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Meeting Minutes of:
ILLINOIS DEPARTMENT OF PUBLIC HEALTH
Special Commission on Gynecological Cancers – Meeting 6

April 25, 2024
11:00 a.m. until 12:00 p.m.

Attendees

Members in Attendance		Guests and IDPH	
Kimberly Richardson Kandis Draw Matthew Pickett Shannon MacLaughlan-David Cherie Taylor Nita Lee Emma Longley-Barber Kayla Nixon-Marshall Brittani Savage Leah Hoeniges Patricia Walter Rep. Camille Lilly		Sarah O'Connor – Host – IDPH Carrie Allen – IDPH Jenn Ludwig – IDPH Lisa Masinter – IDPH Maura Quinlan – IDPH Julie Davis – IDPH Guests Tess Hasan Matthew Grande Elizabeth Campbell Angela McLemore Dr. Caryn Peterson	
		Members Not in Attendance	
		Linda Kasebier Kim Jay Amina Ahmed Daniela Matei Sen. Mattie Hunter	

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Call to Order

Meeting called to order at 11:02 am by Sarah O'Connor-Bennett. Motion brought by Kimberly Richardson and seconded by Shannon MacLaughlan.

Approval of Minutes:

Motion to approve minutes was brought by Nita Lee and was seconded by Kayla Nixon-Marshall.

Introductions & Welcome

Welcome given by Kimberly Richardson. Kimberly requested that each sub-committee stick to 5-6 minutes to leave ample time for the guest speaker.

Items Discussed:

Sub-Committee Reports

- Early Screening and Risk Reduction

- Dr. Nixon shared that Kim Jay and Matthew Grande have been able to create a first draft of their portion of the report. This was reviewed at the last meeting, and feedback was given to incorporate into the next draft.
- The draft started with a focus on screening, defining the cancers that are not able to be screened for. And then moves into looking at the role of community health workers, primarily in the way that they help bridge gaps.
- Dr. Nixon hopes that this could be a start that leads up to the content that the other sub-committees will be able to include and build upon.
- Wants to include survivor stories, as well as provider stories. Intend to create a survey for survivors to submit their written stories.
- Looking forward to the next draft and has the intention to disseminate this more broadly to the other subcommittees for additional edits.
- Kimberly thinks that including provider input will be great to give an additional perspective creating a well-rounded listening session. Thinking that it might be beneficial for legislators to understand things that impede work of providers.
- Dr. MacLaughlan wanted to mention Dr. Hunter Holt, who has conducted focus groups on cervical cancer prevention amongst providers. She feels that this connection would be beneficial to the group so that they are potentially able to use the data from these focus groups.
 - Requested that Matthew Grande remind her to make this introduction.

- Diagnosis, Treatment and Survivorship

- Dr. Lee began with information on the domains (diagnosis, treatment and survivorship) that

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- they want to make sure are covered. Including that she believes that it would be beneficial for sub-committees to help Matthew identify different themes that should be included in listening sessions so that all areas are covered.
- The group is still in discussions on what they feel will be the best way to integrate the personal stories into the report. Feeling that these are important, but the group would also like to ensure that they are also linking the report to action items.
 - Dr. Lee indicated that the sub-committee has begun conducting a gap analysis, acknowledging what exists within Illinois, and then identifying what is needed. The group has split this analysis into the three main domains that they are focused on.
 - Dr. Barber indicated that the gap analysis will serve as a framework as the group begins drafting their report.
 - The group is trying to decide whether testimonies from survivors and providers should stand alone or if they should be integrated throughout the report to drive home/highlight important points that the group is trying to make. Using the example that a gap in genetic testing might be paired with a story about a survivor who had family members who had cancer but did not receive testing to look for mutations. Believing that this could illustrate the desired response from legislators.
 - Dr. Nixon agreed that this is the conversation their sub is having as well, considering starting with these testimonies.
 - Kimberly wanted to know the extent that the group wants to go with listening sessions. Acknowledging that it is important to have a diverse group of survivors represented in these sessions. She then asked whether this would be live or virtual, especially concerned with how information will be coded.
 - Dr. Lee felt that in person listening sessions might generate more information, and while it might take time to code the qualitative data that it is possible.
 - Dr. MacLaughlan mentioned that Dr. Peterson (the guest speaker) has a lot of experience with data of this type so she might be a good person to ask for guidance.
 - Dr. MacLaughlan thinks that it would be beneficial to use what is heard in listening sessions to then inform the recommendations that the commission provides. Envisioning that some of the survivors might be able to present the document to the state assembly.

