For example, he/she doesn't communicate with healthcare providers at all)
- I do not wish to say

[order\_num: 14; slide\_id: 13] type: question

**Think about your office visits. How much help does he/she get from his/her supporters to communicate with providers?**

- He/she mostly communicates with providers him/herself
- He/she mostly communicates with providers him/herself, but someone helps him/her some of the time
- Someone else does most or all of the communication
- I do not wish to say

[order\_num: 15; slide\_id: 15] type: question

**In general, how would you rate his/her health?**

- Excellent
- Good
- Fair
- Poor

[order\_num: 16; slide\_id: 16] type: question

**Has he/she been told by a doctor or other health professional that he/she has a chronic physical health condition? Some examples are high blood pressure, diabetes, congestive heart failure, epilepsy or seizures, emphysema, asthma, chronic bowel problems, and chronic pain.**

- Yes
- No
- I do not wish to say

[order\_num: 17; slide\_id: 17] type: question

**Has he/she been told by a doctor or other health professional that he/she has a mental health condition (not including Autism Spectrum Disorders). Some examples are depression, anxiety, or post-traumatic stress disorder (PTSD), schizophrenia, and bipolar disorder.**

- Yes
- No
- I do not wish to say

[order\_num: 18; slide\_id: 18] type: checkall

**What type(s) of health insurance does he/she have?**

- Private insurance (for example, Blue Cross Blue Shield, Aetna, Kaiser, Group Health)
- Medicare
- Medicaid
- Other government insurance (for example, Veterans Administration)
- He/she has insurance, but I am not sure what type
- None
- Other

- I do not know
- I do not wish to say.

(chapter: sup\_pre\_huse: )

[order\_num: 0; slide\_id: 0] type: statement

### Healthcare Use

The next section asks about the person's use of healthcare services. If you are certain that you do not know the answer to a question, answer "Do not know." Otherwise, please give your best guess from the provided answers.

[order\_num: 1; slide\_id: 1] type: checkall

**During the past 12 months, was there a time when he/she needed one or more following types of healthcare, but did not receive it? Check all the types of healthcare he/she needed but did not get.**

- Medical care for a physical health problem
- Preventive healthcare (including routine physical examinations)
- Mental healthcare or counseling
- Dental care (including dental checkups)
- Prescription medicines
- Eyeglasses or contact lenses
- Other

- None of the above
- Do not wish to say

Popup for Preventive healthcare:

Preventive healthcare is healthcare that is aimed at early detection and treatment or prevention of disease. Examples of preventive healthcare may include visits where a healthcare worker performs screening tests

such as pap smears, mammograms, colonoscopies; draws blood to check a cholesterol level; counsels a patient about diet, exercise, tobacco, or alcohol; or performs a routine physical examination.

[order\_num: 2; slide\_id: 2] type: question

**During the past 12 months, how many times did he/she go to a hospital emergency room about his/her own health? (This includes emergency room visits that did or did not result in a hospital admission.)**

- 0 times
- 1 time
- 2-3 times
- 4 or more times
- I do not wish to say

[order\_num: 3; slide\_id: 3] type: question

**During the past 12 months, how many times did he/she see a doctor or other healthcare professional about his/her own health at a doctor's office, a clinic, or some other place?**

- 0 times
- 1 time
- 2-3 times
- 4 or more times
- I do not wish to say

[order\_num: 4; slide\_id: 4] type: question

**Within the past 3 years, has she had a [pelvic exam](#) and/or [pap smear](#)?**

- Yes
- No
- Not applicable (for example, hysterectomy)
- I do not know
- I do not wish to say

Popup for pap smear:

A pap smear is done as part of a pelvic exam. It looks for early signs of cervical cancer. The healthcare provider takes a sample of cells from the uterine cervix and sends them to the lab for examination.

Popup for pelvic exam:

In a pelvic exam, a speculum (an instrument for opening and widening certain passages of the body) is used to open the vagina and aid in visualizing the uterine cervix.

[order\_num: 5; slide\_id: 5] type: question

**Within the past 2 years, has he/she had his/her blood pressure checked?**

- Yes
- No
- I don't know
- I do not wish to say

[order\_num: 6; slide\_id: 6] type: question

**Within the past 10 years, has he/she had a [tetanus vaccine](#)?**

- Yes
- No
- I don't know
- I do not wish to say

Popup for tetanus vaccine:

A tetanus vaccine is a type of immunization that prevents you from getting tetanus. Tetanus vaccines are given as shots. Tetanus is a possibly fatal medical condition, also called lockjaw, which causes severe and long-lasting muscle contractions. Tetanus infections are usually caused by contamination of wounds.

