I, Meghann Reardon, hereby submit this original work as part of the requirements for the degree of Master of Science in Genetic Counseling.

It is entitled:
Parents' and adolescents' access to and impressions of pharmacogenetic results viewed within a patient portal

Student's name:            Meghann Reardon

This work and its defense approved by:

Committee chair: Cynthia Prows, R.II., M.S.N.

Committee member: Drew Barzman, M.D.

Committee member: Xue Zhang, Ph.D.

Committee member: John Lynch, Ph.D.
Parents’ and adolescents’ access to and impressions of pharmacogenetic results viewed within a patient portal

A thesis submitted to the
Graduate School
of the University of Cincinnati
in the partial fulfillment of the
requirements for the degree of

Master of Science

in the Genetic Counseling Program
of the College of Medicine
by

Meghann Reardon
B.S. University of Southern Indiana
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Committee Chair: Cynthia Prows, M.S.N., C.N.S., F.A.AN.
Research Advisory Committee: John Lynch, Ph.D.
Xue Zhang, Ph.D.
Drew Barzman, M.D.
Abstract

**Background:** Pharmacogenetic testing informs healthcare providers of patient’s risk of adverse reactions or the likelihood that a patient will respond to a specific medication. One way that patients are now able to access test results is through online patient portals linked to electronic medical records. The objective of this study was to assess parents’ and adolescents’ access to and impressions of pharmacogenetic test results in a patient portal.

**Methods:** The target population consisted of adolescents and parents of children and adolescents who had pharmacogenetic testing and registered for the patient portal. Invitations were e-mailed or mailed to 453 parents and 323 adolescents. An investigator-developed questionnaire was used to assess parent’s/guardian’s and adolescent’s access to personal health records and pharmacogenetic reports. Participants’ response to results, ability to read results reports, perceived actionability of pharmacogenetic results, and perceived utility of pharmacogenetic results were also measured. Comparisons were made using Fisher’s exact test, and significance was set at p-values ≤0.05.

**Results:** Questionnaires were completed by 61 parents and 29 adolescents. Two-thirds of adolescents and almost half of guardians were not aware that pharmacogenetic testing was a genetic test. Parents with at least a four-year college degree were more likely to report need to speak with their child’s doctor about the results (p=0.041). We found no difference in rated readability of the report nor in perceived utility of the result between guardians and adolescents. We found no difference in positive or negative feelings about results based on the type of pharmacogenetic test.

**Conclusion / Summary:** While most parents and adolescents rated the reports readable and useful, there was some general confusion about the results being genetic tests. More research is
needed to assess the educational needs of both parents/guardians and adolescents when administering pharmacogenetic testing.
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Acknowledgements

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I would like to thank my research advisor, Cindy Prows, for everything she did for me in completing this project and for being there for me when things got rough. I would also like to thank the rest of my research committee, John, Xue, and Drew, for always pushing me to make my thesis better and for their insights.

Additionally, I would like to thank my family for all of their support throughout the process of graduate school. Thank you for always being there to talk to me when things got stressful and for helping me through with your senses of humor.

Finally, I would like to thank my friends, classmates, and program faculty. I could not have gotten through all of this without your caring attitudes and constant encouragement. You all definitely saved the day more than a few times. You constantly remind me that when “…everybody says, ‘you can’t, you can’t, you can’t, don’t try.’/Still everybody says that if they had the chance they’d fly like we do” (The Weepies, 2006, track 7).
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</table>
**Introduction**

Pharmacogenetic testing is genetic-based testing that informs healthcare providers of a patient’s risk of adverse reactions or the likelihood that a patient will respond to a specific medication. These tests search for variations in certain genes known to affect an individual’s ability to absorb, distribute, metabolize, and/or excrete a drug (Payne et al., 2011). The goal of pharmacogenetic testing is to improve the effectiveness and safety of drug therapy, and one test may be used to guide treatment for a patient’s lifetime (Crews, Hicks, Pui, Relling, & Evans, 2012). Although pharmacogenetic testing is a relatively new service, its uptake by healthcare professionals in several specialties to guide treatment is rapidly increasing (Haga, Mills, & Bosworth, 2014).

It is not known whether patients view the results of pharmacogenetic testing differently than the results of genetic testing for disease because pharmacogenetic testing is used to inform decisions about medication type and dosing rather than disease status or susceptibility (Madadi et al., 2011). Pharmacogenetic testing is thought to raise fewer risks of stigmatization, discrimination, and psychological harm compared to genetic testing for disease and to be comparable to non-genetic clinical tests (Haga et al., 2014a).

A primary informational goal when delivering any test result is to facilitate patient understanding about the outcome and how this information will impact medical management. In order for pharmacogenetic testing to be useful, patients must understand their results or the purpose of the test so that they can share this information with other providers. Few studies have investigated the informational needs of patients having pharmacogenetic testing, and currently, no standard recommendations exist regarding the information about pharmacogenetic testing that should be discussed with patients and the language that should be used (Haga et al., 2014a). As
the uptake of personal health records increases, patients will have easier access to lab reports, specifically genetic and genomic lab reports. This access may improve patient understanding, shared decision-making, and adherence with clinical recommendations. These reports may also cause anxiety in some patients because of confusion about the purpose and outcomes of the test. If a patient does not understand the test results or experiences significant anxiety about the results, the benefits of patient access results are limited (Haga et al., 2014b).

One way that patients are now able to access test results is through online patient portals linked to electronic medical records. A personal health record is “a tool to use in sharing health information, increasing health understanding and helping transform patients into better-educated consumers of health care” (Kahn, Aulakh, and Bosworth, 2009). This functionality can be delivered by giving patients access to the health information in the electronic medical record kept by their healthcare providers (Tang, Ash, Overhage, & Sands, 2006). At our institution, an online portal is available for parents/guardians and adolescent/adult patients to access select portions of their electronic medical records.

Personal health records are a means for sharing results with other providers to prevent redundant testing and to encourage providers to consider existing results when prescribing medications (Mills et al., 2013; Tang et al., 2006). However, not all of a patient’s providers will have access to all of his or her records. Patients would then need to access their test results and share them with other providers. This issue of access for multiple healthcare providers highlights the importance of patient comprehension because the fragmented health care system means that, for other providers to have access to these medical records, patients must have enough understanding of their health records in order to be their own advocates (Crews et al., 2012).
There are very few studies assessing parents’ and, especially, adolescents’ access to personal health records or patient portals and the information within them. There is also a need to study the educational needs of patients receiving pharmacogenetic results and of their families. Therefore, the aim of this study was to determine parents’/guardians’ and adolescents’ access to and impressions of pharmacogenetic test results returned in personal health records.

Methods

Study Design

This study was approved by the Cincinnati Children’s Hospital Medical Center Institutional Review Board (ID: 2015-1859). The study used a cross sectional design with data collected between September 2015 and December 2015 using an investigator-developed questionnaire. The questionnaire assessed adolescents’ and parents’/guardians’ access to and impressions of pharmacogenetic results returned in personal health records at Cincinnati Children’s Hospital Medical Center (CCHMC). The pharmacogenetic test results of interest were those of two available panels: the Opioid CYP2D6 Pharmacogenetics Panel and the Psychiatry Pharmacogenetics Expanded Panel. All those who had the Opioid CYP2D6 Pharmacogenetics Panel were enrolled in a previous study in which they received the testing. Those who had the Psychiatry Pharmacogenetics Expanded Panel most often did so at the time of admission to inpatient psychiatry.

The questionnaire included 76 multiple-choice questions. This included 34 multiple-choice questions in six sections: (1) access to personal health records and results reports through the patient portal, MyChart, (2) feelings about pharmacogenetic results, (3) readability of the pharmacogenetic results report, (4) perceived utility of pharmacogenetic testing, (5) perceived
actionability of pharmacogenetic results, and (6) demographics. The remaining 42 multiple-choice questions were used to measure participants’ objective and subjective understanding of pharmacogenetic results, to collect participants’ recommendations for the creation of patient education materials, and to assess participants’ opinions on learning about and viewing genetic test results. The results of these questions are not presented as part of this study but will be used to inform future research.

The questionnaire was designed for online administration and no participant was expected to answer all 76 multiple-choice questions. The questionnaire was developed in RedCap (Research Electronic Data Capture), a secure web-based electronic data capture tool hosted at CCHMC (Harris, et al., 2009). Skip-logic ensured that only those who had accessed MyChart were asked about access to results reports and that only those who had seen a results report were asked about impressions, understanding, and recommendations. If participants had not accessed MyChart before the survey, they were asked for reasons why. Only if participants had not accessed MyChart or had not viewed a results report were they directed to answer questions to assess their opinions on learning about and viewing different types of hypothetical genetic test results.

Two versions of the questionnaire were created as part of this study: one for adolescents (Appendix A) and one for parents/guardians (Appendix B). Each version had an identical number of questions. The differences between the two versions reflected changes in wording of the questions to reflect the perspective of the participant and the demographics collected.

A convenience sample of individuals who did not have access to MyChart and who had not had pharmacogenetic testing pretested the online questionnaire for readability, clarity, navigation, and completion time. Each adolescent, age 13 to 17 years old, was sent a link to the
adolescent questionnaire. A link to the parent/guardian questionnaire was sent to each volunteer who was 18 years or older and who was the parent or guardian of at least one child. Based on feedback from those who pretested the survey, the number of questions per electronic page was reduced.

