

Appendix 54: Characteristics of Included Study Participants (Question 7)

First Author Publication Year, Country of Origin ^a	Sample Size	Sex (% Male; % Female; NR)	Mean Age in Years (SD)	Race ^b	Education ^b	Income	Relationship Status	% With Children	Mutation Status
Aktan-Collan 2011, Finland ¹⁹⁶	248	48.8% male 51.2% female	56.4 (9.0) Range 41 to 82	NR	12.0 years (mean) 3.8 years (SD)	NR	76% Married/ cohabiting	None: 0% 1: 24% 2: 40% 3: 25% 4: 11%	Mutation positive: 100%
Aktan-Collan 2000, Finland ¹⁷²	Baseline: 446 1-month follow-up: 299 1-year follow-up: 271	49% male 51% female	43 (NR) Range 18 to 79	NR	33% Highest level of education is upper secondary or university 67% Highest level of education is primary or vocational education	NR	66% Married/ cohabiting	71%	Mutation positive: 30% Mutation negative: 70%
Aktan-Collan 2013 ¹⁷⁹	208	42.3% male 57.7% female	44.3 (SD 13.1)	NR	11.3 years (mean) 3.5 years (SD)	NR	73.5% Married/ cohabiting	100%	Mutation positive: 30% Mutation negative: 70%
Aktan-Collan 2001 ²²⁴	271	43% male 57% female	43 (NR) Range 19 to 77	NR	62% Educated beyond primary level	NR	72% Married/cohabiting	73%	Mutation positive: 31%
Aktan-Collan 2001 ²⁴⁸	271	43% male 57% female	43 (SD) Range 19 to 77	NR	62% Educated beyond primary level	NR	72% Married/cohabiting	73%	Mutation positive: 31%
Aktan-Collan 2001 ²²⁹	271	Mutation negative: 41% male 59% female Mutation positive: 46% male 54% female	Mutation negative: 45.6 (12.9) Mutation positive: 37.8 (11.5)	NR	Mutation negative: 11.0 years (mean) 3.5 years (SD) Mutation positive: 12.1 years (mean) 3.2 years (SD)	NR	Mutation negative: 74% Married/ cohabiting Mutation positive: 68% Married/ cohabiting	Mutation Negative: 78% Mutation Positive: 64%	Mutation positive: 31% Mutation negative: 69%
Arver 2004, Sweden ¹⁸⁸	21	100% female	42.7 (15.5)	NR	NR	NR	NR	NR	Mutation positive: 33% Mutation negative: 77%

First Author Publication Year, Country of Origin ^a	Sample Size	Sex (% Male; % Female; NR)	Mean Age in Years (SD)	Race ^b	Education ^b	Income	Relationship Status	% With Children	Mutation Status
Balmana 2004, United States ²⁴³	37	30% male 70% female	43.3 (12.9)	94% Caucasian 0% African- American 6% Latin 0% Asian- American	49% < College 51% > College	42.5% < \$75,000 57.5% > \$75,000	30% Single, divorced or widowed 70% Married/ cohabiting	76%	NR
Barrow 2015, United Kingdom ¹⁸⁷	591	NR	NR	NR	NR	NR	NR	NR	NR
Broderson 2004, United Kingdom ²⁴⁴	437	31% male 69% female	NR	NR	NR	NR	NR	NR	NR
Bruwer 2013, South Africa ¹⁶³	80	31% male 69% female	40.8 (SD) Range 21-70	93% Mixed ancestry (Coloured population) and spoke Afrikaans 7% Caucasian with English as a first language	NR	NR	64% Married/ cohabiting	None: 12.5% 1: 21.3% 2: 28.8% 3: 27.5% 4: 7.5% 5: 2.5%	Mutation positive: 100%
Burton-Chase 2014, United States ²²²	74	100% female	40 (8.7) Range 25 to 64	92% White	62% College or higher	NR	72% Married/ cohabiting	77%	Mutation positive: 78% Amsterdam II criteria: 22%
Carlsson 2007, Sweden ²⁰⁵	19	Mutation carriers: 55% male 45% female Non-carriers: 37% male 63% female	Mutation carriers: 51 (Range 33 to 75) Non-carriers: 47 (Range 36 to 64)	NR	NR	NR	NR	NR	Mutation positive: 58% Mutation negative: 42%

