GENETICS AND GENOMICS IN NURSING PRACTICE SURVEY

Dear Registered Nurse:

You are invited to take a survey that will evaluate primary issues in genetics and genomics. As the front line of care, nurses have a central role in seeing that genetic and genomic discoveries lead to disease prevention and population health improvements. We will evaluate a general assessment of your knowledge. Knowing your baseline knowledge will help you determine your learning needs.

Before choosing to participate, please consider that:

• You have been invited to complete this survey because you are a registered nurse. Questions in the survey relate to your current practices, knowledge and opinions about implications of genetic and genomic medicine for preventing and treating common diseases such as cancer, diabetes and heart disease.

• The survey will take about 15-20 minutes to complete.

• Your participation in this survey is completely voluntary and you can choose to skip any questions that you do not wish to answer.

• There are no risks, penalties, or costs to your participation. There are no direct benefits to your participation other than contributing to research.

• Many of the questions relate to your attitudes about genetics and genomics for which there are no right or wrong answers.

• All information you provide is anonymous.

PART ONE

Today's date: _____/_____/_____
        (Month/Day/Year)

1. How important do you think it is for the nurse to become more educated about the genetics of common diseases?

❑ Very important	<P1-1a> 0
❑ Somewhat important	<P1-1b> 1
❑ Not very important	<P1-1c> 2
❑ Not at all important	<P1-1d> 3
❑ Neutral	<P1-1e> 4
❑ Not sure/Don't know	<P1-1f> 999

2. Please indicate whether you think each of the following would be a potential advantage of integrating genetics of common diseases into your practice.

	No Advantage <0>	Advantage <1>	
Better treatment decisions (e.g., which drugs to prescribe)			<P1-2a>
Improved services to the patients			<P1-2b>
Better adherence to clinical recommendations among patients			<P1-2c>

3. Please indicate whether you think each of the following would be a potential disadvantage of integrating genetics of common diseases into your practice.

	No Disadvantage <0>	Disadvantage <1>	
Would take too much time			<P1-3a>
Not reimbursable/Too costly			<P1-3b>
Need to "re-tool" professionally			<P1-3c>
Increase patient anxiety about risk			<P1-3d>
Would increase insurance discrimination			<P1-3e>

PART TWO

1. Each of the following statements relates to the genetics of common diseases and family history taking. By common diseases, we are referring to disorders that arise as a result of interactions between an individual's environment and his or her unique genetic makeup. Common diseases include diseases such as cancer, heart disease, and diabetes. Please indicate how confident you are that you can do each of the following:

	Not at all confident <0>	Confident <1>	
Decide what family history information is needed to tell something about a patient's genetic susceptibility to common diseases.	❑	❑	<P2-1a>
Discuss how family history affects recommended screening intervals.	❑	❑	<P2-1b>
Decide which patients would benefit from a referral for genetic counseling and possible testing for susceptibility to common diseases.	❑	❑	<P2-1c>
Access reliable and current information about genetics and common diseases.	❑	❑	<P2-1d>
Give patients information about the **risks** of genetic testing for common diseases.	❑	❑	<P2-1e>
Give patients information about the **benefits** of genetic testing for common diseases.	❑	❑	<P2-1f>
Give patients information about the **limitations** of genetic testing for common diseases.	❑	❑	<P2-1g>
Facilitate referrals for genetic services for common diseases.	❑	❑	<P2-1h>

2. Please indicate whether you agree or disagree with the following statements.

	Agree <0>	Disagree <1>	Don't know <2>	
A family history that includes only 1st degree relatives such as parents, siblings, and children should be taken for every new patient.	❑	❑	❑	<P2-2a> **KN**
A family history that includes 2nd and 3rd degree relatives such as grandparents, aunts, uncles, and cousins should be taken for every new patient.	❑	❑	❑	<P2-2b> **KN**
Family history taking should be a key component of nursing care.	❑	❑	❑	<P2-2c> **KN**
There is a role for nurses in counseling patients about genetic risks.	❑	❑	❑	<P2-2d> **KN**

PART THREE

1. Are you actively taking care of patients?
    - ❑ Yes   <P3-1a> 0
    - ❑ No (If **NO** skip to **PART FOUR**)   <P3-1b> 1

2. In the past three months, how often have you collected a complete family history from a patient that includes the following components: information on disorders from three generations, and age at diagnosis and death for each affected family member?

    - ❑ Always   <P3-2a> 0
    - ❑ Often   <P3-2b> 1
    - ❑ Occasionally   <P3-2c> 2
    - ❑ Rarely or Never   <P3-2d> 3

3. In the past three months, has any patient initiated a discussion with you about genetics?
    - ❑ Yes   <P3-3a> 0
    - ❑ No   <P3-3b> 1

4. Thinking specifically about patients that you have seen **in the past three months,** please answer the following questions.

	Never <0>	Rarely <1>	Occasionally <2>	Frequently <3>	
In the past 3 months, how often have you used family history information when facilitating clinical decisions or recommendations for your patients?	❑	❑	❑	❑	<P3-4a>
In the past 3 months, how often have you facilitated referrals to genetic services?	❑	❑	❑	❑	<P3-4b>

PART FOUR

1. Do you think that genetic risk (e.g., as indicated by family history) has clinical relevance for the following:

	Not At All <0>	Somewhat <1>	A Great Deal <2>	
Breast cancer	❑	❑	❑	<P4-1a> **KN**
Colon cancer	❑	❑	❑	<P4-1b> **KN**
Coronary heart disease	❑	❑	❑	<P4-1c> **KN**
Diabetes	❑	❑	❑	<P4-1d> **KN**

Ovarian cancer	❑	❑	❑	<P4-1f> **KN**

2. When patients indicate **a disorder in the family**, which of the following pieces of information do you collect in your standard family history assessment? Each family member's:

	Never <0>	Sometimes <1>	Always <2>	
Age at diagnosis of condition	❑	❑	❑	<P4-2a>
Relationship to the patient	❑	❑	❑	<P4-2b>
Race or ethnic background	❑	❑	❑	<P4-2c>
Age at death from condition	❑	❑	❑	<P4-2d>
Both sides of the family (maternal/paternal)	❑	❑	❑	<P4-2e>

3. Thinking about how you support clinical decisions (such as administering drugs prescribed), how important do you think each of the following is to consider?

