

Appendix H. Supplementary Materials



**Down Syndrome Clinic to You (DSC2U):
A National Randomized Control Trial of a Novel Online Platform that Generates Customized
Health Recommendations for Patients with Down Syndrome**

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Table of Contents

- S1: Determination of eligibility
 - Figure S1. The idealized enrollment table
- S2: Guideline Recommendations
- S3: Development of DSC2U Intervention
 - Figure S2a. Screenshot of MGH DSP online questionnaire
 - Figure S2b. Screenshot of clinical narratives automatically generated from online intake form
 - Figure S3. Example of an Excel definition of the Functional Assessment section
 - Figure S4. Caregiver Checklist snapshot Figure S5. Primary Care Provider (PCP) Plan
- S4: Baseline Assessment
- S5: PedsQL Scoring
- S6: Time Frame and Conduct of the Trial
 - Figure S6. Study procedure for two-arm randomized control trial of DSC2U
 - Figure S7. Survey implementation at various time points
- S7: Indications for the Primary Outcomes
- S8: Sample Size Calculations and Power
 - Figure S8. Sample size requirements for a range of effect sizes and drop-out rates.
- S9: Analytical and Statistical Approaches
- S10: Table S1. Baseline characteristics of people with Down syndrome and caregivers (additional variables)
- S11: Table S2. Characteristics of PCPs (additional variables)
- S12: Additional primary outcome analyses
 - Table S3a. Primary outcome: indication and completion of individual evaluations (missing evaluations excluded)

 - Table S3b. Primary outcome: indication and completion of total evaluations (missing evaluations excluded)

 - Table S3c. Primary outcome: completion of indicated evaluations (missing evaluations excluded)
- S13: Subgroups Analyses
 - Table S4a. Subgroup analysis of primary outcome: caregivers who shared Primary Care Plan with PCP before or during wellness visit versus those who did not

 - Table S4b. Subgroup analysis of primary outcome: caregivers who shared Primary Care Plan with PCP before or during wellness visit versus those who did not (differences within groups)

 - Table S5a. Subgroup analysis of primary outcome: participants who completed the 2-week and 7-month surveys versus those who did not

 - Table S5b. Subgroup analysis of primary outcome: participants who completed the 2-week and 7-month surveys versus those who did not (differences within groups)

 - Table S6a. Subgroup analysis of primary outcome: difference between non-Hispanic whites and other racial/ethnic groups

 - Table S6b. Subgroup analysis of primary outcome: difference between non-Hispanic whites and other racial/ethnic groups (differences within groups)

 - Table S7a. Subgroup analysis of primary outcome: difference between adults with DS (>18 years) and children with DS (<18 years)

 - Table S7b. Subgroup analysis of primary outcome: difference between adults with DS (>18 years)

and children with DS (<18 years) (differences within groups)

Table S8a. Subgroup analysis of primary outcome: difference between people with DS who have private insurance versus others

Table S8b. Subgroup analysis of primary outcome: difference between people with DS who have private insurance versus others (differences within groups)

S14: Table S9. Regression analysis - spearman rank correlations

S15: Table S10. Change from baseline on quality of life measures (Mean+SE [95% CI])

S16: Caregiver Checklist – uploaded as a separate file

S17: Primary Care Provider Plan - uploaded as a separate file

S18: Health care outcome survey - uploaded as a separate file

S19: The experience survey for caregivers - uploaded as a separate file

S20: The experience survey for PCPs - uploaded as a separate file

S21: Baseline Assessment – uploaded as a separate file

S1: Determination of eligibility

Potential eligible participants were directed to our study website (www.dsc2u.org) for the eligibility screening questionnaire in English and Spanish and online consent. After selecting a language preference (English or Spanish), in addition to questions about the child's or dependent's biological sex, race and ethnicity, the eligibility screening questions included:

1. Do you have a child or dependent with DS?
2. Is your child or dependent 1 year or older?
3. When is your child's next annual well visit ("PCP visit")?
4. Does your child or dependent currently receive care at a DS specialty clinic? (If the child or dependent was actively followed in a DS specialty clinic, even one out of state. For example, a family from Arizona who travels to Texas each year for their child to be seen in a DS specialty clinic would be ineligible)

To be eligible, the caregiver needed to respond "Yes" to questions #1, #2, and "No" to question #4, and the child or dependent needed to fall within our enrollment quotas. Because the primary outcomes applied to all persons with DS beginning at the age of 1, eligibility was limited to those caregivers whose child or dependent with DS was 1 year of age or older. Because of the study timeline (Figure S7), the PCP visit needed to be scheduled no later than 11 months before the end of the grant period. The caregiver must also have provided a valid e-mail address. We allowed only one patient's caregiver for each participating PCP because multiple patients seen by the same PCP would not have been independent events. In these cases, we offered eligibility on a first-come-first-serve basis. If the caregiver was considered eligible, he or she was then automatically taken to a web page to view our consent form.

DS occurs naturally and proportionally in all races and ethnicities, so our population estimates were proportional to the racial/ethnic distribution of the U.S. population, as reported in the 2010 U.S. Census. To achieve commensurate representation in our study, we applied a quota system in offering enrollment using the race and ethnicity of the individual with DS (not the caregiver). Based on an idealized Enrollment Table (Figure S1), our plan was to enroll participants such that there were: no more than 144 white individuals with DS, no fewer than 25 Hispanic or Latino/Latina individuals with DS, and no fewer than 20 black individuals with DS. We also planned to enroll no more than 120 individuals with DS of one sex. These quotas proved to be important. We could have completed study enrollment in a few weeks without these quotas, but virtually all individuals with DS would have been white and non-Hispanic. National data still show some digital divide by race and ethnicity in access to the Internet and health information; setting enrollment targets allowed time to try to overcome these barriers.

Figure S1. The idealized enrollment table

Recruitment Plan

Total number of study participants expected to be screened:	1500
Total number of study participants expected to be eligible of those screened:	300
Target sample size (use same number stated in milestones):	200

Estimated Final Racial/Ethnic and Gender Enrollment Table

Race	Male (N)	Female (N)	Total (N)
American Indian/Alaska Native	1	1	2
Asian	5	5	10
Black/African-American	13	13	26
Hawaiian/Pacific Islander	1	0	1
White	73	71	144
Multirace	3	3	6
Other race	6	5	11
Ethnicity	Male (N)	Female (N)	Total (N)
Hispanic (Latino/Latina)	16	16	32
Non-Hispanic	83	85	168

S2: Guideline Recommendations

Specifically, the guidelines for the 5 primary outcomes of interest are:

- *Celiac screen*: if symptoms present, obtain tTG-IgA and total IgA annually
- *Sleep study*: performed by 4 years of age and, again, if symptomatic
- *Thyroid test*: TSH should be checked annually beginning at age 1
- *Audiogram*: annually up to age 21, every 2 years thereafter.
- *Ophthalmology examination*: annually, ages 1-5; every 2 years, ages 5-13; every 3 years, ages 13-21; every 2 years, ages 21 and older

S3: Development and Description of DSC2U Intervention

The intervention, DSC2U, is a web-based application for families to get up-to-date, personalized health and wellness information for their loved one with DS. When caregivers access DSC2U online, they are presented with an intake questionnaire in which they are asked to identify current symptoms in their loved one with DS along with any past medical or behavioral diagnoses and any recent blood work or diagnostic testing. DSC2U also contains optional questions about nutrition, education, therapies, life skills, and community resources.

At the MGH Laboratory of Computer Science, we have created a health information technology platform, Sprout Scribe, that delivers a web-based guided online questionnaire to patients or caregivers in a manner similar to other online electronic data capture tools. Uniquely, however, on submission of the completed questionnaire, the system applies a set of custom rules to the submitted data and auto-generates a readable narrative that displays the user- entered data tailored for the reader. This platform has been utilized by the MGH Down Syndrome Program (DSP) for their patient intake (Figure S2a) which prompts caregivers to answer specific health-related questions about the patient with DS before their visit. The platform then transforms this collected data into a custom clinical note (Figure S2b) fit to the specifications and information needs of DS specialists.

The screenshot shows a web-based intake form titled "MGH Down Syndrome Program New Visit Intake Form (Adults) Blood work and Diagnostic Testing". The form is organized into 25 numbered sections. The left sidebar contains a navigation menu with sections 1 through 25. The main content area is currently on section 23, "Blood work and Diagnostic Testing". This section contains several questions with radio button options for "Yes", "No", and "Not sure". The questions are:

- ...seen an audiologist for a formal hearing examination in the past 2 years? (required)
- ...seen an ophthalmologist for a formal eye examination in the past 2 years? (required)
- ...ever had a sleep study performed for obstructive sleep apnea? (required)
- ...had thyroid blood work done in the past 12 months? (required)
- ...had blood work done for celiac disease performed at any time? (required)
- ...had a neck X-ray ("C-spine") ever before? (required)
- ...had a hemoglobin blood test for anemia in the past 12 months? (required)
- ...had a gap smear ever? (required)

Figure S2a. Screenshot of MGH DSP online questionnaire. Comprises approximately 200 questions in 25 sections, covering areas related to demographics, general medical history, current symptoms, education/vocational experience, functional assessment, recreational and diet histories, diagnostic testing, DS community resources, and future planning

The screenshot shows a clinical narrative report generated from the DS online intake. The report is formatted as a consult letter to the referring primary care provider. It includes the following sections:

- Header:** Patient name (Kevin Patient), date (10/15/2014), and provider name (Dr. George Provider).
- Introduction:** A paragraph explaining the purpose of the visit and the patient's background.
- CHIEF CONCERNS:** A list of the patient's primary concerns, such as "increased anxiety and mood changes".
- STRENGTHS:** A list of the patient's strengths, such as "Manners, kindness, knowledge of names".
- DIAGNOSIS:** A statement of the diagnosis based on the patient's history and records.
- PAST MEDICAL & SURGICAL HISTORY:** A list of past medical conditions and surgeries, such as "Hypothyroidism, 'Well-managed'", "Obstructive sleep apnea, 'Well-managed'", "Constipation, 'Well-managed'", "Cognitive decline, 'Well-managed'", "Dry skin, 'Well-managed'", "Hair loss, 'Well-managed'", "Urinary retention, 'Well-managed'", and "Phychoch, 'Well-managed'".

Figure S2b. Clinical narratives automatically generated from the DS online intake, incorporating all relevant caregiver responses. The report is formatted as a consult letter to the referring primary care provider.

DSC2U was developed as an extension of the MGH DSP patient intake process. The extension work done as part of this project involved: (1) the modification of the existing intake as recommended by the Parent/Caregiver and PCP WGs and the Expert Advisory Panel, (2) authoring and identifying new content for the *Caregiver Checklist* and *PCP Plan* as described under Intervention and Controls, and (3) the technical implementation of the *Checklist* and *Plan*.

Analysis and modification of the MGH DSP guided online questionnaire. The MGH DSP patient intake was reviewed and modified by the caregiver, primary care provider (PCP) and expert working groups (WG). Suggested modifications were structural (e.g., replacing/removing questions with a free-text response, changing the question type), as well as content-based (e.g., including customizations applicable to other regions and/or states, new questions emergent from input by our WGs, removal of questions deemed unnecessary or unhelpful, or rewording of questions as recommended by the WGs). Technically, the guided online questionnaire is an Excel file definition (Figure S3) consumed and transformed by Sprout Scribe into a web-based form. Validation of fields and branching logic are included, as is typical of most online

electronic data capture systems. Recommended changes to the form were made by modifying this Excel definition. The Spanish version of the DSC2U questionnaire did not require an entirely new Excel definition, but only the addition of the Spanish translation of each question and response choices to the existing Excel definition (Figure S3).

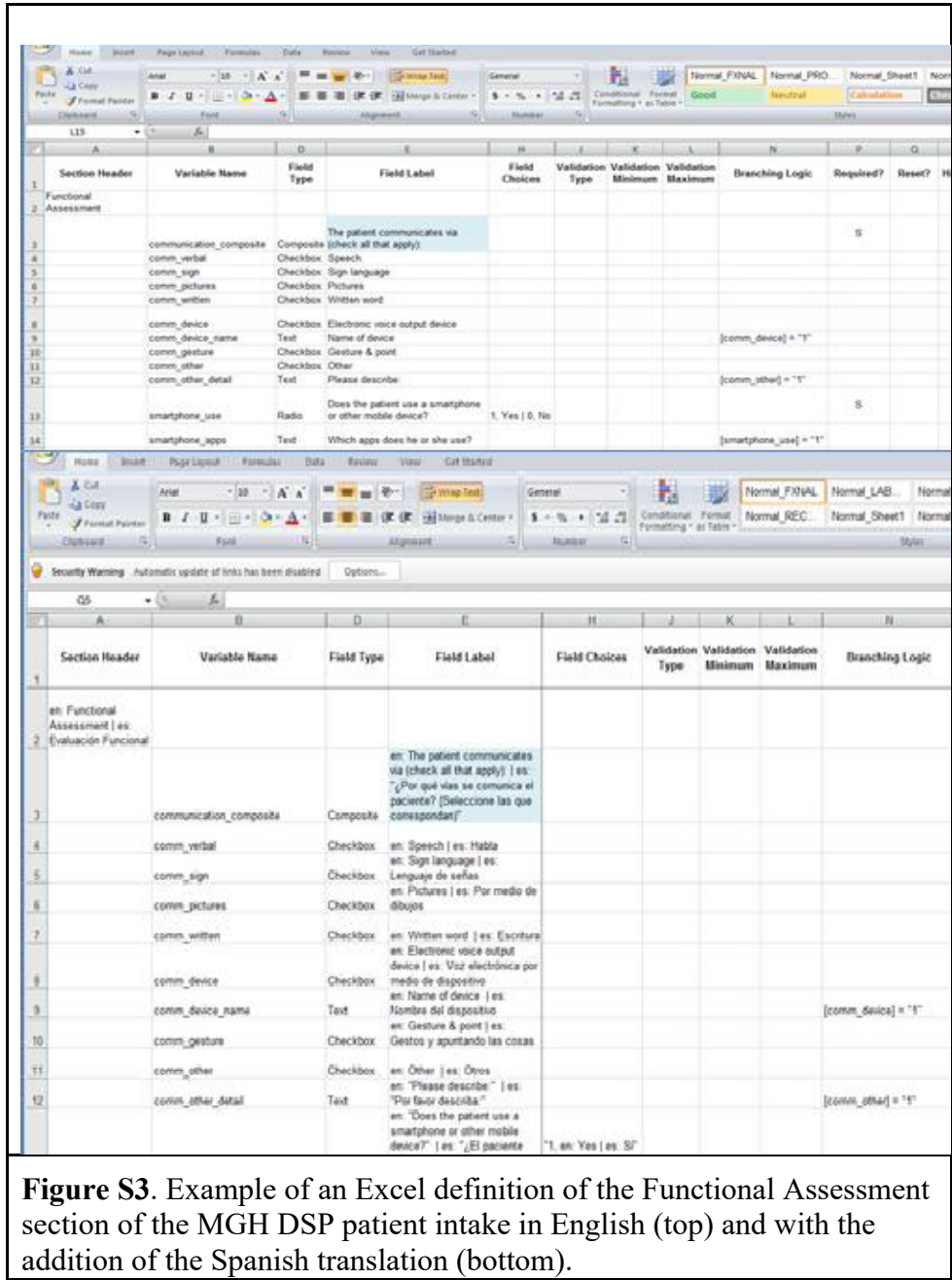


Figure S3. Example of an Excel definition of the Functional Assessment section of the MGH DSP patient intake in English (top) and with the addition of the Spanish translation (bottom).

At the core of DSC2U lies its algorithms—a set of rules that generates recommendations based on specific responses in the intake questionnaire. The rules are based on national guideline recommendations for DS care and expert consensus that were translated into Sprout Scribe algorithms during the initial phase of this grant by the research team and refined with the assistance of the Expert Advisory Panel. Upon submission of the intake questionnaire, the caregiver’s responses are passed through the DSC2U algorithms and results in the *Caregiver Checklist* and *PCP Plan*, which are made available within seconds. The participant receives a notification e-mail with a link to access their personalized Caregiver Checklist and PCP Plan.

Description of the *Caregiver Checklist*

Our Parent/Caregiver WG helped to develop and optimize the content for the *Checklist*. They worked with the Expert Advisory Panel and our research team to develop a clinically sound, parent-meaningful document. The Checklist was a personalized one- to two-page summary report with health care recommendations for their child or dependent (Figure S4). Our Parent/Caregiver WG ensured that the *Checklist* was empowering, direct, succinct, and, above all, affirming. These recommendations were auto-programmed based on the types of answers that respondents provided when completing DSC2U.

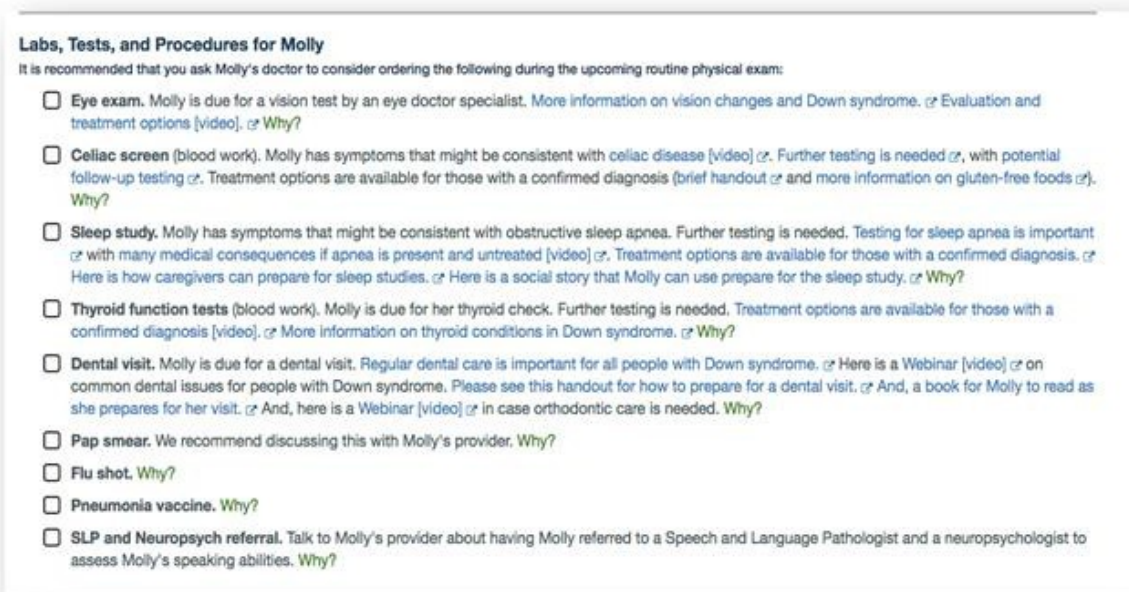


Figure S4. Caregiver Checklist snapshot

For example, if a caregiver of a teenager checked boxes that the individual is gasping, choking, and snorting at night and that the teen has never had a sleep study, these responses triggered a recommendation to discuss a sleep study with the PCP. In addition, not only did the caregivers receive the suggestion of a sleep study, they also received practical information on how to prepare for a sleep study when a participant has an intellectual disability. Similarly, if a respondent checked that a child or dependent with DS is experiencing frequent constipation, bloating, and behavioral problems, they received a recommendation to talk about celiac disease testing with the child’s PCP, because this condition occurs at an increased frequency in patients with DS. The *Checklist* also included tailored recommendations on books and other educational references and community resources that our work groups deemed to be relevant, accurate, and

helpful.

