Thank you for agreeing to take part in this study.

As a reminder, your participation is voluntary. We expect this survey to take about 30 minutes or less. Your responses will help us improve our program and understand the needs of our patients. You will be asked several questions. Some questions will require "Yes" or "No" answers; some will be on a 1-5 scale, and other questions will have multiple answer choices. Everything you tell us will be kept confidential. This means that your responses will only be shared with research team members. When we write our report, nothing will identify you. Please be honest with your responses. You can say whatever you want — nothing will hurt our feelings and nothing you say will have a negative effect on your care. Please remember, you can decline to answer any question and you may end the survey at any time.

HRQOL-4: Healthy Days Measure

1) Would you say that in general your health is:

- Excellent
- Very Good
- Good
- Fair
- Poor
- Don't know
2) Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?

- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10
- 11
- 12
- 13
- 14
- 15
- 16
- 17
- 18
- 19
- 20
- 21
- 22
- 23
- 24
- 25
- 26
- 27
- 28
- 29
- 30
- Don't know

3) Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?

- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10
- 11
- 12
- 13
- 14
- 15
- 16
- 17
- 18
- 19
- 20
- 21
- 22
- 23
- 24
- 25
- 26
- 27
- 28
- 29
- 30
- Don't know

4) During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?

- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10
- 11
- 12
- 13
- 14
- 15
- 16
- 17
- 18
- 19
- 20
- 21
- 22
- 23
- 24
- 25
- 26
- 27
- 28
- 29
- 30
- Don't know

---

**Perceived Risk**

5) In your opinion, compared to other [men/women] your age, what are your chances of developing [heart disease/cancer]?

- Much Lower
- Lower
- Same
- Higher
- Much Higher
- Don't Know

---

**Do you think results from genetic testing will...**

6) ...accurately identify your disease risk?

- Yes
- Probably Yes
- No
- Probably No

7) ...influence what treatment you receive for your current or future medical problems?

- Yes
- Probably Yes
- No
- Probably No

8) ...influence decisions you make about your medical care?

- Yes
- Probably Yes
- No
- Probably No

9) ...influence your or your child's reproductive decisions?

- Yes
- Probably Yes
- No
- Probably No

10) ...influence what medications you take?

- Yes
- Probably Yes
- No
- Probably No

11) ...influence your end-of-life planning?

- Yes
- Probably Yes
- No
- Probably No
Please rate how true each statement is for you by selecting one of the following numbers: 1 - never true, 2 - very seldom true, 3 - seldom true, 4 - sometimes true, 5 - frequently true, 6 - almost always true, 7 - always true.

<table>
<thead>
<tr>
<th></th>
<th>1 Never True</th>
<th>2 Very Seldom True</th>
<th>3 Seldom True</th>
<th>4 Sometimes True</th>
<th>5 Frequently True</th>
<th>6 Almost Always True</th>
<th>7 Always True</th>
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<tr>
<td>12) Your painful experiences and memories make it difficult for you to live a life that you would value.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
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<td>13) You’re afraid of your feelings.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
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<td>14) You worry about not being able to control your worries and feelings.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
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<tr>
<td>15) Your painful memories prevent you from having a fulfilling life.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
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<td>16) Emotions cause problems in your life.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
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<td>17) It seems like most people are handling their lives better than you are.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
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<td>18) Worries get in the way of your success.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
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**Hospital General Anxiety & Depression Scale**

19) You feel tense or 'wound up':
- ○ Most of the time  ○ A lot of the time  ○ From time to time, occasionally  ○ Not at all

20) You still enjoy the things you used to enjoy:
- ○ Definitely as much  ○ Not quite so much  ○ Only a little  ○ Hardly at all

21) You get a sort of frightened feeling as if something awful is about to happen:
- ○ Very definitely and quite badly  ○ Yes, but not too badly  ○ A little, but it doesn't worry me  ○ Not at all

22) You can laugh and see the funny side of things:
- ○ As much as you always could  ○ Not quite so much now  ○ Definitely not so much now  ○ Not at all

23) Worrying thoughts go through your mind:
- ○ A great deal of the time  ○ A lot of the time  ○ From time to time but not too often  ○ Only occasionally
24) You feel cheerful:
   - Not at all
   - Not often
   - Sometimes
   - Most of the time

25) You can sit at ease and feel relaxed:
   - Definitely
   - Usually
   - Not often
   - Not at all

26) You feel as if you slowed down:
   - Nearly all the time
   - Very often
   - Sometimes
   - Not at all

27) You get a sort of frightened feeling like ‘butterflies’ in the stomach:
   - Not at all
   - Occasionally
   - Quite often
   - Very often
These questions are about your child's thoughts and feelings.

