DANA-FARBER CANCER INSTITUTE

Patient ID:

CanSeq

Thank you for agreeing to participate in the CanSeq research study.

For each of the questions below, please select the one response that best applies to you.

There are no right or wrong answers. The information you provide will be strictly confidential.

1. From the list below, please mark the box next to the statement that best describes your current level of physical ability and activity.

☐	I am fully active and able to carry out activities the same as before my cancer diagnosis, without any restrictions.
☐	I have difficulty with physically strenuous activity but I am able to walk and carry out work that is light or based in one location; such as light house-work or office-work.
☐	I can walk and take care of myself, but I am not able to carry out work activities; I am up and about more than half the hours that I am awake.
☐	I am capable only of limited self-care and spend more than half the hours that I am awake in bed or in a chair.
☐	I am completely disabled, cannot carry on any self-care, and am totally confined to a bed or chair.

2. We are interested in some things about you and your health. Please answer the following questions by marking the box that best applies to you.

	Not at all	A little	Quite a bit	Very much
a. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	☐	☐	☐	☐
b. Do you have any trouble taking a long walk?	☐	☐	☐	☐
c. Do you have any trouble taking a short walk outside of the house?	☐	☐	☐	☐
d. Do you need to stay in bed or a chair during the day?	☐	☐	☐	☐
e. Do you need help with eating, dressing, washing yourself or using the toilet?	☐	☐	☐	☐

3. During the past week:

	Not at all	A little	Quite a bit	Very much
a. Were you limited in doing either your work or other daily activities?	☐	☐	☐	☐
b. Were you limited in pursuing your hobbies or other leisure time activities?	☐	☐	☐	☐
c. Were you short of breath?	☐	☐	☐	☐
d. Have you had pain?	☐	☐	☐	☐
e. Did you need to rest?	☐	☐	☐	☐
f. Have you had trouble sleeping?	☐	☐	☐	☐
g. Have you felt weak?	☐	☐	☐	☐
h. Have you lacked appetite?	☐	☐	☐	☐
i. Have you felt nauseated?	☐	☐	☐	☐
j. Have you vomited?	☐	☐	☐	☐
k. Have you been constipated?	☐	☐	☐	☐

4. During the past week:

	Not at all	A little	Quite a bit	Very much
a. Have you had diarrhea?	☐	☐	☐	☐
b. Were you tired?	☐	☐	☐	☐
c. Did pain interfere with your daily activities?	☐	☐	☐	☐
d. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	☐	☐	☐	☐
e. Did you feel tense?	☐	☐	☐	☐
f. Did you worry?	☐	☐	☐	☐
g. Did you feel irritable?	☐	☐	☐	☐
h. Did you feel depressed?	☐	☐	☐	☐
i. Have you had difficulty remembering things?	☐	☐	☐	☐
j. Has your physical condition or medical treatment interfered with your family life?	☐	☐	☐	☐
k. Has your physical condition or medical treatment interfered with your social activities?	☐	☐	☐	☐
l. Has your physical condition or medical treatment caused you financial difficulties?	☐	☐	☐	☐

For the following questions please mark the number between 1 and 7 that best applies to you.

5. How would you rate your overall health during the past week?

Very poor ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 Excellent

6. How would you rate your overall quality of life during the past week?

Very poor ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 Excellent

Patient ID:

Now we would like to know more about how you are **currently** feeling. For each statement below, please choose 1 response that best describes your current feelings.

7. I feel tense or 'wound up':

- ☐ Most of the time
- ☐ A lot of the time
- ☐ From time to time, occasionally
- ☐ Not at all

8. I still enjoy the things I used to enjoy:

- ☐ Definitely as much
- ☐ Not quite so much
- ☐ Only a little
- ☐ Hardly at all

9. I 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

10. I can laugh and see the funny side of things:

- ☐ As much as I always could
- ☐ Not quite so much now
- ☐ Definitely not so much now
- ☐ Not at all

11. Worrying thoughts go through my mind:

- ☐ A great deal of the time
- ☐ A lot of the time
- ☐ From time to time, but not too often
- ☐ Only occasionally