Population, Participant Recruitment & Enrollment

Potential participants were identified using Informatics for Integrating Biology and the Bedside (i2b2), a research data warehouse at CCHMC. The i2b2 framework is based on the Research Patient Data Registry developed at Massachusetts General Hospital (Murphy, et al., 2010). Adolescents were invited to participate if they met the following inclusion criteria: (1) had pharmacogenetic testing since September 2013 by either the Psychiatry Pharmacogenetics Expanded Panel or the Opioid CYP2D6 Pharmacogenetics Panel at CCHMC, (2) were between the ages of 13 and 17 at the time relevant test results were returned, and (3) had signed up for access to MyChart. Parents and guardians were invited if they had a child under the age of 18 years who had had relevant testing since September 2013 and if they had access to MyChart. An i2b2 administrator used the inclusion criteria to query the database and generate a list of adolescents and parents/guardians along with required contact information. The administrator also provided information about potential participants’ gender, age, race, and which pharmacogenetic test each child received. The query did not include gender of the parent who completed each survey.

Through our query of medical records, we identified a target population of 359 adolescents and their parents as well as an additional 139 households with parents or guardians of younger children who had pharmacogenetic testing and were registered for MyChart. Although a working email address is required to register for MyChart, the provided email
address is kept private within the MyChart program. This necessitated reliance on e-mail addresses documented in the demographics section of the EPIC records. Two hundred fifty-one (69.9%) of households with adolescents and 95 (68.3%) of the households younger children had email addresses documented within Epic’s Demographics section. Nine individuals were not sent questionnaires because the email address listed belonged to the adolescent.

Study Procedures

Invitations to participate in the online survey were distributed via email. Parents/guardians were sent an email with an invitation to participate, a description of the study’s purpose, and a unique link, which served as a study identifier. Parents with an adolescent meeting inclusion criteria were sent an additional email with the aforementioned details and instructions to forward the email and link to their adolescent if they consented for the adolescent to participate in the survey. Invitations were sent up to three times to each potential participant family.

Due to poor response rate six weeks after the launch of the online survey, a paper version of the questionnaire (Appendices C & D) was created for those in the target population who did not have an email address listed in the Epic clinical database (see Population, Participant Recruitment & Enrollment). Thirty-six questions from the online survey (Appendix C) were not included in the paper version. These included questions related to objective understanding of pharmacogenetic results, recommendations for the creation of patient education materials, and opinions on learning about and viewing genetic test results. The questions essential to the study aim were retained resulting in a 4 page questionnaire with adequate white space and minimal skip-logic to minimize confusion. Only items that were identical in the paper and online questionnaires were considered for analysis.
Mailing addresses were obtained from the demographic portion of EPIC for 109 of the households with adolescents and 153 of the households with younger children without an email address listed in Epic. Invitations to participate in the paper survey were distributed via mail. Parents/guardians were sent a packet with the first page including an invitation to participate and a description of the study’s purpose. Parents with an adolescent who met inclusion criteria were sent an additional survey with the aforementioned details and instructions to give the survey to their adolescent if they gave consent for him or her to complete it. A postage-paid, preaddressed return envelope was provided in each packet. Paper surveys were mailed once and then again to any nonresponders.

Regardless of version, each participant was given a unique study identifier to track those who had responded. These were used to ensure there were not multiple responses from the same participant and to link participants to demographic information that was collected in the initial i2b2 query. Study data from the electronic surveys were automatically uploaded into REDCap, and data from paper surveys were input manually by one of the researchers.

Statistical Analyses

Data collected from the i2b2 query and the questionnaire were first examined using descriptive statistics. Parents’ email addresses linked to unique IDs were used to deduce the gender of the parent who completed the online survey. This was not possible for parent surveys returned by mail. For comparative analysis, data were collapsed. Initial reactions to pharmacogenetic results were divided into two categories: positive feelings and negative feelings. Positive feelings were curious, happy, informed, interested, and relieved. Negative feelings were angry, confused, overwhelmed, sad, and worried. Few participants indicated that they had neutral feelings, such as indifferent and I didn’t feel anything. Surprised could be
interpreted as either a positive or a negative feeling. Therefore, *indifferent, I didn’t feel anything* and *surprised* were not included in the analysis of differences in feelings between groups.

Readability was measured using a 5-point Likert scale from “Strongly agree” = 1 to “Strongly disagree” = 5. For comparative analysis the 5-point scale was collapsed into two groups: responses of 1 or 2 were designated as “agree,” responses of 4 or 5 were designated as “disagree,” and responses of 3 were considered neutral and were excluded from analysis.

Perceived utility was measured according to the question posed to participants. “How useful do you think this test is?” was measured using a 4-point Likert scale from “Very useful” to “Not useful at all” = 4. For analysis this was collapsed into two groups. Responses of 1 or 2 were designated as “useful,” and responses of 3 or 4 were designated as “not useful.” “This test has helped my/my child’s treatment,” was measured using a 5-point Likert scale from “Strongly agree” = 1 to “Strongly disagree” = 5. For analysis the 5-point scale was collapsed into two groups: responses of 1 or 2 were designated as “agree,” responses of 4 or 5 were designated as “disagree,” and responses of 3 were considered neutral and were excluded from analysis.

Perceived actionability was measured using a 5-point Likert scale from “Strongly agree” = 1 to “Strongly disagree” = 5. For analysis the 5-point scale was collapsed into two groups: responses of 1 or 2 were designated as “agree,” responses of 4 or 5 were designated as “disagree,” and responses of 3 were considered neutral and were excluded from analysis.

We compared readability, perceived utility, and perceived actionability between adolescents and parents/guardians and between parents with different education levels. Parents’ education levels were collapsed into two groups: less than a 4-year college degree and at least a 4-year college degree. All the comparisons were performed with Fisher’s exact test using SAS.
9.3. Because of the exploratory nature of this study, we opted to use \(p \leq 0.05\) to indicate statistical significance.

**Results**

*Participant Characteristics*

*Adolescents*

Of the 241 emailed invitations to adolescents, 18 were returned to the sender as invalid. Likewise, of the questionnaires mailed to 109 adolescents, 9 were returned as undeliverable. Therefore, our potential number of adolescent responders was 323. A total of 32 responses were received. However, one participant was inadvertently e-mailed an invitation to the online survey and mailed a paper survey and completed each differently so both were excluded. Another participant did not complete the first section of the survey and was also excluded. Therefore, we included 29 adolescents in the analysis, which was 9.0% of all the potential adolescent responders (Figure 1). Adolescent demographics captured in the survey are presented in Table 1. The majority of participants were white non-Hispanic high school students who reported receiving at least average grades in school. Most adolescents received psychiatry panel results and reported being in good or excellent health.
Figure 1. Consort diagram of adolescents
Table 1. Demographics of Adolescents (total N=29)

<table>
<thead>
<tr>
<th>Category</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>18 (62.1)</td>
</tr>
<tr>
<td>Male</td>
<td>11 (37.9)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
</tr>
<tr>
<td>African American/Black</td>
<td>2 (6.9)</td>
</tr>
<tr>
<td>Caucasian/White</td>
<td>19 (65.5)</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>1 (3.4)</td>
</tr>
<tr>
<td>More than one race</td>
<td>2 (6.9)</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>2 (6.9)</td>
</tr>
<tr>
<td>Missing</td>
<td>3 (10.3)</td>
</tr>
<tr>
<td><strong>Hispanic/Latino</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0 (0)</td>
</tr>
<tr>
<td>No</td>
<td>26 (89.7)</td>
</tr>
<tr>
<td>Missing</td>
<td>3 (10.3)</td>
</tr>
<tr>
<td><strong>Education Level</strong></td>
<td></td>
</tr>
<tr>
<td>Junior high/middle school</td>
<td>3 (10.3)</td>
</tr>
<tr>
<td>High school</td>
<td>18 (62.1)</td>
</tr>
<tr>
<td>I graduated from high school</td>
<td>5 (17.2)</td>
</tr>
<tr>
<td>Missing</td>
<td>3 (10.3)</td>
</tr>
<tr>
<td><strong>Class Grades (selfreported)</strong></td>
<td></td>
</tr>
<tr>
<td>Above average</td>
<td>11 (37.9)</td>
</tr>
<tr>
<td>Average</td>
<td>12 (41.4)</td>
</tr>
<tr>
<td>Below average</td>
<td>1 (3.4)</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>2 (6.9)</td>
</tr>
<tr>
<td>Missing</td>
<td>3 (10.3)</td>
</tr>
<tr>
<td><strong>Perceived Health (self-reported)</strong></td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>7 (24.1)</td>
</tr>
<tr>
<td>Good</td>
<td>14 (48.3)</td>
</tr>
<tr>
<td>Fair</td>
<td>4 (13.8)</td>
</tr>
<tr>
<td>Poor</td>
<td>1 (3.4)</td>
</tr>
<tr>
<td>Missing</td>
<td>3 (10.3)</td>
</tr>
<tr>
<td><strong>Pharmacogenetic Test</strong></td>
<td></td>
</tr>
<tr>
<td>Psychiatry Panel</td>
<td>22 (75.9)</td>
</tr>
<tr>
<td>Opioid Panel</td>
<td>7 (24.1)</td>
</tr>
<tr>
<td><strong>How interested would you be in having a test that looked at all of your genes?</strong></td>
<td></td>
</tr>
<tr>
<td>Very interested</td>
<td>15 (51.7)</td>
</tr>
<tr>
<td>Somewhat interested</td>
<td>7 (24.1)</td>
</tr>
<tr>
<td>Somewhat not interested</td>
<td>1 (3.4)</td>
</tr>
<tr>
<td>Not at all interested</td>
<td>3 (10.3)</td>
</tr>
<tr>
<td>Missing</td>
<td>3 (10.3)</td>
</tr>
</tbody>
</table>
Of the 44 adolescents we contacted who had the opioid test, 7 (15.9%) responded. Of the 278 adolescents who had the psychiatry test, 22 (7.9%) responded. There was not a significant difference in the proportion of responders between those who had psychiatric pharmacogenetics testing and those who had opioid pharmacogenetics testing (p=0.09, Fisher’s exact test). Of the 200 female adolescents we contacted, 18 (9.0%) responded, and of the 122 male adolescents we contacted, 11 (9.0%) responded. There was not a significant difference in the proportion of responders between those who were female and those who were male (p=1.00, Fisher’s exact test).

