

S10: Table S1. Baseline characteristics of people with Down syndrome and caregivers (additional variables)

Variable and Characteristics		Randomized Group		
		Overall (N=230)	Control (N=113)	DSC2U (N=117)
Person with DS				
PedsQL Psychosocial Health Score	mean±SD (range)	70.5±14.0 (27.5,100)	71.2±13.3 (37.5,100)	69.8±14.7 (27.5,100)
PedsQL Physical Functioning Score	mean±SD (range)	63.1±27.0 (0.0,100)	62.9±28.6 (0.0,100)	63.4±25.4 (0.0,100)
PedsQL Total Scale Score	mean±SD (range)	68.1±14.5 (25.0,98.3)	68.4±15.5 (25.0,98.3)	67.7±13.6 (30.0,93.3)
Caregiver of person with DS				
PedsQL FIM Parental HRQL Summary Score [#]	mean±SD (range)	68.1±18.8 (6.3,100)	67.4±19.6 (6.3,100)	68.6±18.2 (20.0,100)
PedsQL FIM Family Functioning Summary Score [¶]	mean±SD (range)	65.7±22.7 (0.0,100)	65.2±24.6 (0.0,100)	66.2±20.7 (12.5,100)
PedsQL FIM Total Scale Score [§]	mean±SD (range)	65.4±19.0 (6.9,100)	64.9±20.3 (6.9,99.3)	65.8±17.6 (20.1,100)
Time to travel to primary care provider	< 30 minutes	194 (84.3%)	96 (85.0%)	98 (83.8%)
	30–59 minutes	34 (14.8%)	17 (15.0%)	17 (14.5%)
	60 minutes or more	2 (0.9%)	0 (0.0%)	2 (1.7%)
Accessibility of routine blood tests (e.g., CBC, lead)	Very difficult	17 (7.4%)	7 (6.3%)	10 (8.5%)
	Somewhat difficult	26 (11.4%)	14 (12.5%)	12 (10.3%)
	Not very difficult	44 (19.2%)	24 (21.4%)	20 (17.1%)
	Not at all difficult	142 (62.0%)	67 (59.8%)	75 (64.1%)
	[missing]	1	1	0

Accessibility of referral to physician specialist for consultation	Very difficult	2 (0.9%)	0 (0.0%)	2 (1.7%)
	Somewhat difficult	21 (9.2%)	11 (9.7%)	10 (8.6%)
	Not very difficult	68 (29.7%)	35 (31.0%)	33 (28.4%)
	Not at all difficult	138 (60.3%)	67 (59.3%)	71 (61.2%)
	[missing]	1	0	1
Accessibility to complex imaging (CT, MRI)	Very difficult	25 (11.6%)	10 (9.5%)	15 (13.5%)
	Somewhat difficult	31 (14.4%)	17 (16.2%)	14 (12.6%)
	Not very difficult	58 (26.9%)	27 (25.7%)	31 (27.9%)
	Not at all difficult	102 (47.2%)	51 (48.6%)	51 (45.9%)
	[missing]	14	8	6
In the past year, how much has your family spent out of your pocket on health care costs for all members of your household, including [name]?	< \$250	16 (7.7%)	10 (9.3%)	6 (6.0%)
	\$250–499	16 (7.7%)	7 (6.5%)	9 (9.0%)
	\$500–999	23 (11.1%)	9 (8.4%)	14 (14.0%)
	\$1,000–1,999	26 (12.6%)	10 (9.3%)	16 (16.0%)
	\$2,000–2,999	27 (13.0%)	12 (11.2%)	15 (15.0%)
	\$3,000+ [missing]	99 (47.8%) 23	59 (55.1%) 6	40 (40.0%) 17

Abbreviations: **CBC:** Complete blood count; **CT:** Computed tomography; **FIM:** Family impact module; **MRI:** Magnetic resonance imaging; **PedsQL:** Pediatric quality of life; **PCP:** Primary care provider; **SD:** Standard deviation

Notes:

* PedsQL Psychosocial Health Score is the sum of the items over the number of items answered in the Emotional, Social, and School Functioning scales. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better quality of life.

† PedsQL Physical Functioning Score is scaled from 0 (Low) to 100 (High). Higher scores indicate a better quality of life

‡ PedsQL Total Scale Score is the sum of all the items over the number of items answered on all the Scales. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better quality of life.

PedsQL FIM Parental HRQL Summary Score includes 20 items and is computed as the sum of the items divided by the number of items answered in the Physical, Emotional, Social, and Cognitive Functioning Scales. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better functioning.

¶ PedsQL FIM Family Functioning Summary Score includes 8 items and is computed as the sum of the items divided by the number of items answered in the Daily Activities and family Relationships scales. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better functioning.

§ PedsQL FIM Total Score is a sum of all 36 items divided by the number of items answered. It is scaled from 0 (Low) to 100 (High). Higher scores indicate a better functioning.