First Author Publication Year, Country of Origin ^a	Sample Size	Sex (% Male; % Female; NR)	Mean Age in Years (SD)	Race ^b	Education ^b	Income	Relationship Status	% With Children	Mutation Status
Ceballos 2008, United States ²³⁷	Cases: 45 Relatives: 102	Cases: 56% male 44% female Relatives: 44% male 56% female	Cases: 60 (12), Range 38 to 81 Relatives: 52 (15), Range 23 to 86	Cases: 89% Caucasian 11% other Relatives: 94% Caucasian 6% other	Cases: 4% < High school 20% High school 27% Some college 49% College/graduate degree Relatives: 10% < High school 21% High school 34% Some college 35% College/graduate degree	Cases: 16% < \$30,000 38% \$30,000 to \$69,999 47% > \$70,000 Relatives: 23% < \$30,000 44% \$30,000 to \$69,999 33% > \$70,000	NR	NR	NR
Claes 2004, Belgium ¹⁷³	Carriers: 19 Non-carriers: 21	Carriers: 58% male 42% female Non-carriers: 57% male = 43% female	Carriers: 40.7 (11.4), Range 22 to 60 Non-carriers: 42.7 (10.9), Range 19 to 64	NR	Carriers: 47% < High school 11% High school 42% > High school Non-Carriers: 29% < High school 19% High school 52% > High school	NR	Carriers: 21% Single 79% Stable relationship Non-carriers: 14% Single 86% Stable relationship	Carriers: 74% Non-carriers: 67%	Mutation positive: 48% Mutation negative: 52%
Claes 2005, Belgium ¹⁹²	Carriers: 36 Non-carriers: 36	Carriers: 67% male 33% female Non-carriers: 53% male 47% female	Carriers: 38.5 (10.0), Range 18 to 60 Non-carriers: 40.0 (11.8), Range 19 to 67	NR	Carriers: 50% < High school 8% High school 42% > High school Non-carriers: 31% < High school 14% High school 55% > High school	NR	Carriers: 19% No stable relationship 81% Stable relationship Non-carriers: 8% No stable relationship 92% Stable relationship	Carriers: 69% Non-carriers: 64%	Mutation positive: 50% Mutation negative: 50%

First Author Publication Year, Country of Origin ^a	Sample Size	Sex (% Male; % Female; NR)	Mean Age in Years (SD)	Race ^b	Education ^b	Income	Relationship Status	% With Children	Mutation Status
Codori 1999, United States ²⁵⁰	Acceptors: 77 Decliners: 181 From 95 families	Acceptors: 45% male 55% female Decliners: 41% male 59% female	Acceptors: median = 44 (IQR = 23, range 19 to 70) Decliners: median = 50 (IQR = 22, range 22 to 83)	Acceptors: 96% Caucasian Decliners: 100% Caucasian	Acceptors: 16 years (median) 4 years (IQR) Decliners: 15 years (median) 6 years (IQR)	NR	Acceptors: 71% Married/ cohabiting Decliners: 75% Married/ cohabiting	NR	
Cragun 2012, United States ¹⁸⁴	91	59% male 41% female	65.0 (11.9) Range 35 to 93	94.4% White	65.5% At least some college	NR	69.2% Married/cohabiting	NR	NR
de Leon 2004, Italy ¹⁸⁹	164 from 32 families	NR	NR	NR	NR	NR	NR	NR	
Dewanwala 2011, United States ²¹⁰	161	29% male 71% female	46.1 (NR) Range 20 to 75	95% White	72% College graduate	79.8% < \$50,000 20.2% ≥ \$50,000	69.7% Married/ cohabiting 30.3% Not married/ cohabiting	68%	NR
Esplen 2001, Canada and United States ¹⁷⁴	Mutation positive: 23 Mutation negative: 7 Waiting for test result: 20	Mutation positive: 30% male 70% female Mutation negative: 43% male 57% female Waiting for test result: 40% male 60% female	Mutation positive: 44.3 (15.0) Mutation negative: 40.3 (6.8) Waiting for test result: 51.8 (14.8)	NR	NR	NR	NR	NR	NR