*Parents of children and adolescents*

Of the 335 households sent email invitations to parents/guardians, 25 emails were returned to the sender as invalid. Likewise, of the 154 mailed surveys, 10 were returned as undeliverable. Therefore, our potential number of parent/guardian responders was 453. A total of 61 responses were received, which was 13.5% of all the potential parent responders (Figure 2). No surveys were excluded. The majority of parents/guardians were white non-Hispanic with above a high school degree/GED (Table 2).
Figure 2. Consort diagram of parents/guardians
<table>
<thead>
<tr>
<th>Table 2. Demographics of Parents/Guardians (Total N=61)</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>29 (47.5)</td>
</tr>
<tr>
<td>Male</td>
<td>3 (4.9)</td>
</tr>
<tr>
<td>Missing</td>
<td>29 (47.5)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
</tr>
<tr>
<td>African American/Black</td>
<td>3 (4.9)</td>
</tr>
<tr>
<td>Caucasian/White</td>
<td>53 (86.9)</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>2 (3.3)</td>
</tr>
<tr>
<td>Missing</td>
<td>3 (4.9)</td>
</tr>
<tr>
<td><strong>Hispanic/Latino</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2 (3.3)</td>
</tr>
<tr>
<td>No</td>
<td>56 (91.8)</td>
</tr>
<tr>
<td>Missing</td>
<td>3 (4.9)</td>
</tr>
<tr>
<td><strong>Education Level</strong></td>
<td></td>
</tr>
<tr>
<td>High school diploma/GED</td>
<td>8 (13.1)</td>
</tr>
<tr>
<td>Some college</td>
<td>22 (36.1)</td>
</tr>
<tr>
<td>4-year college degree</td>
<td>13 (21.3)</td>
</tr>
<tr>
<td>Master’s degree</td>
<td>9 (14.8)</td>
</tr>
<tr>
<td>Doctoral degree</td>
<td>6 (9.8)</td>
</tr>
<tr>
<td>Missing</td>
<td>3 (4.9)</td>
</tr>
<tr>
<td><strong>Child’s pharmacogenetic test</strong></td>
<td></td>
</tr>
<tr>
<td>Psychiatry Panel</td>
<td>51 (83.6)</td>
</tr>
<tr>
<td>Opioid Panel</td>
<td>10 (16.4)</td>
</tr>
<tr>
<td><strong>Were you ever told your unborn child was at risk for a genetic disorder?</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>5 (8.2)</td>
</tr>
<tr>
<td>No</td>
<td>50 (82.0)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>3 (4.9)</td>
</tr>
<tr>
<td>Missing</td>
<td>3 (4.9)</td>
</tr>
<tr>
<td><strong>Do you have a child who has needed genetic testing for a disease or disorder?</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>16 (26.2)</td>
</tr>
<tr>
<td>No</td>
<td>38 (62.3)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>4 (6.6)</td>
</tr>
<tr>
<td>Missing</td>
<td>3 (4.9)</td>
</tr>
<tr>
<td><strong>Do you have a child who will not be able to live on their own as an adult?</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>5 (8.2)</td>
</tr>
<tr>
<td>No</td>
<td>42 (68.9)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>11 (18.0)</td>
</tr>
<tr>
<td>Missing</td>
<td>3 (4.9)</td>
</tr>
</tbody>
</table>
Of the 71 parents/guardians we contacted whose child had the opioid test, 10 (14.1%) responded. Of the 382 parents/guardians we contacted whose child had the psychiatric test, 51 (13.4%) responded. There was not a significant difference in the proportion of responders between those whose child had psychiatric pharmacogenetics testing and those whose child had opioid pharmacogenetics testing (p=0.85).

Access to Personal Health Records and Results Reports

Out of 29 adolescents, 23 (79.3%) reported having accessed MyChart; out of 61 parents/guardians, 59 (96.7%) reported having accessed MyChart. There was a significant difference in access between adolescents and parents/guardians (p=0.013, Fisher’s exact test). Participants were able to choose more than one reason and their other reasons for not accessing MyChart varied. In the six adolescents who reported not having accessed MyChart, the reasons varied, with *I have never heard of MyChart* being the most common answer (Figure 3). Two parents reported not having accessed MyChart and both selected *I forgot about it* (Figure 4).

![Figure 3. Reasons adolescents report for not accessing MyChart (n=4)](image-url)
Of those adolescents who had logged into MyChart, six reported they had seen psychiatric medicine test results, and two reported they had seen pain medicine test results. Of the eight answers, two adolescents reported having seen both pain and psychiatric medicine test results. Four of the six individuals who said they had seen psychiatric and/or pain medicine test results, indicated that they had not seen genetic test results.

Of those parents/guardians who had logged into MyChart, 22 reported they had seen psychiatric medicine test results, and eight reported they had seen pain medicine test results. Three parents/guardians reported having seen both pain and psychiatric medicine test results. Thirteen of the 27 individuals who said they had seen psychiatric and/or pain medicine test results, answered they had not seen genetic test results.

Reactions to Pharmacogenetic Results

Adolescents and parents/guardians who had seen test results about medications were asked to recall their initial feelings when viewing these results and were able to choose more than one reaction. At least half of the adolescents felt informed or interested after viewing the
results about psychiatric medications (Figure 5) and about pain medications (Figure 6). Similar to the adolescents, at least 50% of parents reported feeling informed after viewing either the results for psychiatric medications or pain medications. Unlike the adolescents, parents reported a diverse range of reactions (Figures 7 – 8).

To test whether the type of genetic testing influences the feelings, we collapsed the data into positive and negative feelings. In parents/guardians whose child had opioid pharmacogenetics testing, 10 (58.8%) positive feelings were reported, and in parents/guardians whose child had psychiatric testing, 35 (68.6%) positive feelings were reported. No significant difference was detected between the two types of test results (p=0.56, Fisher’s exact test). Likewise, we found no significant difference in positive and negative feelings between adolescents who had psychiatric pharmacogenetic testing and those who had opioid pharmacogenetic testing (p=1.00, Fisher’s exact test). Three (100%) and seven (87.5%) positive feelings were reported by adolescents who had the opioid and psychiatric test, respectively. We also compared the positive feelings between parents/guardians and adolescents. Forty-five (66.2%) and ten (90.9%) positive feelings were reported by parents/guardians and adolescents, respectively; no significant difference was found (p=0.16, Fisher’s exact test).
Figure 5. Adolescents’ initial reactions to viewing results about psychiatric medications (n=6)

Figure 6. Adolescents’ initial reactions to viewing results about pain medications (n=2)
Figure 7. Parents’/guardians’ initial reactions to viewing results about psychiatric medications (n=22)

Figure 8. Parents’/guardians’ initial reactions to viewing results about pain medications (n=8)
Readability

Readability of the pharmacogenetic test report was assessed with eight items. We found no significant difference between parents’/guardians’ and adolescents’ responses to these questions (Table 3). Similarly, we found no significant difference in readability of the test report based on parent education level (Table 4).
Table 3. Readability: Adolescents versus Parents/Guardians*