All recruitment language was reviewed by a legal team at Massachusetts General Hospital (MGH) to assure that participants were informed that DSC2U does *not* offer either direct access to physicians at the hospital or to MGH physicians by e-mail, text, telephone, or video conference. We also made clear that DSC2U is not meant to help in emergencies or to address urgent medical issues.

Description of the *PCP Plan*

Our PCP WG was responsible for helping to develop the content for the *Plan* (Figure S5). This group worked with the Expert Advisory Panel and our research team to develop a compact document intended to be a PCP-friendly companion document to the *Checklist*. For example, if a caregiver indicated that the individual with DS has not had thyroid function tests checked in the past 12 months, the *PCP Plan* included a statement such as “According to the parent/caregiver, thyroid function tests have not been checked in the past 12 months. According to the national DS health care guidelines, we recommend that you consider ordering TSH and free T4 during today’s visit.” Our PCP WG emphasized that we needed to be mindful of the tone of our Plans, as we wanted the community-based PCPs to view the Plans as helpful, rather than intrusive.

Recommended Labs, Tests, and Procedures for Molly

(AAP = American Academy of Pediatrics)

- Ophthalmology Evaluation:** Experts recommend an ophthalmologic exam at least every two years for adults with Down syndrome, ages 21 and older.
- Celiac screen (total IgA & TTG-IgA).** Molly’s caregiver indicated that within the past month of completing our intake, she had constipation that is hard to treat, nausea, passing excessive gas, bloating, mood swings, crying easily or for no reason. Molly has never had celiac testing done. Celiac disease is more common in people with Down syndrome.
- Sleep study.** Molly’s caregiver indicated that within the past month of completing our intake, Molly experienced snoring, gasping, snorting, choking during sleep, sleeping on multiple pillows, not feeling refreshed despite adequate sleep, feeling down, depressed, or hopeless, crying easily or for no reason, moving slowly, distress about being alone. Molly has also never had a sleep study. Experts recommend that everyone with Down syndrome be evaluated for sleep apnea if symptoms arise. We would recommend a sleep study to assess for obstructive sleep apnea, which can occur in up to 75% of people with Down syndrome. Research has also shown that patients with Down syndrome may lose up to 9 IQ points within a year when their apnea is untreated.
- Thyroid function tests (TSH & FT4).** Molly’s caregiver indicated that within the past 12 months of completing our intake, Molly has not had her thyroid levels drawn. Experts recommend that everyone with Down syndrome have their thyroid levels checked once annually, given the high incidence of thyroid disorders in patients with Down syndrome.

Potential New Conditions/Diagnoses to be Considered for Molly

We recommend that you consider initiating evaluations for the following conditions that can often co-occur with Down syndrome:

- Depression.** Molly’s caregiver marked that within the past 6 months of completing our intake, Molly has experienced feeling down, depressed, or hopeless, little interest or pleasure in doing things, crying easily for no reason, moving slowly, distress about being alone. Generalized depression is a common co-occurring condition for people with Down syndrome. Resources and book recommendations are on our web page. Psychopharmacological consult should be considered if possible underlying medical causes can be eliminated.
- Arthropathies.** Molly’s caregiver indicated that within the past month of completing our intake, Molly has experienced joint stiffness, joint pain. Gout and osteoarthritis are all common in people with Down syndrome, and a full standard work up should be pursued in patients presenting with symptoms of joint pathology, including a workup for other connective tissue disorders.
- Chronic constipation.** Molly’s caregiver indicated that within the past month of completing our intake, Molly experienced constipation that is hard to treat. Chronic constipation is a common feature in patients with Down syndrome and can lead to behavioral issues if left untreated. Consider obtaining a KUB and trying medication to alleviate the constipation if needed.

Figure S5. Primary care provider (PCP) plan

As drivers of the DSC2U intervention, caregivers were given both the *Checklist* and *Plan*.

As part of the study protocol, caregivers were asked to share the Plan with their child's or dependent's PCP at their upcoming visit. However, it was possible that the caregiver did not share the *Plan* as designed.

S4: Baseline Assessment

The content of the care received by both the intervention and control groups was ascertained through the *Baseline Assessment* survey completed no more than 8 weeks before a wellness visit with the PCP. To minimize loss to follow-up, reminder emails were sent three times about 2 weeks apart, concluding with two telephone calls in the eighth week by our research assistant.

The *Baseline Assessment* requested the following information:

- *Caregiver information*: first name, last name, sex, date of birth, relationship to patient, phone number and address;
- *Patient information*: first name, last name, gender, date of birth, race/ethnicity (NIH standardized format), health insurance, education, marital status, health literacy, numeracy
- *PCP information*: first name, last name, gender, office phone, office address and e-mail (if available), time to travel to PCP
- *Date of annual well visit ("PCP visit") appointment*
- *Current symptoms, health history, and past medical history that would trigger recommendations for our five health care screenings (celiac screen, sleep study, thyroid test, audiogram, and ophthalmology evaluation)*. We assessed these symptoms among other symptoms not related to these conditions to minimize any priming effects. For example, "Does your child snore at night?" might be asked next to "Does your child have any rashes?" (A sleep study might be warranted for snoring, but not for rashes.)
- *Primary outcome measures to assess adherence to national health care guidelines: celiac screen, sleep study, thyroid test, audiogram, and ophthalmology evaluation* (Health Care Outcome Survey)
- *Secondary outcome measures assessing quality of life*: PedsQL 2.0 Family Impact Module; PedsQL 4.0 parent-proxy, standard Short Form 15 Generic Core Scales.

See Section S20 for a copy of the Baseline Assessment.

S5: PedsQL Scoring

PedsQL scoring instructions were used for PedsQL 4.0 parent-proxy standard Short Form 15 Generic Core Scales and PedsQL 2.0 Family Impact Module. Note that the discrepancy in question counts in the scoring instructions for PedsQL 4.0 parent-proxy standard Short Form 15

Generic Core Scales compared with the number of questions in the printed REDCap version of this form is due to slightly different text being used for equivalent questions to different age groups. For example, Question 1 of the parent-proxy report for children 2 to 4 years old uses the verbiage "Walking." This is captured by the REDCap field "walk2," with skip logic that presents that question, only if the individual with DS, is less than 5 years of age. Question 1 of the parent-proxy report for older age groups uses the verbiage "Walking more than one block." This is captured by the REDCap field "walk1" with skip logic that presents that question only if the individual with DS is greater than or equal to 5 years. Although the printed REDCap survey has two fields, "walk1" and "walk2," they represent a single physical functioning question in the PedsQL. Within the physical functioning domain, the same applies to "sport1" and "sport2" and to "chore1," "chore2," and "chore3."

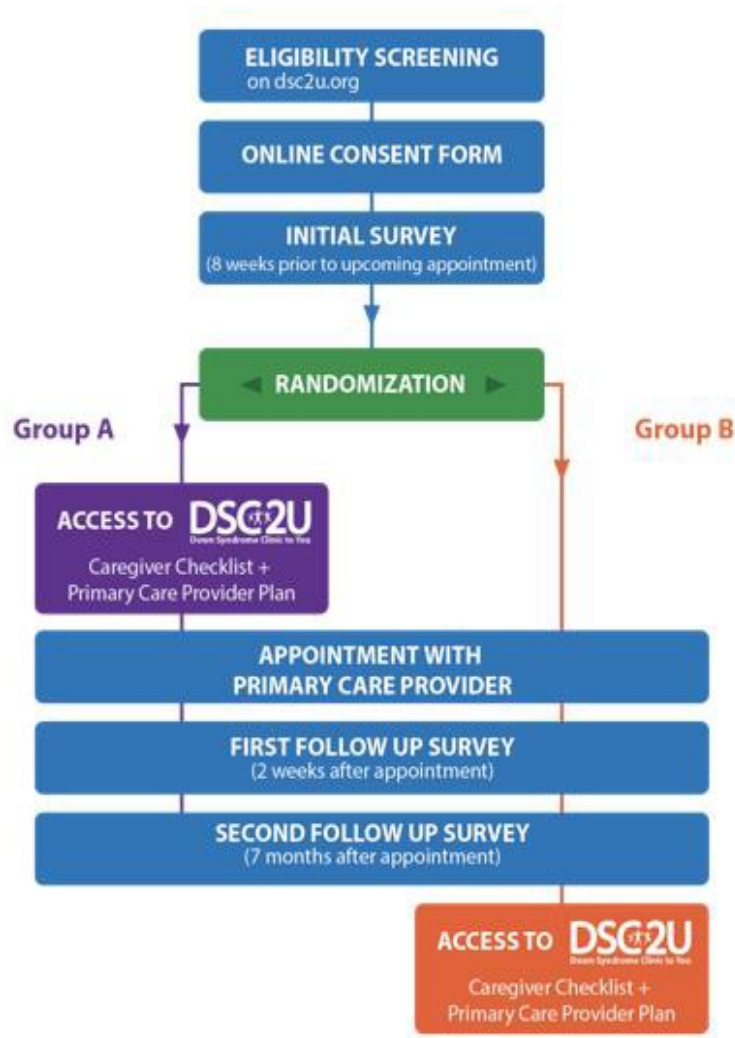
S6: Time Frame and Conduct of the Trial

Once we deemed a caregiver eligible, by the measures described under Participants, we allowed them to view our online consent form. As part of the participant's consent process, we provided them with information about being randomly assigned to either Group A or Group B, as shown in Figure 4. This included written assurance that both groups would get access to DSC2U during the trial (for Group B, this would be at the end of the study). All participants were asked to indicate that they understood the information provided and consented to their full randomized participation.

Once they had provided consent, study personnel were notified via e-mail, and the *Baseline Assessment* was sent electronically to the participant for completion no more than 8 weeks before the scheduled PCP visit. If the survey was not completed a reminder email was sent every two weeks over the course of a six-week period. If still not completed after six weeks (three email reminders later) we gave the subject up to two telephone calls to ask for completion of the survey.

Once the participants had completed the *Baseline Assessment*, we randomized them 1:1 to either the Intervention or the control arm, as shown in the top part of Figure 4 through the green box. Participants were assigned in a 1:1 ratio to DSC2U or wait-list according to a computer-generated randomization schedule constructed with permuted blocks of size 2 and 4, stratified for distance from PCP (three levels: <30 min, 30 to 59 min, and 60 or more min) and type of insurance (two levels, public and private).

Figure S6. Study procedure for two-arm randomized control trial of DSC2U



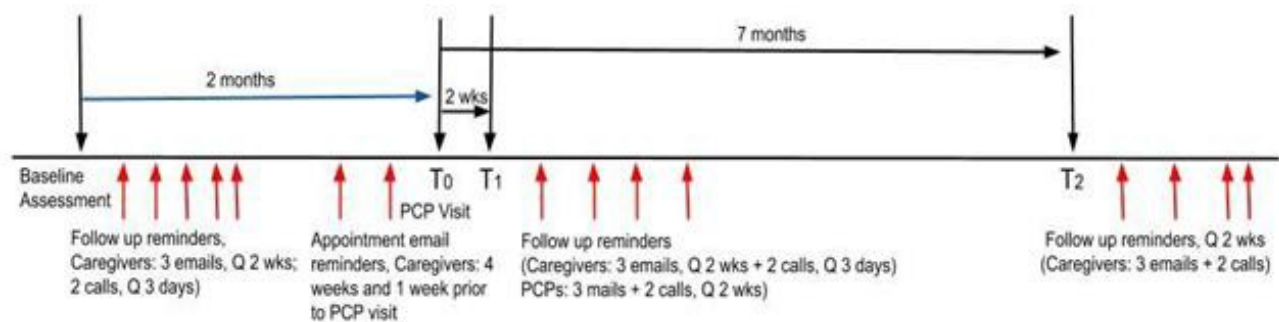
The bottom half of Figure S6 shows what the intervention group (Group A) and the control group (Group B) experienced in the main part of the trial. For the experimental arm (Group A), after the caregivers submitted the *Baseline Assessment*, we emailed them a link to DSC2U (purple box); they could access it with a 4-digit passcode so that they could return to and complete the DSC2U form at their convenience. If DSC2U was not completed, we e-mailed reminders to complete the form at 4, 3, and 2 weeks before their child's or dependent's scheduled PCP appointment. After they completed the DSC2U intake questionnaire, the system immediately sent the participant their personalized *Checklist* and *Plan*; these were accessible in their DSC2U portal, accessible only with the passcode. The *Checklist* and *Plan* could be viewed, printed, or e-mailed to themselves or others at the user's discretion.

After submitting the *Baseline Assessment*, participants in the control arm (Group B) were sent an e-mail message thanking them for their participation in the study. Included was a reminder to let study personnel know if their child's or dependent's scheduled appointment with the PCP had changed.

Figure S7. depicts the steps for communicating with the participants and for gathering data from the various surveys described earlier. Specifically, a maximum of 2 months elapsed between the *Baseline Assessment* and each patient's scheduled visit with the primary care provider (PCP) at time T0.

Before each patient's scheduled PCP visit, we sent the caregiver two reminders for their upcoming appointment. This included a request to let our study personnel know if the date of the appointment had changed. Because the timing between study enrollment and scheduled PCP visit naturally varied among participants, we sent these appointment reminders at approximately 4 weeks, then 1 week, ahead of the scheduled appointment.

Figure S7. Survey implementation at various time points



Baseline: Symptom and health history checklist, Health Care Outcome Survey, PedsQL 2.0 Family Impact Module and PedsQL 4.0 parent-proxy, standard Short Form 15 Generic Core Scales

T0 (PCP Visit)

T1 (Post-visit Assessment 1): PedsQL 2.0 Family Impact Module and PedsQL 4.0 parent-proxy, standard Short Form 15 Generic Core Scales, Parent/Caregiver Experience Survey, and PCP Experience Survey

T2 (Post-visit Assessment 2): Health Care Outcome Survey, PedsQL 2.0 Family Impact Module and PedsQL 4.0 parent-proxy, standard Short Form 15 Generic Core Scales

The *Parent/Caregiver* and *PCP Experience Surveys* were administered approximately 2 weeks after the PCP visit (see Figure S7, T1). This allowed caregivers and PCPs to provide feedback while the office visit was still fresh in their minds. Caregivers were invited by e-mail to complete their *Patient/Caregiver Experience Surveys*. PCPs received their *PCP Experience Surveys* by mail, with an option to complete the survey electronically. PCPs whose emails had been provided by the caregivers also received a direct invitation by e-mail to complete their survey. To minimize loss to follow-up, reminder emails were sent three times about 2 weeks apart, concluding with two telephone calls in the eighth week by our research assistant.

We asked caregivers by e-mail to complete the *Health Care Outcomes Survey* approximately 7 months after the PCP visit (Figure S7, T2). This allowed the maximum time within the

constraints of the grant's timeline to measure whether the recommended health care actions, as mentioned on the personalized *Checklists* and *Plans*, had been implemented. (Some of the health care recommendations—such as getting a sleep study—can take up to 5 or 6 months to be scheduled and ordered in some parts of the country.) Again, to minimize loss to follow-up, reminder emails were sent three times about two weeks apart, concluding with two telephone calls in the eighth week by our research assistant.

S7: Indications for the Primary Outcome

Each customized DSC2U Caregiver Checklist and PCP Plan was the amalgamation of hundreds of rules acting on the caregiver's unique set of responses. The rules that supported the Indications for each of our primary outcomes is detailed below in plain-language.

Primary outcome: Audiology screening

An audiogram was recommended when participants reported the person with Down syndrome:

- was under 21 and had not had a formal hearing exam in the past 12 months.
- OR was under 21 and the participant was unsure whether they had a formal hearing exam in the past 12 months.
- OR was 21 or older and had not had a formal hearing exam in the past 2 years.
- OR was 21 or older and the participant was unsure whether they had a formal hearing exam in the past 2 years.

Primary outcome: Vision screening

An eye exam was recommended when participants reported the person with Down syndrome:

- was under 5 and had not seen an ophthalmologist for a formal eye exam in the past 12 months.
- OR was under 5 and the participant was unsure whether they had seen an ophthalmologist for a formal eye exam in the past 12 months.
- OR was between the ages of 5 and 12 (inclusive) and had not seen an ophthalmologist for a formal eye exam in the past 2 years.
- OR was between the ages of 5 and 12 (inclusive) and the participant was unsure whether they had seen an ophthalmologist for a formal eye exam in the past 2 years.
- OR was between the ages of 13 and 20 (inclusive) and had not seen an ophthalmologist for a formal eye exam in the past 3 years.
- OR was between the ages of 13 and 20 (inclusive) and the participant was unsure whether they had seen an ophthalmologist for a formal eye exam in the past 3 years.
- OR was 21 or older and had not seen an ophthalmologist for a formal eye exam in the past 2 years.
- OR was 21 or older and the participant was unsure whether they had seen an ophthalmologist for a formal eye exam in the past 2 years.

Primary outcome: Screening/evaluation of celiac disease

Celiac screening was recommended when participants reported the person with Down syndrome:

- had never had blood work done for celiac disease and showed symptoms of celiac disease (as defined below).
- OR showed symptoms of celiac disease (as defined below) and the participant was unsure whether they had ever had blood work done for celiac disease.
- OR had blood work done for celiac disease but not within the last 12 months, did not have a prior diagnosis of celiac disease, and showed symptoms of celiac disease (as defined below).
- OR had blood work done for celiac disease but not within the last 12 months, had a

prior diagnosis of celiac disease, was currently on a gluten-free diet, and showed symptoms of celiac disease (as defined below).