12. I feel cheerful:

- ☐ Not at all
- ☐ Not often
- ☐ Sometimes
- ☐ Most of the time

13. I can sit at ease and feel relaxed:

- ☐ Definitely
- ☐ Usually
- ☐ Not Often
- ☐ Not at all

14. I feel as if I am slowed down:

- ☐ Nearly all the time
- ☐ Very often
- ☐ Sometimes
- ☐ Not at all

15. I get a sort of frightened feeling like 'butterflies' in the stomach:

- ☐ Not at all
- ☐ Occasionally
- ☐ Quite Often
- ☐ Very Often

16. I have lost interest in my appearance:

- ☐ Definitely
- ☐ I don't take as much care as I should
- ☐ I may not take quite as much care
- ☐ I take just as much care as ever

17. I feel restless as if I have to be on the move:

- ☐ Very much indeed
- ☐ Quite a lot
- ☐ Not very much
- ☐ Not at all

18. I look forward with enjoyment to things:

- ☐ As much as I ever did
- ☐ Rather less than I used to
- ☐ Definitely less than I used to
- ☐ Hardly at all

19. I get sudden feelings of panic:

- ☐ Very often indeed
- ☐ Quite often
- ☐ Not very often
- ☐ Not at all

20. I can enjoy a good book or radio or TV program:

- ☐ Often
- ☐ Sometimes
- ☐ Not often
- ☐ Very seldom

Next, we'd like to ask you some questions about your experience with and beliefs about genetic testing.

For each of the following items, please mark the number between 1 and 5 that best describes your attitude about having a genetic test.

For me a genetic test is...

21. a. A bad thing ☐ ☐ ☐ ☐ ☐ A good thing
1 2 3 4 5

b. Beneficial ☐ ☐ ☐ ☐ ☐ Harmful
1 2 3 4 5

c. Important ☐ ☐ ☐ ☐ ☐ Unimportant
1 2 3 4 5

22. Before you joined this CanSeq study, did you ever have a genetic test to find out if you are at increased risk for a disease?

☐ Yes
☐ No
☐ Don't Know

23. As far as you know, is each of the following statements about genetics and genetic testing true or false, or are you not sure?

	True	False	Not Sure
a. If a person has a genetic mutation for a disease, the person will always get the disease.	☐	☐	☐
b. Only mothers can pass on genetic diseases.	☐	☐	☐
c. People can be healthy even if they have a genetic mutation for a disease.	☐	☐	☐
d. Genetic testing can be used in adults to find out if they have a greater than average chance of developing certain kinds of cancer.	☐	☐	☐
e. Genetic testing can be used in adults to find out if they have a greater than average chance of developing depression.	☐	☐	☐
f. Genetic testing can be used in adults to predict whether a person will have a heart attack.	☐	☐	☐
g. Genetic testing can be used during pregnancy to find out whether the baby will develop sickle cell disease or cystic fibrosis.	☐	☐	☐

25. Please select 1 statement that best reflects the role you prefer when making decisions about treatment for your cancer.

☐ I prefer to make the decision about which treatment I will receive.

☐ I prefer to make the final decision about my treatment after seriously considering my doctor's opinion.

☐ I prefer that my doctor and I share responsibility for deciding which treatment is best for me.

☐ I prefer that my doctor makes the final decision about my treatment after seriously considering my opinion.

☐ I prefer to leave all decisions regarding my treatment to my doctor.

The questionnaire is almost complete. For the next section, we would like to know a little more about you.

26. How often do you have problems learning about your medical condition because of difficulty understanding written information?
- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

27. How confident are you filling out medical forms by yourself?
- ☐ Extremely
- ☐ Quite a bit
- ☐ Somewhat
- ☐ A little bit
- ☐ Not at all

28. How often do you have someone (like a family member, friend, hospital/clinic worker or caregiver) help you read hospital materials?
- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

29. How good are you at working with fractions?

Not at all good					Extremely good
☐	☐	☐	☐	☐	☐
1	2	3	4	5	6

30. How good are you at working with percentages?

Not at all good					Extremely good
☐	☐	☐	☐	☐	☐
1	2	3	4	5	6

31. When reading a newspaper, how helpful do you find tables and graphs that are part of the story?

Not at all					Extremely
☐	☐	☐	☐	☐	☐
1	2	3	4	5	6

32. When people tell you the chance of something happening, do you prefer that they use *words* ("it rarely happens") or *numbers* ("there's a 1% chance")?

