

Down Syndrome Survey for Physicians, Health Care Professionals & Residents

Summary Report 2016

2016 Down Syndrome Survey for Physicians & Residents

28 respondents

18 physicians (78% pediatricians, 11% General Practitioners, 11% other)

10 medical residents

56% work in the city

82% interested
in clinical guidelines

77% interested
in mental health

35% interested in
learning more about
adolescent care

78% interested
in sleep

78% interested in
psychiatric issues

78% interested in
nutrician & obesity

Physicians

94% have some experience
working with DS

71% have seen 1-5 patients

Medical Residents

60% have attended lectures or
talks about Down syndrome

60% agree that they need more
info about Down syndrome.

30% are family members or
friends with a person with
Down syndrome

Acknowledgements



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Creation of a health care website:

- Will include resources, guidelines and community support
- Will address knowledge gap identified by target group

Delivery: online and easily accessible

Content: based on literature reviews and research

Target users: physicians, health care professionals and residents

The Goal: Comprehensive Care in Down syndrome



The website would include information that provides information on the life-time care of an individual with Down syndrome:

- **Clinical practices, guidelines, and resources**
- **Review of body systems and medical conditions**
 - Physiology/pathology of DS
 - Mental Health
- **Life history**
 - Demographics and epidemiology
 - Interactions with healthcare
 - The child with DS
 - The adolescent with DS
 - The adult with DS/transition into adulthood
 - Long-term outcomes
 - Quality of life
- **Genetics**

Medical conditions in DS

- Cardiovascular abnormalities
- ENT
- Respiratory issues
- Thyroid disorders
- Infertility & sexual dysfunction
- Oncology
- Gastro-intestinal disorders
- Nutrition & obesity
- Vision and Hearing
- Common infections/diseases
- Immunodeficiency or dysfunction
- Osteoporosis & other structural issues
- Dental Caries
- Sleep & Down syndrome
- Epilepsy & other neurological issues
- Neuro-cognitive decline
- Psychiatric Issues
- Alzheimer's disease in Down syndrome

Other Issues

- Education and programs of learning
- Behavioural management
- Transition into adult care
- Late-onset manifestations
- Social integration and quality of life
- Topics on sexuality and family raising
- Aging
- Health care needs and professional support (i.e. dietician, speech therapist, occupational therapist)

Format: Timeline, highlighting common conditions or medical issues occurring at a specific age

- Provides an overview of the Life History of DS topics

Delivery: interactive website platform

- Drop down menus for major topics/objectives
- Organized and streamlined presentation of information
- Links to media materials: resources, literature etc.
- Timeline hosted on website

Website: downsyndromecare.ca

Problem

- What knowledge about DS is missing in Healthcare?
- What is the best way to present this information?

Suggested Solution

- Ask the target audience directly and collect and analyze their responses
- Ask physicians, residents, and fellows

Survey

- Online survey link was distributed to target group
- Data collection and analysis through a REDCap platform

The survey results provide information on:

- Physicians and healthcare professionals' background
- Number of patients with Down Syndrome seen, and degree of experience with DS
- Suggestions regarding the knowledge gap
- Down syndrome topics, resources, and medical conditions of interest to physicians
- Physician comments about DS, family concerns, and life-time care challenges

Physician & Resident Survey Results



Physicians: n=18/63 responded
Residents: n= 10/59 responded

Topic Addressed	Survey Results
Participants' Background	<p>Physicians: 78% pediatricians, 11% general practitioners, and 11% other (one registered midwife and one naturopathic doctor); 56% work in the city</p> <p>Residents: specializations: 30% neurology, 30 % general peds, 10% each in developmental peds, cardiology, nephrology and neonatology; 80% said they wanted to work in the city</p>
Level of experience with Down syndrome	<p>Physicians: most (94%) have some experience with Down syndrome; 71% see 1-5 patients</p> <p>Residents: all actively involved in patient care; 60% attended lectures/talks about Down syndrome and 30% are family members/friends; 50% see more than 10 patients</p>
Verifying Knowledge Gap	<p>Physicians: 50% of pediatricians and general practitioners agree and 50% of general practitioners strongly agree that they need more info about Down syndrome</p> <p>Residents: 60% agree they need more info about Down syndrome; 10% disagree</p>
Topics of interest	<p>Physicians: top three — clinical guidelines (82%), mental health (77%), and adolescent with Down syndrome (77%)</p> <p>Residents: top three — transition into adulthood (70%), quality of life (50%), and the adolescent with Down syndrome (50%)</p>
Medical Conditions	<p>Physicians: top three — sleep and DS (78%), psychiatric issues (78%), and nutrition and obesity (78%)</p> <p>Residents: top three were: epilepsy (70%), neuro-cognitive issues/decline (50%), and cardiovascular abnormalities (50%)</p>
Physician Comments	<p>Questions about Down syndrome: puberty/adolescence, hypothyroidism, transitions and community support, behavioural management, follow-ups/guidelines/screenings</p> <p>Family concerns: sleeping problems, nutrition/obesity, adulthood and behavioural issues, long term care and independence, resources/advising, community support</p>

Roundtable Discussion: Feedback from Parents & Families in collaboration with the DSRF



Topic Addressed	Parents' Concerns
Guidelines, protocols and healthcare checklists	Ways to keep track of long-term follow-ups; appointment set up for appropriate medical screenings; provide more common guidelines for ailments and conditions; push for increased variety of standardized tools and peer reviewed protocols, supported by research; include more electronic files and notification systems
Medical conditions	Acute care, issues such as sleep apnea, thyroid, metabolic syndromes, cardiac follow-ups after surgery, nutrition and addressing obesity; most common concerns: Mental health, Dementia and dieting/nutrition
Approach to care	Keep families informed about Down syndrome research results; focus on preventative care in adult population of Down syndrome; help physicians become knowledgeable about health programs/supports and understand how to communicate well with patients with Down syndrome; establish rapport and trust with patient
Resources needed	Infant development and other healthcare programs; resources and knowledge from the community; information about sexuality; information about adult care/independence
Transitions	What happens between major milestones (pre-school, in school, out of school etc.); ways to keep up with age-appropriate resources (medical and community); continue care in elderly Down syndrome; transition to general practitioners from pediatrics to adult care.
Learning about Down syndrome	Families learned most from other families and community support groups; found that knowledge about Down syndrome may be lacking from physicians, especially from general practitioners