<table>
<thead>
<tr>
<th></th>
<th>Adolescent (n=6)</th>
<th>Parent/Guardian (n=27)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The content in the test report was easy to understand</strong></td>
<td></td>
<td></td>
<td>0.24</td>
</tr>
<tr>
<td>Agree</td>
<td>4 (66.7)</td>
<td>22 (88.0)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>2 (33.3)</td>
<td>3 (12.0)</td>
<td></td>
</tr>
<tr>
<td><strong>I read all sections of the test report</strong></td>
<td></td>
<td></td>
<td>0.19</td>
</tr>
<tr>
<td>Agree</td>
<td>5 (83.3)</td>
<td>25 (100)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>1 (16.7)</td>
<td>0 (0)</td>
<td></td>
</tr>
<tr>
<td><strong>The test report includes information that distracts me from the information I care about</strong></td>
<td></td>
<td></td>
<td>0.55</td>
</tr>
<tr>
<td>Agree</td>
<td>1 (33.3)</td>
<td>8 (61.5)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>2 (66.7)</td>
<td>5 (38.5)</td>
<td></td>
</tr>
<tr>
<td><strong>I like how the report looks</strong></td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>Agree</td>
<td>3 (100)</td>
<td>14 (87.5)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>0 (0)</td>
<td>2 (12.5)</td>
<td></td>
</tr>
<tr>
<td><strong>It was easy to find the information I wanted to know</strong></td>
<td></td>
<td></td>
<td>0.58</td>
</tr>
<tr>
<td>Agree</td>
<td>4 (66.7)</td>
<td>18 (81.8)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>2 (33.3)</td>
<td>4 (18.2)</td>
<td></td>
</tr>
<tr>
<td><strong>The format of the test report was overwhelming</strong></td>
<td></td>
<td></td>
<td>0.27</td>
</tr>
<tr>
<td>Agree</td>
<td>0 (0)</td>
<td>7 (36.8)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>5 (100)</td>
<td>12 (63.2)</td>
<td></td>
</tr>
<tr>
<td><strong>The content in the test report was too difficult to understand</strong></td>
<td></td>
<td></td>
<td>0.55</td>
</tr>
<tr>
<td>Agree</td>
<td>0 (0)</td>
<td>5 (22.7)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>5 (100)</td>
<td>17 (77.3)</td>
<td></td>
</tr>
<tr>
<td><strong>It was easy to find the information that was important for my/my child’s care</strong></td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>Agree</td>
<td>5 (100)</td>
<td>17 (85.0)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>0 (0)</td>
<td>3 (15.0)</td>
<td></td>
</tr>
</tbody>
</table>

Note: Data are shown as n (%) and tested using Fisher’s exact tests.
*Not all participants answered every question about readability. Percentages are reported out of those who agreed or disagreed.
Table 4. Readability by Parent/Guardian Education Level\textsuperscript{*†}

<table>
<thead>
<tr>
<th>Item</th>
<th>Less than 4-year college degree (n=8)</th>
<th>At least a 4-year college degree (n=16)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>The content in the test report was easy to understand</td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>Agree</td>
<td>7 (87.5)</td>
<td>13 (92.9)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>1 (12.5)</td>
<td>1 (7.1)</td>
<td></td>
</tr>
<tr>
<td>I read all sections of the test report</td>
<td></td>
<td></td>
<td>n/a</td>
</tr>
<tr>
<td>Agree</td>
<td>8 (100)</td>
<td>15 (100)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td></td>
</tr>
<tr>
<td>The test report includes information that distracts me from the information I care about</td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>Agree</td>
<td>4 (66.7)</td>
<td>4 (66.7)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>2 (33.3)</td>
<td>2 (33.3)</td>
<td></td>
</tr>
<tr>
<td>I like how the report looks</td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>Agree</td>
<td>4 (100)</td>
<td>8 (88.9)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>0 (0)</td>
<td>1 (11.1)</td>
<td></td>
</tr>
<tr>
<td>It was easy to find the information I wanted to know</td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>Agree</td>
<td>7 (87.5)</td>
<td>10 (76.9)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>1 (12.5)</td>
<td>3 (23.1)</td>
<td></td>
</tr>
<tr>
<td>The format of the test report was overwhelming</td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>Agree</td>
<td>1 (20)</td>
<td>4 (36.4)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>4 (80)</td>
<td>7 (63.6)</td>
<td></td>
</tr>
<tr>
<td>The content in the test report was too difficult to understand</td>
<td></td>
<td></td>
<td>0.52</td>
</tr>
<tr>
<td>Agree</td>
<td>0 (0)</td>
<td>3 (23.1)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>7 (100)</td>
<td>10 (76.9)</td>
<td></td>
</tr>
<tr>
<td>It was easy to find the information that was important for my child’s care</td>
<td></td>
<td></td>
<td>0.53</td>
</tr>
<tr>
<td>Agree</td>
<td>6 (100)</td>
<td>10 (83.3)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>0 (0)</td>
<td>2 (16.7)</td>
<td></td>
</tr>
</tbody>
</table>

Note: data are shown as n (%) and tested using Fisher’s exact tests

*Not all participants answered every question about readability. Percentages are reported out of those who agreed or disagreed.

†Not all parents/guardians answered the question about education level.
Perceived Utility

We asked participants two questions about their perceived utility of the tests (Table 5). In both adolescents and parents/guardians, most participants thought the tests were useful. However, in terms of whether the pharmacogenetic test has helped the treatment, adolescents tended to agree more than the parents/guardians, though no statistical significance was detected likely due to the small sample size. We also found no significant difference in utility based on parent/guardian education level (Table 6).

<table>
<thead>
<tr>
<th>How useful do you think this test is?</th>
<th>Adolescent (n=6)</th>
<th>Parent/Guardian (n=27)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Useful</td>
<td>6 (100)</td>
<td>24 (92.3)</td>
<td>1.00</td>
</tr>
<tr>
<td>Not useful</td>
<td>0 (0)</td>
<td>2 (7.7)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>This test has helped my/my child’s treatment.</th>
<th>Adolescent (n=6)</th>
<th>Parent/Guardian (n=27)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agree</td>
<td>6 (100)</td>
<td>15 (83.3)</td>
<td>0.55</td>
</tr>
<tr>
<td>Disagree</td>
<td>0 (0)</td>
<td>3 (16.7)</td>
<td></td>
</tr>
</tbody>
</table>

Note: data are shown as n (%) and tested using Fisher’s exact tests
*Not all participants answered every question about readability. Percentages are reported out of those who agreed or disagreed.
Table 6. Perceived Utility by Parent/Guardian Education Level*†

<table>
<thead>
<tr>
<th></th>
<th>Less than 4-year college degree (n=8)</th>
<th>At least a 4-year college degree (n=16)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How useful do you think this test is?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Useful</td>
<td>8 (100)</td>
<td>14 (87.5)</td>
<td>0.54</td>
</tr>
<tr>
<td>Not useful</td>
<td>0 (0)</td>
<td>2 (12.5)</td>
<td></td>
</tr>
<tr>
<td><strong>This test has helped my child’s treatment.</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree</td>
<td>2 (66.7)</td>
<td>11 (84.6)</td>
<td>0.49</td>
</tr>
<tr>
<td>Disagree</td>
<td>1 (33.3)</td>
<td>2 (15.4)</td>
<td></td>
</tr>
</tbody>
</table>

Note: data are shown as n (%) and tested using Fisher’s exact tests
*Not all participants answered every question about readability. Percentages are reported out of those who agreed or disagreed.
†Not all parents/guardians answered the question about education level.

Perceived Actionability

We found no significant difference in perceived actionability of pharmacogenetic results between adolescents and parents/guardians (Table 7). We did, however, find a significant difference in the need to speak with a child’s doctor after reading results in MyChart based on parent/guardian education level (Table 8).

Table 7. Perceived Actionability: Adolescents versus Parents/Guardians*

<table>
<thead>
<tr>
<th></th>
<th>Adolescent (n=6)</th>
<th>Parent/Guardian (n=27)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Reading the test result in MyChart prompted me to talk about the result with my/my child’s doctor</strong></td>
<td></td>
<td></td>
<td>0.29</td>
</tr>
<tr>
<td>Agree</td>
<td>5 (100)</td>
<td>17 (68.0)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>0 (0)</td>
<td>8 (32.0)</td>
<td></td>
</tr>
<tr>
<td><strong>I knew what actions to take after reading the report</strong></td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>Agree</td>
<td>4 (80)</td>
<td>18 (78.3)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>1 (20)</td>
<td>5 (21.7)</td>
<td></td>
</tr>
<tr>
<td><strong>I did not need to talk to my/my child’s doctor after reading the test result in MyChart</strong></td>
<td></td>
<td></td>
<td>0.33</td>
</tr>
<tr>
<td>Agree</td>
<td>3 (60)</td>
<td>7 (31.8)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>2 (40)</td>
<td>15 (68.2)</td>
<td></td>
</tr>
</tbody>
</table>

Note: data are shown as n (%) and tested using Fisher’s exact tests
*Not all participants answered every question about readability. Percentages are reported out of those who agreed or disagreed.
Table 8. Perceived Actionability by Parent/Guardian Education Level*†

<table>
<thead>
<tr>
<th>Reading the test result in MyChart prompted me to talk about the result with my child’s doctor</th>
<th>Less than 4-year college degree (n=8)</th>
<th>At least a 4-year college degree (n=16)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agree</td>
<td>4 (50)</td>
<td>11 (78.6)</td>
<td>0.34</td>
</tr>
<tr>
<td>Disagree</td>
<td>4 (50)</td>
<td>3 (21.4)</td>
<td></td>
</tr>
<tr>
<td>I knew what actions to take after reading the report</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree</td>
<td>7 (87.5)</td>
<td>10 (83.3)</td>
<td>1.00</td>
</tr>
<tr>
<td>Disagree</td>
<td>1 (12.5)</td>
<td>2 (16.7)</td>
<td></td>
</tr>
<tr>
<td>I did not need to talk to my child’s doctor after reading the test result in MyChart</td>
<td></td>
<td></td>
<td>0.041</td>
</tr>
<tr>
<td>Agree</td>
<td>5 (62.5)</td>
<td>1 (9.1)</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>3 (37.5)</td>
<td>10 (90.9)</td>
<td></td>
</tr>
</tbody>
</table>

Note: data are shown as n (%) and tested using Fisher’s exact tests
*Not all participants answered every question about readability. Percentages are reported out of those who agreed or disagreed.
†Not all parents/guardians answered the question about education level.

