

The Boston Children's Hospital Down Syndrome Program Clinical Database:

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

Margaret Hojlo, BA¹; Anna Milliken, BA¹; Jennifer Guan¹; Emily Davidson, MD, MPH^{1,2}; Angela Lombardo, BA¹; Katherine Pawlowski, BA¹; Sabrina Sargado, MD^{1,2}; Nathan Simons¹;

Cara Soccorso, PsyD^{1,2}; Sherry Tsai, CPNP¹ & Nicole Baumer, MD, MEd^{1,2,3}

¹ Down Syndrome Program, Division of Developmental Medicine, Boston Children's Hospital

² Harvard Medical School

³ Department of Neurology, Boston Children's Hospital



INTRODUCTION

- Despite a common genotype, individuals with Down syndrome (DS) may experience a wide range of medical and neurodevelopmental conditions^{1,2}, as well as behavioral outcomes^{3,4,5}
- Due to a lack of large, population-based research studies in children with DS, risk factors for co-occurring neurodevelopmental disorders (NDD), medical, and mental health conditions are still largely unknown, and there are limited guidelines for accurate diagnosis and management

OBJECTIVES/AIMS

The Boston Children's Hospital Down Syndrome Program (BCH DSP) created an ongoing prospective clinical database of patients to characterize:

- 1) Patterns of development
- 2) Prevalence and interplay of co-occurring medical, neurodevelopmental, and mental health conditions
- 3) Impact of therapeutic interventions on these conditions

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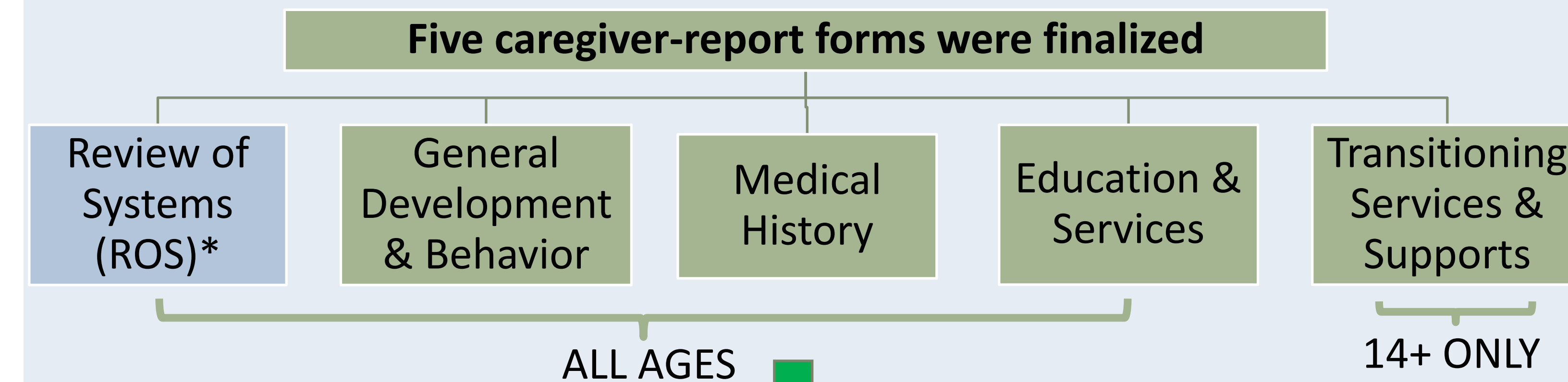
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METHOD: INTAKE FORM DEVELOPMENT

Clinician- and caregiver-report intake forms were developed by the Boston Children's Hospital Down Syndrome Program (BCH DSP) team

- Forms underwent a 6-month testing period in clinic
- An internal REDCap database was created with a separate instrument for each intake form



