Familial Implications of Returning Genome Results

eMERGE III Subgroup
ROR/ELSI
Outcomes
Specific Aim 1:

• Explore attitudes of participants by convening focus groups and/or qualitative interviews.

• Participant perceptions of:
  
  • importance of sharing information
  • importance of targeted education for family members
  • barriers to effective communication with family
  • preferences/suggestions for methods or strategies to contact relatives
Specific Aim 2:

- Conduct surveys, standardized for many components, across sites to assess family sharing/communication activities.
  - Some sites doing baseline pre-results disclosure survey
  - All sites will include small number of consistent items in a post-results survey.
  - Some sites will survey immediately after return of results
  - Some sites will utilize a more in-depth survey to supplement the items asked in the general survey.
Specific Aim 3:

• Collect and collate points to inform system-level guidance for policy making or best practice development pertaining to family communication of positive variants in actionable genes.

• Collect site specific activities currently planned to promote family communication
• Assess factors that lead to variation in methods of communications including materials, approaches and measures of success
• Test various methods of contact
Geisinger patient experience interviews

**DOMAINS**

- Initial experience with result
- Medical follow-up
- Communication with family and friends
- Understanding of the results and resource seeking
- ROR procedures
- Psychosocial reactions to result
- Financial implications of result
- Satisfaction with participation in MyCode
Common themes (very preliminary!)

• All participants shared with some family members
• There were some family members that participants chose NOT to share with
  • Family members too old
  • Family members too young
  • Family member discord
  • Family members would not be interested
• Most used letter provided by ROR team, but some called to tell by phone or in person
• Thought result applied only to women (BRCA)
Site Specific Survey DOMAINS

• Intent to share with family members
• Family Communication
  • Conflict
  • Satisfaction
• Empowerment
• Information Sharing
• Language/Literacy
• Utilization
• Life/Health Insurance Issues
HIPAA, Privacy and ROR Familial Communication

• Group Health initiated conversation with legal counsel re: return of results to family members who receive care within healthcare system

• Hope to convene a group to more broadly address these issues
  • S. Malia Fullerton/Nora Henrikson
  • Robyn Fossey
  • Jen Wagner
  • Bob Wildrin (not confirmed)

Group Health
Mayo
Geisinger
NIH
Outcomes survey: Proband

- For each participant after an actionable variant has been returned:

1. Mother Alive/Available Y/N Shared Y/N
2. Father Alive/Available Y/N Shared Y/N
3. Sisters # Alive _____ # Available for contact
   a) Sister 1 shared result Y/N
   b) Sister 2 shared result Y/N
   c) Sister 3 shared result Y/N
4. Brothers # Alive_____ # Available for contact
   a) Brother 1 shared result Y/N
5. Children #Alive____ # Available for contact
   a) Child 1
Outcomes System related

2. If possible estimate how many of the relatives are cared for within your healthcare system

3. Number of at-risk relatives seen and counseled as a result of the return of results for this proband
   • By 6 months
   • By 12 months

4. Provide the number of familial mutation tests sent related to this proband
   • # relatives per proband with positive mutation high utilization
   • # relatives per proband with negative mutation usual care

5. Reach of cascade screening
   • 1st degree relatives  #Alive  #Informed  #Tested
   • 2nd degree relatives  #Alive  #Informed  #Tested
   • 3rd degree relatives  #Alive  #Informed  #Tested