First Author Publication Year, Country of Origin ^a	Sample Size	Sex (% Male; % Female; NR)	Mean Age in Years (SD)	Race ^b	Education ^b	Income	Relationship Status	% With Children	Mutation Status
Esplen 2003, Canada ²⁰³	220	48% male 52% female	63 (9.6)	NR	52% High school or less 48% Post- secondary	NR	79% Married/ cohabiting 21% Never married, divorced or widowed	NR	NR
Esplen 2007, Canada ¹⁷⁷	314	47% male 53% female	62.1 (9.7)	75% Anglo/North American 18% Anglo/European	52% High school or less 48% College or more	40% \$21,000 to \$50,000 28% \$51,000 to \$80,000 9% > \$81,000	80% Married/ cohabiting 20% Single/divorced/ widowed	NR	NR
Esplen 2015, Canada ²¹¹	155	Affected mutation positive: 47% male 52% female At-risk mutation positive: 37% male 63% female Mutation negative 40% male 60% female	Affected mutation positive: 56 (13), Range 26 to 78 At-risk mutation positive: 40 (11), Range 22 to 62 Mutation negative: 48 (12), Range 25 to 76	Affected mutation positive: 89% Anglo- Saxon At-risk mutation positive: 88% Anglo- Saxon Mutation negative: 95% Anglo- Saxon	Affected mutation positive: 46% High school or less 54% College or more At-risk mutation positive: 37% High school or less 63% College or more Mutation negative: 61% High school or less 39% College or more	NR	Affected mutation positive: 70% Married/ cohabiting 30% Single/divorced/ separated At-risk mutation positive: 82% Married/ cohabiting 18% single/divorced/ widowed Mutation negative: 86% Married/ cohabiting 14% single/divorced/ widowed	NR	NR
Fantini 2007, France ²⁰⁶	77	49% male 51% female	44.27 (14.21)	NR	22% < High school 40% High school 37% University	NR	75% Married/ cohabiting 25% Non- married/divorced/ widowed	NR	NR

First Author Publication Year, Country of Origin ^a	Sample Size	Sex (% Male; % Female; NR)	Mean Age in Years (SD)	Race ^b	Education ^b	Income	Relationship Status	% With Children	Mutation Status
Glanz 1999, United States ¹⁶⁴	426	49% male 51% female	50.0 (16.4) Range 19 to 84	78.9% Japanese 11.7% Hawaiian or part-Hawaiian 9.4% Caucasian	35.7% High school or less 34.5% Some college 29.8% College graduate	NR	63.5% Married/ cohabiting 16.0% divorced, widowed or separated 20.5% never married	NR	NR
Graves 2014, United States ¹⁹⁷	Baseline: 107 6-month follow-up: 85	47% male 53% female	61.2 (14.9) Range 28 to 98	96.8% Caucasian 3.2% Non- Caucasian	23.8% High school or less 76.2% High school or higher	NR	NR	87.90%	Mutation positive: 41.1% Mutation negative: 58.9%
Gritz 1999, United States ²²⁶	269	56% male 44% female	52% ≥50 years	88% White	32% High school or less				
Palmquist 2010 ¹⁶⁵	26 from 3 families	42% male 58% female	Family A: 43 (NR), Range 21 to 63 Family B: 55 (NR), Range 23 to 82 Family C: 29 (NR), Range 21 to 56	1 Caucasian family 1 African- American family 1 Mexican- American family	NR	Family A: \$46,000 (mean) Range \$15,000 to \$75,000 Family B: \$34,000 (mean) Range \$15,000 to \$75,000 Family C: \$32,000 (mean) Range < \$15,000 to \$75,000	NR	NR	NR
Gritz 2005 ²²⁵	155	Affected: 43% male 57% female Unaffected: 36% male 64% female	Affected: 47% ≥50 years Unaffected: :21% ≥50 years	Affected: 85% White Unaffected: 76% White	Affected: 32% ≤ High school 33% Some college 35% ≥ college Unaffected: 26% ≤ High school: 31% Some college 42% ≥ college	Affected: 59% ≤ \$50,000 Unaffected: 54% ≤ \$50,000	74% Married/ cohabiting	Affected: 80% Unaffected: 79%	Affected: Mutation positive: 37% Mutation negative: 63% Unaffected Mutation positive: 29% Mutation

