Pennsylvania Cancer Coalition

Cancer Genetics/Genomics Workgroup

8/14/2023 Meeting Agenda

1. Welcome and Introductions

2. Discussion of Patient Toolkit Progress and Edits
    - Phuong sent her edits a few days ago – Vivian still needs to review them
    - Andrea and Alanna added their edits separately on Phuong's version – two different versions now, Vivian will work to resolve them after the meeting
    - Vivian presented new biomarker testing section of patient toolkit
        - Feedback on biomarker testing section:
            - Add an example of a biomarker for cancer
            - Add some information about how biomarker testing can be used for cancer detection (not just cancer treatment), both for occurrence and recurrence of cancer
            - When distinguishing biomarker testing from genetic testing, add some information about how biomarker testing can only indicate cancer and not if the cancer is familial/hereditary or not
            - Add reference to biomarker testing in Lynch Syndrome section of patient toolkit
            - Remove the statement about talking to your doctor about biomarker testing to see if this may be beneficial – biomarker testing is generally not something that needs to be asked of your doctor during cancer treatment
    - Other feedback on patient toolkit:
        - Add section about paying for health services for cancer – waiting on resources from Peg
        - Simplify the information on what is cancer – too wordy
        - Review language around the term "family cancer" – this is not a term that most healthcare providers would use when talking about familial or hereditary cancers, so may need to consider revising this
        - Instead of having information about genetics, inheritance, etc. under the what is family cancer section, maybe need to create a separate section or provide resources and pictures with this information – there is a lot of information in this section
        - Do research and add resources for finding genetics clinics for specific cancer syndromes, such as Lynch Syndrome clinics, high risk breast cancer clinics, etc. – this would probably go under genetic counseling or may make a separate section for connecting to genetic counselors/genetics clinics

- Andrea suggested maybe we divide up sections so each workgroup member can focus on reviewing that section rather than the entire patient toolkit – this might be something we do after Vivian reviews and makes edits after this meeting

3. Discussion of Needs Assessment Survey – ideas for dissemination
    - First attempt at survey dissemination earlier this year only yielded 35 responses, mostly from genetic counselors
    - Alanna asked to see report that Victoria created on survey results, Victoria's presentation of the survey results was a few months ago so she doesn't remember them
    - Andrea has a running spreadsheet of people/organizations that she and Victoria reached out to for survey participation
    - Need to think of new ideas for dissemination, if we want to make a second attempt
    - Survey is open to all cancer and/or genetics providers and even family practitioners, so we may want to make a second attempt so that we can get more diverse responses

4. Announcements

    a. PCC Annual Meeting 9/14/23 (Remote)
    b. Update your membership profile: https://www.pacancercoalition.org/about-us/join-us/membership-profile

5. Open Discussion