(chapter: sup\_pre\_hbarriers: )

[order\_num: 0; slide\_id: 0] type: statement

## Barriers to Healthcare

The next section has a list of statements. Each statement describes a possible barrier that can sometimes prevent people from getting good healthcare.

[order\_num: 1; slide\_id: 1] type: checkall

**Which of the following barriers keep the person you support from receiving good healthcare? (Select all that apply)**

- He/she does not have a way to get to the doctor's office.
- It is too difficult to make appointments for him/her
- I have problems filling out paperwork
- He/she finds it hard to handle the waiting room
- Sensory discomforts (for example, the lights, smells or sounds) get in the way of his/her healthcare
- We cannot find a healthcare provider who will accommodate his/her needs
- He/she has inadequate social, family, or caregiver support
- I don't understand the healthcare system well enough to support him/her
- Fear, anxiety, embarrassment, or frustration keeps him/her from getting primary care
- We have trouble following up on care (for example, going to pharmacy, taking prescribed drugs at the right time, or making a follow-up appointment)
- When he/she experiences pain and/or other physical symptoms, he/she has difficulties identifying them and reporting them to the health care provider
- He/she has difficulty communicating with the doctors or the staff
- Communication with his/her healthcare providers or the staff is difficult
- The healthcare providers or the staff do not include him/her in discussions about his/her health
- The healthcare providers or the staff do not include me in discussions about his/her health
- His/her behaviors are misinterpreted by the provider or the staff
- The providers or the staff do not take his/her communications seriously
- His/her providers or the staff do not take my communications seriously
- Other
- None of the above
- I do not wish to say

(chapter: sup\_pre\_confidence: )

[order\_num: 0; slide\_id: 0] type: statement

## Confidence with Health and Healthcare

The following set of questions ask about how confident you are with tasks related to the health and healthcare of the person you support.

[order\_num: 1; slide\_id: 1] type: question

**How confident are you that you can make an appointment for the person you support with his/her healthcare provider when needed?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 2; slide\_id: 2] type: question

**How confident are you that he/she can make it to a scheduled healthcare appointment?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 3; slide\_id: 3] type: question

**How confident are you that you can bring what is needed to a healthcare visit?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 4; slide\_id: 4] type: question

**How confident are you that you and the person you support can feel prepared at a healthcare visit?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 5; slide\_id: 5] type: question

**How confident are you that you can get the accommodations he/she needs for a successful healthcare visit?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 6; slide\_id: 6] type: question

**How confident are you that you or the person you support can describe his/her symptoms or healthcare concerns to the provider?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 7; slide\_id: 7] type: question

**How confident are you that you or the person you support can answer the healthcare provider's questions?**

- Not at all confident
- A little confident
- Mostly confident

Totally confident

[order\_num: 8; slide\_id: 8] type: question

**How confident are you that you or the person you support can understand what the healthcare provider says about his/her health?**

Not at all confident

A little confident

Mostly confident

Totally confident

[order\_num: 9; slide\_id: 9] type: question

**How confident are you that you and the person you support can communicate effectively with the healthcare provider?**

Not at all confident

A little confident

Mostly confident

Totally confident

[order\_num: 10; slide\_id: 10] type: question

**How confident are you that you or the person you support can be open with his/her healthcare provider about your feelings or concerns?**

Not at all confident

A little confident

Mostly confident

Totally confident

[order\_num: 11; slide\_id: 11] type: question

**How confident are you that the person you support can handle (physically and/or emotionally) physical examinations, medical tests, or procedures?**

Not at all confident

A little confident

Mostly confident

Totally confident

[order\_num: 12; slide\_id: 12] type: question

**How confident are you that the person you support is being included in healthcare decisions as much as possible?**

Not at all confident

A little confident

Mostly confident

Totally confident

[order\_num: 13; slide\_id: 13] type: question

**How confident are you that you can take part in his/her healthcare decisions?**

Not at all confident

A little confident

Mostly confident

Totally confident

[order\_num: 14; slide\_id: 14] type: question

**How confident are you that he/she can make it through a healthcare visit without a melt-down, shut-down, or severe anxiety?**

