BRIGHT Project Genetic Counseling Protocol Summary
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*All 3 sets of PowerPoint slides may be found in separate files in these supplementary materials.

Overview of Genetic Counseling and Test Reporting Sessions

P16 Session 1 (conducted at initial clinic visit 1)

I. Contracting: Ask the participant his or her understanding of the study and why he or she was invited to participate.
II. Personal history
    a. Briefly review major or chronic issues the patient has that may affect health or impact ability to have cancer screening.
    b. Ask about prior dermatology exams and current sun protection practices.
III. Family history
    a. Ask participant which family members have had melanoma and/or genetic testing.
    b. Review other reported cancers in the family (while not part of the study counseling protocol, participants will be advised if their family history indicates a need for increased cancer screening or additional follow-up for other types of cancers or hereditary cancer syndromes).
IV. Guide participants through a discussion of the study slides (appended)
    a. The risk associated with a *p16* mutation is presented as a range (slide #11) reflecting the variable penetrance estimates reported in the literature. It is explained during the session that inheriting phenotypic risk factors for melanoma (such as red hair) in addition to a *p16* mutation is associated with greater risk, while individuals with fewer phenotypic risk factors will have a lower, but still substantial risk.
V. Evaluate participant's decision to proceed with testing
    a. Based on what they have heard, would they like to be tested?
    b. Individuals who decided to not be tested were informed that they could access testing clinically at any time in the future.
    c. Review the plan to provide and discuss test results at their next visit.
VI. Components of the counseling session unique to the *p16* group and not included in the counseling for the no-test control group were slides 12 (autosomal dominant inheritance), 13 (possible outcomes of genetic testing), and 14 (insurance discrimination)

P16 Session 2 (conducted at clinic visit 2)

I. Address any questions from the prior visit.
II. Disclose *p16* genetic test result.
    a. Assess patient's initial reaction to learning his or her results.
    b. Use the visual aid (slide #3) to illustrate the risks conferred by their mutation.
    c. For those testing positive
        i. Review that the penetrance in Utah families is generally towards the upper range because most of our families have additional phenotypic risk factors.
        ii. Review the risk for pancreatic cancer.

iii. Verbally state that this result means that their children or future children will have a 50% chance of inheriting the mutation.

d. For those testing negative
   i. While the negative test result greatly reduces their melanoma risk, many of our families have phenotypic factors which put them at a slightly higher risk for melanoma compared to the general population risk (~2-fold), and therefore they will still benefit from taking steps to protect their skin.
   ii. Review that they are not at increased risk for pancreatic cancer.
   iii. Verbally state that this result means that they cannot pass the mutation on to their children or future children.

III. Guide participants through the study slides (appended)
   a. Discuss pancreatic cancer screening if the participant has tested positive.

IV. Assess participant's reaction to the management information provided.
   a. Was the information new or consistent with their prior knowledge?
   b. Is there anything that they plan on changing about their screening or sun protection based on what they heard?
   c. What other questions do they have?

V. Conclusion: Inform participants that even after the study ends, the Family Cancer Assessment Clinic at Huntsman Cancer Institute will continue to be a resource for them in the future.

VI. Components of the counseling session unique to the *p16* group and not included in the counseling for the no-test control group were slides 3 (risk associated with a positive or negative test result) and 15 (pancreatic cancer screening recommendations for those who tested positive).

No-test Control Session (for no-test control families, conducted at clinic visit 2)

I. Contracting: Ask the participant his or her understanding of the study and why he or she was invited to participate.

II. Personal history
   a. Briefly review major or chronic issues the patient has that may affect health or impact ability to have cancer screening.
   b. Ask about prior dermatology exams and current sun protection practices.

III. Family history
   a. Ask participant which family members have had melanoma and/or genetic testing.
   b. Review other reported cancers in the family (while not part of the study counseling protocol, participants will be advised if their family history indicates a need for increased cancer screening or additional follow-up for other types of cancers or hereditary cancer syndromes).

IV. Guide participants through a discussion of the study slides (appended)
   a. When explaining the "Risk Factors: High Risk Genes" slides (slides #8 and #9), the genetic counselor informs the participant that mutations in the *p16* gene have been found to explain the risk for melanoma in some families. However, for most families with a high risk for melanoma, the cause remains unknown. Their family is one in which the cause is still unknown, but since the pattern of melanoma is similar to families with known genetic factors, it is likely their risks are also similar to those families.
   b. On the slide "Approximate Lifetime Cancer Risk" (slide #11), the range of risk is presented as a function of being a member of a high-risk family and having additional phenotypic risk factors for melanoma (such as red hair). It is explained during the session that inheriting phenotypic risk factors for melanoma (such as red hair) in addition to being from a high risk family is associated with greater risk, while individuals with fewer phenotypic risk factors will have a lower, but still substantial risk.

V. Assess participant's reaction to the management information provided.
   a. Was the information new or consistent with their prior knowledge?
   b. Is there anything that they plan on changing about their screening or sun protection based on what they heard?
   c. What other questions do they have?

VI. Conclusion: Inform participants that even after the study ends, the Family Cancer Assessment Clinic at Huntsman Cancer Institute will continue to be a resource for them in the future.