Challenges Related to Family Involvement in Clinical Whole-Genome Sequencing: Views of Non-Genetics Providers

Leila Jamal, ScM, PhD, CGC
For The MedSeq Project
Family Communication Matters
Communicating Genetic Information to Patients’ Families

• New issue for non-genetics providers
• Guidelines
  – Discourage providers from contacting relatives directly
  – Encourage providers to help patients to transmit risk information to relatives
  – Little clarity about how
  – Differ for research and clinical spheres

Dheensa et al. 2016 Genetics in Medicine; Wolf et al. JLME 2015
Physician reviews family history information and discloses results from Genome Report

Patient’s electronic medical record

Medical Record Review

Physician & patient outcomes
### Patient and Physician Demographics

<table>
<thead>
<tr>
<th>Characteristic (%) unless noted</th>
<th>Patients (n = 205)</th>
<th>Physicians (n = 20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (sd)</td>
<td>55.2 (11.4)</td>
<td>51.7 (10.0)</td>
</tr>
<tr>
<td>Age range</td>
<td>19 – 85</td>
<td>32 – 65</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>104 (51%)</td>
<td>8 (40%)</td>
</tr>
<tr>
<td>Male</td>
<td>101 (49%)</td>
<td>12 (60%)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic white</td>
<td>177 (86%)</td>
<td>15 (75%)</td>
</tr>
<tr>
<td>Other/No response</td>
<td>28 (14%)</td>
<td>5 (25%)</td>
</tr>
<tr>
<td>Annual Household Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$100,000</td>
<td>71 (35%)</td>
<td>-</td>
</tr>
<tr>
<td>≥$100,000</td>
<td>125 (61%)</td>
<td>-</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did not graduate from college</td>
<td>38 (19%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>College graduate or higher</td>
<td>166 (81%)</td>
<td>100 (100%)</td>
</tr>
</tbody>
</table>
“The most important thing about this was to prevent something, my children’s future... that was what I was concerned about more, that this study might prevent something from happening to them.” (186-P05)
<table>
<thead>
<tr>
<th>Information Sharing</th>
<th>PD surveys</th>
<th>6 month</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Control (n=87)</td>
<td>WGS (n = 97)</td>
</tr>
<tr>
<td><strong>My spouse or partner</strong></td>
<td>Yes</td>
<td>75%</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>11%</td>
</tr>
<tr>
<td><strong>If yes, what type of information?</strong></td>
<td>General information and/or feelings about my info</td>
<td>94%</td>
</tr>
<tr>
<td></td>
<td>My risk and/or my relative’s risk of having a condition</td>
<td>40%</td>
</tr>
<tr>
<td></td>
<td>Possibility of employment or insurance discrimination</td>
<td>2%</td>
</tr>
<tr>
<td></td>
<td>Preventative surgery and/or screening recommendations</td>
<td>18%</td>
</tr>
<tr>
<td><strong>My child(ren)</strong></td>
<td>Yes</td>
<td>52%</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>25%</td>
</tr>
<tr>
<td><strong>If yes, what type of information?</strong></td>
<td>General information and/or feelings about my info</td>
<td>87%</td>
</tr>
<tr>
<td></td>
<td>My risk and/or my relative’s risk of having a condition</td>
<td>40%</td>
</tr>
<tr>
<td></td>
<td>Possibility of employment or insurance discrimination</td>
<td>2%</td>
</tr>
<tr>
<td></td>
<td>Preventative surgery and/or screening recommendations</td>
<td>31%</td>
</tr>
<tr>
<td><strong>Siblings</strong></td>
<td>Yes</td>
<td>54%</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>28%</td>
</tr>
<tr>
<td><strong>If yes, what type of information?</strong></td>
<td>General information and/or feelings about my info</td>
<td>91%</td>
</tr>
<tr>
<td></td>
<td>My risk and/or my relative’s risk of having a condition</td>
<td>51%</td>
</tr>
<tr>
<td></td>
<td>Possibility of employment or insurance discrimination</td>
<td>0%</td>
</tr>
<tr>
<td></td>
<td>Preventative surgery and/or screening recommendations</td>
<td>36%</td>
</tr>
</tbody>
</table>

