

Appendix A Genetic Psychosocial Risk Instrument (GPRI)

The purpose of this questionnaire is to help identify individuals who may need additional support while going through genetic testing. The questions are about your life experiences and feelings about the disease for which you are receiving genetic testing/counseling. Please note that whenever the word "disease" is used, it is referring to the disease for which you are having genetic testing and/or counseling. Please read each statement carefully, then respond by placing a firm checkmark in the most appropriate space.

Name:	Date (dd / mm / yyyy):
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1. I have/had a personal diagnosis of the disease for which I am receiving counseling/testing	(5) Yes	(1) No
2. I have taken care of a very ill parent or another close family member (e.g. sibling) <u>If yes</u> , the illness was related to the condition for which I am receiving counseling/testing	(0) Yes	(1) No
3. I lost a close family member (e.g. parent/sibling) to the disease for which I am receiving counseling/testing <u>If yes</u> , please indicate who the family member was who died (check all that apply): (0) a parent (0) a sibling (0) other (specify) _____	(5) Yes	(1) No

	Strongly agree	Somewhat agree	Neither agree/disagree	Somewhat disagree	Strongly disagree	Not applicable
4. If I learn that I <u>have</u> a genetic mutation, I believe that:						
a. I will have more problems in my life	5	4	3	2	1	0
b. I will change plans for my career/ profession	5	4	3	2	1	3
c. I will have difficulties in my family relationships	5	4	3	2	1	3
5. The disease for which I am at risk is <u>currently</u> causing a significant disruption in my family life	5	4	3	2	1	3
6. I am worried that my test result will impact on my relationship with my significant other (or future partner)	5	4	3	2	1	3
7. I am worried about talking to my children (young or adult) about the heritable nature of the disease for which I'm being tested	5	4	3	2	1	3
8. My worries about the disease affect my daily mood	5	4	3	2	1	3
9. I worry often about my risk of getting the disease	5	4	3	2	1	3
10. I am concerned about my risk of getting the disease	5	4	3	2	1	3
11. I feel guilty that I might pass on the disease risk to my children	5	4	3	2	1	3

	Almost all of the time	Often	Sometimes	Hardly ever	Not at all
12. I have generally felt sad in the past month	5	4	3	2	1
13. I have generally felt nervous and anxious in the past month	5	4	3	2	1

14. I have had emotional problems in the past	(5) Yes	(1) No
15. I have had counseling with a counselor and/or a mental health professional in the past	(5) Yes	(1) No
16. I have been diagnosed with a depressive or anxiety disorder in the past	(5) Yes	(1) No
17. I have had emotional problems that led me to have thoughts about suicide	(5) Yes	(1) No
18. I am now seeing a counselor for one or more of these emotional concerns	(5) Yes	(1) No

19. I am interested in talking with a counsellor about one or more of these concerns	(0) Yes	(0) No
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Instruction to the user: Item #19 is for referral purpose only, no score is assigned. The remaining items all have assigned scores. Because item #4 has three sub-statements, a total of 20 statements/items are included in the scoring. Please sum the score of all items & enter the total score here _____. If it is 50 or greater, and if #19 is Yes, then a psychosocial referral is recommended.

