

McDonald K et al. Supplementary Material

SUPPLEMENTARY TABLE 1: Needs Survey Items

Item	Domain	Need - Yes (%)	High (%)	Mod (%)	Low (%)	Unmet (%)
To have the option of whether or not you would pursue genetic testing for yourself or family members?	Medical	18/19 (95)	14/18 (78)	2/18 (11)	2/18 (11)	4/18 (33)
To understand what had happened?	Medical	35/37 (95)	33/36 (92)	2/36 (6)	1/36 (3)	21/35 (60)
For the coroner and their office to give you honest and accurate information?	Medical	34/37 (92)	27/35 (77)	4/35 (11)	4/35 (11)	9/34 (26)
To understand the medical cause of your child's death	Medical	34/37 (92)	31/35 (89)	2/35 (6)	2/35 (6)	15/25 (43)
For medical professionals to give you honest and accurate information?	Medical	34/38 (89)	25/34 (74)	6/34 (18)	3/34 (9)	6/32 (19)
To understand the possibility of an inherited problem immediately after your child's death?	Medical	33/38 (87)	23/32 (72)	6/32 (19)	3/32 (9)	7/33 (21)
For medical professionals to provide you with the opportunity to ask questions about your child's death?	Medical	33/38 (87)	28/33 (85)	4/33 (12)	1/33 (3)	22/32 (69)
To have the opportunity to see your child following their death?	Medical	32/38 (84)	28/32 (88)	3/32 (9)	1/32 (3)	5/32 (16)
For the coroner and their office to treat you in a respectful and compassionate way, and acknowledge your loss?	Medical	31/37 (84)	23/32 (72)	7/32 (22)	2/32 (6)	10/31 (32)
For information about the benefits and risks of genetic testing for yourself and other family members?	Medical	15/18 (84)	14/15 (93)	1/15 (7)	0/15 (0)	4/15 (27)
To have your general practitioner informed about findings from specialists?	Medical	30/37 (81)	19/30 (63)	7/30 (23)	4/30 (13)	8/28 (29)
For information about what my child's death means for the health of my family?	Medical	30/38 (79)	26/31 (84)	3/31 (10)	2/31 (6)	9/31 (29)
For first responders (e.g. police and paramedics) to give you honest and accurate information?	Medical	28/36 (78)	22/28 (79)	2/28 (7)	4/28 (14)	7/28 (25)
For an opportunity immediately after your child's death to discuss your feelings with a medical professional?	Medical	29/38 (76)	22/29 (76)	6/29 (21)	1/29 (3)	10/28 (36)
For the medical professionals to treat you in a respectful and compassionate way, and acknowledge your loss?	Medical	29/38 (76)	20/29 (69)	6/29 (21)	3/29 (10)	6/28 (21)

To be informed of test results in a timely manner?	Medical	28/38 (74)	22/27 (81)	5/27 (19)	0/27 (0)	8/27 (30)
To be directed to information about specialist clinics and professionals?	Medical	28/38 (74)	18/28 (64)	8/28 (29)	2/28 (7)	9/28 (32)
To understand the genetic cause of your child's death?	Medical	26/36 (72)	18/28 (64)	8/28 (29)	1/27 (4)	18/27 (67)
For you and your family to receive follow-up medical care?	Medical	27/38 (71)	0/27 (0)	6/27 (22)	21/27 (78)	3/27 (11)
For first responders (e.g. police and paramedics) to treat you in a respectful and compassionate way, and acknowledge your loss?	Medical	27/38 (71)	21/27 (78)	3/27 (11)	3/27 (11)	8/27 (30)
For an explanation of the genetic testing options available to you?	Medical	26/37 (70)	13/24 (54)	9/24 (38)	2/24 (8)	6/25 (24)
For advice about medical and/or heart health and any restrictions that may need to be put in place?	Medical	26/37 (70)	18/26 (69)	6/26 (23)	2/26 (8)	2/26 (8)
For referral to a cardiac specialist?	Medical	26/37 (70)	19/25 (76)	4/25 (16)	2/25 (8)	2/26 (8)
For information about medical care if you carry the gene variant?	Medical	13/19 (68)	9/13 (69)	4/13 (31)	0/13 (0)	5/12 (42)
For a health professional to discuss the signs of cardiac problems and when you should be concerned?	Medical	26/38 (68)	16/26 (62)	10/26 (38)	0/26 (0)	6/27 (22)
For professional support in dealing with the worry that there may be an underlying problem even if the cause of death is unclear?	Medical	25/38 (66)	19/24 (79)	3/24 (13)	2/24 (8)	11/25 (44)
For an explanation from a health professional about how the heart works as relevant to your child's condition?	Medical	25/38 (66)	19/24 (79)	5/24 (21)	0/24 (0)	11/25 (44)
For an explanation of the genetic testing options available to you and the process involved?	Medical	24/37 (65)	15/24 (63)	6/24 (25)	3/24 (13)	7/24 (29)
For information about the reliability and accuracy of genetic testing?	Medical	12/19 (63)	8/12 (67)	4/12 (33)	0/12 (0)	4/12 (33)
To have the opportunity to make decisions about how your child's body was treated during the autopsy process?	Medical	23/38 (61)	20/24 (83)	3/24 (13)	1/24 (4)	12/24 (50)
For medical professionals to provide written information in terms that you could understand?	Medical	23/38 (61)	17/23 (74)	5/23 (22)	1/23 (4)	13/23 (56)
For health professionals to be more comfortable using your child's name?	Medical	18/38 (47)	14/17 (82)	3/17 (18)	0/17 (0)	5/17 (29)
For referral to a genetic counsellor?	Medical	15/37 (41)	13/15 (87)	1/15 (7)	1/15 (7)	4/16 (25)