The person with Down syndrome was considered to show symptoms of celiac disease when participants reported that they experienced at least one of the following symptoms within the last month:

- o unexplained difficulty gaining weight
- o constipation that is hard to treat
- o frequent diarrhea
- o frequent vomiting
- o Nausea
- o bulky or foul-smelling stools
- o new accidents with stool
- o passing excessive gas
- o bloating
- OR experienced at least two of the following symptoms within the last 6 months:
 - o overactive, restless, unable to sit still
 - o inattention
 - o impulsive, acts without thinking
 - o easily distracted
 - o uncooperative, disobeys
 - o temper tantrums or outburst or meltdowns
 - o throws or breaks objects
 - o hits self
 - o bites self
 - o hurts herself on purpose (e.g. hitting head, biting hands)
 - o bangs head
 - o Irritability
 - o kicks or hits others
 - o mood changes rapidly for no reason
 - o Aggression
 - o property destruction (e.g. Breaks things, hits walls, throws things)
 - o throws or breaks objects
 - o cries easily for no reason
 - o loss of previously learned skills

Primary outcome: Screening/evaluation of thyroid dysfunction

Thyroid testing was recommended when participants reported the person with Down syndrome:

- had not had thyroid function tests done within the last year.
- OR was unsure whether they had thyroid function tests done within the last year.
- OR had thyroid tests done within the last year, did not have a prior diagnosis of Hashimoto's thyroiditis or hypothyroidism and showed symptoms of hypothyroidism (as defined below).
- OR had thyroid function tests done within the last year, had a prior diagnosis of Hashimoto's thyroiditis for which they were taking medication, and showed symptoms of hypothyroidism (as defined below).
- OR had thyroid function tests done within the last year, had a prior diagnosis of hypothyroidism for which they were taking medication, and showed symptoms of hypothyroidism (as defined below).
- OR had thyroid tests done within the last year, did not have a prior diagnosis of Graves disease, Hashimoto's thyroiditis, hypothyroidism, or hyperthyroidism, and

showed symptoms of hyperthyroidism (as defined below).

- OR had thyroid tests done within the last year, did not have a prior diagnosis of Hashimoto's thyroiditis or hypothyroidism, had a prior diagnosis of Graves disease for which they were taking medication, and showed symptoms of hyperthyroidism (as defined below).

- OR had thyroid tests done within the last year, did not have a prior diagnosis of Hashimoto's thyroiditis or hypothyroidism, had a prior diagnosis of hyperthyroidism for which they were taking medication and showed symptoms of hyperthyroidism (as defined below).

The person with Down syndrome was considered to show symptoms of hypothyroidism when participants reported that they experienced at least one of the following symptoms within the last month:

- o increasing fatigue
- o weight gain
- o constipation that is hard to treat
- o dry skin
- o hair loss
- o feeling too cold

- OR when they showed symptoms of depression (as defined below).

The person with Down syndrome was considered to show symptoms of hyperthyroidism when participants reported that they experienced at least one of the following symptoms within the last month:

- o undesired weight loss
- o frequent diarrhea
- o irregular periods
- o feeling too hot

- OR when they showed symptoms of anxiety (as defined below).

- OR when they showed symptoms of obsessive compulsive disorder (as defined below).

- OR when they showed symptoms of attention deficit hyperactivity disorder (as defined below).

Primary outcome: Screening/evaluation of sleep apnea

A sleep study was recommended when participants reported the person with Down syndrome:

- was 4 or older, had never had a sleep study performed for obstructive sleep apnea, and did not show symptoms of sleep apnea (as defined below), depression (as defined above), or anxiety (as defined above).

- OR was 4 or older, did not show symptoms of sleep apnea (as defined below), depression (as defined above), or anxiety (as defined above), and the participant was unsure whether they had ever had a sleep study performed for obstructive sleep apnea.

- OR had never had a sleep study performed for obstructive sleep apnea and showed symptoms of sleep apnea (as defined below), depression (as defined above), or anxiety (as defined above).

- OR showed symptoms of sleep apnea (as defined below), depression (as defined above), or anxiety (as defined above), and the participant was uncertain whether they had ever had a sleep study performed for obstructive sleep apnea.

- OR has had a sleep study performed for obstructive sleep apnea but not within the last 12 months, does not have a prior diagnosis of obstructive sleep apnea, and shows symptoms of sleep apnea (as defined below),

depression (as defined above), or anxiety (as defined above).

The person with Down syndrome was considered to show symptoms of sleep apnea when participants reported that they experienced at least one of the following symptoms within the last month:

- o snoring
- o gasping, snorting, choking during sleep
- o breathing with open mouth during sleep
- o sleeping on multiple pillows
- o not refreshed despite adequate sleep
- o falling asleep in car on short drive
- o falling asleep/napping at school
- OR exhibited symptoms of depression (as defined above).
- OR exhibited symptoms of anxiety (as defined above).

Ancillary Definitions Utilized by One or More of the Primary Outcome Rule Sets

The person with Down syndrome was considered to show symptoms of depression when participants reported that they:

- were over the age of 4 and in the last 6 months had experienced both feeling down, depressed, or hopeless and little interest or pleasure in doing things.
- OR were over the age of 8, in the last 6 months had experienced feeling down, depressed, or hopeless, and in the last 6 months had experienced at least one of the following symptoms:
 - o cries easily for no reason
 - o moves slowly
 - o loss of previously learned skills
 - o eating too much or eating too little
 - o trouble falling or staying asleep
 - o tense, anxious, worried
 - o distressed about being alone
- OR were over the age of 8, in the last 6 months had experienced little interest or pleasure in doing things, and in the last 6 months had experienced at least one of the following symptoms:
 - o cries easily for no reason
 - o moves slowly
 - o loss of previously learned skills
 - o eating too much or eating too little
 - o trouble falling or staying asleep
 - o tense, anxious, worried
 - o distressed about being alone

The person with Down syndrome was considered to show symptoms of anxiety when participants reported that they:

- were 8 or older and had experienced at least one of the following symptoms in the last 6 Months:
 - o irritability
 - o fears particular situations
 - o chews body parts
 - o general agitation

The person with Down syndrome was considered to show symptoms of obsessive compulsive disorder when participants reported that they:

- were 6 or older and in the last 6 months had experienced ritualistic compulsive behaviors (e.g. checking things/cleaning/grooming), which they found distressing, or which interfered with daily Activities.
- OR were 6 or older and in the last 6 months had experienced getting obsessed with idea or activity, which they found distressing, or which interfered with daily activities.

The person with Down syndrome was considered to show symptoms of attention deficit hyperactivity disorder when participants reported that they:

- exhibited at least two of the following symptoms within the last 6 months:
 - o overactive, restless, unable to sit still
 - o inattention
 - o impulsive, acts without thinking
 - o easily distracted
 - o uncooperative, disobeys

S8: Sample Size Calculations and

Power Preliminary Data

The principal investigator for this trial had conducted a study on the number and type of evaluations required to comply with national recommendations in a sample of 103 patients with DS receiving usual care¹. The results indicated the following distribution of compliance with the five types of evaluations proposed as the primary outcome measure (for Aim 1) for this trial: 9% with 0 evaluations, 18% with 1 evaluation, 22% with 2 evaluations, 27% with 3 evaluations, 15% with 4 evaluations, and 9% with 5 evaluations.² In this sample, all five evaluations were indicated. This distribution has a standard deviation of 1.4 evaluations and conforms closely to a beta-binomial distribution with a mean of 2.5, the expected number of completed evaluations, and rho of 0.15, the pairwise correlation among the 5 Bernoulli events for a given patient of having or not having each of the five recommended evaluations.

Minimum Effect Size

We powered our trial to detect an average treatment effect of 0.6 evaluations. This value is about 0.43 standard deviations of the observed variation in screening evaluations by PCPs based on our preliminary data.² Each one of these five evaluations is considered of paramount importance by the AAP and adult consensus statements in decreasing comorbidities. Further, our Parent/Caregiver Working Group reviewed with us these five evaluations and agreed that they were of critical importance to the health of their children with DS. The proposed minimal treatment effect of interest of 0.6 evaluations would allow us to detect an improvement in the health actions for more than half of our population by at least one evaluation. This would be clinically meaningful for the DS community.

Power Calculations

The primary outcome follows a multinomial distribution, taking integer values from 0 through 5, the count of the number of recommended and indicated evaluations completed for a given

patient with DS. Our preliminary data suggested that a beta-binomial distribution matches the observed distribution well. The variance of a beta-binomial taking values from 0 to n with mean μ and pairwise correlation ρ is $\mu (1 - \mu/n) (1 + (n - 1) \rho)$.

The power for the primary analysis can be estimated from a two-group t-test with unequal variance and Satterthwaite degrees of freedom, controlled by a given difference in means. Assuming all five evaluations are indicated for all participants, the mean number of evaluations among participants randomized to usual care is equal to 2.5. Moreover, pairwise correlation among evaluations is equal to 0.15 as we observed in our preliminary data. Thus, enrolling 200 total parents/caregivers and allowing up to a 14% drop-out rate, we would have 80% power to detect an average increase of 0.6 evaluations completed by the PCP out of the 5 total recommended evaluations we propose to track in this trial (Figure S6).

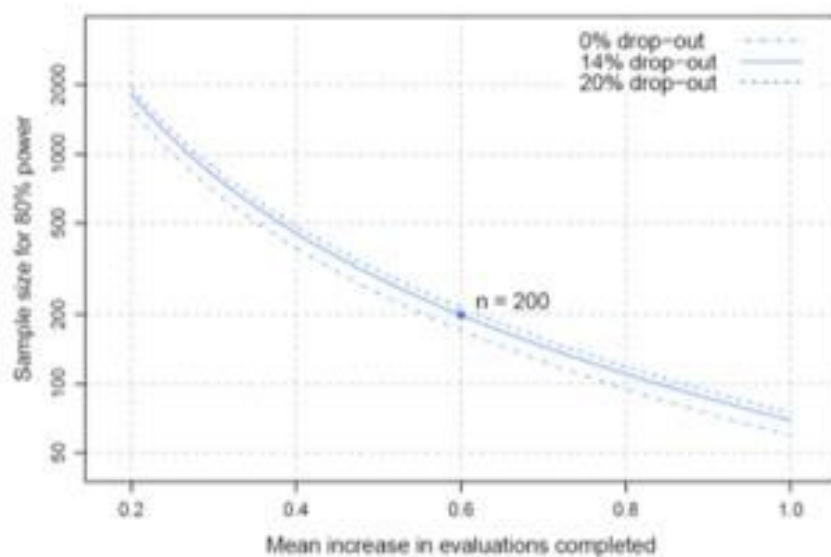


Figure S6. Sample size requirements for a range of effect sizes and drop-out rates

A Monte Carlo simulation applying two-group t-tests to 10,000 sets of randomly generated beta-binomial data with the specified parameters yielded 80% power when the true difference was 0.6 evaluations and a 5% type I error rate when the true difference was zero. The variance was maximal when we assumed that all five evaluations are indicated and at the observed mean of 2.5 evaluations. Thus, deviations from those assumptions in the study sample will result in increased power for detecting a true improvement of 0.6 evaluations.

Power for testing for subgroup differences in the efficacy of the *Checklist* and *Plan* intervention depends on the prevalence of specific subgroups of interest. Broadly, the study would have approximately 80% power for a 3 degree of freedom test of age-group dependent differences in treatment efficacy if the age-group x treatment interaction explained at least 6% of the variation in compliance with recommended evaluations.

We lacked preliminary data on person-to-person variation and covariance among repeated measures for our secondary outcomes. As a general guide, however, for a two-group Wilcoxon rank sum test of normally distributed changes from baseline tested at $\alpha = 0.008$ two-tailed to accommodate the six quality-of-life measures and assuming up to 14% loss to follow-up, the study had 80% power to detect treatment-specific improvements with effect sizes as small as 0.56.

S9: Analytical and Statistical Approaches (Additional Considerations)

Predictors of the primary endpoint and several ordinal measures of participant-reported evaluations of the *Checklist* and *Plan* (how the caregiver would rate the *Checklist*; whether the caregiver would recommend DSC2U to another caregiver; whether the caregiver would reread or re-use links in the *Checklist*; and whether the caregiver would complete the DSC2U intake form again; whether the PCP discussed the *Plan* or any of its recommendations with the caregiver; whether the PCP was interested in any of the information in the *Plan*; whether the PCP agreed with the recommendations in the *Plan*; and how the PCP would rate the *Plan*) were evaluated in a series of ordinal logistic regression models using cumulative logits. Predictors included characteristics of the individual with DS, the caregiver, the PCP, the PCP's practice, the relationship between the PCP and caregiver (e.g., the duration of relationship, quality of communication, and overall visit experience).

S10: Table S1. Baseline characteristics of people with Down syndrome and caregivers (additional variables)

Variable and Characteristics		Randomized Group		
		Overall (N=230)	Control (N=113)	DSC2U (N=117)
Person with DS				
PedsQL Psychosocial Health Score	mean±SD (range)	70.5±14.0 (27.5,100)	71.2±13.3 (37.5,100)	69.8±14.7 (27.5,100)
PedsQL Physical Functioning Score	mean±SD (range)	63.1±27.0 (0.0,100)	62.9±28.6 (0.0,100)	63.4±25.4 (0.0,100)
PedsQL Total Scale Score	mean±SD (range)	68.1±14.5 (25.0,98.3)	68.4±15.5 (25.0,98.3)	67.7±13.6 (30.0,93.3)
Caregiver of person with DS				
PedsQL FIM Parental HRQL Summary Score [#]	mean±SD (range)	68.1±18.8 (6.3,100)	67.4±19.6 (6.3,100)	68.6±18.2 (20.0,100)
PedsQL FIM Family Functioning Summary Score [¶]	mean±SD (range)	65.7±22.7 (0.0,100)	65.2±24.6 (0.0,100)	66.2±20.7 (12.5,100)
PedsQL FIM Total Scale Score [§]	mean±SD (range)	65.4±19.0 (6.9,100)	64.9±20.3 (6.9,99.3)	65.8±17.6 (20.1,100)
Time to travel to primary care provider	< 30 minutes	194 (84.3%)	96 (85.0%)	98 (83.8%)
	30–59 minutes	34 (14.8%)	17 (15.0%)	17 (14.5%)
	60 minutes or more	2 (0.9%)	0 (0.0%)	2 (1.7%)
Accessibility of routine blood tests (e.g., CBC, lead)	Very difficult	17 (7.4%)	7 (6.3%)	10 (8.5%)
	Somewhat difficult	26 (11.4%)	14 (12.5%)	12 (10.3%)
	Not very difficult	44 (19.2%)	24 (21.4%)	20 (17.1%)
	Not at all difficult	142 (62.0%)	67 (59.8%)	75 (64.1%)
	[missing]	1	1	0

Accessibility of referral to physician specialist for consultation	Very difficult	2 (0.9%)	0 (0.0%)	2 (1.7%)
	Somewhat difficult	21 (9.2%)	11 (9.7%)	10 (8.6%)
	Not very difficult	68 (29.7%)	35 (31.0%)	33 (28.4%)
	Not at all difficult	138 (60.3%)	67 (59.3%)	71 (61.2%)
	[missing]	1	0	1
Accessibility to complex imaging (CT, MRI)	Very difficult	25 (11.6%)	10 (9.5%)	15 (13.5%)
	Somewhat difficult	31 (14.4%)	17 (16.2%)	14 (12.6%)
	Not very difficult	58 (26.9%)	27 (25.7%)	31 (27.9%)
	Not at all difficult	102 (47.2%)	51 (48.6%)	51 (45.9%)
	[missing]	14	8	6
In the past year, how much has your family spent out of your pocket on health care costs for all members of your household, including [name]?	< \$250	16 (7.7%)	10 (9.3%)	6 (6.0%)
	\$250–499	16 (7.7%)	7 (6.5%)	9 (9.0%)
	\$500–999	23 (11.1%)	9 (8.4%)	14 (14.0%)
	\$1,000–1,999	26 (12.6%)	10 (9.3%)	16 (16.0%)
	\$2,000–2,999	27 (13.0%)	12 (11.2%)	15 (15.0%)
	\$3,000+ [missing]	99 (47.8%) 23	59 (55.1%) 6	40 (40.0%) 17

Abbreviations: **CBC:** Complete blood count; **CT:** Computed tomography; **FIM:** Family impact module; **MRI:** Magnetic resonance imaging; **PedsQL:** Pediatric quality of life; **PCP:** Primary care provider; **SD:** Standard deviation

Notes:

* PedsQL Psychosocial Health Score is the sum of the items over the number of items answered in the Emotional, Social, and School Functioning scales. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better quality of life.

† PedsQL Physical Functioning Score is scaled from 0 (Low) to 100 (High). Higher scores indicate a better quality of life

‡ PedsQL Total Scale Score is the sum of all the items over the number of items answered on all the Scales. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better quality of life.

PedsQL FIM Parental HRQL Summary Score includes 20 items and is computed as the sum of the items divided by the number of items answered in the Physical, Emotional, Social, and Cognitive Functioning Scales. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better functioning.

¶ PedsQL FIM Family Functioning Summary Score includes 8 items and is computed as the sum of the items divided by the number of items answered in the Daily Activities and family Relationships scales. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better functioning.

§ PedsQL FIM Total Score is a sum of all 36 items divided by the number of items answered. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better functioning.

