

Attachment D1 - Healthcare Provider Survey

This survey is intended for health care providers accessed through: 1) professional organizations; 2) health plans or HMOs; and 3) health care payers/insurers.

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., type of practitioner, medical specialty, practice setting).
2. Understand respondents' awareness of the EGAPP project and products (e.g., evidence reports, EGAPP Working Group recommendations, targeted informational messages).
3. Determine if the respondents have seen any general information on EGAPP or specific products (e.g., written materials about EGAPP, presentations at professional meetings, evidence reports).
4. Determine if the respondent has read any specific products (e.g., published or web-posted evidence report, published recommendations).
5. Get feedback on whether specific products addressed their needs for integrating genetic testing into clinical practice (e.g., knowledge of new genetic tests, providing information to patients).
6. Identify any impact that the specific products have had on the respondents' clinical practice (e.g., decision to offer testing).

EGAPP SURVEY

Form Approved
OMB No.: _____
Exp. Date: _____

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.

Please enter today's 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. What is your role as a healthcare provider?

- Physician
- Laboratory Director
- Physician Assistant
- Genetic Counselor
- Nurse Practitioner
- Certified Nurse-Midwife
- Nurse
- Other (please specify): _____

I am no longer in practice → Please do not continue.

SUBMIT

2. What is your primary specialty?

- General Practice
- Family Medicine
- Internal Medicine
- Obstetrics/Gynecology
- Oncology
- Pathology
- Psychiatry
- Clinical Genetics
- Other (please specify): _____

3. Which best describes the setting in which you practice? (please check only one)

- Hospital
- Group practice
- Private practice
- Staff model HMO
- Academic medical center
- Independent laboratory
- Other (please specify): _____

4. How did you first read or 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 journal/newsletter title)

_____ 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 6

_____ Other (please describe) _____

5. 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

EGAPP Methods: _____ **not used**

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

EGAPP Topics: _____ **not used**

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

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

- _____ Help me to understand the tests and their uses
 _____ Help me to use the tests appropriately in patient care
 _____ Help me to better explain the tests to my patients
 _____ Help me to determine when the tests may be of value to my patients
 _____ Help me to assess potential risks and benefits of using the tests
 _____ Help me determine what intervention to recommend
 _____ Inform me about the consequences of testing or interventions
 _____ Increase my awareness of the potential impact of the test on my patients and their families
 _____ Help me integrate into my practice knowledge about the test related disorders
 _____ Other (please describe) _____
 _____ I have no opinion on potential impact at this time

7. Below are sets of questions about three of the genetic tests on which EGAPP has completed 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 on the genetic 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 his 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

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 or published summary of the evidence report 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 you practice?
___ yes ___ no ___ unsure
If yes, please explain: _____

- iv) Have you read the EGAPP Working Group recommendations about 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 you practice?

yes no unsure

If yes, please explain: _____

vii) Which will be more useful to you in your practice? (Please check one.)

evidence report or published summary of evidence
 recommendations

viii) Are you currently using CYP450 testing for your patients with depression treated with selective serotonin reuptake inhibitors (SSRIs)?

yes no unsure

ix) Please provide any comments about the EGAPP evidence report/published summary or recommendations on the use of CYP450 testing that you feel would improve the information for providers.

Comment box here

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

i) Have you read the EGAPP-sponsored AHRQ evidence report or 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 this information on HNPCC testing change the way you practice?

yes no unsure

If yes, please explain: _____

iv) Have you read the EGAPP Working Group recommendations about the use of HNPCC 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 HNPCC testing change the way you practice?

yes no unsure

If yes, please explain: _____

- vii) Which will be more useful to you in your practice? (Please check one.)
 evidence report/published summary recommendations
- viii) Are you currently using HNPCC testing in patients with newly diagnosed colorectal cancer?
 yes yes- Only patients with a family history of CRC no
 unsure
- ix) Please provide any comments about the EGAPP evidence reports/published summary or recommendations on the use of HNPCC testing that you feel would improve the information for providers.