**Discussion**

*Patient Portal Access*

We found a significant difference in MyChart access between adolescents and parents/guardians (p=0.013). To our knowledge there have been no other studies showing this difference when personal health records are accessible by both parents/guardians and adolescents. One study at Children’s Hospital Boston found that users, including both parents/guardians and patients with a mean age of 9.4 years, accessed their accounts an average of 6.3 times in the first three months after deployment (Bourgeois, Mandl, Shaw, Flemming, & Nigrin, 2009). However, they did not distinguish between parent/guardian and patient users.
Another study found that only around 7% of a practice in the United Kingdom had access to their records through a patient portal (Hannan, 2010). They found that interest was greatest among patients between ages 45 and 74 years. The age groups with the fewest patients with access were those between age 5 and 24 years and those over the age of 85 years. Even in some patients who had access through the patient portal, there was a lack of understanding of how having this access could benefit them.

Half of adolescents who had never accessed MyChart reported never hearing about it. In order for an adolescent at CCHMC to have access to MyChart and, therefore, to be part of this study he/she must go through a process, including signing an assent agreement allowing his/her parents/guardians access to these records as well. Therefore, it is apparent that half the adolescents who did not access MyChart did not understand what they were assenting to or they did not remember being offered registration and signing assent for access. It has been suggested that one mechanism for breaking down barriers to the adoption of personal health records is education (Tang, et al., 2006). The main reasons adolescents reported for not accessing MyChart point to a need for better education about MyChart and how to use it.

Dhanireddy, et al. (2015) found that people, specifically in the underserved urban population, were concerned about stress from reading about their medical conditions and about privacy and security. Both of these reasons were offered as choices of reasons why our participants had not logged into MyChart. However, no one chose either of these reasons. It is possible that people refrain from even signing up for MyChart due to comparable thoughts.
Impressions of Pharmacogenetic Test Results

There appeared to be some general confusion about the results seen in MyChart. It is interesting that 66.7% of adolescents and 48.1% of parents who viewed a pharmacogenetic test result in MyChart seemed to be unaware that it was a genetic test. To our knowledge this is the first study that revealed participants’ may not understand the genetic nature of pharmacogenetic testing. The question of whether a person had seen a genetic test result was initially included in the skip logic to ensure that participants were not made aware of genetic test result based only on the questionnaire. However, we found the results interesting and informative and, therefore, included them.

The confusion may be an issue of adolescent and parent/guardian recall of the details of the test. Fargher, et al. (2007) performed qualitative interviews of patients who had previously undergone pharmacogenetic testing. They found that patients rarely recalled the experience of pharmacogenetic testing and that, when they did, they did not know specific details, such as the type of test.

Several studies have shown that the public’s understanding of genetics is mostly in terms of heredity (Catz, et al., 2005; Condit, 2010; Kessler, Collier, & Halbert, 2007; Molster, Samanek, & O’Leary, 2009). These studies have found that the public has little understanding of molecular genetics and the structural and functional nature of genes. Pharmacogenetic testing can be ordered by treating providers at the point of care to guide medication selection or dosing (Prows, et al., 2009; Prows, 2009). When pharmacogenetic testing is ordered in a clinical setting before it is needed to guide medication therapy, institutions often have clinical decision support available to help clinicians use the information when a relevant drug is being considered (Hoffman, et al., 2014; Peterson, et al., 2015; Weitzel, et al., 2014). When the emphasis of
testing is to guide prescriber action it is reasonable to anticipate that the hereditary nature or family implication of patients’ results may not be discussed. Because patient may not be aware that response to medication may be heritable, it is possible that people do not understand that it is genetic.

Some adolescents and parents/guardians reported having seen genetic test results but not results about psychiatric and/or pain medications. It is possible that these people have had other genetic testing. Participants also reported having seen results about both psychiatric and pain medications. According to medical records, these adolescents and the children of the parents/guardians only had one pharmacogenetic test when the recruitment list was generated. It is possible that additional pharmacogenetic testing was performed by the time the participant completed the study questionnaire. It is also possible participants were confused about the different types of test results that can be viewed in MyChart. At CCHMC, patients admitted to inpatient psychiatry also undergo a drug screen. It is possible they considered the drug screen report when the questionnaire asked, “Have you ever seen test results about pain medicines in MyChart?”

Parents with at least a four-year college degree were more likely to report need to speak with their child’s doctor about the results (p=0.041). Other studies have shown that patients with higher education or literacy are more likely to take an active role in their health care. One study found that patients with at least some college education tended to participate more in health visits (Street, Gordon, Ward, Krupat, & Kravitz, 2005). Another study found that low-literacy patients tended to ask fewer questions than those with higher literacy. They also asked significantly fewer questions about “key medical aspects,” such as treatment regimens and their medical
condition. However, this study used the Rapid Estimate of Adult Literacy in Medicine to measure the health literacy of participants (Katz, Jacobson, Veledar, & Kripalani, 2007).

We found no difference in initial reactions to pharmacogenetic test results based on test taken or between adolescents and parents/guardians. A study of patients who had not had pharmacogenetic testing found that most participants did not expect to have negative feelings if they were to receive an “unfavorable” test result. Although these patients were enrolled in a larger pharmacogenetic study, they had not received results (Rogausch, Prause, Schallenberg, Brockmoller, & Himmel, 2006). In a study of patients’ perceptions of pharmacogenetic research results, approximately 99% of participants reported having positive feelings after receiving results (Madadi, et al., 2010).

**Future Directions**

More research is needed to determine barriers to use of patient portals in our population. It will also be important to assess the educational needs of patients who are receiving pharmacogenetic testing and their parents. Specifically, parents’ and adolescents’ knowledge about the genetic and hereditary nature of pharmacogenetic test results deserve further investigation. Where implementation of pharmacogenetic testing is already actively integrated into clinical care, patient brochures, fact sheets or other types of point of care education measures need to clearly include information about the hereditary nature of drug response genes and potential relevance of results for other biologic family members.

**Limitations**

A limitation of the study is the small sample size, which likely impacted our ability to detect statistically significant differences. The majority of our adolescent and parent/guardian
participants were Caucasian/white. Most of the adolescents in our study were in high school and reported that their health was good or excellent. The homogeneity of the sample suggests that these results may not be readily generalized to other populations. Also, the individuals with opioid test results were all enrolled in another study to receive testing. These participants may have received additional information at the time of testing and results disclosure which may have skewed their responses to the survey. However, we found that the proportion of those who responded was not dependent on which test was done nor did participant responses regarding impressions of test results differ based on type of result viewed in MyChart. However, this is something to be aware of in future studies with this population. It is possible that some parents/guardians completed the adolescent survey because it was sent to them to forward to their adolescents. In the future, it may help to collect participant demographics at the beginning of the survey to minimize the number of parents/guardians completing the adolescent survey.
References:


Hannan, A. (2010). Providing patients online access to their primary care computerized medical records: a case study of sharing and caring. *Informatics in Primary Care, 18*, 41-49.


Appendix A: Online Adolescent Questionnaire

Adolescent MyChart Access

Please complete the survey below.

Thank you!

Prior to this survey, have you ever logged into MyChart?
☐ Yes
☐ No

Why have you not logged into MyChart before this survey? (Check all that apply.)
☐ I have never heard of MyChart.
☐ I never signed up for it.
☐ I forgot about it.
☐ I have been too busy.
☐ I am worried about seeing information that might be in the health records.
☐ I do not know how to use MyChart.
☐ I am worried about privacy.
☐ I do not think there is a reason for me to log into MyChart.
☐ I do not want to use MyChart.
☐ Other

If Other, please specify:

______________________________________________________________

Prior to viewing this survey, how often did you visit MyChart?
☐ Once a week
☐ Once a month
☐ Once every few months
☐ Once a year
☐ Less than once a year

Have you seen lab and test results in MyChart prior to viewing this survey?
☐ Yes
☐ No

Which sections of MyChart have you accessed prior to this survey? (Check all that apply.)
☐ Medical history
☐ Medications
☐ Appointments
☐ After Visit Summaries
☐ Admissions
☐ Discharge Instructions

Have you ever seen genetic test results in MyChart?
☐ Yes
☐ No

Have you ever seen test results about psychiatric medicines in MyChart?
☐ Yes
☐ No

Based on my result, I need special doses of some psychiatric medicines.
☐ Yes
☐ No
☐ Don't know

Have you ever seen test results about pain medicines in MyChart?
☐ Yes
☐ No

Based on my result about pain medicine, I can take codeine.
☐ Yes
☐ No
☐ Don't know
Prior to this survey, when was the last time you viewed these results?

- Within the last week
- Within the last month
- Within the past year
- More than a year ago
- Don't know

How did you first feel when you read your results for psychiatric medicines in MyChart? (Check all that apply.)