-Research and Policy Development

- Dr. MacLaughlan indicated that the group intends to do more work in May on the epidemiology data that has been promised to the commission, using this to open the report to inform about the current status of gynecological cancers and disparities that have been identified.
- The group spent time talking about a general action plan, as well as a symptom action plan coming from the patient/survivor perspective. Additionally, the group discussed care

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- navigation specifically as it relates to gaps or missed opportunities.
- Dr. MacLaughlan used the examples of missed opportunities in the emergency room, prevention/early diagnosis, and making sure a patient is able to see a gynecological oncologist for their surgery.
 - The sub-committee is going to lean on the other two groups in order to inform their policy recommendations, and requests to see their drafts to ensure that they are including this information in their section.
 - Dr. Nixon indicated that she would share their draft once their next draft is completed.

Guest Presentation by Dr. Caryn Peterson

- Dr. Peterson is a Research Assistant Professor in the division of Epidemiology and Biostatistics at UIC School of Public Health
- Kimberly has worked with her on an Ovarian Cancer project for over two years.
- This Ovarian Cancer project is looking at cancer disparities, Dr. Peterson mentions that ovarian cancer is the 5th most common cause of cancer death in U.S Women.
- There have been declines in mortality rates due to treatment advancements over the past few decades.
- Long standing disparities in ovarian cancer survival, particularly between Black and White patients
 - Five-year survival rate for white patients increased from 1975-2015 from 33% to 48%
 - Five-year survival rate for black patients has remained relatively unchanged, with a slight deduction from 44% to 41% during the same time period.
- Goal: Identify the underlying factors driving these differences in order to promote health equity and to ensure that advances in ovarian cancer diagnosis and treatment benefit all patients.
- Two Aims in the project being conducted, which is supported by the Chicago Cancer Health Equity Collaboration.
 - Aim 1-a Evaluate differences in survival outcomes between white and black ovarian cancer patients.
 - Aim 1-b Engage with and disseminate findings to Black ovarian cancer patients in order to receive bi-directional feedback regarding their experiences with their treatment.
- Aim 1-b Established Patient Advisory Panel with 5 ovarian cancer survivors who had been out of treatment for at least six months to better understand experiences.
- Findings of this group:
 - Diagnosis delays – significant lag time between onset of symptoms and confirmed diagnosis. *Noted that all participants had employer-based insurance
 - Patients and primary care providers unaware of symptoms, which caused delays.
 - Poor handoff between gynecologist/primary care physician and the gynecological oncologist that provided treatment.
 - Minimal delays between diagnosis and treatment.
 - Lack of clarity with respect to treatment plans, especially in regard to the providers

