Attachment D5 - General Survey

This survey is intended for consumers accessed through: 1) general healthcare or genetics advocacy organizations, 2) organizations related to specific topics (e.g., Colon Cancer Alliance, National Mental Health Association), and 3) visitors to the EGAPP website.

Note: Skip patterns will be programmed into the online form, making a streamlined survey for respondents.

Objectives – Types of information to be collected include:

1. Identify general descriptive characteristics of respondents.
2. Understand respondents' awareness of the EGAPP process and products (e.g., evidence reports, EGAPP Working Group recommendations).
3. Determine the perceived value of the efforts of the EGAPP pilot project to provide reliable information on genetic tests for health care providers and consumers.

Form Approved
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Evaluation of Genomic Applications in Practice and Prevention (EGAPP) Survey

Introduction to the EGAPP Survey

Evaluation of Genomic Applications in Practice and Prevention (EGAPP) is an initiative launched in 2004 by the National Office of Public Health Genomics (NOPHG) at the Centers for Disease Control and Prevention (CDC). The goal of EGAPP is to establish a systematic, evidence-based process to assess the effectiveness of selected genetic tests that are in transition from research to clinical and public health practice.

If you are familiar with the EGAPP pilot project or the information on some genetic tests that has been collected and made publicly available by EGAPP, we are interested in your opinions on its usefulness. Thank you for your time and willingness to answer the questions.

To evaluate the value and impact of the EGAPP products, an independent consultant has been contracted to survey key stakeholder groups, including healthcare providers, healthcare payers and purchasers, certain policy organizations, targeted consumer groups, and website visitors. Response to these surveys is very important to inform the EGAPP Working Group and CDC about the best methods and approaches for future review of the effectiveness of emerging genetic tests, and about the potential impact of accurate and timely information on genetic tests on current healthcare practices.

Your feedback will provide important information about the relevance of EGAPP products to your practice. The questions relate only to EGAPP-supported evidence reports and EGAPP Working Group Recommendations. Thank you for your time and assistance.

Please note: While taking the survey, please do not use your browser's back and/or forward buttons; please only use the next and previous buttons within the survey. Thank you.

1. How were you directed to this survey? (Please check one)
___ EGAPP web pages on the EGAPPreviews.org or other website
___ CDC's Genomics Weekly Update
___ An e-mail from EGAPP
___ An e-mail from a consumer organization you belong to
___ Other (please specify)

If you indicated you were directed to this survey from a consumer organization you belong to, please specify that organization here: _____

2. In what country do you live?
___ United States
___ Other →Exit survey **SUBMIT.**

3. Please indicate which of the following best describes your interest or role as it relates to genetic testing? (Please select one)
___ Healthcare Provider (e.g., physician, physician assistant, nurse) **(1)**
___ Health plan or insurer **(2)**
___ Company or organization that purchases health policies/plans **(3)**
___ Representative of a medical professional organization **(4)**
___ Healthcare consumer, website visitor, or individual involved in a healthcare or genetics-related advocacy group **(5)**

OR

____ **I have no interest or role related to genetic testing**
If respondent checks this option → Exit survey SUBMIT

If (1), respondent will be linked to Healthcare Provider Survey questions.
If (2), respondent will be linked to Policy/Payer Survey questions.
If (3), respondent will be linked to Purchaser Survey questions.
If (4), respondent will be linked to Policy Survey questions.
If (5) is checked respondent is directed question 4.

4. What is your sex?
___ Male
___ Female

5a. What is your ethnicity?

___ Hispanic or Latino
___ Not Hispanic or Latino

5b. What is your race (Select one or more)?
___ American Indian or Alaska Native
___ Asian
___ Black or African American
___ Native Hawaiian or Other Pacific Islander
___ White

6. Prior to this survey, had you read or heard about EGAPP?
___ yes
___ no →Skip to question 8a (first survey distribution) or 9a (second survey distribution)

___ unsure →Skip to question 8a (first survey distribution) or 9a (second survey distribution)

7. Where have you read or heard about EGAPP activities? (Please check all that apply)
   ____ I read about EGAPP on the CDC or www.egappreviews.org website.
   ____ Information was emailed to me from EGAPP.
   ____ I read about EGAPP in a newsletter.
   ____ I read about EGAPP in another publication.
   ____ A colleague, friend, or family member told me about EGAPP.
   ____ Information from a consumer or other organization.
   ____ Other (please describe) _____