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 you practice?
 yes no unsure
If yes, please explain: _____
- iv) Have you read the EGAPP Working Group recommendations about 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 about the use of UGT1A1 testing change the way you practice?
 yes no unsure
If yes, please explain: _____
- vii) Which will be more useful to you in your practice? (Please check one.)
 evidence report /published summary recommendations
- viii) Are you currently using UGT1A1 testing for your patients with colorectal cancer 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 providers.

Comment box here

[Question 8 will only be asked of those respondents who have read at least one EGAPP-sponsored evidence review/summary or recommendations (i.e., respondents who answered yes to at least one of the following questions: 7.a.i, 7.a.iv, 7.b.i, 7.b.iv, 7.c.i, 7.c.iv.). Others skip to question 9]

8. Using the following response scale, please indicate the relevance of the information from the EGAPP-sponsored evidence reports and recommendations to your clinical practice. (Check the appropriate number)

1=not relevant 2=somewhat relevant 3=relevant 4=very relevant

- | | | | | |
|--|---|---|---|---|
| a) To understand the test-related disorders or drug effect | 1 | 2 | 3 | 4 |
| b) To make informed decisions about patient care | 1 | 2 | 3 | 4 |
| c) To understand the validity of the tests | 1 | 2 | 3 | 4 |
| d) To understand how well the tests perform in the clinical setting | 1 | 2 | 3 | 4 |
| e) To understand the utility and value added of the tests | 1 | 2 | 3 | 4 |
| f) To understand laboratory quality issues | 1 | 2 | 3 | 4 |
| g) To understand how to access the interventions or actions related to the tests | 1 | 2 | 3 | 4 |
| h) To understand the potential benefits of the tests | 1 | 2 | 3 | 4 |
| i) To understand the potential harms related to testing | 1 | 2 | 3 | 4 |
| j) To understand the potential benefits and risks of follow-up testing or intervention | 1 | 2 | 3 | 4 |
| k) To identify the population/individuals for which the tests were developed | 1 | 2 | 3 | 4 |

Attachment D5 - General Survey

This survey is intended for general use with consumers, public health workers, and others 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(s).

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, targeted informational messages), and belief in the need for an evidence review process for genetic tests.
3. Determine if the respondents have seen any general information or products.
4. Determine if the respondents have read any products (e.g., targeted informational messages based on evidence report or Working Group recommendations), and if so, how useful they were.
5. Determine whether the products might have an impact on the respondents' personal decision making or work activities.

EGAPP SURVEY

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).

- Were you directed to this survey from: (please check one)
 - EGAPP web pages on the EGAPPreviews.org or other website
 - CDC's Genomics Weekly Update
 - An e-mail from EGAPP
 - A consumer or professional organization (please specify) _____
 - Other (please specify): _____
- 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, "Please do not continue" → 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 to continue to question 3 and complete this survey.

- How did you first hear about EGAPP activities? (please check all that apply)
 - I read about EGAPP on the CDC or EGAPPreviews.org website
 - Information was emailed to me from EGAPP
 - I read about EGAPP in a newsletter (please specify which one) _____
 - I read about EGAPP in another publication (specify) _____
 - A colleague, friend, or family member told me about EGAPP
 - Information from a consumer advocacy organization
 - Please specify what organization: _____
 - This survey is my first encounter with EGAPP activities → **Skip to question 5**
 - Other (please describe) _____

- 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

EGAPP Methods:

				_____ not used
Userfriendliness	1	2	3	4
Clarity	1	2	3	4
Understandability	1	2	3	4
Value of information	1	2	3	4

EGAPP Topics:

				_____ not used
Userfriendliness	1	2	3	4
Clarity	1	2	3	4
Understandability	1	2	3	4
Value of information	1	2	3	4

5. The EGAPP Working Group has made clinical recommendations based on EGAPP evidence reviews of several tests. Three of the tests are described below.

