

Appendix G. PCP Survey

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Please answer each question by marking the circle to the left of your answer. Please answer the questions as they pertain to [ds_firstname] [ds_lastname].

Are you the primary care provider for [ds_firstname] [ds_lastname]?

- Yes
 No

About how long you have been the primary care provider for [ds_firstname]?

- Less than 6 months
 At least 6 months but less than 1 year
 At least 1 year but less than 3 years
 At least 3 years but less than 5 years
 5 years or more

Did you recently see [ds_firstname] [ds_lastname] for a wellness visit?

- Yes
 No

Oops! We must have the wrong provider. We would be grateful if you could e-mail us at dsc2u@mgh.harvard.edu letting us know if there was another provider in your practice who recently saw [ds_firstname] [ds_lastname].

And, you can STOP completing this survey at this time.

In general, how well do you know [ds_firstname]'s health and medical history?

- Very well
 Somewhat well
 Not very well
 Not at all

In general, how well do you know [ds_firstname]'s psychosocial history?

- Very well
 Somewhat well
 Not very well
 Not at all

In general, how would you rate the quality of your communication with [ds_firstname]'s caregiver?

- Excellent
 Very Good
 Good
 Fair
 Poor

Most Recent Wellness Visit

How much time did you spend with [ds_firstname] at the most recent wellness visit?

- 15 minutes or less
- 16-30 minutes
- 31-45 minutes
- more than 45 minutes

During the most recent wellness visit...

	Yes, definitely	Yes, somewhat	No
Were you able to spend enough time with [ds_firstname]?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Was the caregiver able to provide the information you needed to assess the patient's history and create a care plan?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did the caregiver talk to you about any concerns he/she had about [ds_firstname]'s health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

For each of the following, in the region where you practice, how difficult is it for you to order and obtain results of these tests for patients of a similar age as [ds_firstname]?

	Very difficult	Somewhat difficult	Not very difficult	Not at all difficult
EEG	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain MRI	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thyroid test (TSH and free T4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Celiac disease screen (bloodwork)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Audiogram	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cholesterol screening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Echocardiogram	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Blood test for anemia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleep study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

For each of the following, in the region where you practice, how difficult is it for you to schedule referrals in a timely way for patients of a similar age as [ds_firstname] ?

	Very difficult	Somewhat difficult	Not very difficult	Not at all difficult
Ophthalmology examination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nutrition consultation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neuropsychological assessment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Orthopedic consultation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In order to answer the questions of this survey, did you refer to the [ds_firstname]'s chart?

- Yes
 No

Primary Care Provider Plan

As previously indicated, [ds_firstname] is enrolled in a study about primary care wellness visits for people with Down syndrome. [ds_firstname] should have brought to the recent visit with you a checklist of medical information called the "Primary Care Provider Plan." These questions are about that Primary Care Provider Plan.

Did [ds_firstname]'s caregiver give you a copy of the PRIMARY CARE PLAN before and/or during the wellness visit?

- Yes, before the visit
- Yes, at the visit
- Yes, both before and at the visit
- No

Please answer each question about the PRIMARY CARE PLAN.

	Yes, definitely	Yes, somewhat	No
Did you discuss this PRIMARY CARE PLAN or any of its recommendations with the caregivers?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Were you interested in any of the information in this PRIMARY CARE PLAN?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you agree with the recommendations in the PRIMARY CARE PLAN?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Using any number from 0 to 10, where 0 is the LEAST HELPFUL information and 10 is the MOST HELPFUL information, what number would you use to rate the information in the Plan?

- 0 Least helpful information
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 Most helpful information

Please describe how you felt about getting the PRIMARY CARE PLAN from [ds_firstname]'s caregiver.

About You and Your Practice

Approximately how many patients are in your active panel of patients?

Approximately how many patients with Down syndrome are in your active panel of patients?

How many primary care providers work in your practice?

- < 5 physicians
 5-9 physicians
 10+ physicians

Are you a

- Physician
 Nurse Practitioner or other Advanced Practice RN
 Physician Assistant

Which is your primary specialty?

- Pediatrics
 Medicine Pediatrics
 Family Practice
 General Internal Medicine
 Adolescent Medicine
 Other

What is your speciality?

How many years have you been practicing as a healthcare provider? (If < 1 year, ENTER "00")

What is your gender identity?

- Man
 Woman
 Transgender man
 Transgender woman
 Genderqueer or gender non-conforming
 Other

If Other, please identify.

Are you of Hispanic or Latino origin or descent?

- Yes
 No

What is your race?

- White or Caucasian
 Black or African American
 Asian
 Native American or American Indian
 Hawaiian or Pacific Islander
 More than one race

Would you describe the location of the practice in which you work as

- Urban
 Suburban
 Rural
 Frontier

Are you practicing in a federally qualified community health center (FQCHC)?

- Yes
 No

Thank you for taking the time to complete this survey. Please submit your survey now.

Consumer Assessment of Healthcare Providers and Systems (CAHPS) program" is a program of the U.S. Agency for Healthcare Research and Quality.