S11: Table S2. Characteristics of PCPs (additional variables)

Variable and Characteristics		Randomized Group			Nom P-value*
		Overall (N = 230)	Control (N = 113)	DSC2U (N = 117)	
Practice characteristics of PCPs					
Panel size	mean±SD (range)	2487±1995 (100,15,000)	2511±1729 (100,9195)	2463±2232 (330,15,000)	0.882
Number of patients with DS	mean±SD (range)	10.0±18.1 (1.0,200)	8.4±12.0 (1.0,100)	11.4±22.3 (1.0,200)	0.288
Difficulty obtaining thyroid test (TSH and FreeT4) ^{††}	Somewhat difficult	1 (0.6%)	0 (0.0%)	1 (1.1%)	0.721
	Not very difficult	13 (7.3%)	8 (9.2%)	5 (5.4%)	
	Not at all difficult	165 (92.2%)	79 (90.8%)	86 (93.5%)	
	[missing]	51	26	25	
Difficulty obtaining Celiac screening [†]	Somewhat difficult	1 (0.6%)	0 (0.0%)	1 (1.1%)	0.305
	Not very difficult	18 (10.1%)	12 (13.8%)	6 (6.5%)	
	Not at all difficult	160 (89.4%)	75 (86.2%)	85 (92.4%)	
	[missing]	51	26	25	
Difficulty obtaining an audiogram [†]	Somewhat difficult	10 (5.6%)	3 (3.5%)	7 (7.6%)	0.770
	Not very difficult	59 (33.1%)	31 (36.0%)	28 (30.4%)	
	Not at all difficult	109 (61.2%)	52 (60.5%)	57 (62.0%)	
	[missing]	52	27	25	
Difficulty obtaining a sleep study [†]	Very difficult	13 (7.3%)	5 (5.7%)	8 (8.7%)	0.385
	Somewhat difficult	48 (26.8%)	26 (29.9%)	22 (23.9%)	
	Not very difficult	66 (36.9%)	36 (41.4%)	30 (32.6%)	
	Not at all difficult	52 (29.1%)	20 (23.0%)	32 (34.8%)	
	[missing]	51	26	25	
Difficulty obtaining an ophthalmology examination [†]	Very difficult	5 (2.8%)	3 (3.5%)	2 (2.2%)	0.336
	Somewhat difficult	19 (10.7%)	9 (10.5%)	10 (10.9%)	
	Not very difficult	65 (36.5%)	35 (40.7%)	30 (32.6%)	
	Not at all difficult	89 (50.0%)	39 (45.3%)	50 (54.3%)	
	[missing]	52	27	25	

Variables and Characteristics		Randomized Group			Nom p-value*
		Overall (N=230)	Control (N=113)	DSC2U (N=117)	
Relationship caregiver has with PCP (respondent: caregiver)					
HCAHPS [‡] top- level score (%)	mean±SD (range)	75.1±25.7 (0.0,100)	74.2±24.5 (0.0,100)	75.9±27.0 (0.0,100)	0.625
Wellness visit rating [#]	2	1 (0.5%)	1 (0.9%)	0 (0.0%)	0.395
	4	4 (1.9%)	1 (0.9%)	3 (2.9%)	
	5	4 (1.9%)	2 (1.8%)	2 (1.9%)	
	6	9 (4.2%)	4 (3.7%)	5 (4.9%)	
	7	18 (8.5%)	10 (9.2%)	8 (7.8%)	
	8	46 (21.7%)	26 (23.9%)	20 (19.4%)	
	9	69 (32.5%)	43 (39.4%)	26 (25.2%)	
	10	61 (28.8%)	22 (20.2%)	39 (37.9%)	
	[missing]	18	4	14	
	mean±SD (range)	8.57±1.43 (2.00,10.0)	8.49±1.37 (2.00,10.0)	8.66±1.51 (4.00,10.0)	
Provider rating [¶]	2	1 (0.5%)	1 (0.9%)	0 (0.0%)	0.388
	4	3 (1.4%)	1 (0.9%)	2 (1.9%)	
	5	4 (1.9%)	2 (1.8%)	2 (1.9%)	
	6	6 (2.8%)	3 (2.8%)	3 (2.9%)	
	7	14 (6.6%)	5 (4.6%)	9 (8.7%)	
	8	31 (14.6%)	22 (20.2%)	9 (8.7%)	
	9	71 (33.5%)	40 (36.7%)	31 (30.1%)	
	10	82 (38.7%)	35 (32.1%)	47 (45.6%)	
	[missing]	18	4	14	
	mean±SD (range)	8.84±1.39 (2.00,10.0)	8.76±1.37 (2.00,10.0)	8.93±1.40 (4.00,10.0)	

Variable and Characteristics		Randomized Group			Nom P-value*
		Overall (N=230)	Control (N=113)	DSC2U (N=117)	
Relationship PCP has with caregiver (respondent: PCP)					
How would you rate the quality of your communication with the patient's caregiver? [§]	Excellent	125 (69.8%)	58 (66.7%)	67 (72.8%)	0.347
	Very Good	44 (24.6%)	23 (26.4%)	21 (22.8%)	
	Good	8 (4.5%)	5 (5.7%)	3 (3.3%)	
	Fair	2 (1.1%)	1 (1.1%)	1 (1.1%)	
	[missing]	51	26	25	

How much time did you spend with [name] at the most recent wellness visit?	15 minutes or less	6 (3.4%)	2 (2.3%)	4 (4.3%)	0.489
	16–30 minutes	120 (67.4%)	62 (72.1%)	58 (63.0%)	
	31–45 minutes	47 (26.4%)	20 (23.3%)	27 (29.3%)	
	more than 45 minutes	5 (2.8%)	2 (2.3%)	3 (3.3%)	
	[missing]	52	27	25	
Spent enough time with the patient	No	2 (1.1%)	2 (2.3%)	0 (0.0%)	0.081
	Yes, somewhat	37 (20.8%)	21 (24.4%)	16 (17.4%)	
	Yes, definitely	139 (78.1%)	63 (73.3%)	76 (82.6%)	
	[missing]	52	27	25	
Caregiver able to provide information the PCP needed to assess the patient’s history and create a care plan	Yes, somewhat	14 (8.0%)	11 (12.8%)	3 (3.3%)	0.020*
	Yes, definitely	162 (92.0%)	75 (87.2%)	87 (96.7%)	
	[missing]	54	27	27	
Did the caregiver discuss concerns about the patient's health? ^{††}	No	2 (1.1%)	1 (1.2%)	1 (1.1%)	0.084
	Yes, somewhat	13 (7.5%)	10 (11.9%)	3 (3.3%)	
	Yes, definitely	159 (91.4%)	73 (86.9%)	86 (95.6%)	
	[missing]	56	29	27	

Abbreviations: PCP: Primary care provider; SD: Standard deviation; TSH: Thyroid stimulating hormone

Notes:

*P-value <0.05, ** p-value <0.01, *** p-value <0.001

[†]These variables were scaled from “Very difficult, Somewhat difficult, Not very difficult, Not at all difficult.” The answers not represented (e.g., Very difficult) had zero responses.

[‡]HCAHPS stands for Hospital Consumer Assessment of Healthcare Providers and Systems and is the nationally standardized survey of patients’ perspectives of hospital care.

[#]The Wellness visit rating is scaled from 0–10 with 0 meaning the “Worst wellness visit possible” and 10 meaning the “Best wellness visit possible.” The numbers that are not represented here (e.g., 0, 1, 3) had zero responses.

[¶]The Provider rating is scaled from 0–10 with 0 meaning the “Worst provider possible” and 10 meaning the “Best provider possible.” The numbers that are not represented here (e.g., 0, 1, 3) had zero responses.

[§]These variables included the answer options of “Excellent, Very Good, Good, Fair, and Poor.” If an answer is not included, it is because there was no response.

^{††}These variables included the answer options of “Yes, definitely, Yes, somewhat, and No.” If an answer is not included, it is because there was no response.

S12: Additional primary outcome analyses

Supplemental Table S3a. Primary outcome: Indication and completion of individual evaluations (missing evaluations excluded)

Variable	Randomized Group			DSC2U vs. Control		P-value
	Overall (N = 216)	Control (N = 111)	DSC2U (N = 105)	Rate Ratio (95% Confidence Interval)	Risk Difference (95% Confidence Interval)	
Celiac screen (bloodwork)						
Indicated evaluations	85 (39.4%)	45 (40.5%)	40 (38.1%)	0.9 (0.7,1.3)	-2.5 (-15.8,10.7)	0.781
Indicated evaluations that were recommended or completed	16 (7.4%)	5 (4.5%)	11 (10.5%)	2.3 (0.9,10.7)	6.0 (-1.2,14.0)	0.120
Indicated evaluations that were completed	14 (6.5%)	5 (4.5%)	9 (8.6%)	1.9 (0.6,7.1)	4.1 (-3.0,11.7)	0.275
Evaluations that were not indicated and completed	40 (18.5%)	14 (12.6%)	26 (24.8%)	2.0 (1.0,3.8)	12.2 (1.4,23.1)	0.024*
Sleep Study						
Indicated evaluations	89 (41.2%)	47 (42.3%)	42 (40.0%)	1.0 (0.7,1.3)	-2.3 (-15.7,11.0)	0.783
Indicated evaluations that were recommended and completed	21 (9.7%)	7 (6.3%)	14 (13.3%)	2.1 (0.9,5.9)	7.1 (-1.1,15.8)	0.108
Indicated evaluations that were completed	12 (5.6%)	3 (2.7%)	9 (8.6%)	3.2 (0.9,15.9)	5.9 (-0.3,13.3)	0.077
Evaluations that were not indicated and completed	41 (19.0%)	23 (20.7%)	18 (17.1%)	0.8 (0.5,1.5)	-3.6 (-14.2,7.2)	0.603
Thyroid test (bloodwork)						
Indicated evaluations	43 (19.9%)	23 (20.7%)	20 (19.0%)	0.9 (0.5,1.6)	-1.7 (-12.5,9.4)	0.865
Indicated evaluations that were recommended or completed	25 (11.6%)	13 (11.7%)	12 (11.4%)	1.0 (0.4,2.2)	-0.3 (-9.4,8.8)	1.000
Indicated evaluations that were completed	21 (9.7%)	12 (10.8%)	9 (8.6%)	0.8 (0.3,1.8)	-2.2 (-10.6,6.2)	0.650
Evaluations that were not indicated and completed	126 (58.3%)	54 (48.6%)	72 (68.6%)	1.4 (1.1,1.8)	19.9 (5.0,32.8)	0.004**

Variable	Randomized Group			DSC2U vs. Control		
	Overall (N = 216)	Control (N = 111)	DSC2U (N = 105)	Rate Ratio (95% Confidence Interval)	Risk Difference (95% Confidence Interval)	P-value
Audiogram						
Indicated evaluations	86 (39.8%)	44 (39.6%)	42 (40.0%)	1.0 (0.7,1.4)	0.4 (-13.1,13.6)	1.000
Indicated evaluations that were recommended or completed	28 (13.0%)	8 (7.2%)	20 (19.0%)	2.6 (1.2,7.2)	11.9 (2.4,21.4)	0.014*
Indicated evaluations that were completed	21 (9.7%)	6 (5.4%)	15 (14.3%)	2.6 (1.0,10.3)	8.9 (0.8,17.6)	0.037*
Evaluations that were not indicated and completed	74 (34.3%)	36 (32.4%)	38 (36.2%)	1.1 (0.8,1.6)	3.8 (-9.1,16.8)	0.570
Ophthalmology						
Indicated evaluations	20 (9.3%)	11 (9.9%)	9 (8.6%)	0.9 (0.3,2.2)	-1.3 (-9.6,7.0)	0.817
Indicated evaluations that were recommended or completed	9 (4.2%)	4 (3.6%)	5 (4.8%)	1.3 (0.3,5.9)	1.2 (-4.9,7.6)	0.743
Indicated evaluations that were completed	7 (3.2%)	4 (3.6%)	3 (2.9%)	0.8 (0.1,3.7)	-0.8 (-6.7,5.0)	1.000
Evaluations that were not indicated and completed	123 (56.9%)	56 (50.5%)	67 (63.8%)	1.3 (1.0,1.6)	13.4 (-0.2,26.5)	0.055

Notes:

P-values calculated by Cochran-Armitage trend test. *P-value <0.05, ** p-value <0.01, *** p-value <0.001

Supplemental Table. S3b Primary outcome: indication and completion of total evaluations (missing evaluations excluded)

Total evaluations: Celiac screen, Sleep study, Thyroid test, Audiogram, Ophthalmology	Level	Randomized Group			P-value
		Overall (N = 216)	Control (N = 111)	DSC2U (N = 105)	
Indicated evaluations	0	42 (19.4%)	20 (18.0%)	22 (21.0%)	0.608
	1	67 (31.0%)	33 (29.7%)	34 (32.4%)	
	2	73 (33.8%)	40 (36.0%)	33 (31.4%)	
	3	27 (12.5%)	15 (13.5%)	12 (11.4%)	
	4	6 (2.8%)	3 (2.7%)	3 (2.9%)	
	5	1 (0.5%)	0 (0.0%)	1 (1.0%)	
Indicated evaluations that were recommended or completed	0	134 (62.0%)	77 (69.4%)	57 (54.3%)	0.004**
	1	67 (31.0%)	31 (27.9%)	36 (34.3%)	
	2	13 (6.0%)	3 (2.7%)	10 (9.5%)	
	3	2 (0.9%)	0 (0.0%)	2 (1.9%)	
Indicated evaluations that were completed	0	153 (70.8%)	82 (73.9%)	71 (67.6%)	0.050*
	1	52 (24.1%)	28 (25.2%)	24 (22.9%)	
	2	10 (4.6%)	1 (0.9%)	9 (8.6%)	
	3	1 (0.5%)	0 (0.0%)	1 (1.0%)	
Evaluations that were not indicated and completed	0	38 (17.6%)	24 (21.6%)	14 (13.3%)	0.012*
	1	54 (25.0%)	35 (31.5%)	19 (18.1%)	
	2	56 (25.9%)	23 (20.7%)	33 (31.4%)	
	3	37 (17.1%)	15 (13.5%)	22 (21.0%)	
	4	28 (13.0%)	13 (11.7%)	15 (14.3%)	
	5	3 (1.4%)	1 (0.9%)	2 (1.9%)	

Notes:

P-values from two-sample t-tests. *P-value <0.05, ** p-value <0.01, *** p-value <0.001

Supplemental Table S3c. Completion of indicated evaluations (missing evaluations excluded)

Total evaluations: Celiac screen, Sleep study, Thyroid test, Audiogram, Ophthalmology	Randomized Group			Difference Control v. DSC2U (95% Confidence Interval)	P-value
	Overall (N = 216)	Control (N = 111)	DSC2U (N = 105)		
Indicated evaluations	1.50±1.06 (0.00,5.00)	1.53±1.03 (0.00,4.00)	1.46±1.09 (0.00,5.00)	0.074 (-0.21, 0.358)	0.606
Indicated evaluations that were recommended or completed	0.46±0.65 (0.00,3.00)	0.33±0.53 (0.00,2.00)	0.59±0.74 (0.00,3.00)	-0.26 (-0.43, -0.09)	0.004**
Indicated evaluations that were completed	0.35±0.59 (0.00,3.00)	0.27±0.47 (0.00,2.00)	0.43±0.69 (0.00,3.00)	-0.16 (-0.32, -0.00)	0.049*
Evaluations that were not indicated and completed	1.87±1.33 (0.00,5.00)	1.65±1.33 (0.00,5.00)	2.10±1.29 (0.00,5.00)	-0.46 (-0.81, -0.10)	0.011*

Notes:

P-values from two-sample t-tests. *P-value <0.05, ** p-value <0.01, *** p-value <0.001

S13: Subgroup Analyses: Subgroups were defined by the following attributes: (1) giving or not giving the PCP Plan before or during the wellness visit; (2) completion or not of the 2-week and 7-month surveys after the PCP visit; (3) race and ethnicity comparing white non-Hispanic individuals with DS with all others; (4) age of individuals with DS greater vs. less than or equal to 18 years, and (5) private vs. public insurance coverage. We treated loss to follow-up as wholly non-informative (i.e., completely at random) with respect to non-completion.

Supplemental Table S4a. Subgroup analysis of primary outcome: caregivers who did versus caregivers who did not share the Primary Care Provider Plan with PCP before or during wellness visit

Variable		Member of Caregiver Subgroup			P-value*
		Overall (N=230)	Did not share PCP Plan before wellness visit (N=13)	Did share PCP Plan before wellness visit (N=217)	
Number of indicated evaluations that were recommended or completed [†]	0	134 (62.0%)	7 (77.8%)	127 (61.4%)	0.267
	1	67 (31.0%)	2 (22.2%)	65 (31.4%)	
	2	13 (6.0%)	0 (0.0%)	13 (6.3%)	
	3	2 (0.9%)	0 (0.0%)	2 (1.0%)	
	[missing]	14	4	10	
Number of indicated and completed [†]	0	153 (70.8%)	7 (77.8%)	146 (70.5%)	0.516
	1	52 (24.1%)	2 (22.2%)	50 (24.2%)	
	2	10 (4.6%)	0 (0.0%)	10 (4.8%)	
	3	1 (0.5%)	0 (0.0%)	1 (0.5%)	
	[missing]	14	4	10	
Number of not indicated and completed	0	38 (17.6%)	1 (11.1%)	37 (17.9%)	0.184
	1	54 (25.0%)	2 (22.2%)	52 (25.1%)	
	2	56 (25.9%)	2 (22.2%)	54 (26.1%)	
	3	37 (17.1%)	1 (11.1%)	36 (17.4%)	
	4	28 (13.0%)	2 (22.2%)	26 (12.6%)	
	5	3 (1.4%)	1 (11.1%)	2 (1.0%)	
	[missing]	14	4	10	

Notes:

*P-value <0.05, ** p-value <0.01, *** p-value <0.001

[†]These variables were scaled from 0–5, where each value represents the number of evaluations indicated, completed or recommended. The numbers not represented here (e.g., 4, 5) had zero responses.

