

## **Attachment D4 - Policy Survey**

**This survey is intended for organizations that develop or advocate policy regarding the appropriate use of genetic testing. These include professional organizations (e.g., American Medical Association, American Academy of Family Physicians, American College of Medical Genetics) that develop statements/guidelines/ recommendations, and other organizations (e.g., Secretary's Advisory Committee on Genetics, Health and Society, Genetics and Public Policy Center, public health)**

**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 (e.g., position in organization, role).
2. Understand respondents' awareness of the EGAPP process and products (e.g., evidence reports, EGAPP Working Group recommendations, targeted informational messages).
3. Determine if the respondents have seen any general information or products (e.g., written materials about EGAPP, presentations at professional meetings, evidence reports).
4. Determine if the respondent has read any products (e.g., published or web-posted evidence reports, published recommendations).
5. Get feedback on whether specific products may have impact on policy decisions and/or decisions to develop guidelines.

# EGAPP SURVEY

Form Approved OMB No.: _____ Exp. Date: _____
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## Introduction to the EGAPP Survey

*Evaluation of Genomic Applications in Practice and Prevention* (EGAPP) is a model project initiated in 2004 by the National Office of Public Health Genomics (NOPHG) at the Centers for Disease Control and Prevention (CDC). The efforts of EGAPP are focused around a 13-member independent, non-federal, multidisciplinary EGAPP Working Group. 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.

Products of the EGAPP project include evidence reports on selected genetic tests and published EGAPP Working Group recommendations on the appropriate use of the tests based on the evidence collected. Some evidence reports sponsored by the EGAPP project are conducted and released by Agency for Healthcare Research and Quality (AHRQ) Evidence-Based Practice Centers.

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.

Date: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

**Public reporting burden of this collection of information is estimated to average 10 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for**

reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-XXXX).

1. Which best describes your group? (please check only one)  
 Member of medical professional organization and involved in policy decisions/guideline development

- Other policy organization
- Advisory panel to the government
- Public health program

(Checking one of alternative choices below redirects to Policy/Payer Survey)

- Health plan
- Health insurer
- Staff-model HMO
- Government agency
- Organization of health insurance plans

(Checking one of alternative choices below redirects to Purchaser Survey)

- Small business that purchases healthcare for its employees
- Large company or corporation that purchases healthcare for its employees
- Federal purchaser of healthcare
- Group purchasing organization

I am not affiliated with any group listed. → Please do not continue.

**SUBMIT**

2. Within your group, in which of the following activities are you involved? (please check all that apply)

- Developing policy statements
- Research or data collection to support development of policy
- Developing practice guidelines or recommendations
- Using evidence-based information to make programmatic decisions
- Other: \_\_\_\_\_ Please describe

3. How did you first hear about EGAPP activities? (please check all that apply)

- I read about EGAPP on the CDC or EGAPPreviews.org website
- I heard about EGAPP through a professional journal/newsletter (please specify which one) \_\_\_\_\_
- A colleague told me about EGAPP
- I learned about EGAPP at a meeting (please specify) \_\_\_\_\_
- This survey is my first encounter with EGAPP activities → Skip to question 5
- Other (please describe) \_\_\_\_\_

4. The EGAPP project sponsors the website: *EGAPPreviews.org*. Please rate the three sections of the EGAPP website indicated below, using a rating scale of **1=poor 2=fair 3=good 4=excellent**. If you have not used the section specified, please check 'not used' and move on to the next section.

**Evidence Reports & EGAPP Working Group Recommendations:** \_\_\_\_\_  
**not used**

Userfriendliness	1	2	3	4
Clarity	1	2	3	4
Understandability	1	2	3	4
Value of information	1	2	3	4

<b>EGAPP Methods:</b>				_____ <b>not used</b>
Userfriendliness	1	2	3	4
Clarity	1	2	3	4
Understandability	1	2	3	4
Value of information	1	2	3	4

<b>EGAPP Topics:</b>				_____ <b>not used</b>
Userfriendliness	1	2	3	4
Clarity	1	2	3	4
Understandability	1	2	3	4
Value of information	1	2	3	4

5. In your opinion, does the information which has been developed by EGAPP have the potential to impact policy decisions or guideline development in your organization?  
 Yes  No  Unsure/don't know

If no, please specify why? \_\_\_\_\_

**If no is checked, respondent will be skipped to question 7**

6. What potential impact do you think the information on specific genetic tests developed by EGAPP could have on your organization? (please check only those that apply)