	Not at all <1>	Essential <2>	Don't know <3>	
Genetic Test Result	❑	❑	❑	<P4-3a>
Family history	❑	❑	❑	<P4-3b> **KN**

PART FIVE

The first group of questions is about human genetic variation. Please check the answer that indicates whether the statement is true, false or you do not know.

1. The DNA sequences of two randomly selected healthy individuals of the same sex are 90-95% identical. **KN**
   - ❑ true   <P5-1a-0**>**
   - ❑ false   <P5-1b-1>
   - ❑ don't know   <P5-1c-999>

2. Most common diseases such as diabetes and heart disease are caused by a single gene variant. **KN**
   - ❑ true   <P5-2a-0**>**
   - ❑ false   <P5-2b-1>
   - ❑ don't know   <P5-2c-999>

PART SIX

1. The Essential Competencies and Curricula Guidelines for Nurses in Genetics and Genomics are endorsed as being a standard part of nursing practice. Have you heard or read about these Competencies?

    ❑ Yes   <P6-1a> 0

    ❑ No   <P6-1b> 1

2.

	Excellent <0>	Good <1>	Poor <2>	
Please rate your understanding of the genetics of common diseases.	❑	❑	❑	<P6-2a>
In describing your genetic/genomic knowledge, would you consider it to be	❑	❑	❑	<P6-2b>

PART SEVEN

1. Learning more about genetics and its application to your professional practice:

	Yes <0>	No <1>	
Did your nursing curriculum include genetics content?	❑	❑	<P7-1a>
Since licensure, have you attended any courses that included genetics as a major component?	❑	❑	<P7-1b>

	Yes <0>	No <1>	Don't know <999>	
Do you intend to learn more about genetics?	❑	❑	❑	<P7-1c>
Would you be able to attend a course during work hours?	❑	❑	❑	**<P7-1d>**
Would you attend a course on your own time?	❑	❑	❑	<P7-1e>
Do you think your senior staff members see genetics as an important part of **your** role?	❑	❑	❑	<P7-1f>
Do you think your senior staff members see genetics as an important part of **their** role?	❑	❑	❑	<P7-1g>

PART EIGHT

1. What year were you born? (i.e. 1960)

    _____   <P8-1> TEXT (Number)

2. Are you a member of the American Nurses Association?

❑ Yes   <P8-2a> 0

❑ No   <P8-2b> 1

3. Are you currently a student?
- ❑ Yes   <P8-3a> 0
- ❑ No   <P8-3b> 1

4. Total number of years you have worked in Nursing: _____years   <P8-4> TEXT (number)

5. Your current **primary** functional area (**Mark ONLY ONE**)
- ❑ Administration   <P8-5a> 0
- ❑ Education   <P8-5b> 1
- ❑ Research   <P8-5c> 2
- ❑ Patient care   <P8-5d> 3
- ❑ Student   <P8-5e> 4
- ❑ Other (Please specify_____)   <P8-5f> TEXT

6. What percent of your work-time is spent taking care of patients?   _____% <P8-6> TEXT
(number)

7. What is your current **primary** area of practice or expertise?
- ❑ Staff Nurse   <P8-7a> 0
- ❑ Head Nurse   <P8-7b> 1
- ❑ Nurse Practitioner   <P8-7c> 2
- ❑ Clinical Nurse Specialist   <P8-7d> 3
- ❑ Educator   <P8-7e> 4
- ❑ Supervisor   <P8-7f> 5
- ❑ Researcher   <P8-7g> 6
- ❑ Director/Assistant Director   <P8-7h> 7
- ❑ Consultant   <P8-7i> 8
- ❑ Case Manager   <P8-7j> 9
- ❑ Other (Please specify_____)   <P8-7k> TEXT

8. What is the highest **nursing degree** that you have you received?
- ❑ None   <P8-8a> 0
- ❑ Licensed Practical/Vocational Nurse   <P8-8b> 1
- ❑ Diploma   <P8-8c> 2
- ❑ Associate Degree in nursing   <P8-8d> 3
- ❑ Baccalaureate Degree in nursing   <P8-8e> 4
- ❑ Master's Degree in nursing   <P8-8f> 5
- ❑ Doctorate Degree in nursing   <P8-8g> 6

9. Do you consider yourself to be Hispanic/Latino?
- ❑ Yes   <P8-9a> 0
- ❑ No   <P8-9b> 1

10. Which of the following do you consider yourself? (**Check ONLY ONE**)
- ❑ American Indian/Alaska Native   <P8-10a> 0
- ❑ Asian   <P8-10b> 1

❏ Black/African American   <P8-10c> 2
❏ Native Hawaiian/Pacific Islander <P8-10d> 3
❏ White   <P8-10e> 4
❏ Other (please specify):_____ <P8-10f> TEXT

11. What is your gender?
❏ Male   <P8-11a>
❏ Female   <P8-11b>

Thank you for taking the time to complete this survey.
Your participation is greatly appreciated!