Not at all confident

A little confident

Mostly confident

Totally confident

[order\_num: 15; slide\_id: 15] type: question

**How confident are you that he/she can take medications the way they are prescribed?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 16; slide\_id: 16] type: question

**How confident are you that you or the person you support can do what is needed to follow-up after a visit (for example, make another appointment, get tests done, see a specialist, go to the pharmacy)?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 17; slide\_id: 17] type: question

**How confident are you that he/she can do what is needed to be as healthy as possible? For example, eat a healthy diet, exercise, relax, or brush his/her teeth.**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 18; slide\_id: 22] type: question

**How confident are you that you or the person you support can do what is needed to take care of his/her health conditions (if he/she has any)?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 19; slide\_id: 18] type: question

**How confident are you that the provider will understand the role you play in the healthcare of the person you support?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 20; slide\_id: 19] type: question

**How confident are you that the person you support can change healthcare providers if wanted?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 21; slide\_id: 20] type: question

**How confident are you that healthcare providers will keep health information private or confidential?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 22; slide\_id: 21] type: question

**How confident are you that you or the person you support can find reliable sources of information about his/her health and health conditions?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

(chapter: sup\_pre\_yourinfo: )

[order\_num: 0; slide\_id: 0] type: statement

### Your Information

The next questions are basic information about you, not about the person you support.

We will use your email address to communicate with you during the study. We will also use it to send you your gift card at the end of the study.

[order\_num: 1; slide\_id: 1] type: fillinblank

### What is your email address?

[order\_num: 2; slide\_id: 2] type: checkall

### Which of the following describe your relationship to the persons you support in healthcare settings?

(Check all that apply.)

- Family member
- Foster parent
- Direct support provider
- Friend
- Other

[order\_num: 3; slide\_id: 3] type: birthdate

### When were you born?

birthdate

[order\_num: 4; slide\_id: 5] type: question

### What is your sex?

- Male
- Female
- Other
- I do not wish to say

[order\_num: 5; slide\_id: 6] type: question

### What is the furthest you got in school?

- Less than high school
- High School Diploma or equivalent
- Associates
- Bachelors
- Masters / Graduate Certificate
- Doctorate
- Other

I do not wish to say

[order\_num: 6; slide\_id: 7] type: question

**What is your race? (Pick One.)**

White

Black / African American

Asian / Pacific Islander

Native American / Native Alaskan

Biracial or multi-racial

Other

I do not wish to say

[order\_num: 7; slide\_id: 8] type: question

**Are you Latino or Hispanic?**

Yes

No

I do not wish to say

[order\_num: 8; slide\_id: 9] type: fillinblank

**Is there anything else you would like to tell the researchers?**

(chapter: sup\_pre\_end: no chapter navigation; hidden from navigation; )

[order\_num: 0; slide\_id: 0] type: next\_survey

## **End of First Survey**

Thank you for completing the first survey. When you press next, you will automatically go to the next part of the study

The next part of the study is to create a personalized report about the person you support and what makes healthcare go more smoothly for him or her. After you create the report, you will be able to look at it. With your permission, we will share the report with the person's healthcare provider, and ask them some questions about whether or not it is helpful to them.

next\_survey

# Post-survey for Supporter Participants

[warning\_screen] #1

(chapter: introduction: )

[order\_num: 0; slide\_id: 0] type: statement

## Introduction

Thank you for your participation in this study so far. We hope that you have found some of the study materials useful.

This survey is the last part of the study. It will take about 15 minutes to complete.

This survey will ask you some questions about you, the person you support, and his or her health and healthcare experiences. This survey will also ask you what you thought about the Healthcare Toolkit.

[order\_num: 1; slide\_id: 1] type: birthdate

## When were you born?

birthdate

[order\_num: 2; slide\_id: 2] type: question

## What is your sex?

- Male
- Female
- Other, but prefer to be referred to as “he”
- Other, but prefer to be referred to as “she”
- I do not wish to say

[order\_num: 3; slide\_id: 3] type: question

## Has the person you support seen his/her primary care provider since you started this study?

- Yes
- No, but a visit has been scheduled
- No, and a visit has not been scheduled
- I do not wish to say

(chapter: barriers\_healthcare: )

[order\_num: 0; slide\_id: 0] type: statement

## Barriers to Healthcare

The next section has a list of statements. Each statement describes a possible barrier that can sometimes prevent people from getting good healthcare.

