Patient and Family Perceptions of Pharmacogenomic Testing at St. Jude Children’s Research Hospital

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Background

- PG4KDS is an IRB-approved protocol that enrolls patients at St. Jude Children’s Research Hospital (St. Jude).1 www.stjude.org/pg4kds
- Each participant is pre-emptively genotyped for variations in genes that are known to affect drug therapy.1
- Results for 14 pharmacogenes are placed in the patient’s electronic health record (EHR) and uploaded to the patient portal along with an explanation of the patient’s phenotype and its implications for pharmacotherapy.1
- To date, nearly 7,000 patients have been enrolled in PG4KDS. Age of participants ranges from 1 month to 51 years (median 8 years of age).2
- 95% of patients have at least one high-risk result in their health record.2

Objective

Describe the perceptions of patients and/or legal guardians regarding pharmacogenomic testing provided at St. Jude.

Methods

- A survey was distributed via email to 523 families of patients actively enrolled on PG4KDS who had agreed to be contacted for participation in surveys through St. Jude.
- 128 individuals (24%) completed the survey. All responses were submitted by caregivers of minors.

Results

- Have you received your child’s pharmacogenomic test results?

- Did you understand the pharmacogenomic results when you read them on your own?

- Has your child needed a modification in therapy based on their pharmacogenomic test results?

- Have you shared your child’s pharmacogenomic test results with their non-St. Jude physicians?

Results cont.

- Guardian reported receipt of pharmacogenomic test results.

- Guardian reported understanding of pharmacogenomic test results.

- Guardian awareness of modifications made to patient’s pharmacotherapy based on test results.

- Guardian reported communication of results to physicians external to St. Jude.

Table 2. Demographics of survey respondents.

<table>
<thead>
<tr>
<th>Respondent Relationship to Patient</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td>117 (92%)</td>
</tr>
<tr>
<td>Father</td>
<td>9 (7%)</td>
</tr>
<tr>
<td>Grandmother</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Race</td>
<td>N (%)</td>
</tr>
<tr>
<td>White</td>
<td>112 (88%)</td>
</tr>
<tr>
<td>African American</td>
<td>7 (5%)</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>4 (3%)</td>
</tr>
<tr>
<td>Native American</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Not Reported</td>
<td>4 (3%)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>N (%)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>8 (6%)</td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>120 (94%)</td>
</tr>
</tbody>
</table>

Conclusions

- Guardians report an understanding of pharmacogenomic test results based on education provided during the consent process.
- Survey results indicate that caregivers may not be aware of most/all adjustments made to their child’s therapy based on pharmacogenomic test results.
- A majority of guardians reported that they have not disseminated results to non-St. Jude physicians.
- A process is being developed at St. Jude for a pharmacist to return pharmacogenomic results to non-St. Jude physicians.
- Improving patient and family knowledge of how pharmacogenomic test results are utilized may encourage continued use of these lifelong test results.

References