First Author Publication Year, Country of Origin ^a	Sample Size	Sex (% Male; % Female; NR)	Mean Age in Years (SD)	Race ^b	Education ^b	Income	Relationship Status	% With Children	Mutation Status
									negative: 71%
Pentz 2005 ²³¹	80 from 16 families	39% male 61% female	48 (NR) Range 21 to 81	85% White 10% Hispanic 5% African-American	18% ≤ High school 25% Some college 29% ≥ College graduate	43% ≤ \$50,000 38% ≥ \$50,000	71% Married/ cohabiting	84%	75% of families had a mutation
Koehly 2003 ²²¹	36 from 5 families	42% male 58% female	49 (16.5) Range 21 to 82	NR	NR	NR	NR	NR	
Peterson 2003 ¹⁶⁶	39 from 5 families	38% male 62% female	Family 1: 62 (NR), Range 23 to 81 Family 2: 39 (NR), Range 21 to 56 Family 3: 35 (NR), Range 28 to 45 Family 4: 63 (NR), Range 40 to 73 Family 5: 47 (NR), Range 21 to 63	4 Caucasian families 1 Hispanic family	Family 1: 4 of 10 completed college Family 2: 3 of 8 completed college Family 3: 6 of 7 completed college Family 4: 1 of 5 completed college Family 5: 0 of 9 completed college	Family 1: \$59,000 (mean), \$20,000 to \$100,000 (range) Family 2: \$32,000 (mean), < \$15,000 to \$75,000 (range) Family 3: \$54,000 (mean), \$20,000 to \$100,000 (range) Family 4: \$63,000 (mean), \$30,000 to 100,000 (range) Family 5: \$34,000 (mean), \$15,000 to \$75,000 (range)	Number never married or divorced: Family 1: 1 of 10 Family 2: 3 of 8 Family 3: 4 of 7 Family 4: 0 of 5 Family 5: 1 of 9	NR	number personal history of HNPCC syndrome cancer family 1 (2 of 10); family 2 (3 of 8); family 3 (4 of 7); family 4 (1 of 5); family 5 (2 of 9)
Vernon 1999 ¹⁹⁵	269	56% male 44% female	39% < 50 61% ≥ 50	88% White 12% Non-white	32% ≤ High school 67% > High school	33% ≤ \$30,000 67% > \$30,000	78% Married/ cohabiting 22% not married	84%	NR
Hadley 2003, United States ¹⁷⁰	104	43% male 57% female	43 (median) Range 18 to 83	87% White 7% African-American 3% Hispanic 2% Asian-American 1% Native-American	NR	48% < \$50,000			

First Author Publication Year, Country of Origin ^a	Sample Size	Sex (% Male; % Female; NR)	Mean Age in Years (SD)	Race ^b	Education ^b	Income	Relationship Status	% With Children	Mutation Status
Eliezer 2014 ²³⁰	179 from 26 families	42% male 58% female	39 (NR) Range 18 to 72	97% White	NR	NR	60% Married/ cohabiting	NR	FDRs: Mutation positive: 60% Second and third degree relatives: Mutation positive: 45%
Morris 2013 ²³²	123 from 34 families	42% male 58% female	38.2 (12.75) Range 18 to 72	98.4% Caucasian	52.9% College/graduate degree	NR	56.9% Married/ cohabiting 29.3% Single	NR	NR
Ersig 2011 ²⁵⁷	Index cases: 20 FDRs: 31	Mutation positive: 16% male 84% female Indeterminate: 11% male 89% female	Mutation positive: 49.1 (15.0) Indeterminate: 48.6 (13.3)	100% Caucasian	Mutation positive: 52% College degree Indeterminate: 65% College degree	NR	Mutation positive: 72% Married/ cohabiting Indeterminate: Married/ cohabiting 65%	NR	NR
Ersig 2010 ²⁵¹	Index cases: 10 FDRs: 16 from 11 families	Index cases: 20% male 80% female (n = 8) FDRs: 7% male 93% female	Index cases: 55.3 (8.3), Range 45 to 69 Children: 27.8 (7.3), Range 20 to 41 Siblings: 54.8 (5.3), Range 44 to 62	NR	NR	NR	NR	NR	NR
Hadley 2010 ²³⁴	297 from 38 families	41% male 59% female	42 (NR) Range 18 to 83	96% White	NR	NR	NR	NR	
Ashida 2009 ²³⁶	178 from 24 families	42% male 58% female	39.8 (14.8)	94.9% Caucasian 2.2% African- American	24.1% Graduate degree/training 52.8% College degree 22.2% High school diploma	NR	NR	NR	Mutation positive: 46.1%