If you checked the "I read about EGAPP in a newsletter" response above, please specify that newsletter title here:

If you checked the "I read about EGAPP in another publication" response above, please specify that publication here:

If you checked the "Information from a consumer or other organization" response above, please specify that organization here:

If this is the second survey distribution, respondents will be skipped to question 9a

An expert panel has made recommendations about the use of a specific genetic test (described below) based on a careful review of all available information through the EGAPP project. The test is ***CYP450*** *– a genetic test for use in patients treated for depression with a certain type of anti-depressant drugs (called "SSRIs") to help select the right drug and dose for each person.*

8a. Have you read or heard anything about "CYP450 testing", or about a genetic test that is now available to help doctors choose the correct drug and drug dose for patients diagnosed with depression?
   ___yes ___no ___unsure
   If no or unsure, skip to 11.

8b. Do you remember where you read or heard something about this test?
   ___ Internet
   ___ Other media, such as newspaper or television
   ___ Patient organization website or materials
   ___ From my doctor
   ___ I do not remember
   ___ Other (describe) _____

If this is the first survey distribution, respondents will be skipped to question 11.

An expert panel has made recommendations about the use of a specific genetic test (described below) based on a careful review of all available information through the EGAPP project. The test is ***HNPCC (Lynch Syndrome)*** *– genetic testing that may be used in newly diagnosed colorectal cancer patients and their families to detect an inherited form of cancer.*

9a. Have you read or heard anything about “HNPCC testing” or “Lynch Syndrome testing” or about genetic testing that identifies an inherited form of colorectal cancer?

___yes ___no ___unsure
If no or unsure, skip to 11.

9b. Do you remember where you read or heard something about this test?
___ Internet
___ Other media, such as newspaper or television
___ Patient organization website or materials
___ From my doctor
___ I do not remember
___Other (describe) _____

An expert panel has made recommendations about the use of a specific genetic test (described below) based on a careful review of all available information through the EGAPP project. The test is ***UGT1A1*** *– a pharmacogenetic test for colorectal cancer patients treated with irinotecan**.***

10a. Have you read or heard anything about “UGT1A1 testing,” a pharmacogenetic test for colorectal cancer patients treated with irinotecan?

___yes ___no ___unsure
If no or unsure, skip to 11.

10b. Do you remember where you read or heard something about this test?
___ Internet
___ Other media, such as newspaper or television
___ Patient organization website or materials
___ From my doctor
___ I do not remember
___Other (describe) _____

11. Please indicate your agreement with the following statements as they pertain to genetic testing?

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	No Opinion
a) Good evidence that supports the usefulness of a new genetic test must be gathered before the test can be offered.	○	○	○	○	○
b) Genetic tests that may improve health should be made available as soon as possible even when some evidence is still missing.	○	○	○	○	○
c) I am sometimes concerned about how useful genetic tests really are.	○	○	○	○	○

d) I rely on patient support groups to tell me about the usefulness of genetic tests.

e) I gather information on my own to learn about the usefulness of a genetic test.

f) I am sometimes concerned about whether we really know if a new genetic test is really useful.

g) Information about the usefulness of genetic tests should be readily available to the general public.

h) I rely on my healthcare provider (doctor, physician assistant, nurse, etc.) to tell me about the usefulness of genetic tests.

[The following two questions will be asked only of those respondents who indicated in question 6 that they had heard of EGAPP prior to this survey.]

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	No Opinion
i) I support the work that EGAPP is doing to provide reliable information about genetic tests.	○	○	○	○	○
j) I am concerned that the work that EGAPP is doing will make genetic tests less available to those who need them.					

12. Have you visited the EGAPP website: www.egappreviews.org?
    ___ yes
    ___ no →Skip to question 14

13. How useful did you find the EGAPP website?
    ___very useful _____ somewhat useful ___ not useful

14. If you have other comments you would like to make please do so in the box below.

COMMENT BOX HERE

This is the end of the survey, thank you for your feedback! Click the "Submit" button below to submit your responses. --------→ SUBMIT