Clinical Sequence Evidence-Generating Research Consortium

**Site Staff/EHR Extraction (5 -7 months post-RoR) or PROV ROR-FU2**

Proposed by: CSER CUHEP WG

Version 1.2, Dated 5/2/18

## Follow Through on Medical Actions Attributable to Genomic Testing

**Study personnel survey/EHR data abstraction for patients with primary finding(s): Administer 5-7 months post-ROR**

*Operational details: 1) The study staff extract data (from additional site-specific questionnaires or medical records) about whether actions were taken so that the providers not be surveyed twice. 2) This 5-7 month extraction should be done whether or not the provider completes the post ROR survey (we cannot assume 100% compliance) to determine if actions were recommended in the chart and taken. 3) Some groups may be administering baseline provider surveys for each patient but that is unique to each study and not described further here. 4) The same set of questions would be asked of the provider depending on whether the patient had a positive diagnostic finding or a positive secondary finding. The survey would designate for which type of finding the provider is answering.*

**If provider answered the survey:**

1. ***Are the provider recommendations documented in the electronic health record (please respond for each recommendation)?***
2. What is the data source for information about healthcare action(s) the patient received (E.g, medical record, study data collection, patient questionnaire)

***3. Did the patient receive any of the recommended healthcare action(s) related to the primary findings(s) (please respond for each recommendation)?***

1. ***a. If the patient was not yet eligible to receive the recommended action because of age or timing, please note.***

**If provider does not answer the survey:**

1. What healthcare action(s) (e.g., screening, procedures, drugs, referrals) were recommended to the patient found in the chart related to the primary or secondary findings(s)?
2. Did the patient receive any of the recommended healthcare action(s) related to the primary findings(s) (please respond for each recommendation)?
   1. If the patient was not yet eligible to receive the recommended action because of age or timing, please note.
3. What is the data source for information about healthcare action(s) the patient received (E.g, medical record, study data collection, patient questionnaire)

**For secondary finding(SF) survey:**

1. ***Are the provider recommendations documented in the electronic health record (please respond for each recommendation)?***
2. What is the data source for information about healthcare action(s) the patient received (E.g, medical record, study data collection, patient questionnaire)

***3. Did the patient receive any of the recommended healthcare action(s) related to the secondary findings(s) (please respond for each recommendation)?***

1. ***a. If the patient was not yet eligible to receive the recommended action because of age or timing, please note.***

**If provider doesn’t answer the survey:**

1. What healthcare action(s) (e.g., screening, procedures, drugs, referrals) were recommended to the patient found in the chart related to the secondary findings(s)?
2. Did the patient receive any of the recommended healthcare action(s) related to the secondary findings(s) (please respond for each recommendation)?
   1. If the patient was not yet eligible to receive the recommended action because of age or timing, please note.
3. What is the data source for information about healthcare action(s) the patient received (E.g, medical record, study data collection, patient questionnaire

**For proband participants with a primary or SF:**

1. Was there any attempt at re-phenotyping (additional tests or referrals beyond what was initially ordered by the disclosing provider or specialist) recommended by the study team related to the primary or secondary finding? If so, what was found?

## Cost of follow-up actions (beyond ROR)

**For participants with a positive SF finding:**

**Cost of follow-up actions (beyond ROR)**

1. Was there an attempt by the study team to collect additional family history related to the SF to evaluate **additional** family members beyond what was initially recommended by the provider?
   1. If yes, what family members were evaluated and what was found?