First Author Publication Year, Country of Origin ^a	Sample Size	Sex (% Male; % Female; NR)	Mean Age in Years (SD)	Race ^b	Education ^b	Income	Relationship Status	% With Children	Mutation Status
Ersig 2009 ²¹⁴	69	Mutation positive: 47% male 53% female Inconclusive: 32% male 68% female	Mutation positive: 47.1 (10.6) Inconclusive: 48.6 (11.6)	Mutation positive: 89.5% Caucasian Inconclusive: 93.5% Caucasian	NR	NR	Mutation positive: 78.9% Married/ cohabiting Inconclusive: 74.2% Married/ cohabiting	NR	Mutation positive: 55.1% Inconclusive: 44.9%
Ersig 2009 ²⁰⁹	46	11% male 89% female	54% > 50	100% Caucasian	Highest level of education completed = 3.70 (mean); 1.03 (SD) on a scale that includes 1= less than high school; 2 = high school graduate; 3 = vocational school/some college; 4 = college; 5= graduate school	NR	67% Married/ cohabiting	NR	Mutation positive: 50% Indeterminate: 50%
Palmer 2005 ²⁴⁵	56	Mutation negative: 28% male 72% female Mutation positive: 89% male 11% female	Mutation negative: 40.5 (13.4) Mutation positive: 32.6 (10.6)	Mutation negative: 94.9% White Mutation positive: 94.1% White	NR	Mutation negative: 61.5% < \$50,000 Mutation positive: 29.4% < \$50,000	NR	NR	Mutation positive: 30% Mutation negative: 70%
Hadley 2004 ²¹⁵	56	Mutation negative: 28% male 72% female Mutation positive: 89% male 11% female	Mutation negative: 40.5 (13.4) Mutation positive: 32.6 (10.6)	Mutation negative: 94.9% White Mutation positive: 94.1% White	NR	Mutation negative: 61.5% < \$50,000 Mutation positive: 29.4% < \$50,000	NR	NR	Mutation positive: 30% Mutation negative: 70%
Halbert 2004, United States ²¹²	98	32% male 68% female	68% ≥ 40 32% < 40 years	NR	56% > High school 44% ≤ High school	NR	72% Married/cohabiting 28% Not married	NR	Mutation positive: 22% Mutation negative: 50%

First Author Publication Year, Country of Origin ^a	Sample Size	Sex (% Male; % Female; NR)	Mean Age in Years (SD)	Race ^b	Education ^b	Income	Relationship Status	% With Children	Mutation Status
									Decliners: 28%
Ho 2003, China ¹⁸²	62 from 35 families	61% male 39% female	42 (9.9) Range 18 to 68	NR	NR	NR	NR	NR	Mutation positive: 25.8% Mutation negative: 19.4% Awaiting test results: 32.3% Non-tested: 22.6%
Johnson 2002, United States ²¹³	65	49% male 51% male	26.2% < 50 73.8% ≥ 50	100% White	NR	NR	NR	NR	
Keller 2004, Germany ¹⁶⁷	Participated in information session: 25 Did not participate in information session: 48	Participants: 68% male 32% female Non-participants: 42% male 58% female	Participants: 24% < 40 years, 56% 41 to 60 years, 20% > 60 years Non-participants 19% < 40 years, 60% 41 to 60 years, 21% > 60 years	NR	Participants: 32% < 10 years 36% 10 to 12 years 32% > 12 years Non-participants: 35% < 10 years 27% 10 to 12 years 38% > 12 years	NR	NR	NR	NR
Keogh 2009, Australia ¹⁹⁸	Original ethics protocol: 47 Modified ethics protocol: 59	Original protocol: 53% male 47% female Modified protocol: 41% male 59% female	Original protocol: 46.8 (13.7) Modified protocol: 51.0 (13.9)	NR	Original protocol: 51% Higher education Modified protocol: 54% Higher education	NR	NR	NR	NR
Kidambi 2015, United States ¹⁹⁹	Selective screening: 107 Universal screening: 285	Selective screening: 39% male 61% female Universal screening: 50% male 50% female	Selective screening: 49.4 (15.0) Universal screening: 59.3 (13.9)	NR	NR	NR	NR	NR	Mutation positive: 9.9%