**Bold** indicates majority response. **Green** indicates notable increase in WGS compared to Control.
Familial risk assessment was an unexpected issue

“I hadn’t been thinking about when I need to worry about somebody having an autosomal recessive trait. What about the rest of their family? I mean, it wasn’t even on my radar.” - P01
MDs viewed family communication as patient responsibility

“It’s the equivalent of knowing your patient is using drugs, and you’d like to tell their spouse. You can’t, unless they’re going to hurt somebody. There’s going to be very strict guidelines for how this information can be released to relatives...we just don’t do things that way. It would be nice if we could, but we can’t.” –P10
MDs viewed family communication as patient responsibility

“It's hard to know where that line is...if it's some life-threatening situation, or a condition where early intervention makes a difference, it's hard for the physician not to be able to directly approach family members. But right now, there's no avenue for that.” -C02
Special circumstances might make it ok to contact family members

“In the event of death where there was no prior knowledge of the person's wishes, I think that would be a very different scenario. For something that had ramifications that we could be certain had a high probability of happening, I would reach out first to the person's spouse...” –C06
MDs expressed a need for tools

“I think it would be helpful to have something in print for giving to family members. It's a very weird situation because you are kind of getting involved in the care of people you have never laid eyes on, and never will.“ – P14

“I think there must be ways you can share risk without necessarily sharing specific genetic information about an individual” – C08
Approaches to sharing genetic info with relatives

- Group information sessions with voluntary patient follow up
- Telephone counseling/Telemedicine
- Prospective consent to contact relatives obtained from index patient

"Empowering Families With Hereditary Cancers Through Communication and Education"

Kintalk can help you understand Hereditary Colon Cancer

www.kintalk.org (UCSF)
Summary

• Family involvement in WGS may be a novel challenge for non-genetics providers

• Important throughout the process, but our MDs focused most on sharing results

• Different approaches for different result types?
The MedSeq Project Collaborators

Project Leadership
Robert Green, MD, MPH
Zak Kohane, MD, PhD
Calum MacRae, MD, PhD
Amy McGuire, JD, PhD
Michael Murray, MD
Heidi Rehm, PhD
Christine Seidman, MD
Jason Vassy, MD, MPH, SM

Project Manager
Carrie Blout, MS

Project Personnel
Sandy Aronson, ALM, MA
Danielle Azzariti, MS
David Bates, MD
Jennifer Blumenthal-Barby, PhD
Ozge Ceyhan-Birsoy, PhD
Alexis Carere, MA, MS, PhD
Kurt Christensen, MPH, PhD
Allison Cirino, MS
Lauren Conner
Kelly Davis, PhD

Project Personnel (Cont.)
Dmitry Dukhovny, MD, MPH
Lindsay Feuerman
Margaret Helm, MS
Carolyn Ho, MD
Lily Hoffman-Andrews
Peter Kraft, PhD
Joel Krier, MD
Sek Won Kong, MD
William Lane, MD, PhD
Matt Lebo, PhD
Lisa Lehmann, MD, PhD, MSc
In-Hee Lee, PhD
Kaitlyn Lee
Kalotina Machini, PhD, MS
David Margulies, MD
Heather McLaughlin, PhD
Jill Robinson, MA
Melody Slashinski, MPH, PhD
Shamil Sunyaev, PhD
Ellen Tsai, PhD
Peter Ubel, MD
Rebecca Walsh
Scott Weiss, MD

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Maren Scheuner, MD, MPH
Sue Siegel, MS
Sharon Terry, MA

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George Church, PhD
Geoffrey Ginsburg, MD, PhD
Tina Hambuch, PhD
David Miller, MD, PhD
J. Scott Roberts, PhD
David Veenstra, PharmD, PhD

Protocol Monitoring Committee
Judy Garber, MD, MPH
Cynthia Morton, PhD