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Meeting Minutes of:
ILLINOIS DEPARTMENT OF PUBLIC HEALTH
Special Commission on Gynecological Cancers
Subcommittee Research and Policy Development
Meeting 2

February 26, 2024
 1:00 p.m. until 2:00 p.m.

Attendees

Members in Attendance	Guests and IDPH
Shannon MacLaughlan-David - Chair Leah Hoeniges- Chair Patricia Walter	Sarah O'Connor – Host – IDPH Carrie Allen – IDPH Kaneesha Lewis – IDPH Tessneem Hasan Dr. Dario Roque Juan Avitia Cherie Taylor Kim Jay Nita Lee
	Members Not in Attendance
	Matthew Pickett

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Call to Order

Meeting called to order at 1:00 by Shannon MacLaughlan-David.

Welcome

Dr. McLaughlan-

Motion to Approve Minutes- Brought by Leah Hoeniges, seconded by Shannon MacLaughlan-David.

Special Guest Presentation

Dr. MacLaughlan- David provided a brief introduction for- Dr. Dario Roque (Associate Professor, Gynecologic Oncology Northwestern Medicine) who presented on: **Enhancing Minority Women Participation in Clinical Trials**

- Dr. Roque is working to make clinical trials more accessible to women throughout the state, but has started in the Chicago area.
- The first point made was to understand why this is an issue.
 - Don't know from trials if findings are generalizable to minority populations.
 - Understanding social needs and determinants in trial outcomes,
 - It is important to focus on building trust in medical research and institutions (understanding obstacles to receiving effective medical care)
 - The effect on public trust of the design and conduct of clinical trials this can impact the trials results and impact public health
- Shared information about racial disparity findings over time,
 - indicates that this gap has gotten wider over time, not incidence rates but access to care (informed by clinical trial enrollment)
- Highlighted disparities in clinical trial enrollment, breaking this down by race in tumor site and study type, Dr. Roque also displayed a chart with the publication years of the most recent studies
- Shared information about the most recent studies that have caused practice changes and treatment structure (noted that race is not always reported in these studies, especially in international studies)
- Potential Barriers identified-
 - Historical Factors (Tuskegee Syphilis study, and Henrieta Lacks) and related trust,
 - Socioeconomic Factors (transportation, inadequate or underinsurance, meeting trial requirements while balancing other demands)

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- Cultural Factors (Language barriers)
- Structural Factors (Restrictive eligibility criteria, trial often at large academic medical centers, Medicaid/insurance might be out of network of the medical center)
- Dr. Roque describes the work being done to increase inclusion:
 - Leadership engagement
 - Provider Engagement (very influential factor)
 - Community Engagement (Community Outreach, Lay Recruiters and Navigators)
 - Patient Engagement
 - Overcoming structural barriers
 - Help with identification of open clinical trials to patients and providers
 - Increase awareness and retention
- Dr. Roque has created a site called Empact Chicago, which serves as a trial finder and is for patients/providers use
 - This site is sponsored by Bears Care
 - Website: <https://empactchicago.com/>
- Goals for 2024-
 - Develop partnerships with local care facilities/universities to list open studies on site
 - Patient/Patient advocates focus groups in English and Spanish
 - Make trial finder tool available in other languages
 - Design changes to site to make it more user friendly
 - Creation of a mobile app

Questions:

Patricia asked- About if there was any information about race and genetic testing. Comments about knowledge levels.

Answer: All individuals who are diagnosed with ovarian cancer are referred to genetic counseling, all patients with endometrial cancer tested to look for a syndrome that could raise risk for other types of cancer. Raising awareness is so important and Dr. Roque is looking to expand the site in order to continue awareness and education efforts

Dr. MacLaughlan-David - brings up the potential change in trial requirements to plan for diversity, but notes that this is considered non-binding by NIH. However, FDA holds some studies/drugs more accountable. There was indication that this is a known issue and changes are being made to future trials to be aware about diversity (Dr. Roque highlights that there is a desire to close trials quickly, which might drive the decrease/lack in diversity), Dr. MacLaughlan indicates that she had a conversation with an institution that only used international data and did not contact a local information and identified that this is an issue

Dr. MacLaughlan-David - What needs to be done to drive more accountability in the future?

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Answer: Policy needs to change to allow all patients to go to available trials in any area even out of insurance network. Focus should be paid to overcome potential social barriers for example, transportation assistance should be provided more readily available. There should be more partnership with rural facilities to allow individuals to get some treatment closer to home (blood work etc). Making an effort to remove barriers between patients and care. This could be a partnership between state legislation, drug companies, and trial facilitators, potentially making an effort to open trials at institutions with more diverse patient populations.

Dr. MacLaughlan-David mentions that for the record it is easier to conduct these studies in other countries so that is why we see more information from these studies more quickly, continuing on to mention that the possibility to open studies that are available remotely should be considered.

Kim Jay- Comments from Community Health Worker perspective, and brings up social determinants, wonders if people of color are not being offered these studies, beyond self-enrollment.

Answer: Acknowledged that there is some stigma around what a trial is, main issue lies with lack of open trials in their medical center, and another thing would be even if someone is aware of and is eligible there is a struggle with knowing how to get the patient there to actually participate in the study.

Dr. MacLaughlan-David- indicates that not knowing the options or having the belief that they wouldn't want to participate can drive a lack of participation to a certain degree. Makes the point that when talking to patient about trial it is important to also talk about data and what exists with knowledge of the race of the people participating in these trials.

What needs to be done to make this initiative sustainable?

Answer: The initiative is looking for funding and resources to continue running the site/platform. Mentions how much goes into it and that it is just local to Chicago and that even more would need to be done to expand. Dr. Roque hopes to be able to raise awareness of the good that this platform can do, and potential expansion might be picked up by other organizations and the initiative is ultimately looking for long-term funding.

Dr. MacLaughlan-David wants to begin brainstorming about what parts of this knowledge could be applied to legislation and how it should impact the recommendations from this group.

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Working Group Updates

This agenda item was postponed till next meeting.

Timelines and Deliverables

Tess indicates that the written report is the largest deliverable.

-Looking for policy implications

Tess indicated that each working group will be meeting soon to determine more information that will be able to be integrated into this sub-committee's portion of the report.

This information will be shared at the next meeting.

Open Discussion and Questions

Dr. MacLaughlan-David shared a document that was published by the CDC, infographic containing Gynecologic Cancer Symptom diary (Patricia had sent her this)

Dr. MacLaughlan-David Noticed that this infographic lacks some specific directives to help the patients to know what steps to take and how to advocate for themselves with increased knowledge, hope to hear more information from sub-committees about disparities in information being given, hope to share this document with the full commission.

Patricia- Everything starts with symptoms (from the patient perspective), and then knowing what to do next. Specifies that her question about genetic testing earlier in the meeting was due to racial disparities in regard to knowledge of what genetic testing is, and who is receiving testing. Indicates that she is passionate about this and wants to help others have as much information as they can. Believes that more facilities should share knowledge of EMPACT with their patients.

Sarah O'Connor- shared that she does a lot of other things within the Office of Women's Health and Family Services (OWHFS) and indicates that IBCCP should be knowledgeable about what Dr. Roque is doing. Additionally bringing up that it might be a good idea to have Dr. Roque to present at the women's conference hosted by OWHFS, and that potential partnerships between his work and the state could be beneficial to the work being done.

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Next meeting will be 3/25 and the full commission will be 3/28

Public Comment – NONE

Adjournment

Motion to adjourn at 2:02 PM brought by Patricia Walter, seconded by Shannon MacLaughlan-David.