

**Title:** Creation of a Clinical Intake System and Corresponding Database to Explore Development and Medical Conditions of Individuals with Down syndrome

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**Introduction:** Despite a common genotype, individuals with Down syndrome (DS) may have a wide range of medical conditions (Bull, 2011; Bull 2020), as well as a wide range of neurodevelopmental and behavioral outcomes (Palumbo & McDougle, 2018, Capone, Goyal, Ares, & Lannigan, 2006; Dykens, 2007). However, due to a lack of large, population-based research studies in children with DS, risk factors for co-occurring neurodevelopmental and medical conditions are still largely unknown, and there are limited guidelines for accurate diagnosis and management. The purpose of the clinical intake system and database at the Boston Children's Hospital Down Syndrome Program (BCH DSP) is to create a central collection system for patients' developmental and medical histories that can be utilized to more effectively investigate research topics such as (1) patterns of development, (2) accurate diagnosis of co-occurring neurodevelopmental conditions, (3) the interplay between co-occurring medical issues and neurodevelopmental functioning, (4) the impact of interventions including developmental and behavioral therapies, and (5) the potential for pharmacological treatments in DS.

**Method:** Clinician- and parent/guardian-report intake forms were developed by the BCH DSP team, which consists of three physicians, one nurse practitioner, one psychologist, one project manager, and two research coordinators. The forms underwent an extensive 6-month testing period in clinic in which a research coordinator gathered feedback from families and clinicians about formatting, useability, and process flow. Changes were made accordingly and the current inventory consists of the following parent-report forms: Review of Systems (ROS), General Development & Behavior, Medical History, and Education & Services. A Transitioning Services & Supports form is also completed by families who have a child age 14 or older. Clinicians complete two forms: a Neurodevelopmental & Regression assessment form, and a psychopharmacology intake. Neuropsychological testing results from BCH and outside sources (i.e. schools, private evaluations), are also included in the intake. The ROS and clinician forms are completed at every visit, while all other forms are completed only on an annual basis. In addition to the BCH DSP-generated intake forms, parents may also receive surveys and standardized developmental scales directly through TriVox/Veta Health electronic platforms as part of pre-visit preparation (e.g. ahead of an evaluation or testing session). A corresponding database was created using the secure online REDCap platform, with a separate REDCap instrument for each intake form. Identifiable data is entered into the database by a research coordinator and a research intern, who has DS, on a daily basis.

**Results:** Intake information on 727 unique patients has been entered into the electronic BCH DSP database since July 2018. The completion rate of parent intake forms has gradually increased to ~84% as families grow more accustomed to the pre-visit process. The BCH DSP team reviews the data on a quarterly basis to identify clinically significant findings and formulate targeted research questions. Our first targeted database protocol, which is focused on exploring development patterns, is currently under IRB review at BCH.

**Discussion:** An extensive clinical database for DS patients is feasible and essential for improving clinical care and large-scale research efforts. Next steps of the database that are already underway include the translation of parent intake forms into other languages, and further adaptations for simplifying the intake process during virtual clinic (in light of the COVID-19 pandemic).

**References:**

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