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<tr>
<td>28)</td>
<td>Your child feels sad or empty.</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
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<tr>
<td>29)</td>
<td>Your child worries when he/she thinks he/she has done poorly at something</td>
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<td>30)</td>
<td>Your child feels afraid of being alone at home</td>
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<td>31)</td>
<td>Nothing is much fun for your child anymore</td>
<td></td>
<td></td>
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<td>32)</td>
<td>Your child worries that something awful will happen to someone in the family</td>
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<td>33)</td>
<td>Your child is afraid of being in crowded places (like shopping centers, the movies, buses, busy playgrounds)</td>
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<tr>
<td>34)</td>
<td>Your child worries what other people think of him/her</td>
<td></td>
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<td>35)</td>
<td>Your child has trouble sleeping</td>
<td></td>
<td></td>
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<td>36)</td>
<td>Your child feels scared to sleep on his/her own</td>
<td></td>
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<td>37)</td>
<td>Your child has problems with his/her appetite</td>
<td></td>
<td></td>
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<td>38)</td>
<td>Your child suddenly becomes dizzy or faint when there is no reason for this</td>
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<td>39)</td>
<td>Your child has to do some things over and over again (like washing hands, cleaning or putting things in a certain order)</td>
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<td>40)</td>
<td>Your child has no energy for things</td>
<td></td>
<td></td>
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<tr>
<td>41)</td>
<td>Your child suddenly starts to tremble or shake when there is no reason for this</td>
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<td>42)</td>
<td>Your child cannot think clearly</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>43)</td>
<td>Your child feels worthless</td>
<td></td>
<td></td>
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<tr>
<td>44)</td>
<td>Your child has to think of special thoughts (like numbers or words) to keep bad things from happening</td>
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<td>45)</td>
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Your child thinks about death

46) Your child feels like he/she doesn't want to move

47) Your child worries that he/she will suddenly get a scared feeling when there is nothing to be afraid of

48) Your child is tired a lot

49) Your child feels afraid that he/she will make a fool of him/herself in front of people

50) Your child has to do some things in just the right way to stop bad things from happening

51) Your child feels restless

52) Your child worries that something bad will happen to him/her

53) Planning family activities is difficult because you misunderstand each other

54) In times of crisis you can turn to each other for support

55) You cannot talk to each other about the sadness you feel

56) Individuals are accepted for who they are

57) You avoid discussing your fears and concerns

58) You can express feeling for each other

59) There are lots of bad feelings in your family

60) You feel accepted for who you are
61) Making decisions is a problem for your family
   ○ Strongly Agree  ○ Agree  ○ Disagree  ○ Strongly Disagree

62) You are able to make decisions about how to solve problems
   ○ Strongly Agree  ○ Agree  ○ Disagree  ○ Strongly Disagree

63) You don't get along well
   ○ Strongly Agree  ○ Agree  ○ Disagree  ○ Strongly Disagree

64) You confide in each other
   ○ Strongly Agree  ○ Agree  ○ Disagree  ○ Strongly Disagree

---

**Decision Regret**

65) It was the right decision
   ○ Strongly Agree  ○ Agree  ○ Neither Agree Nor Disagree  ○ Disagree  ○ Strongly Disagree

66) You regret the choice that was made
   ○ Strongly Agree  ○ Agree  ○ Neither Agree Nor Disagree  ○ Disagree  ○ Strongly Disagree

67) You would go for the same choice again if you had to do it over again
   ○ Strongly Agree  ○ Agree  ○ Neither Agree Nor Disagree  ○ Disagree  ○ Strongly Disagree

68) The choice did you a lot of harm?
   ○ Strongly Agree  ○ Agree  ○ Neither Agree Nor Disagree  ○ Disagree  ○ Strongly Disagree

69) The decision was a wise one?
   ○ Strongly Agree  ○ Agree  ○ Neither Agree Nor Disagree  ○ Disagree  ○ Strongly Disagree

---

**Genetic Counseling Satisfaction**

70) Your child's genetic counselor seemed to understand the stresses you were facing
   ○ Strongly Disagree  ○ Disagree Somewhat  ○ Uncertain  ○ Agree Somewhat  ○ Agree Strongly

71) Your child's genetic counselor helped you to identify what you needed to know to make decisions about what would happen
   ○ Strongly Agree  ○ Agree  ○ Neither Agree Nor Disagree  ○ Disagree  ○ Strongly Disagree

72) You felt better about your child's health after meeting with their genetic counselor
   ○ Strongly Agree  ○ Agree  ○ Neither Agree Nor Disagree  ○ Disagree  ○ Strongly Disagree
73) The genetic counseling session was about the right length of time you needed

   - Strongly Agree   - Agree   - Neither Agree Nor Disagree   - Disagree   - Strongly Disagree

