

Multimedia Appendix 1. Caregiver Survey (Prefaced with Survey Consent Disclosure)

Part 1 – Demographics	
What range does the year of birth of your child fall in?	2012-2014 2009-2011 2006-2008 1995-2005 Before 1995
What type of Hirschsprung's Disease (HD) does your child have?	Ultra Short Disease Short Segment Disease (Includes the rectum up to the sigmoid colon) Long Segment Disease (beyond the sigmoid colon) Unsure
At what age was your child diagnosed with Hirschsprung's Disease?	0-1 month 2-12 months 13 months- 4 years > 4 years
What age did your child have their "pull through" surgery?	0-3 months >3months- 6 months >6 months- 12 months >12 months
Give up to 5 problems that your child has, or has had in the past, related to HD:	[open ended] 1. 2. 3. 4. 5.
What is your confidence level to successfully manage this problem?	Not Confident at all Not Very Confident Somewhat Confident Confident Very Confident
<i>*Repeat as above for Problems #2- #5</i>	
How satisfied are you with the current resources provided to you to manage problems that arise with your child's Hirschsprung's Disease? (web-based resources or written material available)	Not Satisfied Not Very Satisfied Somewhat Satisfied Satisfied Very Satisfied
	Comments:
If information was available on how to manage problems related to HD how would you like to obtain this information?	Please rank from 1- 5 (1 is the most desired and 5 is the least desired route) <input type="checkbox"/> Link to a health care site where written guidelines are available (i.e. Winnipeg Children's Hospital home page) <input type="checkbox"/> A report from this project (available on the HD social media sites) <input type="checkbox"/> In a story where a child and parent encounter and resolve a problem (available on the HD social media sites) <input type="checkbox"/> In a video explanation (I.e. Youtube) <input type="checkbox"/> Other: _____