Supplemental Table S4b. Subgroup analysis of primary outcome: caregivers who shared Primary Care Plan with PCP before or during wellness visit versus those who did not (differences within groups)

Outcome measure	Subgroup membership (No = did not share before wellness visit; Yes = did share before wellness visit)	Randomized Group	Mean or Difference [†]	Standard Error	95% Confidence Interval		P-value	
					Lower	Upper		
Number of indicated evaluations that were recommended or completed	No	Control	-0.000	0.463	-0.912	0.912	0.611	
		DSC2U	0.250	0.164	-0.073	0.573		
		DSC2U v Control	0.250	0.491	-0.718	1.218		
	Yes	Control	0.336	0.062	0.215	0.458		0.002**
		DSC2U	0.619	0.066	0.489	0.748		
		DSC2U v Control	0.282	0.090	0.105	0.459		
	Yes v No	Control	0.336	0.467	-0.584	1.257		0.472
		DSC2U	0.369	0.176	0.021	0.716		0.038*
		DSC2U v Control	0.032	0.499	-0.952	1.016		0.949
Number of indicated evaluations that were completed	No	Control	-0.000	0.463	-0.912	0.912	0.611	
		DSC2U	0.250	0.164	-0.073	0.573		
		DSC2U v Control	0.250	0.491	-0.718	1.218		
	Yes	Control	0.273	0.056	0.162	0.384		0.040*
		DSC2U	0.443	0.060	0.325	0.562		
		DSC2U v Control	0.171	0.082	0.008	0.333		
	Yes v No	Control	0.273	0.466	-0.647	1.192		0.559
		DSC2U	0.193	0.174	-0.150	0.537		0.269
		DSC2U v Control	-0.079	0.498	-1.061	0.902		0.873

Number of evaluations not indicated and completed	No	Control	3.000	1.768	-0.485	6.485	
		DSC2U	2.375	0.625	1.143	3.607	
		DSC2U v Control	-0.625	1.875	-4.321	3.071	0.739
	Yes	Control	1.636	0.123	1.393	1.879	
		DSC2U	2.082	0.131	1.824	2.341	
		DSC2U v Control	0.446	0.180	0.091	0.801	0.014**
	Yes v No	Control	-1.364	1.772	-4.857	2.129	0.442
		DSC2U	-0.293	0.639	-1.551	0.966	0.647
		DSC2U v Control	1.071	1.884	-2.642	4.784	0.570

Notes:

*P-value <0.05, ** p-value <0.01, *** p-value <0.001

†Mean or Difference: for a specific subgroup membership and a specific treatment group, the reported values are means. For any comparison, whether between the two treatment groups or between the two sub-group levels or both, the reported values are differences, or differences of differences.

Supplemental Table S5a. Subgroup analysis of primary outcome: participants who completed the 2-week and 7-month surveys versus those who did not

Variable		Member of Caregiver Subgroup			P-value
		Overall (N=230)	Did not complete survey (N=30)	Completed survey (N=200)	
Number of indicated evaluations that were recommended or completed [†]	0	134 (62.0%)	12 (75.0%)	122 (61.0%)	0.352
	1	67 (31.0%)	3 (18.8%)	64 (32.0%)	
	2	13 (6.0%)	1 (6.3%)	12 (6.0%)	
	3	2 (0.9%)	0 (0.0%)	2 (1.0%)	
	[missing]	14	14	0	
Number of indicated evaluations that were completed [†]	0	153 (70.8%)	13 (81.3%)	140 (70.0%)	0.493
	1	52 (24.1%)	2 (12.5%)	50 (25.0%)	
	2	10 (4.6%)	1 (6.3%)	9 (4.5%)	
	3	1 (0.5%)	0 (0.0%)	1 (0.5%)	
	[missing]	14	14	0	
Number of evaluations not indicated and completed	0	38 (17.6%)	3 (18.8%)	35 (17.5%)	0.684
	1	54 (25.0%)	4 (25.0%)	50 (25.0%)	
	2	56 (25.9%)	2 (12.5%)	54 (27.0%)	
	3	37 (17.1%)	5 (31.3%)	32 (16.0%)	
	4	28 (13.0%)	1 (6.3%)	27 (13.5%)	
	5	3 (1.4%)	1 (6.3%)	2 (1.0%)	
	[missing]	14	14	0	

Notes:

*P-value <0.05, ** p-value <0.01, *** p-value <0.001

[†]These variables were scaled from 0–5, where each value represents the number of evaluations indicated, completed or recommended. The numbers not represented here (e.g., 4, 5) had zero responses.

Supplementary Table S5b. Subgroup analysis of primary outcome: participants who completed the 2-week and 7-month surveys versus those who did not (differences within group)

Outcome measure	Subgroup membership: (No = did not complete survey; Yes = did complete survey)	Treatment	Mean or Difference	Standard Error	95% Confidence Interval		P-value	
					Lower	Upper		
Number of indicated evaluations that were recommended or completed	No	Control	0.333	0.254	-0.168	0.835	0.918	
		DSC2U	0.300	0.197	-0.088	0.688		
		DSC2U v Control	-0.033	0.322	-0.667	0.601		
	Yes	Control	0.333	0.063	0.210	0.457		0.002**
		DSC2U	0.621	0.066	0.491	0.751		
		DSC2U v Control	0.288	0.091	0.108	0.467		
	Yes v No	Control	0.000	0.262	-0.516	0.516		1.000
		DSC2U	0.321	0.208	-0.088	0.731		0.124
		DSC2U v Control	0.321	0.334	-0.338	0.980		0.338
Number of indicated evaluations that were completed	No	Control	0.333	0.242	-0.144	0.811	0.664	
		DSC2U	0.200	0.188	-0.170	0.570		
		DSC2U v Control	-0.133	0.307	-0.738	0.471		
	Yes	Control	0.267	0.057	0.154	0.379		0.026*
		DSC2U	0.453	0.060	0.334	0.571		
		DSC2U v Control	0.186	0.083	0.022	0.350		
	Yes v No	Control	-0.067	0.249	-0.558	0.424		0.789
		DSC2U	0.253	0.197	-0.136	0.641		0.201
		DSC2U v Control	0.319	0.318	-0.307	0.945		0.316

Number of evaluations not indicated and completed	No	Control	1.167	0.570	0.042	2.291	
		DSC2U	2.500	0.442	1.629	3.371	
		DSC2U v Control	1.333	0.722	-0.089	2.756	0.066
	Yes	Control	1.676	0.127	1.425	1.927	
		DSC2U	2.063	0.134	1.799	2.327	
		DSC2U v Control	0.387	0.185	0.023	0.751	0.037*
	Yes v No	Control	0.510	0.584	-0.643	1.662	0.384
		DSC2U	-0.437	0.462	-1.347	0.473	0.345
		DSC2U v Control	-0.946	0.745	-2.415	0.522	0.205

Notes:

*P-value <0.05, ** p-value <0.01, *** p-value <0.001

Supplemental Table S6a. Subgroup analysis of primary outcome - difference between non-Hispanic whites and other racial/ethnic groups

Variable		Member of Caregiver Subgroup			P-value
		Overall (N=230)	Did not complete (N=54)	Did complete (N=176)	
Number of indicated evaluations that were recommended or completed [†]	0	134 (62.0%)	32 (62.7%)	102 (61.8%)	0.518
	1	67 (31.0%)	13 (25.5%)	54 (32.7%)	
	2	13 (6.0%)	5 (9.8%)	8 (4.8%)	
	3	2 (0.9%)	1 (2.0%)	1 (0.6%)	
	[missing]	14	3	11	
Number of indicated evaluations that were completed [†]	0	153 (70.8%)	35 (68.6%)	118 (71.5%)	0.243
	1	52 (24.1%)	11 (21.6%)	41 (24.8%)	
	2	10 (4.6%)	4 (7.8%)	6 (3.6%)	
	3	1 (0.5%)	1 (2.0%)	0 (0.0%)	
	[missing]	14	3	11	
Number of evaluations not indicated and completed	0	38 (17.6%)	14 (27.5%)	24 (14.5%)	0.595
	1	54 (25.0%)	9 (17.6%)	45 (27.3%)	
	2	56 (25.9%)	11 (21.6%)	45 (27.3%)	
	3	37 (17.1%)	9 (17.6%)	28 (17.0%)	
	4	28 (13.0%)	7 (13.7%)	21 (12.7%)	
	5	3 (1.4%)	1 (2.0%)	2 (1.2%)	
	[missing]	14	3	11	

Notes:

*P-value <0.05, ** p-value <0.01, *** p-value <0.001

[†]These variables were scaled from 0–5, where each value represents the number of evaluations indicated, completed or recommended. The numbers not represented here (e.g., 4, 5) had zero responses.

Supplemental Table S6b. Subgroup analysis of primary outcome - difference between non-Hispanic whites and other racial/ethnic groups (differences within groups)

Outcome measure	Subgroup membership: (No = did not complete; Yes did complete)	Treatment	Mean or Difference	Standard Error	95% Confidence Interval		P-value	
					Lower	Upper		
Number of indicated evaluations that were recommended or completed	No	Control	0.292	0.150	-0.005	0.588	0.047*	
		DSC2U	0.704	0.142	0.424	0.983		
		DSC2U v Control	0.412	0.207	0.005	0.819		
	Yes	Control	0.345	0.066	0.216	0.474		0.031*
		DSC2U	0.551	0.069	0.415	0.688		
		DSC2U v Control	0.206	0.095	0.018	0.394		
	Yes v No	Control	0.053	0.164	-0.270	0.377		0.746
		DSC2U	-0.152	0.158	-0.463	0.159		0.335
		DSC2U v Control	-0.206	0.228	-0.654	0.243		0.367
Number of indicated evaluations that were completed	No	Control	0.250	0.146	-0.038	0.538	0.089	
		DSC2U	0.593	0.138	0.322	0.864		
		DSC2U v Control	0.343	0.200	-0.053	0.738		
	Yes	Control	0.276	0.058	0.162	0.390		0.256
		DSC2U	0.372	0.061	0.251	0.492		
		DSC2U v Control	0.096	0.084	-0.070	0.262		
	Yes v No	Control	0.026	0.157	-0.284	0.335		0.869
		DSC2U	-0.221	0.151	-0.517	0.076		0.144
		DSC2U v Control	-0.247	0.217	-0.675	0.182		0.258

Number of evaluations not indicated and completed	No	Control	1.708	0.304	1.110	2.307	
		DSC2U	1.852	0.286	1.288	2.416	
		DSC2U v Control	0.144	0.417	-0.679	0.966	0.731
	Yes	Control	1.632	0.134	1.367	1.897	
		DSC2U	2.192	0.142	1.912	2.472	
		DSC2U v Control	0.560	0.196	0.175	0.946	0.005**
	Yes v No	Control	-0.076	0.332	-0.731	0.578	0.819
		DSC2U	0.340	0.319	-0.289	0.970	0.288
		DSC2U v Control	0.417	0.461	-0.492	1.325	0.367

Notes:

*P-value <0.05, ** p-value <0.01, *** p-value <0.001

Supplemental Table S7a. Subgroup analysis of primary outcome - difference between adults with DS (>18 years) and children with DS (<18 years)

Variable		Overall (N = 230)	Member of Subgroup		P-value
			Did not complete (N=182)	Did complete (N=48)	
Number of indicated evaluations that were recommended or completed [†]	0	134 (62.0%)	100 (59.2%)	34 (72.3%)	0.161
	1	67 (31.0%)	57 (33.7%)	10 (21.3%)	
	2	13 (6.0%)	10 (5.9%)	3 (6.4%)	
	3	2 (0.9%)	2 (1.2%)	0 (0.0%)	
	[missing]	14	13	1	
Number of indicated evaluations that were completed [†]	0	153 (70.8%)	117 (69.2%)	36 (76.6%)	0.353
	1	52 (24.1%)	43 (25.4%)	9 (19.1%)	
	2	10 (4.6%)	8 (4.7%)	2 (4.3%)	
	3	1 (0.5%)	1 (0.6%)	0 (0.0%)	
	[missing]	14	13	1	
Number of evaluations not indicated and completed	0	38 (17.6%)	26 (15.4%)	12 (25.5%)	0.009**
	1	54 (25.0%)	39 (23.1%)	15 (31.9%)	
	2	56 (25.9%)	46 (27.2%)	10 (21.3%)	
	3	37 (17.1%)	29 (17.2%)	8 (17.0%)	
	4	28 (13.0%)	26 (15.4%)	2 (4.3%)	
	5	3 (1.4%)	3 (1.8%)	0 (0.0%)	
	[missing]	14	13	1	

Notes:

*P-value <0.05, ** p-value <0.01, *** p-value <0.001

[†]These variables were scaled from 0–5, where each value represents the number of evaluations indicated, completed or recommended. The numbers not represented here (e.g., 4, 5) had zero responses.

Supplementary Table S7b. Subgroup analysis of primary outcome - difference between adults with DS (>18 years) and children with DS (<18 years) (difference within groups)

Outcome measure	Subgroup membership: (No = did not complete; Yes = did complete)	Treatment	Mean or Difference	Standard Error	95% Confidence Interval		P-value	
					Lower	Upper		
Number of indicated evaluations that were recommended or completed	No	Control	0.341	0.070	0.202	0.480	0.003**	
		DSC2U	0.643	0.071	0.503	0.782		
		DSC2U v Control	0.302	0.100	0.105	0.499		
	Yes	Control	0.308	0.119	0.074	0.542		0.680
		DSC2U	0.381	0.132	0.121	0.641		
		DSC2U v Control	0.073	0.178	-0.277	0.423		
	Yes v No	Control	-0.033	0.138	-0.306	0.239		0.809
		DSC2U	-0.262	0.150	-0.557	0.034		0.082
		DSC2U v Control	-0.228	0.204	-0.630	0.173		0.264
Number of indicated evaluations that were completed	No	Control	0.259	0.065	0.131	0.386	0.019*	
		DSC2U	0.476	0.065	0.348	0.604		
		DSC2U v Control	0.217	0.092	0.037	0.398		
	Yes	Control	0.308	0.107	0.097	0.518		0.664
		DSC2U	0.238	0.119	0.004	0.472		
		DSC2U v Control	-0.070	0.160	-0.385	0.245		
	Yes v No	Control	0.049	0.125	-0.197	0.295		0.696
		DSC2U	-0.238	0.135	-0.505	0.029		0.080
		DSC2U v Control	-0.287	0.184	-0.650	0.076		0.121

Number of evaluations not indicated and completed	No	Control	1.776	0.144	1.492	2.061	
		DSC2U	2.214	0.145	1.928	2.500	
		DSC2U v Control	0.438	0.204	0.035	0.841	0.033*
	Yes	Control	1.231	0.229	0.780	1.682	
		DSC2U	1.667	0.255	1.165	2.169	
		DSC2U v Control	0.436	0.342	-0.239	1.111	0.204
	Yes v No	Control	-0.546	0.270	-1.079	-0.013	0.045*
		DSC2U	-0.548	0.293	-1.125	0.030	0.063
		DSC2U v Control	-0.002	0.399	-0.788	0.784	0.996

Notes:

*P-value <0.05, ** p-value <0.01, *** p-value <0.001

Supplemental Table S8a. Subgroup analysis of primary outcome - difference between people with DS who have private insurance versus others

Variable		Overall (N = 230)	Member of Subgroup		P-value
			Did not complete (N=63)	Did complete (N=167)	
Number of indicated evaluations that were recommended or completed [†]	0	134 (62.0%)	40 (67.8%)	94 (59.9%)	0.632
	1	67 (31.0%)	14 (23.7%)	53 (33.8%)	
	2	13 (6.0%)	4 (6.8%)	9 (5.7%)	
	3	2 (0.9%)	1 (1.7%)	1 (0.6%)	
	[missing]	14	4	10	
Number of indicated evaluations that were completed [†]	0	153 (70.8%)	45 (76.3%)	108 (68.8%)	0.519
	1	52 (24.1%)	11 (18.6%)	41 (26.1%)	
	2	10 (4.6%)	2 (3.4%)	8 (5.1%)	
	3	1 (0.5%)	1 (1.7%)	0 (0.0%)	
	[missing]	14	4	10	
Number of evaluations not indicated and completed	0	38 (17.6%)	12 (20.3%)	26 (16.6%)	0.232
	1	54 (25.0%)	20 (33.9%)	34 (21.7%)	
	2	56 (25.9%)	10 (16.9%)	46 (29.3%)	
	3	37 (17.1%)	9 (15.3%)	28 (17.8%)	
	4	28 (13.0%)	7 (11.9%)	21 (13.4%)	
	5	3 (1.4%)	1 (1.7%)	2 (1.3%)	
	[missing]	14	4	10	

Notes:

*P-value <0.05, ** p-value <0.01, *** p-value <0.001

[†]These variables were scaled from 0–5, where each value represents the number of evaluations indicated, completed or recommended. The numbers not represented here (e.g., 4, 5) had zero responses.

Supplemental Table S8b. Subgroup analysis of primary outcome - difference between people with DS who have private insurance versus others (difference within groups)

Outcome Measure	Subgroup membership: (No = did not complete survey; Yes = did complete survey)	Treatment	Mean or Difference	Standard Error	95 % Confidence Interval		P-value	
					Lower	Upper		
Number of indicated evaluations that were recommended or completed	No	Control	0.241	0.127	-0.008	0.491	0.045*	
		DSC2U	0.600	0.125	0.355	0.845		
		DSC2U v Control	0.359	0.178	0.009	0.709		
	Yes	Control	0.366	0.069	0.229	0.503		0.029*
		DSC2U	0.587	0.073	0.444	0.730		
		DSC2U v Control	0.221	0.100	0.023	0.419		
	Yes v No	Control	0.124	0.144	-0.160	0.409		0.390
		DSC2U	-0.013	0.144	-0.297	0.271		0.926
		DSC2U v Control	-0.138	0.204	-0.540	0.264		0.500
Number of indicated evaluations that were completed	No	Control	0.207	0.115	-0.020	0.434	0.234	
		DSC2U	0.400	0.113	0.177	0.623		
		DSC2U v Control	0.193	0.162	-0.126	0.512		
	Yes	Control	0.293	0.064	0.167	0.418		0.111
		DSC2U	0.440	0.067	0.309	0.571		
		DSC2U v Control	0.147	0.092	-0.034	0.329		
	Yes v No	Control	0.086	0.132	-0.174	0.345		0.515
		DSC2U	0.040	0.131	-0.219	0.299		0.761
		DSC2U v Control	-0.046	0.186	-0.412	0.321		0.806

Number of evaluations not indicated and completed	No	Control	1.448	0.252	0.951	1.945	
		DSC2U	1.933	0.248	1.445	2.422	
		DSC2U v Control	0.485	0.354	-0.212	1.182	0.171
	Yes	Control	1.720	0.143	1.438	2.001	
		DSC2U	2.173	0.149	1.879	2.468	
		DSC2U v Control	0.454	0.207	0.046	0.861	0.029*
	Yes v No	Control	0.271	0.290	-0.300	0.842	0.350
		DSC2U	0.240	0.289	-0.330	0.810	0.408
		DSC2U v Control	-0.031	0.409	-0.838	0.776	0.939

Notes:

