APPENDICES

Appendix A. Creation of DSC2U

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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.

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,	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.

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.