First Author Publication Year, Country of Origin ^a	Sample Size	Sex (% Male; % Female; NR)	Mean Age in Years (SD)	Race ^b	Education ^b	Income	Relationship Status	% With Children	Mutation Status
Kinney 2000, United States ¹⁸¹	98	51% male 49% female	64 (13) Range 29 to 90	81% White 19% African- American	20% < High school 45% High school 35% College graduate	NR	71% Married/ cohabiting 29% Not married	NR	NR
Kinney 2000, United States ²⁰²	95	36% male 64% female	44 (13) Range 18 to 72	80% Caucasian 10% African- American 2% Asian	37% ≤ High school 63% College	NR	62% Married/cohabiting 38% Not married	NR	
Kohut 2007, Canada ²¹⁷	105	NR	NR	NR	NR	NR	NR	NR	NR
Kupperman 2013, United States ²¹⁶	General practice: 49 CRC program: 21	General practice: 29% male 71% female CRC program: 62% male 38% female	52.3 (NR)	67% White	72% College degree	47% > \$100,000	49% Married/cohabiting	54%	
Landsbergen 2011, Netherlands ²²³	89	36% male 64% female	55 (median) Range 32 to 85	NR	NR	NR	83% Married/ cohabiting	88%	NR
Landsbergen 2012 ²³³	CRC patients: 81 Partners: 50	Mutation positive: 52% male 48% female Mutation negative: 50% male 50% female	Mutation positive: 48 (10) Mutation negative: 48 (12)	NR	Mutation positive: 61% > High school Mutation negative: 52% > High school	NR	Mutation positive: 100% Married/ cohabiting Mutation negative: 86% Married/ cohabiting	Mutation Positive: 91% Mutation Negative: 89%	
Landsbergen 2009, Netherlands ¹⁹⁴	8	NR	NR	NR	NR	NR	NR	NR	NR

First Author Publication Year, Country of Origin ^a	Sample Size	Sex (% Male; % Female; NR)	Mean Age in Years (SD)	Race ^b	Education ^b	Income	Relationship Status	% With Children	Mutation Status
Leenan 2016, Netherlands ¹⁸³	129 from 33 families who had been tested 16 who had not been tested	Mutation carriers: 44% male 56% female Mutation negative: 34% male 66% female Non-tested: 38% male 62% female	Mutation carriers: 52 (14) Mutation negative: 67 (13) Non-tested: 42 (17)	NR	Mutation carriers: 41% Higher education Non-carriers: 29% Higher education Non-tested: 38% Higher education	NR	Mutation carriers: 78% Married/ cohabiting 8% Single 12% Divorced/separated/ widowed Non-carriers: 76% Married/ cohabiting 10% Single 11% Divorced/separated/ widowed Non-tested: 56% Married/ cohabiting 19% Single 25% Divorced/separated/ widowed	Mutation carriers: 86% Non-carriers: 93% Non-tested: 56%	Mutation positive: 46% Mutation negative: 54%
Lerman 1996, United States ¹⁷⁵	45	44% male 56% female	47.8 (14.1)	83% White 17% African- American	73% > High school	NR	73% Married/ cohabiting	NR	NR
Lindor 2004, United States ¹⁸⁰	414	50% male 50% female	NR	98% Caucasian	NR	NR	NR	NR	MSI-H tumours: 22%
Loader 2005, United States ¹⁶⁹	37	39% male 61% female	59.9 (6.7)	NR	14.9 years (mean) 2.5 years (SD)	NR	69.4% Married/ cohabiting	97.2% Mean number of children: 2.7 SD in number of children: 1.1	Mutation positive: 18.9% Mutation negative: 81.1%
Lynch 1999, United States ¹⁷¹	199 from 7 families	48% male 52% female	43.8 (NR) Range 18 to 92	NR	NR	NR	NR	NR	NR

First Author Publication Year, Country of Origin ^a	Sample Size	Sex (% Male; % Female; NR)	Mean Age in Years (SD)	Race ^b	Education ^b	Income	Relationship Status	% With Children	Mutation Status
Manne 2007, United States ¹⁹¹	125	71% male 39% female	44.6 (6.1)	88% White 6.4% Black/African- American 1.6% Asian/Pacific Islander 1.6% Hispanic 2.4% Other	19.2% High school or less 44.8% Some college/trade school/business school 11.2% 4-year degree 2.4% Some graduate education 22.4% Graduate degree	\$60,000 to \$99,999 (mean)	NR	NR	
McCann 2009, United States ¹⁸⁶	30 from 17 families	37% male 73% female	16.7% < 35 years	NR	NR	NR	80% Married/ cohabiting 3.3% Divorced 3.3% Widowed 13.3% Single	73.30%	NR
Meiser 2004, Australia ²⁰⁰	114	39% male 61% female	Mutation positive: 36.8 (13.2) Mutation negative: 42.7 (12.6)	NR	33.6% No post- school 66.4% Post-school	NR	75.4% Married/ cohabiting 24.6% Not married	78.10%	Mutation positive: 28% Mutation negative: 72%
Collins 2007 ²⁴⁶	73	38% male 62% female	41 (median) Range 21 to 75	NR	Carriers: 78% Post-school education, including trade school Non-carriers: 70% Post-school education, including trade school	NR	Carriers: 63% Married/ cohabiting Non-carriers: 85% Married/ cohabiting	Carriers: 68% Non-carriers: 83%	Mutation positive: 26% Mutation negative: 74%
Collins 2005 ²⁴⁷	114	Carriers: 34% male 66% female Non-carriers: 41% male	Carriers: 36.8 (NR) Non-carriers: 43.1 (NR)	NR	Carriers: 71% post-school education Non-carriers: 65% post-school	NR	Carriers: 56% Married/ cohabiting Non-carriers: 83% Married/	Carriers: 66% Non-carriers: 83%	