- angry
- confused
- curious
- happy
- indifferent
- informed
- interested
- overwhelmed
- relieved
- sad
- surprised
- worried
- I didn't feel anything
- I don't remember
- Other

How did you first feel when you read your results for pain medicines in MyChart? (Check all that apply.)

- angry
- confused
- curious
- happy
- indifferent
- informed
- interested
- overwhelmed
- relieved
- sad
- surprised
- worried
- I didn't feel anything
- I don't remember
- Other

If other, please specify:

________________________________________

03/11/2016 7:37am

www.projectmdcap.org

REDCap
# Adolescent Readability

Please complete the survey below.

Thank you!

---

For the following items, please choose how strongly you agree or disagree.

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>The content in the test report was easy to understand</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I read all sections of the test report</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The test report includes information that distracts me from the information I care about</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I like how the report looks</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I understood what the result meant for me</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>It was easy to find the information I wanted to know</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The format of the test report was overwhelming</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Adolescent Readability 2

Please complete the survey below.

Thank you!

For the following items, please choose how strongly you agree or disagree.

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>23</td>
<td>Reading the test result in MyChart prompted me to talk about the result with my doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>I knew what actions to take after reading the report</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>The content in the test report was too difficult to understand</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>It was easy to find the information that was important for me care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27</td>
<td>I did not need to talk to my doctor after reading the test result in MyChart</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Adolescent Treatment Opinion

Please complete the survey below.

Thank you!

For the following items, please choose how strongly you agree or disagree.

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>The result makes me think I am easy to treat with the listed medicines.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The result makes me think I am hard to treat with the listed medicines.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The test does not make me see myself any differently.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I shouldn't take pain medicines because of the results.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I shouldn't take psychiatric medicines because of the results.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The test results do not change anything for me.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Adolescent Understanding/Action

Please complete the survey below.

Thank you!

Before you saw your results, did you know why the test was being done?
- Yes, completely
- Mostly
- Somewhat
- Not at all
- I did not know the test was being done

After you saw your results, did you understand why the test was done?
- Yes, completely
- Mostly
- Somewhat
- Not at all

I can still have side effects.
- Yes
- No
- Don't know

Other medicines, diseases, or food may affect how certain medicines work for me.
- Yes
- No
- Don't know

Have you discussed the results with your doctor?
- Yes
- No

How useful do you think this test is?
- Very useful
- Somewhat useful
- Not very useful
- Not useful at all
- Don't know

The test has helped my treatment.
- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree
- Don't know
Adolescent Recommendations

Please complete the survey below.

Thank you!

We plan to create information to help people better understand genetic test results that are placed in MyChart. Which topics do you think would help people better understand genetic test results? (Check all that apply.)

☐ Definition of a gene
☐ What the gene(s) listed in the test result do
☐ Why the test was done
☐ What the test was looking for
☐ Accuracy of the test
☐ What the result means for me
☐ What I need to do with the result
☐ How to talk to my doctor about the test
☐ What the test means for other family members
☐ I don't think additional information is needed

How would you want to receive information to supplement genetic test results? (Check all that apply.)

☐ Links to written information so I can choose just the topics I want to learn about
☐ Written information mailed to my home
☐ YouTube video
☐ Speak with my doctor
☐ Audio description I can link to on my computer, phone, or MP3 player
☐ I would not want any extra information
☐ Other

If Other, please specify:

________________________

For the following items, please choose how strongly you agree or disagree.

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Graphs would help me understand the test report</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Pictures would help me understand the test report</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>More common language would help me understand the test report</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Definitions would help me understand the test report</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Breaking the information into short sections would help me find the information I care about</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>
Adolescent Demographics

Please complete the survey below.

Thank you!

How do you describe your health?
- Excellent
- Good
- Fair
- Poor

How interested would you be in having a test that looked at all of your genes?
- Very interested
- Somewhat interested
- Somewhat not interested
- Not at all interested

What grade are you in?
- Less than 6th grade
- Junior high/middle school
- High school
- I graduated from high school
- I dropped out of school

How do you describe your class grades?
- Above average
- Average
- Below average
- Prefer not to answer

How do you describe your race?
- African American/Black
- Alaskan or Hawaiian Native
- American Indian
- Caucasian/White
- Asian/Pacific Islander
- Other
- More than one race
- Prefer not to answer

Are you Hispanic or Latino?
- Yes
- No
- Prefer not to answer
**Adolescent Learning Results**

Please complete the survey below.

Thank you!

It will become more common in the future to test all genes with one blood sample or one spit sample. Doctors, nurses, and scientists are debating which type of gene results adolescents should be able to learn before they become adults. Very few studies have been done to find out the type of gene results adolescents want to learn.

For the following items, please choose how strongly you agree or disagree that you would want to be told about genetic test results that show you...

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Neither agree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>55</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>56</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>57</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>58</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>59</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>60</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>61</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>62</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>63</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>64</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

03/11/2016 7:37am

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REDCap
...have 25 out of 100 chances of having a baby with a genetic disease only if your partner also has the same type of gene result.

66) ...have an abnormal result but the doctors don't know what it means.

67) Please type any comments or thoughts you had when completing these questions.
Adolescent Viewing Results

Please complete the survey below.

Thank you!

MyChart is a place for patients to see some of their medical records. Many test results are placed in MyChart. At Cincinnati Children's Hospital, adolescents can choose to sign up for MyChart with their parents' permission. It is possible to see test results in MyChart before the result are explained by a doctor. We want to learn your opinions about seeing genetic test results in MyChart before the doctor explains the result.

For the following items, please choose how strongly you agree or disagree. Even if a doctor hasn't told me about the result, it should be ok for me to see a genetic test result that...

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>68</td>
<td>...predicts I have a high risk for side effects from certain medicines that may never be needed.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>69</td>
<td>...shows I cannot be treated with certain medicines if needed in the future.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>70</td>
<td>...shows I will develop schizophrenia.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>71</td>
<td>...shows I will develop abnormal heart rhythm that might cause sudden death.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>72</td>
<td>...shows I will develop severe memory loss as an adult and nothing can stop the memory loss.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>73</td>
<td>...shows I will develop cancer as an adult.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>74</td>
<td>...shows I have 25 out of 100 chances to develop schizophrenia.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>75</td>
<td>...shows I have 25 out of 100 chances to have abnormal heart rhythm that might cause sudden death.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

03/12/2016 7:37am

www.projectedcap.org
76) ...shows I have 25 out of 100 chances to develop severe memory loss as an adult and nothing can stop the memory loss.

77) ...shows I have 25 out of 100 chances to develop cancer as an adult.

78) ...shows I have 25 out of 100 chances of having a baby with a genetic disease only if your partner also has the same type of gene result.

79) ...is abnormal but the doctors don't know what it means.

80) Please type any comments or thoughts you had when completing these questions.

81) 25 out of 100 chances is a:

- Low risk
- Medium risk
- High risk
- Don't know

82) Even though the following are the same, which seems like a higher risk?

- 1 out of 4 chances
- 25 percent chance
- 25 out of 100 chances
- Don't know
Appendix B: Online Parent/Guardian Questionnaire

Parent MyChart Access

Please complete the survey below.

Thank you!

Prior to this survey, have you ever logged into MyChart?

☐ Yes
☐ No

Why have you not logged into MyChart before this survey? (Click on all that apply.)

☐ I have never heard of MyChart.
☐ I never signed up for it.
☐ I forgot about it.
☐ I have been too busy.
☐ I am worried about seeing information that might be in the health records.
☐ I do not know how to use MyChart.
☐ I am worried about privacy.
☐ I do not think there is a reason for me to log into MyChart.
☐ I do not want to use MyChart.
☐ Other

If Other, please specify: ________________________________

Prior to viewing this survey, how often did you visit MyChart?

☐ Once a week
☐ Once a month
☐ Once every few months
☐ Once a year
☐ Less than once a year

Have you seen lab and test results in MyChart prior to viewing this survey?

☐ Yes
☐ No

Which sections of MyChart have you accessed prior to this survey? (Check all that apply.)

☐ Medical history
☐ Medications
☐ Appointments
☐ After Visit Summaries
☐ Admissions
☐ Discharge instructions

Have you ever seen genetic test results in MyChart?

☐ Yes
☐ No

Have you ever seen test results about psychiatric medicines in MyChart?

☐ Yes
☐ No

Based on the result, my child needs special doses of some psychiatric medicines.

☐ Yes
☐ No
☐ Don’t know

Have you ever seen test results about pain medicines in MyChart?

☐ Yes
☐ No

Based on the result about pain medicine, my child can take codeine.

☐ Yes
☐ No
☐ Don’t know
Prior to this survey, when was the last time you viewed these results?
- Within the last week
- Within the last month
- Within the past year
- More than a year ago
- Don't know

How did you first feel when you read your child's results for psychiatric medicines in MyChart? (Check all that apply.)
- angry
- confused
- curious
- happy
- indifferent
- informed
- interested
- overwhelmed
- relieved
- sad
- surprised
- worried
- I didn't feel anything
- I don't remember
- Other

How did you first feel when you read your child's results for pain medicines in MyChart? (Check all that apply.)
- angry
- confused
- curious
- happy
- indifferent
- informed
- interested
- overwhelmed
- relieved
- sad
- surprised
- worried
- I didn't feel anything
- I don't remember
- Other

If Other, please specify:

______________________________

03/12/2016 7:50am

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Parent Readability

Please complete the survey below.