*P-value <0.05, ** p-value <0.01, *** p-value <0.001

S14: Supplemental Table S9. Regression analysis – spearman rank correlations

Outcome	Predictor	N	Correlation	95% Confidence Interval		Nom P- value ^{¶¶}	Adj P value ^{##}	Full Adj P- value
				Lower	Upper			
Number of indicated evaluations that were recommended or completed	Person with DS: age at baseline survey	216	-0.094	-0.225	0.040	0.167	1.000	1.000
	Person with DS: sex	216	-0.023	-0.156	0.111	0.736	1.000	1.000
	Person with DS: race	213	0.004	-0.131	0.138	0.955	1.000	1.000
	Person with DS: ethnicity	213	0.044	-0.091	0.177	0.522	1.000	1.000
	Person with DS: primary Insurance at Randomization	216	-0.059	-0.191	0.075	0.390	1.000	1.000
	Caregiver: PedsQL Psychosocial Health Score [*]	215	0.027	-0.107	0.160	0.695	1.000	1.000
	Caregiver: PedsQL Physical Functioning Score [†]	215	0.021	-0.113	0.154	0.761	1.000	1.000
	Caregiver: PedsQL Total Scale Score [‡]	216	0.020	-0.114	0.153	0.771	1.000	1.000
	Caregiver: age at baseline survey	213	-0.063	-0.196	0.072	0.358	1.000	1.000
	Caregiver: gender	216	-0.070	-0.201	0.065	0.308	1.000	1.000
	Caregiver: race	213	0.032	-0.103	0.166	0.639	1.000	1.000
	Caregiver: ethnicity	215	-0.016	-0.149	0.118	0.819	1.000	1.000
	Caregiver relation to person with DS	216	-0.122	-0.251	0.012	0.073	1.000	1.000
	Caregiver educational level	216	-0.141	-0.270	-0.008	0.038	1.000	1.000
	Caregiver marital status?	216	-0.050	-0.182	0.084	0.462	1.000	1.000
	Caregiver: PedsQL FIM Parental HRQL Summary Score [§]	216	-0.050	-0.182	0.084	0.462	1.000	1.000

Caregiver: PedsQL FIM Family Functioning Summary Score [¶]	216	-0.102	-0.233	0.032	0.134	1.000	1.000
Caregiver: PedsQL FIM Total Scale Score [#]	216	-0.063	-0.195	0.071	0.353	1.000	1.000
Caregiver: low health literacy ^{**}	216	-0.037	-0.169	0.097	0.593	1.000	1.000
Caregiver: low numeracy ^{††}	215	0.025	-0.109	0.159	0.711	1.000	1.000
Caregiver: time to travel to primary care provider	216	-0.059	-0.191	0.075	0.387	1.000	1.000
Caregiver: accessibility of routine blood tests	215	-0.094	-0.225	0.040	0.170	1.000	1.000
Caregiver: accessibility for referrals to physician specialist for consultation	215	-0.057	-0.189	0.078	0.409	1.000	1.000
Caregiver: accessibility to complex imaging (CT, MRI)	202	-0.048	-0.185	0.091	0.498	1.000	1.000
Caregiver: out of your pocket health care costs for all members of the household	201	-0.003	-0.142	0.135	0.963	1.000	1.000
Caregiver: HCAHPS ^{‡‡} top-level score (%)	206	0.055	-0.082	0.190	0.431	1.000	1.000
Caregiver: wellness visit rating ^{§§}	206	0.014	-0.123	0.151	0.840	1.000	1.000
PCP: gender	166	-0.010	-0.162	0.142	0.898	1.000	1.000
PCP: race	165	-0.089	-0.239	0.065	0.255	1.000	1.000
PCP: ethnicity	166	-0.059	-0.210	0.094	0.448	1.000	1.000
PCP role (e.g., MD, NP)	167	-0.036	-0.187	0.116	0.640	1.000	1.000
PCP specialty	167	0.037	-0.115	0.188	0.630	1.000	1.000
PCP: years in practice	165	-0.153	-0.299	-0.001	0.048	1.000	1.000
PCP: panel size	150	-0.038	-0.197	0.123	0.642	1.000	1.000
PCP: number of patients with DS	157	-0.047	-0.202	0.111	0.562	1.000	1.000
PCP: practice size	166	-0.013	-0.165	0.139	0.864	1.000	1.000
PCP: practice setting	165	0.045	-0.109	0.196	0.569	1.000	1.000

PCP: federally qualified community health center	167	-0.028	-0.179	0.124	0.718	1.000	1.000
PCP: difficulty obtaining Thyroid testing	167	-0.290	-0.424	-0.145	<.001	0.006	0.056
PCP: difficulty obtaining Celiac screening	167	-0.213	-0.354	-0.063	0.005	0.272	1.000
PCP: difficulty obtaining Audiogram	166	-0.051	-0.202	0.102	0.515	1.000	1.000
PCP: difficulty obtaining Sleep studies	167	0.004	-0.148	0.155	0.963	1.000	1.000
PCP: difficulty obtaining Ophthalmology assessment	166	0.049	-0.104	0.199	0.533	1.000	1.000
PCP: length of relationship with patient	159	-0.056	-0.210	0.100	0.480	1.000	1.000
PCP: familiarity with medical history	167	-0.070	-0.219	0.083	0.371	1.000	1.000
PCP: familiarity with psychosocial history	167	-0.046	-0.196	0.107	0.555	1.000	1.000
PCP: quality of communication with caregiver	167	0.036	-0.116	0.187	0.643	1.000	1.000
PCP: duration of most recent wellness visit	166	-0.004	-0.156	0.149	0.962	1.000	1.000
PCP: were you able to spend enough time with [name]?	166	0.038	-0.115	0.189	0.626	1.000	1.000
PCP: caregiver able to provide information	165	0.003	-0.150	0.155	0.972	1.000	1.000
PCP: did the caregiver talk about any concerns he/she had about [name]'s health?	163	0.195	0.042	0.338	0.012	0.604	1.000

How would you rate the Caregiver Checklist?	Person with DS: age at baseline survey	101	-0.002	-0.193	0.1948	0.982	1.000	1.000
	Person with DS: sex	101	-0.006	-0.201	0.190	0.956	1.000	1.000
	Person with DS: race	100	-0.018	-0.213	0.179	0.860	1.000	1.000
	Person with DS: ethnicity	100	0.234	0.039	0.412	0.018	0.912	1.000
	Person with DS: primary Insurance at Randomization	101	0.019	-0.177	0.214	0.848	1.000	1.000
	Caregiver: PedsQL Psychosocial Health Score*	100	-0.120	-0.309	0.078	0.232	1.000	1.000
	Caregiver: PedsQL Physical Functioning Score†	101	0.002	-0.194	0.197	0.986	1.000	1.000
	Caregiver: PedsQL Total Scale Score‡	101	-0.109	-0.298	0.089	0.278	1.000	1.000
	Caregiver: age at baseline survey	101	0.095	-0.103	0.285	0.345	1.000	1.000
	Caregiver: gender	101	0.089	-0.108	0.280	0.375	1.000	1.000
	Caregiver: race	100	-0.001	-0.198	0.195	0.990	1.000	1.000
	Caregiver: ethnicity	101	0.295	0.106	0.464	0.002	0.127	1.000
	Caregiver: how are you related to [name]?	101	-0.153	-0.338	0.044	0.126	1.000	1.000
	Caregiver: what is the highest level or grade of school that you have completed?	101	-0.127	-0.315	0.070	0.203	1.000	1.000
	Caregiver: what is your marital status?	101	0.033	-0.164	0.227	0.743	1.000	1.000
	Caregiver: PedsQL FIM Parental HRQL Summary Score§	101	-0.099	-0.289	0.098	0.323	1.000	1.000
	Caregiver: PedsQL FIM Family Functioning Summary Score¶	101	-0.039	-0.232	0.158	0.700	1.000	1.000
	Caregiver: PedsQL FIM Total Scale Score#	101	-0.063	-0.255	0.134	0.531	1.000	1.000

Caregiver: low health literacy**	101	-0.093	-0.284	0.104	0.351	1.000	1.000
Caregiver: low numeracy††	101	0.006	-0.189	0.201	0.951	1.000	1.000
Caregiver: time to travel to primary care provider	101	-0.084	-0.275	0.113	0.400	1.000	1.000
Caregiver: routine blood tests (blood counts, lead)	101	-0.075	-0.266	0.122	0.456	1.000	1.000
Caregiver: referral to physician specialist for consultation	100	-0.162	-0.348	0.035	0.105	1.000	1.000
Caregiver: complex imaging (CT, MRI)	95	-0.116	-0.311	0.087	0.260	1.000	1.000
Caregiver: out of your pocket health care costs for all members of the household	100	-0.011	-0.207	0.186	0.914	1.000	1.000
Caregiver: HCAHPS‡‡ top-level score (%)	101	0.209	0.015	0.389	0.034	1.000	1.000
Caregiver: wellness visit rating§§	101	0.215	0.021	0.394	0.029	1.000	1.000
PCP: gender	82	0.040	-0.178	0.255	0.718	1.000	1.000
PCP: race	82	0.089	-0.130	0.300	0.423	1.000	1.000
PCP: ethnicity	82	-0.047	-0.262	0.172	0.672	1.000	1.000
PCP: role (e.g., MD, NP)	81	-0.001	-0.220	0.217	0.990	1.000	1.000
PCP: specialty	82	-0.072	-0.285	0.147	0.517	1.000	1.000
PCP: years in practice	81	-0.052	-0.267	0.168	0.645	1.000	1.000
PCP: panel size	73	-0.089	-0.313	0.144	0.452	1.000	1.000
PCP: number of patients with DS	79	-0.099	-0.313	0.125	0.384	1.000	1.000
PCP: practice size	82	0.055	-0.164	0.269	0.624	1.000	1.000
PCP: practice setting	82	0.143	-0.076	0.349	0.197	1.000	1.000
PCP: federally qualified community health center	82	0.174	-0.044	0.377	0.115	1.000	1.000
PCP: difficulty obtaining Thyroid	82	0.147	-0.072	0.353	0.185	1.000	1.000

testing

	PCP: difficulty obtaining Celiac screening	82	0.136	-0.083	0.343	0.220	1.000	1.000
	PCP: difficulty obtaining Audiogram	82	-0.023	-0.239	0.195	0.839	1.000	1.000
	PCP: difficulty obtaining Sleep studies	82	0.029	-0.189	0.245	0.793	1.000	1.000
	PCP: difficulty obtaining Ophthalmology assessment	82	0.133	-0.086	0.340	0.231	1.000	1.000
	PCP: length of relationship with patient	75	-0.126	-0.343	0.104	0.280	1.000	1.000
	PCP: familiarity with medical history	82	-0.007	-0.223	0.211	0.952	1.000	1.000
	PCP: familiarity with psychosocial history	82	0.089	-0.131	0.300	0.426	1.000	1.000
	PCP: quality of communication with caregiver	82	-0.034	-0.249	0.185	0.762	1.000	1.000
	PCP: duration of most recent wellness visit	82	0.095	-0.124	0.306	0.393	1.000	1.000
	PCP: were you able to spend enough time with [name]?	82	-0.027	-0.243	0.191	0.809	1.000	1.000
	PCP: caregiver able to provide information	81	0.178	-0.042	0.382	0.109	1.000	1.000
	PCP: did the caregiver talk to you about any concerns about [name]'s health?	81	0.091	-0.130	0.304	0.416	1.000	1.000
Would you recommend DSC2U to another	Person with DS: age at baseline survey	101	-0.027	-0.221	0.170	0.791	1.000	1.000
	Person with DS: sex	101	0.023	-0.174	0.217	0.822	1.000	1.000
	Person with DS: race	100	-0.017	-0.212	0.180	0.870	1.000	1.000

caregiver?	Person with DS: ethnicity	100	0.182	-0.015	0.365	0.069	1.000	1.000
	Person with DS: primary Insurance at Randomization	101	0.003	-0.193	0.198	0.977	1.000	1.000
	Caregiver: PedsQL Psychosocial Health Score*	100	-0.157	-0.343	0.040	0.116	1.000	1.000
	Caregiver: PedsQL Physical Functioning Score†	101	0.038	-0.159	0.231	0.708	1.000	1.000
	Caregiver: PedsQL Total Scale Score‡	101	-0.118	-0.306	0.080	0.240	1.000	1.000
	Caregiver: age at baseline survey	101	-0.038	-0.232	0.158	0.702	1.000	1.000
	Caregiver: gender	101	-0.026	-0.220	0.170	0.795	1.000	1.000
	Caregiver: race	100	0.062	-0.136	0.256	0.536	1.000	1.000
	Caregiver: ethnicity	101	0.164	-0.032	0.349	0.099	1.000	1.000
	Caregiver: how are you related to [name]?	101	0.041	-0.156	0.235	0.682	1.000	1.000
	Caregiver: what is the highest level or grade of school that you have completed?	101	0.030	-0.166	0.224	0.764	1.000	1.000
	Caregiver: what is your marital status?	101	-0.051	-0.244	0.146	0.614	1.000	1.000
	Caregiver: PedsQL FIM Parental HRQL Summary Score§	101	-0.102	-0.291	0.096	0.310	1.000	1.000
	Caregiver: PedsQL FIM Family Functioning Summary Score¶	101	-0.102	-0.291	0.096	0.309	1.000	1.000
	Caregiver: PedsQL FIM Total Scale Score#	101	-0.099	-0.289	0.098	0.323	1.000	1.000
	Caregiver: low health literacy**	101	-0.116	-0.305	0.081	0.246	1.000	1.000
	Caregiver: low numeracy††	101	0.032	-0.164	0.226	0.747	1.000	1.000
	Caregiver: time to travel to primary care provider	101	-0.103	-0.293	0.094	0.303	1.000	1.000

Caregiver: routine blood tests (blood counts, lead)	101	0.037	-0.160	0.230	0.716	1.000	1.000
Caregiver: referral to physician specialist for consultation	100	-0.124	-0.313	0.074	0.218	1.000	1.000
Caregiver: complex imaging (CT, MRI)	95	-0.146	-0.338	0.057	0.156	1.000	1.000
Caregiver: out of your pocket health care costs for all members of the household?	100	-0.103	-0.294	0.095	0.306	1.000	1.000
Caregiver: HCAHPS ^{††} top-level score (%)	101	0.140	-0.057	0.326	0.162	1.000	1.000
Caregiver: wellness visit rating ^{§§}	101	0.097	-0.100	0.287	0.331	1.000	1.000
PCP: gender	82	0.109	-0.110	0.319	0.326	1.000	1.000
PCP: race	82	0.144	-0.076	0.350	0.196	1.000	1.000
PCP: ethnicity	82	-0.031	-0.247	0.187	0.780	1.000	1.000
PCP: role (e.g., MD, NP)	81	0.097	-0.124	0.309	0.389	1.000	1.000
PCP: specialty	82	-0.091	-0.302	0.129	0.416	1.000	1.000
PCP: years in practice	81	0.011	-0.208	0.228	0.925	1.000	1.000
PCP: panel size	73	-0.122	-0.342	0.111	0.302	1.000	1.000
PCP: number of patients with DS	79	0.072	-0.151	0.289	0.525	1.000	1.000
PCP: practice size	82	-0.046	-0.260	0.173	0.684	1.000	1.000
PCP: practice setting	82	0.097	-0.123	0.307	0.386	1.000	1.000
PCP: federally qualified community health center	82	0.077	-0.142	0.290	0.488	1.000	1.000
PCP: difficulty obtaining Thyroid testing	82	0.003	-0.214	0.220	0.978	1.000	1.000
PCP: difficulty obtaining Celiac screening	82	-0.020	-0.236	0.198	0.858	1.000	1.000
PCP: difficulty obtaining Audiogram	82	-0.007	-0.223	0.211	0.951	1.000	1.000
PCP: difficulty obtaining Sleep studies	82	-0.105	-0.315	0.115	0.346	1.000	1.000
PCP: difficulty obtaining Ophthalmology assessment	82	0.062	-0.158	0.275	0.581	1.000	1.000

	PCP: length of relationship with patient	75	-0.124	-0.342	0.106	0.286	1.000	1.000
	PCP: familiarity with medical history	82	0.006	-0.211	0.223	0.959	1.000	1.000
	PCP: familiarity with psychosocial history	82	0.091	-0.128	0.302	0.413	1.000	1.000
	PCP: quality of communication with Caregiver	82	-0.177	-0.379	0.042	0.110	1.000	1.000
	PCP: duration of most recent wellness visit	82	0.076	-0.144	0.288	0.498	1.000	1.000
	PCP: were you able to spend enough time [name]?	82	-0.087	-0.298	0.133	0.438	1.000	1.000
	PCP: caregiver able to provide information	81	0.230	0.012	0.427	0.038	1.000	1.000
	PCP: did the caregiver talk about any concerns he/she had about [name]'s health?	81	0.176	-0.044	0.379	0.115	1.000	1.000
Would you re-read/re-use links in the Caregiver Checklist?	Person with DS: age at baseline survey	108	0.126	-0.065	0.308	0.192	1.000	1.000
	Person with DS: sex	108	-0.062	-0.248	0.129	0.524	1.000	1.000
	Person with DS: race	107	-0.022	-0.211	0.168	0.818	1.000	1.000
	Person with DS: ethnicity	107	-0.066	-0.253	0.126	0.499	1.000	1.000
	Person with DS: primary Insurance at Randomization	108	-0.007	-0.196	0.182	0.940	1.000	1.000
	Caregiver: PedsQL Psychosocial Health Score*	107	0.077	-0.114	0.263	0.426	1.000	1.000
	Caregiver: PedsQL Physical Functioning Score [†]	108	-0.037	-0.225	0.153	0.701	1.000	1.000
	Caregiver: PedsQL Total Scale Score [‡]	108	0.050	-0.140	0.237	0.606	1.000	1.000
	Caregiver: age at baseline survey	108	0.034	-0.156	0.222	0.725	1.000	1.000
	Caregiver: gender	108	0.004	-0.185	0.193	0.966	1.000	1.000
	Caregiver: race	107	-0.039	-0.227	0.152	0.690	1.000	1.000

