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Personalized Medicine
April 23, 2013

The ACMG released this recommendation stating that *all* clinical exome and whole-genome sequencing tests that turn up incidental findings on a short-list of almost 60 potential risk factors should be, without question, delivered to the patient regardless of age or their desire to learn about such risks.

(1) The ACMG recommendation disregards contemporary ethical standards and asserts itself as a forecaster and remodeler of society's expectation of ethical treatment from the medical community.

- a. It does this primarily by casting aside the patient's right "not to know" at the expense of their ability to be properly tested and diagnosed for their target condition
 - i. Most easily illustrated by the following quote: the working group "did not favor offering the patient a preference *while recognizing that this breaks with existing ethical norms*"
 - ii. They claim it becomes a fiduciary responsibility of the clinician and laboratory, even though these are not necessarily actionable items
- b. The recommendation suggests that patients have the right to avoid incidental findings by also avoiding genomic sequencing for whatever they actually needed it for: "*Patients have the right to decline clinical sequencing if they judge the risks of possible discovery of incidental findings to outweigh the benefits of testing.*"
- c. It also does this with disregard to the age of the patient; even though pre-testing for adult onset disorders is currently considered inappropriate
 - i. As, "To mask or withhold an incidental finding supersedes the parents' opportunity to discovery a life threatening risk" – yet these aren't curable diseases, the parents can't necessarily benefit from the knowledge
- d. It does this brazenly and not without consideration for the fact that there are not completely tangible benefits to patients; most of the "medical value" is prophylactic surgery or intensive medical surveillance, which raises the possibility of iatrogenic harm due to unnecessary medical surveillance or invasion.

(2) The ACMG recommendation is structured with good intentions, but its hardline on disclosing incidental findings is self-admittedly flawed.

- a. The recommendation seeks to only require the reporting of incidental findings when they are of "medical value for patient care" – a layman's interpretation of this would mean information that is actionable and preventative or prophylactic; amongst the 57 genes that are to be tested for under the ACMG recommendation, a number of them are strong dispositions for cancers that develop late in life.
- b. This knowledge, however, would ultimately creates a system that primarily offers psychological burden rather than true "medical value," which is highlighted by the ACMG as they themselves note that there is "insufficient data on clinical utility to fully support this recommendation" – having a positive genetic test is not equal to developing the disease, nor can it entirely predict severity and onset

- c. On the other hand, opponents of the recommendation are not opposed to offering incidental findings, just their mandated disclosure: “The fact that I support offering them [incidental findings] does not mean I support inflicting them.” – *Susan Wolf, U. Minnesota Law Professor*
 - d. Ultimately dismiss the inconveniences that would make the handling of incidental findings fall in line with contemporary practices by trying to avoid impractical stresses on laboratories.
- (3) The ACMG recommendation sets forth the expectation that physicians are experts in genetic counseling, can properly contextualize the results of all 57 variants with relation to personal history, family history, and can properly debrief patients before and after genomic sequencing.**
- a. They even note that getting clinicians to uniformly inform patients regarding the risks of these 57 genes would be inconsistent – why would they be magically more efficient at the much more daunting task of being genetic experts on 57 different diseases.
 - b. Why do they not discuss that the majority of currently trained physicians are exceptionally removed from the genomic revolution (hence the purpose of this class!)
 - c. At the same time, they offer no attempt at standardizing the reporting on these recommended variants between laboratories, and explicitly take time to mention how we should avoid “over-burdening laboratories” because asking them to “tailor results regarding adult-onset disorders” would simply be impossible (though technically I can’t imagine how).

Closing Remarks

It would seem prudent to maintain the (1) current role of genetic counselors in maintaining patient’s right “not to know” while (2) reporting incidental findings by default when they are truly actionable. It would seem wise to move forward with devising a strategy to (3) standardize genomic reporting between various laboratories and (4) properly educate any patient-facing persons about the complexities of genetic risk factors and potential treatments and preventative care. I also think it is important to (5) limit the exposure of children to the psychological burden such findings could inflict, especially when the finding would only serve to warn a child of adult onset disorders.