

## Attachment D4 - Policy Survey

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

**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 EGAPP and EGAPP products (e.g., evidence reports, EGAPP Working Group recommendations)
3. Determine if the respondent has read any products (e.g., published or web-posted evidence reports, published EGAPP recommendations).
4. Get feedback on whether specific products may have impact on policy decisions and/or decisions to develop guidelines.

## 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 efforts of EGAPP are focused around an 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.

**Public reporting burden of this collection of information is estimated to range between 5 and 10 minutes with an average of 8 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 (0920-0751).**

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. Which best describes your group? (Please check only one)
  - Medical professional organization involved in policy/guideline development
  - Advisory panel to the government
  - Public health program
  - Accreditation organization
  - (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 packages/policies for employees
  - Large company that purchases healthcare packages/policies for employees
  - Federal purchaser of healthcare
  - Group purchasing organization
  - I am not affiliated with any group listed. **→ Exit survey. SUBMIT**
  - Other organization developing or advocating policy: (please describe) \_\_\_\_\_
  
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. Prior to this survey, had you read or heard about EGAPP?
  - yes
  - no **→ Skip to question 5a (first survey distribution) or 6a (second survey distribution)**
  - unsure **→ Skip to question 5a (first survey distribution) or 6a (second survey distribution)**
  
4. Where have you read or heard about EGAPP activities? (please check all that apply)
  - I read about EGAPP on the CDC or [www.egapproviews.org](http://www.egapproviews.org) website.
  - I heard about EGAPP through a professional journal/newsletter.
  - A colleague told me about EGAPP.
  - I learned about EGAPP at a meeting.
  - Other (please describe) \_\_\_\_\_

If you checked the "I heard about EGAPP through a professional journal/newsletter" response above, please specify that journal/newsletter title here:

If you checked the "I learned about EGAPP at a meeting" response above, please specify that meeting here:

**If this is the second survey distribution, respondents will be skipped to question 6a.**

**Following is a set of questions about a genetic test for which EGAPP has completed an evidence report and a recommendation. The test is described briefly before the questions.**

**Cytochrome P450 (CYP450) genotyping is a genetic test proposed for use in patients treated for depression with selective serotonin reuptake inhibitors (SSRIs) to help in selection of drug and dosage.**

5a. Are you aware of the CYP450 genetic test?

- yes
- no → Skip to question 8
- unsure → Skip to question 8

5b. From what source(s) have you heard about the CYP450 genetic test? (check all that apply)

- An EGAPP-sponsored evidence report or published summary
- An EGAPP Working Group recommendation
- Primary research/review article
- Professional organization
- Colleague
- Meeting/conference
- News media
- Other (please specify)

**The following questions refer specifically to the evidence report/published summary and EGAPP Working Group recommendation on CYP450 testing**

5c. Have you read the EGAPP-sponsored evidence report on CYP450 testing, or the published summary of the evidence report?

- yes  no  unsure
- If no or unsure, respondent skips to item 5f**

5d. How understandable did you find the evidence report/published summary to be?

- very understandable  somewhat understandable  not understandable

5e. Will the evidence on CYP450 testing influence the way your organization makes policy decisions or develops guidelines on the use of the CYP450 test in patients with depression treated with SSRIs?  yes  no  unsure

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

5f. Have you read the EGAPP Working Group recommendation about the use of CYP450 testing in patients with depression treated with SSRIs?

- yes  no  unsure

**If no or unsure, respondent skips to item 5k**

5g. How understandable did you find the EGAPP recommendation to be?

- very understandable  somewhat understandable  not understandable

5h. Will the EGAPP recommendation influence the way your organization makes policy decisions or develops guidelines on the use of the CYP450 test in patients with depression treated with SSRIs?

yes  no  unsure

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

5i. Which will be more useful to your organization? (Please check one)

Evidence report/published summary  EGAPP recommendation  Not applicable

5k. Does your organization have a policy in place or guidelines developed on the use of CYP450 testing for patients with depression treated with SSRIs?

yes  no  unsure

5j. Please provide any comments about the evidence report/published summary or EGAPP recommendation on the use of CYP450 testing for patients with depression treated with SSRIs that you feel would improve the information for policy makers.

Comment box here

**If this is the first survey distribution, respondents will be skipped to question 8a.**

***Testing for Hereditary Non-Polyposis Colorectal Cancer (HNPCC or Lynch Syndrome) in newly diagnosed colorectal cancer patients and their families may be offered to a selected subset of high risk patients to detect a heritable form of colorectal cancer.***

6a. Are you aware of genetic testing for HNPCC (Lynch Syndrome) in patients newly diagnosed with colorectal cancer?

yes  
 no → Skip to question 7a  
 unsure → Skip to question 7a

6b. From what source(s) have you heard about genetic testing for HNPCC (Lynch Syndrome)? (Please check all that apply)

An EGAPP-sponsored evidence report or published summary  
 An EGAPP Working Group recommendation  
 Primary research/review article  
 Professional organization  
 Colleague  
 Meeting/conference  
 News media  
 Other (please specify)

***The following questions refer specifically to the evidence report/published summary and EGAPP recommendation on HNPCC (Lynch Syndrome) testing***

6c. Have you read the EGAPP-sponsored evidence report on genetic testing for HNPCC (Lynch Syndrome), or a published summary of the evidence report?

yes  no  unsure

**If no or unsure, respondent skips to item 6f**

6d. How understandable did you find the evidence report/published summary to be?

very understandable  somewhat understandable  not understandable

6e. Will this information on genetic testing for HNPCC (Lynch Syndrome) influence the way your organization makes policy decisions or develops guidelines on the use of this test for patients newly diagnosed with colorectal cancer?