- Help us to understand the tests and their uses  
 Help us to determine when the tests are ready for clinical practice  
 Help us to assess potential risks and benefits of the tests  
 Help us determine if the tests will impact patient treatment/care  
 Help us to understand the safety and effectiveness of the tests  
 Help us to understand recommended test related interventions  
 Inform us about the consequences of testing or interventions  
 Help us to make policy decisions regarding the tests  
 Help us to change current policies about testing  
 Reinforce policies already made about testing  
 Increase our awareness of the impact of testing on patients and their families

Other (please describe) \_\_\_\_\_

I have no opinion on potential impact at this time

7. Below are questions about three of the genetic tests on which EGAPP has commissioned evidence reviews. As appropriate, please answer all questions related to each test. The tests are described briefly before the questions. The tests are:

a) **CYP450** – this test used in patients treated for depression with selective serotonin reuptake inhibitors or SSRIs

b) **HNPCC** – a test for newly diagnosed colorectal cancer patients and their families to detect a heritable form of colorectal cancer

c) **UGT1A1** - a test for colorectal cancer patients to be treated with irinotecan

For the questions below, please place a check in the box only if your response is 'yes'. Check all options that apply.

General knowledge about the test →→→→→

CYP450

HNPCC

UGT1A1

I learned about this testing through a professional organization (specify \_\_\_\_\_)

I learned about this testing through the media

I learned about this testing from a colleague

I learned about this testing in a professional newsletter

I learned about this testing on the internet

I learned about this testing through drug or diagnostics company literature

Other (specify)

**I learned about this testing through the following EGAPP sources:**

Evidence Report commissioned by EGAPP (either full report or a published summary)

Published recommendations from the EGAPP Working Group based on the Evidence Report

Highlights from the Evidence Report or Working Group recommendations (e.g. from your professional organization, in the media)

Other (specify)

**a) Regarding CYP450, please respond to the following questions:**

- i) Have you read the EGAPP-sponsored AHRQ evidence report/published summary on CYP450 testing?  
\_\_\_ yes \_\_\_ no \_\_\_ unsure

If no or unsure, respondent skips to item iv

- ii) How useful did you find the evidence report/published summary?  
\_\_\_ very useful \_\_\_ somewhat useful \_\_\_ not useful

- iii) Will this information on CYP450 testing change the way your organization makes policy decisions or develops guidelines?  
\_\_\_ yes \_\_\_ no \_\_\_ unsure  
If yes, please explain: \_\_\_\_\_

- iv) Have you read the EGAPP Working Group recommendations on the use of CYP450 testing?  
\_\_\_ yes \_\_\_ no \_\_\_ unsure

If no or unsure, respondent skips to item viii

- v) How useful did you find the recommendations?  
 very useful  somewhat useful  not useful
- vi) Will the recommendations about the use of CYP450 testing change the way your organization makes policy decisions or develops guidelines?  
 yes  no  unsure  
 If yes, please explain: \_\_\_\_\_
- vii) Which will be more useful to your organization? (Please check one.)  
 evidence report/published summary  recommendations
- viii) Do you currently have a policy in place or guidelines that outline use of CYP450 testing for patients with depression treated with selective serotonin reuptake inhibitors (SSRIs)?  
 yes  no  unsure
- ix) Did EGAPP information influence your policy decision about CYP450 testing?  
 yes  no  unsure
- x) Please provide any comments about the EGAPP evidence report/published summary or recommendations on the use of the CYP450 test that you feel would improve the information for policy makers.

Comment box here

**b) Regarding HNPCC, please respond to the following questions:**

- i) Have you read the EGAPP-sponsored AHRQ evidence report/published summary on HNPCC testing?  
 yes  no  unsure  
 If no or unsure, respondent skips to item iv
- ii) How useful did you find the evidence report/published summary?  
 very useful  somewhat useful  not useful
- iii) Will the evidence report on HNPCC testing change the way your organization makes policy decisions or develops guidelines on the use of this test?  
 yes  no  unsure  
 If yes, please explain: \_\_\_\_\_
- iv) Have you read the EGAPP Working Group recommendations on the use of HNPCC testing?  
 yes  no  unsure

