

Pennsylvania Cancer Coalition
Cancer Genetics/Genomics Workgroup
1/9/2023 Meeting Agenda

1. Introductions

- a. Alanna Kulchak Rahm, Victoria Wittner, Julia Verbiar, April Barry, Phuong Mai, Marge Wasko, Margaret O’Grady, Hong Truong, Randall Oyer, Elizabeth Dailey

2. Discussion of Provider Survey

- a. The workgroup previously provided feedback about suitability for non-clinical providers. Edits based on this feedback to make the survey more appropriate for non clinical providers was reviewed.
- b. Dissemination plan
 - i. How to track? Makes sense to track when we send it out and to whom from our group.
 - ii. Is there a way to make sure that it doesn’t get sent out to the same group multiple times
 - iii. Should we ask people to not forward?
 - 1. Yes.
 - 2. Instead, invite participants to email us if you have an organization that you would like to send it to.
 - iv. April has an excel spreadsheet to track who it was sent to, email address, who sent, etc.
 - v. Maybe make an announcement at the big meeting for other additions – Yes
- c. How long do we want to leave it open for?
 - i. Reminder emails to those on the list
 - ii. 2 months – keep it open
 - 1. Can be kept open longer based on response rates.
- d. Different links for each of the different organizations? Could be helpful for publication.
 - i. Yes, this should be technologically feasible without compromising anonymity.

3. Patient toolkit

- a. Previous version of patient toolkit distributed to group (Lynch syndrome only)
 - i. Link to provider toolkit:
<https://www.pacancercoalition.org/images/pdf/geneticsgenomics/PCC-Cancer-Control-Genetics-Genomics-Toolkit.pdf>
- b. How to move forward on work from here?
- c. Should the new toolkit be more broad or syndrome specific? Should be more general – when a patient should access a genetics professional, why and how
 - i. People might be worried about something going on but not knowing what syndrome they have. Should provide general advice to get help.
 - ii. And if you have something, here are some of the places you can go for care.

- d. What questions should people ask their oncologist?
 - i. When you might have testing for hereditary cancer – did your doctor ask you about it – organize it in a timely fashion
 - e. What would people ask their family members?
 - i. Family History?
 - f. Broad would also help to keep it updated
 - g. Vivian Duong and Victoria Wittner
 - i. Hong Truong – help with prostate cancer on the toolkit
4. Additional Workgroup Projects
- a. Working with the policy committee: did not hear back from any members interested in this meeting, so we will move forward in setting this up with co-chairs
 - i. Peg O’Grady - Policy
5. Open Discussion