yes  no  unsure

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

6f. Have you read the EGAPP Working Group recommendation on the use of genetic testing for HNPCC (Lynch Syndrome) in newly diagnosed patients with colorectal cancer?

yes  no  unsure

**If no or unsure, respondent skips to item 6j**

6g. How understandable did you find the EGAPP recommendation to be?

very understandable  somewhat understandable  not understandable

6h. Will this recommendation on the use of genetic testing for HNPCC (Lynch Syndrome) influence the way your organization makes policy decisions or develops guidelines on the use of the test?

yes  no  unsure

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

6i. Which will be more useful to your organization? (Please check one.)

evidence report or published summary of evidence  recommendations  Not applicable

6j. Does your organization have a policy in place or guidelines developed on the use HNPCC (Lynch Syndrome) testing in patients with newly diagnosed colorectal cancer?

yes  yes, but only patients with a family history of CRC  
 no  unsure

6k. Please provide any comments about the evidence report/published summary or EGAPP recommendation on the use of HNPCC (Lynch Syndrome) testing in patients with newly diagnosed colorectal cancer that you feel would improve the information for policy makers.

Comment box here

***UGT1A1 testing is a pharmacogenetic test for colorectal cancer that may be offered to patients treated with irinotecan.***

7a. Are you aware of genetic testing for UGT1A1 for colorectal cancer patients treated with irinotecan?

yes  
 no → Skip to question 8  
 unsure → Skip to question 8

7b. From what source(s) have you heard about genetic testing for UGT1A1? (Please check all that apply)

An EGAPP-sponsored evidence report or published summary

- An EGAPP Working Group recommendation
- Primary research/review article
- Professional organization
- Colleague
- Meeting/conference
- News media
- Other (please specify)

**The following questions refer specifically to the evidence report/published summary and EGAPP recommendation on UGT1A1 testing**

7c. Have you read the EGAPP-sponsored evidence report on genetic testing for HNPCC, or a published summary of the evidence report?

yes  no  unsure

**If no or unsure, respondent skips to item 7f**

7d. How understandable did you find the evidence report/published summary to be?

very understandable  somewhat understandable  not understandable

7e. Will this information on genetic testing for UGT1A1 influence the way your organization makes policy decisions or develops guidelines on the use of this test for colorectal cancer patients treated with irinotecan?

yes  no  unsure

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

7f. Have you read the EGAPP Working Group recommendation on the use of genetic testing for UGT1A1 for colorectal cancer patients treated with irinotecan?

yes  no  unsure

**If no or unsure, respondent skips to item 7j**

7g. How understandable did you find the EGAPP recommendation to be?

very understandable  somewhat understandable  not understandable

7h. Will this recommendation on the use of genetic testing for UGT1A1 influence the way your organization makes policy decisions or develops guidelines on the use of the test?

yes  no  unsure

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

7i. Which will be more useful to your organization? (Please check one.)

evidence report or published summary of evidence  recommendations  Not applicable

7j. Does your organization have a policy in place or guidelines developed on the use UGT1A1 testing for colorectal cancer patients treated with irinotecan?

yes  
 no  unsure

7k. Please provide any comments about the evidence report/published summary or EGAPP recommendation on the use of UGT1A1 testing in patients with newly diagnosed colorectal cancer that you feel would improve the information for policy makers.

Comment box here

8. Have you read any EGAPP sponsored evidence reports/published summaries or EGAPP recommendations other than the one mentioned in question in this survey?

\_\_\_ yes \_\_\_ no \_\_\_ unsure

**Respondent directed to 9 if no or unsure to:**

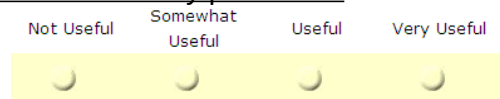
**5a and 8 (first survey distribution)**

**6a and 7a and 8 (second survey distribution)**

**Respondent directed to question 10 if yes to 8 (first and second survey distribution)**

9. If an evidence-based report on a specific test and a recommendation from a credible expert panel were available, please indicate your response to the statements below based on the scale given:

Evidence-based information/guidelines on genetic tests are useful in my practice to:



- a) understand what uses of the test are supported by evidence.
- b) identify the population or individuals for whom the test may be appropriate.
- c) provide expectations for laboratory performance and the estimated clinical validity of the test.
- d) know what actions or interventions may be suggested based on test results.
- e) understand what is known about the balance of benefits and harms related to use of the test.
- f) appreciate the ethical, legal, and social implications related to testing.

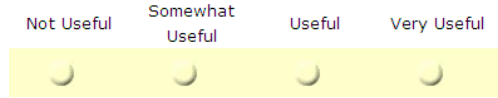
**Respondents answering Question 9 skip to Question 12**

**Question 10 will only be asked of those respondents who have read at least one EGAPP-sponsored evidence review/summary or recommendations**



10. Based on your experience with EGAPP sponsored evidence reports and/or Working Group recommendations, please indicate your response to the statements below based on the scale given:

Evidence-based information/guidelines on genetic tests are useful in my practice to:



- a) understand what uses of the test are supported by evidence.
- b) identify the population or individuals for whom the test may be appropriate.
- c) provide expectations for laboratory performance and the estimated clinical validity of the test.
- d) know what actions or interventions may be suggested based on test results.
- e) understand what is known about the balance of benefits and harms related to use of the test.
- f) appreciate the ethical, legal, and social implications related to testing.

11. In general, how well does the EGAPP process for evidence review and development of recommendations by the independent EGAPP Working Group meet standards that your organization requires for setting policy or developing guidelines?

- Exceeds standards     Meets standards
- Does not meet/Falls below standards     Unsure     Not applicable

12. Have you visited the EGAPP website: [www.egappreviews.org](http://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**