If **no** or **unsure**, respondent skips to **item vi**

- v) How useful did you find the recommendations?  
\_\_\_ very useful \_\_\_ somewhat useful \_\_\_ not useful
- vi) Will the recommendations about the use of HNPCC testing change the way your organization makes policy decisions or develops guidelines on the use of the test?  
\_\_\_yes \_\_\_no \_\_\_unsure  
If yes, please explain: \_\_\_\_\_
- vii) Which will be more useful to your in your organization? (Please check one.)  
\_\_\_evidence report/published summary \_\_\_recommendations
- viii) Do you currently have a policy in place or guidelines that outline use of HNPCC testing for hereditary colorectal cancer?  
\_\_\_ yes \_\_\_yes- Only patients with a family history of CRC \_\_\_ no \_\_\_ unsure
- ix) Did EGAPP information influence your policy decision or guidelines on HNPCC testing?  
\_\_\_ yes \_\_\_ no \_\_\_ unsure
- x) Please provide any comments about the EGAPP evidence reports/published summary or recommendations about HNPCC testing that you feel would improve the information for policy makers.

Comment box here

**c) Regarding UGT1A1, please respond to the following questions:**

- i) Have you read the EGAPP evidence report or published summary on UGT1A1 testing?  
\_\_\_ yes \_\_\_ no \_\_\_ unsure
- If **no** or **unsure**, respondent skips to **item iv**
- ii) How useful did you find the evidence report/published summary?  
\_\_\_very useful \_\_\_ somewhat useful \_\_\_ not useful
- iii) Will this information on UGT1A1 testing change the way your organization makes policy decisions or develops guidelines regarding UGT1A1 testing?  
\_\_\_ yes \_\_\_ no \_\_\_ unsure  
If yes, please explain: \_\_\_\_\_
- iv) Have you read the EGAPP Working Group recommendations on the use of UGT1A1 testing?  
\_\_\_ yes \_\_\_ no \_\_\_ unsure



If no or unsure, respondent skips to item viii

- v) How useful did you find the recommendations?  
\_\_\_ very useful \_\_\_ somewhat useful \_\_\_ not useful
- vi) Will the recommendations on UGT1A1 testing change the way your organization makes policy decisions or develops guidelines regarding UGT1A1 testing?  
\_\_\_yes \_\_\_no \_\_\_unsure  
If yes, please explain: \_\_\_\_\_
- vii) Which will be more useful to your in your organization? (Please check one.)  
\_\_\_evidence report/published summary \_\_\_recommendations
- viii) Do you currently have a policy in place or guidelines that outline use of UGT1A1 testing in colorectal cancer patients treated with irinotecan?  
\_\_\_ yes \_\_\_ no \_\_\_ unsure
- ix) Please provide any comments about the EGAPP evidence reports/published summary or recommendations about UGT1A1 testing that you feel would improve the information for policy makers.

Comment box here

8. In general, does the EGAPP process for evidence review and development of recommendations by the independent EGAPP Working Group meet standards that your organization requires to set policy or develop guidelines?  
\_\_\_ Yes \_\_\_ No \_\_\_ Unsure/don't know \_\_\_ not applicable

If no, please explain: \_\_\_\_\_

**EGAPP is attempting to balance the need of healthcare policy makers and payers for timely information about new genetic tests with a realistic amount of time needed to conduct a systematic review. The next question(s) is/are about the timeframe for the evidence reviews and Working Group recommendations.**

9. Listed below are the tests on which evidence-based reviews have been completed and the amount of time taken to complete each review. Please indicate how helpful the information is for making decisions and setting policy/guidelines given the timeframe for completion.

	Months taken to	Very Helpful	Somewhat Helpful	Not Very Helpful	Not Helpful	Unsure / Don't Know
CYP450	**					
HNPCC	**					
UGT1A1	**					
<i>Insert completed topics here.</i>	**					

\*\* Note: Months taken to complete will be added once evidence reviews are completed.

10. Were you aware that the EGAPP project team has been inviting comments and suggestions for potential topics for review?  Yes  No

**If no, respondent is skipped to #13**

11. Have you sent a comment or suggestion?  Yes  No  Not Applicable

12. Have you had any difficulty finding or accessing the topic suggestion webpage on the

EGAPPreviews.org website?

Yes  No  Unsure/Don't know  Not Applicable

If yes, please explain: \_\_\_\_\_

13. Have you had any difficulty finding or accessing general information about the EGAPP project, the EGAPP Evidence Reports, or the Working Group recommendations?

Yes  No  Unsure/Don't know  Not Applicable

If yes, please explain: \_\_\_\_\_

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

COMMENT BOX HERE

Thank you for your feedback! -----> **SUBMIT**