74) The genetic counselor was truly concerned about your child's well-being

   - Strongly Agree   - Agree   - Neither Agree Nor Disagree   - Disagree   - Strongly Disagree

75) The genetic counseling session was valuable to you

   - Strongly Agree   - Agree   - Neither Agree Nor Disagree   - Disagree   - Strongly Disagree

---

**Health Education Impact Questionnaire (heiQ)**

76) You communicate very confidently with your doctor about your child's MyCode genetic test result

   - Strongly Disagree   - Disagree   - Agree   - Strongly Agree

77) You have very positive relationships with your child's healthcare providers regarding their MyCode genetic test result

   - Strongly Disagree   - Disagree   - Agree   - Strongly Agree

78) You confidently give healthcare professionals information about your child's MyCode genetic test result

   - Strongly Disagree   - Disagree   - Agree   - Strongly Agree

79) You get your needs met from available healthcare resources for your child's MyCode genetic test result

   - Strongly Disagree   - Disagree   - Agree   - Strongly Agree

80) You work in a team with your child's doctors and other healthcare providers for your child's MyCode genetic test result

   - Strongly Disagree   - Disagree   - Agree   - Strongly Agree
Please check each item showing how frequently these comments were true for you during the past 7 days.

81) Do you think about it even when you don’t mean to?
   Not at All ☐ Rarely ☐ Sometimes ☐ Often ☐

82) Do you try to remove it from your memory?
   Not at All ☐ Rarely ☐ Sometimes ☐ Often ☐

83) Do you have difficulty paying attention or concentrating?
   Not at All ☐ Rarely ☐ Sometimes ☐ Often ☐

84) Do you have waves of strong feelings about it?
   Not at All ☐ Rarely ☐ Sometimes ☐ Often ☐

85) Do you startle more easily or feel more nervous than you did before it happened?
   Not at All ☐ Rarely ☐ Sometimes ☐ Often ☐

86) Do you stay away from reminder of it (e.g. places or situations)?
   Not at All ☐ Rarely ☐ Sometimes ☐ Often ☐

87) Do you try not to talk about it?
   Not at All ☐ Rarely ☐ Sometimes ☐ Often ☐

88) Do pictures about it pop into your mind?
   Not at All ☐ Rarely ☐ Sometimes ☐ Often ☐

89) Do other things keep making you think about it?
   Not at All ☐ Rarely ☐ Sometimes ☐ Often ☐

90) Do you try not to think about it?
   Not at All ☐ Rarely ☐ Sometimes ☐ Often ☐

91) Do you get easily irritable?
   Not at All ☐ Rarely ☐ Sometimes ☐ Often ☐

92) Are you alert and watchful when there no obvious need to be?
   Not at All ☐ Rarely ☐ Sometimes ☐ Often ☐

93) Do you have sleep problems?
   Not at All ☐ Rarely ☐ Sometimes ☐ Often ☐

Adjustment to Genetic Information

94) How upset did you feel about your child’s MyCode genetic test result?
   A Little ☐ Somewhat ☐ A Good Deal ☐ A Great Deal ☐

95) How anxious or nervous did you feel about your child’s MyCode genetic test result?
   A Little ☐ Somewhat ☐ A Good Deal ☐ A Great Deal ☐

96) How sad did you feel about your child’s MyCode genetic test result?
   A Little ☐ Somewhat ☐ A Good Deal ☐ A Great Deal ☐

97) How happy did you feel about your child’s MyCode genetic test result?
   A Little ☐ Somewhat ☐ A Good Deal ☐ A Great Deal ☐
98) How relieved did you feel about your child's MyCode genetic test result?
   - A Little
   - Somewhat
   - A Good Deal
   - A Great Deal

99) How much did you feel that you understood clearly your choices for disease prevention or early detection for your child?
   - A Little
   - Somewhat
   - A Good Deal
   - A Great Deal

100) How helpful was the information you received from your child's MyCode genetic test result in planning for the future?
    - A Little
    - Somewhat
    - A Good Deal
    - A Great Deal

101) How frustrated did you feel that there are no definite disease prevention guidelines for your child?
     - A Little
     - Somewhat
     - A Good Deal
     - A Great Deal

102) How uncertain did you feel about what your child's MyCode genetic test result means for them?
     - A Little
     - Somewhat
     - A Good Deal
     - A Great Deal

103) How uncertain did you feel about what your child's MyCode genetic test result means for your child's risk of disease?
     - A Little
     - Somewhat
     - A Good Deal
     - A Great Deal

104) How concerned did you feel that your child's MyCode genetic test result would affect your health insurance status?
     - A Little
     - Somewhat
     - A Good Deal
     - A Great Deal

105) How concerned did you feel that your child's MyCode genetic test result would affect your employment status?
     - A Little
     - Somewhat
     - A Good Deal
     - A Great Deal