Thank you!

For the following items, please choose how strongly you agree or disagree.

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
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<td>The content in the test report was easy to understand</td>
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<tr>
<td>I read all sections of the test report</td>
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<td>○</td>
<td>○</td>
<td>○</td>
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<td>The test report includes information that distracts me from the information I care about</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I like how the report looks</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I understood what the result meant for my child</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>It was easy to find the information I wanted to know</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
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</tr>
<tr>
<td>The format of the test report was overwhelming</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Please complete the survey below.

Thank you!

For the following items, please choose how strongly you agree or disagree.

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<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>23</td>
<td>Reading the test result in MyChart prompted me to talk about the result with my child's doctor</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>24</td>
<td>I knew what actions to take after reading the report</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>25</td>
<td>The content in the test report was too difficult to understand</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>26</td>
<td>It was easy to find the information that was important for my child's care</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>27</td>
<td>I did not need to talk to my child's doctor after reading the test result in MyChart</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>
Parent Treatment Opinion

Please complete the survey below.

Thank you!

For the following items, please choose how strongly you agree or disagree.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>The result makes me think my child is easy to treat with the listed medicines.</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
</tr>
<tr>
<td>The result makes me think my child is hard to treat with the listed medicines.</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
</tr>
<tr>
<td>The test does not make me see my child any differently.</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
</tr>
<tr>
<td>My child shouldn't take pain medicines because of the results.</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
</tr>
<tr>
<td>My child shouldn't take psychiatric medicines because of the results.</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
</tr>
<tr>
<td>The test results do not change anything for my child.</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
<td>Ø</td>
</tr>
</tbody>
</table>
Parent Understanding/Action

Please complete the survey below.

Thank you!

Before you saw your child’s results, did you know why the test was being done?
- Yes, completely
- Mostly
- Somewhat
- Not at all
- I did not know the test was being done

After you saw your child’s results, did you understand why the test was done?
- Yes, completely
- Mostly
- Somewhat
- Not at all
- I did not understand why the test was done

My child can still have side effects.
- Yes
- No
- Don’t know

Other medicines, diseases, or food may affect how certain medicines work for my child.
- Yes
- No
- Don’t know

Have you discussed the results with your child’s doctor?
- Yes
- No

How useful do you think this test is?
- Very useful
- Somewhat useful
- Not very useful
- Not useful at all
- Don’t know

The test has helped my child’s treatment.
- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree
- Don’t know
Parent Recommendations

Please complete the survey below.

Thank you!

We plan to create information to help people better understand genetic test results that are placed in MyChart. Which topics do you think would help people better understand genetic test results? (Check all that apply.)

- Definition of a gene
- What the genetic(s) was in the test result do
- Why the test was done
- What the test was looking for
- Accuracy of the test
- What the result means for my child
- What I need to do with the result
- How to talk to my child’s doctor about the test
- What this test means for other family members
- I don’t think additional information is needed

How would you want to receive information to supplement genetic test results? (Check all that apply.)

- Links to written information so I can choose just the topics I want to learn about
- Written information mailed to my home
- YouTube video
- Speak with my child’s doctor
- Audio description I can link to on my computer, phone, or MP3 player
- I would not want any extra information
- Other

If Other, please specify:

For the following items, please choose how strongly you agree or disagree.

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Graphs would help me understand the test report</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Pictures would help me understand the test report</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>More common language would help me understand the test report</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Definitions would help me understand the test report</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
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</tr>
<tr>
<td>Breaking the information into short sections would help me find the information I care about</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>

03/11/2016 7:50am

www.projectredcap.org

REDCap
Parent Demographics

Please complete the survey below.

Thank you!

What is your highest level of education?

☐ Less than 12th grade
☐ High school diploma/GED
☐ Some college
☐ 4 year college degree
☐ Master's degree
☐ Doctoral degree

How do you describe your race?

☐ African American/Black
☐ Alaskan or Hawaiian Native
☐ American Indian
☐ Caucasian/White
☐ Asian/Pacific Islander
☐ Other
☐ More than one race
☐ Prefer not to answer

Are you Hispanic or Latino?

☐ Yes
☐ No
☐ Prefer not to answer

Were you ever told your unborn child was at risk for a genetic disorder?

☐ Yes
☐ No
☐ Don't know

Do you have a child who has needed genetic testing for a disease or disorder?

☐ Yes
☐ No
☐ Don't know

Do you have a child who will not be able to live on their own as an adult?

☐ Yes
☐ No
☐ Don't know
Parent Learning Results

Please complete the survey below.

Thank you!

---

It will become more common in the future to test all genes with one blood sample or one spit sample. Doctors, nurses, and scientists are debating which type of children’s gene results parents should be able to learn. This section asks your opinions about these issues.

For the following items, please choose how strongly you agree or disagree that parents should be told about genetic test results that show their child...

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>Don't know</th>
</tr>
</thead>
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<tr>
<td>55</td>
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<td>56</td>
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<td>57</td>
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<td>64</td>
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<td>65</td>
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<td></td>
</tr>
</tbody>
</table>

03/11/2016 7:50am

www.projectredcap.org

REDCap
66) ...has 25 out of 100 chances of having a baby with a genetic disease only if the child's partner also has the same type of gene result.

67) Please type any comments or thoughts you had when completing these questions.

68) 25 out of 100 chances is a:

   - Low risk
   - Medium risk
   - High risk
   - Don't know

69) Even though the following are the same, which seems like a higher risk?

   - 1 out of 4 chances
   - 25 percent chance
   - 25 out of 100 chances
   - Don't know
Parent Viewing Results

Please complete the survey below.

Thank you!

MyChart is a place for patients to see some of their medical records. Many test results are placed in MyChart. It is possible for parents to see their child's test results in MyChart before the result are explained by a doctor. We want to learn your opinions about seeing your child's genetic test results in MyChart before the doctor explains the result.

For the following items, please choose how strongly you agree or disagree. Even if a doctor hasn't told me about the result, it should be ok for me to see my child's genetic test result that shows my child...

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>70) …has a high risk for side effects from certain medicines that may never be needed.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>71) …cannot be treated with certain medicines if needed in the future.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>72) …will develop schizophrenia.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>73) …will develop abnormal heart rhythm that might cause sudden death.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>74) …will develop severe memory loss as an adult and nothing can stop the memory loss.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>75) …will develop cancer as an adult.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>76) …has 25 out of 100 chances to develop schizophrenia.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>77) …has 25 out of 100 chances to have abnormal heart rhythm that might cause sudden death.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>78) …has 25 out of 100 chances to develop severe memory loss as an adult and nothing can stop the memory loss.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>79) …has 25 out of 100 chances to develop cancer as an adult.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>80)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
...has 25 out of 100 chances of having a baby with a genetic disease only if the child's partner also has the same type of gene result.

81) ...has an abnormal result but the doctors don't know what it means.

82) Please type any comments or thoughts you had when completing these questions.
Appendix C: Paper Adolescent Questionnaire

1. How do you describe your health?
   ☐ Excellent  ☐ Good  ☐ Fair  ☐ Poor

2. How interested would you be in having a test that looked at all of your genes?
   ☐ Very interested  ☐ Somewhat interested  ☐ Somewhat not interested  ☐ Not at all interested

3. What grade are you in?
   ☐ Less than 6th grade  ☐ Junior high/middle school  ☐ High school  ☐ I graduated from high school  ☐ I dropped out of school

4. How do you describe your class grades?
   ☐ Above average  ☐ Average  ☐ Below average  ☐ Prefer not to answer

5. How do you describe your race?
   ☐ African American/Black  ☐ Alaskan or Hawaiian Native  ☐ American Indian  ☐ Caucasian/White
   ☐ Asian/Pacific Islander  ☐ Other  ☐ More than one race  ☐ Prefer not to answer

6. Are you Hispanic or Latino?
   ☐ Yes  ☐ No  ☐ Prefer not to answer

7. Prior to this survey, have you ever logged into MyChart?
   ☐ Yes  ☐ No
   **If No, please choose the reasons you have not logged into MyChart:**
   ☐ I have never heard of MyChart  ☐ I never signed up for it  ☐ I forgot about it
   ☐ I have been too busy  ☐ I do not know how to use MyChart
   ☐ I am worried about seeing information that might be in the health records
   ☐ I am worried about privacy  ☐ I do not want to use MyChart
   ☐ I do not think there is a reason for me to log into MyChart
   Other, please specify: ____________________________
The remaining questions are for people who have visited MyChart. If you have never logged into MyChart, please return the survey. Thank you for completing the above questions.

8. Prior to viewing this survey, how often did you visit MyChart?
   ☐ Once a week  ☐ Once a month  ☐ Once every few months  ☐ Once a year
   ☐ Less than once a year

9. Have you ever seen genetic test results in MyChart?
   ☐ Yes  ☐ No

10. Have you ever seen test results about psychiatric medicines in MyChart?
    ☐ Yes  ☐ No

11. Have you ever seen test results about pain medicines in MyChart?
    ☐ Yes  ☐ No

If No to BOTH questions 10 and 11, stop here. Thank you for completing questions 1 - 11. Please return the survey in the envelope we provided.

