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Meeting Minutes of:
ILLINOIS DEPARTMENT OF PUBLIC HEALTH
Special Commission on Gynecological Cancers
Subcommittee Diagnosis, Treatment and Survivorship
Meeting 4

April 24, 2024
 11:30 a.m. until 12:30 p.m.

Attendees

Members in Attendance	Guests and IDPH
Nita Lee – Chair (late) Emma Barber – Chair Patricia Walter Cherie Taylor Brittani Savage	Sarah O’Connor – Host – IDPH Matthew Grande- Guest Kimberly Richardson - Guest
	Members Not in Attendance
	Amina Ahmed Kandis Draw Daniela Matei

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Call to Order

Meeting called to order at by Sarah O'Connor at 11:35 AM. Motion called by Cherie Taylor and seconded by Kim Jay.

Welcome

Approval of Minutes: Motion brought by Emma Barber and seconded by Cherie Taylor.

Review of Action Items

- Jumped straight into the next item on the agenda.

Review Rubric for Gap Analysis

- Dr. Barber decided to wait to circle back to the gap analysis when Dr. Lee joined as she did not have a screen that she could share at the time.
- Dr. Barber wanted the group to think about their portion of the report and what they are wanting to include, such as survivor and patient advocate stories, in addition to making points about the gaps within the state. Bringing up the listening sessions that had previously been discussed, asking for any updates and looking for ways to start setting up these listening sessions.
 - Dr. Barber asked Kimberly Richardson if she had any thoughts on how the group could align with the efforts for the listening sessions, but she was traveling so was unable to chime in, this item was tabled with the intention to ask at the full commission meeting the following day.
- Dr. Lee joined a little late so the group was able to circle back to the gap analysis at that time. Dr. Lee realized that she had intended to send out the gap analysis chart for individuals to review and fill in but did not so she apologized for that, and indicated that she would get that out to the group soon.
- Dr. Lee posed the question of whether the group wanted to frame the listening sessions around the identified gap categories in order to gather evidence in that way, perhaps to pass those topics to Matthew who is organizing the session so that they are included. Dr. Barber agreed that that would be a good idea so that the group can share the patient perspective on these specific topics, the group is looking for the most effective way to tell the story.
 - Matthew was able to chime in that although the listening sessions are still in the preliminary brainstorming stage, that it would be great to hear from the sub-committees to know what would be helpful for them to know as they are planning the questions that will be asked.

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- Dr. Lee thought it would be important to go over part of the rubric so that they can highlight some of the key areas for Matthew to include in the listening sessions.
- Dr. Lee mentioned that maybe the group should even add more themes to the chart, bringing up things such as barriers to care so that the group might be able to get different insights depending on the participants of the listening sessions.
- Dr. Lee poses the question of whether the listening sessions would be better if they were structured to follow the cancer continuum, or if it was structured more as a focus group. Discussion regarding this was as follows:
 - Dr. Barber indicated that her initial instinct would be to have it structured as a focus group with some questions from each sub-committee. Specifying for this group that could look like questioning survivors what barriers they faced in terms of diagnosis. Trying to identify gaps in getting to a diagnosis.
 - Dr. Lee also brought up the potential question of what might have helped individuals get to care sooner.
 - Dr. Barber additionally asked if they should also prepare follow up questions, for instance to identify where the barriers were using the examples of provider education, patient side of care, monetary reasons, distance to travel etc. indicating that the group could potentially use these to probe for additional information.
 - Dr. Lee added further that individuals should be asked of the barriers identified which were most impactful, and if they have any ideas of how this could/should be addressed.
 - Dr. Lee asked if any other individuals had any ideas of questions could be recommended to be asked during the listening sessions.
 - Kim Jay brought up the question “Who was your support system?” looking at this not only in the midst of getting a diagnosis but also during treatment and through survivorship.
 - Later in the discussion it was added to this point that it might also be beneficial to ask about caregivers.
 - Cherie posed the question “Where did you receive your education or awareness about your disease?”
 - Patricia also proposed asking if individuals had support or a contact person within their medical team.
 - Cherie talked about her experience of not knowing about her BRCA mutation, thinking that the group could potentially ask about genetic counseling and follow up education.
 - Dr. Barber brought up the idea that the group could ask individuals “Looking back what do you wish you would have known?” trying to identify gaps in knowledge. Giving the example of genetic testing and symptoms/signs.
 - Dr. Lee brought up the point that she hears patients say that they reported signs and symptoms, but they didn’t feel as though they were listened to, thinking that this could maybe also fall under the barriers to diagnosis section.