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- sharing the details of the patient's treatment plan.
- Researchers/clinicians need to be mindful of the trauma that patients have undergone, keeping in mind that this is not just a statistic but is an actual person's experience.
- Aim 1-a uses national clinical oncology database, which uses 1500+ hospitals accredited by the Commission on Cancer, captures 70% of cancer cases in the U.S., data set does not include safety net hospitals, so data is somewhat limited.
 - Study populations was ovarian cancers diagnosed between 2005-2015, ended in 2015 because the study looked at 5-year survival rates.
 - Inclusion Criteria:
 - Black/African American or white.
 - Individuals had to have data on AJCC staging.
 - Belong to one of nine histological classifications (serous epithelial, endometrial epithelial, clear cell epithelial, mucinous epithelia, carcinosarcoma, other epithelial, germ cell, sex cord stromal, and other non-epithelial)
- Shared statistical findings.
 - Black patients diagnosed at younger ages, 61 vs 64.
 - Greater proportion of Black patients diagnosed at stage 4, 40.6% vs 32.4%.
 - Higher portion of Black patients reported comorbidities.
 - Higher portion of Black patients diagnosed with non-epithelial subtypes.
 - Higher portion of white patients diagnosed with endometroid and clear cell tumors.
- Findings of 5-year survival rates, 30% of black patients versus 37% of white patients, this trend persists when looking at epithelial and non-epithelial types.
- 5-year outcomes by histotype and race:
 - Endometrioid Epithelial; 10% Black patients, 14% White patients.
 - Clear Cell Epithelial; 4% Black patients, 7% White patients.
 - Other non-epithelial; 3% Black patients, 1% White patients.
- Looked further at both insurance and facility types, while it was not the case in every insurance/facility type, overall patterns of disparities persisted.
 - When looking at factors that pertain to treatment it is important to consider these disparities.
- The study then looked at the adherence to concordant care as a contributor to disparities.
- Dr. Peterson gave a shout out to Dr. MacLaughlan for helping with identifying what it means to take part in the ICCN, especially guideline adherent care.
 - Those who received guideline adherent care had better outcomes, although disparities are still seen between black and white patients.
 - Outcomes are much worse for those who received nonadherent care.
- Model to predict risk of mortality five years following diagnosis.
 - Model 1 adjusted for age, stage, grade, histology, area level income, insurance type, comorbidity score, and facility type.
 - Model 2- adjusted for the same as model 1 but included ICCN concordant care as well.
- Summary-
 - Racial Disparities in survival persist despite significant treatment advances.
 - Black patients are more likely to be diagnosed at advanced stages – atypical finding in

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- non-screen-detected cancers.
- Non-epithelial tumors are more common in black patients, yet research emphasis remains on epithelial histotypes.
- Factors impacting type of care matter; insurance, facility type, and access to gynecological oncologist.
- Acknowledgements paid to co-researchers, co-authors and especially the participants in patient panel.
- Questions:
 - Dr. MacLaughlan wanted to understand the hazard ratio of 1.13, she understood it as Black women having a 13% higher risk of death even with concordant care. Dr. Peterson clarified that there is a 13% higher risk of death when controlling for clinical characteristics and guideline care, however, she believes Dr. MacLaughlan might be referring to another chart that was comparing Black and White women survival rates when receiving concordant care, it is in this instance that indicated the Black women are still experiencing lower survival rates despite receiving concordant care.
 - Patricia asked about how BRCA 1 and mentioned that she has had cancer 4 separate times which is unfortunate but has allowed her to learn a lot. Patricia wondered how much genetic testing was incorporated in the research being conducted in this study. Mentioned that there is some legislation pending to increase genetic counseling.
 - Rep. Lilly offered information about the Illinois bill that she is working on to increase access to genetic testing. This bill number is HB4562. She also indicated its companion bill is SB2697 which is another genetic testing bill that has arrived in the house of representatives and will be moved for passage within the next 2-4weeks.
 - Dr. Peterson indicated that they had not included genetic testing as a question to the panel, but that this could be included in the next meeting. Dr. Peterson mentions that it was striking to her just how little these types of questions were posed to them as they were presenting with symptoms.
 - In other studies colleagues have run into the fact that people have trouble understanding their family history, might know about a cancer diagnosis but might not know what type or if they had genetic testing etc. Dr. Peterson feels like this shows just how important improvements in education is.
 - Kimberly talked about this information could play into the conversation with legislators on increase in research about rare cancers, as well as tracking individuals with rare cancers but were not BRCA positive. Indicates that findings from this research could lead to action items that are included in the commission's report. Believing that this could lead into more funding for additional research studies.
 - Dr. Nixon asked about the patients in the focus group mentioning that there was delay in diagnosis as well as a poor handoff from primary care physician to gynecological oncologists. Wondered if there was any work on-going to try to make this better?
 - Dr. Peterson discussed that a lot of her work includes data on access to care, talking further about how an individual in the focus group presented with symptoms and had them be misinterpreted which led to misdiagnosis. This individual then went to her gynecologist and saw the infographic on ovarian