- **CYP450** – *this test used in patients treated for depression with selective serotonin reuptake inhibitors or SSRIs*
- **HNPCC** – *a test for newly diagnosed colorectal cancer patients and their families to detect a heritable form of colorectal cancer called hereditary non-polyposis colon cancer or HNPCC*
- **UGT1A1** - *a test for colorectal cancer patients to be treated with irinotecan*

Have you:

- a) ...read or heard anything about “CYP450 testing” or about a genetic test that is intended to help doctors choose the right drug and the right dose to treat depression? ___yes ___no

If yes, please indicate where you have read or heard something about CYP450 testing:

- ___ Internet ___ Other media, such as newspaper or television
 ___ Advocacy group website or materials ___ Professional Organization
 ___ Other _____
 ___ I do not remember

If yes, was the information relevant to ___ your work or ___ your personal interests?

- b) ...read or heard anything about “HNPCC testing” or genetic testing that identifies inherited forms of colon cancer? ___yes ___no

If yes, please indicate where you have read or heard something about HNPCC testing:

- Internet Other media, such as newspaper or television
 Advocacy group website or materials Professional Organization
 Other _____
 I do not remember

If yes, was the information relevant to _____ your work or _____ your personal interests?

- c) ...read or heard anything about "UGT1A1 testing" or a genetic test that is intended to reduce bad reactions to the drug irinotecan (commonly used for treating colorectal cancer)? yes no

If yes, please indicate where you have read or heard something about UGT1A1 testing:

- Internet Other media, such as newspaper or television
 Advocacy group website or materials Professional Organization
 Other _____
 I do not remember

If yes, was the information relevant to _____ your work or _____ your personal interests?

7. Please indicate your agreement with the following statements as they pertain to genetic testing? Please use the following response scale:

1= strongly disagree 2=somewhat disagree 3=somewhat agree 4=strongly agree 5=no opinion

- | | | | | | |
|--|---|---|---|---|---|
| a) Evidence on the <u>safety</u> of genetic tests should be available before the tests can be used in clinical practice. | 1 | 2 | 3 | 4 | 5 |
| b) Evidence on the <u>accuracy</u> of genetic tests should be available before the tests can be used in clinical practice. | 1 | 2 | 3 | 4 | 5 |
| c) I rely on my <u>physician</u> to advise me about the safety of genetic tests. | 1 | 2 | 3 | 4 | 5 |
| d) I rely on <u>advocacy groups</u> to advise me about the safety of genetic tests. | 1 | 2 | 3 | 4 | 5 |
| e) EGAPP provides the kind of information that would help me understand the safety of genetic tests | 1 | 2 | 3 | 4 | 5 |

- f) I am sometimes concerned about how useful genetic tests really are. 1 2 3 4 5
- g) I am sometimes concerned about the accuracy of information I receive about genetic tests. 1 2 3 4 5
- h) I support the work that EGAPP is doing to provide important information about genetic testing 1 2 3 4 5
- i) Information about the safety and effectiveness of genetic tests should be readily available to the general public. 1 2 3
4 5
- j) Distribution of information about genetic tests should be limited to professionals. 1 2 3 4 5
- k) Genetic tests are often misunderstood and may cause false hope for some people. 1 2 3 4 5
- l) Genetic tests are often misunderstood and may cause false alarm for some people. 1 2 3 4 5
- m) Genetic testing should be made available to anyone who wants it. 1 2 3 4 5
- n) Health insurance should reimburse/cover genetic testing when it is medically indicated. 1 2 3 4 5
- o) The general public should have a basic understanding about genetics and genetic testing. 1 2 3 4 5
- p) EGAPP information will be useful to me in my work. 1 2 3 4 5
- q) EGAPP information will be useful to me in my personal life. 1 2 3 4 5
- r) I have a professional interest in genetics. 1 2 3 4 5
- s) I have a personal interest in genetics. 1 2 3 4 5

8. Will information about these genetic tests help you make more informed decisions about using the tests?
 Yes No Uncertain Not Applicable

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

If no, respondent will be skipped to #12

9. Have you sent a comment or suggestion? Yes No

10. Do you plan on sending a comment or suggestion in the future?
 Yes No Not sure

11. 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

12. 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: _____

13. 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**