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- Dr. Lee brought up on the treatment side, whether individuals were provided information about choices for treatment.
 - Kim Jay added to this saying that she sees gaps in patients receiving details on the pathways that they can take. Bringing up the question of whether patients were able to get a second opinion or if their treatment plan was the only information that they received, as well as what their options were afterwards. Dr. Lee questioned whether she meant after diagnosis or after remission, Kim indicated that she felt this question could fall into both categories.
 - Cherie brought up that there should be a question on whether patients received information on clinical trials.
 - Dr. Lee added that questions about quality measures might be beneficial to ask as well. As well as indicating that she feels Kim brought up a good point with survivorship care plans but doesn't know how detailed they should get. Kim Jay said that she thinks it is very relevant because these are things that are often missing.
 - Dr. Lee brought up the question of if goals of different types of treatment were discussed.
 - Kimberly Richardson brought up the question of whether individuals participated in a comprehensive care team discussion after diagnosis but before treatment.
 - Kim Jay thought it would be important to understand if financial coverage was a barrier to treatment, Dr. Lee agrees that financial toxicity during and after treatment is important to understand.
 - Kim shared that she met with someone the previous week, who's daughter was diagnosed and while they were offered a great treatment option, but just couldn't afford it. So asking the question of whether the treatments offered to the patient were things within their means that they were able to take advantage of.
 - Dr. Lee brought up that it might be beneficial to meet with someone in financial navigation to help see what their options might be. Saying that the affect on finances is something that doesn't get talked about often, thinking that this could maybe be added into care navigation.
 - Dr. Lee also brought up social determinants of health screening tools that are becoming more common but that some individuals don't want them to be entered into their electronic records due to fear of bias or potentially having

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these determinants affect the choices they are offered. Kim Jay agreed that this is something that she has seen as a Community Health Worker but that she encourages individuals to try to be as honest as possible so that she is able to help them as much as she can.

- Cherie brought up the mental health portion of all parts of diagnosis, treatment, and survivorship. Thinking that a question about this type of support might be beneficial to ask. Brittani built off this emphasizing the importance of community in all aspects.
- Kim Jay brainstormed a sort of action plan might be helpful in order for individuals to know where to go for information or support, or what actions to take in different circumstances.
- Dr. Lee thinks that it will be important to think more and try to streamline the questions that they will ultimately provide to Matthew.
 - Matthew stated that he thought that these questions were a great start indicating that he will ask the other sub-committees to come up with questions, theorizing that some of the questions might overlap or intertwine.
- Dr. Lee started to discuss whether the group wants to write a draft of the report first and then add the results from the listening sessions in or base report on the listening sessions.
 - Sarah brought up that another sub-committee is hopeful to have their portion of the report completed in the next couple months and thought that maybe it could be helpful to use as a sort of guide for formatting.

Create List of Other Providers and Survivors to Engage

- Dr. Lee indicated that she is meeting with one of the previously identified rural providers, so she will discuss with her to see if she is interested in presenting to the group. Dr. Lee is additionally going to reach out to Dr. Cheng to see if she would be interested in presenting as well.
- It was discussed whether these individuals would be better to present at the sub-committee or full commission level, it was ultimately decided that it might be better at the sub-committee in consideration of time but that all members would be invited to join if they were available.
 - These individuals will be able to provide vital information from the rural perspective.

Diagnosis, Treatment and Survivorship agenda items

- This section is ongoing so there was no new business to discuss at this time, outside of what had already been discussed in previous agenda items.

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Action Items

- Discussed within other agenda items.

Public Comment- None

Adjournment

Motion to adjourn at 12:23 PM made by Nita Lee, seconded by Patricia Walter.