If you answered Yes to EITHER 10 or 11, please continue.

12. Prior to this survey, when was the last time you viewed these results?
    ☐ Within the last week  ☐ Within the last month  ☐ Within the past year  ☐ More than a year ago
    ☐ Don’t know

13. How did you first feel when you read your results in MyChart? (Mark all that apply.)
    ☐ angry  ☐ confused  ☐ curious  ☐ happy  ☐ indifferent  ☐ informed  ☐ interested
    ☐ overwhelmed  ☐ relieved  ☐ sad  ☐ surprised  ☐ worried  ☐ I didn’t feel anything
    ☐ I don’t remember
    ☐ Other_________________________________________________________________

14. Before you saw your results, did you know why the test was being done?
    ☐ Yes, completely  ☐ Mostly  ☐ Somewhat  ☐ Not at all
    ☐ I did not know the test was being done

15. After you saw your results, did you understand why the test was done?
☐ Yes, completely  ☐ Mostly  ☐ Somewhat  ☐ Not at all

16. I can still have side effects.
☐ Yes  ☐ No  ☐ Don’t know

17. Other medicines, diseases, or food may affect how certain medicines work for me.
☐ Yes  ☐ No  ☐ Don’t know
For the following items, please choose how strongly you agree or disagree.

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>18. The content in the test report was easy to understand.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>19. I read all sections of the test report</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>20. The test report includes information that distracts me from the information I care about</td>
<td></td>
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</tr>
<tr>
<td>21. I like how the report looks</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>22. I understood what the result meant for me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. It was easy to find the information I wanted to know</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>24. The format of the test report was overwhelming</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>25. Reading the test result prompted me to talk about the result with my doctor</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>26. I knew what actions to take after reading the report</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. The content in the test report was too difficult to understand</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28. It was easy to find the information that was important for my care</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>29. I did not need to talk to my doctor after reading the test result in MyChart</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
30. How useful do you think this test is?
   □ Very useful  □ Somewhat useful  □ Not very useful  □ Not useful at all  □ Don’t know
For the following items, please choose how strongly you agree or disagree.

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Strongly disagree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>31. The test has helped my treatment</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>32. The result makes me think I am easy to treat with the listed medicines</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>33. The result makes me think I am hard to treat with the listed medicines</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>34. The test does not make me see myself any differently</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>35. I shouldn’t take pain medicines because of the results</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>36. I shouldn’t take psychiatric medicines because of the results</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>37. The test result do not change anything for me</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

38. We plan to create information to help people better understand genetic test results that are place in MyChart. Which topics do you think would help people better understand genetic test results? (Mark all that apply.)

☐ Definition of a gene ☐ What the gene(s) listed in the test result do ☐ Why the test was done

☐ What the test was looking for ☐ Accuracy of the test ☐ What the result means for me

☐ What I need to do with the result ☐ How to talk to my doctor about the test

☐ What this test means for other family members ☐ I don’t think additional information is needed
39. How would you want to receive information to supplement genetic test results? (Mark all that apply.)
☐ Links to written information so I can choose just the topics I want to learn about
☐ Written information mailed to my home  ☐ YouTube videos  ☐ Speak with my doctor
☐ Audio description I can link to on my computer, phone, or MP3 player
☐ I would not want any extra information
☐ Other: ________________________________________________________________

Thank you for taking the survey.
Your opinions will help us improve the way we let people know about their genetic test results.
To email or fax this survey instead of mailing use: Meghann.Reardon@cchmc.org or fax: 513-636-0543
Appendix D: Paper Parent/Guardian Questionnaire

1. What is your highest level of education?
   ☐ Less than 12th grade   ☐ High school diploma/GED   ☐ Some college   ☐ 4 year college degree
   ☐ Master’s degree   ☐ Doctoral degree

2. How do you describe your race?
   ☐ African American/Black   ☐ Alaskan or Hawaiian Native   ☐ American Indian   ☐ Caucasian/White
   ☐ Asian/Pacific Islander   ☐ Other   ☐ More than one race   ☐ Prefer not to answer

3. Are you Hispanic or Latino?
   ☐ Yes   ☐ No   ☐ Prefer not to answer

4. Were you ever told your unborn child was at risk for a genetic disorder?
   ☐ Yes   ☐ No   ☐ Don’t know

5. Do you have a child who has needed genetic testing for a disease or disorder?
   ☐ Yes   ☐ No   ☐ Don’t know

6. Do you have a child who will not be able to live on their own as an adult?
   ☐ Yes   ☐ No   ☐ Don’t know

7. Prior to this survey, have you ever logged into MyChart?
   ☐ Yes   ☐ No
   If No, please choose the reasons you have not logged into MyChart:
   ☐ I have never heard of MyChart   ☐ I never signed up for it   ☐ I forgot about it
   ☐ I have been too busy   ☐ I do not know how to use MyChart
   ☐ I am worried about seeing information that might be in the health records
   ☐ I am worried about privacy   ☐ I do not want to use MyChart
   ☐ I do not think there is a reason for me to log into MyChart
   Other, please specify: ________________________________

The remaining questions are for people who have visited MyChart. If you have never logged into MyChart, please return the survey. Thank you for completing the above questions.
8. Prior to viewing this survey, how often did you visit MyChart?
   - Once a week
   - Once a month
   - Once every few months
   - Once a year
   - Less than once a year

9. Have you ever seen genetic test results in MyChart?
   - Yes
   - No

10. Have you ever seen test results about psychiatric medicines in MyChart?
    - Yes
    - No

11. Have you ever seen test results about pain medicines in MyChart?
    - Yes
    - No

If No to BOTH questions 10 and 11, stop here. Thank you for completing questions 1 – 11. Please return the survey in the envelope we provided.

If you answered Yes to EITHER 10 or 11, please continue.

12. Prior to this survey, when was the last time you viewed these results?
    - Within the last week
    - Within the last month
    - Within the past year
    - More than a year ago
    - Don’t know

13. How did you first feel when you read your child’s results in MyChart? (Mark all that apply.)
    - Angry
    - Confused
    - Curious
    - Happy
    - Indifferent
    - Informed
    - Interested
    - Overwhelmed
    - Relieved
    - Sad
    - Surprised
    - Worried
    - I didn’t feel anything
    - I don’t remember
    - Other

14. Before you saw your child’s results, did you know why the test was being done?
    - Yes, completely
    - Mostly
    - Somewhat
    - Not at all
    - I did not know the test was being done

15. After you saw your child’s results, did you understand why the test was done?
    - Yes, completely
    - Mostly
    - Somewhat
    - Not at all

16. My child can still have side effects.
    - Yes
    - No
    - Don’t know
17. Other medicines, diseases, or food may affect how certain medicines work for my child.
☐ Yes  ☐ No  ☐ Don’t know
For the following items, please choose how strongly you agree or disagree.

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>18. The content in the test report was easy to understand.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>19. I read all sections of the test report</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>20. The test report includes information that distracts me from the information I care about</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>21. I like how the report looks</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>22. I understood what the result meant for my child</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>23. It was easy to find the information I wanted to know</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>24. The format of the test report was overwhelming</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>25. Reading the test result prompted me to talk about the result with my child’s doctor</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>26. I knew what actions to take after reading the report</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>27. The content in the test report was too difficult to understand</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>28. It was easy to find the information that was important for my child’s care</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>29. I did not need to talk to my child’s doctor after reading the test result in MyChart</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
30. How useful do you think this test is?
☐ Very useful  ☐ Somewhat useful  ☐ Not very useful  ☐ Not useful at all  ☐ Don’t know

For the following items, please choose how strongly you agree or disagree.

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly agree</th>
<th>Strongly disagree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>31. The test has helped my child’s treatment</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>32. The result makes me think my child is easy to treat with the listed medicines</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>33. The result makes me think my child is hard to treat with the listed medicines</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>34. The test does not make me see my child any differently</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>35. My child shouldn’t take pain medicines because of the results</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>36. My child shouldn’t take psychiatric medicines because of the results</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>37. The test result do not change anything for my child</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
38. We plan to create information to help people better understand genetic test results that are place in MyChart. Which topics do you think would help people better understand genetic test results? (Mark all that apply.)

☐ Definition of a gene  ☐ What the gene(s) listed in the test result do  ☐ Why the test was done
☐ What the test was looking for  ☐ Accuracy of the test  ☐ What the result means for my child
☐ What I need to do with the result  ☐ How to talk to my child’s doctor about the test
☐ What this test means for other family members  ☐ I don’t think additional information is needed

39. How would you want to receive information to supplement genetic test results? (Mark all that apply.)

☐ Links to written information so I can choose just the topics I want to learn about
☐ Written information mailed to my home  ☐ YouTube videos  ☐ Speak with my child’s doctor
☐ Audio description I can link to on my computer, phone, or MP3 player
☐ I would not want any extra information
☐ Other: ________________________________________________________________

Thank you for taking the survey.
Your opinions will help us improve the way we let people know about their genetic test results.
To email or fax this survey instead of mailing use: Meghann.Reardon@cchmc.org or fax: 513-636-0543