Always prefer words					Always prefer numbers
☐	☐	☐	☐	☐	☐
1	2	3	4	5	6

33. To what extent do you consider yourself a religious person?
- ☐ Very religious
- ☐ Moderately religious
- ☐ Slightly religious
- ☐ Not religious at all

34. To what extent do you consider yourself a spiritual person?
- ☐ Very spiritual
- ☐ Moderately spiritual
- ☐ Slightly spiritual
- ☐ Not spiritual at all

35. Think about how much you try to understand and deal with major problems in your life. To what extent does each of the statements below reflect the way you cope?

	A great deal	Quite a bit	Somewhat	Not at all
a. I think about how my life is part of a larger spiritual force.	☐	☐	☐	☐
b. I work together with God as partners to get through hard times.	☐	☐	☐	☐
c. I look to God for strength, support and guidance in crises.	☐	☐	☐	☐

36. What is your religion? *Please check all that apply.*
- ☐ Protestant (*please specify denomination*):_____
- ☐ Catholic
- ☐ Jewish
- ☐ Born-again or Evangelical Christian
- ☐ Mormon/Latter-day Saints
- ☐ Muslim
- ☐ Buddhist
- ☐ Hindu
- ☐ Unitarian Universalist
- ☐ No religion
- ☐ Atheist
- ☐ Other religion (*please specify*):_____

37. Do you consider yourself Hispanic, Latino/a or Spanish?

☐ No
☐ Yes →

If yes, please select the primary group you belong to from the list below:

- ☐ Mexican (from Mexico), Mexican American, Chicano
- ☐ Puerto Rican
- ☐ Cuban
- ☐ Dominican
- ☐ Other (*please specify*): _____

38. What is your race? *Please check all that apply.*

☐ White	
☐ Black or African American	
☐ American Indian or Alaska Native →	Please tell us the name of your enrolled or principal tribe:
☐ Japanese	
☐ Chinese	
☐ Other East Asian →	Please select your primary East Asian Group below: ☐ Korean ☐ Vietnamese ☐ Taiwanese ☐ Other (*please specify*): _____
☐ South East Asian or Indian →	Please select your primary South East Asian racial group below: ☐ East Indian ☐ Filipino ☐ Vietnamese ☐ Laotian ☐ Guamanian or Chamorro ☐ Hmong ☐ Thai ☐ Pakistani ☐ Cambodian ☐ Other (*please specify*): _____
☐ Native Hawaiian or other Pacific Islander	
☐ Other →	*Please specify:*

39. What is your preferred language?

- ☐ English
- ☐ Spanish
- ☐ Other (*please specify*): _____

40. What is the highest level of education you have completed?

- ☐ None
- ☐ Some grade school (grades 1 to 7)
- ☐ Grade school graduate (grade 8)
- ☐ Some high school (grades 9 to 12)
- ☐ High school graduate or GED
- ☐ Post high school training other than college (vocational, technical, etc.)
- ☐ Some college or Associates degree
- ☐ College graduate
- ☐ Master's degree
- ☐ Doctoral degree

41. As of today, what is your employment status?

- ☐ Employed more than or equal to 32 hrs/wk
- ☐ Employed less than 32 hrs/wk
- ☐ Employed, but on medical leave
- ☐ Full-time student
- ☐ Part-time student
- ☐ Unemployed, seeking work
- ☐ Homemaker
- ☐ Unable to work due to disability
- ☐ Retired
- ☐ Other (*please specify*):_____

42. From the list below, please choose the response that best reflects your current marital status.

- ☐ Legally married or registered domestic partners
- ☐ Living with a partner to whom you are not married
- ☐ In a serious relationship but not living with a partner
- ☐ Single
- ☐ Separated
- ☐ Divorced
- ☐ Widowed
- ☐ Other (Please specify): _____

42a. Some people who join this study are hoping that the sequencing results will help answer questions that they have about their health or their family's health. We cannot promise that the sequencing results will answer your questions. However, if you do have questions you are hoping the study will answer, please use the space below to tell us about them (optional).

_____

_____

_____

Finally, we would like to ask you some questions that will help us to understand whether cancer and other diseases might run in your family.

43. Have you had more than 10 colon polyps in your lifetime?
- ☐ Yes
- ☐ No
- ☐ Don't Know

44. Are your ancestors of Ashkenazi Jewish descent?
- ☐ Yes
- ☐ No
- ☐ Don't Know

45. Are you adopted?

☐ No → **Please continue to next page.**

- ☐ Yes
- ☐ Don't Know

46. Do you have information about your biological family?
- ☐ No → **That is all the questions we have. Thank you very much for completing our survey.**
- ☐ Yes

Please continue to next page.