Two clinician-report forms finalized

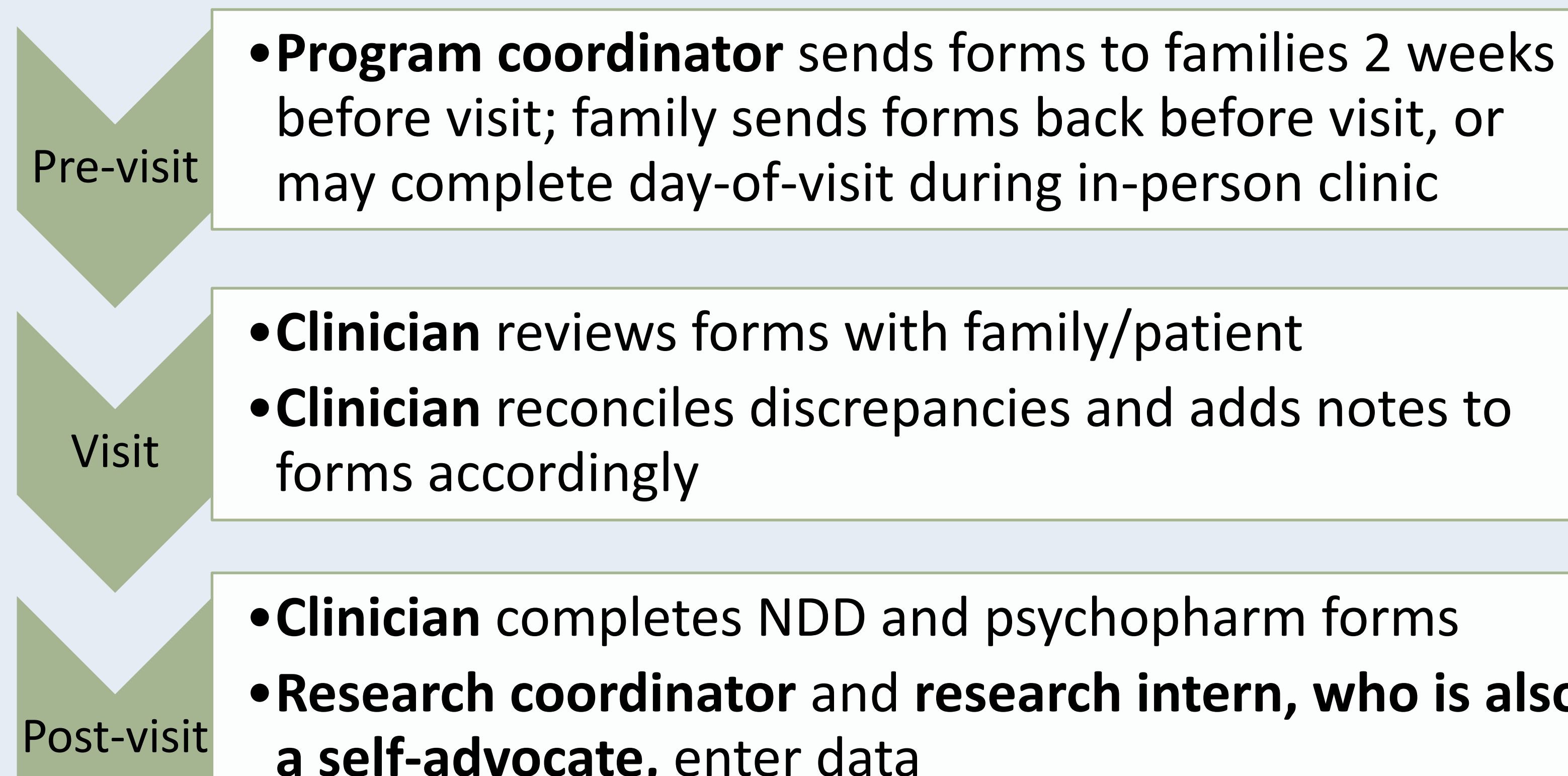
- Neurodevelopmental diagnoses*
- Psychopharmacology history

*These forms are completed for every visit. All other forms are completed annually only.

Also included depending on visit type:

- Neuropsychological testing from outside BCH
- Surveys & developmental scales through an electronic questionnaire system

METHOD: IMPLEMENTATION



RESULTS

- Intake information on **761 unique patients** has been entered into the database since March 2018
- The completion rates of all caregiver intake forms has increased (Table 1) over time
- The **research intern has prepared and entered two types of forms since February 2020**

| Table 1 | March 2021 N=761 | | Change in completion rate since Feb. 2019 |
|------------|---------------------|-------------|---|
| | # | % completed | |
| ROS | 761 | 100 | |
| Gen Dev | 583 | 77 | ↑43% |
| Ed & Serv | 612 | 81 | ↑8% |
| Med Hist | 575 | 76 | ↑12% |
| NDD | 717 | 100 | ↑1% |
| Medication | 168 | 22 | |

- 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 underway at BCH

CONCLUSIONS

- An extensive clinical database for individuals with DS is feasible and essential for improving clinical care and large-scale research efforts
- Next steps of the BCH DSP database are:
 - 1) Training another self-advocate on data preparation
 - 2) Adding a psychosocial screener
 - 3) Completing reconciliation of all caregiver-reported conditions
 - 4) Merging together medical history and NDD forms
 - 5) Translating caregiver intake forms into other languages