Caregiver: ethnicity	108	-0.021	-0.209	0.169	0.830	1.000	1.000
Caregiver: how are you related to [name]?	108	-0.012	-0.201	0.177	0.898	1.000	1.000
Caregiver: what is the highest level or grade of school that you have completed?	108	-0.010	-0.199	0.179	0.918	1.000	1.000
Caregiver: what is your marital status?	108	0.037	-0.153	0.224	0.703	1.000	1.000
Caregiver: PedsQL FIM Parental HRQL Summary Score [§]	108	0.102	-0.089	0.285	0.293	1.000	1.000
Caregiver: PedsQL FIM Family Functioning Summary Score [¶]	108	0.072	-0.119	0.257	0.461	1.000	1.000
Caregiver: PedsQL FIM Total Scale Score [#]	108	0.100	-0.091	0.284	0.302	1.000	1.000
Caregiver: low health literacy ^{**}	108	0.029	-0.161	0.217	0.766	1.000	1.000
Caregiver: low numeracy ^{††}	108	0.028	-0.162	0.216	0.770	1.000	1.000
Caregiver: time to travel to primary care provider	108	0.092	-0.098	0.276	0.341	1.000	1.000
Caregiver: routine blood tests (blood counts, lead)	108	0.057	-0.133	0.244	0.554	1.000	1.000
Caregiver: referral to physician specialist for consultation	107	0.287	0.103	0.452	0.002	0.126	1.000
Caregiver: complex imaging (CT, MRI)	101	0.116	-0.081	0.305	0.245	1.000	1.000
Caregiver: out of your pocket health care costs for all members of the household?	107	-0.083	-0.268	0.109	0.395	1.000	1.000
Caregiver: HCAHPS ^{‡‡} top-level score (%)	108	0.055	-0.136	0.241	0.572	1.000	1.000
Caregiver: wellness visit rating ^{§§}	108	0.046	-0.144	0.233	0.636	1.000	1.000
PCP: gender	88	0.019	-0.191	0.228	0.857	1.000	1.000

PCP: race	88	0.009	-0.201	0.218	0.931	1.000	1.000
PCP: ethnicity	88	-0.005	-0.214	0.205	0.964	1.000	1.000
PCP: role (e.g., MD, NP)	87	0.217	0.007	0.409	0.042	1.000	1.000
PCP: specialty	88	0.125	-0.086	0.326	0.242	1.000	1.000
PCP: years in practice	87	-0.111	-0.314	0.102	0.306	1.000	1.000
PCP: panel size	78	0.037	-0.187	0.257	0.748	1.000	1.000
PCP: number of patients with DS	84	-0.036	-0.248	0.180	0.745	1.000	1.000
PCP: practice size	88	-0.107	-0.310	0.104	0.318	1.000	1.000
PCP: practice setting	87	-0.196	-0.390	0.015	0.067	1.000	1.000
PCP: federally qualified community health center	88	-0.003	-0.213	0.206	0.975	1.000	1.000
PCP: difficulty obtaining Thyroid testing	88	0.005	-0.204	0.215	0.959	1.000	1.000
PCP: difficulty obtaining Celiac screening	88	0.077	-0.135	0.281	0.477	1.000	1.000
PCP: difficulty obtaining Audiogram	88	0.017	-0.193	0.226	0.872	1.000	1.000
PCP: difficulty obtaining Sleep studies	88	0.119	-0.093	0.321	0.267	1.000	1.000
PCP: difficulty obtaining Ophthalmology assessment	88	0.034	-0.177	0.242	0.754	1.000	1.000
PCP: length of relationship with patient	80	0.185	-0.036	0.389	0.099	1.000	1.000
PCP: familiarity with medical history	88	-0.036	-0.243	0.175	0.742	1.000	1.000
PCP: familiarity with psychosocial history	88	-0.000	-0.210	0.209	0.999	1.000	1.000
PCP: quality of communication with caregiver	88	-0.090	-0.294	0.121	0.400	1.000	1.000
PCP: duration of most recent wellness visit	88	0.153	-0.058	0.351	0.152	1.000	1.000
PCP: were you able to spend enough time with [name]?	88	0.011	-0.199	0.220	0.916	1.000	1.000
PCP: caregiver able to provide information	87	-0.099	-0.303	0.114	0.361	1.000	1.000

	PCP: did the caregiver talk to you about any concerns he/she had about [name]'s health?	87	-0.080	-0.286	0.133	0.461	1.000	1.000
Would you complete the DSC2U intake form again?	Person with DS: age at baseline survey	108	0.115	-0.075	0.298	0.234	1.000	1.000
	Person with DS: sex	108	0.036	-0.154	0.224	0.710	1.000	1.000
	Person with DS: race	107	-0.062	-0.249	0.130	0.527	1.000	1.000
	Person with DS: ethnicity	107	0.017	-0.173	0.207	0.859	1.000	1.000
	Person with DS: primary Insurance at Randomization	108	-0.030	-0.217	0.160	0.760	1.000	1.000
	Caregiver: PedsQL Psychosocial Health Score [*]	107	0.093	-0.099	0.278	0.341	1.000	1.000
	Caregiver: PedsQL Physical Functioning Score [†]	108	-0.029	-0.217	0.161	0.762	1.000	1.000
	Caregiver: PedsQL Total Scale Score [‡]	108	0.043	-0.147	0.230	0.657	1.000	1.000
	Caregiver: age at baseline survey	108	0.105	-0.086	0.2848	0.278	1.000	1.000
	Caregiver: gender	108	-0.039	-0.226	0.151	0.687	1.000	1.000
	Caregiver: race	107	0.025	-0.166	0.214	0.799	1.000	1.000
	Caregiver: ethnicity	108	0.064	-0.127	0.249	0.513	1.000	1.000
	Caregiver: how are you related to [name]?	108	0.137	-0.053	0.318	0.155	1.000	1.000
	Caregiver: what is the highest level or grade of school that you have completed?	108	0.060	-0.130	0.246	0.535	1.000	1.000
	Caregiver: what is your marital status?	108	-0.023	-0.211	0.167	0.814	1.000	1.000
	Caregiver: PedsQL FIM Parental HRQL Summary Score [§]	108	0.140	-0.050	0.321	0.146	1.000	1.000
Caregiver: PedsQL FIM Family Functioning Summary Score [¶]	108	0.119	-0.072	0.301	0.220	1.000	1.000	
Caregiver: PedsQL FIM Total Scale Score [#]	108	0.152	-0.038	0.332	0.114	1.000	1.000	

Caregiver: low health literacy**	108	-0.132	-0.313	0.059	0.172	1.000	1.000
Caregiver: low numeracy††	108	-0.045	-0.232	0.145	0.642	1.000	1.000
Caregiver: time to travel to primary care provider	108	-0.007	-0.196	0.182	0.939	1.000	1.000
Caregiver: routine blood tests (blood counts, lead)	108	-0.003	-0.192	0.186	0.973	1.000	1.000
Caregiver: referral to physician specialist for consultation	107	0.081	-0.110	0.267	0.403	1.000	1.000
Caregiver: complex imaging (CT, MRI)	101	0.103	-0.094	0.293	0.302	1.000	1.000
Caregiver: out of your pocket health care costs for all members of the household?	107	0.085	-0.107	0.270	0.384	1.000	1.000
Caregiver: HCAHPS‡‡ top-level score (%)	108	0.050	-0.140	0.237	0.606	1.000	1.000
Caregiver: wellness visit rating§§	108	0.111	-0.080	0.294	0.252	1.000	1.000
PCP: gender	88	0.004	-0.205	0.213	0.969	1.000	1.000
PCP: race	88	-0.104	-0.307	0.107	0.331	1.000	1.000
PCP: ethnicity	88	-0.042	-0.249	0.169	0.699	1.000	1.000
PCP: role	87	0.142	-0.071	0.342	0.189	1.000	1.000
PCP: specialty	88	-0.028	-0.236	0.183	0.797	1.000	1.000
PCP: years in practice	87	-0.021	-0.231	0.190	0.845	1.000	1.000
PCP: panel size	78	-0.112	-0.327	0.113	0.326	1.000	1.000
PCP: number of patients with DS	84	-0.093	-0.302	0.123	0.396	1.000	1.000
PCP: practice size	88	0.028	-0.182	0.237	0.792	1.000	1.000
PCP: practice setting	87	-0.015	-0.225	0.196	0.890	1.000	1.000
PCP: federally qualified community health center	88	0.204	-0.006	0.397	0.055	1.000	1.000
PCP: difficulty obtaining Thyroid testing	88	0.223	0.014	0.413	0.035	1.000	1.000
PCP: difficulty obtaining Celiac screening	88	0.256	0.049	0.441	0.015	0.784	1.000

	PCP: difficulty obtaining Audiogram	88	0.109	-0.103	0.312	0.309	1.000	1.000
	PCP: difficulty obtaining Sleep studies	88	0.108	-0.104	0.310	0.316	1.000	1.000
	PCP: difficulty obtaining Ophthalmology assessment	88	0.061	-0.151	0.267	0.574	1.000	1.000
	PCP: length of relationship with patient	80	0.164	-0.058	0.370	0.145	1.000	1.000
	PCP: familiarity with medical history	88	0.003	-0.206	0.213	0.975	1.000	1.000
	PCP: familiarity with psychosocial history	88	0.013	-0.197	0.222	0.907	1.000	1.000
	PCP: quality of communication with caregiver	88	-0.079	-0.284	0.133	0.464	1.000	1.000
	PCP: duration of most recent wellness visit	88	-0.073	-0.279	0.138	0.495	1.000	1.000
	PCP: were you able to spend enough time with [name]?	88	-0.166	-0.363	0.045	0.120	1.000	1.000
	PCP: caregiver able to provide information	87	-0.142	-0.342	0.071	0.189	1.000	1.000
	PCP: did the caregiver talk to you about any concerns he/she had about [name]'s health?	87	-0.094	-0.299	0.119	0.384	1.000	1.000
PCPs: Did you discuss this Primary Care Plan or any of its recommendations ?	Person with DS: age at baseline survey	36	-0.070	-0.390	0.265	0.683	1.000	1.000
	Person with DS: sex	36	-0.096	-0.412	0.240	0.574	1.000	1.000
	Person with DS: race	36	0.000	-0.329	0.329	1.000	1.000	1.000
	Person with DS: ethnicity	36	-0.505	-0.715	-0.211	0.001	0.062	0.560
	Person with DS: primary Insurance at Randomization	36	-0.172	-0.473	0.166	0.312	1.000	1.000
	Caregiver: PedsQL Psychosocial Health Score*	36	-0.092	-0.408	0.244	0.593	1.000	1.000

Caregiver: PedsQL Physical Functioning Score [†]	36	0.175	-0.163	0.476	0.303	1.000	1.000
Caregiver: PedsQL Total Scale Score [‡]	36	0.079	-0.256	0.397	0.643	1.000	1.000
Caregiver: age at baseline survey	36	-0.155	-0.460	0.183	0.362	1.000	1.000
Caregiver: gender	36	0.165	-0.173	0.468	0.331	1.000	1.000
Caregiver: race	36	-0.138	-0.446	0.200	0.418	1.000	1.000
Caregiver: ethnicity	36	-0.505	-0.715	-0.211	0.001	0.062	0.560
Caregiver: how are you related to [name]?	36	-0.330	-0.594	-0.001	0.046	1.000	1.000
Caregiver: what is the highest level or grade of school that you have completed?	36	0.003	-0.326	0.331	0.985	1.000	1.000
Caregiver: what is your marital status?	36	0.005	-0.324	0.333	0.978	1.000	1.000
Caregiver: PedsQL FIM Parental HRQL Summary Score [§]	36	-0.235	-0.523	0.102	0.163	1.000	1.000
Caregiver: PedsQL FIM Family Functioning Summary Score [¶]	36	0.134	-0.203	0.443	0.431	1.000	1.000
Caregiver: PedsQL FIM Total Scale Score [#]	36	-0.018	-0.345	0.312	0.915	1.000	1.000
Caregiver: low health literacy ^{**}	36	-0.286	-0.562	0.047	0.086	1.000	1.000
Caregiver: low numeracy ^{††}	36	-0.110	-0.423	0.227	0.522	1.000	1.000
Caregiver: time to travel to primary care provider	36	-0.070	-0.389	0.265	0.683	1.000	1.000
Caregiver: routine blood tests (blood counts, lead)	36	-0.058	-0.380	0.276	0.734	1.000	1.000
Caregiver: referral to physician specialist for consultation	36	0.052	-0.282	0.374	0.763	1.000	1.000
Caregiver: complex imaging (CT, MRI)	34	0.051	-0.292	0.382	0.774	1.000	1.000

Caregiver: out of your pocket health care costs for all members of the household?	34	0.164	-0.184	0.476	0.348	1.000	1.000
Caregiver: HCAHPS ^{††} top-level score (%)	35	0.020	-0.315	0.351	0.907	1.000	1.000
Caregiver: wellness visit rating ^{§§}	35	0.102	-0.239	0.421	0.556	1.000	1.000
PCP: gender	36	0.063	-0.271	0.384	0.712	1.000	1.000
PCP: race	36	-0.085	-0.402	0.251	0.620	1.000	1.000
PCP: ethnicity	36	-0.138	-0.446	0.200	0.418	1.000	1.000
PCP: role	35	0.099	-0.242	0.419	0.567	1.000	1.000
PCP: specialty	36	-0.126	-0.436	0.212	0.462	1.000	1.000
PCP: years in practice	35	-0.016	-0.347	0.319	0.927	1.000	1.000
PCP: panel size	34	0.060	-0.284	0.390	0.736	1.000	1.000
PCP: number of patients with DS	36	0.149	-0.189	0.455	0.382	1.000	1.000
PCP: practice size	36	0.159	-0.179	0.463	0.350	1.000	1.000
PCP: practice setting	36	-0.026	-0.352	0.305	0.878	1.000	1.000
PCP: federally qualified community health center	36	-0.289	-0.564	0.044	0.083	1.000	1.000
PCP: difficulty obtaining Thyroid testing	36	-0.138	-0.446	0.200	0.418	1.000	1.000
PCP: difficulty obtaining Celiac screening	36	0.057	-0.277	0.379	0.739	1.000	1.000
PCP: difficulty obtaining Audiogram	36	0.042	-0.291	0.365	0.808	1.000	1.000
PCP: difficulty obtaining Sleep studies	36	-0.101	-0.416	0.235	0.554	1.000	1.000
PCP: difficulty obtaining Ophthalmology assessment	36	-0.030	-0.355	0.302	0.862	1.000	1.000
PCP: length of relationship with patient	33	0.072	-0.279	0.405	0.690	1.000	1.000
PCP: familiarity with medical history	36	-0.037	-0.361	0.296	0.831	1.000	1.000
PCP: familiarity with psychosocial history	36	0.042	-0.291	0.365	0.808	1.000	1.000

	PCP: quality of communication with caregiver	36	-0.217	-0.509	0.120	0.199	1.000	1.000
	PCP: duration of most recent wellness visit	36	0.443	0.134	0.674	0.006	0.274	1.000
	PCP: were you able to spend enough time with [name]?	36	0.040	-0.292	0.364	0.816	1.000	1.000
	PCP: caregiver able to provide information	36	0.289	-0.044	0.564	0.083	1.000	1.000
	PCP: did the caregiver talk to you about any concerns he/she had about [name]'s health?	36	0.289	-0.044	0.564	0.083	1.000	1.000
PCPs: Were you interested in any of the information in this Primary Care Plan?	Person with DS: age at baseline survey	35	-0.303	-0.578	0.0344	0.073	1.000	1.000
	Person with DS: sex	35	-0.127	-0.442	0.215	0.463	1.000	1.000
	Person with DS: race	35	-0.028	-0.358	0.308	0.872	1.000	1.000
	Person with DS: ethnicity	35	-0.280	-0.561	0.059	0.099	1.000	1.000
	Person with DS: primary Insurance at Randomization	35	0.019	-0.316	0.350	0.912	1.000	1.000
	Caregiver: PedsQL Psychosocial Health Score*	35	-0.003	-0.336	0.330	0.986	1.000	1.000
	Caregiver: PedsQL Physical Functioning Score†	35	-0.202	-0.502	0.141	0.239	1.000	1.000
	Caregiver: PedsQL Total Scale Score‡	35	-0.099	-0.418	0.242	0.569	1.000	1.000
	Caregiver: age at baseline survey	35	-0.210	-0.508	0.133	0.221	1.000	1.000
	Caregiver: gender	35	-0.064	-0.389	0.276	0.715	1.000	1.000
	Caregiver: race	35	0.115	-0.227	0.432	0.507	1.000	1.000
	Caregiver: ethnicity	35	-0.280	-0.561	0.059	0.099	1.000	1.000
	Caregiver: how are you related to [name]?	35	0.254	-0.087	0.541	0.136	1.000	1.000
Caregiver: what is the highest level or grade of school that you have completed?	35	0.277	-0.062	0.559	0.102	1.000	1.000	

Caregiver: what is your marital status?	35	0.009	-0.325	0.342	0.957	1.000	1.000
Caregiver: PedsQL FIM Parental HRQL Summary Score [§]	35	-0.102	-0.421	0.239	0.557	1.000	1.000
Caregiver: PedsQL FIM Family Functioning Summary Score [¶]	35	-0.099	-0.418	0.242	0.569	1.000	1.000
Caregiver: PedsQL FIM Total Scale Score [#]	35	-0.151	-0.461	0.192	0.381	1.000	1.000
Caregiver: low health literacy ^{**}	35	0.191	-0.152	0.493	0.267	1.000	1.000
Caregiver: low numeracy ^{††}	35	-0.061	-0.386	0.278	0.725	1.000	1.000
Caregiver: time to travel to primary care provider	35	-0.025	-0.356	0.310	0.884	1.000	1.000
Caregiver: routine blood tests (blood counts, lead)	35	0.162	-0.181	0.470	0.349	1.000	1.000
Caregiver: referral to physician specialist for consultation	35	0.218	-0.124	0.514	0.202	1.000	1.000
Caregiver: complex imaging (CT, MRI)	33	0.115	-0.238	0.441	0.521	1.000	1.000
Caregiver: out of your pocket health care costs for all members of the household?	33	0.237	-0.116	0.536	0.180	1.000	1.000
Caregiver: HCAHPS ^{†††} top-level score (%)	34	0.082	-0.263	0.409	0.642	1.000	1.000
Caregiver: wellness visit rating ^{§§}	34	0.124	-0.224	0.443	0.482	1.000	1.000
PCP: gender	35	-0.018	-0.349	0.317	0.919	1.000	1.000
PCP: race	35	0.213	-0.130	0.510	0.215	1.000	1.000
PCP: ethnicity	35	0.153	-0.189	0.463	0.375	1.000	1.000
PCP: role	34	0.111	-0.236	0.433	0.530	1.000	1.000