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cancer symptoms, which matched her symptoms that had been brushed off. This indicates that further education should be provided to primary care providers to know what to look for when women are presenting with symptoms.

- Dr. Peterson indicated that there was also a delay in diagnosis when being referred to a gynecological oncologist which delayed treatment, as well as unclear communication on treatment plans.
 - This was something that was asked in the focus groups to see if individuals understood their treatment plan, finding that many did not.
- Kimberly wanted the group to think about the fact that if this is happening in the primary setting, to also consider what is going on with individuals who use the ER for health care. These providers don't necessarily get any sort of testing for their symptoms but are sent home with the recommendation to see their provider. This lack of addressing the symptoms the individuals are presenting with, even in the ER setting, can lead to late-stage diagnosis. Thinking that this is a perspective that the group should also consider.
 - Kimberly brings up that she is involved in updating curriculum for emergency room physicians, and there has been added language for acknowledgement of structural factors. Learning more about patient encounters as well as tracking how many times an individual has been seen through "EPIC". Looking at this to start considering that these patients might be experiencing a serious condition that might need more care. She expresses that she is really excited about this change in language in training materials.

Update on Commission Extension

- Kimberly mentions specifically to Representative Lilly that there is not an official extension to the commission and thinks that an official extension would provide more security for the commission to make sure that their work can continue, since it technically expired 12/2023.

Update on Vacancies

- Kimberly mentions a lack of responsiveness by representatives and hopes that Rep. Lilly might be able to speak to her comrades in order to secure these appointments. Mentioning that the group even has recommendations if that would help them move this forward.
- Sarah indicated that there were 7 vacant positions, 6 of them being for survivors.
- Kimberly speaks that she is hoping that the commission report will have a positive response and that there will be someone to champion the work that the commission has been doing over the last year and a half, mentioning to Representative Lilly some of the specific individuals that the group is waiting on appointments from.

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Questions & Closing Comments

- Dr. Quinlan mentioned that the state IBCCP program is now covering genetic testing for patients who need it based on their personal and family history. She spoke at a recent IBCCP lead agency meeting and she hopes that this adds access to genetic testing in a safety net setting.

Public Comment-

- -Angela McLemore had a question about why the National Cancer Database only has 70% of cancers, and why these reports don't include safety-net hospitals? Indicating that she is concerned because these hospitals are the main care centers that some Black women go to. How do we get more participation from these hospitals? And additionally asked about co-morbidities specifically with Black women.
 - Dr. MacLaughlan indicates that National Cancer Database does not include information on co-morbidities due to its complex nature, but there are other sources of research that do include this information. Hopes that the commission can look at structural racism and how it informs co-morbidities and disparities. A lot of work still needs to be done.
 - Dr. MacLaughlan indicates that National Cancer Database collects information from a tumor registry, but that often these safety hospitals don't use these registries so that could be one reason for this lack. Gap in data drives disparities.
 - Kimberly indicated that next month Matthew Pickett will hopefully be able to identify other sources of data that the group can look at to find information on these gaps. Looking on how cancer is billed to insurance, particularly with Medicaid. Attempting to identify how much has been paid out by Medicaid for specific gynecological cancers.

Adjournment

Shannon MacLaughlan-David made a motion to adjourn at 12:07 PM. Seconded by Leah Hoeniges.