Answer the remaining questions to the best of your ability, based on information you may have about your *BLOOD* relatives.

Think about your ***biological MOTHER***.

47. How many sisters does (did) your MOTHER have? _____

48. How many brothers does (did) your MOTHER have? _____

Think about your ***biological FATHER***.

49. How many sisters does (did) your FATHER have? _____

50. How many brothers does (did) your FATHER have? _____

51. Do you believe that an *increased risk of developing cancer* runs in your family?
    - ☐ Yes
    - ☐ No
    - ☐ Don't Know

52. Complete the following table to the best of your ability, for any of your *CLOSE BLOOD RELATIVES* who have ***had cancer***. Please list which family member(s) have had cancer, what type(s) of cancer(s) they have had, and ***the approximate age*** at which their cancers were diagnosed (For example: "60's"). If you do not know the type of cancer or age when diagnosed, please indicate 'don't know.'

    A list of cancers appears on the last page of this questionnaire.

    Close blood relatives include: Mother, Father, Daughter, Son, Sister, Brother, Half-sister, Half-Brother (note mother or father's side)**

Relationship to you (see list above)**	**Type of cancer**	**Approximate age when cancer was diagnosed**
Example: Sister	Breast	60's

53. Please complete the following table to the best of your ability, for any of your EXTENDED FAMILY MEMBERS who are *BLOOD RELATIVES* and have ***had cancer***. Please tell us which family member(s) have had cancer, what type(s) of cancer(s) they have had, and ***the approximate age*** at which their cancers were diagnosed (For example: "60's.") If you do not know the type of cancer or age when diagnosed, please indicate 'don't know.'

    A list of cancers appears on the last page of this questionnaire for your reference.

    Extended family members include: Aunt, Uncle, Grandmother, Grandfather, Niece, Nephew, Female Cousin, Male Cousin.**

Relationship to you (** see list above)	Mother's or father's side	Type of cancer	Approximate age when cancer diagnosed
Example: Aunt	Mother's side	Breast	60's

54. Do you believe that an *increased risk of developing a disease other than cancer* runs in your family?
    - ☐ Yes
    - ☐ No
    - ☐ Don't Know

55. List any hereditary (genetic) diseases ***other than cancer*** that run in your family. Some examples are: Cystic fibrosis, Fragile X, Gaucher's disease, Hemochromatosis, Homocysteinuria, Huntington's disease, Muscular Dystrophy, Neurofibromatosis, Sickle-cell Anemia, Tay Sachs disease, and Thalassemia.

    _____ _____

56. Other conditions may be common in families but are not strictly "genetic", meaning that we cannot identify one gene that explains their pattern in the family. Examples include high blood pressure, diabetes, dementia (Alzheimer's and others), and alcoholism. Please list any conditions that are common in your family.

    _____ _____

    _____ _____

THANK YOU FOR COMPLETING OUR SURVEY!

Survey and Data Management core
qualitative and quantitative research

Patient ID:

List of Potential Cancers

Type of Cancer/Tumor/Malignancy	Type of Cancer/Tumor/Malignancy
• Lung Cancer	• Colon Cancer
• Head and Neck Cancer: o Larynx o Mouth o Palate o Throat o Tongue	• Other Gastrointestinal cancer: o Esophagus o Stomach o Small Intestine o Rectum o Anus o Appendix o Gall bladder/ Biliary tree o Liver
• Breast Cancer (including DCIS)	• Pancreas • Pancreas Islet Cell
• Male Genito-Urinary: o Prostate o Testis o Other	• Female Genito-Urinary: o Cervix o Endometrium (uterus lining) o Uterus o Ovary o Fallopian Tube/Peritoneum
• Kidney	• Bladder
• Hematologic (Blood/Immune): o Leukemia o Hodgkin's Disease o Lymphoma o Myeloma o Waldenstrom's Macroglobulinemia	• Sarcoma: o Bone (Osteosarcoma) o GIST o Soft Tissue Sarcoma (includes Leiomyosarcoma, Liposarcoma, other)
• Skin Cancers: o Melanoma o Basal Cell o Sebaceous Adenoma o Squamous Cell	• Brain Tumors: o Glioblastoma/Astrocytoma o Medulloblastoma o Hemangioblastoma
• Endocrine/Hormonal: o Adrenal gland (cortex) o Carcinoid (lung or abdomen) o Paraganglioma or Pheocromocytoma o Thyroid	