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## APPENDICES

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### Appendix A. Creation of DSC2U

## Appendix A: Creation of DSC2U

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 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 fit to the specifications and information needs of DS specialists. Please see below.

1 Introduction  
2 General Information  
3 Preferred Contact Information  
4 Care Team and Medical Records  
5 Insurance  
6 Concerns You Would Like to Address at the Upcoming Visit  
7 Strengths  
8 Past Medical History  
9 Procedures and Hospitalizations  
10 Prescribed Medications  
11 Supplements, Vitamins, Over-the-counter Medications  
12 Allergies  
13 Review of Systems  
14 Immunization History  
15 Family History  
16 Social History  
17 Assistive Devices  
18 Vocational Experience  
19 Functional Assessment  
20 Recreational History  
21 Nutrition  
22 Life Skills Checklist  
23 Blood work and Diagnostic Testing  
24 Down Syndrome Community  
25 Planning Ahead

MGH Down Syndrome Program New Visit Intake Form (Adults)  
Blood work and Diagnostic Testing

Has the patient...

...seen an audiologist for a formal hearing examination in the past 2 years? (required)  
 Yes  
 No  
 Not sure

...seen an ophthalmologist for a formal eye examination in the past 2 years? (required)  
 Yes  
 No  
 Not sure

...ever had a sleep study performed for obstructive sleep apnea? (required)  
 Yes  
 No  
 Not sure

...seen a dentist in the past 6 months? (required)  
 Yes  
 No  
 Not sure

...had thyroid blood work done in the past 12 months? (required)  
 Yes  
 No  
 Not sure

...had blood work done for celiac disease performed at any time? (required)  
 Yes  
 No  
 Not sure

...had a neck X-ray ("C-spine") ever before? (required)  
 Yes  
 No  
 Not sure

...had a hemoglobin blood test for anemia in the past 12 months? (required)  
 Yes  
 No  
 Not sure

...had a pap smear ever? (required)  
 Yes  
 No  
 Not sure

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,

10/11/2014  
New  
10/11/2014  
Dr. George Provder.  
We had the pleasure of seeing your patient, Kevin Patient, for a consultation, per your request, in the Massachusetts General Hospital Down Syndrome Program, a multidisciplinary tertiary program that offers comprehensive clinical evaluation of children and adults with Down syndrome. As you know, Kevin is a 49-year-old with Down syndrome, who is here to our clinic. Your patient was accompanied today by Mr. Stephen Brother.  
In preparation for this clinical visit, I reviewed the patient's previous records along with our Program's intake form, completed by Mr. Stephen Brother, the patient's sibling.  
During this visit, we addressed the following CHIEF CONCERNS  
1. Increased anxiety and mood changes. The caregiver is "somewhat worried" about this issue.  
STRENGTHS  
Mr. Patient identified the following strengths "blamers, kindness, knowledge of moves".  
DIAGNOSIS  
We requested a copy of the original cytogenetic results for our records.  
PAST MEDICAL & SURGICAL HISTORY  
As you likely already know, this patient has a past medical history that is significant for the following conditions. I reviewed his previous medical records in order to gather part of this information.  
1. Hypertension, "still a problem".  
2. Obstructive sleep apnea, "well-managed". Followed by Dr. Provder, last seen Sept 2014  
3. Constipation, "well-managed". Followed by Dr. Provder, last seen Sept 2014  
4. Cognitive decline, "still a problem".  
5. Dry skin, "well-managed".  
6. Hair loss, "well-managed".  
7. Urinary retention, "still a problem". Followed by Dr. Provder.  
8. "Psychosis", "well-managed". Followed by Dr. Smith.

Clinical narrative 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.

diagnostic testing, DS community resources, and future planning

*Down Syndrome Clinic to You* 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 WGs. 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 consumed and transformed by SproutForms 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.

	A	B	D	E	H	I	J	K	N	P	Q	R
	Section Header	Variable Name	Field Type	Field Label	Field Choices	Validation Type	Validation Minimum	Validation Maximum	Branching Logic	Required?	Reset?	Hidden
1	Functional Assessment											
2		communication_composite	Composite	The patient communicates via (check all that apply)						S		
3		comm_verbal	Checkbox	Speech								
4		comm_sign	Checkbox	Sign language								
5		comm_pictures	Checkbox	Pictures								
6		comm_written	Checkbox	Written word								
7		comm_device	Checkbox	Electronic voice output device								
8		comm_device_name	Text	Name of device					{comm_device} = "1"			
9		comm_gesture	Checkbox	Gesture & point								
10		comm_other	Checkbox	Other								
11		comm_other_detail	Text	Please describe:					{comm_other} = "1"			
12		smartphone_use	Radio	Does the patient use a smartphone or other mobile device?	1, Yes   0, No					S		
13		smartphone_apps	Text	Which apps does he or she use?					{smartphone_use} = "1"			

	A	B	D	E	H	J	K	L	R	R
	Section Header	Variable Name	Field Type	Field Label	Field Choices	Validation Type	Validation Minimum	Validation Maximum	Branching Logic	R
1	en: Functional Assessment   es: Evaluación Funcional									
2				en: The patient communicates via (check all that apply).   es: "¿Por qué vías se comunica el paciente? [Seleccione las que correspondan]"						
3		communication_composite	Composite							
4		comm_verbal	Checkbox	en: Speech   es: Habla						
5		comm_sign	Checkbox	en: Sign language   es: Lenguaje de señas						
6		comm_pictures	Checkbox	en: Pictures   es: Por medio de dibujos						
7		comm_written	Checkbox	en: Written word   es: Escritura						
8		comm_device	Checkbox	en: Electronic voice output device   es: Voz electrónica por medio de dispositivo						
9		comm_device_name	Text	en: Name of device   es: Nombre del dispositivo					[comm_device] = "1"	
10		comm_gesture	Checkbox	en: Gesture & point   es: Gestos y apuntando las cosas						
11		comm_other	Checkbox	en: Other   es: Otros						
12		comm_other_detail	Text	en: "Please describe"   es: "Por favor describe"					[comm_other] = "1"	
				en: "Does the patient use a smartphone or other mobile device?"   es: "¿El paciente	"1, en: Yes   es: SI"					

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).

*Technical Development of the Checklist and Plan.* The Sprout Scribe engine allows for complex and multiple outputs (e-mail, documentation, posting to registry) to be generated on each form submission. For the purposes of this study, two custom narrative reports were auto- and immediately-generated for each DSC2U intake questionnaire submitted: the *Caregiver Checklist* and *PCP Plan*. The content, and the logic driving the content, was implemented as a Handlebars template. Handlebars is a generic template engine that generates text output—HTML, in our case—based on sets of rules. Each narrative report is created by the cumulative effect of hundreds of DSC2U-specific rules applied to the set of responses from each questionnaire. Because of the fine-grained rules detailed in DSC2U, the emergent narrative was customized for the caregiver and PCP not only in its specific recommendations, but also in the provision of the rationale behind each recommendation. The *Checklist* was available in both English and Spanish.