First Author Publication Year, Country of Origin ^a	Sample Size	Sex (% Male; % Female; NR)	Mean Age in Years (SD)	Race ^b	Education ^b	Income	Relationship Status	% With Children	Mutation Status
		59% female			education		cohabiting		
Mesters 2005, Netherlands ²¹⁹	30	27% male 73% female	53 (12) Range 25 to 69	NR	NR	NR	NR	NR	Mutation positive: 37%
Murakami 2004, Japan ²²⁸	42	48% male 52% female	50 (median) Range 21 to 69	NR	59.5% ≥ College		83.3% Married/ cohabiting 9.5% Living alone	78.60%	Mutation positive: 26% Mutation negative: 74%
Petersen 1999, United States ²⁰⁷	Mail surveys: 1,217 Telephone survey: 156 From 650 families	Mail survey: 41% male 59% female Telephone survey: 47% male 53% female	Mail survey: 54.5 (14.7) Telephone survey: 55.1 (14.5)	Mail survey: 96.9% White Telephone survey: 91.9% White 3.4% Black 2.0% Hispanic 2.0% Asian	Mail survey: 28.4% Graduate degree 32.1% College graduate 25.7% Some college 10.5% High school graduate 1.5% No high school Telephone survey: NR	Mail survey: 37.5% > \$75,000 24.4% \$50,001 to \$75,000 17.4% \$35,001 to \$50,000 13.3% \$20,000 to \$35,000 7.3% < \$20,000 Telephone survey: 37.8% > \$75,000 23.1% \$50,00 to \$75,000 14.0% \$35,001 to \$50,000 15.4% \$20,000 to \$35,000 9.8% < \$20,000	NR	NR	NR
Ramsey 2010, United States ²³⁵	Population- based controls: 170 FDRs: 310	Population-based controls: 39% male 61% female FDRs: 37% male 63% female	Male controls: 51.1 (NR) Male FDRs: 48.6 (NR) Female controls: 52.9 (NR) Female FDRs: 47.0 (NR)	NR	Controls: 2% < High school 8% High school 30% Some college 60% College graduate FDRs: < 1% < High school 13% High school 38% Some college 47% College graduate	NR	NR	NR	NR

First Author Publication Year, Country of Origin ^a	Sample Size	Sex (% Male; % Female; NR)	Mean Age in Years (SD)	Race ^b	Education ^b	Income	Relationship Status	% With Children	Mutation Status
Ramsey 2003, United States ¹⁹⁰	CRC patients: 6 FDRs: 4 Controls: 5	CRC patients: 17% male 83% female FDRs: 75% male 25% female Controls: 100% male	NR	CRC patients and FDRs: 100% White Controls: 80% White 20% Asian	CRC patients: 33.3% High school or less 66.7% Some college FDRs: 100% Some college Controls: 100% Some college	NR	CRC patients: 83.3% Married/ cohabiting 16.7% Divorced Relatives: 50% Married/ cohabiting 50% Divorced Controls: 100% Married/ cohabiting	NR	NR
Reeve 2000, New Zealand ¹⁹³	7	57% male 43% female	45 (NR) Range 34 to 64 years	NR	NR	NR	NR	NR	2 mutation- positive males 2 mutation- negative males 2 mutation- positive females 1 mutation- negative female
Roygnan 2008, France ²⁰⁴	7	29% male 71% female	50 (NR) Range 38 to 65	NR	NR	NR	100% Married/ cohabiting	86%	Mutation positive: 100%
Shiloh 2008, United States ²³⁸	Index cases: 67 At-risk family members: 186	50% male 50% female	42.4 (14.0)	95% White 2% African- American 2% Asian 2% Hispanic	NR	59% > \$50,000	64% Married/ cohabiting	80%	Index cases: Mutation positive: 47.8% Indeterminate: 52.2%
Shipman 2013, United Kingdom ¹⁷⁶	11	54% male 46% female	NR	100% White British	NR	NR	NR	NR	NR
Stoffel 2008, United States ²¹⁸	174	30% male 70% female	46.7 (NR) Range 18 to 79	91% White	69% College graduate	NR	76% Married/cohabiting 21.8% Non-married 2.3% Unknown	NR	Mutation positive: 60% Mutation negative: 13% Indeterminate:

