

Study underscores value of Down Syndrome Clinic to You program

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A new software program effectively brings the expertise of Massachusetts General Hospital (MGH) specialists to many more patients with Down syndrome (DS), according to a study published today in *Genetics in Medicine*. Down Syndrome Clinic to You (DSC2U) is a first-of-its kind online health tool aimed at improving adherence to US

national Down syndrome guidelines. This study finds the tool effective. Most caregivers and primary care physicians (PCPs) also reported high satisfaction with it.

The first author of the paper is Jeanhee Chung, MS, MD, primary care physician at MGH. The senior author is Brian Skotko, MD, MPP, director of the Down Syndrome Program and Emma Campbell Endowed Chair on Down Syndrome at MGH.

The study was a national randomized controlled trial of 230 caregivers who had children or dependents with DS but no access to a specialist. Of these, 117 were randomized to receive DSC2U while 113 received usual care. A total of 213 participants completed a seven-month long follow-up evaluation. Those who received DSC2U had a 1.6-fold increase in the number of guideline-indicated evaluations their primary care provider recommended or completed compared with controls.

Clinicians at MGH's Down Syndrome Program launched DSCU2 in August of this year. The program aggregates the clinical experience of specialists and others who care for these patients. It then connects patients' families with customized information to augment the work of local care providers. Skotko and his colleagues see approximately 600 patients a year at their clinic. DSC2U now brings MGH's expertise in caring for individuals with Down [syndrome](#) to families around the globe.

To participate, users are asked to identify current symptoms in their loved one with Down syndrome along with any past medical or behavioral diagnoses and any recent blood work or diagnostic testing. They are additionally offered an optional set of questions about nutrition, education, therapies, life skills and community resources.

Responses are electronically analyzed by an evidence-based set of rules, and the output comprises personalized checklists that can be used during

annual wellness visits with the patient's PCP.

"Rather than asking families around the world to come to Boston, we are instead bringing the most accurate and up-to-date information to families in their home settings," says Skotko.

"About 95 percent of patients with Downs syndrome do not have access to specialist care," he adds. Specialist care is particularly important for them as these patients have a wide range of different health, social, and developmental issues.

More information: Jeanhee Chung et al, A randomized controlled trial of an online health tool about Down syndrome, *Genetics in Medicine* (2020). [DOI: 10.1038/s41436-020-00952-7](https://doi.org/10.1038/s41436-020-00952-7)

Provided by Massachusetts General Hospital

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