[order\_num: 1; slide\_id: 1] type: checkall

**Which of the following barriers keep the person you support from receiving good healthcare? (Select all that apply)**

- He/she does not have a way to get to the doctor's office.
- It is too difficult to make appointments for him/her
- I have problems filling out paperwork
- He/she finds it hard to handle the waiting room
- Sensory discomforts (for example, the lights, smells or sounds) get in the way of his/her healthcare
- We cannot find a healthcare provider who will accommodate his/her needs
- He/she has inadequate social, family, or caregiver support
- I don't understand the healthcare system well enough to support him/her
- Fear, anxiety, embarrassment, or frustration keeps him/her from getting primary care
- We have trouble following up on care (for example, going to pharmacy, taking prescribed drugs at the right time, or making a follow-up appointment)
- When he/she experiences pain and/or other physical symptoms, he/she has difficulties identifying them and reporting them to the health care provider
- He/she has difficulty communicating with the doctors or the staff
- Communication with his/her healthcare providers or the staff is difficult
- The healthcare providers or the staff do not include him/her in discussions about his/her health
- The healthcare providers or the staff do not include me in discussions about his/her health
- His/her behaviors are misinterpreted by the provider or the staff
- The providers or the staff do not take his/her communications seriously
- His/her providers or the staff do not take my communications seriously
- Other
- None of the above
- I do not wish to say

(chapter: confidence\_health: )

[order\_num: 0; slide\_id: 0] type: statement

### **Confidence with Health and Healthcare**

The following set of questions ask about how confident you are with tasks related to the health and healthcare of the person you support.

[order\_num: 1; slide\_id: 1] type: question

**How confident are you that you can make an appointment for the person you support with his/her healthcare provider when needed?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 2; slide\_id: 2] type: question

**How confident are you that he/she can make it to a scheduled healthcare appointment?**

- Not at all confident
- A little confident

- Mostly confident
- Totally confident

[order\_num: 3; slide\_id: 3] type: question

**How confident are you that you can bring what is needed to a healthcare visit?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 4; slide\_id: 4] type: question

**How confident are you that you and the person you support can feel prepared at a healthcare visit?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 5; slide\_id: 5] type: question

**How confident are you that you can get the accommodations he/she needs for a successful healthcare visit?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 6; slide\_id: 6] type: question

**How confident are you that you or the person you support can describe his/her symptoms or healthcare concerns to the provider?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 7; slide\_id: 7] type: question

**How confident are you that you or the person you support can answer the healthcare provider's questions?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 8; slide\_id: 8] type: question

**How confident are you that you and the person you support can communicate openly with the provider about his/her health concerns?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 9; slide\_id: 9] type: question

**How confident are you that the person you support can handle physical examinations, medical tests, or procedures?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 10; slide\_id: 10] type: question

**How confident are you that you or the person you support can understand what the healthcare provider says about his/her health?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 11; slide\_id: 11] type: question

**How confident are you that the person you support is being included in healthcare decisions as much as possible?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 12; slide\_id: 12] type: question

**How confident are you that you can take part in his/her healthcare decisions?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 13; slide\_id: 13] type: question

**How confident are you that he/she can make it through a healthcare visit without a melt-down, shut-down, or severe anxiety?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 14; slide\_id: 14] type: question

**How confident are you that he/she can take medications the way they are prescribed?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 15; slide\_id: 15] type: question

**How confident are you that you or the person you support can do what is needed to follow-up after a visit (for example, make another appointment, get tests done, see a specialist)?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 16; slide\_id: 16] type: question

**How confident are you that he/she can do what is needed to be as healthy as possible? For example, eat a healthy diet, exercise, relax, or brush his/her teeth.**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 17; slide\_id: 17] type: question

**How confident are you that you or the person you support can do what is needed to take care of**

**his/her health conditions (if he/she has any)?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 18; slide\_id: 18] type: question

**How confident are you that the provider will understand the role you play in the healthcare of the person you support?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 19; slide\_id: 19] type: question

**How confident are you that the person you support can change healthcare providers if wanted?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 20; slide\_id: 20] type: question

**How confident are you that healthcare providers will keep health information private or confidential?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

[order\_num: 21; slide\_id: 21] type: question

**How confident are you that you or the person you support can get reliable information about his/her health and health conditions?**

- Not at all confident
- A little confident
- Mostly confident
- Totally confident

(chapter: toolkit\_evaluation: )

[order\_num: 0; slide\_id: 0] type: statement

## **Toolkit Evaluation**

The last questions are about what it was like to use the Healthcare Toolkit.