First Author Publication Year, Country of Origin ^a	Sample Size	Sex (% Male; % Female; NR)	Mean Age in Years (SD)	Race ^b	Education ^b	Income	Relationship Status	% With Children	Mutation Status
									27%
Tomiak 2014, Canada ¹⁷⁸	Acceptors: 12 Decliners: 7	Acceptors: 63% male 37% female Decliners: 71% male 29% female	Acceptors: 59 (median), Range 37 to 77 Decliners: 62 (median), Range 54 to 79	NR	Acceptors: 58% Post- secondary education Decliners: 57% Post- secondary education	NR	NR	Acceptors: 92% Decliners: 57%	NR
van Oostrom 2007, Netherlands ²⁴⁰	96	33% male 67% female	41.0 (13.3)	NR	18.8% < High school 55.2% Some college 26% > College	NR	81.3% Married/ cohabiting 18.7%; Single, divorced, widowed	67.70%	Mutation positive: 29.3% Mutation negative: 70.7%
van Oostrom 2007 ²²⁷	96	33% male 67% female	41.0 (13.3)	NR	18.8% < High school 55.2% Some college 26% > College	NR	81.3% Married/ cohabiting 18.7%; Single, divorced, widowed	67.70%	Mutation positive: 29.3% Mutation negative: 70.7%
van Oostrom 2007 ²⁴¹	96	33% male 67% female	41.0 (13.3)	NR	18.8% < High school 55.2% Some college 26% > College	NR	81.3% Married/ cohabiting 18.7%; Single, divorced, widowed	67.70%	Mutation positive: 29.3% Mutation negative: 70.7%
van Oostrom 2006 ²⁴²	96	33% male 67% female	41.0 (13.3)	NR	18.8% < High school 55.2% Some college 26% > College	NR	81.3% Married/ cohabiting 18.7%; Single, divorced, widowed	67.70%	Mutation positive: 29.3% Mutation negative: 70.7%
Vernon 1997, United States ²⁴⁹	200	54% male 46% female	56.5 (NR)	90% White 10% African- American,	18.8% < High school 55.2% Some	NR	NR	NR	

First Author Publication Year, Country of Origin ^a	Sample Size	Sex (% Male; % Female; NR)	Mean Age in Years (SD)	Race ^b	Education ^b	Income	Relationship Status	% With Children	Mutation Status
				Hispanic, Asian and other	college 26% > College				
Wagner 2005, Netherlands ²⁰¹	70	34% male 66% female	51% 20 to 50 49% > 50	NR	NR	NR	NR	89%	Mutation positive: 100%
Wakefield 2007, Australia ¹⁶⁸	22	32% male 68% female	51.4 (NR)	NR	23% High school 36% Certificate or diploma 27% Undergraduate degree 14% Postgraduate degree	NR	77% Married/ cohabiting 9% never married 14% Separated or divorced 0% widowed	NR	NR
Walsh 2012, United States ¹⁸⁵	8	50% male 50% female	NR	63% Caucasian 25% Asian/Pacific Islander 13% Latino/Hispanic 13% other	38% Some college 38% College graduate 25% Graduate school	13% \$0 to < \$10,000 57% \$30,000 to \$75,000 50% > \$75,000	63% Married/ cohabiting 13% never married 25% widowed	NR	NR
Watkins 2011, Canada ²⁰⁸	23	39% male 61% female	48.9 (13.6) Range 26 to 78	NR	NR	NR	NR	NR	Mutation positive: 100%
Yamashita 2008, Japan ²³⁹	46	48% male 52% female	49.5 (13.0)	NR	NR	NR	83% Married/cohabiting	80%	Mutation positive: 39.1% Mutation negative: 21.7% Indeterminate: 39.1%

CRC = colorectal cancer; FDR = first-degree relative; IQR = interquartile range; MSI-H = high microsatellite instability; NR = not reported; SD = standard deviation; SDR = second-degree relative.

^a Studies with a common (sub) sample of patients are grouped together, with the primary study left-justified in the cell and related studies right-justified in subsequent rows.

^b Descriptive results are presented according to categories reported in the primary studies.