For support and information to understand possible genetic guilt (feelings around having unknowingly passed on a faulty gene to your child)?	Medical	14/38 (37)	11/14 (79)	1/14 (7)	2/14 (15)	8/14 (51)
For support for dealing with uncertainty when waiting for test results to arrive?	Medical	12/38 (32)	8/12 (67)	4/12 (33)	0/12 (0)	5/12 (42)
For information about the confidentiality of genetic testing?	Medical	5/19 (26)	2/5 (40)	2/5 (40)	1/5 (20)	1/5 (20)
For support from your family?	Psychological	34/38 (89)	24/34 (74)	8/34 (24)	1/34 (3)	11/34 (32)
For access to professional counselling or psychological services to deal with your bereavement?	Psychological	28/38 (74)	20/28 (71)	7/28 (25)	1/28 (4)	11/27 (41)
For family/friends to be more comfortable using your child's name?	Psychological	22/38 (58)	17/22 (77)	5/22 (23)	0/22 (0)	9/21 (43)
For professional support in dealing with the long-term difficulties resulting from the death of your child?	Psychological	19/38 (50)	13/19 (68)	5/19 (26)	1/19 (5)	10/18 (56)
For access to talk to other parents who have lost a child?	Psychological	18/38 (47)	8/18 (44)	8/18 (44)	2/18 (11)	11/18 (61)
For support from your community?	Psychological	17/38 (45)	7/17 (41)	8/17 (47)	2/17 (12)	7/18 (39)
For a health professional or resources to help you manage the reactions of others?	Psychological	17/38 (45)	14/17 (82)	2/17 (12)	1/17 (6)	9/17 (53)
For referral to someone to talk to who understands and has been through a similar experience?	Psychological	16/38 (42)	11/16 (69)	4/16 (25)	1/16 (6)	11/16 (69)
For a health professional or resources to help you deal with people who did not know what to say or how to behave?	Psychological	16/38 (42)	11/16 (69)	3/16 (19)	2/16 (13)	10/16 (63)
For a health professional or resources to provide you with advice for dealing with people who expected you to be "back to normal" after your child's death?	Psychological	16/38 (42)	13/16 (81)	3/16 (19)	0/16 (0)	12/16 (75)
For referral to a support group of parents who have been through a similar experience?	Psychological	13/38 (34)	9/13 (69)	4/13 (31)	0/13 (0)	9/13 (69)
For access to someone who could look after your spiritual needs?	Spiritual	17/37 (46)	8/17 (47)	8/17 (47)	1/17 (6)	6/16 (38)
To receive help/advice for taking care of your child's financial matters after death (e.g. closing bank accounts, paying/finalising bills etc)?	Financial	13/38 (34)	8/13 (62)	4/13 (31)	1/13 (8)	5/13 (38)