[order\_num: 1; slide\_id: 1] type: question

**When you used the Healthcare Toolkit, which type of device did you use most?**

- Regular computer (for example, desktop, laptop, notebook, etc.)
- Tablet (for example, iPad, Kindle Fire, Google Nexus, etc.)
- Smart phone or personal data assistant (PDA)
- Other

[order\_num: 2; slide\_id: 2] type: question

**When you used the Healthcare Toolkit, what web browser did you use most?**

- Chrome
- FireFox
- Internet Explorer version 9 or higher
- Internet Explorer version 8 or lower
- Safari
- Opera
- Other

[order\_num: 3; slide\_id: 3] type: question

**How easy was it to use the Healthcare Toolkit web site?**

- Very easy
- Somewhat easy
- Somewhat hard
- Very hard
- I do not wish to say

[order\_num: 4; slide\_id: 4] type: question

**How much of the information in the Healthcare Toolkit was easy to understand?**

- Less than half
- About half
- Most
- All or almost all
- I do not wish to say

[order\_num: 5; slide\_id: 5] type: question

**How important is the information in the Healthcare Toolkit?**

- Not important
- Kind of important
- Very important
- I do not wish to say

[order\_num: 6; slide\_id: 6] type: question

**How useful was the information in the Healthcare Toolkit?**

- Very useful
- Somewhat useful
- Not useful
- I do not wish to say

[order\_num: 7; slide\_id: 7] type: question

**Would you recommend the Healthcare Toolkit to a friend?**

- Yes
- No
- I do not wish to say

[order\_num: 8; slide\_id: 8] type: question

**Would you recommend the Healthcare Toolkit to healthcare providers?**

- Yes
- No
- I do not wish to say

[order\_num: 9; slide\_id: 9] type: fillinblank

**What did you like best about the Healthcare Toolkit?**

[order\_num: 10; slide\_id: 10] type: fillinblank

**What did you like least about the Healthcare Toolkit?**

[order\_num: 11; slide\_id: 11] type: fillinblank

**What did you find most useful about the Healthcare Toolkit?**

[order\_num: 12; slide\_id: 12] type: fillinblank

**Do you have any suggestions for how we can improve the Healthcare Toolkit?**

[order\_num: 13; slide\_id: 13] type: fillinblank

**How did you use the Healthcare Toolkit materials or strategies when the person you support saw his/her healthcare provider?**

[order\_num: 14; slide\_id: 14] type: fillinblank

**How did the visit with the healthcare provider go? Do you think what you learned from the Healthcare Toolkit made a difference in how the visit went?**

[order\_num: 15; slide\_id: 15] type: question

**Did you give permission for us to send the customized accommodations report to the person's healthcare provider? (Though the AASPIRE researchers know your answer, the survey program doesn't :-)**

- Yes
- No
- I do not wish to say

[order\_num: 16; slide\_id: 16] type: question

**Did you go over the accommodations report with the healthcare provider?**

- Yes
- No
- I do not wish to say

[order\_num: 17; slide\_id: 17] type: question

**What effect, if any, do you think the report had on the relationship you and the person you support have with the healthcare provider?**

- It made things a lot worse
- It made things a little worse
- It didn't make a difference
- It made things a little better
- It made things a lot better

[order\_num: 18; slide\_id: 18] type: fillinblank

**Do you think the person's healthcare provider (or the provider's team) will make any changes because of the accommodations report? Include anything they have promised or already done, as well as things**

**you think they are likely to do.**

[order\_num: 19; slide\_id: 19] type: fillinblank

**Do you have any suggestions for how we can improve the accommodations report?**

[order\_num: 20; slide\_id: 20] type: question

**Is it OK for AASPIRE to contact you by email about our studies in the future?**

Yes

No

[order\_num: 21; slide\_id: 21] type: fillinblank

**Is there anything else you would like to tell the researchers?**

(chapter: end\_of\_study: )

[order\_num: 0; slide\_id: 0] type: statement

## **End of Study**

Thank you so much for participating in our research study. We hope that you found some part of it useful as well.

You will get an email asking you how you would like to receive your \$30 for completing the study. If you do not get an email from us in the next two weeks, or if you have any additional comments or questions, you can

Call Angie at 503-725-9634  
Email [studies@aaspire.org](mailto:studies@aaspire.org) .

Thank you again!