PCP: specialty	35	-0.097	-0.416	0.244	0.578	1.000	1.000
PCP: years in practice	34	-0.059	-0.389	0.285	0.740	1.000	1.000
PCP: panel size	33	0.156	-0.198	0.474	0.382	1.000	1.000
PCP: number of patients with DS	35	0.050	-0.288	0.377	0.773	1.000	1.000
PCP: practice size	35	0.030	-0.307	0.359	0.865	1.000	1.000
PCP: practice setting	35	0.193	-0.150	0.494	0.262	1.000	1.000
PCP: federally qualified community health center	35	-0.267	-0.552	0.072	0.116	1.000	1.000
PCP: difficulty obtaining Thyroid testing	35	-0.153	-0.463	0.189	0.375	1.000	1.000
PCP: difficulty obtaining Celiac screening	35	0.032	-0.305	0.361	0.855	1.000	1.000
PCP: difficulty obtaining Audiogram	35	0.140	-0.202	0.452	0.417	1.000	1.000
PCP: difficulty obtaining Sleep studies	35	0.166	-0.177	0.473	0.337	1.000	1.000
PCP: difficulty obtaining Ophthalmology assessment	35	-0.087	-0.409	0.253	0.615	1.000	1.000
PCP: length of relationship with patient	32	-0.039	-0.383	0.314	0.829	1.000	1.000
PCP: familiarity with medical history	35	0.347	0.015	0.610	0.038	1.000	1.000
PCP: familiarity with psychosocial history	35	0.419	0.099	0.660	0.011	0.536	1.000
PCP: quality of communication with caregiver	35	-0.324	-0.594	0.010	0.053	1.000	1.000
PCP: duration of most recent wellness visit	35	0.133	-0.210	0.446	0.443	1.000	1.000
PCP: were you able to spend enough time with [name]?	35	0.000	-0.333	0.333	1.000	1.000	1.000
PCP: caregiver able to provide information	35	-0.107	-0.425	0.235	0.538	1.000	1.000
PCP: did the caregiver talk to you about any concerns he/she had about [name]'s health?	35	-0.107	-0.425	0.235	0.538	1.000	1.000

PCPs: Did you agree with the recommendations in the Primary Care plan?	Person with DS: age at baseline survey	33	-0.342	-0.603	-0.015	0.038	1.000	1.000
	Person with DS: sex	36	0.000	-0.329	0.329	1.000	1.000	1.000
	Person with DS: race	36	-0.103	-0.418	0.233	0.545	1.000	1.000
	Person with DS: ethnicity	36	0.000	-0.329	0.329	1.000	1.000	1.000
	Person with DS: primary Insurance at Randomization	36	0.118	-0.219	0.430	0.491	1.000	1.000
	Caregiver: PedsQL Psychosocial Health Score*	36	-0.025	-0.351	0.306	0.884	1.000	1.000
	Caregiver: PedsQL Physical Functioning Score†	36	-0.056	-0.377	0.278	0.745	1.000	1.000
	Caregiver: PedsQL Total Scale Score‡	36	-0.037	-0.361	0.296	0.831	1.000	1.000
	Caregiver: age at baseline survey	33	-0.178	-0.479	0.159	0.293	1.000	1.000
	Caregiver: gender	36	-0.078	-0.397	0.257	0.647	1.000	1.000
	Caregiver: race	36	0.047	-0.286	0.370	0.783	1.000	1.000
	Caregiver: ethnicity	36	0.000	-0.329	0.329	1.000	1.000	1.000
	Caregiver: how are you related to [name]?	36	0.313	-0.018	0.581	0.060	1.000	1.000
	Caregiver: what is the highest level or grade of school that you have completed?	36	0.035	-0.297	0.360	0.837	1.000	1.000
	Caregiver: what is your marital status?	36	-0.122	-0.434	0.215	0.473	1.000	1.000
	Caregiver: PedsQL FIM Parental HRQL Summary Score§	36	-0.018	-0.344	0.313	0.918	1.000	1.000
	Caregiver: PedsQL FIM Family Functioning Summary Score¶	36	-0.102	-0.416	0.235	0.551	1.000	1.000
	Caregiver: PedsQL FIM Total Scale Score#	36	-0.068	-0.388	0.267	0.692	1.000	1.000
	Caregiver: low health literacy**	36	0.235	-0.101	0.523	0.162	1.000	1.000
	Caregiver: low numeracy††	36	0.075	-0.260	0.394	0.661	1.000	1.000

Caregiver: time to travel to primary care provider	36	0.045	-0.288	0.368	0.795	1.000	1.000
Caregiver: routine blood tests (blood counts, lead)	36	0.107	-0.229	0.421	0.530	1.000	1.000
Caregiver: referral to physician specialist for consultation	36	0.018	-0.313	0.344	0.918	1.000	1.000
Caregiver: complex imaging (CT, MRI)	34	0.129	-0.219	0.447	0.465	1.000	1.000
Caregiver: out of your pocket health care costs for all members of the household?	34	0.076	-0.269	0.404	0.666	1.000	1.000
Caregiver: HCAHPS ^{††} top-level score (%)	35	-0.200	-0.500	0.143	0.245	1.000	1.000
Caregiver: wellness visit rating ^{§§}	35	-0.130	-0.444	0.213	0.453	1.000	1.000
PCP: gender	36	0.239	-0.098	0.526	0.157	1.000	1.000
PCP: race	36	0.000	-0.329	0.329	1.000	1.000	1.000
PCP: ethnicity	36	0.189	-0.149	0.487	0.264	1.000	1.000
PCP: role	35	-0.195	-0.496	0.147	0.256	1.000	1.000
PCP: specialty	36	-0.154	-0.459	0.184	0.367	1.000	1.000
PCP: years in practice	35	-0.213	-0.510	0.129	0.214	1.000	1.000
PCP: panel size	34	0.085	-0.260	0.412	0.628	1.000	1.000
PCP: number of patients with DS	36	0.013	-0.317	0.340	0.941	1.000	1.000
PCP: practice size	36	-0.330	-0.594	-0.002	0.046	1.000	1.000
PCP: practice setting	36	-0.023	-0.349	0.308	0.892	1.000	1.000
PCP: federally qualified community health center	36	-0.198	-0.494	0.140	0.243	1.000	1.000
PCP: difficulty obtaining Thyroid testing	36	-0.189	-0.487	0.149	0.264	1.000	1.000
PCP: difficulty obtaining Celiac screening	36	-0.235	-0.523	0.101	0.162	1.000	1.000
PCP: difficulty obtaining Audiogram	36	0.236	-0.100	0.524	0.160	1.000	1.000
PCP: difficulty obtaining Sleep studies	36	-0.306	-0.576	0.025	0.066	1.000	1.000

	PCP: difficulty obtaining Ophthalmology assessment	36	-0.421	-0.658	-0.107	0.009	0.461	1.000
	PCP: length of relationship with patient	33	-0.280	-0.568	0.071	0.110	1.000	1.000
	PCP: familiarity with medical history	36	0.100	-0.236	0.415	0.558	1.000	1.000
	PCP: familiarity with psychosocial history	36	0.048	-0.285	0.371	0.778	1.000	1.000
	PCP: quality of communication with caregiver	36	0.117	-0.220	0.429	0.494	1.000	1.000
	PCP: duration of most recent wellness visit	36	-0.098	-0.413	0.238	0.567	1.000	1.000
	PCP: were you able to spend enough time with [name]?	36	0.027	-0.304	0.353	0.873	1.000	1.000
	PCP: caregiver able to provide information	36	0.198	-0.140	0.494	0.243	1.000	1.000
	PCP: did the caregiver talk to you about any concerns he/she had about [name]'s health?	36	0.198	-0.140	0.494	0.243	1.000	1.000
PCPs: How would you rate the Primary Care Plan?	Person with DS: age at baseline survey	35	-0.340	-0.605	0.008	0.042	1.000	1.000
	Person with DS: sex	35	-0.055	-0.381	0.283	0.752	1.000	1.000
	Person with DS: race	35	-0.022	-0.353	0.313	0.898	1.000	1.000
	Person with DS: ethnicity	35	0.045	-0.293	0.372	0.798	1.000	1.000
	Person with DS: primary Insurance at Randomization	35	-0.046	-0.373	0.292	0.792	1.000	1.000
	Caregiver: PedsQL Psychosocial Health Score*	35	-0.160	-0.468	0.183	0.355	1.000	1.000
	Caregiver: PedsQL Physical Functioning Score [†]	35	0.117	-0.225	0.433	0.501	1.000	1.000
	Caregiver: PedsQL Total Scale Score [‡]	35	-0.037	-0.366	0.300	0.832	1.000	1.000

Caregiver: age at baseline survey	35	-0.192	-0.494	0.151	0.265	1.000	1.000
Caregiver: gender	35	-0.068	-0.393	0.271	0.695	1.000	1.000
Caregiver: race	35	0.129	-0.214	0.443	0.458	1.000	1.000
Caregiver: ethnicity	35	0.045	-0.293	0.372	0.798	1.000	1.000
Caregiver: how are you related to [name]?	35	0.211	-0.131	0.509	0.218	1.000	1.000
Caregiver: what is the highest level or grade of school that you have completed?	35	0.153	-0.189	0.463	0.374	1.000	1.000
Caregiver: what is your marital status?	35	-0.007	-0.340	0.327	0.967	1.000	1.000
Caregiver: PedsQL FIM Parental HRQL Summary Score [§]	35	-0.304	-0.579	0.033	0.072	1.000	1.000
Caregiver: PedsQL FIM Family Functioning Summary Score [¶]	35	-0.282	-0.562	0.057	0.097	1.000	1.000
Caregiver: PedsQL FIM Total Scale Score [#]	35	-0.299	-0.575	0.038	0.076	1.000	1.000
Caregiver: low health literacy ^{**}	35	0.361	0.031	0.620	0.030	1.000	1.000
Caregiver: low numeracy ^{††}	35	-0.052	-0.379	0.286	0.765	1.000	1.000
Caregiver: time to travel to primary care provider	35	0.131	-0.212	0.445	0.450	1.000	1.000
Caregiver: routine blood tests (blood counts, lead)	35	-0.141	-0.453	0.202	0.414	1.000	1.000
Caregiver: referral to physician specialist for consultation	35	-0.163	-0.470	0.180	0.346	1.000	1.000
Caregiver: complex imaging (CT, MRI)	33	-0.134	-0.456	0.219	0.454	1.000	1.000
Caregiver: out of your pocket health care costs for all members of the household?	33	0.345	0.002	0.615	0.046	1.000	1.000
Caregiver: HCAHPS ^{‡‡} top-level score (%)	34	-0.024	-0.359	0.317	0.894	1.000	1.000

Caregiver: wellness visit rating ^{§§}	34	-0.075	-0.403	0.270	0.671	1.000	1.000
PCP: gender	35	0.037	-0.300	0.366	0.832	1.000	1.000
PCP: race	35	0.038	-0.299	0.366	0.829	1.000	1.000
PCP: ethnicity	35	0.257	-0.083	0.544	0.131	1.000	1.000
PCP: role	34	-0.241	-0.535	0.106	0.165	1.000	1.000
PCP: specialty	35	-0.228	-0.521	0.114	0.183	1.000	1.000
PCP: years in practice	34	0.014	-0.326	0.350	0.938	1.000	1.000
PCP: panel size	33	0.478	0.161	0.706	0.004	0.195	1.000
PCP: number of patients with DS	35	0.294	-0.044	0.571	0.082	1.000	1.000
PCP: practice size	35	0.055	-0.284	0.381	0.753	1.000	1.000
PCP: practice setting	35	-0.071	-0.395	0.269	0.685	1.000	1.000
PCP: federally qualified community health center	35	-0.239	-0.530	0.103	0.162	1.000	1.000
PCP: difficulty obtaining Thyroid testing	35	-0.043	-0.371	0.295	0.806	1.000	1.000
PCP: difficulty obtaining Celiac screening	35	-0.020	-0.351	0.315	0.907	1.000	1.000
PCP: difficulty obtaining Audiogram	35	0.318	-0.017	0.589	0.059	1.000	1.000
PCP: difficulty obtaining Sleep studies	35	-0.069	-0.393	0.271	0.692	1.000	1.000
PCP: difficulty obtaining Ophthalmology assessment	35	-0.192	-0.493	0.151	0.266	1.000	1.000
PCP: length of relationship with patient	32	-0.250	-0.550	0.109	0.163	1.000	1.000
PCP: familiarity with medical history	35	0.267	-0.072	0.552	0.116	1.000	1.000
PCP: familiarity with psychosocial history	35	0.222	-0.120	0.517	0.195	1.000	1.000
PCP: quality of communication with caregiver	35	-0.126	-0.441	0.216	0.467	1.000	1.000
PCP: duration of most recent wellness visit	35	-0.110	-0.428	0.231	0.525	1.000	1.000
PCP: were you able to spend enough time with [name]?	35	0.245	-0.096	0.535	0.151	1.000	1.000

PCP: caregiver able to provide information	35	0.188	-0.155	0.490	0.276	1.000	1.000
PCP: did the caregiver talk to you about any concerns he/she had about [name]'s health?	35	0.188	-0.155	0.490	0.276	1.000	1.000

Notes:

*PedsQL Psychosocial Health Score is the sum of the items over the number of items answered in the Emotional, Social, and School Functioning scales. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better quality of life.

†PedsQL Physical Functioning Score is scaled from 0 (Low) to 100 (High). Higher scores indicate a better quality of life

‡ PedsQL Total Scale Score is the sum of all the items over the number of items answered on all the Scales. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better quality of life.

§PedsQL FIM Parental HRQL Summary Score includes 20 items and is computed as the sum of the items divided by the number of items answered in the Physical, Emotional, Social, and Cognitive Functioning Scales. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better functioning.

¶PedsQL FIM Family Functioning Summary Score includes 8 items and is computed as the sum of the items divided by the number of items answered in the Daily Activities and family Relationships scales. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better functioning.

#PedsQL FIM Total Score is a sum of all 36 items divided by the number of items answered. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better functioning.

**Low health literacy was defined as a response of “sometimes,” “often,” or “always” to any of the following three questions: “How often do you have someone help you read medical materials?” “How often do you need help filling out medical forms?”; and “How often do you have problems learning about [name]’s medical condition because of difficulty understanding written information?” [answer options: Never, Occasionally, Sometimes, Often or Always]

††Low numeracy is defined as an answer of “1 in 100, 1 in 1000, or Don’t know” to the question: “Which of the following numbers represents the biggest risk of getting a disease?” [answer options: “1 in 10, 1 in 100, 1 in 1000, or Don’t know”] or an answer of “1%, 5%, 10%, or Don’t know” to the question: “Which of the following numbers represents the biggest risk of getting a disease?” [answer options: 1%, 10%, 5%, or Don’t know]

‡‡HCAHPS stands for Hospital Consumer Assessment of Healthcare Providers and Systems and is the nationally standardized survey of patients’ perspectives of hospital care.

§§The Wellness visit rating is scaled from 0–10 with 0 meaning the “Worst wellness visit possible” and 10 meaning the “Best wellness visit possible.” The numbers that are not

represented here (e.g., 0, 1, 3) had zero responses.

¶¶ Nom P-value is the comparison-wide p-value with no correction for multiple comparisons

Adj P-value is a step-down Bonferroni adjusted p-value correcting for the 51 predictors evaluated for each outcome measure

*** Full Adj P-value is a step-down Bonferroni adjust p-value correcting for all 459 combinations of predictors and outcomes

S15: Table S10. Secondary outcomes: Change from baseline on quality of life measures (Mean±SE [95% CI])

Measure	2-week post-PCP visit assessment			7-month post-PCP visit assessment		
	Control	Intervention	P-value	Control	Intervention	P-value
PedsQL Psychosocial Health Score [†]	-2.27±0.93 (-4.10,-0.43)	-3.18±0.96 (-5.08,-1.29)	0.468	0.36±1.06 (-1.73,2.44)	-2.33±1.09 (-4.47,-0.19)	0.068
PedsQL Physical Functioning Score [‡]	-0.80±1.88 (-4.51,2.90)	-0.15±1.93 (-3.95,3.65)	0.802	6.26±1.89 (2.53,9.99)	5.96±1.93 (2.15,9.76)	0.907
PedsQL Total Scale Score [§]	-1.55±1.04 (-3.59,0.49)	-1.98±1.07 (-4.08,0.12)	0.761	2.49±1.07 (0.37,4.60)	0.57±1.10 (-1.60,2.74)	0.196
PedsQL FIM Parental HRQL Summary Score [¶]	-2.30±1.22 (-4.70,0.10)	-2.38±1.25 (-4.85,0.10)	0.965	-1.17±1.27 (-3.67,1.33)	-4.02±1.31 (-6.59,-1.44)	0.112
PedsQL FIM Family Functioning Summary Score [#]	-1.83±1.46 (-4.70,1.05)	-0.82±1.50 (-3.78,2.14)	0.619	0.25±1.41 (-2.52,3.02)	-2.04±1.44 (-4.89,0.80)	0.245
PedsQL FIM Total Scale Score ^{††}	-1.77±1.07 (-3.88,0.34)	-0.68±1.10 (-2.85,1.49)	0.469	-0.39±1.08 (-2.51,1.73)	-2.26±1.11 (-4.44,-0.07)	0.219

Abbreviations: **CI:** Confidence interval; **FIM:** Family impact module; **HRQL:** Health-related quality of life; **PCP:** Primary care provider; **PedsQL:** Pediatric quality of life; **SE:** Standard error

Notes:

*P-value <0.05, ** p-value <0.01, *** p-value <0.001

[†]PedsQL Psychosocial Health Score is the sum of the items over the number of items answered in the Emotional, Social, and School Functioning scales. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better quality of life.

[‡]PedsQL Physical Functioning Score is scaled from 0 (Low) to 100 (High). Higher scores indicate a better quality of life

[§]PedsQL Total Scale Score is the sum of all the items over the number of items answered on all the Scales. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better quality of life.

[¶]PedsQL FIM Parental HRQL Summary Score includes 20 items and is computed as the sum of the items divided by the number of items answered in the Physical, Emotional, Social, and Cognitive Functioning Scales. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better functioning.

[#]PedsQL FIM Family Functioning Summary Score includes 8 items and is computed as the sum of the items divided by the number of items answered in the Daily Activities and family Relationships scales. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better functioning.

^{††}PedsQL FIM Total Score is a sum of all 36 items divided by the number of items answered. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better functioning.

References

1. Skotko BG, Davidson EJ, Weintraub GS. Contributions of a specialty clinic for children and adolescents with Down syndrome. *Am J Med Genet A*. 2013;161(3):430-437. doi:10.1002/ajmg.a.35795
2. de Graaf G, Buckley F, Skotko BG. Estimation of the number of people with Down syndrome in the United States. *Genet Med*. 2017;19(4):439-447. doi:10.1038/gim.2016.127